

Exploring the Psychosocial Impact of Long Covid: Coproduction of a Self-Management Tool for People Living with Long Covid

Dr Stephanie Kilinc, Teesside University, Dr Miglena Campbell, Teesside University, Lee Buckle, Teesside University, Dr Judith Eberhardt, Teesside University,
Dr Benjamin Gibson, De Montfort University, Professor Mark Forshaw, Edge Hill University, Dr Sue Becker, University of Hull, Rachel Batchelor, University of Oxford, Sam Rowlands, Teesside University & Joanne Cole, Neuro Key

BACKGROUND

- Unpredictable, relapsing/remitting nature of long-covid symptoms is problematic for people's mental health¹.
- The wide-ranging, fluctuating symptomatology is a distinctive, problematic features, described as "stressful" and "frightening"².
- Relapsing/remitting symptoms can go unrecognised by health professionals who offer rigid advice on symptom management².
- People living with long-covid feel doubted and require psychosocial support³.
- Lived experience research with people with neurological and long-term conditions highlights the psychosocial impact on patients, affecting identity, social interactions and self-efficacy⁴.
- Our self-management research promotes a multi-dimensional, less instructional approach, supporting and enabling people to reflect and act upon the impact of symptoms *within* the context of their own lives and experiences⁵.

AIMS

- To coproduce a self-management tool for people with long covid, addressing the psychosocial impact.
- To promote understanding of the experiences and needs of people living with long-covid.
- To enhance professional practice & public awareness of the psychosocial impact of long

METHODS

- Systematic review⁶ - the psychosocial aspects of individuals' lived experience of long covid.
- 34 research/reports
- Five themes: 1). 'Debilitation'; 2). 'Uncertainty'; 3). 'Sources of Support'; 4). 'Meaning Making: Adjusting to a New Normal'; 5). 'Experiences with Healthcare Services'.

- Semi-structured interviews exploring the experience of living with long covid.
- Six people living with long covid:
 - 2 male, 4 female
 - Aged 36 to 57; duration 4 to 24 months
- Interpretative Phenomenological Analysis⁷.

- Coproduction group - 5 people with long covid.
- Used existing self-management tool for long-term conditions (MyLifeTool) for one month.
- Three workshops to adapt MyLifeTool - reflecting on their experiences of using the tool and the interview and systematic review findings - framework analysis⁸.
- Coproduced an infographic and dissemination event.

NAVIGATING UNPREDICTABLE HEALTH CHANGES

- Participants described living with long covid as a continuous process of adapting to an unpredictable body.
- Symptoms fluctuated daily, making it difficult to plan ahead or maintain a simple routine.
- This unpredictability led some to reevaluate their limits and expectations.

"Some days, by the time I've had a shower, I need a rest. Yet another day, I'm ready to go. But later, the symptoms will always catch up with me"

"My whole day revolves around managing fatigue. If I don't get my rest at the right times, I know I'll suffer for it later"

"I felt misunderstood because people get COVID and bounce back. I feel not believed by my work, my family and even my GP"

"I didn't want to live with it. I wished I'd died of COVID. I felt like a burden. But over time, I've realised that I need to fight for myself and find ways to keep going"

- Beyond the physical struggles, the emotional impact of long covid was a journey filled with frustration, grief, and resilience.
- A sense of isolation was exacerbated by feelings of being misunderstood or disbelieved.
- Despite these challenges, participants demonstrated inner strength, learning to advocate for themselves, manage their mental well-being and find comfort in small, daily routines.

EMOTIONAL ADJUSTMENT AND INNER STRENGTH

ADJUSTING TO A CHANGING SENSE OF SELF

- The unpredictability of symptoms and limitations associated with long covid forced many to redefine their identities.
- They expressed grief over the loss of their former selves.
- The erosion of confidence in their bodies created a sense of disconnect, leaving some feeling trapped and out of control.
- Participants learned to redefine their self-worth and began embracing moments of strength amid ongoing challenges.

"I feel as if I've lost me. I feel out of control of my own life. My body is the decision-maker for me now"

"I used to be so independent, and now I can't even promise I'll be well enough to do something next week. That's something that's really hard to accept"

"I realised I have to be kind to myself. I used to push through everything but now I listen to my body more"

"I have days where I think, 'Maybe this is it, maybe this is my life now.' But then I remind myself that I've gotten through the worst days, and I'll get through this too"

RECONSTRUCTING LIFE AFTER LONG COVID

- Participants described a process of reconstructing their sense of self - a journey of redefining life, navigating resilience and vulnerability and finding ways to move forward within the constraints of a chronic and unpredictable condition.
- Misunderstandings and scepticism from others contributed to feelings of isolation.

"Long COVID doesn't just affect your body - it affects your whole life, your job, your family, your friendships, and even the way you see yourself."

"I never imagined I'd have to explain my illness to people just to be believed. It's like fighting for recognition every single day, even though my body is telling me the truth."

THE JOURNEY TO COPING AND HOPE

- The path to coping with long covid was a gradual process of trial, adaptation, and self-discovery - developing personalised coping mechanisms.
- Participants turned to social support for guidance and validation.
- Although uncertainty about recovery remained, many described a shift in perspective - focusing on small improvements and moments of stability to build a sense of hope and resilience.

CONCLUSIONS

- The experience of long covid extends beyond physical symptoms, profoundly impacting identity, relationships and daily life.
- Participants described a complex process of reconstructing their sense of self, adjusting to new limitations while grieving the loss of their former abilities and independence.
- The unpredictability of symptoms made future planning difficult, adding to the sense of uncertainty.
- By prioritising lived experiences and fostering collaboration, this project addressed critical gaps in psychosocial support for people living with long covid.
- The adapted MyLifeTool and coproduced infographic offer practical steps toward a more holistic, person-centred approach.
- Healthcare services should adopt a specialist multidisciplinary, holistic approach to integrate psychosocial support within their management strategies to improve overall patient outcomes.

NEXT STEPS

- Create a repository of resources and best practice
- Raise awareness and tackle misconceptions
- Strengthen multidisciplinary team approaches
- Elevate the role of expert patients

ACKNOWLEDGEMENTS

Thank you to our coproduction group and participants for sharing your experiences.

This project is funded by the NIHR Undergraduate Internship Programme (NIHR304481). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

1. Owen, R., Ashton, R.E., Bewick, T., et al. (2025). Profiling the persistent and episodic nature of long COVID symptoms and the impact on quality of life and functional status: a cohort observation study. *Journal of Global Health*, 7(15:04006). DOI: 10.7189/ogh.15.04006.

4. Kilinc, S., Erdem, H., Healey, R., & Cole, J. (2022). "Finding meaning and purpose": A framework for the self-management of neurological conditions. *Disability and Rehabilitation*, 44(2), 219–230. DOI: 10.1080/09638288.2020.1764115

6. Eberhardt, J., Gibson, B., Portman, R., Carthy, N., Rowlands, S., Batchelor, R., Kane, L., & Kilinc, S. (2024). Psychosocial aspects of the lived experience of long-COVID: a systematic review and thematic synthesis of qualitative studies. *Health Expectations*. DOI: 10.1111/hex.70071



FOLLOW
OUR
WORK...

