Meeting with public contributors for the ELUCIDate study: Summary Report

13th November 2023

Who we involved

An online meeting was held on 13th November 2023 with one parent/guardian; their teenage daughter; Dr Katharine Looker from ELUCIDate; Dr Carmel McGrath (Research Fellow in Public Involvement); and Ms Lucy Condon (Public and Patient Involvement Facilitator).

What input we wanted

The aims of the meeting were:

- to gain feedback on a written description of the role of public contributors working with the ELUCIDate study;
- to present a part of the ELUCIDate study where anonymous health record data of children across England will be analysed, to inform submission of a written project proposal to the COVID-IMPACT consortium;
- to answer any questions on the COVID-IMPACT part of the ELUCIDate study before sending contributors the plain English summary (from our project proposal) for them to review.

What we discussed

The two Patient and Public Involvement (PPI) contributors felt that the role description read well and included the **important information**.

During the presentation, the parent/guardian raised whether the Covid-19 Schools Infections Survey (SIS)-1 (also being analysed as part of the ELUCIDate study) included antigen testing (which shows whether someone is currently infected). Dr Looker said that it included antigen testing, as well as antibody testing (which shows whether someone was infected in the past). The parent/guardian commented that this is crucial for those with **asymptomatic infection** (infection without any associated symptoms).

She also said that referrals for long-COVID haven't been made because the services aren't there, and sometimes inappropriate referrals have been made. This was especially true early on in the SARS-CoV-2 pandemic. She asked **how we will distinguish between what were useful investigations and services, and what were not**. Dr Looker replied that this will be a limitation, but that we will stratify (split up) the analyses by calendar time in consideration of this.

The parent/guardian asked how long it will take for the COVID-IMPACT project to receive approvals. Dr Looker replied that it should be quite quick as the necessary infrastructure (things like the available datasets, and the ways in which they will be accessed) is already in place: we just need to set out the specific analyses (including the specific data requirements) for our project and have these approved by the consortium. We will also receive feedback on our PPI plans via the consortium. The parent/guardian also asked if we could make **changes to our project as we go along if something isn't working**. Dr Looker answered that this is possible but that we would need to seek ethics approval and approval from our funders, depending on the nature of the change.

The parent/guardian asked whether we will consider **re-infections**. Dr Looker responded by saying that we plan to do this in the future, but will focus on first infections in the first instance: there is much that is still unknown about long-COVID even for the early stages of the pandemic. Learning from the SIS-1 analyses will also inform how we define the term "infection".

The parent/guardian remarked that it would be, "**really validating for patients…to have it in statistics**… When you've been gaslit for so long, for it to be real, in data, is something."

In conclusion, she said she would like:

- **A clear pathway to be developed of what symptoms are experienced and when**
- **To know which are the best treatments for long-COVID**
- **Active screening for long-COVID in medical populations**
- **Funded healthcare pathways to be in place**
- **To find out more about the "weird and wonderful endpoints" of long-COVID like knee pain.**

Dr Looker said that we anticipate that the next meeting (in early 2024) will focus on the specifics of the data analysis and suggested that a training session for contributors might help with this (e.g., to explain the meaning of key scientific terms).

Summary of key points

- Children and young people with long-COVID may not have been given a referral or treatment that helped their long-COVID, especially early on in the pandemic. This is a limitation of our research.
- In our study it will be important to correctly identify as many SARS-CoV-2 infections as possible.
- Our study will need to adapt as our understanding of long-COVID changes.
- Better information for patients and doctors based on what has been learnt by long-COVID studies, together with more NHS resources to screen and treat children and young people with long-COVID, are very important to our contributors.

How we will use this information

The draft plain English summary will be updated following contributor input and submitted to the COVID-IMPACT consortium. We will be mindful that we may need to change which outcomes we plan to investigate. Limitations of the data and analyses, for example around useful and not-useful referrals, will be thoroughly discussed in outputs like written reports.

Next steps

The draft plain English summary, role description, and summary report from the meeting on 11th September 2023, will be emailed to contributors for their comments. Input on the draft plain English summary and role description will also be asked for from young people aged 13-18 years who are part of the Young Persons Advisory Group (YPAG), in order to get additional feedback. The summary report will then be uploaded to the ELUCIDate study website, and the COVID-IMPACT project proposal finalised and submitted. Recruitment efforts will continue for additional 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.