

Introductory meeting with public contributors for the ELUCIDate study: Summary Report

26th February 2024

Who we involved

An online meeting was held on 26th February 2024 with one teenager; their parent/guardian; Dr Katharine Looker from ELUCIDate; and Dr Carmel McGrath (Research Fellow in Public Involvement).

What input we wanted

The aims of the meeting were:

- to familiarise the new Patient and Public Involvement (PPI) contributors with the ELUCIDate study;
- to ask them about their priorities for research and anything they thought was important to share at this time;
- to discuss the ways in which the contributors would be involved with the study, should they be interested in being ongoing contributors.

What we discussed

Our teenage contributor said that she had been infected with SARS-CoV-2 in October 2021, and following this, had been bed-bound for about three months. Though she is much better now, she still has days when she feels unwell. Her parent/guardian commented that it is, “really nice to read other people’s stories [on online support groups] and to know there’s people out there suffering...Originally **it was said that young people shouldn’t be affected by covid, and obviously it’s clear that they have been.**”

The parent/guardian said, “There was **no special consideration for her when it came to her sitting her [GCSE] exams** [apart from rest breaks with no extra time], so with the result, she knew she should have got maybe higher than she did get...there was no support there to give her those special measures...[those] would be very helpful for some people with long-COVID.” The teenager said, “It isn’t talked about much, there isn’t really much evidence or stuff to go off, they just kind of have to guess how to handle it, and use chronic fatigue to try and work around it.” She said that because there has not been much research, it was harder for schools

and exam boards to know how to accommodate the additional needs of those with long-COVID.

The parent/guardian said that it would be **helpful to be given meeting questions in advance**, to help those with brain fog or anxiety to not feel put on the spot.

Summary of key points

- Our contributors felt that a lack of understanding of how children and young people are affected by long-COVID has resulted in a lack of educational support being given.
- Sending our contributors the questions we plan to ask the group in advance of meetings would give our contributors time to think of their responses and therefore feel more able to contribute fully.
- The contributors felt that it was beneficial to talk to other young people and their families about their experiences with long-COVID.

How we will use this information

It will be important to consider sharing our study findings directly with schools and exam boards. We will send our PPI contributors the questions we plan to ask the group in advance of meetings.

Next steps

Additional contributors will be recruited, and regular online meetings set up. Two interested parents/caregivers will be sought to join the advisory group for the study. In between meetings, email updates will be sent to contributors around once a month.

This study is funded by the NIHR School of Primary Care Research (reference 637) and a National Institute for Health and Care Research (NIHR) Advanced Fellowship (reference NIHR302934). The views expressed are those of the author(s) and not necessarily those of the NIHR or the Department of Health and Social Care.

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.