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Citation:

WHEELER, Gemma (2018). A reflective tool to consider notions of healthcare community participation in design. In: CHRISTER, Kirsty, CRAIG, Claire and WOLSTENHOLME, Dan, (eds.) Proceedings of the 5th International Conference on Design4Health Sheffield 4th – 6th September 2018. Sheffield Hallam University. [Book Section]

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A reflective tool to consider notions of healthcare community participation in design

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Abstract
This paper aims to interrogate the meanings and assumptions related to the term 'participation' in design with and within healthcare communities. Drawing on a PhD case study that focussed on patient engagement in spinal cord injury (SCI) rehabilitation, it aims to contribute to this discussion with a novel framework that considers the epistemologies of both healthcare and design.

The proposed framework is informed by well-known models in this area, including Arnstein's Ladder of Citizen Participation (1969), critiques the hierarchical nature of such models, and expands on them by proposing temporal considerations of a design process. The framework encompasses a variety of healthcare community stakeholders at different stages of the design process, and prompts consideration of the role of the designer within such co-design practices.

For the author, the act of populating this framework facilitated a much deeper understanding of how the design methods employed facilitated meaningful participation (or not) within the PhD study. It does not presume to fully define the nature of participation, rather it hopes to provide a starting point for other designers and healthcare practitioners to adapt it to their own contexts, and facilitate collective reflection within and between the fields of design and healthcare.

Keywords: Co-design, Participation, Theory

Introduction

From the foundations of the civil rights movements in the 1960's and 1970's, the notion of public involvement has gained increasing interest in a multitude of fields and contexts, including policy-making, design and healthcare. One of the most influential theoretical frameworks emerging from the former around this time is Arnstein's Ladder of Citizen Participation (1969), shown with additional definition in figure 1 below:

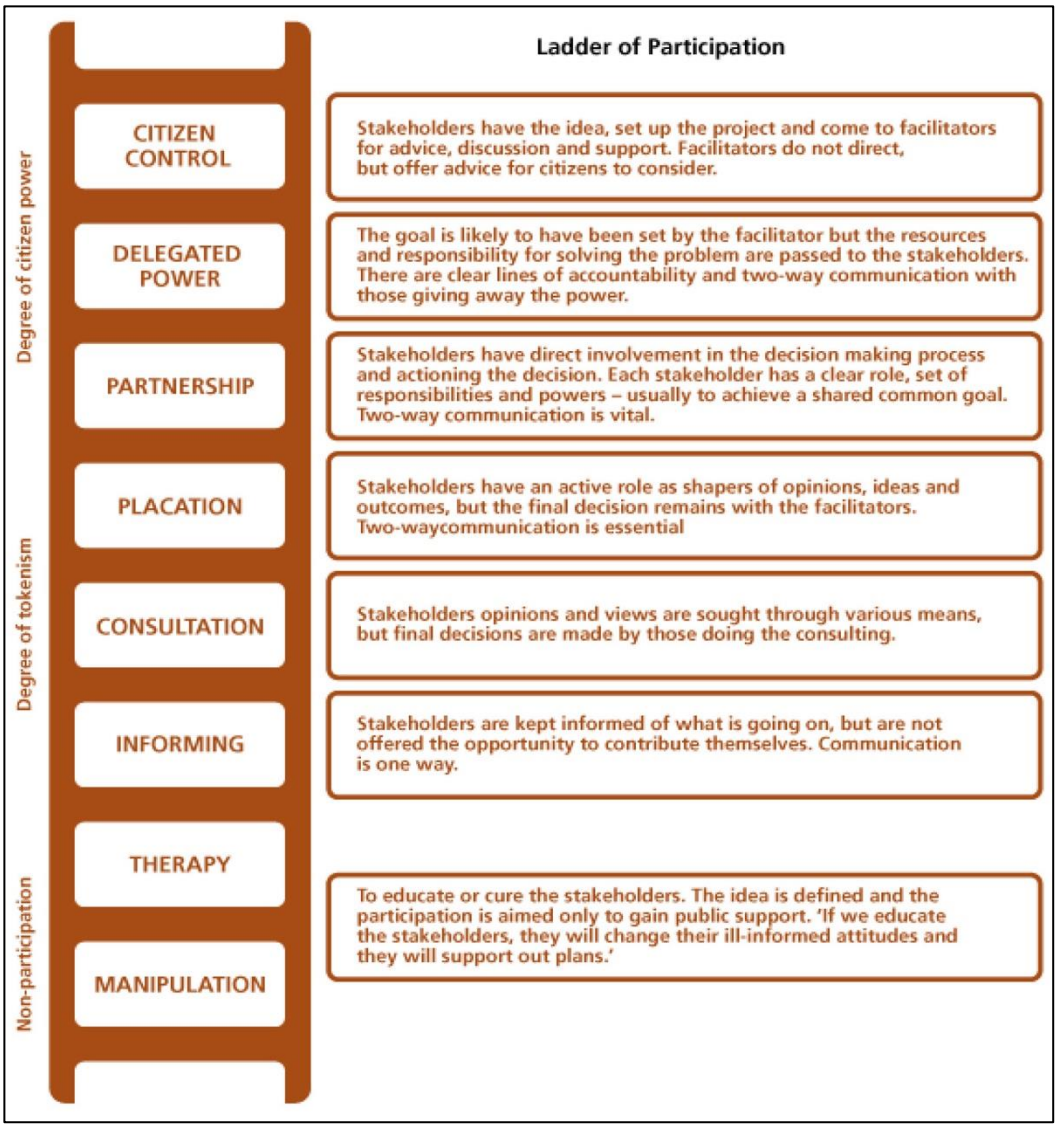

Figure 1: Arnstein's Ladder of Citizen Participation (see Arnstein 1969), with additional detail given by Rosier (2013).

By demonstrating multiple, increasing gradations of 'participation,' Arnstein aimed to convey an understanding that whilst participation is power, some forms of 'participation' (shown in the lower sections) do little to renegotiate traditional power structures. She argues that "participation without redistribution of power is an empty and frustrating process for the powerless" (ibid 216), and frames citizen's active involvement in decision-making as the key contributor to 'citizen power' (see the 'partnership' rung of the ladder in figure 1).

Arnstein's model is still influential today and has been adapted to a variety of contexts (as will be discussed below). However, it is not without criticism. Arnstein herself admits that the reality of participation often doesn't fit within the neat rungs of the ladder, and that key factors affecting distribution of power are omitted, such as race, gender and socio-economic status. More recently, the ladder has been critiqued for its inability to reflect on or relate to the context in which it is used, nor does it provide guidance into how participation can be

progressed within a project (Collins and Ison 2006). Moreover, the hierarchical nature of the model doesn't account for the multiple ways in which people can participate, or how this may change over time (Tritter and McCallum 2006).
Clearly, the notion of participation is complex. This paper will continue by exploring how participation is currently conceptualised in the fields of health and design. For brevity, the scale of participation realised in practice in these fields is omitted (but more fully explored in Wheeler 2018).

Participation in Healthcare
Within the field of healthcare, particular attention has been paid to the traditionally paternalistic nature of doctor-patient relationships since the 1970's. There has been an increasing desire to put patients (and, more recently, their families also) in the centre of their own care, and in the development of healthcare services. Theoretical frameworks that conceptualise this 'participation' as a variable to be measured are well-suited to this context, given that research within healthcare predominantly emerges from the scientific paradigm. It is unsurprising, then, that Arnstein's Ladder remains influential in this context, as shown in figure 2 below:

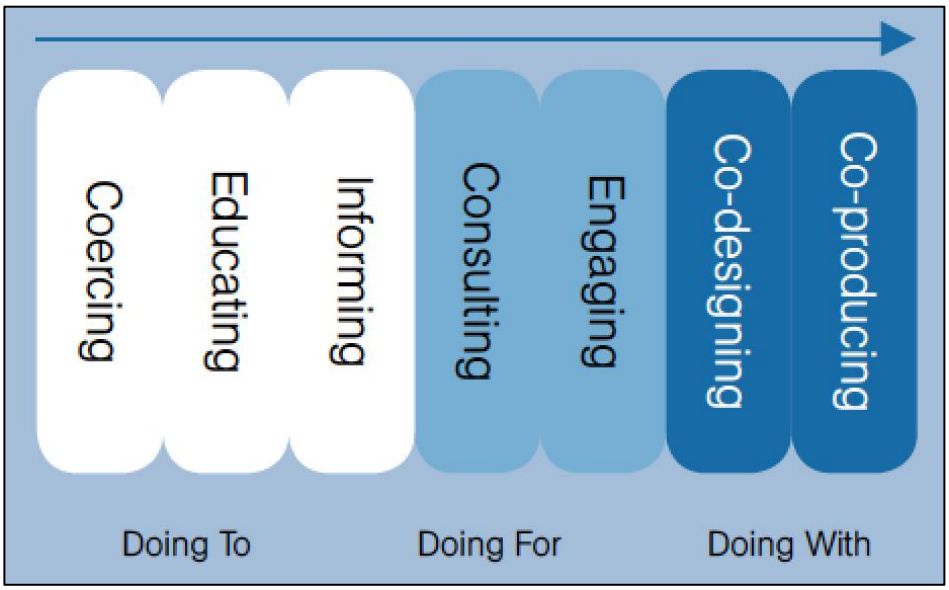

Figure 2: The New Economic Foundation's (NEF) alternative 'Ladder of Participation' (Slay and Stephens 2013).

In their adaptation of Arnstein's classic framework, NEF have chosen more contemporary language related to healthcare and design. The definitions of each level at the 'Doing To' and 'Doing For' territories are largely comparable to Arnstein's, however their use of 'co-designing' rather than 'delegated power' suggest a more collaborative approach between designers, healthcare professionals and healthcare service users. NEF's inclusion of the term 'co-producing' (defined as 'a relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make,' [Slay and Stephens 2013, 3]) also addresses notions of power within the specific healthcare context.

Participation in Design

Notions of participation in Design originated in the Scandinavian workplace democracy movement of 1970's (Simonsen and Robertson 2013). Since then, Participatory Design (PD) has developed a rich history and plethora of tools to facilitate and encourage user participation in the design process. Although the field originally focussed on ICT interventions, it has since inspired a range of co-design approaches (as shown in figure 3 below) and expanded into multiple complex contexts, such as healthcare.

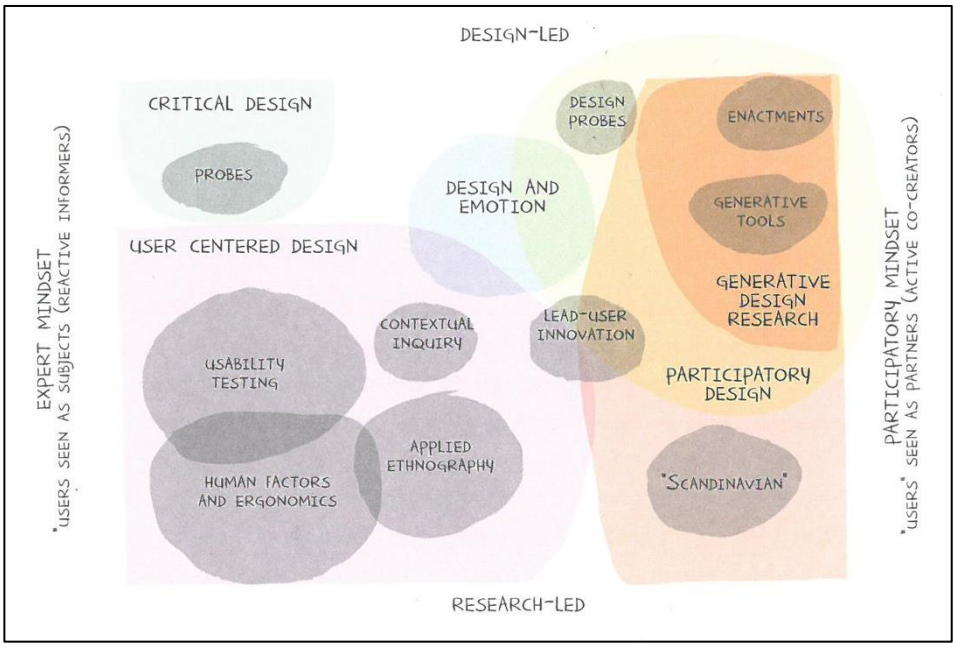

Figure 3: A 'Topography of Design Research' (Sanders and Stappers 2012, 19).

In contrast to healthcare's traditionally positivistic paradigm, the field of design operates with social constructivist approach, which places an emphasis on understanding people's lived experiences and their social interactions. Rather than seeking universal truths, Design aims to engage with the 'messy' nature of reality and the complexity of problems within it. Perhaps due to this complexity, it has been argued that the field of Design has been less successful in reflecting on the nature of participation that it affords in the new contexts it operates within, and with the wider range of (potentially vulnerable) participants it seeks to engage (Kraff 2018). In addition, some argue that the field has privileged the earlier stages of the design process (or 'fuzzy front end') and had 'less focus on the back-end of the development process,' (Almqvist 2017, 2524).

In response, Kraff proposes the using context-specific tools for reflection (see figure 4 below), that can 'give visual form to complex situations, highlight differences between groups and indicate how participants' positions alter over time,' (2018, 60).

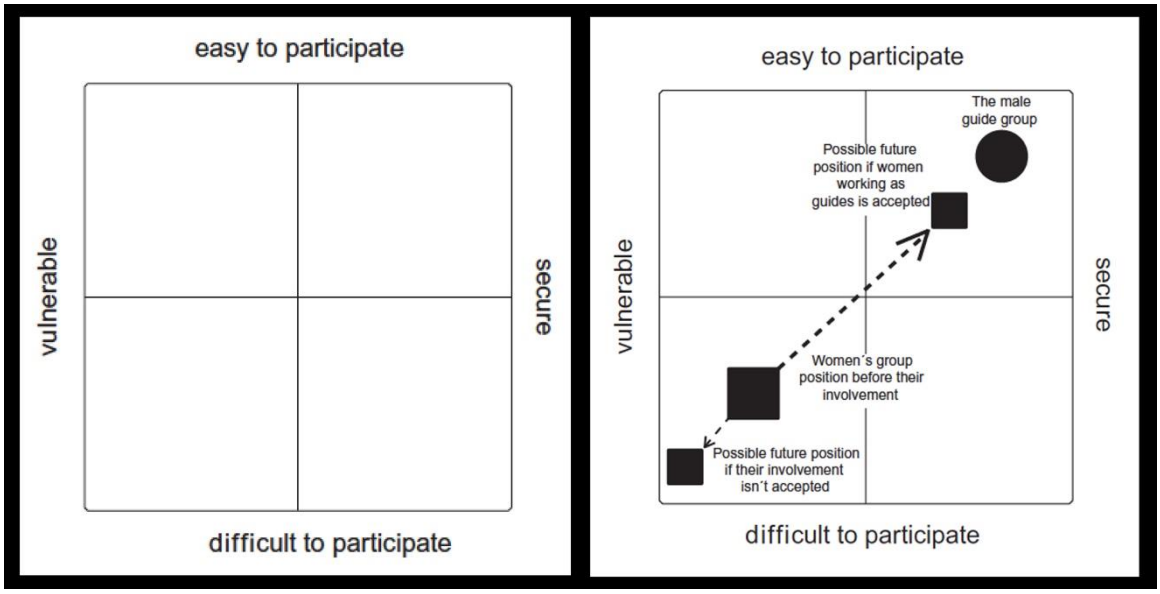

Figure 4: Kraff's tool for reflection (2018). The completed example, shown right, was used to reflect on a project exploring tourism in a Kenyan fishing village community, and demonstrates how male and female participants' standing in their community could have been affected by her study.

Whilst the tool is simple, the arguments underpinning Kraff's model and its temporal considerations were useful in reflecting on the PhD study described in this paper.

Reflecting on Healthcare Community Participation in Design

Context: PhD Study in a Spinal Injuries Unit (SIU)

The participatory framework proposed in this paper was created during a PhD study which aimed to explore and enhance patient engagement in spinal cord injury (SCI) rehabilitation, with and within a host SIU community (Wheeler 2018). The author was embedded within the host SIU, and engaged inpatients, outpatients, family members, 'front line' SIU stuff, senior SIU staff and associated SCI charities. Following a year-long, mixed-method contextual review, it was decided that inpatients and SIU staff would be engaged separately in subsequent co-design activities, in order to protect their ongoing therapeutic working relationships (given that co-design activities can be critical of current situations, or in this case, patient pathways). Since PD generally holds face-to-face interaction as the 'gold standard' of collaboration, this raised questions over the nature of participation afforded to each SIU community stakeholder group. As such, the literature from both healthcare and design (and the models discussed above) were reviewed in order to develop a visual exploration of how the SIU community participated over the course of the PhD study. The findings and implications of this exploration are discussed below.

Outcome: A Participatory Framework that Bridges Healthcare and Design

To enhance its clarity and acceptability to medical audiences (as a key group that this PhD study aimed to contribute to), the notion of a 'ladder' was retained as an anchor point in the framework. Whilst this is placed on a y axis and retains a concern with how power is distributed between participants (as in Arnstein's original ladder), NEF's terminology was used for its relevance to the PhD context – in particular the notions of co-production of

healthcare services. Inspired by Kraff (2018), the framework also adds a temporal dimension along the x axis, to account for how the design project (and therefore modes of participation) evolved over time. To better reflect the context in which it was used, and particular concerns of the project (i.e. engaging stakeholders separately for ethical reasons), each stakeholder group in the SIU community is represented as occupying individual (although sometimes overlapping) territories (inspired by Sanders and Stappers [2012]).

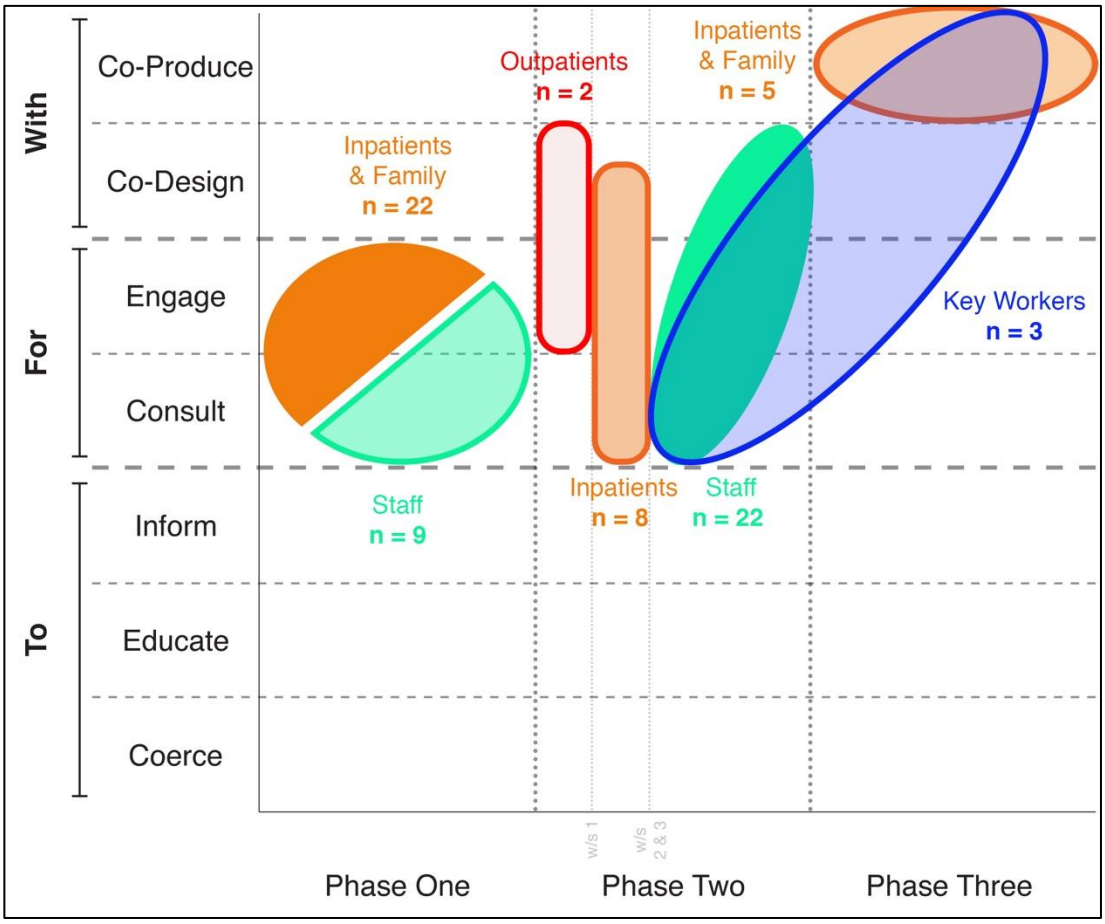

Figure 5: A visual exploration of how various stakeholders in a spinal injury unit participated in a service design project.

Phase One

In Phase One, inpatients, family members and staff members were invited to informal, questionnaire-led semi-structured interviews to understand their perspectives on the focus of the PhD; the Goal Planning Meeting (where a patient, and possibly a family member, meets with their multidisciplinary rehabilitation team approximately once a month, to set rehabilitation goals and review progress made to date). The quantitative and qualitative data from these interviews were used by the author to generate a set of initial rough prototype materials that could potentially be used in a GPM to enhance patient engagement within it.

As the SIU community engaged in Phase One were not invited to make decisions that affected the design process (other than deciding what their priorities for change were), both participant groups are placed in the 'Doing For' levels of the ladder. The territories cover

both ‘Consult’ and ‘Engage’ levels to reflect how some participants had a more ‘active role in shaping the opinions, ideas and outcomes’ (Rosier 2013) than others (i.e. by giving their opinion on the current patient pathway as well as suggesting alternative formats).

Phase Two
Throughout Phase Two, outpatients, inpatients and SIU staff were engaged (in that order) in a series of co-design workshops to iteratively develop the initial rough prototypes. As can be seen, outpatients are placed slightly higher on the ladder than inpatients, as the former made significant changes to the prototype materials. Some members of the inpatient group also made decisions to affect the prototypes, whilst others preferred a more passive role in the co-design sessions, and this is reflected in the longer, slightly lower position of their territory. The SIU staff territory is shown to reach higher levels over time, depicting the change in the nature of design decisions made when enactment activities were introduced in later workshops.

Phase Three
Phase Three entailed the implementation, testing and evaluation of the co-designed intervention in the rehabilitation pathways of three inpatients. A separate (blue) territory has been given to the three ‘Key Workers’ (staff who take ownership of coordinating a patient’s multidisciplinary rehabilitation team, and typically chair GPMs) who were involved in the Phase Two and went on to lead the implementation of the co-designed intervention. Staff and patients used the co-designed intervention autonomously, without any input from the author (other than one ‘design-in-use’ meeting with Key Workers, see Wheeler [2018]), and as such their work is placed in the ‘Co-Production’ levels of the ladder.

Discussion
What does this show?
Whereas ‘ladder’ types of participation frameworks aid reflection on the power dynamics affecting a project, they can present an overly simplistic and static view of the messy reality of human social interaction. Complementing this ‘ladder’ with an x axis in the framework above allows for nuanced understanding of how a design project can evolve over time – providing a ‘snapshot’ overview at a quick glance, or a more nuanced understanding with closer review.

In this case, stakeholder groups were given separate territories on the framework according their role in the SIU community (i.e. inpatients, outpatients, family, staff). However, this technique could also be used in other contexts to acknowledge the role of race, age, gender, etc., in the power dynamics affecting participation, addressing previous critiques of ‘ladder’ models (Arnstein 1969). In addition, the suggestion that stakeholder territories can occupy multiple levels on the ladder addresses other concerns that hierarchical models do not accommodate the multiple ways in which people can participate over time (Tritter and McCallum 2006).

By mapping the PhD study onto this framework, the author can argue that the approach taken was not concerned with ‘Doing To’ the SIU community, and that as the design process progressed, it moved the project from ‘Doing For’ to ‘Doing With’ the community. As such, the framework evidences the value of long-term collaboration between designers and

healthcare communities. In addition, it provides a visual description of the importance of having a core group of clinical staff 'champions' to help lead the implementation of co-designed interventions. In this case, the three Key Workers (shown in blue on the framework), bridged the gap between co-designing in Phase Two, to autonomous co-production in Phase Three.

What are the implications for Design in Health?

For Independent Reflection

The framework above hopes to go some way to acknowledging the messy reality of participation and to respond to recent calls for more situated (almost anthropological) understandings of design practice in context (Suchman 2011). The process of creating and reflecting on frameworks such as this forces designers to reflect on the co-design tools or activities created, what was achieved and how their practice could be improved. For example, by changing the opacity of the stakeholder territories on the framework to reflect the numbers of participants in each group, the author was confronted with the question of whether outpatients and inpatients (total n=10) were as influential or had as much power as SIU staff (n=22) in Phase Two. This in turn highlights the role of the prototypes (initially developed by outpatients and inpatients) in carrying the patient 'voice' forward through to these later stages.

For Group Reflection

Kraff argues that a visual tool 'enables collective reflection and a shared understanding between researchers, since it allows people to see each other's thoughts, rather than just hearing or reading them,' (2018, 61). As such, it could be argued that the framework could be used as a tool for healthcare staff and designers to share and co-develop their understandings of how the former were engaged in the project. Doing so could draw on healthcare practitioners institutional and experiential knowledge, extending their participation beyond the project, into developing the practice of Design in Healthcare.

Implications for Design Practice

The y axis of this framework forces designers to consider what type of power was afforded to participants by the co-design process they facilitated. As such, the act of populating such a framework may respond to recent discussions in the PD literature calling for designers to critically reflect on the influence they have in participatory projects (Light and Akama 2012). Through the addition of an x axis, the framework allows designers to reflect on how participants' involvement evolved (or not) over time. As such, it may encourage designers to give equal consideration to the (often neglected) later stages of the design process (Almqvist 2017).

Conclusion

The fields of Healthcare and Design each have their own history and (somewhat contradictory) conceptualisations of 'participation.' To facilitate mutual learning, frameworks to reflect on healthcare community participation in design projects are needed that are understood and respected by both fields.

In the context of a Design PhD hosted within a Spinal Injury Unit, the author proposes such a framework that, whilst being somewhat specific to this context, could provide inspiration for other Design researchers working with and within healthcare communities. By

complementing Healthcare's need for definable 'measures' of participation with Design's ability to engage multiple stakeholder groups in an emergent, evolving manner, the framework aims to address contextual and temporal critiques of existing frameworks of participation. This framework aims to inspire designers to create their own visual representations of their participatory practice, to support reflective conversations with themselves and their peers. It also aims to invite healthcare communities into this conversation, extending their involvement not just in the design project, but also in its evaluation; including their voice in the development of the field of Design for Health.

Acknowledgements
My warmest thanks are extended to Professor Alastair Macdonald for his reflections on this framework, to my co-supervisor Dr Mariel Purcell, and to the staff, patients and families of the Queen Elizabeth National Spinal Injuries Unit, Glasgow.

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