Illustrating Pain

Communicating the Chronic Pain Experience

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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 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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Last of all, thank you to my friends and family. A special mention goes out to Grace, Owen, Carey, and Alice for being my biggest supporters.

Abstract

Pain is a universal phenomenon, yet it is difficult to understand and put into words. This research explores how pain might be conveyed through visual communication to aid understanding and give insight into the chronic pain experience. Previous studies have underscored the effectiveness of visuals, such as illustrations and graphics, in patient education to make information less overwhelming and easier to digest. Additionally, stories in healthcare can be a powerful tool for conveying information and supporting patients.

Positioned within a narrative inquiry and human-centred design approach, the study values the lived experiences of individuals with chronic pain. The research aimed to capture and present these experiences visually within a resource as a means to reinforce information, recognising the power of storytelling in promoting connection and understanding.

The combination of illustration and storytelling offers a compelling approach to conveying information that is engaging and user-friendly. Despite the abundance of chronic pain resources, there appears to be untapped potential in integrating visual storytelling to develop more emotionally supportive materials. The design outcome presents an alternative to existing resources that illustrates the lived experiences of individuals with chronic pain. Through the integration of narratives, the designed resource is not just informative, but a means to reflect, offering support to individuals in their journey towards improved well-being.

Figures and Tables

Contents

01. Introduction

Positioning the Researcher

I've always loved stories. Growing up, I was drawn to any form of visual storytelling, whether it be movies, comics or documentaries. This passion led me to pursue a design degree specialising in animation. Throughout my studies, I enjoyed crafting narratives and exploring visual styles. I especially liked analysing how a scene's composition, colours, and lighting can evoke emotions to convey a compelling story.

One project I did that deeply resonated with me was an animated documentary titled "David." The short animation was based on an audio interview with a medical student volunteer at a retirement home as she reflects upon her relationship with a deceased resident. It marked a departure from developing my own narratives to communicating someone else's lived experience. Additionally, it was my first exploration into themes of mental health and death. Shortly after, I did an internship with the Good Health Design lab, where I was exposed to the impact of design on healthcare and well-being. This experience sparked my interest in designing for people rather than solely for my personal preferences.

Upon entering the master's program, I initially viewed this project solely as an information design endeavour. However, I gravitated towards storytelling when I discovered its potential in healthcare, particularly in addressing emotionally charged topics and navigating complex experiences. This realisation prompted me to pivot towards an illustrative-based project, leveraging the power of storytelling through visual communication to connect deeply with people.

Across any visual medium, I have always aimed to tell a story or convey emotion. While animation unfolds narratives across multiple frames, illustration, though static, possesses the ability to communicate intricate feelings and ideas with simplicity and clarity. This research project presented an opportunity to push my skills as a designer to create something that sparks a sense of connection and understanding with who I was designing for.

Positioning the Project

Chronic pain is long-term pain that persists beyond the expected period after an injury or illness (Health Navigator, 2023). Understanding the intricate mechanics of chronic pain and how to manage it effectively can be complex. This process can often be frustrating for both patients and doctors as patients often feel like their pain is not being validated, while doctors encounter challenges in educating patients on the causes of their pain (Kenny, 2004). Consequently, chronic pain becomes not only a physical burden but also an emotional challenge, significantly affecting one's quality of life. For those living with chronic pain, finding ways to cope and manage it can feel like a constant struggle.

In light of this, this research project asks the following question:

How might visual communication be used to create a resource that aids patient understanding and conveys experiences of chronic pain?

The inception of this research project was facilitated by the Good Health Design Lab at AUT, who connected me to clinician researchers at TARPS (The Auckland Regional Pain Service). These researchers expressed an interest in exploring how design could aid in conveying the complexities of chronic pain to enhance patient-clinician communication. As I delved deeper into the topic of chronic pain, I came to realise that the experience extends far beyond just the sensation of pain itself. Chronic pain deeply affects multiple facets of an individual's life, including relationships, work, and mental health (Bean et al., 2022). Individuals with chronic pain also contend with stigma, often arising from the condition's invisible nature (De Ruddere & Craig, 2016). Therefore, instead of solely focusing on communicating the physical sensation of pain, I aimed to capture the whole experience, including its emotional aspects. When I shared my research idea with clinicians at TARPS, proposing to create a resource featuring stories and experiences from individuals with chronic pain, they were enthusiastic about contributing their expertise to the project.

Research Question:

How might visual communication be used to create a resource that aids patient understanding and conveys experiences of chronic pain?

Research Aims:

- To understand, capture and convey lived experiences while presenting information about chronic pain through illustrated stories.
- Investigate how integrating stories within chronic pain resources can promote self-reflection and engagement with treatment.
- Explore the role of visuals to support patient-clinician communication and facilitate understanding of chronic pain management.

02. Contextual Review

This contextual review delves into the rationale for incorporating visuals in patient education and using patient narratives within a health context. Furthermore, the chapter explores how visuals can effectively convey the experience of chronic pain, transcending the limitations of verbal or written communication.

Visual Communication in Patient Education

Patient education is crucial in effectively managing chronic pain (Geneen et al., 2015; Joypaul et al., 2019). Many individuals with chronic pain seek information to better understand and cope with their condition. A study on the effect of patient education found that patients experienced changes in their pain perception and self-management after receiving pain education (Mittinty et al., 2018). They also reported lower pain intensity and a more optimistic outlook on recovery (Mittinty et al., 2018). Education empowers patients to actively manage their chronic pain (Geneen et al., 2015). When patients understand the underlying causes of their pain and self-management strategies, they gain a sense of control over their condition (Joypaul et al., 2019).

In tandem with patient education, visual communication effectively conveys complex information to patients (Houts et al., 2006; Osborne, 2006; Stones et al., 2016). Osborne (2006) suggests that healthcare providers employ visuals such as illustrations, pictograms, and graphics to make information less overwhelming and easier to digest. The incorporation of visuals enhances patient understanding of medical information, as opposed to verbal or written communication alone (Houts et al., 2006). Houts et al. (2006) explain that patients, including those with proficient language skills, encounter difficulties comprehending medical information due to their unfamiliarity with medical terminology. Because of mixed literacy levels and cultural backgrounds, images are crucial for effectively communicating health information to increase patient understanding (Houts et al., 2006).

In New Zealand, health literacy is a significant barrier to accessing healthcare (Priston & Searle, 2010). Over 50% of the population has poor health literacy (Priston & Searle, 2010), defined as “the capacity to find, interpret and use information and health services to make effective decisions for health and well-being” (Ministry of Health NZ, 2015, p. 1). Accessing chronic pain services can be hindered by health literacy, which is closely linked with socioeconomic status (Schwarz et al., 2022). Among Māori, health literacy is particularly low (Priston & Searle, 2010), leading to higher rates of pain-related disability and psychological distress (Lewis et al., 2021). Additionally, Māori, Asian, and Pacific people in New Zealand have poorer pain management outcomes than Europeans, possibly due to communication challenges between patients and clinicians from different cultures (Lewis et al., 2021). These statistics underscore the importance of designing information resources that support lower health literacy levels and improve patient comprehension.

An analysis of self-help materials for chronic pain management highlights a significant oversight regarding the limited use of visuals (Stones, 2013) despite their crucial role in enhancing patient comprehension. When visuals were employed, Stones (2013) found that they were predominantly used in an informational capacity with literal interpretations. However, Stones proposes incorporating affective design to align with the supportive messages conveyed with the support resources. Affective design refers to “empathetic, meaningful design that intends to evoke affect” (Stones, 2013, p. 87), in this case, positive emotions. Stone s highlights that positive affect facilitates effective learning, enhances motivation, and leads to more positive opinions. Considering the significance of visuals, further emphasised in Stones’ review, there appears to be an opportunity for designers to assist in aligning visuals with the messages conveyed in chronic pain resources.

The use of visual communication in health information to evoke a positive outlook is an under-researched area that has not been explored in depth. This master’s project proposes a resource that offers a clinical perspective while simultaneously focusing on providing emotional support. This research acknowledges the emotional dimension of the chronic pain experience and seeks to address it through the power of visual communication. By integrating affective design and incorporating visuals, patient resources could inspire hope and provide valuable information in an accessible way.

Visual Representations of Pain

Sharing our pain through words alone often has limitations; as Scarry notes in *The Body in Pain*, “physical pain does not only resist language but actively destroys it” (Scarry, 1985, p. 4). The perspective that Scarry presents is that pain is inherently private and subjective, making it difficult to communicate accurately. Main (2014) echoes this sentiment, acknowledging the invisible nature of chronic pain and proposes that “using creative methods to communicate can aid the articulation of the pain experience visually, providing objectification” (p. 32). Creative methods encompass non-verbal forms of expression such as drawing or painting.
The use of such methods can be seen in *PAIN Exhibit* (2012), an online visual arts exhibition which aims to educate healthcare providers and the public about chronic pain (Figure 1a & 1b). Some of the themes explored in this exhibition are “experiences with healthcare,” “mental health,” and “suffering.” Many of these artworks emanate a chilling atmosphere, evoking a raw and intense emotional response. The motivation behind creating these depictions of pain stems from the frustration of communicating one’s experience and the desire for others to understand and empathise (Main, 2014).

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Figure 1. a) “Resonance: Erasure” by Susan Gofstein. Retrieved from: http://painexhibit.org/en/galleries/portraits-of-pain/ag01_Gofstein/; b) “The Eradicator - Consumed by Chronic Pain” by Dawn Koch. Retrieved from: http://painexhibit.org/en/galleries/pain-visualized/ag02_Koch/

Several studies have examined how people with chronic pain visually represent their experiences (Kirkham et al., 2015; Phillips et al., 2015). In these studies, participants were asked to create drawings that depicted their pain; these drawings then underwent visual analysis. Three main themes were identified in the study by Phillips et al.: pain as an attacker, the nature of pain, and the impact of pain. Many participants portrayed their pain as something external to themselves, often using imagery like monsters, weapons, or abstract forms. Pictures contained metaphorical images and utilised colour and texture to describe pain sensations. For example, pictures included fireworks, flames, lightning, pins and needles, and broken glass. Some of the drawings reflected concerns and beliefs about how pain affected their lives, with the images conveying a sense of being under attack, helplessness, isolation, and fear.

In the study by Kirkham et al., participants produced powerful and vivid abstract pictures. In many of these pictures, pain was portrayed as sinister, accentuated by the use of red and black. These artworks often contained a temporal dimension, illustrating the transition from their pre-pain selves to their current state or depicting relief from pain in the future (Kirkham et al., 2015). Through colour analysis in the drawings, Kirkham et al. find that red symbolises heat and danger, while black conveys notions of oppression and despair. sMany participants depicted their experiences using bold shapes and structures in their images, effectively conveying a sense of alarm and threat. Interestingly, some pictures expressed optimism for the future despite ongoing struggles. This was represented by the presence of glowing yellow light, symbolising hopefulness.

These studies emphasise the utilisation of visual language to convey the pain experience, offering a profound understanding of the pain sufferer’s inner world and the subjective nature of chronic pain. The analyses conducted in these studies provided valuable insights that helped inform the early exploration of this research. While patient-generated images of pain often depict themes of suffering, this exegesis aimed to present well-being narratives to offer a counter perspective. The intention was to communicate to patients that they can lead fulfilling lives despite living with chronic pain.

There are few resources from a clinical perspective that portray pain more artistically. One of these resources is *Tame the Beast* (2017) — an animation created with the aim to communicate hope and guide individuals in their pain recovery (*Tame the Beast*, n.d.). The animation employs visual metaphors, depicting persistent pain as animals (Figure *2*). This creative representation enables a broader audience to grasp the experience of living with persistent pain while effectively explaining the mechanisms of pain to those directly affected. The animation's style, reminiscent of a picture book illustration, enhances its appeal. This is in stark contrast to the typically more intense depictions of pain created by people with chronic pain.

Another resource, *Pain is Really Strange* (Haines, 2015), takes a science-based approach in the form of a graphic novel, outlining how understanding pain is often the key to alleviating its effects. The use of a graphic novel format makes complex concepts such as neuroplasticity much more comprehensible. Both *Tame the Beast* and *Pain is Really Strange* use a visual style that employs a conceptual approach through visual metaphors. The illustrator for *Pain is Really Strange*, Sophie Standing, employs metaphors such as representing pain signals as a dormant bomb ready to explode or depicting the nervous system as a machine (Figure 3). Standing's artistic style skilfully balances the creative representation of these concepts with the incorporation of scientific imagery, delivering an engaging and informative experience to readers.

The differing tones become evident when examining visual representations of pain from both patient and clinical perspectives. Patient-created depictions often convey the darker aspects of pain, which are valid expressions of their experiences. However, it is also possible to portray the chronic pain experience in a more hopeful yet grounded manner, in line with Stones' concept of affective imagery. Patient-generated images of pain provide valuable insights into lived experiences, while resources like *Tame the Beast* and *Pain is Really Strange* are intended to serve as engaging educational tools to help patients reframe their understanding of pain. Building upon this, my research endeavoured to capture and convey lived experiences while presenting information about chronic pain through illustrated stories. Illustration, as a medium, can encapsulate emotions as well as convey information. It is a misconception that illustrations produced to convey information must be conventionally realistic and technical, both in visual language and subject matter (Male, 2007). Nonetheless, there is potential for integrating the emotional facets of chronic pain experiences into health information, offering both clinical and patient perspectives.

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Figure 2. Screenshot of Tame the Beast. Retrieved from: https://youtu.be/ikUzvSph7Z4.

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Figure 3. Illustrations by Sophie Standing. From *Pain is Really Strange*. Haines, S. (2015). Singing Dragon. Retrieved From: https://www.sophiestandingillustration.com/books

Storytelling in Health

The use of narratives in health contexts has gained increasing recognition as a powerful communication and educational tool that shifts the focus onto patients and their experiences with illness (J. B. Gray, 2009). Patient education is usually delivered through direct advice from clinicians, focusing on providing objective information about the disease or condition itself. However, narrative accounts that depict the lived experiences of individuals with the illness may be more beneficial for creating educational materials for patients with chronic conditions (Swift & Dieppe, 2005). The use of storytelling can facilitate the comprehension of information, as readers gain insight from a patient's perspective and then can apply it to their own experience (Wang & Geale, 2015). Patients are more likely to connect emotionally with personal stories, given the innate human inclination for storytelling (Connelly & Clandinin, 1990). Throughout history, stories have served as a means to convey information, learn life lessons, make sense of personal experiences, and articulate one's emotions (J. B. Gray, 2009). In a health context, personal accounts in patient education can also help fulfil various needs, such as granting permission to feel similar emotions and offering information and advice for those lacking social support (Swift & Dieppe, 2005).

Individuals enduring chronic pain often grapple with psychological distress, including conditions such as depression and anxiety (Demyttenaere et al., 2007; Gerrits et al., 2012). Conversely, individuals who feel more in control of their life, despite living with chronic pain, have lower psychological distress, manage pain better and function well daily (Lee et al., 2022). Due to this, Lee et al. believe it is crucial to establish and reinforce the belief among chronic pain patients that their actions can significantly impact their pain management. This belief plays a pivotal role in achieving success in the management of chronic pain, as it encourages proactive use of coping skills and participation in treatment (Lee et al., 2022). Narrative research indicates that storytelling can play a crucial role in promoting calmness, hope, and self-understanding among individuals dealing with chronic pain (Egnew, 2018; Georgiadis & Johnson, 2023). Given the power of narratives in shaping mindsets, leveraging stories could serve as a promising avenue to encourage individuals with chronic pain to adopt a proactive approach in managing their condition.

Health Chronicles (Kneepkens, n.d.) is a project that utilises visual storytelling to construct narratives of individuals' health journeys (Figure 4). Visual storytelling is a narrative approach primarily conveyed through visual media, encompassing mediums like photographs, illustrations, or videos (Caputo, 2003). In contrast to conventional text-based narratives, this method places its emphasis on visual elements, using them to evoke emotions and captivate the viewer. Researchers have recognised the potential of employing visual storytelling within the realm of healthcare communication (Botsis et al., 2020; Drew et al., 2010). Kneepkens' approach involves conducting interviews and creating illustrated maps to delve into the significance of a patient's health within their everyday lives. By encouraging individuals to reflect upon their journey and create goals, the aim is to give them a sense of control over their health and well-being (Kneepkens, n.d.). Stories have the capacity to shape patient perspectives and promote a more holistic understanding of their health experiences (Greenhalgh & Hurwitz, 1999). This exegesis adopts a similar philosophy, recognising the profound impact of stories in fostering self-reflection.

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Figure 4. Patient story from Health Chronicles by Sonia Kneepkens.
Retrieved from: https://www.soniakneepkens.com/health-chronicles

Chronic Pain Narratives

The predominant narrative concerning chronic pain in New Zealand is negative. A content analysis done by Devan et al. (2020) on New Zealand news media's portrayal of chronic pain has shed light on an imbalance in the representation of chronic pain. The most prominent topics identified include discussions on the negative impact of chronic pain, pharmacological pain management (i.e., opioids and medicinal cannabis), and systemic issues influencing chronic pain healthcare pathways (Devan et al., 2020). Less emphasis was placed by the media on the ability to manage pain and lead a fulfilling life (Devan et al., 2020).

It is important to note that evidence indicates chronic pain can indeed be successfully managed with multidisciplinary healthcare input (Gauntlett-Gilbert & Brook, 2018). Given this, Devan et al. believe there is a chance to rectify public misconceptions about chronic pain and contribute to a more balanced and informed portrayal of the condition. This project presents an opportunity to showcase the positive experiences of individuals coping well with pain, whilst acknowledging the challenges they face.

Online first-person narratives offer a unique perspective, directly sharing individuals' viewpoints and personal experiences. In a different study of YouTube videos related to chronic pain, Devan et al. (2021) identified an overarching theme, "the power of storytelling." Personal stories serve as a medium through which individuals communicate their lived experiences with chronic pain, offering assistance and advice to those facing similar challenges. Devan et al. found that, when discussing their pain journey, a notable portion of these narratives emphasised the adverse effects of pain on mental well-being, manifesting as anxiety, depression, and frustration. In many of the videos, the discussions extended to activities and daily life, often accompanied by personal advice and insights (Devan et al., 2021).

First-person narratives enable those living with chronic pain to voice their experiences, potentially providing a sense of validation to the viewer (Forgeron et al., 2019). Many individuals with chronic pain experience isolation (De Ruddere & Craig, 2016), yet stories help cultivate a sense of belonging through shared experiences, which can be affirming (Stenberg et al., 2022). The resource created in this research endeavoured to capture this emotional connection with the viewer by sharing stories from individuals living with chronic pain in a personable and authentic way.

Conclusion

Based on previous research, this project identifies an opportunity to create a resource for chronic pain that effectively presents personal narratives in an informative and visually engaging way. Patient education is a fundamental component in effectively managing chronic pain, as it empowers individuals to take an active role in their own care. Visual communication plays a vital role in simplifying complex medical information and increasing patient understanding. Illustration, in particular, can convey intricate emotions effectively. In addition, storytelling is a valuable tool in health communication, particularly in conveying experiences from the perspective of the patient. In essence, this research sought to harness the power of visual communication and personal narratives to create a resource that provides support to individuals facing the challenges of chronic pain by highlighting the emotional side of their experience.

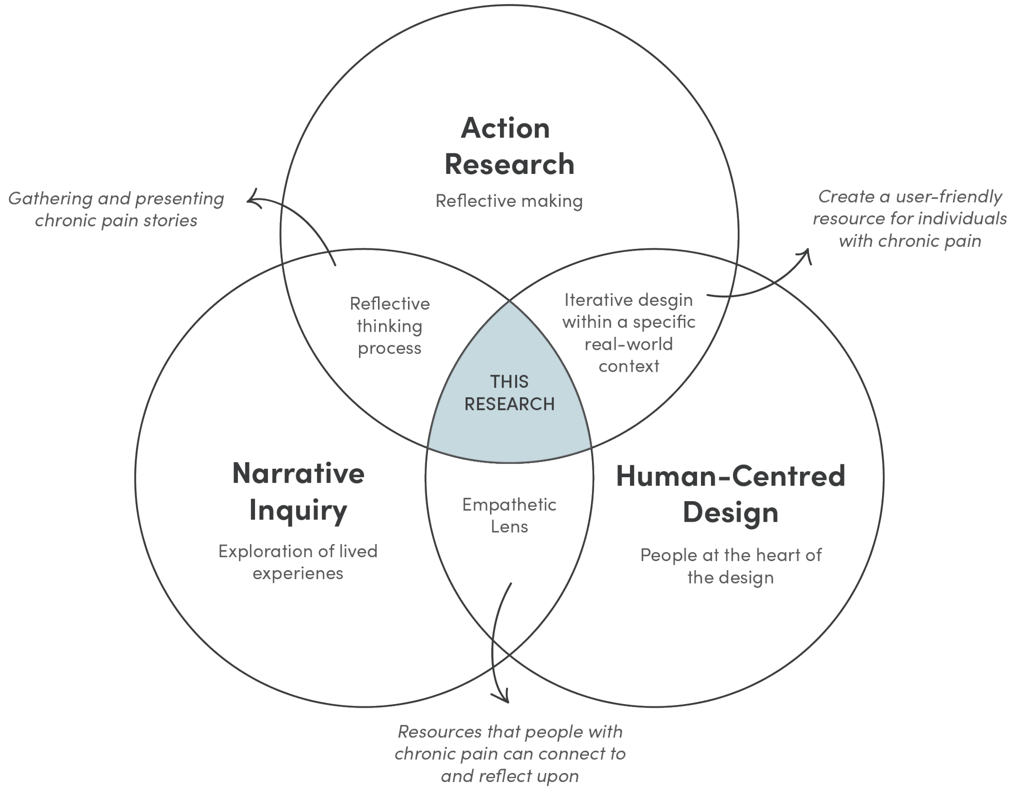


Figure 5. Methodology influences in my practice

03. Methodology

This chapter delves into the methodological approaches that have shaped my research perspective. I have employed a hybrid approach in this practice, combining various methodologies (Figure 5). Narrative inquiry is a research approach that seeks to understand human experiences under the belief that people are natural storytellers (Connelly & Clandinin, 1990). Through collecting and analysing stories, the aim of this research was to gain deep insights into the lived experiences of individuals with chronic pain. The intention was to capture and present these personal narratives within the designed resource as a means to reinforce information, recognising the power of storytelling in promoting connection and understanding. This study is also situated within a human-centred design and action research frameworks, which emphasise the value of research aimed at positive change within communities (Ku & Lupton, 2020; Swann, 2002). Perspectives of people with chronic pain were at the forefront of this research, with the researcher taking an empathetic approach to individuals' experiences. In the upcoming sections of this chapter, I explore each of these methodologies in depth. The main principles were examined, as well as how the methodology influenced my creative practice.

Narrative Inquiry

Narrative inquiry is a qualitative research approach that centres on the exploration of human experiences through the collection and analysis of personal narratives and stories (Connelly & Clandinin, 1990). Daiute (2013) defines narrative as anything from accounts of daily life, stories that spring from the imagination, news reports, and oral or written accounts. Some methods used to collect narratives include interviews, participant observations, written diaries, and archival data (Daiute, 2013). In essence, narrative inquiry is the insights that occur when we read, write, listen to, and tell stories. Importantly, it focuses on the meaning of experience from the perspective of people living it in reality rather than objective truths. Narrative researchers seek ways to understand and then present real-life experiences through the stories of the research participants (Clandinin, 2006).

In a health context, narrative inquiry can be a powerful tool for exploring patients' lived experiences (Wang & Geale, 2015). It allows healthcare professionals to gain a deeper understanding of the human dimension of illness, ultimately leading to more empathetic healthcare practices (Wang & Geale, 2015). Narrative inquiry humanises design by emphasising people's perspectives within the design process, acknowledging that design goes beyond material objects or aesthetically pleasing products (Danko et al., 2006). It is also about understanding the emotions of the individual interacting with the design (Danko et al., 2006). Considering this, narrative inquiry was an ideal approach for developing a patient-centred visual resource that captures the perspectives of individuals grappling with chronic pain.

In visual narrative inquiry, researchers and participants work together to explore and make sense of their experiences using visuals and storytelling (Bach, 2007). Bach specifically examines participant-generated photographs in their research, as these images capture each person's unique perception of the world around them. While experiences are personal on one level, they also intersect with others (Bach, 2007). Unearthing these shared experiences enables stories to resonate and connect with their audience (Bach, 2007).

Bach's methodology provides valuable insights into how individuals perceive their experiences and express their stories through images. I adapted and expanded upon Bach's approach in my practice by using illustration as the primary form of visual storytelling. This method diverges from Bach's realistic snapshots of one's worldview to focus more on the emotional reality. As a qualitative research approach rooted in personal experiences, narrative inquiry is the guiding principle behind this research. In translating stories and experiences into visuals, I used this methodology to delve deeply into the perspectives of individuals grappling with chronic pain. Throughout this research journey, I had to view information, experiences, and design through an empathetic lens, recognising the divergence between my own experiences and the stories I was adapting.

Human-Centred Design

Human-centred design (HCD) is a methodology that places the human experience at the forefront of the design process, aiming to create user-friendly solutions tailored to the users' specific needs (Ku & Lupton, 2020). What sets the HCD process apart from many traditional design approaches is its primary focus on the people for whom the product, system, or service is designed, as opposed to the designer's creative process or the technical aspects (Giacomin, 2014). Naar et al. (2018) state that human-centred design is anchored in two fundamental principles: empathy and prototyping. Empathy is the capacity to deeply connect with another person's experiences and understand the challenges they face (Ku & Lupton, 2020). According to Naar et al., designers should strive to empathise deeply with people and understand behaviour and motivation. Prototyping is the iterative process of making ideas tangible (Naar et al., 2018). Naar et al. also emphasise the importance of sharing prototypes with users for feedback.

Harte et al. (2017) outline four phases of HCD: 1) Specify the user and the context of use; 2) Specify the user requirements; 3) Produce design solutions; and 4) Evaluate designs against requirements. My research loosely followed these phases, serving as a foundation for keeping the intended users at the forefront of the design process throughout the study (Figure 6). Given that this research aims to convey the lived experiences of individuals with chronic pain, this approach ensures that their voices, needs, and emotions are central to the resource's development. Similar to the narrative inquiry methodology, researchers strive to comprehend and empathise with experiences. I integrated this principle into my research through methods such as a contextual review, prototyping and focus groups.

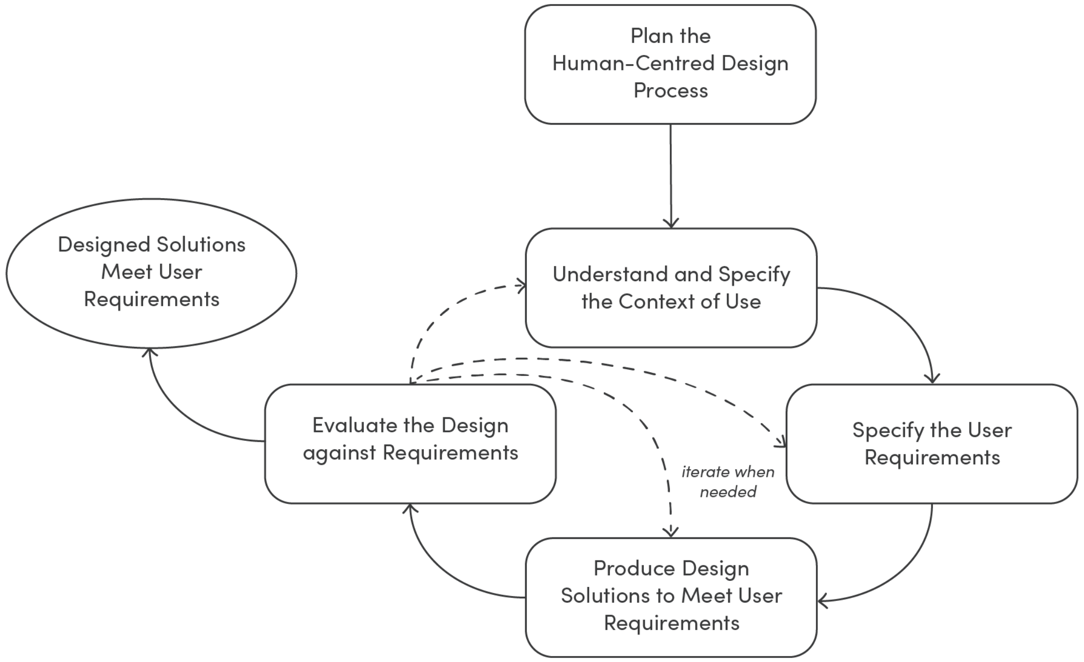


Figure 6. Diagram of HCD phases. Adapted from Harte et al., 2007.

Design Phase	*Understand and Specify the Context of Use*	*Specify the User Requirements*	*Produce Design Solutions*	*Evaluate the Designs Against Requirements*
Methods	Contextual Review Mind Mapping	Narrative Analysis Mind Mapping	Sketching & Drawing Prototyping	Focus Group Prototype Testing

Table 1. HCD Phases with associated methods in my research

Action Research

Action research involves identifying and working to address issues within a specific real-world context (McKernan, 1996). This methodology is undertaken to enhance the researcher’s understanding of problems and subsequently improve the effectiveness of their practice. Working within the context of chronic pain, which I lacked familiarity with, engaging in action research proved instrumental in shaping the outcomes of this study as it progressed.

Action research is an iterative and cyclical process with four key stages: plan, act, observe, and reflect (Swann, 2002). According to McKernan (1996), in the planning stage (stage 1) the problem is defined, followed by a plan of action (stage 2). Evaluation is then undertaken to establish the effectiveness of the action taken (stage 3). Finally, the practitioner reflects upon the results (stage 4), in which a new problem may arise, leading to a new cycle. The cyclical process of action research requires an iterative design approach, which aligns well with the human-centred design methodology that is underpinned by iterative prototyping.

In this research, I adopted the action research approach of critical self-reflective practice (Figure 7). Throughout my documentation, I analysed each stage of my work. Through evaluating the success of my solutions, I was able to identify possible actions for the future and overcome roadblocks in my research, which led to new solutions to meet my goals.

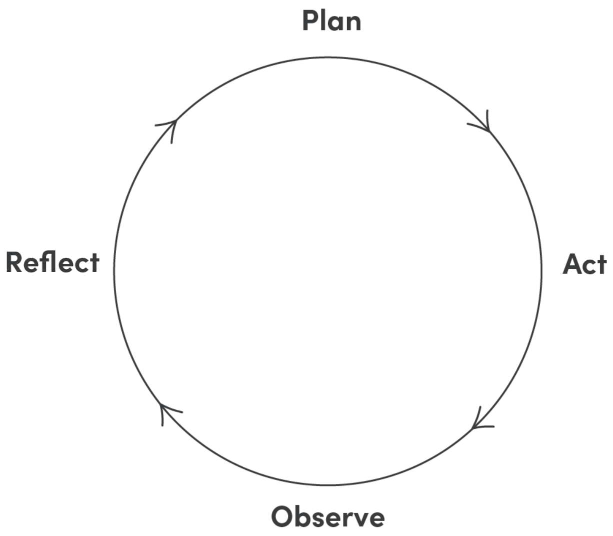


Figure 7. Action Research Cycle. Adapted from McKernan, J. (1996).

Ethical considerations

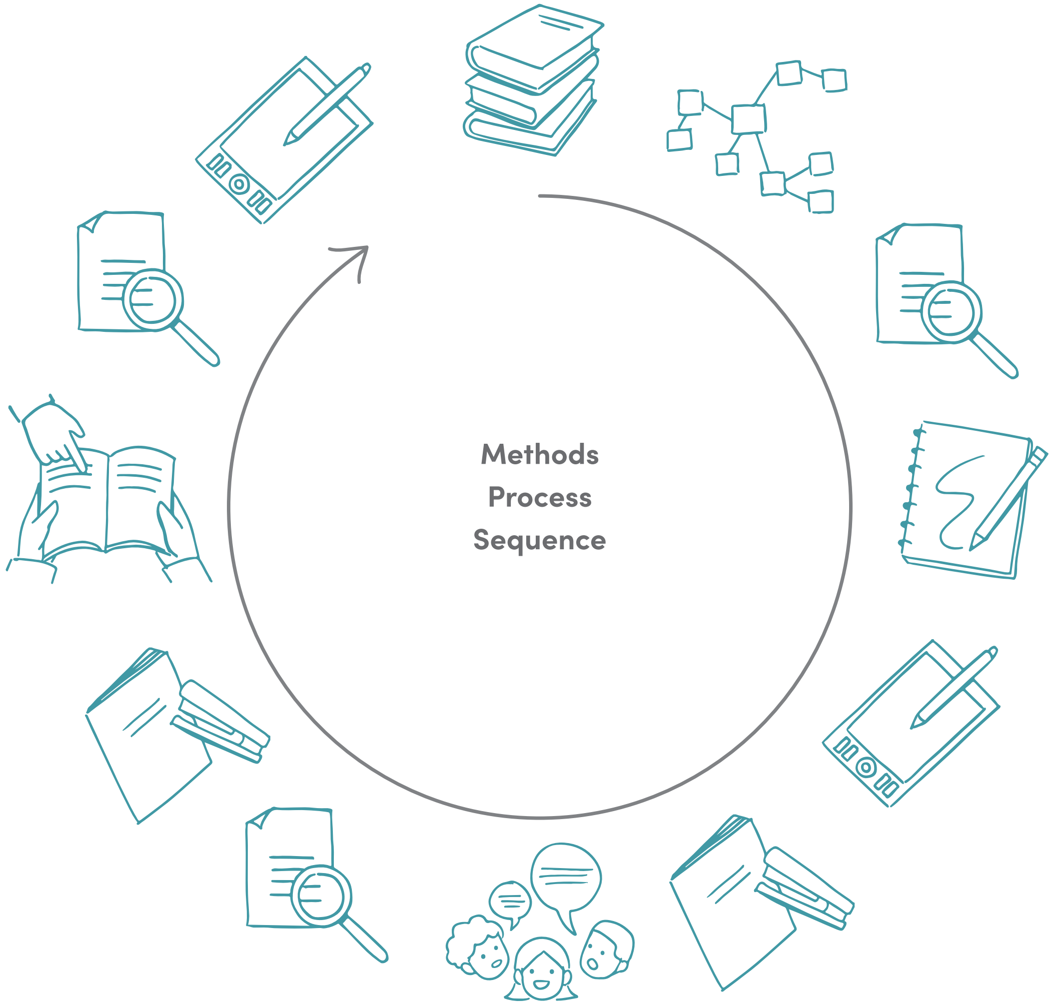
Situated within the HCD framework, the participation of target users is necessary to validate and assess design outcomes. In this research, my primary users were people living with chronic pain. However, given my lack of health expertise, clinician involvement was essential to help guide resource content decisions. Consultation with TARPS (The Auckland Regional Pain Service) was conducted to determine appropriate research methods and recruitment processes.

Formal ethics approval was obtained from Auckland University of Technology Ethics Committee (AUTEC, approval ref no. 23/254). Approval was also obtained from Te Whatu Ora Te Toka Tumai to conduct research at TARPS (See Appendix 1).

Ethical approval was granted to conduct a focus group with TARPS clinicians and a co-design workshop with TARPS patients (hence the reference to a co-design workshop in the consent form and participant information sheet in Appendix 3 & 5). Co-design involves users actively engaging in the design process to improve outcomes (Steen et al., 2011). However, as my research progressed, I recognised that the term “co-design” would not accurately reflect the extent of creative involvement that participants ended up having in the design of the final outcome of this project. Thus, in the Methods section and documentation, this session with individuals with chronic pain is referred to as “Prototype Testing” rather than “co-design.”

Methods

In this section, I explain the methods selected, detailing their implementation in the overarching research process.



Contextual Review

A contextual review is a critical review used to position a study within relevant contexts and identify a rationale (C. Gray & Malins, 2004). I conducted a contextual review at the beginning of this research with the aim of gaining an understanding of chronic pain and the experiences of people living with pain. This process also allowed me to examine the range of existing chronic pain and visual resources in health. I searched for literature through Google Scholar, PubMed, Research Gate and various online library databases. Some of the key terms utilised in the searches were visual communication, patient education, chronic pain story, and pain visualisation.

Immersing myself in pre-existing narratives surrounding chronic pain was crucial in gaining insight into individuals' experiences. Engaging with these personal stories was an integral component of the narrative inquiry approach. As a designer lacking firsthand experience, the contextual review helped me familiarise myself with the perspective of individuals with chronic pain, enabling me to create empathetic representations of their experiences.

Mind Mapping

I used mind mapping throughout my research to aid in identifying key themes and ideas. There are no rules for creating mind maps, making it a natural method of organising and visualising the interactions among the data (Crowe & Sheppard, 2012). Mind mapping was especially beneficial when summarising my contextual knowledge. By visually organising a multitude of ideas across different sources, I gained a clearer perspective on the overarching themes within the stories of people with chronic pain. Mind mapping also helped generate ideas for illustrations. Visualising the information not only eases the processing of information but also assists in breaking down complex ideas (Rustler, 2012).

Sketching & Drawing

As my primary creation method, sketching and drawing was the foundation of my creative process.

> *"Drawing remains the fundamental language of the illustrator"*
> *(Sailsbury, 2022, p. 6)*

Ideation

Drawing serves as a means for design reasoning and can show a designer's thought process (Do & Gross, 1996). I employed sketching as a way to capture my thoughts visually. These initial conceptual sketches were usually rough and low in detail, at times even resembling scribbles (Figure 9). This mode of drawing supports ideation as it is quick and intuitive, allowing ideas to be rapidly processed (Schenk, 2014). Most ideas for my illustrations are first formed in a sketchbook using traditional media, such as markers, ink pens and pencils. Sketching on paper particularly supports the forming of ideas as well as the rapid exploration of alternatives. Schenk (2014) highlights that sketching is fundamentally a process of thinking through drawing, producing spontaneous visual representations intended for the designer's understanding alone.

Figure 8. Sketchbook Drawings

Figure 9. Rough Ink Sketches

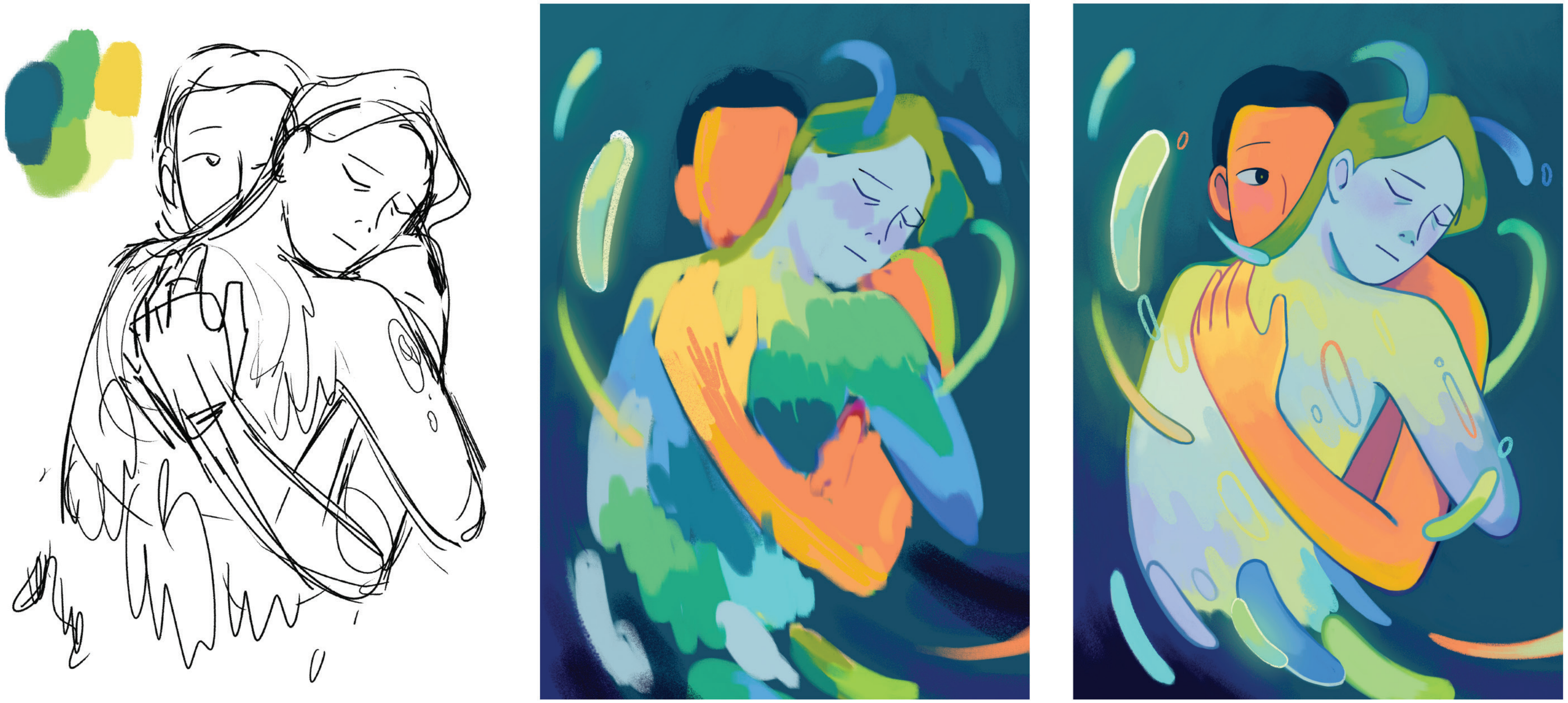
The Illustration Process

Once I sketched out an idea I wanted to explore, I transitioned to refining it digitally using software like Clip Studio Paint and Photoshop. Digital tools offered efficiency and allowed me to experiment more freely with composition and colour. Furthermore, they provided access to a variety of digital brushes that mimic traditional media, which I found offers greater control.

During this digital phase, I first started by cleaning up the initial sketch, ensuring character features were defined and any "mistakes" were corrected (Figure 10). Then, I proceeded to the colouring and rendering stage, where I digitally painted to add depth and dimension to the colours. This process varies slightly each time, as I approach painting quite intuitively (Figure 11). The style of painting was also tested throughout the documentation stage, where I found that time restrictions played a considerable role in the amount of detail I could paint with.

Figure 10. The illustration process from sketch to rendered.

Figure 11. Alternate painting process



Sketch

Painting Rough Colours

Rendering

Prototyping

Prototyping is an essential practice within human-centred design (Harte et al., 2017) and is meant to be shared for feedback and iteration (Naar et al., 2018). In this research, I primarily utilised iterative prototyping, which in the beginning took the form of sketches and progressed to printed booklets in the later stages. Camburn et al. (2017) explain that there are several objectives for creating prototypes. These include exploration, active learning, communication, and refinement. Throughout different stages of this project's development, my prototyping objectives evolved.

Figure 12. Early Printed Prototypes

Following this process, my objective at the very start of the creation process was exploration, focusing on seeking out new design concepts. During this stage, I experimented with various illustration styles and depictions of chronic pain, documenting my process.

Active learning is the process of gaining new knowledge in the design space or context (Camburn et al., 2017). Through creating illustrations, I gained insights into the experiences of individuals with chronic pain. The more illustrations I created, the deeper my understanding grew as I conducted further research alongside the creative process.

Following the illustration exploration stage, I transitioned to visualising how these illustrations could look in the form of a resource, with the goal of communicating my designs to users. The first prototype resource was specifically developed to gather feedback from clinicians at TARPS, leading to further refinements based on their responses. I printed prototype booklets to test how users might interact with the resource, assessing size, colours, scale and layout.

Throughout the printing process, I worked towards refining the prototypes and implementing small changes gradually. This allowed me to identify areas of improvement before finalising designs and creating a completed outcome. Prototype development was also significantly shaped by the feedback and discussion from the focus group and prototype testing session.

Focus Group

A focus group involves a discussion and interaction among research participants and the researcher to generate data (Kitzinger, 1995). Unlike interviews, which centre on an individual's thoughts and ideas, focus groups allow for a variety of perspectives in a group setting (Gibbs, 1997).

A focus group with seven clinicians from TARPS was held at TARPS and was audio recorded with their consent (see Appendix 4 for the PIS & Appendix 2 for Consent Form). The participants represented various professions within the service, providing diverse perspectives. The focus group was instrumental in refining the content and design of the proposed resource to ensure that information was conveyed effectively to patients. Furthermore, it helped identify the key messages clinicians wished to convey to patients that I was able to incorporate into the final product.

The aim of the focus group was to gain insight into patient experiences of chronic pain, patient-facing informational resources on pain, and clinician-patient communication within practice. The focus group took place during the resource prototyping phase to gather feedback and help guide further development. I also sought participants' opinions on their ideal chronic pain resource through a feedback sheet (see Appendix 7 for the feedback sheet & Appendix 6 for tentative discussion questions for the focus group).

Prototype Testing

Prototype testing was conducted in the later stages of design development as the final phase of a human-centred design process. Its aim was to evaluate the design with target users (Harte et al., 2017). In healthcare design specifically, it is important to share prototypes with users to gather feedback (Naar et al., 2018).

The aim of this session was to receive feedback on a later version of the resource and assess whether the illustrations resonated with the participants (See Appendix 8 for tentative discussion questions). Additionally, the illustrations in the prototype served as a way for the participants to discuss their lived experiences so that these could then inform the final design iteration. I also sought participants' advice for other individuals with chronic pain to include in the resource, as well as asking them to describe the resource from a list of adjectives (See Appendix 9 for prototype testing materials).

Prospective participants with chronic pain were approached via a walk-in relaxation session attended at TARPS, where the researcher introduced the research and shared the details of the research, as part of the informed consent process (see Appendix 5 for PIS & Appendix 3 for Consent Form). Three individuals with chronic pain subsequently signed up and took part in the prototype testing session.

Data Analysis

Narrative Analysis

Narrative analysis serves as a method to delve into the stories of individuals and the significance of their experiences (Holloway, 2005). According to Holloway, exploring personal accounts in health research through narrative analysis offers valuable insights into the inner world of illness. This method was used to identify common experiences and emotions that individuals with chronic pain have faced, which then were incorporated into the illustrations.

I employed Riessman's (2008) thematic model of narrative analysis, which involves identifying patterns and meaning within the data to construct a set of themes. These themes are then labelled and grouped, aligning them with the theoretical framework of the research (Nollaig, 2011).

I conducted my narrative analysis over the contextual review and illustration exploration stages as quotes were gathered from secondary research and organised into themes. To refine these themes further, they were grouped into different emotional stages, organising the stories into an overarching narrative. The insights from the narrative analysis directly influenced the structure of the resource.

Thematic Analysis

Thematic analysis is a qualitative research method for identifying, analysing and interpreting patterns and themes within data (Braun & Clarke, 2012). This approach offers flexibility for researchers, allowing them to delve into various facets of data sources such as focus groups, interviews and surveys (Braun & Clarke, 2022). It is a method used to "make sense of collective or shared meanings and experiences" (Braun & Clarke, 2012, p. 57).

In my analysis of the focus group data, I loosely followed the six-phase process described by Terry et al. (2024): familiarising with the data, generating codes, constructing themes, reviewing potential themes, defining and naming themes and producing the report (Terry et al., 2024). Terry et al. note that these phases do not follow a strictly linear progression, and researchers often move back and forth between them.

I transcribed both the focus group and prototype testing discussion. I then familiarised myself with the text, highlighting intriguing conversational quotes and noting general topics of discussion. Following that, I "coded" the data by annotating how these quotes related to my research and their implications. This involved digitally categorising the notes and quotes, utilising visual mapping to identify patterns. Subsequently, the main themes were constructed, and I critically reflected on the key findings in the research documentation. Thematic analysis helped me decipher data gathered from participants into insights that informed my creative work.

Methods Timeline

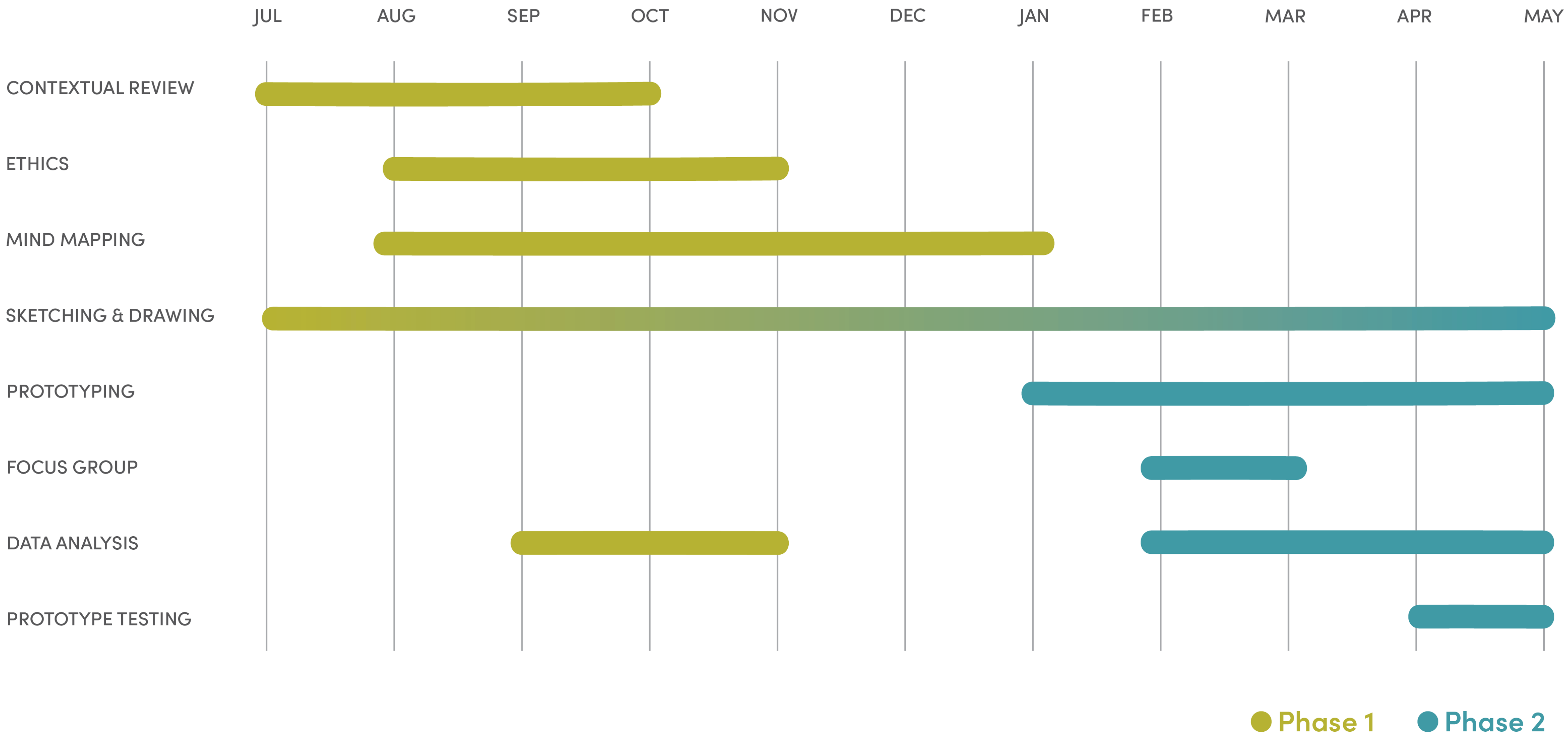


Figure 13. Methods Timeline

04. Documentation of Research

This section documents the creative research process leading to the final design outcome. The research journey started after the initial consultation with TARPS, which informed recruitment processes and provided initial direction for the contextual review. The research documentation is divided into two sections. Phase 1 focuses on the illustration and visual storytelling portion of this research, while Phase 2 follows the resource creation process, including how it was informed by the participants in this research.

Phase 1: Illustration Exploration

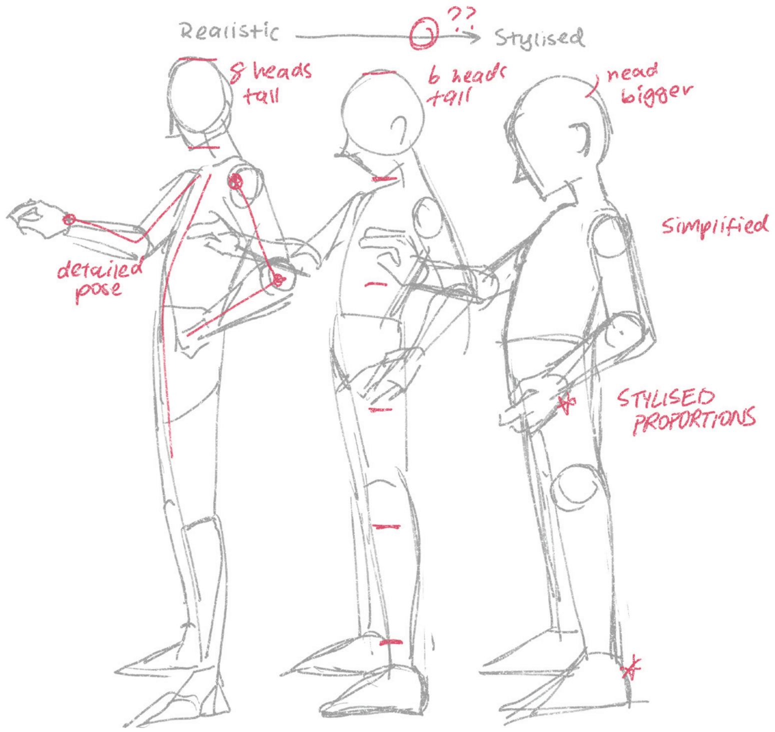


Figure 14. Stylised Body Proportion Sketch

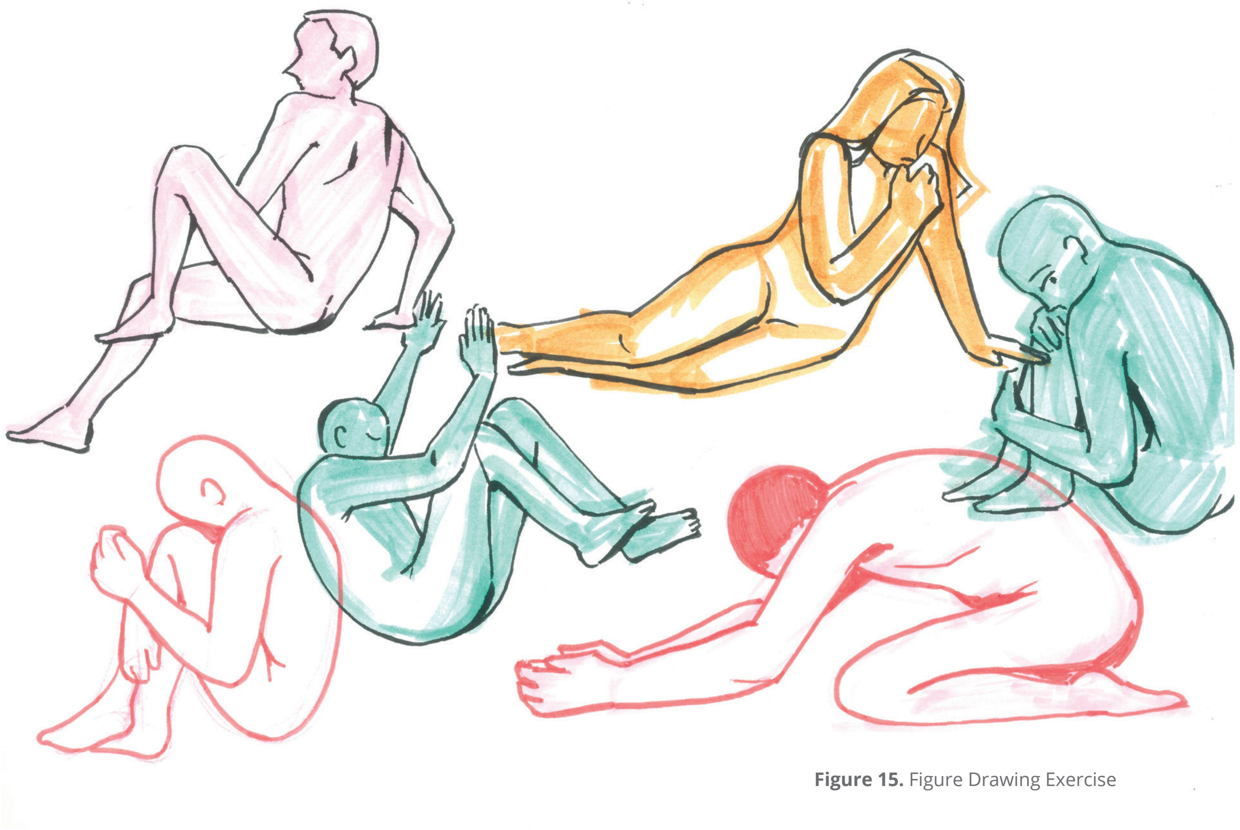


Figure 15. Figure Drawing Exercise

Developing an Illustration Style

According to Male (2007), style is “the distinctive visual language that identifies one’s “mark” or personal iconography.” Different styles have varying suitability for specific purposes and should align with the subject matter and the target audience (Male, 2007). Even though the resource was intended for a health context, the style did not adhere to traditional medical illustration. This was due to the resource’s emphasis on being emotive rather than solely educational in its intent.

Stylised Proportions

Central to this research are the stories of individuals living with chronic pain, making people the primary subject matter. The first step I took to develop a drawing style for this project was to explore the body proportions and shapes of characters before delving into conceptual ideas or stories. Stylisations ranged from “realistic” to stylised proportions. Stylisation usually involves simplifying shapes and exaggerating certain elements (Figure 14). This resulted in less detailed characters, but was generally less time-consuming than detailed anatomically correct poses. Throughout this project, I struggled to strike a balance between detail and simplicity. This challenge continued in later drawing stages, but was important to overcome as I aimed to establish a style that I could reliably employ in the later creation of the resource.

A valuable technique I employed during my style exploration was the practice of figure drawing from reference photos, followed by the process of stylising them (Figure 15). An understanding of human anatomy, acquired through figure drawing, enabled me to explore different ways to represent the human figure. As illustrator Male (2007) states, “Understanding human anatomy and being able to accurately represent the figure will give scope for a breadth of applications to illustration.” Hence, learning how to draw the human body served as a foundation before venturing into stylisation. Periodically, I would return to figure drawing sketches as an exercise to improve my technical drawing skills.

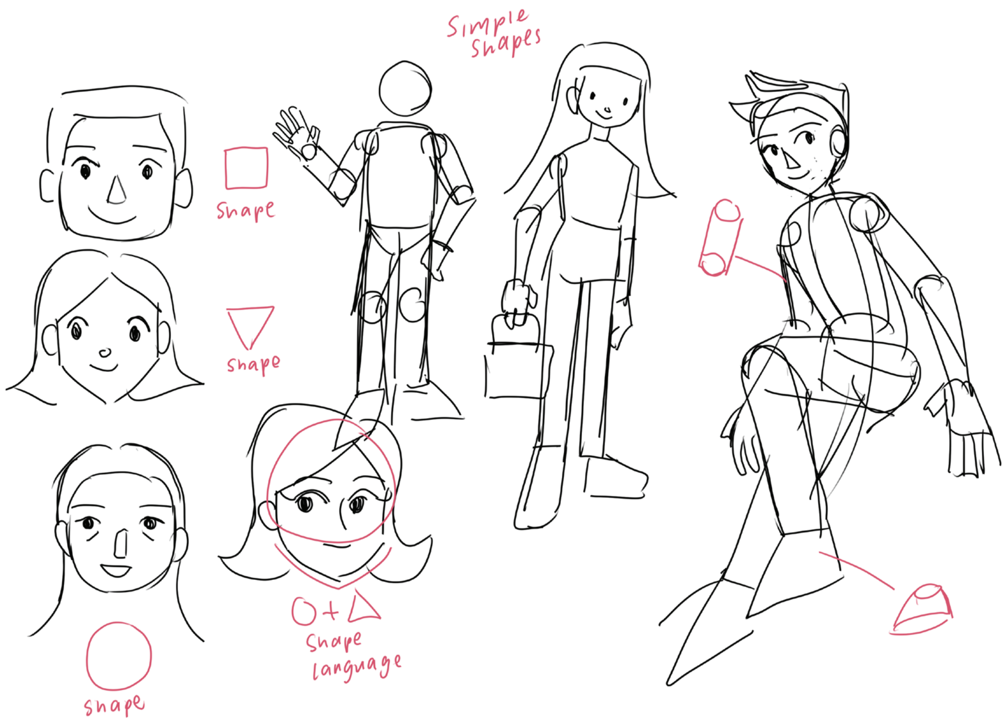


Figure 16. Style Exploration 1: Very simplified proportions & shapes

Figure 18. Style Exploration 3: Semi Realistic

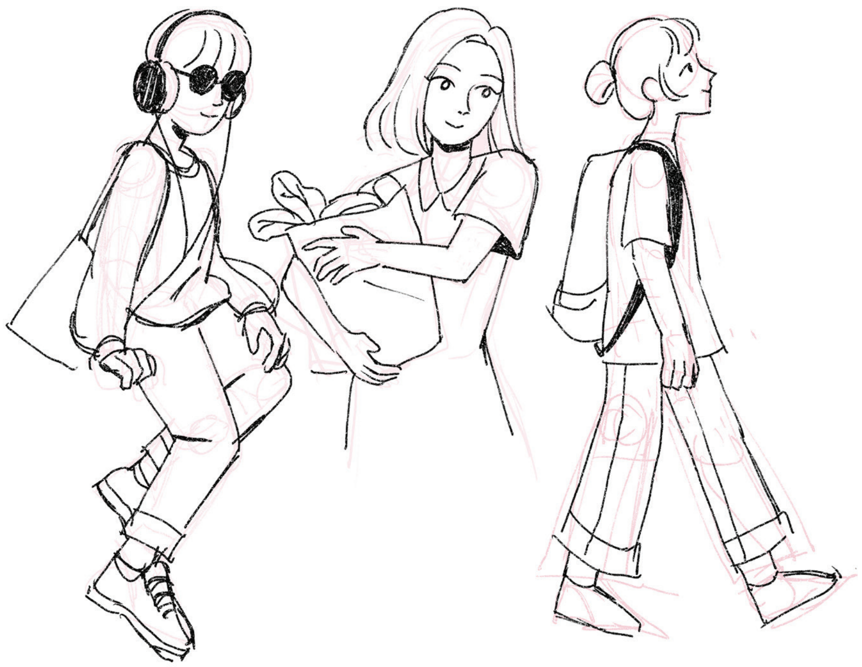


Figure 17. Style Exploration 2. More stylised proportions.

Character Design

Upon completing sketches of various characters, I determined that style 2 would be a suitable starting point for my upcoming illustrations (Figure 17). Style 3 adopted a semi-realistic approach, adhering closer to anatomically correct proportions, making this style ideal for capturing distinct facial features (Figure 18). However, I also anticipated that when combined with colour and background elements, style 3 might become overly intricate. While charming in its simplicity, a limitation of style 1 is that it would be difficult to portray a diverse range of people of varying ethnicities and ages (Figure 16). In light of these considerations, I found myself leaning towards style 2 as a well-rounded option for my upcoming illustration work.

Colour

A large part of my personal illustrative style is my use of colours. I like exaggerating and adding vibrancy, such as hints of hues that wouldn't exist in shadows and highlights but add visual interest. This style plays well into conveying an emotional reality rather than literal representations of experiences. The choice of colours was sometimes influenced by personal feelings as it is inherently subjective. However, I also partially based my decisions on colour theory. To better understand the nuanced responses associated with different colours, I referenced Clark & Costall's (2008) study on colour connotations. I also examined the colour analysis conducted by Kirkham et al. (2015) in their study of people's visualisations of pain, finding many overlaps with the meanings associated with each colour (Table 2). Additionally, I considered the lightness and darkness of a colour, as adding black to colour gives it a negative connotation, regardless of hue (Clarke & Costall, 2008).

	Painting Pain (Kirkham et al., 2015)	*The emotional connotations of colour (Clarke & Costall, 2008)*
Red	"heat", "pain", "anger" (p.402)	"warmth", "high emotion", "rage" (p. 407)
Orange		"happy", "warmth" (p. 407- p. 409)
Yellow	"hope", "light" (p. 404)	"cheery", "warmth" (p. 407- p. 409)
Green/Blue	"positive" (p. 403)	"peaceful", "relaxed", "soothing" (p. 407)
Purple	"gentle" (p.403)	"passive", "calming" (p. 408)
Black/ Darkness	"miserable" (p.403)	"sinister", "negative" (p. 408)

Table 2. Table comparing colour connotations from Kirkham et al. (2015) and Clarke & Costall's (2008) study.

A notable part of my illustrative approach for this project involved avoiding strict adherence to realistic depictions of people or objects. I was inspired by expressionist painting, which presents a more subjective view of the world, distorting it in order to convey a mood or idea (Baldick, 2001). In my work, the emphasis lies in expressing emotions rather than faithfully depicting physical reality. Many parts of the chronic pain experience are intangible, which makes it difficult to express through just illustrations of characters and objects. Colour needed to be used in tandem with the subject matter to express complex thoughts and experiences.

I sometimes also used unconventional colours in characters' skin tones. It was a deliberate choice not to limit characters to a realistic colour scheme, as an expressionist artist might do. Still, I recognised the importance of representing individuals of diverse ethnicities in my work. This was done by selecting skin tones of any hue but maintaining a range of light to dark tones (Figure 19).

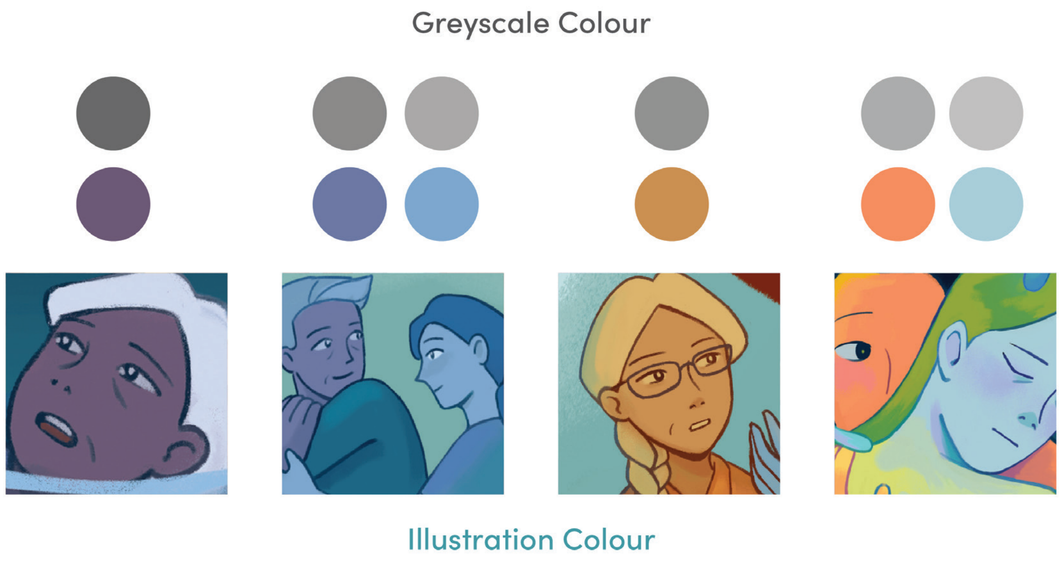


Figure 19. Illustration skin tones in colour and greyscale

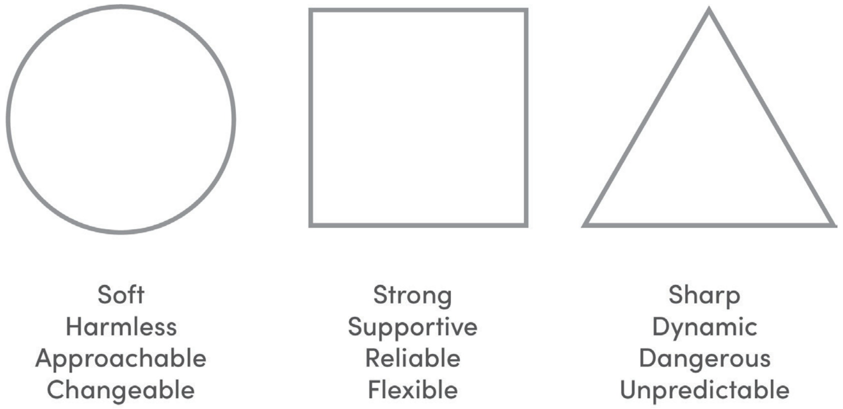


Figure 20. Shape Language. Adapted from Tips & Tricks Shape Language. Walt Disney Family Museum. (n.d). Retrieved from: https://www.waltdisney.org/sites/default/files/2020-04/T%26T_ShapeLang_v9.pdf

Shape and Form

Alongside colour, I tried to convey subtle emotions using shape language in my pieces. Shape language is a concept employed in art and animation to convey meaning based on recognisable shapes (Figure 20). This concept can be applied when designing characters, objects and backgrounds to portray personality and evoke an emotional response (Walt Disney Family Museum, n.d.). Generally, sharp or triangular shapes are seen as more aggressive, whereas rounded, softer shapes are perceived to be more friendly.

In this exercise, I visualised the adjectives and metaphors used by individuals experiencing chronic pain while also taking shape language into account (Figure 22). In order to express a contrasting mood, I used softer, more organic shapes to visually oppose the shapes associated with pain.

> *"Barbed wire wrapped around my feet." (Munday et al., 2020, p. 820)*
>
> *"It feels like I'm burning but I can't put the fire out. It feels like embers are smouldering inside." (Munday et al., 2020, p. 820)*

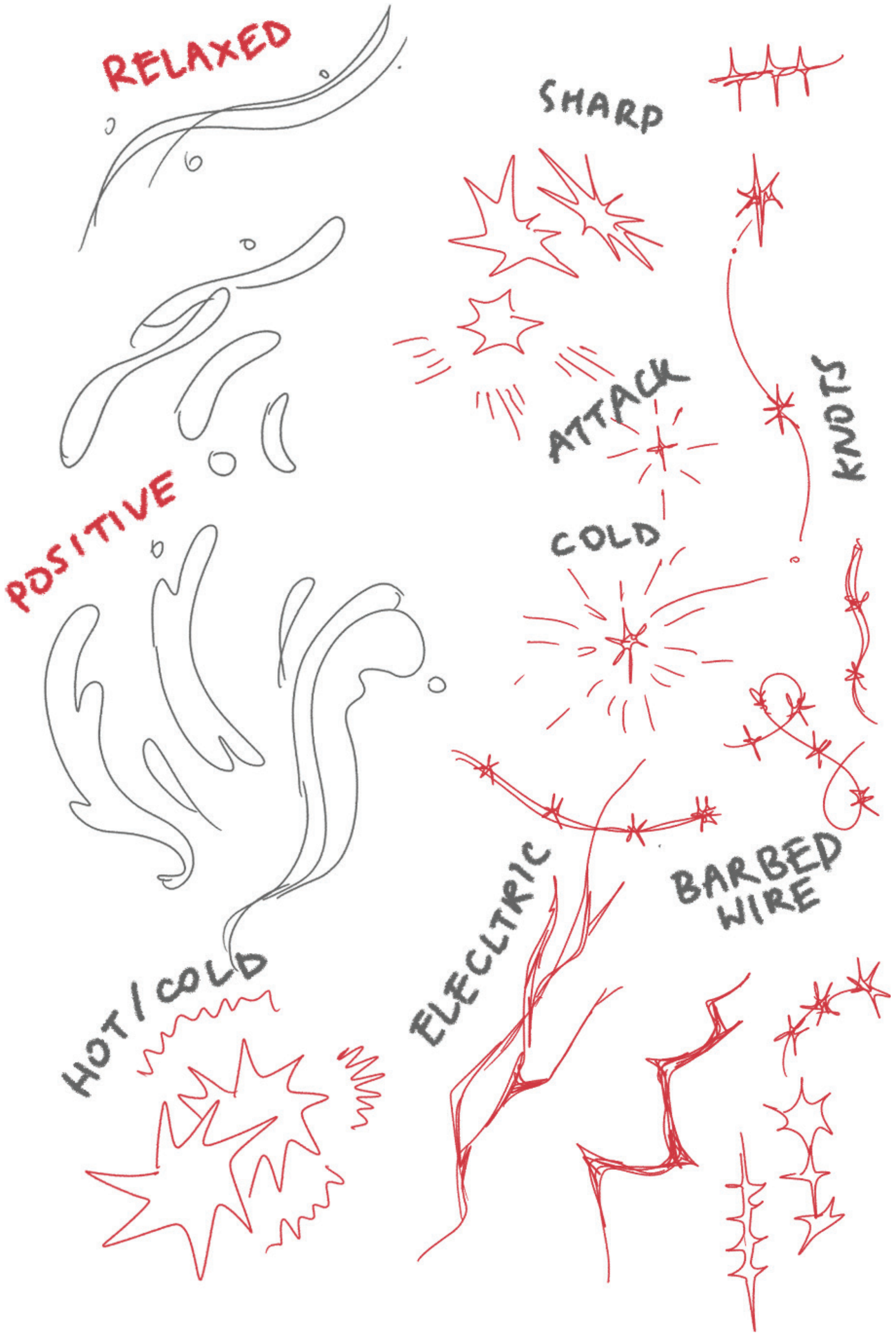


Figure 21. Abstract shape explorations using adjectives and metaphors

Exploring Experiences of Chronic Pain through Illustration

Throughout the course of this research project, the illustrative style underwent a continuous process of development. Aside from character design and proportions, some other style aspects I had to consider were line, colour and texture. This illustration exploration took place prior to my own data collection with participants. During this phase, I drew inspiration from the themes and narratives explored in the contextual review and relied on secondary research materials to inform my thinking.

My primary focus was to explore how to effectively convey meaning and emotions. Throughout this process, I continued to refine my illustration style with the added element of visual storytelling. Each exploration stage explores different subject matter within the chronic pain experience. In this documentation, my thought process behind the imagery and stylistic choices of the illustrations is elaborated upon.

Exploration 1 – Healing Journey

This set of illustrations presents a journey to healing, with each piece expressing a different theme. I attempted to convey this emotional journey through the transitions in colour and using transforming shape language (Figure 22).

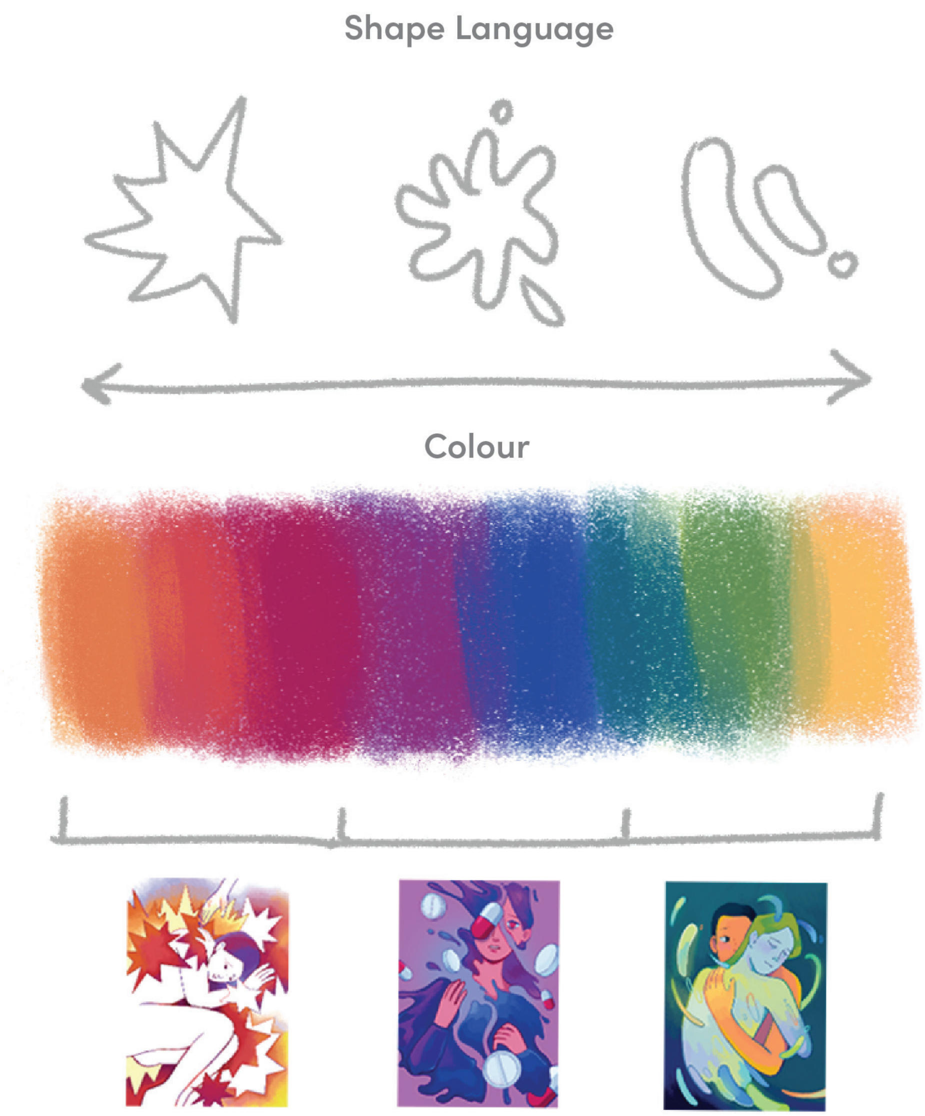


Figure 22. Diagram showing the use of shape language and colour

Figure 23. Drawing Exploration 1a. Overwhelming Pain

> *"She's in chronic pain.*
> *She's lost in it."*

(Devan et al., 2020, p. 97)

> *"It's like living half a life...*
> *There's so many things*
> *I don't do because I am*
> *so sore and tired."*

(Devan et al., 2020, p. 97)

The first theme I explored was the burden and impact of chronic pain on the body. This is shown by a vulnerable character being overwhelmed by sharp, angular shapes. In the study by Kirkham et al., red and black were used to portray pain. I chose red as the primary colour to represent physical pain due to its connotation of heat, which is how a lot of people would describe their pain (Munday et al., 2020). Sharpness is also associated with the sensation of pain, as evidenced by people with chronic pain using imagery of pins, knives and lightning in their visualisations (Phillips et al., 2015).

Figure 24. Drawing Exploration 1b. Side effects of medication

> *“Those drugs left him with no energy, feeling depressed, his memory was shot and he as sleeping at least 14 hours a day...”*

(Devan et al., 2020, p. 98)

The second illustration delves into the side effects of opioid medication to manage pain, particularly on mental health. The character is portrayed as physically broken and melting away, reflecting the emotions of depression and emptiness. The colour scheme shifts towards cooler tones to emphasise the sombre mood.

Figure 25. Drawing Exploration 1c. Supported Healing

> *"I'm now 51 and really wish I could have a pain free day but at least I have friends and family that are so supportive."*

(Chronic Pain Experiences | Healthwatch Derby, 2022, p. 30)

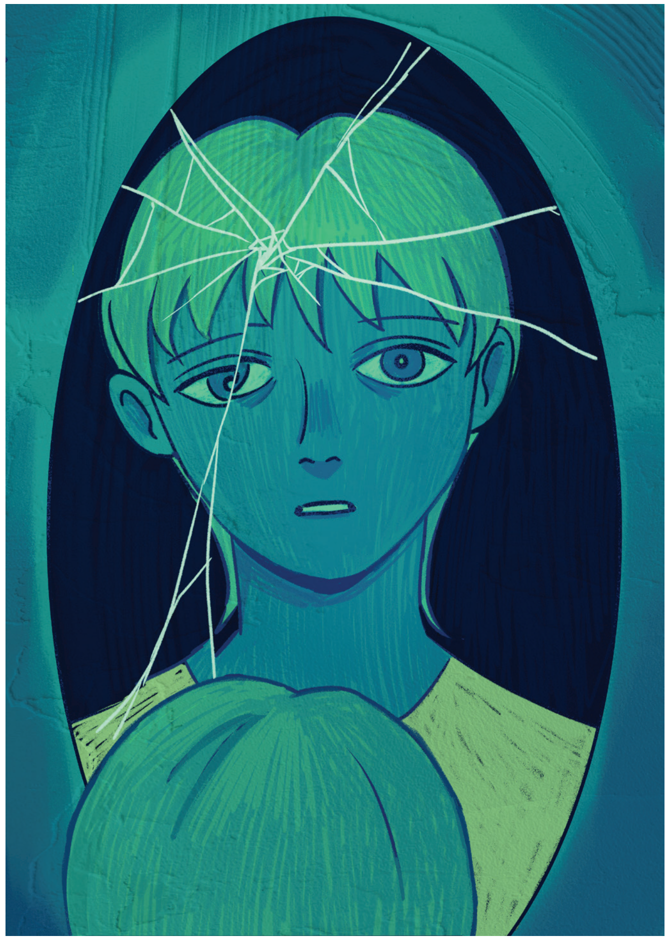
For the last drawing of this set, I wanted to express a sense of comfort and healing. The illustration portrays the character's form in the process of reformation, symbolising the gradual process of learning to live well with chronic pain. It draws inspiration from individuals experiencing chronic pain being able to find solace and strength in the support of their family and friends, acknowledging the crucial role these relationships play in the management of chronic pain (Jamison & Virts, 1990).

Exploration 2 - Identity

This series of illustrations revolves around the theme of identity and the relationship with oneself. In many personal experience narratives, individuals frequently reflected on their lives before experiencing pain, often comparing themselves to their past selves (I Chose to Change: Living with Chronic Pain, n.d.; The Painful Truth, 2014; Kirkham et al., 2015). Each illustration in this series features a "double" or "reflection" of the individual, symbolising this introspective connection. Instead of following a continuous character journey as the last exploration did, each illustration stands on its own. This is why the collection may appear less cohesive. At this stage, I also noticed that I had a tendency to create younger characters. While I intended to portray a diverse range of individuals, it became apparent that I needed to make a more proactive effort to represent a wider age of ages in upcoming illustrations.

Regarding the style, I aimed to simplify the colouring approach. The colouring style in exploration 2 is much "flatter" as opposed to the previous exploration, which featured a more painterly and rendered aesthetic. Rendering in digital art is the process of applying shading, highlights, and details to an image to create more dimension. In Exploration 2, I also utilised more simple line work. The lines maintained a textured quality but were cleaner and did not blend into the colouring. In contrast, the lines of the previous experiment have a softer appearance, blending into the colours of the illustration. While that process of rendering is meticulous, I felt that the illustrations from exploration 1 felt more emotive. I attributed that to the painted texture and a broader range of colours achieved through the rendering, which lends greater visual impact.

Figure 26. Drawing Exploration 2a. Distorted sense of identity



"I don't even recognise the person that I am now."

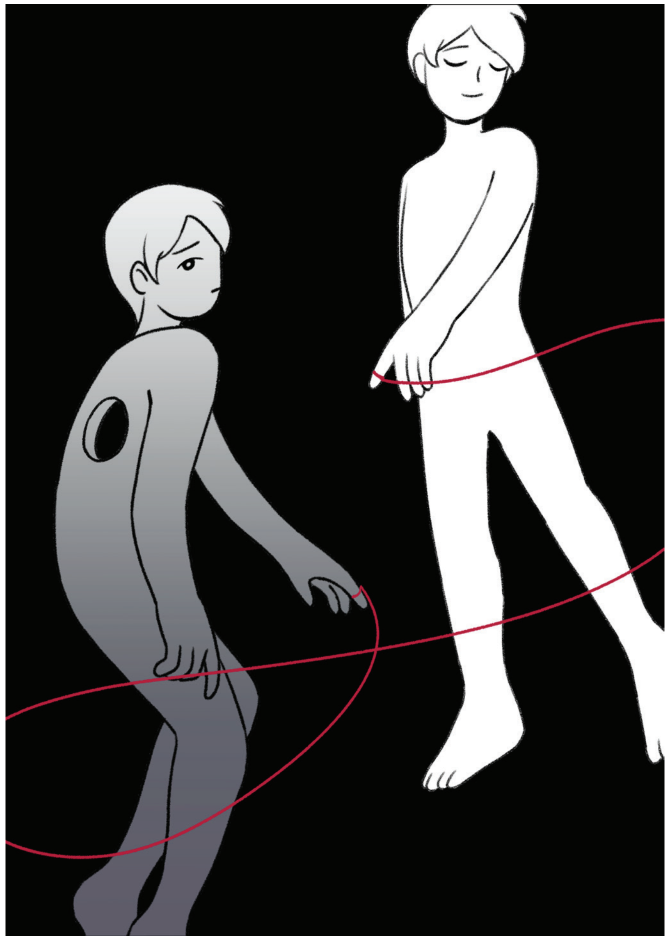
(The Painful Truth, 2014, p. 49)

Figure 27. Drawing Exploration 2b. Self Love

"I also learn to love myself. In the past I would over estimate my ability."

(I Chose to Change: Living with Chronic Pain, n.d., p. 12)

Figure 28. Drawing Exploration 2c. Past and Future Self



"I am not the same person as before I had pain."

(The Painful Truth, 2014, p. 48)

Exploration 3 – Water Analogy

In this exploration, I revisited the approach of depicting a journey or narrative across multiple pieces. To symbolise the emotional journey of chronic pain, I created an analogy using water. I chose water as an analogy due to its fluid, transformative nature. Similarly, our well-being isn't static. It changes like the water, evolving with experiences and emotions. Psychological-distress, such as depression and anxiety, is a huge commonality among those with chronic pain, and it is interlinked (Gerrits et al., 2012). I touched upon some of these emotional aspects in previous explorations but wanted to present them in a different way visually. Subtle shifts in colours were employed to convey the evolving tone throughout the illustrations.

Previously, my approach to illustrating stories began with focusing on a specific theme or aspect of the chronic pain experience. However, as I delved into a broader range of subjects, I noticed that these stories represented various stages of people's journeys. For this exploration, I sought to encapsulate these experiences as a series of illustrations with a conceptual overarching narrative (Figure 34). The intention for this set of illustrations was that the analogy would be integrated throughout the resource, allowing readers to reflect on where they're at in their journey and have hope for improvement in the future.

Figure 29. Drawing Exploration 3a. Engulfed in waves of pain

> *"Pain is part of*
> *my life and I fear*
> *it always will be."*

(The Painful Truth, 2014, p. 26)

Chronic pain significantly affects a person, permeating various aspects of their home, work, and social life (The Painful Truth, 2014). The first illustration in this series portrays an individual feeling overwhelmed by chronic pain like they could be washed away by an uncontrollable force (Figure 29).

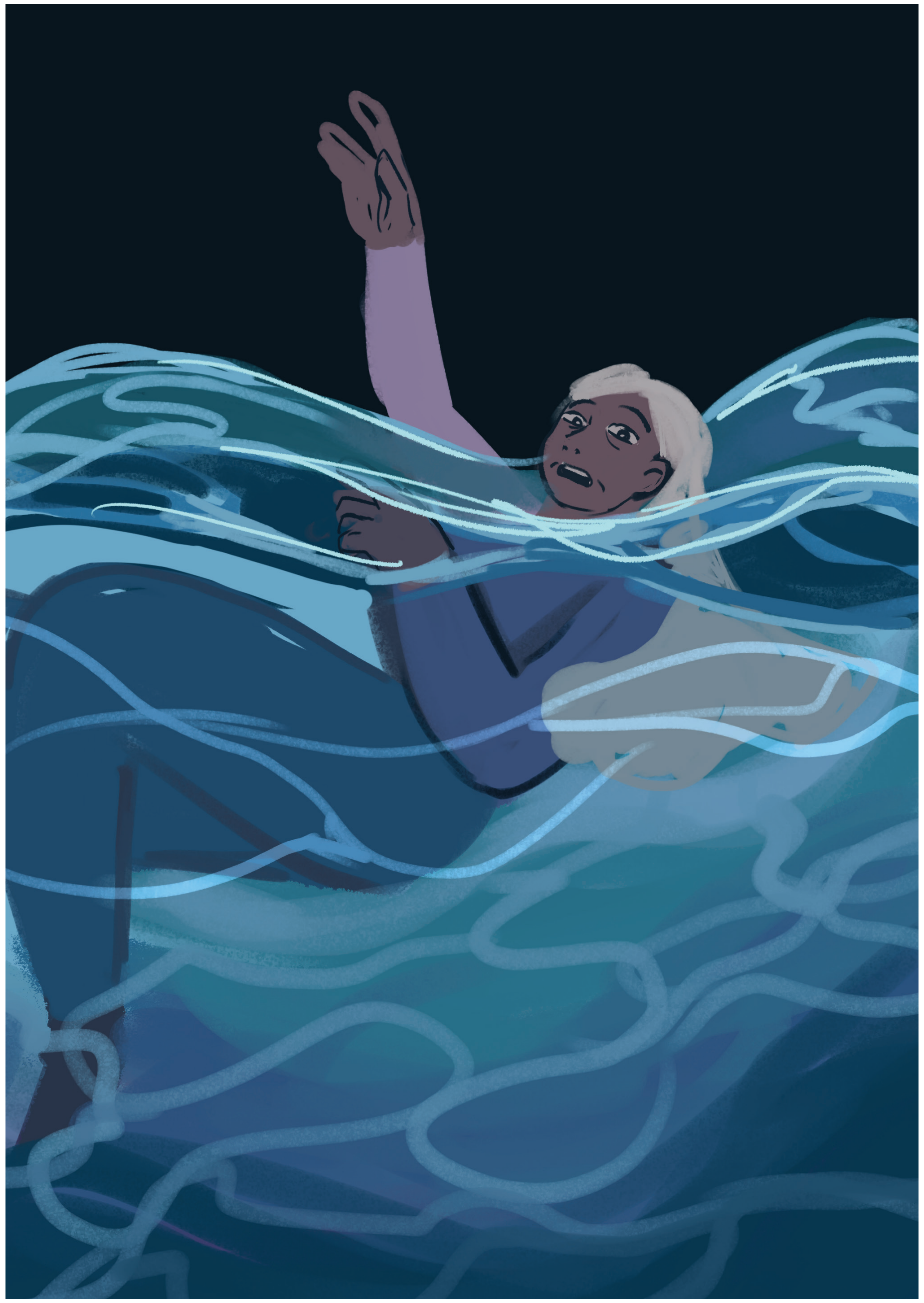


Figure 30. Drawing Exploration 3b. Struggling to stay afloat

> *“It has caused me to struggle with everything on a daily basis.”*

(The Painful Truth, 2014, p. 41)

Individuals with chronic pain learn how to adapt their lives around the pain. However, this could take a while for some, as chronic pain management takes time and sustained effort (Devan et al., 2020). The second illustration in this exploration reflects the struggles one faces when trying to find “solutions” and learn how to navigate their pain (Figure 30). I envision this struggle to be akin to the sensation of drowning, where individuals grapple to stay afloat amidst the challenges.

Figure 31. Drawing Exploration 3c. Submerged in hopelessness

> *“I feel like I don’t have a life anymore. I am just existing.”*

(The Painful Truth, 2014, p. 45)

The third illustration aims to capture the loss of hope brought on by chronic pain. In a state of depression and emptiness, the individual is completely submerged in the water and surrendering to their pain (Figure 31).

Figure 32. Drawing Exploration 3d. Flowing with the current

> *“Slow and steady wins the race and small steps are all it takes to begin to improve the quality of your life.”*
>
> (Devan et al., 2020, p. 100)

Nevertheless, with the right care, managing chronic pain is possible. Some individuals have found success through taking a holistic approach, exercise, psychological strategies and multidisciplinary care (Devan et al., 2020). The next illustration in this series portrays the character taking control of their life, flowing with the water to show a departure from their previous struggles (Figure 32).

Figure 33. Drawing Exploration 3e. Floating serenely

> *"Instead of trying*
> *to find answers,*
> *I'm trying to live*
> *with what I've got."*

(Devan et al., 2020, p. 100)

One of the biggest challenges for individuals with chronic pain is acknowledging the fact that pain is going to be part of their lives for a long time (The Painful Truth, 2014). The concluding illustration symbolises acceptance and the ability to lead a fulfilling life despite pain. The character depicted lies in tranquil waters, attaining a sense of balance through learning to coexist with pain (Figure 33).

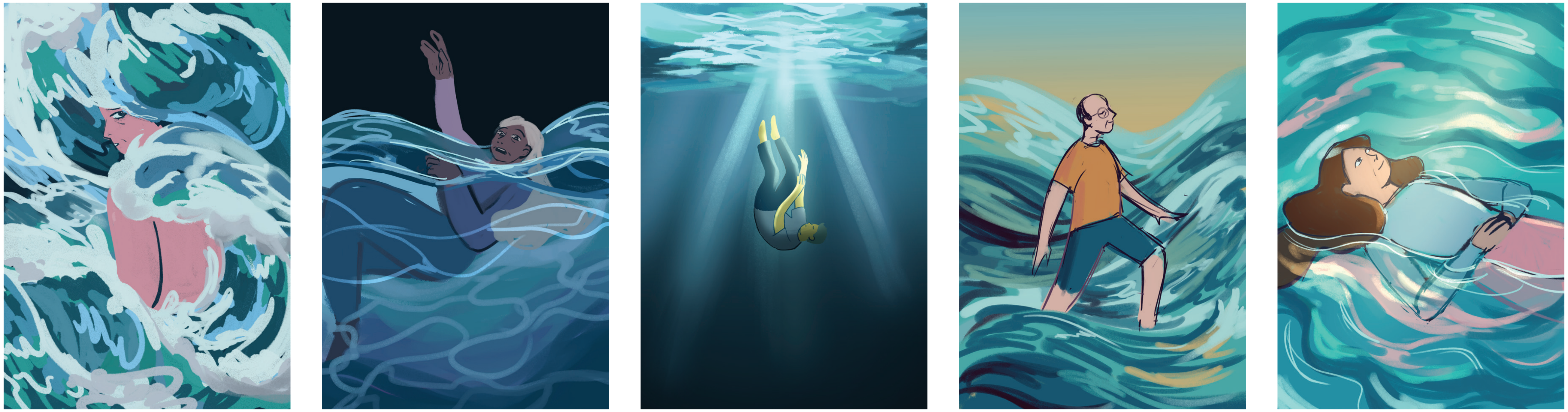


Figure 34. Drawing Exploration 3. Using water to convey different emotional states

Exploration 4 – Moments

In creating this series of drawings, I wanted to take an opposite approach to Exploration 3, opting for a more literal depiction rather than using metaphorical imagery. I believe that with this exploration, I've achieved a balance between a detailed rendering (used in exploration 1) and simple colouring (exploration 2). The painting style in these pieces is not overly blended, allowing the roughness and texture of the brushes to remain visible, providing visual interest.

Taking a more grounded storytelling approach, I aimed to capture simple moments of everyday life. Each illustration hints at the presence of pain, but it is not the central focus. This is shown through the medicine bottle or the sharp abstract forms that visualise pain. In contrast, the flowing shapes and paint strokes symbolise wellness. The goal was to depict characters living well on a daily basis while acknowledging the existence of pain. The underlying message aims to encourage appreciation for small moments and a focus on what one can do rather than what one cannot.

> *"The pain was still there, but I became more joyful."*

(I Chose to Change: Living with Chronic Pain, n.d., p. 24)

Figure 35. Drawing Exploration 4a. Mindful Thinking

Figure 36. Drawing Exploration 4b. Small moments of happiness

> *"I accept my pain and acknowledge it. It's just part of me now and I have bad days when I struggle to function but I just take some paracetamol and think well, tomorrow is another day."*

(Chronic Pain Experiences | Healthwatch Derby, 2022, p. 30)

Figure 37. Drawing Exploration 4c. Living well with pain

"I now am able to appreciate basic things in life...I feel satisfied by just doing that."

(I Chose to Change: Living with Chronic Pain, n.d., p. 12)

Reflection

This phase of drawing exploration allowed me to experiment with different visual styles, colours, subject matter, and ways to convey stories. Comparing these explorations to each other, it is clear to me that exploration 2 is the weakest in execution. While the subject of lost identity after pain was a recurring topic in chronic pain stories, I'm unsure of its relevance in a clinical resource. Exploration 4 stands out due to the stronger use of colour. The warmth conveyed in those illustrations helps communicate the supportive tone I was aiming for in the resource. While both explorations 1 and 3 take a similar approach of depicting a journey throughout a set of illustrations, 3 was more cohesive because it maintained consistent imagery. Overall, I thought that explorations 1, 3 & 4 had strengths worth presenting to participants to test their reception.

Through immersing myself in chronic pain narratives, I gained a better understanding of individuals' experiences. Drawing itself became a powerful tool for me to emotionally connect with the subject matter. This phase was pivotal in identifying the most effective illustration approaches and strengths to take forward. Despite lacking participants to validate my work or provide firsthand knowledge at this stage, I was able to rely on secondary research materials that depicted real stories and experiences of people living with chronic pain to inform these explorations. With the focus group and workshop plans not finalised at this stage, I made the decision to proceed with creating the prototype resource, marking the next phase of my research.

Phase 2: Resource Creation

Developing the Resource Structure

In my contextual review and drawing exploration stages, I gathered quotes from various personal accounts (Figure 40). I began analysing these narratives to weave them together, culminating in illustration exploration 3. This exploration used water as an analogy for the emotional journey of chronic pain, which was inspired by an amalgamation of stories to make an overarching narrative. Doing further narrative analysis, I organised the collected quotes into themes and then categorised them into phases representing different stages of one's journey with chronic pain (Figure 38).

To structure the resource, I framed these phases as questions from the point of view of someone with chronic pain (Figure 39). These questions then served as chapter headers, with each progression marked by illustrations from exploration 3. With the resource outline in place, I started to flesh out the informative sections of the resource, interspersing story quotes throughout.

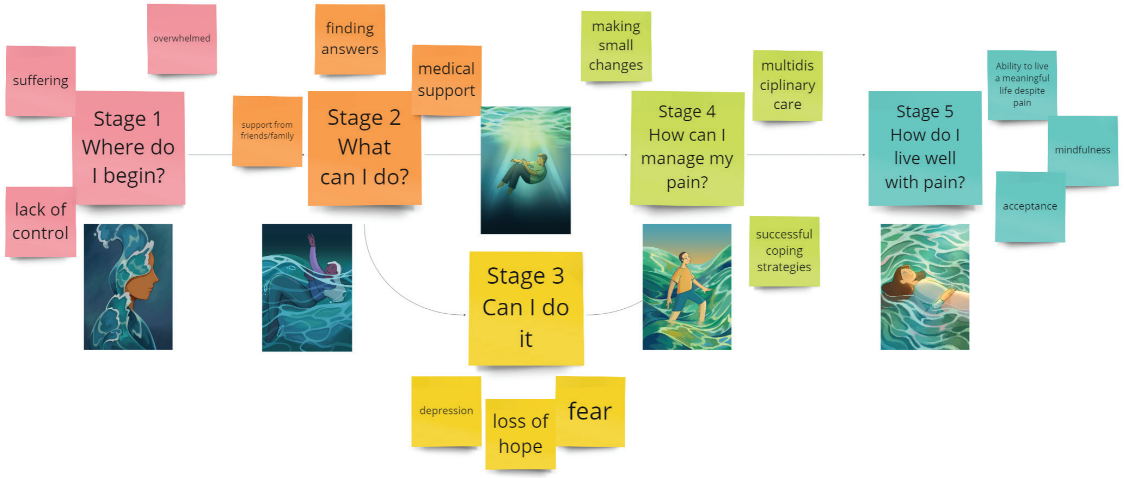
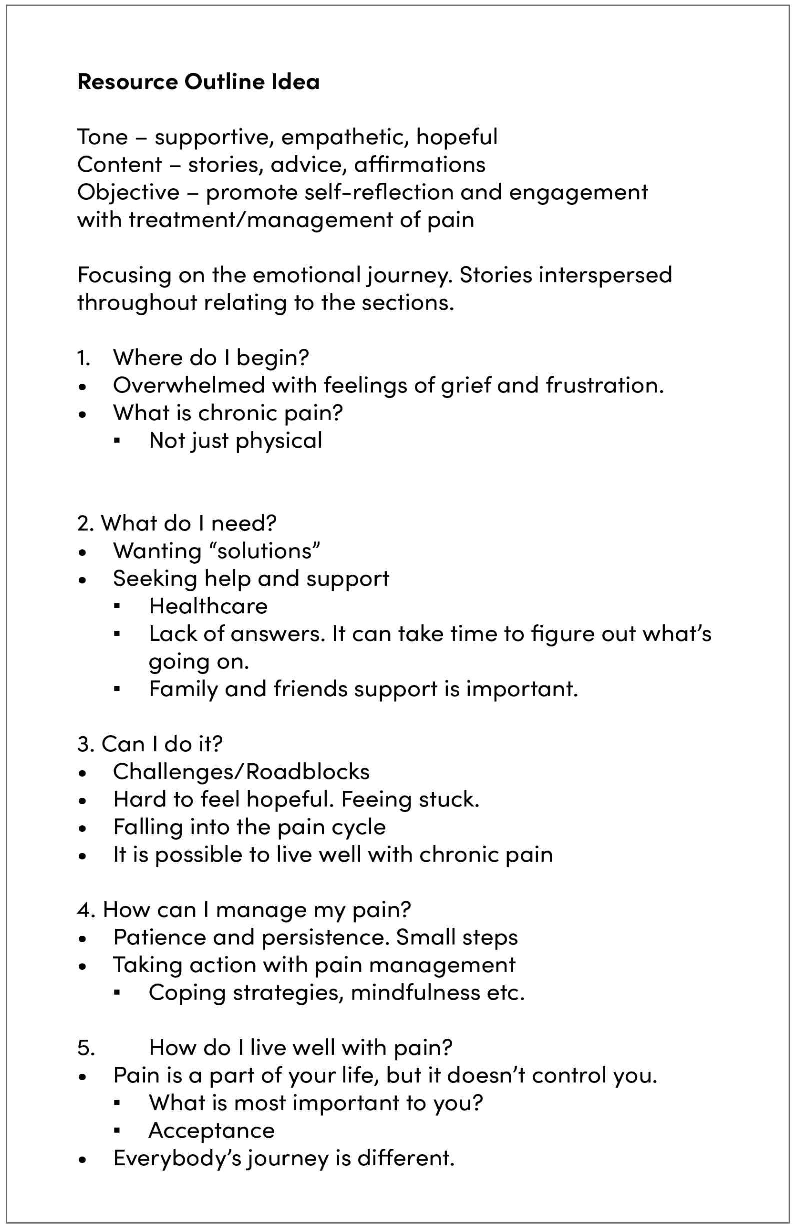


Figure 38. Narrative Analysis 2: Phases



Resource Outline Idea

Tone – supportive, empathetic, hopeful
Content – stories, advice, affirmations
Objective – promote self-reflection and engagement with treatment/management of pain

Focusing on the emotional journey. Stories interspersed throughout relating to the sections.

1. Where do I begin?
- Overwhelmed with feelings of grief and frustration.
- What is chronic pain?
  - Not just physical

2. What do I need?
- Wanting "solutions"
- Seeking help and support
  - Healthcare
  - Lack of answers. It can take time to figure out what's going on.
  - Family and friends support is important.

3. Can I do it?
- Challenges/Roadblocks
- Hard to feel hopeful. Feeing stuck.
- Falling into the pain cycle
- It is possible to live well with chronic pain

4. How can I manage my pain?
- Patience and persistence. Small steps
- Taking action with pain management
  - Coping strategies, mindfulness etc.

5. How do I live well with pain?
- Pain is a part of your life, but it doesn't control you.
  - What is most important to you?
  - Acceptance
- Everybody's journey is different.

Figure 39. Resource Structure

Devan, H., Young, J., Avery, C., Elder, L., Khasyanova, Y., Manning, D., Scrimgeour, M., & Grainger, R. (2020). **Media representation of chronic pain in Aotearoa New Zealand—A content analysis of news media.** 133(1508).

Chronic Pain Experiences | Healthwatch Derby. (2022). Healthwatch Derby. https://nds.healthwatch.co.uk/reports-library/chronic-pain-experiences-2022

I Chose to Change: Living with Chronic Pain—Stories from Patients. (n.d.). Nethersole Institute of Continuing Holistic Health Education.

The Painful Truth: 2,500 people who live with chronic pain tell their story. (2014). Patient and Client Council - Northern Ireland.

“Eventually his life was a nightmare of constipation, drowsiness, depression and memory loss.” (Devan et al., 2020, p. 98)

“Those drugs left him with no energy, feeling depressed, his memory was shot and he was sleeping at least 14 hours a day…” (Devan et al., 2020, p. 98)

Medicine side effects

"It seems I have a choice between being very active and sitting around all day." (Chronic Pain Experiences | Healthwatch Derby, 2022, p. 30)

importance of physical activity

Medical

multidisciplinary care

Not being listened to

“I feel I am left to find answers myself.” (The Painful Truth, 2014, p. 30)

"People don’t understand as you look well, it is an invisible illness.” (The Painful Truth, 2014, p. 23)

Chronic Pain Experience

relationships

“She’s in chronic pain. She’s lost in it.” (Devan et al., 2020, p. 97)

Daily life

I have to live my life around my pain rather than managing my pain to fit in with my life” (The Painful Truth, 2014, p. 41)

Impact on person

“It’s like living half a life. I get home at the end of day wiped out. There’s so many things I don’t do because I am so sore and tired.” (Devan et al., 2020, p. 97)

"I felt like falling into an abyss." (I Chose to Change: Living with Chronic Pain, n.d., p. 17)

"Most days I'm running scared and struggle to cope." (Chronic Pain Experiences | Healthwatch Derby, 2022, p. 32)

“I feel like I don’t have a life anymore. I am just existing”. (The Painful Truth, 2014, p. 45)

depression

Mental Health

"I felt being loved and I gradually came to my senses from a state of confusion. My thoughts became more positive and not to be in desperation anymore. My pain still continued, but it did not worsen which is satisfying." (I Chose to Change: Living with Chronic Pain, n.d., p. 5)

mindfulness

"I accept my pain and acknowledge it. It’s just part of me now and I have bad days when I struggle to function but I just take some paracetamol and think well, tomorrow is another day." (Chronic Pain Experiences | Healthwatch Derby, 2022, p. 30)

“Chronic Illness completely changed my life and who I was as a person.” (Devan et al., 2020, p. 97)

identity

“I am not the same person as before I had pain.” (The Painful Truth, 2014, p. 48)

“I learned to love myself. In the past I would overestimate my ability” (I Chose to Change: Living with Chronic Pain, n.d., p. 12)

“I don’t even recognise the person that I am now.” (The Painful Truth, 2014, p. 49)

Ability to live a meaningful life despite pain

Appreciating life

I now am able to appreciate basic things in life…I feel satisfied by just doing that. (I Chose to Change: Living with Chronic Pain, n.d., p. 12)

acceptance

“Instead of trying to find answers, I’m trying to live with what I’ve got.” (Devan et al., 2020, p. 100)

Positive Attitudes

support from friends/family

“I’m now 51 and really wish I could have a pain free day but at least I have friends and family that are so supportive.” (Chronic Pain Experiences | Healthwatch Derby, 2022, p. 30)

hope

“It is just a part of my life now; I just get up and get on with it.” (The Painful Truth, 2014, p. 51)

successful coping strategies

“My love of art came to me, day by day I would try and train myself to do a little, develop my drawing and watercolour skills.” (Chronic Pain Experiences | Healthwatch Derby, 2022, p. 30)

no energy

“It has caused me to struggle with everything on a daily basis”. (The Painful Truth, 2014)

suffering

Negative Attitudes

“Slow and steady wins the race and small steps are all it takes to begin to improve the quality of your life.” (Devan et al., 2020, p. 100)

“Pain is part of my life and I fear it always will be”. (The Painful Truth, 2014, p. 26)

lack of control

"I feel as though I have no power or control over my life." (Chronic Pain Experiences | Healthwatch Derby, 2022, p. 32)

Figure 40. Narrative Analysis 1: Themes and Quotes

Prototyping

Prototyping at this stage involved matching the themes and meanings of the illustrations to a specific topic about chronic pain to present them in the form of a booklet. The topics were sourced from pre-existing chronic pain information guides in New Zealand, most of which were recommended by clinicians at TARPS (e.g., The Pain Toolkit (Moore, 2017) and Navigating Pain by The New Zealand Pain Society). I utilised mind maps again to organise and rearrange images and information. InDesign was used to experiment with booklet layouts. Leaning into the colourful illustration style, I reflected this quality in the page design. After trying out different headers, I decided to develop a custom typeface to emulate the painterly vibe of the illustrations while still aiming for a clean presentation (Figure 41). This added a more personal and human touch to the design of the resource, aligning well with the emotive subject matter being communicated. Some illustrations also went through iterative refinement and polishing (Figure 42). The resulting prototype was 24 pages long and was used in the subsequent focus group to give the clinicians an idea of the look and feel of the resource.

How do I live well with pain?

It is possible to live well with pain. This often means actively looking for ways to live a good life, even when the pain is still present.

“

Instead of trying to find answers, I'm trying to live with what I've got.

How do I live well with pain?

It is possible to live well with pain. This often means actively looking for ways to live a good life, even when the pain is still present.

“

Instead of trying to find answers, I'm trying to live with what I've got.

Figure 41. Typeface Comparison

Before

After

Figure 42. Polishing Illustration Exploration 3

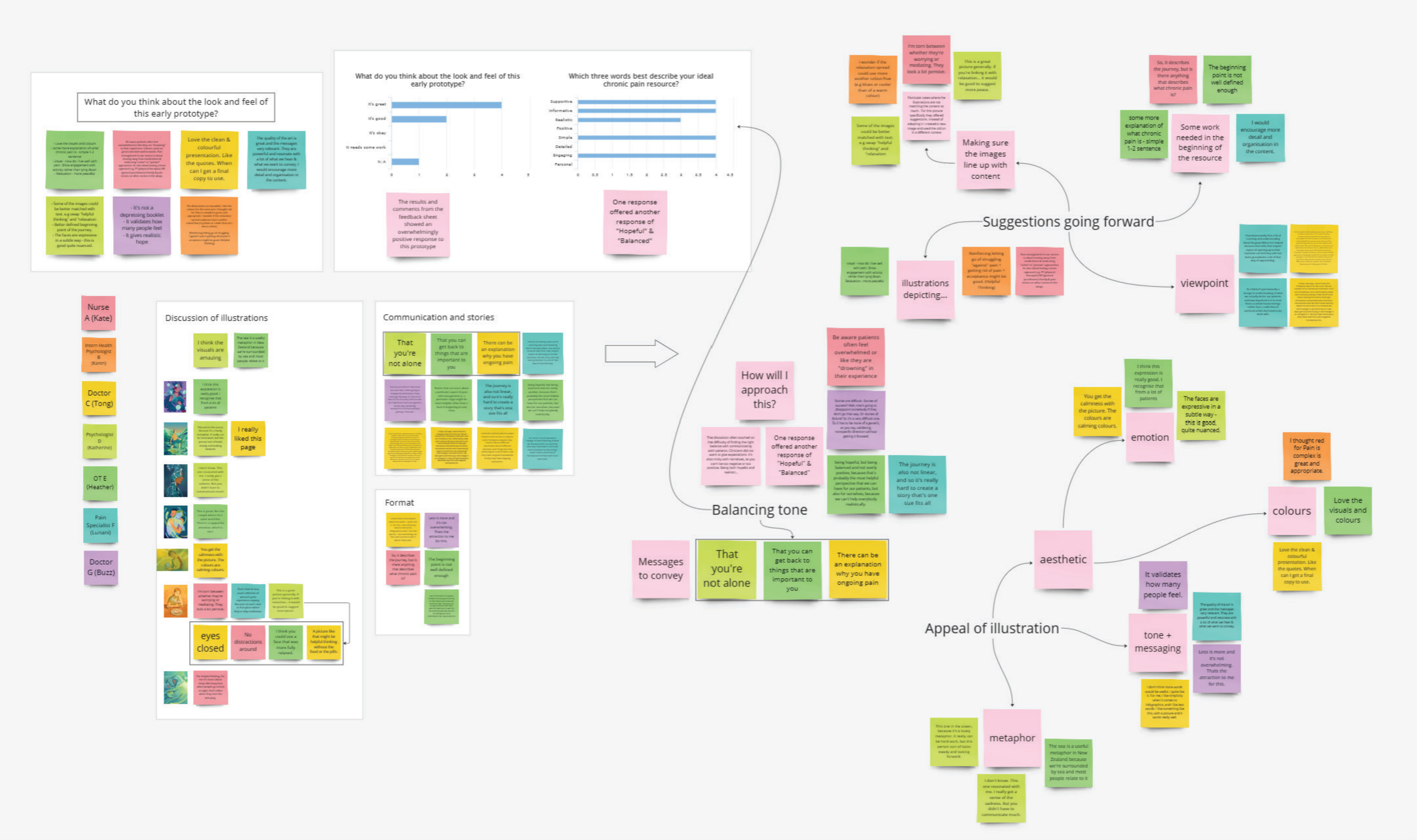


Figure 43. Thematic analysis of focus data

Focus Group with TARPS

The focus group comprised of seven participants, including a nurse, pain specialist, doctors, psychologists, and an occupational therapist. Discussion centred around existing chronic pain resources, patient experiences and communication in practice (See Appendix 6 for focus group questions).
I also sought to receive input on the previous prototype iteration, asking for suggestions and gauging how well patients might respond to it. Alongside the discussion, participants were provided with a feedback sheet to express their opinions on my resource and describe their ideal resource (See Appendix 7 for focus group materials).

The key findings are outlined below and presented as themes constructed based on the data gathered through the focus group discussion and the written feedback.

The appeal of illustration

The comments received from both the feedback sheet and the focus group discussion indicated an overwhelmingly positive response to the prototype presented. Clinicians particularly praised the illustration component, expressing appreciation for the visuals and colours. Many remarked on the sense of “calmness” conveyed by some of the illustrations as well as the expressiveness of the art, recognising familiar emotions from their interactions with patients:

> *“The faces are expressive in a subtle way – this is good, quite nuanced.” – Psychologist D*

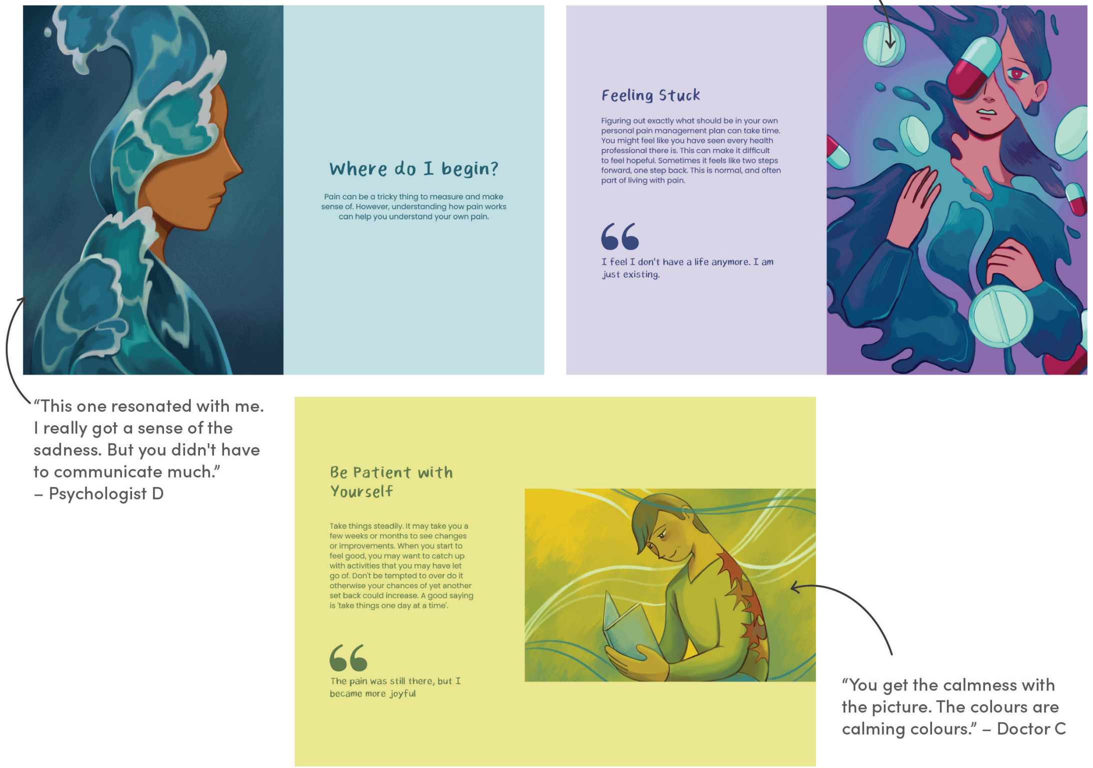
> *“Love the clean and colourful presentation. When can I get a final copy to use?” – Doctor C*

There was a consensus that the illustrations effectively validated common feelings among individuals with chronic pain. Additionally, positive reactions were expressed towards the tone and messaging of the content. Although I had initial concerns about the short informational content, many participants found the simplicity of the text appealing, as the illustrations spoke for themselves:

> *“The quality of the art is great and the messages very relevant. They are powerful and resonate with a lot of what we hear and what we want to convey.” – Pain Specialist F*

> *“Less is more and it’s not overwhelming. Thats the attraction to me for this.” – Doctor G*

“I think this expression is really good. I recognise that from a lot of patients.” – OT E



Where do I begin?

Pain can be a tricky thing to measure and make sense of. However, understanding how pain works can help you understand your own pain.

Feeling Stuck

Figuring out exactly what should be in your own personal pain management plan can take time. You might feel like you have seen every health professional there is. This can make it difficult to feel hopeful. Sometimes it feels like two steps forward, one step back. This is normal, and often part of living with pain.

“

I feel I don't have a life anymore. I am just existing.

Be Patient with Yourself

Take things steadily. It may take you a few weeks or months to see changes or improvements. When you start to feel good, you may want to catch up with activities that you may have let go of. Don't be tempted to over do it otherwise your chances of yet another set back could increase. A good saying is ‘take things one day at a time’.

“

The pain was still there, but I became more joyful

“This one resonated with me. I really got a sense of the sadness. But you didn't have to communicate much.”
– Psychologist D

“You get the calmness with the picture. The colours are calming colours.” – Doctor C

Figure 44. Resource Spreads

Two participants specifically highlighted their appreciation for the water motif I incorporated throughout the booklet (Figure 45). My intention was for the water to serve as a metaphor for mental well-being, and although they interpreted it in slightly different ways, the meaning was still understood:

> *“The sea is a useful metaphor in New Zealand because we’re surrounded by sea, and most people relate to it” – Occupational Therapist E*
>
> *“It’s a lovely metaphor. It really can be hard work, but this person sort of looks steady and looking forward.” – Psychologist D*

How can I manage my pain?

It often isn’t possible to completely eliminate pain, but there are ways to manage it.

“

Slow and steady wins the race and small steps are all it takes to begin to improve the quality of your life

Figure 45. Resource Spread. How can I manage my pain?

Balancing the tone of communication

The discussion often touched on the challenge of communicating with patients. It was intriguing because it delved into the difficulties and misunderstandings surrounding chronic pain from both the clinician and patient perspectives. The discussion highlighted a common scenario where patients come to the clinic after seeing multiple specialists and feeling “confused” and “disillusioned” by their ongoing symptoms. Moreover, system constraints often restrict clinicians’ interactions with patients. Expressing something as overwhelming and complex as persistent pain within these limitations can be frustrating for both patients and clinicians. Patients struggle to articulate their overwhelming experiences, while clinicians find it challenging to explain the complexity of chronic pain.

The conversation delved into how clinicians are typically trained in acute pain management, leading to disappointment for both parties when “chronic pain isn’t fixed with a pill or a procedure.” Like clinicians, patients often have a clear understanding of acute pain, which is universally familiar and short-lived. However, this familiarity with acute pain can lead to mismatched expectations when it comes to chronic pain. This underscored the importance of informing patients about chronic pain to help them manage their expectations effectively. The perspective shared by the group was that they were cautious about being overly positive, recognising that not all patients can realistically expect complete relief from their pain. Specialist F acknowledged the challenge of crafting a “one size fits all” story. Other participants suggested that focusing stories on particular stages of pain management might be more beneficial than presenting a full chronological narrative. This aligned with the approach I had been taking thus far.

> *“Stories are difficult. Stories of success? Well, that’s going to disappoint somebody if they don’t go that way. Or stories of failure? So, it’s a very difficult one. It has to be more of a generic, as you say, validating, nonspecific direction without getting it focused.”*
> *– Doctor G*

The responses from the feedback sheet revealed an almost equal preference for the descriptors “supportive,” “informative,” “simple,” “realistic,” and “engaging” as qualities of an ideal chronic pain resource (Figure 46). Notably, no one chose the terms “positive,” “detailed,” or “personal,” which was consistent with the conversation surrounding communication. One respondent proposed an alternative of “hopeful” and “balanced.” The findings from this activity posed challenges in determining the resource’s direction, as there wasn’t a clear hierarchy in the responses. This reinforced the idea that communicating stories in healthcare requires a delicate balance, something I needed to be mindful of moving forward.

An interesting point was made in the feedback to be aware that “patients often feel overwhelmed or like they are “drowning” in their experience.” This raised a dilemma between choosing to accurately depict these experiences and potentially triggering unpleasant feelings in those who have lived through them. This led me to ponder how different individuals with chronic pain might perceive the same illustrations (Figure 46).

Overall, the key messages and stories the group wanted to convey to patients were that they were “not alone” and “that you can get back to things that are important to you.” They thought the last point in the booklet, to “be patient with yourself”, was a good endpoint. Intern Health Psychologist B had even suggested further “reinforcing letting go of struggling ‘against’ pain” and “acceptance.”

“Images that reinforce “drowning” may inadvertently confirm this experience.”
– Nurse A

Can I do it?

Overtime the challenges start to add up. It’s common to worry about the pain, questioning what’s causing it, whether it will improve, or if it might worsen.

What can I do?

There is no magic solution for persistent pain. It may feel like an uphill battle figuring out what works for you.

“Not sure about this one”
– Doctor C

Figure 46. Water Illustration Spreads

Making sure images align with the content

Although the illustrations were generally well-received, there were instances where some participants felt that they did not align well with the accompanying text, particularly in the “helpful thinking” and “relaxation” sections.

Registered Nurse A pointed out that in the “relaxation” illustration, they were uncertain whether the person depicted was “worrying or meditating.” Psychologist D echoed this observation and stated that “it would be good to suggest more peace.” The group proposed some alterations to the illustration, including using a more “fully relaxed,” “eyes closed” facial expression and eliminating distractions from the surroundings. A quick solution to this would be to swap the illustrations for “helpful thinking” and “relaxation,” as suggested by Psychologist D (Figure 47).

Content Recommendations

Comments were raised regarding the lack of clarity in the opening section. One participant questioned whether the resource adequately addressed the concept of chronic pain, stating, “So, it describes the journey, but is there anything that describes what chronic pain is?” Another participant suggested that a concise explanation consisting of 1-2 sentences would be adequate.

> *“There’s lots of different specialists, lots of different opinions, and things are very confusing for a lot of them, and they have no good explanation of why they have ongoing symptoms.” – Doctor C*

This feedback underscores the importance of conducting further research to develop a clear and simple explanation of chronic pain within the resource. Another valuable suggestion for improving the resource was to emphasise the importance of an individual’s support system.

> *“It’s also about having a team approach, e.g. PT (physical therapist)/GP (general practitioner)/family and pain service or other service in the wings.” – Registered Nurse A*

“I'm torn between whether they're worrying or mediating. They look a bit pensive.”
– Nurse A

Relaxation

Practicing a relaxation technique that suits you can be a really useful skill to add to your pain management plan.

“

I now am able to appreciate basic things in life. I feel satisfied by just doing that.

Swap Illustrations

“distractions”

Helpful Thinking

The thoughts and beliefs we have about pain have a very real impact on the body. Understanding our thinking is a very powerful pain management tool.

“

I accept my pain and acknowledge it. It's just part of me now and I have bad days when I struggle to function but I just take some paracetamol and think well, tomorrow is another day.

“We know that when people go to bed at night, that's often when they start the worrying.”
– Nurse A

Figure 47. Helpful Thinking & Relaxation Spreads

Holistic Viewpoint

An interesting perspective shared by Pain Specialist F was that their learning and understanding of Kaupapa Māori had shaped how they approached communication in their practice. Kaupapa Māori refers to a Māori research approach or principle that centres on Māori values and worldviews (Walker et al., n.d.). One framework for understanding Māori health is Te Whare Tapa Whā, which are the four cornerstones of health and wellbeing: physical, spiritual, family, and mental health (Ministry of Health NZ, 2023). From a traditional Māori perspective, whānau (family) and spiritual equilibrium are just as crucial as the physical aspects of health and illness (Ministry of Health NZ, 2023).

> *"So I think it's just basically a change in understanding of what we actually do for our patients and how important it is to treat them as whole human beings rather than a collection of mechanical bits that need to be dealt with." – Pain Specialist F*

Doctor C had a similar method of explaining pain that mirrors the Kaupapa Māori perspective on health. They discussed the concept of the "four horsemen of pain," those being physical health, relationships, peace and future:

> *"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 friendships, family, work. The third horseman is a horseman of peace. He robs you of your peace. People get anxious, depressed, pissed off, poor sleep. And the fourth horseman robs you of your future, because you can't plan tomorrow and affects your roles, your mana. Because we can't always get rid of pain. A lot of our approach to persistent pain is actually dealing with these areas." – Doctor C*

These perspectives resonated strongly with my project. While I had emphasised through my prototype emotional well-being as a significant aspect of the chronic pain experience, there was potential to expand on this and integrate elements of the Māori health model, especially considering the New Zealand context.

Based on the key findings of the focus group, I was able to make a list of recommendations moving forward:

- Plan content comprehensively before creating additional illustrations, ensuring that illustrations align closely with accompanying text.
- Include a concise description of chronic pain to improve the clarity of the opening section of the resource.
- Emphasise the importance of an individual's support system, such as healthcare professionals and family members.
- Maintain a balanced tone in communication that is hopeful but realistic, validating experiences without overly focusing on success or failure.
- Continue including stories connected to a particular stage of pain management rather than presenting full chronological narratives.
- Acknowledge that chronic pain affects more than just physical health. Spiritual, social, and mental well-being are just as significant.

Reflection

While the focus group occurred later in the development process than initially planned, it provided valuable insights that enabled adjustments to be made prior to finalising the resource. Conducting the focus group at this stage allowed for a more comprehensive discussion on potential improvements, as participants had a clearer understanding of the project's direction. The feedback received was affirming and aligned with the project's goals of presenting information through storytelling and providing empathetic support. Although I initially planned to redo illustrations in styles that had better reception, I received positive comments about most of the illustrations at some point during the discussion. Because of this, I decided not to remove any from the resource going forward and to retest their reception once again with individuals living with chronic pain. While user feedback is important, it was also essential to balance these insights with my own experience and expertise in design to create a resource that is both user-centred and creatively impactful.

Further prototyping

New Illustrations

In response to feedback from the focus group, I then focused on creating additional illustrations to expand the content of the resource (Figure 49). To diversify the page layouts, many of these new illustrations were “spot” illustrations. These are “small free-standing images” which are “vignette in nature” (Male, 2007, p. 188). The addition of these smaller illustrations also serves to accentuate the impact of the full-page visuals.

Defining the Visual Language

To avoid the illustrations being perceived as somewhat disconnected from the content (due to the text being on one half while illustrations were on the other with no connecting elements), I integrated some illustrative elements across the spreads. This adjustment helped create a more harmonious balance of text and image elements within the page (Figure 50). Additionally, I focused on creating consistency in visual elements throughout the resource, drawing inspiration from my exploration of shape language during the illustration stage. Incorporating these shapes as part of the visual language helped tie the different illustrations together.

Figure 48. Prototype developed for testing

Chapter header pages have illustrative water elements

Shapes flowing from illustration to text side

Can I do it?

Overtime the challenges start to add up. It’s common to worry about the pain, questioning what’s causing it, whether it will improve, or if it might worsen.

Relaxation

Practicing a relaxation technique that suits you can be a really useful skill to add to your pain management plan. Relaxation skills are very important for tense muscles in the body and for unwinding the mind.

“

I now am able to appreciate basic things in life. I feel satisfied by just doing that.

Seeking Support

Persistent pain doesn’t only affect the person with pain. Pain changes the way we interact with other people and often forces us to change the way we live our lives. In this way, it also impacts on our family, friends and colleagues. Being successful in pain self management means getting both help and support from others.

“

I’m now 51 and really wish I could have a pain free day but at least I have friends and family that are so supportive.

Figure 50. Illustrative elements across spreads

Support from healthcare professionals

What is Chronic Pain?

Pain is one of the body's important alarm systems, designed to protect us and warn us that we are under threat. Acute pain usually occurs in response to hurt or illness, for example a sprained ankle.

In "Chronic" or "Persistent" pain, the physical hurt or illness has often partially or fully resolved, and yet pain persists. In some cases, there is no clear initial injury or illness. This does not mean the pain is not real!

Simple description of chronic pain

Seeing Healthcare Professionals

It can be frustrating when multiple visits to healthcare professionals don't give clear answers. However, healthcare professionals play a vital role in your support network. Work closely with your healthcare team so they can help you find a pain management plan that is right for you.

Finding someone you trust is essential as you navigate how to manage your pain.

> I am very grateful to the help I have been given. Most of the people I have seen have always been kind and they do what they can.

Movement

Staying active is an important part of managing pain. Some people worry that exercise might worsen their pain. However, this is not true. Regular stretching and exercise decrease discomfort and strengthen weak muscles.

You can start by finding simple ways to move more and sit less throughout the day. Activities like golf, gardening, or playing with the grandchildren are great ways to stay physically active.

> Slow and steady wins the race and small steps are all it takes to begin to improve the quality of your life.

Smaller illustrations

Relaxation could be...

Meeting friends for a coffee...

Going on a walk..

or listening to some music...

"passive" and "active" options

social interactions

Examples of what relaxation could be

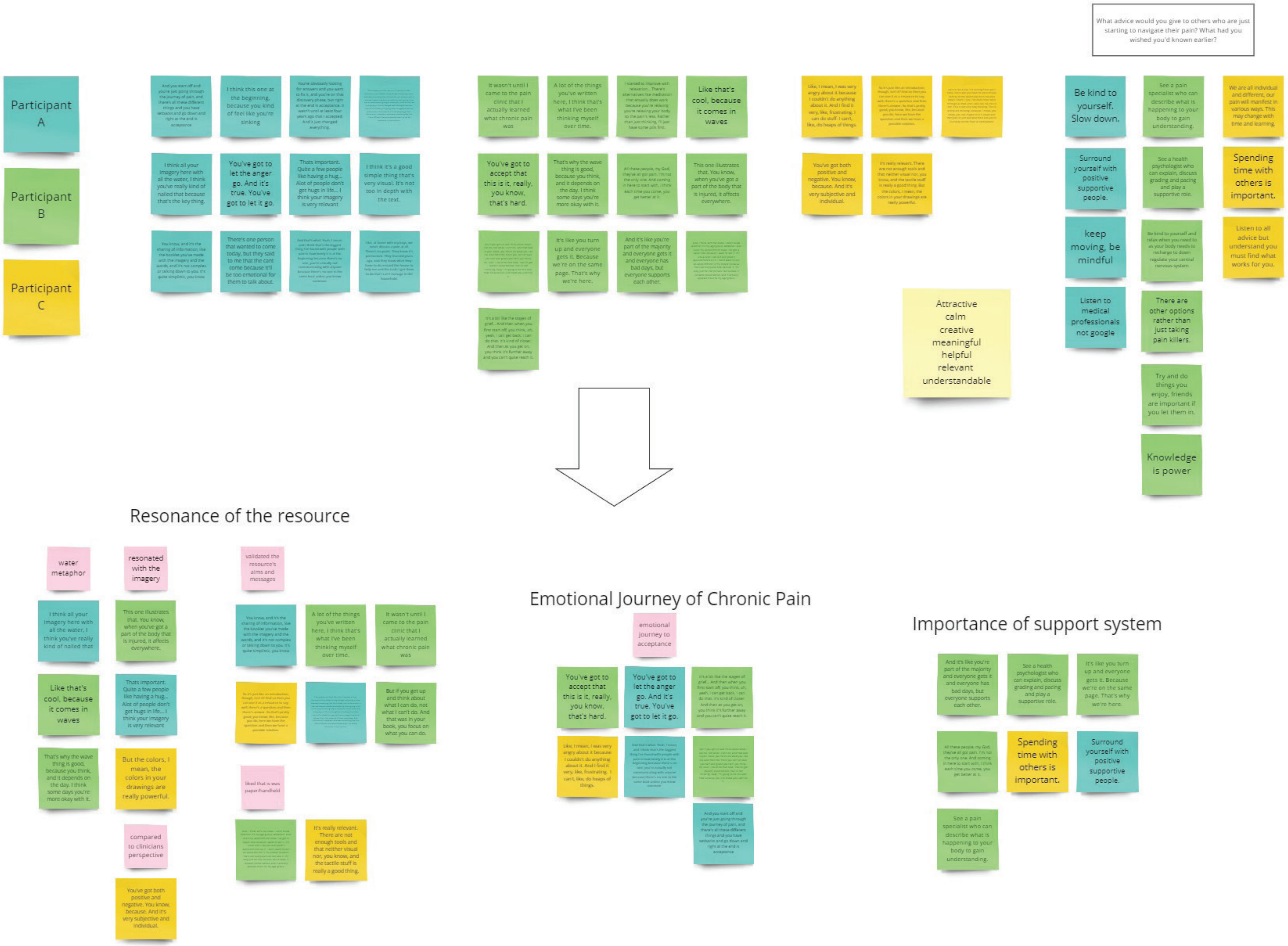
Figure 49. New Illustration Spreads

Colour

Initially, the illustrations were not restricted by a specific colour scheme, as each piece had deliberate colour choices. However, during the prototyping phase, I found that the combination of these illustrations in the form of the booklet resulted in a disjointed appearance. To create a more unified visual experience throughout the booklet, I opted to adhere to a more consistent colour scheme going forward.

TARPS clinicians were especially drawn to the calming atmosphere of the illustrations. In response, I decided to emphasize this aspect further. I adjusted the hues of previous illustrations to align with the new overall aesthetic, focusing mainly on shades of yellows, greens, and blues. These colours are often associated with warmth and peacefulness (Clarke & Costall, 2008), reflecting the tone I aimed to establish for this resource.

Figure 51. Colour Alterations



And you start off and you're just going through the journey of pain, and there's all these different things and you have setbacks and go down and right at the end is acceptance

I think this one at the beginning, because you kind of feel like you're sinking

You're obviously looking for answers and you want to fix it, and you're on that discovery phase, but right at the end is acceptance. It wasn't until at least four years ago that I accepted. And it just changed everything.

I think all your imagery here with all the water, I think you've really kind of nailed that because that's the key thing.

You've got to let the anger go. And it's true. You've got to let it go.

Thats important. Quite a few people like having a hug... Alot of people don't get hugs in life... I think your imagery is very relevant

I think it's a good simple thing that's very visual. It's not too in depth with the text.

You know, and it's the sharing of information, like the booklet you've made with the imagery and the words, and it's not complex or talking down to you. It's quite simplistic, you know

There's one person that wanted to come today, but they said to me that the cant come because it'll be too emotional for them to talk about.

It wasn't until I came to the pain clinic that I actually learned what chronic pain was

A lot of the things you've written here, I think that's what I've been thinking myself over time.

I started to improve with relaxation... There's alternatives like meditation that actually does work because you're relaxing you're relaxing your body so the pain's less. Rather than just thinking, I'll just have some pills first.

Like that's cool, because it comes in waves

You've got to accept that this is it, really, you know, that's hard.

That's why the wave thing is good, because you think, and it depends on the day. I think some days you're more okay with it.

All these people, my God, they've all got pain. I'm not the only one. And coming in here to start with, I think each time you come, you get better at it.

This one illustrates that. You know, when you've got a part of the body that is injured, it affects everywhere.

It's like you turn up and everyone gets it. Because we're on the same page. That's why we're here.

And it's like you're part of the majority and everyone gets it and everyone has bad days, but everyone supports each other.

It's a bit like the stages of grief... And then 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, you think it's further away and you can't quite reach it.

Like, I mean, I was very angry about it because I couldn't do anything about it. And I find it very, like, frustrating. I can do stuff. I can't, like, do heaps of things.

You've got both positive and negative. You know, because. And it's very subjective and individual.

It's really relevant. There are not enough tools and that neither visual nor, you know, and the tactile stuff is really a good thing. But the colors, I mean, the colors in your drawings are really powerful.

Attractive
calm
creative
meaningful
helpful
relevant
understandable

What advice would you give to others who are just starting to navigate their pain? What had you wished you'd known earlier?

Be kind to yourself. Slow down.

Surround yourself with positive supportive people.

keep moving, be mindful

Listen to medical professionals not google

See a pain specialist who can describe what is happening to your body to gain understanding.

See a health psychologist who can explain, discuss grading and pacing and play a supportive role.

Be kind to yourself and relax when you need to as your body needs to recharge to down regulate your central nervous system.

There are other options rather than just taking pain killers.

Try and do things you enjoy, friends are important if you let them in.

Knowledge is power

We are all individual and different, our pain will manifest in various ways. This may change with time and learning.

Spending time with others is important.

Listen to all advice but understand you must find what works for you.

Resonance of the resource

I think all your imagery here with all the water, I think you've really kind of nailed that

This one illustrates that. You know, when you've got a part of the body that is injured, it affects everywhere.

You know, and it's the sharing of information, like the booklet you've made with the imagery and the words, and it's not complex or talking down to you. It's quite simplistic, you know

A lot of the things you've written here, I think that's what I've been thinking myself over time.

It wasn't until I came to the pain clinic that I actually learned what chronic pain was

Like that's cool, because it comes in waves

Thats important. Quite a few people like having a hug... Alot of people don't get hugs in life... I think your imagery is very relevant

But if you get up and think about what I can do, not what I can't do. And that was in your book, you focus on what you can do.

That's why the wave thing is good, because you think, and it depends on the day. I think some days you're more okay with it.

But the colors, I mean, the colors in your drawings are really powerful.

It's really relevant. There are not enough tools and that neither visual nor, you know, and the tactile stuff is really a good thing.

You've got both positive and negative. You know, because. And it's very subjective and individual.

Emotional Journey of Chronic Pain

You've got to accept that this is it, really, you know, that's hard.

You've got to let the anger go. And it's true. You've got to let it go.

It's a bit like the stages of grief... And then 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, you think it's further away and you can't quite reach it.

Like, I mean, I was very angry about it because I couldn't do anything about it. And I find it very, like, frustrating. I can't, like, do heaps of things.

And you start off and you're just going through the journey of pain, and there's all these different things and you have setbacks and go down and right at the end is acceptance

Importance of support system

And it's like you're part of the majority and everyone gets it and everyone has bad days, but everyone supports each other.

See a health psychologist who can explain, discuss grading and pacing and play a supportive role.

It's like you turn up and everyone gets it. Because we're on the same page. That's why we're here.

All these people, my God, they've all got pain. I'm not the only one. And coming in here to start with, I think each time you come, you get better at it.

Spending time with others is important.

Surround yourself with positive supportive people.

See a pain specialist who can describe what is happening to your body to gain understanding.

Figure 52. Thematic analysis of prototype testing data

Prototype Testing

Prototype testing was conducted in the later stages of design development as the final phase of a human-centred design process. Its aim was to evaluate the design with target users (Harte et al., 2017). In healthcare design specifically, it is important to share prototypes with users to gather feedback (Naar et al., 2018). The aim of this session was to receive feedback on a later version of the resource and assess whether the illustrations resonated with the participants (See Appendix 8 for tentative discussion questions). Additionally, the illustrations in the prototype served as a way for the participants to discuss their lived experiences so that these could then inform the final design iteration. I also sought participants' advice for other individuals with chronic pain to include in the resource, as well as asking them to describe the resource from a list of adjectives (See Appendix 9 for prototype testing materials).

Prospective participants with chronic pain were approached via a walk-in relaxation session attended at TARPS, where the researcher introduced the research and shared the details of the research, as part of the informed consent process (see Appendix 3 for Consent Form). Three individuals with chronic pain subsequently signed up and took part in the prototype testing session.

Validation of the Resource

Overall, the feedback on the prototype was positive, with participants expressing that the images were relevant and resonated with them. Similar to the clinician focus group, participants with chronic pain recognised the resource's objectives and intended tone. When presented with a list of adjectives to describe the resource, all participants selected "calm," "creative," "meaningful," "helpful," and "understandable."

> *"The booklet you've made with the imagery and the words, and it's not complex or talking down to you. It's quite simplistic." – Participant A*

> *"But the colours, I mean, the colours in your drawings are really powerful." – Participant C*

Participant C highlighted that this resource would be a great "introduction" to chronic pain, referencing the concise content and structure:

> *"You can use it as a resource to say, well, there's a question and then there's answer. So that's pretty good... here we have the question and then we have a possible solution."*

Despite some clinicians in the focus group cautioning against using images depicting individuals "drowning," the imagery resonated with participants with chronic pain who acknowledged that it was part of their experience. Participant A saw themselves as "supported" by the water, as they drew a connection to aqua therapy. Participant B noted that pain also "comes in waves," echoing the intended meaning where the form of the waves reflects the mental state during different chronic pain phases.

> *"I think all your imagery here with all the water, I think you've really kind of nailed that." – Participant A*

> *"That's why the wave thing is good, and it depends on the day. I think some days you're more okay with it." – Participant B*

Some clinicians in the focus group expressed concern about depicting negative aspects of pain, recommending keeping a balanced tone that was hopeful yet grounded and acknowledging experiences without fixating on success or failure. However, participants living with pain seemed to interpret the illustrations differently, likely influenced by their own lived experience with chronic pain:

> *"You've got both positive and negative. You know, because. And it's very subjective and individual." – Participant C*

Based on such responses, it appeared that I had managed to achieve this balance through my illustrations.

In addition to the feedback on the illustrations, there were positive remarks regarding the resource being a printed booklet. Participants appreciated that the prototype resource was physical, paper-based and handheld rather than digital. Participant C expressed that the resource was "really relevant" as "there are not enough tools that are visual" or "tactile." The group agreed that a physical resource is more likely to prompt deeper thought. This aligns with the resource's goal to encourage engagement and reflection.

> *"Also, I think with the book... it initiates conversation, and it actually appeals more to my age group." – Participant B*
>
> *"Something like the booklet you've done which is tailored toward visuals is something that's going to be more receptive and going to make you think more than just going on Doctor Google and probably just going down a negative warren." – Participant A*

The Emotional Journey of Chronic Pain

As participants were looking at the illustrations, they started delving into their own personal experiences. They shared similar sentiments about how difficult the journey towards acceptance was. Participant B likened this journey to the "stages of grief," a concept that closely mirrors the structure of my resource, with each chapter representing different emotional phases of the chronic pain journey. Both this group and clinicians agreed that acceptance was a good point to end the resource on.

Participant C shared their past struggles with anger, and Participant A echoed the sentiment, expressing that "you've got to let the anger go." These remarks underscored the wide range of emotional experiences shared by individuals with chronic pain.

> *"And you start off and you're just going through the journey of pain, and there's all these different things, and you have setbacks... and right at the end is acceptance." – Participant A*

The conversation reaffirmed the insights from the narrative analysis I conducted on the chronic pain experience. While many of these topics were already touched upon in the resource, the discussion with participants with chronic pain further reinforced the emotional complexities surrounding pain and how important it is to acknowledge them. This conversation also highlighted how the sharing of stories can effectively spark conversation and encourage individuals to reflect on their own experiences.

The Importance of Shared Experiences

The group also shared what advice they would give to others starting to navigate pain, drawing from their years of experience in the TARPS service. They commonly mentioned that relaxation and meditation had significantly helped them - topics that were covered in my resource. While I had emphasised in the prototype resource the importance of support systems such as healthcare professionals, family, and friends, the participants also highlighted the value of connecting with others who experience chronic pain. Participant A talked about the loneliness experienced at the onset of pain. However, participants expressed feeling less isolated after connecting with others in similar situations, such as through the meditation sessions held at TARPS.

> *"That's important. That's something we do at the group. Quite a few people like having a hug..." – Participant A*
>
> *"It's like you turn up and everyone gets it. Because we're on the same page. That's why we're here." – Participant B*

The insights from the participants with chronic pain reaffirmed the significance of shared stories and experiences in fostering a sense of belonging that I uncovered through my contextual review.

> *"A lot of the things you've written here, I think that's what I've been thinking myself over time." – Participant B*

Consequently, incorporating participants' words of advice, in addition to the stories already in the resource, would enhance and further strengthen its capacity to provide support for readers.

Based on the key findings from the prototype testing session with participants with chronic pain, a list of recommendations for the final design iteration was compiled:

- Emphasise support not only from family, friends, and healthcare professionals, but also from others with chronic pain experiencing similar challenges.

- Continue addressing the emotional complexity surrounding chronic pain. Consider illustrating additional participant stories to acknowledge the wide range of emotional experiences.

- Prepare the booklet for printing to enhance usability, including features such as a cover design, table of contents, page numbers, and an introduction.

Reflection

While this session initially planned to use co-design methods, due to delays in the ethics approval process, this session ended up focusing on discussion and feedback. While a workshop with more participatory methods would have greatly benefited the early creation stage, receiving input towards the end of the creative process proved to be successful. It allowed for the presentation of a more comprehensive output, and it was clear that participants appreciated the direction I had taken.

Given the proximity of this session to the focus group with clinicians, there was insufficient time to implement all suggested changes before presenting this version of the prototype to patients. Nonetheless, the response was positive, and no major changes to the current content needed to be made. The final refinement stage occurred in the weeks following the submission of the exegesis. This involved adding a few new illustrations to reflect focus group and prototype testing feedback, as well as minor wording edits, ultimately preparing it for professional printing (Figure 55) (See Appendix 10 for final design outcome).

“I mean, I was very angry about it because I couldn't do anything about it. And I find it very frustrating.”

– Partcipant C

Figure 53. Sketch 1 based off participant stories

“It’s a bit like the stages of grief... And then 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, you think it’s further away and you can’t quite reach it.”

– Partcipant B

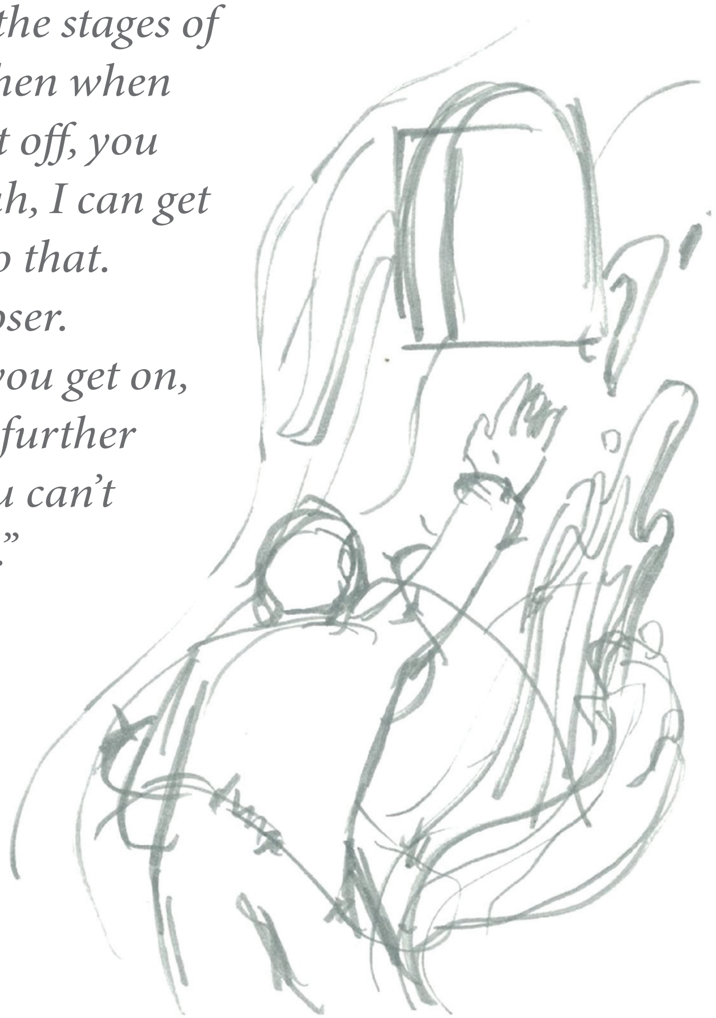


Figure 54. Sketch 2 based off participant stories

Figure 55. Resource cover concept using New Zealand scenery and water motif used throughout the resource. The illustration depicts characters looking towards the horizon, symbolising the start of a journey.

06. Discussion

The Final Design Outcome

This project aimed to explore the use of visual communication in creating a resource that might aid patient understanding and convey experiences of chronic pain. My primary objectives were to present information about chronic pain through illustrated stories and use these stories in the resource to promote engagement and reflection. The final design outcome is an illustrative visual resource for chronic pain, developed iteratively through an action research cycle. Additionally, the project embraced a narrative inquiry and human-centred design approach, placing a strong emphasis on empathetic design.

Visuals for user-centred health information

As established in the positioning of this research project, many healthcare professionals encounter challenges in educating patients about chronic pain (Kenny, 2004). Kenny (2004) explains that the difficulty stems from the complexity of chronic pain, as patients frequently hold the misconception that it is solely physical. Similarly, in this research, the clinician participants shared their observations that patients struggle with realising that there is no quick fix.
A participant with chronic pain succinctly expressed that "knowledge is power." This notion mirrors the findings of the contextual review that education and adopting self-management strategies allow individuals to regain a sense of control (Geneen et al., 2015; Joypaul et al., 2019). While informational resources are abundant online for chronic pain, one participant in this study noted how it's easy to get overwhelmed and spiral into negativity. Healthcare providers have expressed concerns over the trustworthiness of information online and the risk of patients easily misinterpreting information surrounding chronic pain (Devan et al., 2019). Furthermore, unfamiliar medical terminology makes health information difficult for patients to understand (Houts et al., 2006). Existing literature shows that visual communication is both engaging and effective in conveying complex health information to patients (Houts et al., 2006; Osborne, 2006; Stones et al., 2016). I aimed to use more emotive imagery, resulting in a more inviting presentation compared to typical health information design that can feel impersonal. Participants thought the resource was visually appealing and were attracted to the use of colour. The clinician participants particularly appreciated the simple presentation, as it facilitated better comprehension of the information provided. Overall, this suggests the potential for visuals to play an important role in the communication of health information, in ways that are more engaging and receptive that ultimately lead to better understanding.

A resource for reflection, support, and belonging

Through emotional connection, stories can shape perspectives and promote a holistic understanding of healthcare experiences (Greenhalgh & Hurwitz, 1999). Previous studies suggest that personal accounts in patient education can also help fulfil various needs, such as granting permission to feel similar emotions and offering information and advice to those lacking social support (Swift & Dieppe, 2005). The chronic pain participants in this research described their experience as lonely and isolating. Still, they found a sense of support in connecting with others who shared similar experiences. Patient perspectives can sometimes be undervalued in healthcare (Nakarada-Kordic et al., 2020), despite them being experts in their own conditions and lived experiences. Some of the reasons patients are motivated to participate in health research is to support others in similar situations and improve care for others (McCarron et al., 2019).
One participant from the prototype testing session expressed similar reasons, saying:

> *"That's why I came today. I think it's good to give back."*
> *– Participant A*

By incorporating quotes and brief snippets of stories throughout the resource, I wanted to give readers a similar sense of camaraderie, allowing them to connect with the content on a personal level.

The illustrated visuals I created appeared to be impactful and reflective of participants' experiences with chronic pain. Although not every individual may relate to every experience depicted, illustration is inherently subjective. This was evident from a variety of interpretations from clinician and chronic pain participants in this research, with some participants deriving meanings that differed from my original intent. This made me realise that the precise portrayal of their experiences in the imagery is not crucial, as people view illustrations through the lens of their own experiences. Conceptual illustration can depict many ideas through different ways of communication, such as visual metaphors and expressionism (Male, 2007). Its value lies in its ability to prompt deeper interpretation (Male, 2007). Ultimately, the illustrations I created were able to spark conversation about personal experiences, fulfilling the aim of promoting self-reflection.

Visuals serve not only to convey information but also, as Stones (2013) suggests, to evoke positive emotions and engage viewers on an emotional level. This insight suggests an opportunity for designers to play a crucial role in aligning visuals with the messages communicated in chronic pain resources. The prototype resource aligned with messages the clinicians at TARPS aimed to communicate, which were about working towards acceptance and encouraging individuals to take proactive steps towards management. The final designed resource maintained this messaging, placing a strong emphasis on promoting well-being despite the challenges of living with chronic pain.

Navigating the Healthcare Space as a Designer

As an inexperienced design researcher, I faced numerous unforeseen challenges, mainly underestimating the time required for ethical approval and navigating healthcare systems. The locality approval to conduct research with TARPS was contingent on getting university ethics approval; both were lengthy processes that impacted my project timeline. The locality approval required multiple layers of approval, each of which took considerable time to secure due to slow communication. Given the demanding nature of healthcare services such as TARPS, it was understandable that my research was not prioritised highly. These challenges are not uncommon for designers working in the healthcare field, where communication and ethics processes can be complex and time-consuming (Groeneveld et al., 2018).

However, I adapted and learned from these obstacles, adjusting my plans to accommodate evolving circumstances. The delays in data collection led to alterations in the plans. Consequently, participants had a more significant influence in the later stages of my research rather than the initial exploration phase that I had originally planned for. Designing in the realm of health often involves navigating unfamiliar territory, as many designers are driven by a desire to make change despite the steep learning curve (Nakarada-Kordic et al., 2020). Early in the design process especially, I had to make decisions without user input about subject matter I had no firsthand experience in. However, participant collaboration was invaluable in addressing any uncertainties I had.

Establishing connections with TARPS allowed for collaboration opportunities with both clinicians and patients, contributing to the success of this research. Clinician participants were open to embracing design, showing a positive response to my prototyped resource which offered an alternative approach to the majority of existing chronic pain resources. This experience mirrored that of previous researchers who found that the involvement of healthcare providers in design for health projects is crucial to drive meaningful progress (Nakarada-Kordic et al., 2017). Without a shared desire to explore new approaches or to make impactful change, designers would struggle to reach their target users.

At the core of design for health is being able to empathise with both those using and providing services, to offer solutions that consider multiple perspectives (Nakarada-Kordic et al., 2020). In undertaking this research, it became clear to me that designers can play a pivotal role in driving positive change through collaboration with healthcare providers and patients.

The value of design for health

Measuring the benefits and impact of design is challenging, particularly when it is aimed to evoke positive emotions. “Positive design” contributes to the subjective well-being of individuals (Desmet & Pohlmeyer, 2013), designing with a holistic view of health rather than just an “absence of disease” (Nakarada-Kordic et al., 2020, p. 214). Communicating the value of design within healthcare can be difficult, especially if there aren’t tangible results (Groeneveld et al., 2018). While my design outcome aimed to support communication and facilitate understanding, the success of other aims, such as promoting self-reflection, is harder to assess but still provides value to the patient experience. While this research was patient-centred, a resource that focuses on patient narratives might be able to support clinician education in building empathy and viewing patient experiences holistically (Powell et al., 2013).

Currently, the healthcare system views design as “nice-to-have” but not necessarily of high priority (Nakarada-Kordic et al., 2020, p. 219). Implementation of design solutions in healthcare is often hindered by factors such as cost, existing processes and resistance to change within the healthcare system (Groeneveld et al., 2018; West, 2020). While these factors are beyond my control, it was gratifying that both participants with chronic pain and clinician participants validated and saw potential in the prototype resource I presented to them.

It is important to recognise that design projects aren’t always done with the intention of replacing current practices but can serve to demonstrate what is possible (West, 2020). While this research does not propose a definitive design solution to an existing problem, it highlights the value of design to the well-being and positive experience of users. The findings in this research around the use of visuals and stories in resources are just a small step in harnessing the potential of design in healthcare. Despite its seemingly intangible benefits, design has real value in supporting the healing journey for patients as well as patient-clinician communication (Chamberlain & Craig, 2017; Houts et al., 2006; Osborne, 2006). Through using compelling visuals to tell stories of subjective experiences, design can help build empathy and understanding from a patient’s point of view; this in turn has the potential to positively influence the quality of care provided to patients.

Limitations & Further Research Opportunities

Data Collection

To illustrate stories of chronic pain, I primarily relied on secondary research materials rather than firsthand data collection. Initially, I had planned to engage chronic pain participants in a co-design process. While in-depth interviews are typical for narrative inquiry research, I hypothesised that conducting one-on-one interviews might be intimidating and reminiscent of a medical appointment for participants. People living with chronic pain frequently have to recount their stories to healthcare professionals multiple times, so I opted against this approach. Another reason for relying on secondary data for initial prototyping was the research approval process delays. As a result, when the session with participants with chronic pain occurred, it centred around “prototype testing.” Participants discussed the resource and offered feedback, rather than engaging more meaningfully in the content design and creative process. If this session had been conducted earlier in the research process, the stories shared might have been able to influence the initial creation stage of the resource. In future research, it would be ideal to involve individuals with chronic pain throughout the design process, allowing them to have more input in decision-making.

Diverse Participation

While the study was aimed towards the general population with chronic pain, the fact remains that Māori and Pasifika experiencing pain have greater unmet needs (Lewis et al., 2021). Additionally, while over 50% of the New Zealand population has poor health literacy, among Māori, health literacy is particularly low (Priston & Searle, 2010).

Recruiting participants through TARPS for this research was challenging, as clients had to be approached independently of TARPS. Introducing the study in the relaxation session held at TARPS – a one-off opportunity - was agreed by the service to be the least intrusive way to recruit individuals with chronic pain. However, due to this being a voluntary walk-in session, there was no way of knowing who would be present on the day. Consequently, given that Māori and Pasifika communities are already underrepresented in pain services (Lewis et al., 2021), it was likely that they would have been underrepresented in this research as well.

Given New Zealand’s unique cultural context, a resource tailored specifically to New Zealand would be ideal. However, it would have been inappropriate to incorporate Te Reo Māori without proper consultation, especially considering the timeframe constraints of a master’s project. While this aspect fell outside the scope of my research, it presents an area worthy of further exploration should the study be continued. Ultimately, future research should involve a larger and more ethnically diverse group of participants to evaluate visual communication’s effectiveness in the resource thoroughly.

Conclusion

This research project sought to explore the value of visual communication in creating resources that enhance understanding and convey experiences of chronic pain. Findings revealed that designers can play an important role in conveying complex health information. Visuals and narratives could potentially serve as a way to connect emotionally with people, fostering more compassionate practices. The importance of design in healthcare goes beyond offering solutions; it involves empathy and the humanisation of healthcare experiences. Although measuring the impact of visual design can be challenging, its significance cannot be ignored.

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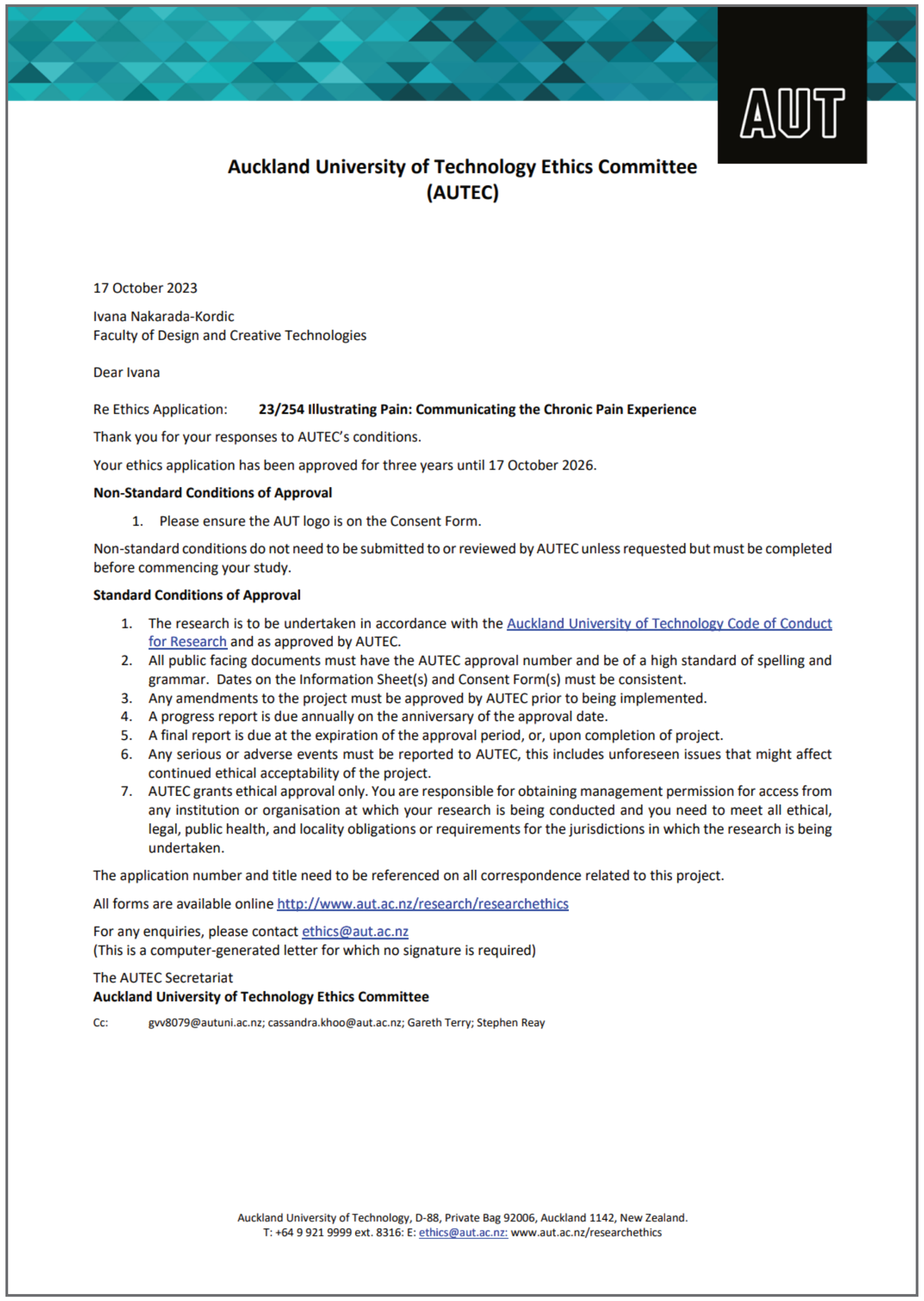
08. Appendices

Appendix 1 – Ethics Approval



AUT

Auckland University of Technology Ethics Committee
(AUTEC)

17 October 2023

Ivana Nakarada-Kordic
Faculty of Design and Creative Technologies

Dear Ivana

Re Ethics Application: **23/254 Illustrating Pain: Communicating the Chronic Pain Experience**

Thank you for your responses to AUTEC's conditions.

Your ethics application has been approved for three years until 17 October 2026.

Non-Standard Conditions of Approval

1. Please ensure the AUT logo is on the Consent Form.

Non-standard conditions do not need to be submitted to or reviewed by AUTEC unless requested but must be completed before commencing your study.

Standard Conditions of Approval

1. The research is to be undertaken in accordance with the Auckland University of Technology Code of Conduct for Research and as approved by AUTEC.
2. All public facing documents must have the AUTEC approval number and be of a high standard of spelling and grammar. Dates on the Information Sheet(s) and Consent Form(s) must be consistent.
3. Any amendments to the project must be approved by AUTEC prior to being implemented.
4. A progress report is due annually on the anniversary of the approval date.
5. A final report is due at the expiration of the approval period, or, upon completion of project.
6. Any serious or adverse events must be reported to AUTEC, this includes unforeseen issues that might affect continued ethical acceptability of the project.
7. AUTEC grants ethical approval only. You are responsible for obtaining management permission for access from any institution or organisation at which your research is being conducted and you need to meet all ethical, legal, public health, and locality obligations or requirements for the jurisdictions in which the research is being undertaken.

The application number and title need to be referenced on all correspondence related to this project.

All forms are available online http://www.aut.ac.nz/research/researchethics

For any enquiries, please contact ethics@aut.ac.nz
(This is a computer-generated letter for which no signature is required)

The AUTEC Secretariat
Auckland University of Technology Ethics Committee

Cc: gvv8079@autuni.ac.nz; cassandra.khoo@aut.ac.nz; Gareth Terry; Stephen Reay

Auckland University of Technology, D-88, Private Bag 92006, Auckland 1142, New Zealand.
T: +64 9 921 9999 ext. 8316: E: ethics@aut.ac.nz: www.aut.ac.nz/researchethics

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Te Whatu Ora
Health New Zealand
Waitematā

Te Whatu Ora
Health New Zealand
Te Toka Tumai Auckland

05 November 2023

Stephen Reay
Auckland City Hospital
Te Whatu Ora Te Toka Tumai
Auckland

Title: Living with Pain: A co-design research project with clinicians and chronic pain patients to improve the communication of this complex lived experience.

The study is a student's Masters Thesis. The student's are creating an informational resource featuring illustrations of chronic pain stories in the hope that it will help people who have chronic pain.

While the study does not seek to improve health gains for Māori the investigators reflect their understanding of tikanga Māori and intend to approach the study in an inclusive way.

I think the participant and co-design pamphlets/brochures are great although they lack data sovereignty responses and cultural contact details.

There are opportunities to incorporate Māori beliefs and values into the study and it is an opportunity missed to grow safe practitioners and therefore improve health services to Māori, by not ensuring the study addresses these beliefs and values.

As this is part of the student's academic requirements I am allowing a certain amount of leeway and saying the study does not require Māori approval, rather than ask for a re-submit.

Hei konā mai

Helen

HA Wihongi

Dr Helen Wihongi (ia)
Ngāti Porou, Te Whānau a Āpanui, Ngāpuhi
National GM Māori Research
Te Whatu Ora and Te Aka Whai Ora
waea pūkoro: +64 9 486 8920 ext. 43204 | **īmēra:** helen.wihongi@waitematadhb.govt.nz
Waitakere Hospital, Health West Building, Rm G 46 | Private Bag 93-115, Henderson, Auckland 0650

Te Whatu Ora
Health New Zealand

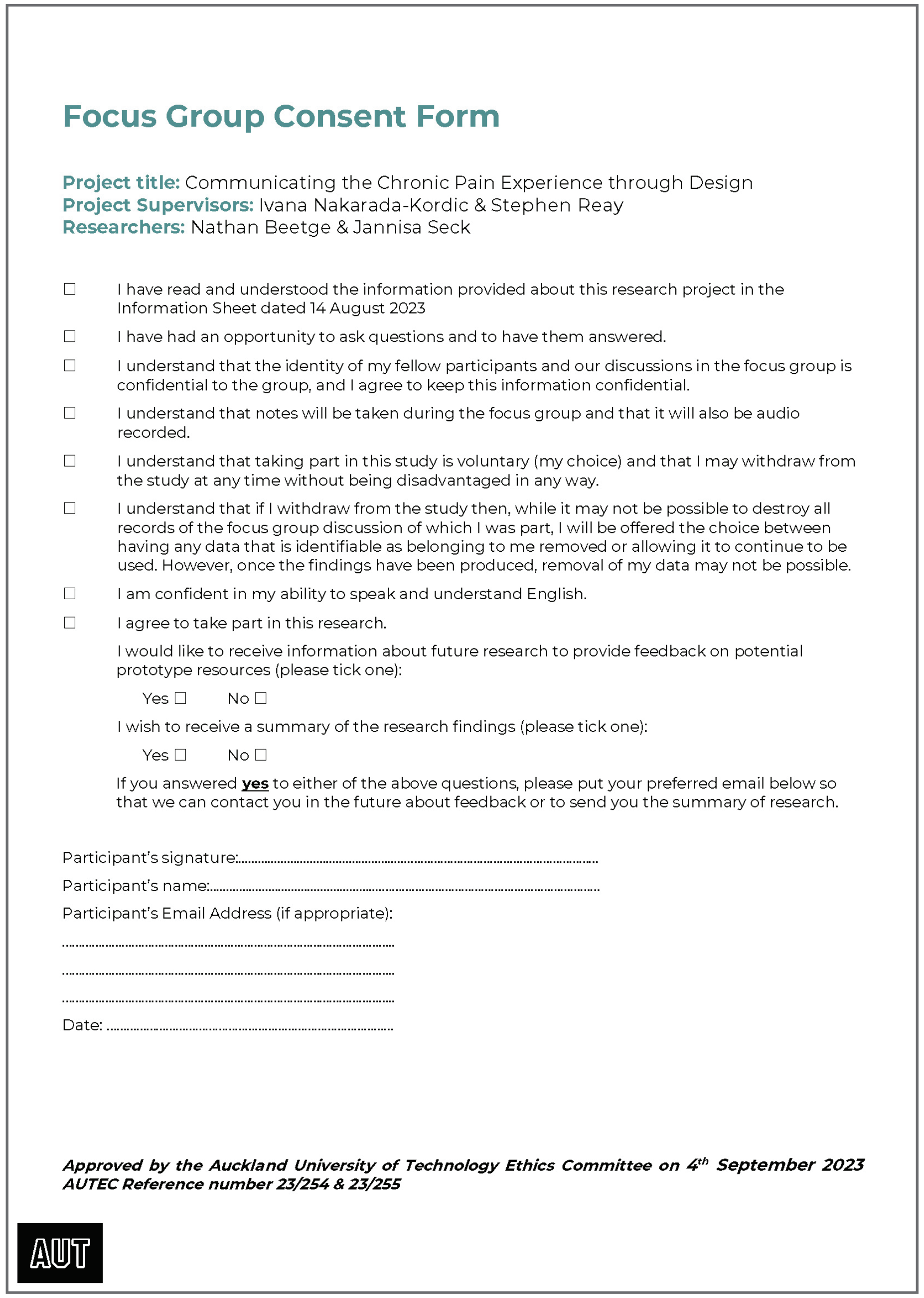
Te Aka Whai Ora
Māori Health Authority

Te Whatu Ora – Health New Zealand
TeWhatuOra.govt.nz

Te Aka Whai Ora – Māori Health Authority
TeAkaWhaiOra.nz

Te Kāwanatanga o Aotearoa
New Zealand Government

Appendix 2 – Focus Group Consent Form



Focus Group Consent Form

Project title: Communicating the Chronic Pain Experience through Design
Project Supervisors: Ivana Nakarada-Kordic & Stephen Reay
Researchers: Nathan Beetge & Jannisa Seck

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 14 August 2023
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that the identity of my fellow participants and our discussions in the focus group is confidential to the group, and I agree to keep this information confidential.
- ☐ I understand that notes will be taken during the focus group and that it will also be audio recorded.
- ☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ☐ I understand that if I withdraw from the study then, while it may not be possible to destroy all records of the focus group discussion of which I was part, I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ☐ I am confident in my ability to speak and understand English.
- ☐ I agree to take part in this research.

I would like to receive information about future research to provide feedback on potential prototype resources (please tick one):

Yes ☐ No ☐

I wish to receive a summary of the research findings (please tick one):

Yes ☐ No ☐

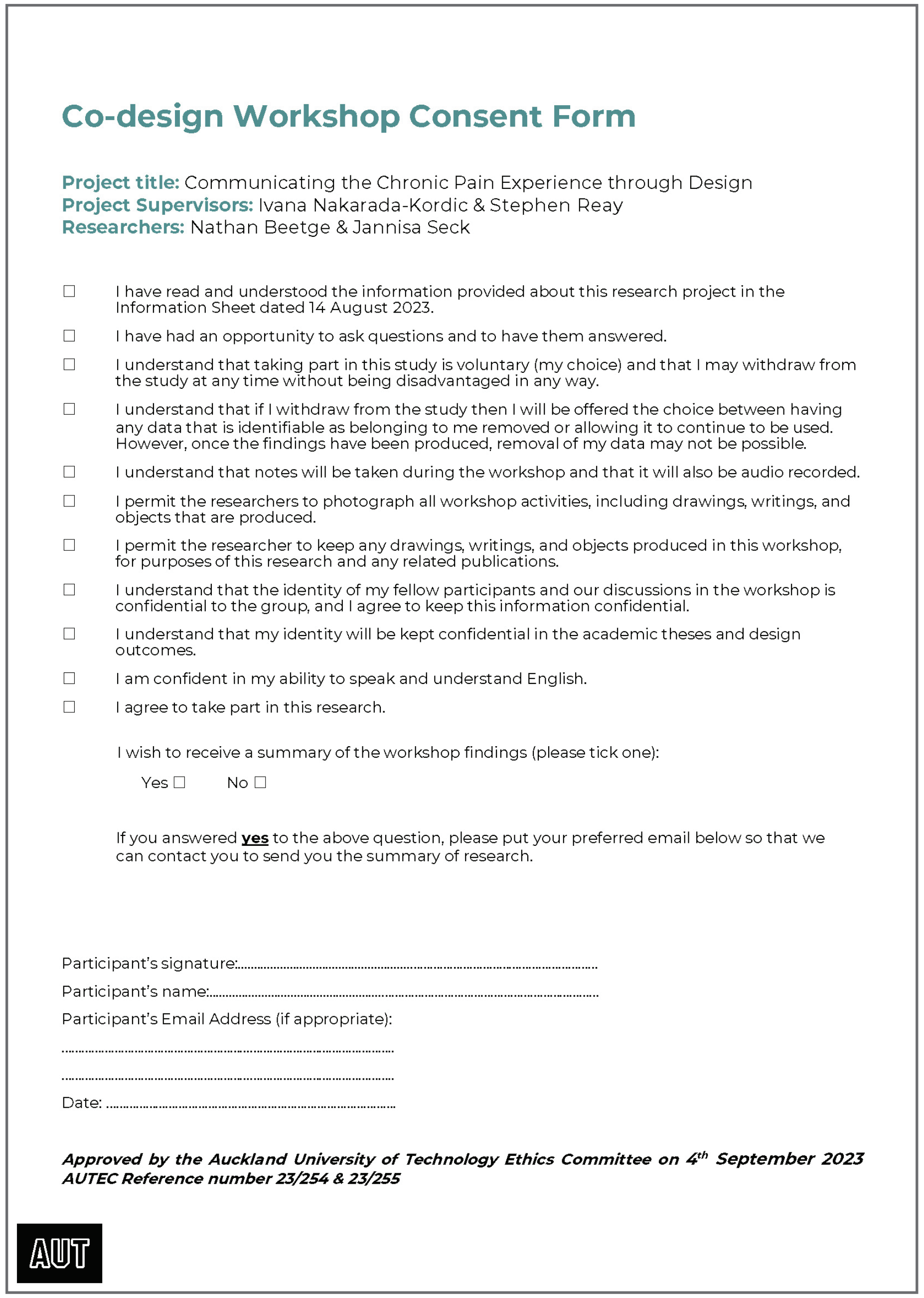
If you answered **yes** to either of the above questions, please put your preferred email below so that we can contact you in the future about feedback or to send you the summary of research.

Participant's signature:……………………………………………………………
Participant's name:……………………………………………………………
Participant's Email Address (if appropriate):
……………………………………………………………
……………………………………………………………
……………………………………………………………
Date: ……………………………………………………………

Approved by the Auckland University of Technology Ethics Committee on 4th September 2023
AUTEC Reference number 23/254 & 23/255

AUT

Appendix 3 – Prototype Testing Consent Form



Co-design Workshop Consent Form

Project title: Communicating the Chronic Pain Experience through Design
Project Supervisors: Ivana Nakarada-Kordic & Stephen Reay
Researchers: Nathan Beetge & Jannisa Seck

- ☐ I have read and understood the information provided about this research project in the Information Sheet dated 14 August 2023.
- ☐ I have had an opportunity to ask questions and to have them answered.
- ☐ I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without being disadvantaged in any way.
- ☐ I understand that if I withdraw from the study then I will be offered the choice between having any data that is identifiable as belonging to me removed or allowing it to continue to be used. However, once the findings have been produced, removal of my data may not be possible.
- ☐ I understand that notes will be taken during the workshop and that it will also be audio recorded.
- ☐ I permit the researchers to photograph all workshop activities, including drawings, writings, and objects that are produced.
- ☐ I permit the researcher to keep any drawings, writings, and objects produced in this workshop, for purposes of this research and any related publications.
- ☐ I understand that the identity of my fellow participants and our discussions in the workshop is confidential to the group, and I agree to keep this information confidential.
- ☐ I understand that my identity will be kept confidential in the academic theses and design outcomes.
- ☐ I am confident in my ability to speak and understand English.
- ☐ I agree to take part in this research.

I wish to receive a summary of the workshop findings (please tick one):

Yes ☐ No ☐

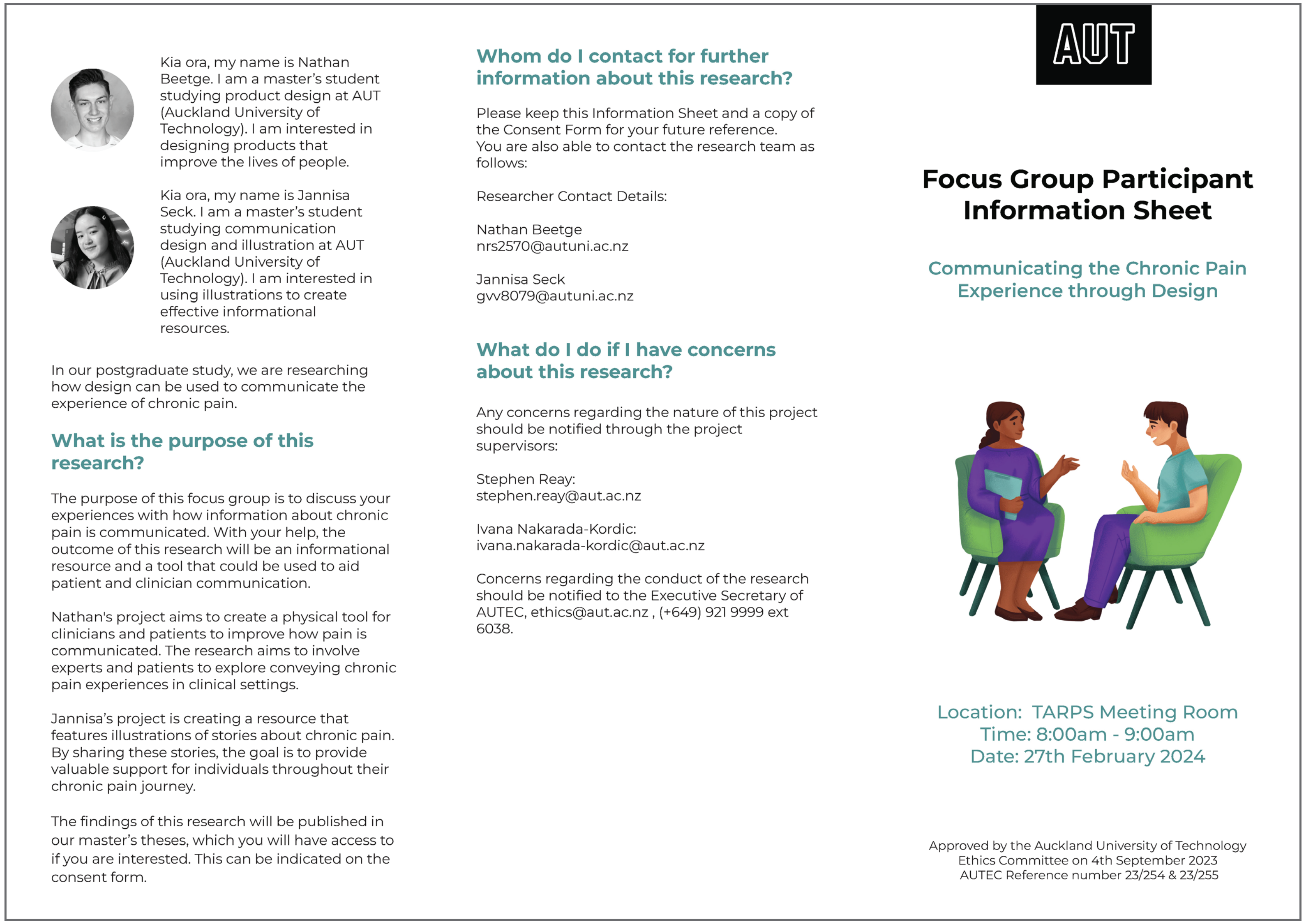
If you answered **yes** to the above question, please put your preferred email below so that we can contact you to send you the summary of research.

Participant's signature:……………………………………………………………
Participant's name:……………………………………………………………
Participant's Email Address (if appropriate):
……………………………………………………………
……………………………………………………………
Date: ……………………………………………………………

Approved by the Auckland University of Technology Ethics Committee on 4th September 2023
AUTEC Reference number 23/254 & 23/255

AUT

Appendix 4 - Focus Group Participant Information Sheet



Kia ora, my name is Nathan Beetge. I am a master's student studying product design at AUT (Auckland University of Technology). I am interested in designing products that improve the lives of people.

Kia ora, my name is Jannisa Seck. I am a master's student studying communication design and illustration at AUT (Auckland University of Technology). I am interested in using illustrations to create effective informational resources.

In our postgraduate study, we are researching how design can be used to communicate the experience of chronic pain.

What is the purpose of this research?

The purpose of this focus group is to discuss your experiences with how information about chronic pain is communicated. With your help, the outcome of this research will be an informational resource and a tool that could be used to aid patient and clinician communication.

Nathan's project aims to create a physical tool for clinicians and patients to improve how pain is communicated. The research aims to involve experts and patients to explore conveying chronic pain experiences in clinical settings.

Jannisa's project is creating a resource that features illustrations of stories about chronic pain. By sharing these stories, the goal is to provide valuable support for individuals throughout their chronic pain journey.

The findings of this research will be published in our master's theses, which you will have access to if you are interested. This can be indicated on the consent form.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference. You are also able to contact the research team as follows:

Researcher Contact Details:

Nathan Beetge
nrs2570@autuni.ac.nz

Jannisa Seck
gvv8079@autuni.ac.nz

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified through the project supervisors:

Stephen Reay:
stephen.reay@aut.ac.nz

Ivana Nakarada-Kordic:
ivana.nakarada-kordic@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, ethics@aut.ac.nz , (+649) 921 9999 ext 6038.

AUT

Focus Group Participant Information Sheet

Communicating the Chronic Pain Experience through Design

Location: TARPS Meeting Room
Time: 8:00am - 9:00am
Date: 27th February 2024

Approved by the Auckland University of Technology Ethics Committee on 4th September 2023
AUTEC Reference number 23/254 & 23/255

How was I identified and why am I being invited to participate in this research?

You have been invitted to participate as a member of the TARPS service at Greenlane Clinical Centre and as a clinician working in the field of chronic pain.

What will happen in this research?

The session will last for approximately 1 hour. A discussion will be held by the student researchers where you will be asked questions about resources and communicating chronic pain experiences. Please note that this focus group will be audio recorded and handwritten notes will also be taken.

How will my privacy be protected?

Throughout the focus group, you will not be anonymous to others participating - including the researchers. This means people will know your name and what you say during the focus group. It is expected that you and the other focus group participants will respect and maintain each other's privacy.

Given that TARPS will be named in research outputs, we are able to provide limited confidentiality. For our master's theses, all names will be changed – with your permission to protect your privacy. Audio recordings and consent forms will be securely stored for a period of six years after which they will be destroyed.

What are the discomforts and risks?

We don't expect much discomfort and risk during this focus group. However, you could feel discomfort in the length of the session and sharing your opinions within a group setting.

How will these discomforts and risks be alleviated?

We hope to create a supportive, comfortable experience within the focus group for you to share your thoughts and ideas. To do this, the researchers are happy to answer your questions and concerns at any time before or during the focus group. You can also leave the focus group at any time, no questions asked.

What are the benefits?

We, the researchers, will benefit from this research as it will help us complete our qualifications. We also gain experience as researchers by running a focus group. We hope you will benefit from this research, as your expertise and insights could potentially lead to the improvement of chronic pain resources in clinical settings. By participating, you will have the opportunity to contribute to design research that aims to improve the communication of chronic pain information and experiences.

How do I agree to participate in this research?

If you would like to participate, we will ask you to sign a consent form before the start of the focus group. Your participation in this research is voluntary (it is your choice), and whether or not you choose to participate will neither advantage nor disadvantage you.

You can withdraw from the study at any time. Suppose you decide to withdraw from the study. In that case, you will be offered the choice between having any data identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What are the costs of participating in this research?

There is no cost to you participating in this research other than around 1 hour of your time. Participation will include a contribution towards the cost of transport and parking.

Will I receive feedback on the results of this research?

You can indicate on the consent form if you would like to receive a summary of the research findings.

Appendix 5 - Prototype Testing Information Sheet

Kia ora, my name is Nathan Beetge. I am a master's student studying product design at AUT (Auckland University of Technology). I am interested in designing products that improve the lives of people.

Kia ora, my name is Jannisa Seck. I am a master's student studying communication design and illustration at AUT (Auckland University of Technology). I am interested in using illustrations to create effective informational resources.

In our postgraduate study, we are researching how design can be used to communicate the experience of chronic pain.

What is the purpose of this research?

The purpose of this co-design workshop is to discuss your experiences with how information about chronic pain is communicated. With your help, the outcome of this research will be an informational resource and a tool that could be used to aid patient and clinician communication.

Nathan's project aims to create a physical tool for clinicians and patients to improve how pain is communicated. The research aims to involve experts and patients to explore conveying chronic pain experiences in clinical settings.

Jannisa's project is creating a resource that features illustrations of stories about chronic pain. By sharing these stories, the goal is to provide valuable support for individuals throughout their chronic pain journey.

The findings of this research will be published in our master's theses, which you will have access to if you are interested. This can be indicated on the consent form.

Whom do I contact for further information about this research?

Please keep this Information Sheet and a copy of the Consent Form for your future reference.
You are also able to contact the research team as follows:

Researcher Contact Details:

Nathan Beetge: nrs2570@autuni.ac.nz
Jannisa Seck: gvv8079@autuni.ac.nz

How will my privacy be protected?

Throughout the workshop, you will not be anonymous to others participating - including the researchers. This means people will know your name and what you say during the workshop. It is expected that you and the other workshop participants will respect and maintain each other's privacy.

We will maintain your confidentiality by removing all directly identifiable information in research outputs. For our master's theses, all names will be changed – with your permission to protect your privacy. Audio recordings and consent forms will be securely stored for a period of six years after which they will be destroyed.

What do I do if I have concerns about this research?

Any concerns regarding the nature of this project should be notified through the project supervisors:

Stephen Reay:
stephen.reay@aut.ac.nz

Ivana Nakarada-Kordic:
ivana.nakarada-kordic@aut.ac.nz

Concerns regarding the conduct of the research should be notified to the Executive Secretary of AUTEC, ethics@aut.ac.nz , (+649) 921 9999 ext 6038.

AUT

Co-design Workshop Participant Information Sheet

Communicating the Chronic Pain Experience through Design

Approved by the Auckland University of Technology
Ethics Committee on 4th September 2023
AUTEC Reference number 23/254 & 23/255

How was I identified and why am I being invited to participate in this research?

You have been invited to participate as a client of the TARPS service or have been invited through attending a relaxation session at TARPS.

How do I agree to participate in this research?

If you would like to participate, please get in touch with us through email to receive a consent form. Your participation in this research is voluntary (it is your choice), and whether or not you choose to participate will neither advantage nor disadvantage you.

You can withdraw from the study at any time. Suppose you decide to withdraw from the study. In that case, you will be offered the choice between having any data identifiable as belonging to you removed or allowing it to continue to be used. However, once the findings have been produced, removal of your data may not be possible.

What will happen in this research?

The session will last for ap hproximately 130 minutes, including a 15-minute break, and will consist of an interactive workshop divided into two parts. During this workshop, we invite you to, should you wish, share your experiences with chronic pain. You will be able to express your thoughts, feelings, opinions, and needs regarding this topic through discussion and creative methods.

Part 1:
For the first part of the workshop, you will be working with Jannisa Seck to give input on a prototype resource featuring illustrated stories from individuals with chronic pain. These illustrations will be used as prompts for discussion about your own experience and stories.

Part 2:
For the second part of the workshop, you will work with Nathan Beetge to explore ways you communicate the experiences of chronic pain. Firstly, you will be invited to create a physical representation of your pain and how your clinician views it. Then, you will assess and give feedback on a prototype tool kit and objects.

Please note that this workshop session will be audio recorded so we can work closely with you and give our full attention to what you have to say. With your permission, artefacts produced as part of these workshops will be collected and photographed for documentation as part of research.

What are the discomforts and risks?

We don't expect much discomfort and risk during this workshop. However, you could feel discomfort in the length of the session and sharing personal stories and experiences.

How will these discomforts and risks be alleviated?

We hope to create a supportive, comfortable experience within the workshop for you to share your thoughts and experiences. If you are uncomfortable with any prompt/question ask, you can choose not to answer.

The researchers are happy to answer your questions and concerns at any time before or during the workshop. You will be able to take breaks, pause, or stop participation in research activities if any physical discomfort is felt. You can also leave the workshop at any time, no questions asked.

AUT Student Counselling and Mental Health is able to offer three free sessions of confidential counselling support for adult participants in an AUT research project. These sessions are only available for issues that have arisen directly as a result of participation in the research and are not for other general counselling needs. To access these services, you will need to:

- Drop into our centre at WB203 City Campus, email counselling@aut.ac.nz or call 921 9292.
- Let the receptionist know that you are a research participant, and provide the title of my research and my name and contact details as given in this Information Sheet.

You can find out more information about AUT counsellors and counselling on https://www.aut.ac.nz/student-life/student-health-and-wellbeing/counselling-and-mental-health-support

What are the benefits?

We, the researchers, will benefit from this research as it will help us complete our qualifications. We also gain experience as researchers by running this workshop. Taking part in this research gives you the opportunity to share your experiences and support with others with similar experiences. With your contributions, we hope that this research could lead to the development of creative resources for individuals with chronic pain.

What are the costs of participating in this research?

There is no cost to you participating in this research other than 130 minutes of your time. Participation will include a contribution towards the cost of transport and parking.

Will I receive feedback on the results of this research?

You can indicate on the consent form if you would like to receive a summary of the research findings.

Appendix 6 - Focus Group Runsheet & Discussion Questions

10 mins – Introduction and Welcome

Welcome participants and give information about the research. Ask if they have any questions.

Participants will fill out a demographic form and consent form.

15 mins – Introduce Research Aims + Activity

Show prototype sample. Give feedback sheet.

- How do you think patients would respond to a resource like this?
- Do you have any improvements or suggestions for me going forward?

Leading into questions

20 mins – Chronic Pain Resources

Questions w/ follow ups:

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 excites you?
- Where do you think there could be improvements in the informational resources you currently give to patients?
- How important is patient education in improving outcomes? In what ways can it support patients during their health journeys?

10 mins – Patient 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?
- What things do patients like to see, read or hear when talking about their pain?
- Why is that story important or meaningful?

10 mins – Communicating Chronic Pain

What about these illustrations best represent pain/experience? what pain/experience could be represented?

- How could you use these to explain broadly what the experience is like for them?

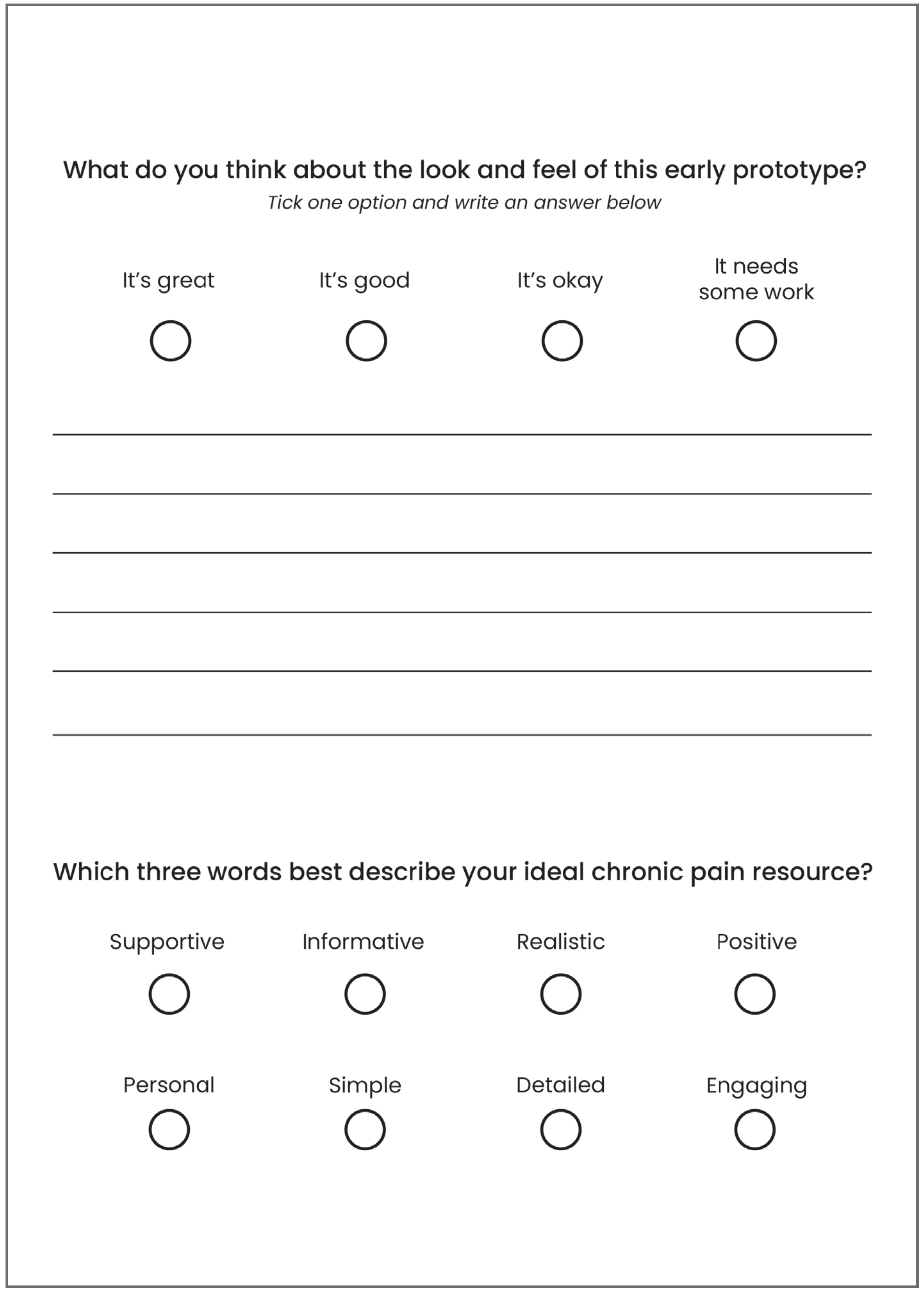
What are some of the challenges you experience when communicating with your patients?

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

5 mins – Debrief

Any further comments or questions?
Give koha

Appendix 7 - Focus Group Feedback Sheet



What do you think about the look and feel of this early prototype?

Tick one option and write an answer below

It's great	It's good	It's okay	It needs some work
○	○	○	○

Which three words best describe your ideal chronic pain resource?

Supportive	Informative	Realistic	Positive
○	○	○	○
Personal	Simple	Detailed	Engaging
○	○	○	○

Appendix 8 - Prototype Testing Runsheet & Discussion Questions

10 mins – Introduction

Welcome participants
Make sure consent forms are signed

25 mins – Prototype Booklet Discussion

Introduce Research + Aims

Tentative Questions:
- What do you think about the look and feel of the resource?
- What is your interpretation of these images (water)? What do you think of using water as a metaphor for mental health?
- Which images resonated with you and why?
- In what ways do the illustrations reflect your experiences?
- In what ways could the illustrations more closely reflect your experiences or the experiences of others you know?
- Are there any topics in the resource missing that you think would be helpful to others?
- What kinds of stories do you want to hear more of? And do you think you have a story that you think would help someone else?

15 minutes – Writing Activities

How would you describe this prototype resource?

What advice would you give to others who are just starting to navigate their pain?
What had you wished you'd known earlier?

15 minutes – Debrief

Final discussions and summary
Give koha

Appendix 9 - Prototype Testing Materials

Name: ______________________________

How would you describe this prototype resource?

Please circle or mark as many words as you need that best describe your experience

Appealing	Creative	Fun	Powerful
Attractive	Disconnected	Helpful	Professional
Boring	Empowering	Impersonal	Relevant
Busy	Engaging	Inspiring	Simplistic
Calm	Entertaining	Intimidating	Straight Forward
Clear	Enthusiastic	Inviting	Stressful
Compelling	Meaningful	Optimistic	Understandable
Complex	Motivating	Overwhelming	
Comprehensive	Expected	Patronizing	
Confusing	Friendly	Personal	

Name: ______________________________

What advice would you give to others who are just starting to navigate their pain? What had you wished you'd known earlier?

Write an answer below

Appendix 10 - Final Design Outcome

Seeking Support

Persistent pain affects more than just the person experiencing it. It changes the way we interact with other people, such as friends, family and colleagues. Being successful in pain management requires help and support from those around us.

“I'm now 51 and really wish I could have a pain free day but at least I have friends and family that are so supportive.

I mean, I was very angry about it because I couldn't do anything. And I find it very frustrating.

While it might seem isolating, many individuals with chronic pain share these struggles. You are not alone.

28

At home with my boys, we never discuss pain at all. They know it's permanent. ey learned years ago, and they know t they have to do around the house elp me and the tasks that I can't age in the household.

"It's a bit like the stages of grief... And then 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, you think it's further away and you can't quite reach it."

26

Pain is Complex

Pain affects the entire body, including our emotions, thoughts and even our immune system. It can affect every area of life, including physical, spiritual, social, and mental well-being. The complexity of this can make pain feel overwhelming.

I get home at the end of day wiped out. There's so many things I don't do because I am so sore and tired.

12

13

Seeing Healthcare Professionals

It can be frustrating when multiple visits to healthcare professionals don't give clear answers. However, healthcare professionals play a vital role in your support network. Work closely with your healthcare team so they can help you find a pain management plan that is right for you.

Finding someone you trust is essential as you navigate how to manage your pain.

I am very grateful to the help I have been given. Most of the people I have seen have always been kind and they do what they can.

17


very angry about
couldn't do anything
nd it very frustrating.
While it might seem isolating, many individuals with chronic pain share these struggles. You are not alone.