THE LANGUAGE OF PAIN

PROJECT REPORT AUTUMN 2024

OVERVIEW

The Language of Pain was a creative research project that used arts-based methods to explore the expression of pain narratives. The three-month pilot study brought together 36 lived experience experts (people living with chronic pain), a professional researcher, an arts facilitator, an occupational therapist, and two project managers most of whom met regularly in a hybrid setting[1].

The Language of Pain adopted a participatory approach. Everyone involved in the research worked together without privileging a particular set of expertise or type of knowledge. Input from lived experience experts in early consultations shaped the project design. Creative and reflective insights from all involved informed the focus of creative sessions and how the project unfolded.

This report introduces the project, reflects on the emergent design of the study and decisions made, and what we learned. The report draws from insights shared through weekly reflections, creative practice, artwork, and group discussion to understand the personal and collective experience of expressing the lived experience of chronic pain through arts-based methods.

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[1] In this report we use the term lived experience expert to acknowledge the unique and valuable insights and expertise that people living with pain bring to the project. We use the abbreviation LEE when quoting the insights, reflections, and contributions of the lived experience experts.

ACKNOWLEDGEMENTS

We would like to thank all the lived experience experts who contributed their time, reflections, insights and expertise – we could not have undertaken the project without you. Thanks are due to members of the Language of Pain working group (Tef Asante, Tim Atkinson, Ruth Barber, Taian Dove, Mira Hirtz, Anne Kingston, Rob Miller, Eliza Saunters, Jo Young), which emerged from this study and who took the time to read and provide feedback on the draft of this report. Thank you also to the facilitators Natasha Lohan and Florence Usher, research fellow Dr Rebecca Stancliffe, and project managers Poppy Harrison and Jasmine Wilson. We would also like to thank Ian Peppiatt and Molly Black for their AV support throughout the project.
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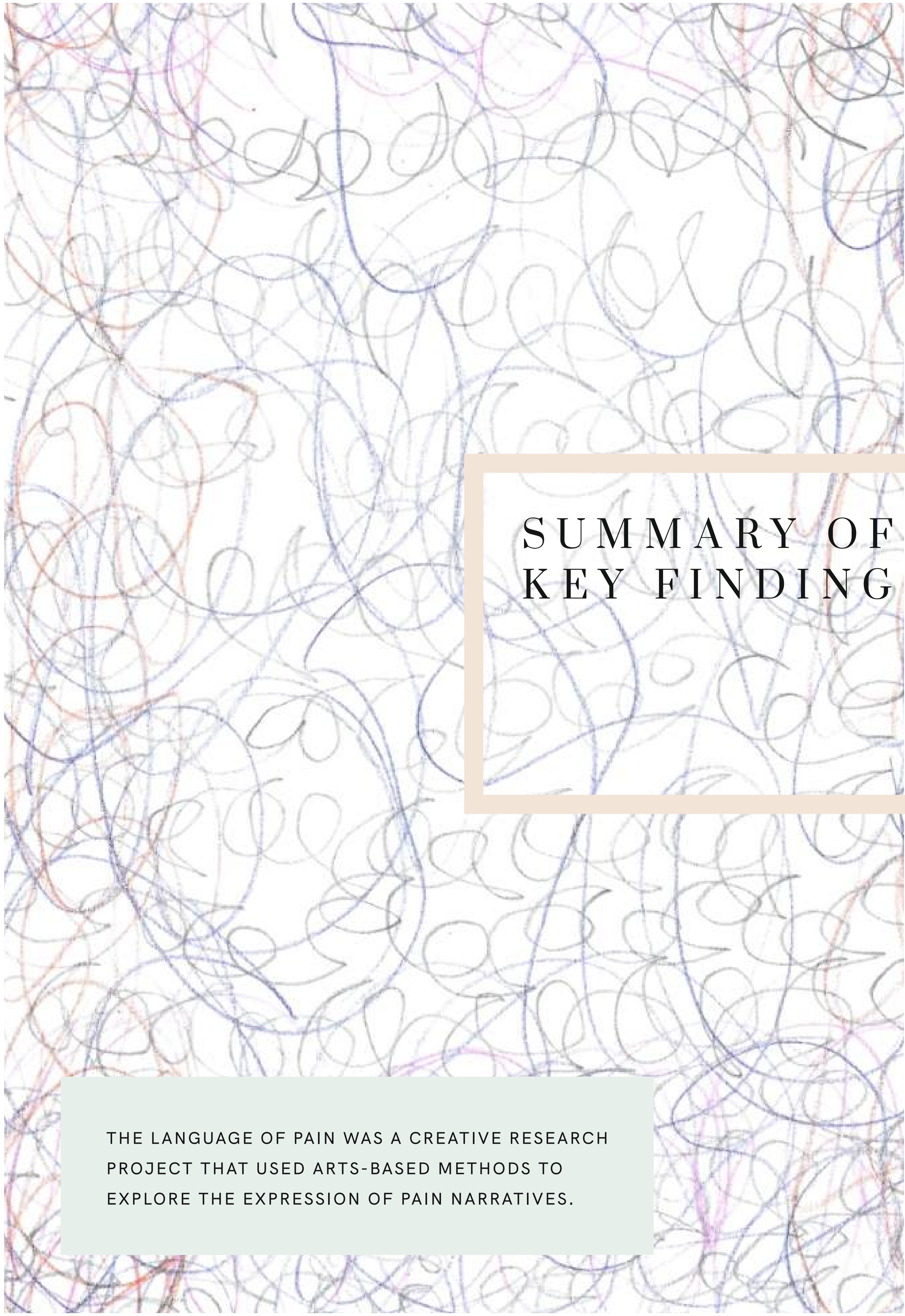
PART ONE

PART TWO



SUMMARY OF KEY FINDINGS

THE LANGUAGE OF PAIN WAS A CREATIVE RESEARCH PROJECT THAT USED ARTS-BASED METHODS TO EXPLORE THE EXPRESSION OF PAIN NARRATIVES.

- The Language of Pain project was described as “an expression of a community” that helped people to feel that they are not alone.
- The project created a safe space and productive framing for expressing and sharing experience.
- Chronic pain has a measure of incommunicability which can present challenges for expressing experience and being understood.
- Articulating the experience of chronic pain is easier, more holistic, enlarging, and more nuanced through arts-based methods, generating a unique expression of what is going on with the body.
- In exploring themes such as the invisibility of pain, the experience transformed how some lived experience experts conceptualise pain.
- Creative tasks stretched the imagination and could distract from pain.
- The value of creative process without a predefined purpose was a valuable new experience for some.
- Creative expression helped individuals to identify as more than their medical history and pain.
- Some lived experience experts found motivating themselves to attend sessions to be challenging, but they always felt better afterwards. Practicing an ethics of care, with an emphasis on looking after oneself, supported each person to explore and determine for themselves how best to engage with the creative experience.
- The project oscillated between participatory and co-produced research. Lived experience experts reported that their inclusion did not feel tokenistic in any way; they felt heard, their insights and experiences valued, and felt they had a key role in shaping the direction of the project.
- Hybrid delivery was new to the Trinity Laban team, and we recognised the importance of normalising the hybrid environment to ensure online engagement was neither secondary nor inferior to the in-person experience. While the value of in-person experiences was stressed, hybridity was celebrated because it allowed lived experience experts to choose their mode of engagement depending on how they felt and their personal circumstances.

IN THIS SECTION WE INTRODUCE OUR CREATIVE RESEARCH METHODOLOGY AND REFLECT UPON THE ROLE OF CREATIVE EXPRESSION FOR ARTICULATING THE EXPERIENCE OF INVISIBLE HEALTH CONDITIONS.

PART ONE

PROJECT BACKGROUND

The Language of Pain was developed in response to Singing for Pain Management (SfPM), an arts and health programme delivered by Trinity Laban in 2021. SfPM highlighted that sharing the experience of living with chronic pain with family, friends, and medical professionals can be challenging. In recognising the difficulty of expressing something felt through language which can be loaded with preconceptions, The Language of Pain set out to explore how the arts could be used to express what it means to live with chronic pain.

Project planning commenced in April 2022. Research priorities that emerged from SfPM were developed and refined by the Trinity Laban team which, at the time, included:

- A research fellow and dance professional with expertise in arts and health research.
- A freelance arts facilitator specialising in the use of voice and sound arts with experience working in hospital and arts settings.
- An occupational therapist working for an NHS community therapy rehabilitation team and who supports Trinity Laban arts and health groups.
- A project manager experienced in facilitating arts and health programmes.

The evaluation of SfPM identified that participants have unique insights into how the impact of arts and health programmes could be evidenced (Stancliffe & Faith-Kelly, 2022). Responding to this, as well as research recommendations to integrate stakeholders more in shaping research agendas (Chappell et al., 2021; Crickmay et al., 2021), the team was keen to work closely with lived experience experts in planning and facilitating the creative research. Funding allocated to Trinity Laban by UKRI for participatory research provided the possibility to explore co-production.

TOWARDS CO-PRODUCTION

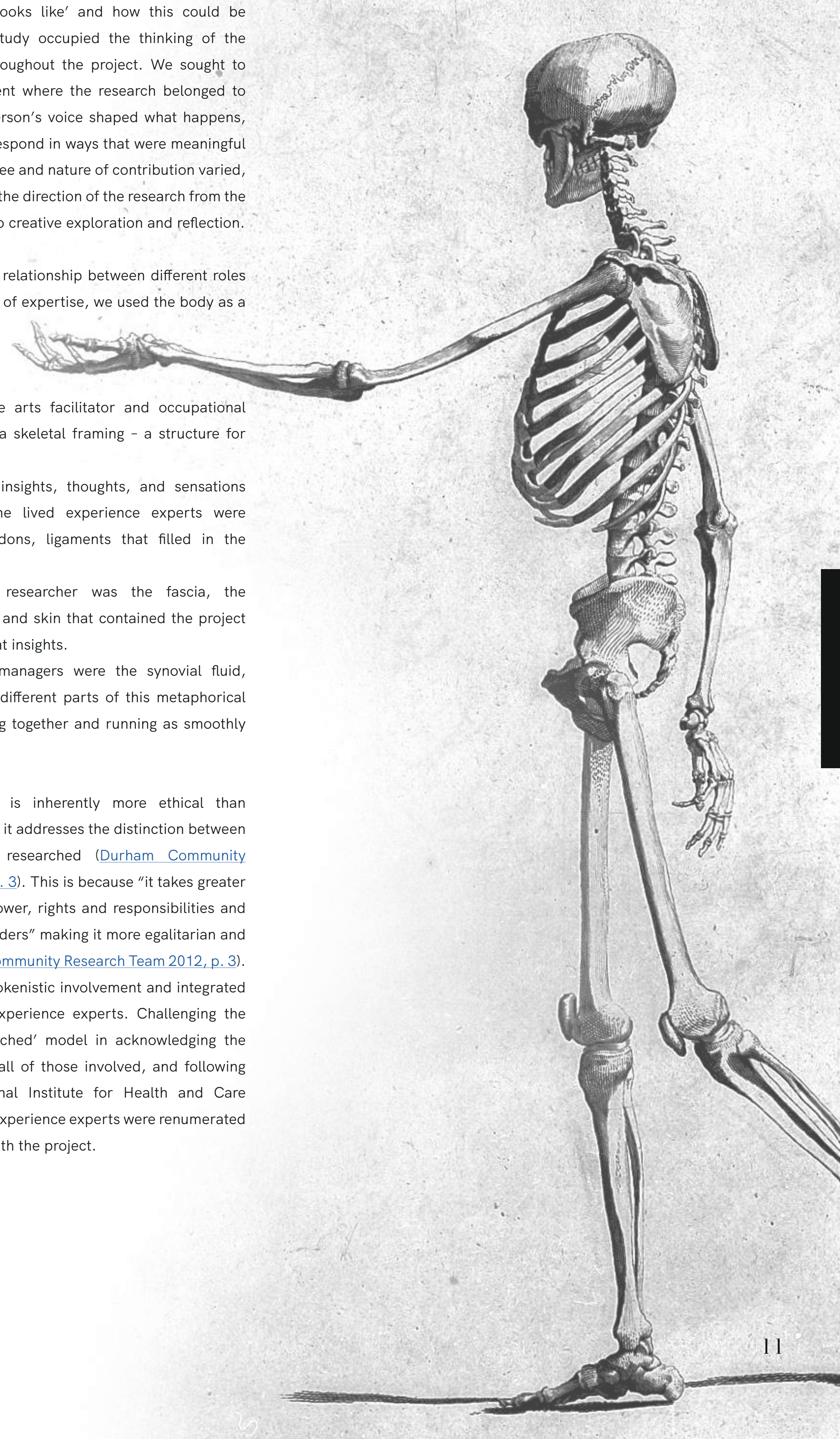
Participatory research is a spectrum characterised by different degrees of involvement and decision making (Durham Community Research Team, 2012). In co-production individuals usually or typically described as participants or research subjects are involved in all stages of the study, from designing the research question through to disseminating findings (Barke et al. 2020). People with lived experience "become co-researchers – that is, they become equal partners in shaping research and discovering new knowledge. This makes the research stronger and more effective at delivering change" (University of York 2020).

Acknowledging that each person's journey is different, in The Language of Pain we explored individual subjective experience and narratives. The project was informed by Havi Carel's philosophy of ill-health. Carel writes:

> “ in cases of conscious adults, we usually take each person to be the ultimate authority on his or her own sensations, feelings, and experiences. Because of this first-person authority the experience of illness contains a measure of incommunicability that should be acknowledged.
> (2016, p. 476)

This neatly encapsulates our desire (and the necessity) to work with lived experience experts.

Co-production challenges traditional power dynamics in research by valuing the expertise of experience rather than prioritising academic knowledge. Integrating different ways of knowing can increase the dialogue with and relationship to society through context-relevant research (Darby 2017). In co-produced work, responsibility and ownership is transferred to all of those involved, although what this looks like and the scale of involvement depends on the project. In the Language of Pain our approach oscillated between participatory research and co-production, determined by the time constraints of a pilot study.



What co-production 'looks like' and how this could be realised in the pilot study occupied the thinking of the Trinity Laban team throughout the project. We sought to establish an environment where the research belonged to everyone, that each person's voice shaped what happens, and individuals could respond in ways that were meaningful to them. While the degree and nature of contribution varied, the collective informed the direction of the research from the consultations through to creative exploration and reflection.

In framing the working relationship between different roles that drew upon a range of expertise, we used the body as a visual metaphor:

- as facilitators, the arts facilitator and occupational therapist created a skeletal framing – a structure for creative work.
- in bringing their insights, thoughts, and sensations to the project the lived experience experts were the muscles, tendons, ligaments that filled in the skeletal structure.
- the professional researcher was the fascia, the connective tissue, and skin that contained the project and united different insights.
- and the project managers were the synovial fluid, ensuring that the different parts of this metaphorical body were working together and running as smoothly as possible.

Participatory research is inherently more ethical than 'traditional' research as it addresses the distinction between researchers and the researched (Durham Community Research Team 2012, p. 3). This is because "it takes greater account of issues of power, rights and responsibilities and the roles of all stakeholders" making it more egalitarian and democratic (Durham Community Research Team 2012, p. 3). We sought to avoid a tokenistic involvement and integrated the insights of lived experience experts. Challenging the 'researcher and researched' model in acknowledging the time and expertise of all of those involved, and following guidelines from National Institute for Health and Care Research (2021), lived experience experts were renumerated for their engagement with the project.

CONSULTATIONS

16 lived experience experts took part in online (n=12) or in-person (n=4) consultations. The consultations were advertised to SfPM participants and the wider community through mailing lists, and social media platforms. We requested information from prospective attendees in advance of the consultations to ensure that we were able to meet their comfort and access needs.

Each consultation started with an introduction to the Trinity Laban team, an outline of our research prioritises arising from the SfPM evaluation, and the concept of co-research. A group discussion then focused on the following questions:

1. What is the individual and collective meaning of the arts? When, how, and why have the arts and creativity felt useful and valuable in your life?
2. In focusing on our lived experience of chronic pain, what ideas, questions, or themes might we explore?
3. How can we create an environment that feels safe, supportive, and comfortable for your engagement and creative expression?

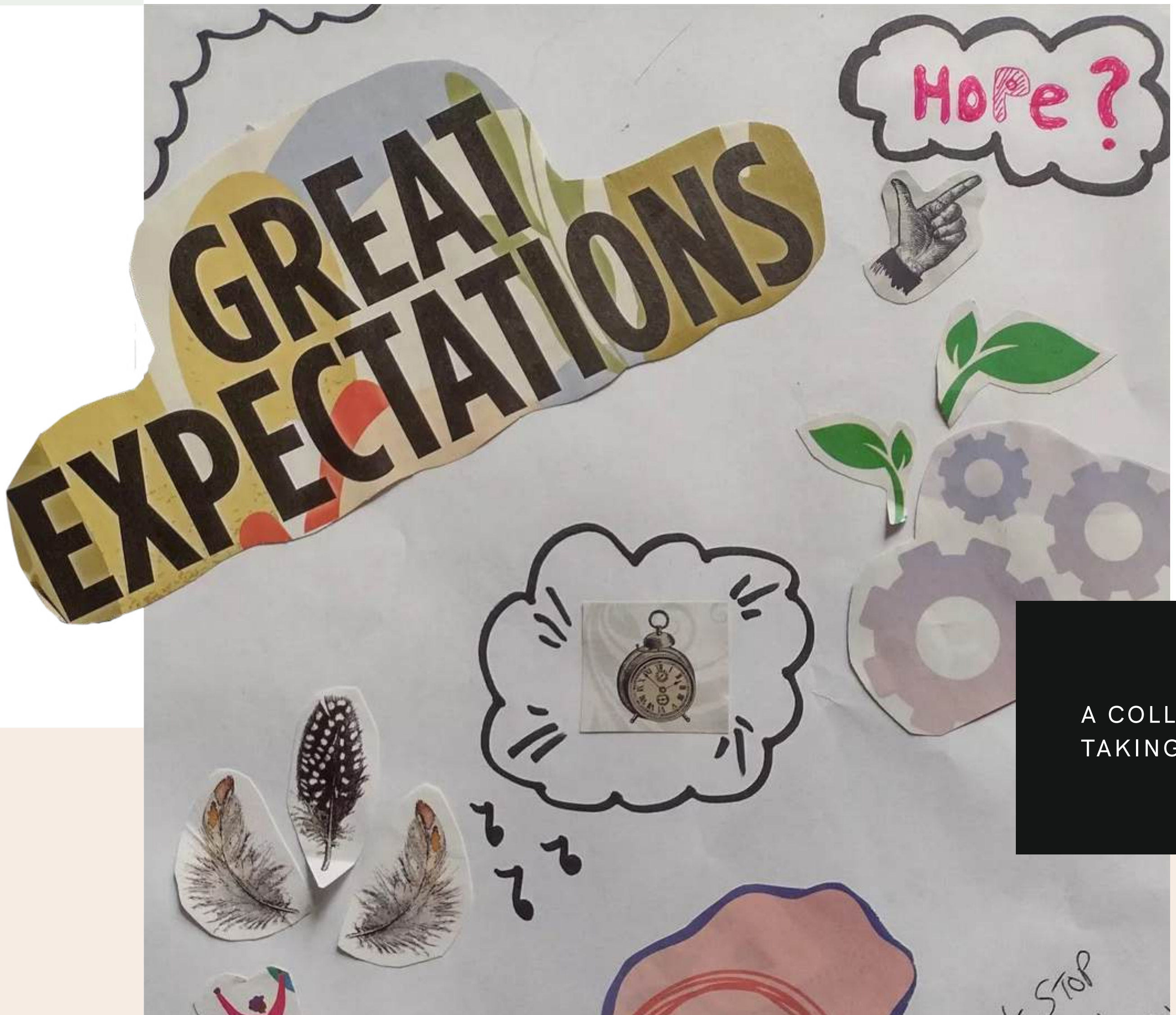
Here are selected insights from the consultations:

- Individual pain narratives are different but there are commonalities in experience.
- An individual’s experience of pain can be diminished because “everybody thinks they know what yours is like”. Because most people have “suffered pain of some sort or another”, it can be difficult to share one’s experience of pain without feeling you are exaggerating or minimising the pain.
- There is a perceived lack of public understanding, empathy, and awareness about invisible health conditions such as chronic pain. Self-imposed limitations arise with expectations of normative behaviour when in public, cultural, and institutional spaces.
- Individuals spoke of the bereavement they experience when no longer being able to do the things they had done before their ill-health. Some people found that chronic pain forced them to think creatively in how to manage pain in various ways encountering experience and knowledge that might not otherwise have been available.
- In wanting to be recognised as something other than pain and illness, there was an invitation to consider how to engage creatively without concentrating on pain. On the other hand, an interest in entering a dialogue with one’s pain, to externalise subjective experience, and embrace the full spectrum of thoughts, feelings, and emotions was expressed.
- The option of attending creative sessions in-person and online would allow individuals to determine their mode of engagement depending on how they were feeling on any given day.

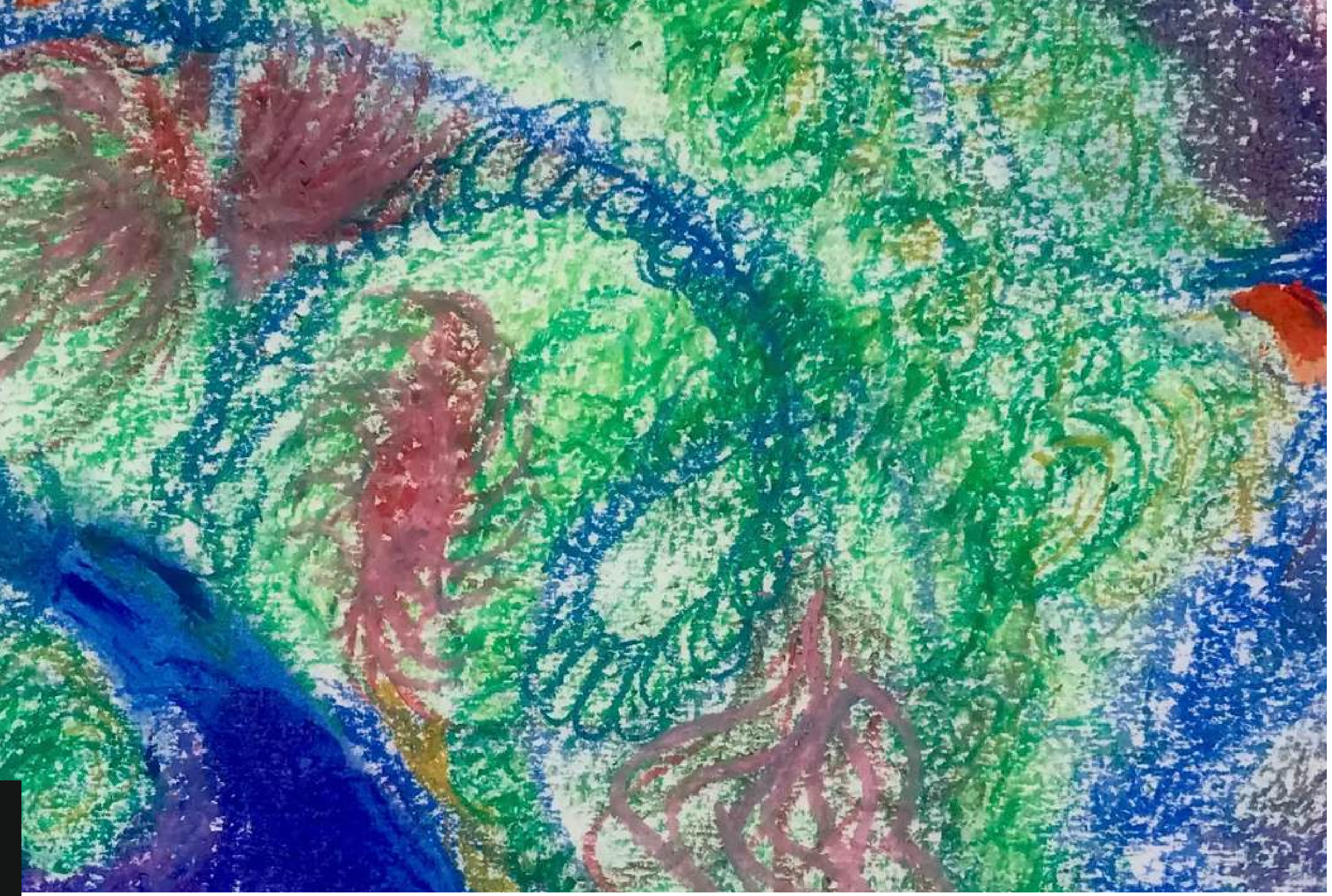
The consultation discussions shaped how we framed the creative research project. The desire expressed for a hybrid approach has the most immediate impact on project design.

PROJECT SIGN-UPS

Following the consultations, 48 people identifying as lived experience experts signed-up to take part in The Language of Pain project. The level of interest was unexpected and informed the design of the pilot. To accommodate as many people as possible, we created two research groups each meeting fortnightly for five creative sessions lasting 1.5 hours, with additional time built-in for socialising. A third longer (3.5 hours) Sunday ‘in-person only’ group was created, open to anyone who wanted to attend. Concurrent to the creative research, monthly discussion sessions were held to unpack key themes of the research. Accommodating the number of sign-ups limited the number of sessions organised for each group. The decision meant that varied and diverse voices and experiences contributed to the project. On the other hand, there was less time to establish a group connection in the hybrid setting and to explore themes in depth. At the project end, 29 of the 48 people registered (60%) to take part had attended creative research and/or discussion sessions.



A COLLAGE REPRESENTING THE EXPERIENCE OF TAKING PART IN THE LANGUAGE OF PAIN (LEE 10).



WORKING IN A HYBRID ENVIRONMENT: AN EMERGENT PRACTICE

In the pre-project consultations, the value of in-person experiences was stressed but it was also recognised that it can be challenging for different reasons (e.g., ill-health, location, and caring responsibilities). For people living with chronic pain, travelling could be so taxing that by the time they arrived at a venue they would be left with no energy reserves to contribute meaningfully and enjoy sessions. A preference for hybrid engagement was determined, allowing individuals to attend the project in person or join online if they were having a bad day and for those living further afield to engage with the study. Furthermore, for housebound individuals the option of attending online would enable them to feel part of a community. We could have decided to offer distinct in-person and online sessions, but we were curious to see how a hybrid approach would work.

Supporting creative exploration and expression in a hybrid setting was one of the greatest challenges encountered by the Trinity Laban team. The approach, which significantly shaped the project, was discussed at length in project planning and consistently reflected upon as the study evolved. We felt that it was important to normalise the hybrid environment so that online engagement was neither secondary nor inferior to the in-person experience. We embraced the challenge, recognising that our understanding of best practice would be emergent.

Initially, the facilitators wanted to share the same physical space for hybrid delivery. The arts facilitator and occupational therapist were working together for the first time and wanted to optimise the interpersonal dialogue in supporting the emergence of the work. However, the static position of the camera created something of a ‘proscenium arch’ and facilitators were seen to address either online or in-person attendees but not the collective. This was not an issue for inward-focused activities such as the warmup where parity could be created through verbalised guided instruction, nor was it a problem when working in small groups when the facilitators could move between spaces. But it was a struggle to engage simultaneously with both spaces when working as a collective.

Through reflection, the facilitators recognised that they were unable to appreciate the experience of hybridity, in particular the perspectives of online attendees, without experiencing it for themselves. The format shifted so that one facilitator was in the physical space and the other joined the online community generating a more balanced sense of engagement and equalising the experience for online attendees. Lived experience experts reflected that the online facilitator became “one of them […] in a contained box’ by herself on the screen” resulting in greater camaraderie (LEE 10).

Online delivery and engagement in national lockdowns during the COVID-19 pandemic highlighted the impact of screens on physicality, spatiality, visibility, and immersion in performing arts practice (Stancliffe 2021). For online attendees, the digital device used to connect to the Language of Pain sessions would inform experience: the bigger the screen the greater the immersive potential. We recognised that several people joined the sessions on tablets and mobile phones meaning that they needed to hold or prop up the device for optimal visibility. Furthermore, with these devices, the limited number of frames visible at any one time would make it challenging to see the whole group and the creative outputs shared (LEE 11).

While the Trinity Laban team could not control the screen experience of online attendees in this project, we could optimise the visual information available for in-person attendees. This would, in turn, inform the visual image received by those participating from home. With the support of the AV department the optimum hybrid set-up was explored. Using a projector screen presented the Zoom image as big as possible to encourage expansive activity in the physical space and allow a greater use of peripheral vision. However, the design of the Laban building (where the sessions would take place) meant that the light coming in through the glass walls (and inability to block it out) made it difficult to see the projected image. We had to opt for a monitor with a smaller than ideal screen. To ensure that in-person attendees could see each other, activities were grouped more closely to the monitor than we would have liked to. This meant that it was not possible to make full use of the studio space when working collectively. It also meant that peering into the screen narrowed the use of focus.

To normalise the presence of the screen it was used as a creative tool, a frame for experience. In creative tasks we imagined that we could traverse the screen, reaching through and beyond the frame. Online attendees were encouraged to work with their cameras on, at least when checking in at the beginning of each session, to help establish a sense of community within the hybrid environment. There were days when lived experience experts were too tired to have their cameras on: being visible on camera can feel confrontational because it feels as though you are always on display.

Breakout rooms made the online experience feel more intimate and personal, providing an opportunity to chat and share sensitive issues (LEE 5, LEE 10, LEE 26). The opportunity to self-organise and self-govern in smaller groups supported autonomy, yet the experience depended on the dynamic of the group. One lived experience expert felt anxious about who they would be paired with (LEE 18) while another found it "quite tiring" having to lead and found it easier when the facilitators assisted in directing the conversation (LEE 13). In turn, the facilitators found it challenging to determine the different levels of support required for self-directed activities. When working in-person it is possible to "slip into" group activities, but entering break out rooms can feel like "crashing into the space".

Concerned that online creative exploration would be difficult, one person was "surprised" that the hybrid set-up worked so well:

> I actually feel less self-conscious and more at ease contributing and allowing myself to be vulnerable about my experiences of pain.
> (LEE 18)

For some, face-to-face communication was preferred allowing for the reading of expressions and the nuance of body language and energy (LEE 14, 16). It was suggested that virtual attendance was "perhaps not as rewarding" as the in-person experience because the "joy of being together" could not be replicated (LEE 6). One person reflected upon "how it would be nice to be in the studio with others, sharing our kinetic energy" but has learned that:

> adjustments and compromises are part of my condition and I am incredibly grateful to have access to technology so I can engage and participate from home. (LEE 10)

USING A PROJECTOR SCREEN (IMAGE BELOW) WOULD HAVE BEEN AN IDEAL SET-UP FOR HYBRID VISUAL INFORMATION EXCHANGE. HOWEVER, BECAUSE OF STUDIO LIGHTING WE HAD TO ADOPT A SMALLER SCREEN (TOP RIGHT IMAGE) WHICH CONFINED THE USE OF PHYSICAL SPACE IN THE STUDIO.

Bones as stiff as board, forcing movement to come, slow
and steady, body craving warmth, softness and being still.
No wish to move today, sadness in my bones, heaviness
in my heart. Yet the day calls me to move, to begin, to start
the process of being. Start small, go easy! Little stretches
that poke into the discomfort, testing my resilience to the
pain, knowing that pushing through will allow me to feel
more normal, to look like others and not the crunched
over stiff body of an old arthritic woman.
My heart feels heavy but somewhere in my body I hear,
‘I am a mover, come on, you can do this, MOVE’. So, the
process continues, each shift slowly easing,
each move allowing flow to begin deep in the tissues,
knowing that moving has a dual purpose this morning,
to ease my bones and soften the sadness in my heart.
Pain always worse when emotional resilience is depleted.
I roll gently on the floor, it’s not much, but it’s enough.
The sense of the earth underneath me, supporting, bones
heavy into the ground, heart pressed by hand’s pressure
on my chest.
Rocking back and forth, soothing memory of something
I can’t quite pin down, but my mother is there, her voice
soothing the pain, softening the sadness.
(LEE I)

> I try to walk each day, as far as possible.
> This is one of my favourite spots, on a bridge, where the reflections changes with the weather and the seasons. No two days are alike. And that's like constant, chronic pain conditions - no two days are alike. But some days, the sun shines, there's a warm, gentle breeze and you can simply, "be" and enjoy, without that irritating background noise (pain) interfering.
> There are other days when the sun still shines, but all you are aware of is the dark clouds on the horizon, that sense of foreboding, the knowing that you might be coping, now, but things are about to change.
> And then there are the days when the rain pours. I'm hoping in these sessions to explore different ways of communicating these feelings and, in doing so, to learn techniques (perhaps) to keep those clouds at bay, to notice them, maybe, but not let them spoil the day.
> 'Be it so; It is an injury,' said I, 'to this day
> To think of any thing but present joy
> (LEE 12)

AN EXPRESSION OF A COMMUNITY: A SPACE TO BE HEARD

The lived experience experts had a range of health conditions (see wordcloud). The length of time living with chronic pain ranged from a few years to more than 30. Pain was described as complicated, constant but ever changing (LEE 18), periodic and episodic in structure
(LEE 28, LEE 3, LEE 6).

Individuals spoke of different versions of themselves, referring to the 'old' and 'new' me, lives before and after chronic pain. One person described how the old them chose "to ignore and push through fatigue and pain for years, driven by the stress of work and wishing to live a full life" until chronic pain forced them to stop working (LEE 6).

Life was described as an "ongoing project" that involves "making compromises and trying to reframe the negative thoughts/emotions" to attach to those compromises (LEE 10). Some refused to allow the pain to define them (LEE 11, LEE 4), not wanting to lose themselves in catering "to others' expectations and needs" (LEE 4). One person stated:

> “ I have full acceptance of my pain and am very much a glass half full person ever seeking to improve my health but set myself no expectations.
> (LEE 6)

Different approaches to pacing were highlighted. One person described how slowing down allowed them to move at a faster pace in their lives (LEE 4). Another described taking each day as it comes hoping to find flexibility alongside living with pain (LEE 18), while someone else explained that they plan what they can for their week making room for spontaneity to encourage them "to be present to what is" (LEE 3). Another lived experience expert makes a "considered decision to do too much", planning activities that they know "may cause an adverse reaction and pain" because the benefit to their wellbeing "outweighs the pain" (LEE 6). Someone described their experience of oscillating between living a full life and accommodating pain:

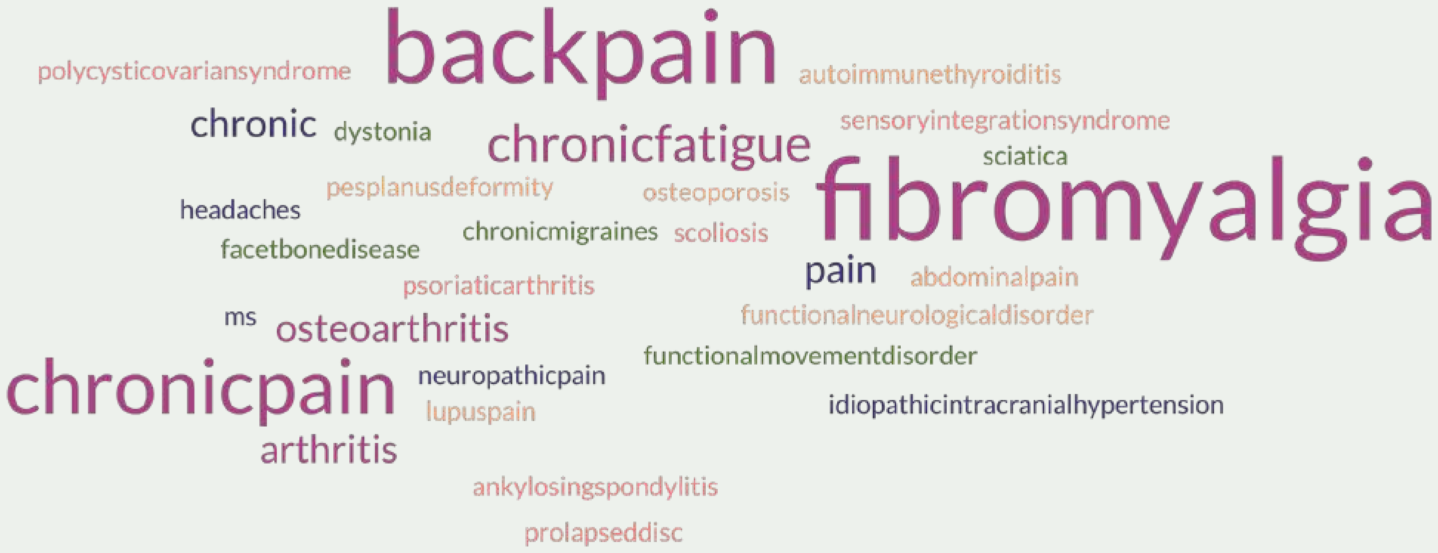
> “ I find myself in a state of denial that my pain controls me, [...] my actions [...] my thoughts have succumbed to the defeat, that pain is always a part of me [...] the choice to not give the pain a voice. So emotionally, I feel stuck in the constant cycle of saying yes to life [...] even though I can't because my body has already made its decision [...] Another day of nothing because it's simply too much. Overwhelmed by my lack of space between no pain and no gain. How can the world be my oyster when I've never seen or swam the sea? I choose to see through the pain as a journey to become surer of who I am. I need to keep on keeping on. Even if it's one step at a time.
> (LEE 28)

The lived experience experts brought a wealth of personal and professional experience to the project from fields including dance, yoga, visual art, crafts, singing, and writing. For some, creative engagement was already part of their everyday lives while others had not engaged in creative and artistic activities since childhood.

The group was diverse in age and demographic with a "wide diversity of backgrounds, personalities, approaches, perspectives, and ways of thinking and approaching things [...] The group diversity and sharing of ideas and thoughts was synergetic and allowed a virtuous circle of idea generation and thoughts to benefit all" (LEE 6). For one person:

> “ The most touching thing about the session is how different we all were. In age, ethnicity, and backgrounds [...] it took me a while to distinguish the facilitators from us the attendees.
> (LEE 26)

Connected by experience, the project was described as a "gathering" and "an expression of a community" that was "full of life despite pain" (LEE 18). In the "thought provoking" (LEE 18) and inspiring (LEE 12) sessions, it was interesting "to hear everyone's experiences of pain and creative expression" (LEE13). One person described how they were inspired, in awe, and impressed "at how each person identified and related their experience of pain"
(LEE 15).



A WORD CLOUD REPRESENTING THE HEALTH CONDITIONS OF LIVED EXPERIENCE EXPERTS TAKING PART IN THE LANGUAGE OF PAIN.

EXPERIENCE OF THE CREATIVE RESEARCH

Working together and sharing experience was described as motivating, understanding that “although our experiences and journeys are different, we are on the same quest for peace, solitude, and pain free bodies” (LEE 15). In focusing on creative and artistic engagement, making “something greater than the sum of the parts we brought was so uplifting” (LEE 12) and acted as a reminder and/or realization that individuals are not alone (LEE 11, LEE 12). The value of the shared space was further highlighted in reflections:

> “ I don’t generally tend to engage with group activities but have an overall impression that this could only be beneficial to my wellbeing (LEE 4).

> “ Sharing in the small groups gave me the impression that there is still a lot of desire to talk about our conditions, pain and how we manage. It is a relief to come together with people who understand your experience (LEE 7)

> “ The fact we never necessarily have to mention pain was evident to me again this week but when I work in the small groups there is such a mutual understanding and respect that this is an expression of our pain because it is an expression of ourselves.
> (LEE 18)

Having previously experienced challenges in discussing the lived experience of pain and trauma with others, the opportunity to listen and relate to others was beneficial (LEE 13). One person explained:

> “ It’s a very surreal feeling to live your life knowing that the majority do not understand what chronic pain is [...] it struck me to know that there are others who go through untold pain [as well] and to be in the same room at the same time and not to be judged is a very unique feeling that I have not been allowed in any other circumstance (LEE 4).

Several people described feeling nervous at the start of the project (LEE 1, LEE 13), unsure about what to expect (LEE 2, LEE 17, LEE 22), apprehensive about not knowing who else would be involved (LEE 5), anxious about what they would be asked to do (LEE 17, LEE 26), and concerned about sitting for a long time (LEE 1, LEE 26). Yet once engaged, they found the experience to be joyful, uplifting, releasing, lively and interactive, relaxing, friendly and informative (LEE 1, LEE 14, LEE 13). Watching others express themselves helped one person overcome their feelings of shyness, and another was “put at ease straight away” as they were “made to feel welcome” because everyone was joining in (LEE 17). Others reflected:

> “ I felt relaxed and comfortable with the organic process of the session and watched myself unfold amongst total strangers. (LEE 14)

> “ I also had so much fun and laughter along with the challenges today. Everyone was kind and compassionate. (LEE 23)

> “ I appreciated everyone’s feedback - so unique and wholesome. I can feel the strength, tenacity, and commitment to sharing our individual experiences, and I hope this will continue in whatever way the project wants to develop, shape and grow - I’m all in! (LEE 14)

In walking into the building where in-person attendees gathered, one person felt their pain dissipate:

> “ it was an exhilarating experience with an overwhelming feeling of connectivity and love. This would normally be something that would put me off, make me turn around or second-guess myself as to whether I should be in certain situations. I compare it to when going to the doctors, knowing that I’m going to discuss the pain I feel generally low and anxious due to the feeling of knowing there is no understanding of my stressors (LEE 4)

Another explained that the project meant “not having to explain yourself” (LEE 22), and another reflected:

> “ I realise that I have been judged by others on my pain as my condition is not always apparent. So, I’ve been told to pull myself together by family and friends and strangers. So, it’s been hard going, to get accepted for who I am and to accept my pain as part of the process (LEE 23)

For some, The Language of Pain was an opportunity to feel useful, finding a renewed sense of purpose (LEE 10, LEE 13). This was identified as important because a lack of purpose can negatively impact wellbeing and, for one person, has been “the hardest thing to come to terms with” (LEE 10). The project gave structure to the week, exercised the brain, and supported engagement with others, all of which was beneficial for self-esteem and confidence (LEE 10). One person explained that:

> “ When I was well and working, I was very creative in my jobs [...] so it’s very hard for me now that my creative life is limited. So, I have to find outlets which this study is helping me to find, and it is definitely having a therapeutic effect (LEE 13)

This person facilitated part of a creative research session, sharing a drawing practice they find useful for pain management. Reflecting on the impact of this they explained that the opportunity:

> “ showed me the steps that I have made within myself that I was able to do it [facilitate the activity]. I really enjoyed preparing it as gave me a bit of purpose and focus that week as I prepared a bit each day within my pacing envelope. I had a very stressful week, and it took me away from it which helped loads. (LEE 13)

THE INVISIBILITY OF PAIN

Central to lived experience of chronic pain is the invisibility of pain, a theme that regularly appeared in reflection and discussion. Society's projection of "wellness onto an unwell body" means that if ill-health is "not apparent and very, very visible, you're made to feel like you are lying" (LEE 7). Subsequently, one person described putting on "a brave positive face" to mask the pain so not to "alarm others": "using humour as a coping mechanism is easier than showing reality of chronic illness" (LEE 13). Another person described their pain in the following way:

> "Pain is an amoeba. It can't be seen with the naked eye but spends time nibbling away my innermost parts. Just as how the amoeba develops pseudo legs and crawls about, that's how the pain walks through my body especially at nights (LEE 15).

The image of an amoeba resonated with others. In response to this idea, an artist shared how they work with the idea of invisibility to create:

> "little drawings with my pen which I paint over with white so it's hardly visible anymore because [...] I can't quite locate it, but I know it's there. Sometimes it's really easy to locate it. Sometimes it's not easy to know in which depth it exactly lies or what exactly is happening. It's more like a little chaos [...] I often paint with a lot of white because I feel a lot of numbness sometimes as well, and it's almost like these areas that I can't feel or really understand [...] but I'm not quite sure if anybody else would really perceive that from just looking at them. (LEE 7)

Lived experience experts described at length their experiences of working with medical professionals. When "something clicks they [the doctors] take you more seriously" (LEE 2) but until then it can be a difficult and frustrating journey (LEE 28, LEE 22). Finding support can be a process of "trying to access the right person and trying different routes, different types of therapies and trying to find the right person that can help you" (LEE6). One person shared their experience:

> "It took ages for anyone to even listen and mildly understand. I was treated as if I was mad, unbalanced, crying wolf even because tests and tests didn't show anything. The only significant test was where they thought I had arthritis [...] eventually they sent me to a rheumatologist who simply gave me a leaflet and that was it!! (LEE 22)

It was highlighted that feeling like a hypochondriac or attention-seeker can lead to disengagement with the medical system (LEE 2). Everyone acknowledged that the limited amount of time health professionals can dedicate to each patient is part of the challenge. Furthermore, it is felt that system "can't seem to cope with people who have got several things wrong" (LEE 7).

PAIN IS AN AMOEBA. IT CAN'T BE SEEN WITH THE NAKED EYE BUT SPENDS TIME NIBBLING AWAY MY INNERMOST PARTS. JUST AS HOW THE AMOEBA DEVELOPS PSEUDO LEGS AND CRAWLS ABOUT, THAT'S HOW THE PAIN WALKS THROUGH MY BODY ESPECIALLY AT NIGHTS (LEE 15).

RESISTING LANGUAGE

Chronic pain has a measure of incommunicability, and this was the primary motivation for the creative research project. We explored arts-based methods as an alternative to language which can be limited in describing experience and is often loaded with preconceptions. A writer joining The Language of Pain is "fascinated (as well as frustrated) by pain", explained that:

> I'm always looking the right word, a good metaphor, the best way to communicate thoughts and feelings. As a teacher, I strive to impart knowledge and ideas and a love of language. But (as Elaine Scarry says) 'Physical pain does not simply resist language, it actively destroys it, bringing about an immediate reversion to the sounds and cries a human being makes before language is learned.' So, I'm at bedrock trying to re-build the bridges of language, to find a form of words that works or to combine different form of communication in a form especially for pain. (LEE 12)

The creative research sessions helped to think about the language used to described pain and how this was received by others (LEE 23).

> I've been wondering how to express my relationship with chronic pain and its impact on my life and until this afternoon [when we met for The Language of Pain] I just couldn't think of how to do this [...] for me, 'regular' speech/dialogue seems inadequate, I find the words petering out on my tongue as I try and explain - this can be because I am so very bored of trying to make sense of it myself, or trying to make sense of it for others. Or because I am so tired, or my brain and my mouth seem to have disconnected from each other, or because I feel guilty and ashamed, or feel a fraud, or I'm just plain fed-up of 'obsessing' about myself/health. (LEE 10)

The ableism of language and the speed of communication was highlighted how one could feel as though they appeared less intelligent if it took them a while to get their words out (LEE 4).

Lived experience experts described the necessity of having to categorise their pain within pre-existing frameworks to medical professionals:

> They don't give you a chance to describe something different. So sometimes it's difficult because it doesn't fit, so you don't know what to say, what kind of pain (LEE 8)

It is not "really easy to get through" to medical professionals because feelings need to be "put into a specific box" so that the treatment path is clear (LEE 7). Different kinds of medication will be prescribed for a stabbing pain than for burning pain, but it is necessary to choose the closest category, even if the pain does not fit into "prescribed boxes" (LEE 7). While "language can put things into specific boxes, metaphors can be useful" because of the link to imagery which can be helpful in sharing experience:

> Sharing my experience of pain can be quite difficult and emotional. I would like to relate to it as a sudden turbulent storm emerging from a rough sea, trying to destroy everything in its path. Then suddenly there is peace (LEE 15).

PICTURES AND IMAGES

In The Language of Pain, we used images to communicate in a language without words. Talking about pain is a temporal expression of symptoms in which someone "can latch onto anyone thing in the list" and choose to highlight or prioritise something for whatever reason (LEE 7). In comparison, images present all the information at once to generate a more holistic explanation:

> with this drawing [...] now you have a clear view that there are a lot of different parts, and you can't really ignore any of them. (LEE 7)

Images can articulate the multiplicity of pain, that the experience is more complex than only sensation. It is:

> also so much about the everyday and how the social life changes and how the mood changes and all of this. And I can't often separate that from the feeling of pain very easily. I often feel like [...] trying to describe the pain maybe also describes all of these things at the same time, but not everybody is really interested in these other bits. (LEE 7)

While putting "a word to the pain is really difficult [...] it can be easier to show or describe in an image-based way" (LEE 7). Using a diagram of the body can communicate to family and friends what someone is going through (LEE 4, LEE 7) and "seems to help to make people more curious" (LEE 7). Although, using images to 'speak' to medical practitioners did not spark the same curiosity (LEE 5) leading one person to suggest that "there is not much interest for alternative means of conveying sensation "because it doesn't lead to a prescription" (LEE 7). Pre-drawn images of bodies, such as those offered by pain specialists, can help highlight where the pain is:

> Sharing my (fairly gruesome) images of how I see myself with pain (lee 18). I see my pain as sharp, spiky, radiating outwards. My daughter sees this picture as a dandelion losing its fluffies. Interesting how different our perspectives are. Me living in pain and her living with me in pain (lee 18)

Here, notes can provide context and colour-coding can indicate the qualities and depths of pain. "The pain is different every day and it's different shapes and it's different colours" (LEE 6). Sometimes the use of images is not always "about the pain as such directly. It's what mood you're in" (LEE 6).

The project highlighted that images are not always about representation and communication but can make you feel better, and/or be a mechanism for understanding for oneself how the pain feels, "or what's going on," (LEE 7). An artist involved in the project explained:

> I paint a lot. I started to paint a lot because of my experience of chronic pain. Not just to communicate it to others, but it's almost a cathartic experience to express it somehow and give it a reality helps, so that it's not intangible. I often understand through that process a lot more about how I feel. So that's for me a whole other thing about what images can do. (LEE 7)

Images can offer a unique expression of what is going on in the body, a sense-making mechanism which can in turn enable more words to come. In this sense, pictures, images, and drawings could also form a personal archive of experience, a reference point to refer to what was going on at a particular time.

SHARING MY (FAIRLY GRUESOME) IMAGES OF HOW I SEE MYSELF WITH PAIN (LEE 18). I SEE MY PAIN AS SHARP, SPIKY, RADIATING OUTWARDS. MY DAUGHTER SEES THIS PICTURE AS A DANDELION LOSING ITS FLUFFIES. INTERESTING HOW DIFFERENT OUR PERSPECTIVES ARE. ME LIVING IN PAIN AND HER LIVING WITH ME IN PAIN (LEE 18)

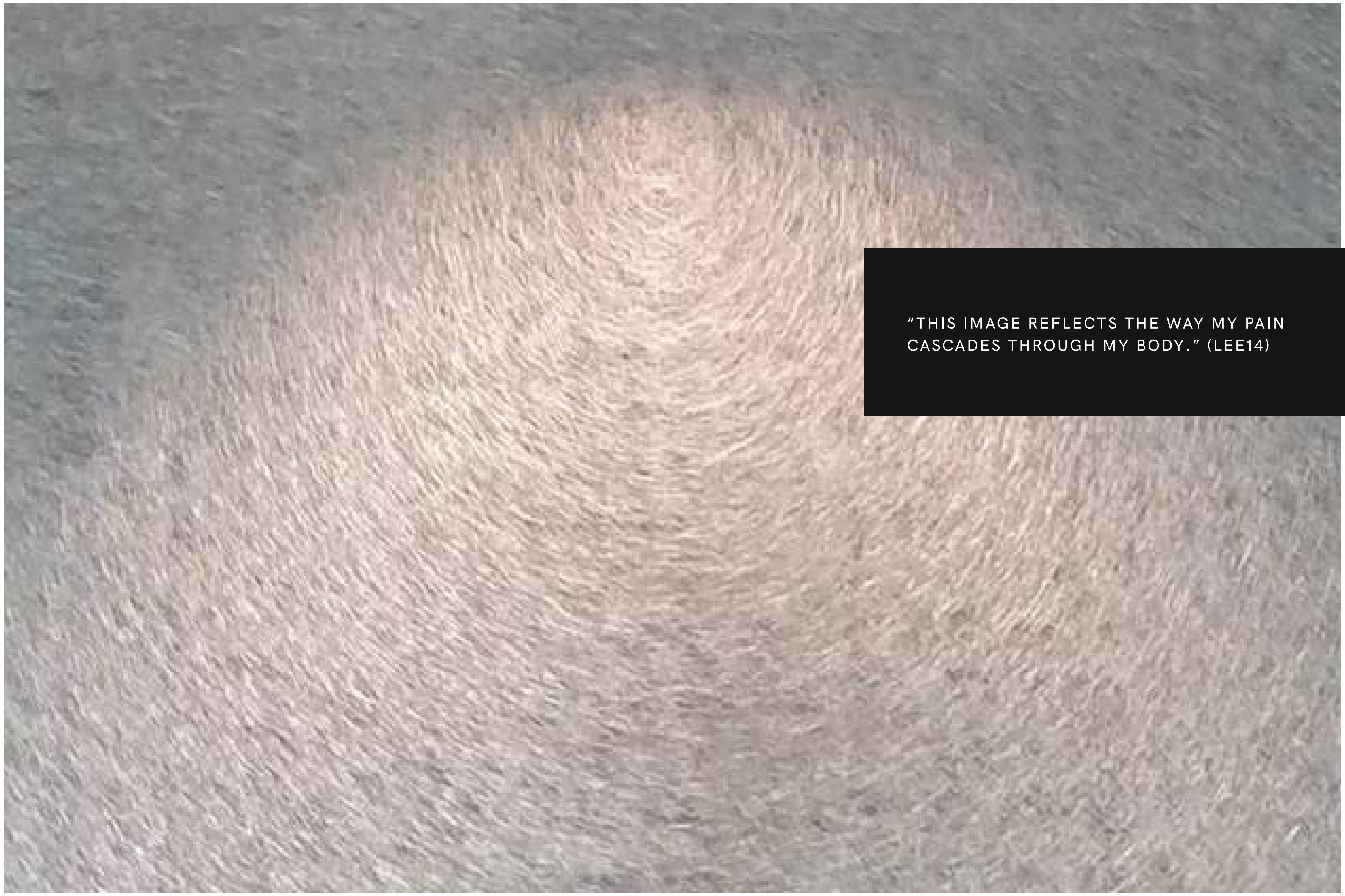
Painting and making images can be a means to resource what the individual needs at a particular moment in time. Using art to "purge your body in pain" constitutes a dialogue with oneself and can feel "similar to when someone listens to you" (LEE 6). It is:

> "more about having a dialogue in which I am not judged, in which I do not need to use words and in which I can use my painful experience for a creative process, make it into something good [...] It's actually helping you deal with your own pain by just expressing it. It's like a dialogue without words. (LEE 7)

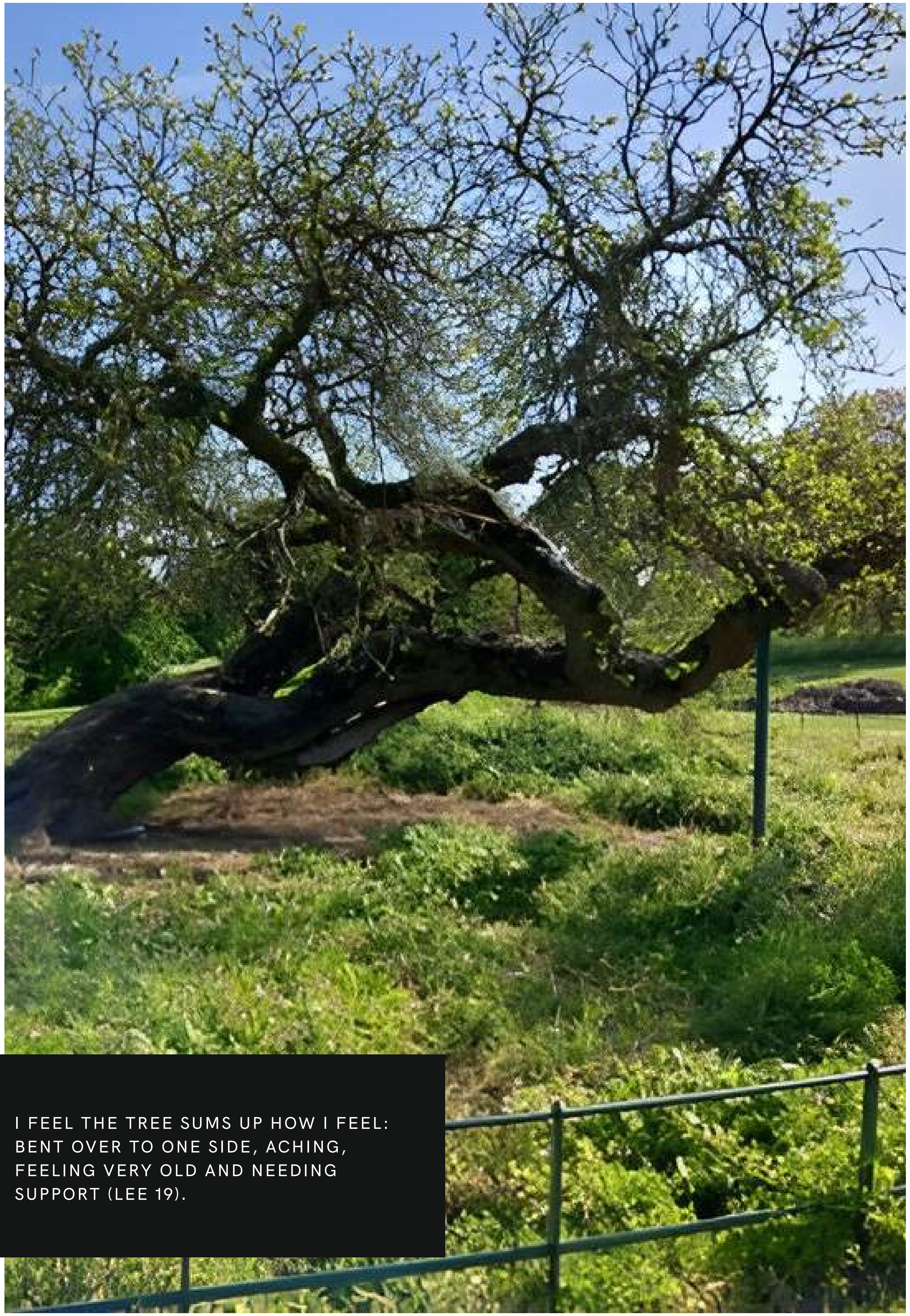
Images can be used to express feelings:

> "I paint a lot [...] But I don't want to describe the pain [...] I just would like to show the anger in some way. Sometimes [...] I would like to describe the opposite, not my pain, but the other things [...] to relieve me, because sometimes thinking, thinking about the pain and thinking about the stress make you more stressed. So sometimes I would like to draw nice flower, completely opposite of what I feel. And sometimes, you don't need to share with the things with the people [...] because you'd like to be hidden. You don't want people know you are in pain, or you are in suffering or whatever. (LEE 8

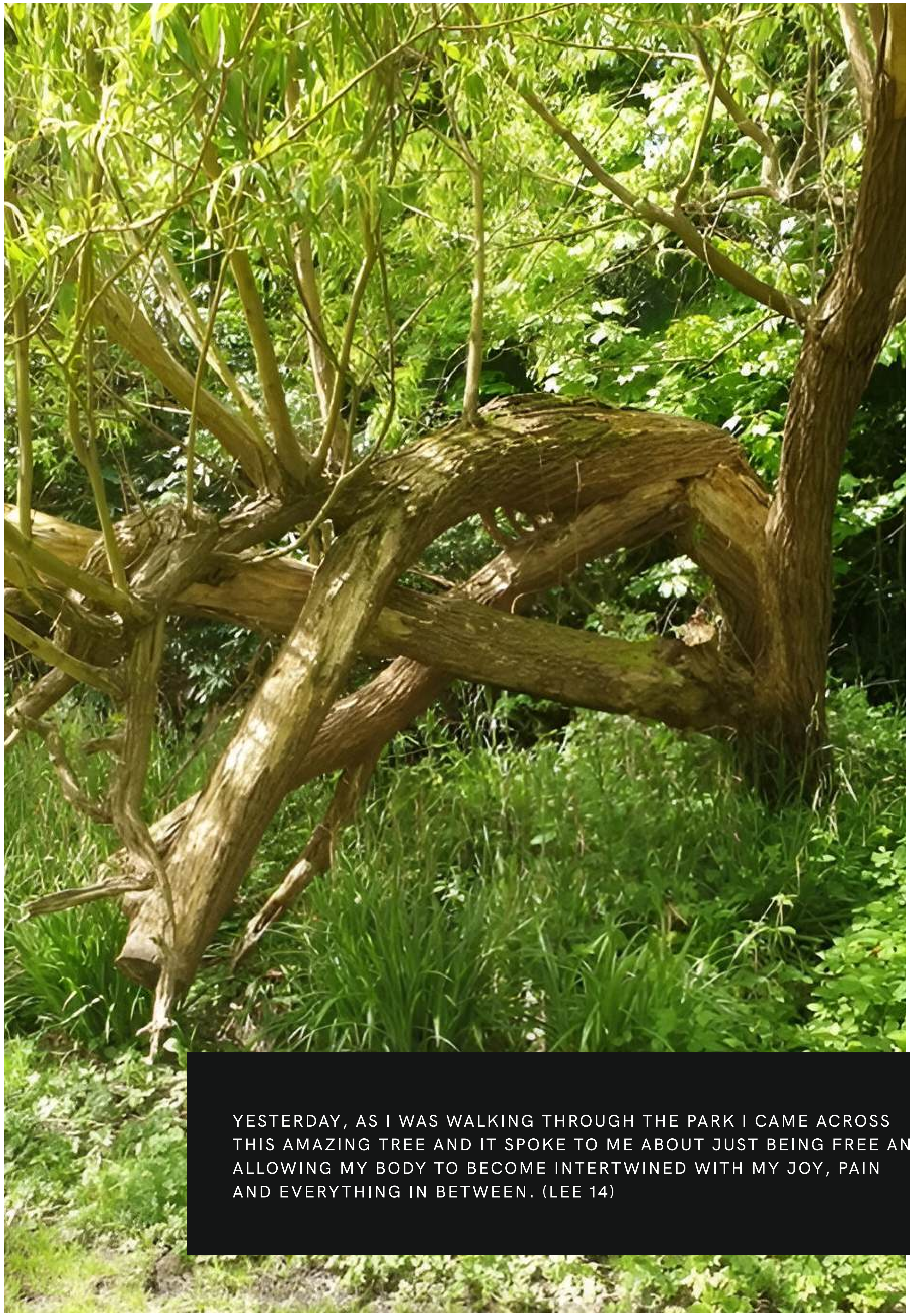
Used to relax, images can be used to "ease a bit of pain" (LEE 7). For example, if you are stressed an image or video of the sea or a waterfall can help (LEE 7). Using art and creativity to "meet the pain where it is" can have a distancing effect, serving as a distraction method or pain management technique – an outlet for pain.



"THIS IMAGE REFLECTS THE WAY MY PAIN CASCADES THROUGH MY BODY." (LEE14)



I FEEL THE TREE SUMS UP HOW I FEEL: BENT OVER TO ONE SIDE, ACHING, FEELING VERY OLD AND NEEDING SUPPORT (LEE 19).



YESTERDAY, AS I WAS WALKING THROUGH THE PARK I CAME ACROSS THIS AMAZING TREE AND IT SPOKE TO ME ABOUT JUST BEING FREE AND ALLOWING MY BODY TO BECOME INTERTWINED WITH MY JOY, PAIN AND EVERYTHING IN BETWEEN. (LEE 14)

> The deer in the centre of Marc's painting - in one interpretation - could represent how my life has stopped, become frozen, shattered. For years I had been bounding through the forest, trying to ignore pain and fatigue, until I couldn't. In my early forties I found a job I loved, which drew upon my varied life, work and creative experiences, and I had planned to undertake a master's to continue and develop this career - but ill-health up-ended these plans.
>
> So, the painting could represent shattered and frozen hopes and dreams [...] the deer could also be me throwing my head and voice up to the moon and howling [the facilitator's] chant (from last week's session) deliciously out of tune, joyously mispronouncing the words and scaring the socks off the dark, creeping beasties to the right of the painting which regularly need to be kept at bay.
>
> (LEE 10)

PART TWO

IN PART TWO WE DISCUSS THE LANGUAGE OF PAIN PROJECT IN MORE DETAIL AND TOUCH UPON THE PROJECT’S IMPACT.

EMERGENT DESIGN

The creative sessions were not didactic but employed approaches common to participatory arts. The project was emergent in design, responsive to the contribution of all involved. Ongoing reflection from everyone (lived experience experts, the arts facilitator, the occupational therapist, the professional researcher, and project managers) was crucial to shaping the direction of the project. The "adaptive approach" was described as "pioneering" and beneficial for those involved (LEE 6).

Creative expression was fundamental to exploring and sharing personal and collective experience. Each week adopted a different focus: movement, voicework, drawing, writing, poetry, and songs were all used as means for creative expression. End of session discussions reflected on the experience of the activities, and group Padlets provided a space for ongoing reflection and collaboration outside of scheduled sessions[2]. Padlet morphed into a communal space for asynchronous communication where experience, creative outputs, and resources (e.g., podcasts, news articles, and book recommendations were shared[3]. Throughout the project the Trinity Laban team elicited suggestions and ideas for what could be explored in future sessions, and invited lived experience experts to facilitate parts of the session if they wanted.

THE BODY: AGENCY, AUTONOMY, AND SUPPORTING ENGAGEMENT

Agency and bodily autonomy were crucial to the project. The lived experience experts had a lot of knowledge about their bodies and well-established self-management skills. Reminders to respond physically and creatively in ways that make sense and feels best were embedded into all activities. Chairs, cushions, yoga mats, and large bean bags were provided in the physical space so individuals could determine how they positioned themselves. Online attendees working from home were encouraged to utilise any props to ensure comfort.

> “ Each week the sessions have brought some unique experiences through art which has helped to take the focus off the daily pain (LEE 9).

Tiredness, exhaustion, and pain meant that motivation could be a challenge:

> “ I battled with myself somewhat whether to attend as I felt so exhausted, and motivation had plummeted - but I am so glad I made the decision to ‘do’ the session from bed (!) as a compromise (LEE 10)

> “ I felt nervous about joining group again this week pain was not good and was feeling really tired [...] the session was just what I needed my pain was not great and I was going to cancel but changed my mind last minute and I am so glad that I did. (LEE 17)

Some reported challenges joining creative sessions when in pain or tired which could impact concentration (LEE 10, LEE 17, LEE 15).

PROJECT STRUCTURE AND DESCRIPTION

Each session followed a similar structure:

1. Coffee and catch up
2. Welcome to the space and checking-in
3. Entering into the space: guided warmup / somatic tracking
4. Solo or group creative exploration
5. Sharing and reflection
6. Closing circle

A short comfort break usually followed the guided warm-up. Striking a balance between getting to know each other, working together, and reflecting on the experience of the session was an ongoing consideration.

1. COFFEE AND CATCH UP

Establishing a sense of community and belonging was important to the project as it would support the sharing of individual and collective experience. Social time was built into each session: the physical space opened 30 minutes before the session start and light refreshments were provided for in-person attendees to help them settle into the space. The online space opened 15 minutes before the start of the session, and everyone was encouraged to chat over a cup of tea.

Early on, attempts were made to socialise in a hybrid manner. While working well for those in the studio, the experience was less fluid and comfortable online. When the physical space was unmuted the sounds of people arriving and talking beyond the microphone's reach created a jarring and discombobulating soundscape and disrupted the conversational flow for those in the virtual space. Restricting the social time to in-person only and online only made it easier to establish group connections.

This time before the start of the session was also an opportunity for the Occupational Therapist to check in with individuals' needs and, at times, provide coaching and/or support.

2. WELCOME TO THE SPACE AND CHECKING IN

At the start of the project in-person attendees were invited to wear nametags to help get to know each other while online attendees were identifiable by their Zoom handle. Because it was not possible for online attendees to read the nametags, physical descriptions based on clothing were written into the Zoom chat and repeated later where necessary. Name games helped with familiarisation[4].

In welcoming everyone to the hybrid space, the session structure was verbally introduced, written on a whiteboard in the studio, posted in the Zoom chat, and uploaded to Padlet. The group then ‘checked into’ the space by choosing a word to describe how they felt.

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[2] Lived experience experts shared insights about the project through written reflections, voice notes, drawings, poems, and visual imagery. One-to-one Zoom meetings were held for individuals experiencing challenges in reflecting upon their experience. The Trinity Laban team also reflected in similar ways.

[3] The ease of using Padlet was nicely encapsulated by one person who felt that it didn't make them feel like "a complete tech-dinosaur" (LEE 10). However, the inability to share multiple images in a single post felt limiting to some who were concerned about taking up too much space through multiple postings.

[4] In a call and response activity, for example, group members took turns saying their name accompanied by a gesture of their choosing, both of which were then repeated by the group. This improvised gesture tapped into spontaneity and was an early opportunity for creative expression.

3. ENTERING INTO THE SPACE: GUIDED WARM-UP / SOMATIC TRACKING

> I felt very at ease and really comforted to know I was in a safe space to be – mentally, physically and psychologically (LEE 26)

Somatic practice – placing the body at the forefront of experience – was central to the project. Attending to the present moment and the process of doing was prioritised over outcome. From the start, the collective worked with physical, mental, and emotional awareness. Recognising that how we feel is not stable but in flux meant that we met the body anew with each session: recognising, listening, and honouring where we are at without judgement.

Everyone was invited to work from a posture that made sense for their body on that day. Recognising that being seated in front of the screen is a default setting, individuals were encouraged, where possible, to work from a space away from the screen and chair, particularly if they were participating from their home environments. The collective was encouraged to take off their shoes, spread their toes, and feel their connection to the ground. There was an invitation to close the eyes for those who felt comfortable in doing so, follow instructions, and respond intuitively. Closing the eyes and turning attention away from the screen encourages deeper attention towards how one is feeling.

> I enjoyed the warm-up in which we faced away from the screen and the way it did not tell me how to move but rather used imagery. This allowed me to find a softness in my body and a soft compassion towards how it felt. (LEE 7)

Somatic tracking and guided warm-ups set the precedent for the remainder of the session by establishing a foundation for witnessing bodily experience and sensation. In some sessions, entering into the session took the form of a 'body scan', an invitation to focus attention on the sensations of different parts of the body systematically from head to toe. In response to this task, one person reflected:

> I like the contrast of focus and drifting - when my mind slips off to an even more restful plane and then returns to focus on the next area of the body. I've realized that I've never thought about body scans in the following way before: that I get comfort/rest/ease from my body - words I don't regularly associate with my body! (LEE 10)

The importance of breath was emphasised, and this was found to have a relaxing, releasing, and calming result:

> I really enjoyed the breathwork. This took me away to spaces that reminded me of my childhood. Feeling warm sensations that mimic nature's elements, gave my whole body the opportunity to just be in the moment and to feel the energy cascading through my - sometimes scrambled - network. Overall, the session was lively and interactive, and I came away with a sense of release. (LEE 4)

> Thursday's session gave me hope - that all is not lost in living with chronic pain. This session bellowed out my breath with its warmup and relaxation exercise. This has reinvigorated my soul to use these techniques and just to have some fun. It takes away the constant focus of my pain and turns it into a collective cacophony of joyful expression. (LEE 14)

> The breathing exercises were more deliberate. I could lose myself in each body part and feel the tightness slowly drain away. (LEE 14)

In some weeks, guided improvisation encouraged attention outwards towards the physical environment. Prompts were given to move around the physical space, explore different levels, notice previously unseen details, and acknowledge other bodies. Taking time to witness, to stop, and be curious helped to connect people to their environment. Movement helped connect to the body and allowed for the expression of self through the pain. A dance practitioner joining the project as a lived experience expert articulated the contradictory nature of "being in pain while moving but knowing that movement itself was the going to be the cure" (LEE 1).

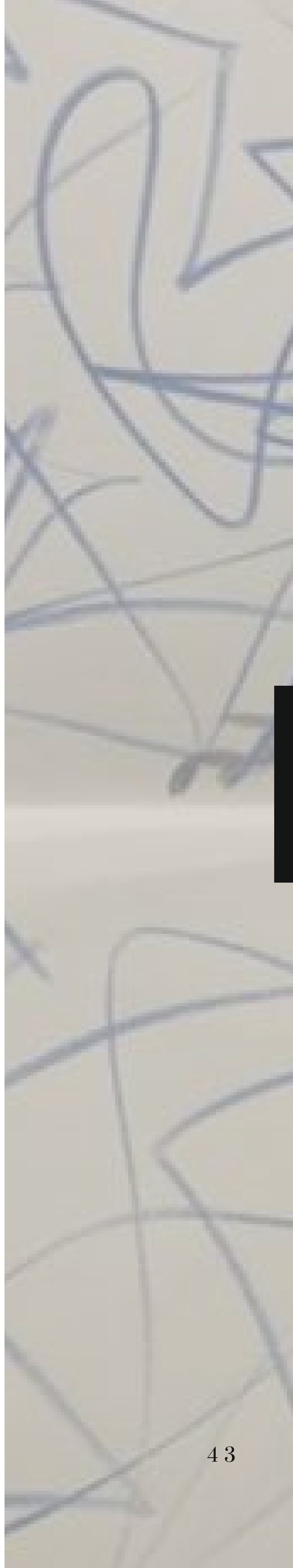
Some found that the movement and breathing exercises released "trapped feelings:

> The way the facilitators and other participants joined in made me feel safe and secure and listened to more than I have ever experienced. Some of the work brought me to tears as I felt, for the first time, validation. As I started crying, I couldn't stop. Then, I was feeling lighter. (LEE 23)

Another person reflected that their tearful response was indicative of "trauma that needs releasing" (LEE 13). A third person who usually tries to "suppress deep feelings, so crying is very rare" found tears 'rolling down their cheeks' in one session: "That suppression of feelings I'm convinced is a causal factor in my chronic pain" (LEE 6).

The art facilitator's philosophy that "we sing to feel good, not sing to sound good" guided voice work. Turning attention to how you feel rather being concerned about how something sounds and "what you think others find acceptable" (LEE 6) was a powerful sentiment for many. Voicework and singing was introduced slowly with warm-ups and fun songs (LEE 19). The reassurance that they could engage with their own energy especially on 'bad days' when "using the voice is often painful [… and] requires a level of stability and breath" that can be a challenge (LEE 7) was appreciated by many.

The creative warmups were fun and revealed the creativity, generosity, and supportiveness of the group. One popular warm up was "passing the object" which encouraged creativity in movement and sound. Described as "pass the parcel - in a multiverse dimension", the task involved passing an imaginary object between people in the hybrid space: amongst those gathered in a circle in the studio and through the screen for people taking part remotely. Making the connection between the physical and virtual spaces was fun and facilitated interaction between the online and in-person communities (LEE 19). The task was an opportunity to "Embrace how you feel and know you can keep going" regardless (LEE 22). The 'object holder' decided what the object represents and its dimensions, qualities, and characteristics. They decided how it moves and the sound it makes.



Imbued with meaning, the collective understood the need to take care of this precious imagined object:

> This is the energy ball speaking to me: Passing the energy, look how I changed, look how changeable I am, look how pain can change, my soft hum became a face full of joy, of open laughter, full and joyful, with a care for all and others. Look how I change, how I wish I could feel that free, easy, beauty, light and with ease. You can because I am you, you are me and this is you. I see this expression as a way of sharing the burden of pain and how this expression of beauty is actually an expression of pain. How pain is fluid, adaptable and can be shared and can be supported by others. That it is not a single sensation experienced by a single individual but a collective experience that relies on what is happening all around us as to whether this experience is pleasant or insufferable. In sharing our interpretations this felt supportive and feelings of joy were more overpowering than the pain itself. (LEE 18)

One person explained how the object "took control and blended with my energy […] I was able to stretch and express myself in ways that I haven't done since primary school" (LEE 17). Another reflected that, for them, the object was "filled with of our emotions and pain" and the task allowed them to release "it all and then pass [the object] on so that others can do the same" (LEE 7). A lived experience expert wrote a poem about the passing the object:

> From emotional to calming… you are not alone…
> here whenever needed
> I was feeling a bit emotional
> The object came to me
> Warm feeling came over
> The object calmed me and said
> You're going to be okay
> Let it out before it breaks out
> Hold me and let my calm energy comfort you
> You see as you hold and appreciate
> Its rubbing on you
> Keep a hold until you are ready
> I'll be here for you whenever I'm needed
> Don't feel alone
> Embrace how you feel and know you can keep going
> (LEE 22)

The responses to the task were as unique as each person, and intuitive explorations were received without judgement. The task was most successful when the group emulated the object holder's physical and vocal response. Sometimes this materialised organically, at other times was found through prompts. The collective found that they were able to share their experience of pain without having to make explicit reference to it:

> “ Something about the “object passing” seemed to get under my skin, somehow, and transformed itself from the light, airy, sunny thing I received [from another person] to something very dark and heavy, eventually settling into something calm and weighted. All without any conscious thought whatever! (LEE 12)

> “ I had such strong feelings and emotions based on that ball, or whatever we wanted it to be [the task] was actually us all sharing the burden of pain and I honestly felt it was such a respectful gesture, almost ritualistic in how we gave each other such gentleness and strength to share the heavy weight of pain. I have no idea why, but it was hugely symbolic for me even if it was not intended to be. (LEE 18)

> “ I feel I get so much out of this exercise. To me the ball feels like it filled with my emotions and pain and I'm letting go of it freeing myself and sharing with others their own movements and feelings as we work together. (LEE 17)

Somatic tracking, improvisation, and creative tasks were powerful ways to start the creative research sessions. “Engaging with the body in a calm, focused way” provided “a seamless transition from the body scan to movement and sound” (LEE 10). Described as “exhilarating and fulfilling” (LEE 15) one person reflecting that they “would have happily done this [the warmup] for the whole session” (LEE10).

4. SOLO OR GROUP CREATIVE EXPLORATIONS

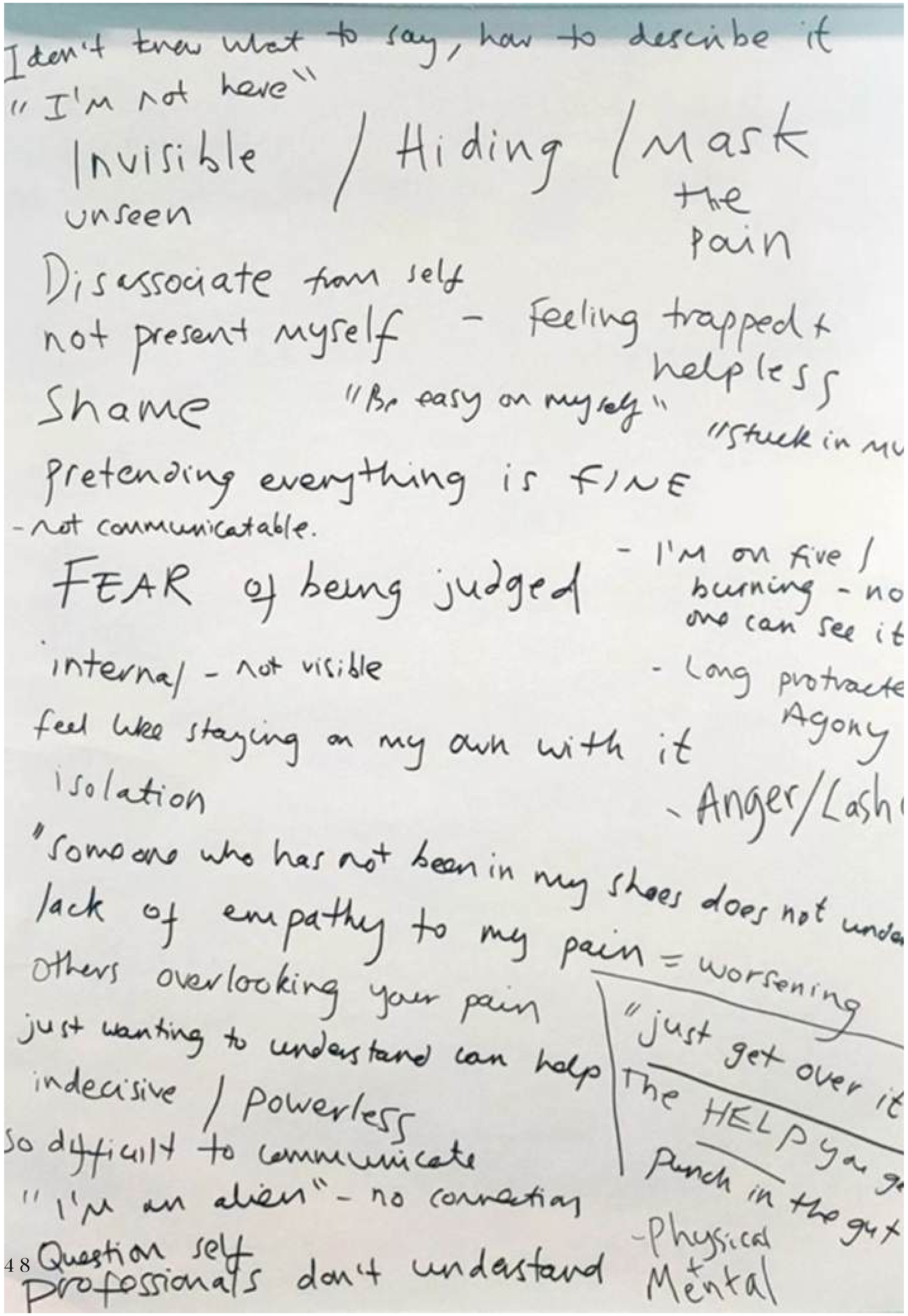
Creative exploration followed the warmup, the focus of which changed weekly in response to how the group was working and what they were working with. Not predetermined, the structure emerged according to the needs of the group as perceived by the facilitators or articulated through the reflection of lived experience experts. Sometimes solo tasks were explored, at other times activities were collaborative. Each activity was designed to be accessible, meeting people where they are 'at' in terms of prior experience and allowing everyone to respond in their own way. The activities explored during the five-week pilot study are described below along with individual and collective experience.

WEEK 1: WHAT WOULD YOU LIKE OTHERS TO KNOW ABOUT YOUR EXPERIENCE?

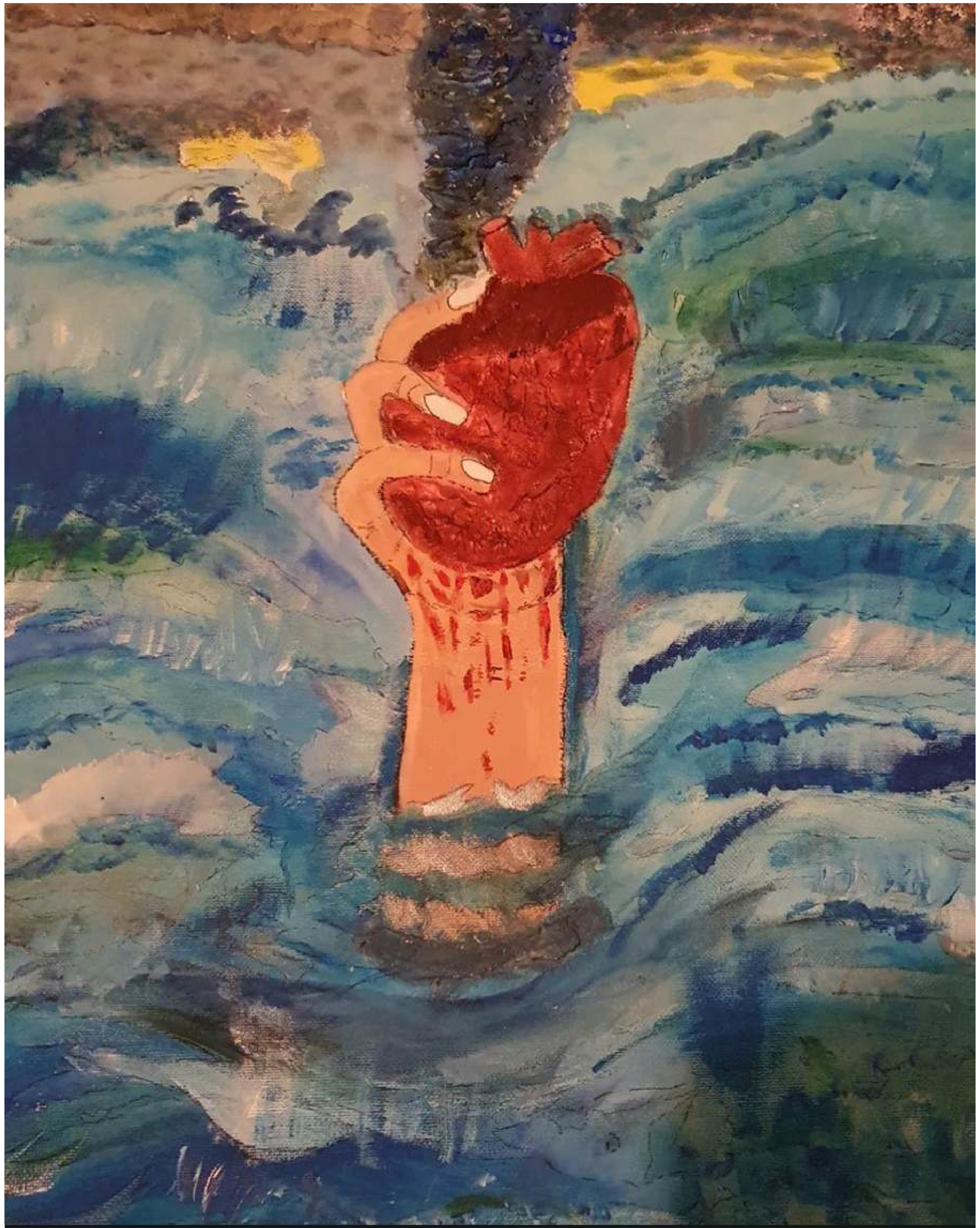
Week 1 provided an opportunity to consider individual and collective experiences of chronic pain. The collective was asked: What would you like others to know about your experience? Here is a selection of the responses:

- Pain is debilitating, it makes you very tired.
- Pain is totally devastating and deteriorates mood.
- The pain can change your whole day if you allow it.
- Don't let the pain hold me down. I feel it, but don't dwell on it.
- My brain is moving at 500 miles an hour, but my body can't.
- Managing and manoeuvring: how pain impacts what we want to do.
- You can't see pain, but you can feel it. It can appear invisible to others.
- Not expressing pain does not mean you are not in pain. You become acclimated to it, find ways to appear better, to manage better. That doesn't mean the original pain is diminished.
- It would be great to be treated with acceptance and not judgement, to feel listened to about the pain and not be told it's all in my head.
- You can't see me hurting when I smile… but how much of my happiness is grit.
- Mourning the loss of what I used to have but gaining a balance of what I have now. Grief. Loss. Coming to terms with it.
- When you're in pain constantly it becomes your baseline, sometimes you can forget or zone out of that pain.
- Not all pain is the same. It affects us all in different ways. No matter how much people might have in common, pain is individual. And there is no hierarchy of who experiences pain.
- Each person's experience of pain is different it is very hard for people to understand what you are experiencing […] Only you can tell your story.
- I don't constantly have the same level of functioning. I am the same person, but just because I could do something one day, doesn't mean I can perform at that standard the next.
- People don't understand your level of pain, especially when you used to be able bodied.
- It is hurtful when you need help, but people make you wait for help.
- I would like others to not feel sorry for me, but I would appreciate help and support whenever possible without always having to ask.

The collective was then asked how they shared such experiences, and what happens if words are not enough? The lived experience was described as “inexpressible”. Invisible conditions make expression challenging and “communicating the real meaning of daily, grinding pain” is a beyond language skills. It was suggested that no “one medium is capable of carrying the full weight of the experience” of living with pain but “exploring a multi-sensory format to creatively express the overwhelming lived experience” of chronic pain could be “more successful than language” (LEE 12).



I don't know what to say, how to describe it
"I'm not here"
Invisible / Hiding / Mask the pain
unseen
Disassociate from self
not present myself - Feeling trapped + helpless
Shame "Be easy on myself"
"Stuck in my
pretending everything is FINE
- not communicatable.
- I'm on fire / burning - no one can see it
FEAR of being judged
internal - not visible
- Long protracte Agony
feel like staying on my own with it
isolation
- Anger/Lash
"Someone who has not been in my shoes does not unde
lack of empathy to my pain = worsening
others overlooking your pain
"just get over it
just wanting to understand can help
The HELP you g
indecisive / powerless
So difficult to communicate
Punch in the gut
"I'm an alien" - no connection
- Physical + Mental
Question self
professionals don't understand



LEFT: MIND MAP FROM SUNDAY SESSION WEEK 1.
RIGHT: A PAINTING SHARED IN WEEK 2 THAT ILLUSTRATES THE EXPERIENCE OF LIVING WITH CHRONIC PAIN (LEE 17).

WEEK 2: SHARING AN OBJECT

In week 2, each person was requested to bring an object to the session that symbolized the experience of living with pain, or an aspect of it. In small groups, each person shared their object and were then tasked with developing a creative 'presentation' of what they collectively shared to the whole group. The image on the previous page is one example of an object brought to the session. It is an illustration of "what living with mental health anxiety and chronic pain feels like". The painter explains:

> Just like the sea, pain can be unpredictable. One day you can be caught in a storm and the sea water rush over you. You feel overwhelmed and have heart palpitations and mixed emotions. Other days you could be more calm and collected. You just never know until you open your eyes. (LEE 17)

The "very worthwhile" and "very useful" task (LEE 18, LEE 6) was an opportunity to have:

> a dialogue in which I am not judged, in which I do not need to use words and in which I can use my painful experience for a creative process, make it into something good (LEE 7).

The task was an opportunity "to show how we are connected through having chronic pain" (LEE 17).

> Seeing and hearing everyone's presentations and experiences was quite overwhelming and the empathy I felt for others knowing they live as I do, but in their own lived experience, was again a feeling of connection. All I sensed was bravery as a group and the bravery of each individual in such a compassionate and respectful way. (LEE 18)

Some were keen to delve deeper into the objects, to "see and hear [in more detail] what everyone had brought along as the 'presentations' may not have captured this" (LEE 10). One person felt that the creative presentation of the objects meant that "a few voices were lost in translation" and echoed the desired to "hear everyone's individual voice about why they choose a particular object/item to conve their own pain" (LEE 14). More time was needed for both individual sessions and the project as a whole.

WEEK 3: ANIMAL ALLY: DRAW, WRITE, AND TELL

Through moving, drawing, and writing, Week 3 explored a relationship to an imaginary animal. Toward the end of the warmup, everyone was asked to picture an animal that could or would act as an ally to them. Though a guided improvisation, we moved alongside and in partnership our animal ally. This movement task moved seamlessly into a drawing activity, trying to maintain the improvisational frame of mind. Using the drawing materials collected before the session, we were instructed to draw our animal ally in whatever form came to mind (abstract, literal etc.). Drawing then moved into automatic writing with the invitation to converse withour animal allies.

The imagined animals supported individuals in different ways. One person spoke of finding freedom despite
their pain:

> I draw the pigeon. The life without freedom is very very bad and like a life in the prison. Despite my chronic pain, I am like a pigeon flowing in the air and can go everywhere with freedom and singing all the times. (LEE 20)

Another reflected how their needs and movement qualities have changed:

> My animal ally was a tortoise. I have 2 pet tortoises which I adore and spend a great deal of time loving and caring for while also trying to care for myself which at times it gives me a gentle nudge [...] My life has changed drastically and I've gone from being like a wild cat to living life like a tortoise but I have to follow the flow with same needs as tortoises and build positive life with healthy food, water, sunlight, warmth, and gentle slow movements. And just like my tortoises, I hide in my shell also if feeling unsafe in my environment. (LEE 13)

Two lived experience experts both imagined a lion as their animal ally:

A male lion just popped into my head as my ally at that moment in time.
Its soft mane gave me comfort.
Its underlying power gave me strength.
Its prone position made me feel relaxed.
Its habitat in the sun gave me warmth.

Its frequent fictional association as being man's friend a subliminal influence perhaps. "The Cowardly Lion" in The Wizard of Oz presents it as unthreatening.
It's ....zzzzzz.
(LEE 6).

It was great to reconnect with my 'lion' - which I identified as my 'higher power' a number of years ago; it's good to remember he is always by my side!

As I was drawing my lion, I remember thinking ' ooh I hope I have enough time to finish' and trying not to get too distracted by the thought!

Sharing our animals in the break-out sessions felt special and participants shared generously. (LEE 10)

Toward the end of the session, we shared our experience, “listening and seeing what other people had written and drawn” (LEE 9):

> Chatting about [my experience of the task] and hearing from others about theirs was an eye opener for me. This brings lots of joy to me. As what they were saying explains the task that we’ve created. Working on this task in a group has helped me to change my thinking towards how I normally relate to my pain. (LEE 11)

For some, the process of connecting movement with drawing and writing was a “new experience” (LEE 13). The “beautiful”, “gentle and nurturing”, stimulating, yet very relaxing task (LEE 18, LEE 10, LEE 6, LEE 7) helped some bring out their inner suppressed creativity. Individuals were immersed in the flow of the creative dialogue:

> Transforming what I am going through into an image and to connect with it was very helpful for me mentally. (LEE 11)

> The first drawing exercise became so automatic that I lost myself in the process. (LEE14)

It brought back memories of drawing for pleasure but that “for many years now haven’t really made time to do” (LEE 9), making it possible “to connect with a part of me that’s laid dormant for far too long” (LEE 14).

WEEK 3, PART 2: NEUROGRAPHIC ART

Lived experience experts were invited to lead tasks or activities during the pilot study. In week 3, one person delivered a ‘neurographic art’ tutorial focusing on allowing the unconscious to emerge through drawing. They explained that: “What we focus on is what we will attract into our lives. What we give our thoughts to and give our energy to is what comes back to us” (LEE 13). The focus of the activity was to explore the subconscious mind and to make sense of any chaos. First, it was necessary to ‘set the scene’ and everyone was encouraged to find a nice comfortable space from which to work, surrounded by our favourite art resources. We begin by focusing on the breath, breathing deep into the belly, helping us to get into a mediative state. We then turned our focus to an issue or problem and scribbled this on the page, externalising feelings and emotions in whatever manner we wanted. Once this was done, the second stage was to spend time “smoothing the edges”, turning harsh lines into curved ones: “The sharp edges in your life are put on paper, and then you smooth them out. Then you add the colour, focus on the breathing, the happy, the beauty”.

The intention of the task is not to be perfect, but to recognise that we have the resources to transform and adapt the workings of the mind. The lived experience expert found the facilitation to be a positive experience that:

> I really enjoyed presenting [...] and was pleased with the feedback and that people were excited and seemed to want to explore the topic for themselves [...] the simple activity has given me some relief and hope it does others too. (LEE 13)

The group found the tutorial relatable and fascinating (LEE 22, LEE 18) and several people immediately adopted the practice outside of the session.

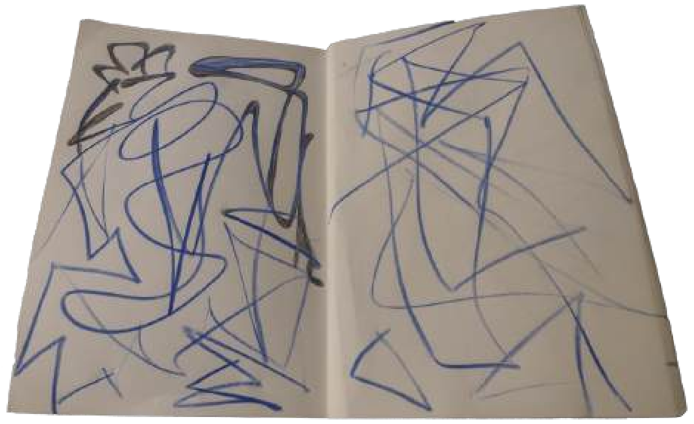
> I absolutely loved it! Scribbling was a great release, and I remember thinking - I want a massive piece of paper for this!! It was incredibly freeing and for me, there was no room for ‘perfectionist’ thoughts, and then the ‘smoothing’ out of the edges was calming and meditative - I didn’t want to stop! (LEE 10)

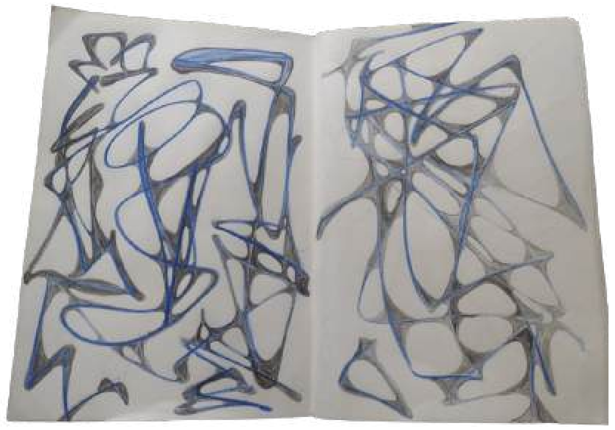
> I think this activity really connected so many aspects - difficult thoughts, breath, and then movement (of hands). I carried on ‘taming’ my edges over the next few nights before I went to sleep - a great thing to do! This made me think about how I use creativity/creative activities - as a distraction, to give me a sense of purpose, but I think I also connect it with being productive rather than using it to explore/reflect/manage pain - this is something I need to think about...it’s like I want to separate these areas of my life maybe? I’m also wondering whether there is a connection with why at times I disengage, or have resistance to being creative? Anyway, at the end of the session I was greatly energized - so much so I had a shower AND nipped out to the shops to get provisions! (LEE 10)

It brought back memories of drawing for pleasure but that “for many years now haven’t really made time to do” (LEE 9), making it possible “to connect with a part of me that’s laid dormant for far too long” (LEE 14).

The activity was described as an opportunity to “let go of my angst and smooth out the quirky bends” (LEE 14). Others noted:

> It really felt like it accessed so many parts of me that are deeply saddened by pain [...] using art and movement with the pencil and pens opened up a whole new level in my brain to accepting of life with pain. (LEE 18)
>
> “I found this way of letting go the best experience I’ve had in relation to the chronic pain I suffer, it’s like letting go and letting it out”. (LEE 22)





AN EXAMPLE OF THE NEUROGRAPHIC ART ACTIVITY. UNTAMED (ABOVE) AND TAMED (ABOVE RIGHT) SCRIBBES.

WEEK 4: AUTOMATIC WRITING

Week 4 explored automatic writing:

> I loved the writing activity, and I was visualizing my M.E. monster and having a conversation with it about giving my health a break. The magnifying the word exercise I found very interesting and is something I will use again. The word that stood out to me was monster! (LEE 1)

> We had to identify words that described how we felt while doing the movements and sounds [earlier in the session]. We were invited to write words and allow our pencils to flow. We then had the opportunity to share our experience with a partner then reflect our joint experience by feeding back to the rest of the group. Interestingly, my colleague and I had similar words which we created verbal and well as movements to demonstrate to the rest of the group. It was a unique experience. (LEE 9)

> The session made me see that when, we each wrote words to describe how, we felt about our pain, it offers insight into, the negative connotation connected with pain. But that we can turn, this around and learn to established new positive thoughts, which may then lessen the impact of the pain. (LEE 23)

WEEK 5: COLLAGE

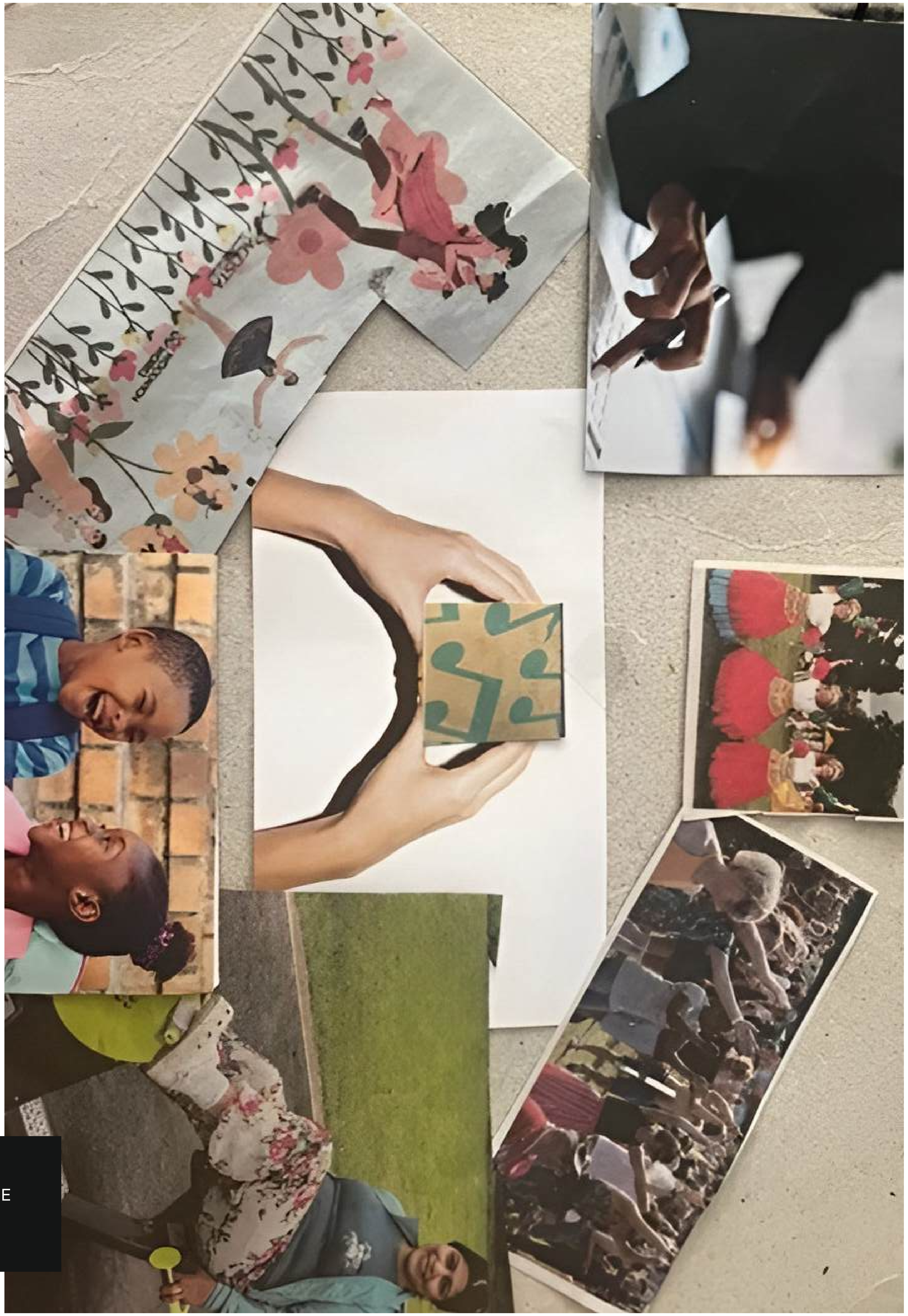
Collage was used in the final week of the pilot project as a reflective tool. Materials were provided for in-person attendees and online attendees were asked to collect magazines, newspapers, fliers, and images, anything they had to hand. Some created collages using their digital devices, creating presentations that were accompanied by music.

Individuals created displays relating to their "relating to their own pain journey and what they hoped for the future" (LEE 23). The task was described as:

> A simple way of becoming aware, once more, what creativity can do for me: it takes me into processes which are not anticipated and show me that my state of being can shift unexpectedly. This feels very relevant when it comes to dealing with chronic pain! (LEE 7)

A lived experience expert explains their collage, which is presented here on the right:

> The centre photo illustrates the dancing we have done whilst the image to the [bottom right] side shows us during our times of movement. Next to that is the image of the lady on the exercise machine which represents us doing exercises except without the machine. Beside that image it shows the laughter we have had the opportunity to share alongside the times we have danced together, (not physically but mentally together) giving ourselves permission to put aside the pain. Finally, the image of the finger on the keyboard is a reminder that I took the sessions online whilst the last image in the centre represents the love of music 🎶 and how it was very central for me in helping to NOT focus on the pain (LEE 9).



A COLLAGE REPRESENTING THE EXPERIENCE OF THE LANGUAGE OF PAIN PROJECT

The collage below represents the desire to continue with the research:

> be able to be there in person and enter into a process with the group - a collective embarks on a project that could actually lead to some kind of product (an internal sharing of creative outcomes for example, or even a public one). The wish to be in a room filled with art materials that we just dedicate ourselves together (LEE 7)

Since "Pain is abstract - it cannot directly be seen, it is in the mind, the task was described as providing "a fertile source to link to ideas" The collage on the top right features an image of Mars (top left) representing chronic pain sufferers as living "in another world, often not understood by others".

The map (top of the collage) depicts how "our bodies, mind, physiology and symptoms are all linked". "Pain sufferers are linked by having similar but perhaps infinitely different personal experience of it". The article Badgers come out to play (top right) stands as a reminder of "the importance of relating to ourselves and to nature; the powerful healing potentially provided by being more child-like (more carefree, more open and expressive, more fun!)" (LEE6).

Described as a "hasty collage offering" the collage on the bottom right depicts:

> discomfort in the bottom right-hand corner and that lava flow of pain, fighting against the wind and wanting to curl up in a ball. Then digging deep, seeking with curiosity, evoking creativity, expanding. The sense of blossoming, flourishing as we sounded together, moving softly, imagining my animal body emerging, resting softer than soft... resetting, refreshing, recharging" (LEE 1).

THE COLLEGE BELOW REPRESENTS TO DESIRE TO CONTINUE WITH THE RESEARCH:

COLLAGES REPRESENTING THE EXPERIENCE OF THE LANGUAGE OF PAIN PROJECT

CLOSING CIRCLE

Each attendee was invited to share something positive or something they noticed about engaging with the creative tasks at the end of each session. These ‘popcorn’ moments were an opportunity to re-group, close the session, and say goodbye for now. The session ending was intended to help individuals leave with something resourceful. The closing circle also meant that the facilitators could help to ascertain if anyone had a difficult experience so that they could follow-up and offer support.

REFLECTING ON FACILITATION

The expertise of the Trinity Laban facilitators was praised by the lived experience experts. Described as “open”, “caring”, “sensitive and encouraging” (LEE 16, LEE 5, LEE 15), the facilitators “listened intently” and “enabled us to be at ease despite the challenges we face” (LEE 5, LEE 15). One person explained that:

> “ the way the facilitators and other participants joined in made me feel safe and secure and listened to more than I have ever experienced. Some of the work brought me to tears as I felt, for the first time, validation (LEE 23).

The “effort to make [the project] inclusive and understanding” was appreciated (LEE 18). The project was described as a safe space (LEE 22, LEE 23) and the session were “crafted and held with care” (LEE 1).

The sessions were fun, and the facilitators were “animated with no inhibitions of playing” (LEE 13):

> “ The facilitators were superb, who not only guided us through the activities, but also through their warmth and actions made it easy to feel at home and free up our minds and remove or lessen any inhibitions in speaking, moving and interacting as our inner child-like self wanted to. This in turn relaxed me and stimulated my thinking (LEE 6)

One person reflected on the quality of inter-personal relationships:

> “ I know this isn’t therapy, but it is a therapeutic engagement. For me, it’s always at least 90% the person, that relationship between you and the facilitator [...] but then, of course, there’s that person’s knowledge [...] an approach to engagement with humans and it’s unconditional positive regard. It’s that thing of being just completely authentic and real. And humans know, when you’re in some sort of therapeutic-ish engagement, when someone is not being authentic [...] it comes down to the individual humans – the facilitators, or the researcher, or the support, or the admin or whatever. And I don’t think you can learn about it. You can try and teach it, but I think it’s just a very genuine thing from inside. And that’s what I feel was present in this. And I’ve been in lots of situations where it’s not present. (LEE 10)

IMPACT

In the context of the UK’s Research Excellence Framework, impact is defined as an effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia[5]. Impact criteria and priorities “encourage top-down, expert-led change” (Darby 2017, p. 232). While the linear conception of impact “from incident to effect [...] has resonance with masculine forms of power/knowledge relations” (Pain, 2014 p. 21), impact informed by feminist praxis would involve:

> “ reciprocal, collaborative relations [...] that are both deep and flat, in opposition to hegemonic power [...] feminist knowledge co-production is relational, taking place through a more diverse and porous series of smaller transformative actions that arise through learning among all of those involved. (Pain 2014, p. 21)

Participatory approaches can generate more effective research and relevant impact (Barke et al. 2020). The Language of Pain was an opportunity to examine how participatory and co-produced creative research impacts lived experience experts and transforms professional practice.

Some lived experience experts had experience of engaging with previous projects where their presence felt tokenistic or there was a lack of genuine interest in their contributions. Inversely, those engaged with The Language of Pain felt heard, their insights valued, and felt they shaped the direction of the study. Speaking about this, one person explained:

> “ this is a few years ago now so maybe things have changed, but there is an element of tokenism about having your expert by experience on board the project, in a meeting, but then the person is often, in my experience, ill-equipped to deal with that situation that they’ve been sort of thrown into [...] I suppose in some ways there is always a tiny bit of cynicism about these things [...] I have witnessed this and people [lived experience experts] are not given enough support. (LEE 10)

When asked about what felt different about The Language of Pain they said:

> “ I suppose it is very much all of your approaches... you’re very good at not assuming knowledge. [In my previous experience] whoever’s running something has their ideas about their project or what the answers are, so in a way they’re not actually that interested [in what the lived experience expert has to say] because if you invite someone to a big, scary meeting, and then you don’t even get them to contribute, then really they are not interested in that person’s views or feelings. I have seen that, and it is just a completely outrageous behaviour, and of course that absolutely did not happen here. (LEE 10)

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[5] “The REF is the UK’s system for assessing the quality of research in UK higher education institutions. It first took place in 2014 and 2021. The next exercise is planned for 2029” (REF 2024).

In response to this, another person explained:

> I've very much enjoyed listening to everybody else's feedback, and I'll just preface what I'm about to say by saying that that, for me, has been one of the great values of the whole project. The fact that I've been able to learn in so many different ways from so many different people's experience. And going back to what [LEE 10] was saying about the tokenism that can sometimes exist where lived experience people are concerned, that's really been the great skill that the facilitators have brought to this project. And through that skill, enabled us to feel like co-collaborators [...] it's drawn out from us the things that have been necessary to make the project work as a collaboration for everybody who's been involved. That's not easy. And I really just want to amplify that [...] Because for me, having had that very negative experience of being the tick box token representative on a number of occasions, working with people whose immense skill has been to draw the best out of us, or draw something different out of us, just draw an imaginative response from us on the subject of our lived experience has been mind-blowing, really. (LEE 12)

The pilot study explored participatory and co-produced research to give voice and agency to the expertise of experience. In response to this, one person reflected:

> Having the opportunity to be heard in ways that I can manage my pain rather than being instructed all the time is quite beneficial for me
> (LEE 4).

The end of the pilot study was described as "the beginning of a new journey" (LEE 14). Activities explored during The Language Pain helped Lived experience experts relax and feel grounded. One person stated that it's "definitely something I am taking forward to do more of in my everyday life it's so needed" (LEE 17). Another person said that they would continue "to draw on its concepts and probably replicate the session cycle too" (LEE 6).

> The project stretched my imagination in recognising me as a person I can find an expression of me in sound and interesting phrasing not just medical history and pain. (LEE 1)
>
> This week's session I was a really taken aback through self-discovery (LEE 4)

Others spoke explicitly about the experience in relation to chronic pain. Reflecting on their experience of pain, one person stated: "Being in this group has given me further insight into pain and the impact it can have on one's body" (LEE 15). Another spoke about a renewed awareness of the body:

> My body is speaking to me, as I haven't been listening to the cries of despair of my inner child. Therefore, she's found the only way to connect my mind and body is to make me aware of chronic pain. And this fragmentation of the body and soul have been deserted for so long. I have disassociated and daydreamed through my childhood and into my fifties without realising that my body was trying to get my attention in the form of pain. (LEE 23)

One person described the impact of greater bodily awareness on their experience of pain:

> I have become more physically aware of my body and my symptoms, which, in turn through acknowledgement, has allowed me to experience shorter outbursts or milder physical symptoms than I normally would. (LEE 4)

Improved awareness gained through The Language of Pain was particularly impactful for one person:

> I just wanted to speak on the effects of the research [...] I've been a lot more aware of the world that I live in. I feel like my role in this research has allowed me to reposition my role in life, in general. I think a strong message that has stood out for me doing this project, I've been able to find a motto, "I can choose to live in pain, or I can choose to live in suffering." And at the end of the day, we all go through pain but a lot of us could choose to suffer a lot less through the pains that we go through [...] I've just been a lot more fulfilled in the pain that I've been feeling because I know that I'm not alone [...] that awareness allows us to be more at peace with ourselves. And so, this project has really helped me be more at one with myself. And I felt that my role in this research, it's bigger than this research, it's now my life, just making it a purpose of choosing not to suffer just because I've been through pain. (LEE 28)

A question throughout project was expressing pain creatively versus using creativity to help understand and live with pain, both of which are intertwined. One may generate an emotional response and perhaps be triggering (expressing pain), the other may evoke more play and joy (using creativity to live with pain). One person described the power of creative expression:

> Expression equals "something good" for me. When I can express an experience, even a difficult or painful one, this experience already feels less worthless and hard. It softens and becomes a tangible moment with size, weight etc. rather than a nameless reality (LEE 7)

On this one person reflected that at the start they were "a little bit worried or concerned about actually sharing experiences about pain because you seem to dig a bit further into it if you are focusing on it" (LEE 1). They had worked hard to not define themselves as someone in pain, but a person that has pain as something within their life (LEE 1). They were concerned that focusing on the pain in the project would "almost enhance the pain" (LEE 1). They said:

> one of my concerns [was] that it would pull me back into the whole concept of thinking about pain and discomfort. And actually, it didn't do it at all. It did exactly the opposite (LEE 1)

Another person reflected:

> It's not that I've not thought about pain or discomfort during the course of the project, but it's that what I've thought has been challenged and changed. It's that element of just not regarding that attention in the same way and actually transforming it from a negative emotion to something more positive and creative has been quite an important benefit from my point of view [...] I can't say that I've not thought any less about pain or that anything the project has done has been a distraction from the pain. But it has challenged me to find different ways of regarding it, different ways of dealing with it, different ways of conceptualizing it. And it's also challenged me to transform that basic sort of somatic experience into something, even in very basic terms, something more creative [...] that's part of why I still find myself having to process some of the things that have happened because it has had that transformative effect in some respects. So, the legacy is ongoing. (LEE 12)

Some made connections to the role of arts and creativity for pain management. The tasks were described as "warm and endearing, safe and comforting" enabling one person to broaden their "horizons in terms of pain management" through "creative outlets [...] a space where the pain I have can be alleviated" (LEE 4). Another said: "I recognise that art really helps, I use music in a therapeutic manner as it helps to block the pain" (LEE15). The "unique experiences [...] helped to take the focus off the daily pain" (LEE 9) and offered "some inspirational ways to manage pain" (LEE 13).

Some lived experience experts found new ways of conceptualizing pain. In response to a discussion session drawing from Havi Carel's critical phenomenology, one person reflected:

> I found this really interesting, a lot of things resonated… 'alive, but detached from everyday living'.. 'changes what you know and changes your values'… 'Illness and philosophizing - both transformative experiences'… 'Re-learning to look at the world…uprooting yourself from dogmas (LEE 28)

In other discussion, we turned our attention to what Raquel Meseguer refers as an "aesthetics of rest." After listing to Meseguer's *Dream of public resting spaces* we reflected on the themes of metamorphosis and perceptions which materialised in the podcast. One lived experience expert shared the following poem by Donna Ashworth.

> If only we could see the power in rest. If only we could attach to it the worth it so deserves. If only we could open our minds to the idea that everything in nature has its time to rise and it's time to descend. That each of these acts is as important as the other. And that is exactly as it must be. If only the ability to allow our bodies space to heal was awarded the same badge of honour given to busyness and stress in this life. If only we could realise, resting is very much doing.

> Listening to Raquel today, as I'm taking time out to rest, due to my swirling pains - I'm minded to take notice … not just of myself but the invisible community that I want to connect with. (LEE 14)

> This workshop really did widen my horizons on how I subconsciously view lack of capability and naturally associate it with disability. When we break down that word disability; it is understood that society itself inflicts segregation and discrimination on people who are obviously suffering but heightens the level of diminishing when it cannot be seen. This is shocking to me, that we are taught to consider others before ourselves. When we want to put our legs up on the bus/train because of the pain, I'm seen as anti-social despite there being the extra space to do so. I'm just made to feel awkward or selfish- when people should just respect each other's needs for space, no matter how they vary. (LEE 28)

Early on, a lived experience expert noted that "If you can influence the thinking of one person, they will hopefully go on to transform future engagement with others" (LEE 6). While the project focused on the impact of those involved, our collective explorations into language, imagery, and creative expression demonstrates the potential for sharing experience in ways that could foster empathy and understanding from others. The project made one person "think more of how I could describe my pain to someone, in written word, pictures and music" (LEE 5).

PROJECT DESIGN: LEARNING AND SOME PRACTICAL CONSIDERATIONS

Here we list some observations relating to project design and engagement that have not been reflected on elsewhere in the report and which are feeding into Trinity Laban's community arts practice.

WORKING WITH INFORMATION

- It was difficult for some lived experience experts to concentrate on written materials. We created audio-visual recordings of written materials and circulated these to those involved in the project. In response to this, this report is available as an audio-visual recording.
- However, lengthy video materials can present challenges for engagement when an individual has limited energy. We began to divide files into chapters.
- Drawing is not accessible to everyone. Some lived experience experts asked to use their digital device to respond creatively to some tasks.

FINDING A BALANCE

- The pilot study presented opportunities to explore arts-based methods. Longer sessions, multiple sessions working on the same task or activity, and a longer overall project would permit deeper and more sustained examination. However, many of the lived experience experts commented upon how much they enjoyed dipping into the activities explored in the pilot.
- Finding the balance between creative practice, discussion, and sharing was a continuous point of reflection. The depth of sharing in small groups could not always be replicated when working as a collective because of time limitations. In our 90 minute sessions, people were sad not hear from everyone individually and were concerned that reporting only the highlights to the whole group left out people's input and experience. Creative exploration and sharing requires time, and one or both of these are compromised with short sessions. Building in comfort breaks and screen breaks would help to accommodate longer sessions and avoid zoom fatigue.

CO-PRODUCTION

- We are interested in working with lived experience experts in all stages of a project, including data collection, data analysis, and decisions about dissemination. However, the time restraints of the pilot study meant that it this was not feasible. Co-produced research demands a lot more time for all areas of the work than might initially be envisaged.

REFLECTIONS

- It was assumed that lived experience experts would submit reflections willingly. While many were forthcoming, acknowledging their role in the development of the research, many did not offer insights beyond the creative sessions. Futhermore, because the creative sessions were fortnightly and because the reflections were asynchronous some people forgot to reflect upon their experience. Nevertheless, it was important that the project belonged to everyone and that each person responded according to their needs and interests. Therefore, engagement varied.
- Support should be given to facilitate reflective practice. We used questions as prompts to guide reflection and lived experience experts could submit their reflections in any format (written, verbal, artistic forms). Short one-to-one Zoom calls were arranged for individuals wishing to reflect on their experience with the support of the researcher.

DIGITAL PLATFORMS AND DEVICES

- Padlet was for many an easy to use and intuitive platform. However, it is important to recognise that some people require additional support and training to use digital tools. It is also necessary to take time to properly introduce tools and provide an explanation and demonstration of how they work.
- We used Canva for a mind-mapping exercise using digital post-it notes. This task was challenging for almost everyone involved. People felt "fleeting panic" and overwhelmed when unable to make the technology work. One person said that it felt "like another failure along with the physical limitations we face".
- The Language of Pain highlighted the importance of supporting digital inclusion where possible. In recent projects, we have partnered with a Community Interest Group whose mission is to address the needs of those whose ability to access the internet and other digital technologies is limited.
- Knowing more about the types of devices that people are working on would help to support experience as we would know more about how they are engaging with different materials.

THE NEED FOR A COMMUNITY AGREEMENT

- Late arrivals frustrated group members as it could be disruptive to the experience.
- Arriving late meant missing the welcome into the space, the session overview, and the warmup which are important (and not incidental) elements of the session.
- Ideally, the social time built in before the session start should mitigate late arrivals owing to transportation or technical issues. However, not everybody wants to (or is able to) socialise before the start of sessions.
- At the start, a shared understanding of behaviour and etiquette was assumed. Discussions about mobile phone use, photography, and consent are needed before the project starts.
- Remote access to the sessions meant that it is possible to connect from everywhere with internet connection. The benefit of this is that people can connect from the comfort of their home or an equivalent private space. The downside is that individuals connect while on public transports, while driving, or in cafes which are not appropriate physical spaces for the embodied creative approach that characterised the project.

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