

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

28th November 2024

Who we involved

An online meeting was held on 28th November 2024 with three parents/guardians of young people with long-COVID as Patient and Public Involvement (PPI) contributors. Also attending the meeting were an ELUCIDate researcher and a meeting 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 help everyone to get to know one another;
- to get input from our PPI contributors on how they would like meetings to be run and whether they might like any training;
- to introduce the first analyses being done for the COVID-IMPACT part of the ELUCIDate study;
- to get input on the wording of descriptions of these analyses;
- to get input on some first results.

What we discussed

After an initial icebreaker, the meeting facilitator led a 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 said that they found having the pre-meeting information, and then the summary report afterwards, helpful. They said that **the pre-meeting information helped them remember things**, especially for those who were suffering from long-COVID themselves. They added that if there were any significant study developments between meetings then they would appreciate an **email update**. The contributors **liked the idea of training**, especially if this could contribute towards their Continuing Professional Development (CPD) hours.

The ELUCIDate researcher introduced the COVID-IMPACT part of the ELUCIDate study. **COVID-IMPACT is a consortium (a group of researchers) who are able to securely access anonymised NHS data such as GP and hospital data, COVID tests and vaccinations, and which medicines are prescribed.** Currently, there are more than 400 COVID-IMPACT researchers from over 50 institutions (such as universities) across the UK. There are many separate projects (ours is “CCU079”) but researchers work together to share expertise.

Through COVID-IMPACT, a second ELUCIDate researcher is securely accessing anonymised data for school-aged children in England. To begin with, she is investigating **how an initial 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. For the analyses, **diagnoses will be grouped into categories based on type**, e.g., respiratory, cardiovascular, etc.

Our contributors noted **many reasons their children may not have been given diagnoses** (of long-COVID and of other conditions) despite there being a need. One contributor said, “...a huge issue with long-COVID [is] you’re not getting the diagnosis [when] you know you’ve got certain conditions...**[doctors] are [reluctant] to put it on your record sometimes...**it gets fobbed off as mental health or something else, anxiety, and [an] over-worrying mother.” She said, “There is a lot of talk in the [long-COVID] community about how some specialists are not accepting long-COVID anymore...they are just **moving to put it under ME-CFS** [myalgic encephalomyelitis/chronic fatigue syndrome]...**long-COVID clinics seem to be closing** so GPs almost don’t want to diagnose it cos they’ve nowhere to refer to.”

She also described how she and her daughter have been “really badly gaslit...her lips were turning blue when she went outside in the cold...subsequently she would panic because she was suffocating...they thought it was anxiety.” Also she felt there was a general lack of support with conditions such as urinary dysfunction (not being able to control when to wee) not being picked up. She further described being “endlessly in limbo” waiting to see a specialist for POTS (postural orthostatic tachycardia syndrome). “I don’t know whether there’s anything on her record really [in terms of diagnoses]...**I don’t really know if anything is a firm diagnosis.**” She continued, “**We’ll wait ‘til there is something in place and then we’ll seek medical support...**that’s not an uncommon situation.”

Another PPI contributor said, “Since my son has been diagnosed with long-COVID, no-one [no doctors] wants to see him.” She explained, “**The only people who are giving him the diagnoses are private specialists** and then it’s difficult to get that put into his NHS record...they just [note] everything as post-COVID or long-COVID...but don’t actually write [down] all his symptoms.” She added, “**I don’t know how much is coded by his GP.**”

The third contributor echoed that, “It seems like long-COVID now is something that just isn’t a diagnosis anymore, it’s been almost just forgotten about.” She commented on the **lack of communication back to GPs of diagnoses made in hospitals**, and that ME-CFS clinics focus on pacing (advising people to spread out activities and rest in between). This might result in fewer diagnoses of other conditions.

We are currently producing a detailed document (“Statistical Analysis Plan”) setting out how the analyses will be done. Although this is intended for other researchers, **we would like the title and summary of our Statistical Analysis Plan to be easily understandable.**

To help with this, the ELUCIDate researcher asked the PPI contributors for their thoughts on terms commonly used to describe these types of analyses. These were: Diagnoses, Conditions, Sequelae, Health data science, Data-driven, Codes & code lists, and Phenotypes. She explained that when we just use the word “Diagnoses” on its own, people sometimes think we mean just long-COVID diagnoses, whereas we are looking at a very wide range of possible diagnoses associated with infection. Also she said that the term “Condition” might sound like something from the Victorian era (!). One PPI contributor said, “**Most people understand the word ‘Diagnosis’.**” The contributors said that **the term “Phenotypes” might be excluding to many people, or open to misinterpretation. Contributors suggested “Subtypes”, “Concerns” and “Complications”** as alternatives.

Two possible titles for the analyses were put to the contributors:

(1) Risk of long-term sequelae in secondary care following SARS-CoV-2 and general respiratory infections among school-aged children and young people in England

or

(2) Risk of diagnoses in secondary care as a consequence of SARS-CoV-2 and other respiratory infections among school-aged children in England.

Contributors preferred the second title but suggested **clarifying that we are interested in ongoing (i.e., persistent) health issues following infection, and that “diagnoses” means of new issues rather than those that are pre-existing.** Contributors suggested using the term “**school-aged people**” to avoid it sounding like the study was only on young children, or that young people over the age of 18 years were included. (The term “school-aged individuals” was subsequently suggested as another alternative by the ELUCIDate researcher.)

Next, the ELUCIDate researcher put two suggestions for a description of the analyses to the contributors:

(1) *“A **wide range** of long-term sequelae? diagnoses? will be explored by using hospital records of diagnoses **grouped into categories** defined by **type** (e.g., digestive, respiratory, cardiovascular, etc.) for **ease of investigation**. We will systematically investigate the association between infection and **each diagnosis category in turn**. By doing this our aim is to **not limit analyses** to pre-conceived ideas of where associations lie.”*

or

(2) *Our aim is to take an **exploratory approach**. First, we will **systematically investigate associations** between infection and hospital-based diagnoses using **high-level diagnosis categories**. Each diagnosis category will be defined by **type** (e.g., digestive, respiratory, cardiovascular, etc.). Second, and based on these initial results, we can explore whether there are associations with **sub-categories** of diagnoses or with a single diagnosis.”*

The contributors thought the second description was much easier to follow, except for the word “high-level”, suggesting instead “grouped diagnosis categories”. The facilitator suggested that the word “systematically” could be removed. The contributors also liked the use of bold font to make it easier to read and understand.

Finally, the ELUCIDate researcher showed the PPI contributors some results for the patterns of SARS-CoV-2 infection and other respiratory infections before and during the pandemic. The

second ELUCIDate researcher has produced these results to understand patterns of infection before starting to look at the associations with diagnoses.

Summary of key points

- Our PPI contributors liked having pre-meeting information. In the future, they would value study updates by email, and training.
- Our study is analysing how an initial SARS-CoV-2 infection affects new diagnoses, and separately, how a non-SARS-CoV-2 respiratory infection affects new diagnoses, grouping the diagnoses together by type. Contributors were happy with the term “Diagnoses” and suggested this be used together with a term like “Subtypes”, “Concerns” or “Complications”. They said that this term should make it clear that the diagnoses we are interested in capturing in our analyses are new, rather than pre-existing issues, and that they reflect the persistent health issues associated with long-COVID.
- Plain English is best for ease of understanding, avoiding words like “high-level” and “systematically”.
- There are many reasons why diagnoses may not be recorded in NHS healthcare records despite there being a need. This is important to consider in interpreting our results. Furthermore, our contributors have commented that long-COVID care is now being moved to ME-CFS clinics, which may further affect which diagnoses are made.

How we will use this information

We will continue to send our PPI contributors pre-meeting information. In addition, we will email our contributors with study updates in between meetings and provide information about available training.

We will include a plain English title and summary in our Statistical Analysis Plan which reflects the input of our contributors.

It is a limitation of our study that unrecorded diagnoses, diagnoses made privately, and diagnoses not given or sought despite there being a need, will be absent in NHS healthcare records, and it will be important to highlight this when writing up our analyses.

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 meet again in six months, and will email the contributors with any important study updates in the meantime.

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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.