

See me, Hear me, Know me

DIGITAL DESIGN FOR HEALTH STORYTELLING

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THESIS

Abstract

Interest in both narrative medicine and electronic health records have increased over the past 30 years. However, current electronic health records are unlikely to be patient-focused or to use narrative modes of care. Recent studies within the UK have indicated that there is a need to incorporate patient stories into health records, particularly for those with long-term conditions.

The aim of this project was to understand how digital tools can support people with multiple long-term conditions in making sense of and conveying their health stories. Outcomes from the project include recommendations for the design of such tools, alongside digital prototypes which embody the participants' health stories. The project also used a narrative-led methodology to explore how a phenomenological approach can contribute to digital design for health and care.

Five adults with multiple long-term conditions participated in the project, and research was carried out individually in three stages. Firstly, semi-structured interviews were used to understand each participant's health story. Secondly, participants worked with the researcher to co-design a visual representation of their story. Finally, digital prototypes based on their health story were reviewed with the participants.

The findings from the project are a set of recommendations which can be used to inform future digital design for health storytelling. Future research could explore other areas such as collaborative health storytelling or technical implementation of tools.

Keywords: health, narrative medicine, storytelling, digital design, interaction design

Declaration

I, Marissa Cummings, declare that this submission of full thesis for the degree of Master of Research (MRes) meets the regulations as stated in the course handbook.

I declare that this submission is my own work and has not been submitted for any other academic award.



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Glossary of Terms

Items marked with an asterisk (*) are discussed in considerable further detail within the text.

Term	Definition
Biomedical medicine	This is the doctor-patient model of medicine as used in most hospitals and healthcare facilities in the UK, which focuses on a biomedical view of illness, as opposed to a more holistic, social model.
Borderline personality disorder (BPD)	A personality disorder which may result in emotional instability, disorganised thinking, and impulsive behaviour.
Digital tool	A piece of software designed to assist the user in completing a task.
eHealth	Broadly used to refer to the use of electronic systems, devices, and processes within healthcare.
Electronic health record (EHR)*	An electronic system for storing patient health data, often used in a clinical context.
Fibromyalgia	A long-term condition which causes fatigue and chronic pain all over the body. Often shortened as <i>fibro</i> .
Health story*	The personal narrative of a health-related experience. Also referred to as <i>illness narratives/stories</i> .
Irritable bowel syndrome (IBS)	A condition which affects the digestive system, causing cramps, bloating, diarrhoea, and constipation.
Lean UX	A cost-effective approach to user experience (UX) research used in industry, in which the minimum amount of research needed is done at each stage of development in order to progress work to the next stage.

Meningitis	An inflammation of the membranes surrounding the brain and spinal cord, which can be fatal if not treated quickly.
Multimorbidity*	A person with multimorbidity has two or more health conditions. People with multimorbidity usually have one primary condition; additional conditions are referred to as <i>co-morbidities</i> .
Multiple sclerosis (MS)	A lifelong condition that affects the brain and spinal cord, causing problems with vision, balance, movement, etc. The majority of people with MS are diagnosed as relapsing-remitting (RRMS). People with RRMS have relapses lasting days or months where their symptoms worsen. They then improve over a similar period of time. This is opposed to progressive MS, which gradually worsens over time.
Myalgic encephalomyelitis (ME)	A condition which results in overwhelming fatigue, pain, and loss of endurance. Referred to by various names, such as myalgic encephalomyelitis/encephalopathy (ME), chronic fatigue syndrome (CFS), and post viral fatigue syndrome (PVFS). I have used ME, as that is the term which is preferred by people with the condition (The ME Association, 2020), although the NHS use ME-CFS (NHS Scotland, 2010).
Narrative medicine*	A type of healthcare practice based on narrative techniques, for example: storytelling of illness narratives, active listening and narrative analysis by healthcare professionals, journaling and reflection by healthcare professionals.
Polycystic ovary syndrome (PCOS)	A condition which can cause irregular periods, excess androgen, and cysts which form on the ovaries. PCOS may result in fertility issues and can also lead to other conditions later in life, such as diabetes.
Post-traumatic stress disorder (PTSD)	An anxiety disorder which can arise as the result of stressful, frightening, and/or traumatic experiences.
Postural tachycardia syndrome (PoTS)	A condition which causes an abnormal increase in heart rate when sitting or standing, resulting in dizziness, fainting, shaking, and heart palpitations. The acronym can sometimes be written as <i>POTS</i> . I have used <i>PoTS</i> to align with usage by the NHS.

Psoriatic arthritis	A long-term condition which causes stiffness, swelling, and pain in the joints, linked with the skin condition psoriasis. If left untreated, it may worsen over time and permanently damage the joints.
Reynaud's disease	A condition which affects blood circulation and can cause pain and numbness in the hands and feet.
Satisficing	A strategic approach which serves to meet the minimum need of the most users. The term is a portmanteau of <i>satisfy</i> and <i>suffice</i> .
Secondary cancer	Secondary cancer occurs when the cancer cells spread from the first (primary) tumour location throughout the body. NHS (2018) defines this as Stage IV, the final stage of cancer. Secondary cancer is not usually curable. This is also called <i>metastatic</i> cancer.
Self management*	Self management encompasses a variety of practices used by people with long-term conditions to manage their health. I have used the term here with no hyphen, as consistent with use in Scottish healthcare.
Stigma*	I am using the definition given by Hatzenbuehler et al. (2013): "[T]he co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised"
Story-centred care*	A practice of caregiving which uses health stories (the telling of, listening to, and co-creation of) as a means of facilitating person-centred care.
Usability	A measure of how easy or difficult it is to use something. Software with poor usability is confusing and difficult to use.
User	In software terminology, this would be the person who is intended to use the final product.

1 *Introduction*



Increasingly, patients are unwilling to tolerate a kind of medical treatment that, however technologically sophisticated, casts them into the role of passive and depersonalized recipient... More and more, ill people are not content to settle for disease management: instead, they want to be healed.

(Hunsaker Hawkins, 1999, p.150)

This project comes at a crossroads. Over the last 50 years, there has been an increasing understanding in medicine of the need to recognise and treat the whole person within the context of their life (Engel, 1977; Kleinman, 1988). This understanding, combined with a growing interest in philosophy on the narrative self (Ricoeur, 1986), has led to the development of narrative medicine, a field which adopts a narrative approach towards caregiving (Charon, 2006). Research has shown that the use of narrative and story in care has tremendous benefits for people with health conditions: improving their mental health and wellbeing (Smith and Liehr, 2014; Chuang et al., 2018), improving the quality of their care (Charon, 2006), and also promoting cooperation between them and healthcare professionals (Mattingly, 2009). The use of stories, which I am more

explicitly characterising within this project as *story-centred care* is therefore perfectly in line with NHS Scotland's commitment to respect, listen to, and work cooperatively with patients (Realistic Medicine, 2020).

At the same time, our world has become increasingly digital, and healthcare has been no exception to this trend. In 2014, the NHS committed to going “largely paperless” with the adoption of electronic health records (EHRs) (NHS England, 2014). Now over 200,000 people are registered on the NHS App, where they can check their medical records, order prescriptions, book appointments, and more (NHS Digital, 2020). However, this communication is almost entirely one-way: *what will happen to you*. While this may be suitable for occasional users, people with long-term conditions may

prefer to adopt a more empowered approach towards their care (Ferguson and e-Patient Scholars Working Group, 2007), and this passive characterisation is unlikely to satisfy them.

Of particular interest here are people with multiple long-term health conditions (multimorbidity). The lived experiences of people with multimorbidity are not well-understood, in part because the current healthcare system primarily focuses on single conditions (Aiden, 2018). The difficulty here is not just patients communicating with their healthcare professionals, but also healthcare professionals communicating with each other. Medical services are increasingly fragmented, meaning continuity of care is a major concern (Salisbury, 2013). Guidance on the treatment of conditions is likely to differ and even conflict, forcing people to attempt to reconcile differing advice by themselves (Liddy et al., 2014).

Treating people with multiple conditions is becoming a pressing concern in healthcare as, due to longer lifespans and improved medicine, their numbers are steadily growing. 50

million people in Europe are estimated to be multimorbid (Rijken et al., 2016), with approximately 432,000 of these living in Scotland (Barnett et al., 2012).

This project builds from “Backpack”, led by The Glasgow School of Art as part of the Digital Health and Care Institute, which investigated the requirements for designing a Personal Data Store for people with long-term health conditions (Teal et al., 2017). The participants in the project described their exhaustion in having to share their story with each new healthcare professional, and how *not* being able to do this led to endless difficulties for them – for example, when a healthcare professional arranged an appointment at a location which they were unable to access due to disability. From this, the Backpack team developed a *Health Story* concept: “a space for the person to share their story in their own words, using video or written narrative, supported by key dates and facts” (p. 26).

In this project, I extended this concept and explored how health stories can be used more broadly: as a means of creative expression and personal empowerment, and also as a

tool for people to shape and reflect on their care. Adopting a phenomenological approach of dialogic research, I worked closely with participants in an iterative cycle of fieldwork, analysis, and reflexive practice. The fieldwork was completed under COVID-19 lockdown in Scotland, which created logistical constraints in working with participants.

Throughout the fieldwork, I attempted to first gain a deep, narrative understanding of each participant's health story. I then drew on my practice as a digital interaction designer to translate this into individual prototypes. Each prototype embodied a different approach towards the design of a digital story-centred tool, directly inspired by that participant's story. Through the analysis, I also determined overall findings which illustrate what the design priorities of such a

tool might be. Across all the participants, we can see goals of understanding the big picture of illness, a need to convey their experiences to others, and also to challenge scepticism around their conditions and gain support in managing their health. Participants also had the opportunity to share and reflect on their experiences during the project, allowing them to better understand themselves.

These outcomes lay the groundwork for further research on the design and development of digital health storytelling tools and also illustrate how design for digital health can take an empathetic, narrative approach.

1.1 Research Questions, Aim, and Objectives

1.1.1 Research Questions

- How can digital tools support people with multiple long-term conditions in making sense of and conveying their health stories?
- What can a narrative-led methodology teach us about designing digital health tools?

1.1.2 Aim

Prototype digital tools for people living with multiple long-term conditions which capture and convey their health stories.

1.1.3 Objectives

- Work with people living with multiple long-term conditions to understand their health stories, taking a phenomenological, narrative-led approach over several iterations
- Using reflexive practice, design prototypes of digital interfaces for telling health stories which capture each participant's unique perspective
- Reflect with participants on the completed prototypes, and the value of health stories in self management and facilitating “good conversations” (Health and Social Care Alliance Scotland, 2018) with healthcare professionals

2 *Literature Review*



2.1 Introduction

In this chapter, I have laid out the various bodies of research which impact my project. Firstly, I discuss long-term health conditions, specifically issues related to multimorbidity and approaches to care (both by healthcare professionals and the individuals themselves). Next, I give an overview of design for digital health and the various challenges within the field. Finally, I discuss the concept of health stories as situated within three different frames of storytelling: self-storying, storying with others, and cultural stories.

2.2 Long-Term Health Conditions

2.2.1 Multimorbidity

Due to modern improvements in healthcare technology and longer lifespans, more people in the world are living with multimorbidity (two or more long-term health conditions). The World Health Organisation (WHO) estimates that there are 50 million people in Europe living with multimorbidity (Rijken et al., 2016). In Scotland, a study of 1.8 million patients showed that 24% were affected by multimorbidity (Barnett et al., 2012). It is also common for people with a long-term condition to develop mental health problems (e.g. depression and anxiety), resulting in multimorbidity (Gürhan et al., 2019).

Because the current health system is aimed at treating single conditions, people with multiple conditions are likely to suffer from fragmented treatment (Salisbury, 2013). They may also have trouble communicating with healthcare professionals offering conflicting advice for dealing with different conditions (Liddy et al., 2014). Previous research

suggests that including patients' stories in medical records could be a way of giving healthcare professionals a better picture of their circumstances (Sadler et al., 2017), and there has been a call for further research into the holistic experience of living with multimorbidity (Aiden, 2018).

WHO have identified key measures for improving the health of people with multimorbidity (Rijken et al., 2016). Of these, the ones which are of the most interest to us within the scope of this project are:

- Adopting a person-centred care approach, supported through the use of electronic health records (EHRs)
- Support and education for people to take on self management of their health

2.2.2 Person-Centred Care

Person-centred care, an approach to caregiving which prioritises the individual, underpins the ambition for care within Scotland. The NHS defines this as “providing care that supports people to achieve the level of health that gives them the best opportunity to lead the life that they want” (NHS Greater Glasgow and Clyde, 2020). In practice, this means that healthcare professionals should (Realistic Medicine, 2020):

- Listen to and understanding patient preferences
- Work in partnership with patients and make mutual decisions
- Make sure patients are informed and understand the available options

Therefore, person-centred care requires healthcare professionals to have an understanding of a person’s life and current circumstances. This follows an overall trend in medicine called the *biopsychosocial* approach, which emphasises the importance of having a holistic

understanding of patients (Engel, 1977). Continuity of care is an important part of achieving this holistic understanding, especially as many patients now have to see multiple healthcare professionals (Royal College of General Practitioners, 2019). Previous work suggests that continuity can be improved by including stories or profiles written by patients in their medical records (Teal et al., 2017; Health and Social Care Alliance Scotland, 2017).

2.2.3 Self Management

An important component of person-centred care is self management: the “strategies individuals perform to live well with long-term conditions, including medical, role and emotional management” (Audulv et al., 2019, p.367). The term is used quite broadly and may also encompass a person’s tools and support networks, as well as general behaviours which promote a healthy lifestyle. Self management activities are inherently empowering, as they put the person with the health condition in charge of their own care (Figure 1) (Dubberly et al., 2010).

Self management is a key component to both improving a person's overall health and also reducing their use of care resources (and thus, the cost incurred by the healthcare provider) (NHS Education for Scotland, 2012; Barker et al., 2018). It has been widely adopted as an approach worldwide and is part of the strategy used by the NHS and the UK and Scottish Governments for the management of long-term health conditions (Long Term Conditions Alliance Scotland, 2008; NHS England, 2014).

The impact of multimorbidity on self management is not straightforward. While some people may become overwhelmed by their conditions, there is also evidence that people with multimorbidity may become better at self management than people with a single condition, because they develop more complex coping techniques and have to critically evaluate potentially conflicting medical advice (Liddy et al., 2014).

TABLE 4.1 SHIFT IN FRAMING FROM TRADITIONAL
HEALTHCARE PROVISION TO SELF-MANAGEMENT

	Traditional healthcare frame	Emerging self-management frame
Scope	Relieve acute condition Now	Maintain well-being Over a lifetime
Approach	Intervention; treatment Expert-directed Apply standards of care Lengthy regulatory pre-approval	Prevention; healthy living Self-managed Measure, assess, and adjust; iterate Learn and adapt as you go
Subject	Symptoms and test results	Whole person, seen in context
Response	Prescribe medication	Improve behavior and environment
Relies on	Medical establishment	Individual, family, and friends Social networks, others like me
HCP as	Authority, expert Dispensing knowledge	Coach, assistant Learning from patients
Patient as	Helpless, childlike Taking orders	Responsible adult Setting goals; testing hunches
Relationship	Asymmetric, one-way Command and control	Symmetric, reciprocal Discussion and collaboration
Records	HCP's notes of visit Sporadic Dispersed between offices Managed by HCP	Patient's notes; data from sensors Continuously collected Connected; aggregated Controlled by patient

HCP = healthcare provider.

Source: From H. Dubberly, R. Mehta, S. Evenson, & P. Pangaro. (2010).
Reframing health to embrace design of our own well-being. *Interactions*, 17, 56–63.

Figure 1: Self management vs the traditional healthcare frame. Table. Source: Jones (2013), adapted from Dubberly et al. (2010).

2.3 Digital Design for Health

Electronic health record (EHR) is a generic term used to describe a variety of digital tools for storing health information. A review of the US market showed over 350 EHR vendors, with a total of more than 600 individual products (Jones, 2013). Within the UK, the use of EHRs is similarly diverse:

Electronic records are stored by GPs, hospitals..., mental health providers and in some community care settings. There is great variation in the type and use of electronic record systems between geographical regions and even between departments within hospitals.

(POSTUK, 2016, p.1)

Many EHRs are used solely by healthcare professionals, with no patient-facing component at all. In England, the NHS has released the NHS App, which people can use for a variety of

health-related tasks such as checking their medical record or booking appointments (NHS Digital, 2020). However, there is currently no way to for users add information to their record or participate in two-way conversations with a healthcare professional.

Over the past 10 years, there has been an increasing focus on the issue of poor design within EHRs and a call for a more design-led, person-centred approach for eHealth systems (Jones, 2013; Marcial, 2014; Shariat, 2014; Morrison, 2019). This is aligned with a shift in the broader field of digital design towards greater empathy and consideration of individual users (Dean, 2015; Meyer and Wachter-Boettcher, 2016; Scottish Government, 2019).

Some effort has been made to introduce standards for the design and implementation of EHRs. In the UK, both the NHS and the National Institute for Health and Care Excellence (NICE) have published standards (NHS Digital, 2019; NICE,

2019). However, such standards may be insufficient as there are no means of enforcing them, and they are more likely to focus on system design rather than usability (Jones, 2013). New initiatives such as NHSX (2020) aim to address this by developing user experience standards for health systems within the NHS, but resolving these issues will take time.

Several recent projects have independently identified a need for patients to include their story in their health record as part of a person-centred approach, although this has yet to be implemented within NHS systems. Each of these projects envisions the way this story would be implemented slightly differently (Table 1).

The approach within this project in combining storytelling with eHealth is unique, and it was difficult for me to find anything comparable – applications which I looked at during scoping tended to be either one or the other. On the eHealth

side, a similar project I came across was Helix Centre's Amber Care Plans (2020), a digital tool for advance care planning, although it is no longer active. The tool doesn't focus on storytelling but does allow users to assemble and share plans for their health, thereby defining a kind of future health story. On the storytelling side are a few tools for collaborative storytelling, such as Sutori (<https://www.sutori.com>), a presentation tool. This allows multiple people to work together to assemble story timelines, including written descriptions and media.

This project focuses on the design of patient-facing health storytelling tools which could be included in or linked to an EHR, and does not cover questions of implementation. A discussion of how this could be addressed in future work can be found in Chapter 7.

Table 1: Comparison of recent UK research on health stories in medical records.

Project	Focus of the work	Health stories should include...
Backpack Teal et al., 2017	Identifying the requirements of people with multiple sclerosis for a Personal Data Store which records health information	<ul style="list-style-type: none"> • Short written summary of story • Timeline of events • Important facts for treatment (e.g. recent test results) • Video of person and their environment
OurGP Health and Social Care Alliance, 2017	Designing tools for digitally enabled GP practices	<ul style="list-style-type: none"> • Bulleted description of lifestyle and living situation • Issues which may affect patient communication with their GP (e.g. anxiety) • Goals for treatment
Sadler et al., 2017	Building a Learning Health System aimed at healthcare professionals which would improve the care of stroke survivors	<ul style="list-style-type: none"> • Information on past treatments to improve continuity of care • Vignettes describing a projected future health story

2.4 Health Stories

2.4.1 Understanding Health Stories

Reclaiming story is part of our birthright. Telling our story enables us to be heard, recognized, and acknowledged by others. Story makes the implicit explicit, the hidden seen, the unformed formed, and the confusing clear.

(Atkinson, 1998a, p.7)

Some health stories may cover the entire course of someone's life, while others may be limited to a single episode. The consistent feature of these is that they describe the person's *life*: that is, their daily social interactions and physical existence beyond the clinical setting. A useful differentiator here is given by Kleinman (1988), who distinguishes between *illness problems* and *illness complaints*. *Illness problems* can be seen as the broader psychosocial problems which arise from one's illness, whereas *illness complaints* are the more specific

biomedical issues which someone brings to their doctor.

When looking at health narratives, narratives should cover the scope of a person's illness problems, as well as their complaints. By this definition, medical records used by healthcare professionals are *not* health stories (at least, not of the kind I have considered within this project), as they are written without any input from the patient, and generally focus solely on their biomedical symptoms.

In the following sections, I discuss three frames for health storytelling: self-storying, storying with others, and cultural stories. Each of these informs the other, so while in one sense these frames are embedded (Figure 2), in another sense they are cyclical (Figure 3). Health stories originate within the self and then are shared with others. This mutual understanding passes into a wider frame, generating ideas on a societal level of what it means to have a particular condition or to be "unwell". These cultural stories then, in turn, can be adopted by individuals and used to inform self-storying.



Figure 2: Concentric frames of storytelling. Diagram. Source: author's own.

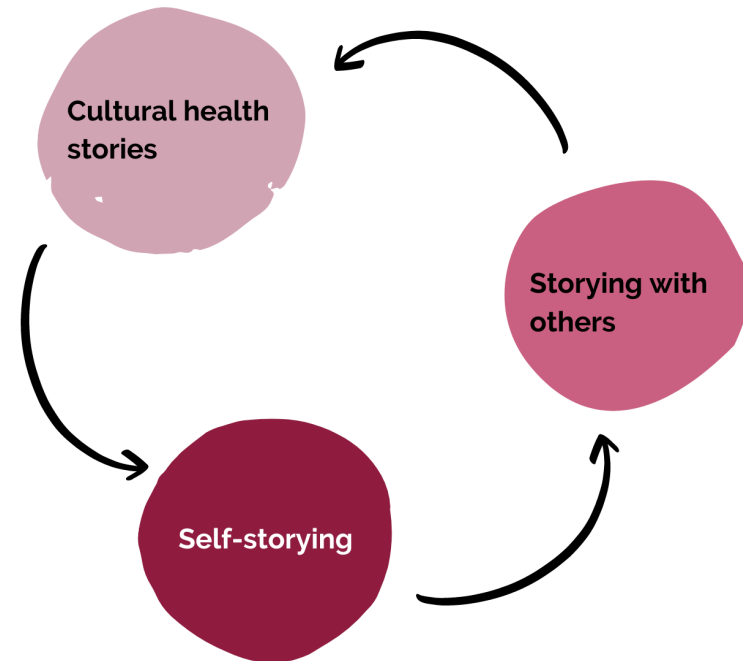


Figure 3: Cycles of storytelling. Diagram. Source: author's own.

2.4.2 Self-Storying

Much has been written about the concept of *narrative identity* – the idea that one’s self essentially comes into being through forming the narrative of one’s experiences (Ricoeur, 1986; Sacks, 1986; Bruner, 2003). Just as the process of illness disassociates someone from their body, the process of storytelling allows them to reconcile themselves with their new body and provide themselves with a way of understanding its experiences (Frank, 2013). In the words of Arthur Kleinman: “The illness narrative is a story the patient tells, and significant others retell, to give coherence to the distinctive events and long-term course of suffering.” (1988, p.49)

In simpler terms, there are two essential functions of health self-storying:

- **Identity construction**, in which the person uses storytelling to reconstruct a life-story which has been disrupted by illness

- **Sense-making**, in which the person uses storytelling to understand why and how an illness has happened

The former is essentially about understanding *oneself*, whereas the latter is more about understanding the particular *condition*. Kleinman refers to this type of sense-making as *explanatory models*:

They respond to such questions as: What is the nature of this problem? Why has it affected me? Why now? What course will it follow? How does it affect my body? What treatment do I desire? What do I fear most about this illness and its treatment? (1988, p.121)

We can therefore further differentiate between these two functions by saying that whereas identity construction may tend towards the philosophical, sense-making is more pragmatic and used to practically inform decision-making.

The construction of one's health story is an active process by the individual. To paraphrase Tim Ingold's (2020) arguments on makers, storytellers are standing on a threshold. On one side are the "raw materials" of storytelling – in this case, a bald account of events in chronological order. On the other side emerges the constructed story (Figure 4).

The word *constructed* here is used to denote the ongoing process of making, rather than to refer to a finished product. (One's story, just like one's life, is a continuous process.) The making of a story is a deliberate act by the storyteller, who may, for example, choose to ignore or minimise the importance of certain events. Ingold (2015; 2020) therefore argues that storytelling can be considered in the same category as walking: as a linear progression which moves around, among, and between events (Figure 5).

This selective process can lead to an absorbing concern over whether a particular story is "true" (Strawson, 2004). Within the scope of this project, I have addressed this by using the idea of *validity* rather than *reliability* (Aull Davies, 2002). Stories may not always be *reliable*, in the sense that (as

previously observed) the narrator may omit certain events, either deliberately or not, in the telling. However, such stories are *valid*, in that they represent the particular emotional truth as expressed by that individual. Frank (2012) also emphasises here the importance of considering the story as a made object, which allows us to examine the story separately from the actual series of events.

The telling of a health story is therefore an active process of construction and selection by the storyteller. This idea runs contrary to the cultural perception of being "unwell", which usually shows the individual as a passive recipient. A health condition, or a health story, is portrayed as happening *to* someone. However, the opposite is also true. Health stories may happen to people, but *people* also happen to *health stories*.

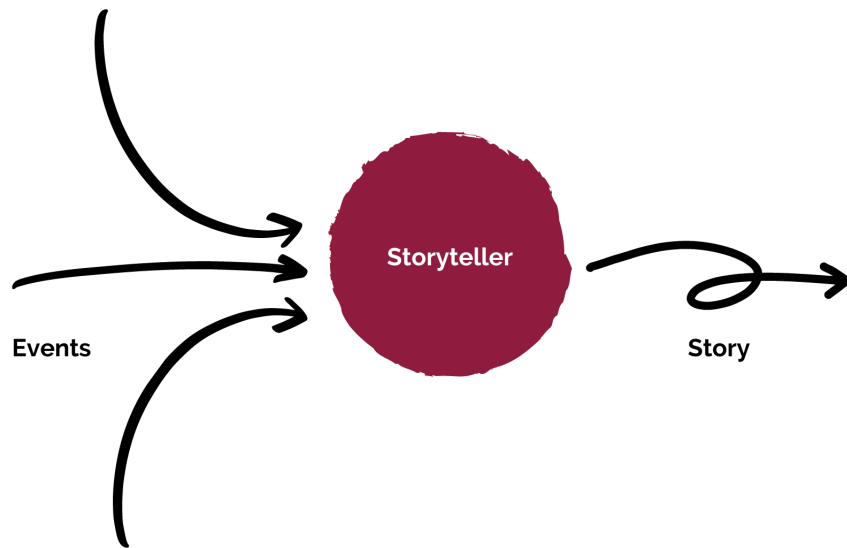


Figure 4: Storyteller as transformer. Diagram. Source: author's own.

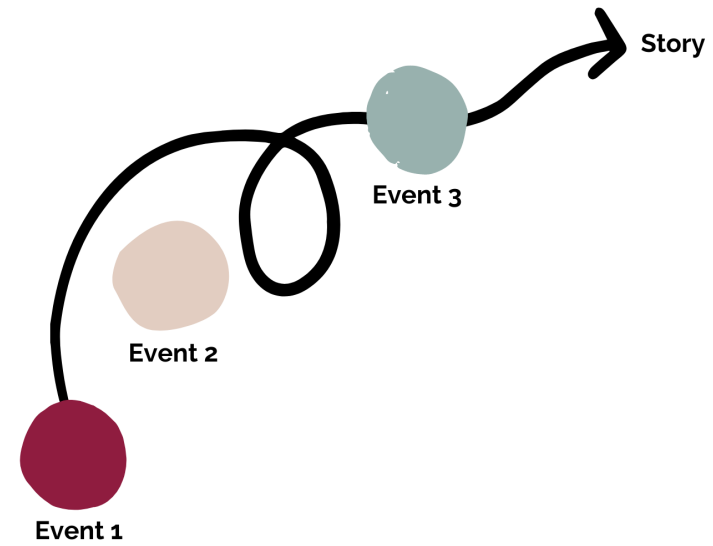


Figure 5: Constructing a narrative from a chain of events. Diagram. Source: author's own.

Frank (2013) argues that some people are more naturally inclined towards storytelling than others (what he calls *communicative bodies*). Some may even choose to publish their stories publicly. Anne Hunsaker Hawkins refers to such stories as *pathographies*: “a form of autobiography that describes personal experiences of illness, treatment, and sometimes death” (1999, p.1). She contends that such stories provide an important means for people to process their personal experiences, and to assert their personhood after a sometimes dehumanising process.

The potential of storytelling to improve people’s sense of wellbeing has also been observed in clinical practice, where studies have shown that people’s mental health improved after sharing their health story with a healthcare professional (Smith and Liehr, 2014; Chuang et al., 2018). Within the UK, there are multiple programmes which focus on the capture and dissemination of health stories (Trowbridge, 2018; Storytelling For Health 2, 2019; Hardy and Sumner, 2020), both as a way of empowering people with long-term conditions and to educate health professionals.

2.4.3 Storying with Others

When I got out of hospital, my first impulse was to write about my illness. While sick people need books...to remind them of the life beyond their illness, they also need a literature of their own. Misery loves company – if it's good company.

(Broyard, 1992, p.12)

The act of telling one’s story positions the teller in a relationship with the listener. Health stories can be told to any number of other people within someone’s circle (Frank, 2013; Teal et al., 2017), including health professionals, families, friends, caregivers, and “disease-mates” (Ferguson and e-Patient Scholars Working Group, 2007, p.37). While undergoing cancer treatment, Frank (2013) recorded telling different versions of his health story 8 times in a single day. These stories will also change based on who they are being told to – the story which told to a healthcare professional, for

example, will not be the same one shared with a co-worker (Bruner, 2003; Frank, 2012).

Health stories can be a useful resource for other people who have been recently diagnosed with similar conditions, as a way of learning about their condition through the experiences of others (Hunsaker Hawkins, 1999). Such networks play an important role in supporting people through their illness, and health stories are a key way in which information is shared (Ferguson and e-Patient Scholars Working Group, 2007). This act of sharing information with others may form an important part of a person's identity, allowing them to both recognise and celebrate the expertise that they have developed in their condition (Kleinman, 1988).

The concept of using health stories as part of treatment is not a new one. Narrative medicine, a field that has emerged over the past 30 years, formalises both storytelling and co-creation of health stories as a methodology for healthcare (Charon, 2006). In narrative medicine, healthcare professionals are encouraged to view their patient's

pathographies as literary narratives and to examine them using literary techniques. This covers a wide variety of practices and techniques used in a clinical context, including authoring of pathographies by patients, active listening to stories by healthcare professionals, and authoring of patient pathographies and self-reflections (e.g. through journaling) by healthcare professionals. My interest here is primarily in the authoring of stories by patients, and active listening by healthcare professionals. Charon describes the doctor as the "vessel" for the patient's story, after which they become the "ventriloquist" for expressing that narrative in terms of the patient's care (2006, p.132).

Cheryl Mattingly (1991) differentiates between this telling of the past and the co-creation of the future as *storytelling* and *story making* (p. 1000) The new story created during this process becomes their *prospective treatment story* (p. 1001). She emphasises that such stories are not necessarily always rosy. Healthcare professionals may deliberately invite patients to reflect on past challenges to prepare them for future ones (Mattingly, 2009).

There have been objections to narrative medicine, particularly as opposed to biomedical medicine. Seamus O'Mahony (2013) argues that there is a danger for narrative techniques to become intrusive and overstep patient boundaries, especially if they are led by the healthcare professional. It can also lead to a blurring of roles between patient and healthcare professional, which may prevent effective treatment. This underlines the importance of allowing narrative techniques to be patient-led, and for having well-defined roles between patients and caregivers.

Although the concept of narrative medicine is well-established, I am choosing to use a different term to describe the focus of the work: story-centred care¹. Story-centred care positions the health story as the both the starting and end point of their treatment, with the storyteller as the primary

owner. I have chosen not to use the more established term of *narrative medicine* as it is aimed at healthcare professionals – the listeners, not the storytellers. In addition, narrative medicine is not in and of itself equivalent to person-centred care, as shown in the criticism of it above. Furthermore, the term *narrative medicine* also encompasses other activities such as journaling/storytelling done solely by healthcare professionals. Finally, the use of the word *story* emphasises the story itself as the focus and facilitator of caregiving activities.

2.4.4 Cultural Health Stories

2.4.4.1 Archetypes

In forming their health stories, people draw from the wider body of stories which already exist in the world, making it possible to categorise them. Both Frank (2013) and Hunsaker

¹ The term *story-centred care* has sometimes been used in the literature to refer to Smith and Liehr's (2014) *story theory*, which focuses on the promotion of wellbeing by listening to people's health stories. My definition expands on this to examine how stories can be used more generally within caregiving.

Hawkins (1999) have attempted to describe genres for health narratives. These are shown in Figure 6, grouped by theme. I have omitted three genres which are not relevant to this work: *broken*, where the person is made physically incapable by their illness of telling their story without assistance; *borrowed*, in which another story is co-opted to tell one's story; and *death*, where the story ends in the person's death.

The type of construct that a person chooses to define their narrative will emerge from a dialogue between the person's cultural perceptions of illness and their personal experience (Kleinman, 1988). These constructs may also change over time, as the person's experience and perception of their illness progresses.

However, Hunsaker Hawkins (1999) provides a cautionary note in observing how the creation of pathographies (and the use of constructs within them) can become formative. Through the process of applying a narrative construct, the person is provided with a lens with which to view their experience – a technique which is sometimes deliberately employed by healthcare professionals in story making

(Mattingly, 2009). Such constructs can therefore become distressing to people if they do not match their personal experience. This emphasises the idea although people may draw from universal constructs in forming their own stories, the stories which they create are ultimately their own.

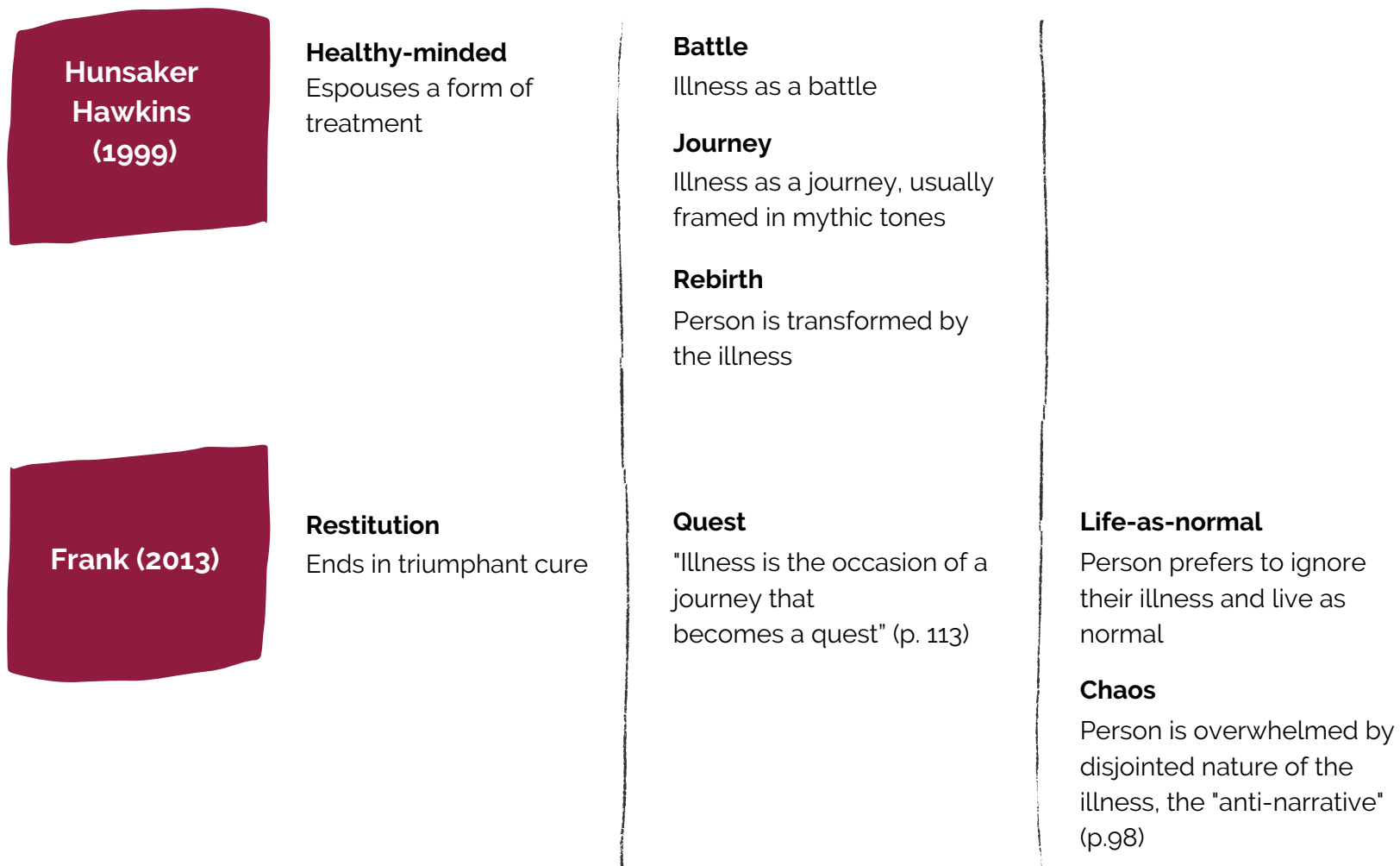


Figure 6: Comparison of narrative genres from Frank (2013) and Hunsaker Hawkins (1999). Diagram. Source: author's own.

2.4.4.2 *Stigma*

In addition to broader archetypes, stories of particular conditions are also culturally understood, both within the medical profession and beyond. Negative portrayals of a condition have an enormous impact on people's mental health and wellbeing (Goldberg, 2017). People with stigmatised conditions have a harder time developing relationships and building support networks (Horan et al., 2009). They may also be reluctant to disclose their condition to others, for fear of how they will be perceived (Mooney, 2006).

Invisible illnesses (conditions which are not visible to the outside observer) may be treated with greater scepticism from friends, family, and even healthcare professionals (Sea Gold, 2020), even though that such conditions can be enormously debilitating (Pederson and Hochstetler-Mayer, 2016). This social stigma can be devastating, as it undermines the very networks of care and support that people with long-term health conditions rely on (NHS Scotland, 2010), and also

makes them more likely to be doubted when they describe their negative experiences to others (Goldberg, 2017).

Hatzenbuehler, Phelan and Link have defined stigma as “the co-occurrence of labeling, stereotyping, separation, status loss, and discrimination in a context in which power is exercised” (2013, p.813). They argue that stigma forms a root cause of poor health outcomes on a population level, as summarised in Figure 7.

The stigma associated with a condition is not only expressed on an individual level through personal interactions, but may also be formalised through medical classification and treatment guidelines. This may then, in turn, reinforce personal prejudices. For example, a recent study found a significant difference between the way that patients with multiple sclerosis (categorised as a biomedical condition) were treated versus patients with myalgic encephalomyelitis (categorised as a psychiatric condition) (Lacerda et al., 2019). The treatment guidelines for myalgic encephalomyelitis (ME) have been criticised on ethical grounds (O’Leary, 2019;

Geraghty and Blease, 2019), showing a recognition in the medical community that such stigma exists.

It is therefore not surprising that people with stigmatised conditions are more likely to suffer from depression (Pederson et al., 2017), have suicidal ideation (Newton–John, 2014), and overall to be at greater risk of suicide (Roberts et al., 2016; Pederson and Brook, 2017).

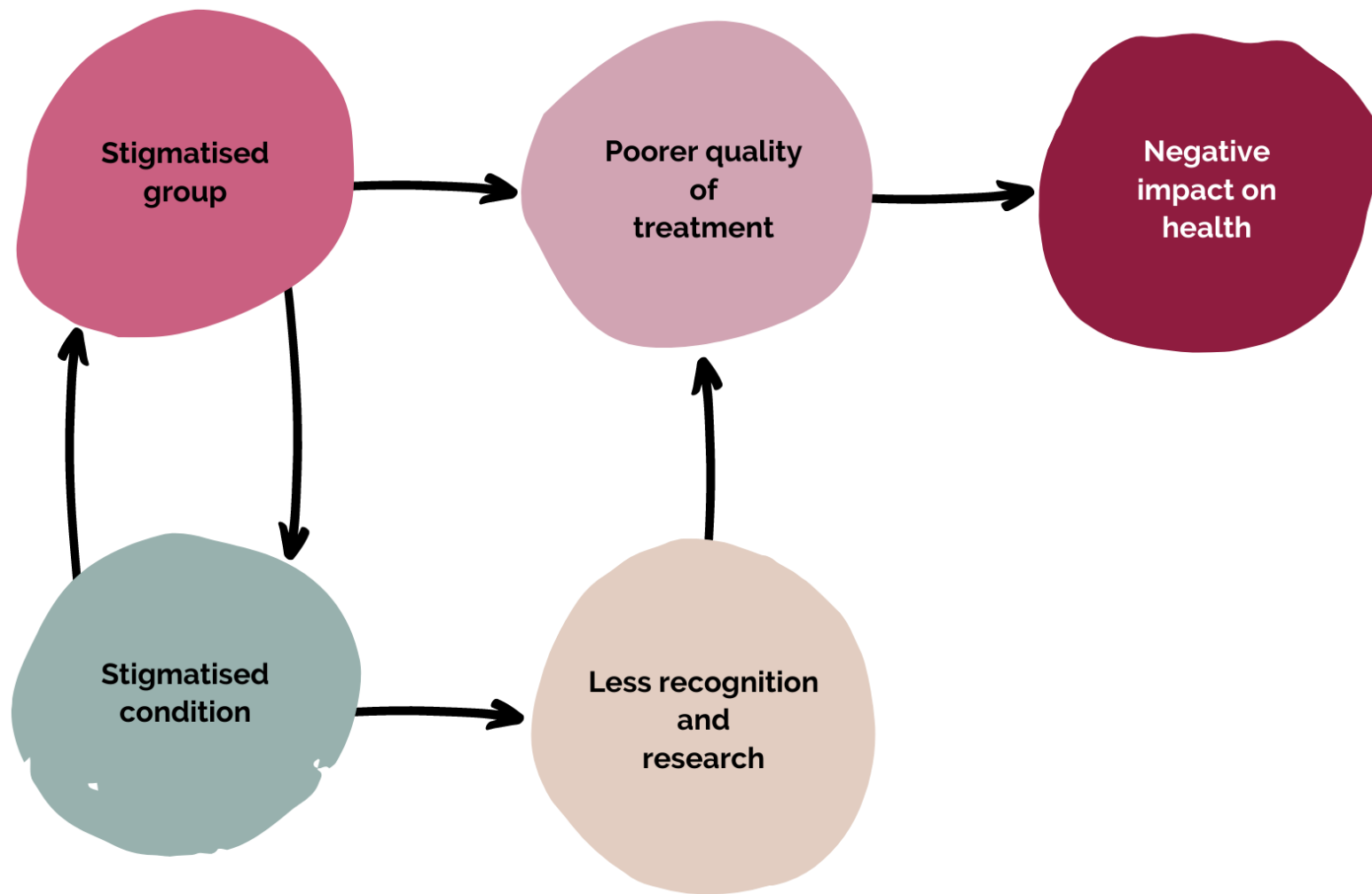


Figure 7: Effect of stigma on health outcomes, summarising Hatzenbuehler, Phelan and Link (2013). Diagram. Source: author's own

2.5 Summary

In this chapter, I have discussed the three major areas that impact this research: long-term health conditions, digital design for health, and health stories. From this discussion, certain themes have emerged which help to define an idea of designing for story-centred care.

Firstly, there is a need to put people first – both in approaches to care and in digital design. As designers, this requires us to adopt an empathetic and humanising approach which prioritises the needs of the individual, rather than the group. Secondly, people with conditions should have ownership over their care, and be recognised as developing expertise in their health over time (Kleinman, 1988). This includes authoritative ownership over their health stories and how they are communicated.

Finally, storytelling can promote care. Telling one's own story improves one's sense of wellbeing (Smith and Liehr, 2014), and incorporating people's stories into their treatment

allows healthcare professionals to care for them better (Charon, 2006). However, storytelling can also harm. Stories which conflict with individual experiences (Hunsaker Hawkins, 1999) or negatively portray conditions (Hatzenbuehler et al., 2013) have a wide range of negative impacts, from personal distress to poorer treatment across entire populations.

These themes illustrate the personal nature of story-centred care, and also the level of power and authority which storytelling brings. I have used these to further inform my approach towards the methodology, as discussed in the following chapter.

3 *Methodology*



3.1 Introduction

Designing digital tools for health stories combines two different areas of research: narrative medicine (framed here as story-centred care) and digital design.

Narrative medicine has a *de facto* standard methodology: narrative research, informed by hermeneutical phenomenology (Frank, 2012). As shown in the literature review, story-centred care centres on the person with the long-term condition and the lived experiences of their health, giving a theoretical standpoint which is based in constructivism and interpretivism. Hermeneutical phenomenology is consistent with this stance.

Digital design also has a *de facto* standard methodology: Human-Centred Design (HCD) (Cooper, 1999). HCD draws from a variety of design practices and incorporates aspects of design ethnography, participatory design, empathetic design, and co-design (Steen, 2011). As such, it does not have a single theoretical standpoint.

In addition to both of these approaches, the project incorporates my practice as a digital interaction designer. Story-centred care dictates that the ownership of the story should remain with the storyteller. Therefore, I needed to allow my practice to be directed by the participants, while still being able to contribute from my expertise (not an uncommon challenge within HCD, as observed by Mark Steen (2011)).

I have chosen to resolve this by using dialogical narrative research to inform a process of reflexive prototyping, under a theoretical positioning of phenomenology. I have described this new approach as *Dialogic-Reflexive*. Figure 8, inspired by Michael Crotty (1998, p.4), illustrates how the theoretical framing informs the methodology and methods.

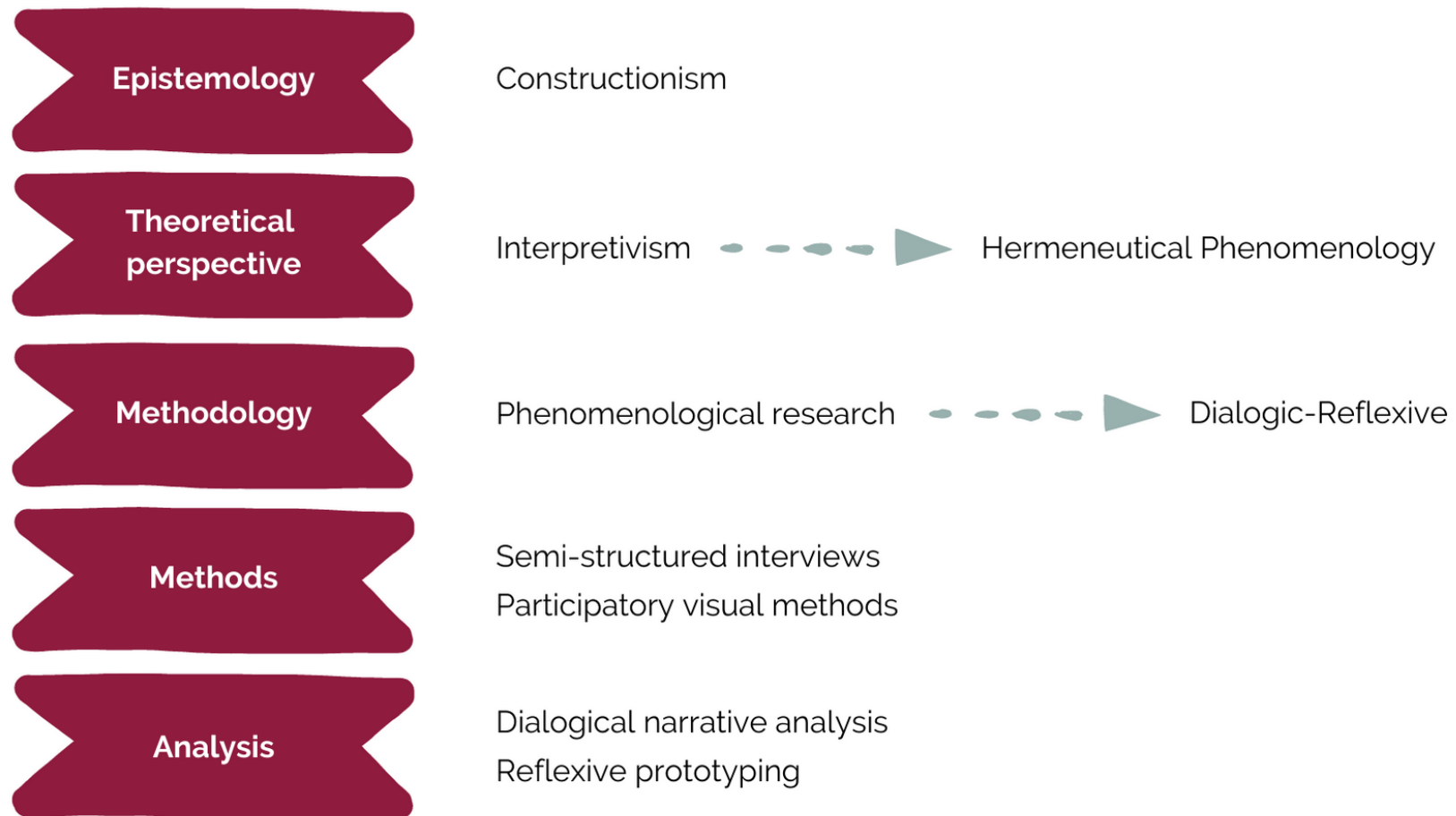


Figure 8: Theoretical positioning of methodology. Diagram. Source: author's own, adapted from Crotty (1998, p.4)

3.2 Theory: Hermeneutical Phenomenology

Phenomenology was first described by Edmund Husserl (1983) in 1900–1901. It focuses on the “actual phenomena of experience, where other [traditional] approaches might be concerned with abstract world models” (Dourish, 2004, p.30). The phenomenological school I have adopted here is *interpretive phenomenology*, first proposed by Martin Heidegger (1962), also called *hermeneutical phenomenology*. The main difference between Heidegger’s theories and those of Husserl is that Heidegger rejected the concept of *bracketing* in which the researcher is meant to *suspend* or *bracket* their “scientific, philosophical, cultural, and everyday assumptions” (Moran, 2002, p.11). Instead, Heidegger turned to hermeneutics, which comes from the study of the Bible (Moran, 2002). Hermeneutics tells us that understanding of phenomena is both “enabled and also limited by understandings that have already been set in place” (Frank, 2012, p.94).

From a research perspective, such an approach is inherently reflexive, as it positions the researcher within the work (Thompson, 2018). Through the process of carrying out the research, the researcher becomes a vehicle for hermeneutical interpretation and analysis in what Ingold (2013) calls *knowing from the inside*.

As discussed in the previous section, hermeneutical phenomenology is commonly used for narrative research in healthcare because of its focus on individual experience (e.g. the work of Smith and Sparkes (2004), who have examined narrative themes in the health stories of men with sports injuries). HCD, on the other hand, has no unifying stance. As a result, it has been criticised as casting other fields such as ethnography in a service provider role, where practitioners “cherry pick” methods to form a “mixing pot” of hybrid approaches (Crabtree, 2004, p.196).

Digital design based on phenomenology has been used in research (Dourish and Button, 1998; Dourish, 2004; Wright et al., 2008), although it is not commonly used in industry. The closest match that I have identified to the approach used within this project is the work of Frauenberger, Good and Keay-Bright (2010), in which children were asked to draw

designs for educational software, although that project did not incorporate narrative research.

3.3 A Dialogical-Reflexive Approach

3.3.1 Dialogical Narrative Research

In this project, I have applied a phenomenological approach through the use of *dialogic research*. I am greatly indebted here to Arthur Frank's (2012) concept of *dialogical narrative analysis*, the principles of which are described below:

- The research is **non-finalisable**: “no one – especially the researcher – ever has ‘the whole story’” (Frank, 2012, p.103)
- The researcher talks *with* participants, not *about* them
- The researcher and the participants have *mutual recognition*, i.e. understanding that research exists within the context of people's lives and must acknowledge that context

In this approach, the work happens as an ongoing dialogue between the participants and the researcher, with the participants taking on the role of co-researchers. Participants are in control of their contribution to the research and retain

the right to change it. They are considered as experts in their own experience, and their participation in the research is a contribution of that expertise. This is similar to Finlay's (2009) reflexive-relational approach, in which the research is co-created between the participant and the researcher.

This framing gave me an approach towards the research, but only limited guidance in understanding the activities and structure for carrying it out. For this, I have turned to Cara Broadley's (2013) Participatory-Reflexive methodology.

3.3.2 Participatory-Reflexive

The Participatory-Reflexive approach is based largely on participatory design, which comes from Scandinavian research done with trade unions in the 1970s (e.g. Nygaard and Bergo (1975)). Participatory design is democratic in that it seeks to engage with users as experts in their field. With the rise of HCD, participatory design has been readily adopted as one of the standard methodologies used in digital design

projects (IDEO, 2015). The term *reflexive* within the Participatory-Reflexive name refers to Broadley's use of autoethnographic drawings as a form of reflexive analysis, discussed further in Section 3.7.2.

I chose not to adopt participatory design as an overarching approach, because “most people are poor reporters or predictors of their own preferences and behaviour when presented with speculative...scenarios” (Hall, 2013, p.81). In other words, people may talk accurately about what they *currently* do, but not about what they *might* do. Given that there is currently no digital tool (as far as I am aware) designed for health storytelling, I was not able to rely on

participants' experiences of using similar tools. However, I have incorporated participative methods as it is consistent with the dialogic approach.

Broadley's activities were carried out in cycles, organised into stages of Orientation (comprising activities such as desk research), Participation, Evaluation-in-Action, Tool Response Analysis, and Reflexive Analysis. I have followed the same overall format, but given the smaller scale of my work, I have simplified my approach into four stages rather than five (Figure 9).

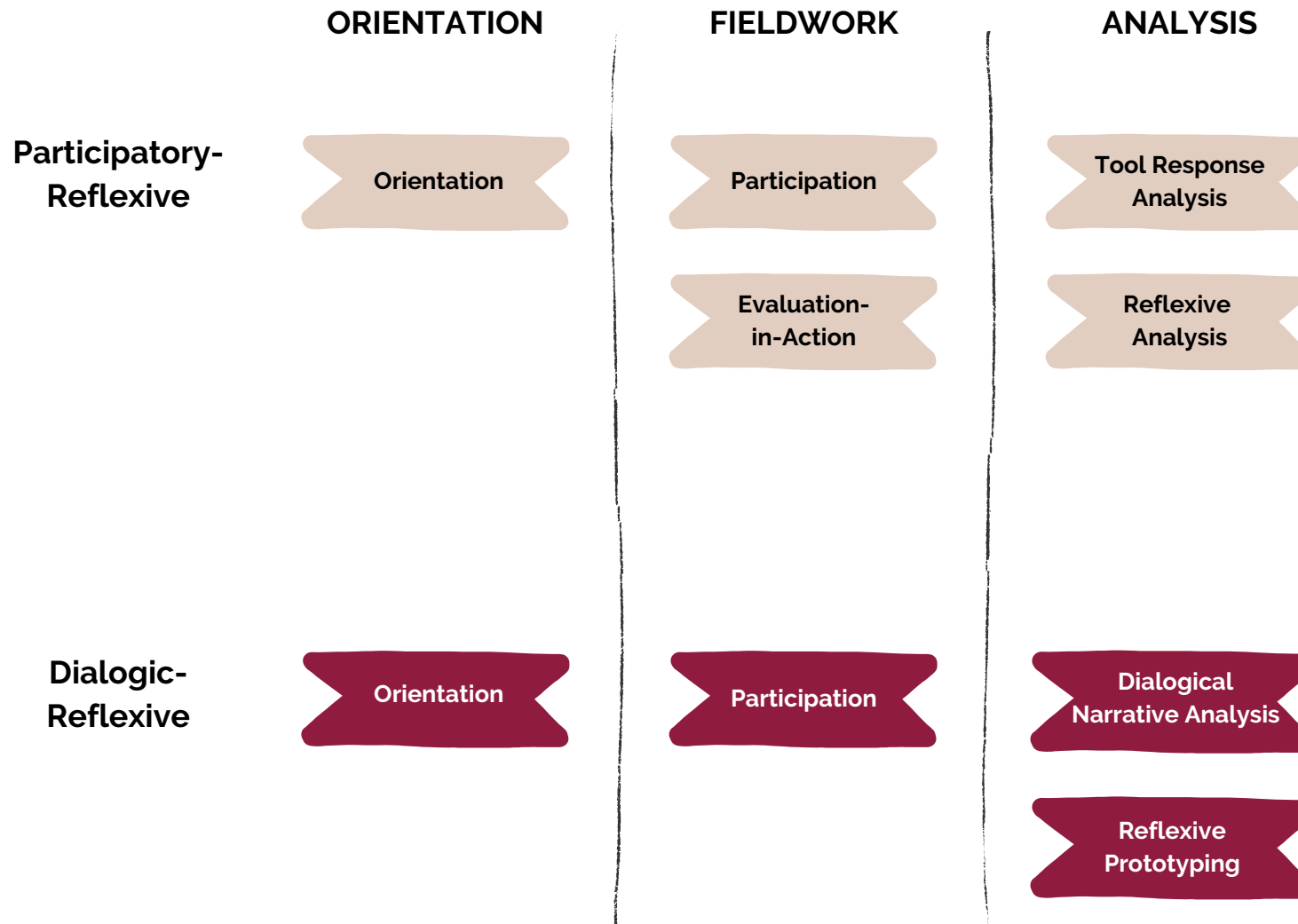


Figure 9: Comparison with Broadley's (2013) Participatory-Reflexive Methodology. Diagram. Source: author's own

3.4 Methods

To best understand how digital tools can support health storytelling, I used reflexive, semi-structured interviews to drive a process of co-creation with the participant. The reflexive format required repeated engagements – a format which also fit well with my dialogic approach. Using this format, I organised the project into cycles of activity, each of which commenced with a 1:1 participant workshop (Figure 10).

Following each workshop, I used a process of narrative analysis (Frank, 2012) to inform my own reflexive prototyping practice. The output of this was then carried forward to form the foundation of the next cycle.

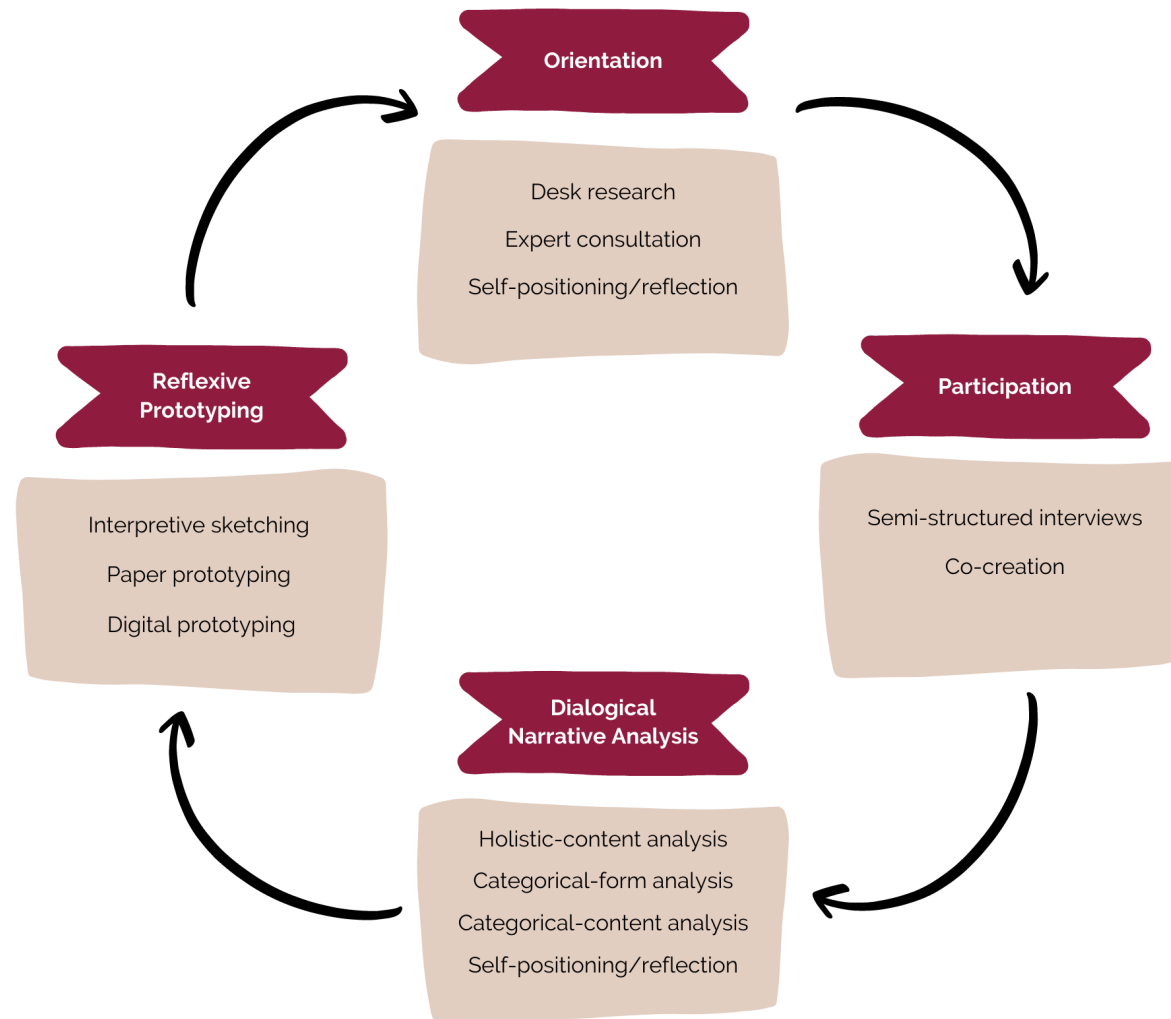


Figure 10: Method cycles within a Dialogic-Reflexive methodology. Diagram. Source: author's own.

3.4.1 Reflexive Interviewing

In reflexive interviewing², the interview is carried out on conversational terms, without attempting to adhere too closely to a script (Ellis and Berger, 2003; Ellis, 2004). The researcher may also share their own relevant experiences during the interview, while still keeping the focus on the participant.

In this project, I chose not to apply the more intimate approach advocated by Ellis and Berger (2003) in which the researcher and the participant become equal conversational partners. As a novice researcher, I felt that I didn't have the experience to maintain the necessary boundaries to conduct this type of research. I also felt that it was important that my voice not dominate the work, given the direction from the literature: "An interview is like a conversation, but it is not a conversation. ...[T]he other person is the one doing the talking. You are the one doing the listening." (Atkinson,

1998c, p.10). Instead, I have used a semi-structured format in which I selected questions or topics from a pre-prepared list.

Reflexive interviews are also episodic, with periods of reflection in between (Pessoa et al., 2019). This format gives both the researcher and the participant space to expand on topics from previous sessions. It also allows the participant to verify the researcher's analysis, creating a "shared intelligibility" which in turn adds further rigour to the research (Thompson, 2018). Reflexive interviews are designed to build trust between the researcher and the participant and are well-suited to personal and/or emotional topics. This results in richer, more detailed data than could be got from a single interview in a more formal setting.

Within this project, the episodic format allowed me to develop an understanding of *how* and *why* my participants told their health stories. Having never worked in healthcare

² The term preferred by Ellis and Berger (2003) is *reflexive dyadic interviewing*. However, in contemporary usage the term *reflexive interviewing* is more commonly used, whereas *dyadic interviewing* refers to interviewing multiple people at once.

before, it also allowed me to gain experience of listening to people's health stories and to develop empathy with my participants' experiences.

3.4.2 Co-Creation

The term co-creation refers to “any act of collective creativity, i.e. creativity that is shared by two or more people” (Sanders and Stappers, 2008, p.6). In this project, the entire dialogic research process acted as one long act of co-creation, working with the participant to move towards the end goal. Within this, I have used two approaches: participatory visual methods and co-design.

Participatory visual methods (PVMs) have emerged from qualitative research in health and social sciences. PVMs have been praised as giving participants a voice within the work and empowering their perspectives (Gubrium et al., 2014). In my project, I have applied the PVM methods of object elicitation, graphic elicitation, and photovoice. In both object elicitation and graphic elicitation, participants are shown something (either an object or a graphic representation,

respectively) during an interview and asked to discuss it with the researcher (Crilly et al., 2006). In photovoice, participants are asked to take pictures around a particular theme. All of these methods were used in conjunction with the reflexive interviews to put participants at ease and also allow me to *dig into* certain topics with them (Olfiffe and Bottorff, 2007).

A similar approach often used in HCD is co-design (Sanders and Stappers, 2008). In co-design, the design researcher acts as a facilitator, creating toolkits which allow the participants to take on the role of co-designers. The focus in co-design is therefore not on what participants *say* but on what they *make*. Co-design can be a useful way of gaining insight into designing for the future (Steen, 2011). However, Ezio Manzini (2016) has critiqued co-design as undermining the designer's role into an administrative function, and instead advocates for “dialogic cooperation”(p.58) between designers and users. Although most of what we did during the project can be framed as a type of co-design, we also did this as an explicit activity during one of the participant workshops. This also incorporated elements of elicitation, in that the co-designed

artefact also served as a talking point to discuss and validate my understanding of their story.

The ethics and research design of both PVMs and co-design needs to be carefully considered. As researchers are using artefacts which have been selected and/or co-produced by the participants, consent needs to be explicit and given repeatedly (Black et al., 2018). Such methods are also not inherently empowering (Switzer, 2017). Participants may still

be disempowered through poor research design: for example, if the technology is too complicated for them to be able to engage with without assistance (Packard, 2008). I have discussed how this impacted the fieldwork design of the project in Section 4.3.

3.5 Narrative Analysis

It has been argued that stories must be analysed in their entirety (Atkinson, 1998b; Frank, 2012), rather than applying a thematic approach. An interesting example illustrating this point comes from Simonds and Christopher (2013), who describe attempting to do joint thematic analysis with representatives of a Native American/Alaskan Native (NA/AN) community. The representatives struggled with the task, stating that they felt it was “disrespectful” and that “having scattered categories and breaking apart people’s stories loses the meaning and the understanding of the whole picture and purpose of the story” (Simonds and Christopher, 2013, p.2187).

I was concerned with honouring my participants and the stories that they were telling me. However, I also felt that it was important to identify overall findings. I have attempted to reconcile this by progressively applying different layers of narrative analysis, described by Lieblich et al. (2011) as follows:

- **Holistic-content analysis:** understanding a story in its entirety
- **Categorical-form analysis:** understanding how a story is told by examining its form
- **Categorical-content analysis:** understanding a story’s overarching categories/themes

First, I used holistic-content and categorical-form analysis to understand each participant’s story, which then informed the rest of their engagement within the project. Once this had been established, I then used categorical-content analysis to pull out the findings, first within each individual story, and then across all the participants. I also applied Frank’s (2012) dialogical approach, going back to my participants at each stage to verify my analysis.

3.6 Reflexive Analysis

3.6.1 My Practice

Prototyping comes from a long history of both art and engineering, in which artists and engineers would develop a rough model of a concept to let them try an idea without wasting costly materials. Rapid prototyping assisted by computers emerged in the 1960s with the work of Herbert Voeckler (Bennett, 2020) and now prototyping is standard practice for an HCD approach within digital design (IDEO, 2015).

My background is in software development and design, and the iterative prototyping method which I used is one that is common to HCD. I have outlined this generally in Figure 11, omitting techniques which I have not applied within the project. The intention is to start with a very rough concept, which is then refined through iterative stages of validation into a high-fidelity design. *Fidelity*, in this case, is relative to the level of polish needed for a software product which could be publicly released (Rudd et al., 1996).

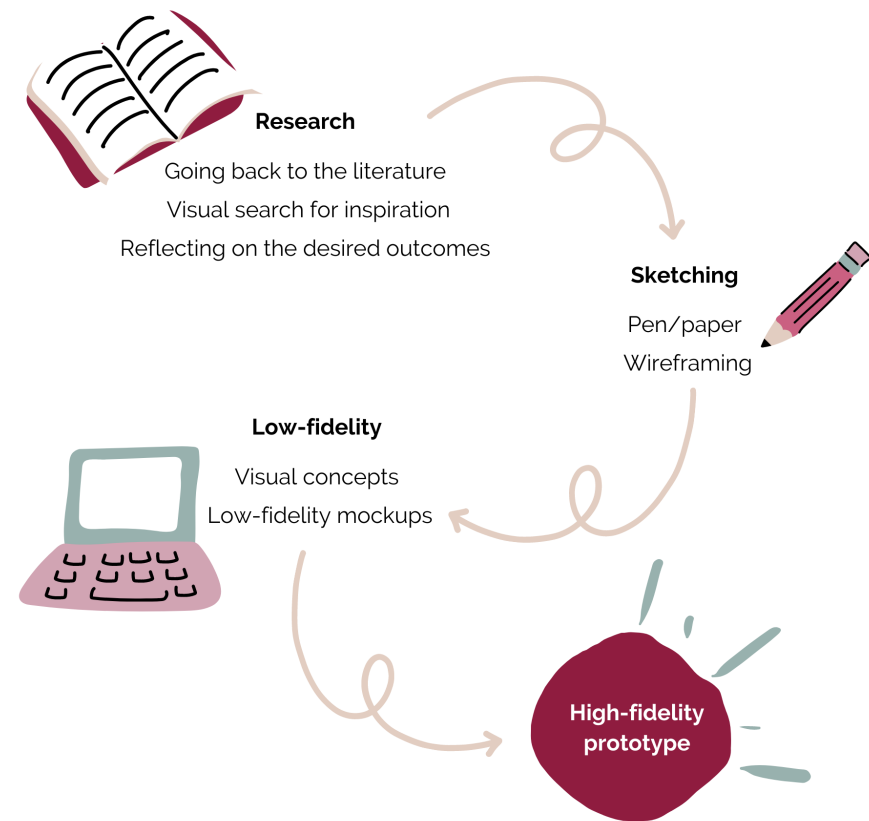


Figure 11: My reflective practice. Illustration. Source: author's own.

I first like to begin by assembling a *palette of ideas* using findings from the literature. I add to this with further research, doing a visual search for related imagery, and looking at interfaces that solve similar problems. I would then begin sketching out rough ideas using pen and paper. The most promising sketches are worked up digitally using Sketch (<https://www.sketch.com/>), a vector illustration software designed for digital prototyping. A more detailed explanation of the prototyping activities used for this project can be found in Chapters 4 and 5.

The approach that I am applying within this project is quite unusual, in that it attempts to create prototypes which are highly personalised for each individual. A more common approach would be to use fictional user profiles called *personas* (Cooper, 1999). In this approach, research activities would be carried out with groups of participants. The findings from this research would be abstracted to create personas (e.g. Figure 12), which would then be used to design a more generalised prototype.

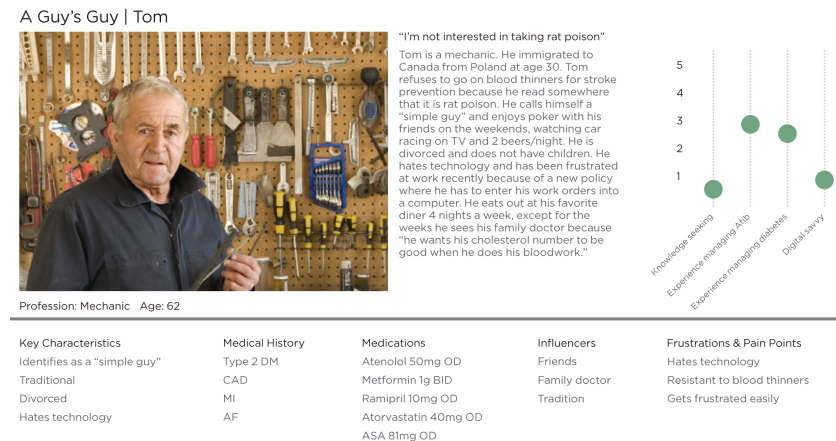


Figure 12: Example of a persona for healthcare design. Illustration. Source: Jones (2013, p. 110), courtesy of the Health Design Lab.

In this project, I have done the opposite. Rather than generalising early on, I have preserved the participants' individual data in its entirety all the way through the prototyping stage. The result is that I have developed designs based on real people and their experiences and perspectives, not abstractions. This could therefore be viewed as being analogous to a lead user approach (Steen, 2011), a methodology often used in sports design where a product is designed around a single, expert user's requirements. In this case, my participants' experiences of having multiple health

conditions have made them “experts” in skills related to their care (Liddy et al., 2014).

I have chosen not to use personas for the following reasons. Firstly, it has been argued that the use of personas is inappropriate within a health context because they fail to capture the complexity of the illness experience (Portigal, 2008; Jones, 2013). Secondly, health stories are inherently personal, making a personalised approach an appropriate choice. This is consistent with the phenomenological standpoint that I have adopted in the work. Thirdly, it felt important to ensure that the stories and voice of the participants remained present throughout. The resulting prototypes carry the unique viewpoint of the participant whose story they have emerged from.

3.6.2 Prototyping as Analysis

I have framed prototyping as both a creative and an analytic activity – an understanding influenced by Broadley’s Participatory-Reflexive methodology (discussed in Section 3.3.2) and Creative Analytic Practices (CAP).

The term Creative Analytic Practice (CAP) was originated by the sociologist Laurel Richardson (2001), who takes the postmodern viewpoint that the use of prose for research is only a convention, and that creative practices are equally valid.

CAP...is both “scientific”—in the sense of being true to a world known through empirical work and study—and “literary”—in the sense of expressing what one has learned through evocative writing techniques and forms.

(Lewis-Beck et al., 2004)

Broadley’s project applied a similar approach, using autoethnographic drawing to add another layer of analysis by showing Broadley’s experiential interpretation of the data as a design researcher. This, combined with the framing from CAP, demonstrates how a reflexive, creative practice can take on an analytic role.

3.7 Participant Recruitment

Participants in the project were adults with multimorbidity (two or more health conditions) based in Scotland. As I chose to adopt a phenomenological approach, only 5 participants were recruited for the project to permit time to fully explore each participant's health story.

Participants were primarily recruited via local support groups. The groups were selected by identifying conditions that have a high likelihood of multimorbidity. To that end, I decided to target recruitment efforts at groups for myalgic encephalomyelitis (ME). ME has a very high instance of multimorbidity – a recent study of ME patients found that over 80% had co-morbidities (Castro-Marrero et al., 2017). This meant that people in the ME groups were very likely to meet my recruitment criteria. I was also interested to learn how issues related to stigma and invisible illness, as are common with ME, might impact storytelling.

3.8 Ethics

The project began during Phase 1 of COVID-19 lockdown in Scotland, meaning that it wasn't possible to do face-to-face interviews. As a result, all of the workshops were designed to be carried out remotely using a video conferencing service.

Oral consent was obtained from the participants in their first session and recorded as part of their data. I included a second formal consent checkpoint midway through the work, but informal reminders were given to them during each engagement. During the checkpoints, participants could review what had been produced/discussed so far and note if there was anything which they would like omitted from the output. This is consistent with a dialogical approach (Frank, 2012), and also followed best practice in allowing participants to review the final product of the research before finalising consent (Black et al., 2018).

To ensure the anonymity of the participants, they were asked to select a pseudonym that would be used to identify their contribution. All of the output from these sessions has been reviewed and anonymised using their pseudonym, with any identifying information removed. Participant sessions were also carried out individually, meaning that no participants were ever in contact with each other at any time. This is consistent with the in-depth phenomenological approach that I wanted to take, as well as giving the participants additional privacy.

3.9 Summary

In this chapter, I have discussed how the principles of story-centred care that emerged from the literature were used to shape the methodology. The two most important of these are:

- Storytellers must be respected, by giving them continuing ownership over their story
- Stories must be respected, by approaching them holistically

I have attempted to apply these principles through a dialogic approach, in which I worked with each participant individually to make sure that their voice (literally and figuratively) was preserved throughout the work. This was also carried through to the methods. The reflexive interview format allowed me to develop a holistic understanding of each participant's story over time, and then use this understanding to inform a process of co-creation with the participant.

In the next chapter, I will discuss how I applied the methodology while carrying out the fieldwork.

4 *Fieldwork*



4.1 Introduction

In this chapter, I discuss how the fieldwork was carried out. Firstly, I explain how the participants were recruited. Secondly, I discuss how the fieldwork was designed, including the selection of the tools and considerations of digital security and privacy. Finally, I go over each step of the fieldwork, explaining what was done at each stage.

Fieldwork was carried out in three cycles, each of which commenced with a 1:1 participant workshop which was used to drive the work for that cycle (Figure 13). The workshops were designed around each participant following a structure. So, while no individual workshop was the same as any other, they all followed the same overall format which is described in this chapter. Throughout this project, my path as a researcher can be viewed as a *dialogic wave* following the approach described by Frank (2012): moving away from the participant and then returning for validation/consent checkpoints and workshops.

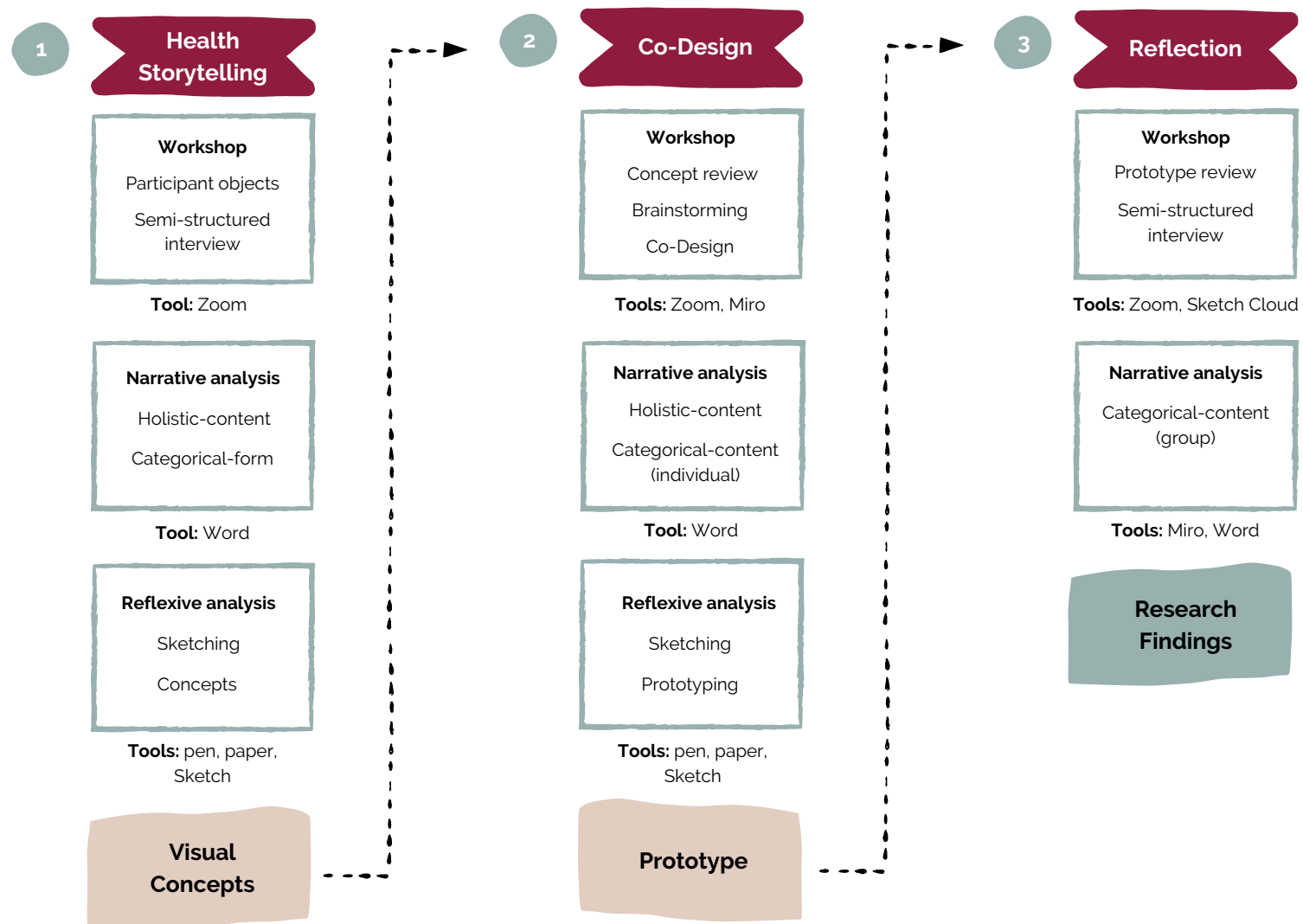


Figure 13: Details and order of fieldwork activities. Diagram. Source: author's own.

4.2 Participants

I contacted 8 support groups for recruitment: 1 group supporting older people, 1 group supporting people with multiple sclerosis (MS), and 6 groups supporting people with myalgic encephalomyelitis (ME). The group for MS and two groups for ME agreed to pass along information to their members, the others did not respond. A friend also distributed information about the project in a closed support group for postural tachycardia syndrome (PoTS) on Facebook.

In each case, interested parties were directed to a webpage that I created (<https://futurehealthandwellbeing.org/see-me-hear-me-know-me>) with information about the project and my contact information. Table 2 shows the final cohort.

Once participants joined the project, they were sent an information pack in the mail which contained a paper copy of the project information sheet and consent form for their reference.

The project information sheet and consent form can be found in **Sections 1.1 and 1.2** of the Appendix.

Table 2: List of research participants.

Pseudonym	Gender	Age	Conditions³	Recruitment method
Lee	F	31	Psoriatic arthritis, fibromyalgia, polycystic ovary syndrome (PCOS), Raynaud's disease	Patient support organisation ⁴
Rhona	F	38	ME, borderline personality disorder, fibromyalgia, post-traumatic stress disorder (PTSD), depression, anxiety, chronic migraines, irritable bowel syndrome (IBS), Raynaud's disease, postural tachycardia syndrome (PoTS)	PoTS support group
M	F	39	Relapsing-remitting MS (RRMS), chronic depression, early menopause	MS support group
Sharon	F	51	Secondary breast cancer, ME	ME support group
Tedhead	M	53	ME, chronic depression, irritable bowel syndrome (IBS)	ME support group

³ Refer to the Glossary of Terms for further information on conditions.

⁴ Lee's job is related to patient advocacy and support. She volunteered for the project after I contacted the organisation that she works for about recruitment.

4.3 Selection of the Tools

The tool selection required careful deliberation, as the technology within a project may be disempowering for participants if it is too difficult for them to use (Packard, 2008). I chose Zoom (<https://zoom.us/>) for the interviews as it is one of the simplest conferencing tools and doesn't require an account to use, meaning that it can be used anonymously.

I also used Miro (<https://miro.com/>), an online whiteboard tool to enable the participant to engage and interact with the visual concepts during the co-design process. This was chosen instead of sharing the materials via Zoom to enable participants to more actively contribute and have ownership, an important principle of story-centred care. I also worked to address any power imbalance during the co-design activity in Miro by:

- Sending participants a “Getting Started” tutorial before the session so that they could learn to use the tool beforehand if they wished
- Building in time to orient participants to Miro and let them practice using the functionality
- Regularly checking back with them during the session to make sure that they felt comfortable with the direction of the work and my interpretations

For each workshop, I planned multiple fallback options which could be used if participants had any problems. For example, if a participant was unable to connect to Miro themselves, I planned to share my screen with them and have them direct my actions.

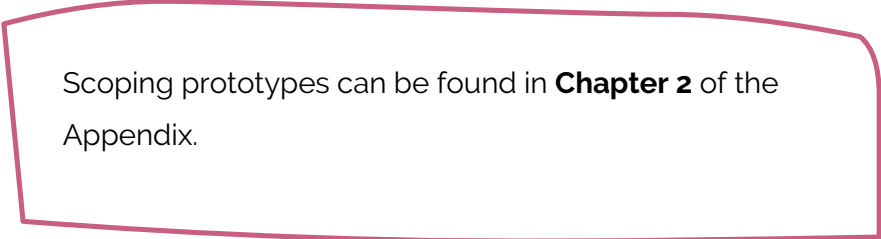
4.4 Digital Security and Privacy

As the participants were interacting with me online, digital security and privacy were major concerns. During each session, I used a Zoom Pro account to ensure the highest level of security. Each session was recorded locally (i.e. not through a cloud service). Access to the Miro collaborative workspaces was through a unique password-protected link which I shared confidentially with the participant during the session. I also discussed the issue of digital security and privacy with my participants, so that they would be aware of potential risks and know not to share access details with anyone else.

Participant data which contained identifying information was stored on an external hard drive kept in a secure location. Only I had access to the drive throughout the project. Any data stored on the cloud was anonymised beforehand to make sure it did not include identifying information.

4.5 Scoping

Before engaging with participants, I did some initial scoping and practice prototyping. I worked with publicly available, published narratives, and also interviewed a family member with multimorbidity. The purpose of the scoping was to test and refine the methodology and to deepen my understanding and empathy of living with a long-term condition. I refined the prototypes by soliciting feedback on them from my supervisors and peers. Although untested, they served to familiarise me with the context and consider what would be needed for the participant work.



Scoping prototypes can be found in **Chapter 2** of the Appendix.

4.6 Cycle 1: Health Storytelling

4.6.1 Workshop

For my first workshop with the participant, I used a semi-structured interview to elicit their health story. The purpose of this was twofold. Firstly, I wanted to get to know the participant and learn about their history. Secondly, I was interested in learning *how* they told their story.

I developed a list of questions based on the health story prompts developed by Marini (2019), which were designed to elicit a comprehensive health story using minimal English to maximise the level of understanding. I started by converting each prompt into a question format and then edited and condensed these down into the final list of questions.

In the first workshop, I opened the session by orienting them to the project and recording their consent. I then moved on to asking basic questions about the participant: age, list of health conditions, etc. Before the workshop, each participant had been asked to select an object or objects which

represented their health to them as a form of object elicitation, taking inspiration from material culture research such as Buse and Twigg's (2016) study of the handbags of women with dementia. I hoped to learn more about how the participants perceived themselves through their choice of object. Following the session, participants were asked to take a photograph of their object(s) for inclusion in the project, as a simple form of photovoice (Fraser and al Sayah, 2011).

Interview questions for Workshop 1 can be found in **Section 1.3** of the Appendix.

4.6.2 Research Journaling

Following the workshop, I used reflexive journaling (Meyer and Willis, 2019) to record my immediate impressions and to reflect on my presence within it. This formed an initial

analysis. I did this using a set of prompts adapted from the field notes template used in the work of Warner et al. (2012), in which the researchers interviewed people who were being cared for at home.

Research journal prompts can be found in **Section 1.4** of the Appendix.

4.6.3 Transcription & Story Editing

I then transcribed the portion of the interview which focused on their health story, following the guidance from Atkinson (1998b) in prioritising readability. The transcription was then edited to rearrange the events into chronological order, creating a version of the participant's health story in their own words. The story was emailed back to the participant to allow them to review and edit it, should they wish. This acted as an additional validation/consent checkpoint to confirm

that the participant was still happy to include all of their information.

Participant story creation process is explained in further detail in **Chapter 4** of the Appendix.

4.6.4 Holistic-Content & Categorical-Form Analysis

I used holistic-content and categorical-form analysis (Lieblich et al., 2011) to gain a deep understanding of each participant's story. The process of transcribing and editing the participant's story had already given me a certain level of holistic understanding. I combined this with a more formal analysis using a series of prompts, modified from the narrative elements in health stories identified by Charon (2006):

- **Frame:** Where is the story located in the world? How does it emerge?
- **Form:** What forms can be identified within the story (genre, metaphor, structure, allusion, diction)?
- **Time:** What order is the story told in? What period does it cover? What is its pacing?
- **Plot:** What happens in the story?
- **Desire:** What does the narrator hope to achieve by telling the story? What does the reader/listener hope to achieve through reading/listening to it?

Categorical-form analysis prompts can be found in **Section 1.5** of the Appendix.

4.6.5 Reflexive Analysis

Using the findings from the narrative analysis, I developed a *palette of ideas* for each participant's prototype by doing further reading, doing visual searches around key

themes/motifs, and looking at existing digital applications. Pen and paper sketches allowed me to quickly iterate through different concepts.

Once I had a single design concept in mind, I used Sketch (<https://www.sketch.com/>) to create an illustration which incorporated all of the major aspects of the design, and to which I could refer to during prototyping. I have developed this technique through my professional work, loosely inspired by Style Tiles (<http://styletil.es/>), “a design deliverable consisting of fonts, colors and interface elements that communicate the essence of a visual brand” (Warren, 2012). My take on this could be referred to as Concept Tiles, as it focuses more on the ideas rather than presentation. The result is something closer to an illustration rather than a traditional web layout.


The initial designs were kept low-fidelity so that my participants would feel comfortable criticising them (Pernice, 2016). My focus was to create components or “hooks” which the participant could use as a springboard for creativity.

4.7 Cycle 2: Co-Design

4.7.1 Workshop

In the second cycle, each participant was invited to participate in a workshop with me on Miro, using the initial visual concepts I had created. In the workshop, I used a series of participatory activities and discussion to build up to a co-design session, in which we created partial representations of the participant's health story using the concepts.

Figure 14 shows a blank (unpopulated) version of the Miro layout I created to use for the workshops. Selected screenshots from each individual workshop have been given in Chapter 5 of the thesis, in the sections for each participant.



Detailed images of the Miro template used for Workshop 2 can be found in **Section 1.6** of the Appendix.

4.7.1.1 *Orientation*

Upon entering the workshop, participants were first given an introduction and then taken through a series of brief tutorials to orient them to Miro. I interspersed these tutorials (shown in Figure 14 in pink) throughout so that each piece of functionality was introduced as the participant needed to use it. I also limited the amount of functionality that I was using in an attempt to keep the tool accessible to the participants, as discussed in Section 4.3.

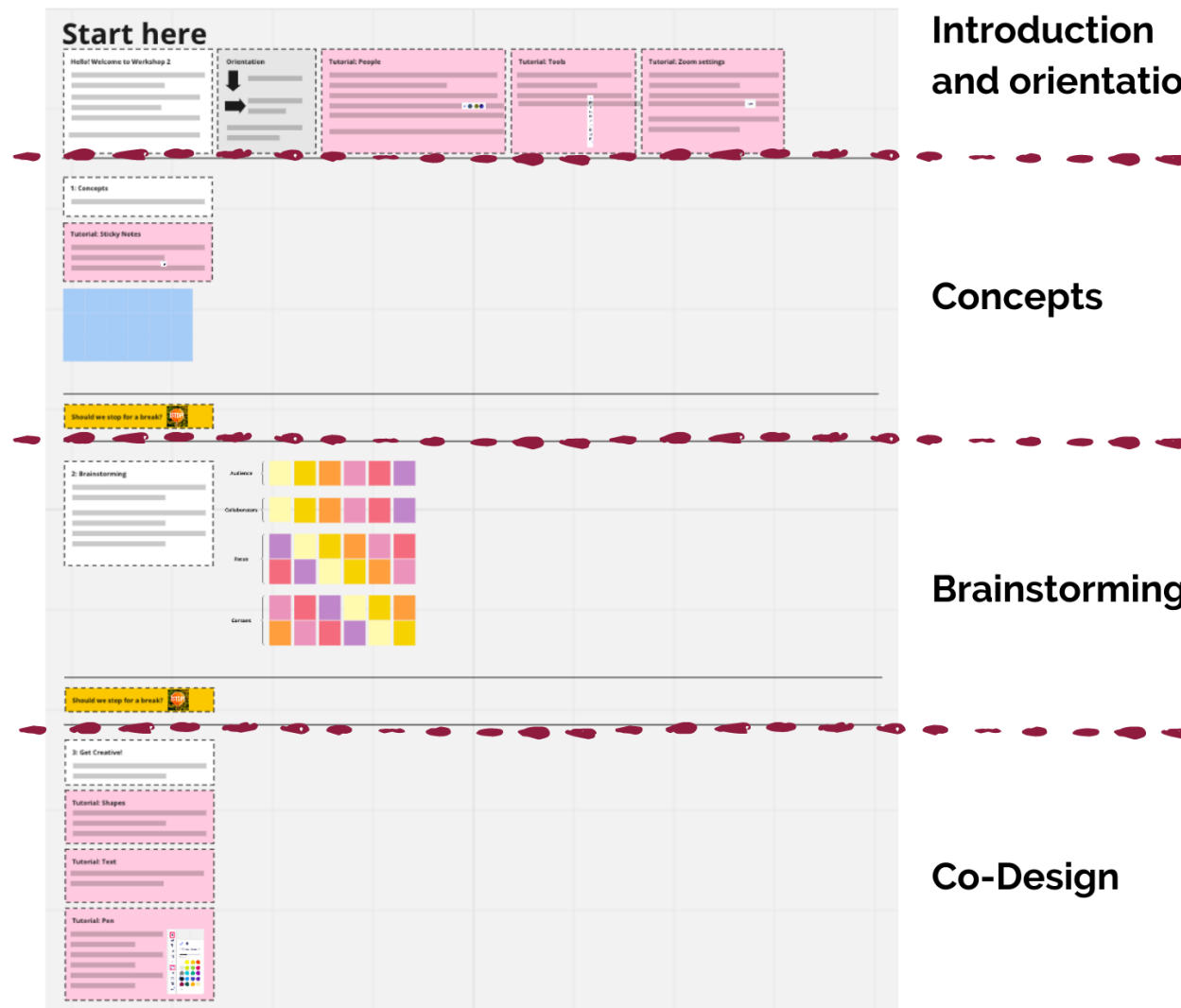


Figure 14: Screenshot of Miro layout for Workshop 2. Image. Source: author's own.

4.7.1.2 Validation of the Concepts

Following the introduction, I talked through the concepts which I had developed for their prototype, based on my analysis of their health story in Workshop 1. I also shared visuals which had inspired my thought process, as well as diagrams and other representations from the literature on related ideas which I felt were relevant to their story and might give additional ideas for the co-design session. The participants were then invited to discuss and critique the concepts as a form of graphic elicitation (Crilly et al., 2006). This was used as an initial validation of the concepts.

4.7.1.3 Brainstorming

In preparation for the co-design activity, I next asked the participant to brainstorm with me by answering a series of prompts. In effect, this operated as a short semi-structured interview.

- **Audience:** who am I telling this story to?

- **Collaborators:** are other people contributing to this story (family, friends, healthcare professionals), or am I the only author?
- **Focus:** What do I want someone to understand about me after reading it? What am I trying to convey?
- **Content:** What information about myself would I include?

4.7.1.4 Co-Design

Finally, participants co-designed representations of their health story with me (Sanders and Stappers, 2008) using tools based on the concepts: shapes, images, and text templates. The ideas from the brainstorming activity were used to guide the work. This process gave me further insight into the participant's thinking, and also allowed me to validate the concepts by observing how participants interacted with them (Kawulich, 2005). An example of a participant co-design session is shown in Figure 15. All of the participants' sessions can be seen in Chapter 5.

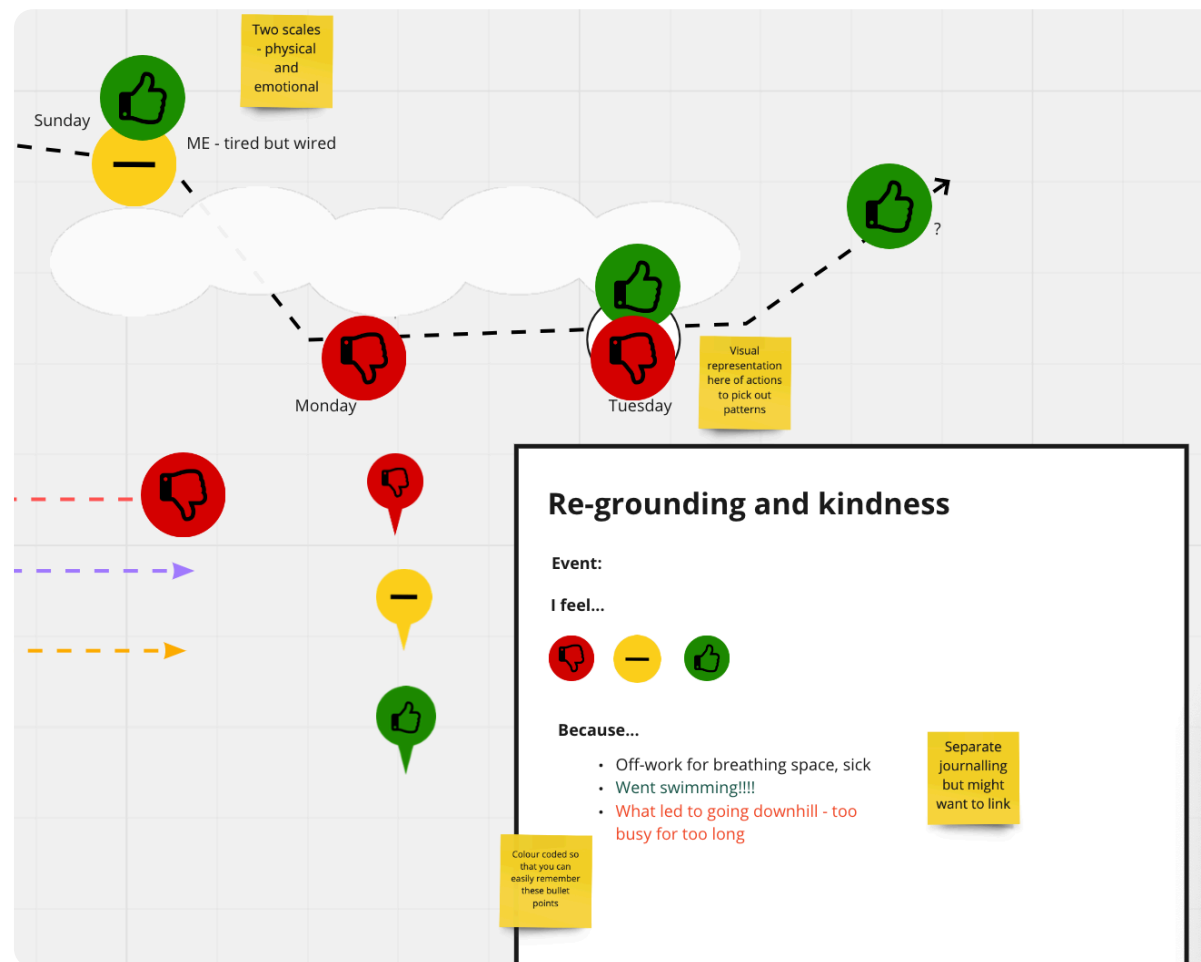


Figure 15: Example of a participant co-design session in Cycle 2. Image. Source: author's own

4.7.2 Research Journaling

Immediately following the workshop, I again carried out research journaling using the same method as described in Section 4.6.2. In this cycle, it was particularly useful to reflect on what had worked or not worked to improve my planning for further participants.

4.7.3 Holistic-Content & Categorical-Content Analysis

Following the workshop, I reviewed the recordings of the participant and wrote up a summary of our discussion, directly transcribing any important quotes. I organised this according to the workshop activities, noting the main points which had emerged from each and also any particular feedback/actions noted by the participant. The summary was again sent to the participants for review.

The written summary of the workshop added to my holistic understanding of the participant's story from the previous workshop. I also carried out categorical-content analysis

(Lieblich et al., 2011) to identify the categories for each individual participant. First, I noted any overarching categories that had emerged from the first interview. I then compared these with the second interview. The prompts that I had already used for the brainstorming served as a useful way of organising these findings. Using these, I wrote brief written descriptions of the categories for each participant.

4.7.4 Reflexive Analysis

Using the outcome of the analysis along with the feedback/actions from the participant, I developed each of the initial concepts into a simple high-fidelity prototype using the functionality in Sketch (Figure 16). Sketch allows the user to build up prototypes by using hotspots to link series of screens together, simulating navigation and simple interactive elements such as modals, etc.

The goal of the prototyping at this stage was to turn the rough concepts from Workshop 2 into something which resembled an actual user interface. I focused on representing the key aspects of each prototype which had emerged from

Workshops 1 and 2 as being important to the participant, without trying to illustrate every single interaction. I was able to use the discussion in Workshop 2 as an initial validation to ensure that I had covered all of the points raised by the participant.

Design conventions used for all prototypes are given in **Chapter 3** of the Appendix.

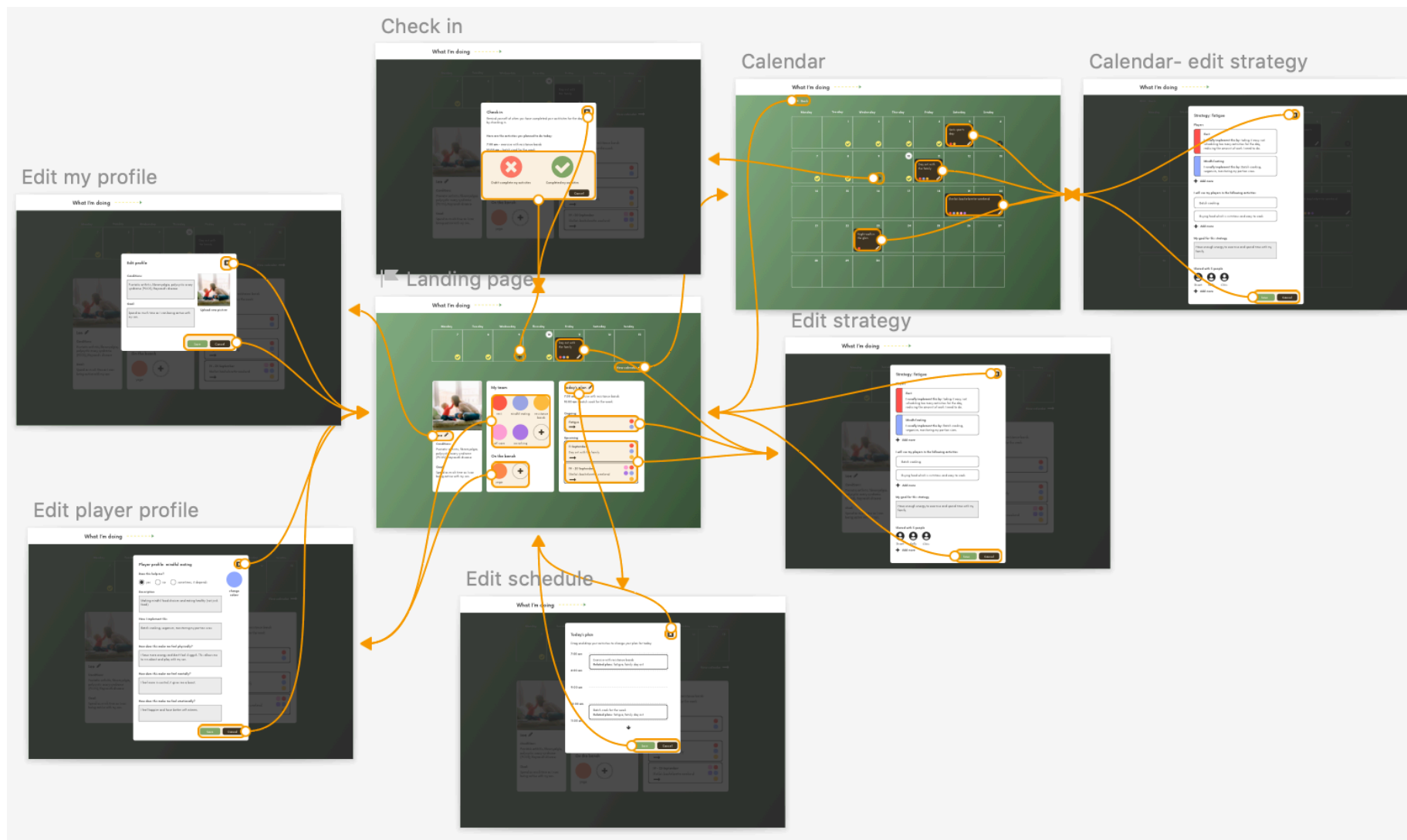


Figure 16: Linking screens to create a prototype in Sketch. Image. Source: author's own.

4.8 Cycle 3: Reflection

4.8.1 Workshop

For the final workshops, I hosted the prototypes on Sketch Cloud and sent a link to the participants which allowed them to interact with it directly. The first part of the workshop was devoted to walking the participants through the prototype. Then, participants were allowed to freely explore the prototype if they wished. The exploration acted as graphic elicitation, initiating a conversation between the participant and myself on their reactions to the prototype. This discussion and my observations of the participants' interactions with the prototype also served to evaluate the designs. The prototype remained available online to the participant after the workshop, and they were invited to send me further feedback and reflections if they wished.

Following the prototype exploration, I carried out a final semi-structured interview. The purpose of the interview was to more formally get feedback from the participants on their

experience of the project and to understand their perspectives on the work. The results of this were then used to validate the research questions and methodology.

Finally, I closed the workshop by thanking the participant for their time. Following the workshop each participant was sent a unique printed booklet of their story to keep for future use, along with a thank you card which I designed for the project (Figure 17).

Interview questions for Workshop 3 can be found in **Section 1.7** of the Appendix.



Figure 17: Booklets of participant stories and postcard, with names obscured. Image. Source: author's own.

4.8.2 Categorical-Content Analysis

Following the workshop, I wrote up a summary of our discussion along with a transcription of any key quotes. This was again sent to the participant for a final review. I then used several phases of categorical-content analysis (Lieblich

et al., 2011) to identify the overarching categories across all of the participants' stories:

1. I reviewed the transcription and notes from all of the workshops and pulled out key points from each. In Miro, I recorded each point onto a card (either as a summary or a direct quote).
2. Using Miro's Frame object, I roughly grouped the cards into high-level categories.
3. I then set up columns for each group using Miro's Kanban template and organised the cards into sub-categories (shown in Figure 18).
4. I did a final pass to review the columns and confirm that the cards were in the correct sub-category.

This process allowed me to pull out overall findings which can inform the design of future health storytelling tools.

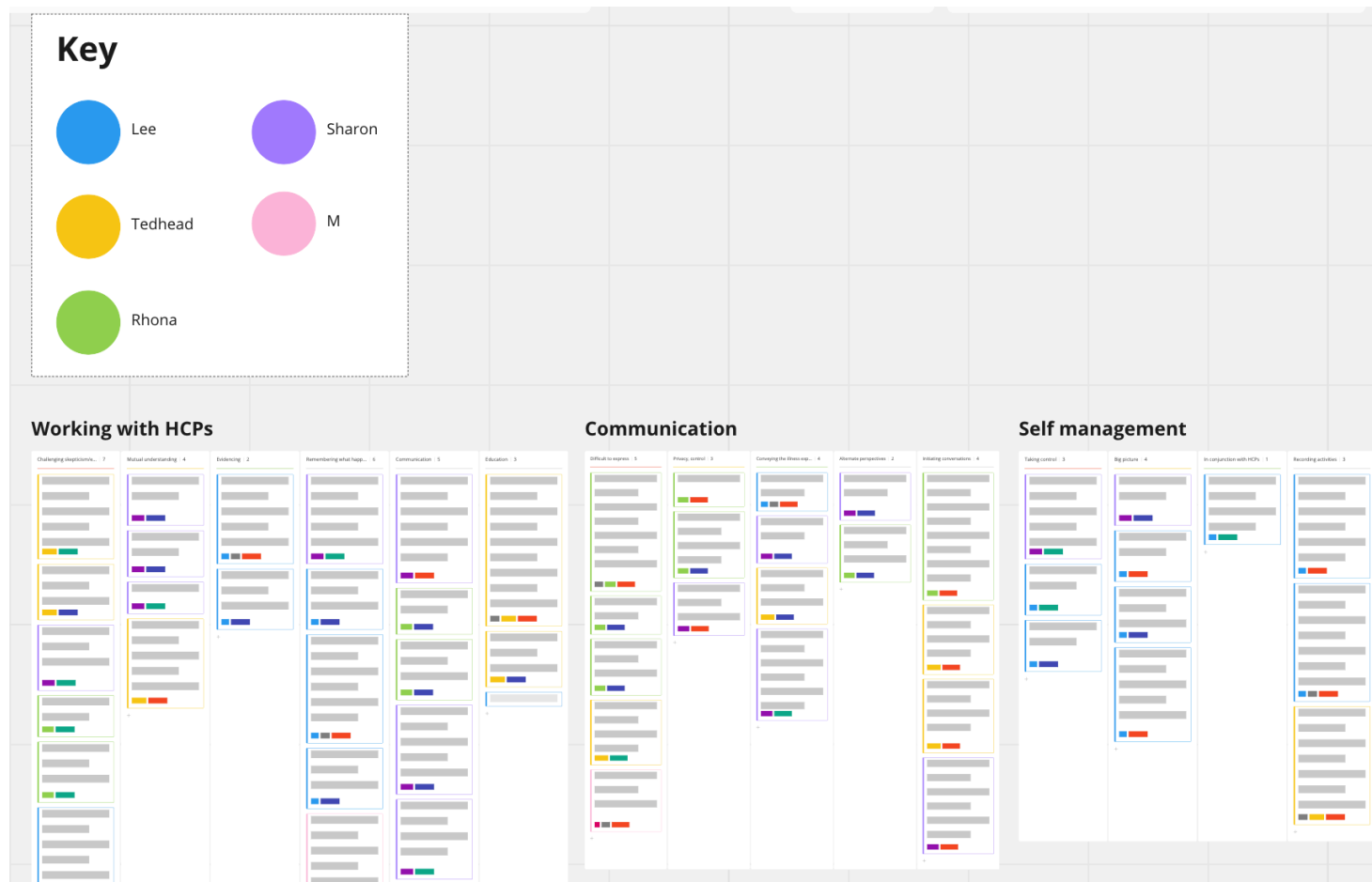


Figure 18: Detail screenshot of categorical-content analysis in Miro. Image. Source: author's own.

4.9 Summary

In this chapter, I have described how the fieldwork was carried out. I first recruited a cohort of 5 participants, primarily from local support groups. I then worked closely with participants and verified the research dialogically over three cycles.

Cycle 1 focused on getting to know the participants and understanding their health stories. I used several layers of narrative analysis to understand each participant's story, from which I created visual concepts using my own Concept Tile approach.

In Cycle 2, I used a combination of graphic elicitation and semi-structured interviewing to drive a participative co-

design session using the concepts that I had created. This served to verify the concepts and also allowed me to see how the participant might use them in practice.

From this feedback, I expanded the concepts further into interactive prototypes. We examined these in the Cycle 3 workshop as a final validation. We then closed with a short interview to understand the participant's views on the prototype and experiences of the project.

In the next chapter, I present the participants' health stories and show how they are expressed in the concepts and prototypes.

5 Health Stories



5.1 Introduction

Throughout the research, the participants' health stories remained at the core of the work. In this chapter, I present each participant's story and show how it evolved over the course of the project through the fieldwork and analysis.

Firstly, I present a summary of the story from Cycle 1 and the highlights from their narrative analysis. Next, I discuss the prototyping process and how their story was transformed over Cycles 2 and 3 into the final prototype. Finally, I present images of the visual concepts and prototypes, divided by cycle. For Cycle 2, I show the visual concepts which were presented in the workshop, followed by an image of the co-design activity with the participant (as discussed in Section 4.7.1.4). For Cycle 3, I present images of key screens from the final prototype. I also give

a link to the full prototype which can be interacted with online.

These prototypes begin to answer my initial research question of how digital tools can support people with multiple long-term conditions in making sense of and conveying their health stories. I then expand on this in the following chapter through the presentation of the overall findings.

More detailed information about each participant, including their full health story, can be found in the Appendix – the relevant location is referenced at the start of each section.

5.2 Lee

5.2.1 Story

Lee's complete story can be found in **Chapter 5** of the Appendix.

Lee was diagnosed with psoriatic arthritis almost 10 years ago when she was in her early twenties. The treatment of her arthritis and investigations into her health then led to an additional diagnosis of fibromyalgia. Lee was determined to have a child, and while attempting to conceive she was subsequently also diagnosed with polycystic ovary syndrome (PCOS). Eventually, she had a child after several years of managing without medication. Lee's current focus is on self managing her conditions through diet and regular exercise with a personal trainer.

Referring back to the genres of health storytelling discussed in Section 2.4.4.1 (Hunsaker Hawkins, 1999; Frank, 2013), the genre of Lee's story could be best described as either *life-as-normal* or *healthy-minded*. Lee's goal was to use self management to control her conditions so that she could live her life as normally as possible. The idea of control is often presented somewhat negatively in health story literature (e.g. Frank, 2013). Lee's story presents an alternative in which control is linked to empowerment.

5.2.2 Prototype

I know you're offering advice, or you think you're offering advice, but this is what *I'm* doing.

(Lee)

Lee is a football fan, so for her prototype I used a sport metaphor to show a health story which is told *through* self management activities. Individual self management activities take on the role of *players* which can be selected by Lee to form a *strategy* which will help her overcome particular obstacles. Strategies can be ongoing (e.g. dealing with daily fatigue) or short-term (e.g. planning for a social event).

Lee can also record *player profiles* in which she can record detailed information about each activity. This reflects the ideas which emerged through Lee's interview. Firstly, self management techniques might not work for a particular individual, despite being well-evidenced in the literature as beneficial. The *player profile* gives her a space to record and remember what has worked in the past.

Similarly, a technique might work for someone in one situation but not another. I have expressed this in her prototype by showing that some activities can be *on the bench* (i.e. not currently in use).

Techniques also have both costs and benefits. For example, Lee described exercise as being beneficial for her in the long-term, but in the short-term it made her more tired. The *player profile* allows her to record the pros and cons of activities, reflecting this perspective.

This provides a nuanced understanding which can still build upon simpler, commonly used frameworks for describing the illness experience such as Spoon Theory (Miserandino, 2003), which uses spoons as a finite unit for measuring energy levels.

Lee: Concepts & Prototype

View Lee's complete prototype online: <https://bit.ly/36ZEap1>

Lee's Concepts (Cycle 2)

1 What I'm doing

2

3

4

5

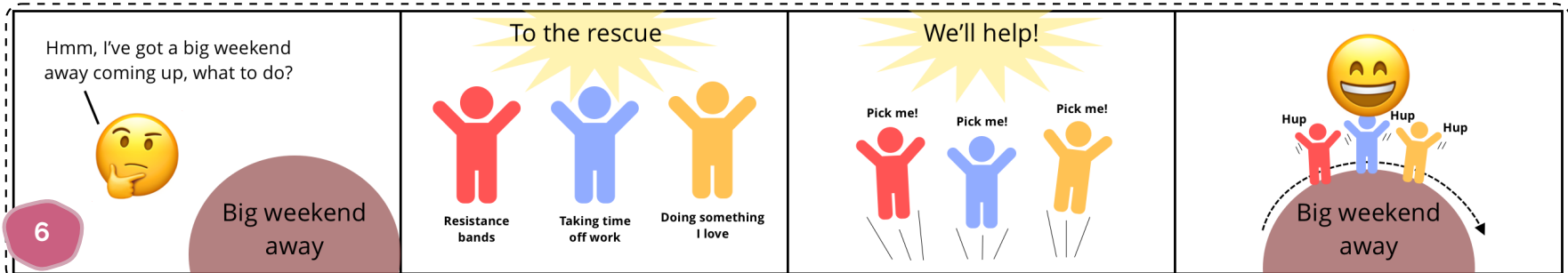
What I'm doing - developing your own practice of self management
Players - activities which have overall strengths and weaknesses, as well as for your specific conditions
Obstacle - something which you know may negatively impact your health
Assembling a team - understanding what works for you, and for which situations
Strategies/plays - groups of self management activities which can help deal with a specific obstacle
Big picture - zooming out to see the overall progress towards a goal, and how plays interact

Player Profile
☒ Yes! This helps me
Physically, this makes me feel...
 I feel a lot better after stretching using the resistance bands. It really helps loosen things up in the morning and reduces the pain.
Mentally, this makes me feel...
 Doing exercise clears my head and gives me a space to relax with myself.
Emotionally, this makes me feel...
 I feel proud of myself for sticking with it, and more in control when I am exercising.

Choreography

Screenshot of Miro board from Workshop 2

1. Concept for "big picture" view showing a timeline of activities moving around obstacles
2. Written description of concepts
3. Comic illustrating the idea of self management activity "players" assisting Lee over an obstacle
4. Self management activity "player profile"
5. Choreography notation showing the inspiration for the big picture view (<https://bit.ly/3qvkja1>)



6

Player Profile

☒ Yes! This helps me

Physically, this makes me feel...

I feel a lot better after stretching using the resistance bands. It really helps loosen things up in the morning and reduces the pain.

Mentally, this makes me feel...

Doing exercise clears my head and gives me a space to relax with myself.

Emotionally, this makes me feel...

I feel proud of myself for sticking with it, and more in control when I am exercising.

7

6. Self management comic (detail)

7. Self management player profile (detail)

8. Co-design session with Lee

8

Player profile: Mindful Eating

- Describe it
 - Making mindful food choices, not eating junk food - veganism, portion sizes, alternatives
 - Batch cooking
- Does this help me? (yes/no)
 - yes
- How does this make me feel physically?
 - Have more energy, can exercise, do things with my son, run about, don't feel sluggish
- How does this make me feel mentally?
 - In control, boosts how I feel, happier
- How does this make me feel emotionally?
 - Happier, better self esteem

Strategy for dealing with fatigue

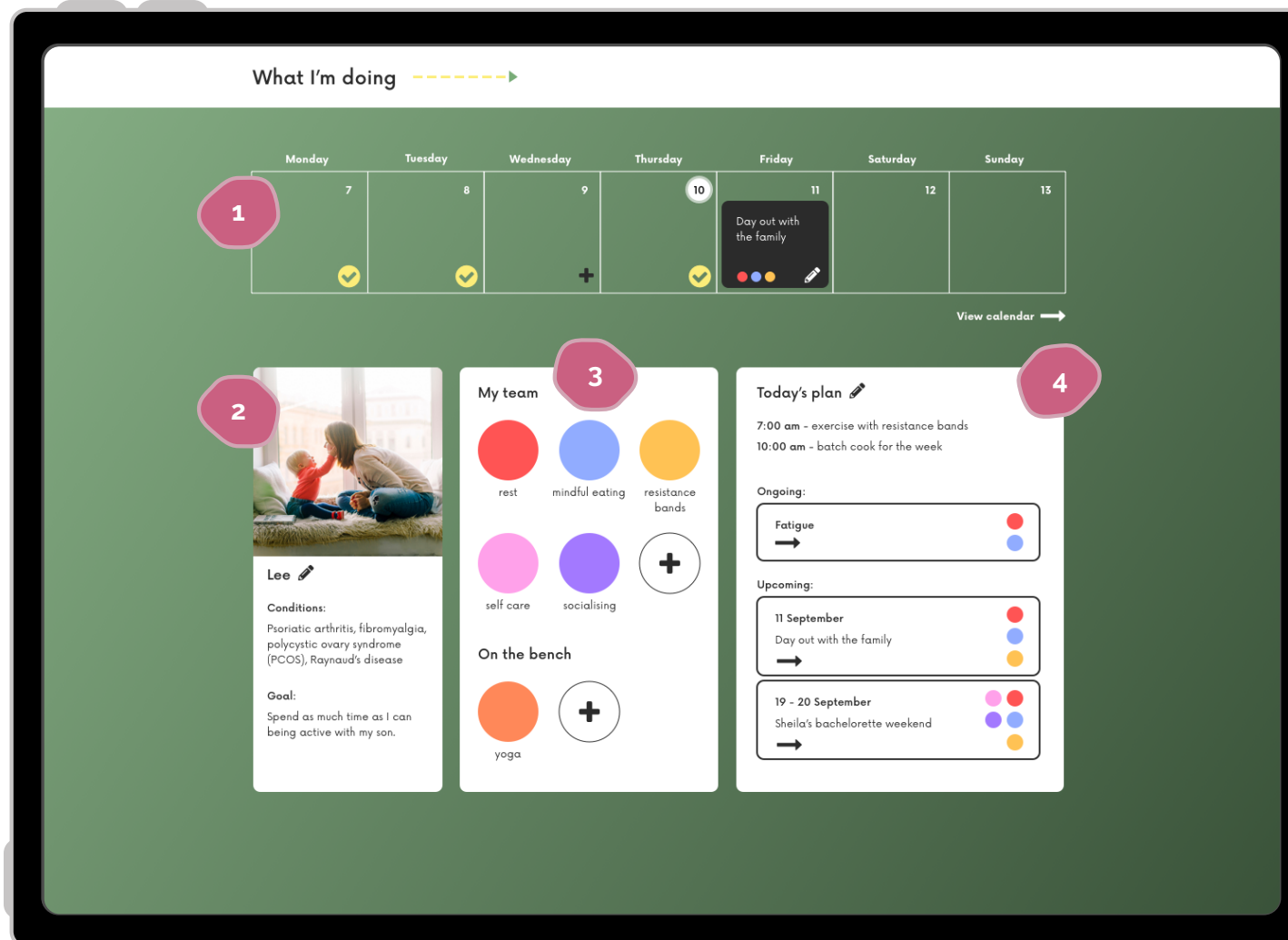
- This obstacle is fatigue it's a problem because (obvious)
- My players are
 - Rest
 - Mindful eating
- I'll use them by...
 - Batch cooking
 - Buying food which is easy to cook and nutritious
- My goal is
 - Having enough energy to exercise

Contributors: Personal trainer, Husband

Audience: Friends, Co-workers, Rheumatologist

Lee's Prototype (Cycle 3)

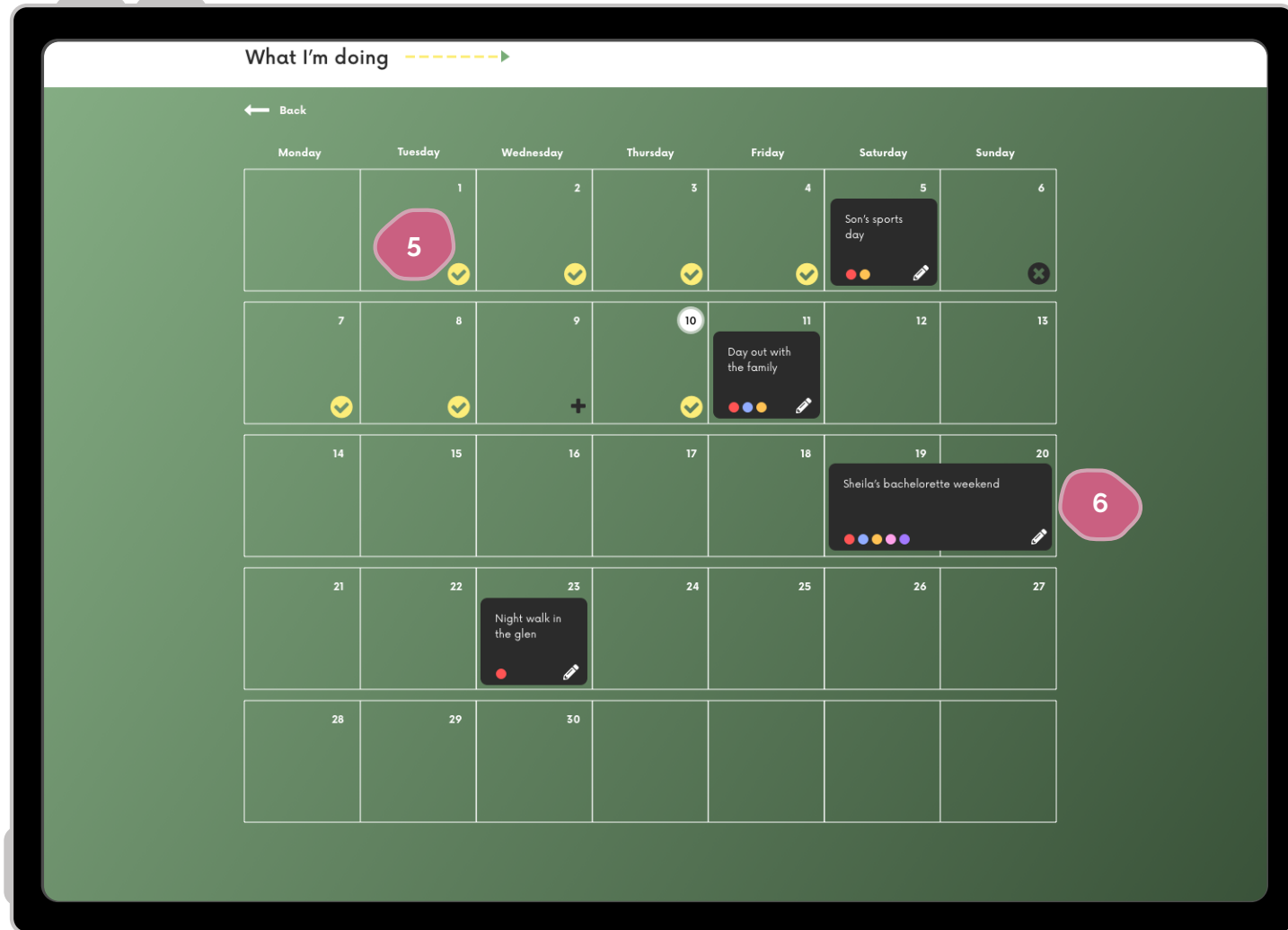
1. Weekly view
2. User profile
3. Self management team with player profiles
4. Today's plan: schedule and current strategies



Landing page

5. Daily check-in

6. Deploying a strategy to deal with a particular obstacle/event



Monthly calendar view

7. Editing a player profile

8. Editing a self management strategy

7

Player profile: mindful eating

Does this help me?

☒ yes ☐ no ☐ sometimes, it depends

Description

Making mindful food choices and eating healthy (not junk food).

How I implement this

Batch cooking, veganism, monitoring my portion sizes

How does this make me feel physically?

I have more energy and don't feel sluggish. This allows me to run about and play with my son.

How does this make me feel mentally?

I feel more in control, it gives me a boost.

How does this make me feel emotionally?

I feel happier and have better self esteem.

change colour

Save Cancel

8

Strategy: fatigue

Players

Rest

I usually implement this by: taking it easy, not scheduling too many activities for the day, reducing the amount of work I need to do.

Mindful eating

I usually implement this by: Batch cooking, veganism, monitoring my portion sizes.

+ Add more

I will use my players in the following activities

Batch cooking

Buying food which is nutritious and easy to cook

+ Add more

My goal for this strategy

Have enough energy to exercise and spend time with my family.

Shared with 3 people

Stuart Kelly Chris

+ Add more

Save Cancel

5.3 Rhona

5.3.1 Story

Rhona's complete story can be found in **Chapter 6** of the Appendix.

Rhona herself described her story as a *journey*, but it can also be viewed as Hunsaker Hawkins' idea of *rebirth*. Rhona has suffered from a number of more minor conditions starting in her early teens and was diagnosed with ME after becoming ill in 2014. Rhona felt that her illness forced to put her life in perspective, after which she decided to make a change for the better. After seeking help with her mental health, she was diagnosed with borderline personality disorder (BPD) in 2018.

Because of her conditions, Rhona likes to be alone at times. She also keeps a blanket with her, which she uses to physically separate from others when she is feeling

overwhelmed. At the same time, Rhona enjoys spending time with her friends – a contrast that I have described as *hiding/showing*. Rhona started an online support group for people with ME and often socialises with group members. Emotional connections with others are very important to Rhona, and she views her support network as critical for self managing her conditions.

Just to have somebody else say, "This is normal for BPD, you're going to be *fine*. It will pass.", sometimes that's just what you need... Even though I'll never be cured, the one thing to recovery is support systems... Even though I isolate myself from everyone, they all understand that I'll come back in a few days' time and I'll be fine again.
(Rhona)

5.3.2 Prototype

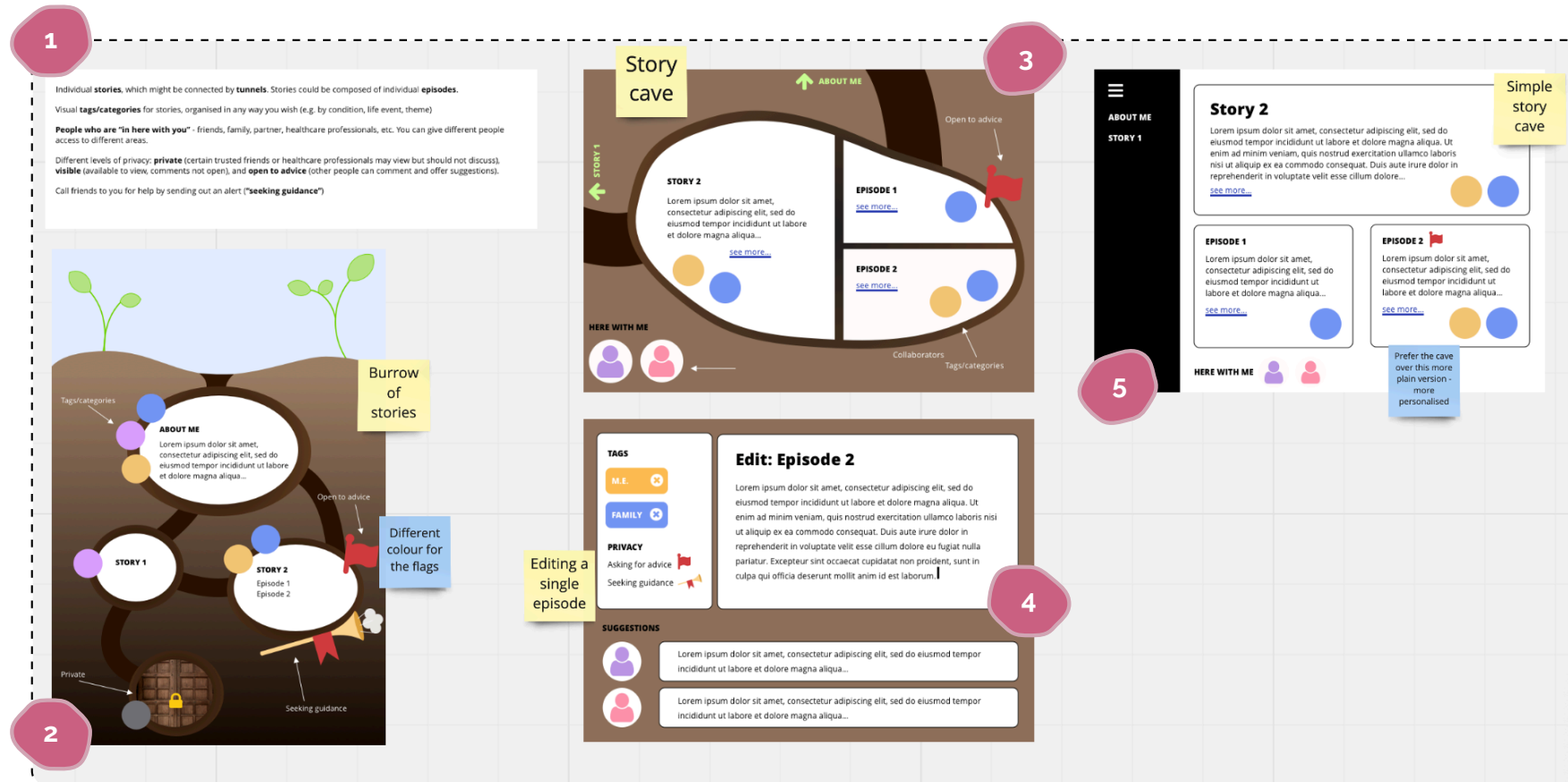
Rhona's love of enclosed spaces resulted in the idea of a *burrow of stories*, in which individual stories are connected together. Each story could be composed of separate episodes, grouped together into a *cave*. Caves can also contain different groups of collaborators who are *in here with you*, playing on ideas of both togetherness and moving through a physical space.

Following Rhona's theme of *hiding/showing*, I also explored ideas of how content could move through different levels of privacy. At the default level, content is simply visible to others. Rhona could also have *private stories* which are only visible to herself, or which she could choose to selectively share with certain trusted friends or family members. On the other side, Rhona may have parts of her story where she is actively seeking input or advice from others. In cases of urgent need, Rhona can *seek guidance* by sending out a call for help from collaborators – an idea inspired by her interest in using angel cards for spiritual guidance.

Rhona: Concepts & Prototype

View Rhona's complete prototype online: <https://bit.ly/33agEV5>

Rhona's Concepts (Cycle 2)



Screenshot of Miro board from Workshop 2

1. Written description of concepts

2. Burrow of stories (blue comment from Rhona)

3. Story cave containing multiple episodes

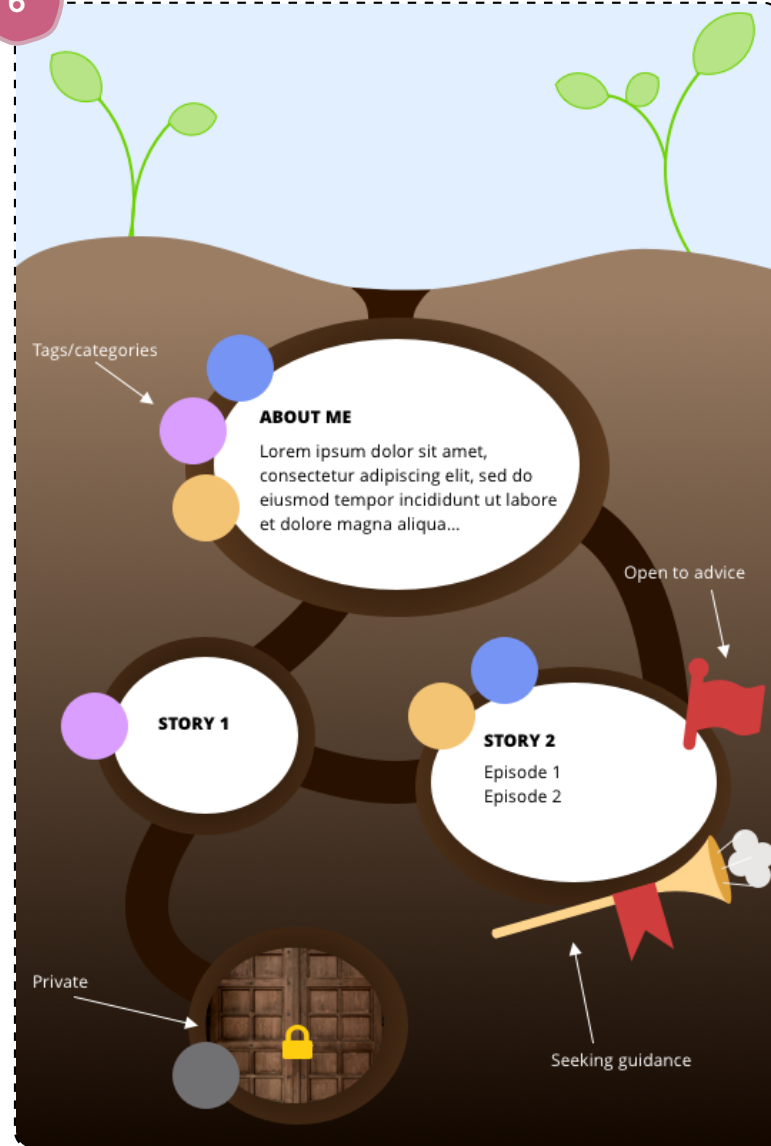
4. Editing a single episode

5. Editing an episode - alternate layout (blue comment from Rhona)

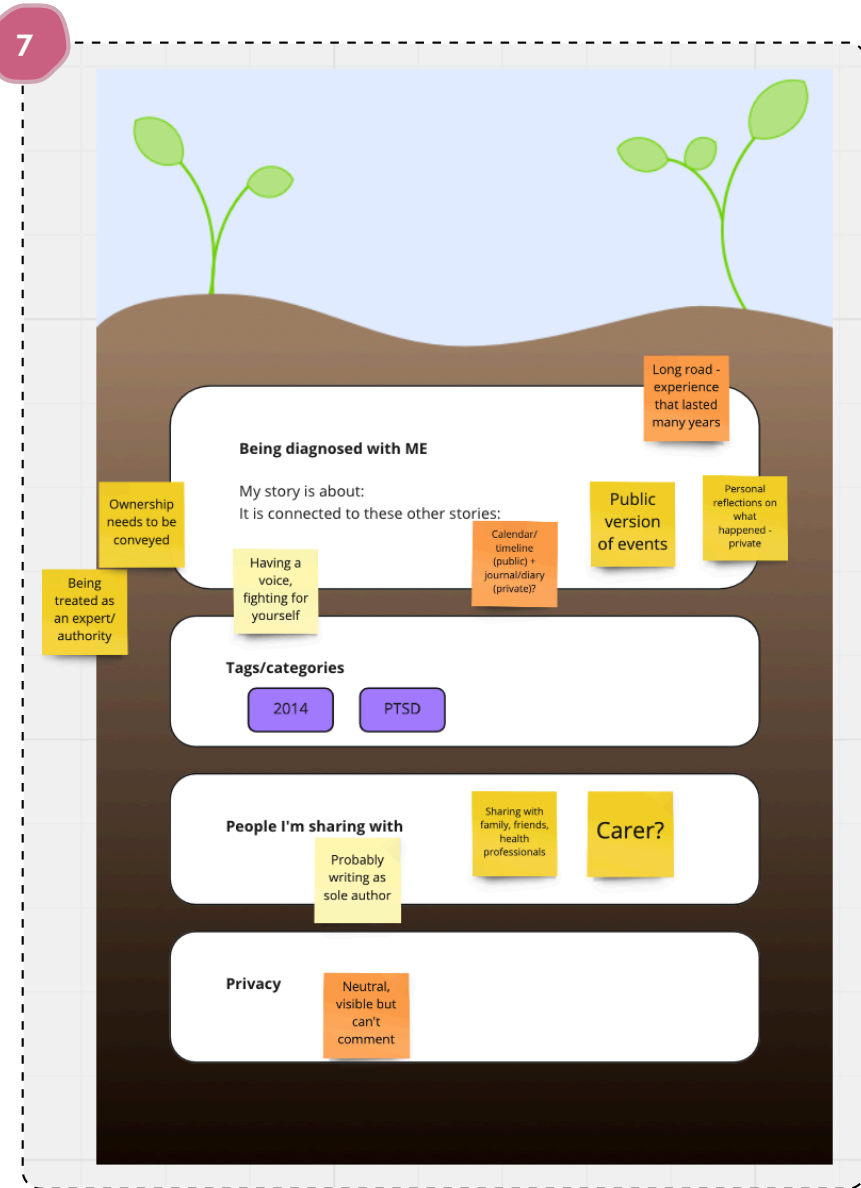
6. Burrow of stories (detail) - following page

7. Co-design session with Rhona - following page

6

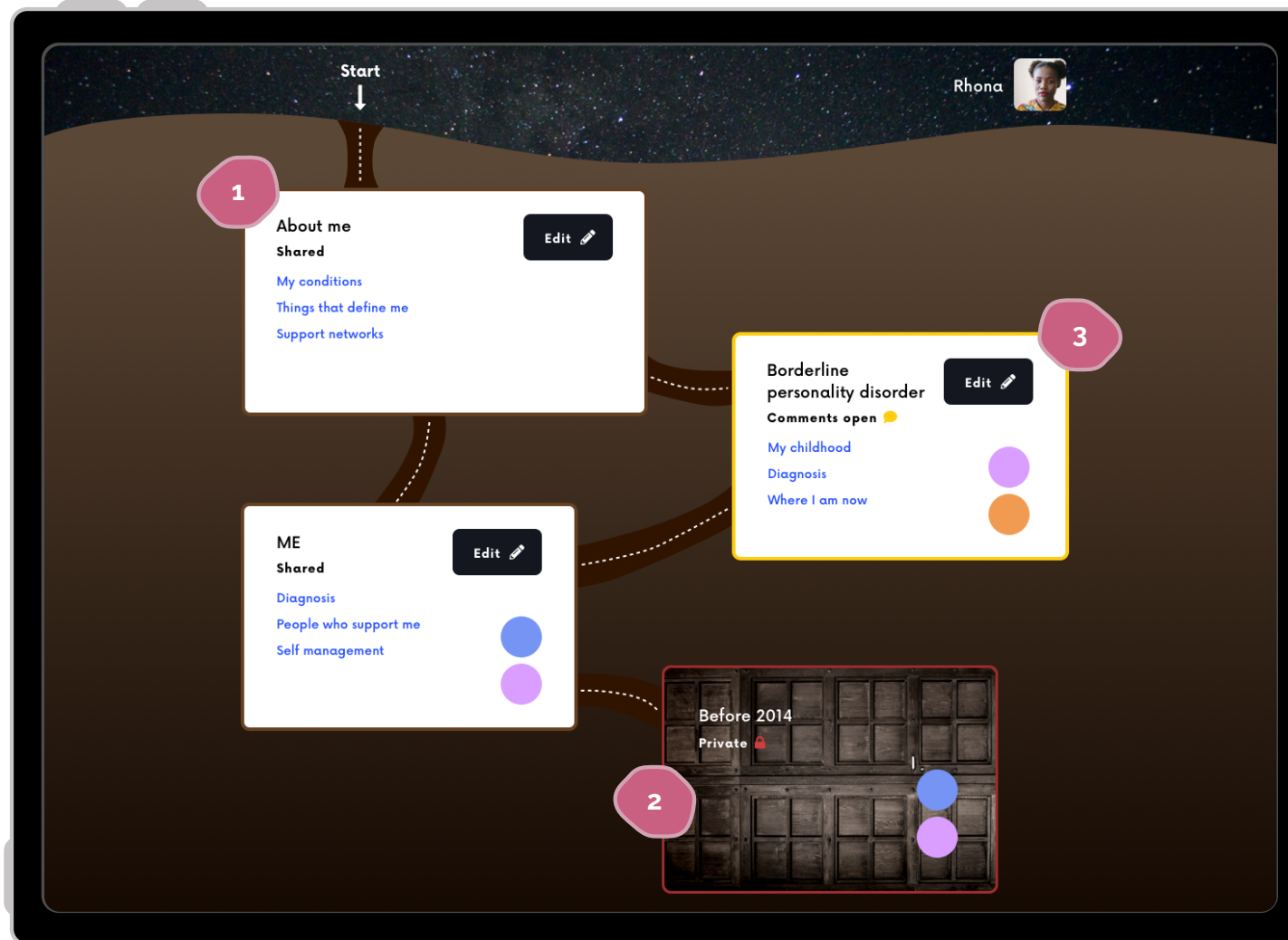


7



Rhona's Prototype (Cycle 3)

1. Story with episodes, shared with collaborators
2. Private story only visible to author
3. Story with episodes, open for comments by collaborators

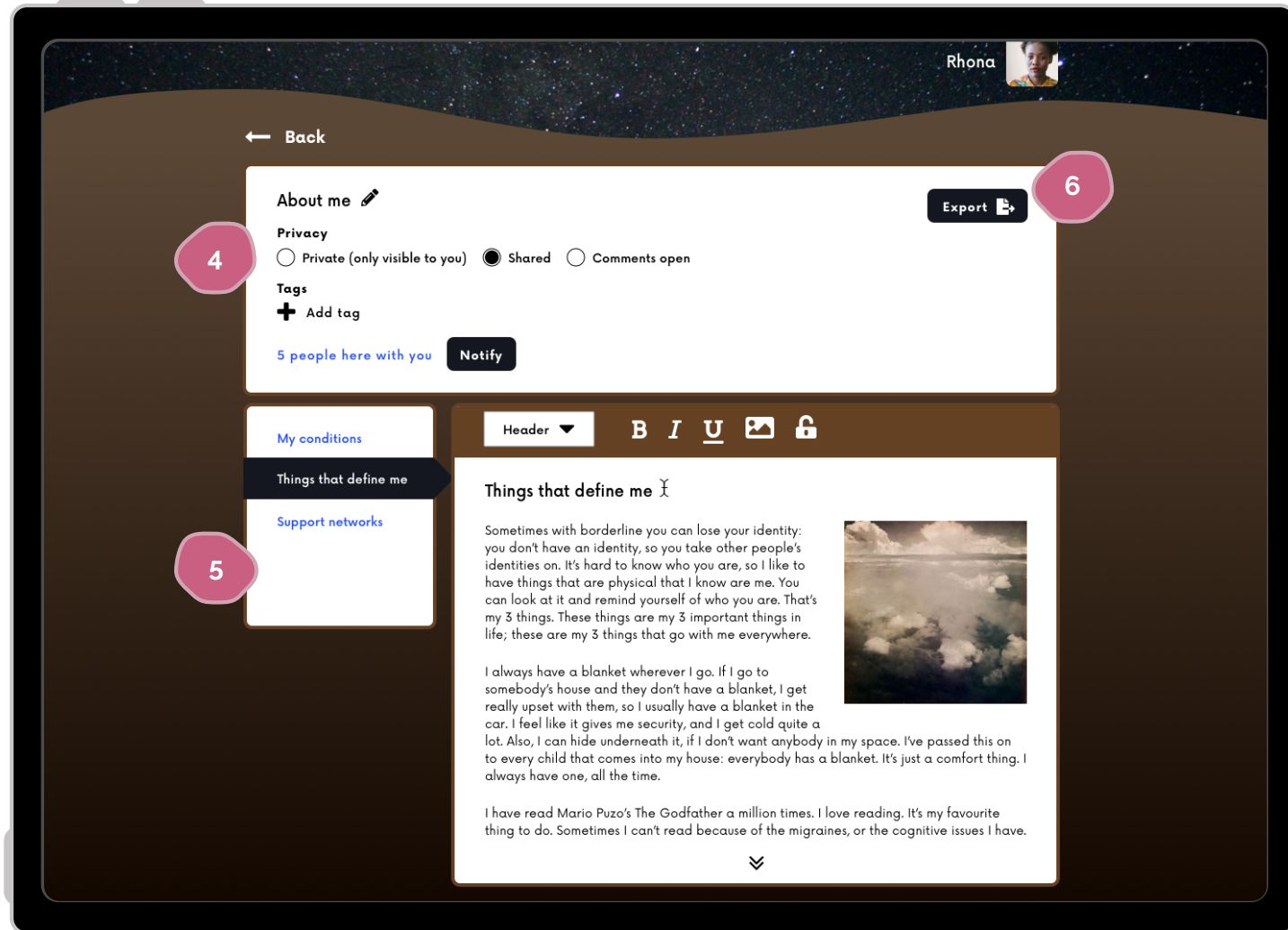


Landing page

4. Story settings

5. Episodes within the story

6. Export out a copy of the story



Editing a story

7. Collaborator access settings

8. Notifying friends and asking for help

7

Sharing

Currently shared with 5 people

	Read	Edit	Comment	Export
Susan	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
David	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Laura	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Frances	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Michael	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>

+ Add more people

8

Notify

Send notifications to 5 people

Message 53/160

Hi guys, I could really use your help with something. ǻ

Cancel Send ↗

5.4 M

5.4.1 Story

M's complete story can be found in **Chapter 7** of the Appendix.

M was first diagnosed with depression 13 years ago when the infant son of her cousin died unexpectedly. In 2015, M was also diagnosed with relapsing-remitting MS after she began having unexplained problems with her vision. Her diagnosis made her resolved to enjoy her life as much as possible while she still could. Her story could therefore be described using Hunsaker Hawkins' idea of *rebirth*, although she doesn't follow any of the more spiritual models that Hunsaker Hawkins describes. More recently M was also diagnosed with early menopause. So far, she has found that more of a positive than a negative now that she is managing her menopause symptoms using hormone treatments.

M's approach to storytelling is matter-of-fact, using very little metaphor. The primary theme from M's story could be described as *memory*. It is important to M that she remember and honour the events that have happened to her (both good and bad), and also that she is able to accumulate as many good memories as she can during her lifetime. She feels that she has a "finite amount of time", as her MS could progress to the point in the future where she is no longer able to do things.

Being diagnosed with a lifelong condition makes you view things differently. I'm not in a wheelchair yet, but I could end up there. So, if there's anything I want to do, I'm going to do it now.

(M)

5.4.2 Prototype

I struggled to come up with a single concept from M's story, as there were multiple themes to work from. Initially, M's focus on "living in the moment" and socialising suggested a social media analogy to me. M was the only participant who didn't mention any difficulties working with healthcare professionals, so I didn't use them as an intended audience. Instead, I designed a concept for a platform which M could use to keep in touch with her friends from MS support groups. The focus of the concept was on trying out new experiences, recording memories in a *memory wall*, and sharing events and encouraging friends.

However, when we looked at the concept together in Workshop 2, it became clear that M wasn't satisfied with this idea. She isn't a big fan of social media and felt that the design was too much like Facebook, although she did like the idea of visually representing her memories.

As M didn't like the concepts, for the co-design activity we used an earlier idea that I had sketched out around a theme of

light and dark. M's story contained elements of deep sadness, but also humour and joy. I suggested the idea of portraying these as spotlights and shadows, providing a visual representation of M's emotional state over the course of the story. Because M generally told her story in vignettes, the story would be broken down into smaller events, mapped out chronologically.

In the final design, I re-incorporated the idea of the *memory wall* which M liked from the social media concept, but this time as a *garden*. Memories were represented as flowers which can be linked to stories in M's life (and vice versa). M could set a *mood* on each story which would generate a light/dark mode on the overall view.

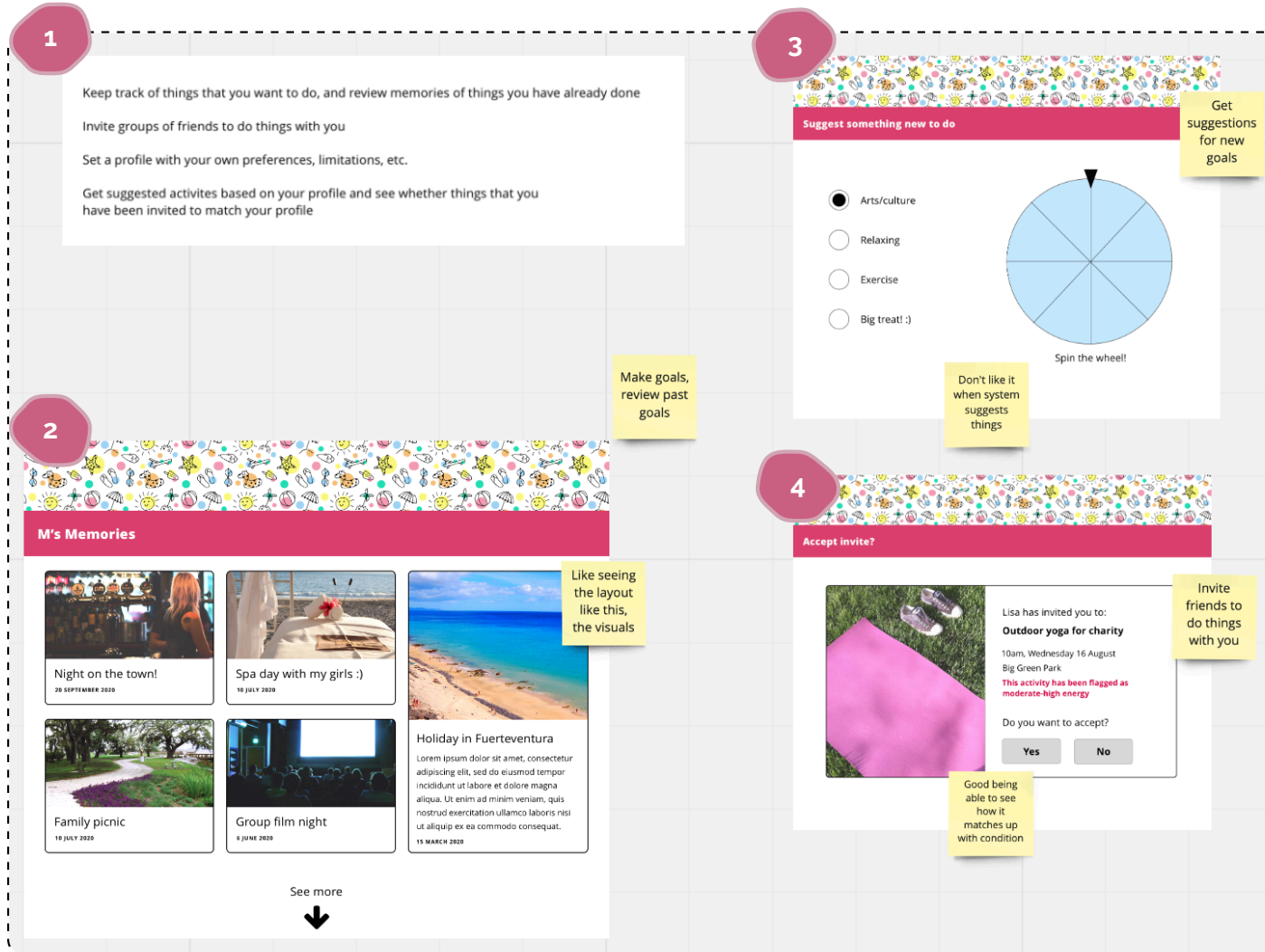
M also wanted friends to be able to communicate with her about her story, but only in a general way. I represented this by allowing friends to post reactions on her story as emojis, and also message her directly using a contact form.

M: Concepts & Prototype

View M's complete prototype online: <https://bit.ly/2Hqhk0P>

M's Concepts (Cycle 2)

1. Written description of concepts
2. Memory photo wall (additional comment from M)
3. Get suggestions for new goals and activities (additional comment from M)
4. Accept an event invite (additional comment from M)
5. Memory wall (detail) - *following page*
6. Accept invite (detail) - *following page*



Screenshot of Miro board from Workshop 2

5

M's Memories



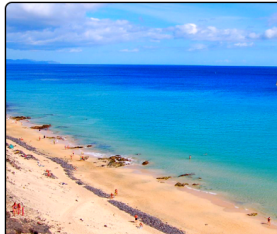
Night on the town!

20 SEPTEMBER 2020



Spa day with my girls :)

10 JULY 2020



Holiday in Fuerteventura

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat.

15 MARCH 2020



Family picnic

10 JULY 2020



Group film night

6 JUNE 2020

See more



6

Accept invite?



Lisa has invited you to:

Outdoor yoga for charity

10am, Wednesday 16 August

Big Green Park

This activity has been flagged as moderate-high energy

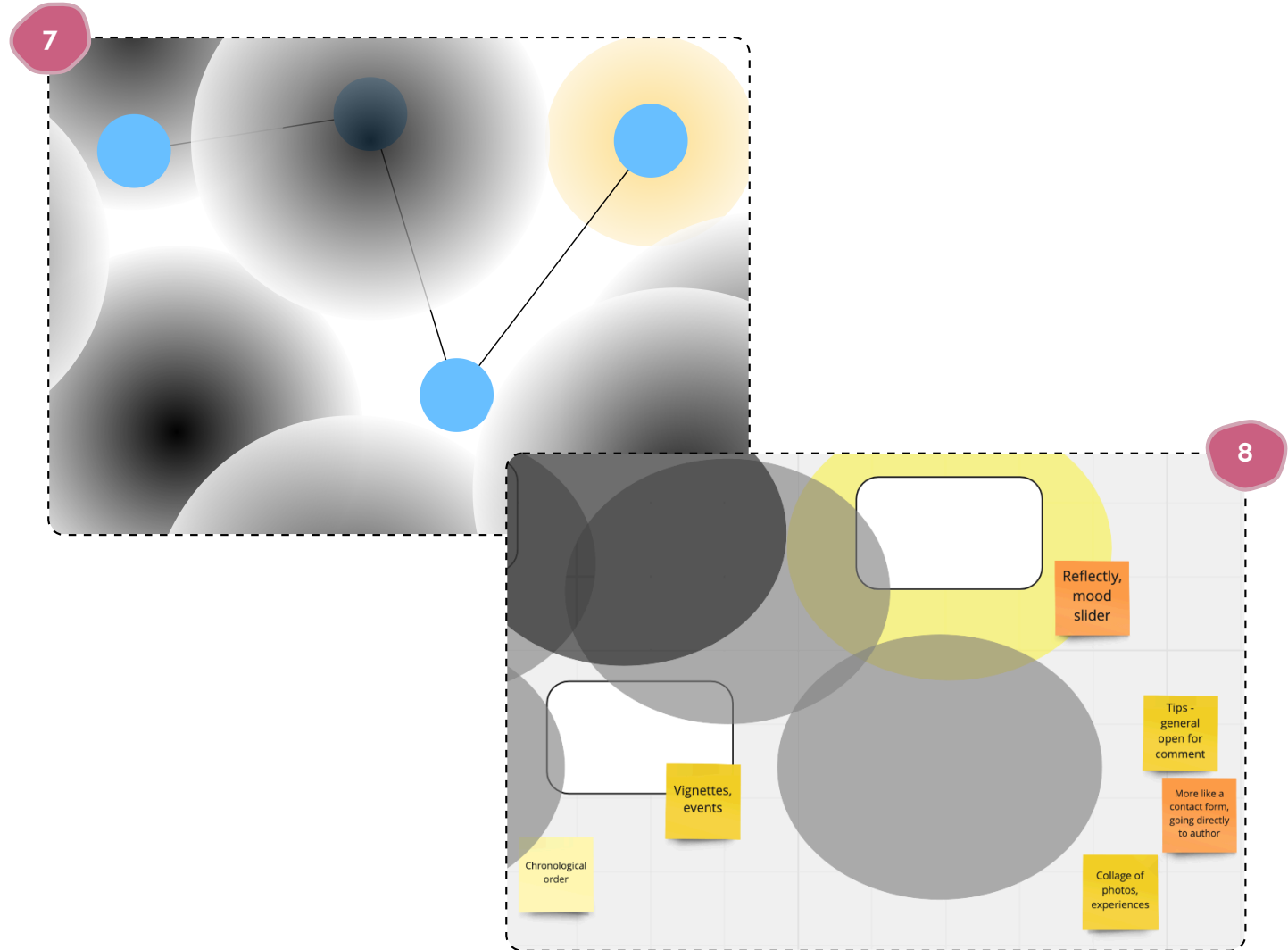
Do you want to accept?

Yes

No

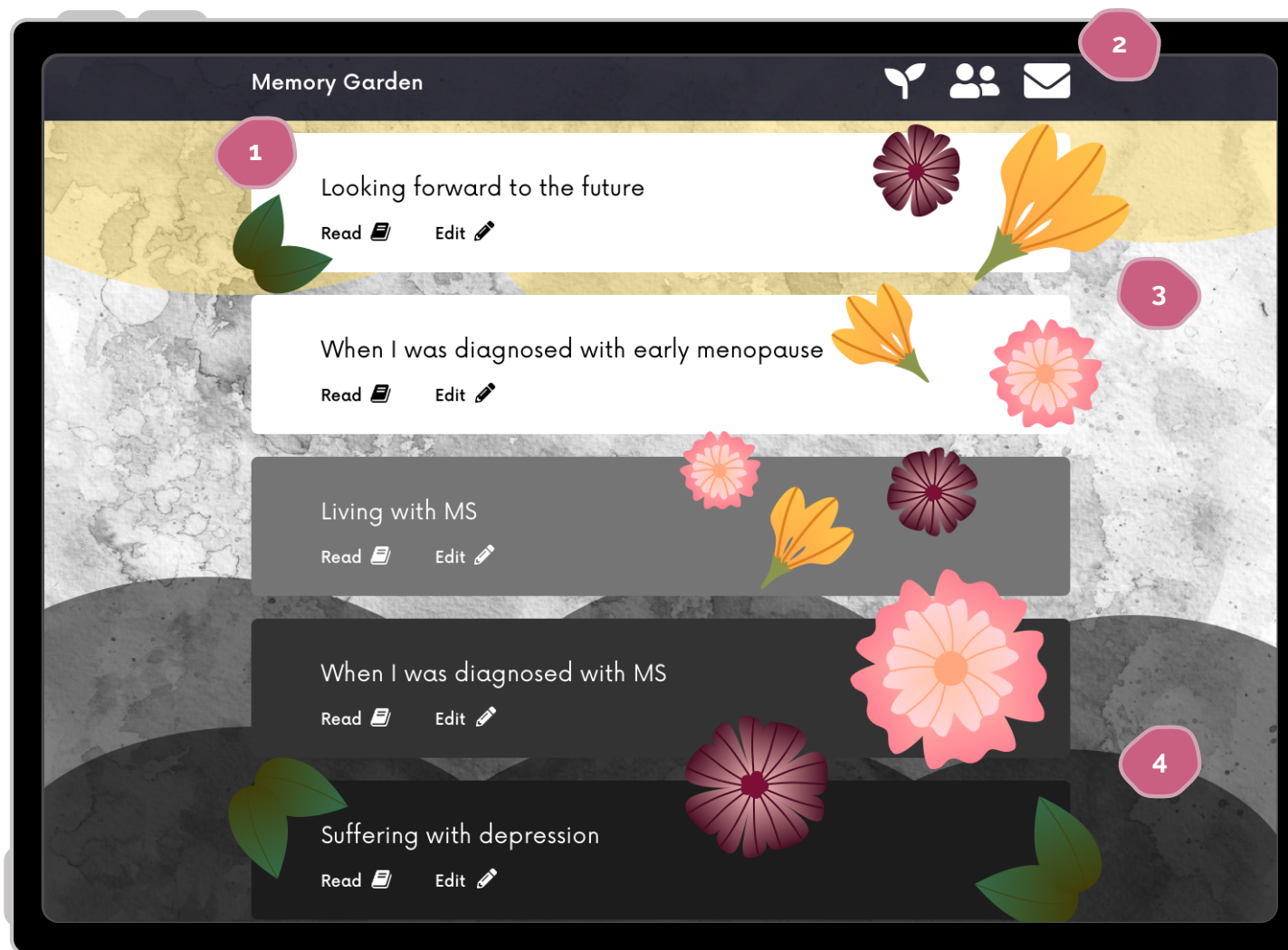
7. Light and dark concept

8. Co-design session with M



M's Prototype (Cycle 3)

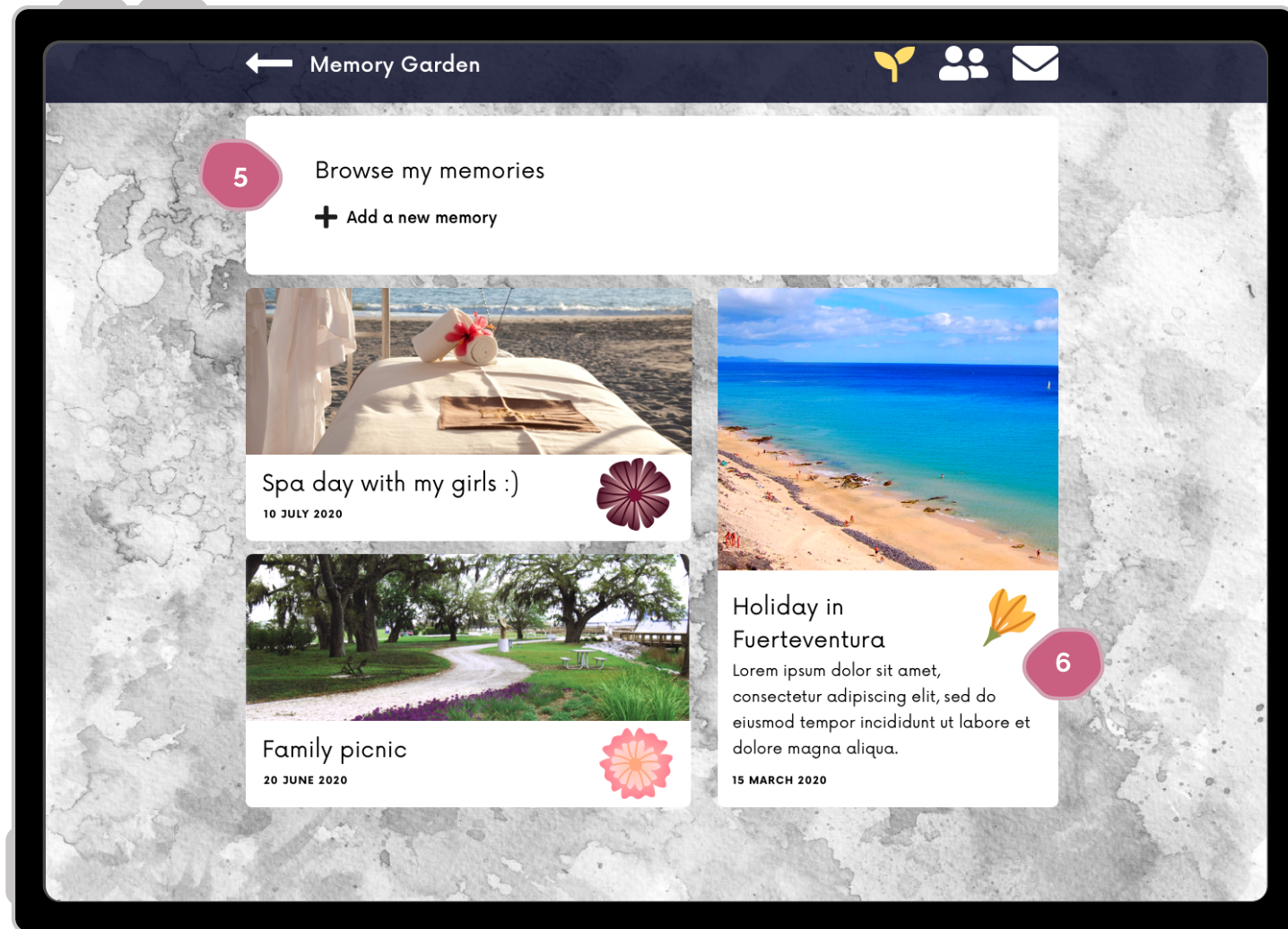
1. Individual story/
vignette
2. Navigation menu
3. Flowers
representing
memories
4. Clouds of
darkness and
light reflecting
the mood of
each story



Landing page

5. Add a new memory to the garden

6. An individual memory containing photos and description



Memory garden

7. Add a reaction

8. See related memories

9. Set a mood for the story - affects whether this story generates a light or dark cloud on the main page



Editing a story

5.5 Sharon

5.5.1 Story

Sharon's complete story can be found in **Chapter 8** of the Appendix.

Sharon began suffering from overwhelming fatigue 20 years ago, after which she was diagnosed with ME. Since that time her condition has progressed to the point where eventually she could no longer maintain her job and her own home. In 2012, she was also diagnosed with breast cancer, which was treated with surgery. Her ME had started to improve in recent years, but she then received a secondary breast cancer diagnosis in 2019. She is now able to live independently and focuses on managing treatments for her breast cancer (both privately and through the NHS). The genre of Sharon's story is best described using Hunsaker Hawkins' *journey*. The story

could also be categorised as *healthy-minded*, given Sharon's interest in alternative medicine.

The main themes which emerged from the story were *understanding* and *navigation*. Sharon discussed her desire to have “mutual understanding” with healthcare professionals: they needed to understand what was going on with her, but she also needed to understand and be in control of what was happening to her.

...[N]avigating one's way through one's own health, understanding it from a personal perspective, and understanding it from society's point of view, and navigating one's way with that through the NHS and...with alternative practitioners as well is quite a challenge. It's hard to stay on course.

(Sharon)

5.5.2 Prototype

In her interview, Sharon discussed how hard she found it to “stay on course” with her treatments, given all of the various routes that she had available to her. This included understanding her feelings towards her health and that of those around her, as well as keeping track of treatment options (both the “official” ones provided through the NHS as well as alternative practitioners).

Before she became unwell, Sharon enjoyed outdoor activities such as hillwalking and cycling. I combined this with Sharon’s metaphor of the compass to create the concept of a health *trail map* which maps out different treatment routes. The map would clearly state Sharon’s overall goals, as well as the potential outcomes of each treatment, helping Sharon to determine whether a particular treatment route met her goals. The concept of peaks and valleys illustrates how one’s condition progresses over time.

I also suggested the idea of *trail notes*, which could be used by Sharon and others involved in her care. This idea was

originally fairly simple, using a traffic light model to record emotional state and space for notetaking. We expanded this during the co-design activity in Workshop 2 to include tracking of emotional and physical states as well as recent activities.

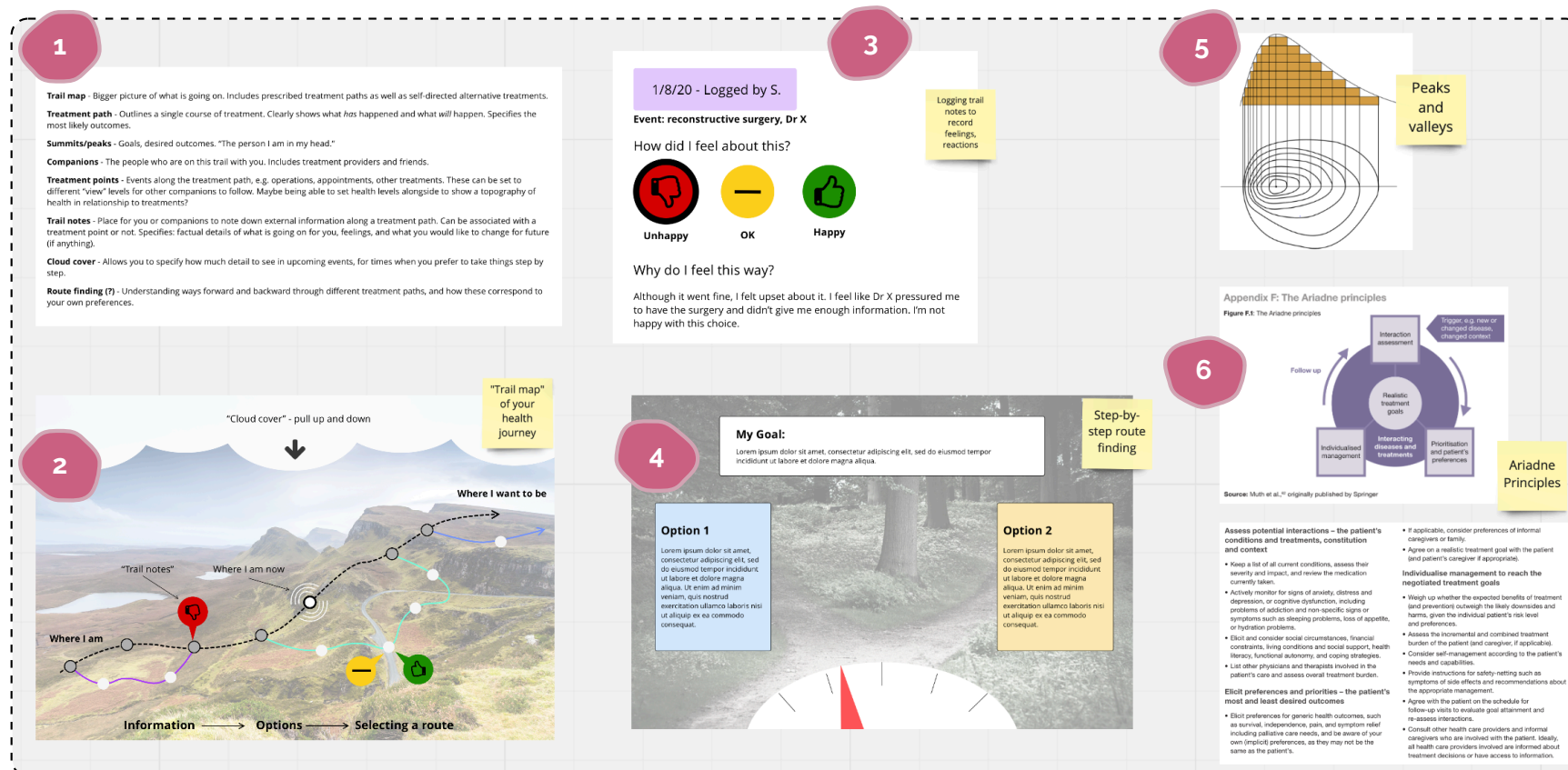
Another theme that emerged during Sharon’s interview was information sharing. During acute periods of care, Sharon could enable a Follow Me feature which would allow interested friends and family to get updated on her treatment schedule so that they can easily check in with her.

Sharon also mentioned that, as a person with a life-threatening condition, she sometimes found it too overwhelming to know the details of what was happening. For this, I came up with the concept of *cloud cover*, a screen which can be pulled up or down on the main page. Using this would let Sharon control how much detail she sees, and how far into the future her map will extend. When cloud cover is enabled, it could also flag to friends and healthcare professionals that Sharon does not want to have detailed discussions about her health.

Sharon: Concepts & Prototype

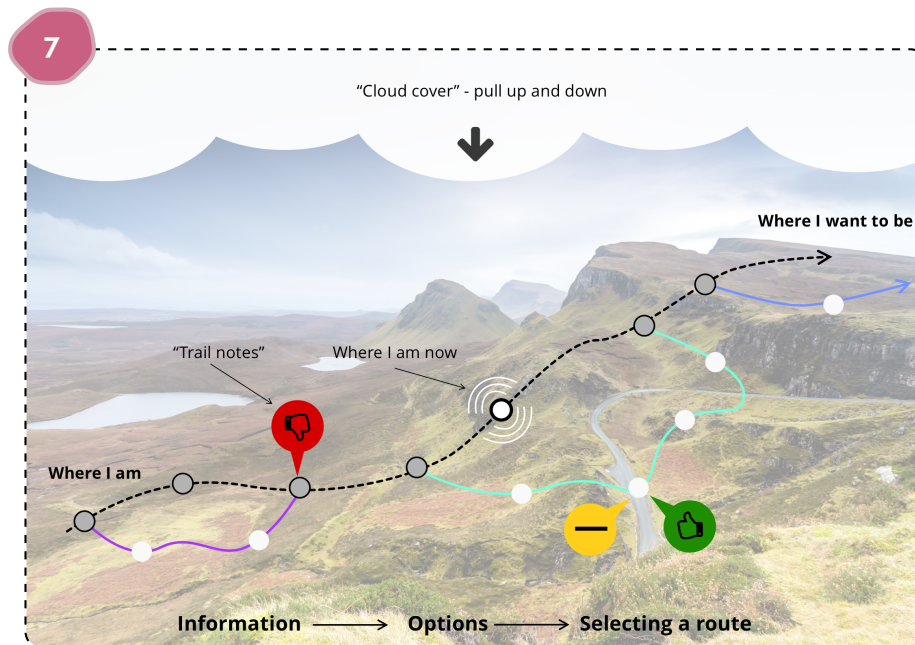
View Sharon's complete prototype online: <https://bit.ly/3fBOJCE>

Sharon's Concepts (Cycle 2)



Screenshot of Miro board from Workshop 2

1. Written description of concepts
2. Health journey as a trail map
3. Logging daily trail notes
4. Step-by-step route finding for treatment paths
5. Elevation drawing, illustrating the idea of peaks and valleys (<https://bit.ly/3lpzoX2>)
6. Ariadne principles for treatment of people with multimorbidity, showing an idea for route finding (Aiden, 2018, p.45)



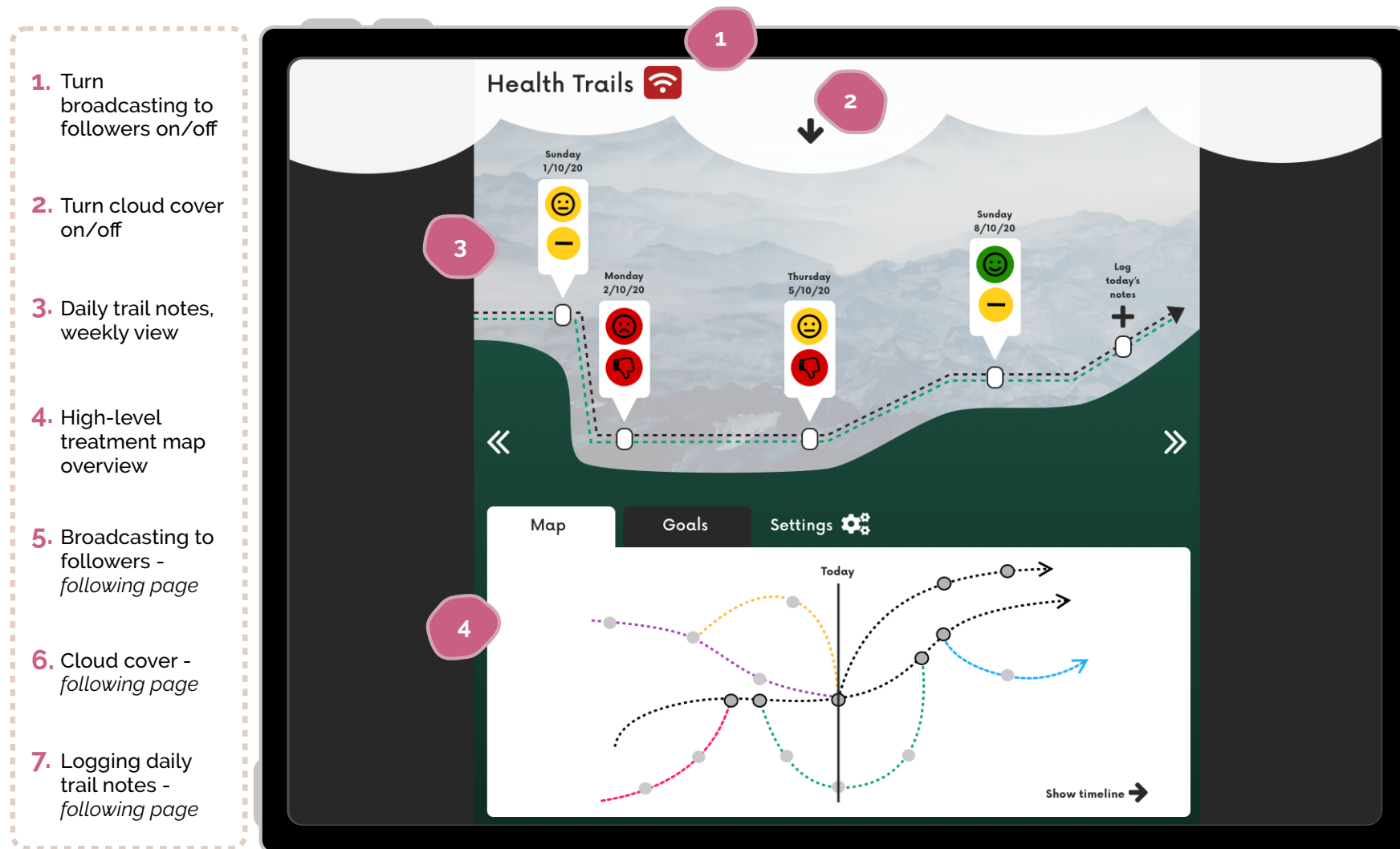
7. Health trail map (detail)

9. Co-design session with Sharon

8. Daily trail notes (detail)



Sharon's Prototype (Cycle 3)




Landing page

5

Sunday
1/10/20

Broadcasting

While broadcasting is on, your friends will automatically receive email notifications of your upcoming treatment dates. Your friends will also be able to add your treatment dates to their calendar.


Broadcasting is currently ON 

Turn broadcasting OFF **Cancel**

6

Cloud cover is ON




While this is enabled, you will not see daily logs and friends will be notified not to discuss treatment details with you.






7

Re-grounding and kindness

Emotionally I feel...

 Negative  OK  Positive

Physically I feel...

 Bad  Neutral  Good

What happened today?

Sick and off work for breathing space.

What made me feel better?

Went swimming outside!

What made me feel worse?

Too busy for too long, not getting enough rest.

Save and Close **Cancel**

8. Personal goal to compare against outcomes

9. Outcomes for different treatments

10. Events on different treatment paths

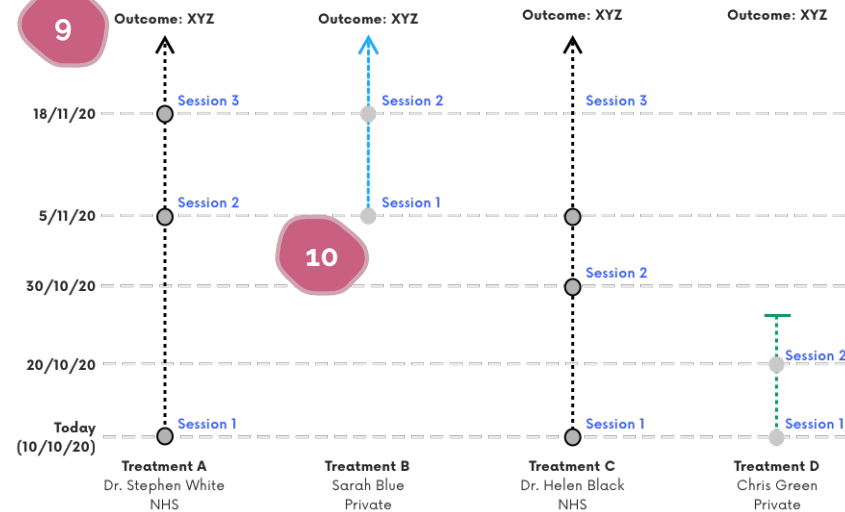
Ongoing Treatments

← Back

8

My goal: Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua.

9



Route finding for treatment paths

5.6 Tedhead

5.6.1 Story

Tedhead's complete story can be found in **Chapter 9** of the Appendix.

Tedhead has lived with depression since being diagnosed in his mid-teens, although he now feels that he can manage this using medication. In 2003, he also began to have problems with irritable bowel syndrome (IBS) and periods of fatigue. Tedhead became seriously ill in 2010 and was subsequently diagnosed with ME. Within two years he had become so ill he could no longer work. The genre of his story is probably closest to Frank's idea of the *quest*, in that Tedhead has a specific goal: that one day, there will be a treatment or cure for ME.

Hope was a reoccurring theme in Tedhead's story. He felt that it was easy to "burn up" one's hope in the search for treatments, many of which were false. This also demonstrates Tedhead's attitude towards hope as a finite resource, which must be conserved for the future (analogous to Spoon Theory (Miserandino, 2003)). Tedhead felt that it was important to accept that hope of returning to one's previous life was futile, and yet at the same time, he found that he couldn't give up hope entirely. He referenced a song, *The Mary Ellen Carter* by Stan Rogers, to describe this (lyrics can be found in Chapter 9 of the Appendix):

The thing about that song is that it offers *hope*. ...Unfortunately, in ME, there is no such hope... You have to live with the constraints that you now find yourself in, because there isn't even a *treatment*, let alone a cure. But that, for me is too negative. I have to live with some hope, and that song is the song of hope.

(Tedhead)

5.6.2 Prototype

Because of Tedhead's interest in sailing, I came up with the idea of portraying his health story as a *ship's log*. Tedhead struggles with fatigue because of his ME, so entries could be recorded as video if he is feeling too tired to type. Treatment events, such as appointments, could also be appended with a log entry to describe his thoughts on what happened.

Tedhead and I discussed different ideas around representing hope, as this was a major theme in his story. Originally, I suggested the idea of coins, but he felt that a better representation might be a plant – something that has to be nurtured. I incorporated this into the final design with the idea of a *hope flower*. The flower has several increments which could be adjusted up or down to show Tedhead's current hope level. This could then be used for personal reflection or shared with others.

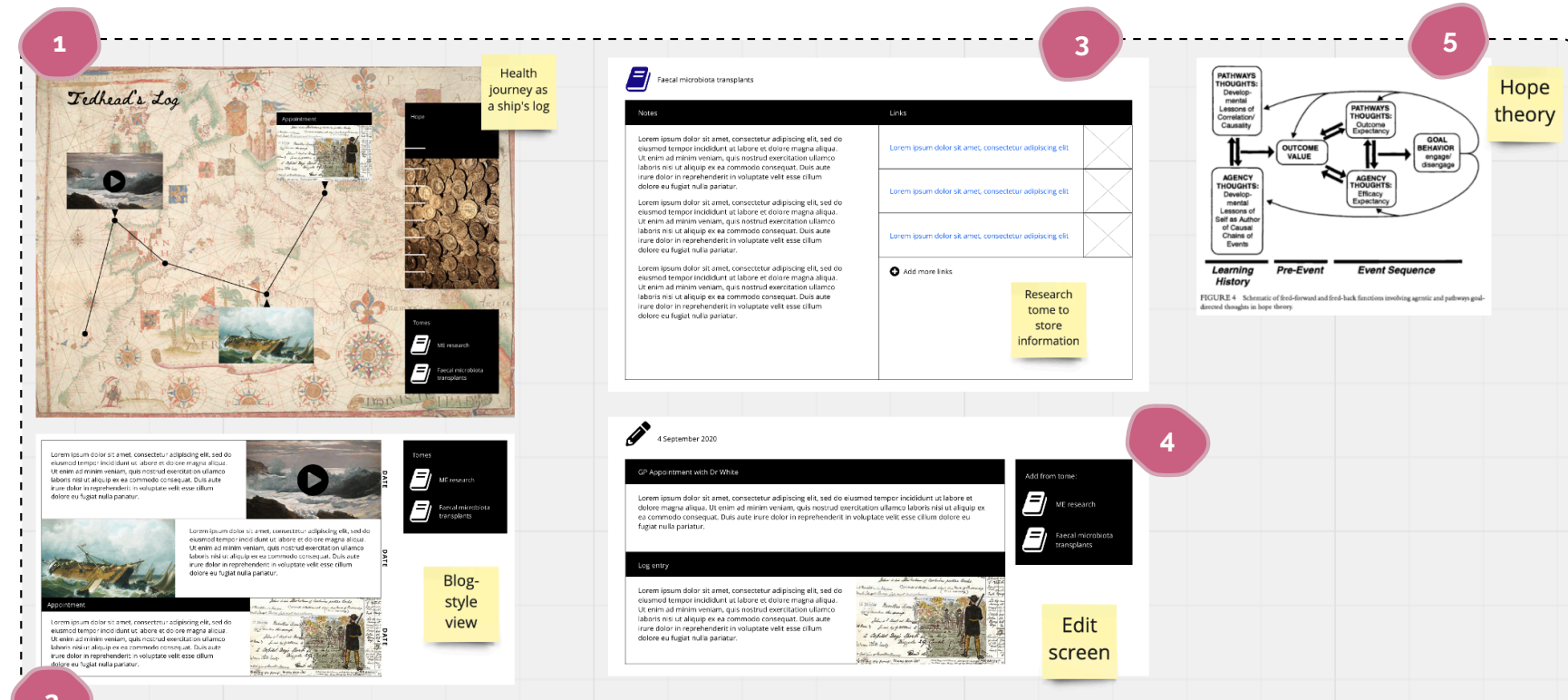
Because Tedhead does considerable research on his conditions, the concept also includes the idea of *knowledge tomes* (at Tedhead's suggestion, these were later renamed *research rutter*⁵ to reflect the nautical theme). These are areas where Tedhead could record notes and resources on particular topics which he is interested in, such as potential treatment options. The rutters can also be linked to log entries, as a loose form of citation. A healthcare professional could use these to learn about something which Tedhead is interested in and to understand Tedhead's approach towards his illness (as in Kleinman's (1988) idea of explanatory models). He is very involved with patient advocacy, so in the final design, I represented this by showing the research rutter as a joint work with several co-authors.

⁵ A book used to record information about navigation, local customs, descriptions of locations, etc., which acted as a supplement to the ship's log.

Tedhead: Concepts & Prototype

View Tedhead's complete prototype online: <https://bit.ly/35Yq7Rj>

Tedhead's Concepts (Cycle 2)



Screenshot of Miro board from Workshop 2

1. Health journey as ship's log
2. Alternate layout for ship's log using a more typical blog style
3. Research tome to store information (later renamed "research rutter")
4. Editing a single log entry
5. Hope theory, illustrating a potential way of representing hope (Snyder, 2000)
6. Health journey as ship's log (detail) - following page

Tedhead's Log



Appointment

Hope



Tomes



ME research



Faecal microbiota
transplants

7



4 September 2020

GP Appointment with Dr White

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat. Duis aute irure dolor in reprehenderit in voluptate velit esse cillum dolore eu fugiat nulla pariatur.

Log entry

Lorem ipsum dolor sit amet, consectetur adipiscing elit, sed do eiusmod tempor incididunt ut labore et dolore magna aliqua. Ut enim ad minim veniam, quis nostrud exercitation ullamco laboris nisi ut aliquip ex ea commodo consequat. Duis aute irure dolor in reprehenderit in voluptate velit esse cillum dolore eu fugiat nulla pariatur.



Add from tome:



ME research



Faecal microbiota transplants

Research tome

links to papers
- many forms
(media?),
annotationssummary of
understanding,
reflectionsWhat kind of
information
would you like
to store here?Would be
used for
rebuttals

7. Editing an entry (detail)

8. Co-design session with Tedhead

8

Hope

Plant - dies,
witheres, can
be nurtured,
multiplies

Tedhead's Prototype (Cycle 3)

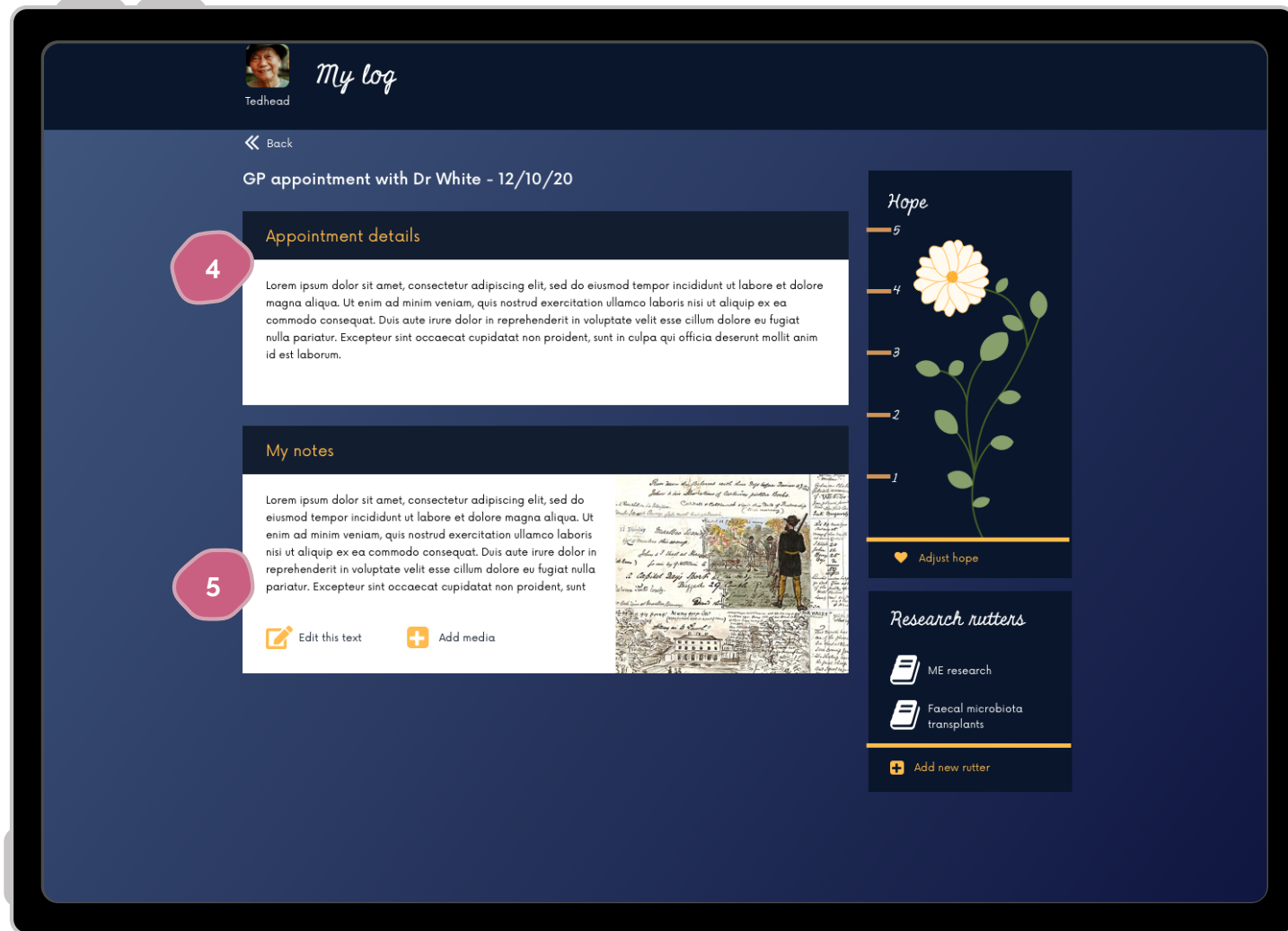
1. Timeline of log entries
2. Hope flower showing Tedhead's current status
3. Research rutters



Landing page

4. Appointment details as part of a daily entry

5. Personal notes and reflections as part of a daily entry



Editing an entry

6. Tab to view a summary of this rutter

7. Resource links combined with personal annotations

8. Add new resource link

9. Tab to manage sharing options for collaborators

10. Tab to view history of changes to this rutter



Research rutter - resources tab

5.7 Summary

In this chapter, I have presented all of the individual results and findings. Each participant had a unique perspective on their health and health storytelling, which is reflected in their final prototype.

Lee was very focused on the present and using self management to control her conditions. Her prototype uses a sport metaphor to illustrate this, putting Lee in charge of a team of self management players.

Rhona liked sharing her story with others, but there were certain elements which she felt very private about. Her prototype represents this through a *burrow* in which stories may be shared or kept hidden.

M's story was a mixture of joy and sadness. At first, I found it hard to come up with a concept for M, but we ended up going with the idea of a *light and dark memory garden* in which M could look back on everything she had experienced.

Sharon is balancing two long-term conditions (including one terminal condition), and she discussed how difficult it was to navigate the different treatment options available to her. Her prototype uses a *trail map* metaphor to illustrate moving through treatment paths to achieve a goal.

Tedhead used a nautical metaphor to discuss his frustration with the way his health was managed by others and the difficulty of maintaining hope over time. I continued the nautical theme into his prototype, using a metaphor of a *ship's log* and *research rutter*. We also used the metaphor of a *flower* to talk about nurturing hope.

Although each participant was unique, there are also commonalities across all of them. In the next chapter, I will discuss the overall findings which emerged from the research, along with how these address the research questions.

6 Findings & Discussion



6.1 Introduction

In this chapter, I present the overall findings that emerged from the categorical-content analysis (discussed in Section 4.8.2) of the participants' health stories from the previous chapter. These findings answer my original research questions:

- How can digital tools support people with multiple long-term conditions in making sense of and conveying their health stories?
- What can a narrative-led methodology teach us about designing for eHealth?

Throughout the fieldwork and analysis, I broke down the first question by trying to understand *who* participants might share their health stories with, *why* they were telling their story, and also *what* they wanted others to learn. I use this same approach here by first describing the potential

audiences and collaborators identified during the project (*who*). Next, I discuss the various goals for a health storytelling tool, and how these vary by audience (*why* and *what*). I then list the functionality needed to support these goals. A summary of the findings is shown in Figure 19.

Finally, I answer the second research question by discussing the validation of the methodology and my personal reflections on the research experience.

A summary of the implications for design which relates the audiences, goals, and functionality can be found in **Chapter 11** of the Appendix.

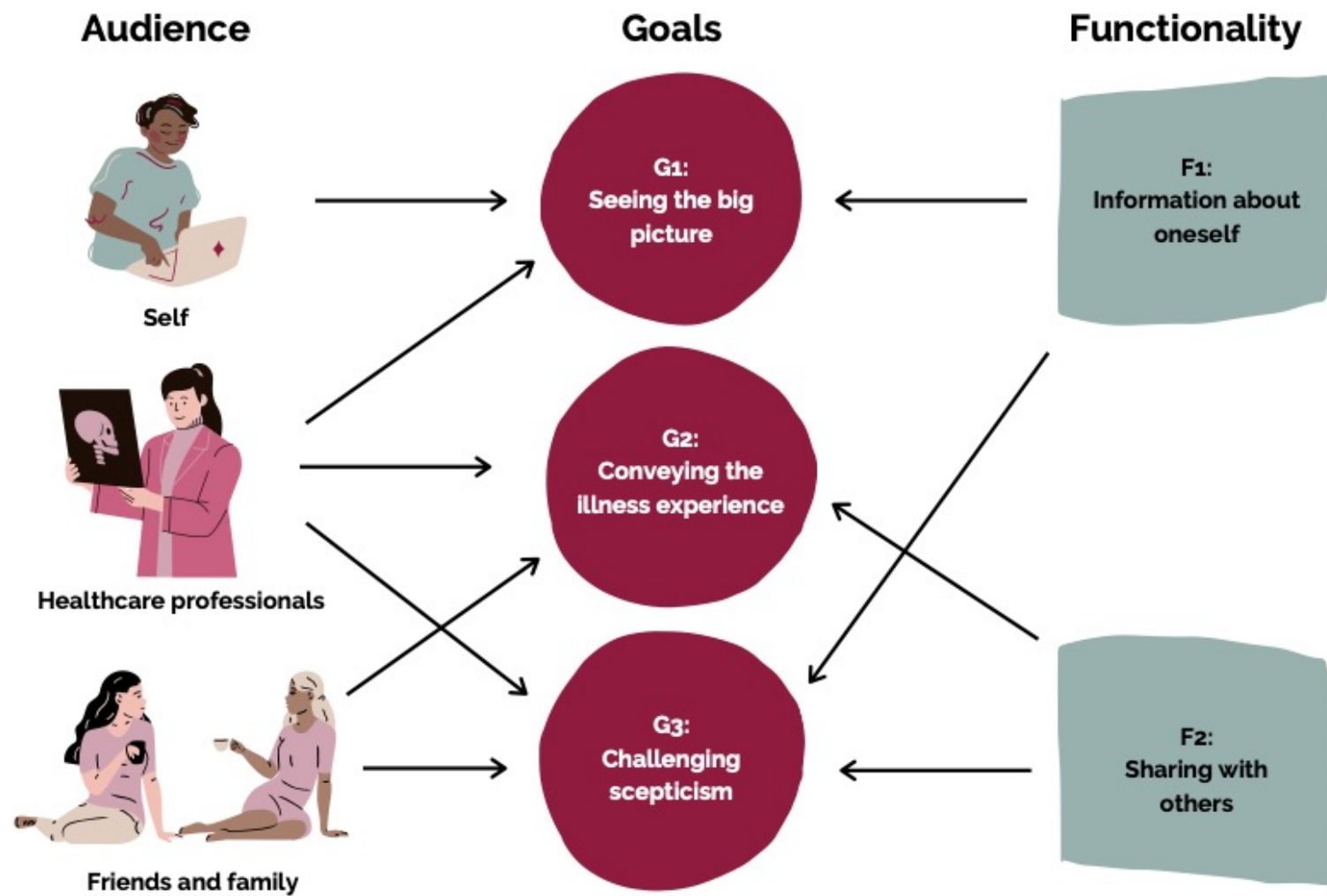


Figure 19: Summary of the findings. Diagram. Source: author's own.

6.2 Who: Audience

Over the course of the project, the participants identified different audiences for a storytelling tool, shown in Table 3. The most popular of these were family and friends, healthcare professionals, and the participants themselves (self). Collaborators are also likely to play varying roles. For example, Lee talked about how she might work with her physical trainer to *create* a diet plan, but that her husband would need to be involved in actually *carrying it out*. Collaborators in carer roles were generally viewed as operating in a more privileged capacity, as they are *in the story* with the storyteller. Tedhead suggested that his wife might like to use such a tool to create her own story as a carer, which could then be linked with his own.

Privacy was important to all the participants, especially Rhona. She emphasised the importance of being able to control privacy at a very fine level: by the person, content type, and even individual elements. Participants also observed that it would be useful in many situations to be able to export out a summary of one's story. This would allow

stories to be shared without giving someone access to the tool itself. Rhona particularly discussed wanting to do this when seeking support from official bodies.

Similarly, while every participant spoke about “disease-mates” (Ferguson and e-Patient Scholars Working Group, 2007) as being an important part of their support, several said that they would only want to give such friends a general update without specifics – for example, as with Tedhead’s *hope flower*.

...[N]early all the people I know with ME inevitably struggle with low mood and I imagined a social networking app in which you could check in with friends each day to see how tall their flowers are – the flower might stand for mood more generally, rather than just hope.

(Tedhead)

Table 3: Audiences and collaborators identified by participants.

	Lee	Rhona	M	Sharon	Tedhead
Family/friends	X	X	X	X	X
Healthcare professionals	X	X	X	X	X
Self	X	X	X	X	X
Disease-mates	?	?	X		X
Alternative healthcare professionals	X			X	
Co-workers	X	X			
Official bodies (e.g. government)		X			X
Advocacy groups					X

Blank = not important ? = sometimes important X = important

6.3 Why & What: Goals

Although participants had different opinions on what the goals of a digital health storytelling tool would be (Table 5), three overarching categories emerged across all of the participants:

- G1. Being able to see a *big picture* view of their story and remember what had happened to them
- G2. Conveying the illness experience to others
- G3. Challenging scepticism about their health

There was some overlap between these: for example, a participant might want to use information about their health to *convey the illness experience* to someone (G2), but also to *challenge scepticism* (G3).

Different goals were considered to be important depending on what the intended audience was (Table 4). Of the three categories, only the first (G1) was aimed at *both* the self and

others. The other two were entirely outward-facing.

Referring back to the three storytelling frames discussed in Section 2.4.1, the overarching goal categories can be viewed as moving from self-storying towards cultural health stories (Figure 20).

Table 4: Goal categories by potential audience.

Audience	G1	G2	G3
Healthcare professionals	X	X	X
Family/friends	X	X	X
Self	X		
Disease-mates	X	X	X
Alternative healthcare professionals	X		
Co-workers		X	
Official bodies (e.g. government)		X	X
Advocacy groups	X		X

Table 5: Goals of a storytelling tool identified by participants, organised by overall category.

G1: Seeing the big picture

	Lee	Rhona	M	Sharon	Tedhead
G1.1 Recording memories	?	X	X	?	?
G1.2 Self-reflection	X	?	X	X	X
G1.3 Daily self management	X			X	?
G1.4 Understanding one's conditions and treatments				X	X

G2: Conveying the illness experience

	Lee	Rhona	M	Sharon	Tedhead
G2.1 Supporting communication		X	?	X	X
G2.2 Getting support	X	X	X	X	
G2.3 Inviting alternate perspectives/sense-making		X		X	

G3: Challenging scepticism

	Lee	Rhona	M	Sharon	Tedhead
G3.1 Evidencing what has happened	X	X			X
G3.2 Sharing knowledge		?	X		X
G3.3 Education and advocacy				?	X

Blank = not important ? = sometimes important X = important

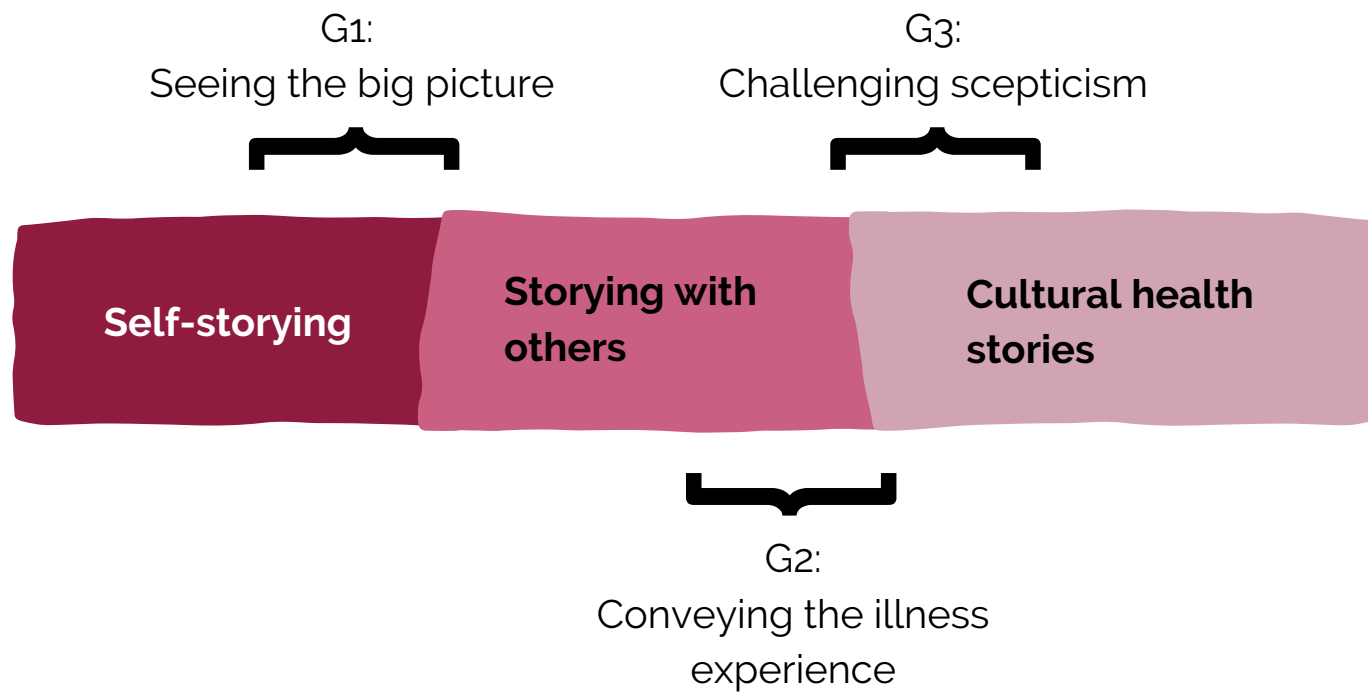


Figure 20: Goal categories related to storytelling frames. Diagram. Source: author's own.

6.3.1 G1: Seeing the Big Picture

Further exemplary quotes for G1 can be found in **Section 10.1** of the Appendix.

One of the primary goals mentioned by participants was being able to look back and remember what had happened to them (G1.1), either for self-reflection (G1.2) or to celebrate “small wins” (Lee). This included both positive and negative events, as embodied in M’s *light and dark memory garden*, and was viewed as important for mental health.

It's easy to forget things... [T]he memory wall...is a fantastic idea. Because it's not all bad...there is some good bits in there as well. It's not all rubbish.
(M)

Recording details of daily self management (G1.3) was important to many of the participants, and they wanted to be able to use the tool to build an understanding of trends and patterns (as shown in both Lee and Sharon’s prototypes). Being able to see how activities affected one’s health, and to plan positive activities in, was considered useful.

I might be doing the same things consistently, like working out, mindful eating... But then, I might still need those same...players when I'm going to have that day out, as well, but just factoring in more rest. ...Seeing that planned in definitely does help.
(Lee)

Appointments with healthcare professionals tended to be infrequent, so remembering details of activities was also practically useful. Participants related this to evidencing (G3: *Challenging Scepticism*), saying that they felt they sometimes needed to “prove” what they had been doing to healthcare professionals.

Recording information was also important for participants to understand their conditions and ongoing treatments (G1.4). This was particularly noted by Sharon (who was undergoing numerous treatments for her cancer) and Tedhead (who felt dissatisfied with the treatment options suggested by healthcare professionals).

6.3.2 G2: Conveying the Illness Experience

Further exemplary quotes for G2 can be found in **Section 10.2** of the Appendix.

Participants identified many situations in which a health storytelling tool could act as a useful aid to conversation (G2.1). Firstly, participants found it difficult to initiate deeper conversations or express concerns, even in a clinical context. A tool could act as a “talking point” by providing details about their health, while still giving them control over how much to show collaborators. Secondly, participants spoke

about the difficulty of articulating events, particularly when they impacted mental health. A visual tool could support this by giving them more abstract ways to convey emotions. For example, Rhona spoke about wanting to include images and animations in her story.

There were also scenarios in which participants might want to give information about their health without speaking to someone directly. This could be because of storytelling fatigue (Frank, 2013; Teal et al., 2017), because of an uncomfortable topic, or because their condition prevented them (e.g. being too unwell).

I like that I can message people as well, I really like that aspect of it... Sometimes it's hard to maybe speak on the phone, or sometimes it's just a bit awkward as well. I think, for me...everything's got to seem like I'm ok. I find it really hard to ask for help in the first place, but...I quite like that idea of just

sending a message and people can access it... For me that would be extremely beneficial.

(Rhona)

On a practical level, participants also wanted to be able to coordinate communication among the healthcare professionals they saw (reflecting the findings from Teal et al. (2017)). This included being able to quickly give new professionals an idea of their history, personality, and concerns. From healthcare professional perspectives, these personal details provide “ways in” (Teal et al., 2017, p.24) to understanding their patients and what is important to them.

Conveying the nature of the illness experience was also important for participants in gaining support from others (G2.2). Whether someone “got it” made a big difference to the level of support offered. A health storytelling tool could promote empathy and understanding amongst a person’s support networks, simply by giving others insight into the

illness experience – particularly important to stigmatised conditions (e.g. NHS Scotland, 2010)

[Secondary breast cancer is]...such a devastating diagnosis on the one hand, on the other hand, if you're going to have any life-threatening condition it's a good one to have because people get it. Or think they get it. There's no question marks over it; there's understanding and compassion from people. ...It's chalk and cheese compared with the ME world.

(Sharon)

Finally, the act of discussing one’s health with others could also act as a form of reflection. Participants discussed wanting to make sense of what was happening by gaining outside perspectives from friends, family, and disease-mates (G2.3).

6.3.3 G3: Challenging Scepticism

Further exemplary quotes for G3 can be found in **Section 10.3** of the Appendix.

Participants often felt that they needed to challenge scepticism from others, something which directly impacted their mental health. This was discussed more by participants who felt that their conditions were stigmatised by others, which is consistent with similar research (e.g. Lacerda et al., 2019).

In many cases, participants felt that they needed to evidence their conditions to others (G3.1), also relating this to the overall goal of *getting support* (G2). This was true even when working with healthcare professionals. Participants often felt that they understood their conditions better than the professionals they were working with – consistent with the

patient as expert model for people with chronic illness (Kleinman, 1988).

There was also an aspect of education, where participants wanted to share understanding and advice with others (G3.2). Tedhead's *research rutter*, for example, focused on the documentation and sharing of knowledge about ME and possible treatments. Sharing with healthcare professionals was viewed as being particularly important when their opinions diverged from the patient, especially regarding treatment.

Communicating with medical professionals is by far the hardest nut to crack...because the entire 'social contract' with your doctor is predicated on them having knowledge and power and the patient having an unmet need. When challenging their misconceptions about illness the patient challenges this whole model: the patient has knowledge...but not power; the doctor may or may

not have an unmet need - the need to be better informed and transform their practice.

(Tedhead)

Participants also related knowledge sharing to patient advocacy (G3.3), something that was particularly important to Tedhead. He viewed his story as something which he could share with others to make change – both to individual opinions, and also on a societal level.

6.4 Desired Functionality

The functionality identified by participants can be divided into two categories (shown in Table 6):

F1. Tracking information about oneself

F2. Sharing with others

Many of these are self-explanatory, so in this section I will focus on discussing key insights from the functionality.

Within the first category (F1), the most important feature was tools for tracking mental health (F1.1), which was mentioned by every participant. This was considered to be of much greater importance than tracking physical health (F1.6), which only two participants mentioned. Every participant had experienced difficulties with mental health, which is not uncommon among people with long-term conditions (Liddy et al., 2014). This implies that a health storytelling tool should accommodate deeply personal and emotional modes of storytelling.

Privacy (F2.1) was very important in the second category (F2), with participants wanting to control what was available to be viewed or edited. In some cases, participants wanted information to be visible only to themselves (as in Rhona's *private story* option). While all the participants wanted to share their story with others, they also wanted to limit how collaborators could interact with it (F2.2, F2.3)

The categorical-form analysis (Lieblich et al., 2011) of the participants' health stories (discussed in Section 4.6.4) also illustrates how health storytelling tools should be structured. Firstly, the way that people told their stories was quite varied, with some preferring an episodic approach, and others telling it end-to-end. Secondly, participants often separated stories by timeframes within their life, rather than by condition. This is reinforced by the literature, which shows that conditions in people with multimorbidity often become intertwined (Aiden, 2018). These points suggest that storytelling tools need to be open-ended, modular, and easily extendable.

Table 6: Features/functionality of a storytelling tool identified by participants, organised by category.

F1: Information about oneself

	Lee	Rhona	M	Sharon	Tedhead
F1.1 Mental health tracking	X	X	X	X	X
F1.2 Written accounts (journaling)		X	X	X	X
F1.3 Visual representations and media		X	X		?
F1.4 Record of self management activities	X			X	?
F1.5 Goals				X	X
F1.6 Physical health tracking	X			X	
F1.7 Treatments and outcomes				X	X

F2: Sharing with others

	Lee	Rhona	M	Sharon	Tedhead
F2.1 Privacy & access controls		X	X	X	X
F2.2 Discussion/messaging features		X	X		?
F2.3 Story export feature	X	X		X	
F2.4 Knowledge/research recording		?	?		X
F2.5 Features supporting collaborative advocacy work					X

Blank = not important ? = sometimes important X = important

6.5 Validation of the Methodology

Further exemplary quotes on the methodology can be found in **Section 10.4** of the Appendix.

6.5.1 Benefits

All of the participants commented positively on the methodology during the final interview in Workshop 3, particularly the dialogical aspect. Having the “final say” on whatever data I had collected gave them an important sense of ownership in the project and helped them feel that I respected their authority.

Many participants expressed enjoyment over seeing their stories interpreted into the prototypes. For some participants, it was the first time that they had ever recounted their complete story to someone. This positive feedback is reflective of the literature, which shows that health storytelling promotes a sense of wellbeing (Smith and

Liehr, 2014; Chuang et al., 2018). They also liked the experience of mutual reflection, commenting that the dialogic process had given them additional insights into their story.

...You've listened to everything that I've said, you've documented everything accurately, and you've had a think about how it all...interacts. ...[Y]ou've been able to pull things out of conversations and then come back and say, "Well, this is what I was thinking." ...[Y]ou've just took it from my mind, and actually seeing it laid out has been brilliant. And you've made it so easy to do, just with...a conversation.

(Lee)

The personalised, phenomenological approach also had particular benefits for eHealth research. The 1:1 interview format allowed participants to discuss things which they might have felt uncomfortable talking about in a group setting, leading to additional insights (Pessoa et al., 2019). The remote engagements also worked well, as participants were in their own homes and physically separated from me, creating a safe research space. The inclusion of the real, lived experiences which came out through this approach gives an additional impact to the final prototypes which wouldn't have been possible when using personas.

Being able to return to the participants multiple times also proved to be crucial for validating understanding and developing ideas. Because the final prototypes were dialogically co-created between myself and the participant (Finlay, 2009), they embody both of our perspectives. Participants viewed this as a positive, saying that they could never have envisioned what I had designed, but they still felt it was reflective of themselves.

I think it reflects my perspective really, really well. ...I don't know how you do it, what you've come up with. I like what you've come up with. I feel like I can connect with it...

(Rhona)

6.5.2 Difficulties and Limitations

The dialogic aspect of the research also created a limitation, in that the work doesn't reflect what the participant might have come up with independently.

Another difficulty was that none of the participants had defined opinions at the start of the project on what a health storytelling tool should be like. Understanding how to draw out these ideas was challenging for me as a researcher. Up until the final workshop, the work that we were doing was largely conceptual: participants were interacting with the concepts themselves, rather than an interface. This meant that at times it was hard for me to know what questions to ask, or for participants to know how to answer. On the other

hand, this lack of boundaries also sent the research in some unexpected (and interesting) directions.

It's been a step into the unknown for me. I had really no idea what to expect when we started off with it.

(Sharon)

6.5.3 Remote Fieldwork

Because the research started under COVID-19 lockdown, I planned for the fieldwork to be carried out remotely. This had pros and cons. Working remotely allowed participants to join who might otherwise have been prohibited due to their conditions (e.g. due to exhaustion, limited mobility, etc.) or because of scheduling restrictions.

However, this approach also had some drawbacks. Firstly, the workshops were necessarily limited to what was possible to

do with participants online. Secondly, the participants themselves were limited by their technical ability (as discussed in Section 4.3). This was also influenced by what devices they chose to use and/or were available to them (e.g. a tablet as compared to a laptop). Finally, additional time needed to be built into each session to account for technical difficulties. Running the workshops remotely required careful planning around what tools and functionality to use, as well as preparing fallback options. Again, the feedback from the participants here was positive, implying that I was able to address these issues successfully.

It has to be done online, and there are limitations with that. But I think we've worked well through them. ...And you've been able to adapt as we went along. Such as today, you...knew Plan A might not work so there was a Plan B in place.

(Sharon)

6.6 Personal Reflections

It is difficult to convey within the thesis format what a deeply moving experience this project has been. To listen to someone's health story is to hear about some of the most difficult times in someone's life. Its themes of hope and despair go straight to the heart of what it means to be human.

Throughout the project, I found it hard to balance my personal feelings about the participants with maintaining a "professional" distance in the role of researcher. There were many moments where participants become deeply emotional while telling their story. Ellis (2004) has argued that denying participants a connection while they are sharing personal information is both harmful and unethical as a researcher. As the goal of phenomenological research is to gain a deep understanding of someone's experiences, that requires a commitment as a researcher to not shy away from those

experiences. In this I have been guided by Lisa Tillman-Healy:

For a mutual, close, and/or lasting friendship to develop between every researcher and all participants is unrealistic. Regardless, we can approach respondents from a stance of friendship, meaning we treat them with respect, honor their stories, and try to use their stories for humane and just purposes.

(2003, p.745)

6.7 Summary

In this chapter, I have discussed the overall findings and how they address the research questions. The first question that I set out to answer was to understand how health storytelling tools should be designed to help people understand and convey their health stories. I have answered this by breaking it down into three parts as follows.

Who: The most popular audiences which were mentioned by every participant were: family/friends, healthcare professionals, and themselves.

Why & What: Participant's goals for the tool can be broken down into three categories. First, participants wanted to be able to see the *big picture* of their health story (G1), both to remember details of events and for self-reflection. Second, participants wanted to use their story to *convey their experience* to others (G2). And third, participants wanted to *challenge scepticism* about their conditions by presenting evidence and external research to others (G3).

Functionality: The functionality which would be needed to support the tool can be divided into two areas: *tracking information about oneself* (F1) and *sharing with others* (F2).

My second research question was to understand how adopting a narrative-led methodology might impact the work. Throughout, I believe that this gave me additional empathy as a researcher and insight into participants' experiences which I could not have gotten otherwise. However, this approach also had some difficulties and limitations which I have discussed here.

In the final chapter, I discuss how the work can be carried forward into the future and the conclusions from the research.

7 Future Research & Conclusions



7.1 Future Research

Digital design for health storytelling is a relatively new area of research with a wealth of opportunity for new tools which can support wellbeing. During the literature review, I was unable to identify any other research specifically looking at how digital tools for health storytelling should be implemented. This project provides a starting point, but further research is needed to understand this.

The personalised approach adopted within this project has both benefits and drawbacks. Human-centred design processes, especially in a corporate environment, are largely focused on *satisficing*, an approach which focuses on the minimum requirements to meet the needs of most users (Simon, 1956). This is the basic principle behind strategies commonly used in industry such as *lean UX* (Gothelf, 2011). Conversely, designing for individuals led to greater design insights, but in more specific areas. To illustrate this point: if one imagines a radar chart surrounded by different areas of insight, the personalised approach would be a star, whereas a

more general (e.g. *satisficing*) approach would be a circle (Figure 21). Future research would need to be done to “fill in” areas not covered by the personalised approach.

Jones (2013) also defines design processes as moving through three stages:

- **Generative** – Generating ideas for design
- **Democratic** – Refining ideas through group consensus
- **Strategic** – Using refined ideas to define a strategic design direction

Within this, work can also be seen as being on a spectrum being *open* and *structured*, depending on how much the researcher controls the process. Using this framing, the work that I have done in this project would be described as being *guided* (i.e. between open and structured) and at a *generative* level (Figure 22).

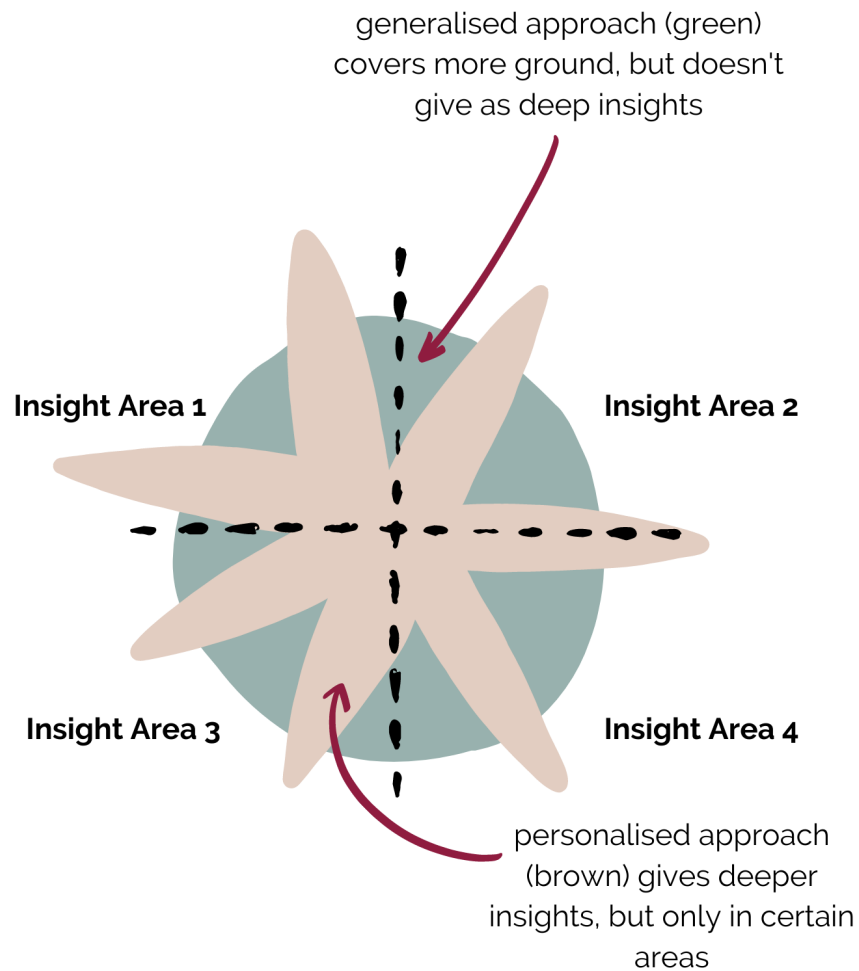


Figure 21: Insights in a personalised approach vs a generalised approach. Diagram. Source: author's own.

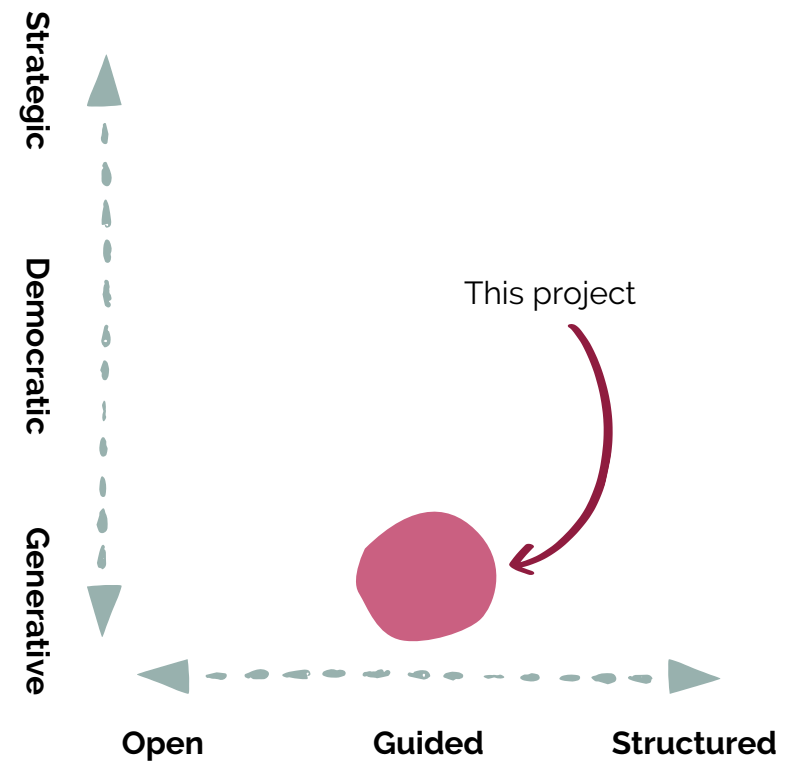


Figure 22: Mapping of this project's dialogic approach. Diagram. Source: author's own, inspired by Jones (2013, p. 291)

This understanding helps to illustrate four directions for future research:

- Understanding how the findings from this project generalise to a wider group (validating the research)
- Filling in the gaps not covered by this project
- Defining a strategic design direction for digital health storytelling
- Re-applying the same approach with a different participant group

Many of the findings from this project reflect points from the literature review, which implies that they do represent wider perspectives. However, future research with a wider group of participants would help to demonstrate this and also determine whether what the priority of these findings are across a larger population.

The current research is also limited in certain ways. Firstly, I have not included potential collaborators. Future work could be done to understand the perspectives and requirements of

collaborators: for example, healthcare professionals, friends, family, and carers. Secondly, I have not covered how storytelling tools could be technically implemented, although I have discussed areas of functionality. Further research could establish how this would be done. The technology that is being used for eHealth systems is also rapidly changing, especially due to the need for remote treatment under coronavirus (COVID-19) (Latifi and Doarn, 2020).

Before COVID...the way that you interacted with healthcare professionals...was definitely face-to-face. You never e-mailed your doctor...it was very old-fashioned. Whereas things are changing now so rapidly. ...I guess it's likely...they'll develop a specific platform [for communicating with your GP]. ...We don't know what that platform is, but we'd like to think it would be possible to share these [health stories].

(Tedhead)

Future research could also be used to flesh out the findings presented here, specifically regarding different conditions. Problems with mental health are very common amongst people with long-term conditions (Liddy et al., 2014) and health storytelling has been shown to have a positive effect on wellbeing (Smith and Liehr, 2014). This would indicate that a digital tool for health storytelling could be extremely beneficial for people with mental health conditions – a theme which I hope to explore through my future doctoral work.

All of the work outlined above would help to progress the research from its current, generative, stage to a democratic stage. The final step would be to understand how a strategic design direction could be defined for digital health storytelling, building on the previous work.

An alternate approach to future work would be to re-apply the process used here. All of the participants in this project commented positively on seeing the representations of their health stories, again illustrating that health storytelling can

be beneficial to mental health and wellbeing (Smith and Liehr, 2014). This implies that the methodology could be used in a clinical setting and/or incorporated into therapy. The finished stories which participants received at the end of the project were important as something that they could take away and use with support networks, reflecting *G2: Conveying the Illness Experience* from the project findings. This benefit is beautifully illustrated in the following comment from Lee, who talked about sharing her health story with her family:

Something kind of clicked with my mum and I've heard her speaking with people and explaining how my conditions affect me and why I take my medication instead of questioning it. That is a massive thing so thank you for giving me this opportunity.

(Lee)

7.2 Conclusions

Knowing how to tell one's health story isn't easy. But it's good to do it. ...It's a helpful thing to revisit, and to view one's own journey, and where I'm at, and what I've been through. To remember, and to share, somehow.

(Sharon)

Previous research has identified a need for health stories to be included within patients' medical records in a clinical context (e.g. Teal et al., 2017; Sadler et al., 2017; Health and Social Care Alliance Scotland, 2017), and has also shown the many benefits which care based on storytelling can bring (e.g. Charon, 2006; Mattingly, 2009; Smith and Liehr, 2014). Despite this, there has been little research on how health stories can best be incorporated into digital tools.

In this project, I set out to understand how digital tools can support people with multiple long-term conditions in making sense of and conveying their health stories. I have

also adopted a phenomenological methodology which makes participants' health stories central to the research. These stories evolved over the course of the project through the analysis and fieldwork, culminating in individual prototypes which encapsulate each participant's health story as well as their priorities for a health storytelling tool.

The project findings have been summarised in three parts: potential audiences, goals, and functionality for future health storytelling tools. This shows that people with health conditions desire to share their health stories with others and would like to have a digital tool which would help them with

this. This was confirmed in the final interview, during which all of the participants said that they would use a tool like their final prototype. Several of the participants also asked what would happen to the prototypes and expressed a hope that they would be realised in future.

This project provides a starting point for understanding how digital tools for health storytelling can be designed and implemented in future. Furthermore, this work can inspire conversations on how incorporating health stories into research can create an empathetic, humanistic approach in design for digital health.

8 *Prototyping Image and Text Credits*



8.1 Lee

8.1.1 Workshop 2 Concepts

Feuillet, R.-A. 1701. *Choregraphie, ou, L'art de décrire la dance* 2nd ed. Paris: Gilles Paulus du Mesnil.

Oosterloo, L. 2009. *Grass texture*. [Online]. [Accessed 15 September 2020]. Available from: <https://www.flickr.com/photos/26577588@N06/3811405243>.

8.1.2 Workshop 3 Prototype

Shevtsova, D. 2018. *Baby touching woman's face*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.pexels.com/photo/baby-touching-woman-s-face-1257110/>.

8.2 Rhona

8.2.1 Workshop 2 Concepts

Projekt_Kaffeebart. 2020. *Church door*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.needpix.com/photo/966996/church-door-goal-door-wooden-door-wooden-gate-church-dom-abbey-wood>.

8.2.2 Workshop 3 Prototype

Nuzzenz. 2015. *Night sky*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.flickr.com/photos/75976370@N08/20422190292>.

RF_Studio. 2019. *Portrait photo of a woman*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.pexels.com/photo/portrait-photo-of-woman-3061374/>.

8.3 M

8.3.1 Workshop 2 Concepts

Casa Velas Hotel. 2009. *SPA Ritual Set up*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.flickr.com/photos/38026792@N03/4172938501>.

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<https://www.flickr.com/photos/64401168@N00/7624416272>.

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<https://www.flickr.com/photos/toasty/1125019024/>.

North Charleston. 2010. *Riverfront Park*. [Online]. [Accessed 10 December 2020]. Available from:
<https://www.flickr.com/photos/36686551@N06/4333186302>.

8.3.2 Workshop 3 Prototype

TwinklePowderySnow. 2012. *Coffee stain texture*. [Online]. [Accessed 10 December 2020]. Available from:
<https://www.deviantart.com/twinklepowderysnow/art/Coffee-Stain-Texture-hi-res-321702656>.

8.4 Sharon

8.4.1 Workshop 2 Concepts

Golightly, C. 2014. *Trotternish*. [Online]. [Accessed 18 September 2020]. Available from:
<https://www.flickr.com/photos/90987566@N07/17585435270>.

Romary. 2006. *Elevation lines principle*. [Online]. [Accessed 18 September 2020]. Available from:
https://commons.wikimedia.org/wiki/File:Courbe_niveau.svg.

8.4.2 Workshop 3 Prototype

Meyer, S. 2016. *Sky*. [Online]. [Accessed 10 December 2020]. Available from:
<https://www.flickr.com/photos/135859384@N05/24267866461>.

Morillo, C. 2018. *Woman smiling at the camera*. [Online]. [Accessed 10 December 2020]. Available from:
<https://www.pexels.com/photo/woman-smiling-at-the-camera-1181686/>.

8.5 Tedhead

8.5.1 Workshop 2 Concepts

Bradford, W. 1861. *Shipwreck off Nantucket (Wreck off Nantucket after a storm)*. [Online]. [Accessed 10 December 2020]. Available from: [https://commons.wikimedia.org/wiki/File:Shipwreck_off_Nantucket_\(Wreck_off_Nantucket_after_a_Storm\)_MET_ap1971.192.jpg](https://commons.wikimedia.org/wiki/File:Shipwreck_off_Nantucket_(Wreck_off_Nantucket_after_a_Storm)_MET_ap1971.192.jpg).

Daily Mail. 2012. *The watercolour diaries of a 19th century country gentleman (who preferred keeping a diary of his hunting exploits to work)*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.dailymail.co.uk/news/article-2085661/Solicitor-George-Coopers-diaries-insight-Victorian-life-watercolour-paintings.html>.

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PxHere. 2017. *Old money*. [Online]. [Accessed 10 December 2020]. Available from: <https://pxhere.com/en/photo/1383655>.

8.5.2 Workshop 3 Prototype

Chevanon Photography. 2019. *Old man smiling*. [Online]. [Accessed 10 December 2020]. Available from: <https://www.pexels.com/photo/old-man-smiling-2421934/>.

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