

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

18th July 2024

Who we involved

Online meetings with members of the Bristol Young People's Advisory Group (YPAG <https://generationr.org.uk/bristol/>) were held on:

- 23rd May 2024 with 5 members aged between 12-14 years old
- 27th June 2024 with 6 members aged between 15-20 years old

Contributors were eligible to be selected for the meeting regardless of whether they have had COVID or long-COVID. An ELUCIDate researcher and a Patient and Public Involvement (PPI) facilitator led the meeting.

What input we wanted

The aims of the meeting were:

- to introduce the ELUCIDate study;
- to gain insight into whether YPAG members have experienced long-COVID themselves or know someone who has, and the members' understanding and knowledge of long-COVID;
- to answer any questions from YPAG members.

What we discussed

After introducing each other and the ELUCIDate study, the ELUCIDate researcher used polling software (mentimeter.com) to start the discussions. A summary of the five questions with answers is as follows:

1. *Do you know someone with long-COVID?*
 - **All contributors had heard of long-COVID**, but few 12-14 year old contributors knew someone who has had long-COVID. **Most of the older group knew someone who has or has had long-COVID.**
2. *How common do you think long-COVID is in people your age?*

- Contributors **varied in how many people they thought have been affected by long-COVID** in their age group, but **it was generally considered to be common** (between 3-10 per 100 students).
- These estimates were based on how many people they knew who had identified as experiencing long-COVID and included the whole range of symptom severity.
- It was also noted by the contributors that it is difficult to count how many people have long-COVID due to low reporting, different experience of symptoms, or not recognising symptoms as being due to long-COVID.

3. Name up to five long-COVID symptoms you can think of

- Sickness, sore throat, chest & body aches/pain, vomiting, cough, fatigue, shortness of breath, dizziness, loss of taste & smell, and 'flu symptoms (headache) were all noted as symptoms of long-COVID. Contributors also identified conditions such as diabetes and eczema.
- Out of these symptoms, **vomiting, loss of taste & smell, fatigue, and chest pain were considered to be important symptoms** to live with.
- Having a sore body was also thought likely to impact on energy levels.
- **Chest pain was discussed as a worrying symptom** and one that could exacerbate anxiety.
- Contributors also agreed that if all the symptoms were constant, like dizziness and shortness of breath, then this would have a **significant impact on engaging with activities**.
- Older contributors thought that some of these symptoms could be **easily dismissed by others** and not easily treatable ("can't do anything about it").

4. How long do you think someone is unwell with long-COVID for?

- Contributors from both groups thought someone could be unwell for between 7-12 months.
- Contributors thought being unwell for this length of time would be **very tedious and isolating** and would have a major impact on mental health.
- Older contributors recognised that time scale was difficult to measure due to different individual experiences. The **lack of timeline and "no end" was considered to be an important point of frustration**.
- Contributors suggested that **fluctuations in symptoms** due to weather, stress and overworking could be possible.

5. Use five words to describe what it would feel like to be unwell with long-COVID

- **Devastating, tired, depressing, painful and sad**, were used by contributors to describe how it could feel to be unwell with long-COVID.
- Older contributors identified the potential loneliness and isolation associated with being physically restricted and emotionally cut off from relationships through lack of understanding by others.

Additional thoughts

- Contributors thought that the inability to try new things and be social were very important as this would mean losing connection to people and things in their lives.
- They also noted that they'd miss out on their education if they were unwell for a very long time.

- Contributors thought that online and in-person peer support groups would help to maintain connection with others, while peer or teacher allies could help with support in school.
- Light exercise was also suggested to help with recovery.
- **Continuing with school was important** to contributors. A number of suggestions were proposed, noting the need to adapt these to the different needs of each individual. For instance, younger contributors suggested being able to do school work remotely, via online or recorded lessons. Contact with teachers to ask questions was also suggested.
- Older contributors weren't sure how schools could help, other than special considerations, especially if long-COVID was rare and only applied to a small number of students. However, general teacher training to recognise and support students who are struggling with long-COVID was considered important.

Summary of key points

Long-COVID was considered to be common by most contributors. Most older Bristol YPAG contributors were aware of someone who has had long-COVID. There was good understanding of long-COVID among contributors of all ages. All contributors understood that there was a range of symptoms that could be experienced when unwell with long-COVID and that these symptoms could fluctuate and last for a long time.

Furthermore, contributors thought that being unwell for a long period of time would mean an inability to be active and social, and that a loss of social connection would risk poor mental health. Loss of education was also mentioned as an important impact of being unwell with long-COVID.

Contributors suggested several things that could help those unwell with long-COVID, including teacher, peer and online support, access to virtual classrooms & support from schools, and light exercise/activity.

How we will use this information

The points raised in this meeting will be used in conjunction with those from groups of young people with long-COVID and their parents/guardians. Together, these opinions, experiences, and what is important to contributors will inform how we communicate our findings to children and young people affected by long-COVID, their families, doctors, schools, and the public. This is important to increase understanding of long-COVID and to ensure relevance to patients and their peer networks.

Next steps

This summary report will be sent around to attending YPAG members for comment. There will be no specific follow-up with this group of YPAG members. However, we plan to invite Bristol YPAG members to discuss the ELUCIDate study in future meetings.

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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.