

TRINITY LABAN

The *Language* of Pain

Online creative research centring lived
experience and experiential knowledge

PROJECT REPORT 2026

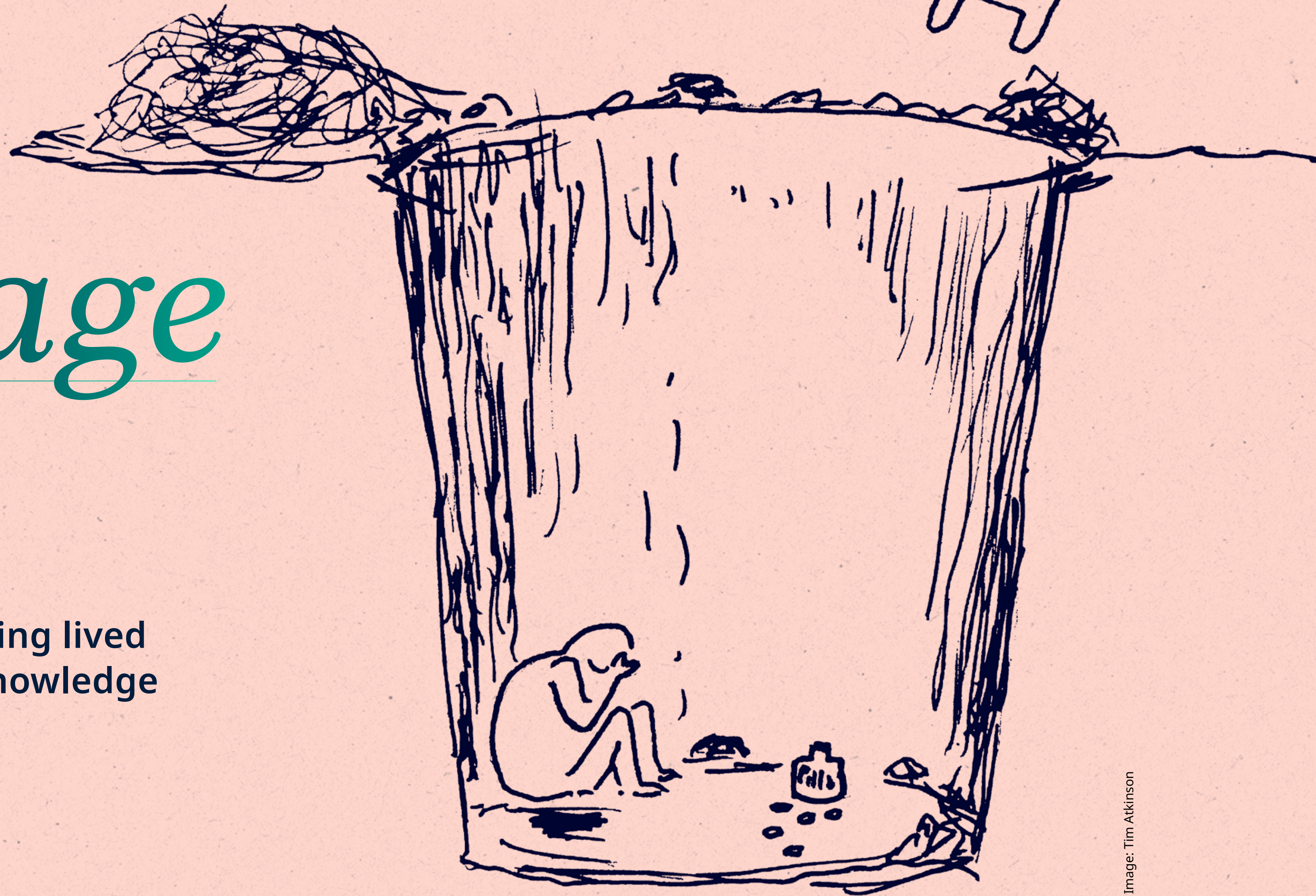


Image: Tim Atkinson

Executive summary

*I want to know how the arts and pain talk to each other
I think that pain and illness are deep parts of those who experience it
That they choreograph us
And that can be made visible through the arts
It can be explored
A dance between what is known and what is unknown*

MIRA, PADLET, SEPTEMBER 2026

The Language of Pain is an arts and health research project that gives 'voice' to the invisible and often denied experience of chronic illness and pain. Through various arts-based methods, underpinned by somatic practice, the project interrogates understandings and orientations toward chronic pain. By listening to pain rather than seeking to cure it, the project emphasises chronic illness as a socially situated and embodied phenomenon. Resisting the deficit model of ill-health, we focus on what it means to live well with chronic illness. The research is co-constructed, centres lived experience, and is grounded in shared leadership and collective decision-making. We adopt an ethics of care where the body comes first, we show up as we are, and resist performing wellness. Our creative research takes place solely online to accommodate our health and comfort needs, addressing the need for and importance of remote practice for public engagement.

In this report, we:

- highlight the centring of lived experience as transformational for how research is done, for understanding pain narratives, and for the project's co-researchers;
- introduce the emergent and iterative research design as essential to both working towards co-production and arts-based enquiry;
- discuss our use of arts-based methods;
- introduce our somatic-informed practice and how it supports increased somatic confidence and somatic authority;
- emphasise the importance of creative process over product;
- discuss how our creative practice embraced the possibilities and limitations of Zoom.

Alongside this report, a multimedia film, documentary, and 'practice with us' resources were launched in September 2026 as part of Pain Awareness month.

Access *The Language of Pain* resources here:



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The collective: *An expression of a community*

The Language of Pain Collective is formed of eight creative individuals and artists exploring the intersection of art and health. We have experience as movement practitioners, writers, crafts professionals, teachers, media artists, and art enthusiasts. The collective is “bigger than the sum of the parts” (Ruth, Padlet, January 2026). Each person “brings something that only they really could” (Peter, Padlet, January 2026). “We all come bringing our own unique experiences, of pain and life that creates a very rich and meaningful discussion” (Ruth, Padlet, November 2025). The group is united by lived experience of ill-health, a belief in the power of creative practice, and the wish to express that which often remains invisible: the experience of pain and how it choreographs and defines our bodies. We share a belief in the arts to give ‘voice’ to pain and agency to individuals. We use somatic movement practice to tap into embodied knowledge and various creative approaches to examine our different orientations towards the body, pain, and illness.

We look forward to our sessions and are grateful to be part of the community. Emma and Tim discussed what it means to be part of the collective:

There are so many positive things. The joy of the connection of the group. Weirdly, that kinda felt established fairly quickly [...] It is really a strange thing. But I suppose, for whatever the issue, the problem, the thing of finding your tribe and the camaraderie [...] That is such an incredible thing that someone kind of gets it, that you don't have to explain in detail, or that judging thing.

Emma, peer interview, June 2026

I look for connection, for sharing, for a dive into the unknown, and a place for gentleness and softness with myself and others. For radical listening to what is present and needed.

MIRA, PADLET, SEPTEMBER 2025

I'm with you 100%. It is the joy of being part of that collective and having that shared understanding, knowing you don't need to offer any explanation. You can actually just be, and be seen for who you are without any front, without the need to make allowances, or accommodate anything. I suppose, the honesty of that has been joyful. The fact that we've had a safe space where we can express ourselves in whatever way we choose. Utter and total honesty, with no judgement. Nothing at all about rights or wrongs, just everything counts. I think the biggest joy for me has just been hearing everyone else's tales about the kinds of things we've done and the activities we have engaged with, and seeing the wonderful ideas everyone's had. It's been quite remarkable. It's got me thinking more creatively than I have done for ages. The ideas, they generate their own energy, don't they?

Tim

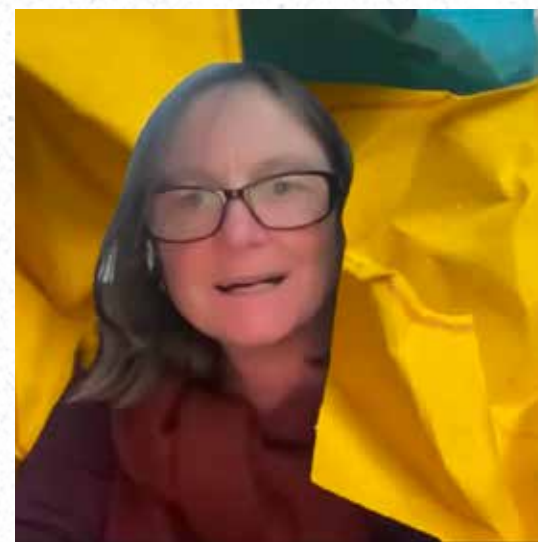
The Collective



Charlotte Mackie

Co-researcher, invited collaborator, project manager

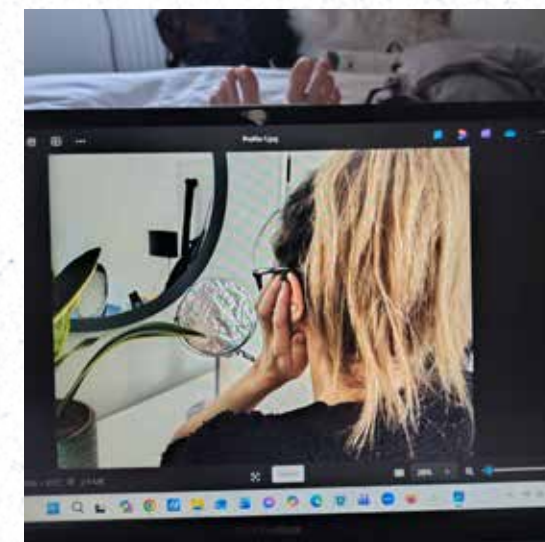
Charlotte is an Arts Project Manager and Producer. She works on a freelance basis with a number of arts organisations, individuals and networks to support the running of projects and programmes, and produce touring work.



Dominique Rivoal

Co-researcher, invited collaborator, filmmaker

Dominique is an independent filmmaker whose practice explores somatic and relational approaches to filmmaking. Through the camera and the screen, her work explores how embodied attention can foster alternative ways of being with, relating, and communicating lived experience.



Emma Saunders

Co-researcher

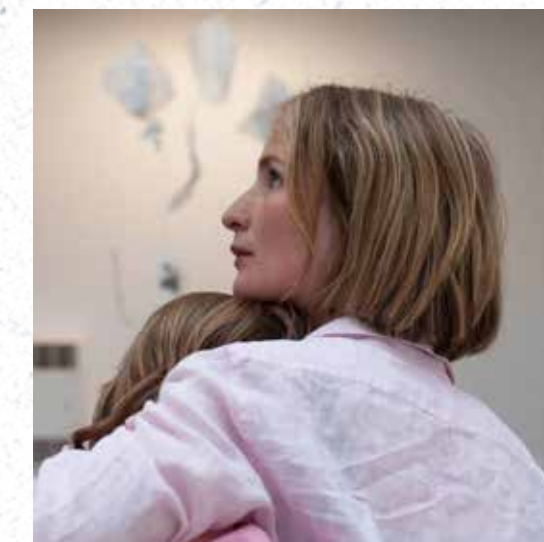
Prolific petition signer; writer to MP; urban backyard gardener and kitchen window bird watcher. (I know 'watcher' isn't a real word, but it just totally captures what I do almost everyday!)



Jo Young

Co-researcher

I'm Jo. I'm a beach love / spoonie warrior who loves tortoises, e-bikes, art, music and tai chi. I'm on a healing creative journey. One wobbly step at a time.



Mira Hirtz

Co-researcher, Artist lead

Mira is a movement artist and curator living between Germany and UK. She thinks a lot about art in all its multiple ways, mainly as a medium that invites for encounter, embodiment, dialogue and critical reflection. Often that includes a collective process and spans across various disciplines, from science to ecology to health. She also loves to dance and hike.



Peter Nagle

Co-researcher, invited collaborator, composer

I'm a composer, performer and researcher based in London.

I'm interested in how people in different art forms interact when we collaborate.

I aim to build communities in my work.



Rebecca Stancliffe

Co-researcher, Principal Investigator

Rebecca is a dancer and qualitative researcher whose work explores how structures, systems, and environments shape communities, human experience, identity, and agency. She loves reading, walking, gardening, and cooking.



Rob Miller

Co-researcher

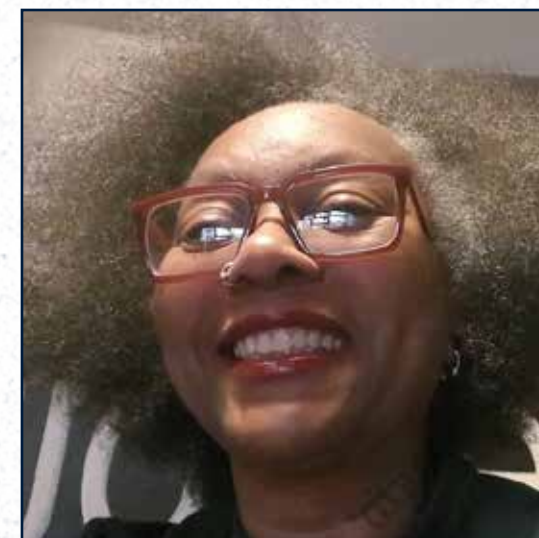
I enjoy live music from classical to punk, from electronic to upbeat jazz. Church services and concerts at Southwell Minster instantly relax me; even just passing through the church does. I am passionate about and actively care for nature, my community and for others.



Ruth Barber

Co-researcher

I'm a yoga teacher and mum who has lived with pain for 20 years. I love walking. I like music I can dance to. I enjoy calm and peace. And often find this by being in or near water. Breathing and moving with kindness help me live with pain. I love growing vegetables with my family and watching the deer and hares that leap about in my wee village near Glasgow. I've usually got a cup of tea in one hand and a library book in the other!



Tefnut Huntress Asante

Co-researcher

I'm a Solitary Witch

A Shapeshifter

And - a Two-Spirit Being

Who lives with chronic pain



Tim Atkinson

Co-researcher

I'm a father, a teacher, a writer, a singer; gardener, painter, and sometime wild swimmer. I've had to carry a heavy daily burden that sometimes makes all that hard to remember... but I'm getting stronger!

I feel supported by the group to share and develop a fluid expression of my creativity that sits outside of the norms and conventions of my lived experience with chronic pain.

TEF, PADLET, SEPTEMBER 2025

I appreciate everyone's presence in the group; we're all an asset in our own way.

JO, PADLET, JANUARY 2026

The project created a space where we can be vulnerable and reveal our experience to others (Emma, Padlet, September 2025). Tef reflected:

Just to be vulnerable [...] I just really appreciate each and every one who brings so much of themselves to this space. You can be quite vulnerable, but I feel that the space really holds whatever we bring. The way in which it's been set up [...] it's very open but also contained [...] Say, for example, something came up and it triggered me, I can speak with Rebecca, I know I could do that and feel supported, do you know what I mean? So, it's more than what happens in those two hours. It's what happens after as well.

peer interview, June 2026

Ruth reflects that "the support and warmth of our collective means it never feels hard work" and we come away from each session "with such admiration and fondness for everyone and their ability to share with bravery and compassion". (Padlet, November 2025, September 2025)

Digital tools are essential to our creative practice. We depend on Zoom and online platforms (e.g. Padlet) to collaborate in ways that accommodate our health needs. For the last three years, we have been cultivating an approach to practicing online through synchronous and asynchronous approaches. To extend the possibilities of our work, the collective was joined by three collaborators for this phase of our research: a composer and a filmmaker who have expertise in interdisciplinary creative practice, and a project manager with experience in inclusive community arts practice.

I saw aspects of myself that were validated by the collective, which gave a voice to the creative process. I can acknowledge my limitations, but I don't have to be defined by them

TEF, PADLET, DECEMBER 2025

Project *background* *and aims*

***The Language of Pain* is an arts and health research project that gives ‘voice’ to the invisible and often denied experience of chronic illness and pain. Devised in response to the evaluation findings of Trinity Laban’s Singing for Pain Management programme (2021), the practice-led research started with a co-designed pilot study (2023), after which a working group was formed that became known as *The Language of Pain Collective*. From September 2023 to June 2025, the collective explored themes and ideas arising from the pilot study through discussion, somatic-informed creative practice, as well as reviewing literature, artwork, and media materials.**

In the most recent phase of the project (September 2025-September 2026), we sought to establish our practice and explore the mediatisation of pain narratives. Through various arts-based methods, underpinned by somatic practice, the research explores our understanding of what it means to live well with chronic ill-health. Centring lived experience, the research is co-constructed, grounded in shared leadership and collective decision-making. We reflect on this approach, the roles and responsibilities of everyone involved, and

the structures that enable and support a process that works towards co-production. The project takes place entirely online to accommodate our health and comfort needs. We contemplate the value of remote practice and consider how it shapes and informs our collaborative work.

Immersion in the creative, emergent, and iterative process is primary. But to frame and structure our enquiry we set out to create a multimedia film with the hope that we might create something that increases awareness of what it means to live well with chronic ill-health by expressing experiences and knowledge that are often overlooked. The decision to explore the possibility of a multimedia film reflects our online approach to creative practice. Film serves as a creative medium for documenting, editing and sharing the material generated through our process, and we embrace the poetic device of storytelling to focus on the lived experience of chronic pain. To support this vision, a composer and filmmaker were invited to join the collective, contributing their insights, skills and expertise to the collaborative process. The multimedia experiment that was developed exhibits a snapshot of what is important about our work.

The elements that resonated with me were storytelling, control and curiosity. How do we, as individuals and as a collective share our creative stories in a way that broadens the debate within a medical framework and the wider community?

TEF, PADLET, SEPTEMBER 2025

In this report, we introduce and discuss four aspects of our research:

1. deepening our understanding of what it means to live well with chronic pain;
2. exploring arts-based methods for the expression of pain narratives;
3. foregrounding experiential knowledge in research by working towards co-production;
4. cultivating an approach for effective online collaborative creative practice.

Read about *The Language of Pain* pilot study here:



Watch the recording of our Zoom webinar here:



Project *structure*

The project team met fortnightly on Zoom for two hours, with each session structured along similar lines.

We began by saying hello, checking in with how we were feeling, and catching up on recent news or events. The value of starting in this way cannot be underestimated. Because we meet online, it is important to re-establish connection and to replicate the informal social check-ins that are typically excluded in Zoom meetings. Grounding exercises then oriented us towards the body and these focused on listening to and honouring what the body tells us without judgement. The focus gradually shifts from interiorisation to externalisation as we moved into creative exploration, artmaking, reflection, and discussion. Each session ended by saying 'goodbye for now' to acknowledge the ongoing nature of our work. We discuss our Zoom-based practice in more detail later in this report.

Between sessions, everyone was allocated an hour for individual asynchronous reflection and/or creative practice. Using this time to process individual and collective experience was a crucial element of our work, inviting us to consider what we would like to explore in future sessions. Sharing the results of our inter-session practice on Padlet (a digital canvas and collaboration tool that will be discussed in more detail toward the end of this report) was a way to stay connected beyond Zoom sessions.



Jo's creative introduction.

PHASE 1:

Introducing, exploring and experimenting

(4 SESSIONS)

The project began with creative introductions, which was an opportunity for the collective to reunite after the summer break and to meet the invited external collaborators for the first time. Each person developed a self-portrait to introduce themselves as they wish to be known. We use *self-portrait* in an expanded sense. The portrait did not need to be figurative, and could speak to our experience, interests and inspiration, contemplate the role of arts and creativity in our lives, and/or explore our relationship to the project. The following parameters were given:

- Allocate one hour to create your introduction;
- There are no right or wrong approaches or responses;
- The creative introduction should be original work;
- You will have five minutes to share your work;
- Consider how you want to present your introduction (e.g. does it 'speak' for itself? Do you want to provide a verbal explanation?).

The task was an opportunity to contemplate our preferred materials and techniques and those aspects of ourselves we wanted to make visible to others. The introductions were as diverse as the collective and included: a poem, a haiku, videos, physical and digital collages, a painting, presentations, and a game of snakes and ladders.

Workshops were facilitated in the sessions that followed with a session on deep listening led by Peter (composer and external collaborator), witnessing led by Dominique (filmmaker and external collaborator), and collage and stop motion animation led by Mira (collective member, artistic lead for the project). The workshops introduced new ideas and perspectives, expanding our understanding of what might be possible in our research by introducing skills and expertise that complemented those already offered by the collective. This phase was a chance to play and experiment and provided space to consider what Phase 2 might look like.

PHASE 2:

Creative expression

(10 SESSIONS)

The themes, approaches, and tasks explored in Phase 2 were not predetermined. Our approach was responsive: we reflected on the success, challenges, potential and limitations of a given session, which informed what we did next. In instances when a concept did not organically materialise through practice, discussion and reflection, requests were made for ideas, suggestions, and facilitation. Toward the end of this phase, the collective also responded via a survey on where they would like to take their creative practice, thoughts and ideas they would like to explore, and any training or support they wanted or needed to realise a creative idea. Phase 2 forms the bulk of our practice-research, and we anticipated that the collective would take ownership over the direction of the research.

This phase included:

- A workshop led by Tim that looked creatively at using written language to express and communicate, and exploring ownership and power;
- A workshop led by Jo focusing on somatic weather;
- Sounds scores (e.g. creating and performing chance poems inspired by Padlet data that we performed, experimenting with speed and dynamics);
- Movement scores (e.g. mirroring the gestures and movement of others);
- Improvisation;
- Experimenting with virtual Zoom backgrounds to create digital collages;
- Drawing and creative writing (e.g. on themes such as connection, threads, roots);
- Collage;
- Playing with the idea of an embodied camera, inspired by Dominique.

PHASE 3:

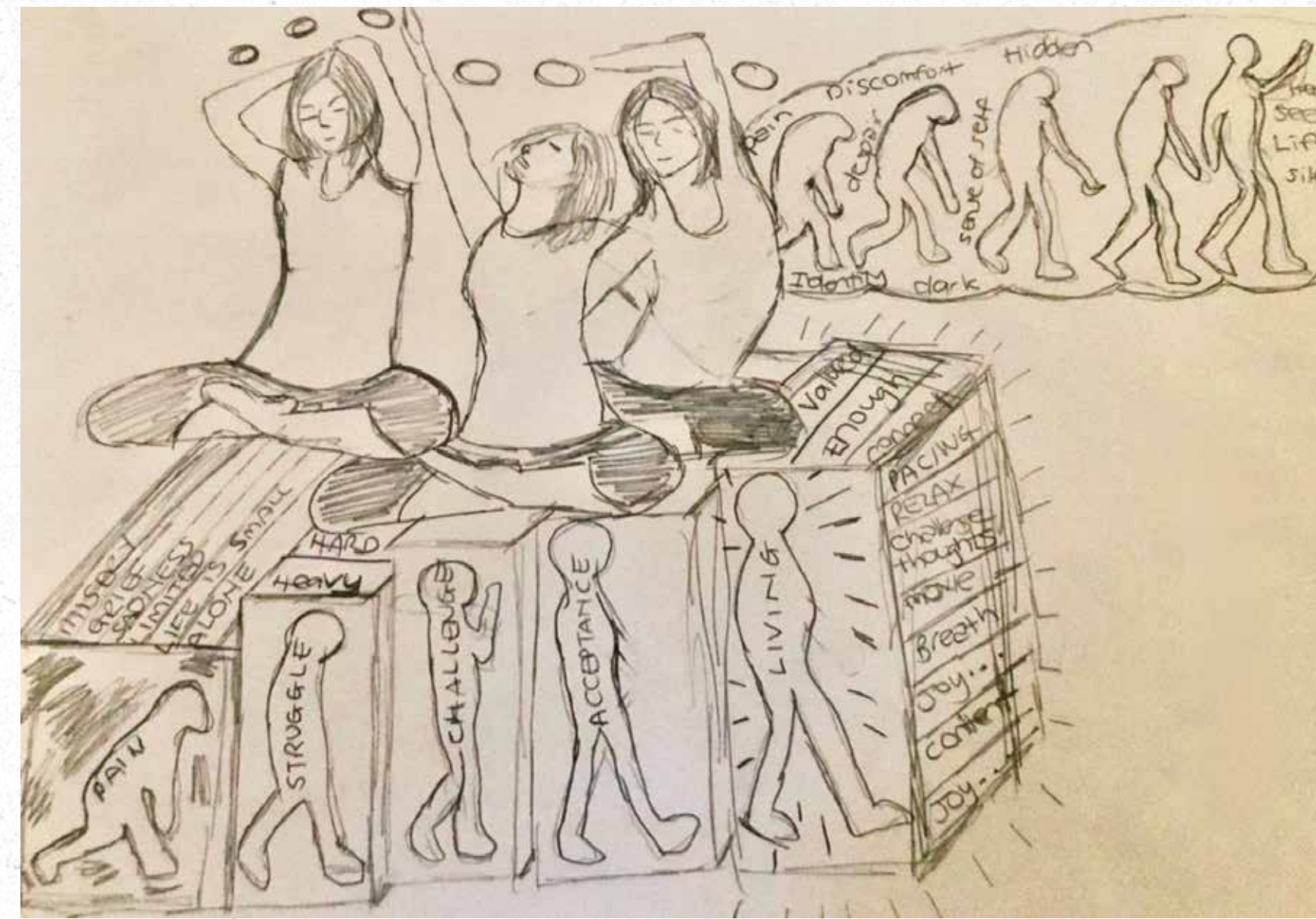
Resource building

Unlike Phases 1 and 2, in Phase 3 the collective did not meet regularly online. Instead, there was greater emphasis on independent working as different resources were developed for dissemination (blog posts, videozine, practice with us resources). Since the collective were no longer meeting fortnightly, this phase presented some challenges. A weekly schedule structured this stage of the research, hoping to keep everyone on track. However, we realised the value of regular meetings to keep us accountable and drive the project forward.

PHASE 4:

Launch, dissemination, reflection

This report, a short documentary, web resources, and a multimedia experiment, was launched during an online event during Pain Awareness month in September 2026. More than 300 people joined us from across the globe, from countries including Australia, Bangladesh, Cameroon, Canada, England, Germany, Ireland, Jordan, New Zealand, Singapore, Slovenia, Spain, Switzerland, Taiwan, and USA. Attendees included artists, healthcare professionals, people living with chronic pain, clinical researchers, sports massage therapists, osteopaths, pain specialists, people working in creative health, and caregivers.



A reflection inspired by *The Language of Pain* by Ruth.

I was scribbling yesterday and this [image above] appeared on the page after thinking about our last meeting... something about the evolving nature of pain, evolving bodies, evolution of this group, the confines and advantages of technology/online, the sharing of ourselves in this group and out of this group.

Ruth, Padlet, September 2025

can be beaten into submission
but the horse
This does work, in a way,
becomes sullen and suspicious.
it will kick and buck wildly
lently yanking on its bit and bridle
taming a wild mustang is to break its spirit.

pa i n

embroiled in an impossible battle.

A gentler approach

curiosity

'horse whisperer'

trains wild animals by
to their language.

gentle and calm, yet alert and vibrant.

Living With Chronic Pain

emerge

*What is pain with life hidden inside...
What is life with pain hidden inside...
When pain is overwhelming, life is small.
When life is bigger, pain becomes less
(overwhelming)*

RUTH, PADLET, DECEMBER 2025

*Pain is ache, not peace
Sore, not calm
Agony, not serenity
Suffering, not comfort
Distress, not relief
Torment, not harmony
Misery, not ease
Discomfort, not tranquility
Hurt, not joy
Burning, not contentment
Stinging, not love
Throbbing, not calm
Gnawing, not peace*

JO, PADLET, DECEMBER 2025

*No one sees how hard we work
simply to live, to be...*

RUTH, PADLET, OCTOBER 2025

*We are on the “rubbish tip” of
society’s model citizens. The mal-
functioning underclass.*

ROB, PADLET, JANUARY 2026

*I couldn’t help but think of how pain comes knocking at the door, a
friend or a stranger, is it yours, is it mine?
Who does this belong to?
Do I belong to the pain or does the pain belong to me?
Do I hold on to it or is it holding on to me...?
Am I looking after the pain or is it looking after me?
Is it protective anymore, does it have a purpose anymore?
Do I have a purpose if I am not in pain....is pain my purpose...?*

RUTH, PADLET, NOVEMBER 2025

Chronic pain is defined as pain persisting longer than three months.

"Approximately 8 million adults report chronic pain that is moderate to severely disabling" an estimated "43% of adults (just under 28 million people) currently live with a degree of chronic pain in the United Kingdom", and "up to 30% of young adults of working age (18-39 year olds)" may be affected by chronic pain

Fayaz et al. 2016 quoted in British Pain Society 2024

Chronic pain was "the leading condition in 2019 for impact upon healthcare use and mortality"

Watt et al. 2023

Chronic pain is "one of the most prominent causes of disability worldwide"

Vos et al. 2016

Yet, despite the prevalence of chronic pain, diagnosis is not always straightforward. Some people wait years to find out what is wrong and it can take longer to learn ways to manage their conditions.

The medicalised body

In healthcare contexts, the body is presented as an object to be read. The medicalised body, Helen Fielding argues, "that is read from the anatomical chart, the sonograph, or the genetic map is the body that has been reduced to the level of cognition or representation" (1999, 80). In such instances, the body is reduced to a spatial object and therefore dismissed as a temporal object (see Fielding 1999). In detaching the body from temporality, the variable nature of chronic pain becomes harder to conceptualise. In medicalised contexts, illness presents itself as an object, as "something to be addressed, quantified, measured, and mastered" (Welsch 2022, 29). However, there are not necessarily visible or measurable markers of chronic illness. The experience of pain can be all encompassing but undetectable to the observer, revealing a disparity between the subjective lived body and the objective medicalised body, which presents challenges for diagnosis.

There is an emphasis on verbalising pain experiences in healthcare contexts. Elaine Scarry (1985) argues that what can be verbally represented can be politically represented. Yet, by their very nature, invisible health conditions have a measure of incommunicability, and finding the right language to express pain can be a significant challenge. Language can be restrictive and not always aligned with corporeal experience. However, as Joanna Bourke suggests: "Perhaps it is not that people-in-pain find it impossible to communicate their suffering but that witnesses to pain don't want to hear" (2017).

Interesting how, again, some of the context refers to binaries can/can't, will/won't, is (in pain)/isn't, when we know that so much of our lived experience is much more nuanced than this. But the words, concepts, diagnoses and qualifying criteria all push us down these narrow tunnels.

TIM, PADLET, DECEMBER 2025

Epistemic injustice

Havi Carel (2016) notes that the individual living with ill-health is the ultimate authority on their illness and the impact that it has on their lives. However, this understanding, this “unique contribution,” is an “advantage [that] often goes unacknowledged [...] or [is] discounted because the patient has no formal medical training” (Carel 2016, 50). Experiential knowledge, which is based on subjective and lived experience rather than formal training and education, is perceived as less valuable and credible than knowledge generated through academic or scientific research (Beresford 2020). Peter Beresford (2020) explains that accounts and narratives of lived experience will be viewed as less legitimate and authoritative when “traditional positivist research values are accepted” because they

“will be seen as ‘close to the problem’, they cannot claim they are ‘neutral’, ‘objective’ or ‘distant’ from it. So, in addition to any discrimination and oppression they already experience, they are likely to be seen as a less reliable and a less valid source of knowledge”.

Experiences that can be rationalised are legitimised, while other ways of knowing are discredited. Chronic pain sufferers can therefore experience what Miranda Fricker (2007) terms *epistemic injustice* when told they are exaggerating their pain by health professionals (see Stancliffe, Atkinson, and Barber 2026).

Fricker (2007, 1) cites two basic everyday epistemic practices: “conveying knowledge to others by telling them, and making sense of one’s own social experiences”. Epistemic injustice discredits ways of knowing and opportunities to render experiences intelligible. Fricker explains: “any epistemic injustice wrongs someone in their capacity as a subject of knowledge, and thus in a capacity central to human value” (2007, 5). S. Kay Toombs points out, “the physician and

patient constitute the meaning of illness from within the context of different “worlds” - each “world” providing its own horizon of meaning” (1990). Nevertheless, in testimonial exchange, a discursive exchange in which knowledge is imparted from speaker to hearer (Fricker 2007, 16), what happens when the experiences of a chronic pain sufferer are minimised, denied or overlooked? When they are not positioned as a credible speaker?

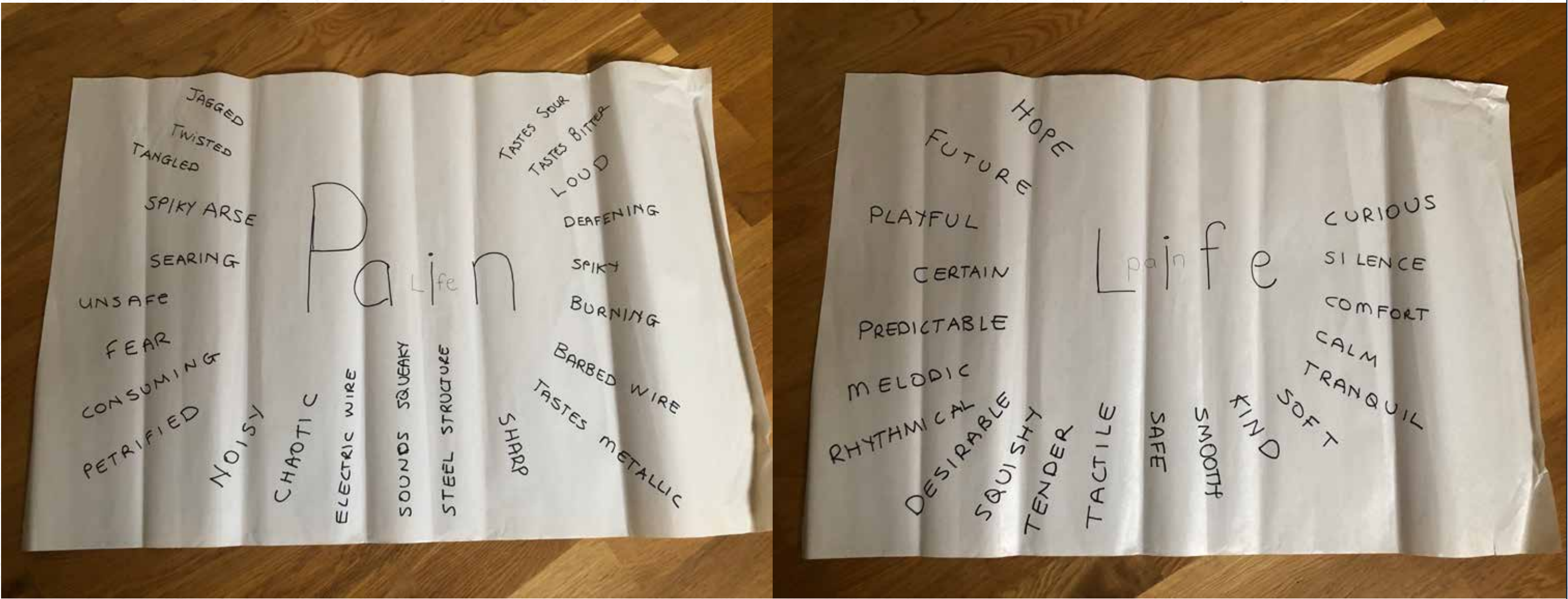
“Medical diagnosis represents a complex epistemological practice that simultaneously produces scientific knowledge and exercises social power.”
Ungar-Sargon 2025, 1

Language

Inspired by the power of language, Tim led a creative session exploring the capacity of language, reflecting on its use in healthcare contexts (e.g. appointments, correspondence, medical notes). He identified that much of that language is technical, but it can also be (dis-)empowering. Phrases such as “just try to” and “you’ve got to fight this!” implies the patient is not as fully invested in their treatment and recovery as they could be. And when recording symptoms, phrases such as “patient denies” and “patient claims” implies doubt or mistrust. Such language can take away a patient’s agency and impact their testimonial authority. The language is not intentionally harmful. It is historically contingent, developed over time through a paternal and one-sided approach where patients are passive receivers of medical expertise (Tim, Zoom, December 2025).



A screenshot of Tim’s session focusing on language.



Lists focusing on pain and life by Ruth.

Tim notes that words can be negative and harmful, but they can also be positive and supportive. The premise of Tim’s session, therefore, was to explore how to articulate experience so that we might take control over our language. We started by creating a shopping list of words: our favourite words, of all the things that pain is, and of the things that pain isn’t. These lists were a starting point, Tef explains, an “opportunity to be honest with my pain – and tell it like it is” (Padlet, December 2025).

With pain experiences ill-understood in general as well as pain suffers, Fricker (2007, 7) suggests that the speaker and listener are labouring with the same inadequate tools. Taking control of language might, in some way, mitigate *hermeneutical*

marginalisation (Ficker 2007), which refers to gaps in concepts that arise from inadequate tools for interpretation and conceptualisation. *Situated hermeneutical inequality* prevents people from making sense of an experience which is strongly in their interest to render intelligible (Fricker 2007, 7), so perhaps different tools of expression and interpretation might help to bridge the gap between speaker and listener and present different perspectives for knowledge production. Along these lines, *The Language of Pain* Collective are interested in the capacity of arts-based methods to express something of the experience of living with chronic pain.

Numerology

By Tim Atkinson

I am a number, a figure
I choose to mean pain:
It's amount and severity,
Degree and intensity.

I am the numbers, too,
I count down from a century,
Or upwards in threes:
My displacement activity.

I am the numberless days
In an opioid haze;
The wages unearned,
Or the benefits claimed.

I am the numberless hours
Sitting, waiting my turn
To be tested and measured
Along with the others.

I'm the number I choose
On your one-to-ten scale
You insist must be lower —
Because you have the power,

And I need your permission
So it seems, to feel bad.
So I grimace and nod,
And try not to feel sad

That a stroke of your pen
Always changes the tune,
While I measure my days
In the counting of spoons.

Power and social expectations

Differently positioned subjects have divergent relations to social and power structures that generate normative standards of the world and the attitudes of those who inhabit them (Guenther 2020). These structures marginalise, pathologise, and discredit certain experiences of the world (Guenther 2020). For example, the experiences of disabled and chronically ill persons are overlooked and invisibilised, meaning that they are written out of the present and future (Kuppers 2022). Robert McRuer's (2020) notion of *compulsory able-bodiedness* highlights the taken for granted assumptions of what the body can do and the hegemonic status of able-bodiedness or able-mindedness. Emma Sheppard (2020, 39) articulates the "broad construct of disability, as both lived experience and identity—created through ableism" in the following way:

Disabled bodyminds are those who fail to perform heteronormative, flexible, independent, proper bodyliness, at the right time and in the right amount of time. Disabled bodyminds are too slow, too fast, too uncontrolled, too reliant, too different, too much and also not enough [...] To be disabled, a person does not have to fail at performing all of these, but instead fail to measure up to the ideal of the 'normal' in ways which intersect with their other social markers as racialised, gendered, sexualised, aged, and classed bodyminds.

Compulsory able-bodiedness neglects and ignores somatic difference.

What is important to note is that not all chronic pain sufferers identify as disabled. Sheppard (2020, 40) suggests: "We can understand chronic pain as part of the broad umbrella of disability; people may experience chronic pain as a part or effect of their disability, or they may have chronic pain as their disability or impairment."

Chronic illness disrupts neoliberal ideals and social expectations of what it means to be a useful member of society (see Hay 2010, Kafer 2013, Pieri 2025). This stance can lead those with chronic health conditions to feel as though they are non-model citizens on "the rubbish tip" of society, a "mal-functioning underclass" (Rob, Padlet, January 2026). The feeling is heightened by marginalisation and scapegoating (see Disability Rights UK 2024, Healy 2025, Ryan 2020). However, Sara Wasson (2018) points out that the narrative of a coherent self (e.g., being fit and healthy) is a social construction imbued with privilege. Furthermore, Elena Backhausen, Benjamin Wihstutz, and Noa Winter highlight that the transient nature of good health:

Disability is, as Margaret Price has argued, "essentially unpredictable." It is so for many reasons. First of all, most people will at some point in life become disabled themselves, but they usually do not know when. On the one hand, ageing is closely connected to high risks of impairment, chronic illness, and dementia, which implies that non-disabled people will, for the most part, not stay able-bodied or able-minded forever but should rather be identified as TAM or TAB – temporally able-minded or temporally able-bodied. (2024, 1)

In light of this, and the fact that chronic pain affects a significant minority of people, greater understanding and awareness of what it means to live well with chronic illness is necessary.

Changing the narrative

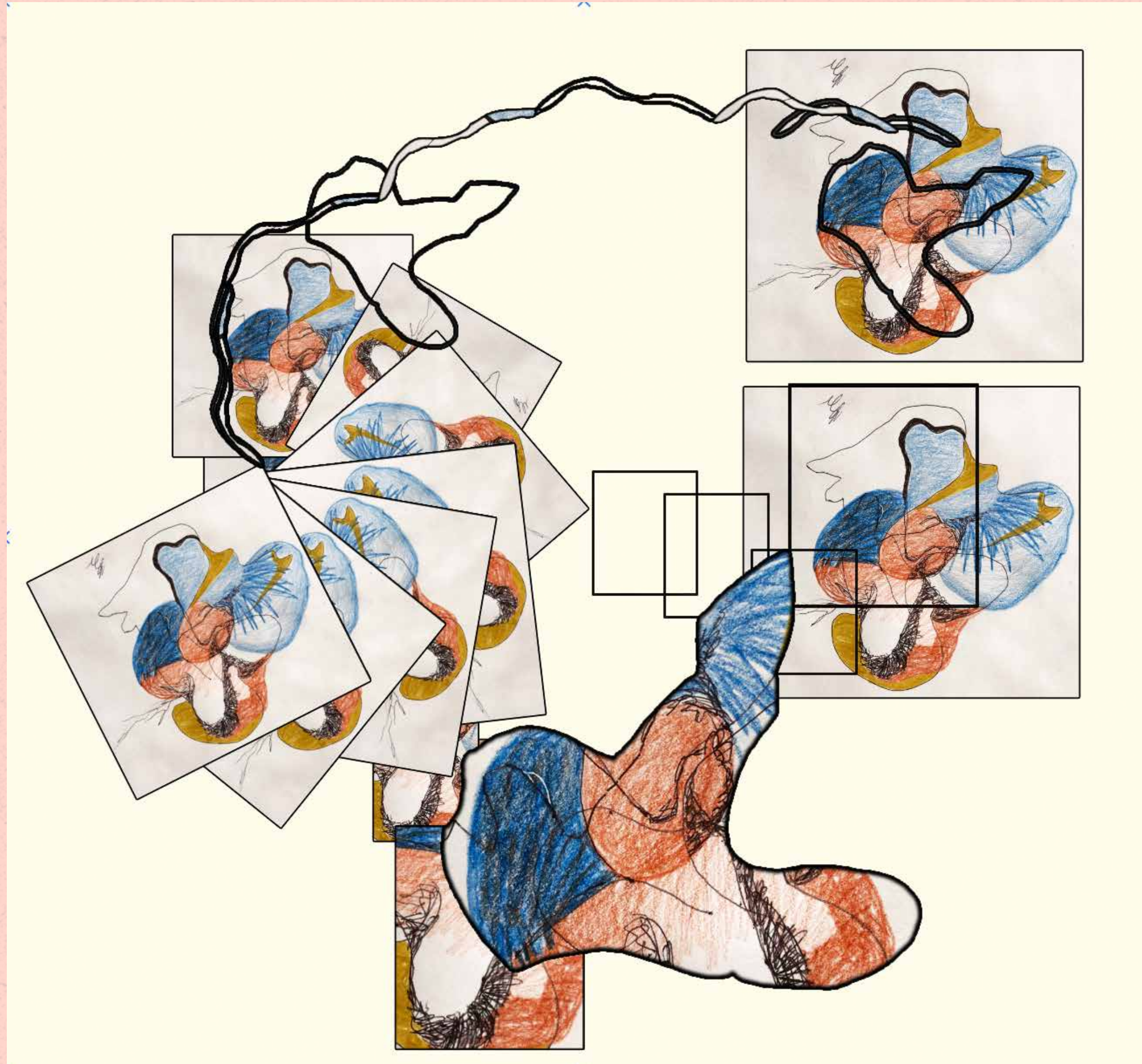
Recent media narratives demonstrate a need to reorient the narrative toward what it means to live well with chronic health conditions. In response to a news segment on *Scotland Tonight* Ruth shared on Padlet:

*I felt it was the same as every piece on pain that makes it to mainstream media and always has the underlying emphasis that there should be some kind of treatment, and still very much promotes a highly traditional medical view of pain, and that the holistic view is somehow inferior or a last resort, when we know that looking at pain holistically is the key. I came away with the feeling that, yet again, pain was portrayed as 'I have been let down and so looked to a community group to assist me' rather than 'look how great and effective tailoring pain support to an individual person using community and creative options is'.
(October 2025)*

Another example is Channel 4's *Living Well with the Drug Free Doctor* (2026), which presents alternatives to pharmacological interventions, champions the power of the mind-body connection, and highlights how small changes to everyday life can make a difference for health and wellbeing. However, despite the emphasis on healing based on empowerment, the emphasis on prevention, cure and healing presents only a partial picture. The programme offers hope of finding a cure for chronic pain for those willing to 'rewrite' their health story. But what if the cited solutions don't work? Where or to what do individuals turn if they don't yet understand their pain or know how to manage their condition? It can be an isolating and difficult journey trying to understand one's body and what works for relief and management, especially when there is little support for resourcing different approaches and awareness of what those approaches might be.

I started the session feeling quite low in energy and finished feeling like a different person.

RUTH, PADLET, OCTOBER 2025



What kept coming back to me was the concept of a collage:
a flat surface that composes different parts and by that
creates relationships, dynamics, compression, and spaces.
So, I continued to work with a digital collage using one of
my drawings to reflect on how I felt and what I sensed in our
session. I am adding some words to it here:

messiness
improvisation
... in drafts
playful and sincere and generous storytelling

the energy used to reach across
that gesture to reach across
communicates
something
precious

layering
rectangles of screens and zoom and pictures
and between all these fragments
something
communicates
reaching across
hidden
glitching
refreshing
touching

Is it my internet connection or yours that creates that?

MIRA, PADLET, SEPTEMBER 2025

A whole-person approach

While medical and pharmacological intervention were not an explicit focus of *The Language of Pain* research, the subject materialised in discussion, reflection, and artwork given its role in the lived experience of chronic pain. Our shared understanding is that there is no one-size-fits all approach to pain management. What works for some does not work for others. Rob explains that it is important that each person does what they “feel they need to do” because it is not always clear what is beneficial or counter-intuitive (Padlet, January 2026). The importance of a whole-person approach was acknowledged throughout our project. Physical exercises prescribed by healthcare professionals may be beneficial, but they can also feel overwhelming. Exercise prescriptions, Emma reflects, can “remind me I am a ‘failure’ because I am unlikely to complete everything” (Padlet, January 2026). An important contribution of *The Language of Pain*, therefore, is how somatic-informed arts practice (e.g. a practice that focuses on subjective experience and perception) can support the development of bodily understanding, confidence, and authority.

Chronic pain has “been noted to have a dramatic effect on patient’s levels of well-being” (Angner et al. 2009 quoted in Carel 2009, 130). Outsider perceptions of illness are “usually seen as bad luck or a disaster that strikes an individual”, and there is a tendency to focus on negatives such as the “shrinking of the ill person’s world, bodily doubt, and loss” (Carel 2016, 130-131). Thinking about illness as the absence of health overlooks the active subject experience of being in the world, and the complexity of physical, mental, and social well-being dimensions. Carel argues that well-being in illness can be cultivated, but it “is not something that happens automatically; it is the result of a process of adjustment and reflection” (2016, 142).

When a person becomes ill, fundamental features of embodiment are disrupted. This disorientation has been categorised as five losses: loss of wholeness, certainty, control, freedom, familiar work (Toombs 1987), which “represent the lived experience of illness in its qualitative immediacy” (Carel 2016, 42). Following L. A Paul (2014), chronic illness is *epistemically transformative*, changing the experience of personhood (see also Paul 2025). Emma’s creative introduction (right) is a poignant account of the transformative effect of illness.



A screenshot of Emma’s creative introduction

Scan the QR code to watch Emma’s creative introduction



The Language of Pain positions ill-health as socially situated, complex, and messy. We push back against stable narratives of health, resist binaries and tidy convenient descriptions in order to enlarge our understanding of what it means to live well with chronic pain. We adopt a community approach (rather than self-determination) that is grounded by shared experience and explicit recognition that we cannot know what other people's pain is like. Our research does not focus on prevention or cure. Instead, we explore what it means to live with chronic ill-health, and how we might make "our lives bigger than the pain, not the other way around" (Ruth, Padlet, January 2026). Donna Harraway asserts that:

The knowing self is partial in all its guises, never finished, whole, simply there and original; it is always constructed and stitched together imperfectly, and therefore able to join with another, to see together without claiming to be another (1988, 586).

The work of knowing ourselves is therefore an ongoing endeavour that necessarily extends beyond the lifetime of *The Language of Pain* project.

The research is aligned with the radical model of disability, which builds upon the social model of disability. The social model of disability argues that disability is caused by the way society is organised and by physical, environmental and attitude barriers that people face, in contrast to the medical model which positions disability as a problem to be solved by individuals and/or healthcare professionals (and traditionally by the latter). Where emphasis is placed on self-determination and mastery of one's destiny, blame may be attributed to personality types, as Ruth reflects:

A phrase I often use at the end of my yoga classes is 'simply feel your body and listen'. I don't know if other people get a sense of what I mean by that. For me, I hear sensations, feelings, bodily sensations. I am an introvert/empath/highly sensitive/high alert person who hears people, listens intently... this made me think of how often, in some beliefs, chronic pain is described as a personality type that holds onto pain, is more sensitive to pain lasting longer than acute pain for protection...I am not saying I believe this but it is often cited and can be interpreted as a blame on the person as to why we have pain... (Padlet, October 2025)

The radical model of disability is a development of the social model, acknowledging that disability is also a political construction. As such, when people talk about feeling as though they are on the rubbish heap of society, are told they are exaggerating their pain, or are informed that they can cure their pain through a few simple exercises performed at home, these experiences or suggestions are not abstract from power. There is, Fricker argues, an interdependence of power, reason and epistemic authority (2007, 34).

It feels like there are great things bubbling under the surface of the blanket of oppression that are patriarchal systems [...] this challenge to acceptance in a society that is capitalist, consumerist, neoliberal rather than accepting. Akin to some stuff I have read on Buddhist secondary suffering [...] The example of the wild stallion beaten into submission as opposed to being treated with a gentle horse whisperer. Do we as a society figuratively beat pain into submission or do we treat it curiously and welcome its challenge like a horse whisperer? (Ruth, Padlet, November 2026)

Consequently, informed by institutional and societal lack of trust in their experience, chronic pain sufferers can begin to mistrust their bodies, experience lack of agency, and feel like inferior and unproductive citizens.

Summary

The Language of Pain aims to redress this imbalance in different ways:

1. Adopt a whole-person approach to understanding pain experiences.
2. Emphasise chronic illness as a socially situated and embodied phenomenon.
3. Embrace somatic difference.
4. Resist stable narratives of health and avoid tidy convenient descriptions of illness.
5. Resist the deficit model of ill-health and focus on what it means to live well with chronic illness.
6. Work to recognise and ensure that experiences and knowledge of ill-health are foundational to the work.
7. Explore co-production as a means to establish equal partnership where professional researchers, artists, and people with live experience work together to design, explore, and evaluate the work.
8. Remunerate everyone involved in the project.
9. Establish a flat pay structure so all co-researchers are remunerated equally.
10. Understand the necessary structures, mechanisms and skills for co-production to address power imbalance, support agency, and encourage equal contribution to research practice.
11. Explore the role and value of arts-based methods for articulating pain narratives, and consider what these offer knowledge production.
12. Our somatic-informed approach allows us to explore our relationship to the body, learning what works for us and what doesn't. The intention here is to develop somatic confidence and authority. In doing so, we recognise that each person's pain is different, and what works for one person might not work for another.

Somatic-informed Creative Practice

Image: Mira Hirtz

The Language of Pain

24

Since pain experiences are often denied, overlooked, or minimised, *The Language of Pain* explored the relationship to our bodies and individual orientations toward pain. In each session, we turned our attention inwards, tuned into different senses, and listened to what our bodies told us, seeking to honour our experiences without judgement. The body comes first. Our somatic-informed approach to creative research aimed to develop somatic confidence and somatic authority. Kindness and understanding in our dialogue with pain was at the heart of our practice. We attended to the subjective body and explored how to render experiences intelligible, not through the rationalising effect of language but through feeling, sensing, and listening.

We began each session with grounding tasks that were usually verbally directed. We turned away from the screen or turned off our cameras: we did not need to be seen by others, and we did not need to see others. Instead, we focused on the internal landscape of the body, enlarging this space and our quality of attention through breathwork, body scans, meditation, and gentle movement. As we settled in the space and into breath patterns, we learned to listen and recognise what is happening.

Ruth often facilitated this part of the session. A yoga, mediation, and therapeutic relaxation teacher, Ruth's instructions emphasised positive thinking and established a safe space for independent exploration and trusting one's experience, which was empowering. Settling into the space and into our bodies set the scene (Tim, Padlet, December 2025), offered a soothing start (Rob, Padlet, January 2026), and set "the tone for a relaxed and open creative space" (Jo, Padlet, November 2025). Emma reflects:

From the start of our Language of Pain adventure, I have always appreciated our warm-up exercises [...] They are like a golden thread, an umbilical cord (!) that lengthens and allows me a bit of space between the world I inhabit outside of our Zoom sessions and what is going on in my body and brain just before I log-in to Zoom. I always find this 'pause' grounding and calming (and often don't want to leave that space!). But I also feel it connects us, unifies us. Today, I was thinking if only Ruth could whizz around the world and provide these moments to our so-called 'world leaders', I wonder if the outcomes of meetings would be different...

Padlet, December 2025

My arts may be simple now but it's a reflection of my current journey and it's a reminder that even in the darkest moments, creativity can be a beacon of hope.

JO, PADLET, SEPTEMBER 2026

These explorations were valuable beyond our fortnightly sessions and became part of personal pain management toolboxes (Tef, Padlet, January 2026). In one session, Ruth focused on "Caring heart", which involved sounds, gentle movement, and a hugging gesture so that we might imagine touch. We experimented with sanskrit sounds/vibrations, and an "autogenic relaxation that focuses on the words heavy, warm and peace". On Padlet, Tim thanked Ruth for:

providing so many invaluable exercises for us to use day-to-day. I find the "my ___ is heavy" phrase a very useful relaxation exercise when I'm in bed, before sleep, a time when, for various reasons (lack of other distractions probably chief among them) my pain can often suddenly roar back with a terrible fury. Telling my body it is safe and heavy, warm and calm etc. usually manages to send that beast trotting off back to its lair.

December 2025

As well as orienting ourselves toward the body, somatic practice provided a foundation for creative exploration. It was an integral part of our work because they "account for the fact that we can think creatively and collaborate effectively for the remainder of each session" (Tim, Padlet, January 2026).

Space inside the body

In one session, Mira led *The Spaces Within*, an exploratory awareness exercise that focused on the breath, imagery, and gentle movement to connect to the inner sensations of the body, and could be undertaken from any posture: lying, sitting, standing, or moving through the space.

The meditation, gentle movements, and stretches while lying on the floor felt peaceful and much needed for my aches and pains. Focusing on where we felt the breath, with a kind curiosity, was a soothing experience and a good way to explore pain in the body and check in taking the space inside us.

Jo, Padlet, November 2025

I was so grateful for the body-based meditation Mira started the session with. I was in a lot of 'discomfort and irritation' with my spine and visualizing my vertebrae, the space between and the space around, was so helpful and at one point the pain had ebbed into the background and I was free!

Emma, Padlet, November 2025



Scan the QR code to explore
The Spaces Within for yourself

In this session, my body became buoyant in a way that I haven't experienced since being that 'carefree' child oh so long ago. I felt safe and held throughout the experience and, for that moment, I became an anchor and I could feel myself slowly descending amongst the corals and reefs. I could extend parts of my body that had laid dormant and feel the sound of its rhythm.

Tef, Padlet, November 2025

We used our experiences of Mira's *The Spaces Within* to create a collage with plain coloured paper. Rather than fixing the collage, we moved one shape at a time and took a photo. The photo series was then brought to life in the form of a short stop motion film.

Ruth reflects on her experience:

After the beautiful calmness of the first breathing practice, I scribbled this drawing in my notebook. I had been lying on the floor then rolled onto my side but with a strong sensation of still lying flat. I was playing around in my mind afterwards with the idea of being in two experiences at the same time... lying flat and rolled to side, being in pain and not in pain, being defined by pain and not needing to be defined by pain, thriving but only surviving, being me but not being me, would life have been different not in pain... working but not working as self-employed... alive but also not alive

Padlet, November 2025



Ruth's notebook drawing.

Moving onto the collage stop-motion exercise:

When I cut out the paper, I was trying to replicate the feeling of rolling around on the floor whilst also lying flat and creating space. The rolling person trying to nestle into the space of the lying person. However, when I looked at the stop motion, I felt a bit like a window looking into my own vulnerability. It cries out vibes of an inner child looking lost with the image on the left-hand side then finally finding comfort and being held by the image on the right-hand side.

I'm sitting with the discomfort of this inside me.

The still images bring something completely different to the stop motion.

I ponder on this as to how different perceptions keep popping up in our sessions. Different perceptions of pain, perceptions of sound, how we hear things, how we see things. And now how we perceive imagery when still and when in motion. How this relates to pain in me. I crave silence and stillness, but I need motion and movement to get there. I need walking outdoors each morning to survive the stillness of each day.

Ruth, Padlet, November 2025



Scan the QR code to see Ruth's stop motion



A screenshot of Tim's stop motion animation

Tim reflects on his experience:

I tried hard not to think about what I was doing in creating and animating the shapes but the sense or feeling I was getting was very much hard-soft/sharp-smooth with related shapes gradually transforming into something similar but somehow 'kinder' as the animation progressed.

It was almost like a visual representation of a relaxation or mindfulness exercise, where what you begin with (tension; intrusive thoughts) isn't necessarily removed but is assuaged or soothed in some way, which is not unlike approaching pain from the perspective of somatic tracking, consciously de-coupling all connected feelings (fear, anger, sadness) and trying to attain a calmness that allows a dispassionate contemplation of your situation. Easier said, of course, than done!

Padlet, November 2025

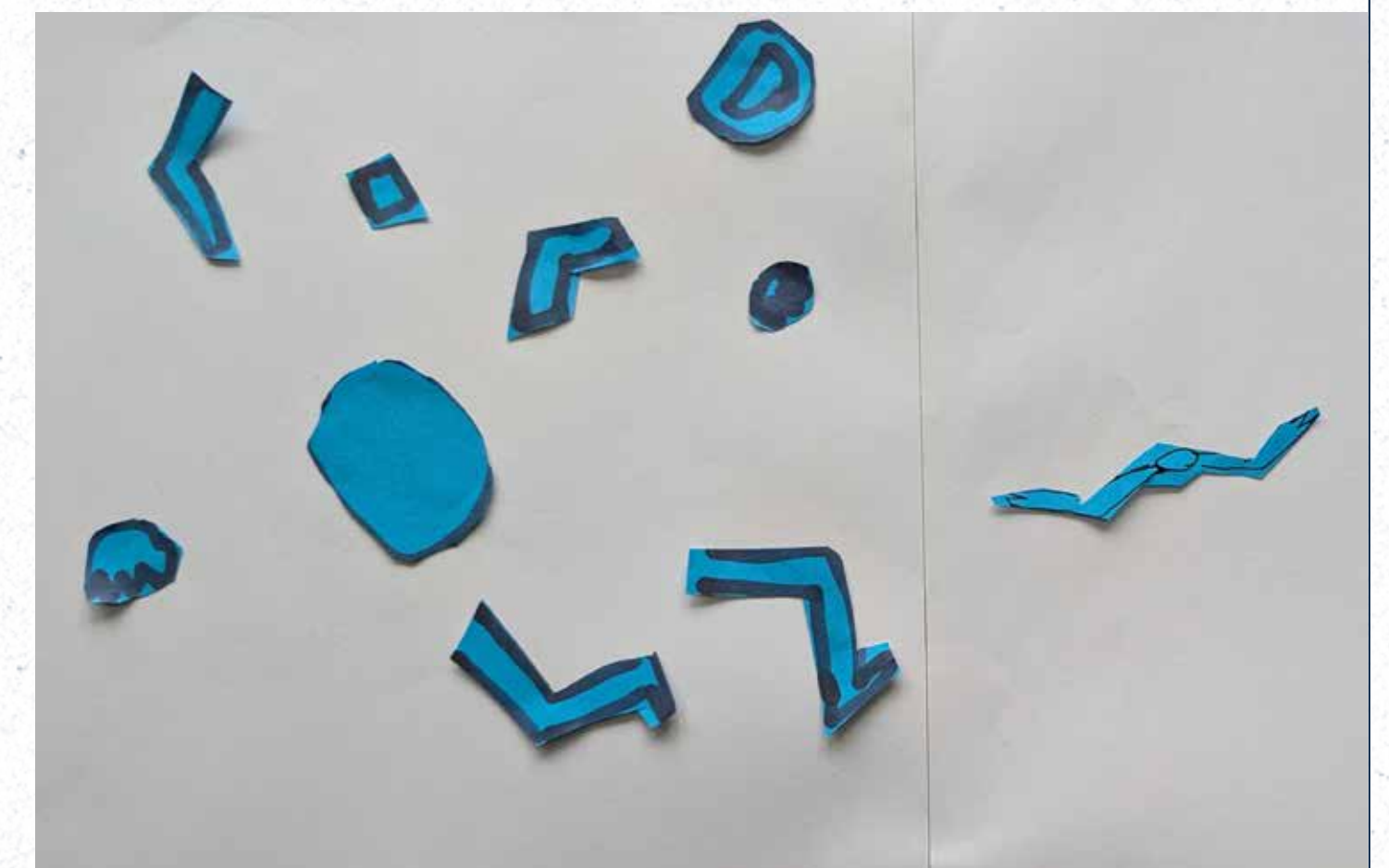


Scan the QR code to see Tim's stop motion

And Rob reflects on his:

I felt very relaxed following Mira's meditation. Rather than focussing purely on breathing and body scanning, I liked the use of other themes such as dreaming. I felt as though my limbs were so relaxed they were separating from my body which inspired my collage of a spacemen floating in space and his body parts slowly parting a floating away in different orientations and directions - ENTROPIC

Padlet, 2025



A screenshot of Rob's stop motion animation
Spacewalk to Entropy

Witnessing

As well as turning our attention inwards, we also explored the relationship to our physical environments. In one session, Dominique guided us through Barbara Dilley's *The Five Eye Practices* (see 2015), a score that focuses on different qualities of attention and focus, starting with closed eyes, followed by exploring peripheral vision, then attending to the environment through 'infant eyes' (which involved making the familiar things unfamiliar by seeing them as though for the first time), to looking for the gaps between objects, and finally directed looking. Introducing different ways of seeing invited multiplicity, enlarging our perceptual and sensorial capacity. We became aware that focal attention is not binary (on or off, visible or not visible) but can be characterised by qualitative and spatial difference.

From the 'tuning in' of the guided looking task to the brilliant discovery of the 'infant eye', seeing things for the first time, learning to see [...] the whole exercise was astonishing and enthralling.

Tim, Padlet, October 2025

Exploring Dilley's score felt important because of the screen's role in mediating our practice. Turning our attention away from the screen and towards our home environments established a different relationship to the space of participation. Jo described the task as:

a new experience for me, and I found it very invigorating. I do get frustrated when having to stay in bed with pain and fatigue, so seeing my environment through new infant eyes was a somatic experience for me, helping with shifting my perspective. This activity very much helped me to see the beauty in my environment.

Padlet, October 2025

Jo found therapeutic value of "observing my little world from different eyes" by "taking pictures of the art in my flat at odd angles and enjoying playing with the lighting and mirrors (Padlet, October 2025). Tef was inspired to:

re-ignite my passion for photography [...] being attentive to what is in the frame and all around it. My sensory perception is opening up to alternative viewpoints as I meander around my local area.

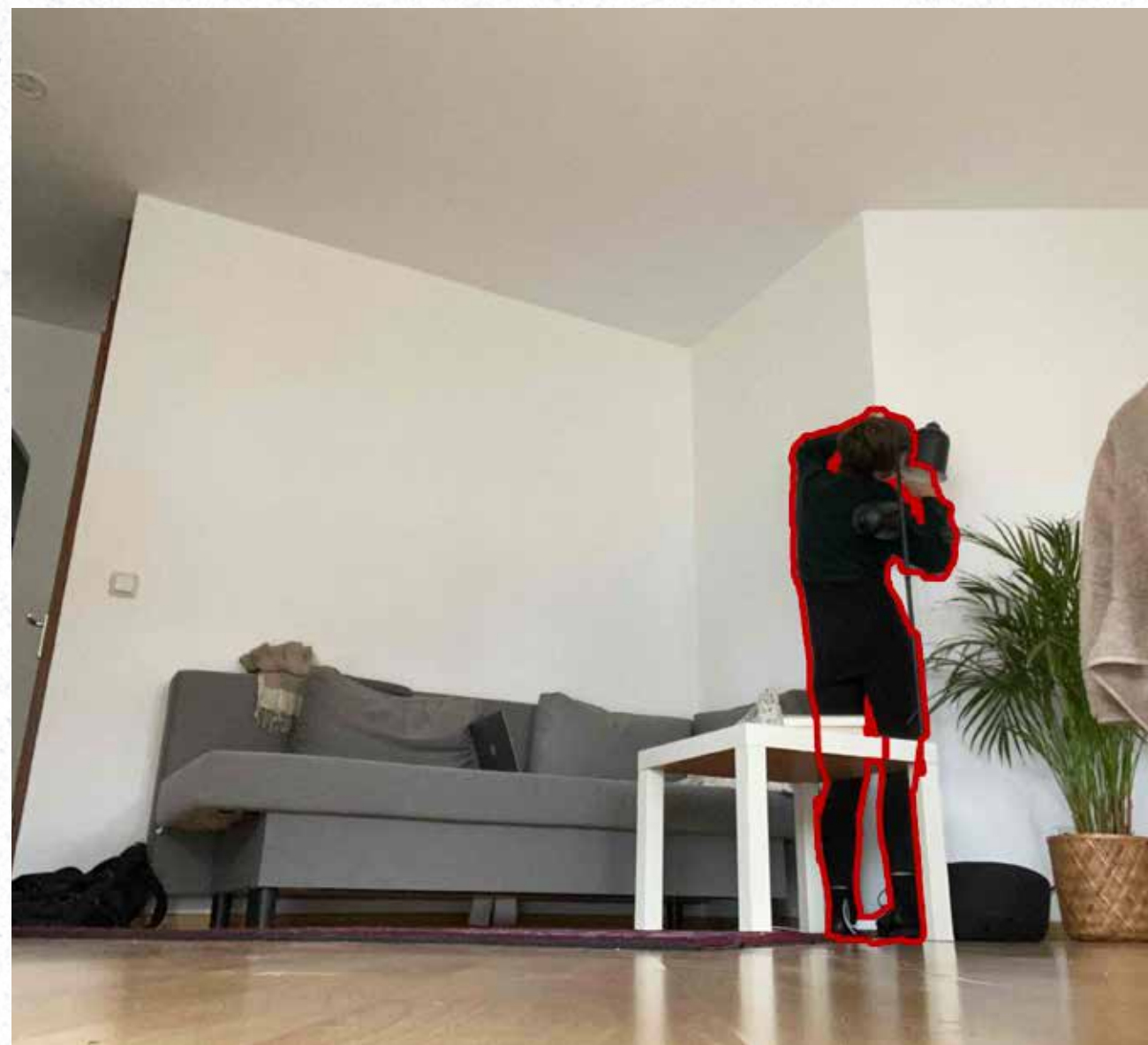
Padlet, October 2025

As with other grounding tasks, the focus on looking and seeing prepared us for the creative exploration (moving and witnessing) that followed. Dominique described witnessing as "a supportive gaze that suspends judgment while also attending to one's own body in the relational context" (Padlet, October 2025). In pairs, we worked in breakout rooms. One person explored movement and stillness for five minutes and were witnessed by their partner, before swapping roles. The intention was exploratory, not performative. In other words, this was an opportunity to move around in space while feeling supported by an onlooker.

Mira and Jo worked together. Mira moved first while Jo witnessed. She reflected on how Dilley's score encouraged her to play, exploring how to "squeeze into gaps and corners" of her space:

I continued this in my flat, looking for gaps, then trying to fit in, and from there looking again. What does the camera see? Which weird perspectives and new objects seem to emerge through this? And what do I see at the same time? So many dimensions! And a deep pleasure to be reminded of them.

Mira, Padlet, October 2025



Witnessing this exploration, Jo:

found Mira's expressions and movements to be playful, like a kitty exploring an environment. She was playful with myself and the screen. I found it very comical as she was hiding and peeping at me and used her whole space, even under the table.

Padlet, October 2025

Jo's approach to the task illuminates the difference that we celebrate in our work:

I explained to Mira that my mobility was low, so I moved and explored the space of the screen while moving the camera and the top of my body in different rhythms.

Jo, Padlet, October 2025

Jo adapted the task, "playing with the screen, panning in and out, trying to communicate non-verbally" (Jo, Padlet, October 2025). Mira joined in, mirroring and expanding upon Jo's actions. Jo "found it so fun and felt like my body was moving with Mira's [...] it felt very natural to move together like this" (Padlet, October 2025).



Mira's creative reflection on looking for gaps in her environment.

After this exercise in pairs, we returned to the main meeting room to explore how we could replicate the gestures and movements we witnessed on screen. Ruth described the task as:

so unpredictably enjoyable. It brought a sense of connection between our own natural mannerisms. This strong feeling of connection between us was especially prominent in this session as we looked intently at ourselves, at each other and at the world around us.

We started by copying each other's habitual movements like touching the face, glasses, hair, and it spread as we got more confident in adding more gestures. It was the very beginning that felt poignant as we gently and tentatively copied each other. I have no idea what others were thinking but I felt like I was looking carefully so I could mirror. But did that person mean to move their hand or hair or was that them just taking their own normal body mannerisms?

Ruth, Padlet, October 2025

These witnessing tasks enabled us to explore the qualitative and attentional difference between looking, seeing, and watching, and to reflect on what kinds of gaze we typically employ. How is our vision employed when working on screen? And could a different visual relationality mitigate Zoom fatigue and expand the creative possibilities of our practice? How often do we take time to notice the hidden gestures and sub-conscious mannerisms? And attend to the space and dynamics of their performance?

Listening

Peter facilitated a session to prompt thinking into the role of sound in our lives and within our creative research. In advance of the session, the deaf percussionist Evelyn Glennie's *Hearing Essay* (2015) was signposted. Writing about the misconceptions of D/deafness, Glennie argues that to "understand the nature of deafness, first one has to understand the nature of hearing" (2015). She describes hearing as "a specialised form of touch" and sound as "simply vibrating air which the ear picks up and converts to electrical signals, which are then interpreted by the brain" (2015). Yet, "For some reason we tend to make a distinction between hearing a sound and feeling a vibration, in reality they are the same thing [...] Even someone who is totally deaf can still hear/feel sounds" (Glennie 2015). To ground our practice, the session started with exercises on deep listening based on the practice of composer Pauline Oliveros. Oliveros differentiates between hearing and listening: hearing as "the physical means that enables perception" and listening as giving "attention to what is perceived, both acoustically and psychologically" (2005, xxii).

We explored hearing and feeling sounds, exploring how we attend to our bodies and our environments. Peter asked us to "break all the rules of Zoom meetings" by turning our microphones on and listening to the sounds in our connected, albeit fragmented, digital environment. We created sounds to tune into the lag and latency of Zoom (highlighting the challenges of sound work online) and then listened to what we perceived in the combined space of our home and Zoom environments. We experimented with two audio settings: the default 'eliminate background noise' where Zoom filters the sound to foreground the speaker's voice (useful for meetings) and 'original sound for musicians' which allows more sounds from one's space to feature. The exercises invited us to reflect on the unnatural experience of sitting still in front of the screen and how (surprisingly) energy consuming it is. We noted that we heard more the longer we sat quietly, what kinds of sounds were foregrounded in our listening, and what sounds from our personal environments are picked up by Zoom.

After the break, we each shared a sound that was meaningful to us and were invited to describe how it 'touches' us, whether physically, perceptually, emotionally, or in some other way. We had been invited to prepare for this in advance of the session. Sounds included music excerpts, recordings of nature (e.g. seagulls, the sea), and everyday life (e.g. the sounds of public transport). Sounds felt or heard inside the body also featured. For example, Mira described the sound of her cracking her joints, a sound that she could not share with the group, or at least didn't know how to. She reflected on

the qualities of inner hearing, how sounds travel through and within the body, and to what extent they are audible to others.

Emma reflected on her experience of listening to the sounds selected and shared by the collective:

Peter spoke about 'deep listening', which reminded me of the phrase 'exquisite listening' which is used in therapeutic terms. I wanted to try and fully honour the sounds shared by the group. This resulted in me getting really close to my laptop to hear as much as possible. I didn't want to look at the screen and be distracted, I just wanted the purity of the sound - so that what I heard wasn't influenced by what I saw, and I wanted to try and absorb the sound into my body.

Padlet, October 2025

In focusing on the difference between hearing and listening, Ruth contemplated the connection between sounds, communication, and understanding:

On zoom you only hear, feel your own sound but does it fit in with the sound of 'society' or does it not fit in? [...] Links to the theme of communication, how we communicate our pain, what do others hear/feel, what do we reveal nonverbally that others, possibly healthcare professionals, need to hear/feel/see. In pain what is the overlap in our senses.... Hearing, feeling, seeing, etc. It comes back to the idea: do they see what I see? Do they experience what I experience?

Padlet, October 2025

Masking

We mentioned earlier in this report Tim's session that focused on the capacity of language and its (dis-)empowering character. We created shopping lists of words: our favourite words, all the things that pain means to us, all the things pain isn't.

Examples of what pain is included:

Blocked sink - drain - sewer
Repetitive - at different times of the day
Gnawing, gnashing feelings
Irritated - sharpness - cut squeezed with lemon
Reassess my movements/position - lost spontaneity
Thumping sensations

Tef, Padlet, December 2025

Splaunch. Blurgggh. Things that aren't even English I have been using to describe my pain.
ME is a Monday morning.
ME is my monster.

A dark entity inside of me that I am constantly trying to squish down a bit like a Marvel character. That's how I've had to sort of differentiate it and put it aside from me.

Jo, Zoom session, December 2025

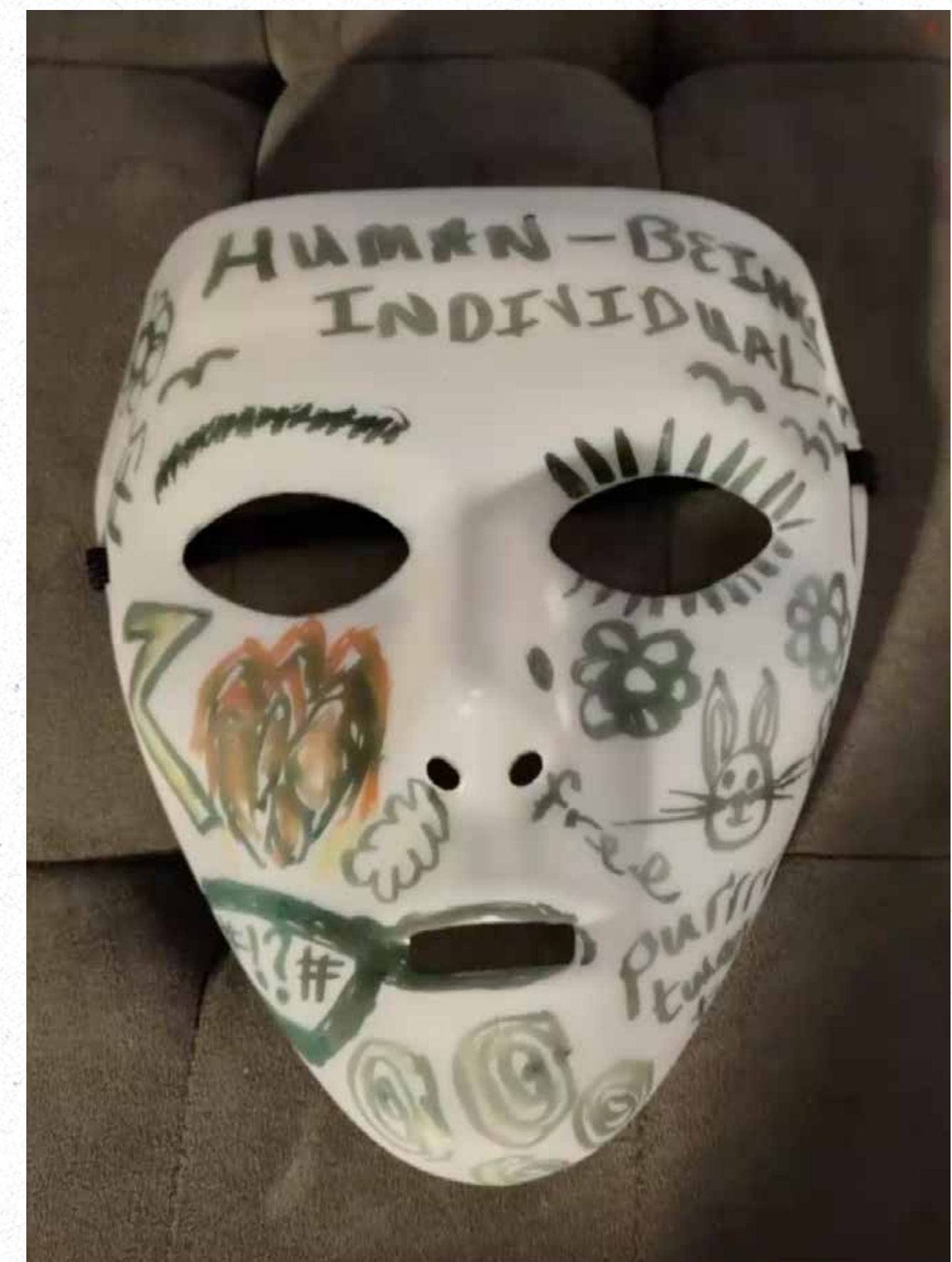
In response to our lists, Tim spoke about sense-making and control:

The sense, if there is any, can come after. Minutes, hours, weeks, months, even years. And it doesn't even need to come. None of this needs to make any kind of rational sense. It's important, and what you have shared makes this very clear, it's important to be able to try, however hard, to apply some words to it and just see how it feels. Just try them out. Because I think, by doing that, however difficult it is and however inarticulate we sometimes feel, we are at least beginning to take a tiny bit of control of our lives back. We're not handing it over to somebody else and having to learn their specialist language, or their authoritarian way of describing what we're feeling and what we're doing. I am really keen to explore those elements of control. And we're kind of educated out of it as patients, in the traditional sense of the word. We are, literally, very patient.

Zoom session, December 2025

When I look at all our decorated masks I smile at their individuality, they have been transformed from a hard, white plastic, slightly scary thing, into something other, capturing aspects of ourselves.

EMMA, PADLET, DECEMBER 2025



Emma's response to the masking task.

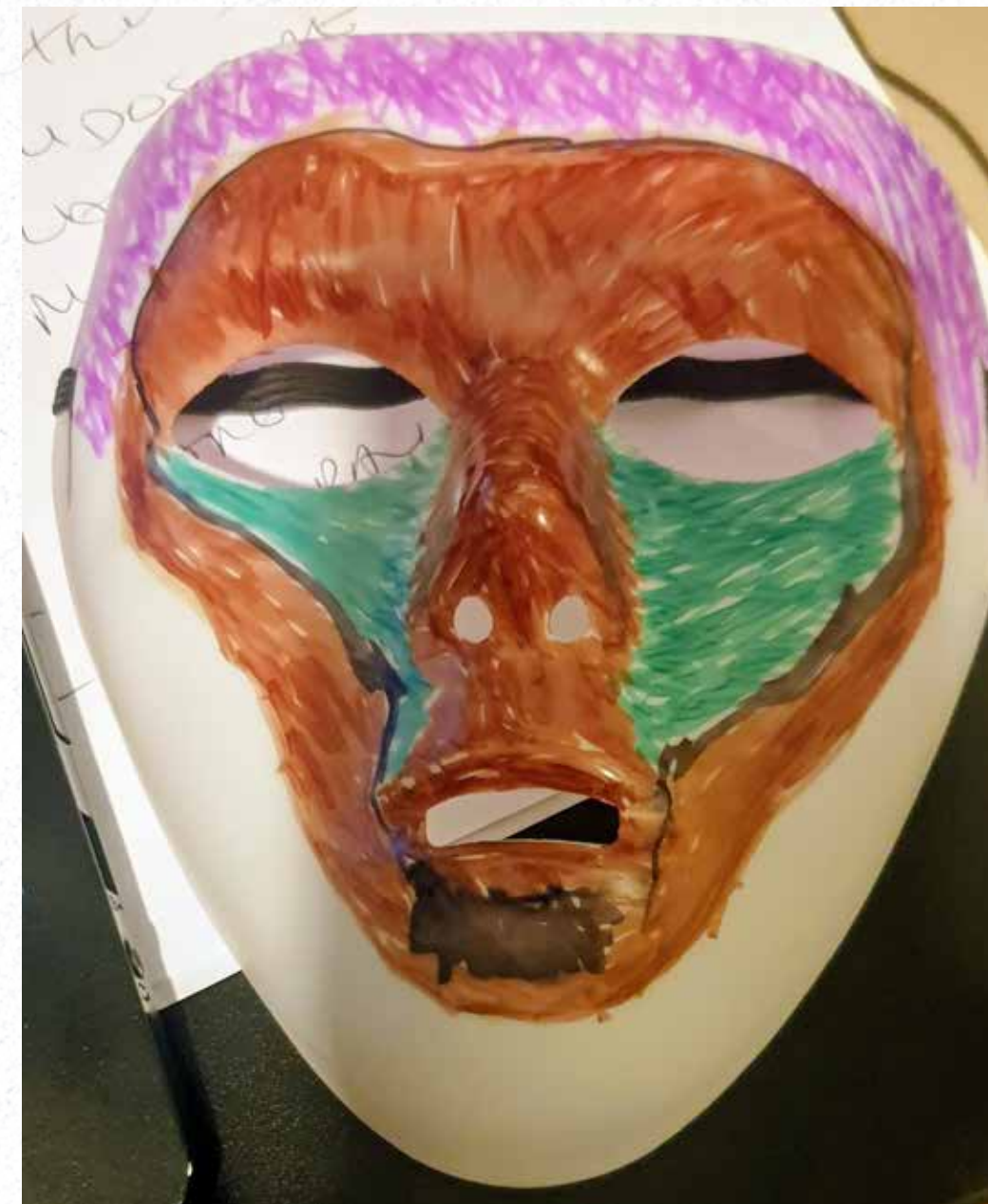
Taking control of our own narratives was explored further in a creative task Tim led on masking. We were invited to think about the perceptions and definitions imposed on people living with pain and how this contrasts our experience and situations as we would like them to be. "Masking is so much a part of what we all do (whether in pain or not) and the reasons for, the good and bad and problems/solutions it brings are fascinating to think about" (Tim, Padlet, December 2025). Emma reflected that "masking can be very useful in helping us navigate/get through life [...and] and can both protect and be exhausting" (Padlet, December 2025).

This dichotomy between public and private, outer/inner, well/ill etc is fascinating because, really, there's no binary distinction for anyone: we're all at different places on the continuum, which makes the need for a mask (of whatever kind) somehow restricting. And yet it also provides a communications short-cut at other times, rather like the range of badges people can now buy to identify various hidden disabilities.

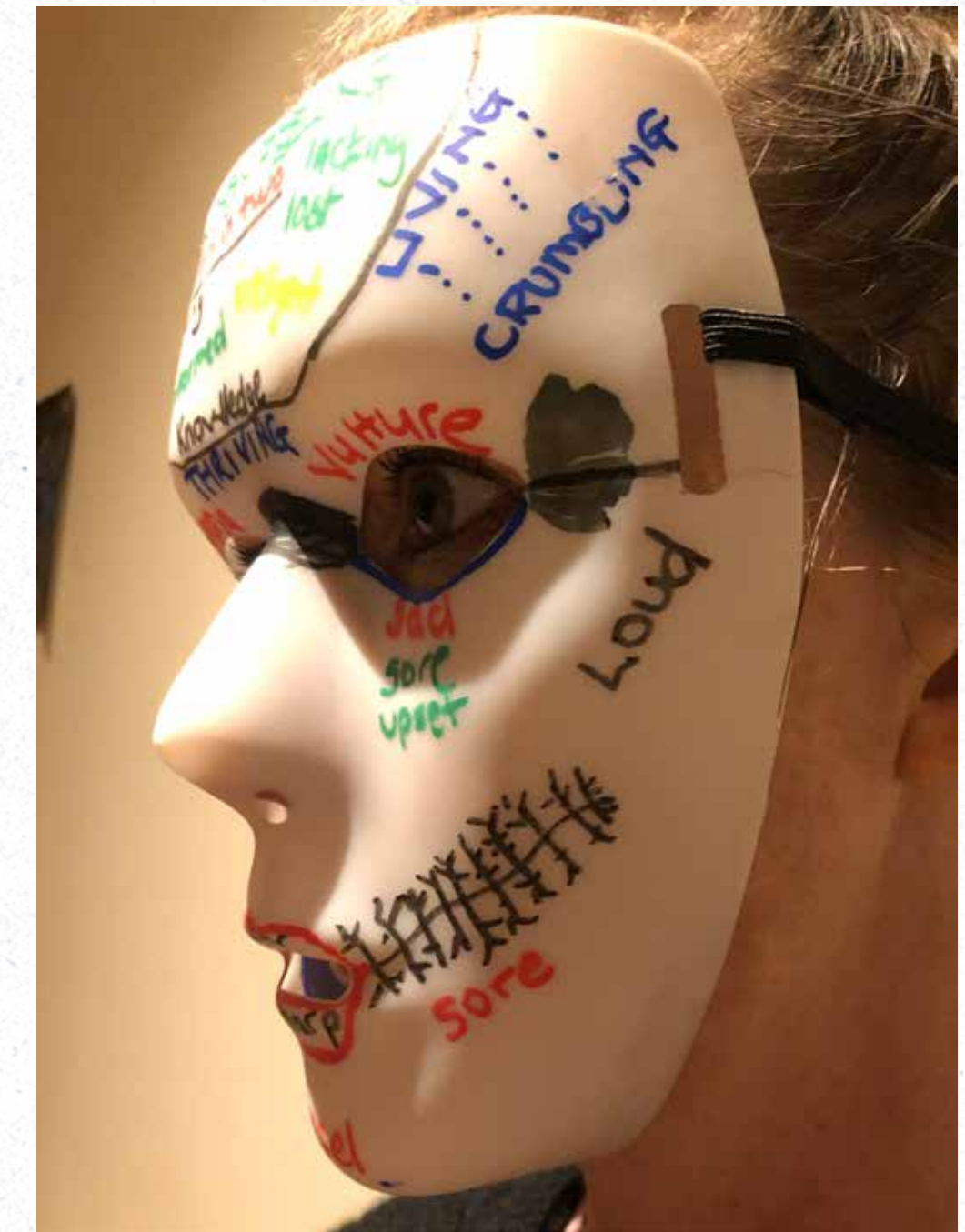
Tim, Padlet, December 2025

In preparation for the session, the collective received masks and coloured pens in the post. Tim

invited us to consider how we wanted to embellish our masks, perhaps using our lists of words as inspiration. What would we like the mask that we present to the world to look like? Perhaps we could focus on personal definitions of who we think we really are or how we wish to be seen. We could emphasise the words we want to hear in conversations with clinicians, the benefits office, or health service. The mask could be aspirational, or present two sides of our experience.



Tef's response to the masking task.



Ruth's response to the masking task.



Rebecca's response to the masking task.

The task was an open proposition to explore what face we present to the world and what we hide, which therefore goes unrevealed or unseen. For Rob, this “masterstroke” of an expressive task was a chance to explore “the multiple facades that we all display”, and he drew a vertical line down the middle of his mask to represent the “contrasting sides of pain” (Rob, Padlet, December 2025). Jo also divided her mask, writing the words *pain, distress, torment, hurt, and suffering* on one side and *peace, calm, harmony, joy, and warrior* on the other. In response to Jo’s mask, Tim reflected that “the two halves are clearly delineated but not equal, almost as a statement of intent and cleaving to all that is positive in spite of the negative distractions of pain” (Padlet, December 2025). Tim reflected that Mira’s approach was intriguing:

and is something I’ve often felt: the pain is like a shadow or something always in my peripheral vision, or like some sleeping creature, always likely to wake and come roaring from its lair. That somehow seems to chime with your instinct that our lives in pain are nothing if not multi-layered, with many onion-like skins to peel and reveal different emotions, reactions, situations. As usual, the reflections on an activity are every bit as stimulating and thought-provoking as the activity itself.

Padlet, December 2025

The task inspired Jo to reflect on masking with “fellow pain warrior friends” outside of the collective. She was “struck by how universally we mask our physical and mental pain, mostly to protect others” (Jo, Padlet, December 2025). In asking *How do you think masking affects your healing journey?* Jo found the responses insightful:

Some [friends] felt masking delayed their getting support and treatment. Others noticed it strained relationships over time. One realised masking became a habit, making it hard to recognise themselves and their own needs. We focused our healing creative time that day on unmasking our art, creating self-portraits with genuine expression that reflected our true selves and deeper emotions.

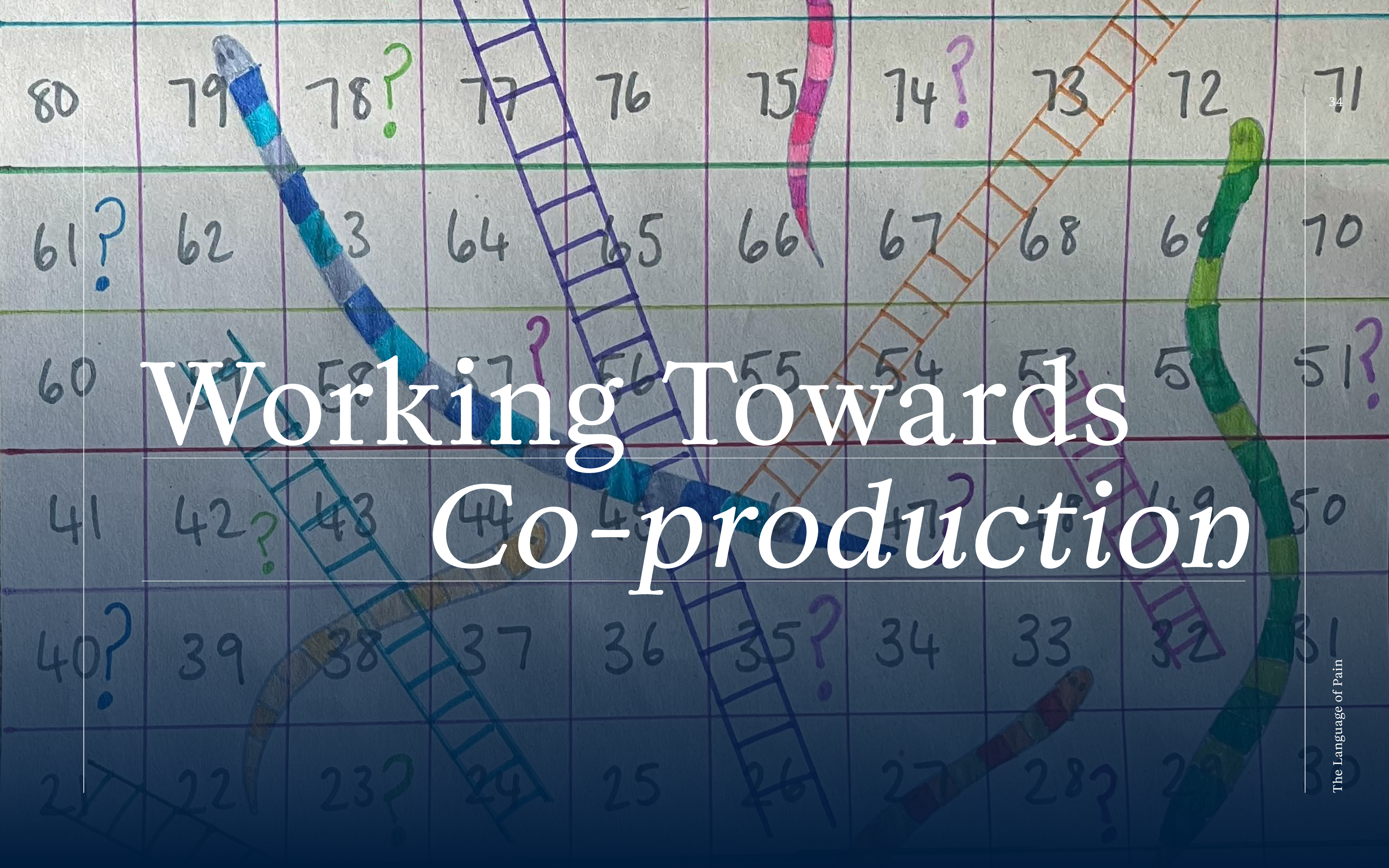
Padlet, December 2025



The collective wearing the masks created.

I feel this bit of sadness now. I have a vision of walking into a consultation room wearing my mask, donning a feather headdress, a ra-ra skirt, jangly bells on my ankles, and still I wouldn’t be seen/heard/understood. Even with all that get up, I can just imagine – ‘So Ms Saunders, on a scale of one to ten, what number is your pain today?’

EMMA, PADLET, DECEMBER 2025



Working Towards Co-production

Traditionally and historically only professional researchers were considered the people with the skills and experience to do academic research. The systematic marginalisation of people with lived experience is an epistemic injustice (LeBlanc and Kinsella 2016), discrediting ways of knowing and opportunities to render experiences intelligible (Fricker 2007). There is a moral and ethical imperative to include lived experience insight in knowledge production, and there is increasing recognition that it can contribute vital insights and perspectives. Partnering with people with lived experience can increase the relevance of research and rectify historic “epistemic disparities” in knowledge production (Brett et al. 2012, LeBlanc and Kinsella 2016).

The organic nature of each individual, but also of the group makes it extremely unpredictable; almost completely unpredictable in every way. It reminds me of a Mexican Wave but is much more variable due to the ever-changing movements that any one person did at any stage, and who was more in leading mode rather than who was more in following mode. What are the group dynamics – is it supportive or confrontational? To what extent do you like or dislike someone? Who draws your attention most? What stimulus are you more likely to respond to? Sound? Vigorous movements or subtle ones?

ROB, PADLET, NOVEMBER 2025

I think what I’m trying to crawl towards here is an idea about trying to comprehend something I have no direct experience of. This is partly a matter of listening of course, but I sometimes feel that puts the onus on you [lived experience experts] to explain rather than me to understand. But I think there’s an idea about empathy here – of finding experiences that may not be the same or comparable in terms of the impact on one’s life but offer a way in to finding an empathic connection that helps get me closer to that state of being, even if I can’t really get there. A lot of what we talk about is your desire to find the language to convey your experience but it’s maybe as much about all of us trying to create an atmosphere of empathy and curiosity to build understanding.

PETER, PADLET, DECEMBER 2025)

Democratising knowledge production

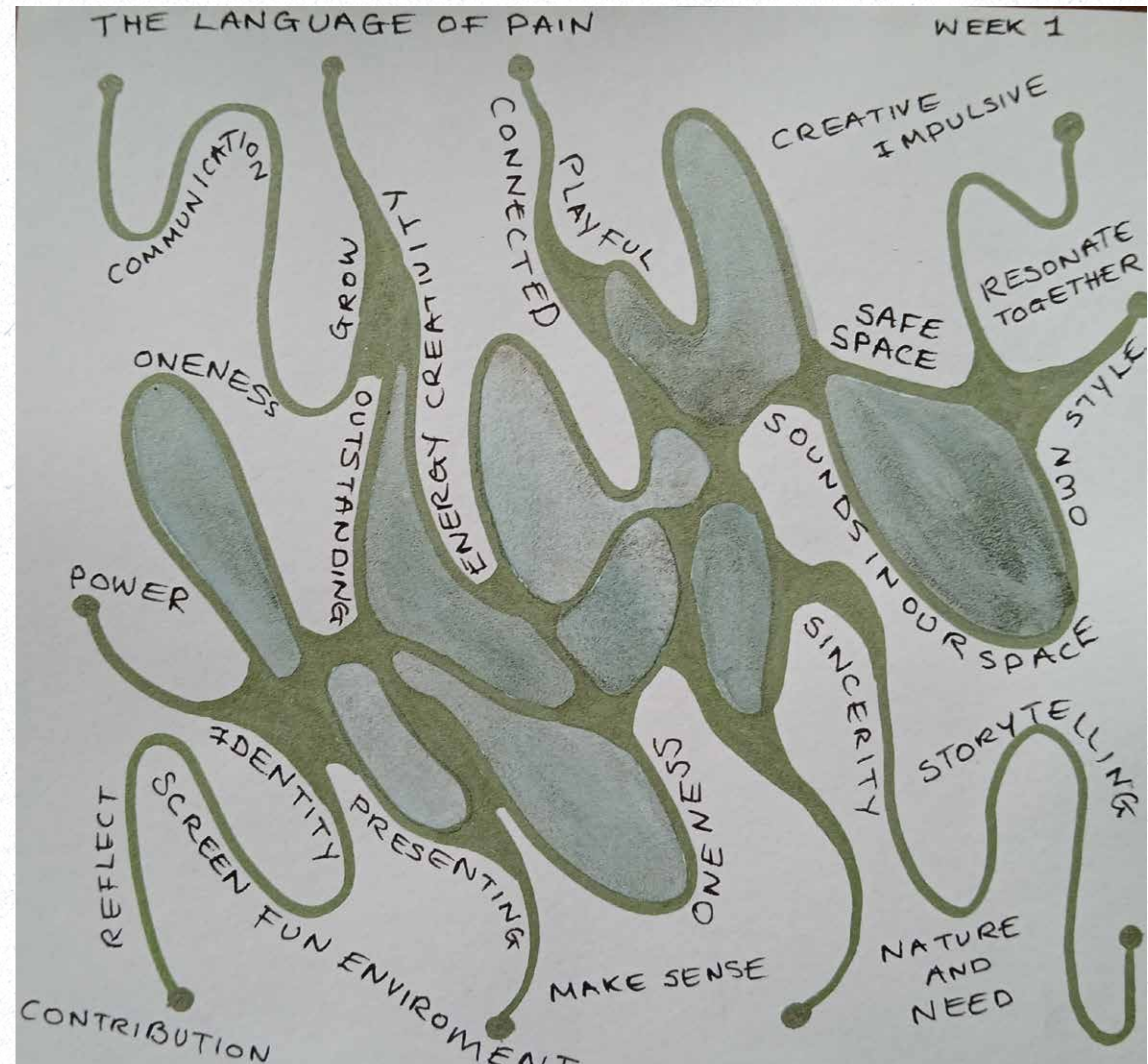
it is widely understood that lived experience input is necessary for context-relevant and impactful research. However, true collaboration is often lacking. Emma and Tim (peer interview, June 2026) reflect on tokenism:

Expert by experience is quite a big term, and I think it's a bit of a patsy to make people feel better when they're asked questions in research, in clinical research projects, if I'm honest. I'm always asked at the end of the clinical discussion what do you think? And 'Oh, we have a patient in the room: what do you think?' They're never called patients; it's PPIE in the jargon. But lived experience expert is how we're all described, but I'm not sure anyone subscribes to that as a genuine term. I think it's a bit of a sop, really, to make us feel better. But not in this project. 'Rebecca, Rebecca, I don't mean you; I don't mean this project!' I think it's just a widespread term that is misused and misapplied.

Tim

Totally. Years ago, I was doing a role [at a hospital] and I remember taking a former patient to attend this quarterly meeting, or something. There was something going around and asking for people's thoughts and reflections. And at no point did they ask the person that was next to me [...] Wheel out the patient from the ward to attend the meeting, good man for coming along. It's problematic, isn't it.

Emma



It is. There is good practice as well. There is a lot of very good and genuine co-production where the expertise of having lived a life with chronic pain is valued and treated as such, but there is an awful lot that is not done well but is still badged in that way, branded in what way, which I think is a bit of a misnomer, really.

Tim

When done well, co-production democratises knowledge production and rebalances epistemic disparities.

A core intention for *The Language of Pain* was to develop creative research informed, shaped, and directed by lived experience. Everyone was positioned as a collaborator involved in shaping the direction of the process. Charlotte reflected:

The balance of decision making and working in this equitable space is always at the front of Mira and Rebecca's minds and I am adjusting to this. I am quite used to making quick decisions or being part of conversations where they are made, whether quickly or in stages or over a period of time, and this is nicely different.

reflective notes, November 2025

Some members of the collective were more active, making suggestions about what ideas and methods to explore, and volunteering to devise and lead elements of the process (e.g. grounding exercises, creative tasks, outputs). We resisted the facilitator-participant model common in community arts practice in our choice of language and in how sessions were modelled (e.g. the term co-researcher instead of participant was used). An external collaborator frequently referred to members of the collective as participants indicating conceptual challenges associated with adapting to co-production as a novel approach to research.

Interesting chat with Rebecca today about facilitation as a word and how we think of it as a version of leading, albeit less didactic, and how, in this project, the two external facilitators are fulfilling the true meaning of the word: to make (something) easier / to help (something) run more smoothly and effectively. When it comes to the latter, I like to think that is the part of what I am doing too and facilitation is never a word I would have aligned myself with before.

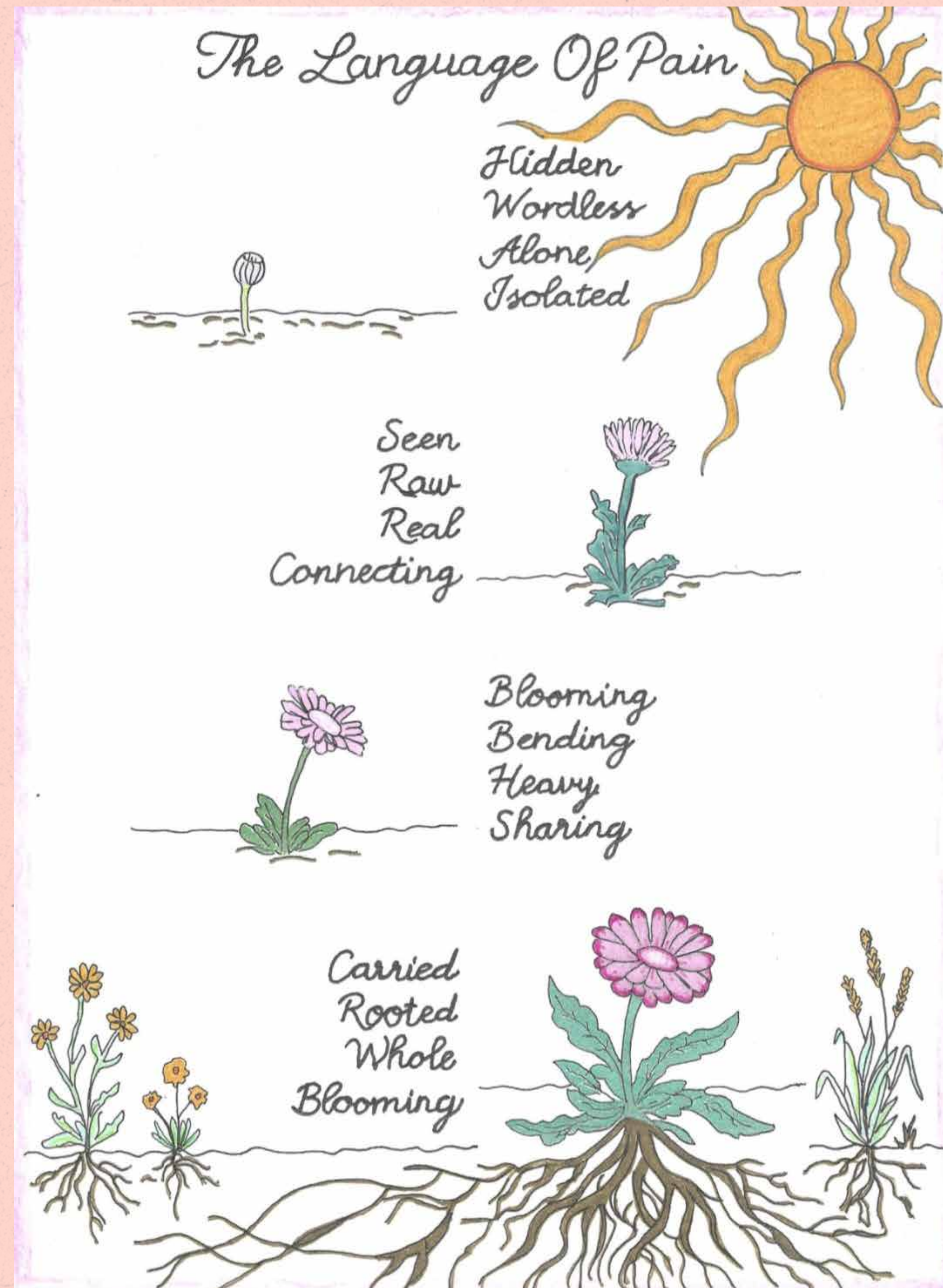
We were brought onto this topic through discussing how the sessions so far have been very creative and full of sharing and different ideas and how it now needs to shift into 'output mode' (feels the wrong phrase). And I think this is more challenging or maybe just different in a space like this where one person 'taking charge' won't work. I admire how Rebecca can support and guide this without taking over.

Charlotte, reflective notes, February 2026

We hoped for collective and distributed decision-making so that each person would feel they had part ownership of the project. Rebecca conceptualised the project as working towards co-production. Everyone was involved in creative practice, generating data, and reflecting on the project, and knowledge dissemination was undertaken by individuals to varying degrees (e.g. blog posts, podcasts, conference presentations, social media promotion). Rebecca undertook the task of data analysis. The length of the project (14 sessions over eight months) and the plans to develop resources during Phase 3 did not provide enough time for distributed data analysis. However, it is hoped that skills development (e.g. workshops on research methods and data analysis) will be a core feature of the next iteration of *The Language of Pain*. Here, it feels important to highlight that it has been a lengthy process of getting to a point where full co-production might be realised. Since 2023, Rebecca has been researching how to support co-production, the skills and qualities that support co-production, and the degree to which different elements of our creative research can be co-produced, and the collective has been involved in this process.

*I'm on a quest to find
balance and calm. Art
and creativity help me
on this journey.*

JO, PADLET, SEPTEMBER 2025



Jo's creative account of her
experience of *The Language of Pain*.

Remuneration

The Language of Pain creative health research would not exist without the input of lived experience experts whose insights, contribution, and experience are foundational. We therefore wished to model a practice whereby the knowledge and experience of what it means to live with chronic pain are understood as a vital part of the project. The Language of Pain is built upon the understanding that everyone involved is a collaborator, contributing to the research based on their knowledge, skills, and expertise. We did not therefore differentiate between individuals involved with the project as part of their ordinary professional capacity and those who were not. People with lived experience are knowledge keepers; not to compensate them is exploitation (Cheff 2018, 6). It is therefore necessary that the time and contribution of lived experience experts is recognised to be as important as anyone else in the project. Informed by the desire to challenge the ‘researcher and researched’ model, and following guidance on best practice from *National Institute for Health and Care Research* (NIHCR) guidelines (2024), all co-researchers are remunerated for their contribution to the project (e.g. engagement with creative practice sessions, asynchronous reflection, peer interviews, dissemination activities).

Remuneration:

- challenges the traditional hierarchy of research since it values and acknowledges different kinds of knowledge;
- acknowledges that this research only exists because of lived experience insight;
- goes some way to help co-researchers feel integral;
- serves as a reminder that people with lived experience are not engaged with research that is done to them but are project partners.

Remuneration is not without its concerns and issues:

1. It is necessary to ensure that co-researchers understand the implications of payment for their tax affairs and how it may impact any benefits they receive, since payment can trigger a review of eligibility for welfare.
2. For co-researchers on benefits, there is an invisible cost of engagement. There can be significant emotional labour (stress, anxiety, fear, uncertainty) when it comes to how remuneration can impact their lives.
3. There are ethical considerations particular to our focus on chronic illness and pain. It was important to ensure that remuneration did not exert undue influence on the decision to engage with the research. We did not want individuals to attend project sessions against their better judgement if they were unwell or to ignore what their body is telling them. We discuss this further in the section Not Performing Wellness.

Conceptualising co-production

In the 2023 pilot study, in the early stages of exploring what co-production might look like, the different roles involved in the collaborative enquiry was conceptualised using the body as a visual metaphor:

- the facilitators created a skeletal framing – a structure for creative work;
- in bringing their insights, thoughts, and sensations to the project; 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;
- 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.

This concept has evolved since the collective was formed. The responsibility of creating a structure for our work and filling it in has been the purview of everyone involved in this phase of *The Language of Pain*.

Challenges & learning

Working towards co-production has not been without its challenges, and within the context of this work there is further work to be done. For example:

1. Developing a shared understanding of the roles, responsibilities, and expectations of co-researchers to support the personal and collective responsibility to drive the project and knowledge generation.
2. Greater understanding of the different ways that individuals contribute to the project according to interests, needs, and experience.
3. Understanding what mechanisms need to be in place to ensure open and honest discussion when tensions and challenges arise.
4. Understanding how to make the offer of skills development attractive.
5. Continued work to acknowledge the importance of crip time (see Kafer 2013) in project management and delivery.

Co-production lacks a clear methodological and theoretical framework. Rebecca reflects on the learning from this project:

1. Working toward co-production is far messier and more time-consuming than 'traditional research'.
2. There is a wealth of invisible labour necessary to ensure the smooth planning and delivery of the research.
3. Working towards co-production demands a different kind of leadership to traditional approaches to research. Strong leadership informed by feminist methodologies, mutual respect, and commitment to rebalancing epistemic disparities is needed.
4. The social and political skills of negotiation are important to ensure that everyone's voice and contributions are heard, respected, and honoured.
5. Reflecting on the role of the professional researcher and de-centring power is ongoing.
6. Recognising that different stages of the project need more or less structure, guidance, and freedom.
7. The importance of establishing a community agreement from the start of the research.

the language of pain

A Productive Unravelling: *Emergent & Iterative Design*

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In *The Language of Pain*, we dive into co-research and put lived experience at the heart of creative practice and storytelling. The project was emergent in design, developing in an iterative fashion in response to collective input. Artwork, reflections, discussions all informed how the project unfolded. The creative process was central to the project.

What we're doing, week-by-week, is our creative expression. Maybe whatever emerges at the end of the project needs to be a dynamic mash-up of all the things we've done along with our reflections on how it's made us feel? Who knows? I'm finding myself less and less concerned with an end product, as such, and more and more convinced that what we do, our efforts each session and our lives between sessions, are the product.

Tim, Padlet, January 2026

To ensure, as much as possible, that the project evolved according to the needs and interests of everyone involved, *The Language of Pain* was an emergent project. A project structure was devised at the start to give form to the creative process, but the content of each phase and each session was not determined in advance. The time allocated between each session was important for reflecting on what we had done, planning where to go next, and allowing everyone's input to inform the direction of the research. In this way, ideas emerged in dialogue. We are all parts of a moving jigsaw puzzle. The practice is not about an individual's idea, but about "the space in between where things emerge" (Dominique, Padlet, January 2026).

We have such a strong element of collapsing into each other and somehow producing something so meaningful. It reminds me of the [pilot study] report and its emphasis on creative arts representing the voice of pain in a unique way. This emergence of expression and pain management coupled together.

RUTH, PADLET, SEPTEMBER 2025

Reflective practice

Exploring somatic-informed arts-based methods to articulate lived experiences of ill-health has been central to *The Language of Pain* since its inception. Reflective practice was an integral and cumulative way of working, embedded in the project as a creative, active, and interactive process. We reflected on:

- our experiences of grounding exercises and the changes for our bodyminds;
- what the various tasks and experiments we explored offer;
- the dynamics of the group, how we worked independently and together, and power structures as we worked toward co-production;
- the role of digital media in mediating our practice.

The reflective process was creative and embodied. We worked with writing and different forms of artistic expression to externalise insights, process our experiences, and deepen self-awareness, which cumulatively fed into the development of the project.

We did not measure the project in terms of its instrumental worth, but explored its impact on individuals. Reflection provides a powerful learning opportunity. Everyone involved in *The Language of Pain* examined their experience, which was important because we conceive of impact holistically, as “emergent and non-linear; responsive and relational” and empowering (Darby 2017, 230). What do we learn about ourselves? Our identity? How is our learning connected to others? How does our thinking, approach, and practice change?



A photograph of Ruth's creative introduction.

A space for not knowing

The project can be described as a productive unravelling. Our practice sought to make space for not-knowing and while artists are prepared to deal with uncertainty, not everyone is comfortable working in that way. For example, one member of the collective described how they spent a lot of time at the start of the project trying to organise ideas and establish a plan or direction for the work.

Creative processes are just that: processes. A constant learning, re-learning, evaluating, and re-evaluating that gradually allows for a clearer understanding of what one is working towards and what works (and what doesn't). Nevertheless, a continuous point of reflection was how to establish some kind of structure so that there were outcomes that the group could work towards while leaving enough freedom to be responsive to the insights developed through the process.

To structure and focus our creative practice, we set out to experiment with what a multimedia representation of our creative work might look like. Working towards an end-product that might be shared with others was a new approach for the collective and, at times, consumed our thinking. Inevitably, there was a tension between committing to creative exploration and the idea of a polished output. This is where the value of the invited collaborators, Dominique as a film maker and Peter as a composer, made itself known. Our collaboration, our approach to teamwork where different people in the project contribute different skills, meant that the creativity of the collective (borne of adversity) was complemented by professional experience of organising and shaping creative process into a product of some form.

The Language of Pain sessions are a welcome break from the daily hamster wheel and cycle of chronic illness. I'm stuck in a loop of endless medication, repeating appointments, hospital trips, physio, occupational therapy, dieticians... team after team for which I know I'm lucky and grateful, but there's no real end in sight for my chronic fatigue. The Language of Pain provides a respite from the daily meh grind!

JO, PADLET, JANUARY 2026

Not performing wellness



A screenshot of Tim engaging asynchronously with a project session



Scan the QR code to see Tim's improvisation.

Central to our practice is the crucial recognition that pain experiences are different, unique to the individual. We cannot know what another person's pain is like, but we know our bodies better than anyone. Therefore, what engagement with research looks like may differ between co-researchers. We strove to establish a framework for our practice-research that did not encourage performing wellness. We work with reasonable accommodations, not to tame illness and health histories but to instead bring these things to the table and, in turn, to show up as we are. It was important that we could engage with the creative process in ways that met our needs as well as examines our interests.

In keeping with the desire to develop somatic confidence and somatic agency, each person was responsible for their bodies. What this looked like was different for each person, but included:

- Developing an understanding of how to prepare for each session.
- Learning what self-care practices were needed after project sessions.
- Attention to pacing.
- Tailoring and adapting movement explorations, and determining for oneself how small or expansive responses were.
- Working from postures, positions, and spaces that make sense to us.
- Working with props (e.g. weighted blankets).

As well accommodating the physical experience of living with chronic illness, screen breaks were built into each session to accommodate the cognitive load of ill-health. Recognising that one's headspace can be just as difficult to understand and manage as the physical, the opportunity to step away from the screen and the creative process was a strength in our approach to online practice.

In keeping with our resistance to performing wellness, all sessions were recorded to provide the possibility for asynchronous practice. To underscore the importance of listening to and honouring the body, collective members could choose to engage asynchronously if they were not feeling well enough to attend a project session or had to attend a medical appointment. Remunerating co-researchers for asynchronous engagement (and not only attending the live sessions) was an important element of our ethical approach and sought to encourage a practice where we do what is right for our bodies. Since real-time practice research sessions were fortnightly, access to the video recordings meant individuals did not have to choose between attending sessions or missing out if they felt unable to be 'present' in 'real-time'.

What meaningful asynchronous engagement looked like depended on session content. Co-researchers could practice alongside the recording and develop a creative response, or an alternative task was suggested. Tim's experience exemplifies this approach. He reflects:

Even viewed 'after the event' I got the energy and buzz from the activities [...] Even though I wasn't doing this 'live' (as-it-were) I found the connections between both the members of the group working in pairs and between 'me and you' [the collective] incredibly powerful [...] the newly-minted connectiveness that seemed to grow between you all (I could feel it, even watching the videos), the whole exercise was astonishing and enthralling.

Tim, Padlet, October 2025

I really value the ongoing work of this project – the creative means of establishing some connection across what often seems to be an unbridgeable gap. We're all struggling to navigate a complex and traumatic experience, a fact made harder by being so often reduced to mere numbers.

TIM, PADLET, SEPTEMBER 2025

The collective, in turn, engaged with Tim's creative response.

This was brilliant Tim. It was as if we were all in your space and part of each other's space at the same time. Very clever.

Ruth, Padlet, October 2025

So loved watching your video Tim, and it was really powerful watching you connect to the session and the pair performances, and create your own personal, interconnected performance. And adding sound creates a whole other layer to your video.

Emma, Padlet, October 2025



Online *Practice*

MiraHirtz
3 months ago
Mira's song

Chat room

Inspiration

Thinking in draft...

Thank you
time to watch
sorry that I
rough before

Thinking in draft...

The COVID-19 pandemic highlighted the potential of online practice for cultural engagement. In response to the global pandemic, the *digital turn* increased opportunities and expanded possibilities for arts and culture as video conferencing platforms became ubiquitous in many households. During the pandemic, platforms such as Microsoft Teams, Zoom and Adobe Connect were adopted at an unprecedented pace. Such tools circumnavigated the inability to meet in person and, instead of coming together in a physical space designated for group activity, teachers and students, facilitators and participants, were united in a virtual world. Remote provision was transformative. However, as Elena Backhausen, Benjamin Wihstutz, and Noa Winter note: "Accessibility requirements that people with disabilities and chronic illnesses had been asking for were granted when non-disabled people found them beneficial" (2024, 5). During the pandemic, people living with chronic health conditions could access artistic and cultural activities previously inaccessible to them. However, there is a risk that the same provision disappears when it is no longer necessary, convenient, or desirable for organisations, businesses, and institutions.

Our sessions are a testament to the power of an on-screen community within the comfort of our homes.

JO, PADLET, NOVEMBER 2025

We are all there in the creating of the experience that is building towards our mutual creative expression as part of this project. We are all creating our individual realities and being privileged, through the medium of Zoom, Padlet, email etc., to share in the realities created by others. And that is the most important point of all.

TIM, PADLET, OCTOBER 2025

Softness, hardness, comfort, warmth, coldness, isolation, connection; the push and pull of our online platform and our experiences.

EMMA, PADLET, SEPTEMBER 2025

The digital turn for community arts has been largely reversed since lockdown measures were lifted, with activities returning to dedicated cultural spaces and institutions such as theatres, studios, community centres. Yet, we must remember communities for whom challenges in accessing in-person provision is their lived reality. There remains a need for remote practice. Matthew Reason reminds us that “without access and inclusivity there can be no cultural democracy – there can be no social justice” (2022), and thus it is necessary to examine the potential of online creative health programmes, understand the possibilities, limitations, and aesthetics of screen-based engagement, and interrogate frameworks and practices for access and inclusion.

Since *The Language of Pain Collective* formed in September 2023, our creative practice has taken place online, which affords an approach that accommodates our health and comfort needs. It is also the basis through which our practice-research can happen. An unnaturalistic environment for community arts engagement, our approach requires us to suspend the privileging of a particular kind of co-presence that is valued in community arts practice and consider new aesthetical and relational modes of working. What is the reality of developing a collaborative creative practice in a digital environment? How can we ensure that a creative process mediated through a platform such as Zoom is neither secondary nor inferior to in-person experiences but a valuable space in its own right?

The safety and security of our digital space have enabled me to unmask my creativity and be true to my own self-expression.

TEF, PADLET, SEPTEMBER 2025

I spend so much time with screens, laptops, phones, working with them and communicating. I want to explore these digital formats creatively. I want them to be more playful, and more meaningful. I want them to be somatic, and physical, and feel softer.

MIRA, PADLET, SEPTEMBER 2025

(How) Does the “space” support creative collaborative enquiry?

Cultivating an approach to practising together online was an underlying consideration for the project. In this space, the co-presence typically expected in community or creative health programmes is fractured and, in its place, a different kind of co-habitation emerges. On Zoom, people are technologically connected, yet spatio-temporally distributed as they come together from different physical environments. However, video conferring tools are neither neutral nor simply instrumental. They mediate experience and practice. In other words, we do not merely use technologies such as Zoom, nor have an unfiltered experience of the world when using it (see Rosenberg and Verbeek 2015). Digital media co-construct experience, perception and understanding. It is necessary, therefore, that online practice is not merely a replica of what would happen in physical environments (e.g. the dance studio, music practice room). The combination of technologies and practice establishes a new relation and therefore different perceptual and bodily transformations.

Toward the start of the project, there were some negative associations to remote practice as a couple of people were reminded of the psychological challenges of only meeting online during the COVID-19 pandemic. However, we all agreed that the benefits of establishing an online practice outweighed the negatives.

In the virtual environment, three-dimensional figures (people) sit before two-dimensional visual representations (people on screen). Each person occupies a single frame creating a patchwork quilt of contributions. An early theme in our practice was collage, which we used to characterise the aesthetics of Zoom: partial representations of bodies ‘sitting’ side by side on the screen, “a collage of individual stories” (Ruth, Padlet, November 2025). It is not possible to engage with all the videos in this digital collage at once. Instead, it is only possible to view activity frame by frame. Each frame occupies the same spatial territory – in this project, one eleventh of the available visual data – but is not equal in our attention. What we attend to is determined by what catches our attention, and this is one factor we considered and explored in developing our practice.

For my creative reflection I’ve been deliberately seeking out all the ‘good’ that Zoom was and is, and the connections it maintained during lockdown, continues to maintain day-to-day and, of course, maintains for us during our creative sessions [...] all creative expression needs a conduit, be it ink or paint or screen or some other carrier.

TIM, PADLET, OCTOBER 2025

Rob described the group as inhabiting “a separate bubble/plane/dimension/universe. Our own separate virtual world with only us in it (given that external environmental factors did not burst the bubble)” (Padlet, November 2025). Others reflected on the camaraderie of working in this space:

I loved looking up at my laptop screen from time-to-time and watching you all, it made me smile. It felt like we were cheer-leading each other on in this strange realm we occupy of being not together-together.

Emma, Padlet, November 2025

I did not expect our first session to touch me so deeply. And it truly amazed me that I felt connected to everybody, even though I was in the middle of a work trip, even though we hadn't met in a while, even though it was on Zoom and not in person, and even though we had new (amazing) members in the group.

Mira, Padlet, September 2025

The experience of meeting online for our practice-research invited reflections on what it would be like to practice together in the same physical environment:

This group really is a collective extraordinaire! How did we all gather together with such greatness! It makes me wonder how it would have been if we met in person as opposed to being in all our own environments. Would it be the same rich respectful interaction...

Ruth, Padlet, October 2025

It felt like we were all sitting around a big table. I've often wondered how, if at all, it would have been different if we had all been... all the difficulties of getting there notwithstanding... if somehow you could all be in the same space somehow, would have changed the dynamic or not?

Tim, peer interview, June 2026

I wonder whether if we were all around a big table, would we have been looking at what other people were doing and thinking 'oh, mine's not good enough'. Or, 'I won't do it like that, I'll do it like this'. Or would we be inspired? It's a really interesting to think about. We had the camaraderie of that shared activity, but without being.... we were observed, but not observed.

Emma, peer interview, June 2026

The patchwork quality-softness of our private stories held together by the hi-tech, patchwork quilt that is Zoom. Torn edges, scissor neat edges, over-layering, layering of our individual and collective collage of expression

EMMA, PADLET, SEPTEMBER 2025

Technological anxieties

Everyone in the collective had prior experience of working on Zoom. Accessing the Zoom environment was therefore straightforward. Besides the standard and expected (although no less frustrating) connectivity issues and temporal lags (which Peter noted “can strangely enhance rather than disrupt what’s being communicated” (Padlet, September 2025)), our Zoom-based creative practice sessions went without a hitch. The online space became more challenging when we changed Zoom settings (e.g. turning on original music for musicians), sharing sound through the computer to others in the meeting (e.g. selecting “Computer Audio” in the advanced settings of ‘sharing sound’), or sharing our screens. In such instances, somebody talked through the process while others followed. Written instructions were also shared on Padlet to support more complex navigations taking place outside of project sessions or anticipation of a future session.

Fear and anxiety about technology going wrong is a curious phenomenon that must be taken into consideration when working online. We experimented with uploading the artwork we created as virtual backgrounds, and this could induce panic because it meant photographing and uploading materials which involved toggling between devices. And, since people have different devices and technological set-ups, giving advice on the mechanics was not always straightforward.

Emma found a creative way to minimise technological panic of in-the-moment online navigation, choosing to record a film for her creative introduction (in week one of the project):

I thought filming myself (something I hadn't done before) would act as a bit of a shield from presenting 'live' in case I had a 'spotlight effect' panic, and/or got tearful! I guess I was trying to control the situation.

Emma, Padlet, September 2026

Beyond the stress of in-session technological tasks, there were ongoing concerns from individuals that they were not technologically literate enough and expressed greater comfort using tactile and analogue media. It was in such moments that the recognition that we each bring something different to the project was important, as demonstrated in Tim’s response to a collective member’s Padlet post:

Don't think you need to worry about being low-tech. Your reflection makes it clear why we're working together so well as a group – it's because we all bring different skills and we seem, somehow, to have the capacity to bring them together in a form that is definitely more than the sum of its parts! But your skills are the wonderfully soothing, grounding, inspiring and energising 'starters' you've been doing which are an integral part of each session. I'm sure they account for the fact that we can think creatively and collaborate effectively for the remainder of each session.

Padlet, January 2026

TAKEN DAILY:

- At least one walk
 - Many cups of tea
 - Moment of joy and smile at the beauty of nature
 - Yoga in any form I feel able
 - Breathing/pranayama
 - Yoga Nidra (relaxation) three times a day.
 - On waking, during the day, and at night
 - Nourishing and brightly coloured food
 - Plenty of water
 - Music on headphones and dance with joy.
- Smile and laugh.



USE DAILY, OR AS REQUIRED:

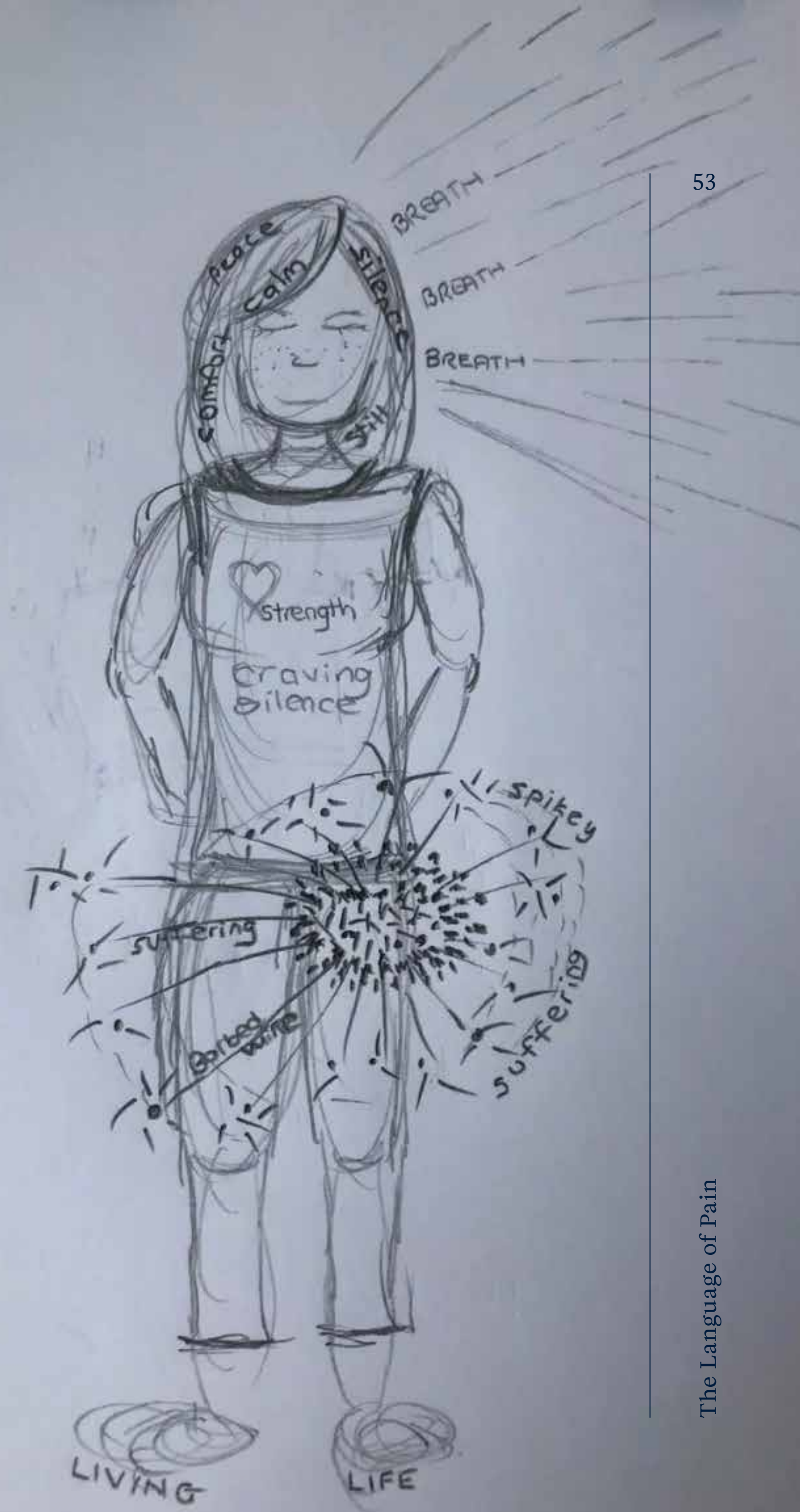
- Mantras or affirmations
- 'I am wise, I am strong, I am committed to healing'
- 'I am enough'
- 'I adapt to life with utmost grace'

EMERGENCY FIRST AID (USE AS REQUIRED):

- Resting and doing whatever you can to be comfortable
- Cancelling anything that feels overwhelming and can wait
- Specific breathing for different occasions
- Specific relaxations for different occasions
- Nourishing and caring visualisations and meditations
- Music that invokes joy or grief
- Crying freely without fear
- Visualisations/memories of pleasant and positive experiences to evoke heightened feelings of joy or excitement
- Swim and enjoy the freedom of movement in water

Warning: this prescription is safe to take every day as needed. No risks or adverse effects.

RUTH, PADLET, JANUARY 2026



Meeting the screen

We reflected on the ways in which Zoom features in our creative practice. Is the platform simply the means through which we work together? A mediating space that makes our work possible? Or should the environment be an explicit focus? If so, to what extent should the aesthetics of Zoom inform what we do? Since little in this project was predetermined, and (almost) anything was possible, we sought to work in ways that could accommodate the interests and needs of the collective. The process encountered both approaches: our primary emphasis was on low-tech analogue practice and we foregrounded attention toward the body and physical or tactile means of expression: drawing, writing, painting, collage. But we also experimented with the possibility of video.

It was necessary to take into consideration how we practice and how we relate to digital media. The screen, for example, dominates our visible world, pulling us out of the physical environments. It is also a space where, typically the body stops while the mind stays active. This tendency, and the pull of the screen, has implications for how we orient ourselves to the body. Given that our practice is mediated through Zoom, we were both mindful and curious about our relationship to the screen.

How do we arrange our bodies in relation to the screen, habitually and intentionally?

- Is the screen fixed (e.g. desktop) or portable (e.g. laptop, tablet, phone)?
- Where is our device placed? On a desk or table, or somewhere else?
- Does portability inform where we position ourselves in our physical environments?
- Does this positioning create physical or metaphorical obstacles? For example, does sitting in an office chair make standing or moving a less attractive or likely option?
- How does the location and placement of the screen inform engagement?
- Is there space to move around and away from the screen? Is there room to lie down yet still be able to access the screen?
- (How) does the screen's placement facilitate access to drawing, writing, and arts materials?
- (How) does our relationship to the screen support or hinder my needs?

*I became aware of the different locations we all inhabited through the digital screen.
I felt as though I had visited each landscape, as I listened to our individual - creative introductions.*

TEF, PADLET, SEPTEMBER 2025

The second consideration is how a 'typical' meeting format could support some elements of our work (e.g. hellos, sharing work, discussion) and be resisted for others (e.g. grounding exercises, creative practice). There can be communication challenges when a group meets on Zoom. When there are 11 people in the digital environment, it is everyone's responsibility to acknowledge how the space is used and to ensure one's voice does not dominate. While the technological set-up makes it tempting to experience the space as a dialogue (an individual addressing a screen of people), a multi-directional approach needs to be adopted. Taking time to read people in each Zoom frame is one way to create more space in the conversation and hopefully cultivate an approach that supports collective decision-making and creative enquiry. This would become important for our creative practice, reminding us to create space for a coherent image so that details are not lost amongst a sea of activity.

Somatic practice and creative engagement

For the somatic grounding exercises and for much of our creative practice explorations we either turned away from the screen or turned off our cameras. In this way, we often practiced independently-together as we were guided through activities, supported by the group while immersed in our creative practice.

It was necessary to think beyond the ease and convenience of the traditional online meeting set-up. We wanted to embrace and explore the possibilities and limitations of the medium. We explored how physical practice meets the digital landscape, and how analogue practices meets mediation. What are the dynamics for communication, for expressing and receiving? Some imagined the screen as a partner in our experience:

In the breathing exercises I felt like a kind of see-saw, as if I was breathing into the screen and receiving the breath and then sending it back into the screen. It was more a sense of sound than actually hearing. Like I felt the sounds coming from other screens rather than hearing them.

Ruth, Padlet, October 2025

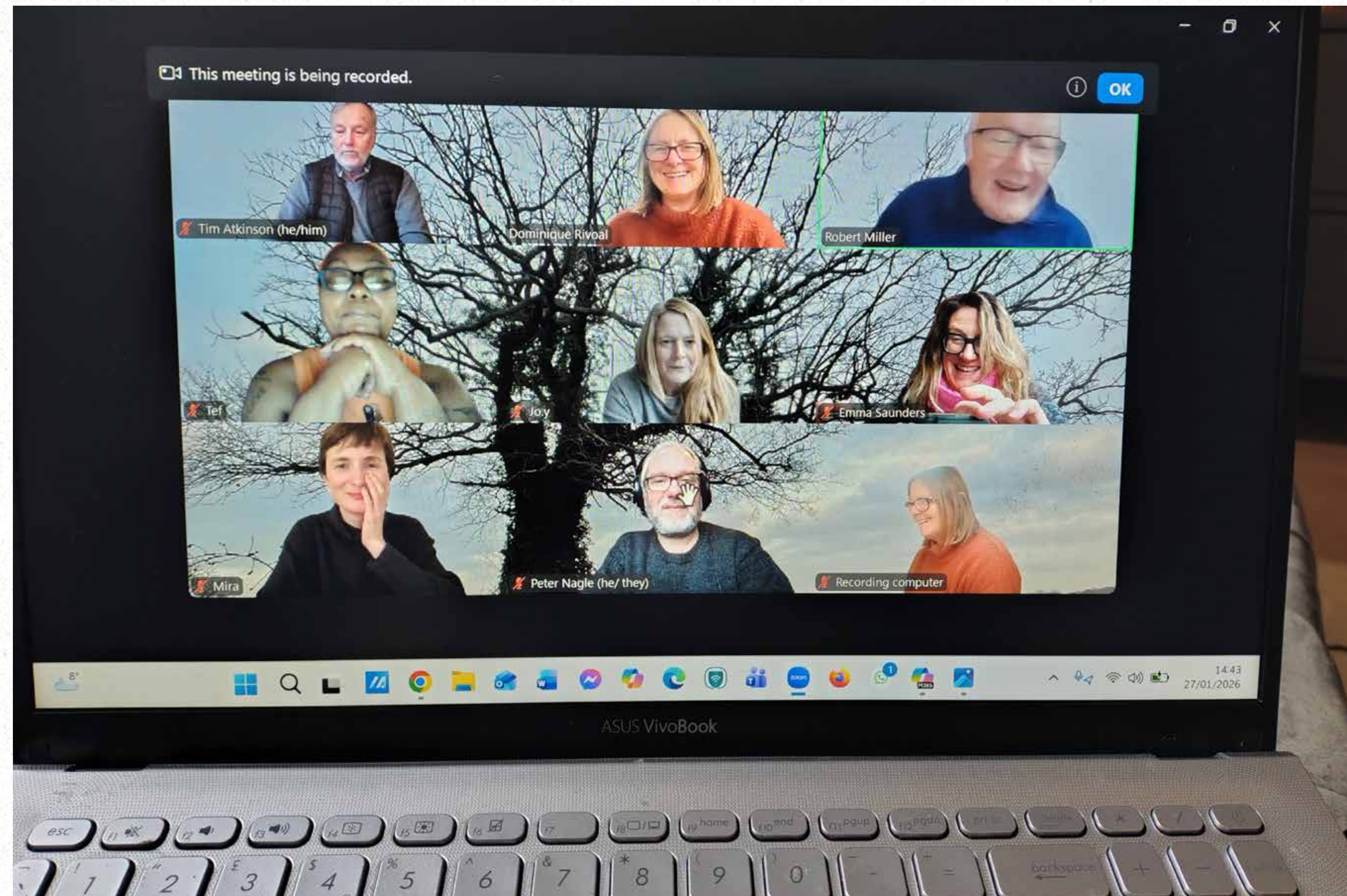
We explored movement collaboration through the screen. For example, in the “mirroring game” we experimented with copying the everyday habitual gestures of each other. This game of looking and noticing invited a “different mode of concentration on the screen, something a bit wider and more flexible than the binary on/off concentration” of typical video calls (Peter, Padlet, November 2025). It also facilitated “a sense of a connected group rather than a patchwork of discrete images of people” (Peter, Padlet, November 2025).

Zoom’s framing was a source of contemplation. We recognised that we could not physically break out of our rectangular containment and reach into each other’s environment, but perhaps we could conceptualise bridging spaces in a different way? Perhaps we could use our hands to expand the four sides of the Zoom tiles and imagine spilling into other’s spaces? (Ruth, Padlet, September 2025), or ‘break out’ of our containment by relocating ourselves in the physical environment (Emma, Padlet, September 2025). We played with the aesthetic of containment, of what was visible inside our Zoom window, framing our movement in such a way that involved “popping in and out of the screen” and “opened up endless possibilities for activities” (Jo, Padlet, January 2026).

In *The Language of Pain*, our shared practice space is the Zoom environment, but we practise from the personal and private spaces of our homes. Naturally, as described above, our physical environment informs our engagement, consciously or otherwise. Yet, for the most part our everyday environments are hidden from view. The Zoom frame provides entry into this world, yet we share only that which is within reach of the camera and microphone. We might then consider the online lifeworld as a curated space, as each person determines what to reveal. This led us to devise tasks using space creatively.

The tree activity was a beautiful collaboration, bringing us all together on the beautiful branches

JO, PADLET, JANUARY 2026



A screenshot of Dominique's virtual jigsaw puzzle.

As is common practice, sometimes individuals used virtual backgrounds to hide cluttered spaces or show their personality. We explored how virtual backgrounds could be incorporated into our creative practice, sometimes using the artwork created during our sessions. As Jo suggested, we could:

create an artistic freeze frame before a session that expresses our current moods and emotions, a drawn picture, a photo etc and share it on our background screen for our opening intro sharing session [...] see what kind of collage we can create from our mood backgrounds.

Padlet, January 2025

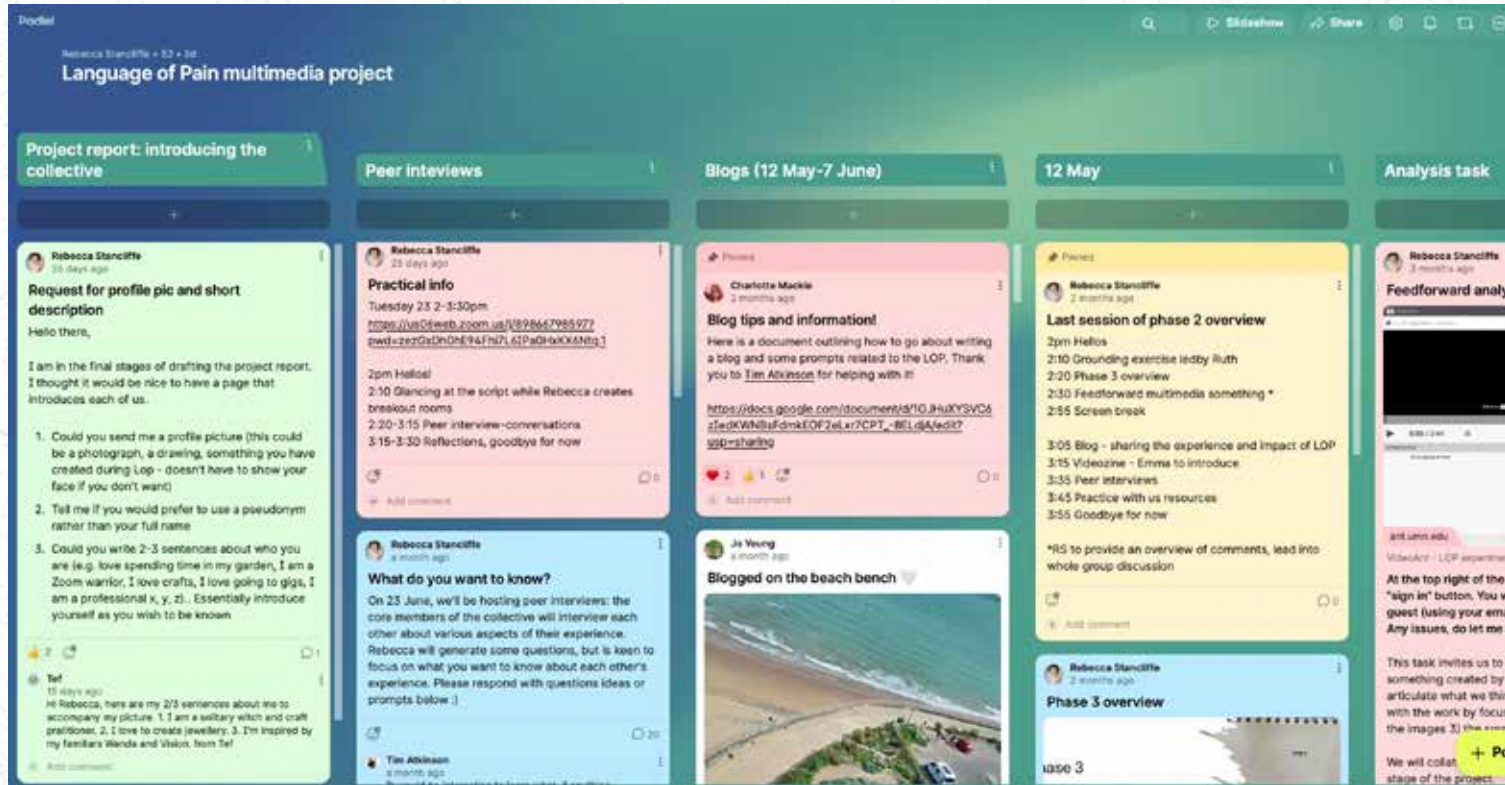
In a task led by Dominique, we pieced together our Zoom tiles to create a virtual jigsaw puzzle. Many of us had previously only worked in such a way that assumed that the order of appearance in a video conferencing meeting is a matter of chance, that the spatial organisation of attendees is not the same for everyone. However, Dominique's task was a surprise to us all. Each person was assigned an image to upload as their virtual background and then we were asked to click and drag the Zoom tiles to arrange each background, piecing together the fragments to create a picture of a tree. Peter reflected that:

once we'd all got our backgrounds sorted and panels ordered, it occurred to me: this is the first time I've been in a Zoom call where I'm pretty certain that what I'm seeing is exactly what everyone else is seeing.

Padlet, January 2026

Padlet

Padlet, a digital canvas and collaboration tool, was an important space for asynchronous engagement with the practice research. Padlet was used in the 2023 pilot study and for the collective’s work since, with a new Padlet space created for each project phase. The collective reflected that, in previous years, the wealth of Padlet content became overwhelming as the research developed and could negatively impact the intention for the space. Establishing a clear structure, with designated columns, became essential for both managing and navigating different kinds of activity. In this project phase, our unpublished Padlet page was designed to serve several functions:



A screenshot of Padlet

I have been browsing through and reflecting on our collective work on Padlet. The wealth and depth of ideas and inspiration is phenomenal. Such grateful contributions from everyone.

JO, PADLET, NOVEMBER 2025

- **Information:** The first column concerned the practicalities of the project. It contained the Zoom link for each session, a descriptive overview of project phases, important dates, and links to session recordings.
- **Chat room:** A column for conversation and connection.
- **Thinking in draft:** A space for sharing session and project ideas.
- **Inspiration and sharing:** A place to share resources such as podcasts, articles, news reports, and artwork.
- **Grounding tasks:** Audiovisual excerpts from project sessions were available for use outside of sessions.
- **Session plan and session reflections:** Separate columns for sharing what we did in our creative sessions and in our practice outside of sessions.

As the number of columns increases over time (i.e. two new columns are created for each project session), the Padlet canvas expands, and the user needs to scroll from left to right and top to bottom to access content. For ease of access, sessions plans and reflections were organised in reverse chronological order so insights from recent sessions were visible when opening Padlet and content for later sessions found by scrolling to the right of the canvas. Crucial posts were pinned (e.g. suggestions and guidance for reflections) so they could be found easily, with responses filed beneath.

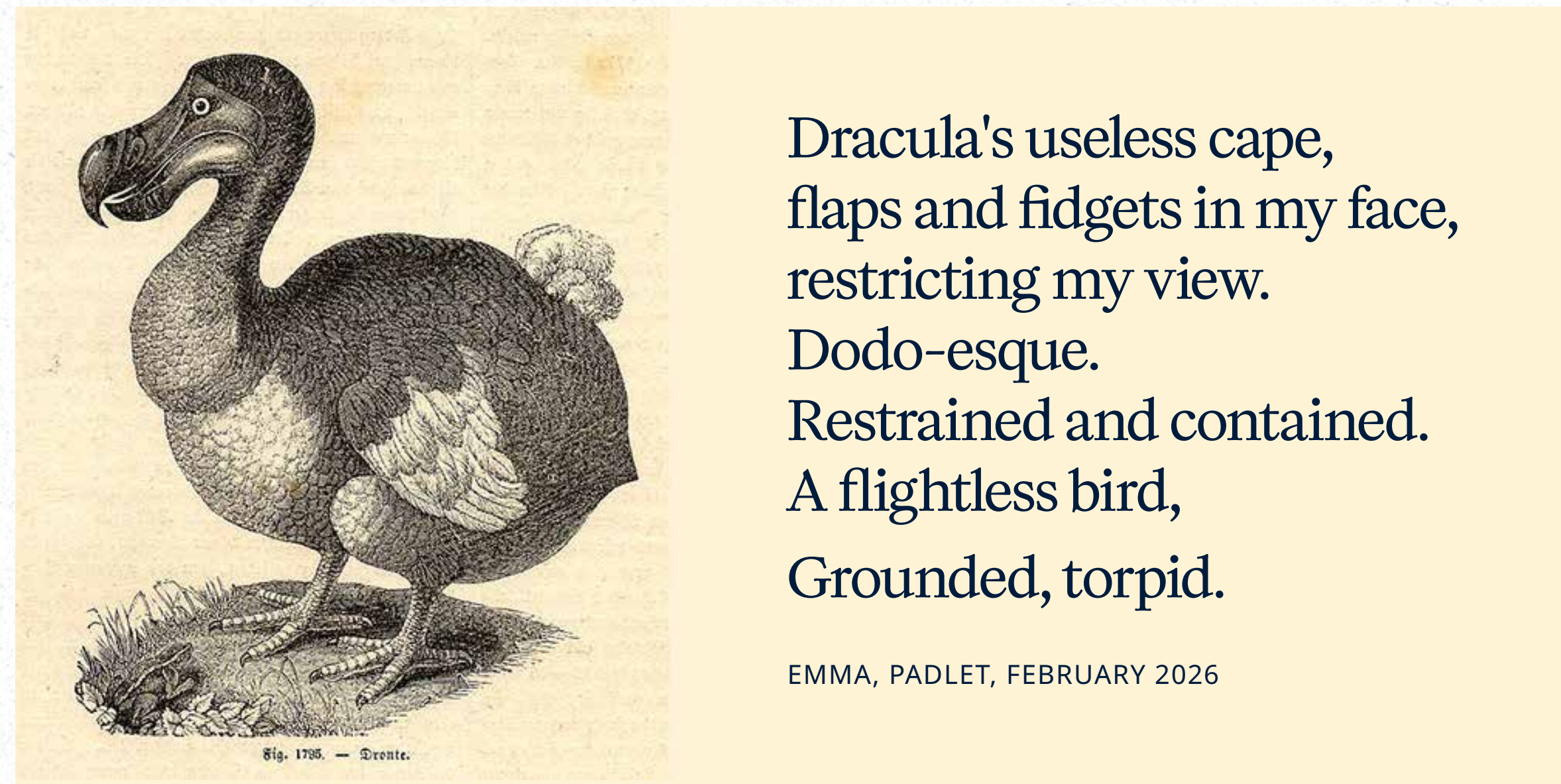
Everyone involved in the project was assigned ‘administrator’ status which grants editing and management capabilities. Typically, however, Rebecca and Charlotte managed the layout with the rest of the collective posting within the framework provided.

As well as supporting our practice-research and aim to work towards co-production, Padlet was a vital source of research data. Padlet data can be exported (as CSV or Excel files) or downloaded (e.g. attachments such as images, sound files, PDFs). Padlet's text-based content was downloaded as an Excel spreadsheet and the raw primary was thematically analysed to inform research findings, including those featured in this report.

Padlet data also became a stimulus for creative explorations. For example, recognising the wealth of Padlet posts and the generosity of contributions, Emma wondered what would happen if the content of Padlet was run through a word cloud generator. Was there potential for developing “some kind of text response/poem using (some of) the words selected?” (Emma, Padlet, December 2025). Rebecca downloaded Padlet’s text-based contributions and copied the data into a word cloud generator. This image was used to inspire what the collective called word soups, from which poems and collages were developed.



Scan QR code to hear an instant poem generated from Padlet data.



Emma's instant poem Dodo-esque generated from Padlet data.



A word cloud created in January 2026 from Padlet data, focusing on the top 100 words.



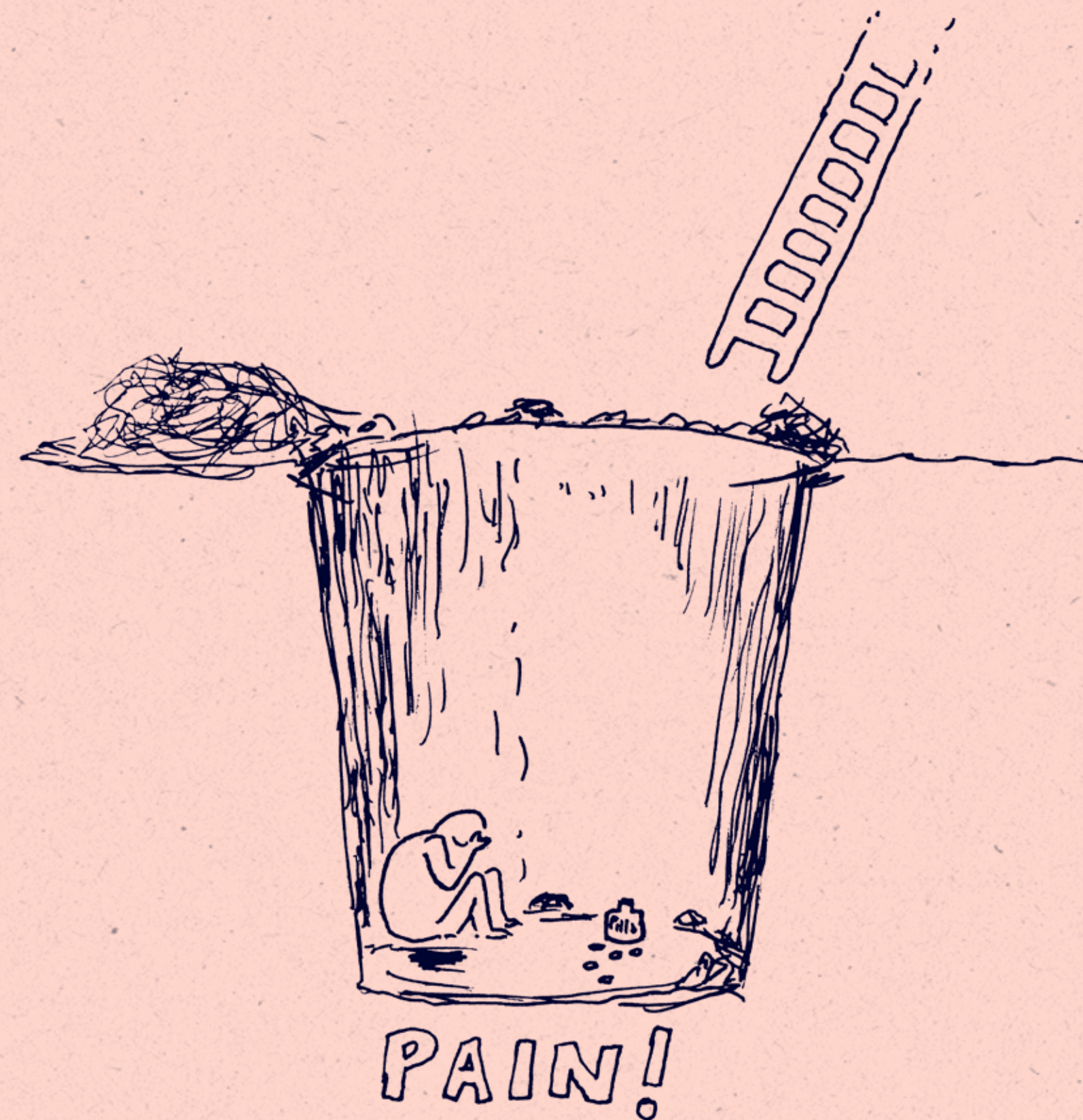
**Scan to listen to
Emma's instant
poem Dodo-esque**

Reflections, next steps, and *future research*

The Language of Pain was an emergent, iterative and messy creative research project. The immersive process of practice-research has strengthened our resolve in the importance of co-production for knowledge generation, deepened our understanding of the importance of arts and creativity, and has generated more questions and avenues to explore.

- The importance of immersion in the **creative process** has been identified as central to *The Language of Pain*. Further research is needed to understand the value and role of different methods, and the specific aesthetic, creative, and artistic contributions of different approaches (for example, see Chappell et al. 2021).
- In *The Language of Pain*, there was ongoing discussion of **arts and creativity for expression and for pain management**. While did not position expression and pain management as binaries, we are curious about how they sit on a continuum, and this presents an avenue for future research.
- There were multiple references to the power of the arts to connect with **memory** and to transport us to different places, emotions, and physical and emotional states. Further research could support the examination of expression and pain management highlighted above.
- **Nature** was an important and recurrent theme that materialised in our creative practice and project reflections, although not a theme we explicitly explored. There is potential for considering an online approach to creative practice that embraces environments beyond the screen.
- We often referred to our practice as a process of **not knowing**, which is a characteristic common to artist practice. However, not-knowing how a project will evolve and what the result will be can be an uncomfortable experience for some. On reflection, what it means to be part of a creative process formed the content of many people's reflections but was assumed rather than examined collectively. For future research, an introduction to practice-research and discussion about the nature of artistic and creative enquiry would be beneficial.
- *The Language of Pain* was, in many ways, **autoethnographic**: an approach that combines autobiography (self-reflection) and ethnography (cultural analysis) and treats individual stories and insights as primary data. In the next phases of the project, when establishing a fully co-production project, we would like to centre this methodology in our practice-research.
- The slow creative practice modelled in *The Language of Pain* can be described as **'cripistemological'**: how illness and disability shape what we know, how we produce knowledge, and how we navigate the world. Rebecca came across *cripistemology* at the end of this research phase and would like to explore this further.

- We have used the phrase **toward co-production** to describe the project to acknowledge that not all elements were co-produced. As the collective's collaborative practice develops and matures, we will continue to explore how the research can be led more by chronic pain sufferers and what structures, support, and resources are required to facilitate that.
- **Co-creation and co-production are time-consuming non-linear processes.** A structure was devised to accommodate different phases of the project, including creative practice, reflection, and resource development. In Phases 1 and 2 of the project the collective met fortnightly which supported momentum and helped accountability for independent practice (e.g. creative practice and reflection taking place between project sessions). In comparison, much of Phase 3 focused on independent working (i.e. blog writing, creating a videozine, developing multimedia resources) and, without fortnightly sessions driving the practice, some people's motivation dwindled. This was not universal. However, it highlights the need for greater consideration and accommodation of individual working methods, communicative styles, and preferences. This will involve continued work to acknowledge the importance of **crip time** (see Kafer 2013) in project management and delivery.
- Although this phase of the project ran for a year (September 2025-September 2026), the collective only met for 14 sessions of creative practice, 28 hours in total. This time included saying hello at the start of each session and time to say goodbye at the end. Additional time for creative practice and reflection was allocated in-between live sessions. We reflected on whether **meeting fortnightly** was preferable or if there was a desire for more frequent working. The collective liked the fortnightly structure, especially because the time between each session felt as though it lapped quickly.
- A composer and a filmmaker were invited to join the collective for this project, bringing skills and expertise that were missing from the collective and to introduce new ideas and methods for creative exploration. Any fear and anxiety of inviting new people to join the collective was short-lived. The collaborators were warmly embraced and slotted seamlessly into the process. However, the **absence of lived experience** of chronic pain presented some perceptual and conceptual challenges about orientations toward pain and expressions of it. Peter notes the importance of curiosity and empathetic connection throughout the creative process. Nevertheless, there was a feeling of disappointment from some that not all outputs were co-produced and concern that they might not accurately reflect the collective's experience. There are several considerations here:
 - There is further work to be done to explore the role, responsibilities, and expectations of the **co-researcher** role so that there is a shared understanding that supports the personal and collective responsibility to drive the project and contribute to knowledge generation.
 - Further exploration of the **different ways individuals contribute** to a project according to interests, needs, and experience is needed.
 - Explore what mechanisms need to be in place to ensure **open and honest discussion when tensions** and challenges arise.
 - Invite **pain experienced collaborators** to join future projects.
- We work with a desire to resist the screen as much as possible to listen to what the body is telling us. Our somatic-informed practice is often verbally-led and aurally-received, yet recognise that this practice is not inclusive to our peers in the Deaf/deaf community. What might a **more accessible Zoom-mediated somatic-informed practice** look like?



This image came to me almost as a dream.
 I'm at the bottom of a dark pit called pain; on the floor
 is a bottle of pills representing traditional medical
 support and intervention.
 It might help while I'm down there, but it's not getting
 me out. Perhaps nothing is.
 But week-by-week there's a ladder – The Language of
 Pain project – and it's getting longer.
 One day it'll reach the bottom of the pit and I will
 have the strength to put my foot on the bottom rung
 and slowly heave myself up and maybe out.
 I won't ever be free of the pain.
 But I'll be in a different place.

TIM, PADLET, JANUARY 2026

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Hear from our co-researchers on their experience
of *The Language of Pain*.

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**More information about *The Language of Pain*
can be found on our website:**

<https://www.trinitylaban.ac.uk/research-and-knowledge-exchange/our-research/the-language-of-pain/>

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