

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

10th July 2024

Who we involved

An online meeting was held on 10th July 2024 with six teenagers (five female, one male), an ELUCIDate researcher, and two meeting facilitators including one teenage 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 welcome our Patient and Public Involvement (PPI) contributors to the first meeting just for children/young people with long-COVID (the long-term effects of COVID-19), and to continue to help everyone get to know each other;
- to recap the overall aims and methods of the ELUCIDate study;
- to recap the training which took place in the previous meeting on 13th March;
- to introduce the first analyses being done for the ELUCIDate study;
- to get input from our contributors on what might affect our results.

What we discussed

The teenage facilitator started by leading an icebreaker. Contributors commented that this was something they enjoyed and would like to do regularly. They also said they would like a break during meetings.

Next, the researcher summarised the ELUCIDate study: what the research wanted to find out, the datasets we will use, and the types of outcomes we will look at such as symptoms and diagnoses of new conditions. She also recapped the last meeting's training, in which the terms "exposure", "control/unexposed group" and "risk ratio" were explained.

The researcher is currently analysing data from the COVID-19 Mapping and Mitigation in Schools (CoMMInS) study. This looked at SARS-CoV-2 (COVID-19) infection in primary and secondary schools in and around Bristol <https://commins.org.uk/>. From November 2020 to

December 2021, the CoMMInS study visited schools to test children for SARS-CoV-2 infection approximately once every half term.

Although CoMMInS didn't ask people being tested whether they had long-COVID specifically, it did record whether they had experienced particular symptoms since the last time they tested them. We are calling these "recent symptoms". Data on recent symptoms were collected for all school children taking part in the CoMMInS study, not just those infected with SARS-CoV-2.

CoMMInS collected data on recent symptoms over multiple study visits. In the ELUCIDate study we aim to use these data as an indicator for long-COVID. For example, we could compare whether individuals with SARS-CoV-2 infection were more likely to have repeated recent symptoms during the CoMMInS study than uninfected individuals.

The questions on symptoms in CoMMInS were intended to be general, and school children taking part were supposed to record any occurrence of a particular symptom, not just occurrences of those symptoms caused by SARS-CoV-2.

The symptoms which CoMMInS asked about were:

- Shivers/chills
- Cough
- Runny nose
- Sneezing
- Sore throat
- Shortness of breath or difficulty breathing
- Headache
- General muscle/joint aches/pains
- Unusual tiredness fatigue/exhaustion
- Nausea (feel like vomiting)
- Vomiting
- Abdominal (tummy) cramps
- Diarrhoea
- Rash on toes or feet
- Rash elsewhere
- Loss of smell
- Loss of taste
- Other symptoms

In this meeting, the ELUCIDate researcher asked the contributors if there was anything they could think of that might affect our analyses/results.

One contributor commented that, "the use of the word recent may confuse some children as there's no given time frame". The researcher explained that CoMMInS had asked whether a particular symptom had been experienced since the last time the questionnaire was completed, and that the term "recent" was our way of describing those symptoms. However, **remembering what symptoms were experienced** over a long period of time, such as several weeks, would likely be difficult, especially for those people who took part who had missed one or more study visits. This could be **an issue for those with long-COVID in particular**. As one contributor commented, "I have brain fog and I usually forget my symptoms." It was also suggested by

another contributor that people who took part might only experience a symptom once, and therefore might either forget they experienced it, or not think it was worth recording.

A contributor said, “I think it’s hard to distinguish between what is COVID/long-COVID and what is ‘normal’ to me now.” This might mean that **some symptoms are not recorded because they are seen as ‘normal’**, for example, people who took part who had long-COVID might have thought their low energy levels were normal because they had got so used to feeling tired.

In the meeting, the ELUCIDate researcher asked everyone how well they thought parents/guardians would be able to record their symptoms (if filling in the questionnaire on their behalf). One contributor said, “I think my mum would probably know more how I’ve been than I would,” while another commented, “There are so many [symptoms] that I forget to mention most of them,” meaning that **parents/guardians might not accurately record symptoms experienced by their child**.

Another contributor suggested that, “The person could have an issue like asthma that causes them to cough instead of COVID.” Based on their comment, the ELUCIDate researcher suggested that study participants **might not record some symptoms if they knew they were not caused by COVID-19** (for example, caused instead by asthma, as our contributor noted), knowing that the study was about COVID-19. Similarly, if a study participant was aware that they had had COVID-19 infection, they might subsequently be **more aware of what symptoms they’d had**.

The researcher then asked if there were any **symptoms relevant to long-COVID that were not captured** in the CoMMInS list of recent symptoms. Discussions highlighted the following **missing symptoms**:

- Chest pain (suggested by researcher)
- Vision difficulties
- Brain fog/forgetfulness
- Cramps in legs
- Peeling hands
- Loss of mobility
- Postural tachycardia syndrome (PoTS) (when your heart rate increases very quickly after getting up from sitting or lying down <https://www.nhs.uk/conditions/postural-tachycardia-syndrome/>)
- Iron deficiency
- Blotchy cheeks
- Anxiety/depression (suggested by researcher)

The researcher suggested that blotchy cheeks and rashes might be less noticeable on darker skin types, and that more generally, **people may experience symptoms in different ways**.

Contributors mentioned the impact their symptoms can have, either on being able to attend school (“a lot of children are too unwell to go to school”) or take part in lessons (“[dizziness means that] I also can’t concentrate at all and I need stuff in school repeated and broken down to make sense to me”). **If people taking part were ill this could affect whether they came in to school to be tested for SARS-CoV-2 or completed the questionnaire about their symptoms.**

Summary of key points

- CoMMinS provides really useful information on SARS-CoV-2 infection and symptoms in children and young people in schools. However important symptoms relevant to long-COVID, such as brain fog, were not included in the questionnaires for CoMMinS.
- It is challenging to remember symptoms that have occurred over a period of several weeks. Symptoms seen as “normal” may not have been recorded. Parents/guardians may not necessarily record symptoms accurately. These issues may be particularly relevant for children/young people with long-COVID.
- Some symptoms may not have been recorded if they were not considered relevant.
- Some symptoms may have been experienced in different ways by different people, and this may have further affected symptom recording.
- Children who were poorly may have missed study visits.

How we will use this information

The limitations of the data and analyses, as outlined above, will be thoroughly discussed when writing reports. In particular, important symptoms not captured by CoMMinS but potentially relevant to long-COVID will be highlighted.

Next steps

We will email contributors to ask for their comments on this report. It will then be put on the ELUCIDate study website. We will meet again in three months' time to share some findings, as well as ask our contributors for their suggestions and input on how they would like the meetings to run and on what group rules they would like.

This study is funded by the NIHR School of Primary Care Research and a National Institute for Health and Care Research (NIHR) Advanced Fellowship. 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.