Sheffield Hallam University

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

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Section I

Presentation Type

Please indicate the type of work you will submit by choosing only one of the categories presented below.

- ☒ Long paper
- ☐ Short paper
- ☐ Tale(s) from the field
- ☐ Workshop

Track(s)

To facilitate the reviewing process and ensure the best possible framing of your work, please indicate the main and up to two secondary tracks from the list below.

- ☐ Main ☐ Secondary - Design for diversity and inclusion
- ☐ Main ☐ Secondary - Design for communication and branding
- ☐ Main ☐ Secondary - Design for culture
- ☐ Main ☐ Secondary - Design for education
- ☐ Main ☐ Secondary - Design for empathy, engagement and fun
- ☒ Main ☐ Secondary - Design for health and wellbeing
- ☐ Main ☐ Secondary - Design for innovation, management and services
- ☐ Main ☐ Secondary - Design for new materials and new manufacturing technology
- ☐ Main ☐ Secondary - Design for product use and experience
- ☐ Main ☒ Secondary - Design for self-reflection, imagination and disruption
- ☐ Main ☐ Secondary - Design for social innovation, circular economy and sustainability
- ☐ Main ☐ Secondary - Design for tech and digital interactions

Paper by invitation?

If a particular track co-chair invited your submission, please mark as such and include their name.

- ☐ Yes - Co-chair name:
- ☐ No

Section II

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

Abstract (600 words maximum)

Summary

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, with provider variation, often lacking 'joined up' provision between acute hospital and community care.

This project utilised a co-design methodology to identify patient and provider needs for PD services in the Plymouth NHS Trust and 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'. We were mindful of this throughout our process. Further, the tools and resources were intended to facilitate independent living for people with PD, yet importantly, enable them to do so from an informed position. This resulted in resources facilitating both the mobilisation of complex knowledge and self-reflection.

Method

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, Parkinson's Charity representatives and health services researchers from Plymouth and Exeter Universities.

The co-design process was structured around five co-design workshops.

1. Initiating the collaboration: Lego® Serious Play®
2. Understanding the Service: Service Journey Mapping, Personas, Disease Trajectory Models, Ideal Service Maps
3. Ideas, Development, Prioritisation and Prototyping: Ideation Games, Mock-ups, Body Storming, Role Plays, Prioritisation
4. Design 'Hack': Prototyping
5. Presentation of prototypes, testing and planning

Prior to, between and after each workshop, design studio activities were:

1. Planning and preparation
2. Data recording and analysis: interrogating the data as *designers*
3. Reflection: reflecting on the data and workshop as *design researchers*
4. Making: making resources, data collection tools and prototypes
5. Communication: ongoing communication with participants

Results

Five concepts developed were: a Parkinson's Patient passport, New service and local information; a media campaign; a card deck to support self-reflection; a self-management support and general information package. Of these, the media campaign was paused awaiting national charity support. The other four concepts

became the Home-based care pathway through a process of four further co-design workshops. They are being trialled with 150 patients in the South West region.

Discussion

Within healthcare, one of the biggest challenges is getting new ideas into practice (Greenhalgh and Wieringa, 2011). Coproduction is offered as a possible mechanism for addressing issues that cause this (Greenhalgh et al, 2016). However, the predominant epistemology in health services research devalues the voices of professionals and patients. It is questionable whether 'real' coproduction can happen whilst such hierarchies of evidence exist (Rose & Kalathil, 2019).

We have suggested that the creative practices of design (Langley et al, 2018) used within co-design processes reduce or even remove these hierarchies, enabling effective embodiment (within prototypes) of experiential knowledge of professionals and patients and the latest scientific research knowledge. Since outputs of co-design processes embody these different forms of knowledge (Rycroft-Malone et al., 2004), they become easier to implement; reducing the translation gap.

Framing design and co-design in this way (as a knowledge creation and mobilization process) has been effective for the authors, enabling them to work easily with healthcare professionals and health services researchers. It is a 'lens' they understand and appreciate the value of.

We encourage other designers working in this space to consider framing their work in this way. Designers using co-design are also encouraged 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.

Keywords (5 maximum)

Parkinson's disease, Home-based Care, Co-design, Knowledge Mobilization, Power

References (APA v6)

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