

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

11<sup>th</sup> September 2023

## Who we involved

An online meeting was held on 11<sup>th</sup> September 2023 with two parents/guardians who each attended with a teenage daughter; Dr Katharine Looker from ELUCIDate; and Dr Carmel McGrath (Research Fellow in Public Involvement).

## What input we sought

The aims of the meeting were:

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

## What information we got

**Questions** about the study from the PPI contributors were: how long will it last, when are the first analyses expected, and which NHS services will be included? The PPI contributors thought that the research questions were appropriate. One asked whether we expected the study to produce a different long-COVID definition to those that already exist. Dr Looker responded by saying it was hoped that the study would find associations with specific symptoms. She said the study will be able to potentially identify different presentations (symptom groups) of long-COVID, and will consider the long-term outcomes of children with lingering health effects who don't meet long-COVID definitions as well as those who do.

Issues raised by the PPI contributors were concerns about consistency of healthcare when moving from paediatric to adult long-COVID NHS services, and frustration at GPs "letting time just pass" rather than offering "concrete **treatments**". Dr Looker suggested that an implication for our study is that we might find associations between long-COVID and particular prescriptions and other interventions, but that not all of these associations may reflect the optimal management of long-COVID if different things were being tried to see if they helped.

Dr Looker also suggested that private healthcare and other treatments paid for by the families will not be included by the study so are a hidden **unmet need**. Then PPI contributors reflected that they thought that a lot of parents were “going down that route”, that it was hard to capture everything and that the study did “miss a lot” including the “vast” amount of research families undertake and array of things families try themselves. One contributor commented that they, “hit that point of, long, long ago, where we don’t even bother with the GP most of the time, because, what’s the point, nothing happens”. Dr Looker said that one advantage of using the Schools Infection Survey (SIS) data linked to health record data is that these data can be used to estimate the number of children with long-COVID who don’t go to their GP.

Another issue mentioned by a PPI contributor was around GPs and some parents, “not putting two and two together” to make the **link between SARS-CoV-2 and symptoms**, especially since the symptoms (which are often non-specific) can “mimic other things”, and there being a “mismatch” between GPs and specialist long-COVID services. Dr Looker mentioned that the study also plans to analyse the long-term outcomes of children and young people with fever, as a marker for other infections which have long-term health effects but also as a marker where testing for SARS-CoV-2 was not done or a diagnosis of infection was not recorded. She also said that use of a control (uninfected) group will help in trying to exclude other causes of symptoms.

Finally, a concern was raised about how many children the study was expecting to find who **hadn’t had the infection**, and about how to handle **re-infections**. Dr Looker responded by saying that, in the first instance, follow-up for the controls will stop when they acquire a SARS-CoV-2 infection, and follow-up for the exposed group will be only for their first infection (but that re-infections will be considered later on). She also said that the analyses will be split by calendar time according to when there is greater versus lesser certainty around infection status of the study participants.

## Summary of key points

- Treatments are a priority for our PPI contributors.
- While clinical guidelines for long-COVID are still being established, prescriptions and referrals for children and young people with long-COVID may not be optimal.
- There is substantial unmet need for healthcare, such as families choosing self-management or private healthcare over NHS GP services in response to their frustrations at accessing appropriate care. Some of this unmet need will be able to be addressed using the linked Schools Infection Survey data, but not everything will be able to be captured.
- The ability to identify infections is key to correctly classifying children as either being exposed to SARS-CoV-2 or not exposed (controls).

## How we will use this information

Alternative explanations for associations found in the data will need to be considered, and discussed in outputs. Unmet need for care not addressed through this study will need to be discussed in outputs as a limitation, as will limitations around identifying infections.

## 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. Written input by email will be invited on a study proposal that is currently being drafted. In between meetings, email updates will be sent to contributors approximately monthly.

*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](mailto:press-office@bristol.ac.uk).*