Co-designing a Care Plan Guide app to support early conversations about end-of-life care in dementia

Abstract. Talking about death and end-of-life care (EoLC) can be a sensitive topic for people affected by dementia and their families. However, recent research [1] has identified the need for people living with dementia (PLwD) to start planning timely discussions about their future care to help their family and professional carers to confidently make decisions on their behalf when they are no longer able to do so themselves [2]. This paper describes a five-stage iterative co-design approach aimed at understanding the type and nature of these sensitive discussions and developing a resource to support PLwD, their families and carers. The resource took the form of a Care Plan Guide app, as a tool to help initiate early discussions about anticipatory care planning [3] in dementia for PLwD to ensure good personalized care and that important wishes were honoured. The paper highlights the importance of the involvement and active collaboration of families living with the illness. It discusses lessons learned, reflections and recommendations for approaching co-designing healthcare digital resources for sensitive EoLC issues that may have wider applications than for PLwD.

Keywords: co-design research, patient and families' engagement, prototyping digital resources.

1 Introduction

Today, designing healthcare improvements requires active collaboration. Over the last decade there has been considerable design effort to make a contribution to quality of care and living well by focusing on engaging people in design processes to redesign healthcare services, products and experiences [4, 5, 6]. Engaging people who are living with a health condition is especially important when designing healthcare improvements, as they are the individuals who receive care and treatment in their everyday lives [7].

The SEED (Supporting Excellence in End-of-life care in Dementia) programme, funded by the National Institute for Health Research [8], one of the largest studies of its kind to date, explored how best to enable both service providers and service commissioners to deliver better quality, community-based care to people living with dementia towards the end of life [9, 10]. Findings from a large qualitative study, conducted as a work package within the SEED programme, identified 7 key components which contributed to the provision of good quality end-of-life care in dementia [1] (see Figure 1).

In this paper we describe the co-design approach and present recommendations from the design-led researchers' work package, which formed a work package within the SEED study. These researchers were based in [*Reference to add before submitting final draft*]. We particularly focus on the challenges, benefits and implications of the co-design approach, to address one of these key components, 'timely planning discussions', through the involvement of key stakeholders in the design of digital resources to acknowledge and embody all their needs in the discussion of emotive and challenging scenarios at this stage of life.

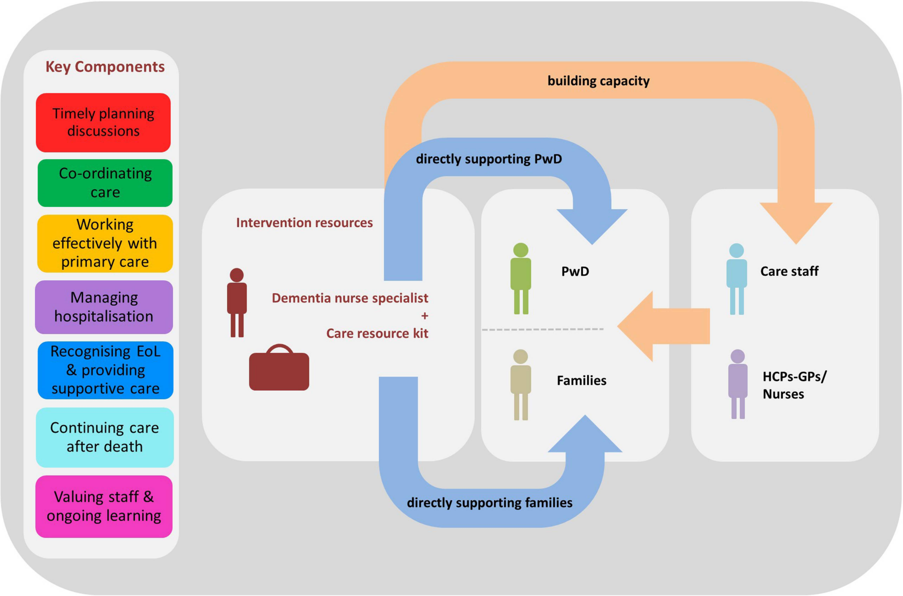


Fig. 1. The SEED intervention.

2 Context: end-of-life care in dementia

Research focused on improving dementia care should involve people living with the illness and their families, in addition to care professionals. Facilitating such engagement with people living with severe dementia is challenging, as their memory and speech deteriorates [11]; in addition, their families may find talking about end-of-life issues upsetting. Regardless, it is particularly important for PLwD to have the opportunity to talk about their wishes and beliefs about their future care whilst they are able to do so to enable their family and professional carers to anticipate care planning and to confidently make decisions on their behalf when they are no longer able to do so themselves [2].

If such discussions, usually called 'advance care planning' by professionals, are to be had, PLwD and their families need to feel confident that their wishes and preferences will be acted upon; this will be assisted by formally recording in writing such discussions and decisions, and sharing this information with healthcare professionals [12]. However, research to date has shown that having such sensitive discussions with people with dementia about planning ahead for future care is difficult; healthcare professionals struggle to find the right time, whilst patients and families may be reluctant to record their wishes in case they change their minds at a later date [13, 14]. There thus appears to be a need for resources and/or tools to help initiate these early discussions about anticipatory care planning in dementia, not only for families living with the illness but also for healthcare professionals [15]. Using the findings from [1], the SEED study developed a dementia nurse-led intervention which was tested in primary care settings [16].

The SEED data also suggested the need for a ‘care resources kit’ targeting the 7 key components in Figure 1, which would help the dementia nurse specialists deliver the intervention, work more effectively with patients and their families and improve the knowledge and skills of the PLwD’s usual healthcare team. This paper now describes in detail how the design-led researchers in the SEED team used a co-design approach to work with PLwD, their families and professional carers, to develop a resource to help initiate and support discussing, making and documenting plans for future care, particularly for end of life (key component 1 of Figure 1) [17]. We call this resource a Care Plan Guide (CPG).

3 A co-design approach to developing a Care Plan Guide app

A co-design approach was seen as integral and, indeed, essential to ensure a meaningful and useful resource was created to support planning end-of-life care for PLwD and their families and to ensure, as far as possible, the views and needs of all stakeholders were equally represented in its design. The concept of co-design *“enables a wide range of people to make a creative contribution in the formulation and solution of a problem. This approach goes beyond consultation by building and deepening equal collaboration between citizens affected by, or attempting to, resolve a particular challenge. A key tenet of co-design is that users, as 'experts' of their own experience, become central to the design process.”* [18, 19].

Ensuring the involvement of all relevant stakeholder groups (PLwD, family carers, paid carers, doctors, nurses, support workers and occupational therapists) was an important aspect of our co-design approach. Our co-design approach comprised two main phases (see Figure 2):

1) Development of an initial prototype of the CPG via internal project workshops with i) the multidisciplinary SEED team which included a patient and public involvement (PPI) representative, and ii) the project’s external PPI advisory group (PPIAG), and
2) Refinement of the prototype through external workshops involving newly recruited participants from the key groups listed above.

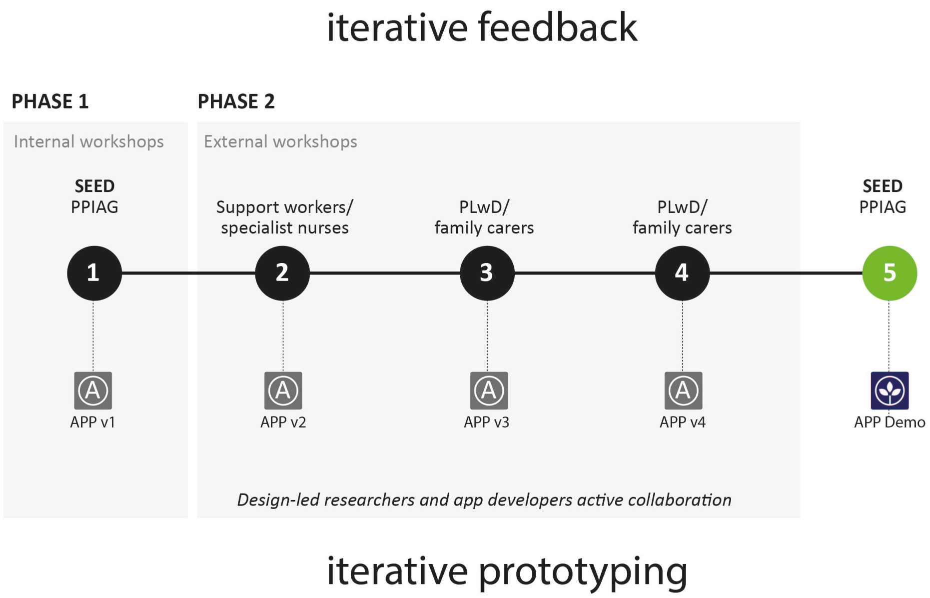


Fig. 2. A co-design approach as an iterative process.

3.1 Phase 1: Determining the content and format

In Phase 1, a paper-based prototype (in the form of a printed booklet) was constructed to take to the PPIAG. This prototype contained the following 5 key planning materials identified from [1] initial scoping research:

1) lasting power of attorney (health & welfare; and property & financial);
2) advance statement;
3) advance decision to refuse treatment (including non-resuscitation);
4) making a will; and
5) funeral planning.

Current resources for each of the above comprise disparate documents, located separately with no overall style, coherence or consistency of accessibility or language. The ambition was to bring these together into a single coherent and unified resource where recorded wishes and progress on decisions could be kept together in a single place. For the initial prototype presented to the PPIAG, each of the above plans comprised an overview, general introduction to each plan, details and links to further information, and a record of progress of – and decisions against – each plan.

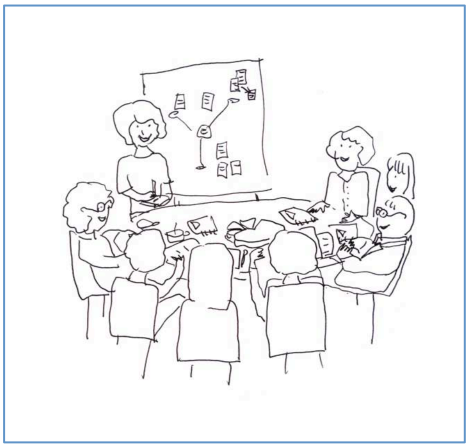
While the concept was welcomed, and a paper-based version was seen as one option, initial feedback from the PPIAG suggested the need also for a digital form of the CPG. The design-led researchers then developed a first stage digital prototype app to be discussed and refined in the subsequent co-design workshops in order to achieve the best prototype to test in care sites.

3.2 Phase 2: Refinement of the prototype

The involvement of key stakeholder groups was organised in an iterative process for collecting feedback and prototype refinement, taking into account all key stakeholders' views on – and requirements for – the development of the CPG prototype app.

In Phase 2, we conducted three external workshops involving people with mild/moderate dementia and their family cares and professional carers (see Figure 2). For workshop 1, a group of professionals (registered nurse and support workers) was recruited from a specially designed community complex with six supported households, which aimed to create a family atmosphere for older people requiring full-time care, including those with dementia. This service was provided by a not-for-profit organization and was characterized by a stable senior management team and a large core workforce. This service had participated in the earlier qualitative work by [1]. Potential participants were identified through the service manager and invited to attend a co-design workshop. Participants in the remaining two groups (workshops 2 and 3) were invited to participate through the support of the project manager at Alzheimer Scotland for Dementia Circle groups, who acted as "gate-keeper" to identify potential participants and introduce the researchers to the groups. Prior to conducting these workshops, the design-led researchers were invited to present the study to the Dementia Circle group members and provide information sheets and criteria for participation. This provided an opportunity for the group to meet the researchers and ask questions regarding the study. Later, group members informed the project manager about their wishes to take part of the study and a day and time was arranged for the researchers to return and conduct the workshops.

These three external co-design workshops (see Figure 2) were held with 20 participants. Workshop 1 comprised 9 participants: 8 support workers and 1 registered nurse; Workshop 2 comprised 7 participants: 2 PLwD, 3 family carers and 2 occupational therapists; and Workshop 3 included 4 participants: 2 family carers and 2 PLwD. The format for each co-design workshop was similar (see Figure 3). Here the aim was to engage participants in collective dialogues to gather their feedback on how the CPG app (as a new resource under development) could be improved.



Specific questions discussed in the workshop included:

- The concept of the CPG
- Content
- Format
- Language
- Medium
- Design
- Title
- Other comments

Fig. 3. The workshop set-up.

In each of the workshops, tablets with the CPG app prototype were made available to participants to interact with and to express their own suggested improvements. Participants were also each asked to complete a workbook questionnaire to capture their individual comments on key aspects of the CPG (see Figure 4). In the preparation of the prototypes, guidelines were referred to for age- and dementia-appropriate design [20, 21, 22].

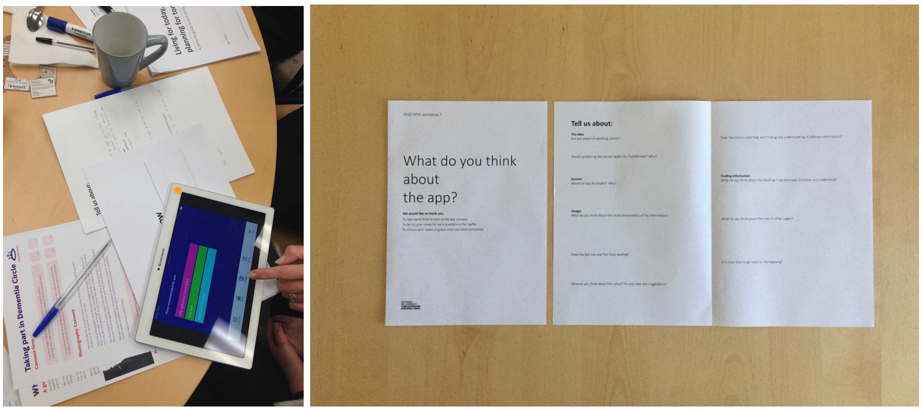


Fig. 4. The mock-up of the CPG app and workbook.

Feedback on the general CPG format (see Figure 5), with its overview, general introduction to each plan, detail and links to further information, with all information kept in a single place together with the record of progress and decisions against each plan, were all seen as helpful. Suggested improvements, such as to the navigation, the way colour was used to differentiate different sections, font size, and arrangement and amount of text, were embodied in further versions of the CPG app for subsequent workshops. The initial use of acronyms and formal legal language were regarded as unhelpful and later revised. Although some individuals in these workshops were unable to use, or were not at ease in using, apps, preferring the printed version, tablet- or phone-based interaction was regarded by the younger generations in the families as convenient, enabling them to make direct links to further web-based resources. Other suggestions included customising the format and text-size and use of voice-command features to enhance usage.

Redefining the CPG prototype also required the active collaboration of app developers and the design-led researchers at the [*Reference to add before submitting final draft*]. Here the researchers were collecting feedback to be shared with app developers in order to collectively reflect about user, technical and care requirements to achieve the best CPG app demonstration.

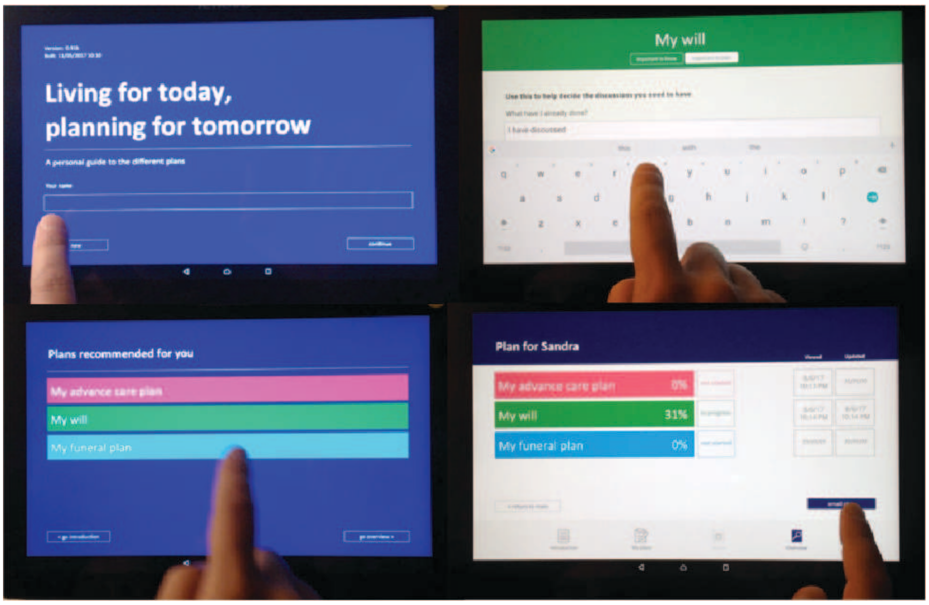


Fig. 5. The CPG app prototype overview, for example, involving a registration page (left side above), a menu page with recommended plans (left side below), a plan page with sections to fill with information (right side above) and the summary page with an overview of the completed plan to validate and send it to family carers/ healthcare professionals by email (right side below).

As the use of the CPG app would involve all stakeholder groups in end-of-life discussions at some point, its development required input from each of these group. Although there was an overlap of interests, each stakeholder group had particular interests typified in Figure 6. For example, PLwD tended to be concerned more with the terminology used (to avoid unfamiliar jargon), legibility, layout and navigation within and between sections. Family carers were more typically concerned with alternative (to paper-based) formats such as websites and apps, to enable more interactive and engaging discussions and to enable access to further web-based resources. The concern of support workers and specialist nurses typically related more to how the resource could best help them to support family carers.

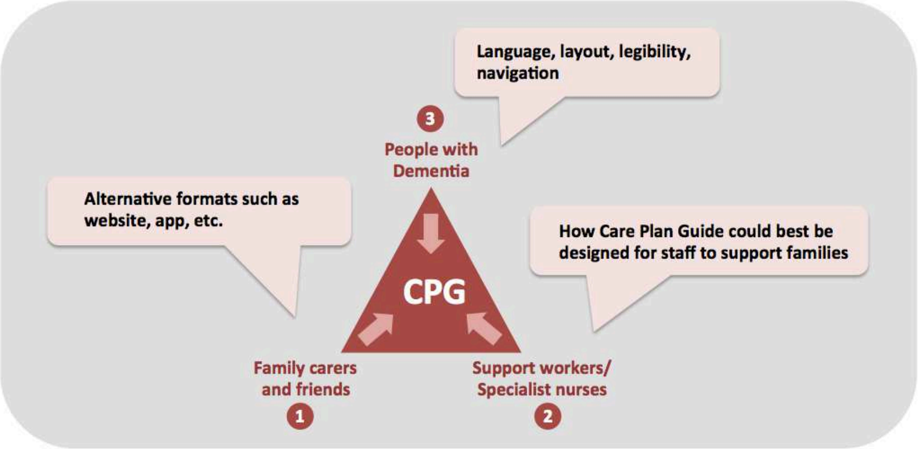


Fig. 6. Focus of feedback from different stakeholder groups.

4 Reflections and recommendations for co-designing healthcare digital resources

In developing new digital resources, the tendency has been for devices to be created by technologists for older people with little reference to the specific requirements of end users [23]. The involvement of PLwD in co-design and co-development approaches has been increasing [24, 25, 26, 27], but is limited in the area of assistive technologies which have the potential to improve quality of life and sustain independence. However, expectations are changing with the realisation that older people can continue to contribute, even when compromised by illness and/or disability. In dementia care, international consensus recently advocated user engagement at all stages of technology development as an extension of the principles of person-centered care [28]. Although our research contributed to the issue of engaging PLwD in co-designing digital resources, a number of practical considerations still remain that make a participatory co-design approach quite challenging. Other priorities in the SEED programme precluded us from trialing the app in a stand-alone form. However, from our experience in this work, we can provide the following conclusions and recommendations.

4.1 Provide time and space to explain unfamiliar technology

Undertaking 'user' research projects for digital resources involving older people presented certain challenges. We had to be adaptable and flexible, as our older participants did not always know much about apps or digital resources. Although apps and digital resources are common in our lives, this does not mean everyone knows enough about them. By the same token, we could not assume that they were not familiar with aspects of digital technology. We found it important to provide the appropriate time and space up front to determine people's level of familiarity with digital technology and to provide more information about apps if required.

4.2 Provide appropriate tools for engagement

Providing tablets with the mock-up of the interactive CPG app helped participants to engage with and to navigate through the content via the user interface. This actively stimulated their thinking and discussion about the redesigning of improvements. The iterative evaluation, by the different stakeholder groups, of the app-based prototypes, helped us identify early not only what was effective, but also what was problematic, and how features could be improved.

Following these three external workshops, the prototype app was brought back and presented to the PPIAG (see Figure 2). This discussion helped identify, distinguish and clarify two separate needs: 1) 'how' to initiate these difficult conversations about timely planning discussions; and 2) 'what' needs to be discussed, decided and recorded, as well as the legality of any documents. The final CPG prototype had addressed the latter, but not the former, highlighting the need for this aspect to be addressed in future work. The varied discussion around the prototype reflected the different degrees of 'comfort' with apps that different generations have with these kinds of digital resources.

4.3 Create a positive experience for exploring sensitive topics

Our observations showed that the co-design process proved to be a positive experience for participants. For example, participants mention at the end of workshops, "it shows that people care about things like that" and "it shows lots of information I didn't know". The project manager of Dementia Circle also mentioned "It was a good step in helping families in a gentle and thoughtful way. We don't talk or think enough about the practicalities of death. We all left the session with good intentions". Despite our concerns and anxiety around the highly sensitive research topic, the most important insight that we gained from this project was the form of active collaboration in the workshops. A more convivial workshop experience was created along the lines of an intimate 'death café' [29, 30] but with a sharper focus on the 5 plans in the app, where discussions could happen while everyone ate cake and drank tea in a calm environment. This stimulated PLwD and their families to create something together. Fundamentally, this demonstrated – through our practice – that we care about people's sensitive and emotional issues and that we appreciated this as an opportunity for mutual learning for both the participants and the researchers. Participants were enthusiastic and indeed welcomed and valued research addressing the sensitive and potentially distressing area of end-of-life and planning ahead for future care. Our model of stakeholder involvement has helped move the discourse from that of designing 'for' to that of designing 'with' [31] its stakeholders in these very sensitive matters around end-of-life care.

4.4 Further application

Overall, participants indicated that the CPG, as a general concept, would not only positively address the intended purpose of facilitating timely planning discussions between PLwD and their families and carers, but would also be helpful for many other individuals needing difficult and sensitive discussions to anticipate appropriate care planning for the end of life. With the current COVID-19 epidemic, it is perhaps timely that these types of discussions are able to be more widely held and the tools to support these are made more appropriate and widely available [32].

ETHICS APPROVAL

Ethical approval was granted by [*Reference to add before submitting final draft*] Research Ethics Committee and research approval from Alzheimer Scotland in February 2017.

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