



Long COVID in children: A report summarising the views of young people, parents and doctors

'Long COVID' is commonly used to describe signs and symptoms that continue or develop after acute COVID-19¹.

Our study, 'Enhancing the Utilization of COVID-19 Testing in Schools', is looking at the characteristics of long COVID and COVID-19 infection in children. In this study, we aim to use data from the Bristol-based COVID-19 Mapping and Mitigation in Schools (CoMMinS) study¹, along with information from Electronic Patient Records, and the COVID-19 Schools Infection Survey (SIS)², to find out more about the characteristics of:

1. **long COVID in children**, such as how it is clinically recorded, treated and managed by the health-care system
2. **asymptomatic COVID-19 infection in children** compared to symptomatic infection, such as whether symptomatic infections are more likely to lead to long COVID
3. **COVID-19 re-infection in children**, such as whether multiple infections are more likely to lead to long COVID.

To help inform our research questions and methods, we gathered views about long COVID in children from young people, parents and doctors between 9 March and 30 April 2021. This report summarises the findings from:

- an online meeting with **seven young people** aged 13-18 years from the NIHR Bristol Biomedical Research Centre Young People's Advisory Group (YPAG)
- an online meeting **with five families** whose children, aged 10-16 years, have long COVID or suspected long COVID
- a survey completed by **four GPs and one paediatrician**, and an online meeting with **two paediatricians**.

We first summarise the key findings from all three groups taken together and what these findings mean for our study, and then present the detailed findings and implications from each of the three groups in turn.

Note: The interviews were conducted before the launch of NHS England's long COVID care pathways.

¹ University of Bristol, in partnership with Bristol City Council, Public Health England (PHE) and Bristol schools

² The Schools Infection Survey is jointly led by the London School of Hygiene and Tropical Medicine (LSHTM), PHE, and the Office for National Statistics (ONS)



Key findings

Diagnosis of long COVID in children

The COVID-19 pandemic is ongoing and we are at an early stage in our knowledge.

Clinical understanding of long COVID in children is currently extremely limited. Long COVID in children is not well defined, and it may be difficult for doctors to distinguish between long COVID and other conditions. We still need to understand whether long COVID is a new condition in itself, or a group of conditions like post viral fatigue, which we already know about.

For these reasons, long COVID is likely to have been under-diagnosed to some extent to date, although it is still unclear what exactly 'long COVID' in children means.

Symptoms of long COVID in children

Symptoms attributed to long COVID varied between the families we spoke to, and the symptoms their children had experienced were more wide-ranging than those listed on the NHS websiteⁱⁱ.

Of the symptoms listed by the NHS for long COVID, feeling sick or stomach pain, extreme tiredness, and headaches were the symptoms commonly ranked as most 'harmful' by young people and by families whose children have long COVID or suspected long COVID.

Asymptomatic infections and long COVID

Young people were concerned about spreading COVID-19 to vulnerable people without realising. The risk of health outcomes among children with COVID-19 infection might be overestimated if those events are more likely with severe COVID-19 infection, and severe infection is more likely to be diagnosed.

Re-infection

Re-infection in children seems to be possible but very rare. Nevertheless, how often re-infection occurs might be underestimated if infections are not always recorded. Young people thought that there needed to be more awareness of the possibility of re-infection. There was concern among the families about the impact of re-infection on long COVID symptoms.

What this means for our study

Looking more broadly at things like GP and hospital visits, and school attendance, might be a more useful and feasible way at this time of assessing how COVID-19 has affected children. However, we also need to be aware of things like the extent to which healthcare is accessed according to need, and absence from school due to self-isolation, which will affect what we are measuring. Also, we may miss the impact on children with milder symptoms.

Feeling sick or stomach pain, extreme tiredness, and headaches will be important symptoms to consider in our study.

We need to consider that some health measures, such as asymptomatic infection, are not always recorded.



Views of Young People's Advisory Group

We gave each participant a list of 20 possible long COVID symptoms, adapted from the NHS website.

We asked them to imagine experiencing these symptoms, then to rank them from most harmful to least harmful.

Eight young people completed the ranking. Seven of them joined a meeting, where we discussed how they had each ranked the symptoms and their reasons why.

As far as we know, none of the group had experienced symptoms of, or had been diagnosed with, COVID-19 or long COVID. However, some said they knew other people who had experienced symptoms of COVID-19 or long COVID.

Symptoms of long COVID

- Their rankings showed that feeling sick or stomach pain, extreme tiredness and chest pain were most commonly considered as being the most harmful, in theory.
- The young people thought these kinds of symptoms would be more harmful because they would affect their ability to carry out day-to-day activities, such as school work, paid work, sport and socialising.

“You’d really struggle to want to go out or make friends and keep those friends if they were often going out and you couldn’t because you didn’t feel well enough to do so. It would really impact your social life. And if you couldn’t make it to school it would impact your future because you couldn’t keep up with your schoolwork and keep your grades up”

- They thought that unfamiliar symptoms, such as heart palpitations or dizziness, would be more harmful or scary than symptoms they may have experienced previously with other illnesses.
- Most thought that milder but longer-lasting symptoms would have a greater impact on their quality of life than more severe but short-lived symptoms.

“The illness would make you unwell but the things you couldn’t do because of the illness would make you worse”

- Talking about symptoms that would limit their independence prompted some participants to express concerns about how the pandemic is affecting young people’s mental wellbeing.
- Feeling like the pandemic is “something we’ll never get away from” resonated with the group.

Asymptomatic COVID-19 infection

The young people worried about having COVID-19 without showing any symptoms, because they might pass on the infection to other people, especially those who were older or more vulnerable.

Possible long COVID symptoms:

extreme tiredness
shortness of breath
chest pain
memory problems
difficulty sleeping (insomnia)
heart palpitations (pounding, fluttering or beating irregularly, for just a few seconds or for minutes)
dizziness
pins and needles
joint pain
depression
anxiety
tinnitus (hearing ringing or buzzing from inside your ears)
earache
feeling sick or stomach pain
diarrhoea
loss of appetite
cough
headaches or fever
sore throat
changes to sense of smell or taste

“Someone my age could easily have it and spread it without even knowing.”

COVID-19 re-infection

Although they weren't worried about getting COVID-19 more than once, they thought that people generally needed to be more aware that it was possible to be re-infected.



What these young people want to know

The young people we spoke to said they would like to know more about how common long COVID is, how rates of long COVID vary between people of different ages, and what happens to people who have long COVID.

They also wanted to know about the rate of asymptomatic COVID-19 infection, compared to infection with symptoms, and the rate of re-infection – and again, whether these rates varied depending on age.



What this means for our study

Chronic debilitating symptoms such as sickness and fatigue are key symptoms to consider in our analysis. They would have a substantial impact on young people's physical and psychological wellbeing and affect their ability to carry out day-to-day activities like school work and socialising.



Views of families whose children have long COVID or suspected long COVID

We advertised the study to two online UK campaign groups for parents whose children are experiencing long COVID symptoms. Each family who responded received a survey asking them which of 20 possible long COVID symptoms their child or children had had – along with any other symptoms – and to rank the symptoms from most harmful to least harmful, based on their experiences.

Seven questionnaires were completed by five families (one Mum completed a questionnaire for each of her three children). These five Mums, each with one of their children ranging in age from 10-16 years, then joined a meeting to discuss their responses.

We couldn't reflect the individual experience of every family we spoke to in this report. Instead, we have tried to give a picture of their experiences as a whole, and think about what this might mean for our study.

We are also aware that their children's symptoms are likely to be at the more severe end of the spectrum, and that their experiences may not reflect those of other families with children who have long COVID or suspected long COVID.

Symptoms of long COVID

- The children were experiencing many, and often very severe, symptoms associated with long COVID.
- Their rankings showed that extreme tiredness, feeling sick or stomach pain, and headaches were commonly considered to be the most harmful symptoms. Severity tended to be the main reason for ranking symptoms as 'most harmful', particularly those symptoms which could be a sign of a life-threatening illness.

- One Mum commented that those symptoms which characterised active COVID-19 infection (in her family's case, this was fevers) were difficult to manage because it meant, "school constantly send... home and for COVID testing...we would permanently be self-isolating."
- The children were also experiencing many other symptoms that weren't listed on the NHS website. These included allergies and eye problems, cognition problems, problems with swallowing, weakness to the extent of being unable to stand, muscle twitches, swelling and pain in the fingers or toes, peeling feet, rashes, nosebleeds, urinary stress incontinence, testicular pain, breast pain and swelling, and vaginal or ovarian pain.
- The children experienced cycles or fluctuations of symptoms, seeming to be getting better but then relapsing.
- Some children were missing school due to ongoing symptoms.
- Symptoms were having a massive impact on the children's day-to-day lives, and on their families, both physically and psychologically.

"Some of the symptoms were so acute at the time, had us [meaning her daughter] doubled over in pain and were really concerning, like the acute breathlessness or really bad stomach pains. And then others were the things that perhaps weren't so severe but have been with us for so long that they have continued to have a domino effect, so things like the fatigue that interrupts socialisation, interrupts schooling, interrupts anything that you would want to do."

"Three symptoms of severe headache, severe abdominal pain and joint pains now, are not only physically debilitating but psychologically debilitating as well. So it's a double whammy."

Diagnosis, treatment and support

- Many of the children had not been tested for COVID-19 when they first had symptoms of infection, as testing was not widely available at the time.
- One Mum thought her family had been infected more than once, having first been diagnosed on the basis of symptoms only in March 2020, and then having one child test positive in November 2020 when her family all had symptoms again. The second time was apparently associated with a "massive surge" of long COVID symptoms.
- The GP had been the starting point for trying to access care for the children, with multiple early GP consultations (predominately by telephone) – one Mum noticed on her daughter's record that she had contacted the GP over 40 times about her symptoms.
- Three of the children had received a clinical diagnosis of long COVID from a healthcare professional, and two families believed their child has long COVID on the basis of their symptoms/experience (including other family members being affected and diagnosed).
- For those children that had been diagnosed, it had taken a long time to get this diagnosis. The Mums had similar experiences of being "patronised", "dismissed" or "fobbed off" by "sceptical" doctors. One Mum said she had felt she couldn't go to the GP at all for her daughter, especially as all three of her children had got long COVID, because of her own experience with trying to access care for her own long COVID. Another Mum said her son was also "under the radar".
- The picture that emerged was that it wasn't possible to keep going to the GP "all the time". Instead, the families had to "accept" that they should only go to the GP with the most severe and worrying symptoms.

“We saw a GP then, again she just thought it was something viral that would pass. I suggested COVID-related but she was adamant it doesn’t affect children.”

“The GP I have to say was really helpful except that she had no idea what to do because there wasn’t any care pathway. She kept saying: ‘There’s no care pathway for children with long COVID’.”

- The types of secondary care services the families had accessed and tests they had been given had been very variable, and again, getting these had been a lengthy struggle.
- It was mentioned that three children had been referred to a paediatrician. One had received an electrocardiogram (ECG), chest x-ray and blood tests as a result.
- One child had been referred to the Gastro Department, although she had been previously diagnosed with coeliac disease so was already known to the service. She was given a chest x-ray which showed lung damage so was referred to Respiratory under the Children’s Hospital. She was subsequently given an ECG, lung function test, CT scan of her lungs and blood tests. She has now been referred to the chronic fatigue team.
- Another child had been seen by a cardiologist and been given an ECG and echocardiogram, been referred due to hives, and been referred to Ophthalmology.
- Two Mums mentioned an oxygen saturation test being done. One child had been referred for physiotherapy.
- It was mentioned that one child and one sibling had been hospitalised at least once as a result of long COVID, and that two children and one sibling had visited A&E at least once.
- One child had been referred to a long COVID clinic which was “essentially...the chronic fatigue clinic”. Another had been “shut down” about long COVID clinics, while another was told, “They’re not for children.”

“He did an ECG and also a lung function test there and then, and also referred her for a CT scan of her lungs and an echocardiogram and various bloods, but even then he was still saying: ‘Long COVID is very rare in children. I want to do all these tests to check because there probably might be something else going on’. It wasn’t until we’d had all the tests done that he said: ‘I think you’re probably right, it is long COVID, we’ve ruled everything out’.”

- Three of the Mums said they were reluctant to continue to push for care for their children because they were worried about coming across as a “neurotic, troublesome woman” or a “hysterical mother”.



What these families want to know

The families we spoke to had lots of questions which they thought should be researched. These included:

- why symptoms such as fatigue, breathlessness, gastrointestinal symptoms, and joint pain and swelling, and neurological symptoms such as ‘brain fog’, are experienced, and how they can be treated
- whether the virus persists in the body
- why it has affected their children in particular
- whether re-infection can make long COVID more severe
- what the long-term implications of long COVID on health and the body are.

What this means for our study

The families' responses highlight issues that our study needs to consider:

- **The number of children with long-term health outcomes of COVID-19 infection may not be accurately reflected by the number with a long COVID diagnosis.** Only some of the children who took part in our survey had had a clinical diagnosis. And, as not all symptoms may be listed in patients' electronic health records, using symptom reporting to identify long COVID cases may also be difficult. It is likely that the families we spoke to were experiencing symptoms at the more severe end of the spectrum. Families with children with milder symptoms may not present to their GP at all. At the same time, it is not clear what is meant by 'long COVID' in children. Many had also experienced 'unusual' symptoms and it is not clear what is causing these symptoms.
- **Some COVID-19 infections will not have been recorded, affecting the measurement of long-term health outcomes.** Testing was not routinely available early in the pandemic when many of the children we heard from were infected. Asymptomatic infections, milder symptomatic infections and re-infections in particular may be under-recorded. The risk of long-term health outcomes among children with COVID-19 infection might be overestimated if those events are more likely with severe COVID-19 infection, and severe infection is more likely to be diagnosed. We need to consider how we define the 'exposed' group (the group with the cause under investigation) and how we define the 'unexposed' group when measuring the risk of long-term health outcomes. Data from antibody tests (which demonstrate whether someone has been infected in the past) may be useful.
- **The numbers of children recorded as having referrals, tests or treatment for long COVID symptoms may under-represent need.** Not all parents of children with long COVID symptoms will have been able to access treatment.
- **It might be difficult to determine the average length of long COVID currently.** All the children still had long COVID symptoms, with many getting new symptoms over time. It's also difficult to know when children with long COVID have recovered because so many symptoms are experienced, and the long-term effects may not have been seen yet.



Views of doctors

We sent a survey to GPs (via the mailing list for the University of Bristol's Centre for Academic Primary Care) and paediatricians (via University of Bristol contacts) in Bristol asking them about their professional experiences of long COVID in children. We received five responses: four from GPs and one from a paediatrician (a paediatric infectious diseases specialist).

We're aware that not all those who responded saw patients every day. Their responses might also be different to those we might have got from doctors in areas with different COVID-19 infection rates.

Symptoms and diagnosis of long COVID in children

- The small number of GPs we heard from said they hadn't seen any cases of long COVID in children and young people, although two said they had seen cases of extreme tiredness in children which was associated with COVID-19.
- The paediatrician had seen infrequent cases (referrals to outpatient clinic) of extreme tiredness, difficulty sleeping/insomnia, dizziness, cough, headaches and fever. They thought that extreme tiredness and difficulty sleeping/insomnia may best characterise long COVID in children and young people, and that extreme tiredness has a significant impact on this age group.

“Parents are worried about prolonged low-grade fevers, children feel tired.”

- Current clinical understanding of long COVID in children and young people seems extremely limited. Long COVID was thought to have affected different children in different ways but also to be not yet well defined. Their answer to most questions about long COVID was that it’s much too early to say.

“I think GPs are still getting their heads round long COVID in general – never mind in kids.”

- They thought there might be an association between long COVID and conditions such as chronic fatigue.

“There is lots of anxiety around it and there is little experience to be 100% reassuring.”

- The doctors didn’t seem to think re-infection was a clinically important concern on the basis of it being considered rare.

Two paediatricians from outside the Bristol area also took part in an online meeting, where we discussed research priorities for our study, and what issues we might encounter.

- They commented that it wasn’t yet known whether long COVID is a condition in itself or a group of conditions. They also commented that it isn’t consistently recorded in health records.
- They thought that as post viral fatigue and other complications are possible with viral infections, it was possible that long COVID symptoms could be explained similarly.
- Rather than having a predetermined idea of how long COVID presents in children, they felt we should keep an ‘open mind’.



What these doctors want to know

The paediatricians we spoke to thought that exploring the following questions might help us better understand long COVID in children:

- When did long COVID in children first start being seen and recorded, and what is the pattern of long COVID diagnoses over time?
- What symptoms do children with long COVID have, and can these be attributed to other conditions?
- What diagnoses, GP and hospital appointments, and school absences have children with long COVID had, both previously and subsequently?
- Is there any association between long COVID in children and things like social factors, ethnicity, and parental health? Do cases tend to cluster within families?



What this means for our study

The doctors’ responses highlight issues that our study needs to consider:

- **It might be difficult to accurately count the number of children with long COVID.** Long COVID in children is currently poorly understood by doctors. Even the clinical definition is not yet defined. It might also be difficult to separate out long COVID and other conditions.
- **Looking more broadly at symptoms, GP and hospital visits, and school attendances, would be useful at this time.** These may give us a better picture of how the COVID-19 pandemic has affected children, especially while long COVID in children remains poorly defined.

ⁱ <https://www.nice.org.uk/guidance/NG188>

ⁱⁱ <https://www.nhs.uk/conditions/coronavirus-covid-19/long-term-effects-of-coronavirus-long-covid/>

Acknowledgements

We would like to thank our participants for their valuable contribution. The study is funded by Health Data Research UK (HDR UK) under the “Rapid funding call to use and enrich the data within the Data & Connectivity National Core Study (NCS) capability”. Participants from the Young People’s Advisory Group and participating families were paid at an hourly rate of £22 for attending the online meetings and completing the surveys. Funding for participant reimbursement came from the NIHR Bristol Biomedical Research Centre. The views expressed are those of the authors and not necessarily those of the NIHR, the NHS, the Department for Health and Social Care or Public Health England.

