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From research method to community resource: Co-developing a body mapping toolkit for peer support with Long Covid patients

Maaret Jokela-Pansini [a], Oonagh Cousins [a,b], Jo Dainow [b], Beth Greenhough [a,*]

[a] School of Geography and the Environment, University of Oxford, Oxford, United Kingdom
[b] Long Covid Support, United Kingdom

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ABSTRACT

The paper describes the development of a Body Mapping Toolkit for Long Covid Patients, co-created in collaboration with the patient-led organisation Long Covid Support. We discuss how the use of body mapping, a participatory and arts-based research method, can support a more holistic and embodied understanding of Long Covid attentive to the way illness experiences are shaped by patients' social, cultural, and economic contexts. We further demonstrate how, through collaboration with patient organisations, body mapping might be extended beyond this research application to create spaces for peer support within the Long Covid community. Toolkit redevelopment was informed by three online body mapping workshops with a total of 13 participants, two follow-up feedback workshops and a feedback survey, all conducted in 2024. Our findings demonstrate that online body mapping workshops provide a safe space and opportunity to process experiences through creativity and storytelling and an accessible and flexible way for people with particularly challenging symptoms and restrictions to discuss their experiences with others. We also reflect on some of the limitations and challenges we encountered, and how we sought to mitigate these. The article thereby: (i) contributes to current approaches in medical humanities, medical anthropology and health geography concerned with centering patient narratives of illness experience; (ii) illustrates the value co-producing knowledge and resources with patients; and (iii) offers an example of how creative methods can be drawn on as a resource for both research and peer support.

1. Introduction

Recent medical and social scientific research has recognized patient knowledge is crucial for understanding health and wellbeing for those living with chronic illness, including 'what it feels like, what challenges it poses to living a productive and fulfilling life, and how to manage symptoms and flare-ups' (Greenhalgh et al., 2024). This is also the case for Long Covid patients. The term Long Covid refers to a range of post-acute and long-term health effects that follow SARS-CoV-2 infection, which can be disabling. Alternative terms include post-COVID, post-acute COVID, post-acute sequelae of SARS-CoV-2 infection (PASC), chronic COVID, and long-haul COVID (Hossain et al., 2023). Estimates suggest that 6–7% of adults and around 1% of children who experience acute COVID-19 symptoms go on to develop Long Covid, impacting approximately 400 million people globally (Al-Aly et al., 2024). Patients have reported over 200 different symptoms associated with Long Covid, affecting multiple organ systems, with the fatigue, Post-Exertional Malaise (PEM), and cognitive dysfunction being amongst the most common (Davis et al., 2021). The condition can profoundly disrupt lives, not only through its effects on physical health but also by straining social, economic, and mental well-being (Davis et al., 2021; Greenhalgh et al., 2024; Jokela-Pansini et al., 2024). Given its complexity and prevalence, Long Covid represents a significant challenge to healthcare systems and economies worldwide (Al-Aly et al., 2024).

Although research has advanced, much remains to be understood about the illness's diverse impacts, underlying biological mechanisms, and potential treatments (Al-Aly et al., 2024). Diagnosis is complicated due to the range and variability of symptoms, and can involve a mix of biomarkers, functional evaluations and imaging (Abbas et al., 2025). This heterogeneity also makes treatment complex, and clinical management approaches are often symptom-based (ibid.), something often experienced by patients as a sense of being 'bounced' between different specialists. This is compounded by a general lack of clear clinical

* Corresponding author. School of Geography and the Environment, University of Oxford, South Parks Road, Oxford, OX1 3QY, United Kingdom.
E-mail addresses: maaret.jokela-pansini@ouce.ox.ac.uk (M. Jokela-Pansini), oonaghcousins@longcovid.org (O. Cousins), jodainow@longcovid.org (J. Dainow), beth.greenhough@ouce.ox.ac.uk (B. Greenhough).

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pathways for both diagnosis and treatment, with patients and health care providers advocating for both further research and guidance on managing Long Covid and improved collaboration and coordination between healthcare providers to address the complex needs of Long Covid patients (Sunkersing et al., 2024). Patients describe how they try and mitigate gaps in clinical knowledge and treatment availability through advocacy and seeking to track and manage their own symptoms (Skilbeck et al., 2023), however, this can prove challenging given (as noted above) Long Covid patients often suffer with both fatigue and cognitive dysfunction. Body mapping can play a key role in addressing this challenge (Jokela-Pansini et al., 2024).

Body mapping is a qualitative research method commonly used in social sciences, medical research, grassroots advocacy work and art therapy to explore personal and collective experiences, particularly in relation to health (Cornwall, 1992; Crawford, 2010; MacGregor, 2008; Solomon, 2025; Vaughan et al., 2022), including from the perspective of carers and family members (Pizzolati, 2022). Participants visually express their experiences through drawing, writing, and collaging responses to guided questions on life-sized body outlines, facilitating the sharing of personal narratives. This arts-based method is especially well-suited for individuals who may struggle to articulate their experiences verbally (Boydell, 2020; Jokela-Pansini et al., 2024), reflecting how arts-based methods have proven to be a powerful way to overcome participants' discomfort when talking about sensitive topics (Charon, 2001), empowering patients to recognise the value of their lived experience as an insight into disease and its impacts (MacGregor, 2008). Other similar tools, such as pain maps, have been used in chronic illness management, which allow patients to visually communicate pain, discomfort, and emotional burdens that may not be captured by standard diagnostic tools (von Baeyer et al., 2011).

This paper describes and reflects on the co-development of a body mapping toolkit, in collaboration with the charity Long Covid support, designed to help individuals and organisations conduct their own body mapping activities and workshops. The toolkit described here build on a previous study (2023-2024) which used body-mapping workshops to explore womens' diverse experiences with Long Covid. These workshops generated compelling accounts of patients' lived experiences of Long Covid, including the impact of the illness on the ways patients viewed themselves and their difficulty in finding any form of adequate support (Jokela-Pansini et al., 2024). Significantly, these workshops also served as a form of therapeutic landscape (Gesler, 1992; Lea, 2008) for many participants, acting as one of the few safe and supportive spaces they had found where they could discuss their experiences with peers. This then led to a new proposal and collaboration with the patient-led charity Long Covid Support, which would seek to find a way of sustaining the peer-to-peer benefits of the body mapping workshops beyond the confines of the original study. We translated the body-mapping methodology and the questions into a toolkit for patient-led peer support, helping patients communicate their experiences to family, friends, and potentially wider audiences (the toolkit for individuals can be accessed here. This paper draws on the three online body mapping workshops we ran to develop and test the toolkit resources, and feedback from research participants gathered during two follow up sessions and a survey, along with our reflections as patients, facilitators and researchers.

The paper has three aims. First, we recognise that understanding Long Covid holistically requires appreciating not just its physical symptoms but also its broader effects on individuals' social roles, economic participation, and emotional well-being. Insights from research in medical humanities, medical anthropology and health geography on chronic illness (Moss and Dyck, 2003) and illness narratives (Klein, 2016) has shown that peoples' experiences of chronic illness are shaped by the wider social, economic and cultural contexts within which they are embedded, generating diverse, situated and embodied experiences of disease (Crooks and Chouinard, 2006; Greenhalgh and Hurwitz, 1999; Moss and Dyck, 2003). Central to this approach is the integration of patient narratives into both research and healthcare practice. Inspired by this work, this paper explores the use of body-mapping as an arts-based research tool and patient peer support resource. By doing so, we aim to contribute to knowledge and practices around arts and health and the ways arts may support and enhance wellbeing, including through allowing the articulation of aspects of health and illness which are hard to put into words (Eli and Kay, 2015; Jokela-Pansini et al., 2024). More broadly, we contribute to current debates in health humanities on the therapeutic effects of such methods, which 'advocate on behalf of the person who seeks healthcare and whose biological manifestations of illness and disability may be addressed by healthcare but whose psychic and social suffering are not' (Garden, 2015, p. 77).

Second, this paper contributes to ongoing debates in health humanities, public health, health geography and other health-related research demonstrating how participatory, patient-centered methods can provoke a shift from studying wellbeing in space, to creating spaces for the co-production of wellbeing through collaboration. As Callard and Perego (2021; see also Long COVID Groups, 2024; Miyake and Martin, 2021) argue, recognising patients as co-producers of health knowledge has been crucial to shaping responses to Long Covid, much of which has been driven by grassroots, patient-led initiatives.

Thirdly, we close with some reflections on the possibilities for Long Covid research which critically engages not only with patient narratives and experiences, but which critically and constructively reflects on its own contribution to patient experience and the possibilities of developing concrete outcomes that serve the communities engaged in the research process. We demonstrate how the impact of creative methods may potentially be expanded through the re-purposing of research methods as resources for peer support and community involvement, creating a legacy. Such steps are important if we are to move away from extractive models of research whereby the benefits of research - such as the kinds of safe community spaces created through our earlier body mapping workshops – are limited, transient and dependent on time-constrained research funding.

2. Materials and methods

Working with colleagues from Long Covid support we created an outline of our body mapping process. We then held three 2 hour online workshops between March and April 2024 with a total of 13 participants, 3-4 participants in each workshop, followed by two online follow-up sessions (1 hour, n = 8), in 2023-2024, where we shared these materials with participants and encouraged them to use these to create their own body maps. We also collected data from a feedback survey (n = 11). Ethics approval (SOGE C1A 2415) was granted by the University of Oxford's Central University Research Ethics Committee. Participants provided written consent prior to participation in this research. We aimed to create a safe, supportive space for participants to share their experiences on their own terms, whilst gaining insights into how we might adapt our research protocol to create a tool and resource for community peer support.

2.1. Participant recruitment and preparation

To recruit participants for the workshop, we advertised on Long Covid Support's social media pages. This platform allowed us to connect with a large community of Long Covid patients, making recruitment relatively straightforward, but with the caveat that this excluded patients who are not active on social media and who may lack connections and resources to access support, a consideration for future research. All participants were recruited via Long Covid Support. Inclusion criteria included: (i) a self-diagnosed experience of Long Covid; (ii) being over 18; and (iii) being able to give informed consent. Those aged under 18 and those not able to give informed consent were excluded in line with the ethics clearance received for this project. In total we recruited 13 participants for the toolkit development workshops. Of these the majority were female (12). All were aged over 18, and workshop

discussions suggested a range of different age brackets and backgrounds, although we did not systematically collect demographic data. Once we had collected expressions of interest, we distributed further information explaining that the workshops were for research purposes. We also highlighted that they would hopefully provide an opportunity for peer support and that we aimed to create a tool to help those living with Long Covid communicate their experiences. After confirming the groups for the workshops, we sent out preparation details outlining the resources needed to make the maps.

To maximise the accessibility of the workshop for people with Long Covid, many of whom needed to minimise social contact to reduce the risk of reinfection or who were significantly limited in their ability to travel, we chose to run all workshops online. Conducting the workshops online posed some practical challenges regarding resource accessibility. Usually, body mapping workshops take place in-person, with the researchers providing the necessary materials, including body sized pieces of paper. For our online workshops we provided instructions for creating body maps and gathering materials (effectively the first draft of what was to become our toolkit). Participants could either draw their body map outline by hand, with assistance or freehand, or use a pre-drawn outline we provided, which they could print at home. Apart from the body map, essential materials included blank A4 sheets of paper, colored markers/pencils/pens/crayons, old magazines or newspapers for collage, and glue. Additional materials were suggested but not required, such as colored or tissue paper, paint, and craft supplies. If participants lacked essential materials, we offered to send them supplies upon request. Only one participant requested additional materials; all others had the necessary supplies.

The first email with instructions was followed up by a second email closer to the event date, which included consent information, link to the teams meeting, workshop timings and the prompt questions (see Table 2). We carefully considered how to present this information and break it into manageable sections. Previous research (Jokela-Pansini et al., 2024) and advice from our collaborators at Long Covid Support suggested that people with Long Covid often have limited mental capacity as a result of cognitive impairment, which can impact their ability to process information. Requesting participants to read excessive amounts of information can also trigger Post-Exertional Malaise. We therefore sought to achieve a balance between providing participants with enough information to ensure they were fully informed and prepared for the workshop, while communicating the preparation information as simply and clearly as possible. Participants received a £30 gift token as in acknowledgment of their time and contribution.

Table 1
Structure of workshop.

Stage	Approximate time (minutes)	Purpose
Introduction	10	To greet participants and familiarise them with the research project and body mapping process. To provide safety and support information. Participant and facilitator introductions.
Mindfulness exercise	5	To set a calm tone for the workshop, encourage participants to check in with themselves, and focus on embodied experiences.
Creative/Language Exercise	5	To assist participants in overcoming any hesitations or anxiety about drawing and encourage them to explore visually representing their feelings and experiences.
Body mapping/break as you need	50	Participants engage with body mapping. Screens and microphones are turned off. The prompt questions remain on the screen.
(Optional) Sharing of Body maps and discussion	40	To invite participants to share their body map with others and discuss their experience of the workshop. Participants were asked to email a photo of their body maps so facilitators could share them on the screen during discussion.

2.2. Running the workshops

The workshops were designed to demonstrate and test the processes and activities to be set out in the toolkits under development. The workshops consisted of the following structure: 1) introduction, 2) mindfulness exercises, 3) creative/language exercises, 4) body mapping, and 5) sharing of the body maps and discussion (see Table 1).

Following a brief introduction, we began the workshop with a mindfulness 'body-scan' exercise to help participants settle in and check in with their bodies and feelings. We made it clear that the exercise was optional and asked participants to honour their comfort level throughout. Following this, we tested two different creative exercises in different workshops, one focused on drawing and the other on language. These creative activities aimed to encourage participants to explore approaches for visually representing their experiences whilst also helping alleviate any hesitancy about engaging in creative work. The creative exercise consisted of two rounds where participants had 45 seconds to draw something that represented their feelings. The aim was to freely create expressive marks, such as lines and shapes, without the pressure of producing literal representations. Similarly, the language exercise involved two rounds where participants had 45 s to write as many words as they could to describe their feelings, again focusing on free expression. These exercises would also potentially be included in our toolkits.

Once we had settled participants into the workshop, we turned to the main activity of creating body maps. The instructions on how to body map were kept purposely open to interpretation, encouraging people to body map about their experience on their own terms. To help participants think about their own experience, we provided prompts (see Table 2) and explained that participants could respond to as many or as few of them as they wished. As mentioned above we also provided these questions in the preparation email and noted that, while it was entirely optional, participants could choose to reflect on the prompting questions beforehand if they wished. This was intended to give participants a clearer understanding of what body mapping would involve, helping them feel more prepared and comfortable.

To maintain engagement and flow, we assigned different facilitators to lead specific sections of the workshops. This not only varied the rhythm and broke up the session but also aligned with findings from Vaughan et al. (2022), who similarly observed that rotating facilitators helped sustain participant engagement.

Feedback from the workshops fed into the design of our final toolkit packages, including a self-directed body mapping exercise (Toolkit for Individuals) and a set guidance for facilitators looking to run their own body mapping workshops (Toolkit for Facilitators). The toolkit for individuals was launched at an online webinar hosted by Long Covid Support in June 2025. We are currently in discussions with Long Covid Support about seeking further funding to support running workshops using the Toolkit for Facilitators.

2.3. Supporting participant safety, comfort and confidentiality

When designing the toolkit development workshops it was essential to consider pacing, a key aspect of managing Long Covid. Pacing involves managing daily activities by taking regular breaks and allowing for rest, with both the frequency and duration tailored to the severity of symptoms (McDuff et al., 2025). The workshops lasted 2 hours, but we included frequent breaks. We emphasised from the beginning that participants were welcome to take breaks or leave the workshop at any time if needed. We clearly communicated the structure and length of the

Table 2
Prompt questions to guide body mapping exercise.

1. **Life before Long Covid.** How did you experience your health before the symptoms started? Write a sentence/draw an image about how you experienced your health before.
2. **Symptoms.** What kind of symptoms do you experience and where in your body do you experience these symptoms?
3. **Living with Long Covid.** Do you feel that Long Covid has affected your ability to live day-to-day? Where in your body would you draw the impact of Long Covid?
4. **Emotional Impact.** What kind of emotions do you associate with the experience, and where would you place them in your body? Where in your body do you feel weakness or strength?
5. **Support with Long Covid.** Do you feel that you have received support throughout your journey with Long Covid? What kind of support did you receive, and what kind of feelings did this leave in your mind and body?
6. **Improving your quality of life.** What kind of support would you need to improve your quality of life?

workshop in advance, enabling participants to assess whether they had the capacity to complete it.

Incorporating lived experience into our facilitator team provided a safer and more empathetic environment where participants could feel better understood and supported. We introduced ourselves as a small research team comprising two researchers from the University of Oxford who have previous experience working on health and wellbeing with ethnographic methods, and a representative from the charity Long Covid Support, who brought lived experience of the disease. One of the researchers is also a trained yoga teacher and prepared and held mindfulness exercises.

In-person workshops facilitate the detection of participants in distress and allow for immediate support to be provided. This is more difficult during online workshops. To address this, we aimed to create a supportive and informal atmosphere throughout the workshops, encouraging participants to share their needs and seek assistance freely. We invited participants to interrupt us at any time if they required help or had questions. To ensure participant safety in our online body mapping workshops, we implemented four important measures:

1. All participants provided informed consent, ensuring that all participants understood the nature of the workshop and how their information would be used.
2. We offered the option for participants to turn off their cameras or to use alternative names, allowing them to engage comfortably.
3. We also adopted Chatham House Rules, which emphasised that personally identifying information shared during the workshop would remain confidential and not be attributed to any individual participant.
4. We explained that participants may interrupt any time or take breaks whenever needed. This is particularly important with patients who may struggle with low energy levels.

These steps collectively created a safe and supportive environment, with the aim of enabling participants to express themselves freely and share their experiences without fear of judgment or exposure.

2.4. Follow-up sessions and feedback survey

One to two weeks after the workshops, we held two optional follow-up sessions to provide participants with an opportunity to share their experiences and offer feedback. These sessions had no formal structure and served as an open space for discussion. Eight participants attended the follow-up workshops. Offering ongoing support, including through these follow-up sessions, proved essential for most participants. Some participants emphasised the importance of knowing the scheduled dates for the follow-up sessions in advance, as it provided a sense of certainty about the availability of ongoing peer support and discussion. We also sent out a feedback survey (Table 3) which was completed and returned by 11 of our 13 participants.

3. Results

In this section we summarise the feedback we received from workshop participants in the follow-up sessions and survey. This feedback was then drawn on to develop the toolkit, which provides instructions for both individuals and group facilitators to create their own body maps. The majority of the feedback focused on the technical aspects of the toolkit design, including the importance of preparation and piloting (3.1); the value of online platforms for increasing accessibility (3.4); the need to adapt the pace of body mapping to suit chronically ill participants (3.5) and the need to put in place post-workshop support and follow-ups (3.6). Further feedback also drew attention to the strengths of body mapping in terms of reflecting the depth and complexity of lived experience (3.2) and creating space for peer-to-peer support (3.3).

3.1. Preparation

Overall feedback from participants suggested the workshops were well-organised with all participants rating the quality of materials highly (4 or 5/5) and 10 out of 11 participants also rating the support offered by facilitators and the warm-up exercises as either 4 or 5/5 (see Table 4). We also noted the need to specifically adjust the mindfulness

Table 3
Feedback survey. Where questions were multiple choice, the options are listed in brackets. Where participants were asked for a rating out of 5, 5 indicated the most positive rating.

Thank you for taking the time to complete this feedback form. Your input is greatly appreciated!

1. How easy was the workshop's preparation material to understand? (Rating scale: 1 to 5)
2. If you encountered any challenges with the preparation materials, please specify here:
3. How would you rate the facilitator's support and guidance throughout the process? (Rating scale: 1 to 5)
4. If you have any suggestions for improving facilitator support, please specify here:
5. How would you rate the warm-up exercises (mindfulness/creative exercise)? (Rating scale: 1 to 5)
6. If you have any suggestions for improving the warm-up exercises, or think either of them are not necessary, please specify here:
7. How did you find the duration of the workshop? (too short/just right/too long)
8. Do you think there were too few/too many breaks in the workshop? (too few/just right/too many)
9. Do you feel that the workshop offered a beneficial level of peer support? (Yes definitely/Yes somewhat/Not really/Not at all)
10. Do you feel that this workshop improved your ability to communicate your experiences to others? (Yes definitely/Yes somewhat/Not really/Not at all
11. What (if anything) did you most enjoy about the workshop?
12. What (if anything) did you find challenging/did not enjoy? If you have suggestions on how to improve this, please specify:
13. Would you recommend this workshop to others? (yes/maybe/no)
14. How would you rate your overall experience? (Rating scale: 1 to 5)
15. Do you have any other suggestions for improving the workshop?

Table 4
Summary of quantitative feedback data (average rankings).

Survey Question	Mean average rating 5 = highest rating
How easy was the workshop's preparation material to understand? (Rating scale: 1 to 5)	4.5
How would you rate the facilitator's support and guidance throughout the process?	4.5
How would you rate the warm-up exercises (mindfulness/creative exercise)?	4.6
How would you rate your overall experience?	4.45

exercise to account for participants' lived experiences of Long Covid: The instruction to take a deep breath, a common feature of mindfulness exercises, can be triggering and uncomfortable for those left with breathing difficulties as a result of Long Covid.

3.2. Creative methods allow for depth and complexity in reflecting in lived experience of disease

Participants valued the opportunity to engage in creative expression through body mapping as it provided a unique and meaningful way to explore and communicate their experiences, with 10 out of 11 workshop participants agreeing that the workshop improved their ability to communicate their experiences to others (see Table 5). For some this creative process encouraged deeper self-reflection, as one participant noted: 'I loved doing it as a group and then discussing each of them afterwards, but I really loved how it made me think of things for myself afterwards too. It is an exercise I can see myself doing again alone many more times.' Visual methods also helped participants find new ways to express the complexities of their condition. By visually representing their personal journeys with illness, they could convey emotions and insights that were difficult to articulate in words alone. A big part of this process was for participants to articulate images and identities of 'former' and 'changed' self and finding comfort in visually seeing that others felt the same way too. Some participants even drew two versions of their bodies, a before and after body map to depict their changed view of themselves (see Fig. 1), while others chose to take the exercise in an entirely different direction and forgo the body outline completely (see Fig. 2). One participant shared 'I love being creative, so it was great to express my illness in a creative way.' In this sense, the activity became both a space of self-reflection and a powerful way for participants to feel seen, heard, and understood—offering a depth of expression that traditional interview or focus group techniques might not have achieved.

3.3. The importance of peer support

In our follow-up sessions several participants expressed that being able to share their experiences with others in similar situations was a highlight of the experience, with 9 out of 11 respondents to the feedback survey saying agreeing that the workshop offered a beneficial level of peer support (see Table 5). One participant shared 'I loved being able to share with, and listen to, others in similar situations,' while another noted 'It was nice for everyone to present their maps and to share mine and be seen.' This peer support aspect reflects calls for patient-centered research, which see people living with the illness as active agents of co-producing knowledge about the impact of the illness on their lives, as well as their needs – something that body mapping enables through its visual, holistic approach that gives time for participants to reflect on what they feel, what they want to say, and how they want to say it.

Table 5
Summary of quantitative feedback data (scale).

Survey Question	Reponses
How did you find the duration of the workshop?	just right (9); too long (2)
Do you think there were too few/too many breaks in the workshop?	just right (9); too few (2)
Do you feel that the workshop offered a beneficial level of peer support?	yes definitely (5); yes somewhat (4); not really (1); not at all (1)
Do you feel that this workshop improved your ability to communicate your experiences to others?	yes definitely (2); yes somewhat (8); not really (1)
Would you recommend this workshop to others?	yes definitely (n = 8); maybe (n = 3)

3.4. Online workshops can make research accessible

Hosting the workshops online also addressed a critical gap in peer support for patients with severe Long Covid who often experience profound isolation due to debilitating symptoms and become disconnected from their social networks. Online workshops helped address this issue by providing the flexibility for participants to join from anywhere, eliminating the need for travel and allowing them to participate from the comfort of their homes and to easily leave when they needed to by simply turning off Teams. Many attended while lying in bed or on their sofas. Being at home in a virtual setting also allowed participants to do things in their own time.

3.5. Pacing is key

For some participants (2 out of 11 feedback survey responses) the duration of the workshop proved too long, leading some individuals to leave before the session concluded. Others (2/11) suggested more breaks were needed during the session (see Table 5). This underscores the importance of pacing for people with Long Covid, which involves managing daily activities through regular breaks and rest, tailored to the severity of their symptoms. For those with more severe Long Covid a 2 hour workshop, despite including breaks, exceeded their capacity. As one patient commented: '[I was] too exhausted by the end to listen coherently to all of them [other participants].' We also learnt from participants how they anticipated and prepared themselves for the potential of experiencing a 'crash' post-workshop. They spoke of carefully calibrating how many spoons they had to participate—a way for chronically ill people like those with Long Covid to estimate their energy levels for daily tasks (McDuff et al., 2025).

3.6. Post workshop support is very important

A sense of security not only meant feeling safe during the workshop but also afterwards. For some the workshop ended rather abruptly, suggesting a need to perhaps incorporate a cool down element, such as a mindfulness exercise, at the end of each session. This could help participants shift smoothly out of the workshop environment, promoting a sense of closure and well-being. Feedback from participants underscored the importance of feeling supported not only during the workshops but also in the days that followed. Many emphasised the value of having follow-up emails from the organisers and sessions scheduled shortly afterwards, which provided continued space for peer support and discussion: 'I found the session much more emotionally draining/charging then I had anticipated and could have done with a debriefing session at the end of that week or the following'. This continuity, it was suggested, would help to reinforce the sense of community fostered during the workshops.

4. Discussion

This paper had three key aims. Firstly, we sought to explore the use of body-mapping as an arts-based research tool and patient peer support resource, which allows for a more holistic understanding of patient experiences of living with Long Covid. Feedback from our workshops

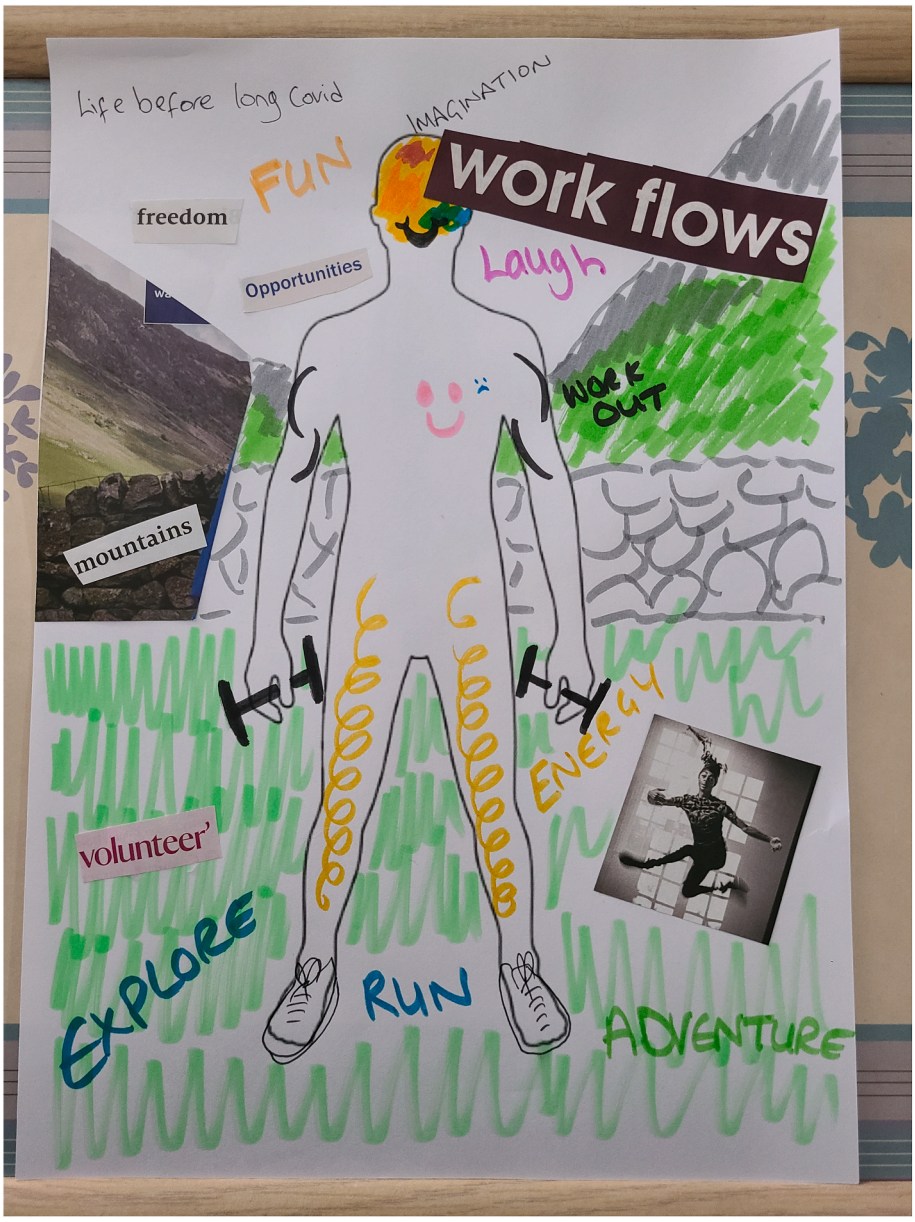


Fig. 1. Images of a participant's 'before' and 'after' Long Covid body maps (reproduced with participant's permission)

further evidences the value of body mapping for capturing patients' lived experiences of not only Long Covid symptoms, but also how Long Covid had profoundly reconfigured their lives. It also raises awareness of the emotional impact of articulating the scale and scope of these impacts for participants (4.1). Secondly, our workshops evidenced the value of collaborative, participatory, patient-centered methods (4.2), and the important role they can play in facilitating testimonial justice by centering patient narratives. Thirdly, the toolkit offers an example of how researchers can re-purpose their research methods and tools to create a legacy, extending the benefits of the research beyond the duration of the specific project (4.3). We expand on each of these aims below. In addition, we also reflect on the value of running the workshops online (4.4) and some of the limitations we encountered, including balancing our desire to be inclusive with the needs and capacities of our chronically ill participants (4.5).

4.1. The value of a holistic approach

Firstly, our research supports claims that Long Covid requires examining not just its physical symptoms but also its broader effects on individuals' social roles, economic participation, and emotional well-being. Illness is not merely about physical and psychological symptoms but an embodied, spatially situated experience shaped by social, cultural, economic and political contexts (Brown et al., 2018; Moss and Dyck, 1999). For many participants, living with Long Covid has been a challenging and often traumatic journey, marked by stigma, isolation, and a lack of understanding from others. For some participants the body mapping workshops were the first opportunity they had had to openly discuss their experiences with people who could relate and understand. This process frequently elicited a wide range of emotions, both during the workshop and afterwards, with some participants remarking it took them a few days/weeks to recover from it emotionally. Despite the emotional intensity of the workshops, many found the experience to be positive, as it offered them a valuable opportunity to process their



Fig. 1. (*continued*).

experiences. This shows how place-based wellbeing encounters are best approached as 'a relational outcome, as something that emerges through a complex set of transactions between a person and their broader socio-environmental setting' (Conradson, 2005, p. 338; see also Bell et al., 2015).

Body mapping is a method which is particularly well suited to articulating embodied and situated understandings of patients' lived experiences. This demonstrates how patient narrative plays a significant role in body mapping, as it allows participants to create a visual narrative of their life experiences, echoing previous research. Arts-based health research highlights creative methods as a way to explore complex situations and experiences (Kara, 2020). For some participants, the workshops also helped to address hermeneutic injustice -the absence of shared interpretive resources needed to understand and articulate one's social experience. In simpler terms, this refers to lacking the language or concepts to make sense of one's own reality. This challenge is particularly acute for people with Long Covid, as core symptoms such as cognitive dysfunction and memory issues can significantly impair the ability to think clearly, recall events, and express oneself. Similarly, Witmore (2004, p. 60) describes visual methods as mediation, which is 'a process that allows us to attain richer and fuller translations of bodily experience and materiality that are located, multi-textured, reflexive, sensory and polysemious' (see also Pink, 2009). Visual methods like body mapping generally bypass linguistic barriers and allow richer expressions of emotions, pain, but also, of identity (Bowes-Catton et al., 2021; Jokela-Pansini et al., 2024). As for Hawkins (2015, p. 256), drawing for the participants, then, 'was more important for what was apprehended of place through practice, rather than what was represented in the finished piece'.

4.2. The value of participatory, patient-centered methods

Secondly our workshops demonstrated how participatory, patient-centered methods can provoke a shift from studying wellbeing in space to creating spaces for the co-production of wellbeing through collaboration. A key strength of these workshops is their ability to foster connection among participants, offering comfort as individuals shared their experiences with others facing similar challenges. Through

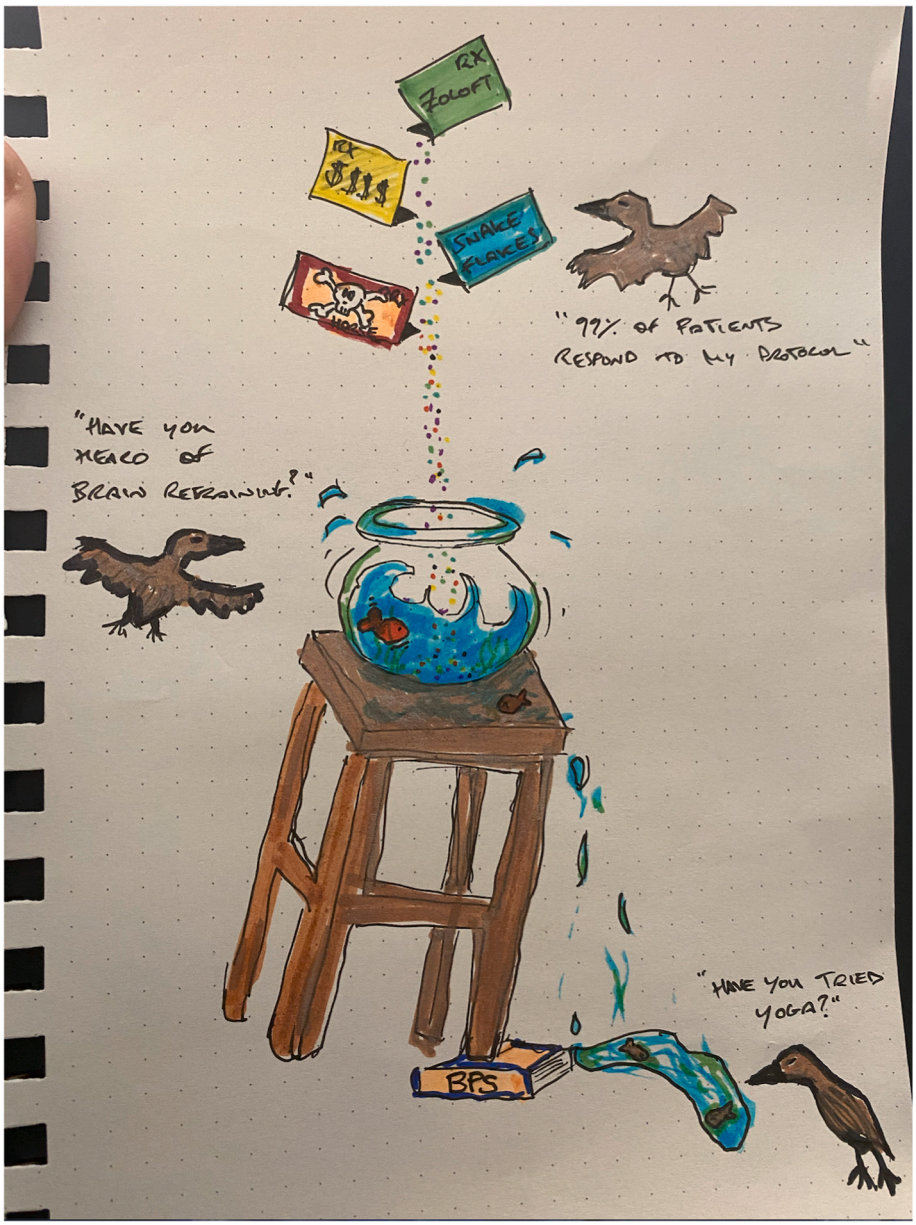


Fig. 2. One participant's creative interpretation of the body mapping exercise (reproduced with participant's permission).

collective reflection and mutual support participants were able to help one another find the words to describe their experiences, offering a shared framework for meaning-making (Barnard, 2025). Maintaining this sense of connection was essential for the sessions' success, and despite our concerns, we found that the online format was able to achieve this. Our body mapping workshops became spaces of support and connection through the virtual space, co-produced by the participants through narratives, gestures of empathy, a shared awareness of each other's struggles, and visual storytelling (body mapping).

Encouraging discussion between participants is crucial for fostering connection. In online formats it can be more challenging for individuals to naturally speak up, so it is important to explicitly invite comments and create opportunities for interaction. The warm-up creative and mindful exercises at the beginning of the workshop were crucial for opening the conversation. We found that once participants understood it was an open and welcoming space, the conversation began to flow more naturally. The workshops offered a counter-space for testimonial injustice – a prejudice through which the speaker is misjudged and perceived as epistemically lesser, and their knowledge is discredited due to such prejudice – which Long Covid patients reportedly often face in healthcare settings. This ties into other researchers', such as Alwan's (2021a, 2021b) work around Long Covid, which urges healthcare professionals to believe and listen to patients' voices. Feeling and knowing that others understand you and take your testimony seriously fostered the space of support even more. It is important to note that the level of connection and interaction can vary depending on who attends (Jokela-Pansini, 2021). Factors such as age differences, gender, diverse backgrounds, and varying personal experiences can influence the likelihood of forming connections, and it is worth considering whether to group participants of similar ages or gender and ensuring a minimum of three participants can help increase the likelihood of meaningful engagement.

4.3. *Creating a legacy*

Thirdly, we have demonstrated how the impact of creative methods may potentially be expanded through the repurposing of research methods as resources for peer support and community involvement, creating a legacy. A key outcome of these workshops was the design of a

toolkit which can be used by individuals or groups to run their own body mapping sessions. On 27 June 2025 we held a webinar, hosted by Long Covid support, launching our Toolkit for Individuals. To date (10th September 2025) our toolkit for individuals has been downloaded over 1000 times. The facilitators' guide for those interested in running their own body-mapping sessions is available upon request. As our study shows, body mapping can be a useful method for supporting patients to communicate their experiences, but it should be handled with care. This is why we encourage facilitators to reach out to us first if they are interested in using the toolkit with groups (http://www.visualisinglongcovid.org) .

4.4. The value of the online format

In addition, our workshops highlighted the value of the online format. While body mapping is generally seen as being suited to small, in-person settings, several participants whose symptoms would have prevented them from attending an in-person session were able to join because the workshops were held online. Similar to Vaughan et al. (2022) our team initially had reservations about conducting the body mapping workshops online. We were unsure whether we could recreate the 'psychologically safe space' that had been so effective in our in-person sessions. However, many participants expressed how valuable it was to engage in the workshop from the comfort of their own familiar and personal environment. Being at home allowed them to feel more at ease, which in turn fostered a sense of security and openness during the creative process. This setup also enabled participants to use their own preferred materials and creative tools—whether it was specific types of paper, pens, or other materials—which enhanced their capacity for creative expression, such as including actual objects such as batteries to describe their energy levels or needles to depict the symptom of pins and needles. By having access to tools they were comfortable with participants were able to more freely explore and communicate their experiences in ways that felt natural and authentic to them.

The flexibility this offered participants was key. As Kafer (2013, p.27) notes in the context of disability and disabled bodies, expectations of 'how long things take' are based on very particular minds and bodies. It is crucial to maintain a balance between offering support and respecting participants' autonomy. Everyone's experience of Long Covid is unique, along with their individual needs and comfort levels. Providing care involves offering flexible options that accommodate varying levels of participation, enabling participants to engage at their own pace. By doing so, it is possible to create a supportive environment where participants feel genuinely heard and respected, allowing them to navigate their experiences in a way that is meaningful to them. We found ourselves having to adjust the pacing and organisation of our workshops to allow participants to join from the comfort of their beds and sofas. The sharing of the body maps and the subsequent discussions emerged as a form of micro-social geography (Parr, 2000), where participants co-constructed meaning, support, and solidarity. For some this also provided an opportunity to prepare themselves for the after-effects of the workshop, with some setting aside time to rest or having snack easily to hand to replace flagging energy levels, something we then built into the advice given in our toolkits. Online body mapping workshops, then, can be a valuable tool for addressing the critical gap in support for patients with severe Long Covid, offering an accessible platform that meets their specific needs. These findings resonate with studies that emphasise the realities and needs of people for support and care, which take place everywhere rather than only in physical and institutional settings (Andrews et al., 2012; McKeever and Coyte, 2002, p. 25), and how patient peer support groups often happen in virtual spaces (Mullard et al., 2023). However, it is important to acknowledge that the workshops, although conducted online, were not accessible to everyone.

4.5. The limitations of body-mapping

It is important to remain mindful that body mapping, while empowering for some, may feel invasive or uncomfortable for others especially when dealing with sensitive or traumatic issues (Crawford, 2010). There are also logistical challenges, such as the time-intensive nature of the process and the need for skilled facilitators who can guide participants through potentially emotional and difficult experiences. Ethical considerations are critical to ensure that participants feel safe and supported throughout the process (Gastaldo et al., 2018). These questions are particularly important when working with people who are severely ill and need extra care throughout the workshop (and in many cases, also afterwards). Working with members of affected communities to co-design research methods and tools can serve to mitigate these risks. For example, for some a 2 hour workshop was too demanding, and participants suggested instead the workshop could be divided into two or three separate sessions spread across two to three weeks: an initial session for introduction and instruction on body mapping, followed by a period for participants to create their body maps, a session for presenting the maps, and finally a follow-up session. While there are steps we could take to enhance accessibility further, it is also important to acknowledge some individuals experience symptoms so severe that even the most accommodating formats remain out of reach, highlighting that this type of research cannot fully include those with the most severe forms of the illness.

5. Conclusions

Body mapping is a powerful method that facilitates meaningful peer support by allowing individuals to visually express their experiences and emotions. Conducting our toolkit development workshops online enhanced accessibility, especially for individuals with more severe symptoms who may otherwise have been unable to attend in-person sessions. These benefits can be sustained by approaching research collaboratively and thinking about how the tools and spaces created through research might be shared with and sustained in the community in the longer term. However, implementing body mapping requires a thoughtful and sensitive approach, particularly when involving participants who may be dealing with challenging or potentially traumatic experiences. Ensuring appropriate support throughout the process, including offering follow-up sessions, is essential to provide a safe environment for participants.

Our research has also highlighted one route through which we might seek to sustain the positive legacies of qualitative social science research sensitive to the ongoing needs of patient communities. This project sought feedback on the body mapping process in a way which allowed participants to feed into the repurposing of body mapping to produce a toolkit for peer support. By involving members of the Long Covid community in the development and co-design of this resource, both through the workshops and through ongoing collaboration with the charity Long Covid Support, we have sought to find a way that allows the benefits of body mapping to be extended beyond the limited timeframes and geographies of our funded work. Feedback from the community to date has been extremely positive, and Long Covid Support is looking into how they might also be able to facilitate future peer support sessions using the toolkit. We look forward to seeing how the toolkit is shared and used in the future.

Ethics statement

This study received ethical approval from the University of Oxford Central University Research Ethics Committee, approval reference: SOGE C1A 24 15.

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CRediT authorship contribution statement

Maaret Jokela-Pansini: Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Oonagh Cousins:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Jo Dainow:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing. **Beth Greenhough:** Conceptualization, Data curation, Formal analysis, Funding acquisition, Investigation, Methodology, Project administration, Writing – original draft, Writing – review & editing.

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Data availability

The authors do not have permission to share data.

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