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PhD study report : Understanding the roles of the designer in healthcare: A practice-based study into supporting adolescents with long-term conditions.

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PhD study report

Understanding the roles of the designer in healthcare: A practice-based study into supporting adolescents with long-term conditions.

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Overview

This paper reports on an ongoing PhD study based within Lab4Lving, a transdisciplinary research group in design, healthcare and creative practice within Sheffield Hallam University's Art & Design Research Centre.

Increasingly, design is becoming a recognized activity within the context of healthcare, with an increase in the use of design methods and approaches in development and research. This 'research through design' study explores design practice and design thinking in health and wellbeing through the lens of the Pain Management Service at Sheffield Children's Hospital.
Through case studies with the therapists and the young people, the study seeks to understand the role of participatory design methods in service improvement, and to see if the transfer of design skills to adolescents within the service has an impact on their self-management.
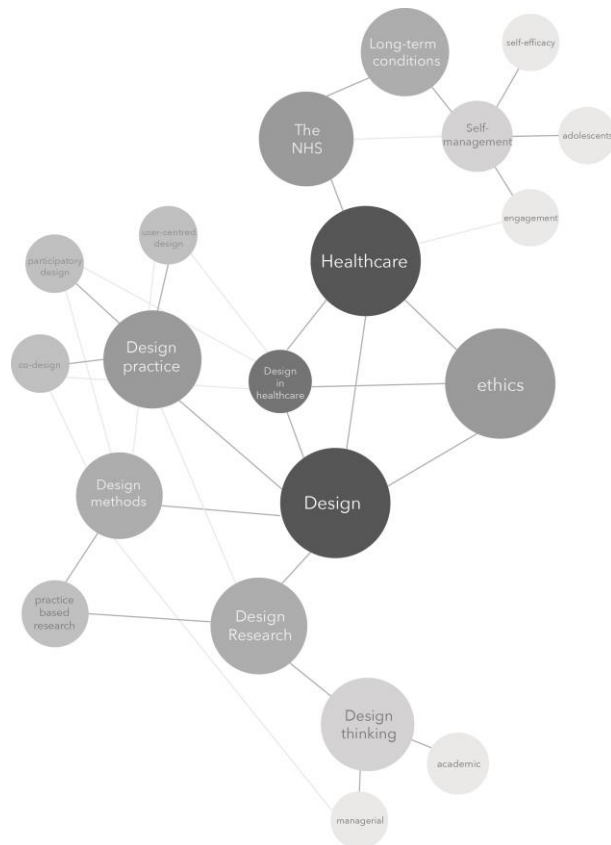
Background

Figure 1: an illustration of the scope of the literature

The Royal Society for the encouragement of Arts, Manufactures and Commerce (RSA) proposes that design is a form of resourcefulness (Campbell, 2009) and that to overcome the challenges within contemporary society, citizens need to become more engaged, self-reliant and resourceful. They state that designers could play a role in this by sharing their skills and knowledge. In 2009 the RSA proposed a series of projects to explore the idea of using design in areas of society, such as healthcare, where the skills of resourcefulness and self-reliance were needed.

The UK National Health Service (NHS) is facing increasing complexity and costs due to advances in medical technologies, an increasingly ageing population, changes in lifestyle and work practices (Cottam and Leadbeater, 2014; Holman and Lorig). This results in people surviving for longer with conditions and diseases that previously would have resulted in death (e.g. stroke, asthma, diabetes), these conditions are defined as long-term conditions (Department of Health, 2012) and account for around 70% of NHS spending (Cottam and Leadbeater, 2004).

To manage these LTCs the NHS has to shift from a traditional paternalistic model of healthcare, where patients are traditionally passive in respect to

expert health professionals (Barlow, 2002; Ellins, 2005), to encouraging patients to take a much more active role, doing the majority of condition management themselves (known as self-management) (Health Foundation, 2011). There is increasing recognition that the aim of this movement from passive to active endeavours is '*not to reduce contact overall but rather support a different pattern of contact which may lead to fewer crises and inpatient admissions*' (The Health Foundation, 2011 p.7) and to move care away from a one-size-fits-all solution towards a culture of developing new relationships with patients to help empower and engage them.

Research into what conditions create successful self-management and what good programs might look like show that it can be a *'complex concept poorly understood'* (Lau-walker and Thompson, 2009) with support varying widely across conditions and age ranges. Findings indicate key areas that need to be addressed include day-to-day problem solving skills (Ellins, 2005), self-efficacy and confidence issues (Lau-walker, 2009), and the need to increase knowledge, skills and competencies to assist in the management of conditions (Health Foundation, 2011).

In recent years there has been an increase in design methods and approaches within healthcare development and research. The Arts and Humanities Research Council (AHRC) commissioned the report 'The State of the Art of Design in Health' (Chamberlain, 2015), which sought to establish greater understanding of this growing relationship, and to explore and understand the contribution of design to healthcare. It suggested that these *'Design-led participatory approaches help the NHS think differently'* (Design Council, 2008).

With an increased interest in the use of design to tackle contemporary problems (Brown, 2008; Campbell 2011; Design Council 2007), design thinking is becoming more popular and acceptable as a problem solving strategy. Following on from successes in the business and managerial sector, research is starting to explore its impact in healthcare contexts.

Recent projects have explored the role of design thinking with people who have a Spinal Cord Injury (SCI) introducing them to design skills and practices either as part of a workshop (Campbell, 2011) or as part of rehabilitation sessions offered during a rehab setting (Craig, 2013, Wostenholme, 2014). Qualitative feedback suggests that the programs left patients thinking more creatively about problem solving. Participants reported increased confidence and independence and those who were inpatients reported having a mental stimulation they didn't receive from other therapies. This lead to the suggestion that design thinking workshops as part of rehabilitation can contribute to increased self-efficacy and engagement in self-management

behaviours in people with an SCI. However, the team recognized that more work was needed to demonstrate replicability.

It should be noted that there are conflicts and debates between the discourses of design thinking, the first being an academic discourse on what designers do and how designers operate; to '*create knowledge for its own sake or for the communication to design students'* (Johansson-Skoldberg, 2013). The second originates in the business and managerial sector where design thinking strategies are used as a tool for innovation and can be viewed as a *'popularized, management version', 'where design practice and competence are used beyond the design context… for and with people without a scholarly background in design'* (ibid, 2013). Many, such as IDEO (2015) and service design tools (2009) have made their resources available to the public as a way of opening up design methods to the wider community. It could be said that this approach of design thinking is more outward looking; it seeks to explore what design can offer to others and how to engage others in design.

Context

This study works with the Pain Management Service at Sheffield Children's hospital (SCH) specifically on the Chronic pain branch of this service. The chronic pain team work with children and young people who have had pain that continues for more than three months post injury or persistent unexplained pain.

Chronic pain management uses a biopsychosocial approach. Some medication is used to help control symptoms; however, the majority of treatment focuses on pain management (PM). PM is about learning to live with and alongside pain. It includes education around pain as well as learning skills such as activity pacing and sleep management to aid self-management. The therapists can see patients for as little as three sessions over six weeks or multiple sessions over childhood.

In recent years the therapists have seen a dramatic rise in their case loads, resulting in increased pressure on the service and a need to think of new and innovative ways to reduce waiting times and patient visits whilst maintaining the quality of the service and the results for the patients.

Methods

Through the lens of the Pain Management Service at SCH, this study uses mixed methods through two case studies and comes from a social constructionist approach[i]. It utilizes reflective practice on the various roles of the designer throughout. Because this is a practice based study, a mixed

methods approach uses practice to help understand the research questions and in order to be able to adapt to complexities of conducting research within a clinical team.

The case studies are as follows:

With the pain management therapists, design methods will be used to:
- Understand the team and service
- Develop the service using service design methods
- Understand how changes in the service support the adolescents

With the adolescents, design methods will be used to:
- Explore creative ways to visualise and share experiences of chronic pain and self-management
- Develop design thinking skills
- Understand the relationship to self-management

The study has been through the NHS ethics review procedure and has approval to recruit up to 15 participants to be involved in a series of four design workshops and complete cultural probes (activities to complete at home to give insights into their lives) over a 6-10-month period.

Practice

This article focuses on the work with the pain management therapists and the methods and practice used.

Shadowing and interviews

This study had an extended set up phase during which the researcher spent time building relationships and gaining an understanding of the service. In order to do this, a series of interviews and a six-month period of shadowing was undertaken. Interviews focused on the team members' roles, and shadowing included observing multidisciplinary (MDT) clinics, 1:1 therapy sessions and team meetings.

Mapping and diagrammatizing

low engagement
unmanaged condition

high engagement
managed condition
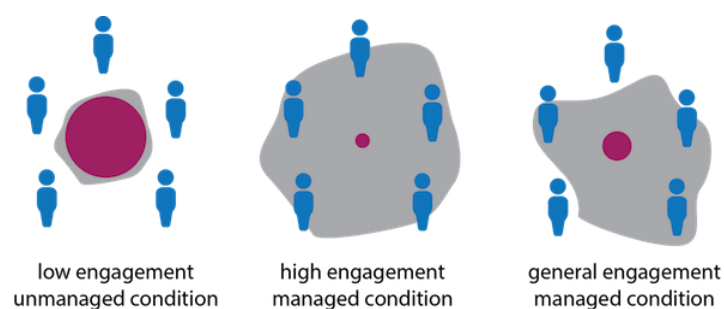
general engagement
managed condition

Figure 2. Model of engagement and management

As a response to these methods, and to help the researcher make sense of the service, and the teams' roles within it, a series of maps and diagrams was developed. These included diagrams to understand the relationships between engagement and management (figure 2) and a series of maps looking at the distribution and crossover of skills between therapists within the service (figure 3).
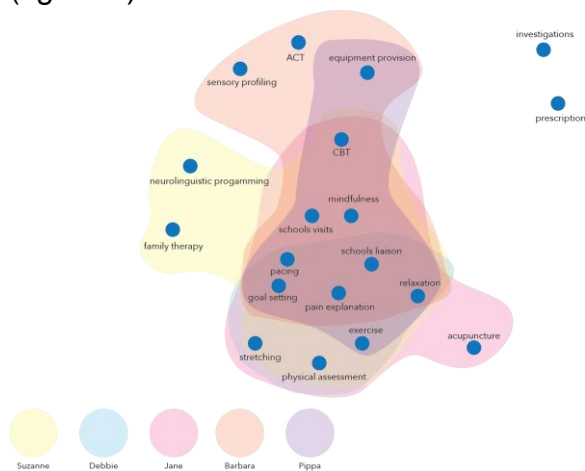

Figure 3. Therapists' skills mapped together

Design Workshops

As part of re-evaluating the service and developing service provision a design-led workshop was run for the therapists' staff development day. This workshop used service design methods such as user journey mapping (figure 4) and persona creation to enable the team to visualize and critically reflect upon their service and their roles within it.

Figure 4. Map of patients' journeys through the Pain Management Service

Insights and reflections

On an extended set up phase

In co – or participatory design-based research activities, the set-up phase (planning and liaison with participants) can often be short. There can be problems with this approach when designers enter environments they do not fully understand, and work alongside people they do not yet have a secure relationship with or try to make a design intervention fit into an established community or way of operating. Trying to build the necessary knowledge and relationships quickly can cause problems if design researchers and participants do not fully understand one another.

In this case the shadowing process formed an extended set-up phase that was crucial to developing relationships and service knowledge. It allowed the team a chance to get used to the researcher's presence, to share things at their own pace, without feeling pressured or burdened.

On mapping and diagrammatizing
The maps and diagrams were key to developing understanding between the researcher and the team. The diagrams became conversation pieces between the clinicians and the designer, visually helping to un-pick complexities, support language and overcome barriers.

The researcher regularly used diagrams and visual means to help diffuse situations when she felt tensions and frustrations developing, taking time away to reflect on the situations. In this way the diagrams were crucial for developing relationships, introducing the ideas and tools of design even if they were not part of the service design process.

The skills maps were initially developed as part of a sense making exercise for the researcher. However, they were most insightful when used with the team in the context of the away day workshop, becoming a conversation piece between people to help understand the range of their collective skills. For the team members, the maps created a space of visual reflection; for individuals to reflect on and reveal their own practice; and for collective dialogue around the teams practice as a whole. In this way it has been important that the maps are not seen as 'finished' or 'too polished' allowing for alterations to develop them together giving them a sense of ownership over the designer's practice (figure 5).
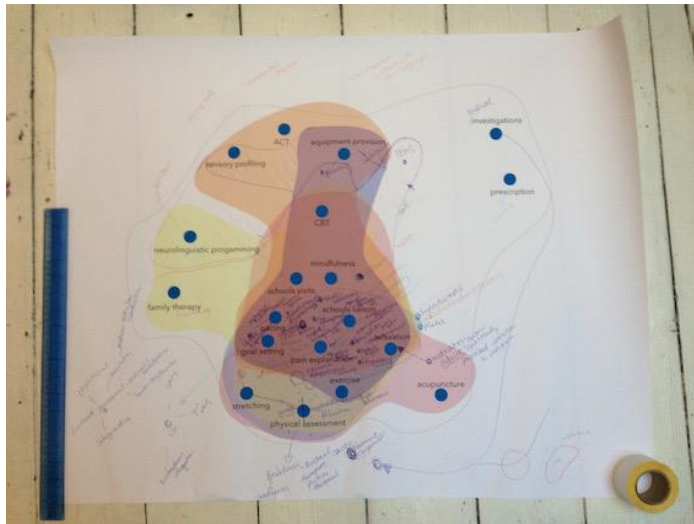
Figure 5. Team changes to the shared skills map

On the design workshop
The design workshop was the first opportunity the researcher had to facilitate a series of design methods. Feedback and reflection from the team reported how much they enjoyed the creative activities and the speed at which they had managed to get through a vast amount of information. The workshop allowed the team to explore and summarize things they have been having conversations about for months, if not years.

'The workshops helped move us along with big conversations that may have taken much longer without your intervention'

has enabled us to 'rise above' the complexity of individual work – following your lead rather than trying to problem solve in habitual old ways.
Feedback from pain management therapists

The visual outputs successfully allowed the team a space to reflect on what they already know about their service, highlight many of the complexities, and create new knowledge through shared diagrams and understanding.

Future Work

Going forwards, the study will continue to use design methods to improve the service, reflecting on the different methods, the processes the designer goes through and the complexities of working with a clinical team in the NHS.

As well as this, the researcher will shortly begin recruiting for the adolescent workshops, which will commence in the summer term of 2017. They will be interviewed pre and post their involvement in the workshops. Any visual materials they might produce will also undergo visual analysis with any

practice produced throughout this study evaluated in relation to the context that it was developed. Workshops will be audio recorded and photographs will be taken throughout. The researcher will work with the psychologists in the pain team to see if there are any psychological measures that might be useful in measuring self-efficacy, which she will then situate in the wider literature.

These interviews and outputs will be used to help determine what self-management means to these young people as individuals and provide the baseline for any changes that might occur as a result of being involved in the design workshops.

Acknowledgements

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Biography
Rebecca Partridge is a Design Researcher and PhD candidate within Lab4living at Sheffield Hallam University. Her work focuses on using design practice, service design and design methods within a healthcare. She is interested is using design to improve healthcare and understand the role of the designer within it.

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Captions
Figure 1. an illustration of the scope of the literature
Figure 2. Model of engagement and management
Figure 3. Therapists' skills mapped together
Figure 4. Map of patients' journeys through the Pain Management Service
Figure 5. Team changes to the shared skills map

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[i] Social Constructionism is a theoretical perspective based on the belief that all knowledge and therefore meaningful reality is constructed by human beings and their interactions within the social world. Meaning is not discovered, but constructed (Crotty 1998)