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Co-designing resources for knowledge-Based self-reflection for people living with Parkinson's disease to better enable independent living

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Co-designing resources for knowledge-based self-reflection for people living with Parkinson's disease to better enable independent living

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Abstract. Parkinson's disease (PD) is a complex progressive neurodegenerative disease. Individuals experience PD in a variety of ways, leading to difficulty in diagnosis, acceptance and on-going management. Service provision is complex and varied depending on provider, often with a lack of 'joined up' provision between acute hospital care and community care.

This project utilised a participatory design methodology to identify patient and provider needs for PD services in the South West Peninsula (UK). A co-design approach was then used to develop tools, resources and service structures to meet these needs.

The application of co-design in healthcare settings is fraught by challenges of power dynamics between healthcare professionals and 'patients'. This can create difficulties in eliciting the 'voice' of the patient, or in facilitating their genuine engagement or agency in the process. Specific features of our co-design process sought to address these issues.

The tools and resources resulting from this process aimed to facilitate independent living for people with PD, yet importantly to enable them to do so from an informed position, understanding complex medical knowledge in the context of their own personal life and priorities. As such, the resources intended to facilitate both the mobilisation of complex knowledge and self-reflection.
The final resource pack has recently entered a feasibility trial of 150 people living with PD.

1 Background

Parkinson's disease is the second most common neurodegenerative disorder. It is caused by death of nerve cells in the brain, primarily those producing the neurotransmitter dopamine, although other neurotransmitter systems are also affected [1]. The main symptoms of Parkinson's are related to movement (motor symptoms): slowness (bradykinesia), stiffness (rigidity) and shaking (tremor). Other aspects of movement, such as balance, speech and swallowing, are also affected. In addition to these movement related symptoms, people with Parkinson's also experience non-motor symptoms [2]. These include problems with thinking and memory, mood, bladder and bowel function, sleep and blood pressure control. The symptoms of Parkinson's vary greatly between individuals as well as with disease duration.

This individualised experience leads to difficulty in diagnosis, acceptance and on-going management. There is currently no cure for Parkinson's. Symptoms are managed through a combination of drugs and lifestyle (i.e. exercise, diet, sleep hygiene), with input from different healthcare professionals such as: Speech and Language Therapists, Dietitians, Occupational Therapists, Physiotherapists, Parkinson's Nurse Specialists and Parkinson's Specialist Consultants [3].

Drug management is complex and gets more complex with each passing year. Dosage and frequency of doses is unique to each individual and has to be empirically determined. Consultants set a 'titration' process, where dose and frequency are iteratively increased by the patient based on guidance from the consultant, until motor symptoms are optimally balanced against any side effects of the medication [3].

The provision of Parkinson's services is complex and varied. Services in the South West Peninsula cover acute and community settings, cross multiple regional and budgetary boundaries, a large geographical and rural area and have staffing pressures from unfulfilled roles, long-term sick-leave and increased patient numbers. Current provision following diagnosis is modelled on standard time-locked (usually six monthly but can be up to 2 years due to service pressures) clinic reviews that fail to meet the evolving needs of patients and their carers, and contributes to staff stress. Patients often travel long distances to attend these reviews that are often conducted by doctors who are not Parkinson's specialists, meaning the broad spectrum of disease manifestation is not explored in the consultation, resulting in problems not being identified or treated. Additionally, these reviews often do not result in any change in management.

The lead consultant for PD services in Plymouth had a vision of creating a more "joined up" service that supported people with PD when they needed support, but also enabled them to live their lives as 'normally' as possible. She reached out to the team at Lab4Living to initiate a co-design process giving them complete autonomy over planning and delivering the co-design process, securing an unrestricted educational grant from a pharmaceutical company to support the initiative.

2 Method

2.1 Participants

The participants included: People living with Parkinson's and their families and carers, Parkinson's Specialist Nurses, Community care teams, Therapy Specialists, Consultant Neurologists, Finance officer, a Primary Care physician, Parkinson's Charity representatives and representatives of local health services research groups from Exeter University and Plymouth University.

2.2 Guiding principles of co-design

Within all the co-design work and collaborative work with participants, we followed a key set of principles. These were:

- Valuing different perspectives
- Adapting co-design methods and tools to the needs of the group or individuals
- Visibility and transparency
- Valuing different forms of knowledge
- Less talking, more doing

More detailed information describing these principles and how they are practically deployed can be found in Langley et al. [4]. The way that these principles are enacted within a co-design workshop is through the use of visual- and design practice-based activities (i.e. creative activities or making mock-ups). In order to build participants' confidence with each type of activity, the skills involved are always 'practised' by setting a quick, 'throwaway' task on a trivial topic first, before asking participants to use the activity purposefully for the project. This is underpinned by the thinking articulated in Langley et al. [5], arguing that these practice tasks not only generate knowledge but additionally manage the group dynamic and hierarchies, re-distributing power and enabling equal and meaningful contribution by all participants.

2.3 Co-design activities

Table 1. First phase co-design workshops (approx. 12 months) and design tools used in each.

| Workshop number & attendees	Purpose of the session	Design Tools used
Workshop 1 (n=36 + 2 design researchers)	Initiating the collaboration: setting expectations, sharing experiences and creating a set of ground rules for our co-design process.	Lego Serious Play

Workshop 2 (n=17 + 2 design researchers)	Understanding multiple facets of the current service, including: • What are the current service experiences? • Who are the (multiple) service users, and what are their service journeys like? • How does the broad geographical 'jurisdiction' of the service affect the way it runs? • What does a Parkinson's disease trajectory look like? • What would an ideal service look like?	Service Journey Mapping Personas Disease Trajectory Models Ideal Service Touchpoints
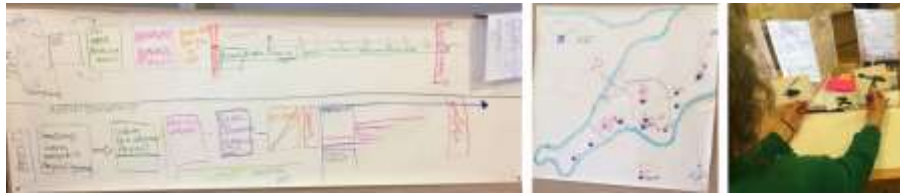
Workshop 3 (n=22 + 2 design researchers)	Ideas development, prioritisation and prototyping: Ideation, idea exploration and development, sorting and prioritisation exercises, knowledge stratification exercises (what levels of knowledge family, friends, co-workers, general public etc might need about PD) and prototyping methods, selection of five top ideas.	Ideation Games Mock-ups Body Storming Role Plays Impact vs Effort charting

Workshop 4 (n=20 + 5 design researchers)	Design 'Hack': Supported by a larger team of designers, the participants were divided into five teams and each allocated an idea and a designer. Ideas were 'fast-tracked' through prototyping, feeding back to the wider group	Prototyping

at critical steps. Plans were drawn up for prototype refinement, production and delivery to key stakeholders for testing in context.

Workshop 5 (n=23 + 2 design researchers)

Presentation of prototypes, testing and planning: Prior to this workshop the designers spent time developing the ideas further, creating high-fidelity prototypes to the specification set (collaboratively) in the previous workshop. These were presented to the group who generated plans for the 'what next' such as testing, implementation or further funding. This workshop was also a celebration event the project so far.

Prototype Presentations and Role Plays

Party Poppers

Prior to, between and after each workshop, several kinds of design studio activity were required:

1. Planning and preparation: planning the workshops and preparing activity resources and data collection tools

2. Data recording and analysis: digitally capturing all the data from the workshops after each workshop, laying out on a project wall, interrogating the data as *designers,* thinking about the solutions

3. Reflection: reflecting on the data and the workshop itself as *design researchers,* reflecting on the effectiveness of the workshop methods and tools as 'stewards' of equity and power balance between stakeholders, and as tools for knowledge creation and sharing between stakeholders

4. Making: making resources and data collection tools for the subsequent workshops, making prototypes to stimulate, provoke or build on ideas and develop them further in preparation for the next workshop

5. Communication: preparing a summary of each workshop and the studio activity between workshops to feedback to participants. Additionally, participants were asked to complete on-going data collection activities between workshops

A second phase of four further co-design workshops was required to take four of the developed concepts and turn them into final outputs to be used in the next phase of the project – development of the Home Based Care Pathway. These are outlined below:

Table 2. Second phase co-design workshops (approx. 14 months) for implementation.

Workshop identification	Purpose	Design Tools
Workshop 1 (n=14 + 2 design researchers)	Preparing for implementation: Combining the technology and the concepts from first phase co-design into Home Based Care Pathway. Understanding service resource requirements. Identifying the stresses of implementation, trialling and evaluation of the new pathway.	Technology and concept prototypes and probes Service mapping Blue prints and visualization tools Implementation planning and stress identification
Workshop 2 (n=18 + 2 design researchers)	Service resource mapping and stress testing: Exploring the service blueprints from previous session and adding greater detail to the resource requirements. Subsequent scenario-based (role play) stress testing of the pathway using personas.	Service and resource mapping Personas Scenarios and role play
Workshop 3 (n=30 + 1 design researchers)	Detailed co-design of patient facing data and reports: This session focused on one crucial aspect - the reports that patients will receive with data about their motor and non-motor symptoms. The group co-designed the reports to ensure they were meaningful and useful (i.e. would be able to prompt action). It was important to enable patients to make sense of this data and then to consider it in the wider context of their life, family and personal goals.	Data visualisation and information presentation modelling activities Interface and report design

Workshop 4 (n=22 + 1 design researchers)	Launch event: Presentation of the whole patient pack, 'live' user testing and feedback.	Prototyping testing and user feedback

This second phase of co-design work for implementation was followed by a final phase of intensive design and feedback iterations as the last details of the content for piloting were developed and refined, using both digital and some physical prototypes, emailed or mailed to staff and patient representatives for them to review, try and critically respond to.

3   Results

3.1   Process

Phase 1 co-design work rapidly introduced us to the physical needs of people living with Parkinson's in the context of co-design. Our 'design partners' gave us valuable feedback about avoiding writing activities and the need to accept big and 'wonky' writing if necessary, the use of big Lego, plenty of water and toilet breaks, accommodating frequent medication reminders and many other practical considerations to collaborating with them.

The phase 1 co-design work identified the needs of different stakeholders, specified the problems with current services (as well as areas that are working well), generated and developed ideas and prototyped them. The methods used (described in Tables 1 and 2) allowed individual reflection, the sharing of all perspectives and collaborative prioritization of key issues. Time and space was given to gradually identify root problems and shared goals of the group, and the visual nature of data collection tools represented knowledge and input of all participants equally. All of this helped to level hierarchies, engage participants meaningfully, facilitate mutual learning between participants and, in turn, generate valuable (and valued) solutions. In this way, the co-design tools can be viewed as tools for *knowledge creation* and sharing, and as 'stewards' of equity.

The phase 2 co-design work was focused more on refinement rather than generation of new ideas. This involved prioritizing and consolidating the multiple concepts generated in phase 1, but also ensuring that these concepts would work in the real, complex contexts of healthcare services and people's lives. In other words, 'design for implementation.' The importance of the continued involvement of all stakeholders at this stage (unlike many other examples of co-design in healthcare) cannot be underestimated. Designerly methods (such as prototyping and role play) allow low-risk, early testing of ideas before they are too detailed, and elicit the tacit knowledge from participants' lived experiences (as service providers and users). This can 'flag' potential challenges earlier and 'fix' them prior to implementation (saving time and money, as well as reducing risk, compared to learning these lessons 'live').

Co-design processes can often be evaluated by the quality and efficacy of the outputs developed from them (as described further below). Beyond this, though, feedback from participants themselves has been positive:

"This project has had a different approach and an interactive style. It's made me work with people who I would not normally interact with. We have worked with patients and their families. They have been at the heart of everything we have discussed and addressed. It's been genuine co-design with patients."

STAFF MEMBER, SW PENINSULA PARKINSON'S SERVICE

"I've really enjoyed the exposure to different methods and ideas to support creative thinking. It's challenged me to think outside the box"

PERSON LIVING WITH PARKINSON'S

The high participant retention rate (shown in tables 1 and 2) also suggests that participants felt valued in the process by choosing to continue their involvement in the project. Travelling to, and staying for the duration of, full-day workshops can be challenging considering the symptoms of people living with PD, and demanding workloads of PD healthcare professionals. Indeed, whilst this is not often discussed in academic literature, care was taken not just in the planning of effective co-design tools, but importantly also in the creation of a comfortable, relaxed environment for participants. We have found that the design researcher often plays multiple roles in such sessions, being receptive and reactive to the mood and needs of participants as the first priority.

3.2 Outcomes

Four of the five original concepts developed in phase one[1] have been combined into one cohesive output - the Home Based Care Pathway.
The Home Based Care (HBC) Pathway includes a pack of information and tools, owned by the patient (fig. 1), to support three key elements; self-management, triggered contacts and remote monitoring. The pack includes; a Parkinson's patient passport (fig. 2), New service and local information (fig. 3); a card deck to support self-reflection (fig. 4); a self-management support and general information package (fig. 5).

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[1] The fifth concept, a media campaign which aimed to 'mythbust' common misconceptions around PD, will not be developed further in this project.

Figure 1: The Home Based Care Pathway pack as it arrives with the patient.

Figure 2: Parkinson's patient passport

Figure 3: New service and local information

Figure 4: A card deck to support self-reflection

Figure 5: A self-management support and general information package

The HBC Pathway is currently being evaluated and further refined with 150 patients and three separate Parkinson's care delivery teams in Plymouth, West Devon and East Cornwall.

4   Discussion

Within healthcare, one of the biggest challenges is getting new ideas into practice [6]. Co-design or coproduction is being offered as a possible mechanism for addressing some of the issues that cause this translational gap [7]. However, the dominant episte-mology in health services research is one that privileges positivistic, quantitatively

measurable data over experiential or tacit knowledge, so it is questionable whether 'real' coproduction can genuinely happen while hierarchies of evidence exist [8].

We have suggested that the creative practices of design [5], used within a co-design process, help to reduce or even remove these hierarchies, give patients agency and voice and enable the effective embodiment (within the prototypes) of the experiential knowledge of professionals and patients as well as the latest scientific knowledge of researchers and research literature. It is because the outputs of co-design processes embody these different forms of knowledge, that they become easier to implement – and reduce the translation gap [9].

Framing the design and co-design process in this way; as a knowledge creation and knowledge mobilization process, has been effective for the authors at enabling them to work in the healthcare sector, with healthcare professionals and health services researchers. It is a 'lens' that they can understand and appreciate the value of, as it relates directly to addressing a known challenge of getting research into practice.

We would encourage other designers wanting to work in this space to consider framing their work in this way, and perhaps more importantly, to all designers who use co-design, to consider their process in this way - as one of eliciting and embodying experiential knowledge of users and service providers, along with contextual knowledge and the latest research evidence from the relevant field. This can support 'evidence-informed' design outputs without stifling creativity and imagination.

5   Conclusions

The participatory design methodology described in this paper has been shown to be effective in addressing the power dynamics inherent in co-design in healthcare. By striving for equal, meaningful involvement of patients, carers and healthcare professionals, a care pathway has been designed, supported by a resource pack to empower people living with PD in the assimilation of complex medical knowledge in the contexts of their own lives. This, in turn, hopes to support their independent living from an informed position.

6   References

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