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Making sense of pain: Participatory design approaches to understanding and supporting people living with chronic pain

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Abstract: Pain is universal, yet its invisible nature makes it difficult to express or understand. Understanding the intricate mechanics of chronic pain and how to manage it effectively can be particularly challenging. This paper describes research exploring how human-centred design, transdisciplinary collaboration, and participatory approaches can produce diverse design outcomes that support the management and treatment of chronic pain. Two case studies are presented: 1) an exploration of how pain might be expressed through illustration and storytelling to offer insight into lived experience, and 2) how experiences of pain could be made more tangible through physical artefacts to support patient–clinician communication. The resulting design outcomes – an illustrated resource for patients and a tangible toolkit for use in therapeutic settings – present novel alternatives to existing communication tools. The involvement of both learned experts and those with lived experience ensured these outcomes were relevant, usable, and implementable in real-world contexts.

Keywords: chronic pain; participatory design; health communication; sense making

1. Introduction

Pain is a universal experience, yet it is difficult to describe and understand. The International Association for the Study of Pain (IASP) describes it as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (Raja et al., 2020, p. 1977). Another widely cited definition states that “pain is whatever the experiencing person says it is, existing whenever he/she says it does” (Herr et al., 2019, p. 404). Evolutionarily, pain has been seen as a survival mechanism, alerting us to danger or harm (Sutherland et al., 2022). Yet pain also has emotional and spiritual dimensions and can be experienced differently depending on gender, culture, age, and other

socio-demographic factors (Honkasalo, 2000; Clarke & Iphofen, 2013; Mills et al., 2019). These layers make pain a complex and deeply personal experience (Johnson, 2025).

Chronic pain — a type of persistent pain that lasts or recurs longer than three months (Barke, Korwisi, & Rief, 2022) — is the leading cause of disability globally (Vos et al., 2015), affecting an estimated 31% of the population worldwide (Steingrímsdóttir et al., 2017). Chronic pain can have profound physical, psychological, and socioeconomic impact on individuals and society; it can significantly affect one's quality of life, leaving people unable to undertake or participate in 'everyday' activities, including work (Adams & Salomons, 2021; Clarke & Iphofen, 2013; Koesling & Bozzaro, 2021; Majedi et al., 2020). It can lead to social isolation, anxiety and depression (Stubhaug et al., 2024), and in extreme cases, suicide (Racine, 2018). For those living with chronic pain, finding ways to cope and manage it can feel like a constant struggle (Bruce et al., 2023).

1.1 Communicating and Understanding Chronic Pain

Understanding the intricate mechanics of chronic pain and how to manage it effectively can be complex. What is commonly experienced in chronic pain patients is the mysteriousness of their pain — it is an invisible and an independent inward experience (Eccleston, 2018; Clarke & Iphofen, 2013; Koesling & Bozzaro, 2021; Werner & Malterud, 2005). This means that people who do not have chronic pain (and sometimes those who do) struggle to understand this persistent pain (Clarke & Iphofen, 2013; Koesling & Bozzaro, 2021; Werner & Malterud, 2005; Wynne-Jones et al., 2011).

Communicating multifaceted personal experiences, like chronic pain, is difficult. The problem of miscommunication can significantly affect health outcomes and patient-clinician relationships (Henry & Matthias, 2018).

Patients often feel that medical explanations of pain do not adequately reflect or capture their lived experiences. Existing pain assessment tools do not address the complexity of living with chronic pain and reduce experiences down to a number, image, or word. Therefore, conversations around chronic pain often lack nuance and a complete understanding of a patient's lived experience. This process can often be frustrating for both patients and clinicians. Patients often feel like their pain is not validated, while clinicians encounter challenges in educating patients on the causes of their pain (Kenny, 2004). Additionally, chronic pain patients often want a diagnosis — proof that their pain is real and can be cured (Nettleton, 2006).

1.2 Narratives and Artefacts for Communication

The use of narratives in health contexts has gained increasing recognition as a powerful communication and educational approach that shifts the focus from physical symptoms alone to patients' experiences with illness (Gray, 2009). Stories have the capacity to shape patient perspectives and promote a more holistic understanding of their health experiences (Quah et al., 2023). Many individuals with chronic pain experience isolation (De Ruddere & Craig, 2016). Therefore, personal stories, shared experiences and everyday understandings often resonate more deeply than clinical descriptions (Frank, 2004) and help cultivate a sense of belonging (Stenberg et al., 2022). Sharing our pain through words alone, though, 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). Scarry (1985) presents a perspective that pain is inherently private and subjective, making it difficult to communicate accurately. Main (2014) echoes this sentiment and suggests that creative approaches can help articulate pain visually, offering a way to externalise and make sense of the experience.

Design can make personal stories, experiences, and ideas tangible (Reay et al, 2015). It does this through visuals, objects, services, systems, and the design of experiences, allowing the user to engage and reflect (Chon, 2022). In healthcare, visual communication can make medical information easier to understand. Illustration, in particular, can convey intricate emotions and support storytelling.

Similarly, tangible artefacts can help people connect meaningfully with the world around them (Norman, 2013), prompt us to think more deeply about our experiences, and can reveal our genuine needs and wants (Grudin, 2010). Design artefacts can act as catalysts to 'scaffold conversation' (Chamberlain & Craig 2013). They offer a means for individuals and groups to reflect on, recall, imagine, and articulate aspects of their everyday experiences, emotions, and routines, creating openings for mutual understanding and connection (Marshall et al. 2014). Such artefacts can provoke exploratory dialogue. This is most effective when participants are given the freedom to contribute their own interpretations, creativity, and ideas (Chamberlain & Craig 2013). A notable advantage of critical artefact-based approaches is that, even when the artefacts themselves remain constant, they possess the capacity to cross boundaries of culture, language, and age (Chamberlain & Craig, 2013).

In this paper, design is understood as a way to explore and make sense of the world. The goal was to show how collaborative, participatory design can produce practical, tangible resources that support communication and care for people living with chronic pain.

The research is presented as two interconnected case studies. Case study 1 explored how visual communication — specifically illustration and storytelling — can be used to convey the lived experience of chronic pain. Case study 2 investigated how design can support communication between chronic pain patients and clinicians by making the invisible and complex experience of chronic pain more tangible.

2. Methodology

This research adopted a practice-based, human-centred, participatory design methodology within a qualitative interpretive framework**,** and drew on collective discussion, reflection, and feedback to inform iterative design development.

2.1 The Research Context

An opportunity was identified within our transdisciplinary team of Design for Health researchers to work with a public Regional Pain Service (Pain Service) to explore communicating the chronic pain experience through design. Pain Service offers outpatient services including clinical assessment and management of acute and chronic pain utilising a multidisciplinary approach. The clinical team consists of Pain Medicine Specialists, Clinical Nurse Specialist, Occupational Therapist, Psychiatrist, Physiotherapists, Psychologists and a Pain Fellow. The service provides a three-week pain programme, an individual pain self-management programme, and walk-in relaxation classes open to people living with chronic

pain. The invitation to participate in research was extended to clinicians working in the service as well as clients. Clinician recruitment was facilitated by the service; prospective participants with chronic pain were approached via a walk-in relaxation session at the Pain Service, where the master's research students supervised by our team ([I-NK, SR, and CK] – the primary researcher for Case study 1 [JS] and Case study 2[NB]) introduced the research, and provided written information sheets as part of the informed consent process. In addition, researchers in chronic pain were recruited via publicly available email as part of Case study 2. Ethical approval was obtained for all aspects of the research (Auckland University of Technology Ethics Committee (AUTEC) approval ref no. 23/254, and 23/255, respectively).

2.2 Methods

Qualitative methods — including a clinician focus group (n=7) (Case studies 1 & 2) and interviews (n=3) with pain researchers (Case study 2 only), a co-design workshop with people with lived experience of chronic pain (n=3) (Case study 1 & 2), thematic and narrative analysis, and reflective, iterative practice to guide design decisions — were all employed to ensure that the outcomes were empathetic, user-centred, and contextually relevant to the New Zealand healthcare context. The discussion and the activities in the clinician focus group and the workshop with people with chronic pain were structured to focus on the aims and objectives of Case study 1 in the first half, and Case study 2 in the second half. The details are provided below for each case study.

3. Case Study 1 – Illustrating Pain

This arm of the research aimed to explore how illustration and storytelling could be used to convey the lived experiences of individuals with chronic pain to build understanding and connection. It was motivated by the recognition that visual storytelling can humanise healthcare communication, foster empathy, and support self-reflection. It also responded to the need for resources that are accessible to people with varying levels of health literacy, particularly in the New Zealand context, where Māori and Pasifika populations are disproportionately affected by chronic pain and face systemic barriers to care (Priston & Searle, 2010; Lewis et al., 2021).

The research unfolded in two phases: 1) understanding the experiences of pain through illustration exploration and 2) resource creation using an iterative participatory approach. In the first phase, the focus was on finding a visual language that could convey what it feels like to live with chronic pain. Building on insights from phase 1, phase 2 involved developing the resource structure, aligning the themes and meanings of the illustrations with specific chronic pain topics, and prototype iteration based on clinician and lived experience input.

3.1 Understanding Pain Through Illustration

To understand chronic pain and the experiences of those living with it, a narrative inquiry based on personal stories was conducted. At this stage, participant input was not yet available, so secondary sources of real-life accounts informed early visual explorations. Translating these stories into visuals enabled reflection and emotional connection, with

quotes distilled into single illustrations to convey complex emotions and experiences (Figure 1).

Figure 1 Early illustration explorations.

A notable part of the illustrative approach for this project involved avoiding strict adherence to realistic depictions of people or objects. The primary researcher [JK] drew inspiration from expressionist painting, which presents a more subjective view of the world, distorting it in order to convey a mood or idea (Baldick, 2001). The emphasis of the illustrations lay in expressing emotions rather than faithfully depicting physical reality (Figure 2).

Figure 2 Rough gestural ink sketches.

Many aspects of chronic pain are intangible, making them difficult to express through simple illustrations of characters or objects. To convey these experiences, colour and shape were used alongside subject matter to communicate complex emotions and sensations (Figure 3).

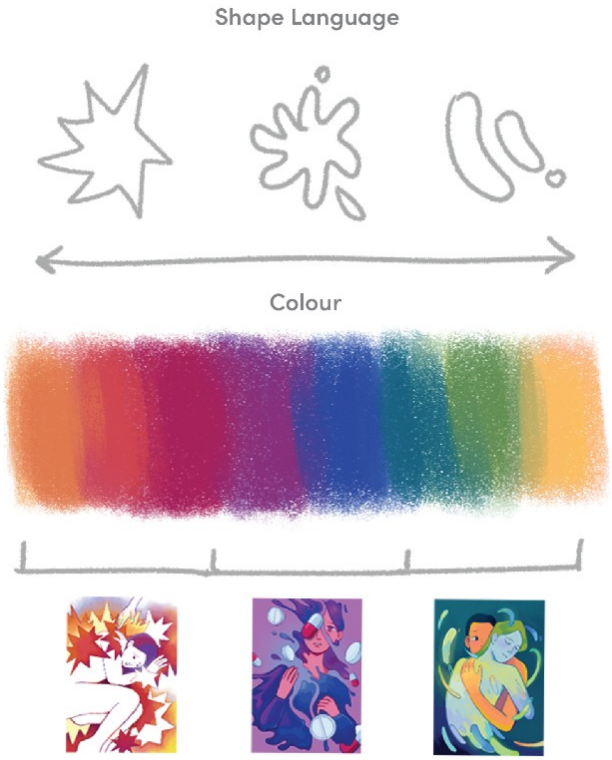

Figure 3 Diagram showing the use of shape language and colour.

Colour and shape were used to communicate emotional and sensory qualities of pain, drawing on both subjective interpretation and existing research on colour connotations and visual representations of pain (Clarke & Costall, 2008; Kirkham et al., 2015). Shape language — a concept from art and animation that conveys meaning through recognisable forms — was also employed to express subtle emotions. Descriptive words and metaphors used by individuals to talk about their pain were translated into abstract shapes: sharp, jagged forms represented pain described as “electric,” “cold,” or “like barbed wire,” while softer, rounder shapes were used to suggest relief and contrast the intensity of pain (Figure 4).

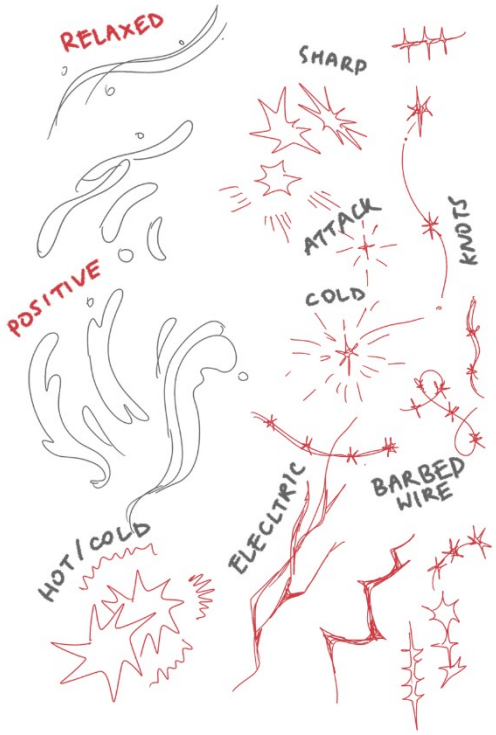

Figure 4 Abstract shape explorations reflecting metaphors and adjectives to describe pain.

One illustrative exploration, which used water as an analogy for the emotional experience of chronic pain, informed the decision to frame the resource around an overarching narrative (Figure 5).

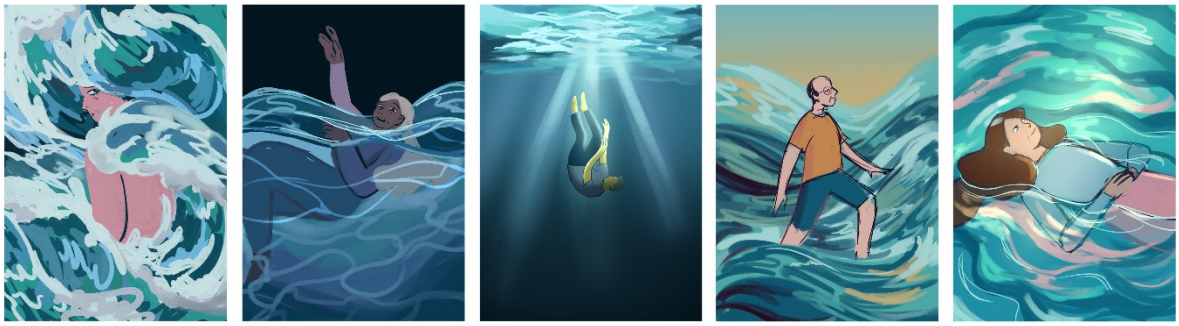

Figure 5 Illustration exploration using water to convey different emotional states.

Through narrative analysis, quotes gathered from a range of personal accounts were organised into thematic categories that reflected different stages of the chronic pain journey (Figure 6).

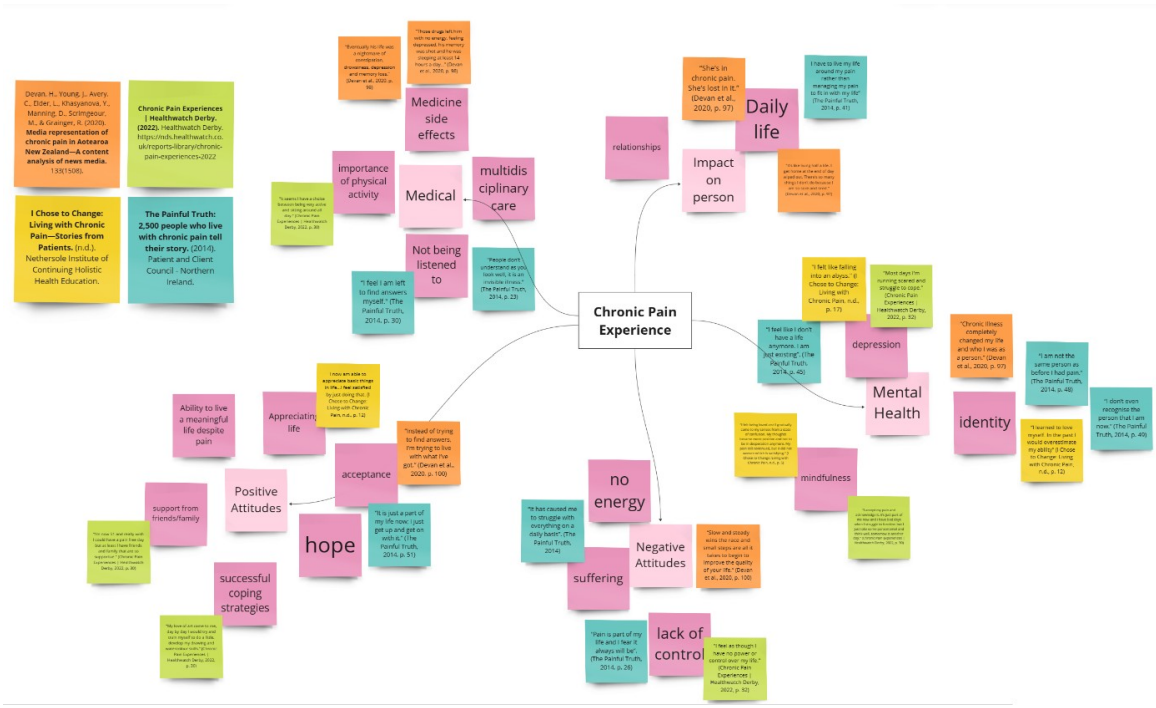

Figure 6 Narrative analysis 1: Themes and quotes.

Each phase of the narrative was then presented as a reflective question from the perspective of someone living with chronic pain. Within this framework, the informative sections were developed, interwoven with story excerpts throughout (Figure 7).

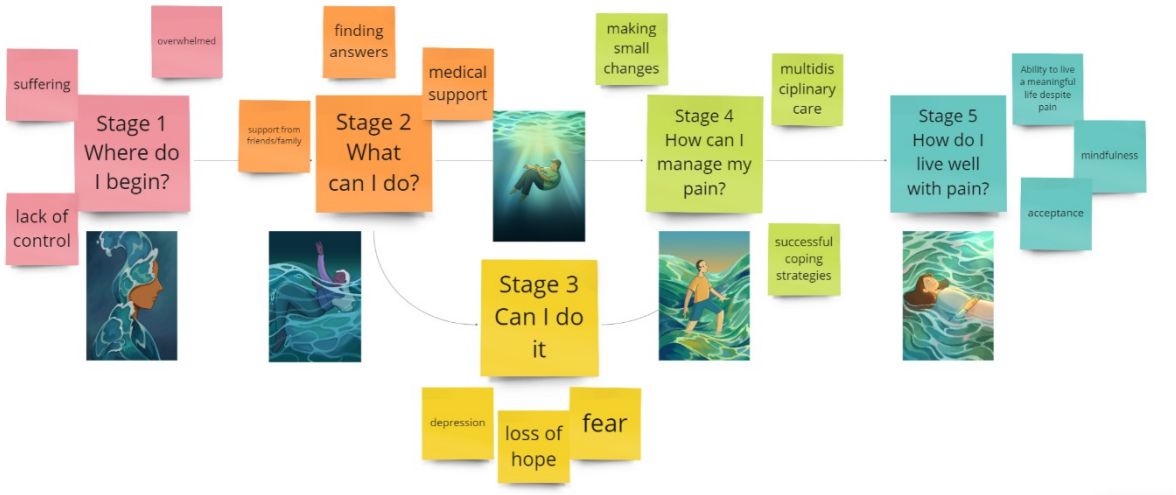

Figure 7 Narrative analysis 2: Sorting themes into phases

Prototyping subsequently involved aligning illustrations with specific chronic pain topics to create a 24-page booklet, with topics drawn from the existing New Zealand resources recommended by pain clinicians (e.g., *The Pain Toolkit*, Moore, 2017; *Navigating Pain*, New Zealand Pain Society, n.d) (Figure 8).

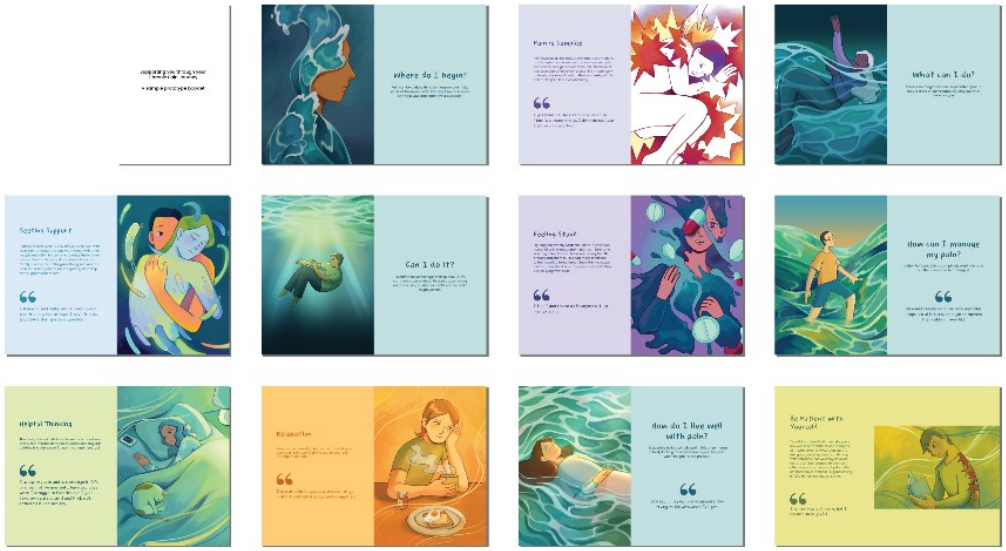

Figure 8 Prototype tested in the focus group.

3.2 Resource Creation Through Participatory Design

The next phase of research was focused on developing the structure of the resource, followed by cycles of testing and iteration. A focus group with pain clinicians was conducted to gain a deeper understanding of how they perceived and communicated with respect to chronic pain, their experiences in supporting patients, and what they considered important in developing patient-facing pain resources. This insight was instrumental in identifying the

key messages, refining the structure, 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 to incorporate into the final product. Discussion centred around existing chronic pain resources, patient experiences and communication in practice. The prototype (Figure 8 above) was presented to gather feedback on the overall look and feel of the resource; participants also provided a written description of their ideal resource.

The feedback received was affirming. In particular, clinicians highlighted the need to emphasise the importance of an individual's support system (such as healthcare professionals and family members). From a traditional Māori perspective, whānau (family) and spiritual equilibrium are just as crucial as the physical aspects of health and illness (Durie, 1998). A Pain Specialist noted how their understanding of Kaupapa Māori — an approach grounded in Indigenous values — shapes patient communication, highlighting the need for the resource to reflect these principles. In Aotearoa New Zealand, Te Whare Tapa Whā frames wellbeing holistically across physical, spiritual, family, and mental dimensions (Durie, 1998). Another clinician similarly described chronic pain through the "four horsemen of pain" — physical health ("he comes in and robs you of the physical things that you can do - most patients will relate to that"), relationships ("he robs you of your relationships, your friendships, family, work"), peace ("people get anxious, depressed, pissed off, poor sleep"), and future ("because you can't plan tomorrow and affects your roles, your mana [power, agency, control]"). This feedback shaped the next prototype iteration, emphasising support systems, a hopeful yet realistic tone, and recognition that chronic pain affects social, spiritual, and mental wellbeing. Design decisions were guided to communicate a holistic, relational understanding of pain aligned with Te Whare Tapa Whā. Additional illustrations were subsequently created to expand content and refine the visual language (Figure 9).

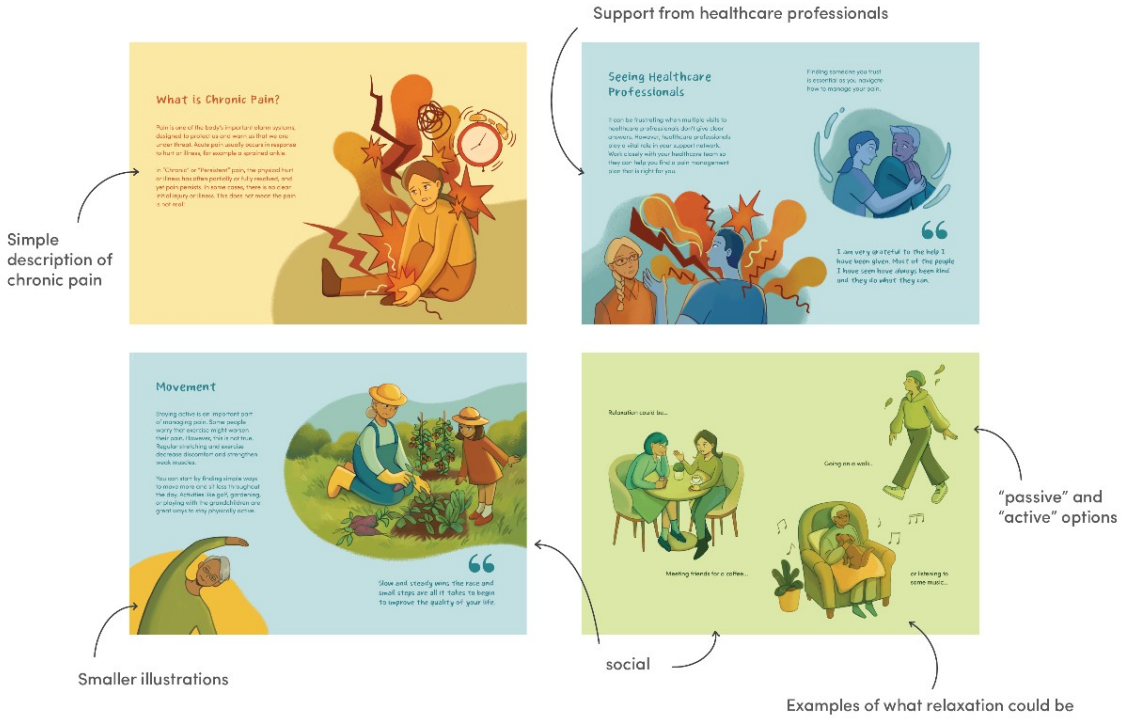

Figure 9 Added illustration spreads based on clinician feedback.

Clinicians in the focus group responded positively to the calming atmosphere of certain illustrations; consequently, the adjusted colour palette focused on shades of yellow, green, and blue — colours often associated with warmth and peacefulness (Clarke & Costall, 2008) — to support the intended tone of the resource. This iteration of the resource was tested with participants with lived experience of chronic pain to explore whether the illustrations resonated and to prompt discussion of their experiences to inform the final refinements (Figure 10).

Figure 10. Refined page spreads with more cohesive colours and illustrative elements.

Participants living with chronic pain commented on the look and feel of the resource through discussion and by describing the resource from a list of adjectives provided. They were also asked in what ways the illustrations could more closely reflect their experiences or the experiences of others with chronic pain, and about their interpretation of images used, especially the use of water as a metaphor for mental health. Additionally, the illustrations in the prototype served as a way for the participants to discuss their lived experiences so that these, with their permission, could then inform the final design iteration. Participants' advice for other individuals with chronic pain to include in the resource was also sought.

Overall, the feedback on the prototype was positive ("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 B)), 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." One participant highlighted that the 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," this imagery resonated with participants with chronic pain, acknowledging that this was part of their experience. One participant saw themselves as "supported" by the water, as they drew a connection to aqua therapy. Another 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: "That's why the wave thing is good, and it depends on the day. I think some days you're more okay with it."

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….and it's very subjective and individual"(participant B).

Participants valued that the prototype was physical, paper-based, and handheld rather than digital. One participant described it as "really relevant," noting that "there are not enough tools that are visual" or "tactile." The group agreed that a physical resource is more likely to prompt deeper reflection, aligning with the goal to encourage engagement and thought. Feedback from this session reinforced the importance of addressing the emotional complexity of chronic pain and incorporating firsthand stories to represent a wider range of experiences. The resource was also refined for usability and prepared for printing, with final touches including a cover design, table of contents, page numbers, introduction, and new participant stories (Figure 11).

Figure 11 Final printed booklet.

The final resource reflected the messages clinicians at the Pain Service wanted to convey: fostering acceptance and encouraging proactive steps in pain management. It maintained this focus while placing added emphasis on promoting well-being despite the challenges of living with chronic pain.

4. Case Study 2 – Understanding Experiences: A Chronic Pain Toolkit

This part of the research explored how design and physical artefacts can help patients communicate their experience of chronic pain in a clinical setting. The use of tangible artefacts was inspired by prior design work using physical objects to think and talk through about complex experiences (e.g., *Exhibition in a Box* (Chamberlain & Craig, 2013); *Printing my Pain* (Lab4Living,n.d.); *Things for Thought* (Zino et al., 2021). Mäkelä (2005) frames artefacts as embodied knowledge that reveal insights when interpreted, describing them as "a method for collecting and preserving information and understanding". Similarly, Sanders and Stappers (2014) emphasise the role of artefacts in co-design as tools for expressing thought. The research unfolded in two phases: (1) physical prototyping informed by a review of literature and interviews with pain researchers to understand how people with chronic pain experience and describe their pain, and (2) testing and iterating prototypes with people with lived experience, clinicians, and researchers.

4.1 Phase 1: Explorations of Pain Through Making

The prototyping process began by asking: What might pain look like if it had form? Early explorations included speculative artefacts, such as P.I.L.L.S (Pain Intensity Levels and Life Scales) a critical take on pain from clinician's point of view (Figure 12).

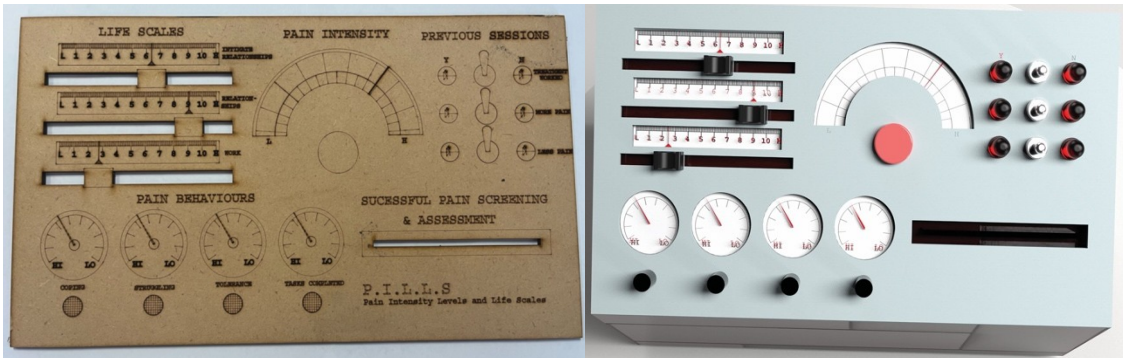

Figure 12 Laser cut prototype and a render of P.I.L.L.S.

Interviews with pain researchers and literature from this phase highlighted the effectiveness of metaphors in communicating chronic pain (Declercq et al., 2023; Johnson et al., 2023; Munday et al., 2020; Téllez, 2018). Metaphors often compare pain to objects or experiences, conveying both sensation and emotion — for example, one patient described stabbing pain as "two large stakes being plunged through both my temples and through the bottom of my skull" (Munday et al., 2020, p. 821), capturing location, motion, and intensity far beyond the word "stabbing" alone. Metaphors inspired prototyping of objects that tell a richer, more expressive story of pain. To explore this, descriptors such as throbbing, aching, stabbing, itchy, heavy, and shooting were drawn from literature describing lived experience. Early prototypes were quick material experiments in clay and 3D print, created to test how these sensations might take shape (Figure 13). Some ideas, like "itching," appeared better conveyed through texture rather than form, yet texture alone proved insufficient to express the complex (i.e., not just physical, but also emotional) nature of pain.

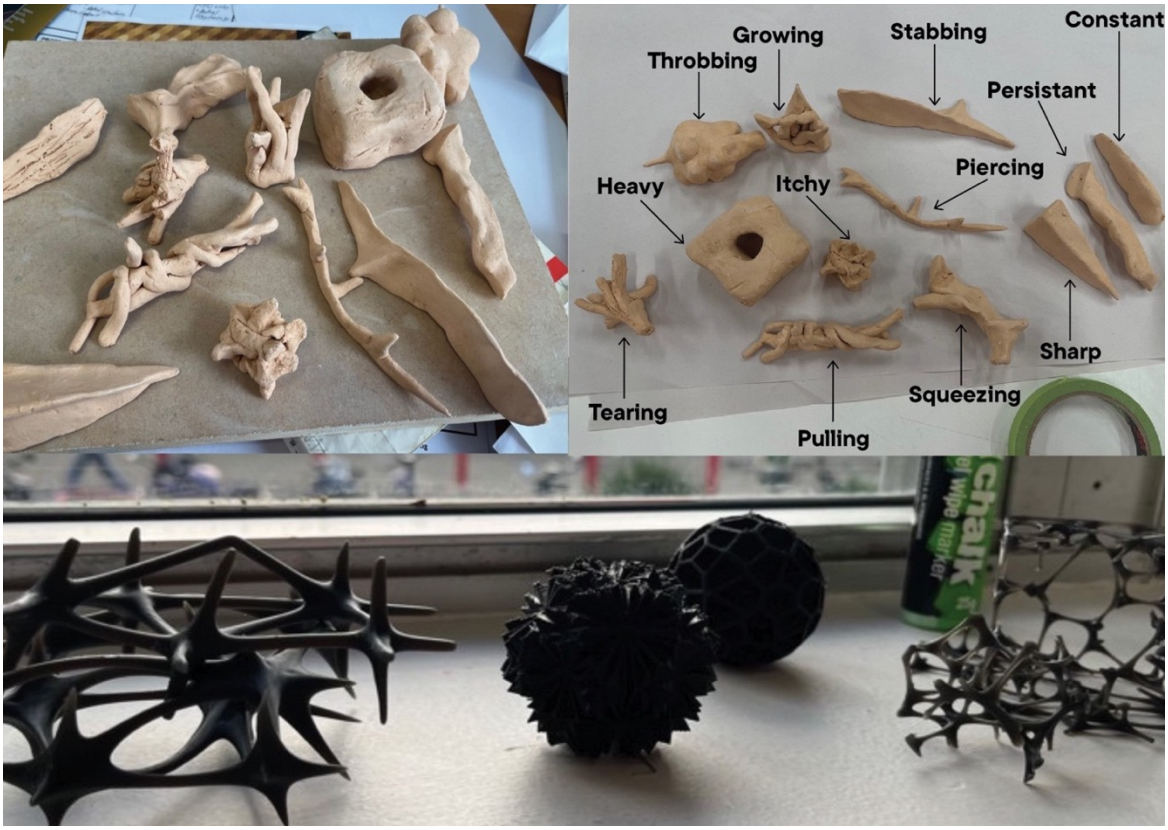

Figure 13 Giving form to pain based on descriptors (top). Making pain into 3D printed objects (bottom).

Curiosity then turned to materials — how they felt, moved, or resisted touch. Silicone, rubber, glass, and ceramics proved most compelling; their flexibility, stretch, and fragility suggested different qualities of pain. The objects became more interactive and complex, reflecting the messy, multifaceted nature of chronic pain (Figure 14).

Figure 14 From left to right: Polyurethane rubber ball; Testing silicon stretchiness; Glass shard test; Glass test in a particular form. Testing a stress ball's interactivity; Refined clay objects from descriptors; Rope exploration for making interactive objects.

In developing the prototype objects, cultural differences in interpreting pain were considered (Antunovich et al., 2024; Chen et al., 2008; Lane & Smith, 2018). To allow diverse patients to express their values and worldviews in a clinical setting, simple, muted-colour objects with varied materials and modes of interaction were created and tested with both clinicians and patients in Phase 2 (Figure 15).

Figure 15 Prototypes: brought to focus group (top left), bag activity in patient workshop and researcher interviews (top right), brought to interviews for feedback (bottom left), and to workshop and first interview (bottom right).

4.2 Phase 2: Participatory Design and Iteration

At each interaction with participants in this phase of the research, physical prototypes developed as part of material exploration were presented for testing and feedback. An activity was created to explore how touch alone could offer a different, more embodied experience than sight and see how this could, in turn, affect how a sensation is communicated verbally. The activity involved participants reaching into small opaque bags containing a range of materials (blunt glass chips and nails, cellophane, clay and rubber pieces) without looking at the contents and describing what they felt, focusing on sensation rather than identifying the materials (Figure 16).

Figure 16 Bag activity prototypes.

Touch encouraged participants to articulate the intangible qualities —textures, sounds, and movements— that sight alone cannot convey. This approach highlighted pain metaphors through touch and guided the project toward an activity-focused, sensory toolkit. The activity was then used in the co-design workshop with patients and the second round of interviews with pain researchers.

Patients in the co-design workshop also engaged in an activity that involved using Lego building bricks and Lego® Technic™ materials with more malleable putty material to physically represent their pain experience (Figure 17) and then describe what they had made. This was to inspire the next iteration of artefacts, how the toolkit's objects could be used, and what is essential for chronic pain patients to communicate.

Figure 17 Participants' models made in the workshop.

An agreed-upon criticism among participants was that the prototypes were too sharp and aggressive and needed to describe the lasting impacts of chronic pain (i.e., the chronic pain journey). Clinicians and researchers also referred to the number of sharp objects that might cause patients to exaggerate their pain as they look aggressive and overwhelming. Chronic pain patients, however, seemed to resonate more with interpretive figurative objects that did not explicitly look like pain. Participants indicated how they like talking about pain in groups, learning from each other's stories, and how they hoped the toolkit could be implemented in a pain management group setting to encourage and help these discussions.

A significant theme of size and weight was identified among the lived experience group, with one participant saying they wanted "various sizes" represented in the toolkit. Another participant described their pain as "heavy and a mess", portraying pain as burdensome. They also described their pain as "heavy and physical, and it saddles you". Participants added that the "weight" of the object was "great" in communicating their pain, and wanted different weights incorporated in the toolkit.

Temperature and colour were also used to describe pain. Colours also played a part when participants with chronic pain made models of their pain experience, with one participant indicating colours symbolised how chronic pain changes: "Yeah, and it's all different colours because it can be different and it can move different places, and then it hits you unaware when you get a nerve pain or something." With the objects, participants with lived experience also described how chronic pain is unpredictable and pain sensations are constantly changing:

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

Another described chronic pain as "like a long [dinosaur's] tail and it's got a mace on the end of it — just when you're least expecting, it turns around and whacks you." Pain researchers also talked about the changeability of pain: "So sometimes pain is tight or sometimes pain is burning. But sometimes pain is fire, or sometimes pain is cold, you know?" (Pain Researcher participant). Pain researchers also celebrated that the toolkit was "physical" and it gave patients "the choice to do things" and "talk about it." Pain clinicians and researchers all saw the sensory toolkit as most suitable for an initial assessment and to guide pain management. Since it was a creative tool, it needed to have clear, guided instructions for use, so that both the clinicians and the less creative-inclined patients could understand its use:

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

The final design, *Understanding Experiences: A Chronic Pain Toolkit*, includes four sensory bags, 15 objects, and a booklet with three activities to explore how pain feels rather than just how it is described (Figure 18 & 19). The *Bag Activity* encourages engagement with sensations like crunching through touch and sound to help describe the nuances of pain. The *Pain Journey Exercise* has patients select objects representing their past, present, and desired future with pain. The *PRISM Activity* uses the principles of an existing clinical pain assessment tool - Pictorial Representation of Image and Self Measure (PRISM) (Kassardjian, et al., 2008). In this exercise, patients position the toolkit objects (instead of the original plain discs) representing aspects of their life, including pain, in relation to a "self" object (originally, disk). With the original PRISM, the distance between disks is measured to indicate the impact of each factor on the self; the *PRISM Activity* encourages a more descriptive account of each factor, reflection and questions to begin a conversation.

Figure 18 Final toolkit.

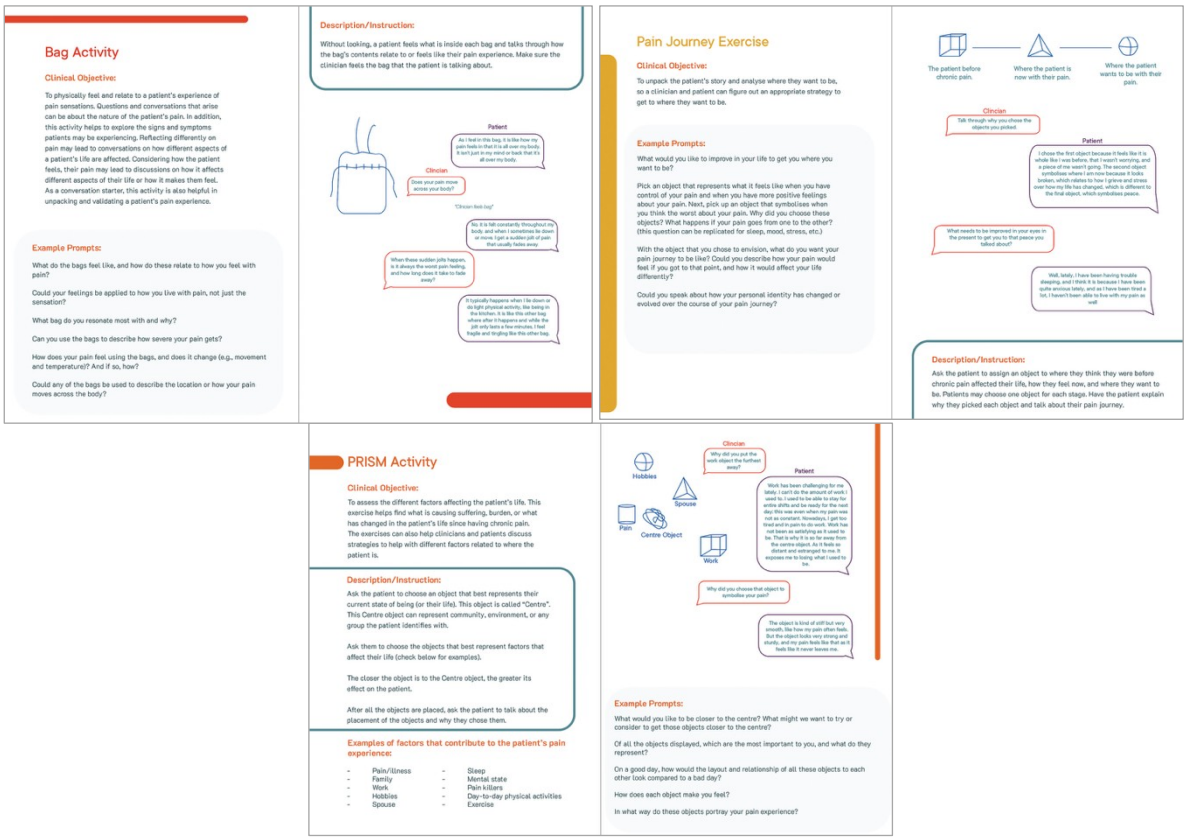

Figure 19. Exercise instructions: Bag Activity; Pain Journey Exercise; PRISM Activity

5. Discussion and Conclusion

While presented as two case studies, the projects are interconnected and cumulative. Case Study 1 focused on translating lived experiences of chronic pain into visual and narrative forms that support reflection and recognition. Case Study 2 extends this work into the clinical encounter, transforming these insights into interactive, sensory artefacts that enable communication in practice. Together, they demonstrate a progression from representing pain to mediating conversations about pain, with each outcome informing and strengthening the other.

5.1 Making Pain Communicable

Across both case studies, design expands the language available to communicate chronic pain. Clinical tools often reduce pain to simplified descriptors or numerical scales, which can fail to capture its lived complexity (Clarke & Iphofen, 2013; Koesling & Bozzaro, 2021). In contrast, the illustrated booklet enables emotional and experiential aspects of pain to be externalised through narrative and visual form, while the toolkit supports metaphorical and embodied expression through touch and interaction. These artefacts do not replace verbal communication but augment it, offering multiple entry points for expression.

This aligns with work positioning artefacts as mediators of knowledge and meaning-making (Sanders & Stappers, 2014; Mäkelä, 2005), and with research highlighting the role of visuals

in improving understanding and recall in healthcare communication (Houts et al., 2006; Osborne, 2006). In doing so, these approaches allow patients to articulate aspects of their experience that might otherwise remain unspoken, supporting richer and more nuanced dialogue in clinical settings.

5.2 From Representation to Interaction

A key contribution of this research is the shift from representational to interactive modes of communication. The booklet operates as a reflective resource, supporting sense-making over time, whereas the toolkit enables dynamic, in-the-moment dialogue between patients and clinicians. This distinction highlights how different forms of design intervention can support communication across contexts of care - private reflection and shared clinical interaction.

Importantly, both approaches embrace ambiguity and interpretation rather than seeking to standardise expression. This reflects arguments that design artefacts can scaffold conversation and provoke exploratory dialogue (Chamberlain & Craig, 2013), particularly in the context of complex experiences. The collaborative process also enabled insights generated through visual storytelling in Case Study 1 to be translated into the more interactive, practice-oriented tools developed in Case Study 2.

5.3 Design as Mediator in Healthcare Relationships

When diverse voices come together meaningfully, collaboration becomes creative and integrative, enabling novelty and innovation (Dillon, 2008; Reay et al., 2021). In both case studies, design functioned as a mediator within the patient-clinician relationship, enabling multiple perspectives to surface (Nakarada-Kordic, 2020). Participatory design approaches flatten hierarchies, amplify patient voice, and build trust (Nakarada-Kordic, 2017), requiring clinicians to engage with new, design-led ways of working (Craig et al., 2019). This enabled mutual learning: patients communicated their experiences more fully, and clinicians developed a deeper understanding of the complexity of chronic pain. These dynamics extended through the designed artefacts, shifting interaction from a predominantly verbal, clinician-led exchange toward a more participatory and exploratory dialogue.

This aligns with Design for Health scholarship emphasising participatory approaches in rebalancing power and fostering trust (Nakarada-Kordic et al., 2017; Groeneveld et al., 2018), and with broader literature highlighting design's relational and communicative value in healthcare (Chamberlain & Craig, 2017; Male, 2007). Although such contributions may be difficult to capture through conventional healthcare metrics (West, 2020), their value lies in fostering understanding, validation, and more relational forms of care.

Conclusion

This paper demonstrates how participatory design can generate artefacts that reshape how chronic pain is communicated and understood. By introducing visual, narrative, and sensory modalities, the research moves beyond reductive clinical descriptions toward more nuanced and relational forms of communication. The findings suggest that design not only supports communication but actively expands it, offering alternative "languages" through which patients and clinicians can engage with complex, subjective experiences.

Future work could explore how such approaches are embedded into routine clinical practice and adapted across different healthcare contexts.

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