

Public contributor meeting with young people with long-COVID for the ELUCIDate study: Summary Report

6th March 2025

Who we involved

An online information session was held on 6th March 2025 with three female teenagers with long-COVID. Also attending the meeting was the person leading the session (the Information Session Lead), an ELUCIDate researcher, and a meeting facilitator. (Facilitators are people who run the meetings, send out emails, and are available to answer any questions.)

What input we wanted

The aims of the meeting were:

- to continue to help everyone get to know each other;
- to deliver an information session on health research to our three teenage contributors to:
 - further empower them within their PPI (public and patient involvement) role for the ELUCIDate study
 - provide a super-curriculum activity to support their post-16 and post-18 journeys.

What we discussed

Following an initial icebreaker, the Information Session Lead ran an interactive session called, “What is health research? Why is it important?”

A range of different topics were covered in the session:

Health research in the news

Different headlines of articles on health such as, “One in four children have ‘problematic smartphone use’” (from <https://www.theguardian.com/society/2019/nov/29/one-in-four-children-have-problematic-smartphone-use>) were presented. A discussion was held on how headlines could be misleading, or have different interpretations. In the smartphone example, it was discussed how the term “problematic” was not defined. Contributors talked about where they got their health information from, such as from family and social media.

Types of health research

Different research methods (like surveys, interviews, and clinical trials), and when a particular research method might be used, were discussed. For example, contributors suggested that a survey could be used to find out how many people had received a vaccine, while interviews could be used to find out why some people get vaccinated, and others don't.

Health research can help overcome bias

The importance of health research to determine whether something could improve public health (which is termed an "intervention") was explained. This might be a particular medicine, or guidance to patients given by doctors. Health research provides scientific evidence for doing things a particular way, rather than basing this on conventional wisdom (the usual way of doing things). An example given was that it used to be thought that lying babies down to sleep on their front was best for babies, until a systematic review (one that methodically summarises all the studies that have been done previously) showed that lying babies down to sleep on their back was in fact best.

Health research needs to be used

The Information Session Lead talked about how large studies generally provide better scientific evidence than small studies (since in small studies, results are more likely to be due to chance), and the importance of actually using study results to improve the treatment and care of patients – rather than these results being left forgotten and gathering dust! For example, studies may be published but not seen by the people who help decide which new interventions are used.

What we plan to do next

We will email contributors to ask for their comments on this report, and then upload the report to the ELUCIDate study website. We will also provide a summary of the session for all our contributors, including those who were unable to come to the meeting. We will then meet again in three months' time to share recent progress from our study and get further input from our contributors.

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If you are a journalist and are interested in finding out more about the ELUCIDate study, please contact the University of Bristol's Media and PR Team: +44 117 428 2489; press-office@bristol.ac.uk.