

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

14th February 2024

Who we involved

An online meeting was held on 14th February 2024 with one parent/guardian; their teenage son; an ELUCIDate researcher; and a meeting facilitator.

What input we wanted

The aims of the meeting were:

- to familiarise the new Patient and Public Involvement (PPI) contributors 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 contributors would be involved with the study, should they be interested in being ongoing contributors.

What we discussed

The parent/guardian said that her son was infected with SARS-CoV-2 in January 2022 and has had long-COVID for about two years. At the time of his first infection, he mostly had “gastric [symptoms], peely hands, fever...sleeping all the time”. In autumn 2022 he managed a term of school, but then in January 2023 he had a “really high fever” and his fatigue returned. His parent/guardian suspected he had become re-infected with SARS-CoV-2, although she said it may have been a different infection that caused his symptoms to reoccur. It was at this time that he also lost his mobility (he couldn’t walk properly).

The teenager said that their **personal priority for research was treatment**. Their parent/guardian said that doctors in A&E “didn’t do anything” so they had to “go down the private route in order to get treatment, and actually **some of them [private treatments] are helping**.” After the initial infection, they went to A&E “about four or five times” and each time, “they [the doctors] said we don’t know what’s going on, and then just leaving us”. The parent/guardian said, “It was really frustrating, I knew my child was really unwell and I wasn’t getting help anywhere.” Their GP made a referral to a paediatrician (a doctor who specialises in child illness), but with a six-month waiting time for an appointment, they went to a private

gastroenterologist (a doctor specialising in the digestive system) instead. The private gastroenterologist did various medical investigations which “ruled everything else out” and diagnosed the teenager with long-COVID and chronic fatigue. The gastroenterologist said he thought the teenager had post-COVID inflammatory bowel. He was put on a liquid-only diet for about a month, and also did pacing, (doing activities a little at a time, with rest in between) which meant that his symptoms improved.

However, he then lost his mobility. They went to A&E and he was told, “We think it’s just post-viral inflammation of muscles” and to take ibuprofen. The parent/guardian said, “**It was really shocking because I had a child that could walk, and then suddenly couldn’t**, he was crawling round the house, he was trying to pull himself up on the doorway...I was lifting him onto the toilet, lifting him into the bath.” The GP was, “really helpful, but couldn’t do much.” The GP subsequently made an urgent paediatric referral. At the paediatrician appointment they were told it was post-COVID but it was “almost like [the paediatrician] didn’t really want to know what was going on.” A blood test was performed for glandular fever but they were told “after that I’ll discharge you”.

At this point the family asked their GP and paediatrician for a referral to a long-COVID clinic. They also asked for a referral to occupational therapy, and saw a private physiotherapist in the meantime. They bought a wheelchair, mobility scooter and zimmer frame themselves. The parent/guardian said, “It felt like we were just being just left, no-one really was interested...**it just felt like he’d been forgotten about.**” School “rang once to see how he was” as he wasn’t attending school, and it took a year to get support from an online tutor. Up until then the parent/guardian had to home-school her son and email his teachers for work.

It took a year to get into an NHS long-COVID clinic, and when they did, “they only wanted to talk about the symptoms and didn’t have much to offer.” The parent/guardian said, “There’s loads of NHS long-COVID clinics, but...they just ask about the symptoms and then they just say, ‘Oh we’ll try to get you back in school,’ there’s no real plan there.” She said her son **kept being asked by a psychologist about anxiety and depression, which he didn’t have, and it was held within Child and Adolescent Mental Health Services, which was “really odd...[the doctors] thinking almost like it was psychosomatic [caused or made worse by a mental factor]...just labelling it...we found that frustrating ‘cos he certainly had physical symptoms.”**

She said they had also seen a rheumatologist (a doctor specialising in joint and muscle disorders) who said, “I think he’s just scared of walking.” She had replied, “What child just wakes up one day and just decides to crawl around the house?!” She said, “It just seems so blinkered...a lack of curiosity, they [doctors] just didn’t want to know, if they don’t understand something they don’t want to talk about it, it was really strange.” The parent/guardian is a GP herself: “**I thought being a GP that I’d be able to access help, and that hasn’t been the case...it just feels like a lot of gaslighting, no-one’s listening, no-one really wants to do anything about it.**”

With the private clinics, “they seemed to be following the research in other countries” and her son was prescribed three medications which helped his mobility. She commented, “**There is research out there and it is helping kids...[we need to be] doing something about them [the symptoms]...the longer they’re left, the harder it is to treat.**”

Summary of key points

- The severity of symptoms of long-COVID in children and young people can be shocking.

- Being able to access relevant treatment on the NHS is a key priority for our contributors.
- Our contributors said that research and treatments are available which can help children/young people with long-COVID. However, it is very difficult to access these through the NHS, even for those who are doctors themselves.
- Our contributors felt abandoned by the NHS and that doctors are often dismissive of long-COVID. They felt they had no other option but to access healthcare privately.
- Our contributors found that long-COVID clinics do not currently offer access to the range of healthcare specialities needed to treat long-COVID. Placing long-COVID clinics within paediatric mental health services is another way in which patients and their families feel that their experiences are being dismissed and invalidated.
- Our contributor described how his symptoms of long-COVID have interrupted his education and time at school.

How we will use this information

We will produce information on long-COVID for patients and their families, and for doctors, with the aim to include the types of healthcare needs for long-COVID. In doing this, we will need to be mindful of the healthcare needs which are hidden due to families accessing private healthcare, and from lack of appropriate NHS referrals. We are not able to fully account for this in our study, although we will try to produce an estimate of unmet healthcare needs.

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.