Participatory Co-design: Approaches to Enable People Living with Challenging Health Conditions to Participate in Design Research

S. Neves, A. Macdonald, M. Poole, and K. Harrison Dening

Abstract People are living longer and are affected by challenging chronic, lifestyle- and age-related conditions such as dementia and stroke. The increasing number of people living with challenging health conditions highlights social concerns and their implications for the successful delivery of healthcare services. Research on improving dementia care [Alzheimer's Disease International (2016) World Alzheimer Report 2016: Improving healthcare for people living with dementia: coverage, quality and costs now and in the future. Alzheimer's Disease International, London] shows a need to involve people living with dementia, their families, and health and social care professionals when designing improvements to their healthcare services. In addition, involving patients recovering from stroke in discussions about rehabilitation services has been considered important to enable making decisions that better address their health care needs [Kristensen HK, Tistad M, Koch LV, Ytterberg C (2016) The importance of patient involvement in stroke rehabilitation. PLOS One 11(6). 10.1371/journal.pone.0157149]. This paper presents two case studies of a participatory co-design approach used to engage people; (a) living with dementia, and (b) recovering from stroke in design research, where co-design-led methods were used to enable participation. The paper describes the importance of each of the roles of—and relationships between—individuals involved in the participatory co-design research process and how people living with challenging health conditions are enabled to participate in a form of three-way relationship. It discusses lessons learned, reflections and recommendations for a new collaborative model

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for people living with challenging health conditions engagement to enable a more equal and reciprocal partnership for participation in design research into healthcare improvements.

Keywords Participatory co-design research · People living with challenging health conditions' engagement · Co-design-led methods

1 Introduction

As a consequence of people living longer, there is increasing prevalence of chronic and age-related diseases, which can lead to people having to live with challenging health conditions (PLwCHC). Lifestyle choices, modifable risk factors and other illnesses can also lead to challenging outcomes, adding to the list of conditions to which people will need to adapt their lives. These health outcomes can invariably be life-changing, so it is important that PLwCHC are involved in the decision-making processes that can affect not only their treatment, recovery, rehabilitation and care, but also their successful adaptation to modified lifestyles. The issues arising from living with challenging health conditions are developed in Sect. 2 below.

Health reports highlight that *"involving patients in making important decisions about their lifestyle or their healthcare improves their experience of healthcare and the quality of their lives"* [3, p. 5]. The recognition of the importance of PLwCHC's actual voice in healthcare research is clearly emerging [1, 2], as only they can provide valuable insights that may be useful to improve future care and living experiences to better meet their needs, derived from their own personal experiences and aspirations [4, 5]. By acknowledging that PLwCHC possess invaluable experiential knowledge and promoting an equal partnership between health and social care professionals (HSCPs), PLwCHC and design researchers, we can enable more equitable participation to include, *"not just those who are already more able, articulate, and socially advantaged"* [6, p. 17]. This allows us to construct a more balanced discourse and bring forth new insights that might otherwise be difficult to achieve. If the experiences and insights of PLwCHC are acknowledged as being fundamental to understanding and developing better care and lifestyle experiences, how can they be better involved in the research and development of these, particularly given that individuals can be living with very challenging conditions? Various models of participatory engagement have been used in healthcare, each with their strengths and weaknesses, and these are discussed in Sect. 3 below.

In Sect. 4, two case studies are used to discuss how particular aspects of a three-way relationship—between PLwCHC, HSCPs and design researchers—were acknowledged and rebalanced using participatory co-design-led methods to better engage PLwCHC in research and to provide new insights that could be used to improve their future experiences. The first was a doctoral study to enhance the patient mealtime experience in stroke rehabilitation [7]. The second was a study concerned with supporting excellence in end-of-life care in dementia [8, 9]. Section 5 reflects on the value of interrogating and rethinking models of participatory engagement, particularly given the challenges of design research and co-designing with PLwCHC. Also discussed is a model that emerged during these two studies which recognised the value of building and supporting a three-way relationship between PLwCHC, HSCPs and design researchers. Recommendations for further work are made in Sect. 6.

2 Issues arising from Mealtime Experience in Stroke Rehabilitation and End-of-Life Care in Dementia

Two challenging health conditions are discussed here: dementia and stroke. The prominence of dementia and stroke highlights social concerns and their implications for the successful delivery of health and care services.

2.1 Context 1: The Mealtime Experience During Stroke Rehabilitation

In the context of stroke, research focused on improving stroke rehabilitation services should involve patients recovering from stroke (PRfS) in decision-making [2]. Engaging PRfS in research is especially important when designing healthcare improvements, as they are the individuals who receive care and treatment in their everyday lives [7]. Facilitating such engagement with PRfS is challenging, as, when a stroke occurs, it requires a series of sometimes life-changing adjustments or adaptations to be made by the individual or family so that s/he can continue to conduct his/her daily life. People recovering from stroke can experience physical weakness and be easily fatigued and may be depressed or have underlying neurological and cognitive conditions [10, 11]. They may have difficulty in articulating thoughts, with speech that might be 'slurred', and with limited movement on one side of their body, due to paralysis and/or weakness [10, 12, 13]. These conditions render them unable to perform everyday routines or make adaptations without someone to help them [14]. In addition, recovering from stroke involves people having either a short or long stay in hospital [15]. In particular, people who present with eating difficulties need a longer hospital stay [16] whilst they are undergoing a process of having to rehabilitate their swallowing function or are (re)learning the everyday, taken-for-granted act of eating. Thus, rehabilitation becomes central to both the survival and recovery of people affected by stroke.

If such a recovery process is to be had, PRfS need to experience mealtimes in hospital every day; this will be assisted by eating dishes with appropriate food textures to rehabilitate their swallowing function, along with assistance in transporting food to the mouth and handling the cutlery during that time [17]. Thus, there is a need to better understand this context of the mealtime in hospital through the patient's perspective. Research has shown that the patient's mealtime experience during stroke rehabilitation is poor [18, 19], which may be demotivating and is a negative factor in influencing recovery. Research from a doctoral study [7] focused on improving the mealtime experience for patients in stroke rehabilitation and contributed to the issue of engaging PRfS in co-designing an improved patient experience. Ideas for an improved mealtime experience were incorporated into a new scenario. This was used, as a design tool, to communicate—to the stroke rehabilitation community—opportunities to enhance the quality of patient experience so as to better address patients' needs and aspirations. This is described in detail in Sect. 4.1 below.

2.2 Context 2: End-of-Life Care for People Living with Dementia

Recent research focusing on improving end-of-life care in dementia [20] has identified the need for people living with dementia (PLwD) to start planning timely discussions about their future care to help their family and professionals to confidently make decisions on their behalf that are aligned with their wishes and preferences when they are no longer able to do so themselves [21]. Research focused on improving dementia care should involve people living with the condition, and their families, in addition to care professionals. Facilitating such engagement with people living with advanced dementia is challenging, as their memory, speech, recall and word sequencing deteriorates [22]; in addition, talking about death and end-of-life care (EoLC) can be a sensitive topic for their families. Regardless, it is particularly important for PLwD to have the opportunity to talk about their wishes and beliefs regarding future care whilst they are able to do so. If such discussions 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 health and social care professionals [23]. However, research to date has shown that having such sensitive discussions with PLwD about planning ahead for future care is difficult; healthcare professionals struggle to find the right time, whilst the person and their families may be reluctant to record their wishes in case they change their minds at a later date [24, 25]. There thus appears to be a need for resources and/or tools to help initiate these early anticipatory care planning discussions, not only for families living with the condition, but also for healthcare professionals [26]. In the SEED programme [8], our research contributed to the issue of engaging PLwD in co-designing digital resources to address these issues. This took the form of a Care Plan Guide app, as a tool to help initiate early discussions about anticipatory care planning [27] for PLwD to ensure good personalized care and that important wishes were honoured. The approach and process are described in detail in Sect. 4.2 below.

3 Models of Participatory Engagement used in Healthcare

Evidence shows that members of the wider public and patients, when they are involved in research, can make a difference in healthcare decision-making processes [28]. This raises the question of how to approach the design of participatory engagement. An understanding of strategies for patients' involvement [29] can have different results on the healthcare system, depending on the purpose of the research. For example: (1) conducting research *with* rather than *on* patients can result in researchers obtaining a better understanding by placing a focus on ensuring that data are collected appropriately; (2) involving a wider range of stakeholders can result in obtaining a wider understanding from different perspectives about the matter in discussion; (3) adopting a patient-led approach can help to identify health priorities for change; and (4) encouraging patient participation can help to develop new levels of knowledge and consequently help patients obtain a better understanding of the outcomes achieved [29, p.195]. Various models of engagement and participation have been developed in healthcare, such as those by Savory, Arnstein [30] and NEF [31]. Arnstein's was the influence for the more recent NEF model, using the analogy of a 'ladder' showing the possible modes of participation from passive coercion to active co-production (Fig. 1).

Over the last two decades, a number of participatory design (PD) models have also been described to actively consider when working on new methods for healthcare improvements [5, 6, 32, 33]. These models had the objective of creating conditions for involving collaboration as a way to drive innovation in healthcare. In seeking collaboration, these models focus on co-creation, co-production and experience-based co-design. However, a recent review of public and patient involvement (PPI) models [34] concluded these were still too narrow, often tokenistic, not acknowledging equality and diversity. What they suggest is *"the adoption of models and*

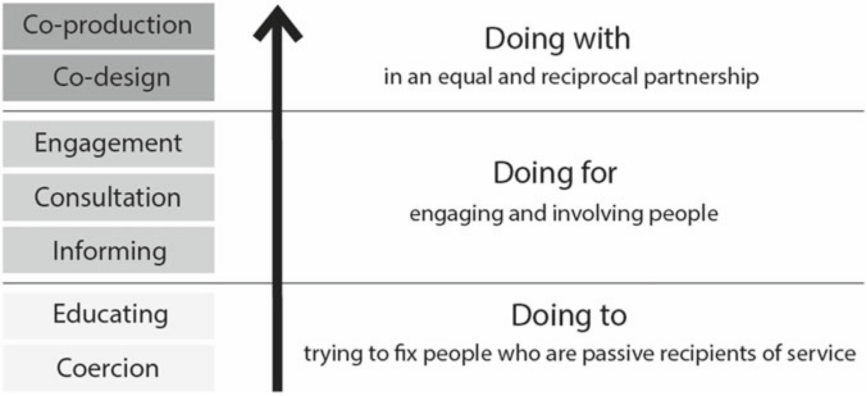

Fig. 1 The shifting nature of engagement (Adapted from: New Economics Foundation (2014) Commissioning for outcomes and co-production. A new model for commissioning public services.)

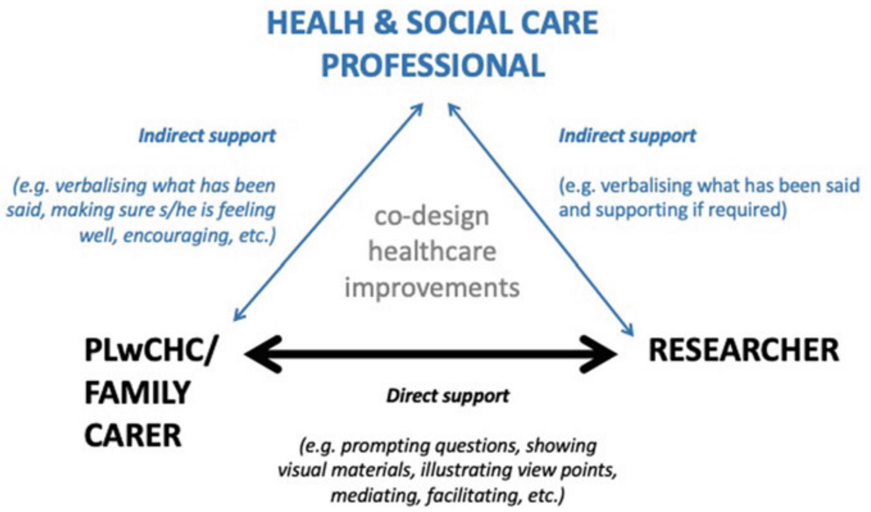

Fig. 2 A participatory design model that brings a conceptual three-way relationship to enable PLwCHC, HSCPs and design researchers to work together in a more equitable partnership in research into the improvements of healthcare

frameworks that enable power and decision-making to be shared more equitably with patients and the public in designing, planning and co-producing healthcare" [34, p. 626]. In fact, participatory design models are increasingly being adapted as a way of engaging people with a variety of health conditions [35–40]. The shortcoming of these adapted models is that PLwCHC can be at a disadvantage due to their modified capabilities as a consequence of a health condition. Think, for example, how PLwCHC can experience physical weakness and be easily fatigued or have difficulty articulating their thoughts. A participatory design model, using a conceptual three-way relationship (see Fig. 2) between PLwCHC, HSCPs and design researchers, can enable a more equable participation which goes beyond a single tool to support patients who have difficulties with speaking [41], in adapting methods to suit each individual [37] and personalizing [36] and supporting their creative tasks [42]. As highlighted in Sect. 2, the impacts that stroke and dementia have on an individual's functionality reveal people who may be highly dependent on health and social care professionals and/or their families, both for understanding what they are trying to say, and in performing physical activities [43]. Having health and social care professionals work alongside design researchers is essential in this area of research, due to the designer's lack of clinical knowledge. A question arises about whether HSCPs' voices might dominate those of the PLwCHC when working together in co-design activities. How do we use co-design-led methods to rebalance dialogues to better represent PLwCHC, while encouraging health and social care professionals to play more of an assisting role for both the PLwCHC and the design researcher? In the following section, we will show how this conceptual three-way relationship emerged through reflections on Case Study 1—exploring future possibilities at mealtime experience in stroke rehabilitation and then was used more consciously in Case Study 2—co-designing a Care Plan Guide app to support early conversations about end-of-life care in dementia.

4 A Three-Way Relationship in Co-design

4.1 Case study 1: Exploring Future Possibilities at Mealtime Experience in Stroke Rehabilitation

This research study was developed in collaboration with a hospital stroke rehabilitation unit (SRU) within the National Health Service Scotland. Rehabilitation following acute treatment is an important component of the continuum of care [44, p. 47]. Stroke patients can remain in an SRU for several weeks [15]; rehabilitation in hospital is crucial in restoring patients' functionality to allow them to recover as much as possible before returning home.

The project information sheet was required to follow the UK's National Research Ethics Service (NRES) governance requirement for community care research in the UK, thus the design researcher was required to understand and use appropriate medical language in order to make informative and constructive proposals that made sense to the healthcare community. An ethics application was submitted to NRES and was granted. In this, the criteria for recruitment were clearly defined—people who: had a clinical diagnosis of stroke; were outpatients at the SRU but were still undergoing the recovery process at home and/or were in day-hospital-based care; had experience of the mealtime element of stroke rehabilitation in their stay in hospital; and who presented of a variety of stroke-related difficulties at mealtimes. Potential participants were identified through the Stroke Manager, by initially approaching those nurses who support patients in their own homes after discharge from hospital and utilising their knowledge and experience to determine who would be interested in participating. Three women and two men were invited. Although they all had participated in the previous stages of the research, just three patients attended on the day of the co-design workshop. The reasons two did not appear were not revealed. Stroebe, Stroebe and Schut [45, p. 238] report that this seems to happen often when working with patients, which is problematic for research: *"because they fear that this might increase their grief"* or *"because they have "got over it", and do not want to look back"*. Conversely, this group of PRfS may have been perfectly happy to participate on a one-to-one basis in their homes, but may have struggled to cope in a group, due to their conditions, particularly when required to interact in social situations [46]. However, the three patients who did attend the workshop had a sufficiently varying range of capabilities and mealtime experiences to meet our objectives, i.e., not only those who were more able to participate [6], but also those who possessed the key characteristics of the inclusion criteria for the specific population being studied

[47]. The figure below (see Table 1) provides details about PRfS participating in the co-design workshop, illustrating their characteristics.

Before we start to demonstrate how this workshop was developed, it is important to explain how this socialised and materialised situation was created to support and promote a collective dialogue (see Fig. 3). Two nurses attended the workshop in order to indirectly support communication and assist PRfS with any health situation if required. Two design students at the Glasgow School of Art also attended this workshop to help visually illustrate the PRfS's voices throughout the workshop. Structuring this workshop was based on the idea of 'design-by-playing' as a way to encourage participants to express their ideas in different ways.

Ensuring that PRfS' capabilities were supported was fundamental to allowing nurses to be involved in design research. Here, nurses were involved for a specific role: to assist PRfS in verbalising during participatory work. Some participants were

Table 1 The PRfS who participated in the workshop

PRfS	Time in hospital at time of interview (in weeks)	Stroke conditions	Age	Gender
P1	15	Swallowing difficulties Cannot speak Cannot walk	66	Woman
P2	15	Swallowing difficulties Cannot get up out of bed	52	Man
P4	5	Swallowing difficulties Weakness on one side	75	Man

Fig. 3 The environmental overview of the workshop conducted with patients, involving the researcher (R), two nurses (N), three PRfS (P), two design students as facilitators (F) and a participant's relative as assistant (Family)

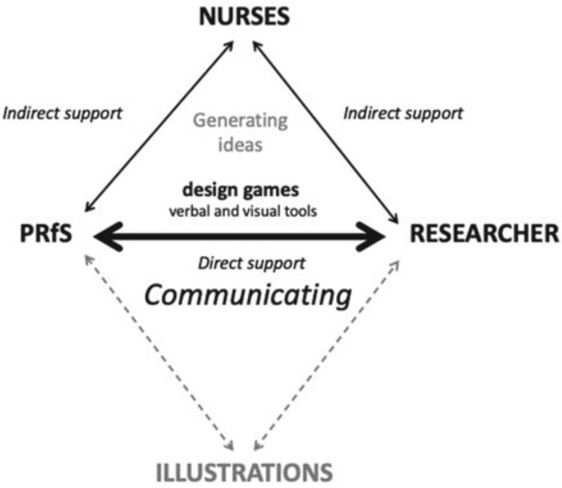

Fig. 4 The conceptual three-way relationship showing: the nurse indirectly supporting communication between the PRfS and the researcher (e.g., by verbalising what the patient said to clarify any issue to the researcher or simply helping PRfS to verbally express what he/she was saying); the researcher directly mediating a conversation with PRfS (e.g., prompting questions, encouraging participation), PRfS (e.g., sharing views, ideas, experiences), tools (e.g., game boards, colour cards, etc.) and illustrators (e.g., illustrating PRfS's views on game boards on the wall to allow everyone see what we were doing together)

unable to speak, having to use an iPad to communicate, while others had difficulties verbalising their views due to a 'dribbling mouth', giving the design researcher some difficulties in understanding clearly what they were saying. Here the nurse brought into play their knowledge about patients. This underlines the issue of trust: the PRfS, hearing the nurse's verbalising of their contribution, was important in allowing PRfS to witness and verify her/his response instead of this just being the nurse's own opinion or view.

How to best to engage PRfS in this study was enhanced by using a conceptual model to acknowledge the three-way relationship (see Fig. 4) between nurses, PRfS and the design researcher during a workshop to co-design an improved mealtime experience (over that described in Sect. 2.1 above).

Given the assistance that PRfS would require, we were aware that involving a nurse could inhibit PRfS being open with their views. To address this issue, co-design-led methods were selected and materials were designed to support communication and promote rich dialogues between PRfS and the design researcher. The methods involved *"exploratory design games"* [48] to facilitate participation. 'Games' in the sense used here are not competitive but exploratory in nature, centred on structuring participatory co-design activities through play as a performative design activity of 'design-by-playing' [49–51]. Instead of putting an emphasis on participants competing to win a game, these games involve pieces, boards and rules to encourage people to express their thoughts meaningfully, and to help create a common

Fig. 5 Tools developed showing a storyboard (top) to map patients' ideas about the mealtimes throughout three stages—before, during and after the mealtime—under four themes: sensorial, physical, social, and emotional (colour cards on the left side below), and the format of the workshop while playing the mapping game (right-hand bottom illustration)

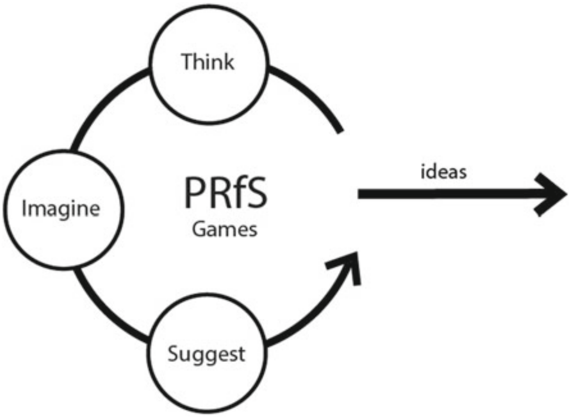

Fig. 6 The workshop set-up with PRfS acting in a game that connects thinking (what if), imagining (the magical situation) and suggesting (what would make a significant difference at mealtimes) to explore ideas

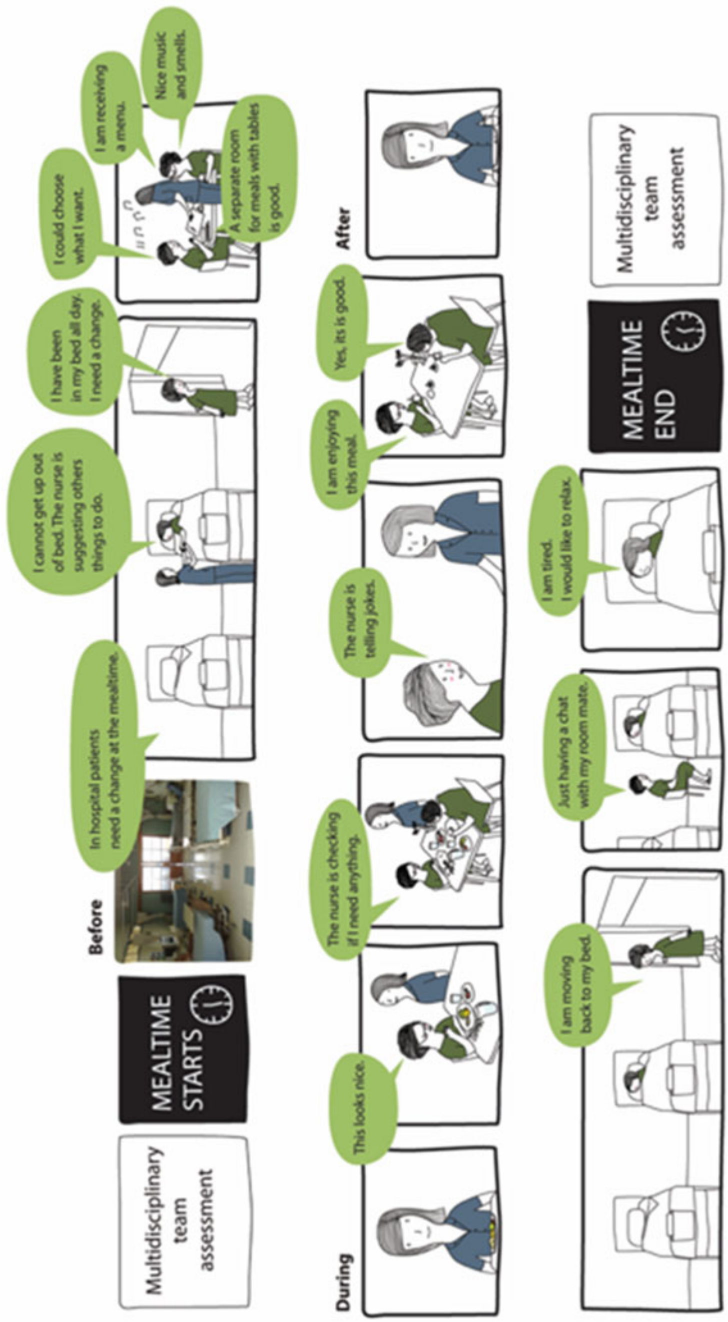

Fig. 7 Building the mealtime scenario based on PRfS' ideas for improved mealtime experiences

language (see Fig. 5). Here, PRfS were not asked to perform physical tasks, such as making artefacts to evoke ideas [52, 53], as this would be too challenging for them. Instead, there was a need to involve PRfS in 'playfulness' experiences [50] that supported and encouraged their participation in the creative dialogues, through a more convivial approach. The aim of designing games emerged to evoke PRfS' thoughts, but the attempt at playing games created an active and supportive dialogue for PRfS, revealing both verbal and visual components. This also allowed PRfS to see—collectively—what they were saying. In particular, it provided patients with a sense of being part of something to bring about change in future experiences.

This workshop was designed with the important point of collecting ideas from the PRfS and then using these ideas to generate creative directions to build a new mealtime scenario concept. In doing so, the workshop with PRfS entailed 'games' to connect thinking, imagining and suggesting (see Fig. 6).

This was seen as a research process that allowed continuing exploration of the PRfS' ideas within three stages of the mealtime experience (before, during and after) from three different ways of thinking: (1) what if?; (2) the magical situation; and (3) mapping what would be significant to change in the future [7]. The first game was focused on stimulating the patients' reflections about designing. By prompting a question as a game piece, "What if the mealtime experience was created by your favourite chef? How would s/he create it for the patient?" The intention was to invite PRfS to change their position of expertise, as a way of inspiring participants to express ideas. The second game aimed to evoking PRfS' desires and aspirations. Here the word 'magical' was used in the sense of exploring what is unknown. The idea was to obtain a better understanding of what the most delightful and enjoyable experiences would be like. The third game was focused on encouraging participants to think about what can be done to improve the mealtime for patients undergoing stroke rehabilitation in hospital. In exploring this idea of what can be done, a mealtime storyboard was created to invite PRfS to suggest ideas of what should be done. This helped open up a discussion around improving key aspects, e.g., space, atmosphere, food menu, and key social interactions. In doing so, this also helped the design researcher to start building an improved mealtime scenario (see Fig. 7) based on the PRfS' contributions, facilitated through outcomes devised from the games' activities.

4.2 Case study 2: Co-designing a Care Plan Guide App to Support Early Conversation about End-of-Life Care in Dementia

This study (2) was part of the larger SEED study [8] involving a co-design process (see Fig. 8) with a range of relevant stakeholder groups [9] to co-develop a Care Plan Guide app as a tool to help initiate early anticipatory care planning discussions (over that described in Sect. 2.2 above). Engaging PLwD in this co-design process required the support of Alzheimer Scotland (AS). Alzheimer Scotland provides local support to help people and their families live with dementia [54]. Engaging PLwD in this research required following both the Glasgow School of Art Ethics Policy and Alzheimer Scotland Ethics requirements. An ethical application was submitted to the Glasgow School of Art and AS and both were granted. In this, the criteria for recruitment were clearly defined; people who: were living with mild/moderate dementia and/or family, relatives, friends with experience in dementia. Potential participants were identified through the project manager at Alzheimer Scotland for Dementia Circle, by initially approaching those dementia groups in their communities and utilising their knowledge and experience to determine who would be interested in participating. Two local groups, A and B, at Alzheimer Scotland for Dementia Circle were invited. From the local group A, 2 PLwD, 3 family carers and 2 occupational therapists working with PLwD attended on the day of the co-design workshop 3. From the local group B, 2 PLwD and 2 family carers attended on the day of the co-design workshop 4.

Engaging PLwD and their family carers in design research was developed by using, again, the three-way relationship model (see Fig. 9), this time between the project manager at Alzheimer Scotland for Dementia Circle, PLwD/family carers and the design researcher in the two workshops (3 and 4) to co-develop the digital Care Plan Guide (CPG) prototype app.

In this Case Study (2), the format of the workshops (see Fig. 8, workshops 3 and 4) were similar (see Fig. 10). The project manager at Alzheimer Scotland's Dementia

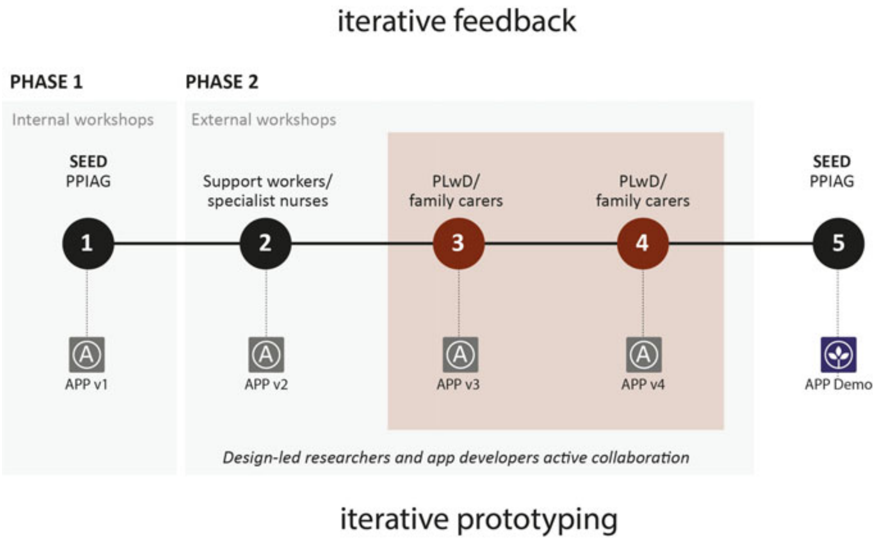

Fig. 8 The co-design approach as an iterative process. Our co-design approach comprised two main phases: (1) development of inicial prototype via internal workshops with (i) the multidisciplinary SEED team which included a patient and public involvement (PPI) representative, and (ii) the project's external PPI advisory group (PPIAG) and (iii) external workshops involving PLwD and family carers at Alzheimer Scotland for Dementia Circle

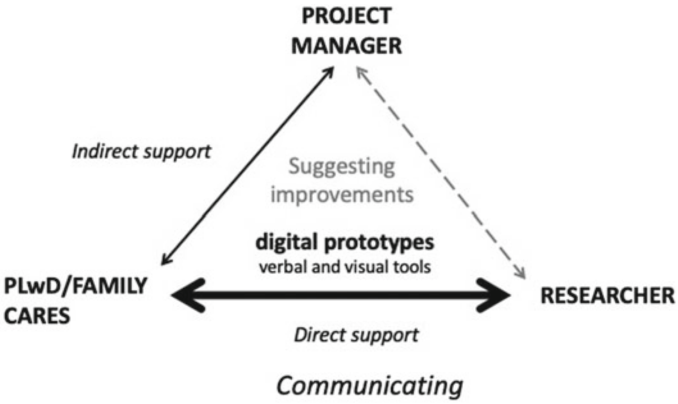

Fig. 9 The three-way relationship, as a model, showing how the project manager indirectly supports communication (e.g., encouraging by talking with PLwD or by writing down what the person wants to say but is too timid to do so). The design researcher supports direct communication with PLwD and their family carers (e.g., prompting questions, encouraging by talking about their participation, illustrating their views on a map on the wall, mediating their conversation, facilitating any issue emerging at the time). PLwD and their family carers are actively participating in the dialogue (e.g., sharing views, ideas, opinions and experiences) and digital prototypes (e.g., tables with CPG prototype app installed) as interactive objects to allow everyone experiment and have a say about it

Circle attended both workshops in order to indirectly encourage individual participation. Here, the environmental arrangements were similar to case study 1, however, structuring these two workshops were based on this idea of testing, discussing and refining the first stages of the CPG digital prototype app from the PLwD and their family carers' perspectives and opinions, and then using their feedback to make improvements to build the best possible CPG prototype app.

We were aware that talking about 'death' and 'end-of-life care' would be a difficult and sensitive topic for the participants and that some participants may not be comfortable talking about it straight away with a 'stranger'. As in the previous Case Study (1), we also considered it important to involve the project manager at AS to work alongside the design researcher and PLwD/family carers in the two workshops. Here the project manager was involved for a specific role: introducing the researcher to the groups before the workshops actually began to allow them to become familiar with the purpose of the study, and during the workshops to stimulate participants to express their views, as she had worked with the groups and knew their anxieties and life stories. Some participants were comfortable in talking about and expressing their opinions, while others were timid, or, perhaps, had some difficulties in talking about these sensitive issues, so having someone familiar alongside them was important to generate trust and confidence. Although we applied the model of the conceptual three-way relationship that emerged in the previous Case Study (1) (Fig. 4), in this Case Study (2), the model required some adaptations (see Fig. 9). For example, the project manager had a different role and the methods used had a different purpose. In

Fig. 10 The environment overview of workshops 3 and 4 conducted with PLwD/Family carers, involving the design researcher, the project manager at Alzheimer Scotland's Dementia Circle, and the participants

Case Study 1, the aim of involving nurses was to support PRfS to verbalise their ideas and wellbeing. In Case Study 2, the aim of involving the project manager was to allow PLwD to feel comfortable talking about sensitive issues such as 'death' and 'end-of-life care'. The tools used in Case Study 1 were designed to encourage thinking and create a convivial and visual experience while conversations were happening. Here, PLwD/family carers were asked to interact with tablets with the prototype of the Care Plan Guide (CPG) installed to enable the participants to navigate through the content of each screen and to express their own suggested improvements (see Fig. 11). The aim of involving digital prototypes such as an app in the workshops was to create an iterative dialogue. In addition, a workbook questionnaire was also provided to capture individual comments on key aspects of the CPG, e.g., content, format, language, medium, design and title.

Feedback on the general CPG format (see Fig. 12), with its overview, general introduction to each plan, details 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 the navigation, the

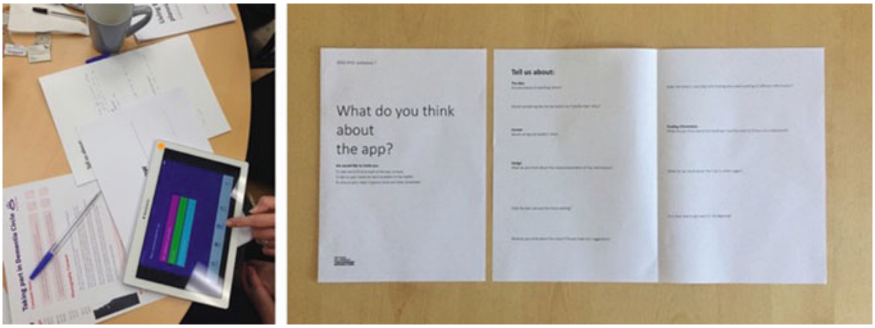

Fig. 11 The mock-up of the CPG app and workbook

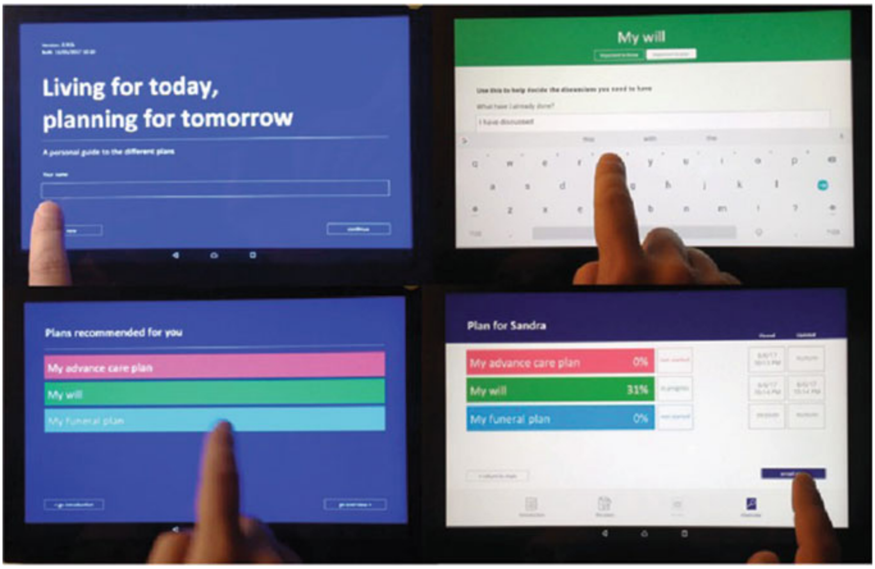

Fig. 12 Sample CPG app prototype screens showing the registration page (left side top), a menu page with recommended plans (left side below), a plan page with sections to fill with information (right side top) and the summary page with an overview of the completed plan to validate and send it to family carers/healthcare professionals by email (right-hand bottom image)

way in which colour was used to differentiate different sections, the font size, and the arrangement and amount 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 were 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 smartphone-based interaction was regarded by the younger generations in the families as being convenient, enabling them to make direct links to further web-based command features to enhance usage.

Feedback from PLwD and their family carers helped the design researchers, in collaboration with the GSA's app developers, to continue redefining the CPG prototype app based on improvements required and to collectively reflect with them on the best CPG app configurations to achieve optimum user, technical and care requirements.

5 Discussion and Reflection on the Outcomes

Involving people having to live with challenging health conditions in research, such as those in Case Study 1 affected by stroke, or those in Case Study 2 living with dementia, requires a sensitive approach, recognizing not only the disability, but also empowering and supporting capability. Within the context of healthcare, there has been a lack of conceptual clarity about how to better enhance and support PLwCHC to make a more equable contribution in these types of multi-participant design research activities. Approaches to participation seem often to reflect more on the perspectives of healthcare providers [55], and repeated calls advocate for the meaningful engagement of PPI in research [29] to improve healthcare [34]. Indeed, there has been a discernible shift in PPI thinking from 'doing to', through 'doing for' to 'doing with' people, i.e., from 'coercion' to 'co-design' 'and co-production' [31].

Participatory design (PD) values are based on: giving democratic voice and agency to people; the growing emphasis on the social and material network of stakeholders; putting people and tools together in interacting to design for change; and designing for and with people, because this is seen as being a source of valuable information to create new services and experiences. Despite the progress of PD models in healthcare contexts, PPI in healthcare improvements is still limited [5, 6, 32, 33]. Recent observations highlight that engagement approaches and methods are largely focused *"on inputs, activities and processes (the methods of gathering data, how to capture views,* etc.*) over impact and outcomes"* [56, p.22]. However, the value of the direct participation of PLwCHC can be wider reaching in design research.

Based on our experience of developing a three-way relationship with HSCPs, PLwCHC and design researchers, we came to the same line of thinking as Cottam [57]. Here, the three-way relationship, as a model, suggests creating capability to support PLwCHCs' individual ability to collaborate. The benefit of this model is that allows connections to be created and communities to work together to create change.

In Case Study 1, when looking at the impacts of stroke on people, it became clear to us that the participatory co-design approach would require particular attention because of the conditions and vulnerability of the kind of people with whom we would be working and the settings in which they are located. Thus, this combination of a three-way relationship with nurses, PRfS and the design researcher and the use of co-design-led methods helped to support individuals' capabilities to enable the engagement of these people in the research. In fact, the co-design-led methods used, such as the 'games' we developed, created a space for this socio-material assemblage to be enacted, thereby changing the dynamics of constructing conversations by allowing new forms of information to be mobilised. Think, for example, how combining visual (storyboards, games) and verbal (prompt questions, voices for verbalisation) components helped to develop ‘communicative artefacts’ (scenarios) which operate as a vehicle for communication within the healthcare setting. Instead of focusing on using a single tool to support patients with difficulties in speaking [41], we demonstrated the value of multiple adaptable tools to support participants with a range of difficulties in the conversations by providing a more convivial experience for them. This changed the perception of PRfS from that of one who is passive, in recovery, to one who has sufficient agency to suggest how to improve the quality of the healthcare experience, in this case, the mealtime experience. Fundamentally, involving this particular group in co-design required new ways of thinking about the set-up of activities in order to support patients’ well-being rather than influencing feelings of embarrassment [46].

5.1 Issues to Consider in Co-design

Formatting dialogues by using *“exploratory design games”* [48] created opportunities to stimulate PRfS’ discussions in different ways, such as playing what if and imagining. However, playing games brought some challenges; while playing the second game, the magical situation, one participant felt the need to stop for some fresh air. The nurse mediated, and the researcher paused the workshop for 10 min, restarting after checking that all participants felt well enough to continue, when the game returned to ‘play’ mode. What seems to emerge here is that it is not enough only for researchers and designers to adapt methods and strategies to each individual in design practices [37], but also that they need to become mediators [58] and to be adept at dealing with unexpected situations to ensure well-being. This leads us to reflect on the complexity of designing participatory activities in healthcare-related design research, revealing the need to rethink ways of capturing and sharing information, and demonstrating the value of providing materials and situations to involve mediators (here these were the nurses and the design researcher) with different expertise and knowledge types to re-frame a social and material practice to support PRfS in creative dialogues.

In addition, using games revealed some challenges in getting PRfS engaged in this idea of ‘thinking about the future’. For example, in playing ‘the magical situation’, PRfS revealed their thoughts about things that had happened in the past, rather than describing more imaginative, projected thoughts about what would be more desirable for the future, perhaps highlighting the issue of uncertainty within patients’ confidence about their future, or that ‘future thinking’ is a way of thinking that is very familiar to designers, but perhaps unfamiliar to many other people, particularly when they are concerned about their current health. Their concerns about the future might be quite different to those of the researcher’s: the issue is one of how to bring together the people's agenda with the researcher's enquiry and to help them understand what might be mutually important and why.

5.2 Steps to Consider when Co-designing 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 [59]. The involvement of PLwD in co-design and co-development approaches has been increasing [60–63], but is limited in the area of assistive technologies that have the potential to improve quality of life and sustain independence. However, expectations are changing with the realization 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-centred care [64]. Although the three-way relationship 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.

Based on our experience in Case Study 2, undertaking 'user' research projects for digital resources involving older people required being adaptable and flexible, as our older participants did not always know much about apps or digital resources. We found it to be important to provide time and space up front to determine people's level of familiarity with digital technology and to provide more information about apps if required. In addition, we found it important to provide tablets with mock-up of the interactive CPG app, as it helped participants to engage and to navigate through the content via the user interface. This actively stimulated their thinking and discussion about the redesigning of improvements. Our observations showed that the co-design process proved to be a positive experience for participants. For example, participants mention at the end of the 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' [65, 66], but with the sharper focus on the five plans in the app, where discussions could happen while everyone ate cake and drank tea in a calm environment. This demonstrated—through our practices—that we care about people's sensitive and emotional issues and that we appreciate this as an opportunity for mutual learning, for both participants and the researchers. The three-way relationship, as a model, has helped drive the discourse in these very sensitive matters around end-of-life care.

6 Conclusion and Recommendations

Enhancing experiences and developing digital resources and services around the complexities of healthcare contexts, such as for stroke rehabilitation for PRfS and end-of-life care for PLwD, with all the accompanying issues of sensitive data, and ethical and usability issues, presents a considerable challenge. The central ambition of this chapter has been to demonstrate the value of this three-way relationship, as a model that entails an effort to enable, encourage and motivate the participation of PLwCHC in design research in the context of stroke rehabilitation and dementia care. Rather than presenting our work as a new methods approach, our new collaborative model served to enable the PLwCHC to participate in a more equal and reciprocal partnership in suggesting and designing healthcare improvements. Overall, a partnership between HSCPs and design researchers, as a general concept, would not only positively address the intended purpose of supporting individual capabilities, but would also be helpful to build a new practice that bring a range of skills to work together. Having developed the three-way model in stroke and dementia contexts, we feel that the model is very flexible and certainly benefit other design practices to involve other people with similar needs. According to our experience, there are at least two aspects of the model that make it suitable for additional forms of public engagement: (1) it combines multi-professional agencies to strengthen individual capability to collaborate; and (2) it allows an exploration of techniques and tools to support communication, so it makes it possible to access a diversity of information based on individual needs and experiences. With the current COVID-19 epidemic, it is perhaps timely that new forms of participatory engagement are available to be used more widely to foster partnerships between people with a range of skills, experience and perspectives to engage and make shared decisions about the future of healthcare.

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