LIVING WITH PAIN

A design research project with chronic pain patients and clinicians to improve the communication of their complex pain lived experience.

Exegesis in support of practice-based Thesis
Master of Design
Auckland University of Technology

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Attestation of Authorship

I hereby declare that this submission is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person (except where explicitly defined in the acknowledgements), nor used artificial intelligence tools or generative artificial intelligence tools (unless it is clearly stated, and referenced, along with the purpose of use), nor material which to a substantial extent has been submitted for the award of any other degree or diploma of a university or other institution of higher learning.

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Contents

Abstract 9
Positioning Statement 11

Chapter 01 - Contextual Review **13**
Chronic Pain 17
Chronic Pain Experiences 19
Interpreting and Navigating the Chronic Pain Experiences 23
Communicating Chronic Pain to Clinicians 27
Treatment for Living with Chronic Pain 29
Clinical Tools to Assess Patient's Pain 33
The Role of Design to Support Improved Health and Wellbeing 37
The Opportunity for this Research 43
Research Question 44
Aims 44

Chapter 02 - Methodology **45**
Project Timeline 48
Action Research 49
Research Methods 51
Design Methods 52

Chapter 03 - Documentation of Research **81**
Research and Making Map 83
Discovering the Problem and How to Design a Solution for it 85

Defining the Research Project 121
Developing the Research Project 163
Final Product 245

Chapter 04 - Discussion **259**
Limitations 266

References 269
Appendices 277

ABSTRACT

Chronic pain is a persistent pain that lasts over three months. Those who have chronic pain may have to go to various specialists, clinicians, and programs for their pain. Communicating multifaceted personal experiences, like chronic pain, is difficult. Chronic pain's invisible nature makes it so that others cannot easily express or understand it. The problem of miscommunication then significantly affects health outcomes and patient-clinician relationships. This research explored the role of design to help make these conversations more effective through the development of objects to make experiences of pain more tangible. Making experiences 'symbolic' through objects was hoped to create room for discussion and support patients in better communicating their feelings. This may result in clinicians better understanding patients, who may, in turn, be able to understand their clinician better. Literature shows improved patient outcomes where there is a beneficial patient-clinician relationship.

Through The Auckland Regional Pain Service (TARPS), practising experts in chronic pain were recruited, along with those who have been in active chronic pain management and continue to live with chronic pain. Their involvement was supported using an action research framework to develop a design solution that meets the different needs of the participant groups.

The project demonstrated the complex nature of the chronic pain experience and how using design can assist in unpacking chronic pain. Furthermore, the creative methods used help show how design may help support New Zealand's health system. The design of the individual objects and the supporting toolkit demonstrate the potential for physical resources to help facilitate conversations and the sharing of ideas that otherwise may not have happened.

POSITIONING STATEMENT

My background in this research is that of a product designer. Therefore, I have experience in utilising design to improve experiences through objects. Product design can range from designing objects for better usability to creating new products and services that enhance users' lives. With this research project, as the researcher, I have never experienced chronic pain. Initially, I struggled to know what a chronic pain experience entailed. For this reason, it was important to me that I involved chronic pain clinicians and those who have chronic pain in my research. This meant that patients' and clinicians' input could challenge my assumptions and inspire new ideas and direction in the research project. My role was as a conversation facilitator; I was not creating a tool to measure pain but searching for a way for patients and clinicians to express themselves better and understand each other. My interest in design and its relationship with complex ideas drew me to this project. Design can help communicate complex ideas and help people navigate the experiences attached to them. Pain and, more specifically, chronic pain are complex experiences that often need to be unpacked to be understood. I was interested in how design, more specifically, through the creation of objects, can help reveal peoples 'truths' concerning their experiences. In this way, products can help make tangible experiences and make it easier to communicate with others.

Throughout this project, it was interesting to see how experiences are constructed, the interpretation of shared experiences, and how simple objects can make these conversations happen to unpack these personal lived narratives.

CONTEXTUAL REVIEW

Introduction

The IASP (International Association of the Study of Pain) defines pain as “an unpleasant sensory and emotional experience associated with, or resembling that associated with actual or potential tissue damage” (Raja et al., 2020, p. 1977). This means that an individual in pain may experience a feeling that creates discomfort and changes in emotions, which can be, but not always be, caused by tissue damage (Raja et al., 2020). This definition of pain is commonly used in clinical practices, nursing practices, and pain management services (Sonneborn & Williams, 2020). However, this definition has been debated by pain experts, for it is argued to be a broad definition and does not consider the subjective, personal, and diverse experiences to be had with pain. The IASP definition of pain has been revised and differs from the original 1979 version (Treede, 2018). The meaning from the 1970s was similar, yet compared to the modern definition, it is very narrow: “An unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (Raja et al., 2020 p. 1977). The meaning of this definition from the 1970s did not consider pain’s emotional or psychological aspects

(Raja et al., 2020). Another common definition in pain medicine, especially nursing, is “Pain is whatever the experiencing person says it is, existing whenever he/she says it does” (Herr et al., 2019, p. 404). Some may consider this definition contentious in pain medicine, as it excludes those who cannot self-report their pain (Herr et al., 2019).

Pain can be categorised as acute, chronic, and episodic (Gil & Cheng, 2023). Acute pain is a temporary pain defined by tissue damage often associated with injury or pain felt after surgery (van Griensven, 2017). In comparison, chronic pain is a persistent pain that lasts over three months (Royal College of Physicians & NICE, 2021). Episodic pain, or breakthrough pain, can be pain that occurs spontaneously or in a transitionary period, like after the treatment of painkillers (Mercadante et al., 2002). Episodic pain is considered a “transitory exacerbation” (p. 833) over the baseline of where pain being experienced by the individual typically is (Mercadante et al., 2002). These categories of pain can be further defined by three other categories: nociceptive, neuropathic, and nociplastic pain (Mears & Mears, 2023). Nociceptive describes tissue damage or inflammation (Igolnikov et al., 2018). Similarly, neuropathic is damage to sensory nerves (Murnion, 2018). Both neuropathic and nociceptive are caused by brain mechanisms responding to physical damage. Recently, a third term has been coined for conditions where the patient cannot tell how bad their pain is, called nociplastic pain (Sutherland et al., 2022). Nociplastic pain manifests when the brain becomes hypervigilant and exaggerates patients’ pain (Bułdyś et al., 2023). Nociplastic pain usually appears when there is no apparent tissue damage.

Traditionally, pain was viewed as a survival tool to warn or caution against an event, object, or experience (Sutherland et al., 2022). If the body hurts or causes pain, your body is telling you to change an action being done or was done (Honkasalo, 2000). Pain also exists emotionally and spiritually, making pain a complex and multifaceted experience for each person (Scarry, 1985). Many factors influence the interpretation of pain, such as gender, sex, culture, age, and other socio-demographic influences (Bendelow & Williams, 1995).
has context menu

Chronic Pain

The focus of this research is chronic pain. Chronic pain is defined as persistent pain that lasts longer than three months (Royal College of Physicians & NICE, 2021). In New Zealand, 21.3% (around 894,000) of adults had chronic pain in 2022-2023 (Annual Update of Key Results 2022/23, 2023). Chronic pain can be described under the terms of Musculoskeletal, Complex Regional Pain Syndrome, and Fibromyalgia (Bair et al., 2009; Haight et al., 2021; Halawa & Edwards, 2015). Musculoskeletal refers to pain in the muscles and bones (El-Tallawy et al., 2021). More specifically, musculoskeletal pain can appear also in joints, ligaments, and tendons (Arendt-Nielsen et al., 2011). Complex regional pain syndrome, commonly seen after surgery or injury, can be described as a "disproportionate" (p. 1) pain to what should be felt and for how long (Bruehl, 2015). It is commonly partnered with hypersensitivity to pain or touch by the region in pain and, in severe cases, visible changes in skin or growths in the affected area (Bruehl, 2015). Fibromyalgia is a chronic disorder specific to a disease in which tender pain is felt throughout the whole body and can be considered a musculoskeletal type of pain (Halawa & Edwards, 2015). The length of chronic pain depends on the severity of various factors such as ethnicity and the socio-demographic status of individuals; however, two common factors are age and weight (Majedi et al., 2020).

Chronic Pain Experience

Chronic pain can affect a patient's physical, emotional, and spiritual aspects of their life (Honkasalo, 2000; Iphofen, 2013; Mills et al., 2019). In extreme occurrences, constant, persistent pain can make individuals with chronic pain disabled (e.g., making them unable to move and have agency), which can result in isolation or an inability to undertake or participate in 'everyday' activities, whether it is religious practice or ability to work (Bair et al., 2009; Iphofen, 2013; Koesling & Bozzaro, 2021; Kugelmann, 1999a; Majedi et al., 2020). What is commonly experienced in chronic pain patients is the mysteriousness of their pain - chronic pain's existence is invisible and is an independent inward experience (Eccleston, 2018; Iphofen, 2013; Koesling & Bozzaro, 2021; Werner & Malterud, 2005). This means people who do not have chronic pain (and sometimes those who do) have trouble understanding persistent pain (Iphofen, 2013; Koesling & Bozzaro, 2021; Kugelmann, 1999b; Werner & Malterud, 2005; Wynne-Jones et al., 2011). In the work setting, individuals living with chronic pain sometimes cannot do their jobs as their pain can be debilitating (Fisher GS et al., 2007; Kugelmann, 1999a). In such events, they commonly seek assistance from the organisation they are a part of. However, most of the time, their management does not believe they are in pain as they appear well, and they may consequently be rejected from specific work benefits (Kugelmann, 1999a). Such situations of individuals without chronic pain not believing in understanding the existence of chronic pain may cause frustrated individuals with chronic pain and create feelings of distrust, leading to depression, suicide, and a breakdown in relationships (Forgeron et al., 2010; Mills et al., 2019; Themelis et al., 2023; Werner & Malterud, 2005). Along with others who may not believe in the existence of chronic pain within individuals, another common experience with those living with chronic pain is an addiction to opioids and painkillers to solve their pain (Cheatle et al., 2023; Kathiresan et al., 2020).

Frequently, patients may use metaphors to help describe their pain (Munday et al., 2020). Consequently, a well-known pain assessment questionnaire (The McGill Questionnaire) uses similar words and language via a list of 78 adjectives (i.e., itchy, flickering, dull, sore, etc.) to help patients describe their pain. However, some of these words are unnecessary, as studies have found that most patients use common language when describing their pain. People who experience chronic pain describe their chronic pain in many ways, including metaphors. A recent study found that patients commonly used eight types of metaphors to describe their pain: Causes of Physical Damage, Common Pain Experiences, Electricity, Insects, Rigidity, Bodily Misperception, and Death and Mortality (Munday et al., 2020). Causes of physical pain were the most common

in the Munday et al. (2020) study. They referred to participants describing their pain in terms of temperature, weight, pulling, sharp objects, or related to movement like “throbbing or shooting” (p. 821). These terms came from metaphors saying that it feels like a “hot knife” (p. 822) or “razors, pins, and shards of glass” (p. 821) and “as if sandpaper is being rubbed over my skin” (p. 822). Common pain experience was where study participants used other painful experiences to describe their chronic pain. Experiences included pregnancy (or childbirth), flu, working out, and having a bruise or fracture. Electricity and insects were used to describe the feeling of pain like insects or lightning across the skin. Rigidity was referred to as stiffness or immobility. Bodily misconception could refer to those with phantom limb pain, as in this study, the participants felt the original pain was not part of them. Finally, participants thought of death, or the process, when describing their pain. Saying such metaphors as “I can feel pieces of me die” (p. 824) and “the pain in my head makes me feel like I am going to die” (p. 824)

Interpreting and Navigating the Chronic Pain Experience.

Chronic pain can be a mystery to those who have it, causing some who have it to question themselves and what they are feeling (García-Rodríguez et al., 2023; Koesling & Bozzaro, 2021; Newton et al., 2013). Additionally, chronic pain patients may often want a name or diagnosis, something that can prove the pain they are feeling is real and something that can be cured (Rhodes et al., 1999). Chronic pain affects all facets of a person's life, including physical, spiritual, and mental (Honkasalo, 2000; Iphofen, 2013; Mills et al., 2019). How the patient navigates the world may influence how they interpret and experience their chronic pain, so their cultural values and beliefs play a part in understanding their lived experience with chronic pain (Lane & Smith, 2018).

Different cultures[1] interpret pain uniquely. Those who are Chinese can often view pain as an experience that must be endured and may not be shown outwardly, for they may be pressured to appear strong and healthy for their family, as some in Chinese culture are family-orientated (Lewis et al., 2023; Tung & Li, 2015). Also, appearing strong may extend to interactions with those in healthcare (Chen et al., 2008). This aligns with Confucius's beliefs of showing self-restraint and not expressing discomfort (Tung & Li, 2015). Pain is often viewed as an invader[2] due to karma or fate or not having a balance or harmony of energy, as seen in Taoist philosophy (Chen et al., 2008). Some Chinese may think this imbalance of energy, or pain, may have been caused by a change in environmental conditions and hence might describe their pain as wet or cold (Lewis et al., 2023). Individuals who are Chinese also have mentioned that their chronic pain causes them to feel sadness, anger and impatience (Lewis et al., 2023). Emotions like these may be rooted in the Chinese culture's stigma against cancer and the pain it causes (Lewis et al., 2023). This stigma could cause other feelings towards pain, like helplessness and loss of control or catastrophising pain (e.g., like it is torturing the individual) and, in severe cases, towards suicidal ideation (Lewis et al., 2023).

Māori view their health as connected to the psychological, physical, social, and spiritual (Pain | Mamae (Frailty Care Guides 2023), n.d.). Hoeta et al. (2020) did a systematic review to see if there were any culturally relevant questionnaires that “capture” (p. 44) the Māori pain experience. They identified that Māori associate their whakapapa and whanau with their experience with pain, as Māori view themselves as part of a larger community. Experiences like this were identified in this study as being in conflict in pain management and clinical spaces, for clinicians can view pain as an individual physical experience.

They then discuss how whānau involvement in pain management is essential, as whānau can be “health advocates” (p. 44) for those who may be hesitant to talk about their pain to clinicians. Family involvement in healthcare for Māori may come through their

1 Māori and Chinese were chosen as they help show different perspectives and both groups are commonly found in the New Zealand health system, and both groups share a difficult time in the New Zealand health system (Rata & Zubaran, 2016).

2 Something foreign that has entered the body and is unwanted.

close cultural ties to whānau and whakapapa being important (Hoeta et al., 2020). Māori often mention as well that cultural practices to manage pain are ignored by clinicians also (Hoeta et al., 2020). Also, Hoeta et al. (2020) say that spiritual aspects should be addressed in clinical practice when treating pain in Māori. For example, they suggest that Māori often feel looked down upon by their clinicians when they want to practice traditional healing or home remedies, making Māori feel their clinicians could be ignoring their beliefs (Hoeta et al., 2020; Magnusson & Fennell, 2011; Mcgavock et al., 2012; McGruer et al., 2019).

From a kaupapa Māori point of view, it is better to involve and engage Māori in the process of whakapapa. Whakapapa is one's ancestry and cultural roots. Hoeta et al. (2020) suggest that whakapapa be involved in pain assessment to give a sense of belonging and empowerment in an isolating, hurtful time. Further, the involvement of whakapapa in healthcare can give mana (control over self) to manage chronic pain within Māori.

Communicating Chronic Pain to Clinicians

Patients who frequently go to various types of clinicians must have a functional and practical relationship with them to get the best results (Bair et al., 2009; Henry & Matthias, 2018; Miller et al., 2017; Shebeshi et al., 2023; Upshur et al., 2010). The relationship impacts how a patient and a clinician interact with each other (Sullivan et al., 2021). For example, patients are less likely to communicate with a clinician if their experience is one that they are not satisfied with (Bair et al., 2009). In terms of chronic pain, patients are often met with disbelief or distrust in their narrative of pain by medical persons (Sullivan et al., 2021). However, it is hard for clinicians to judge and assess pain for painkillers as there is no objective way to measure a patient's need for painkillers, for example (Gourlay et al., 2005). So, clinicians may rely on tools or their knowledge to assess patients' pain objectively (Dansie & Turk, 2013). Patients may also cultivate a relationship with other clinician-like figures in management classes and pain services (Upshur et al., 2010). As chronic pain is hard to live with, patients may be recommended to or find management classes and pain clinics to learn to live with the pain (van Griensven, 2017). These clinics and management classes may implement different therapy strategies and exercises to help relieve or teach individuals how to live with chronic pain (Hylands-White et al., 2017).

Treatment for Living with Chronic Pain

There are contrasting thoughts, opinions, needs and wants between chronic pain clinicians and their patients regarding the use of painkillers to treat or manage chronic pain (Ekelin & Hansson, 2018; King, Steven A, 2019; Mishriky et al., 2019; Morillon et al., 2023; Norton & Dibb, 2023). For example, patients may be hesitant to take painkillers because of the risk of adverse ramifications like stigma, addiction, or other side effects (McCracken et al., 2006; Werner & Malterud, 2005; Wilbers, 2015). This example speaks to a much larger issue within the clinician-patient relationship. The role of pain treatment is complicated and unique for each patient (Dassieu et al., 2022). Painkillers (especially opioids) can be very effective in treating pain, yet they have become problematic globally due to being highly addictive (Ling et al., 2011). Medical Practitioners may struggle then to prescribe their patients an effective pain killer, as there are potential challenges associated with addiction as a consequence (Gourlay et al., 2005; King, Steven A, 2019; McCracken et al., 2006). In addition, patients may often be wary of taking strong painkillers as they are concerned about the risk of getting addicted or the stigma that surrounds it of them being perceived as a "junkie" (Norton & Dibb, 2023, p. 1433). Clinicians, however, are the ones who decide if their patients get painkillers (Norton & Dibb, 2023). This is not always straightforward for the clinician as there may be complex decision-making involved. There are cases where some patients catastrophise the pain they have to get painkillers, while others downplay it to avoid medication, then impacting their pain in the long term (Ekelin & Hansson, 2018). As a result, it can be difficult for a clinician to adequately determine their patient's pain, so they often use various assessment tools to help them (Glajchen, 2001; McCracken et al., 2006). Some patients want their clinician to see their pain as it affects their whole person rather than as a symptom or being treated as acute pain. When treated like acute pain, or as a symptom, chronic pain can usually be reduced to the patient's need for painkillers (Norton & Dibb, 2023). The clinician then may ignore the patient's need for the clinician to validate their pain's existence and its effects on their life (Norton & Dibb, 2023).

Along with painkillers, therapy is often used as an alternative to help patients manage their pain. Many types of therapy can help relieve chronic pain. There is physical, creative, and more technologically involved therapy (Ahmed et al., 2023; Aytar et al., 2023; Hass-Cohen et al., 2022). There are many therapeutic solutions, but no one solution exists for all individuals with chronic pain (Morillon et al., 2023). Some examples are creative art, physiotherapy, and virtual reality. Creative art therapy focuses on art and craft making that helps make meaning around the pain (Hass-Cohen et al., 2022). On the less creative side, physiotherapy

teaches patients how to cope with their pain through physical exercise (Aytar et al., 2023). Virtual reality is relatively new and has been implemented through headsets to help with chronic pain (Ahmed et al., 2023). Virtual reality therapy aims to provide patients with an interactive experience that promotes exercise and activities they cannot do in reality. It is more accessible and cost-effective than painkillers (Ahmed et al., 2023).

Some chronic pain clinicians, most of the time, assess the patient's pain in the context of painkillers (Ekelin & Hansson, 2018). While painkillers are one factor to assess for, a clinical evaluation of pain is complicated as chronic pain is invisible and a multi-faceted persistent experience (Strassels, 2006). Some clinical tools have been created to help with chronic pain to aid clinicians in assessing and judging, in an objective way, how the pain may be affecting their patient.

Clinical Tools to Assess Patient's Pain

Numerical Rating Scale (NRS) and Visual Analogue Scale (VAS)

NRS and VAS are the most used in health care as they are quick and efficient in assessing general pain (Dansie & Turk, 2013). The NRS use numbers and asks people to rank their pain on a scale from 1-10 (10 being the worst). The VAS uses a scale with various faces or other images portraying different types of pain (Hawker et al., 2011). Patients will be asked to choose an image that best represents their pain. Both assessment tools are efficient and take little time to get patient pain information. When it comes to individuals with chronic pain, their pain experience is multifaceted, so having these individuals sum up their whole experience by a number or one image reduces the nuances in their experience (Bosdet et al., 2021).

The McGill Pain Questionnaire (MPQ)

Created by Ronald Melzack, Joel Katz, and Mary Ellen Jeans at McGill University in Canada in 1975, the MPQ is a List of 78 words that address the feeling of pain, what changes your pain, what increases and decreases pain, and the strength of pain (Ngamkham et al., 2012). Since 1975, clinicians have widely used it as it addresses many aspects of a patient's pain. Furthermore, it can be translated and used across cultures (Edirisinghe et al., 2021). Short forms of the MPQ have been created (SF-MPQ), including a couple of words and scales assessing aspects of the patient's life (Short-Form McGill Pain Questionnaire, n.d.). The MPQ is criticised for needing to be updated (e.g., it does not clearly illustrate a patient's pain in its full complexity) and should be used with other pain assessment tools (Main, 2016).

EPPOC

EPPOC (Electronic Persistent Pain Outcomes Collaboration) has a range of questionnaires that are used mainly by the ACC (Accident Compensation Commission) in Aotearoa, New Zealand, to cover costs for pain management and services (Pain-Management-Og.Pdf, n.d.). The initial questionnaire includes an intensity and interference scale, a depression and stress scale, a self-efficiency scale, and a catastrophising scale (Tardif et al., 2017).

A specific criticism of the EPPOC questionnaire - as it is used in Oceania the most - is that it does not address the cultural considerations of Māori (Hoeta et al., 2020). This is because a Māori view of health is holistic through whakapapa and whānau. The questionnaire does not have any section that takes into consideration Māori cultural views (Antunovich et al., 2024; Hoeta et al., 2020; Mcgavock et al., 2012; McGruer et al., 2019).

PRISM

Pictorial Representation of Illness and Self-measurement, or PRISM, is primarily used in chronic illness but has been adapted for chronic pain (Tomioka et al., 2021). Patients and their clinicians use the tool to assess suffering (Tomioka et al., 2021). It works by the clinician drawing the patient on paper, usually represented by a circle or sometimes a disc. Next, the patient places discs, however close or far within the paper, by the circle representing the patient. In most cases, the disk is representative of illness; the distance (or separation) symbolises how much the chronic illness affects the patient (Tomioka et al., 2021). If the disk is close to the self, the patient may find it difficult to control the illness and symptoms, significantly affecting their life and suffering (Peter et al., 2016). If the illness is chronic pain, the closer the illness disc is to the self, the greater the severity of the pain.

PRISM is an effective tool as it can be altered so the clinician can learn specifics about how the illness affects the patient's life (Kassardjian et al., 2008). In one study by Kassardijian et al. (2008), researchers altered PRISM to assess its effectiveness when assessing suffering and relationships with chronic pain patients (Kassardjian et al., 2008). Along with an illness and pain disc, they have healthcare and a spouse or other close family member discs (Kassardjian et al., 2008). The closer these discs are to the self, the more positive impact they have on the patient and illness (Kassardjian et al., 2008). PRISM can be an excellent way to assess the patient's life, illness, and other factors affecting their life while experiencing chronic pain. In this way, it is one of the most holistic pain measures.

The Role of Design to Support Improved Health and Wellbeing

Design can be used to make personal stories and ideas tangible (Bill et al., 2015a). It does this through objects, services, systems, and the design of experiences, allowing the user to engage in something that allows reflection (Flusser, 1999). Designing well-designed products allows for criticism of our experiences and reveals our genuine needs and wants (Grudin, 2010). To do this, design can make objects that reflect experiences which are understandable and valuable for people to interact meaningfully with the world around them (Norman, 2013). Design can allow for reflection and often lead to problem-solving through design's instinctive way of inspiring idea creation (Brown & Kātz, 2009).

In the context of this research, design is viewed as a tool to navigate the world and make meaning of the world. One design project that displays this is the "Exhibition in a Box" (Chamberlain & Craig, 2013). In Exhibition in a Box, users unpack a box filled with objects and pictures - using them as props for discussion (Figure 1). It was designed for seniors in homes to talk about their experiences (Chamberlain & Craig, 2013). Exhibition in a Box uses objects to help people engage and better understand or make sense of their experiences or reality, allowing personal experiences to be discussed and explored. Exhibitions in a box show design can allow the user to

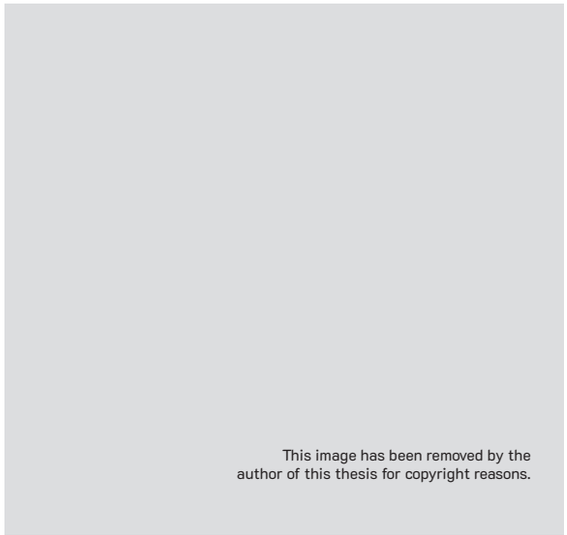

Figure 1.
Exhibition in a Box contents and being used.

(Exhibition in a Box, n.d.) https://lab4living.org.uk/projects/exhibition-in-a-box/

think critically about the world around them, as these props become “alive” for participants and have given meaning to them through conversation. These types of conversations may lead to problem-solving in the users’ lives. In this way, the design facilitates but also liberates users to engage, talk, and realise what has been on their minds (Elsbach & Stigliani, 2018). Exhibition in a Box engages users in reflective conversation through aesthetics and form to make motives and wants tangible.

Alternatively, The Things for Thought Toolkit has participants converse through haptically feeling objects (Zino et al., 2021). In contrast to Exhibition in a Box, form and aesthetics are less focused on, and instead, the basis of the toolkit is textures and touch. Things for Thought Toolkit allows users to pick clay objects (Figure 3) from a bag, put them under a cloth, and feel them (Figure 3). The participants follow what the cards say to stimulate conversation and relate it to the objects they are feeling (Zino et al., 2021). One of the reasons the toolkit’s design works is that it can allow users to reflect upon ideas from themselves and those around them.

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Figure 2. Assortment of objects from the Things for Thought Toolkit. (Zino et al., 2021, p. 86)

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Figure 3. Thinking Through Objects. (Zino et al., 2021, p. 94)

More closely related to the research subject matter, the project Printing Pain, Dulake et al. (2017) used design to describe stories and experiences of chronic pain (Printing Pain — Digital Materiality Lab, 2017). Dulake et al. (2017) designed software (Figure 5) where young adults with chronic pain could use 3D modelling software to help visualise their pain and 3D print these visualisations (Figure 5).

The personal aspect of this project comes from the users creating an object resembling their unseen experiences that turns into tangible objects that can communicate what previously was unseen. Showing how design is cooperative, Printing Pain was done with chronic pain experts whose knowledge was used and interrogated to create a product that works for patients and psychologists (Printing Pain — Digital Materiality Lab, 2017).

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Figure 4. Example of the Printing Pain software in use. https://digitalmateriality.cargo.site/Printing-Pain (Printing Pain — Digital Materiality Lab, 2017)

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Figure 5. Objects made in the Printing Pain project. https://digitalmateriality.cargo.site/Printing-Pain (Printing Pain — Digital Materiality Lab, 2017)

The Opportunity for this Research

With the help of pain researchers who were consultants to the project, there was an opportunity to work with The Auckland Regional Pain Service (TARPS) to explore the chronic pain experience from the perspective of clinicians and patients. TARPS is a pain management service that has programs and sessions to help those with chronic pain, including a three-week pain program, individual pain self-management program, and relaxation class. The three-week pain program and the pain self-management program are where those with chronic pain meet individually with pain specialists and experts or as a group for the best way to manage and navigate their pain. Before joining the program, individuals with chronic pain may meet with those working at TARPS to see if participating is appropriate for them. However, there is an option for individuals with chronic pain to do the relaxation class, which is a walk-in session that teaches meditation techniques and exercises to relax and provides a place to rest for those with chronic pain. (TARPS (The Auckland Regional Pain Service) · Healthpoint, n.d.)

TARPS is very involved with patients and active clinicians helping those with chronic pain. Therefore, patients and clinicians have experience and need a tool to improve communication with chronic pain patients. Involving these active clinicians, experts in chronic pain, and chronic pain patients, allows the project to change and reflect the needs and wants of chronic pain patients and their clinicians. With their advice, the researcher can reflect upon and then make objects

based on what they say; then, the objects can be criticised for further improvement.

Research Question:

How might using design methods help patients communicate their experience with chronic pain in a clinical context?

Aims:

- Help patients better understand their chronic pain experiences and their clinicians.
- To improve the clinician-patient relationship with respect to how chronic pain experiences are communicated with physical objects.
- Have patients feel validated and respected after talking about their chronic pain.
- Work with clinicians, patients, and experts to create a tool that improves chronic pain communication.

METHODOLOGY

This chapter presents an overview of the action research methodology used to guide the research (Figure 6). I will then present an overview of each method and its application in the research. The research was set in a social constructivist paradigm, which was used to help consider how people construct their experiences and what they mean to them as they navigate through society (Adams, 2006; Armstrong, n.d.; Exploring Social Constructivism, n.d.). As this research project is based on the experience of patients and clinicians, all methods are based on a qualitative research framework, so the research project can better understand people and systems in chronic pain (Bourgeault et al., 2010). The research project's design methods, which were informed by the research methods, used the UK's Design Council Double Diamond framework. The Double Diamond has the names discover, define, develop, define, and deliver for each stage of the framework (Ball, 2019). In practice, In practice,The Double Diamond framework was used to help guide the overall design project's methodological approach, rather than be used as an explicit framework.

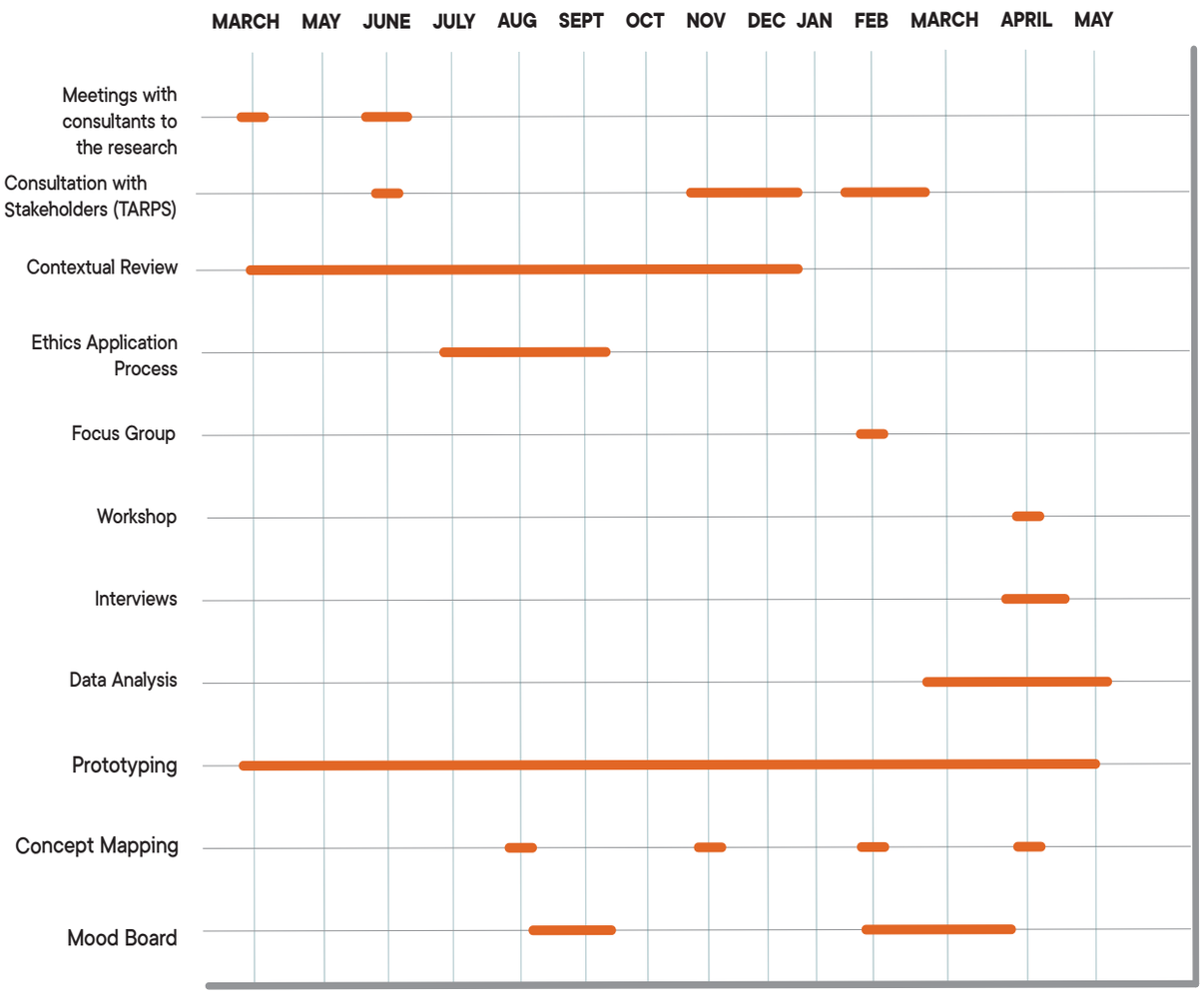

Figure 6. Timeline of the project showing key stages of the research and methods used.

Action Research

Action Research (AR) is commonly used to create change in organisations in areas such as education and healthcare (Gray, 2004). Action Research supports researchers to do this by involving participants within the research project so researchers and participants can have similar values (Argyris et al., 2008; McNiff & Whitehead, 2002). Using AR can help researchers explore participants' experiences and realities and help explain and interpret social problems and experiences, primarily for the researcher (Gray, 2004).

Knowledge is used in different ways and stages in AR as the researcher learns or gains new knowledge throughout an action research process (McNiff & Whitehead, 2002). Action Research supports researchers in repeating a process of planning, acting, observation and reflecting (Figure 7) (Argyris et al., 2008; Cherry, 1999; Gray, 2004; Kemmis et al., 2014; McNiff & Whitehead, 2002, n.d.). Various stages in AR may overlap and can become more fluid and open while findings develop and change through action (Kemmis et al., 2014). An integral part of using AR is reflecting (Reason & Bradbury, n.d.), as researchers can gain knowledge by reflecting on what participants say and do (Gray, 2004; McNiff & Whitehead, 2002; Reason & Bradbury, n.d.). The researcher may also use AR to improve solutions through the researcher's practice (Cherry, 1999; Gray, 2004; Kemmis et al., 2014; McNiff & Whitehead, 2002).

In the context of this research, I used AR to help me better understand the chronic pain experience as it pertains to a clinical setting and what it is like to communicate such an experience. Furthermore, AR was used to inform and influence my practice (design) through the reflection and planning stages of the AR process (Cherry, 1999; Gray, 2004). Knowledge in this research project was generated by making objects that reflected the experiences of patients and clinicians and then replanning after feedback.

Feedback was also provided by others who are not in the chronic pain space, specifically other designer students. Having a variety of inputs and critiques from different perspectives relevant to my research allowed my project to evolve and result in a deeper, more rigorous outcome.

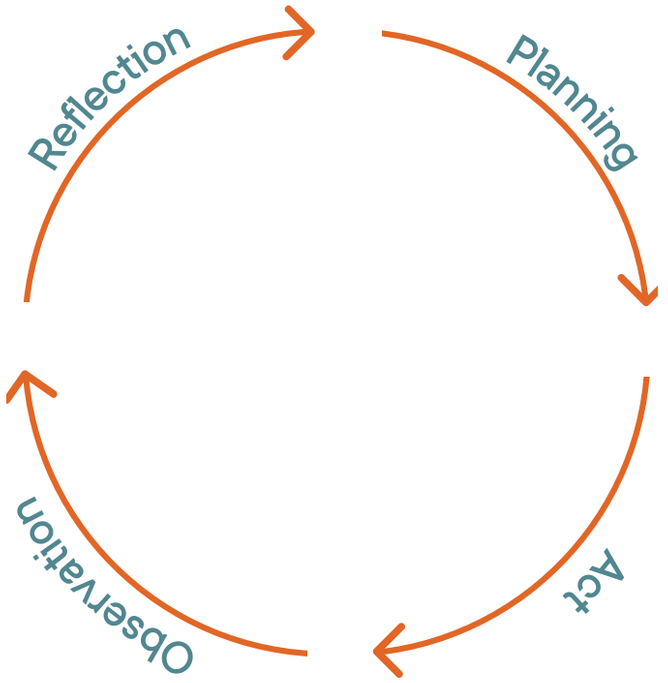

Figure 7. An Action Research Process: Different Stages in a Action Research (McNiff & Whitehead, 2002, p. 40)

Research Methods

Contextual Review

Conducting a contextual review (CR) means investigating and examining existing knowledge around a topic (Dawidowicz, 2010; Harris, 2019; Snyder, 2019). This method gives the research project a foundation in the existing knowledge that is thoroughly researched (Dawidowicz, 2010). Doing a contextual review was a helpful starting point for acquiring fundamental knowledge surrounding chronic pain. Undertaking a CR also helped me discover new research areas by making what was relevant to the research project visible as I gained access to new knowledge and ideas. In this research project, CR was an excellent way to support my knowledge acquisition and help me develop new assumptions, which could be made sense of (and challenged) through prototyping. I used contextual review to help make it visible and provide evidence of knowledge gaps and opportunities within my research context.

I started conducting a contextual review by using keywords related to my research question and putting them into research engines. The keywords were words like communication, chronic pain, chronic pain patients, chronic pain clinicians, pain, and patient. These keywords were used in search engines like the AUT library and Google Scholar. Articles were picked by their relevance to the research project by reading abstracts and summaries. These papers were then summarised with new keywords being found and new searches done with those keywords. New lines of research were found by using the references of articles found and doing additional searches with those keywords. Finding related articles was used with a tool called Litmaps where putting in different papers found related literature or that cited the paper searched.

When conducting CR, it was important to examine the relevant subject matter related to chronic pain and the research project's research question. Moreover, with relevance, studies and other peer-reviewed literature had to be well-detailed while being transparent and detailed about what was being investigated.

Focus Group

In focus groups or “group interviews” (p.28), researchers act as moderators and ask a group of participants questions to start a conversation and gather opinions around a topic (Acocella & Cataldi, 2021). With the researcher acting as a moderator or facilitator, the participants answer and converse about the questions asked (Acocella & Cataldi, 2021). It is essential in focus groups to have a non-confronting setting and environment so that conversation can happen and participants and researchers cannot shut down opinions (Morgan & Krueger, 1993). A focus group method was chosen in this research, as through conversation, a group’s purposes or aims may be explored within the research project’s context (Liamputtong, 2024). With chronic pain clinicians, focus groups were used to discover the particular motives and reasons for what clinicians needed or wanted when communicating with their patients and why there is misunderstanding and misinterpreting around chronic pain.

This method was chosen for working with clinicians, as focus groups are useful when needing a method that can fit within 45 minutes while also stimulating conversation. Clinicians are busy, so having a method to get them to talk together quickly and engage in the research made focus groups the most feasible choice. Focus groups can also bring people together on a topic (Acocella & Cataldi, 2021; L.Morgan, 1993). Therefore, this method allowed clinicians to converse about what they do daily with each other and the researcher more easily. Focus groups also helped to support the examination of the emergence of expert opinions on the topic of chronic pain.

Examining collective expert opinion also meant the research project looked at where there were disagreements, agreements, and opinions among clinicians. Doing this allowed me to understand what is shared and not with clinicians, the types of experiences that can happen in patient sessions, and the thinking around them. With this in mind, using a focus group allowed me to further my design work to best address various issues that may arise in the clinical chronic pain space.

Clinical participants were recruited through TARPS (The Auckland Regional Pain Service), as there was access to clinicians with diverse backgrounds who know each other and are active in working with chronic pain patients. Recruitment happened with a consultant close to the research project emailing the staff at TARPS and making them aware of the focus group would be happening. Along with the email, a short blurb about the focus group and the focus group information sheet was attached to the email. Recruiting through TARPS and having TARPS notify the clinicians of the

research created an easier way to prepare and organise the focus group. Additionally, having the focus group at TARPS allowed the clinicians to be more inclined to participate in the research as the focus group was where they were working. Having participants who knew each other allowed for a more comfortable and open setting, meaning participants having conversations and stating their thoughts and opinions was more likely to happen.

A single focus group was conducted with seven clinical participants. In this research, the focus group had a less rigid structure, which helped facilitate more conversation than approaching the focus group as a way to search for particular answers to the questions asked specifically. After handing out consent and demographic forms and starting the audio recording, I showed prototypes to introduce and give context to the research project. Then, I asked for feedback on my prototypes (Figure 8). I had a list of indicative questions I wanted to ask:

- What clinical resources are out there for chronic pain that are beneficial for those with chronic pain?

- What of those clinical resources are the best at making patients feel understood and strengthening the relationship between you and your patient?

- How do you ensure you understand and respond to a patient about their pain?

- Why do you think the patient responds the way they do?

- How do you approach uncooperative patients or ones who do not communicate well?

- What are some of the challenges you experience when communicating with your patients?

- How do you go about in encouraging or advising your patients with chronic pain?

- What information do you need help understanding from patients?

- What information do you give to patients that they struggle to understand?

After asking questions, follow-up questions were sometimes asked for clarification or to stimulate more conversation. Some indicative questions were not asked as participants had already answered them, or there needed to be more time to ask within the 45-minute focus group.

Figure 8. Prototypes brought to focus group for feedback.

Co-Design Workshops

Co-design workshops provide a collaborative space where participants can creatively explore topics and articulate their needs to contribute to a solution (Steen et al., 2011). This method allows the researcher's assumptions to be challenged by the participants, thus aligning the researcher's values with what participants may hold (Fitzpatrick et al., 2023). Co-design workshops encourage a partnership and creative collaboration between the researcher, participants, and the research project (Moll et al., 2020). Through various creative exercises, participants can engage with the research by being potential users (Fitzpatrick et al., 2023; Moll et al., 2020; Steen et al., 2011).

Co-design workshops may have activities that facilitate sharing experiences through conversation and help generate ideas for developing a solution (Steen et al., 2011). In this research, the purpose of a co-design workshop was to create a deeper and more detailed look at patients' chronic pain experiences using design activities and creative prompts rather than just asking questions of patients. Chronic pain is a personal experience, so having participants speak through objects they made may help alleviate some of the distress of talking about their experiences. As my project was about physical experiences with objects, having participants create tactile objects and using them to describe them made sense to the research project.

Recruiting chronic pain patients was undertaken through TARPS. I arranged a time with the clinicians at TARPS to go in person after a relaxation class with chronic pain patients attending (per TARPS's recommendation). This happened between TARP's three week program so that the workshop does not happen during a busy time for TARPS and their patients. Upon meeting the patients after their relaxation class, I briefly introduced my research project and what would happen in the workshop. After the introduction, workshop information sheets were handed out, and the patients were given a period to ask questions. If they were interested, they could sign a consent form there, or they could sign it at the workshop. I then organised a date and a time with the patients that would be suitable for them. The patients were free to email the researcher if they were interested in the workshop or had any questions.

The workshop had 3 participants, with two who emailed before informing they were coming and one turning up on the day. The workshop started with an introduction. After the consent forms were signed, the audio recording started.

I showed participants a prototype of the toolkit (Figure 9.) while explaining the inspiration behind each object and describing how the toolkit worked. Participants

then were able to question and comment on the prototypes and exercises. Afterwards, I asked participants questions about their thoughts and feelings about the toolkit. Indicative questions that were asked were:

- Could you see yourself using these objects with a clinician, and how?

- What do you feel is missing in this toolkit?

- Would you use these objects to describe your pain experience?

- Are the exercises okay for you, and would you like a more structured or open conversation with your clinician?

- Do you resonate more with the interactive objects or more with the visual objects?

- What do these objects do well?

After giving feedback on prototypes, there was a break before the activity. The activity consisted of participants using Lego building bricks and Lego Technik materials with more malleable putty material (Play-Doh) to physically represent their pain experience. After they had made their models, they were asked to detail what they had made. This was to give ideas and inspiration to my making process, how the toolkit's objects could be used, and what is essential for chronic pain patients to communicate.

Figure 9. Prototypes brought to the workshop and first interview for feedback inside prototype box.

Figure 10. Prototype bag activities brought to workshop and interviews for feedback.

Expert-Interviews

Expert interviewing is a research method based on sharing and obtaining knowledge through dialogue (Witzel & Reiter, 2012). An expert interview involves questioning participants as the research project gains information on participants' lived experiences and knowledge surrounding the research project's subject matter (Brinkmann & Kvale, 2018). Through expert interviews, experts were asked to give feedback on prototypes and share knowledge with the researcher about their experience with chronic pain communication.

In my research, expert interviews were aimed at getting feedback from chronic pain experts on the developed prototypes in the later stages of the project. I wanted to receive feedback on the usefulness of the toolkit, how it might be used in practice, and the implementation of the toolkit in a clinical context. The experts for this research were mainly researchers who had participated in and written several chronic pain research papers. In this way, the expert's knowledge was broad enough to know both the clinician's points of view (as all interviewees had a clinical background) and had worked alongside chronic pain patients to know somewhat how they thought.

Experts were recruited by searching online and checking their backgrounds to see if they could offer an expert opinion in the context of the research project. If so, they were emailed (email found in the public domain) with information about the research and what would take place in the interview. Expert interviews happened at their place of work, as that was most accessible for interviewees.

The three roughly 45-minute interviews started with me giving the interviewee a copy of the consent form and, afterwards, starting the audio recording. I began the interviews by detailing my research project and showing my prototype toolkit and exercises (Figure 9 - 11). Prototypes changed from interview to interview as I was still making throughout the time between interviews. After showing and detailing the prototype objects and exercises, I asked the participants if they had any first thoughts or comments and then proceeded to my questions. The questions were open-ended and changed as the interview went along.

The indicative questions were:

- Did I miss any representation of pain?

- What could you think can represent the pain you talk about?

- What can be improved upon in this toolbox?

- What do you think is done well about the toolbox?

- Can you see this being implemented with clinicians and chronic pain patients, or is there another setting where you see this living? For example, would this tool be good for a therapy session or pain management?

- Do I have the right balance of objects? Should I have more?

- Are the activities explained well in the booklet? Should I include more or less?

- Are there any other opportunities or gaps you see this toolkit filling that is more than just in the clinical setting?

Indicative questions were intended to start a conversation with the interviewee. While interviewees did not have to strictly adhere to a question(s), they were encouraged to talk about their position and the context around their answers. Information gathered from these interviews was valuable in supporting minor adjustments to the toolkit; if the changes were more major, they would be ideas and possibilities for future directions.

Figure 11. Prototypes brought to second and last interview for feedback.

Data Analysis

Thematic analysis

Thematic analysis (TA) is a data analysis method that can help a researcher construct the generation and exploration of recurring themes and patterns within a data set, providing valuable insights into the participants' perspectives (Terry & Hayfield, 2021). Thematic analysis is undertaken by finding meaning-based patterns across data sets (Terry & Hayfield, 2021). Within TA, participants' reflections and interpretations of the world around them are seen as data and then analysed (Guest et al., 2012; Lochmiller, 2021; Terry & Hayfield, 2021).

Thematic analysis was used in this research project as it is a qualitative research tool and can be used with design projects (Lin, 2019). With the complexities of chronic pain experiences, TA provided me with an approach to construct themes about what was essential to those who dealt with and had chronic pain from a data set containing varying opinions (patients, clinicians, clinical experts and my practice as a designer). Constructing themes allowed me to develop insight that was used in my design practice. Thematic Analysis was a helpful approach to help unpack what patients and clinicians experience.

After transcribing and listening to the audio of my focus group, co-design workshop, and interviews, I followed the six stages of TA (Terry & Hayfield, 2021). The six stages are familiarity with your data set, coding, initial theme generation, developing and reviewing themes, defining and naming final themes, and writing up findings. Thematic analysis was used the same way across data sets from co-design workshops and focus groups. Interviews were the exception. In this case, all data from interviews were combined to create a single data set, with data from expert interviews analysed together rather than separately.

After listening to the audio, reading the transcript, and looking at the notes from the focus group, workshop, and interviews, I coded the respective data sets. Coding incorporated assigning a label or name to a part of the data, highlighting the relevance of what was said in that part (Terry & Hayfield, 2021). This was done by writing notes (beside the sections of data being coded) of text and denoting a code to it. The initial theme generation process began by looking at the list of codes and then constructing prototype themes from that list, which were then reviewed and developed. Reviewing and developing meant looking at themes to ensure they were relevant to the research question or too broad and were insightful (Terry & Hayfield, 2021). Finally, themes were named and defined in a way that made sense to the research and audience reading the findings. The analysis and conclusions of each data set were then summarised and written up.

Semiotic analysis

Semiotic analysis is an approach that helps the researcher focus on how participants interact with objects and use them to make meaning (Ilstedt, 2002). In this research project, I explored the design of objects and how people might use them to help make sense of the world around them. This was to help me better understand the chronic pain experience and how it may look when represented as tangible objects. Semiotic analysis can also look for metaphors when interacting with objects (McDonagh et al., 2003). Metaphors make the unseen (in this case, chronic pain) into words or objects. I studied the metaphors in the literature and also by participants to serve as inspiration in prototyping. Metaphors are commonly used in chronic pain communication, so learning their meanings in this context and translating this meaning into products was intended to benefit the research (Declercq et al., 2023; Munday et al., 2022).

This approach was used in workshops where participants handled objects and used them to make meaning of their chronic pain experience. Semiotic analysis was used in conjunction with thematic analysis in this research project where participants interpreted the meaning of prototypes or objects they made, and then themes were constructed.

The themes were then analysed from the point of view of how these objects created meaning for the participants. Looking at transcripts and the photographs of models participants made and using semiotic analysis, I could study the meaning given by participants to objects. Through this analysis, I could refine my prototypes to resemble the chronic pain experience and make it closer to a tangible experience.

Design Methods

Prototyping

Prototypes are artefacts, sometimes physical objects, that portray features or convey meaning to someone else (Camburn et al., 2017). By doing this, prototypes can then better inform future actions, as artefacts are more accessible to judge and criticise when they are tangible (Camburn et al., 2017; Matthews & Wensveen, 2015; S. Reay et al., 2017; S. D. Reay et al., 2017; Stappers, 2014).
Prototypes can be effective explorations and tools for reflection on the project and the research project's subject matter. This means that prototypes can act as props to conversations that otherwise would not have happened or help explain ideas and the meaning of the conservations being had (Bill et al., 2015).

With chronic pain being a personal experience, having participants speak through objects was thought of as potentially being more engaging, as this method was hoped to help participants better explain the complexities of their experiences. This process was also viewed as beneficial in helping those who may not have been effective communicators. Prototyping also showed, in essence, what the research project was about so participants could better advise or inform me about the trajectory of the research project and where I might want to focus my attention and effort.

At the beginning of the research project, prototyping took the form of mock-ups (quick iterations) of ideas or to test specific ideas quickly and effectively (Camburn et al., 2017). This bypassed the time-consuming manufacturing processes associated with more refined models. Mock-ups provided a foundation, leading to more refined models, particularly as my experience in working with specific materials and making processes developed. Subsequently, more refined models were functionally and aesthetically closer to the final models and were more detailed than mock-ups. These more refined models allowed participants (and myself) to give more specific and focused feedback. Functional models were made between mock-ups and refined prototypes to test users' interactions with objects or how materials might work with objects. Functional models were used to test the interactions someone might have with the prototype, along with textures, materials, making processes, and form. This was to assess how these different aspects may function and work for a user and, if successful, were incorporated in refined models or refined further.

Throughout the research project, prototypes were used to make or give form to the assumptions I generated from my reading. Doing this allowed me to review my assumptions and challenge them.
From this, I could respond to participants' feedback and improve the prototypes by developing them

further. This process was often cyclical; aspects of a refined prototype did not operate as intended and led to new mock-ups, functional prototypes, and new ways of making (Figure 12). This iterative action research process slowly helped me to get closer to a final design, have it work, and relate to participant experiences.

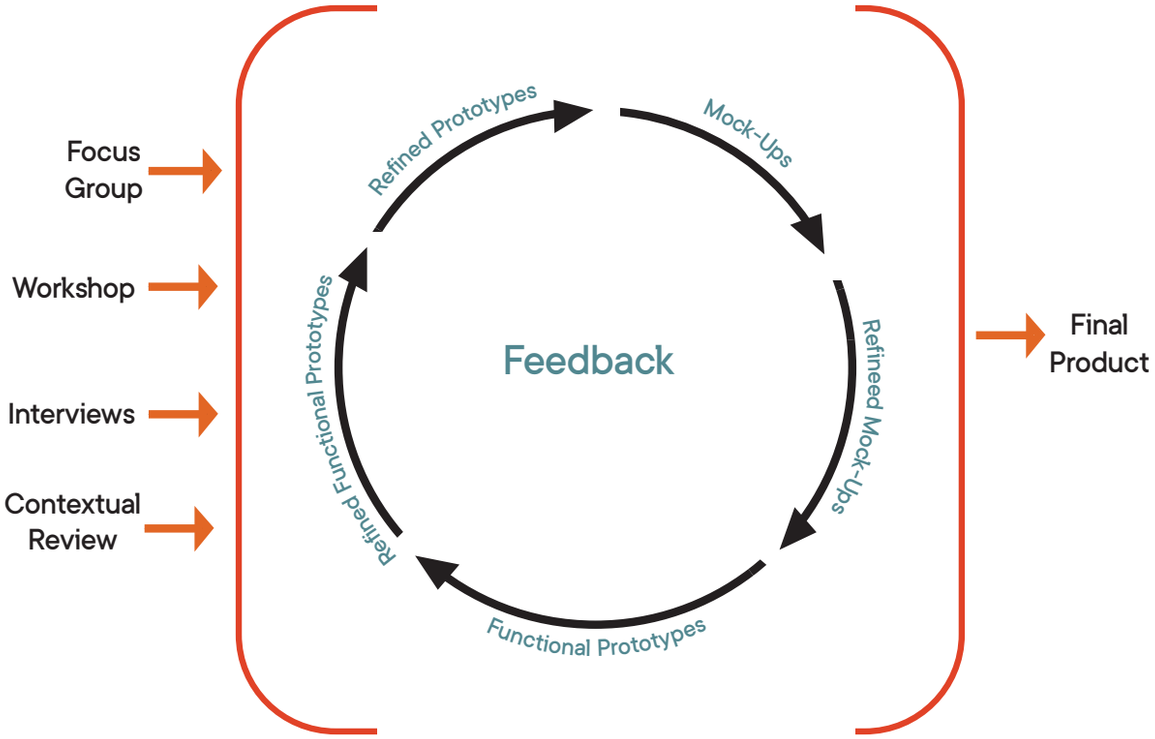

Figure 12. The process of prototyping undertaken in the research.

Assumptions were made and challenged by the research methods, which informed the prototyping and led to the final object/ solution.

Mood Boarding

Within product development, mood boards are considered a way to evaluate and inform aesthetics and design (Endrissat et al., 2016). Mood boarding is helpful in a design process as a visual-based method through which the researcher collects images related to the design theme (Chang et al., 2014). Mood boards provide a way to visualise research and show different aspects the researcher aspires for the project to look like, for example, colours or patterns. Visualising these attributes inspired me to innovate, create various designs, and test the visual language of my design work (Mcdonagh & Storer, 2004). Mood boards helped me see my preferred design choices and define what appealed and worked for each of my designed artefacts/objects.

Mood boarding was used when designing the final ‘packaging’ of the toolkit and, to a limited extent, was used to help explore potential visual interpretations of chronic pain. The packaging mood boards were sourced online by searching keywords ‘modern retro’ or ‘modern abstract’ (the reasons these terms were chosen are explained in the next chapter). I then collected and collated images that served as inspiration for the design of the packaging and the aesthetic of the toolkit. Artwork that inspired the chronic pain aspect of the research project came from artwork painted at TARPS. Where some chronic pain patients painted what their pain experience felt or looked like to them. Artwork of chronic pain expression was also identified when undertaking the contextual reviews, where some individuals who experienced chronic pain visualised their chronic pain through different mediums.

Concept Mapping

Concept mapping is a way of visualising and mapping ideas (Kane & M.Trochim, 2007, 2009). By doing this, it becomes easier to evaluate and assess ideas. Concept mapping also encourages building relationships between ideas (Kane & M.Trochim, 2007). This organises and creates new ideas (Kane & M.Trochim, 2007).

Following the action research methodology of reflection, many ideas were constructed from reflecting and sometimes observing. These needed to be organised and sorted in a way that also produced more ideas and inspiration for making. Concept mapping allowed space for refining and developing objects while supporting the generation of additional ideas that were used as the basis of a new concept or to improve an existing concept.

When prototyping, I created many objects representing different aspects of chronic pain. Concept mapping these objects helped me to group objects that accurately portrayed chronic pain and those that did not. I also mapped which were similar in depicting ‘similar pain’. Concept mapping was used to determine the toolkit’s name by listing potential names and eventually narrowing it down to a few.

Ethical Considerations

Having chronic pain patients, clinicians, and experts was essential for conducting a qualitative research study with an action research methodology. Involving these types of participants allowed the research project to relate, recognise, and create something that reflected the participant's motives and wants related to chronic pain communication. Participants in the research project also challenged the researcher's assumptions. They informed the researcher of the lived experiences of some who have chronic pain, dealt with chronic pain patients, and researched chronic pain. Chronic pain patients were involved in co-design workshops, clinicians in focus groups, and chronic pain experts in expert interviews.

The researcher had an ethical responsibility to consider the time all these groups would set aside to participate, so it was essential to make the sessions involving participants run as efficiently as possible. The researcher also had to keep in mind that for chronic pain patients, chronic pain is a sensitive topic to some and participating in something for an extended period may tire chronic pain patients. Therefore, the researcher ensured chronic pain patients could make themselves comfortable, get up, walk around, and take breaks when needed.

AUTEC gave Formal ethics approval on 8th September 2023 (23/255). While amendments to the application and various appendices were approved on 11 October 2023.

DOCUMENTATION OF RESEARCH

Throughout this chapter, my research journey is detailed, along with my making. I came to this research to explore design's ability to help understand complex ideas. Those at Good Health Design raised the point of chronic pain, and as I became interested in it, I pursued a research project on it. The research documentation shows how I started from this point to my final product and how my knowledge and research changed using the Action Research framework. Within this journey, many prototypes were made, testing many aspects of what goes into designing objects to communicate the chronic pain experience. This included looking at interaction, aesthetics, and usability. These factors are assessed so patients can put meaning into the objects to help communicate pain. This chapter also details how participants in focus groups, workshops, and interviews shaped my making processes and learning.

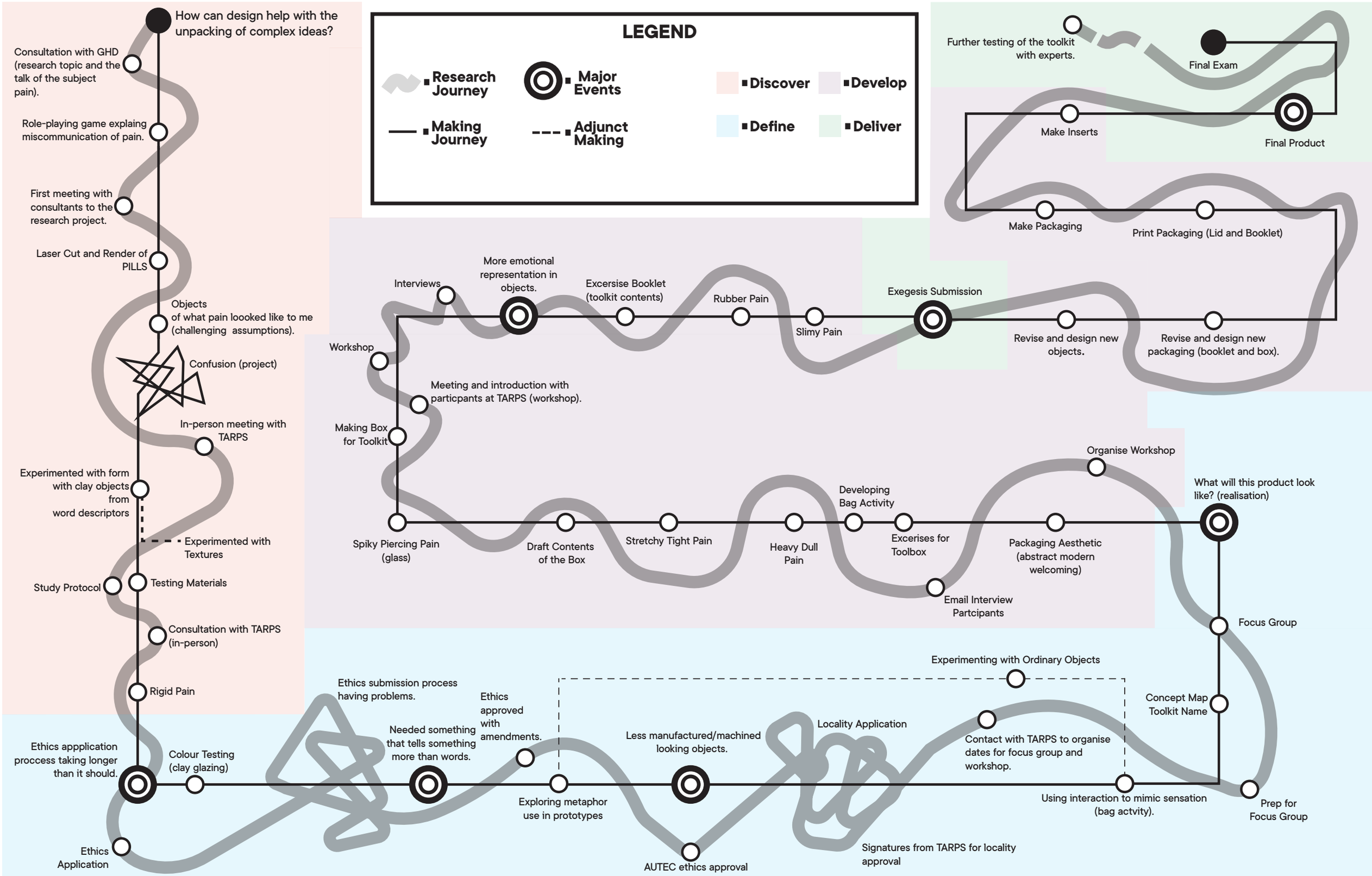

Figure 13. Map of the research journey showing key phases and decision-making stages

Discovering the Problem and How to Design a Solution for it.

At the start of my research, I needed to improve my understanding of pain, so I started by reading and exploring the literature. This helped me become more informed about the topic. I started exploring ideas through making with the knowledge I gained from reading. I gave form to some of my thinking and made visible the assumptions I had concerning the topic of chronic pain. In the early stages of my practice, these primarily consisted of quick ideations or mock-ups of my assumptions at that time.

I began with a role-playing exercise that consisted of a calculator, paper, pens and pencils (Figure 14). The artefact was created to show people outside the research project my current thinking and assumptions about chronic pain communication. The role-playing exercise had participants describe their feelings with a calculator, followed by a drawing activity. This exercise was to show that sometimes, in health, chronic pain patients often have their pain reduced to a number, and that is limiting to explaining g the nuances of their experience. On the other hand, the drawing activity gave participants a creative way to explain and express their feelings. The role-playing game gave a very surface-level understanding of the experiences felt by chronic pain patients. Though people outside the project understood the contrast I was trying to portray, the complexities of the pain experience and what clinicians need to know from patients were lost. The roleplaying activity reduced

Figure 14. Role-paying game contents.

and summarised my research too much, losing the portrayal of the complexities of the chronic pain experience.

From here, I continued to play around with communicating the chronic pain experience through creative means. Instead of showing the miscommunication of pain, I showed the complexity of the chronic pain experience, which was missing from the previous artefact. To get away from the role-playing game, my next artefact would be from the clinician's point of view. I made a speculative artefact of a

technological device that can calculate the severity of someone's pain - P.I.L.L.S (Pain Intensity Levels and Life Scales).

I quickly ideated a prototype with a laser-cut version (Figure 15) and a render (Figure 16). Laser-cutting provided a way to do a mock-up effectively so I could evaluate my ideas promptly.
PILLS included scales measuring chronic pain's effect on the patient's life, assessing pain behaviours, and previous chronic pain sessions. Also, PILLS included a plug-in where the clinician can combine it and use other pain assessment results to calculate, with the other pain scales, the hypothetical pain severity the patient would have.

What was successful about PILLS was that it allowed me to start thinking of the different factors within the clinical setting that patients experience and how clinicians assess chronic pain. Through this, I started unpacking the factors of the chronic pain experience, which I thought clinicians analysed. PILLS, however, firmly focused on the clinical side and neglected the patient's pain experience. When making PILLS, those details were supposed to be metaphorical. However, having the details of the patient's pain experience not unpacked did not allow conversations to happen around the chronic pain experience. Instead, the artefact focused on the clinician and portrayed the project as not improving the communication between patients and clinicians.

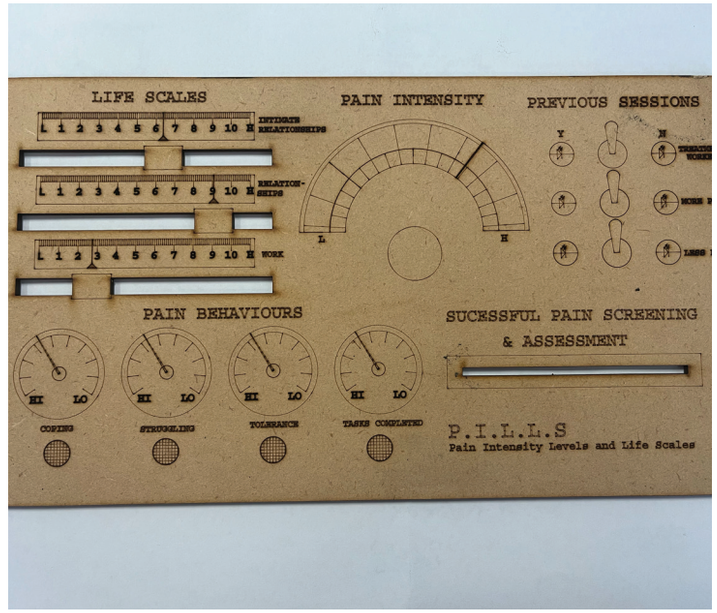

Figure 15. Laser cut version of P.I.L.LS with labels.

Figure 16. Render of P.I.L.L.S

PILLS was a good starting point for me to start thinking about the research project and challenge my assumptions. PILLS mirrored my thinking at that time that clinicians were the problem of miscommunication, and they were the ones at fault. Putting these assumptions into a physical object allowed them to be challenged and proven wrong. They were easier to assess and interrogate as the ideas became easier to interact with.

Meeting the Consultants for the Research

Good Health Design, helped organise experts to consultant in this research project. The consultants were pain researchers who have been involved in chronic pain research projects. In the first meeting, I discussed my project and what I would like to do with this research project. By explaining my project to them, they were able to organise possibilities and opportunities for the research project to involve chronic pain patients and clinicians. This led to many more online and in-person meetings, where we worked together to try and include participants. With these consultants, I was able to collaborate and work with TARPS (The Auckland Regional Pain Service), which meant having a recruitment pool of active chronic pain clinicians and chronic pain patients. TARPS's association with the research project meant that a legitimate organisation involved with chronic pain was willing to work with the research, giving the project some validity, which was needed in the ethics process.

Confusion in the early stages of the project

In the early stages of my research project, I needed better clarification of what my aims were. Furthermore, I needed to know my place and position in the research project, what I aimed to design, and what it meant to the participants involved. At this time, I kept reading the literature, making my assumptions tangible and critiquing them. At this stage in the research, I knew I wanted to make pain tangible and representative of tactile objects, so I started making 3-D printing objects that looked like pain from my perspective.

3-D printing objects was an efficient way to start assessing the objects as soon as possible. When 3-D printing the objects, I tried different 3-D printing process types. Some objects were printed with resin, while the spiky ball object was printed with FDM (Fused Deposit Manufacturing) (Figure 17). This was to start using different making processes early, so I could learn them and potentially use them later in the research project for other ideas. The objects were visual representations of pain as a feeling and an experience.
The square 3-D printed object was the most symbolic and meaningful portrayal of the pain experience (Figure 18). The object showed a piece of the person experiencing pain being ripped out to symbolise the patient's feelings of living with pain. In one sense, this made this object the most successful of all three, as it communicated a meaningful story and experience. However, all the 3-D printed objects were more personal to my interpretation of the pain experience. When presenting the objects to my peers, they understood how

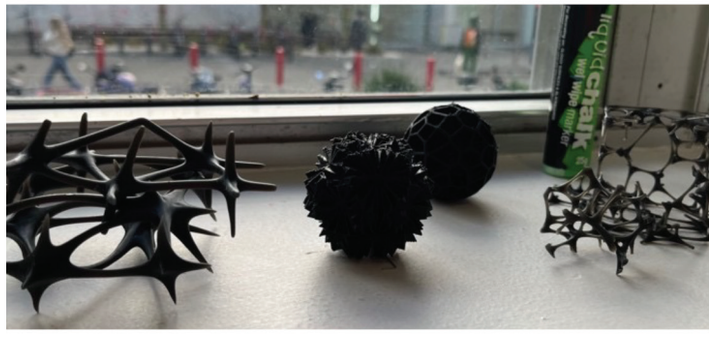

Figure 17. 3-D printed objects
Resin printed (left and right) FDM printed (centre)

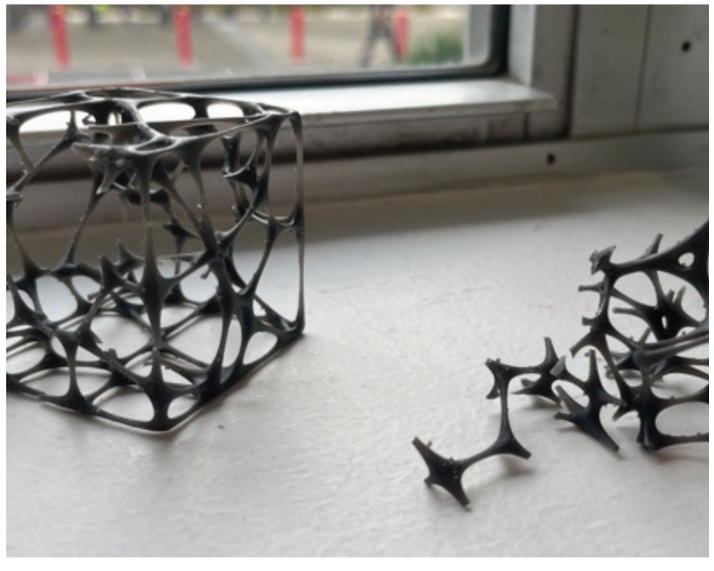

Figure 18. Resin printed cube
symbolising loss

they looked like pain. However, they had trouble using the objects to describe pain experiences they knew and had. The feedback of these objects reminded me that in making objects, they have to be used by others and that they do not have to be specific to what I think pain is. In contrast, I would start using experiences from chronic pain patients to inspire my making.

At this point in the research, I needed clarification and guidance on what else I could make. Though I had some ideas from the 3-D printed artefacts, like using a more patient-driven narrative to put into objects, I was still determining what the project could be and what opportunity I was fulfilling with my future outcome. I needed help with my research project's objectives, aims, and direction. To prevent the project from stagnating, I kept reading literature about pain. My contextual review at this point covered many topics surrounding pain, but as I read more and made more, it became more specific and relevant to my research question and aims.

Making clay objects from Pain Descriptors

To incorporate more chronic pain experiences into my prototypes, I wrote a list of words that describe pain that I can recall from reading chronic pain articles and some that are used in the McGill pain questionnaire (Figure 19). This list of words became a jumping-off point for me to start making objects from a chronic pain perspective rather than my own. I used clay to make objects inspired by these descriptors, as clay was cheaper and faster than 3D printing. I could quickly iterate with clay and put pain descriptors into tactile form (Figure 20). Making these objects encouraged me to start thinking of the objects' form and putting into form specific pain descriptors patients may communicate to their clinicians.

When testing these clay objects with my peers, the response was that the clay material portrayed fragility, and the forms generated were more able to be related to pain than the 3-D printed objects. Interacting with these objects was very limited and was more of a visual representation you could pick up and look at. There were some of the clay objects that were more relatable to my peers. These objects were simple in form yet abstract enough to put meaning into (Figure 21).

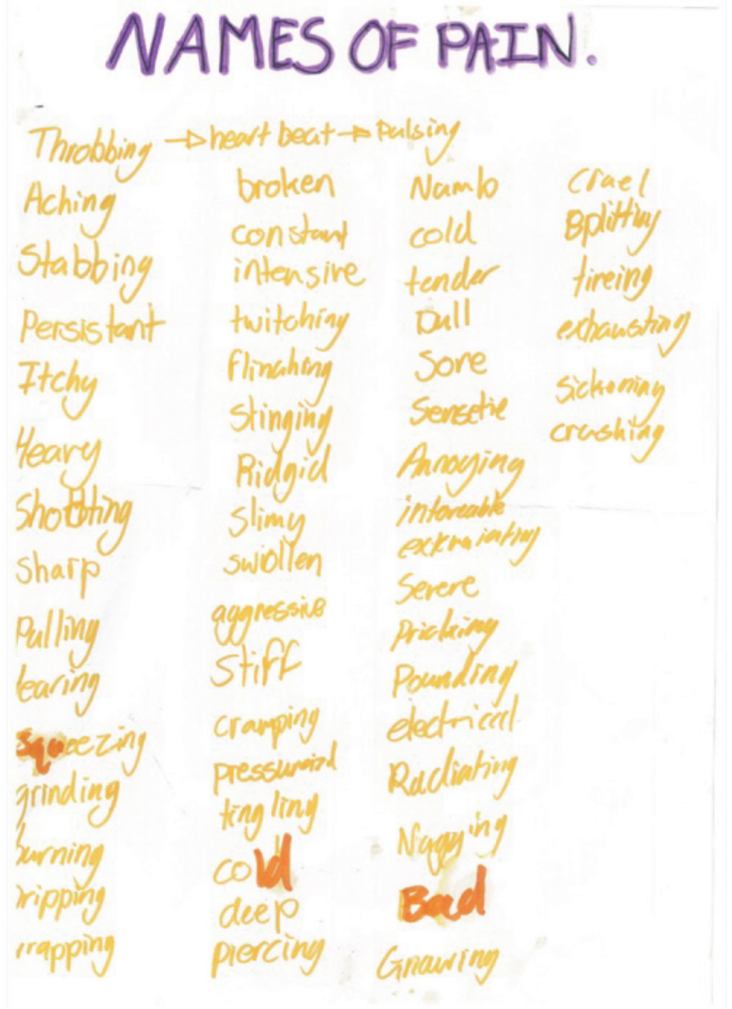

Figure 19. Pain descriptor list

Making these objects taught me that clay-making was a quicker and more efficient way to get ideas into a tangible form. Clay also served as a material that could make more natural organic forms, contributing to my objects' success. Furthermore, the clay objects demonstrated that the pain experience could be communicated through objects. To improve the communication of this experience, the clay objects showed there needs to be a focus on interaction, form, and aesthetics to create an effective communication tool.

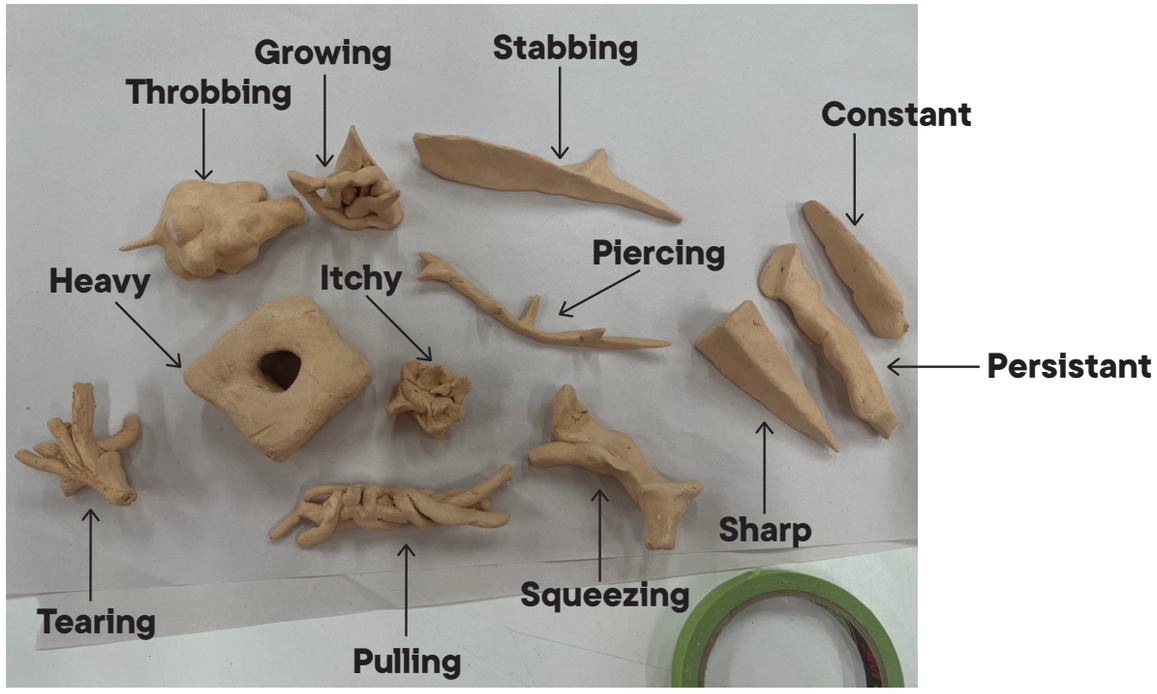

Figure 20. Clay objects with corresponding pain descriptors

Figure 21. Final clay objects

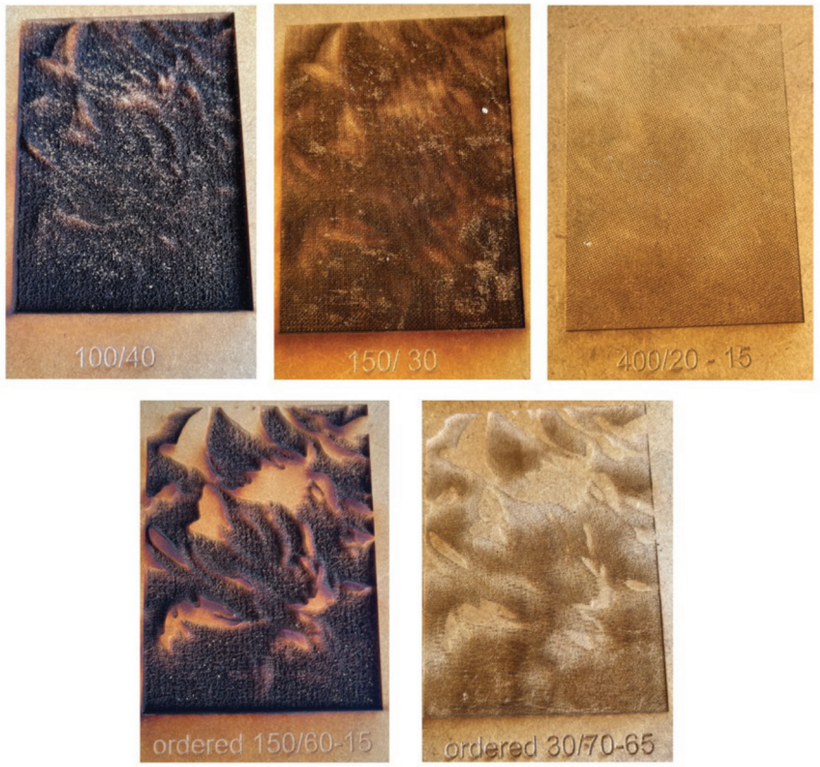

Figure 22. Final Textures. Speed and power underneath each texture

Testing if Textures Could Mimic Pain Sensations

Following wanting to make more interactive objects, I wanted to see if textures could affect pain communication. What I wanted from the textures was to mimic or help describe the pain sensation through touch. I decided on a texture that would suit this test, one that would be simple, and laser-cut it on MDF wood as it would be the quickest way of testing my assumption. After a few tries, I had enough prototypes to determine whether this process would be used in my project. Two textures showed how I wanted 3D textures (the two in the far left in Figure 22). However, these prototypes struggled to portray any meaning or experience. The textures instead communicated a more pleasurable experience than any pain sensation, nor could I see it applied in a way that could.

This process showed me that textures affect how users interact with objects. However, it should not be focused on in this research project but be incorporated into the objects I make. It is better to start with the object first, as this research project is about tactile objects used to communicate the chronic pain experience.

First in-person Meeting with TARPS

Working with The Auckland Regional Pain Service (TARPS) allowed chronic pain patients and clinicians to be involved in the research. While at the Greenlane Clinical Centre, where TARPS is based, I introduced myself and my project and learnt what TARPS does. The first meeting went well and was followed up by other meetings consisting of organising dates, signing forms, and clarifying questions they had about my research project and I had about recruitment.

When meeting TARPS, they introduced me to some of the art chronic pain patients made during some of their classes. One example is someone who painted a picture of shattered glass and how it resembled his life being changed from having chronic pain (Figures 23 and 24). Artwork like this around TARPS was inspiring and gave some ideas on how to look at art done by those with chronic pain and involve it in my making.

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Figure 23 Example of artwork at TARPS

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Figure 24. The description below Figure 22 artwork

Testing Materials

As I was still early on in the research project and still confused about what the research project would be, I started testing materials and occasionally different forms. Investigating materials this early allowed me to learn about the process of making some materials, the limits of what they could do, and how they could be used in my project.

Flexicast

A common chronic pain descriptor I kept seeing in the literature was the word squeezing. I set out to make a bouncy ball-like object which the patient could squeeze in their hand to describe a squeezing pain. I 3D printed a ball shape with different holes to make the form different and interesting. To make the squeezy ball, I needed to have the 3-D print put into a silicon mould I poured into. This is because flexicast quickly pulls away from silicone when set. Flexicast is a polyurethane rubber that can be squishy, bouncy, or hard, depending on the grade of flexicast. This made flexicast the right choice for creating a squishy ball. Flexicast is a two-part polyurethane rubber material, so after I mixed the two parts, poured them into the mould, and let them set for 24 hours, I could remove them and see the squeezy ball (Figure 25).

The ball was the right idea for making an interactive object for patients to describe their squeezing pain

compared to the clay objects. The choice of material was correct for what I was trying to do, and it was a good test of what the material feels like and does. Despite this, the object needed an informed reason for why its form was the way it was, as it did not enhance the experience of the ball. To be able to describe anything that comes with squeezing pain, the form itself must inform visually, as well as using it, that it is a squeezing pain, so it is easier to communicate. With this in mind, flexicast was a material that I would consider in the future for a squeezing squishy experience.

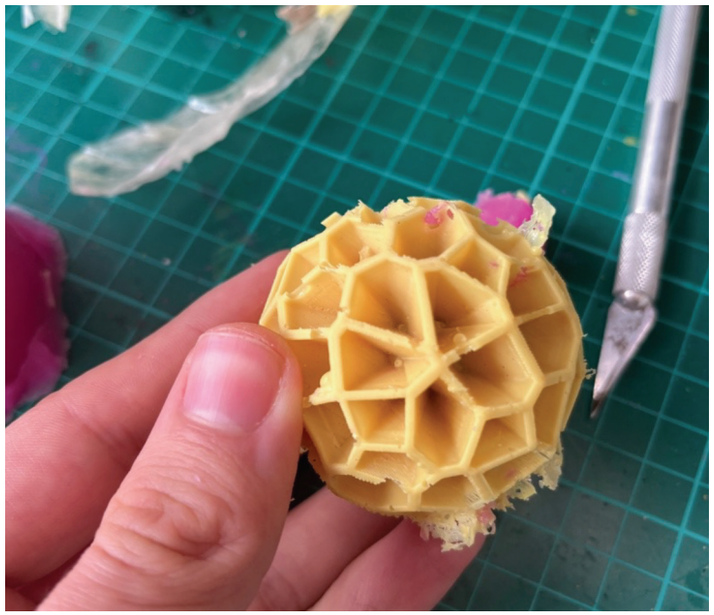


Figure 25. Flexicast ball set and out of the mould.

Figure 26. Silicone mould being made around 3-D printed object.

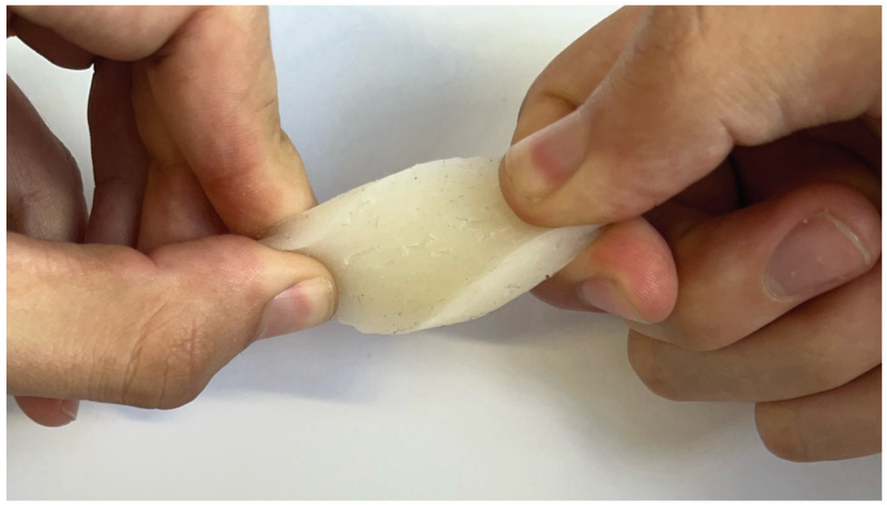


Figure 27. Platsil being stretched.

Platsil (stretchy pain process)

Another common descriptor that I could not make out of clay was stretching. With a similar process to the squeezy ball, I made a 3-D object that I thought resembled a stretchy pain and made a pinkysil mould around it (Figures 26). The material I wanted to test first was silicon, as I knew silicon can be stretchy. One material I heard about was platsil. A silicone that is soft and stretchy. To test it, without wasting time and material, I made a little test of it in a cup.

After the platsil set, the test showed the material was what I wanted: a soft, stretchy material (Figure 27). However, for the whole object I 3-D printed, making it out of platsil would cost up to $50. This was too expensive at this stage in this research project, and the form for the stretchy pain object did not elicit any ‘stretching pain experience’ in my view; therefore, I did not develop it.

This process made me aware of the material cost I am making with these objects. Since I am making a product that could be implemented, I have to be mindful that it could be replicated and affordable to potential customers. This object also reminded me to think about form more profoundly and reflectively. It was here that I stopped making 3-D printed objects to test form and instead explored form with clay. Clay gave more detail, and I could make more complex and simple forms. The process also amplified the idea that forms of objects have to be obvious enough that patients and clinicians can see it as a type of pain, yet using it can be extrapolated to relate to other experiences that it affects or the object elicits.

Alginate

After testing platsil, I wanted to see if there was a more cost-effective stretchy material. I tried Alginate, a plaster often used by dentists to make moulds of people's teeth. It is made by mixing alginate powder with water. I used it because I wanted to see if I added enough water, it would go stretchy, and if so, it could serve as an alternative to platsil. After testing some of it, the alginate became hard, brittle, and unlike the stretchy material, I wanted (Figure 28). This process informed me that there were better materials than alginate for making objects as it was more of a mould-making material.

Figure 28. Alginate after it sets

Wax

I used a mould I made before this research project to see if wax could communicate chronic pain. The wax process was simple and quick. I poured hot wax within the mould while sealing up the join lines and wrapping rubber bands around it to ensure the wax would stay in the mould (Figure 29).

The result was a very plain object (Figure 30) that did not look like it could be used to communicate chronic pain; instead, it was more relaxing interacting with it as it was soft and smooth. This process showed that I would use something other than wax when it came to my making. Wax does not last when handled as the object's form changes when it reacts to form. In addition, the material did not communicate anything of value which a chronic pain patient could use to describe the pain experience. Form-wise and material-wise, I chose not to continue developing this object as its form was too sculptural to be used in chronic pain communication and because of the material limitations of wax.

Figure 29. Wax is set

Figure 30 Wax object done

Glass Fusing and Glass Casting

Broken and shattered were other pain descriptors that I kept seeing in the chronic pain literature, which I thought could be made into a glass object. I was made aware of a process of glass fusing, where I could break glass bottles and fuse them in a kiln. I wanted to have these glass chips stuck together in some glass-shard-looking form to communicate broken and shattered. My first time trying this, I broke a Coke bottle into pieces, laid the shards out on ceramic paper and put it in the klin.

This first test (Figure 31) was successful but was not there yet as the pieces did not look shardy enough. Moreover, the first test had a see-through quality that reminded me of fragility, another aspect that could be attributed to the chronic pain experience. For my second test, I wanted the glass to have a sharper look but not be sharp enough to hurt someone who would handle it. This second test (Figure 32) was worse than the previous one. For this test, I put it in the kiln at a higher temperature, but it fused too much, which made the fusing too smooth. The second test also needed the transparent quality I liked in the first.

Both tests had qualities I admired, such as a shard glass look, but it would have been better if it had been an object that could be held rather than a flat surface. This process showed I could involve glass in some way in my

Figure 31. First try of glass fusing.

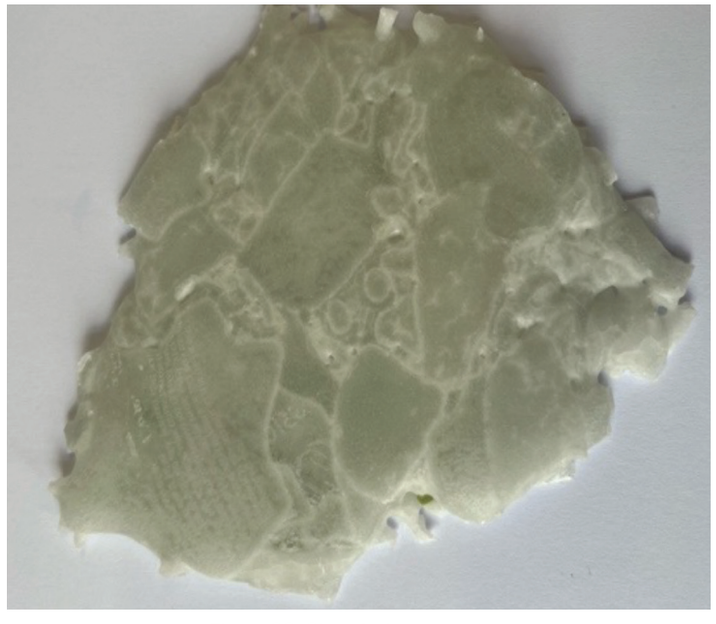


Figure 32. Glass fusing second try.

Figure 33. Broken coke bottle glass objects before firing

Figure 34. Gaffer glass object before firing

research project, and it would be a good symbol for those who describe their chronic pain experience through the words brokenness and shattered.

To make a glass object, I tried the glass cast process. The first time I did it, I got one of the 3D printed models I had printed before (the spiky ball from Figure 17) and made a copy of it–a larger one and a smaller one. This was a process to test glass casting, so I was not worried about form, but I chose the spiky ball as it looked sharp and spiky, which was close to what I wanted the final object to look like. The glass casting process included getting these 3-D objects, making a silicon mould, and then pouring wax into it to create a plaster silica mould (lost wax mould). From here, the wax is melted out of the plaster silica mould, leaving a hollow mould to put glass into. I broke up more glass bottles with one mould to try to melt them into a spiky ball shape. I first tried this on the smaller ones (Figure 33) and chose gaffer class for the bigger object (Figure 34). There was a more likely chance of gaffer glass working than the Coke bottles, as gaffer glass is made for glass casting.

Once out of the kiln, the broken Coke bottle glass mould did not melt but fused at the pour point. The gaffer glass object was successful, though, as it came out with much detail (Figure 34 and 35). The object's weight was fascinating and unexpected, and it related to how

some patients describe their pain as heavy. One of the negatives of the object is that it looks more like an art piece than a tool that can communicate pain. This may be because it looked very symmetrical and was pleasing to look at it. However, this was better than the sheets of broken glass, as it was a handheld object that could be interacted with. Nonetheless, the object's form stopped it from being a communication device as it looked more like an art piece, but at the same time, it was too structured and literal. A fine line was discovered between having objects too structured and analytical and being too creative and interpretive. The objects in my research project must be on this line where patients can be creative with them but also be analysed and help the clinician and their assessment.

Figure 34. Finished gaffer glass object.

Figure 35. Finished gaffer glass object for scale.

Rigid Pain

Like the stretchy pain object, rigid pain could not be represented in clay as it corresponds to moving. I wanted to make a bendy silicone object that was hard to move so there would be some resistance and symbolise rigidity when the patient moved it. For a quick mock-up of this idea, I made a simple cylinder-shaped mould that could hold a wire at two ends so the wire would be in the middle of the cylinder (Figure 36). To avoid air bubbles, I made the rod from RTV silicone, a thicker, slow-setting silicone.

The rod (Figure 37) failed to communicate rigid pain as it was too bendy and did not resist movement when bent. The wire inside also poked out of both sides and tore through the silicone over time. I 3-D printed caps to go on both sides, but they would often fall off and ruin the rod's appearance. However, this prototype was functional in portraying my idea, but it needed a stiffer wire inside to portray rigidity.

To make the rod look more like a pain object, I got a wire and made it look like barbed wire (Figure 38). When I read metaphors in chronic pain, barbed wire was said to describe a patient's pain (Munday et al., 2020a). The wire I used down the middle this time was thicker and had a higher tensile than the previous wire. This was an effort to make the rod stiffer and more rigid. Using the

Figure 36. Open mould after the silicone set. Demonstrating how the mould worked with the wire being held at the bottom.

Figure 37. Finished silicone rod with cleaned-up ends.

Figure 38. Barbed wire to be made into a silicone rod

Figure 39. Barbed wire silicone rod test

same mould and material as last time, I tried a different method to speed up the pouring process: slowly injecting a syringe of silicone into the mould. This did not help, and with the wire being barbed, the silicone sunk to the bottom of the mould (Figure 39). To avoid this issue, I changed the mould to have a bigger pour hole.

With the new mould, I made a new barbed wire with a new silicone transil to see if it differed from RTV silicone. Transil is a faster-setting silicone and is softer than RTV. It turned out to be too soft for the barbed wire and started tearing. However, the wire inside was the right tensile and was hard to bend. Still, I decided not to do the barbed wire or transil, as transil was too soft and squishy to use. The barbed wire would constantly tear the silicone, so I decided to use the same wire but have it not barbed.

When I started to test the colour, I put red pigment in the silicone mixture to create a red swirl that looked like blood. I tried different amounts of red pigment, but it made the objects look too red and gruesome, while other models had the wire not sitting in the middle, thus tearing or breaking the silicone (Figure 40).

All these different processes (Figure 41) taught me more about the process of silicone and that making more interactive pain is more complicated than making visual

clay objects. The rod I made first was the better one as it could be used repeatedly to symbolise, to an extent, rigid pain. However, more research and prototyping were needed to make an interactive pain object for patients to describe rigid pain.

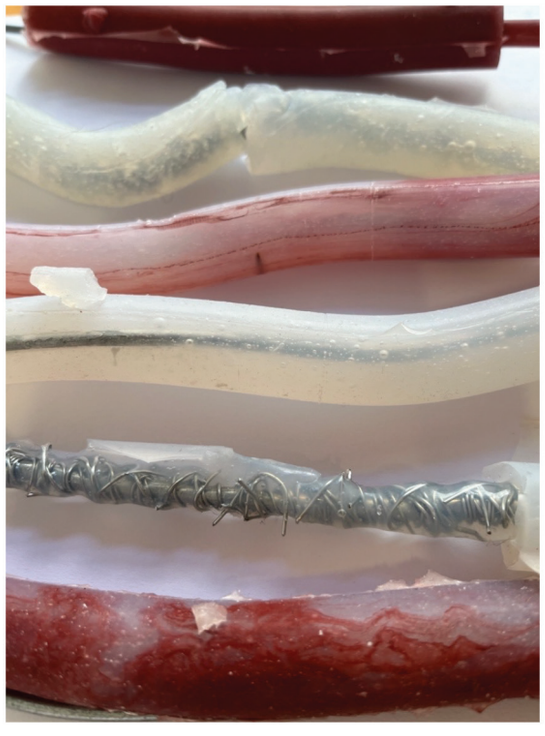


Figure 41. Close-up on silicone rods.

Figure 40. All silicone rod tests.

Defining The Research Project.

Facing Difficulty with the Ethics Process

Getting ethics approval meant filling out the ethics application (EA1). This process was lengthy and confusing for me. This was because the application was a daunting and vital piece of the research project. I needed clarification about most of the sections, and it took many draft edits. During this confusion, I started doing my study protocol with a framework offered by Good Health Design. This helped lay out and break down the research project. The ethics process required me to consider what this project aimed to do and how it would involve participants. In addition, I often needed clarification on the wording as I misinterpreted sections in the EA1 application extending the ethics process.

This process made me lose a lot of time, but it was a valuable experience thinking in detail about my project and how it will be conducted. What made this process difficult was that I was still lost in my project and now had to think about what the project was aiming to do. Though it was a challenge, it was beneficial for me to think and organise my research in terms of the research methodology and how I will analyse data and engage with participants.

This was a very laborious time in the research project and immobilised me in my research journey. All I did and was thinking about was ethics; I also stopped reading and making. From the first application to the amendments, the ethics process made me realise that this research project will sometimes be challenging, but I must keep researching and stay organised. I then implemented an organising system where I organised what I needed to do under broad categories and put what I needed to do in each category. This process helped me visualise what I needed to do and clear my mind while doing the ethics application.

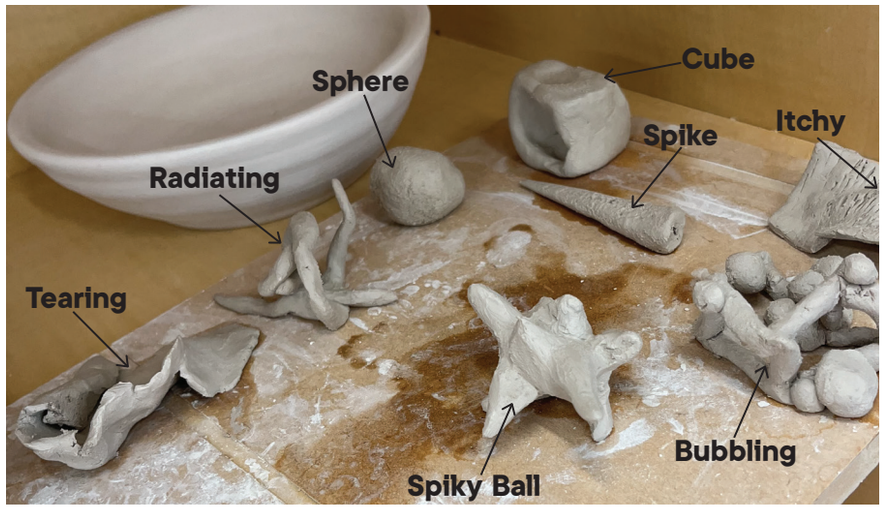


Figure 42. The second round of clay objects with corresponding pain descriptors they were inspired by.

Figure 43. Close-up on the second round of clay objects.

Second Round of Clay Objects

Towards the end of the ethics process, I started making again, and since clay had proven in the past to be a quick and valuable way to explore objects in my project, I did a second round of clay objects. This time, I wanted clay objects to be simpler and more ‘open’ compared to the previous clay objects. The simpler forms would be objects like a sphere, cube, spike, and a spiky ball (Figure 42). What inspired these clay objects were the word descriptors I did not use last time from my list, like tearing, bubbly, itching, and radiating. With some of the objects, I returned to doing textures as words like “itching” lent themselves to have a textual element.

Doing clay objects again was an effective way to get my mind back into making and engaging in reading. Having textures on the clay objects was the best use of textures, as there were a few different textures, which added to the interaction with the object. The simple objects were highly effective and sometimes told more of a story than the other clay objects because they were so ‘open’ (Figure 43). However, being so ‘open’ might make it hard for the clinician to interpret or analyse objects. This proves that my objects can be simple and less busy than prior clay objects, and textures can be incorporated, but they must tie in and enhance the object's interaction.

Testing Colours

While experimenting with form, I also wanted to explore how colour could communicate chronic pain. A quick way to do this was to glaze clay objects. Making clay objects was fast, and glazing allowed me to test various colours simultaneously. Moreover, I also wanted to attempt to make a ‘slimy’ pain, which I thought glazing could do. After being brushed with glaze (Figure 44) and put into the kiln, I had a range of objects of different colours and forms (Figure 45).

This quick experiment told me that colours do not say much about pain or its experience. I could have had various forms; however, this process was to test colours, not form. In fact, I thought the objects that tested form were more effective in communicating pain than those that tested colour. However, colours could be like textures, where it is better in partnership with an object’s form to improve its ability to communicate an attribute of pain.

Figure 44. Clay objects with glaze on before being fired again

Figure 45. Finished glazed clay objects.

Using Metaphors in Prototypes

After I did more clay objects, it became apparent that I could not keep making objects associated with descriptors as there were so many descriptors of pain, with my original list having more than 50 descriptors. Having 50 objects would be impractical and overwhelming for the clinician and the patient to choose from and talk through. I needed a way to make these objects symbolic of many aspects of the chronic pain experience rather than looking at one-word descriptors.

I then came across some papers that discussed metaphor use in chronic pain. These papers researched metaphors used specifically to communicate chronic pain. The papers highlighted that metaphors used in chronic pain are an effective way to communicate pain (Declercq et al., 2023; Hunt, 2021; Johnson et al., 2023; Munday et al., 2020a, 2022; Téllez, 2018). If I could have these metaphors symbolise or encourage metaphor use, I thought it could benefit chronic pain communication. The metaphors I encountered used comparisons to objects and common pain descriptors that showed emotion and how the pain symbolically felt. This was demonstrated by Munday et al. (2020), who demonstrated a patient describing a stabbing pain, “ I have two large stakes being plunged through both my temples and through the bottom of my skull” (p. 821). The metaphor gives more information than just the word stabbing; instead, it tells the emotion behind it, the location, the movement, and the emotion associated with the pain. What this means for my research is that there needs to be a way to encourage metaphor use between clinicians and patients, and the metaphors found in literature can serve as inspiration in making prototypes that tell a story.

The Objects I Make Need to be Less Manufactured and more Interpretive.

Through concept mapping, I noted that the objects I thought were successful were very ‘irregular’, meaning they had no pattern or order. For example, a successful clay spike ball would have spikes around the object without ‘regularity’ or particular distribution. I questioned why this was common and shared among the successful objects, but by reading the literature, the answer was clear. Pain is very complex, and many factors determine how a person might navigate it.

Machined products have a way of flattening meaning and telling users what the product is rather than what the product can be. This was important for my project as manufactured products have a set of unseen meanings the user must abide by for the object to work. However, with my objects, it is the opposite; they are supposed to be open, used in many ways, and interpreted by the users. Nonetheless, there must be some indication of what this object is and how it can be used while being open enough for patients and clinicians to interpret the meaning of what each other says. Around this time, I was also reading into the cultural aspects of pain, where each culture interprets pain differently (Antunovich et al., 2024; Chen et al., 2008; Lane & Smith, 2018). Culture is just one aspect that affects how patients see their lives, so having objects where patients can express their cultural values and worldview in a clinical setting may improve understanding between clinicians and patients.

Using concept mapping allowed me to reason and challenge the objects I made and then think of new ways of making them. Through this process, I learned that I wanted my objects to explore nuances in the pain experience while also being able to be used by most chronic pain patients. Simple, muted coloured objects with multiple materials and ways of interaction were how I defined the products I made moving forward. Furthermore, I wanted the objects to bridge cultural understanding between patients and clinicians and for patients to put their meaning into objects.

Locality Agreement Process

Formal locality approval was needed for workshops and focus groups on TARP's premises. This stalled the project at a time as it was challenging to get all the required signatures in a timely fashion, and thus, the project was stalled for more than three weeks. This delayed much of what was scheduled, and the research had to be postponed. This process showed that there needs to be space in research for delays as other people are busy, and sometimes, it takes some time for them to communicate on less essential matters. The project was further slowed when correspondence was slow, and focus groups and workshops had to be organised between TARPS's three-week pain program. The research project should have accounted more for the clinician's busy work life so that it would not have impacted the research as much as it did (while some delays were factored into the original plan based on recommendations in the consultation process, the extent of the delays was not able to be foreseen).

The workshop and focus group were further delayed as most of this was getting organised late in the year (Christmas, etc.), so they were pushed back into the following year, 2024. This changed a lot of the research project's schedule, as it was an incredibly stressful time trying to catch up and organise these dates. However, this time in the process, I kept making and reading, allowing me more time to explore and assess the prototypes I had made.

Experimenting With Making Mock-Ups With Found Materials.

I wanted to create more complex and interactive objects consistent with my making. I did rapid mock-ups of what I was thinking and reading contextually to do this. Through this process, I could test different materials and the ideas I had very efficiently. Especially as I was stuck in developing my making, using mock-ups would allow me a starting point to expand on. It was also an excellent opportunity to start making objects inspired by metaphors.

Grinding - Rocks In Straw (Figure. 47)

Grinding was one of the words and common metaphors in chronic pain. Along with grinding, metaphors included crunching and cracking. As they are similar, I wanted to make a glow stick-type object where it cracks when bent. I started noticing when I described what I wanted to make; I kept saying, “like rocks rubbing against each other”. Hence, I got a straw and small rocks, put them inside a straw and closed the ends with wire (Figure 46). I made two different versions of this, one with smaller rocks and the other with larger rocks mixed with the smaller ones (Figure 47).

This mock-up effectively gave the feeling of grinding and crunching when rubbing the straw. The mock-up also demonstrated what I wanted to make regarding grinding and crunching and could be used as a springboard for other ideas to make around a grinding and crunching pain. Further, it served as an example of what I wanted in an interactive pain object.

Figure 46. Straw with the rocks pictured inside of it. Fastened at both ends with wire.

Figure 47. Grinding pain objects.

The left has small rocks inside. On the right are big and small rocks inside the straw.

Barbed wire with yarn (Figure 48)

As Munday et al. (2020) mentioned, barbed wire is seen in metaphors around chronic pain. I did this before when making my silicon rod, but this time, I wanted to make a less aggressive, sharp one but one that resembled nerves. I twisted red yarn throughout the wire so you can still bend and move the wire without getting poked. Also, red yarn was chosen to test colour again, and it turned out successful as it added interest to the object and had a functional use. Furthermore, the object tested the assumption of whether using metaphors could inspire making objects. The object needs to be refined more to be implemented as a clinical tool.

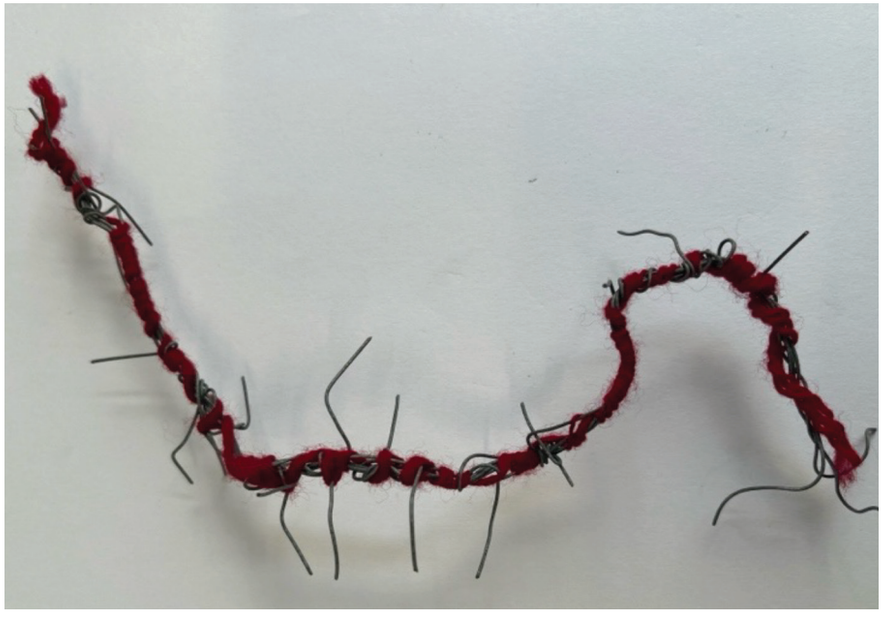


Figure 48. Barbed wire with yarn.

Stress Ball (Figure 49)

As said before, squeezing is used frequently in chronic pain communication. To attempt squeezing again, I got a stress ball filled with rice and wrapped in balloons. Surprisingly, the stress ball communicated the squeezing experience as I understood it quite well and better than previous prototypes. The ball had a rigid and grainy feeling while squeezing, adding an interesting and uncomfortable interaction. The squeezing object reminded me that developing a squeezing pain can be very simple to make.

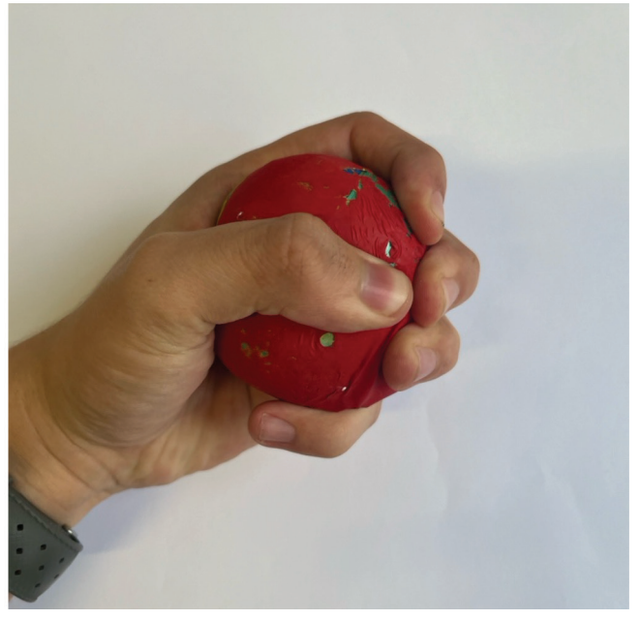


Figure 49. Stress ball getting squeezed.

Cotton Balls in Rubber Bands (Figure 50) and Wooden Cube in Rubber Bands (Figure 51)

The cotton ball and wooden cube in rubber bands were inspired by what I thought the chronic pain experience was like. When reading about chronic pain experiences, it felt to me that individuals with chronic pain were wound tightly, with stress and anxiety, as their life was consumed with pain. The cotton ball object (Figure 50) symbolised the preciousness of humanity now constrained by the individual's pain (rubber bands). The wooden cube object (Figure 51) symbolised a person trapped by their pain. The rubber bands were wound tightly around the cube and portrayed that at any moment, they could 'let go' like the emotions and pain felt inside a individual with chronic pain's body.

These explorations helped me think about the chronic pain experience from a different point of view, one that was not literal but more metaphorical. Since it was a quick mock-up, I could be more free-flowing and descriptive with the objects. The objects served as a reminder that I can get creative with making objects and be more interpretive in putting into form the chronic pain experiences I read about.

Figure 50. Cotton balls wrapped up in rubber bands.

Figure 51. A red wooden cube wrapped in rubber bands

Figure 52. Rope object with rubber bands.

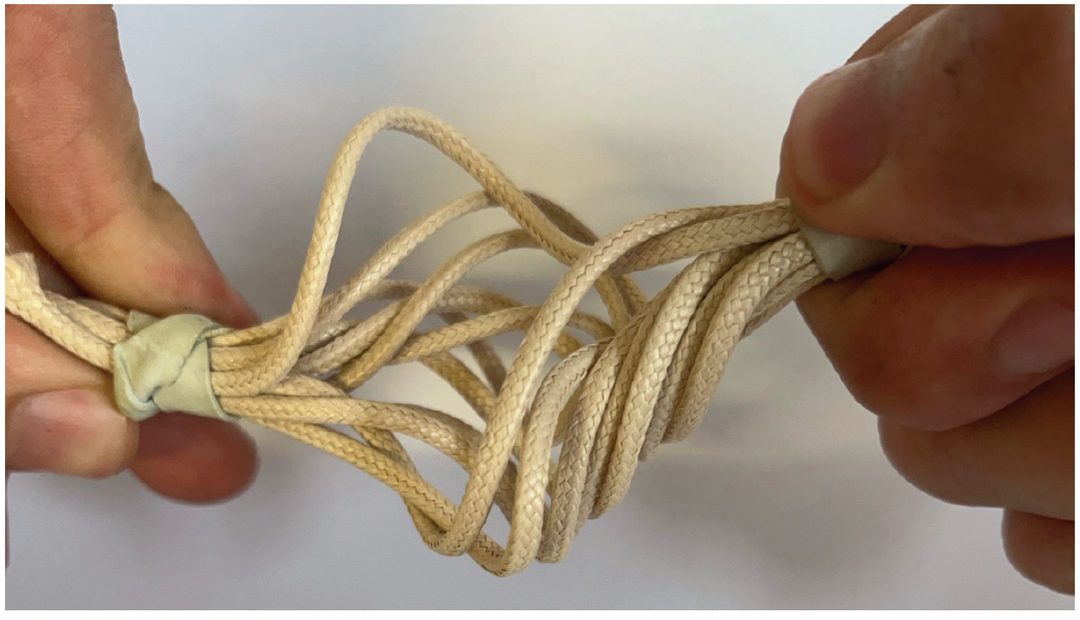


Figure 53. Rope object symbolising throbbing or loose stringy pain.

Rope with Rubber Bands (Figure 52)

With this object, I tried to make a pulling, tight, or knotted pain object reminiscent of a muscle. Again, I wanted to make it interactive as I only had a few with the prototypes I made. I then got some rope, cut it and fastened it with rubber bands.

This was one of my most successful mock-ups, as it was interactive and open enough to interpretation. The rope object allowed the patient to make the object their own and change it to be more representative of their experience (Figure 53). Therefore, different conversations could be had depending on how the patient uses the object. While the object was successful, it would need further development to look more suited in a clinical context.

Polystyrene Ball with Needles (Figure 54)

Though I have previously made spiky objects, I wanted to see if other spiky balls in other materials could communicate something different from those I had made. Instead, the polystyrene ball with needles did not tell me anything new about spiky pain, and previous objects were more effective in communicating a spiky pain.

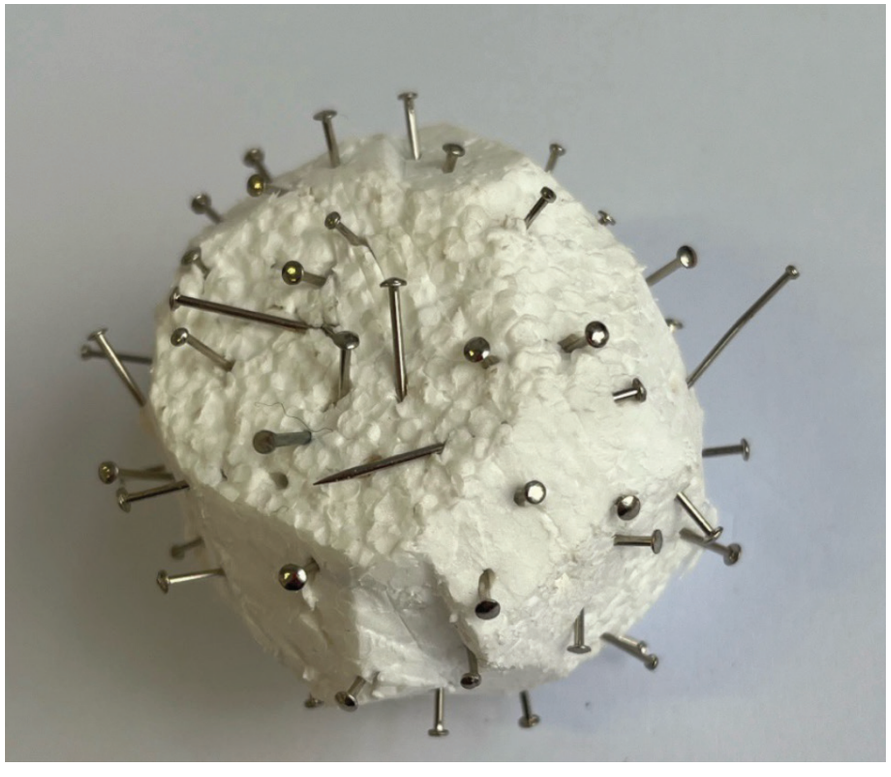


Figure 54. Polystyrene ball with needles.

Figure 55. Late November progress picture of all the making I have done.

As I had done a lot of making, I took stock of all the prototypes I had made until late November. This was a good way of assessing everything I had done and where I needed to go next. It was also encouraging to see how far I had come and to keep developing my prototypes.

Concept Mapping the Toolkit's Name

Even though I was still unsure about my research project's outcome, I knew I wanted a toolkit that improves communication between patients and clinicians. I was getting stuck on what the toolkit should be, so I turned my attention to concept mapping a name for it in order to inspire me. I began by listing names of the potential toolkit or ones that might influence others. I then generated more when I started talking about it with my design peers (Figure 56).

After limiting the names to a few and concept mapping more, I landed on Understanding Experiences: A Chronic Pain Toolkit. The name was chosen for its simplicity, clarity, and invitingness.

I named the toolkit "Understanding Experiences" as it means:

- The toolkit is about better understanding the patient's experience,
- Understanding what the clinician is thinking and saying about the patient's experience
- Having the patient feel understood and validated in their pain
- Improving clinician's and patients' understanding of chronic pain

The name was also appealing as it was concise and easy to say, and it also extrapolated in a meaningful way what the toolkit was about.

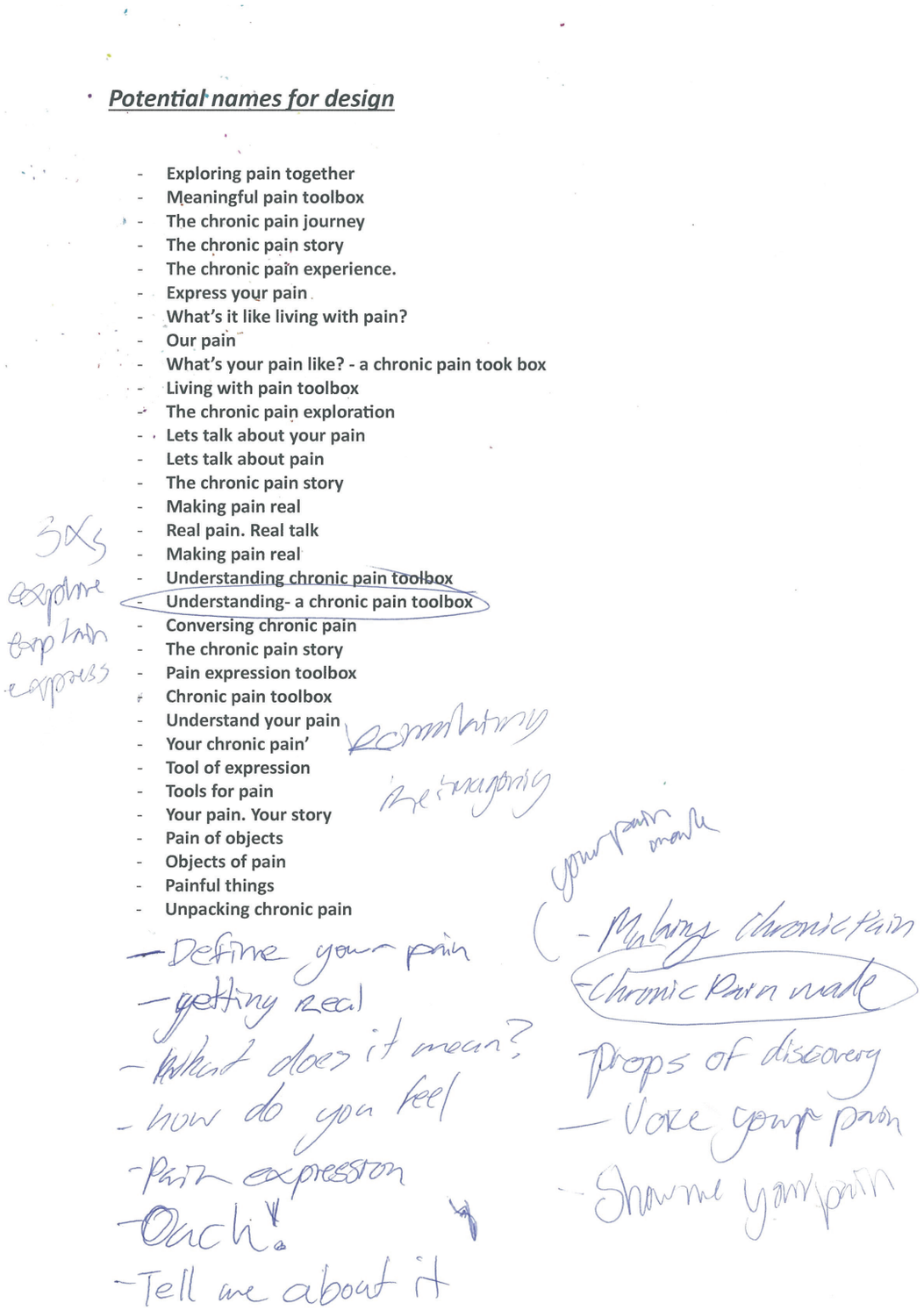


Figure 56. Concept map of potential names of the tool kit

Penned-in names were generated with peers. Circled names are the ones I liked the most.

Figure 57. Trying the bag activity with peers. Glass chips and clay spike bag activity on the table.

Creating the Bag Activity

With some of the glass chips that broke during the glass casting process, I had an idea to test my theory of whether feeling objects gives a different experience than looking at and interacting with an object. The idea came from me rubbing and handling the class chips in my hand and being reminded how it feels when I rotate my wrist and there is a crackling sound. To test what I was thinking, I provided my design peers with two bags, one with clay spikes and one with glass chips, and I put forward to describe the sensation they felt by putting their hand in the bag and not looking (Figure 57). I explicitly said they were describing the sensation and not guessing the material. At first, they were confused, but when one person started describing what they felt with the clay spikes, saying it “was brittle and rough”, my peers began describing what they felt. They discussed ideas and possibilities of the bag activity and encouraged me to develop it further. Some in the group stated that it was symbolic of the chronic pain experience, where it is felt and not seen. Others said there should be a range of materials for the bags, and how they enjoyed that sound plays a part in the activity. All these ideas allowed the generation of new ideas that differed from the objects I made, and instead, this activity was more interpretive.

The bags were further refined to have one with cut-up wire (Figure 58) and another with cellophane (Figure 59),

and I also tried one with rubber (Figure 60). The wire bag was made to resemble insects, as mentioned in metaphors used by chronic pain patients (Munday et al., 2020a, p. 823). This one effectively gave a different experience than the clay and glass bags with a different sound. Similarly, the cellophane bag was an attempt to mimic a crunching pain. Like the wire bag, it gave a unique experience compared to the others. The one I did not choose was the bag full of rubber pieces as it would have been better as an object, and as a bag activity, it did not have any significant experience using it that could have been added to the other bags. Making these bags allowed me to incorporate pain metaphors in a different way, which is not objects. Also, this bag activity further defined and narrowed down what my project would look like as I realised I wanted an activity-based toolkit.

Figure 58. Wire bag activity.

Figure 59. Cellophane bag activity.

Figure 60. Rubber bag activity.

Focus Group

The overall issue addressed in the focus group, as mentioned by clinicians of TARPS, was the chronic pain patients' expectations and the lack of fulfilment of those expectations by their clinicians. When I showed the focus group participants my prototypes, it seemed they wanted them to be more developed. Toward the end of the session, the clinicians started suggesting ideas for my project, which were helpful as they started to understand where I was coming from.

I constructed three themes from the focus group data that related to the research question:

- How clinicians are taught to think.
- Patients' realities of chronic pain are complex.
- Failures in chronic pain communication are common.

How clinicians are taught to think.

Most of the participants agreed that one of the most significant hurdles in chronic pain communication is that most clinicians misunderstand the topic of chronic pain. The biggest reason was their training and education, which led to misunderstandings on the topic.

“The model we are trained is an acute pain”...“The annoying thing is that at a postgraduate level, chronic pain is not taught. We're taught on the acute model; chronic pain is just acute pain which hasn't been treated yet”. **(D1)**

Participants suggested that the main problem on the clinical side is a lack of education and knowledge on chronic pain, with the occupational therapist **(OT)** of the group saying, “Well, because medical science is really limited on what it can do for chronic pain.” A different doctor **(D2)** used a metaphor to describe the dilemma clinicians have with chronic pain:

“ We are trained to fix mechanical machines, cars that are mechanical, but unfortunately, what we're actually having is that there's one brand new hybrid vehicle that's got mechanical components and electronic components, and we don't know actually how to fix electronic bits because we didn't design it, we didn't build it. We have got no ports to plug it and change it or reprogram it. We just have techniques to fix and diagnose mechanical bits.”

As clinicians view pain as acute, participants suggested that because of this thinking, clinicians often think chronic pain can be fixed:

“Modern medicine has allowed things to be done very quickly. You get a diagnosis quickly,”... “you get an MRI. And we expect that if you can see the problem, that's the issue”... “Medication is only about 200 years old. Our understanding is in the infancies, in the development stage, but people expect that because we have antibiotics that treat infections so well, it translates to all the other medications we have. But that is not a good assumption.” **(D2)**

“Is it also that we have treatments? But it’s what we are taught to expect” ... “Psychology and physiological treatments People often expect to have a medical treatment.” **(OT)**

Additionally, this type of thinking hasn’t changed because clinicians have confidence in their knowledge of treating pain. As the anaesthetist **(A)** of the focus group said:

“I think it's that, you know what You know, this is what I know. This is where I work. This is my world. So, it falls outside of that experience. And all the comfort level is set up to reinforce that this is what I do... so I'll use me as anaesthetist. As an anaesthetist, my drugs work.” **(A)**

Patient's realities of chronic pain are complex.

A common view among the clinicians was that there was a misunderstanding of pain where patients have expectations of what their chronic pain is and how it should be evaluated. This led to negative feelings about their pain (e.g. uncertainty). To manage these feelings, Patients often sought clinical help. Following a clinician's suggestions, much of the patient's reality is shaped around the clinician's influence. This leads to misdiagnoses and misunderstandings of what chronic pain is:

"Many a times I've seen patients with neuropathic pain and it could have been dealt with early on by the doctor that saw them, but they didn't actually give a very good explanation on what the symptoms were. It's only until they came to us, and [the patient says] I think we've got a nerve injury in this area. [The clinician at TARPS] Show[s] them a picture and say, oh, yeah, it fits. But when you look at people's letters before they say...I think that our surgeons say, I think this patient's got nerve pain. Full stop. That's it. That's all they get." **(D2)**

Patient misunderstanding was closely related to what clinicians inform patients about their pain. Where one participant, a registered nurse (RN), said even patients think of their persistent pain through the lens of acute pain:

"We're trying to get a starting point with many people that I work with just to get that differentiation"..."Acute pain and chronic pain have got nothing in common. So the patients are still thinking in acute pain model and possibly many of our healthcare colleagues as well." **(RN)**

Another participant (psychologist **(P)**) echoed **RN**'s sentiment:

"So a lot of people come with an expectation that there is a fix for this pain, and that's the challenge that we have to unpack because they become very disappointed that's not what we are about. So because we've got the two-word pain clinic."**(P)**

Along with patients wanting to "fix" their pain. Patients often were met with "disappointment" as there was a breakdown in expectation for their pain to be "fixed.":

"So that's the mentality. So the disappointment when reality is faced that chronic pain isn't fixed with a pill or a procedure or a manipulation or whatever, there's a disappointment across the board, disappointment with the patient that they were promised to be fixed"..."disappointment with the practitioner who promised to fix it and didn't. And so by the time they write to us, there is an overwhelming sense of disillusionment and disappointment across the board." **(D2)**

Along with disappointment, an agreed-upon word among participants to describe the chronic pain patients' relationship was "betrayal."

"A GP can only get 15 minutes, 30 minutes max if they book a double appointment. And so for someone to try and begin to describe something that's overwhelming and complex and difficult to grapple with in that time, it's disappointing- frustrating for both clinician and patients, at least to that sense of betrayal, breakdown of relationship disappointment. Again, betrayal." **(A)**

"Betrayal, that's a good word." **(D1)**

"Yeah, I like that." **(D2)**

D2 had another helpful metaphor for what he must explain to patients when he first meets them as he felt patients do not understand their chronic pain, so he puts it like this:

"[Pain] comes with the four horsemen of pain and the four horsemen of apocalypse. The first horseman is a horseman of physical health. He comes in and robs you of the physical things that you can do. Most patients will relate to that. The second horseman is a horseman of

relationship. He robs you of your relationships, your friendship, your family, work. The third horseman is a horseman of peace. He robs you of your peace. People get anxious, depressed, pissed off, poor sleep. I kind of get this. And the fourth Horseman robs you of your future because you can’t plan tomorrow. It affects your roles, your manner. Because we can't always get rid of pain. A lot of our kind of approach to persisting pain is actually dealing with these areas that have been affected.”

Failures in Chronic Pain Communication is Common

Focus group participants agreed that there is nothing in the chronic pain clinical space regarding letting patients tell their stories. Participants suggested there was a strong disconnect between the patient expecting the clinician to fix it and what the clinician can do to fix the pain. Clinicians, or those in healthcare, are indicated by participants not to be trained in knowing how to communicate with their patients regardless of whether they have chronic pain.

“I'm anaesthetist before I was a pain specialist, and nowhere in that was I trained in how to communicate with somebody and understand the text of my words, or understand and listen to them. So, my pain training involves learning how to listen to a person, validate them, understand where they're coming from. So it's not necessarily going to be everyone's experience.” **(A)**

Another participant agreed and added that there is a change in how communication is viewed in health:

“I used to work on the burn ward at [Redacted], and it was really interesting going on ward rounds with the plastic surgery consultants, and there are a few things that occurred to me. One is that decades ago; there was absolutely no emphasis on the soft skills. And a lot of learning has been done in medical education by academics that focus on that and how important soft skills are.” **(OT)**

Some participants gave reasons why, explaining that clinicians rely on their knowledge as chronic pain communication is complex:

“I think it's really complex. It's sort of partly dispositional, partly training, and partly the environment that people operate in.” **(OT)**

The anaesthetist reinforced the idea that position and training hinder communication, saying:

“Orthopaedic specialists are way over here, again, in terms of words being a tool that you use and experiences being a valid way of communicating with the person, of connecting with a patient”... “I've certainly observed situations where, because I did surgical training before I did anaesthetics, sitting with a specialist during my training, where they would talk the phrase out without even being aware of the impact of that word landing on the patient”... “And then here in the pain clinic, they'll come in, and the words they'll say from their orthopaedic specialist, I've got bone on bone, and it's wearing away, and I've got only so many months to live.” **(A)**

One participant tried to explain why there is trouble communicating chronic pain from the point of view of the clinician and patient:

“And a lot of people aren't comfortable with other people's emotions, don't want to hear their stories, so they go down a certain branch. We love hearing the stories, and it's part and parcel of what we do.” (RN)

“Because people are often cautious about saying stuff in case they sound like they're a little bit crazy” **(RN)**

Some focus group participants gave ideas on improving chronic pain communication and challenged how stories operate in chronic pain:

“So being taught in how to set it up so that a person feels comfortable and honoured and valued”... “I've found, personally, that a lot of learning and understanding about Kaupapa Māori has helped because that mihi, that respect aspect of opening up so that someone can feel very safe”... “And I think that's where Te Reo Māori definitely has such a strength to offer us as clinicians. So that's been part of my journey.” **(A)**

One of the doctors explained the conundrum of clinicians telling stories with patients:

“Stories are difficult. It's a really good question, but they are difficult. There's laws against our self-disclosure, so that narrative is out of the window. And some of them left with one of the particular stories that we can tell. Stories of success. Well, that's going to disappoint someone. If they don’t go that way. Or stories of failure. Well, that's the story. That you don’t want to tell. So it's a very difficult one. So it has to be more of. A generic, as you are saying, validating, nonspecific direction without getting it focused. That's a long way of way saying, good question. I don't know the answer.” **(D1)**

While the **A** challenged the actual structure of stories, hinting at patients needing help to create a story. Saying:

“Journey is also not linear and, so it's really hard to create a story. That's a one-size-fits-all tool.”

Developing the Research Project

After the bag activity and my design peers' suggestions of the activity being included in the final outcome, I decided the final product should be an activity-based toolkit. The toolkit would contain different objects and be used with different exercises, such as the bag activity. Having a clear idea of my design allowed me to develop and refine my prototypes suited to a more defined context. I could start designing for something but also have a concept for participants to critique and give feedback on.

The Aesthetics and Packaging Design of the Toolkit

Since I had a clear idea of what the toolkit would be, I started designing an aesthetic and exploring colours and patterns for the toolkit. I searched on Google for images with keywords like “modern retro” or “modern abstract”. The reason for these keywords is that the toolkit needed to appeal to clinicians (modern) and indicate what will be in the toolkit (the toolkit’s objects are abstract). I started creating a concept map (Figure 61) of the images I liked and designed based on the aspects I liked from specific images.

My first designs were too busy and complicated and should have said something about what was inside the toolkit (Figure 62 and 63). Instead, it was a bunch of random

This image has been removed by the author of this thesis for copyright reasons.

Figure 61. Aesthetic concept map. Images gathered from the internet using “modern retro” and “modern abstract”.

patterns that did not tell the user who this toolkit was for or what it was. I started playing with shapes and making a person out of them to show that the toolkit was about exploring human experiences, yet it did not look appealing (Figure. 64). Instead of random shapes, I decided to make each object in the box symbolised by an icon and then arrange the icons on the cover in an attractive way. After trying a few arrangements(Figure 65 and 66), I landed on one I liked (Figure 67).

Designing the aesthetic for the toolkit was difficult as a lot of balancing and aspects had to be considered. Also, it was challenging for me as I am a product designer, not a communication designer.

Figure 62. First try at designing packaging for the toolkit

Figure 63. Second try at designing packaging for the toolkit

Figure 64. Making a person out of shapes

Figure 65. First attempt at making packaging that involved symbology of the objects inside the toolkit.

Figure 66. Second attempt at making packaging that involved symbology of the objects inside the toolkit.

The aesthetic needed to appeal to the clinicians as they would own the toolkit while also appealing to the patient when presented. Although clinicians may not be concerned with the box's design and more with the function, the toolkit's design identity must still be appealing. I had to find the balance of the packaging not looking like another clinical tool but still recognised as one so that patients would not be daunted or tired of another clinical tool to assess their pain but would be more interested and excited to use it.

Figure 67. Final packaging design.

Contents of the Box and Exercises

Now that I had the aesthetics and some idea of what the toolkit would contain, I started figuring out the exercises to accompany the objects. The exercises were a way to give structure to the clinical appointments and an idea of how to use the objects for the clinician. I first drafted up four exercises for this toolkit. The first is a bag activity where patients put their hands in the bags without looking and relate their pain experience to their feelings and hearing. The purpose of this activity was as a conversation starter for the clinician to start understanding the basics of their patient's pain experience. The next was a conversation activity where the patient used the objects as props to talk through their pain experience. At the same time, the clinician asks questions, and a conversation starts to develop. The other activity was a PRISM (see contextual review) activity where objects are used instead of discs, and patients discuss why they chose specific objects to symbolise the factors affecting their pain experience. This exercise creates a deeper analysis of the patient's pain experience than the usual way PRISM is used, as the patient can explain each factor affecting their life in more detail.

Lastly, I wanted an activity based on what was mentioned in the focus group, as one participant mentioned having a swirly oil artwork to depict pain. The activity would have some paper with oil swirls on it where different areas would be darker than others; the patient would place an object that best represented their pain on this paper. The darker areas would mean the pain is more severe, while the lighter parts showed pain as less severe. The patient would move their objects around as the clinician would ask how their pain felt while doing specific tasks. This activity was soon abandoned as three exercises were plenty for the toolkit, and what the activity was trying to do seemed irrelevant as the bag activity could be used to describe how severe the patient's pain was.

Designing the exercises made it feel like the toolkit was finally coming together and also made me start assessing the objects I had to facilitate the activities of the toolkit. This meant having enough objects for PRISM for the patient to explain many factors in their pain experience. It also meant having a diverse amount of interaction with people talking about their pain. The exercises were written up very open and unstructured to give the clinician an idea of what they could do with the objects (Figures 68-70). The exercises in the toolkit were inspired by looking at some of the other pain assessments (covered in the contextual review), which I put into a graph in relation to one another (Figure71). This revealed not only inspiration on how to frame the exercises I make but also to include PRISM as it is effective in assessing the patient's pain experience in a unique way.

PRISM Activity

How is the pain your patient is feeling affecting their life?

This activity is used to see how different factors affect a patient's life with pain.
Instructions:

- Have the patient choose an object that best represents their current state of being and how they feel. This object will be called "self".
- Ask them to choose then objects that best represent factors that affect their life(e.g. work, family, pain, painkillers, hobbies, spouse)
- Tell the closer the object is to their "self", the greater its effect on the patient.
- After all the objects are placed, ask the patient to talk about the placement of the objects and why they chose those objects.

Example:

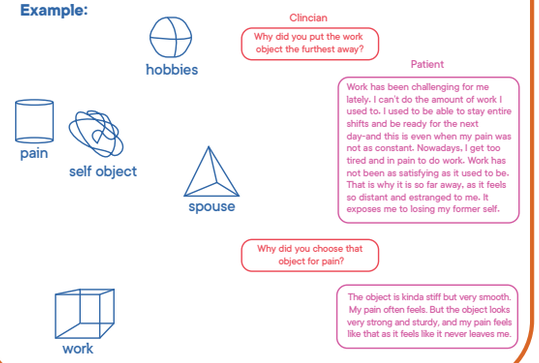


Figure 68. PRISM activity instructions.

Bag Activity

What sensations might you be feeling?

Feel what's in the bag (don't look).

Find a bag that 'relates' to your pain , and explain/think what you have chosen this bag. You may need more than one bag to help explain how your pain feels to you.

Example:

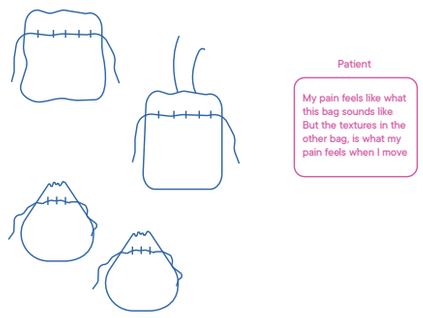


Figure 69. Bag activity instructions.

Objects

Can you and your patient talk about the pain they are experiencing?

Talk through and discuss, with the objects, about your pain experience. Any aspect of the objects (e.g. texture, size, weight, and visual) can be used and a number of the objects can be used as well.

Example:

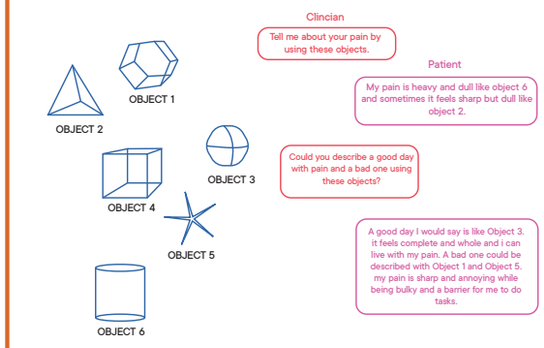


Figure 70. Object activity instructions

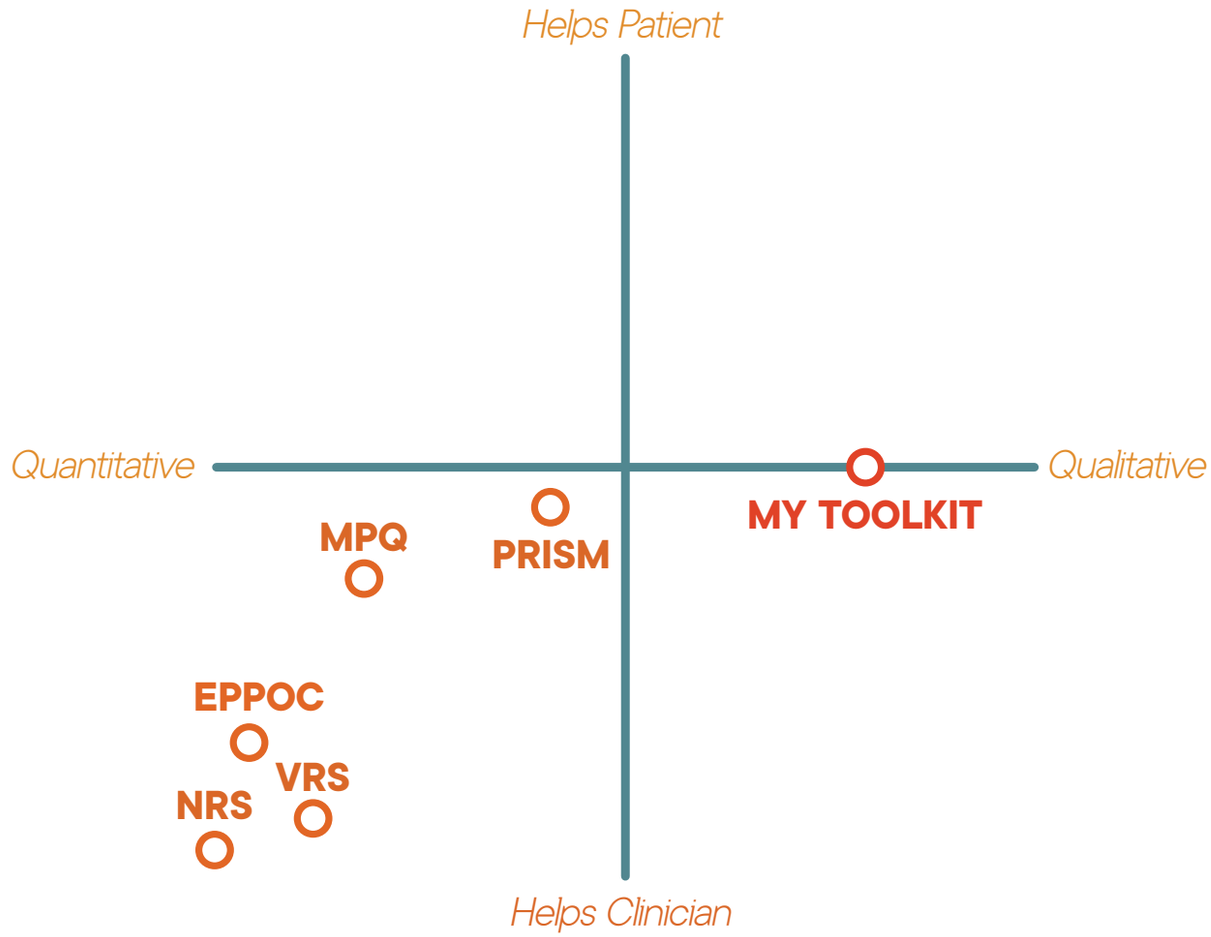


Figure 71. Different pain assessments from contextual review graphed in relation to where I want my toolkit to be.

Metal Object (Heavy, dull pain)

The literature often describes a heavy, dull pain through metaphors and descriptors. To make this into a tangible object, I decided to make a metal object. To do this, I 3-D printed an object that best resembled a heavy, dull pain in form with large spheres to symbolise heaviness and swollenness and spikes to show the sharp pain that occasionally happens with heavy pain.

After 3-D printing an object, I made a ceramic shell around it by dipping it in slurry and then in sand ten times over a couple of days (Figure 72). The cast is put into the kiln so the 3-D print inside evaporates and the ceramic shell hardens. Bronze was then poured into it. Bronze was chosen as it is a heavy, accessible, and affordable metal. After the bronze cooled, I broke the ceramic shell off by hammering and removing the residue with wire brushes (Figure 73). I decided to leave it with a rough texture to avoid the machine look and make it feel more interesting with the round and sharp feeling it already had,

The bronze object effectively portrayed a heavy, dull pain (Figure 74 and 75). The object was heavy and embodied the metaphor of heavy and dull well. Regarding the object's size, it was a nice shape to hold and was not too heavy, especially with the weight. While feeling it, I felt I could also embody aching, as I found it feels like when my bones or muscles are tired. Like all the objects I made, they were from my interpretation of pain metaphors; however, this object was quite successful in my mind, and I would bring it to the workshop to get feedback from chronic pain patients. to see if my assumptions were correct.

Figure 72. Ceramic shelling process over 3-D printed object.

Figure 73. Removing ceramic shelling off the bronze object.

Figure 74. Final metal object.

Figure 75. Final metal object from different angle

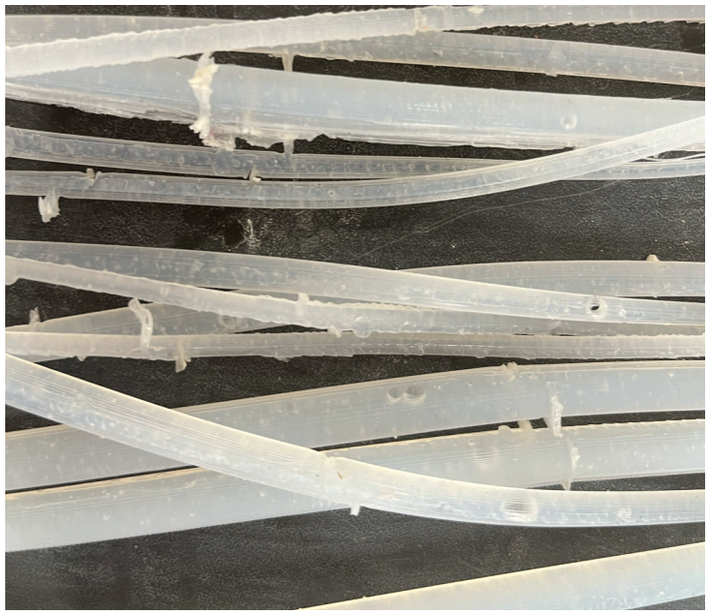


Figure 76. Close up on stringy pain and its air bubbles.

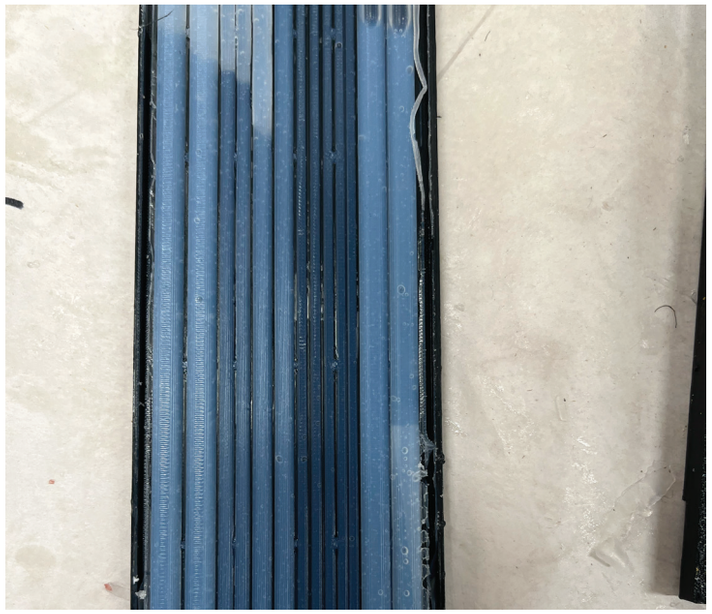


Figure 77. Silicone sinking to the bottom after pouring, then putting together, the two part mould.

Stretchy Tight Pain.

Using the quick mock-up of the rope object (Figure 52) as inspiration, I wanted to develop this further as participants in the focus group resonated with it, and there were more possibilities this object could have. For example, having the object be stretchy as well to be more interactive. I began 3-D printing a mould with variable diameters to see which would work when I poured RTV silicon into it. RTV was chosen because it was strong enough to stretch without breaking, which was needed with how thin I wanted the individual strings. After the RTV set, I noticed the strings had a few air bubbles (Figure 76), but they did not break when stretched. However, there was still potential for the object to break over time with these air bubbles. To avoid air bubbles, I did another try where I put the silicon on one side of the mould and the other and put the mould together to try and avoid air bubbles. Doing this made a worse result as the silicon sank mainly to the bottom of the mould (Figure 77). On the third time, I tried injecting it to have better control over the air bubbles entering the mould; however, this created more air bubbles as the syringe pumped air into the mould as the silicon flowed into it Figure 78). For my final try, I got tubing, and I put the silicon down it by injecting it and closing the overside when it started flowing out. I also tried cutting the tubing in half and putting the silicon on each half. As I had

leftover silicon, I put the rest on one side of the mould to see if an open-face mould would better avoid air bubbles. This test was better because these prototypes had little to no air bubbles. However, these prototypes felt weirder as they were primarily semi-cylindrical. In addition, I attempted to put handles on either side of the silicone strings so they were easier to twist and interact with. I tried RTV silicone handles and laser-cutting acrylic plastic handles (Figure 79). However, these did not look appealing, and when shown to other participants in workshops and interviews, they were fine using these strings without any handles and were very expressive when using them. This included actions I would not have thought of doing with the strings.

I stayed with the first trial as it was the one that had the least amount of air bubbles. However, the air bubbles added an interesting experience along with the rough exterior of the object. These ‘mistakes’ made the object much more interesting and stayed away from the manufactured look that I was avoiding. Having the stringy, muscular-looking object in the toolkit meant there was an interactive element to the toolkit. Where there were a lot of still objects, having something where patients could interact with and do various actions could allow for more diverse conversations to happen while using the toolkit. The object was also more open than the other objects, where patients could address different

aspects of their pain experience, not just the sensation but how other parts of their life may be affected by their pain (which appeared with participants in the workshop when they used the object). This meant that when the object was used, it could create deeper conversations and reflection. This idea would be useful to apply to the other objects in the toolkit.

Figure 78 Silicone strings getting air bubbles from syringing in the silicone into the mould.

Figure 79. RTV handle with laser acrylic plastic holder on the other end

Figure 80. Assortment of was shard objects,

Figure 81: Half spiky ball test and simple stacked glass test after casting.

Glass Object

As the previous glass objects did not portray the shardy brokenness I wanted, I made wax objects by hand rather than 3-D objects to make moulds. To accomplish this, I made thin sheets of wax and broke them into shard-looking pieces. I then arranged the broken wax pieces in different arrangements to create a broken shard object (Figure 80). From here, the process was the same as when I did the 3-D printed object: I made a plaster-silica mould around the wax object, melted the wax out of it, and put gaffer glass on top. Since the shapes had complex arrangements, there was no certainty that the glass would melt throughout the mould. So, I chose three test objects to investigate if the glass casting process could work with these types of shapes.

I aimed to make a hand-held shard-like ball object out of glass. To test if it could be made, I did a flat piece of wax with different shards to act like half of the ball. For the other test object, I chose a more complex arrangement and a very simple stacked one that would most likely work. All these models had good results (Figure 81); however, the flat shard object had some pieces that broke off (Figure 82). This is most likely due to the wax pieces not being firmly attached to each other when I made the object. Another problem with the same object was removing it from the pour pot. The model was difficult to clamp down and shattered when the grinder

separated it from the pour pot (Figure 83). This meant that the glass ball object had to have its shards firmly attached with a clear, distinct pour point that could easily be removed. However, the objects successfully showed a shardy glass object that could portray a patient's pain while also testing different colours. I brought both yellow glass objects to the focus group, but both were met with poor reception, and clinicians did not try to interact with them. Instead, they thought it looked too sharp to pick up. I considered this an opportunity to improve the form as I was confident in it. After all the subsequent iterations, I could show and get feedback at the workshop to see if a glass object is needed in the toolkit.

I repeated the same process to make the shardy ball out of wax (Figure 84) into glass while being reminded to stick the shards together firmly. The final object was very interesting and came out how I wanted. The problem the object had, in my view, was that it looked too beautiful instead of a prop that could describe pain; patients could be distracted by how pretty it looked when using it to communicate pain. Despite this, the glass object gave another dimension to the toolkit, as glass can be portrayed as fragile, broken, piercing, and sharp. This object could be interpreted in many ways, and the size and weight added to the experience while interacting with it. This object could have been made better as there

Figure 82: Pieces breaking off of blue glass object.

Figure 83. Shattered glass object.

was plaster in the cracks, which was hard to wash out. However, this was an object that went over well at the workshop, with patients being very intrigued with it and interviewers seeing the possibility of it being used to describe joint pain.

Figure 84. Wax shard ball before getting a plaster silica mould around it

Making the Toolkit's Box

The toolkit's box had to be simple. If this toolkit were to be replicated, it would need to be made of a material that would be affordable and accessible. Also, the box needed to be light enough to carry around, especially for its large size. This meant making the box out of paper and cardboard, as these materials are light, accessible, and affordable. My first box was small and made of card paper. The process of making it was tracing around another box net I had on card paper, then cutting, folding, and glueing it together. In making this first box, I noticed that the method of making it was not difficult and could be sped up if the box net was laser-cut. I thought the card paper was strong enough, and if it needed to be strengthened, cardboard could be cut and fitted into the box walls with a cardboard bottom for extra strength. Overall, making the box this way allows for changes and can, in the end, make a solid box.

For my second box-making method. I tried vinyl wrapping. This included cutting and constructing a box with cardboard and then wrapping it with vinyl . The process was difficult as I tried it on a larger-sized box, and stretching and moving the vinyl over the cardboard was challenging. Furthermore, the feeling and look of vinyl did not appeal to me either, as I thought it would not be suitable for my box, especially since it would be larger than the one made.

Figure 85. The making of the first mock-up of the toolkit's box.

Carrying on from the first test, I decided to make the first mock-up of the box for the toolkit . After getting the measurements I wanted, I got paper that was not too thick as that would be hard to fold, but thick enough that the box would be durable. I designed, then laser-cut the box net and started folding it (Figure 85). The first mock-up was to give me an idea and feel of the size and see if it would work for the toolkit. I was happy with the box size, but I would only go that size as I struggled to find a piece of paper big enough to fit the net, and any bigger would not be comfortable to carry around. At first, I thought this box was very flimsy. However, it stayed solid and mostly undamaged after being taken to the workshop and interviews. This first mock-up allowed me to take it to participants in the workshop and interviews to show a general size and scale of what the toolkit will look like. From here, I could think of other ways to improve or add to the packaging. One way was printing my packaging design on paper and then folding it. Another is to add a cardboard insert for the objects to sit in so the patient and clinician can see all the objects laid out rather than digging through all the objects.

Workshop

Showing my prototypes to chronic pain patients at the workshop was an excellent way to challenge my assumptions surrounding chronic pain. Where they not only showed that patients are capable of communicating in-depth about their pain experience but also provided new ideas for prototypes. An agreed-upon criticism among participants is that the prototypes are too sharp and aggressive and need to describe the lasting impacts of chronic pain (e.g. the chronic pain journey). Participants indicated how they like talking about pain in groups, learning from each other's stories, and how they wanted the toolkit implemented in a pain management group setting to encourage and help these discussions. This is so patients can create a support group between those new to their chronic pain journey and those further along. Workshop participants expressed that they enjoy the tactile experience and that there needs to be more tools like the toolkit, adding that the more chronic pain resources there are, the better.

I generated three themes that were portrayed in the workshop that relate to my research question:

- The chronic pain experience can be made tangible.
- The lived experience of chronic and its effect on day-to-day life.
- Discussing chronic pain with other patients, clinicians, and those who do not have chronic pain.

The chronic pain experience can be made tangible.

Giving participants my prototypes encouraged them to explain how they view pain and its experience. Furthermore, participants suggested that patients are tactile people. A participant (Participant One **(P1)**) said they "think people are tactile" and that objects would create "good discussion" surrounding the chronic pain experience. It was also identified that patients think there is a need for tactile objects as the healthcare system and the world around them are technological. Participant 2 **(P2)** hinted at this and affirmed that tactile experiences encourage conversation:

"And even my appointment book, I've got a paper one because I want to see it. It's visual, and then I can put everyone's appointments on it. I don't want to put an appointment on my phone because then, not everyone else can see it. It's only just for the person. But that book initiates conversation, and it actually."

Participant Three **(P3)** encouraged a need for more physical experiences when communicating pain. They hinted that involving physical objects would be "relevant" as there "are not enough tools" and "the tactile stuff is a really good thing."

Along with constructed themes around the opportunity to have tactile experiences, participants highlighted how they could talk through objects. A significant theme of size and weight was shown through participants giving feedback on objects, with **P1** saying they wanted "various sizes" represented in the toolkit. **P2** also described their pain as "heavy and a mess", portraying pain as burdensome. They carried on and said their pain is "heavy and physical, and it saddles you". Participants added that the "weight" of the object is "great" in communicating their pain and wanted different weights incorporated in the toolkit as well:

"Weight is good. It's very different from this one here. Just, you know, doesn't weigh anything, really." **(P3)**

Temperature and colour were also used to describe pain; patients seemed to want these incorporated into the toolkit. Furthermore, they used temperature and colour to describe pain:

"I think something that maybe reflects temperature because that's a big thing, like cold and hot. Getting the hot. And the cold. Where the limbs go, limbs go hot and cold change colour a lot." **(P1)**

"That is what I've said about my feet. They're either freezing hot or burning cold." **(P3)**

"Freezing hot or cold. Yeah, or hot." **(P1)**

"I get the same thing." **(P2)**

"The feet just goes, one foot will be blue cold and the other one's normal. And then it just constantly changes." **(P1)**

Colours also played a part when participants made models of their pain experience, with one participant indicating colours symbolise how chronic pain changes:

"Yeah, and it's all different colours because it can be different and it can move different places, and then it hits you unaware when you get a nerve pain or something." **(P2)**

This may mean that different colours represent different experiences for some patients.

The lived experience of chronic pain and its effects on day-to-day life.

This theme was informed by participants frequently referring to their pain being like a “journey”. This was seen when they would talk about their lived experiences of pain and when constructing their pain models. This was related to statements made about how chronic pain is constantly changing and unpredictable and how patients seek clinical help to “control” their pain. Participants also expanded upon the complexities of chronic pain, what it does, and how patients view their pain throughout their “journey”. During the early stages of the pain journey, a participant highlighted that they thought patients:

“Fixated on the pain and just being fixated on what the actual cause is, when the actual cause is not what you think it is.” **(P1)**

This most likely leads chronic pain patients to go to clinicians to help live with their chronic pain. Chronic pain patients at the workshop conversed about the failures of different therapies clinicians offered them. **P1** indicated there was no conversation about how they felt about different therapies when going to their clinician:

“Starting your pain journey, [prototype objects] like this can make people maybe think a little bit differently and initiate a conversation about why did you feel that? As opposed to sitting there with a pain psychologist who, you know, there's no disrespect to anyone who sits here and tells you, start fluttering your eyelids, what one lady was doing...And I just knew that wasn't going to work for me. And then another one was like tapping.” **(P1)**

This insinuates that clinicians base decisions on their own understanding rather than the patient’s experience. This could lead

to the patient wasting their time with a clinician or misunderstanding their pain. In terms of a journey, **P2** said it felt like they were going backwards in their journey to manage their chronic pain:

“I went to physio and she was doing these exercises, and I just kept on failing at them. I couldn't do them. It just would be flare up after flare up, and I'd try and try”...“feeling like I was just stagnating or going backwards. And then once my surgeon said, don't do physio, come along to TARPS, that I learned to just grade that”...“because it takes a while to get up the steps of the ladder to get up to where you want to be”...“So that was once I got my head around. Oh, okay, I can do that. And it was more manageable through a different physio.” **(P2)**

P2 expanded on this to hint that there is a type of hopelessness associated with this patient experience where clinical practices feel like they aren’t working, and the patient blames themself. However, as said in the previous quote, when a program like TARPS works for the patient, there is a sense of relief.

“And so rather than me thinking, oh me, I'm trying my best, but I'm getting nowhere, I'm going backwards” ... “once I knew what was going on in my body and what I could do about it and manage it's kind of grading up and it's kind of more manageable.” **(P2)**

As chronic pain is not like the more common acute pain, there is difficulty in understanding it. In terms of managing chronic pain, patients have first to understand it. As one participant said:

“Because when I first went to this pain specialist [Redacted] he's awesome. And he explained that the sensitisation thing, it's like a light bulb at moment like, oh, okay. So that's what's happening in that. But no one had ever said it before...So actually knowing and how to

manage it.” **(P2)**

Participants also theorised that patients, to manage their pain, look or get the wrong information. P3 seemed to say that part of the journey of understanding is knowing there are no right or wrong answers, but it is about the patient’s experience when they are managing their pain.

“There's so much conflicting information and, you know, you say, oh, I shouldn't be like this. But then you are like that. And there are no right answers or wrong answers.” **(P3)**

Other participants agreed with this and stated that Google or “Doctor Google” is a source of information for some chronic pain patients. It was also suggested that most patients go through a “discovery” stage where they are searching for answers for their chronic pain. When patients get an answer that does not work for them, the patient may get overwhelmed or depressed:

“This makes me think like a lot of people in their discovery are probably using Google or going online, whereas something like [the toolkit] is something that's going to be more receptive and going to make you think more than just going on Doctor Google and looking at random crap” … “and probably just going down a negative warren, where that's the majority of how people get their information nowadays, whereas something like [the toolkit], that's different because people aren't as tactile anymore.” **(P1)**

P1 indicated that there needs to be better resources to explore the subjective experience of chronic pain and how it could help patients understand their pain. Participants also touched on the emotional aspect of the chronic pain experience with all the “negative” emotions a patient may feel. Participants agreed that a frequent emotion they felt was anger, and part of the journey of chronic pain participants seemed was learning not to be angry anymore:

“I was really angry. I was angry. I was angry about it. I was angry that

I could do stuff I couldn't, like do heaps of most things. I couldn't do a kind of arm up properly past here. You know, washing is just not that exciting, but, you know, it has to be done.” **(P3)**

“Yeah, and that’s life. It's not going to be clean space. There's going to be bumps in the road.” **(P2)**

“Anger's a big thing”… “You got to let the anger go. And it's true. You've got to let it go.” **(P1)**

“It's a bit like the stages of grief, really, I think, with the anger.” **(P2)**

“It is it is” … “When you first start off, you think, oh, yeah, I can get back. I can do that. It's kind of closer. And then as you get on your side, it's further when you can't quite reach it.” **(P3)**

As suggested in this conversation between participants, the emotional side of chronic pain comes from its debilitating effect. Participants indicated their experience of sleep changed and how a task those without chronic pain take for granted–walking upstairs– patients could no longer do.

“It's just the brain…Before you're going to sleep or you're finally in bed. At the end of the day, the brain is just unleashing everything.” … “And the ringing of the ears, oh god silence, is it? No” **(P2)**

When it came to walking upstairs, **P2** said, “It feels like Mount Everest,” while **P1** said he only uses the stairs “three or four times a year” as it is “too much”. In addition to how chronic pain changes the patient’s life, chronic pain itself is constantly changing. With the objects, the patients mentioned a more “malleable” one to suggest an object that could change and morph. Regarding a journey, **P1** mentioned there are “roadblocks early on”; as all participants described in their models, there is a point of acceptance and control. The sensation of pain also changes. With the objects, the patients also described how chronic pain is unpredictable:

“So the first one with the nails, it just kind of makes you aware of the nervous system and the pain, whereas this one is, to me, is because of the different shapes and the edges. It's like the unpredictability of at all.” **(P1)**

P3 affirmed this by comparing an object to a dinosaur’s tail and saying:

“[Chronic pain is like a] long tail and it's got a mace on the end of it with just when you're least expecting, it turns around and whacks you.”

The surprising and unexpectedness of chronic pain may be as it is constantly changing. This is what may invite patients to want to control and manage their pain. Moreover, when patients described chronic pain as a journey, it always ended with an acceptance stage:

“Because that whole, like, **[P1]** was saying that getting to a stage of acceptance, you know, and initially, like, you have an injury, you have a recovery period, maybe you have to learn how to write, to walk, to speak properly again, all those kind of things. But then you work hard, you have got through all that, and then you still go. A Whole pile of crap on you.” **(P3)**

Acceptance of chronic pain seems to suggest an understanding of not what chronic pain is but what it can do and how it functions inside patients. By understanding, patients get control and can manage the pain they are experiencing:

“It's just kind of like the journey, really, as opposed to the pain itself, because I've accepted the pain and, you know, like, I'm sitting here now, and it's just radiating through my whole body, but I'm mentally able to control it. But. So it's more the journey.” **(P1)**

Discussing chronic pain with other patients, clinicians, and those who do not have chronic pain.

Chronic pain patients highlighted how they communicate differently with people they interact with. For example, with other chronic pain patients, they may feel there is a sense of community and a support system among other chronic pain patients. The workshop participants mentioned having the toolkit as a group activity within pain management so that everyone could discuss and learn from each other. Contrasting this is how chronic pain patients seemed annoyed or tired of telling people and explaining their pain to those who do not have it. In fact, **P1** gave a reason as to why not more people turned up to the workshop, saying:

"And that's why I think some people wouldn't have come today because it's just the talking about [Chronic pain experience]."

It seems from the comments from participants that patients have a difficult time expressing their pain to others who do not have chronic pain, as **P1** put it because they have not accepted it. However, there seem to be different reasons why. One participant hinted that it is because they are tired of explaining:

"And other people, too, not just you, but people in your environment, everyone goes, what is wrong? What's wrong?"... "just back off." **(P3)**

Before in the workshop, they added:

"You know, you don't actually want to have that huge interaction with people, telling them all the details and stuff, like." ... "I don't tell people ever." **(P3)**

P1 gave a response to **P3** in how he reacts to others asking him about his pain:

"As soon as I tell people, it's neurological with the spinal cord in the brain that shuts them up."

This seems to suggest that people without chronic pain often question the chronic pain patients' condition as they do not understand it. However, this may be the reason why patients are drawn and more likely to talk to each other as other chronic pain patients are more likely to understand their experiences:

"Yeah, and you're not the minority. Like when you go out.. they talk about their lives and jobs, you know, they just don't get it. Right, and it's like you're part of the majority here, and everyone gets it, and everyone has bad days. Everyone supports each other, and you get sent stuff" ... "And it just helps with understanding." **(P2)**

Participants evoked that there is loneliness when you have chronic pain, and there is a search for a community that understands:

"I think that's the biggest thing I've found with people with pain is how lonely it is at the beginning because there's no one. You're not. You're actually not communicating with anyone. There's no one in the same boat unless you know someone." **(P1)**

"And it's like coming on the Wednesday relaxation class. It's like you turn up, and everyone gets it because we're on the same page." **(P2)**

"But we don't sit around and talk about pain either." **(P3)**

Patients seek understanding; the most understanding people of their condition are other chronic pain patients. Even when patients are not talking about pain, they share an underlying, somewhat familiar worldview that gives them a sense of community. With the toolkit, this

‘community’ can unpack their experiences and learn from each other in a way you cannot with a clinician, as one participant suggests:

“Everyone has preconceived ideas or schools of thought like **[P2]** experience with repeat surgery and this and that”... “But what I'm saying is when you're one-on-one, it's quite narrow. But if you're in a group thing where you've got [the toolkit], and you're hearing **[P2]**, you're hearing **[P3]**, and you know, and other people talking, it's going to put light bulbs going on, it's going to make you think about other things, about your pain, and I can relate to that.”... “I'm not alone.” **(P1)**

Interviews

While two of the interviews followed the workshop, I could ask chronic pain experts about patients' responses from the workshop in addition to showing a prototype of my toolkit. In general, the chronic pain experts interviewed expressed interest in the toolkit. Two participants stressed that there is nothing like this and that the toolkit was "original". The prototypes offered an idea of the toolkit, which had the chronic pain experts offer feedback on how to develop the toolkit.

Two themes were created from the three interviews that related to the research question:

- Function of the toolkit in a clinical context.
- Representation of the pain experience.

Function of the toolkit in a clinical context.

One of the foremost queries I had for the chronic pain experts about the toolkit going into the interviews was whether it worked as a clinical tool and the best way to implement it. Going in with these questions promoted conversations about what clinicians are trying to achieve and looking for when assessing chronic pain. Participants suggested that the goal of clinical appointments with chronic pain is to help patients manage their pain with **IP1** (Interview Participant 1), saying, “The reason that we do assessments is to try and guide management.”

Participants expanded on the clinician’s goals when assessing chronic pain and questioned the toolkit’s ability to help clinicians:

“So that's. I mean, that's one of the things is why. How does [the toolkit] help with that? Because it's all about us having this time together. We want to know how I manage this person. So that's what all the questionnaires are about. What type of pain do they have? How intense is it? How is it impacting them” **(IP1)**

“But I guess in terms of, like, What's the benefit of [the toolkit] as being able to? Express verbally. Your inner experience. Maybe there's some therapeutic benefit of being able to have another person understand how it feels.” **(IP2)**

“I guess some common examples may be that you might want to know about as a clinician might be sleep. Because that's really important from a therapeutic perspective and understand how he feels person.” **(IP3)**

However, the participants pointed out that while the toolkit needs to be explicit in how it helps clinicians, they showed it could be used to explore some aspects of the chronic pain experience they do investigate. Participants suggested that through learning how to help patients manage their pain, the clinician looks at the lived experience

of chronic pain:

“It might be working on things like their anxiety. It's nothing at all to do with the joints or whatever. Let's go to a sleep clinic and try and get that sorted, work out. You know, what are the stressors in their life? It's those sorts of things. So then it's kind of. That's why the emotional part is important because that's one of the things you can change, is looking at how you manage.” **(IP1)**

In addition, **IP3** added clinicians are looking at “signs and symptoms” that indicate any “nerve damage”. They mentioned descriptors “could help give you clues as to what's actually happening mechanically differently”. Participants also explored how the toolkit could be used in specific clinical appointments because of the time it might take to use the toolkit. With regular pain assessments, the participants suggested clinicians may prefer them as they are quicker:

“So if you have to do all your normal stuff, people who have time to have a good conversation with them, our one you can do in 15 minutes, and you get a conversation, and you get the numbers out of it.” **(IP1)**

Contrasting this, **IP1** also noted how that might be in conflict in terms of benefiting the patient as patients want to tell their story of chronic pain:

“So we just had our pain society meeting” … “and so there were some people there with chronic pain who, when one of the key things was that you need to listen to them, but it's really hard, you know, you've got a set time and a set number of sessions. She said, you know, one of the key things was, don't rush them to look, we've got to do this. It's about listening to them.” **(IP1)**

While the toolkit may stimulate conversation, it is important that the function of the toolkit efficiently gives effective results. To solve this time issue, participants noted that a more structured instruction booklet along with clear guidelines might help clinicians better

implement the toolkit in their clinical sessions:

“Maybe like a guideline”... “around how a clinician uses it and what they get from it”... “or a guideline around how the patient wants to present it to their clinician. You know, maybe it's even more empowering if they have the are given this object, and they are told you could potentially use these or others to come back and express what your pain is.” **(IP2)**

“I think that would be useful, or maybe with more. More guidance or options perhaps that might Be useful” ... “How you might be able to use? That might be useful.” **(IP3)**

Embodying what the participants said about time and structure, they used the PRISM example in the prototype instruction booklet as one exercise that worked well, with **IP3** saying that PRISM “is the best thing “ in the toolkit. This may be because of the structure and how it is clear what the clinician is looking for when conducting PRISM. Other chronic pain experts explained why pain descriptors are not helpful in a clinical context. Participants mentioned that having a toolkit that helps express and create conversations may be more beneficial for pain descriptors. In addition, **IP1** acknowledged how metaphor use may be more useful:

“I agree that conversations are the best thing. It's about how [objects] used to direct the conversation and what [the clinician] gets out of them, because, like, the McGill [questionnaire] kind of separated it out into different things. But, the only useful part of it was a neuropathic pain ones, really. And there are better questionnaires for identifying neuropathic pain.” ... “We used to use it. I would never use it now. It's just the words on it. Like, I read it and think, oh, my goodness, what is Gnawing pain?”

“It's really hard for people to describe how their pain actually feels, and some people will come up with really interesting, weird, crazy descriptions.”... “but not many people actually come up with that. You know, like it's kind of stands out when they do. And so a lot of people just are like it's pain or, you know, it's sharp or it's achy or something” ... “it's like its words don't really express. So I think [the toolkit] is cooler for being able to come up with some metaphor about what maybe it actually feels like. It’s sparking some kind of communication tool about that.” **(IP2)**

Participants informed me to be aware that the objects within the toolkit may need to have some changes to the exercises to include consideration of cultures and those with complex regional pain syndrome in their hands.

“So one of the reasons we adapted PRISM was that for a lot of cultures here, self isn't the most important thing...So it could be one is an individual, there's a waka, marae, a group of people. So I think that's important for some of the collectivist cultures, which is pretty much all the cultures here, apart from Europeans, that helped them better, that it's not just about them. That's not the important thing.” **(IP1)**

“People have like extreme sensitivity to touch, which you get in your hand with complex regional pain syndrome. Then they won't want to touch this bag either, and they definitely won't want to touch those sharp objects.” **(IP2)**

The chronic pain experts largely agreed that the toolkit would be well suited for occupational therapy, therapy settings, or group settings. It was highlighted by a participant that occupational therapists (OT) and pain psychologists as they already do creative activities:

“Most clinicians are not going to come up with super cre- unless

they're the OT's. The OT's like the most creative Clinicians, most clinicians, are not going to come up. With like super creative Ways, but that's. I mean, that's like just a massively." **(IP2)**

IP2 also went on to mention that since it is a creative tool, it needs to be very clear in what it does so clinicians can understand and so can less creative-inclined patients:

"I think people work in healthcare and potentially patients too though you know patients as anyone and some of them are really are going to be like what? What do we do With that? What's the point? Or maybe there would be initial kind of hesitancy or lack of thinking of the benefits."

The toolkit was mentioned to live in a pain program, and there is a group element that would help in discussing pain:

"I think especially in something like a group pain program. I totally agree that something like this could be really nice, expressive way of people exploring their pain and." **(IP2)**

"It's probably best suited to an initial assessment, either. Either in a like a tertiary pain seems like TARPS. Potentially, you know, the in a short assessment and like ACC pain management services, which are, yeah. That that we would do you tend to have more time. You might have 40 minutes an hour." **(IP3)**

Representation of the pain experience through objects to communicate chronic pain.

This theme was constructed around participants reviewing and giving feedback on prototype objects. The chronic pain experts interviewed all, in some way or another, emphasised the need for variety and how the objects should be different in weight, shape, and size to give the patient the “flexibility” to choose what object they can resonate with. Chronic pain experts also showed interest and demonstrated how the objects can benefit patients' communication of their experience. Objects can show the invisible inward experience, as one participant said, referring to the bag activity :

“But I think it's good for people, for them to kind of feel like this is what it feels like. This is what it feels like inside of me.” **(IP1)**

Communicating through objects gives the patient a sense that their pain is real. The patient conversing with the objects might encourage validation and understanding from the clinician. **IP2** suggested involving a validation tool within the toolkit for the clinician could help the patient:

“I really think from a patient perspective, there's a lot of benefit in purely validation. And so, like, if you had [an exercise], how to use [the toolkit] to validate someone's pain, patients would love that. And there was some instruction of” ... “acknowledging that the pain they're experiencing is read. That it feels like [used object], and that must be really hard, you know?” **(IP2)**

Participants also celebrated that the toolkit is “physical”, and patients “get the choice to do things, and they get to talk about it.” This caused participants to give ideas for the toolkit. All participants

agreed that the current prototype objects were too “spiky” or showed “sharp pain”. **IP1** was the most vocal on this point, saying:

“I get a tiny bit worried with all the sharp spiky things” ... “I guess I get worried that patients, they often catastrophise, and they're imagining”... “This is what my knee looks like, and we don't want them to be doing that. And so that kind of concerned me a little bit.” **(IP1**)

They went on to add that having so many of these sharp and spikey objects could be daunting to the patient and highlighted that “sharp, spiky pain or tight pain or cold” in being represented in my objects may be useless. Further, they reasoned that is why the “[McGill Questionnaire] is gone. Not used as much now.” Because it is indicated, there is no value to the clinician knowing that. However, these sharp, spiky objects can be shown in the toolkit but hinted by participants to be limited. **IP3** demonstrated how it can resemble some pain:

“Like for me, with my”... “hip pain for a long time, that was sort of this dull ache. It was there all the time. And then also it's really occasional, and it's really sharp pain.”

Another common agreed-upon point among chronic pain experts interviewed was to involve more of the “emotional aspects” **(IP1)** within objects. Participants wanted a wide range of feelings patients felt involved in the objects:

“Fatigue’s a big issue. People have really poor sleep and pain”... “But, yeah, the fear, anxiety, depression.” **(IP1)**

Sleep was a significant factor to explore within the chronic pain

experience. With **IP1** saying:

“And using some explanations about” “you've had a really bad night's sleep. In the morning, it might feel like this, but after a good. It might feel like this. So, how do we work on your sleep? Showing them relationships between, you know, moods and stress and things.” **(IP1)**

Another participant wanted to have the concept of loss shown through the objects:

“I don't know” … “if there's a way to express loss. Emotional pain or feeling. Like hollow, like grief. Like that aspect of like, so we'd say pain has a sensory aspect, but it also has, like, cognitive evaluative aspects where we're understanding it and thinking about it. But it also has the emotional aspect. And you can't really separate them.” **(IP2)**

IP3 wanted more exploration around the mental state in the chronic pain experience:

“One thing that's probably here would be like that's missing, That would be quite important” … “How does it affect your psyche and your optimism and your mood and like how you know like that those things? Would probably be quite important.”

Addressing the emotional aspect within objects might help the patient manage and control their pain as it is one of the few factors the clinician can help them with:

“That's why the emotional part is important because that's one of the things you can change, is looking at how you manage.” **(IP1)**

Along with involving the emotional side of the chronic pain experience within objects, participants had other ideas for what objects should be created or were missing from my toolkit. Two participants mentioned

moving pain:

“Yeah, like moving inside the body, like maybe it's shooting and going from one place to another or it feels like movement going on inside the body, all that sort.” **(IP2)**

“like throbbing. I don't know how you do that, but something like that. You know, the sort of shooting throbbing electric shocks type and. It's different” … “The other thing that's kind of interesting is whether the pain comes and goes, or whether it's constant and changes evolves all the time is it constant or its only there with like movement.” **(IP3)**

For the most part, all participants wanted more variety as to give the patient more choice.

“It would be good to have different colours and have different weights and maybe something that's more dynamic.” **(IP3)**

Two participants had a common opinion that there should be objects that elicited a ‘pleasant’ response so the patient could focus on the good within their pain experience. This is to help patients envision where they want to be:

“If you had some nice ones and then sort of saying, you know, how does it go from this to that?” **(IP1)**

“Yeah, maybe some kind ones that are like good things in your life too. because, yeah, these are these are really good for expressing sharp pain.” **(IP2)**

Temperature was also highlighted by participants to be portrayed by the objects along with more colours:

“So sometimes pain is tight or sometimes pain is burning. But sometimes pain is fire, or sometimes pain is cold, you know?” **(IP2)**

“Yeah, maybe if you had a range of different colours, that could be an option.I think there's some pretty common”... “Not across cultures, but certainly in sort of European culture, I'd say, are really common ones around like dark black, signifying the dark moods, dark emotional like red signifying, burning, hot and blue signifying cold. And so those sorts of things you probably.” **(IP3)**

Objects need to be more Emotional.

In the interviews and workshops, most participants mentioned that the objects I had presented were all sharp and aggressive-looking. A participant in the workshop said that the sharp objects are good at describing the first acute pain patients experience; this was not the toolkit's goal, as the toolkit was to describe the whole chronic pain experience. Chronic pain experts also referred to the number of sharp objects that might cause patients to exaggerate their pain as they look aggressive and overwhelming.

Seeing the objects, I understood where the participants were coming from as most of these objects were made with an acute pain mindset instead of applying an aspect of the chronic pain experience to the objects. Furthermore, in thinking from an acute perspective, I focused more on the sensation of pain rather than the effects of pain, like tiredness, anxiety, and anger. This may be because I avoided making it because making such objects seemed complicated, and I assumed it would come out in conversation when describing the pain sensation. Chronic pain patients, however, seemed to encourage more interpretive figurative objects that do not explicitly look like pain, as they seemed to resonate more with them. This does not mean objects explicitly showing sharp, aggressive pain could not be in the toolkit. However, there needed to be a variety of objects to allow a discussion around the physical, emotional, mental, and spiritual factors that are affected by chronic pain.

Third Round of Clay Objects

I made some quick forms looking at the emotional aspects of the chronic pain experience. As both interviews and workshops highlighted, there needed to be more emotional-looking objects. As sleep was an important topic highlighted in interviews and the workshop, I made clay objects representing sleep or fatigue (Figure 86). My idea was to make a clay object that looked like it was collapsing in on itself or could not support its own weight. These objects were all made from what I think tired looks like. Previously, I would not have done such abstract interpretive objects. However, those in the workshop seemed to resonate more with the abstract interpretive objects and suggested that the objects I had were too literal and portrayed acute pain. When I brought one of the clay fatigue objects to two interviews, one participant described how it could be used to symbolise hollowness and how a part of the patient has been changed and will never return.

I then made tangled clay objects (Figure 87) and other objects symbolising different aspects of the chronic pain experience (Figure 88). The tangled objects were inspired by one participant in the workshop, who said he uses yarn with his pain psychologist to describe their pain. I then made these large, knotted pain objects out of extruded clay. Furthermore, I made sure to make them, and other clay objects, larger as many participants in the workshop mentioned that there needed to be more

Figure 86. Clay objects representing sleep or fatigue.

Figure 87. Tangled clay objects.

of a range of sizes, especially bigger ones. The tangled knotted objects turned out well and differed from the other objects I had in the toolkit in terms of size and form. These accurately portrayed the emotional side of the chronic pain experience as they portrayed to me the mess or confusion of the chronic pain experience. However, these objects may be better made as interactive objects where the patients can try ravelling them and making them knotted again.

The other clay objects focused on different aspects of pain that needed to be developed or were made as a reaction to what was said by participants in the workshop and interviews. One was a growing pain, where I made different-sized spheres connected to one another. This was mentioned in the first interview, where the participant mentioned making something growing and all-encompassing. The other clay object was my attempt at making a cold pain by making a clay object that looked like water and would be glazed with different blues. Participants in the workshop used many water metaphors to describe their pain experience and wanted an object to symbolise coldness. I developed the ‘squeezing pain’ concept by getting a ball of clay and squeezing it. The reason I made this object was to create something visually interesting and maybe more accessible to those who have pain syndromes or illnesses in their hands, as squeezing a ball might be painful. All these objects improved what was previously made and

added more variety to the toolkit that addressed the more emotional lived experience of chronic pain. This is important as the toolkit would be better if the objects were all different, as it would be more likely that various conversations would arise.

Figure 88. Clay objects that were inspired by what was said in the workshop and interviews.

Figure 89. Different flexicast grades leaking into each other as mould did not close properly.

Figure 90. Objects containing different flexi cast grades.

Rubber Pain Object

As I have done the flexicast process before, I knew it would make a good material to mimic a squeezing pain. Like last time, I wanted to make an interactive object, but to symbolise stress or throbbing this time. I first made a mould with various round organic shapes of different sizes. The shapes were round and organic because I was trying to decrease the number of aggressive objects inside the toolbox.

Along with being different sizes and shapes, the objects would also be different in different Flexicast materials, which meant they would all feel different when squeezed. This was to test which rubber would be the best for this. While pouring the rubber into the mould, it started leaking into the other objects, causing there to be different types of rubber in each part of the mould (Figure 89). This resulted in the objects having different types of rubbers combined within them (Figure 90). This caused them to be hard in some parts of the object and soft in others, creating a different but interesting experience when squeezing them. Sometimes, when these objects were squeezed, there would be some resistance, or in other areas, you could not squeeze them at all, while in others, you could squeeze the object more easily. In this way, the object could act and encourage conversations about the different factors of the chronic pain experience.

Out of all these prototypes, I chose the one you could squeeze but also had the best arrangement of the different rubbers within it (Figure 91 and 92). The object played with different feelings and could encourage descriptions of maybe throbbing, how it feels when an area is impacted, or how soft or sore an area could be. Along with the feel, the object's shape was simple but interesting enough to put meaning into. The colour was also different from other objects in the box, so in this way, it answered the request of some workshop and interview participants wanting more colours.

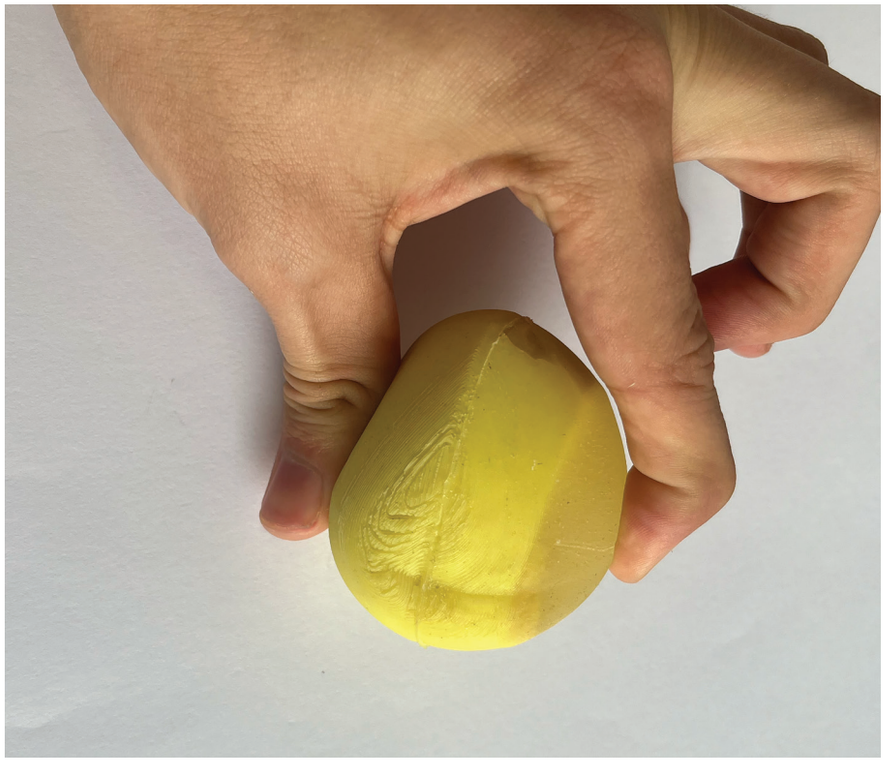


Figure 91. Final rubber object that was chosen.

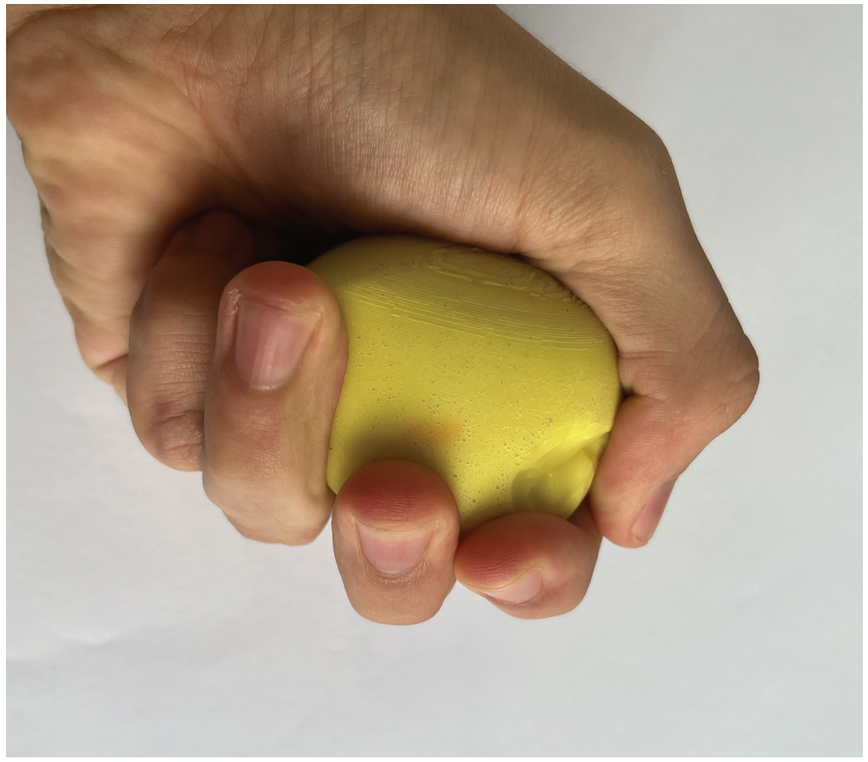


Figure 92. Squeezing the final rubber object.

Figure 93. Feeling oobleck.

Figure 94. Failed homemade slime.

Making Slimy Pain

While reading the literature around chronic pain, there were a few metaphors and descriptors that involved slimy and sticky to describe pain (Munday et al., 2020b). Turning these words and metaphors into physical objects, I wanted to make a slime ball the patient could squeeze and push. Firstly, I made a quick mock-up to test my assumptions by making some oobleck (a mix of cornstarch and water).

After feeling the oobleck, I was reminded of how my stomach feels when queasy (Figure 93). This was close to what I was looking for; however, with oobleck, it was messy and did not stay long, so I decided to make my own slime. This consisted of combining contact solution, baking powder, and PVA glue. This did not turn out as expected, as it turned very wet and liquid-like (Figure 94). However, I put it in some plastic wrap, and again, it was getting closer to what I wanted (Figure 95). It was more malleable than the oobleck and had a wet and slimy feeling, but it was too wet and would leak out over time. After making my slime, which did not work, I bought slime and put it inside balloons. I did this first in slightly bigger balloons (Figure 96), which were only partially filled with slime. This was similar to the slime in the plastic wrap but was more of what I was looking for. This object was more malleable and something you could make bubbles or round spheres with (Figure 97). I then tried smaller

balloons where one was full of slime and the other with less slime (Figure 98). The one with more slime was tighter and had a different feeling than the one with less, whereas the one with less slime was flatter and saggier. The tighter one was more effective as more could be done with it, such as it could be pulled, squeezed, and loosened up the more I interacted with it. Additionally, the tighter one seemed to deal with a lot of handling, while, like the bigger balloon prototype, the balloon with less slime seemed to tear and became saggier the more you squeezed it.

Again, having another interactive object with a different colour adds more variety to the toolkit, making conversations more varied when using the objects. The colour red was chosen because the focus group, workshop, and interview participants mentioned they would like some objects to represent hot and cold pain. Hence, the red object could symbolise something hot, for example, lava, as it is red and feels like a liquid. Also, workshop participants wanted a malleable object in the toolkit, like a “stress ball”. In my mind, this object accurately resembled what they wanted in that sense. However, this object may be too close to the rubber one as they are both squeezing pain, and their interactions are very similar. Both objects will need further testing with users to see if they are similar or different in how they can communicate chronic pain.

Figure 95. Squeezing the homemade slime in some plastic wrap

Figure 96. Squeezing some store bought slime in large balloons.

Figure 97. The bought slime in large balloons was good at being malleable but when relaxed it would be saggy.

Figure 98. Squeezing the final red slime ball.

Figure 99. The final red slime ball I was happy with. It was very malleable and could be tight or soft depending on how it was interacted with.

Figure 100. Final prototypes in the Understanding Experiences Toolkit.

Figure 101. Final bag activities.

Figure 102. Packaging mock up.

FINAL PRODUCT

Figure 103. Lid and what is first seen in the final toolkit.

Figure 104. Close up of the inside of the final toolkit.

Figure 105. Contents of the final toolkit.

Figure 106. PRISM exercise in action.

Figure 107. Bags for the bag activity.

Bag Activity

Clinical Objective:

To physically feel and relate to a patient's experience of pain sensations. Questions and conversations that arise can be about the nature of the patient's pain. In addition, this activity helps to explore the signs and symptoms patients may be experiencing. Reflecting differently on pain may lead to conversations on how different aspects of a patient's life are affected. Considering how the patient feels, their pain may lead to discussions on how it affects different aspects of their life or how it makes them feel. As a conversation starter, this activity is also helpful in unpacking and validating a patient's pain experience.

Example Prompts:

What do the bags feel like, and how do these relate to how you feel with pain?

Could your feelings be applied to how you live with pain, not just the sensation?

What bag do you resonate most with and why?

Can you use the bags to describe how severe your pain gets?

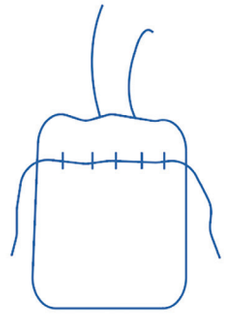
How does your pain feel using the bags, and does it change (e.g., movement and temperature)? And if so, how?

Could any of the bags be used to describe the location or how your pain moves across the body?

Figure 108. Bag Activity information within instruction booklet.

Description/Instruction:

Without looking, a patient feels what is inside each bag and talks through how the bag's contents relate to or feels like their pain experience. Make sure the clinician feels the bag that the patient is talking about.



Patient

As I feel in this bag, it is like how my pain feels in that it is all over my body. It isn't just in my mind or back that it's all over my body.

Clincian

Does your pain move across your body?

Clinician feels bag

No, it is felt constantly throughout my body, and when I sometimes lie down or move, I get a sudden jolt of pain that usually fades away.

When these sudden jolts happen, is it always the worst pain feeling, and how long does it take to fade away?

It typically happens when I lie down or do light physical activity, like being in the kitchen. It is like this other bag where after it happens and while the jolt only lasts a few minutes, I feel fragile and tingling like this other bag.

Pain Journey Exercise

Clinical Objective:

To unpack the patient's story and analyse where they want to be, so a clinician and patient can figure out an appropriate strategy to get to where they want to be.

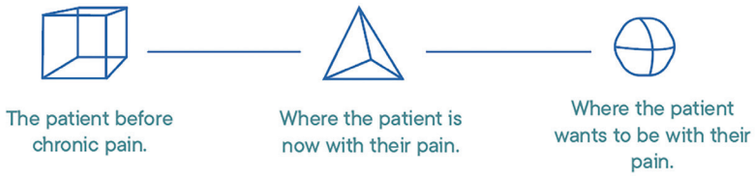
Example Prompts:

What would you like to improve in your life to get you where you want to be?

Pick an object that represents what it feels like when you have control of your pain and when you have more positive feelings about your pain. Next, pick up an object that symbolises when you think the worst about your pain. Why did you choose these objects? What happens if your pain goes from one to the other? (this question can be replicated for sleep, mood, stress, etc.)

With the object that you chose to envision, what do you want your pain journey to be like? Could you describe how your pain would feel if you got to that point, and how it would affect your life differently?

Could you speak about how your personal identity has changed or evolved over the course of your pain journey?



Description/Instruction:

Ask the patient to assign an object to where they think they were before chronic pain affected their life, how they feel now, and where they want to be. Patients may choose one object for each stage. Have the patient explain why they picked each object and talk about their pain journey.

Figure 109. Pain Journey Exercise information within instruction booklet.

PRISM Activity

Clinical Objective:

To assess the different factors affecting the patient's life. This exercise helps find what is causing suffering, burden, or what has changed in the patient's life since having chronic pain. The exercises can also help clinicians and patients discuss strategies to help with different factors related to where the patient is.

Description/Instruction:

Ask the patient to choose an object that best represents their current state of being (or their life). This object is called "Centre". This Centre object can represent community, environment, or any group the patient identifies with.

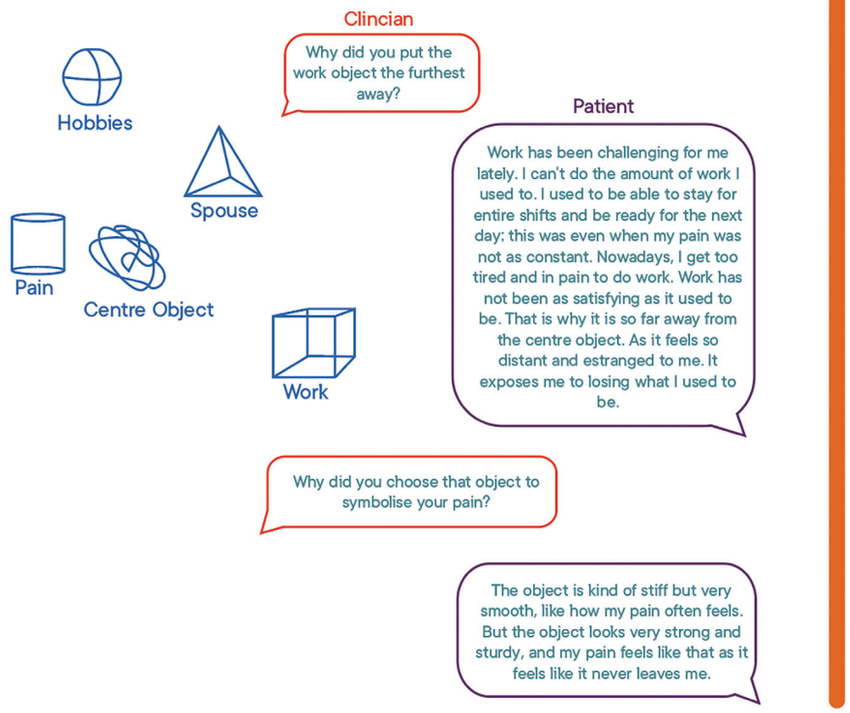
Ask them to choose the objects that best represent factors that affect their life (check below for examples).

The closer the object is to the Centre object, the greater its effect on the patient.

After all the objects are placed, ask the patient to talk about the placement of the objects and why they chose them.

Examples of factors that contribute to the patient's pain experience:

- Pain/illness
- Family
- Work
- Hobbies
- Spouse
- Sleep
- Mental state
- Pain killers
- Day-to-day physical activities
- Exercise



Example Prompts:

What would you like to be closer to the centre? What might we want to try or consider to get those objects closer to the centre?

Of all the objects displayed, which are the most important to you, and what do they represent?

On a good day, how would the layout and relationship of all these objects to each other look compared to a bad day?

How does each object make you feel?

In what way do these objects portray your pain experience?

Figure 110. PRISM Activity information within instruction booklet.

Figure 111. Objects of the toolkit.

DISCUSSION

Many pain assessment tools are available to clinicians to investigate chronic pain. However, none involve using physical objects to help patients express their pain experiences. Analysis of both literature and participant data in this research project showed many of the assessments for chronic pain were reductive to the patient's pain and whole pain experience (Bosdet et al., 2021; Herr et al., 2019; Hoeta et al., 2020; Karcioglu et al., 2018; Main, 2016; Turk & Melzack, 2011). Even the most inquisitorial approach, PRISM, a qualitative pain assessment tool, does not usually use objects to help patients talk through their pain (Tomioka et al., 2021).

All participants from focus groups, workshops, and interviews were interested and showed enthusiasm toward the potential for using objects to help patients express their chronic pain experience. They were favourable for the potential of the Understanding Experiences Toolkit and its potential use in the chronic pain clinical setting. Both the literature and participants indicated that there was a clear need for a chronic pain toolkit that improves the communication of chronic pain in a way that helps make pain tangible. Thus, having objects that the patients can use to act as their chronic pain and explain it, can make communication easier as the objects become representative of the patient's experiences and where chronic pain is no longer an 'unseen experience' (Ameri & Kurtzberg, 2022; Iphofen, 2013; Koesling & Bozzaro, 2021). Clinicians at focus groups highlighted that they were unaware of a resource that lets patients tell their stories while helping clinicians assess their patients' pain. Focus

group participants also explained how complex the communication of chronic pain can be, and there was often not a clear understanding of the patient's chronic pain by clinicians.

There is a general acknowledgement by chronic pain experts in interviews that having a toolkit that assists patients in exploring their chronic pain might help clinicians. This will lead clinicians to understand their patients' chronic pain experiences better and make more informed judgements regarding their patients. Doing this may help patients understand their pain better and converse with their clinicians about what they tell them. This prevents a common scenario brought up by clinicians in the focus group, where clinicians often misinform patients unintentionally, as clinicians and patients mostly do not understand chronic pain. In turn, the Understanding Experiences toolkit can help improve the patient-clinician relationship by helping to make patient expectations clear and then, with the toolkit, work through these expectations. Patient participants in the workshop indicated that the more diverse set of chronic pain tools patients have access to, the better. These participants stressed the importance of focusing on the pain journey and how it was to live with chronic pain. They suggested that the prototype toolkit would be helpful for this, especially as an introductory tool for those who are starting to figure out their chronic pain experience to begin thinking about their chronic pain.

Final Product: Understanding Experiences Toolkit

Using research and design methods within a social constructivist framework and action research methodology, a toolkit was created with the participation of chronic pain patients and clinicians. A toolkit prototype was further tested and evaluated by chronic pain experts. The toolkit contains structured exercises and physical objects for clinicians and patients to improve chronic pain communication. Thereby considering participants' experiences and turning them into objects or artefacts that respond to, or give form to, insights from these experiences. The structured exercises help the clinicians organise appointments to what they want to focus on while giving them ideas on what they can do with the objects. The toolkit also has unstructured activities that allow clinicians and patients to choose modes of engagement that may work best for them. Chronic pain patients can communicate with their clinicians through objects to detail and converse about their pain experience through the objects. For example, they may be asked to choose an object that best represents their pain on a bad day and talk through why, which then has the clinician respond with questions. This creates an opportunity for clinicians to learn more about a patient and their pain while the patients can reflect more on themselves and the chronic pain they are experiencing.

By designing objects with design methods, I made the pain experience tangible. Hence, the pain experience is no longer an unseen experience but can be manifested in some way through objects. Making pain 'real' means it can be more easily communicated rather than being reduced or shown by something not genuinely representative of the patient's pain (Bosdet et al., 2021; Herr et al., 2019; Hoeta et al., 2020; Karcioglu et al., 2018; Main, 2016; Turk & Melzack, 2011). In addition, clinical focus group participants explained how complex chronic pain communication is with a patient, and there was not a clear understanding of the patient's chronic pain experiences by many clinicians.
This may cause patients to be misunderstood in their pain and receive the wrong information from their clinician, resulting in the patients being "betrayed". The clinicians in the focus group pointed to patients' expectations that their pain can be fixed as the reason for this. The Understanding Experiences Toolkit can work towards improving this patient-clinician relationship while making the patient's expectations understood and, with the toolkit, working through these expectations with the clinician.

The Understanding Experiences toolkit builds upon Dulake et al. (2017) in making pain tangible and purposeful so the clinician can use it as a viable tool to explore their patient's pain. Using objects to describe a patient's pain has been attempted to an extent by Dulake et

al. (2017). While Printing Pain objects are created by patients, only one is made at a time in response to an individual's specific experience. Limiting a patient's ability to communicate through one object at a time, the Printing Pain project is inefficient as the objects created must be built using CAD and printed. This is not clinically practical and would require expertise and equipment that not every clinician has. Furthermore, the objects presented by Dulake et al. (2017) respond to a specific moment rather than being props for conversation that can last for more than one clinical session. As such, while Dulake et al. (2017) provide an interesting and relevant response to broadly communicating the experiences of individuals, the objects may not open up meaningful clinical conversation as they are limited to specific experiences. In contrast, the Understanding Experiences Toolkit provides exercises and structured ways for patients and clinicians to interact with objects to open up opportunities for more in-depth conversations. Like the chronic pain experts in the interviews, chronic pain patients saw potential in my prototypes, indicating a need for such a toolkit. Both patients and clinicians discussed where and how the Understanding Experiences Toolkit could be implemented—for example, a pain management class or clinic. The chronic pain patients in the workshops suggested and agreed that the tool could be used in a group setting specifically where, as a group, they can talk through their pain experiences. This could bridge gaps and have the wisdom of patients who

have had chronic pain for a long time shared with those recently diagnosed with chronic pain. There might be a need to change aspects of the toolkit produced in this research project to adapt to a larger group setting. Because this toolkit was based on the clinical-patient relationship, the exercises might need to change along with more objects to account for different groups.
In interviews, chronic pain experts suggested that implementation within occupational therapists' and pain psychologists' clinical appointments might be the most realistic pathway to implementation. This is because occupational therapists and pain psychologists do activities that focus on creating a conversation. As some interviewees suggested, occupational therapists and pain psychologists typically have longer appointments and could use a tool, like the Understanding Experiences Toolkit, during the first assessment stage. Furthermore, these two occupations' clinical settings are conversation-focused, so having a tool to improve communication may be the most useful to them (Driscoll et al., 2021; Goodall & Brown, 2022). The Understanding Experiences toolkit may also be used as a research device. Researchers may find it helpful to use the toolkit to investigate how participants communicate pain. Whether metaphor or pain descriptors, the tool can be used with clinicians or patients to study pain communication. While patients commonly communicate their sensations of pain and their lived experiences of chronic pain, Understanding Experiences can help unpack these experiences in research (Declercq et al., 2023; Téllez, 2018; Thompson et al., 2021). This was seen in the workshop on chronic pain, where patients talked through their pain through a journey when making objects of their pain experience. Chronic pain patients demonstrated in the workshop that there are different aspects of chronic pain, not just the feeling, but getting to a place of acceptance and understanding of their pain. Therefore, the Understanding Experiences toolkit can assist clinicians or researchers in unpacking these experiences.

Limitations

Recruiting

Recruiting chronic pain patients from TARPS took work, with only three participants turning up to the workshop. This meant there needed to be an opportunity to have more diverse conversations. Also, knowing that different cultures interpret pain differently means having more diversity in the workshop, which would have been beneficial. The low number of participants also likely affected the number of prototyping ideas, as there were fewer models made by participants. More participants may have resulted in more ideas for the toolkit and more potential ideas to improve or change within the toolkit.

Organisation's time

As I was working with an organisation, I was limited by their operational constraints, including their limited time

to support the research. Consequently, communication and signing of forms were limited to when my contacts in TARPS had time out of their busy day to help with forms, etc. The time pressure on clinicians also meant the workshops and focus groups had to fit into breaks in their pain programme to avoid disrupting any events or activities. With constant emailing and meetings with TARPS, the workshops and focus groups could be organised within their three-week pain program and with participants.

While the methodologies worked well in this research project, this project could have also benefited from being a co-design project. This means the research project involves participants from the inception, where participants design and are continually involved by challenging and providing ideas on design prototypes (Sanders & Stappers, 2008). Co-design would have worked for this project because, as a person who does not have chronic pain, I benefitted from the feedback from chronic pain patients always to interrogate my assumptions and design a product that is from their experiences rather than mine interpreting theirs through literature and data collection. This process was not possible in this research as working with a chronic pain organisation and with both clinicians and patients would be challenging and impractical. Clinicians are very busy, and people who experience chronic pain have good days and bad days with pain. Regularly involving them in the

research project would be tiring and interfere with more important matters, like taking part in the three-week pain programme with TARPS. As a designer engaging in a new research arena, I found it challenging to know what would be possible at the initiation of this project. Now that I have built relationships with participants and better understand the chronic pain landscape, it is possible to consider how further development of the toolkit and its implementation through a specific service, such as TARPS, could be undertaken using co-design. This would be an appropriate next step for the research.

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APPENDICES

Appendix 1: Locality Approval

Stephen Reay

Art and Design |

AUT

Kia ora / Dear Stephen,

Locality approval for research – Te Toka Tumai Auckland

The Research Review Committee Te Toka Tumai Auckland (RRC) would like to thank you for the opportunity to review your study and has given approval for your research project.

A+ 9981 (AUT23/255) Living with Pain: A co-design research project with clinicians and chronic pain patients to improve the communication of this complex lived experience

Your Institutional approval is dependent on the Research Office having up-to-date information and documentation relating to your research and being kept informed of any changes to your study. It is your responsibility to ensure you have kept Ethics and the Research Office up to date and have the appropriate approvals. Te Toka Tumai Auckland locality approval may be withdrawn for your study if you do not keep the Research Office informed of the following:

- Any communication from Ethics Committees, including confirmation of annual ethics renewal
- Any amendment to study documentation
- Study completion, suspension or cancellation

More detailed information is included on the following pages. If you have any questions please do not hesitate to contact the Research Office.

Ngā mihi/Yours sincerely,

Mary-Anne Woodnorth

Manager, Research Office, Auckland City Hospital, on behalf of RRC

Te Toka Tumai Auckland

TeWhatuOra.govt.nz

PO Box 92024, Auckland, 1142

Waea pūkoro: +64 9 307 4949 ext 23854

Appendix 2: Workshop plan

Workshop plan:

Jannisa – greeting.
- Introduction (hers then mine)

Jannisa runs her half of the workshop.

Break

Introduce prototypes and box (1 hour)

Questions:

- Could you see yourself using these objects with a clinician, and how?
- What do you feel is missing in this toolkit?
- Would you use these objects to describe your pain experience?
- Are the exercises okay for you, and would you like a more structured or open conversation with your clinician?
- Do you resonate more with the interactive objects or more with the visual objects?
- What do these objects do well

Ask participants if they want a break. If not continue:

Introduce making activity.

- **Give participants 10 minutes then ask them to explain their objects**

Appendix 3: Interview plan

Interview Run Through

Thanks for doing interview and give consent sheet

Explain toolbox.

- Bags
- Objects
- Exercises

Toolbox is a rough prototype and final designs colour, and packaging is yet to be done

This toolbox makes pain tangible and more easily communicated so that there is more conversation and does not reduce the patient's pain to a scale or number. I based most of my objects around metaphors commonly used and studied in literature by chronic pain patients.

To get started with the toolbox, there are three exercises that are summed up in this booklet. The box will be roughly this size **(show prototype box)**. It will have a designed lid with a fancy insert to have all the objects laid out, organised, and stored well. With the three exercises, the first is a bag activity where patients put their hand in without looking and use sound and feeing l to describe how it relates to their pain **(show bags and objects will be in them)**. Next is the object exercise, where patients use the objects to describe their pain. For example, this is dull and heavy like this or sharp and piercing like that. Finally, there is a PRISM activity. Are you familiar with PRISM (Pictorial Representation of Illness and Self Measure)? The patient will assign different objects to factors that affect their life with pain. They will start assigning an object of self or an object that best symbolises their whole pain experience and do the same for family, pain, and work for example. The distance between the objects between self and e.g. family speaks to the impact it has on their life. So, if the pain object is close to self, then it speaks to the patient not being able to control symptoms and how their pain erodes their lives. There are some objects I have yet to make. There will be a silicone slime ball which you can squeeze to symbolise squeezing, queasiness, or sliminess. Another is another bag activity with rubber balls for a squeezing throbbing sensation. Also, this toolbox is very open, and clinicians are free to use the objects as they like and do not necessarily need the ones in the booklet for this toolbox to work.

**Do you have any questions? **

Indicative Questions:

Did I miss any representation of pain? what could you think can represent the pain you talk about?

What can be improved upon in this toolbox?

What do you think is done well about the toolbox?

Can you see this being implemented with clinicians and chronic pain patients or is there another setting you see this living in? e.g. this tool would be good for a therapy session or pain management?

Do you think I have the right balance of objects? Should I have more?

Are the activities explained well in the booklet? do you think I should include more or less?

Are there any other opportunities or gaps you see this one filling that isn't just in the clinical setting?

Appendix 4: Focus Group Plan

Questions with follow ups:

Communicating chronic pain

What are the things you do to ensure you understand and respond to a patient about their pain?

- Why do think the patient responds the way do?
- How do you approach uncooperative patients or ones who do not communicate well?

What are some of the challenges you experience when communicating with your patients?

- How do you go about in encouraging or advising your patients with chronic pain
- What information do you struggle understanding from patients
- What information do you give to patients that they struggle understanding

Clinical resources and chronic pain resources

What clinical resources are out there for chronic pain (for example screening & assessment) that are beneficial for those with chronic pain?

- What out of those are the best at making patients feel understood and then maybe also strengthening the relationship between you and your patient?

What informational resources or tools have you recommended to patients that you found most helpful? What was most successful about it?

- What is your opinion on visual or creative resources within a clinical setting? Do you think patients respond better to visualised information?
- Where do you think there could be improvements in the informational resources you currently given to patients?
- How important is patient education in improving outcomes? In what ways can it support patients during their health journeys?

Clinical/ nonclinical chronic pain experiences

What kinds of stories do you think are important to tell people learning to manage their pain?

- What are some of the commonalties you see in patient's chronic pain stories that can be said in a phrase or a sentence (go around the group)
- In what ways do you know that patients manage with their pain?
- What things do patients like to see, read or hear when talking about their pain?

What are some of the clinical experiences you hear from patients about going to see someone for their pain? What is the process and journey like?

- Are the negative experiences due to a bad relationship with the clinician? Or the clinician not understanding their pain?

What, in your opinion, could be improved in clinical visits for chronic pain patients that might help both you and patients?

How do you know when to prescribe a specific treatment that's appropriate to patients?

- What do you balance your professional opinion with the patient's opinion?
- How often does it happen that your professional opinion gets into conflict with patients.

1. Nathan Introduction – admin (10 minutes)
2. Nathan introduces project and research aims (5 minutes)
3. Jannisa introduce project and research aims (15 minutes)
    - Jannisa – show sample, do activity, leading into...
4. Questions (20 minutes)
    a. **Clinical resources and Chronic pain resources**
    b. **Clinical/ nonclinical chronic pain experiences**
    c. **Communicating chronic pain**

Finishing focus group – thanks (5 minutes

Run Through

Time	Event	Person
10mins**	**Introduction and welcome** Welcome and information about research. (Questions there are any about the research) Participants will fill out demographic form and consent form.	Nathan
5 mins	**Nathan Introduction and Research aims.** Show objects and ask for general comments and update where the project is going.	Nathan
15 minutes	**Jannisa introduction and Research aims + Activity** Show sample. Do activity + discussion	Jannisa
	- How do you think patients would respond to a resource like this? - Do you have any improvements or suggestions for me going forward? leads into questions	
20 mins	**Clinical resources and Chronic pain resources** Questions w/ follow ups: What clinical resources are out there for chronic pain (for example screening & assessment) that are beneficial for those with chronic pain? - What out of those are the best at making patients feel understood and then maybe also strengthening the relationship between you and your patient? What informational resources or tools have you recommended to patients that you found most helpful? What was most successful about it? - Is there anything out there that is helpful to patients or excite you? - Where do you think there could be improvements in the informational resources you currently given to patients? - How important is patient education in improving outcomes? In what ways can it support patients during their health journeys? **Clinical/ nonclinical chronic pain experiences Part 1** What kinds of stories do you think are important to tell people learning to manage their pain? - What are some of the commonalties you see in patient's chronic pain stories that can be said in a phrase or a sentence (go around the group) - What things do patients like to see, read or hear when talking about their pain? - Why is that story important or meaningful? **Communicating chronic pain** Questions w/ follow ups: - What about these (illustrations and objects) best represent pain/experience? what pain / experience could be represented?	Nathan + Jannisa
	- How could you use these to explain broadly what the experience is like for the patient or what a clinical experience is like with them? What are the things you do to ensure you understand and respond to a patient about their pain? - Why do you think the patient responds the way do? - How do you approach uncooperative patients or ones who do not communicate well? What are some of the challenges you experience when communicating with your patients? - How do you go about in encouraging or advising your patients with chronic pain? - What information do you struggle understanding from patients ? - What information do you give to patients that they struggle understanding	
5mins	**Debrief** Cover off points noted (Jannisa and Nathan) Any further comments or questions? **Thanks** Give gift cards	Jannisa

Script / Cue cards

Greet Participants

[Nathan] Thank you everyone for coming today we are very glad you could set time aside and come to this focus group. My name is Nathan and this is Jannisa. we are designers trying to re design chronic pain recourses to improve the communication of chronic pain. In this focus group, we will be asking question to you as a group and maybe individuals as well. We welcome discussion and debate about any responses or questions being asked or talked about but always please be respectful of others. Before we get started a few housekeeping if at any time you do feel uncomfortable about what is being talked about it or you just need to leave you can and we won't judge you. But there are snacks you can have throughout the focus group if you need. Also, any names of people or of clinics will be redacted in any of the research out puts. To remind you this focus group will be audio recorded and will start after we take in the forms and here, they are.

Stephen Reay

Art and Design |

AUT

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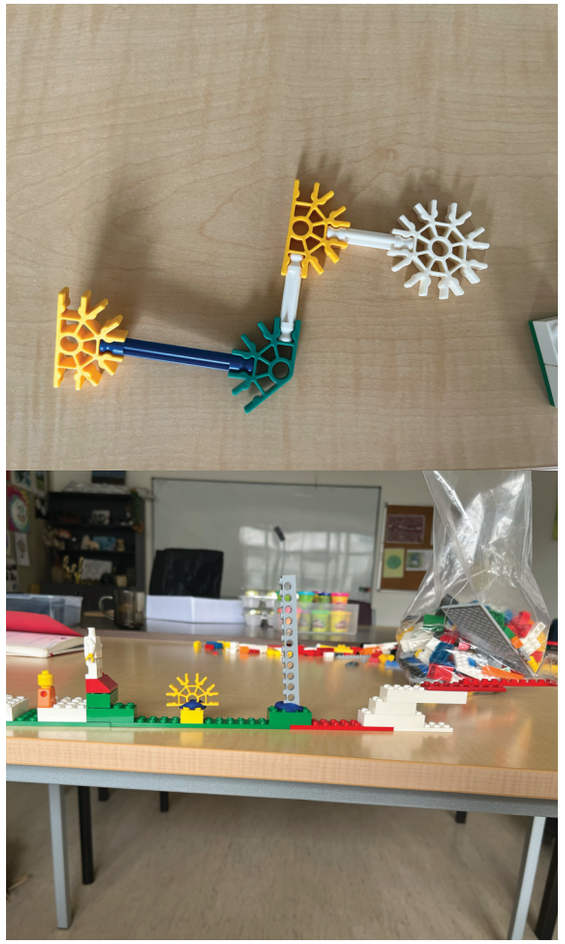
Appendix 5: Workshop Participant Made Models

P3's Models
Description:

"Well, maybe this one is about different textures of pain and that I have a slightly unrealistic idea that eventually I will be able to open a magic door and find this little special thing inside there. Because in reality, I know that's not even a thing, but. So this is. Yeah, that's it. And I'm full of anxiety because I feel like I have to go. But, yeah, it's like just all over the place. And this is how, as soon as you get comfortable and maybe get something soft, there's a whole different level of. Everything goes in a different direction"



P1's Models

Description:

"Yeah. So my one's basically me, just different"

"not just a one dimensional kind of person up and down that's functionally, physically functioning. So now it's just, you know, this is kind of random anyway, and that's just basically my journey. No pain and just the ups and downs, people coming down, you know, navigating different things and then kind of like acceptance. And then I've been working on this thing with [denote somones name' for about nearly a year, this visualisation, and currently I'm at the top of a precipice. It's a big cliff expanse looking over, and I'm up there with a couple of people, and I'm looking out, and we're at the point where now where we're discussing what I'm seeing because, I mean, I can do anything I want."

"So, I mean, yeah, so it's just kind of like the journey, really, as opposed to the pain itself, because I've accepted the pain and, you know, like, I'm sitting here now, and it's just radiating through my whole body, but I'm mentally able to control it. But. So it's more the journey."

P2's Model

Description:

"That's the central pain, its sharp underneath, and. But it does radiate, and the arrows are all over the place with the whole body. But it does come in layers of pain. Like, sometimes it's worse than others, or it feels deeper or nagging or just in your face more. So it does come in different layers. And that symbolizes a steering wheel that. I like to think that I'm in charge of the pain now."

"Because when I started off, that steering wheel wasn't there. It was ruling me, kind of thing. Medication, that was just that it . But now there's other things. But I like to think that I'm in charge of what's happening with me because. Yeah. So what that indicates."