

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

October 2024

## Who we involved

Two online meetings were held on 14<sup>th</sup> October 2024 (four teenagers: three female and one male) and 21<sup>st</sup> October 2024 (two female teenagers). Two meetings were held as no single date was convenient for all our Patient and Public Involvement (PPI) contributors. Also attending the meetings were two ELUCIDate researchers, and meeting facilitators. (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 get input from our PPI contributors on how they would like meetings to be run;
- to introduce the first analyses being done for the COVID-IMPACT part of the ELUCIDate study;
- to get input from our contributors on some first results for infection and diagnosis trends from the COVID-IMPACT project.

## What we discussed

The discussions from the two meetings are summarised together below.

Following initial icebreaker(s), the meeting started with a facilitator-led discussion about the format of the meetings and agreed group principles (things like respecting the opinion of others and keeping information about group members confidential). Contributors commented that they **liked the icebreakers and getting to know the other contributors**. They also liked the current way meetings were run in terms of things being explained on meeting slides and in reading sent ahead of the meetings. The contributors said they found pre-reading helpful to **know what to expect from the meetings** and to plan what to say. **Interactive sessions** with things like live quizzes and using emojis as responses were mentioned as being particularly enjoyable and contributors said they would like these to continue.

Contributors felt that an hour was the right length for the meetings, but would like **more time spent talking or using the 'Chat' function** rather than listening to presentations, to help them stay focussed. During discussion time, the contributors agreed that it would be nice to end screen sharing of slides, so that they could **see each other more easily**. Contributors also really valued more than one meeting, or a catch-up at least, if necessary to **accommodate everyone's availability**.

Suggestions for group principles, posted live on a Mentimeter (an online tool for anonymously submitting comments) were, **"Understanding that everyone's situation/symptoms are different," "If people are having an off day and they're not feeling too well...understand that they may not be participating as much,"** and **"Having a little reaction to what we are saying in the 'Chat' so we know our opinions are being heard."** Contributors also said that it was important to be kind and respectful and to let others say everything they wanted to **without interruption**.

Next, the two ELUCIDate researchers summarised the **COVID-IMPACT** part of the ELUCIDate study. It was explained that during the COVID-19 pandemic, the British Heart Foundation Data Science Centre (led by Health Data Research UK) set up a consortium (group of researchers) called CVD-COVID-UK to understand how SARS-CoV-2 infection (i.e., Covid infection) might affect heart diseases in the UK.

This then led to COVID-IMPACT, which is an expansion of the consortium's purpose to look at the impact on SARS-CoV-2 infection on health more generally. The consortium currently consists of more than 400 people from over 50 institutions (such as universities) across the UK. COVID-IMPACT researchers can securely access anonymised health data such as GP data, hospital data, COVID tests and vaccinations, and which medicines are prescribed. There are many separate projects (ours is "CCU079") but researchers work together to share expertise.

Through COVID-IMPACT, an ELUCIDate researcher is securely accessing anonymised data for school-aged children in England. To begin with, she is investigating **how a (first) SARS-CoV-2 infection affects new diagnoses of (any) health conditions**, and separately, **how a non-SARS-CoV-2 respiratory infection affects new diagnoses of (any) health conditions** (examples of health conditions are asthma, migraine, diabetes and ear infection).

Before the researcher looks at how infection affects diagnoses, she first needs to **understand how SARS-CoV-2 infection, other respiratory infections, and diagnoses, have changed over time**. For example, patterns of SARS-CoV-2 infection will be affected by how much testing is done and by lockdowns.

Firstly, a figure (graph) showing diagnosed SARS-CoV-2 infection and other respiratory infections in children and young people before and during the pandemic was shown to the contributors. Contributors were invited to explain the figure (to check it was understandable) and give possible reasons for the patterns that they could think of (and that we might have missed). Contributors identified **peaks** in diagnosed infection, and noted some **similarity between patterns of SARS-CoV-2 infection and other respiratory infections**. As well as lockdowns, school opening/closing, SARS-CoV-2 variant, and amount of testing, they suggested that **behaviour patterns** (e.g., socialising), **vaccination, weather and travel** (both related to how much people socialise with each other), and **handwashing in schools** could be contributing to the patterns. The ELUCIDate researcher further suggested that some respiratory infections may have been due to SARS-CoV-2 infection but not identified as such,

especially early in the pandemic before testing was widely available. These infections would therefore have been categorised as “other” respiratory infections.

Secondly, some figures (graphs) were shown to the contributors for hospital-based diagnoses in children and young people before and during the pandemic, and after testing stopped. The figures were grouped by category of diagnoses (such as respiratory, and digestive). The figures showed a **steep decline in diagnoses at the start of the pandemic** due to a decrease in children and young people going to hospital. Following that, diagnoses fluctuated (went up and down) considerably. Contributors suggested things like **changing seasons** causing fluctuations. They also noted some **similarities between patterns of infections and patterns of diagnoses**. There may be some factors (such as access to healthcare during the pandemic) which affect both how many infections were recorded and how many diagnoses were made. Asthma was mentioned as an example of a respiratory condition potentially being made worse by respiratory infections including by SARS-CoV-2. Contributors noted the particularly large peaks and troughs in numbers diagnosed (changes up and down) for respiratory conditions, and contrasted this with the smaller fluctuations for neurological diagnoses.

One issue that was raised was that **for contributors joining on a mobile phone, it is more difficult for them to view results images** presented during the meeting.

The ELUCIDate researcher plans to look further back at non-SARS-CoV-2 respiratory infections and hospital diagnoses before the pandemic, to **see what pre-pandemic patterns were like** and whether patterns have returned to “normal”.

Some ways in which PPI input has shaped the research so far were shared with the group, along with how contributors might like to get involved further. We will follow up with contributors about this.

## Summary of key points

- Contributors would like more opportunity in the meetings to talk with each other and see each other on screen. They valued interaction and having reactions to their input.
- Being supportive of each other came up frequently as something the contributors felt was important, such as recognising that everyone has different symptoms and situations, understanding that having long-COVID can affect individuals’ ability to participate, and making sure everyone has the opportunity to be heard fully.
- We need to consider how we can share results images more effectively with contributors viewing these on their phone.
- Many factors affect the patterns of SARS-CoV-2 infections, other respiratory infections, and hospital diagnoses seen in children and young people. It is important to understand the reasons for these patterns. In particular, we need to understand any factors (like healthcare access, or weather) that may cause patterns in infection and diagnoses to be correlated (both affected similarly at the same time). We will then try to account for these factors when we investigate how infections are creating a need for subsequent diagnoses. If it is not possible to do this, we will discuss them as a limitation of our analyses.

## How we will use this information

We will set aside more time in our young person PPI meetings for our contributors to talk with each other without slides up. We will work with our contributors to identify ways to

accommodate contributors with differing symptoms and severity of symptoms and help everyone contribute. One way could be to keep a live Mentimeter running after the session for contributors to give input in their own time, and subsequently sending a link and reminder to contributors.

Throughout our analyses we will be mindful of creating graphs that are easily understandable, and the information needed to inform children and young people with long-COVID and their families, and the wider population. As an immediate action point we will think about how we can make our materials accessible for contributors viewing them on their phone.

We will continue to think about factors that have shaped patterns of infections and diagnoses. In particular, we will consider how our analyses can account for correlations between infection and diagnoses in investigating infection as a reason for diagnoses.

## **Next steps**

We will email contributors to ask for their comments on this report, and then upload the report to the ELUCIDate study website. We will update our role description to reflect the input received from our contributors. We will also follow-up with the contributors about being involved further with the research. We will then meet again in three months' time.

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