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The Value of a Research Through Design approach to explore Healthcare Service Provision

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The Value of a Research Through Design approach to
explore Healthcare Service Provision

Rebecca Anne Partridge

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Abstract

This thesis reports on a research-through-design (RtD) PhD study. This sought to integrate Design skills and approaches as part of service provision within a healthcare team at Sheffield Childrens Hospital. Working with the chronic pain (CP) team it used a mixed-method approach to understand how design practice could be used to understand context and develop relationships with stakeholders. This supported the development of workshops to explore if demonstrating design skills and approaches to adolescents with CP could have an impact on their management behaviours.

Literature suggests there is an increasing demand for design methods outside of the traditional design field. Both by designers, who find themselves working in other disciplines and non-designers, as a route to problem-solving and innovation. In particular, the complexity of health services provision and the call for increased innovation has led to increased use of design methods in healthcare to develop services and as a method to support problem solving in patients.

There are complexities when conducting this type of design-led project in healthcare, where there can be conflicting worldviews on evidence and knowledge, and strict ethical procedures to contend with. This thesis follows the journey of the researcher as they navigate this whilst ultimately remaining true to a RtD approach to explore healthcare service provision.

The study provides new insights on RtD in healthcare. Interviews and reflective practice suggest that design practice was successful to understand the context, build trust, visualise services, understand service complexity and navigate difficult topics. Self-report data from the workshops found that adolescents enjoyed the sessions and there was some acquisition of 'designerly' skills.

The study adds to knowledge in the field. It acknowledges the potential value of design to support adolescents but recognises that this has a long way to go with much more work needed. Key findings are: The study argues the value of research through design in healthcare to support healthcare service provision and the future need to articulate this to a healthcare audience. In order to present some of this study approach to healthcare it argues the need of design facilitation to be a recognised design practice. And further unpacking of the specific skills that design professionals can bring to this sector. the recognition of which would encourage design involvement earlier in studies. Finally based on experiences from the study it provides recommendations for other design researchers.

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Chapter One: Introduction

1.1 Overview

This thesis represents a document that covers a three-year research study that sought to integrate Design skills and approaches as part of service provision within a healthcare team at Sheffield Childrens Hospital. In particular, it sought to understand how design practice could support condition management in adolescents who have long term conditions. It used a Research through Design approach to explore and gain insight into how to conduct design research in a hospital setting, navigating the complexities of using design approaches in this context. As a result, the studies original aims and objectives outlined here evolved over the duration of the enquiry.

All the research including that which was not as successful in terms of outcomes is presented here for clarity and discussed at the end of the thesis. It is important to remain transparent and honest about how the research approach shaped the project. This is discussed in detail at the end of this thesis.

Study Aims

- To investigate the impact design workshops might have on a patient population's condition management
- To explore how design practice can support the development of relationships with healthcare providers
- To contribute to the discussion on the role of the design professional when design methods are used in healthcare

Study Objectives

- To gain ethical approval through NHS ethics procedures,
- To conduct a literature review and period of design ethnography to establish a group of patients to work with,
- To run a series of workshops that demonstrate design skills and methods to patients,
- To use design ethnography to build a relationship with the patients' healthcare providers and to work with them to integrate these workshops into the current management practices offered,
- To use qualitative and quantitative measures to analyse the workshops,
- To make recommendations for other design researchers in healthcare based on reflective practice conducted throughout.

Contributions

This thesis would like to offer the following contributions to knowledge:

- Research through design is a valuable approach to explore and develop healthcare service provision.
- Design facilitation should be a recognised design practice to counteract the undervaluing of design professionals and to distinguish between design facilitation (by a designer) and other forms of facilitation (by non-design professionals).
- Three key recommendations to support practice in design in healthcare are:
 - Encouraging the use of NHS research ethics approvals to demonstrate rigour in design research,
 - Factoring in a set up phase in design research,
 - Becoming key partners in the grant writing processes.

1.2 Thesis Format and Chapter Overview

To help guide the reader in navigating this thesis, it has been split into three key sections,

Groundings, Practice and Findings.

Chapter One: **Introduction**

This is the current chapter that introduces the study the thesis structure and the reader to the research.

Groundings

I use the groundings section to situate the work and provide the reader with background information to understand the rationale behind the study. There are three chapters in groundings. The first is a contextual review that covers literature on design, healthcare and design in healthcare. The second provides a background to design research, and the third is the methodology chapter.

Chapter Two: **Contextual Review One**

The first chapter is a contextual review of the literature that surrounds the fields of design and healthcare and the intersections between them. It situates this in contemporary society where a growing need for innovation is driving the use of design methods in other fields. This chapter also introduces a key area that this thesis adds to knowledge to; the discussion around the role of the professional designer in healthcare research.

Chapter Three: **Design as Method**

This is a key chapter in this thesis. The contextual review introduces design research. It uses literature to frame what design research is and presents the approach of research through design. It considers where this work fits in the debate around design research and what constitutes design research.

Chapter Four: **Methodology**

In the methodology chapter, the reader will gain an understanding of the mixed methods approach used. As well as the individual methods and where and how they were applied.

This chapter also includes the study design, and information on ethical approvals.

Practice

In this section the reader will find the practice of this study. It is divided into three chapters to separate out the initial immersive practice, the design practice with the chronic pain therapists and finally the workshops with the adolescents. Each chapter provides a description of the methods used and the analysis and findings of the work.

Chapter Five: **Immersion**

The fifth chapter is Immersion, it covers the methods used to; understand the context of this study, decide a patient population, develop the adolescent workshops, and build a relationship with a clinical team. It introduces the process to gain access to Sheffield Children's Hospital. Then it covers the design ethnography, interviews, sense making and visualisation practice before ending with a short summary of reflections from this period. In this chapter, there is also information on an 'explain your pain' workshop that were not a part of this study but provided insights for the study.

Chapter Six: **Therapists**

The sixth chapter, Therapists, is where you will find information of the work with the therapy team and the work that were undertaken. The interactions (four workshops and one resource session) are summarised at the start of the chapter, followed by detail on the individual methods and practice. At the end of this chapter analysis from the staff interviews is presented.

Chapter Seven: **Adolescents**

The seventh chapter (and final chapter in the practice section) provides detail on the workshops with the adolescents. In this chapter the reader will find an account of the ethical approvals to conduct the study. It provides detail on the overall aims and what

happened in each workshop. At the end of the chapter the analysis of the Likert scales, Interviews and questionnaires is covered along with a summary of the findings.

Findings

The last section of the thesis is findings. There are two chapters in this section; discussion and contributions. In this section I bring together all the learnings from the study consider them against current literature and summarise the contributions this study brings.

Chapter Eight: **Discussion**

Chapter eight in this thesis is the discussion chapter. It draws together the findings and reflections from the practice of this study with the literature presented in contextual review one and two. This is split into four short essays that cover; Healthcare procedures and the challenges for designers in healthcare, the case for early immersive practice, the importance of design methods and designers and finally the findings and limitations of demonstrating design skills to adolescents.

Chapter Nine: **Contributions**

The final chapter of this study is a summary of the three contributions that have been derived from the discussion. The contributions relate to the value of Research through design as an approach to explore service provision in healthcare, the recognition of design practice and learnings for others working in this field. Each contribution is followed with implications and recommendations for future practice.

1.3 Prologue

I begin this thesis by introducing the reader to the backstory of how this study came

about, and the personal rationale behind the research. I started the journey to becoming a design researcher ten years ago on a MDes Product Design course. At the time, I had little idea of what I wanted to do beyond the degree except become a ‘designer’, although my knowledge about what a designer was and where they worked was limited. I had always believed that design had the ability to support others, but felt that much of it happened through the development of physical things. The course structure was focused on developing the skills and competencies needed in the consideration and application of the design of physical products. In terms of research, within the course attention was given to research for design and understanding users. However, this was often undertaken in the form of secondary sources obtained via the internet.

My first exposure to design as a research tool within healthcare came in 2010 when, as a student, I took part in a piece of research funded by The Royal Society for the Encouragement of Arts, Manufactures and Commerce (RSA) through Lab4Living¹ (L4L) at Sheffield Hallam University (Craig et al 2013). This was a collaboration with the Princess Royal Spinal Injuries Centre (Sheffield), and I helped to facilitate a series of design workshops (Figure 1). These aimed to apply inclusive and participatory design principles



Figure 1: Facilitating Design Workshops ‘Spaghetti Challenge’

1 Lab4Living is a trans-disciplinary research group. It is a collaboration between the Art and Design and Health and Social Care Research Centres at Sheffield Hallam University. The group focus on design, healthcare and creative practices to address real world issues that impact on health and wellbeing. <http://www.lab4living.org.uk/>

to improve participants' ability to control their environment and manage life with their spinal injuries. This was a scoping study to see how feasible this work was, but the patient feedback was positive. The experience of working on this project provided me with the first opportunity I had to see how a designer's skills could be used outside of the 'product' design, making world and to explore variance in the meaning of the term design.

This experience developed an interest in design in healthcare and closer working with patients that continued through the final year of my degree, where I decided to focus my study on healthcare related products. During this year, I worked closely with User-Centred Healthcare Design² and Lab4living, a relationship which I believe was seminal to my



Figure 2: Final Year Student Projects- Portable Oxygen Cylinder and Mobile Infusion Pump

decision to move into a career as a designer researcher within the context of healthcare and wellbeing. Using these relationships to support working in partnership with the end users, I developed concepts for a portable oxygen cylinder and a mobile infusion pump (Figure 2). This introduced me to a range of design research methods associated with the area of co-design, and developed an appreciation of the value of developing products with their users.

² <http://www.uchd.org.uk/> UCHD was a five-year project funded by the United Kingdom National Institute for Health Research (NIHR) as part of the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) for South Yorkshire that looked specifically at the use of design in health and social care.

After finishing this degree in 2012 I joined the Art and Design Research Centre (ADRC) at Sheffield Hallam University (SHU), which housed both the UCHD and Lab4Living research groups, as a design researcher. During this time, I developed knowledge of different design research approaches and techniques, was exposed to different aspects of design research (such as bid writing, design methods and dissemination), and gained experience of working with a range of healthcare professionals and service users. Part of this role was to adapt and develop methods and activities that could be used as part of design workshops to inform the development of products or services in healthcare. I found myself drawn to the exploratory aspects of these workshops with an enthusiasm for facilitating creative tasks.

However, these workshops were often part of a formal design process, where there was a predefined idea of what the outcome might be. This contrasted to my previous experience within the Spinal Injuries project, which was about demonstrating design principles rather than developing an outcome. I was keen to know more about the use of design principles outside of or alongside the formal (outcome driven) processes.

I was able to explore this further in a Lab4Living project that continued on from the previous RSA work (Craig et al 2013). This extension of the work was funded by the Health Foundation's Shine programme³. It introduced a programme of design thinking sessions as part of rehabilitation on the spinal injury inpatient unit to explore its impact on self-efficacy (Wolstenholme et al 2014). My role as lead facilitator included the delivery of the sessions as well as a substantial amount of preparatory work to develop the content (Figure 3).

3 The Health Foundation's Shine programme aimed to provide teams with the resources to develop and evaluate innovative ideas to improve quality of care. Projects each have one of three overarching aims: supporting people to be active partners in their own health and care; improving the safety of patient care; or improving quality while reducing costs <https://www.health.org.uk/programmes/shine-2014>



Figure 3: Facilitating a Design Thinking Session with a Patient on the SCI Rehab Ward

The qualitative outcomes of this project showed a positive impact on the participants' approach to managing their condition (more information on these outcomes can be found in Contextual review one). Yet I reflected on many aspects of the project that hadn't been so successful or that I might like to have approached differently. The short timeframes of the project (due to funding requirements) to develop the intervention and recruit participants left little time to understand the context, build a relationship with the staff and explore the most appropriate activities or ways to run the intervention.

My experience across this and other projects seemed to show that problems with timeframes and misunderstanding the importance of these beginning phases seemed to be common in research projects. Furthermore, both studies had worked with patients who had a spinal cord injury and I wondered how this design practice might work with other patient groups.

Another query that came out of this work was one of sustainability and the role that design and the designer played beyond the duration of project. At the end of the project, workshop activities were packaged into a series of resources that we intended staff to use with patients. However, we had trouble engaging with some of the staff throughout the project and therefore did not know much about their practice. The result was that

despite confidence in the content of the resources created, positive comments from participants and our best efforts to try to leave a legacy, we could not guarantee the use of the resources beyond the intervention. Furthermore, we had not had the opportunity to explore what might occur differently if a non-designer was to deliver the resources. I was left with many questions about better ways to engage and interact with staff when working in healthcare, particularly on projects that use design practice to challenge established conventions and practices with open ended outcomes. This seemed to provide another argument for placing higher value on the set-up phase of a project to understand the context and build relationships. I was coming to realise that this was particularly important as the two disciplines (design and healthcare) had very different backgrounds, different research 'languages' and little knowledge of each other.

The projects that I worked as a design researcher on enabled me to develop my skills both as a facilitator and researcher using design activities to explore participant empowerment, understanding, mindset development and culture change, as well as physical or service outcomes in the context of health care. Whilst these early projects allowed me to explore these methods, the constraints of funding and time often meant that outcomes were prioritised over reflection and exploration.

When the call went out for PhDs, it felt like the right time in my research career to start to explore some of this further. I had three years' experience working as a design researcher, and was excited to be able to direct my own research study. The experiences described above helped to shape the direction and structure of this PhD study. It has allowed for a more in-depth study and reflection on these types of activities without the time and funding restraints that come with research grants. I was also fortunate enough that throughout the duration of this study, I continued to work as a design researcher supporting other healthcare related projects to add to my research experience.

1.4 Setting

Sheffield Children's Hospital

Sheffield Children's Hospital NHS Foundation Trust (SCH) is one of only three dedicated children's hospital trusts in the UK. It has grown exponentially since it first opened in 1876 following outbreaks of infectious disease during the industrial revolution (the Children's Hospital Charity n.d.). It now receives more than 260,000 patients every year. SCH provides a full range of services for children and young people (including trauma, community and mental health care) across Sheffield and South Yorkshire, and receives specialist referrals from across the UK and internationally. The hospital is host to a significant amount of research, it is home to the Sheffield Children's Clinical Research Facility (CCRF), which opened in 2008 and was the first of its kind in the UK (Sheffield Children's Hospital n.d.). This study takes place within the Pain Management Service (PMS) at SCH. It focuses on the Chronic Pain (CP) branch of this service.

Chronic Pain

Pain is normal and is usually associated with injury or disease, the treatment of which will make the pain better (Butler and Moseley 2013). However, sometimes this pain does not get better, due to difficulties in treating the disease, or lasts much longer than normal tissue healing (Sheffield Children's Hospital n.d; Butler and Moseley 2013). Pain that continues to be persistent or recurrent for more than three months becomes the disease itself and is classed as Chronic Pain (American Pain Society Task Force 2012). In some cases the pain is unexplained as there is no known physiological cause or was not the result of an injury. Chronic Pain is known to affect large numbers of children and young people at some point in their lives and studies show that there is a gender bias towards girls (Odell and Logan 2013). During the process of trying to diagnose and manage pain, patients will most likely have encountered many medical professionals and undergone multiple medical investigations (Gauntlett-Gilbert and Eccleston 2007). This can result in

disrupted school attendance, impacts on a patient's social life and will most likely have a detrimental impact on their wellbeing as their worlds become 'smaller' (Neal 2016; Goodchild 2016; Robinson 2016).

It is recognised that the best way to manage chronic pain is through a multidisciplinary team using a biopsychosocial approach (Odell and Logan 2013). Sometimes medication is used to help control symptoms and in extreme cases surgical interventions such as nerve blocks are used, however the majority of treatment focuses around pain management (PM).

PM interventions are about reducing pain's effect on daily life. There is a strong focus on education and holistic management strategies such as; activity pacing, sleep management, exercise and de-sensitisation (Sheffield Children's Hospital n.d; Davies 2016; Odell and Logan, 2013). The aim of these strategies is to foster an ability to cope with the pain, manage it and facilitate recovery to as high a level as possible by working with children, young people and their families (Sheffield Children's Hospital n.d).

Sheffield Pain Management Service

The Sheffield Pain Management Team deals with children and young people who have acute (pain related to injury or illness), procedural (as a result of a clinical procedure) and chronic pain (Sheffield Children's Hospital n.d.). Referrals to the Pain Management Service (PMS) for CP fall predominantly in the 11-16 age range. The PMS is a multidisciplinary team made up of doctors, specialist nurses, therapists and psychologists. The majority of pain management interventions are delivered by the therapists.

There is no formal documentation of the history of the SCH PMS, as far I have been able to ascertain, and therefore, the following account is compiled through conversations and interviews with the therapy team (Davies 2017; Goodchild 2017; Neal 2017; Robinson 2017).

The service started with one doctor and one therapist, and gradually grew over a period of around 20 years during which it took on two more therapists, expanded into a multidisciplinary team and introduced more clinics to respond to increased demand.

One of the therapists described how the growth of the service was never static, with staff members working different hours and days from each other to cover demand. This meant that as a service (both the therapy service and the wider pain service) there was very little time to bring the team together to consider their service provision and direction in a strategic plan, in their words 'the goal posts kept moving' (Davies 2017). This increase in demand came to a head in 2014/15 when there was a huge increase in referrals (one therapist estimated that between January and April there was a 100% increase) and with one therapist on leave for part of that time, significant strain was placed on the service. As a result, the team decided to appoint another therapist to join the therapy team.

Around a similar time to this new team member joining, the team experienced a changeover of medical leadership; the consultant who had helped to set up the service retired and a new leader stepped in. Therapist memories of this time recount a subtle change of direction, a need to tighten up boundaries and processes, and the need to reduce burden on the service.

Section One

Groundings



Chapter Two: Contextual Review One

The following chapter is a summary of literature to situate the thesis in the wider landscape of academic literature and theory. What is covered here are the overarching topics of design, health, and design in health. This chapter sets out the current research and literature to demonstrate where the gaps are and why it was important for this research to be conducted.

This first contextual chapter covers three key sections

- Design's movement into other disciplines
- Design in healthcare
- The context of health and young people

Review Strategy

Following evidence from Greenhalgh and Peacock (2005), this study used a variety of strategies to review the literature in the field.

At the beginning of this study a primary review of the literature was conducted using the following terms:

- Design
- Health(care)
- Design in healthcare
- Healthcare design
- Service design and healthcare
- Design thinking
- Design methods
- Designerly
- Long term conditions
- Chronic conditions
- Condition management
- Self-management

- Design and behaviour change

From this, key texts were identified and a snowball (or citation) technique was used to identify further literature that was of relevance to the study. Online research profiles were used to understand in more depth the scope and citations of some authors. These key texts also included those which were known to the researcher and supervisors prior to the study.

This approach was iterative, and the review spanned the three-year period of the study. Further primary reviews were conducted as the project expanded to include new search terms (such as design and adolescents/teenagers). Furthermore, some texts were added as a result of conversations with academics and healthcare staff.

Further search terms:

- Adolescents
- Teenagers
- Healthcare
- Long term condition
- Chronic health
- Design
- Self management

2.1 A Drive for Innovation

Challenges in contemporary society, such as population growth, political, economic and environmental factors and social divisions, are creating drivers for innovation (Kimbell 2011). As such, language and terminology (such as innovation and design thinking) that have historically been attributed to design, are finding their way into other domains and increasingly becoming socialised as a means of practice (Carlgren 2013). As a result, designers and the discipline of design is finding a role beyond the conventional 'design

studio', and working in increasingly varied contexts such as policy making, healthcare and education, in order to address different sorts of problems.

To unpack this transition into other contexts there is a need to understand what it is about a designer and the discipline of design that supports and succeeds in innovation. Work to understand, define and articulate the discipline of design, what it is that designers do and how they think, is not a new area of academic study (Thies 2015; Kimbell 2011). Early work by scholars such as Jones (1970), and Buncanan and Margolin (1995) explored how designers undertake designing. Subsequent researchers conducted extensive work with both experienced designers and design students through; interviews, observations, case studies, experimental studies, simulation, reflecting and theorising (Cross 2007; Lawson and Dorst 2009; Lawson 2004). They explored the cognitive processes and practices of designers to understand the thinking and methods that are used in design activity (Kimbell 2011). This work uncovered skills that can be attributed to designers regardless of design disciplines such as architecture or industrial design (Cross 2011).

One of these skills that distinguishes a designer from other fields and disciplines is their ability to create tangible things through a process of physical and digital sketching, three-dimensional (3D) modelling, and prototyping (Cross 2006; Lawson 1990). These skills, referred to as codes by Cross (2006) and as representations and experimentations by Lawson (1990), are regarded to be the language of design (Cross 2006). This is evident through the creation of tangible outputs that allow a designer to understand what may or may not work. The outputs also serve as a record of the process, an external memory space for the designer and their work. The creation of tangible things translates abstract requirements, ideas and concepts into concrete objects (Cross 2006). These objects can also be used to communicate and share ideas, and in this sense, are known as 'Boundary Objects'. These boundary objects (Star 2010) are those which 'inhabit several intersecting social worlds and satisfy informational requirements of each'. They have strong cohesive properties and are flexible and recognisable across cultures.

Another insight from the work to define the discipline of design is its unique approach to understanding problems and developing solutions to them. In many fields a problem-focused approach is used, where time is typically spent analysing a problem before moving on to consider a plan of action and solutions. By contrast, according to Cross (2006) and Lawson (2011), in design these activities are contemplated simultaneously. Lawson 1990, called the designer's approach 'solution-focused' ways of working, offering that designers may understand the problem more as they develop a range of solutions. In some instances, this process might not appear to be sequential or even rational. Solution-focused ways of working often present as a more fluid back and forth action between the problem and solution spaces. The exploratory process of challenging both leads to greater understanding and in the end a more diverse range of solutions (Cross 2011; 2006; Dorst 2006).

The work by academics suggests that designers also possess non-tangible skills; those that cannot be seen or do not have a physical manifestation. Some of these non-tangible skills relate to the confidence, approaches and mindset of the designer; their ability to ask 'what if' questions and take risks, their comfort in ambiguity and confidence in their own creative abilities (Cross 2006; Campbell 2009). These types of skill are often tacit, come naturally through experience (Cross 2011; Wood, Rust and Horne 2009). Sanders and Stappers (2008, 15) state:

"By selection and training, most designers are good at visual thinking, conducting creative processes, finding missing information, and being able to make necessary decisions in the absence of complete information"

Other skills relate to the reflexivity of a designer. Schon (1987) states that designers 'think in action' and are naturally reflective, observing the world and making meaning of those observations. The confidence within these approaches is manifested in a designer's ability to learn from 'failure'; designers are optimists, innovative and use their imagination, according to Cross (2011). In addition, Tonkinwise (2011) states that designers have skills

in the creative manipulation of forms and visual elements to create a cohesive aesthetic or style that are crucial to the success of a proposed design solution.

One of the arguments for the increased use of design to drive innovation lies in these non-tangible skills. For example, the Royal Society for the Encouragement of Arts, Manufactures and Commerce (RSA) proposes that design is a form of resourcefulness (Campbell 2009).

“Ready to improvise and prototype, brave in the face of disorder and complexity, holistic and people-centered in their approach to defining problems, designers have a vital role to play today in making society itself more resourceful ”
(Campbell 2009, 1)

They argue that, whilst still valuing the profession of design, designers could share this skill with other citizens, enabling them to foster their own sense of resourcefulness, create behaviour change and overcome the challenges within contemporary society (Campbell 2009).

The RSA is not alone in this view; those within the design profession also support the notion that design is uniquely placed to respond to the challenges of contemporary society. Designer, David Swann, in his chapter for Design in Health (2017), agrees with this sentiment, stating that *“our innate, creative and innovative nature will need to be harnessed”* (27) to rise to the challenges of the 21st Century. In addition, Cottam and Leadbeater (2004) argue that accepted thinking on economic and social issues needs to be challenged through design innovation. And Manzini (2017), believes that design is important in ‘shape shifting’ new societal futures.

Designers working in these cross-sector, interdisciplinary collaborations are often faced with a range of multifaceted issues. These ‘wicked’ problems can be open, complex and multi-dimensional, without a clear or optimal answer (Rittel and Webber 1973; Buchanan

1992). They do not suit traditional problem solving methods, where a problem can be easily defined and a solution can be found through a defined process and outcome (Thies 2016; Muratovski 2016). Therefore, new and innovative approaches and ways of thinking are required such as a solution focused approach to frame, explore and propose solutions to them. As such, literature suggests that designers have long been working with these types of problems (often more akin to those that people have in everyday life), as design practice is an activity which works with and often embraces messiness, intuition and uncertainty (Dorst 2006; Cross 2006).

However, despite the suggestion that designers are well skilled and experienced to work on these contemporary issues, design methods are increasingly being used without designers. This is something that academics who have studied the discipline of design find difficult. Lawson (2009) and Kimbell (2012) suggest that one cannot separate the designer's skills and thought processes from the methods used and proposed solution. Further studies show that the experience of the designer will have an impact on the process, range of options and outcomes (Cross 2006; Lawson and Dorst 2009; Schon 1983), and therefore the designer is integral to the process.

2.2 The rise of Design Thinking

This increase in demand for design methods without designers has led to the emergence of a concept referred to as 'Design thinking'. Johansson-Sköldberg, Woodilla and Çetinkaya (2013) outline two key areas that encompass the term. The first is a discourse within professional design and academia (within the design discipline) that seeks to define what is distinctive about what designers do and how they operate "(to) *create knowledge for its own sake or for communication to design students*" (Johansson-Sköldberg, Woodilla and Çetinkaya 2013, 124). The second, and more recent use of the term is within business and managerial sectors. Here design thinking methods and strategies are used as a tool for

innovation, using iterative, user-centred approaches to encourage empathy and ‘out of the box’ thinking (Carlgren 2013; Thies 2015; Kimbell and Street 2009).

The recent interest in design thinking within business suggests that this is a new concept. However, Kimbell (2011, 2), states that Design thinking is not a new practice, but a new term that reassembles “*some of the approaches, knowledge and practices of professional designers*”. It was borne out of the academic discourse in the 1970s and 80s to define design methods. Since then, in the academic realm the concept has been shifted by various scholars as they add to the debate on what design and designing is (Kimbell and Street 2009) with many moving away from the term all together. However, the term remains strong within business and managerial literature with increased public attention to Design Thinking attributed to IDEO⁴, an innovation consultancy led by CEO Tim Brown. Brown believes that thinking like a designer can transform the way organisations develop products, services, processes and strategy (Brown and Katz 2009), sharing his view through a series of books and TED talks.

With so many uses and discussions on the term there is no one distinct authoritative definition. Despite their differences, both discourses use models to help to understand and communicate the process of design (Kimbell and Street 2009; Lawson and Dorst 2009). Within the academic area much of this relates to the skills summarised earlier in this chapter. Models are commonly reflective, process documenting tools used to summarise and communicate to others the steps, stages and spaces that designers work within (Cross 2011, 2007; Lawson 1990) or the way in which designers’ frame and solve complex problems in unique ways (Buchanan 1992; Kimbell and Street 2009).

4 A global design consultancy, known for its pioneering human centred design work. CEO Tim Brown is also known for TED talks, books on human centred design and online method kits.

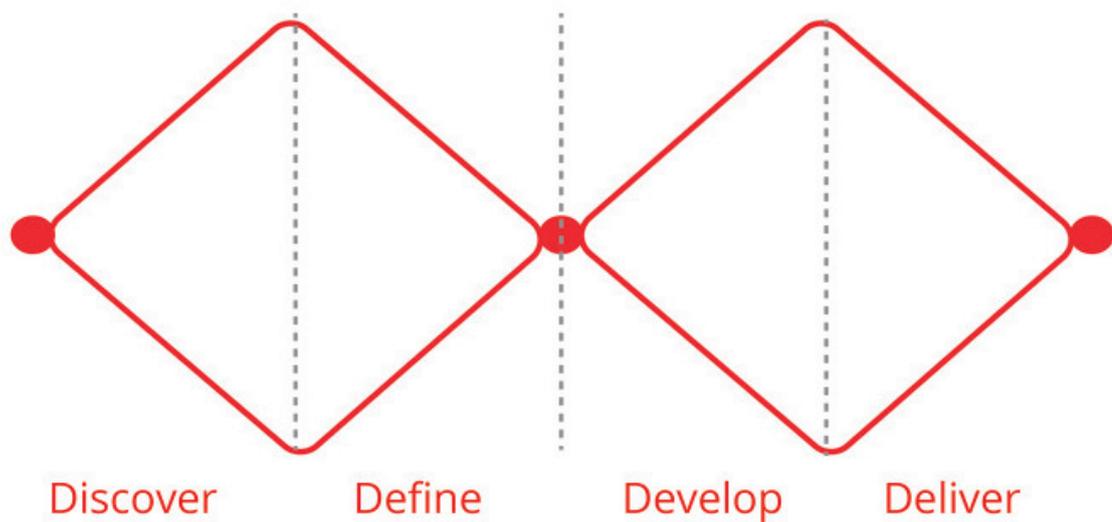


Figure 4: UK Design Council’s Double Diamond- A model to describe the phases that designers move through, it features a series of divergent and convergent stages.

In contrast, the business sector uses models as methods for problem solving and innovation; the majority present a linear process method something designers argue can be unrealistic in solving wicked problems. The Design Council (2007) sought to document how design has become formalised as a business process, yet there is no single comprehensive model to design.

Instead a variety of processes and methods were in use, depending on the problem to be tackled. This highlights that the role of design in business is not ‘clear and well understood’ despite an increased acceptance (Hernandez et al 2017). As part of their work the Design Council developed the Double Diamond diagram to describe a design process, which, unlike a linear model, is a series of phases which focus on the divergent and convergent aspects of the design process (Figure 4).

This encouragement to use design methods has resulted in an increase in ‘how to’ books and literature both within the business field and to more general public. Many of which have no reference to, or development on academic theory (Johansson-Sköldberg, Woodilla and Çetinkaya 2013). In recent years there has also been an increase in ‘toolkits’. Examples such as the Inclusive design toolkit (Clarkson et al 2007) and IDEO’s human centred design toolkit (2011), Design kit: The field guide to human centred design (2015)

and the website service design tools make resources available to the public as a way of introducing these design methods to the wider community in contexts such as schools.

There is some conflict between these different applications of this term Design Thinking. Those with a background in academia are frequently sceptical of the theoretical underpinning of the managerial use of the term. Many academics view it as a positivistic⁵ approach that narrows design down to a simplified, sequential step process often applied without trained designers (Figure 5). This step process is commonly supported by a series of tools for innovation with little explanation of which methods to use in what context, or how they should be adapted to certain situations (Badke-Schaub, Roozenburg and Cardozo 2010). Knowledge creation in the managerial area is often fast paced, and can be disseminated using blogs and published books, with no peer review processes or perceived academic rigour. This contrasts with the academic world of journal articles and research outputs where knowledge on a subject is ratified through peer reviewed dissemination and discourse.

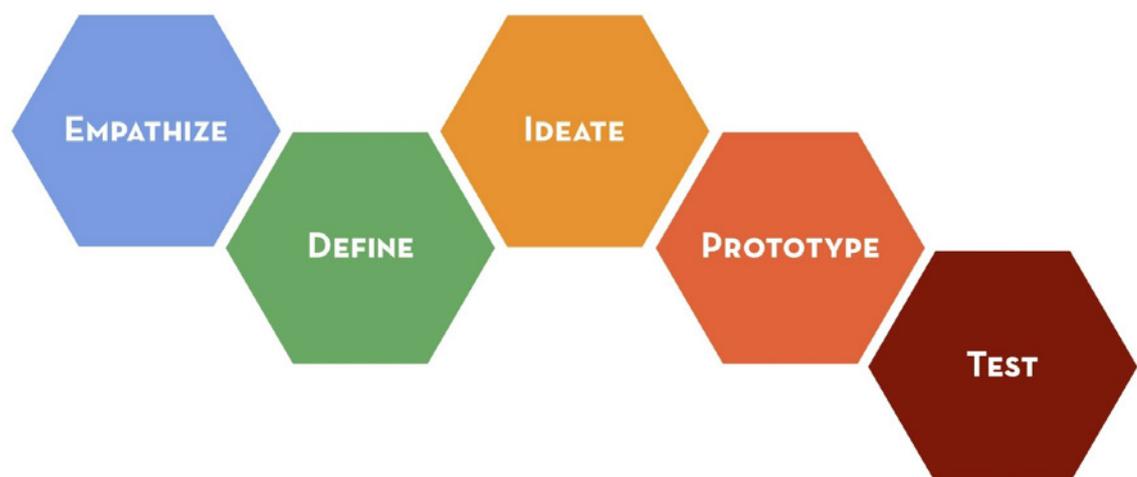


Figure 5: An example of a model of design thinking from d.school

⁵ Positivism is a theoretical perspective grounded in the belief that all knowledge can be observed and scientifically verified (Crotty 1998)

However, it could be said that the managerial approach of design thinking is more outward looking and inclusive. It seeks to exploit the problem-solving aspects of design to explore what it can offer to others and how to engage others to make design more accessible (Kimbell 2011). Design here is not the privileged domain of a few designers. Despite the conflicts, this proposition is, however, also recognised by some academics. Lawson and Dorst (2009, 32) state that Design Thinking processes can help to structure design work and *“enables non-designers to understand design, albeit in a limited way, by relating to a common activity (problem solving is, after all, an incessant universal human activity)”*. There is also a real legitimacy to the idea of Design Thinking with the publically funded UK Design Council that advocates for people to use Design Thinking methods in innovation for better user-centred design (Kimbell 2011).

As more sectors use and find success in Design Thinking and the use of design methods, there is an increased debate in academia about where the professional designer fits. Of increasing concern to academics is this use of Design Thinking without any input from design professionals. There is a growing discussion on the competences needed to use design methods, and the importance of specific skills and training. For example, many businesses will use design as a process, even where there is little or no design training in their companies (Hernandez et al. 2017). Business and managerial sectors have a desire to use Design Thinking problem-solving on challenges facing their organisations with little or no consideration for a designer’s role. Burdick in her 2009 talk summarises this issue below:

“For some time now, academics, business leaders, and journalists have celebrated Design [Thinking sic] as the saviour for failing corporations, the secret of savvy managers, and the resurrection of the MBA.... ‘design’ is not the discipline that we know and love—that is, it’s not the province of design practitioners, researchers, and educators. Instead, ‘Design’ is variably a value-add, an everyday event, a working method, a byproduct, a literacy, and a complete abstraction. And frequently designers are nowhere to be found.” (Burdick 2009, 3)

Academics reason that whilst non-design professionals might find some success with design methods, there is an increase in quality and depth when an experienced designer is involved. Cross (2006; 2011) argues that everything around us has been designed, and it is the quality of this design that affects us all and impacts on our quality of life. Lawson (2004; 1979) believes that this 'quality' comes from a certain type of knowledge, skill and expertise that can only come from the experience of design and design training. Lawson and Dorst (2011) distinguish between those who engage in design thinking and those who make 'creative leaps'. The former being '*activities (that) may look like design but in reality, they turn out to be little more than a series of choices or perhaps simple problem solving*'. A further distinction is made between those novices who consciously follow a series of stages and steps and the trained designer who will do things unconsciously and automatically.

Academics argue that without a trained designer, the tangible aspects of designing are lost, the 'thinking' is separated from the 'doing', there is a lack of aesthetics, critique and quality, and the process is over simplified (Tonkinwise 2011; Cross 2011). This competence is important; it argues the need for trained design professionals since their involvement has a bearing on the outcome of using the design methods.

"The application of design thinking in a design process thus requires relevant tools, but it also requires design competence in order to obtain valuable results, just like the carpenter needs competence to thoughtfully use the hammer. Anyone can build a chair, but the propensity of the chair to be attractive, well-functioning, and safe, etc. increases when competence is included in the process... If design is viewed solely as methods, distinct features are missing."
(Thies 2016, 18)

The quote above demonstrates that an argument can be made that design thinking skills can only take a non-professional so far, and that the skills (of a trained designer or other professional) such as drawing, high fidelity prototyping and lateral thinking are required past the idea generation and innovation stage. This is most easily understood in product

design disciplines where physical prototypes are necessary, but is harder to demonstrate in others such as service design where the outputs and prototypes might not be tangible (Macdonald 2017).

This subject of the use of design methods with or without designers presents many questions that are still up for debate. This review has highlighted that one of the drivers for the use of design in other sectors is its ability to work with wicked problems (Sanders and Stappers 2016). One of the successes of design to tackle these problems lies in the experience, competencies and skills of the designer and not solely in the methods. However it is clear that some sectors are having success with the use of design methods alone, particularly in innovation. With the growth in other sectors using design methods, there is much more to be demonstrated regarding the skills of a design professional, points at which their skills are required, and the sorts of problems that they should be involved in tackling.

In addition, for those sectors who are using design methods (such as business), questions remain on how you can upskill the people involved to increase their competencies in using the methods and what impact this upskilling might have. Furthermore, questions remain on the best process by which these skills can be shared or taught, for example, Smulders and Subrahmanian (2010) question, 'Can you teach design thinking in a few courses?' 'In a way isn't that just teaching people to be creative in well-defined problems'?

2.3 The Demand for Design in Healthcare

One of the sectors in which there has been an increased demand for design methods and approaches is within healthcare development and research (Chamberlain, Wolstenholme and Dexter 2015). This is linked to a need for increased innovation, collaborative ways of working (Design Council 2013), and new ways of thinking on complex problems (Design

Council 2007). There is also a desire to include users' perspectives and experienced based ideas in the process of design (Chamberlain, Wolstenholme and Dexter 2015). The potential benefit that design and designing can contribute to the healthcare sector has been recognised in reports by UK organisations such as NESTA (Horne, Khan and Corrigan 2013) and The Design Council (Cottam and Leadbeater 2004, Campbell 2009) who encourage the use of design methods in the development of public services.

Understanding this relationship between design and health has been the focus of some recent publications. The AHRC commissioned report 'The State of the Art of Design in Health' (Chamberlain, Wolstenholme and Dexter 2015) sought to establish a greater understanding of the growing relationship between healthcare and design and to document exemplars of contribution and impact. The report highlights diverse design-led activities that use a variety of design methods and produce a range of outputs. The authors conclude that;

"the methods and approaches of design can engage with the diverse stakeholders to deliver the innovative outcomes that health and social care needs to respond to the challenges that face society today and on-going."
(Chamberlain, Wolstenholme and Dexter 2015, 52)

Another publication, Design in Health, brought together 26 case studies of design research in healthcare. Analysis of these 26 studies identified seven key challenges or themes and five emergent trends. The challenges refer to demands and issues that healthcare faces to which design is called to respond. Examples include non-communicable diseases, long term conditions, and wellbeing and mental health (Tseklevs and Cooper 2017). Both publications highlight the value and importance of design research and the 'leading role' that they can take in responding to healthcare demands.

The debate on the use of design with or without designers is also growing within the design and health literature as more of healthcare is exposed to design methods. It is

recognised that not all designers are trained or prepared for a role that addresses complex healthcare challenges and that the impact of design is not always clearly communicated. One suggested reason for the challenge that designers face is due to perceptions of design; people tend to associate design with physical things. However, as Sklar and Naar (2017) point out, *“when design is done well, the practice of design is invisible to the end user; a person navigates a hospital with ease for example”, “for the healthcare industry to realise the value it can gain from design, designers need to prove their work goes far beyond aesthetics”* (380). As a result, the value of design is not widely known and designers are not always a key part of project teams (Tseklevs and Cooper 2017; Chamberlain, Wolstenholme and Dexter 2015; Sklar and Naar 2017).

Macdonald (2017) suggests there are three positions that designer can take in healthcare: acting as designers in a consultancy model; involving and empowering non-designers to design alongside themselves (through methods such as co-design⁶): or relinquishing their own involvement by providing tools and processes to healthcare professionals. The final position is the one that is most like the use of design thinking methods in business sectors.

A recent co-design initiative that falls under this final position is the Experienced Based Co-Design methodology (EBCD) which has demonstrated a degree of successful healthcare innovation without the involvement of a design professional (Macdonald 2017). According to Donetto et al (2015), EBCD was first used in 2005 by healthcare professionals trying to create a more patient centred NHS. It is one of the early, well-known, formalised ways that design methods were used in healthcare (Bate and Robert 2007). Their use of participatory methods to engage and design alongside users led to the development of a free online toolkit of replicable methods, a ‘how to’ guide that formalised their process (Point of Care Foundation 2013).

6 Co-design is a method of design that involves end users and stakeholders as partners in the design process, generally through the use of creative methods delivered in workshops.

With a dramatic increase in uptake over the past decade its methods have been used and adapted to many settings, demonstrating economic benefit, service innovation and improved professional experiences⁷.

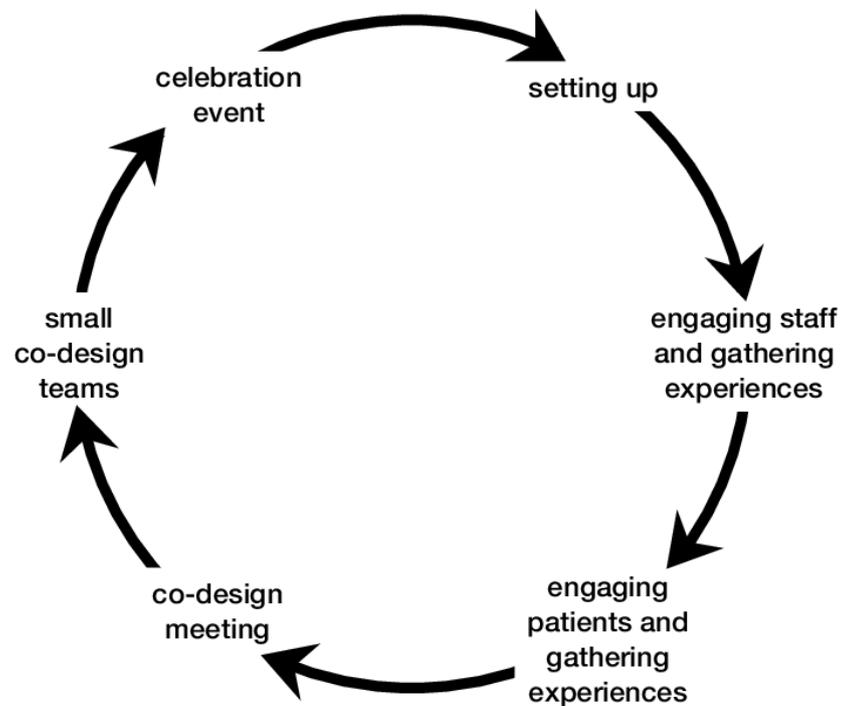


Figure 6: EBCD process model

Similar to the business sectors use of Design Thinking, the EBCD method (Figure 6) and subsequent resources were developed to use the methods of design and design processes without the need for support from professionally trained designers (Locock et al 2014). Although many have engaged with the EBCD resource, few projects have used the whole process and many have left out some of the more challenging steps (such as the co-design sessions).

Because of this, EBCD is often criticised by designers for its limited tangible service improvement, lack of ideation tools and is often described as ‘design like’. Furthermore, when the methods are used in isolation or without some of the more challenging steps there have been questions raised about the level of innovation achieved (Bowen et al

7 Examples of many of the successes of EBCD can be found in a summary by Locock 2014

2013). The critique is that, in EBCD activities, design methods have been distilled down into a simplified process. There is no recognition of the complexities that come with context or an appreciation for a designer's skills and experience (Burdick 2003). It is suggested that both are factors in projects leaving out the more challenging steps.

An example of design methods facilitated by designers can be found within service design. Alongside EBCD, Service Design is another design approach that is increasingly being used within healthcare (Design Council 2013; Chamberlain, Wolstenholme and Dexter 2015). Similar to EBCD in many of its methods, it is a way of working, but importantly is usually facilitated by a designer. Service Design considers user communities throughout the process, in an attempt to create value, relevance and stakeholder buy-in (Stickdorn and Schneider 2011; Kimbell 2011).

Recognised as profession since the early 2000s but with references to methods from a decade before that (Sangiorgi and Prendeville 2014), Service Design (unlike EBCD) does not necessitate a fixed process, solution or product. It is iterative and non-linear, and uses mixed methods to engage stakeholder representatives (Polaine, Lovlie, and Reason 2013). It has its roots in visual design techniques such as journey maps and personas, and also utilises methods such as shadowing from ethnography in the social sciences (Stickdorn and Schneider 2011; Stickdorn 2018). Service Design in healthcare moves away from traditional approaches wherein services, medical devices and health informatics have typically been designed in isolation from each other and their stakeholders. In healthcare contexts, it can help provide new opportunities to improve the delivery of products and services (Chamberlain 2017).

The contrast between EBCD and Service Design highlights the unique challenges that the profession of design faces as it finds itself working in other contexts. It has been argued that because of increasing pressures on money and resources on the NHS there is a desire to replicate the methods of a designer (through techniques like EBCD) without paying

the cost of the design professional. Others argue that the problem is the undervaluing and misunderstanding of design professionals. If their role looks too much like mere facilitation, then the skills of the designer, such as producing tangible embodied evidence through design prototyping and creating and capturing new meanings through design processes, are not fully articulated or understood (Macdonald 2017).

Macdonald supports this position on the undervaluing of designers in relation to healthcare practice's notion of evidence. He proposes that design and design processes do not fit within the conventional and institutional practices of healthcare and what that community understand as evidence. In this area, scientific tradition and evidenced-based practices such as Randomised Control Trials are the gold standard (Macdonald 2017; Jones 2013; Furniss et al. 2015) and within this scientific view, 'valid' design research cannot be recognised (Chamberlain, Wolstenholme and Dexter 2015). This can result in designers being expected to adapt to, and understand the established healthcare sector norms and conventions. In doing so it makes it difficult to articulate the value of the design professional within a design process. This lack of understanding means that designers are unable to support the health communities who might benefit from the involvement of a designer (Chamberlain, Wolstenholme and Dexter 2015).

2.4 Design and Behaviour Change

An area that demonstrates the potential of design's impact in healthcare, relates to behaviour change. Design and human behaviour are inherently linked (Craig and Chamberlain 2017). The design of something will elicit a response from us as we interact with it and form an opinion of it. The design of something can encourage or force us to behave in certain ways (Fry 2008; Niedderer 2013; Norman 1988).

Through a series of case studies, Craig and Chamberlain (2017) highlight the positive

impact that design methods can have on behaviour change by actively engaging people using visual methods, recognising holism and pooling expertise. The case studies were: the innovative design of a neck collar; the use of open design to engage young people with cystic fibrosis to design products to manage their medication; and the use of Design Thinking workshops with people who have a spinal cord injury to better manage their condition. The design methods used by designers in these projects positively impacted on behaviour. For example, new behaviours developed out of the projects; people could use their strengths to *'move forwards in a different way'*. Design offered a new approach, showing people what they were able to do (Craig and Chamberlain 2017).

The case studies used cover a range of design methods and approaches. The Design Thinking workshops are particularly interesting. They derive directly from the RSA's belief that design could support society by sharing some of the designer's non-tangible skills (mentioned earlier in this chapter). In their project 'Design and Society', the RSA (2009) proposed that design can help those who need to be resourceful. To explore this theory, they identified healthcare and condition management (specifically those with a spinal cord injury) as a place in which there was a need for resourcefulness and placed a call for projects in this area.

This is the background to consecutive studies by Craig et al (2013) and Wolstenholme et al (2014) that have explored design's impact on behaviour change in long term conditions. The first study, in response to the RSA's call, undertook exploratory inpatient Design Thinking sessions at the Princess Royal Spinal Injuries Centre Sheffield. The second introduced Design Thinking sessions as part of a rehabilitation program offered at the same unit.

Activities used in both sessions were intended to develop patients' abilities in skills attributed to designers (covered at the beginning of this chapter), with a focus on the non-tangible. For example, encouraging creative thinking, and building confidence to

communicate and prototype their ideas. The aim was to empower people to take control of their interactions with their environment and future plans as they learned to cope with their injuries. Feedback from patients who took part in the sessions suggested they had a change in perspective on approaching the problems they might face in the future, with increased confidence to try new ideas. Quantitative data taken as part of the second study showed statistically significant, positive changes on self-efficacy measures. This leads to the suggestion that design thinking workshops as part of rehabilitation could contribute to increased self-efficacy that could lead to engagement in management behaviours in people with a spinal cord injury (SCI) (Wolstenholme et al 2014).

In recent years, there has been increasing interest in understanding how design skills can be applied to encourage behaviour change in long term conditions. As far as the literature suggests, the studies reported here that focus on developing design abilities to empower and upskill patients with health conditions are novel. Design for behaviour change in the context of healthcare is an emerging field with much scope for investigation and development. There is scope for research that builds on the groundwork set by the studies discussed here. For example, further research might usefully explore the methods and contexts of use, understand where the work fits with other behaviour change strategies and build on the discussion around the role of design and the designer in healthcare.

2.5 Adolescents and Long term Conditions

The UK NHS was conceived in 1948. At that time, the major health crises of the UK were those attributed to acute conditions, where patients primarily had a short episode of illness and were treated as inpatients in hospital (Cottam and Leadbeater 2014; Wanless 2002). Recent advances in medical technologies as well as an increasingly ageing population, changes in lifestyles and work practices have meant that people now survive for longer with conditions and diseases that previously would have resulted in a sooner death,

e.g. stroke, asthma and diabetes (Wanless 2002). As a result, health systems around the world have seen a shift; the challenges of acute illness in previous centuries have largely been replaced by an increase in long term conditions and the associated challenges of managing people living with such conditions (Cottam and Leadbeater 2014; Wanless 2002; DoH 2012).

The Department of Health (DoH) (2012) defines these long term conditions (LTCs) as those that cannot, at present, be cured, but can be controlled by medication and other therapies. Long term conditions vary considerably. Genetic (or congenital) conditions, such as cystic fibrosis, will be with a person for the entirety of their lives, whilst others might develop a LTC later in life (acquired), such as diabetes or cancer. Some of these LTCs will have a terminal prognosis within a short timeframe. Others will have symptoms that flare up periodically, and some will require continual control and management strategies over a natural life course.

Long term conditions place a huge strain on the NHS. There are an estimated 15 million Britons (30% of the population) living with a LTC (Cottam and Leadbeater 2014), which accounts for around 70% of NHS spend, 80% of GP consultations, 60% of hospital bed days and two-thirds of emergency admissions (Ellins and Coulter 2005; Goodwin et al 2010). The Commons Health Select Committee predict that this will rise to 18 million Britons by 2025. The increase in some LTCs is exacerbated by lifestyle factors such as smoking, physical inactivity, obesity, poor diet, and increased alcohol consumption (Wanless 2002).

To reduce the strain on the health service, successfully managing these LTCs has been a priority for the NHS since the 1990s. In contrast to acute conditions (in which much of the condition management is completed by healthcare professionals), most LTC management is completed by those who live with a LTC, their families and caregivers (Health Foundation 2011). The NHS recognises that effective management of health and wellbeing results in a better quality of life for patients, reduced use of NHS resources and, in turn, reduced

healthcare costs (Goodwin et al 2010).

With this shift in care provision philosophy, patients are now expected to take a much more active role, doing most of their condition management themselves (Health Foundation 2011). This contrasts with a more traditional, paternalistic model of healthcare, where patients are traditionally passive in respect to expert health professionals (Barlow 2002; Ellins 2005) This more traditional model is historically used in acute condition management, an approach that Coulter (2002) describes as 'disempowering and demeaning'. However, there will be times, perhaps during an exacerbation of symptoms, where this paternalistic model is still required.

It is recognised that this shift in the philosophy of healthcare provision presents a challenging and difficult task for the healthcare service; the professionals delivering the service and the patients who may need to develop skills to support their condition management (Cottam and Leadbeater 2004). However, this movement from passive to active endeavours should *'support a different pattern of contact which may lead to fewer crises and inpatient admissions'* (The Health Foundation 2011, vii). It is hoped that by adopting this approach the patient-physician partnership will transform into a more equitable, collaborative partnership with more empowered, active patients reducing the burden on the NHS (Health Foundation 2011; Alexander et al 2012).

Research suggests that most patients with LTCs do want to take an active role in the management of their conditions (Picker Institute 2005; Flynn, Smith and Vanness 2006). However, identifying an appropriate approach and programmes to support these patients is complex and affected by a huge range of factors including age, social and cultural issues, the condition itself, the patient's personality, their support networks, and physical and mental resilience (Ellins and Coulter 2005; Lau-Walker and Thompson 2009; Flynn 2006). Research to date has focused on a relatively small number of conditions and age ranges

and might not represent the wider capacity of patients who self-manage⁸ (Ellins and Coulter 2005). For example, in 2012 the Department of Health (DoH) released a report on child health outcomes. A key recommendation of this report was the need for focus on adolescent health. The report highlighted that of all the age groups in the UK, it was the only one that had not seen significant health improvements over the past three decades, with long term condition outcomes worse than in adults (Department of Health 2012; Davies 2013). At the time of the report in 2012, adolescents⁹ made up 12% of the population. An estimated 15-20% of these adolescents have a significant ongoing healthcare need that relates to a long term condition (Sawyer 2005). A key recommendation from the report was to equip children and young people (adolescents) with skills and knowledge. To enable them to navigate the complexities of life, manage long term conditions and improve health outcomes (Department of Health 2012).

8 Self-management (SM) is a holistic term generally defined as the management of one's health. Lorig and Holman (2003) argue that we all self-manage, regardless of health status, whereas others define it in relation to a specific condition (Lau-Walker and Thompson 2009). Self-management definitions include; having the knowledge and skills to support your own health confidently, managing medication and treatment regimes alongside diet and lifestyle, carrying out normal roles and activities and managing the emotional impact. This is all within the context of a person's psychosocial, financial and social circumstances (DoH 2012; Lorig and Holman 2003). However, the term self-management is a contentious term so it is not used here; instead, this thesis refers to condition management to cover all forms.

9 Adolescence is defined by the WHO as the ages between 10 and 19, although some class adolescents up to 24 to include those classed as young adults. This can be further broken down into; early adolescence (10-14), late adolescence (15-19) and young adulthood (20-24). (Sawyer et al. 2012). In this study the WHO definition is used.

A focus on adolescent health is important, not only to support current adolescents but to impact on a generation's health behaviours. Health patterns and the foundations of a good mental health are formed during adolescence (Department of Health 2012). Health behaviours that are established during this time are likely to continue and underpin a person's adult health (Sawyer et al 2012; Department of Health 2012; Lemer, Cheung and Davies 2014). Therefore, a greater focus on this life stage is a window of opportunity to make a valuable investment in future societies and future healthcare demands. This is recognised by Tseklevs and Cooper (2017, 2263), who state that the challenge of design (and healthcare) is to focus on preventative services, that *"favour and place emphasis on living healthier in older years"* and suggest that designers could shift to focus their contributions through the life course from "prenatal, childhood, adulthood".

A further reason to focus on adolescence health is to support the balance between risk taking behaviours and health management behaviours. Adolescence is a stage at which increased autonomy can mean an increase in risk-taking behaviours (Sawyer et al 2012). Combined, these negative risk-taking behaviours can lead to lower levels of health for those who have long term conditions. The result is often lower participation in the activities needed to maintain good health such as; taking regular medications, completing exercise routines and making dietary and lifestyle choices that support their health. Conversely, it is in adolescence that individuals take over management of their own health conditions from their parents (DoH 2012). Learning positive health behaviours that continue into adulthood can have vast benefits in terms of health including increased life expectancy, increased self-confidence and self-control, improved quality of life and decreased pain and depression, all of which can lead to a reduction in the use of healthcare services (Kirk et al 2010).

What is still relatively unknown is how to encourage and support adolescents with long term conditions to improve their health and engagement with healthcare services, engage them in research and give them greater prominence in health agendas (DoH 2012; Sawyer

et al 2012; Barlow 2002; Lemer 2014). Despite presenting with very different challenges to other age groups, adolescents are underrepresented as a standalone group in healthcare research (Sawyer 2012; Lemer, Cheung and Davies 2015). Historical understandings have resulted in this age group usually being placed alongside children or occasionally in the older ages, with adults. A specific focus on adolescent health is much younger as a practice in comparison to child health. For example, the International Paediatric Association was established in 1910 whereas the International Association of Adolescent Health was only established in 1987.

Where there have been studies, they have generally focused on a few conditions such as asthma, diabetes, cystic fibrosis and specific day-to-day management (DoH 2012; Barlow et al 2002). In many cases, adolescents are not represented in the studies and instead the transfer of self-care models designed for adults is commonly undertaken, often unsuccessfully (Milnes and Callery 2003; Hawley 2005 cited in Kirk et al 2010). Therefore, general condition management literature is relevant here and represents the industry standard.

The following indicators of condition management are considered the same across all age populations; medical management of a condition, carrying out normal roles and activities, and managing any emotional impact (Lorig and Holman 2003). For these to be achieved successfully research indicates that management approaches need to develop day-to-day problem solving skills, increase self-efficacy, improve confidence issues, and increase a patient's knowledge, skills and competencies (Ellins 2005; Health Foundation 2011). A review by the Health Foundation (2011) suggests that management programmes based upon changing a person's behaviour can be successful and that changing certain behaviours can improve health outcomes.

The approaches to help patients to manage their condition can be varied and are supported by a range of strategies and materials including; booklets, lectures, exercise

sessions, leaflets and role play. Routines and practices can be managed or delivered by health professionals or laypersons, and can be condition specific or generic (Barlow 2002; Lawn and Schoo 2009).

Studies that have considered where further knowledge is needed to support adolescents specifically have examined the following areas: developing independence and confidence for greater self-efficacy; supporting adolescents to make positive contributions and live full lives (Kirk and Beatty 2010; Sawyer et al 2007); education and coaching in problem solving, information giving and skills training (DoH 2012; Sawyer and Aroni 2005; Lindsay et al 2014; Kirk et al 2012); engaging adolescents in the development of and participation in research, and finally peer support and group sessions (Sawyer and Aroni 2005).

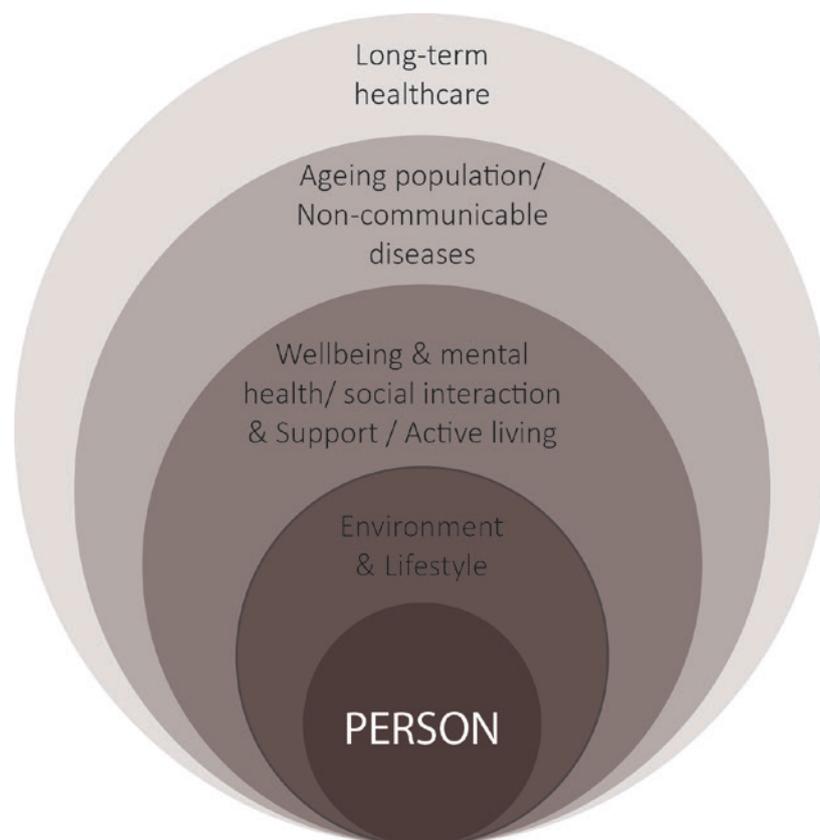


Figure 7: Casual Relationships Between the Challenges in Design for Health (Tseklevs and Cooper 2017)

This question of how best to support patients in the management of a long term condition could, by its nature, be defined as a wicked problem (Prendiville 2017). Complex patients with identical diagnoses and possibly some shared symptoms will still need different treatment regimens and will see different doctors, as well as having different social, family and financial situations that impact on their healthcare experiences (Craig and Chamberlain 2017). Furthermore, long term healthcare in general is influenced by many factors. Tsekeleves and Cooper (2017) suggest that there might be a causal relationship between the seven identified challenges (from their analysis of 26 case studies), further demonstrating the complexities of long term health (Figure 7). These complexities can be compounded when the patient population is adolescents, as they learn to take more control over their lives, their health, seek increased autonomy and engage in more risk-taking behaviours. If supporting condition management is defined as a wicked problem, then as this review suggests, designers and design methods are well placed to consider solutions.

This contextual review situates my enquiry in relation to issues concerning the use of design and design practices within the healthcare sector. It has introduced how and why these fields are interacting and highlighted some of the tensions between them. More importantly it has revealed how the interaction between these disciplines has provided much scope for research and further investigation. Two of these areas are of relevance to this study and its contributions. The first relates to long term conditions within healthcare, the management of which is contextualised as a wicked problem.

There is already a precedent for research in this area. Research presented as part of this review has established groundwork on design thinking, condition management and behaviour change. Research by Craig (2013) and Wolstenholme (2014) demonstrates that developing design thinking skills in people who have a spinal cord injury has a positive impact on confidence, self-efficacy, problem solving and generating ideas. As far as a

literature review shows, there has been no research yet that applies a similar method to other conditions or to adolescents. There is a demand, however, to include adolescents in healthcare research as a focus on a life stage model or preventative healthcare. In fact, a scoping review of the literature suggests that adolescents have not been engaged in any type of design research outside of product development. Therefore, this study is situated within this gap in the literature.

The second area in which this study is situated relates to the role of the professional designer in healthcare. Design Thinking is an increasingly popular and acceptable problem-solving strategy. This review has commented on some of the controversies that have developed from this. For example, the way that designers' skills and processes are being used to tackle problems without the input of a trained designer. Or how the types of problems, such as wicked problems, that designers generally deal with do not fit the linear problem solving model that non-designers apply to them. There is still much scope to understand these issues and what impact they might have, both on the designed solutions and the value of the design professional. Since many of the complexities of healthcare, and healthcare service provision, are presented as wicked problems, this study, which explores design methods in healthcare, intends to contribute to this developing discussion.

Chapter Three: Design as Method

This chapter covers the context, history and different types of design research, and outlines the type of design research that this study has undertaken. It covers how knowledge is generated in this type of research, and importantly juxtaposes this with knowledge and evidence generation in the healthcare context. Finally, this chapter introduces some of the unique approaches of design research.

3.1 The Historical Context of Design Research

“Prior to the turn of the century the word research carried no specific scientific meaning and predated the division of knowledge into arts and sciences”
(Frayling 1993, 1)

Historically design was taught in vocational design schools. Here the onus was on the accomplishment of skills in design crafts, and research was undertaken as part of the design process or in terms of design history. The idea of design research is a relatively new concept in comparison to the sciences which were taught in universities where research had always been a key component. Therefore, understanding on design research and design knowledge (as research) is relatively modern. Key to this history is the Design Science decade in the 1960s, where an attempt was made to understand design with objectivity and rationality in a similar way to the sciences (Frankel and Racine 2010). As a result, the 1962 Conference on design methods established design as a valid scientific research subject (Frankel and Racine 2010; Gedenryd 1998) and resulted in the founding of the Design Research Society in 1966 (DRS website 2018).

During the 1970s, some design academics began to reject design science. They were concerned that it was not the right approach to understanding design knowledge due to its simplistic comparisons and distinctions (Schon 1983; 1987). Simon (1996) was one of the first to conceive design as a distinct subject and form of research different from

science and the humanities, suggesting that Design research (as opposed to scientific research) is not conducted for its own sake but to improve real-world situations, to “transfer existing situations into preferred ones” (67). A further argument for the rejection of design science relates to the context of design. Glanville (2015) argued that you cannot separate out design and research, neither can you separate design from the artefacts and objects produced or the behaviours that are a result of it (Cross 2006, 2011; Glanville 2015). It is out of this rejection of design science that Rittel and Webber (1973) introduced the idea of wicked problems mentioned in the previous chapter. Subsequently, wicked problem theory was viewed as the antithesis to the scientific approach with its inadequate sequential structured methodology (Frankel and Racine 2010) generally based on deductive and inductive forms of logic. In addition, wicked problems require abductive logics which design practices and research methods are founded upon.

In recent years, there has been much discussion of design research methods and approaches, evidenced by an increase in literature and design conferences and fuelled by the influence of the internet as the field advances to face the challenges of society (Frankel and Racine 2010). Rather than the previous one-size-fits all approach to research and design, the growth in the field represents the breadth of work and the wide range of approaches used in the pursuit of knowledge.

3.2 Design Research Approaches

Muratovski (2016) believes what separates the practice of design from design research is the difference between the goals and outcomes of each. Designers will seek a solution to a brief whereas design researchers would try to address a larger set of questions alongside it. For this to be successful, self-reflection is a necessary component (Burdick 2003).

Whilst Muratovski might have found a straightforward differentiation between the two, there is much debate amongst academics on how best to categorise or summarise the multiple approaches within design research. One of the most cited categorisations of research in the arts and design are Frayling's (1993) categories of Research *into* design, Research *for* Design and Research *through* Design (RtD). This final category '*through*' design is the closest to 'actual design practice' (Findeli 2004 cited in Godin and Zahedi 2014) in comparison to '*for*', where designers and their practice are 'the object of study', or '*into*' which looks objectively at design from outside the discipline (such as historians, psychologists or economists).

This final category of Research through Design (RtD) is related to the research contribution the 'practice' of design brings, and has since been associated with terms such as; practice-based, design-led research, constructive design research, project-grounded research and research-oriented design (Belcher 2014; Jonas 2007; Koskinen et al 2011). It "takes advantage of the unique insights gained through design practice to provide a better understanding of the complex and future-oriented issues in design and other fields" (Godin and Zahedi 2014).

This variety of terms is a result of the discourse, development, misrepresentation and criticism of Frayling's original categories (Belcher 2014). In their paper to 'demystify' the approaches to research through design, Godin and Zahedi (2014, 2) found that, despite their differences "*these authors are all concerned with an underlying shared goal; establishing aspects of research done through the design process and its resulting product*" with "*no vital contradictions*". In summary, the key to RtD is the construction of knowledge through a combination of practice, reflection on that practice, and the creation of outcomes, strategies or artefacts.

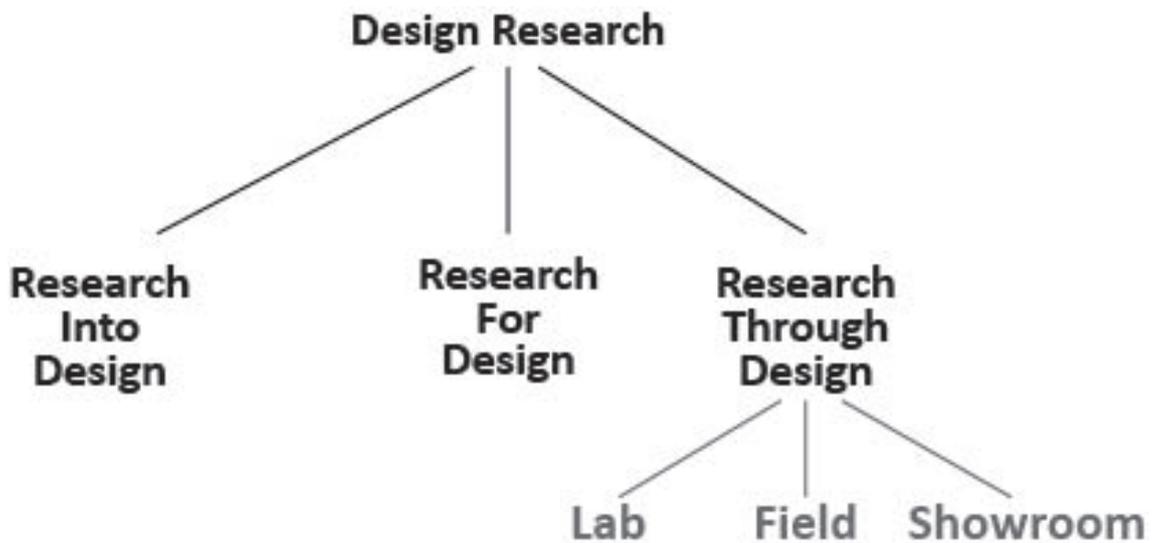


Figure 8: A tree diagram demonstrating contexts within Research through Design adapted from Frayling 1993, also discussed by Koskinen et al. 2011 (taken from Wheeler 2018)

Figure 8 shows how the approach and applications of RtD can occur within different contexts. These are the lab, the field and the showroom (Frayling 1993; Koskinen et al 2011). There are important distinctions between these contexts as they can influence the processes, assessments and role that design plays in the research (Mullaney 2016). The lab context is associated with testing pre-determined hypotheses through the use of prototype testing and evaluation. Design that happens within the showroom is associated with provocations or independently observable artefacts. Its aim is to generate design to make people think and debate through exhibitions similar to approaches found in fine art. Neither the lab or the showroom is a suitable for exploratory or generative studies; instead, for these sorts of study the field approach is appropriate (Koskinen et al 2011). Field research is all about context. Those who use a field approach to RtD follow things in their natural setting to contextualise and make meaning of them.

The contexts outlined by Koskinen et al (2011) rely on the production of artefacts in context to develop knowledge and as such argue that the knowledge is embedded in these artefacts, therefore they provide a physical outcome of the work. Another distinction of artefacts as outcomes in design research is offered by Candy (2006). Candy distinguishes

between practice-based or practice-led research. Practice-based research creates new knowledge through practice and the outcomes (artefacts) of that practice. In contrast, in practice-led research knowledge is created through the nature of the practice, and any artefact is not the main focus (Muratovski 2016 see Candy 2006).

These views on design research provide discussion on what constitutes RtD, but do not offer much information on how to conduct this type of research or what the methods of this practice might look like. Research through design is not a singular method or approach, instead it is nuanced, for example there is a multitude of ways that design practice intersects with design research (Wenseveen and Matthews 2015). Koskinen et al (2011) discuss how some methods of RtD research in the field are borrowed from interpretive social research. For example, design ethnography combines methods such as observation and interviews with design prototypes. The ethnographic methods inform the prototypes which are then placed back in context for further observation and development.

What is known is that for all types of research through design (practice-based or practice-led), methods need to be described in words and written about in detail to allow for discourse and comprehensive understanding, something which is pertinent in academic enquiry (Candy 2006).

3.3 Designerly Ways of Knowing

This discussion above has largely focused on the physical nature of design research; the prototypes, artefacts or things that can be interacted with. However, as was covered in chapter one, whilst it is a large component, there is more to a designer's practice (and subsequently the practice of design research) than the tangible things it produces. To fully understand design research involves an understanding of the approaches and mindsets that underpin it.

Muratovski (2016) states *“designers are still perceived as people who ‘make’ rather than people who ‘think’”(190)*. Design research links to ‘designerly ways of knowing’ or ‘design cognition’ (Sangiorgi and Scott 2015; Lawson 2011) which refers to the ways that designers innately know, think and act.

For academics such as Nigel Cross (2001), the understanding of these designerly ways of knowing has been key in the movement away from design science towards what he refers to as a ‘design discipline’. In ‘designerly ways of knowing’, Cross (2007) states that the ‘uncovering and understanding’ of these skills proves that there is an ‘expertise’ in design with its own features that are different from the generic models of problem solving (founded in the design science movement).

Furthermore, Cross (2007) states that design has its own distinct intellectual culture, but to reduce confusion and controversy, design research (and by extension - all research) should be:

- Purposive (worthy and capable of study)
- Inquisitive (should seek to acquire new knowledge)
- Informed (conducted with awareness of previous, related research)
- Methodical (planned and carried out in a disciplined manner)
- Communicable (generating and reporting results that are accessible by others)

(Cross 2007)

This is important, since articulating these designerly ways of knowing and approaches to research provides and communicates a legitimacy to those outside of design research. It also lays the foundations to the argument for design methods and designers to facilitate them.

3.4 The Fuzzy Front End

The previous chapter covered the movement to produce linear process models by those who are trying to use design processes in innovation and problem solving. These models are designed to be clear and communicable to all. What these models fail to communicate, though, is the ‘front end’ of the process. This front end is often referred to as ‘fuzzy’ (Figure 9), characterised by uncertainty, ill-defined processes, ad hoc decisions, chaos and ambiguity (Almqvist 2017; Sanders and Stappers 2016). It is a designer’s ability to navigate and embrace this that distinguishes design research from other forms of research.

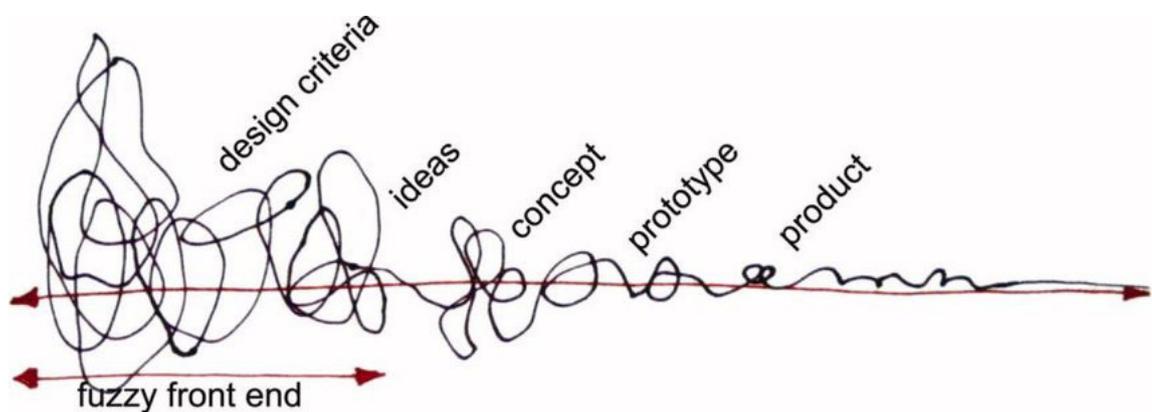


Figure 9: The Fuzzy front end of design (taken from Sanders and Stappers 2016)

During this phase, what is to be designed (or not designed) is unknown, through exploration and open ended questions, the aim is to develop and understanding, identify challenges and opportunities. This front end is crucial to the success of the more traditional processes that might follow; ideas, prototypes, testing etc. (2008).

A designer’s involvement and skills, particularly when engaging stakeholders, in these early stages is known to have a ‘positive impact’ with ‘long range consequences’ and is increasingly important. A designer engaged in this process will utilise skills in “creative processes, finding missing information, and being able to make necessary decisions in

the absence of complete information” (Sanders and Stappers 2008, 15). However, their methods and approaches might widely vary depending on the context, many of which might not be visible. As a result, articulating the importance of this phase (and remaining upfront about the complexities) to those outside of the profession is crucial to conduct design research.

Rather than try to articulate design research to individuals from outside design (such as those from scientific disciplines) in terms that they might understand (as with the design science movement), this ‘fuzzy front end’ adds to the argument put forward by theorists such as Rittel and Webber (1973), Glanville (2015), and Cross (2006). They believe that design research (and the knowledge gained through it) is a distinct subject that cannot be separated from behaviours, artefacts and objects. The fuzzy front end does not present a straightforward explanation of design research; it acknowledges the unknown, and the designers role in navigating through it.

3.5 Knowledge and Evidence in Design and Health

“Research normally means to seek deeply, with intensity. What is sought is reliable, new knowledge” Glanville 2015, 11

Research in healthcare has primarily emerged from the scientific disciplines with an objectivist approach. This maintains that reality exists independently of observation and objects can be studied to uncover their meaning (Crotty 1998). In contrast, designers generally conduct their research under the epistemological umbrella of social constructivism, whereby reality is not governed by a single truth that is waiting to be uncovered, instead, there are multiple realities which are constructed as we engage with the world and the people and objects within it (Crotty 1998).

Because of these opposing world views, evidence and knowledge are viewed very

differently between the disciplines. Scientific knowledge is a description of 'what it is' (Glanville 2015) and 'universal truths' (Fischer 2007), whereas design knowledge is '*a sense-making activity*' (Krippendorf 2007) concerned with what does not yet exist but might do (Glanville 2015).

Aristotle (384-322 BC) distinguished two main types of knowing (or knowledge). These are knowledge which is theoretical (known as Sophia), and knowledge based in practice, but referring to Sophia (known as Phronesis). Knowledge in design and design theory is Phronesis, a human and social construction based in practice. It is grounded in complex details where the circumstances are changeable, context specific or unable to be generalised (Glanville 2015).

Whilst both disciplines are "*looking at the world and imposing structure on it*" (Archer 1981), there are conflicting viewpoints on evidence. These include the impact the person conducting the research can have on the outcome or the role that they play in the research. To be fully repeatable, consistent and generalisable in the sciences, the researcher has no impact on the outcome (Glanville 2015). As Frayling (1993, 3) states, "*(a researcher) must submerge his subjectivity and personality in order to study it*", and the subsequent knowledge will remain for as long as it is not disproved. Ideally it will be the subject of continuous retesting (Glanville 2015).

This position is in stark contrast to much of design research which is often exploratory in nature and where knowledge is constructed (Cross 2007). In accordance with Phronesis evidence needs to be 'good enough' and not 'right or true' (Glanville cited in Wheeler 2018). There is not one perfect solution waiting to be uncovered; instead, it acknowledges the possibility of other potential solutions particularly within the complexities of wicked problems. Constructivist design research approaches focus on methods which collect qualitative data. This data can then be analysed for patterns and themes which allow the researcher to interpret the findings. Contrary to science, the designer is 'active' in the

research through ways such as how the research question is posed, which methods are selected, and the interpretation of the results with the aim to create something that does not yet exist.

Within the field of medicine, traditionally scientific evidence (from an objectivist epistemology) is focused on finding truths about the world through generalisable results often gained through quantitative means. Therefore measurable data that is repeatable and consistent is generally accepted as the main way to ratify research findings (although they might be supported by qualitative means) (Mullaney 2016; Cross 2007). Scientific methods are deemed to be rigorous, tested and controlled; they ensure the safety of patients, particularly when it comes to introducing a new drug treatment for illnesses, new medical procedures or devices. By this notion, the Randomised Control trial is viewed as the 'gold standard' in healthcare, as it embodies the high scientific, ethical and financial standards expected in healthcare research. However, there is a growing discussion that suggests that quantitative approaches alone cannot tell the full story of people's lived experiences (Wheeler 2018). And it is by this notion that Cross and others, suggest *'perhaps science rather had something to learn from design'* (Cross 2001).

As designers find themselves increasingly working in healthcare (and increasingly healthcare demands design methods and approaches) these opposing views make it crucial for the better articulation (and subsequent understanding) of RtD approaches. For example, one of the scientific paradigm's understanding of rigour is replicability. As no two designers will approach a problem or seek to solve it in the exact same way (Wheeler 2008), rigour in RtD cannot be judged in this way. However, demonstrating the rigour in RtD, through Cross's (2007) outlines of how design research should be conducted can demonstrate the validity of outcomes and the rigour in the process. This can be enhanced through documentation and 'being able to account for the decisions made throughout the process' (Wheeler 2018).

This chapter has summarised key literature on the practice of design research. It has provided information on the different forms, contexts, approaches and methods. Importantly these have been framed within the wider debate on the legitimacy of design research within other disciplines, and the need to better understand and articulate design as a distinct subject.

This research was conducted as a piece of practice-led research through design within the field context in healthcare. Design practice and iteratively designed artefacts are used to create knowledge and reflect on it. Furthermore, it acknowledges the ‘fuzzy front end’ of design research, embracing the uncertainty and using design practice to navigate this period

What this research seeks to do, through reflective practice and in-depth documentation, is describe the methods, processes and decisions. The intention is that this will add to the academic discussion on RtD, providing rigour and value to the study that can be communicated in the field of healthcare.

Chapter Four: Methodology

Following the previous chapter, which covered the history of and approaches to design research, this chapter begins with a summary of the methodological approach that was taken to conduct this study. It then briefly recaps the aims and objectives before introducing the mixed methods approach and the methods used. The chapter finishes by introducing the study design and information on ethical approvals.

4.1 Research Position

This research was conducted as a piece of practice-led research through design to explore, understand and seek new knowledge on how design practice could support adolescents who have long term conditions. Within this it sought to gain insights into how to conduct this sort of research in a hospital setting. In line with social constructivism (Crotty 1998), whereby knowledge is constructed (as opposed to waiting to be uncovered), it engages design practice to create knowledge and reflects on the complex nature of the context in which I am working (children's healthcare), the professionals who provide care within it, and the lived experiences of people managing a long term condition.

Importantly, it acknowledges differences in the worldview between the research approach and the context of the study. Recognising the impact that this might have, this study embraces the emergent nature of the study and the uncertainty of the 'fuzzy front end' of design research by using design practice to navigate this period.

4.2 Aims and Objectives

Aims

- To investigate the impact design workshops might have on a patient population's condition management,
- To explore how design practice can support the development of relationships with healthcare providers,
- To contribute to the discussion on the role of the design professional when design methods are used in healthcare.

Objectives

- To gain ethical approval through NHS ethics procedures,
- To conduct a literature review and period of design ethnography to establish a group of patients to work with,
- To run a series of workshops that demonstrate design skills and methods to patients,
- To use design ethnography to build a relationship with the patients' healthcare providers and to work with them to integrate these workshops into the current management practices offered,
- To use qualitative and quantitative measures to analyse the workshops,
- To make recommendations for other design researchers in healthcare based on reflective practice conducted throughout.

A Mixed Method Approach

In the previous contextual review chapters, it was illustrated that this study is situated between two disciplines with opposing worldviews, distinctive backgrounds, histories and epistemological viewpoints. In addition, the design research approach uses a range of methods to support the pursuit of knowledge. To satisfy the aims and objectives of this research (by producing evidence that constitutes knowledge in both design and healthcare

disciplines) and remain true to the research position, a 'mixed method' (also known as multi-method) approach has been applied. This can refer to both the combining of qualitative and quantitative methods and the use of multiples of either kind of method (Mullaney 2016).

Despite their different ontological backgrounds, qualitative and quantitative methods can be viewed as 'complimentary strategies' rather than 'competing and contradictory'. It allows a researcher to choose 'the appropriate method for addressing specific research questions' to combine data in 'new and unique ways' (Snape and Spencer 2003; Muratovski 2016). It is to take advantage of the strengths of the different qualitative and quantitative research paradigms that this study has chosen to apply a mixed method approach in this study.

Qualitative research aligns with social constructivism as it examines how people experience the world. It produces rich descriptions of emergent concepts and theories and "describes and displays phenomena as experienced by the study population" (Ritchie 2003, 31). Quantitative research describes, generalises and simplifies things, enabling the production of data over large numbers (Muratovski 2016). This quantitative data is viewed by some as 'facts' that come from research involving statistics and, as a result, some disciplines (for example, those from a traditional scientific paradigm) give qualitative data a lower status (Mullaney 2016). However, whilst quantitative methods are better at verifying and testing existing theories than they are at developing new ones, this can, as Ritchie (2003) suggests, "leave many potential questions unanswered, misconceived or inadequately understood". Consequently, for some research questions it is "not possible to generate a comprehensive understanding of phenomena by studying it using only one approach", and using both methods will provide different types of insight (Ritchie 2003).

4.3 The Methods

“It is therefore very clear that one does not begin by choosing a method. Methods can be sufficiently flexible to grow naturally from the research question, and in turn from the nature of the social setting in which the research is carried out.” Holliday 2016 20

This section gives detail to the methods used within the study. As stated in the quote above by Holliday (2016), the choice of methods in design research can be emergent, agile and selected as the research inquiry developed. This contrasts with the scientific approach in which methods are often predefined and set from the start of a study. This emergence is reflected in this study; whilst some methods were implicated from the start, others were introduced as the project developed. More information on the choice of method and where it was introduced can be found in the ‘practice’ section of this thesis.

Design Methods

A series of approaches known as design research techniques or methods were used in this study. These methods are visual or physical in nature, user-centred, participatory and creative, and often adapted to the context. They are founded upon abductive reasoning (concerned with what ‘may’ be), and convergent and divergent modes of thinking (Dorst 2015; Cross 2011). Crucially these methods can be used as standalone methods to gain understanding and insight and to build a picture of the context or can be used to validate observations and understandings gained from other sources (Thies 2016). A succinct summary of many of these can be found in the service design literature where they are commonly used (Stickdorn 2010; 2018). Some of these that were adapted for context and used in this research include:

- Co-creative workshops: A facilitated design workshop during which many design methods are used. Data gathered through methods prior to this workshop is often interpreted and brought along for review.
- Persona creation: developing a series of personas that bring together various characteristics to represent similarities between groups or people (Stickdorn 2010;

2018).

- User journey mapping: visualisations to illustrate an archetypal sequence of steps or the human process of moving through a series of stages.

Another design method used in this study is system mapping. System mapping is an umbrella term for the visualisation of systems. It is used as a way of sense-making, to “construct plausible understanding”, that can be tested with others through action and conversation (Prendiville 2017; Weick 1995). Prendiville (2017) discusses mapping and sense making within service design, referring to it as a human-centred practice to make sense of data by navigating the unknown through translation and visualisation. The subsequent presentation of this data is happening in increasingly varied ways including growing numbers of physical manifestations (Gwilt 2013).

Usually these design research methods are applied as part of a design process, by working through divergent and convergent stages. They are used with the end aim of a physical or service outcome or to gather specific data on a subject. Some of the methods used with the adolescents in this study were a continuation of work by Craig et al (2013), Campbell (2011) and Wolstenholme et al (2014) who adapted and developed design techniques and activities to teach and demonstrate design principles through the design workshop. The focus of these workshops is to illustrate elements of a design process, or a designer’s approach through experiential activities rather than design solutions, physical outputs or data.

Design Ethnography: Observation and Shadowing

As stated in chapter three, a RtD approach combines and borrows some methods from other fields, such as those from Ethnography (Koskinen et al 2011). Therefore, the categorisation of this method going forwards comes from design literature sources. A conventional ethnography (from social science and anthropology) is a fully sustained engagement observing or participating in a social setting. It employs an ethnographic

approach to provide rich insights into social interaction, beliefs and perceptions (Holliday 2016; Madden cited in Muratovski 2016). Traditional ethnography happens over an extended timeframe (ranging from many months to years). However, researchers outside these traditional disciplines are applying an ethnographic or ethnomethodological approach (Holliday 2016) in much shorter timeframes, something Handwerker (2001) refers to as 'quick ethnography' (collecting analytic data in 90 days or less).

Nova (2014) discusses the recent phenomenon of 'design ethnography'. Where those conducting research through design use ethnographic approaches such as observation and interview techniques. They aim to develop understanding of a person or people's 'behaviours, wants, needs, habits, expectations and fears' through the 'appropriation of ethnographic tools and vocabulary'. This design ethnography is shorter in timeframe usually due to constraints such as funding, time pressure and project limitations. As such this 'step-in-step-out' approach includes cases where one might spend only portions of a day or week, or select specific elements to study with a team (Muratovski 2016). For many, the first-hand contextual experience is the main intention. Stickdorn and Schneider (2018) class design ethnography as a research method to 'challenge assumptions and understand people and context', and state the following as service design methods; auto ethnography, self-ethnographic approaches and observations.

Design ethnography was selected for this study as a data collection technique as it is particularly useful when conducting research outside of one's own discipline. For designers, this first-hand experience allows them to build an understanding of the context. To achieve this, the methods of observation and shadowing were used.

Observation is a commonly used visual field research technique that is used by designers (Nova 2014; Muratovski 2016). It enables 'events, actions and experiences' to be seen first-hand by the researcher. This is especially useful for processes which involve several players and where an understanding of non-verbal communications is likely to be

important' (Ritchie 2003 p 35). Observation involves taking the role of an eyewitness to see; structures, settings, behaviours and interactions in a systematic fashion (Madden cited in Muratovski 2016). Shadowing, is a technique that involves following staff members as they go about their usual role to observe their behaviours and experiences (McDonald 2005). What is important about both methods is that they are a type of visual research that focus not just on the individual but also the environments, spaces, structures and settings they are within (Muratovski 2016).

Prototyping

The word prototype derives from a Greek word 'prototypon' which means 'first or early form' (Stickdorn et al 2018). Prototyping is a method employed by designers to 'test' ideas and concepts, from early in the design process. Sanders and Stappers (2016) define a prototype as 'anything that someone builds to represent a 'product' or experience before the actual artefact or event is completed' (p62) or a 'choreographed experience' of possible futures. A prototype allows a designer to externalise and extend their thinking to make ideas tangible and communicate with others (Sousanis 2015).

Traditionally made from wood or foam, prototypes are used to demonstrate elements of a visual language on a physical product. However, prototyping now covers a wide range of activities used to help understand what something might 'work like' or 'look like' in the 'expression of possible futures' (Sanders and Stappers 2016). This expansion of what constitutes prototyping is in part a result of the shifting foundations of the design discipline as it moves into new roles, working on wicked problems, and the development of design methods.

Prototypes can take many forms such as 3D models, storyboard drawings, and enacted scenarios. They may be used to understand the whole of an idea or just a portion of it (Stickdorn et al 2018), and they may be high or low fidelity. What is crucial about a prototype is that it should 'generate useful feedback' and 'drive an idea forward'. When

developing (or conducting) a prototype, it is important to consider how 'polished' it should present, since a less polished prototype can often enable more honest and imaginative critique (Brown 2008; Stickdorn et al 2018).

Prototyping is something that Cross (2011) relates to 'learning from failure', where a designer might use prototypes to learn what may or may not work before investing too heavily in an idea. He also suggests that prototyping opens new possibilities as people engage with a physical representation of their ideas. As Brown (2008) suggests, the aim of a prototype is not to finish, "*it is to learn about the strengths and weaknesses of an idea and identify new directions that further prototypes might take*".

Interviews

The interview is a research method that can be found in a range of research approaches and methodologies such as post modernism, feminism and constructivism (Legard, Keegan and Ward 2003). The interview is a form of 'conversation with purpose' or 'collaboration' between a researcher and a participant to gather data, gain understanding, share reflection and enquiry. Usually interviews are guided by a series of questions and can take many forms ranging from a fully structured interview to an informal chat (Madden cited Muratovski 2016; Stickdorn and Schneider 2018).

The choice of interview form is often directed by the relationship between the interviewer and interviewee and the intention of the data from the interview. In this study, two forms of interview were undertaken. To provide reliable, comparable data, in-depth, semi-structured interviews were employed, following a heuristic approach (Ritchie 2003; Douglass and Moustakas 1985). Chosen as the approach recognises the researcher's experience as key player in the research process and as a person with a strong relationship with the interviewee prior to the interview. It invites the interviewer to step outside of the traditional role and to express their own feelings, allowing the understanding to develop via a collaboration between researcher and participant (Legard Keegan and Ward

2003). To reflect this, the interview schedule is more reflexive and less structured, and the interviewer provides topics for discussion that are negotiated together. Furthermore, to create greater equality and allow meaning to emerge, both parties share reflections, emotions, thoughts and opinions where appropriate (Legard, Keegan and Ward 2003; Douglass and Moustakas 1985).

The other interview approach conducted was a more formal semi-structured interview approach. This approach is often selected when there is a strong sense in advance of the issues that needs to be explored and when studies have an emphasis on comparison. It was chosen here for its ability to provide opportunities for extended feedback whilst keeping a topic on track. As such, although conversational in manner, the interview schedule was closely structured; key questions were asked the same way each time. Space was allowed for further discussion should the participant want to elaborate, however there was no room for participants to guide or add to the topics (Muratovski 2016; Legard, Keegan and Ward 2003).

Surveys

Surveys take many formats and are used to provide large amounts of generalizable data. They are often used when there is a need to distribute to many people with little to no travel costs. Two types of survey were used in this study. One of these was the questionnaire, a qualitative method that allows participants to provide a short written response to a series of questions. Whilst questionnaires might enable some participants to answer more truthfully (as there is no face to face interaction), many people find questionnaires a nuisance to complete and do not return them. This can mean that those which are returned do not represent a true sample (Muratovski 2016).

The second was a five scale Likert survey, one of the most popular scales which consists of a series of statements that generally go over a five-point scale from 'strongly agree' to 'strongly disagree'. This allows research participants to rank their response rather than

give a single yes/no answer.

Field Notes and Reflective Practice: Recording and Reflection

This research concurs with the theoretical position that people are affected by being studied and that the relationship between the 'researcher and social phenomena is interactive' (Snape and Spencer 2003). It acknowledges the role of the active researcher within the study, whose presence, personality, skills and experience will all have a bearing on the research outcome. To reveal this positionality, reflexive practice methods were engaged throughout the inquiry to understand how it might 'disturb the surface of the culture (of) investigat(ion)' (Holliday 2016) and see what and how the interaction might result in 'new knowledge for both parties' to make transactions, interactions and practices transparent. Furthermore, reflective practice accounts for the subjective nature of design practice, documenting interpretations and judgements, making them 'visible and open for critique' (Stolterman 2008 62)

Engaging in reflective practice through means of a research (reflective) diary is also crucial in demonstrating rigour and transparency within design research (Frayling 1993; Arthur and Nazroo 2003). It is important to document design decisions, processes and reflections in an honest way that reflects; 'intentions prior to intervention', 'observations during intervention', 'analysis following intervention' and 'the effect on the next cycle of action' (Frayling 1993; Bec 2015). Doing so, shows design research to be a 'systematic method of enquiry' that fits into both 'research and practice' (Zimmerman, Stolterman and Forlizzi 2010 311).

Another method used to capture reflective practice was field notes. In ethnographic research, field notes are a common form of data collection both in primary data and used to support and give more depth to other methods (Arthur and Nazroo 2003). Field notes summarise what a researcher might see and hear outside of what can be recorded via

other means (such as video or audio recordings). Field notes are written either during or soon after an encounter.

Qualitative Data Analysis

There are a varied number of ways to approach qualitative data analysis, that focus around 'coding' or 'theming' data (this could be words, sentences or whole paragraphs) into categories (Ryan and Bernard 2003). This coding is an intensive and time-consuming process as the data is regularly revisited and compared to ensure the meaning is correct. One of the key things to consider is whether to use an inductive or deductive approach (Bradley, Curry and Devers 2007), that is, whether to impose a predefined set of codes onto a data set or to allow the codes to emerge from it. Once coded, this data can then be used to uncover links within and across data sets.

Ritchie, Spencer and O'Connor (2003) describes the analytic hierarchy. A framework of analytic tasks to help a researcher organise and make sense of data according to key themes and concepts. It is a systematic grounded theory approach, this is inductive, hypotheses develop from the data which is organised into main topics and sub themes to make sense of the data.

The process of conducting a qualitative data analysis can be summarised as follows:

- Researchers familiarise themselves with the data (by transcribing or reading transcripts multiple times),
- Each line of data is assigned a code or code(s) to reflect the concept or theme it is concerned with,
- Data and codes are then revisited multiple times, comparing the content of the data to the code to ensure they reflect the same concept,
- Codes are organised into sub categories or themes to add nuance and make sense of them,
- The analysis is deemed finalised when no new codes emerge and when the structure

of themes and sub themes is organised to make best sense of the data.

(Brady, Curry and Devers 2007; Ritchie 2003; Ryan and Bernard 2003)

4.4 Ethics

It is a given that research should be conducted in an ethical manner, where ethical standards guide and direct researchers during their decision-making processes (Muratovski 2016; IDEO 2016). This requirement for ethical standards in research and practices dates to the Nuremberg code of 1947, after World War 2, in response to the biomedical experiments that were conducted on prisoners of war and other historical cases (Muratovski 2016; Furniss et al 2015). Subsequently the World Medical Association adopted the 'Helsinki Declaration' whose principles include respect for the individual, their right for make informed decisions, and the need for special 'ethical vigilance' with vulnerable groups (Furniss et al 2015). To implement this, strict ethical guidelines, procedures and checks must be adhered to (although the exact format of these vary between institutions).

Academic and healthcare research recognises that research ethics can be a considerable challenge for those who work outside of a healthcare context and who might see the process as *'laborious, unaccommodating, bureaucratic and delay[ing] research'* (Furniss et al 2015, 6). Nevertheless, any studies with human participants will require ethical approval from within academic and healthcare systems. Furniss et al (2015) states that it is not the basic principles of the Helsinki declaration that present difficulties for researchers, it is navigating the procedures, formalities and governance that surround them.

There are sound principles behind these ethical standards, checks and processes. They are in place not only for the for the safeguarding of research participants, to protect them from harm and potential adverse consequences. They are also in place to protect the researcher, the participant's wider families, and the organisations in which the research

is conducted (Muratovski 2016). Ethical governance in the UK includes the design and management of a research study. Therefore, as part of ensuring high quality research, the researcher is required to carefully examine their research proposal and the specifics of how to conduct the study. This is then submitted to an ethics board for review.

Despite the challenges, Furniss et al (2015) point out that research ethics approval from the NHS can give credibility to a study, and some journals or dissemination routes will only accept submissions that have been through an ethical review. For those academic studies which do not go through NHS ethics, they should at the very least have been subjected to some sort of university ethics (Furniss et al 2015).

All design research should be conducted in an ethical manner in accordance with design research ethics guidelines (IDEO 2016). In addition, formal ethical approval was required for this study, since the patient population (adolescents) are classed as vulnerable participants. Therefore, my study was subject to the following ethical governance and procedures across the university and the NHS:

- Sheffield Children's Hospital research passport, honorary contract and letter of access (Appendix 1)
- Sheffield Hallam University Research Ethics committee approval (Appendix 2)
- NHS Research Ethics Committee (REC) Proportionate review (Appendix 3)
- Sheffield Children's Hospital local site permissions (Appendix 5 and 6)

Ethical approval was granted for this study on the 20th January 2017. Following a series of amendments, final ethical approval was granted on 7th July, 2017.

4.5 Study Design

This section provides an overview of the study design. It situates the methods within the study and provides an overview of each aspect of the study. This section begins by giving the reader an overview of the original study design followed by the final study design. It is presented in this way to visualise the emergent nature of the approach taken and the impact that this has on the study design, the identification of new lines of enquiry to answer questions that were not anticipated at the start. The change reflects the iterative nature of design research, the complexities of conducting research as a designer in the NHS and embracing the ‘fuzzy front end’. Further information about these changes to the study design can be found in the discussion chapter.

Original Study Design

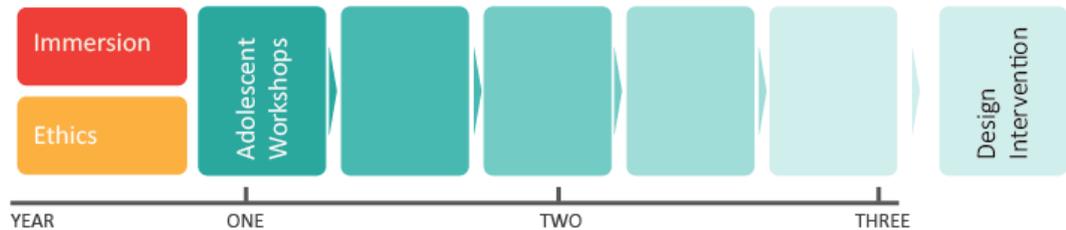


Figure 10: Illustration of the Original Study Design. Red and yellow represent one area of practice and blue represents another.

There were two planned areas of practice within this study (see figure 10):

- Immersion and Ethics- understanding the context for the study, building a relationship with the team and gaining ethical approval,
- Adolescent workshops- sharing design skills and approaches with the adolescents through a series of workshop iterations.

Final Study Design

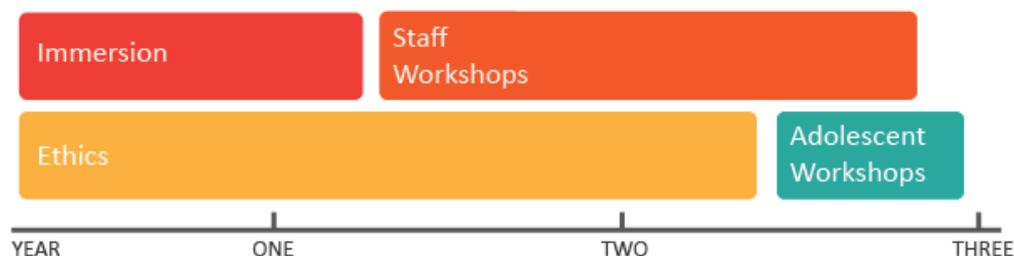


Figure 11: Illustration of the Final Study Design. The additional area of practice is represented in the orange block.

There are three areas of practice within the final study design (see figure 11):

- Immersion: Understanding the context for the study, building a relationship team and gaining ethical approval.
- Design Practice with Pain Management Therapists: Reflecting on current service provision and developing current PM practices.
- Adolescent workshops: Sharing design skills and approaches with the adolescents.

Immersion

This practice was used to inform decisions on, and build and understanding of, the context for this study. The primary aim of immersion was to establish a group of patients to work with and build a relationship with the team. Furthermore, it was hoped that building a knowledge of condition management behaviours would help to establish where the adolescent workshops might situate and have impact. The knowledge gained through this practice would directly feed into the ethical approval process. Finally, it was anticipated that establishing a relationship with the team members would support the integration of the workshops into the current service provision.

Methods

To embrace the uncertainty and unpredictability at the beginning of design research, a

range of methods were selected in this first stage of the study.

Design Ethnography

Design ethnography (as understood within design literature) was conducted in two stages to provide first-hand experience to support a comprehensive understanding of the different specialisms within SCH (that provided outpatient therapy care).

The first was a three-month period of observation employed to build an understanding of the different patient disciplines at the hospital and help inform the selection of a patient population. Observations took place within multidisciplinary team (MDT) outpatient clinics, holiday therapy groups and intensive therapy sessions.

The second stage followed the decision to work with the specialism of chronic pain. This was a longer, but more focused period of observational fieldwork was conducted using a step-in-step-out approach (Muratovski 2016). The aim of this field work was to gain first-hand experience and build up experiential knowledge about the patient population and their condition management behaviours, as well as the Pain Management Team and their roles. This was done over 40 hours of observing MDT clinics, patient therapy sessions and shadowing some therapists for short periods. Throughout the use of these methods a reflective diary was kept and field notes were written, where appropriate and possible to do so.

Literature Review

A scoping literature review to identify key texts was conducted to support the experiential knowledge from the design ethnography. This aimed to provide a wider context for adolescents with long term conditions, support the selection of a patient population and look for gaps in the knowledge on condition management.

Sense Making and Visualisation

The aim of the design practice was to create models and visualisations of the understanding gained through the design ethnography. Their purpose was to 'sense make' through the translation and visualisation of knowledge and data. Some of these visualisations would just be to support the researchers understanding. Others would be to communicate ideas and test comprehension, and discussed with staff members from the PM team.

Interviews

The aim of the interviews in this phase of the study was to support an understanding of the individual roles within the PM service. Interviews followed a formal semi-structured approach, where each clinician was asked the same questions for ease of interpreting and comparing the data (see Appendix 7 for interview schedule). Interviews were audio recorded and then translated into a visualisation of the data, to make sense of roles and responsibilities and similarities and differences.

Field Notes and Reflective Practice

Field notes and reflective practice from this stage would be used to support an analysis of how design practice can support the development of relationships with healthcare providers. To be discussed alongside the methods and approaches in the wider context of design research. The aim is that insights drawn from this will be used to create recommendations to help other design researchers working in a healthcare context.

Design Practice with Pain Management Therapists

The design practice with the Pain Management Therapists was not part of the original study design. Instead it developed in response to the immersion period, therefore the methods used here reflect the iterative and responsive process of this practice. The

overarching aim of this work was to continue to explore how design practice can support the development of relationships with healthcare teams by responding to an identified need and build better researcher understanding of PM therapy. It was intended that the knowledge gained through this would feed into the workshop plans for the adolescent study and add to a discussion on design methods in healthcare. Further aims that emerged included; to demonstrate design skills and approaches to the PM therapists and to provide a space for them to visually reflect on current service provision using design methods. Finally, it was hypothesised as this body of work emerged with the therapists, that supporting the PM team might have an indirect impact on adolescents (through improved service provision) and therefore might support the overall aim of the study indirectly.

Methods

Design Workshops:

Five iterative half-day design workshops were conducted, as part of the PM team's 'away days' for development and training. Activities within these workshops used creative design methods to provide space for reflection, development and discussion.

Activities and methods used within these design workshops included:

- Sense Making / Visualisation: The presentation of visualisations from earlier sense making practice, as well as creating real time visualisations in response to discussions and activities during the sessions. The aim was to provide a communication piece that would validate observations and understandings gained from other sources or conversations.
- Personas: To build on the understanding of the groups of patients that are in the service creating group profiles. This aimed to get the therapists to focus on themes and commonalities rather than individual stories.
- Journey Mapping: To provide a visual representation of the journey a patient

takes through PM. The aim is to allow for discussion and reflection with the therapists through both the creation of the visual and reflection of the outcome.

- Creative design practice: The use of activities and creative methods for inspiration, communication and discussion. The aim with these is to encourage the therapists into certain modes of thinking and gain new insight as a result.

Prototyping

The prototyping method was employed in the development of a patient information resource pack that was part of the therapist practice. Various approaches were employed, from impromptu / low fidelity prototypes within a workshop to more refined prototypes created outside of the workshops. The aim of the prototype was to elicit feedback from the team on the concepts and to externalise thoughts and ideas to enable discussion and commentary.

Interviews

The primary method to analyse the practice with the therapists was through an in-depth semi-structured interview. The interview schedule would be less formal in recognition of the relationship built between the researcher and the team. The structure was loosely based around four key areas (early involvement with the team, evolution of research role, the series of workshops and the impact of design research in health) with ideas for questions in each. The workshop followed an informal format, questions were not set and the interview was flexible to respond to topics the therapists wanted to cover. In addition, images of the activities, practice and workshops were provided to help with memory of the sessions and to form part of the conversation. The interviews were conducted at the end of the series of workshops, audio recorded and transcribed. Analysis of the transcripts was conducted through a qualitative data analysis to draw out the key themes.

The aim of these interviews was to gain feedback on their involvement in the design research and their experience of design methods, particularly in relation to their impact on PM therapy and as a means to build a relationship. Findings will be used as part of a discussion on how design practice differs from other interventions that they might have experienced in healthcare to contribute to a discussion on designers facilitating design methods. Findings will also be used to support recommendations for others working in the field.

Reflective Practice

Throughout the work, reflective practice was used to capture thoughts, feelings and experiences after the workshops and to help to demystify the process of how one workshop plan moved to another. Findings were used to reflect on the growing relationship, any complexities or difficulties that occurred, and how these were overcome.

Adolescent Workshops

The aim of the practice with adolescents was to explore how design practice could support adolescents who have a long term condition. This was done through workshops with adolescents who have chronic pain. The intention was to build on groundwork by other academics by exploring this type of practice in a new context. Within this context, the workshops also sought to enable the researcher to gain insights on how to conduct this sort of research in a healthcare setting.

Recruitment

Participants were recruited through the Chronic Pain Service. To be eligible for inclusion in the study participants had to:

- Be between the ages of 11-16¹⁰,
- Have received at least one session of Pain Management Therapy,
- Be able to speak English,
- Have no immunocompromising conditions, and
- Be cognitively able to engage (an anecdotal measure determined by the pain nurses).

Potential participants would receive information about the study either during a therapy session or through the post. The information included a flyer about the study, separate information sheets for parents and adolescents, and a cover letter with the date of the workshops on (Appendix 9).

Methods

Design Workshops

Design workshops were the primary method used to conduct this phase of the study. Their purpose was to demonstrate design methods and approaches to the participants through creative and experiential activities, group work, explanations and exemplars. Participants were recruited to two workshops that took place at SHU, each lasting three hours. The intention with the activities was to allow a safe space to learn a new skill without focusing on the condition, or the participants' experiences of CP. Instead it was reiterated throughout that the participants were here because they had CP and that the aim of the work was too see how design might help them.

Likert Scale

A Likert scale was used as a quantitative method to help analyse the experience of attending the workshops and to establish any impact they might have on the patients.

Participants completed three times over the two workshops, rating statements

¹⁰ A slight adjustment to the WHO definition of adolescents to fit with the UK's schooling years. Those between 11-16 will be in secondary education.

that related to their abilities and confidences in various design related tasks. The scale ranged from 'strongly disagree' to 'strongly agree' with 12 statements on the measure (Appendix 10). These scales were statistically analysed to look at individual changes and those across all respondents.

Questionnaire

Questionnaires are a qualitative survey method to support the understanding of the impact of the workshops on adolescents. Their focus was on the experience of the workshops, any impact they might have had and any application to their management behaviours (Appendix 11). Questionnaires were emailed to participants via parents/guardians. Responses from these questionnaires were placed in a table and subjected to a qualitative data analysis.

Interview

Semi-structured formal interviews were the final method used to analyse the workshops. These provided more depth on the experience of the session and any application to a participant's management behaviours. The interview schedule was adjusted for those who returned a questionnaire to avoid any repetition of questions (see Appendix 12 for interview schedule). Again, the interview data was audio transcribed and analysed through a qualitative data analysis.

This chapter has provided the reader with a summary of the need for the mixed methods approach used in this study. It has then gone on to give an overview of each method before moving to the study design section that situates each method within the study. This chapter has also provided some background information on the importance of conducting research ethically, and highlighted the ethical approvals required to conduct this research. In the next section of this thesis, the practice of the study will be presented and analysed over three chapters.

Section Two

Practice



Figure 12: Birthday cake and candles. Output from a description and building game with adolescents

The previous section of this thesis sought to; situate the study, introduce where it seeks to add to knowledge and outlined the methodology and methods used in the pursuit of this knowledge. This next section of the thesis is concerned with the practice used within and generated from the study. This section is split into three chapters; Immersion, Therapists and Adolescents.

Narration

The narrative of this thesis now moves to a first-person narrator. This reflects the embedded nature of a designer within their research practice, recognising that as no two designers will approach a problem in the same way, it is important to provide a written record that might highlight the researchers bias. It also recognises the role played by interactions with other stakeholders and the influence that they have on the process. This change to a first-person narration hopes to provide transparency through clear documentation of the decision-making process.

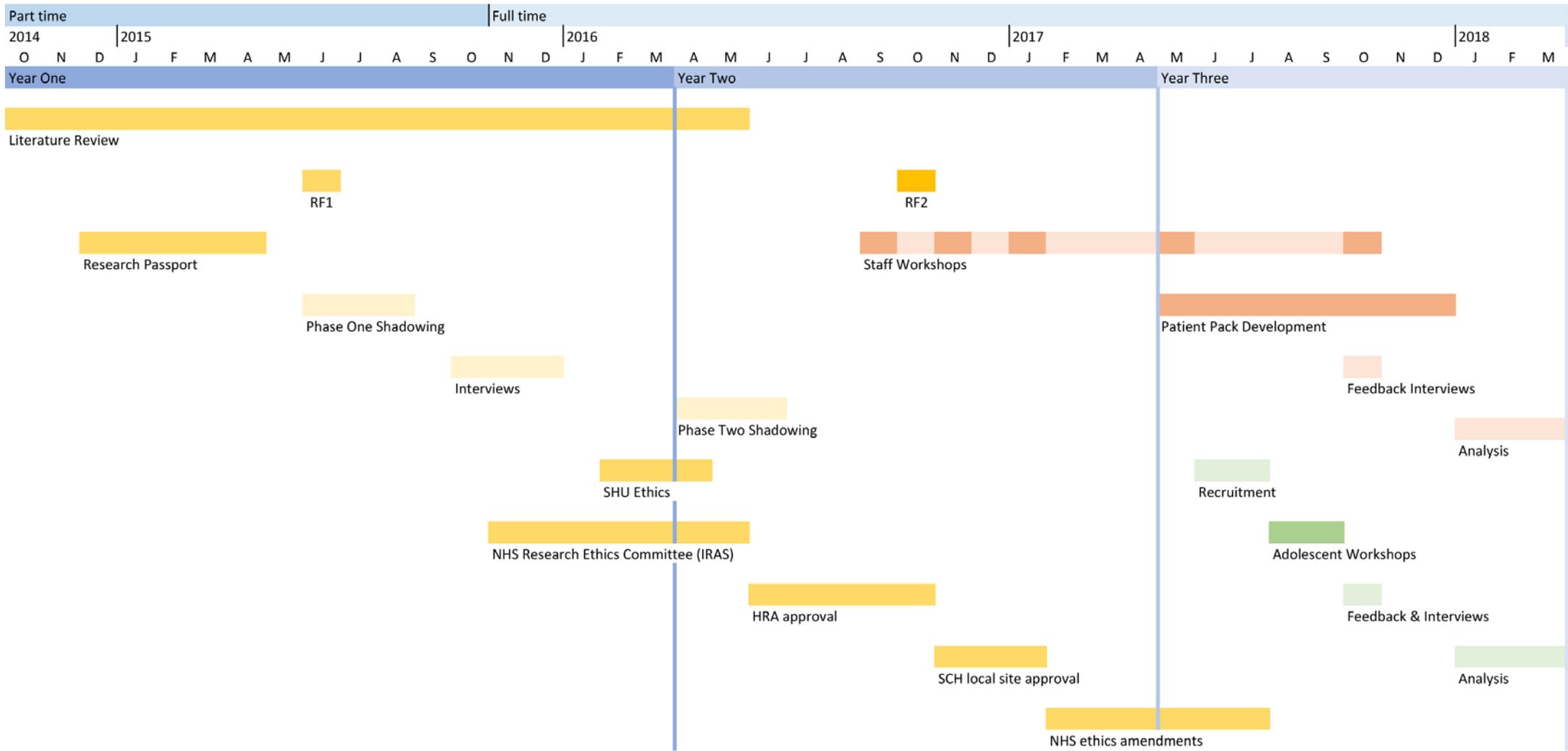


Figure 13: Study timeline

Chapter Five: Immersion

This chapter outlines the first section of practice in the study: Immersion. It covers the methods used to inform decisions on, and build an understanding of, the context for this study. This includes; selecting a patient population, understanding condition management behaviours and building relationships with staff members. It begins by introducing the process to gain access to Sheffield Children’s Hospital to undertake this work. It then covers the two stages of design ethnography, the interviews and presents the sense making and visualisation practice, before ending with a short summary of reflective practice from field notes and journal entries.

5.1 Gaining Access

To access clinical teams and their patients in order to understand the context, official access permissions need to be granted. A research passport is the first requirement for a non-NHS employee¹¹ to gain access in an NHS hospital. It involves a series of pre-engagement checks, that hospital staff would have been subject to as part of their recruitment (occupational health screening, Disclosure and barring (DBS) checks). A research passport provides safety guidelines for the hospital’s responsibilities to a researcher, which enables them to spend time conducting Patient and Public Involvement ¹² (PPI) work. The letter of access received as part of this study covers access to the hospital site but is not concerned with the ethics of any research study ¹³ that is conducted.

11 It is worth noting that those students who are enrolled on healthcare courses and who work in the NHS as part of their academic course (e.g. on placement) do not require a research passport as part of their course enrolment sets up this access for them

12 Patient and Public Involvement, refers to an active partnership between researchers and public and patients. It is concerned with encouraging this partnership within all aspects of the research, including in the early scoping phases of a study design, and leads all the way through to dissemination.

13 Even with a research passport no research can take place without formal NHS Research Ethics Committee (REC) approval, which takes place through the Integrated Research Application System (IRAS).

Through previous experience of gaining a research passport to access healthcare environments I had learned that these processes can take time, particularly when trying to navigate two different institutions (university and NHS) and coordinate R&D support at both. Therefore, this process started early in the second month of the study. The total time from beginning the application to gaining a letter of access took five months with access granted on the 30th April 2016 (figure 13).

5.2 Design Ethnography One

Once I had obtained a research passport, the first step was to undertake a period of observation at Sheffield Children's Hospital (SCH). The Primary reasons for this were; To inform the selection of the patient participants (supported by a literature review), to confirm the inclusion and exclusion criteria for the study and to select a condition(s) and age range of children to work with for the study.

The selection of a patient population was crucial. The workshops would seek to understand how design skills and approaches can support those with long term conditions; a study situated in literature that links to behaviour change and wicked problems. It was therefore important to select a population who had long term management needs that required behaviour change in a multitude of ways (as such, the best way to manage their condition is a 'wicked' problem) rather than short interventions or singular skills based tasks. I was looking for a patient population where patients were 'stuck' or 'narrow in their thoughts and approaches, rather than those that might just need further equipment or products to support them.

Through supervisory discussions it was suggested that much of condition management outside of medical regimes is done by therapists and therefore observations within the therapy department would be a good place to start. I was introduced to the research

steering group via my NHS supervisor who acted as a 'gatekeeper' (Muratovski 2016). This meeting allowed the opportunity to introduce myself and my proposed work. After this the following teams identified themselves as interested in follow up; Metabolic Bone, Respiratory, Community and Early years, Limb reconstruction and Pain Management.

What followed was a three-month period of observational fieldwork across Metabolic Bone, Community and Early years, and the Pain Management Teams, using a step-in-step-out approach (Muratovski 2016). These included; observing therapists during therapeutic sessions, sitting in on MDT clinics, observing patient treatment sessions and attending holiday groups such as a bike riding skills session for patients with Dyspraxia. Any time available in between the formal sessions was used to have informal chats about my work, their work and their patients. During this fieldwork I was an 'outsider' (Muratovski 2016) allowed to observe and listen but not to actively engage (this was entirely appropriate as most of the activities they were conducting were therapeutic).

As part of this practice it felt inappropriate to write any notes during the interactions (particularly when there were only three people in the room). Instead, to avoid making people feel uncomfortable, any observations and reflections about the experiences were written after the session. Despite the duration (three months), contact time was limited due to the summer holidays when staff were on annual leave and patients were on holiday. Staff shortages meant that there were many missed emails and phone calls.

I used these observations to; look at the sorts of management behaviours that patients were learning, understand how their condition impacted on their lives and to establish if they could cognitively engage in the workshops. I tried to deduce what complexities there were with their condition management, such as; motivation to do exercises, difficulties in adapting to new equipment and emotional wellbeing. Alongside this, I was trying to determine which teams were receptive to my work, and could see links to their patient population, something I deemed important as I would be likely need their support during

the study. I used this experience to inform the decisions on the patient population and therapy team with which to move forwards. Early on, when followed up after the steering group, the Limb reconstruction team felt that they were too short staffed to support the project, and respiratory proved difficult to get hold, of so I did not pursue these teams further. The community team were welcoming and interested in the study, but had a greater need for innovations in physical design 'products'. Many of their patients with neurological disorders were cognitively unable to engage or were learning short skills based management behaviours such as riding a bike or teeth brushing- rather than long term lifestyle change behaviours. Therefore, in discussion with the therapists it was deemed the patients would not be appropriate for the study. Two teams that I spent time with, Pain Management and the Metabolic Bone team (specifically those with Osteogenesis imperfecta (OI)) were interested in the study. They could seek links to their patient populations who have complex long term management needs with physical and emotional manifestations. As such, they conduct day-to-day management of their condition in a multitude of ways.

5.3 Design Ethnography Two

The second phase of design ethnography was more intensive and focused, it intended to build strong relationships with the teams and develop a comprehensive understanding of the conditions and how they are managed. During this time, I spent over 40 hours observing Multidisciplinary team (MDT) clinics across OI and Chronic Pain. I was intentional about the time I spent with the teams, trying to find the balance between spending enough time to allow them to become familiar with and to get to know me but not burdening the teams with my presence, allowing them space to go about their usual work without feeling observed. I therefore attended no more than one clinic per team per week.

It was not unusual for people to observe the MDT clinics and often there could be up to six team members in the room (doctor, nurse, therapist, psychologist, myself and another

observing professional). Often the rooms could feel crowded with many people taking notes about the patients and families. As a result, similar to the previous phase, I attended the clinics and reflected on my observations afterwards.

Due to space within clinics and the availability of the team members, I spent more time with the Chronic Pain than the OI team. As a result, I had less opportunity to build the OI team's understanding of the proposed workshops and felt a conflict in their expectations of what they would be, particularly around the design of physical support aids. I felt the OI team become less engaged with the work, and eventually the decision was made to only recruit from the Chronic Pain service.

Observing the MDT clinics was a valuable way to see the range of patients that are in the service and how their conditions manifested themselves. It allowed me to think about the types of patients that I might be working with and highlighted things I might need to be mindful of when running workshops such as; psychological concerns, mobility and confidence. It also provided insight into dynamics between the clinical team and with the patients/families. I had first-hand experience of the different ways that interactions, power and voice manifested in the sessions.

Despite the success of the MDT clinics in terms of understanding patient population and in building a sense of familiarity between the teams and myself, they did not bring much clarity around staff roles. I gained a superficial understanding of the medical and therapeutic roles (e.g. within the pain team consultants provided medical management and interventions such as drugs or nerve blocks, psychologists were involved when there were potential psychological causes or factors). However, the clinics did not give much insight into individual management behaviours, how these were demonstrated and what was the process by which they were learned. This was an important factor to understand, as the design workshops were to support management behaviours, therefore an understanding of these would be crucial to the success of the workshops.

To understand more about these behaviours, I enquired about the possibility of shadowing some of the individual team members from therapies, psychology and nursing. The aim behind the shadowing was to observe first-hand what happened within therapies, to see the methods, approaches and management techniques that were used to see where they might fit within my own practice.

Only a few of the team members were happy for me to do this. I sensed that for many of them they were uncomfortable with having someone observe their individual practice, particularly when some of the subjects might be sensitive in nature. Building a therapeutic relationship is important and they were aware of the different dynamic that comes with someone observing a session. A few members of the team did allow me to sit in on their initial or 'introductory' sessions with a young person as this is often very meta-level and doesn't go into too much depth. However, beyond that they agreed to keep me up to date with the patient's progress but did not invite me to attend any further sessions. These updates did not happen due to patient caseloads and time pressures, and it was clear that this method would not allow me to build the full picture of management that required. Therefore, to keep up engagement and build my understanding in a way that was more comfortable for the staff, I decided to conduct interviews with them.

5.4 Sense Making

During the periods of design ethnography, I found that there was a language barrier created through different definitions and understandings of terminology used by the clinical teams and myself. This was particularly noticeable around the word 'design'. Design to the team members often meant something specific, usually product or systems related and they could not see the relationship to behaviour change and condition management. This resulted in regular struggles to communicate how my practice was something other than a design 'therapy' or developing new products and services.

To support my explanations and to communicate better with the teams I developed a series of visuals to inform them about my practice; the first to show how I envisaged design to support condition management and how it might fit within the service (figure 14) and the second to represent my understanding of how engagement affects management (figure 15).

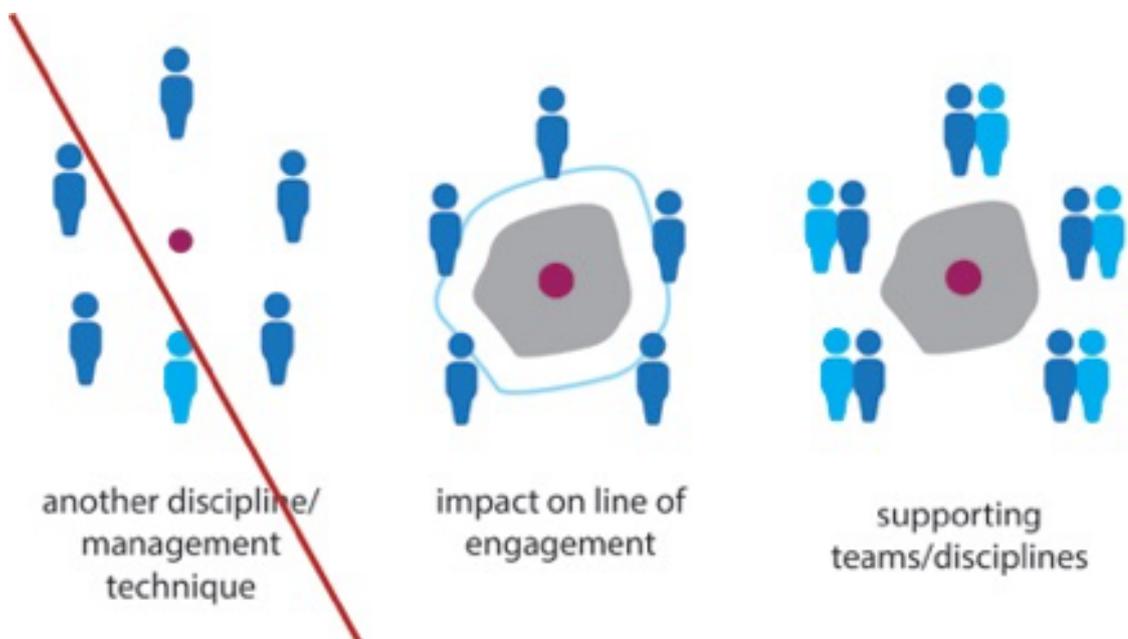


Figure 14: Visualisation to represent design's role in the Pain Management Service. Anything in light blue represents design, the dark blue represents the Pain Team, the purple is the patient and the grey is engagement. If a participant was highly engaged and managing well, the grey area would reach the figures. The image on the left demonstrates that design would not be another management technique provided (such as therapists providing sleep techniques or consultants prescribing medicines). The central image shows how the aim is to impact on a participants' engagement in management behaviours, moving the grey area outwards. The final image on the right represents the instinct that the more time I spent with the team, the greater the likelihood that opportunities to support them would arise.

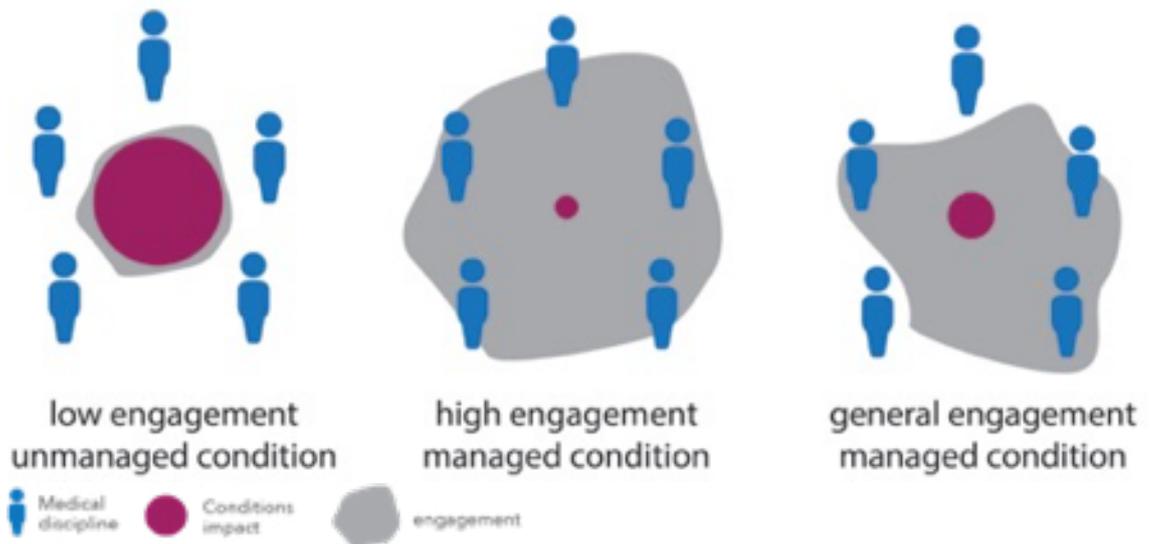


Figure 15: Diagram to represent the link between engagement and management. This diagram demonstrates the link between engagement and management; The greater the level of engagement (grey area) the less impact the condition has (purple centre) as the better managed it is. Engagement in this diagram refers to more than seeing the clinician and includes techniques such as taking medication or doing therapeutic exercises.

Both diagrams were used during conversations with the team on what constitutes good engagement and what impacts and changes the line. They proved useful in the building the staff's understanding of where I see my work in the service as a support to what is already going on rather than an entirely separate entity. It led to discussions about my skills and practice and helped them to see where I might be able to support them. Furthermore, the development of these diagrams was the first introduction the team had to my practice; the experience was positive in building our relationship and a shared understanding. Using visuals allowed me to overcome the language barriers I had experienced and support the language I was using. It enabled me to clarify potential roles and ideas even if the exact methods or workshop activities could not be confirmed at this point.

5.5 Interviews

As part of understanding the different roles and techniques in pain management, I invited all pain management staff members to an interview. In total 10 were interviewed. The interviews focused on understanding what their clinical role was and what their day to day work looked like. I also wanted to understand their view on managing chronic pain, what they saw as the management activities of their patient population, the role that they take to support these and what barriers there might be to their success.

These were organised via email or face to face and took place across the various hospital sites at a time convenient to the clinician; they lasted around half an hour, which included time for the clinician to ask me any questions that they might have. The interviews were semi-structured and audio recorded. There was a basic structure for the interview but follow on questions were asked where appropriate, and questions were allowed to naturally lead onto others.

Rather than conduct a formal analysis on the interviews, I used creative practice to help me to make sense of the interview data by visually representing common themes and concepts.



Figure 16: Developing the Staff skills map

From the interviews and ethnographic practice, it was clear that there were many similarities between the different roles of the team members, particularly between Occupational Therapists and Physiotherapists, where it was hard to determine who was from which discipline. To make sense of these similarities and understand what the differences are I developed a visual map of the team members individually and collectively (figure 16 and 17). As the basis for this mapping, I summarised the key interviews looking for any clear mention of pain management techniques and created maps to represent the skills and skill cross overs across the whole team.

I developed further maps to describe the skills and activities of the Pain Management Therapists. These maps provided more in depth understanding of specific techniques and looked at the range of skills across the team (figure 18). Sharing these visuals with the therapists was the catalyst to our work together. They were used during a design workshop (more information on this is in the next chapter) to help the team reflect on

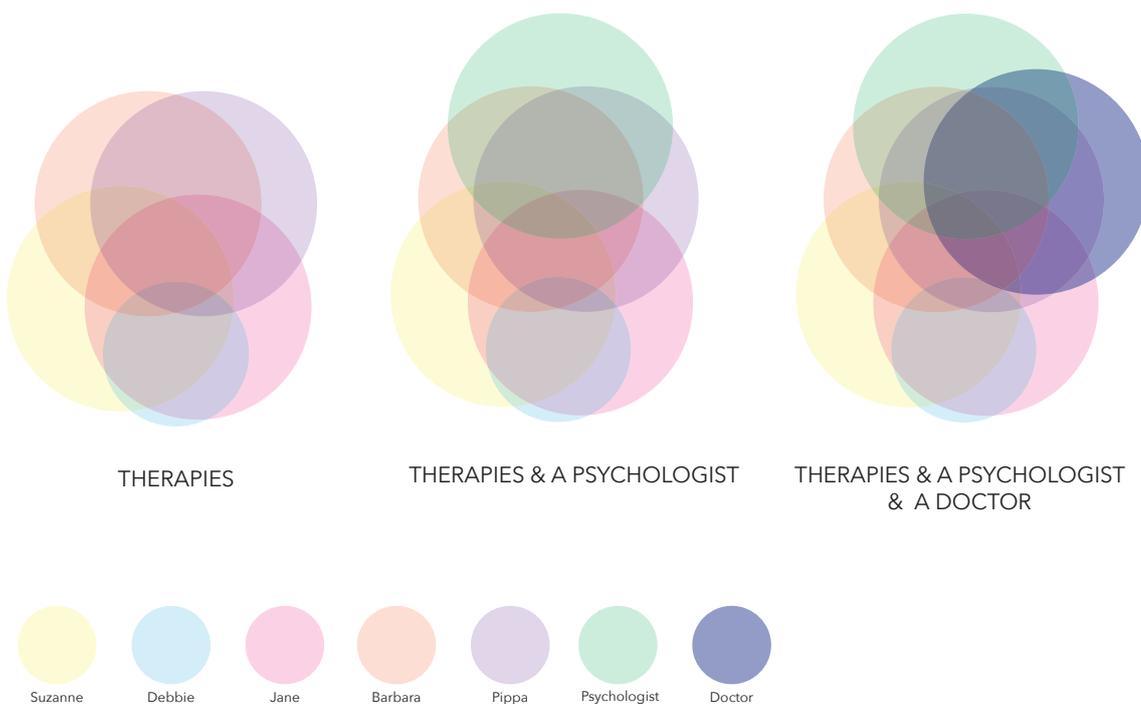


Figure 17: Example of skills crossover map between various team members

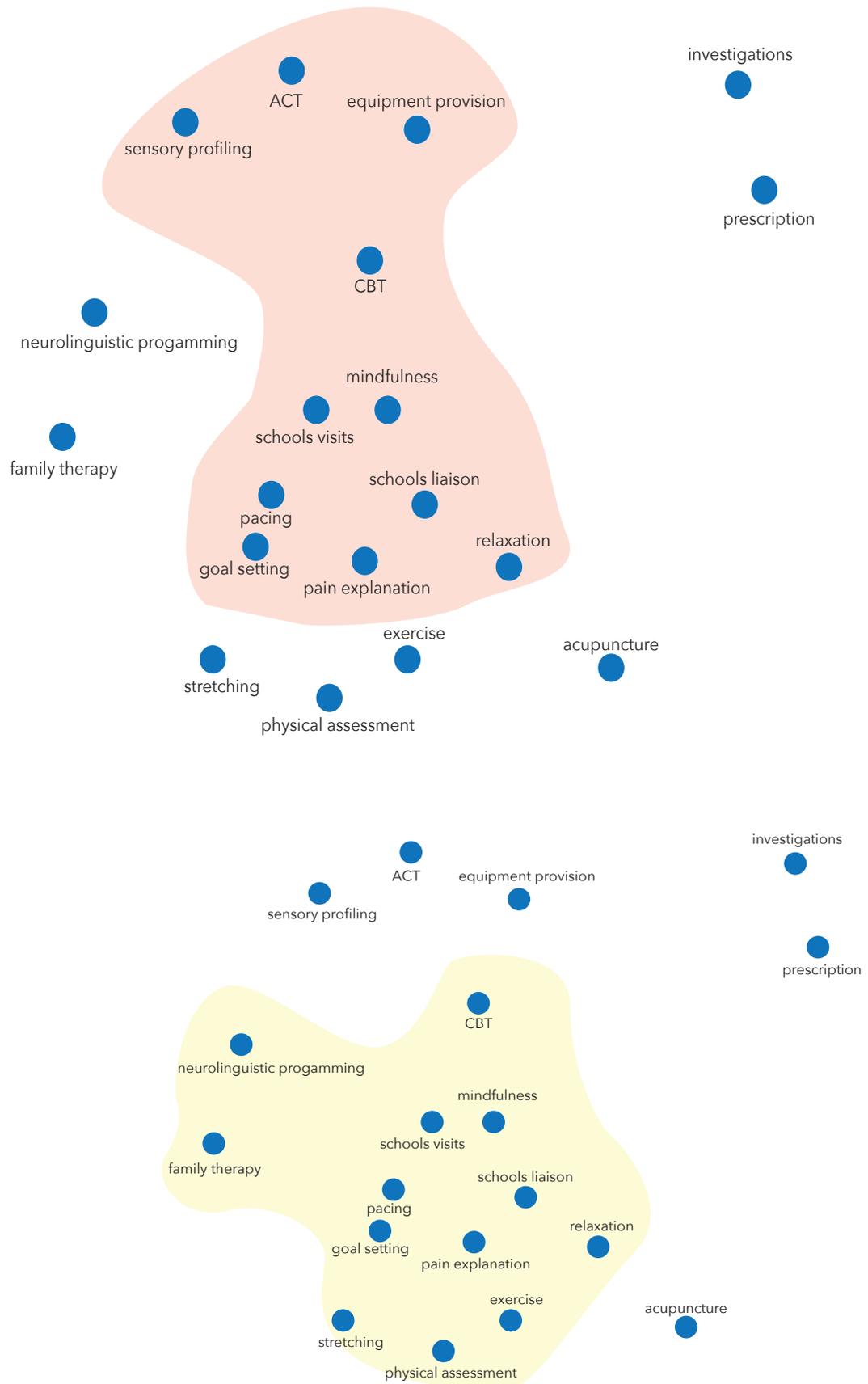


Figure 18: Individual skills maps of an occupational therapist (top) and a physiotherapist (bottom)

their service offering.

During this workshop therapists were given time to reflect on and edit their individual skills maps before combining them (figure 19). This created a space of visual reflection for their own practice and for collective dialogue around the team's practice. The combined results presented a much more complex diagram than had originally been created, it added new skills and activities as well as depth to the previous iteration. The original had enabled me to start to make sense of different roles and cross overs of skills; however, the therapists believed it was too simplified to show the full range of their abilities and the nuances between them.



Figure 19: The edited team skills map

The process of visually combining these maps together created a space for dialogue. The map itself became a conversation piece to place ideas and thoughts on- to externalise and make them tangible. The edited map would have been difficult to explain or clearly

describe to anyone who was not involved in the process. However, both the therapists and myself agreed that this was not important; the process of editing and discussing had provided the space for reflection and knowledge the team and I needed.

5.6 Explain your Pain Workshop

The 'Explain your Pain' workshop was initiated by a therapist from the service, who highlighted the difficulties that adolescents have when trying to explain their pain, which can reduce the help and support they receive. This was not part of, or did not derive from any part of my study or time spent with the team. It was a separate project that I facilitated in my role as design researcher within Sheffield Hallam University. I include it here as part of this study as it helped to inform my understanding of the patient population. As the 'explain your pain' workshops ran before the main workshops within this study they were a useful testing space to build relationships and gain insights into the PM service providers and community.

The workshop used imaginative participatory methods to explore visualising the experience of living with chronic pain. The aim was to give a space for the adolescents to think about how they might explain their pain in ways they might not have thought of before. A series of stations were devised with different mediums through which to 'explain your pain', these included; If your pain was a noise what would it sound like? If it was a meal what would it be? What does your pain look like? After completing the stations, the participants reflected on the different mediums, thinking about which might be helpful or could be developed into more practical forms of explanation for themselves.

This was my first contact in a designer facilitator role with adolescents living with chronic pain. They engaged well with the creative methods and reported enjoying using the different mediums although described some as difficult. The workshops provided a positive affirmation for the potential of this type of engagement for the development of

5.7 Reflections on Immersion

The immersion phase of this study enabled me to determine the group of patients with whom I would conduct the workshops, build a relationship with the clinical team and demonstrate visual design practice. Throughout, I kept field notes and engaged in reflective practice about my experiences, these are used as part of a discussion on the outcomes of this work at the end of this thesis. However, some of these reflexive activities provide an insight into decisions made throughout this period and inform the subsequent therapist and adolescent work. In the interest of providing transparency within this research, these reflections are provided here.

On the Effect of my Presence in Therapeutic Sessions

“Sometimes I feel uneasy being in the room, what effect does my presence have on the session? – I am unable to say anything, but should I? I need to trust the clinicians, I presume they would mention if I should leave to make the space more comfortable for the patient”

“Due to patient confidentiality and to be as unobtrusive as possible I decided to write no notes today and instead just observe”

(Authors reflective notes, June/July 2015)

During clinics or therapeutic sessions, I was introduced either by a clinician or invited to introduce myself to the patient and family as part of the introductions. On some occasions patients and family decided that they did not want me in the room and after the introductions I would leave before their consultation. On other occasions, I used my discretion to remove myself from the room when it felt appropriate for the privacy of a family, or if the clinicians asked me to do so since the number of people in the room was overwhelming for the patient. This also provides an insight into why I chose not to write, draw or record anything during the sessions. I was already aware that my presence had an impact and I did not want to increase this further.

On the Structure of Pain Management Therapy

“the service is so open ended’... ‘nobody takes anything away from a session”

“What are their roles? Does everyone understand these roles? What’s everyone’s aims and goals for a session?”

“Where does design fit and align? How might it compliment them? Where will it align? Will it contradict?”

(Authors reflective notes after shadowing, March- June 2016)

In notes written after a session shadowing a physiotherapist I mention the structure of pain management sessions and not fully comprehending what it was or what the aims were. The therapists all seemed to have a different approach to pain management, use different activities, or have conflicting views on how many sessions there would be and how long people would be in a service for. It felt very important to get a grasp on this, to understand where the design workshops would or wouldn’t align. Also, during my observations, I noted that much of the therapy was talking based, it was a lot to take in, yet the patients received nothing to support or summarise the session afterwards.

On Knowing when to Introduce more Creative Methods

“When and how to step out as an outsider with my expertise? Will they (clinicians) need the same insider process to understand my work? How will I let them become insiders with limited time etc. if they don’t feel like insiders in my work how will that affect our relationship”

(Authors reflective notes, June 2016)

Early in the contextual review, I had concerns about the transition from conducting design ethnography to the design workshops. Whilst observing the pain team I was the outsider and they the experts. However, when it came to conducting the design workshops, the roles would switch. I would be the ‘expert’ and they the outsiders, yet I needed them to feel comfortable with the design practice without the length of time or the ability to

be immersed in it like I had. This led me to question whether I should have used more creative methods earlier.

“Should I have used more creative methods-such as visual ethnography or demonstrated activities from the (other) workshops?”

(Authors reflective notes, January 2018)

During this period, my notes reflect a conflict within about what and when I should be demonstrating my practice and design skills. Based on experiences from previous projects I believed that it was important to use methods that were familiar to the therapists (observations, interviews etc.) to make them feel comfortable and demonstrate my desire to learn about their work. In my reflections, I found the design ethnography to have made this transition easier; formulating ideas for my study whilst being around the team allowed me to see opportunities and understand where they might fit within the current service. The more time I spent building a relationship with the team, the more interested they were in learning about my role as a design researcher. Therefore, by the time I presented them with my first piece of design practice (the maps), they welcomed the opportunity to see some of my work and were willing to engage with it.

On Explaining ‘Design’

There are multiple entries in my reflective notes about the difficulties I was experiencing communicating design and design research. Many times I was placed on the spot and asked to explain what my study was or what my background was. This was hard to articulate as the person’s experience and perception of design had a huge impact on their understanding.

“I still don’t feel I’m explaining what I mean by design in this and exactly what my workshops might look like or achieve”

“Problem with linking design to problem solving-makes it easier for people to be able understand it, but does mean that it makes it seem like it is a simple process which it isn’t. How can I balance out the need to have a process

for explanation (double diamond) and show the actual messy and complex process? The double diamond is a great tool to give an overview, but I don't want to simplify it too much-need to show that there is a difference between what design can do."

(Authors reflective notes, July 2015)

I had worked hard over the time to help the core team understand the study, so noted in a journal entry the difficulties that I encountered when a new person visited the team and I only had a few moments to explain the work.

"Everyone else I had met before so didn't need to do an explanation- perhaps I should meet him separately' Consultant frustrating!! Didn't understand, kept questioning decisions, unhappy/concerned? Perhaps me and how I explained it?' perhaps he's entrenched in clinical research so cannot 'see' "

(Authors reflective notes after a therapy group meeting, July 2016)

On the Term 'Self-management'

'I spent a lot of time with just Physios (who had a very specific view of self-management) – this was partly my fault as I had used the term self-management, (side note-what exactly do I mean by self-management, before exploring with children and caregivers perhaps I should understand my own view!)

'What is self-management? What does it mean to me and other clinicians/caregivers/where do our ideas cross or conflict each other?'

(Authors reflective notes on observations, July 2015)

Another term that I found had various definitions and meanings was 'self-management'. These specific views meant that when I used the term, I often found myself confused by their answer as they imposed their understanding of the terms design and self-management to mean something very different to my own. Literature around the term is also complex, much of it noting that it is a contentious term. Therefore, it was early in the study that I learned to use the terms 'condition management' or 'management behaviours' to encompass a wider spectrum of ideas of self-management.

This chapter has provided depth on the immersion practice. It has gone into detail about the methods used to understand the site of the inquiry, select a patient population and build a relationship with a clinical team. It has highlighted some of the difficulties encountered during this phase, and the methods used to overcome them through iterative practice and creative methods. Finally, in this chapter some thoughts and reflections recorded during this period have been presented to provide transparency in respect of some of the decisions made throughout.

In the next chapter of this thesis the practice with the Pain Management Therapists, where design practice was used to provide space to reflect and develop for both myself and the team is documented and discussed.

Chapter Six: Therapists



Figure 21: Images from staff workshops

This chapter provides detail on the practice used with the Pain Management Therapy team. The methods used reflect the iterative nature of this element of the study, as the research responded to the needs of the therapy team. This work was initiated by a desire to spend time reflecting on the therapy offering, and was a result of a variety of factors that included increased referrals, a new therapist and my request to know more about the Pain Management Therapy (PMT). The aim of the work was to use participatory design workshops to visualise and allow the therapists to critically reflect upon the service, and to progress my knowledge of PMT to support the development of the adolescent workshops.

The chapter begins with a summary of all the interactions that took place with the staff during this period, providing an overview and summarising the aims. It then moves to give more detail on the individual methods and practice before discussing some reflective thoughts and the findings of the interviews used to analyse this part of the study.

6.1 Overview



Figure 22: Elements of the service explored in work with therapists

Workshop One: Reflections

The aim of the first workshop was to provide a space to visualise and critically reflect upon the current Pain Management Therapy offering. It focused on the three key elements of; the therapists, the patients and the Pain Management Service. Key activities in this session were;

- Feedback and development on staff skills maps
- Persona creation to consider the patient 'groups' in the service
- Using the personas' to 'map' patients journey though Pain Management Therapy

The process of visualising these elements provided space for discussion and highlighted areas where more work was needed. It clarified the skills within the team and provided a summary of the patients rather than focusing on individual cases. However, there were differing opinions between the therapists on what the core PMT offering was, how long

patients should be within the service for and what the best approach to pain management was.

Workshop Two: Understanding

The focus of the second workshop was to create more time and space for discussion and reflection on 'what does Pain Management Therapy look like, using the patient personas and staff skills maps to consider any variety that there might be. To facilitate this I developed some of the visuals from the previous workshop and produced new ones based on my interpretations of the discussions.

At the end of this workshop we had negotiated a meta level overview of a PMT stage process model. Recognising that due to the variations in staff skills and experience and the subjective nature of pain, these were phases that patients moved between rather than a linear process. What was still unknown was the breadth of variation in approaches that therapists took (in terms of therapeutic techniques and models of intervention), and what physical resources (paper, flyers, information sheets, supporting materials) were used to support them.

Resources

The third interaction with the team was organised to try and expose this breadth of physical resource in the therapy department. To discuss what fitted with the core PMT offering and the stage process model and what might be peripheral or out of date. Naturally each therapist will have their own individual style and preference for resources, but as the service had grown organically over so many years the range and volume of these had become overwhelming. Resources were categorised into those which are used by all staff, those which individuals use and those that are out of date or no longer of use to the service. They were labelled to identify which part of PMT and the process model they aligned to (figure 23). Discussions highlighted some resources therapists would find helpful that are not available.



Figure 23: Resources to support resource session. Stickers provided for labelling and categorisation

Workshop Three: Looking Forwards



Figure 24: Resources to support workshop three.

The next half day workshop was organised when the therapy team was just about to enter another period of change. The team leader was stepping down having spent 25 years building the service and leading the team, her role was taken up by the newest member of the therapy service. I spoke with the new team lead to discuss how this was a pivotal moment for the team; an opportunity for the remaining therapists to take some ownership of the way that the service might run going forwards.

The workshop aimed to provide a space to start to think about some of the imminent changes and to continue to reflect on the service offering and the potential introduction of new ways of working. There were three main areas of focus; Consolidation and discharge, Patient resource and information and Future hopes and aspirations (figure 24). This workshop was also used as an opportunity to reflect on all that we had already achieved during our period of work together (figure 25).



Figure 25: Materials displayed around the room to support reflection on work achieved so far

Workshop Four: Summaries

The previous workshops were used as a space for reflection, inevitably this was the catalyst to some service development which started in the workshops. However, mostly it fed into changes behind the scenes and discussions with team leads etc., I supported this if required, but was not directly involved. I was involved in the patient resource pack and

between the third and fourth workshops there had been ongoing prototyping to develop this.

The final workshop with the team was a shorter session to gain feedback on some outputs from the previous workshop. There was also an activity to summarise the key elements of pain management and to produce a learning and therapeutic resource.

6.2 Practice

Team Skills Maps



Figure 26: Developed team skills map to show the different levels of pain management skills/strategies

The skills maps were developed to visualise the data from interviews that were conducted with the Pain Management Team during the immersion practice. An in-depth summary of how these were produced and used with the staff during the first workshop can be found

in chapter five. Following their feedback and developments, I reflected on the edited map and created another visual representation of the team (fig 26). There appeared to be three different levels they had highlighted; those skills that the patients can see (such as pain management strategies and techniques), those that the patient can't see (such as referrals, form filling and team roles and responsibilities) and those that do not currently affect the patient (service aspirations). When presented to the therapists during the second session they agreed that there were levels to their roles. But they felt it is hard to separate out entirely and the edited, original map that integrated them all together was, for them, the best representation; reflecting the complexity and depth to their roles and skills.

Personas

One of the aims of this work was to consider service provision with regards to increased referrals. Personas were used to give the therapists the opportunity to reflect on the patients who receive PMT, and consider how they allocate caseloads or if certain types of patients matched well to therapists' skills. The aim was to look at the range of patients within the service by focusing on commonalities rather than individual differences and or patient stories.

To help achieve this the therapists were facilitated to design and construct a series of personas, using a bespoke template. The categories for this were based on characteristics witnessed during MDT clinics (how the pain presents, how it affects a person's life, what their living situation is) as well as more generic categories (what are their hobbies, characteristics to describe them) to create a holistic picture of the patient. Therapists each created two personas based on their experiences; one who was a more 'complex' patient and another who they might class as 'straightforward' (figure 27).

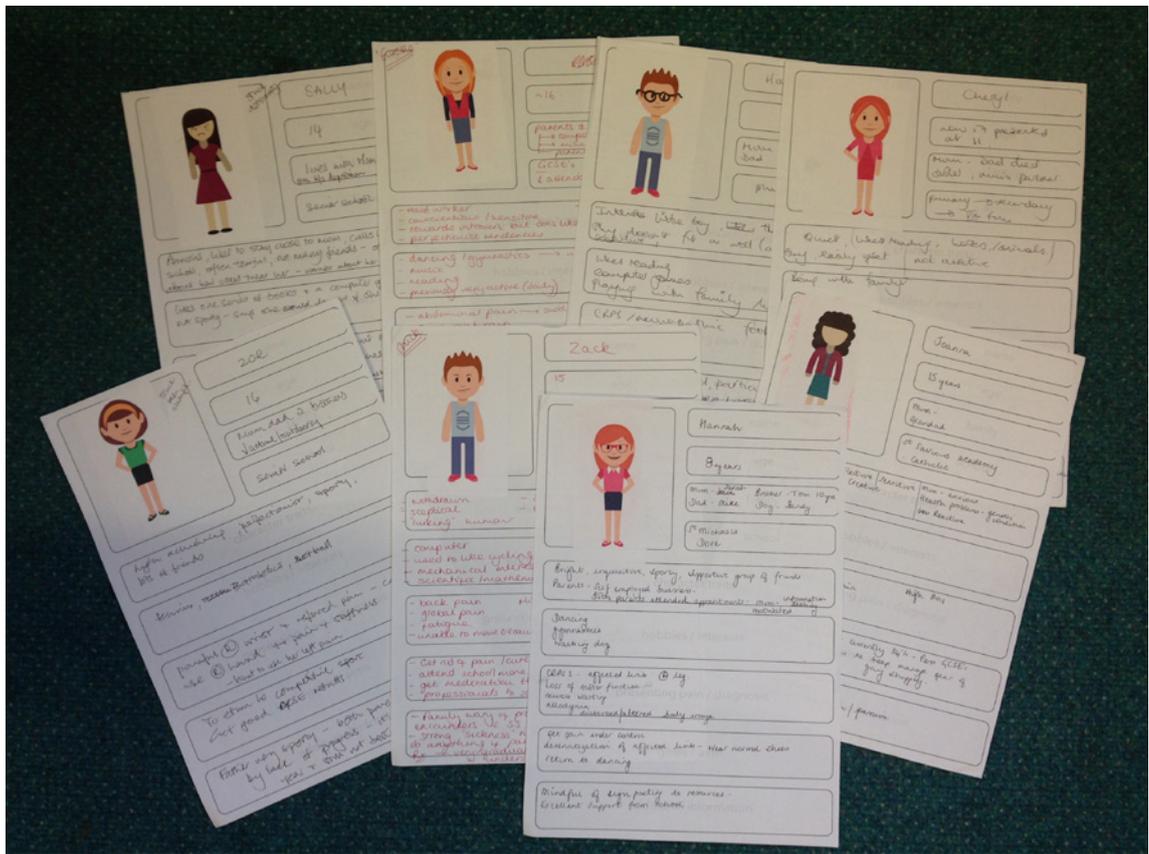


Figure 27: Patient Personas.

These were ‘introduced’ to each other and any similar characters combined. Then there was a discussion to edit some to ensure that each category represented a difference manifestation of the characteristic across the personas (for example, to ensure that all the different family groups or age ranges were represented). The conversations around patient allocation were interesting, there was unanimous pushback against patient profiling, that might see individual therapists only treating a certain type of patient (e.g. headaches or primary age children). Therapists desired to use their full range of skills rather than being ‘boxed in’. They did however recognise that some had skills that might support certain patients. They felt patient allocation could be on more of a case-by-case basis that was dependant on each therapists’ current case load and the needs of the patient.

In the next workshop refined visuals of the personas developed were presented back to ensure that the representations were true (figure 28). Over a short discussion, the team agreed that they were satisfied with the range and representations and that the visuals could be used in education and training or when considering any service changes.



Harvey, 8



Family



Characteristics

- Intense
- Thoughtful
- 'a bit different'
- Sensitive



Holidays



Reading



Computer games

Goals/Aims	Additional information
<p>Full-time school. Walk normally. Sleep better.</p>	

Figure 28: Revised personas presented to the team.

I found that the process had supported my understanding of the patients in the service and would help when planning the adolescent workshops. The personas exposed a much broader range of patients than I had experienced during my time shadowing MDT clinics and highlighted some of the complexities of which I might need to be mindful.

Journey Mapping

To understand the current PMT service and highlight variations between staff approaches, visual journey mapping techniques were used. Each therapist was given a sheet of paper and less than five minutes to map what six sessions (based on the number of 'interactions' or 'contacts' that the therapists had speculated was the average during previous interviews) of PMT might involve. They were asked to focus on techniques and interventions, considering an 'ideal' scenario (figure 29).

Using this and the personas, therapists annotated a larger sheet to illustrate what sort of journey their persona might have experienced. I asked them to focus on what might have happened in each phase, whether this persona would have fitted the 'ideal' and where

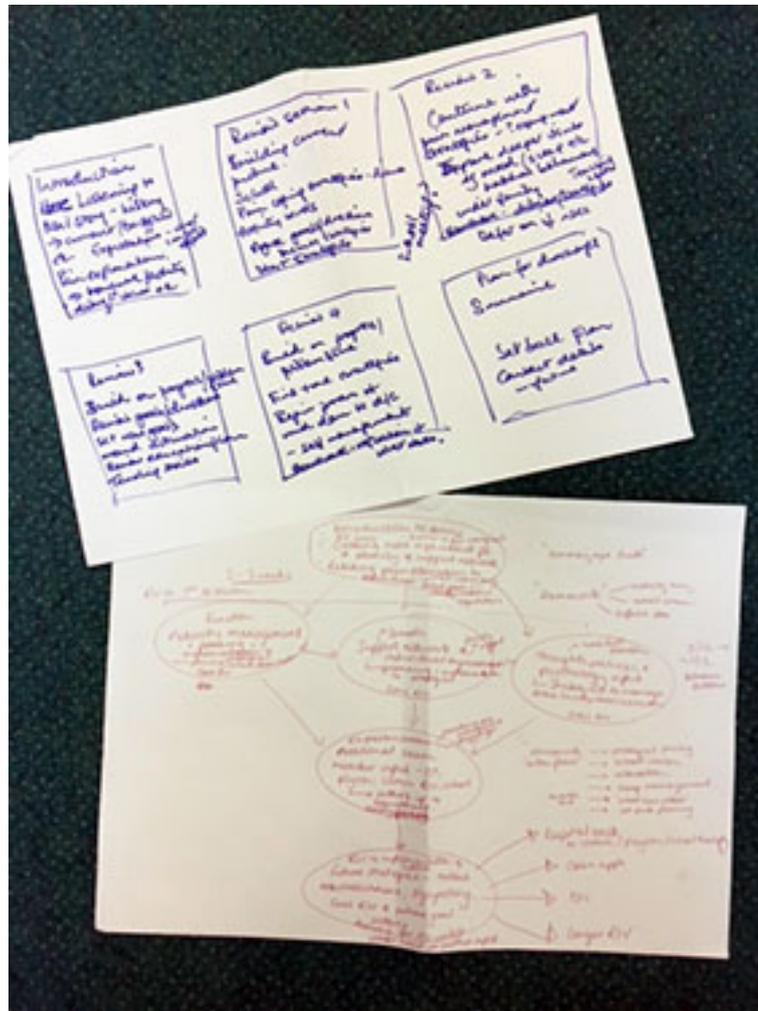


Figure 29: Initial process mapping. Annotated six sessions of PMT.



Figure 30: Outcome of journey mapping exercise

they might have become 'stuck' or had a eureka moment (figure 30).

Like the edited skills maps, the outcome looked complicated, but the team reflected that is was realistic; the process is multifaceted and complicated. Listening to the therapists describe the persona journeys helped to develop my understanding of what PMT entails. Furthermore, it visualised areas of complexity, highlighted phases that needed more unpacking (such as what are the core techniques and education all patients receive) and emphasised some of the difficulties and inconsistencies in the process, such as discharge.



Figure 31: Visualisations to make sense of the pain management stages

After the workshop, I spent time reflecting on the annotated six stages and journey map, trying to make sense of the service phases to visualise 'what does Pain Management Therapy look like' (Figure 31). The result was a 'five stage process model' shared back with the team during workshop two. To provide depth to the overview each therapist

annotated a copy based on what interventions, techniques or support they would provide in each phase. I then negotiated these comments together by cutting up, adding to and annotating a large version of the model (Figure 32). The result was a five-stage model, where the third stage, which covered the bulk of pain management strategies, was split further down into five elements (figure 33).

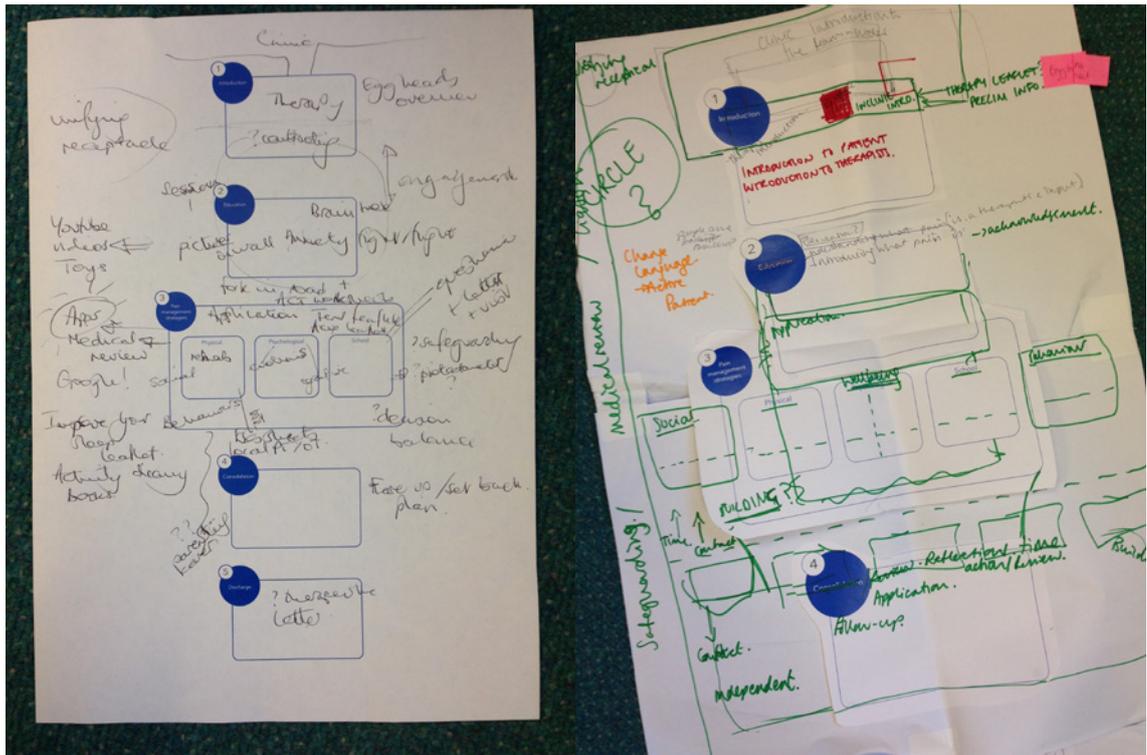


Figure 32: Annotating the five phase process model

It required careful navigation to get to a consensus, recognition was given to the need for variation, and there being stages or phases that a patient might move between. The process facilitated conversations between the therapists about their different ways of working and approaching PMT. Considerations were given to the boundaries of the therapy service and where the therapists' interventions start and stop. For example, does PMT begin in clinic or at the first session?. Again, inconsistencies in discharge were highlighted. This linked to a wider discussion on patients who get re-referred, the implications of this, and the expectations of therapy held by the wider service team.

Pain management- stage model

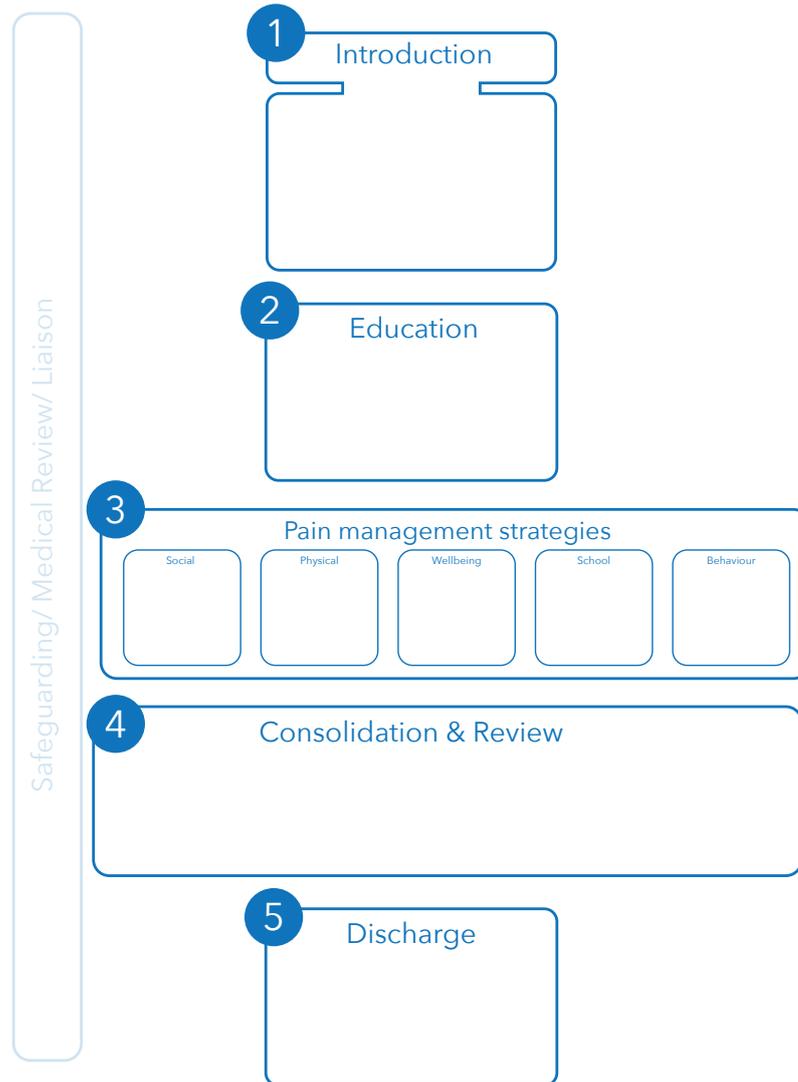


Figure 33: Final five-stage process model

Discharge Planning

Time spent reflecting on the service in the first two workshops highlighted discharge and consolidation to be least understood elements of the service with a wide variation of approaches. As a result, some patients were in the service receiving regular therapy for many years, and others no longer actively received treatment but were never formally discharged. There was no clear process or standardised documentation this.

The intention in the third workshop was to understand what the multiple perspectives on PMT were and the variations in how it takes place. In the first activity therapists were asked to describe discharge in; three words, a sentence and a paragraph (Appendix 13).

Next a copy of the stage process model was provided to consider; where the idea of discharge should be introduced, was it a point in time or a series of stages, what would it look like at each phase. Then each therapist was given a persona and asked what discharge would look like to them. Finally, on card cut outs they considered what the wider team members thought discharge from therapies was and when it happened (figure 34). Using a whiteboard, I facilitated the negotiation and combination of these individual responses, which resulted in key themes (figure 35).

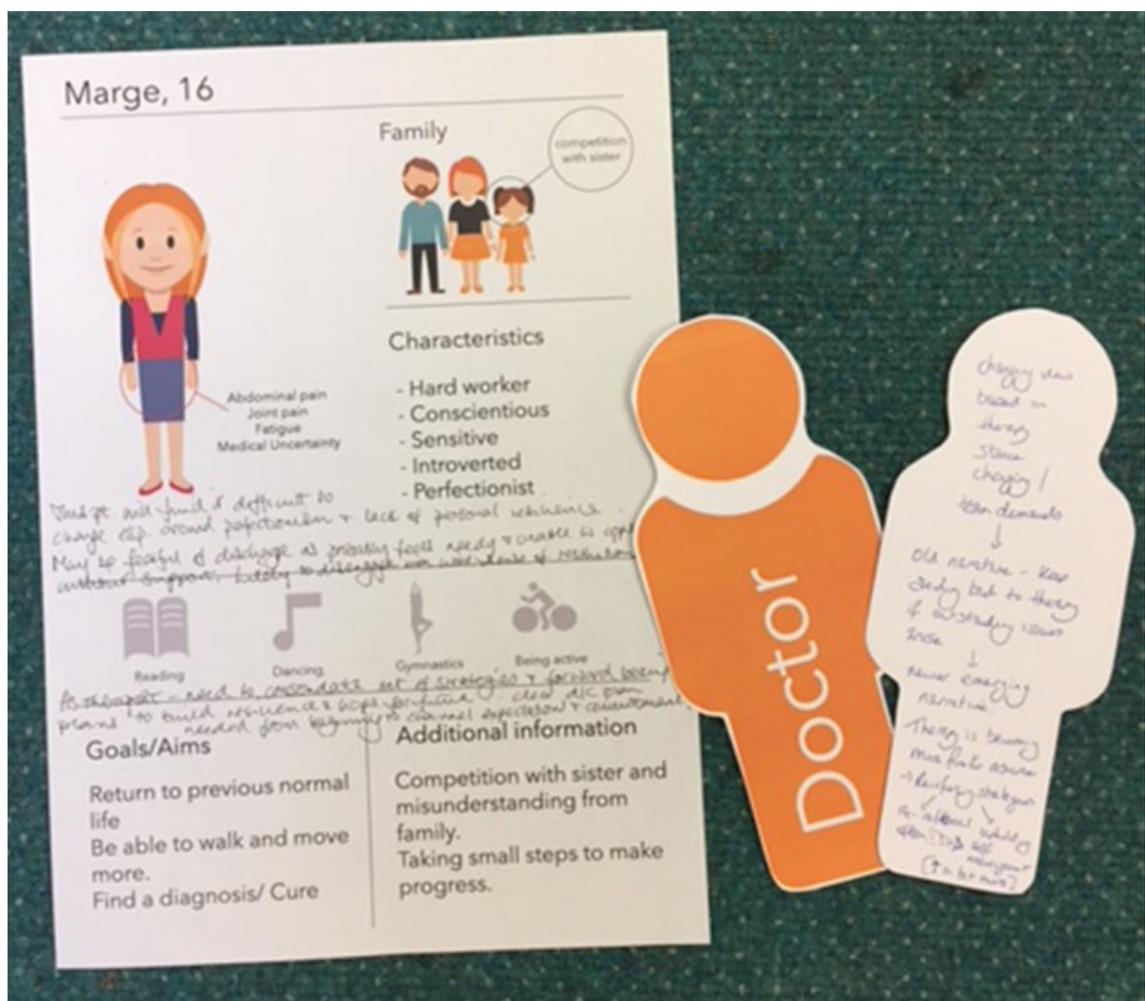


Figure 34: Outputs from workshop three: What does discharge look like to staff and patients.

Alongside the key themes and grouped categories, there had been a fruitful discussion between the therapists. The discussion focused on the habits that they had fallen into and the implication on their work loads. They also covered what discharge involves and

the need to be more explicit about it upfront; framing it as a positive part of a therapeutic process. One person reflected that when there was no clear therapy model or episodes of care to define the service, wider team members (doctors/nurses) will often refer patients back into PMT, even when therapists have completed the key pain management skills or the patient hasn't fully engaged previously.

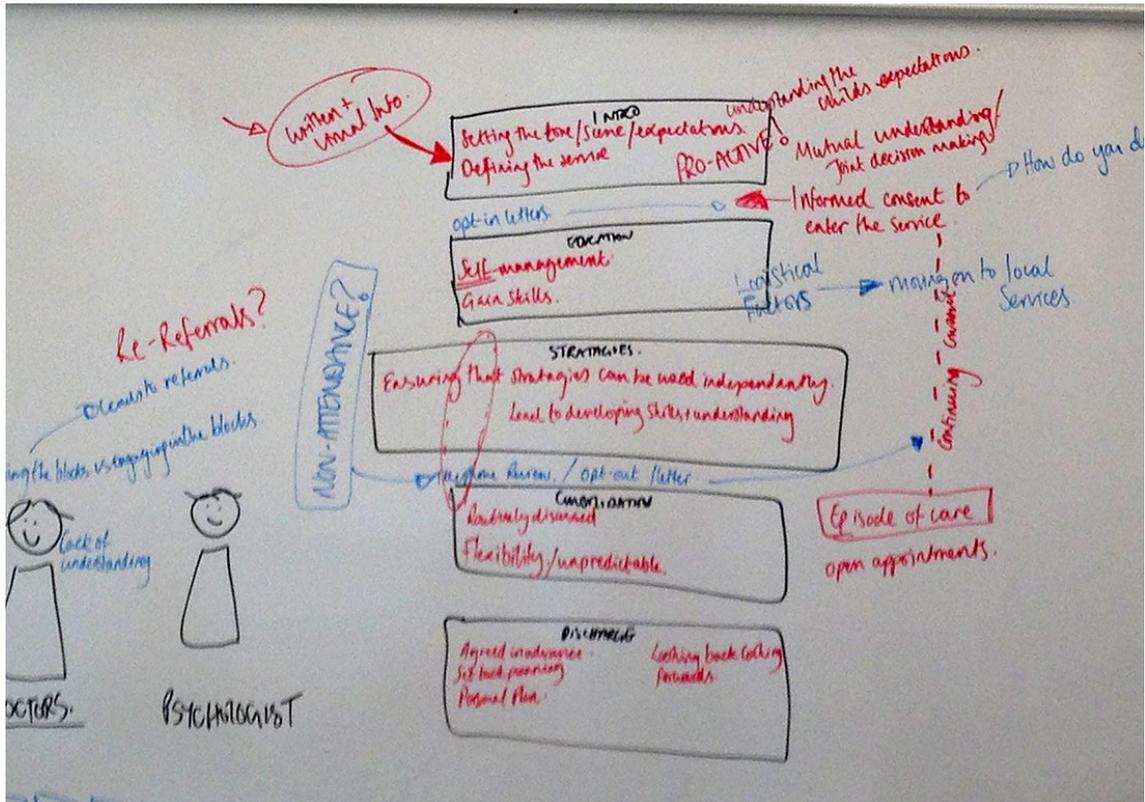


Figure 35: Combining group thoughts on discharge to consider what discharge looks like in the process

Key Pain Concepts

To aid in the reflection of the key elements of PMT and help consolidate some of the discussions on the core offering, the NOIjam¹⁴ key pain concepts were used. Therapists were each given a set of the 10 concepts and asked to group and sort them based on their expertise and experience. During this sorting, they considered if there was a hierarchy or order to the concepts. They then worked together to edit and adapt the concepts to

14 NOIjam- Neuro Orthopaedic Institute collaborative. Research institute that focuses on the neurological understanding of pain.

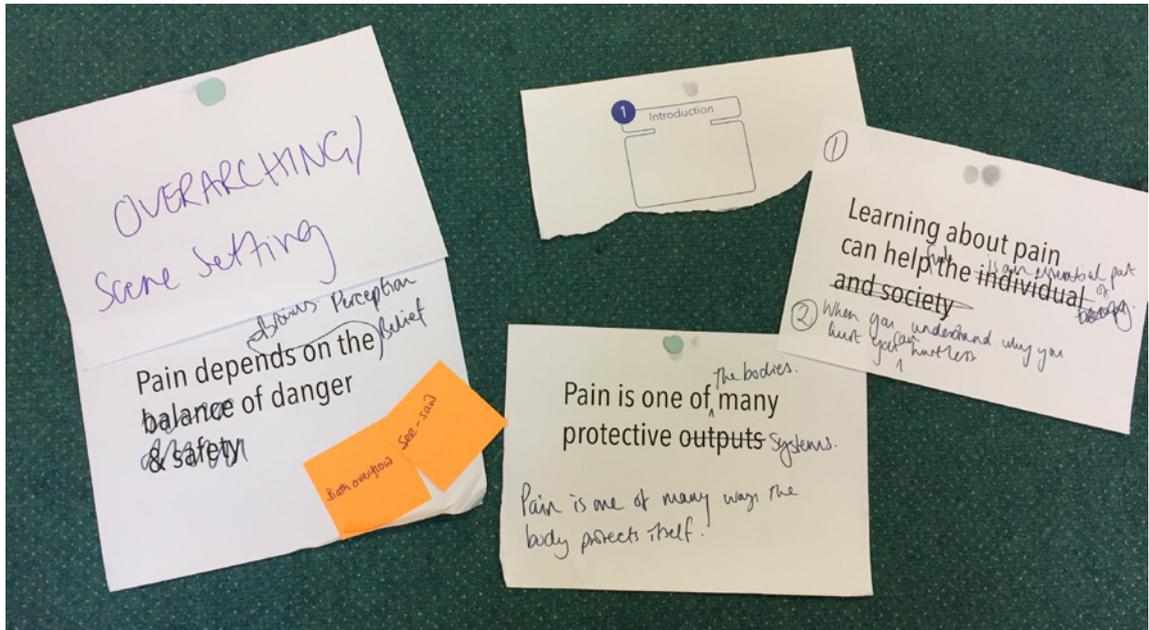


Figure 36: Exploring the key pain concepts

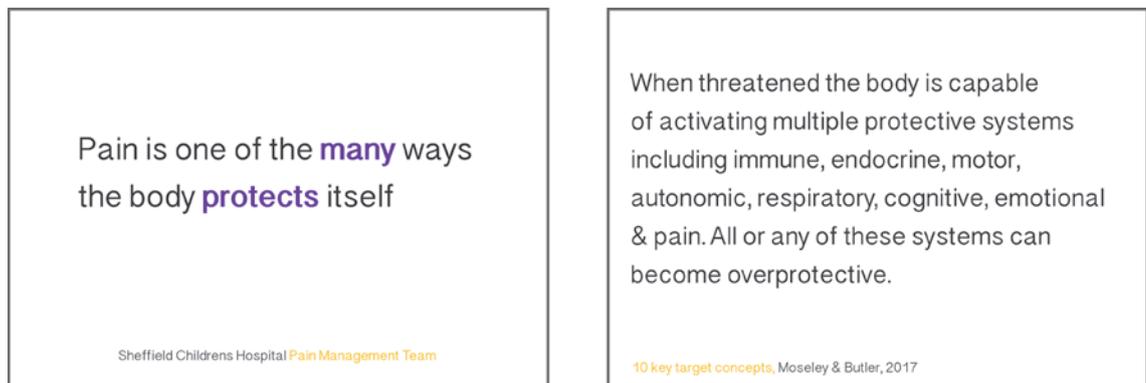


Figure 37: Example of key concept card; Front (l) Back (r)

suit them and their own practice-specifically in their experience of working with children rather than adults (figure 36).

Following this session, a deck of ten key concept cards (one concept per card) was produced (figure 37). The therapy staff use these as a resource during therapy sessions with patients and families. Additionally, some of the wider team are using these as a teaching resource to help others understand the key pain concepts.

Creative Practice

Alongside the key activities summarised above, other creative design practice was used in the sessions to engage and gain feedback from the teams. Templates were designed

to support these activities. For example, during the third workshop speech bubbles were used to get the teams to think about the future of the service. Each therapist had three speech bubbles on which they wrote what they would like the service to have achieved in three months, one year and three years. These formed the basis to think about priorities moving forwards. The team unanimously decided the focus should be on uniting service provision that could be supported by a patient resource or information pack with a clear brand.

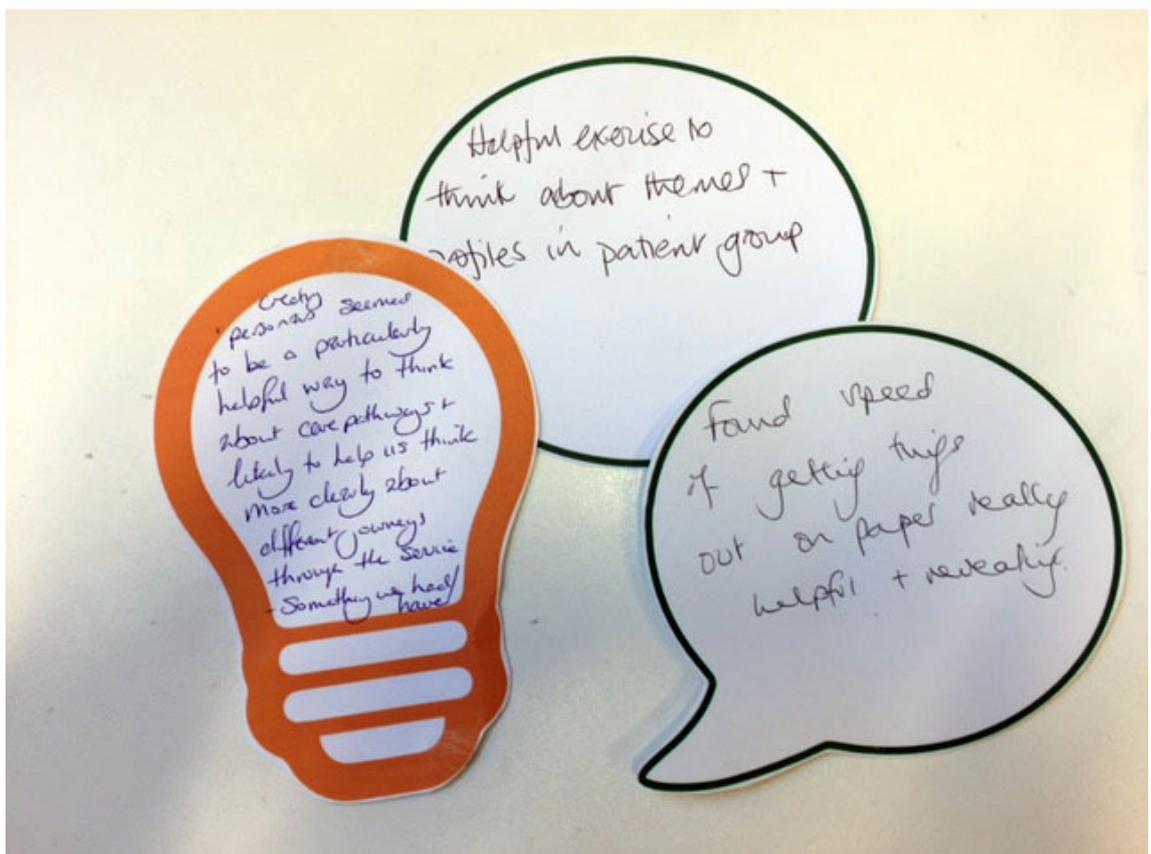


Figure 38: Examples of feedback on previous practice

In another example, to provide feedback on staff experiences of the workshop activities so far, maps, outputs and photographs of previous work were placed around the room along with a short summary that covered; what we did, why we did it and what I learned from it. I left a series of shaped cards (lightbulbs for key moments, exclamation marks for difficulties and challenges and speech bubbles for general comments), which the therapists wrote on and attached to provide their reflections (figure 38).

Patient Resource Pack

Reflections on the therapy services resources and information began during workshop two. After the initial process model was developed the team were keen to look at what type of patient information or resources they could use to support the service and consolidate the various approaches within it. This started with the categorisation of current resources in the department (Fig 39). The session showed the scope of the resources in the department, uncovering key information as well as resources that were redundant or needed updating and indicating difficulties in locating certain ones. The process also highlighted tensions as preferences for certain resources were uncovered and opinions differed on which should constitute a 'core' resource. Difficult conversations were navigated when therapists felt a resource had been imposed upon the service by a team member without consultation or agreement.



Figure 39: Session to categorise the resources in the PMT department.

A system developed whereby a therapist would share a resource and the stage to which it correlated. A discussion would then follow and stickers were used to distinguish between a 'core' resource that all staff used or one that a single therapist used. There were further stickers to cover 'information for staff use only', 'less used but useful'. It was obvious that a one size fits all approach to streamlining these resources would not work. Therapists have different skills, training, experience and expertise, they also come from different backgrounds and follow different therapeutic models. If the aim was to lead to a central patient information pack or staff resources then there would need to be flexibility to allow for differing styles of both therapists and patients.



Figure 40: Mapping the resources onto the stages to understand the depth of resources in the service

To develop this idea further I considered the outputs from the session, mapping them onto the stages (figure 40). From this I created three basic prototypes (a workbook for staff and patients to complete, a folder for the addition and removal of information, and a series of overview pages for the stages to which staff could add all their own resources) and presented them to the team for discussion during the third workshop. These provoked a conversation about how didactic the resource should be, all staff felt strongly that a prescribed format for pain management would not be appropriate, but could not agree on what alternatives might work.

To move the discussion forwards, I designed an activity to try and uncover where they did agree. Everyone was given three sheets of paper folded into a booklet and five minutes to mock up what they believed should be included in a central information resource (figure

41). When combined, the overall elements and order of stages, with a few variances, were consistent across all therapists. What was not clear was the exact information. To clarify this each therapist was provided with a presentation folder to fill with the key information and resources, to create their own 'patient information resource'.

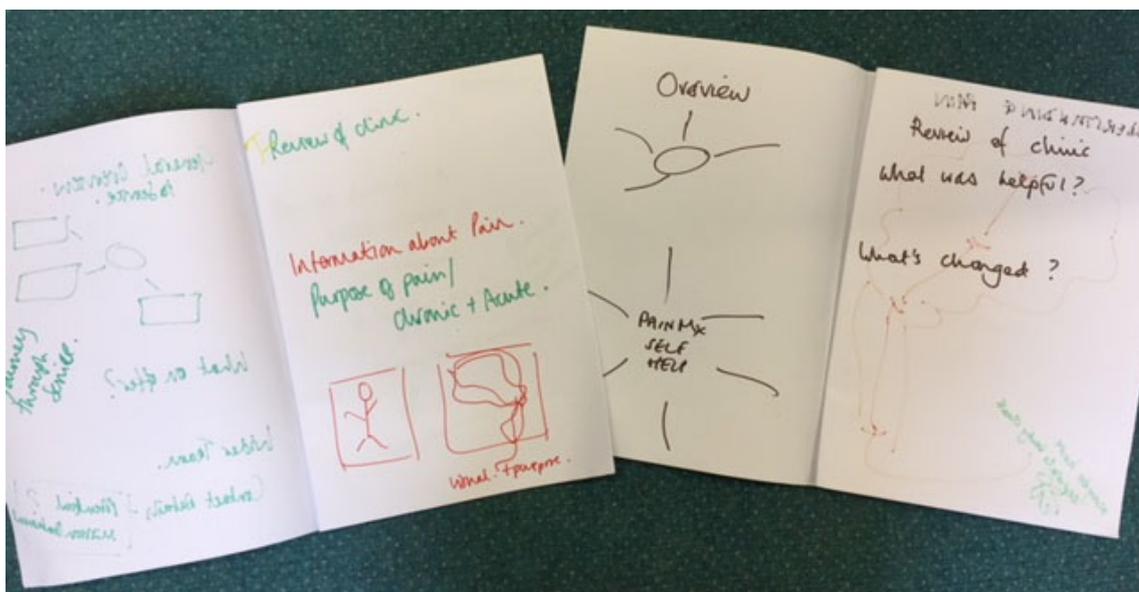


Figure 41: Staff mock ups of central information resource

Once returned (after three weeks) I went through each folder and created a coding scheme to help order and categorise the information (figure 42). This activity illustrated that the staff were working in a similar order through PMT that corresponded to the process model (for example starting with information on pain education, understanding the impact of pain before moving on to more specific techniques such as pacing). However, there was a large variation in the information and specific resource sheets used that matched the findings from the resource session.

Through a series of four prototypes and based on the learning from the mock ups, a patient resource pack was developed. Prototypes were provided to the staff for feedback, which would feed into the next iteration. Through the development process it was established that the pack would provide; general service information on pain management, some pain education and provide a way of understanding the impact on the patient. These

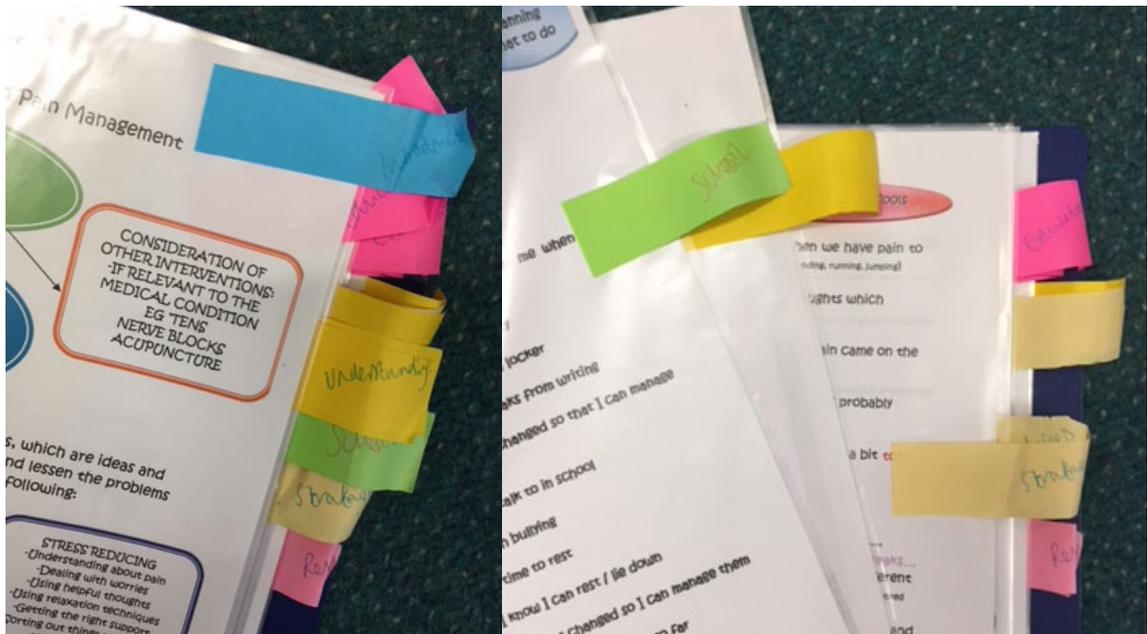


Figure 42: Creating a coding scheme to order and categorise the information.

elements would be the same for all patients and specific to Sheffield Pain Management Service. Beyond this, it would be flexible, staff could personalise the pack with further information sheets depending on the patients' needs. For example, not all patients would need information on sleep or pacing or mindfulness techniques. Finally, out of date resources would need updating.



Figure 43: Pain management Icons

To unify the various elements, a visual language was developed for the service. This was based around a series of icons (image 43) that made up the 'guide to pain management', a resource developed to support the introduction to Pain Management Therapy (figure 44). These nine icons each linked to a part of pain management that the therapists offered, and were used to provide a visual reference throughout. This visual reference was also used for those resources that were not part of the main pack. An icon would be placed on the sheet to link it to the correct part of PM.

Guide to the Sheffield Pain Management Therapy programme



Figure 44: Guide to Sheffield Pain Management Therapy programme

The final patient resource pack is thirteen pages long and presented in a presentation folder (image 45). This format was chosen to allow staff to annotate the sheets and to add other resources where appropriate. Presentation folders are also easily available, allowing the team to easily replicate the pack. The first few pages cover information about the service and PMT. Then there are a series of pages with various body and limb outlines to support the therapist to understand a patients' pain, and give a 'pain explanation'. Finally, the team developed a 'pain cycle' and a 'recovery cycle' to illustrate the effects of pain (fig 46 and 47). To go with this resource pack a patient information leaflet was developed based on the 'guide to pain management' which is handed to patients in clinic (Appendix 21).

To support the service in using these, 200 copies were provided to the service to cover the next years' referrals and to allow them time to look for a sustainable source of funding for further folders.



Figure 45: Final Resource folder



Figure 46: Recovery Cycle

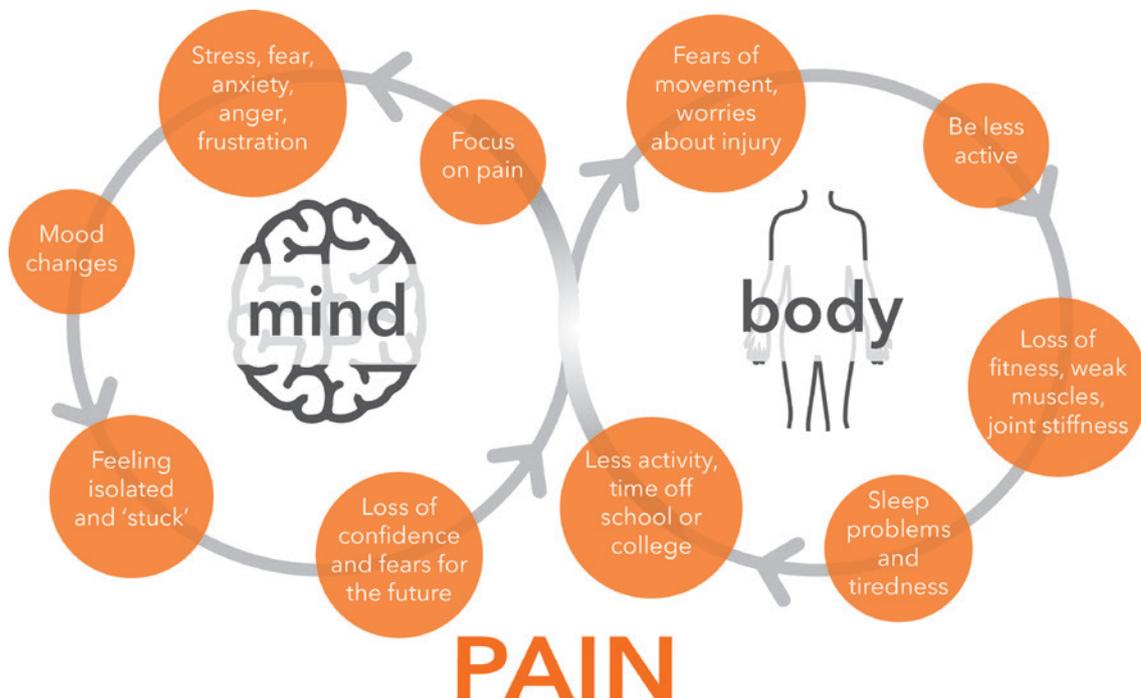


Figure 47: Pain Cycle

6.3 Reflections

So far, this chapter has summarised the work with the Pain Management Therapists. Focusing on methods used in the mutual understanding and reflection on the service and the development of a patient resource pack. It will now cover my reflections on this, and then move to discuss the analysis and findings from the interview data.

These reflections focus on the thoughts and reflections written around each interaction with the therapists. Broader reflections that support this practice contribution to knowledge can be found in the discussion chapter of this thesis.

Communication across Hierarchies

The team are all experienced therapists working alongside each other at a similar level. Therefore, the hierarchies came from time and position in the service, rather than experience. Prior to the workshops some of the therapists mentioned that they felt unable

to challenge the leadership, particularly with regards to new therapy resources and how to manage patient caseloads. When trying to discuss change, conversations often went around in circles with no progression on the topic. As a result, silo-ed ways of working had developed to avoid confrontations and maintain a sense of control.

From discussions and observations, I was aware of these hierarchies when planning the workshops. To mitigate these issues, during the activities, individual opinions and experiences were captured and recorded before any group discussions. I ensured that these individual responses were recorded visually, providing an external record that remained visible when combining ideas. I also found the visual record useful to support my facilitation, as I could refer to an individual experience if I felt it was left out of the group consensus.

This record was also useful when views conflicted. Individual reflection captured and externalised instinctive unfiltered responses. The therapists could talk to and about what they had recorded, and to and about what the others had recorded, rather than to each other personally. If one person was leading the direction or conversations got stuck in a certain area (which is often when people lost their train of thought) they could refer to the record of their own idea in front of them to focus their input.

The importance of working in this way was highlighted during the third workshop. The therapists were having an ad hoc discussion on ideas for a patient pack. They fell into their old patterns of communication, with no space to reflect on personal opinions or any visual means to structure and externalise their discussion. The conversation did not progress until I stepped in with an impromptu structure for them to record their own ideas, which I then helped facilitate into a shared starting point.

Supporting Design Ethnography

This work, whilst not originally part of the study design, has been invaluable to develop my

understanding of PMT. The design ethnography had enabled me to; build a relationship with the team, gain first-hand experience of the patients in the service, meet the wider Pain Management Team and observe interactions between all parties. This work built on this by showing the nuances of PMT, the complexities of the service, the nuances of team skills and the entire range of patients with whom the service interacts.

The design ethnography and workshops complimented each other in my journey to understand the service. For example, through design ethnography alone I could not make sense of what pain management interventions were. I reflected after the first workshop that one of the reasons why I might have struggled to understand this was because the team approached it in different ways and there was no 'core service offering'. It was only after visualising these approaches together that it started to make sense. However, the success of the workshops relied heavily on the earlier period of work. Without a relationship between myself and the team, they would not have taken the dedicated time to come to these sessions, or seen the benefit in them. Also knowledge gained through observations, interviews and shadowing enabled me to create the initial structures on which the activities would scaffold. Additionally, my time observing the service gave me an external perspective that encouraged me to share my own understandings. There were times where I found discrepancies with the team accounts and my experiences. As such I could challenge the team as well as use my external position to ask naïve questions.

Visual Process

As a design researcher, my practice is tangible. I use visual methods to support my thought processes and map my understandings. These workshops reminded me of the value of sharing these representations with others and the depth of knowledge this sharing brings. For example, I took the interview data and built my knowledge of the team skills by producing a visual representation. This provided one level of knowledge, but gaps were filled in and further depth added once these were shared with the therapists. I also found that my understanding of something developed more quickly when supported by

a visual made collaboratively rather than individually, as was the case with the patient journey mapping. However, it was important to design the initial visualisation template to encourage subsequent participant contributions and mitigate against the difficulties that sometime occur when faced with a blank piece of paper.

6.4 Analysis

Interviews

The primary method to analyse this work was an in-depth semi-structured interview that took place a few months after the last workshop (due to both mine and their workloads). The aim of this was to allow the therapists an opportunity to provide feedback on their involvement in design research, their experience of design methods and the impact of the work. The structure was loosely based around four key areas (Early involvement with the team, evolution of research role, the series of workshops and the impact of design research in health) with ideas for questions in each. The workshop followed an informal format, questions were not set and the interview was flexible to respond to topics the therapists might raise. In addition, images of the activities, practice and workshops were provided to help with memory of the sessions and to form part of the conversation.

Each interview lasted for around an hour. At the start of each interview I explained what they were going to be used for, the format of the interview, the topics to be covered and then confirmed that they were happy to be audio recorded before I turned on the voice recorder. These audio recordings were then transcribed and subjected to a qualitative analysis as outlined in the methodology chapter.

Qualitative Analysis

To start the analysis, each interview was printed and read through to re-familiarise myself with the data. An initial coding was then conducted to summarise the transcripts (fig 48). These were then re-read to check, add additional codes or propose new codes



Figure 49: Organising the data into themes and categories



Figure 50: Codes and category development for individual interviews

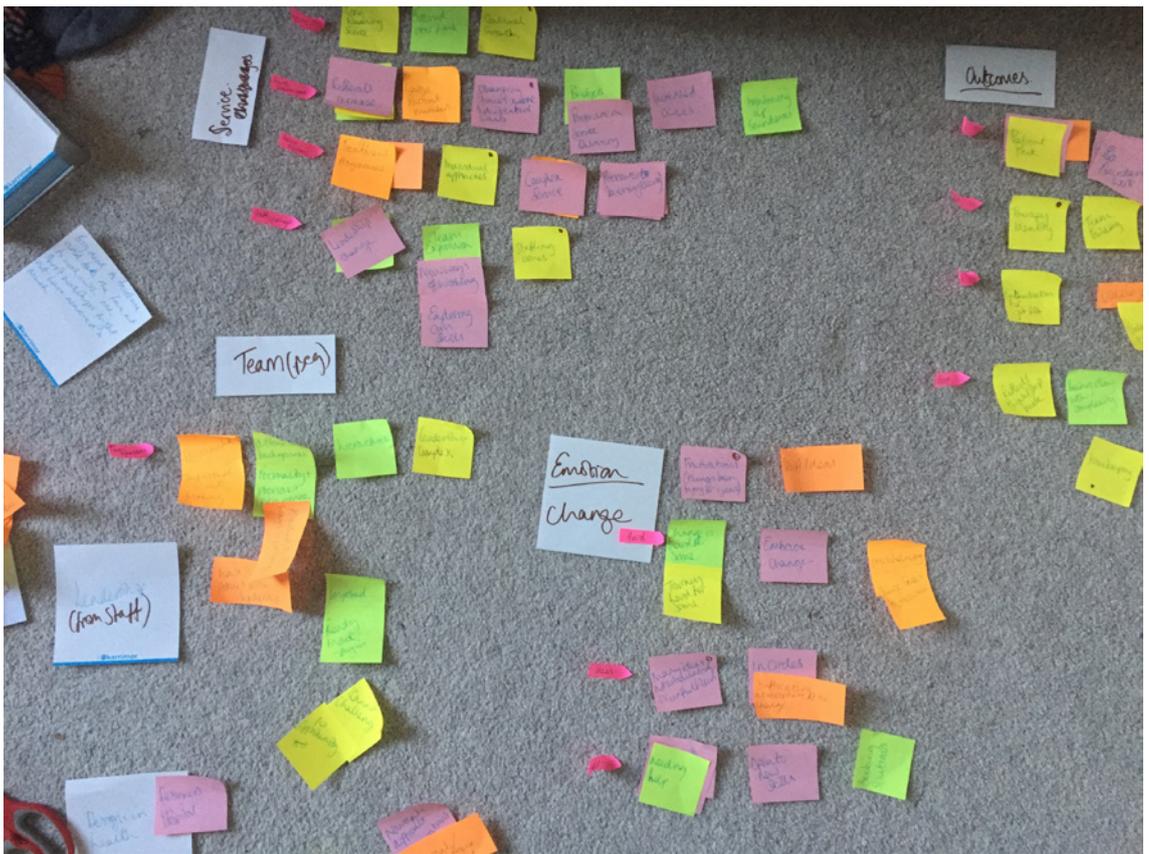


Figure 51: Combining the individual interview analysis

Theme	Category	Sub category
Background information on the Pain Management Service	The development of	Evolution and Growth
	Service Challenges	Referrals increase Large Patient numbers Type of Patient Need to modernise Financial Pressures
	Delivery of PMT	Treatment Program Patient/ Family characteristics
	Staff changes	Leadership change New therapist
Therapy Team	Dynamics	Disconnected Experience and styles of working Personality Communication
	Style of Leadership	Buy in Opportunity to Challenge
Therapy service development	Change is harder for some than others	
	Embracing a change	
	Big task to undertake	Overwhelming
	Support	Need help
Other development approaches	Previous experiences	
	Microsystems	
Outcomes of work	Therapy service	Treatment process and Patient pack Patient engagement Discharge Group work
	Tangible	
	Team	Team building Communication
	Personal	Enthusiasm for job role Value
Pain talking workshops	Need for neutrality	Transparency issues
	Understanding	Misunderstanding and confusion
	Conflict in my role	
Adolescent workshops	World view	Stuck
	Different approach	Perspective/ unique
	Impact of the workshops	
	Overlap with therapy	Similar to therapeutic process
Beyond PhD	Publishing	Dissemination
	Continuation of this work	
Design facilitator	External person	Outsider perspective external voice/ fresh pair of eyes Neutral
	Skills	Project management Design skills and training
Relationship built between us	Contextual review	Building a relationship Trust Support
Design	The value of design	
	Design skills	
	Knowledge of design	Understanding of design vague
	Explanation	Difficulties
Time	Taking the time	Lack of time to share usually
	Value of clinical time	
	Length of time	Making changes takes time
Approach / Format	Speed	New
	Novel	Engaging
	Clear	
	Challenging	
	Collaborative	Shared knowledge/ consensus / consolidate Ownership Hierarchies Permission
	Tacit knowledge	
	Visual	Visual over verbal tangible/accessible externalised
	Having a clear focus	Narrowing down Change in focus Positive

Figure 52: Qualitative analysis structure for Staff interview data

Findings Summary



Figure 53: Staff interview themes

There were 13 themes generated from the qualitative analysis of the staff interview data (figure 53). The largest frequency of data is found in the approach and format theme, closely followed by the outcomes of the work. The themes; background information, therapy team and therapy service development, relate to information about the service before our work. They set the scene for the responses and findings, but are not included in the findings discussed here. There is an even spread of data across the rest of themes with responses well distributed across the four interviews.

In depth findings

Outcomes

This analysis highlights that the outcomes from the workshops are multiple and varied, spanning physical and service outcomes, as well as less tangible areas such a team and

personal development.

Prior to starting this work there was no clear service delivery, a long waiting list and many patients in the service. Discharges were not routinely happening and patients could remain on the therapists lists for many years. The therapists were working as separate individuals and there was no clarity on service provision or boundaries to PMT.

Interview data indicates a positive impact on the Pain Management Service. As a direct result of the workshops there is a clear therapy process supported by the patient resource pack. Discharge is now a proud part of this process and introduced to patients early on as a positive point in their pain management. There is a consensus on the PMT offering and boundaries to the work that they can offer. In addition, the therapists have new 'brand' to their service, a visual marker of the work that they have undertaken.

"It just helps focus things and the process, so families are clearer about what they're doing and certainly I feel a bit clearer about the whole process that's involved."

"has been a definite shift about almost introducing the idea of discharge and episodes of care right from day one"

(Occupational Therapist A)

The team recognise that there is more work to be done, but that they now have a shared basis to start from. For example, there is a desire to explore group sessions to reduce caseloads further and to continue to refine resources to fit within the patient pack. In addition to those that are tangible, there are outcomes from this work that are not physical and relate to the impact on the team and personal practice.

"That sense of value which I talked about before, but we feel valued as a team, because we feel proud of ourselves"

(Occupational Therapist B)

Interviews indicate that the team has a clearer identity, improved communication and on

an individual basis renewed enthusiasm for their job roles. The team feel value and pride in the work they do with patients and in the process that they have been through to get to this place. This is demonstrated by their desire to disseminate it beyond their own team and practice and to publish their work.

The Value of Time to Reflect

The Pain Management Service had grown organically over a period of 23 years. In this time, patient numbers dramatically increased and the therapy service grew to cope with the increasing demands. However, there had been no dedicated time in this period to consider the service delivery, therapy processes and how best to manage the ever-increasing caseloads.

This body of work with the pain therapists provided the team with this dedicated time. Findings from the interview data show the value that the team placed on having this. Taking time out from their practice allowed them an opportunity to stop and reflect and come together as a team. It was recognised by the therapists that workshops facilitated by an external person required a level of commitment from them that they otherwise would not have given, with one therapists saying;

“Would x have felt committed enough to come to a meeting if it had just been us chatting? So the fact that you were leading it, it made it different and special. So we have put a lot of time, if we added it all up, which we probably would not have done”.

(Occupational Therapist B)

This highlights the importance of the commitment to this body of time by the team as a whole;

“We’ve had to make a commitment as a team to working through it, so we’re not passive receivers of service, as it were”.

(Occupational Therapist B)

For example for two of the workshops team members came along on their days off

showing a real commitment.

Taking the time to do this work together provided a space to 'take breath', 'focus' and 'step back'. One of the therapists described it as personally refreshing and enthusing and an opportunity to see a bird's eye view. Findings also indicate that the value of time to reflect is not only in the shared commitment and dedicated time, but the presence of an external facilitator to provide a focus and guide this time in order to make the best use of it.

A Clear and Visual Approach to Collaboration

The background information theme of this analysis provides an insight into the difficulties that the team had in communicating with each other and working together to come to a consensus on topics. The therapists were disconnected from each other, working in very different ways. When they did try and discuss topics, they would get cover the same topic over and over without progressing forwards on anything.

It is clear from the data that the team found the approach collaborative, bringing together their individual views to create consensus. Furthermore, the approach provided focus, reduced hierarchies, gave permission for all therapists to contribute, valued their contributions and ultimately created a sense of joint ownership over any decisions and outcomes.

"this whole thing has been hugely collaborative. I've felt included and I've felt I had a voice and I've felt that I can offer an opinion and that that opinion is valid in a way that I hadn't ever really felt within the therapy team up until that point"

(Physiotherapist A)

"Yes and that's really key, isn't it, that everything that we've got up here is shared. It's not one person's vision or thought process even"

"Bring us all together and suddenly something new pops out of it, which is nobody's and everybody's, and that's what that is, which makes it so strong"

(Occupational Therapist B)

Key to this ability to be collaborative was the visual nature of the workshops and the focus on commonalities and not differences. This was particularly valuable to this team who found conversations on these topics challenging. This approach prioritised visual over verbal, where ‘a picture tells a thousand words’ and the team could ‘recruit different aspects of thinking in a way that feels less hard work’. The process of creating visuals made knowledge tangible and accessed the team’s tacit knowledge of their practice through instinctive answers.

“I think the other thing was that we recorded it.... There’s quite a bit of power just in that, in recording. I suppose we’re so used to trying to come to a consensus of opinion that you don’t get that recording of what you’ve thought about it along the way.”

(Physiotherapist A)

The quote above highlights an important part of these findings. There is recognition of the value of visual practice to provide a record of a person’s individual ideas, thoughts and contributions, and the team’s thought process. Using visual mapping methods also externalised and depersonalised some of the more complex conversations in the team and made ideas tangible and accessible. That is not to say that the findings suggest the approach was without challenge, it was a new way of working for some of the therapists who found it challenging to work in this way without extended time for reflection and discussion.

Within the interviews the staff mentioned other approaches they had experienced or heard about for service development and team building. There are other approaches and other methods of facilitation that they could have used, some of which might look similar to the design methods. However, they all agreed that previous team building workshops had not achieved the level of communication that this work has. Furthermore, they did not feel that other service development approaches would have been as holistic or produced such embedded or tangible outcomes.

The Importance of Building a Relationship

One of the themes from the analysis is relationship. Data in this theme finds that the time spent doing the contextual review had a large impact on the team's desire and ability to engage with myself as a design researcher;

"I think having that preliminary time to really understand what we do and why we do it and how we do it was really helpful and it felt like we had a colleague rather than somebody that had just been catapulted in"

(Occupational Therapist A)

"You can't immediately go to them, 'Look at all these things,' because you have to build the relationship in order to have permission to do"

(Physiotherapist A)

Spending time getting to know the service before introducing my practice allowed the team to trust me, which had a direct impact on the time and commitment that the team were willing to give to our work together. Also, the team recognised the value of a facilitator with experience and knowledge about the team in providing focus and guiding the workshops.

"I appreciate that you've come on a journey with us, haven't you, with the service, and understood, like you say, the complexities of the families, the types of conditions they might have, the impact it has on their lives, and you were in that position then to be able to run that workshop respecting all of that, so that was interesting"

(Occupational Therapist B)

What this also highlights are how insights into a team's working practices provide a facilitator with knowledge which enables them to consider how best to engage a team, as discussed here by one of the therapists;

"I think one of the things that didn't add to that burden was knowing that you would just keep quietly coming back to us and come up with a different way, say okay, we'll do it in this way"

(Physiotherapist B)

The Value of Facilitation

The Pain Management Service was facing vast complexities in terms of the service delivery and overarching philosophy of the service that it needed to overcome. The therapists couldn't see a way to approach this and found the idea 'overwhelming'. It is documented in the findings that previous attempts to consider how best to approach this had not achieved anything, and instead pushed people further into their individual practice.

What the staff found beneficial about this work was having a facilitator who could guide them through the process. Additionally, what was important about the facilitator in this work was not only that they were an external person, but that they also had a knowledge about the team and the service. Therefore, they provided a new perspective and subsequently their role was more than just as a facilitator. They worked alongside the team providing their own insights as well as asking 'insightful questions' and summarising the conversations in the room.

"fresh pair of eyes to come in and look at the processes that we use, the resources that we use, how we engage with families, how we deliver our treatment – the whole package really."

(Occupational Therapist A)

Another quality of the facilitation that supported this work was the practice of thinking ahead. At moments when the team were becoming too focused on a topic or struggling to see the wider picture;

"then I suppose what became apparent, it felt to me like you could see a way ahead for us that we couldn't see, that there was a way through what we were trying to do, and because we were in it, it was like not being able to see the wood for the trees"

(Physiotherapist A)

"having somebody outside who's almost holding the vision a little bit while you do the horrid bit".

(Physiotherapist B)

“You’ve always pulled everything together and sometimes it might look a bit chaotic, but it is a shared vision. It’s about bringing together diverse thoughts in people, putting them together and then creating something else”

(Occupational Therapist B)

What these quotes highlight is the designers’ skill to not only facilitate the process, but also to engage in the process through listening to the conversations, interpreting the visuals, asking questions and providing insights from their own experience. Moreover, the design researcher can hold the overall aim of the work to draw together with the participants views and represent that to them in real time.

Understandings and Misunderstandings of Design

Finally, the analysis highlights a lack of understanding on the role of design in healthcare the team had prior to this work. Specifically, around design and design processes that do not have a product or tangible outcome. Furthermore, it shows that even once someone has experience of these processes they still struggle to communicate the value to others within healthcare.

When asked what prior knowledge they had about design or expectations for the study, therapists admit that during the contextual review phase they were unclear. Their previous knowledge was generally focused around ‘product outcomes’, or they related the skills that I discussed with regards to the adolescent workshops to skills within their own practice.

“No, and I think that was a real puzzle for us all to begin with, trying to understand that there wouldn’t be a product specifically at the end of it or a new thing for people to use. It felt very nebulous and hard to understand to begin with.”

(Physiotherapist A)

The following interview data highlights the wider gap in the knowledge when one of the therapists discussed with others that they had a designer working with the team;

“Trying to explain at that point what you were doing, when I think I was only just beginning to understand [...] I think the biggest query people have is how can design help health? Why are you working with a designer? Surely you should be working with somebody else”

“Trying to explain, particularly when you started running the groups and other people in the team, in our wider therapy team, trying to feedback that you were running these groups – how does a design person, what can they possibly bring to a child with pain? It’s been tricky, it has been tricky, because in people’s heads there isn’t the overlap really”

(Occupational Therapist B)

In both instances, the team work and the adolescent workshops, the wider team were confused about the involvement of a designer. The therapists found it challenging to communicate their experience of design, they could speak of its value, but struggled to communicate the methods and processes.

“It was hard to begin with. The nurses in particular, as you know, are a force to be reckoned with..... I have explained it, but I’ve just kind of not got drawn into conversations about the benefits of it or the rights and the wrongs. I suppose I’ve tended not to be drawn on it, or I sold it, ‘Oh it’s brilliant, we talked about this and it was really helpful,’ or, ‘We drew this map and it was a complete mess.’ I don’t know if I’ve explained it....”

(Physiotherapist A)

As part of our work together a physical outcome was produced in the patient information pack. This was a positive addition to the service welcomed by both staff and patients. However, as the following quotes demonstrate, when it came to communicating the work involved to get to that point, the physical document was a red herring. People would focus on the physical outcome rather than the process. This concerned the team because for them the real value of the design support was the focus rather than the product.

“This, in a way, is almost a by-product, in the nicest possible way, because it’s fantastic and it’s really brought us all together, but it’s not just about the fact that you’ve put some nice logos on there and it reads nicely. For me that’s not what you’re about.”

“We’ve been working with a designer and this is what’s come out,’ they will say, ‘Ooh yes, you’ve made it look nice.’ That’s not what it is at all”

(Occupational Therapist B)

In this chapter, the practice with the Pain Management Therapists has been summarised along with the methods for analysis and the findings from this analysis. I have also provided my reflections on the process. This element of the study emerged from a period of design ethnography. Key insights from this practice show that it had a positive impact on the Pain Management Service, both through service development and building the team capacity of the staff. Furthermore, the approach was novel, visual and collaborative, enabling input and valuing the voice of all members within a team with complex relationships. This highlighted the importance that the team placed on having a facilitator to guide them through the process. Finally, the analysis found that knowledge of this type of design in healthcare is minimal, demonstrating the difficulties when trying to articulate the value to others.

Chapter Seven: Adolescents

This final chapter in the practice section provides detail on workshops to demonstrate design skills and approaches to adolescents with chronic pain. The chapter begins with a summary of the ethical approvals procedures to conduct the study. It then covers the overall aims of the workshops and the recruitment process before providing a description of the individual sessions. The end of the chapter covers the methods used to analyse the impact and presents the findings.

7.1 Ethical Approval Process

The NHS ethics process was initiated after the first phase of design ethnography, once there was a clearer idea of the patient population with which I would be working with. All NHS ethics approvals go through the central system IRAS and I worked closely with a staff member in the R&D department at SCH to support the application. Due to its low risk, qualitative nature, this study did not have to go to a full ethics board and instead went through a proportionate review panel. It took seven months from starting the forms to receiving a favourable opinion from the review panel on the 26th May, 2016.

Following this, the application went to the Health Research Authority (HRA) for review, due to a backlog in their system, this took 6 months to be approved on the 25th October 2016 (see appendix 4). The final process was local site permissions from SCH, for this another document was submitted and final permissions and approval was granted on the 17th January 2017, fifteen months after the process was started (appendix 6).

During the planning process for the workshops, it was realised that amendments needed to be made to the supporting documents. I made two amendments to my documents, the first, changes to an information flyer, went in as a major amendment due to the large changes in layout and content (figure 54). This was submitted on the 24th February 2017 and was approved on the 12th April 2017.

Are you interested in finding out about how design could help support you in managing the challenges of living with a long term condition?

Rebecca is a PhD researcher from Sheffield Hallam University (SHU) who is running a series of workshops and activities to explore what design might be able to offer you.

This is not the sort of design that you will have experienced in school's design and technology classes. Design in this study is an everyday skill and mindset for engaging in creative thinking. Design is used to explore how and why things are, as well as problem solve and give us tools to communicate our ideas.

This study hopes to

- Increase your knowledge of design skills
- Provide a creative space to share your views & opinions
- Increase your confidence to problem solve
- Support you in your self-management goals

You will be given a £20 high street voucher as a thank you for taking part.

If you are interested and would like to find out more please contact a member of your clinical team or email r.partridge@shu.ac.uk

Sheffield Hallam University | Art and Design Research Centre | Sheffield Children's NHS Foundation Trust | Date: 16.05.16 Version: 1

Sheffield Hallam University | Art and Design Research Centre

SUPPORTING YOUNG PEOPLE WHO LIVE WITH PAIN

Are you aged 11-16 and receiving pain management?

A research project with designers from Sheffield Hallam University

If you are between 11-16, in secondary education and receiving pain management then we would like to invite you to take part in a series of workshops and activities to see how we could support you.

The project aims to enable you to;

- Share experiences
- Learn new skills
- Be creative

These workshops will be led by a Designer, who is interested in understanding more about what it's like to live with chronic pain, and see if some of the skills she teaches you will help you to manage it better.

If you'd like to be involved in this series of fun and creative workshops and activities, ask your therapist for more information.

Sheffield Children's NHS Foundation Trust | Date 07.02.17 Version 3

Figure 54: Recruitment flyer amendments

The second, changes to the layout and minor wording of an information sheet went through as a non-substantial amendment (Figure 55). This was submitted on the 23rd June 2017 and approved on the 7th July.

Sheffield Hallam University | Art and Design Research Centre | Sheffield Children's NHS Foundation Trust

Supporting young people who live with pain- Information for Young People
A research project with designers from Sheffield Hallam University

You have been given this information sheet as you have expressed an interest in the above project. Please read the following information to help you decide if you would like to take part.

What is the Project?
 This project explores ways to support young people who live with pain, visualise their views and experiences and increase self-management skills. The project will be run by a PhD researcher, who has experience in service and product design.

What does design have to do with living with pain?
 This is not the sort of design that you might have experienced in your school's design and technology classes. We will not be developing new things products, so do not worry if you think you're not good at drawing or making.

Design can be a confusing term. The term design in this project relates to the way designers work. For example; Product designers make new items such as kettles or bikes, Graphic designers will create images like logos to advertise things and architects design buildings. Whilst these jobs are all different, the designers have many skills and techniques in common, such as, being creative, visually communicating their ideas and problem solving.

It is thought that these skills can be used by anyone to help them in their everyday lives. We want to see if sharing these skills with young people who have chronic pain can help

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Figure 55: Information sheet amendments, submitted for review with track changes

7.2 Workshop Overview

The aim of these workshops was not to teach adolescents to be a designer or how to go through a design process. It was to introduce design skills and build confidence to use them so that they might approach the world more explicitly like a designer and apply those skills to challenges they might face daily. For this reason, there was no in-depth explanation or demonstration of a design process. However, the activities were run in an order to infer that they could be used in a process (where one might ideally come before another) but it was not explicit that they had or needed to be part of a process.

Earlier in this thesis I presented a literature review that summarised the skills of designers and considered the ways these are shared with others through design practice and design thinking. Key skills summarised from this, that the workshops would focus on were (See figure 56 for the handout of mindsets given to adolescents):

- Communication
- Observation
- Prototyping
- Questioning
- Experimenting
- Creativity
- Gaining knowledge and understanding
- Optimism
- Perspective
- Opportunity

The intention was to use design techniques to illustrate and demonstrate these skills through experiential activities. These were adapted and developed from various sources

SUPPORTING YOUNG PEOPLE WHO LIVE WITH PAIN: MINDSETS



Figure 56: Mindsets handout

that included; Craig et al (2013), Campbell (2011), Sustar et al (2013) Wolstenholme et al (2014), and IDEO’s design toolkit (2011). Not all skills had specific activities attached to them and some activities would embody more than one skill.

In the interests of keeping the sessions interactive and experiential, the activities varied in length. I included videos to illustrate certain points and purposefully did not use PowerPoint (to avoid a presentation style delivery), instead short explanations were given by myself using printed pictures and images where necessary. Presentation and sharing

by the participants was encouraged. To ensure participants had an opportunity to share, they worked individually or in pairs before sharing with the wider group.

In keeping with personal experience and literature, the workshop activities and discussions did not focus on their application to the participants' experiences of CP. There is a benefit to allowing a safe space to learn a new skill without focusing on the condition (Wolstenholme et al 2014), allowing participants to build confidence where the stakes aren't too high if they do not succeed first time. Instead I reiterated throughout that they were here because they all had CP and I was interested in understanding how the skills might be used to support them manage it.

Living with chronic pain can cause disruptions to an adolescents' school attendance so workshops needed to fit around school hours. I did consider running sessions after school or on the weekends, but the CP team members advised that for many, these times are not ideal due to fatigue and tiredness. There was consensus within the team that the workshops would need to run in school holidays as adolescents had more time and energy to engage. Once all the amendments to ethics had been approved the workshops were scheduled for the 8th and 22nd August 2017 during the summer holiday. Two workshops



Figure 57: Participants in workshop One

would be held on each of these days. A further 1:1 session was run in early October for a participant who was unable to make the second of the two workshops.

I made my experience and role explicit to the adolescents at the start of the sessions explaining that I have no training in Pain Management Therapy. Therefore, I could not support the young people in these techniques should something come up. However, should they feel uncomfortable or have any problems they should speak to me and I would contact a suitable person such as parent/guardian or therapist. Participants had to sign in and out of the sessions and parents/guardians had to provide a contact telephone number where they could be reached during the workshop if necessary. The workshops were supported by another design researcher and one of the Pain Management therapists attended one of the first sessions.

7.3 Recruitment

In the original recruitment strategy information packs (information sheets, flyers and cover letters) were to be handed to potential participants by therapists during PM sessions. Due to the time to gain ethical approval there was only a two-month period for recruitment to two specific dates during the school holiday. However, after a couple of weeks I had few initial enquiries about the project as few packs had been handed out. Therapists often forgot during sessions to mention the workshops and struggled to find time in-between to post out information to those they were not scheduled to see. The strategy was flawed and continuing with it could mean low recruitment numbers or a need to find new workshop dates.

Consequently a new strategy was devised, therapists could still give targeted information in sessions and I provided large posters of the flyer as a reminder. In addition, I sent information packs to each of the 192 patients from Pain Management Therapy who fitted the inclusion criteria inviting them to attend the two August workshops. From this there

were 25 expressions of interest, received through phone calls, emails from parents or guardians or via the therapists. Of these 25 expressions of interest, 15 adolescents were recruited and attended the first workshop, 11 of these returned for the second workshop. Reasons why the other four did not return include; forgetting about the session, one was too unwell and two unknowns. One person could not attend the second workshop but completed a 1:1 session later.

Of the ten people who expressed interest but were not recruited, reasons were given such as; couldn't attend both sessions, wanted to know if there would be alternate dates, adolescents were too unwell, families were on holiday, parents were not happy for their child to attend without them or the parents had health complexities which meant they could not get their child to a session. (See appendices 16 and 17 for consent forms for this study.

7.4 Workshop One

The first workshop focused on how designers see and experience things, with an emphasis on;

- Observation
- Perspective
- Questioning and Knowledge
- Understanding
- Opportunities.

Activities were developed to allow participants to experience how they might see things in a different way or from an alternate perspective to their own, demonstrating that there is more than one way to frame a problem or view a situation. The intention was to encourage the adolescents to be inquisitive, explorative and frequently ask questions.

This might enable them to see opportunity where they might previously have seen none and to consider that even in areas where our view might be very 'set' or 'fixed' there is always something new to learn. This was particularly relevant to pain management. Throughout my time in the team I had come to understand that many of these adolescents can become very 'stuck' in their worldviews, as they try to deal with the pain. Often their lives become diminished, they do less, see less people and move less, struggling to be flexible for fear of increasing their pain. This was summarised by one of the therapists;

'A lot of the young people that we work with often feel very stuck and their life has shrunk considerably. A lot of the cognitive processes that they perhaps previously had around problem-solving, being creative, thinking big picture, they're not employing in any way, shape or form'

(Occupational Therapist A)

The workshop activities aimed to build participant confidence in learning how to employ design skills and provide a safe space to practice them so that they might find opportunities to apply them beyond the workshops. Furthermore, the first workshop intended to prepare the participants for the more advanced creative thinking activities in the second workshop, supporting the adolescents to see how building knowledge and looking for opportunities for change can provide the foundation for creative ideas. (see appendix 15 for workshop plan)

The first workshop began with introductions based on optical illusions placed around the room, followed by an introduction to the mind-sets outlined above using videos from IDEO's Design kit (2011). It then moved into an activity where the adolescents shared what they understood design to be and who designers were. This was important as it was assumed that everyone in the room would have different experiences and perceptions. As a facilitator, I needed to be aware of these to be ready to introduce other concepts, build their knowledge about design and manage expectations. Building on this, a further activity was adapted from Sustar et al's (2013) co-designing with young people project, The cool

wall. The cool wall (figure 58) is a popular culture reference; participants worked in pairs to place images (of products, services and ambiguous items) on the wall. Discussing their choices encouraged them to think about their perceptions of design, why they like or dislike things and how it might affect them. They were also asked to consider what might make something cool, or who might have a differing opinion to them, introducing them to the idea that other people's perceptions and opinions might differ from their own.



Figure 58: 'Cool Wall' activity

To introduce the idea of personal perspectives I adapted a traditional party description game (where you need to describe a word without saying five key words that relate to it), first used by Wolstenholme et al, (2014) to show how everyone describes things differently and to highlight the multitude of approaches people might take to solving the problem. Further activities required the adolescents to categorise and re-categorise words to mimic how designers might continually question, reflect, re question and think about things (figure 59). Or conversely, to look very closely at something (a game box, a logo, a packet of biscuits), to break it down into smaller components and to question the design decisions (why is the box so big for a small card game? Why have they placed this image there?). This activity adapted from Campbell (2011) also encouraged participants to understand what is key in the identification of something (for example, what identifies

a game box as a box to hold a game) and the spectrum of influences and options that surround it. To stimulate discussions after an activity or to illustrate a topic I used videos or images. For example, I presented the evolution of the tin opener to show how there can be small progressive changes (better handles, grips, different colours) as well as introducing larger paradigm changes of perspective that might lead to entirely reconsidering the way something is done (i.e. the introduction of the ring pull and the Heinz fridge pack).

The final activity adapted from Campbell (2011), saw the adolescents interviewing another member of the group and creating a drink that represented them (figure 60), it was made clear that this was to be a drink that they were like, not that they would like. It demonstrated how they might be able to build knowledge of something or someone and provide their own meaning and interpretation. The activity aimed to get them out of literal thinking and build their creative confidence. Metaphors were encouraged, for example; you might place a cherry on top because this person has a lot of confidence. The activity demonstrated how you can summarise knowledge in creative and imaginative ways. The session wrapped up with summary of the activities and mind-sets and an overview and introduction to the second workshop.



Figure 59: 'Categorising activity'

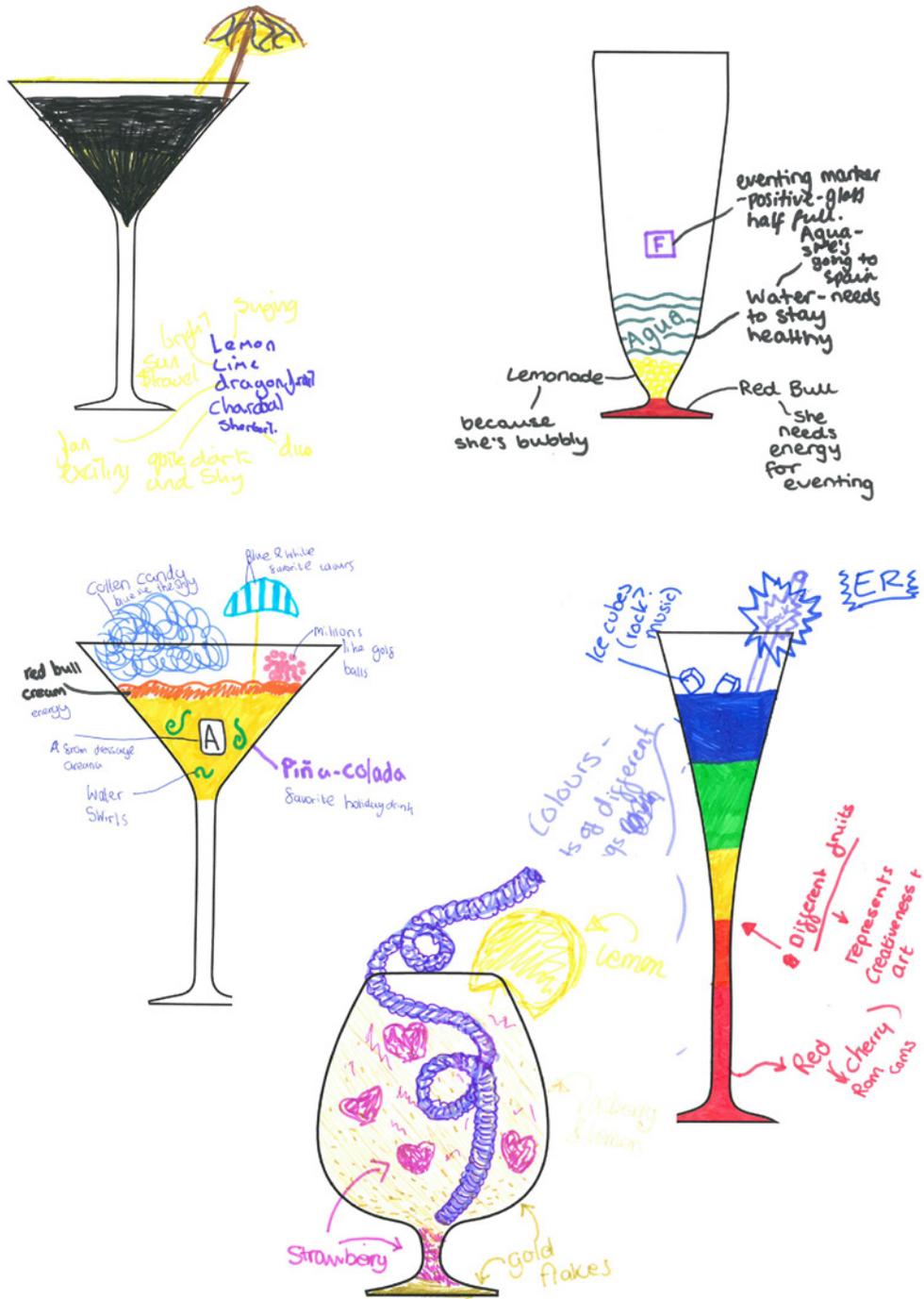


Figure 60: Examples of drinks created to represent participants

7.5 Workshop Two

The focus of the second workshop was on how designers imagine and create things, with an emphasis on;

- Communication
- Prototyping
- Optimism and Creative Confidence
- Experimenting
- Learning through failure.

For many young people who have chronic pain they often become 'stuck' in a particular way of life as they feel 'safe' doing things in certain ways that they know will minimise their chance of pain. If they try to do something outside of this and it does not work or achieve what they had hoped (or if one of these safe ways suddenly causes pain) then it can be viewed as a failure. The adolescents are unlikely to try or do it again, and can feel a sense of personal failure that contributes to low mood and reduces the likelihood of trying something new that might help. However, pain management encourages careful and progressive actions to increase movement, activity and participation to reduce the impact of pain on a person's life.

The intention with the second workshop was to enable the participants to recognise their creative abilities, provide them with techniques to support idea generation and build their confidence in the value of their ideas. It also aimed to help them communicate their ideas and reframe their perception of failure into a learning opportunity as a way to move concepts forwards. In order that these design leaps could be made and new and innovative solutions can be generated there needs to be a degree of optimism and a safe space to come up with crazy or wacky ideas. The workshops aimed to embody this

safe space so that ideas could be explored and learning generated. (see appendix 18 for workshop plan)

The session began with a warm up activity and a recap of the workshop aims, including its potential links to the management of CP. The first few activities focused around creative thinking and techniques to come up with creative ideas and easing the participants into the notion of 'wacky' ideas by combining image cards, people cards and question cards from Wolstenholme et al (2014) and The Idea Game (realize AB 2010). This activity encouraged the participants to generate ideas through the interrogation of a 'thing' or by considering how somebody else might use it.



Figure 61: Screen shot of future cinema. 'star trek predicts the flip phone'

To support the idea of a safe space to think creatively and without restraint we set ground rules. Principles such as; 'no idea is a bad idea', 'build on the ideas of others' and 'encourage wild ideas' were established. This was reiterated by 'Circles' a warm up activity that demonstrated how we self-edit ourselves. Adolescents were given a two-minute time cap to turn as many of the 30 circles on a page into 'things' by adding additional pen marks. Most filled less than half the page, and no one repeated a concept (such as a range of faces or different fruits). To further encourage the ethos of 'grand ideas' and 'no

such thing is a bad idea' we screened a 'future cinema'. Clips of programmes such as Star trek and Tomorrows world were shown to the participants to illustrate how things that might have once seemed impossible are now part of mainstream culture, such as mobile phones and 3D printing (figure 61).



Figure 62: Building and description game 'A briefcase'

The next section of the workshop was aimed to help people consider how they might communicate and prototype their ideas. Using an engaging description and building game that encourages experimentation, prototyping based on the idea that 'there is no such thing as failure'. (figure 62). This activity and subsequent discussion encouraged the participants to think about how they could communicate and try their ideas with others and to consider what they might learn when things don't go as planned. The idea being that when thinking about their activities outside of the workshops conversations could begin to focused on working with others, embracing some uncertainty and complexity,

and breaking things down to manageable ‘trials’.

The end of the second session and final activity of the workshops was a short design challenge in pairs (figure 63).. It was a practical application of the skills and mind-sets illustrated throughout the workshops. The participants were first asked to consider all they could about the challenge, thinking about it from multiple perspectives and considering why things are currently done a certain way. Then they began to question some of the assumptions about the challenge and consider where the limits and boundaries to generate ideas are (what can change and what cannot). Next they generated ideas for this challenge and developed one of them, suggesting how they might prototype or test (and what they hoped to learn from it) before presenting their ideas back to the group.

Better clothing for an astronaut	New ways to remember to water plants
--	--

Figure 63: Challenge card examples for the final design challenge

7.6 One to One Workshop

The 1:1 second workshop followed the same format as the group session, however due to time restraints we were unable to complete the design challenge at the end. In this workshop, I took the role of facilitator and participant to partner up with the adolescents for the activities.

7.7 Reflections

The duration of time to gain ethical approval and subsequent amendments to the application had a dramatic impact on the start date for the adolescent study. What was supposed to be an 18-month period of recruitment and workshops to explore different approaches to the study ended in two-month recruitment period with only one round of workshops. This was disappointing, and as such there is still much more to understand about the ways the sessions could be run, the activities that are used, the format of the sessions and the best way to gain feedback and evaluate the work. The following reflections are based on the planning and execution of the workshops that did happen. Reflections about the wider impact of delays on the study can be found in the discussion chapter.

On Recruitment

As stated the initial plan for recruitment was slow. I had suggested that it would be good to have some dedicated time with the staff to show them the session plans and the activities within the workshops to help support their recruitment. They were keen for this, however, for a variety of reasons that include service pressures and annual leave this did not happen. This would have also been in addition to the therapist workshops for which the team were already struggling to find and protect time.

Recruiting for these studies takes persistence and approaches might need to change. The decision to change recruitment tactic was a success. However, the process was laborious and involved hand writing addresses on the 192 packs in the pain nurses' offices as ethical procedures stated no patient data could leave the hospital. To get these I had a list of patient NHS numbers and each one was individually entered into a database. I was constrained by the times that the nurses were available to let me sit in their office and when a computer was free as I had no access to this database otherwise. If I was a

staff member conducting research within the NHS, this process and my access to patient information would have been much easier.

On Participants

Despite only recruiting for two specific dates, the recruitment was a success, so much so that I had more than expected and put on additional sessions to reduce the patient numbers in the groups. Prior to the session, the only information that I asked about a patient's condition was if they had any access issues. I wanted the participants to feel as comfortable as possible so it was up to them to decide how much they might want to share about their condition and experience. I found this also meant I had no preconceived opinions or expectations and was not influenced by their previous experiences. The other facilitators and myself reflected that there was a good energy in the room for the workshops. During the first workshop, it was only when I mentioned chronic pain that one of the facilitators remembered that the young people had chronic conditions.

During the workshops the adolescents naturally partnered up with the person / people who they were sat nearest to on the table. When returning for the second session, they gravitated back into these partnerships (if they were both in the same session again). Throughout the sessions, the participants became chattier and relaxed with one another. However, in one of the second sessions there were a trio of participants working together where one of them did not seem as relaxed. This person subsequently became quieter and contributed less as the session went on. The layout of the room and the comfort of the other pairings made it difficult to move this person and so more facilitation was required to try and keep this person engaged.

All the participants engaged in the activities, no one refused to join in or showed signs of not wanting to be involved. One participant who was so nervous to attend they almost did not get out of the car, was visibly chattier, participating and engaging by the end of the session.

On Communicating to Others

One of the first things that the participants did was to write down their expectations for the sessions and what they understood of design. Looking back at these there was a huge variety of responses. Most participants did not know what they were expecting and their experience of design came from school. This suggests that their knowledge of this area of design was very limited as they had no expectations, and most of design in school is based around design technology and the manufacture of things.

It will be interesting to know how the adolescents communicate the sessions to others. One of the facilitators reflected 'it will be interesting to see if parents hearing about the workshop and skills second hand will immediately see the relevance or if this is something that will need to be communicated to them'.

On the Link to Pain Management

As mentioned earlier in this chapter, due to literature and previous experience I decided not to focus any of the activities around pain management and young people's experience of pain (such as sleeping, pacing or difficulties attending school). I strongly believe that learning a skill or developing a mind-set should be done in a safe space, where the stakes are low if the person does not succeed first time. Instead, activities were more game like and unrelated to pain. Throughout the session, I eluded to ways that these skills could be used always mentioning pain alongside other applications such as transport, school, family life and hobbies. As such it was hard to know throughout how much people could see a link or relate it to their own experiences.

Despite none of the activities relating to pain, it was clear that in some of the pairs of participants they were sharing their pain experiences with each other. This was unprompted from myself. As a facilitator put it

"by pairing participants together throughout the workshop, I suspect they

were able to grow comfortable sharing with that person. Making it possible to be more open when tasks came up which were slightly more personal or challenging”.

(Joe, Design researcher, Reflections after workshop one)

This could be seen in differences when sharing with the wider group. All the participant pairs were happy to share the outcomes of their activities, however, at one point I asked them to think about something from their own experience (not relating to pain) and they appeared considerably less comfortable sharing with the wider group than they did in the safety of their pairs.

Had there been more time to develop the workshops and explore them further then a 1:1 session might have been an appropriate place to consider if any of the activities, or perhaps a summary activity could link to the pain experience, as these sessions would not involve any sharing with a wider group and create a safe space to allow a facilitator to go into more depth.

7.8 Analysis and Findings

The workshops aimed to understand In what ways can design practice support the condition management of young people with a long term condition. As stated previously, analysis used mixed methods of; Likert scale surveys, questionnaires and semi structured interviews. The results of these will be used to form the basis of a discussion on this study’s contribution to knowledge. In this section I will describe the analysis process and the findings.

Likert Scale

In total, there were 11 full data sets from the survey (those participants who completed

Supporting young people who live with pain
Self evaluation questionnaire workshop one

Name: [REDACTED]
Age: [REDACTED]

Rate how much you agree or disagree with the following statements:

I am observant of the world around me



I am inquisitive about why things are how they are



I can see things from differing points of view to my own



I am good at understanding my problems



Figure 64: Part of a completed Likert survey. Blue marks are for beginning of workshop one, red marks for end of workshop one.

both workshops) and four incomplete data sets (those that only attended the first workshop). Participants ranked their responses three times against statements that related to their abilities and confidences in various design related tasks such as 'I am good at coming up with ideas to help address my problems' or 'I can see things from differing points of view to my own' (figure 64).

To analyse the surveys the responses were scanned, overlaid and data points labelled as follows; 1 for the beginning of workshop one, 2 for the end of workshop one and 3 for the end of workshop two (figure 65).

To incorporate the data that fell between the points on the scale, the scale was translated

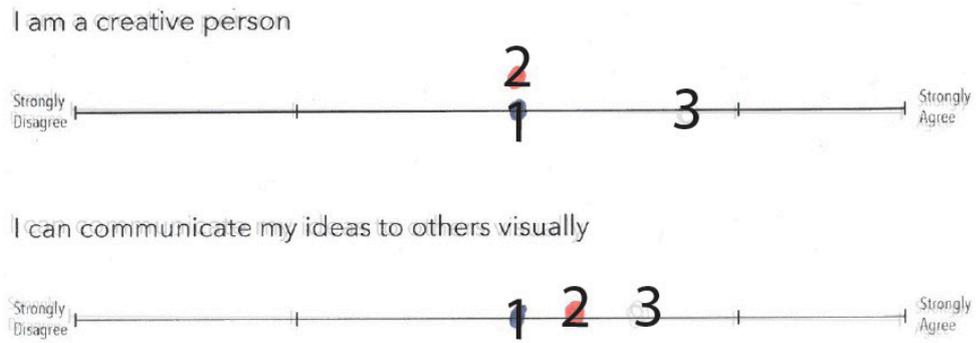


Figure 65: Step one in analysing the Likert Scales

from 5 points to 9 points. Where Strongly disagree was -2, Strongly agree was 2 and the middle point was 0. The other points went up in 0.5 increments (Figure 66). The points were transferred to a spreadsheet, any data points that fell between points on the scale were rounded to the nearest 0.5. So, for the example in figure 66 Data point 1 scored 0, Data point 2 score 0 and data point 3 scored 0.5 (This was rounded down rather than up, if the participant had wanted to score 1, then they would have placed a mark on that line, however the choice to go just below it awards it a 0.5).

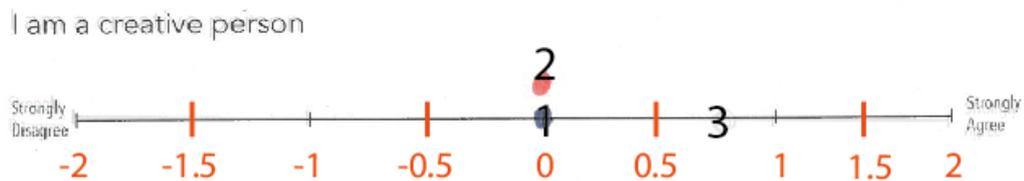


Figure 66: Scale translated into 9 points

To help make sense of the data, various diagrams were produced to see the data visually and look for general trends across the whole set. The first (figure 67) looked at the general direction of change and the second (figure 68) looked at the overall 'feel' of the data responses, where of the 132 responses, 16 were negative changes, 84 were positive and 32 had no change. Whilst these diagrams could give an idea of general trends within the data a more in-depth analysis was required to look at the average trends in the data. graph (figure 66). See appendix 17 for full data set.

Q3: I can see things from differing points of view to my own

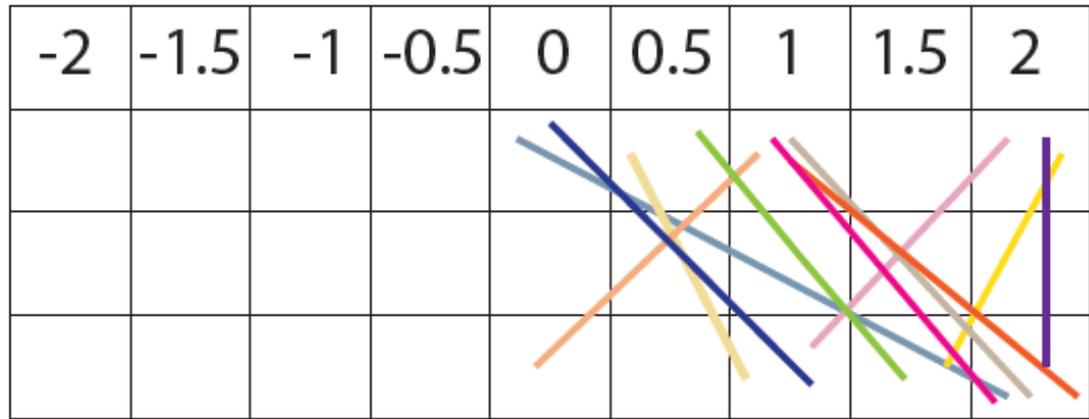


Figure 67: Making sense of the raw data from Likert Scales. This diagram shows the responses to question three and the change in response from the first to the last scale (top to bottom), each coloured line represents a different participant.

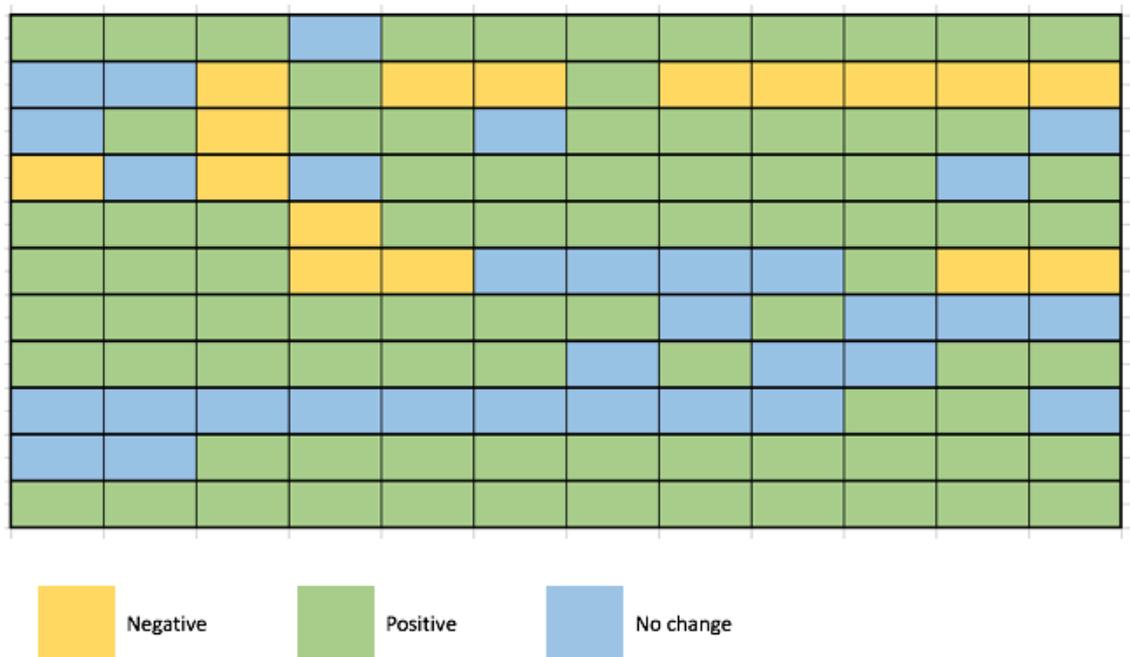


Figure 68: Changes across the Likert scale data. Each rectangle represents the change in response from beginning to end of the workshops. Yellow represents a negative change, green is a positive change and blue is no change.

Data points One (beginning of the first workshop) and three (end of the second workshop) were analysed to look at the change in response over both workshops. The difference between the two data points was recorded (a change from 1 to 1.5 would be a 0.5 difference, a change from 2 to 1 would be a -1 difference). Then the average difference was calculated from the 11 responses for each of the 12 statements and plotted on a graph (figure 69). See appendix 17 for full data set.

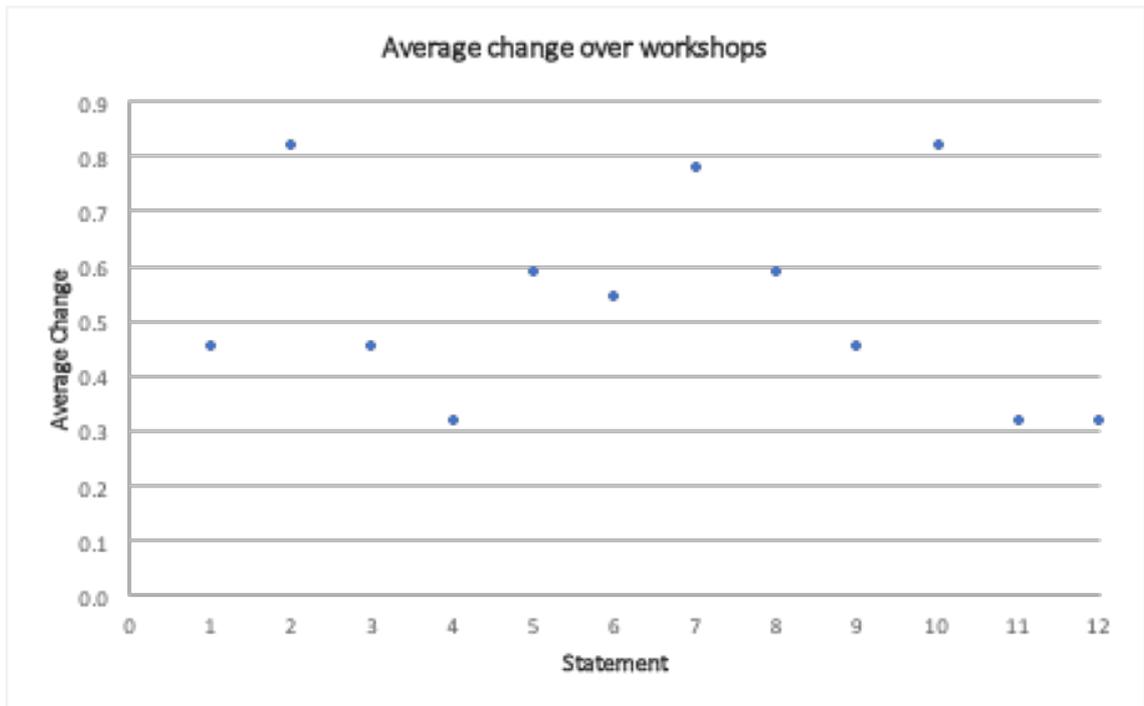


Figure v9: Graph to show average change across the data set

Across all 12 statements there was an average increase in how much participants agreed with the statements from the beginning to the end of the workshops. The lowest was in increase of 0.3 and the highest was 0.9. The highest changes are attributed to statements; 2: I am inquisitive about how and why things are how they are, 7: I am resilient if my ideas don't work and 10: I can communicate my ideas to others visually. The average change over all the responses was an increase of 0.6.

Findings from the Likert scale survey data show that for all statements the adolescents rated, there was a positive increase from the beginning to the end of the workshops. Furthermore, over the whole data set there were only 16 negative responses (12%). Half of these can be attributed to one participant. Whilst we cannot know the reason for these changes from this data, it could suggest that it is an anomaly. We are also not in a position to know whether a negative movement on the scale is indicative of a negative response or impact to the session. 64% of the responses were positive and the final 24% had no change.

These figures show a positive impact from the workshops, where participants rated

Experience <ul style="list-style-type: none"> • Beneficial • Worthwhile • Interesting • Enjoyment • Unique/ unusual • Thought provoking 	Mindset/ skill <ul style="list-style-type: none"> • Outside the box • Lateral thinking • Imagination • Perspective/ point of view • Analysis • Positivity and confidence • Mindset change • Skills • Design knowledge 	Application <ul style="list-style-type: none"> • Confidence • Hopes/expectations in Dealing with pain • New approaches • Managing pain • Pain explanation • Visualisation • Distraction • Sharing and Voice • School • Work/job-future • Everyday life
Group <ul style="list-style-type: none"> • Sharing experiences • Everyone takes part • Different approaches • Meet others 	Approach <ul style="list-style-type: none"> • Unique • Everyone takes part • No pain discussion • Activity 	Format <ul style="list-style-type: none"> • Workshop environment

Figure 71: Qualitative analysis; Themes and categories from patient questionnaire data

Finally, to understand the frequency of the responses in the categories, data within individual categories was inputted into excel to create a series of charts. This was done in two ways. The first was to understand the overall frequency of the data within categories (figure 72). The second looked at the spread of data across the respondents to understand any potential weighting to the data. Finally a chart was created for each participant to understand the spread of their data across the thematic analysis.

Six categories emerged (figure 73). The frequency of data within these categories varies, as does the number of respondents whom the data comes from. In some instances, one participant provides many data points for one category, and in others there is an even spread of responses across all seven respondents. The two categories with the largest frequency of data include responses from all seven participants.

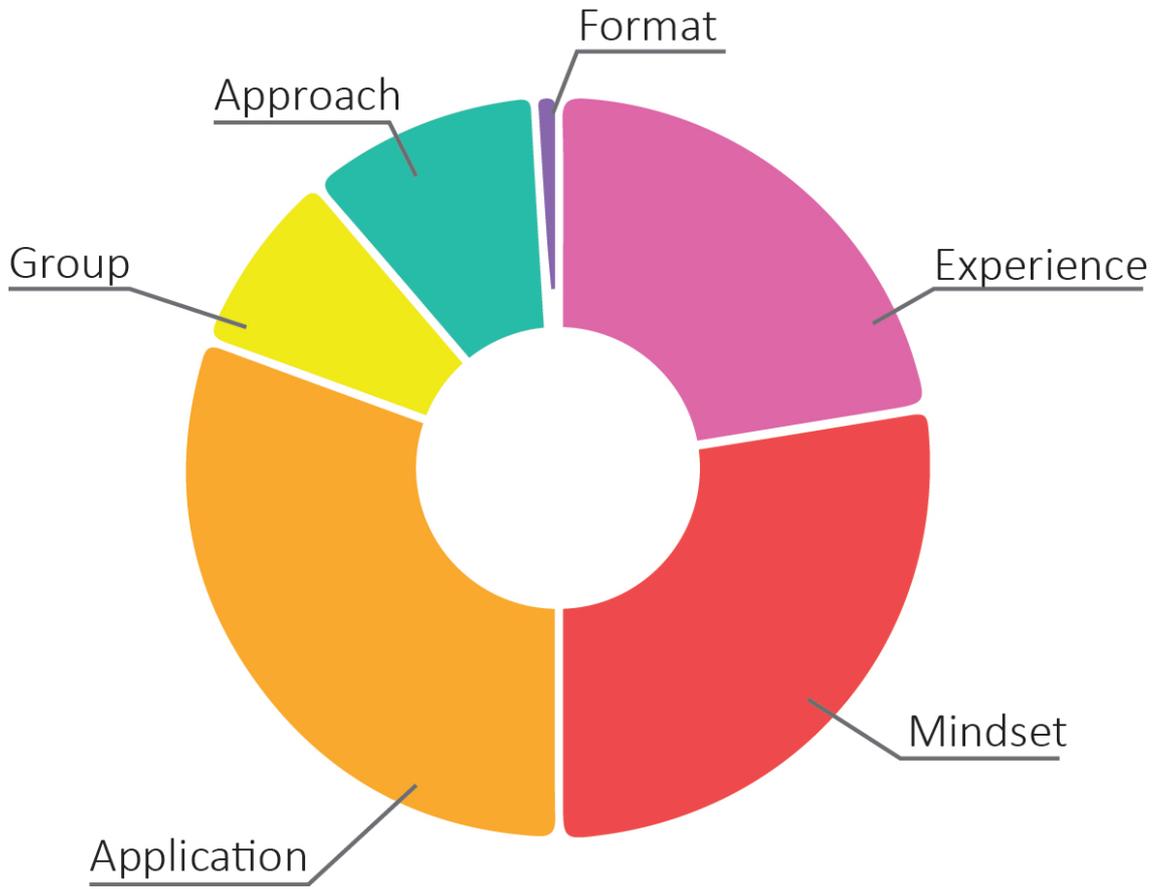


Figure 72: Frequency of responses within the qualitative analysis for questionnaires.

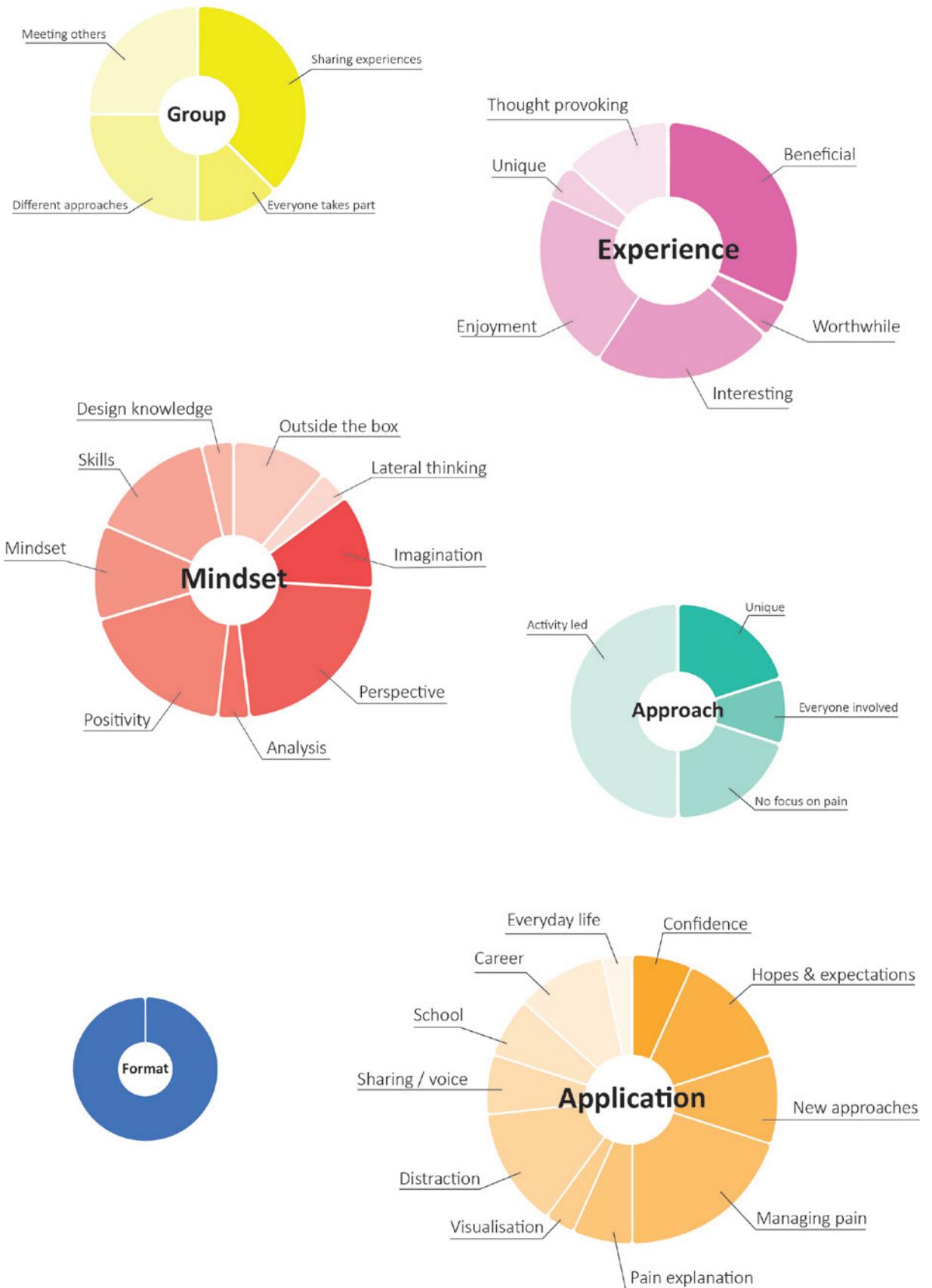


Figure 73: Breakdown of qualitative analysis for Questionnaire data per theme. The size of the theme relates to its frequency in the overall analysis.

Findings

A Positive Experience

The questionnaires show that the experience of attending the workshops was positive and engaged the participants. All seven participants had data in this category, and all but one mentioned that the experience was beneficial. Responses showed that they enjoyed the workshops, finding them to be; 'Fun, useful and interesting'. Furthermore, the experience was described as thought provoking, worthwhile and helpful.

A Novel Approach

Findings from the content analysis have demonstrated that the participants enjoyed the approach of the workshops, citing them as 'unique'. The skills in the workshop were demonstrated by activities and this was positive for the participants who enjoyed using activities that 'keep(s) everyone involved and thinking'. Furthermore, one participant mentioned that the workshop did not focus on pain and that this provided 'A different way of looking at pain without discussing it in a serious/negative way.'

The Development of Mindsets and Skills

The workshops enabled participants to develop mindsets and skills, with all but one of the participants mentioning it specifically. Within this theme there were nine categories, the largest of which was perspective, four of the seven questionnaires returned mentioned the specific development of a mindset to look at things from different perspectives, for example;

'To look at things from different perspectives and to be optimistic'
'Looking at things from a different perspective, and asking why.'
'Yes, because it made me look at my pain from a different point of view.'

Some of the mindsets and skills were mentioned as a standalone technique, without any detail on its application; 'to look at things in a different perspective', 'I learned to think

outside the box, its a new skill that I am now developing'. Whereas others were mentioned with a reference to their application in pain management;

"I have learnt to use my imagination and think of other ways to deal with my pain that I wouldn't normally think of"

"Yes, because it made me look at my pain from a different point of view."

Some of the responses appeared tentative, the participants recognised that they had learned a mindset but that they had not used it yet, for example one participant wrote; 'I believe that I have got skills from the workshop that could possibly help me with my confidence', and another said, 'we used lots of skills that we could use in day to day activities'.

The Application of New Skills

Further insight to how the participants applied these skills can be found within the theme 'application'. The categories in this theme cover; how the learning has influenced their current management techniques, specific examples of their application and areas for application. Within this category all 7 participants had at least one data point. Six of these had data across multiple categories that demonstrated multiple applications of the skills they learned.

Some of the methods of application focus on now, others are specific to pain management and some link to areas of life not related to pain. Those who mentioned the influence over their current pain management related it back to developing confidence; 'you have to think outside the box to achieve your goal, if you can do this, nothing can stop you', and having new approaches 'I think outside the box and don't rely on the simple methods to decrease or stop my pain' and 'I've used design to help me understand pain and really consider 'outside of the box' pain management techniques'. Other ways and places application include; at school, at work in the future and as a distraction technique.

Some did not go into much depth, for example 'It helps to manage your pain' and 'They taught me stuff which has helped me in dealing with my pain'. Only one participant did not mention an application or a link to pain management and instead stated; 'The activities we did we're interesting but it was hard to link it back to my problem'. However, in other question responses they refer to 'discovering different ways to deal with my pain', suggesting some discrepancy in their response.

Sharing the Pain Experience

Findings indicate that adolescents with chronic pain benefit from meeting others with the same condition. This enables them to share experiences and see how other people deal with their pain. Meeting others was also related to feeling less alone; 'Yes, I made me think that it not just me having to deal with pain'. Seeing others with their condition enabled the adolescents to consider; 'why some solutions help people more than others' and talk to people of their own age about their experiences. This data indicates that participants will share their experiences with each other even when not prompted through the workshop or activities.

Limitations in the Method

The response rate is a limitation in this method. Of the 12 adolescents who completed both workshops only seven of them responded to the questionnaire. This means that the results might not be a true depiction of the impact of the workshops, as we cannot know whether those who didn't respond would agree or disagree with the above. There is also little negative feedback within this data set, which again, could be different if all 12 had responded.

Another limitation is that the responses would have been led by the question. Despite conducting an inductive qualitative analysis, inevitably there will be a bias in the responses due to the phrasing of the question. This will have had an impact on the analysis and subsequent categories. Furthermore, the higher number of responses could be a result of

the way a question was phrased, the frequency of response might not correlate with the level of impact or importance to the participant.

Interviews

Two of the participants agreed to a short semi-structured interview. Interview Participant A (IPA) chose to come to the university and the other (IPB) was interviewed at the hospital. The interview questions varied slightly between the two participants as IPA had already completed a questionnaire. Therefore, rather than repeat the questions, the interview schedule was adapted to get more depth on their previous answers. The interview schedules for both IPA and IPB can be found in appendix 11.

These interviews were analysed in using the same qualitative analysis approach described in this thesis for the staff workshops and adolescent questionnaires. Codes were generated from the individual transcripts before being categorised and re-categorised to make the most sense of the data. The final Themes, categories and sub categories can be see in fig 74.

These categories and codes were then populated with data from the interview transcripts (this can be found in appendix 21) to provide examples and more depth. This was done for both categories (and for each interview separately. The interview data findings provide further insight to the application of any workshop skills that the interviewee's learned. There were seven themes in total (figure 75). In all but one of these categories there was an even spread of data distribution across both IPA and IPB.

<p>Preparation</p> <ul style="list-style-type: none"> • Expectations <ul style="list-style-type: none"> ○ Intrigue ○ Unsure ○ Task based • Incentives <ul style="list-style-type: none"> ○ Previous design workshop ○ Voucher • Information <ul style="list-style-type: none"> ○ Clarity <p>Future Participants</p>	<p>Mindsets/skills</p> <ul style="list-style-type: none"> • Current <ul style="list-style-type: none"> ○ Creativity • Mindset <ul style="list-style-type: none"> ○ Questioning / understanding ○ Feeling more creative ○ Changes in (mindset) ○ Less negative ○ More open minded ○ Perspective ○ Growth • Skills <ul style="list-style-type: none"> ○ Reinforcement <p>Activities</p>	<p>Application</p> <ul style="list-style-type: none"> • Variety • When 'stuck' • Explanation • Making <ul style="list-style-type: none"> ○ Visual • Goals <ul style="list-style-type: none"> ○ Sports/hobbies • School <p>Pain management</p>
<p>Experience (personal)</p> <ul style="list-style-type: none"> • Approach <ul style="list-style-type: none"> ○ Unusual ○ Pain discussion ○ Experiential Learning • Beneficial <p>Positive</p>	<p>Group (and others)</p> <ul style="list-style-type: none"> • Sharing <ul style="list-style-type: none"> ○ Techniques ○ Recommend • Meeting others <ul style="list-style-type: none"> ○ Learning <p>Variations</p>	<p>Impact</p> <ul style="list-style-type: none"> • Voice/ autonomy <ul style="list-style-type: none"> ○ Health Professionals <p>Pain levels</p>

Figure 74; Qualitative analysis; Themes and categories from patient interview data

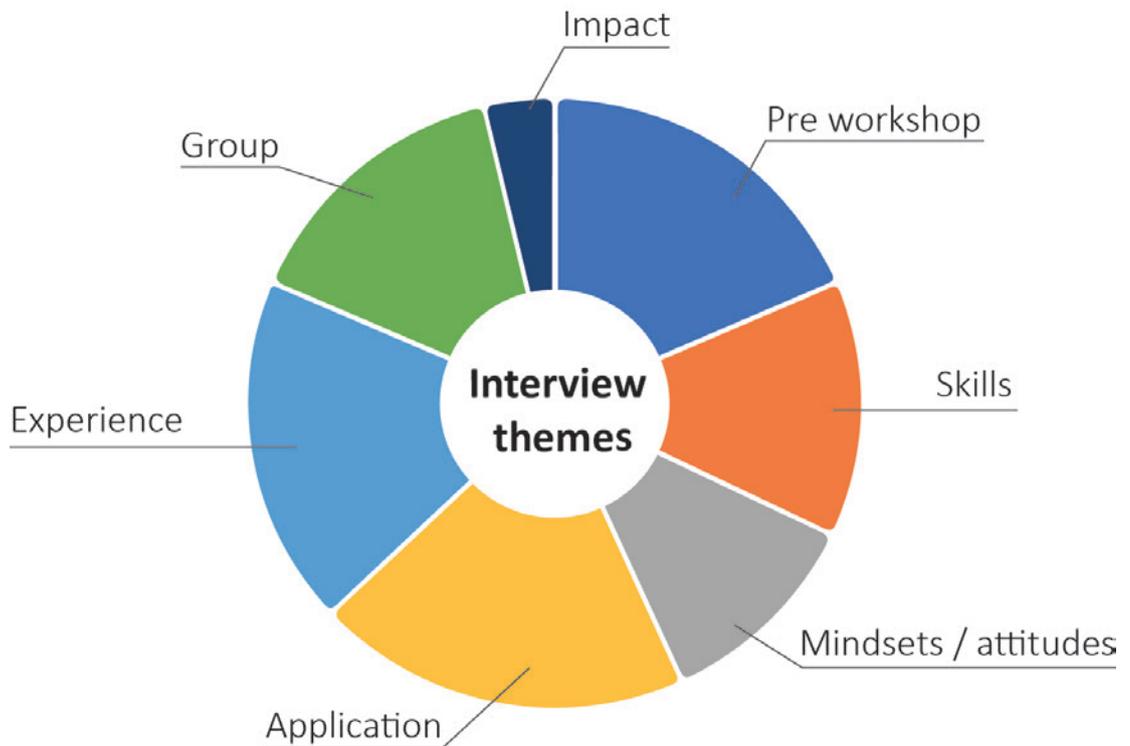


figure 75: Frequency of responses within the qualitative analysis for Interviews.

Findings

Reasons for Attending

The interview data gives an insight to what might have prompted the patients to take part in the workshops. Whilst they did not know what to expect, both interviewees mentioned that they were intrigued by the session and the link between design and pain; 'I was quite intrigued to come along and see what would happen', 'I was interested in how like design and stuff was gonna work with pain'. Another driver to attend for one of the participants was that they had attended and enjoyed a previous design workshop at the university. Neither mentioned the high street voucher (provided as a thank you for attending the study) as an incentive.

Difficulties in Understanding the Workshops

All participants received an information pack prior to attending. Findings suggest that whilst they might have been intrigued by the workshops, neither were entirely sure what the workshops were about or exactly what would happen. However, despite this ambiguity, one suggested that they do not think that they would provide more detail in future iterations;

"I'm not sure it's kind of hard because they kind of let you know enough but then you go to something and its quite nice to like um go open minded... actually I don't know if I would include more detail". (IPB)

Furthermore, the suggestion was that this type of learning is experiential and while this posed a problem for the adolescents when they tried to explain the sessions to those who had not attended; 'I feel like if you're like an outside person its harder to understand if you're not actually in the session', feedback also suggests that there is a benefit to not knowing as it ensures those attending are open minded.

Skills, Mindsets and Attitudes

Interview data suggests that the two participants felt they had learned skills through the workshops, specifically mentioning; questioning, perspective and creativity. One of the participants found themselves using the skills learned to encourage questioning about how and why things are how they are.

“the whys I found that kind of helpful actually, I’ve just started doing that all the time now- I’ve started doing it a lot but it probably annoys a lot of people but yeah I’ve started doing it a lot more if I see something I’m like why do that and why not that” (IPA)

As a result of the workshop the participants feel that they are thinking differently about their pain. Many adolescents with chronic pain find that they become stuck in particular patterns of behaviour and their worlds shrink as a result, this is explained by one of the interviewees here;

‘I think a lot of people find they have quite a fixed mindset, because you know a way for you works, and you’re comfortable in that and this links to pain as well. if you’re comfortable in what you’re doing you don’t have to change it, perhaps through fear that that’s not gonna work’ (IPB)

This change to think differently about pain and to move out of this way of thinking was referred to by one of the interviewees as ‘feeling like more like, growth mindset about exploring different options and not just one way of thinking’. Furthermore, the reference to thinking differently also includes a change in attitude to be less negative and fearful which in turn enables them to be more open to trying new things.

Places of Application

The largest theme from this analysis with the highest frequency of data is application. Both young people interviewed could see multiple applications for their new skills in pain management and in other areas of life. They found the approaches to be flexible, enabling people to use them as individuals in ways that might differ from others; ‘I can use it in a

way that no one else might want to use in and they can use it in a way that I might not want to use it'. The data finds that there is no direct impact on pain levels mentioned however applications can be seen to a wide variety of pain management.

One interviewee gave a specific example of how the workshops have helped her to explain her pain better and to a wide variety of people;

"the first question would be so what is your pain? where is it? whatever, and I would never know what to say and would just turn to mum but she wouldn't know either. So it's very difficult I wouldn't know how to. It's always really difficult for me so they'd always leave that question out, so I never really knew what to say but now I kind of have a better understanding because I can, I can use other things to describe it as such so I can use like things around me, so I can say it's a bit like this or a bit like this" (IPA)

In addition, she also mentioned how since the workshops she wants to develop a communication tool to aid her in explaining her pain by making it visual;

"What I really want to do is like make my own booklet kind of thing on pain and like my pain so that if people ask instead of me trying to awkwardly stand there I can say well here's a piece of paper with everything on that you need to know". (IPA)

Another specific example given was in goal setting. A participant found that the workshops made them think differently about their goals and as a result they were back to doing more sports and hobbies;

"the whole time I've just been focused on my end goal..... but the workshop helps you kind of, not adapt but look at things from kind of hobbies that I've had and really enjoyed. From netball I enjoyed the fitness aspect, I'm really competitive so I enjoyed that so then I've taken that and taken up other kind of sports and hobbies that I probably didn't think about before" (IPB)

Positive to not Focus on Pain

When running this type of workshop, it is positive for participants to attend a workshop that did not directly focus on their pain. They could learn the skills from the workshops and apply them to their pain management without discussing it directly. This approach is

novel, as participants are used to speaking about their pain.

The Importance of Meeting Others

Participants highly rated the group element of the workshops. Pain management Therapy is run as 1:1 sessions so it is rare that they would meet someone else with their condition. They had a positive experience from meeting and being in the same room as many people who are also living with pain. They also suggest that being around people who also have pain enables you to learn from them.

“I thought that was really good because it was nice to be surrounded by people who have pain because I don’t know anyone who has similar things so it was really nice to be but without talking about it, it was just like underlying” (IPA)

In this section I have presented you with the analysis and findings for the adolescent workshops that sought to understand; ‘In what ways can design practice support the management of young people with a long term condition’. I used a mixed method analysis to understand the outcomes and presented the three methods here. Findings suggest firstly that learning about design practice can have a positive impact on young people with chronic pain. This can be seen through the development of designerly skills and mindsets that are being used to support pain management. Secondly group workshops were deemed to be a positive place for young people to meet people living with similar conditions to them. Thirdly, these skills can be learned without discussing someone’s pain experience, which can be positive for those who find the discussion of pain can make pain worse.

Study Start:
Section Three
Findings

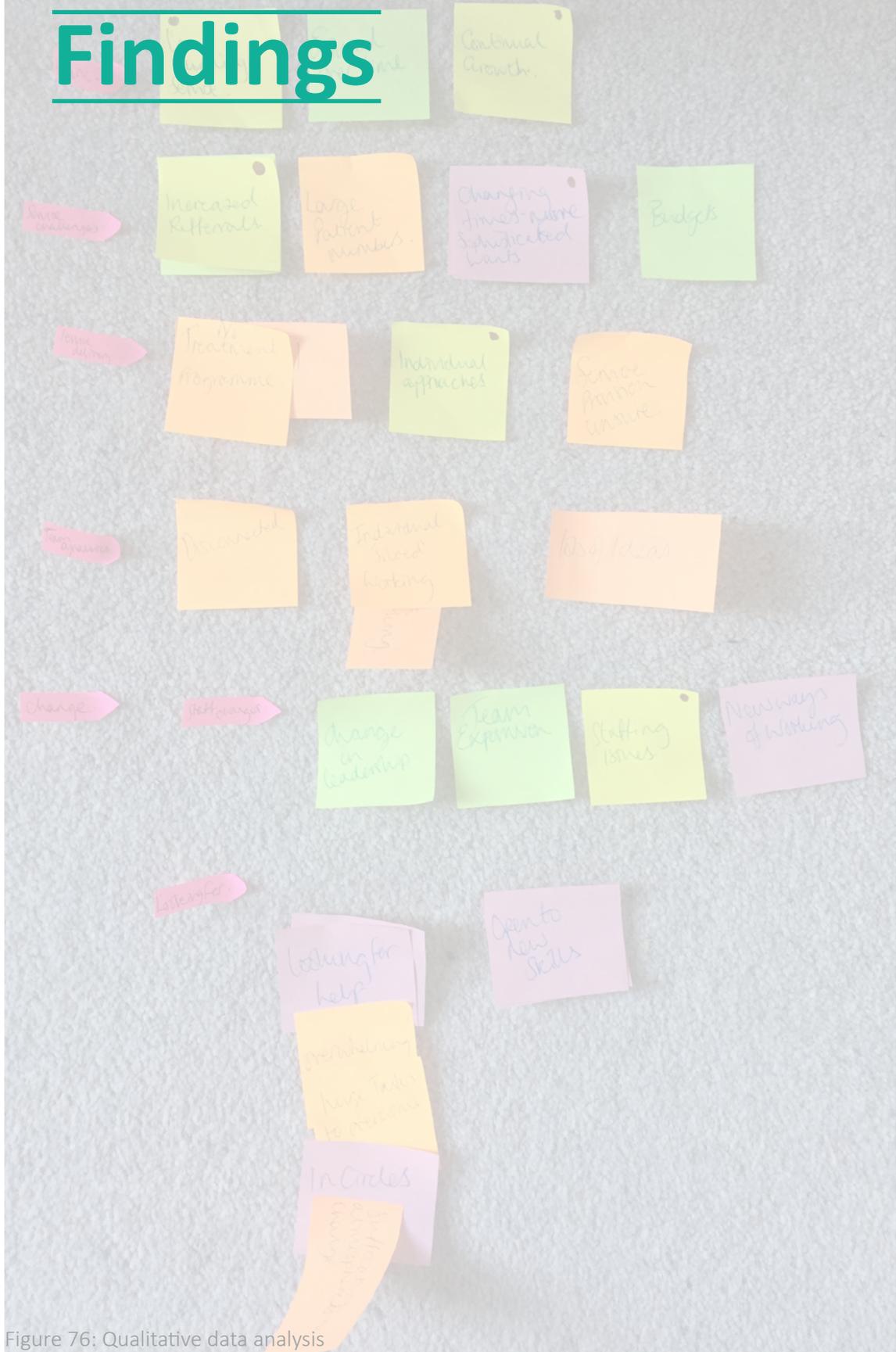


Figure 76: Qualitative data analysis

This last section of the thesis draws together the various elements of the study over two chapters. The first is a discussion chapter that draws together the findings and reflections on the practice of this study with the literature presented in contextual review one and two. The final chapter of this thesis provides a final overview of the study against the aims and objectives, summarises the contributions to knowledge, and provides a series of recommendations.

Chapter Eight: Discussion

Chapter eight draws together the findings and reflections on the practice of this study with the literature presented in contextual review one and two. This chapter is based on four discussion essays that draw together the findings and reflections of the study and situate it within the literature. Each one focuses on a key part of the study. The four essays are:

- Design and healthcare procedures: Challenges for designers in healthcare.
- The case for early immersive practice
- The importance of design methods *and* designers
- Workshops to demonstrate design skills to adolescents; Findings and limitations

These discussions will be used in the next chapter to frame the following contributions to knowledge:

Claim One:

Research through design is a valuable approach to explore and develop healthcare service provision.

Claim Two:

Design facilitation should be a recognised design practice to counteract the undervaluing of design professionals and to distinguish between design facilitation (by a designer) and other forms of facilitation (by non-design professionals).

Claim Three:

Three key recommendations to support practice in design in healthcare are:

- The use of NHS research ethics approvals should be encouraged to demonstrate rigour in design research,
- Design research should factor in time for a set up phase,
- Designers should be key partners in the grant writing process.

This thesis also offers a short summary and series of recommendations for others who might want to explore the development of designerly skills in adolescents with long term conditions.

8.1 Design and healthcare procedures. Challenges for designers in healthcare.

This first discussion provides the reader with more detail on the ethical procedures that this study was subject to. This account provides an insight into the operational complexities mentioned in chapter six. It explores how design skills were used to navigate these complex issues alongside a discussion of the impact they had on this study. It also places these within a wider context, considering the implications to other designers conducting research in healthcare. As such, it poses a series of recommendations that might support others working in this field.

Ethical Approvals in Healthcare

In chapter one, I gave an overview of the background to this study. I summarised that due to challenges in contemporary society and a rethinking of the role of design and the designer, designers find themselves working in increasingly varied contexts (Kimbell 2011). One such context is healthcare, wherein problems are considered 'wicked' (Rittel and Webber 1973; Buchanan 1992) and design methods are in demand. As such, design in healthcare is an emerging field in which designers are working in unfamiliar environments on complex and multifaceted problems which have no clear cut or optimal answer.

In chapter three of this thesis, I summarised the worldviews of design and healthcare. I stated that healthcare is a complex discipline, whose understanding of knowledge and evidence differs from designs. Due to the historical context of healthcare research and the importance placed on the randomised control trial, there are strict ethical practices and procedures to be adhered to. This study was conducted as a piece of research in the NHS. Therefore, navigating worldviews and developing an understanding of the process was a crucial part, not only for developing knowledge to support a personal understanding, but for a wider discussion on research ethics in design in healthcare.

Ethical Approval in this Study

As stated in chapters four and seven, there were a total of four procedures this study was subject to across the University and the NHS. The first, gaining a research passport allowed access to the hospital sites to develop the study design, understand the context and select a patient population. After this, the NHS ethical approval process could begin, taking a total time of fifteen months from start to finish.

The original main research enquiry sought to explore ways that design practice could support the management behaviours of adolescents with long term conditions. In the original study design, the intention was to do this through a series of workshops over an 18-month period. The workshops were to be used to develop methods and activities to demonstrate design practice, explore various modes of delivery, understand how other methods (such as cultural probes) could support the workshops and look at appropriate ways to evaluate them. It would be an iterative process; feedback received after each workshop would be used for evaluation and development for the next cycle. However, the complexity of gaining NHS ethical approval made original the plan inoperable, due to the time available to recruit for and run these workshops, which was reduced from 18 months to 4 months. The knock-on effect of this was to allow for only one round of workshops.

Furniss et al (2015, 6) state that research ethics can be a considerable challenge for those who work outside of a healthcare context and who might see the process as “laborious, unaccommodating, bureaucratic and delay[ing] research”. The process of undertaking this research affirms this statement. There were multiple challenges and delays during the process which can be attributed to many factors. Some of these were not specific to the ethics process or to the NHS but were a part of usual working practices. These included those due to staff and Christmas holidays, other work commitments and a change in personnel dealing with the application.

Other reasons that impacted on the research were differences in worldviews and operational procedures encountered. For example, the research was delayed by the creation of a new Health Research Authority (HRA). Introduced in January 2015, the HRA took over the role that local NHS R&D sites previously performed, combining the NHS research ethics committee (NHS REC) with NHS standards, governance and legal compliance. At the time the study had received a favourable opinion from the NHS REC (meaning that ethical approval had been granted), the HRA had a backlog of applications that was taking around six months to complete, so this study was behind those.

Amendments to the recruitment materials also caused further unexpected delays, as the researcher was unfamiliar with the procedures and classifications for substantial and non-substantial amendments. As a side note, this was complicated further by file format issues which highlight other challenges faced by the design research community; the documents were produced using a graphics programme typically used by designers which does not demonstrate the 'track changes' that the boards were used to.

Navigating between Institutions

One of the biggest challenges for the research approval process was navigating between two institutions; one in design higher education the other in healthcare. Whilst many projects go through a university research ethics committee (REC), full NHS ethical approvals within an education academy and particularly in a school of design are rare. There is little guidance in place to navigate the process and whilst there were people in both institutions who understood their own internal procedures, they had minimal understanding of the others.

For example, both institutions usually sponsor their projects. Through a lengthy a series of emails and phone conversations, it was established that since this was a PhD study, the university would be the sponsor. But instigating this proved to be complex; the sponsor could not be confirmed until the university research ethics committee had approved the

study. However, the Sheffield Hallam University (SHU) REC was waiting for the outcome of NHS REC before they approved the study. Yet, the application to get the approval from the NHS REC could not be submitted until the study was sponsored for insurance purposes. After much discussion, it was decided to apply to the SHU REC to confirm the sponsor and insurance, the outcome of which would be accepted pending NHS approval down the line.

Communication and Worldviews

All NHS ethics applications are submitted online via the Integrated Research Application System (IRAS). NHS ethics has its history in quantitative studies such as the randomised control trial (RCT). Within such methodologies, the researcher is expected to know exactly what will happen and when (for example, what dose of drug the participants receive and how often). Therefore, IRAS applications are a lengthy and thorough process. To be included at the time of submission are (amongst others) all workshop plans, information sheets, interview schedules and evaluation measures. After the immersion practice I confirmed a patient population for recruitment and the age range of the participants. But due to the nature of Research through Design (RtD), it was difficult to produce many of the supporting documents at the time I submitted the application.

Design research is inherently emergent, iterative and reflexive, and there are many unknowns (Sanders and Stappers 2016). Consequently, it is often difficult to define an exact workshop structure or to know the relevant interview questions for evaluation at the beginning. Many of the variables are established when the intervention takes place. As I did not want to compromise the RtD approach to developing activities and outcomes, I provided a variety of options for workshop content or areas that I might ask questions in, justifying my reasons against RtD methodology. Because of this, the process took much longer than anticipated, with many refinements and revisions to ensure there was enough detail for assessors to understand how the aims of the study would be achieved, whilst leaving enough ambiguity to allow the research knowledge to emerge.

“At times this process felt lonely and frustrating; I felt like I was going around in circles and hitting dead ends. I would finally feel like I had a grasp on the process only to discover that I had not done something quite right, or I needed something else from somewhere else to proceed, or the language I was using didn’t ‘translate’ to an audience in healthcare. So much of my time navigating ethics felt like trying to answer the ‘chicken and the egg’ with both sides needing something from the other before proceeding.

At other times the process helped me to structure my decisions, and forced me to resolve issues that I might have dwelled on for a long time. When I sent over documents to the hospital that didn’t come back because the methods were unclear or ambiguous, that felt like an achievement - all those hours of trying to articulate this study had worked.” Reflective Practice, March, 2018

To add further complication, much of the language within the IRAS application was not language that I, as a design researcher, was familiar with, creating confusion about what the correct information to provide in the sections should be. The support team in R&D at SCH had great experience in ethics applications, but design practice was not familiar to them; they too found it hard to extract the right information and understand elements of the work.

The Benefits of Going Through NHS Ethics

Furniss et al (2015) state that despite the challenges, research ethics approval from the NHS can give credibility to a study, and there are other positive impacts that can be identified. Going through ethics procedures interrogates the study ensuring it has a level of rigour. Despite delaying the planned research activities, navigating through this process refined and strengthened the study design, scrutinising it, and forcing decisions and a closer consideration of issues that might not have been considered such as: how long exactly would participants be involved? Over what period? How exactly would they be recruited? Who would they go to if they were unhappy? And what would happen to their data if they decided to withdraw? It can also help to mitigate difficulties that might emerge through or because of the research enquiry.

The time spent editing the application helped me to refine the language used to explain the study, by trying to provide explanations that were clear and understood by the R&D department. In turn, this helped me to verbally articulate the potential benefits of the research to healthcare staff. Chamberlain, Wolstenholme and Dexter (2015) acknowledge the importance of this, recognising that if the full variety of the design profession is to benefit healthcare contexts, then there is a requirement to be better at articulating the value and impact of the practice.

Tensions Identified

This study highlights the complexities of conducting research in healthcare as a designer. There are clear time implications, as described above, to a study that goes through NHS ethical approval, and there is a balance to be found between the aspirations of a design-led research inquiry and the procedural correctness rightly required when working with patients. At the very least, navigating ethical procedures has time implications, and for those studies that have not factored this in or made assumptions about how long it will take, it will be hard to achieve both the NHS REC and conduct the study as planned.

It has been discussed here that ethical approvals provide rigour to a study, but the process by which this is gained is inflexible. Currently to go through the procedure of gaining ethics approval, the designers are the ones more likely to have to alter their practice and align with the methods of the scientific discipline, particularly in terms of how they talk about their practice. The concern is that the (design) language that does bridge could be at risk of being over simplified. For example, focusing on specific methods or outcomes rather than the overall methodology could be limiting in the scope of the design work. This would reduce the design practice to a few single methods and remove the flexibility to be responsive, it also ignores the non-tangible design practice mentioned in this thesis.

The skills of the designer

What this study demonstrates is how a design-led enquiry is well placed to navigate these types of complex procedural hurdles. As stated in chapter three, design is used to working with 'Wicked' problems, those that do not suit traditional problem solving routes (Thies 2016). By this definition, this process can be defined as a 'Wicked' problem, whereby, navigation of the procedures, institutions and the opposing worldviews does not have an easily defined answer. Instead, an emergent, solution focused approach is required.

The solution-focused approach applied in this study, is a skill that defines a design approach (Lawson 1990). For example; trying to negotiate the right 'solution' involved framing the project in various ways, and proposing a range of options, such as; presenting multiple workshop plans and using a range of language. Importantly, if these options don't succeed designers are resourceful optimists who learn from failure (Campbell 2009, 2011). Designers use a continual learning process, that looks for the optimum solution rather than give up or compromise on their approach. This can be seen in this study as the process refined, built and strengthened the study with each new attempt. Campbell (2009) states that designers have confidence and a comfort in ambiguity. It is these skills which enable designers to negotiate, adapt and push the boundaries of procedural processes where others might not.

Recommendations

Chapter three outlined the difficulties in understanding and articulating design research, specifically RtD, to those outside of the discipline. It discussed how as a result, design research can be undervalued, as often the practice is simplified when explained by scientific means. The scientific disciplines value stringent ethical review procedures. I propose that rather than try to avoid NHS ethics procedures (for example by classing studies as service improvement), the process can be used to demonstrate the rigour of design research. It should not be understatement that an RtD study with NHS ethical approval puts it on a par with other NHS research giving recognised credibility to the work.

However, as theorists suggest, design is a distinct discipline and should not be simplified (as was the case in the design science movement) (Schon 1983; Glanville 2015). Therefore, it is important that designers do not fall into the trap of simplifying their practices to fit the ethics procedures. Particularly as some emergent studies and practices might be unable to find a way to satisfy the ethics process and needs of both disciplines. Designers should trust in their skills and methods to successfully navigate this process despite the time and impact that it might have. If healthcare is to benefit from design, then their processes need to adapt also. This could be facilitated through a large change in the ethical approvals system. However, this is unlikely; more likely would be to educate those who work in hospital R&D departments on design practice. These people would then be able to support the application process to ensure that ethical approvals allow for the iterative nature of design research. The generation of successful exemplar case studies, such as created in this research, would also help inform hospital R&D staff for future applications.

Similarly, many of the issues experienced in this study are a result of university procedures. Universities also need to find better ways of supporting and facilitating NHS ethics applications, particularly for those disciplines whose practice might differ greatly from traditional healthcare research. Keeping up to date knowledge on the procedures and creating clear links with a named person at local hospitals would support this. Another example, the research passport, conducts pre-employment checks (Disclosure and Barring, Occupational health) that NHS employees receive. This is something which automatically happens to students enrolled on healthcare courses in universities. Potentially design students could receive the same passport as required. Although the majority of designers may not work in a healthcare setting (unless the course is based in healthcare, such as a design in health masters), lecturers and design supervisors would be informed of these practices so that they can signpost students and avoid delays to studies.

Some of the delays that this study experienced were unfortunate, such as the application going to the HRA at a time when there was a backlog. Another designer conducting this

type of research at a different time might find the process much quicker. However, the system is complex and procedures can change at any time. Therefore, if a study is to go through NHS REC, it is important to allow the time for this in the study design. Recognising that there might be difficulties in articulating a study, and allowing appropriate time to navigate this will go a long way to mitigating any impact that delays might have on conducting the research. Ideally, the process should start as soon as a project is accepted (this might be before the official start date of the work). A further suggestion is that those who conduct research in this field should not only prepare practically as stated, but also mentally; understanding this to be an iterative process and as much a part of the research than other design tasks. Design researchers need to draw upon their skills in navigating the 'fuzzy front end' to determine what they are able to progress with in the study should there be any delays.

As the field of design in healthcare continues to grow, there will be greater numbers of designers who need to navigate ethical approvals. These recommendations are particularly relevant to those who are leading their own projects. However, they provide important learning for those whose projects are led by healthcare teams. It argues the case that designers need to be involved in steering a project and be part of applying for ethical approval, in order to mitigate against the scope of design research being constrained by a non-disciplinary understanding of design research methodology.

8.2 Research through Design; The case for Early Immersive Practice

The second discussion of this thesis relates to the set-up phase of a RtD inquiry in the healthcare context (referred to in this document as immersion). It discusses the design approaches utilised and the impact of the immersion practice on the study. It will situate the discourse in literature set out in chapters two and three. It provides further recommendations for design research in healthcare, particularly around study design, and argues the case for the importance of a design approach and early immersive work in projects.

Overview

In chapter two, I outlined Macdonald's (2017) three positions that a designer can take when working in healthcare (acting as designers in a consultancy model; involving and empowering non-designers to design alongside themselves or relinquishing their own involvement by providing tools and processes to healthcare professional). These models relate to the 'designing' element of a study and refer to how designers can engage health professionals in the design process. An assumption in this is that the process they are engaged in has well defined parameters and all stakeholders are on board. These positions do not mention the study design or early phases, referred to in chapter three by Sanders and Stappers (2016) as the fuzzy front end, which are characterised by "uncertainty, ill-defined processes, ad hoc decisions, chaos and ambiguity". This is the same for much of the literature presented in chapter two; the focus is on the outcomes of design research in healthcare, or the areas that design could contribute to. There is little focus on how a designer's abilities, approaches and methods navigate and embrace the uncertainty in the early stages of a study and how this is crucial to achieving a 'positive impact' with 'long range consequences'.

The immersion phase of this project primarily centred around two stages of design ethnography. It was part of the study design, based on the understanding that it would be a crucial and fundamental approach necessary to the success of the study. The immersion phase aimed not only to support the research design (through the selection of an age range and condition), but also to guide the content for the workshops (through an understanding of management behaviours) and for the integration of the study (through relationships built with staff to support the work).

In this study the immersion influenced in a positive way all elements of the study to some degree. This supported the emphasis placed on allowing it to guide much of the study design before commencing the workshops (though there was still much to learn about the management behaviours of adolescents with CP). As a result of this approach to the research, new lines of enquiry were identified, not least the body of work with the therapists that followed.

There is much to unpack about the approaches and methods of design used during this phase, and how I believe they contributed to the outcomes and the overall success of the project. Some of this contribution is practical, such as informing the selection of an age range and patient population. However, the emergent approach to build the enquiry provided other contributions such as building a relationship of trust with the CP team. It is this relationship of trust which I provided the right conditions for the study to take place and led to the body of work with the therapists.

Time

Previous experiences of the set-up phase in design research activities show that it can be short. This is often due to project timescales, funding restraints or in interdisciplinary projects where others have defined the research process parameters already. Within projects where all stakeholders have been a part of writing the bid, or there is a pre-existing relationship then this is often less of a problem. Negotiations will have happened

and many of the challenges and opportunities will have been defined.

However, when this phase is ill-considered, short or undervalued, potential problems can arise such as; difficulties engaging multilevel stake holders or trying to make an intervention 'fit' into an established community or way of operating.

As mentioned in the introduction to this thesis, experience has shown that in order to work successfully with a group of patients, and to integrate any outcomes in a service, there needs to be a relationship of trust with the clinical team, not least because they act as gatekeepers to the patients. In this case the team agreed with this premise. When asked if they would have supported the project when I first met them, one therapist stated; "No because we wouldn't have trusted you. We're very protective of our families because we want them to get better, so no, I don't think we would" (Physiotherapist, PMT).

A characteristic of a design approach outlined earlier in this thesis is the ability to be comfortable with ambiguity. In this research, the immersion period formed an extended set-up phase that was crucial to developing relationships, service knowledge and to identify other lines of enquiry. The length of time allowed the team to get used to the researcher's presence and share information at their own pace, without feeling too pressured to engage alongside their clinical work. Using a collaborative approach ensured that the study remained open to other lines of enquiry to identify and define the study.

On a practical note, a further benefit, from the researcher's perspective, was the ability to experience the pressures placed on a service due to factors such as staff holidays, seasonal demands, planned absences and staff changes etc., rather than receiving a narrow 'controlled' snapshot that might only show a portion of the real picture. Overall, this time built a strong relationship between researcher and therapists. In their final interview one of the occupational therapists said of this time, "So actually, I think having that preliminary time to really understand what we do and why we do it and how we do it

was really helpful, and it felt like we had a colleague rather than somebody that had just been catapulted in” (Occupational Therapist, PMT).

Creative methods and mixed methods

Design research is flexible in its use of methods, in that, rather than sticking to a predefined set it borrows methods from other disciplines. Using design ethnography allowed the team to become familiar with me in their own environment through methods that they had knowledge of and were comfortable with. In reflections in chapter five, I shared concerns that as a design researcher I should have been using more creative methods (such as visual ethnography or workshops). However, the contrasting concern was that in these early stages as I had no prior experience or relationship with a team they would not have engaged. This was confirmed during the final interviews with the team where one said; “You can’t immediately go to them, ‘Look at all these things,’ because you have to build the relationship in order to have permission to do that. It is that standing back and understanding” (Physiotherapist, PMT).

It was important to demonstrate a genuine interest in learning about their work, to recognise their expertise and respect the time and impact there might be on their clinical practice during this phase. By using methods that they recognised (observations, interviews), I believe made them feel comfortable and imposed least on their clinical work. Furthermore, my desire to build this understanding and show an interest allowed them to begin to trust me and my work, and encouraged them to engage with me.

In chapter five I also documented how sense making practices, such as the creation of maps and diagrams, clarified what I was learning and observing through design ethnography. Rather than analysing or responding to the data (such as reflective logs and interview audio) in the way that other practitioners might, the design approach created tangible outputs that could then be used for discussion with the team to facilitate their own learning too. These might be classed as boundary objects, they were used to communicate and

share ideas to clarify and develop understanding (Star 2010). It was therefore inevitable considering the approach taken, that a new line of enquiry would emerge from this stage. As I learned about the team and the service and they learned about my skills and practice, mutual lines of enquiry began to emerge. They sought support to reflect on their service and I wanted to build a greater understanding of it.

The two examples above (design ethnography and boundary objects) are a demonstration of how design combines methods. This provides a unique approach to the collection, analysis and subsequent presentation of this data into tangible visual outputs. This is relevant to 'Wicked' problem theory as the sense making practices help to unpack and make sense of complex information. In this study, I used methods familiar to the team to build an understanding and then used design practice to visually reflect this knowledge back to the team to highlight where there might be missing information, language miscommunications and to see if they agreed. This aligns with Prendiville 2017, who states that sense making 'constructs plausible understanding'. This thesis argues that the use of design practice to interpret and support design ethnography provides a greater depth of understanding between stakeholders than other practices.

Informing the Patient Population

Observing multiple MDT clinics was a valuable way to see the range of patients in a service. It allowed me as a researcher to see different groups of patients that I might be working with and highlighted things to be mindful of when running workshops (e.g. psychological concerns, mobility issues or the confidence of the patients). Moreover, the number of MDT clinics that I attended exposed me to a larger range of the community, than if I had solely based my knowledge on the 6-8 patients I would have seen over just one or two clinics. It also supported the definition of my inclusion and exclusion criteria for recruitment.

Some insight could also have been gained through other methods, for example, by speaking

with clinicians, or reading patient notes and literature on the subject. However, this might have presented an overly clinical perspective or one that has already been interpreted by another. This first-hand experience gained through immersion was recognised by the team; “I appreciate that you’ve come on a journey with us, haven’t you, with the service, and understood, like you say, the complexities of the families, the types of conditions they might have, the impact it has on their lives, and you were in that position then to be able to run that workshop respecting all of that, so that was interesting.” (Barbara, Occupational Therapist, PMT). This response also suggests that this practice also added to the team’s ability to trust me and facilitate recruitment to the workshops.

Language Barriers

As highlighted in chapter five there was a problem with the understanding of language used by both me, as a design researcher, and the clinical teams I was observing. This is something that Muratovski (2016) highlights to be aware of when conducting ethnographic research. Researchers need to be able to explain their ideas, processes and motivations to lay audiences. Muratovski suggests that there is often a need for ‘persuasion, negotiation and pleading’, so close attention needs to be paid to the way that researchers communicate with others (2016 p57).

Whilst he refers to this problem in terms of language, such as foreign languages, dialects and accents, this research has demonstrated that it can also refer to the ‘language of disciplines’ and the meanings attributed to terms or words across professions. In this study, recognising when language problems arose enabled me to actively seek to overcome them through the use of sense making practices such as diagrams or by changing the terminology I used. This is something to be mindful of when working in a discipline outside of one’s own. Misunderstandings that are not clarified might have significant detrimental effects to the study design, such as using the wrong measurement or recruiting the wrong participants, or in the relationship between stakeholders (by using inappropriate or incorrect terminologies).

Summary and Recommendations

Emergent research enquiries are a key part of RtD. The discussion here highlights the importance of this approach when working in healthcare. This immersion phase was vital to the success of this study, underpinning workshop construction, patient population selection and also providing space and time to learn how to interact and integrate with the team in a complex environment.

It has demonstrated the success of this phase to gain a team's trust and support for a project. As more designers find themselves working in healthcare, recognising the importance of this will become increasingly necessary. This discussion has demonstrated the need for and benefit of a set up or immersion phase. The relevance and value of this needs to be better accounted for as a part of design and health project models to come. Future designers working in this field, need to argue its value, and articulate the skills they possess and methods they might use to navigate the early stages and optimise a project. This proposition adds to Tskeleves and Cooper's (2017) argument that designers need to be a key part of the team in design in healthcare. I suggest that they need to have greater involvement in writing research bids and grant proposals rather than simply being written into them which can often be the case. This would allow for a more collaborative, open ended space for enquiry lines to be defined. Design researchers need to demonstrate the value of design beyond aesthetics (Sklar and Naar 2017) and that in this formative part they can help to shape a study

A designer's ability to navigate the early stage of a research project supports Cross's (2001) argument that there is increased quality and depth when a designer is involved. This disputes the rise of design thinking and the simplification of design methods and processes that might ignore the intricacies of the early stages (without the presence of a designer in the team). In areas like healthcare, Design thinking that follows strict processes are likely to result in sub-optimal outcomes due to the complex and ill-defined nature

of the problems that are characteristic of it. Sanders and Stappers (2008) support this premise; when discussing the 'fuzzy front end' they argue the need to articulate both the importance and the complexities of this phase to conduct high quality design research.

That is not to say that the immersion phase will be easy; it is hard to know how long this period will take and what methods and resource will be used during it. This will have an impact on project timelines and finances. Furthermore, RtD is a comparatively new discipline, within healthcare research, whose evidence may not be valued as highly as that of other, more traditional scientific models. In some cases, and in the short term, especially as healthcare learns to value knowledge contributions from design research, designers will continue to be brought in for certain elements of projects rather than as key team members. In these instances, other design methods, such as those used in service design (journey mapping, service safaris, personas) are well placed to build some level of understanding, to bring multilevel stakeholders together and to build a relationship of trust.

8.3 The Importance of Design Methods and Designers

The third discussion in this thesis looks at the practice used with the pain management therapists. It aims to unpack the specifics of what the design approach achieved in this part of the study. It summarises the impact of the work, and situates it in the wider literature on design methods and designers presented in chapter two. It argues that designers should be involved in the use of design methods and processes, and the recognition of facilitation as a design practices would support this. It suggests that designers can use their creative processes such as sense making practices (for example, to articulate ethnographic findings) and optimise the success of the study.

Overview of Design Practice with Staff

As stated in chapter four, the design practice with the staff was not part of the original study design. It was an emergent enquiry that was identified after the initial immersion period through the mutual interest of myself and the therapists to explore the service provision. Through the immersion period it transpired that the pain management therapists were interested in continuing the enquiries of this phase, these included time and space to reflect on their work and someone to help facilitate this process. Information on the design practice that was used with the staff can be found in chapter six, this discussion will focus on the outcomes of this type of practice and relate it to the unique contribution of design.

As documented in chapter six, design practice was provided this space to consider their service provision and to build researcher knowledge. The therapists described this design-led approach as clear, visual and collaborative, stating that their contributions were valued and they felt included in the process. This process also led to the creation of a patient resource pack and a series of services changes developed and implemented outside of this PhD.

In the findings of the staff practice (covered in chapter six), various impacts are documented. Some of these are personal and professional impacts, such as the team feeling that they are now working smarter, feel reinvigorated in their job roles and communicating better with each other. On a wider service level, anecdotal evidence (based upon routinely collected data) suggests it has helped to regulate the service; over the time-period of the work referrals are still increasing, however, episodes of care (the amount of interactions patients have with PM therapists) have decreased, discharge is more routine and patients are in the service for a shorter period of time.

This participatory approach supported the study design of the adolescent workshops where service understanding was used to develop workshop content. It also provided the therapists with a greater understanding of design practices and how they could increase their knowledge to support the sessions. In terms of sustainability planning, the hypothesis suggests that if a team is well functioning, it is more receptive to this type of work and able to sustain it. To understand what can be learned from this approach it is necessary to consider how design practice enabled these outcomes and what the challenges are of working in this way.

Design Facilitation

In chapter two I discussed how, through approaches such as EBCD and the rise of design thinking, design methods are increasingly being utilised without the support of professionally trained designers (Locock et al 2014; Kimbell 2011). It is suggested that one of the reasons for this in healthcare is the undervaluing of a design professional since often the designer's role is perceived as 'mere facilitation' (Macdonald 2017). Importantly, this study used participatory design methods facilitated by a design researcher and therefore provides an opportunity to discuss the potential value of 'design facilitation' as a specific approach.

Previous attempts to explore the PM service offering had left the therapists overwhelmed

by the complexities and unable to see a way to approach change. The visual design methods used in this study provided a novel approach and way of thinking to consider data to the team. Analysis from the interviews shows that the work was focused around reflection and consensus, ensuring that everyone's opinions were heard and valued. It also navigated and negotiated hierarchies, moving the team through difficult conversations and successfully clarifying processes. Crucial to this outcome was the record produced through sense-making diagrams and visuals. The approach ensured that everyone has equal opportunity to share their views and a visual record of both individual contributions and group consensus was kept. The importance of both the visuals and the skill of facilitation by the designer to achieving this was noted by the participants:

“You’ve always pulled everything together and sometimes it might look a bit chaotic, but it is a shared vision. It’s about bringing together diverse thoughts in people, putting them together and then creating something else” (Occupation therapist, PMT)

Much of this visual material was not produced through a prescribed design method (such as a creative thinking activity or journey mapping). Instead it was produced as a sense making activity by the design researcher, for both my personal knowledge and the professional care-providers, to draw together the multiple perspectives and experiences. Some were produced on the spot, while others were created outside of the session. This key skill is summarised by Schon (1987) in his statement that designers ‘think in action’, observing the world and making meaning of it. In both instances, a process of sense making, thinking and reflection took place before a representation was created (Lawson 1990). I was not following a prescribed process or activity (such as those outlined in some design thinking processes). Instead, like many designers, I allowed my skills and experience to guide the practice and generate a visual output (such as the staff skills maps and stage diagram) to translate abstract ideas into something concrete (Cross 2006). These representations then became ‘boundary objects’ (discussed in the previous section). In their feedback, many of the staff mentioned that as a facilitator, I had a way of ‘seeing’

or providing 'perspective', 'holding the idea' and navigating a way through the complexity. This links to both Schon's (1982) view that designers are naturally reflective and Lawson's (1990) solution-focused ways of working, whereby a designer will contemplate the analysis of a problem and solutions to it simultaneously (which in this case might have been a consensus on a topic or an agreed order to a process). As Sanders and Stappers (2016) state, through selection and training, designers have a way of finding missing information and conducting creative processes. Even when working through common design techniques, such as service journeys maps (a well-defined method), a designer will do more than facilitate the process. They will ask questions, look for elements that need expansion and draw the output together to create an overall meaning. This demonstrates how a designer engaged in this process is doing much more than 'mere facilitation'. They are often guided by a series of tacit skills and knowledge rather than following a set process (Rust and Horne 2009). These skills and knowledge are a result of experience and training (Lawson & Dorst 1980) that develops these unconscious and automatic skills.

Summary and Recommendations

This study is a clear demonstration of the benefit that design and design led research practices can play in healthcare. It adds to a growing body of knowledge in this area and aligns with literature that suggests that when designers are not involved in the research process there is often limited tangible service improvement, a lack of ideation tools, and the more challenging steps are left out (Bowen et al 2013; Burdick 2003). It supports the argument that a designer's skills and experience provide an ability to navigate complexities, establish frameworks, go into greater depth, and produce more innovation around a healthcare issue or problem. Indeed, Cross (2007) argues that designers are integral to the design process, and that one cannot separate the designer's skill from the methods applied. What this practice with the therapy staff demonstrates is the value of a designer to facilitate design methods. Schon (1987) states that designers 'think in action' and are naturally reflective, observing the world and making meaning of those observations. It is this ability to use both tangible and non-tangible skills (and the ability

to do it simultaneous to facilitation) that adds to the case for designers to be involved in the process.

This discussion now draws in literature from chapter two on the rise of design thinking. As Brown (2009) stated, thinking like a designer can transform the way organisations develop products, services, processes and strategy. This design thinking movement outside of academia should not be dismissed, as it provides value and benefits to those who engage in it (Kimbell 2011). It has also opened the field of design to make it more accessible and enable non-designers an understanding of it (Lawson and Dorst 2009). This is an important tension to acknowledge. More needs to be understood about how to reconcile these seemingly disparate approaches. For example, perhaps more needs to be understood, and better articulated, on both sides of the debate about the appropriate conditions for a design professional's input or when a design thinking process could be used instead. Some of this might depend of the complexity of the problem or how well defined the parameters are. I suggest that in healthcare, where most problems are 'wicked', a designer's professional input is needed to navigate these complex conditions, as opposed to simply applying a design-like process facilitated by a non-designer.

There needs to be greater a recognition and a better articulated definition of a designer's skills to support decisions of designer or design skill involvement. Muratovski (2016) states "designers are still perceived as people who 'make' rather than people who 'think'". To counter this, this study suggests that design facilitation needs to be recognised as a practice of designers. Recognising design facilitation as a practice of RtD would help to articulate this value and distinguish it from the mere facilitation of design methods. Key to this is that the facilitator has design training and experience and therefore utilises both tangible and non-tangible design skills.

8.4 Workshops to demonstrate design skills to adolescents; Findings and limitations

The final discussion of this thesis focuses on the adolescent workshops. The process to set up these workshops and the delays that this caused were well described in chapter seven and will not be repeated here. It will start with a summary of self-reported workshop findings, before considering the limitations of the evaluation and finally situating this alongside literature to draw conclusions and recommendations.

Summary of Findings

The project was successful in developing a program of workshops to demonstrate design skills and approaches to adolescents. It focused on key skills that designers use to approach problems and apply to the process of generating solutions for them (more information on this was provided at the beginning of chapter seven).

Findings presented in section 7.8 of chapter seven suggest that the workshops were successful in providing a positive and engaging experience for participants. They provided a unique approach to potentially develop new designerly mindsets and skills in the adolescents. Some participants reported that they could see a link between the skills and their PM. These included; trying new PM techniques, developing confidence to 'give things a go', and seeing things from another's perspective. Some of the adolescents reported that they had found specific applications to support managing their pain. Others were not yet using the skills but could see opportunities where they might in the future. In discussion with the therapists about the sessions, some linked the potential success of the workshops to opening a young person's worldview, as many become stuck or fixed in their ways of thinking.

However, this was a small scale sample with no longitudinal data or verified measures of

behaviour change or self-efficacy. More work is required to understand the measurable impact as well as what different formats the sessions might take, how the activities might be developed, and the best ways to evaluate the sessions (such as a follow up to see any long term impacts).

Learning a Skill in a Safe Space

Following learnings from Wolstenholme et al (2014), I decided to not explicitly link the activities in the workshops to the management of chronic pain. The intention was to allow the adolescents to learn the skills and build their confidence through a neutral activity. Pain management was mentioned in the workshops, and the participants had been recruited knowing that the overall aim was to look for a link to PM, however personal experiences or challenges were not used as examples around which to frame the activities. This allowed participants to consider where and how they might apply the experiences to their lives outside of the session (to pain management or something else entirely).

The findings show that adolescents could see a link to the thinking behind the designed activities experienced in the workshop and their pain management behaviours. Adolescents stated in their feedback that they were using the mindsets to think about their pain and how they manage or might manage it in the future. This demonstrates the benefit of allowing a safe space in which to master a skill before applying it to one's own situation.

Peer Support and Meeting Others

For many, this was the first opportunity that they had to meet someone else with their condition. One of the findings is the value the participants placed on meeting others in a similar situation to themselves. This is unsurprising, given that peer support and group work is a well-documented successful approach to supporting young people with long term conditions (Sawyer and Aroni 2015). However, these group approaches are uncommon; in the Sheffield pain management service, there are currently no group

sessions. This finding has been useful learning for the service provision of PM at SCH. The use of methods without directly linking to pain management has the therapists reflecting on different or additional ways to support the adolescents.

Future work in this area needs to be mindful of the value placed on meeting others if it chooses to explore other formats such as one-to-one sessions. Another consideration is around the makeup of workshop participants and whether the groups need to be condition-specific. The workshop sessions in this research have demonstrated how design related skills and ways of thinking can be introduced without tailoring to a specific management behaviour or experience. This suggests that cross condition groups would also be successful. This idea is supported by literature, suggesting this approach can be beneficial, particularly when the number of people with a condition are relatively small, and when many young people with these illnesses share much else in common (Sawyer and Aroni 2015).

Limitations

It is important to be upfront about the limitations of any research study and to acknowledge the boundaries and scope of the work. This is important for others who might want to replicate the study or conduct a similar research in this area.

The main limitations in the evaluation of the adolescent study relate to the type and timeframe of the data collected. A mixed method approach was used (Likert scales, questionnaires, interviews and reflections) with the aim that it might present a broader picture of the outcomes. However, an evaluation can only be conducted on the data received and therefore the results will have a bias towards those who returned the questionnaires and attended an interview. To try to counteract this bias, Likert scales were completed by all participants to provide some balance to the data.

When analysing the Likert scales, it was recognised that as people's views are subjective

(what one person scores a 2 might be a 0 for another) the findings would need to look at overall trends rather than a straight comparison. Also, whilst on their own they are interesting, individual data sets would not be appropriate to compare against another's without placing assumptions or surmising from the data (for example; person A is more optimistic than person B as they rated themselves higher). Where there are negative changes across the data we do not know what this means, a negative change might mean that a participant has a more realistic view of their own abilities or that their abilities have decreased.

Another limitation relates to subjectivity. For example, the Likert data cannot account for the variances in participants' moods or know what implication this might have had on the results (for example did low mood reflect to a low score). Or perhaps the way the question or statement was posed guided their response. Neither can we be sure of the truth of the data. Participants might have answered based on how they wanted to feel or what they believed the researcher wants to hear. This is particularly pertinent to those participants who scored themselves as 'strongly agree' on their first Likert scale. As there was no higher place to score we are unable to know if the sessions had an impact from this data alone. Whilst no change is demonstrated it is not known whether this is because there was no change or because there was no higher possibility to rate. As there was no clinically validated measure of the workshops all potential changes and impact on self-management are self-reported and cannot be clinically proven in terms of behaviour change. Finally, the follow up time for the patient questionnaires was short and so little is known about the long-term impact of these workshops on the patient population.

Situating the Findings in Literature

There has been increasing interest in recent years to understand how design skills can be applied to encourage behaviour change in long-term conditions. These workshops stemmed from a body of research that suggests those who engage in the design process are more resourceful, and have increased self-efficacy and more creative confidence

(Campbell 2011; Wolstenholme et al 2014; Craig et al 2013). These studies demonstrated the potential value of applying design skills to encourage behaviour change, but proposed that more work was needed to explore this further and look at the transferability to other areas.

This study suggests that this application of design skills could transfer, both to an entirely different patient group (adolescents with chronic pain) and a different mode of delivery (group outpatient workshops as opposed to one to one inpatient sessions). Chapter two highlighted research by Sawyer (2007; 2005), Kirk (2010; 2012) and the Department of Health (2012) on the current understanding of how to best support adolescents to manage conditions, that highlight a field in which much is still to be understood. Therefore, any future work in this area should align to both behaviour change and the gaps in the current literature on adolescent healthcare.

Furthermore, the approach of this study aligns to many health and wellbeing areas where intervention development is needed such as developing independence and confidence, support to make positive contributions, coaching in problem solving, peer support and group sessions. Perhaps the most obvious place where this research resonates is in the context of assisting the need for interventions that help develop problem solving skills. As Sawyer and Aroni (2015) state 'A key tenant of self-management support is education and coaching in problem-solving'. As covered in the literature on design thinking, many of the design skills are linked to the idea of problem solving. The findings suggest that learning about design skills and practice can support condition management.

Another way that this study shows that design could support condition management is through the design related skills of experimenting and learning through failure. According to Sawyer and Aroni (2015) young people learn by doing which means that at times they need to experience failure to learn from their mistakes. Design skills can support this learning, as it encourages a person to reframe the idea of a mistake to a learning

experience to see what might be done differently. The workshops provided a safe space to learn these skills and make mistakes.

It should be noted that the researcher recognises that the participants who have been through the workshops are not to be seen as professional designers any more than another non-trained person. However, they have been introduced to the use of design mindsets and activities to challenge and approach problems to think about them differently and more creatively. This closely aligns to much of the reasoning behind design thinking, innovation and idea creation. Literature tells us that the term design thinking both describes the skills that designers train and employ in their practice and is a method used by those outside of the profession as a process to engage in problem solving and creativity (Johansson-Sköldberg, Woodilla and Çetinkaya 2013). In addition, Lawson and Dorst (2009) state that Design Thinking processes can help to structure design work and “enable(s) non-designers to understand design, albeit in a limited way, by relating to a common activity (problem solving is, after all, an incessant universal human activity)” (32).

It is therefore possible that the learning of design skills by non-designers to change mind sets does not need to include designers in the demonstration or learning process. As discussed in chapter two, there are many available resources to engage those outside of the design profession in design thinking through which skills in problem solving could be learned. Embracing the notion that citizens can learn these skills (as Campbell (2009) suggested, to encourage resourcefulness), does not undervalue the role of the professional designer whose knowledge, as proposed, is essential in the application of these skills. Design mind sets can be learned but to be a designer and tackle complex problems requires skill and training. If designers might not be required in this process then the potential benefits of workshops such as those in this study could be of interest and accessible to any health professional or training scheme (such as therapists). Furthermore engaging with those who have embraced the idea of designing and design thinking is beneficial to support the design process.

Chapter Nine: Contributions

This final chapter covers the specific contributions and related recommendations. Here I will summarise the key points from the previous chapters' discussions to frame the contributions and provide a series of recommendations for design practice and further investigation.

It has been stated throughout this thesis, that whilst there were initial aims and objectives, much of this research was emergent in nature and new lines of enquiry included in the study. To reflect this this chapter begins with a short recap on the original aims and objectives.

9.1 Meeting the Aims and Objectives

To investigate the impact design workshops might have on a patient population's condition management

- Conduct a literature review and period of design ethnography to establish a group of patients to work with,
- Run a series of workshops that demonstrate design skills and methods to patients,
- Use qualitative and quantitative measures to analyse the workshops.

To investigate the impact that design workshops might have on condition management, I designed a programme of workshops that demonstrated design practice and skills to adolescents with chronic pain. An in-depth account of these workshops can be found in chapter seven. The activities within these were based on skills the of design professionals as presented by scholars such as Nigel Cross, Brian Lawson and Lucy Kimbell, which was presented in contextual review one.

To select a patient population to work with, I undertook an immersion period of design ethnography in Sheffield Children's Hospital's Physiotherapy and Occupational Therapy Service, where I developed a relationship with the Pain Management team and selected

chronic pain as the patient population. More detail on chronic pain can be found in chapters one, five and six. As a result of this immersion period a new line of enquiry was identified to explore PM service provision. The choice of age range was informed by a literature review into the management of long term conditions. Literature from the Department of Health and academics such as Susan Sawyer led me to discover that adolescents are an under-represented group of patients and so I decided to work with adolescents between the ages of 11-16 (more information on adolescents and long-term conditions is in contextual review one).

Due to delays in the ethics process that are covered in chapter seven the original plans for the workshop changed, instead only one round of workshops was completed. Fifteen patients were recruited, with eleven returning for the second session. A mixed methods approach was applied to try to understand the impact of these workshops on the adolescents' pain management behaviours. Feedback from the workshops show an engaging and positive experience, and self-reports provide an insight into some development of designerly skills. A full analysis of the workshops cannot be completed due to low numbers, no longitudinal data and lack of validated measures. For full details of these findings, go to chapter seven of this thesis.

To explore how design practice can support the development of relationships with healthcare providers

- Use design ethnography to build a relationship with the patients' healthcare providers and work with them to integrate these workshops into the current management practices offered.

In the study design section of chapter four and in chapter five I summarised why it was so important to develop a relationship with the clinical team. I undertook a period of design ethnography to build this relationship and understand more about the patient population. In chapter four I discuss how other design practice, such as sense making and

visual mapping, was used to support this period. In a discussion on this set-up phase in chapter eight, I discussed how the methods and duration of time built a strong relationship of trust with the team. These methods also led to an additional line of enquiry with the chronic pain team that was used to explore service provision (more information on this is in chapter six).

Due to the delays in ethics described at the beginning of chapter 7, the original expansive plan to develop the programme of workshops and explore how to integrate them into the service could not be realised during the time of this study. However, the team are currently in talks to consider how they might integrate some of the activities and group sessions into their pain management offering.

To contribute to the discussion on the role of the design professional when design methods are used in healthcare

- Make recommendations for other design researchers in healthcare based on reflective practice conducted throughout,
- Gain ethical approval through NHS ethics procedures.

This study has been conducted as a piece of practice-led, research through design in healthcare. Therefore, the whole study provides contributions and learnings to this aim. To support this, I engaged in reflective practices throughout the study. I describe in chapter six and discuss in chapter eight how the design facilitator was crucial in the emergent design-led sense making practices with the staff. All three of the practice chapters add to discussion and recommendations on the role of the design professional in healthcare, which will be summarised in the following contribution section.

The second objective was achieved. NHS ethical approval was achieved on the 7th July 2017, following a series of delays and amendments (more information about these processes

can be found in chapter six, and in the discussion in chapter eight). The ethical approval was a complicated and lengthy process that I learned much from. These learnings also form part of a contribution to the discussion on design research in healthcare, leading to a series of recommendations for other design researchers conducting work in this field.

Additional lines of enquiry

The additional enquiry (exploring service provision with the pain management therapists) formed a major part of this study. As is the nature of design research, new lines of enquiry add new aims and objectives to a study. The body of work with the PM therapists (Chapters five and six) provided space to explore what it is about design methods and approaches that is unique and specifically, what they could bring to research in healthcare. This contributed recommendations and new knowledge on the value of Design and the design professional for the NHS.

9.2 Summary of Contributions

I offer the following contributions to knowledge that are a result of this practice.

- Research through design is a valuable approach to explore and develop healthcare service provision.
- Design facilitation should be a recognised design practice to counteract the undervaluing of design professionals and to distinguish between design facilitation (by a designer) and other forms of facilitation (by non-design professionals).
- Three key recommendations to support practice in design in healthcare:
 - The use of NHS research ethics approvals should be encouraged to demonstrate rigour in design research,
 - Design research should factor in time for a set up phase (in the context of healthcare),
 - Designers should be key partners in the grant writing process.

Whilst not a key contribution that this thesis can offer, also provided is a final summary of recommendations for those that might want to explore the development of designerly skills in patients with long term conditions.

9.3 Contribution One: Research through Design is a valuable approach to explore and develop projects in healthcare service provision.

The first contribution of this thesis argues that Research through Design is a valuable approach to explore and develop projects in healthcare service provision. Crucially in the early stages to support project definition, build relationships and develop researcher knowledge. It argues that a RtD approach in the early stages of projects (e.g. set up, identifying lines of enquiry etc) produces superior outcomes.

This study has demonstrated the significant unique contribution that RtD brings to the whole research process, from identifying lines of enquiry, building relationships, navigating institutions procedures, collecting and analysing data. It provides an exemplar study to show the value and depth that designers and design methods bring to a project when included as a valued partner in the study (Macdonald 2017; Chamberlain, Wolstenholme and Dexter 2015, Tskeleves and Cooper 2017).

It was stated in chapter three that there is still much to be understood about a RtD approach, specifically what the methods of this practice look like. This study provides insight into these. Specific examples of methods that a RtD approach brings have been demonstrated in this study. One of these relevant to the early stages of a study is a unique, flexible, mixed method approach that combines and borrows methods from other disciplines. This allows complex service understanding to be gained and supports the navigation of the 'fuzzy front end' (Sanders & Stappers 2016) to understand the context, develop lines of enquiry and build trust between a researcher and the healthcare team. Sense making visual practices (including Boundary objects) are used to translate data, findings and visualise understanding from a range of methods. This creation of visuals provides an innovative approach to consider complex service offerings in the NHS and

overcome the challenges of the 'language of disciplines'.

Also demonstrated throughout this study are the range of skills (cognitive processes and practices) employed by a trained design professional in design activity. These include; The creation of tangible things (Lawson 1990; Cross 2006), solution focused ways of working (Lawson 1990), comfort in ambiguity (Campbell 2009; Cross 2006) and a reflexive nature that observes and makes meaning of those observations (Schon 1987). These skills combine to allow the designers to navigate, negotiate and find missing information to make decisions (Sanders and Stappers 2016). Furthermore, these design skills provide the conditions to flatten hierarchies and negotiate difficult conversations.

Literature presented in Chapter 2 shows that there is an increased need for smarter ways of working and a drive for innovation in healthcare (Design Council 2013). RtD is well placed to answer this call to develop new products, services and working practices in the face of the complexities and challenges in healthcare (Chamberlain, Wolstenholme and Dexter 2015). Carlgren (2013) stated that increasingly language, terminology and methods traditionally from the field of design are being utilised in healthcare research (Carlgren 2013). Examples of this include involvement predefined by those outside the field such as; design thinking, service improvement or co-design workshops. Or those approaches such as EBCD where the methods and process of design are practiced without any input from a trained designer (Locock et al 2014; Kimbell 2011)

RtD in this study has demonstrated clear outcomes that include; tangible service development, new ways of working and increased personal satisfaction. This is a timely contribution that offers a supportive approach for the set-up of studies that intend to use design methods such as co-design workshops. RtD can be used to build relationships, define lines of enquiry, and optimise the use of design methods.

Recommendations

Recommendation One

To develop further exemplar case studies of research through design in healthcare

Further exemplar case studies of Research through design would build a body of evidence to support the development of RtD as an established research approach in healthcare.

Recommendation Two

Work to further understand and articulate the methods and approaches of RtD specific to healthcare

Further studies should seek to demystify the RtD approach, specifically in relation to the methods and mind sets employed by the professionals. Discourse amongst design researchers in this field should focus on the variety within and develop consistency in the articulation of this approach. This would add to a body of knowledge on what does and doesn't constitute RtD, and create consensus on what the approach entails.

Recommendation Three

To articulate the value of a RtD approach to healthcare audiences

To establish RtD as a valid approach in healthcare is not just about exemplar case studies and understanding the methods. The language of disciplines needs to be bridged to articulate the value to a healthcare audience. The importance of demonstrating this value to a wider healthcare audience cannot be understated. Part of this might involve looking at current healthcare service research methods to see where this might align, as well as identifying champions and dissemination through academic channels to encourage adoption and spread. If this does not happen then increasingly design approaches will be misappropriated and design will be 'written in' to grant proposals as a discreet stage to research.

9.4 Contribution Two: Design Facilitation as a Recognised Form of Design Practice

This thesis argues that design facilitation is a distinct form of design practice. It proposes to the design community that recognising design facilitation as a practice of RtD would help to articulate its value, and distinguish it from the mere facilitation of design methods (by non-design professionals). This study has demonstrated this design facilitation in the therapist workshops (where design methods were facilitated with the team) and with the adolescents (where design approaches and mind sets were demonstrated).

RtD is related to the research contribution the 'practice' of design brings (Koskinen et al 2011). Much of this practice might be tangible (prototypes, artefacts or things that can be interacted with), and therefore easier to demonstrate to those outside the field. Koskinen et al (2011) argue that in the field context of RtD, knowledge is embedded in produced artefacts.

However, Candy (2006) argues that the artefact is not the main focus in practice-led research; an artefact may or may not be produced but it is the practice itself that is important. For example, design facilitation might include leading a team through a design activity, drawing a map to visualise a conversation in real time, directing a group to prototype their ideas and supporting the process. Or it might involve listening to the conversation taking place between others, reflecting on this conversation, making sense of it and presenting this back to the group. In all these cases an artefact may or may not be produced.

The recognition of design facilitation would support the notion that designers ought to be understood as people who 'think' as well as 'make' (Muratovski 2016). It provides insight into the methods and approaches of Research through Design. It also articulates the

importance of ‘designerly ways of knowing’, the expertise of the designer, and supports Cross’s (2007) argument that one cannot separate the designer’s skill from the methods applied. Schon (1987) states that designers ‘think in action’ and are naturally reflective, observing the world and making meaning of those observations. It is the ability of a designer to do these things simultaneously that is captured in design facilitation.

Implications

Design facilitation aligns with ‘designerly ways of knowing’ whereby the thought processes and mind sets that underpin design practice argue a distinct design expertise. In a society where design methods are being used for problem solving and innovation, design facilitation provides a justification for designers being involved in these processes. It articulates what designers bring above and beyond what might be perceived as ‘mere facilitation’, drawing on their training and experience to utilise both tangible and non-tangible design skills. It is an important contribution to the growing understanding of Research through Design and what the methods and approaches might look like within the field context of healthcare. Communicating this has implications on demonstrating design practice in a way that it might be valued better by others outside of the discipline. This is particularly pertinent in healthcare, with the increased demand for design and the rise in the use of the EBCD method.

Recommendation 4

To develop better understandings of where design facilitation sits with other domains of design practice

If design facilitation is to be recognised as a form of practice and argued as a reason why designer should be involved in the communication of design methods, then there is a need for a better understanding of how this fits with the growing domain of Design Thinking and EBCD, mentioned in this study.

Both Design Thinking and EBCD have demonstrated that they achieve a degree of success

(although there is debate about the level of impact that is achieved). Is the argument that design methods are the privileged domain of designers? Or that in some circumstances design facilitation is required and not in others? A comparative study would be useful to explore the differences between what facilitation and design facilitation achieve. A comparative study might also help to understand whether and when certain problems and situations require a designer facilitator input or not.

9.5 Contribution Three: Key recommendations to support design practice in healthcare

The first contribution was aligned to the emergent nature of design research and the value and benefit of this approach. However, it has been recognised within this work that there has been procedural learnings that would provide an easier journey for others who might wish to embark on studies of this nature. Therefore, the final contribution from this thesis is a series of recommendations based on learnings from this study. These recommendations add to a growing body of knowledge to support design researchers working in the field of design in healthcare. These are; encouraging the use of NHS research ethics approvals to demonstrate rigour in design research, factoring in a set up phase in design research, and becoming key partners in the grant writing processes.

Recommendation 5

The use of NHS research ethics approvals should be encouraged to demonstrate rigour in design research

I propose that NHS ethics procedures can be used to demonstrate rigour in design research, aligning it to the high standards that the health sector discipline values and providing credibility to a study. Furthermore, the approvals process can help refine and scrutinise a design study and develop the language used to communicate it to a healthcare audience. This approach will not be appropriate for all studies, but for those that do decide to gain NHS ethical approvals, the study design needs to allow for the time that this application can take as well as any delays in the system.

Recommendation 6

Design research should factor in time for a set up phase

This thesis has demonstrated the need for a set up or immersion phase in order to optimise a project. As more designers find themselves working in healthcare, this will

become increasingly necessary in studies where the context is unfamiliar and there is no existing relationship between stakeholders. Crucially it builds relationships with clinical teams, gaining trust and support for a project. Furthermore, this period can help to shape a study design and the choice of methods.

This recommendation aligns with Sanders and Stappers' (2008) 'fuzzy front end', and the need to articulate its importance in high quality research design. I suggest that to support this, designers should discuss the aims of the phase (such as relationship building and gaining trust, understanding context and introducing stakeholders to design methods) rather than in terms of the methods used (as these will be decided as this period is navigated). In cases where a dedicated set up phase is not possible, designers should consider how their practice might support this on a smaller scale.

Recommendation 7

Designers should be key partners in grant writing processes

I recommend that designers have greater involvement in writing healthcare related research bids and grant proposals (as opposed to being written into them). This would allow a degree of control over the research design (such as building in an immersion or set-up phase) and enable them to steer a project to optimise the use of design methods. This aligns with Tskeleves and Cooper (2017), who argue that designers need to be a key part of the team in design in healthcare. Involvement from the early stages would also support better communication of the value of design to those outside the discipline and provide designers with a greater understanding of other disciplines that they might be working alongside.

9.6 Recommendations for future work to develop designerly skills in adolescents with long term conditions.

Overview:

Learning about design skills could increase designerly skills in patients with long term conditions. This has the potential to reduce the burden on healthcare service provision

The study found that demonstrating design skills and approaches to adolescents with a long-term condition could have a positive impact on management abilities. The study suggests that learning about design practices develops skills and mindsets and that these could be applied to support management behaviours in chronic pain patients.

literature suggests that those who engage in the design process are more resourceful, have increased self-efficacy and more creative confidence (Campbell 2011; Wolstenholme et al 2014; Craig et al 2013). Prior to this study, the majority of this research had been conducted with patients who have a spinal cord injury. Therefore, this study was novel in its patient population, demonstrating that the concept can transfer to a different patient group (adolescents with chronic pain) and a different mode of delivery (group outpatient workshops).

The study finds that there is a potential in this approach to support adolescents with long term conditions, in particular those with Chronic pain. As stated earlier in the thesis, limitations in the study mean that more work is required in this area to understand the full implications. Further work in this area could contribute knowledge on how to support this patient population, and add to a growing body of evidence on how design can support behaviour change in long term conditions.

Potential research implications:

Further research could generate new knowledge that is timely and would have a potential significant contribution that is important in developing the field of design and behaviour change in a healthcare setting. Furthermore, it could expand the knowledge of what design can do to support behaviour change in healthcare and long-term conditions. As a result of this research, studies that aspire to encourage behaviour change in patient populations might look to use design skills and processes to support their programmes and understand any impact.

Further work in this area is important as sector research calls for better support for adolescents with long-term conditions. As an underrepresented group, this has implications for developing new interventions aimed specifically at adolescents, recognising the need for distinct interventions for this population.

The workshops in this study provide an insight into how adolescents could be better supported. They provide a method that might equip children and young people (adolescents) with skills and knowledge, enabling them to navigate the complexities of life, which was a key recommendation from the Department of Health's 2012 report. Furthermore, they provide an insight into how to best support adolescents through developing independence and confidence, support to make positive contributions, coaching in problem solving and peer support and group sessions (Sawyer and Aroni 2015).

Recommendations for further work in this area

Recommendation 8

Studies that seek to encourage and support management behaviours should consider the use of design practice to develop mindsets and skills as part of their programmes.

Furthermore, studies in this area should consider not directly discussing a patient's condition and instead look to allow patients to develop skills in a safe environment where

failure is not so concerning

Recommendation 9

Work is needed to understand how best to deliver these methods and whether or not a designer is needed to be involved or other professionals could develop these skills equally well.

Recommendation 10

Future studies might consider the various formats this workshop might take, developing the activities and running the sessions with different patient populations and across conditions. More work is needed to look at how the findings align with behaviour change literature and measures to understand the impact on self-efficacy.

9.7 Conclusion

This thesis has reported on a three and a half year research through design study that sought to integrate Design skills and approaches as part of service provision within a healthcare team at Sheffield Childrens Hospital. Throughout the period of the study, the scope of the research expanded to include working closely with the therapists, to understand the context of chronic pain management, and subsequently for this community to reflect on and develop elements of the service. Mixed methods were used to conduct and analyse the enquiry. The findings of this study were summarised into three contributions to knowledge with a series of recommendations for future practice.

Final Note

I began this research at a point in my career where I had three years' experience as a design researcher in healthcare, but still had much to learn. This study has been enlightening and frustrating at times, but it has remained true to the emergent and responsive nature of design research. I have valued the time and opportunity it has provided to develop myself both personally and professionally, more than can be portrayed in this thesis. I will be forever grateful to the funders of this study, the staff and patients who were involved in it and the support I received from within the university. I look forward to seeing what the future holds.

Word Count:

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D Floor Stephenson Wing
Sheffield Children's NHS Foundation Trust
Western Bank, Sheffield S10 2TH

Tel: 0114 226 7846 Fax: 0114 226 7844

www.sheffieldchildrenscr.nhs.uk

30th April 2015

Dear Rebecca Partridge

Letter of access for research

As an existing NHS employee you do not require an additional honorary research contract with this NHS organisation. We are satisfied that the research activities that you will undertake in this NHS organisation are commensurate with the activities you undertake for your employer. Your employer is fully responsible for ensuring such checks as are necessary have been carried out. Your employer has confirmed in writing to this NHS organisation that the necessary pre-engagement check are in place in accordance with the role you plan to carry out in this organisation. This letter confirms your right of access to conduct research through Sheffield Children's NHS Foundation Trust for the purpose and on the terms and conditions set out below. This right of access commences on 30th April 2015 and ends on 30th April 2018 unless terminated earlier in accordance with the clauses below.

You have a right of access to conduct such research as confirmed in writing in the letter of permission for research from this NHS organisation. Please note that you cannot start the research until the Principal Investigator for the research project has received a letter from us giving permission to conduct the project.

You are considered to be a legal visitor to Sheffield Children's NHS Foundation Trust premises. You are not entitled to any form of payment or access to other benefits provided by this organisation to employees and this letter does not give rise to any other relationship between you and this NHS organisation, in particular that of an employee.

While undertaking research through Sheffield Children's NHS Foundation Trust, you will remain accountable to your place of study Sheffield Hallam University but you are required to follow the reasonable instructions of your nominated manager Professor Paul Dimitri in this NHS organisation or those given on her behalf in relation to the terms of this right of access.

Where any third party claim is made, whether or not legal proceedings are issued, arising out of or in connection with your right of access, you are required to co-operate fully with any investigation by this NHS organisation in connection with any such claim and to give all such assistance as may reasonably be required regarding the conduct of any legal proceedings.

You must act in accordance with Sheffield Children's NHS Foundation Trust policies and procedures, which are available to you upon request, and the Research Governance Framework.

You are required to co-operate with Sheffield Children's NHS Foundation Trust in discharging its duties under the Health and Safety at Work etc Act 1974 and other health and safety legislation and to take reasonable care for the health and safety of yourself and others while on Sheffield Children's NHS Foundation Trust premises. Although you are not a contract holder, you must observe the same standards of care and propriety in dealing with patients,

staff, visitors, equipment and premises as is expected of a contract holder and you must act appropriately, responsibly and professionally at all times.

If you have a physical or mental health condition or disability which may affect your research role and which might require special adjustments to your role, if you have not already done so, you must notify your employer and the Trust (Dr Gillian Gatenby- Research Directorate Manager) prior to commencing your research role at the Trust.

You are required to ensure that all information regarding patients or staff remains secure and *strictly confidential* at all times. You must ensure that you understand and comply with the requirements of the NHS Confidentiality Code of Practice (<http://www.dh.gov.uk/assetRoot/04/06/92/54/04069254.pdf>) and the Data Protection Act 1998. Furthermore you should be aware that under the Act, unauthorised disclosure of information is an offence and such disclosures may lead to prosecution.

Sheffield Children's NHS Foundation Trust will not indemnify you against any liability incurred as a result of any breach of confidentiality or breach of the Data Protection Act 1998. Any breach of the Data Protection Act 1998 may result in legal action against you and/or your substantive employer.

You should ensure that, where you are issued with an identity or security card, a bleep number, email or library account, keys or protective clothing, these are returned upon termination of this arrangement. Please also ensure that while on the premises you wear your ID badge at all times, or are able to prove your identity if challenged. Please note that this NHS organisation accepts no responsibility for damage to or loss of personal property.

We may terminate your right to attend at any time either by giving seven days' written notice to you or immediately without any notice if you are in breach of any of the terms or conditions described in this letter or if you commit any act that we reasonably consider to amount to serious misconduct or to be disruptive and/or prejudicial to the interests and/or business of this NHS organisation or if you are convicted of any criminal offence. You must not undertake regulated activity if you are barred from such work. If you are barred from working with adults or children this letter of access is immediately terminated. Your employer will immediately withdraw you from undertaking this or any other regulated activity and you **MUST** stop undertaking any regulated activity immediately. Your substantive employer is responsible for your conduct during this research project and may in the circumstances described above instigate disciplinary action against you.

If your circumstances change in relation to your health, criminal record, professional registration or suitability to work with adults or children, or any other aspect that may impact on your suitability to conduct research, or your role in research changes, you must inform the NHS organisation that employs you through its normal procedures. You must also inform your nominated manager in this NHS organisation.

Yours sincerely



R&D Manager, Sheffield Children's NHS Foundation Trust

**cc: HR department at Sheffield Children's NHS Foundation Trust
HR department of the substantive employer (and provider of honorary clinical contract, where applicable)**

Re: Ethics application for consideration

[Redacted]

Sun 17/04/2016 20:59

Ethics

To: Partridge, Rebecca [Redacted]

[Redacted]

Dear Rebecca,

Sorry for the delay. I have looked at your application in details and it all seems in good order. You have provided detailed information on the relevant aspects of the application. I would request you please to slightly amend two aspects as follows:

On the SHUREC2 form Section B item 9 you mentioned that the data will be available on SHURDA for 5 years, the standard is 10 years as you have rightfully mentioned in the Data Management Plan. Please add the proviso in the Data Management Pan that your project will detail the conditions for access as agreed with the participants, and what format the data will be available, and the purposes of access. The SHURDA staff will act upon your instructions every time anyone requests access to the data. You will probably organise the data in directories where only aggregate data are available for those participants who expressed their option this way while other data such as videos or sound recordings for participants who have agreed to full disclosure etc.

Also, I would advise that only data in digital format are to be made available, other outputs from the project that you will keep in a locked cabinet while the research is in progress will be discarded at the end of the research. It would be impractical and onerous to keep hard copies and control access otherwise. I believe that is what you mean.

Finally, you are aware that you still require NHS ethical clearance and I understand that you have already applied for this.

Please send the amended forms to Andrea for archiving, and the NHS clearance as soon as it is available.

Kind regards,

[Redacted]

Co-Chair of Faculty Research Ethics Committee

[Redacted]

Appendix Three: NHS ethics approval forms (IRAS)

The IRAS application form is completed through an online portal, and therefore any copies (such as this) are classed as drafts. The form begins with a series of screening questions and then goes into more depth on the study.

For the purposes of this thesis personal information has been removed and to reduce the size, some of the final declarations and signatures have been left out. Some sections remain blank, and will have been completed by the R&D department at SCH before submission.

<p>Please enter a short title for this project (maximum 70 characters) Design Practice in Health: PhD</p>
<p>1. Is your project research?</p> <p><input checked="" type="radio"/> Yes <input type="radio"/> No</p>
<p>2. Select one category from the list below:</p> <p><input type="radio"/> Clinical trial of an investigational medicinal product</p> <p><input type="radio"/> Clinical investigation or other study of a medical device</p> <p><input type="radio"/> Combined trial of an investigational medicinal product and an investigational medical device</p> <p><input type="radio"/> Other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice</p> <p><input type="radio"/> Basic science study involving procedures with human participants</p> <p><input type="radio"/> Study administering questionnaires/interviews for quantitative analysis, or using mixed quantitative/qualitative methodology</p> <p><input checked="" type="radio"/> Study involving qualitative methods only</p> <p><input type="radio"/> Study limited to working with human tissue samples (or other human biological samples) and data (specific project only)</p> <p><input type="radio"/> Study limited to working with data (specific project only)</p> <p><input type="radio"/> Research tissue bank</p> <p><input type="radio"/> Research database</p> <p>If your work does not fit any of these categories, select the option below:</p> <p><input type="radio"/> Other study</p>
<p>2a. Please answer the following question(s):</p> <p>a) Does the study involve the use of any ionising radiation? <input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>b) Will you be taking new human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No</p> <p>c) Will you be using existing human tissue samples (or other human biological samples)? <input type="radio"/> Yes <input checked="" type="radio"/> No</p>
<p>3. In which countries of the UK will the research sites be located? <i>(Tick all that apply)</i></p> <p><input checked="" type="checkbox"/> England</p> <p><input type="checkbox"/> Scotland</p>

Appendix Three: NHS ethics approval forms (IRAS)

- Wales
- Northern Ireland

3a. In which country of the UK will the lead NHS R&D office be located:

- England
- Scotland
- Wales
- Northern Ireland
- This study does not involve the NHS

4. Which review bodies are you applying to?

- HRA Approval
- NHS/HSC Research and Development offices
- Social Care Research Ethics Committee
- Research Ethics Committee
- Confidentiality Advisory Group (CAG)
- National Offender Management Service (NOMS) (Prisons & Probation)

For NHS/HSC R&D offices, the CI must create Site-Specific Information Forms for each site, in addition to the study-wide forms, and transfer them to the PIs or local collaborators.

5. Will any research sites in this study be NHS organisations?

- Yes
- No

5a. Are all the research costs and infrastructure costs for this study provided by an NIHR Biomedical Research Centre, NIHR Biomedical Research Unit, NIHR Collaboration for Leadership in Health Research and Care (CLAHRC) or NIHR Research Centre for Patient Safety & Service Quality in all study sites?

- Yes
- No

If yes and you have selected HRA Approval in question 4 above, your study will be processed through HRA Approval.

If yes, and you have not selected HRA Approval in question 4 above, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

5b. Do you wish to make an application for the study to be considered for NIHR Clinical Research Network (CRN) support and inclusion in the NIHR Clinical Research Network (CRN) Portfolio? Please see information button for further details.

- Yes
- No

If yes, you must complete a NIHR Clinical Research Network (CRN) Portfolio Application Form immediately after completing this project filter and before submitting other applications. If you have selected HRA Approval in question 4 above your study will be processed through HRA Approval. If not, NHS permission for your study will be processed through the NIHR Coordinated System for gaining NHS Permission (NIHR CSP).

6. Do you plan to include any participants who are children?

- Yes
- No

7. Do you plan at any stage of the project to undertake intrusive research involving adults lacking capacity to consent

Appendix Three: NHS ethics approval forms (IRAS)

for themselves?

Yes No

Answer Yes if you plan to recruit living participants aged 16 or over who lack capacity, or to retain them in the study following loss of capacity. Intrusive research means any research with the living requiring consent in law. This includes use of identifiable tissue samples or personal information, except where application is being made to the Confidentiality Advisory Group to set aside the common law duty of confidentiality in England and Wales. Please consult the guidance notes for further information on the legal frameworks for research involving adults lacking capacity in the UK.

8. Do you plan to include any participants who are prisoners or young offenders in the custody of HM Prison Service or who are offenders supervised by the probation service in England or Wales?

Yes No

9. Is the study or any part of it being undertaken as an educational project?

Yes No

Please describe briefly the involvement of the student(s):
PhD study- Student is chief investigator

9a. Is the project being undertaken in part fulfilment of a PhD or other doctorate?

Yes No

10. Will this research be financially supported by the United States Department of Health and Human Services or any of its divisions, agencies or programs?

Yes No

11. Will identifiable patient data be accessed outside the care team without prior consent at any stage of the project (including identification of potential participants)?

Yes No

Integrated Research Application System
Application Form for Research involving qualitative methods only

The Chief Investigator should complete this form. Guidance on the questions is available wherever you see this symbol displayed. We recommend reading the guidance first. The complete guidance and a glossary are available by selecting [Help](#).

Please define any terms or acronyms that might not be familiar to lay reviewers of the application.

Short title and version number: (maximum 70 characters - this will be inserted as header on all forms)
Design Practice in Health: PhD

PART A: Core study information

1. ADMINISTRATIVE DETAILS

A1. Full title of the research:

Exploring the role of applied design practice in supporting adolescents with long term conditions

A2-1. Educational projects

Name and contact details of student(s):

Name and contact details of academic supervisor(s):

Academic supervisor 1

Address

Post Code

E-mail

Telephone

Fax

Academic supervisor 2

Address

Post Code

E-mail

Telephone

Fax

Appendix Three: NHS ethics approval forms (IRAS)

Academic supervisor 3		
Address		
Post Code		
E-mail		
Telephone		
Fax		
<p>Please state which academic supervisor(s) has responsibility for which student(s): Please click "Save now" before completing this table. This will ensure that all of the student and academic supervisor details are shown correctly.</p>		
Student(s)	Academic supervisor(s)	
<p>A copy of a <u>current CV</u> for the student and the academic supervisor (maximum 2 pages of A4) must be submitted with the application.</p>		
A2-2. Who will act as Chief Investigator for this study?		
<p><input checked="" type="radio"/> Student <input type="radio"/> Academic supervisor <input type="radio"/> Other</p>		
A3-1. Chief Investigator:		
Post		
Qualifications		
Employer		
Work Address		
Post Code		
Work E-mail		
* Personal E-mail		
Work Telephone		
* Personal Telephone/Mob		
Fax		
<p>* This information is optional. It will not be placed in the public domain or disclosed to any other third party without prior consent. A copy of a <u>current CV</u> (maximum 2 pages of A4) for the Chief Investigator must be submitted with the application.</p>		
A4. Who is the contact on behalf of the sponsor for all correspondence relating to applications for this project? This contact will receive copies of all correspondence from REC and HRA/R&D reviewers that is sent to the CI.		

Appendix Three: NHS ethics approval forms (IRAS)

Title Forename/Initials Surname
Address
Post Code
E-mail
Telephone
Fax

A5-1. Research reference numbers. Please give any relevant references for your study:

Applicant's/organisation's own reference number, e.g. R & D (if available): SCH-2036

Sponsor's/protocol number:

Protocol Version:

Protocol Date:

Funder's reference number:

Project

website:

Additional reference number(s):

Ref.Number	Description	Reference Number
------------	-------------	------------------

Registration of research studies is encouraged wherever possible. You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you have registered your study please give details in the "Additional reference number(s)" section.

A5-2. Is this application linked to a previous study or another current application?

Yes No

Please give brief details and reference numbers.

2. OVERVIEW OF THE RESEARCH

To provide all the information required by review bodies and research information systems, we ask a number of specific questions. This section invites you to give an overview using language comprehensible to lay reviewers and members of the public. Please read the guidance notes for advice on this section.

A6-1. Summary of the study. Please provide a brief summary of the research (maximum 300 words) using language easily understood by lay reviewers and members of the public. Where the research is reviewed by a REC within the UK Health Departments' Research Ethics Service, this summary will be published on the Health Research Authority (HRA) website following the ethical review. Please refer to the question specific guidance for this question.

There are an estimated 15 million people in the UK living with a long term condition, effective self-management of these can result in better quality of life for patients, reduced use of NHS resources and in turn, reduced healthcare costs.

Adolescents are reported as facing great challenges and not doing as well as they could. Adolescence is a complex stage when there is an age of increased risk taking behaviour, significant developmental change and increased desire for autonomy. It also the point in time when those who have a long-term condition will begin to navigate and take more control of their self-management needs, in order to get through this, they need skills and knowledge that

Appendix Three: NHS ethics approval forms (IRAS)

will help them to navigate the complexities of life.

This study will use applied design practice to explore self-management in adolescents who have Chronic Pain and Osteogenesis Imperfecta (OI). Through group design skill workshops, interviews and activities that look at their day to day lives, they will cover strategies to allow participants an insight into the process of design practice and allow them to see how it might fit within their own lives.

A6-2. Summary of main issues. Please summarise the main ethical, legal, or management issues arising from your study and say how you have addressed them.

Not all studies raise significant issues. Some studies may have straightforward ethical or other issues that can be identified and managed routinely. Others may present significant issues requiring further consideration by a REC, R&D office or other review body (as appropriate to the issue). Studies that present a minimal risk to participants may raise complex organisational or legal issues. You should try to consider all the types of issues that the different reviewers may need to consider.

Participation in workshops carries minimal issues.

Issues in the development of the study:

Conditions to work with: In order to decide the appropriate groups to work with I spent time with the staff in different departments at Sheffield Children's hospital.

Age range: The decision to work with adolescents has been influenced by reading and research around the idea that adolescents are under researched in healthcare. Adolescence is also a time when the transition of self-management behaviours moves from the parent/caregiver to them. It is also a time of increased risk taking behaviours, so an appropriate point to look at self management.

Parents and caregivers: Because adolescents still have close relationships with their parents/caregivers and are not fully independent, the workshops will be conducted with parents and caregivers where they wish to be involved. They will be aware of all the activities that we conduct with the adolescents, however where appropriate we will group the parents and participants separately to ensure that we hear the patient voice.

Potential Issues arising from the study:

Talking about experiences: Some participants might feel uncomfortable talking about their experiences. The workshops will be held in a safe environment and we will do all we can to alleviate concerns and embarrassment by making participants aware they they only have to share as much as they wish and do not have to talk about anything they do not want to.

Introducing ideas of change: The design skills that the study will teach the participants are general design skills, they focus on areas such as creative thinking, seeing things from another's perspective, working with others and prototyping. These are all skills which designers use everyday to overcome complex tasks, and that everyone to an extent uses. The workshops will be focused on increasing confidence to use these skills.

Participants will also be taught about communication and team work and that any things they wish to try with regards their self management should be done in partnership with those around them.

A6-3. Proportionate review of REC application The initial project filter has identified that your study may be suitable for proportionate review by a REC sub-committee. Please consult the current guidance notes from NRES and indicate whether you wish to apply through the proportionate review service or, taking into account your answer to A6-2, you consider there are ethical issues that require consideration at a full REC meeting.

Yes - proportionate review No - review by full REC meeting

Further comments (optional):

Note: This question only applies to the REC application.

3. PURPOSE AND DESIGN OF THE RESEARCH

A7. Select the appropriate methodology description for this research. Please tick all that apply.

- Case series/ case note review
- Case control
- Cohort observation
- Controlled trial without randomisation
- Cross-sectional study
- Database analysis
- Epidemiology
- Feasibility/ pilot study
- Laboratory study
- Metanalysis
- Qualitative research
- Questionnaire, interview or observation study
- Randomised controlled trial
- Other (please specify)

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

To increase the knowledge and skills of design practise in adolescents who live with a long term condition.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

Secondary questions:

How can design practice explore and visualise issues around self-management?

Does learning about design practice increase engagement in self-management behaviours?

Objectives:

To increase participants knowledge of the design process

To gain insight into participant's lives, how they self-manage and what challenges they might face.

To develop methods that work in a healthcare context

Explore where design practice could fit within a medical model of self-management

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Long-term conditions are a huge financial cost to the NHS, and with an estimated 15 million people in the UK living with a one, effective self management is important not only for better quality of life for patients, but also to reduce NHS resources and costs.

The Department of health's 2013 report; Our Children Deserve Better; Prevention Pays (Davies, 2013), recommends equipping children and young people (adolescents) living with long-term conditions with the skills and knowledge to navigate the complexities of life and improve health outcomes. In addition, Susan Sawyer in a series of articles in 2012 explored the health outlook for adolescents, and found that they are often forgotten about in healthcare research; either grouped with children or adults, they are rarely focused on individually. This is concerning as adolescents present with very individual challenges to both children and adults. Adolescence is an age of increasing autonomy along with an increase in risk taking behaviours, combined these can lead to lower levels of health, and for those who have long-term conditions, lower participation in the activities needed to maintain their health.

Through Design Practice, this study seeks to explore self-management with adolescents and see if it can have a positive influence on participants to engage in self-management behaviours at this transitional stage in their development.

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Design practice has had excellent results as an innovative force in other areas of industry. There are a variety of terms to describe Design practice, one of which 'Design Thinking' was first described by Tim Brown (Brown, 2009), who believes that thinking like a designer can transform the way organisations develop products, services, processes and strategy.

Another definition is; 'having an understanding of the approaches and methods of design and applying these to think creatively about complex problems, posing questions and suggesting ways to solve them. It is about developing a long-term creative and explorative mind-set through skills such as lateral thinking, prototyping and verbal and visual communication. Design thinking uses design as a process as well as a result.' (Shine 2012 report, 2014). Design brings together people from different backgrounds, flattens hierarchies and gives a framework for people to work within.

Emily Campbell (2009) talks of design as resourcefulness, and the need for designers to share their skills with society in order to close the gap between our behaviour and aspirations, to enable us to be more resourceful and self-reliant. Gjoko Muratovski, 2016, speaks of the changing face of design, the ever-complex problems that designers face and a movement from 'product creation' to 'process creation'. Using design as a 'thinking process' for complex problems is still a new concept in healthcare, however tool kits have been developed to use design methods in education, schools, businesses and by students for innovation.

The studies that have explored these ideas in healthcare have done so with positive results. The RSA piloted a training programme to teach design to people with spinal cord injuries as a route to independence, resourcefulness and to have greater control over their lives (Campbell 2011). The programme left patients thinking more creatively about problem solving and they reported increased confidence and independence. The Art and Design Research Centre at Sheffield Hallam University have undertaken further work in this area in two projects. The first ran exploratory inpatient design thinking sessions at the Princess Royal Spinal injuries centre, and the second introduced a design thinking sessions as part of the rehabilitation programme offered at the unit. Qualitative feedback from both of these found that patients had a change in perspective on problem solving, had more confidence to try different ideas and solutions and think creatively, they also found it a mental stimulation they didn't receive from other therapies. Quantitative data showed statistically significant positive changes on self-efficacy measures, leading to the conclusion that design thinking workshops as part of rehabilitation can increase self efficacy and engagement in self-management behaviours in people with a spinal cord injury.

With promising initial research into how design practice can support patients with complexities in their lives, and a need to support adolescents in their self-management at a complex time in their lives. This study intends to explore these issues together.

A14-1. In which aspects of the research process have you actively involved, or will you involve, patients, service users, and/or their carers, or members of the public?

- Design of the research
- Management of the research
- Undertaking the research
- Analysis of results
- Dissemination of findings
- None of the above

Give details of involvement, or if none please justify the absence of involvement.

PPI is not appropriate as participant views are part of the research, in planning and developing the sessions as the workshops go forward.

I will engage them in the dissemination to explore ways of sharing the findings with peers and healthcare professionals beyond the thesis.

4. RISKS AND ETHICAL ISSUES

RESEARCH PARTICIPANTS

A15. What is the sample group or cohort to be studied in this research?

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Select all that apply:

- Blood
- Cancer
- Cardiovascular
- Congenital Disorders
- Dementias and Neurodegenerative Diseases
- Diabetes
- Ear
- Eye
- Generic Health Relevance
- Infection
- Inflammatory and Immune System
- Injuries and Accidents
- Mental Health
- Metabolic and Endocrine
- Musculoskeletal
- Neurological
- Oral and Gastrointestinal
- Paediatrics
- Renal and Urogenital
- Reproductive Health and Childbirth
- Respiratory
- Skin
- Stroke

Gender: Male and female participants

Lower age limit: 11 Years

Upper age limit: 16 Years

A17-1. Please list the principal inclusion criteria (list the most important, max 5000 characters).

- Adolescents with Chronic Pain
- Adolescents with Osteogenesis Imperfecta (OI)
- Between the ages of 11-16

A17-2. Please list the principal exclusion criteria (list the most important, max 5000 characters).

- Anyone who is cognitively unable to engage in the study
- Immunocompromised
- Unable to speak English

RESEARCH PROCEDURES, RISKS AND BENEFITS

A18. Give details of all non-clinical intervention(s) or procedure(s) that will be received by participants as part of the

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research protocol. *These include seeking consent, interviews, non-clinical observations and use of questionnaires.*

Please complete the columns for each intervention/procedure as follows:

1. Total number of interventions/procedures to be received by each participant as part of the research protocol.
2. If this intervention/procedure would be routinely given to participants as part of their care outside the research, how many of the total would be routine?
3. Average time taken per intervention/procedure (minutes, hours or days)
4. Details of who will conduct the intervention/procedure, and where it will take place.

Intervention or procedure	1	2	3	4
Initial information given	1	n/a	10 minutes	Information will be given physically in clinics and also posted out to potential participants by Clinical Staff members at Sheffield Childrens hospital
Informed consent conversation	1	n/a	30 minutes	Informed consent will happen a minimum of a week after the initial information will be given by: Principal Investigator-Rebecca Partridge
Activity pack for outside the workshops (cultural probes)	3	n/a	1 week	These will be conducted in the participants home environments. The Principal Investigator, Rebecca Partridge will brief the participants on these.
Design Practice Workshops	3	n/a	3 hours	These will be run either at Sheffield childrens hospital or at Sheffield Hallam university, depending on suitability of room and space at the time of booking. They will be run by the Principal Investigator-Rebecca Partridge
Self efficacy Questionnaires	2	n/a	30 mins	Self efficacy questionnaires such as the Patient activation measure will be given before and after involvement by: Principal Investigator-Rebecca Partridge
Interviews	2	n/a	30 mins	These will happen before and after participants involvement. The location will be a public place in Sheffield, but has yet to be confirmed as it will be led by where the participant feels comfortable. They will be done by:Principal Investigator-Rebecca Partridge

A21. How long do you expect each participant to be in the study in total?

Participants will be involved in the study from May 2016 to March 2018.

A22. What are the potential risks and burdens for research participants and how will you minimise them?

For all studies, describe any potential adverse effects, pain, discomfort, distress, intrusion, inconvenience or changes to lifestyle. Only describe risks or burdens that could occur as a result of participation in the research. Say what steps would be taken to minimise risks and burdens as far as possible.

Inconvenience.

Being involved in the study could be seen as an inconvenience in terms to having to attend three workshops over a series of weeks, and may impact on their daily lives and routines.

The intention is to run the workshops in a time period that is felt to be appropriate to the participants, the aim is that this will be during their summer holidays 2016. But will be flexible to evenings or weekends, this will be a discussion that takes place with the participants and their parents as part of the informed consent session.

Activity burden

Before the first workshop and between the others participants will given a series of activities to complete. This could be seem as burdensome on their time.

To reduce this the participants will be made aware that their involvement in the project does not rely on them completing the activities, but they are greatly beneficial. The activities will also be fun to do and so should encourage them to participate and bring them enjoyment.

Interview

The interviews will be conducted in an environment that the participants are happy with, and they will be made aware

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that they do not have to answer anything that they are uncomfortable with. The interview questions will be developed with the clinical teams at sheffield children's hospital to consider their appropriateness.

A23. Will interviews/ questionnaires or group discussions include topics that might be sensitive, embarrassing or upsetting, or is it possible that criminal or other disclosures requiring action could occur during the study?

Yes No

A24. What is the potential for benefit to research participants?

Increased knowledge in Design skills
Voicing their views
Increased self efficacy and confidence
Increase in self management behaviours

A26. What are the potential risks for the researchers themselves? (if any)

Emotional engagement/ attachment to the participants and stress.

The researcher has previous experience working with those who have long term conditions and so feels that these will be minimised.

RECRUITMENT AND INFORMED CONSENT

In this section we ask you to describe the recruitment procedures for the study. Please give separate details for different study groups where appropriate.

A27-1. How will potential participants, records or samples be identified? Who will carry this out and what resources will be used? For example, identification may involve a disease register, computerised search of social care or GP records, or review of medical records. Indicate whether this will be done by the direct care team or by researchers acting under arrangements with the responsible care organisation(s).

Potential participants will be identified through their appropriate teams at Sheffield Children's hospital (either the chronic pain service, or Metabolic bone team).

A27-2. Will the identification of potential participants involve reviewing or screening the identifiable personal information of patients, service users or any other person?

Yes No

Please give details below:

A28. Will any participants be recruited by publicity through posters, leaflets, adverts or websites?

Yes No

If Yes, please give details of how and where publicity will be conducted, and enclose copy of all advertising material (with version numbers and dates).

Participants when approached by the clinical team members will be given an information leaflet about the study (See attached-file name).

This leaflet may also be posted to potential participants who are identified, along with the covering letter (see attached-file name)

A29. How and by whom will potential participants first be approached?

Potential participants and their parents will be sent via post an advertisement flyer and Information sheet. Clinical team members will also have flyers and information sheets available during clinical sessions such as therapies and will draw participants' attention to them.

Once participants have received the information they will be given at least a week to consider if they would like to be involved. They can contact the researcher using the contact given on the information sheet. Any participants and their parents who express to clinical team members that they would like to be involved or know any more information will have their contact details passed onto the researcher who will contact them directly to answer any questions they might have. This contact will initially be on the phone but if appropriate could be at the children's hospital or Starbucks located nearby.

A30-1. Will you obtain informed consent from or on behalf of research participants?

Yes No

If you will be obtaining consent from adult participants, please give details of who will take consent and how it will be done, with details of any steps to provide information (a written information sheet, videos, or interactive material). Arrangements for adults unable to consent for themselves should be described separately in Part B Section 6, and for children in Part B Section 7.

If you plan to seek informed consent from vulnerable groups, say how you will ensure that consent is voluntary and fully informed.

The parents/guardian of the adolescent who wishes to take part will give consent to the study and the adolescent will give assent. The consent forms, information flyers and information sheets are all attached with this form. The consent forms also include consent to photography and recordings of the participants. An adolescent may consent to the study and choose not to have their photograph/recording taken.

If you are not obtaining consent, please explain why not.

Please enclose a copy of the information sheet(s) and consent form(s).

A30-2. Will you record informed consent (or advice from consultees) in writing?

Yes No

A31. How long will you allow potential participants to decide whether or not to take part?

Participants will be given at least a week to decide if they want to take part in the study.

A33-1. What arrangements have been made for persons who might not adequately understand verbal explanations or written information given in English, or who have special communication needs?(e.g. translation, use of interpreters)

Those who are unable to speak English will not be involved in the study

A35. What steps would you take if a participant, who has given informed consent, loses capacity to consent during the study? Tick one option only.

- The participant and all identifiable data or tissue collected would be withdrawn from the study. Data or tissue which is not identifiable to the research team may be retained.
- The participant would be withdrawn from the study. Identifiable data or tissue already collected with consent would be retained and used in the study. No further data or tissue would be collected or any other research procedures carried out on or in relation to the participant.
- The participant would continue to be included in the study.
- Not applicable – informed consent will not be sought from any participants in this research.

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Not applicable – it is not practicable for the research team to monitor capacity and continued capacity will be assumed.

Further details:

The nature of the data means that it will not be possible to withdraw all data from the study. For example audio recordings of workshops cannot be destroyed as they will include data from other participants.

In this situation any input to the data from the individual who has withdrawn would not be used.

If you plan to retain and make further use of identifiable data/tissue following loss of capacity, you should inform participants about this when seeking their consent initially.

CONFIDENTIALITY

In this section, personal data means any data relating to a participant who could potentially be identified. It includes pseudonymised data capable of being linked to a participant through a unique code number.

Storage and use of personal data during the study

A36. Will you be undertaking any of the following activities at any stage (including in the identification of potential participants)? (Tick as appropriate)

- Access to medical records by those outside the direct healthcare team
- Access to social care records by those outside the direct social care team
- Electronic transfer by magnetic or optical media, email or computer networks
- Sharing of personal data with other organisations
- Export of personal data outside the EEA
- Use of personal addresses, postcodes, faxes, emails or telephone numbers
- Publication of direct quotations from respondents
- Publication of data that might allow identification of individuals
- Use of audio/visual recording devices
- Storage of personal data on any of the following:
 - Manual files (includes paper or film)
 - NHS computers
 - Social Care Service computers
 - Home or other personal computers
 - University computers
 - Private company computers
 - Laptop computers

Further details:

The use of personal addresses, emails and telephone numbers will be used to send potential participants information on the study, these will not be seen or used outside of the clinical care team until participants have consented and given the researcher their preferred method of contact.

Publication of direct quotes will be during dissemination.

A37. Please describe the physical security arrangements for storage of personal data during the study?

The use of personal addresses, emails and telephone numbers will be used to send potential participants

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information on the study, these will not be seen or used outside of the clinical care team until participants have consented and given the researcher their preferred method of contact.

Once personal data is used outside of the clinical care team it will be stored securely at the university. Any physical copies of information with personal or identifiable data on them including interview, video or audio notes will be kept in a locked filing cabinet at the university any digital copies of the information will be kept on a university computer on the central research data file storage Q drive.

Participants will consent to the use of photography video recording for the study, they will be made aware that no images taken will be used for dissemination or publicity without their further consent.

If for any reason this data needs to be taken away (for example interview recordings on a Dictaphone) it will be de-identified for both physical and digital copies, in addition digital copies will be password protected or digitally encrypted to ensure safety in the unfortunate event that they are misplaced. The only people that will have access to these passwords will be the researcher and members of the supervisory team

A38. How will you ensure the confidentiality of personal data? Please provide a general statement of the policy and procedures for ensuring confidentiality, e.g. anonymisation or pseudonymisation of data.

Once personal data is used outside of the clinical care team it will be stored securely at the university. Any physical copies of information with personal or identifiable data on them including interview, video or audio notes will be kept in a locked filing cabinet at the university any digital copies of the information will be kept on a university computer on the central research data file storage Q drive.

Participants will consent to the use of photography video recording for the study, they will be made aware that no images taken will be used for dissemination or publicity without their further consent.

If for any reason this data needs to be taken away (for example interview recordings on a Dictaphone) it will be de-identified for both physical and digital copies, in addition digital copies will be password protected or digitally encrypted to ensure safety in the unfortunate event that they are misplaced. The only people that will have access to these passwords will be the researcher and members of the supervisory team.

Exceptional circumstances where confidentiality may not be preserved include any points where safeguarding or duty of care issues arises. Participants will be made aware of this in the consent process and they will agree to this within the assent form. Participants will be encouraged to share any safeguarding information with an appropriate person who can help such as their parents or clinical care team. Or they might agree that the researcher can share this information on their behalf. In exceptional circumstances the researcher will share this information without speaking to the participant, they will discuss the appropriateness of this with their supervisor first.

A40. Who will have access to participants' personal data during the study? Where access is by individuals outside the direct care team, please justify and say whether consent will be sought.

No personal data will be used outside of the clinical care team until after consent is given. After that the following people will have access:

The lead researcher
Supervisors of the lead researcher
Members of the clinical team at the hospital

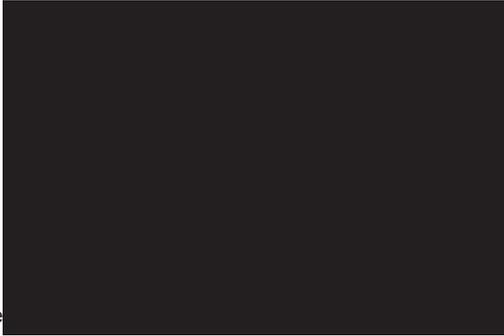
Storage and use of data after the end of the study

A41. Where will the data generated by the study be analysed and by whom?

The data will be analysed by the lead researcher in the UK, at the university or at the lead researchers home address. All personal data will be de-identified before it leaves the university.

A42. Who will have control of and act as the custodian for the data generated by the study?

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Post	
Qualifications	
Work Address	
Post Code	
Work Email	
Work Telephone	
Fax	

A43. How long will personal data be stored or accessed after the study has ended?

- Less than 3 months
- 3 – 6 months
- 6 – 12 months
- 12 months – 3 years
- Over 3 years

A44. For how long will you store research data generated by the study?

Years: 5

Months:

A45. Please give details of the long term arrangements for storage of research data after the study has ended. Say where data will be stored, who will have access and the arrangements to ensure security.

Research data will be stored in line with Sheffield Hallam Universities procedures. The universities research data archive will be used to archive all data for a period of 5 years post the completion of the PhD to allow for further analysis and review and aid any future queries or disputes regarding intellectual property, research conduct or the actual results of the research. This will include original digital and audio recordings as well as any transcripts.

Any research images, recordings and videos will be destroyed 5 years after the study. However any that were used during publication and dissemination will not be destroyed.

INCENTIVES AND PAYMENTS

A46. Will research participants receive any payments, reimbursement of expenses or any other benefits or incentives for taking part in this research?

- Yes No

If Yes, please give details. For monetary payments, indicate how much and on what basis this has been determined.

Participants will be offered a £20 high street voucher as a thank you for their time and involvement and to value them taking part. They will also be offered £20 towards the expenses of travelling to the workshops. This is proportionate to the time commitment and based on the average taxi journey to and from the Hospital or University.

A47. Will individual researchers receive any personal payment over and above normal salary, or any other benefits or incentives, for taking part in this research?

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Yes No

A48. Does the Chief Investigator or any other investigator/collaborator have any direct personal involvement (e.g. financial, share holding, personal relationship etc.) in the organisations sponsoring or funding the research that may give rise to a possible conflict of interest?

Yes No

NOTIFICATION OF OTHER PROFESSIONALS

A49-1. Will you inform the participants' General Practitioners (and/or any other health or care professional responsible for their care) that they are taking part in the study?

Yes No

If Yes, please enclose a copy of the information sheet/letter for the GP/health professional with a version number and date.

PUBLICATION AND DISSEMINATION

A50-1. Will the research be registered on a public database?

Yes No

Please give details, or justify if not registering the research.

This is not a clinical trial so not appropriate and no other suitable clinical register exists at this time

Registration of research studies is encouraged wherever possible.

You may be able to register your study through your NHS organisation or a register run by a medical research charity, or publish your protocol through an open access publisher. If you are aware of a suitable register or other method of publication, please give details. If not, you may indicate that no suitable register exists. Please ensure that you have entered registry reference number(s) in question A5-1.

A51. How do you intend to report and disseminate the results of the study? Tick as appropriate:

- Peer reviewed scientific journals
- Internal report
- Conference presentation
- Publication on website
- Other publication
- Submission to regulatory authorities
- Access to raw data and right to publish freely by all investigators in study or by Independent Steering Committee on behalf of all investigators
- No plans to report or disseminate the results
- Other (please specify)

A52. If you will be using identifiable personal data, how will you ensure that anonymity will be maintained when publishing the results?

Not applicable

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A53. Will you inform participants of the results?

Yes No

Please give details of how you will inform participants or justify if not doing so.

The participants will be consulted as part of the study as to how they would like to be informed of the results, so it is unknown at this point.

5. Scientific and Statistical Review

A54-1. How has the scientific quality of the research been assessed? Tick as appropriate:

- Independent external review
- Review within a company
- Review within a multi-centre research group
- Review within the Chief Investigator's institution or host organisation
- Review within the research team
- Review by educational supervisor
- Other

Justify and describe the review process and outcome. If the review has been undertaken but not seen by the researcher, give details of the body which has undertaken the review:

For all studies except non-doctoral student research, please enclose a copy of any available scientific critique reports, together with any related correspondence.

For non-doctoral student research, please enclose a copy of the assessment from your educational supervisor/ institution.

A59. What is the sample size for the research? How many participants/samples/data records do you plan to study in total? If there is more than one group, please give further details below.

Total UK sample size: 10

Total international sample size (including UK):

Total in European Economic Area:

Further details:

A60. How was the sample size decided upon? If a formal sample size calculation was used, indicate how this was done, giving sufficient information to justify and reproduce the calculation.

Specific conditions
Small sample groups
Availability of people (opportunity sampling)
Anyone within inclusion criteria able to be involved
Aiming for 5 from each condition-good size for workshop groups
10 total for discussion data

A62. Please describe the methods of analysis (statistical or other appropriate methods, e.g. for qualitative research) by which the data will be evaluated to meet the study objectives.

Due to the iterative nature of the research other data analysis methods may be necessary throughout the study.

The qualitative data will be organised into themes for discussion within the thesis. Interviews and audio recordings will be transcribed to allow this. This will be done manually, however use of the software Nvivo may be sought to confirm and check the themes. These themes will be used to look for patterns within the data and will lead into categories for discussion in the study.

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With any visual data produced these will undergo visual analysis, exploring the imagery and looking for themes within the pictures/drawings/models.

6. MANAGEMENT OF THE RESEARCH

A63. Other key investigators/collaborators. Please include all grant co-applicants, protocol co-authors and other key members of the Chief Investigator's team, including non-doctoral student researchers.

Title	Forename/Initials	Surname
Post		
Qualifications		
Employer		
Work Address		
Post Code		
Telephone		
Fax		
Mobile		
Work Email		

A64. Details of research sponsor(s)

A64-1. Sponsor

Lead Sponsor		
Status:	<input type="radio"/> NHS or HSC care organisation	Commercial status:
	<input checked="" type="radio"/> Academic	
	<input type="radio"/> Pharmaceutical industry	
	<input type="radio"/> Medical device industry	
	<input type="radio"/> Local Authority	
	<input type="radio"/> Other social care provider (including voluntary sector or private organisation)	
	<input type="radio"/> Other	
	<i>If Other, please specify:</i>	
Contact person		
Name of organisation		
Given name		
Family name		

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Address Town/city Post code Country Telephone Fax E-mail
Is the sponsor based outside the UK? <input type="radio"/> Yes <input type="radio"/> No
<i>Under the Research Governance Framework for Health and Social Care, a sponsor outside the UK must appoint a legal representative established in the UK. Please consult the guidance notes.</i>

A65. Has external funding for the research been secured? <input checked="" type="checkbox"/> Funding secured from one or more funders <input type="checkbox"/> External funding application to one or more funders in progress <input type="checkbox"/> No application for external funding will be made
What type of research project is this? <input type="radio"/> Standalone project <input type="radio"/> Project that is part of a programme grant <input type="radio"/> Project that is part of a Centre grant <input checked="" type="radio"/> Project that is part of a fellowship/ personal award/ research training award <input type="radio"/> Other
Other – please state:
Please give details of funding applications.
Organisation Sheffield Hallam University Address
Post Code Telephone Fax Mobile Email
Funding Application Status: <input checked="" type="radio"/> Secured <input type="radio"/> In progress
Amount:
Duration Years:

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Months:

If applicable, please specify the programme/ funding stream:

What is the funding stream/ programme for this research project?

GTA PhD Scholarship at Sheffield Hallam University

A66. Has responsibility for any specific research activities or procedures been delegated to a subcontractor (other than a co-sponsor listed in A64-1) ? Please give details of subcontractors if applicable.

Yes No

A67. Has this or a similar application been previously rejected by a Research Ethics Committee in the UK or another country?

Yes No

Please provide a copy of the unfavourable opinion letter(s). You should explain in your answer to question A6-2 how the reasons for the unfavourable opinion have been addressed in this application.

A68-1. Give details of the lead NHS R&D contact for this research:

Title Forename/Initials Surname

Organisation
Address

Post Code
Work Email
Telephone
Fax
Mobile

Details can be obtained from the NHS R&D Forum website: <http://www.rdforum.nhs.uk>

A69-1. How long do you expect the study to last in the UK?

Planned start date: 01/05/2016

Planned end date: 01/04/2018

Total duration:

Years: 1 Months: 10 Days: 1

A71-1. Is this study?

Single centre
 Multicentre

A71-2. Where will the research take place? (Tick as appropriate)

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Note: in this question to NHS indemnity schemes include equivalent schemes provided by Health and Social Care (HSC) in Northern Ireland

A76-1. What arrangements will be made for insurance and/or indemnity to meet the potential legal liability of the sponsor(s) for harm to participants arising from the management of the research? Please tick box(es) as applicable.

Note: Where a NHS organisation has agreed to act as sponsor or co-sponsor, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For all other sponsors, please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (NHS sponsors only)
 Other insurance or indemnity arrangements will apply (give details below)

Please enclose a copy of relevant documents.

A76-2. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of the sponsor(s) or employer(s) for harm to participants arising from the design of the research? Please tick box(es) as applicable.

Note: Where researchers with substantive NHS employment contracts have designed the research, indemnity is provided through NHS schemes. Indicate if this applies (there is no need to provide documentary evidence). For other protocol authors (e.g. company employees, university members), please describe the arrangements and provide evidence.

- NHS indemnity scheme will apply (protocol authors with NHS contracts only)
 Other insurance or indemnity arrangements will apply (give details below)

Please enclose a copy of relevant documents.

A76-3. What arrangements will be made for insurance and/ or indemnity to meet the potential legal liability of investigators/collaborators arising from harm to participants in the conduct of the research?

Note: Where the participants are NHS patients, indemnity is provided through the NHS schemes or through professional indemnity. Indicate if this applies to the whole study (there is no need to provide documentary evidence). Where non-NHS sites are to be included in the research, including private practices, please describe the arrangements which will be made at these sites and provide evidence.

- NHS indemnity scheme or professional indemnity will apply (participants recruited at NHS sites only)
 Research includes non-NHS sites (give details of insurance/ indemnity arrangements for these sites below)

Please enclose a copy of relevant documents.

A78. Could the research lead to the development of a new product/process or the generation of intellectual property?

- Yes No Not sure

PART B: Section 7 - Children

1. Please specify the potential age range of children under 16 who will be included and give reasons for carrying out the research in this age group.

The study will include adolescents from the ages of 11-16.

The decision to work with adolescents has been influenced by reading and research around the idea that adolescents are under researched in healthcare. Adolescence is also a time when the transition of self-management behaviours moves from the parent/caregiver to them. It is also a time of increased risk taking behaviours, so an appropriate to look at self management

Design Practice as a tool in self-management to explore complex issues and change mindsets an emerging field of study, and has yet to be explored with adolescents. Design methods have been used extensively in other areas of industry such as management, marketing and education where it is seen as an innovating force to create change in complex situations.

The focus of adolescents in this study is supported by the report; Our Children Deserve Better; Prevention Pays (Davies, 2013) which recognises that young people today face great challenges and are not doing as well as they could. Adolescence is an age of increased risk taking behaviour, significant developmental change and increased desire for autonomy. It recommends equipping young people living with long-term conditions with the skills and knowledge to navigate the complexities of life and improve health outcomes. Susan Sawyer (date) supports this stating that adolescents are under represented in healthcare research, usually grouped with children or adults, they need a category of their own.

2. Indicate whether any children under 16 will be recruited as controls and give further details.

There will be no control group in this study

3-2. Please describe the arrangements for seeking informed consent from a person with parental responsibility and/or from children able to give consent for themselves.

Potential participants and their parents will be sent via post an advertisement flyer and Information sheet. Clinical team members will also have flyers and information sheets available during clinical sessions such as therapies and will draw participants' attention to them.

Once participants have received the information they will be given at least a week to consider if they would like to be involved. They can contact the researcher using the contact given on the information sheet. Any participants and their parents who express to clinical team members that they would like to be involved or know any more information will have their contact details passed onto the researcher who will contact them directly to answer any questions they might have. This contact will initially be on the phone but if appropriate could be at the children's hospital or Starbucks located nearby.

The parents/guardian of the adolescent who wishes to take part will give consent to the study and the adolescent will give assent. The consent forms, information flyers and information sheets are all attached with this form. The consent forms also include consent to photography and recordings of the participants. An adolescent may consent to the study and choose not to have their photograph/recording taken.

4. If you intend to provide children under 16 with information about the research and seek their consent or agreement, please outline how this process will vary according to their age and level of understanding.

Children under 16 will receive an advertisement flyer and an information sheet. The information on these is the same information that their parents will receive.

The study itself uses methods which are understandable and familiar to the participants, they will have knowledge of workshops and interviews etc.

The age group of 11-15 will have significant levels of understanding for the terms in the information sheet and the study itself. The information sheet has been written in lay terms and terms have been clarified throughout.

Copies of written information sheet(s) for parents and children, consent/assent form(s) and any other explanatory material should be enclosed with the application.

A10. What is the principal research question/objective? Please put this in language comprehensible to a lay person.

To increase the knowledge and skills of design practise in adolescents who live with a long term condition.

A11. What are the secondary research questions/objectives if applicable? Please put this in language comprehensible to a lay person.

Secondary questions:

How can design practice explore and visualise issues around self-management?

Does learning about design practice increase engagement in self-management behaviours?

Objectives:

To increase participants knowledge of the design process

To gain insight into participant's lives, how they self-manage and what challenges they might face.

To develop methods that work in a healthcare context

Explore where design practice could fit within a medical model of self-management

A12. What is the scientific justification for the research? Please put this in language comprehensible to a lay person.

Long-term conditions are a huge financial cost to the NHS, and with an estimated 15 million people in the UK living with a one, effective self management is important not only for better quality of life for patients, but also to reduce NHS resources and costs.

The Department of health's 2013 report; Our Children Deserve Better; Prevention Pays (Davies, 2013), recommends equipping children and young people (adolescents) living with long-term conditions with the skills and knowledge to navigate the complexities of life and improve health outcomes. In addition, Susan Sawyer in a series of articles in 2012 explored the health outlook for adolescents, and found that they are often forgotten about in healthcare research; either grouped with children or adults, they are rarely focused on individually. This is concerning as adolescents present with very individual challenges to both children and adults. Adolescence is an age of increasing autonomy along with an increase in risk taking behaviours, combined these can lead to lower levels of health, and for those who have long-term conditions, lower participation in the activities needed to maintain their health.

Through Design Practice, this study seeks to explore self-management with adolescents and see if it can have a positive influence on participants to engage in self-management behaviours at this transitional stage in their development.

Design practice has had excellent results as an innovative force in other areas of industry. There are a variety of terms to describe Design practice, one of which 'Design Thinking' was first described by Tim Brown (Brown, 2009), who believes that thinking like a designer can transform the way organisations develop products, services, processes and strategy.

Another definition is; 'having an understanding of the approaches and methods of design and applying these to think creatively about complex problems, posing questions and suggesting ways to solve them. It is about developing a long-term creative and explorative mind-set through skills such as lateral thinking, prototyping and verbal and visual communication. Design thinking uses design as a process as well as a result.' (Shine 2012 report, 2014). Design brings together people from different backgrounds, flattens hierarchies and gives a framework for people to work within.

Emily Campbell (2009) talks of design as resourcefulness, and the need for designers to share their skills with society in order to close the gap between our behaviour and aspirations, to enable us to be more resourceful and self-reliant. Gjoko Muratovski, 2016, speaks of the changing face of design, the ever-complex problems that designers face and a movement from 'product creation' to 'process creation'. Using design as a 'thinking process' for complex problems is still a new concept in healthcare, however tool kits have been developed to use design methods in education, schools, businesses and by students for innovation.

The studies that have explored these ideas in healthcare have done so with positive results. The RSA piloted a training programme to teach design to people with spinal cord injuries as a route to independence, resourcefulness and to have greater control over their lives (Campbell 2011). The programme left patients thinking more creatively about problem solving and they reported increased confidence and independence. The Art and Design Research Centre at Sheffield Hallam University have undertaken further work in this area in two projects. The first ran exploratory inpatient design thinking sessions at the Princess Royal Spinal injuries centre, and the second introduced a design thinking sessions as part of the rehabilitation programme offered at the unit. Qualitative feedback from both of these found that patients had a change in perspective on problem solving, had more confidence to try different ideas and solutions and think creatively, they also found it a mental stimulation they didn't receive from other therapies. Quantitative data

Appendix Three: NHS ethics approval forms (IRAS)

showed statistically significant positive changes on self-efficacy measures, leading to the conclusion that design thinking workshops as part of rehabilitation can increase self efficacy and engagement in self-management behaviours in people with a spinal cord injury.

With promising initial research into how design practice can support patients with complexities in their lives, and a need to support adolescents in their self-management at a complex time in their lives. This study intends to explore these issues together.

A13. Please summarise your design and methodology. *It should be clear exactly what will happen to the research participant, how many times and in what order. Please complete this section in language comprehensible to the lay person. Do not simply reproduce or refer to the protocol. Further guidance is available in the guidance notes.*

The study will use a mixed methods approached based on design research methods that come from a constructivist approach.

Participants are consenting to be involved in a study, which explores how design could support them in the self-management of their long-term condition through a variety of methods. Amongst others ways, support in this context refers to;

- Allowing participants to voice, share and display their views using creative methods
- Explore challenges they might face within their self-management
- Increase their confidence to problem solve to overcome some of these challenges
- Increase active self-management behaviours such as;
 - o Controlling diet,
 - o Undertaking physiotherapy
 - o Sharing and seeking appropriate help within environments such as schools, taking control of medications and so forth)

The study uses design research methods, which differ from the design technology that participants will likely have experienced in school, these generally focus around developing an idea for an object, drawing and then building it. The focus in this study is Design as a mind-set or an everyday skill for engaging in creative thinking, asking how and why things are, problem solving and communicating our ideas.

Participant involvement in the study will last around 6-8 months during this time they will be interviewed twice, invited to a maximum of 4 workshops, complete a questionnaire and be given some activities (based on the cultural probe method) to do at home. Involvement in this study is in addition to and will have no effect on the usual treatment they might receive as part of clinical care.

Workshops

The workshops will be in groups of around 4-5 adolescents who have the same condition, and will cover a series of strategies that allow participants an insight into the process of design practice and allow them to see how it might fit within their own lives.

During these participants will be given the opportunity to talk about their experiences and share their views both as a group and individually. There will be activities during these workshops that will explore and develop their design skills. The workshops will last up to 3 hours at a time, and will be in Sheffield.

The final workshop design has yet to be completed as it is intended to be iterative to respond to the participants' interests and needs. The first workshop will be an introductory session to the study (see overview below). Subsequent workshops will be developed in response to outcomes and discussions from the previous ones.

Introductory session overview:

- Introducing ourselves
 - o Who are we
 - o What are our design skills
- Aims/goals
 - o What do we want out of the sessions?
 - o What do we think we might do?
 - o Is there anything we do/don't want to do
 - o Any fears or worries about the project
- What is Design
 - o What is good/bad design
 - o How does Design affect us
 - o What different types of design are there
 - o Where do we encounter design
- What does self-management mean?
 - o What is my condition

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- o What does self-management mean to me?
- o What self-management behaviours do I have to do?
- o Where is it hard/easy
- o How will it change, as I get older?
- o How confident do I feel about self management
- Design councils-double diamond-what is the design process
- o Explanation of design practice and process and how it fits with the sessions.

Subsequent sessions will cover design skills such as:

- Having empathy
- Gaining perspective
- Seeing the 'whole' of something
- How do I know what the problem is
- Creative thinking
- Communication of ideas
- Prototyping
- Teamwork

Below are examples of the types of activities that might be used to cover these:

- Challenges (how many circles can you turn into objects in 2 minutes)
- Design projects(if you combined a rollerskate and a water bottle what would you get)
- General activities (order these words from most important to last important)
- Games (such as the card game taboo)
- Discussion/ feedback groups,
- Presentations
- Drawings

These workshops will be audio recorded, and photographs will be taken throughout. The recordings will be analysed along with any outputs.

Home activities (based on the cultural probe method)

In order to illicit responses from participants about their lives and experiences, throughout the study participants will be given activities to complete at home, this will happen no more than 3 times. The first time will be before the study begins, once during the workshop time period and once at the end of the study.

Designed to give insight to the researcher and allow participants another way of expression, as words can be hard.

Examples of what participants might be asked to do include;

- Keeping a short diary
- Taking pictures of favourite places
- Fill in a colour chart of emotions
- Mark places on a map

Interviews

Participants will be interviewed before they partake in any of the activities for the study. This will be done either on the phone or in person. The interviews will be semi structured and based around their experiences, what they know design to be and how they self-manage.

This interview will be repeated after their involvement in the study. This will be a repetition of the previous interview with the addition of a section to understand their experience of the workshops.

These interviews will then be transcribed and a thematic analysis will take place.

Questionnaires

At the end of each workshop and activity the participants will be given a short questionnaire to share their views on what they have done.

The researcher also intends to use the Patient Activation measure to look at scores of self-efficacy and readiness to engage in self-management behaviours.



Health Research Authority

Miss Rebecca Partridge
[Redacted]

Email: hra.approval@nhs.net

25 October 2016

Dear Miss Partridge

Letter of HRA Approval

Study title: Exploring the role of applied design practice in supporting adolescents with long term conditions
IRAS project ID: 196207
REC reference: 16/LO/1000
Sponsor: Sheffield Hallam University

I am pleased to confirm that **HRA Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications noted in this letter.

Participation of NHS Organisations in England

The sponsor should now provide a copy of this letter to all participating NHS organisations in England.

Appendix B provides important information for sponsors and participating NHS organisations in England for arranging and confirming capacity and capability. **Please read *Appendix B* carefully**, in particular the following sections:

- *Participating NHS organisations in England* – this clarifies the types of participating organisations in the study and whether or not all organisations will be undertaking the same activities
- *Confirmation of capacity and capability* - this confirms whether or not each type of participating NHS organisation in England is expected to give formal confirmation of capacity and capability. Where formal confirmation is not expected, the section also provides details on the time limit given to participating organisations to opt out of the study, or request additional time, before their participation is assumed.
- *Allocation of responsibilities and rights are agreed and documented (4.1 of HRA assessment criteria)* - this provides detail on the form of agreement to be used in the study to confirm capacity and capability, where applicable.

Further information on funding, HR processes, and compliance with HRA criteria and standards is also provided.

It is critical that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

IRAS project ID	196207
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Appendices

The HRA Approval letter contains the following appendices:

- A – List of documents reviewed during HRA assessment
- B – Summary of HRA assessment

After HRA Approval

The document “*After Ethical Review – guidance for sponsors and investigators*”, issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

In addition to the guidance in the above, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the [HRA website](#), and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the [HRA website](#).

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at <http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/>.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

Appendix Five: SCH protocol for site specific approvals

Following NHS Research Ethics and HRA approval, local site approvals were required, and applied for using the following form. Personal Details and some sections not relevant to the study have been removed.



FULL STUDY TITLE

Design and chronic conditions; A Qualitative study using Design Practice to explore the activation of adolescents in self management techniques who have Chronic Pain and Osteogenesis Imperfecta.

SHORT STUDY TITLE

Design and chronic conditions; Exploring the activation of adolescents in self management

STUDY NUMBER (you will obtain this on registration)

DATE AND VERSION NUMBER

14th February 2016
Version 1

Sponsor's Representative Dated

Chief Investigator Dated

LAY SUMMARY (max 300 words)

The use of design practice to explore self-management in adolescents with long-term conditions

This PhD study funded by Sheffield Hallam University will run design workshops with adolescents who have chronic pain and Osteogenesis Imperfecta (OI).

Design Practice as a tool in self-management to explore complex issues and change mindsets an emerging field of study, and has yet to be explored with adolescents. Design methods have been used extensively in other areas of industry such as management, marketing and education where it is seen as an innovating force to create change in complex situations.

The focus of adolescents in this study is supported by the report; Our Children Deserve Better; Prevention Pays (Davies, 2013) which recognises that young people today face great challenges and are not doing as well as they could. Adolescence is an age of increased risk taking behaviour, significant developmental change and increased desire for autonomy. It recommends equipping young people living with long-term conditions with the skills and knowledge to navigate the complexities of life and improve health outcomes. Susan Sawyer (2014) supports this stating that adolescents are under represented in healthcare research, usually grouped with children or adults, they need a category of their own.

Principal Research Question/objective:

To increase the knowledge and skills of design practice in adolescents who live with a long term condition.

Research Questions:

- How can design practice explore and visualise issues around self-management?
- Does learning about design practice increase engagement in self-management behaviours?

Study aims:

- To increase participants knowledge of the design process
- To gain insight into participant's lives, how they self-manage and what challenges they might face.
- To develop methods that work in a healthcare context
- Explore where design practice could fit within a medical model of self-management

Recruited through Sheffield Children's hospital, participants will go through a series of workshops and activities that will cover strategies to allow participants an insight into the process of design practice and allow them to see how it might fit within their own lives.

1.0 **BACKGROUND (max 600 words)**

A long-term condition is one that cannot, at present, be cured, but can be controlled by medication and other therapies. The management of these is a huge cost to the NHS with an estimated 15 million people in the UK living with a long term condition, effective self-management results in a better quality of life for patients, reduced use of NHS resources and in turn, reduced healthcare costs.

The Department of health's 2013 report; Our Children Deserve Better; Prevention Pays (Davies, 2013), recommends equipping children and young people living with long-term conditions with the skills and knowledge to navigate the complexities of life and improve health outcomes. It is widely evidenced that events that happen in early life affect health and wellbeing in later life, the report recognises that young people today face great challenges and are not doing as well as they could.

This is innovative research that uses applied design practice in a context that it has not been before; with a group of participants who are underrepresented (adolescents) in healthcare research and who could benefit from the potential positive outcomes of the research.

Susan Sawyer in a series of articles in 2012 for the lancet explored the health outlook for adolescents, how they are often forgotten about in healthcare research; either placed with children or adults they are rarely put in a category of their own. However adolescents present with very individual challenges to both children and adults as they go through increased change in their own lives. Adolescence is an age where people develop their autonomy, and have an increase in risk taking behaviours, these can lead to lower levels of health, and for those who have long term conditions, lower participation in the activities needed to maintain their health. Susan summarises her series of articles with the conclusion that there is a need to explore specific health interventions for adolescents.

This research seeks to find out if engaging in design practice can have a positive influence on participants to engage in self-management behaviours at this transitional stage in their development.

Design practice has had excellent results as an innovative force in other areas of industry. There are a variety of terms to describe design practice, one of which is 'Design Thinking' that was first described by Tim Brown (Brown, 2009), who believes that thinking like a designer can transform the way organisations develop products, services, processes and strategy.

A further definition is; Design Thinking is understanding the approaches and methods that designers use and applying these to think creatively about problems, posing questions and suggesting ways to solve them. It is developing a long-term creative and explorative mind-set through skills such as lateral thinking, prototyping and verbal and visual communication (Shine 2012 report, 2014). It brings together people from all backgrounds, flattens hierarchies and gives a framework for people to work within. Design thinking is about using design as a

process as well as a result. Emily Campbell (2009) talks of design as resourcefulness, and the need for designers to share their skills with society in order to close the gap between our behaviour and aspirations, making us more resourceful and self-reliant. These two ideas; design as resourcefulness and using the methods and approaches of designers to pose questions and solutions, have not had much exploration in a healthcare setting, however tool kits have been developed for use in education, schools, businesses and by students for innovation. The studies that have explored these ideas in healthcare have done so with positive results. The RSA piloted a training programme to teach design to people with spinal cord injuries as a route to independence, resourcefulness and to have greater control over their lives (Campbell 2011). The programme left patients thinking more creatively about problem solving and they reported increased confidence and independence. The Art and Design Research Centre at Sheffield Hallam University have undertaken further work in this area. The first ran inpatient design thinking sessions at the Princess Royal Spinal injuries centre, qualitative feedback from these pointed towards a change in perspective on problem solving, and confidence to think more creatively. Patients also mentioned enjoyment to engage in a different sort of activity at the unit (Craig et al, 2013) The second body of work by Sheffield, funded by The Health Foundation, introduced design thinking workshops to increase self-efficacy as part of the rehabilitation programme offered at the unit. Using the double diamond tool (Design Council 2005) as a framework to structure the sessions around, qualitative data found patients had increased confidence in problem solving, and resourcefulness, were thinking more creatively trying 'out of the box' idea's, and similar to the previous work found it to be a mental stimulation they didn't receive from other therapies. Quantitative data showed statistically significant positive changes on self-efficacy measures, leading to the conclusion that design thinking workshops as part of rehabilitation can increase self efficacy in people with a spinal cord injury which in turn encourages them to engage in self management behaviours.

- A clear explanation of the main research question i.e. the hypothesis to be tested.
- Explanation of why the study is appropriate, potential benefits to patients/health.
- Service, relevance to current policies and priorities.
- Description of the indication, its diagnosis, incidence, current treatments and their limitations.
- Description of the treatment under investigation including reference to any previous evidence of its usefulness.
- A statement of what would be a worthwhile improvement in study outcomes.
- What evidence there is that the treatment under investigation may achieve this?

2.0 **STUDY OBJECTIVES AND PURPOSE (max 300 words)**

To increase the knowledge and skills of design practise in adolescents who live with a long term condition.

Secondary questions:

How can design practice explore and visualise issues around self-management?

Does learning about design practice increase engagement in self-management behaviours?

Objectives:

To increase participants knowledge of the design process

To gain insight into participant's lives, how they self-manage and what challenges they might face.

To develop methods that work in a healthcare context

Explore where design practice could fit within a medical model of self-management

- State the purpose of performing the study (e.g. student project, commercial/non commercial trial, licensing).
- State the primary and secondary objectives

3.0 **STUDY DESIGN (max 600 words)**

The participants will be involved in the design of the research, as each workshop will develop on from the next, with input from the participants on aspects/activities they would like to explore further.

I will engage them in the dissemination to explore ways of sharing the findings with peers and healthcare professionals beyond the thesis.

Participants will be involved in the study from May 2016 to March 2018.

The workshops will cover a series of strategies that allow participants an insight into the process of design practice, and allow them to see how it might fit within their own lives. The final workshop plan will be immersive as the study progresses. This is to allow it to be responsive to the participants' wants and needs.

There will be an introductory session to the study either conducted in a group or individually (depending on availability) subsequent workshops will be developed in response to outcomes and discussions from the previous ones.

Below is an overview of the sorts of topics and strategies that will be covered. They might take the form of challenges, design projects, general activities, games, discussion/ feedback groups, and presentations, drawings etc.

Introductory session:

Appendix Five: SCH protocol for site specific approvals

- Introducing ourselves
 - Who are we
 - What are our design skills
- Aims/goals etc
 - What do we want out of the sessions?
 - What do we think we might do?
 - Is there anything we do/don't want to do
 - Any fears or worries about the project
- What is Design
 - What is good/bad design
 - How does Design affect us
 - What different types of design are there
 - Where do we encounter design
- What does self-management mean?
 - What is my condition
 - What does self-management mean to me?
 - What self-management behaviours do I have to do?
 - Where is it hard/easy
 - How will it change, as I get older?
 - How confident do I feel about self management
- Design councils-double diamond-what is the design process
 - Explanation of design practice and process and how it fits with the sessions.

Subsequent sessions will cover:

- Design Skills
 - Having empathy
 - Gaining perspective
 - Seeing the 'whole' of something
 - How do I know what the problem is
 - Creative thinking
 - Communication of ideas
 - Prototyping
 - Teamwork

Inconvenience.

Being involved in the study could be seen as an inconvenience in terms to having to attend three workshops over a series of weeks, and may impact on their daily lives and routines.

The intention is to run the workshops in a time period that is felt to be appropriate to the participants, the aim is that this will be during their summer holidays 2016. But will be flexible to evenings or weekends, this will be a discussion that takes place with the participants and their parents as part of the informed consent session.

Activity burden

Before the first workshop and between the others participants will given a series of activities to complete. This could be seem as burdensome on their time.

To reduce this the participants will be made aware that their involvement in the project does not rely on them completing the activities, but they are greatly beneficial. The activities will also be fun to do and so should encourage them to participate and bring them enjoyment.

Interview

Appendix Five: SCH protocol for site specific approvals

The interviews will be conducted in an environment that the participants are happy with, and they will be made aware that they do not have to answer anything that they are uncomfortable with. The interview questions will be developed with the clinical teams at sheffield children's hospital to consider their appropriateness.

Under researched group

The scientific integrity of a study and the credibility of results obtained are largely dependent upon the study design. A description of the study design should include the following:

- A description of the type/design of the study, e.g. double-blind, placebo controlled, parallel design, etc.
- Plans for actively involving patients, service users, and/or their carers, or members of the public in aspects of the research process (including design, management, undertaking the research, analysis, dissemination.) If no involvement please justify.
- Summary of treatments being compared with reasons for choice of comparison group.
- The expected length of time for which each participant will participate in the study for and the sequence and duration of all study periods.
- Description of all procedures (sequentially) to be performed, identifying what is standard and non-standard care where possible.
- The criteria for discontinuation of parts of the study or the entire study.
- A schematic diagram of the study design, procedures and stages (can be in a form of a table).
- The study will start with the first patient's Informed Consent signed.
- The last patient's last protocol-defined assessment will mark the as the end of the study.

Primary and Secondary Endpoints

- A specific statement of the primary and secondary endpoints, if any, to be measured during the study.

General Information

- Summary of known and potential risks and benefits to human participants.

Use within the study

- Detail of who will be performing the treatments.
- Is the treatment invasive/does it involve radioactive substances?
- Arrangements for continuation of treatment for study participants after the end of the study.

4.0 **SELECTION OF PARTICIPANTS (max 300 words)**

Potential participants will be identified through their appropriate teams at Sheffield Children's hospital (either the chronic pain service, or Metabolic bone team). The researcher has been working closely with these teams developing links.

Any members of these services who fit the inclusion criteria of an OI/ Chronic pain diagnosis between the ages of 11-15 will be informed of the research by a therapist or nurse from the team, using information leaflets.

Any participants who are interested will then have their contact details passed onto the researcher who will contact them directly to answer any questions they might have and consent them to the study.

Participants when approached by the clinical team members will be given an information leaflet about the study (See attached-file name).

This leaflet may also be posted to potential participants who are identified, along with the covering letter (see attached-file name)

The researcher will meet with the potential participants individually with their parent/caregiver where appropriate. They will explain the study verbally and also have written information for the participants to take away.

Potential participants will be able to consent at that point or take the time to consider the study further and consent at a later date.

Both the parents and the adolescent will need to consent to the study.

- Adolescents with Chronic Pain
- Adolescents with Osteogenesis Imperfecta (OI)
- Between the ages of 11-16

- Anyone who is cognitively unable to engage in the study
- Immunocompromised
- Unable to speak English

Interviews

Self efficacy Questionnaires

Design Practice Workshops

Activity pack for outside the workshops (cultural probes)

- Source of participants (where they come from and why this group is appropriate).
- Number of centres involved.
- Expected number of eligible participants available per year and proportion of these expected to agree to the study

Inclusion Criteria

- List the inclusion criteria defining who is eligible for the study.

Exclusion Criteria

- List the exclusion criteria. Consider contra-indications to study treatments, incompatible concurrent treatments, and recent involvement in other research.

5.0 **PARTICIPANT RECRUITMENT (max 300 words)**

Appendix Five: SCH protocol for site specific approvals

Details of recruitment process including:

- Method of recruitment (e.g. via adverts, clinics).
- Payment of participants.
- Details of procedures, tests, screening carried out to assess study suitability.
- Provision of participant information sheets.
- Gaining patient consent; how consent will be obtained, who will gain consent, whether a witness will be present, how long the participant will have to decide, the arrangements for non-English speakers and special groups.
- Detail of enrolment procedure.

Randomisation

Including detail and justification for each of the following:

- Patient/cluster randomised design (randomising individuals or groups e.g. general practices, wards).
- Type of randomisation to be used – simple, block, stratified, minimisation. If stratified include definition of stratification variables. If blocked define block sizes and whether these will vary.
- Use of equal or unequal allocation between treatment arms.
- Information regarding how randomisation will be implemented (including who, where, how).
- Approach to be used to conceal allocation (e.g. sealed envelopes, telephone central allocation office, computerised randomisation, etc)

Blinding and other measures taken to avoid bias

- Detail and justification for measurements to be blinded, level of blinding to be used – e.g. blinding of participants/investigators/assessors (i.e. double-blind, single-blind, open) and how blinding will be implemented.
- Other measures taken to minimise/avoid bias.

Participant compliance

- Recording of patient compliance information (what will be recorded, when and where).
- Detail of follow-up of non compliant participants.

Withdrawal of participants

Participant withdrawal criteria and procedures identifying:

- When and how to withdraw participants.
- The type and timing of any data to be collected for withdrawn participants.
- Whether participant should be replaced and if so the methods for doing this.

Appendix Five: SCH protocol for site specific approvals

- The follow-up procedures for withdrawn participants.

Data collection

Provide a detailed list of all data (outcome variables, explanatory variables, etc) to be collected, with each description including:

- Source of the data (e.g. patient questionnaires, patient notes, electronic data, procedure).
- Time point for collection (baseline, during treatment, at follow-up point).
- Who will collect the data?
- Why the data are being collected (e.g. baseline comparison data, main outcome, and important prognostic/explanatory variable).
- Whether the data are gathered using a standardised tool (e.g. McGill pain score), by means of a procedure (in which case full details should be supplied). If a non standard tool is to be used, detail on reliability and validity should be given.
- What form the data will take (e.g. binary, continuous/numeric, time to event).
- Describe methods used to maximise completeness of data (e.g. telephoning patients who have not returned postal questionnaires).
- Include data collection forms as appendices.

6.0 DATA HANDLING AND RECORD KEEPING (max 300 words)

All personal data will be kept in a filing cabinet in a locked room at Sheffield Hallam University.

- State the person responsible for data collection, recording and quality.
- Describe procedures for data collection and recording (software to be used, location of the data, etc).
- Detail methods implemented to ensure validity and quality of data (e.g. double entry, cross validation, etc).
- Describe procedures for security/storage of data.
- Describe procedures for retention of source data including the duration and location.
- Include statement on adherence to Data Protection Act 1998.

STANDARD STATEMENT ON DATA PROTECTION

Data will be collected and retained in accordance with the Data Protection Act 1998.

STANDARD STATEMENT ON STORAGE OF RECORDS

Study documents (paper and electronic) will be retained in a secure location during and after the study has finished. All source documents will be retained for a period of 5 years following the end of the study.

7.0 ACCESS TO SOURCE DATA (max 300 words)

The sponsor will permit monitoring and audits by the relevant authorities, including the Research Ethics Committee and the Medicines and Healthcare products Regulatory Agency (MHRA). The investigator will also allow monitoring and audits by these bodies and the sponsor, and they will provide direct access to source data and documents.

8.0 **STATISTICAL ANALYSIS (max 300 words)**

Context analysis

- Detail of the variables to be used to assess baseline comparability of the randomised groups and how these will be reported (e.g. means, standard deviations, medians, proportions).
- Detailed plans for statistical analyses of primary and secondary outcomes including:
 - Summary measures to be reported.
 - Method of analysis (justified with consideration of assumptions of the method, structure of the data, e.g. unpaired, paired, and hierarchical, etc).
 - Plans for handling missing data, non compliers and withdrawals in analysis.
 - Plans for predefined subgroup analyses.
- Statement regarding use of intention to treat (ITT) analysis.
- Detail of approach for interim analyses and criteria for early termination of the study.
- Detail of any non statistical methods that might be used (e.g. qualitative methods).
- Statement of who will carry out analyses and at what point.

Sample size calculation

- Study sample size, for multi-centre studies the projected sample size for each site.
- Estimates used (e.g. size of the clinically important effect to be detected, drop out/non compliance rates).
- Assumptions made (e.g. assumptions of Normality).
- Relevant justification (i.e. appropriate references or clinical arguments).
- Allowance for planned subgroup analyses.
- The power of the study.
- The level of significance to be used.
- Statistical criteria for terminating the study.
- Procedures for accounting for missing, unused or counterfeit data.
- Procedures for reporting any deviations from the statistical plan.
- The selection of participants to be used in the statistical analyses, e.g. all eligible participants, all dosed participants, all randomised participants, etc.
- An estimate of the recruitment period for the study (calculated based on the expected number of eligible and recruited participants available per year) with justification that the required sample sizes will be attainable in practice.

9.0 **SAFETY ASSESSMENTS (max 300 words)**

- Specification of safety parameters and the methods for timing, assessing, recording and analysing safety parameters.
- Definition of serious adverse events for the study which are expected e.g. hospitalisation in terminally ill patients.
- State which serious adverse events will not be reported.
- Detail the procedures that will be followed in the event of adverse events in the study – who has what responsibility?
- Describe the type and duration of follow up of participants required after an adverse event/adverse reaction.

Stopping/discontinuation rules and breaking of randomisation code

- Define completion and premature discontinuation of the study.
- Describe procedure regarding decisions on discontinuation of the study (e.g. interim analyses, role of data monitoring committee).
- State documentation to be completed if part/all of the study is discontinued.
- Describe circumstances under which the randomisation codes may need to be broken and the procedure for this.

Monitoring

- Arrangements for monitoring/auditing conduct of the research.
- Detail of any other steps taken to ensure quality of research.
- Use and role of data monitoring groups and steering groups, etc.

The study will be monitored and audited in accordance with the Monitoring Standard Operating Procedures of the university. All study related documents will be made available on request for monitoring and audits by the Sponsor, the relevant Research Ethics Committee or other licensing bodies.

10.0 ETHICAL CONSIDERATIONS (max 300 words)

Issues in the development of the study:

Conditions to work with: In order to decide the appropriate groups to work with I spent time with the staff in different departments at Sheffield Children's hospital.

Age range: The decision to work with adolescents has been influenced by reading and research around the idea that adolescents are under researched in healthcare. Adolescence is also a time when the transition of self-management behaviours moves from the parent/caregiver to them. It is also a time of increased risk taking behaviours, so an appropriate point to look at self management.

Parents and caregivers: Because adolescents still have close relationships with their parents/caregivers and are not fully independent, the workshops will be conducted with parents and caregivers where they wish to be involved. They will be aware of all the activities that we conduct with the adolescents, however where appropriate we will group the parents and participants separately to ensure that we hear the patient voice.

Potential Issues arising from the study:

Ensuring skills are used in the appropriate way: The design skills that the study will teach the participants are general design skills, they focus on areas such as creative thinking, seeing things from another's perspective, working with others and prototyping. These are all skills which designers use everyday to overcome complex tasks, and that everyone to an extent uses. The workshops will be focused on increasing confidence to use these skills.

A concern might be that a participant may feel very empowered in their creativity and want to try something different in their self-management than how they currently are, which might not be appropriate. Both the Children's hospital staff and parents/caregivers will be aware of all the activities, ensuring that they know what skills we are teaching. Participants will be informed that design is about working with others and therefore any creative changes should be done in partnership with everyone around them.

Description of ethical issues for the study.

Ethics and R&D approval

The study will be conducted in compliance with a Research Ethics Committee favourable opinion, including any provisions for Site Specific Assessment, and local Research and Development approval. The study will also be conducted in accordance with the International Conference for Harmonisation of Good Clinical Practice (ICH GCP), and the Research Governance Framework for Health and Social Care (2nd Edition).

- Complete and return progress report requests and notify the Directorate of Research & Innovation when your research is completed. At the point of completion, please submit your findings and any publication or presentations of your findings.
- Inform the Directorate of Research & Innovation If you decide to terminate this research prematurely, by sending a report and indicating the reason for the early termination.
- Advise the Directorate of Research & Innovation of any unusual or unexpected results that raise questions about the safety of the research.

In line with our continued commitment to the above mentioned laws, guidance and statutes, it will be necessary for the Directorate of Research & Innovation to be involved in the conduct of your study as it progresses. Therefore, please ensure that your documentation, including this letter is maintained in the Investigator Site File the appropriate manner and up-to-date.

The target date for recruitment of the first participant is **17th February 2017**. If you are unlikely to meet this target date, please let us know as soon as possible.

I would like to take this opportunity to wish you every success with your project. If you have any questions or we can be of any further assistance to you, do not hesitate to contact the Directorate of Research & Innovation.

Yours sincerely



Dr Jane Pearson
Associate Director Research & Innovations

Cc Professor Paul Dimitri, Principal Investigator

Appendix 1
Documents reviewed:

General Questions:

Name

Job role

Day to day roles and activities

What is chronic pain

Client group/population

Study focused questions:

What does self management mean to you? (activation?)

What self management behaviours do your client group need to engage in

What do you think barriers to engagement are?

Example case study of an engaged/non engaged person

Activation engagement strategies.

Introduction- Outline purpose:

These interviews will be used as part of the qualitative analysis of my PhD. They will be recorded and transcribed. The team members will be sent the transcription of their interview if they wish so that they can have a final veto. I will analyse the transcriptions to understand the value and impact of the design research project within the team. I will place quotes from these interviews throughout my thesis, and alongside my reflections and use these to understand my contribution to knowledge.

Need to state that Positive & Negative feedback is necessary

The purpose of these interviews is to

- Get feedback from the staff on my involvement in their team, understand how they felt relationships were built and developed.
- Find out what they believe the impact of the design research process has been.
- Find out their views on the benefit of Design research in healthcare
- To see where the views and thoughts are similar and different between the team members and myself.
- Understand the journey from their point of view and see how the process and practice have affected it.

Order of questions

- Introduction/beginning of involvement with the team
To support my understanding of building relationships with the team
- Nature/ evolution of my role within the team
To see if they also see a change/progression of my role
- Workshop process-activities/ outputs / practice
To support an understanding on the impact of the practice
- Perceived impact of Design research in health
- (if time) patient workshops

Questions-chronological

- I wanted to start by asking you about when you first joined the service. Can you tell me a bit about what it was like/what was going on within the service. First impressions?
 - *I joined around a similar time that Barbara started in the service, when there was an increase in patient numbers, and a disconnect between the different team members who did not have a unified 'core service'*
- Can you tell me about the point at which you became aware of myself as a designer wanting to become involved with the team? (What made you want to pursue/interested in working with me?)
- We've built a good relationship over the time- how do they feel that has come about?
 - Want to understand how Barbara feels this relationship was built.
 - *I was introduced to the team via Suzanne*

- *Early interviews & MDT clinics & shadowing- how did they feel to have a designer involved?*
- Reflecting back- what was your understanding of my role/why I was getting involved with your team?
 - *I found explanations hard because I was aware that many wouldn't have much previous experience of Design in the way that I was working- design as research.*
- Did you have any previous experience or knowledge of design research in healthcare? Or any preconceived ideas about what we might be doing?
 - *I remember finding parallels between the misunderstanding and blurring of roles within chronic pain and the blurring of roles/misunderstanding with design research.*
- Could you tell me a bit about what you feel my role within the team has been?
- Do you feel that it has changed over time? (What points and how)- **could introduce timeline at this point if needed**
 - *I believe that the nature of my role within the team has evolved in response to the needs of the team and the complexities of the ethics process I was going through at the time.*
 - *Understanding the team in relation to my own workshops- mutual work on team roles & understanding- supporting the team through staff/service changes (evaluation etc)*
- Looking at the timeline could you tell me what for you have been key points on the journey and what impact you feel they have had on the team?
 - *I believe that throughout but particularly in the beginning the design research was about understanding and reflection- with the benefit of not looking to produce an outcome we could be as exploratory as needed. It was novel to me to use design purely as a reflective tool.*
 - *I felt that there were a variety of roles and approaches that individual team members were taking, they all had a similar thread running through them but there was not so much unity within the team. The need for a more streamlined approach and the staff changes led towards thinking about a united Sheffield pain management approach which enabled these different approaches but ensured there was a continuity between them all.*
 - *This evolving role is important in my understanding of the process- we never set out to have an initial output or to redesign anything.*
 - **Which activities did you get the most out of? Or the least out of?**
 - **Which areas did you not find useful/ enjoy?**
 - **What parts did you not enjoy- these could be process related**
 - *There were points on the journey where I found it hard to mediate between the team members/ felt I was being pulled in certain directions which didn't feel even across the team. For example the day looking at resources was a*

difficult one to facilitate and the energy in the room with the team felt strained.

- The physical outcome of this work has been the patient pack that we have developed, at what point do you remember this being introduced as a concept? Aside from the patient pack what do you feel have been other impacts/learning from this work? (Team changes etc.)
 - Have worked closely with Barbara throughout the workshops
 - How else might you have achieved where they are now?
 - What has 'design' brought/added which is unique?
 - What external factors do we need to be mindful of? (Suzanne leaving etc.)
- Need to talk about some of the extenuating/external factors (changes in staff leaving, Barbara promotion) and what impact we feel that they have had on the project.
- What has the impact been on Barbara from the experience?
 - Has her practice/ understanding evolved in any way? What has she learned
 - We have worked particularly closely together.
- How have you explained the work/ my role within it to others? (ask to reflect the early days before patient pack) How have you thought about your role in the process?
- Could you tell me about anything you have heard from your patients about the design workshops they have been through?

Cover letter



11th March 2016

Clinical team or R&D department,
Sheffield Children's Hospital,
Western Bank,
Sheffield,
S10 2TH

Dear

We would like to invite your child to take part in the following study;

**Exploring the role of applied design practice in supporting
adolescents with long term conditions**

This study will be run by Rebecca Partridge, a PhD student from the Art and Design research Centre at Sheffield Hallam University

Please find enclosed here information sheets for both you and your child to have a read over.

For any further information please refer to your clinical team or the contact information on the sheets provided.

Many thanks

(Name of member of clinical team)

Participant Information sheet



Supporting young people who live with pain- Information for Young People

A research project with designers from Sheffield Hallam University

Please read the following information to help you decide if you would like to take part in the above project.

What is the project?

This project explores ways to support young people who live with pain, visualise their views and experiences and increase self-management skills. The project will be run by a PhD researcher, who has experience in service and product design.

What does design have to do with living with pain?

This is not the sort of design that you might have experienced in your school's design and technology classes. We will not be developing new things or products, so do not worry if you think you're not good at drawing or making.

Design can be a confusing term. The term design in this project relates to the way designers work. For example; Product designers make new items such as kettles or bikes, Graphic designers will create images like logos to advertise things and architects design buildings. Whilst these jobs are all different, the designers have many skills and techniques in common, such as, being creative, visually communicating their ideas and problem solving.

It is thought that these skills can be used by anyone to help them in their everyday lives. We want to see if sharing these skills with young people who have chronic pain enables them to share their experiences better and if they can be useful in supporting you to do your pain management.

What will I have to do?

The study is taking place over 6 months, however your involvement will only be for a portion of that time, during which you will be invited to take part in couple of workshops and, if you would like to, given some activities to do at home.

The workshops will be in groups 4-5 young people who are also living with pain, they will last up to 3 hours and will be in Sheffield. During the workshops you will do activities and games to develop some of your design skills, share your experiences of living with pain and talk about your goals and aims.

Outside of these workshops you will be invited to do some activities at home, these aim to explore your experience of living with your condition, find out more about yourself and see how you might be able to use design skills in everyday life. Examples of what you might be asked to do include; keeping a short diary, or taking pictures of your favourite places.

There will be a short interview before and after your involvement.

What will I gain from taking part?

We hope that taking part will enable you to have your voice and views heard, explain your experiences in an interesting way, increase your knowledge of design skills, and help to support your pain management sessions.

As a thank you for taking part in the study you will receive a £20 high street voucher and £20 towards the expenses of travelling into the workshops.

What am I consenting to?

If you choose to take part in the study both yourself and your parent/guardian will need to give consent. This consent covers you taking part in the study which includes; workshops, interviews, activities and questionnaires. There is also a consent form for any photography or audio recording that might happen over the course of the study.

Participant Information sheet

What happens if I want to withdraw from the study?

You can withdraw from the study at any time, any things you produced as part of a group will still be used in the study, but you will not be identified through these. Any interviews and recordings will be destroyed and you will be removed from any photography.

Is there anything else you think I should know?

During the study you will be encouraged to talk about your experiences and share your views. We will respect your confidentiality and nothing will be shared outside of the groups unless otherwise discussed. Direct quotes and images might be used in sharing the findings of the project, but not before we have checked that you are happy with the exact wording and image.

What happens after I have been involved?

The findings will be written up for the PhD study, there will also be some papers written for conferences and/or journals. During the study I will speak to you about how you would like to be informed of any findings and how we could share them.

What happens now?

You do not have to take part in this study but if you are interested, or would just like to find out a bit more, please contact myself either via email at r.partridge@shu.ac.uk or on the phone on 07915086734. You can also speak to members of your pain management team, who will put me in contact with yourself.

Parent/ Guardian Information sheet



Supporting Adolescents who live with pain- Information for Parents & Guardians

A research project with designers from Sheffield Hallam University

Please read the following information to help you decide on whether your child can take part in the above project.

What is the project?

This project explores ways to support young people who live with pain, visualise their views and experiences and increase self-management skills. The project will be run by a PhD researcher, who has experience in service and product design.

What does design have to do with living with pain?

This is not the sort of design that your child might have experienced in their school's design and technology classes. We will not be developing new things or products, so your child should not worry if they think they're not good at drawing or making.

Design can be a confusing term as it means different things to different people. The term design in this project relates to the way designers work. For example; Product designers make new items such as kettles or bikes, Graphic designers will create images like logos to advertise things and architects design buildings. Whilst these jobs are all different, the designers have many skills and techniques in common, such as, being creative, visually communicating their ideas and problem solving.

It is thought that these skills can be used by anyone to help them in their everyday lives. We want to see if sharing these skills with young people who have chronic pain enables them to share their experiences better and if they can be useful in supporting them to do their pain management.

What will they have to do?

The study is taking place over 6 months, however their involvement will only be for a portion of that time, during which they will be invited to take part in a couple of workshops and, if they would like to, be given some activities to do at home.

The workshops will be in groups 4-5 young people who are also living with pain, they will last up to 3 hours and will be in Sheffield. During the workshops they will do activities and games to develop some of their skills, share their experiences of living with pain and talk about their goals and aims.

Outside of these workshops they will be asked to do some activities at home, these aim to explore experiences of living with pain, find out more about themselves and see how they might be able to use design skills in everyday life. Examples of what they might be asked to do include; keeping a short diary, or taking pictures of your favourite places.

There will be a short interview before and after their involvement.

What will they gain from taking part?

We hope that taking part will enable them to have your voice and their views heard, explain their experience in an interesting way, increase their knowledge of design skills, and help to support their pain management sessions

As a thank you for taking part in the study they will receive a £20 high street voucher and we will contribute £20 towards the expenses of travelling into the workshops.

What am I consenting to?

If your child chooses to take part in the study both yourself and your child will need to give consent. This consent allows your child to take part in the study which includes; workshops, interviews, activities and questionnaires. There is also a consent form for any photography or audio recording that might happen over the course of the study.

Participant Information sheet

Can they withdraw from the study?

Your child can withdraw from the study at any time, any things they produced as part of a group will still be used in the study, but they will not be identified through these. Any interviews and recordings will be destroyed and they will be removed from any photography.

Is there anything else you think I should know?

During the study they will be encouraged to talk about their experiences and share their views. We will respect their confidentiality and nothing will be shared outside groups unless otherwise discussed. Direct quotes and images might be used in sharing the findings of the project, but not before we have checked that both you and your child are happy with the exact wording and image.

What happens after I have been involved?

The findings will be written up for the PhD study, there will also be some papers written for conferences and/or journals. During the study I will speak to your child about how they would like to be informed of any findings and how we could share them.

What happens now?

Your child does not have to take part in this study but if you or they are interested, or would just like to find out a bit more, please contact myself either via email at r.partridge@shu.ac.uk or on the phone on 07915086734. You can also speak to members of your clinical team, who will put me in contact with yourself.

Recruitment Flyer



Are you aged
11-16 and
receiving pain
management?

SUPPORTING YOUNG PEOPLE WHO LIVE WITH PAIN

A research project with designers from Sheffield Hallam University

If you are between 11-16, in secondary education and receiving pain management then we would like to invite you to take part in a series of workshops and activities to see how we could support you.

The project aims to enable you to;



Share experiences



Learn new skills



Be creative

These workshops will be led by a Designer, who is interested in understanding more about what it's like to live with chronic pain, and see if some of the skills she teaches you will help you to manage it better.

If you'd like to be involved in this series of fun and creative workshops and activities, ask your therapist for more information.

Sheffield Children's 
NHS Foundation Trust

Supporting young people who live with pain

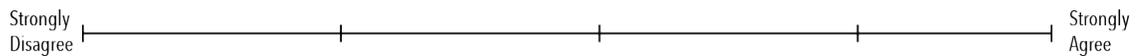
Self evaluation questionnaire workshop one

Name:

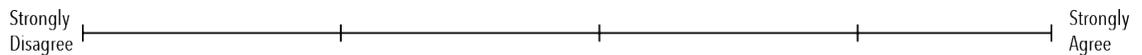
Age:

Rate how much you agree or disagree with the following statements:

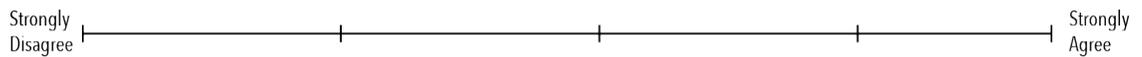
I am observant of the world around me



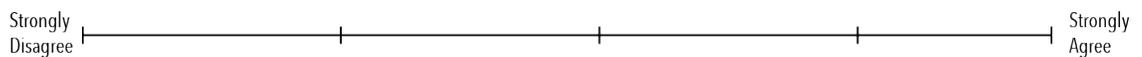
I am inquisitive about why things are how they are



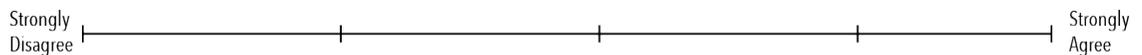
I can see things from differing points of view to my own



I am good at understanding my problems



I am good at coming up with ideas to help address my problems

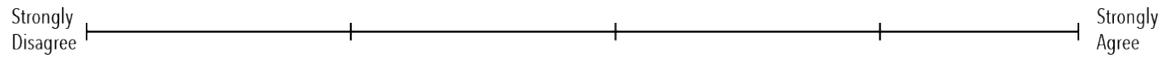


I explore all ideas, even the ones that might be unusual

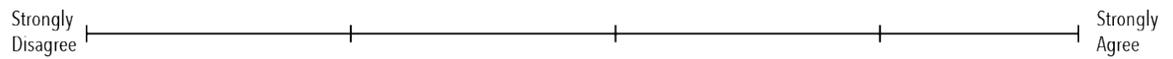


Appendix Ten: Likert Scale

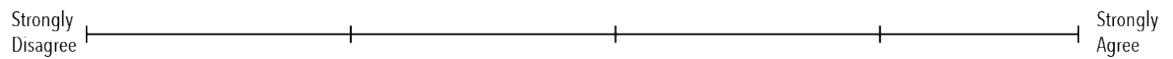
I am resilient if my ideas don't work



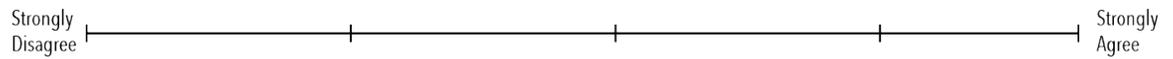
I enjoy working with others to come up with solutions



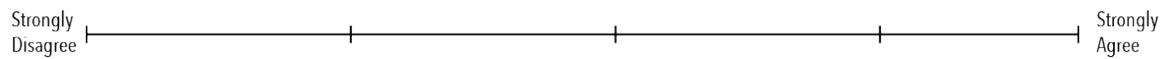
I am a creative person



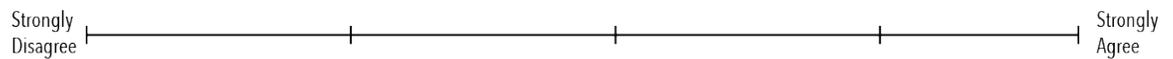
I can communicate my ideas to others visually



I am good at overcoming challenges



I am optimistic



Appendix Eleven: Adolescent Feedback Questionnaire

This questionnaire was sent to all participants around six weeks after the end of the second workshop.

Thank you for taking the time to answer the following questions on the supporting young people who live with pain workshops. Please give examples or explanations where possible.

Please remember that all feedback is helpful, even if you are worried that it is negative- it will help us to plan better sessions in the future so try and answer as honestly as you can 😊

This questionnaire should take around 10 minutes to complete.

Name:

Age:

Questions

1. Did you enjoy the workshops? Could you share some reasons why?
2. Was there anything you didn't like about the workshops? Could you share why?
3. What skills, mind sets or activities can you remember from the workshops?
4. Did the workshops make you think about your pain or experience of living with pain differently? If so- how?
5. Have you used any of the skills, mind sets or activities to help you with your pain management? Can you give any examples?
6. Can you think of how what you learned might be useful in the future?
7. Would you recommend the workshops to other young people who are living with pain? (Tell us why you would or wouldn't)
8. How would or have you described the workshops to others?

Appendix Twelve: Adolescent Interview Schedule

Interview schedule for any adolescents who were happy to be interviewed about their involvement in the workshops. The schedule is based on the questionnaires and adolescents were given the option of either.

1. What interested you about coming to the workshops?
2. Can you remember what you were expecting or hoping from the workshops at the beginning?
3. Where the workshops what you were expecting? (if not why not? Tell us a bit about why)
4. What did you enjoy about the workshops?
5. Was there anything you didn't like about the workshops? Could you share why?
6. What skills, mind sets or activities can you remember from the workshops?
7. I don't know if you are currently living with pain or not but could you tell me if the workshops made you think any differently about it or reflect back on it and how?
8. Have you used any of the skills, mind sets or activities to help you with your pain management? Can you give any examples?
9. Can you think of how what you learned might be useful in the future? (General life/pain management etc)
10. Would you recommend the workshops to other young people who are living with pain? (Tell us why you would or wouldn't)
11. How would or have you described the workshops to others?

Discharge in 3 words

Re consolidation, summarising, agreement

Closing the intervention

End of episode

Discharge in a sentence

A process which usually includes a collaborative discussion to summarise and consolidate the treatment journey and agree an ending

Agreeing to finish working together and preparing the patient to continue with strategies and lifestyle changes independently

Family (& child) are, ideally, confident to continue with current plan of activity with or without the support of local therapy or have disengaged

Discharge in a paragraph

The family and child opt to stop therapy appointments. This may be/would be in a dialogue with the therapist, either face to face, by phone or other message. The child and family may feel that they are sufficiently confident to continue their "work" in regaining their lifestyle without therapist input. However they may decide now is not the time!

A process which usually includes a collaborative discussion with service user and family with a view to agreement in ending treatment. Aims could include the summary's of what has been achieved and may be taken forward without requiring ongoing intervention. Discharge also includes liaison to and with other professionals and administrative actions.

The agreed end to an episode of care, which includes a review of progress so far and a plan for on going self directed strategies and recovery focused behaviours. Discharge may also include a discussion and plan for managing setbacks or recurrence of symptoms in the future.

Appendix Fourteen: Summary of Qualitative Analysis from Therapist Interviews

	Category	Subcategory	Codes	Data points	S	P	J	B	Summary	
	Background information on the Pain Management Service	The development of	Evolution & Growth	3	2		1		Service had grown organically over a 23 year period. Quite fast growth in recent years. No time to stop and think or plan service growth in a strategic way.	
		Service Challenges	Referrals increase Large Patient numbers Type of Patient	7	1	2	3	1	Dramatic increase in patient referrals over short time period. Many patients on the book. Waiting list increasing. Large patient workloads	
			Need to modernise	4	3			1	Out of date resources. Times have changed, technological advances. New approaches to pain management	
			Financial Pressure	2		1	1		Pressure from new leadership to work smarter. Accountability for money and service and new team members	
		Delivery of pain management therapy	Treatment Programme	11	1	1	5	4	No clear cohesive model of the therapy process. Patients and families in the service for long periods of time. Lots of different models of working across the service. No treatment programme.	
			Patient/ Family Characteristics	2	1	1			Complex families often left down by other areas of healthcare system. A lot to take on board and understand	
		Staff changes	Leadership change	2		1	1		Change in medical team lead	

Appendix Fourteen: Summary of Qualitative Analysis from Therapist Interviews

			New therapist	2	1		2		Increased referrals had led to pressures on staffing levels and a new team member to come on board.	
	Therapy Team	Dynamics	Disconnected	5		1	2	2	Everyone working as individuals, separate from each other. Disconnect between staff members and ways of running pain management. Not a coherent group	
			Experience & styles of working	5	1		3	1	Lots of different backgrounds and experience between the team members, everyone working in different ways. Beginnings of patient profiling for certain therapists.	
			Personality	3			3		Personalities different from each other- had an impact on the dynamics. Lots of people at high levels working alongside each other.	
			Communication	2		1		1	Communication between team members wasn't great- would go over things for hours	
		Style of Leadership	Buy in	2			2		Leader often bought things to the group 'ready and finished' without consultation or an opportunity for comment	
			Opportunity to Challenge	4			3	1	Team members did not feel that they could challenge or make comments on what had already been decided or produced	
	Therapy service development	Change is harder for some than others		5	2		2	1	Change was not welcomed so well by everyone in the team. Others had difficulties in accepting the changes needed. One team member felt that the season of change was a good time to evaluate role and whether or not to stay in team.	
		Embracing a change		3			1	2	Welcoming of change, not sure of any particular direction	
		Big task to undertake	overwhelming	4			1	3	Understanding that what needed to change was a large task	

Appendix Fourteen: Summary of Qualitative Analysis from Therapist Interviews

		Support	need help	5	1	3		1	Recognition that help was needed and open to opportunities for help	
	Other development approaches	Previous experiences		5		2	3		Team had some previous experience of other away day or development approaches. Don't believe that they would have been as good as the design approach. Also don't feel that they were as easy to engage with or as embedded in approach	
		Microsystems		1	2				Microsystems was mentioned approach but recognized that it would not have gone as far as we got	
	Outcomes of work	Therapy service	Treatment process & Patient pack	11		3	2	6	Clear therapy process and patient pack to support the process. Clarity in the idea of patient treatment	
			Patient engagement	2		1		1	Positive patient feedback and engagement in the pack	
			Discharge	3		1	2		Discharge introduced at beginning of the process and more patients being actively discharged from the service.	
			Group work	1			1		Group work is possible (from seeing the adolescent workshops)	
		Tangible		6	1	1	1	3	Tangible outcome/thing. Recognition that if you just see the thing it takes the merit out of the process. First time have tangible results from a change process	
		Team	Team building	4	1		1	2	Clearer team identity. Closer as a team from creating something together	
			Communication	3				3	Communication better between the team. More willing to challenge and be direct with each other.	
		Personal	Enthusiasm for job role		3	1	2		renewed enthusiasm for job role.	

Appendix Fourteen: Summary of Qualitative Analysis from Therapist Interviews

			Value	7	2	4	1	Contribution in the team feels valued. Sense of pride across team. Opinion is valued and acted upon. Sense of value from being allowed to go through a long sustained process.	
	Pain talking Workshops	need for neutrality	transparency issues	1			1	Staff weren't sure about how the pain talking workshops and my role in that would affect the work we were doing together.	
		Understanding	Misunderstanding and confusion	8		3	2	3 Team members unable to understand what the pain talking workshops and long term aims of the project were about. Was hard to understand a difference in my role and work between the two.	
		Conflict in my role		4			2	2 There was a point that I decided to step back from the work and this was recognized and understood.	
	Adolescent workshops	World view	Stuck	1			1	Young people with pain can have very narrow worlds that they find it hard to see out of.	
		Different approach	Perspective / unique	4			2	2 Approach of the workshops was different and allowed people to see things from a different perspective. Allowed them to see how they could develop skills without focusing on pain.	
		Impact of the workshops		5			2	1	2 Making a change by opening up peoples perspectives, positive impact of being in a room with other people who have pain
		Overlap with therapy	similar to therapeutic process	3				3 There are cross overs between therapy approach and the design skills. The approach to not focus on pain was important.	
	Beyond PhD	Publishing	dissemination	4			3	1 The team are looking at ways that they could publish and share this work to tell and show people what they've done. Team want to hear more about the young people workshops	

Appendix Fourteen: Summary of Qualitative Analysis from Therapist Interviews

		Continuation of this work		6		3		3	There is a desire to continue this work and look at the wider pain management team to build a sense of cohesion there. Interested to know if design work can be built into therapeutic practice.
	Design facilitator	External person	Outsider perspective external voice/ fresh pair of eyes	7	3	1	2	2	An external person with a fresh eyes to look at the problem- able to see through. External support to help with the process.
			Neutral	2	1		1		Neutrality was important to ensure everyone's voice shared.
		Skills	Project management	5	5				Design facilitator had project management skills to hold the project and keep it going and had respect for the pressures on the team members in a healthcare service.
			Design skills and training	3	2	1			Design facilitator had design skills and training to support the project. Design thinking was implicit in the activities and planning for the work.
	Relationship built between us	Contextual review	Building a relationship	4		1	2	1	Contextual review was important in building an understanding of the work and the people that they work with. The time to wait before bringing in my work and skills was appreciated.
			Trust	5	1	1	3		Built up trust between myself and the team. Built a relationship. Felt more like a colleague
			Support	2	2				Supportive to the team
	Design	The value of design		2	1			1	The team value design
		Design skills		4	2	1	1		Value in the skills of a designer and experience that they can bring

Appendix Fourteen: Summary of Qualitative Analysis from Therapist Interviews

		Knowledge of design	Understanding of design Vague	7	1		3	3	Initial understanding of design can be hard. Other people find it hard to understand why the team have worked with a designer. Initially the work was hard to define
		Explanation	Difficulties	3			1	2	Explaining the work to others is hard
	Time	Taking the time	lack of time to share usually	12	4	1	3	4	It's important and helpful to take the time and space out to think and reflect. Have to make a commitment to the work and that includes time.
		Value of clinical time		4			3	1	Important to value clinicians' time and value their job role without adding or expecting too much additional
		Length of time	Making changes takes time	4	2			2	It takes time to make changes, also team feels like they have achieved a lot in the period
	Approach / Format	Speed		6		1	1	4	Having to complete tasks in a short period of time focused thinking and avoided long drawn out conversations.
		Novel	New	4		2	1	1	It was a new approach for the team. Although some of the methods are similar to ways that they would work
			Engaging	5	2	3			Process was fun, creative and engaging
			Challenging	2			1	1	There were points when it was challenging
		collaborative	shared knowledge/ consensus / consolidate	10	3		4	3	Process has been collaborative and brought together all different ideas
			ownership	4			2	2	People feel as though they have 'ownership'
	Process		levelled hierarchies	3	1			2	Levelled hierarchies in the team
			Voice/ permission	5			1	4	Everyone has had a chance to have their voice heard and share their thoughts and opinions.
		Tacit knowledge		2			2		Gut knowledge and feeling has been brought out

Appendix Fifteen: Plan for Adolescent Workshop One

	<p>Introducing the key themes</p>	<p>view. Questioning-asking why Understanding-knowledge of why things are Opportunity-seeing areas for change -place up posters of each one as I talk about it.</p> <p>Learning to look at and observe the world differently to change our perspective/gain understanding. In some ways a type of 'Zooming out' If you can only see something in the same way each time you'll always approach solving it the same way and there will be no 'new' ideas and innovations. Designers often do not solve problems they understand the problems and pose suggestions and ideas. e.g. example of needing a faster horse rather than thinking of a new car.</p>
<p>10.20-10.25 (build) 10.25-10.35 (words)</p>	<p>Understanding design activity</p>	<p>Going to do an activity to start thinking about what a designer is/what they do. Because the term design can be confusing, it means lots of things to many people. Before we can start to learn the techniques they use we need to think about who they are.</p> <p>Start by opening up/understanding and changing our perspective on what a designer is (think outside the boundaries of architect, product designer, graphic designer etc.) to the broader picture of design.</p> <p>Who is a designer?</p> <ul style="list-style-type: none"> • In partners use the body parts to build what you think a designer 'looks' like, • Look at the descriptive words and think about 3/4 that you think would be used to describe a designer and think about why. • Look at the skills/activities/tools of a designer- take 2/3 you most associate and why. <p>Share with the rest of the group -stick the posters around -choose one word and one skill-why (can't repeat but can say if you had the same)</p> <p>(think about what common words/themes are coming up) Feedback why we have done this- Hopefully everyone has been thinking about what skills a designer has. Either preconceived ideas to be challenged or participants are already thinking more laterally.</p>

Appendix Fifteen: Plan for Adolescent Workshop One

<p>10.35-10.45</p> <p>10.45-10.50</p>		<p>Cool wall Break down into pairs again- look at your objects and think about if they are 'cool' or 'not cool'. Why? Do you have differing opinions? Share with the rest of the group and place 1 or 2 on the wall.</p> <p>The activity was to think about why design is important/ what makes design good or bad. Start considering the things that we interact with daily. How often do we ask if something is good or bad design? And then think about why? What are the reasons for our reaction.</p> <p>Hopefully can see that design is a combination of the different skills that designers have and the outputs they create. Everything is designed, even services.</p> <p>Video on design skills or service design https://vimeo.com/73619059 - the value of design</p>
<p>10.50-11</p> <p>10.50-10.54</p> <p>10.54-10.56</p> <p>10.57-11.00</p>	<p>Activity</p>	<p>Taboo- PERSPECTIVE Traditional party game that you might have played. Get into pairs again, different ones from before. First way- Traditional way in pairs</p> <p>Second-think and share individually.</p> <p>What did you notice? Who was surprised with how people described things? Was it easy/hard/did it get harder? First way forces you to think about it different Other peoples perspective Simple/safe demonstration of seeing things from a different perspective. Viewing things from a different angle/perspective.</p>
<p>11.00-11.05</p> <p>11.05-11.10</p>	<p>Observation Activity</p>	<p>Categories-OBSERVATION Get into groups of 3/4 each group has a theme which there are pictures for. What can you tell us about your images? Look at the images-how similar/different are they? Share back with the group</p>

Appendix Fifteen: Plan for Adolescent Workshop One

		<p>in perspective on the problem.</p> <p>I mentioned earlier that designers often do not solve problems-design didn't solve a new can opener in this way, it reframed and posed solutions by 'zooming out'.</p>
11.50-12.00	Deconstruction Activity	<p>Deconstruction Activity-QUESTIONING/UNDERSTANDING</p> <p>5 minutes deconstruction from me- asking questions about it literally but also asking further questions of those answers.</p> <p>Its got a picture of a face on it-why-makes you think of someone laughing-why someone laughing-because laughing implies fun and the game is supposed to be fun</p> <p>It's a square box-why-because it holds the game-but the game is not that big-why-because it has a bigger shelf presence-why so people buy it etc.</p> <p>Breaking something down into its smallest parts, trying to understand the design decisions that have gone into it.</p> <p>Take in a range of things and ask them to pick one to deconstruct in pairs.</p> <p><i>Food packaging, bouquet of flowers, logo, Eggbox, Washing powder box, Jewellery, Restaurant interior</i></p>
12.00-12.15		<p>Write down and question all that you can about the object. Use the cue cards to help. Can do multiple.</p> <p><i>Functional/material (what its for/what its made of, how its made and why)</i></p> <p><i>Meaning/association (what something makes you think of and why)</i></p> <p><i>Asking 'why' of every question</i></p> <p>Share back to the group:</p> <ul style="list-style-type: none"> • what is the object for? ('to carry a game', ' to advertise perfume' • Something else you found and why you think it's that way.

Appendix Fifteen: Plan for Adolescent Workshop One

12.15-12.30	<p>Creating a Drink for someone</p> <p>Discussion on Empathy</p>	<p>Create a drink- UNDERSTANDING & OPPORTUNITY</p> <p>Going to do an activity which demonstrates some of the skills in a fun way. Show how digging deep and creating understanding leads to opportunity</p> <p>Partner up and find out about the other person. 3 minutes each to interview them. Write notes on what they're like, hobbies, where they live etc. Do not focus on pain.</p> <p>Switch</p> <p>Now create a drink for that person- a drink that represents them and their personality. Not a drink that they like but that they are like. Think of your insights/understandings-make a list of things you have found out, and consider how you can represent those things. Draw and label your drink</p> <p>Also come up with a name and decoration (straws/umbrellas etc)</p> <p>For example your drink could include:</p> <ul style="list-style-type: none"> • choose pomegranates because their unusual and your person has unusual hobbies • a fizzy drink because this person is bubbly and has lots of energy • Smooth orange juice because someone is well liked • A cherry on top because this person has a lot of confidence • In a non see through glass because the person is shy <p>Share it back with the person.</p> <p>A couple of people to share with the wider group.</p> <p>Constructing for people, making layers, creating your own meaning in something-the opposite of the deconstruction activity. You find out about someone and then you create your own meaning to portray that person to someone. It also demonstrates how designers will often think in metaphors to get their creative juices flowing.</p>
12.30 If times	Introduction to next week	<p>Creative cinema clips-</p> <p>Next time will be about how we can imagine and create things in the future,</p> <p>Will think about how we come up with ideas and communicate those ideas to others.</p>
		<p>Also be a mini design challenge.</p>

CONSENT FORM

Exploring the role of Design to support adolescents who have long-term conditions

Please circle all that you agree with:

Has somebody else explained this project to you? Yes / No

Do you understand what this project is about? Yes / No

Have you asked all the questions you want? Yes / No

Have you had your questions answered in a way you understand? Yes / No

Do you understand it's OK for your child to stop taking part at any time? Yes / No

Are you happy for your child to take part? Yes / No

If any answers are 'no' or you don't want to take part, don't sign your name!

If you do want to take part, you can write your name below

Your name _____ Date _____

The person who explained this project to you needs to sign too:

Name of Researcher Date Signature

Thank you for your help.

1 for participant; 1 for researcher site file;

Exploring the role of Design to support adolescents who have long term conditions
IRAS ID: 196207
Version: 1
Date: 05/05/16

DATA CONSENT FORM

Exploring the role of Design to support adolescents who have long-term conditions

Consent form for use of your data

During the workshops we may take photographs and make audio and video recordings of the activities in which you participate.

We may use these in two different ways:

Sharing with researchers and people working in design and health/social care

The findings of this research will be shared with researchers in our own and other Universities and people who work in design, health and social care and related professions. This will be in the form of an academic Thesis. It may also be in the form of academic papers, presentations and talks, trade or professional magazine articles, and electronic forms such as CDs & DVDs.

Sharing with the general public

We would also like to share the design work we do together with a wider general public audience, such as via university marketing, paper articles, public presentations and talks, and web sites.

In each of these publications and presentations we will use parts of the images and recordings we have made to illustrate the activities that took place and the things we have found out. Our aim is to share the designing and research that we have done together, and we will always ensure that your views and ideas are accurately represented. Images and recordings will also never be used for profit.

You can either be anonymous or recognisable in what is used. You can change your mind about this at any time.

Being anonymous

We will make text copies of what people say in any audio and video recordings. If we include quotes from these texts in papers, articles and presentation slides we will change the names of those talking so that they cannot be identified. We may also include quotes from text that you have shared with us but, again, we will not put your real name alongside them. We will also not use audio clips and either edit you out, use photographs taken from behind or blur your face from any photographs or video clips.

Being recognisable

We may use photographs, audio clips or video clips as illustrations in which you can be recognised. We might also use text quotes from what you have said or notes that you have shared with your real name.

Project name: Exploring the role of Design to support adolescents who have long-term conditions

Please answer the questions below and then sign the form.

Exploring the role of Design to support adolescents who have long term conditions

IRAS ID: 196207

Version: 1

Date: 05/05/16

Appendix Seventeen: Data Consent Form

I agree to recordings of me being used in research and professional publications and presentations (please tick one):

EITHER Anonymously **OR** Recognisably

I agree to recordings of me being used in general public publications and presentations (please tick one):

EITHER Anonymously **OR** Recognisably

Name of Parent/Guardian

Date

Signature

Name of Participant

Date

Signature

Name of Person taking consent

Date

Signature

When completed: 1 for parent; 1 for researcher site file;

Exploring the role of Design to support adolescents who have long term conditions

IRAS ID: 196207

Version: 1

Date: 05/05/16

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Appendix Eighteen: Plan for Adolescent Workshop Two

		<p>Recap key skills/words from last week; Observation, Perspective, Questioning, Understanding, Opportunity.</p> <p>Those were the skills that we were trying to understand that related to how we see and approach the world now.</p> <p>Can anyone think of an example where they've used those skills in the past 2 weeks? Which one stuck the most in your mind?</p> <p>Introduction to today's skills/mindsets: These are about exploring the world as it could be: Communication- the importance of and confidence to communicate and share our ideas even when it's difficult. Prototyping-try it, give it a go, learning through doing Optimism/creative confidence- having the confidence to have a go. http://www.designkit.org/mindsets/3 Experimenting, Learning through failure- learning that failure can sometimes be a positive thing- because valuable lessons are learned. http://www.designkit.org/mindsets/1 Idea generation – coming up with new ideas, pushing boundaries and feeling creative.</p>
10.20-10.35	Warm up- How many uses	<p>How many uses can you think of for: Lemon Brick CD Fork</p> <p>Pair up</p> <p>Put your image/object in the middle and write down how many uses you can think of for an object around the edge. <i>After a couple of minutes</i> For more inspiration-Use Cue cards- different places in the house & different people/characters (from the idea game)</p> <p>Share back with the rest of the group-</p> <ul style="list-style-type: none"> • What was your object? • What were two obvious uses for it • Two less obvious/adventurous ideas? <p>Feedback: Much more than is obvious/that we can see. It's ok to have silly/funny ideas/ something which seems like it could only have one or a couple of functions often has more. Links back to last week's gaining perspective/seeing something from a different perspective</p>

Appendix Eighteen: Plan for Adolescent Workshop Two

<p>10.35-10.50</p>	<p>Creative thinking 1</p>	<p>Image and question cards</p> <p>Start combining some of the skills learned last week with creative thinking skills & Questioning to see opportunity</p> <p>In Pairs</p> <p>Each pair has a series of images & a set of questions and set of people & bluetak</p> <p>Turn over an image, Ask the 3 questions of it, (record your answers on the sheets provided) Turn over a person card- look at your answers to the three questions and adapt/develop them to suit your person/profession.</p> <p>You may find it easier to come up with ideas from some rather than others-don't stress, move on if you get stuck.</p> <p>Need to think of a way to record</p> <p>Share back to the group 1 of your examples,</p> <p>Feedback-how does this link to what we learned in the last session? (opportunity, questioning etc- ideas can come out of the questions)</p> <p>Sometimes all we need to do to start thinking creatively is question and understand things better. A technique for creative thinking can be to think of alternative ways to achieve the same aim (think back to the can opener demonstration.</p>
<p>10.50-11.10</p>	<p>Communication activity</p>	<p>Buy Making materials</p> <p>Take it in turns to describe and make Could use actions? – not the thing but the making of it.</p> <p>Share back- how did you find it?</p> <p>Discussion on prototyping-different ways that people might do it- Pictures/ images/ examples -Acting things out, eg we could turn this room into an airplane/or if we were thinking about creating a new job for someone in the team-act out the roles. -we could make something out of anything. E.g this paper could be a new drug therapy and we would see how we all interacted with it.</p>

		<p>-Trying out new signs or places for signs, UCHD, stood/followed and placed signs along someones route -We could use lego/or playmobile -We could make a storyboard.</p> <p>In practical terms with prototyping it can be easy to think what is the one thing I need to trial, so for example related to shopping it might be transport. Start small and see how it goes. Keep everything else the same until you are confident. Isolate each thing. You might just try the travelling part and not the shopping, and try a few ways until something seems right</p>
11.10-11.25	Future cinema	<p>Star trek-Ipad /mobile phone https://www.youtube.com/watch?v=IKH0Ippc87E Tomorrows world-phone -2.07 https://www.youtube.com/watch?v=vix6TMnj9vY&list=PLphh7NYWd5GRPug4_ccSOkCsVdbfPzD6- Truman show- Reality TV Home computer https://www.youtube.com/watch?v=EC5sbdvvnvQM&index=9&list=PLphh7NYWd5GRPug4_ccSOkCsVdbfPzD6- Tomorrows world-home office https://www.youtube.com/watch?v=aJ6SbvrjxZA</p> <p>What did people think? What did they all have in common Demonstrating the idea of going for 'blue sky ideas'- those which seem out there/beyond current abilities and why its not silly to do so. May eventually be within the realms of what is possible. Come up with the big ideas and then work backwards-for example star trek 'phone' was really about communication on the move.</p>
11.25-11.50	Creative thinking 2	<p>Two piles of images & Blue tak/post its</p> <p>Combining images/ideas together to come up with new ones, try and think of a couple per image combination if possible.</p> <p>5 mins towards the end Take your favourite idea and develop it 'tell us about how it would work/who it would be for etc.</p> <p>Share back</p>
11.50-12.20	Design challenge	<p>Short design challenge: Non product creative thinking</p> <p>Question statement & Image</p>

Appendix Eighteen: Plan for Adolescent Workshop Two

		<ol style="list-style-type: none"> 1. Consider the problem-what do you think might currently be the issues/who else do you need to consider? (5 minutes) 2. Use some techniques to come up with new ideas (5 minutes) 3. Pick 1 idea to develop- support from the facilitators (5) <i>Use the inspiration cards to encourage development.</i> 4. Can you make a prototype here? (5 minutes) <ol style="list-style-type: none"> a. How would you prototype it? b. What are you trying to learn from your protoype? c. 1 key thing. d. What is a measure of learning or success? <p>Share back with the group.</p>
	Summary	Rating sheets Hand out mindset sheets-summarise the skills. Vouchers

Appendix Nineteen: Adolescent Questionnaire Data

	Did you enjoy the workshops? Could you share some reasons why?	Was there anything you didn't like about the workshops? Could you share why?	What skills, mind sets or activities can you remember from the workshops?	Did the workshops make you think about your pain or experience of living with pain differently? If so how?	Have you used any of the skills, mind sets or activities to help you with your pain management? Can you give any examples?	Can you think of how what you learned might be useful in the future?	Would you recommend the workshops to other young people who are living with pain? (Tell us why you would or wouldn't)	How would or have you described the workshops to others?
A	Yes. I did enjoy them because they were interesting and helpful but fun at the same time.	no	To look at things from different perspectives and to be optimistic.	Yes, because it made me look at my pain from a different point of view.	Yes. I use some of the analysing activities to see what I have to do in the situation I am in.	At school, with my pain management and when I am older in work.	Yes because I think they were helpful and useful and could benefit your pain management.	Fun, useful and interesting.
C	I really enjoyed the workshops because we used lots of skills that we could use in day to day activities	I liked everything	The building one and the taboo one	Yes because some of the activities help you look at things from different perspectives and I thought about the exercises and how to deal with it	Yes. At school when we are working and I change my mindset to thinking I can do it, the same with my pain	When I'm working with a team in a job and need to look at everyones perspectives	Yes. Because I found them really helpful and you could use them to deal with your pain	Really fun and keeps everyone involved and thinking. It helps you think about different skills too.
E	I did enjoy the workshops because I got on with everyone taking part		I learned to have a positive mindset and also to look at things in a different perspective			To not think about the worst that might happen when I get pain	I would because it has helped me	It helps to manage your pain and it helps you to think differently when you get pain
F	Could you share some reasons why? Yes I enjoyed the workshops. They taught me stuff which has helped me in dealing with my pain.	Nothing	It gave me ideas about how to distract myself when I am in pain to help me deal with it.	Yes, I now understand more about living and coping with pain.	es, I have started to try drawing and things to distract myself when my pain is bad.	I hope using then things I learnt will help me deal with my pain from now on.	es, if it helps just a bit it's better than living with pain.	Learning how to do things when you are in pain to take your mind off it.
G	I really enjoyed the workshops! I thought they were a great opportunity to meet others going through similar issues, but without necessarily having to discuss pain. I also thought it was a good opportunity to learn about design and how it can help with explaining pain.	No, I thought it everything was really good.	Looking at things form a different perspective, and asking why.		I have – I've used design to help me understand pain and really consider 'outside of the box' pain management techniques.	I actually really think that design should be used more often with people going through pain. I have often found that explaining where pain is and what it looks like very difficult. This is therefore challenging for doctors to understand what they're dealing with. Often it's difficult to find words to explain illnesses when you don't 'look ill' so design has really shown me a new way of describing it	I definitely would recommend the workshops to others living with pain, it has certainly opened my eyes and hopefully it could do for others!	A different way of looking at pain without discussing it in a serious/negative way. Also an eye opener to tackling pain form different points of view, and in different ways without relying on other people.
I	Yes found the workshop very helpful,was able to talk to people of my own age that had the same problems as myself	No everything was just perfect,if anything to have a extra session may be in a park or museum,a different enviroment would be good.	Played taboo,talking about our to manage our pain.	Yes,I made me think that it not just me having to deal with pain.	Let people know when I'm in pain and learned to speak out	Do activities too take my mind of things.	Basic learning that I can share a problem.	Helpful, exciting and sharing experiences,well worth attending.

Appendix Nineteen: Adolescent Questionnaire Data

K	Yes, I thought it was a unique session. Ive never been to one like it before but it made me think outside the box and use my imagination to discover different ways to deal with my pain.	The activities we did we're interesting but it was hard to link it back to my problem. In some ways though, it was a good thing because I enjoyed the activity wihtout having to remind myself of the pain.	I learned to think outside the box, its a new skill that I am now developing. I did the building brick activity that taught me to use my imagination and think of different ways to use a brick instead of the simple purpose .i.e. to build something.	Not necessarily but in some activities, we were told to think about how we could use them to deal with our pain. It was interesting to explore other ideas.	I have learnt to use my imagination and think of other ways to deal with my pain that i wouldnt normally think of. I think outside the box and don't rely on the simple methods to decrease or stop my pain.	In the future, I believe that I have got skills from the workshop that could possibly help me with my confidence and job ideas too.	Yes, I think it is helpful to explore different paths to deal with pain. The workshop helped me to understand that there are more types of pain than my own and we all cope with it in different ways, this helps to understand the solutions and why some solutions help people more than others.	I'd descibe the workshop as interesting. It's a workshop thats unique, you have to think outside the box to achieve your goal, if you can do this, nothing can stop you.
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Questionnaire analysis, data for each category.

Each colour represents a different respondent. This exercise was also completed per respondent to see if the data showed anything interesting.

Combined content analysis with quotes

Code

Experience (22 data points in total from 7 participants)

Beneficial (7 data points from 6 participants)

'I did enjoy them because they were interesting and helpful but fun at the same time.'
'Yes (I) found the workshop very helpful'
'Yes because I think they were helpful and useful'
'Yes. Because I found them really helpful'
'I would because it has helped me'
'if it helps just a bit it's better than living with pain.'
'Helpful, exciting'

Worthwhile (1 data point from 1 participant)

'well worth attending'

Interesting (5 data points from 3 participants)

'I did enjoy them because they were interesting and helpful but fun at the same time.'
'The activities we did we're interesting'
'It was interesting to explore other ideas.'
'Fun, useful and interesting.'
'I'd describe the workshop as interesting.'

Enjoyment /fun (5 data points from 4 participants)

'I really enjoyed the workshops!'
'I did enjoy the workshops'
'Yes I enjoyed the workshops.'
'I did enjoy them because they were interesting and helpful but fun at the same time.'
'Really fun'

Unique/ unusual (1 data point from 1 participant)

'Yes, I thought it was a unique session.'

Thought provoking (3 data points from 2 participants)

'it has certainly opened my eyes and hopefully it could do for others!'
'I think it is helpful to explore different paths to deal with pain'
'A different way of looking at pain'

Mindset/ skill

Outside the box (3 data points, 2 participants)

'I learned to think outside the box, its a new skill that I am now developing'

'I've used design to help me understand pain and really consider 'outside of the box' pain management techniques.'

'have to think outside the box'

Lateral thinking (1 data point from 1 participant)

'I have learnt to use my imagination and think of other ways to deal with my pain that i wouldn't normally think of'

Imagination (3 data points, 1 participant)

'it made me think outside the box and use my imagination'

'I did the building brick activity that taught me to use my imagination'

'I have learnt to use my imagination and think of other ways to deal with my pain that i wouldn't normally think of'

Perspective/ point of view (6 data points from 4 participants)

'To look at things from different perspectives and to be optimistic'

'to look at things in a different perspective'

'Looking at things form a different perspective, and asking why.'

'Yes, because it made me look at my pain from a different point of view.'

'some of the activities help you look at things from different perspectives'

'When I'm working with a team in a job and need to look at everyones perspectives'

Analysis (1 data point, 1 participant)

'Yes. I use some of the analysing activities to see what I have to do in the situation I am in.'

Positivity & confidence (5 data points 3 participants)

'To look at things from different perspectives and to be optimistic'

'I learned to have a positive mindset'

'To not think about the worst that might happen when I get pain'

'I believe that I have got skills from the workshop that could possibly help me with my confidence'

'if you can do this, nothing can stop you.'

Mindset change (3 data points, 3 participants)

'At school when we are working and I change my mindset to thinking I can do it.'

'helps you to think differently when you get pain'

'Also an eye opener to tackling pain form different points of view, and in different ways'

Skills (4 data points, 4 participants)

'we used lots of skills that we could use in day to day activities'

'They taught me stuff which has helped me in dealing with my pain.'

'I learned to think outside the box, its a new skill that I am now developing'

'It helps you think about different skills too.'

Design knowledge (1 data point, 1 participant)

I also thought it was a good opportunity to learn about design and how it can help with explaining pain.'

Application

Confidence 2 from 2

'At school when we are working and I change my mindset to thinking I can do it,'

'you have to think outside the box to achieve your goal, if you can do this, nothing can stop you.'

Hopes/expectations in Dealing with pain 4 from 4

'The activities we did we're interesting but it was hard to link it back to my problem'

'I hope using then things I learnt will help me deal with my pain from now on.'

'could benefit your pain management.'

'you could use them to deal with your pain'

New approaches 3 from 2

'I think outside the box and don't rely on the simple methods to decrease or stop my pain.'

'I think it is helpful to explore different paths to deal with pain'

'form different points of view, and in different ways without relying on other people.'

Managing pain 6 from 6

'They taught me stuff which has helped me in dealing with my pain'

'and use my imagination to discover different ways to deal with my pain.'

'I thought about the exercises and how to deal with it'

'Yes. I use some of the analysing activities to see what I have to do in the situation I am in.'

'I've used design to help me understand pain and really consider 'outside of the box' pain management techniques.'

'It helps to manage your pain'

Pain explanation 2 from 1

'a good opportunity to learn about design and how it can help with explaining pain.'

'Often it's difficult to find words to explain illnesses when you don't 'look ill' so design has really shown me a new way of describing it, without words.'

Visualisation 1 from 1

'design has really shown me a new way of describing it, without words.'

Distraction 4 from 2

'It gave me ideas about how to distract myself when I am in pain to help me deal with it.'

'I have started to try drawing and things to distract myself when my pain is bad.'

'Do activities too take my mind of things.'

'Learning how to do things when you are in pain to take your mind off it.'

Sharing & Voice 2 from 1

Let people know when I'm in pain and learned to speak out'

'Basic learning that I can share a problem.'

School 2 from 2

'At school when we are working and I change my mindset to thinking I can do it,'

'At school, with my pain management'

Appendix Twenty: Questionnaire Analysis; Categories and quotes

School 2 from 2

'At school when we are working and I change my mindset to thinking I can do it,'
'At school, with my pain management'

Work/job-future 3 from 3

'when I am older in work.'
'When I'm working with a team in a job and need to look at everyones perspectives'
'I believe that I have got skills from the workshop that could possibly help me with my confidence and job ideas too.'

Everyday life 1 from 1

'we used lots of skills that we could use in day to day activities'

Group

Sharing experiences 3 from 2

'I thought they were a great opportunity to meet others going through similar issues'
'was able to talk to people of my own age that had the same problems as myself'
'sharing experiences,'

Everyone takes part 1 from 1

'and keeps everyone involved and thinking.'

Different approaches 2 from 2

'The workshop helped me to understand that there are more types of pain than my own and we all cope with it in different ways'
'this helps to understand the solutions and why some solutions help people more than others.'

Meet others 2 from 2

'I did enjoy the workshops because I got on with everyone taking part'
'Yes, I made me think that it not just me having to deal with pain.'

Approach

Unique 2 from 1

'Yes, I thought it was a unique session.'
'It's a workshop thats unique,'

Everyone takes part 1 from 1

'and keeps everyone involved and thinking.'

No pain discussion 2 from 1

'I thought they were a great opportunity to meet others going through similar issues, but without necessarily having to discuss pain.'
'A different way of looking at pain without discussing it in a serious/negative way.'

Appendix Twenty: Questionnaire Analysis; Categories and quotes

Activity 5 from 3

'In some ways though, it was a good thing because I enjoyed the activity without having to remind myself of the pain.'

'The building one and the taboo one'

'Played taboo,

'I did the building brick activity that taught me to use my imagination and think of different ways to use a brick instead of the simple purpose'

'some of the activities help you look at things from different perspectives'

Format

Amount of sessions 1 from 1

'if anything to have an extra session may be in a park or museum, a different environment would be good.'

Content Analysis per question with Quotes

Did you enjoy the workshops? Could you share some reasons why?

Experience

'I did enjoy them because they were interesting and helpful but fun at the same time.'

'Yes (I) found the workshop very helpful'

'I really enjoyed the workshops!'

'I did enjoy the workshops'

'Yes I enjoyed the workshops.'

'Yes, I thought it was a unique session.'

Skills

'I also thought it was a good opportunity to learn about design and how it can help with explaining pain.'

'it made me think outside the box and use my imagination'

'we used lots of skills that we could use in day to day activities'

'They taught me stuff which has helped me in dealing with my pain.'

Application

'we used lots of skills that we could use in day to day activities'

'They taught me stuff which has helped me in dealing with my pain.'

'and use my imagination to discover different ways to deal with my pain.'

'a good opportunity to learn about design and how it can help with explaining pain.'

Group

'I did enjoy the workshops because I got on with everyone taking part'

'I thought they were a great opportunity to meet others going through similar issues'

'was able to talk to people of my own age that had the same problems as myself'

Approach x2

Appendix Twenty: Questionnaire Analysis; Categories and quotes

'I thought they were a great opportunity to meet others going through similar issues, but without necessarily having to discuss pain.'

'Yes, I thought it was a unique session.'

Was there anything you didn't like about the workshops? Could you share why?

Format

'if anything to have a extra session may be in a park or museum, a different environment would be good.'

Experience

'The activities we did we're interesting'

Application

'The activities we did we're interesting but it was hard to link it back to my problem'

Approach

'In some ways though, it was a good thing because I enjoyed the activity without having to remind myself of the pain.'

What skills, mind sets or activities can you remember from the workshops?

Skills/mindsets

Outside the box

'I learned to think outside the box, its a new skill that I am now developing'

Imagination

'I did the building brick activity that taught me to use my imagination'

Perspective x4

'To look at things from different perspectives and to be optimistic'

'to look at things in a different perspective'

'Looking at things from a different perspective, and asking why.'

Positive x2

'To look at things from different perspectives and to be optimistic'

'I learned to have a positive mindset'

New skills

'I learned to think outside the box, its a new skill that I am now developing'

SKFRDWACHHSHscER

Approach x3

'The building one and the taboo one'

'Played taboo,

'I did the building brick activity that taught me to use my imagination and think of different ways to use a brick instead of the simple purpose'

Appendix Twenty: Questionnaire Analysis; Categories and quotes

Application

'It gave me ideas about how to distract myself when I am in pain to help me deal with it.'

Did the workshops make you think about your pain or experience of living with pain differently? If so- how?

Skills/mindsets

'Yes, because it made me look at my pain from a different point of view.'

'some of the activities help you look at things from different perspectives'

Application

'I thought about the exercises and how to deal with it'

Approach

'some of the activities help you look at things from different perspectives'

Group

'Yes, I made me think that it not just me having to deal with pain.'

Experience

'It was interesting to explore other ideas.'

Have you used any of the skills, mind sets or activities to help you with your pain management? Can you give any examples?

Skills/mindsets x3

- Analysis

'Yes. I use some of the analysing activities to see what I have to do in the situation I am in.'

- Mindset change

'At school when we are working and I change my mindset to thinking I can do it.'

- Imagination

'I have learnt to use my imagination and think of other ways to deal with my pain that i wouldn't normally think of'

- Lateral thinking

'I have learnt to use my imagination and think of other ways to deal with my pain that i wouldn't normally think of'

- Outside the box

'I've used design to help me understand pain and really consider 'outside of the box' pain management techniques.'

Application

- Analysing the situation

'Yes. I use some of the analysing activities to see what I have to do in the situation I am in.'

- Can do attitude

'At school when we are working and I change my mindset to thinking I can do it.'

- School

Appendix Twenty: Questionnaire Analysis; Categories and quotes

- *'At school when we are working and I change my mindset to thinking I can do it.'*
- **Distraction**
'I have started to try drawing and things to distract myself when my pain is bad.'
- **Outside the box pain management techniques**
'I've used design to help me understand pain and really consider 'outside of the box' pain management techniques.'
- **Sharing**
'Let people know when I'm in pain and learned to speak out'
- **Voice**
'Let people know when I'm in pain and learned to speak out'
- **New approaches**
'I think outside the box and don't rely on the simple methods to decrease or stop my pain'

Can you think of how what you learned might be useful in the future?

Application

- **Pain explanation**
'Often it's difficult to find words to explain illnesses when you don't 'look ill' so design has really shown me a new way of describing it, without words.'
- **Visualisation**
'design has really shown me a new way of describing it, without words.'
- **Hopes/expectations in Dealing with pain**
'I hope using then things I learnt will help me deal with my pain from now on.'
- **Distraction**
Do activities too take my mind of things.
- **Areas of application**
 - **Work/Job**
'when I am older in work.'
'When I'm working with a team in a job and need to look at everyones perspectiv
'I believe that I have got skills from the workshop that could possibly help me wit
my confidence and job ideas too.'
 - **School**
'At school, with my pain management'

Skills/ mindsets x2

Perspective/ point of view

'When I'm working with a team in a job and need to look at everyones perspectives'

Positive mindset

'To not think about the worst that might happen when I get pain'

Appendix Twenty: Questionnaire Analysis; Categories and quotes

Would you recommend the workshops to other young people who are living with pain? (Tell us why you would or wouldn't)

Experience

'Yes because I think they were helpful and useful'

'Yes. Because I found them really helpful'

'I would because it has helped me'

'if it helps just a bit it's better than living with pain.'

'it has certainly opened my eyes and hopefully it could do for others!'

'I think it is helpful to explore different paths to deal with pain'

Application

'could benefit your pain management.'

'you could use them to deal with your pain'

'Basic learning that I can share a problem.'

'I think it is helpful to explore different paths to deal with pain'

Group

'The workshop helped me to understand that there are more types of pain than my own and we all cope with it in different ways'

'this helps to understand the solutions and why some solutions help people more than others.'

How would or have you described the workshops to others?

Approach

'and keeps everyone involved and thinking.'

'A different way of looking at pain without discussing it in a serious/negative way.'

'It's a workshop thats unique,'

Experience

'Fun, useful and interesting.'

'Really fun'

'A different way of looking at pain'

'Helpful, exciting'

'well worth attending'

'I'd describe the workshop as interesting.'

Mindset/ skill

'It helps you think about different skills too.'

'helps you to think differently when you get pain'

'Also an eye opener to tackling pain form different points of view, and in different ways'

'have to think outside the box'

'if you can do this, nothing can stop you.'

Application

'It helps to manage your pain'

'Learning how to do things when you are in pain to take your mind off it.'

'form different points of view, and in different ways without relying on other people.'

Appendix Twenty: Questionnaire Analysis; Categories and quotes

'you have to think outside the box to achieve your goal, if you can do this, nothing can stop you.'

Group

'and keeps everyone involved and thinking.'
sharing experiences,



Pain Management Service

Resource Folder

Welcome to the Pain Management Therapy Service at Sheffield Children's Hospital

Our Pain Management Service provides assessment, treatment and support for children and young people with chronic pain, and their families.

This resource folder can help you to develop an effective approach to managing pain and the impact that pain can have on your every day life. As you develop your resource folder it will become a practical guide for your recovery now, and in the future as a toolkit whenever you need it.

The pack will give you the opportunity to identify what is important to you and to start working towards your hopes and plans.

We aim to:



Work together to actively manage pain



Empower young people



Facilitate recovery

Our therapy team



Occupational Therapists
& Physiotherapists

Your therapist is:

Other people you might meet on your journey



Psychologists &
Psychiatrists



Nurses



Doctors

Useful contacts

If you need to make or change a therapy appointment please call 0114 271 7227

The Pain Nurse Specialists can be contacted on 0114 271 7397
available Mon to Fri 8.30am-4.30pm

Introducing the Sheffield Children's Hospital Pain Management Programme.

This is an active coping program to help you make the most of your pain therapy sessions and gain skills and understanding to use now and in the future.

The programme includes information about pain, how it works in the body and how our bodies and minds adapt to living with long term pain. It also takes into account the things that are important to you so that you can work on these in the sessions and outside in your daily life.

Introduction

1

The Pain Team includes; Pain Doctors, Nurses, Psychologists, Physiotherapists and Occupational Therapists, some of whom you may have met in your clinic appointment. After the first clinic appointment you will have been given information about this programme and sent an opt in letter to see a named therapist- either an Occupational Therapist or a Physiotherapist.

Education: Explaining pain

2

Your first sessions will focus on understanding your pain. Your therapist will be able to share with you up to date information about pain, and the effects of pain on our minds and bodies. This will be the foundation for the range of treatments and strategies covered in the programme.

Education: Self awareness

3

Identifying what's important to you and why its worth the effort to work through the programme. Active coping means taking a proactive role in your recovery. This includes finding out about your problem, making plans and exploring different ways of doing things. Passive coping is rarely helpful-this is about waiting for someone to 'fix' your pain, avoiding activity or relying only on medication to reduce your pain.

Pain management

4

This stage explores pain management ideas covering all aspects of your day to day life, with priorities set together with your therapist. These might include practical plans for increasing movement and mobility, starting or returning to activities, improving sleep, desensitisation, sorting out problems with school, help with low mood and anxiety, improving your social life and supporting your family to help you.

Review

5

Making sure that we're on the right track, going in the right direction for you and working on things that are important to you. The therapists work very closely with other members of the team to make sure that you have the right advice and support with your pain management including any medications you might be taking.

Discharge

6

Your therapist will plan with you when discharge is likely to happen. This is usually when you have worked through the programme or got as far as you can at the time. You will have a plan of how to continue your programme and what to do if you notice things are becoming more difficult (a setback plan). Discharge from Pain Therapy does not usually mean discharge from the Pain Service. You will still be under your consultant unless they too feel you don't need to be seen anymore. If you are taking medication prescribed by the consultant they will continue to review you.

Guide to the Sheffield Pain Management Therapy programme

Understanding Pain: Understanding about the importance of pain in our bodies, how it works and why pain can become a longer lasting problem.

Setting Goals: Setting goals to help you work towards the things that are important to you, both now and in the future.



Reducing Stress: Learning more about stress and how it links with pain. Finding ways to deal with stress and getting the support you need.

Pacing: Balancing activity with rest and sleep to help you build a strong base for recovery.



Pain Management



Thoughts, feelings and actions: Understanding how thoughts and feelings affect your mood and activities.

Problem Solving: Helping you to resolve practical problems, such as managing school or seeing friends more. Managing set backs in your health.



Relaxation & Mindfulness: Exploring different ways to help your body and mind relax and improve wellbeing.

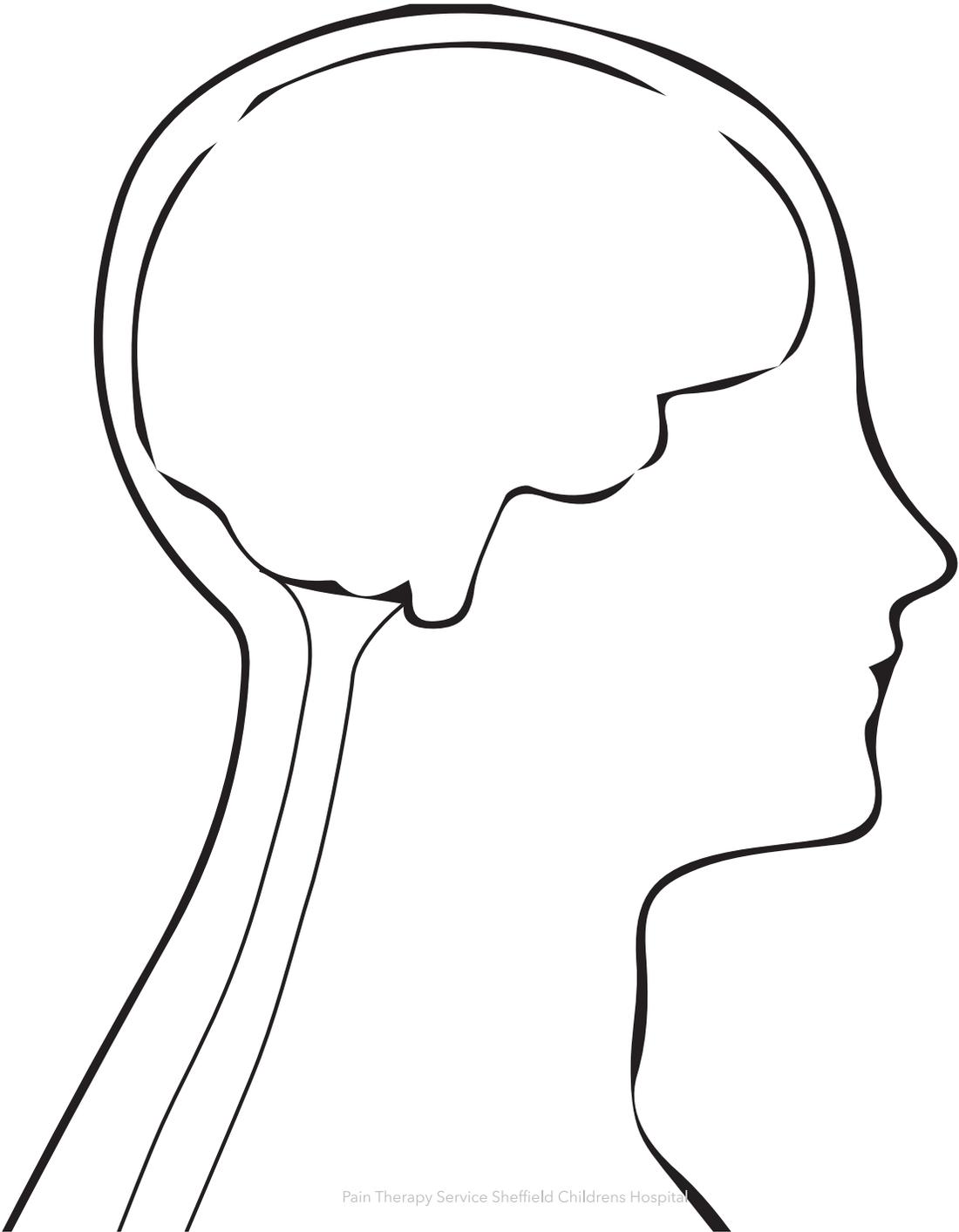
Rehabilitation: Helping you to build up strength and fitness using activities and exercise. Finding ways to do the things that are important to you.



Sleep management: Exploring ways to help you get the best possible nights sleep.

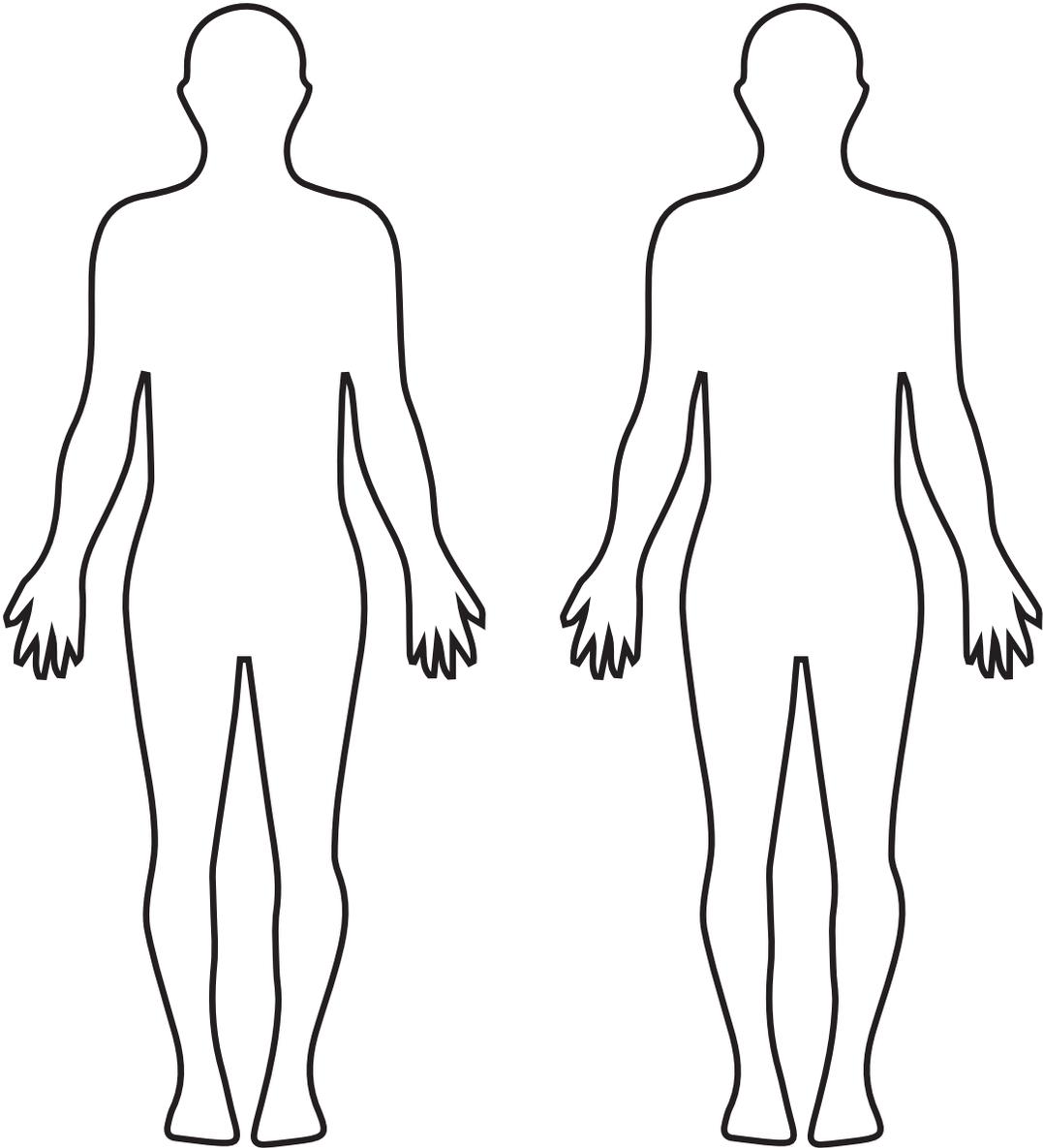


Understanding your pain





Understanding your pain





Schools checklist

You might find that whilst you learn to manage your pain you need additional support at school/ college to help you feel supported.

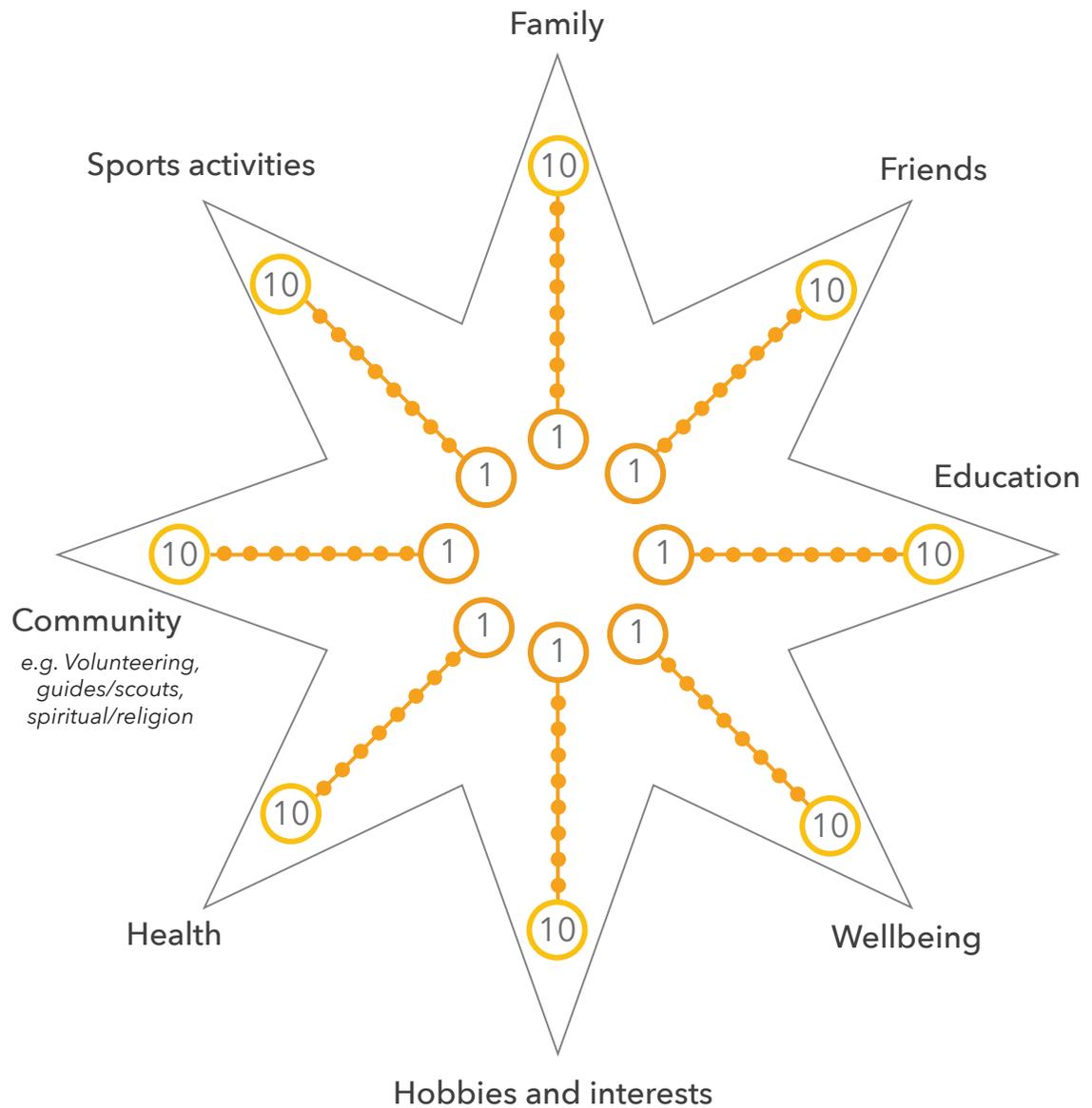
Things that I think could help me in School

Tick anything that you think would help you

- To know that staff at school understand my problems
- To have a pass that explains my needs to all staff
- To leave class early/ late to avoid the rush
- To be able to move around in class when I need to
- To have homework/ teaching materials provided for me when i am absent from class or need to leave early.
- To have help regarding stairs e.g. access to a lift key
- To have somewhere to leave heavier things e.g. a locker
- To have support with note taking / breaks from writing
- To have my timetable / number of subjects changed so that I can manage my workload better
- To have a mentor / someone that I can talk to at school
- To have help with friends / issues with bullying
- To have 'timeout' from lessons to rest
- To have a place in school where I know I can rest / lie down
- To have time out during PE/ PE sessions changed so that I can manage them
- To have classes changed so that I don't have to walk so far
- To have special arrangements for exams
- To have help with medication in school
- To have seating I am comfortable with
- To have a professional letter for school
- To have special arrangements for toileting



What matters to me?



Pain Management Therapy Service: Appointment Summary & Action Plan

Date:
People Present:

Consultant:

Summary of appointment:

Action Plan:

Next Appointment:

Therapist Signature:

Date:





The pain cycle

Pain can change our behaviour and make us think and feel differently. We might try to protect the part of the body that hurts, change the way we stand or walk or do less of the things we usually do.

Doing less can create problems in our muscles and other body systems- this leads to loss of fitness (called deconditioning) - making it more difficult to be active.

Our confidence and mood might change as we avoid activities, see friends less and start to feel worried about longer term hopes and plans.

The result is a cycle that affects all aspects of our lives. The picture below shows how our minds and bodies get pulled into the pain cycle.





The recovery cycle

To break the Pain Cycle we need to change what we do and how we think about pain and activity.

The recovery cycle shows us how this can happen:

