



CONVERSATIONS ABOUT COVID

Event overview

This public involvement and engagement event, held on the 28 September 2022, was part of the University of Glasgow ARCadia 'Festival of Ideas' to celebrate the opening of the [Advanced Research Centre](#) in Glasgow.

The aim was for the Glasgow university research community, particularly the Long Covid researchers to meet with members of the Public and Patients to enable a sharing of thoughts on how we involve people in research.

The event was a collaboration between the Long Covid Scotland lead by Chris White and the Glasgow University Covid Public and Patient Involvement steering group lead by Tracy Ibbotson.

To facilitate discussion there was a short introduction on the Long Covid research process by the Glasgow research community and the importance of Public and Patient Involvement. The speakers were:

Professor Kate O'Donnell	Why we need research
Dr David Blane	How has PPI input affected research?
Dr Janet Scott	How has PPI input affected a grant application?
Chris White	Why the patient perspective is important

(Presentations are available on request please contact Tracy Ibbotson if you would like a copy).

This was followed by round table discussions, moderated by event facilitators, covering the following topics:

- Reflections on Presentations
- Surprises from Presentations
- Benefits from Long Covid research
- Concerns about Long Covid research

Summary of the event

Participants

Approximately 25 people took part in the discussions including the event team. Notes were taken from the discussion and have been summarised below. In addition to this, those attending were asked at the end of the event to provide feedback. From the feedback we know that some participants identified themselves as lay members of the public, NHS, or University staff/students.



**LONG COVID
SCOTLAND**

Emerging Discussion Themes

Th groups were asked to consider four questions and the comments are summarised below:

Question 1 Reflections on Presentations

- Isolating, people don't understand, it gets dismissed as just mental health problem
- Feeling judged for not being well
- Uncertainty what kind of day is it going to be
- how can health professionals support people with covid and long covid
- What support is there for the impact on wellbeing, emotions, family jobs etc
- PPI groups give access to research where NHS have long waits and lack of treatment,

Question 2 Surprises from Presentations

- More females, LC is different from Covid
- Women with LCs seen as hysterical
- Did not realise the amount of research
- Post covid April 2020 recruiting for studies through GPs
- Lack of coding in GP

Question 3 Benefits from Long Covid Research

- Don't feel alone on this road
- Be more public so people can find out
- Collaborative research
- LC clinics - critical mass of expertise from research cohort of professionals and patients
- Scot strategy should integrate primary care
- Future political pressure is important
- Make a fuss in the media

Question 4 Concerns about Long Covid Research

- Funding is reliant on profit making companies
- Not enough research being demonstrated to the public for reassurance-
- Non-PCR test time window- couldn't get into studies
- Are the right people reacting to Long Covid i.e., GPs/Politicians/employers

Feedback

19 participants provided feedback and 14 of which were lay people, and 5 was NHS/Uni students/staff. The feedback was very valuable and will help shape future events as well as helps us provide updates to those who expressed an interest on learning more and potentially getting involved.



The key points raised through the feedback were:

More time to talk about our experiences
More sign posting and information access.
More info about how to get involved
Opportunities to sign up to participate in research
Difficult to find venue
Maybe an organised break
A more joined up approach to questions and their outcomes in smaller groups
More meetings
Possibly a longer session for more information and involvement
Nothing really. Just found it a little difficult to find venue

Graphic illustration of the event

A graphic artist produced a pictorial representation of the discussions summarising the short talks and the key discussion points. Please find that at the end of this document.

Next steps and further PPIE opportunities

If there is anything missing in our summary of the event, please let us know by getting in touch with Tracy (tracy.ibbotson@glasgow.ac.uk). We want to ensure that we have accurately captured the discussions from the event.

We hope it was an informative and inspiring day for you. But more importantly, we have been inspired by you, your feedback and insights.

Following on from this initial discussion, the University of Glasgow PPI group in collaboration with the Long Covid Scotland would like to continue this discussion about how we can involve people in research projects about the Long Covid. If you would like to be kept up to date with these opportunities, suggest an idea, or would like to comment in this report please contact tracy.ibbotson@glasgow.ac.uk

For more information on the Long Covid Scotland, please visit <https://www.longcovid.scot/support>

Thank you!



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