

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

19th February 2024

Who we involved

An online meeting was held on 19th February 2024 with one teenager; Dr Katharine Looker from ELUCIDate; and Dr Carmel McGrath (Research Fellow in Public Involvement).

What input we wanted

The aims of the meeting were:

- to familiarise the new Patient and Public Involvement (PPI) contributor with the ELUCIDate study;
- to ask them about their priorities for research and anything they thought was important to share at this time;
- to discuss the ways in which the contributor would be involved with the study, should they be interested in being an ongoing contributor.

What we discussed

Our contributor said that she was infected with SARS-CoV-2 in October 2021 and that she'd "had a rough time with it." She has asthma (a chronic inflammation condition of the airways), and when reflecting on her symptoms during her SARS-CoV-2 infection she said, "my breathing wasn't very good, and my heart wasn't very good either." She returned to school after she recovered from her infection. However, a week later, she had to go home early as she couldn't concentrate, due to a migraine and visual disturbance ("the board was too bright, it was all too loud"). She went to her GP who said, "Oh we think you've probably got long-COVID." Our contributor said she only went to her GP once. She said that this GP appointment was the only time she really spoke to anyone about her long-COVID, as, "**I didn't know if anyone would understand what I was going through in that moment.**"

She said initially she had long-COVID for about six months. She said, "My legs...**I couldn't really walk upstairs very well or walk around very well.**" She said by the time she was infected with SARS-CoV-2 a second time, six months after her first infection, the symptoms had faded a bit. However, she continued to have "brain fog, really bad, and my legs still go from time to time, and sometimes I feel my heart it will suddenly start pounding."

Throughout, she has **managed her symptoms herself**. She took two weeks off school after her long-COVID diagnosis but has been attending school since then. She commented, “I just had to learn how to manage it and not complain about it as much (!).”

Summary of key points

- Our contributor is managing her symptoms herself and has only been to her GP once, despite describing some severe symptoms.
- Our contributor described feeling that no-one really understands the symptoms she is experiencing.

How we will use this information

We will produce evidence-based information on long-COVID for children and young people with this condition and their families. Hopefully this will enable children and young people to feel supported and understand their symptoms better. As well as this, we will aim to produce information for schools and the general public, to increase awareness of long-COVID in children and young people.

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. In between meetings, email updates will be sent to contributors around once a month.

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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.