Reconciling traditional healthcare-related and design-based approaches to explore and enhance patient participation in spinal cord injury rehabilitation

Gemma Wheeler

Submitted in fulfilment of the requirements for the
Degree of Doctor of Philosophy

The Glasgow School of Art
School of Design

May 2018

Abstract

A Spinal Cord Injury (SCI) results in partial or complete loss of sensation and/or function below the level of injury, affecting every aspect of daily life. SCI rehabilitation is a long, complex process that aims to equip patients with the skills needed for the rest of their lives. The initial aim of this study was to create more or enhanced opportunities for patient participation within this rehabilitation process, using a mixed-methods approach to explore and collaboratively shape the experiences of patients, family and healthcare professionals within it.

This research began with a 12-month, in-depth contextual review of the host spinal injury unit (SIU) to identify potential opportunities for enhanced patient participation. Qualitative and ethnographic research methods, such as interviews with SIU staff and observations of rehabilitation events, were found to be crucial in generating a detailed understanding of the rehabilitation process and embedding the researcher within the unit. Design-based methods were then used to collaboratively develop the contextual review findings, including an exploratory pilot study with a group of the SIU community. From this, the Goal Planning Meeting (GPM), where patients, family and SIU staff members meet to discuss progress and set rehabilitation goals, was established as the site for intervention.

A combination of observations, interviews and conversation mapping methods were used to triangulate the experiences of participants in the GPM, generating four main aims, or 'Experience Goals,' for the subsequent co-design process. From this, the researcher generated several prototype materials that aimed to support patients' understanding of the GPM and their role within it. The prototypes were co-developed with outpatients and SIU inpatients and staff in a series of workshops with the aim of meeting these experience goals. The final phase of the study involved the implementation and mixed-methods evaluation (using observations, interviews and conversation mapping methods) of the intervention in the rehabilitation pathway of three patients.

The co-developed intervention includes a second prognosis meeting, a meeting to set long-term rehabilitation goals (that address both staff and patient priorities) and simplified

documentation of the Goal Planning Meeting. Although each patient engaged with it differently, evidence suggests that the intervention led to enhanced patient understanding of their rehabilitation progress, and more opportunities for staff to incorporate the patient's personal priorities into their practice and the patient’s rehabilitation pathway.

This study also makes three claims with regards to designing for patient participation;

1. Designing to enhance participation in rehabilitation processes should consider the diversity of roles and perspectives involved in service encounters like the GPM
2. Designing for enhanced patient participation needs to acknowledge that participation is not a monolithic concept
3. Designing for enhanced participation requires an embedded participatory design process able to guide a progressive process of adoption and change not only with patients, but also for the key professional practices involved.

In summary, this PhD study is concerned with the complimentary relationship between ‘traditional’ and ‘design-based’ research methods to collaboratively and robustly explore, communicate and positively shape the experience of group healthcare consultation events for staff and patients alike.

Contents

Part A: Involving Patients in shaping their own healthcare

Part B: Patient and public involvement in healthcare service development

Part C: Discussion

Part D: Implications for the study

List of Appendices

List of Tables

1 Introduction

2 Contextual Review

3 Literature Review

7 Phase Two Findings

8 Phase Three Findings

List of Figures

2 Contextual Review

3 Literature Review

4 Methodology

5 Study Design

6 **Phase One Findings**

7 **Phase Two Findings**

8 Phase Three Findings

9 Comparing Phase One and Phase Three Results

10 Discussion One: Engaging the SIU community in a participatory service design process

Appendices

Preface

The study described in this thesis draws from and contributes to the fields of design and health, in the context of SCI rehabilitation. The following preface will describe the opportunities that both fields had previously identified in this context, and how their complimentary aims have been consolidated into an initial research question, 'Can design approaches be used to explore and enhance patient participation within spinal cord injury rehabilitation?'

Rehabilitation

According to the Chartered Society of Physiotherapists (United Kingdom), rehabilitation is concerned with 'enabling and supporting individuals to recover or adjust, to achieve their full potential and to live as full and active lives as possible,' (2017). Rehabilitation can take many forms and can be required for a multitude of reasons, from doing simple physical exercises after surgery, to re-learning communication skills following a Stroke, etc.

Rehabilitation is arguably an active form of healthcare, as patients are required to take part in prescribed activities, rather than passively accepting a medicine (although the two can be required concurrently). Patient participation in rehabilitation has been linked to improved outcomes and decreased depression among patients (Baker et al., 2001), as well as 'reduced burnout rates among physical therapists,' (Payton et al., 1990, Payton & Nelson, 1996). Research into enhancing patient participation has become a concern in a variety of healthcare contexts, such as in the patient-doctor interaction (Roter, 1977), decision-making (Guadagnoli & Ward, 1998) and patient safety (Longtin et al., 2010). Within the specific context of this study, people with a spinal cord injury have described participation in rehabilitation as a 'necessary prerequisite for successful care and rehabilitation,' but also stressed that staff had an important role to play in facilitating and encouraging this (Lindberg et al., 2013). As such, research initiatives that address the roles of patients and staff in the former's participation would have clear benefits to this community.

Design and Rehabilitation

In 2009, the Royal Society of Art (RSA) published the ‘Design and Society’ manifesto, stating that design can ‘re-awaken citizens’ own resourcefulness.... and persuade them that they know more than they think about how problems might be solved,’ (Campbell, 2009, p7). By identifying the SCI population as ‘a group of people who needed to learn to be resourceful,’ the ‘Design and Rehabilitation’ initiative was formed. This initiative began with a three-day design workshop with eight spinal cord-injured people, which aimed to inspire creative thinking and ‘give confidence and independence by teaching... creative design tools and techniques,’ (Campbell, 2011, p3). Michael Beirut, a peer reviewer of the initiative, said the workshops made ‘a strong case for “the relationship between design-thinking and having a sense of agency in one’s environment and one’s life,”’ (Campbell, 2011, p25).

The RSA then developed this pilot into the ‘Design and Rehabilitation’ workshops in 2011 (Campbell, 2012). These workshops were facilitated by partnering three of the leading spinal injury units in the UK with local universities, including a collaboration between the host organisations of this PhD study; the Queen Elizabeth National Spinal Injuries Unit (QENSIU) and The Glasgow School of Art (GSA).

All three universities in the ‘Design and Rehabilitation’ initiative reported positive outcomes, despite taking different approaches to the study (Campbell, 2012). The GSA study found that people with a spinal cord injury ‘possess at least some of the same skills as designers,’ (Macdonald, 2013, p191) as did the team working between Sheffield Hallam University (SHU) and the Sheffield Princess Royal Spinal Injuries Centre, who added that the patients also anecdotally described enjoying their involvement in the project (Langley et al., 2013). Although the initiative was exploratory in nature, it also provided a stimulus for some participants to continue exploring the potential of teaching design methods to spinal cord-injured individuals, where Wolstenholme et al. (2014) found such initiatives can be considered as contributing to self-management practices, as well as enhancing patient’s experiences of being in hospital.

Following this pilot study, a strong desire emerged from both the GSA and QENSIU to find a way to continue their collaboration, and to explore the ways in which their two cultures could be brought together. Meanwhile, across the country, the pilot was also inspirational for the researcher, who was then involved with the Sheffield-based team as an undergraduate student at Sheffield Hallam University. In her role as a workshop facilitator, she was able to see for the first time the strength of design-led approaches in engaging people in discussing their current and potential future experiences. It could be argued, then, that this PhD study actually began, at least in the mind of the researcher, several years before the work described in this thesis.

Complimentary aims

Two key arguments were drawn from the above pilot work to inform the start of this PhD study. Firstly, if there is evidence to suggest that design approaches have the potential to enhance one's sense of agency over one's life (Campbell, 2011), they may be beneficial in enhancing a spinal cord-injured individual's agency to participate within their rehabilitation, possibly leading to enhancing outcomes and wellbeing. Secondly, the findings from the GSA and SHU studies (that patients have the capacity to participate in design-led activities, and can enjoy doing so) provide practical and ethical rationales for involving patients in research initiatives that affect them. It also raises questions whether the wider spinal injury unit community (such as a patient's family members, or staff, given they have such a supportive role) could also be engaged in such research projects, and as such the study aimed to take a participatory approach.

Rather than take an 'outside-in' approach (i.e. entering the rehabilitation context as a designer for the purposes of teaching ‘design’), as in the RSA initiative described above, this scope of this study instead facilitated an 'inside-out' approach (i.e. developing an understanding of the rehabilitation context as a researcher, then looking out to the field of design to further refine this understanding and explore opportunities for intervention). Given that the fields of scientific- and design-based research each have particular strengths in exploring current situations as well as creating new ones (Rodgers & Yee, 2015), this study began with the research question, 'How can traditional and design-based approaches be used together to explore and enhance patient participation within spinal cord injury rehabilitation?'

Acknowledgements

This study has been made possible by the generous funding of the Arts and Humanities Research Council's Collaborative Doctoral Award (grant number AH/L002906/1).

I would like to extend my warmest thanks and gratitude to my supervisors, Professor Alastair Macdonald and Dr Mariel Purcell, for their unwavering support, both academically and personally.

I would also like to thank Mr David Allan for his role in setting up this study, and Dr Alan McLean and Mr Matthew Fraser for their continued enthusiasm for this work at the Queen Elizabeth National Spinal Injuries Unit, Glasgow.

From the Glasgow School of Art, I wish to thank Dr Nicky Bird for keeping me on track, and Dr Alison Hay for all of her help with the ethics process.

Thank you also to the staff at Spinal Injuries Scotland, for your interest in this work and for bringing a fresh perspective.

-

There aren't enough words in the world to thank my family for their incredible support. Dad, thank you for teaching me to be curious. Mum, thank you for teaching me to be sensitive. Nana and Grandad, thank you for your constant encouragement (and for always keeping the kettle on).

To all of my inspirational friends - thank you for keeping me going. Becca Partridge, Soph Boden, Amy Williams, Dave Craig and Elliot Morgan – thank you for the laughter and wisdom across the miles. Beth Strachan and Mary Hunter, my X-Men, thank you for your strength and showing me new opportunities.

My special thanks go to Chris Redford, for keeping me smiling and well-fed, and for his help in digitizing these diagrams.

-

I feel very fortunate to have found such a fantastic team here in Glasgow. To my colleagues; Gayle Rice, Sandra Neves, Susan Wan, David Loudon, Mafalda Moreira, Jessica Argo, James Hutchinson and Marianne McAra - thank you for your advice, our discussions, and for making the move to a new city so easy (and so fun).

-

Thank you to my friends and colleagues at Lab4Living, Sheffield, especially to my mentors Dr Claire Craig and Dr Joe Langley for showing me the possibilities of design, health, care and wellbeing, and for setting me on this path.

-

Most importantly, I am incredibly grateful to the nameless heroes of this study. To the patients, family members and staff at the Queen Elizabeth National Spinal Injuries Unit, thank you, thank you, thank you. Without your generosity of time, experience and spirit, this study could not have happened.

Declaration

I, Gemma Wheeler, declare that the enclosed submission for the degree of Doctor of Philosophy consisting of textual thesis meets the regulations stated in the handbook for the mode of submission selected and approved by the Research Degrees Sub-Committee. I declare that this submission is my own work has not been submitted for any other academic award.

Student:

Signed: Date:

Supervisory Support

Primary Supervisor:

Signed: Date:

List of Acronyms

ADL - Activity of Daily Living
ADLs - Activities of Daily Living
AHRC - Arts and Humanities Research Council
EBCD - Experience-Based Co-Design
FIM - Functional Independence Measurement
GPM - Goal Planning Meeting
GSA - Glasgow School of Art
Host SIU - Host Spinal Injury Unit
IPA - Interpretive Phenomenological Analysis
KW - Key Worker
NSCISB - National Spinal Cord Injury Strategy Board
NTSCI - Non-Traumatic Spinal Cord Injury
OT - Occupational Therapist
PD - Participatory Design
PDAs - Patient Decision Aids
Physio - Physiotherapist
PIP - Person Important to the Patient
QENSIU - Queen Elizabeth National Spinal Injuries Unit
RCT - Randomized Controlled Trial
RSA - Royal Society of Art
SCI - Spinal Cord Injury
SCIM - Spinal Cord Independence Measurement
SD - Service Design
SDM - Shared Decision Making
SIS - Spinal Injuries Scotland
SIU - Spinal Injury Unit
SHU - Sheffield Hallam University
TSCI - Traumatic Spinal Cord Injury

01 Introduction

1.1 Background

There is good evidence that actively involving patients as partners in the design and management of treatment interventions leads to improved outcomes and experience (NHS England 2017). Policy directives within the United Kingdom have focused on developing strategies to increase levels of patient participation, as exemplified in the Five Year Forward View (NHS England, 2014) and the National Health and Social Care Standards (The Scottish Government, 2017), reflecting health paradigms that give increasing responsibility to patients to self-manage their condition. As highlighted in the preface of this thesis, this can have particular resonance with people living with long-term conditions, such as spinal cord injury.

However, whilst policy and evidence strongly advocate for the active participation of patients in their treatment, it is more difficult to define how this is embodied in practice. The Scottish Government (2015) recently reflected that whilst co-production and people powered health were key strategies, the implementation of these approaches was ‘proving harder to realise.’ The challenge remains that whilst theoretically approaches to increasing patient participation and self-management are posited as important things to do, current healthcare services (as yet) lack the necessary tools and approaches to implement and affect change.

The fields of design and design research have a strong history, and a plethora of tools and designerly approaches, concerned with involving those not formally trained in design in the creation of products, buildings, technology, and (more recently) in services, experience, interventions, etc.

One of the challenges therefore is how to bring these designerly tools and approaches to an embedded, collaborative position with healthcare contexts. As will be discussed in the Literature Review chapter of this thesis, examples do exist, yet they are not widespread nor are they often fully implemented. A greater understanding still needs to be developed in relation to how patient participation in healthcare can be enhanced, how designers might work more effectively in healthcare settings and environments, and how impact of these interventions might be realised (and, where successful, scaled up). This thesis examines the role of design, most notably participatory service design, in the context of healthcare services for people undergoing rehabilitation for spinal cord injury (SCI).

1.2 Outline of this study

In response to these challenges, there are two key aims driving this study:

- To explore how designers can operate in a participatory manner with and within healthcare service contexts
- To explore how to design for enhanced patient participation, in particular for spinal cord injury rehabilitation

As a researcher, addressing these aims involved becoming embedded in the unit and working with the inpatients and their families during their rehabilitation journey following a highly physically and emotionally challenging life-changing spinal cord injury. Of equal importance, it also involved working with the Spinal Injury Unit (SIU) healthcare staff (both clinical and therapy), as well as outpatients, who are considered ‘lifelong patients’ due to annual check-ups and the evolving nature of learning to live with an SCI.

As a designer by training, it also involved understanding and reconciling the two fields of healthcare and design, carefully crafting an embedded position within the SIU and responding to the epistemological, practical and ethical challenges of designing collaboratively with such a complex context.

1.3 Intention

This PhD seeks to build an understanding of what design, particularly participatory approaches to service design, can offer in seeking to enhance patient participation, and the involvement of healthcare service communities in doing so. It does not, in any way, aim to undermine the crucial work already happening in contexts such as the SIU, instead it hopes to offer propositions as to how such work can be reinforced and supported in new ways.

The work detailed in the following thesis will provide an evidence base to recommended reframing the notion of patient participation as a non-monolithic concept that can happen at different levels and following different strategies, as every patient is different. As will be established in the Contextual Review, this is particularly true for the heterogeneous SIU inpatient community. By focussing on a key SCI rehabilitation event, the Goal Planning Meeting, it is proposed that designing for enhanced participation in rehabilitation pathways must consider the diversity of roles and perspectives involved, where 'co-production' occurs not just in traditional patient-professional dyads but among a range of different actors, including family members. Reflections on the effectiveness (or not) of the approach taken in the study, given in the Discussion chapters, will highlight the need to take a mixed-methods, embedded, participatory approach to the co-development of rehabilitation pathways, with consideration of the wider service community that events such as the GPM affect, and are affected by. The researcher was able to cultivate such an embedded position due to the collaborative nature of this PhD study, as detailed in the next section.

1.4 Setting

The host university, The Glasgow School of Art (GSA), and the host spinal injury unit, The Queen Elizabeth National Spinal Injuries Unit (QENSIU), Glasgow, collaboratively applied for, and were awarded, funding for this PhD study (the Arts and Humanities Research Council's Collaborative Doctoral Award, grant number AH/L002906/1). As such, the researcher had equal access to both research institutions. This included a private office in the host spinal injury unit (SIU), which allowed the researcher to become truly embedded in the research context and adapt her methodology accordingly (as will be detailed further in the main thesis). As part of this collaboration, the researcher also benefitted from the supervisory support of senior staff from both sites; a Professor of Design acting as primary supervisor at GSA, and a Consultant in Spinal Injuries acting as co-supervisor at QENSIU, who are referred to as the design-based supervisor and healthcare-based supervisor (respectively) throughout the main thesis.

1.5 Problematising participation

Working across the different paradigms of health and design is fraught with complexity, not least due to the terminology. It is recognised that the terms 'participation' and 'participatory' have numerous meanings, both in relation to the aimed-for outcome of this study (enhanced patient participation) and to the aimed-for process (engaging the healthcare community in participatory approaches to service design). Both concepts will be explored more fully in the Contextual Review and Literature Review chapters of this thesis (respectively), but this section aims to give some clarity from the outset.

The choice of patient ‘participation’ as the focus of this PhD is deliberate and distinct from other terms such as ‘compliance’ or ‘activation,’ in that it is more concerned with addressing the asymmetry of power inherent within traditionally paternalistic healthcare structures. As will be discussed in the following chapter, ‘participation’ is not a clearly defined concept, but this study considers it to frame the patient-professional relationship as one of equals, foregrounded in notions of mutual learning and collaboration towards shared health goals. In some instances, patient ‘participation’ may be considered as falling under the umbrella of, or as a higher-level form of patient ‘engagement’, which is understood in terms of how a person thinks, feels and acts in relation to their health and health management. A patient may be ‘engaged’ by providing information that is relevant to them as an individual, but the patient may be ‘participating’ in educational activities by asking questions, providing their own information of their experience of health management, etc.

In terms of participatory processes, the PhD draws on the Scandinavian tradition of Participatory Design to reinforce its approaches to Service Design. The founding principle of this tradition is the belief that those who will be affected by a design process have the right to influence it (Schuler and Namioka, 1993), as opposed to North American approaches, which are regarded as more akin to user-centred design (where ‘users’ are consulted and studied, rather than actively engaged in the design process).

1.6 Thesis structure

The chapters in this thesis can be separated into four main stages, as summarised in table 1.1 below:

Stage	Related Chapter(s)
1: Locating the opportunity for intervention	2: Contextual Review
2: Planning the main study	3: Literature Review
	4: Methodology
	5: Study Design
3: Conducting the main study	6: Phase One Findings
	7: Phase Two Findings
	8: Phase Three Findings
4: Reflecting on the main study	9: Comparing Phase One and Phase Three Findings
	10: Discussion One: Engaging the SIU community in a participatory service design process
	11: Discussion Two: Designing to enhance patient participation in SCI rehabilitation
	12: Conclusion

Table 1.1: An overview of the thesis structure.

Each stage of the PhD will now be described briefly in terms of its related chapters.

1.7 Locating the opportunity for intervention

1.7.1. Contextual Review

The contextual review may be considered more akin to a primary study, in that the understandings gained from a traditional literature-based exploration of the context (biomedical understandings of SCI and its associated rehabilitation processes) were reinforced by a situated, in-depth, year-long period of primary research within the host SIU (including observations of rehabilitation activities, shadowing SIU staff on day and night shifts, and direct contact with patients and family members). These medical and experiential insights were then reflected back to the SIU community and collaboratively developed using design-led methods (including the diagrammatic exploration of qualitative data). In this manner, the researcher was able to cultivate an embedded position within the SIU, build working relationships with the SIU staff, demonstrate the benefits of using design-led methods to understand complex healthcare contexts, and establish the site for intervention collaboratively with the SIU community. As a result, the study continued with the hypothesis that new or enhanced materials or processes could be introduced into the Goal Planning Meeting (GPM - a monthly meeting between the patient and their multidisciplinary rehabilitation team to set functional goals and review progress made towards them) to enhance patient participation within it.

1.8 Planning the main study

1.8.1 Literature Review

After a review of the relevant literatures from design and healthcare, it was established that both fields have undergone a simultaneous, yet separate increase in focus on enhancing patient and/or public participation. This was found both in the topics of patient participation in their own healthcare (see Part A of the Literature Review) and also in healthcare service development approaches (see Part B of the Literature Review). This review was useful in terms of highlighting methods or tools from each of the fields that could be useful in the main study of this PhD (such as the prototyping techniques of Participatory Design, or the visualisation methods of Service Design), and also in terms of highlighting gaps in the literature, such as a need for rigorous evaluation of the intervention.

1.8.2 Methodology and Study Design

The methodology chapter begins by contrasting the two seemingly disparate worldviews of design and healthcare, and how they seek and legitimise different forms of knowledge. A specific understanding of Design Research is given, and a case is made for its use as a complementary approach alongside scientific research methods, particularly through the use of prototyping and prototypes as a means and vehicle for inquiry.

The approach taken to the main study is then summarised in the Study Design chapter, in three linked phases. Phase One seeks to understand the GPM experience from the perspectives of patients, family members and staff, and the opportunities for change within that. Phase Two aims to engage the SIU community in a co-design process to enhance patient participation within the GPM, in response to the emergent priorities for change. Finally, Phase Three seeks to introduce and evaluate the impact of the co-designed intervention. These three phases and their findings are discussed in the next stage of the PhD, 'Conducting the main study.'

1.9 Conducting the main study

The three chapters located in 'Conducting the main study,' present the findings of each phase of the study concisely, with minimal discussions or references to the related literatures (which are located in the Discussion chapters of this thesis).

1.9.1 Phase One Findings

The mixed-methods approach taken to Phase One was found to be effective in exploring and evidencing the multiple perspectives of the GPM (from patients, family members and staff). The use of quantitative, qualitative and diagrammatic questions in the questionnaire-led interview was particularly useful in highlighting opportunities for change as well as perspectives on the current GPM format. The visual mapping of the GPM conversation was also useful in demonstrating clearly and objectively, for the first time, the scale of patient passivity within it.

From these findings, four Experience Goals were generated (with support from the supervisory team) to guide Phase Two of the main study.

1.9.2 Phase Two Findings

The researcher generated three initial prototype materials in response to the Experience Goals derived from Phase One. The SIU community was then engaged in a series of co-design workshops to iteratively co-develop these prototypes until a resolved intervention was ready for testing. The SIU participant groups (outpatients, inpatients and staff) were engaged separately in order to protect their on-going working relationships and to tailor the sessions according to their physical, emotional or logistical needs. As such, the prototypes were considered design concepts but also vehicles to carry experiential, behavioural and institutional knowledge anonymously between the participant groups, facilitating creative collaboration between them.

The co-designed intervention was named The Co-Plan Process, and consisted of several linked activities (each supported by bespoke materials) spanning approximately 2 months of a patient's rehabilitation pathway, as summarised below:

- An 'Introduction to Rehabilitation' information booklet, to clarify the rehabilitation pathway and the patient's role within it.
- A 'Consultant Meeting' to clarify the patient's prognosis, and to begin asking the patient about their priorities for rehabilitation.
- A 'Key Worker Meeting' to review the patient's prognosis and priorities, and to set long-term rehabilitation goals accordingly.
- A patient-owned record of the short-term goals is made at each GPM.

1.9.3 Phase Three Findings

After introducing the co-designed intervention into the rehabilitation pathway of three patients, the methods used to establish the 'baseline' GPM experiences of patients, family members and key workers were repeated for comparison.

Although the GPM conversation did not change significantly (and as such the GPM conversation mapping methods were not repeated), interview data suggests that two of the three patient participants had more or different opportunities to participate in their goal planning process as a result of the intervention. Although each patient participant engaged with the intervention slightly differently, in general staff found that discussing a patient's prognosis and personal priorities for their rehabilitation was particularly useful, whilst some patients felt that visualising their rehabilitation progress was helpful to them. Diagrammatic aspects of the questionnaire-led interviews also suggest that patients have a more accurate understanding of their progress through using the intervention, although this conclusion is based upon a small patient sample.

1.10 Reflecting on the main study

This final section is reflective in nature, and relates the findings to the relevant literatures in order to better understand the contributions and implications of this work to the fields of both Design and Healthcare. After a brief discussion on the complimentary nature of traditional and design-based research approaches, this thesis concludes with a summary of the study’s limitations and recommendations for future work.

1.11 Main arguments

This study hopes to demonstrate the strengths of bringing a participatory approach service design into complex healthcare contexts, particularly its ability to elicit deeper insights into rehabilitation experiences and facilitating creative collaboration between inpatients, outpatients, family members and healthcare professionals in co-developing these experiences. It argues that such an approach must be carefully crafted, informed by and responsive to a deep understanding of the context, and the relationships, tools, processes and epistemological norms within. By working from such an embedded position, designers can support healthcare communities in exploring new practices and roles, in a low-risk way without jeopardising their ongoing working relationships.

The researcher argues that designing for enhanced patient participation is a specific form of designing, which must acknowledge a broader conceptualisation of the term ‘participation,’ support a wider network of co-production (to include family members and friends), and in this context, accommodate the highly individual and evolving nature of SCI rehabilitation.

Stage One:

Locating the opportunity for intervention

02 Contextual Review

2.1 Introduction

This chapter will begin by describing the approach to the contextual review, followed by a review of the terms associated with patient involvement in healthcare. It will then explore the context of SCI, its associated rehabilitation processes, and the patient, family and staff experiences of them both using the available literature, plus qualitative and ethnographic methods. It will conclude by further exploring the Goal Planning Meeting (a regular point of treatment decision-making between a patient and their care team) with visual and provocative methods before confirming it as an appropriate site for intervention in this study.

2.2 Methodological approach to the Contextual Review

Section	Research Question	Method(s)
2.3	What is patient participation?	Literature Review
2.4	What is a SCI?	
2.5	What is the experience of SCI?	
2.6	What is the SCI rehabilitation process?	Literature Review (including SIU process documentation) and semi-structured interviews with senior SIU staff
2.7	What is the patient experience of the SCI rehabilitation process?	Literature Review
2.9	What is the patient experience of learning to live with a SCI through the rehabilitation process?	Primary research: observations of rehabilitation activities and direct contact with the SIU community
2.10	How can the data gathered be analysed more clearly and usefully?	Diagrammatic Exploration
2.11	Is the Goal Planning Meeting (GPM) an appropriate site for intervention?	Thematic coding of primary research data and a rough pilot with a patient and his rehabilitation team

Table 2.1: A summary of the research questions and methods used in the Contextual Review chapter.

The introductory chapter has set out the broader landscape within which this enquiry is situated and suggested the potential of design approaches to enhance patient participation of people living with spinal cord injury (SCI). The contextual review offers a more detailed consideration of the nature of SCI, initially by defining spinal cord injury and outlining the main treatment approaches that are used. This is arguably a view from the ‘outside’ – a biomedical understanding of the management and treatment of the SCI. Further investigations of the literature available sought to offer a view as presented by people living with the condition, and their experiences. Initial searches of the grey literature and narrative accounts of people with SCI yielded little information, and so the researcher undertook a year-long, in-depth ethnographic study of the host SIU (including observations of rehabilitation activities, shadowing SIU staff on day and night shifts, and direct contact with patients and family members) to develop a more situated, experiential understanding of SCI rehabilitation. This generated a large amount of rich, descriptive, qualitative data, which was coded inductively to establish the key themes emerging from the context (the process of which is described in section 2.11.4, see appendix 1 for a more detailed review of qualitative data analysis approaches).

In the spirit of this PhD and its subject matter, a more nuanced understanding of the SIU context was informed and underpinned by the community where the study was being undertaken. To achieve this, design-led methods of visualisation and enactments were employed to develop and reflect the researcher's insights back to the SIU community, to elicit deeper forms of tacit and behavioural knowledge in the participatory development of their shared understandings. This latter half of the review, therefore, sits between a traditional literature review and a methodology for engagement of individuals within the study.

Given the potential vulnerability of the SIU inpatient and family community, the researcher chose to learn about the context as unobtrusively as possible to begin with, with slowly increasing contact with the management staff, front-line staff, inpatients and family members (in that order, with the initial group extending invitations to meet the next group, and so on) as well as outpatients and staff from spinal injury-related charities. Taking the time to gradually build working relationships with SIU staff and to learn how to work sensitively with the inpatient community (and avoid disrupting the daily SIU routines) was key to developing a rich understanding of the context and cultivate an embedded, confident position within the SIU context.

Each of the activities within the contextual review was primarily concerned with understanding the SIU community and practices in relation to patient participation. As already alluded to in the previous chapter, the notion of 'participation' (and its related terms, 'compliance,' 'activation' and 'engagement') is complex and required further review before venturing into the SIU context.

2.3 Patient involvement in healthcare

2.3.1 Patient compliance

Patient 'compliance' is mostly discussed in terms of adherence to medication, medical advice and/or attending appointments (Giuffrida and Torgerson, 1997), where common approaches to measurement are quantitative and professional-led (including pill counting, chemical tests and simple self-reporting scales, see Greene et al., 1975 and Morisky et al., 1986). Research into the determinants of compliance was particularly common in 1970's and 1980's (Morisky et al 1986) the aim of which being to enable healthcare professionals to put appropriate interventions in place (i.e. education or even financial incentives). As such, compliance is largely considered a paternalistic term, where the patient is given little agency in their own health behaviour change.

2.3.2 Patient activation

Greene et al. define 'activation' as 'a term referring to the knowledge, skills, and confidence a patient has for managing his or her health care,' (2013, p1299), suggesting a slight shift in locus of control towards the patient. 'Activation' is commonly measured by the Patient Activation Measure (Greene and Hibbard, 2011), with a shortened version also available (Hibbard et al. 2005). Higher levels of patient activation have been linked to better health-related outcomes (Greene & Hibbard 2011), better self-management behaviours (Hibbard et al., 2007) and better consultation experiences, even when consulting with the same physician (Greene et al., 2013). This latter study found that care experience is 'transactional,' shaped by both providers and patients, suggesting strategies to improve the patient experience should therefore focus not only on providers but also on 'improving patients' ability to elicit what they need from their providers,' (ibid, p1299). Recent studies suggest that patients can be supported according to the level of activation they are currently at, and also supported in building their knowledge, skills and confidence to increase this level (Hibbard & Greene, 2013). The notion that confidence and information are needed to support skills in taking an assertive role in their own healthcare has interesting implications for this study. However, these are still 'skills' in following medical professionals' expert opinions, rather than considering the patient as a source of knowledge also, as found below.

2.3.3 Patient engagement

There has been a growing focus on patient engagement in health and social care policies, research and initiatives in recent years, the benefits of which will be discussed in section 3.3.2. Despite growing attention, 'there is little consensus about what patient engagement means,' to the point where it has become a 'fragmented concept lacking of a unique definition,' (Barello et al., 2012). Carmen et al. (2013) describe how it is also used synonymously with terms such as 'patient activation' and 'patient- and family-centred care,' with definitions being concerned with behaviours, cognitive factors, relationships, contexts and organizational features.

Whilst 'engagement' appears to be understood in relation to qualitative factors, these factors often undergo a form of translation into quantitative measures (if they are measured at all). For example, Wasson and Coleman (2014) describe 'health confidence' on a scale of 0-10 as an 'effective proxy' to measure patient engagement (see fig. 2.1), and Graffigna et al. (2015) developed the Patient Health Engagement Scale following a systematic review of the medical literatures, where patient engagement is understood in terms of how a person thinks, feels and acts in relation to their health and health management.

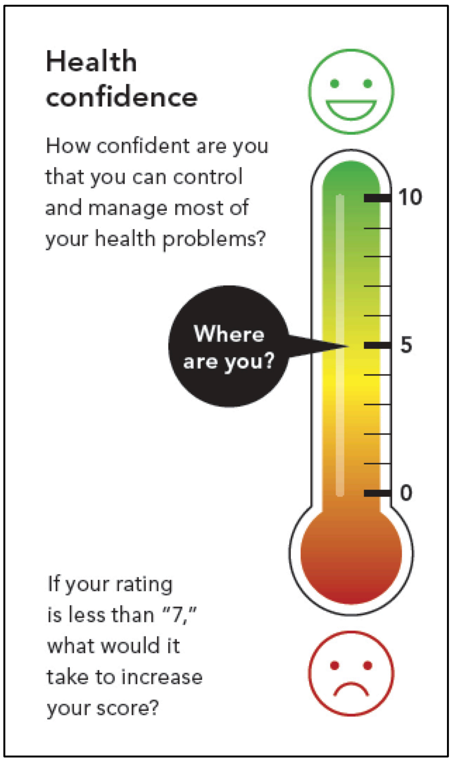


Fig. 2.1: Wasson and Coleman's tool to measure 'Health Confidence' (2014)

Engagement, then, is clearly a broad concept. This study's main focus (a patient's direct involvement, and influence over, their immediate healthcare experience) may come under the umbrella term of 'Engagement,' (and indeed, this term was found more frequently in the literature and in conversations with SIU staff) but may be more specifically defined as 'participation,' as discussed below.

2.3.4 Patient participation

Patient participation is sometimes discussed in terms of the re-design of healthcare services, as a means to improve patient safety, and is largely applied to (shared) decision-making about, and management of, chronic conditions (Longtin et al., 2010). However, ‘the concept of patient participation remains poorly defined despite abundant literature,’ and, as above, it is used interchangeably with terms such as ‘patient collaboration, patient involvement, partnership, patient empowerment, or patient-centred care,’ (ibid, p53). Additionally, the term can refer to diverse activities such as ‘decision making, self-medication, self-monitoring, patient education, goal setting, or taking part in physical care,’ (ibid).

As such, measures of ‘participation’ vary greatly. In some instances, participation is understood in qualitative terms, such as in General Practitioner (GP) consultations where the term can refer to ‘the degree to which patients asked questions, were assertive, and expressed concerns and the degree to which physicians used partnership-building and supportive talk (praise, reassurance, empathy) in their consultations’ (Street et al., 2005). Within the medical literatures, attempts to measure participation quantitatively have led to discussions on the complex nature of the phenomenon itself. For example, Lenze et al. (2004) generated a 5-point staff-reported scale of measuring participation in Physiotherapy and Occupational Therapy activities, which they found needed to be increased to 7 when tested in practice. The authors also found that participation tended to increase over time, and that patients with less severe disabilities tended to participate more. Other studies have corroborated these findings, suggesting that a patient’s increasing ability to manage their condition over time is also supported by gaining more information and stabilising emotionally as well as physically (Lenze et al., 2004). These latter points are interesting to consider within SCI rehabilitation, where perception of the disability caused by the injury may affect a patient’s participation, as well as other factors such as emotion, fatigue, medical complications, etc.

Eldh (2006) notes that, within the medical literature, no studies of patient descriptions or experiences of participation could be found. Through interviews and content analysis with patients and staff (which in itself is unusual in the literature) she found that a mutual understanding of patient participation consists of three key factors:

- Patient participation is being provided with information and knowledge in order for one to comprehend one's body, disease, and treatment and to be able to take self-care actions based on the context and one's values
- It involves providing the information and knowledge one has about the experience of illness and symptoms and of one's situation
- It occurs when being listened to and being recognised as an individual and a partner in the health care team

As patients' descriptions of participation were 'close to the dictionaries' description of "sharing,"' (ibid, p5), and since the factors above emphasise the importance of both patient and staff roles in facilitating participation in healthcare, the term 'participation' in this sense resonates most closely with the aims of this research. The consideration of patient 'experiences, as well as the positioning of the patient as an equal contributor, is key in this study's aim to address the asymmetry of power in the patient-professional relationship (as will be explored in the Literature Review chapter).

2.3.5 Summary

Within the healthcare literature, patient participation often remains understood as a single variable to be measured, where healthcare professionals' observations of a patient's 'participatory' behaviour (i.e. taking part to a greater or lesser extent in the prescribed activities or medication regimes) are translated into quantitative measures to be improved upon.

However, in this study, patient participation is understood as a shift towards more interactional behaviours, addressing the asymmetry of power between patient and healthcare professionals through mutual learning and recognises the complex qualitative factors affecting it (i.e. emotional and physical stability).

2.4 What is a Spinal Cord Injury?

2.4.1 Introduction

This section aims to explain a spinal cord injury (SCI) in terms of its medical effects, the impact of these effects and their prevalence and incidence. Clinical literature and introductory meetings with the (then) director of the host spinal injury unit (SIU) generated an overview of the biomedical consequences of an SCI, in preparation for a more focused exploration of SCI rehabilitation in the next section.

2.4.2 What is a Spinal Cord Injury?

Overview

A spinal cord injury is classed as a neurological injury, where damage to the spinal cord results in full or partial loss of sensation, movement and/or bodily functions below the level of injury. According to the National Spinal Cord Injury Strategy Board (NSCISB), ‘few disabilities produce the devastation of a spinal cord injury. The effects extend beyond the individual patient and include the impact on the immediate family and society in general,’ (2012, p3).

With sufficient acute care and rehabilitation, people with an SCI have no significant reduction in life expectancy. As such, the rehabilitation process must prepare a spinal cord-injured individual for the rest of their life.

There are several causes and types of SCI, which affect the way a person is treated, rehabilitated and continues to live their life after discharge, as summarised below.

Causes: Traumatic and Non-traumatic

Traumatic spinal cord injuries (TSCI’s) are the most common, such as damage to the spine caused by falls, traffic incidents and sports. Non-traumatic spinal cord injuries (NTSCI’s) are the result of medical issues, such as infection, skeletal malformation, spinal tumours and spinal cord stroke.

Type: Level of injury

Due to the way nerves are distributed through the body from the spinal cord, the higher the level of injury to the spinal cord, the more extensive the effect. As shown in fig. 2.2 below, the spinal cord and column are divided into three main areas known as Cervical, Thoracic and Lumbar regions (even lower injuries can occur in the Sacral and Coccygeal regions, however these levels of SCI are rare and will not be discussed further in this study). The vertebrae in each area are numbered, for example C1-C7, T1-T12 and L1-L5. The letter and number of the vertebrae where the injury occurred are used to identify the level of a person's SCI.

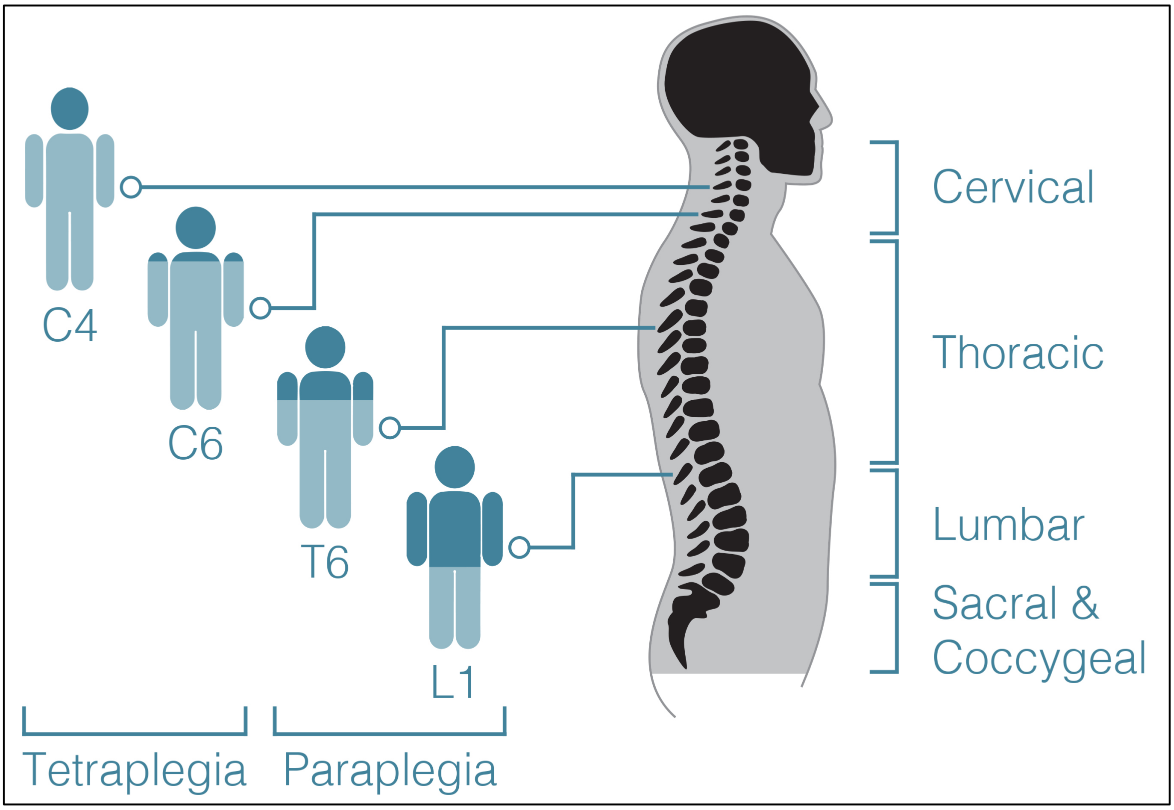


Fig. 2.2: A diagram explaining how the level of SCI affects functional loss.

Cervical

Injuries to the cervical region of the spinal cord result in tetraplegia (sometimes referred to as ‘quadriplegia’), meaning all four limbs are affected to varying degrees. People with higher-level injuries often require artificial ventilation immediately after injury and possibly long-term.

Speaking and swallowing, plus head, neck and sometimes shoulder movement remains unaffected for cervical injuries. As such, people with this type of injury may be able to use electric wheelchairs with chin or pneumatic controls and can be independent in terms of vocally directing their care, but they will be dependent on caregivers to carry out these tasks.

Lower cervical injuries allow incrementally more movement of the upper limbs, from elbow flexion, wrist extension, elbow extension and finger flexion. This, in turn, gives more ability to carry out activities of daily living (ADLs) more independently e.g. washing, dressing, grooming and toileting. People with cervical injuries have fully or partially paralysed lower limbs also.

Thoracic

People with thoracic injuries have normal upper limb function and have the potential to be fully independent with activities of daily living, manual wheelchair propulsion, housework and driving. The lower the injury the greater the level of trunk stability, so inpatients with thoracic injuries are given training in advanced wheelchair skills (such as navigating rough terrain, kerbs and stairs). People with lower thoracic injuries may be able to walk shorter household distances i.e. therapeutic walking with walking frames and lower limb orthoses.

Lumbar

People with lumbar injuries are often able to walk greater distances unassisted and are fully independent with ADLs. This group of inpatients receive advanced wheelchair skills training, as part-time or full-time wheelchair use may be necessary. Some patients with lumbar injuries achieve functional walking with aids (Medscape, 2013).

Type: Complete and Incomplete

SCI's can be either complete or incomplete at any level. A complete injury means there is no transmission of nerve signals below the level of injury, meaning the resulting loss of function below that level is very unlikely to be regained. An incomplete injury, as the name suggests, means that some nerves remain intact and are still able to function. Depending on which nerves remain, some level of sensation or motor control may remain and potentially be improved, however this cannot be guaranteed. As such, incomplete lesions 'can lead to increased anxiety', as 'it may not be possible to predict functional outcome,' (Grundy and Swain, 2002, p55).

2.4.3 Effects of SCI

Common effects

As discussed above, all complete or incomplete injuries at any level result in full or partial loss of muscle movement and/or sensation below the level of injury (respectively). Because of this, an individual with a SCI is taught to be vigilant in preventing pressure sores that could be caused by sitting/lying in one position for too long or by wearing inappropriate clothing.

As well as the more obvious effects of paralysis, a person with an SCI also experiences loss of spontaneous control of their bladder and bowels, and as such must learn techniques to manage this (for example, the use of catheterisation or manual evacuation). However, people with higher-level injuries have more limited options for bladder and bowel management due to reduced power and dexterity of the upper limbs and hands.

Individual effects

Neurological pain can be an issue for people with a SCI. Although this is often treated or managed during rehabilitation, for some it can remain a part of daily life.

Spasticity (involuntary movement of muscles below the level of injury) can be problematic in making rehabilitation activities more difficult, but can help to maintain muscle bulk and possibly bone density (Grundy and Swain, 2002). This is more prevalent in people with incomplete spinal cord injuries, and can be managed with medication or through 'passive stretching' of the affected limbs.

Sexual function may be affected to a varying degree or not at all. Fertility is unimpaired in women but may be partially or substantially decreased in men. There are various treatment options available for sexual function and fertility.

Autonomic dysreflexia is a potentially life-threatening complication affecting people with SCI's at the mid thoracic level and above, who are unable to regulate their blood pressure after experiencing a painful stimulus below the level of injury. For example, when an uninjured person experiences pain from a stubbed toe, following a short period of high blood pressure, their body has a reflex to adjust the blood vessels and regulate blood pressure accordingly. However, a person with a SCI cannot feel the stubbed toe, so they are unaware that there is a problem. The rising blood pressure is not regulated by their bodies and escalates, putting them at risk of stroke if it is not recognised and treated. Patients are taught to be aware of symptoms such as headaches, dizziness, sweating, and anxiety, and tablets can be taken to relieve the high blood pressure while the stimulus is identified and removed.

2.4.4 Impacts of SCI

Cognitive

There are no cognitive implications of an SCI, although some people suffer a brain injury and SCI in the initial incident. However, the effects of an SCI in combination with a brain injury will not be included in this study.

Physical

With any form of paralysis it often becomes more difficult to navigate the everyday environment, including the individual's own home, which may require alterations if it is not suitable for a wheelchair user. Some homes cannot be made suitable for wheelchair use, so some people with a SCI require rehousing. Brisenden (1986) discusses this in terms of the 'social model' of disability, suggesting that unlike the 'medical model' of disability (which locates the disability in the reduced bodily functions resulting from an incident or illness), it is actually the unsuitability of the environment that is the disabling factor.

Psychological

Sustaining a devastating injury such as a SCI, and the drastic changes in lifestyle that are necessary as a result, can provoke a range of emotions and psychological difficulties including guilt, issues with identity, post-traumatic stress disorder and problems with memory, concentration and problem solving (Grundy and Swain, 2002). These, and others, will be explored more fully in section 2.5.

Financial

Financial stability naturally affects how a person copes with a SCI (Grundy & Swain, 2002). Approximately 20% of the patients in the spinal injury unit (SIU) featured in this study have a legal claim to funding and approximately 20% of patients return to work, however the majority of patients require long-term state funding (Allan, 2013).

On a broader, societal level, NSCISB explain that 'the financial cost is considerable,' (2012, p3).

2.4.5 Rehabilitation Needs

Effective initial treatment of a suspected SCI and the avoidance of complications requires specialised treatment and 'a high level of input from a dedicated multidisciplinary team' (NSCISB, 2012, p3). This is facilitated, after initial stabilisation at the scene of the incident or in the local receiving hospital, by transfer to a Spinal Injury Unit (SIU). Management of SCI in an acute specialised unit is associated with reduced mortality, increased neurological recovery, shorter length of stay and reduced cost of care, compared to treatment in a non-specialised centre (Grundy and Swain, 2002).

The rehabilitation process (following initial stabilisation of the injury) aims to reduce the impact of the injury on a person's daily life so that they can live as fully and as independently as possible. The 'success' of this rehabilitation is dependent on the extent of a person's injury but also on the individual's personal circumstances and preferences. As such, staff must work with patients to find body management techniques (such as bowel and bladder continence) that fit into the patient's lifestyle, reducing the risk of further medical complications (Grundy and Swain, 2002).

2.4.6 Incidence of SCI

Incidence in the UK

There are estimated to be 40 000 people, of all ages and backgrounds, living with a spinal cord injury in the UK (Back Up Trust, 2014). Studies of aetiology, age and gender are rare for this population, with the exception of a recent longitudinal demographic study of the host SIU (McCaughey et al., 2016). As such, incidence will be discussed in terms of the Scottish population of spinal cord-injured individuals over the 20 years prior to this study (1994 – 2013).

The Queen Elizabeth National Spinal Injuries Unit (QENSIU) patient population

Incidence

According to McCaughey et al., 1638 patients sustained a TSCI in Scotland between 1994 and 2013 (2016, p2), an incidence rate that is 'comparable with that found in other studies in Western Europe,' (p4). NTSCI's are much less commonly referred to QENSIU, with '292 patients with NTSCI admitted to the QENSIU for specialist care' during this time period (p2). As such, for brevity, this introduction will describe the demographic information for TSCI's only.

Causes

McCaughey et al. state that 'the most common cause of TSCI in Scotland was falls,' which became significantly more common over the study period, 'from 41.6% between 1994 and 1998 to 60.0% between 2009 and 2013' (p2-4). The second and third most common causes for TSCI were road traffic collision and sports respectively.

Level of injury

The number of TSCI's in Scotland resulting in a cervical injury has increased over the 20 years prior to this study, 'from 58.4% between 1994 and 1998 to 66.3% between 2009 and 2013,' (p3), making a significant majority of the patient population.

Age

McCaughey et al.'s study indicated that 'the mean age at which TSCI occurred in Scotland was 47.2 years,' (p3) which had increased significantly over the study period; from 44.1 years to 52.6 years, with older patients more commonly sustaining their injury due to a fall. It is important to note that this trend also mirrors the rising average age of the Scottish population.

Gender

During the 20-year study period, McCaughey et al. found that the proportion of males sustaining an SCI remained 'relatively stable' at 75.2%; a population split that is 'within 5% of the rate found in the majority of studies in Europe,' but predict that 'the proportion of females sustaining a TSCI will rise,' given the associated increase of TSCIs caused by falls in the elderly (p4-5).

2.4.7 Summary

A spinal cord injury is a devastating event that affects all areas of an individual's life, including movement, sensation, bodily functions, where that individual lives and where they can work (if at all). Acute care and rehabilitation of the injury aims to support the individual to live as independently as possible, but the potential for this varies depending on the level of injury sustained.

The diversity of the spinal cord-injured population, the varying effects of an SCI and the varying degrees of success within treatment and rehabilitation all contribute to the individuality of each person's experience of living with their SCI. Although there are some functional similarities between people of similar levels of injury, it is not possible to describe a typical SCI lifestyle.

However, due to the rich demographic data available for this study's spinal cord-injured population, some recent trends in SCI incidence should be acknowledged. For example, a significant increase in the number of older people sustaining cervical injuries presents implications for the provision of acute care and rehabilitation, such as the potential for co-morbidities.

2.4.8 Implications for the study

The literature reviewed in this section describes the injury and its effects in a biomedical way. This is vital in establishing an overview of SCI and the general rehabilitation needs, but does not give an indication of the experience of SCI, nor does it present a clear picture of the rehabilitation process (where this study will be situated). The collaborative nature of this study (between the university and the host SIU) will facilitate face-to-face contact to explore these issues, but before any contact is made with the staff, patients or family members, the relevant medical literatures were reviewed to ensure the researcher conducted herself in an informed and sensitive manner within the SIU. This will be presented in the next two sections.

2.5 What is the experience of Spinal Cord Injury?

2.5.1 Introduction

The literature available concerning the experience of SCI mainly described the point of injury and life after discharge, largely from medical practitioners' perspectives in a quantitative manner, as described below.

2.5.2 Experience of SCI post-discharge

Patients have reported believing that their extended stay in an SIU had 'institutionalised them', and the sense of not belonging in their own home upon discharge can lead to feelings of frustration and loss (Dickson et al., 2011). After spending potentially months in a specialist hospital environment, SCI individuals have described that 'while [they] were pleased to return home to their loved-ones, they seemed to feel that they were sacrificing their care and amity in doing so,' (ibid).

Depression

'Depression is probably the most frequently studied psychological variable among persons with spinal cord injury,' (Elliott and Frank, 1996, p816), yet when attempting to provide a brief overview of this research, the researcher found several conflicting views and disagreement in the level of impact depression has, as outlined below.

It could be assumed that sustaining an SCI would be followed by a period of depression for the average person. Indeed, some literature claims that this is a necessary component in learning to cope (Weller and Miller, 1977) and that a person with an SCI must be in denial if they do not (at least initially) experience this (Stewart, 1977). However, Frank et al. state that ‘contemporary research has failed to support this view and has provided evidence that depression is maladaptive in rehabilitation and adjustment,’ (1987, p611) – a position supported by other, unrelated studies (Judd et al., 1989).

Hancock et al. (1993) found that, compared to a control group matched for age, sex and education, only one third of people living with an SCI were more anxious and depressed than their able-bodied counterparts (according to self-administered questionnaires). As such, the authors claim that it ‘supports the increasing evidence that severe depression and anxiety are not inevitable following SCI, and that it is not necessary to display depressive behaviours in order to adjust well,’ (p355).

This view is also shared by Dickson et al., who state that incidences of SCI individuals experiencing clinical depression varies from 15% - 35% (2011). Of the longitudinal studies available, it appears that the rates of anxiety and depression experienced by spinal cord-injured people change little over time, and psychological distress has been found to be more strongly linked to the presence of medical complications rather than the severity of the injury itself (Scivoletto et al., 1997).

This review does not intend to underestimate the suffering of anyone who has sustained an SCI, or the people close to them. It simply aims to highlight that assumptions cannot be made about a person’s ability to cope, and to recognise the difficulty of gaining insight into such a life-changing event. In terms of this PhD, it can be determined that the majority of the inpatient community of an SIU can be safely engaged in exploring the experience of sustaining an SCI, providing suitable gatekeeping is in place that can highlight patients who may not wish to discuss these matters.

Adjustment

Dickson et al. (2011) provide an extensive review of the literature summarising the factors affecting adjustment to SCI, including (among many others) personality factors, purpose in life, locus of control and social support. However, their own Interpretive Phenomenological Analysis (IPA) of the post-discharge experience of SCI individuals, Dickson et al. found that the biggest difficulties in adjustment were a loss of camaraderie, a lack of post-discharge care and other people's reactions to SCI (2011). Clearly, adjustment is an individual experience, but 'most SCI individuals make a positive psychological adjustment... [which is] enhanced over time,' (ibid).

Some patient narratives choose to highlight these positive adjustments, with one narrator explaining how '[the injury] could be the best thing that's ever happened to me. Physically, the worst, but mentally; I'm happier. I know who I am,' (Glory Film Co, 2011).

Quality of life

People living with an SCI tend to have lower self-evaluation of quality of life than non-injured people (Dickson et al., 2011). Whilst 'the reported quality of life of people who have a spinal cord injury remains stable during the first year following discharge,' (Kennedy & Rogers, 2000), quality of life scores have been found to be 'better in persons injured many years ago, as compared with those recently injured, suggesting an adaptive process operating over a long period,' (Westgren & Levi, 1998, p1433). It has also been found that the 'presence of complicating medical problems, such as severe pain, problematic spasticity, and incontinence, seem to have more negative effects on [quality of life] than the extent of SCI as such,' (Westgren & Levi, 1998, p1433, see also Dijkers, 1999).

However, in a review of the literature concerned with the quality of life in people with SCI, Hammell signposts studies that highlight 'the wide variety of research designs and instruments, modes of analysis and sample characteristics that make comparisons and overall conclusions problematic,' a problem exacerbated by 'conceptual ambiguity surrounding the use of different terms, such as 'life satisfaction', 'well-being' and 'quality of life',' (2004, p494). Hammell states that to investigate a context-dependent subject such as 'quality of life' would 'require the use of both qualitative and quantitative methods to tease out and illuminate different dimensions of this complexity,' (p497).

Identity

Over a series of semi-structured interviews with people with an SCI 3-5 years after their injury, Carpenter concluded that the experience of gaining an SCI raised issues of 'rediscovering self', where the 'alteration in body image and physical functioning... were seen as separate from the internal concept of self,' (1994, p619). Carpenter's interviewees also described the need to 'challenge the stereotypes and attitudes of disability... and to change their own subjective experience of disability,’ (p621, see also Dickson et al., 2011 and Hancock et al., 1993).

Public appraisals of SCI

Unfortunately, the stigma associated with disability is still prevalent. As Dickson et al. (2011) explain, some people can assume that a person with a SCI has mental health issues as well as a physical disablement. Dickson et al.’s interviewees also reported feelings of frustration that ‘they were no longer treated as an equal,’ or feeling invisible, embarrassed or worthless when ‘people would talk to whoever accompanied them in their wheelchair as opposed to them directly.’ As a result, many interviewees reported ‘withdrawing completely from social situations.’ In their recommendations following this study, Dickson et al. call for greater public awareness of SCI and its reality. This suggestion is corroborated by Morris et al., who found that ‘able-bodied individuals’ appraisals of disability after imagined SCI are much more negative than the actual appraisals of disability in real spinal cord-injured individuals,’ (2013, p338).

Relationships

DeVivo and Fine found that, in comparison with US averages, ‘substantially fewer marriages and more divorces occurred than were expected,’ (1985, p501) in people with an SCI within 3 years of injury. Additionally, some people with a SCI find that friends from before their injury can struggle to cope and are unsure how to act around them, or even stop visiting them altogether (Glory Film Co., 2011, Dickson et al., 2011).

Experiences of spousal caregivers

Insights from section 2.4 have emphasised the vital role of family members, perhaps none more so than those who choose to take on the role of primary caregiver. Dickson et al. (2010) provide the first Interpretative Phenomenological Analysis (IPA) exploring the impact this has on spousal caregivers, and identify 3 main themes in the interviews conducted:

- The emotional impact of the spinal cord injury; including the anxieties related to their partner’s extended stay in the SIU, a sense of “mourning” the sudden loss of their spouse and the lives they had once known,’ and uncertainty of what their new lives will bring.

- The post-injury shift in relationship dynamics; many participants reported taking on a more ‘maternal’ role, particularly following the loss of a sexual relationship and a need to carry out tasks of intimate personal hygiene for their spouse. Participants appeared to feel guilty about the changing feelings towards their spouse, but ‘many participants seemed to come to terms with the profound changes in their relationship dynamics over time,’ and for some, ‘although their relationship was altered... the bond between them actually became much stronger.’
- The impact of caregiving identity; participants reported difficulties in ‘marrying [their] caregiver role with the challenge of sustaining [their] own identity,’ reporting feelings that ‘their wellbeing became secondary to that of their injured partner,’ and experiencing a ‘lack of freedom or spontaneity.’

It is worth noting that Dickson et al.’s work was conducted with the same outpatient community as the host SIU for the study, and as such her findings may be more generally applied to the current research.

2.5.3 Discussion

The majority of studies exploring the ‘experience’ of spinal cord injury do so through quantification of subjective experiences, using scores of anxiety, depression, quality of life, etc. Although this plays an important role in providing robust, generalisable evidence to guide healthcare provision, it cannot provide an understanding of the whole, human, lived experience of these conditions (Dickson et al., 2010, 2011, Hammell, 2004). Although many studies make great efforts to compare the experience of spinal cord-injured individuals with ‘controls’ in terms of their demographic data (i.e. age, gender, education), ‘people with an SCI’ are still largely (if not, perhaps, intentionally) discussed in a homogenic manner. Nolan (2013) provides a review of the literature of male experiences of SCI where only eight papers were identified, and also highlights the ‘scarcity of literature on the female experience of spinal cord injury,’ (p588).

Given the far-reaching nature of the impact of SCI, familial caregivers must also be given equal consideration when exploring the ‘experience’ of it. Dickson et al. (2010) provide a rich ‘insider’s perspective’ in a field largely dominated by quantitative approaches. They suggest that a lack of opportunities to contribute during their partner’s inpatient rehabilitation (particularly during the early stages), and subsequent feelings of loss of control, may contribute to the anxiety felt by caregivers approaching their loved-one’s discharge. As such, Dickson et al. advocate for caregivers to be ‘more actively involved (or at the very least consulted) in decision-making processes and care provision during the rehabilitation period.’ This provides further support to and extends the hypothesis presented in the Introduction chapter that facilitating a greater sense of agency within the SCI rehabilitation process may help both patients and their family members adjust to life post-discharge.

2.5.4 Summary

The limited literature available on the experience of living with an SCI suggests that rates of long-term clinical depression aren’t as high as may be assumed with such a life-altering event. Although self-rated quality of life scores tend to be lower in spinal cord-injured individuals than in the rest of the population, evidence suggests that most make a positive adjustment to their new situation, with the presence of secondary complications causing more distress than the extent of the injury itself. The reactions of and relationships with other people play an important role in a person’s experience of SCI, particular when they may be struggling with issues of their own identity in a ‘new’ body.

2.5.5 Implications for the study

Whilst section 2.4 has presented an overview of trends within the spinal cord-injured population's experience of SCI post-discharge, accounts of the SCI rehabilitation process (and patient experiences within it) were not forthcoming in the medical literature. As such, this contextual review will continue by exploring the host-SIU's specific rehabilitation processes.

2.6 What is the SCI rehabilitation process?

2.6.1 Introduction

In this section, QENSIU documentation, interviews with QENSIU staff and QENSIU research seminars were reviewed to better understand the SCI acute care and rehabilitation process.

2.6.2 Introduction to the Spinal Injury Unit (SIU)

General Principles

Prior to the second world war, spinal cord injury had a high mortality rate. However, in 1944, Stoke Mandeville hospital set up a SCI-specific unit to showcase various techniques (largely credited to Professor Sir Ludwig Guttmann) to dramatically reduce morbidity

(Buckinghamshire Healthcare, 2014). This changed the opinion of SCI, which traditionally was not considered as something to be treated [Allan, 2013]. The Spinal Injuries Association (2009, p7) neatly summarises the foundations of SCI treatment and rehabilitation:

> ‘Principles for the management of this diverse patient group have moved on from issues of survival and now aim to minimise impairment, prevent further disability and optimise activity and participation... Specialist spinal cord injury care incorporates the core components of acute care, restorative rehabilitation, reintegration into the community and long term follow-up into a seamless clinical service’.

Although general principles of best practice are shared across spinal injury units (SIU’s), a ‘universal model of care has not been adopted across the service,’ (Spinal Injuries Association, 2009, p8). This suggests there is an opportunity to enhance SCI rehabilitation delivery on a local scale, with the potential to expand to other SIU’s.

The Queen Elizabeth National Spinal Injuries Unit (QENSIU)

QENSIU, one of twelve specialist spinal injury centres in the British Isles (see fig. 2.3) and the only SIU to serve the Scottish population, receives approximately 500 referrals a year. Of these, approximately 150 – 200 are admitted, as the SIU will only receive patients who have a spinal cord injury (that is not progressive). Approximately half of the patients transferred to QENSIU do so within 48 hours after injury, with others require immediate treatment in their local hospital first.

Fig. 2.3: A map depicting the locations of the twelve specialist spinal injury units across the UK (Spinal Injuries Association, 2009).

Within QENSIU, there is an acute care ward that holds 12 beds and a rehabilitation ward that holds 36 beds. Tetraplegic patients will usually stay in the unit for approximately 6 months, whereas paraplegic patients (who have a greater rehabilitation potential) typically tend to stay for 9 months (McCaughey, 2014). There are currently approximately 3000 patients registered to QENSIU living in the community.

2.6.3 QENSIU Rehabilitation Pathway

To begin exploring the acute care and rehabilitation processes, the QENSIU Patient Pathway document was reviewed for a general orientation. The pathway shows a multidisciplinary approach including medical staff, nursing, physiotherapy, occupational therapy, psychology and social work. The role each discipline plays in an individual's SCI acute care and rehabilitation, and how that changes as the patient progresses, is summarised below.

Patient Pathway

After being initially stabilised at the scene of the incident (in the case of TSCI), including ventilation if necessary, the spinal cord-injured individual will be taken to either their local receiving hospital (if immediate treatment is needed) or to their national SIU.

The roles of staff during acute care and rehabilitation have been summarised within a map of the host SIU, shown in fig. 2.4. In addition to the SIU staff, a Social Worker will become more involved in the rehabilitation process towards the end of a patient’s stay, ensuring their community needs are met in time for discharge.

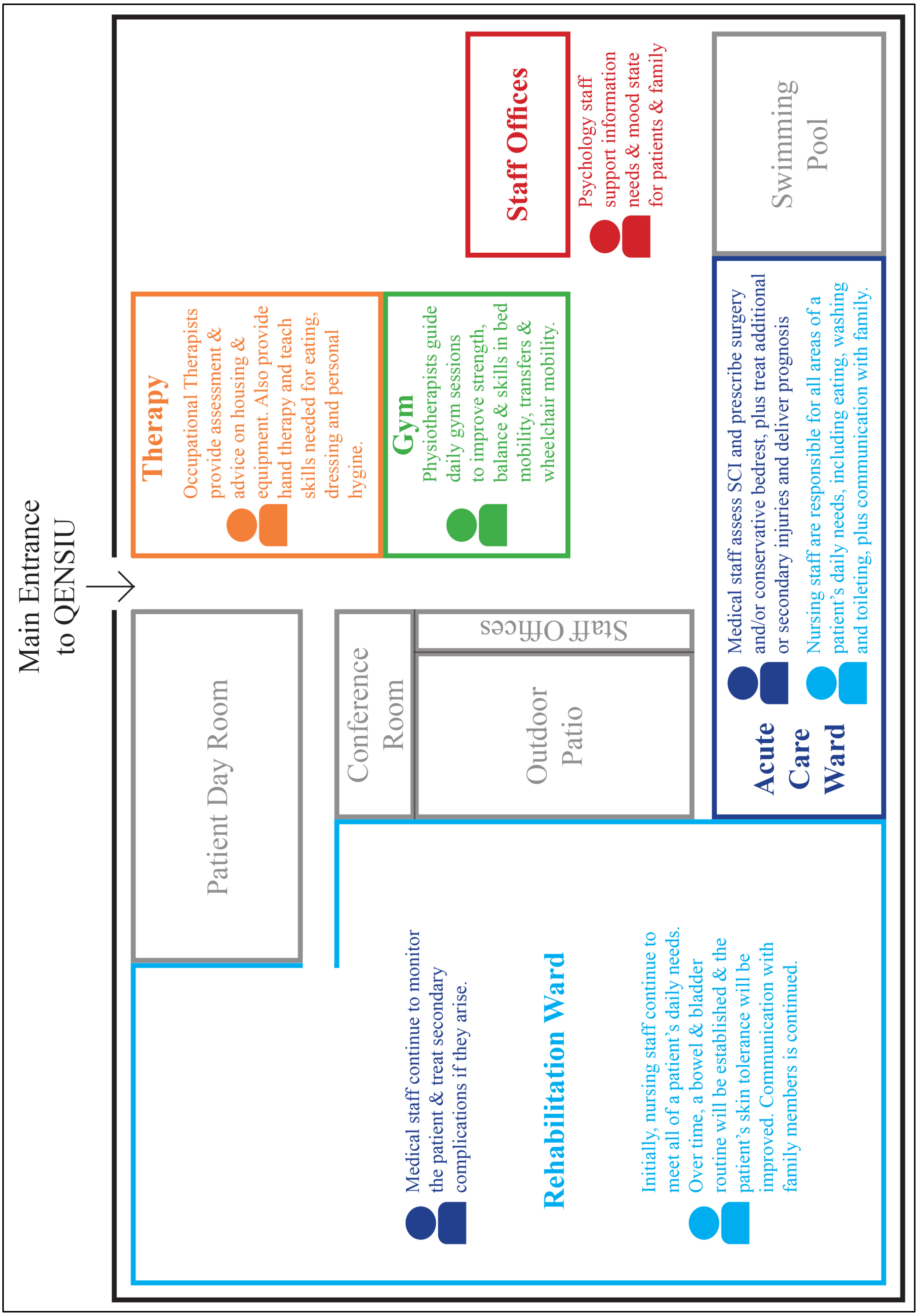


Fig. 2.4: A simplified plan of QENSIU with associated staff roles.

Analysis of the Patient Pathway

After developing an overview of the acute care and rehabilitation process, as well as the responsibilities for each department within the SIU, the researcher annotated the patient pathway (provided by the host SIU in a large printed format) with her initial thoughts, questions and interests (as shown in fig. 2.5). Many of these annotations focussed on the transfer of information and how the patient/family members retain this, as well as an interest in how patient progress is communicated.

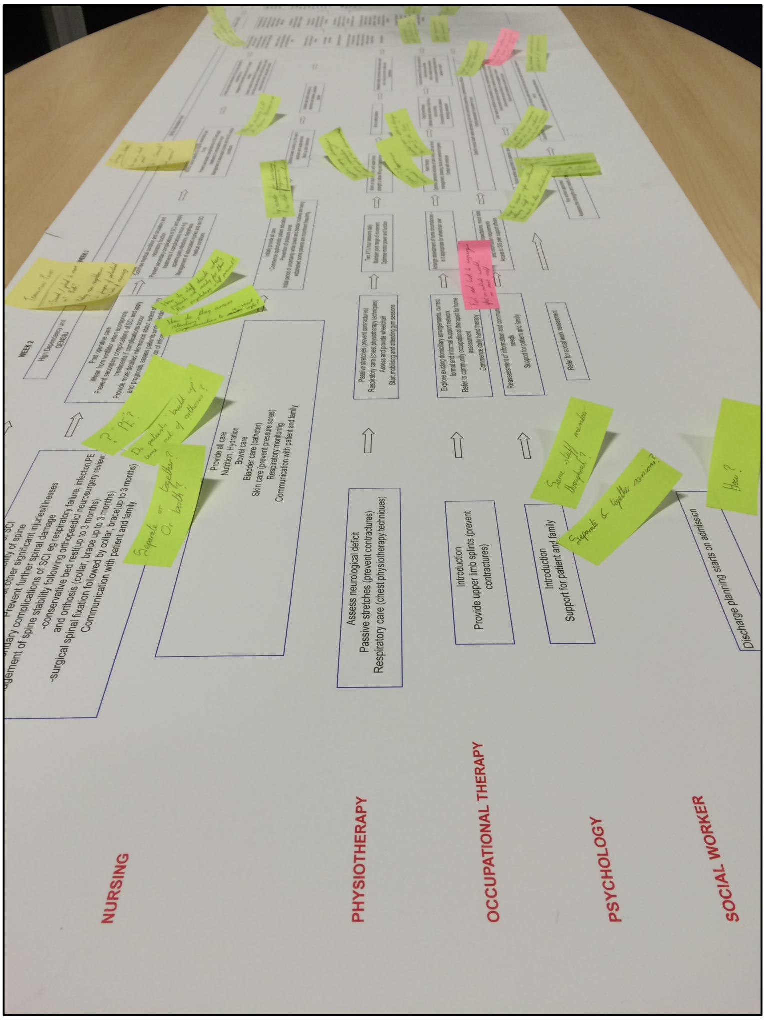


Fig. 2.5: Annotations of the QENSIU Patient Pathway.

What remained unclear from the Patient Pathway was the way(s) in which each discipline meets its responsibilities, or how they work together to support a patient's journey through the unit. The researcher was also unsure how patients and/or family members are practically engaged in the responsibilities of each department described, as well as the 'milestones' that dictate when a patient is ready to progress to the next stage of their rehabilitation.

As such, a series of semi-structured interviews with senior QENSIU staff was arranged to explore this further.

2.6.4 Staff Interviews

A series of 11 informal, semi-structured interviews was arranged via email with senior staff across the SIU, including nursing, physiotherapy, occupational therapy and discharge coordination. Email addresses were given to the researcher with each staff member's permission via the co-supervisor. Each invitation email contained details of the study, the purpose of the interview and a copy of the consent form they would be asked to sign if they agreed to participate. Completed consent forms were gathered from each participant and securely stored on hospital premises.

Interviews ran between 60 and 90 minutes, with handwritten notes taken by the researcher. A topic guide (see appendix 2) was prepared ahead of the interviews to guide the conversation. Topics included the staff member's background, their role, how they interact with patients and how they coordinate with the rest of the SIU. Although this guide aimed to give structure to the interview, the researcher also explained that she would welcome other, related topics that would enhance her understanding of the SIU community.

2.6.5 Findings from Staff Interviews

Some of what was described in the staff interviews corroborated and/or expanded upon the process shown in the Patient Pathway documentation. However, beyond this, the informal discussions began to elicit more information about the unquantifiable elements of the rehabilitation process, in terms of staff's experiences and their perceived experiences of patients, as discussed below.

An unusual healthcare model

It is important to acknowledge that SCI deals with a very different type of healthcare than normal. Traditionally, the expectation is that a doctor will make you as well as you were before your illness or injury, however this is not often possible after sustaining an SCI. Staff instead discuss the concept of a lifestyle managing the effects of an SCI as the 'new normal'.

Working relationships

Another difference between the SIU and most healthcare contexts is the longer length of stay for inpatients, and as such the long-term working relationships that staff can develop with them. Several rehabilitation staff members commented that this was important to them, describing how they will often introduce themselves to the patient early in their journey, perhaps months ahead of actually working with them. Others also explained that they will follow a patient's progress through the acute care ward ahead of working with them in the rehabilitation ward, either through informal interactions or in multidisciplinary meetings. Indeed, Grundy and Swain also highlight that 'factors which contribute to establishing close and supportive relationships between staff and patients often blur boundaries between professional and personal roles,' (2002).

It is clear that the senior staff interviewed place a high priority on getting to know the patients as much and as early as possible. For example, one rehabilitation ward nurse explained that she tries to find out about a patient's personal priorities and 'anchor' the rehabilitation activities onto that (i.e. to attend your cousin's wedding, you need to have a stable bladder routine, be able to sit in your chair for 8 hours, etc.).

Changing relationships over time

As inferred from the Patient Pathway document above, a patient's journey through the SIU involves a transfer of responsibility from staff to patient. This process could arguably be said to begin in earnest when the patient moves from the acute care ward to the rehabilitation ward – a transfer which has reportedly been described by a patient as 'like moving from the Hilton to a Travelodge'. Although this was said in humour, the contrast between the acute care ward (a comforting environment with up to 24 hour, one-to-one nursing) and the rehabilitation ward (with its 36 beds and focus on independence) has proven difficult for many patients in the past.

Ownership

Many staff members highlighted the concept of ownership (of the injury and its management), making it clear that the patients who take this ownership during their stay in the SIU are often more able to cope in the community.

Flexible nature of care

Staff must be adaptable and responsive to the daily needs of patients and colleagues. This is particularly true for patients with incomplete injuries, whose potential progress is uncertain, but all patients share the risk of complications (such as a bladder infection) delaying their rehabilitation. As well as practical needs, staff must also be responsive to the 'patient's pace,' using their experience to judge when a patient is ready for more information or to try new activities.

Coordinating departments

There are a range of daily, weekly and monthly meetings that help to coordinate the various SIU departments in their care for the patients on an individual and group level. Established, shared documentation allows each member of a department to inform and receive feedback from these meetings via their senior member. This is to be expected from a hospital that relies on a multidisciplinary approach, but interestingly most staff members interviewed emphasised the informal, ad-hoc, daily contact with other departments as key to creating a 'symbiotic relationship.' It was not surprising, therefore, to learn that a majority of the senior staff interviewed have been working at the unit since it opened in 1992, some 'working up through the ranks' to reach their senior position today.

Changes in SCI rehabilitation

During their 10+ years each of delivering SCI rehabilitation, several staff members reported changes in the way they interact with the patient community. The changes in the SIU population have already been discussed in terms of demographic data (i.e. age, level of injury), but the staff interviews added to this by describing a shift in some (particularly younger) patient attitudes towards the pathway provided. The staff described a more critical, perhaps 'consumer-like' attitude, with a growing importance to explain the 'why' behind rehabilitation options suggested for patients. This is arguably a positive indicator that at least some of the patient population is ready for greater control over their rehabilitation, as is the aim of this study. However, it was also explained that this more pro-active approach, combined with the heightened emotions of patients and their families, can sometimes lead to conflict with staff; particularly during times of decision-making such as the Goal Planning Meeting (described below).

The family role

Although the literature describes how family members often take on a role of caregiving (Grundy and Swain, 2002), staff interviews elaborated on this, describing how family members learn to be a part of the patient's 'new normal'. It was explained that families need to be given the same information as patients, and that this is achieved through formal processes (such as a 'Relatives Education Day', with informative presentations from each department) and on an ad-hoc basis (such as during visiting times).

It is clearer, following the staff interviews, that the family role is substantial and adds another layer of complexity to information transfer from staff within the SIU context.

2.6.6 Discussion

By combining insights gained from QENSIU process documentation ('what we do') with informal interviews with senior staff members ('how we do it'), a clearer account of SCI rehabilitation has been created whilst also beginning to build working relationships with senior staff in the host SIU. This process also ensures that the researcher is familiar with the SIU context before making any contact with the patient community.

Although this study is centrally concerned with the patient experience of SCI rehabilitation, it must be considered that patient experience is facilitated by staff experience. As a result, it is important to get to know the staff as people, with their own concerns and daily routines, and understand the experience of delivering SCI rehabilitation. It was found that face-to-face, semi-structured discussion was effective in this. The interviews also provided an opportunity for the staff to learn more about the researcher and the study, many of whom then invited the researcher to attend rehabilitation activities they were involved in. This included Patient Education Sessions and social events, which are described in more detail in section 2.8.2.

The SIU staff made it clear that it is not possible create a 'one size fits all' solution, and that care must be relevant to individual patients. What also became apparent is that there is a large resource of staff experience to draw from, so any designed interventions must be clear in their use but also flexible to accommodate staff's tacit knowledge. However, this collective experience may also come with traditional or 'set' ways of thinking. As such, inertia may need to be overcome in making changes in the rehabilitation process, which must be considered when attempting to engage staff later in the study.

2.6.7 Summary

SCI rehabilitation is a complex, non-linear, first-time journey for patients within an established network of SIU staff. The experience and interdependencies of this staff ecosystem guides a patient towards achieving their individual functional rehabilitation potential.

Whereas medical staff (i.e. consultants) have a high level of input in the early acute phases, and are the first providers of information, their role reduces over time to monitor the patient and advise on treatment of secondary complications. Nursing staff, whilst also having a high initial input into the patient journey, remain heavily involved throughout the process as patients learn techniques to manage the bodily effects of their injury.

Physiotherapy and OT staff provide increasingly more input into the journey as the patient becomes more physically fit (and therefore able to learn more functional skills) and their equipment/housing needs become clearer.

2.6.8 Implications for the study

The insights generated to this point have explained the rehabilitation process, who is involved and what they are responsible for. However, an understanding of the patient experience of the SCI rehabilitation process is not yet clear and as such will be the focus of the next section.

2.7 What is the patient experience of the SCI rehabilitation process?

2.7.1 Introduction

Before accepting invitations from senior QENSIU staff to observe rehabilitation activities, the medical literature was consulted for any insights available into the SIU inpatient experience. Although some useful narrative accounts and qualitative investigations were found (Glory Film Co, 2011, Dickson et al., 2011), it was established that there is a paucity of literature that seeks to understand the patient perspective of SCI rehabilitation.

2.7.2 Experience of SCI rehabilitation

Patients are required to be immobilised in bed until the spinal column is stable. This stability can be achieved either by surgery or by natural healing of the spinal bones during a period of ‘bed rest.’ For patients, this initial phase of bed rest can be a ‘frustratingly slow’ process, where you ‘just stare at the ceiling’ and ‘listen to the noises around you,’ (Glory Film Co, 2011). In some of the outpatient narratives available, spinal cord-injured individuals describe how talking to other patients in the room around them helped them to deal with this stage, and describe how ‘it’s weird because you feel like you know them so well, but you have no idea what they look like,’ (Glory Film Co, 2011). The rehabilitation process itself is not discussed in detail, other than in giving generic advice such as to ‘try to relax’ and to ‘take things one day at a time.’ This may be due to time restrictions of the video narrative format of these sources, or perhaps one could infer that the rehabilitation process is not one the narrators would like to remember or discuss. In either case, one can assume that this initial phase at least must feel disorientating and isolating.

It could also be inferred that the rehabilitation process itself is complex and perhaps difficult to understand, given that in a study on nursing staff and patients’ perceptions of a

UK-based SIU, readmission patients ‘rated Programme Clarity to be significantly greater’ than first admission patients and staff with and without more than a year’s experience (Krishnan et al., 1988, p289). As such, the authors of this study call for SIU’s to focus on improving the clarity of their ‘rehabilitation programme, its rationale and relevance to recovery and everyday functioning,’ from the patient’s perspective (ibid, p292).

According to a series of interviews with SIU outpatients by Dickson et al. (2011), camaraderie between the patients ‘facilitated coping during the rehabilitative period’ and contributed to feelings of security within the SIU. Many participants reported feelings of fear about returning home, where ‘they would be “on their own” .... [and] have to deal with the harsh reality of their injuries.’ As described above, Dickson et al. (2010) reported similar feelings of anxiety about discharge from spousal caregivers. Grundy and Swain concur that discharge can be a ‘considerable challenge’ for patients and their families, who at that point are ‘often having to cope with lack of stamina; loneliness; social isolation, and the changed relationship caused by injury,’ (2002).

2.7.3 Discussion

Although some key studies (i.e. Dickson et al., 2011) provide rich insights into the patient experience of rehabilitation, this is facilitated through reflective interviews after they have returned home, and as such elements of hindsight may affect the way the interviewees related their accounts. Literature on the experience of the rehabilitation process itself is not common, however, so there is a need to gain a better understanding of this for the purposes of this study.

2.8 Initial emergent issues

2.8.1 General areas of interest

Having built a broad understanding of SCI, its effects and the associated rehabilitation processes, the next step in developing an experiential understanding of the context will be to conduct primary research with the host SIU staff, inpatients and their families, involving observations and direct contact. Several potential issues to consider or address have already emerged from the work done to this point and will be used to give focus, but not dictate, the primary research process. These include:

- Enhancing the communication of expectations, from both patients and staff, given the need for both parties to work together towards the patient’s ‘new normal’ of health.

- Guiding, or facilitating richer discussions to help staff get to know the patient, so rehabilitation activities (such as learning a new bladder management technique) can be ‘anchored’ in the patient's existing interests or priorities.
- Supporting patients in developing a sense of ‘ownership’ over their rehabilitation, and the complex set of skills that must be learned from a network of staff.
- Considering ways in which family members can be more involved in the rehabilitation process, and the potential need to support both staff and patients as the latter move into positions of greater control.

As well as the general considerations listed here, two potential contexts for intervention were identified from the initial review and are described below.

2.8.2 Education

As suggested by the patient pathway, and confirmed by the staff interviews, the transfer of information from staff to patients is a cornerstone of SCI rehabilitation, and the processes by which this is achieved will be a point of interest going forward with this study. As well as the ad-hoc, opportunistic education described above, hour-long presentations on each rehabilitation topic (i.e. bowel and bladder management, skin tolerance, etc.) are provided once a week in the ‘Patient Education Sessions’. These sessions are run in 10-week blocks twice a year. In addition, a ‘Relatives Education Day’ condenses the 10-week course into a full day of presentations for family members of patients. The Spinal Practice Education Facilitator explained how she would like more methods of interaction from the patients and/or relatives in these sessions, and invited the researcher to attend them.

2.8.3 Goal Planning

The rehabilitation of each patient is guided by long-term and short-term goals. Approximately once every 4 weeks, each patient will meet with their assigned nurse, physiotherapist, occupational therapist and discharge coordinator (they may also invite 1-2 people important to them, such as a spouse, if they wish). During this ‘Goal Planning Meeting’, each department will report on the progress made so far by the patient and what the rehabilitation aims are for the next 4 weeks. There are strict criteria that the patient must meet before beginning the Goal Planning process, namely; the patient must understand what has happened, they must have received their diagnosis and they must be medically stable.

If a patient is not deemed able to make decisions for themselves, a Case Conference takes the place of the GPMs. The process of a Case Conference is similar to that of the GPM, except that decisions are made by the multidisciplinary rehabilitation team and the patient's family with patient input where possible. However, patients with additional needs such as this will not be directly involved in this study.

Staff members describe the Goal Planning Meeting as important in coordinating the team, identifying needs and helping to support the patient. It is also described by staff as 'empowering' for the patient and a process that 'increases their physical or vocal ability.' This clearly has resonance with the study's aim to explore patient participation within the rehabilitation process and will be a point of interest in the primary research, described in the next section.

2.9 What is the patient experience of learning to live with an SCI through the rehabilitation process?

2.9.1 Introduction

Although the literature can provide insight into the medical perspective of SCI (such as prevalence of clinical depression, etc.), the patient perspective of SIU rehabilitation is still unclear. In this section, the processes and staff-patient interactions by which rehabilitation is facilitated will be explored through observation, informal discussion, invitation into patient pathways and shadowing QENSIU staff. This ethnographic study generated a large amount of descriptive data from which several themes and activities of interest were identified.

2.9.2 Process of observation

The researcher conducted an in-depth contextual study over one year, facilitated by a research base within the SIU. According to Flyvbjerg, 'concrete experiences can be achieved via continued proximity to the studied reality and via feedback from those under study,' (p223, 2006), suggesting that this was a robust approach. Aside from the regular, informal, ad-hoc interactions that occur from spending time on the wards, the study was informed by 9 patient education sessions, 1 relative's education day, 8 goal planning meetings, 8 multidisciplinary staff meetings, 2 ward rounds, 1 day shift and 1 night shift shadowing acute care nursing staff, 1 day shift and 1 night shift shadowing rehabilitation nursing staff, 1 occupational therapy kitchen session, 1 outpatient clinic, 2 research seminars, 3 extra-curricular events and 9 miscellaneous staff meetings.

Anonymised, handwritten, ethnographic notes and sketches were taken during all observations, with the exception of the extra-curricular activities, where it was more practical to take notes after the event. These notes were then transcribed into separate Microsoft Word© documents, where points of interest were highlighted and the researcher's initial impressions were added in italics (a formal coding process of the data was conducted at a later stage, see 2.10).

2.9.3 Ethics

Disclosure Scotland was applied for and granted before the researcher had any contact with patients in the SIU. The researcher was then guided by the University's ethics office to ensure ethical conduct. Verbal consent was obtained before observations were made that included patients and/or their family, and written consent was requested before using any data in reports or presentations. In the case of tetraplegic patients, who were unable to give written consent, a witness could sign on their behalf or audio-recorded verbal consent was also sufficient.

Separate information letters and consent forms were written by the researcher and approved by the university ethics department for the purpose of these initial observations. The SIU media consent form and exemplar research consent forms from Leeds University and Edinburgh University were considered in the design of these.

Completed consent forms and all ethnographic notes were securely stored within the hospital premises at all times. Examples of the information letter and consent form used for the initial observations are available at https://radar.gsa.ac.uk/5828.

Organisational procedures, such as those in place to approve consent forms, were found to be equally as important as ethical practice of a more human nature. During the course of the contextual study, the researcher decided to leave observations early or not to attend some planned observations due to patients experiencing distress or staff struggling to find time in their workload. The loss of potential data in these cases was offset by the development of respectful working relationships with patients, family and SIU staff. These instances were rare, and if they were able, almost all staff and patients were keen to share their time with the researcher. As Woodcock and Georgiou describe, people can be 'eager to participate in research that [could] help the community to which they [belong],' (p149, 2007).

2.9.4 Method of analysis

This ethnographic work generated a large amount of descriptive data, including perceived emotional responses, the tools used, how information is transferred and how staff change their approach according to a patient's needs. During the course of the observations recurrent themes began to emerge. These themes were collected (with contributing evidence still identifiable to the source discipline and event) and presented to supervisors from the university and the host SIU, as well as the director of the SIU at the time, for discussion during four joint supervisory meetings. These meetings allowed corroboration, correction and/or expansion of some of the opportunities for investigation the researcher was presenting, which in turn guided further observations.

2.9.5 Key Observations

A significant benefit of this longitudinal ethnographic approach was a clear understanding of the daily routines of patients and staff members in the SIU. This included an awareness of how the rehabilitation activities may change for patients with different levels of injury or at different stages in their rehabilitation. As well as this practical understanding, experiential knowledge was developed and summarised into the key themes below.

Daily life is highly structured

From being woken up at the same time each morning, to getting to the gym sessions on time, to monitoring the time elapsed since last being turned in bed (to prevent pressure sores), a SIU inpatient's lifestyle is very regimented. Through immersion in the SIU, it became more apparent how many interactions with a patient are mediated through various documentation, particularly for nursing staff who often work irregular shift patterns. Despite this, it was clear that the staff observed work very hard to maintain strong working relationships with their patients.

Working relationships

As discussed above, the working relationships in SIU's are developed over a much longer period than in most healthcare services and are often much stronger because of this. In the initial stages of inpatient stay this manifests in terms of emotional support, as one acute care nurse explains:

> ‘Sometimes you feel like you need to be a psychiatric nurse as well. It’s usually at night when the lights are off that people want to talk... I’m glad [when they want to] talk.’

Although it would not be appropriate to sit in on these types of conversations, nursing staff were also observed approaching and spending time with distressed family members, away from the patient. There is no place in the QENSIU documentation to explain this part of the rehabilitation process, yet it is clearly crucial to patients’ and family members’ development. Other, perhaps uncredited work in which strong working relationships enhance a patient’s progression is the seemingly natural way in which staff members differentiate their approach according to the patient with whom they are trying to engage. This may include using different, simpler language or involving family members to a greater or lesser extent.

Information

Patients will almost always meet their consultant on their first day in the SIU, as they will conduct the initial neurological assessment and often have an accurate idea of the patient’s prognosis from the beginning. However, patient awareness and retention varies during this first meeting, and with most patients a lot of things that were discussed ‘crop up again’ several weeks later. It was explained that it is difficult to judge when a person is ready to hear and discuss their prognosis and other types of information; some patients are very ‘in the moment’ and want to know about that given week, whereas some are very future-thinking and ‘pragmatic’. It appears that each patient must be guided towards the staff’s level of knowledge about their injury, as and when they are ready.

Ownership

Until this observational period, staff and literature had discussed the importance of patients taking 'ownership' of their injury but only in abstract terms. In practice, it appears that this occurs in many small, different ways. For example, patients are able to accept or deny their prescribed medication, so to help patients to learn about their medication and make an informed decision, the medication may be described in terms of its effects rather than its name.

Due to the personal nature of some rehabilitation activities, such as bowel management, some patients struggle to engage with ‘taking ownership’ and believe that they will ‘sort it out’ once they return home. However, staff explained that the time to ‘sort’ these routines is within the SIU, and there is a need to engage patients with their own injury and to take responsibility of their resulting care.

Whilst some ownership is offered to patients gradually, other rehabilitation services for additional support are optional from the beginning, including psychological support, chaplaincy, social events and specialist drop-in services such as for sexual issues.

Decision-making

Given the interest in enhancing patient participation within SCI rehabilitation, key points of decision-making were a focus throughout the observations and are summarised below:

- Multidisciplinary Meeting – this weekly meeting gathers senior staff from each department to discuss the SIU on a macro level, without patient involvement. Overall progress of each patient case is discussed briefly, with coordinated problem solving and estimations of potential progress.
- Ward Rounds – a selection of senior staff visit each patient at their bedside 3 times a week to discuss actions to be taken over the next few days, such as any investigations that are required in that time. It is not clear if patients always understand the reasons for these investigations, such as x-rays, or if they get the results. Discussions are short and patients do not often contribute.
- Goal Planning Meeting (GPM) – As discussed in section 2.8.3, the GPM presents an opportunity for patients to be actively involved in multidisciplinary discussions about their treatment and rehabilitation. However, it was observed that patients did not choose to speak much, if at all, during the meeting.

2.9.6 Discussion

Throughout the observational period, almost all patients were receptive to the researcher's interest in their experiences and did not object to her observing rehabilitation activities. Nor did the patients object to the researcher knowing about the personal aspects of their experience (i.e. bowel and bladder management), often discussing these frankly with her and even making jokes. As such, it is reasonable to deduce that any proposed intervention may address topics of a sensitive nature if it is relevant to the rehabilitation activity.

In general, the SIU staff were also very welcoming to the researcher and to the study, particularly once they understand more about it. It is widely understood that the current model of rehabilitation does not work for every patient, and they are receptive to new ideas and change. This is a positive indication that staff may be meaningfully engaged in later, generative stages of the intervention design.

2.9.7 Limitations and Challenges

A list of limitations of the whole PhD study is given in section 12.6. In terms of this observational period, however, the management of the very large amount of data gathered was particularly challenging. The handwritten notes taken during the contextual review were transcribed and anonymised, generating 62 rich data sets. As the specific focus of the study was not yet identified, the data was highly descriptive in nature, considering the needs and experiences of staff, patients and family members. This was compiled into a report, using a hypothetical patient's journey through the unit to structure the data (i.e. describing the events that most patients experience in sequence, highlighting the different options available to the patient population according to their injury level). This was found to be useful in terms of gathering the data together into a single document, but less successful in enhancing the researcher's understanding of the SIU context at a more abstract level, and the opportunities within that for intervention.

2.9.8 Summary

Over a longitudinal ethnographic study of the host SIU, a rich overview of patient and staff's experiences of the SCI rehabilitation process was generated. The transfer and retention of information and ownership of a patient's injury appears to be strongly linked to 'successful' rehabilitation. The processes by which this transfer takes place is strongly supported by the SIU staff's experience and emotional intelligence in adapting their methods according to the patient they are working with. Although the daily life in the SIU is highly structured, staff (in general) are welcoming to new approaches that may help a patient to participate in their rehabilitation further.

2.9.9 Implications for the study

Although the ethnographic study was successful in generating a rich picture of SIU life, and embedding the researcher in the SIU community, the amount of data gathered makes it problematic to identify one site for intervention. As such, the data will now be analysed through different, visual methods individually and with the SIU community.

2.10 How can the data gathered to date be analysed more clearly and usefully?

2.10.1 Introduction

In order to move beyond a detailed ‘micro’ view of the SIU towards an abstract conceptualisation of the unit and its processes, and the opportunities for intervention within it, the researcher conducted a ‘diagrammatic exploration’ as a form of analysis to better make sense of the data she had gathered to date. This section describes the method and findings of this approach and discusses them against related literatures. It was found that the creation and shared development of diagrams that represented the ethnographic and qualitative data had several benefits, and highlighted the Goal Planning Meeting as a potential area for intervention.

2.10.2 Diagrammatic Exploration

Stage One: Sense-making through diagram creation

The researcher began the process of diagram creation by re-reading through the written report described in section 2.9.7. This helped the researcher to gain further familiarity with the data, reassurance that all of her experiences in the SIU were represented and to begin thinking about how better collective sense could be made of the data from these individual observed events. Whilst reading through the report a second time, the researcher drew as many original diagrams as were required to cover the many different events observed and recorded in the written document – 79 in total. These sketch diagrams showed a combination of environment, process, tools and the role of and relationships between the people involved either in a particular situation or SCI rehabilitation as a whole (see fig. 2.6 for examples).

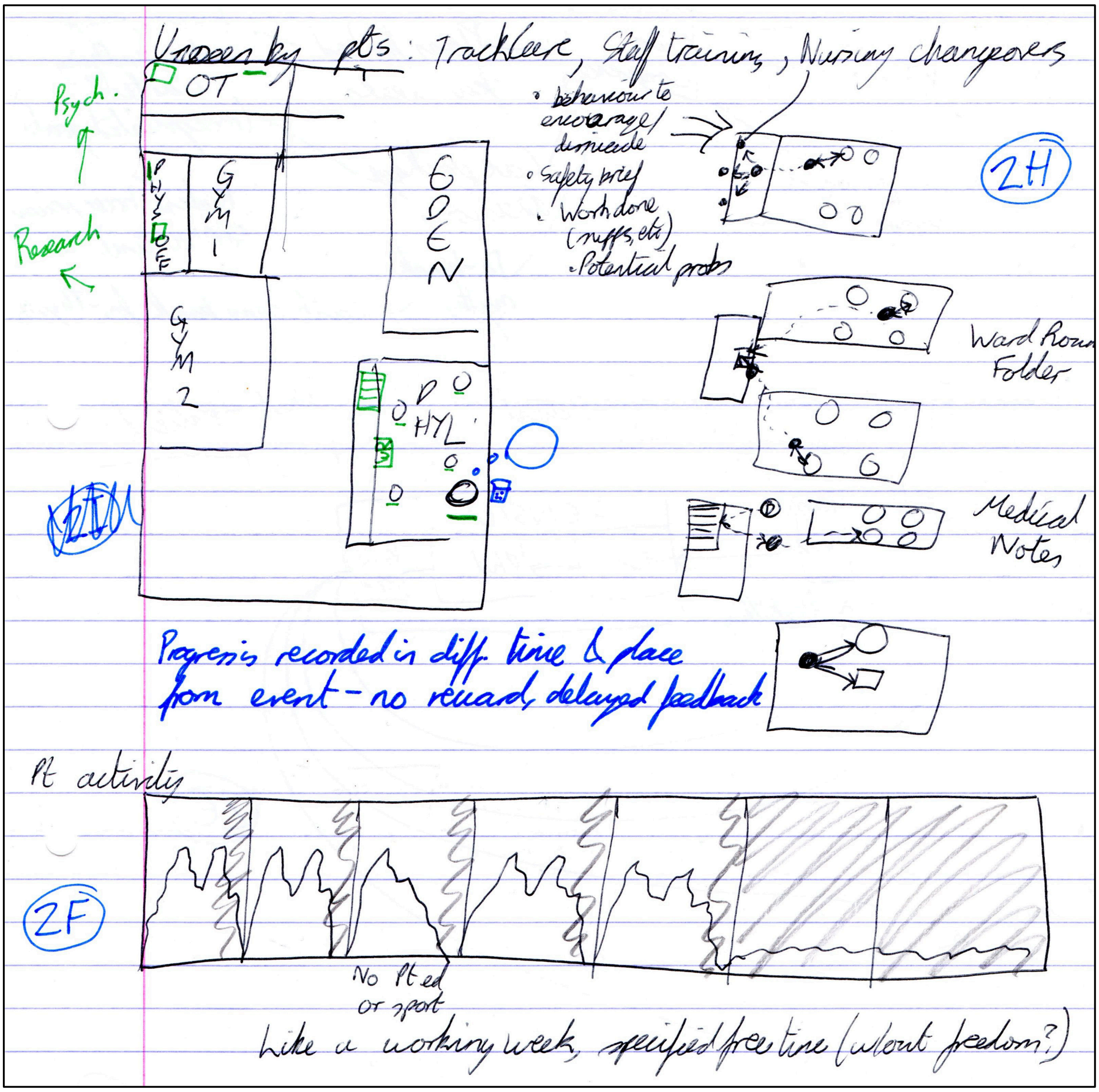


Fig. 2.6: Examples of the initial sketch diagrams of SIU observations.

At this point, the researcher no longer needed to refer to the written report described in section 2.9.7, and could begin to condense the original collection of sketch diagrams. Each diagram was revisited and assessed by the researcher for meaning and clarity. Of the original 79 diagrams, 10 were discarded (after being deemed incomplete or to contain information that was better represented elsewhere) and the remaining 69 diagrams were assigned an identifying number (1-69). Each numbered diagram was then revisited to consider the main themes that were represented within it. These themes were compiled into a list with their corresponding diagram numbers, by reviewing each diagram in turn and either adding its number to an existing theme or creating a new one. In this way, the collection of 69 diagrams were sorted into 14 groups within 7 main themes; environment; projection; context; working relationships; goal planning; agency; and models of practice. So, for example, one item on the list could read as 'Theme: Working Relationships. Sub-group: Transfer of Ownership. Related diagrams: 5, 9, 36, 41.' The researcher could then bring together all of the sketch diagrams relating to a particular group and draw 1-2 summary diagrams; creating the final set of 36 diagrams to represent the findings of the observational study. Each diagram was scanned into a PDF document with a short, explanatory paragraph and sent to both of the researcher's supervisors for review and comment. See fig. 2.7 for a diagram of the process, and appendix 3 for a selection of the digitised diagrams.

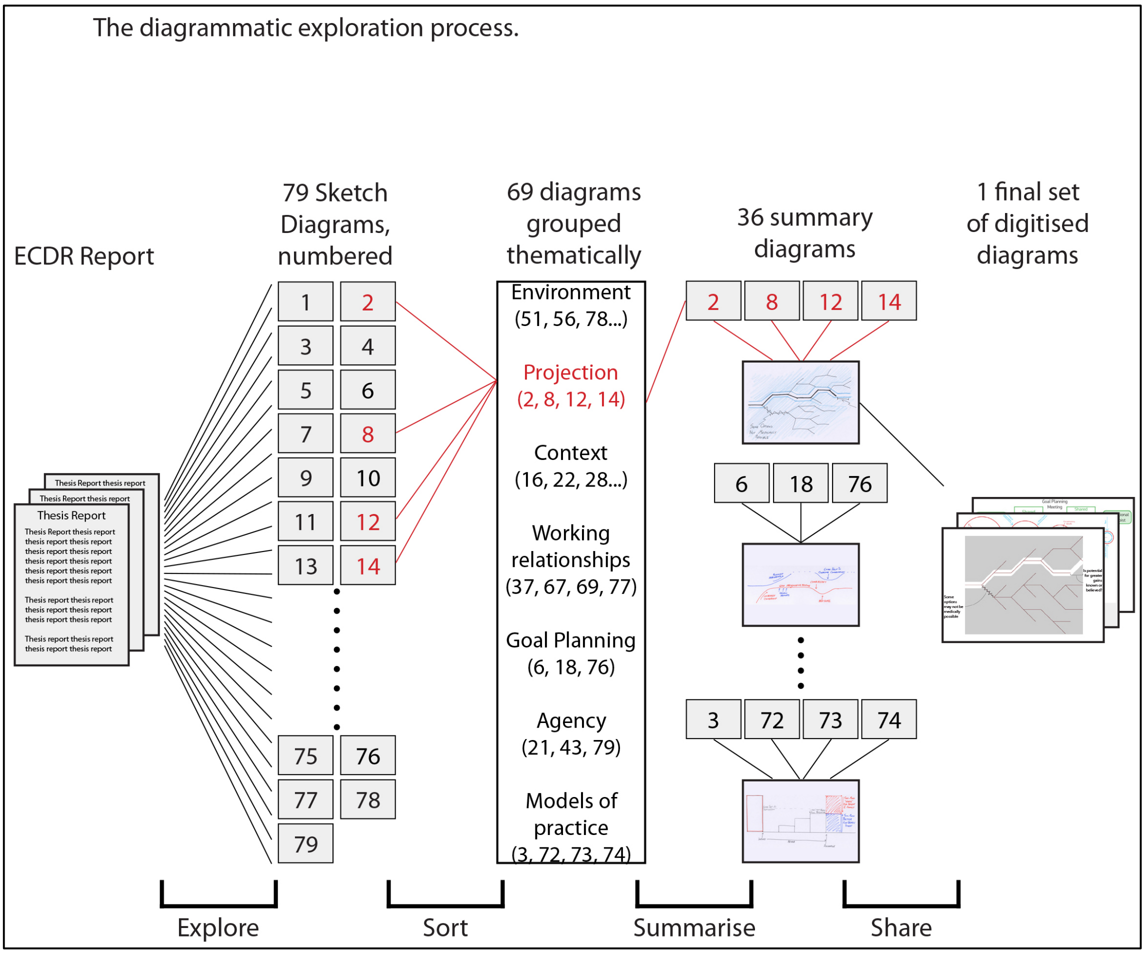


Fig. 2.7: The diagram creation process.

This first stages of diagram development (the 'explore,' 'sort' and 'summarise' phases) were crucial for developing the researcher's understanding of the SIU context. Discussing these diagrams with the supervisory team then played an important role in developing a shared understanding of how the researcher viewed the context. Clearly, it is important to describe the healthcare context in both macro and micro levels to the design-based supervisor, so that he can support the researcher appropriately. In this project, the supervisor based in healthcare also found the diagrams demonstrated a sound understanding of what happens within the SIU quickly, clearly and concisely. Knowing that the researcher has achieved this understanding allows both supervisors to discuss opportunities for the interventional stage with the student confidently. As such, we can describe this first stage of diagrammatic exploration of an observational study as a sense-making activity for the nature of the PhD itself, for the researcher individually and with her supervisory team.

Stage Two: Sense-making through diagram co-development within the SIU

Eight senior staff members from across the host SIU were individually invited to discuss, corroborate and/or develop these diagrams further. Whereas Stage One aimed to make sense of the data with the supervisory team for the purposes of the PhD study, Stage Two focussed on making sense of what is happening in the SIU, with staff and volunteers.

Prior to the interviews with SIU staff, the majority of the hand-drawn diagrams were digitally reconstructed using InDesign© and Photoshop©. However, some of the original diagrams (relating to agency theory) were omitted from this new set, as the aim of these interviews was to discuss the observational data only. One set of diagrams was printed for each interview, and shared between the staff member and the researcher during the discussion. At the start of each interview, the researcher explained that this was a feedback and developmental session, and encouraged the staff to interrupt the explanation of each diagram to concur, dispute or expand upon it.

Although blank paper and pens were available to alter the diagrams or to draw new ones, each staff member preferred the researcher to do the drawing – perhaps highlighting a methodological gap to empower or give confidence to the staff to do this themselves, thus possibly reducing any researcher bias.

Whilst some diagrams were simply explained by the researcher and confirmed by the staff member, others were able to facilitate discussions of abstract concepts (see fig. 2.8), highlight the assumptions of the researcher (see fig. 2.9) and elicit tacit knowledge of the staff that may not otherwise have been triggered (see fig. 2.10).

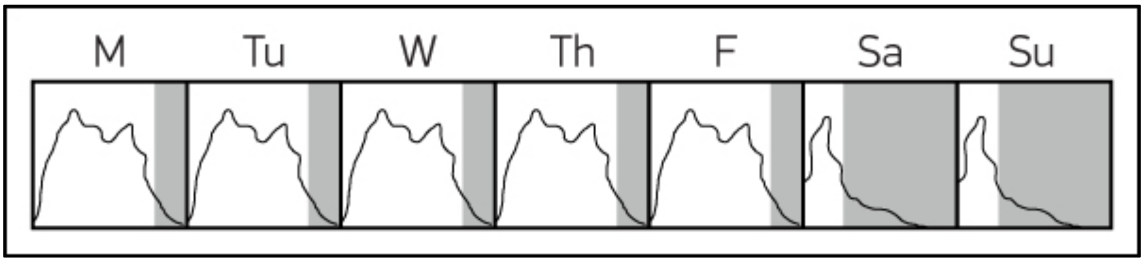


Fig. 2.8: A diagram depicting the patient's 'business' over a given week was originally intended to communicate the monotony of inpatient routines. However, when discussed with staff, it became clearer that patient 'business' matched that of the therapy staff's Monday-Friday working week. This then raised questions of 'patient ownership' - if a patient is mostly busy when staff are present, it seems logical that the patient may attribute at least some ownership of the rehabilitation process to the staff.

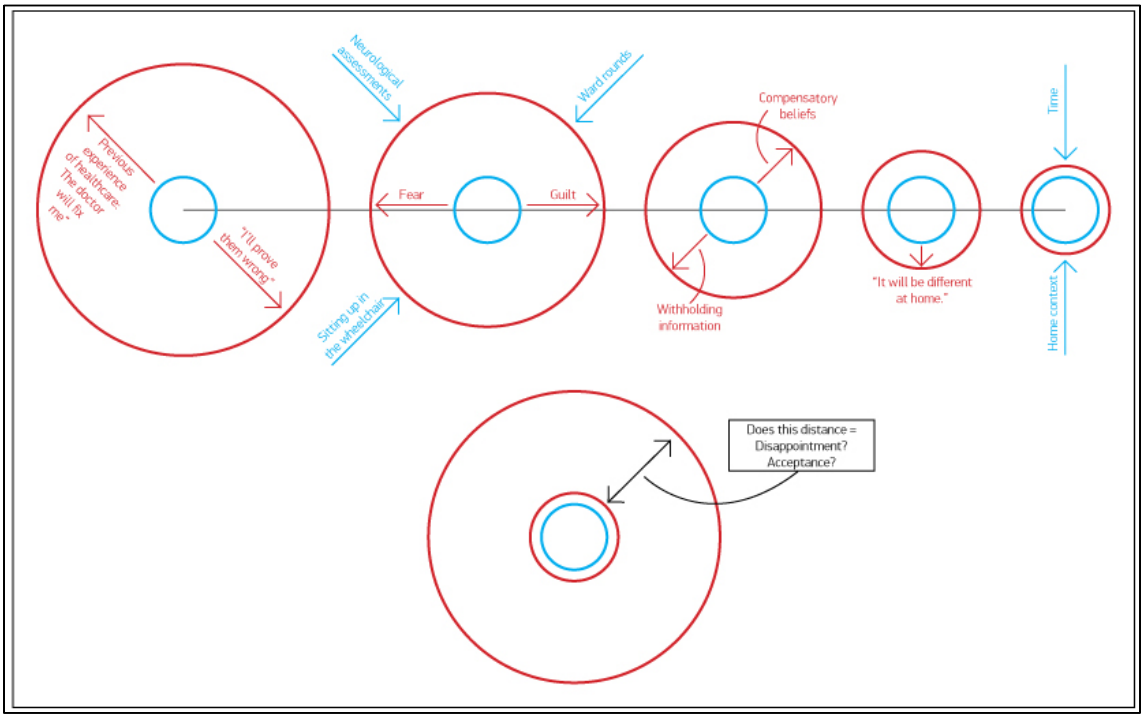


Fig 2.9: This diagram was used to explore the concept of 'managing expectations', and how the rehabilitation process, over time, may sometimes need to help patients realign their expectations (shown in red) to the clinical potential (shown in blue). However, in discussions with staff, the negative assumptions of the researcher (that patient expectations must be reduced) became apparent, with one staff member highlighting that some patients need to be encouraged that 'they won't be in bed for the rest of their lives.'

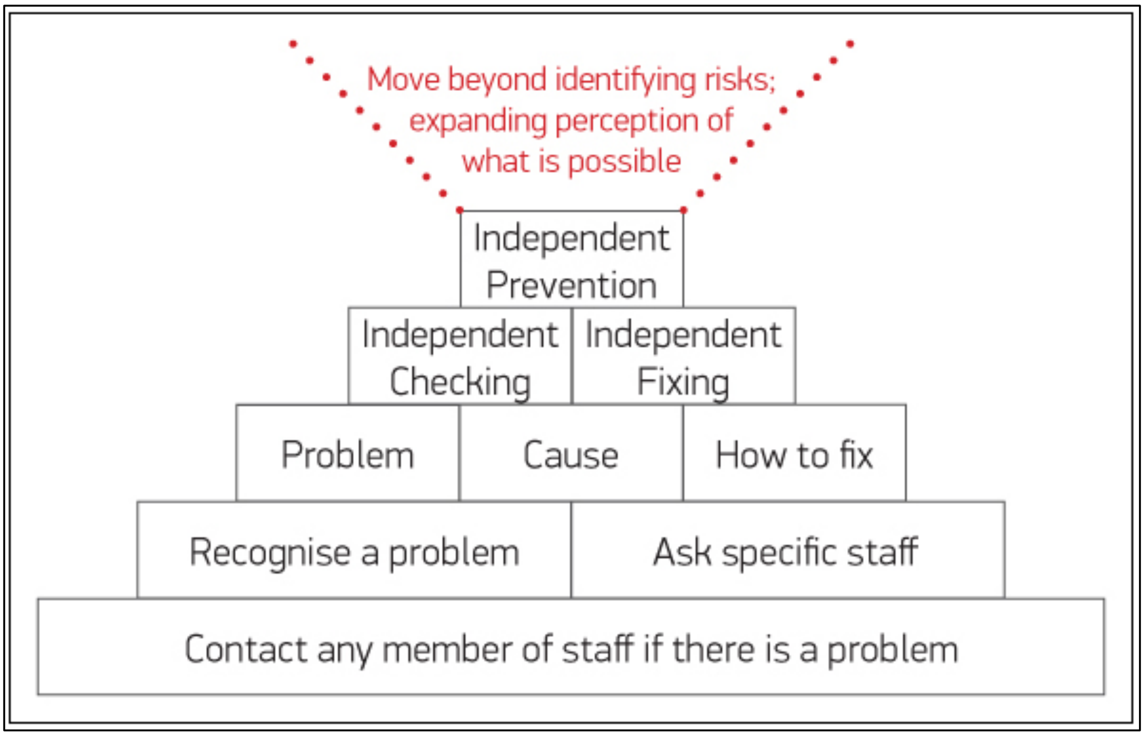


Fig. 2.10: This diagram originally depicted the skills in preventative healthcare that must be taught to patients, with the ultimate goal of 'independent prevention' of secondary complications (shown in black). However, staff explained that the best outcome would actually be for patients to expand their perceptions of what they think is possible, so the diagram was amended to reflect this (shown in red).

All of the diagrams contributed to developing a mutual understanding between the researcher and the SIU community, not only of past observations but also of potential directions for future work. This is best exemplified in fig. 2.11, which depicts the diagram created to represent the Goal Planning Meeting (GPM); where a patient, their care team and usually 1-2 people important to the patient (e.g. spouse, parent) meet regularly to review progress and set rehabilitation goals for the few weeks following the GPM.

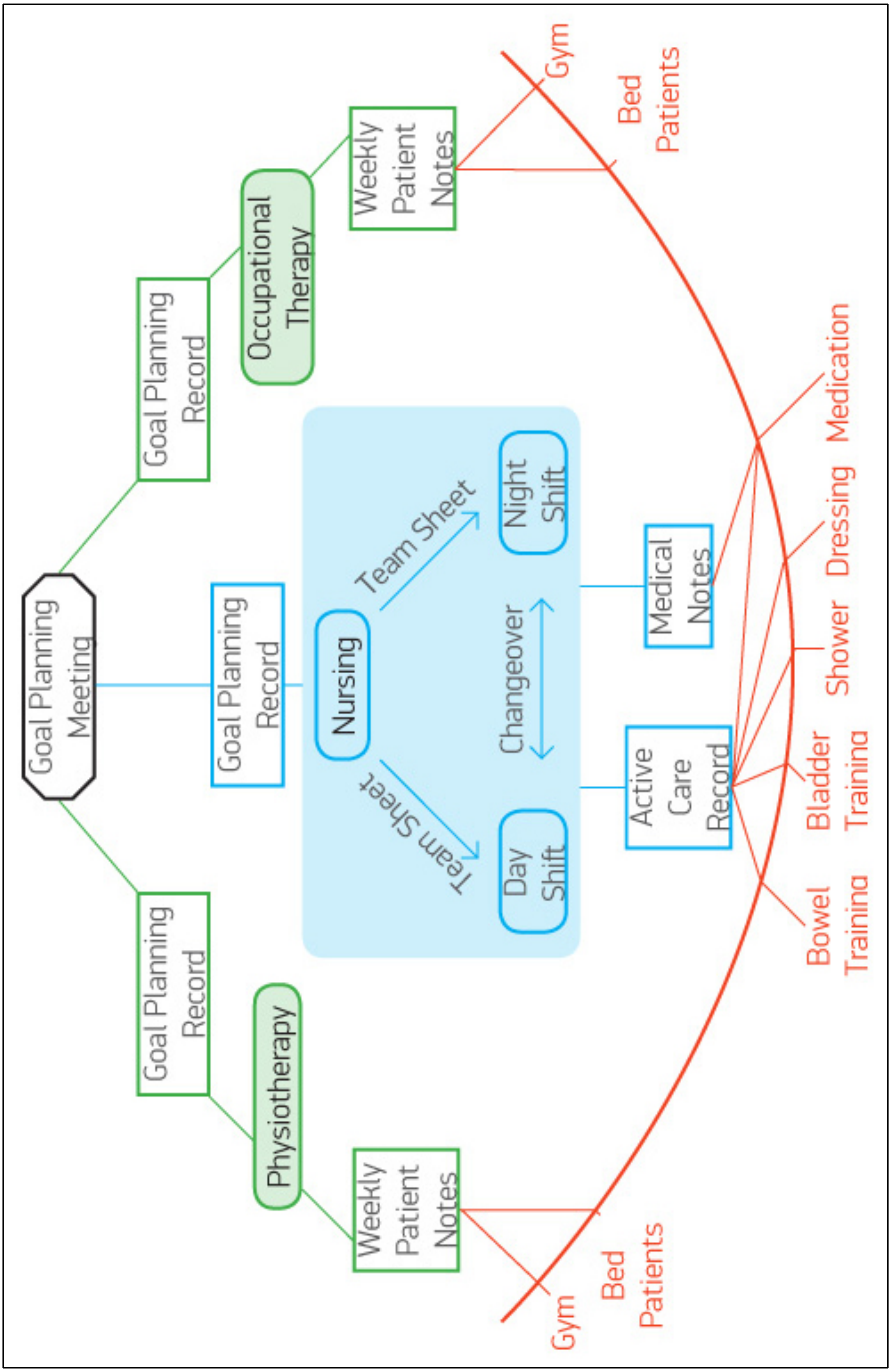


Fig. 2.11: A diagram of the people and tools used within a Goal Planning Meeting. Individual patient activity (here shown in red) is recorded by SIU staff in departmental notes (here separated into nursing, shown in blue, and therapy departments, shown in

green). Each care team member then summarises a patient's progress in their individual goal planning records before each meeting, and uses this record to report back to the rest of the care team and to inform any decisions made about the patient's rehabilitation.

As discussed in section 2.8.3, the GPM is a key part of rehabilitation for the majority of patients, and an opportunity to take more ownership over the management of their injury by being included in decisions made about their care. However, by mapping out how all of the individuals involved contribute to the GPM, there is arguably a distance between the patient activity (shown in red) and the meeting itself; raising the question of whether the meeting structure supports patient participation. The diagram located this issue in the process rather than in the people involved, as the records of progress (in their current format) require staff mediation and possibly restrict opportunities for patients to take charge of the meeting. Indeed, constructive discussion of this diagram acknowledged the role that the current process, and materials supporting it, may have on both staff and patient behaviours within it (for example, the patient is almost always the only member of the meeting who does not bring their own notes to support the discussion). This in turn suggested a hypothesis that new GPM materials or protocols could be introduced to facilitate more participatory behaviours from the patients. These materials could aim to reduce this 'distance' between a patient and their own GPM discussed above, support different types of interaction and encourage collaborative decision-making; confirming the GPM as a potential site for intervention.

2.10.3 Discussion

The creation and co-development of the diagrams supported the researcher's transition from observational to interventional stages in the PhD journey. The initial creation and gradual consolidation of the diagrams to explore what was observed encouraged question-centric modes of thinking, actively reflecting on the SIU context without prematurely inferring a problem and a potential solution. As diagrams are able to show the relationships between people, tools and processes simultaneously, they are particularly suited to complex research contexts such as healthcare and were able to communicate a sound understanding of the SIU to both supervisors quickly, clearly and concisely.

Inviting staff to comment and alter the researcher's diagrams during these developmental stages also inferred a sense of trust and shared ownership of the project, in anticipation of future participatory interventions. Building working relationships and setting expectations of how a design researcher (who is unusually placed in the SIU context) will work is crucial, and positive staff comments such as ‘It’s nice to see that we’re doing something right,’ (Patient Education Nurse) suggested that the diagrams demonstrated that the researcher isn’t only looking for problems.

This process also maintained a sense of transparency in the methods used and allowed the researcher to give feedback to the SIU community sooner. By extending this method of ‘sensemaking’, the researcher was able to reach a ‘consensual understanding’ (Jones, 2013, p26) with the host SIU staff. Presenting the design researcher’s observations to healthcare staff as a visual, tangible material to work with navigated potentially problematic differences in language and work culture, supporting rich discussions and utilising the invaluable experience of the SIU community. In this way, the GPM was mutually agreed as a potential site for intervention and a tentative hypothesis was formed, suggesting that the new materials or protocols could be introduced into the GPM to enhance patient participation within it.

2.10.4 Reflections on the literature

Visual Communication

Although this process was conducted without a search for prior examples, it is interesting to refer to the literature to reflect on what was achieved (or not) by this diagrammatic exploration. Tufte, a pioneer in visual communication, describes the role of the designer in such activities:

> ‘...the task of the designer is to give visual access to the subtle and the difficult - that is, the revelation of the complex.’ – Edward Tufte, The Visual Display of Quantitative Information.

However, the diagrammatic exploration process was not concerned with representations of a finite data set, as Tufte is known for, but rather with giving 'visual access' to a complex ecosystem of people, tools and processes, and the relationships between them, within the host SIU.

Diagrammatic Exploration or ‘Formulation’?

After sharing and discussing the diagrams with the SIU’s clinical psychologist, the researcher was advised that the process resembled a method used in psychology and psychotherapy known as ‘formulation’. There are many definitions of formulation (either as an object or an event), but essentially a formulation aims to gather and understand various circumstances (perhaps clinical, environmental or social) that contribute to an individual experiencing a particular disorder (Johnstone and Dallos, 2014). These formulations are often done in collaboration with the service user, and sometimes mapped in a causal, descriptive diagram (see fig. 2.12).

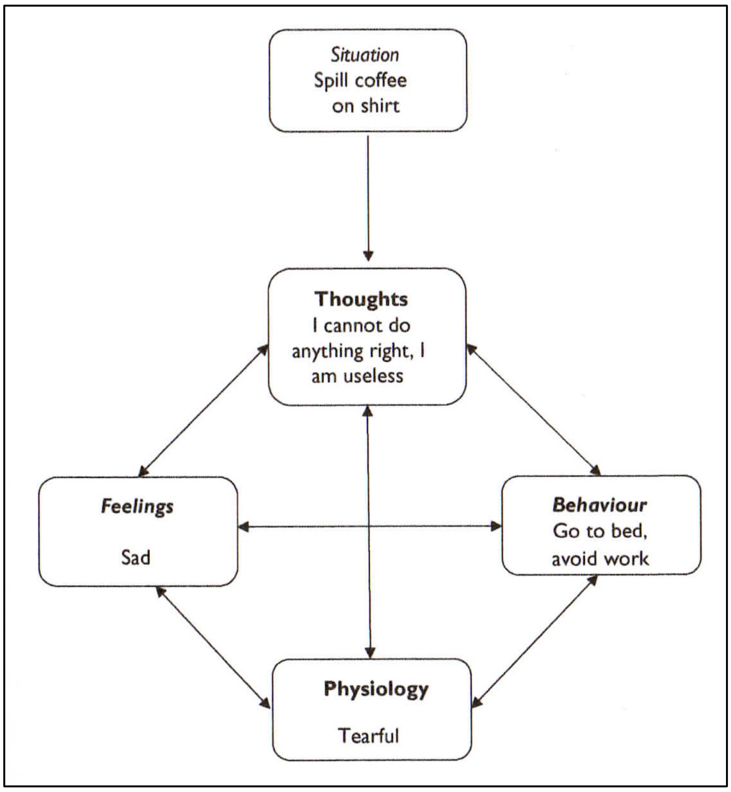


Fig. 2.12: An example of a Formulation found in the field of psychology (Johnstone and Dallas, 2013, p25).

Like the diagrammatic method above, formulations create hypotheses in a format that can be shared, understood and developed by people from various disciplines and backgrounds. They also help to isolate the problem space by gathering all of the key information in one place and/or highlight any gaps in information needed (p9). Whilst some psychologists claim the process as unique to their profession, others state that ‘formulating is something we all do as human beings’ (p233) and we can ‘compare the process of formulation to a form of creative curiosity’ (p71). It is not surprising, then, that another discipline such as design came across a similar method without prior knowledge of formulation. What may be unique in this design-led approach is the variety of visual styles and content to facilitate discussion about abstract concepts, such as ‘ownership’, and the integration of possible future scenarios or ideas into the existing context either by the designer or ‘in the moment’ with SIU staff as new knowledge is evoked.

Sensemaking

We have discussed above how the diagrams facilitated individual and collective 'sensemaking' of the SIU context, and opportunities for intervention within it. Weick (1995) is often credited for formalising a 'sensemaking' process that focuses on the meaning attributed by individuals to organisational events, rather than focusing on organisational outcomes. Mills et al. (2010) provide a critique of the model, claiming that it does not take into account the impact of power or agency in context (and develop Weick's model accordingly). The use of diagrams in this study visualised each member of the SIU community equally, and was able to highlight and discuss issues of power (i.e. who was involved or not involved in particular meetings) in a non-accusatory manner. This was found to be crucial when trying to identify an appropriate site for intervention without appearing to attribute blame or damage working relationships with staff.

Furnas and Russell (2005) state that 'sensemaking can be a core professional task in itself, as it is for researchers, designers, or intelligence analysts,' which 'arises when we change our place in the world or when the world changes around us,' (p1). It could be argued, therefore, that the new addition to the SIU community (the researcher) and her participatory efforts to make sense of her new environment, invited SIU staff to reconsider the work context that they were very familiar with; giving them an opportunity and permission to do so with a critical eye.

Sensemaking as an act of Participatory Design

Glanville characterises design 'as a conversation, usually held via a medium such as a paper or pencil, with an other (either an 'actual' other or oneself acting as an other) as the conversational partner,' (1999, p88). Although this may at first seem a tenuous link to define diagrams as an act of design, it is important to remember that, according to Bowen et al., 'design involves problem setting as well as problem solving,' (2010, p3). Taking the ethnographic and qualitative data gathered to date and translating them into visual representations begins a 'conversation' with the data; representing a more humble approach to that which the researcher has learned so far by suggesting that it is not finished or definitive. By opening up this 'conversation' to include the participants of interviews and observations, in a format unhindered by discipline-specific language, the study is made more rigorous by creating an opportunity for staff to verify or develop the conclusions drawn from the data. Ethically and politically this also makes the study stronger by eliciting the voice of those who may potentially be affected by the future intervention beyond this initial phase of gathering data.

2.10.5 Summary

The researcher and the SIU staff used the diagrams created from the data gathered as a shared material to verify the findings to date, discuss abstract ideas equally, recognise the hard work and successes of the SIU, elicit the various (and sometimes conflicting) priorities of the many people involved in SCI rehabilitation and identify potential opportunities for intervention. It can be argued that the behaviours of staff and patients in the GPM are at least partially dictated by the materials used within it. As such, a hypothesis is posed that new or different GPM materials or protocols could be introduced into the GPM to encourage more participatory behaviours by the patient.

2.10.6 Implications for the study

Although the hypothesis stated above seems feasible, this has been drawn from a less traditional approach. To better address the host clinical environment's concern with robust evidencing, she decided to proceed by triangulating the suitability of the GPM as a site for intervention with two other modes of analysis; a traditional 'coding' method and a rough pilot with a patient with whom the researcher had built a working relationship during the observational period.

2.11 Is the Goal Planning Meeting an appropriate site for intervention?

2.11.1 Introduction

Following the cooperative diagrammatic exploration of the ethnographic data to date with SIU staff, the Goal Planning Meeting was identified as a potential site for intervention. In this section, we will begin with a detailed explanation of the GPM as observed in the ethnographic study. Next, a coding process of the observational data will be conducted to establish if the GPM is reflective of issues surrounding patient participation experienced across the unit, and if so what these issues are. The results from this coding process are then used as guides to create prototype materials to test in a mock GPM with a patient and his care team. In this pilot, we will test the hypothesis that new materials may facilitate new, more participatory behaviours in the GPM. In practice, the prototype materials were actually more effective in generating new conversations between the patient, staff and the researcher, and raised further questions about the experience(s) of the GPM.

2.11.2 What is the Goal Planning Meeting (GPM)?

The researcher was invited to attend eight GPMs of five different patients, with handwritten ethnographic notes taken in each. Invitations were extended after introduction by the co-supervisor and/or informal contact with patients during Patient Education Sessions or presence in the rehabilitation wards.

Preparing for the meeting

A patient and their key worker (a member of the patient's rehabilitation team assigned to coordinate the efforts of the team[1]) will work together to complete the 'Goal Planning Checklist' booklet (see appendix 4 for examples of the contents) at the start of their rehabilitation, in the middle and at pre-discharge. The booklet aims to identify gaps in knowledge and progress made towards addressing them, covering each aspect of care and addressing levels of depression and anxiety. Level of independence and existing knowledge are given numerical values by the key worker, using the 'Guide to Knowledge' booklet to guide this scoring. These scores appear to be for clinical use only, rather than for the patient. Indeed, one keyworker stated they did not like asking some questions as patients can sometimes 'panic', asking 'am I meant to have done this?' [GPM.1]. Some patients also get agitated by the use of clinical measures to denote their progress, as they have no prior knowledge of the measures to understand it in real life terms. Interestingly, the 'Goal Planning Checklist' was not mentioned by staff or by the patient in any of the GPM's observed (although it must be acknowledged that this is a relatively small sample).

A patient should meet with their key worker before the GPM to 'coordinate, help identify needs and feedback to team – all different ways to support the patient,' (Rehabilitation Ward Nurse). However, the key worker often does not have time to do this.

The Meeting

Meetings are chaired by the key worker or a discharge coordinator if the key worker is absent. In the first meeting, the key worker explains the goal planning process to the patient and that the patient can take a more active role in the meeting 'once you know what goes on more,' [GPM1].

---

[1] As a reminder, the rehabilitation team includes the patient's assigned nurse, physiotherapist, occupational therapist and discharge coordinator. The patient's assigned consultant and social worker, as well as the SIU's clinical psychologist, may attend the GPMs also.

Each member of the care team takes his or her turn to report the progress the patient has made since the last GPM. The Goal Planning Progress Chart (see appendix 5) is used to record the goal from the previous meeting, the action taken and new goal set in that day's meeting.

When discussing progress, phrases such as '[patient name] has done stairs,' raised questions of whether patients are explicitly aware of this 'sign off.' Additionally, progress may sometimes be described in terms of clinical measures (i.e. '[patient name] requires 25% assistance in dressing their top half' or 'he's a FIM6 with dressing'), as this is how it is recorded in the discharge coordination notes. This corroborates the idea that the documentation used to record interactions may have an effect on the way the interaction is conducted.

The idea of certain skills unlocking others was present in most meetings, and without the clinical experience that the staff have, this can be a difficult concept to understand. The interdependencies of these skills between departments also adds to this complexity. For example, learning the skill of transferring from one surface to another (in sessions with their physiotherapist) can lead to a patient trying new equipment such as a shower chair (usually with their occupational therapist) and learning new methods of washing (often practiced with their nurse). Furthermore, some skills, such as upper body strength, have no point of completion so progress is difficult to measure [GPM.5.].

Meetings may also involve discussing a particular problem a patient is having with the whole care team. This often results in a coordinated effort to solve the problem together, for example a patient may progress quicker in learning their 'transfers' if they are encouraged to practice them on the ward as well as in the gym.

It was observed that goals tend to be set by the rehabilitation team based on what they expect the patient to be capable of, and unless the patient objects, this is agreed as a goal for the next meeting. Some goals are set based on trust, as a patient does not have prior experience with which to judge whether they can, for example, learn a new type of transfer. To illustrate this point, therapy staff sometimes uses phrases such as 'I have no doubt you will manage with x,' and 'it's a personal choice, but I know you can do this,' [GPM1]. Patients must also trust that the staff fully understand the true extent of their progress when setting these goals. Patients are asked if they have any questions at the end of each staff member's report, but goals suggested by the staff are rarely disputed and patients often say very little during the meetings. Occasionally, however, a patient may interrupt a report because they don't want the staff to assume too much progress has been made [GPM1] [GPM6], which was later discovered (through informal discussion) to be because the patient was afraid of being discharged too early.

Patients may choose to invite their spouse or family to their GPMs. It is a chance to explain in more detail about the management of SCI and to reconcile different ideas about the best route to take through rehabilitation. According to staff, the 'scary' nature of these decisions and the pressure that both patients and family members are under can often result in conflict during GPM's, although this was not observed first-hand.

Unless a patient takes their own notes, such as on their mobile telephone as observed in GPM.5. and GPM.6., there are no notes provided for the patient to take away after the meeting. As such, it can be difficult for a patient to keep track of their simultaneous goals independently. This manifested in GPM.3, where it was found a patient regularly forgot to try a new undressing technique, which if mastered, could negate the need for specialist dressing equipment post-discharge.

Discharge Case Conference

The Discharge Case Conference is the last meeting in a patient's goal planning programme. It runs in the same way as a GPM, except that minutes are taken and a discharge date is set (usually within 4 weeks of the discharge case conference) [GPM.8.]. However, this date will only remain if the patient is ready at the time, and patients sometimes worry about this [GPM6]. For some patients, this is the point where they realise the importance of making the most of their time in the SIU [GPM.4., GPM.8.].

2.11.3 Reflections on the Goal Planning Process

By gathering all of a patient's rehabilitation team together with the patient, the GPM logically presents an opportunity for patients to discuss and take part in making decisions about their care. Yet, in reality, very few patients were observed to be speaking at all in the meetings. This could perhaps be due to the well-rehearsed, very structured nature of the meeting, or perhaps a patient may assume a passive role since they are the only participant without documentation to prepare for or to record the meeting. The language used may also promote a passive role, with unfamiliar clinical terminology occasionally being used as shorthand between staff members. As well as a shared language, staff also share experience in estimating how long skills may take to learn or the probability of complications with a given rehabilitation technique – arguably further (unintentionally) excluding the patient. Finally, assumptions made by patients, such as the concept that they may be discharged too early if staff overestimate their progress or abilities, can lead to patients exercising control over the information they present in the meeting, perhaps making the meeting unnecessarily distressing for patients and family.

There appears to be several opportunities for intervention in the GPM, possibly addressing issues of communication, power distances and visualisation of progress, although this will be explored more fully in the following coding process.

2.11.4 Coding Method

Initial data assessment

Prior to conducting the coding process, the quantity, quality and range of the data collected were assessed. It was established that the data gathered were very descriptive, including emotional responses of the patient, family and staff in the events described. Despite covering a range of processes and events, an overall interest in patient participation could be seen. Observations of the Goal Planning Meetings (GPM's) appear to describe it as a place where many of the emergent themes of the contextual study converge, with 'real life' examples of broad terms such as 'control'. However, until this point, this data had only been informally analysed for the purposes of joint supervisory meetings. Although the academic report and diagrammatic exploration activities (described in section 2.10.2) served as modes of analysis, the researcher felt that a more formal coding process of the observational data would contribute to the robustness of study, as expected in a clinical environment such as the SIU.

Coding technique

NVivo software was used as a tool to inductively generate themes (see appendix 1 for a full review of qualitative data analysis) and then apply them. To do this the text to be coded (transcribed notes from the observational period, coded one 'event' at a time) was reread several times to enhance the researcher's familiarity with it. The software was then used to highlight any phrase or word that stood out as noteworthy or representative in some way and attribute a theme. In this first generative phase, the researcher created a new theme when it was felt necessary. Next, the researcher reviewed the list of themes generated to assess if any could be combined, or merged into main themes and sub-themes, and edited the themes accordingly. Finally, the researcher reviewed each phrase attributed to each (perhaps edited) theme to ensure the coding was still consistent.

Coding process

A coding pilot was conducted by the researcher on the notes taken at a GPM and a patient education session. Several themes found in the patient education session (such as ‘projection’) were repeated in the GPM, so the coding process was extended to the rest of the observational data.

The full set of notes taken in the GPM’s (n=8) were coded first, after which the themes were reviewed again to check for consistency (as described above). Each remaining ‘set’ of notes (i.e. patient education notes, shadowing nursing staff notes, etc.) were then coded in turn, reviewing and/or amending the list of themes generated after each set. Once all notes had been imported and coded, each phrase attributed to each theme was reviewed a final time.

2.11.5 Coding Findings

Brief explanations of the most common themes are provided below (please see appendix 6 for a full list of themes as presented in the NVivo software, with associated reflective comments, in a report submitted to the supervisory team for review and discussion).

Progression

This is to be expected in a rehabilitation unit, given that each activity aims to contribute to a patient’s recovery in some way. The concept of ‘unlocking steps’ (i.e. a patient may need better skin tolerance before they can attempt certain transfers) became apparent in staff’s explanations of the rehabilitation process. The transfer of progress across departments (i.e. practicing a transfer that was learnt in the gym in the ward) was another common sub-theme, and the patient’s role in this could be considered.

Projection

Again, this is a logical theme to expect, especially in the Goal Planning Meeting, which focuses on predicting how much progress is feasible to expect in an individual patient. Sub-themes within progression highlighted that the conversations moved between projection ‘to post-discharge,’ ‘to discharge’ and ‘to normal life’ (listed here in order of frequency). Other sub-themes including ‘breaking down the steps,’ where staff would verbally explain how a long-term goal could be achieved, but this was not written down for the patients.

Network Navigation

'Staff teamwork' was a common sub-theme within the GPM's, highlighting the meeting's importance in coordinating a multidisciplinary approach. The current rehabilitation format does not require patients to instigate this 'network navigation' themselves, yet this could potentially be a useful skill post-discharge.

Context

The use of 'context' was spread quite equally between observations in GPMs, multidisciplinary meetings, patient education, the relative's education day and the Occupational Therapy Kitchen. Few observations of translating the 'textbook' or 'best practice' skills taught in the SIU to a patient's specific circumstances were made, highlighting the (to some extent necessary) rigidity of the rehabilitation pathway.

Barriers to Participation

Although this is coded from the researcher's observational perspective, many of the barriers identified (including clinical language, lack of information, fear/unknowns and lack of supporting materials) have been corroborated by the supervisory team.

Patient Participation

The researcher found it interesting that most of the observed instances of patient participation could be considered 'negative', i.e. countering the progress reported by staff by highlighting the areas they still struggled with. Most of the observed interactions coded here were located in the GPM's, but of course patients will be physically interacting more in the less observed areas of the SIU, such as gym sessions, activities of daily living, etc.

2.11.6 Discussion of the coding process

By coding the observational data in isolation, the conclusions drawn may be at risk of bias. As such, the main themes and example phrases were presented to the supervisory team for verification. As this phase mainly serves as additional analysis to corroborate the suitability of the site of intervention, rather than draw specific conclusions, additional verification was not sought.

It is interesting to note that the term 'working relationships' did not appear as a code in this process. This term was certainly discussed in the diagrammatic exploration of the thesis report, so perhaps we can consider if this is due to the particular writing style of the researcher, or perhaps if the nature of the diagrams encourages a more ‘systems-thinking’ approach.

2.11.7 Implications for the study from the coding process

It is suggested that the most frequently occurring themes (progression, projection, network navigation and context) plus the barriers to and observed instances of patient participation can provide a good evidence base for focus areas of the initial prototypes to use in the following pilot session, described below.

2.11.8 Pilot Method

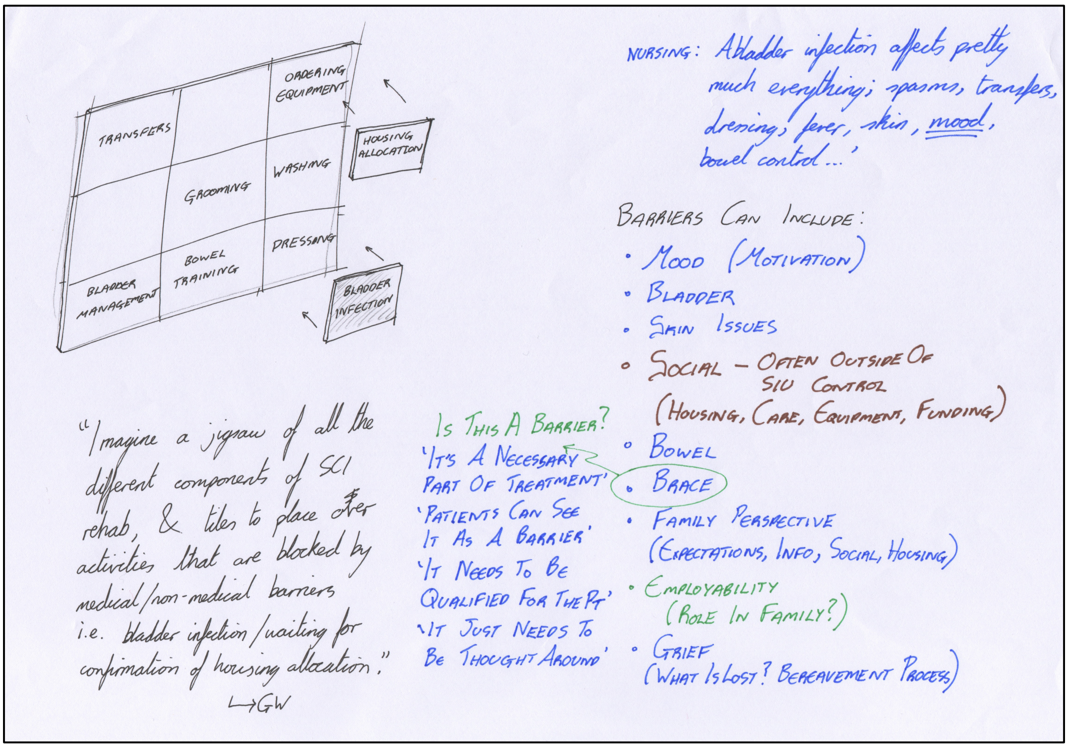
A quick, rough pilot was conducted to test the idea that the introduction of a new material into the GPM could encourage different types of interaction between the patient and staff. A patient who had been involved in the observational phase of the study, who had expressed an interest in its purpose, was recruited informally through ad-hoc interaction. Given that the pilot was considered additional to his normal level of care delivered in the SIU, further ethical approval was not deemed necessary. Once the patient, ‘Peter’ (a pseudonym) agreed to participate, his rehabilitation team were individually invited to participate also.

The pilot was conducted over one week in 4 sessions, as follows:

1. *Generative discussion session with staff.* The key themes discussed in section 2.11.5 were used to guide a generative conversation on how the patient could be better supported to participate in the Goal Planning Meetings (GPM’s). Key themes (and sub groups) were given individual A3 sheets in the shared table space, and the researcher recorded staff feedback, priorities and discussions on these sheets either directly or on post-it notes (see fig. 2.13). Additional sheets were created in real-time as concept ideas emerged. Present were a senior occupational therapist, a lead nurse, a discharge coordinator, a senior physiotherapist, a rehabilitation ward sister and a visiting consultant.

Fig. 2.13: Set-up of the rough pilot generative session with staff.

2. *Generative discussion session with Peter.* The session was conducted in the same manner as with staff, in the same room with the same original materials. Peter was not shown the results from the generative session with staff, or vice versa.
3. *Creating the concepts for use in the pilot.* The A3 sheets from both generative sessions were condensed into a set of A4 concept sheets, using any and all ideas from the discussions. On these concepts the supporting or critical comments from the staff and Peter were added (indicating the discipline or patient making the comment). A selection of concepts is available in appendix 7, with examples in fig. 2.14 and fig. 2.15.



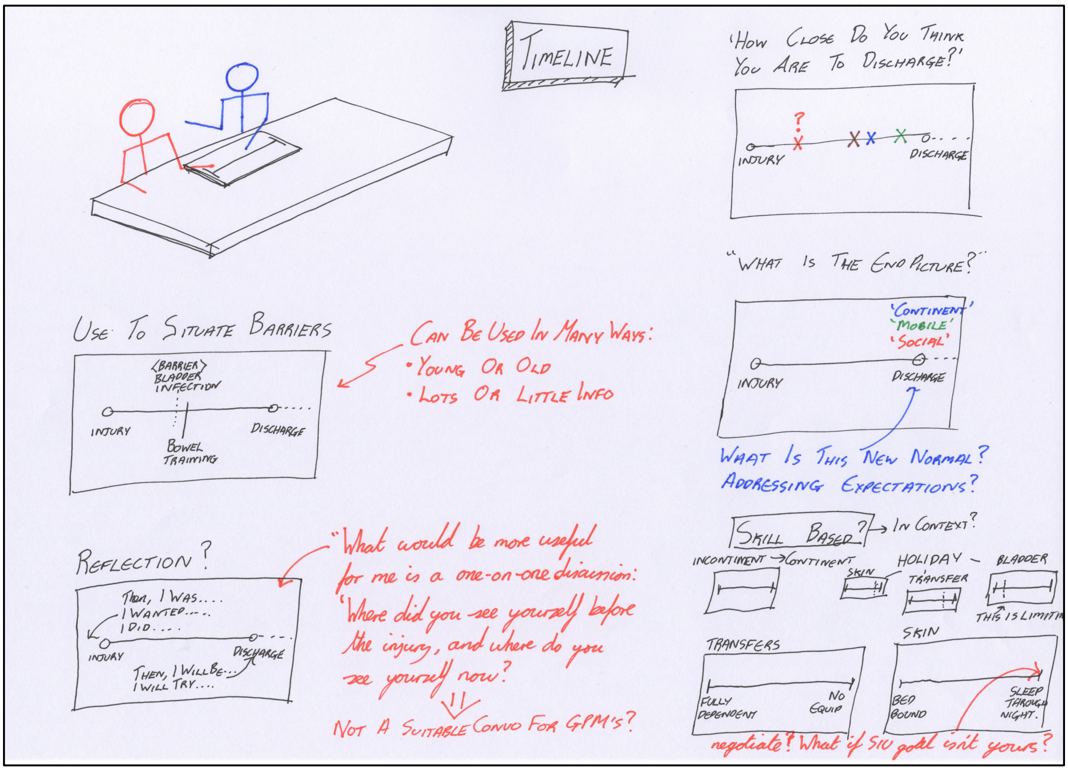
NURSING: A bladder infection affects pretty much everything; spasms, transfers, dressing, fever, skin, mood, bowel control...'

BARRIERS CAN INCLUDE:
- MOOD (MOTIVATION)
- BLADDER
- SKIN ISSUES
- SOCIAL – OFTEN OUTSIDE OF SIU CONTROL (HOUSING, CARE, EQUIPMENT, FUNDING)
- BOWEL
- BRACE
- FAMILY PERSPECTIVE (EXPECTATIONS, INFO, SOCIAL, HOUSING)
- EMPLOYABILITY (ROLE IN FAMILY?)
- GRIEF (WHAT IS LOST? BEREAVEMENT PROCESS)

IS THIS A BARRIER?
'IT'S A NECESSARY PART OF TREATMENT'
'PATIENTS CAN SEE IT AS A BARRIER'
'IT NEEDS TO BE QUALIFIED FOR THE PT'
'IT JUST NEEDS TO BE THOUGHT AROUND'

"Imagine a jigsaw of all the different components of SCI rehab, & tiles to place over activities that are blocked by medical/non-medical barriers i.e. bladder infection/waiting for confirmation of housing allocation."
↳GW

Fig. 2.14: Concept sheet to make tangible goals and barriers to progress.



'HOW CLOSE DO YOU THINK YOU ARE TO DISCHARGE?'

"WHAT IS THE END PICTURE?"

WHAT IS THIS NEW NORMAL? ADDRESSING EXPECTATIONS?

USE: TO SITUATE BARRIERS

CAN BE USED IN MANY WAYS:
- YOUNG OR OLD
- LOTS OR LITTLE INFO

REFLECTION?

"What would be more useful for me is a one-on-one discussion: 'Where did you see yourself before the injury, and where do you see yourself now?
⇓
NOT A SUITABLE CONVO FOR GPM'S?

negotiate? What if SIU goal isn't yours?

Fig. 2.15: Concept sheet to discuss the rehabilitation journey with a timeline.

4. *Staged GPM.* Peter and his entire rehabilitation team were able to attend the session, so their experience in working with this patient made them well suited to 'act out' a GPM with him and the prototypes. Whilst the original aim of the pilot

was to trial several different low-resolution ideas in this session, several versions of the 'timeline' concept were chosen instead. This was to avoid any potential difficulties that participants may have in changing 'mindset' several times in the one hour available in the group's schedules. Paper prototypes of the timeline concept, plus materials to alter them (pens, post-its, etc.) were laid out in the conference room as shown from the patient's point of view in fig. 2.16.

Fig. 2.16: Set up of the staged GPM session with Peter and his rehabilitation team.

The session began with an explanation that the concepts presented weren't about to be introduced formally into the SIU, and that they could and should be changed as they were used. Staff were also encouraged to remember that the paper format may not be final - ideas could become apps, presentations, etc. The researcher explained the 5 prototypes available, and Peter chose the first material to test. However, in practice, none of the materials were used to any great extent. Instead, they sparked an interesting discussion, as summarised below.

2.11.9 Pilot Findings

Through discussion of how the prototype materials could be used, it became clear that there are differences in how the patient and his rehabilitation team experience the same

GPM event. Staff members also seemed to have differing ideas of what the purpose of the GPM is or should be. All participants concurred that long-term goals aren't communicated very effectively in the current GPM format, and that everyone would benefit by helping staff to get to know their patient.

Additionally, the pilot session highlighted the need to move beyond conversations of 'what is' and to support conversations between staff and/or patients about 'what could be.' Consideration must also be given to how staff and patients can share thoughts and experiences on the current rehabilitation system without risking their ongoing working relationships.

2.11.10 Pilot Discussion

Given that the prepared materials for the pilot were more effective in stimulating new conversations than testing the original hypothesis, it could be concluded that they acted as 'probes' rather than 'prototypes' (as will be discussed in chapter 11).

By building upon the insights generated from 'traditional' research methods, such as qualitative and ethnographic investigations, with more visual and provocative approaches such as the diagrammatic exploration and pilot, many different facets of the SCI rehabilitation experience have been explored and integrated into the conclusions drawn. This mixed-methods approach has been effective in generating new insight whilst maintaining a rigour in the study, and will be continued into the next stages.

2.11.11 Summary

The Goal Planning Meeting appears to be an appropriate site for intervention within this study. Previous observations of the GPM suggested that staff and patient behaviours may be (at least partly) dictated by the materials and protocols used therein. As such, the hypothesis that new materials or protocols could be introduced into the GPM to facilitate more participatory patient behaviours was suggested, but further confirmation of the GPM as the site for intervention was sought first. By exploring the GPM observations further in a formal coding process, it became clear that many of the themes emerging (such as 'progression,' 'projection' and 'use of context') were reflective of the rehabilitation process as a whole, and as such warranted continued exploration. By inviting a known patient and his care team to trial new materials in a staged GPM, it was confirmed that the Goal Planning Process did not currently have a clear purpose or structure for all participants, and as such is an entirely appropriate opportunity for intervention.

2.11.12 Implications for the study

Through the contextual review, several research questions have emerged to guide the intervention stages:

- What are the current experiences of staff, patients and family members in the GPM?
    - To be addressed in chapter 6
- How can we engage the SIU community in co-developing a new material or protocol to enhance patient and/or family participation in the GPM, whilst also protecting their current working relationships with staff?
    - To be addressed in chapter 7
- What are the effect(s) (if any) of a co-developed intervention in the GPM?
    - To be addressed in chapters 8 and 9

To begin approaching these questions, this study will continue with a review of the relevant literatures needed to guide the methodology and study design of this research.

Stage Two:

Planning the main study

03 Literature Review

3.1 Introduction

This study touches many fields. However, as will become clear below, it aims to contribute to the field of (Participatory) Service Design for healthcare, more specifically with regard to the topic of patient participation and rehabilitation. It will also explore the extent to which the SIU community (including patients) can be actively involved in shaping healthcare service provision, and what opportunities recent work in PD and Service Design might offer to this issue. It also identifies shortcomings and fundamental differences and potential misunderstandings in separate epistemological approaches brought together in this study which make the nature of the study problematic, issues which require to be resolved in the design of the study and in the methodology to address the problem and research questions.

As a consequence, this literature review will be structured as follows:

- Part A will seek to provide a brief history and an account of current approaches to involving patients in their own, individual healthcare. In other words, this section aims to understand the progress already made towards the goal of this study – enhanced patient participation in their own rehabilitation pathway.
- Part B will seek to provide a brief history and an account of current approaches to involving patients (sometimes alongside healthcare professionals) in healthcare service development. In other words, this section aims to understand how others approach the process used by this study – co-development of the rehabilitation pathway with the SIU community. This section will explore approaches to healthcare service development in healthcare, Experience-Based Co-Design, Participatory Design and Service Design, with a focussed review of participatory approaches to service design in healthcare.
- Part C will provide a discussion on what has been learnt from the literature reviews and what is yet to be explored, particularly within the SCI context, and how this may inform the methodology discussed in the next chapter.
- Part D will identify the main implications for the study derived from the literature review and accompanying discussion.

3.2 Approach to the literature review

Please see appendix 8 for a description of the literature review strategy.

Part A: Involving Patients in shaping their own healthcare

3.3 Patient participation in general clinical encounters

3.3.1 A brief history

It is largely agreed that attention has been given to the traditionally paternalistic model of healthcare since the 1970's, as being ‘disempowering and demeaning’ (Coulter, 2002) and embodying a conflict between autonomy and health, and between patient and physician values (Emanuel & Emanuel, 1992).

The idea of ‘patient participation’ has established itself as a growing area of interest amongst healthcare practitioners and researchers. Although there is no single definition of patient participation, and it is often interchanged with ‘patient collaboration, patient involvement, partnership, patient empowerment, or patient-centred care’, it is generally thought of as being concerned with the shift from the traditionally paternalistic medical model with a passive patient role, towards one where the patient is a key player in their own healthcare (Longtin et al., 2010).

The 1990’s and early 2000’s saw a wealth of studies and interest from the healthcare research community concerning the quality and styles of doctor-patient interactions, where ‘active forms of patient participation’ included communication behaviours such as ‘asking questions, expressing concerns and being assertive,’ (Andersen, 2010, p151). A focus on more equal patient-professional interaction has been a focus in recent policy documents (i.e. ‘Our health, our care, our say’, Department of Health, 2006), Healthcare Trust guidelines (Eaton et al., 2012) and even in the founding of dedicated councils (i.e. the Scottish Health Council, NHS Scotland). Some call for practitioners to view consultations between patients and doctors as ‘combining two forms of expert knowledge’ (Holmes-Rovner et al., 2007), and progress made towards this ideal is often measured using feedback surveys, to understand patient satisfaction or their care experience (discussed in more detail in Part B). In fact, the modern focus on patient experience has led to some calling this the ‘era of the patient’ (Tai-Seale et al., 2016). Despite this, however, Holmes-Rovner et al. argue that ‘patients have become so trained to operate in a health care environment where their values are not assessed that they begin to believe that they’re actually not relevant,’ (2007, p605). As such, we can deduce that there is still some progress to be made, which will be explored further in this review.

3.3.2 Rationale – why involve patients in shaping their own healthcare?

Principally, involving patients in their own healthcare planning is considered ethically the right thing to do (Tai-Seale et al., 2016) with 'compelling evidence that patients who are active participants in managing their health and health care have better outcomes' (Coulter & Collins, 2011, pvii) and demand fewer resources (Bekker et al., 2004). As such, promoting and facilitating greater patient engagement is seen as ‘the best way to ensure the sustainability of health systems,' (Coulter, 2006, p2).

3.3.3 Do patients want to be involved?

Although some patients don’t want to participate in their healthcare, and the proportions of this vary in different studies (Longtin et al., 2010), it is generally agreed that most patients do want to play an active role (The Picker Institute Europe, 2005, Flynn et al., 2006). Desire for active involvement has seen to vary with the patient’s age, educational status and disease severity, plus ethnic and cultural differences, but Coulter and Ellins argue that this only explains part of the difference and that it is important for clinicians to ask their patients what kind of role they want to play (2006, p57). Coulter and Magee (2003) believe that, at the very least, 'almost everyone wants clinicians to listen, explain and answer their questions,’ whilst Ridd et al. (2009) argue that 'there is also compelling evidence that patients want to be treated as a whole person and that they want to work with clinicians whom they trust.’ This suggests that patients want to work in a more ‘human’ way, not just on the physician’s terms but also in a way that leaves room for their own expertise.

3.3.4 The Four Models of the Patient-Physician Relationship

The way in which patient engagement is discussed in the literature can sometimes seem to suggest a binary state of involvement – either active or passive. However, Emanuel and Emanuel (1992) suggest that patient engagement can consider the way patient’s values can play a role in medical decision-making. In their ‘Four Models of the Patient-Physician Relationship’ (as adapted into the diagrams below), a physician can either; present their preferred choice of treatment (the Paternalistic model); present all of the medical information, and allow the patient to choose their preferred option (the Informative model); help a patient choose which option is best based on the medical information and patient's values (the Interpretive model); or facilitate a discussion on what health-related values are embodied in the treatment options available to the patient (the Deliberative model).

Above: Paternalistic Model

Above: Informative Model

Above: Interpretive Model

Above: Deliberative Model

Fig. 3.1: The Four Models of the Patient-Physician Relationship, adapted from Emanuel and Emanuel, 1992.

Although the models above are by no means definitive, nor do they take into account evolving patient-professional relationships over time, they do provide interesting ways in which to reconsider how both parties can contribute to the discussion, as well as what is discussed (i.e. whose values and for what purpose). Emanuel and Emanuel suggest that some models (such as the Deliberative model) offer better experiences for the physician as well, by accommodating their values and allowing them to simply 'care'.

Several of these concepts, and the questions they raise, may be useful to take forward in this PhD study, including:

- Are patient values fixed or transitory?
- How do we define patient autonomy? Do staff want to aim for the same definition?
- Do staff require new skills development to support new patient roles?
- Are we aiming for patient choice or patient care? Or a combination of both?

Mol (2008) offers some interesting contributions to the latter point in her book ‘The Logic of Care’. She adds that simply giving patients a choice over their treatment options, although well intentioned, may increase patient anxiety by shifting the responsibility for any negative consequences onto them. Importantly, she also draws attention to the fact that ‘care’ itself ‘is not a transaction in which something is exchanged...but an interaction’ (p21), so perhaps (particularly in the case of long-term rehabilitation situations) we need to move beyond thinking of one-off interactions and on to how the patient travels through the care pathway? This mindset also subtly shifts the patient into a more equal position, as an essential part of the ‘interactions’ and even as one of the care team. Moreover, whilst more traditional models of healthcare try to ‘separate facts from values...the logic of care attends to them jointly,’ (p53). Considering the patient’s contribution as equally important and affected by medical knowledge in this way again arguably reduces the 'power distance' between healthcare ‘provider’ and ‘receiver’.

3.3.5 What is the current state of patient engagement in the NHS in the United Kingdom?

The majority of studies found within the medical literature concerning patient engagement fall into the category of improving ‘Patient Centred Care’[2], quite often facilitated through the use of Shared Decision Making (SDM) and usually supported by Patient Decision Aids (PDAs). Richards et al. (2015) argue that although patient centred care is the ‘central mission of healthcare,’ it has not yet been realised in practice. To understand this, the following section will explore the methods, impacts and issues surrounding SDM.

---

[2] Defined as compassionate and empathetic care that responds to a patient’s needs, values and preferences, as well as providing emotional, physical and educational support with the involvement of family and friends (Committee on Quality of Health Care in America, 2001)

3.3.6 Shared Decision-Making (SDM)

What is effective SDM?

SDM is described as a process that respects patient autonomy and promotes patient engagement (Elwyn et al., 2010) by reducing information asymmetry (Tai-Seale et al., 2016). Coulter and Collins (2011) argue that SDM is characterised by giving patients evidence-based information, and requires clinicians to recognise and respect the patient's role, learn advanced communication skills and use a range of tools/techniques to share information, communicate risk and facilitate deliberation on which is the best treatment choice for a specific patient in a specific situation.

Whilst some SDM approaches are facilitated only by communication skills training for clinicians, coaching for patients and patient decision aids (PDAs) have been shown to help SDM (Coulter & Ellins, 2006). PDAs usually contain evidence-based information related to a particular condition and the treatment options available (including the likely risks or benefits of each), with many now available online (see www.decisionaid.ohri.ca and www.thedecisionaidcollection.nl). When effective, the use of PDAs can reduce patient passivity and decisional conflict, as well as help patients to arrive at decisions earlier (Holmes-Rovner et al., 2007).

What are the benefits of SDM?

The use of SDM has been shown to increase patient satisfaction (Coulter, 2002, Holmes-Rovner et al., 2007), knowledge (Evans et al., 2007, Coulter, 2007, Elwyn et al., 2010), outcome (Evans et al., 2007) and adherence (Coulter, 2007, Elwyn et al., 2010), as well as realign patient expectations (Coulter, 2007).

How much is SDM used?

SDM is becoming more popular in the UK, Canada and United States, but the implementation of SDM has been difficult and slow (Elwyn et al., 2010) with patchy implementation of PDAs (Coulter & Collins, 2011), meaning UK patients rarely get effective support to make decisions (Coulter, 2010, Coulter & Ellins, 2007).

The limited uptake of SDM or PDAs has been associated with a lack of a strong push from professional associations or coordinated performance measures (Coulter et al., 2015), as well as system inertia (Richards et al., 2015). Researchers argue that new attitudes to patient engagement need to be embedded into organisations (Elwyn et al., 2010), as some staff may fear it will take too much time in an already overburdened schedule (Coulter &

Elwyn, 2002, Coulter & Collins, 2011, Coulter 2010), although the evidence contradicts this (Elwyn et al. 2010).

Beyond the practical and organisational difficulties, Tai-Seale et al. (2016) argue that patients may hesitate to use PDAs through fear of being labelled ‘difficult’ and can be discouraged by unprepared clinicians. Societal norms and the current lack of ‘permissiveness’ of the healthcare environment may also affect patients’ willingness to engage, as well as the patient’s confidence and comorbidities (Longtin et al., 2010).

Very few of the reviewed interventions in SDM targeted the behaviours of both staff and patients. Tai-Seale et al. describe this as ‘akin to anticipating an elegant waltz emerging on the ballroom floor when only one partner has taken dance lessons,’ (2016, p605-606). In their own work, the authors found that priming patients with a 2-minute video (which ‘normalised setting a joint agenda, asking questions, and requesting information on other options’) before their consultation, providing the patient with written materials to prepare for and document the consultation, and providing staff with regular SDM training, patients gave more positive feedback on scores of reported experience of care, perceived involvement in care and consumer assessments. Qualitative feedback from patients was limited in this study, but it is worth noting that they did find the patient-held record to be useful and increased their sense of control.

3.3.7 The NHS and the Informative Model

From the evidence reviewed above, we can assume that patient engagement, at its best, is realised in the form of SDM. When describing SDM, Brock and Wartman (1990) describe a ‘fact-value division of labour’, and arguably this resonates with Emanuel and Emanuel’s ‘Informative’ model described above, where a physician works to provide the facts, and the patient works to evaluate these facts against their values to make a choice. Whilst this may not reach the ‘ideal’ of the ‘Deliberative Model’ described by Emanuel and Emanuel (1992), this still an improvement on the traditional ‘Paternalistic Model’ and offer important insights into how to approach enhancing patient engagement.

3.3.8 Discussion

It appears that simply providing tools and training techniques to staff to facilitate SDM, or any aspect of patient-centred care, is not enough to change healthcare delivery in a meaningful, sustainable way. Interventions that hope to create change must explicitly address the (new) roles of the patient and the healthcare provider, but methods to do this are rare in the literature. It has been suggested that patients should always be asked how they would like to participate, although a patient's answer may be influenced by their previous experience(s) with healthcare providers, not knowing they can participate or by simply trying to be polite (Coulter, 2007). As such, the ways in which patients are offered to engage in their healthcare must provide a comfortable experience.

Despite robust quantitative evaluations of patient-focused interventions, most qualitative data tends to report the healthcare providers' experience rather than the patients', suggesting a gap in the literature which could be addressed in this study. Indeed, Eaton et al. (2012) have called upon the UK's National Institute of Clinical Excellence (NICE) to elaborate further on their published guidelines to use patient experience, arguing that patient experience should be measured, evaluated and improved upon rather than simply captured. The various methods used in chapter 2 to elicit and capture patient experience may offer a contribution in this area.

Finally, the majority of studies available focus on standalone consultations between a patient and an individual healthcare professional, rather than the repeated group consultations in the Goal Planning Meeting. Given the paucity of SCI-specific interventions in the literature, Part A will continue with a review of the Goal Planning Processes in business, healthcare and SCI rehabilitation.

3.4 Patient participation in the Goal Planning Process

3.4.1 Introduction

Research into goal setting theory began as early as the 1960's, although this was largely in a business context. By the late 90's this had progressed into medical contexts, where practitioners began to call for more practical frameworks that could be used in day-to-day practice. In 2002, Locke and Latham published their 'practically useful' framework, which was adopted by many professionals in many contexts (and is still used as a key reference today). From the 2000's onwards, goal-setting research has focused on evaluations of efficacy, where most studies in healthcare conclude it is a worthwhile exercise from patient and staff perspectives.

3.4.2 Goal-Setting Theory

Locke and Latham's 'practically useful' framework (see fig. 3.2), has been particularly well received and adapted by several other disciplines.

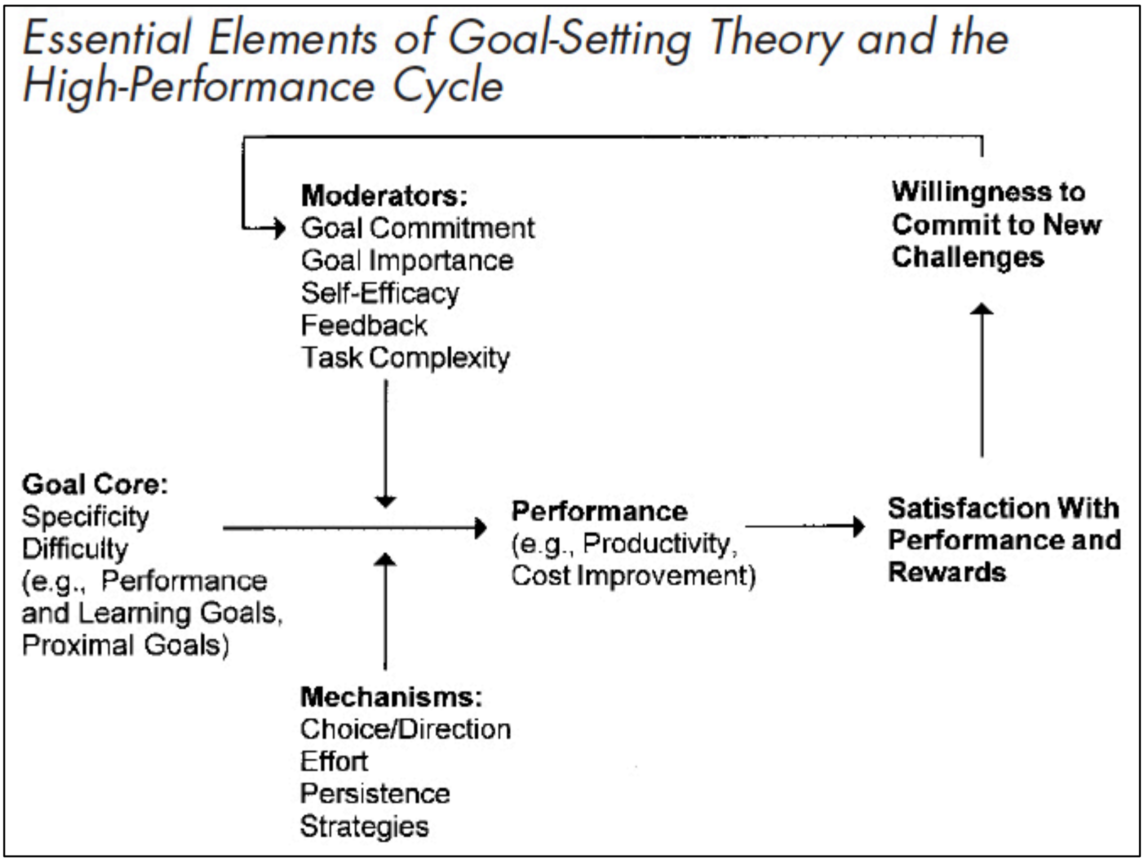


Fig. 3.2: Locke and Latham (2002) describe the key elements present during effective goal planning and their interdependencies.

Locke and Latham (2002) also stress the need for summary feedback on progress made towards goals; a concept that resonates with the purpose and content of the SIU GPMs observed in chapter 2. This chapter will continue, however, with a focus on healthcare.

3.4.3 What is a (good) goal in healthcare?

According to Wade, ‘a goal is the state or change in state that is hoped or intended for an intervention or course of action to achieve’ (1999) and ‘might refer to matters affecting the patient, the patient’s environment, the family or any other party. It is a generic term with no implications about time frame or level,’ (1998).

To be considered ‘patient-centred’, goals must be relevant to patient desires, not staff agendas (Randall & McEwen, 2000). However, specific methods to write patient-centred goals are rarely addressed in the literature (Donnelly et al., 2004) and as observed in the contextual review, staff mostly use informal methods to engage individuals personally (ibid).

The SMART framework (Hersey & Blanchard, 1988) can aid patient-centred goal setting, where a SMART goal is described as Specific, Measurable, Achievable, Realistic and Time-bound. However, Bovend'Eerdt, Botell and Wade (2009) instead recommend that a goal be made of four parts: target activity, support needed, quantification of performance and time period to achieve the desired state. In either model, measurable goals are considered to be beneficial as they are linked with skill acquisition and positive psychological benefits (Duff et al., 2004).

One established method of measuring progress is known as Goal Attainment Scaling, although this is not used in the host SIU. Originally developed by Kiresuk and Sherman for use in a mental health service (1968), Goal Attainment Scaling involves setting goals within a specified timeframe, weighting them by importance, and setting different levels of over or underachievement with appropriate scoring (see Malec, 1999). For example:

Goal: Gemma is currently walking 6000 steps a day. She will increase her activity to 8000 steps a day by 12/07/16.

Activity on 12/07/16	**Score**
2000 steps a day	-2
4000 steps a day	-1
6000 steps a day	0
8000 steps a day	+1
10000 steps a day	+2

Table 3.1: A fictional example of Goal Attainment Scoring.

However, Hurn, Kneebone and Cropley (2006) demonstrate mixed opinions of the reliability and sensitivity of Goal attainment scaling practices, and as such will not be considered further in this study to avoid overcomplicating the intervention.

Several studies support the idea that a mix of short- and long-term goals is best (Latham & Seijts, 1999, Bar-Eli, Hartman & Levy-Kolker, 1994), and may also help teams of healthcare professionals to collaborate and focus on the patient (Wade, 1998).

3.4.4 What is Goal Planning in Rehabilitation?

Duff et al. (2004) describe rehabilitation as a process where previously lost or new skills are learnt, and as such it involves behaviour change. Goal Planning, therefore, is an asset to this process as it is comprised of two main components; identifying needs and a behaviour change strategy (such as the GPM).

Identifying needs

Identifying needs usually requires staff to consult a condition-specific framework of potential patient needs, and apply a scoring system to each need; creating a detailed picture of the patient's functional ability or independence. The main frameworks and scoring systems are described below:

- The Needs Assessment Checklist with simple 4-point rating scale describing patient's knowledge and ability of each need. This has been shown to be a clinically reliable tool (Kennedy, Smithson & Blakey, 2012), psychometrically valid (Berry & Kennedy, 2002) and useful to structure Goal Planning Meetings (Duff et al. 2004). See table 3.2.

Needs Assessment Checklist, National Spinal Injury Centre, Buckinghamshire		**Independence Rating Scale, National Spinal Injury Centre, Buckinghamshire**	
Activities of Daily Living	+	3	Complete Independence
Skin Management			
Bladder Management			
Bowel Management		2	Moderate Independence (Knows quite a lot, needs practise)
Mobility			
Wheelchair & Equipment		1	Mostly Dependent (Knows a little, attempted once)
Community			
Discharge Coordination		0	Complete Dependence (No knowledge or attempts)
Psychological Issues			

Table 3.2: A summary of the needs assessment and scoring models used in the National Spinal Injury Centre, Buckinghamshire (adapted from Duff et al., 2004, p278).

- The Goal Planning Checklist (table 3.3), with a 7-point Functional Independence Measure (FIM) and 4-point knowledge score (table 3.4) as used in the host SIU. In recent years, the Spinal Cord Injury Measure (SCIM) has been trialled to potentially replace these scores, but at the time of writing both FIM and SCIM scores are measured. The Goal Planning Checklist is arguably a clearer framework of needs, but recorded scores may be more understood (and therefore better serve) staff rather than patients.

Goal Planning Checklist, QENSIU	**Scores Used**
1) How do you feel?	Anxiety and Depression Scores
2) Everyday activities	FIM
3) Skin	FIM + Knowledge
4) Bladder	FIM + Knowledge
5) Sexual Issues/Fertility	Other
6) Autonomic Dysreflexia	Knowledge
7) Bowel Management	FIM + Knowledge
8) Chest Management	Knowledge
9) Joint Management	Other
10) Mobility	FIM + Other
11) Equipment	Knowledge + Other
12) Accommodation	Other
13) Social Issues	Other
14) Schooling	Other
15) Employment / Further Education	Other

Table 3.3: A summary of the needs assessment topics and associated scores used in QENSIU.

Functional Independence Measure (FIM)				**Knowledge**	
7	Complete Independence	No Helper Needed	+	4	100% Recall by the patient
6	Modified Independence				
5	Supervision	Helper Needed		3	75% Recall by the patient
4	Minimal Assistance				
3	Moderate Assistance			2	50% Recall by the patient
2	Maximum Assistance				
1 (Ventilated)	Verbally Independent			1	? [Missing from guidelines, assumed 25%]
1	Total Assistance				

Table 3.4: A summary of the independence and knowledge scores used in QENSIU

Alternative scoring systems

Whilst FIM more accurately measures the burden of care, SCIM is the only SCI-specific measure and as such is often more highly recommended (Anderson et al., 2008). However, alternative frameworks suggest that including the patient’s perception of their independence can help staff to get to know the patient and encourage their participation (see the Canadian Occupational Performance Measure, Donnelly et al., 2004).

Whichever method or scoring system is used, needs assessments are most often conducted once early in rehabilitation and once at the point of discharge. Donnelly et al. argue that a mid-point assessment may more accurately reflect the evolving nature of SCI rehabilitation (2004).

Behaviour change strategy

The National Spinal Injuries Centre in Buckinghamshire, England, describes how GPMs are used to 'operationalise' the identified needs to make them 'personally meaningful' for the patient, where 'a global goal is set, together with specific targets to achieve the goal,' (Duff et al., 2004). In QENSIU, staff in GPMs were observed to continue using FIM/SCIM scores, as in the Goal Planning Checklist, but made no reference to the checklist itself.

3.4.5 Patient involvement in Goal Planning

In clinical rehabilitation in general, patient involvement is associated with greater adherence (McGrath, Marks & Davis, 1995), goal attainment (Willer & Miller, 1977) and behavioural change (Wade, 1998).

In SCI rehabilitation, patient involvement is also particularly recognised as being important (Wade, 1998, Byrnes et al., 2012, Duff et al., 2004) and can enhance predictions of functional outcomes (Schönherr et al., 2000). Taking part goal planning is thought to facilitate a sense of control in patients, something that is often lost after SCI (Foley, 1998, MacLeod & MacLeod, 1996), enable patients to be actively involved in their rehabilitation (Duff et al., 1999, MacLeod & MacLeod 1996) and spend less time in 'disengaged behaviours,' (Kennedy, Walker and White, 1991)

Post-discharge, active patient involvement in SCI rehabilitation is linked with better physical and psychological adjustment (Norris-Baker et al., 1981) as well as participation in the community (Foley, 1998).

Interestingly, Byrnes et al. (2012) found that patient satisfaction with Goal Planning increased not only in relation to their participation, but also when patients had an understanding of the role of each professional.

3.4.6 Particular Goal Planning needs of the SCI patient community

According to Byrnes et al. (2012), patient barriers to their participation in goal planning may include unrealistic goals, lack of understanding, motivation and psychological distress, as well as medical complications.

As observed in the contextual review, successful goal planning may rely on patients having an understanding of the process and their prognosis. It is useful here to remember that whilst patients are encouraged to attend patient education sessions (which discuss a range of topics including anatomy and techniques to manage the bowel, bladder and skin integrity), the information given is generic rather than tailored to the specific patient's prognosis.

The Goal Planning process itself must also use clear language and be flexible (due to the evolving nature of SCI rehabilitation), and healthcare professionals should remember that a successful outcome might mean different things to different people (Foley, 1998).

3.4.7 Perspectives on Goal Planning

In clinical rehabilitation in general, opinions on goal planning are varied. Some studies report that goal planning activities provide motivation and reassurance for patients, whilst increasing the focus and collaborative nature of staff activities (Young, Manmathan & Ward, 2008). However, others state that in observed GPMs, the translation of patient wishes into written goals is not clear (Barnard, Cruice & Playford, 2010) with no consensus on the best practice of doing so (Scobbie et al., 2013) and goals tend to be set and owned predominantly by the staff (Playford et al., 2000).

In the specific context of SCI rehabilitation opinions are also mixed. According to Foley, ‘subconsciously goal planning is often seen as an inconvenience to both patient and staff,’ (1998, p148). On the other hand, other reviews (including two internal, unpublished audits by the host SIU), are generally positive, suggesting that the process helps patients to manage their rehabilitation and adjust to their injury (see Byrnes et al., 2012). However, the studies referenced here employ traditional, Likert scale-based questionnaires with space for additional comments, which may provide less opportunity to reflect on and critique the Goal Planning process in detail. In conducting this literature review, studies specifically aimed at understanding the experiences of patients, family members and staff could not be found, suggesting a gap in the literature that could potentially be addressed in this PhD study.

3.4.8 Previous interventions in Goal Planning

In general clinical rehabilitation, several novel approaches to enhancing patient engagement in goal planning have been discussed in the literature. Culley and Evans (2010) document a study using text messages as reminders of previously set rehabilitation goals for people with a brain injury. Harty, Griesel and van der Mewe (2011) describe how Talking Mats® have been used to help patients to prioritise goals and achieve consensus in goal planning consultations. Scobbie et al. (2013) describe a community-based stroke rehabilitation goal planning process that used a patient-held record as part of its approach. Patients described how the record was a useful guide in the early stages of their rehabilitation, helped them to monitor their progress and helped family members to understand and support their goals, although some felt the paperwork was excessive. Health professionals agreed that it was useful as a reference for patients and helped to make progress clearer, but experienced some logistical problems in incorporating the documentation and the extra time required to use it into their existing practice. Although there are very few studies in SCI rehabilitation concerning patient engagement in goal planning, several ideas and potential issues to anticipate can be taken from the limited work done in other areas described here.

3.4.9 Conclusion

The National Spinal Injuries Centre's (Buckinghamshire, United Kingdom) original Goal Planning model was simple, and it could be inferred that as additional functionality was added to the meetings in the host SIU (such as the use of FIM and SCIM scores), the purpose of the meeting has become less clear and as such may not be as useful for the patient as it could be.

Although many sources agree that patient involvement in goal setting is beneficial and can lead to increased patient engagement in rehabilitation, positive psychological adjustment and feelings of control, few studies provide robustly evidenced frameworks to facilitate this. Additionally, no studies could be found that suggest methods to prepare patients for SCI rehabilitation prior to the first GPM and few studies focus on the patient, family or staff's experiences of SCI goal planning processes. A mixed-methods approach may contribute to the literature by providing a (localised) understanding of the patient experience, rather than satisfaction, of the Goal Planning process and as such may suggest novel ways to intervene within it.

The terms 'goal planning' and 'goal setting' are often considered synonymous (Wade, 1998), but this study will use the following definitions:

- 'Goal Planning' will be used to denote the whole process of needs assessment, goal setting and reviewing progress.
- 'Goal Setting' describes the (collaborative) setting of goals in a GPM.

Part B: Patient and public involvement in healthcare service development

3.5 Engaging patients and the public in improving healthcare services

3.5.1 Introduction

In this section, studies from the medical and design literatures will be reviewed to understand how patient experience has been defined, valued, captured and used in healthcare service development interventions.

3.5.2 Why involve the public in healthcare service development?

It has been suggested that public involvement in healthcare service development could be ‘an important strategy in tackling the democratic deficit in the health services,' increase public confidence in the NHS and even benefit society as a whole (Coulter & Ellins, 2006, p253). In fact, the reasons for doing so are so convincing that NHS organisations have had a statutory obligation ‘to involve and consult patients and the public about health service planning’ since 2001 (ibid, p249).

3.5.3 Do the public want to be involved in healthcare service development?

Whilst the British public appear to support their right to be involved in healthcare service development, 'they appear to be less keen on getting involved when actual opportunities arise,' (ibid, p255). The Picker Institute Europe (2005) suggests that most members of the public just want to have good interactions with qualified, caring professionals and that a small minority want to be consulted about service developments that don’t affect them directly. As such, it could be argued that interventions that hope to involve the public must consider if and how they are providing a worthwhile experience for those participating.

3.5.4 How are patients and the public currently involved in healthcare-led service improvement projects?

Coulter and Ellins (2006) provide a detailed history of how and when different approaches to public involvement arose. For the purposes of this review, however, it is sufficient to say that the main methods used in healthcare-led interventions can be summarised as patient feedback (including distinct methods of capturing patient satisfaction and experience), consultation, deliberation, participation groups and lay representation. The first on this list, patient feedback, remains the most prevalent method used today and as such will be reviewed in detail.

Patient Feedback

In 1997 the British government set out a programme to improve the quality and patient-centred focus of NHS care. The National Patient Survey Programme (which became mandated in England in 2001) was a key part of this programme, which aimed to measure healthcare provider performance against patient expectations. In more recent years, the focus of this approach has evolved from patient satisfaction surveys (although they are still used) to gathering patient views of their care experience. Since April 2015 all NHS patients experiencing any healthcare service in England have been invited to provide feedback (Coulter et al., 2014).

Patient Satisfaction

Patient satisfaction has many definitions and can be used as a process or outcome measure, and mostly include a patient’s preferences and expectations. Satisfaction is usually represented via a quantitative survey, where scores can be influenced by age (Jenkinson et al., 2002), hearsay, cultural norms and health status (Coulter, Fitzpatrick & Cornwell, 2009).

Quantitative surveys have been described as effective if the target improvement areas and patient priorities are clear (Coulter, Fitzpatrick & Cornwell, 2009). However, satisfaction scores can provide a 'limited and optimistic picture' (Jenkinson et al., 2002), perhaps misleadingly so (Coulter, Fitzpatrick & Cornwell, 2009).

Coulter and Cleary state that many patient surveys are poorly designed and don't produce actionable results, so are often simply used as marketing tools (2002). Additionally, Coulter, Fitzpatrick and Cornwell argue that satisfaction surveys tend to focus on the priorities of healthcare providers rather than patients, and that whilst measuring satisfaction is ‘easy’, it can foster cynicism and resentment from staff if the process is not useful or does not lead to improvements (2009).

Patient Experience

Patient experience is said to elicit what actually occurred in a healthcare event rather than the patient’s judgement of it. Whilst both are perceptions, the former is considered to be more useful (Coulter, Fitzpatrick & Cornwell, 2009). Patient experience surveys are 'less subject to variations in expectations' (Coulter & Cleary, 2002, p12), bias (Coulter, Fitzpatrick & Cornwell, 2009) or ceiling effects (Cleary et al., 1992). Although the results from reports of patient experience are harder to summarize (Coulter, Fitzpatrick & Cornwell, 2009) they are generally easier to interpret (Coulter & Cleary, 2002). As such, they are more actionable (Coulter, Fitzpatrick & Cornwell 2009) and can be used to monitor and develop services (Jenkinson et al., 2002).

Impact of collecting patient experience data

Whilst the uptake of measuring patient experience has grown in popularity, less effort has been put into using that data to drive improvements in healthcare services (Coulter et al., 2014, Fitzpatrick & Cornwell, 2009). Coulter et al. describe a ‘chasm’ between gathering information and creating structures for change, arguing that ‘it is unethical to ask patients to comment on their experiences if these comments are going to be ignored,’ (2014, p3).

3.5.5 Current state of public participation in healthcare service development

Crawford et al. (2002) conducted a systematic review of medical literatures between 1966-2000, where only 42 papers of non-survey methods of public involvement could be identified (with no consensus on which are the best methods). In general, organisations that used these methods (including 'patient forums and participation groups, citizens’ juries, public meetings and user representation at meetings,' p264) changed their attitudes to involving patients and found that it often led to a change in service provision. However, the reported experience and impacts of using these methods suggest that the reality of public participation in healthcare service development is limited, including concerns that public involvement was simply used to 'rubberstamp' pre-existing decisions made by management staff, difficulties in translating the insights into coherent ideas for service improvement (Strobi & Bruce, 2000) and a 'strong power imbalance' in patient-professional discussions (Lindhorst et al., 2001).

In summary, the public involvement methods that offer public involvement beyond giving feedback are in reality not commonly used, or do not often offer genuine involvement when they are.

3.5.6 Evidencing the impact(s) of public participation in healthcare service development

Many of the studies reviewed by Crawford et al. (2002) focussed on a qualitative evaluation of the processes used to involve the public, rather than evaluating the impact of the change(s) made on patient satisfaction, health outcomes or patient quality of life. In their extensive review of patient-focussed interventions, Coulter and Ellins conclude that, in general, ‘the evidence base for public involvement is relatively weak,' and in many cases the 'outcomes described in the studies are usually ones that are not readily amenable to measurement,' (2006, p263). They suggest that a set of clear, intended aims are needed in order to establish an agreed evaluation framework across healthcare providers.

3.5.7 Barriers to public involvement

As well as lack of clear aims described above, Coulter and Ellins describe how barriers to public involvement can be organisational (i.e. ‘resource limitations’ or ‘professional or managerial resistance’), operational (i.e. ‘problematic relationships between stakeholders’ or ‘unsuitable choice of methods’) and personal (i.e. ‘perceived lack of (own) expertise,’ ‘scepticism about the impact of participation’ or ‘consultation fatigue’) (2006, p256).

3.5.8 Discussion of public involvement in healthcare service development

In light of the discussion above, we can argue that patient experience is considered necessary data to capture, with a range of qualitative and quantitative approaches embedded in regular clinical practice. However, there is a gap between capturing the data and using it to drive improvements, with concerns over whether public involvement may only ‘rubberstamp’ established decisions. We could argue, then, that within these approaches public participants are perhaps involved too late in the process to provide meaningful contributions.

It must be noted that in many cases, the intention to involve patients and the public in shaping healthcare service provision is strong, but in practice public engagement using these methods is actually low. Several factors could be considered to contribute to this, apart from the practicalities describe above:

- In Part A, it was acknowledged that patients may need tools or support in eliciting and understanding their own values in regards to shaping their individual healthcare pathways. However, in the literature reviewed in section 3.5, there are few documented efforts to support participants in clarifying their opinions or experiences.
- Again, several authors included in Part A suggested a need to ask patients how they want to be involved in shaping their individual healthcare pathways. This may

also be worthwhile when asking patients to shape healthcare services more generally, but no evidence of this could be found.

- Finally, the studies reviewed did not describe any methods to reconcile the potentially different worldviews of service users and service providers/administrators who are asked to work together. If public participants are engaged for their experiences as patients, but then told to share and use these experiences in a healthcare 'world', it is unsurprising that their contributions are generally passive given the paternalistic nature of healthcare described in Part A.

Robert et al. state that, whilst mainstream approaches to improving patient experience are too focussed on quantitative measures and the 'engrained perception of patients and family as passive sources of data,' the Experience-Based Co-Design method believes 'Patients provide insight, wisdom, and ideas, and we urgently need to include them more creatively as partners in change,' (2015, p2).

3.6 Experience-Based Co-Design (EBCD)

3.6.1 History

In the early 2000's, the NHS Institute for Innovation and Improvement (NHS III) began to look towards design theory, tools and techniques in response to a call for a more patient-centred NHS (Donetto et al., 2015, Bate & Robert, 2007). The first iteration of this methodology was known simply as Experience-Based Design, but its practitioners quickly recognised a need to actively involve patients in the process, and so switched to a more collaborative approach - EBCD (Donetto et al., 2015).

3.6.2 Approach

As inferred in its name, EBCD is 'based on the foregrounding of experience' (Donetto, 2015, pp231). The approach is also centred on the idea that improvements to healthcare services should address all 3 elements of 'good design,' which Berkun (2004, see also Bate & Robert, 2007) identifies to be Performance (how well it does the job), Engineering (how safe, well made and reliable it is) and The Aesthetics of Experience (how the whole interaction with the design feels). It is important to highlight that the 'aesthetics' component is not simply the 'soft' side to design or how 'pretty' it is, but is in reality a crucial factor in how the user experiences the service (Donetto et al., 2015).

To conduct an EBCD project, Robert et al. (2015) suggest using a six-stage process over approximately 9 to 12 months, which includes:

1. ‘Setting up the project
2. Gathering staff experiences through observation and in-depth interviews
3. Gathering patient and carer experiences through 12-15 filmed narrative based interviews
4. Bringing staff, patients, and carers together to share their experiences of a service and identify their shared priorities for improvement, prompted by an edited 30 minute “trigger” film of patient narratives[3].
5. Small groups of patients and staff work on the identified priorities (typically 4-6) over three or four months
6. Celebration and review event,’ (2015, p1).

The EBCD approach represents a replicable set of methods, which when coupled with robust evidencing of the impact of the co-designed interventions, can make it a trusted methodology in healthcare research (Donetto et al., 2015).

3.6.3 What has been achieved by EBCD?

EBCD has experienced a steady and increasing uptake. According to Donetto et al., ‘a recent international survey of EBCD projects in healthcare services identified 59 projects implemented in six countries (Australia, Canada, England, the Netherlands, New Zealand, and Sweden) during 2005-13 and a further 27 projects in the planning stage,’ (2015, p229). These projects have been situated in a broad range of clinical contexts including ‘emergency medicine, drug and alcohol services, cancer services, paediatric diabetes care and mental healthcare,’ (sic).

Survey feedback from those who delivered EBCD projects suggests that the approach is successful in engaging patients and staff, whilst practitioners appreciate the adaptability of the approach to different contexts or local needs (Donetto et al., 2015, p235).

It has been noted that the ‘sharing of stories and emotional maps helped to build trust and create alliances for change between patients and staff,’ (Bowen et al., 2013, see also

---

[3] To address concerns of costs of an EBCD project (in both time and money), a condensed version of the EBCD approach known as Accelerated Experience Based Co-Design (AEBCD) (see Locock et al., 2014).

Bowen et al. 2011 and Wolstenholme et al. 2010), and staff have felt 'as if they were reconnecting to the beliefs and values they had when they first chose healthcare as a profession.' (Robert et al., 2015). As such, EBCD's strong emphasis on collecting and using patient experience arguably goes some way to addressing the reliance of the NHS on patient satisfaction scores (Bate and Robert, 2007).

3.6.4 Impact of EBCD interventions

The type of improvements or new additions to healthcare services instigated by EBCD projects are often incremental in nature, for example providing better information for patients. Although some practitioners (often from professional design backgrounds) have felt underwhelmed by these small changes (Bowen et al., 2013), it is argued that they can be 'immensely valuable to patients,' (Donetto et al., 2015, p237, see also Moore and Buchanan, 2013) and 'the partnership between patients and staff in making these small changes often leads to deeper, longer term changes in attitudes and behaviours,' (Robert et al., 2015, p2).

3.6.5 Challenges of EBCD

It has been suggested that 'conflict and tension – often relating to issues of power dynamics - can emerge between patients and staff. This may be especially true if patients find it difficult to express their views because of a previous experience of very poor care,' (Robert et al., 2015, p2). Thompson et al. expand on this by highlighting that 'handing over some control and power to patients is novel but it is unclear how this power is, or should be, re-negotiated when the patients are at their next appointment and staff return to their daily roles,' (2015, p2).

In terms of the practicalities of EBCD, the challenges associated with arranging multiple, sequential meetings involving patients (who may have medical issues) and staff (who already have full schedules), often in a hospital setting (where time and space is at a premium) cannot be overestimated.

3.6.6 Criticisms of EBCD

Scale

Some of the design community feel that the incremental nature of EBCD interventions may be due to a lack of ideation tools, which can lead to co-design teams converging 'early on simple "quick fix" solutions without sufficient divergent thinking,' (Bowen et al., 2010). In response, Thompson et al. (2015) have demonstrated how the inclusion of tools such as future groups, analogies and physical props have allowed outpatients and staff to invest more of their ideas and feelings in an EBCD project, 'leading to the generation of meaningful ideas,' (although their definition of 'meaningful' is not clear).

Impact

Donetto et al. note that whilst 'most of the completed or on-going [EBCD] projects involve some, more or less structured, form of evaluation...robust studies of EBCD projects remain scarce.' (2015, p229). Some exceptions, however, are available (Bowen et al, 2013; Iedema et al, 2010; Piper et al, 2012, Tsianakas et al, 2012).

The long-term benefits of EBCD interventions are also largely unknown (Thompson et al., 2015, Bowen et al., 2013), as are their effects on the health outcomes of those using them (Freire and Sangiorgi, 2010).

Genuine engagement

According to Bowen et al., interviews with patient participants in EBCD projects suggested that their 'perception was that they were not "doing" the designing,' but 'although not seeing themselves as designers, some participants did discuss generating ideas' (Bowen et al., 2013, p236). This distinction between generating ideas and designing suggests an opportunity to actively involve patients in this translation from 'idea' to 'design,' to enhance their perceived ownership over a co-design project.

Power

Despite common concerns in the literature over power distances between staff and patients in EBCD projects, and in co-design projects more generally, it has been noted that guidance on how to actually address this gap is not prevalent (Donetto et al., 2015, Bowen et al., 2013). Farr (2013) suggests that the fact that many EBCD projects are hosted by an institution may have an impact on patient ownership or willingness to engage in the project from the beginning.

3.6.7 Discussion of EBCD

Although 'the approach is based on the foregrounding of experience' (Donetto et al., 2015, p231) and it uses principles that have long been a part of design (such as 'touchpoints,' see section 3.8.3), Robert and Macdonald (2017) suggest that EBCD uses 'design-like', rather than 'designerly' methods, which are described as follows:

- Design-like: draws on design-based tools, which are used by non-designers in a Participatory Action Research approach 'as part of a quality improvement intervention' (p117). Whilst design-based approaches are often bespoke, EBCD is repeatable by nature.
- Designerly: the process is led by professional designers, with methods rooted in Participatory Design and iterative prototyping, within a Service Design approach (as will be reviewed in the next section). The design tools employed offer new ways of approaching the work, e.g. a focus on making sense of lived experiences and improving interactions.

The authors highlight that healthcare's adoption of co-design practices is 'confronted by a predominantly positivistic paradigm which relies upon objective (independent) scientific methods of inquiry, such as experiments and statistics,' (p117). They conclude by arguing for combining evidence-based and experience-based methods, as explored in the Methodology chapter of this thesis.

3.7 Participatory Design

3.7.1 Democratic origins

The field of Participatory Design (PD) emerged within the 'various social, political and civil rights movements of the 60's and 70's' (Simonsen and Robertson, 2013, p1). It has its roots in the Scandinavian workplace democracy movement, where it was acknowledged that the introduction of computing technology had the potential to transform workplaces. The movement aimed to involve the workers who would use the computing technology from the early stages of its introduction, in order to develop their work practice, allowing them to 'extend their skills while automating the tedious and repetitive parts of their work,' (ibid, p2). By bringing together 'the expertise of systems designers/researchers and the situated expertise of the people whose work was to be impacted by the change,' the approach 'built on the workers' own experiences and provided them with the resources to be able to act in their current situation,' (Sanders and Stappers, 2008, p7, see Bødker, 1996). This sense of facilitating a sense of 'agency' within the 'users' is a key characteristic of PD, as elaborated further below.

3.7.2 What are the key principles of Scandinavian approaches to PD?

Early writings in PD critiqued the contemporary cultural, political and economic values at play in the existing systems of integrating new technologies into workplaces. These writers argued that the then current systems resulted in a top-down view of the organisation that ignored the ‘social, embodied and contingent nature of everyday work practices,’ (Simonsen and Robertson, 2013, p4), and as such often led to poor working conditions for those using the new technologies. Instead, they advocated a ‘grass-roots’ way of exploring embodied human experiences, knowledge and behaviours, and giving ‘primacy to human action and people’s rights to participate in the shaping of the worlds in which they act,' (ibid); ideas which remain central to PD practice today.

Bratteteig et al. argue that for ‘pragmatic as well as for democratic reasons… the discussion of both what the problem is and what the solutions could be should be discussed where all stakeholders are invited,’ and that this worldview ‘leads us to three core perspectives: having a say, mutual learning and co-realisation,’ (2013, p129), which will be briefly summarised below:

Having a say

This first perspective can be summarised as a concern with ‘genuine participation’ and how to facilitate this (Bødker et al. 2004). It is argued that a PD process must allow for ‘all types of competencies and expert arguments to have weight and respect,’ where participants are supported in expressing themselves, and can be confident that what they say will have an influence (Bratteteig et al., 2013, p129).

Mutual learning

As well as political foundations discussed above, there are also pragmatic rationales to involving users, which ‘stresses the need for users and developers to learn together about possible and useful technical solutions,’ (Simonsen and Robertson, 2013, p6). As a field, PD is known for giving importance to the ‘mutual respect for different knowledge… a commitment to joint negotiation of project goals… and a dedication to develop tools and processes to facilitate participation,’ (Blomberg and Karasti, p89).

Co-realisation

The third key perspective that defines PD is the use of ‘making’ to support having a say and mutual learning. In the early stages of PD, this process of design-by-doing helped non-professional designers to engage in the design process by accessing their practical knowledge about the work process, and how IT could support these practices in the future (Roberson and Simonsen 2013). This concern with practice remains in contemporary PD approaches, recognising that:

- technologies and practice influence and evolve each other, so they should be considered together in the design process (Suchman and Trigg, 1991)
- practice is a social activity, which requires collaborative making tools to enable exploration and communication of it

To facilitate ‘having a say,’ ‘mutual learning’ and ‘co-realisation’ in an embodied manner that takes into account the contexts of practice, the act of prototyping has become key to PD, as described below.

3.7.3 Prototyping

PD is known for its use of tangible methods of discussing current and potential future situations, particularly prototyping, which is argued by some as the most important technique in the field (Bratteteig et al., 2013, p133). Prototyping is an iterative process and can take place in many forms, using a range of materials for high or low resolution manifestations of ideas.

Prototypes can be useful to engage ‘users’ across early to later stages of the design process, and provide a low-risk way of exploring possible futures collaboratively (Brandt & Grunnet, 2000). Even if the prototypes are crude, they can materialise the idea, ‘making the invisible visible, turning the fiction into something tangible’ and ‘invite people to make it genuine’ (Akama and Prendiville, 2013, p37).

According to Sanders and Stappers, designers are ‘natural facilitators of collective prototyping activities,’ (2012, p25), highlighting that whilst the experience and knowledge of the user is paramount in PD, designers still have a crucial role in making the ideas visible (Sanders and Stappers, 2008). These physical manifestations of ideas can act as a ‘boundary object,’ or an object that can ‘give meaning to different participants even though they have different professional practices and professional languages,’ (Brandt et al., 2013, p148). As such they are able to facilitate ‘mutual learning’ and ‘co-realisation’ in a non-specific language that enables ‘having a say’ across disciplines and hierarchical boundaries.

3.7.4 Development and reach of PD

Whilst many PD projects remain concerned with the development of workplace ICT interventions, its focus has been ‘extended to include the design of interventions for domestic and community spaces,’ (Blomberg and Karasti, 2013, p87) including educational domains, museums, urban planning and leisure (Bratteteig et al., 2013).

As the contexts of PD have expanded, practitioners and researchers within this field have developed a ‘rich heritage’ of tools and methods (sometimes looking out to other fields and methodologies) to address the challenges these new contexts bring. For example, ethnography, with its roots in anthropology, has been a key concern of PD since the early 1980’s (see Blomberg and Karasti, 2013).

According to Bratteteig et al., PD ‘traditionally stops when the design result is handed over to the use context, but today’s information technologies can also be modified and customised by the users’ (2013, p138). In recent years, this has led to research into ‘design-after-design’ and concepts of ‘infrastructuring’ (see Björgvinsson et al., 2010), which will be reviewed in chapter 11 of this thesis.

More recently, criticisms have emerged that PD has ‘lost its commitment to workplace democracy and worker empowerment, instead emphasising technology efficiency… where workers (users) are simply participating to provide input to design,’ (Blomberg and Karasti, 2013, p89). This distinction between PD and approaches closer to user-centred design will be explored in the next section.

3.7.5 PD and User-Centred Design

Sanders and Stappers (2008) discuss how the field of PD as ‘led by the North Europeans’ has evolved alongside and been influenced by American approaches to PD, the latter being closer to User-Centred Design. User-Centred Design operates under more pragmatic motives, rather than political, for involving ‘users’ in the design process (Holmlid, 2009), where the user is considered the passive ‘subject’ to be observed and/or interviewed by professional researchers (Sanders and Stappers, 2008).

Although the research and practice of both fields emerged as part of a general trend over the last 70 years of ‘moving closer to the future users of what they design,’ (ibid, p5), they can be differentiated by the agency placed with the ‘user,’ and the purpose of the project, as demonstrated in the following topography:

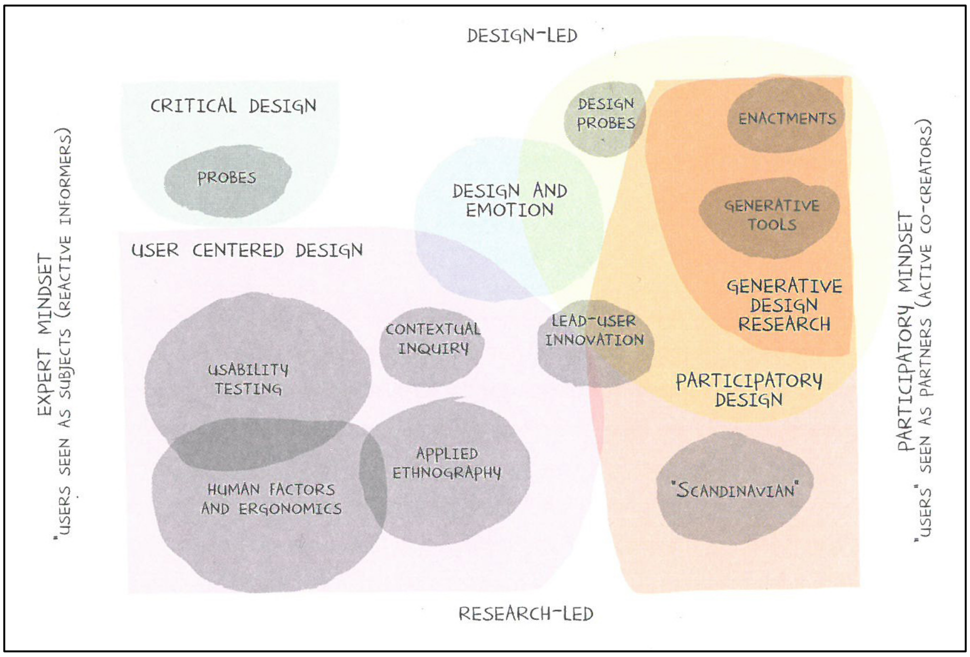


Fig. 3.3: 'Topography of Design Research' (Sanders & Stappers, 2012, p19)

Sanders and Stappers describe how, within the PD area of this landscape, the 'notions of co-creation and co-design have been growing,' although the terms are 'often confused and/or treated synonymously,' (2008, p6), with varying ideas of who should be involved in the design process, when and how. In a more recent review of the design discourse, Mattelmäki & Visser (2011) still note the same interchangeability of terms. For clarity, this study will follow Sanders and Stappers' popular use of the term 'co-design' to refer to 'the creativity of designers and people not trained in design working together in the design development process,' (2008, p6).

Sanders and Stappers go on to describe how, as designers move closer to the future users of what they design, the 'fuzzy front end' of the design process has been growing, as illustrated in fig. 3.4 below:

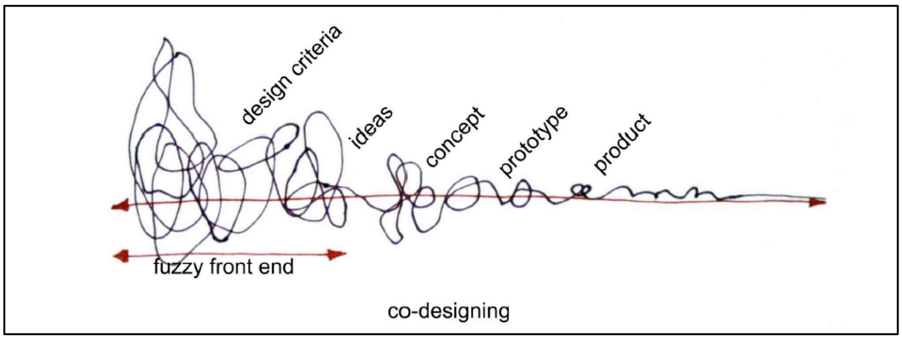


Fig. 3.4: The 'fuzzy front end' of the design process (Sanders and Stappers, 2008)

During this phase, generative research design activities (described below) are employed to fully understand the users, the context of use and the opportunities for design. This 'front end' of the design process is 'often referred to as 'fuzzy' because of the ambiguity and chaotic nature that characterise it… [and] it is often not known whether the deliverable of the design process will be a product, a service, an interface, a building, etc.,' (Sanders and Stappers, 2008). Thus, the outcome of a participatory approach to design is no longer limited to ICT-based interventions.

Involving 'users' in problem definition and development of solutions is considered crucial to the success of a PD project, but also accounts for why it has taken quite some time to gain traction since its origins in the 1970's (Sanders and Stappers, 2008). Among other reasons (such as being antithetical to consumerism), a co-design approach requires the belief that everyone can be creative and can contribute valuable knowledge to the design process, which can threaten existing power structures or hierarchies within organisations. By providing people with the tools to express their hopes, dreams, experiences and creativity (discussed below), they can be considered more than 'users' and the 'functionality it implies with the term use,' (Akama and Prendiville, 2013, p30). In this way, both users and designers can be considered 'everyday people', bringing an 'empathic orientation' to the co-design process (ibid, see also Sanders and Stappers, 2008). Moreover, the knowledge of 'users' is considered a different form of expert knowledge – they are the 'virtuosos' of their own experience domains (Sanders, 2001). This reflects a change in focus in the field of design, from products, to 'broader human goals and propagates the ability of design to tackle complex societal problems,' (Pirinen, 2016, p27) where a focus on multiple stakeholders' lived experiences is key. This is reflected in the emergence of new design fields, such as Service Design (as will be discussed in the following section) and Experience Design.

The latter field, Experience Design, suggests that engaging a diverse group of participants in a co-design process may be well supported through the use of 'experience goals,' which articulate a clear set of aims for the intended experience of the co-designed product, process, service, etc. (see Karvonen, et al., 2012). They are understood as a practical and easily understandable method to support participation from non-designers, where the focus on experience, rather than specific outcome, helps to keep the scope of the design open for longer until the true context of the issue being designed for is understood (Kaasinen et al., 2015). Although no examples of deploying this method in healthcare contexts could be found, this may be relevant to this study's efforts to collaborate with patients, family members and staff of the host spinal injury unit.

3.7.6 Generative design research tools

Many of the generative design research tools can be organised by the understanding that any given person will have different types of knowledge about a given context, including explicit, observable, tacit or latent knowledge. Some of these knowledge types, such as 'explicit' or 'observable', are easier to share than others. Different tools and techniques, then, can be matched to elicit each type of knowledge, which can be roughly grouped into what a person says about a given context, what a person does in a given context and what a person makes about a given context (see fig. 3.5). The latter activity, making, is sometimes supported by a tool known as 'Make toolkits' (see fig. 3.6), which use a collection of ambiguous stimuli materials to allow participants to create a collage describing their experiences, hopes or dreams about a given context (Sanders & Stappers, 2012).

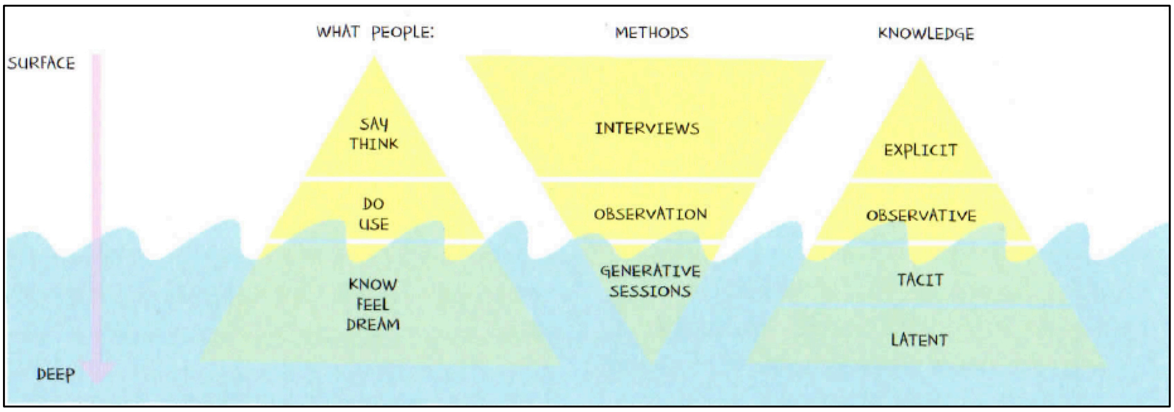


Fig. 3.5: Methods that address what people say, do or make about a given context related to different levels of knowledge (Sanders and Stappers, 2012, p67).

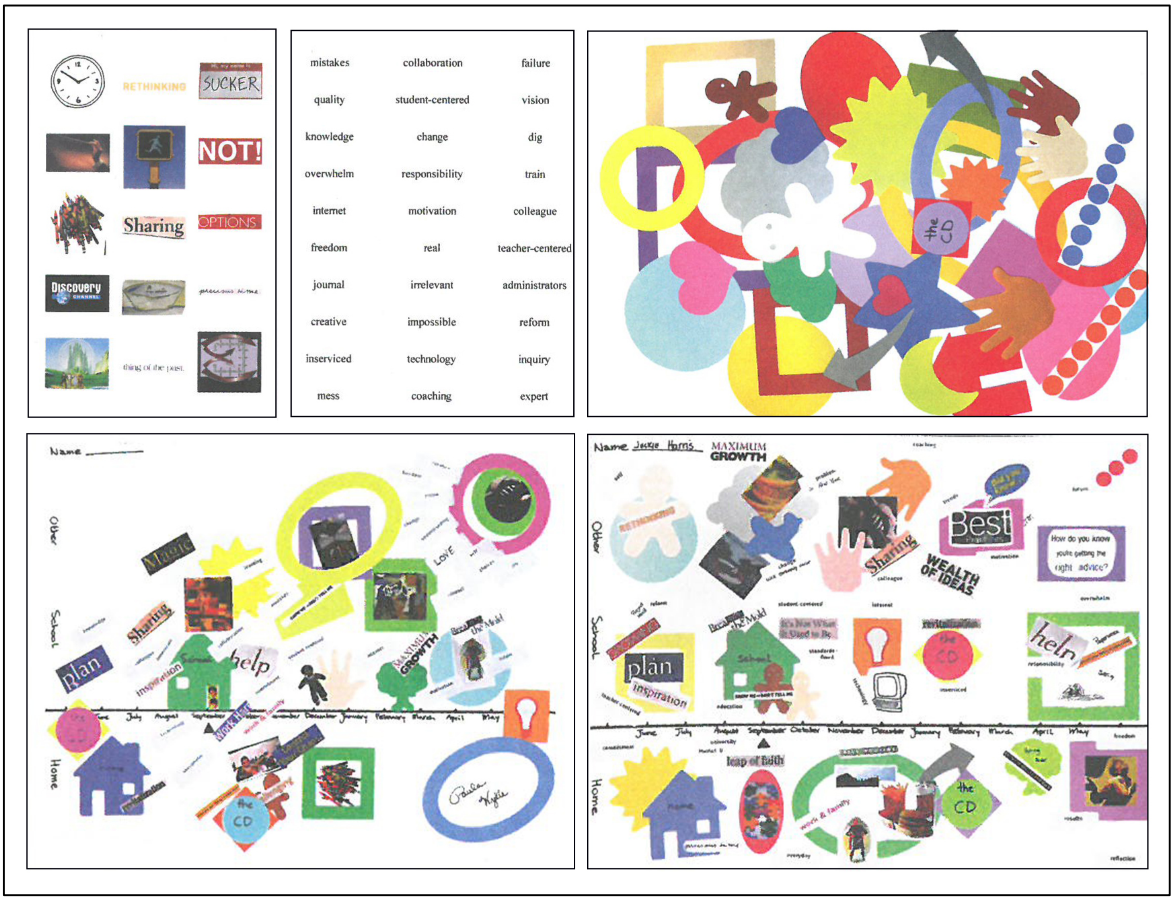


Fig. 3.6: Example of a Maketoolkit using symbols and words to communicate hopes and experiences (Sanders and Stappers, 2012, p89)

As can be seen in fig. 3.5, tools and methods traditionally associated with the social sciences are included within the framework. However, it is important to note interviews or observations within design research are not conducted to explicitly define a phenomenon, but to inform future scenarios. The tools used in ‘generative sessions’ move beyond those methods inspired by the social sciences (i.e. observation) into design-led techniques to elicit knowledge that is harder to understand or articulate, such as what a person knows, feels or dreams.

3.7.7 Summary

From its origins in the Scandinavian workplace democracy movement, PD has gone on to inform a variety of other fields and to develop a rich heritage of methods, tools and techniques to support non-professional designers in shaping the futures they will be a part of, for both political and practical reasons. Crucially, PD considers all participants’ contributions to co-design as equal, taking the stance that each person is the ‘virtuoso’ of their own experience, and is able to work creatively and collaboratively across disciplines and hierarchies with appropriate support from design tools and facilitation.

Whilst this study aims to take a participatory approach to enhancing patient participation, it is important to note that any co-designed intervention must operate within the wider SIU service context. As such, the following section will review the field of Service Design, before going on to explore how (participatory) service design approaches have engaged in healthcare contexts.

3.8 Service Design

3.8.1 Origins

The field of Service Design first emerged as a theoretical concept in 1990s (Sangiorgi and Prendiville 2017a). The first professional Service Design consultancy, LiveWork, opened in 2001 (Young and Warwick, 2017), as well as Engine Service Design soon after (Kirchberger and Tether, 2017).

The term Service Design has roots (and borrowed terms) in business and 'Service Marketing' (Sangiorgi and Junginger, 2015) and was originally considered a phase in 'New Service Development' (NSD) (Sangiorgi and Prendiville 2017a, p1-2), where 'service design' was considered the 'first step in the process of bringing new services "online"' (Johnson, 2000, p5). However, as Holmlid et al. point out, the sequential nature of NSD '[does] not reflect the character of the service,' or 'the contextual nature of SD' (p97).

Over time, designers developed their ability to engage users and creatively work with field data to imagine possible futures; setting them apart 'as a missing resource in managerially-dominated culture' (Sangiorgi & Prendiville, 2017a, p6). Despite being relatively young, Service Design has now developed into its own field of design (and inquiry).

3.8.2 Definitions

Service Design, above all else, is human-focussed (Van Dijk, 2011) and considers users as much more than statistics (Stickdorn, 2011). It distinguishes itself from many other design disciplines in that it 'brings the user into the centre of the development of services,' (Pirinen, 2016, p27) and that it is the experiences and behaviours of users that are the main data in every stage of the service design process. However, the ways in which user input is gathered and represented, or how users are engaged directly, varies according to project or practitioner, as will be discussed in section 3.11.3.

Sangiorgi and Prendiville (2017a, p4) give a concise overview of the multiple definitions of Service Design as ‘adopting a constructivist approach to innovation,’ (see Kimbell, 2011) that is ‘centred around the practice of understanding, mapping and communicating customer experiences,’ (see Stigliani and Fayard, 2010). It is important to consider that there may be more than one user group for a service (Stickdorn, 2011) and that the service providers can also be considered a secondary user (Miettinen, 2011).

Service Design thinking, meanwhile, is described as ‘collaborative, holistic, iterative and visual’ (Sangiorgi & Prendiville, 2017a, p4, see Stickdorn & Schneider, 2010). As a mindset, Service Design reportedly ‘interferes with existing social, organizational, and economic structures and as such the field of SD has a very inter-disciplinary foundation and practice… It is a field that acknowledges how designing happens in a complex world,’ (Eriksen, 2012, p57).

For clarity, this study’s definition of Service Design is aligned with that given by Sangiorgi and Prendiville as a ‘human centred, creative and iterative approach to service innovation’ (2017a, see also Meroni and Sangiorgi, 2011).

3.8.3 Development

In their overview of the development of the field, Sangiorgi and Prendiville (2017a) propose three main shifts in focus:

1. *Points of interaction.* This early stage, also known as the ‘interaction paradigm’, is supported by ‘designers’ perspective on services as sociomaterial configurations of artefacts and interactions (Yu & Sangiorgi, 2018, referencing Kimbell, 2011, Stigliani & Fayard 2010). In short, it encompasses a focus on the moments and materials/technology used when a consumer or user interacts with the service. The ‘human-centred approach’ that designers bring to these points of interaction (or ‘touchpoints’) is based on understanding people’s perspectives, as well as engaging them in the design process (building on PD practices) to create positive experiences (ibid).

2. *Organisational transformation.* In this stage, designers have moved from the ‘periphery’ of a service (i.e. ‘touchpoints’ or ‘interaction channels’) to understanding and developing the organisational structures and service delivery

mechanisms 'that enable the aimed-for experiences' (ibid). As such, service design began to consider, or question, the values and relationships at the heart of organisations, and 'had to acknowledge deeper implications of organizational transformation,' (ibid, p3). To achieve this arguably requires a more embedded approach, with some Service Design researchers and practitioners calling for designers to work 'with and within services' (Sangiorgi and Junginger, 2015).

3. *Into new spaces.* Sangiorgi and Prendiville (2017a) argue that another key shift in Service Design is its expansion into new service sectors (with interest in the particular challenges of working with/for healthcare, as will be explored in section 3.15), as well as the interest and use of its methods by non-designers. Within a healthcare context, this shift can be seen in NESTA's 'People Powered Health' initiative (2013) and the scale of EBCD projects to date (see section 3.6.3).

3.8.4: Co-created value

In parallel to Service Design's development as a field, understandings of what is meant by 'service' have also evolved, in particular in the shift from being based on a 'goods-dominant logic' to a 'service-dominant logic' (Vargo and Lusch, 2008). In the former, traditional view, the value offered by a service was considered to be 'embedded in goods or exchanged and consumed at the point of service delivery,' (Sangiorgi and Prendiville, 2017a, p4). However, in service-dominant logic[4], the service user does not 'consume' (or 'destroy') value, instead value creation is considered interactional, in collaboration with the user through the service process (Vargo and Akaka, 2009). Given that service users 'uniquely perceive and contextually determine value,' (Yu & Sangiorgi, 2018), a service-dominant logic is an 'inherently customer-oriented and relational perspective' (Vargo and Akaka, 2009, see Vargo and Lusch, 2008).

The implications of service-dominant logic are far-reaching, from questioning the (traditionally positivistic) worldviews of fields such as service research (Tronvoll et al. (2011), to reforming notions of 'value' and providing foundational principles for fields such as service science (Vargo and Akaka, 2009). However, this study will simply take forward the concept reframing the service user (or patient) as a co-creator of value (rather than passive consumer of care), where 'value' can be considered positive rehabilitation experiences, potentially facilitated through participatory patient behaviours.

---

[4] Sometimes referred to as simply 'service logic.'

Holmlid et al. explain that a service logic perspective opens up design to reconfigurations of power between service users and providers, not only in the co-design process (as above) but also in the service itself (2017, p103). They suggest that the process of service design can be considered 'realignments' of how service users and providers interact with each other, and that the role of designed materials, technologies or other resources in mediating these interactions requires designers to be 'interpreters of socio-technical and material contexts and practices,' (Wetter-Edman & Moritz, 2015, p4, see also Verganti, 2008, and Kimbell, 2012). This aligns well with this PhD study's current hypothesis that engaging the SIU community in a co-design process for new GPM materials or processes may support more participatory patient behaviours.

The notion of 'co-creation of value' through the service process resonates with the core principles of PD (Blomberg, 2009), and arguably also with its more recent concerns with concepts of 'design-after-design' (Ehn, 2008) or 'infrastructuring' (as discussed in section 11.5).

3.8.5 Service Design Tools

Service design is inherently a multidisciplinary approach (Stickdorn & Schneider, 2011) that has adapted and integrated tools, concepts, methods from various design fields (including product, communication, and interaction design) and non-design fields (such as service marketing and management) (Sangiorgi and Prendiville, 2017a). According to Stickdorn, Service Design is an iterative and non-linear process, but can be roughly separated into four stages of exploration, creation, reflection and implementation (2011, p128-135). The aims and associated tools of these four stages are summarised below, but the key approaches used in healthcare service design will be reviewed in detail later in the chapter.

1. *Exploration*

- Understand the culture of the company or service context. Here the use of 'Shadowing' a service provider (i.e. following and observing them for a period of time, without interrupting their usual work activities) to better understand the service context and their role within it, can be useful.
- Identify the problems from the customer's (or perhaps patient's) perspective, and visualise the findings. This helps to simplify the processes involved in a service and make them seem more changeable. Here 'Customer Journey Maps' (visualising the route a customer takes through a service, identifying touchpoints

and emotional aspects associated with them, see fig. 3.7) can assist with analysis and dissemination of the findings.

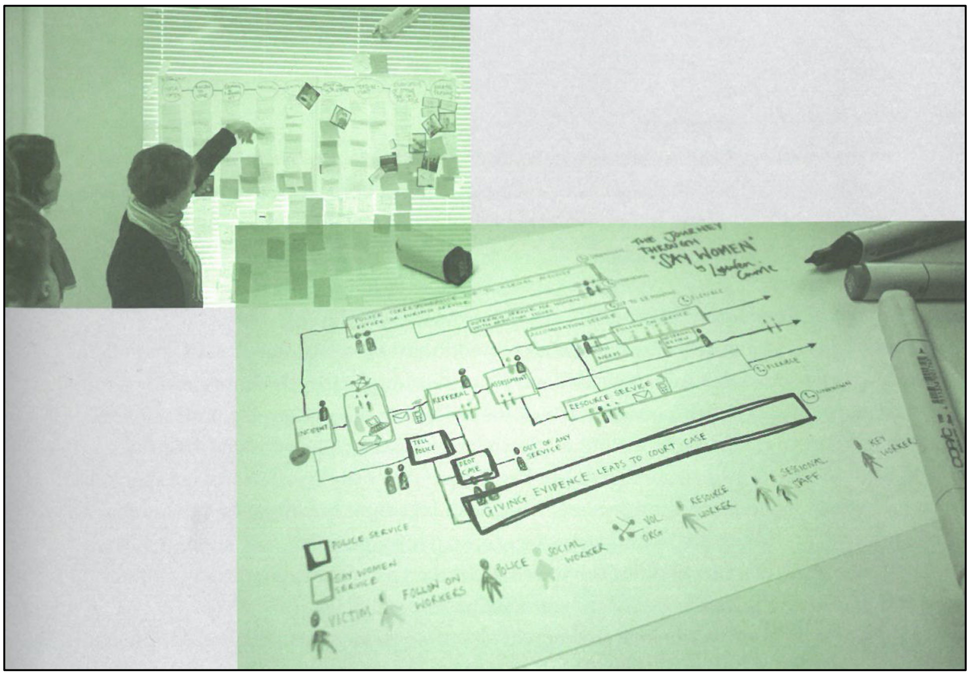


Fig. 3.7: Example of a Customer Journey Map (Stickdorn & Schneider, 2011, p161)

2. *Creation*

- Involve all stakeholders in generating ideas to address the identified problems, supported by tools to consider the user's perspective. Pirinen argues that 'representations by designers' (such as customer journey maps, as well as personas, scenarios, etc.) can become 'effective boundary objects,' in this process (2016, p20, see also Carlile, 2002).

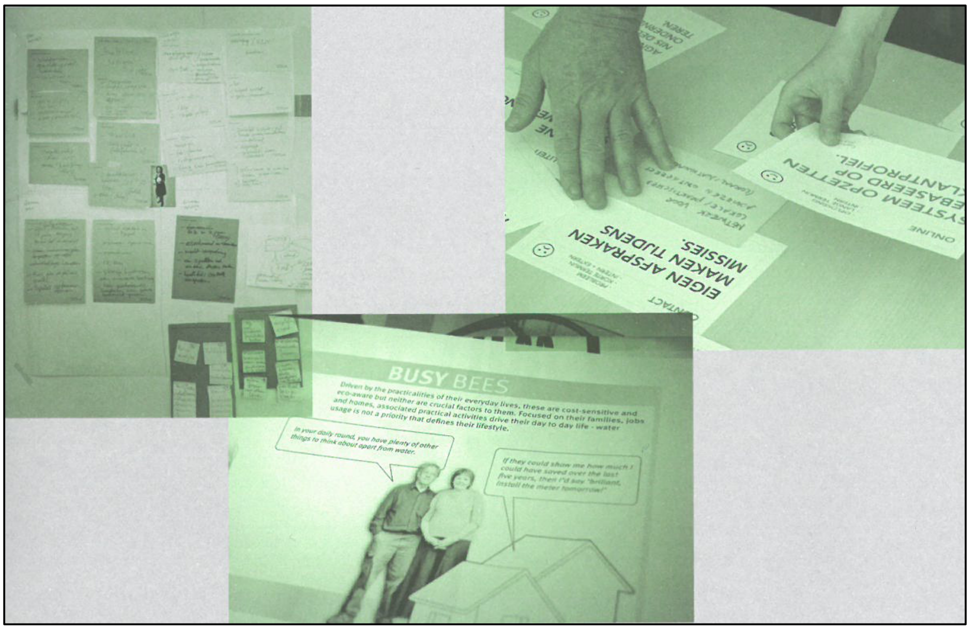


Fig. 3.8: ‘Personas’ (or fictional characters that represent a particular group and their shared interests) can be used to explore the design proposal and/or co-created with participants to explore user needs (Stickdorn and Schneider, 2011, p179).

3. *Reflection*

- Visualise the ideas to anticipate their emotional aspects.
- Use prototyping and roleplay techniques to encourage meaningful engagement from stakeholders. Here ‘service prototypes’ are considered a simulation of a service experience, which may be supported by props or physical touchpoints.
- Test and retest, often through enactment activities.

4. *Implementation*

- Plan, implement and review interventions based on a consistent service concept (where staff motivation and management support is key).

Miettinen (2011) explains that the iterative nature of the approach allows each new concept to incorporate the results of the behavioural testing of the previous iteration.

3.8.6 Beyond methods

Whilst early resources such as Stickdorn and Schneider’s ‘This is Service Design Thinking’ have played a vital role in collating the methods described above, laying foundations and entry points for people entering the field, Light and Akama (2012) argue that a focus on methods detaches them from the practitioner and the messy realities of the contexts service designers work within, and ‘commodifies’ them as something that can be easily replicated. Akama and Prendiville also note a ‘persistent trend in Service Design where methods alone have become king, as a way to legitimise the field and a practical way to ‘be a service designer,’ (2013, p31-32). They suggest ‘designing services’ as a better term to denote design as a continuous process and differentiate the verb from the noun. Sangiorgi and Prendiville have since acknowledged this work (and that of others) the title of their 2017 book, ‘Designing for Service,’ to include considerations of

- ‘an exploratory process that aims to create new kinds of value relation between diverse actors within a socio-material configuration,’ (Kimbell, 2011, p41) where ‘the distinction between goods and services is not important (ibid, p49)
- The immersive nature of service worlds and their entanglement with social life (Blomberg and Darrah, 2015)
- The concept of designing as happening before, during and after a design project, somewhat in line with PD concepts of ‘design after design’ and ‘design in use’ (Ehn, 2008).

In relation to the latter point, Freire and Sangiorgi (2010) discuss similar concepts in the context of healthcare, and the involvement of healthcare service providers and users at each of these stages. They suggest that, as healthcare services seek to move towards more empowering, collaborative models of healthcare delivery, design methodologies have also shifted in focus from notions of co-design to co-production and co-creation, as summarised in fig. 3.9 below:

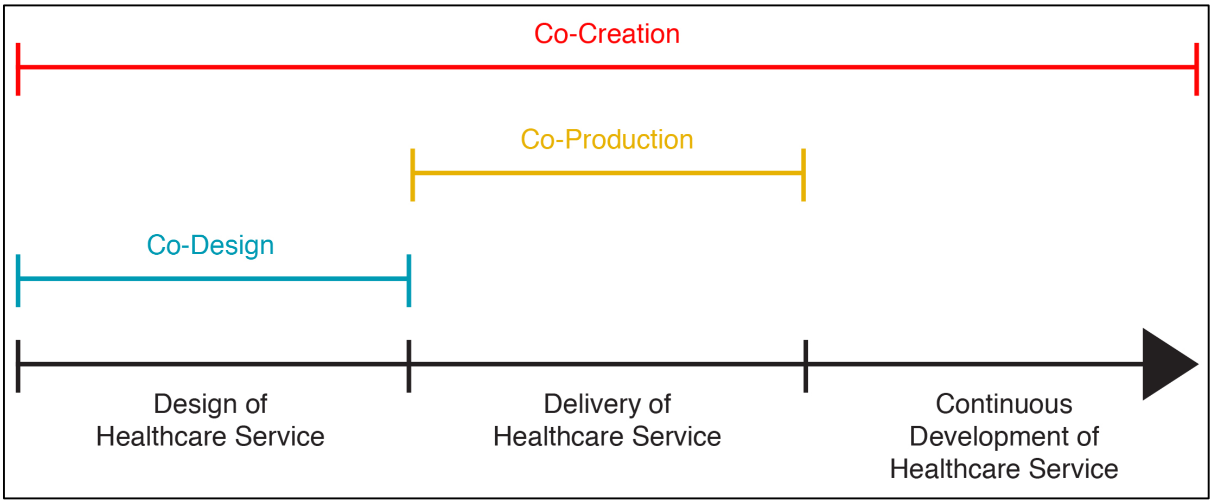


Fig. 3.9: A diagram situating notions of co-design, co-production and co-creation in service development processes (adapted from Freire and Sangiorgi, 2010).

In this diagram, co-design is seen as the involvement of patients, professionals and community in the design of healthcare services (in line with Sanders and Stappers, 2008), where the final design is implemented by professionals. Co-production instead suggests an equal and reciprocal partnership between professionals and users in healthcare service delivery, 'shifting the balance of power, responsibility and resources from professionals to individuals,' (Freire and Sangiorgi, 2010, p3). Co-creation, as suggested in the diagram above, 'happens when users are central not only to the design of services, but also to their production and continuous development,' (ibid).

Despite being a relatively young field, Service Design has clearly developed rapidly and expanded its contexts and concerns reflectively, as described in the following section.

3.8.7 Landscape of SD research & practice

In 2014 the Service Design Research Network published a report on the current landscape of Service Design research and practice. As well as developing maps of Service Design-related activity in the UK and key research areas, the network also produced a map of the different sectors of service design research focus, shown below:

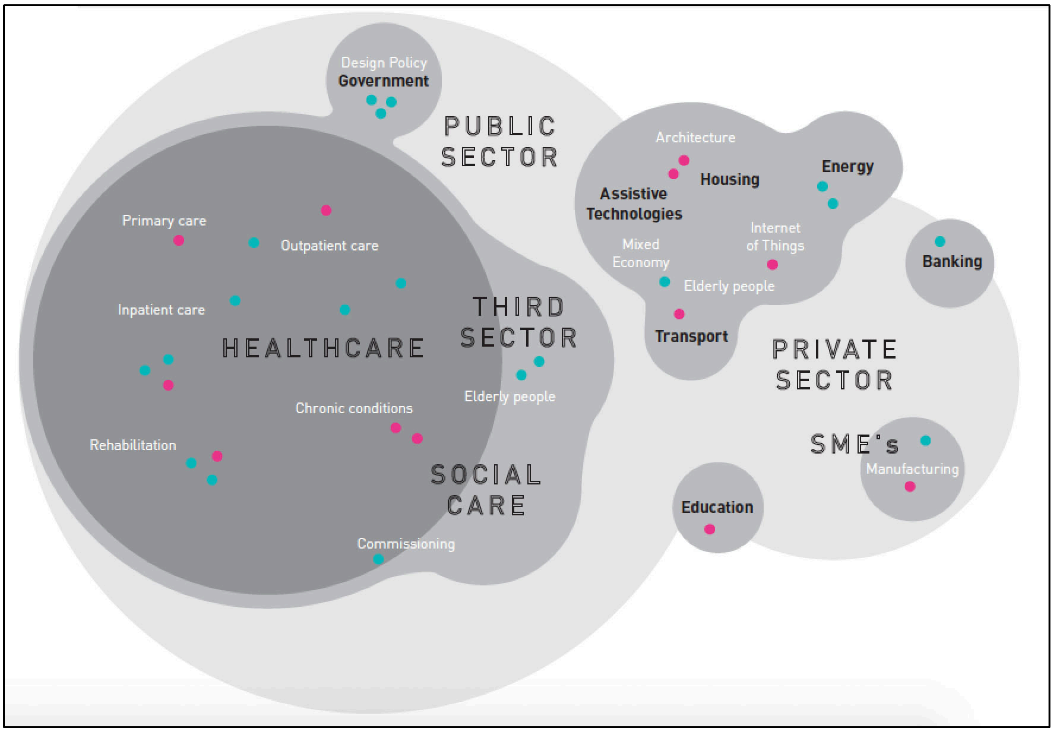


Fig. 3.10: A thematic and sectoral map of the Service Design research landscape (taken from Sangiorgi et al., 2014).

As can be seen in fig. 3.10 above, the majority of projects (shown by the blue dots) and PhD studies (represented in pink) are situated in the healthcare sector (which will be reviewed more fully in section 3.10 below).

Following on from this report, the Arts and Humanities Research Council (UK) funded the Design for Service Innovation & Development (DeSID) report, to investigate the specific contributions of Design to New Service Development (Sangiorgi et al., 2015). In reviewing 6 case studies of service design in public, private and digital sectors in the UK, with supporting evidence from an international context, and expert input in a reflective workshop, it was found that (among many other findings) that designers 'work both on a goods and service logic,' the latter being useful to 'enable deeper transformational change processes,' (ibid, p4). It was also found that the engagement and working relationships between the designer (or design organisation) and client organisations, as well as the project contexts, affected the outcomes generated. The authors suggest that designers work with clients in parallel, collaborative or integrated models to either inform, drive or enable change within the organisation, where iterative prototyping can support more collaborative ways of working. This gives further support then, as in the PD review previously, that engaging the client service organisation (the host SIU) in a participatory manner can lead to more transformational outcomes, and that prototyping activities are a strong method of facilitating this.

3.8.8 Criticisms and challenges of Service Design

It has been argued that Service Design is missing a 'culture of assessment' (Maffei et al., 2013) in order to develop as a field, as few projects present rigorous evaluations or question the impact of their interventions (Freire and Sangiorgi, 2010, Sangiorgi and Prendiville, 2014, Sangiorgi and Junginger, 2015). Others argue that service designers need to become better at evidencing their work, particularly in the public sector where time and money constraints can present additional challenges (Sangiorgi and Prendiville, 2017a, p6). This is particularly true in healthcare (Donetto et al., 2015) where designers arguably 'need to learn how to better relate not only to different evaluation approaches and forms of knowledge but also to the complex social systems in which they find themselves operating,' (Robert and Macdonald, 2017, p128). Additionally, 'big challenges remain of reconciling differences in cultures, methods, expectations, forms of 'evaluation' and constructions of 'evidence' and 'knowledge'' (ibid., p118). These tensions will be explored further in the Methodology chapter of this thesis.

Another criticism of Service Design is the limited adoption and/or implementation of its outcomes (Greenhalgh et al., 2004, Holmlid et al., 2017, Sangiorgi, Prendiville & Ricketts, 2014). In some cases, this may be because designers reportedly do not ‘pay attention to economics’ (Mulgan, 2014) or perhaps because they ‘don’t yet pay enough attention to the back stage/infrastructure processes, and potention for continued innovation’ (Sangiorgi, Prendiville and Jung, 2017, quoting Grinevich 2015). This suggests, then, a need to ensure those that deliver and ‘receive’ the service, or those involved in the co-production of the service, are crucial contributors in the service design process, as discussed below.

3.8.9 Participatory approaches to Service Design

Sangiorgi and Clark (2004) make a strong case for taking a more participatory approach to service design, arguing that ‘service active participants’ bring their resources, competencies and capacities to the design process, and that their contributions are ‘crucial’ in creating a successful service. A participatory approach to designing services, they suggest, may avoid conflict in the implementation of service ‘encounters’ by synchronising the goals and perspectives of service users and providers.

Holmlid (2009) extends this argument by highlighting the complimentary nature of participatory and service design approaches. Both fields, according to Holmlid, share ‘emancipatory objectives’ but could also learn from each other. Whilst participatory design could benefit from using methods of visualisation and co-creating value, service design could be enhanced by embedding socio-cultural theories into its practice.

Given the collaborative nature of services, it is unsurprising that the involvement of non-designers in service design innovation has gained increasing attention, (Sangiorgi, Prendiville & Ricketts, 2014). However, Collins, Cook and Choukeir (2017) suggest that whilst public participation is often stipulated as a requirement by service commissioners, it can be blocked by the time frames allocated (i.e. insufficient time to make connections within the service context, coordinate activities, make tools, secure commitments, etc.) or by an inability to predict the outcomes of the project (which is problematic if ethical approval must be sought first), which can lead to tokenistic participation of service users. Moreover, Pirinen (2016) states how ‘co-design for services necessitates working across organisational, sectoral and jurisdictional boundaries and divergent realms of knowledge,’ (2016, p28), highlighting further challenges to consider when planning a participatory service design approach, particularly in a healthcare context, as discussed below.

3.9 Design in healthcare

3.9.1 Overview

As pressures on public services such as healthcare continue to rise, increasing attention is being paid to the potential of design tools, methods and approaches in addressing diverse and complex public challenges (Wetter-Edman & Moritz, 2015, Parker & Heapy, 2006). Moreover, ‘design for health is now emerging as a discipline of its own’ (Tsekleves and Cooper, 2017, p3) which is valued for its ‘innovative, human-centred and participatory approaches by which design brings an outside-in perspective to the development of these organisations,’ (Holmlid & Wetter-Edman, 2013).

3.9.2 Landmark studies

A landmark study to consider is the first project from RED (a group established by the Design Council in 2004 with a focus on socially-motivated, design-led innovations), which aimed to create a holistic service for people living with diabetes in the Bolton (United Kingdom) area. Despite limited implementation of the new service tools and concepts co-designed with local residents, support networks and hospital staff, this project (and others described in Freire and Sangiorgi, 2010) demonstrated the more radical healthcare service developments that can be created with design-led methodologies.

Building on this work, UK Design Council published a White Paper in 2006 introducing the term ‘Transformation Design’, suggesting that the skills and process of design are well suited in both defining and tackling the increasing complexity of modern challenges, not least of all in the area of healthcare (Burns et al. 2006). Based on user-centred design principles, Transformation Design engages multiple stakeholders, opening up the design process to those involved in the context, where design is ‘fulfilling the role of connecting patients’ and healthcare professionals’ views’ (Neves, 2014, p49). The aim of transformation design is to ‘achieve a collaborative change rather than to put a specific product or service in use’ (Wetter-Edman & Moritz, 2015, p2). Sangiorgi develops this idea further, suggesting that ‘Transformative Services’ arguably suggest ‘new models of service co-production where citizens are not perceived as passive users but active collaborators in the solution and where organisations actually release some of the control to users in order to achieve this,’ (2010, p3, see also Sangiorgi, 2011). Whilst Service Design is characterised by ‘a high degree of involvement of different actors in the service processes (Wetter-Edman, 2011), Wetter-Edman & Moritz argue that Service Design ‘becomes transformational’ when ‘people not traditionally trained as designers, use design tools and methods… [with] the purpose to build capacity for continuous change within the organization (2015, p3, see Junginger, 2006). This clearly has implications for this study, which aims to enhance the participatory nature of a complex healthcare service system.

3.9.3 The 'State of the Art of Design in Health'

In 2013, a network of experts in Design in Health in the United Kingdom was founded to establish and discuss what had been achieved in this area to date. Using their expert knowledge, a systematic review of database literature and 'grey literature', the network identified 1912 articles, with 453 in scope (Chamberlain et al., 2015, p15). Only 15 of these studies were located in a 'rehabilitation' context (p20), highlighting the novelty of this PhD study.

The report concluded that the design community has shown a significant and growing expertise in engaging hard to reach groups with participatory methods, which has the potential to flatten the hierarchies that are typical in healthcare. The network also argues that design is well positioned to answer the recent call from the NHS for 'new, empowered patient relationships,' (NHS England, 2014), but to gain traction and respect in working in healthcare contexts, designers must learn to communicate their work in terms and formats understood by the healthcare community.

Part B will now conclude with a thorough review of Participatory Service Design approaches to healthcare service improvement.

3.10 (Participatory) Service Design in Healthcare

3.10.1 Introduction

This part of the literature review aims to better understand the landscape, trends and achievements of participatory service design approaches within healthcare service contexts, illustrated by key examples, in order to position this PhD study and its objectives. The specific details of the strategy taken in this review (including sources, search terms and eligibility criteria) can be found in appendix 8, and is summarised in fig. 3.11 below:

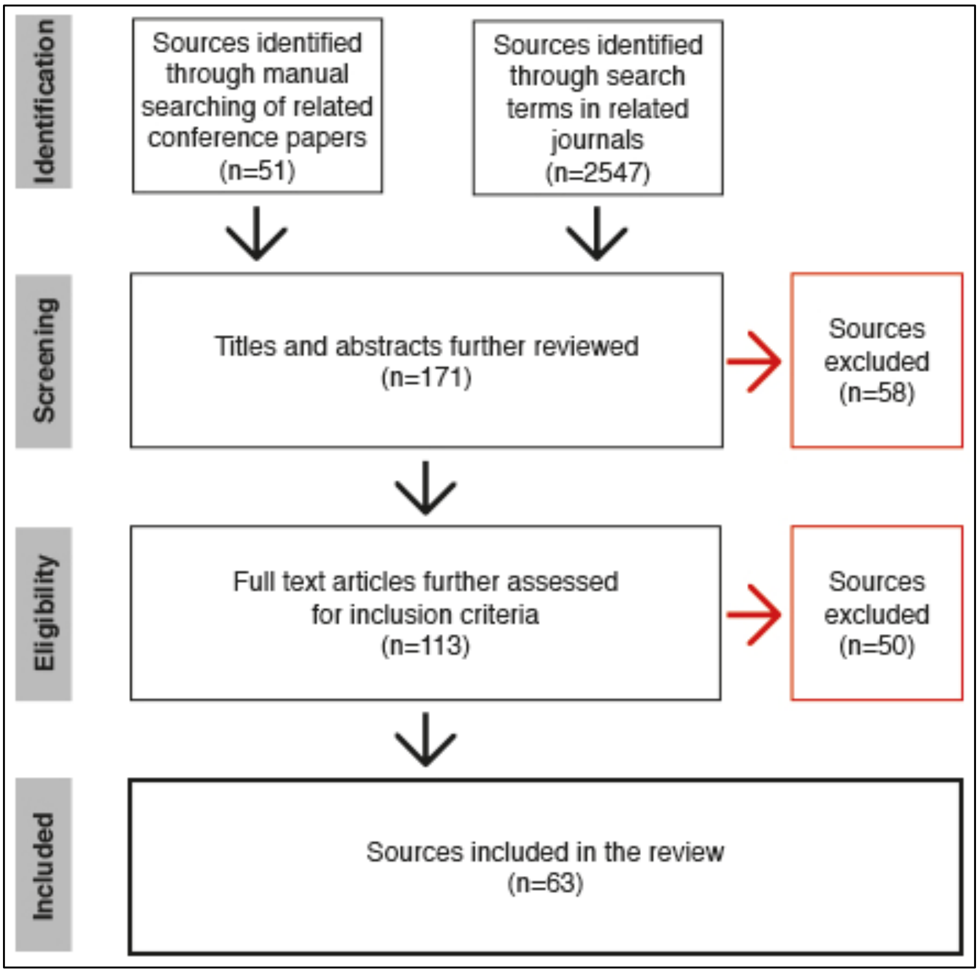


Fig. 3.11: A diagram of the strategy taken to the (participatory) service design in healthcare literature review.

The literature review will begin with a focus on service design for healthcare services in general. After giving a brief overview of the publications considered in terms of their context, outcomes and to what extent the healthcare community (defined as patients, family members, carers and/or healthcare professionals) were involved in the study or project, the review will discuss the ways in which service design methodology and tools have been used in healthcare service contexts to date.

The review will then focus on design-led approaches to enhance patient participation in rehabilitation and consultation contexts, followed by a summary of how the main challenges associated with design in healthcare have been anticipated in the literature to date.

3.11 What is the landscape of participatory service design approaches to healthcare service improvement?

3.11.1 Contexts

The papers reviewed covered a range of topics, the most popular concerning emergency departments, mental health, care coordination and/or patient pathways, as well as health service development in general. Other topics included cancer, cardiology, chronic disease, diabetes, elderly care, hospital acquired infections, healthcare consultations, hospital nutrition, gastroenterology, GP practices and orthopaedics.

There is also a growing interest in using design-led methods in care for people with dementia and their carers, but as stated in the eligibility criteria of this review (appendix 8), only those publications whose discussions had methodological implications for this work were included.

The remainder of the papers included drew on a large range of topics to support a theoretical discussion or position paper.

3.11.2 Outputs

Approximately one third of the papers reviewed were position papers, theoretical discussions or descriptions of method(s), supporting earlier statements that, to date, service design has largely been concerned with methods (Akama & Prendiville, 2013) but is reflective on its progression as a field.

Approximately as many papers again described cases where design-led methods were used for research purposes, where the deliverables at the end of the project included advice for future innovation, opportunities for service development or insights into the patient/carer experience in order to imagine better solutions.

The remaining third (approximately) of papers reviewed in this section described creating a prototype ready for testing, a prototype tested in clinical contexts, or (in just a few cases) a new or enhanced material or process that has been successfully implemented in the clinical context.

3.11.3 Involvement of healthcare community

The researcher found it somewhat difficult to establish a clear summary of the extent of the involvement of the healthcare communities in the literature reviewed, particularly as some sources would claim to use ‘participatory methods’ in reference to gaining feedback from focus groups, rather than actively involving them in the co-design process. Moreover, the use of the term ‘workshop’ was ambiguous. In some cases, this could refer to standalone activities to learn about service needs (i.e. developing scenarios with service users), or in others it referred to several linked workshops bringing multiple stakeholder groups together to co-design improvements to the healthcare service.

It became clear, however, that participatory approaches to healthcare Service Design tend to mostly, or only, involve healthcare professionals. Indeed, other studies have noted the tendency for patient representations (i.e. personas) to replace active patient engagement (Neves, 2014). Although healthcare professionals will be greatly affected by any changes to the service they deliver, it has been suggested that failing to involve patients risks ‘operating with an expert mindset’ (Bødker & Granlien, 2008), given that healthcare ‘experts’ have a particular set of experiences and knowledge unavailable to – and different from - service users.

When patients are involved, their role can often be to provide feedback to later stage prototypes. Whilst patient feedback may go on to inform changes to the prototype, there is arguably benefit to extending their influence by involving them in earlier stages of the co-design process.

In support of this argument, this review also found that those projects which facilitated the creative involvement of multiple stakeholder groups, supported by long-term ethnographic work in the healthcare context (i.e. observations, shadowing, interviews with staff and patients, etc.) were more likely to create a cohesive service concept (Macdonald & Teale, 2011), get the co-designed intervention tested in the clinical contexts or in a Randomised Control Trial (Macdonald, Loudon & Taylor, 2014), achieve implementation in practice (Chamberlain and Partridge, 2017, Starnino, Dosi & Vignoli, 2016) and/or catalyse new, transformational ways of working outside of the new service deliverable (Johansson, Vink & Wetter-Edman, 2017, see also Yee & White, 2016).

Few of the consultancy or university-based projects described themselves as ‘embedded’ (see Oosterholt & Simonse, 2016) or having had a long-term period of immersing themselves in the clinical context prior to design work (see Starnino, Dosi & Vignoli, 2016). Instead, these types of close collaborations are more often facilitated by ‘Living lab’ partnerships, described as ‘fundamentally collaborative spaces, which often consist of public-private partnerships who aim to address complex societal challenges by foregrounding user-involvement and real-life experimentations,' (see Raey et al., 2017a, for a full discussion).

3.12 What does a Service Design perspective offer healthcare service improvement?

3.12.1 A focus on experience

Carr et al. (2009, from a project titled Design in Practice) suggest that healthcare services are often viewed as processes rather than experiences, and that viewing it through the lens of Service Design provides an alternative view that considers the patient's perspective as they travel through it. Additionally, they suggest that clinicians, who often look for evidence-based solutions, could be supported by SD tools and approaches to leverage their tacit, experience-based knowledge about their local practice and communities (and that 'service design [could] benefit by learning how to take the synergy between evidence based medicine and experience based design more seriously,' ibid, p11, see also Carr et al., 2011).

Several examples in the literature demonstrate how the objects used to mediate a healthcare service can shape the patient's experience of it, and so can be redesigned for preferred experiences (for example, cancer radiation therapy technology, see Mullaney, 2016, or emergency department waiting areas, see Starnino, Dosi & Vignoli, 2016). This also applies to materials to support patient-professional communication (see Boess et al, 2013) and professional-professional communication (see Chamberlain & Partridge, 2017). As such, considering the healthcare service as an interrelated network of people and objects, or taking a socio-material perspective, has interesting implications in trying to enhance patient experiences.

3.12.2 Notions of value co-creation

A service logic perspective also has important implications for healthcare services and the power dynamics within them. By positioning the patient as a 'co-creator of value' within this paradigm, they are taken out of the traditional passive role expected in a paternalistic model of healthcare (see Andersen, 2010 and Moll, 2010) and given the opportunity to actively contribute to the patient-professional interactions. Oosterholt & Simonse (2016) discuss this in relation to clinical encounters between a patient and their physiotherapist (see fig. 3.12 below), highlighting that both parties have insight to offer.

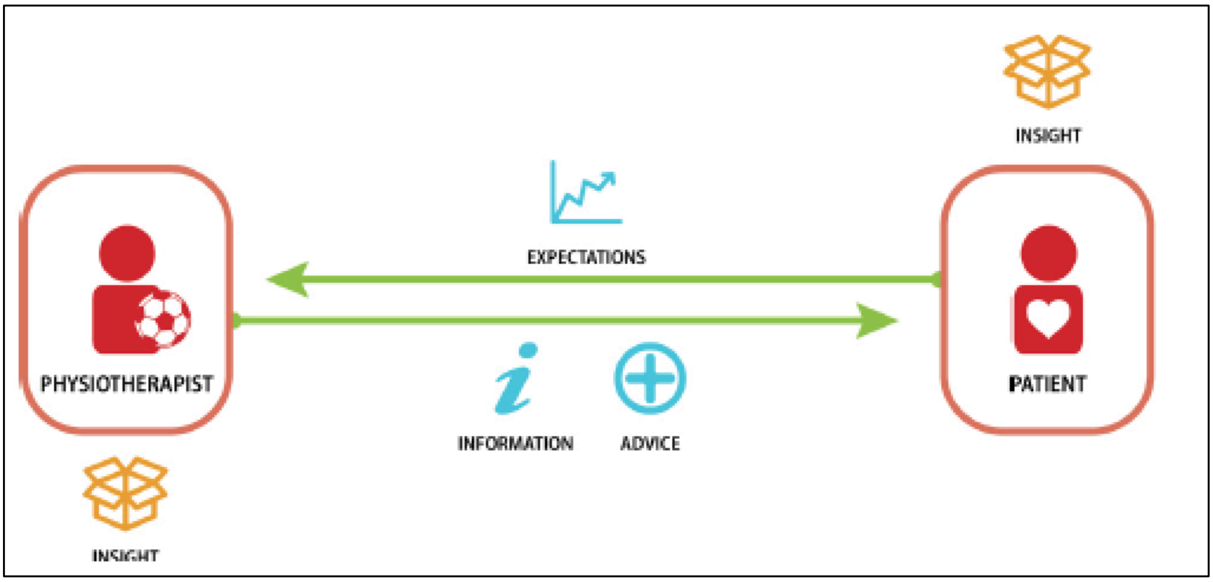


Fig. 3.12: A model of 'value exchange' within a clinical encounter between a patient and their physiotherapist (Oosterholt & Simonse, 2016).

However, this PhD study suggests that when this model is extended to longer-term working relationships (as in the SIU), the patient arguably has more to offer in this 'value exchange' than simply their expectations, as implied in fig. 3.12 above.

Hyde and Davies extend this argument further, suggesting that the patient's role in 'co-creating value' also implicates them as 'co-producers (with staff) of both organizational culture and organizational performance,' (2004, p1424). This suggests a need to safeguard the current organizational performance (i.e. staff's ability to provide at least the same level of care for their patients alongside the renegotiated roles between them), although explicit discussions or advice related to this could not be found in the reviewed literature.

3.13 Participatory Service Design Methods

In the literature reviewed, general descriptions of using Service Design tools and approaches in healthcare contexts highlight their ability to support patients and healthcare professionals in understanding complex, interrelated healthcare services (Carr et al., 2009) support staff's empathic understandings of service users (Raijmakers, 2013, Schepers et al., 2011, Wetter-Edman & Moritz, 2015) and imagine radically new solutions or support innovative behaviours (Carr et al. 2009, Wolstenholme, Grindell & Dearden, 2017, Schepers et al., 2011).

The specific contributions of the most common methods discussed in the reviewed literature (visualisation, prototyping and enactments/service prototyping) are described in the following sections.

3.13.1 Visualisations

Visualisations have been used for a variety of purposes, with varying degrees of healthcare community involvement. Hahn and Zimmerman (2011) provide a case study comparing 'traditional, causal' visualisations of existing quantitative data gathered by a hospital ward to those generated by professional designers (see fig. 3.13).

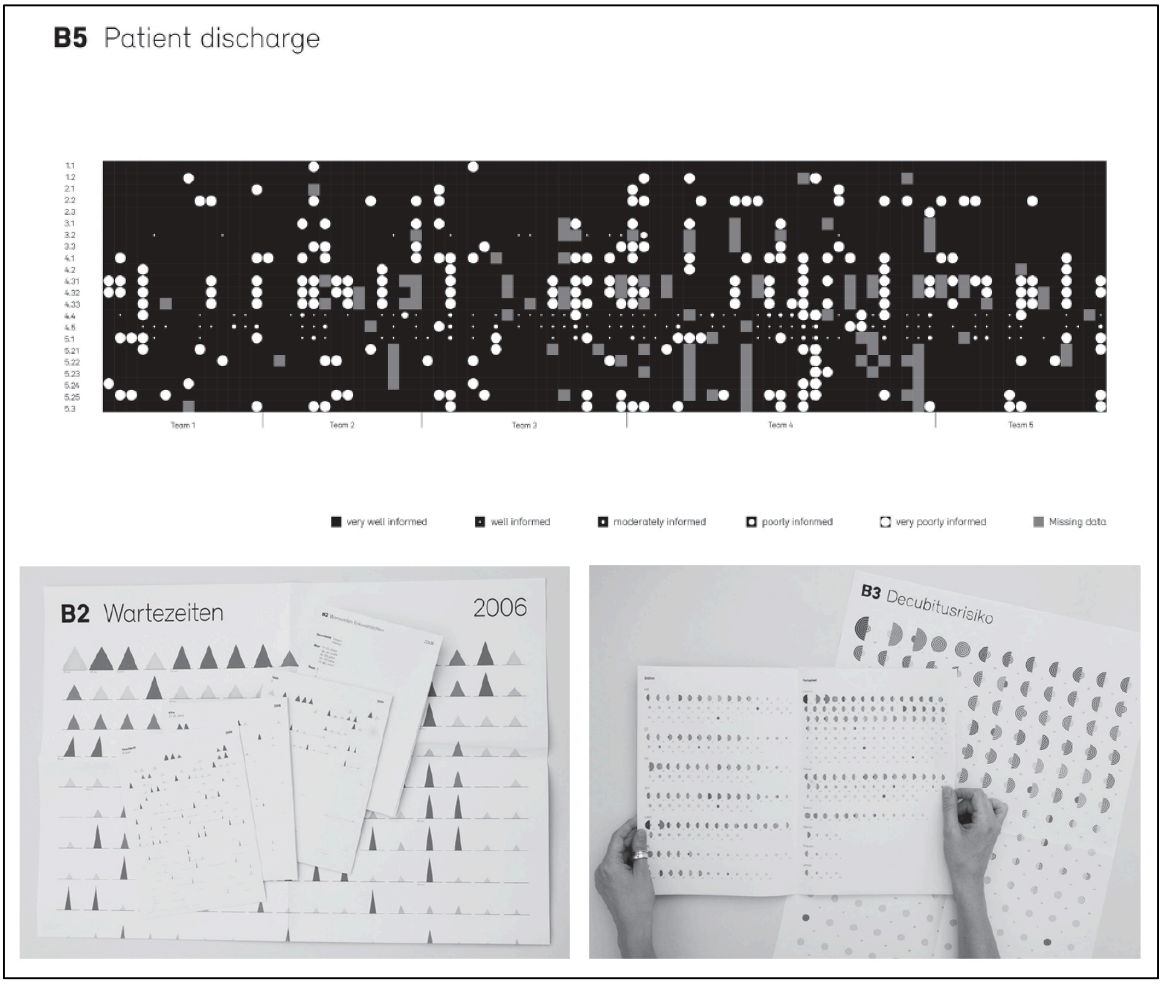


Fig. 3.13: Examples of designerly visualisations of data routinely captured by hospital wards, such as patient discharge times (top), waiting times (bottom left) and risk of pressure sore (bottom right), taken from Hahn and Zimmerman, 2011.

Whilst design is often attributed to explorations of 'what could be', it was found that design-led visualisations of 'what is' data (shown above) uncovered new insights, and identified new patterns or correlations. Beyond this, the visualisations were said to 'admit' new questions, being well-suited to group discussion and having a ‘certain emotional value,’ (ibid). Although the healthcare community were not involved in their creation, the new conversations afforded by the visualisations were said to encourage further service development.

In other cases, visualisations supported data gathering, with particular strengths in making abstract concepts tangible and easier to share with those who may affect positive change (see Carey et al., 2017). Visualisations of patient pathways in particular have been found to support patients in discussions of current and preferred future healthcare experiences, and communicate these insights to staff (Oosterholt & Simonse, 2016, Kronkvist, Järvinen & Leinonen, 2012).

Raey et al. (2017b, p67) describe how a visualisation of the patient pathway can be an important output of design projects in their own right, as it is an ‘effective tool that reduces a sophisticated whole – e.g. a complex health service and its procedure – to a comprehensible representation of its major elements, including the relationship between them.’ Indeed, several notable examples in the literature have shown great benefits to enhancing patient understanding of where they are in a particular healthcare process, what to expect, and why (see fig. 3.14).

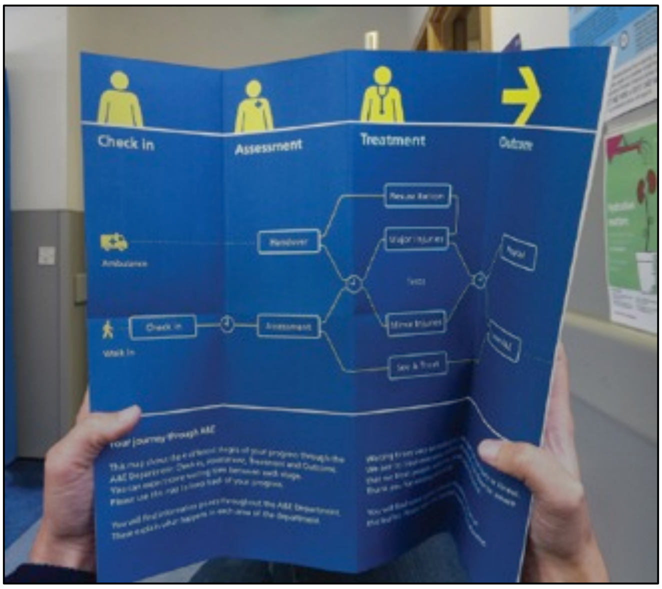


Fig. 3.14: The Design Council (2011) found that improved communication of the patient pathway, and reasons for waiting times, dramatically reduced violence and aggression in Accident and Emergency departments across the UK.

As such, visualisations can be useful tools in facilitating mutual learning (a cornerstone of PD) between patients, staff and designers when eliciting or communicating knowledge about healthcare service processes or experiences. Interestingly, the strength of visualisation in evaluation and in decision-making processes, as found in the DeSID project (Sangiorgi et al., 2015, discussed in section 3.8.7), did not come across in the review, suggesting an opportunity to explore these strengths in a healthcare context.

3.13.2 Prototyping

As with the use of visualisations, prototypes have invited input from the healthcare community in various ways. In some cases, designers have created a prototype material or process to support the healthcare service based on ethnographic observational or interview data, and used this prototype to elicit deeper, more meaningful feedback from staff or patients (Boess et al., 2013, Macdonald et al., 2014). Other studies have used iterative prototyping activities as the basis for co-design workshops, where the prototypes can spark new ideas or show what is needed for a cohesive service *(*ten Bhömer & Tomico, 2013) and make these ideas tangible to help healthcare service professionals and users see ‘what is’ and ‘what could be’ (van der Lugt & van der Laan, 2017, Raey et al., 2017b).

Prototyping, then, may be particularly useful in helping to overcome the inertia or ‘set’ ways of working in many healthcare contexts. Raey et al. (2017b) suggest that prototypes also address the challenges associated with bringing multiple disciplines together by acting as a ‘stabilising narrative,’ enabling differences in culture or opinion to be resolved between the designer and clinicians, and embodying the progress being made together.

Prototypes also have a crucial role to play in healthcare service development by using them in enactment activities, or service prototyping, allowing staff to ask new questions (Johansson, Vink & Wetter-Edman, 2017) or try new behaviours in a low risk, low cost way (Coughlan et al., 2007).

3.13.3 Service prototyping

Service prototyping can be conducted as a means to learn more about the patient experience (sometimes from multiple perspectives, see Mullaney, 2016), and as a means to developed a co-designed service concept.

However, as Starnino, Dosi and Vignoli point out, 'service prototyping in healthcare is a rarity,’ (2016, p576). They suggest that testing a service prototype in actual use, with regular opportunities for staff to suggest changes during the test, is important to understand professionals' needs in the complex reality of healthcare services.

3.13.4 Summary: The role of the designer and designing in aesthetic disruption

Several sources describe the benefits of the designer's 'outsider position' to the healthcare service, either in their ability to maintain an open imagination 'without falling into existing situations or battling against conflicts of interests,' (Carr et al., 2009, p10-11) or in their ability to highlight and bring to discussion 'taken-for-granted' aspects of the service (Raey et al., 2017b). Related to this, Vink, Wetter-Edman & Aguirre (2017) provide an interesting discussion on what they feel is the crux of the designer's offering to healthcare service redesign. They argue that whilst there has been a growing emphasis of designers' strengths in their different ways of *thinking* about a context (see Kimbell, 2012), there should also be equal consideration given to design's offerings of new ways of *doing*. They suggest that design methods, such as those described above, draws on the strengths of the 'bodily experience' of design, and can stage an 'aesthetic disruption' that allows the healthcare community to challenge their assumptions about a service, and step out of their traditional habits or ways of experiencing that service, in order to contribute to service innovation.

Wetter-Edman, Vink & Blomkvist (2018) have found that, in their own practice, 'destabilizing the habitual action of participating actors' has been important not only for staff who are used to 'delivering' the service in particular ways, but also to patients who are used to 'receiving' the healthcare service, leading to the latter questioning their own agency in healthcare appointments. They report how, through collaborative prototyping activities, 'staff and patients increasingly began to engage in actions that diverged from the norm in an attempt to realize patients as partners in their own care' (ibid, p14), with staff taking steps outside of the activities with service designers to support these new patient roles in practice. As such, the authors argue that 'micro-level' aesthetic disruptions are 'a critical part of service innovation on a macro-level by catalysing institutional change,' (Wetter-Edman, Vink & Blomkvist, 2018, p2).

The notion of aesthetic disruption, and it's potential in renegotiating patient-professional roles towards more participatory practices, is encouraging. However, the examples given above concern the interaction and experiences between one patient and one healthcare professional, and as Vink, Wetter-Edman and Aguirre highlight, further research is needed in broader multidisciplinary contexts (2017).

3.14 What is the landscape of participatory service design approaches to enhancing patient participation in rehabilitation?

3.14.1 Contexts

Of the few sources that could be found in this category, most were concerned with stroke rehabilitation (Macdonald, Loudon & Taylor, 2014, Tosoa, 2017, Lemke, 2017, Lemke et al., 2017, Nielsen & Poulsen, 2013, Szaniawski et al., 2015), as well as individual examples concerned with chronic pain management in children (Partridge, 2017) and renal blood testing (Gradinar et al., 2017).

3.14.2 Outputs

As in the previous section, outputs from the projects in this category included; enhanced understandings of the complex lived experience of patients (Nielsen & Poulsen, 2013, Szaniawski et al., 2015); guidelines or recommendations for future service improvements (Nielsen & Poulsen, 2013, Szaniawski et al., 2015, Tosoa, 2017); co-designed prototype visualisation interfaces ready to gain patient and/or staff feedback (Gradinar et al., 2017, Lemke et al., 2017, Lemke, 2017); and prototype visualisation software tested in a series of Randomised Control Trials (RCTs) (Macdonald, Loudon & Taylor, 2014).

3.14.3 How do the cases frame 'enhanced' participation?

Skills

In a PhD position paper, Partridge (2017) posits that children going through chronic pain services may be supported through enhancing their resourcefulness and ability to self-manage their pain through the transfer of design skills (informed by the RSA project in which this study also has its roots). As such, enhanced participation is framed as enhancing the range of skills at the child's disposal to manage their condition independently.

Knowledge

Gradinar et al. (2017) aim to enhance patient participation through alternative, visual methods of sharing the results of renal blood testing. They state that visualisations of complex numerical healthcare data can meet the needs of medical professionals whilst also being more useful for patients, who as a result are able to be 'more actively involved in managing their own condition' (2017, p2363). Whilst this is an important goal, it could be argued that further exploration is needed into how enhanced patient understanding of clinical test results can empower patients to use this information in the healthcare consultation, or in everyday life.

Compliance

As outlined above, the majority of papers reviewed in this section were concerned with Stroke rehabilitation. More specifically, they aimed to enhance participation by encouraging patients to take part in their prescribed exercises more frequently or more effectively, either through gamification (Szaniawski et al., 2015, Tosoa, 2017) or through the 'un-learning' of 'non-use' of the limb(s) affected by Stroke (Lemke, 2017, Lemke et al., 2017).

Envisage

The Envisage project also originally sought to enhance patient efficacy in rehabilitation exercise, but through the use of visualisations to support patient-professional interactions. However, beyond this, the authors found that visualising patients' movements as they took part in stroke rehabilitation exercises, in real time, actually 'aided understanding for patients, enhanced communication between patient and therapist, and provided an objective tool for therapists to monitor progress and communicate this to patients' (p226). They suggest that, in doing so, the 'social distance' between patient and professional was bridged, suggesting the potential for enhanced patient participation in the clinical encounter (see also Loudon et al., 2013).

This case was also the only source that could be found that took a long-term, 'participative co-development and iterative prototyping approach' with outpatients and therapists (Macdonald, Loudon & Taylor, 2014) which 'cumulatively embodied the collective needs and preferences of survivors (participating as proxy patients) and therapists, as well as the trials leads (biomedical engineers),' (Macdonald, 2014, p382). As such, the co-developed visualisations were 'found to be an important socially-enabling tool,' in healthcare service development as well as in the healthcare service itself.

The functional, iteratively developed prototype visualisation went on to be tested in a series of RCTs which, unusually, took a mixed-methods approach to 'shift the RCT design towards more of an awareness of, and engagement with, the pragmatics and 'messiness' of the real world physical rehabilitation context and to understand, acknowledge and allow for the dynamics, narratives and behaviours in that setting,' (Macdonald, 2014, p383).

Discussion

To this point, the literature reviewed has highlighted the paucity of studies concerning patient participation in rehabilitation, particularly outside of one-to-one patient-professional consultations or in contexts that consider the wider healthcare service. However, it has also demonstrated the potential for design-led methods, particularly prototyping, to uncover new, mutually beneficial interactions and behaviours between patients and healthcare professionals. Two examples could be found in the wider co-design literature that corroborate the potential for prototype materials to renegotiate the roles between patients and professionals, as discussed below.

3.14.4 Design-led approaches to enhancing patient participation in healthcare consultations

Physiotherapy following hand surgery

Björgvinsson & Hillgren (2004) discuss a slightly different approach to exploring patient participation through their use of 'on the spot experiments.' Rather than anticipate new forms of patient-professional interaction, they instead introduced video-recording equipment into existing physiotherapy consultation spaces (for patients recovering from hand surgery) to explore the ways in which patients and professionals appropriated it in use. In observations of the consultations, it was found that 'the design of the recording station supports the development of new social protocols of negotiation and agreement between therapist and patient, since the patient as well as the therapist may initiate and terminate recordings. This opens new possibilities for reconsidering the patient's position in rehabilitation viewed as a collective undertaking,' (Sokoler et al., 2007). This has important implications for the co-design process of this study, suggesting that lower resolution prototypes, or less defined service prototyping activities, may allow for the emergence of patient-professional interactions unanticipated by the designer.

The patients involved in the 'on the spot experiments,' were given the video recordings made to take home with them. In follow-ups with these patients, it was found that the video recordings helped patients to remember more details about their physiotherapy exercises, measure how much progress they had made since their consultation, and better explain their injury and rehabilitation process to family members, or other healthcare professionals (Björgvinsson & Hillgren, 2004). This suggests that documentation of consultations, even in non-traditional forms such as this, have the potential to support patients in engaging with their recovery in new ways.

Cardiology consultations

Notions of 'the participatory patient' (Andersen, 2010) or 'the patient as service co-creator,' (Moll, 2010) have also been explored in the development of a Personal Health Record for remote monitoring of heart patients living with implanted advanced pacemakers. A prototype record (co-designed with patients and clinicians over three workshops, after an initial ethnographic study of the context) allowed patients to self-report their health condition and medication list to their cardiologist prior to each consultation. In one reported case, this patient input highlighted new health issues which were otherwise unreported by the pacemaker (Andersen, 2010), positioning the patient as an important actor in their care coordination.

Moll argues that this reconfiguration of the patient role is made possible through 'the lens of service,' and that doing so allows for a 're-conceptualization of the work of patients to be recognized as activities of value co-creation. Thereby appreciating the relation between designing the active patient and designing for value co-creation.' (2010, P165). The authors argue that the prototype 'empowers' patients who are motivated, by 'formalising' the work that they already do (such as taking notes of their health condition over time), but also suggest that further work in this area should 'take into consideration and inscribe means for patients to be less active and participating patients,' (2010, p154).

Whilst this example makes a strong case for positioning the patient as a co-creator of value in the healthcare service (an idea rarely explored to the point of implementation), it further highlights the need to further explore what it means to design for patient participation, and what patients can, or want, to 'bring to the table' in their new roles. Even in the Patient Health Record, the patient's input remains scripted (the patient can input via medication lists or a questionnaire), limiting their ability to shape the agenda of the consultation.

3.15 Challenges and opportunities of conducting co-design in healthcare service contexts

According to Mønsted & Onarheim, it can be useful to separate the issues associated with designing with and/or for healthcare service communities in terms of conceptual and pragmatic challenges (2010).

Conceptually, such collaborations may experience a 'clash of professional ecosystems' when the hierarchical healthcare organisation, with a 'sense of accountability focussed on precision and control' meets design-led approaches, which are 'necessarily more fluidly organised' due to the 'wicked' nature of the problems they address (van der Lugt & van der Laan, 2017, p2064). Additionally, generating a sense of motivation or buy-in from the healthcare community can be challenged by 'cynicism of staff with previous unsuccessful experience of improvement projects,' and a 'need for mandate by senior management,' (Griffioen et al., 2017). It is not surprising, therefore, that the review found multiple recommendations to build a community around the service design project, taking a 'bottom up' approach and putting 'people, the commissioners, service providers, and users at the heart of the process,' to achieve the greatest impact (Yee & White, 2016, p17). According to the literature, fostering such a community requires the building of trust and reconciliation of divergent goals (Pirinen, 2016) through a shared vision and sense of empathy for the service users (Nicolas et al., 2012).

Pragmatically, the building of a shared vision for the project has been said to support consensus in design decision-making in multidisciplinary co-design groups (Carr et al., 2009), and that transparent documentation of these decisions can support ongoing learning throughout the design process,' (Raey et al., 2017b, p78). However, there is little guidance in the literature of what form such archiving should take.

Logistically, barriers to conducting co-design activities with healthcare included the costs of running workshops *(*Altuna & Jun, 2014), limited time available to conduct the project (Björgvinsson & Hillgren, 2004), time restraints for involving staff who already have high workloads (Mønsted & Onarheim, 2010) and the availability of all users at the same time and place (Mønsted & Onarheim, 2010, Altuna & Jun, 2014), which can lead to inconsistent involvement (Altuna & Jun, 2014).

Given that staff time is limited, Johansson, Vink and Wetter-Edman (2017) report that tensions can arise when they are asked to spend time on transformational activities not obviously linked to service improvement, suggesting a need to make clear links between the co-design activity at hand and broader 'transformational' aims, such as enhancing patient participation.

Whilst the nuances of engaging staff are discussed in some detail, patients are often simply described as 'difficult' to get involved *(*Altuna & Jun, 2014), perhaps for ethical reasons*,* (Gradinar et al., 2017) or because 'the physical and cognitive condition of some stakeholders can also be a barrier,' (Mønsted & Onarheim, 2010, p160). A wider review of the design literature shows that co-design tools have been developed for the inclusion of people who have had a stroke (Neves, 2014), autistic adults with learning disabilities (Gaudion et al., 2015), people with aphasia (Wilson et al., 2015), cognitive and sensory impairments (Slegers et al., 2015) and visual impairments (Metatla et al., 2015), but given the paucity of design projects focussed on SCI in general (other than those reviewed in the preface of this thesis), this PhD study is in a position to contribute to the literature in this area.

Part C: Discussion

3.16 Discussion

3.16.1 Introduction

This literature review has demonstrated the simultaneous, but mostly separate, shifts in focus on increasing user participation in Healthcare and Design. This is true both for engaging patients in shaping their own, individual care pathways and for engaging patients as citizens in shaping healthcare service provision. This section will now discuss what has been learnt, and is still yet to be explored, about designing to enhance patient participation in (SCI) rehabilitation.

3.16.2 Role(s) of the 'user'

Throughout the literature review, the people who we intend to engage in the PhD study have been collated under different terms (according to the field being reviewed), including 'citizen,' 'patient,' 'stakeholder' and 'co-designer' (see appendix 9 for a review of these terms in detail). In short, however, consideration of these terms and acknowledgement of the roles 'users' may inhabit helps to highlight that participation isn't always equal, and it is this asymmetry of power that is the context of this PhD study. The study aims to engage the host SIU inpatients within a co-design process, where they may inhabit patient, citizen, stakeholder and/or co-designer roles, possibly (to some extent) simultaneously. SIU staff, too, may need to balance commitments associated with being an individual stakeholder (i.e. with personal work practices being challenged and possibly altered), a citizen of the SIU community (i.e. with a duty to ensure the best possible experience for patients) and as a co-designer (i.e. imagining new futures in a context which is not traditionally creative). As such, the methodology taken forward must be sensitive to this, and allow participants to lead the ways in which they wish to participate.

3.16.3 How is participation supporting (or not supporting) a stronger patient engagement with rehabilitation processes?

Unfamiliar roles in participatory healthcare models

As discussed in Part A, there is evidence to suggest that most patients want an active role in their healthcare, yet a comfortably active role can mean different things to different people and it has been suggested that patients should be asked how they would like to be involved on an individual basis. However, there is little advice available on how to inform patients about the roles available to them, nor on how to prepare both patients and staff for their new roles (despite several authors stating a need for this). Indeed, other than Tai-Seale et al.’s (2016) example, very few interventions target the behaviours of staff and patients, and given that patients have been ‘trained’ to believe that their input isn’t relevant (Holmes-Rovner et al., 2007) or fear being labelled ‘difficult’ (Tai-Seale et al., 2016), any proposed intervention may need to make explicit the ‘arena’ of the consultation.

Participation in SCI rehabilitation

Much of the literature available in Part A of this review considered one-on-one healthcare consultations, where the dominant modes of patient involvement, or ‘patient-centred care’, tended to utilise aspects of Shared Decision Making (SDM), often supported by Patient Decision Aids (PDAs). Whilst this is better than no patient participation at all, this follows an ‘informative’ model of patient-doctor relationship (Emanuel & Emanuel, 1992), engaging the patient in a ‘transaction’ rather than a ‘caring’ interaction (Mol, 2008).

The healthcare literature was clear in the theoretical benefits of patients actively taking part in a goal planning, in SCI rehabilitation and more generally. However, in practice, case studies or advice on setting ‘patient-centred’ goals were not forthcoming, suggesting the specific aims and context of this PhD study may address a gap in the medical literature.

Experiences of active patient involvement in their own healthcare

Many of the patient-centred interventions found in the literature used quantitative measures of change in health status as their primary evaluation tool. However, this study is concerned with enhancing a less easily measurable outcome –patient participation – which may be more suited to social science-based methods (i.e. semi-structured interviews), particularly given the heterogeneous nature of the SCI patient population. However, it was not common to find in-depth interviews with patients concerning their experiences using such interventions, instead evaluations tended to focus on healthcare professionals’ experience of delivering them. This, then, shows the potential for this study to contribute to the literature with a thorough evaluation of patient experiences related to their participation in SCI rehabilitation.

3.16.4 How is participation supporting (or not supporting) a transformation of healthcare services toward more participatory practices, including staff?

The healthcare context is deeply rooted in traditional ways of working grounded in scientific evidence, with established power dynamics between a patient and their healthcare professional(s). What has become apparent from the reviewed literature is that bringing in a design perspective can be well suited to navigating some of these challenges, and can contribute to developing patient-centred services by leveraging and validating new and different forms of knowledge. The strength of design-led methods such as visualisation, prototyping and service enactment activities lies in their ability make this knowledge visual and tangible, to translate and synthesise the perspectives of the healthcare community so that it can be more easily shared, understood and collaboratively developed (across disciplinary and hierarchical boundaries) into cohesive services concepts that better reflect the complex, interdependent nature of healthcare needs today.

3.16.5 Where does the PhD study sit within the literature?

This study is positioned in the growing area of Service Design that is concerned with taking participatory approaches with and within a healthcare community. Through this lens, the experiences of patients as they navigate the service come into focus, rather than viewing the patient pathway in a traditional process-driven manner. The review has demonstrated the potential for co-designed artefacts, including visualisations, in enhancing patient experiences of healthcare, affecting positive behaviour changes and mediating productive working relationships between patients, families and healthcare professionals.

More specifically, the study is also concerned with repositioning the patient within these healthcare services, focussing not just on the patient experience but also on the patient role. Service logic notions of considering the patient as a co-creator of value can have interesting implications in rehabilitation contexts, in order to renegotiate patient-professional roles towards more participatory practices, but to date this has largely been unexplored. In other words, this study is concerned with exploring what it means to design for patient participation in a complex healthcare service, and what patients, families and healthcare staff can contribute to the co-creation of such services.

3.16.6 What has been achieved in this area to date?

Whilst there is agreement in the literature that healthcare communities can and should be involved in healthcare service development, and some positive steps made towards this end, the conceptual and pragmatic difficulties in doing so are well documented. Moreover, projects taking a participatory approach to service development tended to either a) engage patients in creative methods to learn about their experiences, to generate a set of recommendations, or b) involved only healthcare staff in co-design activities. There is a gap, therefore, to consider ‘patient experience,’ and staff work practices alongside potential patient roles as an active contributor and a co-creator of value in the healthcare service.

In the whole review, only one example could be found of gathering inpatient input in situ, through the use of patient diaries[5] (Elg et al., 2012). This thesis argues that there may be subtle differences in involving inpatients and outpatients in co-design activities, and exploration of this concept may go some way to answering Mønsted & Onarheim’s call for more segmentation of user groups, especially in healthcare, and a need to 'move beyond the ideal that involved users must constitute a group that represents the multiplicity of needs and perspectives,’ (2010, p162).

The lack of inpatient involvement may partly be due to the fact that few studies in the featured literatures focussed on rehabilitation contexts, where inpatient stay is longer. This review found that the majority of the papers concerned with rehabilitation framed ‘enhancing patient participation’ in terms of doing more of what the healthcare professional(s) advised, such as exercises. Whilst this is still an important part of a patient’s functional recovery, it could be argued that this is still somewhat a compliance-based, medical model of framing patient participation. Whilst some of the rehabilitation-based sources reviewed reported changes in patient-professional communication and recognition of potential patient agency, as a result of testing their prototypes with healthcare communities, only one study could be found that drew on the Service Logic notion of considering the patient as a co-creator of value (based in a one-to-one healthcare consultation). As such, there is space to further explore what service design-led epistemology of ‘participation’ can bring to multidisciplinary rehabilitation contexts.

In terms of implementation and impact, it has been highlighted that most service design projects in healthcare focus on the ‘fuzzy front end’, and there has been ‘less focus on the back-end of the development process, both in practice and in academia,' (Almqvist, 2017, p2524). The literature reviewed shows a growing proficiency in engaging healthcare

---

[5] This project was also the only source to highlight the need to ensure anonymity in the patient input, so that they may ‘feel secure’ that their comments wouldn’t affect their future healthcare.

communities in using design-led methods to learn about patient experiences, and in some cases iterating prototype materials or services, but with fewer studies documenting co-design, implementation or evaluation processes. More ‘transformational’ outcomes are linked to longer term or ‘embedded’ projects, but again, few examples could be found with the aim of enhancing patient participation in rehabilitation or in healthcare services more generally.

Part D: Implications for the study

3.17 Implications for the study

3.17.1 Introduction

This study is addressing an underexplored area in participatory service design research by focussing on rehabilitation services, and unique in its focus on a multidisciplinary rehabilitation planning meeting such as the GPM. The literature review also highlighted that inpatients are rarely involved in situ at any stage in participatory service design projects, and few designers are able to operate from an 'embedded' position within the hospital context. All of these issues have implications for how the main study will address the three main research questions identified during the contextual review, as discussed below.

3.17.2 Research Question One: What are the current experiences of staff, patients and family members in the GPM?

After identifying the Goal Planning Meeting (GPM) as a potential site for intervention in the contextual review (Chapter 2), this study turned to the healthcare and business literature available to better understand its history and place within the wider trend for active patient involvement. It became clear that each SIU approaches the process of goal planning slightly differently, and there is not a tradition of exploring patient experiences within it. Additionally, the medical literature does not approach the observation made in this study's contextual review that patients, staff and family members may experience the same GPM differently. So, the information on the other processes and frameworks of goal planning available may be a useful resource, but this study will need to proceed with a deeper, structured investigation into goal planning experiences and attempt to establish a 'baseline' of patient participation within them.

From the design literature, Mullaney's (2016) notion that one must look at patient experience from different perspectives will be used to address this research question, using a triangulation of patient, family and staff perspectives to better understand the GPM experience. Frameworks for considering 'experience' from EBCD will be useful in attempting to explore this, and as found in the previous review, the use of visualisations can support participants in reflecting on and sharing their experiences. The data gathered needs to be useful, understandable and respected by both staff and patients in the following co-design activities, so a mix of quantitative and qualitative approaches may be needed.

3.17.3 Research Question Two: How can we engage the SIU community in co-developing a new material or protocol to enhance patient and/or family participation within the GPM, whilst also protecting their ongoing working relationships with staff?

Approach

There are few precedents of engaging SIU communities in co-design activities (other than those described in the Preface of this thesis) so much of the practicalities of the study design must be based on the contextual review observations. Any activities involving staff or patients will need to fit into the rehabilitation timetable, other staff commitments and possibly visiting times. The tools and methods themselves may need to be adapted to accommodate limited dexterity and increased fatigue associated with some spinal injuries.

Methods

On a more conceptual level, the previous review has highlighted the strengths of a design-led approach in addressing the highly routinized and hierarchical nature of healthcare services, using methods such as visualisations, prototyping and enactments to elicit, validate, communicate, synthesis and leverage knowledge for creative collaboration. On the other hand, little guidance is available on how to address the reported difficulties in reconciling the different epistemologies of healthcare and design. As such, the researcher aims to work in a flexible, responsive way, adapting her approach as needed based on her knowledge of the SIU and how to work harmoniously within it.

Participants

Although many of the approaches reviewed hold face-to-face collaboration between healthcare professionals and patients as the ‘gold standard’, some have reported tensions between staff and patients through the renegotiation of power, but with little advice on how to safeguard patient-professional relationships. As such, it may be more appropriate to initially engage patients and professionals separately to avoid any risk of damaging their crucial, ongoing working relationships. Methods will be chosen that facilitate collaboration and continuity despite this lack of face-to-face contact, such as iterative prototyping and the ‘Experience Goal’ method described in section 4.9.2.

This study may also contribute to the literature by exploring the hypothesis that outpatients and inpatients should be included in rehabilitation service improvement projects for the 'hindsight' and 'current' experiences they hold respectively.

Designing for enhanced participation

The literature suggests that co-designed materials can be introduced into patient-professional interactions to support patient understanding or efficacy in therapy exercises. However, there is room to explore how else a patient could contribute in roles of 'value co-creation,' and how to safeguard staff's duty of care (in these unfamiliar roles) when patients are empowered to do so. Given that this study is situated in the GPM, where (potentially shared) decisions are made that shape a patient's rehabilitation pathway, there is a lot of scope to explore these ideas.

3.17.4 Research Question Three: What are the effect(s) (if any) of a co-developed intervention in the GPM?

As discussed throughout this chapter, robust evaluations of collaborative service development projects are not common in healthcare- or design-led approaches. Here may be an opportunity to explore how design-led methods can be enhanced by both qualitative and quantitative measures to understand (new) patient and staff experiences, evaluate impact of the intervention and suggest future improvements, and as such may better communicate its findings to both design and healthcare audiences. However, the fundamental epistemological differences between the fields of healthcare and design must to be acknowledged, as discussed in the next chapter.

04 Methodology

4.1 Introduction

At this stage of this PhD study, an in-depth contextual review of the host SIU (Chapter 2), supported by a targeted literature review of relevant healthcare and design literatures (Chapter 3), has been used to frame the site and purpose of intervention. In this chapter, the aims of the PhD study are revisited and followed by a brief discussion on the worldviews of Scientific and Design Research. This discussion leads to the proposal that these seemingly contrasting worldviews can instead be considered complimentary.

Whilst this study has an emergent quality, this chapter explains the overall methodological approach taken and why, as informed by the literature and the preliminary contextual reviews.

4.2 Aims and objectives

The main aims of this PhD were to engage the SIU community in the co-design of an enhanced Goal Planning Meeting (GPM) that better supported patient participation. ‘Participation’ was understood as akin to an ‘interaction’ rather than a ‘transaction’ (Mol, 2008), where patients and healthcare professionals are understood to be experts in their own domains (Edh, 2006), with valuable knowledge to share and use to affect the rehabilitation practice.

Informed by the insights gained in chapter 2, the main objectives of the study were as follows:

- Phase One: Develop a clear understanding of the GPM from patient, family and staff perspectives, and opportunities for improvement within them.
- Phase Two: Engage the SIU community (which is understood to include staff, outpatients, inpatients and their families) in a co-design process that addresses the power dynamics inherent in a hospital context, and does so in a way that protects their on-going working relationships.

- Phase Three: Integrate the co-designed GPM intervention into the rehabilitation pathway, and capture a rich understanding of the 'new' GPM experience from patient, family and staff perspectives.
    - As well as conducting a rigorous evaluation of the effects of the intervention, this study also aimed to evaluate the co-design process employed.

To achieve these objectives, the researcher intended to continue working in an 'embedded' way within the SIU; in other words, continuing to be based in the hospital setting, being 'present' on the wards as much as possible, and ensuring the design-led methods were being introduced in a manner that is sensitive to the context. However, design-led methods and healthcare contexts are subject to different worldviews that can be difficult to reconcile, as explored below.

4.3 Scientific paradigm

Research within healthcare predominantly emerges from the scientific paradigm, the key principles of which are outlined below. It is worth noting that this study, based in the host SIU, is framed by this epistemology, or in other words this is how the SIU staff see the world and how their practice is framed. As such these worldviews must be considered alongside the researcher's own when working in healthcare contexts.

4.3.1 Ontology and Epistemology

The field of scientific inquiry adopts an objectivist approach which maintains that reality exists independent of observation, and the objects within it have ingrained meaning(s) that can be studied. Within the scientific community, a structuralist stance is often employed, which holds that generic principles can act as governing rules to predict, determine or explain a multitude of situations. Scientific knowledge, then, is a description of 'what is,' and concerned with 'universal truths' (Fischer, 2007). Scientific 'evidence' is concerned with that which is provable and repeatable, where the knowledge gained can often be generalised and applied to other situations.

4.3.2 How is research conducted?

Scientific inquiry is often based on established, testable hypotheses, mostly using quantitative methods of exploring measurable effects, generating discrete (i.e. numerical or true/false) data to inform provable conclusions.

From a healthcare perspective, the Randomised Controlled Trial (RCT) is largely considered the ‘gold standard’ in medical research, often for the purposes of testing the efficacy of a new drug treatment. The key principles of the RCT, which are applied to many other scientific research methods to varying degrees, include the randomization of participant selection to avoid bias (although efforts may be taken to ensure a range of participants from specific demographic groups such as age, gender, weight, etc.) and the use of a ‘control’ group who do not receive the intervention, where participants are unaware of which group they belong to (see Sibbald, 1998).

4.3.3 Strengths and Weaknesses

The scientific approach can be considered very necessary in the field of medicine, in terms of understanding and purposefully allocating the correct treatment for a particular illness, etc. The role of evidence-based approaches to healthcare service improvement has also been discussed earlier in this thesis (see section 3.5, also Carr et al., 2011). However, it has been established that the use quantitative measures alone are unable to account for people’s lived experiences, or the reasons behind their thoughts and feelings (Sutton & Austin, 2015) and as such can limit the scope for innovation within healthcare services.

4.4 Design paradigm

4.4.1 Ontology and epistemology

Designers often employ a Social Constructivist approach, which maintains that reality is not governed by a single discoverable truth, and that knowledge is considered a social construction as we engage with the objects and people within it. This worldview accounts for the idea that people may experience the same phenomenon differently, and as such design work seeks to understand and use these multiple experiences.

This approach places an emphasis on understanding people and their social interactions, not to create ‘correct’ or ‘provable’ solutions, rather to engage with ‘real world’ situations and the ‘messy’ or ‘wicked’ nature of the problems within it (Glanville, 2015, see Rittel & Webber, 1973). In other words, whilst scientific inquiry aims to establish ‘what is’, design ‘will always be about creating something that does not yet exist,’ and as such the aim of design inquiry is to bring together the ‘real’ and ‘ideal’ states (Nelson and Stolterman, 2003, p31).

4.4.2 Evidence in Design Inquiry

Within the design paradigm, ‘knowledge’ and understandings of what is ‘real’ is grounded in the complex details and relationships in everyday life, which is also described as ‘phronesis’ or ‘practical’ knowledge (Glanville, 2015). The criterion for ‘evidence’ within phronesis knowledge is that which is ‘good enough’ to help us act (Glanville, 2015). This evidence does not need to be ‘right’ or ‘true’ as understood in the scientific sense, and by aiming for ‘good enough’ the possibility to try again is opened up (p20), which accounts for the iterative nature of many design projects. Using knowledge or conclusions that are ‘good enough’ is a concept derived from the work of pragmatist philosophers such as William James and John Dewey, and potentially opens up design research to a wider range of participants, including those not formally trained in design practice.

4.4.3 How is research conducted?

Design research has its roots in Action Research, which is described as ‘any research into practice undertaken by those involved in that practice, with an aim to change and improve it,’ (The Open University, 2005). It is characterised by ‘a self-reflective spiral of cycles of planning, acting and observing’ and aims to build a ‘two-way flow of information, knowledge and expertise between researchers and practitioners,’ (Elg et al., 2012, p331-2). Research through Design’s similarities to Action Research will be highlighted throughout this section, but it distinguishes itself through its ‘designerly’ approach to taking and reflecting on action.

Design Research can be considered as distinct from scientific research (Saikaly, 2005) and as strictly related to ‘designerly ways of knowing’ (Sangiorgi & Scott, 2015, see Cross, 2001). It focuses on ‘specific, intentional and non-existing’ situations rather than the ‘universal and existing’ knowledge sought in science-based inquiries. The design process or ‘design experiments’ (Eriksen & Bang, 2013) are increasingly at the core of Design Research (Sangiorgi & Scott, 2015) to the point where ‘design work becomes inseparable from research’ (Koskinen et al., 2009). Although method is crucial to scientific research, Sangiorgi and Scott urge designers not to simplify their approach to mimic this, and to instead establish ‘guiding frameworks and... critical mindsets to help contextualise and evaluate one’s own work within wider social dynamics of change,’ (2015, p114-5).

The simplest distinction to make within multiple ways of conducting Design Research is whether it is informed by theory or if it is practice-focussed. The latter uses design projects as a ‘research strategy to enable exploratory investigations of indeterminate (‘fuzzy’) research problems or multivariate (‘messy’) situations when specific research questions emerge only as the practical work develops,’ (ibid). As this is in concert with the complex context of this PhD study, the following sections will explore the practice-focussed branches of Design Research.

Christopher Frayling (1993) is often cited for suggesting that Design Research can be categorised as being research ‘into’, ‘for’ or ‘through’ design. Research into Design is usually theory based, for example a historical retrospective of a particular design style (Sangiorgi & Scott, 2015). Research for Design can be considered ‘practice-based’, which involves the analysis of design processes or artefacts, but not necessarily production of original artefacts (Scrivener, 2009). The final category, Research through Design, can be considered ‘practice-led’, where design practice leads the whole research process, closer to an action research methodology (also referred to as practice-centred research, Rust et al. 2000).

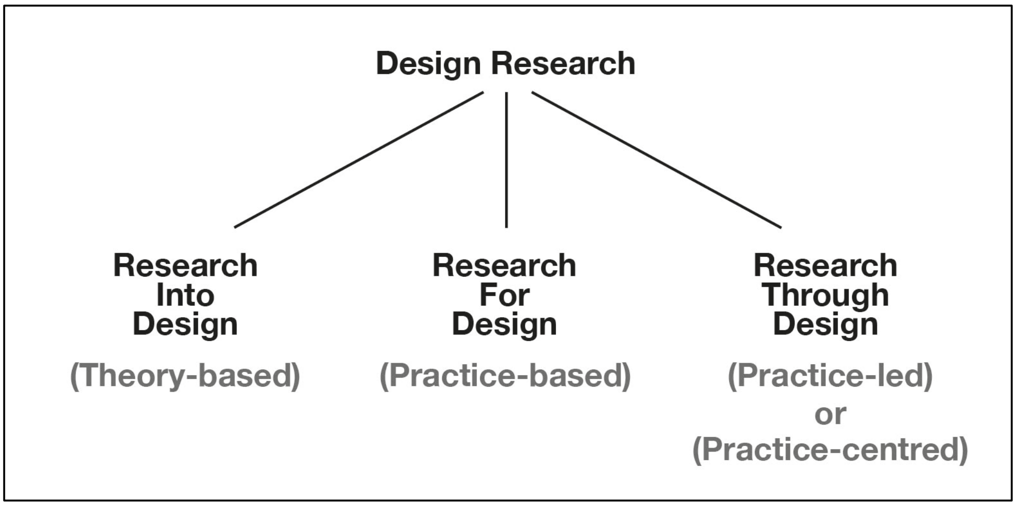


Fig. 4.1: A tree diagram of the main approaches within Design Research (adapted from Frayling, 1993).

4.4.4 Research through Design (RtD)

Research through Design (RtD) has largely been discussed within the field of Human-Computer Interaction, although in recent years it has become an ‘increasingly recognised approach to research in any discipline,’ (Godin & Zahedi, 2014). Unlike its counterparts (research into or for design), practitioners of Research through Design have yet to reach consensus on ‘best practice’, as ‘no agreed upon research model existed for […] designers to make research contributions other than the development and evaluation of new design methods” (Zimmerman, Forlizzi, & Evenson, 2007, p. 493). In a review of the RtD literature, Godin and Zahedi found that whilst the term was given several definitions, or compared with similar practices (such as constructive design research, practice-led research and project-grounded research), none of the definitions were necessarily contradictory, and that they were all ‘concerned with an underlying shared goal: establishing aspects of research done through the design process and its resulting product,’ (2014, p1668).

For the purposes of this study, RtD was understood in line with Zimmerman and colleagues’ description as the “process of iteratively designing artifacts as a creative way of investigating what a potential future might be” (2010, p312). This cyclical nature of RtD highlights its roots in Action Research, however it is distinctive in its use of designed artefacts to investigate an ‘ideal’ situation (Nelson and Stolterman, 2003). Indeed, it is argued that the knowledge generated by RtD is embedded in these iteratively designed artefacts, as discussed in section 4.9.1.

4.4.5 Contexts of RtD

Frayling (1993) suggests that Research through Design can occur within contexts of the lab (i.e. testing pre-determined hypotheses), the field (i.e. real-world contexts) or the showroom (design outputs viewed as independently observable artefacts, similar to exhibitions of fine art).

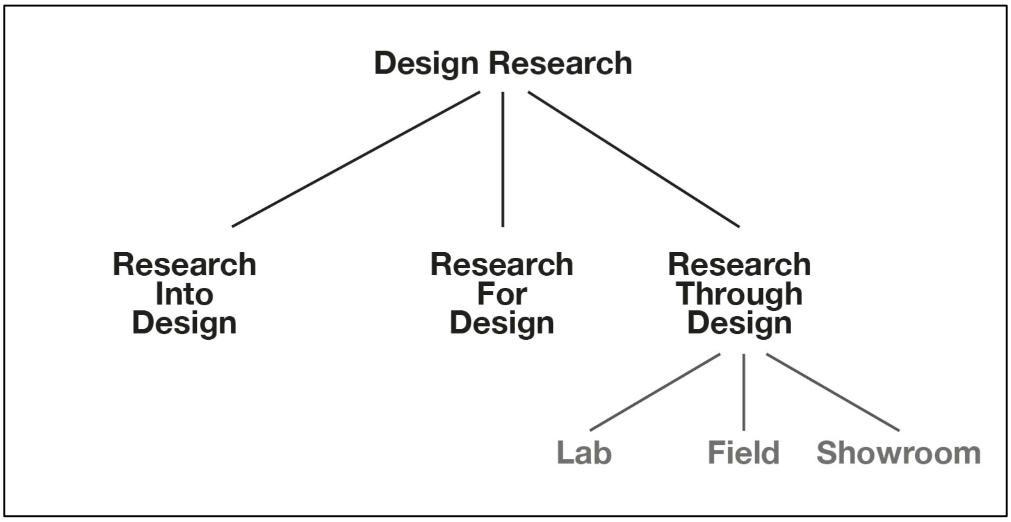


Fig. 4.2: A tree diagram demonstrating the main contexts within Research through Design, adapted from Frayling, 1993 and also discussed by Koskinen et al., 2011.

4.4.6 Strengths and weaknesses of design research

Mullaney argues that the tools used in design inquiry are more suitable for handling the 'real', which is 'continually being created, while the true is predetermined' (2016, p63). As discussed in the literature review, the field of design has a history in eliciting, understanding and using people's lived experiences in order to improve them. It also acknowledges that 'how one individual understands an object or behaviour can be drastically different than another individual's understanding of it,' (Mullaney, 2016, p63) and is able to work with these (sometimes conflicting) perspectives constructively (see Ehn, Nilsson and Topgaard, 2014).

However, much like its roots in Action Research, the results of an RtD inquiry can be difficult to evaluate, as no two designers may approach the same problem and produce similar artefacts (Zimmerman et al. 2007). However, rather than judge RtD on its replicability (as in the scientific paradigm), Biggs and Büchler suggest that "rigor in research is the strength of the chain of reasoning, and that has to be judged in the context of the question and the answer" (2007, p69), and that if the process is judged to be rigorous, then the claim of the outcome is validated. In summary, rigour in a RtD approach can be enhanced by documenting and being able to account for the decisions made throughout the process, or in other words, how, when and why the iteratively designed artefacts were changed.

4.5 Differing worldviews on participation

As discussed in the literature review, the way in which healthcare- or design-led approaches to service improvement involves the 'users' varies, and this discussion is equally as valid in the context of research. Collins, Cook and Choukeir (2017) provide an interesting discussion on the different interpretations of 'participation,' including positivist notions of representativeness and constructivist approaches to participation.

4.5.1 Representativeness

According to Collins, Cook and Choukeir, 'the notion of representativeness draws heavily upon conventionally positivist assumptions about objectivity; for example, does the sample of users represent adequately the demographic profile of the population that will be using the service, or will the insights of the designer get skewed?' As discussed above, this approach may be more prevalent in scientific paradigms.

4.5.2 Constructivist approaches to participation

From the field of anthropology, the 'crisis of representation' (Said, 1989) led to new ways of thinking about how people can be 'depicted linguistically, symbolically and aesthetically (Hall et al., 2013); [and] how we as designers and researchers turn knowledge into insights, weaving those into the design process… and acknowledging our own part in shaping this interpretative process,' (Collins, Cook & Choukeir, 2017, p107). This demonstrates a more reflective approach to involving 'users'' insight in design research, more in line with design's social constructivist worldview, that pays attention to the 'power dynamics of a specific process or context [which] might serve to privilege some voices and silence others,' (ibid).

Speaking from a Service Design perspective, Cook, Collins and Choukier also take this argument further, stating that 'while service designers are equipped with valuable visual, communication, narration and creative thinking to represent the under-represented imaginatively,' (as discussed in the literature review), 'they should build into their own practices the time and space for critical reflection about these representations that they are crafting,' or 'critical participatory practices,' (2017, p113).

4.6 Epistemological Approach and Methodology

4.6.1 Overview

This PhD study took a Research through Design approach to explore and shape patient, staff and family experiences of the GPM, drawing on the fields of Participatory Design and Service Design to address issues of power and the complexity of the SIU rehabilitation service. This was in line with the researcher's social constructivist worldview and belief that such a complex context (the SIU) and experience (SCI rehabilitation) cannot be understood nor improved by quantitative methods alone. The review of RtD approaches has highlighted that this methodology could have taken several forms, so for clarity the three 'pillars' supporting it (a focus on experience, a participatory approach and co-creating value), are each described below.

4.6.2 A focus on experience

Although this study is concerned with patient participation, existing metrics of measuring participation (such as the Patient Activation Measure, as described in section 2.3) were not used as they may limit the scope knowledge produced about the GPM, and ways to enhance it. Instead, a focus on eliciting and using experiential data was used to inform priorities and potential opportunities to enhance the GPM, and to consider the multiplicity of perspectives of the GPM productively. Additionally, it was considered that even with the best intentions, a co-designed intervention may not improve patient participation, but may improve the patient, family or staff experience of it, which is still important to capture during evaluation stages of the study. As discussed in the EBCD literature, asking members of the healthcare community (including patients) to share their ‘experience’ of a situation (rather than their evaluation of it) elicits richer, more useful data for design (Bate and Robert, 2007), and also allows them to lead the discussion, in line with the participatory principles of the methodology (discussed below).

4.6.3 Participatory approach

Although this study did not intend to develop an ICT-based intervention, the core principles of Participatory Design (rooted in the Scandinavian workplace democracy movement) formed a key pillar in the methodology of this study. These principles include the concepts of ‘having a say’ (the political stance that those who are affected by a design have the right to be involved in its creation), mutual learning (the pragmatic stance that those affected by a design are best placed to shape it) and co-realisation (the use of ‘making’ to flatten hierarchies and effectively share knowledge).

Robert and Macdonald argue that a key tenet of a Participatory Design approach is its potential to create an open space where traditional power structures are suspended, ‘where differing views of ‘evidence’ and ‘knowledge’ are not mutually exclusive’ (2017, p120) and a plurality of opinions can co-exist, usefully. Within the specificities of this study, this translated into tailoring the co-design process to engage the multiple ‘virtuosos’ (Sanders, 2001) of the various SIU experience domains at each stage of the study, including outpatients, staff, inpatients and their families, and using methods that allow participants’ participation to be influential and legitimised (Simonsen & Robertson, 2013). This also involved adapting the workshop structure and tools to anticipate the potential physical and emotional limitations associated with SCI.

4.6.4 Co-creating value in the GPM encounter

As a field, Service Design has become practised in considering how multiple actors (and resources) can come together to ‘co-create’ value through a service encounter (Sangiorgi & Prendiville, 2017a). This concept formed the third ‘pillar’ of this study’s methodology, or more specifically, considering the ways in which patients, staff, families, and supporting materials, can promote and facilitate patient participation within the GPM service encounter.

The specific tools taken from the fields of Participatory Design and Service Design to reinforce these ‘pillars’ will be discussed below.

To support participation from SIU staff as equal partners in this process, and to enrich the knowledge derived from the RtD approach, the methodology also chose to incorporate approaches and types of ‘evidence’ that may be better understood, or respected, by the (scientific) healthcare community (i.e. quantitative measures) in a mixed-methods approach, described below.

4.7 Mixed-methods approach

4.7.1 Overview

It can be hard to reconcile quantitative and qualitative methods as they come from distinctive (opposing) worldviews (Mullaney, 2016). However, this study takes the view that they can each provide ‘distinctive kinds of evidence’ (Ritchie, 2003, p38) and can be complimentary in providing a richer picture of ‘what is’ in order to inform the design process (Hagen, 2014).

4.7.2 Mixed-methods for enhanced data collection

Mullaney (2016) provides an example of a mixed-methods approach to exploring patient ‘experience’ as richly as possible within the context of radiotherapy. She argues that quantitative methods can’t replace the insights generated through qualitative means, but they can be useful in dealing with ‘big data’ and providing knowledge that is more sharable across disciplines. As such, quantitative methods were chosen alongside qualitative methods more traditionally found in design-led approaches to explore the multiple perspectives of the GPM. As mentioned above, these quantitative measures were not found through existing patient participation surveys, but rather were used to explore facets of ‘experience’ in a comparable way across participants (i.e. Likert scales, further details are given in the next chapter).

Although the contextual review and literature review established that the SCI patient population is diverse, and that the SCI rehabilitation is a highly individual experience, scientific approaches to considering the range of demographic factors (such as age, gender, incomplete or complete SCI) present in the participants engaged in the study were also taken forward, in order to demonstrate a respect for scientific traditions and to at least account for the potential bias present in the data collected.

Mullaney also took the 'mixed-methods' approach one step further by including 'design experimentation' as a 'third dimension,' drawing on Eikeland's (2006) model of three traditional research approaches: 'observation', 'asking questions' and 'experimentation'. In her work, this took the form of Design experiments (Eriksen & Bang, 2013) but arguably could also include other design-led methods such as visualisation, prototyping, etc.

The methodology used in this study employed quantitative, qualitative and design-led methods together to develop a rich understanding of the current GPM experience, in order to inform initial design proposals and to guide the collaborative, iterative development of these proposals (or 'prototypes', as discussed below) into the co-designed intervention. This triangulation of GPM experience was repeated after the implementation of the intervention to demonstrate equal consideration of impact and evaluation.

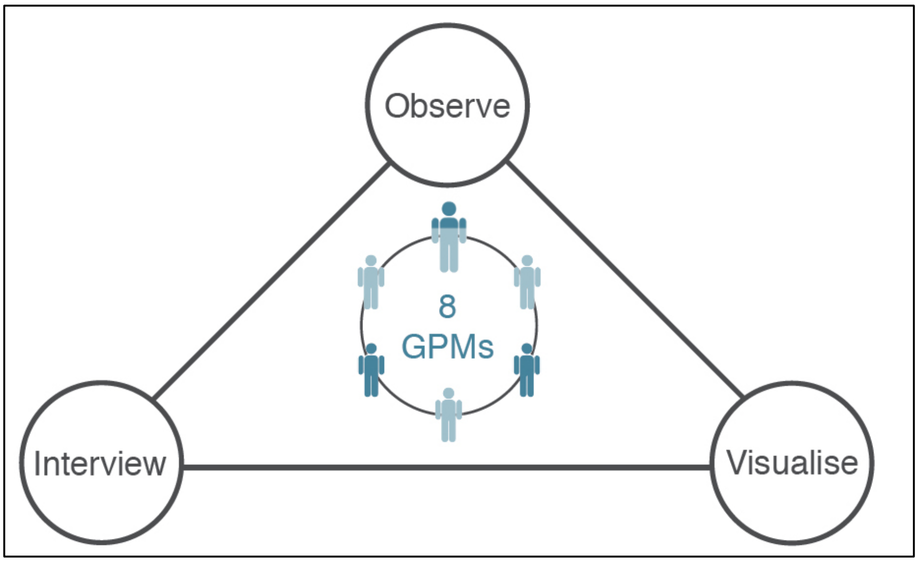


Fig. 4.3: A representation of the mixed-methods approach used to investigate multiple experiences of the GPM

4.7.3 Mixed-methods to enhance collaborative working

Hagen (2014) described using mixed-methods as a way of showing humility and openness to the research traditions respected by the healthcare context in which she was working. She and her colleagues also found that 'adapting design tools to connect and integrate both perspectives as inputs for the design,' and 'showing the source of all insights' was useful. As such this methodology chose to encourage staff 'buy-in' by creating a sense of transparency and rigour in the co-design process; by making clear links between the design priorities and a quantitative and qualitative evidence base; and by ensuring the reasoning behind on-going design decisions were documented and clear.

4.8 Methods to understand the GPM experience(s)

4.8.1 Overview

The following methods were used to identify the priorities for improvement within the GPM, to inform the first iteration of the prototypes used in Phase Two. This data was also used to establish a 'baseline' of the GPM experience, to be compared with the GPM experience after intervention. Although 'experience' is inherently subjective and therefore difficult to objectively compare before and after intervention (as in scientific research), the methodology aimed to capture any trends or key differences that emerged.

4.8.2 Qualitative methods

Ethnography, with its roots in anthropology, has been a key concern of Participatory Design since the early 1980's, as discussed in section 3.7.4. Additionally, Sangiorgi and Prendiville (2017a) describe how the field of Service Design has also seen a rise in anthropological and practice-based descriptions of services, understanding services within socio-material and cultural contexts (see also Blomberg and Darrah, 2015). Given the complexities of SCI rehabilitation and the interdependencies of the various rehabilitation disciplines alongside supporting materials, ethnographic observation of the GPM was chosen as a key method of studying the GPM experience.

4.8.3 Design-led methods - visualisation

Design's strength in using methods of visualisation to make sense of complex situations, and engage non-designers in this sense-making process, has been established in the literature review of this thesis. In this methodology, visualisation methods were chosen to generate as objective a view of the GPM as possible, by mapping the time each GPM participant spent talking on generic rehabilitation topics (such as medication, skills training, etc.) along a timeline (see section 6.5). This allowed the SIU staff in particular to understand the different kinds of 'evidence' that can be generated from design-led methods, and that such methods can engage with quantitative data (such as time spent talking) creatively and usefully, with an aim to highlight opportunities for intervention.

4.8.4 Questionnaire-led interviews

The mixed-methods approach described above is perhaps best exemplified in the use of a questionnaire-led, semi-structured interviews with patients, family and SIU staff members, which contained quantitative (i.e. tick-box or Likert-scale) questions, qualitative (i.e. open-ended) questions, and diagrammatic (i.e. visual) questions (see section 5.5).

Incorporating a mixture of question types in this way allowed the participants to somewhat guide the discussion (due to the open-ended nature of the qualitative questions), whilst also gathering some data than can be easily compared between patients before and/or after the intervention (in the quantitative questions) and ensuring that all of the domains the researcher wanted to discuss were at least raised. Additionally, it could be argued that both the quantitative questions (which are quick and easy for the participant to complete) and the diagrammatic questions (which could allow for a greater nuance of expression where words may give a limited understanding of a given topic) increased the likelihood that at least some data would be gathered from patients who chose not to talk in a lot of detail, or who had difficulty in expressing themselves.

4.8.5 Qualitative Data Analysis

As highlighted above, qualitative data were gathered both before the intervention (Phase One) and after the intervention (Phase Three). These data were transcribed and uploaded into NVivo© (a qualitative data analysis software), and analysed according to the aims of each Phase (see appendix 1 for a full introduction to qualitative data analysis).

The Phase One qualitative data were analysed by coding the transcripts deductively (Pope, Ziebland & Mays, 2000), using the questionnaire items as a guiding framework[6] (see appendices 10-12 for examples of the questionnaire used in Phase One semi-structured interviews). In this way, the researcher could collate all of the participants' insights around consistent, robustly evidenced areas of interest in the GPM experience (informed by the contextual review and literature review, as described in 5.5), and interpret them within participant groups (i.e. patient, family and staff's separate experiences) as well as more generally across the SIU community. This allowed the researcher to create evidence-based

---

[6] According to Ryan and Bernard, 'a priori themes come from the characteristics of the phenomenon being studied; from already agreed on professional definitions found in literature reviews; from local, commonsense constructs; and from researchers' values, theoretical orientations, and personal experiences,' (2003, p88).

summaries, with illustrative quotes, of the current GPM experience from multiple perspectives (given in section 6.8). This was considered sufficient analysis to inform the development of the initial prototypes and Experience goals for Phase Two (see section 6.10), and an appropriate time commitment given the number of participants involved.

The Phase Three qualitative data, which aimed to give a rich description of the (new) GPM experience using the intervention, was analysed using an integrated approach to coding (Bradley, Curry & Devers, 2007), using a pre-defined guiding framework as well as an inductively developed set of codes that are ‘obtained gradually from the data,’ (Pope, Ziebland & Mays, 2000, p114). This was to ensure topics of interest were addressed whilst also leaving room for emergent, unexpected findings, in line with this study’s social constructivist stance. As in Phase One, the questionnaire items (informed by the Phase One questionnaire and the format of the intervention, see appendices 13-15) were used as an initial guiding thematic framework and applied deductively the qualitative data. The data gathered within these pre-defined themes were then reviewed and analysed inductively, creating new or more nuanced themes as necessary (discussed in sections 8.6-8.9, with further details given in appendix 16).

4.8.6 Quantitative data analysis

The quantitative questionnaire items allowed for discrete, numerical ratings of aspects of the GPM experience to be derived and compared. This quantitative data can be summarised across the participant groups to statistically show how much of the SIU population agrees with a particular statement about the GPM experience, or how often participants felt certain topics were covered appropriately in the GPM discussion. As Ali and Bhaskar have it, ‘statistical analysis gives meaning to the meaningless numbers, thereby breathing life into a lifeless data,’ (2016, p662). As such, quantitative methods were not included in the methodology simply to satisfy the expectations of a traditionally scientific SIU staff cohort, but rather they brought new meaning and depth to the understanding of the GPM experience.

It should be noted that whilst the field of statistics has a rich heritage of complex processes of analysis, this study aimed to understand the GPM experience enough to act within it, rather than explicitly and definitely describe the phenomenon. As such, simpler forms of quantitative data analysis were deemed sufficient, such as percentages of patient vs staff participants that agreed with a particular statement, etc.

4.8.7 Visual data analysis

By its nature, the act of visualising (in the manner described above) is a form of analysis itself. By abstracting the detail of a given situation and its components, the researcher aimed to more clearly see general trends or to identify key issues, and to be able to share these insights with the SIU community to be developed further.

4.9 Methods to co-design the GPM experience(s)

4.9.1 Prototypes and Prototyping in Design Research

Prototypes are a hallmark of many forms of Design Research (Wensveen & Matthews, 2015, p262), and indeed throughout the contextual and literature reviews of this study a focus has emerged on how artefacts can help to structure particular experiences or guide staff-patient collaboration in creating them. It is widely acknowledged that prototypes act as 'manifestations of design ideas that concretise and externalise conceptual ideas' (Wensveen & Matthews, 2015, p262), but in a research context we can consider the 'the process of iteratively designing artefacts as a creative way of investigating what a potential future might be,' (Zimmerman et al., 2010, p313). Research through Design as 'research that imagines and builds new things and describes and explains them' is also referred to as 'constructive design research' (Koskinen et al., 2011, p6).

Whilst prototyping is often used for furthering design agendas (i.e. prototyping for practice), Wensveen and Matthews suggest that 'new properties come to light' when they are used for research purposes (2015, p263). They go on to provide four models that frame how prototypes can be used, with the hope to 'erode the idea that "Research through Design" is a (singular) research method or approach, in favour of the view that there are a multitude of legitimate intersections between design research and practice,' (p263). As above, these models can be mapped onto existing models of design research (see fig. 4.5), and are summarised from Wensveen and Matthews' descriptions below.

1. *Prototypes as an experimental component.* Here the prototype can be thought of as a 'physical hypothesis,' where its appearance, functionality, interactivities and context are treated as variables and altered independently to investigate its effects in use. This can arguably be mapped onto the 'lab' branch of Research through Design.

2. *Prototypes as a means of inquiry*. In this approach prototypes are deployed to generate understandings about contexts of use or users. This arguably fits within the 'field' branch of Research through Design.
3. *Prototypes as a research archetype*. Here, prototypes represent physical embodiments of concepts and their role is 'exemplary or ostensive,' perhaps best places in the 'showroom' context of Research through Design.
4. *The process of prototyping as a vehicle for inquiry*. In this approach the prototyping process is 'documented, analysed, critically assessed and written up,' (p269). Here the contribution is not in the design output itself but in how it was crafted. Horst (2011) describes prototypes as 'platforms for participation' where users can make real-time changes to a design concept. Although this may be applied to any of the three branches of Research through Design, the inclusion of users in the prototyping process (as in this study) suggests a focus on the 'field' context.

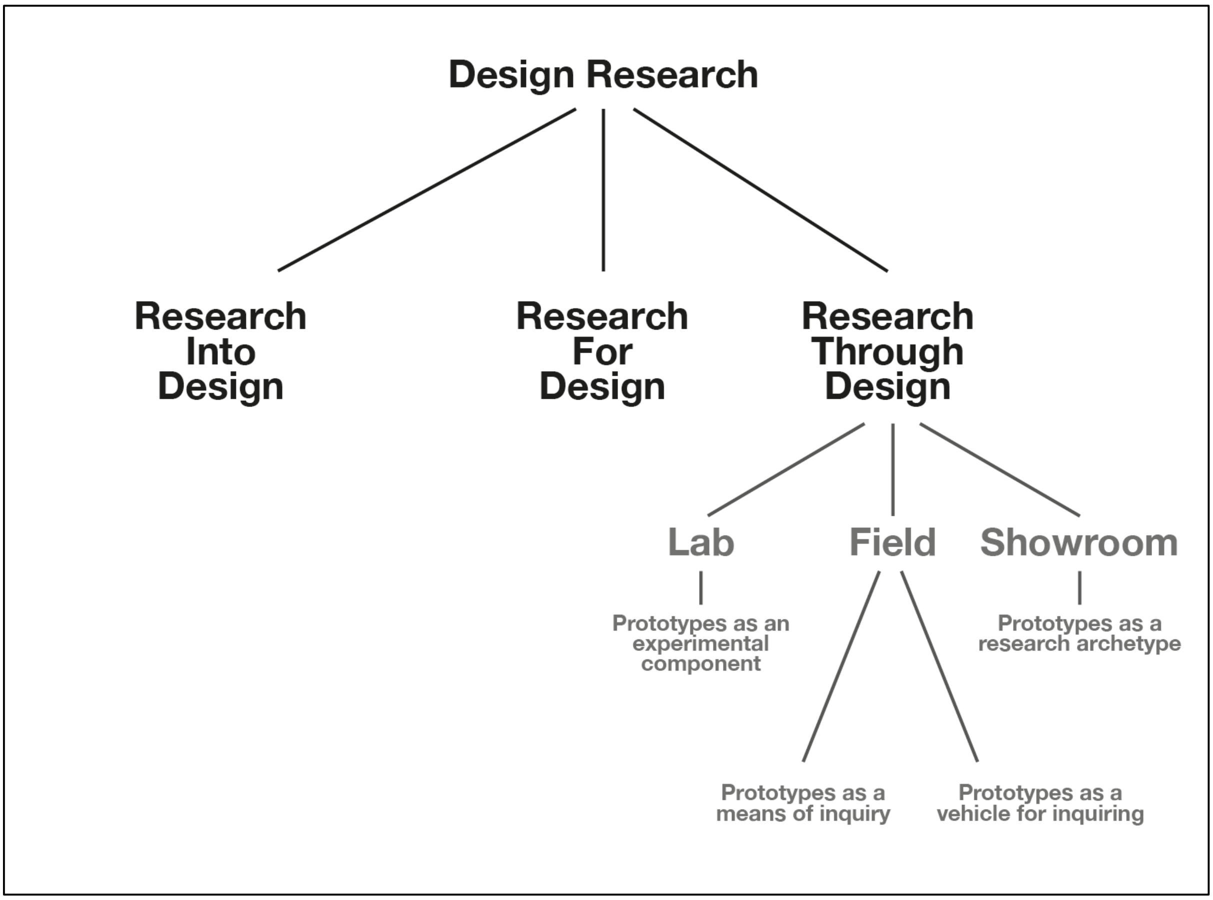


Fig. 4.4: A tree diagram representing the roles of prototypes and prototyping processes within Research through Design. Adapted from Frayling, 1993, Wensveen & Matthews, 2015, and Sangiorgi & Scott, 2015.

It is important to acknowledge that the roles of prototypes can overlap and the ‘same prototype can feature in different roles in the pursuit of different design contributions’ (Wensveen & Matthews, 2015, p271). Both of the roles situated in the ‘field’ context (prototypes as a means and vehicle for inquiry) were considered applicable within this PhD study, given its concern with how the SIU community could be collaboratively and creatively engaged to enhance the rehabilitation experience.

Stappers et al. (2015) argue that prototypes can also help to give a Design Research project the same ‘unity’ that Scientific Research embodies by subscribing to a consistent theory or method. This unity can be reached by ‘a commitment to achieving an improvement in the phenomenon under study, where either a designed prototype or a flexibly defined framework provide the central focus of the work,’ (p163). To support this, prototypes can ‘give direction to the research, help to focus attention and demarcate the boundaries of interest,’ (p171), which when considered alongside the concept of ‘experience goals’ was considered particularly applicable to this study’s co-design process.

4.9.2 Experience Goals

Experience goals (as described in section 4.9.2) can be particularly useful when engaging diverse groups of participants, and as such were considered relevant to this study’s efforts to collaborate the SIU community.

Whilst maintaining a general focus on ’participation’, the findings from the Phase One exploration of the current GPM experience (chapter 6) were used to guide the development of these experience goals. This facilitated a more participatory approach to establishing the guiding framework for the co-design process, where the experience goals were used in two ways; a) to maintain a clear, shared purpose in the co-design activities; and b) to act as an evaluative framework in order to establish when the co-designed intervention was ready to be implemented.

4.10 Ethics

Design work, in general, is inherently a moral activity as its outcomes can affect people’s actions, choices and experiences (Verbeek, 2011). Within the SIU the ethical considerations were arguably much higher, as it aimed to collaborate with newly spinal cord injured-people, and their family members. This particular group of participants may have had practical, medical and emotional issues affecting their ability or desire to participate, which were assessed and considered at all times. As the work was conducted within a hospital context, the anonymity of patients and staff members not participating, but in the vicinity of research activities, was also considered. The safety of the participants (including patients) and the design researcher was considered, but was agreed to not be in question due to the low-risk nature of the study activities and the large volume of healthcare professionals present in the hospital environment.

The appropriate ethical committees within the university and hospital contexts were consulted prior to (and when necessary, during) the study to ensure ethical conduct. Informed consent was obtained from all participants in the study, who were then given the opportunity to withdraw from the study at any time. Full details of the ethical code of conduct will be described in the next chapter.

4.11 Conclusion

Whilst subscribing to a social constructivist worldview, the methodology of this study recognised the complimentary potential of incorporating approaches traditionally found in scientific and design-led fields together, and the importance (for practical and pragmatic reasons) of taking a participatory approach to designing for healthcare services. This mixed-methods approach was chosen with the hopes of generating a deeper knowledge of GPM experiences, and as such drive meaningful, sustainable, positive change within it. In addition, the methodology aimed to communicate to both medical and design audiences, and as such the contributions of quantitative, qualitative and design-led methods were each considered valuable, and in combination, the whole was considered ‘greater than the sum of its parts,’ (Mullaney, 2016).

05 Study Design

5.1 Introduction

As discussed in the previous chapter, a mixed-methods approach will be employed to understand, co-develop and experiment within the host SIU's Goal Planning Process, with the overall aim of enhancing patient participation in SCI rehabilitation. Central to this process is the collaborative elicitation and use of experience data from and with the SIU community, where outpatients, inpatients, family members and staff members are considered to offer equally valuable contributions.

Here it is important to note that, within the GPM itself, patients do not always ask family members to attend. Instead, they may prefer to invite close friends or even legal assistance. As such, the study will be investigating the experiences of staff members, patients, and the People/Person Important to the Patient (PIP). The PIP may be a family member, but this term will be used from this point forward for simplicity and inclusivity.

This chapter will describe the study design as set out into three main phases:

- Phase One: Understanding the multiple perspectives of the current GPM process
- Phase Two: Engaging the SIU community in a series of prototype-led co-design workshops
- Phase Three: Testing and evaluating the co-designed intervention.

This chapter will then conclude with a summary of the ethical protocol used to guide the process.

5.2 Phase One: Research Questions

There are two questions driving the first phase of this study:

1. What are the 'baseline' experiences and opinions of the GPM from the perspectives of patients, PIPs and staff?
2. What are the priorities for change within this experience?

Question one will be addressed directly in the methods used, whereas the answers to question two will become more apparent through analysis of the data collected.

5.3 Phase One: Method Summary

Phase One will consider eight GPM's (of eight different patients) as case studies for investigation. This sample size was chosen for feasibility to complete within 1 month by a single researcher whilst still being large enough to include a variety of patient situations (i.e. injury level, time spent on the rehabilitation ward, etc.). The experiences of patients, PIPs and staff members will be triangulated using a mixed-methods approach, including; ethnographic observation and note-taking during the GPM; audio recording and conversation visualisation of the GPM; and semi-structured interviews with the patient, PIP and key worker after the GPM. These methods are described individually in more detail below.

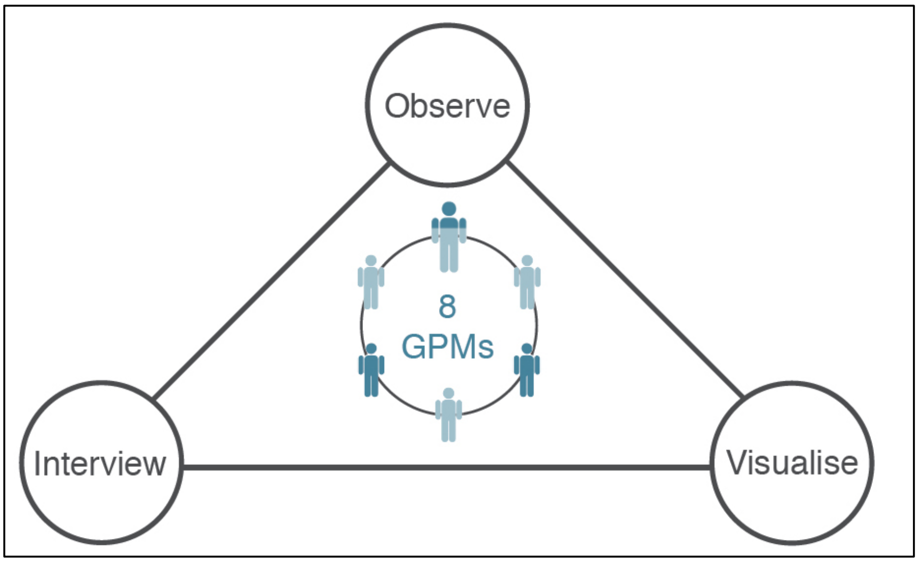


Fig 5.1: A representation of the mixed-methods approach used to investigate multiple experiences of the GPM.

5.4 Phase One: Method 1: Observations

After recruiting the patient and asking permission of the staff and PIPs involved, (see section 5.8 below), the researcher will passively observe the GPM, sitting in the back of the meeting room to minimise the influence of her presence. During these observations, the researcher will take notes and/or on any perceived barriers or bridges to patient participation in the meeting displayed by any of the meeting participants. This may include behaviour, speech, tools used, body language, etc. An observation matrix was developed for this purpose, however after trialling this in a GPM (not included in the Phase One results), it was found to hinder rather than assist the researcher's note-taking. So, a more ad-hoc approach will be taken to note-taking instead.

5.5 Phase One: Method 2: Questionnaire-led, Semi-Structured Interviews

5.5.1 Questionnaire Content

The patient, PIP and key worker will be invited to a semi-structured interview after the GPM, guided (but not dictated by) a questionnaire developed by the researcher. The content of the questionnaire has been developed so that it can be comfortably delivered between 60-90 minutes, to avoid causing patient fatigue with too long a discussion. The questionnaires are tailored to each group, yet similar enough to compare perspectives (see appendices 10-12). As well as asking for non-identifiable demographic data (such as age, injury level, number of GPMs attended to date), the questionnaire uses a mix of open-ended, Likert-scale, tick-box and diagrammatic questions, informed by a range of key sources:

- Bate and Robert (2007) encourage researchers to invite participants to give short narratives of their experience, rather than ask if they were satisfied with a particular aspect of it. This goes beyond simple open-ended questions, and allows participants to set the agenda for the discussion, which the researcher can then probe with related questioning. Additionally, their definition of 'experience' of a product or service (quoting Alben, 1996, as 'how well people understand it, how they feel about it while they are using it, how well it serves its purpose, and how well it fits into the context in which they are using it') has been used to structure the different sections of the questionnaire.
- The review of Goal Planning literature has been essential in understanding how the host SIU's GPM structure relates to that of other units. This has inspired questions that address patient/PIP knowledge of their short-term and long-term goals, as well as perspectives on the progress made towards them.
- The medical literature states that not all patients want full participation in their healthcare all of the time (Baker et al., 2001). As such, it is important to discuss

not only the level of participation perceived by the patient, PIP or key worker, but also how satisfied they are with it and, if applicable, what they might prefer.

- The Design literature has highlighted the importance of understanding the GPM within the wider rehabilitation system, and the agency that objects as well as people can have in an interaction. As such, the questionnaire also addresses the meeting environment and its effect on the rehabilitation journey more generally.
- From the contextual review, it was observed that one purpose of the GPM appeared to be the transfer of information, and that some staff members were concerned about the language used in doing so (such as the use of FIM scales to communicate progress made). Expectations and perceived aims of the meeting are also addressed in the questionnaire, as the contextual review highlighted some disparity between patient and staff views of this. Some of the themes that emerged from the Diagrammatic Exploration of the contextual review could also be explored further, and are exemplified in the diagrammatic questions shown below in figures 5.2 and 5.3:

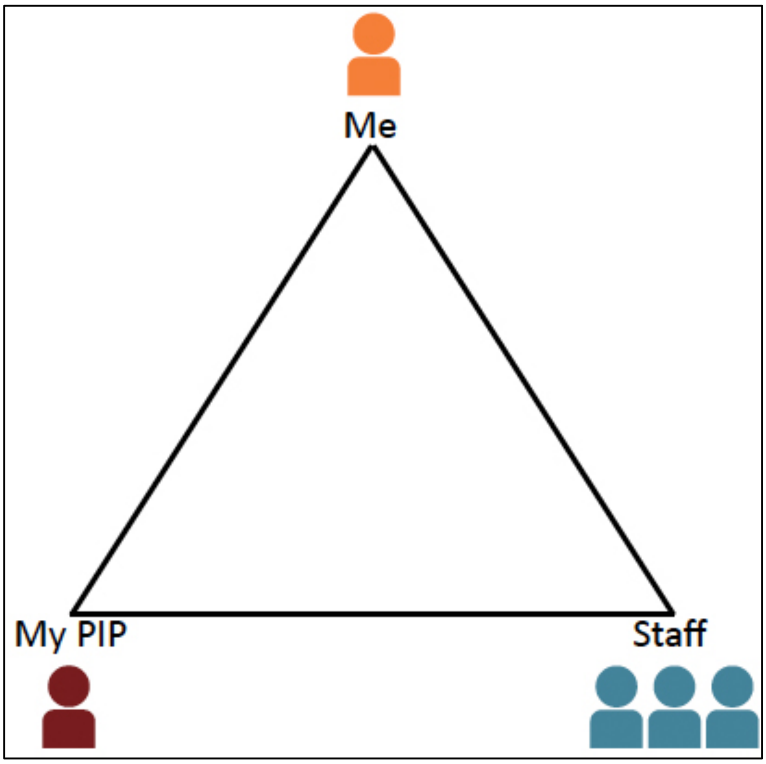


Fig. 5.2: One diagrammatic question that asks participants to show who they think is involved, or who has most influence over, decision-making in the GPM. As well as indicating where they think decision-making happens currently, they will also be asked where they would prefer it to happen, if they could change it.

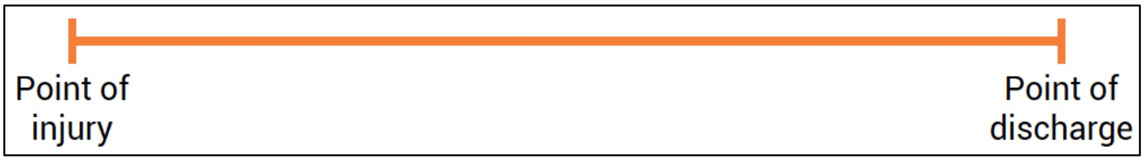


Fig. 5.3: A diagrammatic question that asks participants to indicate how much progress they think they/the patient has made in their rehabilitation journey.

Both diagrammatic questions are arguably able to show nuance in opinion whilst being able to clearly compare the perspectives of patients, PIPs and staff members. It also encourages participants to explain their perspective, rather than simply state whether they are satisfied or not, and introduces a future-focussed element to the discussion. It is important to remember that some patients with higher level injuries (and as such, with limited dexterity) may not be able to draw on the diagrams themselves. In these cases, the researcher will slowly move a pen in the diagram area until the patient tells her when to stop and make a mark.

5.5.2 Questionnaire language

Fitzpatrick and Hopkins describes how, in healthcare-led research approaches, patients generally prefer not to use 'attitudinal language to describe their views' such as the terms 'satisfied' or 'dissatisfied' (1993, p82). They expand upon this by suggesting that 'normative effects' can be avoided by using language that reflects 'more natural ways in which respondents might talk about their health care' (p8). So, whilst the language used in the questionnaire maintains a level of objectivity, it also draws on the researcher's experience of how patients and professionals discuss SCI and the associated rehabilitation processes. The semi-structured, informal nature of the questionnaire-led interviews will also encourage more natural modes of discussion.

In addition, the term 'engagement' was used more frequently in the questionnaire language, as the researcher's experience in the contextual review suggested that this was more widely used and understood by the SIU community. As discussed in section 2.3, patient 'participation' can be considered a more active or interactional form of patient 'engagement', and whilst the former remains the core focus of this study, the broader term of 'engagement' was used to capture more nuanced accounts of the SIU community's experiences.

5.5.3 Questionnaire format

Thompson describes how ‘the public should be listened to for establishing the domain of concerns but also they should indicate the relative weight to be given to components of care,’ (1993, p26). Other authors in the medical literature also describe the importance of patient priorities, but little advice is given on how to establish this (although some design-led examples do exist, see the Talking Mats© system). Although several studies and reviews exist in the medical literature that aim to establish patient priorities for recovery to retrospectively inform SCI research and/or healthcare delivery (Simpson et al., 2010 and Bragge et al., 2015), literature concerning patient perspectives on and priorities for the rehabilitation process itself is not as forthcoming. As such, the questionnaire topics will be printed onto separate A4 pages, which the participant can then order in terms of highest-lowest priority for change at the end of the interview.

5.5.4 Questionnaire validity

Iteration is important in developing a survey (Fitzpatrick & Hopkins, 1993, p8), and after several redrafts of the questionnaire, specialist staff (both the healthcare- and design-based supervisors) were asked to review it for face validity (i.e. how well it appears to address its aims, as recommended by Baker et al., 2001). Fitzpatrick provides further detail on methods of establishing content validity and criterion validity (1993, p10-11), but as the questionnaire has exploratory intentions rather than being used as a scientific measure of effect, supervisory review (and review by the University Ethics Committee, see section 5.23) is considered sufficient.

5.5.5 Questionnaire delivery

As mentioned above, the questionnaire-led interviews will be conducted in a semi-structured, informal, conversational style. A less rigid approach such as this facilitates expansion on the answers given. This creates a space to ‘uncover the “but” part of answers’ (Baker, 1993, p58) and to try to understand how views are formed.

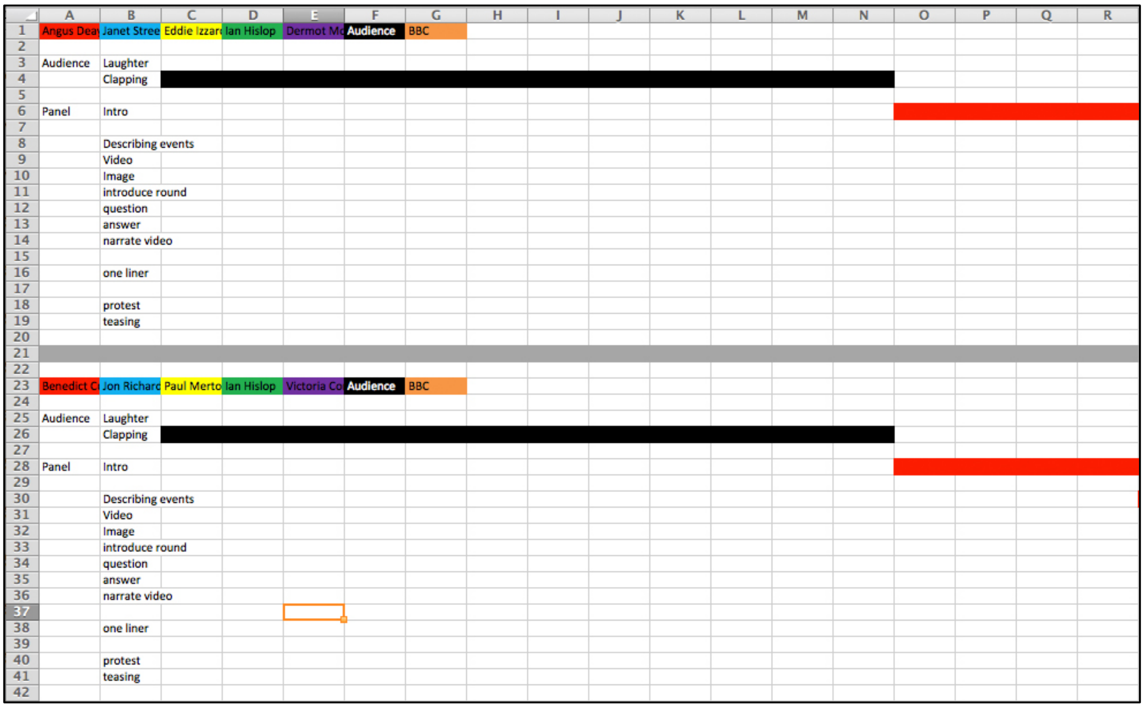
Wherever possible, PIP interviews will be scheduled first (as they may have travelled specifically to attend the GPM), followed by the patient (to avoid allowing too much time to pass between the GPM and reflection on it) and then the key worker (who are often only available at the end of the working day, or may choose to self-complete the questionnaire).

The literature emphasises the importance of guaranteeing participant confidentiality (Fitzpatrick, 1993, p8, Pryce-Jones, 1993, p89), so a ‘safe’ space is needed in which to conduct the questionnaire-led interview. Permission will be sought to use the conference room in which the host SIU conducts all of its GPMs, as ‘clinical rooms should be avoided,’ when carrying out research activities such as this (Pryce-Jones, 1993, p91). Additionally, using the same environment where the GPM took place may aid reflection on the participants’ experience of it, as described in Participatory Design literature (Simonsen and Robertson, 2013).

5.6 Phase One: Method 3: Visualisations of the GPMs

Each GPM will be audio recorded to evidence observations and inform the GPM visualisation method. After all the GPMs have been observed and recorded, a selection of three (one patient’s first GPM, one patient who has had more than one GPM, and one patient’s final GPM) will be thematically analysed (discussed in section 4.8.5). The conversation in each GPM will then be (separately) visualised on a graph, using the emergent thematic framework along the y-axis and time along the x-axis. In this way, each participant’s contribution to the conversation can be anonymously mapped in terms of what they were discussing and for how long. By giving each participant a different colour, the interaction between participants can be somewhat objectively represented and shared.

This visualisation method was trialled using publicly available audio of multiple people speaking together (see figures 5.4 and 5.5 below). It was found feasible and potentially useful (showing a repeating pattern in conversation which wasn’t noticed by simply listening to the audio) but also time-consuming. This provided a rationale to apply this method to a limited selection of the GPM audio gathered.



	A	B	C	D	E	F	G
1	Angus Dea	Janet Stree	Eddie Izzar	Ian Hislop	Dermot Mc	Audience	BBC
2							
3	Audience	Laughter					
4		Clapping					
5							
6	Panel	Intro					
7							
8		Describing events					
9		Video					
10		Image					
11		introduce round					
12		question					
13		answer					
14		narrate video					
15							
16		one liner					
17							
18		protest					
19		teasing					
20							
21							
22							
23	Benedict C	Jon Richard	Paul Merto	Ian Hislop	Victoria Co	Audience	BBC
24							
25	Audience	Laughter					
26		Clapping					
27							
28	Panel	Intro					
29							
30		Describing events					
31		Video					
32		Image					
33		introduce round					
34		question					
35		answer					
36		narrate video					
37							
38		one liner					
39							
40		protest					
41		teasing					
42							

Fig. 5.4: Two examples of the pilot conversation mapping visualisation, showing the themes and people involved, for demonstration purposes and not representing any data collected. The audio represented here was collected from two episodes of the BBC series ‘Have I Got News For You,’ last accessed 2015 at https://www.youtube.com/watch?v=-hrLgu7nr_c and https://vimeo.com/58296976. Themes (along the y axis) are consistent but the people involved change between the two examples.

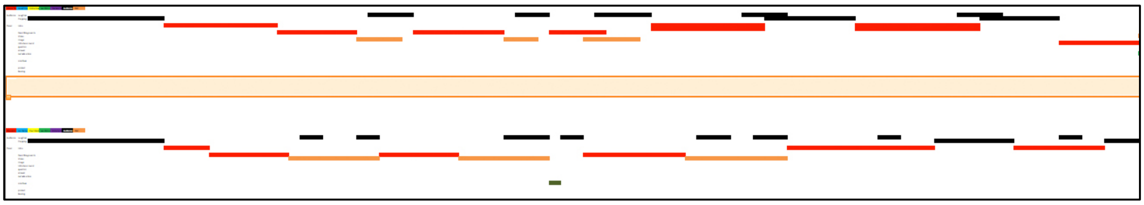


Fig. 5.5: The full maps of approximately 2 minutes of audio described in fig. 5.4.

The visualisations above suggest that most episodes of ‘Have I Got News for You’ follow a similar pattern in the first 30 seconds of the show. Perhaps, then, analysing the audio data of the Goal Planning Meeting in this way may also reveal or evidence patterns in communication.

Several other software programs were trialled to create the conversation visualisations, such as NVivo. A search was conducted for other software created for similar purposes, (with only one result of note, see Angus et al., 2012), but Microsoft Excel (used in the examples in figures 5.4 and 5.5 above) was found to be the easiest, quickest and most flexible option available.

It must be stated that some researcher bias may be present in terms of creating the thematic framework, but it is hoped that transparency in how this is created will mitigate this. Although the visualisation of the GPM audio will be conducted by the researcher, both design- and healthcare-based supervisors will be consulted to check the emergent thematic framework and the results of the visualisation.

5.7 Phase One: Patient participant inclusion criteria

Patient, PIP and staff input into Phase One can be seen in fig. 5.6 below.

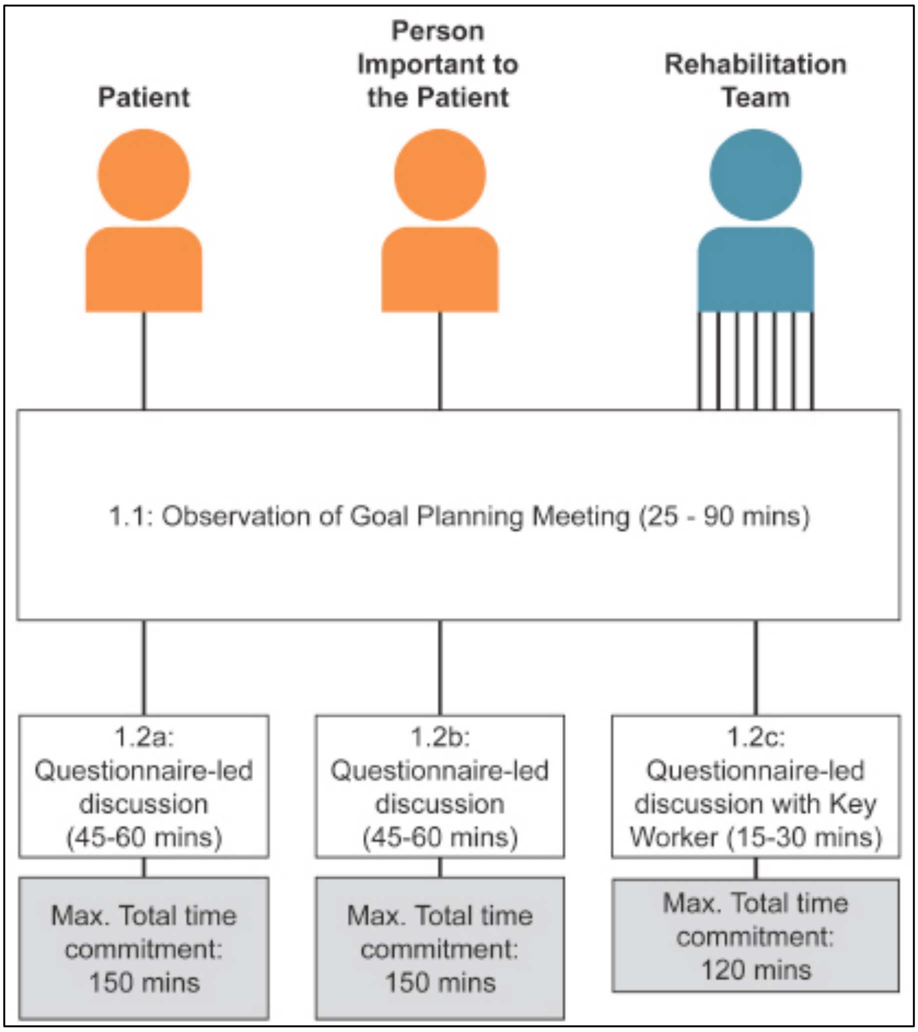


Fig. 5.6: A flow chart of patient, PIP and staff input into Phase One of this study design, as used in the participant information letters.

There are many variables that may affect a patient’s experience of the GPM, outside of personality types. Phase One will attempt to include patients across a range of the following categories (listed in order of priority), although this will be dependent on the inpatient population during the one-month window allocated to conduct Phase One:

- Rehabilitation progress: the study will aim to recruit an even spread of patients in their first, middle and final GPMs.
- Injury Level: According to McCaughey et al. (2015), the majority of injuries in the host SIU are at a cervical level (66.3% between 2009 and 2013), so if possible more than half of the patients recruited should have higher level injuries to reflect the host SIU population.
- Age: McCaughey et al. (2015) state that the average age of the host SIU patients has increased in recent years, with more older patients being admitted due to falls. As such, a higher proportion of older patients should be recruited if possible.
- Gender: Over their 20-year study, McCaughey et al. (2015) found that the ratio of male to female patients being admitted to the host SIU remained relatively stable at approximately 3:1, so if possible, this study should aim to recruit a similar gender distribution.

It is important, particularly in this initial phase of the study, to recruit patients within a range of the variables described above, but also with a range of attitudes to the rehabilitation process (something far less measurable). Doing so may go some way to addressing the issue of patient bias, as it could be assumed that the patients who are more amicable to take part in a research study could also be more motivated to actively participate or have positive experiences in their rehabilitation. As Pryce-Jones suggests, it may be important to make participation in research activities as easy as possible to encourage the majority of patients to take part in the survey, not just the motivated population (1996, p96).

5.8 Phase One: Approach to recruitment

5.8.1 Viable sample size

Up to ten GPMs (with associated observation, interviews and audio recording) will be attended to account for the potential for some patients to withdraw their participation at a later date, with the intention of obtaining at least 8 full case studies.

Within each GPM, interviews with the patient and their key worker are necessary to consider it a full case study. Interviews with PIPs will be sought wherever a PIP attends the GPM, but they are not deemed necessary to consider the GPM as a valid case.

5.8.2 Scheduling

Clearly, it is vital that this research does not interfere with the patient or key worker rehabilitation schedules, so they will be free to choose the best time for their interview (ideally as soon after the GPM as possible). With this in mind, key workers will be given the option to attend a semi-structured interview, or to take the questionnaire away with them to fill in when they choose (with the researcher's contact details in case they have any questions).

5.8.3 Recruitment Process

The participant inclusion criteria listed in section 5.7 above will be used to guide a discussion with a staff member who arranges every GPM in the unit. Through this initial discussion, ten GPMs (of different patients) across a one-month period will be identified as potentially suitable to capture a range of GPM experiences. This list will be taken to the co-supervisor, a consultant in the host SIU, for approval. Once approved, the co-supervisor will act as gatekeeper to the SIU community, and introduce the researcher to the identified potential patient participants. During these introductions, the researcher will arrange a convenient time with the patient to return and explain the project more fully. During this second meeting, if the patient is interested, the researcher will provide an information letter to read in their own time, as well as a copy of the consent form they will be asked to sign if they agree to take part. A separate information letter and consent form will also be given to the patient to pass on to their PIP, if the patient feels the PIP may also be interested. The researcher will then return to the patient (and PIP, if possible) 2-3 days later to answer any questions, and sign the consent forms if they agree to participate.

5.9 Phase One: Data Collected

A range of quantitative, qualitative and visual data will be gathered that aims to triangulate the GPM experience from patient, PIP and staff perspectives. By its nature, experience data is subjective, although the visual representation of the GPM conversation aims to give as objective a view as possible of the conversations within it.

5.10 Phase One: Analysis

As a mixed-methods approach is being used to explore the GPM experience, several methods of analysis will also be required.

5.10.1 Observations

The researcher will collate and summarise the notes taken during the GPMs observed, to highlight any common or influential barriers or bridges to participation. It is important to highlight what is working as well as areas that could be improved.

5.10.2 Interviews

Answers to open-ended questions will be collated and summarised by question in patient, PIP and key worker groups according to the process described in section 4.8.5. Likert-scale, tick-box and diagrammatic questions will be compared within the individual GPM cases to highlight any aspects of the GPM where perspectives diverge.

5.10.3 Visualisation

Once thematically analysed and visually mapped, the GPM conversation visualisations will be condensed and printed to look for patterns in communication that may highlight priorities for change. For example, the conversation may follow a repeating structure, or certain staff disciplines may focus more on certain topics, etc.

5.10.4 Experience Goals

Both thesis supervisors will then be invited to meet together with the researcher to discuss, develop and/or corroborate any conclusions drawn from analyses, from both design and healthcare perspectives. From these conclusions, or priorities for change, 3-5 Experience Goals (as described in section 4.9.2) will be established to take forward into the next stages of the study. Given the experience of both supervisors in their respective fields, and the long-term immersion of the researcher in the SIU context, these Experience Goals will certainly achieve the ‘good enough’ status needed to proceed (see section 4.4.2).

Although this may not be considered a ‘participatory’ method of deriving the Experience Goals, the data informing them comes from across the SIU community. It is arguably necessary to afford the researcher the authority to make decisions such as this in order to maintain momentum in a healthcare-based project, and to capitalise on the limited contact time available with patients, PIPs and staff in the following stages of the study.

5.11 Phase Two: Research Questions

As in Phase One, two interdependent research questions drive Phase Two of the study:

1. How can outpatients, inpatients, PIPs and staff be engaged in a co-design process?
2. What new or enhanced material or process can be introduced to the Goal Planning Process to potentially support patient participation within it?

With this in mind, the data collected in Phase Two concerns the process and outcome of co-design activities with and within the SIU community.

5.12 Phase Two: Method

5.12.1 Initial Prototypes

Before conducting the workshops, the researcher will generate 3-5 initial paper-based prototypes that each embody one or several of the Experience Goals. They may do so by facilitating different patterns of communication or perhaps by making some aspects of the GPM conversation more tangible (i.e. recording information that is commonly forgotten or misunderstood), depending on the issues highlighted in Phase One. As discussed in section 5.10.4, the researcher is given authority to create these initial prototypes in this study independently in order to maintain momentum in the study. These initial prototypes will be deliberately simple in format to encourage open interpretation by the SIU community, and as such they can be considered physical embodiments of potential design directions emerging from the Phase One data, rather than extensive design work conducted independently by the researcher.

5.12.2 Workshop Participants

The structure of the co-design workshops, and who is involved when, is best shown in the flow chart used in the participant information letters (see fig. 5.7 below).

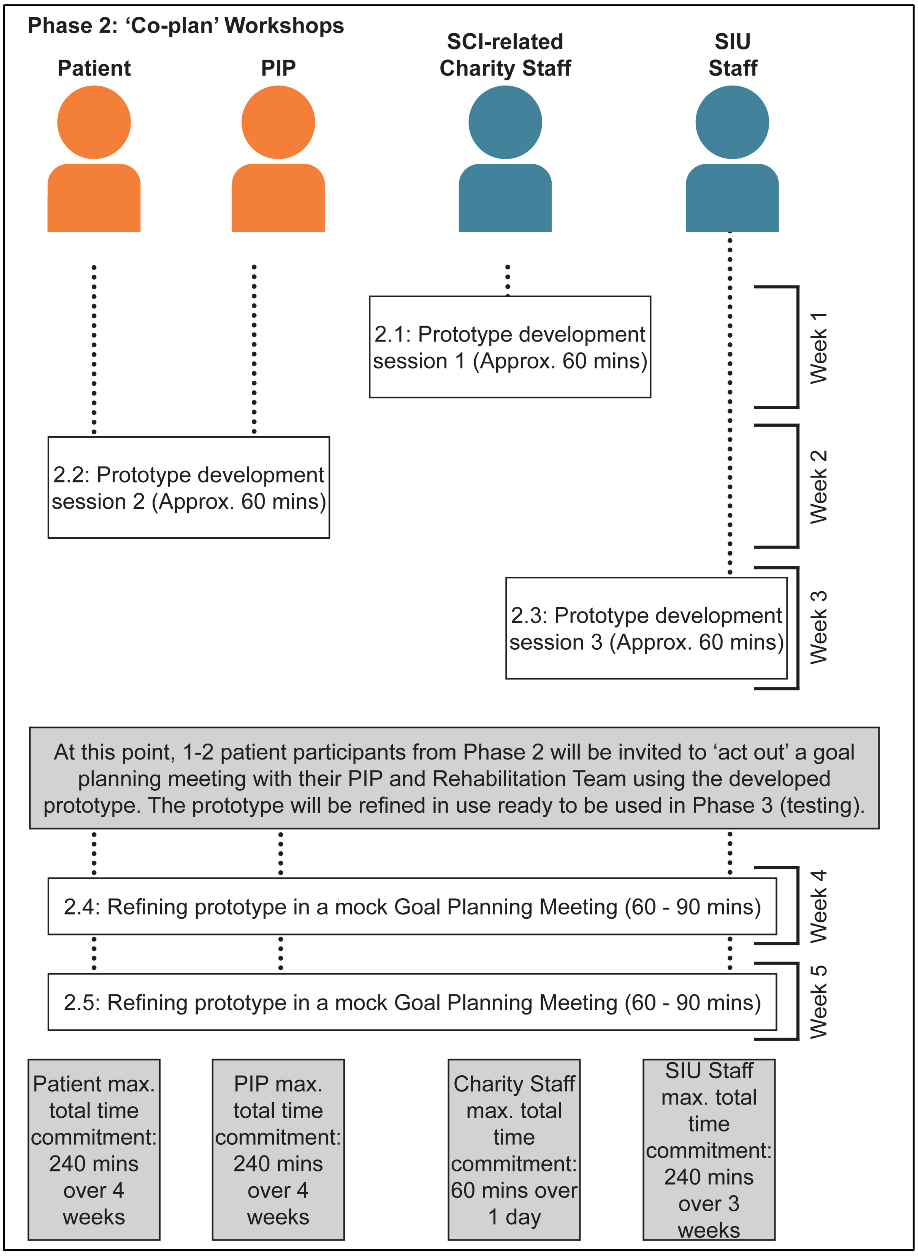


Fig. 5.7: Flow chart demonstrating how and when the SIU community will be involved in the co-design workshops. Two sessions have been dedicated to refining the prototype (2.4 and 2.5) to potentially include input from greater numbers of participants (due to the high demands on staff and patients' time, greater attendance may be facilitated by providing two opportunities to participate).

As can be seen above (and discussed earlier in this thesis) prototype-led workshops will be used to allow the SIU community groups (i.e. outpatients, inpatients and staff) to collaborate whilst preserving anonymity and therefore protecting continuing working relationships. In this way, the SIU community can speak its mind in the initial workshops (potentially including contradictory voices), when conversations may still critique the current rehabilitation process, then come together towards the end of the process when activities focus more on refining the new intervention.

The order of the initial workshops represents a desire to establish what is wanted from the (often less vocal) patient group in the intervention first, before then moving on to incorporate staff desires and practical knowledge of how to make the intervention work in the rehabilitation process. The first workshop will involve outpatients only (through established contacts with a spinal injury charity) to gather hindsight experience (i.e. ‘this would have been useful back then,’) and also to vet the initial prototype proposals before introducing them to the (arguably more vulnerable) inpatient group. Prior experience working with the charity staff in the contextual review for this thesis suggests that they will be comfortable explaining to the researcher (without taking offence) if any of the concepts seem inappropriate or not useful.

5.12.3 Workshop Structure

As discussed above, the workshops themselves will be led by the discussion and development of prototypes. The activities and materials to support this will be designed week by week, reacting to the input of the SIU community. Decisions on the structure of each workshop will be based on the form of the prototype by the end of the previous session, as well as from notes or conversation during the previous session that is not directly embodied in the physical prototype. Activities to meet these emergent needs will be drawn from a prepared catalogue of tools and materials (described below) that aim to help participants explore, interact with, edit or ‘perform’ the prototype, as well as how to consider it within the rehabilitation context. These activities aim to help participants to consider ideas as changeable, and to encourage non-committal or ‘playful’ engagement with the prototypes to elicit their vast experience and tacit knowledge. This may be particularly useful for staff groups, considering their aversion to ‘making marks’ in the diagrammatic exploration activity in section 2.10.

The catalogue of tools described above can be split into two categories (although there may be some crossover between the two); tools to aid creative thinking and tools to edit the prototype itself.

5.12.4 Tools for creative thinking

Although it is assumed that the workshops aim to create a new process or material to introduce into the GPM, successful development of the prototypes will require participants to consider its use within the wider rehabilitation system. As such, tools such as ‘A Day in the Life of...’ (where participants are asked to consider a patient’s or staff member’s daily routine) or a service journey map (as commonly used in EBCD and other service design approaches) could be useful.

The way in which the prototype is presented may also help the creative process within the workshops. For example, a new information sheet could be presented not as a printed material (suggesting the content is already decided) but as a toolkit, with types of information presented as separate, physical components for participants to sort through, prioritise and place into the prototype. Given the limited dexterity of some participants, these ‘components’ may be easier to manipulate if mounted onto foamboard. This ‘components’ approach could also be applied to current GPM materials (such as the Goal Planning Checklist), so current knowledge and resources can be drawn upon without being influenced by their current rigid structures. In ‘toolkit’ activities such as these, where no permanent marks are made, photographs must be taken to capture the results of the participants’ efforts.

A collection of miscellaneous materials will be collected and brought to each workshop to facilitate ad-hoc, rough representations of ideas or interactions (see fig. 5.8 below), such as Lego™ figures (to act as ‘player pieces’), chocolate coins (perhaps to explore ideas of progress rewards), modelling clay (to consider 3 dimensional concepts), coloured yarn (to visualise connections), and so on.

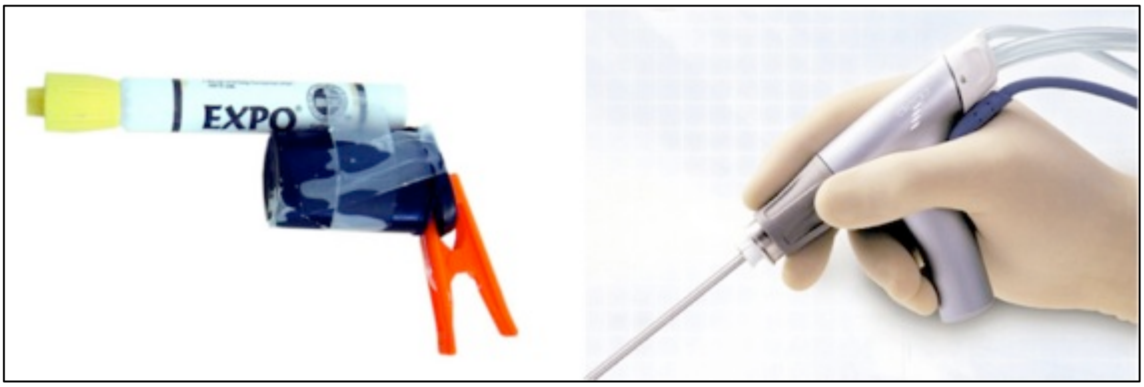


Fig. 5.8: A side-by-side comparison of a rough prototype generated by IDEO, a design and innovation consultancy, in consultation with a group of surgeons, and the final product it led to (images taken from Suzuki, 2010, see tinyurl.com/y86rw4mw).

Posters of the Experience Goals derived from Phase One will also be displayed in each workshop and used to guide or evaluate idea development whenever necessary.

5.12.5 Tools to edit the prototype (in real time)

It is important that the co-design activities do not unintentionally cause embarrassment or highlight the difficulties that some patients may have with dexterity. As such, ballpoint pens have been chosen for their resistance to bleeding through the paper (i.e. if held in one spot for too long) and crayons that did not look child-like, as they do not require much pressure to make a mark, have been sourced.

A collection of props may also be useful to edit or act out the prototype, such as ring binder folders, clipboards, computer tablets, etc.

5.12.6 Documenting the workshops

Each workshop will be audio recorded (if consent is granted by all participants) and handwritten notes will be taken by the researcher of any points made by participants that cannot be immediately embodied in the prototype. After each workshop, the researcher will reflect on the session's activities and the participant's engagement with them, taking handwritten notes to evaluate the process each week. These notes on the co-design process will be gathered and summarised concurrently, but separate to, the co-design outcome.

5.12.7 Role of the researcher

An emergent and reactive workshop structure such as this requires the researcher to adopt the roles of facilitator (of the co-design activities) and synthesiser (of the multiple views expressed during the activities). As such, the researcher must be prepared to be very much 'in the moment' and reactive to the needs expressed by participants, as well as any needs that are not verbalised (for example, if a patient displays signs of distress at the conversation topics or physical fatigue).

Whilst remaining 'in the moment' the researcher must also be able to maintain a critical distance to the co-design activities in order to reflect upon their effectiveness at a later stage. As it will likely be difficult to maintain a balance between the two perspectives, audio recording and handwritten notes will be crucial during the workshops.

5.12.8 Finalising the prototype

The Experience Goals developed in Phase One will be used as evaluation criteria to decide when the prototype(s) are ready to be tested in use, as well as staff consensus that they are satisfied that the intervention will not cause harm or distress.

5.13 Phase Two: Participant Inclusion Criteria

To represent the outpatient group of the SIU community, staff members from an SCI-related charity will be invited to participate in the study. This is partly for logistical reasons (the staff regularly visit the SIU anyway) and also because the nature of their work indicates an interest in improving services and resources for people who have sustained a SCI. This study will invite outpatient participants who have been discharged from the SIU after initially sustaining their injury for more than 2 years, as several sources in the literature indicate that this can be the minimum period to adjust to life in the community following an SCI (Macdonald, 2013).

For both inpatient and outpatient groups, participant selection will not be restricted or based on their age, gender, occupation or type or level of injury. However, inpatients and outpatients will only be invited to participate if they are medically stable and not undergoing heightened emotional distress at the time of the workshop.

There are no exclusion criteria for staff or PIP participants, providing the latter are not undergoing heightened emotional distress at the time of the workshop.

5.14 Phase Two: Approach to recruitment

All participants will be approached individually by the researcher, rather than using generic recruitment methods such as posters or blanket emails. This is to ensure participant numbers are manageable, to convey a more personal approach and to address any uncertainties potential participants may have about the workshop content.

5.14.1 Outpatients

Previous work with the spinal injury charity during the contextual review and informal, ad hoc contact within the SIU has established contact with potential outpatient participants. Senior staff (n=2) will act as gatekeepers to any other charity staff members who wish to participate in the workshops. The workshop with outpatients aims to recruit a minimum of 2 and maximum of 5 participants.

5.14.2 Inpatients

As in Phase One, the co-supervisor will act as gatekeeper to the patient population, although patients already familiar with the study will not need to be re-introduced to the researcher. These patients who have already been involved in Phase One (if they are still an inpatient at the time of the workshops) will be given first refusal on attending the inpatient workshop. This workshop with the inpatient group aims to recruit a minimum of 3 and maximum of 6 participants.

5.14.3 PIPs

Inpatient participants will act as gatekeepers to their own PIPs, as they will be asked to invite the PIP and pass on information letters on behalf of the researcher during visiting hours (as in Phase One). Because of this, the maximum number of PIP participants matches that of inpatients (n=3-6).

5.14.4 Staff

Due to the researcher's long-term immersion in the SIU, she will approach potential staff participants individually. If the co-supervisor feels that certain staff members who aren't familiar with this study would offer particularly useful contributions the workshops, she will act as gatekeeper to introduce the researcher to them.

5.15 Phase Two: Data Collected

The tacit knowledge and desires of participants (as service deliverers and receivers) will be embodied in the iterative developments of the prototypes. Additional notes will be taken if the information given by participants does not relate to specific changes to the prototypes (for example, further commentary on the current rehabilitation process).

Separate to the commentary on the output of the design process, the researcher will maintain a reflective account of the co-design process to evaluate the effectiveness of the activities chosen.

5.16 Phase Two: Data Analysis

The main output of the co-design workshops, the intervention, will be analysed by testing it in use.

By the end of the series of workshops, the researcher will be able to collate and summarise the notes taken after each workshop to draw some conclusions on effective methods to engage healthcare communities in collaborative service development projects.

5.17 Phase Three: Research Questions

Phase Three represents a more traditional 'test and evaluation' style of research, with 'baseline' data from Phase One being used to judge if a positive effect has been made through use of the intervention. As such, two final questions lead this phase of the study:

1. What effect (if any) does the intervention have on the patient, PIP and staff experiences of the GPM?
2. Does this effect, if present, address the Experience Goals generated in Phase One?

5.18 Phase Three: Method

The co-designed intervention will be tested in use in the rehabilitation pathway of three patients. As the form of the intervention is not yet known, the only detail that can be planned at this point is that the new or enhanced process/materials will be used in 2 consecutive GPMs of each patient. If certain staff members are responsible for delivering or facilitating the intervention, the researcher will arrange a meeting with them between the first and second GPM, to give staff an opportunity to feedback (which Bate and Robert term 'formative evaluation', 2007, p156) and make minor changes if necessary (a form of 'design after design', Björgvinsson et al., 2012).

The methods used to explore the GPM experience in Phase One will be repeated after the introduction of the intervention in Phase Three, in order to gather comparable data. This includes:

- Ethnographic observation, note-taking and rough sketching in all six GPMs (two GPMs per patient). As before, particular attention will be given to perceived barriers and bridges to participation, as well as direct use of or reference to the intervention.

- Audio recording of all six GPMs and visualisation of the conversations in the second GPM (when participants are more familiar with the intervention) using the same thematic framework as Phase One.
- Questionnaire-led, semi-structured interviews with the key worker, Patient and PIP (where possible) after the second GPM. The majority of questions from Phase One will remain unchanged, particularly the diagrammatic and Likert-scale questions, to facilitate clear comparisons between Phase One and Phase Three data. New questions may be added if the development of the prototype requires new measures of experience. Specific questions relating to the co-design approach will be included in the staff questionnaires, drawing on the work of Bate and Robert (2007), such as ‘how would you describe what you and others have been doing to someone who did not know about it?’ or ‘were there any points in the project that made you feel sad, mad or glad?’ (p169).

5.19 Phase Three: Participant Inclusion Criteria

SIU community involvement in Phase Three is planned as follows:

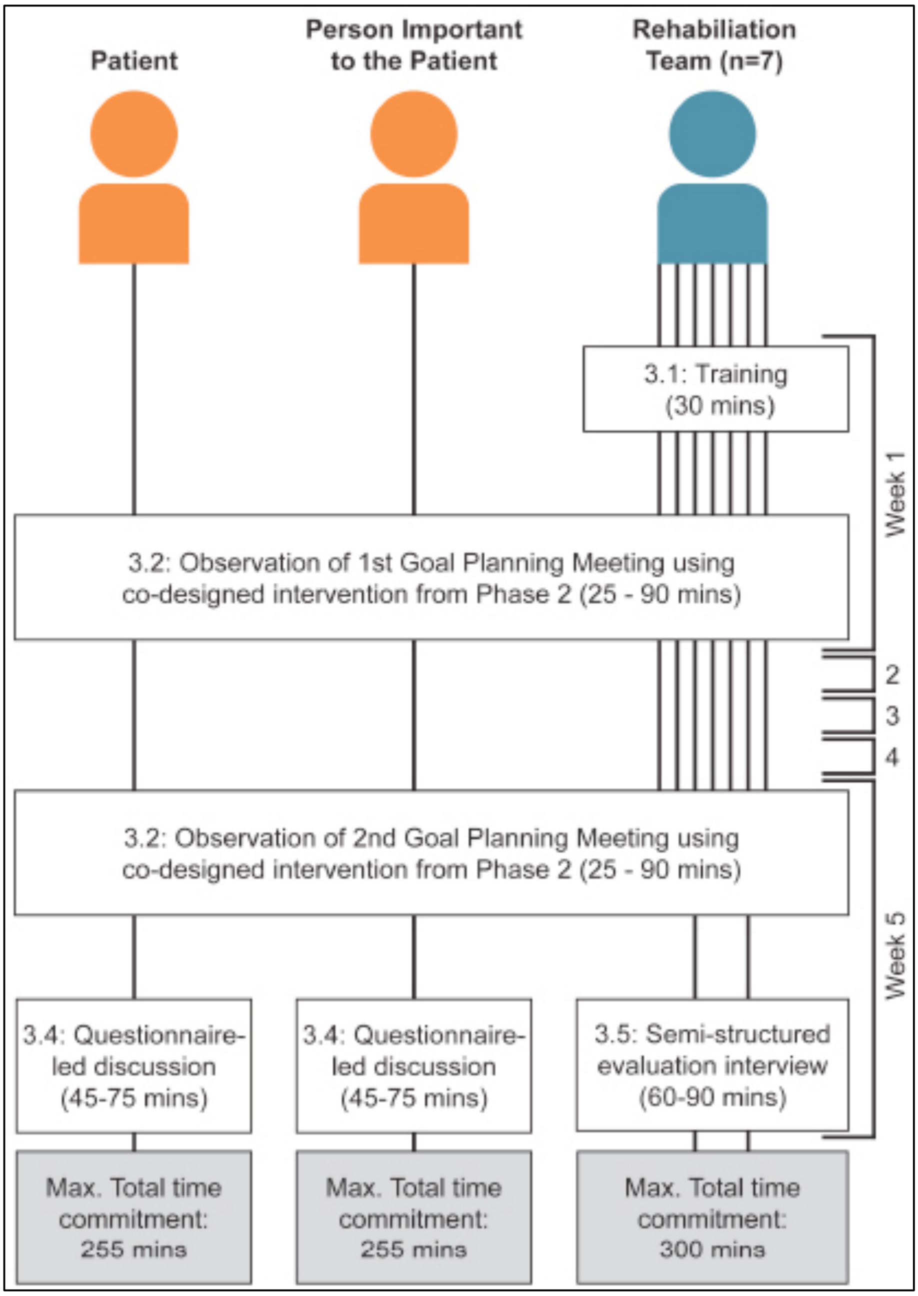


Fig. 5.9: A flow chart depicting staff, patient and PIP involvement in Phase Three of this study (as much as can be planned prior to the co-design of the intervention). It is important to note that the participants would be attending the GPM sessions regardless of the study, so the actual additional time commitment outside of the standard rehabilitation pathway is due to the staff training and post-GPM interviews.

Patient participants must be medically stable, aged between 16 and 80 years old and not undergoing heightened emotional distress at the time of intervention. If the patient develops a medical or emotional complication during the testing period, the intervention activities will be delayed if possible or discounted.

The key workers and rehabilitation team members involved in the study will be dictated by the prior recruitment of patient participants, although several senior staff members (who have been involved with this study from the beginning) hope to be available to take the key worker roles.

PIP participants will be dictated by prior recruitment of patient participants; however, their participation is entirely voluntary and not necessary to make a complete case study.

5.20 Phase Three: Approach to Recruitment

As mentioned above, three patients will be recruited during Phase Three of the study with two patients considered the minimum viable number to discuss the initial effects of the intervention. Greater numbers of patients will not be recruited in case of further patient withdrawal, as three patient cases will already likely require a significant time commitment from staff, as well as from the researcher (to conduct observations and interviews). As the risk of medical complications is high in SCI patients, a generous amount of extra time will be allocated to complete Phase Three, in the event of GPMs being delayed by, for example, a patient developing a pressure sore.

Although there will be a limited number of patients suitable and available for recruitment into Phase Three (due to the limited time allocated to conduct it), it is hoped that some similarity will be able to be maintained across the three patients, such as gender, or whether they have a tetraplegic or paraplegic injury. By exercising some management over the variables within the testing group some general conclusions may be able to be drawn about the effect of the intervention. Although this cannot be guaranteed, it is worth attempting to enhance the robustness of the study wherever possible.

Patients and PIPs will be recruited using the same method described in section 5.8.3 for Phase One, with the co-supervisor once again acting as gatekeeper to the patient population. Again, the researcher’s familiarity with the SIU’s rehabilitation staff will allow for direct staff recruitment once the patient participants have been identified.

5.21 Phase Three: Data Collected

As in Phase One, a range of quantitative, qualitative and visual data will be gathered that aims to triangulate the GPM experience from patient, PIP and staff perspectives. As before, visualisation of the conversations within the GPMs aims to create as objective a view as possible of the interactions between meeting participants. Additionally, staff experiences of the co-design process will be explored to support future development of this research approach.

5.22 Phase Three: Data Analysis

An integrated approach to qualitative data analysis will be applied to the transcriptions ethnographic observations and qualitative interview data (as described in section 4.8.5 and appendix 1). As in Phase One, visualisations of GPM audio recordings will be generated (of each patient's second GPM), as well as visual comparison of Likert-scale and diagrammatic questions within each patient case (to establish any divergence of perspectives in, for example, who is involved in decision-making).

The conclusions drawn from the Phase Three analysis can then be compared with the 'baseline' experience of the GPM established in Phase One, to better understand the effect (if any) of the co-designed intervention. Some of the visual data or analysis can be directly compared before and after the intervention, such as the conversation maps and diagrammatic questions. However, the individuality of each patient's rehabilitation pathway, and their unique perspective of it, cannot be ignored, so these comparisons can only be considered tentative indications of whether the intervention is generally beneficial or not.

5.23 Ethics

Approval will be sought from both NHS-based and University-based ethics boards prior to starting the study (described below).

5.23.1 West of Scotland Research Ethics Service

A summary of the study, including the methods to be used and approximate numbers of participants, was sent to the local National Health Service Scientific Officer (via contact with the co-supervisor). After reviewing the summary, the Scientific officer advised the co-supervisor that the study did not require a full Integrated Research Application System

(IRAS) ethics application, as the project was considered ‘service development’ rather than pure research (see appendix 17). As such, a full ethical application was conducted internally through the host University.

5.23.2 The Glasgow School of Art Ethics Committee

The application forms, supporting study summaries, examples of participant information letters and consent forms can be found at https://radar.gsa.ac.uk/5828. The application was accepted on first submission to the university ethics board (see appendix 18).

In addition to obtaining informed consent (described in section 5.8.3), ethical protocol guided the way the study was conducted in terms of the following main aspects:

- Ensuring participants are aware that they may withdraw their participation at any time, and they are comfortable during all of the study activities.
- Protecting data (anonymising all study materials, and using password protected electronic files stored in locked filing cabinets in hospital premises. Digital materials will be duplicated and securely stored in a similar manner at the university site.).
- Ensuring the link between participant data and participant identity was broken (i.e. using pseudonym names for participants, storing the key to patient identities and their consent forms in a separate place to the data).

As none of the materials used or activities planned in the study carried any heightened danger to the physical or psychological health of participants or the researcher, risk assessments were not necessary.

5.23.3 Ethics Amendments

The ethics department was contacted after Phase One and after Phase Two of the study, when the most appropriate structure for the co-design workshops and intervention became more apparent. Changes to the planned study design were approved on first application (with details available at https://radar.gsa.ac.uk/5828). The results and final structures of the workshops and intervention are described in the following chapter.

Stage Three:

Conducting the main study

06 Phase One Findings

6.1 Introduction

As discussed in section 5.2 of the Study Design chapter, Phase One aims to answer two research questions:

1. What is the ‘baseline’ experience and opinion of the GPM from the perspectives of patients, PIPs and staff?
2. What are the priorities for change within this experience?

A mixed-methods approach will be used to address these questions, including ethnographic observation, visualisation of the GPM audio recordings and questionnaire-led, semi-structured interviews.

This chapter will primarily be of interest to healthcare audiences, as it reveals some new insights into the experience of the GPM. The chapter begins by detailing the process and results of recruiting and scheduling patients, PIPs and staff to participate in Phase One. It will then describe the main findings from each of the methods used and conclude by translating these findings into four Experience Goals, which will inform Phase Two of this study.

6.2 Recruitment

6.2.1 Number of Participants

The findings detailed below are informed by nine GPM cases. The purpose of this chapter is to highlight general insights (evidenced by specific cases) that can be used to inform the development of several Experience Goals, and as such the findings are presented by topic, rather than on a case-by-case basis. Future work could provide further, more specific, insights into the GPM experience by tracking individual patients through the different topics discussed, i.e. ‘Pt.D felt comfortable asking questions but didn’t feel involved in decision-making, why is this?’

6.2.2 Patient Demographics

The majority of patients were male (as reflective of the SIU patient population), across a range of ages as shown in fig. 6.1.

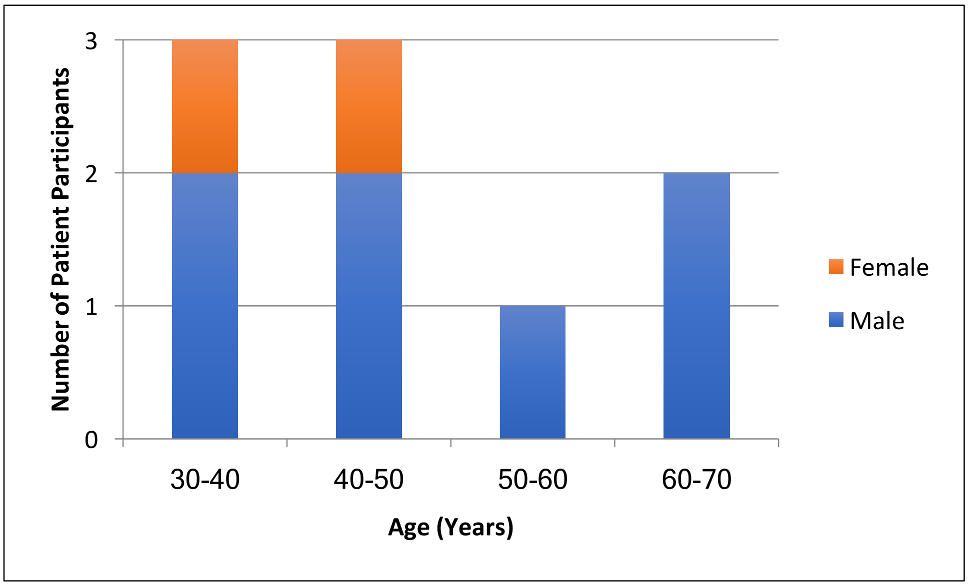


Fig. 6.1: A graph depicting the number of male and female patient participants in each age bracket.

The majority of patient participants in Phase One had sustained paraplegic injuries (n=7) and most were attending their second GPM, as shown in fig. 6.2 below:

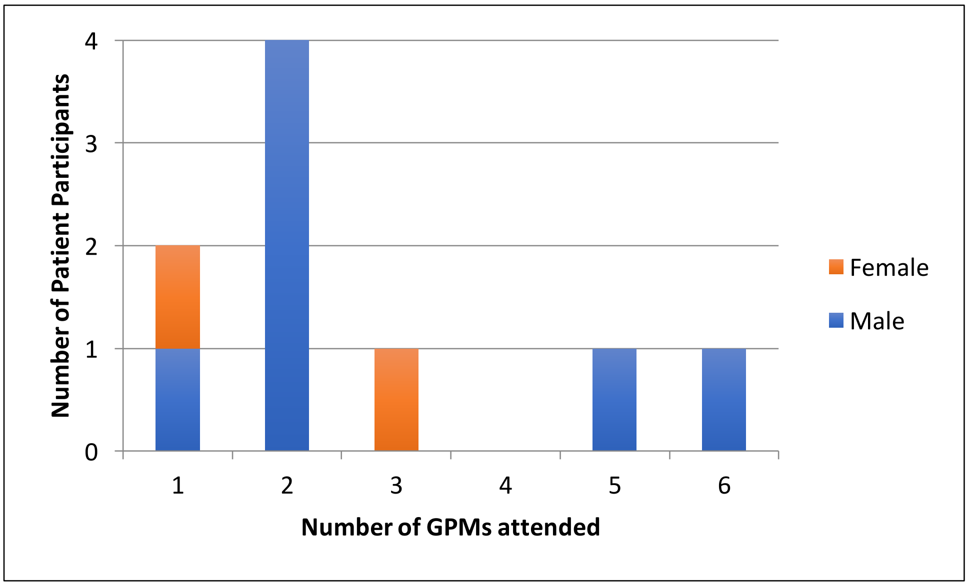


Fig. 6.2: A graph depicting how many GPMs each patient participant had attended (including the GPM observed by the researcher).

Three of the GPMs observed were the patient's final meeting (also known as their Discharge Case Conference). For one patient, this was her third GPM and for the other two patients it was their second GPM.

6.2.3 PIP and Key Worker Demographics

As described in section 5.8.3, PIP and key worker participants were dictated by the patients recruited. Five of the nine GPM cases had a PIP in attendance, all of which were the patient's spouse and all of whom agreed to participant in Phase One of this study. All of the key workers agreed to participate in Phase One and chose to take the questionnaire away to fill in when their schedule allowed. All returned the questionnaire except one.

6.3 Scheduling

As Phase One involved observing pre-scheduled meetings, the date and time of the GPMs could not be (and did not need to be) negotiated. All of the recruited PIPs agreed to conduct the questionnaire-led interview immediately after the GPM (in some cases with a short break first), and all patient interviews were conducted within one week of the GPM. Several patients needed reminding or asked to have their interview rescheduled due to fatigue or unexpected visitors which, of course, was accommodated.

Discretion was needed when choosing a time to remind patients about their interview, for example if they looked visibly tired or unwell, in the middle of medical procedures or if they had several visitors. The researcher did not approach participants when they were gathered in the family area outside of the ward space or day room. With so few private spaces in the SIU available to patients and their families, it was important to respect their need to separate their rehabilitation and social activities. As well as being the right thing to do ethically, this arguably also led to stronger working relationships in the long-term.

6.4 Findings from Observations

None of the participants showed any indications of being affected by the researcher's presence in the meetings. This may have been helped by relaxed, repeated interactions with the patient prior to the meeting (such as simple visits to the wards to check on their wellbeing, and double-checking on the day of the GPM that the researcher still had permission to attend).

Many of the observations made during the GPMs echoed those discussed in the contextual review, such as limited patient dialogue and each staff member bringing their own notes or records to report in the meeting (whilst patients neither brought nor recorded any notes).

Most of the handwritten notes taken during the GPMs were used to prompt reflection in the questionnaire-led interviews, rather than generate concrete findings of their own. For example, in one of the observed GPMs, a staff member suggested that another three weeks would be enough time for the patient to reach his final goals before discharge. The patient vocalised his agreement with this, after which his wife glanced at him with a look of surprise. Although this is only a subtle cue, widely open to interpretation, the researcher took a note of this and raised the topic in the patient's interview. This in turn prompted a discussion about his worries about reaching his functional potential before discharge and uncertainty about whether rehabilitation continues after this date – a concept that may not have otherwise emerged.

Interestingly, some of the rough sketches of patient and PIP postures created in the meeting could be interpreted as demonstrating 'closed' body language, perhaps providing further evidence of them taking a passive role in the meeting (see fig. 6.3).

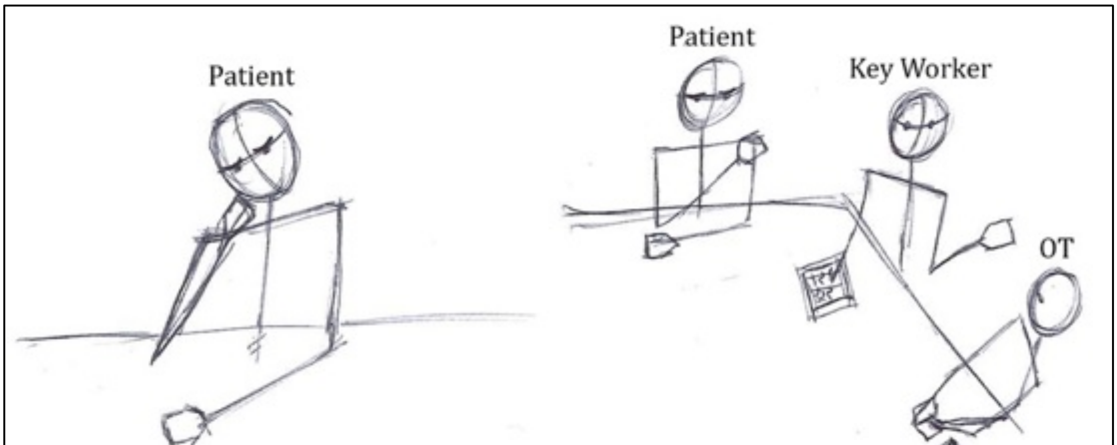


Fig. 6.3: Two examples of rough sketches of patient and staff postures from Phase One (taken from different GPMs).

In conclusion, the passive patient behaviour noted during the contextual review is consistent in most GPMs that the researcher attended, even several months after the original observations were made, and corroborates the focus of this study.

6.5 Visualisations

6.5.1 Generating the thematic framework

After all of the GPMs were audio recorded, three cases were selected to be visualised (as discussed in section 5.6) using simple random sampling. To begin, the researcher listened to all three audio recordings (approximately one hour long each) to gain familiarity with the content. Next, she listened to each recording again, taking notes of as many themes possibly relating to the content as possible. The themes were not abstract; instead they were categories of the conversation topics such as ‘medication,’ ‘progress made,’ ‘new goal set,’ etc. Following this, the themes were condensed where possible, for example ‘wheelchair’ and ‘long handled mirror’ could be condensed into an umbrella label of ‘equipment’.

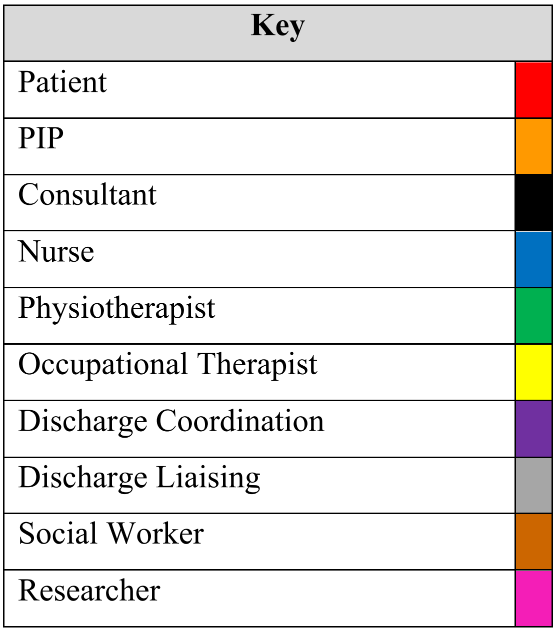
Now that the basic themes were established, it was important to place them in a meaningful order along the y-axis of the conversation map. Given that Phase One is interested in how patients participate or are represented in the meeting, it was logical to group the themes into ‘Staff Expertise’, ‘(Hypothetical) Shared Knowledge’ and ‘Patient Expertise’ (see fig. 6.4).

Patient Expertise	Feelings Hopes Worries Questions Own context Outside experience Thanks Agree/No questions Humour Intro/Explaining GPM
(Hypothetically) Shared Knowledge	Previous goal
	Assistance needed Progress Problem/Difficulty/Risk Equipment Medication Next steps
Staff Expertise	New Goal
	Predicted progress SIU measures Explanation of SCI/system Encouragement Advice

Fig. 6.4: The final, ordered list of themes used to map the GPM conversations.

6.5.2 Mapping the GPM Conversation

With the themes established, each participant in the meeting was assigned a colour (see fig. 6.5 below). There was no need to differentiate between different staff members of the same discipline, as only one of each would attend each GPM, and each meeting would be visualised separately.



Key	
Patient	🟥
PIP	🟧
Consultant	⬛
Nurse	🟦
Physiotherapist	🟩
Occupational Therapist	🟨
Discharge Coordination	🟪
Discharge Liaising	▩
Social Worker	🟫
Researcher	◼

Fig. 6.5: The key of each GPM participant included in the conversation mapping method.

Next, each participant's contribution to the meeting could be mapped into the matching theme, in the appropriate colour, for the corresponding length of time (rounding up to the nearest second, where one cell in the Microsoft Excel© spreadsheet represented one second). When participants talked over each other, care was taken to represent both contributions simultaneously on the graph.

Once all three meetings had been mapped onto separate graphs, each one was revisited again to check the timings were accurate. The researcher conducted the full mapping process, with periodic consultation with both supervisors.

6.5.3 Using the visualisations

In the standard Microsoft Excel© format, the GPM maps took several metres to print in long-form. To make any patterns within the visualisation more apparent, the maps were significantly condensed to fit onto one landscape A3 sheet (see appendix 19). Although each specific theme can be difficult to identify towards the end of the map, the clear boundaries between the main categories of 'Staff Expertise', '(Hypothetical) Shared Knowledge' and 'Patient Expertise' still afforded useful interpretation of the data. For the purposes of discussion in this chapter, fig. 6.6 provides a condensed image of the three GPM maps.

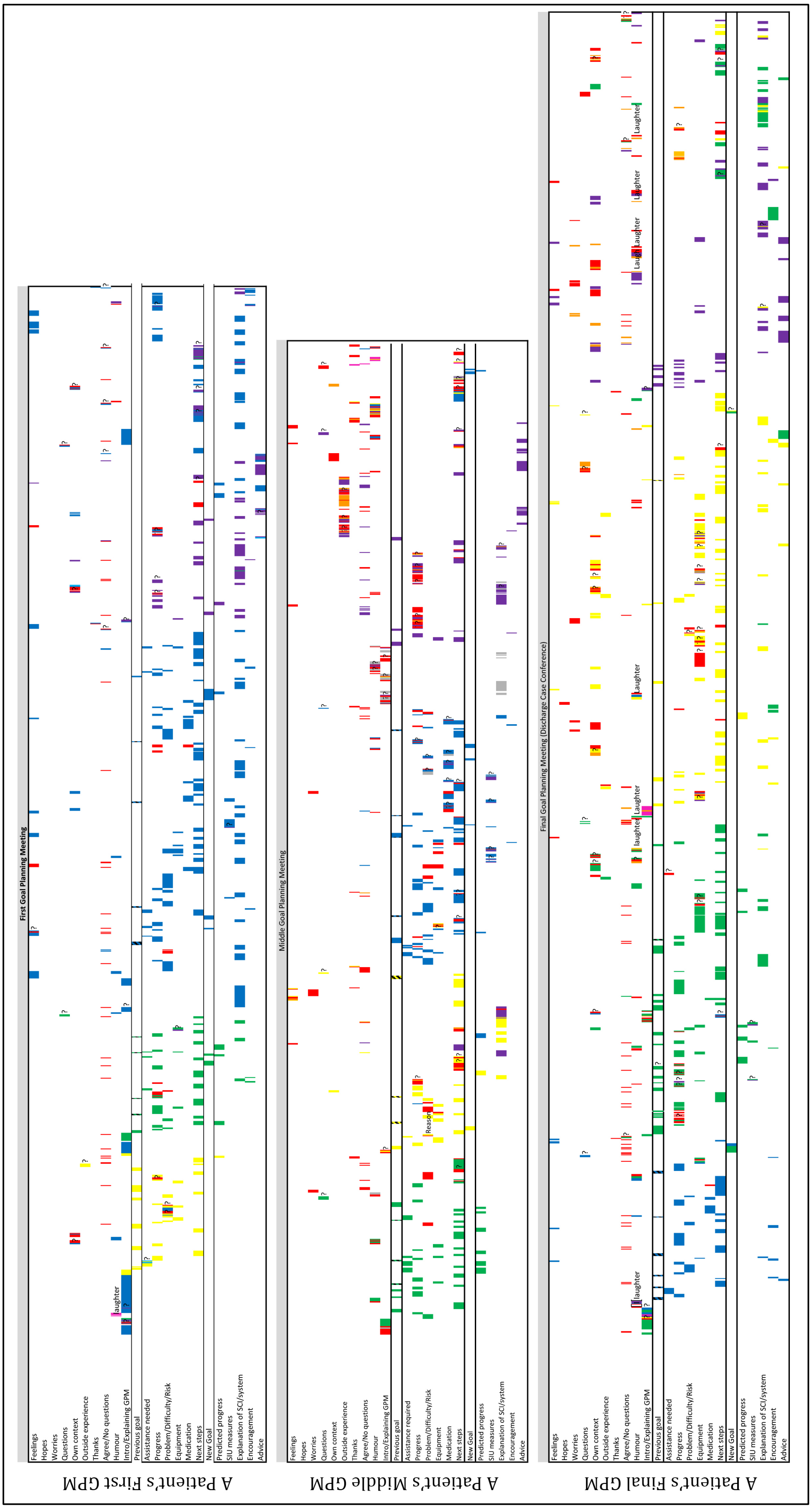


Fig. 6.6: Three GPM conversation maps using Phase One data, where patient input is shown in red.

6.5.4 Reading the Visualisations

The GPMs in this spinal unit (or in any spinal unit, to the researcher's knowledge, have never been analysed or mapped in this way before, and as such they form a unique contribution given that they were able to elicit new knowledge and new forms of evidence about the nature of the conversation within.

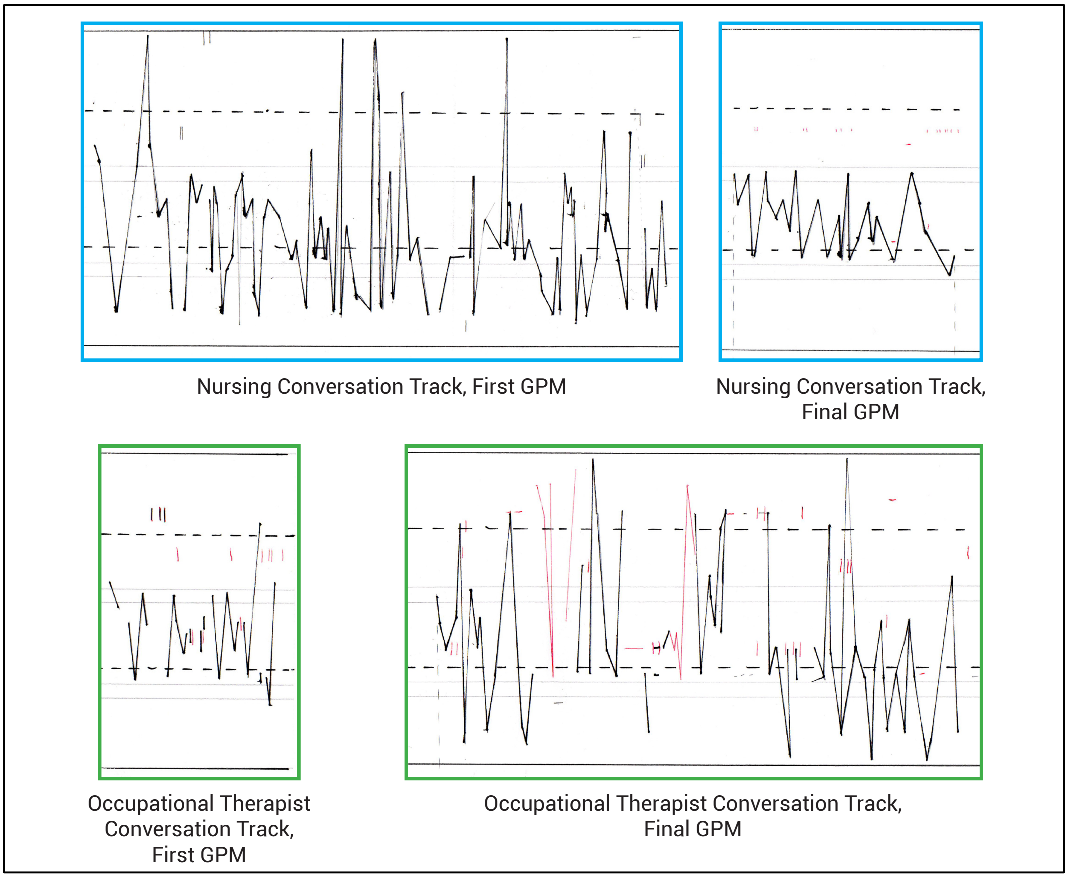
The researcher arranged a joint discussion between the researcher and both design- and healthcare-based supervisors, where it was agreed that there are no clear, repeating patterns in communication throughout the GPMs mapped here.

It was also noted that there is a small amount of red markings, indicating that the patient does not speak very much (particularly when the condensed version of the map above eliminates shorter contributions such as 'Right,' or 'Yep,'). The healthcare-based supervisor commented that, although it was generally known that patients tend not to speak a lot in the meetings, the extent of their passivity is much clearer when demonstrated in the GPM maps.

Perhaps one consistency across the three maps is how little the top third of the map (the designated area for topics the patient is an expert in, such as their home environment, their questions or their emotional responses) is populated. Interestingly, it is often only populated by staff contributions when it is used, suggesting elements of advocacy or patient representation (which is not necessarily a bad thing, but may not equate to equal patient participation). This top third of the map is most populated in the Discharge Meeting map (the lowest image in fig. 6.6), but perhaps this knowledge could be more useful if introduced earlier in the rehabilitation process?

6.5.5 Additional visualisation

Given the extensive time and care put into creating these maps, and the novelty of the approach, the researcher experimented with further methods of visualisation using the maps shown in fig. 6.6 as a resource. A small sample of Nursing and Occupational Therapy conversation 'pathways' was created by connecting the mid points of each consecutive section in the map (see fig. 6.7 below).



Nursing Conversation Track, First GPM

Nursing Conversation Track, Final GPM

Occupational Therapist Conversation Track, First GPM

Occupational Therapist Conversation Track, Final GPM

Fig. 6.7: Conversation ‘pathways’ of Nursing and Occupational Therapy staff in the first and final GPM maps. Patient input is shown in red.

Although only a small sample is shown above, this analysis suggests that Nursing staff may speak more in the patient expertise domain in earlier meetings, with reduced input over time, and vice versa for Occupational Therapy staff. Although this may be mostly due to the fact that the initial rehabilitation priorities are located in the nursing domain (i.e. establishing an appropriate method of managing a patient's bladder, bowels and skin integrity), this may also suggest that patients experience greater anxiety about the practicalities of returning home (issues located in the therapy domain) as they approach their discharge date. However, this is speculation by the researcher, so bringing these forms of mappings back to those involved in the GPMs for comment on what they reveal (or not) would potentially be an interesting area of further research.

6.6 Questionnaire-led Interviews: Process

6.6.1 Conducting the Interviews

On average, each questionnaire took between 30 and 90 minutes to complete. Through several ad-hoc interactions with each patient participant (and their spouse, in some cases) prior to the interview, it was clear that this variation in time taken to complete the interview corresponded to each participant’s natural ‘talkativeness,’ rather than inconsistencies in the questionnaire format or delivery.

Although some participants took less time to complete the interview than others, all appeared to be happy to do so. In fact, some patient participants explained that they felt grateful for an opportunity to give feedback. Those who spent longer to complete the interview often gave rich detail about their own circumstances and medical difficulties they had experienced, rather than necessarily giving information directly relevant to the questions asked. However, the researcher did not directly interrupt these accounts as it appeared to be helpful for the participants to share their stories. In situations where the participant began sharing their concerns or worries, the researcher sympathised with their situation, explained that she was not qualified to give medical advice and suggested an appropriate staff member to talk to.

6.6.2 Analysing the Interviews

For the visual questions (such as those involving Likert-scales) or diagrammatic questions (such as discussing decision-making and progress made towards discharge), the questionnaires were scanned and edited to allow side-by-side comparison of participant responses both within the GPM case and across cases.

The researcher chose to transcribe the audio recordings of the qualitative interview answers to enhance her familiarity with the responses given. As discussed in section 4.8.5, the transcriptions were uploaded into the NVivo software package, where questionnaire items were used as a pre-defined set of codes and applied inductively – allowing the researcher to generate evidence-based summaries of Patient, PIP and Staff perspectives on the GPM (given in section 6.8).

6.7 Questionnaire-led Interviews: Visual data

6.7.1 Communication

Each of the communication-related questions described in this section were explored using Likert-scale questions, which can be found in appendix 20.

With the exception of one patient and one PIP, all participants indicated that they felt 'completely' comfortable asking questions in the GPM. It is interesting that most of the questions asked by patients and PIPs in the observed GPMs appeared to have been prepared prior to the meeting, or to reflect pre-existing concerns, rather than being reactive to the information being discussed in the meeting.

The majority of patients and PIPs stated that they felt staff 'completely' understood their point of view, but with 3 patients and 1 PIP indicating they felt staff understood their point of view more than 'sometimes' but less than 'completely'. One failing of this question, however, is that it did not ask patients whether they felt staff understood their point of view in general lifestyle matters, or just the topics they consider relevant to rehabilitation.

When asked whether they felt that the staff understand what they, as the patient, were capable of achieving, most patients and PIPs interviewed felt that they did, as represented in fig. 6.8 below.

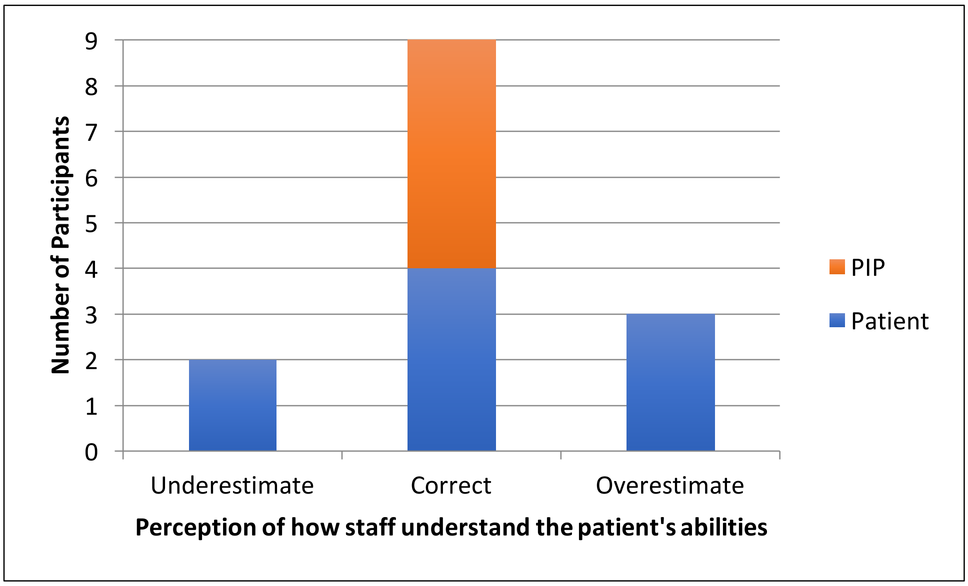


Fig. 6.8: A graph depicting how many patients and PIPs felt staff underestimate, understand or overestimate a patient’s abilities.

6.7.2 Estimating Progress

As discussed in section 5.5.1, patients, PIPs and key workers were each asked to estimate how much progress had been made towards the patient’s discharge on the date of the observed GPM using a simple timeline diagram.

In each GPM case, the key worker’s estimation of progress made was taken to be the most accurate, due to their experience of working with many different patients. By comparing the answers given by patient and (where applicable) PIP participants to the key worker’s benchmark, differences in perception of progress can be highlighted, as shown in fig. 6.9.

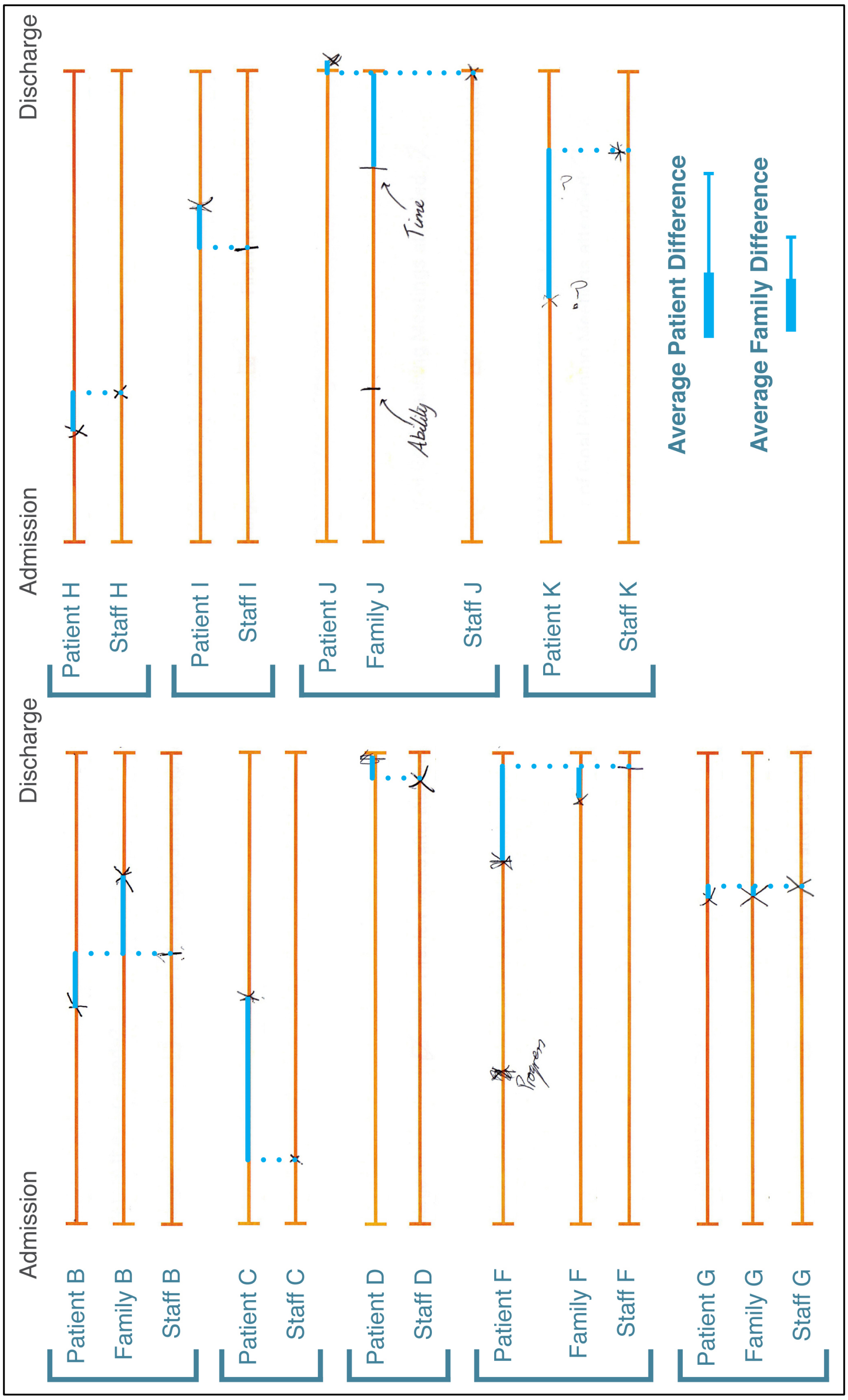


Fig. 6.9: Patient, key worker and (where applicable) PIP perceptions of progress, with differences in estimation from the key worker benchmark highlighted in light blue. Average and maximal differences in perception from key worker estimations are shown in the lower right corner of this figure.

As can be seen above, patient, key worker and/or family perceptions of progress made by the patient can often be quite disparate. Although this is a comparatively small sample of the host SIU population, this finding is arguably worth taking forward into Phase Two of the study.

It is interesting to note that Patient F and PIP J chose to differentiate ‘progress’ into functional ‘ability’ and ‘time’. In other words, two participants felt that although their progress was not close to their functional potential, their time remaining in the SIU was running out. This reflects the anxieties of being discharged too early described above in section 2.11.2 of the Contextual Review chapter.

6.7.3 Decision-making

As discussed in section 5.5.1, patients, PIPs and key workers were each asked to indicate on a simple diagram how much influence patients, PIPs and staff had on decision-making in the GPM. A full side-by-side comparison within and between the GPM cases can be seen in appendix 20. It was found that some general conclusions could be drawn across all 9 GPM cases, whereas others were dependent on whether a PIP was present in the meeting. In general, there was a desire for decision-making to include staff and patients (and where appropriate, PIPs) equally. Interestingly, the majority of key workers felt that staff make most of the decisions, and wanted to change this to include patients and/or PIPs more.

In meetings that included a PIP, patients tended to report feeling more involved in decision-making in the current GPM system than patients attending the GPM alone, as shown in fig. 6.10 below.

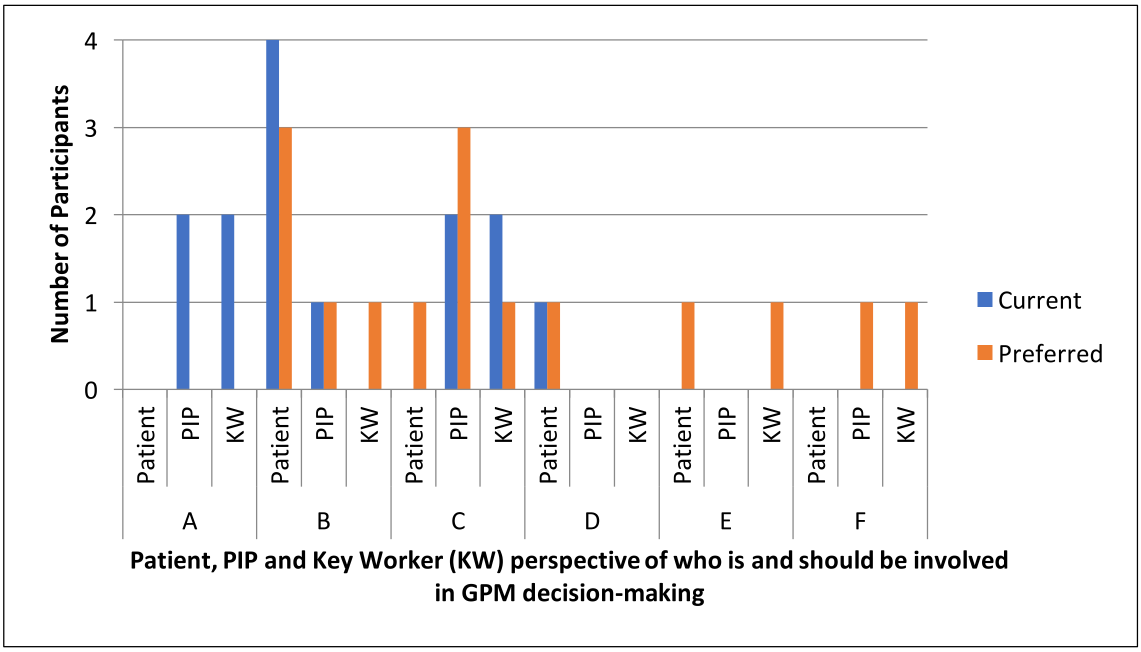


Fig. 6.10: A graph depicting patient, PIP and key worker perspectives of who is (current) and who should be (preferred) involved in decisions in the GPM. Key: A = Staff, B = Patient & Staff, C = All Participants, D = Staff & PIP, E = Patient & PIP, F = Patient.

This provides some evidence (albeit from a small sample) of the supportive or facilitative effect of having a PIP in the meeting, and that it can positively influence actual or perceived involvement in decision-making.

6.8 Questionnaire-led interviews: Verbal data

6.8.1 Language

Most patient and PIP participants gave positive responses about the language used in GPM, such as ‘fine,’ ‘understandable’ and ‘relaxed.’ A small proportion of the participants described confusion during discussions of medication or the grading system used to assess wheelchair skills:

> ‘It's hospital chat, they forget that not everybody understands,’ PIP.F

So, although staff are making effective efforts to speak in terms that everyone in the meeting can understand (i.e. not using FIM scores as shorthand), it can have an excluding effect on patient participation when medical language is used. A focus on a shared, equal language must remain a priority going forward in this study.

6.8.2 Environment

Most patients and PIPs gave positive or neutral comments about the room where their GPM took place. However, one PIP described how her husband looked uncomfortable in his first GPM (which the researcher did not attend);

> 'I felt that it was, the, coming in here, and being at the top of the table, and "this is your meeting, [Pt.J]," and I think he was just "Woah." But, once it started, it was fine.' – PIP.J

Although some of the details PIP.J describes are specifically about the GPM environment, it's important to note that after the immediate impression the patient adjusted. Perhaps, then, it could be inferred that the bigger contributor to Pt.J's discomfort was the not knowing what to expect in his first GPM, or his role in it when told 'this is your meeting.' The concept of mapping out the GPM process in more detail for patients was also echoed in patient suggestions of how to improve the experience:

> 'Maybe to let you know what to expect in your first goal planning meeting, whereas I was going in blind. Alright, you may be hearing snippets off of other patients and that, but it shouldn't be other patients really telling you,' – Pt.B

> 'They could tell you what they're going to do in the next meeting,' Pt.J

6.8.3 Information

The interviews gave mixed accounts of what people consider relevant to the GPM discussion. For example, some patients and PIPs felt that information such as home routines, experiences from day trips, personal worries and personal goals were separate from the GPM discussion. However, the researcher did not observe any instances where this was enforced by the staff dialogue or behaviour in the meeting, so patients may only be assuming what is relevant to the GPM discussion from prior experience in healthcare consultations. This study has already established that the GPM has much greater potential for patient participation than standard healthcare consultations (such as a local General Practitioner appointment), so perhaps the scope of the GPM agenda could be made more explicit prior to, or during, the meeting?

6.8.4 Progression

When asked about the purpose or aim of the GPM, all participants described how the GPM provides an update of progress, with one patient discussing how you need to 'complete each stage' as some staff members were 'all up in the air at the moment until [he got] further through the OT and the physio departments,' (PtB). Several participants described how receiving feedback on progress and being set new goals is motivating for patients (including patients themselves).

6.8.5 Patient Role

The majority of patient and PIP participants' descriptions of their responsibilities in the meeting suggested that they were adopting a passive role; to listen to the staff reports of progress and their expectations for the future, then to ask questions if necessary. Many were content with this role, but perhaps this was because they were unsure of the format of the GPM or because the meeting wasn't necessarily a 'bad' experience, as illustrated in the following quotes:

> 'I didnae [didn't] really ken [know] what's expected, so I was quite glad that they're telling you what to do,' Pt.H

> 'I had, well, I was certainly offered to, er, if I had anything I wanted to say, but everything is going pretty straight forward,' Pt.I

This again suggests that some patients may not desire a more active role in the meeting unless it is clear what that role involves, or what information they can bring to the meeting that is relevant. As has been seen throughout the study, however, the SIU patient community is diverse, and some patients were more critical about their role in the GPM:

> 'The last meeting we were at, [Key Worker B] sort of took the, the lead role and everything. I don't think that's right - it's my meeting, it's all to do with me,' Pt.B

> 'I always feel like I, er, am just there to listen to everyone's comments, erm, and then obviously myself comment if I have anything else to add or maybe have something that's compromising what they're saying,' Pt.F

The latter quote in particular suggests that, for a patient to take an active role in the meeting, they need to take a more confrontational position. Although this may not equate to arguing with the staff, the act of adding to or 'compromising' what the staff suggest may feel impolite to some patients – perhaps enough to dissuade them from participating at all. Perhaps there are other ways to invite patient participation, or perhaps a new GPM material could facilitate a more 'turn-taking' style of interaction, as in a board game?

6.8.6 How the GPM helps patients

When describing how the GPM helps them in their rehabilitation, patients commonly used the phrase 'gives them goals to work towards,' which can be motivating. This is echoed in the literature, but no patients gave examples (even when asked directly) of how they use knowledge of their goals in their daily rehabilitation. With this in mind, it could be worth considering, moving forward, if patient motivation could be enhanced with more tangible ways to transfer the goals set in the meeting into the daily rehabilitation schedule. If there were a more direct, explicit link between decisions made in the GPM and their daily activities, would patients be more able to participate in the GPM itself?

6.8.7 PIP Role

Patients and PIPs generally described the PIP's role as supporting the patient, which included listening to what the staff had to say, asking questions (perhaps if the patient had forgotten to ask) and helping to make preparations for discharge. Pt.B in particular was very vocal about wanting his wife to be involved in the GPM, but was mindful of the difficulties of that:

> 'I feel as if [PIP.B] is due to be involved in absolutely everything - she's my partner. She's been through this just as much as I'm going through it... [but] this meeting lasted about 20 minutes, and all things, six different people throwing six different things at ye, can be a bit overwhelming,' Pt.B

With this in mind, it must be considered that, for some patients, 'active involvement' may also mean providing enhanced opportunities for the PIP to participate in the GPM, without making their role too daunting. It may also suggest that patients and/or PIPs could benefit from being given time to gather and consider the suggestions made during the meeting before decisions can be meaningfully made by them.

6.8.8 How the GPM helps PIPs

PIPs (and one patient) commonly described how it helped them to understand what is ‘expected’ of patients in terms of their potential for functional recovery and the kinds of activities they are involved in within the unit. PIPs felt this helped them to get one cohesive picture of where the patient is at in their rehabilitation journey:

> ‘It helps me understand, erm, at what stage [Pt.G] is in his rehab, erm, what he still has to achieve, and what he may hopefully achieve by the time of discharge, so therefore, I kind of, I kind of grasp an idea of what he'll be able to do and not be able to do, on discharge, and therefore lets me start thinking about what aids I need to put in place, or what I need to do to assist, and things like that,’ PIP.G

Pt.B described how this is important, as the PIP can be 'on the outside looking in', patients can forget to tell them everything they have achieved and patients also have many informal interactions with staff that their PIPs don't know about.

6.8.9 Staff Role

As discussed in the contextual review, each staff member reports back to the group the work they have been doing with the patient since the last meeting and sets new goals for the patient during the following (approximately) four weeks.

6.8.10 How the GPM helps staff

Many of the patients and PIPs suggested that an important role of the GPM is to help coordinate their multidisciplinary rehabilitation team:

> ‘So they can come together more or less, so everybody's, y'know, in the loop kind of thing...’ Pt.F

> ‘Just to get them together to say ... what they're trying to implement as for when she comes home, y'know making sure she's got equipment, and er, various visits, and to see if that had been done,’ PIP.F

The use of ‘they’ or ‘them’ rather than ‘we’ or ‘us’ is worth noting in these statements, and indeed when asked to describe what happened in their GPM, several other patient comments suggested that the meeting mainly served the staff needs:

> 'They kind of just told me that I'd achieved the things that they'd set out to achieve,' Pt.D

> 'Staff run through, erm, where they were at,' Pt.K

> 'So all the professionals knew, each stage of my care and my progress,' Pt.G

Although this conclusion has been inferred from the language used by several different patients, Pt.B also expressed the same sentiment more explicitly:

> ‘It's good that you have these Goal Planning Meetings, but erm...what's it actually doing? People... I feel as if people that work in here, that have got a role in here, have got tick boxes to tick, and once these tick boxes are ticked, then that's fine - they've done it! But it doesn't really help individual person - 'cos every person that comes into these meetings is totally different,’ Pt.B.

Although it is important that the GPM helps the staff to coordinate their efforts, it appears that the focus on the individual patient (which is undoubtedly central to each staff member’s practice) can sometimes be lost in the current GPM process.

6.8.11 Decision-making

Three of the patients interviewed felt that decision-making doesn't happen in GPM's, but as stated above, some patients seem content with taking a more passive role in the GPM. Interestingly, it was mainly the key workers who commented that patients should be more involved in decision-making, perhaps through education, information or an awareness of what they can achieve:

> ‘Decisions tend to be weighted towards staff as patients not [sic] always aware of what they can achieve,’ KW.I

> ‘Staff should educate patients to allow them to make their own decisions,’ KW.F

> ‘Patients [are] not gaining, or willing to gain the information to enable them to make informed decisions -> so relying on staff to make decisions,’ KW.B

The latter comment suggests that although resources are available for patient education, patients need to be motivated to use them for them to be effective. This echoes other staff sentiments about encouraging patients to be active in their rehabilitation, such as KW.I's suggestion for 'more conversation around patient responsibilities and the important [sic] of rehabilitation.' A desire for clarity of patient responsibilities was also voiced from the patient community:

> 'Because I'm supposed to be 'up as able' they don't help me, and I don't want to ask for help because I want to be independent... little things, like going to the shower room... whether they think that I can do that on my own, or if I should be doing that on my own is fuzzy,' Pt.F

This suggests that patient-professional working relationships may be enhanced by making staff and patient responsibilities explicit, in each patient case, rather than using umbrella terms such as 'up as able'.

6.8.12 Goals

Goals were not described as being collaboratively set and agreed upon by patient participants. As has been the case with other findings so far, the patient community had mixed opinions on how acceptable this is. Whilst some patients and PIPs stated that they didn't feel the need to set their own goals (or that their personal goals weren't 'relevant', see section 6.8.3 above), others expressed an interest in sharing this activity:

> 'I appreciate their input, but of course I want control as well,' Pt.F

> 'I think patients should be able to suggest a goal, because it might be something that's important to them, but not necessarily important to the nursing staff,' PIP.G

Although there is a division in opinions regarding collaborative goal-setting, the fact that there is some desire for it from patients (and a consistent desire for it from staff) suggests that it is worth pursuing in the next phase of the study. As stated in the literature, some patients may not want to participate until they know more about what participating entails.

Going forward, it is also worth considering that participants almost always use the term ‘The Goals’ as synonymous with ‘Hospital Goals’ or ‘Functional Goals.’ During the contextual study staff described how patients can be more involved when their functional goals are ‘anchored’ onto personal goals, for example in order to attend a daughter’s wedding a patient will need have certain levels of skin tolerance, bladder and bowel management, etc. However, if staff members aren’t aware of a patient’s personal priorities, this collaborative style of interaction is made more difficult. As such, this study should consider the information asymmetry from both patient and staff perspectives – whilst staff can teach patients about SCI rehabilitation process, patients can also teach staff about their personal goals or home situation, if the GPM process facilitates this. In other words, an acknowledgement of both staff and patient agendas, considering how the SCI requires functional management as well as integration into an existing lifestyle, could be an interesting direction going forward.

6.8.13 Feelings after the GPM

Most patients and PIPs reported that they felt neutral after the GPM, as well as glad to hear about the progress made by the patient or by the staff on the patient’s behalf (such as OT staff coordinating with architects for housing alterations, etc.). However, some patients and PIPs, particularly in the cases where the researcher attended a patient’s final GPM, discussed their anxieties about their imminent discharge date. These concerns related to fears of being abandoned once they left the SIU, worrying that their discharge date was too early or a desire to have more time with their physiotherapists:

> ‘You try and get the most out of the physio side of things like that, but there's only so much you can get done, y'know what I mean? And another [thing], I wanted the max. full month... but what's another week going to do, y'know what I mean?’ Pt.J

> ‘[So you want them to acknowledge that] that they're not just washing their hands of you?’ Researcher
> ‘That's what worries me. That's really my worry, but I also recognise that he can't be here and taking up... He needs to be out of here, and the bed for someone else, but, don't, don't abandon us either... I think that's where he might feel he's gonna get abandoned, so I think that's why he's staying, he's trying to hang on in here as long as, 'cos he needs the rehab, and the pals!’ PIP.J

This patient and PIP couple also echo findings in the literature that the camaraderie between SIU inpatients is a crucial resource for patients (Dickson et al., 2011). Another PIP's commentary on her anxiety about discharge also suggests that she and her husband had prepared for the meeting together to create strategies that may enable the patient to stay longer:

> '[Pt.F] said the only question he was going to have was... "how will he do back wheel balance?" or something, 'cos that's the only thing he can't do, and that might have got him to stay a wee bit longer, but I think that was the reason to ask that question, so he could stay a wee bit longer,' PIP.F

Although their intention clearly wasn't to deceive the staff, there are elements here that could be interpreted as trying to 'work the system' that predates them and their needs, rather than necessarily feeling an equal part of a meeting about this particular patient.

6.9 Discussion

6.9.1 Conducting Phase One

Encouragingly, both patient and PIP participants were generally pleased to take part in Phase One and to share their stories, even if some needed gentle reminding when trying to fit the interview into their rehabilitation schedule. Key workers also seemed happy to take part, and the option to complete the questionnaire themselves, when their schedule allowed, was useful. Flexibility in the researcher's schedule was key to gathering a high response rate and to developing positive working relationships in this phase, which may in turn have led to gathering richer data (although this is just speculation).

Whilst the informal, friendly approach taken in Phase One was crucial to maintaining positive working relationships, and some participants clearly benefitted from sharing their stories, issues or worries, there were several occasions when the researcher needed to remind participants that she was unable to give advice. The safety and comfort of the participant was given first priority at all times, yet the wellbeing of the researcher in emotionally demanding contexts such as SCI rehabilitation is rarely discussed in the literature. Taking a caring approach whilst maintaining a professional distance presented an unexpected challenge for the researcher, but was acknowledged at this stage in anticipation of the remainder of the study.

6.9.2 Mixed-methods

Whilst most of the detailed findings were gathered from the semi-structured interviews, the less traditional research approaches also demonstrated their complimentary potential. For example, the conversation visualisations showed clearly, for the first time in this unit and perhaps in the United Kingdom, the objective extent of patient passivity in the GPM beyond anecdotal accounts from staff or ethnographic observation. Additionally, the inclusion of diagrammatic questions, such as the decision-making triangle, allowed less talkative participants to give a clear, nuanced opinion on an abstract concept, in a format that could be compared easily with other participants in the same meeting. As such, a strong case can be made for the necessity of a mixed-methods approach in complex contexts such as SCI rehabilitation, to create opportunities for participants to express themselves in methods best suited to them.

6.9.3 Consensus or divergence?

As discussed at the very beginning of this study, there is no ‘typical’ SCI patient. Although there are demographic trends in the SIU patient community (see section 2.4.6), the diversity of age, background, social status, etc., of the participants is mirrored in the mixed opinions gathered in Phase One. This may be problematic for scientific research disciplines, however the pluralistic view of the GPM gathered instead compliments the upcoming co-design process by uncovering and prioritising a range of opportunities for change. It is important that the final focus of the co-designed intervention is not narrowed too early, so that ideas can be explored beyond discussing them and through ‘experiencing’ them, using design-led approaches such as prototyping and enactment.

6.10 Developing the Experience Goals

As outlined in section 5.10.4, a joint meeting between the researcher and both design- and healthcare-based supervisors was arranged to discuss the Phase One findings and to agree on a set of Experience Goals to take forward. Prior to the meeting, the researcher sent both supervisors an executive summary of the findings from each method. The researcher brought all of the supporting materials and large-scale printouts of the GPM Conversation Maps (see appendices 19 and 20) to the meeting.

In the discussion of the findings to date, each supervisor brought their own rich experience and knowledge of the relevant literature. The design-based supervisor’s experience in exploring and intervening in situations involving multiple people and materials was crucial in unpacking the findings presented, and in identifying opportunities for design within them. The healthcare-based supervisor, being based in the host SIU, contributed her knowledge of the staff involved, the rehabilitation practices in question and how this research needed to communicate to a medical audience. The novel methods used by the researcher also elicited new knowledge from the healthcare-based supervisor about the familiar SIU context, such as ideas suggested by staff in the past of how to improve the GPM (but were not put into practice). Throughout the discussion both supervisors enquired about the evidence used to support conclusions given in the summaries, such as how many participants corroborated a certain statement or the process used to complete the diagrammatic questions.

At the end of the meeting (approximately 3 hours) a set of four experience goals were agreed upon, described below. It was also agreed that the data gathered in Phase One was rich enough to allow the researcher to create the initial set of prototypes to use in Phase Two independently.

6.11 Experience Goals

This section will now present the four experience goals to be taken forward into Phase Two, alongside a summary of the evidence supporting them.

6.11.1 The patient is more engaged

Although this has been the aim of this study from its initial stages (here using the broader aim of ‘engagement’ with the hopes of facilitating ‘participation’), this experience goal now has a more nuanced evidence base supporting and explaining it. For example, the GPM conversation maps objectively showed, for the first time in a SCI rehabilitation context, how little the patient participants spoke during three GPM cases. Additionally, the language used by patient and PIP participants in the interviews suggested that in order to participate, they must place themselves in a confrontational position (to ‘add’ to or ‘compromise’ what the staff are saying). The patients’ and PIPs’ less conscious and repeated use of ‘them’ rather than ‘us’ also suggested that the GPM currently better serves the needs of the staff, or at least that is how it is perceived. The fact that the staff are the only participants with materials to refer to in the meetings, and that these materials are already filled out prior to the meeting, also corroborates this idea.

6.11.2 The patient knows what happens in the meeting

Several participants described not knowing what to expect in their first GPM, and the anxiety caused by this. Beyond the emotional effects of this, however, an unclear idea of the structure and agenda of the GPM and what information is relevant to the meeting may also hinder patient participation within it.

6.11.3 The patient has a clear idea of where they are in their rehabilitation journey

The participants of Phase One unanimously described the purpose of the GPM as including a summary of progress made to date. However, when asked to indicate the patient's progress on a rehabilitation timeline diagram, Patient, PIP and key worker estimations were often disparate. Further analysis suggested that the patient's proximity to their discharge date also affected patient and PIP estimations of progress made. If perspectives on topics such as progress could be synchronised, perhaps some of the anxieties described by patients leading up to their discharge date could be avoided.

6.11.4 The patient has a clear idea of their responsibilities

A need to clarify patient's goals and responsibilities has been suggested by both patient and key worker participants in the Phase One interviews. This is perhaps understandable when patients must learn from and manage multiple rehabilitation disciplines, as well as navigate institutional language such as ‘up as able’.

Given the richness of the data collected in Phase One, it would be possible to generate more than the four Experience Goals listed here. However, these goals are perhaps the most transferable across the diverse patient community, and provide ample focus to guide the co-design workshops in Phase Two.

Although the role of the PIP has been omitted from the goals for simplicity, it will remain a key consideration as the study continues.

6.12 Conclusion

A mixed-methods approach to exploring the GPM experience has been effective in addressing the research questions for Phase One; by establishing multiple patient, PIP and key worker perspectives of the current GPM experience as well as highlighting opportunities for intervention within it. A set of four Experience Goals was distilled from these findings, which will now be taken forward into Phase Two to guide the creation and co-development of prototype GPM materials and/or processes.

07 Phase Two Findings

7.1 Introduction

By the end of this chapter, the reader will have gained an understanding of how the researcher prepared for the co-design process and adapted her approach in response to the practicalities of working in a complex healthcare context. In doing so, she successfully engaged a range of participant groups from the SIU community (outpatients, inpatients and staff) in shaping the intervention to be taken into Phase Three.

The chapter will begin with an explanation of how the researcher created the initial prototypes (with the Experience Goals developed in Phase One as her starting point) and scheduled the co-design workshops in collaboration with the SIU.

Section 7.5 will then go on to describe the actual co-design process as a series of seventeen ‘Events’, with the inclusion of individual staff meetings and independent design work as necessary additions to the planned weekly workshops. For brevity, these Events are described in concise summaries (figures 7.15–7.35). These summaries are also supported by an overview of the evolution of each prototype, termed ‘Prototype Development Journeys,’ (see appendix 21), and detailed views of the prototype iterations are available in appendices 22-25. Following this, the multiple components that comprise the intervention are described in turn (and given in appendices 26a-26k).

This chapter is necessarily descriptive in nature. A discussion on the approach taken and the nature of outpatient, inpatient and SIU staff engagement in it is located in chapter 10.

7.2 Developing the initial prototypes

7.2.1 Process

The rich data gathered during Phase One, plus the four Experience Goals developed from that data, gave the researcher an evidence base to develop three initial prototypes independently. To begin, the researcher sketched as many immediate responses as she could think of to meet experience goals, whilst keeping her wider contextual knowledge in mind. These sketches included concepts for new or enhanced meetings, materials and processes. Similar concepts were then grouped together and summarised into three simple prototypes, which were presented to both design- and healthcare-based supervisors for approval prior to implementation in the workshops.

This section will now present the three initial prototypes (paper-based materials to be completed in the GPM) to be taken forward into the first co-design workshop, with examples of how they could be populated or used in the GPMs. These filled-in examples (figures 7.2, 7.5, 7.7 and 7.8 below) are hypothetical situations suggested by the researcher, rather than suggestions made by workshop participants.

7.2.2 Initial Prototype One: Timeline

Timelines have been used frequently in discussions with staff and patients throughout the PhD study so far to discuss a range of issues or ideas. The timeline is a simple concept to understand and can be used to provide a quick, visual indication of progress.

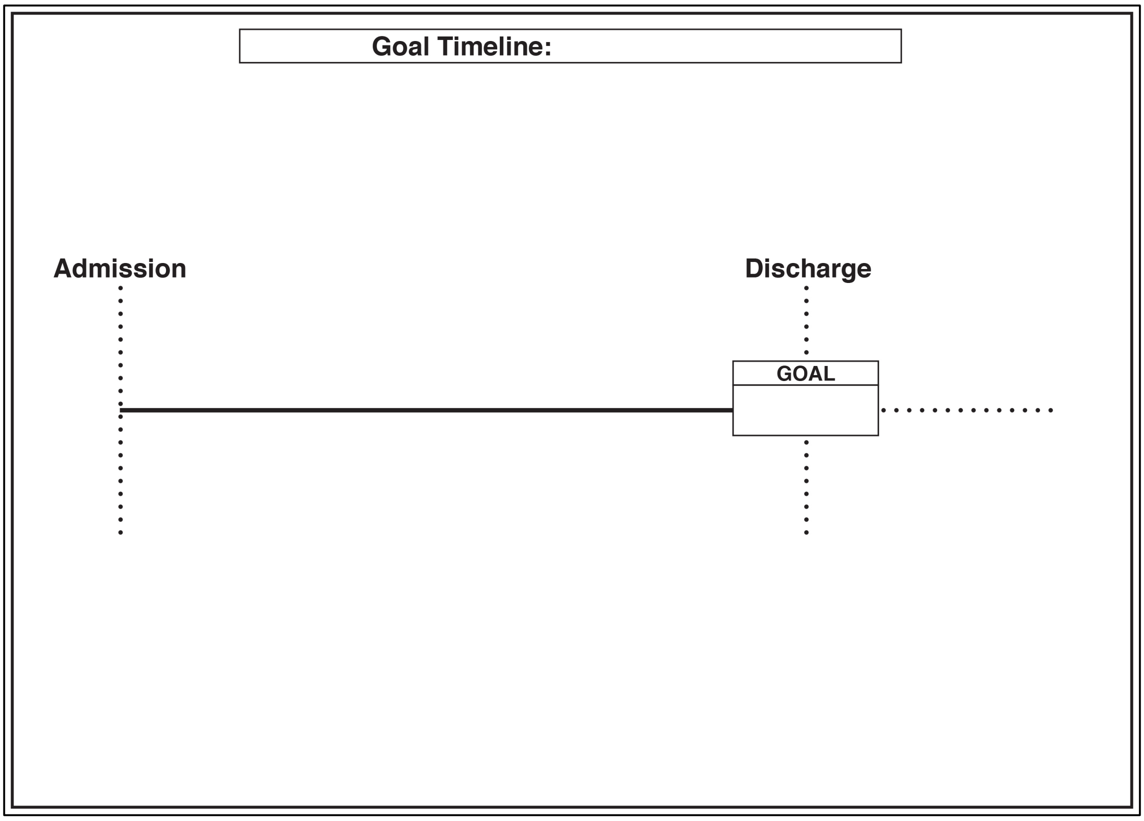
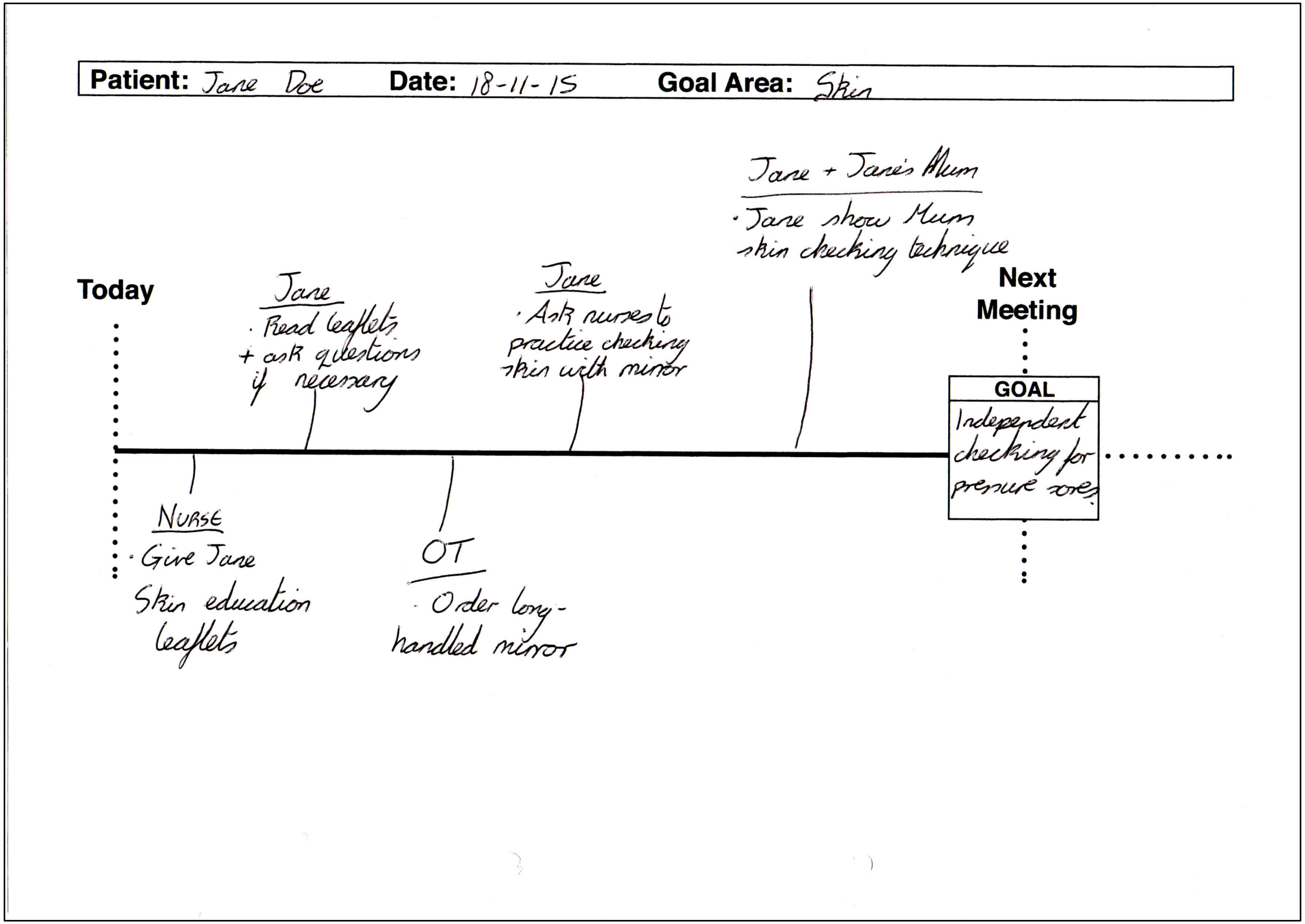


Fig. 7.1: The initial ‘Timeline’ prototype.

In this format, it is suggested that each Long-Term Goal (LTG) is assigned a separate, A4 timeline, which is taken to each GPM. The responsibilities of each individual can be added as the patient progresses towards that LTG, as shown in fig. 7.2 below.



Patient: Jane Doe **Date:** 18-11-15 **Goal Area:** Skin

Fig. 7.2: An example of one way of using the timeline prototype.

These timeline sheets could also be used in an ‘agenda card’ approach, to learn about patient priorities in a sorting activity, or to reinforce patient education about which skills are needed for which activities (as demonstrated in fig. 7.3 below).

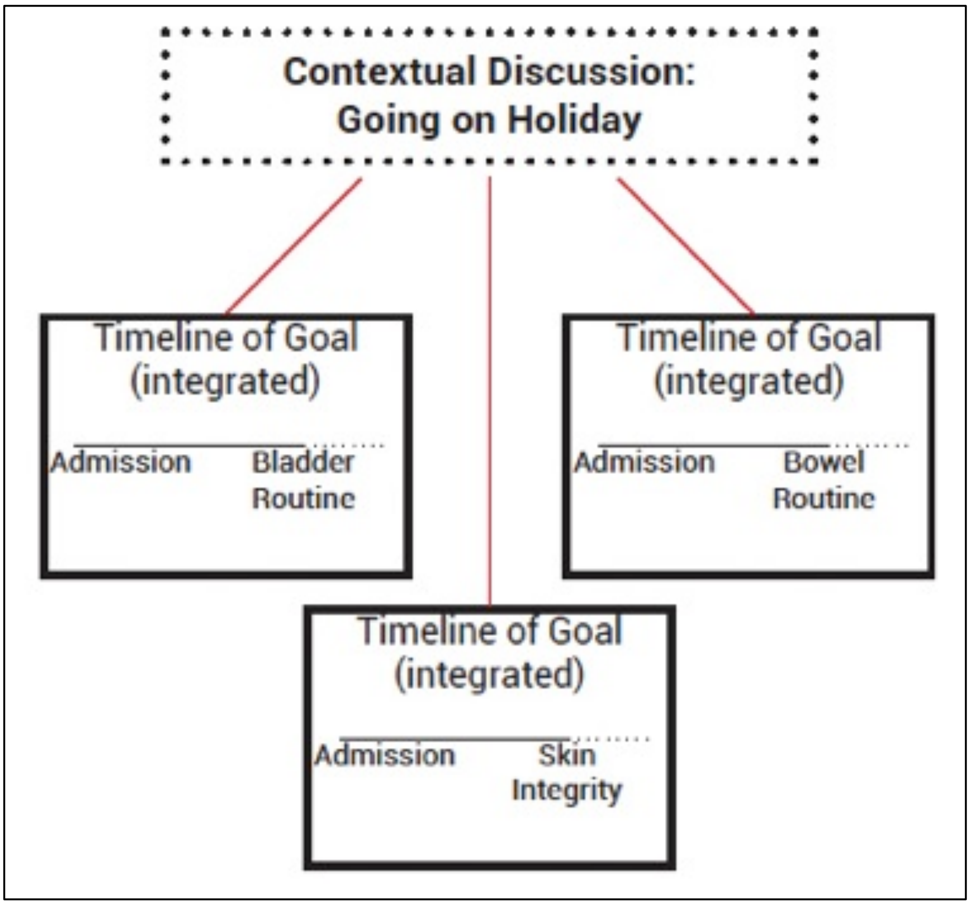


Fig. 7.3: A diagram showing how multiple timeline sheets can be used to support discussions on progress needed to attain a personal goal, such as going on holiday.

7.2.3 Initial Prototype Two: Daily Routine

Rather than structure the GPM conversation by department, this prototype suggests anchoring the GPM agenda on the patient’s daily routine.

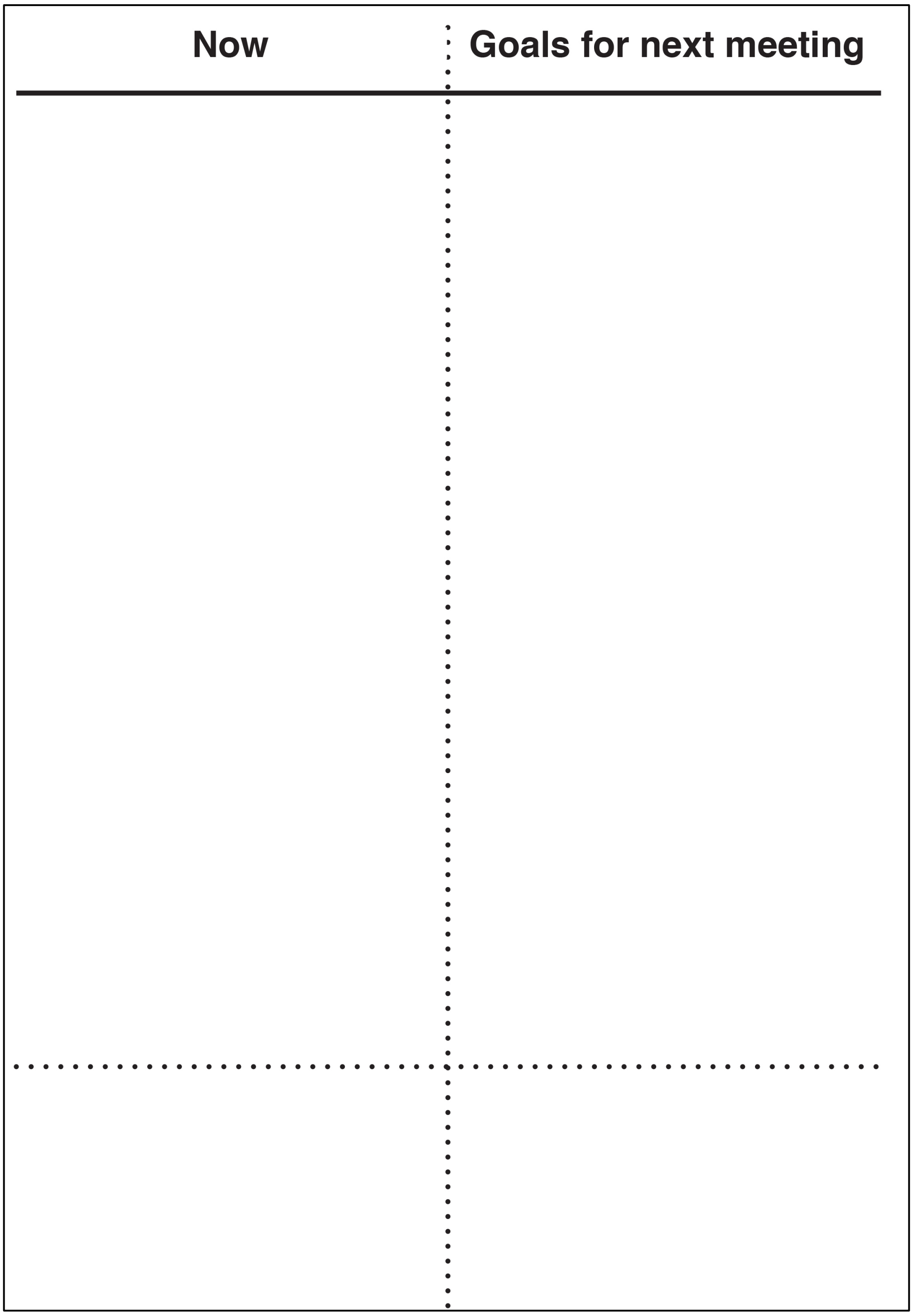
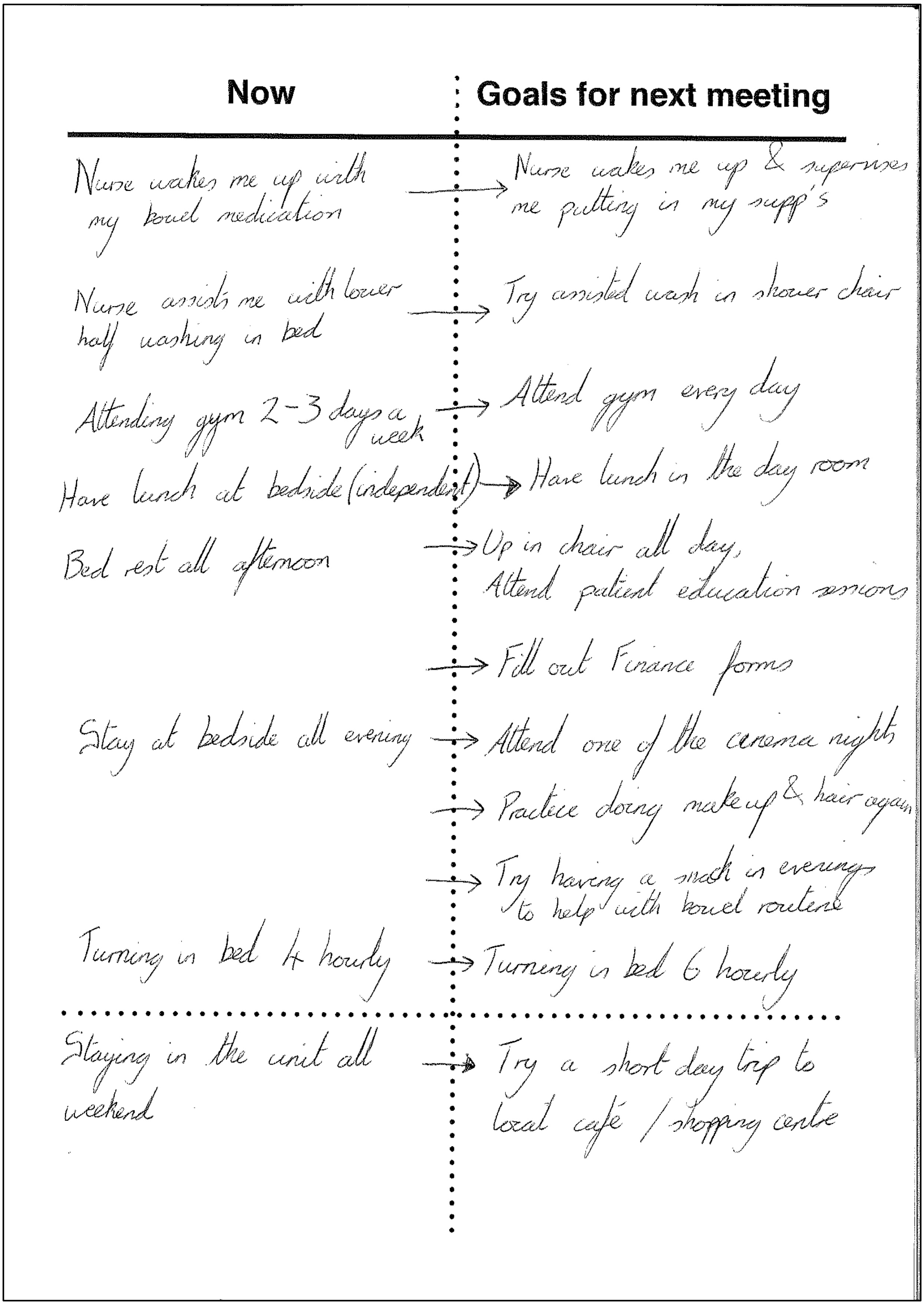


Fig. 7.4: The initial ‘Daily Routine’ prototype.

Current progress can be recorded by describing (briefly) how a patient completes tasks (such as ‘washing’) in the left column, then how the patient should aim to complete the same task by the next GPM in the right column (see fig. 7.5).



Now	Goals for next meeting
Nurse wakes me up with my bowel medication	Nurse wakes me up & supervises me putting in my supp's
Nurse assists me with lower half washing in bed	Try assisted wash in shower chair
Attending gym 2-3 days a week	Attend gym every day
Have lunch at bedside (independent)	Have lunch in the day room
Bed rest all afternoon	Up in chair all day, Attend patient education sessions
	Fill out Finance forms
Stay at bedside all evening	Attend one of the cinema nights
	Practice doing make up & hair again
	Try having a snack in evenings to help with bowel routine
Turning in bed 4 hourly	Turning in bed 6 hourly
Staying in the unit all weekend	Try a short day trip to local café / shopping centre

Fig. 7.5: An example of how the Daily Routine prototype could be completed in one GPM. A new sheet will be needed in each meeting, but all of the goals will be located on this single sheet.

Discussing daily activities in this way may help the patient and/or PIP to better understand how the different departments work together to achieve integrated goals. For example, in terms of ‘washing’, if nursing staff can help improve a patient’s skin tolerance, they can then try new transfers with physiotherapy staff and try a new shower chair with the occupational therapy staff.

Formatting the GPM in this way also allows the patient’s home routine to be gradually integrated into the hospital routine, and perhaps to facilitate conversations about ‘the end picture’ (i.e. what the patient and staff are aiming for).

7.2.4 Initial Prototype Three: Goal Wheel

This tool continues the idea of considering goals as a collaborative effort from several disciplines in a patient’s rehabilitation, whilst also creating an equal space for patient and PIP agendas.

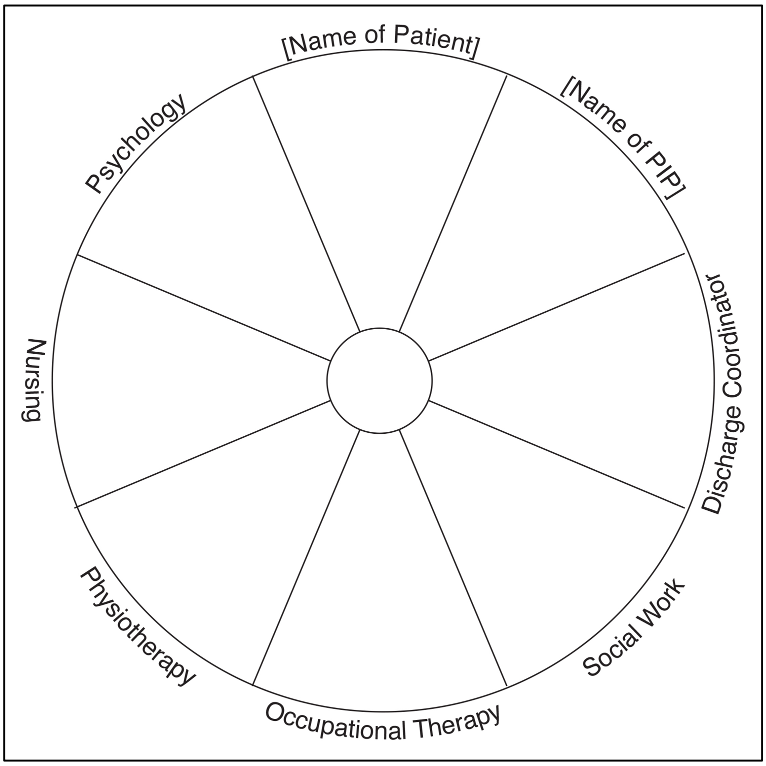


Fig. 7.6: The initial ‘Goal Wheel’ prototype (with guiding notes).

This material could also be used to delegate responsibilities or create a visual understanding of the transfer of these responsibilities. Figures 7.7 and 7.8 below demonstrate two different ways of using this prototype.

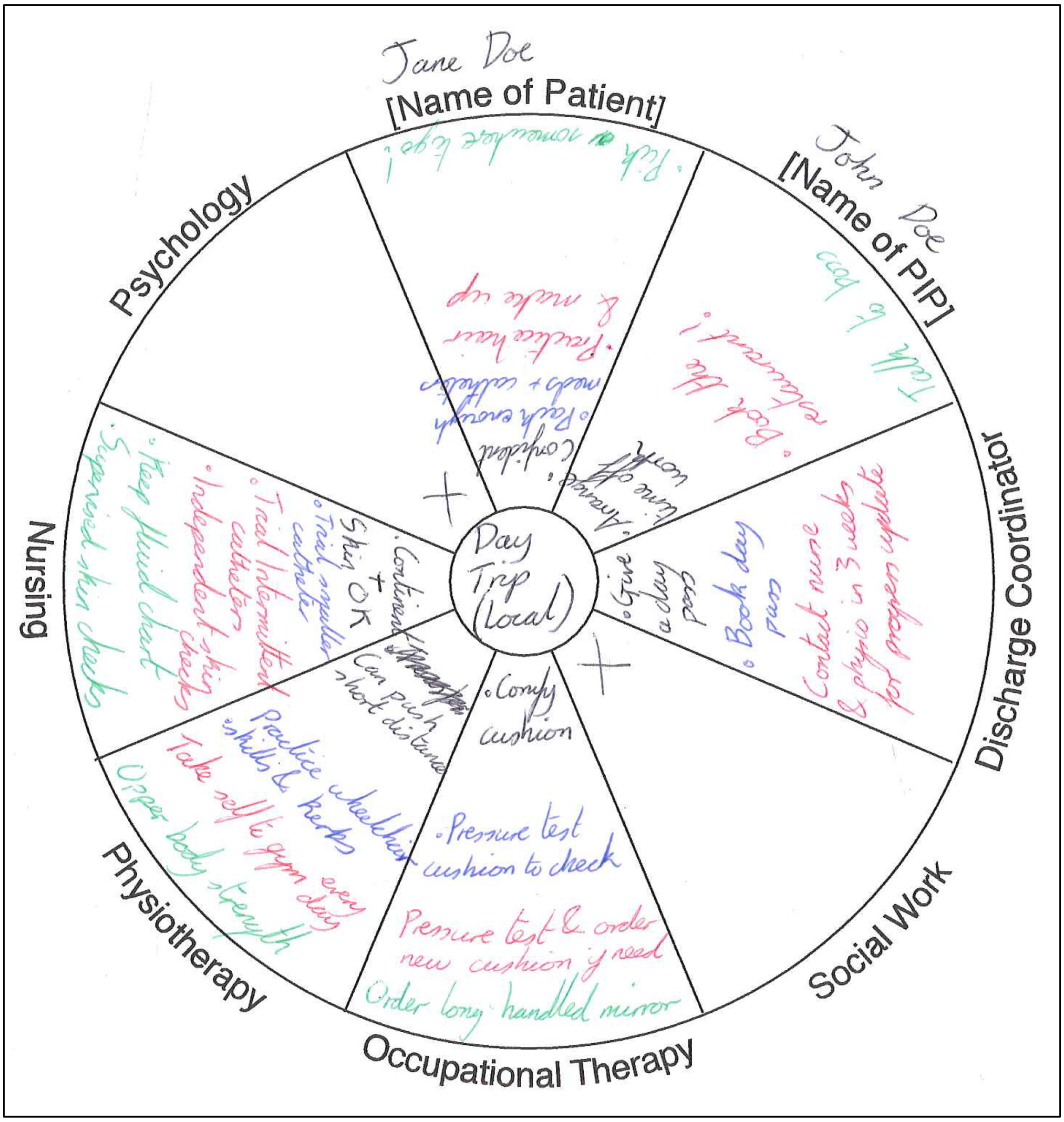
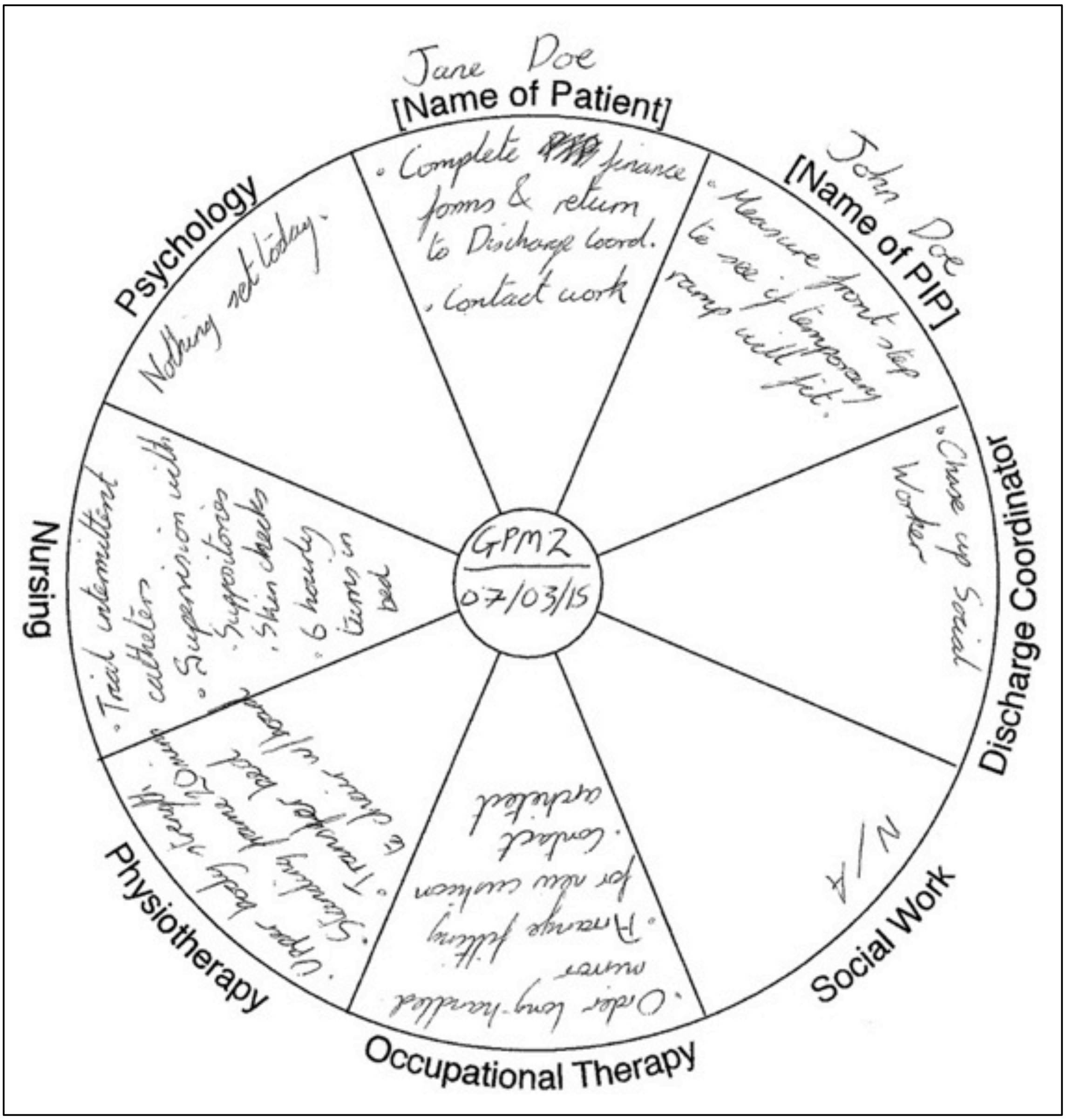


Fig. 7.7: An example of how the Goal Wheel prototype could be used over several GPMs for long-term goals. The overall long-term goal is written in the middle, with discipline-specific goals that contribute to that written in the centre of each segment (here shown in black). Each discipline then works from the outside-in towards the long-term goal at each meeting (here the series of meetings, and goals set at each, are shown in multiple colours).



Jane Doe

• Complete finance forms & return to Discharge Coord.

• Contact work

John Doe

• Measure front step to see if temporary ramp will fit.

• Chase up Social Worker

N/A

• Order long-handled mirror

• Arrange fitting for new cushion

• Contact architect

• Upper body strength

• Standing frame 20mins

• Transfer bed to chair w/board

• Trial intermittent catheters

• Supervision with suppositories

• Skin checks

• 6 hourly turns in bed

Nothing set today.

GPM2

07/03/15

Fig. 7.8: An example of how the Goal Wheel prototype could be used once to record the short-term goals set in a GPM.

With the three initial prototypes ready for use, the researcher could begin to plan the co-design workshops.

7.3 Planning the workshops

7.3.1 Planned Structure

As discussed in section 5.12, this phase of the study aimed to strategically engage different types of knowledge from different participants in a range of workshop and enactment activities, as summarised in table 7.1 below. The design-based supervisor was consulted during this planning phase, who contributed his experience in conducting similar activities.

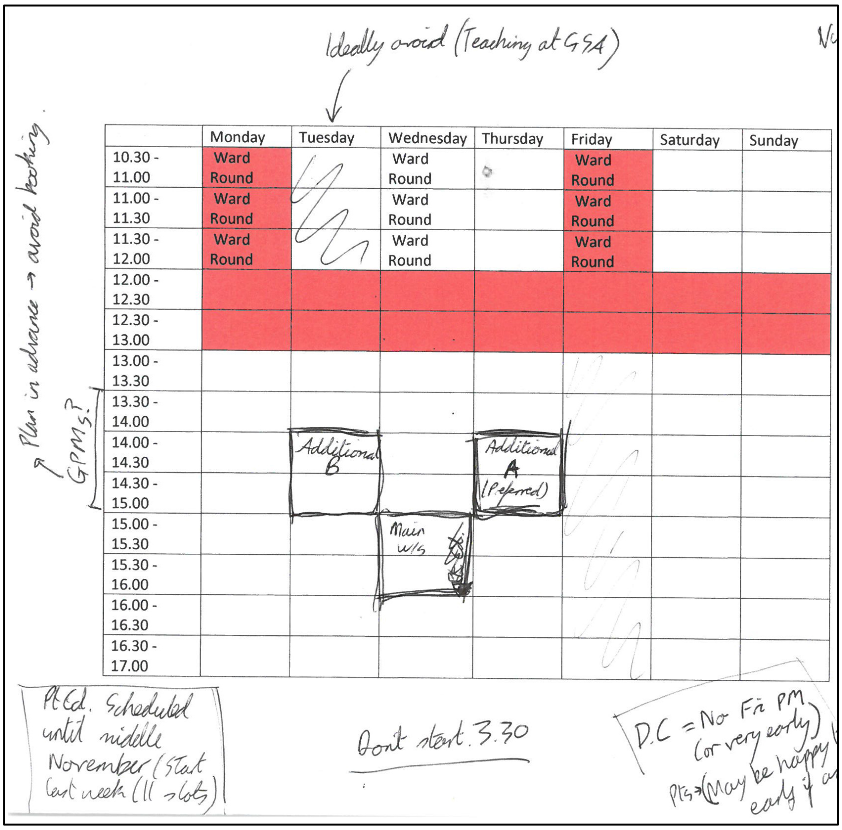
Workshop Number	Participants	Types of knowledge	Types of activity
1	Outpatients	‘Hindsight' or 'Lived’ Experience	Prototype development
2	Inpatients	‘Current’ Experience	Prototype development
3	SIU Staff	Practical and 'Service Delivery' Experience	Prototype development
4	1-2 inpatients, 1-2 PIPs (if applicable) and SIU staff	Behavioural and experiential knowledge to refine the intervention	Prototype refinement in a mock GPM
5	1-2 inpatients, 1-2 PIPs (if applicable) and SIU staff	Behavioural and experiential knowledge to refine the intervention	Prototype refinement in a mock GPM

Table 7.1: A table of the planned workshop structure.

With this in mind, the researcher could then approach senior staff members across the main rehabilitation departments (including nursing, physiotherapy, occupational therapy, patient education and psychology) to find a suitable weekly slot, over at least 5 weeks, to conduct the workshops.

7.3.2 Scheduling

The researcher aimed to find a weekly slot of approximately 1 hour to conduct the co-design workshops in the SIU, with minimal impact on the patient and staff rehabilitation schedules. Although online tools exist to facilitate group scheduling (such as Doodle Poll©), the researcher’s experience in the unit suggested that some key staff members do not have much time to check their emails but are always helpful in ad-hoc conversations on the ward. As such, the researcher printed a one-week timetable to facilitate individual, face-to-face scheduling, gathering each staff member’s availability, time periods allocated to specific rehabilitation activities and additional notes (see fig. 7.9).



Ideally avoid (Teaching at GSA)

Plan in advance → avoid booking.

GPMs?

	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
10.30 - 11.00	Ward Round		Ward Round		Ward Round		
11.00 - 11.30	Ward Round		Ward Round		Ward Round		
11.30 - 12.00	Ward Round		Ward Round		Ward Round		
12.00 - 12.30	🟥	🟥	🟥	🟥	🟥	🟥	🟥
12.30 - 13.00	🟥	🟥	🟥	🟥	🟥	🟥	🟥
13.00 - 13.30							
13.30 - 14.00							
14.00 - 14.30		Additional B		Additional A (Preferred)			
14.30 - 15.00							
15.00 - 15.30			Main w/s				
15.30 - 16.00							
16.00 - 16.30							
16.30 - 17.00							

Pt Ed. Scheduled until middle November (Start last week (11 slots)

Dont start 3.30

D.C = No Fri PM (or very early)

Pts → (May be happy early if a

Fig. 7.9: The timetable tool used to collate and use staff schedules in face-to-face conversation (cropped to preserve anonymity of some participants).

This face-to-face negotiation led to a clear demonstration of the SIU staff's buy-in to this PhD study, when the Patient Education Liaison Nurse offered to condense the Patient Education timetable to accommodate the researcher's workshops into the same weekly slots. The researcher assisted in the re-scheduling of the Patient Education sessions (liaising with the speakers assigned to each week's session) and gratefully accepted the weekly slots remaining. As such, the co-design workshops did not use time when staff and patients would normally be working together, so their impact on the rehabilitation schedule and visiting hours was as low as possible.

7.3.3 Workshop Resources

Section 5.12.3 of the Study Plan chapter described how the workshop content will be structured week by week, according to the outcomes of the previous session. To prepare for this reactive approach, the researcher created a 'library' of tools that could be useful in assisting participants in engaging with and developing the prototypes. These tools were potentially reusable across several workshops with different participant groups, and aimed to anticipate potential difficulties of co-design activities in healthcare contexts. These difficulties were highlighted through the researcher's integration into the unit and from the design literature.

How will the prototype work with other people?

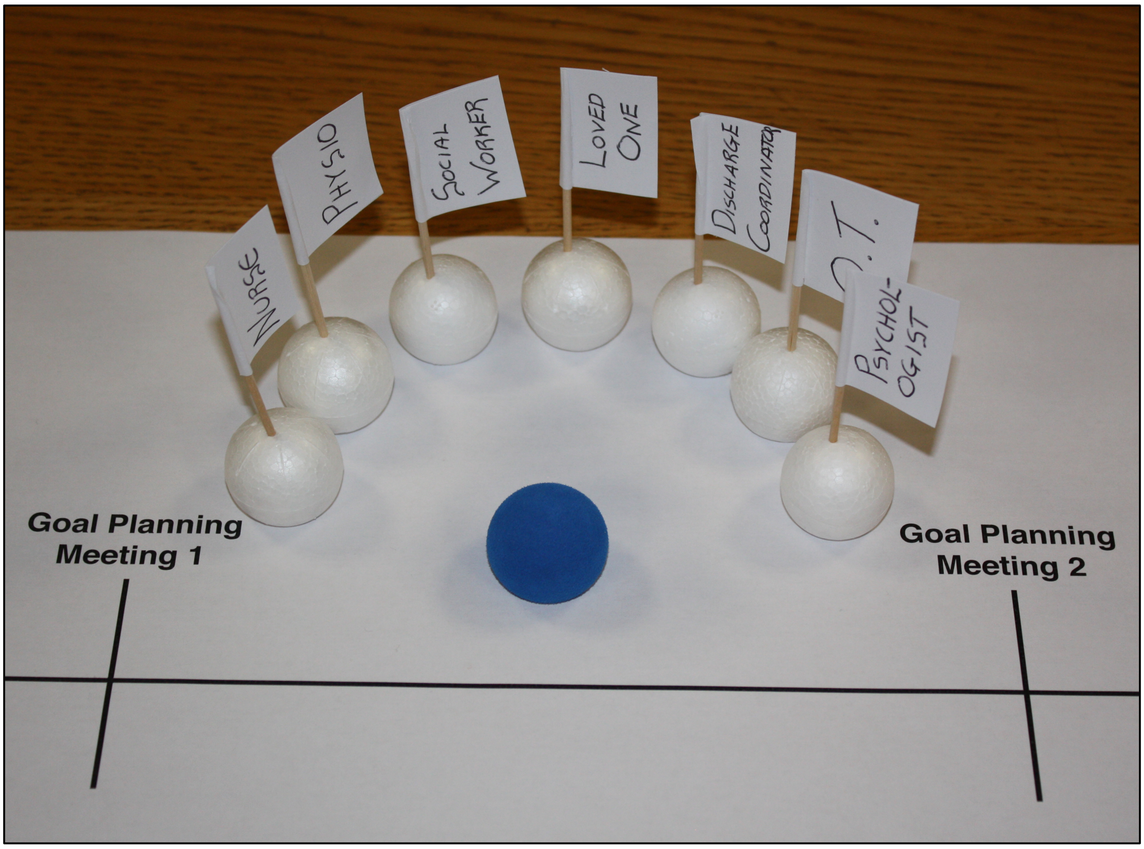


Fig. 7.10: A collection of character pieces representing each participant usually present in a GPM.

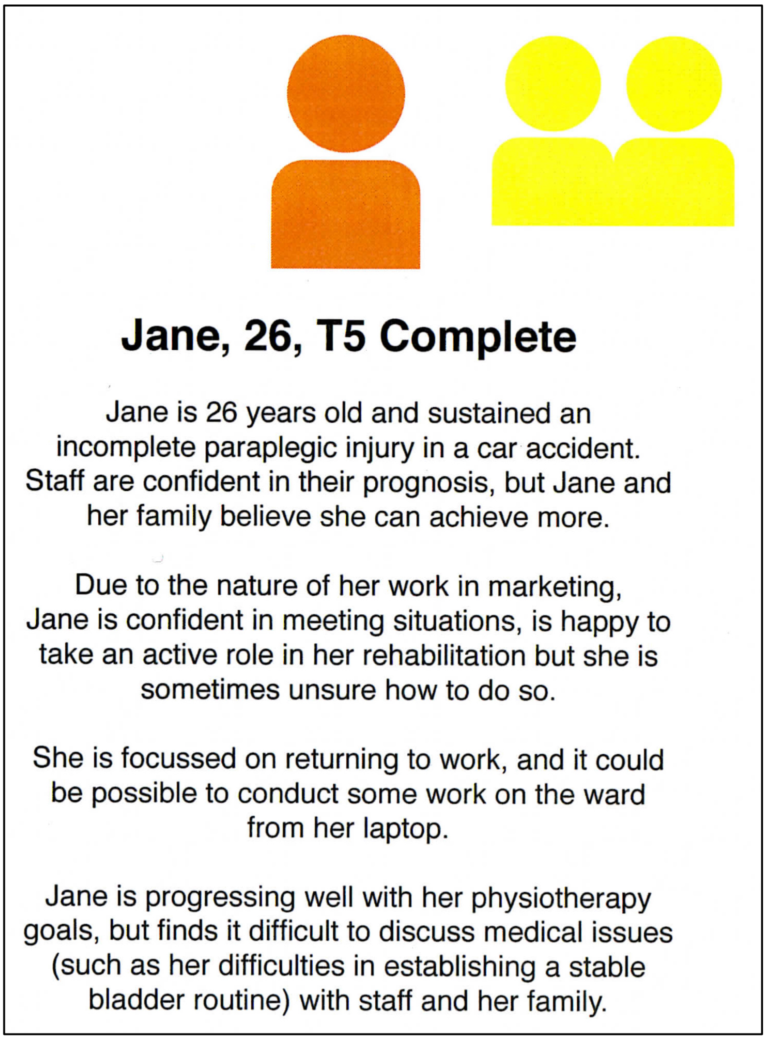
A collection of player pieces was created of each participant in the GPM, to help collaboratively discuss scenarios where the material is used in a group situation or when deciding who should be involved.

A set of four patient personas were also created to support more detailed, empathetic discussions of how future patients may engage with the materials. The personas were created by first populating a table of four headings; 'prognosis', 'issues', 'home circumstances' and 'motivation for recovery', using anecdotal or first-hand experience with the host SIU community. The details used for this were not specific to one particular patient (for example, many patients experience 'lingering skin issues') and care was taken not to breach anonymity of the participants in this study to date. A small sample of this table from a number of patients is shown in table 7.2 below:

Issues	**Circumstances**
Withholds Information	Very active PIP involvement, providing outside information
Scared of being discharged too early	Family live far away - hard to involve them
Lingering skin issues	Very educated - used to chairing meetings in work
Progressing well in physio. but refuses to engage with bowel management	Young, still very reliant on parents
Unsure of responsibilities	Previously worked as a bricklayer
Wants to deal with SCI at home, so doesn't address problems in SIU	Has 2 young children at home
Motivation	**Prognosis**
Work - does work from laptop in the ward	Uncertain - many co-morbidities
Mothering to others in the SIU	Clear physiotherapy goals, unclear medical goals
Wants complete PIP involvement	Disputed between patient and PIP
Doesn't feel own goals are relevant	Good, clear
Focussing on present, day-to-day goals	Needs to aim higher
Doesn't go to the gym regularly	Believes surgery will improve the prognosis

Table 7.2: Examples of the items used to create a range of personas.

Four items (one from each heading) were then grouped together to create a diverse range of four personas. However, the main persona used throughout the workshops was ‘Jane Doe’, shown in fig. 7.11 below:



Jane, 26, T5 Complete

Jane is 26 years old and sustained an incomplete paraplegic injury in a car accident. Staff are confident in their prognosis, but Jane and her family believe she can achieve more.

Due to the nature of her work in marketing, Jane is confident in meeting situations, is happy to take an active role in her rehabilitation but she is sometimes unsure how to do so.

She is focussed on returning to work, and it could be possible to conduct some work on the ward from her laptop.

Jane is progressing well with her physiotherapy goals, but finds it difficult to discuss medical issues (such as her difficulties in establishing a stable bladder routine) with staff and her family.

Fig. 7.11: The Jane Doe persona used to support the co-design workshops.

How does the material fit into the SIU context?

Longer timelines to represent the total rehabilitation pathway (from injury to discharge), as well as more focussed timelines to show before, during and after the GPM, were printed across several A3 sheets to support contextualised discussion of the prototype materials.

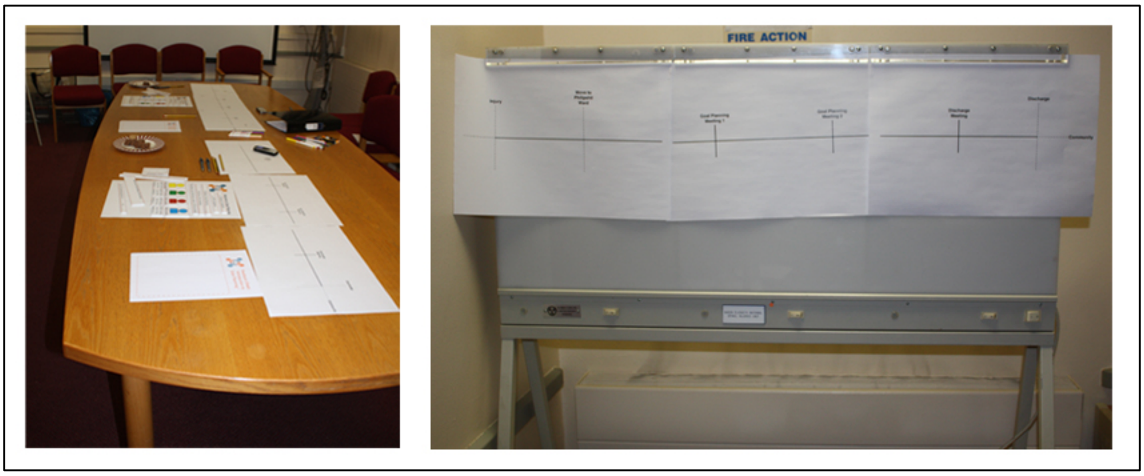


Fig. 7.12: Service journey timelines that can be displayed differently according to the workshop participants. For example, small groups of patient participants benefitted from tabletop discussions, whereas large groups of staff could more easily see wall-mounted timelines.

Does the material meet the minimum requirements?

Flashcards of each topic discussed in the current Goal Planning system were created to consider the current GPM meeting content more tangibly, for example to facilitate sorting or checklist activities.

Fig. 7.13: Goal Planning Checklist Flashcards

Additionally, posters of the Experience Goals created in Phase One were printed (in A3 and A4 formats, to either display on the wall or use on the table space) to guide the workshops. As will be seen in chapter 10, the Experience Goals could be used to gently steer workshop conversations back on track, or as evaluation criteria, etc.

Fig. 7.14: Experience Goals posters.

7.4 Conducting the workshops

7.4.1 Structure

As might be expected in a complex context with multiple participant groups, the actual workshop timetable became more complicated than the structure described above. Rather than conducting five, hour-long workshops, the co-design process in reality needed a series of seventeen workshops, meetings and independent design work (conducted by the researcher). This approach became more necessary after the staff groups were included, as their schedules were more affected by last minute changes and (as will be described below) several conflicting design directions emerged from the staff community. Table 7.3 below gives an overview of the actual co-design process.

Event Number	**Who was involved**	**Activity**
1	Outpatients (n=2)	Prototype development
2	Healthcare-based Supervisor	Meeting
3	Inpatients (n=4)	Prototype development
4	Inpatients (n=4)	Prototype development
5	SIU staff (n=6)	Prototype development
6	SIU staff (n=7)	Prototype development
7	SIU staff (n=1+1+1)	Individual meetings
8	SIU staff (n=8)	Enactment
9	SIU staff (n=2)	Enactment
10	SIU staff (n=2)	Enactment
11	SIU staff (n=9)	Enactment
12	Design-based supervisor	Meeting
13	SIU staff (n=1+3)	Individual meetings
14	Researcher	Independent design work
15	Key Workers (n=3)	Intervention proposal and refinement
16	Healthcare-based Supervisor	Meeting
17	Researcher and SIU Community	Independent design work and final adjustments

Table 7.3: An overview of the seventeen events in the actual co-design process, with each participant group assigned a colour for clarity.

Although the researcher conducted design work between every stage shown above (in terms of editing the prototype to reflect the workshop outcomes), the specific ‘Independent Design Work’ stages shown above represent more radical changes in the prototype development based also on the researcher’s experience rather than purely from the SIU community input.

7.4.2 Ethics

The recruitment and ethics processes have already been described in the Study Design chapter of this thesis, so to avoid repetition in each workshop ‘event’ below it is perhaps enough detail to state here that outpatient and staff groups were invited to participate by email or in person, given a copy of the information letter and consent form in advance, and asked to sign the consent form at the end of the workshop. Informed consent was obtained from inpatient participants prior to their workshop sessions.

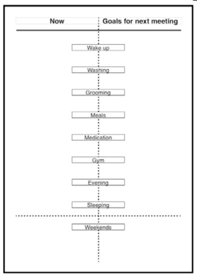
7.5 Events

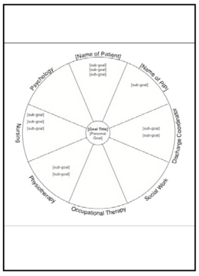
An 11000-word commentary report was generated describing each workshop event in turn (for the researcher’s reflections, and not included in this thesis), which generated interest from the host SIU staff. However, for the purposes of this discussion, the collection of workshops, meetings and independent design work will now be described through a series of ‘Event’ summaries. This approach aims to maintain a concise, intellectual enquiry by focussing on the tools created, activities planned and key outcomes affecting the prototype development. It is hoped that this approach will lend a transparency to the process that is often lacking in current co-design literature, and is particularly important when working in complex contexts with multiple participant groups.

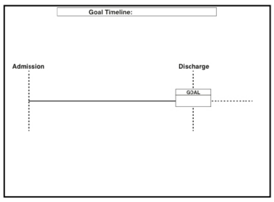
Event 1: Workshop 1: Outpatient Participants

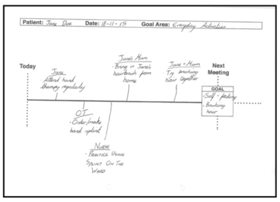
Participants: One male, one female, SCI charity staff

Prototypes: Initial Daily Routine, Timeline and Goal Wheel concepts (blank copies and copies completed with a fictional patient's goals).

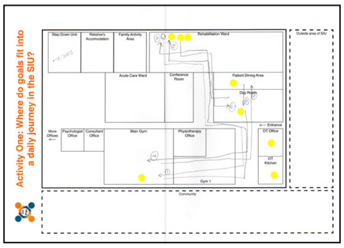


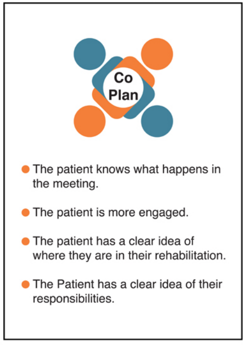




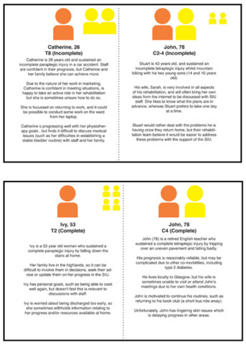


Tools: 'Day in the life of an inpatient' map, Experience Goals, Personas





- The patient knows what happens in the meeting.
- The patient is more engaged.
- The patient has a clear idea of where they are in their rehabilitation.
- The Patient has a clear idea of their responsibilities.



Activities

1. Brief catch up of the Phase One method and results.
2. Warm up activity, drawing a typical day in the unit (see above).
3. Discuss each prototype in turn, using other tools to explore how it could be used and understood in the SIU context.
4. Wrap up, final thoughts and clarify main points to explore.

Comments

The intervention must make it clear that rehabilitation is about the patient's personal potential – what about an 'Introduction to Goal Planning' meeting or information sheet?

There is a need to accommodate a wider range of goals, such as social goals like 'eat meals in the day room' rather than in bed.

The Daily Routine prototype could be hard to use in practise, but participants liked the idea of it forming 'an agreement or contract' between patients and staff – what about a patient-owned Goal Planning Folder?

The Timeline prototype was considered 'stronger,' particularly in terms of understanding the order and dependency of short-term goals.

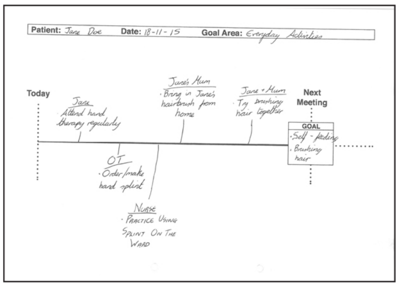
There is a need to help patients understand their prognosis - how and when could this information be reinforced in the rehabilitation pathway?

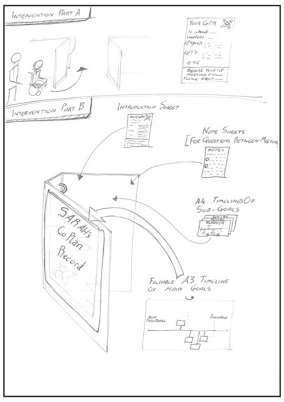
Fig. 7.15: An overview of the people, tools, activities and outcomes from Event 1.

Event 2:
Meeting with
Healthcare-based
Co-Supervisor

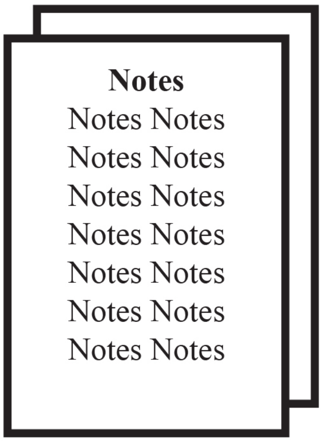
Participants: Healthcare-based Supervisor

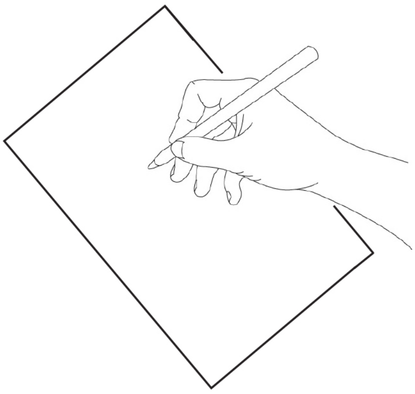
Prototypes: Initial Timeline prototype and sketch ideas from Event 1.





Tools: Notes from Event 1, plus additional paper and pens.





Activities

The researcher updated the Co-Supervisor on the main points of interest and concepts emerging from Event 1, using the notes and sketches made.

Comments

Many of the notes from Event 1 make reference to a patient's 'end goals' - the intervention must be clear in how you communicate this as 'the point when the best place to continue your rehabilitation is in the community.' A second prognosis meeting could be an opportunity to further clarify these 'end goals' and other terms or processes taken for granted by staff. The intervention must support staff in all of the changes it introduces - even a simple discussion about rehabilitaiton priorities will be very different between an older man and young mother.

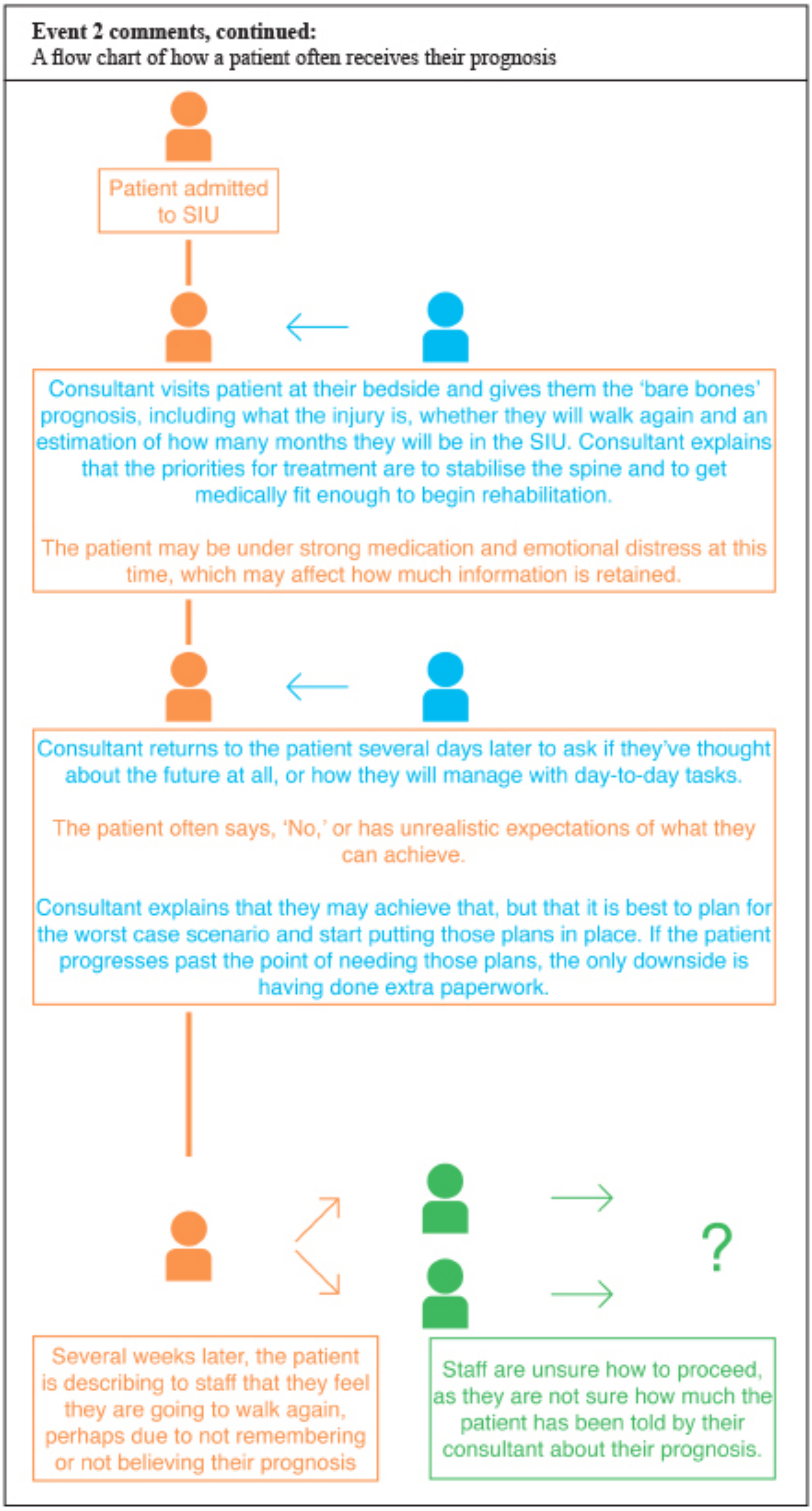
Fig. 7.16: An overview of the people, tools, activities and outcomes from Event 2.

Prognosis protocol

Whilst the information given in the Event summaries aim to provide a concise overview of the co-design process, additional contextual information is required at this point to fully explain the relevance of introducing a second prognosis meeting.

In Event 2, the idea of explaining the GPM process prior to the patient's first meeting, as well as the outpatient participants' comments about an unclear prognosis, prompted the co-supervisor to suggest introducing a second prognosis meeting several weeks into the rehabilitation pathway. It was suggested that this may also address the resonant needs of the staff, as explained in the prognosis flow chart in fig. 7.17 below.

According to the co-supervisor, discussing the prognosis in more detail could help communication between the patient and staff across different departments, allow patients to prepare for their GPMs and possibly enhance the focus of the GPM itself by clarifying the concept of 'end goals'.



Event 2 comments, continued:
A flow chart of how a patient often receives their prognosis

Patient admitted to SIU

Consultant visits patient at their bedside and gives them the 'bare bones' prognosis, including what the injury is, whether they will walk again and an estimation of how many months they will be in the SIU. Consultant explains that the priorities for treatment are to stabilise the spine and to get medically fit enough to begin rehabilitation.

The patient may be under strong medication and emotional distress at this time, which may affect how much information is retained.

Consultant returns to the patient several days later to ask if they've thought about the future at all, or how they will manage with day-to-day tasks.

The patient often says, 'No,' or has unrealistic expectations of what they can achieve.

Consultant explains that they may achieve that, but that it is best to plan for the worst case scenario and start putting those plans in place. If the patient progresses past the point of needing those plans, the only downside is having done extra paperwork.

Several weeks later, the patient is describing to staff that they feel they are going to walk again, perhaps due to not remembering or not believing their prognosis

Staff are unsure how to proceed, as they are not sure how much the patient has been told by their consultant about their prognosis.

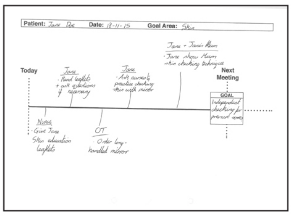
Fig. 7.17: A flow chart explaining how a patient currently learns about their prognosis.

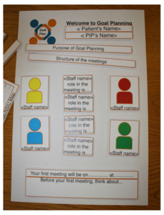
Event 3:

Workshop 2: Inpatient Group

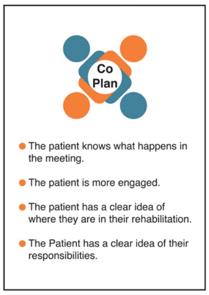
Participants: 1 female, 3 male paraplegic inpatients.

Prototypes: Blank/completed Timeline concept, ‘Introduction to GPM’ Game.

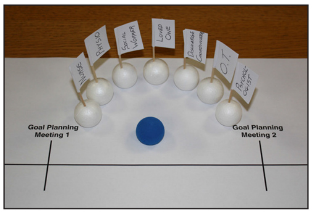


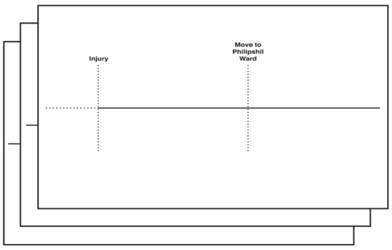


Tools: Experience Goals, Character Pieces, Large Rehabilitation Timelines



- The patient knows what happens in the meeting.
- The patient is more engaged.
- The patient has a clear idea of where they are in their rehabilitation.
- The Patient has a clear idea of their responsibilities.





Activities: Discuss and edit each concept in turn, using the tools:

1. Concept One: ‘Introduction to Goal Planning’ event, shortly after moving onto the Rehabilitation Ward.
2. Concept Two: Prognosis Meeting, to set ‘end goals’ for discharge on a timeline of the whole rehabilitation journey (from injury to returning to the community).
3. Concept Three: Task Timelines: A4 timelines showing the tasks planned for each ‘end goal’ for the next 4 weeks, to be used in the Goal Planning Meetings.

Comments

The large rehabilitation timeline was the only tool used consistently.
To be involved in the GPM, patients need to be involved and informed much earlier – perhaps an ‘Introduction to Rehabilitation’ meeting instead? The transition to rehabilitation ward is a difficult, confusing time. Patients need a clear understanding of what each discipline is responsible for in this ward, and a timeline of key rehabilitation events would also support this. Participants stated, without prompting, that they would have preferred a clearer understanding of their prognosis earlier and were positive about the idea of a second prognosis meeting. Finally, patients stated that personalised goals should be set collaboratively in the meeting, but patients may need support in thinking about their personal priorities. Participants felt patients should have their own record of the GPM.

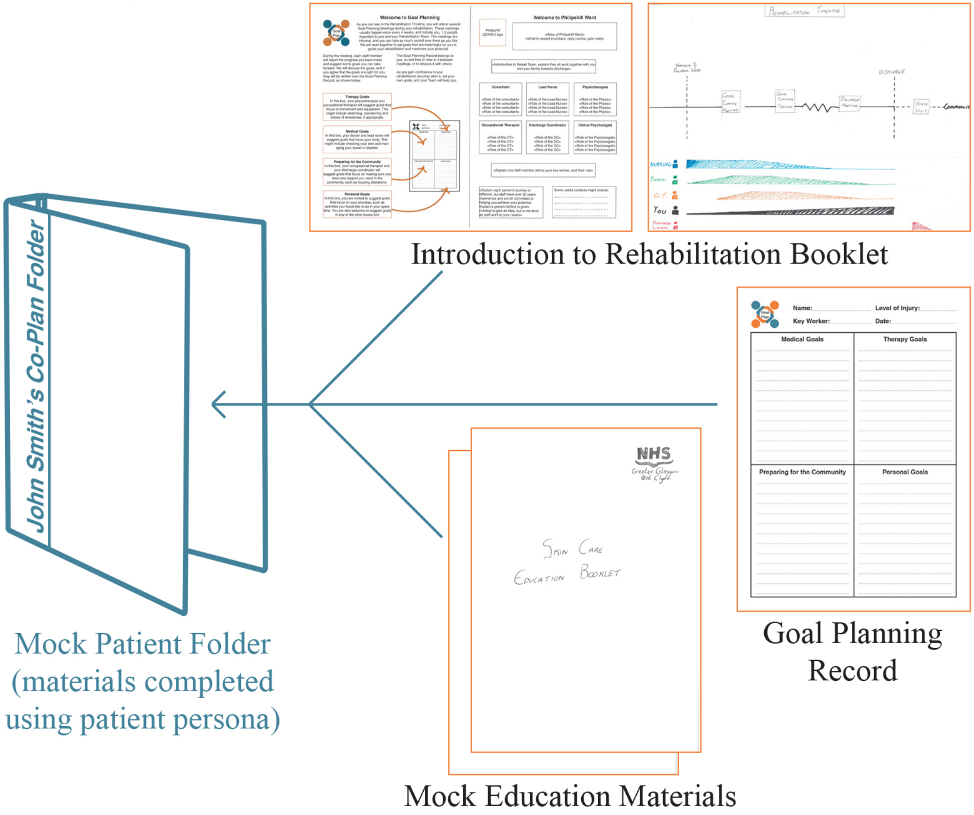
Fig. 7.18: An overview of the people, tools, activities and outcomes from Event 3.

Event 4:

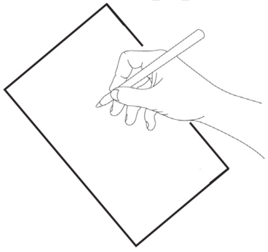
Workshop 3: Inpatient Group

Participants: 1 female, 3 male paraplegic inpatients.

Prototypes: Mock patient folder with redrafted prototype materials.



Tools: Additional paper and pens.



Activities

Informal discussion and feedback on each prototype in turn.

Comments

Participants suggested minor changes to some details in the 'Introduction to Rehabilitation booklet, and were happy with the Goal Planning Record. It was suggested that when staff discuss goals in the GPM, they should make it clear that they can be adapted according to patient priorities. One participant suggested that 'goals and achievements get mixed up' and that perhaps progress should be covered in the first 10 minutes of the GPM. This participant also suggested that 'Goals belong to staff, progress belongs to patient.' This is an interesting idea to take forward.

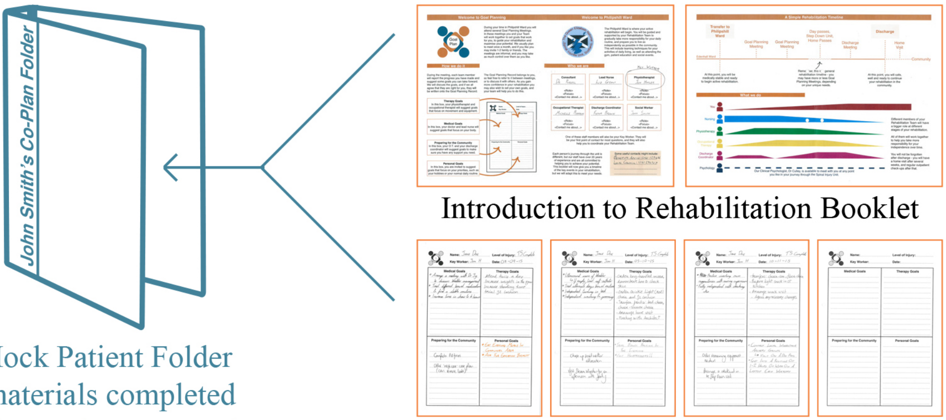
Fig. 7.19: An overview of the people, tools, activities and outcomes from Event 4.

Event 5:

**Workshop 4:
Staff Group**

Participants: SIU staff (Medical, Therapy, Discharge)

Prototypes: Mock patient folder with redrafted prototype materials.

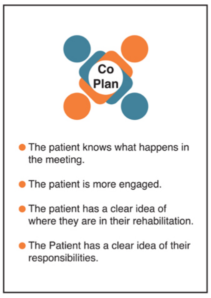


Mock Patient Folder
(materials completed
using patient persona)

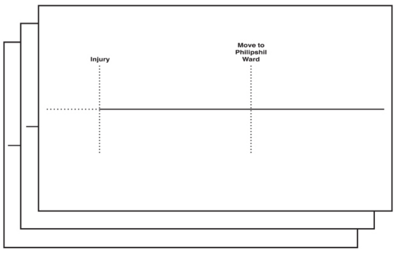
Introduction to Rehabilitation Booklet

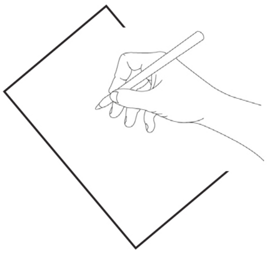
Completed Goal Planning Records

Tools: Experience Goals, Rehab Timelines, plus additional paper and pens.



- The patient knows what happens in the meeting.
- The patient is more engaged.
- The patient has a clear idea of where they are in their rehabilitation.
- The Patient has a clear idea of their responsibilities.





Activities

The researcher explained each prototype in turn, using blank copies and the mock patient folder, encouraging the staff to edit them as necessary.

Comments

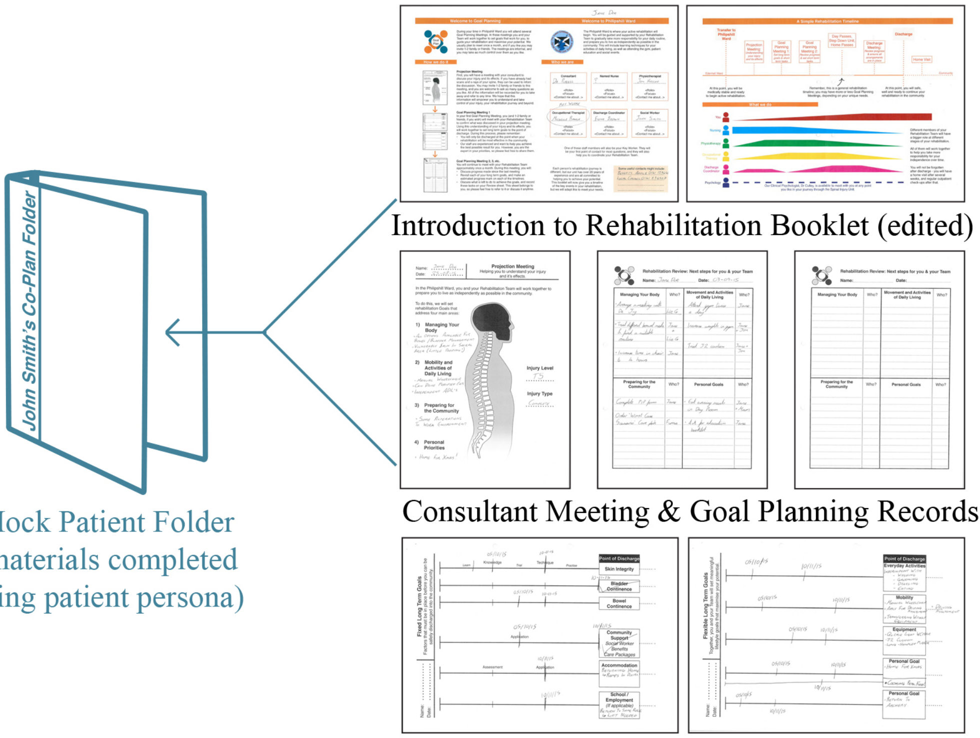
Staff contributed verbally whilst the researcher took notes and edited the prototypes in real time. Most contributions related to minor changes in the formatting, such as different headings or signposting useful resources.
Discussions on the completed Goal Planning Records highlighted a need to separate ‘goals’ and ‘to-do’s’.
The prototypes do not yet relate the short-term goals to the long-term goals, although this could be helped by using different language in the GPM.
A second prognosis meeting would be useful for staff and patients, especially if supported by a 3D model of a spine and printouts of the patient’s x-rays. All staff agreed the Consultant should conduct the meeting, but all of the rehabiliation team need to know what has been said. As such, a supporting material will be needed to take notes on what has been said, for the patient to keep and to share with their rehabilitation team.

Fig. 7.20: An overview of the people, tools, activities and outcomes from Event 5.

Event 6: Workshop 5: Staff Group (Unit Meeting)

Participants: SIU staff (Medical, Therapy, Discharge)

Prototypes: Mock patient folder with redrafted prototype materials.



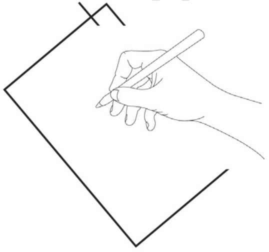
Introduction to Rehabilitation Booklet (edited)

Consultant Meeting & Goal Planning Records

Fixed & Flexible Long Term Goal Timelines

Mock Patient Folder (materials completed using patient persona)

Tools: Additional paper and pens.



Activities

The researcher explained each prototype in turn, using blank copies and the mock patient folder, encouraging the staff to edit them as necessary.

Comments

Staff received the redrafted prototypes very positively, with a few questions about how to use the materials and a few minor changes to the structure. Potential issues were identified and resolved through group discussion. The researcher now needs to find distinct-looking patient folders and storage options, to avoid patients accidentally making notes in hospital records. Staff suggested conducting a mock GPM with the new materials to test them more fully. Staff felt that this mock should only involve staff members whilst the materials are being refined, so ‘we can be really awkward with each other, and find out if it works alright or not.’ (Patient Education Nurse).

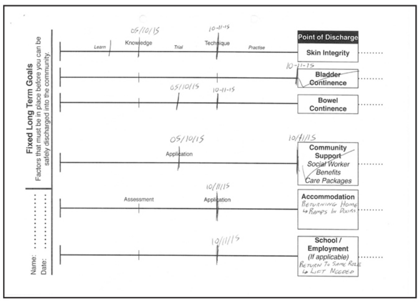
Fig. 7.21: An overview of the people, tools, activities and outcomes from Event 6.

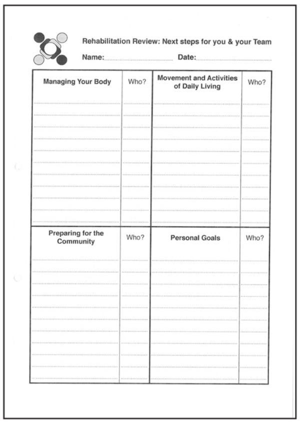
Event 7:

Individual Staff Meetings

Participants: Psychologist, OT, Discharge Coordinator

Prototypes: Long-term Goal Timelines and Goal Planning Record.



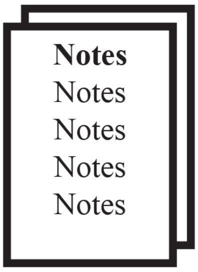


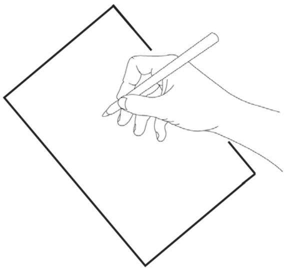
Rehabilitation Review: Next steps for you & your Team

Name:............ Date:............

Managing Your Body	Who?	Movement and Activities of Daily Living	Who?
Preparing for the Community	Who?	Personal Goals	Who?

Tools: Notes on outstanding issues, plus additional paper and pens.





DRESSING PATIENT DUPLICATE NOTES	BLADDER CONTINENCE PATIENT DUPLICATE NOTES	PATIENT DUPLICATE NOTES
SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES
SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES
SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES
SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES
SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES
SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES	SIU RESPIRATORY PATIENT DUPLICATE NOTES

Left: Example of the ‘stickies’ resource described below.

Activities

Individual meetings with three staff members to clarify unresolved issues with the prototypes, such as appropriate headings for long-term goals.

Comments

Goals need to be communicated and recorded in SMART terms (Specific, Measurable, Achieveable, Relevant, Time-bound).
The materials shouldn’t switch between landscape and portrait formats, as some patients won’t be able to tilt their heads or turn the pages themselves.
We may need to further consider how short- and long-term goals relate.

The Consultant Meeting must use unambiguous language and provide a consistent message from the rest of the team.

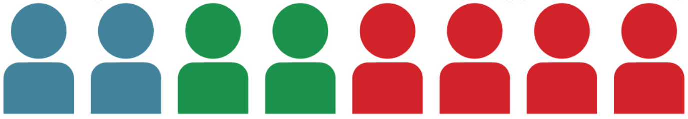
When discussing the best headings for short- and long-term goal records, the OT suggested using an existing resource in the SIU - printable adhesive labels known as ‘stickies’. The OT suggested the long-term goal headings could be printed and applied onto generic timelines in the patient’s order of priority. This will be developed into a full prototype for the next workshop.

Fig. 7.22: An overview of the people, tools, activities and outcomes from Event 7.

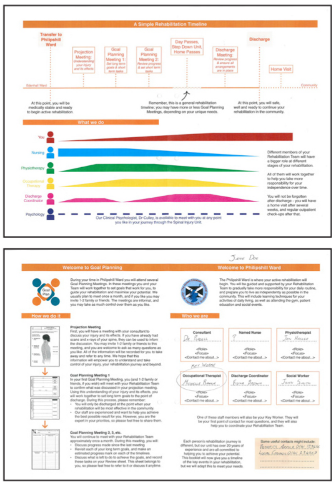
Event 8:

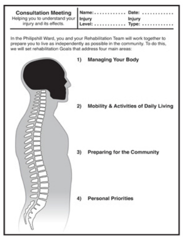
Enactment 1: Staff Group

Participants: SIU staff (Medical, Therapy, Discharge)

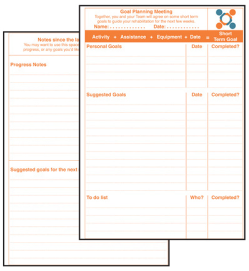


Prototypes: Blank copies of each material below.



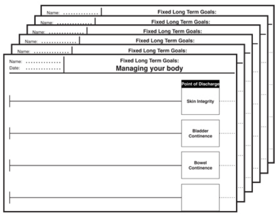


Consultant Meeting Record

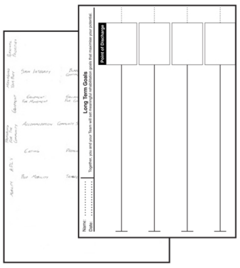


GPM Record

Introduction to Rehabilitation



Long-Term Goals: Option A



Long-Term Goals: Option B

Activities

The researcher began by explaining the changes made to the prototypes since the last workshop, including the addition of the ‘stickies’ concept. Each stage of the intervention was explained by the researcher, supported by a set of process flow charts given to each participant.

After a detailed discussion on the Consultant Meeting, the staff were given the option to trial the previous method of setting long-term goals or the new ‘stickies’ prototypes. The staff chose to trial the latter, and the OT took the lead on using the prototypes to act out aspects of a Key Worker Meeting.

Comments

The intervention must provide enough structure to be delivered consistently. Setting the long-term goals using the ‘stickies’ method may take longer, so this activity should be a separate, preparatory meeting with the Key Worker prior to the first GPM. The ‘stickies’ method may also make the conversation jump between the different disciplines in the meeting.

Staff began to conduct short enactments using the materials without being prompted, and identified several potential issues; how to keep track of several different pieces of paper, how to handle disparate views of progress between the patient and staff; how to record ‘goals’ and ‘to do’s’.

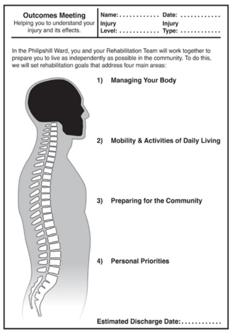
Staff suggested several solutions to address the above issues by using the materials differently, rather than by making large changes to the prototypes. After some minor formatting changes, participants agreed that a full, staff-only enactment of each stage of the intervention is necessary to progress.

Fig. 7.23: An overview of the people, tools, activities and outcomes from Event 8

Event 9:
Enactment 2a:
‘Patient’ and
Consultant

Participants: Consultant and Nurse (acting as a patient)

Prototypes:
Consultant
Meeting Record



Outcomes Meeting
Helping you to understand your injury and its effects.

Name:............ Date: ....
Injury Level: .... Injury Type: ....

In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community. To do this, we will set rehabilitation goals that address four main areas:

1) **Managing Your Body**

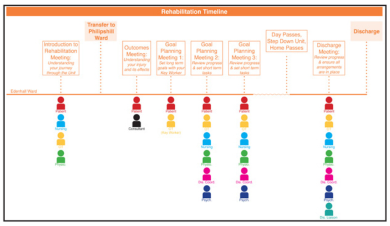
2) **Mobility & Activities of Daily Living**

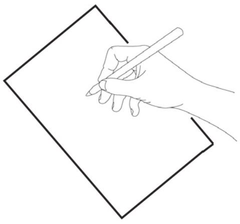
3) **Preparing for the Community**

4) **Personal Priorities**

Estimated Discharge Date:............

Tools: Intervention timeline to assist the ‘patient’s’ understanding of the process (as he was new to the project), a 3D model of the spine, plus additional paper and pens to support ad-hoc changes if needed.





Activities

The Consultant and ‘patient’ conducted a mock Consultant Meeting using the prototype and supporting materials. The researcher was passive during the meeting except one interruption to check when the Consultant wished to use the Record. The researcher took notes on aspects that worked well.

Comments

The Consultant used natural, empathetic, clear language and did not need guidance from the researcher to conduct the meeting. All participants agreed that the Consultant Meeting Record should be completed at the end of the meeting, to preserve the ‘flow’ of the conversation.
The ‘patient’ preferred the idea of individual meetings with the Consultant and Key Worker prior to the first GPM ‘rather than being pitched in with a whole group of people talking over them.’
The Consultant predicted that the real patients will ask more questions, but that the Consultants will be happy to ‘play it by ear a little bit’.
The Consultant Meeting Record was referred to several times during the meeting, suggesting that it infers a clear meeting structure that ensures all of the necessary topics are covered. The Consultant chose to record the topics discussed under each heading rather than details of the discussion.
Neither participant suggested any changes, other than the Consultant will need to be reactive to how much information each patient is ready for.

Fig. 7.24: An overview of the people, tools, activities and outcomes from Event 9.

Event 10:
Enactment 2b:
‘Patient’ and
Key Worker

Participants: OT Key Worker and ‘patient’

Prototypes: The ‘stickies’ of long-term goals headings and blank timelines.

PERSONAL PRIORITIES

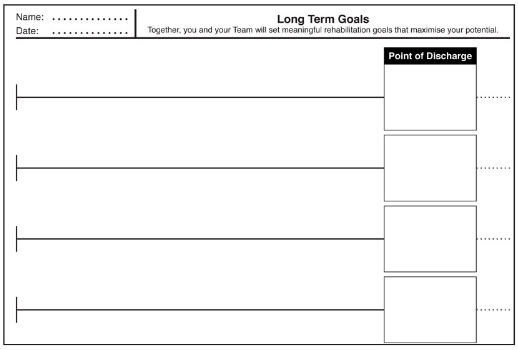
MANAGING YOUR BODY
Skin Integrity:
Bladder Continence:
Bowel Continence:

MOBILITY & ACTIVITIES OF DAILY LIVING
Bed Mobility:
Transferring:
Getting Around:
Eating:
Washing:
Dressing:
Grooming:

PREPARATION FOR THE COMMUNITY
Accommodation:
Community Support:
Education/Work:

EQUIPMENT
Equipment For Movement:
Equipment For Daily Living:
Other Equipment

OTHER
Social Activities:
Driving:
Sexual Issues/Fertility:
Other Equipment:
Autonomic Dysreflexia:
Chest Management:
Joint Management:



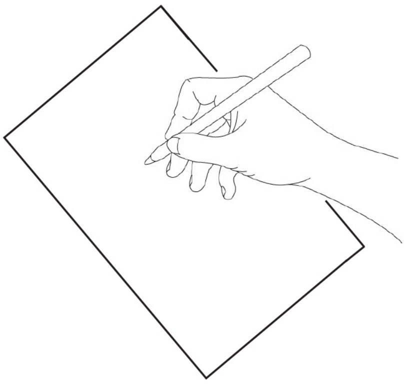
Name: ....
Date: ....

Long Term Goals

Together, you and your Team will set meaningful rehabilitation goals that maximise your potential.

Point of Discharge

Tools: Additional paper and pens to facilitate ad-hoc alterations if necessary



Activities

The OT Key Worker and ‘patient’ conducted a mock Key Worker Meeting using the prototypes as they felt most appropriate, with no further instructions given to the OT Key Worker.

Comments

There may be no need to mark the progress made on the Long-Term Goal Timelines in this meeting, as the patient will be at an early stage of their rehabilitation.

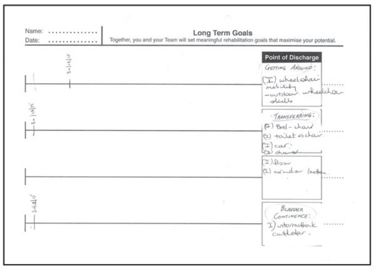
No changes were suggested to the prototypes, but the OT Key Worker was observed writing directly onto the timeline sheets when the ‘stickies’ did not use accurate language or sufficient detail to reflect the patient’s goals.

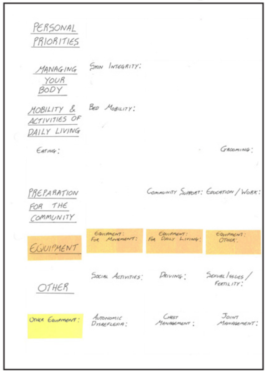
Fig. 7.25: An overview of the people, tools, activities and outcomes from Event 10.

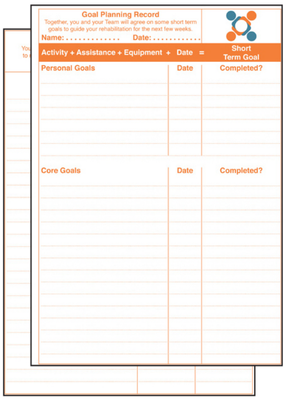
Event 11:
Enactment 2c:
'Patient' and
Rehabilitation Team

Participants: Medical, Therapy, Discharge staff, 'patient'

Prototypes: Long-term Goal Timelines, 'stickies' remaining and the Goal Planning Meeting Record (for short-term goals)

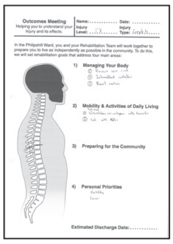

Name: ....
Date: ....
Long Term Goals
Together, you and your Team will set meaningful rehabilitation goals that maximise your potential.
Point of Discharge
Getting Around:
(I) wheelchair mobility
-outdoor wheelchair skills
Transferring:
(I) Bed-chair
(I) toilet & chair
(I) car
(I) shower
(I) floor
(I) armchair (settee
Bladder Continence:
I) intermittent catheter

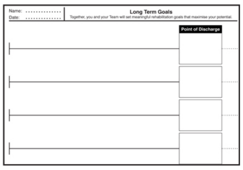


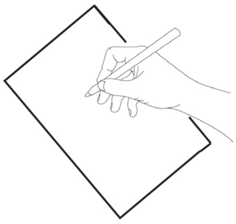

Goal Planning Record
Together, you and your Team will agree on some short term goals to guide your rehabilitation for the next few weeks.
Name: .... Date: ....

Activity + Assistance + Equipment +	Date =	Short Term Goal
Personal Goals	Date	Completed?
Core Goals	Date	Completed?

Tools: Completed Consultant Meeting Record, extra blank Long-Term Goal Timelines and additional paper and pens (to facilitate ad-hoc alterations).


Outcomes Meeting
Helping you to understand your injury and its effects.
Name: .... Date: ....
Injury Level: ..C7.... Injury Type: Complete.....
In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community. To do this, we will set rehabilitation goals that address four main areas:
1) Managing Your Body
① Pressure sore risk
② Intermittent catheter
③ Bowel routine
2) Mobility & Activities of Daily Living
3) Preparing for the Community
4) Personal Priorities
Fertility
Career
Estimated Discharge Date: ....


Name: ....
Date: ....
Long Term Goals
Together, you and your Team will set meaningful rehabilitation goals that maximise your potential.
Point of Discharge



Activities

The staff conducted a mock GPM using the materials as they felt most appropriate (approximately 50 minutes). Staff mostly kept in character other than to confirm details of the patient persona with each other.
The mock GPM was then followed by an 'out of character' discussion on the intervention as a whole and how to proceed (approximately 40 minutes).

Comments

All participants agreed the earlier stages of the intervention were the most successful. The Consultant Meeting was described as 'absolutely vital.'
The Key Worker stated that further detail on the Consultant Meeting Record was needed, so the group agreed that, for the Phase Three trial, Key Workers could be assigned in time to attend the Consultant Meeting and act as a scribe. The Key Worker Meeting was described as particularly helpful to review what the patient had learned in the Consultant Meeting, address any questions or concerns and begin discussing the patient's priorities on the back of that discussion. However, the 'stickies' were difficult to use in reality, and a checklist approach was suggested as an alternative.

(Continued overleaf)

Fig. 7.26: An overview of the people, tools, activities and outcomes from Event 11.

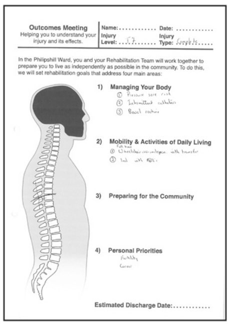
Event 11 Comments, continued

Staff were positive about the Long-Term Goal Timelines as a more understandable view of progress than the SCIM ‘numbers’, as well as being good to highlight the progress the patient has already made in the first GPM. The ‘patient’ felt that the order of goals better reflected how issues may really come to mind for the patients, that he felt ‘very listened to’ and that he could volunteer information important to him.

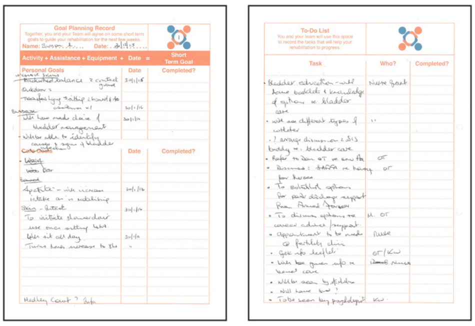
However, ordering the Long-Term Goals by the patient priorities does cause the conversation to jump around between the different disciplines in a GPM. This could be problematic when trying to minute the meeting and when trying to assign SCIM scores, but staff had mixed opinions about whether minutes or SCIM scores are necessary in every GPM. The Goal Planning Record was the hardest material to use, as staff don’t naturally suggest goals in SMART terms. However, some participants still felt it was important that patients have one sheet with all of their goals for the month.

The biggest concern held by staff was the potential for goals to be missed out of the meeting due to the conversation ‘jumping around’ between disciplines. Moving forward, one staff member suggested replacing the ‘stickies’ concept with a material that groups each long-term goal by discipline, and asking the patient to highlight their priorities within each discipline. Another participant suggested that staff could then prepare for the GPM in the normal way and the Key Worker could scribe the short-term goals onto the new Goal Planning Record.

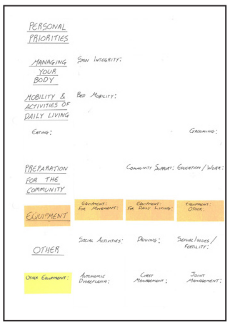
Completed Enactment Materials



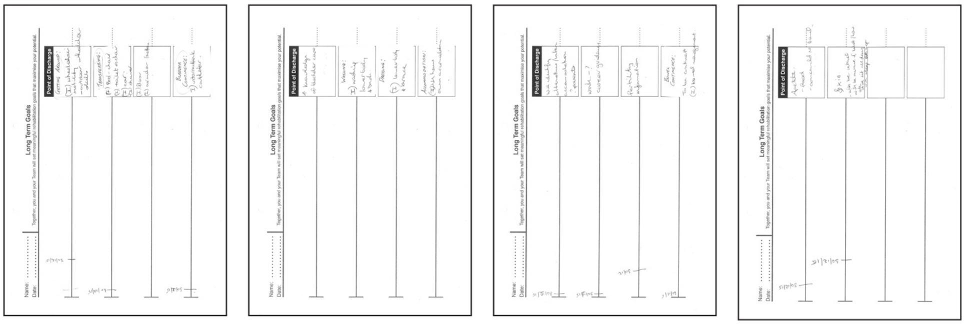
Consultant Meeting Record



Goal Planning Meeting Records



‘Stickies’ left unused



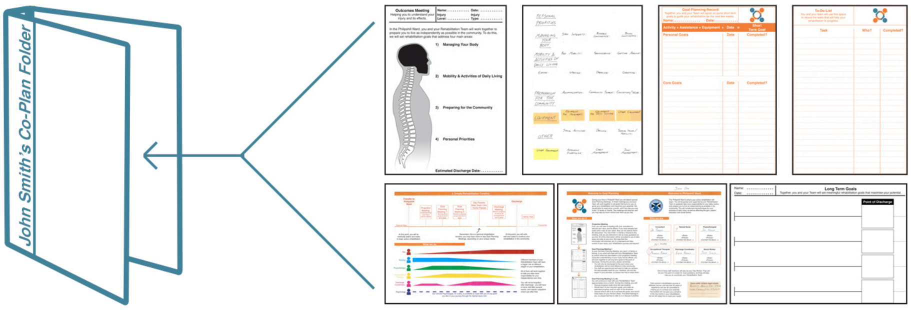
Long-Term Goal Timelines

Fig. 7.27: Continued comments from Event 11.

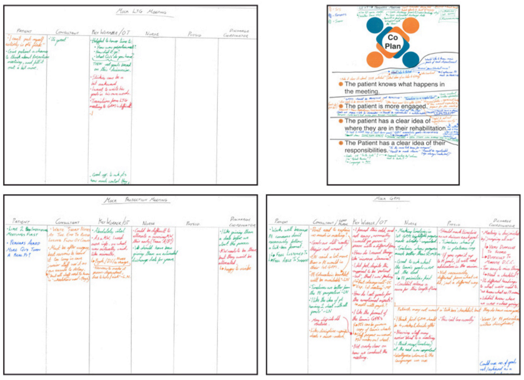
Event 12: Meeting with Design-based Supervisor

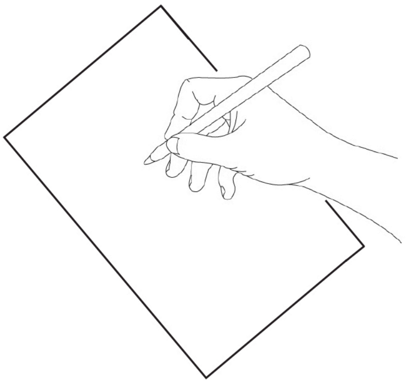
Participants: Design-based Supervisor

Prototypes: Blank and completed prototypes of each intervention stage.



Tools: Collated participant feedback mapped onto tables of events and onto the original Experience Goals, colour coded by discipline.





Activities

Informal discussion on the progress and issues to date.

Comments

After discussing the conflicting viewpoints and sense of inertia in how to move the prototypes forward, the Supervisor suggested collecting all of the long-term goals onto one material; literally getting the patient and staff ‘on the same page’. The researcher agreed that this would also help to reduce the number of materials used in the GPM, and that the long-term goals could be grouped by discipline to avoid making the conversation ‘jump around’ between disciplines.

The researcher spent two days creating several options of the ‘all on one page’ concept to replace the current long-term goal timelines, as shown overleaf. In each prototype, the patient and Key Worker would set the long-term goals together using the headings provided to ensure nothing is missed. The smaller timelines in each box are then used in the GPMs to denote progress made towards each long-term goal.

Fig. 7.28: An overview of the people, tools, activities and outcomes from Event 12.

‘On One Page’ Long-Term Goal grid concepts

Long Term Goals
Goals to aim for by discharge, set by you and your Team.
Name:
Injury Level:
Date:
Injury Type:

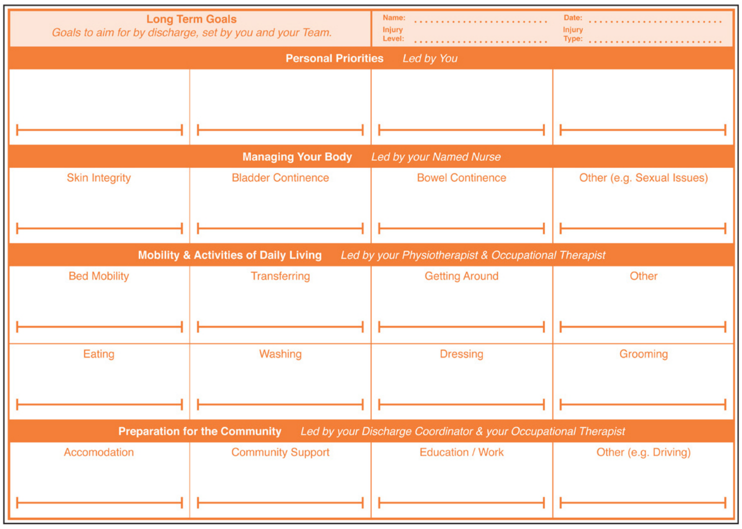
Personal Priorities *Led by You*

Managing Your Body *Led by your Named Nurse*
Skin Integrity | Bladder Continence | Bowel Continence | Other (e.g. Sexual Issues)

Mobility & Activities of Daily Living *Led by your Physiotherapist & Occupational Therapist*
Bed Mobility | Transferring | Getting Around | Other Mobility
Eating | Washing | Dressing | Grooming

Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*
Accomodation | Community Support | Education / Work | Other (e.g. Driving)

Option A



Long Term Goals
Goals to aim for by discharge, set by you and your Team.
Name:
Injury Level:
Date:
Injury Type:

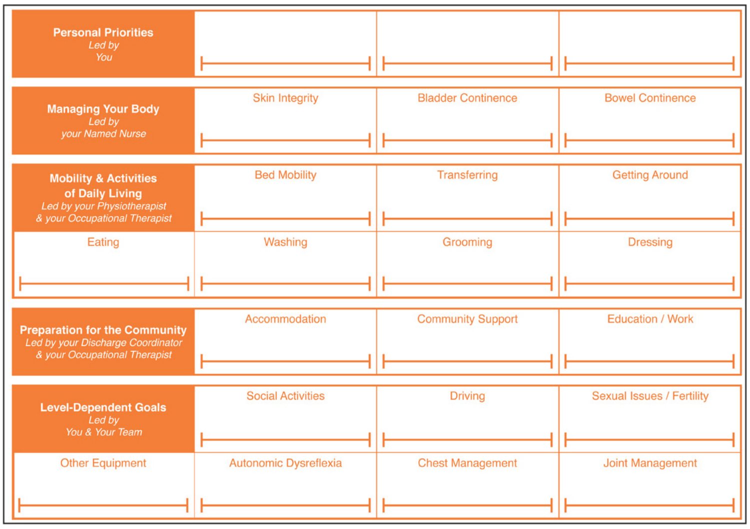
Personal Priorities *Led by You*

Managing Your Body *Led by your Named Nurse*
Skin Integrity | Bladder Continence | Bowel Continence | Other (e.g. Sexual Issues)

Mobility & Activities of Daily Living *Led by your Physiotherapist & Occupational Therapist*
Bed Mobility | Transferring | Getting Around | Other
Eating | Washing | Dressing | Grooming

Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*
Accomodation | Community Support | Education / Work | Other (e.g. Driving)

Option B



Personal Priorities *Led by You*

Managing Your Body *Led by your Named Nurse*
Skin Integrity | Bladder Continence | Bowel Continence

Mobility & Activities of Daily Living *Led by your Physiotherapist & your Occupational Therapist*
Bed Mobility | Transferring | Getting Around
Eating | Washing | Grooming | Dressing

Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*
Accommodation | Community Support | Education / Work

Level-Dependent Goals *Led by You & Your Team*
Social Activities | Driving | Sexual Issues / Fertility
Other Equipment | Autonomic Dysreflexia | Chest Management | Joint Management

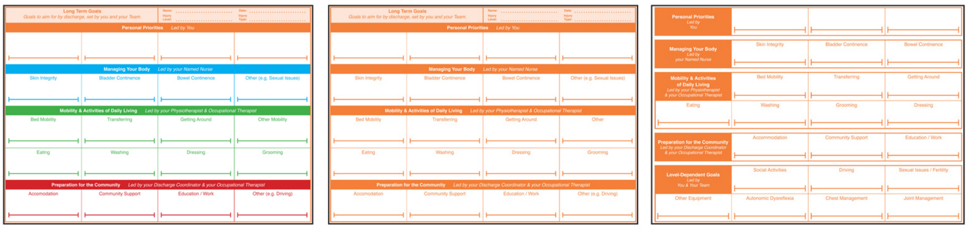
Option C

Fig. 7.29: Continued comments from Event 12.

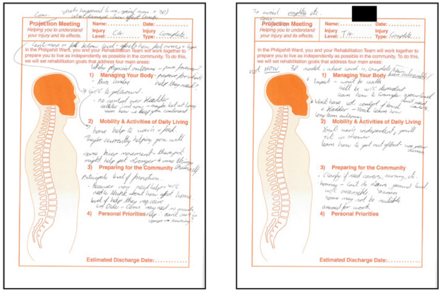
Event 13: Meetings with individual staff members

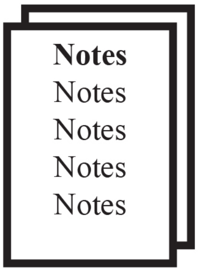
Participants: Psychologist and Phase 3 Key Workers

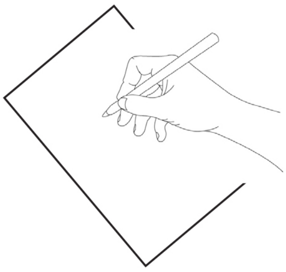
Prototypes: Initial Timeline prototype and sketch ideas from Event 1.



Tools: Blank Consultant Meeting Records, Notes from last session







Activities

The researcher arranged meetings with the Clinical Psychologist (who was unable to attend Enactments 2a, 2b or 2c) as well as the recently allocated core staff who would be acting as Key Workers in Phase Three. These meetings aimed to clarify some of the feedback from the enactments and to propose the 'on one page' concept to support the Key Worker Meeting.

Comments

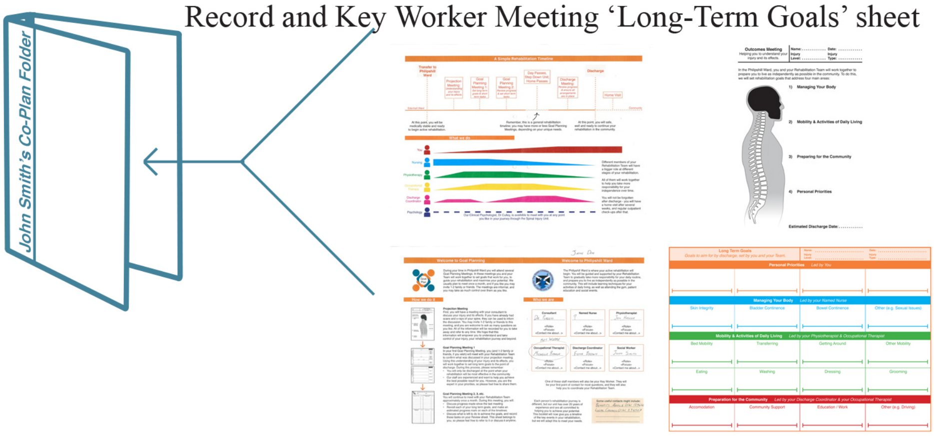
The psychologist provided useful feedback on the format of some prototypes, and advised the researcher to maintain a focus on the short-term goals, as they will be driving the patient's behaviour week-to-week.
The Key Workers gave feedback (using the Consultant Meeting Record as a prompt) on what should be covered in the Consultant Meeting, as well as in how much detail (giving example phrases the Consultant could use).
In a longer meeting with the OT Key Worker, Option A of the 'On One Page' concept was highlighted as the most promising, due to the colour coding of each discipline in the GPM. The Key Worker felt that the prototype gave enough room to write the long-term goals under each heading, but queried how to resolve differences in opinion between the patient and Key Worker if they occur during this process.
Staff highlighted the need for a clear space to write the 'to-do's' in the Goal Planning Record.

Fig. 7.30: An overview of the people, tools, activities and outcomes from Event 13.

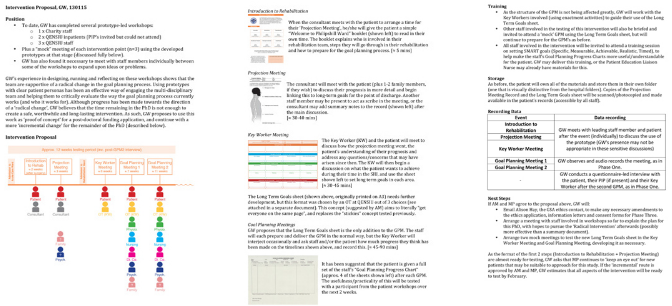
Event 14: Independent Design Work: Cohesive Intervention

Participants: Researcher

Prototypes: ‘Introduction to Rehabilitation’ booklet, Consultant Meeting Record and Key Worker Meeting ‘Long-Term Goals’ sheet



Tools: Cohesive intervention proposal, explaining each stage in turn.



Activities

Review all feedback to date and converge on one cohesive intervention.

Comments

At this point, the staff participants appeared to be divided in how they wished to proceed with the project - either to continue the workshops to create a radical change in the GPMs, or to refine the current prototypes and trial incremental changes to the rehabilitation pathway. The researcher felt that she needed to move outside of her planned role of ‘facilitator’ and make active design decisions in order to commit to a cohesive intervention to take forward. After reflecting on the staff feedback to date, her own design experience and (most importantly) which direction was more likely to provide a smooth, safe experience for the patient, the researcher chose to take the more incremental changes forward into Phase Three. The whole intervention was summarised into a report for both supervisors, including the ‘Introduction to Rehabilitation’ Booklet, the Consultant Meeting and the Key Worker Meeting. The supervisors supported the decisions made, so the researcher took this proposal to the 3 Key Workers recruited for Phase Three.

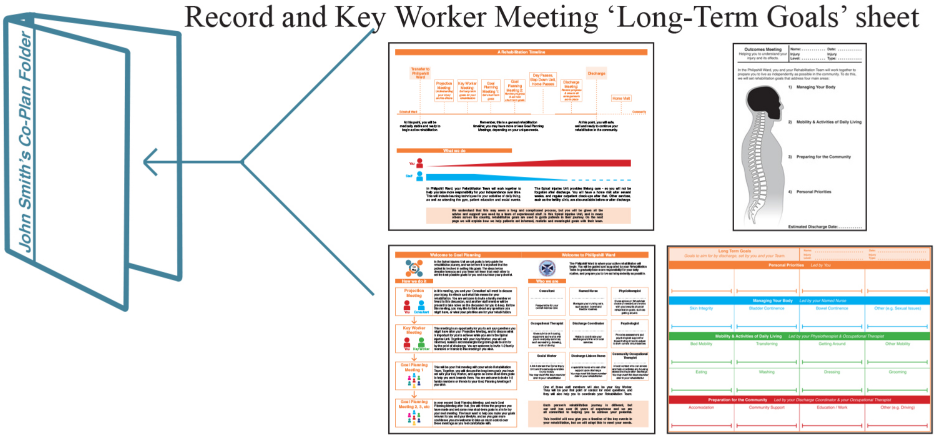
Fig. 7.31: An overview of the people, tools, activities and outcomes from Event 14.

Event 15:

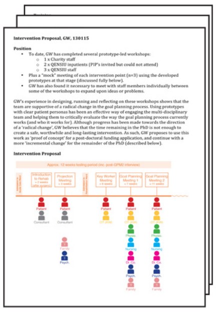
Workshop 6: Key Worker Group

Participants: 3 Key Workers recruited for Phase Three

Prototypes: ‘Introduction to Rehabilitation’ booklet, Consultant Meeting Record and Key Worker Meeting ‘Long-Term Goals’ sheet



Tools: Intervention proposal, plus additional paper and pens.



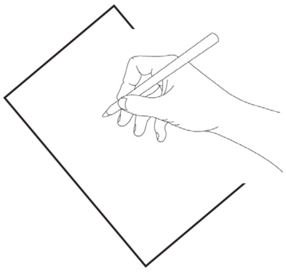
Intervention Proposal, GW, 130115

Position

- To date, GW has completed several prototype-led workshops:
  - 1 x Charity staff
  - 2 x QENSIU inpatients (PIP's invited but could not attend)
  - 3 x QENSIU staff
- Plus a "mock" meeting of each intervention point (n=3) using the developed prototypes at that stage (discussed fully below).
- GW has also found it necessary to meet with staff members individually between some of the workshops to expand upon ideas or problems.

GW's experience in designing, running and reflecting on these workshops shows that the team are supportive of a radical change in the goal planning process. Using prototypes with clear patient personas has been an effective way of engaging the multi-disciplinary team and helping them to critically evaluate the way the goal planning process currently works (and who it works for). Although progress has been made towards the direction of a 'radical change', GW believes that the time remaining in the PhD is not enough to create a safe, worthwhile and long-lasting intervention. As such, GW proposes to use this work as 'proof of concept' for a post-doctoral funding application, and continue with a more 'incremental change' for the remainder of the PhD (described below).

Intervention Proposal



Activities

Staff were asked to take notes if they had any comments or questions whilst the researcher talked through each stage of the proposed intervention. Staff agreed this would be a useful approach, to avoid asking questions that would be answered later and to support discussion in the second half of the meeting.

Comments

Staff were positive about the proposal and agreed to take it forward with some small alterations. This included a suggestion to reformat the ‘On One Page’ sheet into a booklet, to make more space to write the long-term goals (shown overleaf). Staff also requested an agenda to support Consultants in preparing for and delivering the Consultant Meeting, to ensure all of the necessary topics are discussed in an appropriate amount of detail.
After noticing the removal of the Goal Planning Record from the intervention, the staff stated that they would like to trial it in Phase Three.
The group agreed that all staff members should prepare for the GPMs in the normal manner, so that additional staff training would not be needed and so none of the goals that are normally set would be missed.

Fig. 7.32: An overview of the people, tools, activities and outcomes from Event 15.

Long-Term Goal Booklet Concepts (page numbers added for clarity)

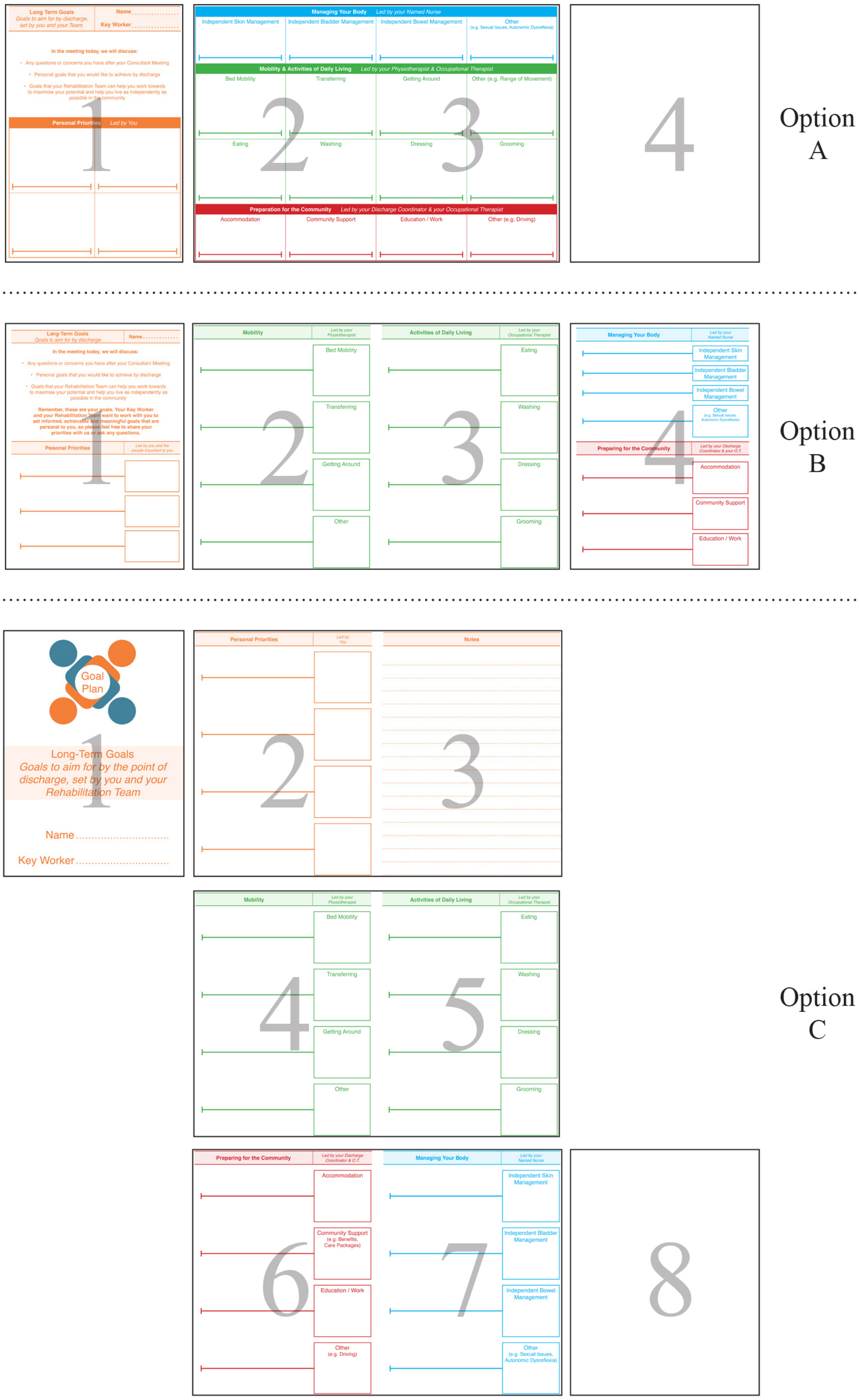
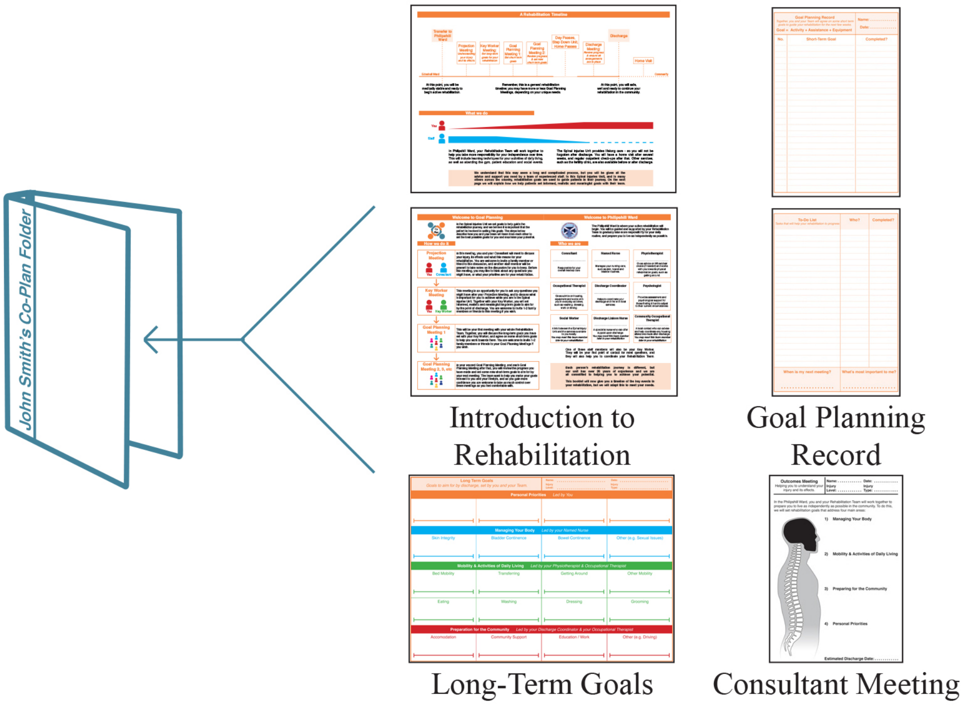


Fig. 7.33: Continued comments from Event 15.

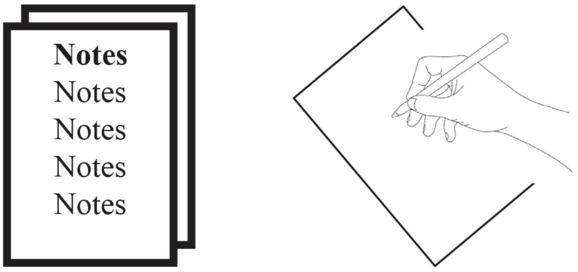
Event 16: Meeting with Healthcare-based Supervisor

Participants: Healthcare-based Supervisor

Prototypes: Blank and completed prototypes for each stage of the intervention



Tools: Notes from Event 15, plus additional paper and pens.



Activities

Informal discussion on the changes made to the intervention proposal after the recent workshop with the 3 Key Workers recruited for Phase Three.

Comments

The Co-Supervisor suggested that the researcher re-draft the current Goal Planning Progress Chart (the SIU resource used by staff to prepare for the GPM) to remind staff they are part of a new Goal Planning system.

The Co-Supervisor also agreed that the intervention should include a Goal Planning Record for the patient to keep, suggesting minor formatting edits.

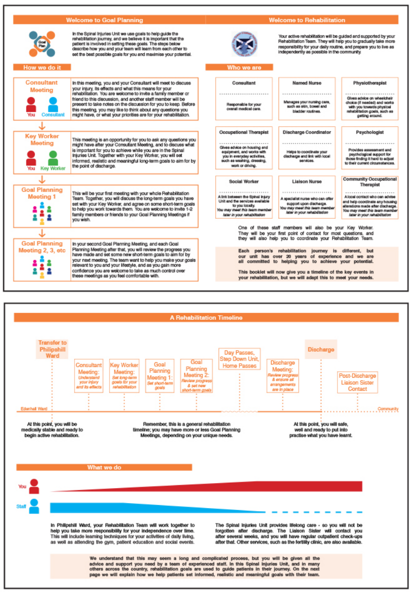
Fig. 7.34: An overview of the people, tools, activities and outcomes from Event 16.

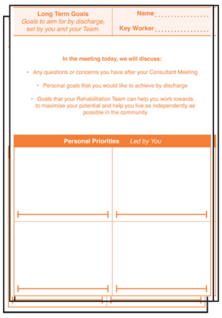
Event 17:

Independent Design Work

Participants: Phase Three Key Workers & SIU staff

Prototypes: 'Introduction to Rehabilitation' and Long-Term Goals Booklets





Long Term Goals
Goals to aim for by discharge, set by you and your Team.

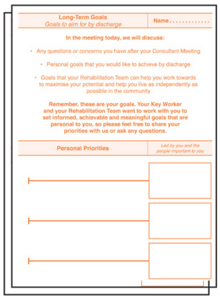
Name.................

Key Worker.................

In the meeting today, we will discuss:

- Any questions or concerns you have after your Consultant Meeting
- Personal goals that you would like to achieve by discharge
- Goals that your Rehabilitation Team can help you work towards to maximise your potential and help you live as independently as possible in the community

Personal Priorities *Led by You*



Long-Term Goals
Goals to aim for by discharge

Name.............

In the meeting today, we will discuss:

- Any questions or concerns you have after your Consultant Meeting
- Personal goals that you would like to achieve by discharge
- Goals that your Rehabilitation Team can help you work towards to maximise your potential and help you live as independently as possible in the community

Remember, these are your goals. Your Key Worker and your Rehabilitation Team want to work with you to set informed, achievable and meaningful goals that are personal to you, so please feel free to share your priorities with us or ask any questions.

Personal Priorities *Led by you and the people important to you*

Long-Term Goals
Goals to aim for by the point of discharge, set by you and your Rehabilitation Team

Name..............................

Key Worker..............................

Activities

A digital copy of the redrafted 'Introduction to Rehabilitation' booklet was sent via email to all staff who had participated in the workshops, who were invited to review the contents before the start of Phase Three.
Concurrently, the three Long-Term Goals booklets were presented to the three Key Workers recruited for Phase Three (individually) to chose one format to take forward, with or without minor alterations.

Comments

Minor changes to the terminology and formatting were suggested for the 'Introduction to Rehabilitation' booklet (from two staff emails and one hand-annotated printout of the prototype emailed to the previous participants).
The Phase Three Key Workers unanimously preferred the double-sided, A3 fold-out version on the Long-Term Goals booklet (Option A), so it was agreed to take this material forward, with the addition of a 'Notes' section on the (currently blank) back page.
It was agreed that the intervention was now ready to test in use.

Fig. 7.35: An overview of the people, tools, activities and outcomes from Event 17.

7.6 Prototype Development Journeys

Whilst the Event summaries given in figures 7.15 to 7.35 above provide an overview of the Phase Two process, the evolution of each individual prototype (eight in total, including the original three developed by the researcher), through to the final set of materials can be more easily traced in the Prototype Development Journeys, shown in figures 7.36 and 7.37 below and available in larger scale prints in appendix 21.

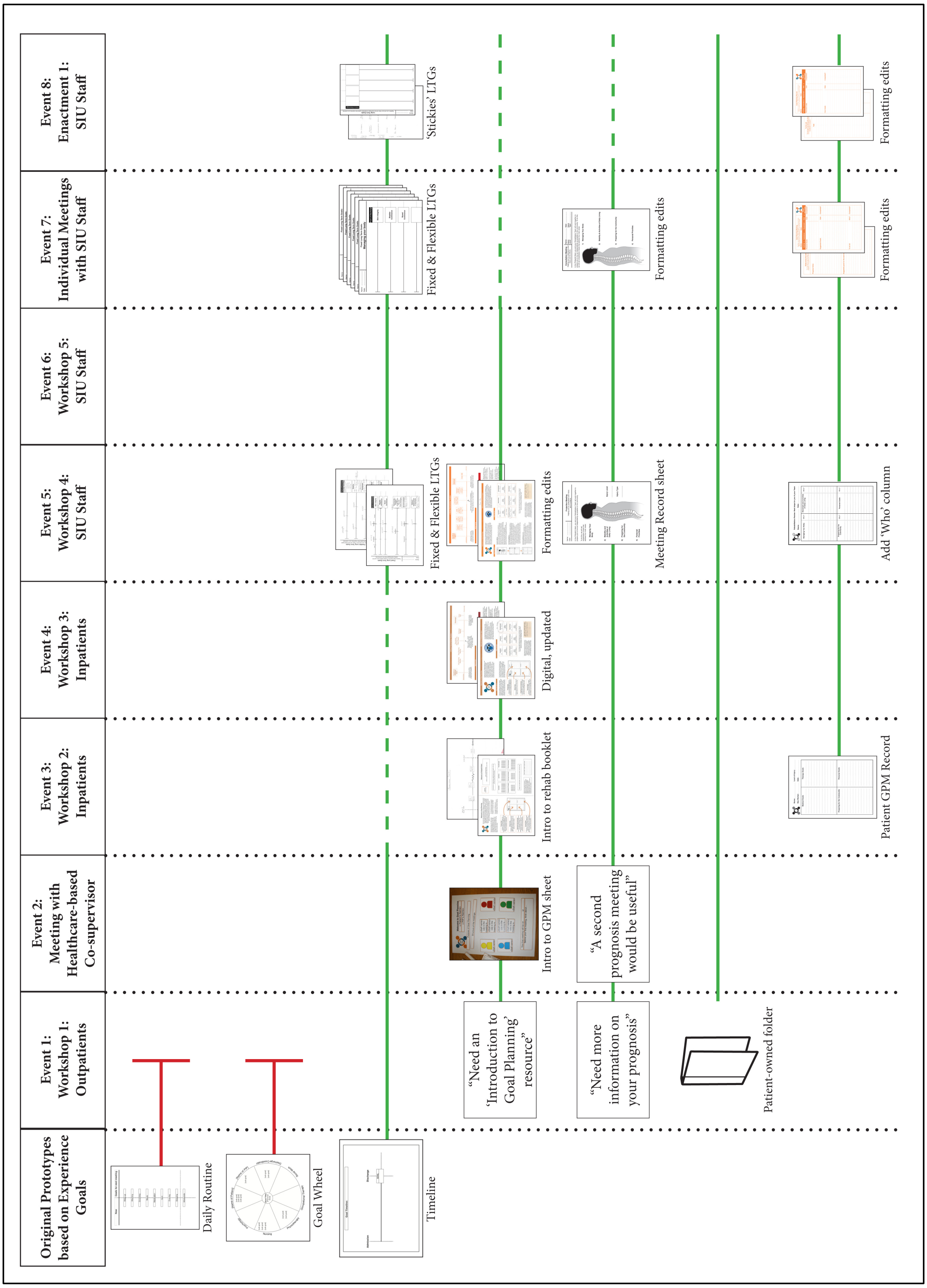


Fig. 7.36: The Prototype Development Journeys for Events 1 – 8.

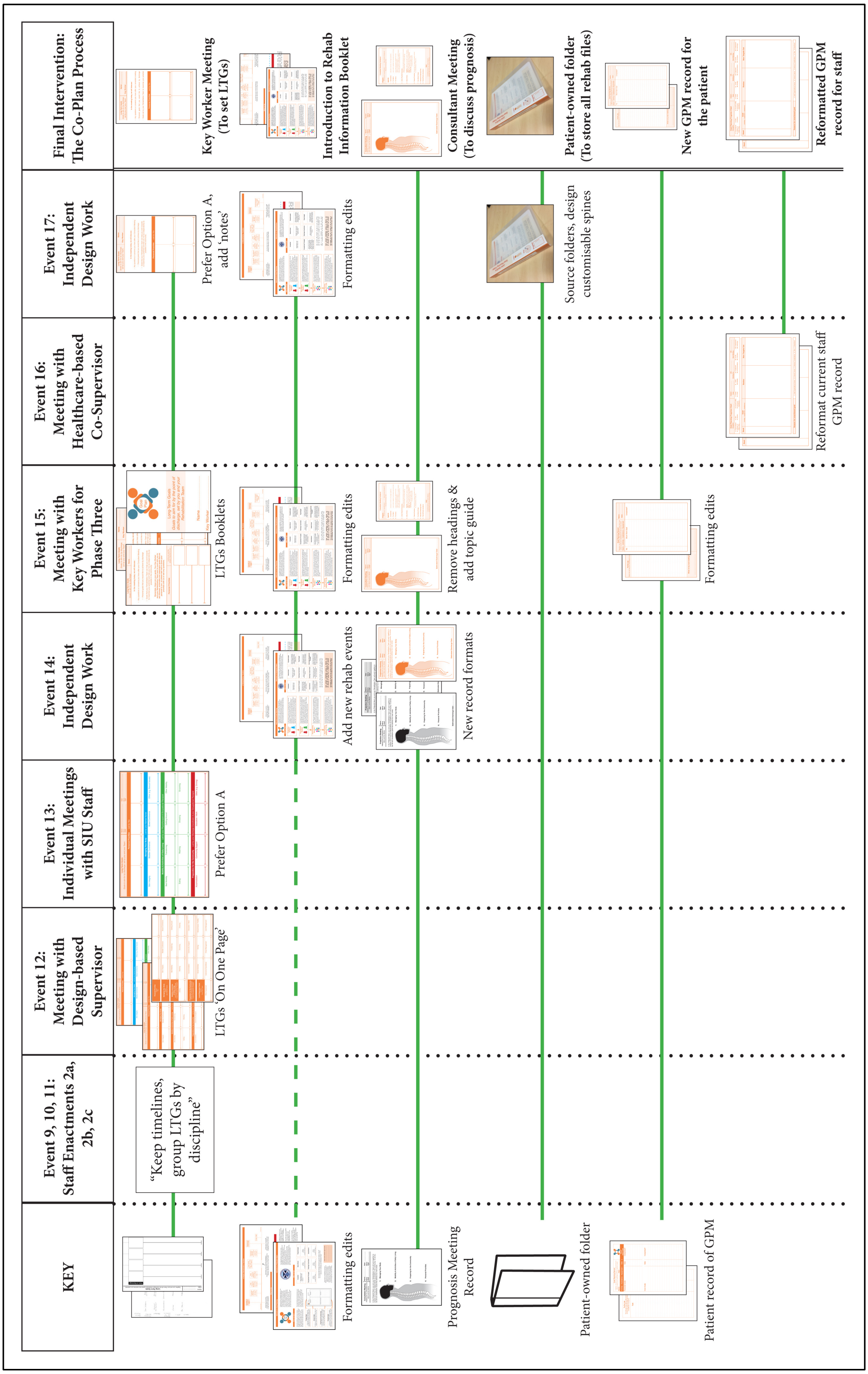


Fig. 7.37: The Prototype Development Journeys for Events 9 - 17.

7.7 The Co-Plan Intervention

7.7.1 Overview

The intervention was named The Co-Plan Process, in order to differentiate it from the current Goal Planning Process. The intervention consists of four main steps, although the fourth step will be observed in two consecutive GPMs for the purposes of this PhD study. The steps, when they take place and their associated supporting materials are located across a rehabilitation timeline in fig. 7.38 below. Note that the diagram below assumes that patient participants will not be identified and recruited until after they transfer onto the rehabilitation ward, however the 'Introduction to Rehabilitation' and 'Consultant Meeting' stages will be conducted earlier if the patient is deemed ready by the healthcare-based co-supervisor. As an example, the diagram demonstrates the journey of a patient who has an occupational therapist as their key worker, however staff from Nursing, Physiotherapy, Psychology and Discharge Coordination may also act as key workers in this SIU.

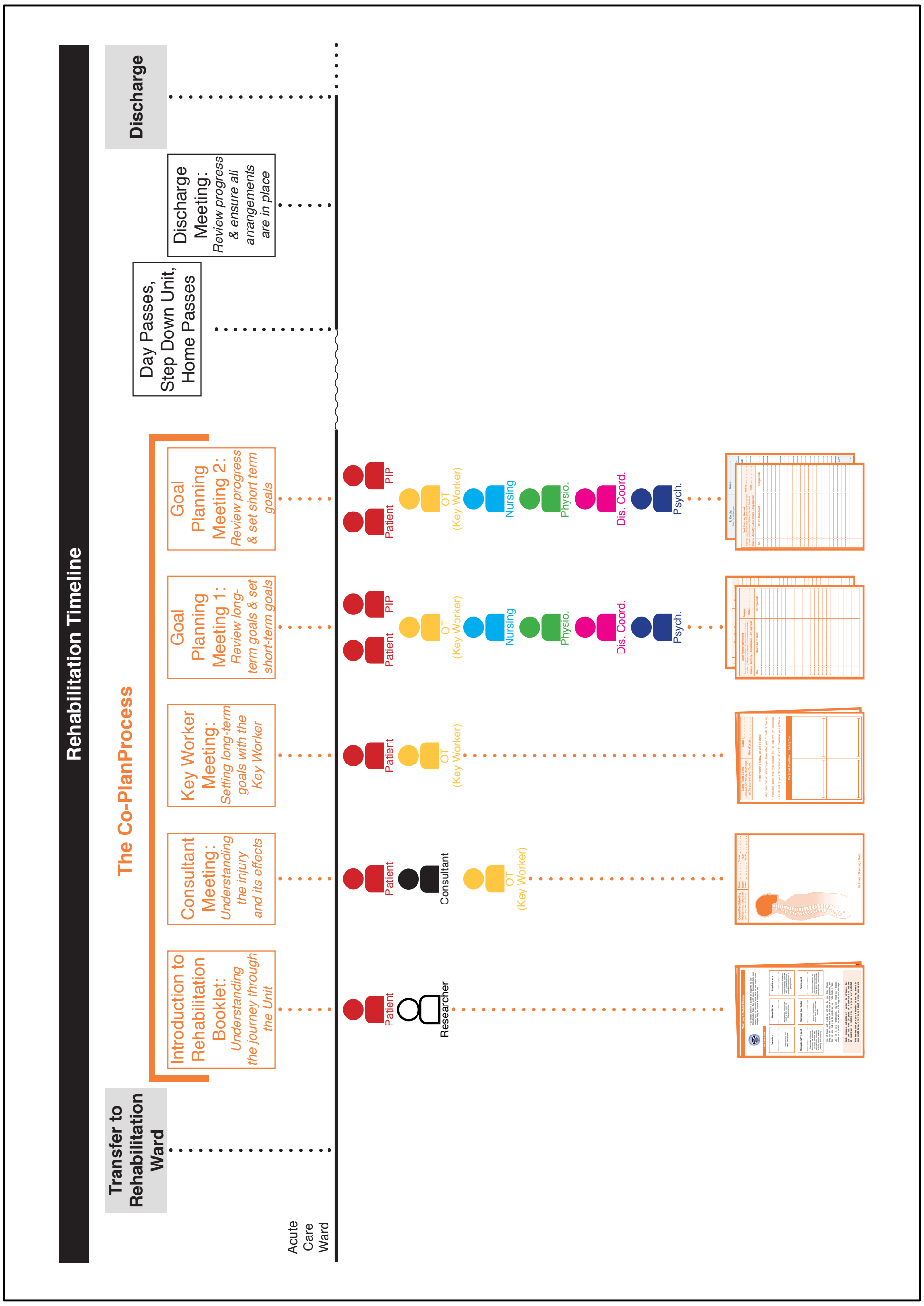


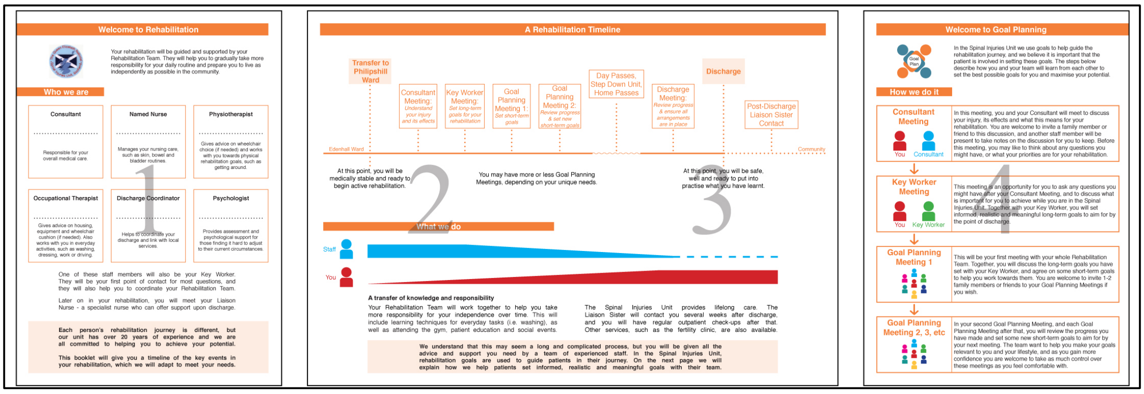
Fig. 7.38: A diagram situating the different stages of The Co-Plan Process within the rehabilitation timeline, with supporting intervention materials.

For clarity, the following chapters will use the term ‘intervention’ to refer to the whole of the Co-Plan Process. The term ‘intervention activities’ will refer to the meetings that constitute the intervention (the Consultant Meeting, the Key Worker Meeting and the Goal Planning Meetings) and the term ‘intervention materials’ will refer to the paper-based materials developed to support the intervention activities.

This section will now continue by describing each step of the intervention in more detail.

7.7.2 Introduction to Rehabilitation

Shortly after transferring onto the rehabilitation ward, the patient will be given an information booklet describing the rehabilitation process and the roles of the different staff disciplines within it (see fig. 7.39 and appendix 26b). The booklet also gives an overview of the Goal Planning process and advises the patient to think about their personal rehabilitation priorities in advance. The booklet will be given in a 'Co-Plan Folder' (shown in fig. 7.40) for the patient to keep and store future rehabilitation materials within.



Welcome to Rehabilitation

Your rehabilitation will be guided and supported by your Rehabilitation Team. They will help you to gradually take more responsibility for your daily routine and prepare you to live as independently as possible in the community.

Who we are

Consultant
Responsible for your overall medical care.

Named Nurse
Manages your nursing care, such as skin, bowel and bladder routines.

Physiotherapist
Gives advice on wheelchair choice (if needed) and works with you towards physical rehabilitation goals, such as getting around.

Occupational Therapist
Gives advice on housing, equipment and wheelchair cushion (if needed). Also works with you in everyday activities, such as washing, dressing, work or driving.

Discharge Coordinator
Helps to coordinate your discharge and link with local services.

Psychologist
Provides assessment and psychological support for those finding it hard to adjust to their current circumstances.

One of these staff members will also be your Key Worker. They will be your first point of contact for most questions, and they will also help you to coordinate your Rehabilitation Team.

Later on in your rehabilitation, you will meet your Liaison Nurse - a specialist nurse who can offer support upon discharge.

Each person's rehabilitation journey is different, but our unit has over 20 years of experience and we are all committed to helping you to achieve your potential.

This booklet will give you a timeline of the key events in your rehabilitation, which we will adapt to meet your needs.

1

A Rehabilitation Timeline

At this point, you will be medically stable and ready to begin active rehabilitation.

You may have more or less Goal Planning Meetings, depending on your unique needs.

At this point, you will be safe, well and ready to put into practise what you have learnt.

2

What we do

A transfer of knowledge and responsibility

Your Rehabilitation Team will work together to help you take more responsibility for your independence over time. This will include learning techniques for everyday tasks (i.e. washing), as well as attending the gym, patient education and social events.

The Spinal Injuries Unit provides lifelong care. The Liaison Sister will contact you several weeks after discharge, and you will have regular outpatient check-ups after that. Other services, such as the fertility clinic, are also available.

We understand that this may seem a long and complicated process, but you will be given all the advice and support you need by a team of experienced staff. In the Spinal Injuries Unit, rehabilitation goals are used to guide patients in their journey. On the next page we will explain how we help patients set informed, realistic and meaningful goals with their team.

3

Welcome to Goal Planning

In the Spinal Injuries Unit we use goals to help guide the rehabilitation journey, and we believe it is important that the patient is involved in setting these goals. The steps below describe how you and your team will learn from each other to set the best possible goals for you and maximise your potential.

How we do it

Consultant Meeting
You Consultant
In this meeting, you and your Consultant will meet to discuss your injury, its effects and what this means for your rehabilitation. You are welcome to invite a family member or friend to this discussion, and another staff member will be present to take notes on the discussion for you to keep. Before this meeting, you may like to think about any questions you might have, or what your priorities are for your rehabilitation.

↓

Key Worker Meeting
You Key Worker
This meeting is an opportunity for you to ask any questions you might have after your Consultant Meeting, and to discuss what is important for you to achieve while you are in the Spinal Injuries Unit. Together with your Key Worker, you will set informed, realistic and meaningful long-term goals to aim for by the point of discharge.

↓

Goal Planning Meeting 1
This will be your first meeting with your whole Rehabilitation Team. Together, you will discuss the long-term goals you have set with your Key Worker, and agree on some short-term goals to help you work towards them. You are welcome to invite 1-2 family members or friends to your Goal Planning Meetings if you wish.

↓

Goal Planning Meeting 2, 3, etc
In your second Goal Planning Meeting, and each Goal Planning Meeting after that, you will review the progress you have made and set some new short-term goals to aim for by your next meeting. The team want to help you make your goals relevant to you and your lifestyle, and as you gain more confidence you are welcome to take as much control over these meetings as you feel comfortable with.

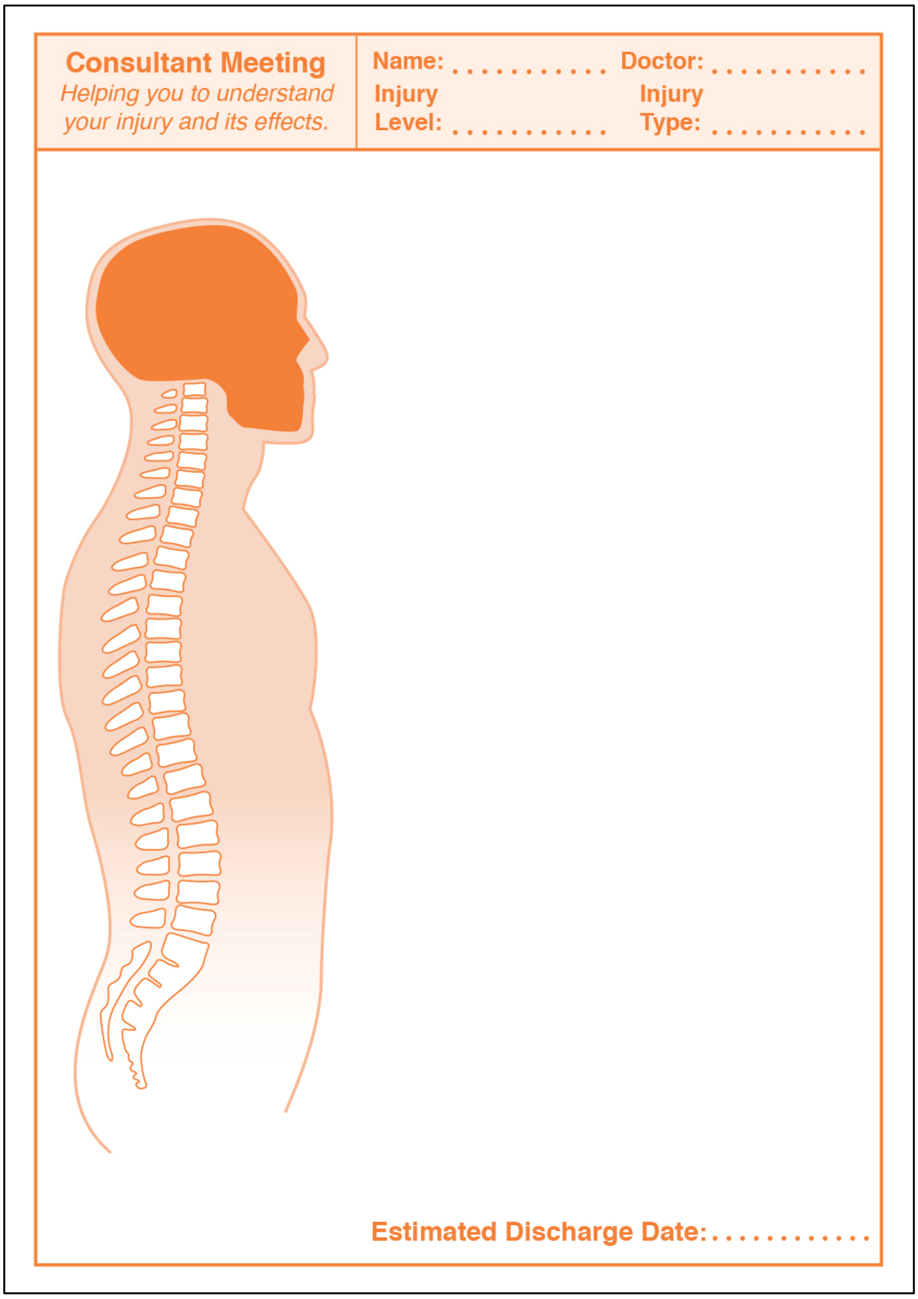
4

Fig. 7.39: The 'Introduction to Rehabilitation' booklet given to Phase Three patient participants (printed double-sided on A3, folded in half, page numbers added for clarity in this thumbnail image).

Fig. 7.40: The Co-Plan Folder, owned by the patient and used to store rehabilitation materials such as the 'Introduction to Rehabilitation' booklet.

7.7.3 Consultant Meeting

Several weeks after their first informal discussion about their prognosis, the patient will be invited to a meeting with their consultant to discuss the injury and its effects. This will include a brief explanation of the anatomy of the spinal cord and the level of the patient's injury, using a 3D model of the spine and printouts of any x-rays or scans the patient has already had. A key worker will also attend the meeting to act as a scribe using the Consultant Meeting Record, available in appendix 26d and shown in fig. 7.41 below. The consultant and key worker will be given a meeting agenda to ensure all of the necessary topics are discussed (if the patient is willing), available in appendix 26e and shown in fig. 7.42 below. Once the meeting is concluded, the Consultant Meeting Record is photocopied or scanned and distributed to the rest of the patient's rehabilitation team, then stored in the patient's Co-Plan Folder.

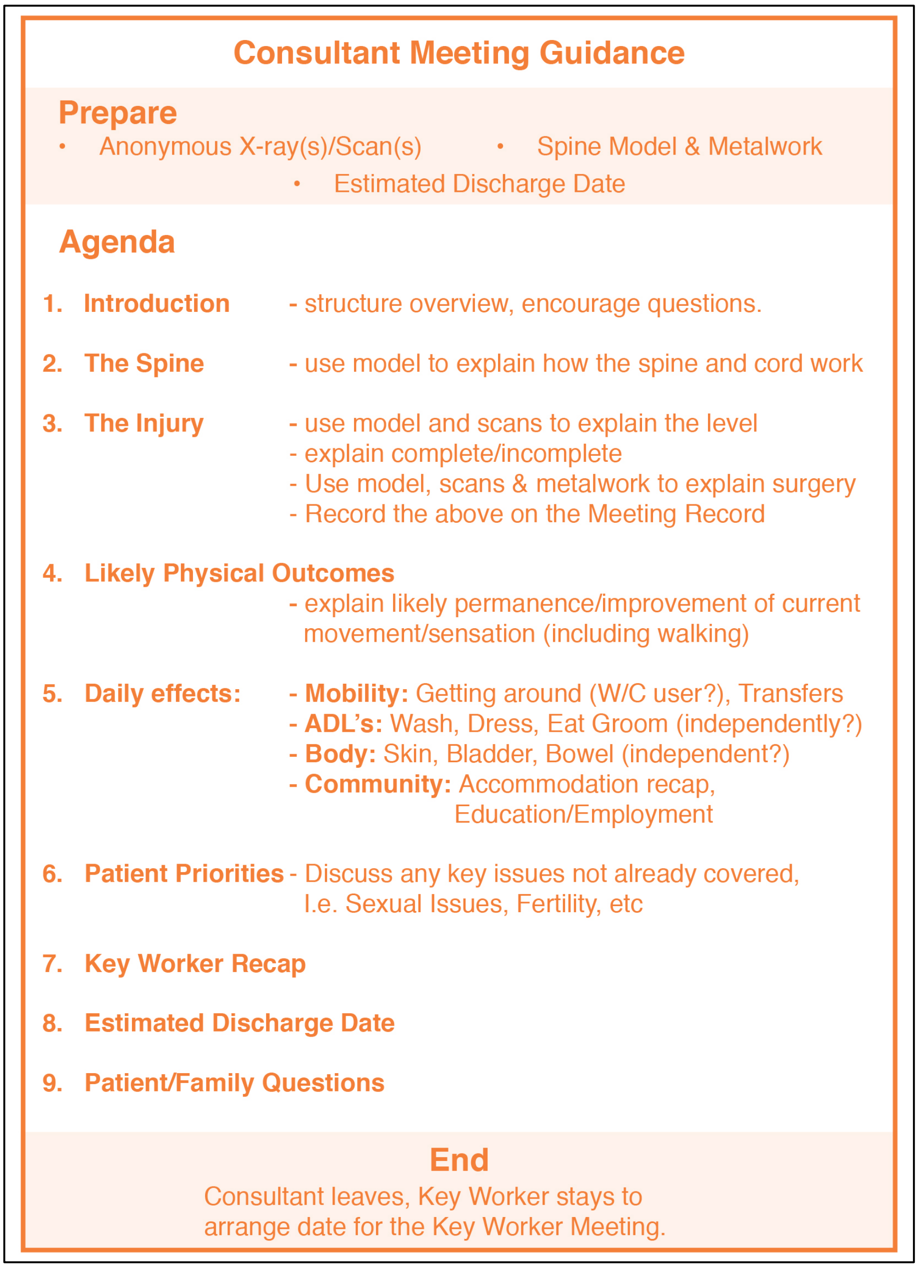


Consultant Meeting
Helping you to understand your injury and its effects.

Name: . . . .
Doctor: . . . .
Injury Level: . . . .
Injury Type: . . . .

Estimated Discharge Date:. . . . .

Fig. 7.41: The Consultant Meeting Record (A4 size) used by the key worker to scribe the Consultant Meeting discussion.



Consultant Meeting Guidance

Prepare

- Anonymous X-ray(s)/Scan(s)
- Spine Model & Metalwork
- Estimated Discharge Date

Agenda

1. **Introduction** - structure overview, encourage questions.
2. **The Spine** - use model to explain how the spine and cord work
3. **The Injury** - use model and scans to explain the level
   - explain complete/incomplete
   - Use model, scans & metalwork to explain surgery
   - Record the above on the Meeting Record
4. **Likely Physical Outcomes**
   - explain likely permanence/improvement of current movement/sensation (including walking)
5. **Daily effects:** - **Mobility:** Getting around (W/C user?), Transfers
   - **ADL's:** Wash, Dress, Eat Groom (independently?)
   - **Body:** Skin, Bladder, Bowel (independent?)
   - **Community:** Accommodation recap, Education/Employment
6. **Patient Priorities** - Discuss any key issues not already covered, I.e. Sexual Issues, Fertility, etc
7. **Key Worker Recap**
8. **Estimated Discharge Date**
9. **Patient/Family Questions**

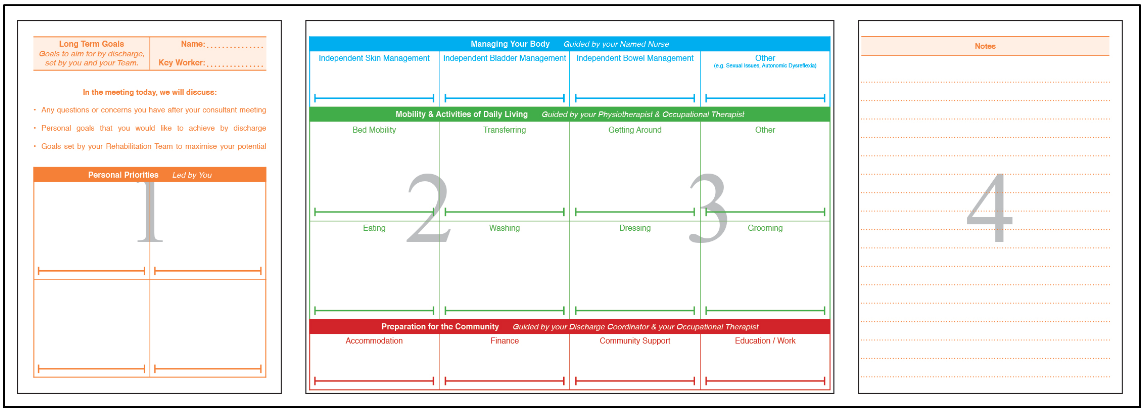
End

Consultant leaves, Key Worker stays to
arrange date for the Key Worker Meeting.

Fig. 7.42: The Consultant Meeting agenda (A5 size) given to the consultant and the key worker prior to the meeting.

7.7.4 Key Worker Meeting

Next, the key worker and the patient meet to discuss the Consultant Meeting and to address any questions or concerns the patient may have about their prognosis. On the back of this discussion, the key worker helps the patient to identify 1-4 personal priorities for their rehabilitation, which are recorded in the Long-Term Goals sheet (available in appendix 26g and shown in fig. 7.43 below). Next, the patient and the key worker collaboratively set realistic long-term goals under each of the rehabilitation headings in the Long-Term Goals Booklet.



Long Term Goals
Goals to aim for by discharge, set by you and your Team.
Name:...............
Key Worker:...............

In the meeting today, we will discuss:

- Any questions or concerns you have after your consultant meeting
- Personal goals that you would like to achieve by discharge
- Goals set by your Rehabilitation Team to maximise your potential

Personal Priorities *Led by You*

1

Managing Your Body *Guided by your Named Nurse*

Independent Skin Management	Independent Bladder Management	Independent Bowel Management	Other (e.g. Sexual Issues, Autonomic Dysreflexia)

Mobility & Activities of Daily Living *Guided by your Physiotherapist & Occupational Therapist*

Bed Mobility	Transferring	Getting Around	Other
Eating	Washing	Dressing	Grooming

Preparation for the Community *Guided by your Discharge Coordinator & your Occupational Therapist*

Accommodation	Finance	Community Support	Education / Work

2

3

Notes

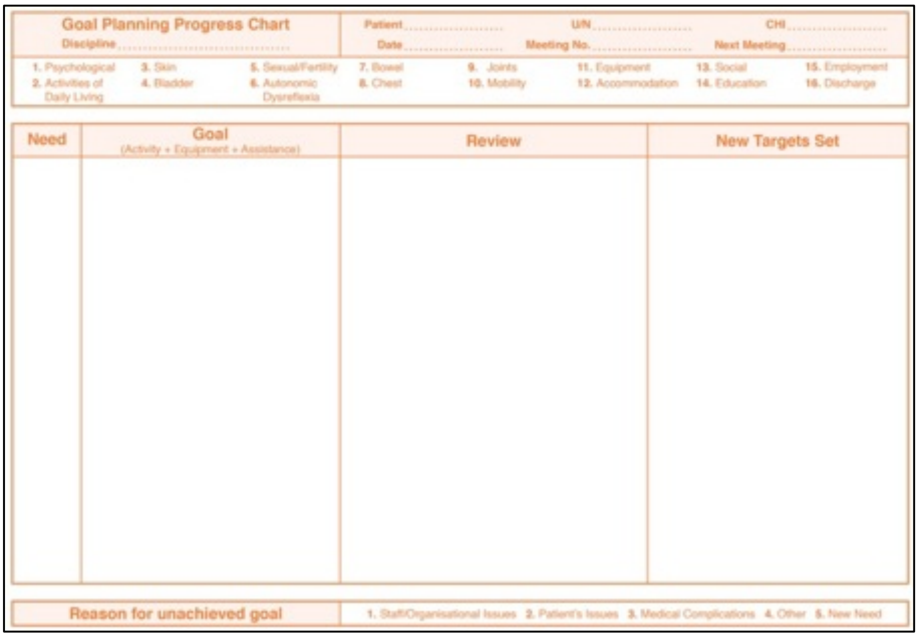
4

Fig. 7.43: The Long-Term Goals sheet used in the Key Worker Meeting and throughout the patient's rehabilitation (printed double-sided on A3, page numbers added for clarity in this thumbnail image).

7.7.5 Goal Planning Meeting 1

The patient's rehabilitation team prepare for the GPM in the traditional manner, using the reformatted Goal Planning Progress Chart (available in appendix 27 and shown in fig 7.44 below). At the start of the meeting, the key worker introduces the patient's personal priorities for their rehabilitation. The staff are then invited to suggest any short-term goals or 'to-do's' that could address the long-term goals in the next four weeks, which are scribed onto the Goal Planning Record (available in appendix 26i and shown in fig. 7.45 below) by the key worker. The key worker then proceeds to address each of the following long-term goals (in the Long-Term Goals Booklet) with the patient and relevant staff member, repeating the progress of scribing goals or 'to-do's' onto the Goal Planning Record.

Whilst the key worker usually chairs the GPM, inviting each staff member present to contribute in turn, the patient may choose to take on some or all of this, depending on their confidence. The Long-Term Goals booklet aims to provide enough structure to facilitate this without forcing any prescribed role onto the patient.



Goal Planning Progress Chart
Discipline ....
Patient .... U/N .... CHI ....
Date .... Meeting No. .... Next Meeting ....

1. Psychological
2. Activities of Daily Living
3. Skin
4. Bladder
5. Sexual/Fertility
6. Autonomic Dysreflexia
7. Bowel
8. Chest
9. Joints
10. Mobility
11. Equipment
12. Accommodation
13. Social
14. Education
15. Employment
16. Discharge

Need	Goal (Activity + Equipment + Assistance)	Review	New Targets Set

Reason for unachieved goal 1. Staff/Organisational Issues 2. Patient's Issues 3. Medical Complications 4. Other 5. New Need

Fig. 7.44: The reformatted Goal Planning Progress Chart (A4 size) used by staff to prepare for the GPM.

Goal Planning Record
Together, you and your Team will agree on some short term goals to guide your rehabilitation for the next few weeks.
Goal = Activity + Assistance + Equipment
Name: ....
Date: ....

No.	Short-Term Goal	Completed?

To-Do List
Tasks that will help your rehabilitation to progress

To-Do List	Who?	Completed?

When is my next meeting? ....
What's most important to me? ....

Fig. 7.45: The Goal Planning Record used to scribe short-term goals and 'to-do's in each GPM. A new Goal Planning Record is used in each GPM (printed double sided on A4, page numbers added for clarity in this thumbnail image).

7.7.6 Goal Planning Meeting 2

At the second GPM, and each GPM following, the meeting begins by reviewing the short-term goals set on the previous meeting's Goal Planning Record. If progress has been made, the key worker 'ticks' the goal as completed. If the goal was not completed, the patient and their rehabilitation team agree to either edit the goal or set the same goal again on a new Goal Planning Record.

Turning to the Long-Term Goals booklet, each long-term goal is addressed in the following manner:

- The patient is invited to show how far along the goal timeline they feel they have progressed. This is discussed with the team until an agreement is made, then that point is marked and dated.
- The patient and relevant rehabilitation team member discuss and agree on a new short-term goal or 'to-do' to be set for the next four weeks, to further address that long-term goal.
- The key worker scribes the goal or to-do onto the new Goal Planning Record.
- These three steps are repeated for each long-term goal in order. It is hoped this will provide a concise, repeated structure to the meeting so the patient knows what to expect and may gain confidence to lead this process over time.

7.8 Ethics Amendments

Upon completing Phase Two, the researcher was concerned that she may not have clearance under her current ethics application to test The Co-Plan Process, as it uses more materials and process than originally predicted. However, after consulting with both supervisors and the contact at the Universities' ethics department, it was agreed that the new stages are simply different methods of conducting rehabilitation activities that already happen in the SIU (for example, the key worker Meeting would replace the current meeting used to complete the host SIU's Goal Planning Checklist). In other words, the total time requirement asked of participants is not significantly greater than that originally applied for. As such, minor amendments were made to the original ethics application, which were granted by the University's Ethics Committee (see https://radar.gsa.ac.uk/5828 for details).

7.9 Conclusion

After conducting a co-design process spanning approximately seventeen 'Events', engaging three SIU-based participant groups, The Co-Plan Process was now ready to be implemented into the rehabilitation pathway of three SIU inpatients and tested in use. The length of the co-design process and the scope of the intervention itself both exceeded original estimations, highlighting the complex nature of the project in terms of designing with, and designing into, the SIU context. A reflection on the co-design process is located in Chapter 10 of this thesis.

8 Phase Three Findings

8.1 Introduction

This chapter will present the findings of Phase Three; where The Co-Plan Process was implemented into the rehabilitation pathway of three patients and evaluated. This chapter will be of interest to both medical- and design-based audiences in terms of the implementation process, methods of evaluation and the outcomes themselves.

All three of the recruited patient participants completed each stage of The Co-Plan Process. The Consultant Meeting was the most successful aspect of the intervention from the staff's point of view, and whilst patient opinion varied, staff reported that the patients generally engaged well in the process and had a better understanding of their injury as a result. The Key Worker Meeting, too, was reportedly useful in different ways for different groups; whilst two of the patients benefitted from regularly reviewing their progress in a visual manner, key workers themselves appreciated having the time and structure to discuss the patients' personal priorities. The key workers also explained that whilst the GPM structure did not change significantly, the patient's personal priorities could be used to make the meeting more 'patient-centred'.

As in the previous two chapters, reflections on Phase Three are omitted from this chapter and will be located later in the thesis (chapter 11) within the wider context of this study.

8.2 Recruitment

The researcher, co-supervisor (a consultant in the host SIU) and the three key workers who agreed to lead the implementation of The Co-Plan process worked together to identify potential patient participants for Phase Three. This was limited by the inpatient population during the testing period, and guided by the staff's experience working with patients in their first few weeks in the SIU. Selection criteria at this stage included being medically stable and not having any other conditions or co-morbidities that may affect their participation in the project (for example, having a learning disability, or having sustained a brain injury at the same time as their SCI). Demographic factors such as age, gender or level of injury were not restricted, although the researcher and staff hoped to identify a group of three patient participants that shared some common criteria.

As in the previous phases of this study, the researcher was introduced to potential patient participants by the co-supervisor, who acted as a gatekeeper. The researcher then met with each patient informally at their bedside several times to explain the study, and ask for their informed consent to participate in the third meeting. The first three patients approached for the study agreed to participate, and their demographic details have been summarised in table 8.1 below:

Name	Patient A: 'Brian'	Patient B: 'Tony'	Patient C: 'Jack'
Age	67	48	17
Injury	C4/5 (Tetraplegic)	T6/7 (Paraplegic)	T5 (Paraplegic)
PIP Involvement	Close relationship with family, who live in the highlands and therefore are unable to visit frequently.	No family or friends involved in GPMs.	Parents are local and visit most days. Very interested and involved in the rehabilitation process where possible.
Key Worker Pseudonym	KWA	KWB	KWC
Key Worker Discipline	Occupational Therapist	Physiotherapist	Nurse and Discharge Liaison

Table 8.1: A table of demographic data for the three patients recruited to participate in Phase Three. The names given above are pseudonyms to protect patient identity.

As can be seen above, the three patients recruited for Phase Three are all male, spanning a large age range and have a variety of PIP input. Whilst two patients, ‘Tony’ and ‘Jack’ share similar levels of injury, and had normal upper limb function, ‘Brian’ had sustained a higher level of injury that was incomplete. In Brian’s case, this meant he was able to move his arms and shoulders but not his hands. The researcher considers this range of participants as likely to produce useful findings, as whilst the gender of participants remains consistent, the diverse ages and levels of injury will test how patients with a range of life experience and dexterity are able to use the materials.

8.3 Scheduling

Once the patient had given their informed consent, the researcher presented them with their Co-Plan Folder, and with a copy of the Introduction to Rehabilitation booklet completed with the names of their rehabilitation team.

From this point, the patient and staff had autonomy in scheduling the Co-Plan activities to better test the intervention as it would be delivered in practice. The researcher was simply informed of the date and time of each activity so that she could attend, or check in with the staff member afterwards (as appropriate).

The researcher was responsible for scheduling the evaluation interview with patients, PIPs and staff after the second GPM, which aimed to be as soon after the event as possible without impacting on the rehabilitation or visiting schedules of participants.

8.4 Training

8.4.1 Prior to implementation

Given that the three key workers leading the implementation of the intervention were very involved throughout the co-design workshops, the need for staff training was minimal. Their involvement in shaping the intervention gave them a good understanding of how to use the materials and when. This understanding was supplemented by one group meeting once the Co-Plan Process had been finalised (see Event 17 of Phase Two) and individual, informal discussions on the same day as each Co-Plan activity, to ensure they were comfortable with what they were being asked to do.

The consultants assigned to the patient participants agreed to lead their own Consultant Meetings, with the key workers present to take notes and give prompts if necessary. Staff training was difficult to organise for these consultants due to their extremely busy schedules, so preparation packs were created for them to read when they were able (note: one consultant was assigned to two patients, so only needed to read this pack once). This pack included a summary of the meeting's purpose (although this had been discussed informally during ad-hoc conversations on the wards), a 'script' resource giving examples of how much detail to go into, and an agenda to take into the meeting as a prompt. This agenda also gave reminders of which materials the consultant should prepare ahead of the meeting, such as printouts of the patient's x-rays or the 3D model of the spine. Given that the consultants regularly give prognosis information to inpatients this was not too unusual a task for them.

The roles of other staff members in the patients' rehabilitation team were largely unaffected in the Co-Plan Process. However, the researcher met with each team member prior to the patients' first GPM (and second GPM, if the rehabilitation team changed at all) to explain the additions of the Long-Term Goals sheet and Goal Planning Record. She also explained that the conversation in the GPM may be slightly different to accommodate these materials, but that this would be led by the key worker. Team members were asked to prepare for the GPM in their normal manner, but to use the updated Goal Planning Progress Chart to do so. It was hoped that this would remind team members that they were participating in a new Goal Planning system that focussed on active patient engagement.

8.4.2 During the intervention

After each patient had completed their first GPM, the researcher arranged a 'Design-In-Use' meeting with the three key workers to address any issues or uncertainties they had with the materials or process, as summarised in the meeting agenda:

1. Feedback from Consultant Meetings and Key Worker Meetings
    a. Collected feedback from consultants and patients
    b. Key worker's comments
2. Goal Planning Meetings
    a. What worked well
    b. Going Forward
    c. Processes to resolve together
3. Researcher's questions for key workers
4. Key worker questions/thoughts/ideas

As well as jointly agreeing how to resolve these issues (for example a minor formatting change to the Goal Planning Record, see appendix 26j), the meeting presented an opportunity to share patient feedback on the intervention to date. This was both useful for the developmental discussion and also motivating for the key workers, who, it must be remembered, were taking on a large task in delivering an unfamiliar rehabilitation process.

When asked during the evaluation interview, the three key workers agreed that the researcher had given sufficient training, as described below:

> 'You can only have so many mocks. No, I think just getting on with it and seeing how it went [was appropriate],' KWB.

8.5 Methods of Capturing Data

As The Co-Plan Process involved multiple activities, some of which were not appropriate to be observed by the researcher, the methods of data collection also varied. These methods are summarised below in the order they were used.

8.5.1 Introduction to Rehabilitation Booklet

Key workers were asked to go through the Introduction to Rehabilitation booklet briefly with the patient, to answer any immediate questions and to allow the patient to read it more thoroughly in their own time. The researcher was not present for this activity, but as it was relatively short in duration, patient and staff perspectives of it were not collected until the evaluation interview.

8.5.2 Consultant Meeting

Neither the researcher nor the staff felt it was appropriate for anyone other than the patient, consultant and key worker to be present for this activity, given the personal and potentially distressing nature of the information being shared. As such, the researcher prepared a condensed evaluation questionnaire to gather the consultant's perspective as soon after the activity as possible. The consultants were given the option to either arrange a time to go through the questions verbally with the researcher, or to answer them as a written questionnaire when their schedules allowed. Both consultants chose the latter, but unfortunately feedback on Tony's Consultant Meeting was not returned.

In addition to this, Consultant A chose to send a formal letter to the senior staff across the main departments of the SIU to give feedback on the Consultant Meeting and to encourage the uptake of this activity with future patients (see appendix 28).

Informal feedback was also gathered in conversation with the key workers on the same day as the Consultant Meeting.

8.5.3 Key Worker Meeting

The researcher did not attend the Key Worker Meetings, to encourage open, candid conversation between the patient and their key worker. Some immediate thoughts were offered by the key workers without being solicited by the researcher, but the majority of data collected (from patients and staff) was gathered during the evaluation interviews.

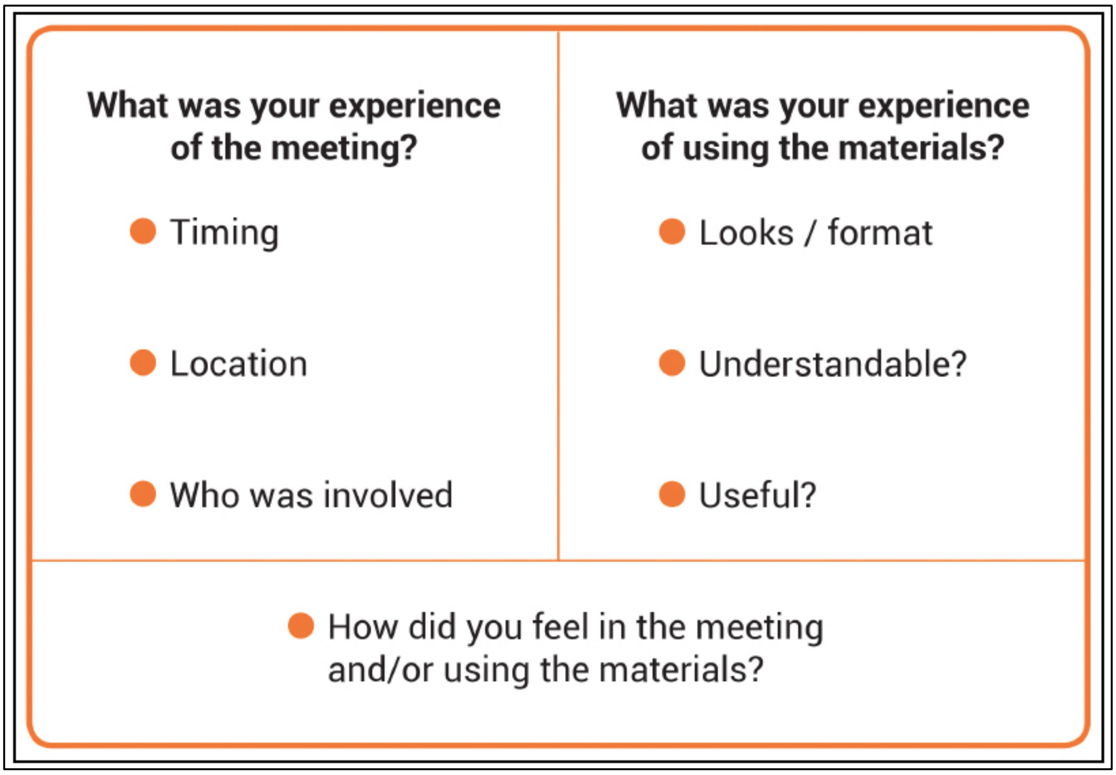
8.5.4 Goal Planning Meetings

As in Phase One, the researcher audio recorded each of the GPMs with permission from everyone involved. She also attended the GPMs as a passive observer, taking handwritten notes and sketches of details that couldn't be captured by audio recording, such as body language. In the event, the notes and sketches taken did not affect the conclusions drawn from Phase Three, and as such will be omitted for clarity of the findings presented.

8.5.5 Evaluation Interview

Mirroring the Phase One methodology, the researcher arranged informal, questionnaire-led interviews with the participants involved as soon after the second GPM as possible. The questionnaire guiding these interviews was based on that used in Phase One, but edited to incorporate the multiple Co-Plan activities, and the Experience Goals used to guide their development. The questionnaire also hoped to achieve a balance between a discussion of participants' experiences and their evaluation of those experiences. In other words, the researcher hoped to gather data that would support further development of the intervention rather than conducting a simple satisfaction survey.

The structure of the questionnaire followed the journey that the patient went through in their rehabilitation, to better support their reflection on the activities. Participants were also supported in considering the many aspects of 'experience' with a prompt card of factors they could consider, such as how long the activity took, how understandable the materials were and how they felt in the process (see fig. 8.1 below). Giving participants the option to choose which aspects of experience to talk about arguably empowered them to set the agenda of the discussion to some extent, and avoided repetitive questioning by the researcher (an important consideration given the patients' busy rehabilitation schedule and limited visiting hours).



What was your experience of the meeting?

- Timing
- Location
- Who was involved

What was your experience of using the materials?

- Looks / format
- Understandable?
- Useful?

- How did you feel in the meeting and/or using the materials?

Fig. 8.1: The ‘experience’ prompt card given to participants during the evaluation interviews.

The questionnaire and ‘experience’ prompt cards were guided by Bate and Robert’s (2007) discussion on ‘experience’ (with reference to Alben, 1996) and ‘good design’ (with reference to Berkun, 2004).

For patients and PIPs, the evaluation interviews were conducted either at the patient’s bedside (for Brian and Tony) or in the Day Room (for Jack and his parents) according to their preferences. Staff interviews were conducted in the researcher’s office in the host SIU.

As described in section 4.8.5, an integrated approach to qualitative data analysis was applied to the transcriptions of qualitative interview data (see also appendix 1).

The findings from these evaluation interviews will now be presented in the two following sections, separated into what the participants said and what the participants drew (or the researcher drew with their guidance, as she did for Brian). The verbal findings will be grouped by the four main Co-Plan activities, with illustrative quotes to support the discussion (with further details available in appendix 16).

8.6 Findings: Verbal Evidence - Introduction to Rehabilitation Booklet

8.6.1 Use

Each key worker went through the 'Introduction to Rehabilitation' booklet with the patient in varying degrees of detail, from explaining each stage of the rehabilitation journey using the timeline diagram (KWA) to giving an overview of what the booklet contained in each section (KWB, KWC). Tony and Jack chose not to read through the booklet again after this introductory activity, but Brian (who was unable to use the booklet independently due to his high-level injury) did revisit and discuss the information inside with his brother and friends who visited:

> 'Nah, [I didn't read it myself]... Ah'm [I'm] tired, ah've [I've] been at the gym all day 'n that,' Jack.
>
> 'Oh yes, I talked to my brother about it, and everything like that. Yeah... He was, he was quite happy with everything that was in it,' Brian.

Jack's parents, who were local and visited often, described how the booklet was helpful to them and gave information they may not otherwise have received at that early stage:

> 'Aye, it just kinda let you know what was gonna be happenin' an' all that as well, the different meetings and things like that, so it was...' Jack's Mother
> 'Did you find out about that stuff any other way?' Researcher
> 'No, just that, aye,' Jack's Mother
> 'I'm not trying to put words in your mouth or anything!' Researcher
> 'No, no, it was just really through, through the folder... I think it was quite, aye, there's quite good information and things like that in it, mm-hmm,' Jack's Mother

8.6.2 Understanding the Rehabilitation Journey

Despite some patients not going through the booklet again, all patient participants agreed it supported their understanding of the rehabilitation journey to some extent. Tony was the most vocal about this point, as illustrated below:

> 'Did you know that [about the rehabilitation process] before you read it? Or did that [booklet] make things a bit clearer?' Researcher

> ‘Naw [no], it made it a bit clearer, because I didn’t really know what to expect,’ Tony

Tony went on to say that the booklet didn’t contain too much information, as did Jack’s parents who also highlighted that it was understandable:

> ‘It was another language that we could understand, it wasnae [wasn’t] big, medical words and things like that, it was, obviously, the things in it, we knew what you were talking about,’ Jack’s Mother.

8.6.3 Benefits for staff

Key worker participants described how the Introduction to Rehabilitation booklet supported them in their role to educate the patient on the SIU processes:

> ‘It let me know that we’d done what we can to give him the information,’ KWA

> 'If all key workers were gonna use that to go through with their patient, you would be making sure that all patients were receiving the same kind of information,' KWB

Like the patient participants, KWB and KWC commented that the format and content of the booklet was good, clear and understandable, but that care may need to be taken to ensure that patients don’t get too caught up in the details given, as rehabilitation journeys don’t always follow the same pattern:

> 'My concern is that maybe people will get kind of obsessed about, “this is what will definitely happen with me,” and although we can say to them, and it can be written in there, “this will be depending on your unique needs,” erm, sometimes people will kind of get caught up in that,' KWA

Despite this, no changes to the booklet were suggested by any of the participants.

8.7 Findings: Verbal Evidence - Consultant Meeting

8.7.1 Timing

All of the staff involved in the three Consultant Meetings felt that they took an appropriate amount to time, with the exception of KWC, who felt that the conversation went into too much detail. When this was raised in discussion, all of the key workers agreed that the meeting could be improved with joint staff training (involving key workers and consultants together) to reinforce the content and detail required.

8.7.2 Patient Involvement

All of the staff involved in Brian and Jack's Consultant Meetings described how the patients asked 'good questions' and were very engaged for at least some of the discussion. Brian in particular appeared to respond very well to this activity:

> 'He really did seem to have a grasp, he found it helpful to have the consultant to be explaining the kind of reasons behind the spinal cord injury, how the anatomy has... made him have a spinal cord injury [and] where it was, I think the patient found that really helpful, he commented on that in the meeting... [and] again at the end of the meeting after the consultant left. I think he found that really helpful,' KWA

> 'I was quite pleased with that. He took the time out to do it, and show me what was wrong with me and everything,' Brian

Tony, on the other hand, did not talk about the Consultant Meeting as positively, although the staff involved later explained that they felt it might have happened too late in his rehabilitation journey to be as useful for him.

Although none of the patients reported being given too much information about their prognosis in terms of being upset or intimidated, Tony and Jack described how they 'switched off' after a while:

> '[It was] boring,' Jack

> 'Ah wasnae, I'm no' sayin' ah wasnae listenin' [I'm not saying I wasn't listening], but...' Tony
> 'No, no, it's a lot of information-' Researcher

> ‘It was a lot to take in at the one time... Cos ah’ve got all that in [the Consultant Meeting Record], wrote in there, and he’s wrote, all the things on it, but, ah read it, but... did I read it? Ah probably didnae read it.' Tony

8.7.3 Staffing

Most participants seemed satisfied with who was involved in the Consultant Meeting, and that it was important to have the key worker present to take notes, to support the conversation during the meeting (using the meeting agenda as a prompt) and to support the patient after the meeting (to answer any immediate questions or concerns). Although Jack agreed with this, his key worker (KWC) and his parents felt that family members should be involved in the Consultant Meeting.

8.7.4 Materials

There was a general consensus among the participants that the materials used in the Consultant Meeting were useful, with family and friends of the patients highlighting the Consultant Meeting Record as being particularly so. Participants (especially the staff) described how the use of the 3D model of the spine, as well as printouts of the patients’ x-rays or scans (where possible) enhanced the meeting, as shown below:

> ‘Patient commented that he understood much more seeing the model of the spine.’ Consultant A (transcribed from handwritten questionnaire)

> 'The bit showing him the spine and showing him exactly where his injury is, and pinching, you know, showing him exactly, that was really good. He was focused completely on that. Showing him the MRI scan, the print out of the MRI scan with the metalwork, and how it’s scaffolded around, he got that... He asked a couple of questions at that point, he actually, mm-hmm. He did. Reasonable questions as well, not, it wasn’t, “Am I gonna walk again?” or anything like that, you know, once we were showing him, you know, he asked would the metalwork be in forever, or would that be taken out at a later date...' KWC

> ‘Models, metal work and patient was given a print out of his CT scans before + after surgery – patient was clearly engaged/interested in this + asked appropriate questions,’ Consultant C (transcribed from handwritten questionnaire)

8.7.5 Helping patients to understand their injury

All of the participants, except KWC, highlighted that they felt the Consultant Meeting enhanced the patient's understanding of their injury. Consultant C suggested that the meeting also raised any assumptions the patient had earlier, an idea that is embodied by Brian's explanation of how he originally thought the nature of his injury was different:

> 'I learnt, I thought it was my vertebrae that I broke, but he showed me it wasn't, it was the spinal cord... he was showing me the thing that I broke, so, that's why I lost my, y'know, my legs? And my hands, but, it was my spinal cord that caused me that... I was quite happy to know that, you know,' Brian

8.7.6 Consultant experience of the Consultant Meeting

Both consultants described their meetings as 'calm,' and that they felt prepared and supported by the Consultant Meeting materials:

> 'Checklist was very useful,' Consultant A

> 'I felt well prepared, the materials were clear and structured + also room for flexibility depending on how the meeting was going,' Consultant C

Several staff members described how the meeting may also be useful for the consultant, in terms of it being a good experience and also for getting to know the patient better:

> 'Do you feel you know the patient any better after this meeting?' Researcher
> 'Yes,' Consultant C
> 'Do you feel that your relationship with the patient is any different after this meeting?' Researcher
> 'Hopefully patient appreciates that as a team we are all working together to achieve his goals,' Consultant C

> 'And again, [Brian] kind of said 'that's been really helpful, now I'm understanding,' I think that was really nice for the consultant to hear and for us to hear and for Brian to hear... I think that the consultant was quite clever and asked the patient, "OK, having heard all this, how long do you think you'll be here?" I think that was quite nice, for us to get an understanding of [what] the

> patient's perspective is of what they've just heard, and how that would affect them. And again, Brian was spot on with that, he was great,' KWA

Although Consultant A felt he already knew the patient very well without the Consultant Meeting, he did describe other, professional benefits to the meeting:

> 'I saw him at least twice a day during his initial couple of weeks but it is good to know explicitly that the key worker heard me discussing things with him,' Consultant A

8.7.7 Key Worker Experience of the Consultant Meeting

KWB and KWC felt that their participation in the Consultant Meeting did not require too much effort, but KWA described how her desire to make a useful resource for the patient made her role quite demanding:

> 'My kind of focus was kind of, "this is for the patient," so... when we all go away the patient's got something to really relate to... I wanna be as clear as I possibly can be for them, so it was a lot to try and do... so that seemed to be OK in terms of me sitting there scribing... but I don't know if everyone would do it the same. People may probably do it better ways than I would do them, maybe we need to try and make sure we got a universal way of recording it,' KWA

This difficulty described by KWA reinforces the idea raised above that further training, with both key workers and consultants, could be useful to clarify how much detail all staff members should include in their discussion or notes.

8.7.8 Impact on future rehabilitation activities

In the quote below, KWB describes how the Consultant Meeting may have achieved its aims in enhancing the transparency of how much a patient has learned about their prognosis:

> 'This should give all the team members 100% confidence in knowing exactly what's been said, 'cos it's all been written down, so they can go to that and say "Oh look, your consultant's said all these things, but that's what it means from

> a physio's point of view, that's what it means from an OT's point of view, that's what it means from a nurse's point of view,"' KWB

This idea was echoed by several staff members, who also described other long-term benefits of the Consultant Meeting including making it easier for staff to address goals (KWA), using the record to remind patients of aspects they may have forgotten (KWB, KWC), making priorities clearer (Consultant A) and empowering the patient to take more control over their rehabilitation (Consultant C).

8.7.9 Improvements

Other than the staff training suggested above, no other changes to the Consultant Meeting were suggested by any of the participants.

8.8 Verbal Findings: Key Worker Meeting

8.8.1 Patient Perceptions

In general, patients described the Key Worker Meeting as a useful activity. Although the patients didn't use the Long-Term Goals sheet on their own outside of the Key Worker Meeting, the patients did not suggest any changes or make any negative comments about the experience, materials or people involved.

8.8.2 Key Worker Perceptions

Interestingly, despite Jack's limited but neutral responses when discussing the Key Worker Meeting, his key worker described how Jack suddenly stopped wanting to indicate the progress he had made on the goal timelines halfway through the meeting, and as such KWC stopped that part of the activity. Although the reason for Jack's apparent discomfort was never established, this example highlights the importance of gathering data from all participants involved (where possible) and giving staff the autonomy to adapt how they delivered the intervention.

The key workers uniformly felt that the meeting did not take too long to conduct, that it helped to identify patient priorities and that it also helped to align the patient with their rehabilitation team:

> 'It was the first time I'd heard [he wanted to drive], it was the first time he'd said anything about a car,' KWC

> ‘Well, sitting down as a key worker, I suppose, and actually setting the long-term goals with the patient, gives you a bit more, it enables you and the patient to know that... you know where it is you’re trying to get to with the patient... and where the team’s trying to get to. Er, which maybe in the current system you don’t get, because just... filling the needs assessment form in... all you’re saying is, ‘all we’re gonna do is find out where you’re at now,’ but there’s no long-term goals set in that instance... so I think by doing [this meeting] the whole team should know, and the patient also should know, where we’re aiming at,’ KWB

KWA also highlighted that the meeting was useful in terms of connecting the information given by the consultant to what’s important to the patient, and in turn connecting that to the goals set:

> ‘I think it was quite helpful, I mean, after the consultant left, we had a wee chat about what we’ve been talking about, erm, and then going back to it when we had the key worker meeting and reinforcing it, I think it made it more meaningful to be able to reflect on that, and kind of it made the process I think more smooth,’ KWA.

Whilst all of the key workers agreed that the meeting helped the patient to understand their long-term goals, KWA suggested that the process might be more difficult for patients with limited potential for functional recovery:

> ‘I think it let him see that there’s a lot of other things going on other than just getting home, and I think to that extent it was helpful for him to know, “OK, to get home, it’s not just a matter of just getting you home, there are other things that need to be in place to allow you to be safe,” – I think that side of it was helpful, erm, but, I’m not sure that delivering all that information at the same time is perhaps the kindest thing to do... I think, it could be overwhelming, and when you see the page with all these different sections, and that, I think that seemed to be quite a lot,' KWA

KWA's sensitivity to her patient's wellbeing may have led her to adapt the Key Worker Meeting accordingly, as her patient, Brian, did not have any negative comments on the activity.

8.8.3 Delivering the Key Worker Meeting

The key workers felt the materials were clear, with enough space and a legible format. KWB, in particular, described the meeting as a productive activity:

> '[I felt] in control? If you like... as in, you know, understanding what we were trying to achieve, er, he seemed to understand what was going on, so I felt it was a successful meeting,' KWB.

Perhaps due to their experience as senior staff, the key workers felt that the meeting was not difficult to conduct, but described how they still felt some discomfort in proposing long-term goals on behalf of their colleagues in other departments. With this in mind, the key workers also raised some concerns about less experienced key workers' abilities to suggest goals outside of their profession. KWB suggested that this could be resolved by training staff to set simpler goals, such as 'continent' rather than 'independently using intermittent catheters', whereas KWC felt the meeting may need more structure. KWA, on the other hand, focussed more on what could be easily replicated more widely, and suggested that the patient's personal goals could be set by any staff member. KWA, in concert with KWB, went on to describe how this identification of patient priorities was perhaps the best part of this meeting, and that it had long-term benefits in the rehabilitation journey:

> 'I think, using the sheets that's got the person's personal goals, I think that has set the tone slightly differently in the goal planning meetings as well... I think just being able to say, "OK," to the team, "this is what's important to the patient," and making that the focus, and being able to... relate, for the patient, what the team are talking about in terms of bladder, bowel, skin, driving, work. It's all related back in some way, to a greater or lesser extent, to the goals that you have... and make it more meaningful, hopefully with a kind of cross-referencing almost?' KWA.

> '[Discussing positive aspects of the Key Worker Meeting] The fact that we've actually identified some specific, personal preferences for the patient, whereas some goal planning systems maybe never do that,' KWB

The quotes above suggest that at least some aspects of the Key Worker Meeting have achieved a shift towards including more of the patient's agenda in the GPM, and that this is a new, positive step forward even for staff with a lot of SCI rehabilitation experience.

8.9 Verbal Findings: Goal Planning Meetings

8.9.1 Enhancing GPM Preparation

KWA described getting to know her patient better through the Consultant Meeting and Key Worker Meeting, and as such being more prepared for his first GPM:

> 'I think going through the process of the Consultant Meeting, and then being with the patient afterwards to clarify, to talk over, to support, I think that was helpful. And I think then going back and meeting individually with the patient, although we do it before in the previous system with the Needs Assessment, I think actually the focus being more the patient, "what's important to you, what do you want to achieve," ... I felt more comfortable with that, and I felt that I was able to understand and represent him better, rather than going through our checklist... I really like this [taps front cover of Long-Term Goal sheet] the "Personal Priorities," I think that really did help [me to] be more prepared, and I felt more confident going into the goal planning meeting being able to say, "OK, this is what's important",' KWA.

Despite this preparedness, KWA, like KWB, felt some nervousness going into the first GPM, as described below:

> 'I was anxious, but I was kind of interested. You know, I was curious to see how it was gonna pan out,' KWA

> 'How did you feel going into that first GPM?' Researcher
> 'Erm, not as relaxed as normal? [laughs] ... purely 'cos you're conscious that you're trying to remember to do everything that we'd already agreed that we'd do in the meeting, erm, er... yeah, and being aware that halfway through, or

> well into it, '[tsk] you've already forgotten to do something,' so then backtracking to do that again. So it was more an unfamiliarity, even though we'd discussed what to do with it... it was also, I think other people have said this, the amount of paper in front of you, you know? Whereas normally you'd have one piece of paper.'

As KWB pointed out above, the feeling that there were too many materials to use in the GPM was reiterated by the other two key workers. These materials will now be reviewed in turn below.

8.9.2 Long-Term Goal Sheet (from the Key Worker Meeting)

Throughout her evaluation interview, KWA made several references to the idea that the identification of patient priorities on the Long-Term Goals sheet made the GPM more 'patient-centred,' as illustrated below:

> 'Being able to say that "Brian and I have met, and this is his personal, this is what's important to him," and being able to say, "OK, based on what these personal goals are Brian, the rest of the team are then going to talk about how they're going to help to get towards that." And to me, that just made the whole thing a bit more smooth, hopefully, and meaningful?' KWA

> 'I liked the feeling of being able to be patient-focussed, and being able to say, "this is what's important to..." – I liked that. But I still felt that the team still had the opportunity to put forward their goals,' KWA

> 'Rather than just going, "OK, your turn, your turn, your turn," [in the GPM] I felt that it let, it lent itself to me doing that, having had the patient-centred goal page let me do that... Or promoted me doing that,' KWA

The repeated use of 'being able to...' in these statements is interesting, suggesting that the materials afforded new behaviours for the staff. This idea was expanded on by KWB, who suggested that the materials may also facilitate new patient behaviours as well:

> 'Doing this system, I suppose, it does give the opportunity, depending on the key worker possibly, and how it's written down, does give that opportunity to say, "Well, OK, you want to try a certain thing, can we set that as a goal?" ....

> Yeah, so maybe it opens that up... it maybe enables the patient to say more, or to feel freer to say things...' KWB

Whilst the key workers found the Long-Term Goal sheet useful in setting patient priorities, Brian and Tony indicated that revisiting the timelines to update the progress they had made was useful to them:

> 'Yes, she, what you have there, she had it down on the paper, and she was marking it, my progress on the thing, you know? From the 10% to 50%, you know, and I was quite happy with that,' Brian (who repeated this sentiment another two times in the interview).

> 'Would you understand your progress as much without this? [the Long-Term Goal sheet]' Researcher.
> 'No, probably not, no,' Tony
> 'OK... I'm not trying to put words in your mouth!' Researcher
> [Both laugh]
> 'No! I know you arenae [aren't], but if ye didnae [didn't] have that, all ye would be gettin' is gettin' asked questions. "How do you feel you're getting on wi'," for talkin's sake, "transferrin', bed mobility, washing. How do you feel you're gettin' on wi' dressin'?" And you would only be giving answers, you wouldnae [wouldn't] be goin', "well, ah feel as if ah'm up here, or here." 'Cos wi' washin' ah'm up top, ah'm here, but a month ago ah was doon there, [because with washing I'm at the top, I'm here, but a month ago I was down there]' Tony

These quotes from Brian and Tony suggest that the timelines helped to quantify their progress, and communicate it in a more meaningful way between themselves and the staff. Tony brought up the timelines again later in the interview to reinforce his point:

> 'Aye, that does help [pointing at the timelines], aye, aye... Aye, 'cos you know how far on, every time you go to the meeting, so you know how far you've came,' Tony

Tony's key worker, KWB, discussed how Tony understood and engaged with the timelines concept, even using it in unpredicted, but appropriate, ways:

> ‘What did you expect to happen in that second GPM?’ Researcher
> 'I expected the acknowledgement that we’d achieved some goals, I hoped the patient would see that he’d moved on and he had, so when he filled in the timelines, he moved those, you know, he moved his, where he thought he was in the appropriate direction, he actually took one of them backwards, and indeed he had gone backward in one area, so... that was appropriate that he was thinking that he’d gone backwards I suppose,' KWB

This example, of a patient moving the progression line backwards, provides a strong argument for designing materials that are flexible enough to be interpreted and used in different ways. However, this flexibility was also the source of difficulty for some staff members, as described by KWA:

> ‘Er, I wasn’t really sure about how the whole timeline thing would work. Erm, and we had talked about that before in our training sessions, and where to put that in, but once we actually got started in the goal planning meeting, I completely forgot about the timeline thing, and got more engrossed in the Goal Planning Record, and making sure we got all that information down,’ KWA

As such, KWA chose to update the progress made on the timelines with the patient outside of the GPM, as described below:

> ‘I found it quite difficult to try and explain to him what I was trying to find out from him. “OK, do you understand that this is when you first came in, this is when you’re discharged, this is what we expect you to be able to do, this is what the goal is, where do you think you are?” So I found that quite hard to do. Once we did that for the first few, he was then saying ‘yeah I’m probably here,’ and again, he was pretty well accurate on most of them, and in terms of saying where he was on the timeline,' KWA

It is interesting to note that the eldest patient involved in the study (who may be more used to a paternalistic healthcare model) who also had a tetraplegic injury (who therefore couldn’t manipulate the material for himself) was still able to engage with the concept. As seen above, Brian highlighted this activity as useful for him, but this may also be due to

KWA persistence and extra effort taken to help him understand the process. Whether other, perhaps less experienced key workers, would go to the same efforts is uncertain.

As described above, KWC detected some discomfort in her patient (Jack) when marking the progress made to date in the Key Worker Meeting, and as such did not return to the timelines activity in the GPMs. KWC, like KWA, also raised concerns over whether the marks made indicated the patient's perception of progress, or a combination of patient and staff perspectives, suggesting a need for further development and training if this concept were to be taken forward after the PhD study.

8.9.3 Goal Planning Record

Out of all of the new materials introduced in the Co-Plan Process, the Goal Planning Record was the most contentious. All of the key workers described some level of difficulty in juggling the record with the other materials present in the GPM (including the Long-Term Goals booklet and the other staff's individual Goal Planning Progress Charts), particularly in its original format:

> 'I definitely felt, "I'm gonna have to put all these pieces back together and put them in the right order, and in fact re-write half of them,"' KWB

However, the key workers agreed that the Goal Planning Record was easier to use once the format had been changed (placing 'goals' and 'to-do's' on separate pages, so they could be used simultaneously, see appendix 26j) following the 'Design-In-Use' meeting:

> 'How did you feel going into that second GPM?' Researcher
> 'More relaxed about it... the fact that you had these new sheets, with the tasks separated from the short-term goals, yeah, the knowledge that we had that [it] would be more straightforward, and having clarified as well what we were meaning by a 'task' as opposed to a 'short-term goal.' I think that helped,' KWB

Despite the difficulties raised by the key workers in using the record, including how to write and talk at the same time, the team appeared to feel the effort was worthwhile if the patient found it useful:

> ‘Erm, but in terms of actually in that first meeting, it was a lot to write. But I think from the patient’s perspective it was probably nice to have that information. I think that’s important,’ KWA

Indeed, several comments from the patients suggest that a written, patient-owned GPM record is a valuable resource:

> ‘Och, no, I love to have what they’re saying written down, I like that. ‘Cos, er, you know what they’re saying, and you’ve got a record of it anyway, that’s the main thing anyway,' Brian

> 'Do you think if we had meeting... but KWC wasn’t writing things down, do you think it would be different, or it would be the same?’ Researcher
> ‘...probably different, because you wouldn’t, if somebody wanted to look through it, you wouldnae know? So, it tells you all about it an’ that.' Jack

Despite Jack stating that he didn’t read the Goal Planning Record himself, his positive description of the material was one of his longest answers in the interview. This, as well as Brian’s enthusiasm for the Goal Planning Record, suggests that patients may like to have the information even if they aren’t ready to physically or emotionally engage with it at that point.

Jack’s parents also viewed the Goal Planning Record positively, as shown below:

> ‘Aye, it was good to read what she’s wrote down on things like that as well, aye,' Jack’s Mother

8.9.4 What was achieved in the GPM?

With so many materials present in the GPM (the Long-Term Goals sheet, the Goal Planning Record, and in some cases the Consultant Meeting Record was also referred to), it can be hard to see the overall effect the Co-Plan process had on the GPM itself. Interestingly, all the staff involved in Phase Three agreed that the actual conversation and structure of the GPM had not changed significantly (and as such the GPM conversation mapping technique from section 6.5 was not repeated), but that the materials were useful as ‘props’ to guide the rehabilitation team towards setting goals more related to the patient’s personal priorities:

> ‘The actual running of the meeting didn’t necessarily feel greatly different, other than, I suppose I felt in more of a position to question, er, other professions as to what goals they’d set, or were going to [be] set, because we’d already set a long-term goal of being able to achieve something, and if the, whichever professional it was, didn’t discuss that in their goals, then it maybe gave me, as a key worker, gave me more of a position to say, “Well, actually, this is the goal we’ve set, have we got any thoughts as to how we’re gonna move towards that goal?”... It helps as a prop, I think, you know,’ KWB

Another staff member observed that the Goal Planning Record was a useful prop to use with the patient in the GPM, involving him in the conversation when trying to establish the progress that had been made:

> ‘I did notice when [Nurse] was feeding back some stuff on behalf of nursing, that [KWC] would go back and check, “So did you go to the education sessions, did you do that?” just to make sure that that was clarified and ticked off, that was what I had noticed,’ Jack’s Occupational Therapist

As well as echoing the sentiments described above, KWB also suggested that the Co-Plan Process allows the long-term goals to be used more frequently in the GPM:

> ‘Again, my experience, I don’t think I’ve ever seen... where the key worker has come armed with a needs assessment, and has gone over through the checklist with the entire team. I don’t think I’ve ever seen that happen, and I must admit I don’t think I’ve done it myself either.... that system said, “What are you doing in the beginning and what you’re doing at the end? And let’s just put it out of the way in-between,” which is possibly a weakness of that, it could have been a strength. So, again, that’s an improvement, having these long-term goals,’ KWB

Here KWB is explaining that whilst the current goal planning system only refers to long-term goals at admission and discharge, the Co-Plan system is strengthened by revisiting the long-term goals more regularly. It could be argued that this may also make the rehabilitation process more connected, with a consistent thread guiding the patient from admission to discharge.

8.9.5 Improvements

As stated above, KWC raised concerns over whether the Co-Plan Process, with its more flexible structure, may in time allow something to be missed out of a patient's rehabilitation:

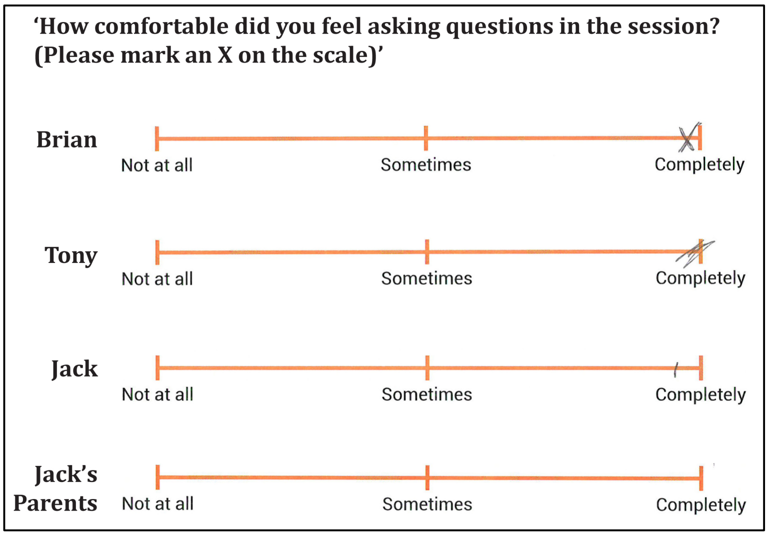
> 'That is my big fear, that we're gonna start leaving holes, because, the net, the structure is not... what we're used to, or there, really. And that might come, but, but, I think it's very heavily reliant on the key worker, and all the different disciplines remembering it, keeping it up here, and I don't know, without a prompt, and I don't know that... it's not cohesive,' KWB

This suggests that whilst some elements of the Co-Plan version of the GPM may be successful individually, they are still viewed as separate elements that could be further developed into a clearer, cohesive system.

8.10 Visual Findings

This next section will present the findings from the visual aspects of the questionnaire guiding the evaluation interviews.

8.10.1 Patient and PIP comfort asking questions in the GPM

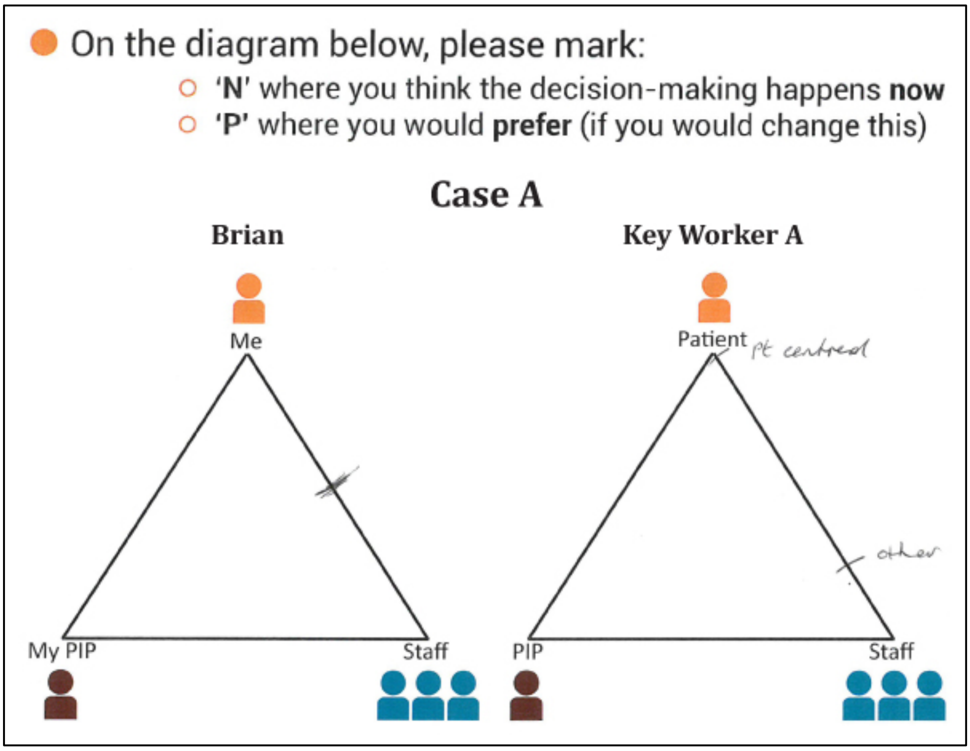


'How comfortable did you feel asking questions in the session? (Please mark an X on the scale)'

Fig. 8.2: The patient Likert scales shown above highlight that each participant felt comfortable asking questions in the GPM. Additionally, Jack's parents also verbally indicated they felt 'completely' comfortable asking questions in the GPM, but did not

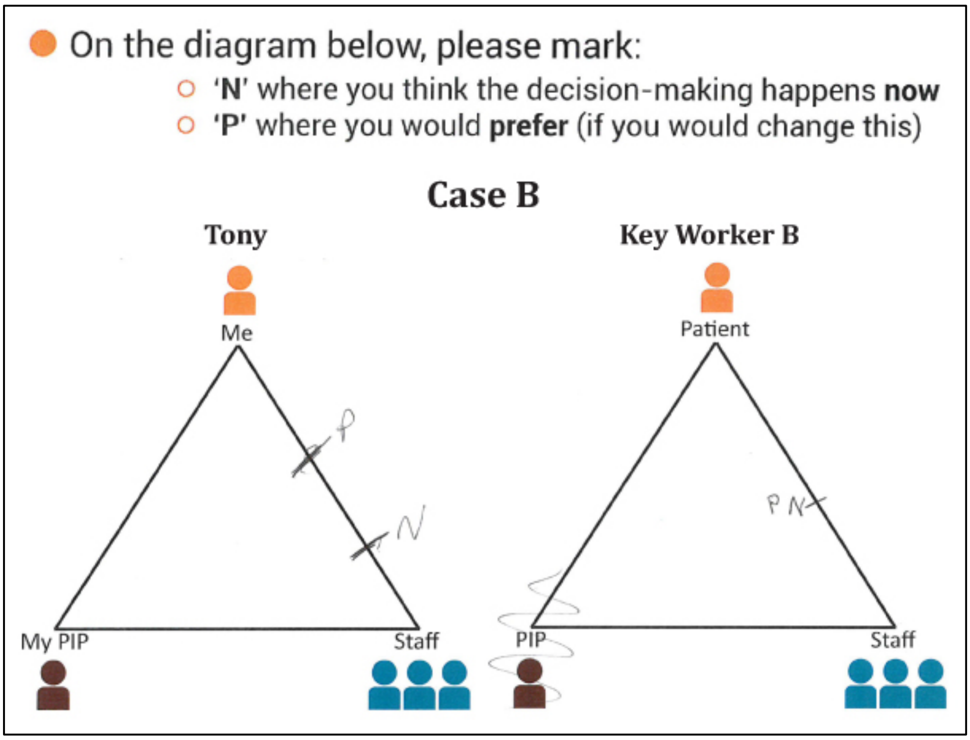
make a mark on this Likert scale in their questionnaire booklet due to the flow of conversation at that point.

8.10.2 Decision-making



- On the diagram below, please mark:
  - ○ 'N' where you think the decision-making happens **now**
  - ○ 'P' where you would **prefer** (if you would change this)

Fig. 8.3: Perspectives of decision-making agency in Brian's GPMs.



- On the diagram below, please mark:
  - ○ 'N' where you think the decision-making happens **now**
  - ○ 'P' where you would **prefer** (if you would change this)

Fig. 8.4: Perspectives of decision-making agency in Tony's GPMs.

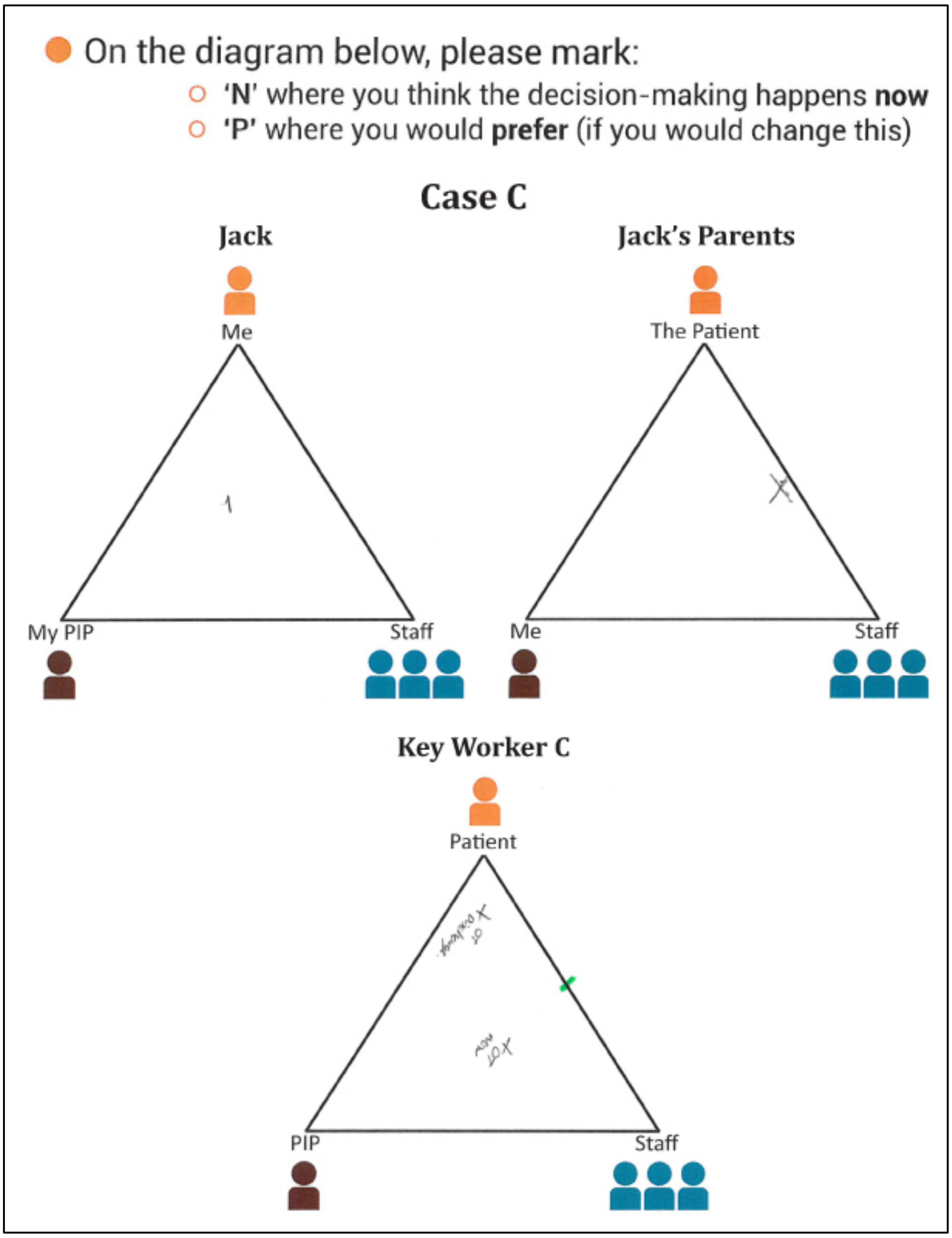


Fig. 8.5: Perspectives of decision-making agency in Jack's GPMs.

From the decision-making visualisations shown above, it can be seen that all participants agree that decision-making is shared, to some extent, between the patient and staff. Interestingly, Tony was the only patient who indicated he would like more agency in this, and he was also observed to be the patient who spoke the most in his GPMs. Additionally, whilst Jack and his key worker felt that Jack's parents were involved equally in decision-making in the GPM, the parents themselves felt that decision were only made between the patient and staff. Finally, the staff based in the Occupational Therapy department were the only staff to make different marks according to different 'types of decisions', such as 'patient-centred' vs 'other' decisions, or 'now' vs 'discharge' decisions. This suggests that, whilst these diagrams afford a more nuanced view of multiple perspectives of decision-making, the concept itself is still widely open to interpretation.

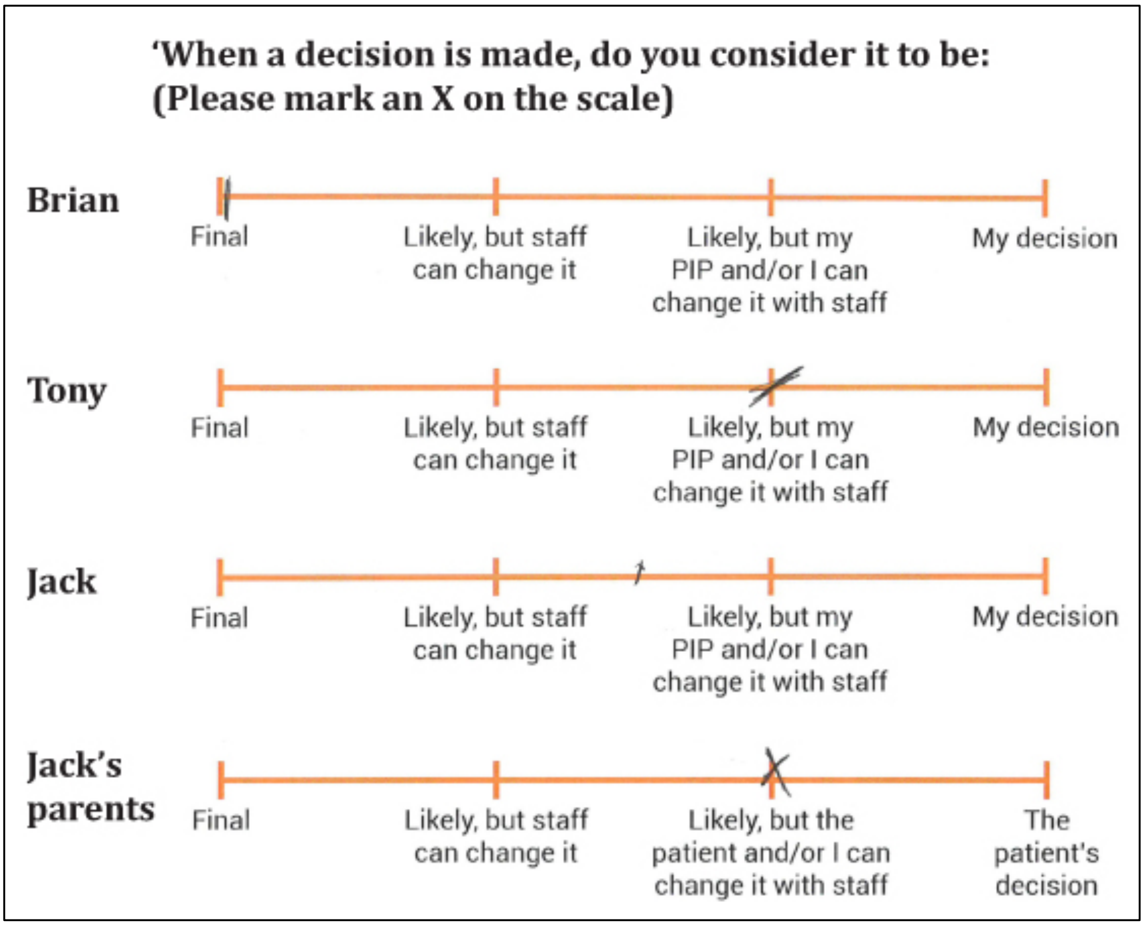


Fig. 8.6: Patient and PIP perspectives on how final decisions made in the GPM are.

From the Likert scales above we can see that, apart from Brian, the other two patient and PIP participants felt they had some agency over changing decisions that had been made in the GPM. It could be suggested that Brian, being older, may be more used to a paternalistic model of healthcare and as such may expect decisions to be 'final,' but this is only speculation.

8.10.3 Rehabilitation Timelines

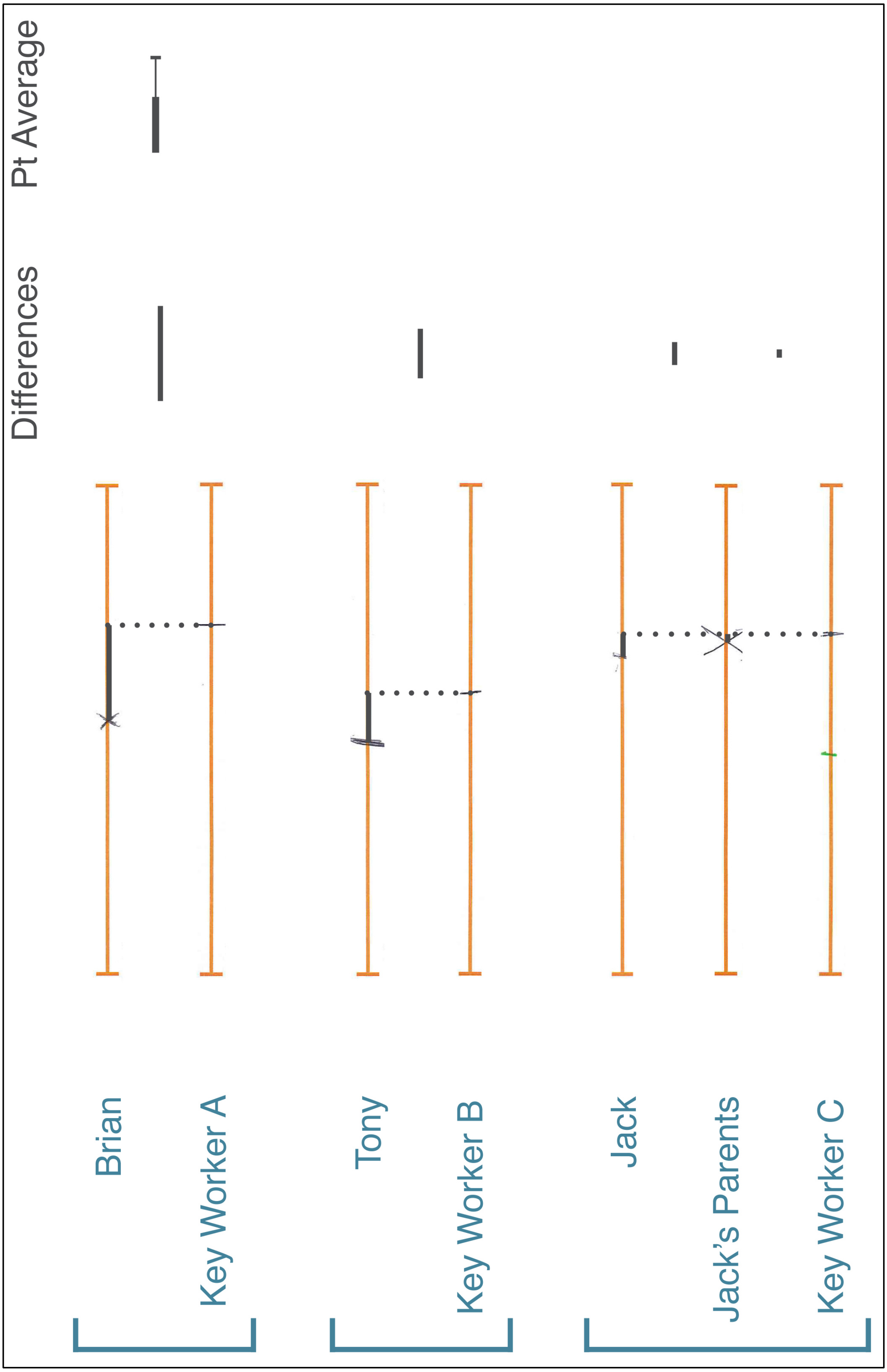


Fig. 8.7: Patient, PIP and key worker perspectives of progress made after the second GPM.

Interestingly, Jack (who had been the most passive patient throughout the Co-Plan activities) had the most accurate view of his rehabilitation progress. The differences in perspective here will be compared to the differences recorded in the Phase One participants in the next chapter.

8.10.4 Staff Understanding

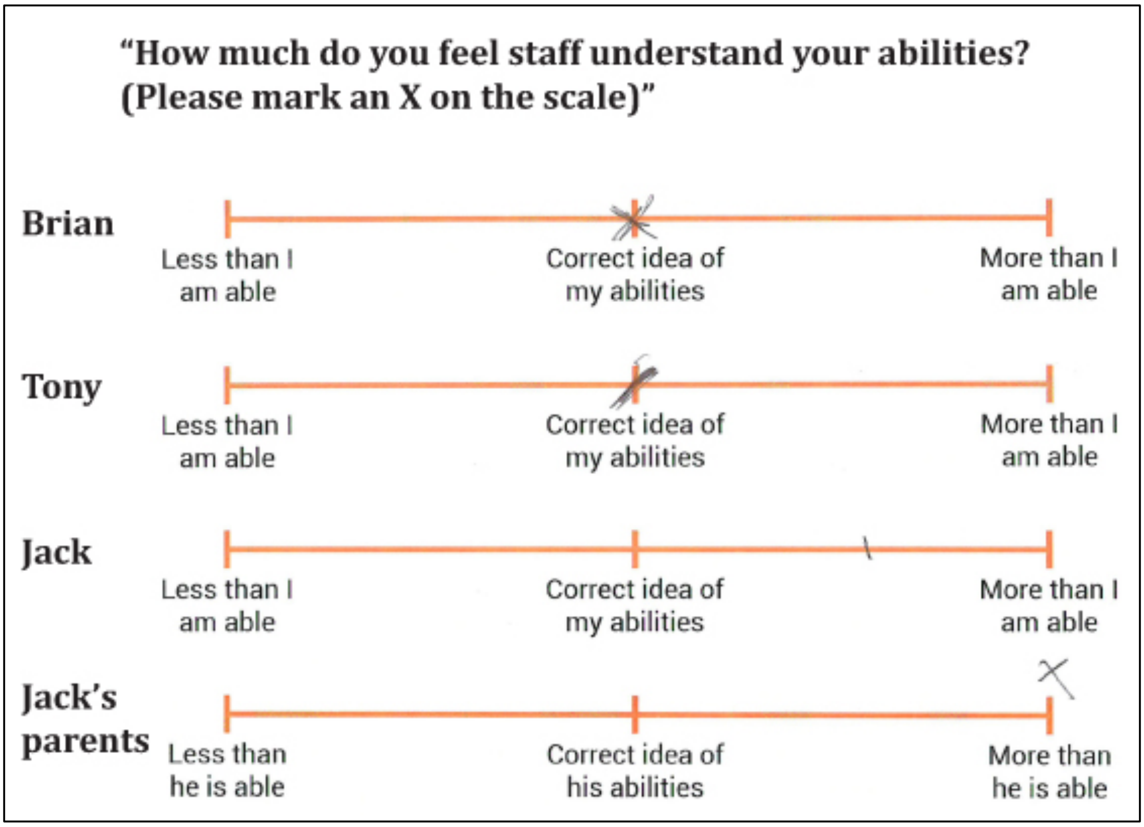


Fig. 8.8: Patient and PIP perspectives on how well staff understood the patient's abilities.

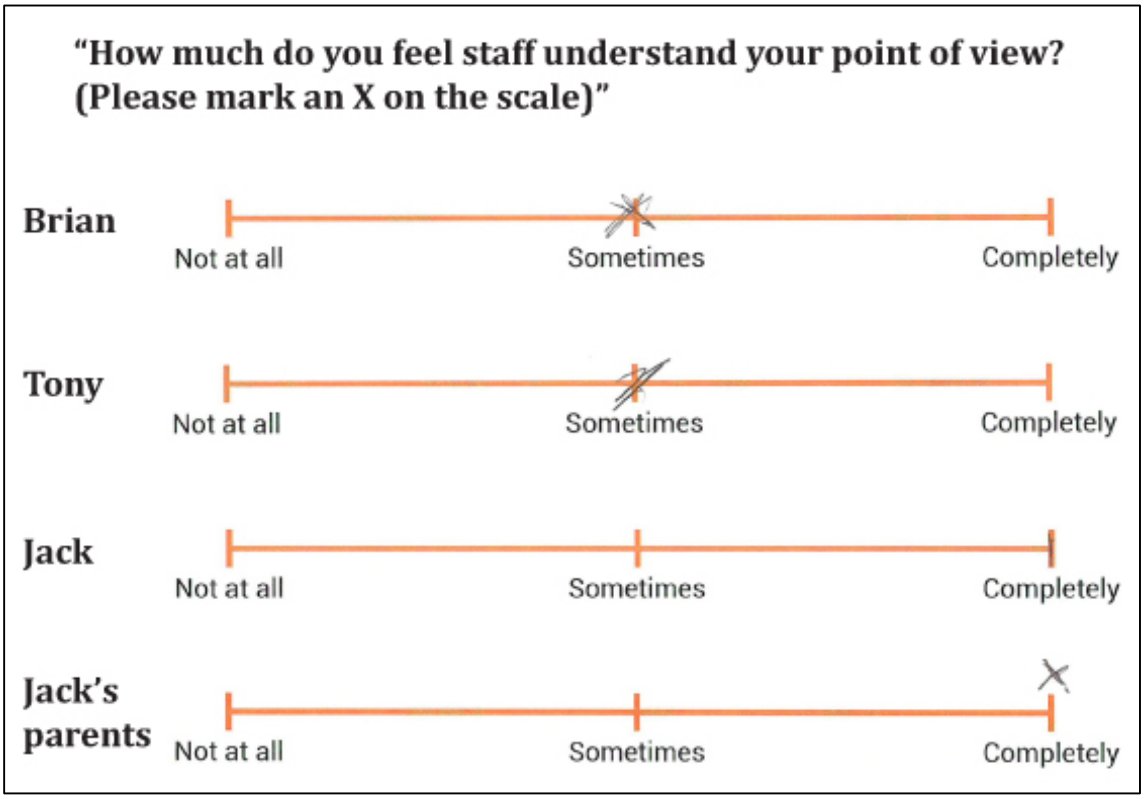


Fig. 8.9: Patient and PIP perspectives on how well staff understood the patient's point of view.

From the Likert scales shown above, it can be seen that whilst Brian and Tony felt staff understood their abilities but perhaps not all of their point of view, Jack and his parents felt staff 'completely' understood their points of view but perhaps, to different degrees, overestimated Jack's abilities. This highlights that the same intervention can be used and perceived differently by different patients, but that the Co-Plan process itself did not cause any significant impact on staff's understanding of their patients.

8.11 Conclusion

The Co-Plan Process has introduced some new, beneficial concepts to the host SIU's rehabilitation process, and also enhanced the researcher's and staff's understanding of the current practices of healthcare professionals within it.

These findings will now be discussed in more detail in the next chapter, against the comparable findings and the Experience Goals that emerged from Phase One.

Stage Four:

Reflecting on the main study

9 Comparison of Phase One and Phase Three Findings

9.1 Introduction

As described in the Study Design chapter, several elements from the Phase One questionnaire–led interview were repeated in Phase Three for comparison (including Likert-scale and diagrammatic questions), and will be presented in section 9.2 of this chapter.

Following this comparison of the visual data, section 9.3 will evaluate the intervention in terms of how it addressed the Experience Goals derived from the Phase One data, with supporting evidence from the questionnaire-led interviews.

Throughout this chapter, the conclusions drawn will be given with minimal discussion, to facilitate a clearer, concise discussion of the study in chapters 10 and 11.

9.2 Comparing visual data with Phase One

9.2.1 ‘How comfortable did you feel asking questions in the GPM?’

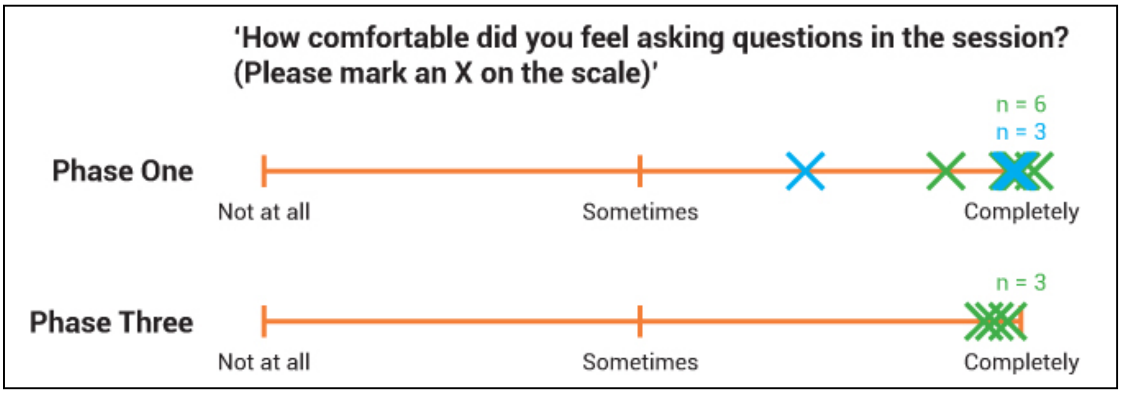


Fig. 9.1: Comparison of Phase One (where green marks indicate patient responses and blue marks represent PIP responses) and Phase Three participants’ comfort asking questions in the GPM.

Whilst there is insufficient evidence to suggest any new effect from using the intervention, this comparison highlights that it didn’t have any detrimental effect in this area, which is still important.

9.2.2 ‘How final do you consider decisions made in the GPM?’

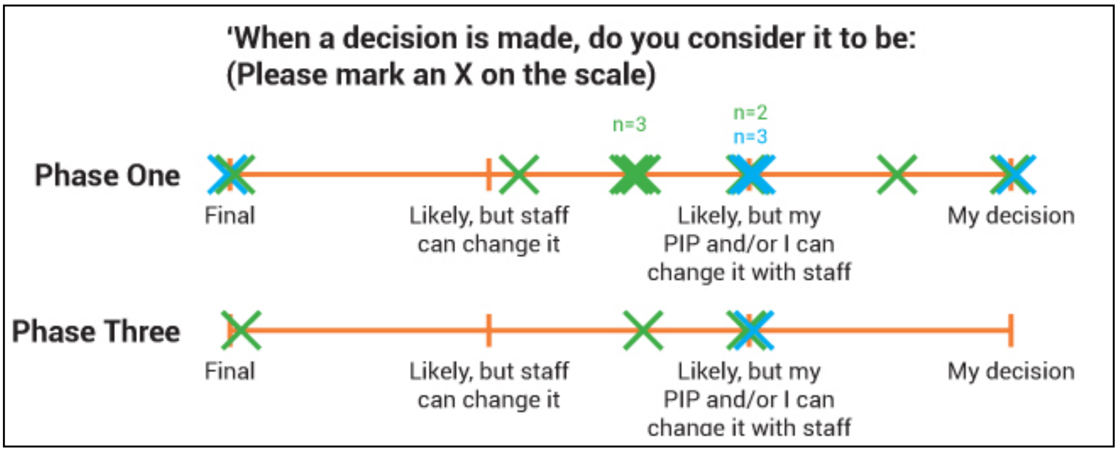


Fig. 9.2: Comparison of Phase One (where green marks indicate patient responses and blue marks represent PIP responses) and Phase Three participants’ perspectives on how final they consider decisions made in the GPM.

A full comparison of patient, PIP and staff perceived involvement in decision-making in Phase Three has been given in section 8.10.2. Interestingly, the patient most vocal in the GPMs, Tony, still highlighted that he did not want full control over decision-making in the GPM:

> ‘I think I’ve got a role to play, because it’s aboot [about] me, know what ah mean? It’s not aboot anybody else. It’s not about anybody else that’s sitting at that table. It’s about none of them.... [later] Ah wouldnae prefer [decision-making] all to be me, know what ah mean? Ah would maybe prefer it half and half?’ Tony

With this in mind, it is important to highlight that enhancing patient participation does not necessarily imply that the patient must make all of the decisions.

9.2.3 ‘Whereabouts would you estimate you are on this rehabilitation timeline?’

In their questionnaire-led interviews (conducted at the end of the intervention), patients, PIPs and key workers were asked to indicate on a rehabilitation timeline how much progress they felt the patient had made to date. By comparing individual cases, and generating an average difference in opinion between the participants in each case, there is some evidence to suggest that patients using the intervention have a more accurate understanding of their progress (see figures 9.3 and 9.4 below).

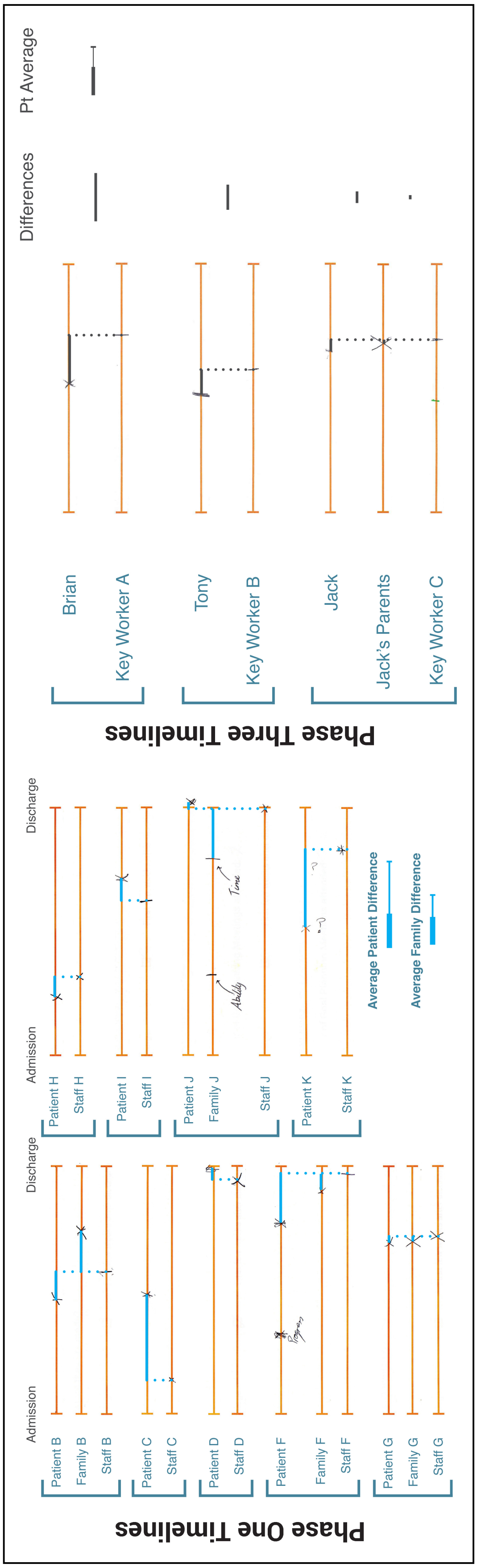


Fig. 9.3: Phase One and Phase Three participants' perspectives on the patient's rehabilitation progress.

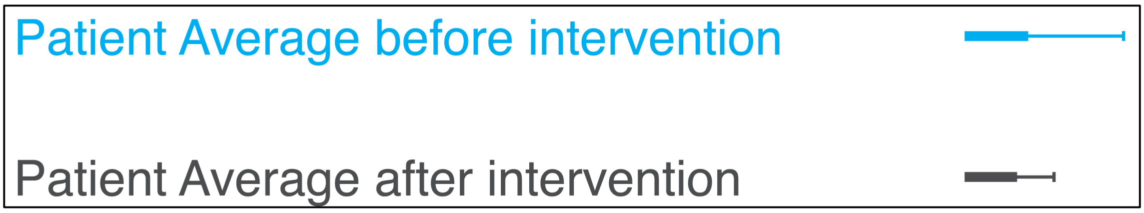


Fig. 9.4: A comparison of the average patient difference in perspectives of progress (compared to their key worker) in Phase One and Phase Three.

This finding suggests that the intervention has at least begun to address the Experience Goals set in Phase One, as discussed below.

9.3 Evaluating the intervention against the Experience Goals

9.3.1 Experience Goal One: The patient is more engaged

General thoughts

Although the potential for response bias must be acknowledged (i.e. interviewees wishing to please the researcher), several responses from the questionnaire-led interviews suggest that two of the patients were generally more engaged:

> ‘I think he is a bit more engaged, I think, the language we’ve used to try and get him a bit more, to get to grips with what his goals are, I hope that would help him feel more engaged,' Brian’s key worker, KWA

> ‘It maybe gave him more chance to speak out, himself. Possibly. Although he’s the sort of character, who, he may well have just reacted in exactly the same way whatever system you gave him... this gives him, I suppose, a bit more permission, it does give him a bit more permission if you like, to, erm, to do that,’ Tony’s key worker, KWB

> ‘Ah do think all that helped. That helps, that... Well obviously I don’t know what it was like before, but... if it didnae have all that [the intervention] before, well, ah wouldnae have helped as much as what it did wi’ that in it, so. So that does help, definitely,' Tony

Whilst Brian and Tony were generally engaging with the process, Jack felt he would not have noticed a difference without the intervention; a sentiment echoed by his key worker:

> 'I don't know if he would be more engaged than what he would have been, if it was done the way previously,' KWC

Nuance in 'Engagement'

Although Brian reported his role in the GPMs as simply to listen to the staff, which could be interpreted as not being actively engaged, he also explained that he felt comfortable with this role. According to his key worker, he was engaged in the Consultant Meeting and Key Worker Meeting, and asked 'good' questions. Even though his injury level prevented him from using the patient folder independently, he did revisit the information inside during visits from his friends and family.

The questionnaire-led interviews also suggested a need to separate the term 'engagement' into 'engagement in activities' and 'independent engagement.' For example, whilst Tony was very vocal in the activities coordinated by staff, and Jack was reported to be very engaged in the Consultant Meeting, neither patient choose to look at the Co-Plan Folder in their own time.

Family Involvement

Both Brian's brother and Jack's parents explained how they had used the patient folder, without prompting from the researcher, and that it was useful in making the patient's situation and the rehabilitation process clearer:

> 'Does any of this at all help you in your role, in his rehabilitation?' Researcher
> 'Aye,' Jack's Mother
> 'Aye,' Jack's Father
> 'I would say it would, erm. It's erm, let us know, obviously the stages and things like that, and helps us know what they require of him, so we can ask him, like, have you done this, have you done that,' – Jack's Mother

9.3.2 Experience Goal Two: The patient knows what happens in the meetings

With the exception of Tony being unsure about the content of his first GPM, all patients and staff reported knowing what to expect in each Co-Plan activity:

> ‘Yeah, oh yes. I know what was going to happen, and what was going to be said and everything, that [Introduction to Rehabilitation booklet] helped me alright,' Brian

> ‘Aye, aye, kinda, obviously, it did let you know, obviously, what he was gonna be daein’ and what kinda things were maybe gonna be said and spoke about and things like that, so aye [the Introduction to Rehabilitation booklet] did help, it let you get a wee bit o’ knowledge about things that were maybe gonna happen, so aye, it was, it was quite handy, aye,’ Jack’s Mother

9.3.3 Experience Goal Three: The patient knows where they are in their rehabilitation journey

Each of the patient and staff participants in Phase Three felt that this experience goal was achieved, with Brian and Tony describing the Long-Term Goals Sheet as being useful in this.

When asked if any of the intervention materials particularly helped him to be involved in his rehabilitation, Tony stated:

> ‘Aye. Aye a lot o’ it did. ‘cos it, obviously helps you, you know where you’re going, you know what you’re gonna do next, and all that,' Tony

Although this is only speculation by the researcher, this suggests that having a clear idea of the rehabilitation process and current position within it may have an impact on patient perceptions of participation.

9.3.4 Experience Goal Four: The patient has a clear idea of their responsibilities

The Phase Three participants had mixed opinions about this final experience goal, which was hard to evaluate as patients did not use their Goal Planning records outside of the GPM. As such, no definite conclusions can be drawn.

9.4 Staff descriptions of the intervention

Although the researcher may have a particular perspective on what the intervention does, it is important to consider how it is perceived by those leading its implementation. When asked how they would describe the intervention to another SIU, the key worker participants had a range of opinions:

> ‘I probably would say we’ve got a PhD student working with us just now, doing a pilot study, and we’re trying a new process with the goal planning...’ KWA [then proceeding to list each aspect of the intervention, in terms of the material and function of each activity]

> ‘I would describe this as a slightly more tuned way of goal planning compared to our normal routine. It’s, erm... I want to say slightly less dogmatic. Maybe ‘dogmatic’ is maybe the wrong term, but less formalized, no, that’s not better. But it’s trying, it’s a goal planning system where you are trying to enable the patient to be more of a leader in their goal setting. But again, that very much depends on the individual,’ KWB

> ‘I would say it was a trial, a project we were doing,’ KWC

It is interesting to note that KWA chose to describe the process in terms of the materials supporting it, perhaps suggesting that the materials and process were shaped by each other. The role of the physical materials in the new behaviours afforded by the The Co-Plan Process will be discussed in Chapter 11 of this thesis.

9.5 Staff evaluations of the intervention

When asked if there were any elements of The Co-Plan Process they would like to continue using, all of the staff involved unanimously and immediately selected the Consultant Meeting:

> ‘I think [The Consultant Meeting] is probably the best part of the whole project... I think this has been so valuable,’ KWA.

> ‘I would say of the whole process [the Consultant Meeting has] been the best change, or the best addition, to the process,' KWB

In addition to this, key workers selected several elements from other materials, such as setting long-term goals that included the patient's priorities, and being able to use those long-term goals more frequently in the GPM:

> 'I think that the intervention, in terms of making sure that we are asking the patient what's important, what their priorities are, I think that, we should have been doing that long before now,' KWA
>
> 'Having the long-term goals set at the beginning is a definite plus, whether it's having it laid out like this, or in any other form, you know. And I think that's a weakness I must admit, I was not as aware of, actually I suppose, because I don't do it like that,' KWB

Staff also described using the Long-Term Goals Sheet as a 'prop' in the GPMs to encourage other staff members to relate the goals they set to the patient as an individual. The key workers also described other instance of using the intervention materials as 'props' including:

- To introduce the rehabilitation team
- To discuss the estimated discharge date
- To check for any questions after consultant meeting in an informal, ad-hoc discussion
- To help patient to understand how many long-term goals are involved in SCI rehabilitation
- To catch up with patient after the staff member took a holiday
- To clarify details that the patient had forgotten or remembered incorrectly from the Consultant Meeting
- To remind the patient of their goals

Patients also described using the materials as 'props'. For example, Tony described how the Long-Term Goals Sheet helped him to communicate what he thought his progress was at the time. Additionally, Jack's parents described using the Goal Planning Record to check Jack had achieved everything he needed to before coming home for the weekend.

9.6 Summary

Given the positive effects of the intervention described above, and the other ways in which the materials have been used as ‘props’ to support other rehabilitation activities, it could be argued that (for the duration of this study, at least) the intervention was integrated into the existing rehabilitation pathway fully and harmoniously. The benefits of being able to work within the ‘real life’ context of the SIU in order to achieve this will form one of the main arguments in the following chapter.

10 Discussion One: Engaging the SIU community in a participatory service design process

10.1 Introduction

This chapter is concerned with the first aim of this research; to explore how designers can operate in a participatory manner in healthcare service contexts.

An in-depth review of (participatory) service design in healthcare literature highlighted that this study is uncommon due to the long-term, embedded nature of the researcher's position in the SIU, and as such it is well-placed to offer an account of how a design researcher may address Sangiorgi and Junginger's (2015) call for designers to work 'with and within' the contexts they are serving (2015). This embedded position has been described as crucial through the entirety of the PhD study, yet the review also highlighted a need for tools or approaches to help designers make sense of such complex contexts.

This study argues that working from an embedded position within the healthcare service is fundamental to clearly understanding and addressing the complexities of such contexts, and is an essential pre-requisite to being able to co-create useful solutions in a harmonious manner that are responsive to the particular needs of that context.

The main lessons learned in this study with regards to embedding the researcher as an individual in the healthcare context (rather than as a 'lab' such as the Design for Health and Wellbeing Lab, New Zealand (www.dhwlab.com) or the Experio Lab, Sweden (experiolab.com)) can be summarised in the following five points.

10.2 Embedded nature of the study

10.2.1 Introductions

The researcher felt more confident in her ability to observe and interact with the SIU sensitively (as part of the contextual review) by conducting a thorough literature review of the nature and experience of SCI first. The researcher found that the way she introduced herself affected how the SIU community engaged with her, or what kinds of information they assumed she would be interested in. For example, the fact that the researcher wore her own clothes in the ward (as opposed to a uniform or 'scrubs') meant that many patients or family members assumed she was a doctor; or introducing herself as a ‘designer’ may lead to discussions on equipment or environment. Instead, to avoid these preconceptions, she simply explained that she was based in the research unit at the SIU, and that she was interested in the patient, family and staff experiences of SCI rehabilitation.

Failing to introduce herself or the project could also affect the research activities. For example, during one night shift (7pm - 7.30am) in the rehabilitation ward, one nurse asked, 'Are you a spy? You've been writing in that notebook all night.' This highlights the importance for researchers to explain their motivations during such observations, and to be transparent in what is being recorded. As discussed in the Contextual Review chapter, feeding back to the SIU community regularly, either verbally, through email or through visual summaries (such as the Diagrammatic Exploration process), also helped foster this sense of ‘transparency,’ and therefore, trust.

Taking care to maintain working relationships with patients beyond these initial introductions also facilitated a deeper understanding of a patient's journey, how it changed over time and the minutiae of daily life on the ward, where staff became accustomed to her presence and ad-hoc invitations to observe further rehabilitation activities or meet new patients were extended (by staff and patients).

10.2.2 Giving and taking time

Patients often wished to talk (for extended periods of time) about subjects not directly related to the research activities. Whilst this again added time to the research activities, the researcher was mindful that the patients were generously giving their time during a very difficult period in their lives and that it was important to be adaptable to their agenda also. As such, the researcher argues that this extra time should be factored into project planning, as well as appropriate support structures for the researcher, given the difficult topics that patients may wish to discuss.

10.2.3 Sense-making and remaining objective

A risk of becoming 'institutionalised' is inherent when spending a long time in a new work context. As described in section 2.10, the Diagrammatic Exploration method allowed the researcher to 'step back' and take a more abstract view of the SIU ecosystem, and created a strong foundation for becoming ‘embedded’ by sharing and co-developing these diagrams with staff. As such, this study contributes to the literature calling ‘research on approaches and tools to increase the ability of designers to make sense of organisational contexts,' (Sangiorgi et al, 2015, p4).

10.2.4 Adaptability

Clearly, research activities in such contexts must be planned with as minimal an impact as possible on the rehabilitation schedule. Following the contextual review, the researcher's knowledge of work routines and the logistics of the spaces available allowed her to plan, facilitate and often reschedule the research activities according to the (sometimes unpredictable) needs of patients, families and staff. This may include the changing work schedules of staff, sudden changes in mood or health status of patients, or simply being sensitive to the fact that family members need time alone with the patient on the day of planned activities. As such, this study argues that design in healthcare contexts requires a certain level of ad-hoc adaptability, such as the extra co-design events arranged for individual staff members who couldn't attend the planned group workshops (see section 7.5).

Within the co-design literature, few examples exist to encourage the participation of people with SCI (see section 3.14). Consequently, the researcher's contextual knowledge was crucial to design research activities which aimed to create a positive experience for participants, by ensuring the workshop length and content was reactive to their individual needs. For patients, this meant delivering shorter sessions with tools that could be easily manipulated (to accommodate the potential for fatigue or limited dexterity). As such, the methods outlined in section 7.3.3 add to this co-design literature.

10.3 Participatory nature of the study

10.3.1 A need for further reflection

With its influences from Participatory Design, this study is a part of what Kraff (2018) describes as the field's expansion, including a broadening of contexts and wider variety of participants, who are no longer limited to workplace employees but also disadvantaged or marginalised groups and communities. She argues that such expansion can be problematic, as 'there has not been enough development of appropriate structures to support the involvement of these new types of participants in new settings (referencing Light and Akama, 2012) and that this growing diversity also 'puts new demands on project reflection,' (Kraff, 2018, p2). She proposes using context-specific tools for reflection (see fig. 10.1), that can 'give visual form to complex situations, highlight differences between groups and indicate how participants' positions alter over time,' (ibid, p1). She further argues that such a tool can enable design researchers to reflect collectively on participation in their projects as they are able to 'see each other's thoughts,' (ibid, p2).

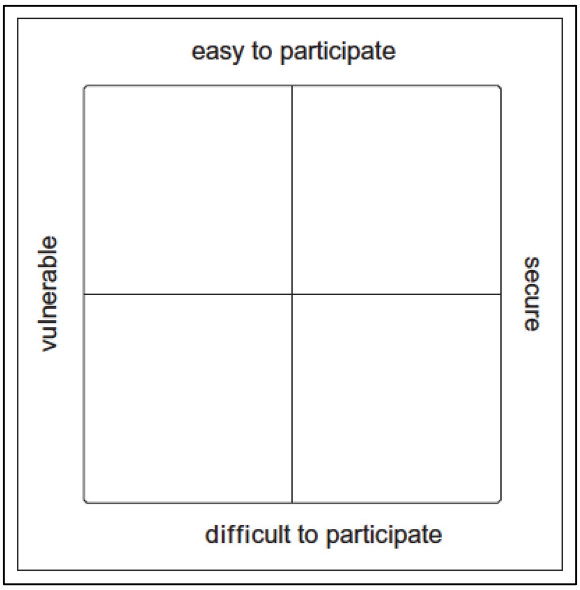
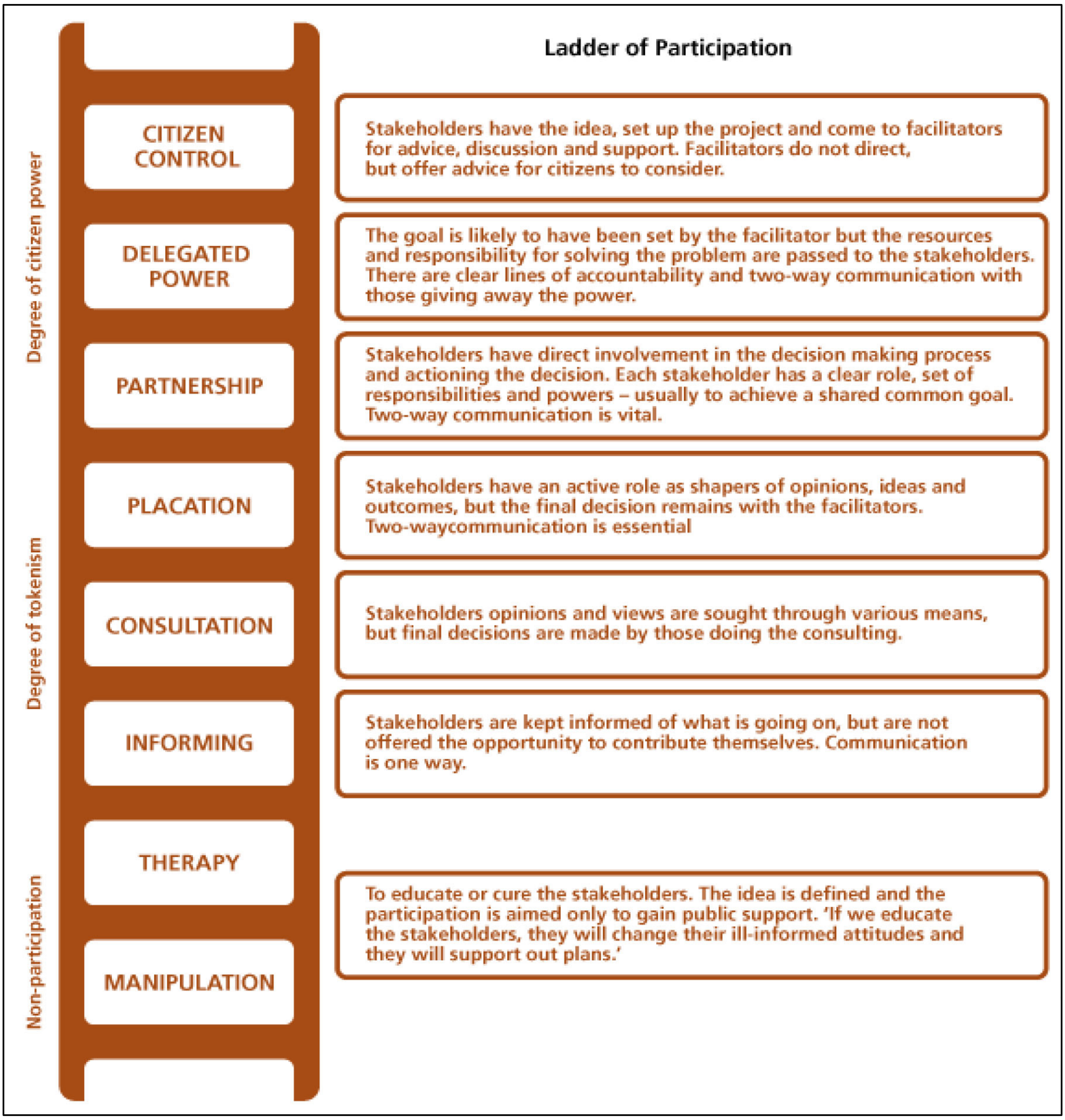


Fig. 10.1: Kraff's tool for reflection considers the impact of participation in her project on her participants' standing in their community (2018).

In a field which largely involves outpatients as representative of the entire patient community (when patient input can be gained at all), this thesis contributes to the participatory service design in healthcare literature by providing a case study of engaging a SIU community (including outpatients, inpatients, family members and staff) in co-design, co-production and (to some extent) co-development of an enhanced rehabilitation patient pathway in a novel, highly complex and interdependent healthcare context. The following discussion aims to draw on the arguments laid out by Kraff (2018) above, and add value to these contributions with deeper reflections on the nature of each stakeholder groups' participation across the main study. In order to inform the creation of a reflective tool more suited to this PhD study, the following section will review a range of extant frameworks for guidance and inspiration.

10.3.2 Participation models

The models reviewed are sourced from a variety of fields, and discussed in terms of the features which are useful to aid reflection on the nature of participation in this study (rather than a full review of their benefits and limitations within this context, or to situate this study's findings within their research communities).



Stakeholders have the idea, set up the project and come to facilitators for advice, discussion and support. Facilitators do not direct, but offer advice for citizens to consider.

The goal is likely to have been set by the facilitator but the resources and responsibility for solving the problem are passed to the stakeholders. There are clear lines of accountability and two-way communication with those giving away the power.

Stakeholders have direct involvement in the decision making process and actioning the decision. Each stakeholder has a clear role, set of responsibilities and powers – usually to achieve a shared common goal. Two-way communication is vital.

Stakeholders have an active role as shapers of opinions, ideas and outcomes, but the final decision remains with the facilitators. Two-waycommunication is essential

Stakeholders opinions and views are sought through various means, but final decisions are made by those doing the consulting.

Stakeholders are kept informed of what is going on, but are not offered the opportunity to contribute themselves. Communication is one way.

To educate or cure the stakeholders. The idea is defined and the participation is aimed only to gain public support. 'If we educate the stakeholders, they will change their ill-informed attitudes and they will support out plans.'

Fig. 10.2: Arnstein's original Ladder of Citizen Participation (1969) with additional annotation from Rosier (2013).

Proposed within the context of policy decision-making, Arnstein's Ladder of Citizen Participation (1969) is one of the oldest models addressing this issue and is still discussed today (McArthy & Wright, 2015). Although this study aimed to reach the higher, arguably more meaningful levels of participation with as many groups of the SIU community as possible, some organisations argue that operating at the lower rungs on the ladder isn't necessarily something to be discouraged, rather they are simply 'different' forms of participation (Involve, 2005).

As can be seen, the terminology used in the ladder itself is not specific to one discipline; instead participants are engaged as ‘citizens’ offering different knowledge and experience to the professionals involved in the context in question. Given that ‘partnership’ is the first level where decision-making directly involves the ‘citizens,’ it could be suggested that involving participants in decision-making is the difference between ‘tokenistic’ participation and ‘citizen power’ – a useful consideration when reflecting on this study.

The New Economics Foundation (NEF, see Slay & Stephens, 2013) have appropriated Arnstein’s ladder to ‘reflect how coproduction builds on previous user/professional dynamics,’ particularly within mental health contexts, as shown in fig. 10.3 below:

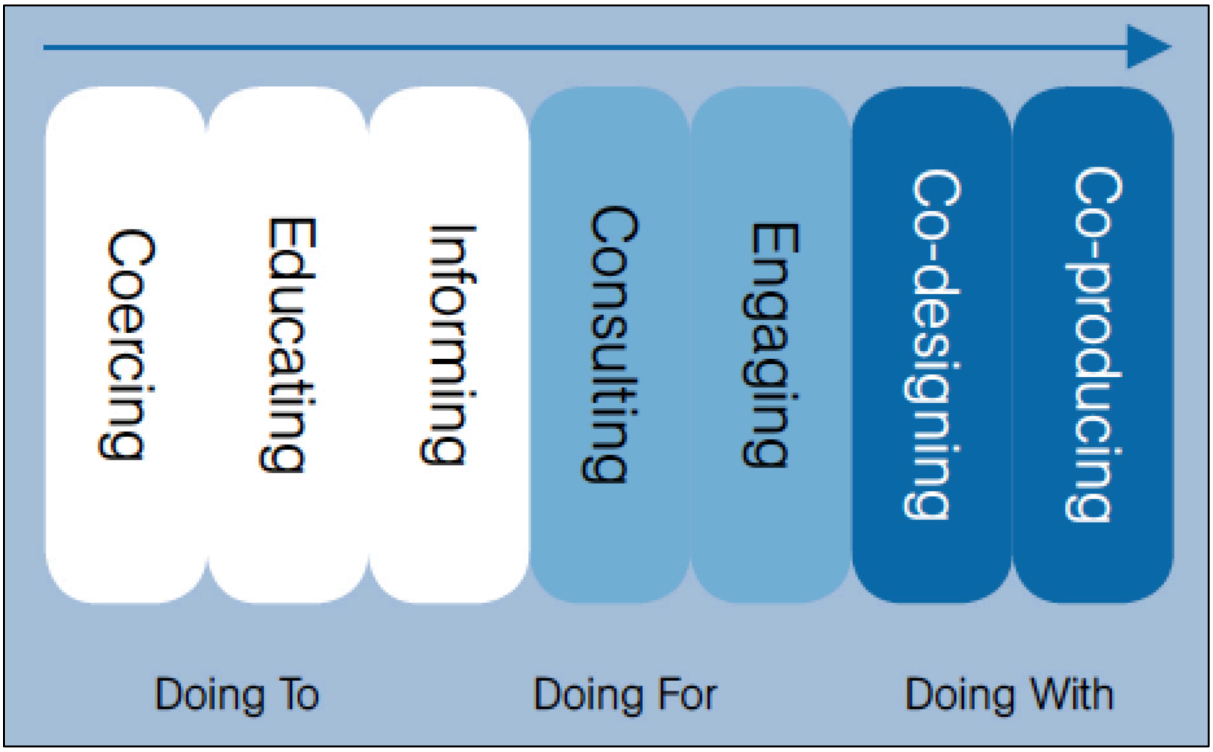


Fig. 10.3: NEF’s Alternative ‘Ladder of Participation’ (Slay & Stephens, 2013)

The more contemporary language used in NEF’s model above, in particular the use of the terms ‘engaging’ and ‘co-designing’ are perhaps more relevant to reflections on this study, and more readily makes a connection between design and healthcare activities. It also bridges the gap between involving patients in designing healthcare services more generally, and in being active participants in shaping their own pathways, with the inclusion of the term ‘co-production,’ as ‘a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities,’ (Slay and Stephens, 2013, p3).

Interestingly, McCarthy and Wright provide a critique of hierarchical models of participation, arguing that participants can take part in various different ways, including emotionally or intellectually, playfully or with goals in mind (2015, p63). Despite this, though, distinctions of what types of participation are afforded (i.e. how much ability patients have to make decisions) and how the asymmetry of power in healthcare is addressed is useful in reflecting on what was achieved (or not) in this study.

Savory provides an alternate healthcare-specific framework for considering PPI (Patient and Public Involvement) in healthcare research in general, shown in fig. 10.4 below.

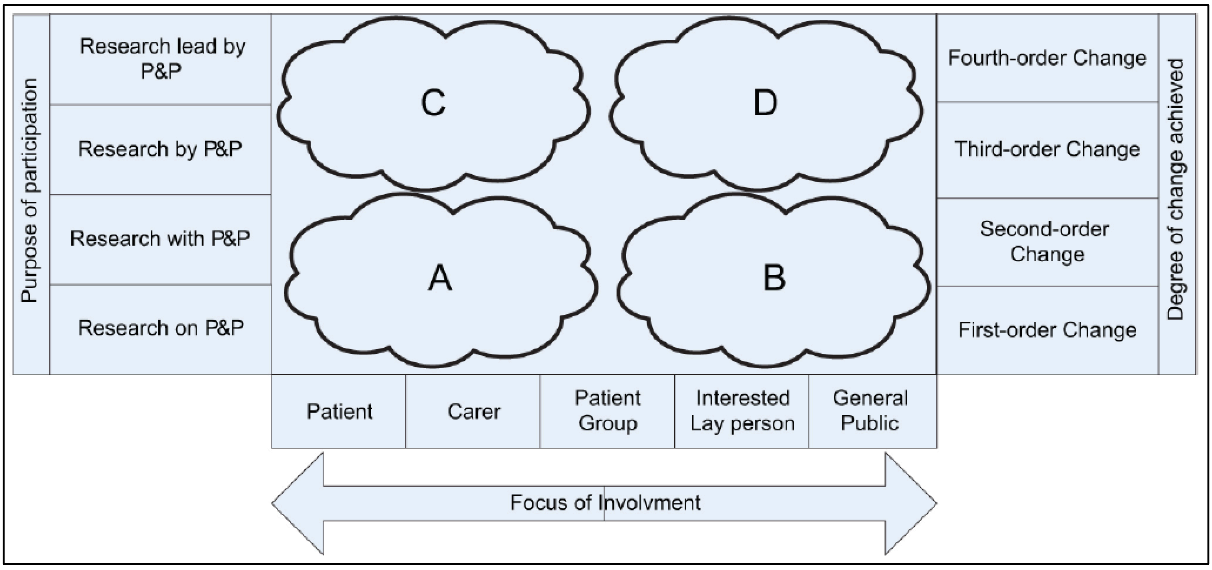


Fig. 10.4: A ‘Framework for mapping various PPI strategies’ (Savory, 2010), where patients or the public are involved to ‘gather data’ (A), gathering wider perspectives (B), user-led, complex involvement strategies for more translative research (C) and ‘public involvement and education’ (D).

It is interesting to note that Savory provides a ‘spectrum’ of PPI groups (on the x axis) within this model. However, the distinction between ‘inpatient’ and ‘outpatient’ is not given (as it is in this study), and whilst a ‘carer’ category is present, this is arguably different to ‘family,’ who may provide other kinds of support and/or advocacy of the patient’s interests. From this model, a clear distinction between which participant groups are involved, to what degree and consideration of the impact they have may be useful in reflecting on this study.

10.3.3 A tool for reflection on the PhD study

After reviewing the various ways participation has been conceptualised (from healthcare fields and otherwise), a framework was constructed in order to approximately represent and reflect on the various ways in which the multiple participant groups participated in the main study of this thesis, shown in fig. 10.5 below.

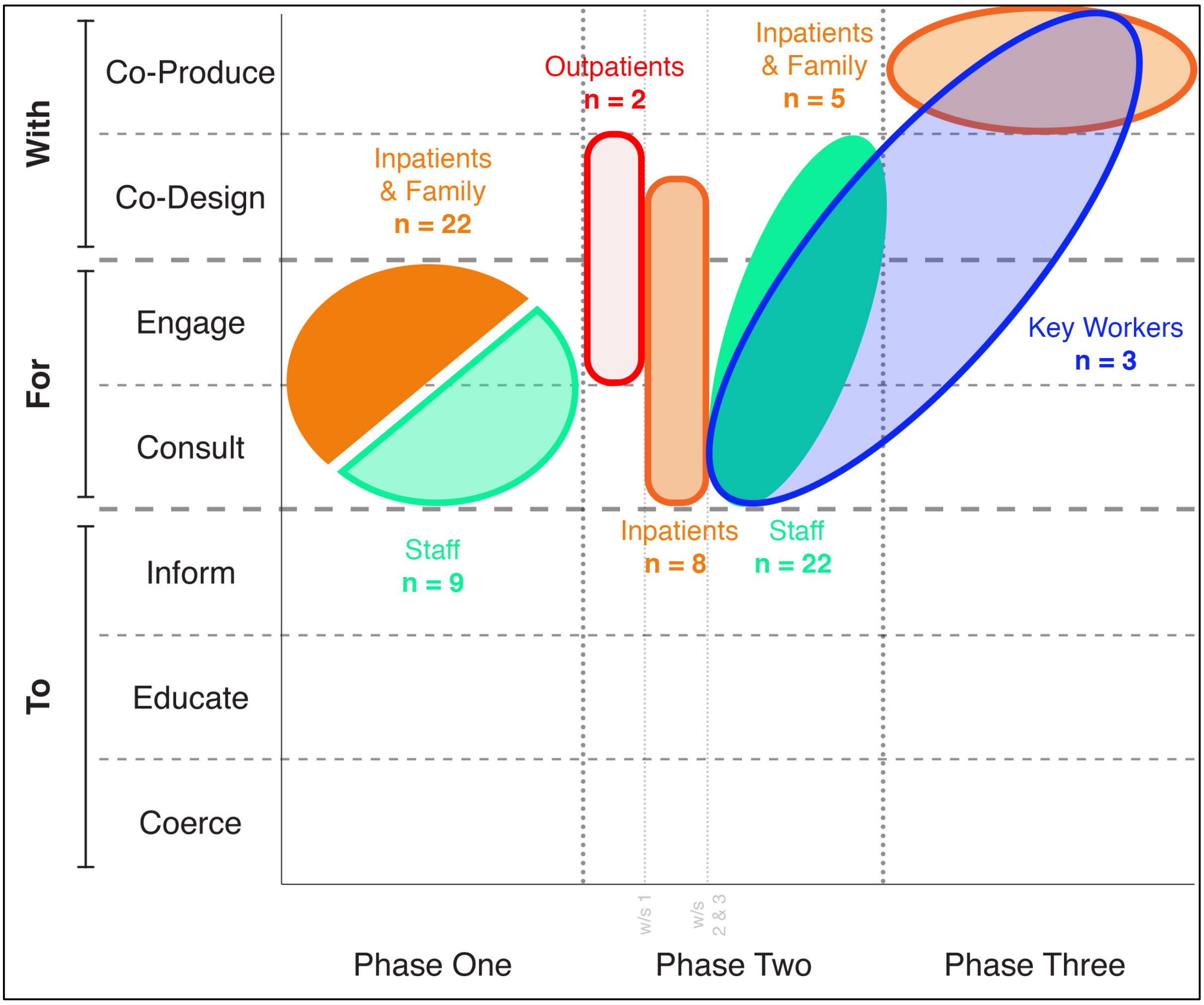


Fig. 10.5: A framework to map the various modes of participation afforded to different participant groups across the main study period, where opacity of the regions reflects participant numbers.

As can be seen above, the study operated above the threshold between ‘doing to’ and ‘doing for’, so communication between the designer and SIU community is two-way. Drawing on the definitions provided by Arnstein and NEF, ‘Consult’ and ‘Engage’ levels involve seeking the community’s views, with less or more influence on the design direction respectively, but without their involvement in decision-making. In ‘co-design’ (as suggested by Sanders and Stappers, 2008), designers and those not formally trained in design collaborate in design processes, where the SIU community take part in decision-making in the design direction. In line with definitions given by Freire and Sangiorgi (2010) and NEF (Slay and Stephens, 2013), ‘co-production’ involves patients and staff delivering the (new) service collaboratively and reciprocally. For the purposes of this study, co-production also refers to the autonomous nature of such implementation, with little to no input from the designer.

The acknowledgement of different participant groups has been expanded beyond that found in Savory’s model, to include inpatients, outpatients, family members, staff and key workers as a vital sub-group of the staff community. The areas attributed to each group in the framework are considered rough territories, for, as McArthy and Wright argue, everyone has the capacity to participate differently (2015). However, in providing this visual, nuanced account of the nature participation in this study, the discussion aims to contribute to Suchman’s call for situated discussions of design practice (2011). The colour saturation of each territory is also indicative of the total number of participants in that group at each stage, to more honestly account for the level of influence, or range of opinions, each participant group may have had in comparison to others.

This tool will now be used to guide a more nuanced discussion on the participatory nature of each phase of the main study.

10.3.4 The participatory nature of Phase One

Within Phase One, all participants were most actively involved during the questionnaire-led interviews, where a combination of quantitative, qualitative and visual questions were used to uncover the multiple GPM experiences. Given the richness of data collected, and participants' engagement with each type of method, this study corroborates Sanders' description of how people can be given 'simple visual tools with which they can express their dreams and aspirations,' (2006, p28). Rather than using complex methods such as 'Maketoolkits', (Sanders and Stappers, 2012) the researcher chose to use visual tools that would be most easily understood by healthcare audiences, such as simple diagrams of the rehabilitation timeline to discuss patient progress, which were still able to elicit deeper, experiential forms of knowledge.

The Phase One methodology is placed within the 'Doing for' levels of the framework above, as opinions on the multiple perspectives of the GPM and priorities for change were shaped by participants’ input, but the researcher took responsibility for analysing this data and developing the initial prototypes for Phase Two.

10.3.5 The participatory nature of Phase Two

There are several aspects to the discussion on how design methods and approaches helped to engage the SIU community in the Phase Two co-design process, including who was involved, when, by which methods, and the need for flexibility and adaptability of approach.

Who

As found in the literature review, outpatients are usually involved as representatives of all patient groups in healthcare- and design-led service improvement projects. However, this study proposes a more nuanced view of 'patient experience' that differentiates between 'current' experience and 'lived' experience, with the position that both are equally valuable. Whilst outpatients were able to provide ‘hindsight’ experience (i.e. their suggestion to create a patient-owned folder, as they felt it was something they may have found useful then), and also to ‘vet’ prototype ideas prior to introducing them to (arguably more vulnerable) inpatients, inpatients were best placed to suggest how co-designed materials may fit into their daily routine, or how much information may be too much, etc.

This differentiation is perhaps more applicable to life-long conditions such as SCI, but may also be worth consideration in other healthcare contexts such as Stroke rehabilitation.

How

The researcher’s familiarity with the SIU and the people within it suggested that the vital inpatient-staff working relationships may be compromised by involving them together in co-design activities (as is the approach of many workplace-based PD projects). The aim for anonymous, creative collaboration between patients and healthcare professionals was achieved by embodying the SIU community’s experiential, behavioural and/or practical knowledge in the iterative development of prototype materials (and as such, the healthcare ‘events’ they supported). The approach was arguably successful, given the candid nature of the conversations in the workshops. As such, this study contributes to the participatory service design literature by making an argument for such ‘distributed participation’ (Altuna & Jun, p323) not just due to practical reasons, but through a deliberate ethical choice, and the strength of iterative prototyping processes in doing so.

In the individual workshops, the use of prototypes also gave enough structure to the meeting to focus group conversations, but were also flexible enough to prompt new ideas and allow participants to explore related tangents. Discussion of these prototypes was supported by the use of two key tools:

- Experience goals, as reminders of the shared aims across the SIU community, helping to maintain focus in discussions and as a set of evaluation criteria to establish when the concept was ‘good enough’ for testing. Several sources in the Literature Review suggest that a clear shared narrative can help overcome the challenges of designing in healthcare, and as such this study contributes to this field with a novel case study of successfully using the Experience Goal method for such purposes in healthcare.
- The use of completed prototypes (i.e. prototypes filled-in with a mock patient's goals) for an enhanced, shared vision of how they could be used, prompting new ideas and anticipating problems that may not otherwise have been found until much later. For example, after reviewing the first mock Goal Planning Record (filled in by the researcher, using her experience observing numerous GPMs) in Event 5, staff commented that the ‘goals’ set were actually a mix of ‘goals’ and ‘to-do’s’, and asked for future iterations of the prototype to allow staff to separate the two categories. In this way, the filled-in prototypes acted as a mirror to staff’s Goal Planning Practices, eliciting new knowledge that may not otherwise have emerged and incorporating that into a new design. It also corroborates what Sanders and Stappers describe as the ability of a prototype to 'confront the world, because the theory is not hidden in abstraction,' (2014, p6, see also Stappers, 2013).

However, it must be acknowledged that participants were reluctant to draw or edit the prototypes themselves. During the workshops, the researcher alternated between taking notes of their comments and altering the prototypes herself to check she understood the changes being suggested, or to suggest expansions on them. The prototype materials were then refined between the workshops to include the issues, feedback and new ideas generated at each session. Whilst the researcher was originally concerned that the process was not ‘participatory,’ on reflection it was apparent that the frequency and scope of verbal contributions from all participants was high from the early stages of the process, with their input steering the design direction.

As can be seen in fig. 10.5 above, the researcher has suggested that the various SIU community groups occupied slightly different territories in the framework, despite all being engaged in prototype-led workshops. It is suggested that the SIU outpatients (n=2) mostly 'engaged' in discussion on the prototypes, providing rich experiential and empathetic knowledge on which ideas to take forward, but as they also suggested entirely new materials they reached into the 'co-design' range also. The individuals within the inpatient cohort (n=8) took part in the workshops in different ways, some remaining quiet, some elaborating on aspects of the prototypes and some suggesting new ideas, and as such their territory is broader. The incline shown in the SIU staff territory suggests an involvement that leans increasingly more towards 'co-design' forms of participation, as later prototypes were used in further design activities such as enactments, where discussions became more firmly focussed on 'realizing a certain desirable future' (Storni, 2013, p51).

Enactments

Staff participants were almost always enthusiastic about arranging and taking part in the enactment activities, as shown by their suggesting a mock GPM before the researcher did (see fig. 7.21). Staff also acknowledged, without prompting from the researcher, that there may be issues in the initial enactment activities, as illustrated in the following conversation:

> 'It's a change of culture so we need to just try and forget the routine of the process that we used before.' Lead Nurse
> 'And if there's bits that we don't like, then we can put that towards... [the researcher], to get that changed,' Patient Education Liaison Nurse
> 'Yes, [the researcher] will want to know!' Consultant

This exchange suggests that whilst the staff participants felt a sense of agency in the project in terms of testing the ideas and using their expertise to suggest changes, the researcher retained responsibility for making the changes and perhaps, as a result, overall accountability for the project.

Although staff engaged with the prototypes fully in the scheduled enactments, they mostly did so following the protocol suggested by the researcher, then collectively critiqued the material and process after the enactment. This approach allowed participants to fully explore the unfamiliar process before judging it, and therefore followed a design-test-redesign-retest pattern in distinct, separate steps (as in scientific research), rather than the 'messy' approach attributed to professional designers, where the acts of testing and designing are harder to separate (Stickdorn and Schneider, 2011). It could be argued, then, that a test-retest approach to developing prototypes with healthcare staff goes some way to reconciling the epistemological differences between the fields of healthcare and design, and contributes to the literature which often states the difficulty of this without providing concrete guidance.

It is interesting to consider that the SIU staff, coming from a medical background, were more able to participate in design activities that more closely resembled 'scientific' paradigms of knowledge creation, in terms of testing a 'hypothesis' (or prototype materials) in a complete experiment (or a full enactment) then discussing the findings (to inform future iterations). This has resonance with what Junginger and Bailey describe as a need to consider 'organisational design pre-texts,' or the 'invisible, unacknowledged, and unarticulated' ways in which staff members can 'actively design' but are 'unaware of their own role as designers or in their own designing practices,' (2017, p34). For example, the contextual review highlighted regular 'test-of-change' meetings between heads of department in the SIU, where alterations to nursing, physiotherapy or occupational therapy practice were suggested, trialled over several weeks, and evaluated at the next meeting – a pattern more similar to the enactment activities rather than the workshop-based group development of prototypes that designers may be accustomed to. Anecdotal evidence of how healthcare professionals (or other participant groups) actually engage in co-design activities is not common in the literature, and this study argues that designers who wish to work in a participatory manner within healthcare services need to be sensitive and adaptable to the most effective modes of participation for each particular co-design community.

It is worth noting that the SIU staff involved in the enactments were reflective on their role-playing, as shown in the exchanges below:

> 'The only thing I was thinking of, ah... y'know to be honest, I haven't been entirely able to put myself entirely in the position of a 17-year-old that doesn't have any experience of this... and I'm thinking too much like a nurse… So I'm coming up with all the stuff that obviously you'd want somebody to come up with,' Acute Care Nurse
> 'Uh-huh, yeah, but they don't! Haha!' Occupational Therapist

> [Later]
>
> ‘I think you actually played the role a bit too well, because... it will be interesting if you [are] allowed to record the first meeting of the actual patient [upon whom the Acute Care Nurse is basing his role], I suspect it won’t resemble this last meeting much at all...’ Physiotherapist

So, whilst the staff participants demonstrated their ability to trial an idea fully immersed in their respective roles, they were also able to maintain a critical distance as to how their ‘performance’ was affected by their professional knowledge and how the enactment may relate to the reality of working with SIU inpatients. These reflections could then be used in discussions of how to develop the prototypes further. As such, staff were able to include their professional, experiential and empathic knowledge alongside creative explorations of new work practices afforded by using the prototype materials, as demonstrated further by the following quote by the acute care nurse (playing the role of the patient):

> ‘Well if I give it from the patient’s perspective over the last two days, where I’ve been at the three meetings, it’s actually been very good, because things don’t necessarily come up, in terms of my concerns, in a tick-box fashion... so I feel that I’m able to bring up things that are genuinely bothering me, that are worrying me, that are a problem for me, and it might not fit in the nice category of, like, a measurable boxes, but, it’s important to me, and I feel that there’s somebody I’m talking to, somebody who’s listening to me, so, it, it is quite good from that [point of view],’ Acute Care Nurse

This suggests that, at least in the case of the acute care nurse, the enactment activity gave the staff involved 'permission to explore new behaviours' (Coughlan et al., 2007, p2) and assess their value in a low-risk way. It also addresses the notion, raised in the Literature Review chapter, that SIU staff may actually be participating in multiple roles, for example as an individual stakeholder (i.e. with personal work practices being challenged and possibly altered), a citizen of the SIU community (i.e. with a duty to ensure the best possible experience for patients) and as a co-designer (i.e. imagining new futures in a context which is not traditionally creative), suggesting that prototyping and enactment activities allowed the staff to explore how the co-designed intervention may impact each of these roles, and alter the design accordingly.

Addressing the asymmetry of power?

The size and saturation of the SIU staff territory compared with inpatient and outpatient territories shown in fig. 10.5 above raises potential issues of representation and whether the smaller patient cohorts, engaged for a shorter duration, were influential in the co-design process at all. Unfortunately, long-term engagement from inpatient groups is difficult to secure, even in contexts such as the SIU with a longer average length of inpatient stay. With this in mind, the outpatient and inpatient groups were engaged in the initial workshops to establish 'what' was wanted, before moving onto 'how' this could be achieved with SIU staff, who had the practical, professional and experiential knowledge to address this question (as well as add their own needs). In addition, the experience goals developed from the Phase One findings were used as a consistent reference for patient priorities for change, and staff commonly asked the researcher about the out/inpatient views on the prototypes in the initial workshops. As such, the staff workshops could perhaps have been improved by creating tangible, easily accessible materials describing the early patient input.

10.3.6 The participatory nature of Phase Three

Other than meeting with the staff regularly to check they were happy in their role, and organising a 'Design-In-Use' meeting (see section 8.4.2), the staff were given autonomy in the implementation of the intervention, and patient and PIP participants engaged with the process as a normal part of the rehabilitation process. As such, the researcher argues that the SIU staff operated within 'Co-Production' and 'Co-Design' territories, and the nature of the co-designed intervention allowed the third inpatient & family cohort (n=5) to take part in 'Co-Production' also (as shown in fig. 10.5 above). As such, this study contributes to the participatory service design in healthcare literature, which has 'less focus on the back-end of the development process,' (Almqvist, 2017, p2524), with a case study of inpatient and family involvement beyond the 'fuzzy front end' through to implementation.

10.3.7 Staff perception of the participatory nature of Phase Two

The descriptions of the co-design process thus far have been based on the researcher's perception, yet this study is concerned with how people can experience the same event differently. When asked how they would describe their role in the project, the three key workers who led the implementation of the intervention had varying opinions:

- KWA described the project as a collaboration, and that both the researcher and the staff needed each other in order to get to the result that they did. She felt that some of the new materials and activities (such as the patient-owned folder and consultant meeting) would not have been approved by senior staff without the researcher advocating that it was worth trying. KWA described her role as ‘I’ve been in the working group,’ and that she took part in consultation, reviewing the service, finding a need, focusing the work on making the best change possible and sharing a lot of information.
- KWB felt that the outcome of a project to enhance the Goal Planning process would have been very different without the researcher's way of doing it. He felt that the study was the researcher’s project that the staff had helped to guide her. KWB felt that his role had been ‘advisory,’ ‘participatory,’ ‘guiding’ and ‘trialling’.
- KWC also felt more strongly that the study was the researcher’s project, and that the researcher had used the staff’s feedback.

Interestingly, KWB and KWC both described the project as being defined by an ‘arts-based’ approach and by the researcher’s different way of viewing the world:

> ‘I think your vision is different from ours, but you come from a different place. You come from a design place, erm, we come from a rehab place, which is... it actually could be polar opposites. The only difference is, erm, practicality, probably, you’re probably quite practical, more than you think you are. You’re definitely adaptable, because you’ve taken everything on, that we’ve asked...’
> KWC

It is interesting that KWC wished to reinforce that the design-based approach did not come at the expense of being practical, highlighting some of the assumptions healthcare practitioners may have about creative practices such as design.

Although the researcher was initially disappointed to hear staff describing their role in the project as mostly ‘informing’, further discussion suggested that this was the role that they preferred. For example, when asked how the researcher could improve her approach, all of the key workers described how they would have liked her to have taken a more assertive position, and to have made some design decisions earlier, by herself:

> ‘I was kind of frustrated at times when... I think probably towards the middle part of the project... my perception was we really weren’t moving that on... I think sometimes we need to be told, “This is it!” And get on with it! …you’ve had all this stuff getting thrown at you, all these different ideas, all these strong-willed people that are really mouthy! Erm, and I think sometimes I would have loved you to have said, ‘This is it, this is what we’re doing, give it a try.’ ... And we’ll take it, we’re big and bad enough and I think sometimes that we do have to be – you’ve always been very positive for us, and I think sometimes we have to hear the negative too,’ KWA

This desire for the designer to take a more assertive position in the co-design team has interesting implications for design practice, particularly in relation to recent discussions in the PD literature calling for designers to critically reflect on the influence they have in participatory projects (Light and Akama, 2012). It could be argued that an effective co-design process in complex healthcare contexts (where staff have high demands on their time) may benefit by establishing the designer as a ‘citizen’ in the SIU co-design community, with ‘responsibilities’ to elicit and capture the various forms of knowledge, but also with the ‘earned permissions’ to make design decisions according to *their* professional capacities, to maintain momentum in the project and clearly defined roles within the team.

11 Discussion Two: Designing to enhance patient participation in SCI Rehabilitation

11.1 Introduction

This chapter is concerned with the second aim of this research; exploring how to enhance patient participation in SCI rehabilitation. As such, this chapter will discuss both methodological and outcome-focused findings and contributions of this study.

For clarity, this chapter uses the term 'prototype materials' to refer to the iteratively developed prototypes used during the co-design process in Phase Two. The term 'intervention' refers to the Co-Plan Process, consisting of multiple ‘intervention activities’ taking place over several months alongside normal rehabilitation activities (as outlined in fig. 11.1 below). The term 'intervention materials' refers to the documentation tools developed to support these events.

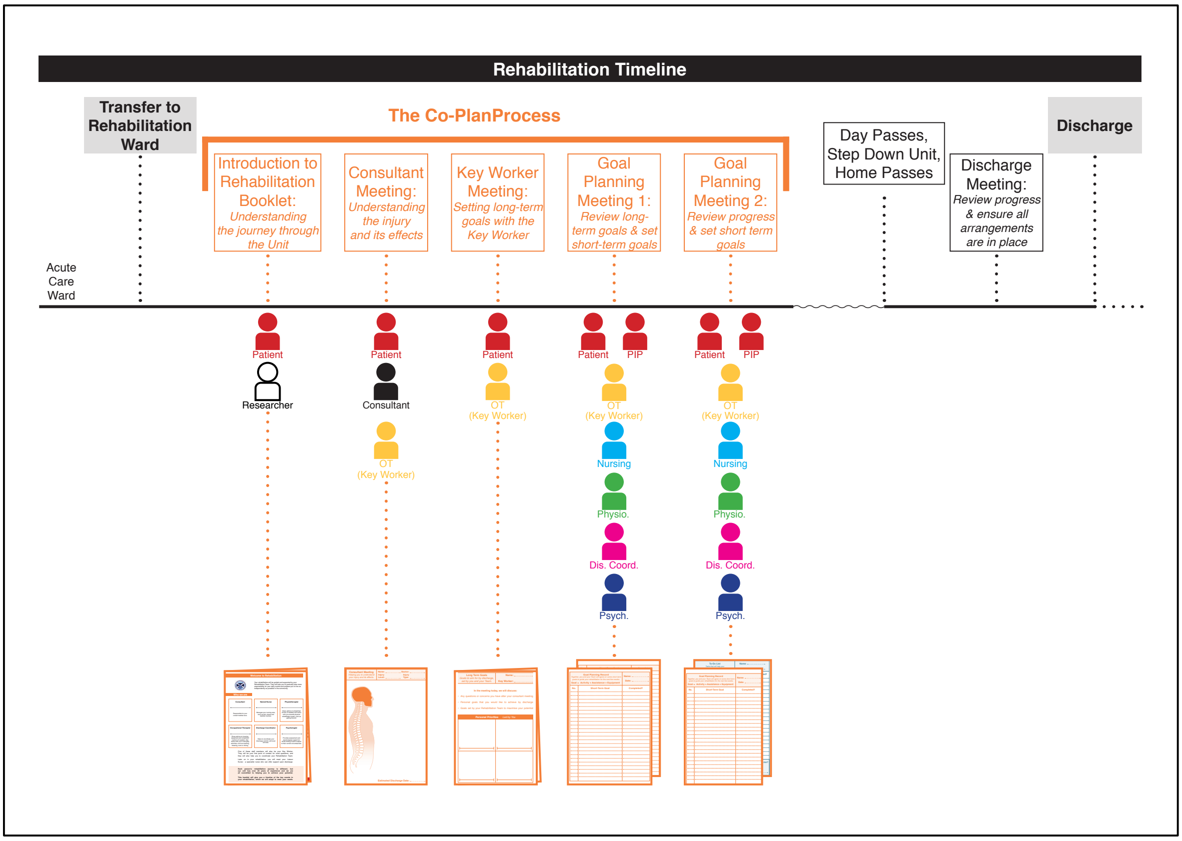


Fig. 11.1: A rehabilitation timeline that differentiates the intervention activities (here shown in orange) from the normal rehabilitation pathway (here shown in black). Note: the

rehabilitation pathway is complex and will vary somewhat between individual patients, perhaps with more GPMs, multiple Day Passes, etc.

11.2 Summary of Contribution

This study proposes that the medical model of rehabilitation, traditionally framed as a patient-professional relationship working toward ‘medical’ goals (i.e. functional restoration) tends to only facilitate certain types of patient participation, arguably related to a model of ‘adherence’ (e.g. more time spent taking part in physiotherapy exercises). The use of only quantitative measures of progress (i.e. FIM) to mediate this relationship also arguably creates a knowledge gap between the patient (who is unfamiliar with these ‘scores’) and the healthcare professional. Whilst this study recognises the primacy of functional restoration, it also contributes to the medical community by demonstrating how a reframing of this model as a process of co-production among different actors, with tools to support mutual learning between them, can facilitate new forms of engagement and participation to emerge. Furthermore, this study has demonstrated the benefits of meaningfully involving the context community in co-developing new rehabilitation pathways to accommodate these new working practices, and the strengths of a design-led, participatory approach in doing so sensitively and effectively.

This study proposes to the design community that designing for complex healthcare services (such as the SIU) is a specific form of designing that requires a responsive, flexible, humble approach informed by an embedded position within the context, which in itself requires time and effort before the ‘designing’ officially ‘begins’. It further argues that in order to bring the epistemological and ‘human-centred’ strengths of design to reframing aspects of the service (as described above), designers must also acknowledge, accommodate and be responsive (rather than antagonistic) to the scientific epistemology and research ‘norms’ of the medical community, where a mixed-methods approach can enhance the findings and evidence the impact (if any) of such projects.

Finally, the findings of this long-term collaboration (which in itself is usual in the literature) suggest that designing for enhanced participation in SCI rehabilitation in particular must recognise the non-monolithic nature of the concept, where incremental changes in practice have the potential for large impact if they are left flexible enough to accommodate the heterogeneous nature of the SCI patient population after the design project ends.

In light of the above, this study is situated in the area of service design research which seeks to understand how (service) design can effectively expand into new spaces, in particularly Sangiorgi, Prendiville and Jung's call for designers to pay attention to their role before, during and after a service design project (2017).

The findings of this study will now be articulated around the core question of how design can enhance participation in spinal cord injury rehabilitation, making three main claims, namely;

1. Designing to enhance participation in rehabilitation processes should consider the diversity of roles and perspectives of all those involved in service encounters like the Goal Planning Meeting (GPM)
2. Designing for enhanced participation needs to acknowledge that participation is not a monolithic concept
3. Designing for enhanced participation requires an embedded participatory design process able to guide a progressive process of adoption and change not only with the patient, but also for the key professional practices involved.

11.3 Claim One: Designing to enhance participation in rehabilitation processes should consider the diversity of roles and perspectives involved in service encounters like the GPM

11.3.1 Summary of the claim

This study has documented the diversity of perspectives of the GPM as an exemplar of a key rehabilitation event. Through this exploration, it was found that co-production is in fact not just between users and a single provider, but it is based on the participation and therefore co-production among different actors, considering also family members or friends. This study argues that investigating this diversity, as emerged in the study, is a fundamental component of designing for an enhanced participation which is effective and responding to diverse practices and needs.

I will now elaborate on each of these points with examples from the study and in relation to the literature from design and healthcare.

11.3.2 Identifying a diversity of perspectives of the Goal Planning Meeting (GPM)

As discussed in section 2.11.9, the rough pilot activity (conducted at the end of the contextual review) uncovered the disparate accounts of how a patient and his care team experience GPMs. By making the initial hypothesis for the main study (i.e. 'introducing new materials or processes into the GPM may facilitate more participatory patient behaviours') tangible through the rough prototypes, and inviting the patient and staff to explore it together through an enactment, the experiential and behavioural knowledge of the SIU community could be incorporated into refining the problem space and study design (i.e. staff and patients experience the GPM differently, so Phase One must develop an understanding of these perspectives).

As discussed in section 2.11.8, the patient and staff participants only used the rough pilot prototypes as intended (to enact a mock GPM) for the first few minutes of the session, after which the prototypes instead acted as a catalyst for different, experience-focussed types of dialogues between the patient, staff and researcher. Notions of the roles of patients, staff and family members, as well as the perceived and intended aims of the GPM, were discussed in a group context for the first time in this study. As such, the prototypes were perhaps more successful as 'probes' in their function, which Sanders and Stappers describe as 'ambiguous stimuli' that provide 'insights for the design process,' (2012, p20). Since its origins in 'Cultural Probes' (Gaver, Dunne and Pacenti, 1999; Gaver et al., 2004), which were described as an 'unscientific and openly designer-centred alternative to studying users' (Mattelmäki, 2008, p66), subsequent variations, definitions and applications have expanded the method into a family of approaches (see Madden et al., 2014). More recently, Mattelmäki (2005, 2008) argues that probes can have a range of aims, including to inspire design; to gather data; to increase participation; and to facilitate dialogue (2005) as well as 'to foster subjective and empathic insights into other participants,' (2008, p67). This suggests a shift away from the designer-as-expert mindset apparent in the 'Cultural Probes' approach and is more closely aligned with the participatory aims of this study.

This generation of new insights about a context through design-led approaches (either using prototypes for enactment activities, or probes to elicit richer discussions) gives further weight to Vink, Wetter-Edman & Aguirre's (2017) argument that the 'bodily experience' of design can stage an 'aesthetic disruption' that allows healthcare communities to challenge their assumptions about a service (see also Schleicher et al.'s discussion on 'Embodied Storming,' 2010). Moreover, it extends this argument and contributes to the literature by applying it to a group setting (rather than one-to-one consultations). On an epistemological level, it has brought a social constructivist concept (that individuals can experience the same event differently) into a traditionally positivistic context (the SIU).

In light of these findings, Phase One of the main study focussed on exploring the multiple ways patients, staff and family/friends experience the GPM, as well as their perceived purpose of the GPM and their current/preferred roles within it. In this way, the GPM was framed as an opportunity for co-production between these three perspectives, rather than between a patient and a single provider, as discussed below.

11.3.3 Evidencing a diversity of perspectives of the Goal Planning Meeting

Relating this claim back to the core question of this discussion, this study argues that design can also enhance patient participation in the SIU by enriching an exploration of the multiple perspectives involved in key rehabilitation activities (see section 5.3 for the mixed-methods approach to exploring patient, family and key workers' experiences in nine separate GPM cases).

Hagen (2014) provides a discussion on the practicalities, challenges and benefits of considering design-led and scientific methods as complimentary approaches, with examples of her own work in healthcare contexts. She (and her colleagues) suggest that while there may be tensions in how evidence or success is conceptualised between the two approaches, the findings from each can enhance the other. Other studies have suggested that a mixed-methods approach to exploring healthcare experiences can generate findings that are ‘greater than the sum of its parts,’ (Mullaney, 2016).

This study both agrees with and challenges these arguments. The researcher suggests that taking a mixed-methods approach involves more than simply using methods of different types; it involves acknowledging, negotiating and reconciling two opposing worldviews to achieve the aims of the study. For example, being seen to take the time to learn about and formally conduct more scientific research approaches (such as collecting quantitative data before and after the intervention, and working with staff to recruit a demographic ‘spread’ of patients) more familiar to the SIU staff arguably enhanced their buy-in to the study, and willingness to try design-led methods. In addition, the structure of the main study differed from most design-led projects in healthcare, in that great care was taken to establish a rich understanding of the GPM experience (from these mixed-methods) both before and after the intervention, acknowledging both the scientific need for a robust evidence base and measure of ‘effect’, whilst also maintaining a social constructivist worldview that can accommodate unexpected results.

However, in line with the discussion from Hagen and Mullaney above, this study found that the more generalizable, ‘overview’ findings from quantitative methods were indeed enhanced with human-focussed, holistic views gathered from qualitative and visual methods, which were also able to give more context or rationale to the answers given, suggest opportunities for change, leave room for unexpected findings and provide new forms of evidence. For example, statistical analysis of the Likert scale questions highlighted that patients who attended a GPM with a PIP tended to feel more involved, a finding that had not previously been discussed, and would be hard to compare perceptions of between patients otherwise. Additionally, the GPM Conversation Map (fig. 11.2) objectively evidenced, for the first time in SCI rehabilitation (to the best of the researcher’s and supervisors’ knowledge) the scale of patient passivity in the GPM (although it is currently unknown how particular this finding is to the host SIU).

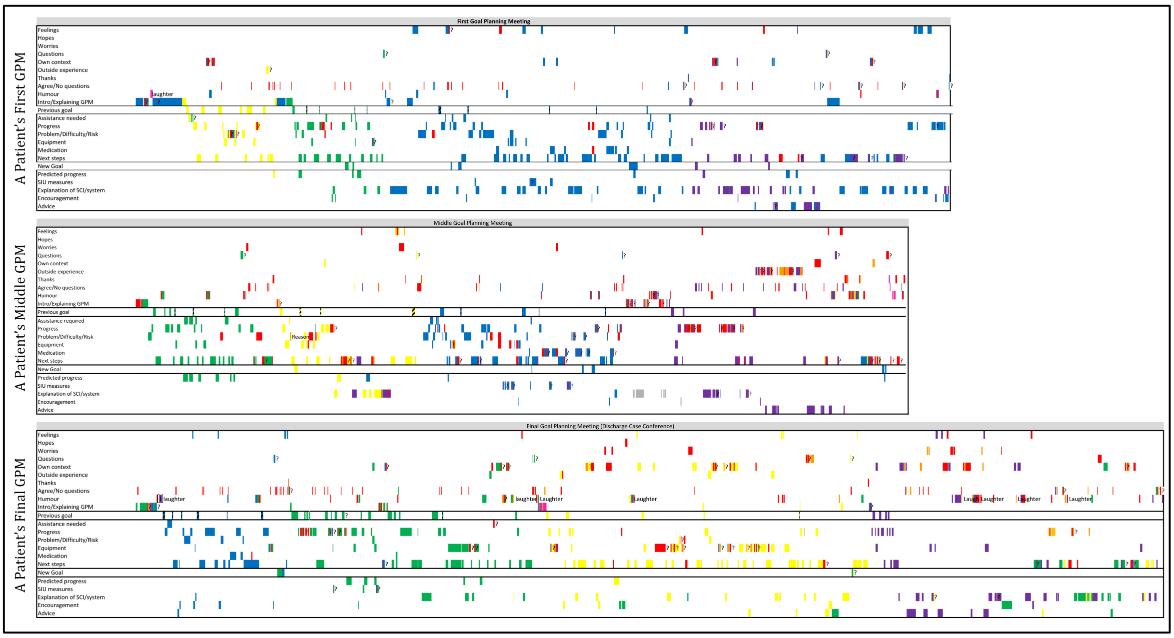
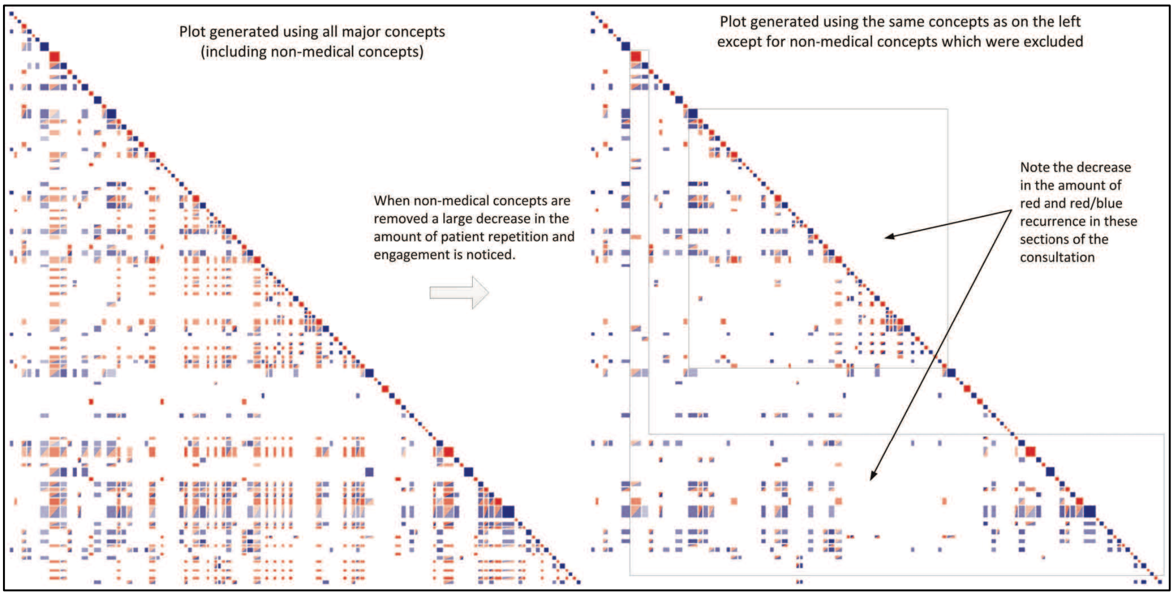


Fig. 11.2: A condensed image of the GPM conversation maps developed in Phase One of the main study (where patient input is shown in red).

Visualisations of patient-doctor communications are uncommon in the medical literature, although Angus et al. (2012) provide an interesting example in their exploration of the 'effectiveness' of Doctor-Patient consultations and the engagement of patients within them (see fig. 11.3).



Plot generated using all major concepts (including non-medical concepts)

When non-medical concepts are removed a large decrease in the amount of patient repetition and engagement is noticed.

Plot generated using the same concepts as on the left except for non-medical concepts which were excluded

Note the decrease in the amount of red and red/blue recurrence in these sections of the consultation

Fig. 11.3: Two examples of visualisations created by Angus et al. (2012), which reportedly demonstrate higher patient engagement with medical concepts when non-medical concepts are included in the conversation also.

Angus et al.'s work, like this study, was interested in exploring levels of patient engagement (defined as taking part in ‘effective’ communication, including ‘task focus’ and ‘rapport building’), but did so in a manner that more closely follows the traditional scientific research model, i.e. testing the effect of changing one variable in the consultation. The Phase One GPM visualisations, on the other hand, were (uniquely) able to accommodate group healthcare consultations and exploratory in nature, and therefore more able to identify unexpected opportunities for change as well as current modes of patient participation. As discussed in section 6.5.4, this included the findings that the visualisations had very little repeating patterns, informing the experience goal, ‘The patient knows what to expect in their meeting.’

In summary, whilst scientific visualisations are able to define ‘what is’ (according to medical measures), design is able to enhance patient participation because it is able to explore ‘what is’ data in creative, questioning ways, as well as collect, visualise and share data that is more accommodating of emergent findings. As such, designerly visualisations are arguably more useful in informing and shaping future, preferred situations.

11.3.5 Comparison of traditional and design-led investigations of the GPM experience

As the host SIU has previously conducted two internal audits on the GPM process using simple Likert-scale surveys (2008, 2013, unpublished), a unique opportunity presents itself to compare the researcher's findings with data gathered using more traditional questionnaire-based methods in the same context (although with different patients). Whilst the previous internal audit delivered a positive review of the GPM process, the mixed-methods review conducted by the researcher instead highlighted several opportunities for improvement (albeit in a more labour-intensive manner). This supports arguments made in the literature that satisfaction surveys, such as the internal GPM audit, are at risk of generating a 'limited and optimistic picture' (Jenkinson et al., 2002). Additionally, it could be that designers, familiar with user experience, can bring particular sensitivities and techniques that can provide different and more nuanced data to help explain the patient experience of healthcare services.

This study argues, then, that acknowledging and investigating this diversity of perspectives as emerged in the study, is a fundamental component of designing for an enhanced participation which is effective and responding to diverse practices and needs.

11.4 Claim Two: Designing for enhanced patient participation needs to acknowledge that participation is not a monolithic concept

11.4.1 Introduction

This claim refers to patient participation within their own healthcare experiences, rather than participation in the development of healthcare services in general. The latter will be more fully explored in the third claim of this discussion (section 11.5).

11.4.2 Existing knowledge

In Part A of Literature Review, it was established that most patients want an active role in their healthcare, but that a comfortably active role can mean different things to different people. Part B of the Literature Review reinforced earlier suggestions that the medical model frames patient participation as a single variable to be measured, often from the clinician’s perspective, where participatory behaviours include asking questions and being actively involved in prescribed activities or medication regimes.

The review of design literature suggested that whilst design has alternative framings of participation (based on notions of co-creation) and is well practised in seeking and using understandings of 'messy realities' and participants' lived experiences in the design process (based on a social constructivist worldview), interventions in patient participation tend to propagate the notion as a monolithic concept (i.e. enhancing patients' active involvement in stroke rehabilitation exercises). Understandings of what patients can bring to co-produced healthcare services, other than 'expectations' or updated medical data, appeared to be largely unexplored.

11.4.3 Co-production in the GPM

Whilst the majority of investigations into patient engagement and/or participation in the medical literature are dominated by concerns over patient-professional dyads (as in Angus et al., above), this study contributes by considering how the patient, family, and multiple healthcare professionals can experience and contribute to the GPM event.

During the contextual review, and evidenced in Phase One of the main study, it was noted that patients generally did not speak much in the GPMs, and that their preparation for the goal planning process consisted of a staff-led needs assessment of functional goals (see appendix 4 for the previous 'Goal Planning Checklist'). However, the Co-Plan Process facilitated two-way communication of information, or 'mutual learning', more in line with co-production forms of healthcare service delivery, 'shifting the balance of power, responsibility and resources from professionals to individuals,' (Freire and Sangiorgi, 2010, p3).

Guiding this shift towards co-production was the Service Design notion of positioning the patient as a co-creator of value in the healthcare service. However, as highlighted in section 3.17.3 of the Literature Review, there has been little exploration of what exactly patients can contribute to such interactions with healthcare professionals in either the medical of healthcare literatures. This study contributes here in several ways. First, it corroborates the importance of making room for and addressing patient expectations of their rehabilitation (as suggested by Oosterholt & Simonse, 2016), and provides novel ways of synchronising patient-professional aims through the Consultant Meeting and Key Worker Meeting. Secondly, the study has shown patients' ability to identify and contribute their values and priorities in setting personal (not necessarily medical) long-term goals, such as Jack's desire to learn to drive (which was previously unknown by his key worker). Brian and Jack also both demonstrated the potential for patients to use their skills in coordinating and updating their friends and relatives on their prognosis and goals, supported by the co-designed materials, extending the network of co-production to include family members. Finally, Tony demonstrated the potential for patients to contribute their perspectives on progress, which can sometimes differ from that of healthcare professionals (see section 8.9.2), to rehabilitation planning using the visual representations on the updated long-term goal sheets.

In summary, in attempting to design a more participatory GPM experience (i.e. beginning with a focus on a ‘touchpoint’), the emergent co-designed intervention suggests that enhanced patient participation needs to be anticipated and scaffolded earlier in the rehabilitation process with a wider co-production network (i.e. looking at the wider organisational structures of the service).

As such, this study proposes a need for more nuance in the term ‘participation,’ and has evidenced multiple ways in which this can manifest, as discussed below.

Participation in activities

This first distinction is more in line with traditional notions of participation, i.e. interactional forms of communication between patients and providers (Eldh, 2006, Mol, 2008), and was best exemplified in the Consultant Meetings with each patient participant. The three key workers involved described how their patients were attentive, asked 'good questions' (i.e. appropriate to their level of injury) and left with an enhanced understanding of their injury (which the contextual review highlighted as necessary for acceptance of the injury and collaboration with staff).

For Brian, his participation in the Key Worker Meeting activity gave KWA a clearer understanding (and documentation) of his personal priorities, which then allowed KWA to act as an advocate for his interests in the GPM (where he preferred to take a more passive role).

Participation through an advocate

Although the term ‘advocacy’ may have connotations of staff speaking for the patient, true advocacy could be helpful for SCI patients in particular, who are already learning many new skills and may be experiencing fatigue, other medical complications and/or high emotional distress during the GPM. A brief review of Spinal Cord, a leading SCI-dedicated journal, found that patients have indeed reported struggling to advocate for themselves (Manns & May, 2007), and healthcare professionals have argued that greater staff awareness of patient priorities 'may be used as a springboard for advocacy and goal setting,' (Anzai et al., 2006). Other than these two studies, literature on patient advocacy within rehabilitation processes is not available. As such, this study contributes with evidence of staff advocacy for the patient's priorities in goal planning being linked to a positive patient experience of rehabilitation.

Participation with materials

Contrary to the expectations of all participants in the Phase Two co-design process, the patients involved in Phase Three rarely accessed the patient-owned folder independently, in their own time (for reasons such as physical limitations, fatigue, or simply forgetting it was there).

Interestingly, Scobbie et al. (2013) found that a similar patient-owned folder was beneficial for both patients and staff in a community-based Stroke rehabilitation initiative. Additionally, a survey study of SCI outpatients found that the ‘vast majority of people with spinal cord injury reported they wished to receive written information,’ after outpatient appointments (Vaidyanathan et al., 2001, p650). A question is raised, then, of whether materials such as a patient-owned folder, or records of clinical interactions, are suitable for inpatient use.

When this question was raised with KWA, KWB and KWC, each (separately) suggested that other 'types' of patient (i.e. those who engage with their rehabilitation process differently, see Street et al., 2005) could come to rely on the folder and use it regularly in their interactions with staff:

> ‘I’m quite sure there’s some of the ladies that would be constantly lifting it up and going like that to you! [mimes pointing vigorously at something in the folder] “I’ve not done this yet!”’ KWC
>
> ‘I can imagine that some people, perhaps when they’re sitting at night on their own thinking, “I’ll pull it out and get a wee look,”' KWA

KWA also suggested that the patient-owned folder may be useful, even if it isn't actually used:

> 'Most people would probably be interested in having the conversation and having things written down, but... I wouldn't be surprised if people didn't actually look at the folders once they were put in their drawer, and I think that's just human nature. But, having the option to look at them is always a good thing,' KWA

Participation through a family member

As mentioned above, this study argues that family members should be considered as part of the co-production team within SCI rehabilitation. The reader may remember how one patient in Phase One (Pt.B) made repeated reference to his wishes for his wife to be fully involved in the rehabilitation process, almost as an extension to himself, corroborating this argument further.

As described in the Phase Three findings, Brian described how he used his folder to explain his injury and rehabilitation goals to his brother (who lived in the Highlands of Scotland and as such was unable to visit the Glasgow-based SIU regularly) and to his friends. Jack's parents also discussed how having the intervention materials to hand in the folder helped them to be involved, through an enhanced knowledge of the rehabilitation process and of what was expected of Jack. Although a firm conclusion can't be drawn from such a small sample of family members, these findings suggest that the intervention materials, held in the patient-owned folder, could go some way towards answering Dickson et al.'s call for family members to be more involved in the SCI rehabilitation process, to potentially reduce their anxiety leading up to discharge (2010).

11.4.4 Related literatures

Graffigna et al. (2015) discuss how patients' participation in their own healthcare can evolve over time (see section 2.3), and that services which are 'better tuned' to a patient's readiness to participate at a given time are more likely to succeed. With this in mind, they suggest that 'complex and multifaceted assessment tools' are needed, so professionals can then deploy the right method of engagement for a particular patient at a particular time. However, the findings from this PhD study suggest that whilst this approach may be useful in providing an evidence base and repeatable method of best practice (and therefore in line with traditional policy-driven modes of innovation), tools that give staff autonomy and allow levels of participation and engagement to unfold in practice may be more practical in SCI rehabilitation, where a patient's medical and emotional state may vary by the hour.

In summary, whilst this study agrees that notions of evolving participation is especially relevant to SCI rehabilitation, it instead proposes a broader, non-monolithic, qualitative conceptualisation of participation, where patients can participate to a greater or lesser extent in different ways or at different times according to their preference or 'readiness.' Referring back to the core question of this study, design can enhance participation though its proficiency in co-creating flexible materials to support multiple types of participation, as will be discussed further in the next claim.

11.5 Claim Three: Designing for enhanced participation requires an embedded participatory design process able to guide a progressive process of adoption and change not only with patients, but also for the key professional practices involved

11.5.1 Introduction

This research documents an embedded approach to change that uses small iterative design and prototyping actions as a way to gradually train and support acceptance and adoption of proposed changes.

11.5.2 Progressive modes of adoption for patients

Part A of the Literature Review highlighted that very few interventions in this context target the behaviours of both staff and patients, with little advice on how to inform patients about the (new) roles available to them (Tai-Seale et al., 2016). Many patients feel that their values are not relevant to healthcare decision-making (Holmes-Rovner et al., 2007), and fears of being labelled 'difficult' can inhibit patients from adopting participatory behaviours (Longtin et al., 2010).

With this in mind, The Co-Plan Process lays the foundations for participatory behaviours with the Introduction to Rehabilitation booklet, empowering patients to participate by clearly describing the patient pathway (which is known to enhance patient experience, see Design Council, 2011) and the patient's role within it. The structure of the Co-Plan Process itself also facilitated patients' gradual adoption of participatory behaviours, from being informed with opportunities to ask questions (with the Introduction to Rehabilitation booklet and Consultant Meeting) through to opportunities for collaborative goal-setting (in the Key Worker Meeting and GPM). These methods have been developed specifically for the SIU contexts, but may be adapted for other long-term rehabilitation contexts such as post-stroke.

11.5.3 Progressive modes of adoption for staff

Progressives modes of adopting new participatory practices is important for staff, ensuring that they are able to anticipate the impact of these changes in their work routines, safeguard their duty of care to their patients, and reduce anxiety about (or opposition to) implementation.

The use of iterative prototyping activities in Phase Two facilitated this progressive mode of adoption, helping to bridge the gap between current and preferred rehabilitation practices (as well as the other benefits described in section 10.3.5). As can be seen in the Prototype Development Journeys (see appendix 21), there were often only small, incremental changes between the prototypes at each co-design ‘Event.’ These small changes to the prototypes (and as such, small changes to the work routines they facilitate) could be agreed gradually at each Event, forming a progressive, rationalised path towards the new rehabilitation practices. The need for a clear ‘evidence trail’ through the design decisions made within healthcare contexts has been established in the literature (Hagen, 2014), and it has been suggested that ‘if the innovation can be broken down into more manageable parts and adopted incrementally, it will be more easily adopted,’ (Lenze et al., 2004, p596).

It could be argued that this approach also incorporated staff training into the co-design process. Involving the staff who will lead the implementation (in this case, KWA, KWB and KWC) from an early stage in the project may have helped to mitigate issues during these later stages (as experienced in seminal healthcare service design projects, see Cottam and Leadbeater, 2004). Beyond this, the key workers’ deep understanding of the rationale behind the co-designed intervention and its intended use allowed them to maintain a sense of agency in how it was integrated (or adapted) into the rehabilitation pathway of real inpatients. This perspective reinforces the need for designers to consider forms of innovations that are more incremental and ad-hoc, as discussed below.

11.5.4 Incremental innovation

Several of the ‘new’ aspects of the Co-Plan process replaced existing events, or as the healthcare-based supervisor put it, did the same things but in a different way. For example, the Key Worker Meeting replaced the traditional ‘Needs Assessment’ process, where the

Long-Term Goals Sheet (see appendix 26g) was used instead of the Goal Planning Checklist (see appendix 4). As such, the Co-Plan Process is considered an ‘incremental’ rather than ‘radical’ innovation.

Suchman advocates for an understanding of the potential contributions of incremental changes, stating that the general ‘negative value attributed to processes of incremental change are part of a form of wishful thinking that aims to bring about desired transformations without the associated costs in time and human effort,’ (2011, p15). This study argues that this is particularly true for innovation in healthcare - a multidisciplinary and traditionally paternalistic context. Whilst ambitious, radical innovations may not succeed in the complexities healthcare practice, incremental changes can be better understood and adapted locally, slowly contributing to wider transformational change (Bate & Robert, 2007, Vink, Wetter-Edman & Aguirre, 2017).

The value of incremental innovation in this study is best exemplified in the Key Worker Meeting, which staff described as giving them ‘permission’ to facilitate participatory practices by creating a time and space to elicit patient priorities (in the Key Worker Meeting) and a ‘prop’ to remind other staff members to consider these priorities (with the Long-term Goals Sheet). These findings corroborate those found in the design literature that ‘performing’ new materials in a healthcare consultation event can facilitate new behaviours between the patient and staff (see Sokoler et al., 2007), and that using materials designed for this may support organisational change (Coughlan et al., 2007).

11.5.5 Ad-hoc innovation

Fuglsang agrees that impactful innovations do not necessarily need to be radical. He states that within the service innovation literature, ‘it has been claimed that small adjustments in relation to particular customers can also be counted as innovation,’ (2010, p67) and that ‘many innovations have a random or emergent character: they become defined and understood only as they develop,’ (p68). This is arguably the case within this study, given that the co-designed intervention expanded far beyond the initial parameters of the GPM to include much earlier stages of the rehabilitation pathway, once the context was better understood and explored with the SIU community.

Fuglsang also describes the potential for ‘ad-hoc’ innovations to emerge unexpectedly within a health or social care service encounter itself, where ‘services are continuously adjusted in relation to clients leading to an expansion of routines,' (2010, p76). These emergent routines can 'lead to the building of new competencies which become an integral part of a service and will change a service indirectly,' (p68, see also Gallouj and Weinstein, 1997). Other terms for this phenomenon include 'Bricolage,' or the 'building of structures or practices from singular events' as opposed to the scientific tradition of 'creating events (changing the world) by means of structures' (Levi-Strauss, 1966). In other words, innovation occurs from adjustments to healthcare practice via front line staff, with individual service users, rather than being imposed by a new policy, for example.

The ability to perform ad-hoc adjustments (or innovations) to practice is particularly important for SIU staff. The primary research conducted in the contextual review highlighted the diversity of the SIU patient population, and that a patient's ability to emotionally and physically engage with and participate in the rehabilitation process will vary, perhaps in a non-linear fashion, over time. Related to this, the researcher also observed the abilities of SIU staff to differentiate their practice according to the patient they are working with, and how the patient is feeling on that day. As such, the flexibility of the co-designed intervention materials to allow such differentiation of practice was integral to its success in the complex realities of SCI rehabilitation. A key example of this in Phase Three came from KWA, who chose to complete the progress timelines in the Long-Term Goals sheet separately from the GPM itself, as she judged that her patient, Brian, was becoming fatigued in the meeting. Brian later told the researcher how useful he found these extra sessions with his key worker (see section 8.9.2), demonstrating a successful ad-hoc adaption to the intervention made by the key worker.

Interestingly, the materials appeared to be accommodating of patient-led ad-hoc innovation also, given that 'Tony' surprised the GPM team (and researcher) by suggesting one of his progress markers in the Long-Term Goals sheet should be moved backwards due to a medical complication (which KWC agreed with).

It has been argued that markers of innovation can include the ways in which ideas open up new use processes (Suchman, 2011), allow for ongoing, evolving 'performances' (Sangiorgi, Prendiville and Jung, 2017, referencing Ingold, 2012) or create novel arrangements with the other activities and entities in that context (Barry, 2001). This approach reminds us of designers' role to 'infrastructure' instead of forcing strongly novel or pre-defined solutions, as described below.

11.5.6 Infrastructuring

Karasti (2014) gives a thorough overview of the notion of 'infrastructuring,' from Neumann and Starr's original socio-technical perspective on information infrastructure (1996), to an active area of PD research today. Key to the notion of infrastructuring are it's 'temporal reconsiderations,' (ibid) and the ideas of 'continuing design in use,' (Henderson & Kyng, 1991) where 'the boundaries between use, design, implementation, modification, maintenance, and redesign are blurred,' (Karasti et al., 2010). By challenging the notion that 'designing' only happens during the design project, Karasti explains how the notion of infrastructuring has 'created opportunities for design-in-use (Ehn, 2008), and extended design towards more open-ended, long-term processes (Björgvinsson et al., 2010, 2012)' (2014, p6).

From a Service Design perspective, infrastructuring has been described as an 'ongoing process of alignments of different agendas within an organisation,' (Sangiorgi & Prendiville, 2017b, p253), which clearly has implications for synchronising patient and staff rehabilitation goals. Sangiorgi, Patricio and Fisk describe how service design has had to 'acknowledge the indeterminate nature of services, accepting the "fundamental inability of design to completely plan and regulate services"' (2017, p59, quoting Meroni and Sangiorgi, 2011, p10). They, like others (see Holmlid, Wetter-Edman & Edvardsson, 2017) suggest how the growing complexity of service design perspectives, and its engagement with power relations between service actors, lead to the need for designers to work with emerging needs, and also in new roles, 'from the ideal of a designer hero to a new ideal of a co-creator champion,' (ibid). The key implication at the core of this is the need to recognise the limitations of what can be known at 'design time' where service design is considered a discreet project, and for designers to 'transform their understanding of what they are designing and aiming to change, from an abstract object or system they can fully control, to a process of dynamic change they need to engage with,' (ibid).

Leaving some design decisions open for the 'users' at 'use time' (beyond 'design time') is an important link to the original ideals of PD, and a powerful concept when designing for enhance participation in healthcare services (where both patients and staff are considered different types of 'user'). The Co-Plan materials resonate with the notion of infrastructuring as they were deliberately left flexible, accommodating 'design-after-design' (Björgvinsson et al., 2012) and 'appreciating different forms of knowledge that are not available/voiced at design time,' (Storni, 2013, p50). This latter point is particularly important when designing for the enhanced participation of the SCI inpatient community, which has been identified as heterogeneous with multiple, varying, and somewhat unpredictable needs over time.

11.6 Summary

This study has taken a participatory service design approach to reconsidering the patient-professional relationship in SCI rehabilitation as one of mutual learning and value co-creation, engaging the SIU community in co-designing, co-producing and (to some extent) co-developing an enhanced patient pathway, which aimed to support patient participation in their rehabilitation process.

Within this collaborative process, a more nuanced view of the SIU community was taken compared with many studies in healthcare services, where ‘inpatients’ and ‘outpatients’ were considered to have unique and equally valuable contributions to the co-design process.

In addition, the study is unusual in its focus on a multidisciplinary healthcare consultation (the GPM), its mixed-methods approach to understanding the patient, family and staff experiences before and after intervention, and its embedded position within the host institution. This study argues that such an embedded position, cultivated through an extended, in-depth contextual review with and within the unit, was crucial to the successes of the PhD study, where the co-designed intervention was fully implemented into the patient pathway of 3 inpatients in situ, leading to reports of shared goal-setting, better inclusion of friends and relatives, and enhanced understanding of their injury and rehabilitation progress.

Through this implementation, recent PD interests in ‘infrastructuring’ or ‘design-after-design’ were found to be resonant with service design in healthcare contexts, where the co-designed materials, left purposefully flexible in their use, were able to draw on healthcare professionals’ skills in differentiating their practice according to the patient they are working with, and also supported patients in leading new, unanticipated participatory behaviours. As such, this study also argues that the notion of participation should be considered more broadly, where patients can be more or less involved in a range of modes of participation, and the wider co-production network (including family and friends) plays an important role.

12 Conclusion

12.1 Introduction

This study began with two key aims, namely:

- To explore how designers can operate in a participatory manner with and within healthcare service contexts
- To explore how to design for enhanced patient participation, in particular for spinal cord injury rehabilitation

However, as highlighted in the Introduction chapter of this study, bringing design approaches into complex healthcare settings (such as the SIU) involves a range of epistemological, methodological, logistical and ethical challenges. This complexity is compounded by ambiguity around the term ‘participation’ and the highly individual nature of SCI rehabilitation.

This chapter will summarise the main lessons learned in bringing a participatory service design approach to addressing the two research aims, with a particular focus on the Goal Planning Meeting[7] as a key rehabilitation event with potential for enhanced patient participation. The insights generated relate to designing with healthcare communities, deeper understandings of the notion of ‘participation,’ and what it means to design for patient participation. The chapter will then conclude with the limitations of the study and recommendations for further work.

12.2 Recommendations for designing with and within healthcare communities

The researcher argues that, to bring the particular strengths of design approaches into healthcare, designers must operate from an embedded position within the healthcare community they wish to serve in order to co-create useful solutions that are responsive to the complexities of that context. It has demonstrated the importance of spending time and

---

[7] A (usually) monthly meeting where a patient, their rehabilitation team, and possibly a family member or friend, meet to discuss rehabilitation progress made to date and to set short-term goals for the next (approximately) four weeks.

effort conducting a thorough contextual review prior to any co-design work, and contributes to the service design literatures by recommending the diagrammatic exploration method as an effective way for designers to learn about new organisational contexts, and develop that understanding collaboratively with the context's community (see section 2.10). The outcomes and insights generated through the contextual review also contribute to the healthcare literature, where explorations of inpatient, family and/or staff experiences of SCI rehabilitation processes, or of Goal Planning in any context, were rare. Visualisations of group healthcare consultations (rather than patient-professional dyads) could not be found, suggesting that the GPM conversation mapping methods (see section 6.5) may be of interest to both research communities.

Once established in the setting, the researcher argues that this deep understanding of the healthcare context is crucial in taking an adaptable approach not just in pre-planning the workshops (i.e. around the known logistical constraints of an actual hospital ward), but also in being responsive to the changing needs of healthcare communities in the moment (i.e. last minute changes in patients' health status or mood, or multiple, unforeseen demands on staff time). The account of the 'messy reality' of designing with and within a hospital community given in section 7.5, as well as the specially-developed, context-specific tools detailed in section 7.3.3, contributes to the participatory service design literature, where few detailed case studies could be found in rehabilitation contexts, and none that engage an SIU community in service improvement activities.

This study has demonstrated the importance of recognising the different, but equally valuable, expertise of inpatients and outpatients during the co-design process (rather than engaging outpatients as representative of the entire patient community, as in much of the literature concerning design in healthcare). It also recommends the use of iterative prototyping workshops to facilitate separate, anonymous, creative collaboration between inpatient groups and healthcare professionals, in order to protect their ongoing working relationships (rather than prioritising face-to-face co-design, as in much of the PD literature).

For healthcare staff participants, the use of enactment activities was particularly useful in incorporating their institutional, practice-based knowledge into the design. Whilst this is not a new claim, the researcher suggests that using a prototype in enactment activities can be considered a way of bridging the epistemological divide between design and healthcare, where the prototype can be considered a 'hypothesis' to be 'tested' in the enactment (more closely resembling a scientific mode of inquiry). Furthermore, the iterative prototyping approach was well suited to overcoming the inertia associated with organisational change in healthcare, as the incremental innovations explored and agreed in each iteration facilitated a progressive process of adoption and change in the staff working practices.

Aiming for transformational changes in practices, such as towards greater patient participation, requires a deeper understanding of how this is realised in day-to-day practice, as detailed below.

12.3 Reconsiderations of the term 'participation'

Rather than considering 'patient participation' as a single variable to be measured, this study proposes a broader, qualitative, non-monolithic conceptualisation that can manifest in different ways, for different people, at different times. It has evidenced particular moments in real patient pathways where 'participation' has been facilitated through activities, with materials, through an advocate, and through a family member. Whilst this does not claim to be an exhaustive definition of the concept, it hopes to open up a wider discussion on the multifaceted nature of patient participation.

12.4 Designing for enhanced participation

This study's focus on the Goal Planning Meeting (a group healthcare consultation event) stands apart from most explorations into patient participation, which are largely preoccupied with dyadic forms of patient-professional relationships. It has co-designed an effective intervention to support participatory patient behaviours within the GPM based on the premise that co-production doesn't occur between a patient and a single healthcare provider, rather it concerns a wider network including the patient's family and friends. It argues that the perspectives and assumptions of these individuals must be identified and explored in order to meaningfully involve them in co-productive healthcare encounters.

Service Design's notion of service users and providers 'co-creating value' together was used to position the patient and/or family member as an agential member of the GPM team. Insights from this study give further detail to what exactly patients can bring to this 'co-creation' partnership (beyond their expectations of the clinical encounter). When supported by the co-designed intervention materials, patients were able contribute their personal values, priorities and non-medical goals to joint goal-setting with staff. Patients also demonstrated skills in communicating their perspectives on rehabilitation progress, and in coordinating their family and friends to support their rehabilitation activities.

Participatory Design's exploration of the notion of 'infrastructuring' was a useful tool to reflect on the 'indeterminate nature of services' (Sangiorgi, Patricio and Fisk, 2017) in the SIU, and the different ways the co-designed intervention was used in each patient case. Insights from this study suggest that the act of infrastructuring is not just within the realm of designers, but that healthcare professionals (who work in rehabilitation services at least) are also well-suited to this form of developing services. Whilst designers have particular sensitivities in creating and collaboratively developing materials as platforms for communication, healthcare staff are practitioners in their own right, and able to use their empathic skills, experiential knowledge and ability to differentiate their practice to particular patients 'in the moment.' As such, the researcher recommends that materials co-designed to support patient participation should be left flexible enough to accommodate 'design-in-use,' informed by the skills of healthcare professionals in differentiating their practice according to the patient they are working with.

12.5 Reconciliation of traditional and design-led methods?

12.5.1 Introduction

Upon completing and reflecting on the study, the researcher argues that adopting a mixed-methods approach in healthcare requires careful crafting that is sensitive to the community it operates within. The ways in which this study was supported by traditional and design-led research methods are summarised below.

12.5.2 Strengths of traditional research methods

The healthcare-based methods used in this study have been crucial in generating a strong foundational knowledge of the SIU context, leading to a more professional and sensitive approach to conducting primary research within it. These methods have also been successful in creating a strong evidence base that is recognisable by healthcare staff, and could be repeated after the implementation of the intervention as another way of exploring its effect. As such, these methods go some way towards addressing the weaknesses of design-based approaches, which often lack rigorous evaluation and can experience difficulties in achieving full implementation of designed concepts within healthcare communities.

12.5.3 Strengths of design-based research methods

Design-based methods (such as visualisations) have been useful for opening up a ‘conversation’ with the data gathered via these ‘traditional’ means (Glanville, 1999) and inviting the SIU community to develop the conclusions and hypotheses drawn from them. Other design approaches (such as prototyping and enactment activities) have been successful in eliciting and incorporating the experiential and behavioural knowledge of the SIU community, engaging them in developing the rehabilitation process and allowing them to trial new behaviours in a low-risk manner. In this way, the strength of the ‘bodily experience’ of design (Wetter-Edman, Vink & Blomkvist, 2018) has been able to address the weakness of more traditional research methods, by confronting the implicit assumptions or routines in a given context, facilitating meaningful collaboration between patients and professionals, and leveraging their different forms of expertise towards transformational aims.

Taken together, it is clear that healthcare- and design-based approaches can achieve more together than they could on their own. Although the difficulties of this form of collaboration must be acknowledged (i.e. it was a long process that required buy-in from both healthcare and design communities to make it work), it is hoped that this study has demonstrated the benefits that occur from such an investment. As such, it is hoped that further healthcare services will embrace the potential for design research with and within their community, and that in turn design researchers will be willing to adapt their tools, methods and general approach to better understand and contribute to such challenging, yet rewarding, contexts.

12.6 Limitations of the study

- Although the embedded nature of the researcher went some way towards normalising her presence throughout the study, the effect of the observer on the observed (also known as the Hawthorne Effect) is well documented in clinical research (see McCambridge et al., 2014).
- The patients who agreed to participate in the study may have already been more actively engaged with their rehabilitation more generally, and may have added a bias to findings as a result. However, it is hoped that general observations on the ward and the extensive time spent with SIU staff, who are able to share their

experiences of working with less engaged patients, may have helped to mitigate this bias.

- Due to limited time, Phase One of the main study reviewed the GPM cases of 9 patients. Whilst this number represents a quarter of the rehabilitation ward (which holds 36 beds), this sample size must still be considered limited and possibly not representative of the entire population of people with a spinal cord injury.
- In Phase Two of the main study, the outpatient and two inpatient workshops engaged small numbers of participants (n=2, n=4 and n=4 respectively). Whilst their contributions cannot, therefore, be considered representative of the whole outpatient or inpatient communities, the small numbers allowed for group ideation, discussing their diverse backgrounds and experiences in relation to the prototypes and provided rich data.
- In Phase Three, the co-designed intervention was introduced to the rehabilitation pathways of three patients, in order to dedicate enough time to each case to elicit deeper understandings of the participants' lived experiences of the SIU. However, this (combined with the diverse nature of the SIU population) limits the generalisability of the findings.
- The bespoke nature of the co-design process, as a result of the embedded approach taken, limits the repeatability of the methodology in other contexts.
- Due to the limited time frame of the PhD study, there is currently no evidence of the long-term impact, if any, of the intervention on patient outcomes or on staff practice. However, as of March 2017, the Consultant Meeting has been implemented into the regular clinical practice in the host SIU, suggesting the potential for such long-term studies.

Some of these limitations could be addressed in future work, as will be described in the next section.

12.7 Recommendations for future work

The researcher would recommend further collaborations between spinal injury units and embedded design researchers on the following topics (although some may be transferable across wider rehabilitation contexts).

12.7.1 Long-term study

The original inspiration for this study was based on the hypothesis that patients may be better supported in the difficult transition to life post-discharge (Dickson, 2011) with more or enhanced opportunities to actively participate in their rehabilitation as inpatients. As such, the first recommendation for further work is to conduct a longitudinal study that follows patients using The Co-Plan Process beyond discharge, in order to establish the long-term effects of the intervention (if any), and in doing so, test the validity of this original hypothesis.

Expanding the use of The Co-Plan Process with a wider inpatient group could also explore and identify further modes of patient participation, contributing to this study's understanding of 'participation' as a non-monolithic concept. This could, in turn, inform the development of rehabilitation events or materials that support particular modes of participation that are either specific to SCI inpatients, or potentially useful in a broader range of rehabilitation pathways.

12.7.2 GPM Conversation mapping

The novelty of the GPM conversation mapping visualisation conducted in Phase One of the main study arguably warrants further investigation. The researcher suggests this could be conducted in several ways:

- More of the same: Repeating the same method across a larger sample of the SCI inpatient community across the country could be beneficial in exploring the nature of participation in other, similar contexts. It could also form the basis of a knowledge mobilisation project between different SIUs in order to compare and develop GPM processes collaboratively.
- Rework the concept: Using the knowledge gained from this study on the non-monolithic nature of SCI patient participation, the SIU community could be engaged in further work to develop the list of 'themes' used to visualise the GPM conversations, in order to generate more focussed, context-specific explorations of collaborative goal planning.
- Mapping specific concepts: This study has demonstrated the SIU staff's ability to elicit, and advocate, patient priorities in the GPM. Perhaps, then, the concept of 'mapping' the GPM conversation could be used to explore the prevalence of staff/patients referring to and using patient priorities in the GPM conversation. Visual evidencing such as this could possibly be used to incentivise the use of

patient priorities; the host SIU already has a system that recognises and rewards 'clean hands' champions, so perhaps a similar system could be established for a 'patient-centred champion'?

12.7.3 Use of patient-owned folders

In the evaluation interviews of Phase Three, the key worker participants suggested that, whilst the patient participants of this study did not use the patient-owned folders in their own time, other 'types' of patient may wish to do so (see section 11.4.3). As such, further work could introduce a patient-owned folder to a wider SIU inpatient cohort, and explore the reasons for use or non-use. Findings may be specific to the SCI patients, or may be transferable across other long-term rehabilitation processes, such as Stroke.

Some research studies have found that the use of prompts when used in combination with patient-owned written information have enabled patients to make changes to particular health behaviours, such as in smoking cessation (Carson et al., 2012) and in Brain Injury rehabilitation (Culley & Evans, 2010). Perhaps, then, future iterations of the patient-owned folder could include a prompt system to better support patients in its use. However, in their review of feasibility of patient engagement approaches, Grande et al. (2014) argue that greater levels of 'patient load' (or amount of work the patient is expected to do in order to benefit from the intervention) decreases the likelihood of interventions being adopted, so this must be considered also.

12.7.4 Ad-hoc innovations in healthcare

The ability of the co-designed intervention to capitalise on staff's ability to differentiate their practice according to the patient they are working with was central to its success. Graffigna et al. (2015) suggest that staff who engage in ad-hoc innovation (particularly those delivering health and social care services) can be supported through regular meetings with their colleagues to share, discuss and reflect on the ways in which they have 'innovated' in their service encounters. As such, further work could explore the use of the Co-Plan Process more widely, with considerations of how knowledge gained in these ad-hoc innovations can be mobilised and 'made social' within the SIU, by 'entering into the stock of knowledge constructed and shared by other individuals,' (Greenhalgh et al., 2004, p607).

12.7.5 Probes approach

Throughout the study, the researcher has been surprised by the candid, detailed discussions she has had with patient and family participants, particularly when some of the designed materials (such as the prototypes used in the co-design workshops) have 'probed' more tacit knowledge, hopes and dreams (Sanders, 2006). It is surprising, then, that there is a paucity of qualitative, in-depth studies concerning the lived experiences of people with an SCI, particularly as inpatients but also as outpatients (with notable exceptions from Dickson et. al, 2011, 2012). This suggests that there is potential in using the empathic probes approach (Mattelmäki, 2008) to explore gaps in the literature concerned with the experiential aspects of SCI, including delicate topics, such as how a person's sexual sense of self may or may not change following SCI (see Anderson et al., 2008, for an initial web-based survey establishing this topic as a research priority).

However the findings of this study are used in the future, the researcher wishes to highlight, once again, that design researchers operating with and within such complex, delicate contexts should conduct their work in a sensitive, embedded and participatory manner.

Appendices

Introduction to qualitative data analysis

Introduction

This section outlines key principles and methods of qualitative data analysis, in order to give theoretical foundation to the approaches taken throughout the thesis. It is informed by more recent discussions of methods outlined in seminal works, such as Glaser and Strauss (1967) and Strauss and Corbin (1990). It is hoped that relocating overviews such as this to the appendices will help to maintain the flow of main thesis, and to avoid repetition in Contextual Review and Methodology chapters.

Overview

Qualitative research can generate a lot of data, which may include 'verbatim notes or transcribed recordings of interviews or focus groups, jotted notes and more detailed "field notes" of observational research,' where transcripts and notes are considered the 'raw data' (Pope, Ziebland & Mays, 2000, p114). Others suggest that sources may also include images or artefacts (Ryan & Bernard, 2003), however this review will focus on analysing text only.

Qualitative research is regarded as an effective way to understand phenomenae in relation to the context in which they occur, and the links between behaviours or concepts that constitute them. Whilst qualitative approaches have traditionally been considered separate from quantitative methods, such 'rigid distinctions are increasingly recognized as inappropriate and counterproductive,' (Bradley, Curry & Devers, 2007, p1759), and qualitative research is becoming 'increasingly common' in healthcare contexts (Ibid, p1758).

General approach

Bradley, Curry and Devers highlight the 'diversity in the disciplinary and theoretical orientation, methods, and types of findings generated by qualitative research' (2007, p1759), so it is not surprising that several sources suggest that there is not one preferred way to approach qualitative data analysis (Ryan & Bernard, 2003). However, there is some consensus that it is an iterative and lengthy process that begins even during data collection, given that the researcher is often '"in the field" collecting the data, [so] it is impossible not to start thinking about what is being heard and seen,' (Pope, Ziebland & Mays, 2000, p114). It is also widely agreed that they should all begin with the researcher familiarising him/herself with the data, either through the process of transcribing interviews or reading through the data, possibly several times (Bradley, Curry & Devers, 2007, Ryan & Bernard, 2003).

Following this, the data can be analysed through a process of coding, which 'provides the analyst with a formal system to organize the data, uncovering and documenting additional links within and between concepts and experiences described in the data,' (Bradley, Curry & Devers, 2007, p1761). The codes[1] themselves can be applied to words, paragraphs or large segments of text to 'help catalogue key concepts while preserving the context in which these concepts occur,' (Bradley, Curry & Devers, 2007, p1761).

---

[1] The term 'code' is sometimes used interchangeably with other terms, as will be reviewed at the end of this section, however the main description of the coding process will continue to use 'code' for clarity.

The coding process largely consists of three main steps; development, finalization and application of the coding structure, as described below.

Developing code structure

The distinguishing characteristic of the variety of qualitative data analysis methods available is whether an inductive or deductive approach is taken to developing the code structure (Bradley, Curry & Devers, 2007).

In an inductive approach, the codes are 'obtained gradually from the data' (Pope, Ziebland & Mays, 2000, p114). This is known as a grounded theory approach, where the hypotheses are developed 'from the ground or research field upwards rather defining them a priori,' (ibid, referencing Glaser & Strauss, 1967), which is also known as 'open coding' (Ryan and Bernard, 2003). To do this, the researcher begins by approaching each line of the text in turn and assigns a code 'as soon as a concept becomes apparent,' (Bradley, Curry & Devers, 2007, p1762), with the aim of being 'inclusive' and initially generating as many codes as possible to reflect the many nuances of the data being analysed (Pope, Ziebland & Mays, 2000). Ryan and Bernard (2003) provide a detailed overview of multiple methods available, including looking for repetition, local or unfamiliar terms particular to that context, metaphors or analogies, transitions in the flow of dialogue, similarities or differences (between different sources), linguistic connectors (for example, incidences of 'is' suggests a causal relationship), missing data (i.e. information or topics which participants seem to deliberately avoid) or theory-related data (more in line with the deductive approach to qualitative data analysis, as described below). Following this, the researcher revisits all of the data in a particular code, and through a process of 'constant comparison' (Glaser and Strauss 1967), (s)he 'compares text segments to segments that have been previously assigned the same code and decides whether they reflect the same concept,' (Bradley, Curry & Devers, 2007, p1762). The code structure may evolve through adding nuance to the codes (i.e. several child codes under one broader parent code) or reducing the number of codes needed, etc.

A deductive approach to qualitative data analysis is less common, but some methods are gaining popularity, such as the 'framework approach' (Pope, Ziebland & Mays, 2000, p114). Rather than distilling codes from the data gathered, a deductive approach begins with an organising framework which helps define a set of codes prior to analysis. According to Ryan and Bernard, 'a priori themes come from the characteristics of the phenomenon being studied; from already agreed on professional definitions found in literature reviews; from local, commonsense constructs; and from researchers' values, theoretical orientations, and personal experiences,' (2003, p88, referencing Bulmer 1979; Strauss 1987; Maxwell 1996). They add that the 'first pass' at developing the coding structure can come from the interview questions themselves, if that is the data collection method used, but suggest that 'even with a fixed set of open-ended questions, one cannot anticipate all the themes that arise before analyzing the data (see Dey, 1993).

As such, some researchers advocate an integrated approach, using a deductive organising framework as well an inductively developed set of codes (Bradley, Curry & Devers, 2007). It has been suggested that whilst an inductive approach can limit researchers in 'forcing' a preconceived idea or theory (see Glaser, 1992), 'preliminary codes can help researchers integrate concepts already well known in the extant literature,' or allow 'new research to benefit or build on previous related insights or theories,' (ibid, p1763).

Finalising, validating and applying a code structure

When no new concepts emerge from reviewing the data, also known as the point of 'theoretical saturation' (see Glaser & Strauss, 1967), the codes and code structure can be considered finalised (Bradley, Curry & Devers, 2007).

The field is somewhat divided in terms of what is considered appropriate validation of the code structure. Some argue that a 'single researcher conducting all the coding is both sufficient and preferred,' particularly in 'studies where being embedded in ongoing relationships with research participants is critical for the quality of the data collected,' (Bradley, Curry & Devers, 2007, p1761), as long as the researcher acknowledges his/her biases and philosophical approaches. Other studies invite several researchers to code the data independently, or review a set of codes against a selection of the data, and then meet to review discrepancies and arrive at an agreement.

How are themes derived from the coding process?

Ryan and Bernard (2003) demonstrate how, within the multiple and evolving traditions of qualitative data analysis, there is sometimes some interchangeability of the terms 'theme,' 'code,' 'category,' or 'label[2].' Some sources suggest the application of different terms to denote a sense of hierarchy (for example, quotes from the texts being analysed are assigned a 'code', several 'codes' can be considered part of one 'category,' and themes are the outcome of analytic reflection of the categories). Others use one term, and denote the structure using child-parent terminology (for example, 'categories' may be separated into 'sub-categories,' which each have several supporting quotes from the literature).

This PhD study is concerned with the identification of themes to explore in a co-design process, supported by evidence from the qualitative data, rather than creating a full and detailed description of the SIU phenomena. For clarity of terms, then, this study will use a 'coding process' to establish 'themes' and 'sub-themes' organised in a manner suggested by Southampton Education School (2012), shown in fig. * below.

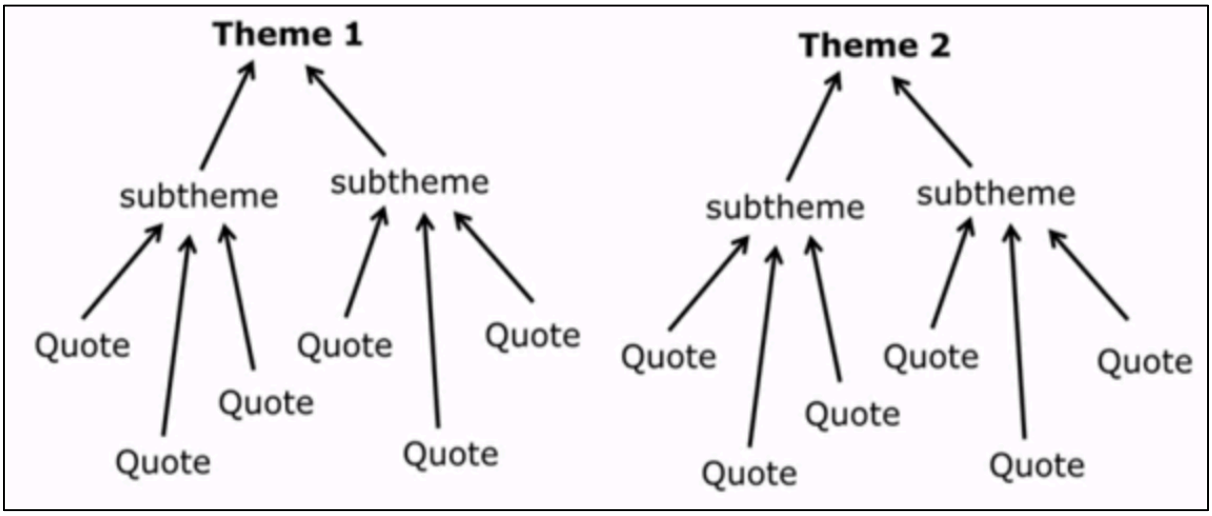


Fig. A1: A 'qualitative analysis classification tree,' (Southampton Education School, 2012)

---

[2] Additionally, the segments of texts being assigned a code are also known as 'expressions,' 'incidents,' 'segments,' 'thematic units,' 'data-bits,' and 'chunks,' (Ryan & Bernard, 2003) although this study will continue to use the term 'quote.'

What are themes?

Themes are ‘fundamental concepts’ (Ryan and Bernard 2003) that ‘characterize specific experiences of individual participants by the more general insights that are apparent from the whole of the data,’ (Bradley, Curry & Devers, 2007, p1760). Themes can emerge not just from what is being said, but also from the type of person saying it (for example, patients who have attended multiple GPMs may have a different perspective than patients who have attended only one). Classification data can be added to sources in qualitative data analysis software such as NVivo (as used in this PhD study) to assist in such reflections.

General advice for coding processes

According to Pope, Ziebland and Mays, qualitative data analysis is ‘systematic and rigorous, and therefore labour intensive and time consuming,’ but Bradley, Curry and Devers also suggest that ‘normal rules and processes should not replace analytic thought itself,’ (2007, p1765). Others suggest that good analysis is focussed on a coherent line of enquiry, reflective without being anecdotal, and able to support any claims made by referring to systematically gathered data (Fielding, 1993).

Experts seem to have differing opinions on the appropriate sample size needed for robust qualitative data analysis, but Pope, Ziebland and Mays suggest that as ‘qualitative studies are not designed to be representative in terms of statistical generalisability… they may gain little from an expanded sample size’ (2000, p115). As such, they argue that sample size ‘should be directed by the research question and analytical requirements, such as data saturation,’ (ibid). In this PhD study, sample size may also be dictated by the number of patient, family and staff participants available, and as such findings of the analysis will be shared with the SIU community for further validation if the researcher is unsure if ‘theoretical saturation’ has been reached.

Initial staff interview guide, 10-01-14

Suggested Topics

Your role in the unit

- Daily activities?
- Weekly activities?
- Monthly, etc, activities? (meetings, etc)
- Shift schedule (days/nights/mixture/regular?)
- Patient's journey through your unit (when, how long, how regular, what activities, how active)

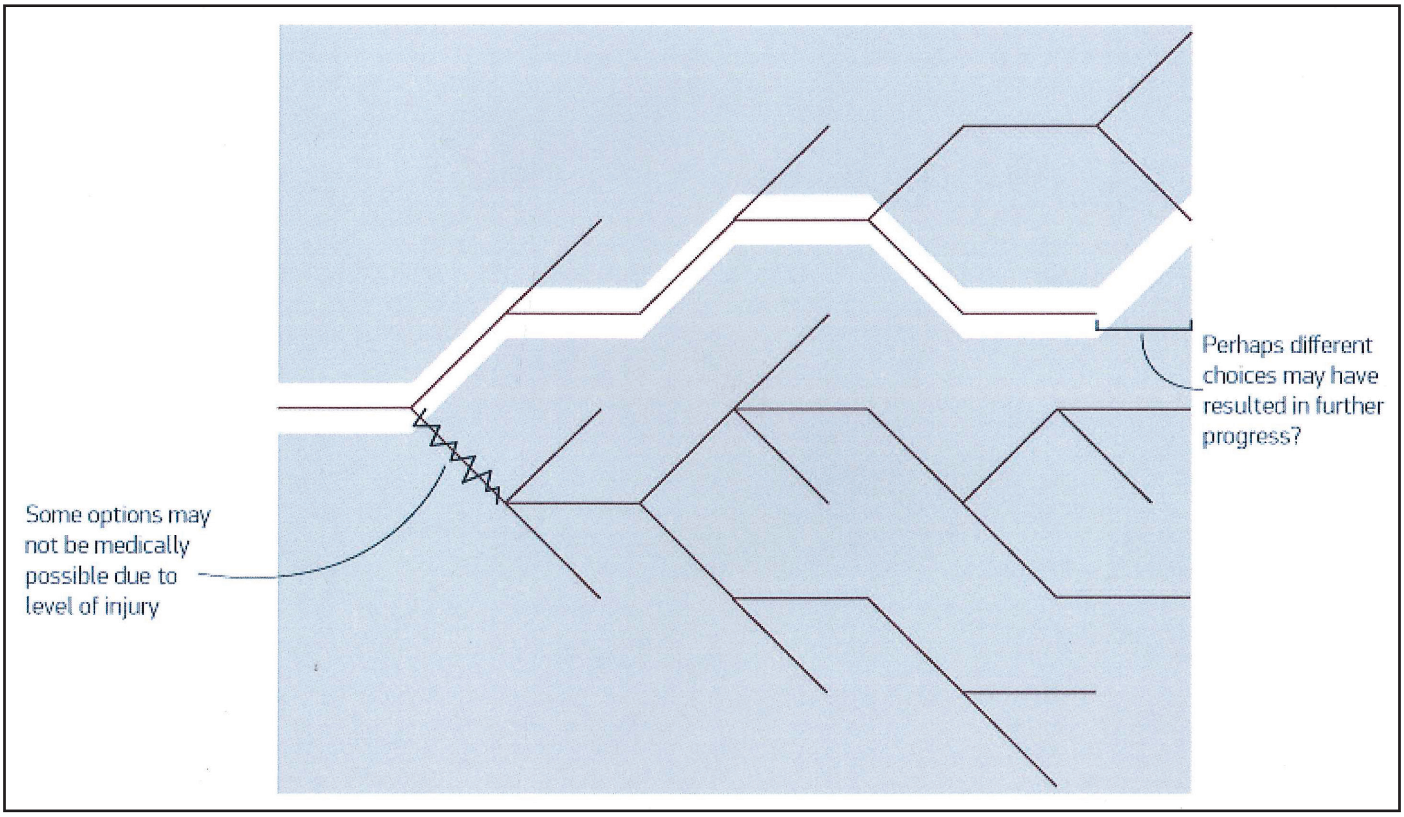
You

- Your background
- Your training
- Did you learn differently on the ward?
- How long have you been in this role?
    - Has much changed in that time, if anything?

Your team

- How many others are on your team?
- How does your role fit in with theirs?
- Do you have any contact with other departments?
    - When, why, how frequently?

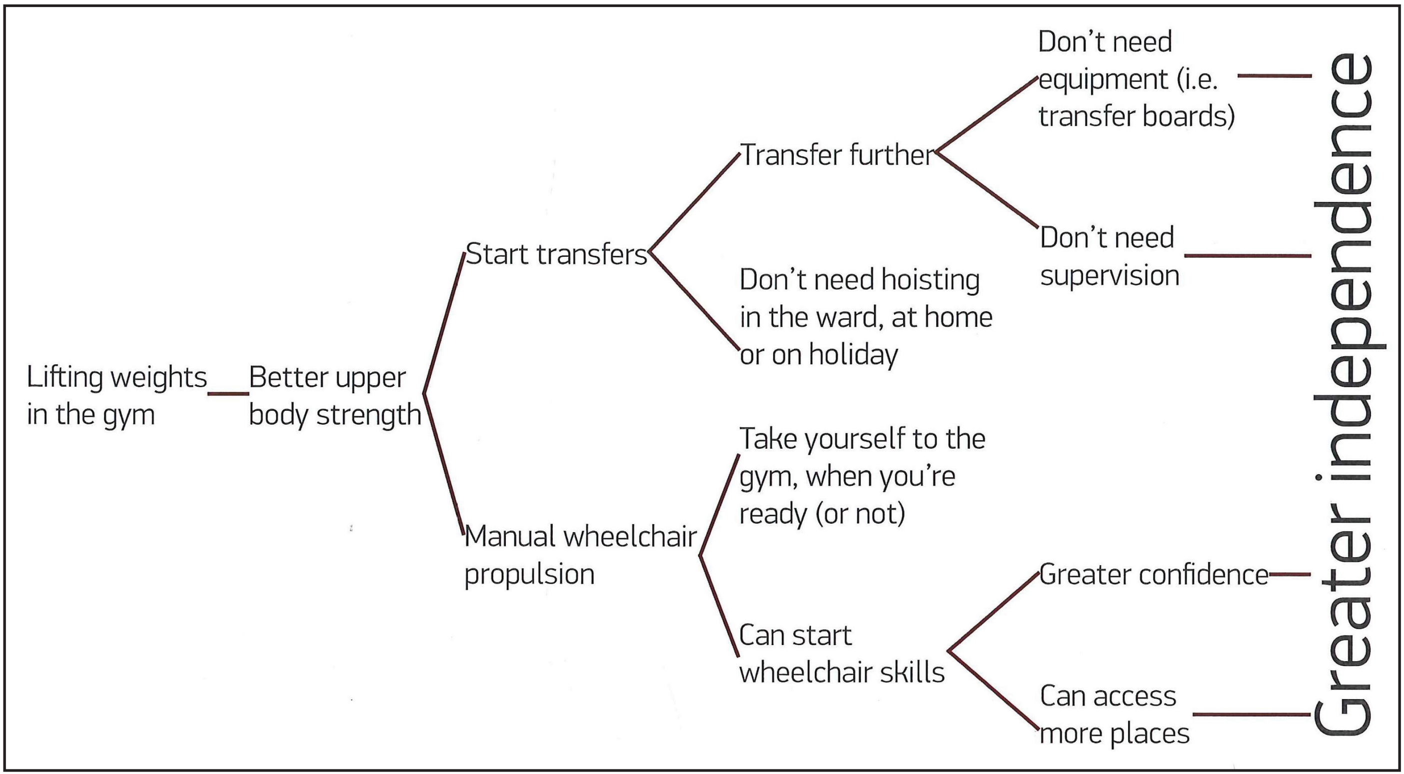
Appendix 3: Selection of diagrammatic exploration outputs


Perhaps different choices may have resulted in further progress?

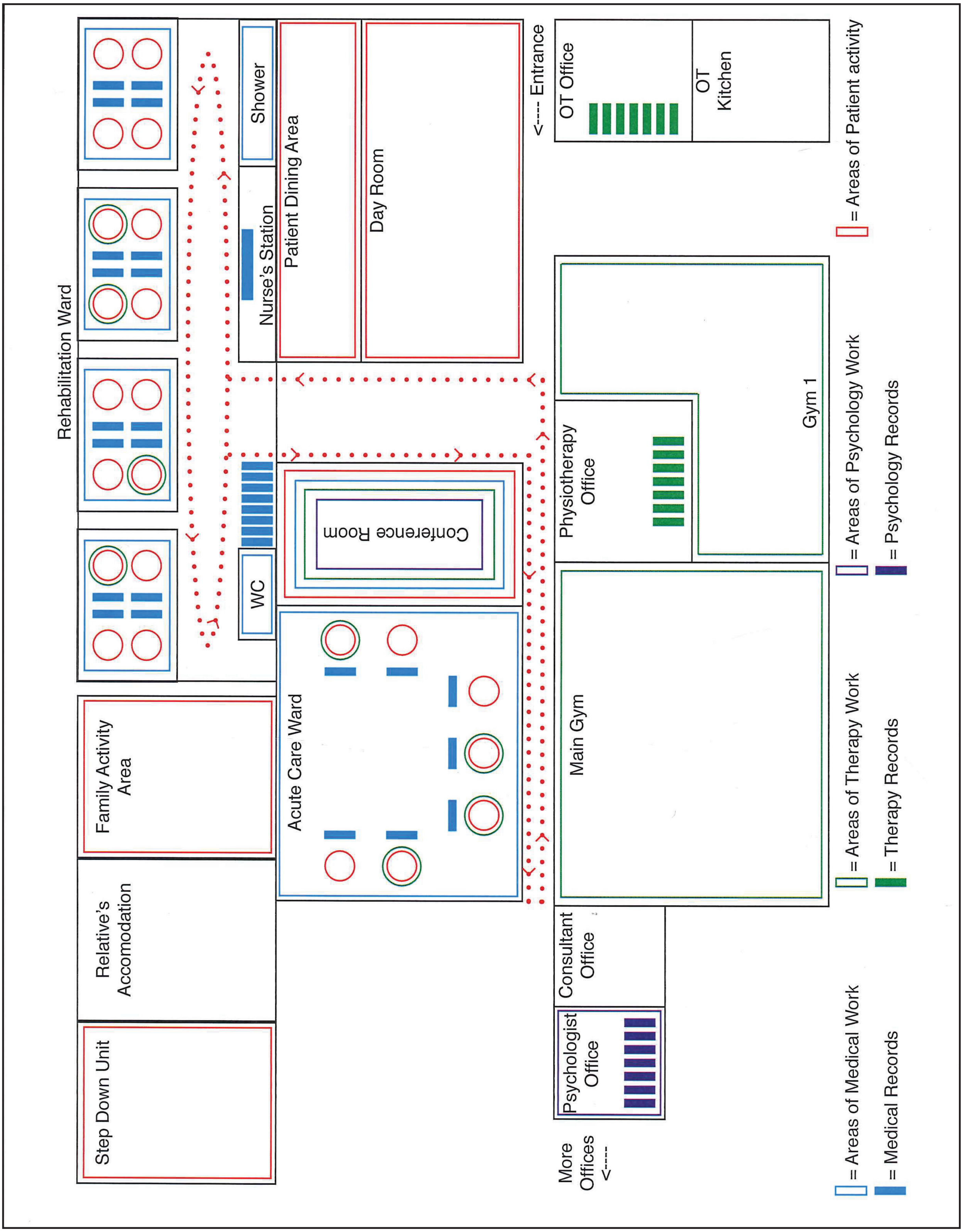
Some options may not be medically possible due to level of injury

Above: A representation of the many different paths a patient could take through the unit (i.e. different methods of bladder management, different transfers learned, etc). Discussion of this diagram suggested that some patients may benefit from being told the reasons why the other options aren't suitable for them - understanding the 'why' as well as the 'what' behind their pathway.

Below: An example of how goals/skills build upon each other. Staff are aware of this logic, but patients may not share this understanding, which may limit their motivation during the earlier stages.

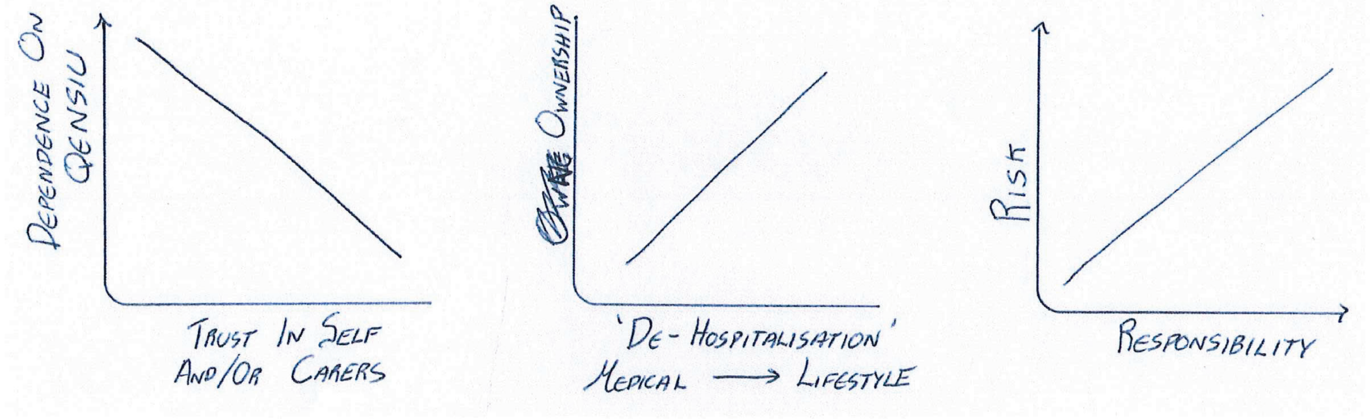


Appendix 3: Selection of diagrammatic exploration outputs

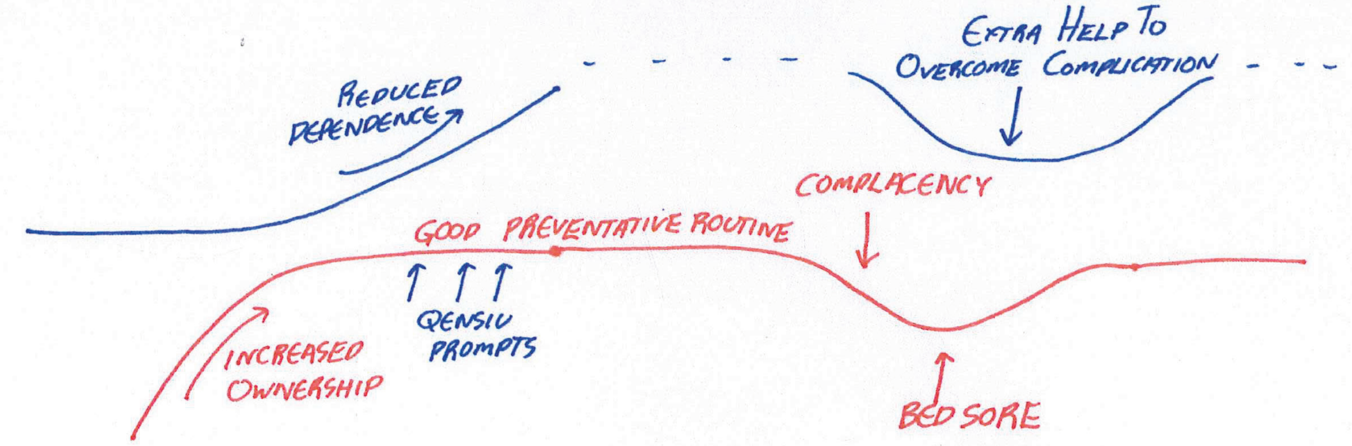


Above: A map of where different ‘types’ of activity occur thorughout the host SIU

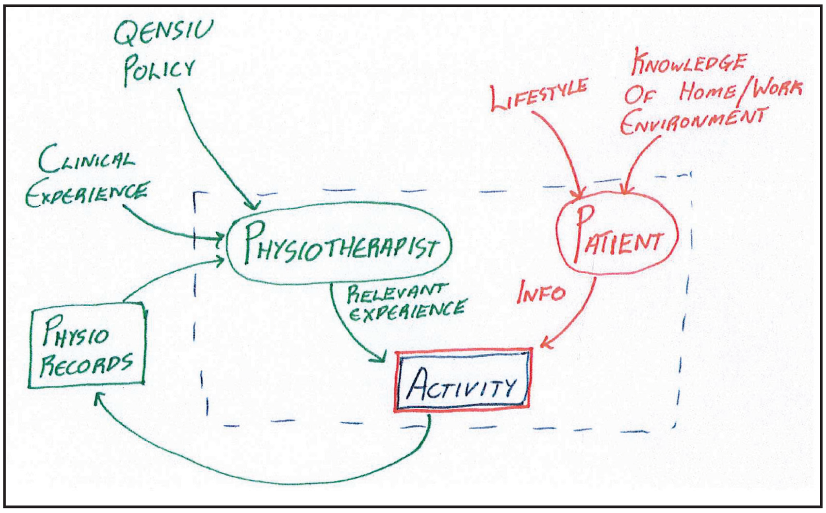
Appendix 3: Selection of diagrammatic exploration outputs

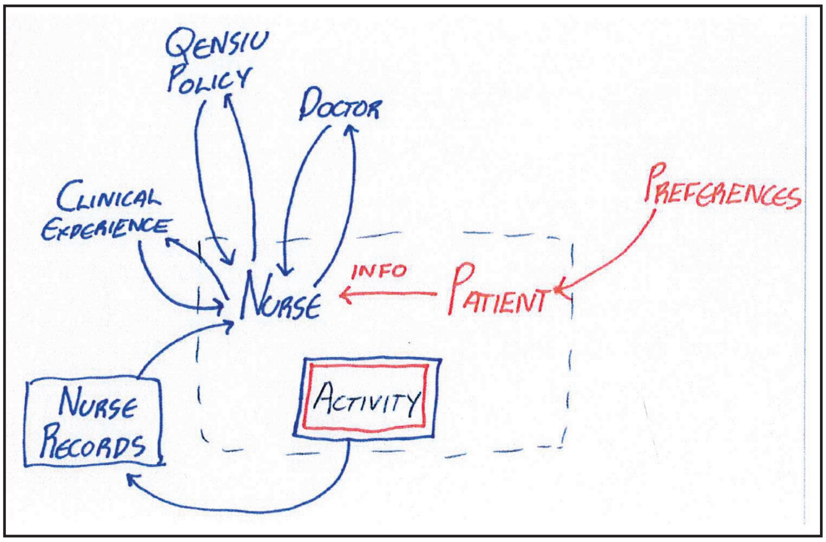


Changing relationships over time.



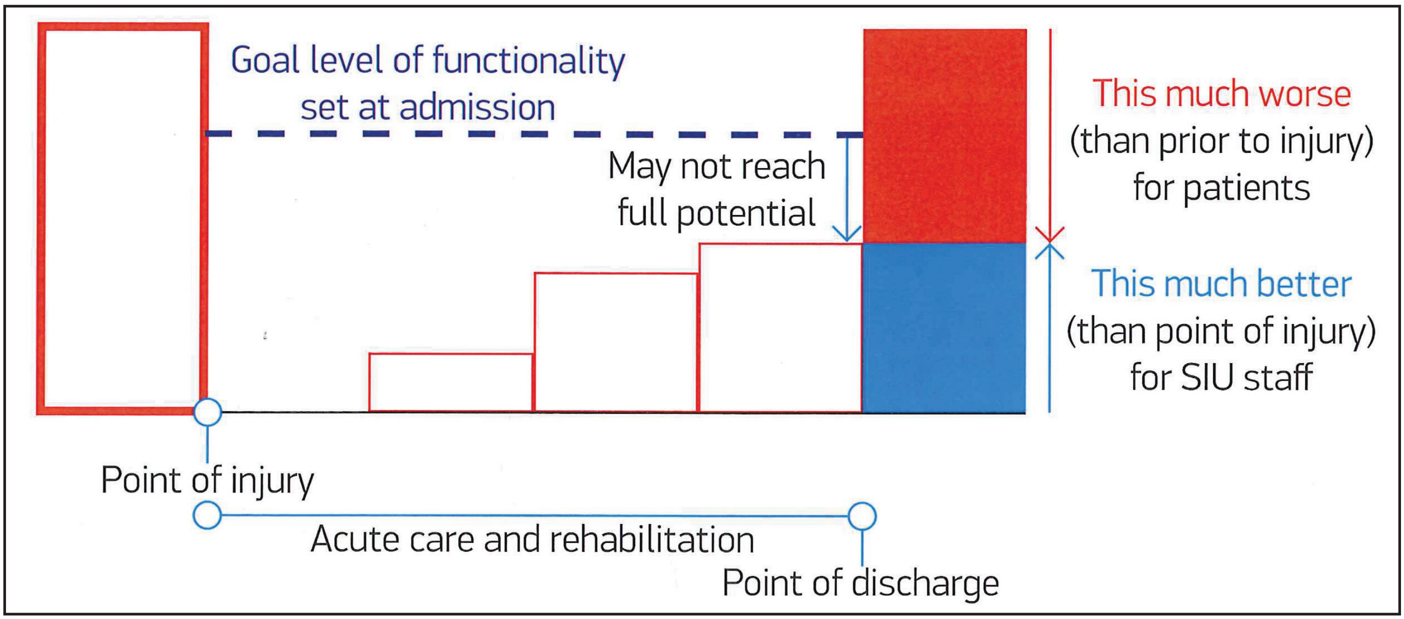
Appendix 3: Selection of diagrammatic exploration outputs



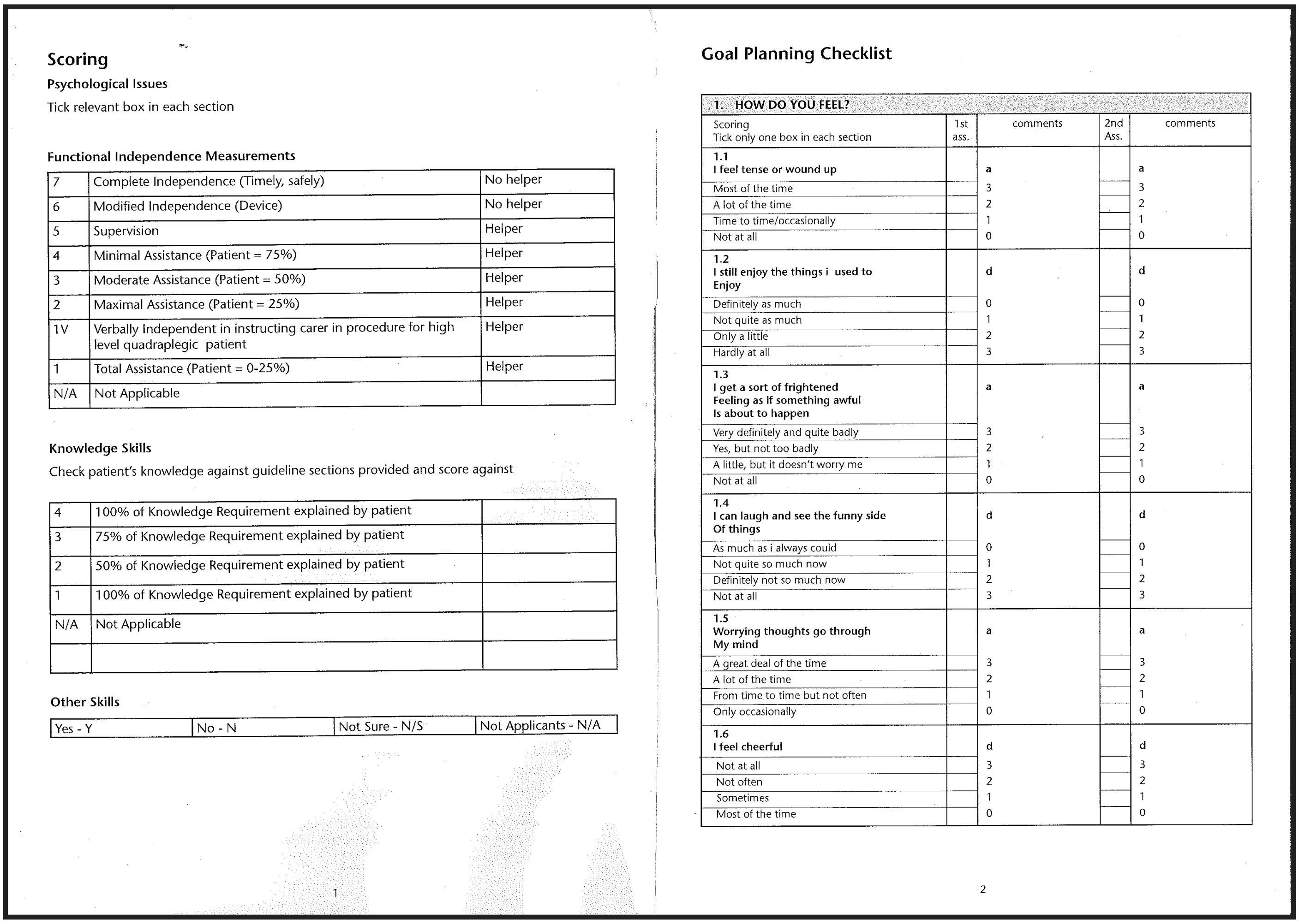


Left: In therapy sessions, patients may be more able to bring in their own contextual information and see immediately how that information affects the activity at hand. Nursing staff tend to conduct activities which require less information from outside the clinical context (although they do still try to get to know their patients 'as people').

Below: One challenge that SCI patients face is accepting that their previous levels of 'normal' functionality probably won't be regained. This can make it difficult to truly work towards the same goals that the SIU staff set, and can affect opinions on whether the rehabilitaiton has been 'successful' or not.



Appendix 4: Examples of the Goal Planning Checklist questions



Scoring

Psychological Issues

Tick relevant box in each section

Functional Independence Measurements

7	Complete Independence (Timely, safely)	No helper
6	Modified Independence (Device)	No helper
5	Supervision	Helper
4	Minimal Assistance (Patient = 75%)	Helper
3	Moderate Assistance (Patient = 50%)	Helper
2	Maximal Assistance (Patient = 25%)	Helper
1V	Verbally Independent in instructing carer in procedure for high level quadraplegic patient	Helper
1	Total Assistance (Patient = 0-25%)	Helper
N/A	Not Applicable	

Knowledge Skills

Check patient's knowledge against guideline sections provided and score against

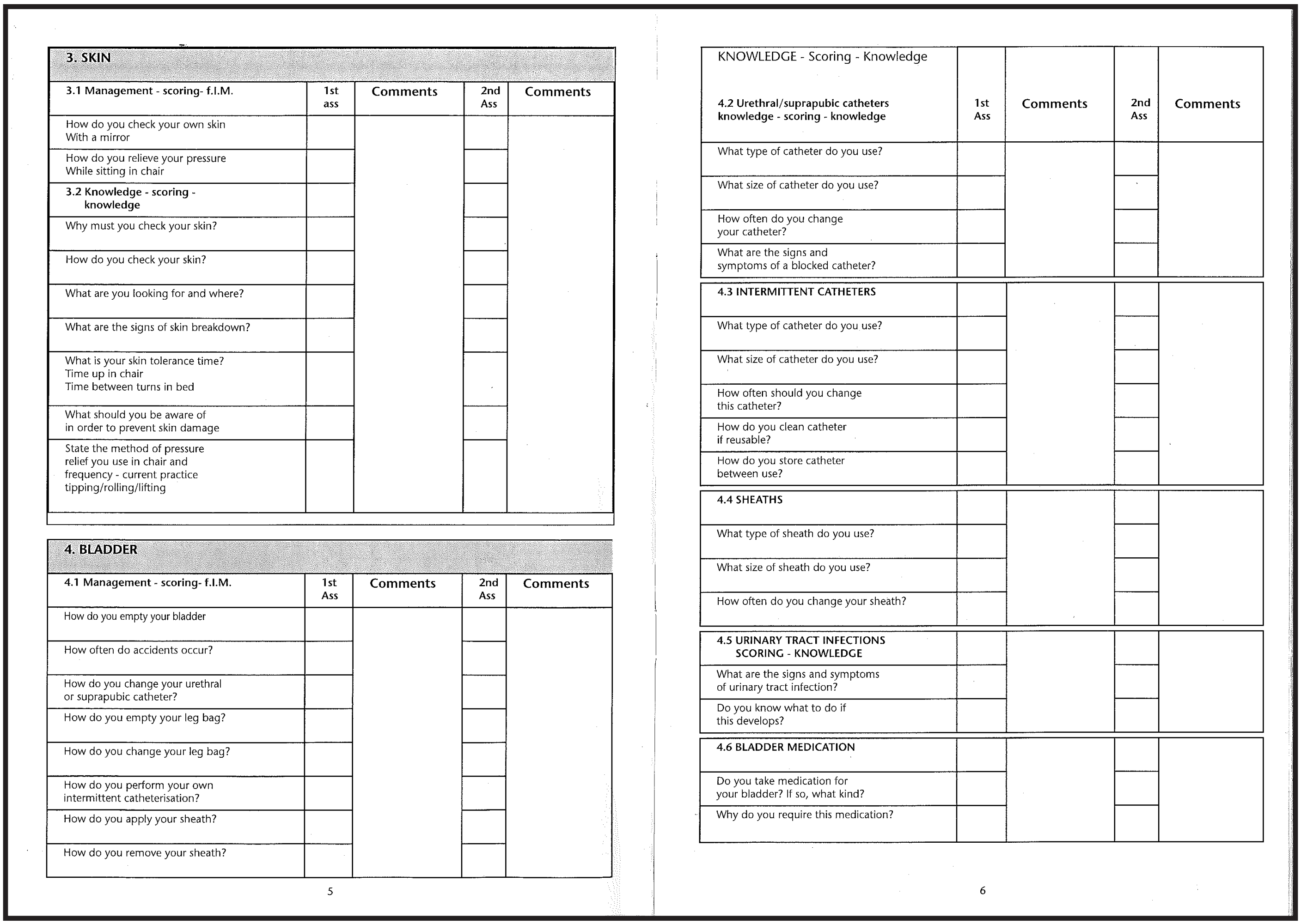
4	100% of Knowledge Requirement explained by patient	
3	75% of Knowledge Requirement explained by patient	
2	50% of Knowledge Requirement explained by patient	
1	100% of Knowledge Requirement explained by patient	
N/A	Not Applicable	

Other Skills

Yes - Y	No - N	Not Sure - N/S	Not Applicants - N/A

Goal Planning Checklist

1. HOW DO YOU FEEL?				
Scoring Tick only one box in each section	1st ass.	comments	2nd Ass.	comments
1.1 **I feel tense or wound up**		a		a
Most of the time		3		3
A lot of the time		2		2
Time to time/occasionally		1		1
Not at all		0		0
1.2 **I still enjoy the things i used to Enjoy**		d		d
Definitely as much		0		0
Not quite as much		1		1
Only a little		2		2
Hardly at all		3		3
1.3 **I get a sort of frightened Feeling as if something awful Is about to happen**		a		a
Very definitely and quite badly		3		3
Yes, but not too badly		2		2
A little, but it doesn't worry me		1		1
Not at all		0		0
1.4 **I can laugh and see the funny side Of things**		d		d
As much as i always could		0		0
Not quite so much now		1		1
Definitely not so much now		2		2
Not at all		3		3
1.5 **Worrying thoughts go through My mind**		a		a
A great deal of the time		3		3
A lot of the time		2		2
From time to time but not often		1		1
Only occasionally		0		0
1.6 **I feel cheerful**		d		d
Not at all		3		3
Not often		2		2
Sometimes		1		1
Most of the time		0		0



3. SKIN				
3.1 Management - scoring- f.I.M.	1st ass	**Comments**	2nd Ass	**Comments**
How do you check your own skin With a mirror				
How do you relieve your pressure While sitting in chair				
3.2 Knowledge - scoring - knowledge				
Why must you check your skin?				
How do you check your skin?				
What are you looking for and where?				
What are the signs of skin breakdown?				
What is your skin tolerance time? Time up in chair Time between turns in bed				
What should you be aware of in order to prevent skin damage				
State the method of pressure relief you use in chair and frequency - current practice tipping/rolling/lifting				

4. BLADDER				
4.1 Management - scoring- f.I.M.	1st Ass	**Comments**	2nd Ass	**Comments**
How do you empty your bladder				
How often do accidents occur?				
How do you change your urethral or suprapubic catheter?				
How do you empty your leg bag?				
How do you change your leg bag?				
How do you perform your own intermittent catheterisation?				
How do you apply your sheath?				
How do you remove your sheath?				

KNOWLEDGE - Scoring - Knowledge **4.2 Urethral/suprapubic catheters knowledge - scoring - knowledge**	1st Ass	**Comments**	2nd Ass	**Comments**
What type of catheter do you use?				
What size of catheter do you use?				
How often do you change your catheter?				
What are the signs and symptoms of a blocked catheter?				
4.3 INTERMITTENT CATHETERS				
What type of catheter do you use?				
What size of catheter do you use?				
How often should you change this catheter?				
How do you clean catheter if reusable?				
How do you store catheter between use?				
4.4 SHEATHS				
What type of sheath do you use?				
What size of sheath do you use?				
How often do you change your sheath?				
4.5 URINARY TRACT INFECTIONS SCORING - KNOWLEDGE				
What are the signs and symptoms of urinary tract infection?				
Do you know what to do if this develops?				
4.6 BLADDER MEDICATION				
Do you take medication for your bladder? If so, what kind?				
Why do you require this medication?				

Appendix 5: QENSIU's Goal Planning Progress Chart

GOAL PLANNING PROGRESS CHART

Name:- U/N:- Date:- Meeting No:- CHI:- Discipline:-

Needs:

1.Psychological
2. Activities of Daily Living
3.Skin
4.Bladder
5.Sexual/Fertlilty
6.Autonomic Dysreflexia
7.Bowel
8.Chest
9.Joints
10.Mobility
11.Equipment
12.Accomodation
13.Social
14.Education
15.Employment
16.Discharge

NEED	GOAL	REVIEW	NEW TARGETS SET

Reason for unachieved goal:- 1. Staff/Organisational Issues 2. Patients Issues 3. Medical Complications 4. Other 5.Staff did not Assess Need

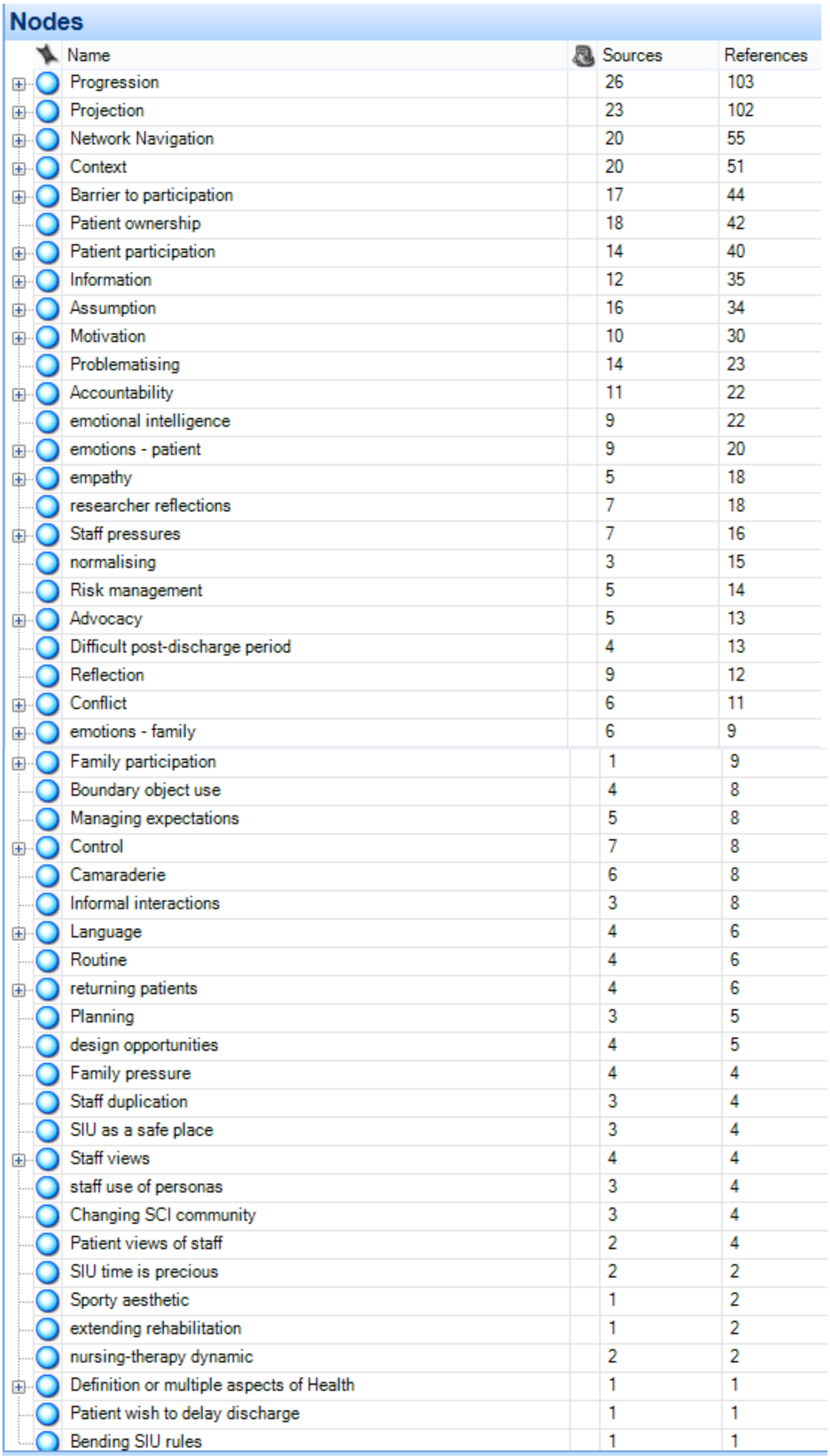
Date of Next Meeting:-

Reviewed 03/13 FB

Appendix 6: Report of findings from Contextual Review coding process

Joint Supervisory Meeting, 16/03/15.

Full set of themes from the full set of observational notes, excluding staff interviews.



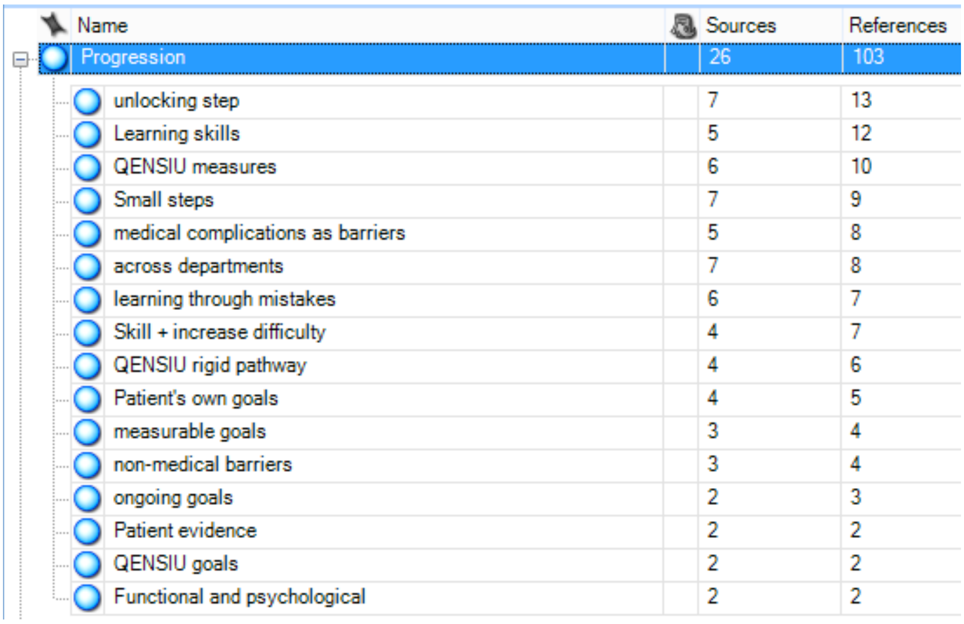
Nodes

Name	Sources	References
Progression	26	103
Projection	23	102
Network Navigation	20	55
Context	20	51
Barrier to participation	17	44
Patient ownership	18	42
Patient participation	14	40
Information	12	35
Assumption	16	34
Motivation	10	30
Problematising	14	23
Accountability	11	22
emotional intelligence	9	22
emotions - patient	9	20
empathy	5	18
researcher reflections	7	18
Staff pressures	7	16
normalising	3	15
Risk management	5	14
Advocacy	5	13
Difficult post-discharge period	4	13
Reflection	9	12
Conflict	6	11
emotions - family	6	9
Family participation	1	9
Boundary object use	4	8
Managing expectations	5	8
Control	7	8
Camaraderie	6	8
Informal interactions	3	8
Language	4	6
Routine	4	6
returning patients	4	6
Planning	3	5
design opportunities	4	5
Family pressure	4	4
Staff duplication	3	4
SIU as a safe place	3	4
Staff views	4	4
staff use of personas	3	4
Changing SCI community	3	4
Patient views of staff	2	4
SIU time is precious	2	2
Sporty aesthetic	1	2
extending rehabilitation	1	2
nursing-therapy dynamic	2	2
Definition or multiple aspects of Health	1	1
Patient wish to delay discharge	1	1
Bending SIU rules	1	1

Appendix 6: Report of findings from Contextual Review coding process

Analysis of the most frequently occurring themes

Progression



Name	Sources	References
Progression	26	103
unlocking step	7	13
Learning skills	5	12
QENSIU measures	6	10
Small steps	7	9
medical complications as barriers	5	8
across departments	7	8
learning through mistakes	6	7
Skill + increase difficulty	4	7
QENSIU rigid pathway	4	6
Patient's own goals	4	5
measurable goals	3	4
non-medical barriers	3	4
ongoing goals	2	3
Patient evidence	2	2
QENSIU goals	2	2
Functional and psychological	2	2

- 'Unlocking step' – This idea appears in the GPM's, the multidisciplinary meetings and once in a patient education session, but only verbally through staff.
- 'Learning skills' - clearly this is a key component of SCI rehabilitation across the whole unit, but my observations have shown it to be particularly prominent in the community challenge, patient education and wheelchair skills sessions.
- 'Small steps' - Reminders of small steps tends to be given to the patients verbally by the staff, or occasionally reported by the patients telling staff 'I did *x* hours in the gym today.'
- 'across departments' – the transfer of progress (particularly between physiotherapy and nursing) is important, but my observational data suggests this is mainly facilitated by staff in the GPM's, or across the unit after a GPM has taken place (i.e. nursing changeovers can report decisions made during GPM's that day).
- 'own goals' – the explicit use or referral to a patient's own goals were not as frequent as I expected, and were mostly in terms of the 'end picture' such as 'getting back to work', or 'getting home'.

Projection

Projection	23	102
Post-discharge	13	24
To discharge	14	22
'Normal life'	7	17
Planning for short term	10	16
breaking down steps	6	9
Plans can change	5	5
use of clinical experience	3	5
Goal deadlines	3	3
trust in staff	1	1

- ‘Post-discharge’ – projection to life ‘post-discharge’ was found across the GPMs, the multidisciplinary meetings and in patient education sessions.
- ‘To discharge’ – Several instances of this theme involved staff appropriating/estimating the time a particular patient would need to learn a particular skill. Staff may try to involve patients in this projection by asking ‘how much longer do **you** think you’ll need?’ but the difference in knowledge and experience leaves the patient unequipped to take part.
- 'normal life' – staff can sometimes help patients to relate to the skills taught in the SIU by relating them to ‘normal life’, usually during GPMs, but also in the Occupational Therapy Kitchen and in some patient education sessions.
- ‘Breaking down the steps’ –a verbal explanation of the steps needed to be taken towards larger goals is usually given to patients by staff during the GPM’s.
- ‘Plans can change’ –SIU staff understand how and when a patient’s planned rehabilitation pathway can change. This understanding is not always shared with the patient, and unrecorded observations suggest this can sometimes be a good thing. However, perhaps some patients may engage with ‘plan A’ earlier if they know it can be changed to ‘plan B’ if it doesn’t suit them?

Network Navigation

Network Navigation	20	55
Staff teamwork	11	21
External to SIU	6	11
sourcing help	2	9
Patient led	3	4
In SIU	2	3

- ‘staff teamwork’ is the only coding in this group which has references in the GPM, highlighting the importance of this meeting in coordinating the efforts of a patient’s care team. However, the current rehabilitation format does not require patients to instigate this ‘network navigation’ themselves, yet this could potentially be a useful skill post-discharge.

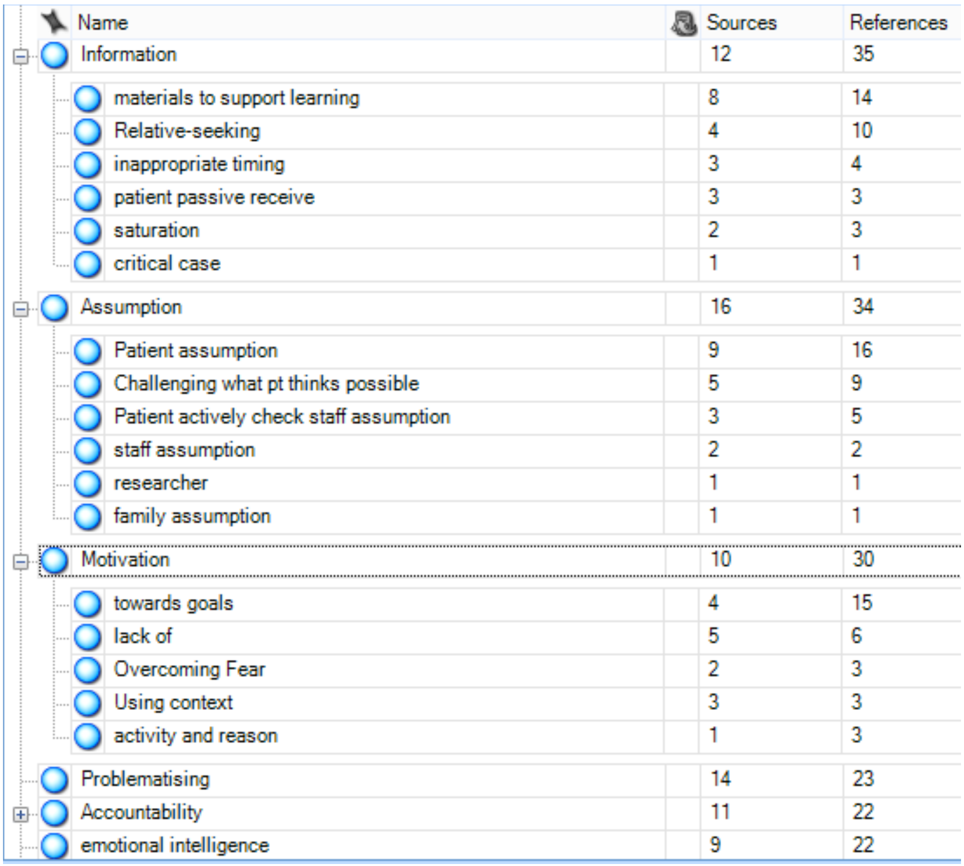
Context

Context	20	51
patient-specific	15	27
real-world	8	18
textbook to personal skills	1	1

The use of ‘context’ was spread quite equally between observations in GPMs, multidisciplinary meetings, patient education, the relative’s education day and the Occupational Therapy Kitchen. Few observations of translating the ‘textbook’ or ‘best practice’ skills taught in the SIU to a patient’s specific context were made, highlighting the (to some extent necessary) rigidity of the rehabilitation pathway.

Appendix 6: Report of findings from Contextual Review coding process

Additional, of interest



Name	Sources	References
Information	12	35
materials to support learning	8	14
Relative-seeking	4	10
inappropriate timing	3	4
patient passive receive	3	3
saturation	2	3
critical case	1	1
Assumption	16	34
Patient assumption	9	16
Challenging what pt thinks possible	5	9
Patient actively check staff assumption	3	5
staff assumption	2	2
researcher	1	1
family assumption	1	1
Motivation	10	30
towards goals	4	15
lack of	5	6
Overcoming Fear	2	3
Using context	3	3
activity and reason	1	3
Problematising	14	23
Accountability	11	22
emotional intelligence	9	22

- ‘Materials to support learning’ are largely experiential (i.e. a ‘show and tell’ of bowel management drugs at patient/relative education days, or using the OT kitchen to consider home alterations) and non-personal (i.e. generic information sheets).
- ‘Inappropriate timing’ – delivering education to patients in groups can be problematic, in the sense that each patient is at a different stage in their rehabilitation when, for example, the lesson on Goal Planning is given – many patients may have already had several meetings before they ‘learn’ about it.

The main ‘assumptions’ observed are:

- If certain tasks are put off, then the discharge date will be put back, due to the patient’s belief that the staff cannot discharge the patient before they have completed every possible goal.
- Patients and their friends/family can worry that the patient will be sent home too early, before either party is ready.
- Some patients may worry that seeing the psychologist may have ramifications, such as delaying their date of discharge.
- Patients who are doing well in their rehabilitation, but who also worry about being sent home too early, have been observed to check the perceived assumptions of staff; i.e. checking their progress isn’t being recorded as higher than it is.

Appendix 6: Report of findings from Contextual Review coding process

Problematising

‘Problematising’ was observed relatively equally across the different areas of the SIU, and the phrase 'problem-solving' is also often used by outpatients. However, recoding this data reminded the researcher that patients also face problems that can't be solved, such as being prone to urine infections despite having a good bladder management technique. In this case, ‘problem-solving’ may instead refer to reducing risk or limiting the effect of the problem.

Participation

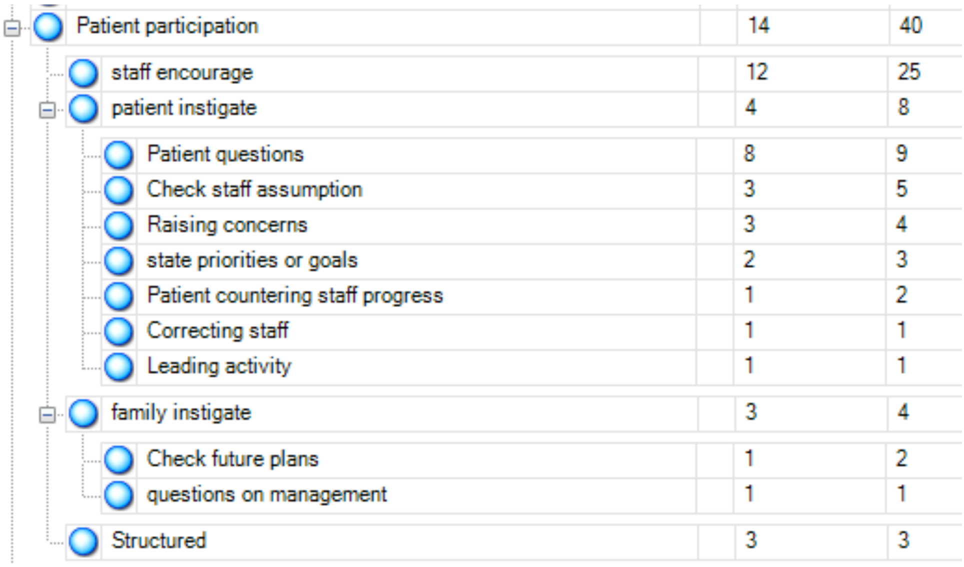
As stated above, this study asserts that the patient’s sense of agency can be related to whether or not they are able to participate in their rehabilitation in the way that they want (keeping in mind that, for some patients, this may mean having the staff make all of the decisions).

Barriers to Participation

Barrier to participation	17	44
Clinical language	7	9
lack of info	4	7
Fear or unknowns	6	7
environment	5	6
Facilitating passive pt role	5	5
lack of supporting materials	3	4
fatigue or illness	2	3
Communication - embarrassment	1	1
patient as 3rd person	1	1
peer pressure	1	1

‘Patient Ownership" was also often coded in areas of patient participation, so analysis of this has been omitted from this summary document.

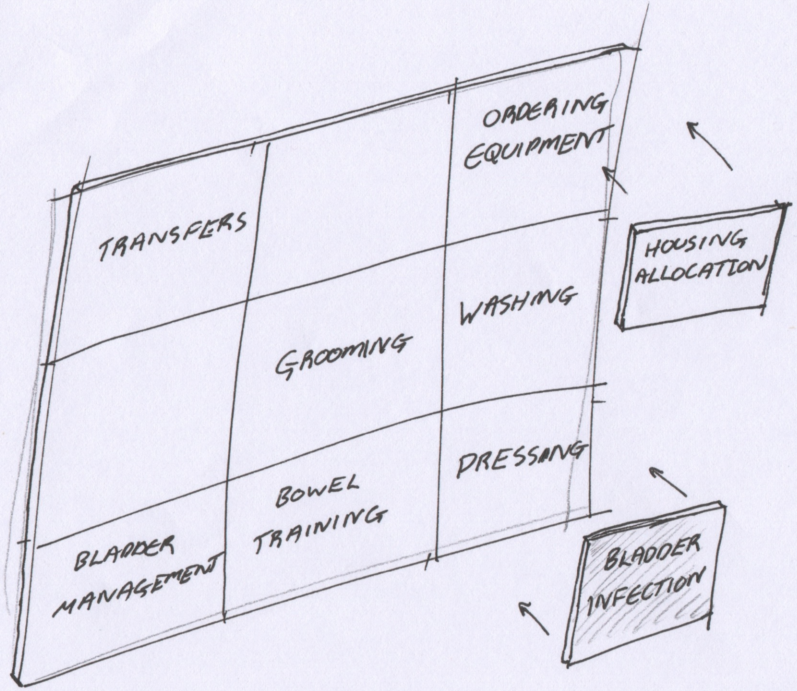
Types of Observed Patient Participation



Patient participation	14	40
staff encourage	12	25
patient instigate	4	8
Patient questions	8	9
Check staff assumption	3	5
Raising concerns	3	4
state priorities or goals	2	3
Patient countering staff progress	1	2
Correcting staff	1	1
Leading activity	1	1
family instigate	3	4
Check future plans	1	2
questions on management	1	1
Structured	3	3

GW found it interesting that most of the observed instances of patient participation could be considered ‘negative’, i.e. countering the progress reported by staff by highlighting the areas they still struggled with.

Appendix 7: Selection of Rough Pilot concepts



NURSING: A bladder infection affects pretty much everything; spasms, transfers, dressing; fever, skin, <u>mood</u>, bowel control...'

BARRIERS CAN INCLUDE:

- MOOD (MOTIVATION)
- BLADDER
- SKIN ISSUES
- SOCIAL – OFTEN OUTSIDE OF SIU CONTROL (HOUSING, CARE, EQUIPMENT, FUNDING)
- BOWEL
- BRACE
- FAMILY PERSPECTIVE (EXPECTATIONS, INFO, SOCIAL, HOUSING)
- EMPLOYABILITY (ROLE IN FAMILY?)
- GRIEF (WHAT IS LOST? BEREAVEMENT PROCESS)

IS THIS A BARRIER?

'IT'S A NECESSARY PART OF TREATMENT'

'PATIENTS CAN SEE IT AS A BARRIER'

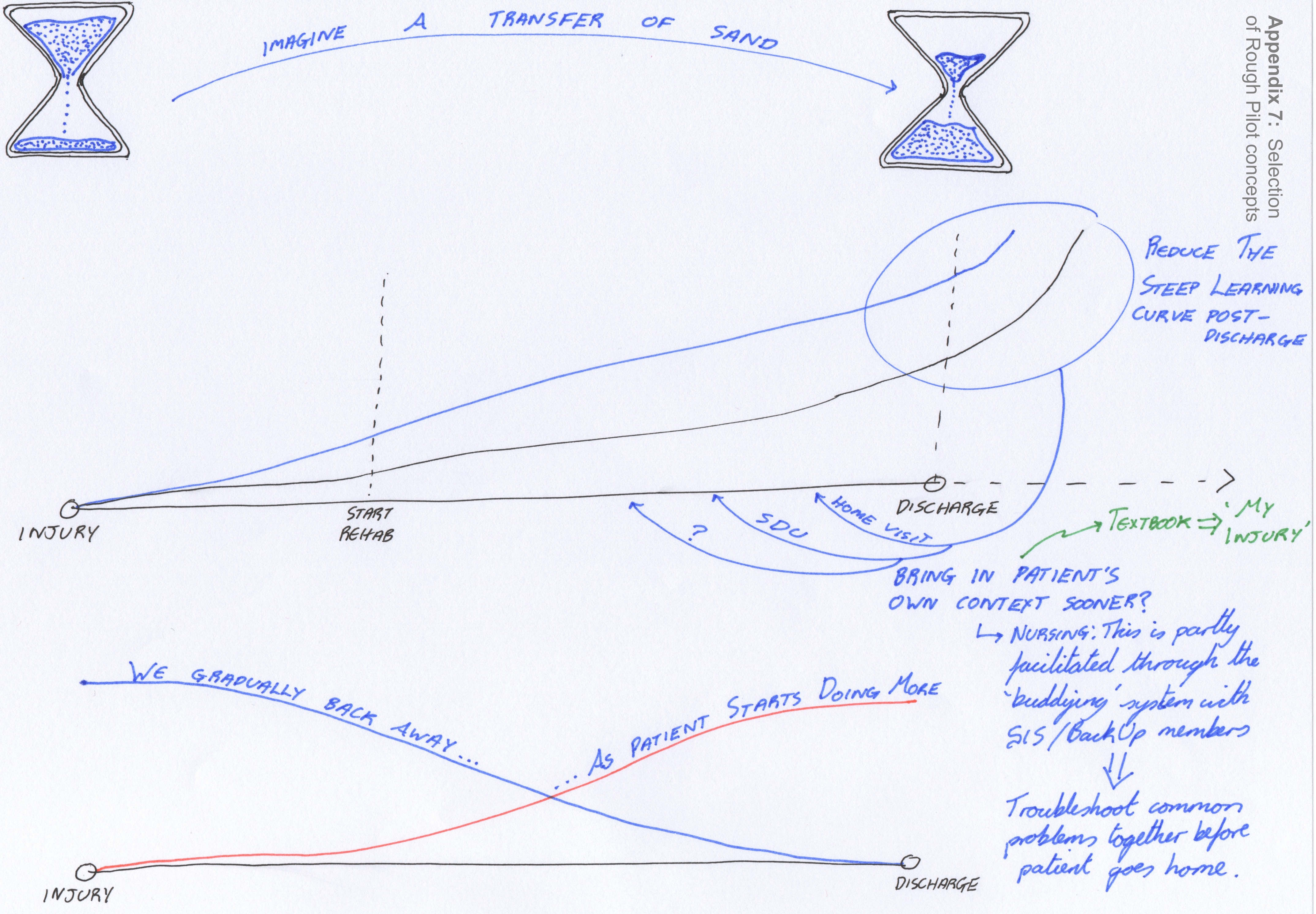
'IT NEEDS TO BE QUALIFIED FOR THE PT'

'IT JUST NEEDS TO BE THOUGHT AROUND'

"Imagine a jigsaw of all the different components of SCI rehab, & tiles to place over activities that are blocked by medical/non-medical barriers i.e. bladder infection/waiting for confirmation of housing allocation."

↳ GW

Appendix 7: Selection of Rough Pilot concepts



REDUCE THE STEEP LEARNING CURVE POST-DISCHARGE

BRING IN PATIENT'S OWN CONTEXT SOONER?

↳ NURSING: This is partly facilitated through the 'buddying' system with SIS/BackUp members

⇓

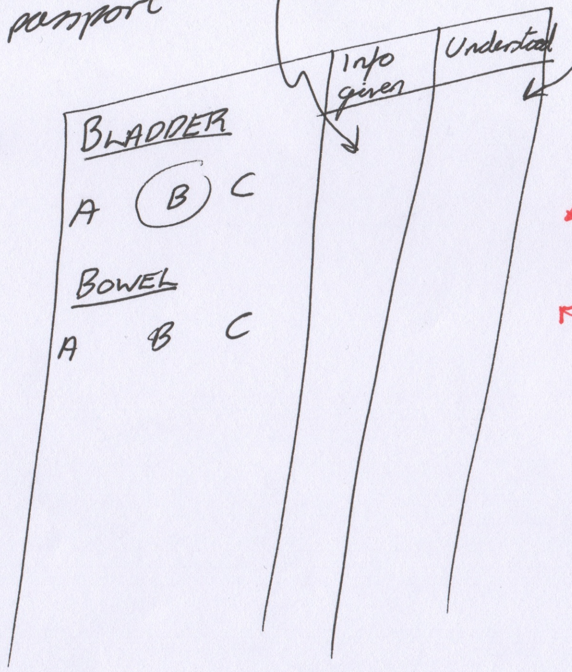
Troubleshoot common problems together before patient goes home.

WE GRADUALLY BACK AWAY… …AS PATIENT STARTS DOING MORE

Appendix 7: Selection of Rough Pilot concepts

'Checking off' style similar to Southport patient passport => Staff sign

Pt/family sign



Possibly suggests first choice is final, & pressure to understand first time.

Adds extra work/accountability

More about education, not GPM?

'We'll approach that when we're ready'

Nursing staff can judge when to give the appropriate leaflets.

When is the right time?

INFORMATION

Patients can be given information by several people in several ways, but still not understand / retain / relate it to their own situation.

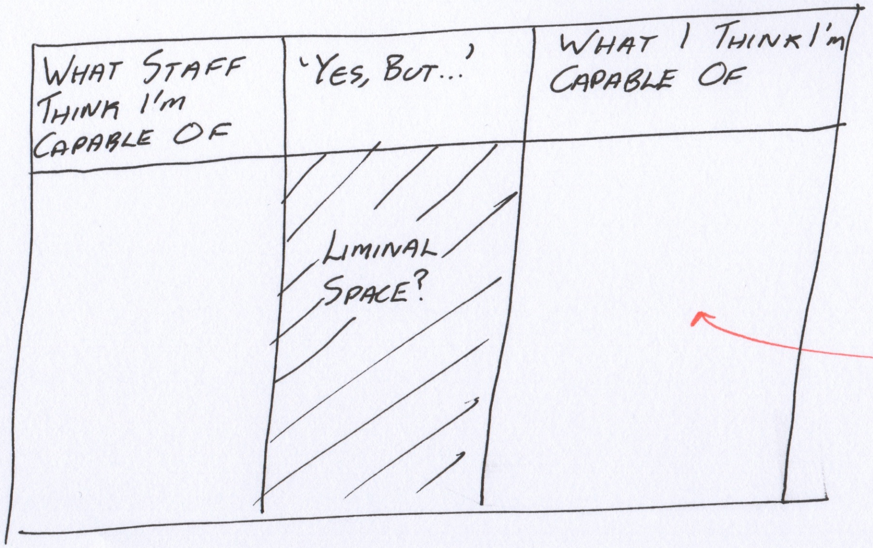
An awareness of the options available, & why, is difficult

INFO. GIVEN CAN BE
- TOO QUICK
- DIFFICULT TO PROCESS
- IN AN INTIMIDATING SITUATION
- UNFAMILIAR LANGUAGE
- LIMITED OPPORTUNITIES FOR FRIENDS & FAMILY

"IT'S AN ACADEMIC ACTIVITY FOR NON-ACADEMIC PEOPLE"

BI-ANNUAL EDUCATION DAY

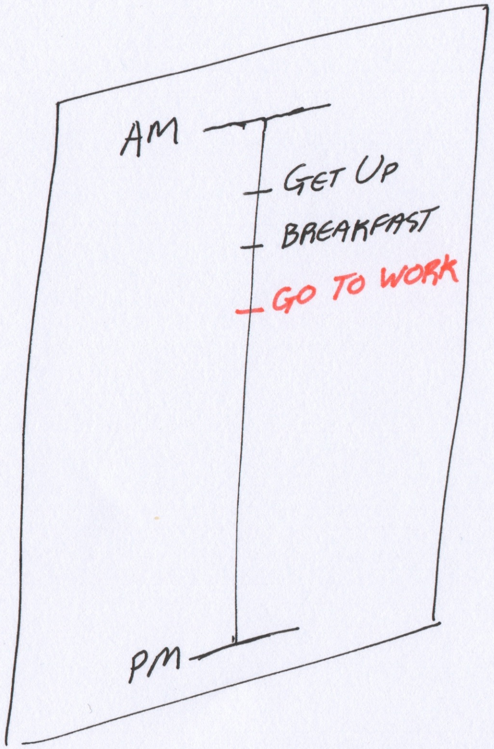
DON'T KNOW WHAT QUESTIONS TO ASK, OR HOW.



"Untenable, Because It Opens Doors To A Level Of Emotion That's Possibly Not Tolerated In That Meeting (GPM)"

Staff Need A Full Understanding Of What Patient Sees As Acceptable
↳ i.e. Goal May Only Be To Sit & Knit

"How Can We Synchronise Patient & Staff Views Of What The Patient Is Capable Of <u>Now</u> And <u>Later</u>?"

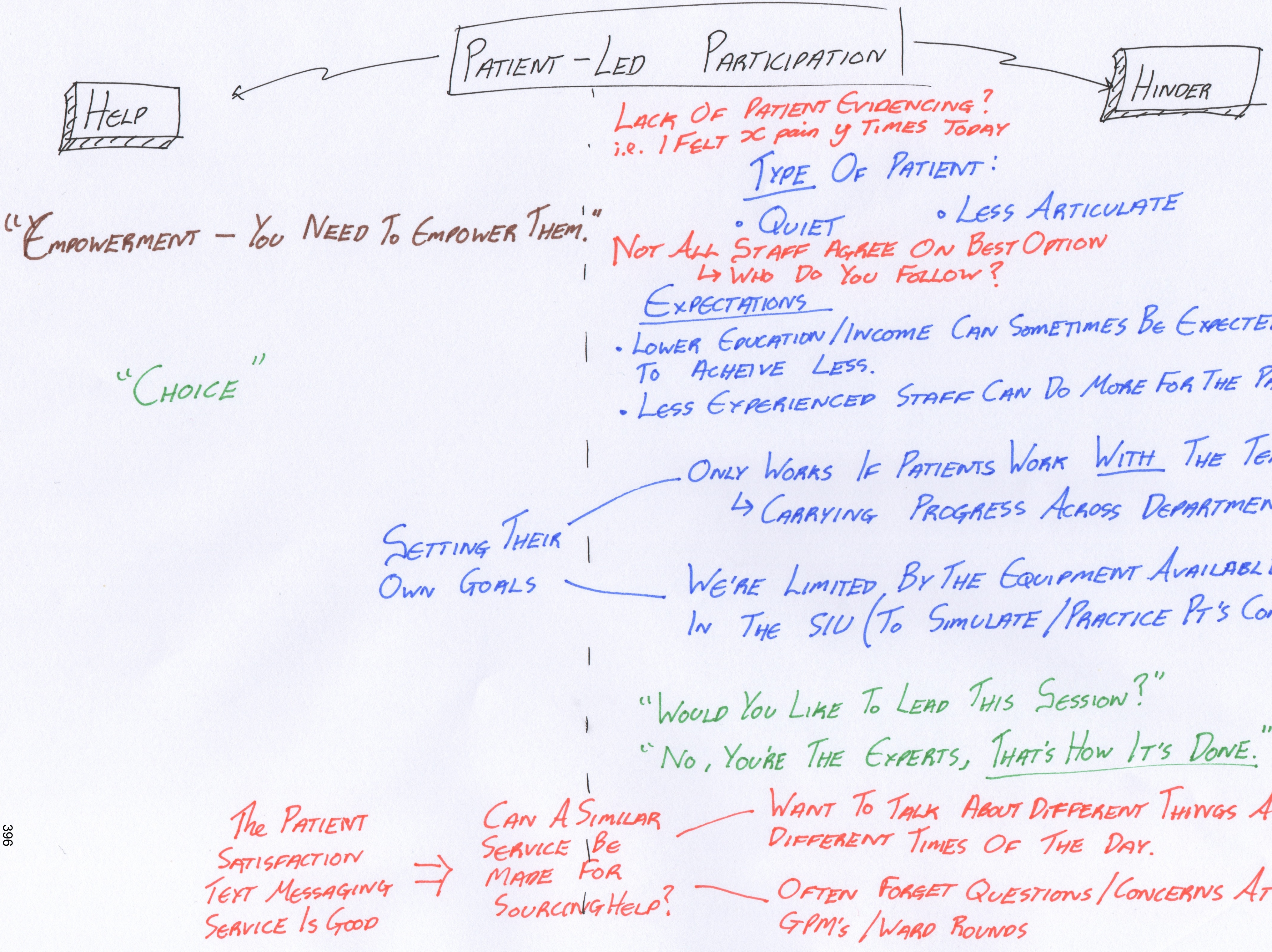


"What if the patients' daily routine structured the meeting, instead of by each department in turn?"

DISCHARGE COORDINATOR: Would take too long?

NURSING:
- Could give realism to ADL's?
- 'How do YOU see your daily activities?'
- Could help the idea of intertwined departments
- We're limited by the equipment available, BUT this could help to introduce their own context
- This is similar to what discharge coordinator writes in a 24 hour care plan.

Appendix 7: Selection of Rough Pilot concepts



PATIENT-LED PARTICIPATION

HELP

"EMPOWERMENT – YOU NEED TO EMPOWER THEM."

"CHOICE"

SETTING THEIR OWN GOALS

THE PATIENT SATISFACTION TEXT MESSAGING SERVICE IS GOOD ⇒ CAN A SIMILAR SERVICE BE MADE FOR SOURCING HELP?

HINDER

LACK OF PATIENT EVIDENCING?
i.e. I FELT x pain y TIMES TODAY

TYPE OF PATIENT:
- QUIET
- LESS ARTICULATE

NOT ALL STAFF AGREE ON BEST OPTION
↳ WHO DO YOU FOLLOW?

EXPECTATIONS
- LOWER EDUCATION/INCOME CAN SOMETIMES BE EXPECTED TO ACHEIVE LESS.
- LESS EXPERIENCED STAFF CAN DO MORE FOR THE PATIENT

ONLY WORKS IF PATIENTS WORK WITH THE TEAM
↳ CARRYING PROGRESS ACROSS DEPARTMENTS

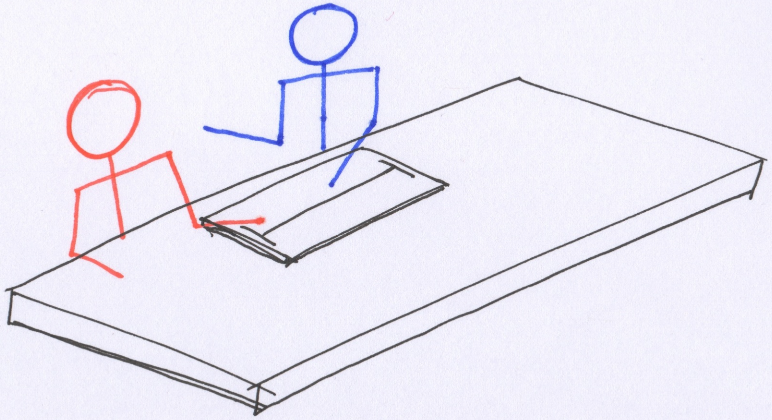
WE'RE LIMITED BY THE EQUIPMENT AVAILABLE IN THE SIU (TO SIMULATE/PRACTICE PT'S CONTEXT)

"WOULD YOU LIKE TO LEAD THIS SESSION?"
"NO, YOU'RE THE EXPERTS, THAT'S HOW IT'S DONE."

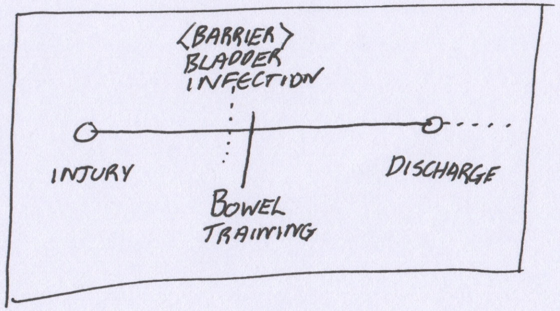
WANT TO TALK ABOUT DIFFERENT THINGS AT DIFFERENT TIMES OF THE DAY.

OFTEN FORGET QUESTIONS/CONCERNS AT GPM'S/WARD ROUNDS

TIMELINE

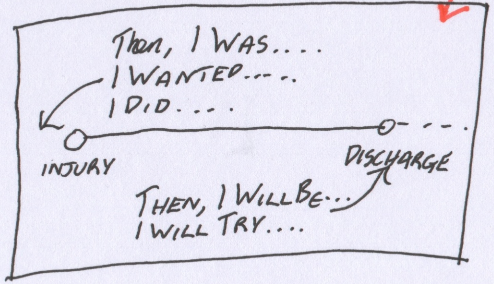


USE TO SITUATE BARRIERS



CAN BE USED IN MANY WAYS:
- YOUNG OR OLD
- LOTS OR LITTLE INFO

REFLECTION?

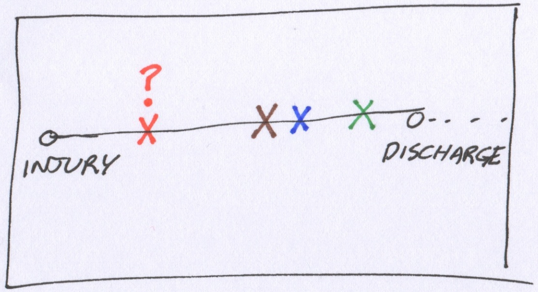


"What would be more useful for me is a one-on-one discussion: 'Where did you see yourself before the injury, and where do you see yourself now?

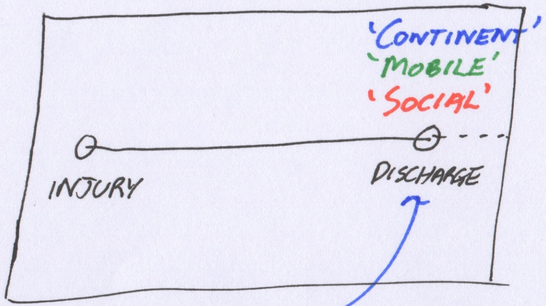
⇓

NOT A SUITABLE CONVO FOR GPM'S?

'HOW CLOSE DO YOU THINK YOU ARE TO DISCHARGE?'

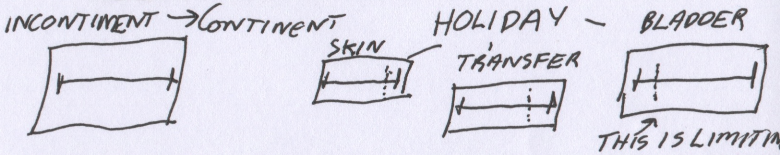


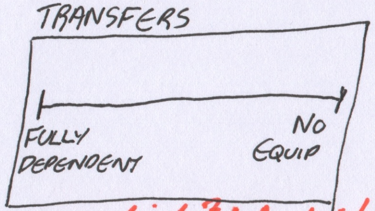
"WHAT IS THE END PICTURE?"

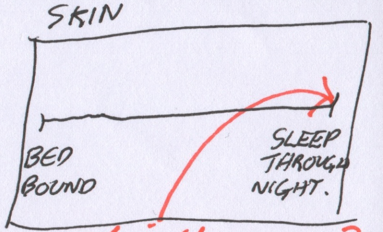


WHAT IS THIS NEW NORMAL?
ADDRESSING EXPECTATIONS?

SKILL BASED? → IN CONTEXT?







negotiate? What if SIU goal isn't yours?

Approaches to the Literature Review

Part A: Patient involvement in shaping their own, individual healthcare

Approach

To approach Part A of this review, both theoretical and case study reports were sought on approaches to involving patients in their own healthcare, and how these approaches have evolved in recent decades. Particular attention was given to how the impacts of these approaches were measured and the difficulties identified (so that they may be better anticipated in this study). As well as informing the study, this review also aimed to improve the researcher’s ability to communicate future findings back to the medical community by better understanding the language used and their points of reference.

Sources

Supervisory advice and online search engines (using terms below) such as Google Scholar were helpful to initially identify high-impact journals in the appropriate areas. This was followed by systematic searches in key journals and conferences proceedings such as The Journal of Rehabilitation Medicine, Clinical Rehabilitation, Spinal Cord, etc. Systematic literature reviews, including Cochrane reviews, were useful to gain a broad picture of patient involvement in healthcare, and to identify key authors. The online research profiles (i.e. ResearchGate) of such authors were then reviewed for deeper understandings of key themes. For example, Angela Coulter (currently based at the Nuffield Department of Population Health) is internationally recognised as an expert in patient engagement and has written extensively on topics such as Shared (medical) Decision Making. The approach to Part A became iterative as the researcher’s understanding of appropriate medical terminology grew and new search terms were included. Literature concerning patient engagement specifically in SCI rehabilitation was sparse, so where it could not be found studies on long-term conditions or chronic disease management (most commonly diabetes, mental health and asthma) were referred to, as it could be argued that they have similar aims to SCI rehabilitation. Additionally, advice from supervisors and peers identified key books to supplement the information given in journals, such as Mol’s discussion of ‘patient choice’ vs ‘care’ (2008). Patient perspectives were sought, but were often difficult to find outside of personal accounts (i.e. blogs).

Appendix 8: Approaches to the Literature Review

Search terms

- (Spinal cord injury) Patient engagement
- (Spinal cord injury) Patient involvement
- (Spinal cord injury) Patient empowerment
- (Spinal cord injury) Self Management
- Active patient involvement
- Consultation
- Doctor patient consultation
- Shared Decision Making
- SDM
- Decision support
- PROM [Patient Reported Outcome Measures]
- PREM [Patient Reported Experience Measures]
- (Rehabilitation) Goal Planning
- (Rehabilitation) Goal Planning Process
- (Rehabilitation) Goal Planning Meeting
- (Rehabilitation) Goal Setting
- (Rehabilitation) Goal Setting Process

Analysis

A ‘Synthesis Matrix’ (Queen Margaret University, Edinburgh) was created using excel, where multiple studies can be summarised and compared in terms of methods, aims, findings, etc, as illustrated below:

Research topic Burnout syndrome amongst ICU nurses	**Author A** Peterson, A.	**Author B** Bannerman, J.	**Author C** Allan,S. and White, M.	**Points to note/comments**
Article title/details				
Research aims				
Methods	qualitative: case study : 6 ICU nurses over 9 months	qualitative: questionnaire: 572 general ward nurses	qualitative: cross-sectional survey of 5956 staff nurses	A = case study over longer research period than B and C (only questionnaires) – significant?
Findings				
Discussion/analysis				
Conclusions				

Fig. A2: An example of a Synthesis Matrix, Queen Margaret University, Edinburgh.

The information from the individual studies could then be consolidated into key themes by summarising each row in the synthesis matrix.

Part B: Patient and public involvement in healthcare service development

Introduction

Part B aimed to frame how the fields of healthcare and design have had a simultaneous, yet mostly separate increasing focus on patient/user engagement in development processes. The approaches taken to understanding both fields are described below.

Approach to understanding the healthcare perspective

The ways in which patient/user experiences have been defined, valued, elicited, captured and also used (with varying degrees of active patient/user involvement) were sought from the medical literatures in a similar method to that described above for Part A, particularly focussing on systematic reviews of patient participation in healthcare service development, and again using a synthesis matrix to consolidate and summarise the results.

Appendix 8: Approaches to the Literature Review

Approach to understanding the design perspective

Initially, overviews of Experience-Based Co-Design, Participatory Design and Service Design are provided to orientate the reader, drawing on landmark publications from each field, such as Routledge handbooks and key design studies that had been explored in her previous Design training. Again, supervisory and peer advice signposted newer publications in the form of books, exhibitions and ‘grey material’.

Following this, the area of (Participatory) Service Design for Healthcare is thoroughly reviewed, using the following strategy.

(Participatory) Service Design in Healthcare literature review

Overview

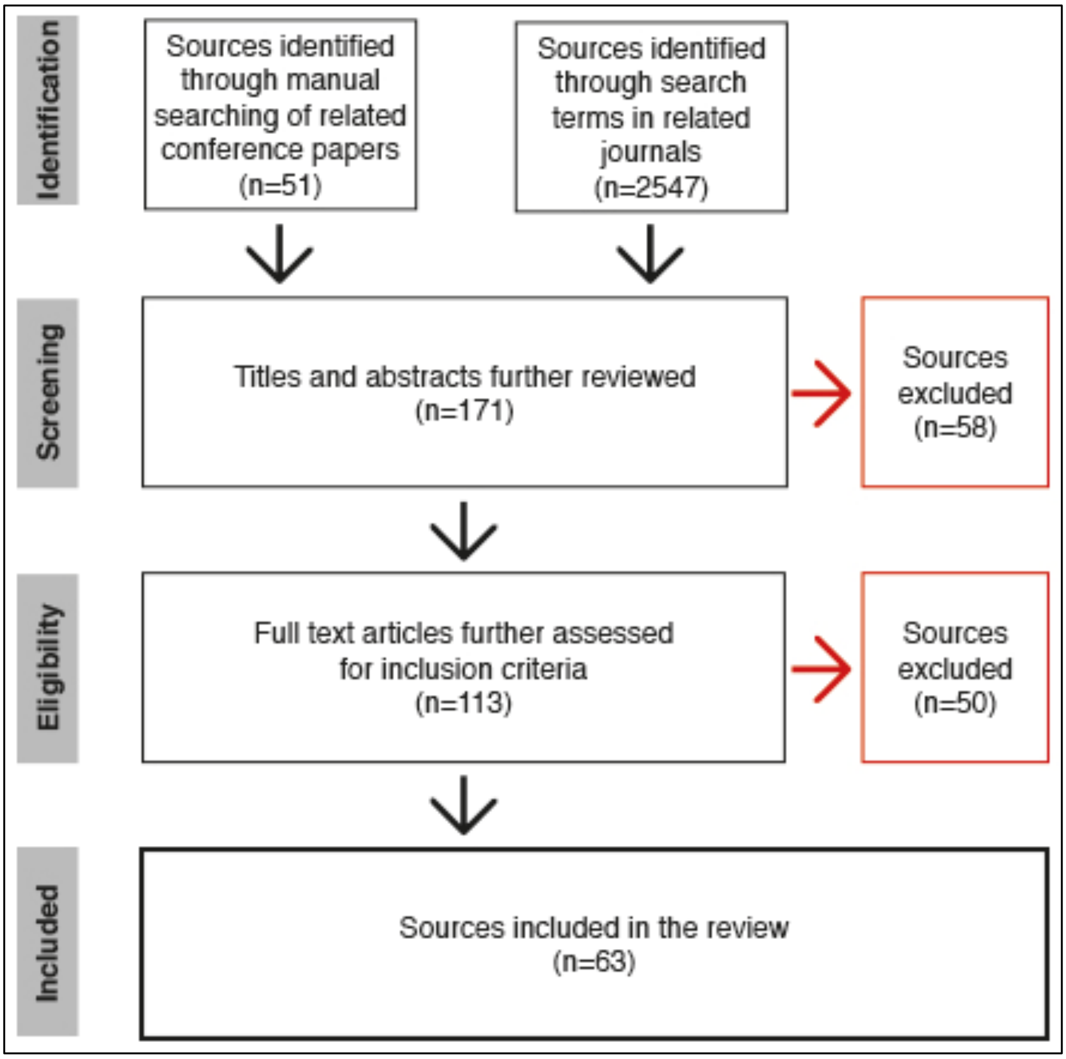


Fig. A3: A diagrammatic overview of the strategy taken to reviewing the (participatory) service design in healthcare literature.

Appendix 8: Approaches to the Literature Review

Sources

A range of design and healthcare journals, reports and conference proceedings were identified as relevant to the review from experience in the PhD to this point, as well as from guidance of the supervisory team and peers. Sources included:

Journals

- Design4Health
- The Design Journal
- CoDesign
- Design Issues
- International Journal of Design
- Design Studies
- British Medical Journal
- Spinal Cord
- Journal of Spinal Cord Medicine
- Journal for Rehabilitation Medicine

Reports

- Service Design Research Network report (Sangiorgi & Prendiville, 2014)

Conference proceedings

- Design4Health Conference Proceedings (all issues)
- Service Design and Innovation Conference (ServDes) (all issues)
- Participatory Design Conference (2010-2016)

Conference proceedings and projects named in the reports were reviewed manually due to the smaller numbers of sources within. Journals were reviewed using the following search terms

Search terms

The search terms used were altered according to whether the journal in question was based in healthcare or design (as terms such as 'patient' would narrow design-based journals, but identify an unmanageable number of unrelated sources in healthcare-based journals).

Search terms for design-based journals

- Healthcare OR health OR service OR rehabilitation OR prototype OR prototyping OR codesign OR co-design OR communication OR coproduction OR co-production
- "Spinal cord injury"
- "Shared decision making"
- "Shared decision-making"

Search terms for healthcare-based journals

- "Spinal cord injury" (discount this term for the Spinal Cord journal)
- "Shared decision making"
- "Shared decision-making"
- "Goal planning"
- "Goal-planning"
- service OR rehabilitation OR codesign OR co-design OR coproduction OR co-production OR collaborative OR collaboration OR consultation OR goal OR goals OR communication OR prototype OR prototyping

Appendix 8: Approaches to the Literature Review

Search terms for design- and healthcare-based journals

- patient AND (journey OR priorities OR centered OR centred OR participation OR agency OR activation OR engagement)

Eligibility criteria

- Concerned with service improvement/development/enhancement etc - not concerned with designing the healthcare environment, products, electronic patient records, use of craft for rehabilitaiton
- Includes some form of healthcare community engagement
- Due to the large number of studies concerned with Dementia, in particular reminiscence therapy or support service for carers, studies in this context were only included if they had transferable findings outside of dementia care/rehabilitation.
- Not concerned with creative activities for their own sake, to enhance patient wellbeing
- Not concerned with services to promote a generally healthy lifestyle
- Not concerned with the creation of new services to support everyday management of chronic illness in the community context (as this affords little staff-patient interaction)
- Include studies exploring patient experience if the data could have an impact on service design
- In spinal cord injury contexts, concerned with adult (over the age of 16) rehabilitation only, as is the scope of the host SIU population
- Based in western countries (as several studies have acknowledged differences in eastern cultures as impacting on engagement with co-design processes, see Hussain, 2012)

Review of the terms associated with the role of the 'user'

Citizen

A Citizen, or someone having citizenship, is a member or resident of an area, nation, country, etc., who is imbued with the rights, privileges and duties associated with it. For example, a citizen of the United Kingdom has the right to free education until the age of 16, and has a duty to pay National Insurance once he/she has a high enough wage. In the context of healthcare, Parsons (1951) suggested the notion of the 'Sick Role' a citizen can take. This concept was originally based on an asymmetrical, hierarchical relationships between an unwell citizen and his/her doctor, where the doctor is best placed to help the citizen fulfil their 'moral obligation' to return to a contributing role in society. Indeed, Guttmann (the forefather of modern SCI treatment) is known for his definition of 'well' as 'productive'. In the context of urban planning and governance, Arnstein is known for her Ladder of Citizen Participation, where she defines citizen participation as a 'redistribution of power,' (1969, p216). Within the contexts of wider social and political movements of the time, she argued that citizen participation should produce real benefit for and with citizens, rather than simply pay lip service to them for the profit of those who traditionally hold power.

The concept of a community of participation is also explored in the field of Participatory Design, in the Deweyan notion of 'publics', as a way of 'framing groups of people and their motivation for undertaking action and pursuing change,' DiSalvo et al., 2013, p200). Dewey argued that 'rather than a singular public, there is a multiplicity of publics… [who are] a group of people brought together around and through an issue, in order to address that issue and its consequences,' (ibid). This opens up participation to include notions of a multiplicity of perspectives and opportunities for action within a given issues (see Le Dantec, 2010).

This raises questions that, although 'people generally want to help a community of which they are a part of,' (Woodcock & Georgiou, 2007), can this also be said of individuals who enter a community unwillingly? Or rather, if the inpatients of a SIU are considered a 'public' or a 'community', can we assume that some, or any, inpatients will want to identify as part of that community and take part in a project to enhance the future patient experience? Findings from the Royal Society of Art’s ‘Design and Rehabilitation’ project suggested that design-led methods allowed patients to describe SCI rehabilitation in a non-autobiographical manner (Macdonald, 2013), so this study operated under the assumption that at least some inpatients will want to contribute.

Patient

In light of the above, it could be argued that the SIU community can be considered a ‘public’, given that the staff, patients and family members are brought together around and through the issues of SCI rehabilitation. However, the term ‘patient’ theoretically takes away a person’s ability to take action on these issues. ‘Patient’ is perhaps best qualified through the understanding that it comes from the term patiency, which is the opposite of agency. As discussed in section *, healthcare systems in the UK are traditionally paternalistic, placing the individual patients as a passive receiver of care. Section * highlights how, despite various patient-centred care initiatives, this passive patient role remains prevalent, and the question of how to reframe the patient as an ‘agent’ or a ‘health seeker’ (Jones, 2013) is a topic of research in multiple fields. This raises the question, then, of how a ‘patient’ can be meaningfully included in a participatory service design project, particularly when they are still very much in the ‘patient’ role (i.e. engaging inpatients may have different implications from engaging outpatients in a co-design process).

Stakeholder

The term stakeholder has slight nuances in meaning across different contexts. Discounting the use of the term in law and in gambling contexts, a ‘stakeholder’ can be considered a person, group or organization that has an interest, concern, is affected by or believes themselves to be affected by an organisation or a project (Post, Preston & Sachs, 2002). However, it is worth noting that, according to stakeholder theory, ‘not all stakeholders are equal,’ for example a customer of a business will have certain entitlements but not to the same level as the business’ employees (ibid). So, whilst the term ‘stakeholder’ can be sometimes used to refer any person related to a co-design context, it does not necessarily infer that each person involved can or should be involved in the same manner.

Co-designer

A co-design approach can bring challenges in that it affects the roles of everyone involved. Sanders and Stappers argue that the professional designer may also take on a researcher role, but that they will still ‘play a critical role in giving form to the ideas,’ (2008, p12). The user too may also ‘play co-creating roles throughout the design process, i.e. become co-designers,’ but the extent of this role will depend on their ‘level of expertise, passion, and creativity of the ‘user’,’ (ibid). The authors argue that ‘all people are creative but not all people become designers,’ but that when given the right tools to express themselves, they can become part of the design team as ‘expert of their experiences,’ (ibid, quoting Visser et al., 2005). As such, the term ‘co-designer’ can facilitate different, or multiple, roles depending on the context and the participant, but unites the co-design group in a common aim to make a meaningful, positive change in the project context.

Co
Plan

Discussing the Goal Planning Meeting

A Patient Perspective

Participant code (assigned by facilitator):

Male/Female:

Age:

Injury level:

Complete or Incomplete:

Date of Injury:

Number of Goal Planning Meetings attended:

Co
Plan

The Goal Planning Meeting

- What did you expect to happen in the session?
- Can you briefly describe what happened in the session?
- What was the aim of the session?
- Did you have a role in the session?
- How would you describe the environment where the session took place?

Co
Plan

Conversation

- **What do you think contributed to the conversation in the session? *(Please tick all that apply)***

Staff knowledge ☐
Staff responsibilities ☐
Staff experience ☐
SIU rules ☐
Staff preferences ☐

My knowledge ☐
My questions ☐
My routines ☐
My experience ☐
My worries ☐
My responsibilities ☐
My expectations ☐
My preferences ☐

PIP knowledge ☐
PIP questions ☐
PIP routines ☐
PIP experience ☐
PIP worries ☐
PIP responsibilities ☐
PIP expectations ☐
PIP preferences ☐

Experience from day trips ☐
Experiences from home ☐
Experiences from the Step Down Unit ☐
Other ____________________

- **Please circle or suggest any items that you would like to be included in the conversation**

- **Do you think the conversation focussed on: *(Please tick all that apply)***

The next few days ☐
Discharge ☐
Living life after injury ☐
The next meeting ☐
First few weeks after discharge ☐
Other ____________________

Co Plan

Communication

- How would you describe the language used in the session?

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

Not at all	Sometimes	Completely

- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*

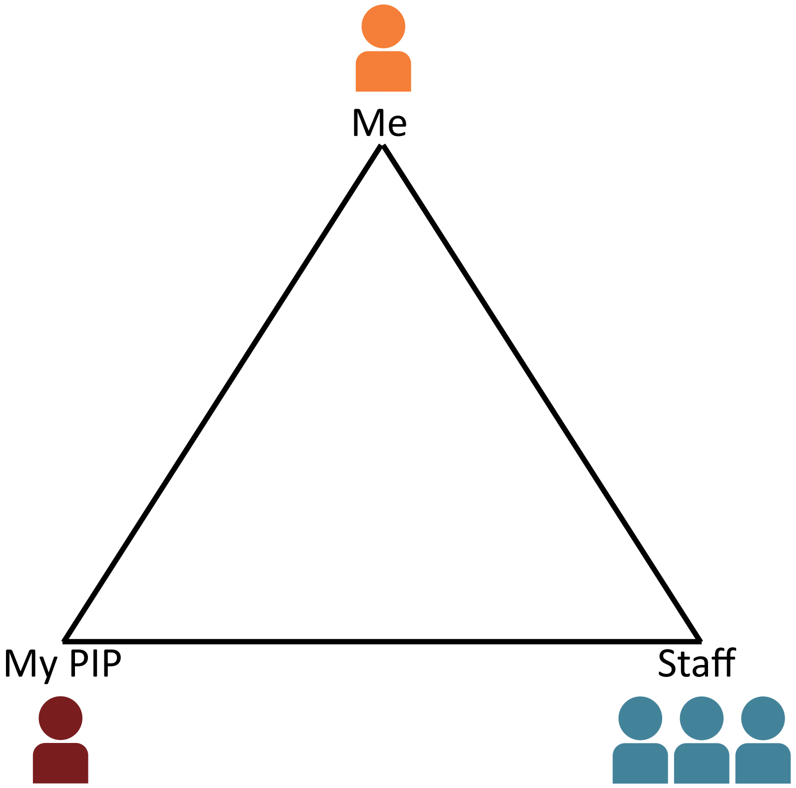
Not at all	Sometimes	Completely

- How much do you feel staff understand your abilities? *(Please mark an X on the scale)*

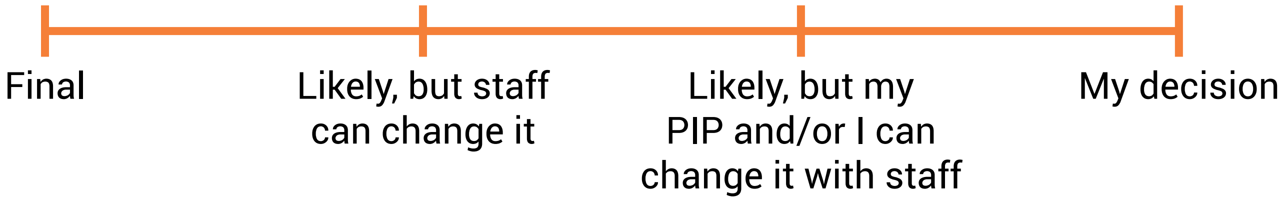
Less than I am able	Correct idea of my abilities	More than I am able

Making Decisions

- On the diagram below, please mark:
  - ‘**N**’ where you think the decision-making happens **now**
  - **‘P’** where you would **prefer** (if you would change this)



- When a decision is made, do you consider it to be:
  (Please mark an X on the scale)



- Do you have enough time to think about decisions before they are made?

Co
Plan

Goals

- **On each scale below, please mark:**
  - **‘B’** at how much you knew about each item **before** this GPM
  - **‘A’** at how much you knew about each item **after** this GPM
  - **‘P’** at how much you might **prefer** to know about each item

What the goals are at the point of discharge

I knew nothing | I knew the right amount | I knew too much

What the short term goals are

I knew nothing | I knew the right amount | I knew too much

How the short term goals join together

I knew nothing | I knew the right amount | I knew too much

How much you have progressed towards these goals

I knew nothing | I knew the right amount | I knew too much

Why you have these goals

I knew nothing | I knew the right amount | I knew too much

- Do you, or would you like to, suggest your own goals? Why, or why not?

Co
Plan

The Goal Planning Meeting

- Can you describe how the person important to you is currently involved in the session?

  You might like to consider:

General information	*Sensitive information*
Making decisions about treatment	*Planning short term goals*
Planning long term goals	*Planning for home*

- Would you like the person important to you to be involved more, or in different ways, in the session?

Making Decisions

- How do you feel when you leave the session?

- Does the Goal Planning process help you in your rehabilitation? If so, how?

- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

Point of injury

Point of discharge

Co
Plan

Discussing the Goal Planning Meeting

A perspective from a person important to the patient

Participant code (assigned by facilitator):

Supporting patient code (assigned by facilitator):

Relationship to patient:

Male/Female:

Age:

Number of Goal Planning Meetings attended:

Co Plan

The Goal Planning Meeting

- What did you expect to happen in the session?

- Can you briefly describe what happened in the session?

- What was the aim of the session?

- Did you have a role in the session?

- How would you describe the environment where the session took place?

Co
Plan

Conversation

- **What do you think contributed to the conversation in the session? *(Please tick all that apply)***

Staff knowledge ☐
Staff responsibilities ☐

Staff experience ☐
SIU rules ☐

Staff preferences ☐

My knowledge ☐
My questions ☐
My routines ☐

My experience ☐
My worries ☐
My responsibilities ☐

My expectations ☐
My preferences ☐

Patient knowledge ☐
Patient questions ☐
Patient routines ☐

Patient experience ☐
Patient worries ☐
Patient responsibilities ☐

Patient expectations ☐
Patient preferences ☐

Experience from day trips ☐
Experiences from home ☐

Experiences from the Step Down Unit ☐
Other ____________________

- **Please circle or suggest any items that you would like to be included in the conversation**

- **Do you think the conversation focussed on: *(Please tick all that apply)***

The next few days ☐
Discharge ☐
Living life after injury ☐

The next meeting ☐
First few weeks after discharge ☐
Other ____________________

Communication

- How would you describe the language used in the session?

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

Not at all	Sometimes	Completely

- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*

Not at all	Sometimes	Completely

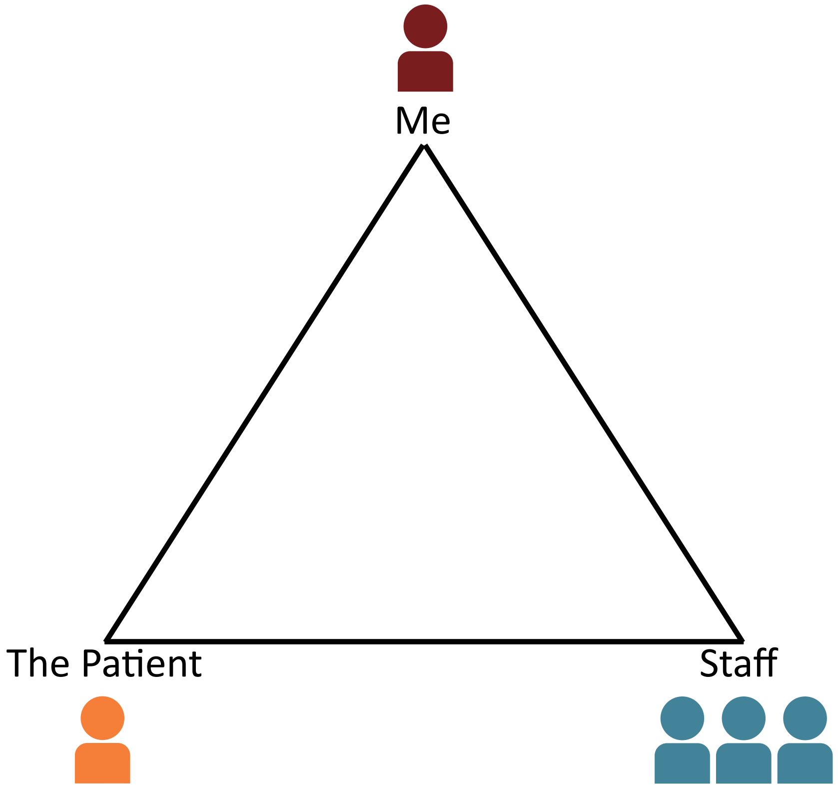
- How much do you feel staff understand the patient's abilities? *(Please mark an X on the scale)*

Less than he/she is able	Correct idea of his/her abilities	More than he/she is able

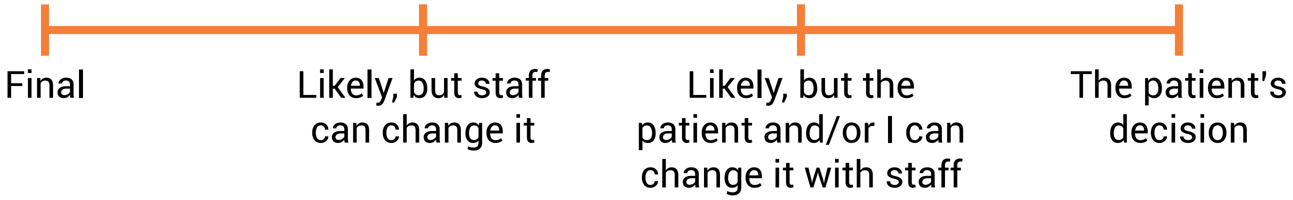
Co
Plan

Making Decisions

- On the diagram below, please mark:
  - ‘**N**’ where you think the decision-making happens **now**
  - **‘P’** where you would **prefer** (if you would change this)



- When a decision is made, do you consider it to be:
  (Please mark an X on the scale)



- Do you have enough time to think about decisions before they are made?

Goals

- **On each scale below, please mark:**
  - **‘B’** at how much you knew about each item **before** this GPM
  - **‘A’** at how much you knew about each item **after** this GPM
  - **‘P’** at how much you might **prefer** to know about each item

What the goals are at the point of discharge

I knew nothing | I knew the right amount | I knew too much

What the short term goals are

I knew nothing | I knew the right amount | I knew too much

How the short term goals join together

I knew nothing | I knew the right amount | I knew too much

How much the patient has progressed towards these goals

I knew nothing | I knew the right amount | I knew too much

Why the patient has these goals

I knew nothing | I knew the right amount | I knew too much

- Do you, or would you like to, suggest your own goals? Why, or why not?

Co
Plan

The Goal Planning Meeting

- Can you describe how the patient is currently involved in the session?

  You might like to consider:

General information	*Sensitive information*
Making decisions about treatment	*Planning short term goals*
Planning long term goals	*Planning for home*

- Would you like the patient to be involved more, or in different ways, in the session?

Co
Plan

Making Decisions

- How do you feel when you leave the session?

- Does the Goal Planning process help you in your role in the patient's rehabilitation? If so, how?

- Finally, whereabouts would you estimate the patient is on this rehabilitation timeline?

Co
Plan

Discussing the Goal Planning Meeting

A Key Worker's Perspective

Participant code (assigned by facilitator):

Key Worker of which patient (assigned by facilitator):

Occupational Title:

Co
Plan

The Goal Planning Meeting

- What did you expect to happen in the session?

- Can you briefly describe what happened in the session?

- Whereabouts would you estimate the patient is on this rehabilitation timeline?

Point of injury

Point of discharge

Co Plan

Conversation

- **What do you think contributed to the conversation in the session? *(Please tick all that apply, and please note that 'PIP' indicates the 'Person Important to the Patient')***

Staff knowledge ☐
Staff responsibilities ☐

Staff experience ☐
SIU rules ☐

Staff preferences ☐

Patient knowledge ☐
Patient questions ☐
Patient routines ☐

Patient experience ☐
Patient worries ☐
Patient responsibilities ☐

Patient expectations ☐
Patient preferences ☐

PIP knowledge ☐
PIP questions ☐
PIP routines ☐

PIP experience ☐
PIP worries ☐
PIP responsibilities ☐

PIP expectations ☐
PIP preferences ☐

Experience from day trips ☐
Experiences from home ☐

Experiences from the Step Down Unit ☐
Other ____________________

- **Please circle or suggest any items that you would like to be included in the conversation**

- **Do you think the conversation focussed on: *(Please tick all that apply)***

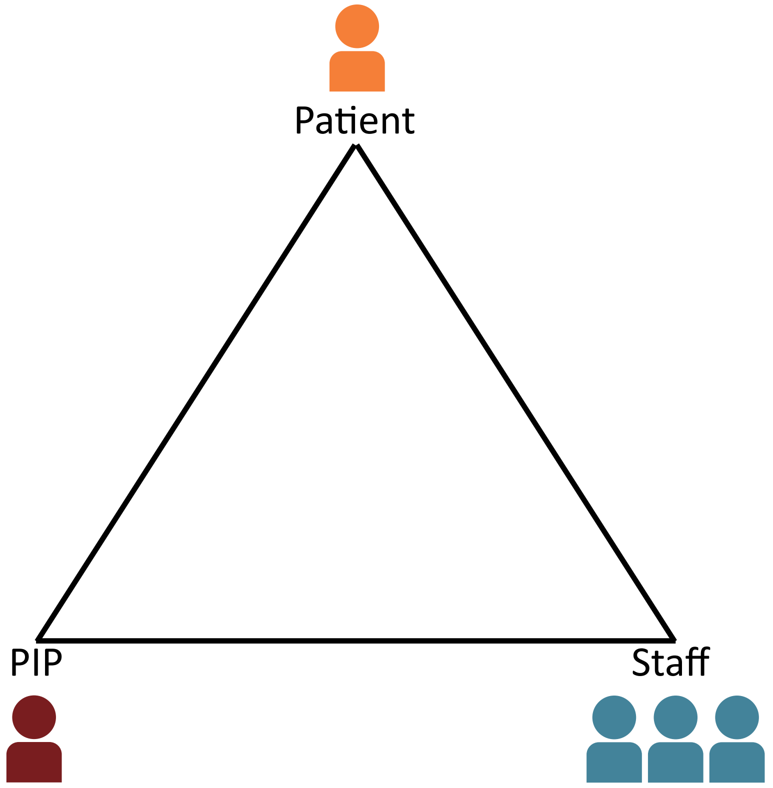
The next few days ☐
Discharge ☐
Living life after injury ☐

The next meeting ☐
First few weeks after discharge ☐
Other ____________________

Co Plan

Making Decisions

- On the diagram below, please mark:
  - '**N**' where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)



- Can you briefly explain why you have placed these marks in these places?

Co
Plan

Goals

- **On each scale below, please mark:**
  - ○ **'B'** at how much you think the patient knew about each item **before** this GPM
  - ○ **'A'** at how much you think the patient knew about each item **after** this GPM

What the goals are at the point of discharge

Patient knew nothing	Patient knew the right amount	Patient had too much information

What the short term goals are

Patient knew nothing	Patient knew the right amount	Patient had too much information

How the short term goals join together

Patient knew nothing	Patient knew the right amount	Patient had too much information

How much the patient has progressed towards these goals

Patient knew nothing	Patient knew the right amount	Patient had too much information

Why the patient has these goals

Patient knew nothing	Patient knew the right amount	Patient had too much information

Co
Plan

Discussing the Goal Planning Process

A Patient Perspective

Participant code (assigned by facilitator):

Male/Female:

Age:

Injury level:

Complete or Incomplete:

Date of Injury:

Number of Goal Planning Meetings attended:

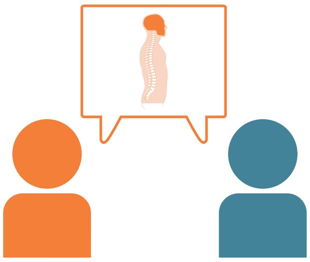
‘Welcome to Rehabilitation’

- Did you use the ‘Welcome to Rehabilitation’ Booklet? If so, when and why?

- Can you describe your experience of using the ‘Welcome to Rehabilitation’ Booklet?

- Did the ‘Welcome to Rehabilitation’ Booklet help you to understand the rehabilitation journey at all?

- Can you recommend any changes to the ‘Welcome to Rehabilitation’ Booklet?



Consultant Meeting

- Can you describe your experience of the Consultant Meeting?

- Did you use the Consultant Meeting Record? If so, when and why?

- Did the Consultant Meeting or the Record help you to understand your injury and it's effects?

- Can you recommend any changes to the Consultant Meeting or the Record?

Key Worker Meeting

- Can you describe your experience of the Key Worker Meeting?

- Did you use the Long-Term Goals sheet? If so, when and why?

- Did the Key Worker Meeting or the Long-Term Goals sheet help you to understand your rehabilitation goals?

- Can you recommend any changes to the Key Worker Meeting or the Long-Term Goals sheet?

Your first Goal Planning Meeting

- How did you feel going into your first Goal Planning Meeting?

- Did you know what to expect from the meeting?

- Did the previous meetings and materials help you to prepare for the first meeting in any way? If so, how?

- How did you feel leaving your first Goal Planning Meeting?

- Did you use your Goal Planning Record at all between your first and second meeting? If so, when and why?

Your second
Goal Planning Meeting

- What did you expect to happen in the session?

- Can you briefly describe what happened in the session?

- What was the aim of the session?

- Did you have a role in the session?

- How did you feel when you left the session?

Goal Planning Meeting Materials

- Can you describe your experience of using the Long-Term Goals sheet and Goal Planning Record?

- Did the Long-Term Goals sheet help you to gain a clear idea of your progress in your rehabilitation?

- Did the Goal Planning Record help you to gain a clear idea of your responsibilities in your rehabilitation?

- Can you recommend any changes to the Long-Term Goals sheet or the Goal Planning Record?

Communication in the Goal Planning Meeting

- How would you describe the language used in the session?

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

Not at all	Sometimes	Completely

- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*

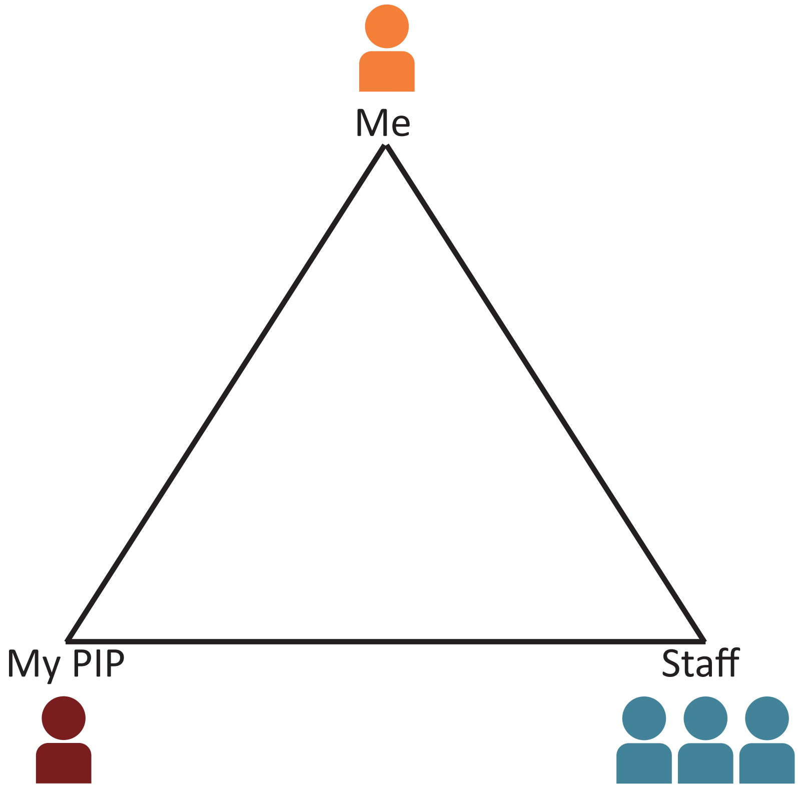
Not at all	Sometimes	Completely

- How much do you feel staff understand your abilities? *(Please mark an X on the scale)*

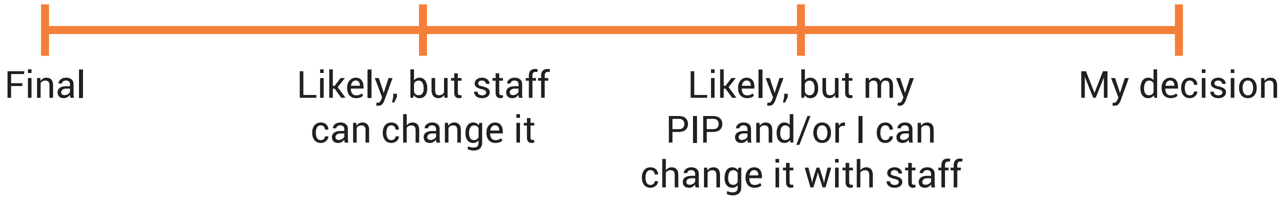
Less than I am able	Correct idea of my abilities	More than I am able

Making Decisions in the Goal Planning Meeting

- On the diagram below, please mark:
  - **'N'** where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)



- When a decision is made, do you consider it to be:
  (Please mark an X on the scale)



- Do you have enough time to think about decisions before they are made?

Involving your PIP in the Goal Planning Meeting

- Can you describe how the person important to you is currently involved in your Goal Planning Meetings?

  You might like to consider:

  General information
  Making decisions about treatment
  Planning long term goals
  Sensitive information
  Planning short term goals
  Planning for home

- Do you think the Co-Plan Process helped your PIP to be involved in your Goal Planning Meeting? If so, how?

- Would you like the person important to you to be involved more, or in different ways, in the Goal Planning Meetings?

The Co-Plan Process

- Did any of the materials help you to be involved in the Goal Planning Meetings? If so, how?

- Do you think the Goal Planning Meetings would be different without the previous meetings or materials? If so, how?

- Does the Co-Plan Process help you in your rehabilitation? If so, how?

- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

Co
Plan

Discussing the Co-Plan Project

A perspective from a person important to the patient

Participant code (assigned by facilitator):

Male/Female:

Age:

Injury level:

Complete or Incomplete:

Date of Injury:

Number of Goal Planning Meetings attended:

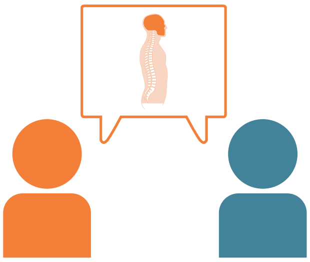
‘Welcome to Rehabilitation’

- Did you use the ‘Welcome to Rehabilitation’ Booklet? If so, when and why?

- Can you describe your experience of using the ‘Welcome to Rehabilitation’ Booklet?

- Did the ‘Welcome to Rehabilitation’ Booklet help you to understand the rehabilitation journey at all?

- Can you recommend any changes to the ‘Welcome to Rehabilitation’ Booklet?



Consultant Meeting

- Did you use the Consultant Meeting Record? If so, when and why?

- If yes, can you describe your experience of using the Consultant Meeting Record?

- Did the Consultant Meeting Record help you to understand the injury and it's effects?

- Can you recommend any changes to the Consultant Meeting Record?

Key Worker Meeting

- Did you use the Long-Term Goals sheet? If so, when and why?

- If yes, can you describe your experience of using the Long-Term Goals sheet?

- Did the Long-Term Goals sheet help you to understand the rehabilitation goals?

- Can you recommend any changes to the Long-Term Goals sheet?

The first Goal Planning Meeting

- How did you feel going into the first Goal Planning Meeting?

- Did you know what to expect from the meeting?

- Did the materials given to the patient prior to the meeting help you to prepare for the first meeting in any way?

- How did you feel leaving the first Goal Planning Meeting?

- Did you use the Goal Planning Record at all between the first and second meeting? If so, when and why?

The second
Goal Planning Meeting

- What did you expect to happen in the session?

- Can you briefly describe what happened in the session?

- What was the aim of the session?

- Did you have a role in the session?

- How did you feel when you left the session?

Goal Planning Meeting Materials

- Can you describe your experience of the Long-Term Goals sheet and Goal Planning Record?

- Did the Long-Term Goals sheet help you to gain a clear idea of the patient's progress in their rehabilitation?

- Did the Goal Planning Record help you to gain a clear idea of the staff and patient's responsibilities?

- Can you recommend any changes to the Long-Term Goals sheet or the Goal Planning Record?

Communication in the Goal Planning Meeting

- How would you describe the language used in the session?

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

Not at all — Sometimes — Completely

- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*

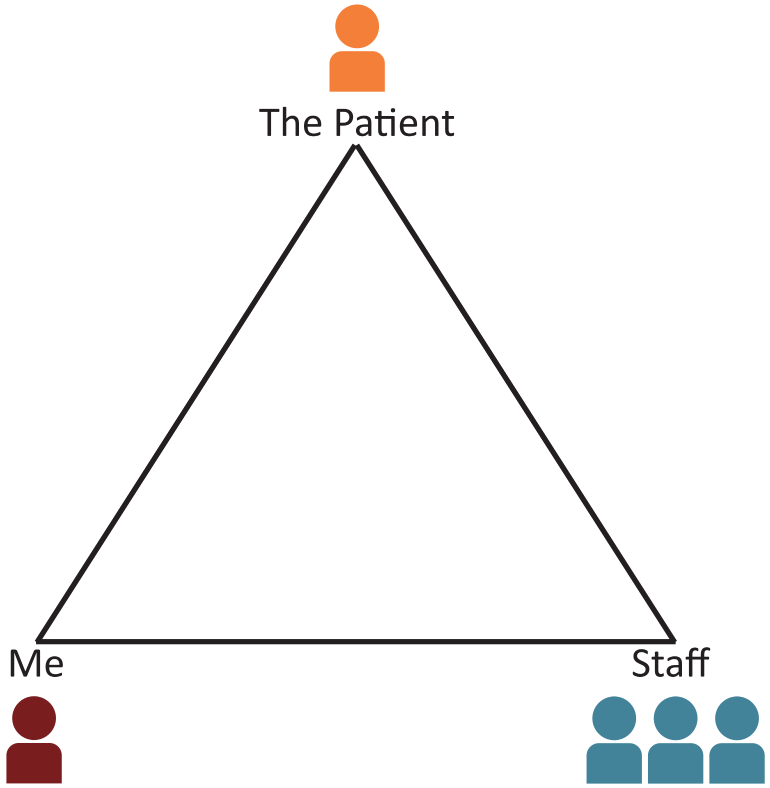
Not at all — Sometimes — Completely

- How much do you feel staff understand the patient's abilities? *(Please mark an X on the scale)*

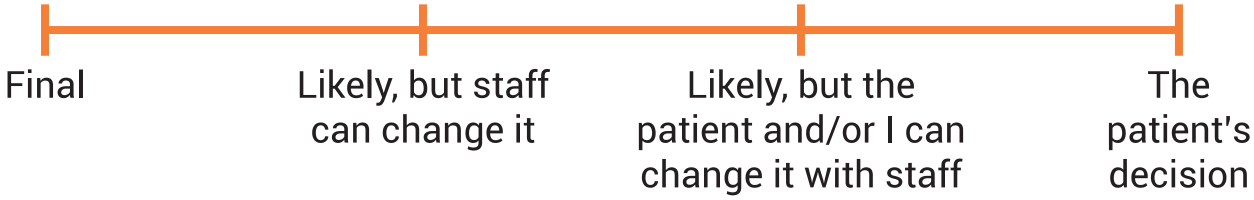
Less than he is able — Correct idea of his abilities — More than he is able

Making Decisions in the Goal Planning Meetings

- On the diagram below, please mark:
  - ○ **'N'** where you think the decision-making happens **now**
  - ○ **'P'** where you would **prefer** (if you would change this)



- When a decision is made, do you consider it to be:
  (Please mark an X on the scale)



- Do you have enough time to think about decisions before they are made?

Involving the patient in the Goal Planning Meeting

- Can you describe how the patient is currently involved in the Goal Planning Meetings?

  You might like to consider:

  General information
  Making decisions about treatment
  Planning long term goals
  Sensitive information
  Planning short term goals
  Planning for home

- Do you think the Co-Plan Process helped the patient to be involved in the Goal Planning Meeting? If so, how?

- Would you like the patient to be involved more, or in different ways, in the Goal Planning Meetings?

The Co-Plan Process

- Did any of the materials help you to be involved in the Goal Planning Meetings? If so, how?

- Do you think the Goal Planning Meetings would be different without the previous meetings or materials? If so, how?

- Does the Co-Plan Process help you in your role in the patient's rehabilitation? If so, how?

- Finally, whereabouts would you estimate the patient is on this rehabilitation timeline?

Co
Plan

Thank you!
Do you have any
comments or questions?

Co
Plan

Discussing the Co-Plan Project

Staff Perspectives

Part A: Your experiences of the intervention

Participant code(s) (assigned by facilitator):

Key Worker of which patient (assigned by facilitator):

Occupational Title(s):

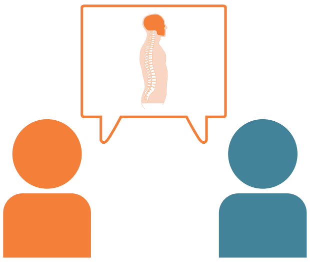
‘Welcome to Rehabilitation’

- Did you use the ‘Welcome to Rehabilitation’ Booklet, either with or without the patient? If so, when and why?

- Can you describe your experience of using the ‘Welcome to Rehabilitation’ Booklet?

- Do you think the ‘Welcome to Rehabilitation’ Booklet helped the patient and/or PIP to understand the rehabilitation journey at all?

- Can you recommend any changes to the ‘Welcome to Rehabilitation’ Booklet?



Consultant Meeting

- Can you describe your experience of the Consultant Meeting?

- Did you use the Consultant Meeting Record, either with or without the patient after the meeting? If so, when & why?

- Do you think the Consultant Meeting or the Record helped the patient and/or PIP to understand the injury and it's effects?

- Can you recommend any changes to the Consultant Meeting or the Record?

Key Worker Meeting

- Can you describe your experience of the Key Worker Meeting?

- Did you use the Long-Term Goals sheet either with or without the patient after the meeting? If so, when & why?

- Do you think the Key Worker Meeting or the Long-Term Goals sheet helped the patient and/or PIP to understand the rehabilitation goals?

- Can you recommend any changes to the Key Worker Meeting or the Long-Term Goals sheet?

The first Goal Planning Meeting

- Did any of the new materials help you to get to know the patient better, or help you to build your relationship with them prior to the first meeting?

- Did the previous meetings and materials help you to prepare for the first meeting in any way? If so, how?

- How did you feel going into the first Goal Planning Meeting using the new materials?

- Did you know what to expect from the meeting and how to conduct it?

- Can you describe your experience of using the Goal Planning Record in the first Goal Planning Meeting?

- How did you feel leaving the first Goal Planning Meeting?

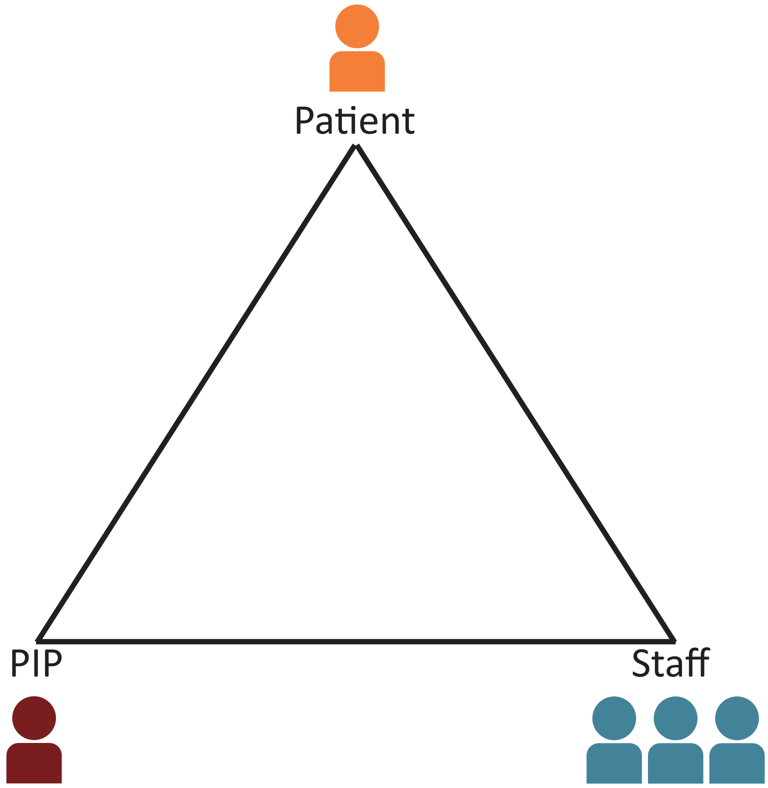
- Did you use the Goal Planning Record at all between the first and second meeting, either with or without the patient? If so, when and why?

The second Goal Planning Meeting

- How did you feel going into the second Goal Planning Meeting using the new materials?
- Did you feel prepared enough to conduct the meeting with the new materials?
- What did you expect to happen in the session?
- Can you briefly describe what happened in the session?
- Can you describe your experience of using the Long-Term Goals sheet in the second Goal Planning Meeting?
- Can you describe your experience of using the Goal Planning Record in the second Goal Planning Meeting?
- How did you feel leaving the second Goal Planning Meeting?
- Whereabouts would you estimate the patient is on this rehabilitation timeline?

Making Decisions in the Goal Planning Meetings

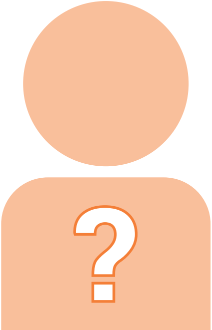
- On the diagram below, please mark:
  - **'N'** where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)



- Can you briefly explain why you have placed these marks in these places?

Part B: The patient's experiences of the project

- How did you expect the patient to react to/use the intervention?
- What was your perception of how the patient experienced the new meetings and/or materials?
- Do you think this particular patient used the meeting and/or materials in different ways than another patient might?
- Do you think the experience goals from the initial study were achieved for this patient? If not, why not?
- Do you think the conversation topics, tone or outcomes of the Goal Planning Meetings would have been different without the presence of the new materials? If so, how?



Part C: Involving the people important to the patient

- How did you expect the PIP(s) to react to/use the intervention?

- What was your perception of how the PIP(s) experienced the new meetings and/or materials?

- Do you think the Co-Plan Process helped the PIP(s) to be involved in the Goal Planning Meetings? If so, how?

- Would you like the PIP(s) to be involved more, or in different ways, in the Goal Planning Meetings?

Part D: Your overall experiences of the project

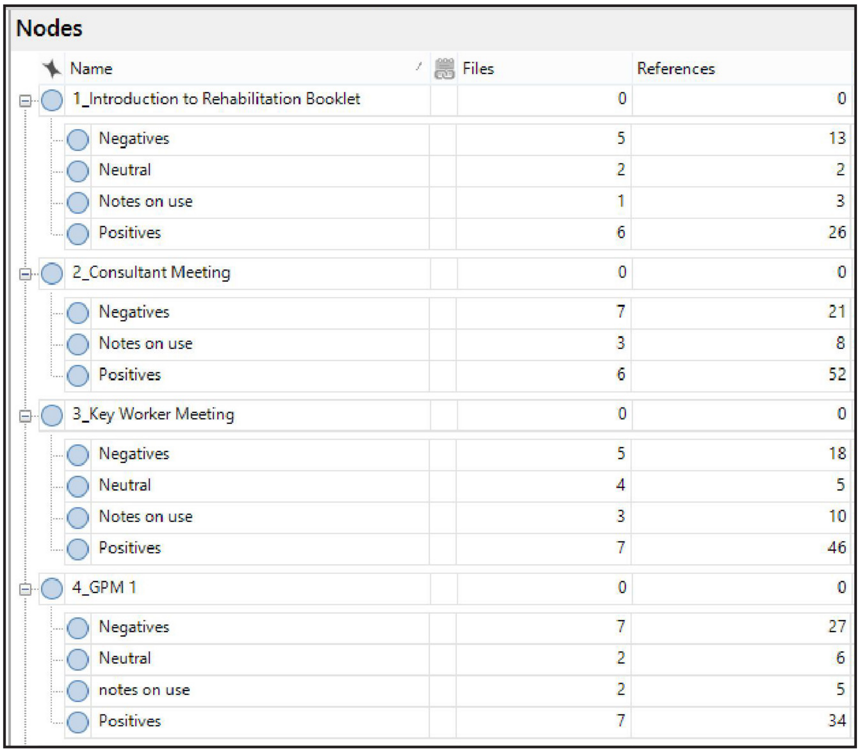
- How would you describe the materials to someone who had not been a part of the project, but who understood SCI rehabilitation and Goal Planning?
- Does the intervention, or any part of it, fit well into the rehabilitation context?
- Does the intervention, or any part of it, not fit into the rehabilitation context?
- Would you like to use any aspect of the intervention more regularly, with or without improvements?
- How would you describe your role in this whole project?
- Do you feel like the intervention comes from and belongs to the SIU community?
- Can you describe any instances when the project and/or intervention made you sad, mad or glad?
- How could I improve my approach in working with the unit, or contexts like this?

Co Plan

Thank you!
Do you have any
comments or questions?

Appendix 16: Findings from Phase Three coding

The organising framework for the deductive approach to Phase Three qualitative data analysis

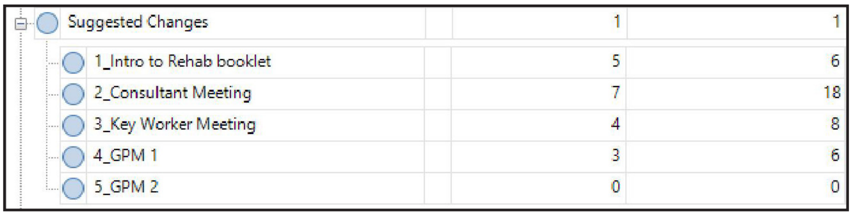


Nodes

Name	Files	References
1_Introduction to Rehabilitation Booklet	0	0
Negatives	5	13
Neutral	2	2
Notes on use	1	3
Positives	6	26
2_Consultant Meeting	0	0
Negatives	7	21
Notes on use	3	8
Positives	6	52
3_Key Worker Meeting	0	0
Negatives	5	18
Neutral	4	5
Notes on use	3	10
Positives	7	46
4_GPM 1	0	0
Negatives	7	27
Neutral	2	6
notes on use	2	5
Positives	7	34

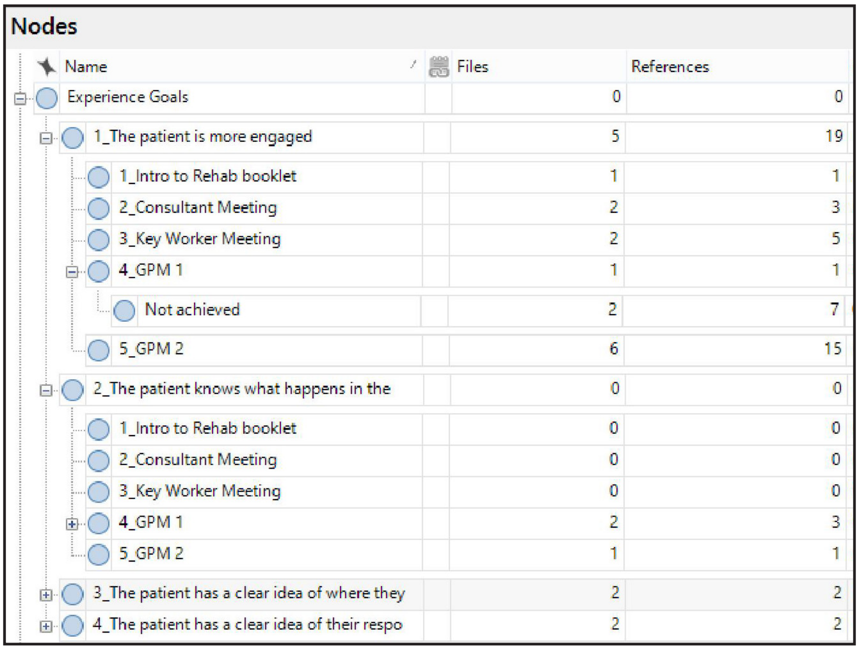
Nodes

Name	Files	References
5_GPM 2	0	0
Negatives	7	20
Neutral	2	2
Notes on use	1	1
Positives	7	41
Aim of GPM	3	3
Enough time to make decisions	4	4
Experience Goals	0	0
1_The patient is more engaged	5	19
2_The patient knows what happens in the	0	0
3_The patient has a clear idea of where they	2	2
4_The patient has a clear idea of their respo	2	2
Family involvement	5	29
Information	0	0
Too much	2	2
Language	4	7



Suggested Changes	1	1
1_Intro to Rehab booklet	5	6
2_Consultant Meeting	7	18
3_Key Worker Meeting	4	8
4_GPM 1	3	6
5_GPM 2	0	0

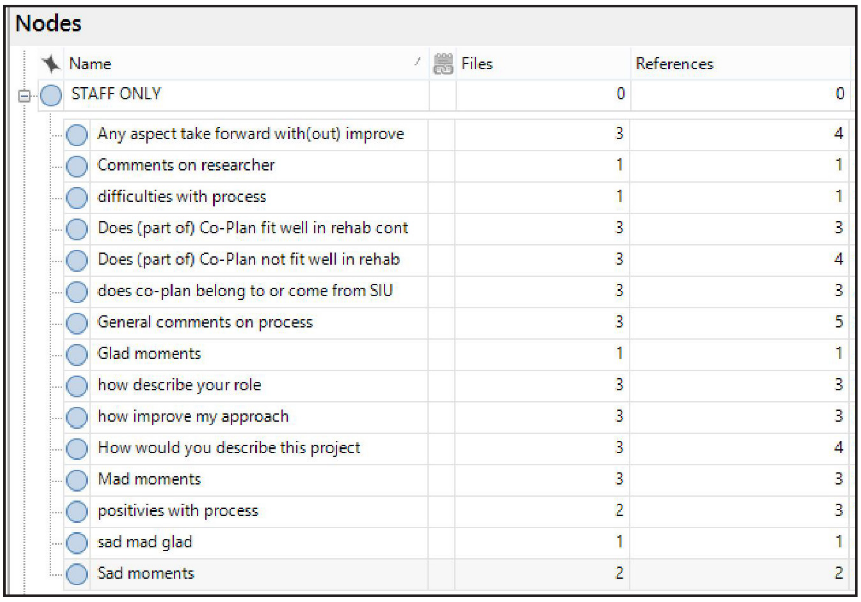
Appendix 16: Findings from Phase Three coding



Nodes

Name	Files	References
Experience Goals	0	0
1_The patient is more engaged	5	19
1_Intro to Rehab booklet	1	1
2_Consultant Meeting	2	3
3_Key Worker Meeting	2	5
4_GPM 1	1	1
Not achieved	2	7
5_GPM 2	6	15
2_The patient knows what happens in the	0	0
1_Intro to Rehab booklet	0	0
2_Consultant Meeting	0	0
3_Key Worker Meeting	0	0
4_GPM 1	2	3
5_GPM 2	1	1
3_The patient has a clear idea of where they	2	2
4_The patient has a clear idea of their respo	2	2

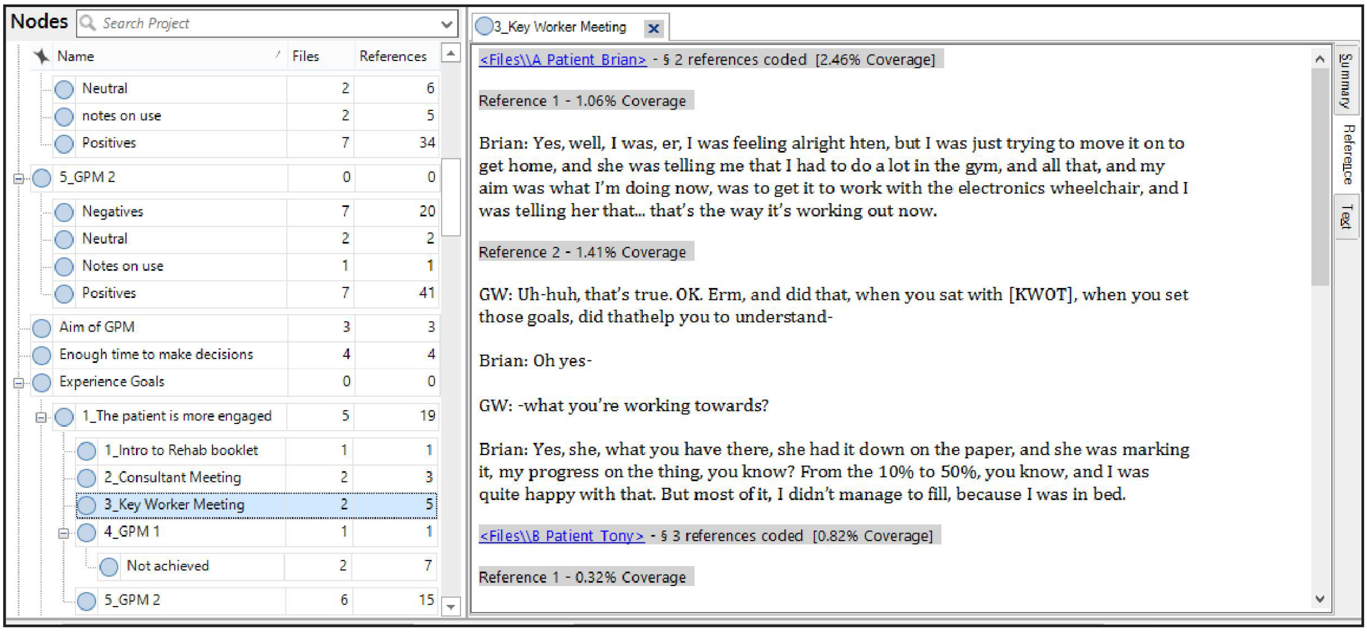
The organising framework for the deductive approach to Phase Three qualitative data analysis (continued)



Nodes

Name	Files	References
STAFF ONLY	0	0
Any aspect take forward with(out) improve	3	4
Comments on researcher	1	1
difficulties with process	1	1
Does (part of) Co-Plan fit well in rehab cont	3	3
Does (part of) Co-Plan not fit well in rehab	3	4
does co-plan belong to or come from SIU	3	3
General comments on process	3	5
Glad moments	1	1
how describe your role	3	3
how improve my approach	3	3
How would you describe this project	3	4
Mad moments	3	3
positivies with process	2	3
sad mad glad	1	1
Sad moments	2	2

Examples of the evaluation interview extracts used to discuss how the experience goal ‘The patient is more engaged’ was met in the Key Worker Meeting



Name	Files	References
Neutral	2	6
notes on use	2	5
Positives	7	34
5_GPM 2	0	0
Negatives	7	20
Neutral	2	2
Notes on use	1	1
Positives	7	41
Aim of GPM	3	3
Enough time to make decisions	4	4
Experience Goals	0	0
1_The patient is more engaged	5	19
1_Intro to Rehab booklet	1	1
2_Consultant Meeting	2	3
3_Key Worker Meeting	2	5
4_GPM 1	1	1
Not achieved	2	7
5_GPM 2	6	15

<Files\\A Patient Brian> - § 2 references coded [2.46% Coverage]

Reference 1 - 1.06% Coverage

Brian: Yes, well, I was, er, I was feeling alright hten, but I was just trying to move it on to get home, and she was telling me that I had to do a lot in the gym, and all that, and my aim was what I’m doing now, was to get it to work with the electronics wheelchair, and I was telling her that... that’s the way it’s working out now.

Reference 2 - 1.41% Coverage

GW: Uh-huh, that’s true. OK. Erm, and did that, when you sat with [KWOT], when you set those goals, did thathelp you to understand-

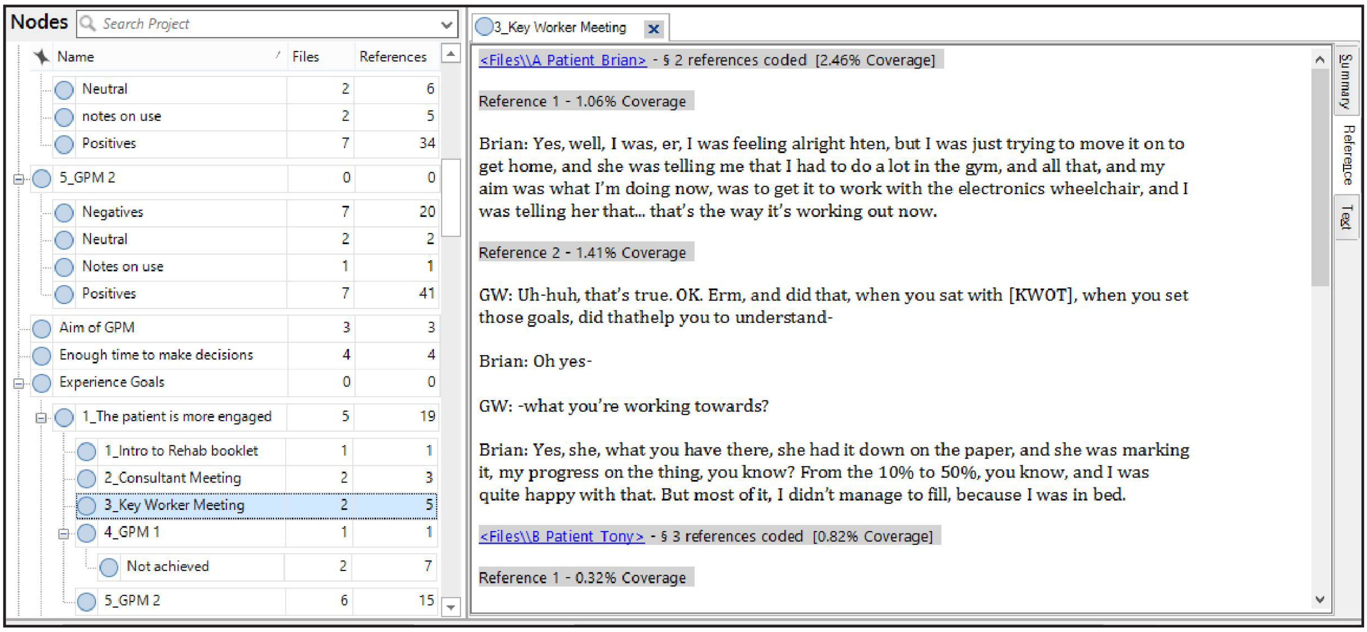
Brian: Oh yes-

GW: -what you’re working towards?

Brian: Yes, she, what you have there, she had it down on the paper, and she was marking it, my progress on the thing, you know? From the 10% to 50%, you know, and I was quite happy with that. But most of it, I didn’t manage to fill, because I was in bed.

<Files\\B Patient Tony> - § 3 references coded [0.82% Coverage]

Reference 1 - 0.32% Coverage


Nodes
Search Project
3_Key Worker Meeting

Name	Files	References
Neutral	2	6
notes on use	2	5
Positives	7	34
5_GPM 2	0	0
Negatives	7	20
Neutral	2	2
Notes on use	1	1
Positives	7	41
Aim of GPM	3	3
Enough time to make decisions	4	4
Experience Goals	0	0
1_The patient is more engaged	5	19
1_Intro to Rehab booklet	1	1
2_Consultant Meeting	2	3
3_Key Worker Meeting	2	5
4_GPM 1	1	1
Not achieved	2	7
5_GPM 2	6	15

<Files\\A Patient Brian> - § 2 references coded [2.46% Coverage]

Reference 1 - 1.06% Coverage

Brian: Yes, well, I was, er, I was feeling alright hten, but I was just trying to move it on to get home, and she was telling me that I had to do a lot in the gym, and all that, and my aim was what I’m doing now, was to get it to work with the electronics wheelchair, and I was telling her that... that’s the way it’s working out now.

Reference 2 - 1.41% Coverage

GW: Uh-huh, that’s true. OK. Erm, and did that, when you sat with [KWOT], when you set those goals, did thathelp you to understand-

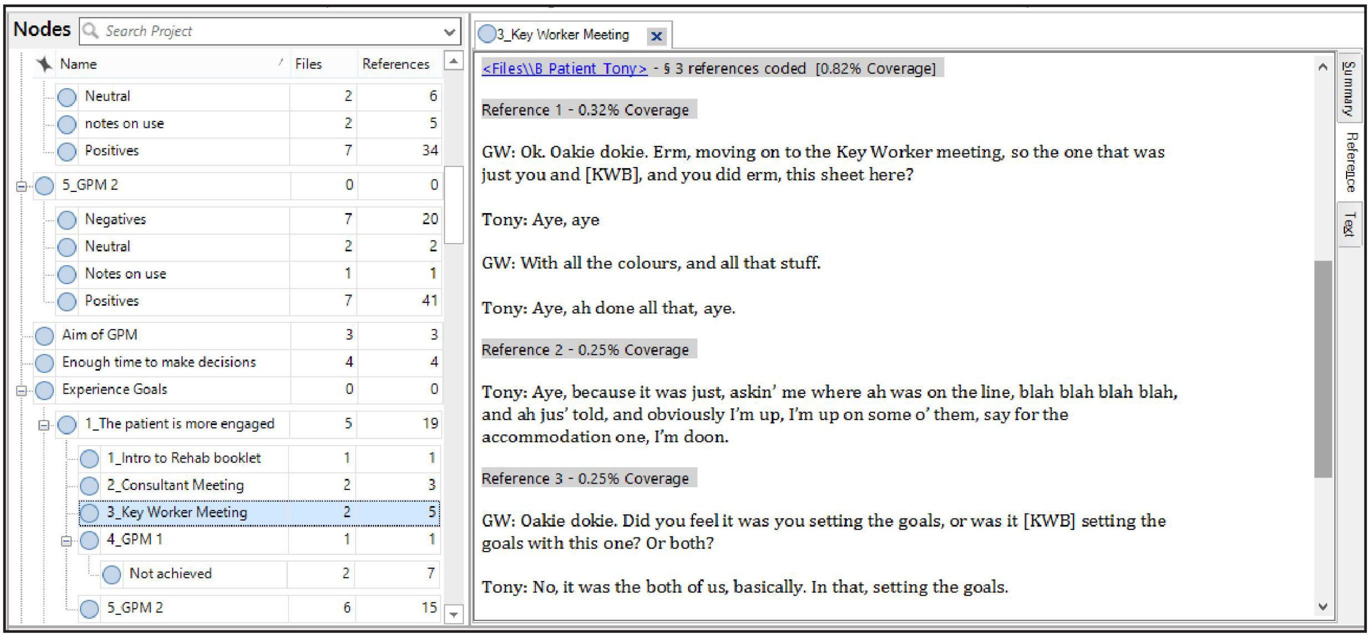
Brian: Oh yes-

GW: -what you’re working towards?

Brian: Yes, she, what you have there, she had it down on the paper, and she was marking it, my progress on the thing, you know? From the 10% to 50%, you know, and I was quite happy with that. But most of it, I didn’t manage to fill, because I was in bed.

<Files\\B Patient Tony> - § 3 references coded [0.82% Coverage]

Reference 1 - 0.32% Coverage



Name	Files	References
Neutral	2	6
notes on use	2	5
Positives	7	34
5_GPM 2	0	0
Negatives	7	20
Neutral	2	2
Notes on use	1	1
Positives	7	41
Aim of GPM	3	3
Enough time to make decisions	4	4
Experience Goals	0	0
1_The patient is more engaged	5	19
1_Intro to Rehab booklet	1	1
2_Consultant Meeting	2	3
3_Key Worker Meeting	2	5
4_GPM 1	1	1
Not achieved	2	7
5_GPM 2	6	15

<Files\\B Patient Tony> - § 3 references coded [0.82% Coverage]

Reference 1 - 0.32% Coverage

GW: Ok. Oakie dokie. Erm, moving on to the Key Worker meeting, so the one that was just you and [KWB], and you did erm, this sheet here?

Tony: Aye, aye

GW: With all the colours, and all that stuff.

Tony: Aye, ah done all that, aye.

Reference 2 - 0.25% Coverage

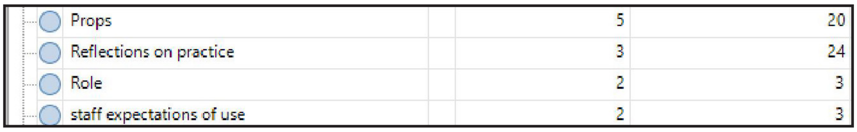
Tony: Aye, because it was just, askin’ me where ah was on the line, blah blah blah blah, and ah jus’ told, and obviously I’m up, I’m up on some o’ them, say for the accommodation one, I’m doon.

Reference 3 - 0.25% Coverage

GW: Oakie dokie. Did you feel it was you setting the goals, or was it [KWB] setting the goals with this one? Or both?

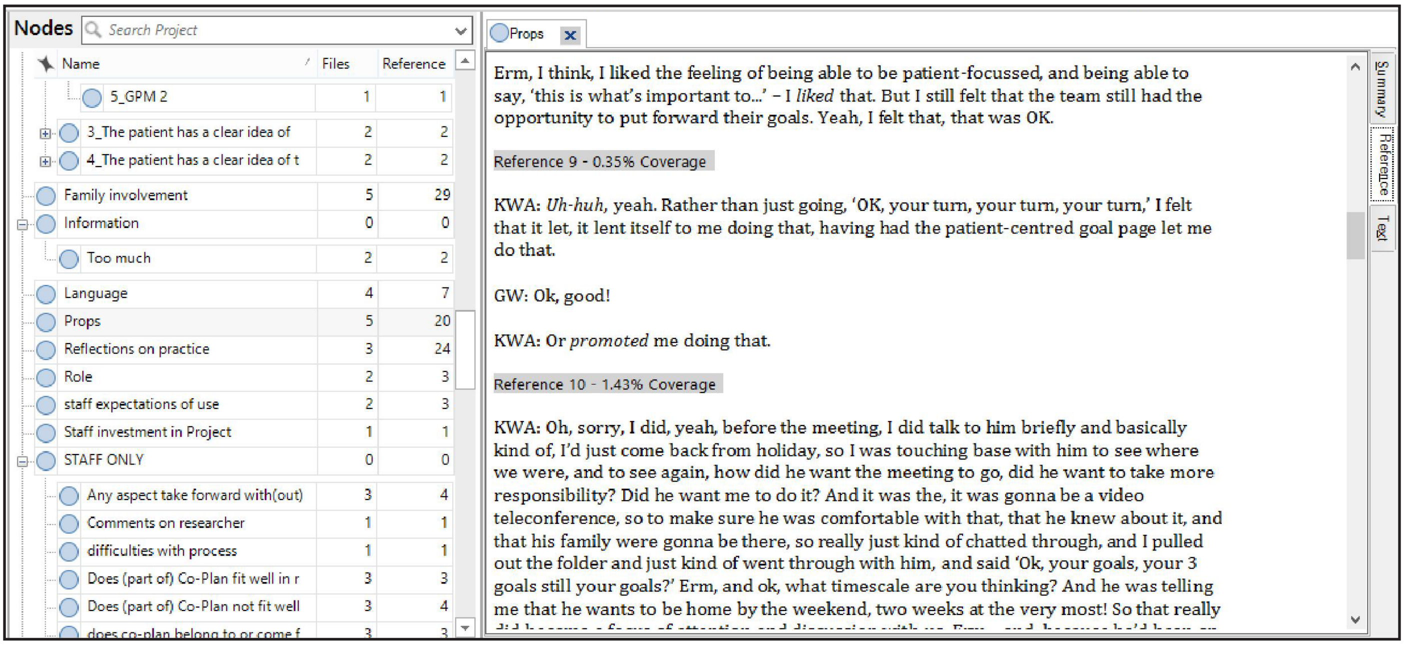
Tony: No, it was the both of us, basically. In that, setting the goals.

Appendix 16: Findings from Phase Three coding



Props	5	20
Reflections on practice	3	24
Role	2	3
staff expectations of use	2	3

The inductively generated themes, and extracts from the evaluation interview supporting the theme ‘props’



Name	Files	Reference
5_GPM 2	1	1
3_The patient has a clear idea of	2	2
4_The patient has a clear idea of t	2	2
Family involvement	5	29
Information	0	0
Too much	2	2
Language	4	7
Props	5	20
Reflections on practice	3	24
Role	2	3
staff expectations of use	2	3
Staff investment in Project	1	1
STAFF ONLY	0	0
Any aspect take forward with(out)	3	4
Comments on researcher	1	1
difficulties with process	1	1
Does (part of) Co-Plan fit well in r	3	3
Does (part of) Co-Plan not fit well	3	4
does co-plan belong to or come f	3	3

Erm, I think, I liked the feeling of being able to be patient-focussed, and being able to say, ‘this is what’s important to...’ – I *liked* that. But I still felt that the team still had the opportunity to put forward their goals. Yeah, I felt that, that was OK.

Reference 9 - 0.35% Coverage

KWA: *Uh-huh*, yeah. Rather than just going, ‘OK, your turn, your turn, your turn,’ I felt that it let, it lent itself to me doing that, having had the patient-centred goal page let me do that.

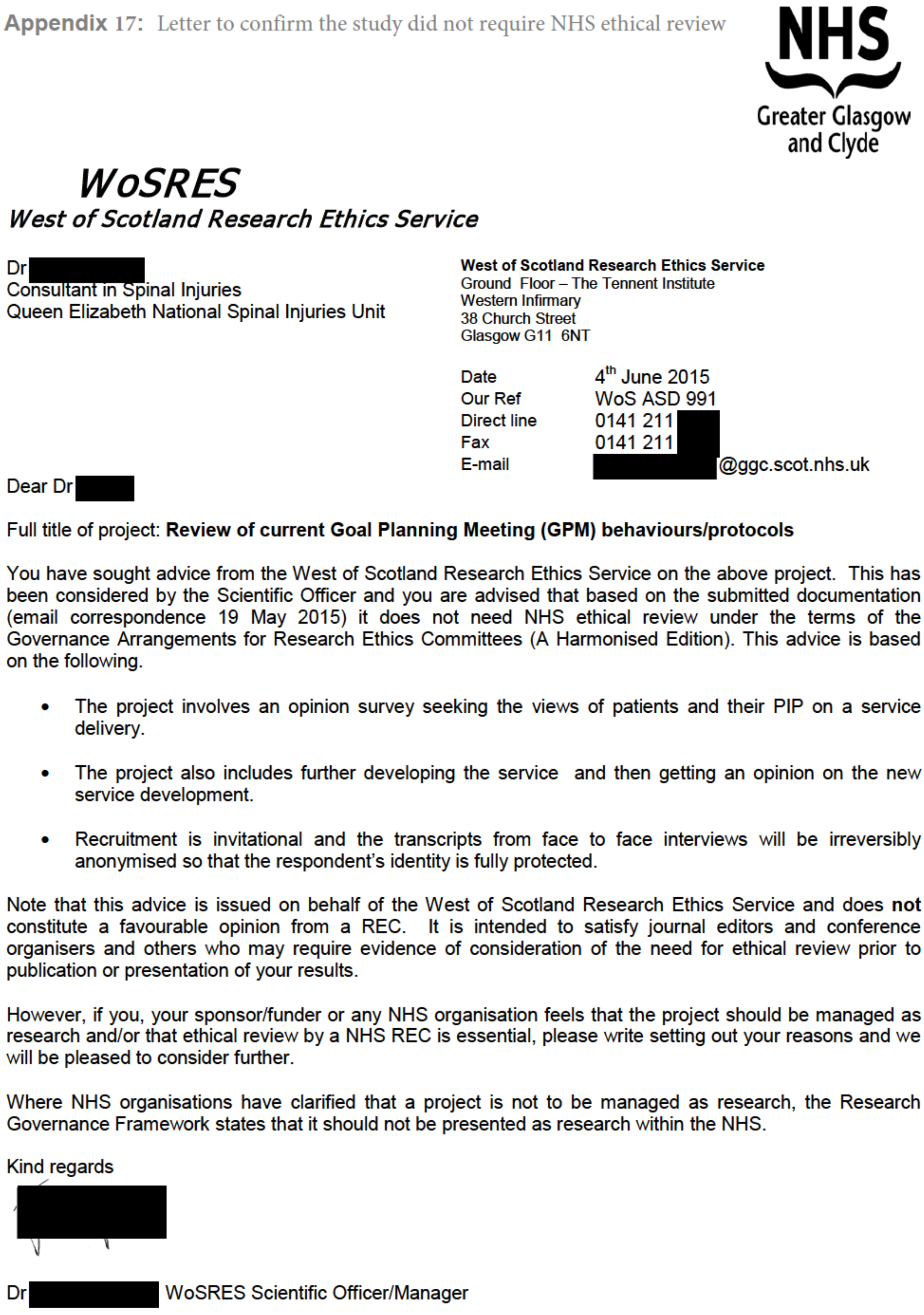
GW: Ok, good!

KWA: Or *promoted* me doing that.

Reference 10 - 1.43% Coverage

KWA: Oh, sorry, I did, yeah, before the meeting, I did talk to him briefly and basically kind of, I’d just come back from holiday, so I was touching base with him to see where we were, and to see again, how did he want the meeting to go, did he want to take more responsibility? Did he want me to do it? And it was the, it was gonna be a video teleconference, so to make sure he was comfortable with that, that he knew about it, and that his family were gonna be there, so really just kind of chatted through, and I pulled out the folder and just kind of went through with him, and said ‘Ok, your goals, your 3 goals still your goals?’ Erm, and ok, what timescale are you thinking? And he was telling me that he wants to be home by the weekend, two weeks at the very most! So that really

Appendix 17: Letter to confirm the study did not require NHS ethical review



NHS
Greater Glasgow and Clyde

WoSRES
West of Scotland Research Ethics Service

Dr [redacted]
Consultant in Spinal Injuries
Queen Elizabeth National Spinal Injuries Unit

West of Scotland Research Ethics Service
Ground Floor – The Tennent Institute
Western Infirmary
38 Church Street
Glasgow G11 6NT

Date	4th June 2015
Our Ref	WoS ASD 991
Direct line	0141 211 [redacted]
Fax	0141 211 [redacted]
E-mail	[redacted]@ggc.scot.nhs.uk

Dear Dr [redacted]

Full title of project: **Review of current Goal Planning Meeting (GPM) behaviours/protocols**

You have sought advice from the West of Scotland Research Ethics Service on the above project. This has been considered by the Scientific Officer and you are advised that based on the submitted documentation (email correspondence 19 May 2015) it does not need NHS ethical review under the terms of the Governance Arrangements for Research Ethics Committees (A Harmonised Edition). This advice is based on the following.

- The project involves an opinion survey seeking the views of patients and their PIP on a service delivery.
- The project also includes further developing the service and then getting an opinion on the new service development.
- Recruitment is invitational and the transcripts from face to face interviews will be irreversibly anonymised so that the respondent's identity is fully protected.

Note that this advice is issued on behalf of the West of Scotland Research Ethics Service and does **not** constitute a favourable opinion from a REC. It is intended to satisfy journal editors and conference organisers and others who may require evidence of consideration of the need for ethical review prior to publication or presentation of your results.

However, if you, your sponsor/funder or any NHS organisation feels that the project should be managed as research and/or that ethical review by a NHS REC is essential, please write setting out your reasons and we will be pleased to consider further.

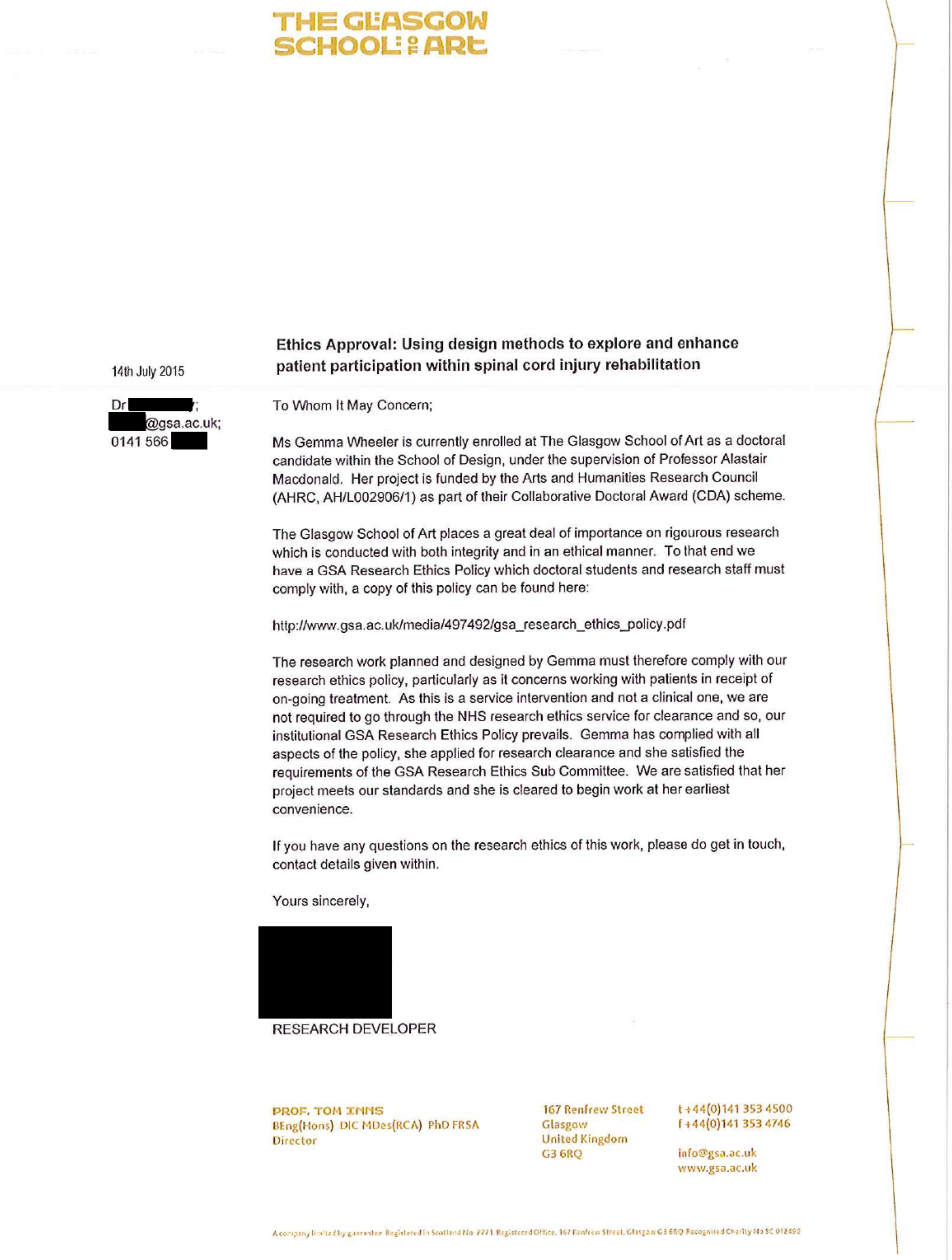
Where NHS organisations have clarified that a project is not to be managed as research, the Research Governance Framework states that it should not be presented as research within the NHS.

Kind regards

[redacted]

Dr [redacted] WoSRES Scientific Officer/Manager

Appendix 18: Letter to confirm the study complied with University ethical review



THE GLASGOW
SCHOOL OF ART

14th July 2015

Ethics Approval: Using design methods to explore and enhance patient participation within spinal cord injury rehabilitation

Dr [redacted];
[redacted]@gsa.ac.uk;
0141 566 [redacted]

To Whom It May Concern;

Ms Gemma Wheeler is currently enrolled at The Glasgow School of Art as a doctoral candidate within the School of Design, under the supervision of Professor Alastair Macdonald. Her project is funded by the Arts and Humanities Research Council (AHRC, AH/L002906/1) as part of their Collaborative Doctoral Award (CDA) scheme.

The Glasgow School of Art places a great deal of importance on rigourous research which is conducted with both integrity and in an ethical manner. To that end we have a GSA Research Ethics Policy which doctoral students and research staff must comply with, a copy of this policy can be found here:

http://www.gsa.ac.uk/media/497492/gsa_research_ethics_policy.pdf

The research work planned and designed by Gemma must therefore comply with our research ethics policy, particularly as it concerns working with patients in receipt of on-going treatment. As this is a service intervention and not a clinical one, we are not required to go through the NHS research ethics service for clearance and so, our institutional GSA Research Ethics Policy prevails. Gemma has complied with all aspects of the policy, she applied for research clearance and she satisfied the requirements of the GSA Research Ethics Sub Committee. We are satisfied that her project meets our standards and she is cleared to begin work at her earliest convenience.

If you have any questions on the research ethics of this work, please do get in touch, contact details given within.

Yours sincerely,

[redacted]

RESEARCH DEVELOPER

PROF. TOM INNS
BEng(Hons) DIC MDes(RCA) PhD FRSA
Director

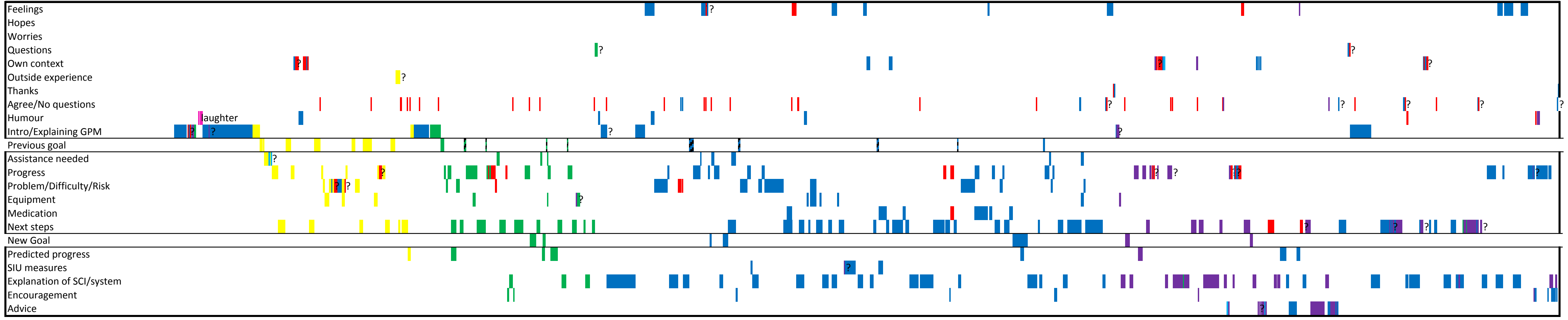
167 Renfrew Street
Glasgow
United Kingdom
G3 6RQ

t +44(0)141 353 4500
f +44(0)141 353 4746

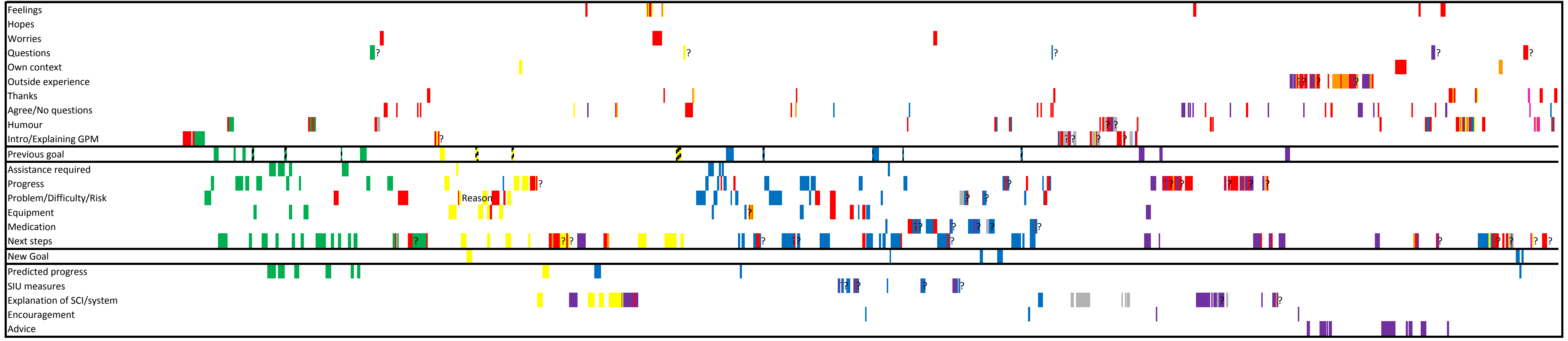
info@gsa.ac.uk
www.gsa.ac.uk

Appendix 19: Goal Planning Meeting Conversation Maps. Made using audio from 3 Phase One GPMs

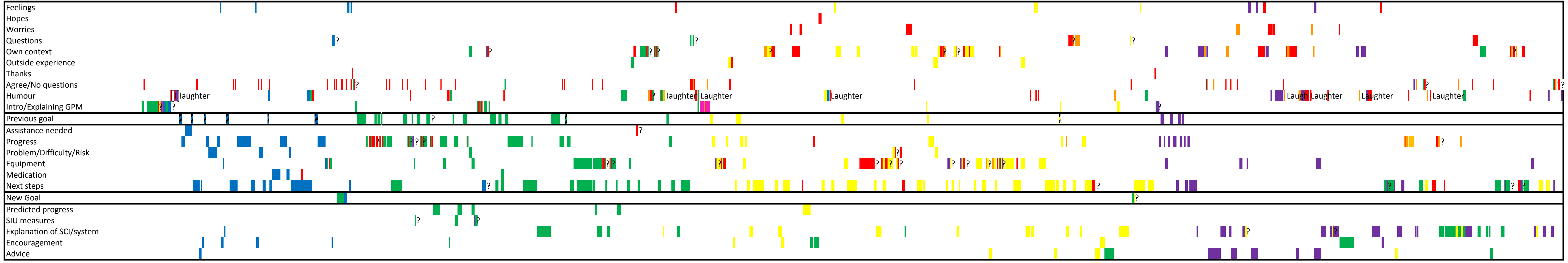
First Goal Planning Meeting



Middle Goal Planning Meeting

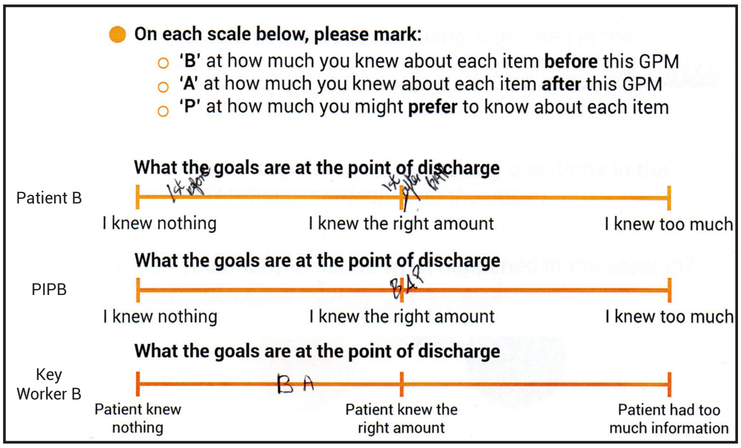


Final Goal Planning Meeting (Discharge Case Conference)



Key	
Patient	🟥
PIP	🟧
Consultant	⬛
Nurse	🟦
Physiotherapist	🟩
Occupational Therapist	🟨
Discharge Coordinator	🟪
Discharge Liaison	▨
Social Worker	🟫
Researcher	▩

Appendix 20
Phase One Visual Data Comparisons
Case: GPMB

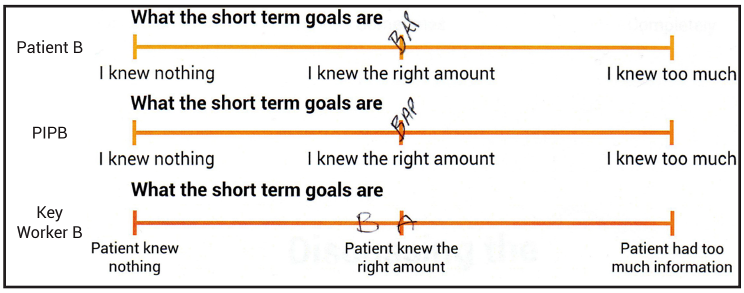


- On each scale below, please mark:
  - 'B' at how much you knew about each item **before** this GPM
  - 'A' at how much you knew about each item **after** this GPM
  - 'P' at how much you might **prefer** to know about each item

Patient B
What the goals are at the point of discharge
1st before
1st after
BAP
I knew nothing | I knew the right amount | I knew too much

PIPB
What the goals are at the point of discharge
BAP
I knew nothing | I knew the right amount | I knew too much

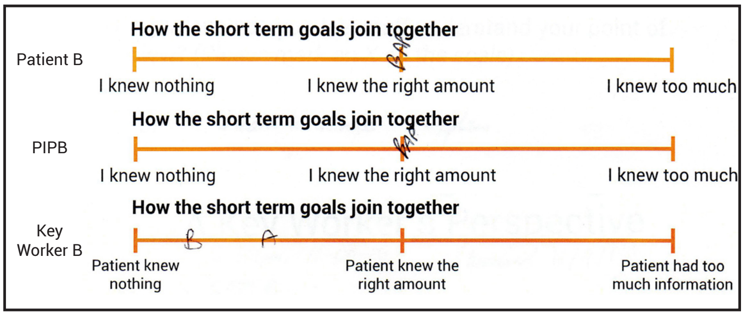
Key Worker B
What the goals are at the point of discharge
B A
Patient knew nothing | Patient knew the right amount | Patient had too much information



Patient B
What the short term goals are
BAP
I knew nothing | I knew the right amount | I knew too much

PIPB
What the short term goals are
BAP
I knew nothing | I knew the right amount | I knew too much

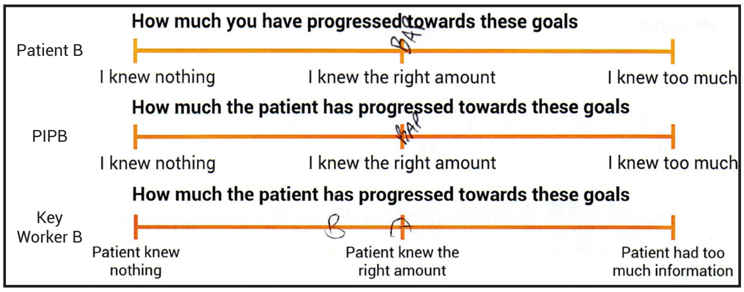
Key Worker B
What the short term goals are
B A
Patient knew nothing | Patient knew the right amount | Patient had too much information



Patient B
How the short term goals join together
BAP
I knew nothing | I knew the right amount | I knew too much

PIPB
How the short term goals join together
BAP
I knew nothing | I knew the right amount | I knew too much

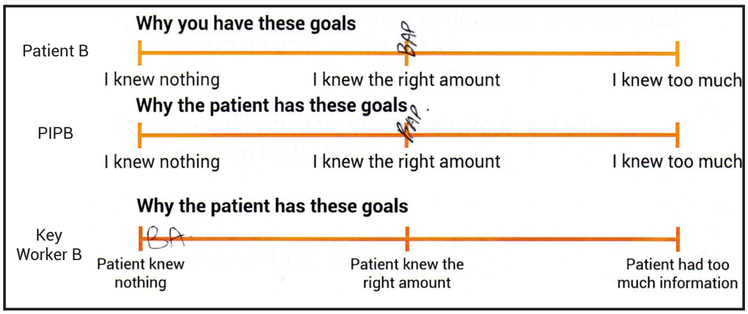
Key Worker B
How the short term goals join together
B A
Patient knew nothing | Patient knew the right amount | Patient had too much information



Patient B
How much you have progressed towards these goals
BAP
I knew nothing | I knew the right amount | I knew too much

PIPB
How much the patient has progressed towards these goals
BAP
I knew nothing | I knew the right amount | I knew too much

Key Worker B
How much the patient has progressed towards these goals
B A
Patient knew nothing | Patient knew the right amount | Patient had too much information



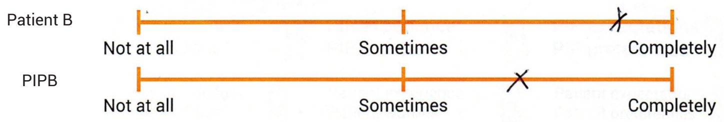
Patient B
Why you have these goals
BAP
I knew nothing | I knew the right amount | I knew too much

PIPB
Why the patient has these goals
BAP
I knew nothing | I knew the right amount | I knew too much

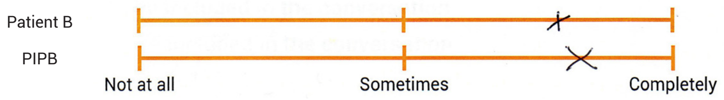
Key Worker B
Why the patient has these goals
BA
Patient knew nothing | Patient knew the right amount | Patient had too much information

Appendix 20
Phase One Visual Data Comparisons
Case: GPMB
Continued

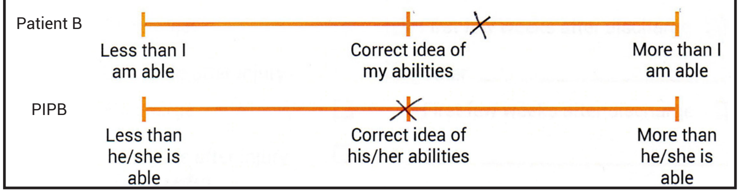
- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)



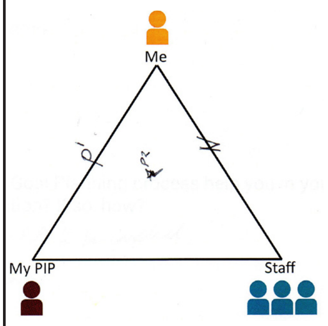
- How much do you feel staff understand your point of view? (*Please mark an X on the scale*)



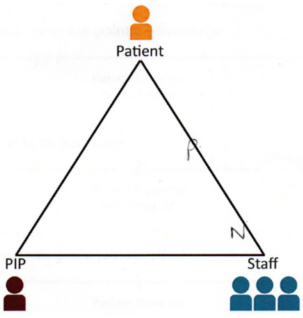
- How much do you feel staff understand your abilities? (*Please mark an X on the scale*)



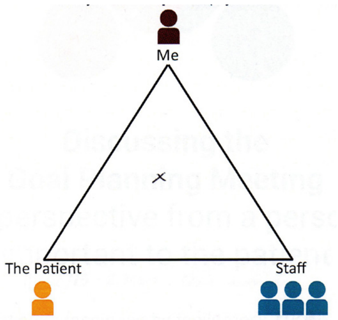
- On the diagram below, please mark:
  - ‘**N**’ where you think the decision-making happens **now**
  - ‘**P**’ where you would **prefer** (if you would change this)



Patient B



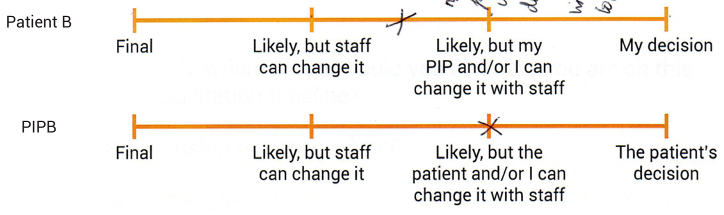
Key Worker B



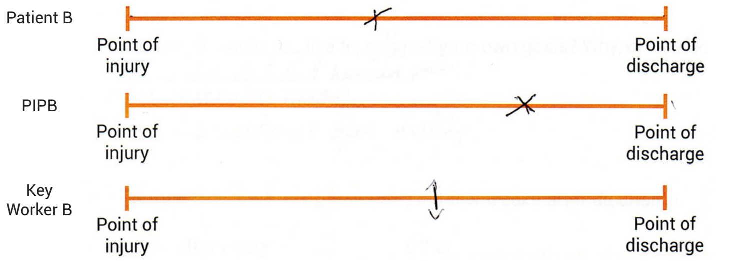
PIPB

- When a decision is made, do you consider it to be: (*Please mark an X on the scale*)

nothing final until done - timescale to change

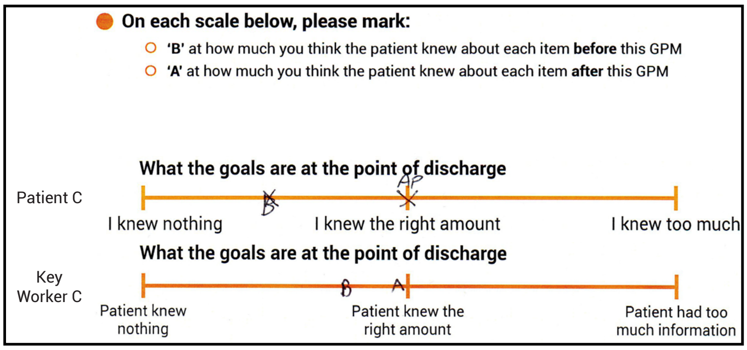


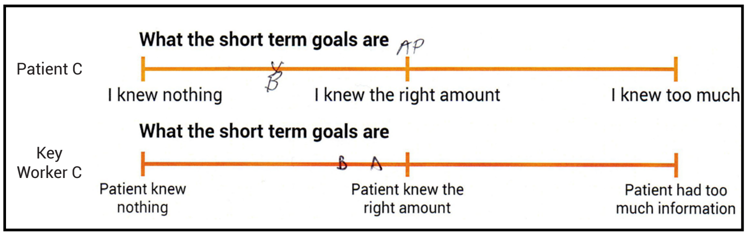
- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

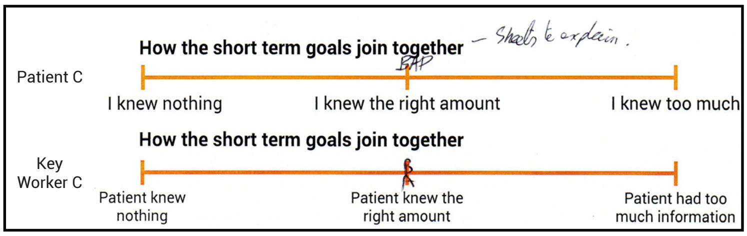


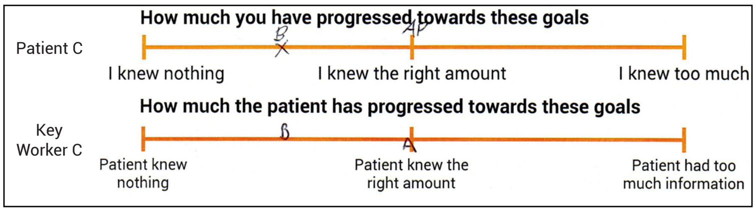
Appendix 20

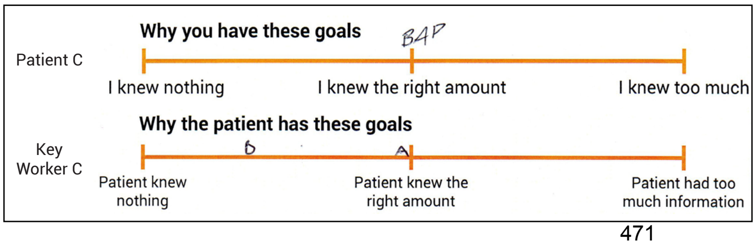
Phase One Visual Data Comparisons Case: GPMC











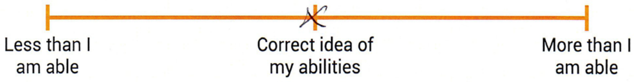
Appendix 20
Phase One Visual Data Comparisons Case: GPMC
Continued

Patient C

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

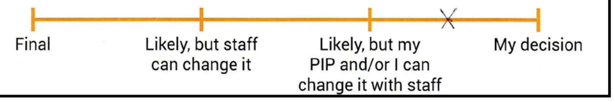
- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*

- How much do you feel staff understand your abilities? *(Please mark an X on the scale)*

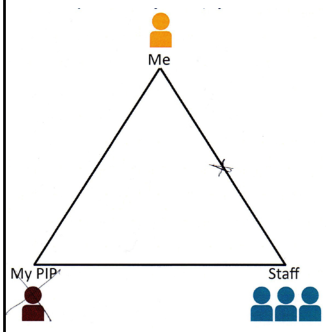


- When a decision is made, do you consider it to be: *(Please mark an X on the scale)*

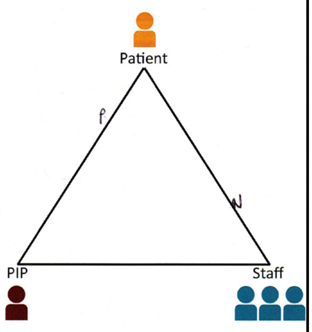
Patient C



- On the diagram below, please mark:
  - '**N**' where you think the decision-making happens **now**
  - '**P**' where you would **prefer** (if you would change this)



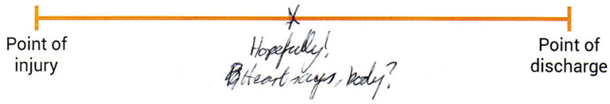
Patient C



Key Worker C

- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

Patient C



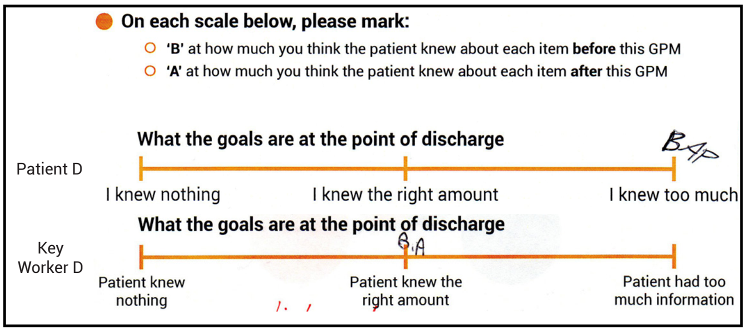
Hopefully!
~~B~~ Heart says, body?

Key Worker C

Appendix 20

Phase One Visual Data Comparisons

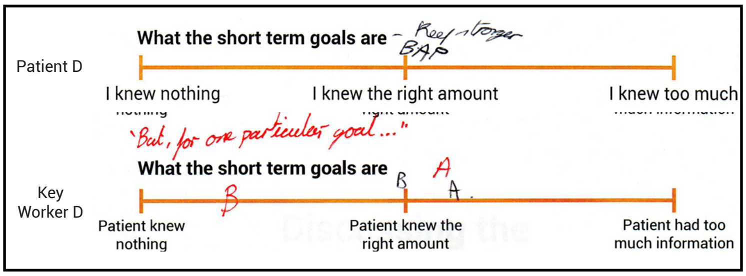
Case: GPMD



On each scale below, please mark:
- **'B'** at how much you think the patient knew about each item **before** this GPM
- **'A'** at how much you think the patient knew about each item **after** this GPM

Patient D
What the goals are at the point of discharge BAP
I knew nothing — I knew the right amount — I knew too much

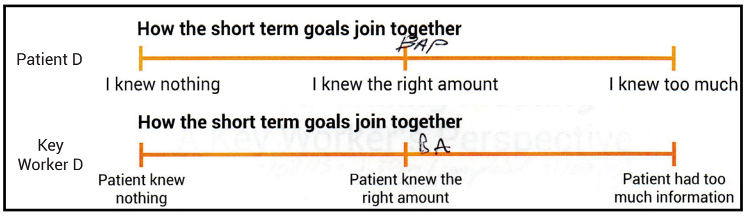
Key Worker D
What the goals are at the point of discharge B A
Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient D
What the short term goals are – Keep stronger
BAP
I knew nothing — I knew the right amount — I knew too much

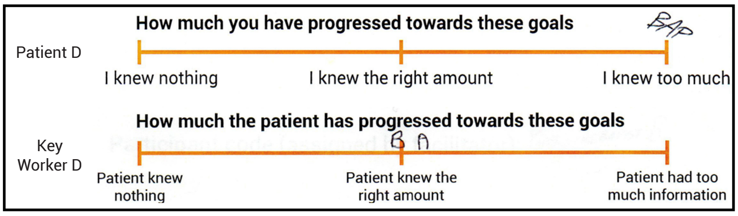
'But, for one particular goal...'

Key Worker D
What the short term goals are B A B A.
Patient knew nothing — Patient knew the right amount — Patient had too much information



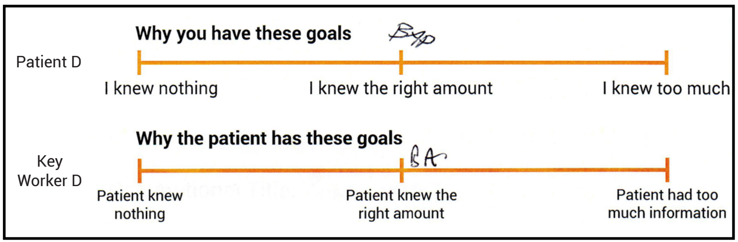
Patient D
How the short term goals join together BAP
I knew nothing — I knew the right amount — I knew too much

Key Worker D
How the short term goals join together B A
Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient D
How much you have progressed towards these goals BAP
I knew nothing — I knew the right amount — I knew too much

Key Worker D
How much the patient has progressed towards these goals B A
Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient D
Why you have these goals BAP
I knew nothing — I knew the right amount — I knew too much

Key Worker D
Why the patient has these goals B A
Patient knew nothing — Patient knew the right amount — Patient had too much information

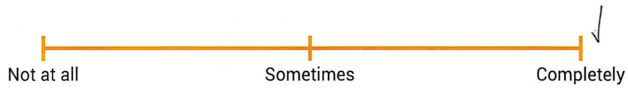
Appendix 20

Phase One Visual Data Comparisons Case: GPMD *Continued*

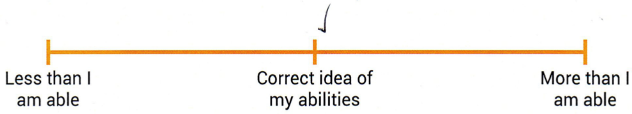
Patient D

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

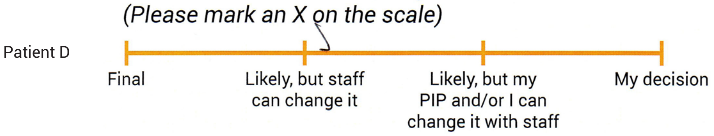
- How much do you feel staff understand your point of view? (*Please mark an X on the scale)*



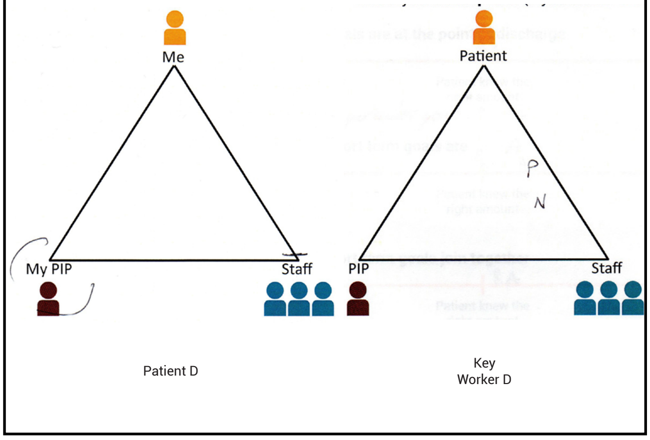
- How much do you feel staff understand your abilities? *(Please mark an X on the scale)*



- When a decision is made, do you consider it to be: *(Please mark an X on the scale)*

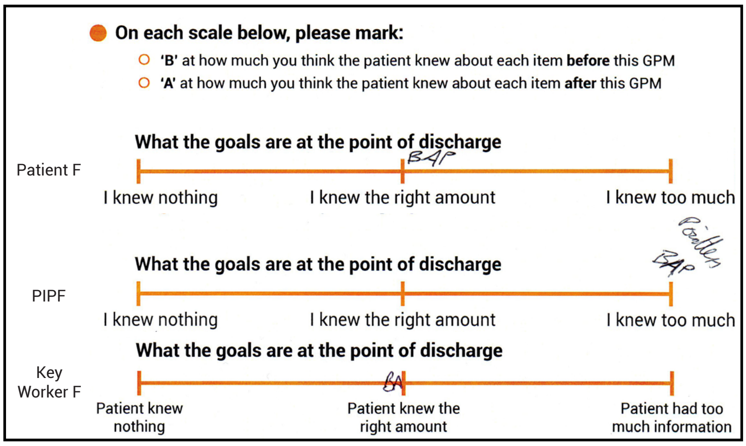


- On the diagram below, please mark:
  - **'N'** where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)



- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

Appendix 20
Phase One Visual
Data Comparisons
Case: GPMF



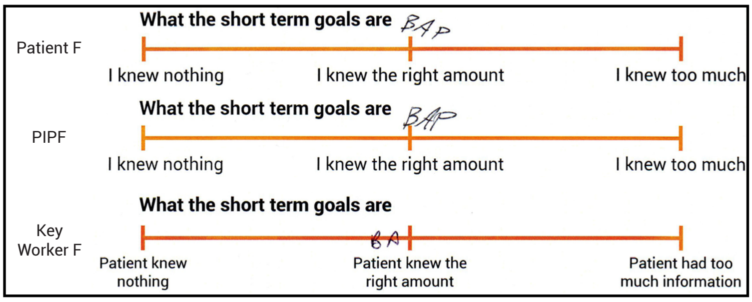
● **On each scale below, please mark:**
- ○ **'B'** at how much you think the patient knew about each item **before** this GPM
- ○ **'A'** at how much you think the patient knew about each item **after** this GPM

Patient F
What the goals are at the point of discharge

Pointless
BAP

PIPF
What the goals are at the point of discharge

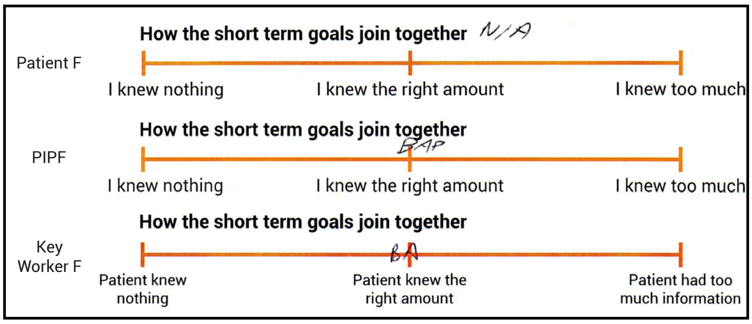
Key Worker F
What the goals are at the point of discharge



Patient F
What the short term goals are BAP

PIPF
What the short term goals are BAP

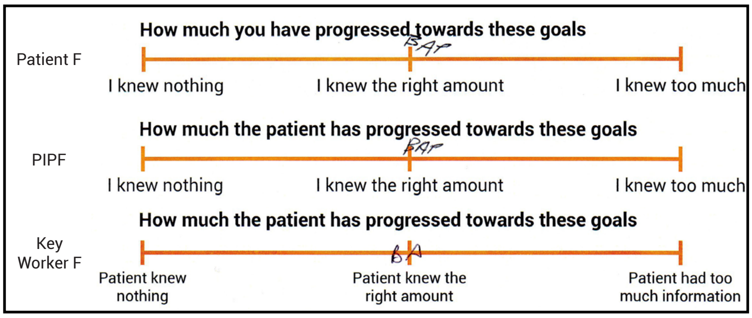
Key Worker F
What the short term goals are



Patient F
How the short term goals join together N/A

PIPF
How the short term goals join together

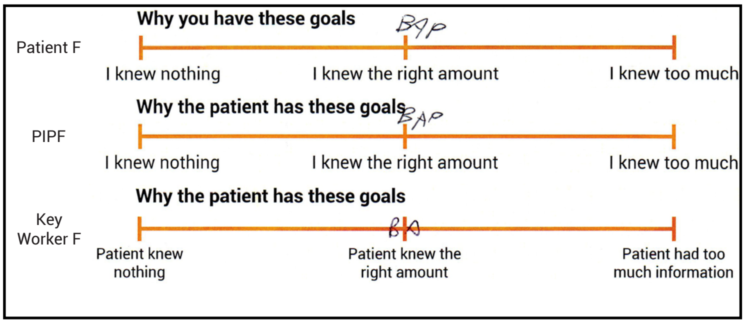
Key Worker F
How the short term goals join together



Patient F
How much you have progressed towards these goals

PIPF
How much the patient has progressed towards these goals

Key Worker F
How much the patient has progressed towards these goals

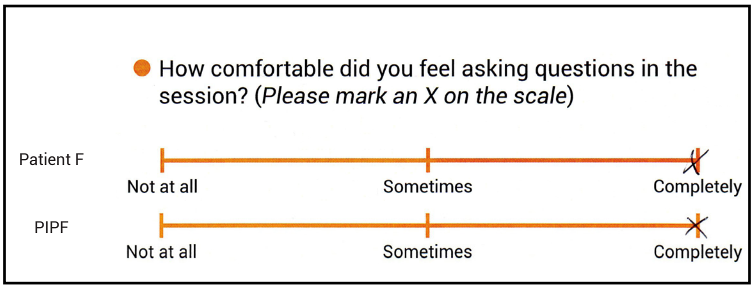


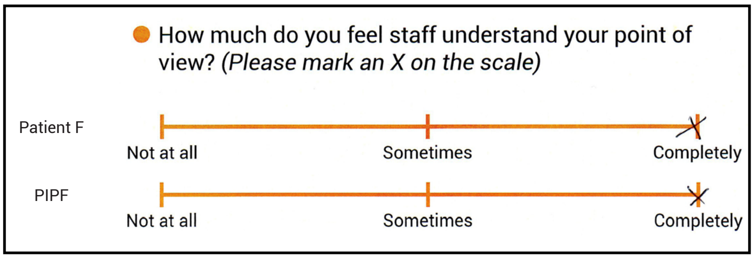
Patient F
Why you have these goals BAP

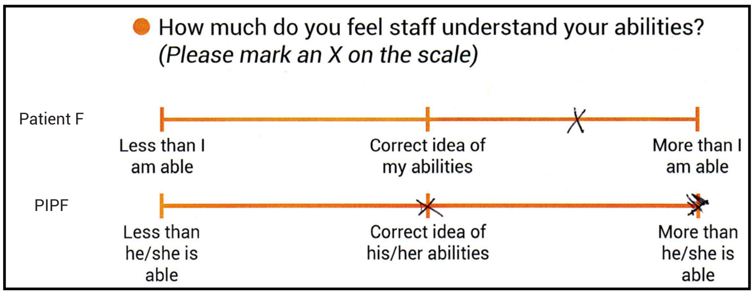
PIPF
Why the patient has these goals BAP

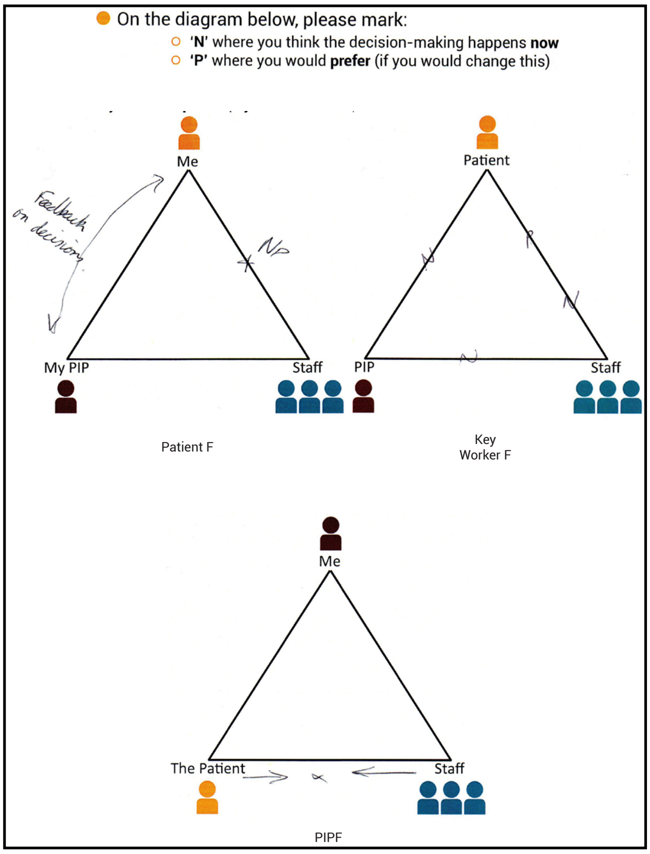
Key Worker F
Why the patient has these goals

Appendix 20
Phase One Visual
Data Comparisons
Case: GPMF
Continued

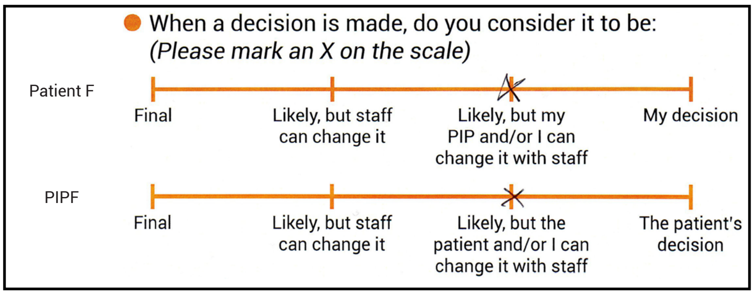

How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

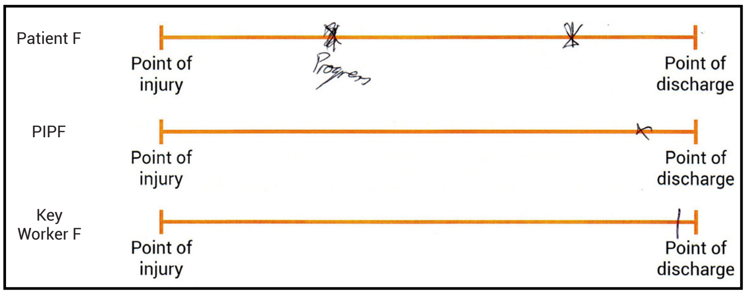

How much do you feel staff understand your point of view? (*Please mark an X on the scale)*


How much do you feel staff understand your abilities? *(Please mark an X on the scale)*


On the diagram below, please mark:

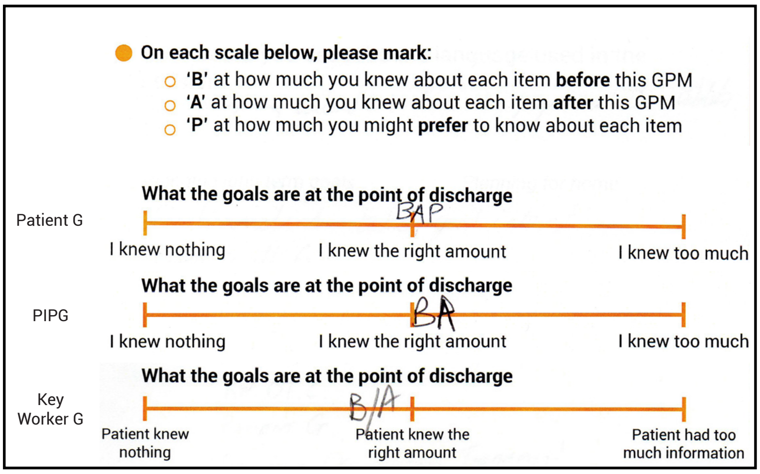
- **'N'** where you think the decision-making happens **now**
- **'P'** where you would **prefer** (if you would change this)


When a decision is made, do you consider it to be: *(Please mark an X on the scale)*



Appendix 20

Phase One Visual Data Comparisons
Case: GPMG

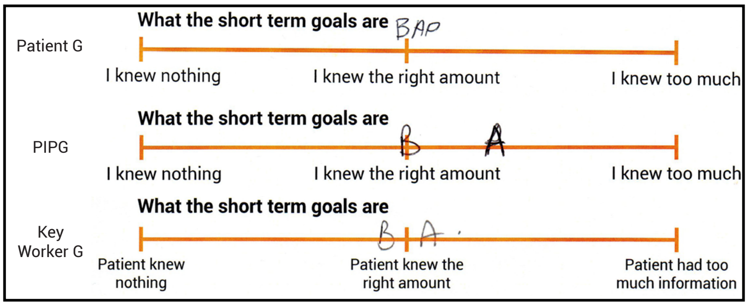


- On each scale below, please mark:
  - ‘**B**’ at how much you knew about each item **before** this GPM
  - ‘**A**’ at how much you knew about each item **after** this GPM
  - ‘**P**’ at how much you might **prefer** to know about each item

Patient G
What the goals are at the point of discharge
BAP
I knew nothing | I knew the right amount | I knew too much

PIPG
What the goals are at the point of discharge
BA
I knew nothing | I knew the right amount | I knew too much

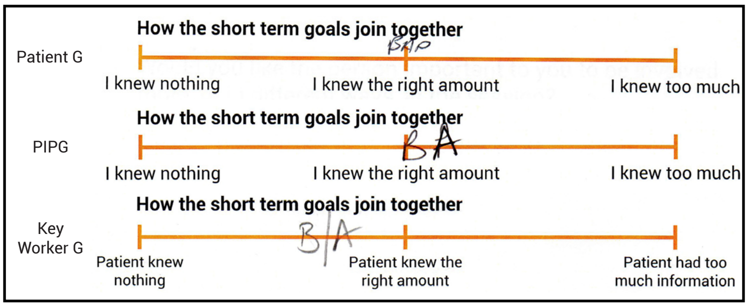
Key Worker G
What the goals are at the point of discharge
B/A
Patient knew nothing | Patient knew the right amount | Patient had too much information



Patient G
What the short term goals are
BAP
I knew nothing | I knew the right amount | I knew too much

PIPG
What the short term goals are
B A
I knew nothing | I knew the right amount | I knew too much

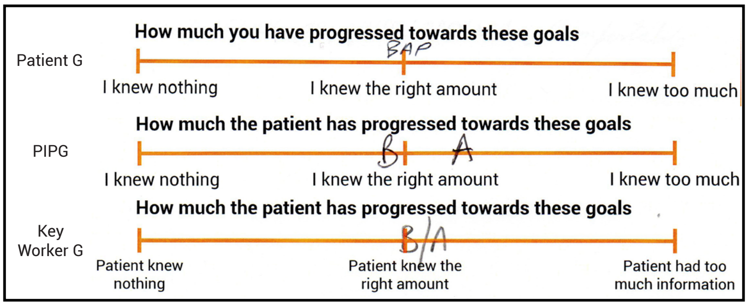
Key Worker G
What the short term goals are
B A
Patient knew nothing | Patient knew the right amount | Patient had too much information



Patient G
How the short term goals join together
BAP
I knew nothing | I knew the right amount | I knew too much

PIPG
How the short term goals join together
BA
I knew nothing | I knew the right amount | I knew too much

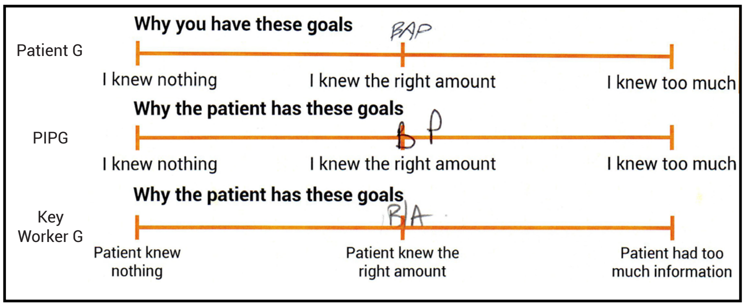
Key Worker G
How the short term goals join together
B/A
Patient knew nothing | Patient knew the right amount | Patient had too much information



Patient G
How much you have progressed towards these goals
BAP
I knew nothing | I knew the right amount | I knew too much

PIPG
How much the patient has progressed towards these goals
B A
I knew nothing | I knew the right amount | I knew too much

Key Worker G
How much the patient has progressed towards these goals
B/A
Patient knew nothing | Patient knew the right amount | Patient had too much information



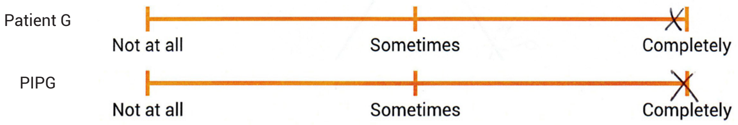
Patient G
Why you have these goals
BAP
I knew nothing | I knew the right amount | I knew too much

PIPG
Why the patient has these goals
B P
I knew nothing | I knew the right amount | I knew too much

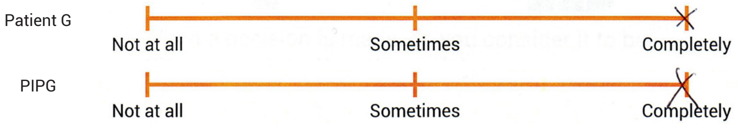
Key Worker G
Why the patient has these goals
B/A
Patient knew nothing | Patient knew the right amount | Patient had too much information

Appendix 20
Phase One Visual Data Comparisons
Case: GPMG
Continued

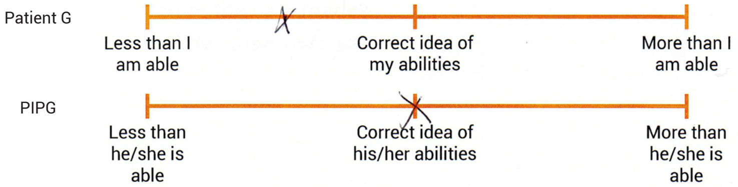
- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)



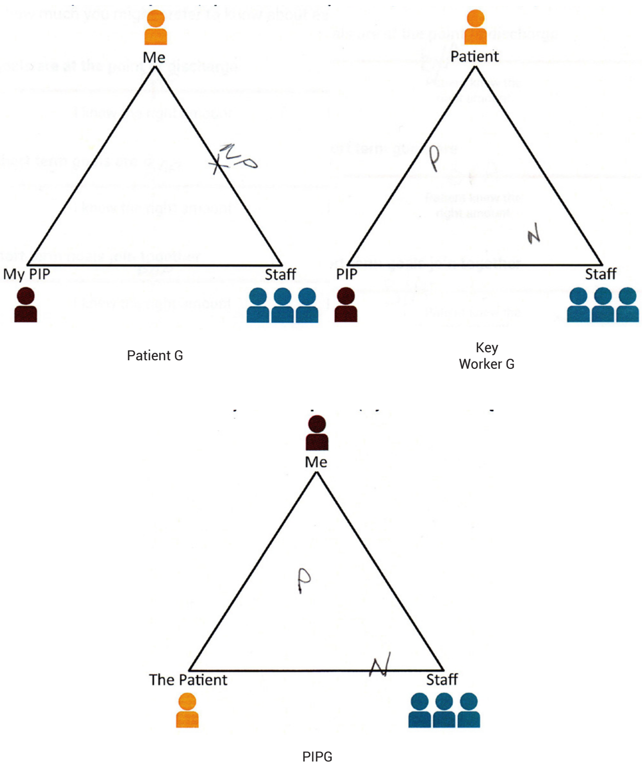
- How much do you feel staff understand your point of view? (*Please mark an X on the scale*)



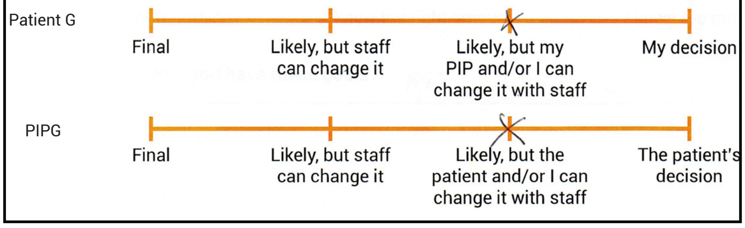
- How much do you feel staff understand your abilities? (*Please mark an X on the scale*)



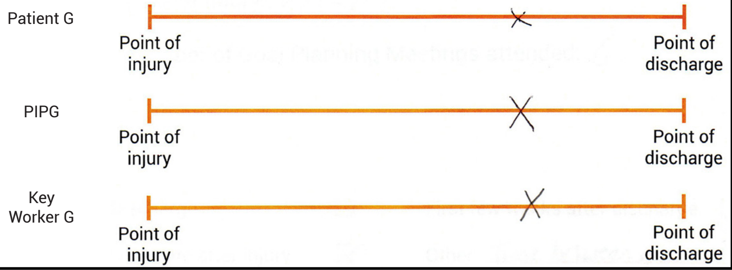
- On the diagram below, please mark:
  - ‘**N**’ where you think the decision-making happens **now**
  - ‘**P**’ where you would **prefer** (if you would change this)



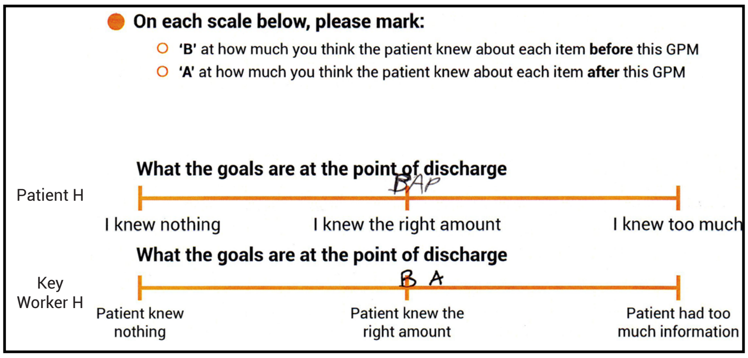
- When a decision is made, do you consider it to be: (*Please mark an X on the scale*)



- Finally, whereabouts would you estimate you are on this rehabilitation timeline?



Appendix 20
Phase One Visual Data Comparisons Case: GPMH



On each scale below, please mark:

- **'B'** at how much you think the patient knew about each item **before** this GPM
- **'A'** at how much you think the patient knew about each item **after** this GPM

What the goals are at the point of discharge

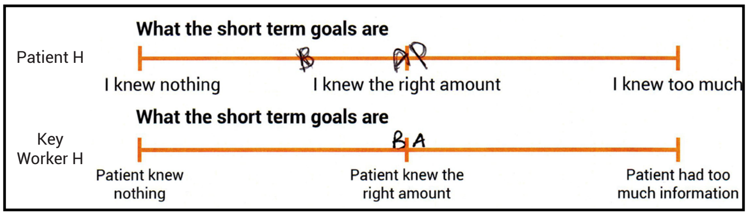
Patient H — BAP

I knew nothing | I knew the right amount | I knew too much

What the goals are at the point of discharge

Key Worker H — B A

Patient knew nothing | Patient knew the right amount | Patient had too much information



What the short term goals are

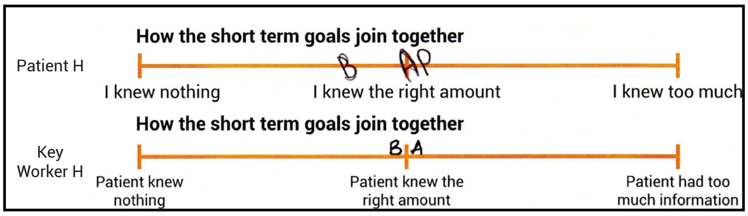
Patient H — B AP

I knew nothing | I knew the right amount | I knew too much

What the short term goals are

Key Worker H — B A

Patient knew nothing | Patient knew the right amount | Patient had too much information



How the short term goals join together

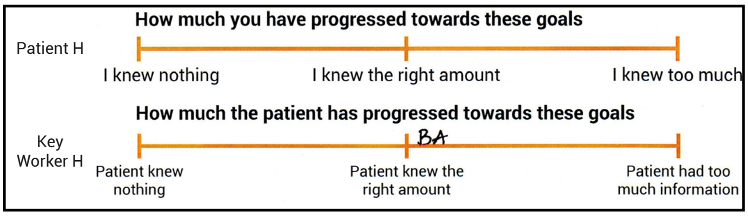
Patient H — B AP

I knew nothing | I knew the right amount | I knew too much

How the short term goals join together

Key Worker H — B A

Patient knew nothing | Patient knew the right amount | Patient had too much information



How much you have progressed towards these goals

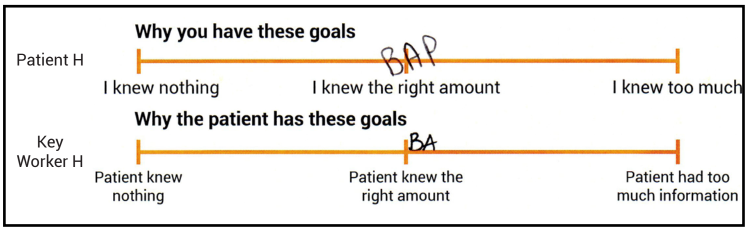
Patient H

I knew nothing | I knew the right amount | I knew too much

How much the patient has progressed towards these goals

Key Worker H — BA

Patient knew nothing | Patient knew the right amount | Patient had too much information



Why you have these goals

Patient H — BAP

I knew nothing | I knew the right amount | I knew too much

Why the patient has these goals

Key Worker H — BA

Patient knew nothing | Patient knew the right amount | Patient had too much information

Appendix 20

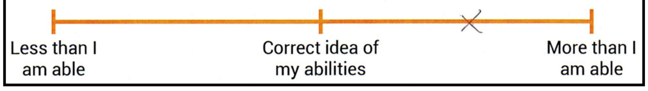
Phase One Visual Data Comparisons
Case: GPMH
Continued

Patient H

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

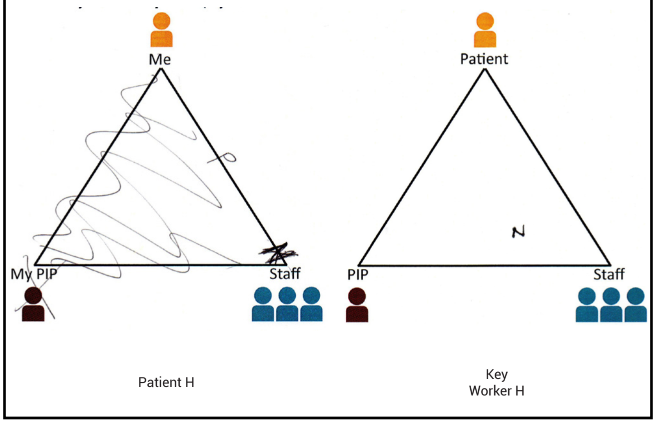
- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*

- How much do you feel staff understand your abilities? *(Please mark an X on the scale)*

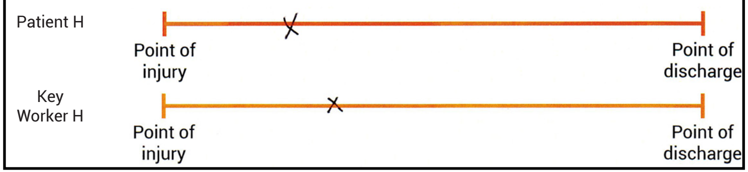


- When a decision is made, do you consider it to be: *(Please mark an X on the scale)*

- On the diagram below, please mark:
  - **'N'** where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)

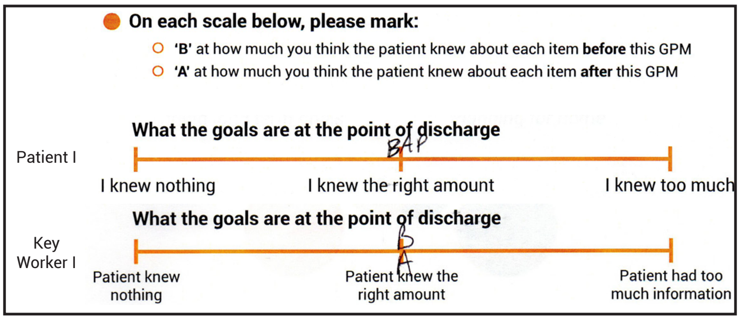


- Finally, whereabouts would you estimate you are on this rehabilitation timeline?



Appendix 20

Phase One Visual Data Comparisons
Case: GPMI



● **On each scale below, please mark:**

○ **'B'** at how much you think the patient knew about each item **before** this GPM
○ **'A'** at how much you think the patient knew about each item **after** this GPM

Patient I

What the goals are at the point of discharge

BAP

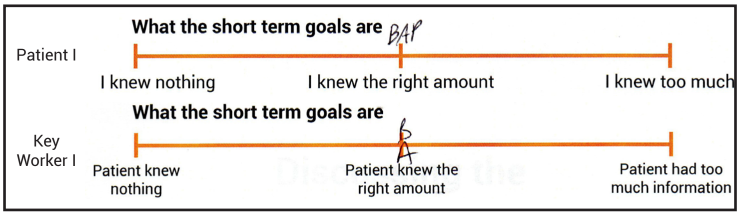
I knew nothing — I knew the right amount — I knew too much

Key Worker I

What the goals are at the point of discharge

B
A

Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient I

What the short term goals are

BAP

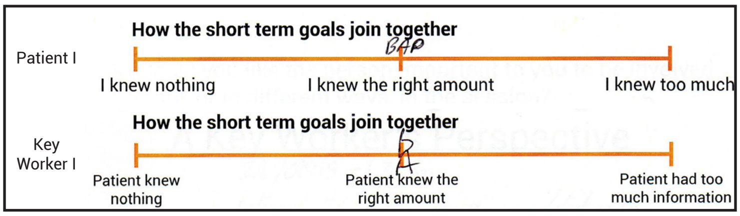
I knew nothing — I knew the right amount — I knew too much

Key Worker I

What the short term goals are

B
A

Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient I

How the short term goals join together

BAP

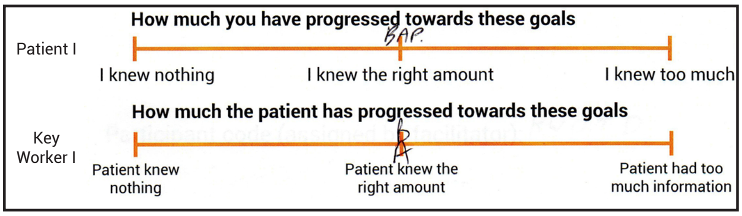
I knew nothing — I knew the right amount — I knew too much

Key Worker I

How the short term goals join together

B
A

Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient I

How much you have progressed towards these goals

BAP.

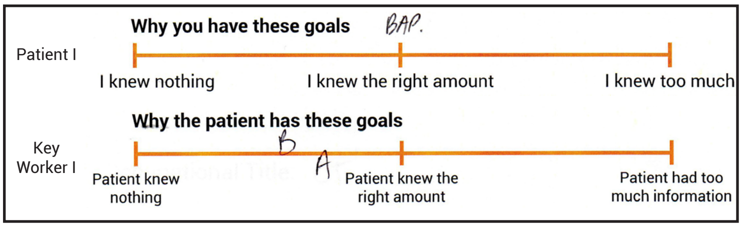
I knew nothing — I knew the right amount — I knew too much

Key Worker I

How much the patient has progressed towards these goals

B
A

Patient knew nothing — Patient knew the right amount — Patient had too much information



Patient I

Why you have these goals

BAP.

I knew nothing — I knew the right amount — I knew too much

Key Worker I

Why the patient has these goals

B
A

Patient knew nothing — Patient knew the right amount — Patient had too much information

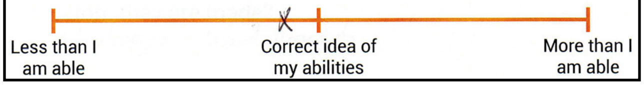
Appendix 20
Phase One Visual Data Comparisons
Case: GPMI
Continued

Patient I

- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)

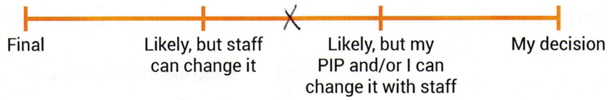
- How much do you feel staff understand your point of view? (*Please mark an X on the scale*)

- How much do you feel staff understand your abilities? (*Please mark an X on the scale*)

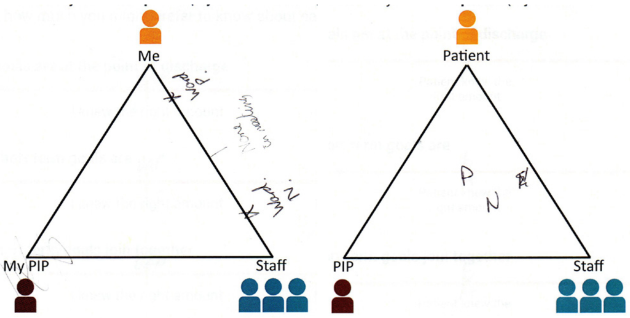


- When a decision is made, do you consider it to be: (*Please mark an X on the scale*)

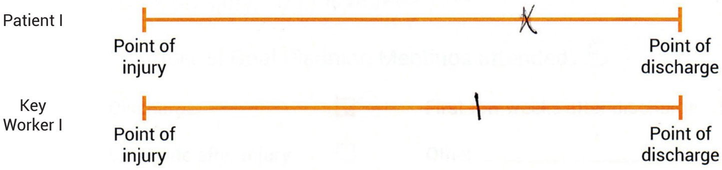
Patient I



- On the diagram below, please mark:
  - **'N'** where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)



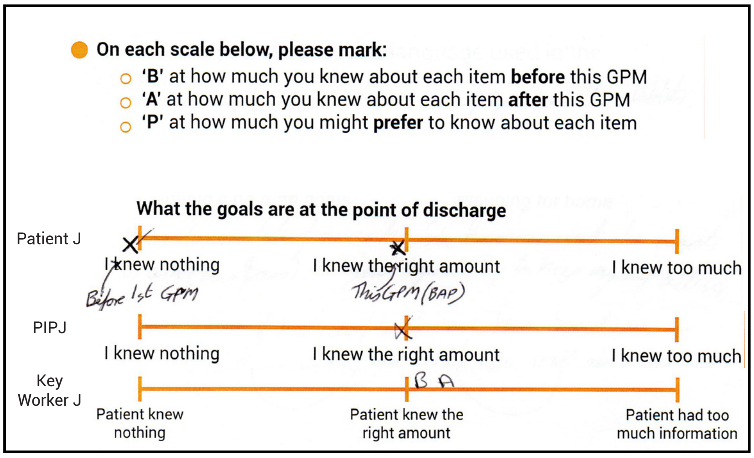
- Finally, whereabouts would you estimate you are on this rehabilitation timeline?



Appendix 20

Phase One Visual Data Comparisons

Case: GPMJ



● **On each scale below, please mark:**

- ○ **'B'** at how much you knew about each item **before** this GPM
- ○ **'A'** at how much you knew about each item **after** this GPM
- ○ **'P'** at how much you might **prefer** to know about each item

What the goals are at the point of discharge

Patient J

I knew nothing — I knew the right amount — I knew too much

Before 1st GPM — This GPM (BAP)

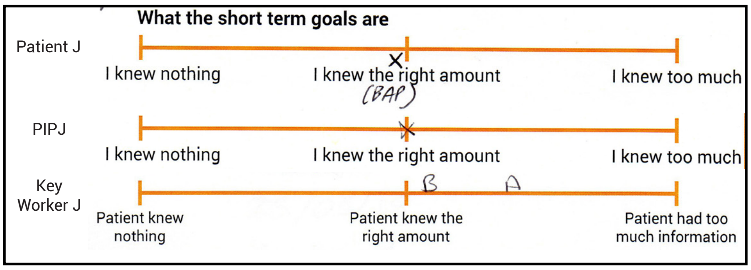
PIPJ

I knew nothing — I knew the right amount — I knew too much

Key Worker J

B A

Patient knew nothing — Patient knew the right amount — Patient had too much information



What the short term goals are

Patient J

I knew nothing — I knew the right amount — I knew too much

(BAP)

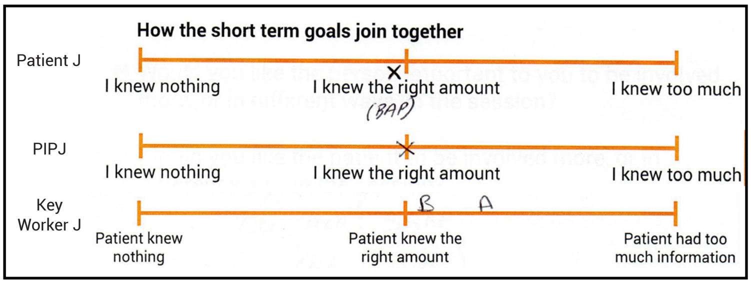
PIPJ

I knew nothing — I knew the right amount — I knew too much

Key Worker J

B A

Patient knew nothing — Patient knew the right amount — Patient had too much information



How the short term goals join together

Patient J

I knew nothing — I knew the right amount — I knew too much

(BAP)

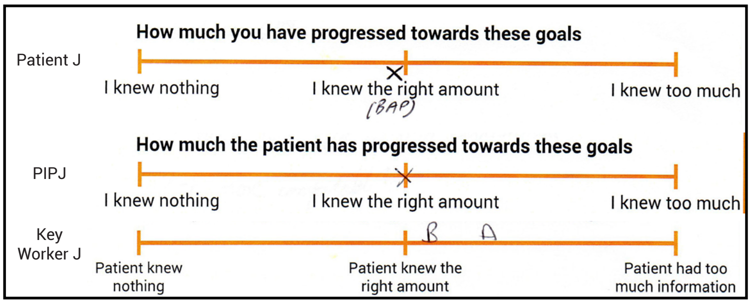
PIPJ

I knew nothing — I knew the right amount — I knew too much

Key Worker J

B A

Patient knew nothing — Patient knew the right amount — Patient had too much information



How much you have progressed towards these goals

Patient J

I knew nothing — I knew the right amount — I knew too much

(BAP)

How much the patient has progressed towards these goals

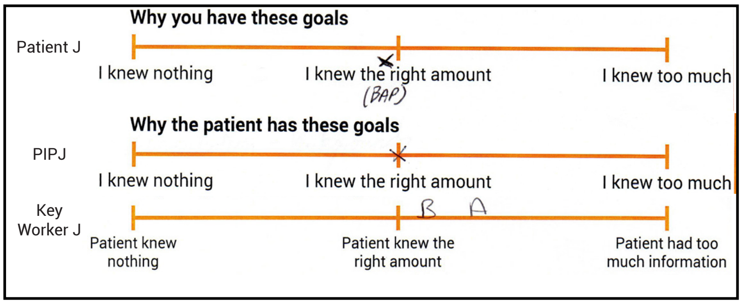
PIPJ

I knew nothing — I knew the right amount — I knew too much

Key Worker J

B A

Patient knew nothing — Patient knew the right amount — Patient had too much information



Why you have these goals

Patient J

I knew nothing — I knew the right amount — I knew too much

(BAP)

Why the patient has these goals

PIPJ

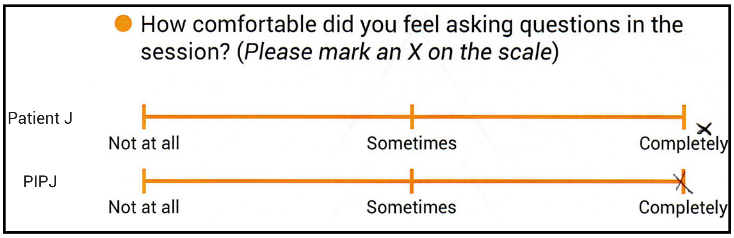
I knew nothing — I knew the right amount — I knew too much

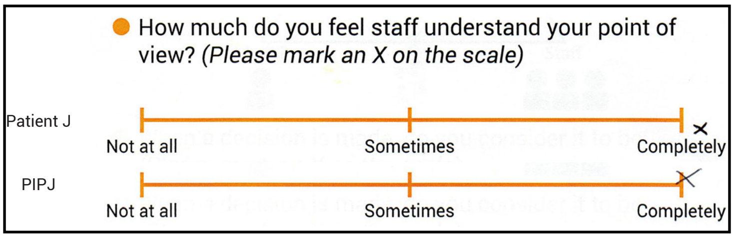
Key Worker J

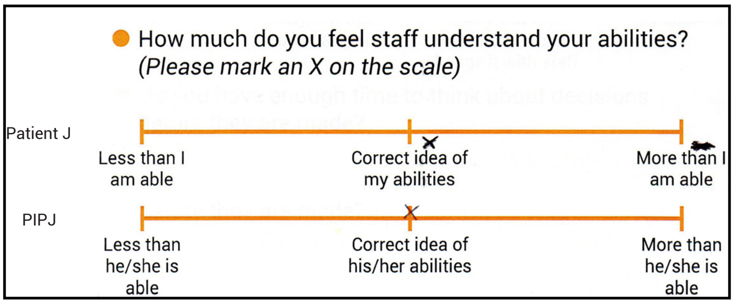
B A

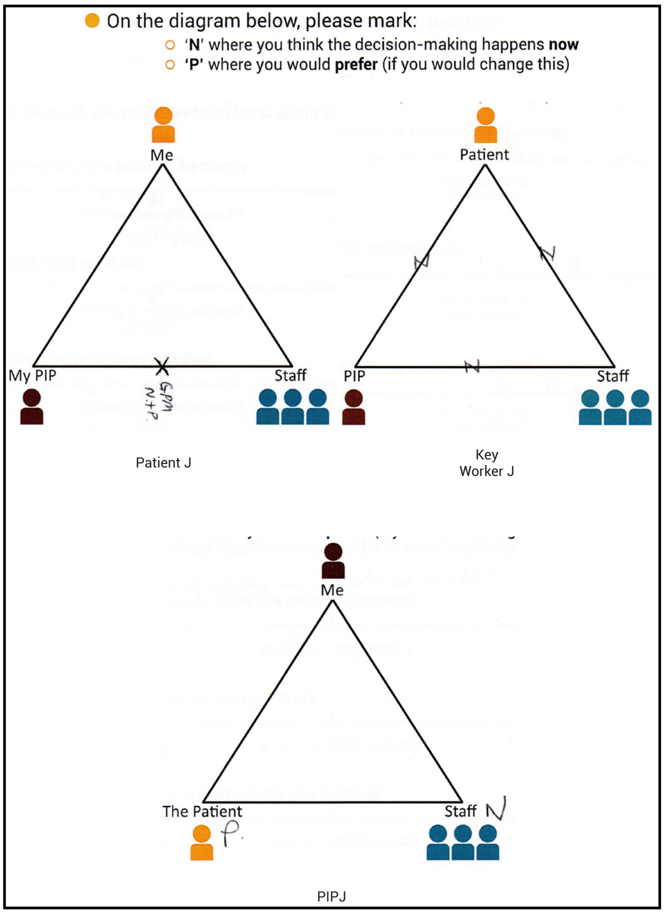
Patient knew nothing — Patient knew the right amount — Patient had too much information

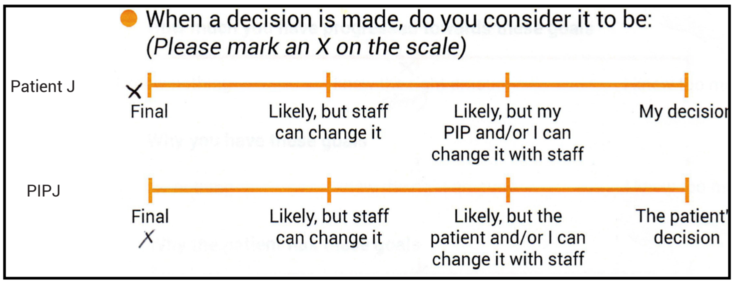
Appendix 20
Phase One Visual Data Comparisons
Case: GPMJ
Continued

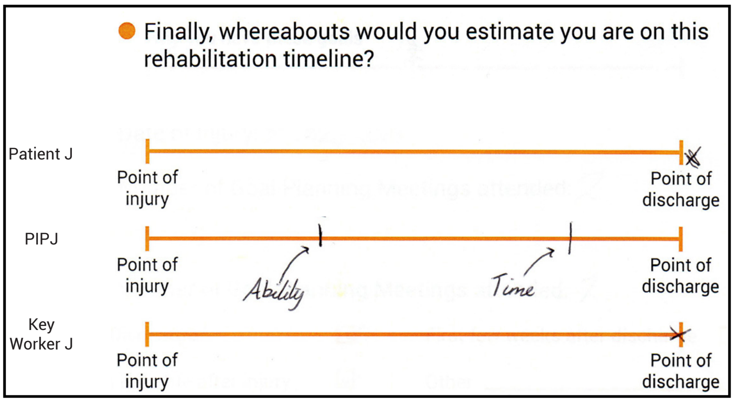

- How comfortable did you feel asking questions in the session? *(Please mark an X on the scale)*


- How much do you feel staff understand your point of view? *(Please mark an X on the scale)*


- How much do you feel staff understand your abilities? *(Please mark an X on the scale)*

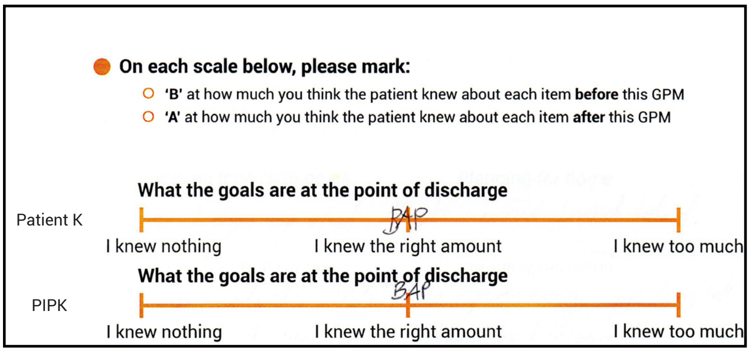

- On the diagram below, please mark:
  - 'N' where you think the decision-making happens **now**
  - 'P' where you would **prefer** (if you would change this)


- When a decision is made, do you consider it to be: *(Please mark an X on the scale)*


- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

Appendix 20

Phase One Visual Data Comparisons Case: GPMK



- On each scale below, please mark:
  - ‘B’ at how much you think the patient knew about each item **before** this GPM
  - ‘A’ at how much you think the patient knew about each item **after** this GPM

What the goals are at the point of discharge

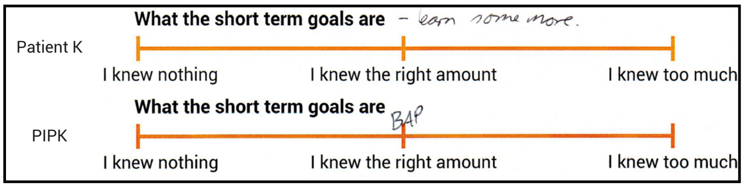
Patient K BAP

I knew nothing I knew the right amount I knew too much

What the goals are at the point of discharge

PIPK BAP

I knew nothing I knew the right amount I knew too much



What the short term goals are – learn some more.

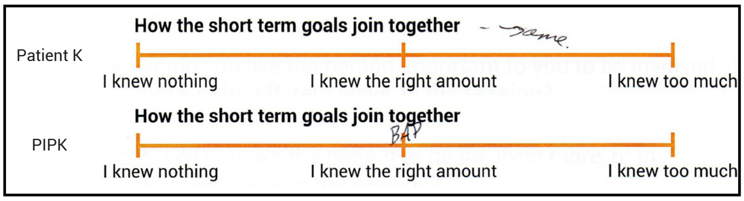
Patient K

I knew nothing I knew the right amount I knew too much

What the short term goals are

PIPK BAP

I knew nothing I knew the right amount I knew too much



How the short term goals join together – same.

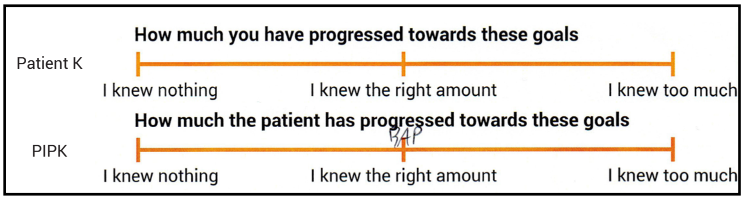
Patient K

I knew nothing I knew the right amount I knew too much

How the short term goals join together

PIPK BAP

I knew nothing I knew the right amount I knew too much



How much you have progressed towards these goals

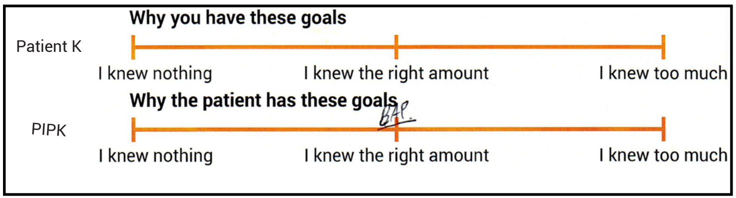
Patient K

I knew nothing I knew the right amount I knew too much

How much the patient has progressed towards these goals

PIPK BAP

I knew nothing I knew the right amount I knew too much



Why you have these goals

Patient K

I knew nothing I knew the right amount I knew too much

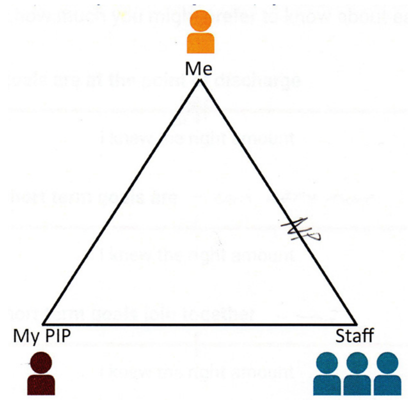
Why the patient has these goals

PIPK BAP

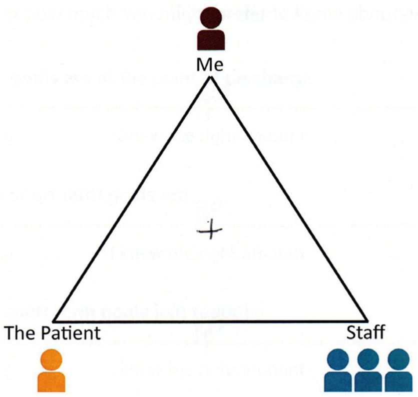
I knew nothing I knew the right amount I knew too much

Appendix 20
Phase One Visual Data Comparisons
Case: GPMK
Continued

- On the diagram below, please mark:
  - **'N'** where you think the decision-making happens **now**
  - **'P'** where you would **prefer** (if you would change this)

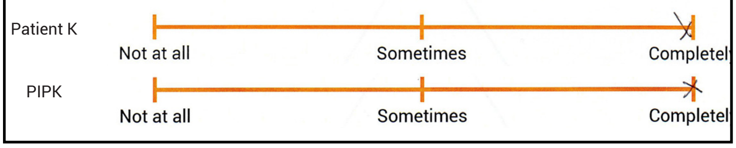


Patient K

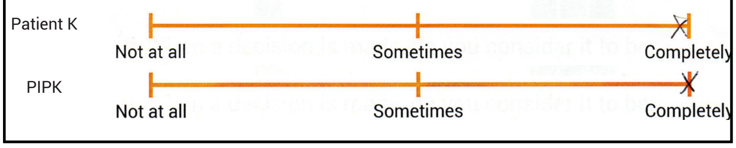


PIPK

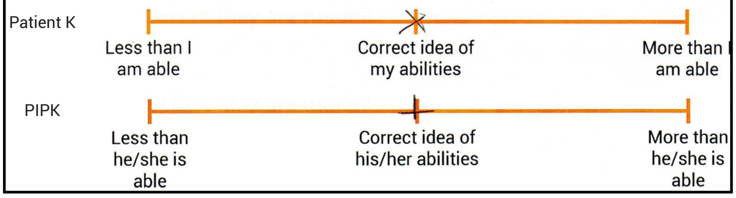
- How comfortable did you feel asking questions in the session? (*Please mark an X on the scale*)



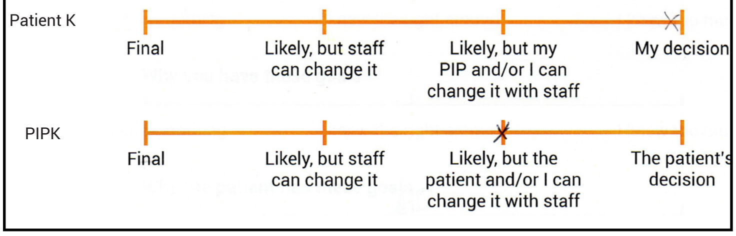
- How much do you feel staff understand your point of view? (*Please mark an X on the scale*)



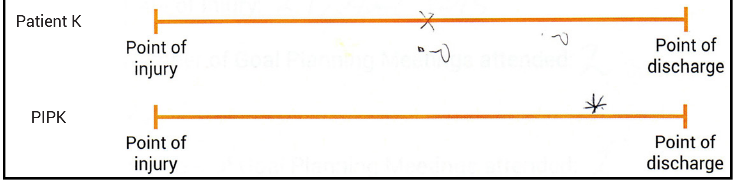
- How much do you feel staff understand your abilities? (*Please mark an X on the scale*)



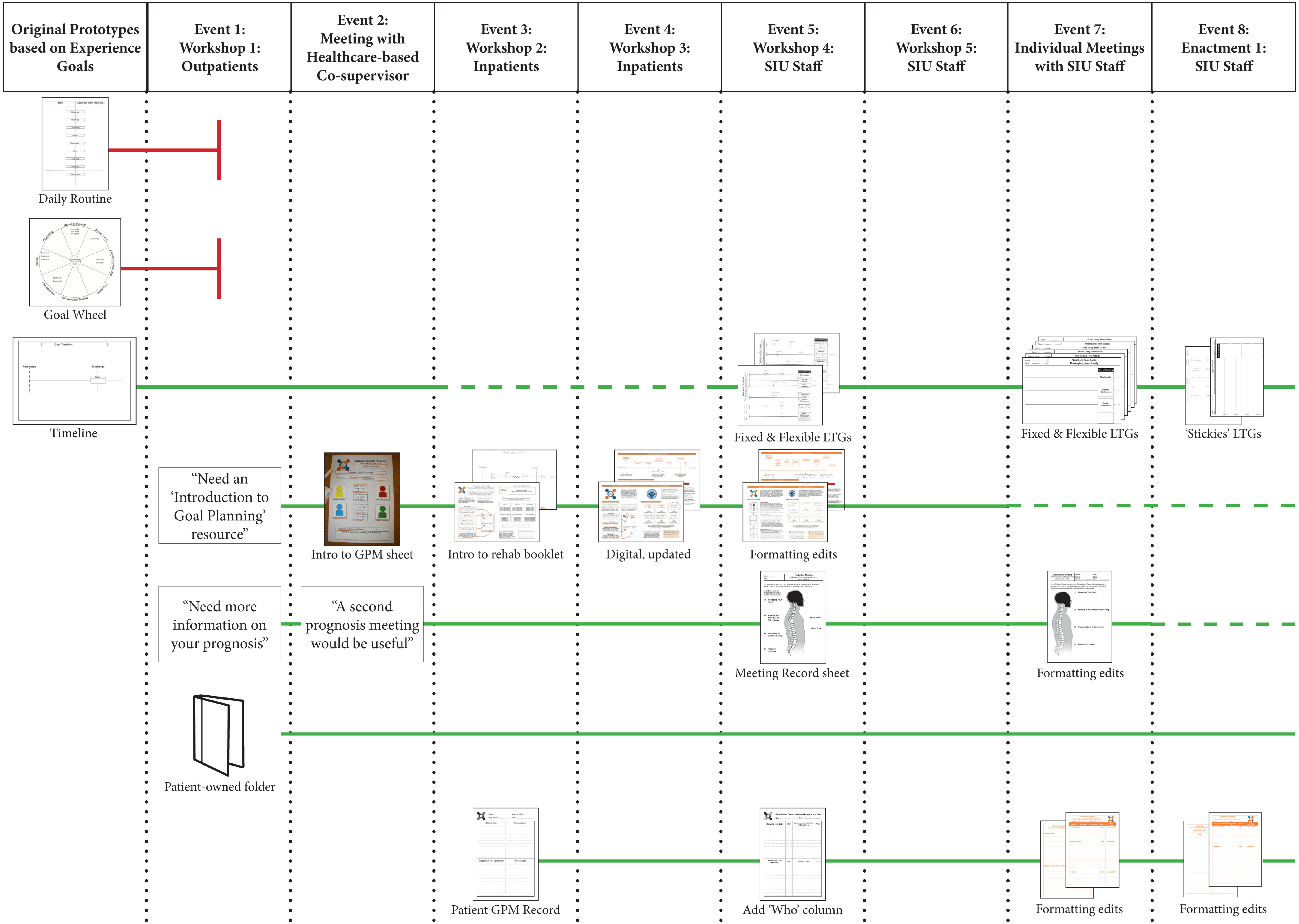
- When a decision is made, do you consider it to be: (*Please mark an X on the scale*)



- Finally, whereabouts would you estimate you are on this rehabilitation timeline?

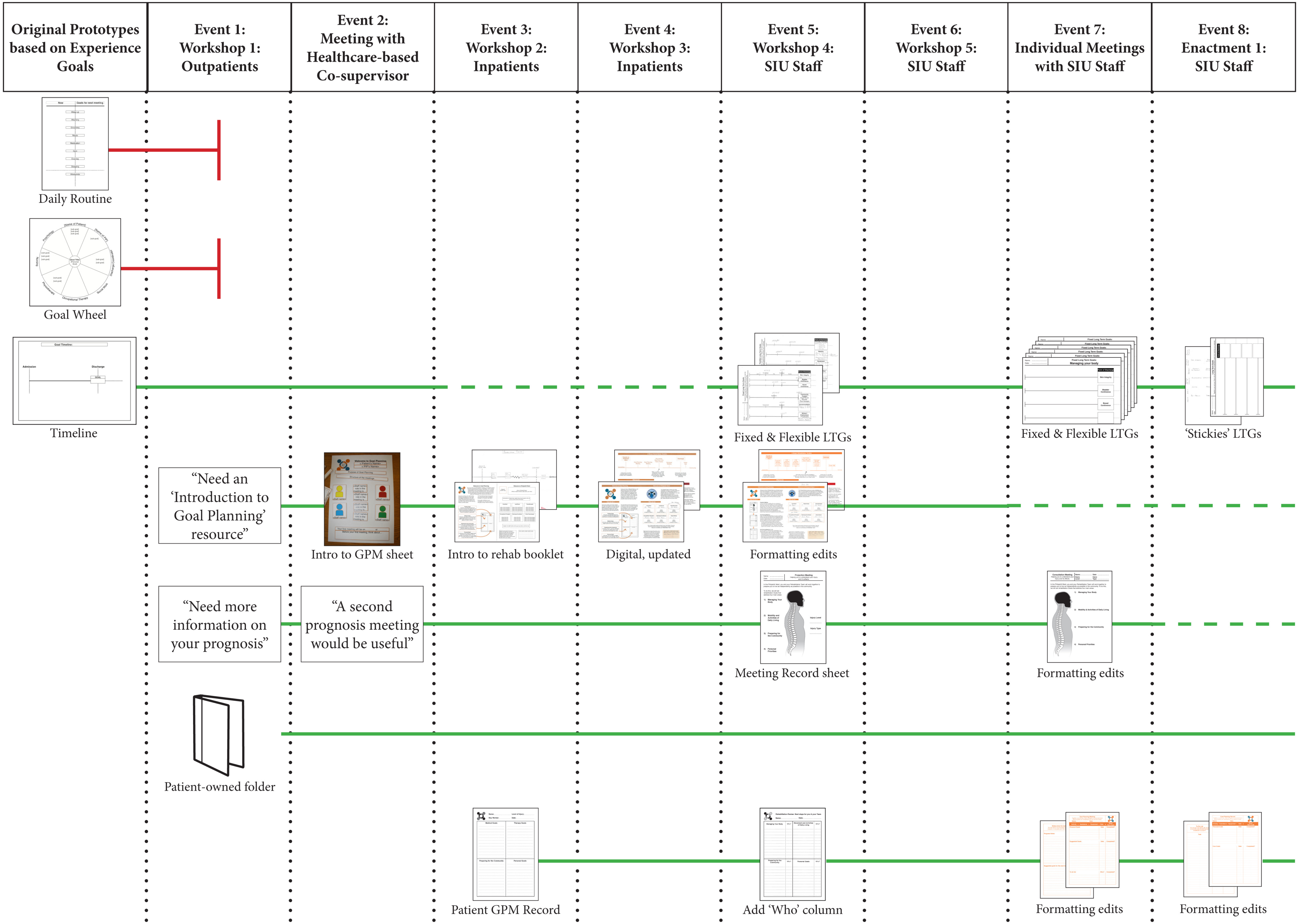


Appendix 21: Prototype Development Journeys. *Part 1 of 2*



Original Prototypes based on Experience Goals	Event 1: Workshop 1: Outpatients	Event 2: Meeting with Healthcare-based Co-supervisor	Event 3: Workshop 2: Inpatients	Event 4: Workshop 3: Inpatients	Event 5: Workshop 4: SIU Staff	Event 6: Workshop 5: SIU Staff	Event 7: Individual Meetings with SIU Staff	Event 8: Enactment 1: SIU Staff
Daily Routine								
Goal Wheel								
Timeline					Fixed & Flexible LTGs		Fixed & Flexible LTGs	‘Stickies’ LTGs
	“Need an ‘Introduction to Goal Planning’ resource”	Intro to GPM sheet	Intro to rehab booklet	Digital, updated	Formatting edits			
	“Need more information on your prognosis”	“A second prognosis meeting would be useful”			Meeting Record sheet		Formatting edits	
	Patient-owned folder							
			Patient GPM Record		Add ‘Who’ column		Formatting edits	Formatting edits

Appendix 21: Prototype Development Journeys. *Part 2 of 2*



Original Prototypes based on Experience Goals

Event 1: Workshop 1: Outpatients

Event 2: Meeting with Healthcare-based Co-supervisor

Event 3: Workshop 2: Inpatients

Event 4: Workshop 3: Inpatients

Event 5: Workshop 4: SIU Staff

Event 6: Workshop 5: SIU Staff

Event 7: Individual Meetings with SIU Staff

Event 8: Enactment 1: SIU Staff

Daily Routine

Goal Wheel

Timeline

Fixed & Flexible LTGs

Fixed & Flexible LTGs

'Stickies' LTGs

"Need an 'Introduction to Goal Planning' resource"

Intro to GPM sheet

Intro to rehab booklet

Digital, updated

Formatting edits

"Need more information on your prognosis"

"A second prognosis meeting would be useful"

Meeting Record sheet

Formatting edits

Patient-owned folder

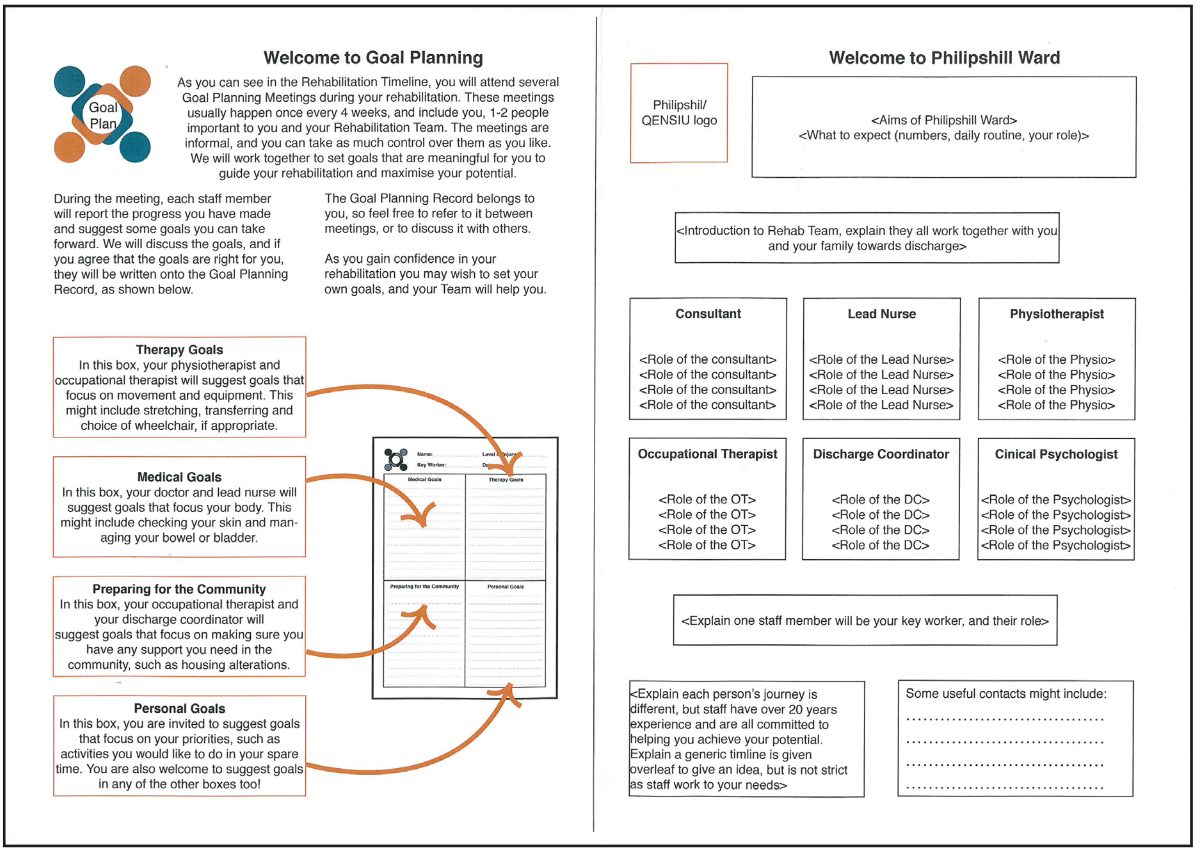
Patient GPM Record

Add 'Who' column

Formatting edits

Formatting edits

Appendix 22
Prototype iterations:
Introduction to Rehabilitation Booklet
Iteration 1



Welcome to Goal Planning

Goal Plan

As you can see in the Rehabilitation Timeline, you will attend several Goal Planning Meetings during your rehabilitation. These meetings usually happen once every 4 weeks, and include you, 1-2 people important to you and your Rehabilitation Team. The meetings are informal, and you can take as much control over them as you like. We will work together to set goals that are meaningful for you to guide your rehabilitation and maximise your potential.

During the meeting, each staff member will report the progress you have made and suggest some goals you can take forward. We will discuss the goals, and if you agree that the goals are right for you, they will be written onto the Goal Planning Record, as shown below.

The Goal Planning Record belongs to you, so feel free to refer to it between meetings, or to discuss it with others.

As you gain confidence in your rehabilitation you may wish to set your own goals, and your Team will help you.

Therapy Goals
In this box, your physiotherapist and occupational therapist will suggest goals that focus on movement and equipment. This might include stretching, transferring and choice of wheelchair, if appropriate.

Medical Goals
In this box, your doctor and lead nurse will suggest goals that focus your body. This might include checking your skin and managing your bowel or bladder.

Preparing for the Community
In this box, your occupational therapist and your discharge coordinator will suggest goals that focus on making sure you have any support you need in the community, such as housing alterations.

Personal Goals
In this box, you are invited to suggest goals that focus on your priorities, such as activities you would like to do in your spare time. You are also welcome to suggest goals in any of the other boxes too!

Name:
Key Worker:
Level of Injury:
Date:
Medical Goals
Therapy Goals
Preparing for the Community
Personal Goals

Welcome to Philipshill Ward

Philipshill/
QENSIU logo

<Aims of Philipshill Ward>
<What to expect (numbers, daily routine, your role)>

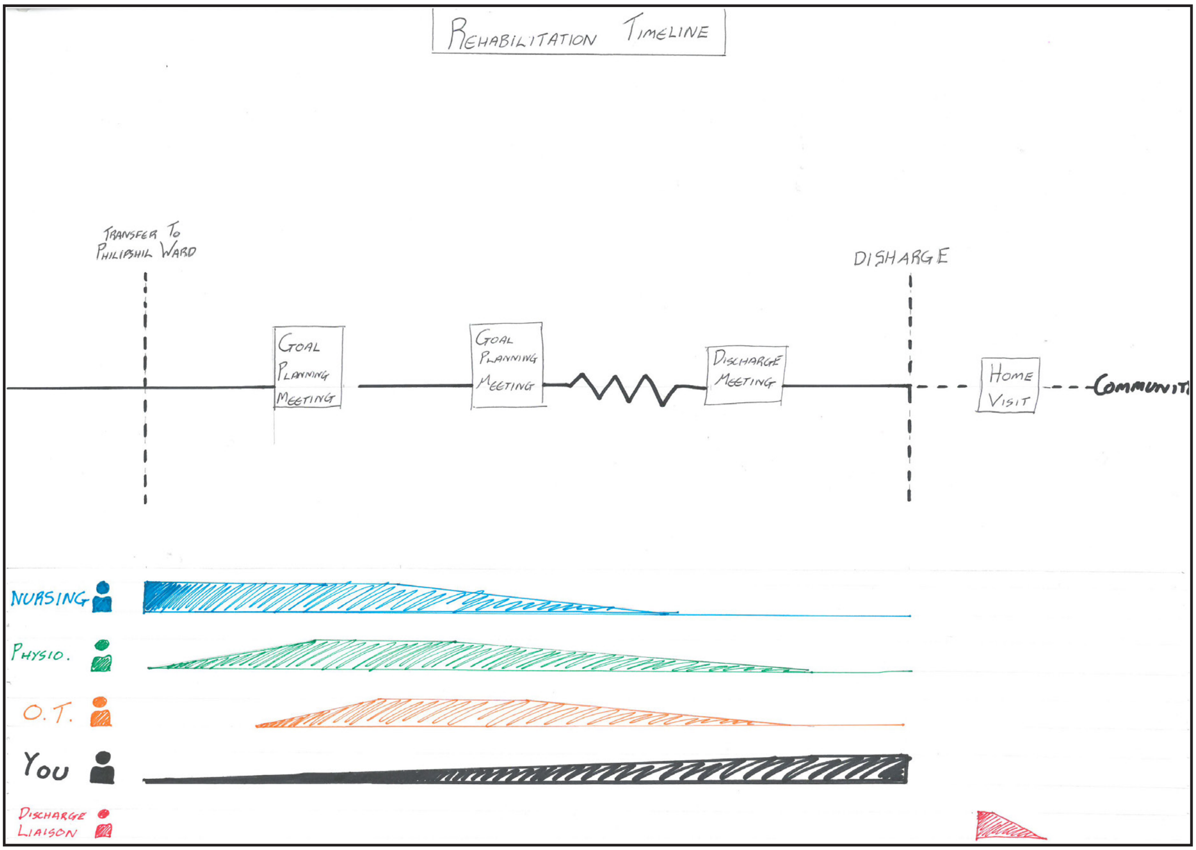
<Introduction to Rehab Team, explain they all work together with you and your family towards discharge>

Consultant	Lead Nurse	Physiotherapist
<Role of the consultant> <Role of the consultant> <Role of the consultant> <Role of the consultant>	<Role of the Lead Nurse> <Role of the Lead Nurse> <Role of the Lead Nurse> <Role of the Lead Nurse>	<Role of the Physio> <Role of the Physio> <Role of the Physio> <Role of the Physio>
Occupational Therapist	**Discharge Coordinator**	**Cinical Psychologist**
<Role of the OT> <Role of the OT> <Role of the OT> <Role of the OT>	<Role of the DC> <Role of the DC> <Role of the DC> <Role of the DC>	<Role of the Psychologist> <Role of the Psychologist> <Role of the Psychologist> <Role of the Psychologist>

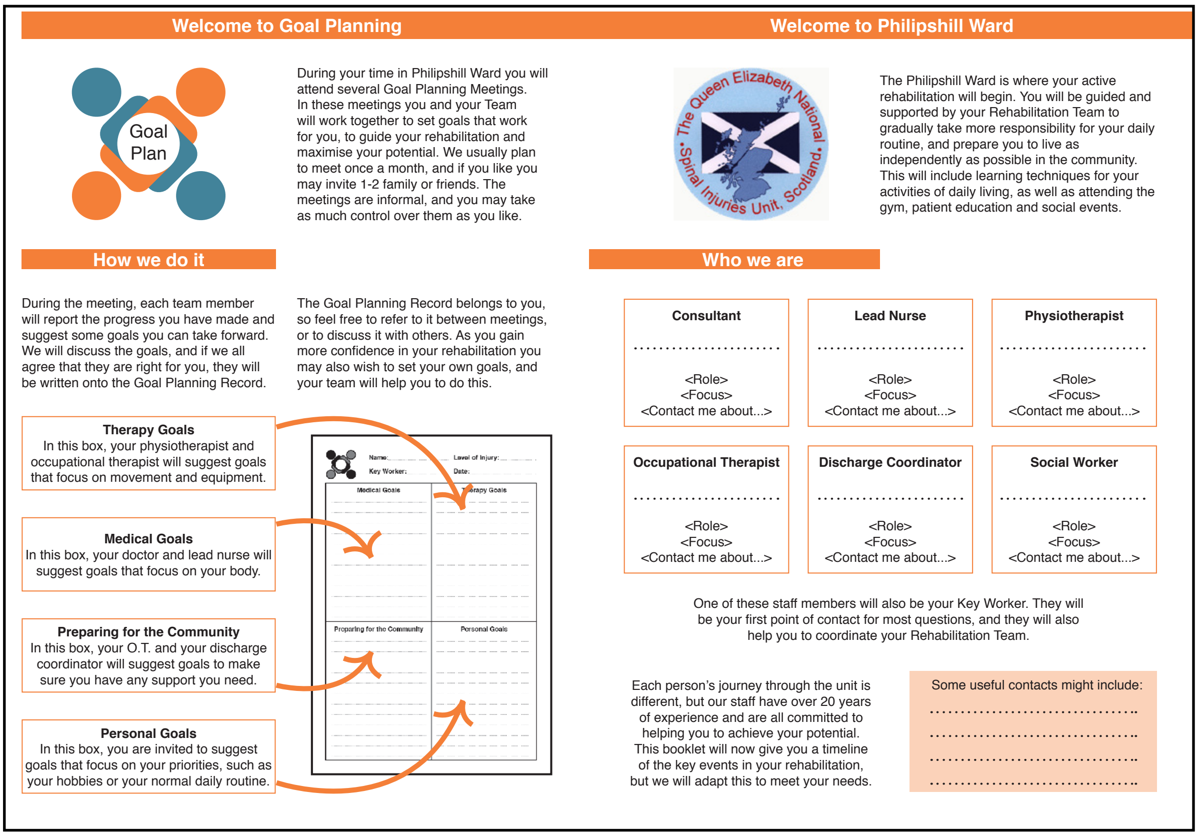
<Explain one staff member will be your key worker, and their role>

<Explain each person's journey is different, but staff have over 20 years experience and are all committed to helping you achieve your potential. Explain a generic timline is given overleaf to give an idea, but is not strict as staff work to your needs>

Some useful contacts might include:
....
....
....
....



Appendix 22
Prototype iterations:
Introduction to Rehabilitation Booklet
Iteration 2



Welcome to Goal Planning

During your time in Philipshill Ward you will attend several Goal Planning Meetings. In these meetings you and your Team will work together to set goals that work for you, to guide your rehabilitation and maximise your potential. We usually plan to meet once a month, and if you like you may invite 1-2 family or friends. The meetings are informal, and you may take as much control over them as you like.

How we do it

During the meeting, each team member will report the progress you have made and suggest some goals you can take forward. We will discuss the goals, and if we all agree that they are right for you, they will be written onto the Goal Planning Record.

The Goal Planning Record belongs to you, so feel free to refer to it between meetings, or to discuss it with others. As you gain more confidence in your rehabilitation you may also wish to set your own goals, and your team will help you to do this.

Therapy Goals
In this box, your physiotherapist and occupational therapist will suggest goals that focus on movement and equipment.

Medical Goals
In this box, your doctor and lead nurse will suggest goals that focus on your body.

Preparing for the Community
In this box, your O.T. and your discharge coordinator will suggest goals to make sure you have any support you need.

Personal Goals
In this box, you are invited to suggest goals that focus on your priorities, such as your hobbies or your normal daily routine.

Welcome to Philipshill Ward

The Philipshill Ward is where your active rehabilitation will begin. You will be guided and supported by your Rehabilitation Team to gradually take more responsibility for your daily routine, and prepare you to live as independently as possible in the community. This will include learning techniques for your activities of daily living, as well as attending the gym, patient education and social events.

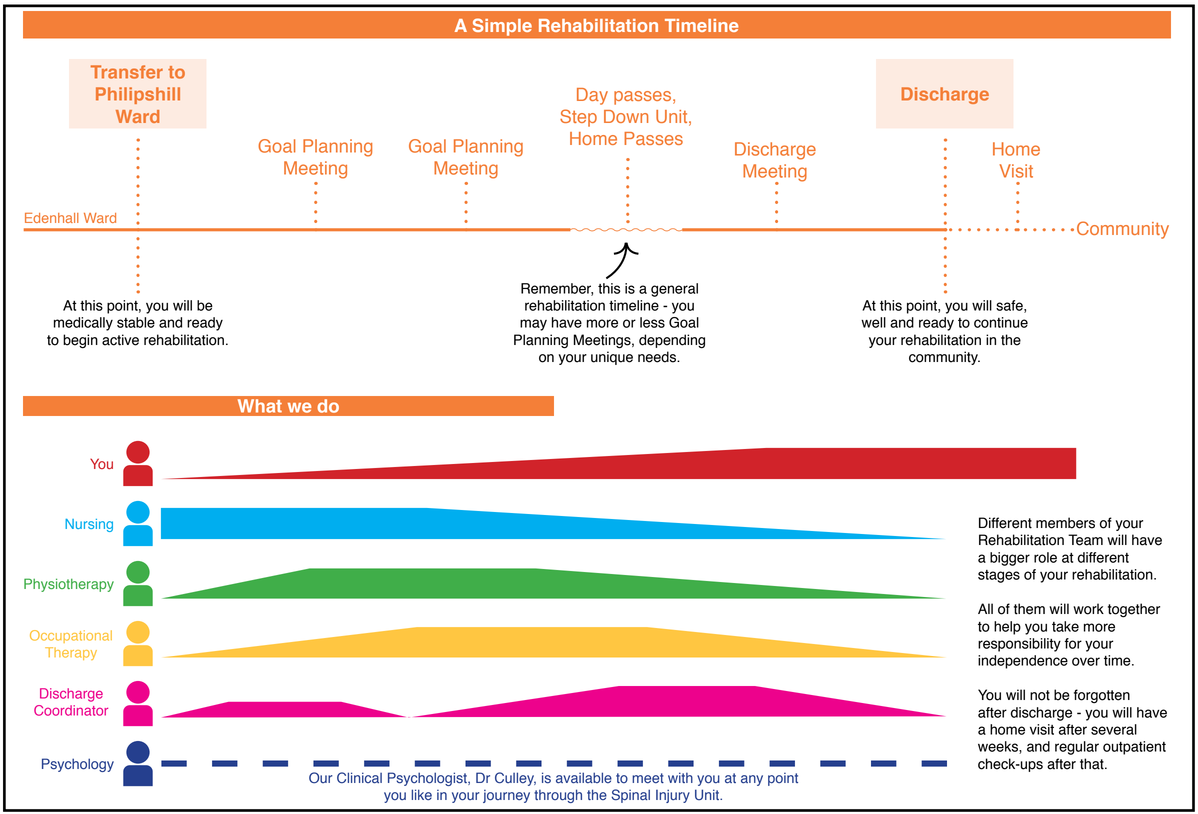
Who we are

Consultant	Lead Nurse	Physiotherapist
.... <Role> <Focus> <Contact me about...>	.... <Role> <Focus> <Contact me about...>	.... <Role> <Focus> <Contact me about...>
Occupational Therapist	**Discharge Coordinator**	**Social Worker**
.... <Role> <Focus> <Contact me about...>	.... <Role> <Focus> <Contact me about...>	.... <Role> <Focus> <Contact me about...>

One of these staff members will also be your Key Worker. They will be your first point of contact for most questions, and they will also help you to coordinate your Rehabilitation Team.

Each person's journey through the unit is different, but our staff have over 20 years of experience and are all committed to helping you to achieve your potential. This booklet will now give you a timeline of the key events in your rehabilitation, but we will adapt this to meet your needs.

Some useful contacts might include:
……………………………..
……………………………..
……………………………..
……………………………..



A Simple Rehabilitation Timeline

At this point, you will be medically stable and ready to begin active rehabilitation.

Remember, this is a general rehabilitation timeline - you may have more or less Goal Planning Meetings, depending on your unique needs.

At this point, you will safe, well and ready to continue your rehabilitation in the community.

What we do

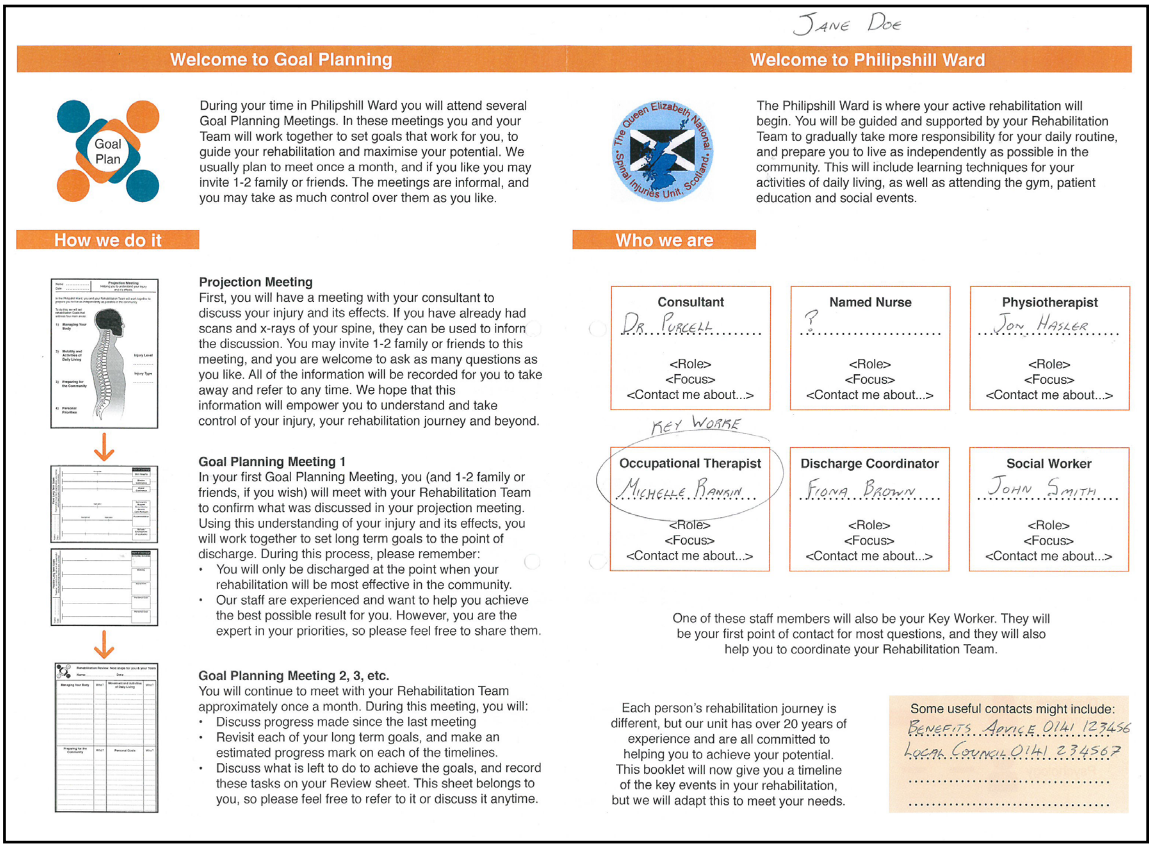
Different members of your Rehabilitation Team will have a bigger role at different stages of your rehabilitation.

All of them will work together to help you take more responsibility for your independence over time.

You will not be forgotten after discharge - you will have a home visit after several weeks, and regular outpatient check-ups after that.

Our Clinical Psychologist, Dr Culley, is available to meet with you at any point you like in your journey through the Spinal Injury Unit.

Appendix 22
Prototype iterations:
Introduction to Rehabilitation Booklet
Iteration 3



Jane Doe

Welcome to Goal Planning

Goal Plan

During your time in Philipshill Ward you will attend several Goal Planning Meetings. In these meetings you and your Team will work together to set goals that work for you, to guide your rehabilitation and maximise your potential. We usually plan to meet once a month, and if you like you may invite 1-2 family or friends. The meetings are informal, and you may take as much control over them as you like.

How we do it

Projection Meeting
First, you will have a meeting with your consultant to discuss your injury and its effects. If you have already had scans and x-rays of your spine, they can be used to inform the discussion. You may invite 1-2 family or friends to this meeting, and you are welcome to ask as many questions as you like. All of the information will be recorded for you to take away and refer to any time. We hope that this information will empower you to understand and take control of your injury, your rehabilitation journey and beyond.

Goal Planning Meeting 1
In your first Goal Planning Meeting, you (and 1-2 family or friends, if you wish) will meet with your Rehabilitation Team to confirm what was discussed in your projection meeting. Using this understanding of your injury and its effects, you will work together to set long term goals to the point of discharge. During this process, please remember:

- You will only be discharged at the point when your rehabilitation will be most effective in the community.
- Our staff are experienced and want to help you achieve the best possible result for you. However, you are the expert in your priorities, so please feel free to share them.

Goal Planning Meeting 2, 3, etc.
You will continue to meet with your Rehabilitation Team approximately once a month. During this meeting, you will:

- Discuss progress made since the last meeting
- Revisit each of your long term goals, and make an estimated progress mark on each of the timelines.
- Discuss what is left to do to achieve the goals, and record these tasks on your Review sheet. This sheet belongs to you, so please feel free to refer to it or discuss it anytime.

Welcome to Philipshill Ward

The Queen Elizabeth National Spinal Injuries Unit, Scotland

The Philipshill Ward is where your active rehabilitation will begin. You will be guided and supported by your Rehabilitation Team to gradually take more responsibility for your daily routine, and prepare you to live as independently as possible in the community. This will include learning techniques for your activities of daily living, as well as attending the gym, patient education and social events.

Who we are

Consultant
Dr. Purcell
<Role>
<Focus>
<Contact me about...>

Named Nurse
?
<Role>
<Focus>
<Contact me about...>

Physiotherapist
Jon Hasler
<Role>
<Focus>
<Contact me about...>

Key Worke

Occupational Therapist
Michelle Rankin
<Role>
<Focus>
<Contact me about...>

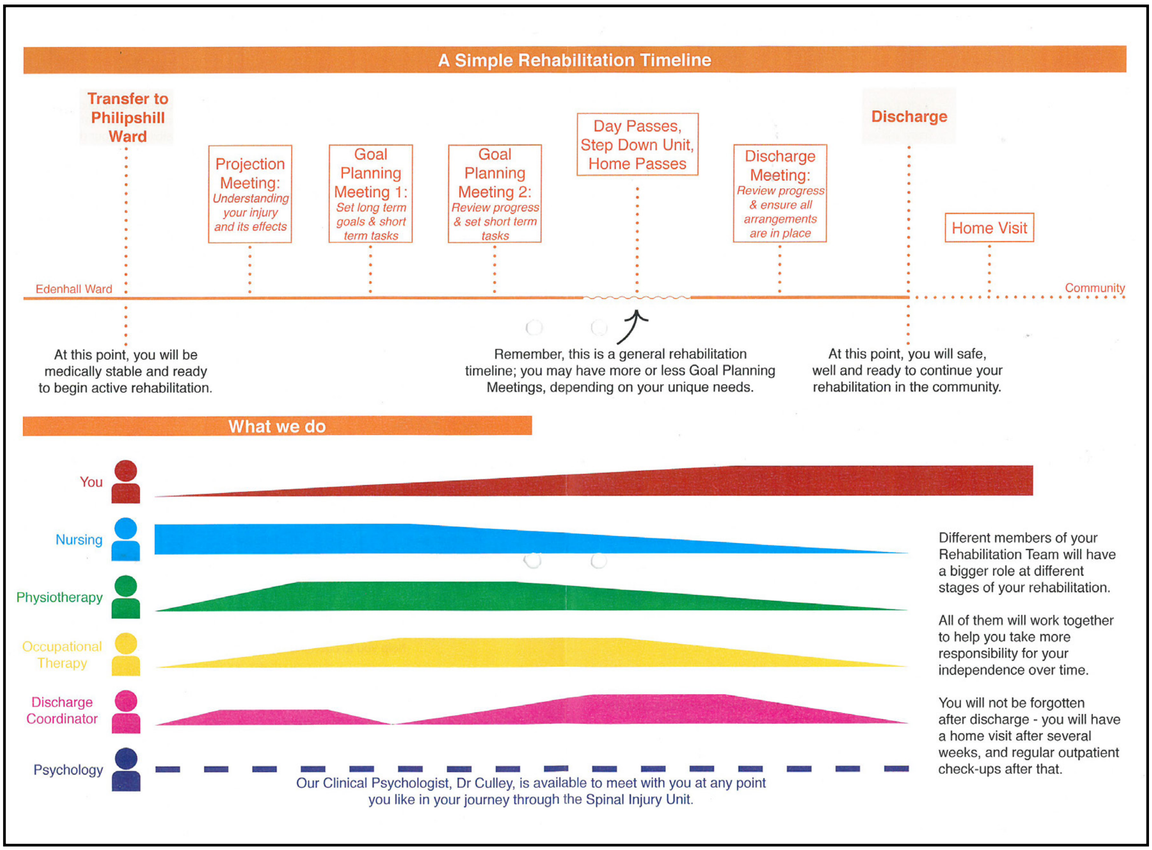
Discharge Coordinator
Fiona Brown
<Role>
<Focus>
<Contact me about...>

Social Worker
John Smith
<Role>
<Focus>
<Contact me about...>

One of these staff members will also be your Key Worker. They will be your first point of contact for most questions, and they will also help you to coordinate your Rehabilitation Team.

Each person's rehabilitation journey is different, but our unit has over 20 years of experience and are all committed to helping you to achieve your potential. This booklet will now give you a timeline of the key events in your rehabilitation, but we will adapt this to meet your needs.

Some useful contacts might include:
Benefits Advice 0141 123456
Local Council 0141 234567
....
....



A Simple Rehabilitation Timeline

Transfer to Philipshill Ward

Projection Meeting: *Understanding your injury and its effects*

Goal Planning Meeting 1: *Set long term goals & short term tasks*

Goal Planning Meeting 2: *Review progress & set short term tasks*

Day Passes, Step Down Unit, Home Passes

Discharge Meeting: *Review progress & ensure all arrangements are in place*

Discharge

Home Visit

Edenhall Ward

Community

At this point, you will be medically stable and ready to begin active rehabilitation.

Remember, this is a general rehabilitation timeline; you may have more or less Goal Planning Meetings, depending on your unique needs.

At this point, you will safe, well and ready to continue your rehabilitation in the community.

What we do

You

Nursing

Physiotherapy

Occupational Therapy

Discharge Coordinator

Psychology

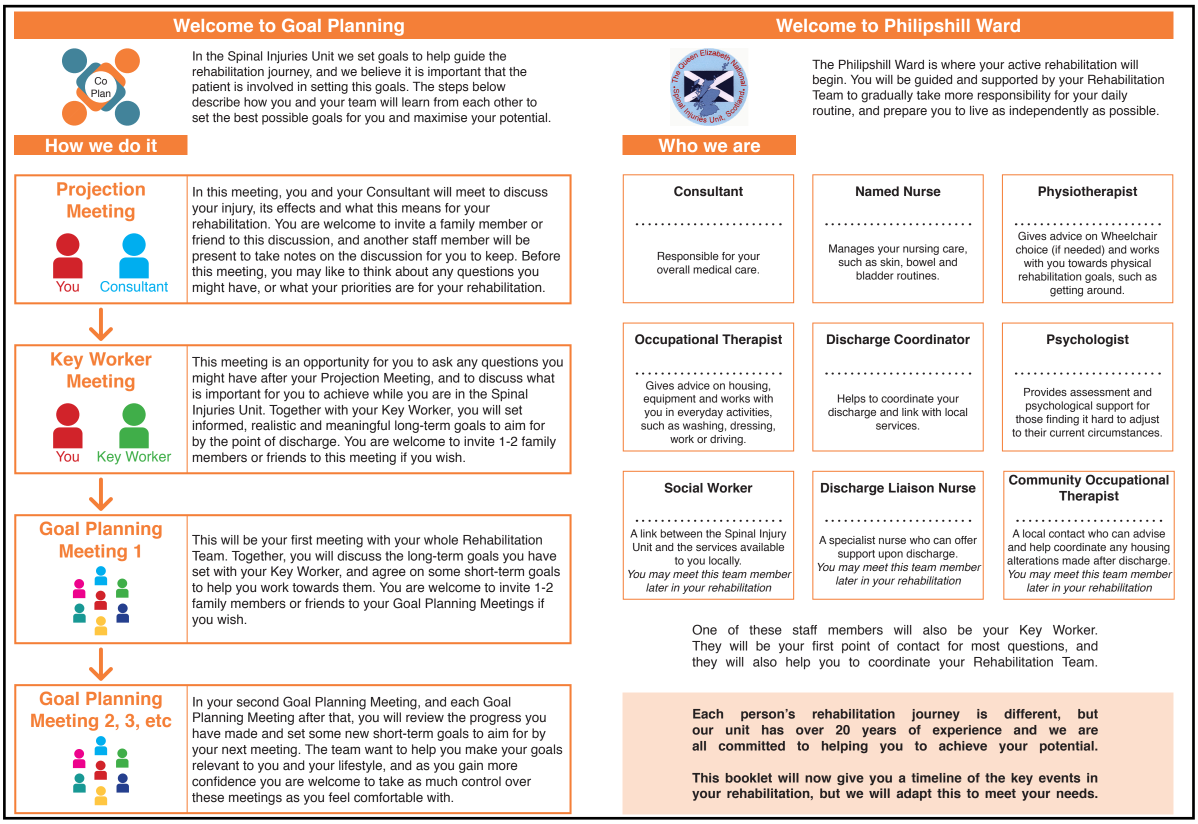
Our Clinical Psychologist, Dr Culley, is available to meet with you at any point you like in your journey through the Spinal Injury Unit.

Different members of your Rehabilitation Team will have a bigger role at different stages of your rehabilitation.

All of them will work together to help you take more responsibility for your independence over time.

You will not be forgotten after discharge - you will have a home visit after several weeks, and regular outpatient check-ups after that.

Appendix 22
Prototype iterations:
Introduction to Rehabilitation Booklet
Iteration 4



Welcome to Goal Planning

Co Plan

In the Spinal Injuries Unit we set goals to help guide the rehabilitation journey, and we believe it is important that the patient is involved in setting this goals. The steps below describe how you and your team will learn from each other to set the best possible goals for you and maximise your potential.

How we do it

Projection Meeting

You Consultant

In this meeting, you and your Consultant will meet to discuss your injury, its effects and what this means for your rehabilitation. You are welcome to invite a family member or friend to this discussion, and another staff member will be present to take notes on the discussion for you to keep. Before this meeting, you may like to think about any questions you might have, or what your priorities are for your rehabilitation.

↓

Key Worker Meeting

You Key Worker

This meeting is an opportunity for you to ask any questions you might have after your Projection Meeting, and to discuss what is important for you to achieve while you are in the Spinal Injuries Unit. Together with your Key Worker, you will set informed, realistic and meaningful long-term goals to aim for by the point of discharge. You are welcome to invite 1-2 family members or friends to this meeting if you wish.

↓

Goal Planning Meeting 1

This will be your first meeting with your whole Rehabilitation Team. Together, you will discuss the long-term goals you have set with your Key Worker, and agree on some short-term goals to help you work towards them. You are welcome to invite 1-2 family members or friends to your Goal Planning Meetings if you wish.

↓

Goal Planning Meeting 2, 3, etc

In your second Goal Planning Meeting, and each Goal Planning Meeting after that, you will review the progress you have made and set some new short-term goals to aim for by your next meeting. The team want to help you make your goals relevant to you and your lifestyle, and as you gain more confidence you are welcome to take as much control over these meetings as you feel comfortable with.

Welcome to Philipshill Ward

The Queen Elizabeth National Spinal Injuries Unit, Scotland

The Philipshill Ward is where your active rehabilitation will begin. You will be guided and supported by your Rehabilitation Team to gradually take more responsibility for your daily routine, and prepare you to live as independently as possible.

Who we are

Consultant
....
Responsible for your overall medical care.

Named Nurse
....
Manages your nursing care, such as skin, bowel and bladder routines.

Physiotherapist
....
Gives advice on Wheelchair choice (if needed) and works with you towards physical rehabilitation goals, such as getting around.

Occupational Therapist
....
Gives advice on housing, equipment and works with you in everyday activities, such as washing, dressing, work or driving.

Discharge Coordinator
....
Helps to coordinate your discharge and link with local services.

Psychologist
....
Provides assessment and psychological support for those finding it hard to adjust to their current circumstances.

Social Worker
....
A link between the Spinal Injury Unit and the services available to you locally.
You may meet this team member later in your rehabilitation

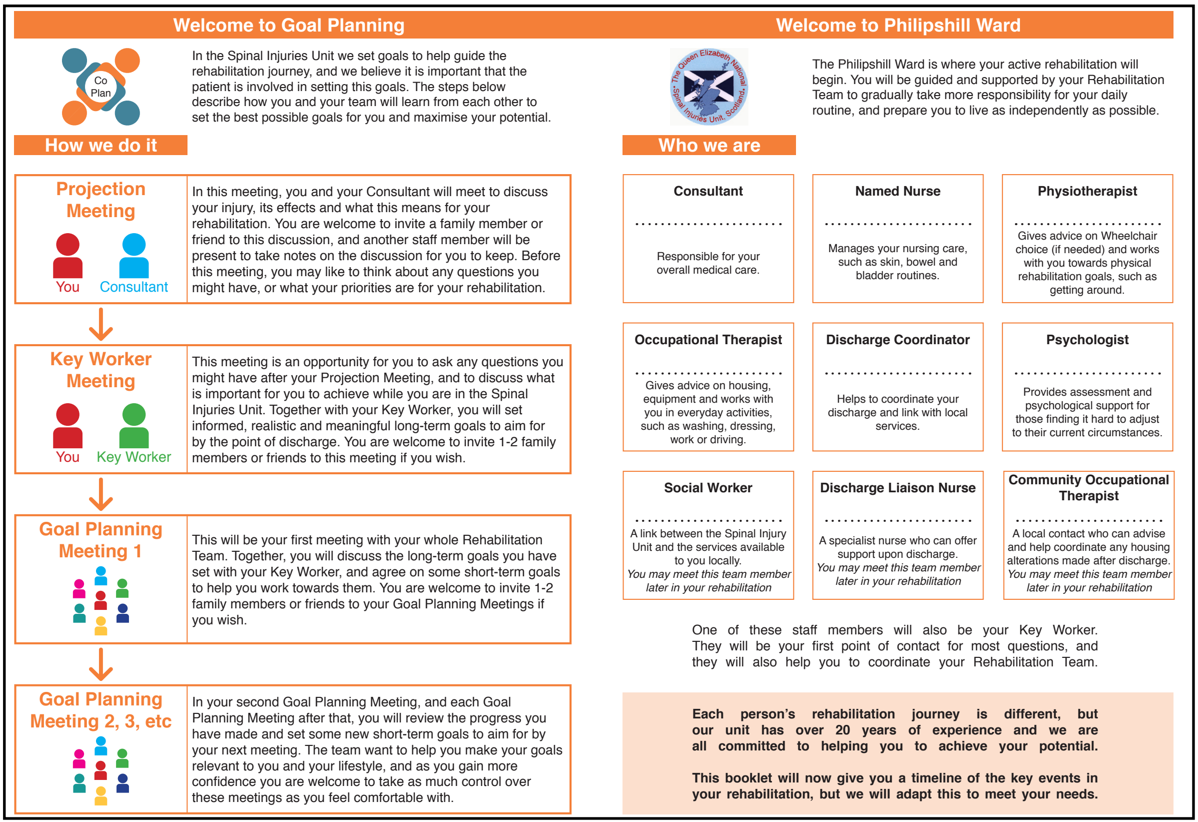
Discharge Liaison Nurse
....
A specialist nurse who can offer support upon discharge.
You may meet this team member later in your rehabilitation

Community Occupational Therapist
....
A local contact who can advise and help coordinate any housing alterations made after discharge.
You may meet this team member later in your rehabilitation

One of these staff members will also be your Key Worker. They will be your first point of contact for most questions, and they will also help you to coordinate your Rehabilitation Team.

Each person's rehabilitation journey is different, but our unit has over 20 years of experience and we are all committed to helping you to achieve your potential.

This booklet will now give you a timeline of the key events in your rehabilitation, but we will adapt this to meet your needs.



Welcome to Goal Planning

Co Plan

In the Spinal Injuries Unit we set goals to help guide the rehabilitation journey, and we believe it is important that the patient is involved in setting this goals. The steps below describe how you and your team will learn from each other to set the best possible goals for you and maximise your potential.

How we do it

Projection Meeting

You Consultant

In this meeting, you and your Consultant will meet to discuss your injury, its effects and what this means for your rehabilitation. You are welcome to invite a family member or friend to this discussion, and another staff member will be present to take notes on the discussion for you to keep. Before this meeting, you may like to think about any questions you might have, or what your priorities are for your rehabilitation.

↓

Key Worker Meeting

You Key Worker

This meeting is an opportunity for you to ask any questions you might have after your Projection Meeting, and to discuss what is important for you to achieve while you are in the Spinal Injuries Unit. Together with your Key Worker, you will set informed, realistic and meaningful long-term goals to aim for by the point of discharge. You are welcome to invite 1-2 family members or friends to this meeting if you wish.

↓

Goal Planning Meeting 1

This will be your first meeting with your whole Rehabilitation Team. Together, you will discuss the long-term goals you have set with your Key Worker, and agree on some short-term goals to help you work towards them. You are welcome to invite 1-2 family members or friends to your Goal Planning Meetings if you wish.

↓

Goal Planning Meeting 2, 3, etc

In your second Goal Planning Meeting, and each Goal Planning Meeting after that, you will review the progress you have made and set some new short-term goals to aim for by your next meeting. The team want to help you make your goals relevant to you and your lifestyle, and as you gain more confidence you are welcome to take as much control over these meetings as you feel comfortable with.

Welcome to Philipshill Ward

The Queen Elizabeth National Spinal Injuries Unit, Scotland

The Philipshill Ward is where your active rehabilitation will begin. You will be guided and supported by your Rehabilitation Team to gradually take more responsibility for your daily routine, and prepare you to live as independently as possible.

Who we are

Consultant
....
Responsible for your overall medical care.

Named Nurse
....
Manages your nursing care, such as skin, bowel and bladder routines.

Physiotherapist
....
Gives advice on Wheelchair choice (if needed) and works with you towards physical rehabilitation goals, such as getting around.

Occupational Therapist
....
Gives advice on housing, equipment and works with you in everyday activities, such as washing, dressing, work or driving.

Discharge Coordinator
....
Helps to coordinate your discharge and link with local services.

Psychologist
....
Provides assessment and psychological support for those finding it hard to adjust to their current circumstances.

Social Worker
....
A link between the Spinal Injury Unit and the services available to you locally.
You may meet this team member later in your rehabilitation

Discharge Liaison Nurse
....
A specialist nurse who can offer support upon discharge.
You may meet this team member later in your rehabilitation

Community Occupational Therapist
....
A local contact who can advise and help coordinate any housing alterations made after discharge.
You may meet this team member later in your rehabilitation

One of these staff members will also be your Key Worker. They will be your first point of contact for most questions, and they will also help you to coordinate your Rehabilitation Team.

Each person's rehabilitation journey is different, but our unit has over 20 years of experience and we are all committed to helping you to achieve your potential.

This booklet will now give you a timeline of the key events in your rehabilitation, but we will adapt this to meet your needs.

Appendix 23
Prototype iterations:
Consultant Meeting Record
Iteration 1

Name: ....
Date: ....

Projection Meeting

Helping you to understand your injury
and it's effects.

In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community.

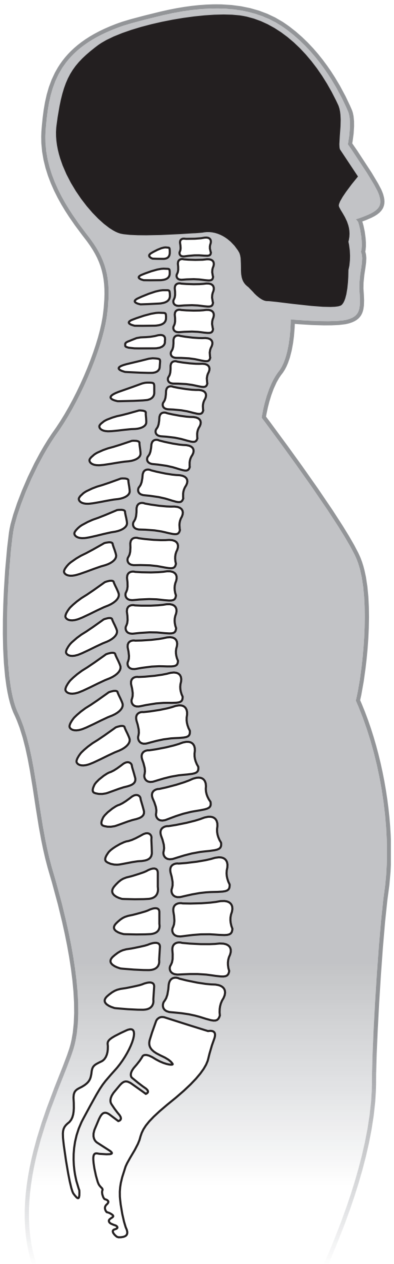
To do this, we will set rehabilitation Goals that address four main areas:

1) **Managing Your Body**

2) **Mobility and Activities of Daily Living**

3) **Preparing for the Community**

4) **Personal Priorities**



Injury Level

....

Injury Type

....

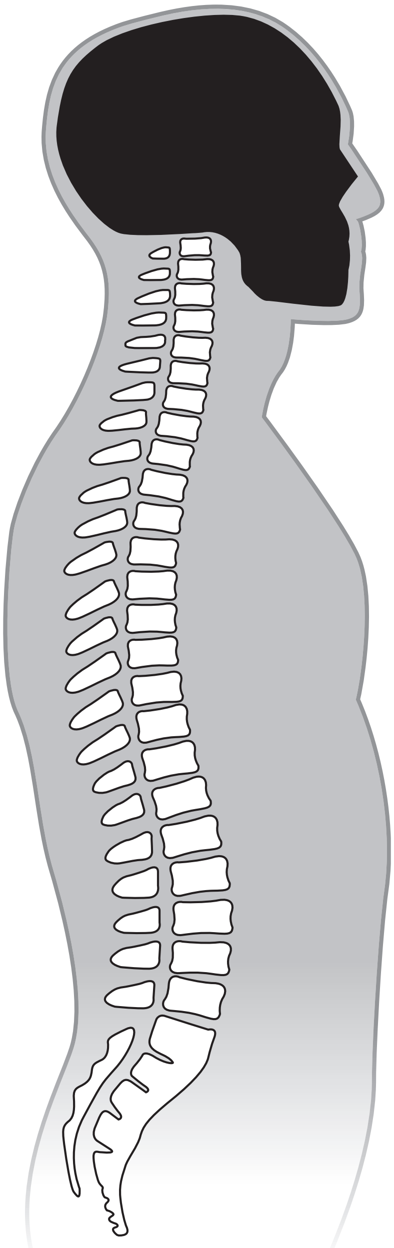
Appendix 23
Prototype iterations:
Consultant Meeting Record
Iteration 2

Consultation Meeting

Helping you to understand your injury and its effects.

Name: . . . . **Date:** . . . .
Injury Level: . . . . **Injury Type:** . . . .

In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community. To do this, we will set rehabilitation Goals that address four main areas:



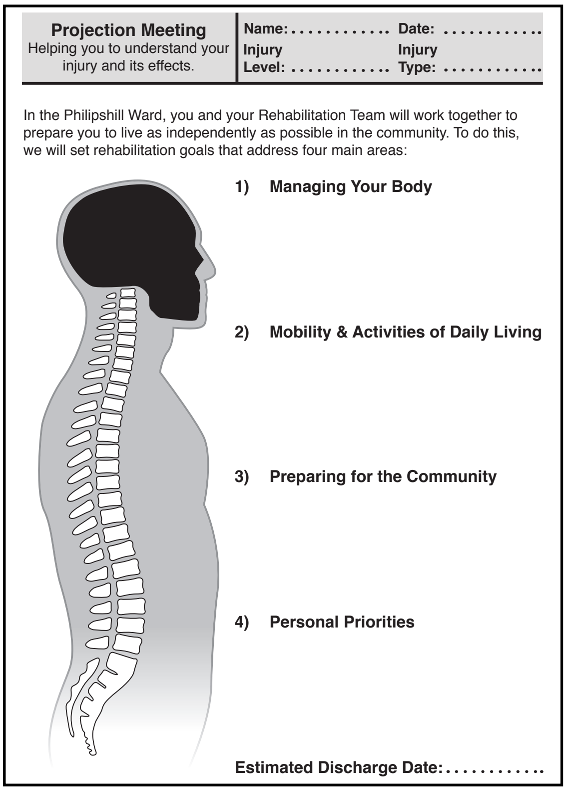
1) **Managing Your Body**

2) **Mobility & Activities of Daily Living**

3) **Preparing for the Community**

4) **Personal Priorities**

Appendix 23
Prototype iterations:
Consultant Meeting Record
Iteration 3



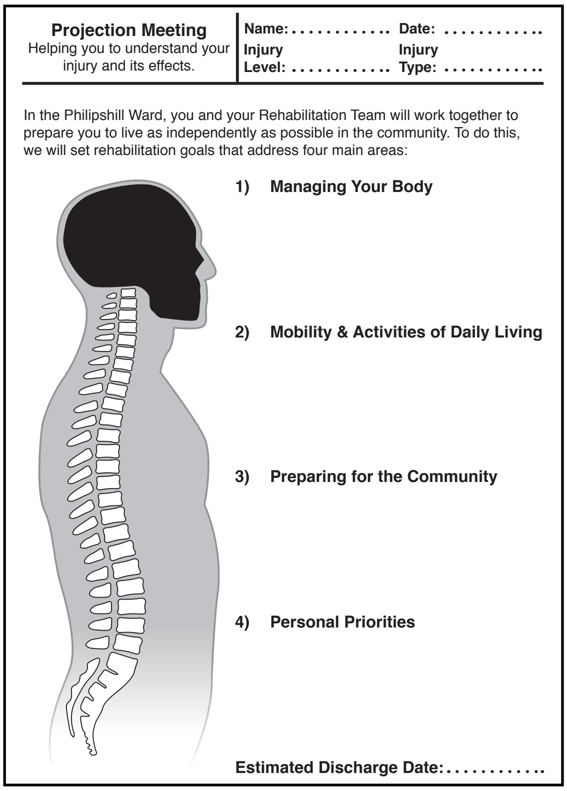
Projection Meeting
Helping you to understand your injury and its effects.

Name: .... **Date:** ....
Injury Level: .... **Injury Type:** ....

In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community. To do this, we will set rehabilitation goals that address four main areas:

1) **Managing Your Body**
2) **Mobility & Activities of Daily Living**
3) **Preparing for the Community**
4) **Personal Priorities**

Estimated Discharge Date: ....



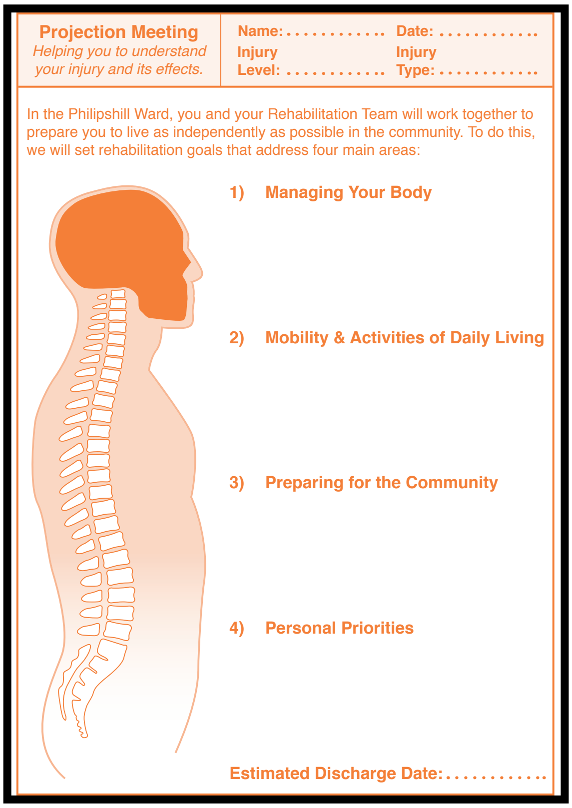
Projection Meeting
Helping you to understand your injury and its effects.

Name: .... **Date:** ....
Injury Level: .... **Injury Type:** ....

In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community. To do this, we will set rehabilitation goals that address four main areas:

1) **Managing Your Body**
2) **Mobility & Activities of Daily Living**
3) **Preparing for the Community**
4) **Personal Priorities**

Estimated Discharge Date: ....



Projection Meeting
Helping you to understand your injury and its effects.

Name: .... **Date:** ....
Injury Level: .... **Injury Type:** ....

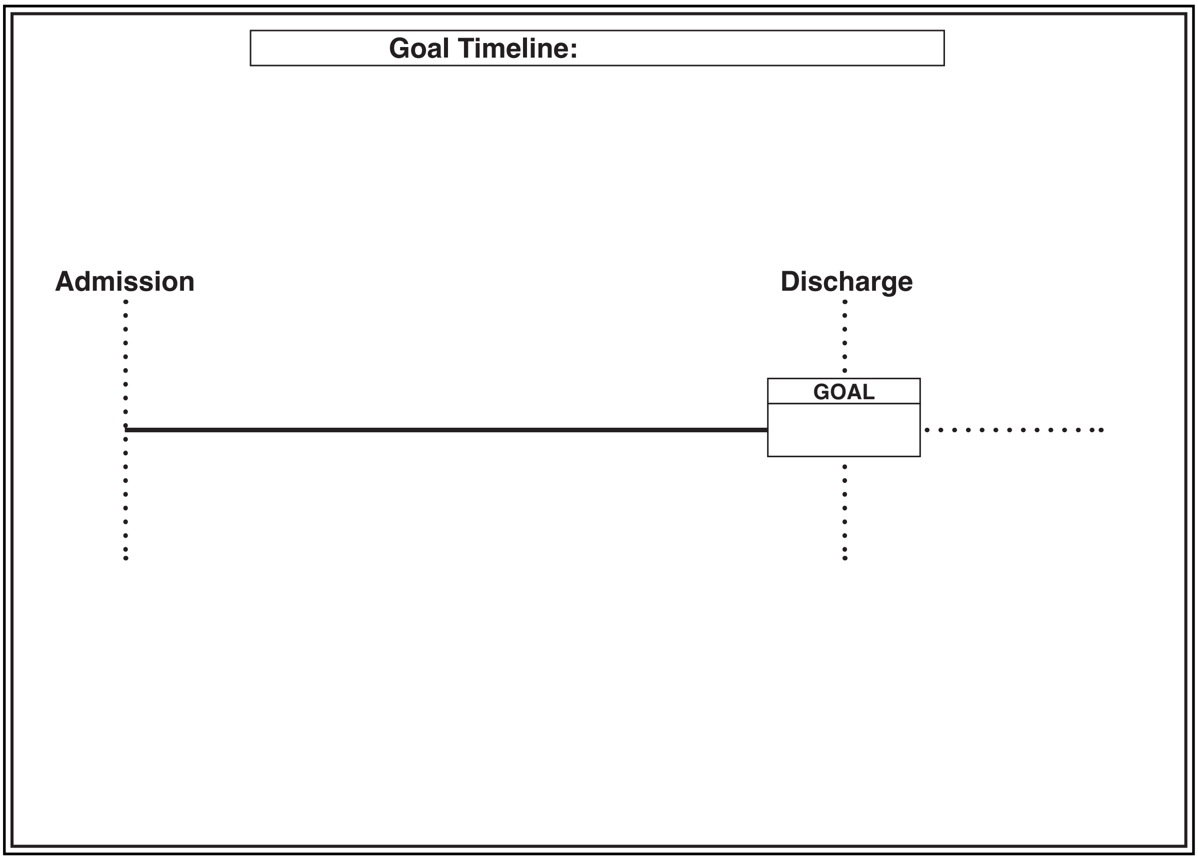
In the Philipshill Ward, you and your Rehabilitation Team will work together to prepare you to live as independently as possible in the community. To do this, we will set rehabilitation goals that address four main areas:

1) **Managing Your Body**
2) **Mobility & Activities of Daily Living**
3) **Preparing for the Community**
4) **Personal Priorities**

Estimated Discharge Date: ....

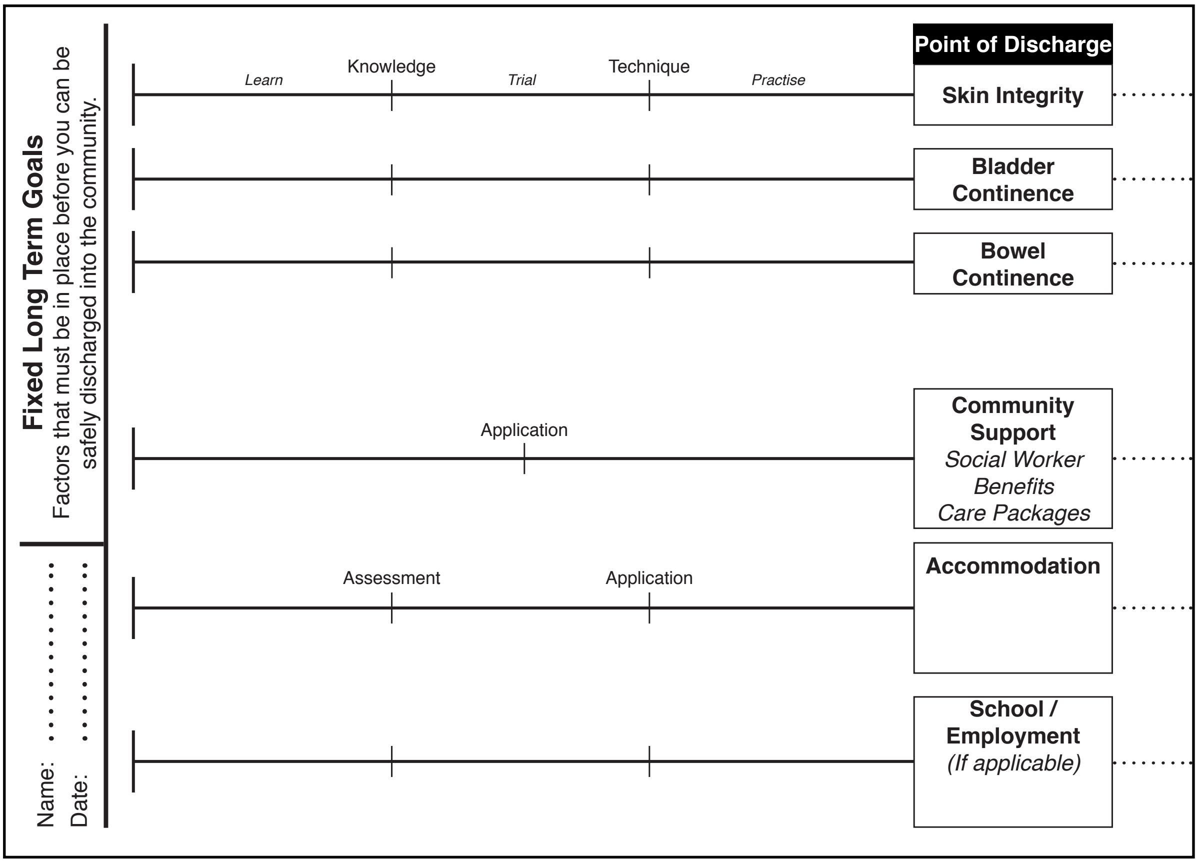
Appendix 24

Prototype iterations:
Long-Term Goals Sheet
Iteration 1



Appendix 24

Prototype iterations:
Long-Term Goals Sheet
Iteration 2



Fixed Long Term Goals
Factors that must be in place before you can be safely discharged into the community.

Name: ……………….
Date: ……………….

Point of Discharge

Skin Integrity ………

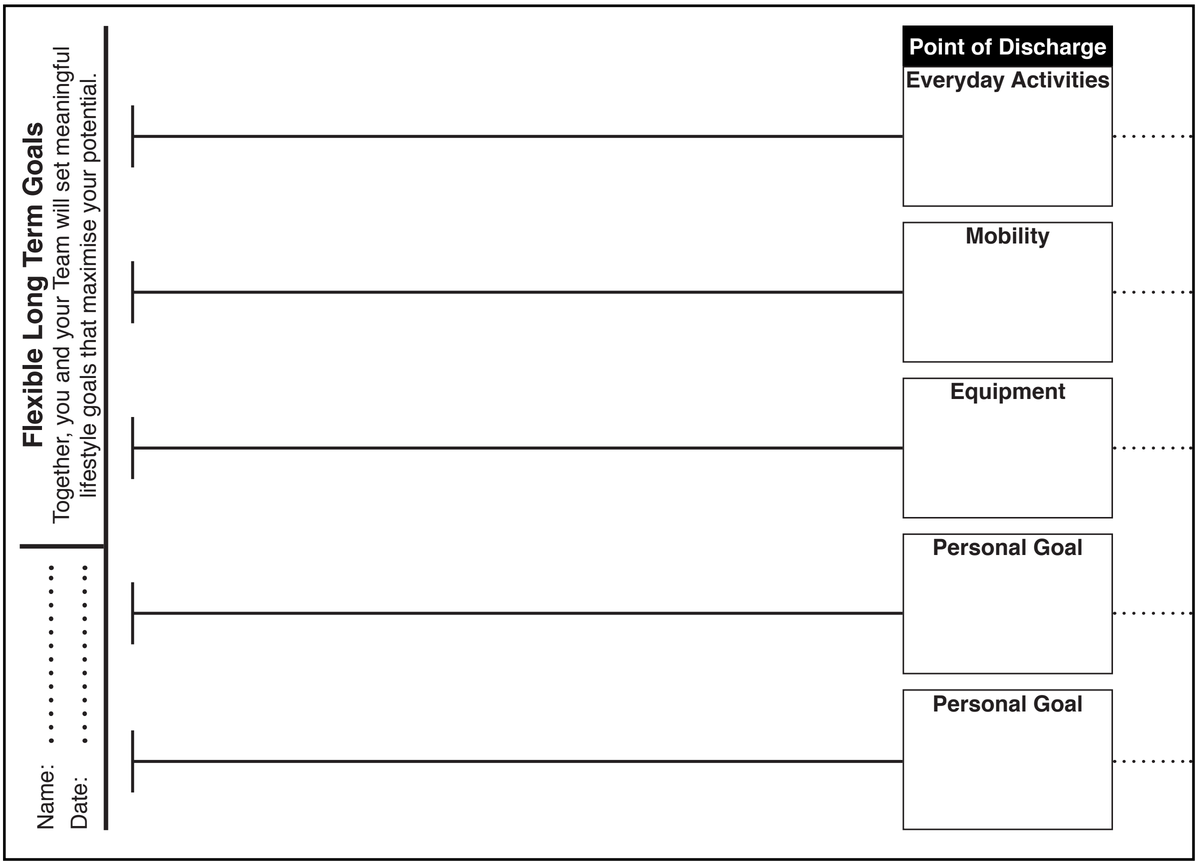
Bladder Continence ………

Bowel Continence ………

Community Support
Social Worker
Benefits
Care Packages ………

Accommodation ………

School / Employment
(If applicable) ………



Flexible Long Term Goals
Together, you and your Team will set meaningful lifestyle goals that maximise your potential.

Name: ……………….
Date: ……………….

Point of Discharge

Everyday Activities ………

Mobility ………

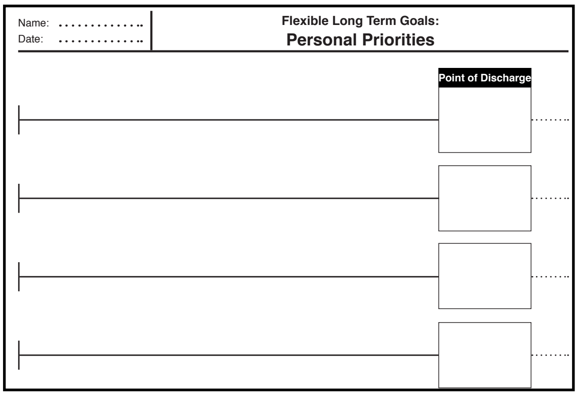
Equipment ………

Personal Goal ………

Personal Goal ………

Appendix 24

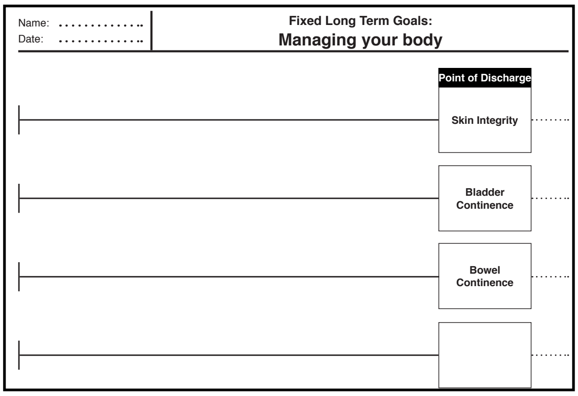
Prototype iterations:
Long-Term Goals Sheet
Iteration 3, Option A



Name: ....
Date: ....

Flexible Long Term Goals:
Personal Priorities

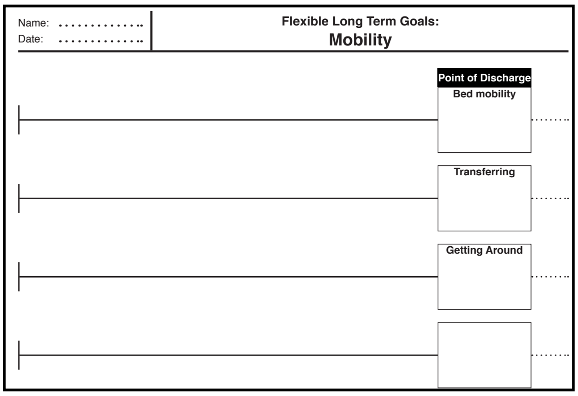
Point of Discharge



Name: ....
Date: ....

Fixed Long Term Goals:
Managing your body

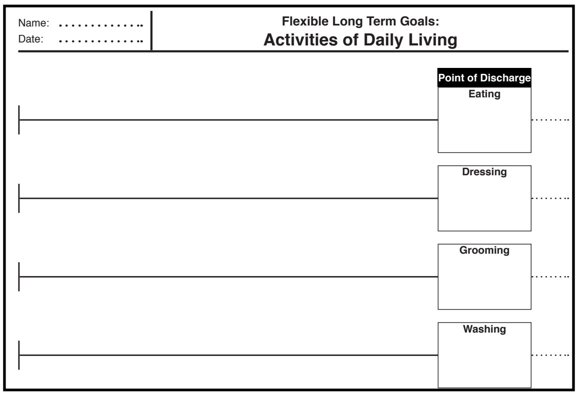
Point of Discharge
Skin Integrity
Bladder Continence
Bowel Continence



Name: ....
Date: ....

Flexible Long Term Goals:
Mobility

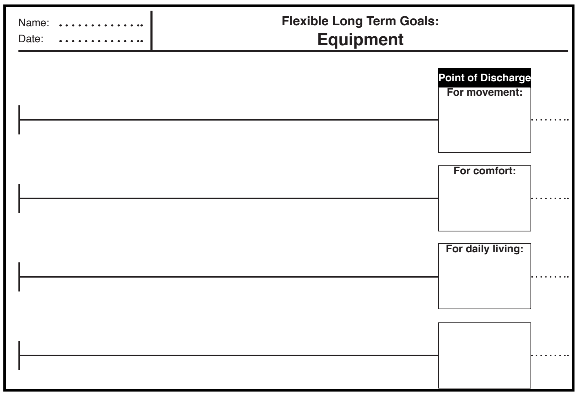
Point of Discharge
Bed mobility
Transferring
Getting Around



Name: ....
Date: ....

Flexible Long Term Goals:
Activities of Daily Living

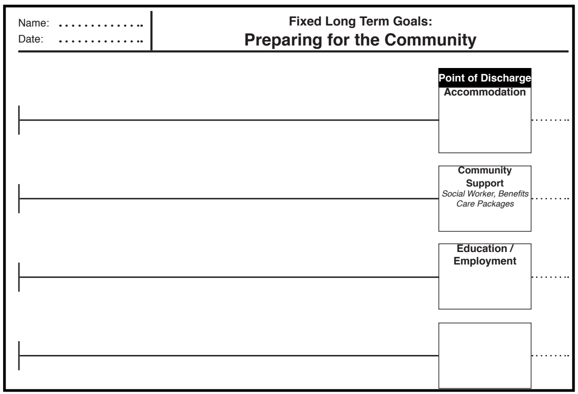
Point of Discharge
Eating
Dressing
Grooming
Washing



Name: ....
Date: ....

Flexible Long Term Goals:
Equipment

Point of Discharge
For movement:
For comfort:
For daily living:



Name: ....
Date: ....

Fixed Long Term Goals:
Preparing for the Community

Point of Discharge
Accommodation
Community Support
Social Worker, Benefits Care Packages
Education / Employment

Appendix 24

Prototype iterations:
Long-Term Goals Sheet
Iteration 3, Option B

PERSONAL PRIORITIES

MANAGING YOUR BODY

SKIN INTEGRITY:

BLADDER CONTINENCE:

BOWEL CONTINENCE:

MOBILITY & ACTIVITIES OF DAILY LIVING

BED MOBILITY:

TRANSFERRING:

GETTING AROUND:

EATING:

WASHING:

DRESSING:

GROOMING:

PREPARATION FOR THE COMMUNITY

ACCOMMODATION:

COMMUNITY SUPPORT:

EDUCATION/WORK:

EQUIPMENT

EQUIPMENT FOR MOVEMENT:

EQUIPMENT FOR DAILY LIVING:

OTHER EQUIPMENT

OTHER

SOCIAL ACTIVITIES:

DRIVING:

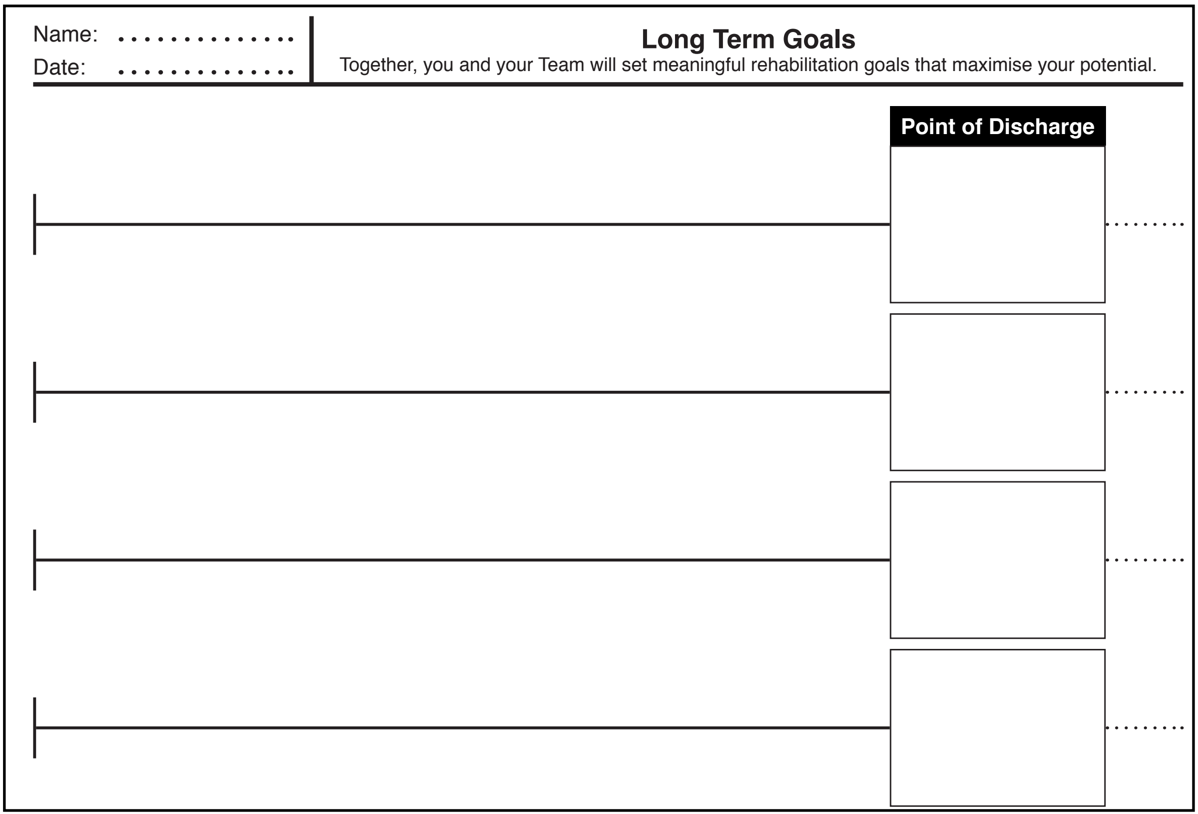
SEXUAL ISSUES/ FERTILITY:

OTHER EQUIPMENT:

AUTONOMIC DYSREFLEXIA:

CHEST MANAGEMENT:

JOINT MANAGEMENT:



Name: ....
Date: ....

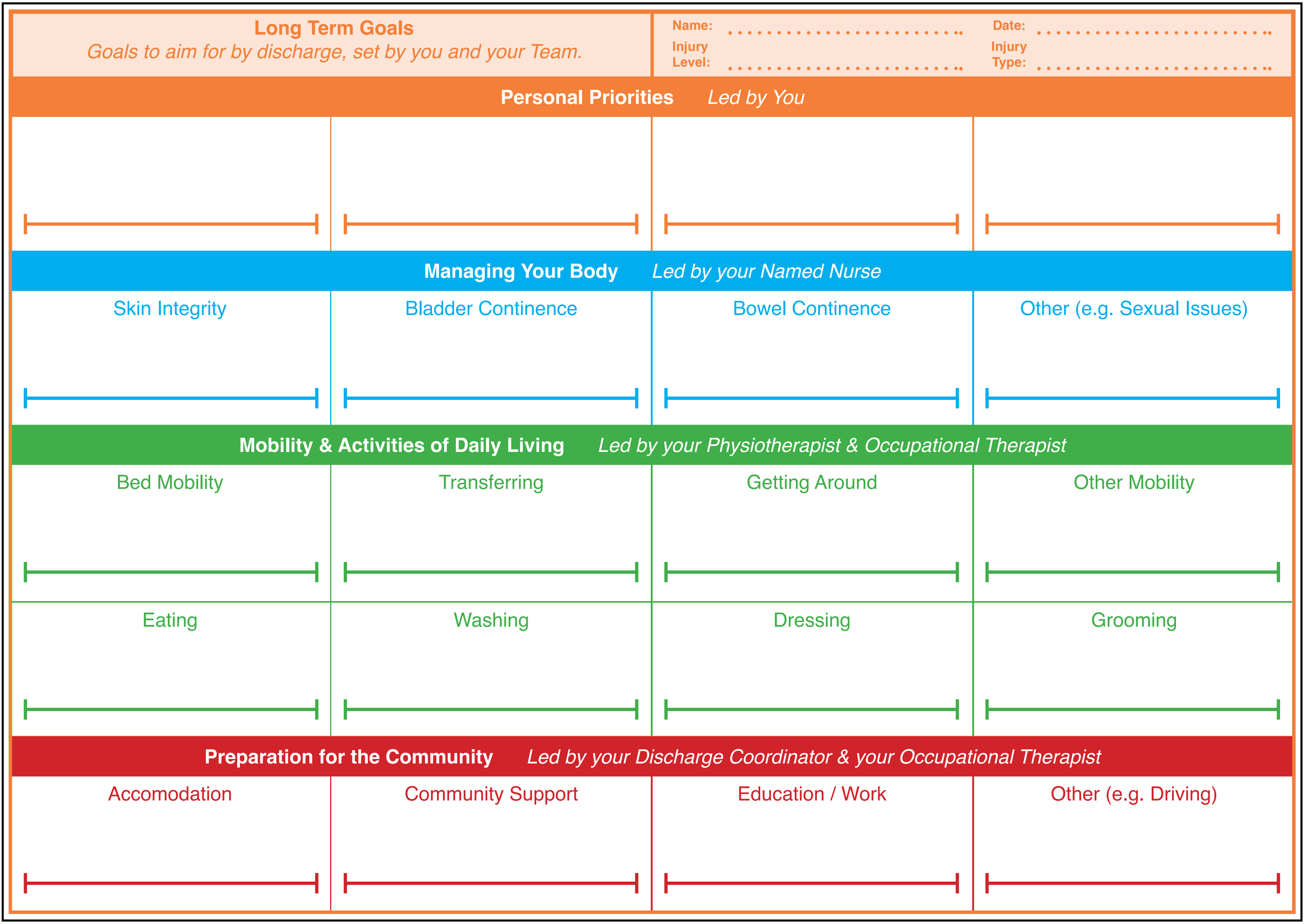
Long Term Goals

Together, you and your Team will set meaningful rehabilitation goals that maximise your potential.

Point of Discharge

Appendix 24

Prototype iterations:
Long-Term Goals Sheet
Iteration 4, Option A



Long Term Goals
Goals to aim for by discharge, set by you and your Team.

Name: ....
Injury Level: ....
Date: ....
Injury Type: ....

Personal Priorities *Led by You*

Managing Your Body *Led by your Named Nurse*

Skin Integrity	Bladder Continence	Bowel Continence	Other (e.g. Sexual Issues)

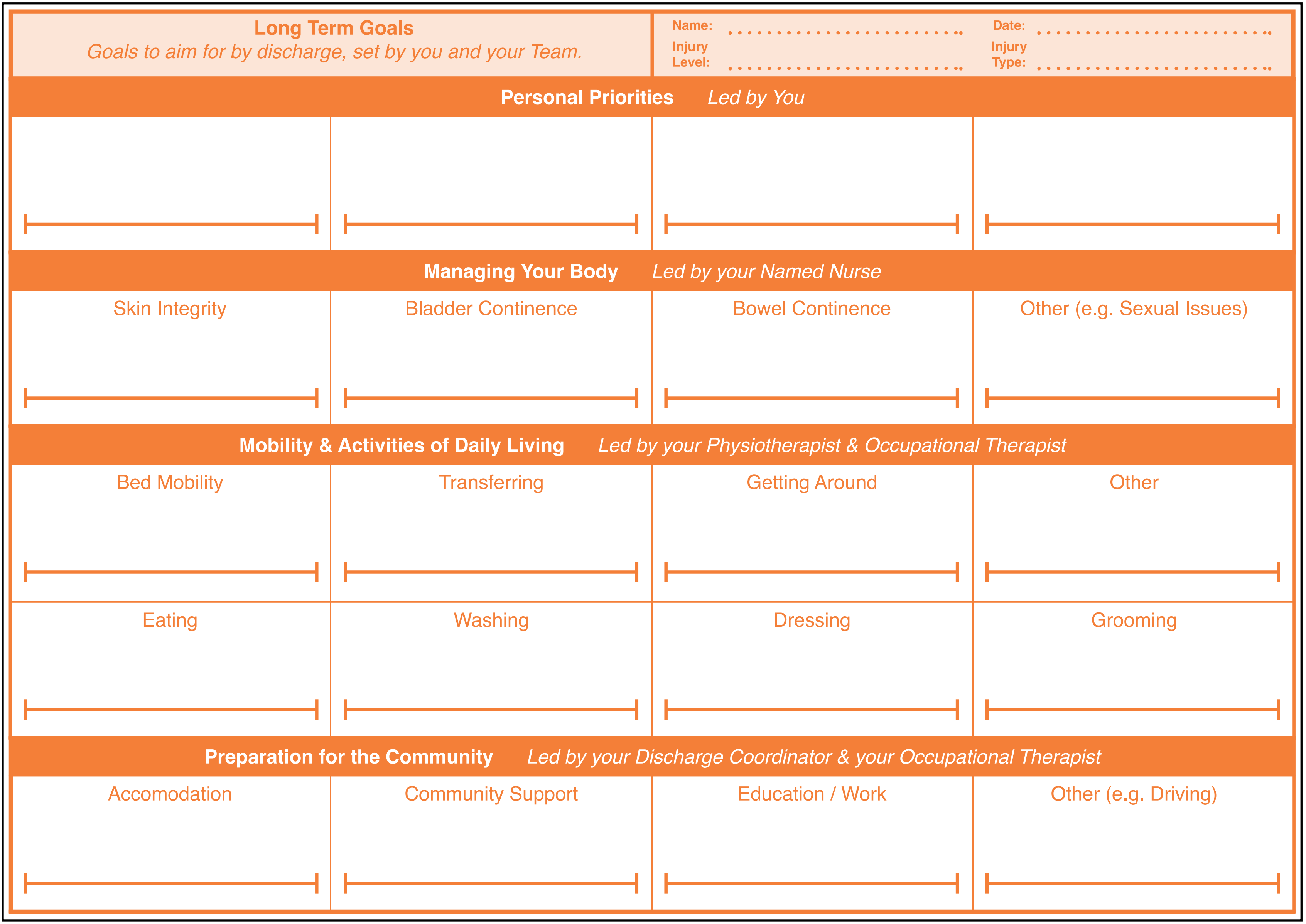
Mobility & Activities of Daily Living *Led by your Physiotherapist & Occupational Therapist*

Bed Mobility	Transferring	Getting Around	Other Mobility
Eating	Washing	Dressing	Grooming

Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*

Accomodation	Community Support	Education / Work	Other (e.g. Driving)

Appendix 24
Prototype iterations:
Long-Term Goals Sheet
Iteration 4, Option B



Long Term Goals
Goals to aim for by discharge, set by you and your Team.

Name: ....
Injury Level: ....
Date: ....
Injury Type: ....

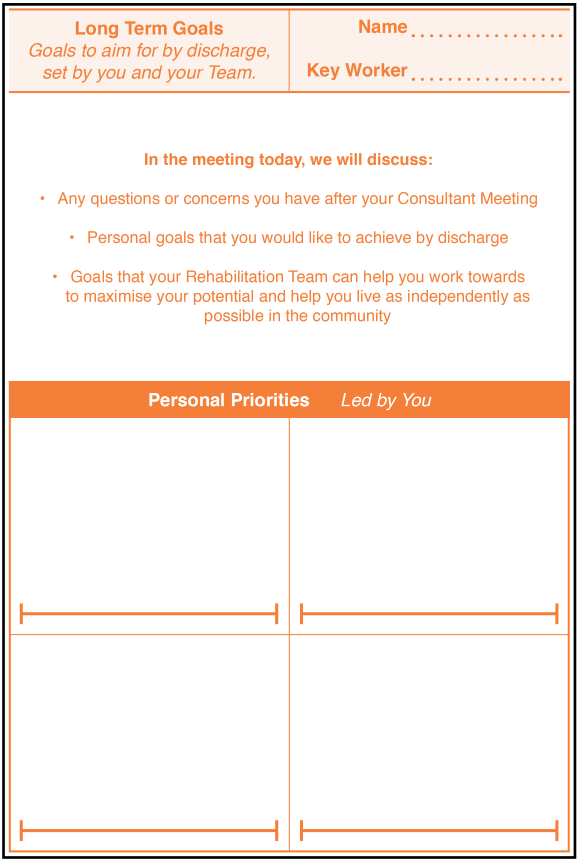
Personal Priorities *Led by You*			
Managing Your Body *Led by your Named Nurse*			
Skin Integrity	Bladder Continence	Bowel Continence	Other (e.g. Sexual Issues)
Mobility & Activities of Daily Living *Led by your Physiotherapist & Occupational Therapist*			
Bed Mobility	Transferring	Getting Around	Other
Eating	Washing	Dressing	Grooming
Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*			
Accomodation	Community Support	Education / Work	Other (e.g. Driving)

Appendix 24
Prototype iterations:
Long-Term Goals Sheet
Iteration 4, Option C

Personal Priorities *Led by You*			
Managing Your Body *Led by your Named Nurse*	Skin Integrity	Bladder Continence	Bowel Continence
Mobility & Activities of Daily Living *Led by your Physiotherapist & your Occupational Therapist*	Bed Mobility	Transferring	Getting Around
Eating	Washing	Grooming	Dressing
Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*	Accommodation	Community Support	Education / Work
Level-Dependent Goals *Led by You & Your Team*	Social Activities	Driving	Sexual Issues / Fertility
Other Equipment	Autonomic Dysreflexia	Chest Management	Joint Management

Appendix 24
Prototype iterations:
Long-Term Goals Sheet
Iteration 5, Option A
[A4 Booklet format]

1



Long Term Goals
Goals to aim for by discharge, set by you and your Team.

Name ....

Key Worker ....

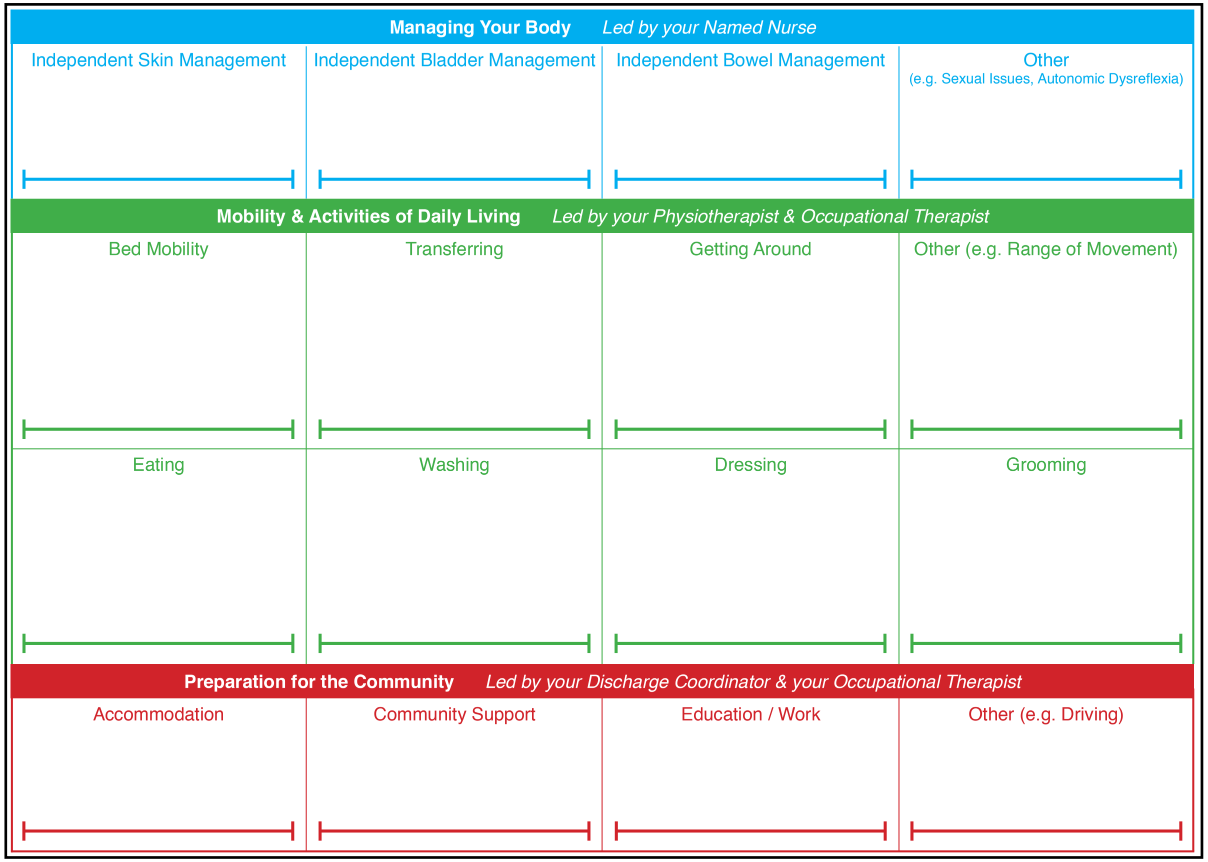
In the meeting today, we will discuss:

- Any questions or concerns you have after your Consultant Meeting
- Personal goals that you would like to achieve by discharge
- Goals that your Rehabilitation Team can help you work towards to maximise your potential and help you live as independently as possible in the community

Personal Priorities *Led by You*

2

3



Managing Your Body *Led by your Named Nurse*

Independent Skin Management	Independent Bladder Management	Independent Bowel Management	Other (e.g. Sexual Issues, Autonomic Dysreflexia)

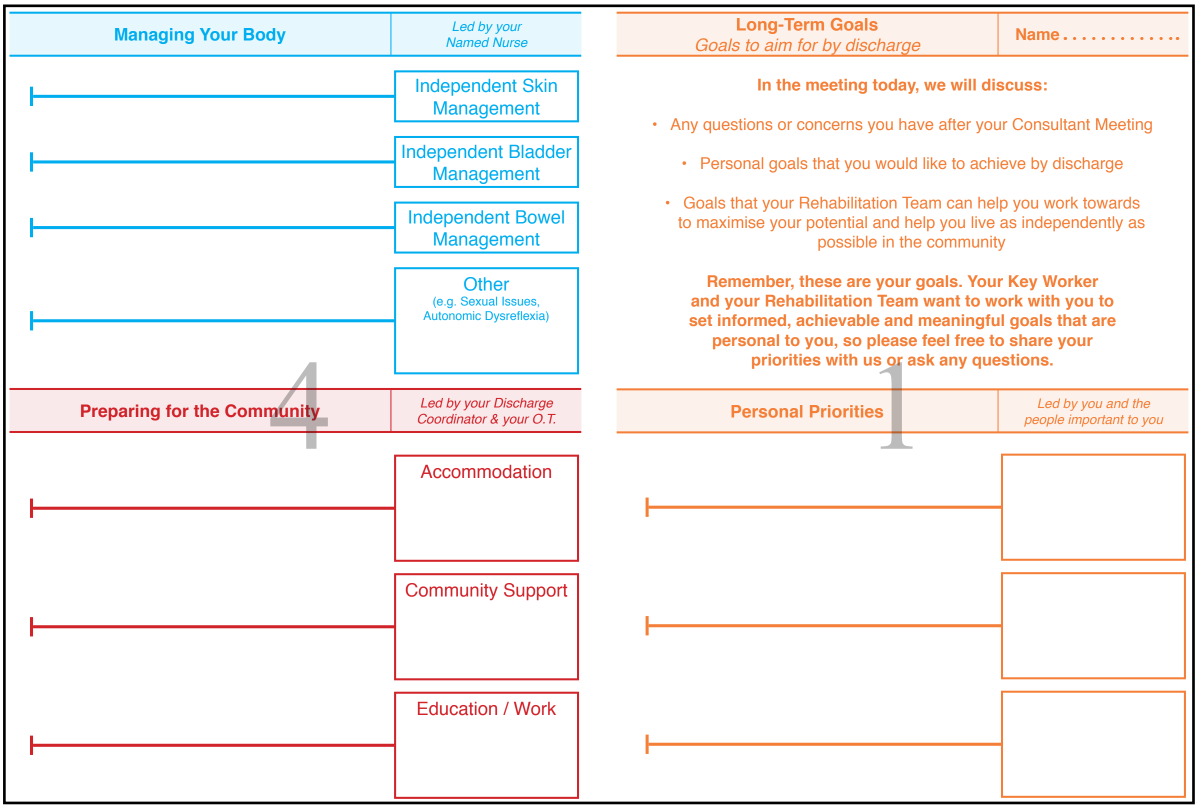
Mobility & Activities of Daily Living *Led by your Physiotherapist & Occupational Therapist*

Bed Mobility	Transferring	Getting Around	Other (e.g. Range of Movement)
Eating	Washing	Dressing	Grooming

Preparation for the Community *Led by your Discharge Coordinator & your Occupational Therapist*

Accommodation	Community Support	Education / Work	Other (e.g. Driving)

Appendix 24
Prototype iterations:
Long-Term Goals Sheet
Iteration 5, Option B
[A4 Booklet format]



Managing Your Body

Led by your Named Nurse

Independent Skin Management

Independent Bladder Management

Independent Bowel Management

Other
(e.g. Sexual Issues, Autonomic Dysreflexia)

4

Preparing for the Community

Led by your Discharge Coordinator & your O.T.

Accommodation

Community Support

Education / Work

Long-Term Goals
Goals to aim for by discharge

Name . . . .

In the meeting today, we will discuss:

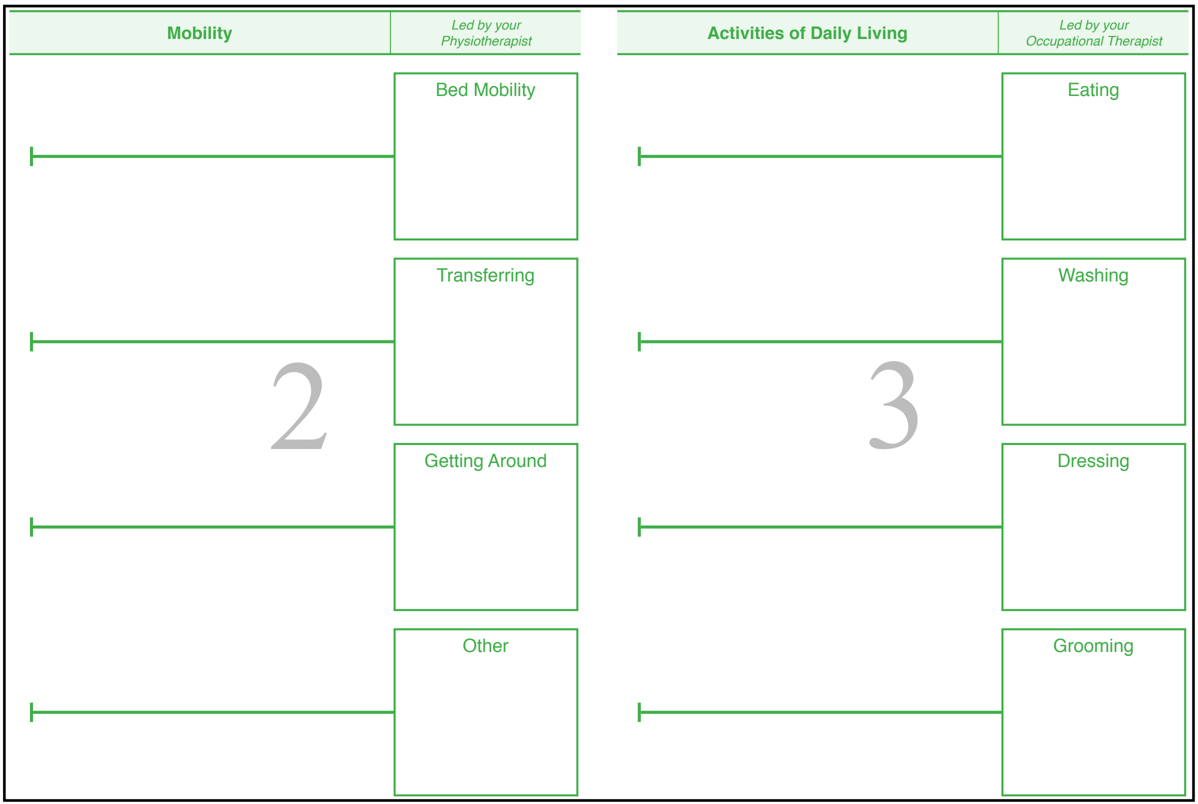
- Any questions or concerns you have after your Consultant Meeting
- Personal goals that you would like to achieve by discharge
- Goals that your Rehabilitation Team can help you work towards to maximise your potential and help you live as independently as possible in the community

Remember, these are your goals. Your Key Worker and your Rehabilitation Team want to work with you to set informed, achievable and meaningful goals that are personal to you, so please feel free to share your priorities with us or ask any questions.

1

Personal Priorities

Led by you and the people important to you



Mobility

Led by your Physiotherapist

Bed Mobility

Transferring

Getting Around

Other

2

Activities of Daily Living

Led by your Occupational Therapist

Eating

Washing

Dressing

Grooming

3

Appendix 38c

Prototype iterations:
Long-Term Goals Sheet
Iteration 5, Option C
[A4 Booklet format]

1

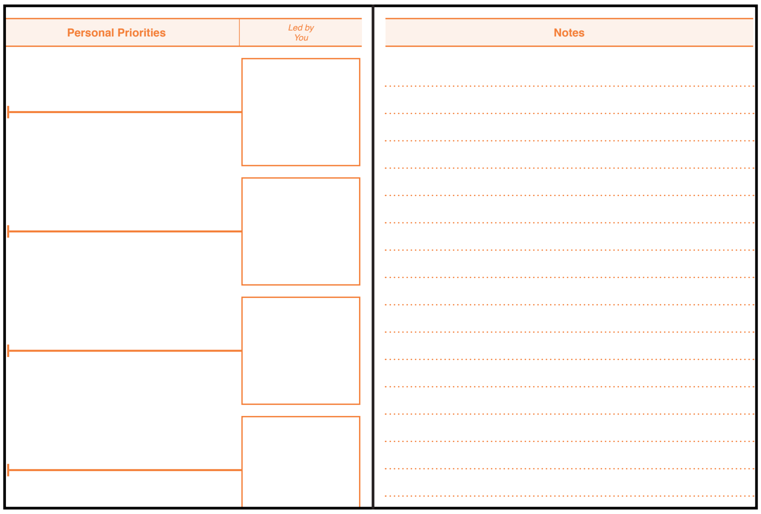
Goal Plan

Long-Term Goals
Goals to aim for by the point of discharge, set by you and your Rehabilitation Team

Name ....

Key Worker ....

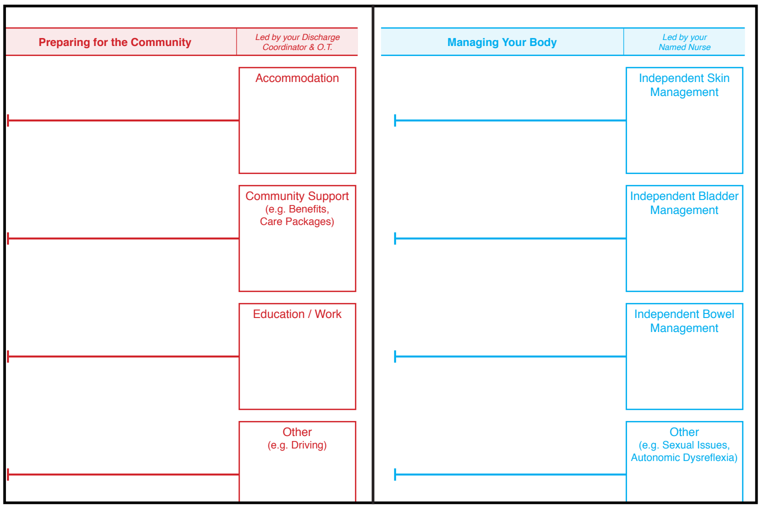
2



Personal Priorities *Led by You*

Notes

3



Preparing for the Community *Led by your Discharge Coordinator & O.T.*

Accommodation

Community Support (e.g. Benefits, Care Packages)

Education / Work

Other (e.g. Driving)

Managing Your Body *Led by your Named Nurse*

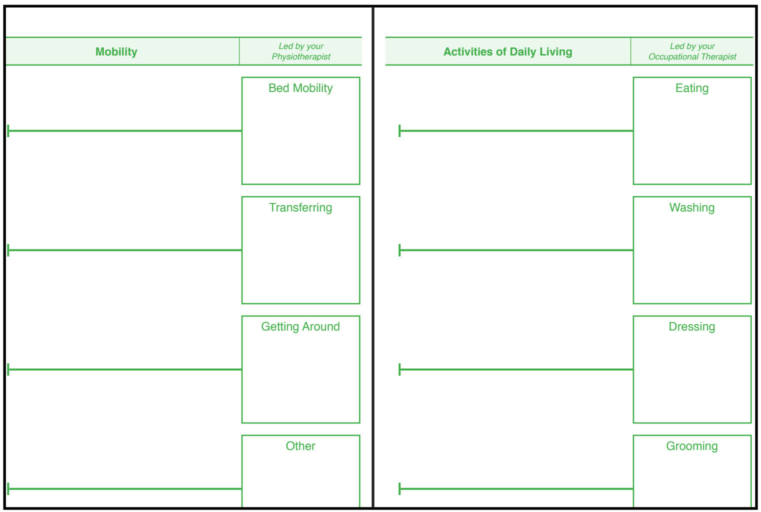
Independent Skin Management

Independent Bladder Management

Independent Bowel Management

Other (e.g. Sexual Issues, Autonomic Dysreflexia)

4



Mobility *Led by your Physiotherapist*

Bed Mobility

Transferring

Getting Around

Other

Activities of Daily Living *Led by your Occupational Therapist*

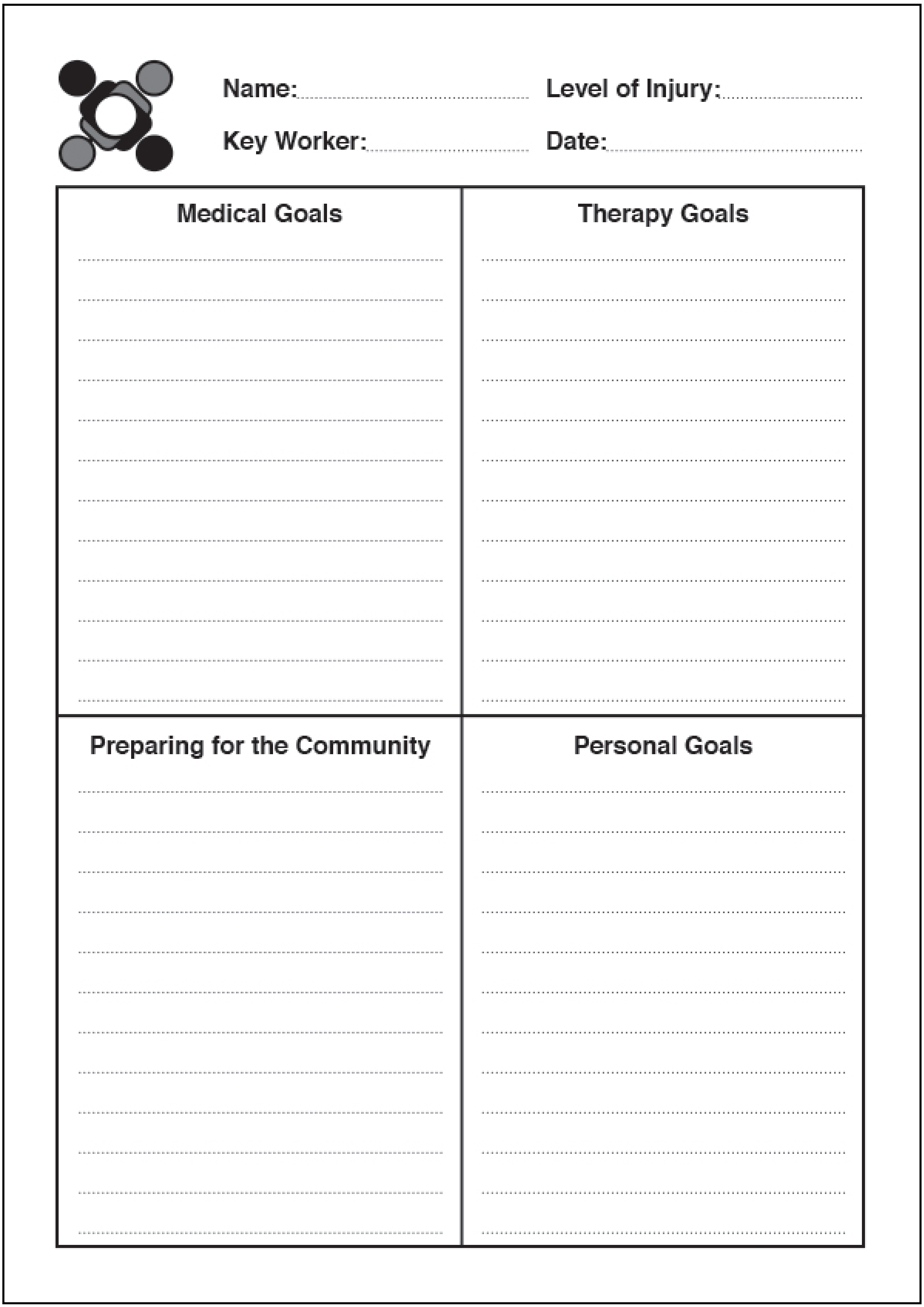
Eating

Washing

Dressing

Grooming

Appendix 25
Prototype iterations:
Goal Planning Record
Iteration 1

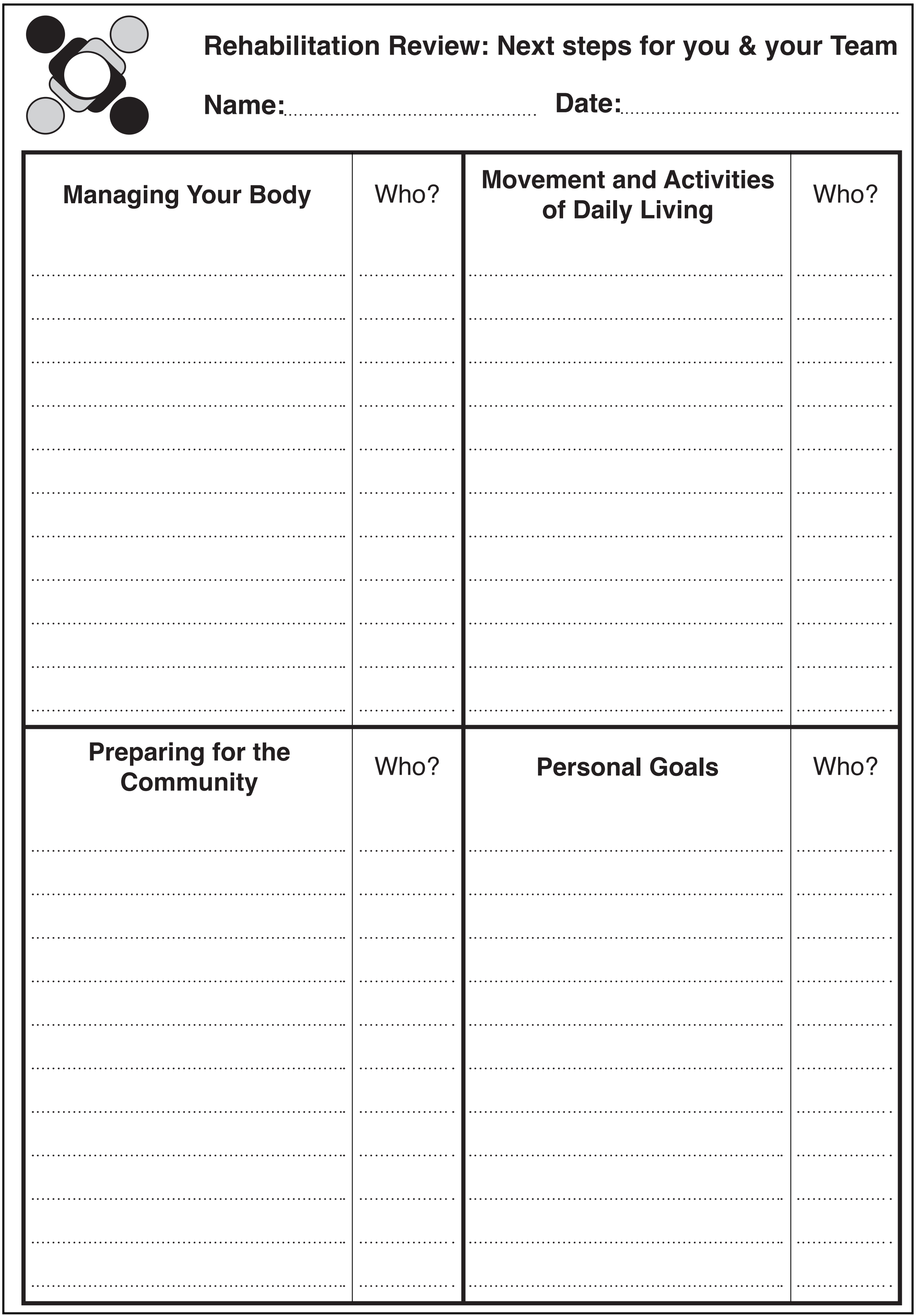


Name:.. **Level of Injury:**..............................

Key Worker:.............................. **Date:**..

Medical Goals	**Therapy Goals**
Preparing for the Community	**Personal Goals**

Appendix 25
Prototype iterations:
Goal Planning Record
Iteration 2



Rehabilitation Review: Next steps for you & your Team

Name:……………………………………… **Date:**………………………………………

Managing Your Body	Who?	Movement and Activities of Daily Living	Who?
Preparing for the Community	Who?	**Personal Goals**	Who?

Appendix 25

Prototype iterations:
Goal Planning Record
Iteration 3
[Printed double-sided, A4]

Goal Planning Meeting

Together, you and your Team will agree on some short term goals to guide your rehabilitation for the next few weeks.

Name: . . . . **Date:** . . . .

Activity + Assistance + Equipment + Date = Short Term Goal

Personal Goals	Date	Completed?

Suggested Goals	Date	Completed?

To do list	Who?	Completed?

Notes since the last meeting

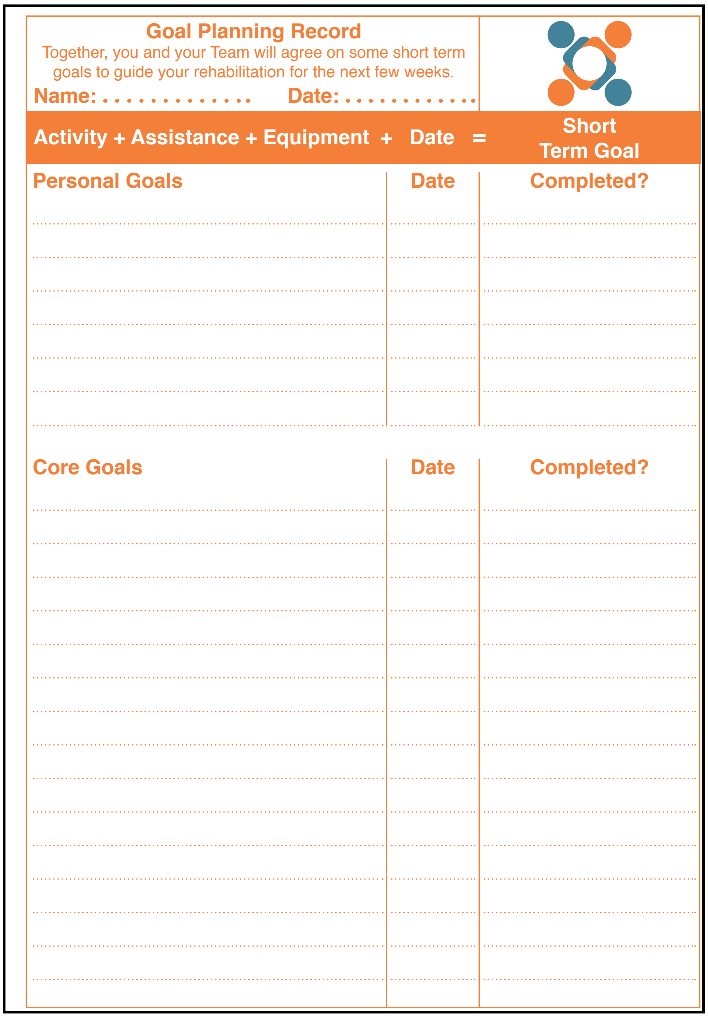
You may want to use this space to take notes on your progress, or any goals you'd like to suggest next time.

Progress Notes

Suggested goals for the next meeting

Appendix 25

Prototype iterations:
Goal Planning Record
Iteration 3
[Printed double-sided, A4]



Goal Planning Record

Together, you and your Team will agree on some short term goals to guide your rehabilitation for the next few weeks.

Name: . . . . **Date:** . . . .

Activity + Assistance + Equipment + Date = Short Term Goal

Personal Goals	Date	Completed?

Core Goals	Date	Completed?

To-Do List

You and your team will use this space to record the tasks that will help your rehabilitation to progress.

Task	Who?	Completed?

Appendix 26a: Co-Plan Folder: Front Page

Goal
Plan

Patient Folder

A place for you to store information about your injury and your goals

Name ....

Key Worker ....

Appendix 26b: Co-Plan Folder: Introduction to Rehabilitation booklet

Welcome to Goal Planning

In the Spinal Injuries Unit we use goals to help guide the rehabilitation journey, and we believe it is important that the patient is involved in setting these goals. The steps below describe how you and your team will learn from each other to set the best possible goals for you and maximise your potential.

How we do it

Consultant Meeting You Consultant	In this meeting, you and your Consultant will meet to discuss your injury, its effects and what this means for your rehabilitation. You are welcome to invite a family member or friend to this discussion, and another staff member will be present to take notes on the discussion for you to keep. Before this meeting, you may like to think about any questions you might have, or what your priorities are for your rehabilitation.
Key Worker Meeting You Key Worker	This meeting is an opportunity for you to ask any questions you might have after your Consultant Meeting, and to discuss what is important for you to achieve while you are in the Spinal Injuries Unit. Together with your Key Worker, you will set informed, realistic and meaningful long-term goals to aim for by the point of discharge.
Goal Planning Meeting 1	This will be your first meeting with your whole Rehabilitation Team. Together, you will discuss the long-term goals you have set with your Key Worker, and agree on some short-term goals to help you work towards them. You are welcome to invite 1-2 family members or friends to your Goal Planning Meetings if you wish.
Goal Planning Meeting 2, 3, etc	In your second Goal Planning Meeting, and each Goal Planning Meeting after that, you will review the progress you have made and set some new short-term goals to aim for by your next meeting. The team want to help you make your goals relevant to you and your lifestyle, and as you gain more confidence you are welcome to take as much control over these meetings as you feel comfortable with.

Welcome to Rehabilitation

Your rehabilitation will be guided and supported by your Rehabilitation Team. They will help you to gradually take more responsibility for your daily routine and prepare you to live as independently as possible in the community.

Who we are

Consultant	**Named Nurse**	**Physiotherapist**
....	....	....
Responsible for your overall medical care.	Manages your nursing care, such as skin, bowel and bladder routines.	Gives advice on wheelchair choice (if needed) and works with you towards physical rehabilitation goals, such as getting around.
Occupational Therapist	**Discharge Coordinator**	**Psychologist**
....	....	....
Gives advice on housing, equipment and wheelchair cushion (if needed). Also works with you in everyday activities, such as washing, dressing, work or driving.	Helps to coordinate your discharge and link with local services.	Provides assessment and psychological support for those finding it hard to adjust to their current circumstances.

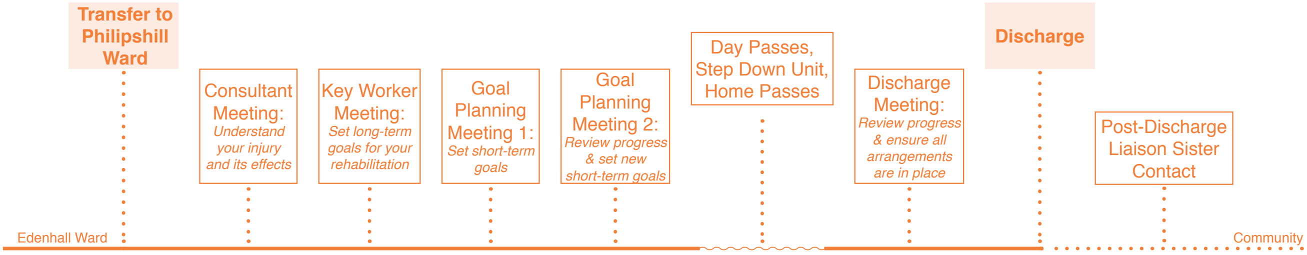
One of these staff members will also be your Key Worker. They will be your first point of contact for most questions, and they will also help you to coordinate your Rehabilitation Team.

Later on in your rehabilitation, you will meet your Liaison Nurse - a specialist nurse who can offer support upon discharge.

Each person's rehabilitation journey is different, but our unit has over 20 years of experience and we are all committed to helping you to achieve your potential.

This booklet will give you a timeline of the key events in your rehabilitation, which we will adapt to meet your needs.

A Rehabilitation Timeline


Transfer to Philipshill Ward

Consultant Meeting: *Understand your injury and its effects*

Key Worker Meeting: *Set long-term goals for your rehabilitation*

Goal Planning Meeting 1: *Set short-term goals*

Goal Planning Meeting 2: *Review progress & set new short-term goals*

Day Passes, Step Down Unit, Home Passes

Discharge Meeting: *Review progress & ensure all arrangements are in place*

Discharge

Post-Discharge Liaison Sister Contact

Edenhall Ward

Community

At this point, you will be medically stable and ready to begin active rehabilitation.

You may have more or less Goal Planning Meetings, depending on your unique needs.

At this point, you will be safe, well and ready to put into practise what you have learnt.

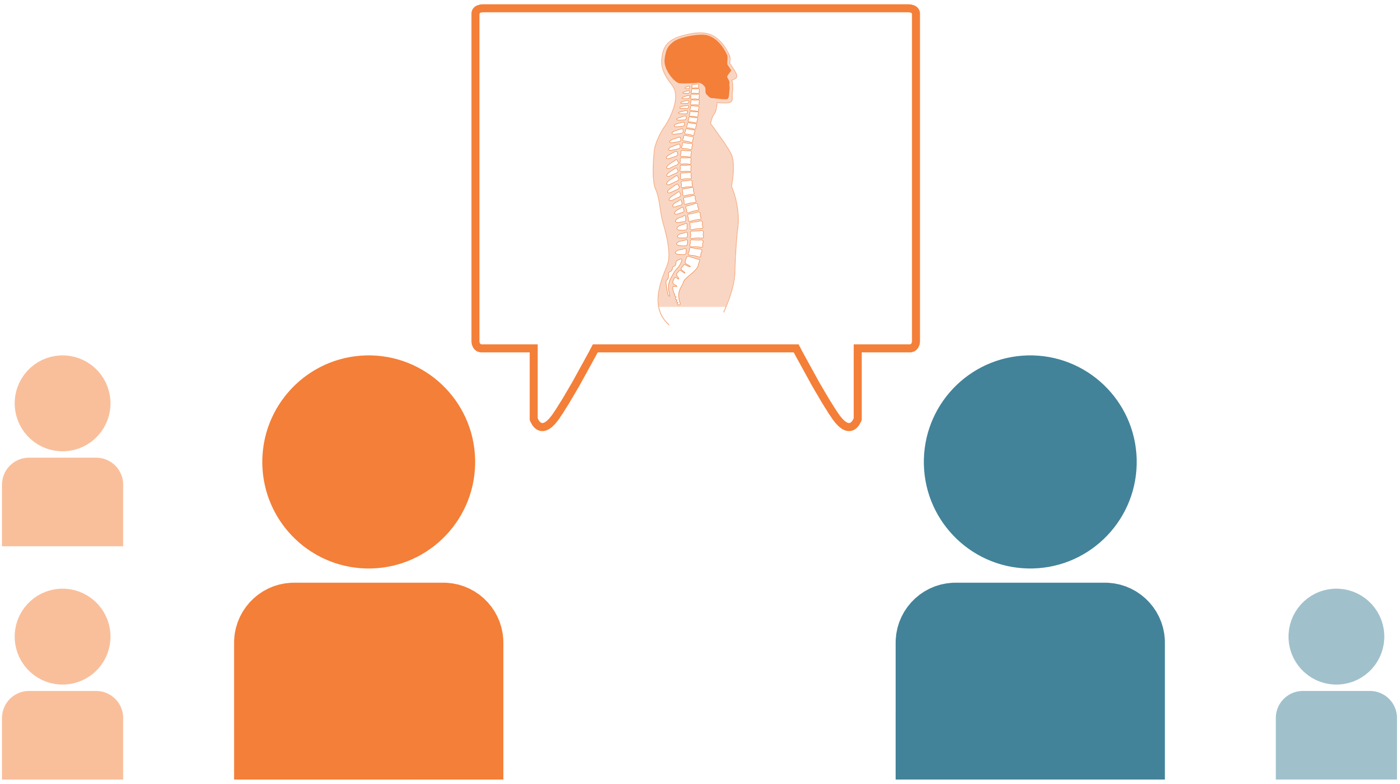
What we do

A transfer of knowledge and responsibility

Your Rehabilitation Team will work together to help you take more responsibility for your independence over time. This will include learning techniques for everyday tasks (i.e. washing), as well as attending the gym, patient education and social events.

The Spinal Injuries Unit provides lifelong care. The Liaison Sister will contact you several weeks after discharge, and you will have regular outpatient check-ups after that. Other services, such as the fertility clinic, are also available.

We understand that this may seem a long and complicated process, but you will be given all the advice and support you need by a team of experienced staff. In the Spinal Injuries Unit, rehabilitation goals are used to guide patients in their journey. On the next page we will explain how we help patients set informed, realistic and meaningful goals with their team.



Consultant Meeting Reminder

Date ………………………………

Time ………………………………

Place ………………………………

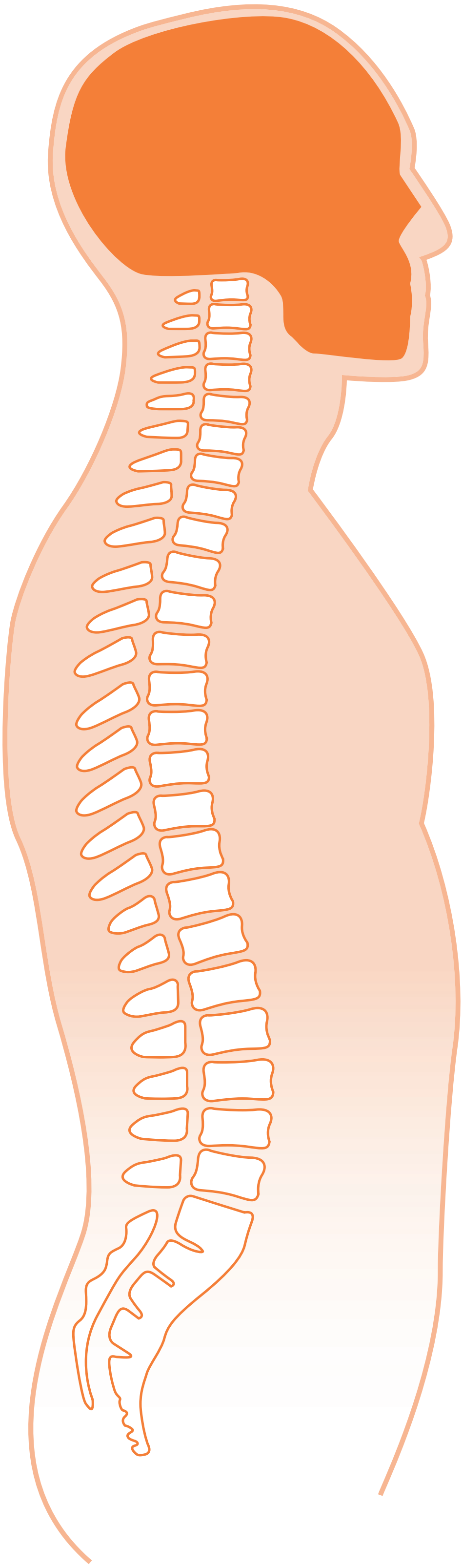
Who ………………………………

Consultant Meeting

Helping you to understand your injury and its effects.

Name: . . . . **Doctor:** . . . .

Injury Level: . . . . **Injury Type:** . . . .



Estimated Discharge Date: . . . .

Appendix 26e:
Co-Plan Folder:
Consultant Meeting Agenda
(Used by staff only)

Consultant Meeting Guidance

Prepare

- Anonymous X-ray(s)/Scan(s)
- Spine Model & Metalwork
- Estimated Discharge Date

Agenda

1. **Introduction** - structure overview, encourage questions.
2. **The Spine** - use model to explain how the spine and cord work
3. **The Injury**
   - use model and scans to explain the level
   - explain complete/incomplete
   - Use model, scans & metalwork to explain surgery
   - Record the above on the Meeting Record
4. **Likely Physical Outcomes**
   - explain likely permanence/improvement of current movement/sensation (including walking)
5. **Daily effects:**
   - **Mobility:** Getting around (W/C user?), Transfers
   - **ADL's:** Wash, Dress, Eat Groom (independently?)
   - **Body:** Skin, Bladder, Bowel (independent?)
   - **Community:** Accommodation recap, Education/Employment
6. **Patient Priorities** - Discuss any key issues not already covered, I.e. Sexual Issues, Fertility, etc
7. **Key Worker Recap**
8. **Estimated Discharge Date**
9. **Patient/Family Questions**

End

Consultant leaves, Key Worker stays to
arrange date for the Key Worker Meeting.

Key Worker Meeting Reminder

Date ....

Time ....

Place ....

Who ....

Appendix 26g: Co-Plan Folder: Long-Term Goals Sheet

Long Term Goals *Goals to aim for by discharge, set by you and your Team.*	**Name:**............... **Key Worker:**..............

In the meeting today, we will discuss:

- Any questions or concerns you have after your consultant meeting
- Personal goals that you would like to achieve by discharge
- Goals set by your Rehabilitation Team to maximise your potential

Personal Priorities *Led by You*

3

Notes

1

2

Managing Your Body *Guided by your Named Nurse*

Independent Skin Management	Independent Bladder Management	Independent Bowel Management	Other (e.g. Sexual Issues, Autonomic Dysreflexia)

Mobility & Activities of Daily Living *Guided by your Physiotherapist & Occupational Therapist*

Bed Mobility	Transferring	Getting Around	Other
Eating	Washing	Dressing	Grooming

Preparation for the Community *Guided by your Discharge Coordinator & your Occupational Therapist*

Accommodation	Finance	Community Support	Education / Work

Appendix 26h: Co-Plan Folder: Goal Planning Meeting Reminder sheet

Goal Planning Meeting Reminder

Date ....

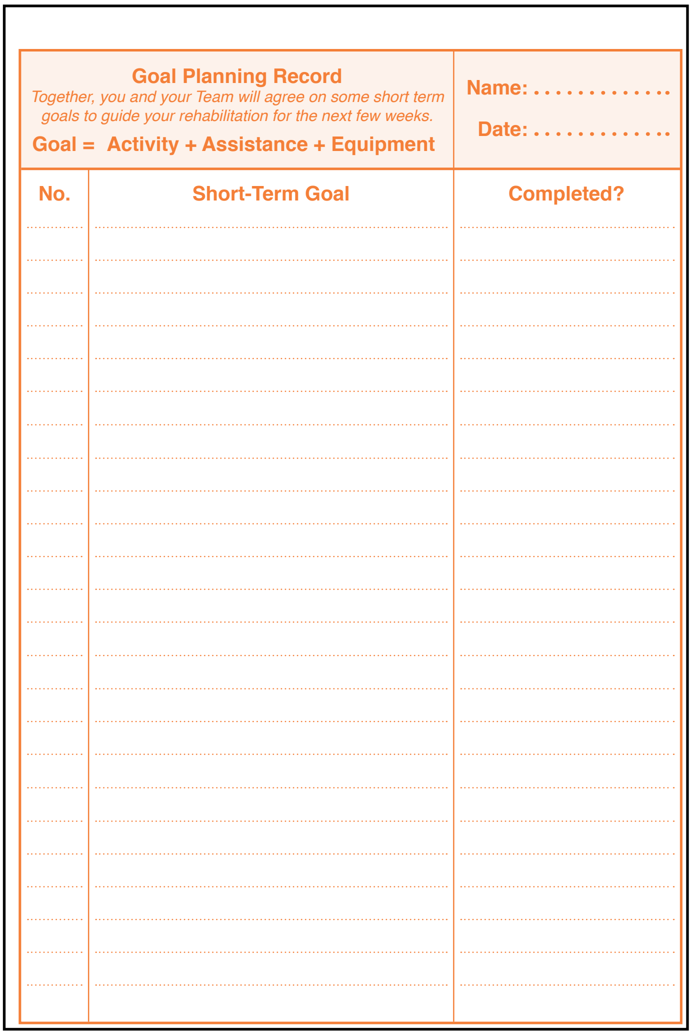
Time ....

Place ....

Who ....

Appendix 26i

Goal Planning Record,
as used in the first GPM
with each patient
(Printed double sided on A4)



Goal Planning Record

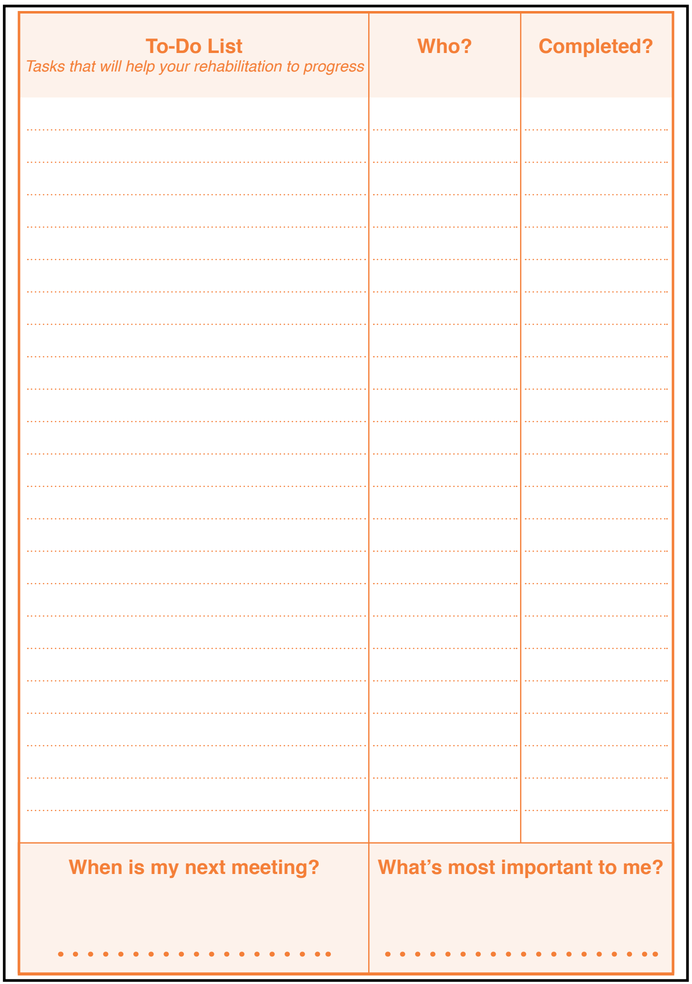
Together, you and your Team will agree on some short term goals to guide your rehabilitation for the next few weeks.

Goal = Activity + Assistance + Equipment

Name: . . . .

Date: . . . .

No.	Short-Term Goal	Completed?



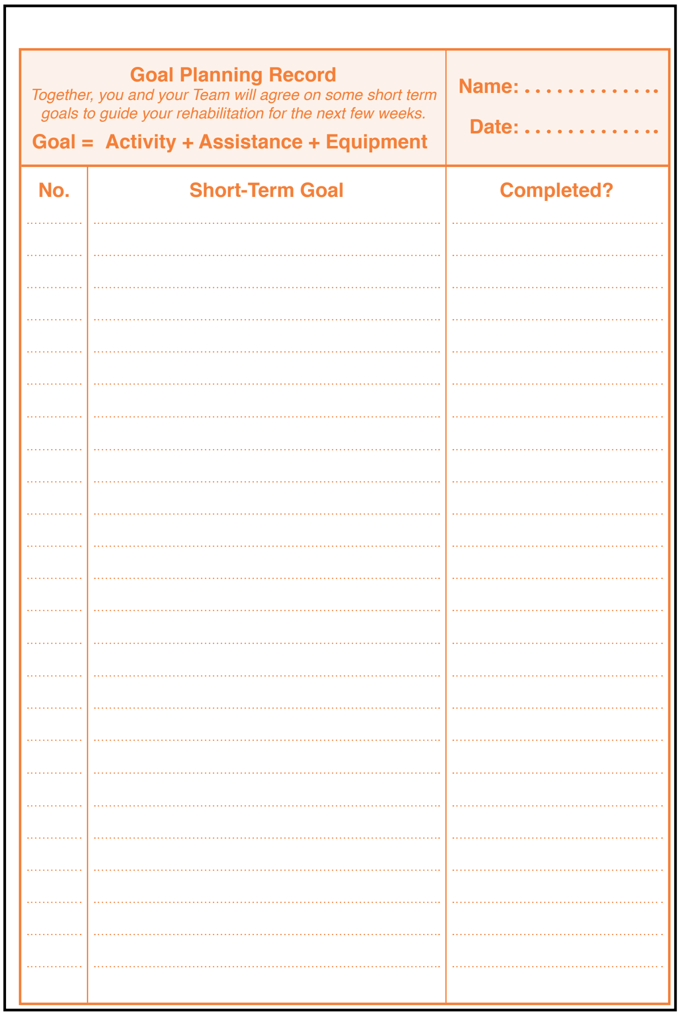
To-Do List *Tasks that will help your rehabilitation to progress*	Who?	Completed?

When is my next meeting?
. . . .

What's most important to me?
. . . .

Appendix 26j

Goal Planning Record,
as used in the second GPM
with each patient
Part 1 of 2
(Printed double sided on A4)



Goal Planning Record

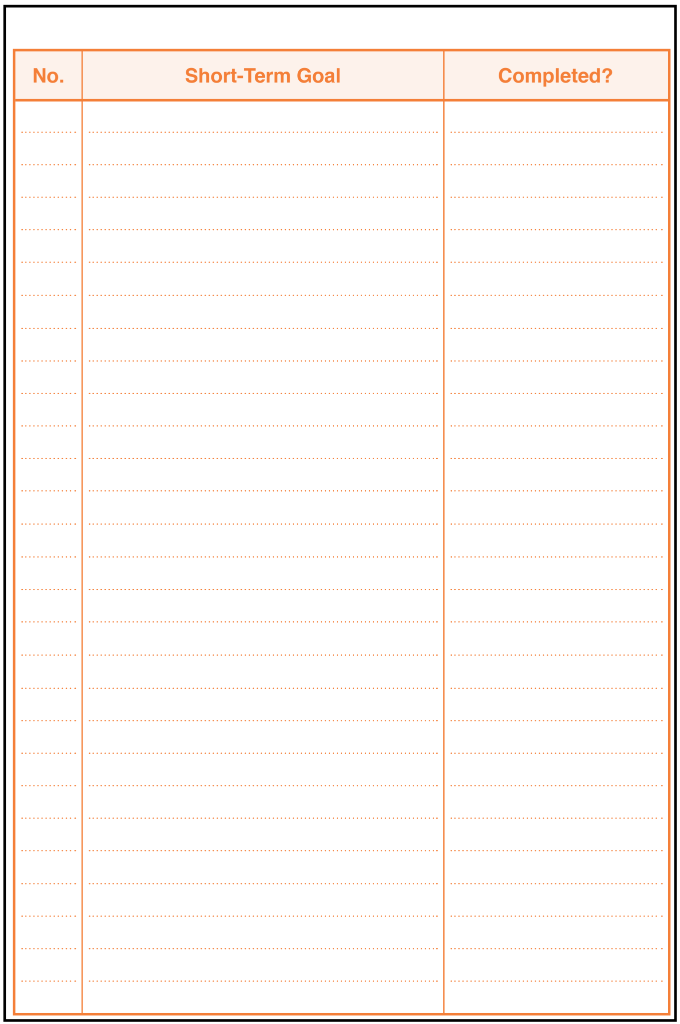
Together, you and your Team will agree on some short term goals to guide your rehabilitation for the next few weeks.

Goal = Activity + Assistance + Equipment

Name: . . . .

Date: . . . .

No.	Short-Term Goal	Completed?



No.	Short-Term Goal	Completed?

Appendix 26j
Goal Planning Record,
as used in the second GPM
with each patient
Part 2 of 2
(Printed double sided on A4)

To-Do List *Tasks that will help your rehabilitation to progress*	**Name:** . . . . **Date:**	
Task	**Who?**	**Completed?**
When is my next meeting?	**What's most important to me?**	

Task	**Who?**	**Completed?**

Notes

Appendix 27: Reformatted Goal Planning Progress Chart (used by staff only)

Goal Planning Progress Chart

Discipline ....

Patient ....

U/N ....

CHI ....

Date ....

Meeting No. ....

Next Meeting ....

1. Psychological
2. Activities of Daily Living
3. Skin
4. Bladder
5. Sexual/Fertility
6. Autonomic Dysreflexia
7. Bowel
8. Chest
9. Joints
10. Mobility
11. Equipment
12. Accommodation
13. Social
14. Education
15. Employment
16. Discharge

Need	**Goal** (Activity + Equipment + Assistance)	**Review**	**New Targets Set**

Reason for unachieved goal	**1.** Staff/Organisational Issues **2.** Patient’s Issues **3.** Medical Complications **4.** Other **5.** New Need

Appendix 27: Reformatted Goal Planning Progress Chart (used by staff only)

Need	**Goal** (Activity + Equipment + Assistance)	**Review**	**New Targets Set**

Appendix 28: Letter from Consultant to SIU staff evaluating the Consultant Meeting

Queen Elizabeth University Hospital
1345 Govan Road
Glasgow G51 4TF
☏ 0141 201 [redacted]

Queen Elizabeth
National Spinal Injuries Unit for Scotland

Administrative Enquiries to:- 0141 201 [redacted]

Email [redacted]@ggc.scot.nhs.uk

Direct line: 0141 201 [redacted]
Liaison Sisters: 0141 201 [redacted]
Out-patient Clinic: 0141 201 [redacted]

Our ref: [redacted]
Date: 4 February 2015

Dear Colleagues

Rehabilitation Pathway Redesign – Outcome of First Formal Consultant/Key Worker Meeting

I would like to share our thoughts of the first formal consultant/key worker patient meeting that we held today using the formal structure. Patient was [redacted], a 67 year old C5 tetraplegic.

<u>Good Points</u>

Both [redacted] and I had gone over nearly all of the issues with the patient before so nothing came as a surprise. He had good recall from previous conversations. The model spine was particularly useful. It was good to set a formal discharge date.

I think we were particularly lucky because despite a very serious injury the patient has been medically very well and alert.

<u>Bad Points</u>

These were minor. There was no imaging available because PACS isn't on the laptops on [redacted]. I have asked for this to be fixed. Afterwards we agreed that I had not spent enough time explaining how the paralysis would affect bowels and bladder.

Overall we think this went very well and I would encourage other people to use the current format.

Best Wishes

Yours sincerely,

[redacted]
Lead Clinician in Spinal Injury
Queen Elizabeth National Spinal Injury Unit for Scotland

Bibliography

AKAMA, Y. and PRENDIVILLE, A. (2013) Embody, Enacting and Entangling Design: A Phenomenological View to Co-Designing Services. *Swedish Design Research Journal.* **1,** 29-40

ALBEN, L. (1996). Quality of experience: defining the criteria for effective interaction design. *Interactions*. **3** (3), 11-15

ALI, Z. and BHASKAR, S. (2016). Basic statistical tools in research and data analysis. *Indian Journal of Anaesthesia*. **60**(9), 662-9

ALLAN, D. (2013). Clinical Director, Queen Elizabeth National Spinal Injuries Unit, Glasgow, Scotland. Conversation with the author, October. Personal communication.

ALMQUIST, J., KELLY, C., BROMBERG, J., BRYANT, S., CHRISTIANSON, T. and MONTORI, V. (2009). Consultation Room Design and the Clinical Encounter: The Space and Interaction Randomized Trial. *Health Environments Research & Design Journal*. **3** (1)

ALMQVIST, F. (2017). The fuzzy front-end and the forgotten back-end: User involvement in later development phases. *The Design Journal*. **20**(1), 2524-33

ALTUNA, A. AND JUN, G. (2014). The Applicability of Online Communities in Health Service Co-Design. In: *Proceedings of Fourth Service Design and Innovation Conference,* Lancaster, UK

ANDERSEN, T. (2010). The Participatory Patient. In: *Proceedings of PDC2010*, 29-11-2010, Sydney, Australia.

ANDERSON, K., AITO, S., ATKINS, M., BIERING-SØRENSEN, F., CHARLIFUE, S., CURT, A., DITUNNO, J., GLASS, C., MARINO, R., MARSHALL, R., MULCAHEY, M., POST, M., SAVIC, G., SCIVOLETTO, G and CATZ, A. (2008). Functional recovery measures for spinal cord injury: An evidence-based review of clinical practice and research. *Journal of Spinal Cord Medicine*. **31** (2), 133-144

ANGUS, D., WATSON, B., SMITH, A., GALLOIS, C. and WILES, J. (2012). Visualising Conversation Structure across Time: Insights into Effective Doctor-Patient Consultations. *PLoS ONE.* **7**(6)

ANZAI, K., YOUNG, J., McCALLUM, J., MILLER, B. and JONGBLOED, L. (2006). Factors influencing discharge location following high lesion spinal cord injury rehabilitation in British Columbia, Canada. *Spinal Cord*. **44**, 11-18

ARNSTEIN, S. (1969). A ladder of citizen participation. *Journal of the American Institute of Planners.* **35** (4), 216-224

BACK UP TRUST (2014). *About spinal cord injury.* [online]. www.backuptrust.org.uk/about-spinal-cord-injury

BAKER, R. (1993). Use of psychometrics to develop a measure of patient satisfaction for general practice. In: FITZPATRICK, R. and HOPKINS, A. (eds.). *Measurement of Patients' Satisfaction with their Care*. London, Royal College of Physicians of London, 57-76

BAKER, Susan, MARSHAK, Helen, RICE, Gail and ZIMMERMAN, Grenith (2001). Patient Participation in Physical Therapy Goal Setting. *Physical Therapy.* **81** (5), 1119-26

BAR-ELI, M., HARTMAN, I. AND LEVY-KOLKER, N. (1994). Using Goal Setting to Improve Physical Performance of Adolescents With Behavior Disorders: The Effect of Goal Proximity. *Adapted Physical Activity Quarterly.* **11**, 86-97

BARELLO, S., GRAFFIGNA, G. and VEGNI, E. (2012). Patient engagement as an emerging challenge for healthcare services: Mapping the literature. *Nursing research and practice.*

BARNARD, R., CRUICE, M. and PLAYFORD, E. (2010). Strategies used in the pursuit of achievability during goal setting in rehabilitation. *Qualitative Health Research,* **20** (2), 239-250.

BARRY, A. (2001). *Political Machines: Governing a Technological Society.* London, Athlone.

BATE, P. and ROBERT, G. (2007) *Bringing User Experience to Healthcare Improvement: the concepts, methods and practices of experience-based design.* Abingdon, Radcliffe Publishing Ltd

BEKKER, H., HEWISON, J. and THORNTON, J. (2004). Applying decision analysis to facilitate informed decision making about prenatal diagnosis for Down syndrome: a randomised controlled trial. *Prenatal Diagnosis*. **24** (4), 265-75

BERKUN, S. (2004). *Programmers, designers and the Brooklyn Bridge. Essays on design, engineering and project management*. [online]. www.scittberkun.com/essays/essay30.htm

BERRY, C. and KENNEDY, P. (2002). A psychometric analysis of the Needs Assessment Checklist (NAC). *Spinal Cord.* **41**, 490-501

BIGGS, M. and BÜCHLER, D. (2007). Rigor and practice-based research. *Design Issues*. **23**(3), 62-69

BJÖRGVINNSON, E., EHN, P. and HILLGREN, P. (2010). Participatory Design and democratizing innovation. In: *Proceedings of PDC2010*, Sydney, Australia

BJÖRGVINNSON, E., EHN, P. and HILLGREN, P. (2012) Design Things and Design Thinking: Contemporary Participatory Design Challenges. *Design Issues,* 28 (3), 101–116

BLOMBERG, J. (2009). Insider trading: engaging and valuing corporate ethnography. In: Cefkin, M. (ed.) *Ethnography and the corporate encounter.* New York, Berghahn Books

BLOMBERG, J. and DARRAH, C. (2015). Towards an anthropology of services. *The Design Journal,* **18**(2), 1771-92

BLOMBERG, J. and KARASTI, H. (2013). Ethnography: Positioning Ethnography within Participatory Design. In: SIMONSEN, J. and ROBERTSON, T. (eds) *Routledge International Handbook of Participatory Design*. New York, Routledge.

BØDKER, K. and GRANLIEN, M. (2008). Participation and Representation – a discussion based upon a case study in the Danish healthcare sector. In: *Proceedings of PDC2008, Indianna*

BØDKER, K., KENSING, F. and SIMONSEN, J. (2004). *Participatory IT Design: Designing for Business and Workplace Realities.* Cambridge, MA, MIT Press

BØDKER, S. (1996). Creating Conditions for Participation: Conflicts and Resources in Systems Design. *Human Computer Interaction,* **11**(3), p215-236

BOESS, S., MELLES, M., ALBAYRAK, A., NETTER, M., GOOSSENS, R., VEHMEIJER, S., KRAAN, G. and LANCASTER, J. (2013). Moving myself: insights for future patient experience journeys in orthopaedics. In: *Proceedings of Design4Health Conference 2013,* Sheffield, UK

BOVEND’EERDT, T., BOTELL, R. and WADE, D. (2009). Writing SMART rehabilitation goals and achieving goal attainment scaling: a practical guide. *Clinical Rehabilitation*. **23**, 352-361

BOWEN, S., A. DEARDEN, P. WRIGHT, D. WOLSTENHOLME, and M. COBB. (2010). Participatory Healthcare Service Design and Innovation. In: *Proceedings of the Participatory Design Conference – PDC'10*, 155– 158. New York, NY: ACM Press.

BOWEN, S., DEARDEN, A., WOLSTENHOLME, D. and COBB, M. (2011). Different views: including others in participatory health service innovation. In: BUUR, Jacob, (ed.) PINC 2011 : Participatory innovation conference 2011, 13-15 January, 2011, Sonderborg, Denmark. Sonderborg, University of Southern Denmark, 230-236

BOWEN, S., McSEVENY, K.M LOCKLEY, E., WOLSTENHOLME, D., COBB, M. and DEARDEN, A. (2013). How was it for you? Experiences of participatory design in the UK health service. *CoDesign*. **9** (4), 230-246

BRADLEY, E., CURRY, L. and DEVERS, K. (2007). Qualitative Data Analysis for Health Services Research: Developing Taxonomy, Themes and Theory. *Health Services Research.* **42**(4), 1758-1772

BRAGGE, P., PICCENNA, L., MIDDLETON, J., WILLIAMS, S., CREASEY, G., DUNLOP, S., BROWN, D. and GRUEN, R. (2015). Developing a spinal cord research strategy using a structured process of evidence review and stakeholder dialogue. Part I: rapid review of SCI prioritisation literature. *Spinal Cord*. **53**, 714-720

BRANDT, E. and GRUNNET, C., (2000). Evoking the future: drama and props in user centered design. In: *Proceedings of the participatory design conference*. New York: ACM Press, 11–20.

BRANDT., E., BINDER, T. and SANDERS, E. (2013) Tools and Techniques. In: SIMONSEN, J. and ROBERTSON, T. (eds) *Routledge International Handbook of Participatory Design*. New York, Routledge

BRATTETEIG, T., BØDKER, K., DITTRICH, Y., MOGENSEN and SIMONSEN, J. (2013) Methods: organising principles and general guidelines for Participatory Design projects. In: SIMONSEN, J. and ROBERTSON, T. (eds) *Routledge International Handbook of Participatory Design*. New York, Routledge.

BRISENDEN, Simon (1986). Independent Living and the Medical Model of Disability. *Disability, Handicap & Society,* **1** (2), 173-178.

BROCK, D. and WARTMAN, S. (1990). When Competent Patients Make Irrational Choices. *New England Journal of Medicine*. **322**, 1595-1599

BUCKINGHAMSHIRE HEALTHCARE (2014) *Guttmann conference 'comes home' to mark 70 years of spinal care at Stoke Mandeville*. [online]. www.buckshealthcare.nhs.uk/About/Guttmann-conference-comes-home.htm

BURNS, Colin, COTTAM, Hilary, VANSTONE, Chris and WINHALL, Jennie (2006). RED Paper 02: Transformation Design. London, Design Council. Available at: http://www.designcouncil.org.uk/resources/report/red-paper-02-transformation-design

BYRNES, M., BEILBY, J., RAY, P., McLENNAN, R., KER, J., and SCHUG, S. (2012). Patient-focused goal planning process and outcome after spinal cord injury rehabilitation: quantitative and qualitative audit. *Clinical Rehabilitation*. **26** (12), 1141-1149

CAMPBELL, E. (2009) *You know more than you think you do: design as resourcefulness and self-reliance.* London, Royal Society of Arts

CAMPBELL, E. (2011) *Design and Rehabilitation: A three-day workshop in design for people with spinal cord injuries*. London, Royal Society of Arts

CAMPBELL, E. (2012) *Report on the RSA's Design & Rehabilitation project at three spinal injury centres.* [online]. <http://www.thersa.org/__data/assets/pdf_file/0006/637215/Design-and-Rehabilitation-Report-at-three-spinal-injury-centres.pdf>

CAREY, D., TENNANT, A., RODGERS, P. and DODD, K. (2017). User-Designed Dementia Care Pathways. *The Design Journal.***20**(1), 2534-50

CARLILE, P. (2002). A pragmatic view of knowledge and boundaries: Boundary objects in new product development. *Organization Science,* **13**(4), 442-455.

CARMAN, K., DARDESS, P., MAURER, M., SOFAER, S., ADAMS, K., BECHTEL, C. and SWEENEY, J. (2013). Patient family and engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs.* **32** (2), 223-231

CARPENTER, C. (1994). The Experience of Spinal Cord Injury: The Individual's Perspective – Implications for Rehabilitation Practice. *Physical Therapy*. **74** (7), 614-628

CARR, V., SANGIORGI, D., BUSCHER, M., COOPER, R. and JUNGINGER, S. (2009). Clinicians as service designers? Reflections on current transformation in the UK health services. *First Nordic Conference on Service Design and Service Innovation*, Oslo, Norway, 24–26 November. Linköping University Electronic Press, 31–41. Available at: http://www.ep.liu.se/ecp/059/004/ ecp09059004.pdf

CARR, V., SANGIORGI, D., BÜSCHER, M., JUNGINGER, S. and COOPER, R. (2011). Integrating Evidence-based and Experience-based approaches in healthcare service design *HERD*. **4**(11), 12-33

CARSON, K., VERBIEST, M., CRONE, M., BRINN, M., ESTERMAN, A., ASSENDELFT, W. and SMITH, B. (2012). *Training health professionals in smoking cessation (review).* [online]. http://cochranelibrary-wiley.com/doi/10.1002/14651858.CD000214.pub2/epdf

CHAMBERLAIN, P. and PARTRIDGE, R. (2017). Co-designing co-design. Shifting the culture of practice in healthcare. *The Design Journal,* **20**(1), 2010-21

CHAMBERLAIN, P., WOLSTENHOLME, D., DEXTER, M., SEALS, E. (2015). *The State of the Art of Design in Health: An expert-led review of the extent of the art of design theory and practice in health and social care.* Sheffield, Sheffield Hallam University.

Chartered Society of Physiotherapists (2017). *What is Rehabilitation?* [online]. http://www.csp.org.uk/your-health/conditions/rehabilitation#what-is-rehabilitation

CLEARY P., EDGMAN-LEVITAN S., MCMULLEN, W., DELBANCO, T. (1992). The relationship between reported problems and patient summary evaluations of hospital care. *Quality Review Bulletin*, vol 18, no 2, pp 53–9.

COLLINS, K., COOK, M. and CHOUKEIR, J. (2017). Designing on the spikes of injustice: Representation and co-design. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

COTTAM, H. and LEADBEATER C. (2004). *Health: Co-creating services (RED paper 01).* London, UK: Design Council.

COUGHLAN, Peter, SURI, Jane and CANALES, Katherine (2007). Prototypes as (Design) Tools for Behavioral and Organizational Change: A Design-Based Approach to Help Organizations Change Work Behaviors. *The Journal of Applied Behavioral Science.* **43**(1), 1-13

COULTER, A. (2002). Patient views of the good doctor. *BMJ.* **325**, 668-669

COULTER, A. (2006) *Engaging patients in their healthcare: How is the UK doing relative to other countries?* [online]. http://www.picker.org/wp-content/uploads/2014/10/Engaging-patients-in-their-healthcare-how-is-the-UK-doing....pdf

COULTER, A. (2007). When should you involve patients in treatment decisions? *British Journal of General Practice.* **57**, 771-772

COULTER, A. (2010). Do patients want a choice and does it work? *BMJ*. **341**, 973-975

COULTER, A. and CLEARY, P. (2002). Measuring and improving patients' experiences: how can we make health care systems work for patients? In: *Measuring Up: Improving health system performance in OECD countries.* OECD, Paris, p211-224

COULTER, A. and COLLINS, A. (2011). *Making Shared Decision Making a Reality*. London, The King's Fund

COULTER, A. and ELLINS, J. (2006). *Patient-focused interventions: A review of the evidence.* London, The Health Foundation.

COULTER, A. and ELWYN, G. (2002). What do patients want from high-quality general practice and how do we involve them in improvement? *British Journal of General Practice*. **52**, S22-S26

COULTER, A. and MAGEE, H. (2003) *The European patient of the future—state of health.* Open University Press, Maidenhead

COULTER, A., FITZPATRICK, R. AND CORNWELL, J. (2009). *The Point of Care: Measures of patients' experience in hospital: purpose, methods and uses.* London, The King's Fund.

COULTER, A., HARTER, M., MOUMJID-FERDJAOUI, N., PERESTELO-PEREZ, L. and VAN DER WEIJDEN, T. (2015). European Experience with Shared Decision Making. *The International Journal of Person Centred Medicine*. **5** (1), 9-14

COULTER, A., LOCOCK, L., ZIEBLAND, S. and CALABRESE, J. (2014). Collecting data on patient experience is not enough: they must be used to improve care. *BMJ.* **348**

CRAWFORD, M., RUTTER, D., MANLEY, C, WEAVER, T., BHUI, K, FULOP, N. and TYRER, P. (2002). Systematic review of involving patients in the planning and development of health care. *BMJ*. **325**

CROSS, N. (2001). Designerly Ways of Knowing: Design Discipline Versus Design Science. *Design Issues.* **17** (3), 49-55

CULLEY, C. and EVANS, J. (2010). SMS text messaging as a means of increasing recall of therapy goals in brain injury rehabilitation: A single-blind within-subjects trial. *Neuropsychological Rehabilitation*, 20(1), pp.103-119

DEPARTMENT OF HEALTH (2006). *Our health, our care, our say: a new direction for community services.* [online]. https://www.gov.uk/government/uploads/system/uploads/attachment_data /file/272238/6737.pdf

DESIGN COUNCIL (2011). *Reducing violence and aggression in A&E.* [online] https://www.designcouncil.org.uk/sites/default/files/asset/document/ ReducingViolenceAndAggressionInAandE.pdf

DeVIVO, M. and FINE, P. (1985). Spinal Cord Injury: Its Short-term Impact on Marital Status. *Physical Medicine and Rehabilitation*. **66**, 501-504

DEY, I. (1993). *Qualitative data analysis: a user friendly guide for social scientists.* London, Routledge

DICKSON, A., O.BRIEN, G., WARD, R., ALLAN, D. and O.CARROLL, R. (2010) The impact of assuming the primary caregiver role following traumatic spinal cord injury: An interpretative phenomenological analysis of the spouse's experience. *Psychology and Health.* **25** (9), 1101-20

DICKSON, A., O.BRIEN, G., WARD, R., FLOWERS, P., ALLAN, D. and O’CARROLL, R. (2011). Difficulties adjusting to post-discharge life following spinal cord injury: an interpretive phenomenological analysis. *Psychology and Health.* **16** (4), 463-74

DIJKERS, M. (1999). Correlates of life satisfaction among persons with spinal cord injury. *Archives of Physical Medical Rehabilitation,* **80**, 867-876.

DONETTO, Sara, PIERRI, Paola, TSIANAKAS, Vicki and ROBERT, Glenn (2015). Experience-based Co-design and Healthcare Improvement: Realizing Participatory Design in the Public Sector. *The Design Journal*. **18** (2), 227-248

DONNELLY, C., ENG, J., HALL, J., ALFORD, L., GIACHINO, R., NORTON, K. AND KERR, D. (2004). Client-centred assessment and the identification of meaningful treatment goals for individuals with a spinal cord injury. *Spinal Cord*. **42**, 302-307

DUFF, J., EVANS, M. and KENNEDY, P. (2004). Goal planning: a retrospective audit of rehabilitation process and outcome. *Clinical Rehabilitation*. **18**, 275-286

DUFF, J., KENNEDY, P., SWALWELL, E. (1999) Clinical audit of physical rehabilitation: patients' views of goal planning. *Clin Psychol Forum.* **129**, 34-38.

EATON, S., COLLINS, A., COULTER, A., ELWYN, G., GRAZIN, N. and ROBERTS, S. (2012). Putting patients first. *BMJ*. **344**, 11

EHN, P., NILSSON, E. and TOPGAARD, R. (eds.) (2014). *Making Futures: Marginal notes on innovation, design and democracy*. London, MIT Press

EHN, Pelle (2008). Participation in design things. In: *Proceedings of the tenth anniversary conference on participatory design*, Bloomington, Indiana, 92-101

EIKELAND, O. (2006). The Validity of Action Research – Validity in Action Research. In: Nielsen & Svensson (eds.), *Action Research and Interactive Research*. Maastricht: Shaker.

ELDH, A. (2006). *Patient participation: what it is and what it is not.* PhD Thesis, Örebro University.

ELG., M., ENGSTRÖM, J., WITELL, L. and POKSINSKA, B. (2012). Co-creation and learning in health-care service development. *Journal of Service Management*. **23**(3), 328-43

ELLIOTT, T. and FRANK, R. (1996). Depression following spinal cord injury. *Physical Medical Rehabilitation*. **77**, 816-823

ELWYN, G., LAITNER, S., COULTER, A., WALKER, E., WATSON, P. and THOMPSON, R. (2010). Implementing shared decision making in the NHS. *BMJ*. **341**, 971-972

EMANUEL, E. and EMANUEL, L. (1992). Four Models of the Physician-Patient Relationship. *JAMA*. **267** (16), 2221-2226

ERIKSEN, M. (2012). *Material Matters in Co-designing – Formatting and Staging with Participating Materials in Co-design Projects, Events and Situations*. PhD Dissertation. Malmö University, Sweden.

ERIKSEN, M. and BANG, A. (2013). Experiments all the way – Diagrams of dialectics between a design research program and experiments. In: *Proceedings of Nordic Design Research Conference 2013*, Copenhagen-Malmo

EVANS, R., EDWARDS, A., COULTER, A. and ELWYN, G. (2007). Prominent strategy but rare in practice: shared decision-making and patient decision support technologies in the UK. *ZEFQ*. **101**, 247-253

FARR, M. (2013). Citizens and the co-creation of public service innovation. In: OSBORNE, S. P. and BROWN, L. (eds.). *Handbook of Innovation in Public Services.* Cheltenham: Edward Elgar, 445–458

FIELDING, N. (1993). Ethnography. In: FIELDING, N. (ed.) *Researching social life.* London, Sage

FISCHER, M. (2007). Four genealogies for a recombinant anthropology of science and technology. *Cultural Anthropology*, **22**(4), 539-615

FISCHER, M. and EREAUT, G. (2012). *When doctors and patients talk: making sense of the consultation.* London, The Health Foundation.

FITZPATRICK, R. and HOPKINS, A. (eds.) (1993). *Measurement of Patients' Satisfaction with their Care*. London, Royal College of Physicians of London,

FLYNN, K. E., SMITH, M. A. and VANNESS, D. (2006). A typology of preferences for participation in healthcare decision making. *Social Science and Medicine.* **63**, 1158-1169

FLYVBERG, B. (2006) Five Misunderstandings About Case Study Research. *Qualitative Inquiry,* 12 (2), 219–245

FOLEY, A. (1998). A review of goal planning in the rehabilitation of the spinal cord injured person. *Journal of Orthopoedic Nursing*. **2**, 148-152

FRANK, R., ELLIOTT, T., CORCORAN, J. and WONDERLICH, S. (1987). Depression after spinal cord injury: Is it necessary? *Clinical Psychology Review*. **7**, 611-630

FRAYLING, C. (1993). Research in Art and Design. *Royal College of Art Research Papers*. **1** (1), 1-5

FREIRE, K. and SANGIORGI, D. (2010). Service Design & Healthcare Innovation: from consumption to co-production and co-creation. In: *ServDes*, Linköping, Sweden, 1-3 December 2010

FUGLSANG, L. (2010). Bricolage and invisible innovation in public service innovation. *Journal of Innovation Economics & Management.* **1**(5), 67-87

FURNAS, G. and RUSSELL, D. (2005). Making sense of sensemaking. In: *CHI '05 workshops*, Portland, Oregon, USA, April 2-7

GALLOUJ, F. and WEINSTEIN, O. (1997). Innovation in Services. *Research Policy.* **26,**537-556

GAUDION, Katie, HALL, Ashley, MYERSON, Jeremy and PELLICANO, Liz (2015). A designer's approach: how can autistic adults with learning disabilities be involved in the design process? *CoDesign*. **11** (1), 49-69

GAVER, W., BOWERS, J., BOUCHER, A., GELLERSON, H., PENNINGTON, S., SCHMIDT,A., STEED, A., VILLARS, N., and WALKER, B. (2004). The Drift Table. In: *CHI '04* Extended Abstracts, 24–29 August, Vienna, Austria, 885–900. New York: ACM Press.

GAVER, W., DUNNE, T. and PACENTI, E. (1999). Cultural Probes. ACM Interactions January/February: 21–29.

GIUFFRIDA, A. and TORGERSON, D. (1997). Should we pay the patient? Review of financial incentives to enhance patient compliance. *BMJ*. **315,** 703-7

GLANVILLE, R. (1999). Researching Design and Designing Research. *Design Issues.* **15** (2), 80-91

GLANVILLE, Ranulph (2015). The sometimes uncomfortable marriages of design and research. In: RODGERS, Paul and YEE, Joyce (eds.). *The Routledge Companion to Design Research.* London, Routledge, 9-22

GLASER, B. (1992). *Emergence V Forcing Basics of Grounded Theory Analysis*. Mill Valley, CA, Sociology Press.

GLASER, B. and STRAUSS, A. (1967). *The discovery of grounded theory.* Chicago, Aldine.

GLORY FILM CO. (2011). *From Darkness into Light.* [online]. https://vimeo.com/73520184

GODIN, D. and ZAHEDI, M. (2014). Aspects of Research through Design. In: *Proceedings of DRS Conference 2014*. Umeå, Sweden

GRADINAR, A., DAVENPORT, J., HILL, H. and COULTON, P. (2017). Improving the Visualisation of Renal Blood Test Results to Enhance Patient–Clinician Communication. *The Design Journal*. **20**(1), 2363-74

GRAFFIGNA, G., BARELLO, S., BONANOMI, A., and LOZZA, E. (2015). Measuring patient engagement: development and psychometric properties of the Patient Health Engagement (PHE) scale. *Frontiers in psychology*, (6) 274

GRANDE, S., FABER, M., DURAND, M., THOMPSON, R. and ELWYN, G. (2014). A classification model of patient engagement methods and assessment of their feasibility in real-world settings. *Patient Education and Counseling.* **95**(2), 281-287

GREENE, J. and HIBBARD, J. (2011). Why Does Patient Activation Matter? *J Gen Intern Med.* **27** (5), 520-6

GREENE, J., HIBBARD, J., SACKS, R. and OVERTON, V. (2013). When Seeing The Same Physician, Highly Activated Patients Have Better Care Experiences Than Less Activated Patients. *Health Affairs.* **32** (7), 1299-1305

GREENE, L., LEVINE, D. and DEEDS, S. (1975). Clinical trials of health education for hypertensive outpatients: design and baseline data. *Prev Med*. **4** (417)

GREENHALGH, T., ROBERT, G., BATE, P. and KYRIAKIDOU, O. (2004). Diffusion of innovations in service organisations: Systematic review and recommendations. *The Milbank Quarterly*, **82**(4), 581-629

GRIFFIOEN, I., MELLES, M., STIGGELBOUT, A. AND SNELDERS, D. (2017). The potential of service design for improving the implementation of shared decision-making, *Design for Health*. **1**(2), 194-209

GRINEVICH, V. (2015). Design and Service Innovation: A Strategic Management Perspective. IN: SANGIORGI, D., PRENDIVILLE, A., JUNG, J. and YU, E. *Design for Service Innovation & Development: Final Report.* [online]. http://imagination.lancs.ac.uk/sites/default/files/outcome_downloads/desid_report_2015_web.pdf

GRÖNROOS, C. and GUMMERUS, J. (2014). The Service Revolution and Its Marketing Implications: Service Logic vs Service-Dominant Logic. *Journal of Managing Service Quality*, **24**(3), 206-229.

GRUNDY, David and SWAIN, Andrew (2002). *ABC of Spinal Cord Injury.* 4th ed., London, BMJ Publishing Group.

GUADAGNOLI, Edward and WARD, Patricia (1998). Patient participation in decision-making. *Social Science & Medicine.* **47** (3), 329-339

HAGEN, P. (2014). *Integrating user experience and evidence-based approaches to design.* [online]. http://www.smallfire.co.nz/2014/01/25/integrating-user-experience-and-evidence-based-approaches-to-design/

HAHN, B. and ZIMMERMAN, C. (2011). Visualizing Daily Hospital Routine. *Design Issues.***27**(3), 72-83

HALL, S., EVANS, J., and NIXON, S. (eds.) (2013). *Representation: Cultural Representations and Signifying Practices.* London, Sage Publications, 2nd Ed.

HAMMELL, K. (2004). Exploring quality of life following high spinal cord injury: a review and critique. *Spinal Cord*. **42**, 491-502

HANCOCK, K., CRAIG, A., DICKSON, H. CHANG, E. and MARTIN, J. (1993). *Paraplegia*. **31**, 349-357

HARTY, M., GRIESEL, M and VAN DER MERWE, A. (2011). The ICF as a common language for rehabilitation goal-setting: comparing client and professional priorities. *Health and Quality of Life Outcomes.* **9**

HENDERSON, A. and KYNG, M. (1991). There’s No Place like Home: Continuing Design in Use. In: GREENBAUM, J. and KYNG, M. (Eds.) *Design at Work: Cooperative Design of Computer Systems*. Lawrence Erlbaum, Hillsdale, 219-240

HERSEY, P. and BLANCHARD, K. (1988). *Management of Organizational Behaviour*. 5th ed., Pearson

HIBBARD, J. and GREENE, J. (2013). What the evidence shows about patient activation: Better health outcomes and care experiences. *Health Affairs.* **32** (2), 207-214

HIBBARD, J., MAHONEY, E., STOCK, R. and TUSLER, M. (2007). Do increases in patient activation result in improved self-management behaviours? *Health Serv Res.* **42** (4), 1443-63

HIBBARD, J., MAHONEY, E., STOCKARD, J. and TUSLER, M. (2005). Development and Testing of a Short Form of the Patient Activation Measure. *Health Serv Res.* **40** (6), 1918-30

HOLMES-ROVNER, M., NELSON, W., PIGNONE, M., ELWYN, G., ROVNER, D., O’CONNOR, A., COULTER, A. and CORREA-DE-ARAUJO, R. (2007). Are Patient Decision Aids the Best Way to Improve Clinical Decision Making? Report of the IPDAS Symposium. *Medical Decision Making*. **27**, 599-608

HOLMLID, S. (2009). Participative, co-operative, emancipatory: From participatory design to service design. In: *Proceedings of First Nordic Conference on Service Design and Service Innovation*. Oslo, 24-26 November 2009

HOLMLID, S. and WETTER-EDMAN, K. (2013). In and for the public sphere. *Swedish Design Research Journal.* **1**(13)

HOLMLID, S., WETTER-EDMAN, K. and EDVARDSSON, B. (2017). Breaking free from NSD: Design and service beyond new service development. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

HORST, W. (2011). *Prototypes as platforms for participation: Designing prototypes for collaborative product development.* PhD, University of Southern Denmark.

HURN, J., KNEEBONE, I. and CROPLEY, M. (2006). Goal setting as an outcome measure: a systematic review. *Clinical Rehabilitation*. **20**, 756-772

HYDE, P. and DAVIES, H. (2004). Service design, culture and performance: Collusion and co-production in health care. *Human Relations.* **57**(22), 1407-1426

IEDEMA, R., MERRICK, E., PIPER, D., BRITTON, K., GRAY, J., VERMA, R. and MANNING, N. (2010). Codesigning as a Discursive Practice in Emergency Health Services: The Architecture of Deliberation. *The Journal of Applied Behavioral Science*, 46: 73–91.

INGOLD, T. (2012). Introduction: The Perception of the User-Producer. In: GUNN, W. and DONOVAN, J. *Design and Anthropology.* London, Ashgate.

INSTITUTE OF MEDICINE (2001) *Crossing the Quality Chasm: A new health system for the 21st century.* Vol. 6. Washington, DC: National Academy Press.

JENKINSON, C., COULTER, C., BRUSTER, S., RICHARDS, N. and CHANDOLA, T. (2002). Patients' experiences and satisfaction with health care: results of a questionnaire study of specific aspects of care. *Quality and Safety of Health Care*. **11**, 335-339

JOHANSSON, L., VINK, J. and WETTER-EDMAN, K. (2017). A Trojan horse approach to changing mental health care for young people through service design. *Design for Health*, **1**(2), 245-55

JOHNSON, S. (2000). A Critical Evaluation of New Service Development Process. In: FITZSIMMONS, J. and FITZSIMMONS, M. (eds) *New Service Development: Creating memorable experiences.* California: Sage Publications.

JOHNSTONE, Lucy and DALLOS, Rudi (2014). *Formulation in Psychology and Psychotherapy.* Routledge, London.

JONES, Peter (2013). *Design for Care: Innovating Healthcare Experience.* New York, Rosenfeld Media

JUDD, F., STONE, J., WEBBER, J., BROWN, D and BURROWS, G. (1989). Depression following spinal cord injury. A prospective in-patient study. *The British Journal of Psychiatry.* **154** (5), 668-71

JUNGINGER, S. (2006). *Change in the Making.* PhD, Carnegie Mellon University.

JUNGINGER, S. and BAILEY, S. (2017). Designing vs. designers: How organizational design narratives shift the focus from designers to designing. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

KAASENEN, E., KARVONEN, H., LU, Y., VARSALUOMA, J. AND VÄÄTÄJÄ, H. (2015). The Fuzzy Front End of Experience Design. In: *Proceedings of NordiCHI, 2014*

KARASTI, H. (2014). Infrastructuring in Participatory Design. In: *Proceedings of PDC2014,* Windhoek, Namibia

KARASTI, H., BAKER, K. and MILLERAND, F. (2010). Infrastructure Time: Long-Term Matters in Collaborative Development. *Computer Supported Cooperative Work*, **19**(3-4), 377-415

KARVONEN, H., KOSKINEN, H., HAGGRÉN, J. (2012). Defining User Experience Goals for Future Concepts. In: VÄÄTÄJÄ, H., OLSSON, T., ROTO, V. AND SAVIOJA, P. (eds) *NordiCHI2012 UX Goals 2012 Workshop proceedings,* TUT Publication series

KENNEDY, P. and ROGERS, B. (2000). Reported quality of life of people with spinal cord injuries: a longitudinal analysis of the first 6 months post-discharge. *Spinal Cord.* **38**, 498-503

KENNEDY, P., SMITHSON, E. and BLAKEY, L. (2012). Planning and structuring spinal cord injury rehabilitation: The Needs Assessment Checklist. *Top Spinal Cord Injury Rehabilitation*. **18** (2), 135-137

KENNEDY, P., WALKER, L. and WHITE, D. (1991). Ecological evaluation of goal planning and advocacy in a rehabilitation environment for spinal cord injured people. *Paraplegia*. **29**, 197-202

KIMBELL, L. (2011). Designing for Service as One Way of Designing Services. *International Journal of Design.* **5** (2), 41-52

KIMBELL, L. (2012). Rethinking Design Thinking: Part II. *Design and Culture,* **4**, 129-148

KIMBELL, L. and BLOMBERG, J. (2017). The object of service design. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

KIRCHBERGER, E. and TETHER, B. (2017). Specialist service design consulting: The end of the beginning, or the beginning of the end? In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

KIRESUK, T. and SHERMAN, R. (1968). Goal Attainment Scaling: A General Method for Evaluating Comprehensive Community Mental Health Programs. *Community Mental Health Journal*. **4** (6), 443-453

KOSKINEN, I., BINDER, T. and REDSTRÖM, J. (2009). Lab, Field, Gallery and Beyond. *Artefact*. **2** (1), 46-57

KOSKINEN, I., ZIMMERMAN, J., BINDER, T., REDSTRÖM, J. abd WENSVEEN, S. (2011), *Design Research Through Practice: From the Lab, Field and Showroom,* New York, Morgan Kaufman.

KRAFF, H. (2018). A tool for reflection—on participant diversity and changeability over time in participatory design. *CoDesign*. **14**(1), 60-73

KRISHNAN, K., GLASS, C., JACKSON, H. and BINGLEY, J. (1988). Patient and nursing staff perceptions of living and working on a spinal injuries unit. *Paraplegia.* **26**, 287-292

KRONKVIST, J., JÄRVINEN, M. and LEINONEN, T. (2012). Games as Design Medium. In: *Proceedings of Third Service Design and Innovation Conference*, Helsinki, Finland

LANGLEY, J., CRAIG, C., GWILT, I., CHAMBERLAIN, P., BATEMAN, R. and PARTRIDGE, R. (2013). Applying inclusive design principles to improve self management in Spinal Cord Injury. In: *Proceedings of the Second European Conference on Design 4 Health 2013*, Sheffield, UK, 3 - 5 July 2013, 144 - 154

LATHAM, G. and SEIJTS, G. (1999). The effects of proximal and distal goals on performance on a moderately complex task. *Journal of Organizational Behavior*. **20**, 421-429

LEMKE, M. (2017). Limited Use Only: Exploring the Design of Everyday Objects for Upper Limb Stroke Rehabilitation. *The Design Journal.* **20**(6), 879-887

LEMKE, M., RAMÍREZ, E. and ROBINSON, B. (2017). Limited use only. How can the design of an everyday object help chronic stroke patients to overcome the learned nonuse of the upper limb? *The Design Journal*. **20**(1), 2397-2417

LENZE, E., MUNIN, M., QUEAR, T., DEW, M., ROGERS, J., BEGLEY, A. and REYNOLDS, C. (2004) The Pittsburgh Rehabilitation Participation Scale: reliability and validity of a clinician-rated measure of participation in acute rehabilitation. *Archives of Physical Medicine and Rehabilitation.* 85(3), 380-4.

LÉVI-STRAUSS, C. (1966). *The savage mind*. Chicago, The University of Chicago Press

LEWIN, S., SKEA, Z., ENTWISTLE, V. ZWARENSTEIN, M. AND DICK, J. (2001). Interventions for providers to promote a patient-centred approach in clinical consultations (Review). *The Cochrane Library.* **4**, Wiley

LIGHT, A., and AKAMA, Y. (2012). The Human Touch: Participatory Practice and the Role of Facilitation in Designing with Communities. In: *Proceedings of the Participatory Design Research Conference*, 61–70. New York, NY: ACM.

LINDBERG, J., KREUTER, M., TAFT, C. and PERSON, L-O (2013). Patient participation in care and rehabilitation from the perspective of patients with spinal cord injury. *Spinal Cord*. **51**, 834-837

LOCKE, E. and LATHAM, G. (2002). Building a Practically Useful Theory of Goal Setting and Task Motivation. *American Psychologist*. **57** (9), 705-717

LONGTIN, Y., SAX, H., LEAPE, L., SHERIDAN, S., DONALDSON, L. and PITTET, D. (2010). Patient Participation: Current Knowledge and Applicability to Patient Safety. *Mayo Clinic Proceedings.* **85** (1), 53-62

LOUDON, D., TAYLOR, A. and MACDONALD, A. (2013). Evaluating the effectiveness of visualising patients' motion data during stroke rehabilitation. In: *Proceedings of Design4Health Conference 2013,* Sheffield, UK

LUSCH, R. and VARGO, L. (2006). Service-dominant logic: Reactions, reflections and refinements. *Marketing Theory,* **6**(3), 281-288.

MACDONALD, A. (2013) Utilizing the designer within: A healthcare case study. In: *Nordic Design Research Conference,* Copenhagen-Malmö 2013

MACDONALD, A. (2014). Socio-technical Infrastructuring to assist Innovation in Healthcare Technologies. In: *Proceedings of NordDesign 2014,* Espoo, Finland

MACDONALD, A. and TEALE, G. (2011). Service innovation in hospital nutrition healthcare through co-design. In: *Proceedings of Design4Health Conference, Sheffield, UK*

MACDONALD, A., LOUDON, D. and TAYLOR, A. (2014). A design-led complex intervention for the stroke rehabilitation service. In: *Proceedings of Fourth Service Design and Innovation Conference,* Lancaster, UK

MACLEOD, G. and MACLEOD, L. (1996). Evaluation of client and staff satisfaction with a Goal Planning project implemented with people with spinal cord injuries. *Spinal Cord*. **34**, 525-530

MADDEN, Diana, CADET-JAMES, Yvonne, ATKINSON, Ian and LUI, Felecia (2014). Probes and prototypes: a participatory action research approach to codesign. *Codesign*. **10** (1), 31-45

MAFFEI, S., VILLARI, B. and FOGLIENI, F. (2013). Embedding Design Capacity in Public Organisations: Evaluation by Design for Public Services. *Swedish Design Research Journal*, **2**(12), 28-34

MALEC, J. (1999). Goal attainment scaling in rehabilitation. *Neuropsychological Rehabilitation*. **9** (3–4), 253–275

MANNS, P. and MAY, L. (2007). Perceptions of issues associated with the maintenance and improvement of long-term health in people with SCI. *Spinal Cord*. **45**, 411-419

MATTELMÄKI T. (2005). Applying probes - from inspirational notes to collaborative insights. *CoDesign*. **1** (2), 83-102

MATTELMÄKI T. (2008). Probing for co-exploring. *CoDesign*. **4** (1), 65-78

MATTELMÄKI, T. and VISSER, S. (2011). Lost in CO-X - Interpretations of Co-Design and Co-Creation. *Proceedings of IASDR'11, 4th World Conference on Design Research,* Delft University.

McCAMBRIDGE, Jim, WITTON, John and ELBOURNE, Diana (2014). Systematic review of the Hawthorne effect: New concepts are needed to study research participation effects. *Journal of Clinical Epidemiology*. **67**, 267-277

McCARTHY, J. and WRIGHT, P. (2015). *Taking [A]part.* London, England, MIT Press

McCAUGHEY, E. (2014). *Research Update*. [Internal presentation]. Held on 7th February, QENSIU

McCAUGHEY, E., PURCELL, M., McLEAN, A., FRASER, M., BEWICK, A., BOROTKANICS, R and ALLAN, D. (2016). Changing demographics of spinal cord injury over a 20-year period: a longitudinal population-based study in Scotland. Spinal Cord, 54, 270-276.

McGRATH, J., MARKS, J. and DAVIS, A. (1995). Towards interdisciplinary rehabilitation: further developments at Rivermead Rehabilitation Centre. *Clinical Rehabilitation*. **9**, 320-326

Medscape (2013) Functional outcomes per level of spinal cord injury. [online]. http://emedicine.medscape.com/article/322604-overview#a1

MERONI, A. and SANGIORGI D. (2011), A new discipline. In: MERONI, A. & SANGIORGI D. (eds), *Design for Services*, Aldershot, UK: Gower Publishing

METATLA, O., BRYAN-KINNS, N., STOCKMAN, T. and MARTIN, F. (2015). Designing with and for people living with visual impairments: audio-tactile mock-ups, audio diaries and participatory prototyping. *CoDesign*. **11** (1), 35-48

MIETTINEN, Satu (2011). Product Design: Developing products with service design applications. In: STICKDORN, Marc and SCHNEIDER, Jakob (eds.). *This Is Service Design Thinking.* Amsterdam, BIS Publishers. 56-67

MILLS, J., THURLOW, A. and MILLS, A. (2010). Making sense of sensemaking: the critical sensemaking approach. *Qualitative Research in Organizations and Management*. **5** (2), 182-195

MOL, A. (2008). *The Logic of Care: Health and the problem of patient choice.* London, Routledge.

MOLL, J. (2010). The Patient as Service Co-Creator. In: *Proceedings of PDC2010*, 29-11-2010, Sydney, Australia.

MØNSTED, T. and ONARHEIM, B. (2010). Segmentation of Users in PD for Healthcare. In: *Proceedings of PDC2010*, 29-11-2010, Sydney, Australia.

MOORE, C. and BUCHANNAN, D. (2013). Sweat the small stuff: A case study of small-scale change processes and consequences in acute care. *Health Services Management Research*, 26: 9–17.

MORISKY, D., GREEN, L. and LEVINE, D. (1986). Concurrent and Predictive Validity of a Self-reported Measure of Medication Adherence. *Medical care.* **24** (1), 67-74

MORRIS, J., SWIER-VOSNOS, A., DUSOLD, J and WOODWORTH, C. (2013) Comparison of able-bodied and spinal cord injured individuals' appraisals of disability. Spinal Cord. 51, 338 – 340

MOULD, G., BOWERS, J. and GHATTAS, M. (2010). The Evolution of the Pathway and its Role in Improving Patient Care. *Quality and Safety in Health Care*,**19**(5), 1–6

MULGAN, G. (2014). *Design in Public and Social Innovation.* London, NESTA

MULLANEY, Tara (2016). *Thinking beyond the Cure: A constructive design research investigation into the patient experience of radiotherapy.* PhD, Umeå University, Sweden.

NATIONAL SPINAL CORD INJURY STRATEGY BOARD (2012). *The Initial Management of Adults with Spinal Cord Injuries.* [online]. http://www.mascip.co.uk/wp-content/uploads/2015/03/The-Initial-Management-of-Adults-with-SCI.-NSCISB.pdf.

NELSON, H. and STOLTERMAN, E. (2003). The Design Way. Englewood Cliffs, NJ: Educational Technology Publications.

NESTA (2013). *By Us, For Us: The power of co-design and co-delivery*. [online]. https://www.nesta.org.uk/sites/default/files/the_power_of_co-design_and_co-delivery.pdf

NEUMANN, L. and STAR, S. (1996). Making Infrastructure: The Dream of a Common Language. In: *Proceedings of PDC1996*, 231-240

NEVES, Sandra (2014) *Enhancing the post-stroke patient experience at mealtime through participatory design: Eliciting, connecting and supporting multi-voicedness.* PhD thesis, Glasgow School of Art.

NHS ENGLAND (2014). *Five Year Forward View.* [online]. http://www.england.nhs.uk/wp-content/uploads/2014/10/5yfv-web.pdf

NHS ENGLAND (2017). *Next steps on the Five Year Forward View.* [online]. https://www.england.nhs.uk/wp-content/uploads/2017/03/NEXT-STEPS-ON-THE-NHS-FIVE-YEAR-FORWARD-VIEW.pdf

NICOLAS, M., HAGEN, P, RAHILLY, K. AND SWAINSTON, N. (2012). Using Participatory Design Methods to Engage the Uninterested. In: *Proceedings of PDC2012*, ROSKILDE, DENMARK.

NIELSEN, L. and POULSEN, S. (2013). When a patient goes home: Meaningful lessons in designing for the patient experience of Cervical Radiculopathy and Stroke paralysis. In: *Proceedings of Design4Health Conference 2013,* Sheffield, UK

NOLAN, M. (2013) Masculinity lost: a systematic review of qualitative research on men with spinal cord injury. Spinal Cord, 51, 588 – 595

NORRIS-BAKER C, STEPHENS MA, RINTALA DH, WILLEMS EP (1981) Patient behaviour as a predictor of outcomes in spinal cord injury. Archives of Physical Medicine and Rehabilitation 62:602-608.

OOSTERHOLT, R. and SIMONSE, L. (2016). Service Pathway: a Case Study of Business Model Design in Healthcare. In: *Proceedings of Fifth Service Design and Innovation Conference,* Copenhagen, Denmark.

PARKER, S. and HEAPY, J. (2006). *The Journey to the Interface.* London, DEMOS

PARSONS, T. (1951). *The social system.* London, Routledge and Kegan Paul.

PARTRIDGE, R. (2017). Understanding the Roles of the Designer in Health Care: A Practice-Based Study into Supporting Adolescents with Long-Term Conditions. *The Design Journal*. **20**(4), 523-532

PAYTON, O. and NELSON, C. (1996). A preliminary study of patients' perceptions of certain aspects of their physical therapy experience. *Physiotherapy Theory and Practice.* **12,** 27-38

PAYTON, O., OZER, M. and NELSON, C. (1990). *Patient Participation in Program Planning: A Manual for Therapists.* Philadelphia, FA Davis Co.

PICKER INSTITUTE EUROPE (2005). *Trends in patients' experience of the NHS.* [online]. http://www.picker.org/wp-content/uploads/2014/10/Trends-in-patients-experience-of-the-NHS.pdf

PIPER, D., IEDEMA, R., GRAY, J., VERNA, R., HOLMES, L. and MANNING, N. (2012). Utilizing experience-based co-design to improve the experience of patients accessing emergency departments in New South Wales public hospitals: An evaluation study. *Health Services Management Research*, 25: 162–172.

PIRINEN, A. (2013). The barriers and enablers of co-design for services. *International Journal of Design,* **10**(3), 27-42

PLAYFORD, E., DAWSON, L., LIMBERT, V., SMITH, M., WARD, C. and WELLS, R. (2000). Goal-setting in rehabilitation: report of a workshop to explore professionals' perceptions of goal-setting. *Clinical Rehabilitation*. **14**, 491-496

POPE, C., ZIEBLAND, S. and MAYS, N. (2000). Qualitative research in health care: Analysing qualitative data. *BMJ.* **320**, 114-116

POST, J., PRESTON, L. and SACHS, S. (2002). *Redefining the Corporation: Stakeholder management and organizational wealth.* Stanford University Press

PRYCE-JONES, M. (1993). Critical incident technique as a method of assessing patient satisfaction. In: FITZPATRICK, R. and HOPKINS, A. (eds.). *Measurement of Patients' Satisfaction with their Care*. London, Royal College of Physicians of London, 87-98

QENSIU (2009). *Audit of Goal Planning Meetings at QENSIU: Function and Patient Satisfaction.* Unpublished.

QENSIU (2013). *Patient perceptions of goal planning audit*. Unpublished.

QUEEN MARGARET UNIVERSITY. *Writing a Literature Review.* [online]. http://www.qmu.ac.uk/els/docs/Writing%20a%20Literature%20Review.PDF

RAEY, S., COLLIER, G., KENNEDY-GOOD, J., OLD, A., DOUGLAS, R. and BILL, A. (2017a) Designing the future of healthcare together: prototyping a hospital co-design space. *CoDesign*. **13**(4), 227-44

RAEY., S., COLLIER, G., DOUGLAS, R., HAYES, N., NAKARADA-KORDIC, I. NAIR, A. and KENNEDY-GOOD, J. (2017b). Prototyping collaborative relationships between design and healthcare experts: mapping the patient journey. *Design for Health*. **1**(1), 65-79

RAIJMAKERS, B. (2013). How to create an internal innovation team using Service Design Thinking. In: *Proceedings of Design4Health Conference 2013,* Sheffield, UK

RANDALL, K. and McEWEN, I. (2000). Writing Patient-Centred Functional Goals. *Physical Therapy*. **80**, 1197-1203

RICHARDS, T., COULTER, A. and WICKS, P. (2015) Time to deliver patient-centred care. *BMJ.* **350**(3)

RIDD, M., SHAW, A., LEWIS, G., SALISBURY, C. (2009). The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives'. *Br J Gen Pract,* **59**, 116–133

RITCHIE, J. (2003). The Applications of Qualitative Methods to Social Research. In Ritchie, J. & Lewis, J. (Eds.), *Qualitative research practice: A guide for social science students and researchers*. London: Sage Publications

RITTEL, H. and WEBBER, M. (1973) Dilemmas in a general theory of planning. *Policy Sciences,* 4, 155-169

ROBERT, G. and MACDONALD, A. S. (2017) Infrastructuring for organisational creativity and quality improvement in the healthcare sector: 'designerly' or 'design-like?'. In: D. Sangiorgi and A. Prendiville (eds), *Designing for service: contemporary issues and novel spaces.* London: Bloomsbury.

ROBERT, G., CORNWELL, J., LOCOCK, L., PURUSHOTHAM, A., STURMEY and GAGER, M. (2015). Patients and staff as codesigners of healthcare services. *BMJ.* **350.** Available at http://www.bmj.com/content/350/bmj.g7714

RODGERS, P. and YEE, J. (2015). *The Routledge Companion to Design Research.* London, Routledge

ROSIER, D. (2013). *Arnstein's Ladder of Participation*. [online]. https://slamtwigops.wordpress.com/2013/08/17/arnsteins-ladder-of-participation/

ROTER, D., HALL, J., MERISCA, R., NORDSTROM, B., CRETIN, D. and SVARSTAD, B. (1998). Effectiveness of Interventions to Improve Patient Compliance. *Medical care.* **36** (8), 1138-61

ROTER, D. (1977). Patient Participation in the Patient-Provider Interaction: The Effects of Patient Question Asking on the Quality of Interaction, Satisfaction and Compliance. *Health Education and Behaviour*. **5** (4), 281-315

RYAN, G. and BERNARD, H. (2003). Techniques to Identify Themes. *Field Methods.* **15**(1), 85-109

SAID, E. (1989). Representing the Colonized: Anthropology's Interlocutors. *Critical Inquiry.* **15**, 205-25

SAIKALY, F. (2005). Approaches to design research: towards the designerly way. In: *Proceedings of 6th International Conference of the European Academy of Design.* Bremen, Germany.

SANDERS, E. (2001). Virtuosos of the experience domain. In *Proceedings of the 2001 IDSA Education Conference*.

SANDERS, E. (2006) Scaffolds for Building Everyday Creativity. In: *Design for Effective Commmunications: Creating Contexts for Clarity and Meaning.* FRASCARA, J. (ed.). New York, Allworth Press

SANDERS, E. and STAPPERS, P. (2008). Co-creation and the new landscapes of design. *CoDesign,* **4** (1), 5-18.

SANDERS, E. and STAPPERS, P. (2012). *Convivial Toolbox: Generative research for the front end of design.* Amsterdam, BIS Publishers.

SANDERS, E. and STAPPERS, P. (2014). Probes, toolkits and prototypes: three approaches to making in codesigning. *CoDesign.* **10** (1), 5-14

SANGIORGI, D. (2010). Transformative Services and Transformation Design. *International Journal of Design,* **5**(1), 29-40

SANGIORGI, D. (2011). Transformative Services and Transformation Design. *International Journal of Design.* **5**(2) 29-40

SANGIORGI, D. and JUNGINGER, S. (2015). Emerging Issues in Service Design. *The Design Journal.* **18** (2), 165-170

SANGIORGI, D. and PRENDIVILLE, A. (2017a) Introduction. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

SANGIORGI, D. and PRENDIVILLE, A. (2017b) Conclusions. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

SANGIORGI, D., PRENDIVILLE, A. AND JUNG, J. (2017). Expanding (service) design spaces. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

SANGIORGI, D., PRENDIVILLE, A., and Ricketts, A. (Eds.) (2014). Mapping and Developing Service Design Research in the UK. [online]. http://www.servicedesignresearch.com/uk/wpcontent/uploads/2014/06/Mapping-and-Devloping-SDR-in-the-UK.pdf

SANGIORGI, D., PRENDIVILLE, A., JUNG, J. and YU, E. (2015). *Design for Service Innovation & Development: Final Report.* [online]. http://imagination.lancs.ac.uk/sites/default/files/outcome_downloads/desid_report_2015_web.pdf

SANGIORGI, D. and CLARK, B. (2004). Toward a Participatory Design Approach to Service Design. In: *Proceedings of the Participatory Design Conference, Vol 2.* Toronto, Canada, 27-31 July 2004.

SANGIORGI, D. and PRENDIVILLE, A. (2014). A Theoretical Framework for Studying Service Design Practices: First steps to a mature field. In: *19th DMI: Academic Design Management Conference: Design Management in an Era of Disruption.* London, 2-4 September 2014.

SANGIORGI, D. and SCOTT, K. (2015). Conducting design research in and for a complex world. In: RODGERS, Paul and YEE, Joyce (eds.). *The Routledge Companion to Design Research.* London, Routledge, 114-131

SAVAGE, R. and ARMSTRONG, D. (1990). Effect of a general practitioner’s consulting style on patients’ satisfaction: a controlled study. *BMJ.* **301**, 968-970

SAVORY, C. (2010). Patient and public involvement in translative healthcare research. *Clinical Governance: An International Journal.* **15**(3), 191-99

SCHEPERS, S., DREESSEN, K. and HUYBRECHTS, L. (2011). Methods for collective creativity in experience design processes for health(care). In: *Proceedings of Design4Health Conference 2011,* Sheffield, UK

SCHLEICHER, D., JONES, P. and KACHUR, O. (2010). Bodystorming as Embodied Designing. *Interactions.* November+December 2010

SCHÖNHERR, M. GROOTHOFF, J., MULDER, G. AND EISMA, W. (2000). Prediction of functional outcome after spinal cord injury: a task for the rehabilitation team and the patient. *Spinal Cord*. **38**, 185-191

SCHULER, D. and NAMIOKA, A. (eds.) (1993). *Participatory Design: Principles and Practices.* Lawrence Erlbaum Associates, New Jersey.

SCIVOLETTO, G., PETRELLI, A., LUCENTE, L. and CATELLANO, V. (1997). Psychological investigation of spinal cord injury patients. *Spinal Cord*. **35**, 516-520

SCOBBIE, L., MCLEAN, D., DIXON, D., DUNCAN, E. and WYKE, S. (2013). Implementing a framework for goal setting in community based stroke rehabilitation: a process evaluation. *BMC Health Services Research*. **13**, 190

SCRIVENER, S. (2009). The Roles of Art and Design Process and Object in Research. In: NIMKULRAT, N and O'RILEY, T. (eds.). *Reflections and Connections: On the Relationship between Creative Production and Academic Research*. Helsinki, University of Art and Design Helsinki. 69-80

SERAVALLI, A. and ERIKSEN, M. (2017). Beyond collaborative services: Service design for sharing and collaboration as a matter of commons and infrastructuring. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

SIBBALD, B. (1998). Understanding controlled trials: Why are randomised controlled trials important? *BMJ*. **316**

SIMONSEN, J. and ROBERTSON, T. (2013). *Routledge International Handbook of Participatory Design*. New York, Routledge.

SIMPSON, L., ENG, J., HSIEH, J., WOLFE, D. and the SCIRE Research Team (2010). The health and life priorities of individuals with spinal cord injury: a systematic review. *Journal of Neurotrauma*. **29** (8), 1548-55

SLAY, J. & STEPHENS, L. (2013). *Co-production in mental health: A literature review.* London: new economics foundation

SLEGERS, K., DUYSBURGH, P. and HENDRICKS, N. (2015). CoDesign with people living with cognitive and sensory impairments. *CoDesign*. **11** (1), 1-3

SOKOLER, T., LÖWGREN, J., ERIKSEN, M., LINDE, P. AND OLOFSSON, S. (2007). Explicit Interaction for Surgical Rehabilitation. In: Proceedings of TEI ‘o7, Baton Rouge, USA, 15-17 Feb 2007

SOUTHAMPTON EDUCATION SCHOOL (2012). [online].
https://www.youtube.com/watch?v=59GsjhPolPs

SPINAL INJURIES ASSOCIATION (2009). *Preserving and Developing the National Spinal Cord Injury Service: Phase 2 – Seeking the Evidence.* [online]. https://www.spinal.co.uk/wp-content/uploads/2015/07/234-590487.pdf

STAPPERS, P. J. (2013). Prototypes as a central vein for knowledge development. In: VALENTINE, L. (Ed.). *Prototyping: design and craft in the 21st century*. London, Bloomsbury, 85-97

STAPPERS, Pieter Jan, VISSER, Froukje Sleeswijk and KELLER, Ianus (2015). The role of prototypes and frameworks for structuring explorations by research through design. In: RODGERS, Paul and YEE, Joyce (eds.). *The Routledge Companion to Design Research.* London, Routledge, 163-174

STARNINO, A., DOSI, C. and VIGNOLI, M. (2016). Designing the future, Engineering Reality: Prototyping in the Emergency Department. In: *Proceedings of Fifth Service Design and Innovation Conference,* Copenhagen, Denmark.

STEWART, T. (1977). Coping behaviour and the moratorium following spinal cord injury. *Paraplegia* **15**: 338–342.

STICKDORN, M. and SCHNEIDER, J. (2011) (eds.). *This Is Service Design Thinking.* Amsterdam, BIS Publishers. 34-45

STICKDORN, M. (2011). 5 Principles of Service Design Thinking. In: STICKDORN, M. and SCHNEIDER, J. (eds.). *This Is Service Design Thinking.*Amsterdam, BIS Publishers. 34-45

STIGLIANI, I. and FAYARD, A. (2010). *Designing new customer experiences: A study of socio-material practices in service design* [Discussion paper]. London: Imperial College Business School.

STORNI, C. (2013). Design for future uses: Pluralism, fetishism and ignorance. In: *Nordic Design Research Conference 2013,* Copenhagen-Malmö

STRAUSS, A. and CORBIN, J. (1990). *Basics of Qualitative Research*. London, Sage Publications

STREET, R., GORDAN, H., WARD, M., KRUPAT, E. and KRAVITZ, R. (2005). Patient Participation in Medical Consultations: Why Some Patients are More Involved Than Others. *Medical Care*. 43 (10), 960-969

STROBI, J. & BRUCE, N. (2000). Achieving wider participation in strategic health planning: experience from the consultation phase of Liverpool's 'City Health Plan'. *Health Promotion International*, **15** (3), 215-225

SUCHMAN, L. (2011). Anthropological Relocations and the Limits of Design. *Annual*

Review of Anthropology. [online]. http://www.annualreviews.org/doi/pdf/10.1146/annurev.anthro.041608.105640

SUCHMAN, L. and TRIGG, R. (1991). Understanding practice: video as a medium for reflection and design. In: GREENBAUM, J. and KYNG, M. (eds) *Design at Work: Cooperative Design of Computer Systems.* Hillsdale, Lawrence Erlbaum Associates, 65-89

SUZUKI, Sushi (2010). *The power of prototyping.*[online]. Last updated 2nd Nov 2010. http://www.paristechreview.com/2010/11/02/power-prototyping/

SZANIAWSKI, M., BOESS, S., KRAAN, G. and GOOSSENS, R. (2015). Enhancing engagement with motor rehabilitation therapy through gamified rehabilitation interactions. In: *Proceedings of Design4Health Conference 2015,* Sheffield, UK

TAI-SEALE, M., ELWYN, G., WILSON, C., STULTS, C., DILLOM, E., LI, M., CHUANG, J., MEEHAN, A. and FROSCH, D. (2016). Enhancing Shared Decision Making Through Carefully Designed Interventions That Target Patient and Provider Behaviour. *Health Affairs*. **35** (4), 605-612

Ten BHÖMER, M. and TOMICO, O. (2013). Interactive prototypes as props in workshops to trigger the design of services for dementia rehabilitation. In: *Proceedings of Design4Health Conference 2013,* Sheffield, UK

THE OPEN UNIVERSITY (2005). *Action Research: A guide for associate lecturers*. [online]. http://www.open.ac.uk/cobe/docs/AR-Guide-final.pdf

THE SCOTTISH GOVERNMENT (2015). *Analytical paper on co-production.* [online]. http://www.gov.scot/Topics/Research/by-topic/public-services-and-gvt/publications/Analytical-Paper-Co-Production

THE SCOTTISH GOVERNMENT (2017). *Health and Social Care Standards.* [online]. http://www.gov.scot/Publications/2017/06/1327

THOMPSON, A., RIVAS, C. and GIOVANNONI, G. (2015). Multiple sclerosis outpatient future workshops: improving the quality of participant interaction and ideation tools within service improvement activities. *BMC Health Services Research*. **15** (105)

TOIVONEN, M., TOUMINEN, T. and BRAX, S. (2007). Innovation process interlinked with the process of service delivery: a management challenge in KIBS. *Économies et Sociétés*. **8**(3),355-384

TOSOA, F. (2017). Sense and movement. Design of a system for sensorimotor rehabilitation after stroke. *The Design Journal.* **20**(1), 2463-72

TRONVOLL, B., BROWN, S., GREMLER, D. and EDVARDSSON, B. (2011). Paradigms in service research. *Journal of Service Management*. **22**(5), 560-585

TSEKLEVES, E. and COOPER, R. (eds.) (2017) *Design for Health*. Abingdon, Oxon, Routledge.

TSIANAKAS, V., ROBERT, G., MABEN, J., RICHARDSON, A., DALE, C. and WISEMAN, T. (2012). Implementing patient-centred cancer care: Using experience-based co-design to improve patient experience in breast and lung cancer services. *Supportive Care in Cancer*, 20: 2639–2647.

VAIDYANATHAN, S., GLASS, C., SONI, B., BINGLEY, J., SINGH, G., WATT, J. and SETT, P. (2001). Doctor-Patient Communication: Do people with spinal cord injury wish to receive written information about their medical condition from the physicians after an outpatient visit or after a readmission in the spinal unit? *Spinal Cord*. **39**, 650-653

Van der LUGT, R. and van der LAAN, T. (2017). Design facilitators' journeys through the jungle of Co- in healthcare. *The Design Journal.***20**(1), 2057-67

VAN DIJK, Geke (2011). Design Ethnography: Taking inspiration from everyday life. In: STICKDORN, Marc and SCHNEIDER, Jakob (eds.). *This Is Service Design Thinking.* Amsterdam, BIS Publishers. 108-115

VARGO, S. and AKAKA, M. (2009). Service-Dominant Logic as a Foundation for Service Science: Clarifications. *Service Science*. **1**(1), 32-41

VARGO, S. and LUSCH, R. (2008). Service-Dominant Logic: Continuing the Evolution. *Journal of the Academy of Marketing Science*, **36**(1), 1-10.

VERBEEK, Peter-Paul (2011). *Moralizing technology: Understanding and designing the morality of things.* University of Chicago Press.

VERGANTI, R. (2008). Design, Meanings and Radical Innovation: A Metamodel and a Research Agenda. *Journal of Production and Innovation Management.* **25**, 436-56

VINK, J., WETTER-EDMAN, K. and AGUIRRE, M. (2017). Designing for Aesthetic Disruption: Altering Mental Models in Social Systems through Designerly Practices. *The Design Journal*. **20**(1), 2168-77

WADE, D. (1998). Evidence relating to goal planning in rehabilitation. *Clinical Rehabilitation*. **12**, 273-275

WADE, D. (1999). Case-mix in rehabilitation: alternative ways of achieving the same goals. *Clinical Rehabilitation*. **13**, 183-185

WASSON, J. and COLEMAN, E. (2014). Health Confidence. [online]. www.aafp.org/fpm

WEICK, K.E. (1995). *Sensemaking in Organizations*. London, Sage.

WELLER, D. and MILLER, P. (1977). Emotional reactions of patient, family and staff in acute-care period of spinal cord injury. *Social Work in Health Care.* **2**(4), 369-77

WENSVEEN, Stephan and MATTHEWS, Ben. Prototypes and prototyping in design research. In: RODGERS, Paul and YEE, Joyce (eds.). *The Routledge Companion to Design Research.* London, Routledge, 262-276

WESTGREN, N. & LEVI, R. (1998). Quality of life and traumatic spinal cord injury. *Archives of Physical Medical Rehabilitation,* **79,** 1433-1439.

WETTER-EDMAN, K. (2011). *Service Design – a conceptualisation of an emerging practice.* Licentiate thesis, University of Gothenburg.

WETTER-EDMAN, K. and MORITZ, S. (2015). Empowering transformation through design inquiry in public healthcare. In: *Proceedings of Design4Health conference,* Sheffield, UK

WETTER-EDMAN, K., VINK, J. and BLOMKVIST, J. (2018). Staging aesthetic disruption through design methods for service innovation. *Design Studies*, **55**, 5-26

WILLER, D. and MILLER, P. (1977). Emotional reactions of patient, family and staff in acute-care period of spinal cord injury: Part I. *Social Work in Health Care.* **2** (4), 369-377

WILSON, S., ROPER, A., MARSHALL, J., GALLIERS, J., DEVANE, N., BOOTH, T. and WOOLF, C. (2015). Codesign for people with aphasia through tangible design languages. *CoDesign*, 11(1), pp.21-34

WOLSTENHOLME, D., COBB, M., BOWEN, S., WRIGHT, P. AND DEARDEN, A. (2010). Design-Led Service Improvement for Older People. *Australasian Medical Journal*, **3** (8), 465-470

WOLSTENHOLME, D., DOWNES, T., LEAVER, J., PARTRIDGE, R., LANGLEY, J. (2014). Improving self-efficacy in spinal cord injury patients through "design thinking" rehabilitation workshops. *BMJ Quarterly Improvement Reports.*

WOLSTENHOLME, D., GRINDELL, C. and DEARDEN, A. (2017). A co-design approach to service improvement resulted in teams exhibiting characteristics that support innovation. *Design for Health.* **1**(1), 42-58

WOODCOCK, A. and GEORGIOU, D. (2007). Project Spectrum; evoking, focusing and demanding action. *CoDesign,* 3 (3), 145 – 157

YEE, J. and WHITE, H. (2016). The Goldilocks Conundrum. *International Journal of Design,* **10**(1), 7-20

YOUNG, C., MANMATHAN, G. and WARD, J. (2008). Perceptions of goal setting in a neurological rehabilitation unit: a qualitative study of patients, carers and staff. *Journal of Rehabilitation Medicine*. **40**, 190-194

YOUNG, R. and WARWICK, L. (2017). Service design and the edge effect. In: SANGIORGI, D. and PRENDIVILLE, A. (eds) *Designing for Service.* London, Bloomsbury

YU, E. and SANGIORGI, D. (2018). Service Design as an Approach to Implement the Value Cocreation Perspective in New Service Development. *Journal of Service Research*. **21**(1), 40-58

ZIMMERMAN, J., FORLIZZI, J., EVENSON, S., ROSSEN, M. and GILMORE, D. (2007). Research through design as a method for interaction design research in HCI. In: *Human Factors in Computing Systems Proceedings of the SIGCHI Conference*

ZIMMERMAN, J., STOLTERMAN, E., & FORLIZZI, J. (2010). An Analysis and Critique of Research Through Design: Towards a Formalization of a Research Approach. In: *DIS '10, Proceedings of the 8th ACM Conference on Designing Interactive Systems,* 310–319, New York, NY, USA: ACM.