

The need for distributed co-design in healthcare contexts

LANGLEY, Joe http://orcid.org/0000-0002-9770-8720, BEC, Remi, WHEELER, Gemma and PARTRIDGE, Rebecca

Available from Sheffield Hallam University Research Archive (SHURA) at:

http://shura.shu.ac.uk/23417/

This document is the author deposited version. You are advised to consult the publisher's version if you wish to cite from it.

Published version

LANGLEY, Joe, BEC, Remi, WHEELER, Gemma and PARTRIDGE, Rebecca (2018). The need for distributed co-design in healthcare contexts. In: CHRISTER, Kirsty, CRAIG, Claire and WOLSTENHOLME, Dan, (eds.) Proceedings of the 5th European International Conference on Design4Health, Sheffield, UK, 4th – 6th September 2018. Sheffield Hallam University. (In Press)

Copyright and re-use policy

See http://shura.shu.ac.uk/information.html



The need for distributed co-design in healthcare contexts

Joe Langley, Remi Bec, Gemma Wheeler and Rebecca Partridge

Lab4Living, Art and Design Research Centre, Sheffield Hallam University, UK

ABSTRACT A growing body of evidence supports the notion that co-design, through a process of collectively translating experiences and ideas into physical prototypes, is vital for successful development and implementation of interventions in the challenging and complex field of healthcare innovation. Co-design sessions are usually facilitated face-to-face with participation from all stakeholders. However, the context of healthcare presents unique challenges, such as; bringing staff and patients together at the same time, staff shortages and lack of capacity, logistical and geographical barriers, rare diseases, compromised immune systems, time pressures and power hierarchies.

For designers working in healthcare, the challenge is to overcome these complexities whilst remaining true to a co-design ethos. As such, we propose that in some cases, it can be more appropriate to intentionally engage stakeholder groups separately through distributed co-design. This paper will reflect on the process and outcomes of several case studies which take this approach, using the notion of 'boundary objects,' (*ref). It will then discuss the implications of this for co-designing, within and without healthcare contexts. The three case studies are:

- An Experience-Based Co-Design project; where staff were unable to attend due to staff shortages and lack of capacity.
- A PhD study focusing on spinal cord injury rehabilitation; where the designer developed separate co-design activities for staff and inpatients to allow candid discussion whilst maintaining ongoing working relationships
- A toolkit to improve hospital wards' use of patient experience data; where health service researchers, alongside various prototype iterations, became 'boundary objects' between different healthcare provider settings and patient representatives.

Keywords: codesign, co-design, co-production, coproduction, boundary object



Introduction

The translation of health services research into everyday practice and widespread use is a significant problem (The World Health Organization 2005), creating what has been termed the second knowledge translation gap (T2) or research-practice gap (Greenhalgh and Wieringa 2011). Coproduction, co-design and other forms of collaborative research are seen as a potential way of bridging this gap. However, they are only likely to be successful if they (a) take a systems perspective, (b) see research as a creative and human-centred endeavour and (c) pay attention to the relationships between the collaborating stakeholders, particularly in addressing power and conflict (Greenhalgh et al. 2016).

The authors have been working in the field of design and co-design within the contexts of health services research, healthcare improvement and healthcare innovation for several years. Over an extensive portfolio of experiences and case studies (Wolstenholme et al. 2014; Reed et al. 2015; Gwilt et al. 2017; Chamberlain and Partridge 2017; Wheeler, Macdonald, and Purcell 2015; Wheeler 2018; Bec 2012) we have utilised a variety of creative approaches from the array of generative methods (Sanders 2003) within the designer's toolkit. In doing so, we have come to understand that these approaches play a vital role in addressing points (a)-(c) outlined above, thereby increasing the likelihood of success.

Throughout these experiences, we have noticed a growing challenge in the ability of frontline healthcare staff to be able to join face-to-face co-design workshops. There are a variety of reasons behind this that include amongst others; a shrinking workforce and inadequate cover for staff. The vast majority of these are policy level factors that are beyond our control. However, in some, more (unusual) cases we might deliberately take a strategy that keeps stakeholders apart, perhaps due to logistical and geographical factors, rare diseases or compromised immune systems.

Collectively these strategies can be described by the overarching notion of 'Boundary Objects,' (discussed below), where the 'object' in some cases has been a space, a person or people, drawings, images or three dimensional (3D) objects (usually prototypes at various resolutions). We will use three case studies to illustrate these strategies before discussing how they fit into the concept of Boundary Objects and why this is a useful way of framing them for future co-design initiatives in healthcare facing similar challenges.

Boundary Objects

Boundary Objects were first proposed and defined by Susan Leigh Star (Star and Griesemer 1989). She described them as objects 'which both inhabit several intersecting social worlds and satisfy informational requirements of each', saying they are vague, have strong cohesive properties and are flexible and recognisable across cultures. Henderson (1991) paraphrases this to describe Boundary Objects as agents that socially organize distributed cognition.



Later Star clarified the scope of an 'object' in the current context of her boundary objects proposition. This opened these objects beyond physical artefacts to include computer programmes, spaces, theory's, drawings or even people. She stated that these 'objects' where 'things' people (or, in computer science, other objects and programs) act toward and with (Star, 2010). The notion of boundary objects has been studied further with specific reference to 'products' and to issues of knowledge 'translation' or 'transformation' (Carlile 2004, 2002).

Case Studies

We will now very briefly outline three case studies:

- A service improvement co-design initiative based on an acute Cardiac Ward in Bradford, UK, utilising an Experienced-Based Co-Design protocol facilitated by designers.
- A PhD study based in Glasgow, UK, focusing on spinal cord injury rehabilitation.
- A toolkit to improve hospital wards' use of patient experience data working with six wards across three hospitals in the Yorkshire region, UK.

Experienced-based co-design with Ward 22

Experience-based co-design (EBCD) is a quality improvement approach that was developed in the NHS for the NHS in 2005 (Bate and Robert, 2007). The approach draws upon `...design sciences to actively engage the user in the redesign of a healthcare experience, using a co-production model, with patients and clinician's working together to create changes.' Importantly, it has been developed as a downloadable toolkit, which it claims can be carried out by healthcare staff with patients and without the need for any design expertise. Coming from a background in design practice, the lead researcher on this project became interested in exploring what might be missing without the design expertise.

The setting for this EBCD project was an acute cardiac ward in Bradford. A group of researchers on the team (including the authors), patient representatives, improvement facilitators and health services researchers carried out observations on the ward. They interviewed/filmed nine previous patients and used the footage to draw together a 'trigger film' (compiled by the designers) illustrating the entire patient journey and their emotional experiences throughout. This was presented back to the group of former patients who suggested some improvements to enhance its representation of their experience. The trigger film was then presented to the ward staff and a map of the typical patient's (emotional) journey was co-created between staff and patients. Themes for improvement were identified by all and then prioritised. From this, staff and patients self-selected the theme they personally wanted to focus on, two of which were taken forward. An improvement facilitator led one theme (focusing on discharge medications) and the designers led the second (concerning Information, Communication and Support).



The second theme ran a series of 6 co-design workshops over a course of 6 months, all of which had great attendance by patient representatives (2 at the first workshop and 4-6 in the following five sessions). However, across the course of all six workshops there was an increasing attrition of staff members that coincided with a depleted staff team (due to long term sickness, no specialist nurses on the agency staff register and delays in recruiting replacements). The final three workshops had no staff representation, so the co-design team needed to explore alternative ways of engaging the staff in the process.

To do this, the ward was visited again and a space was identified that the staff 'passed through' and paused within, at frequent intervals, for 'micro-breaks'. This space was adopted and used to put visual queries on the walls, including illustrations, provocations and prompts. Various prototypes were also placed in the space staff were invited to contribute to their development. In this way, the space and the artefacts the co-design team placed within it, became a boundary object that actively engaged the staff in the co-design process. By using this space, we were able to actively engage with a higher number of staff members, despite challenges of scheduling and staff capacity, ensuring their continued, meaningful participation in the project.

Spinal cord injury rehabilitation in Glasgow

In a recent PhD study (Wheeler, 2018), both traditional healthcare-related and design-based approaches were used to explore and enhance patient participation in spinal cord injury rehabilitation. A key focus of this study was the development of a co-design process that meaningfully involved the Spinal Injury Unit (SIU) community, including inpatients, outpatients, family members, senior SIU staff, 'front-line' SIU staff, and staff from local spinal injury charities. From a year-long, mixed-method contextual review with and within this community, this study recognised the need to protect the ongoing working relationships between inpatients and SIU staff members, which may be compromised by the (somewhat critical) co-design process. As such, outpatients, inpatients and SIU staff were engaged (in that order) separately through an iterative prototyping process. The prototypes themselves were able to elicit tacit, behavioural, experiential and/or institutional knowledge from each stakeholder group about the SIU patient pathway. This knowledge was then embodied in the development of the next prototype iteration, to be shared with the subsequent group. As such, the prototypes facilitated anonymous, creative collaboration between the stakeholder groups. This lead to the development of an effective, multi-stage intervention whilst remaining sensitive to the particular needs of working in a complex healthcare setting.



Co-designing a toolkit to enable ward staff to use patient experience data for improvements

In the UK, significant resource is now allocated to the collection of Patient Experience (PE) feedback and the Friends and Family Test¹ is mandatory for all hospital Trusts. However, the overt emphasis and huge resource allocated to collecting PE data has not been matched by efforts to utilise it and evaluate its impact. In this programme of work, design principles were used as a basis for developing a patient experience toolkit that sought to address this imbalance. Following a process of creative co-design, the aim was to develop a toolkit to improve PE, rather than a toolkit to use PE data; recognising that achieving the second aim might not necessarily lead to the first.

Participants in the co-design process included healthcare professionals (drawn from six wards across the three hospitals in the Yorkshire region), patient representatives, improvement facilitators, staff from PE teams and the researchers. Cycles of co-design prototype iterations were interjected with Action Research cycles; where the toolkit prototype was used in the wards to check and evolve the design, format and content. Whilst the initial stages of the co-design work (a series of three face-to-face co-design workshops) were used to generate prototype V1 (used on the wards in the first round of Action Research), subsequent co-design was carried out in a more distributed fashion as it was not possible to arrange any mutually convenient co-design sessions. We organised 'drop-in sessions' and developed four further prototype variations with specific test/feedback specifications that the action researchers took onto the wards. The co-design dialogue switched from being face-to-face through co-design methods to being orchestrated through the prototypes and the action researchers.

What was (and still is) significant and interesting about this project is the gradual shift in the target end user and the role of the action researchers in the use of the tool. Whilst the action researchers were initially present to *observe* how ward staff used the tool, it quickly became apparent that they instead needed to *support* ward staff in organising, structuring and analysing the PE data to be able to use it. Over the course of the five prototypes, the target end users switched from being ward staff/teams to an entirely new role, the 'PE facilitator'. The profile for this 'PE facilitator' was drawn directly from the roles the action researchers found themselves undertaking, so the end user focus of the toolkit was adjusted to accommodate it. In effect, the action researchers became a part of the prototypes.

Discussion

The arguments presented in this paper do not intend to diminish the value of face-to-face collaboration in co-design activities. The benefits of which are far-reaching and well-documented.

¹ The Friends and Family Test (FFT) is a feedback tool that enables people who use NHS services an opportunity to provide feedback about their experiences.



However, as discussed above, there can sometimes be value in creating a degree of separation between stakeholder groups for logistical, medical or even ethical reasons. To facilitate collaboration across this separation, we found it useful to reframe the artefacts and prototypes created in the co-design process as Boundary Objects. This enabled us to better understand the role of design and designed materials in expanding this network of collaboration.

There is little discussion of the use of Boundary Objects in healthcare, and this paper provides three cases studies that broaden discussion in this area. The first case study, using an iterative prototyping process with a range of separate stakeholder groups, corroborates the common definition of Boundary Objects as materials that carry meaning, and therefore facilitate collaboration, between and across disciplinary and hierarchical boundaries.

However, in reflecting on their rationales, methods and experiences of distributed co-design, the authors found that the parameters of the Boundary Object 'stretched' beyond the original intention and meaning. People and Space became critical elements of the boundary objects in our second and third case studies, reflecting the increasingly complex and distributed nature of healthcare services themselves. As such, the authors would encourage designers and clinical professionals to be reflective and responsive to emergent mechanisms for facilitating collaboration within their own contexts, and the wider network of stakeholders that maybe engaged in future co-design processes as a result.

Conclusions

For various reasons, there is sometimes a need to consider distributed models of co-design in healthcare contexts, where critical stakeholders or stakeholder groups cannot be brought face-to-face. This makes the job of sharing any experiences and identifying relevant tacit knowledge much harder. In these cases, the visualisations and the prototypes created in the co-design process become a vital part of sharing information about participants' experiences, ideas, knowledge and insights, as well as in defining the problem to be addressed and possible solutions.

A useful model to help to frame the purpose and value of these visualisations and prototypes is the concept of Boundary Objects. Taking this idea further, we suggest that the particularly complex and distributed nature of healthcare contexts place additional demands on the co-design process, and that the concept of 'boundary object' or 'objects' can be used flexibly to include people and spaces. In each of these forms, the boundary object helps to communicate between participants across temporal, spatial, professional and disciplinary boundaries. We argue that it is particularly important for designers to pay attention to and make room for such (potentially emergent) mechanisms of distributed co-design in order to better serve the healthcare communities they wish to operate with and within.

References



- B. N. Sanders, E. 2003. "From User-Centered to Participatory Design Approaches." In *Design and the Social Sciences; Making Connections*, 18–25. CRC Press. https://doi.org/10.1201/9780203301302-8.
- Bec, Rémi. 2012. "Creating Physically Active Games for Young Adolescents." *Proceedings of the 11th International Conference on Interaction Design and Children IDC '12*, 331. https://doi.org/10.1145/2307096.2307160.
- Carlile, Paul R. 2004. "Transferring, Translating, and Transforming: An Integrative Framework for Managing Knowledge Across Boundaries." *Organization Science* 15 (5): 555–68. https://doi.org/10.1287/orsc.1040.0094.
- Carlile, Paul R. 2002. "A Pragmatic View of Knowledge and Boundaries: Boundary Objects in New Product Development." *Organization Science* 13 (4). https://doi.org/10.1287/orsc.13.4.442.2953.
- Chamberlain, Paul, and Rebecca Partridge. 2017. "Co-Designing Co-Design. Shifting the Culture of Practice in Healthcare Co-Designing Co-Design. Shifting the Culture of Practice in Healthcare." Edited by Loredana Di Lucchio, Lorenzo Imbesi, and Paul Atkinson. *The Design Journal* 20 (sup1: Design for Next: Proceedings of the 12th European Academy of Design Conference, Sapienza University of Rome, 12-14 April 2017). Rome: Routledge: S2010–21. https://doi.org/10.1080/14606925.2017.1352720.
- Greenhalgh, T., and S. Wieringa. 2011. "Is It Time to Drop the 'knowledge Translation' Metaphor? A Critical Literature Review." *Jrsm* 104: 501–9. https://doi.org/10.1258/jrsm.2011.110285.
- Greenhalgh, T., Jackson, C., Shaw, S., and Janamian, T. 2016. "Achieving Research Impact Through Co-Creation in Community-Based Health Services: Literature Review and Case Study." *The Milbank Quarterly* 94 (2): 392–429. https://doi.org/10.1111/1468-0009.12197.
- Gwilt, Ian, Rebecca Partridge, Rosemary Peacock, Claire Marsh, Laura Sheard, Rebecca Lawton, and Joe Langley. 2017. "Using Co-Design Workshops to Develop a Ward-Level Patient Experience Improvement Toolkit." In *Proceedings of the Fourth International Conference on Design4Health*, edited by Kurt Seemann and Deirdre Barron, 95–98. Melbourne: Centre for Design Innovation, Swinburne University of Technology. https://doi.org/ISBN-13: 978-0-6480892-1-6.
- Henderson, K. 1991. "Flexible Sketches and Inflexible Data Bases: Visual Communication, Conscription Devices, and Boundary Objects in Design Engineering." Science, Technology & Human Values 16 (4): 448–73. https://doi.org/10.1177/016224399101600402.
- Reed, H., J. Langley, A. Stanton, N. Heron, Z. Clarke, S. Judge, A. McCarthy, et al. 2015. "Head-Up; An Interdisciplinary, Participatory and Co-Design Process Informing the Development of a Novel Head and Neck Support for People Living with Progressive Neck Muscle Weakness." *Journal of Medical Engineering and Technology* 39 (7). https://doi.org/10.3109/03091902.2015.1088092.
- Star, Susan Leigh, and James R. Griesemer. 1989. "Institutional Ecology, 'Translations' and Boundary Objects: Amateurs and Professionals in Berkeley's Museum of Vertebrate Zoology, 1907-39." Social Studies of Science 19 (3). SAGE PublicationsLondon: 387–420. https://doi.org/10.1177/030631289019003001.



- The World Health Organization. 2005. "Bridging the 'Know Do' Gap Meeting on Knowledge Translation in Global Health."

 http://www.who.int/kms/WHO_EIP_KMS_2006_2.pdf.
- Wheeler, Gemma. 2018. "Reconciling Traditional Healthcare-Related and Design-Based Approaches to Explore and Enhance Patient Participation in Spinal Cord Injury Rehabilitation," May. http://radar.gsa.ac.uk/5828/.
- Wheeler, Gemma, Alastair Macdonald, and Mariel Purcell. 2015. "Diagrammatic Exploration as a Bridge between Observation and Intervention in Design and Healthcare Research," 13–16. https://research.shu.ac.uk/design4health/wp-content/uploads/2015/07/D4H_Wheeler_et_al.pdf.
- Wolstenholme, Daniel, Tom Downes, Jackie Leaver, Rebecca Partridge, and Joseph Langley. 2014. "Improving Self-Efficacy in Spinal Cord Injury Patients through 'Design Thinking' Rehabilitation Workshops." *BMJ Quality Improvement Report* 3 (1).