

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

24th January 2024

Who we involved

An online meeting was held on 24th January 2024 with one parent/guardian; their teenage daughter; an ELUCIDate researcher; and two meeting facilitators.

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 daughter was infected with SARS-CoV-2 in August 2021. She described how her daughter had been “really, really unwell for about three weeks” at the time of their first infection: “almost in a coma with a temperature...couldn’t move.” The daughter started getting better but a few weeks later began getting “chest pains, palpitations, nausea, feeling really tired.” The parent/guardian said they felt alone and that there was a lack of understanding of what was going on from their daughter’s school and GP. They said that they have **lots of questions about long-COVID** and don’t know how things would pan out over the next few years.

The parent/guardian said her daughter was embarrassed about explaining her long-COVID to her friends and classmates, as they “just think she’s a bit annoying (in a nice way)” as they **don’t really understand**, she’s not in school very much, and she “can’t do what they’re doing”. The parent/guardian commented that, “It’s really strange how some people are affected and others aren’t.” She said that no-one else in their family has long-COVID. She also didn’t know anyone else with long-COVID, although has since been put in contact with a couple of young people with long-COVID.

The parent/guardian said she thought her daughter had been infected with SARS-CoV-2 for a second time in October 2023, and that **re-infection had caused some of the symptoms which had stopped to flare up again**, such as fatigue and nausea: "It seems like it's getting a little bit worse over the last couple of weeks." She said it would be good to know if other people had experienced similar things, and what to expect. She said they are "learning step-by-step" and trying to "adapt and do what we can to help her recover."

When asked how helpful their GP had been, the parent/guardian said they had been "**quite lucky**". When her daughter had begun getting chest pains, palpitations, and other symptoms, the GP "immediately sent her to hospital for some checks" and it was then a case of, "over the next couple of months going backwards and forwards with the GP trying to work out what was wrong." She was referred to a children's unit at their local hospital with a "really nice consultant" who "**understood, was trying to help**". She was given different medications to try every few weeks but "**nothing was really working**".

Later on, the daughter switched to being cared for by a different consultant. The new consultant had a lot of experience working in a chronic fatigue clinic and "quite a lot of insights" so their advice was "quite different". Previously, the advice had been, "You've got to get through this, do more, keep pushing yourself," which the parent/guardian said had made her daughter far worse and meant she had spent "six months in bed not really being able to do much at all." The new consultant said that was, "completely the wrong advice, **it's all about pacing**". The daughter also saw a physiotherapist and, "It was very slow, but gradually [we] started to see little improvements."

Due to the lack of long-COVID clinics it was "**quite difficult to get a referral**" to see a long-COVID specialist. The daughter had a referral to Child and Adolescent Mental Health Services (CAMHS), but CAMHS had been unable to offer her support. The parent/guardian thought this could be because the service has such high demand. The parent/guardian commented, "It's always really difficult to get any support," and that if she, "hadn't been fighting for it all the time you just wouldn't get it." Since the daughter is now under the care of the long-COVID clinic, she doesn't go to her GP very often, and just has occasional meetings with the consultant.

Through the long-COVID clinic the daughter is assigned to multiple healthcare professionals including an occupational therapist, a psychotherapist, and a physiotherapist. The parent/guardian said the best part of being under the care of the clinic was having access to an "**amazing occupational therapist** who had "really helped us, especially with school." The involvement of the occupational therapist, "**made school take it much more seriously.**" She said that previously the school had thought, "[She] didn't really want to go to school, it was anxiety...they couldn't really understand." She said it was, "hard to get through to them how she was feeling. If you, I guess, saw her on a good day, you'd probably think she's completely fine, and then the next day she can hardly move...**people only see one side of things.**"

The physiotherapist has helped the daughter with pacing herself and helping her to do "little things that she could manage to get her back on track." She has had a few sessions with the psychotherapist to manage feelings that have arisen from having long-COVID such as anger and the feeling that no-one understood how her symptoms were affecting her.

The parent/guardian said school had been "fairly understanding" about not putting pressure on to get her daughter into school, although the school had "no...plan really in place," as her daughter was "a bit of an anomaly". She said home-schooling was not offered by the school, and going to school for maybe one or two lessons a week was "really, really difficult" as she'd

be “bombarded by other children who hadn’t seen her for ages” which was “really overwhelming”, the teachers “didn’t know who she was” and she felt “so far behind”. This overwhelming experience meant that she felt anxious and unwell afterwards. Eventually she was given a teach-yourself home-school package which she commented was “really hard when you have low energy and brain fog.” In the end, she was “really lucky” to be given separate educational provision within her school, although she is mixed in with children with behavioural issues and autism, which is challenging as they have quite different needs.

The parent/guardian said her daughter had a constant migraine for about nine months and struggled as “there was nowhere to get any information.” Through online support she had received **suggestions of treatments to try** from other parents/guardians whose children were experiencing similar symptoms. Her daughter subsequently tried hyperbaric oxygen treatment (breathing pure oxygen in a pressurised environment) which she did five times a week for three or four months. The parent/guardian said that, while it could be a coincidence, the migraine gradually got better until after about seven weeks of treatment it stopped completely which was “the best thing ever”. They kept going with the treatment and the daughter started to feel more like herself and “could cope with doing small things, she wasn’t in bed all the time.”

The parent/guardian commented that her daughter is “feisty” and “independent”, “manages things really well” and, “has just done brilliantly considering what she has had to deal with and how difficult it’s been.”

Summary of key points

- Our contributors told us that they have a lot of questions about long-COVID. They have also found that friends and school don’t understand long-COVID, and make negative assumptions. Much better understanding about long-COVID is needed.
- Our contributors found that SARS-CoV-2 re-infection made symptoms worse.
- A GP and consultant had been helpful and understanding for our contributors, but had not known what the best treatment is.
- It had been a struggle to get referrals, due to a lack of specialist clinics, overwhelmed services, and the need for persistence in requesting these.
- The long-COVID clinic provides useful access to multiple healthcare professionals for our teenage contributor. The occupational therapist had been particularly helpful in getting understanding and support from school.
- Our contributors found support networks connecting others with long-COVID very helpful for feeling less alone and for treatment recommendations.

How we will use this information

Long-COVID clinics potentially cover a number of different healthcare areas. This could be a potential challenge for our study in measuring the need for different secondary care services if multiple healthcare areas are “coded” under a single code i.e., it is harder to examine which exact areas are useful and utilised if they are all under the heading “long-COVID clinic visit”. This is something we will need to investigate further. We hope to look at the impact of re-infection with SARS-CoV-2 infection. We will produce information on long-COVID that is tailored for different audiences: patients and their families, doctors, schools, and the public, potentially working with schools to help them share information with young people to help with peer understanding.

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.