

Project workshop report: Women's Experiences of Long Covid

Background

The purpose of this pilot workshop was to assess how body mapping may be used to visualise the diverse experiences of women living with Long Covid in the UK. Using the research method of body mapping – drawing life-sized bodies and answering questions on the body maps with words, pictures, and prompts in a group setting –, the workshops seek to make the multifaceted and individualised experiences of Long Covid more tangible and to provide a space for Long Covid patients to share their experiences.

Highlights

- **Peer support.** Participants greatly appreciated the opportunity to engage in discussions with fellow Long Covid patients. The workshop facilitated a sense of belonging and support and enabled the exchange of knowledge and coping strategies in a psychologically safe space. They found reflecting on the illness collectively as women particularly useful, and participants shared, for example, their concerns regarding hormonal changes in their bodies (see fig. 1). Participants used similar words and expressions, such as feeling like a shadow (fig. 2) or having a low battery. They expressed their interest in co-creating vocabulary and tools with the researchers for patients to express their symptoms. The advantages of feeling safe enough to speak honestly about their experience was highlighted, with many participants sharing their experiences of being dismissed when speaking about their illness.
- **Adapting to participants' needs.** All participants appreciated the visual method, which allowed them to reflect on the questions at their own pace, not having to verbally express their feelings or concentrate on responding to interview questions. The impact of Long Covid on participants' physical capabilities and sensory experiences necessitated adaptations during the workshop: The importance of creating an appropriate physical environment was emphasized. Adequate space and ventilation were essential to ensure the comfort and well-being of participants, especially considering the potential impact of Long Covid on respiratory health. The process of body mapping proved to be challenging at first for some participants. For example, one participant had at first difficulties lying down on the floor. The workshop revealed the balance required for allocating sufficient time to conduct activities and facilitate discussions while considering the participants' physical limitations and the need for breaks and rest. There was also interest in creating an online version of the activity for those unable to attend in person events.

Outcomes

Our findings show a number of the challenges people with Long Covid face, beyond physical symptoms.

- The participants highlighted the diverse perspectives and experiences of people with Long Covid. There exists a wide range of symptoms affecting patients' lives in very different ways. The illness can be as serious as being bedridden long term with no apparent improvement to having a few issues of breathlessness when exercising. Therefore, the experience of the illness is complex and it is important that oversimplified generalisations are not made.
- Participants pointed out that the illness often defied conventional notions of illness, such as feeling well and suddenly ill the next day. They felt that often people around them underestimated the effect on daily activity, the need to pace yourself, and the length of time required to recover. They also felt that people did not believe they were unwell because in many patients there are no visible symptoms. The workshop prompted discussions on how to foster understanding for people with Long Covid. It prompted the question: Why is it that when people do not understand a medical issue, there is an inclination to dismiss its severity and/or psychologise it?
- Participants often highlighted their gender: they spoke about changes in their hormonal functions and doctors not taking them seriously due to being women. The menstrual cycle had a significant impact on symptoms - but most often, this was not even acknowledged by doctors as something that may be relevant.
- Identity was discussed, with participants expressing how they had experienced a shift from 'my former self' to living in a shadow, now completely unable to live the life they once lived. This was strengthened by the temporal dimension of still living in the pandemic, thus living in a different time than others. It was also shaped by the difficulties of not knowing whether recovery was possible, and therefore, whether the participants' lives had been permanently or temporarily altered.
- Participants emphasised the significance of language when it comes to understanding the experiences of Long Covid. One participant said that, given that there are no diagnostic tests for Long Covid, participants are reliant on "their own testimony" when communicating with friends, family, co-workers and healthcare professionals, but she felt this was limited in its ability to convey how serious the illness was. Potentially, due to a lack of medical research around the illness, there is a lack of terminology for the symptoms. Instead, patients need to rely on words which are the closest to their experience, but these words often end up diminishing the severity of the actual symptom. For example, the word 'fatigue' is often used, and this infers a meaning similar to 'tiredness', but the actual experience of this symptom is often drastically more severe and feels much more like a 'deep sickness' than just 'tiredness'.

Conclusions

The body mapping workshop provided an invaluable opportunity for women with Long Covid to connect, share experiences, and visualise the diverse impacts of the condition on their lives. The workshop shed light on the challenges faced by individuals with Long Covid, including the difficulties in articulating their experiences and the need for greater understanding and support from healthcare professionals. The insights gained from this workshop will contribute to a more comprehensive understanding of Long Covid and inform future research and support initiatives. The participants concluded after the workshop that beyond research, body mapping may be a useful method to support Long Covid patients to reflect on and discuss their illness with others, and the researchers will help train community members in the method.

Acknowledgements

We would like to express our thanks to Perspectum for hosting our workshop at the Royal Society. By providing the platform for our study on the lived experiences of Long Covid, they have supported the inclusion of patient voices into the broader conversation on healthcare. Thank you also to Long Covid Support, who, together with Perspectum, helped distribute our recruitment email among their members. The workshop is part of the study 'Living in a chronically ill body: mapping women's experiences with long covid' (funded by the Swiss National Science Foundation), which examines the impact of Long Covid on women's everyday lives, and explores their experiences with healthcare systems, support from family and friends, and interactions with public and private institutions. The workshop patients' participation was paid for by the Swiss National Science Foundation. The workshop took place at the conference AI & Data Science in Healthcare organised by Perspectum on 20 June 2023 at the Royal Society, London

Workshop organisers: Dr Maaret Jokela-Pansini and Prof Beth Greenhough, School of Geography and the Environment, University of Oxford, in collaboration with Long Covid Support (Jo Dainow).

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Images of participants' body maps

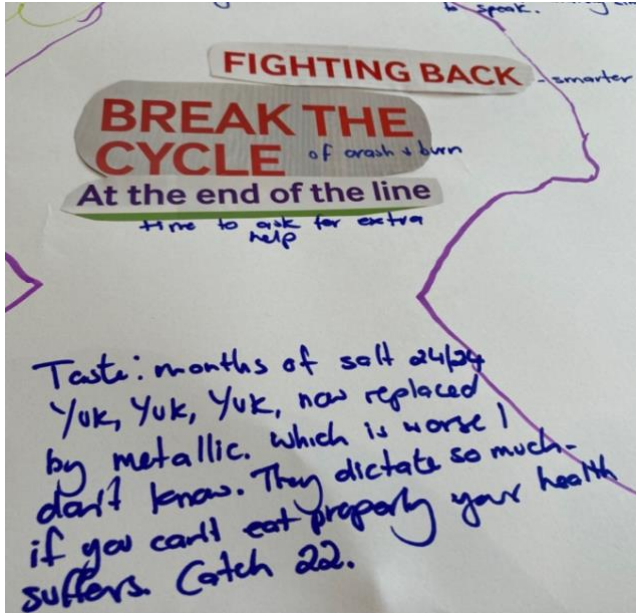


Fig. 1 Caroline's body map

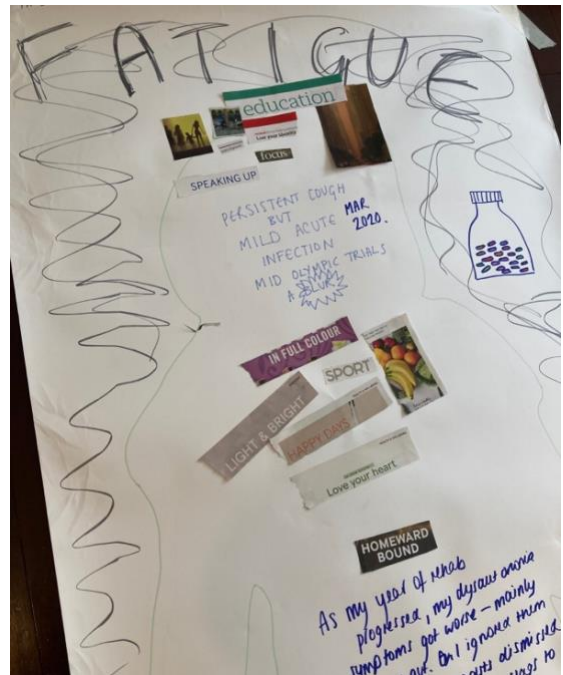


Fig. 2 Lisa's body map

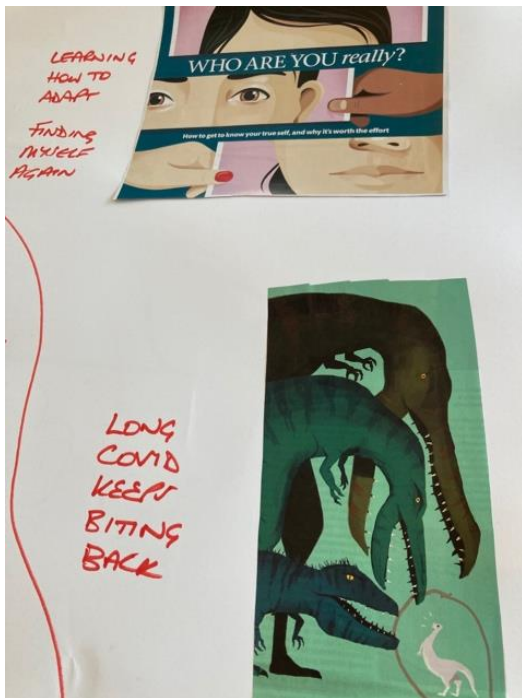


Fig. 3 Phoebe's body map

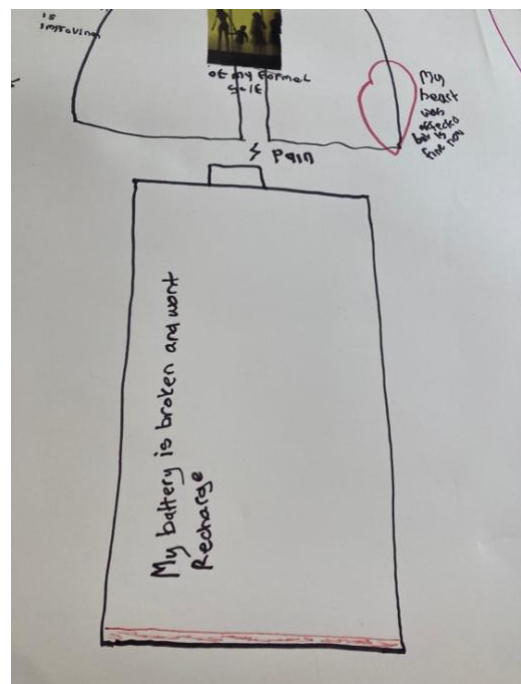


Fig. 4 Molly's body map