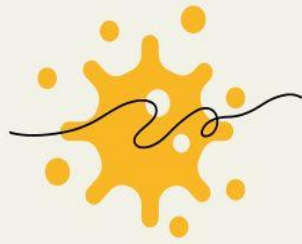


**covid
made
long**



A research project with young people
looking at Long Covid and the long-
term impacts of COVID-19

Young People and the Long Covid Experience: Lessons Since the Early Years of the Pandemic

An Evidence Submission to the Covid-19 Inquiry

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This summary report

This summary report is an evidence submission from the NIHR funded “Covid Made Long Project” led by the London School of Hygiene and Tropical Medicine in collaboration with Imperial College London and Long Covid Kids.

This summary report was prepared by the Covid Made Long study team, comprising: Professor Tim Rhodes (LSHTM); Dr Hannah Cowan (LSHTM); Zaira Clarke (LSHTM); Praveena Fernes (LSHTM); Sammie MacFarland (Long Covid Kids); Viveka Ortega Guzman (Imperial College London); and Professor Helen Ward (Imperial College London).

This summary was coproduced in collaboration with young people living with Long Covid, including an advisory group of 11 young people who contributed as peer researchers to the Covid Made Long Project.

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Background

This submission to the COVID-19 Inquiry is based on **evidence of lived experience** from research funded by the NIHR. This research was undertaken by the London School of Hygiene and Tropical Medicine in collaboration with Imperial College and Long Covid Kids (Contact: tim.rhodes@lshtm.ac.uk).

The aim of this research has been to document, using qualitative interviews, young people's experiences of Long Covid, as well as of COVID-19 and the pandemic.

We have **interviewed 72 young people aged 15-25** in the UK. The first interviews were carried out between January-November 2024, with follow-up interviews undertaken with 30 young people between May 2024 -February 2025.

The study included young people who received a diagnosis of Long Covid from a healthcare professional (n=23), young people experiencing persistent COVID-19 symptoms and self-diagnosed as Long Covid (n=15), and young people who describe persistent and ongoing health effects related to SARS-CoV-2 without attributing them to Long Covid (n=16). The study also captured young people's wider health and wellbeing experiences linked to the pandemic (n=18).

This research project is known as the 'Covid Made Long Project'. This is because a key objective is to map the **ongoing impacts** of Long Covid as well as the **enduring impacts** of COVID-19 and the pandemic in young people's lives.

We summarise evidence in relation to five key themes, based on the accounts of young people:

1. The ongoing challenges of Long Covid
2. Multiple lasting impacts of physical and mental health
3. Not being heard
4. Informal care is vital yet fragile

1 The challenges of Long Covid

Research has noted the social, mental health and economic impacts of the pandemic in the lives of young people.¹ There remains, however, a **need to attend to the particular and pronounced challenges of Long Covid**.² Young people experiencing Long Covid face particular challenges, which have likely been under documented due to the difficulties in gaining diagnosis. **The unfolding effects of Long Covid combine with the social and economic impacts of the pandemic more generally.**

Long Covid can be life changing

Young people in our study explained in detail the life-changing and ongoing impacts of Long Covid in their lives. Here, a young person describes Long Covid as "upending" and as "hellish":

"Who I was prior to Long Covid and who I am now are quite different things [...]. Before the pandemic, it was great, I was happy, I was healthy, I was living a normal life, I was just a normal kid [...]. And then when I got ill, that's when like everything changed [...]. I went from being able to go to school, being able to play tennis and stuff, to being virtually bed bound [...]. I don't leave the house. I can't leave the house. I can't leave the house other than to go to hospital appointments in a wheelchair, and even then it's hard [...]. [It] is tumultuous, up and down, hellish [...]. It has been a real ordeal, life changing, life upending,

like nothing has remained the same [...]. I'm now 17, and it's been a rollercoaster since I was 13". [Aged 17, P4]

Young people also described the multiple physical symptoms linked to Long Covid, which unfolded over time, and which have not gone away:

"Initially it was like cold, flu symptoms [...]. Three weeks later it just kind of all hit me [...]. I was exhausted [...]. I couldn't really do anything for myself anymore, so I had like friends dropping off shopping and things like [...]. I was having migraines. I felt like I couldn't get out of bed. Suddenly a lot of what I was eating was giving me really bad stomach issues, yeah, nerve pain and like muscle spasms [...], really bad nosebleeds, like all the time [...]. Most of those symptoms [persist] still to this day." [Aged 23, P8]

Young people described "intense" periods of illness in the first year of being diagnosed Long Covid that rendered them bedbound and which have lasting psychological, as well as physical, impacts:

"It was like a domino effect, different things keep occurring in my body [...]. I couldn't get out of bed to go to the doctors [...]. I knew I had had Covid, so I knew that the symptoms that I was experiencing was lingering on from that, but I wasn't aware of like how bad Long Covid could be [...]. I felt like I was *dying* [...]. It was the most insane experience I've ever gone through [...]. When I was bedbound, I genuinely thought that my body was like slowly dying [...]. The biggest symptom is like a really severe fatigue, so it's like trying to walk under water when you have like loads of waves trying to push you different directions and you're trying to walk straight. Or like you have like a hangover, you have the flu, you have all these different things all at the same time, like it was just so *intense*. [Aged 25, P73]

For many, the physical impacts of Long Covid are still ongoing. Below, a young person describes how the physical symptoms of Long Covid can feel never-ending:

I was in the fourth year of, and final year of [higher education], when I fell ill, so September 2020, with Covid [...]. I remember finding it hard to move, but it was very different having that in the acute stage [...]. Tightness in the chest, chest pain, and fatigue are always the three symptoms [...]. The doctors were good, they didn't give any update, they said [...]"You've been ill for three months, probably another three months". In the next appointment I had in the three months after, they said, "Oh you've been ill, oh I don't know, nine months, probably give it another nine months" [...]. And now, "Oh, you've been ill four years, ah, we don't know" [...]. I may recover in a few months, even though I haven't in five years, or I may recover in another, I don't know, 50 years, when I'm 76, or I may never recover." [Aged 25, P69]

Whilst government policy in the pandemic has focused on getting children and young people back to school,³ and has coincided with ideas that children and young people are unlikely to experience harm from SARS-Cov-2,⁴ we have documented evidence to the contrary. For many of the young people in our study, SARS-Cov-2 had intense impacts on their health and for several of them these are still ongoing.

Long Covid diagnosis

The scale of the physical impacts of SARS-Cov-2 on children and young people is further complicated by **Long Covid often going undiagnosed**. There can also be uncertainties about how to make sense of the various persistent symptoms linked to SARS-CoV-2.

In addition to those diagnosed, we interviewed young people who reported ongoing physical symptoms, but were not formally diagnosed with Long Covid. Here, a young person reflects on their ongoing

symptoms which they do not know whether to call Long Covid, despite the symptoms persisting after an acute COVID-19 infection and affecting their everyday life:

“The like intensity of it [COVID-19 infection] went away, but the effect that it had on me didn’t really go away for like quite some time. I had to have like loads of chest x-rays, and tests [...]. It seemed like no-one really knew [...]. It is, it was still such a new thing, in 2021 [...]. I was being affected by it for such a like long time afterwards [...]. Respiratory took me on [...] But like all of the tests that they’ve done have not really been like what they expected to find, because like it is so different with it being Covid, not their typical like asthma [...]. Then speech and language therapist, they’re getting involved as well. But no-one seems to really know at the moment [...]. Like coming up to three years since I had it.” [Aged 20, P45]

For this young person, the uncertainty they experience in the present moment relates to their past experiences of medical uncertainty and of fragmented care in the early years of the pandemic. Similarly, another young person talks about the uncertainty of diagnosing their chronic fatigue and respiratory problems which have persisted since their SARS-CoV-2 infection:

“I had it for months, this extreme fatigue, where I just couldn't do anything. I couldn't do anything without like then needing to sit down and have a nap [...]. I do feel like I'm not the same person that I was before I had it [...]. Since having it, like I've just, it'll kind of get to like 10am and I'll crash, and then like I'm really struggling like with my day, and, like I said, my chest, my chest has been bad since. Like now, I've literally just had a chest infection, well, it was a lung infection for three months, and I'm like, I never used to have it.” [Aged 25, P22]

The uncertainty of diagnosis operated across different organ systems, illustrating how the multi-system impact of Long Covid makes it difficult to receive holistic care within a healthcare system divided into organ-based specialities. Below, a young person talks about the diagnostic uncertainty of their ongoing heart problem following SARS-CoV-2:

“I've just got to kind of wait until the big bosses up in cardiology can think of something else or whatnot. I'm still in the process of tests and tests and tests [...]. Obviously it upsets me with like my heart and everything, because certain things like I struggle with, like going up flights of stairs, and it's just rubbish, it's rubbish, like my heart, feeling like it is actually beating out of my chest [...]. I'm really, like I'm young, I shouldn't be having to experience things like that.” [Aged 18, P30]

Our interviews with young people who describe ongoing physical symptoms since infection with SARS-CoV-2, but who are not formally diagnosed with Long Covid, suggests that the actual burden of the condition may exceed what is currently reflected in official figures.

Precarious Futures

Young people living with Long Covid are facing especially **precarious futures**, with **insufficient social support to help them navigate these challenges**. The **multiple and extended impacts of Long Covid and the pandemic alter life transitions and potentials** by **limiting opportunities for work, education, or training**.⁵

Young people in our study described how their experience of illness has made the future more ‘scary’ and unknown:

“The past two years have been really difficult, because I just feel like I'm finding my feet again as this like completely different person [...]. Like everything about me has changed completely, and I don't know if that's Covid-related, or if that's just because, you know [...]. I did nearly die [...]. It's scary. I think the older I become the more I feel like I've just got to get on with it, and less support is actually available [...]. I just, I try not to think about the future, because it just scares me. I think if you'd asked me that before Covid, I would have reeled off like a list of things that I wanted to do and I wanted to achieve and what I wanted to be, and now I just don't know. Like I think it is part of that, like me just taking every day as it comes.” [Aged 23, P46]

The uncertainties of economic future in the face of Long Covid are a particular concern:

“Job-wise I am absolutely terrified to try and get a job because I cannot actually guarantee I'm gonna be there every day, because of how bad the energy levels are, and because of the pain I sometimes experience [...], I feel like I'd probably have no chance to be hired or I'd be fired immediately.” [Aged 18, P23]

Alongside this, young people affected by Long Covid feel that they have become disadvantaged in relation to their chances of getting work:

“There have been a couple of times when doing interviews the conversation will come up “do you have any health conditions which we should be aware of?” So I talk about it there because it's a thing of yes they should be aware of it because it could be an issue [...]. They're understanding in the moment but [...] I think it's something that probably does count against me in terms of getting work unfortunately.” [Aged 22, P43]

The economic uncertainties of Long Covid are amplified and extended for some of our participants by pre-existing chronic ill health, making the future even more insecure:

“I think being someone disabled anyway I think has impacted my experience with Long Covid [...]. I already wasn't great financially because I've never been able to do the whole, oh, just get an extra like just side job [...] I've always had to end up going part-time because of my disabilities anyway and just live off less [...]. That puts you at like a more difficult position to then, if you're already at part-time and then you get a new chronic illness, where does that leave you, where can you go next?” [Aged 25, P40]

Delayed transitions into the world of work also affect young people's wider sense of wellbeing and contribution to society:

“What does it mean to get back to work, when you've never been fully in work [...]. I was still in a really busy conservatoire, so yeah, gigging a bit, but in terms of being out in the world of work, and then fell ill before that happened [...]. The language around employment [...] it's about your wellbeing, and how good it is for you to be able to see other people and feel active, and feel like you're providing something to society [...]. There can sometimes be an undercurrent of how do you make you not a dead weight.” [Aged 25, P69]

A further commonly voiced concern is reduced access to education and learning, and how this compounds precarious work futures:

“Looking forwards, with the health and the general safety of the world going to University would be very difficult for me. Even if I'm well, it would be very difficult if I have to wear a mask and not go into places because, you know, how can I flat-share with people if I'm

wearing a mask? I would love to go to University, I'd like to study computer science at university, and I'd then like to take that on into the world of work, so I hope in the future I can go and join in with things normally and work, or learn [...]. Also, there's the thing of university costs, you know, they're going up a lot, and as someone with Long Covid it's, you know, it's hard to find paid work [...]. If I wasn't doing school, I could probably find a job, but because I have to use all of my energy on school, I can't then use energy on earning money much. [Aged 16, P27]

Two of the young people above (P23 and P69) further emphasize their sense of precarious future in relation to family life and becoming parents:

"I don't think I could give a child a very good life at all, because they need to play, they need to interact with me, and they need to be able to know that I'm there for them. And I will always be there for them but I feel like I kind of like neglect some of their needs because I am like really ill, and just don't have the energy to, and I feel like it would be unfair to rely on my partner to constantly do that for them when I will be their mother, so I've just planned on not having kids at all." [Aged 18, P23]

"I'm [...] 26. I fell ill when I was 21. At what point will I be 30 and unwell, will I be 40, will I never recover? Dysautonomia when I looked it up was a lifelong condition. I have no idea of these things, but it's completely out of my control. It's very scary. I want to have a family. The idea of being a father, feeling anything like I'm feeling now, I couldn't bring a child into this world, knowing that I have responsibilities to care for them. The love that I would have for them, and if I feel barely able to exist in myself, and feel like I'm existing, I couldn't [...]. I hope that to have a family, but that is a very scary thought." [Aged 25, P69]

2 Multiple lasting impacts

The experience of the pandemic for young people has produced **multiple enduring impacts**, including in relation to both mental and physical health.⁶ These extend beyond the early stages of the pandemic, and continue to shape young people's lives today.

Pandemic impacts

The main concern around children and young people in the government's pandemic response was the impact of pandemic measures on young people's mental health and wellbeing.⁷ We heard from young people within our study who were impacted in this way. Here, for example, a young person who has not experienced Long Covid, and whose SARS-Cov-2 infection had little impact on their health, describes the far-reaching effects of the pandemic, especially in terms of mental health:

"Not being melodramatic, but the pandemic has probably been the worst experience of my life. So I don't like to dwell on it, but school during Covid like has such a negative, it's such a negative memory for me [...]. Covid never impacted my health, but it just took a big toll on my mental health [...]. I never left my room, and I was stuck in this room [...]. I just spent my entire life at my desk for 2 years [...]. I remember the first time I left my house after like 4 months, I remember stepping outside and thinking, this looks like a video game because I'd forgotten how the real world looks [...]. Every now and then I realise, oh yeah, this thing would be so much better if Covid had never existed [...]. I have those moments when it all comes crashing down on me. It just kind of feels like this is all Covid's fault and then it kind of just comes crashing back in." [Aged 17, P31]

Below, another young person talks about spiralling mental health concerns rooted in the early years of the pandemic when social media narratives promoted the pandemic as a time to work on fitness goals:

“I was like the happiest person , and then Covid happened, and then over the past few years it’s been a continued struggle to the point where now like I’m on medication. It would be like all of these really harmful posts [...]. ‘Pro-anorexia’ posts as well were massive again [...]. Then I think that was the first thing with my friend, she went into hospital for an eating disorder [...]. By the time I’d started recovering, then my friend died [...]. By the time I’d gone back to school I was in and out of appointments constantly, I was in and out of hospital constantly, and they dealt with it really badly.” [Aged 17, P6]

The isolating impact of lockdown sometimes amplified situations of precarity, impacting on young people’s present lives as well as their futures. As one young woman explained, the experience of isolation led her into situation of abuse and precarious housing:

“I think for me Covid and lockdown destroyed my self-confidence. [...] The start of 2020, I moved away from my family. I moved in with an ex-boyfriend [...]. I lived with my nan at this point and I barely saw her. I spent 90% of my time feeling sorry for myself in my bedroom. But I guess my entire reason for getting in that relationship which didn’t turn out brilliantly was the fact that I felt so lonely and so stuck. [...] We stayed together until 2022 but he just, in the nicest way possible, was an arsehole. [...] When I explained the situation of our relationship to the Council, the lady that I saw at the time said that he was financially abusing me [...]. I had to file a homelessness application because my nan wouldn’t take me back.” [Aged 23, P12]

Pre-existing situations of precarity intensified the impacts of lockdown, and extended their duration. During lockdown, one young woman found herself calling *Shoutline* in part because of feeling unsupported at home linked to problems of addiction in her family. Her experience of lost taste and smell linked to her SARS-CoV-2 infection intersected with an already fragile situation to impact on her mental health:

“I experienced loss of taste [...]. Everything tasted differently [...]. Just anything I had, like I was throwing up after every meal as well, so I did lose quite a lot of weight. [...]. Me losing weight made me fall into like an eating disorder [...], which was like, it was more like a bulimic thing, because I’d see that like me throwing up because of Covid made me lose weight, I like began to like continue that like pattern [...]. Like, say I didn’t have Covid, I wouldn’t have fell into that pattern.” [Aged 18, P17]

As illustrated by this young person’s experience, what might **seemingly look like ‘small impacts’ resulting from SARS-Cov-2 infection**, such as the loss of taste and smell, **can go on to have big and lasting impacts**, such as unhealthy changes to relationships with food. As she explains, “one bad year of Covid carried on as more bad years”. This indicates the way in which **physical impacts of SARS-CoV-2 on young people can amplify social effects of pandemic**. This can result in enduring impacts for those **already in more precarious social situations**, such as those in care, in low paid jobs, with multiple ongoing conditions, or without immediate access to care and support.

Long Covid intersecting with pandemic impacts

As we noted above, the **multiple and lasting impacts of SARS-CoV-2 and the pandemic are at once physical and social**. Moreover, they can be **more pronounced for young people experiencing Long Covid**. The experience of Long Covid not only **extends the physical impacts of SARS-CoV-2** but **further amplifies the social and economic impacts of the pandemic**.

Here, for instance, a young person with diagnosed Long Covid reflects on the **added challenges** of living through lockdown and the early pandemic years at university:

“I didn’t really know anyone outside of my housemates just because I literally had no kind of way to meet them [...]. I think they knew of me but didn’t really know each other. So, in that regard it was quite isolating, because everyone would sort of say like ‘Oh like we’re the uni year that, you know, started with Covid and all these lockdowns, we didn’t get a normal fresher’s, we didn’t get a normal year’. And all this, and that’s true, but I was sort of thinking ‘But you’re not going through *this* [Long Covid] you all still seem to know each other, you still seem to be doing things’. Like, I would have loved to be in their position.” [Aged 23, P50]

Many young people with physical impacts of Long Covid, also experienced mental health impacts from their experience of pandemic. Below, a young person’s account illustrates how her Long Covid intersects with the anxiety and self-harm that she experienced during lockdown:

“They’d mentioned it was Long Covid and I kept just, I remember, I even still do it to this day, but the weeks leading after that I used to be just passed out on the floor, and I’d just always cry, and I’d be like, why me, I’m so young? At this point I was 15 [...]. So I was in hospital, obviously, for this, when my heart was 197 [beats per minute], and there was this girl screaming and crying and I was just so like, I was just so agitated, and my dad just turned to me and he went ‘Oh, maybe she was like...’, because she was screaming like ‘Get off me, you can’t make me stop’, things like this, so my dad just turned to me and went ‘She’s probably just harming herself’. And it was a very flippant remark from my dad, but it obviously made me feel, I, at the point in lockdown where I was having those intrusive thoughts, it was a lot to do with suicide and self-harm, and there were two things that I just, even if I saw the word written out, it would really trigger me and put me back in that place.” [Aged 18, P52]

As highlighted by this young person’s experience, different aspects of physical and mental health linked to COVID-19 and those from the pandemic **can be felt all at once**, including in ways that are disorienting and hard to make sense of.

Long Covid also has social impacts

The **physical impacts of Long Covid also have social effects, which can amplify the negative influences of the pandemic**. In the following account, a young person talks about how their ongoing symptoms of Long Covid coincided with lockdowns during the early years of the pandemic which impacted on their social life and relationships. They describe becoming “isolated” and their “childhood slipping away”:

“It was a lot of monotony [...], doing the same thing every day for weeks on end, not really able to go out [...]. I really like sort of going out in the outdoors and going camping and I couldn’t do any of that [...]. Yeah, rough, rough time [...]. I spent a lot of the time in my back garden, you know, spending time with my friends online, just trying to sort of keep myself, yeah, sane [...]. It was so bleak because it was not, I wasn’t really getting better, it was just sort of the same, you know, timeless. My childhood was pretty much just slipping away, and I couldn’t do anything about it [...]. It severely impacted my sort of time to make friends at [secondary school] with new people [...]. For a long time I was very isolated [...]. No one had really heard of me [...]. We had Covid, and then I had Long Covid, you know, just sort of a blip where no one really knew I existed.” [Aged 16, P37]

Some of the young people we spoke to describe a sense of 'lost personality', which they link to the social impacts of Long Covid as well as to their efforts to manage chronic fatigue and the risks of re-infection:

"It feels like I've lost my personality, which is a really bizarre scenario because I'm having to find new things that I like that I might not fully think relates to me, but I just have to sort of accept it because I don't have energy to like do all the things that I actually want to do [...]. Even if I get like a cold or whatever, like it does set me back, so I do avoid places that are like crowded and things." [Aged 25, P73]

Particular symptoms, such as brain fog, can also lead to particular kinds of social impacts. Below, a young person describes how Long Covid at once **produces physical and social impacts which taken together can affect "every aspect of life"**:

"I can speak but my words don't come out, and I've never had an issue with like speaking before, like I was always very like confident and talkative at school, and now I'm just not at all [...]. I'm so anxious about this stutter, and then just my brain, like my memory's absolutely terrible [...]. It won't absorb any new information. So anything that I learn, after like a couple of hours I just don't know. So it's really difficult with that [...]. It's actually made my like dyslexia almost worse, because I'm really struggling to just learn new information and understand things [...]. It's just affected me in every aspect of my life, to be honest, like work, study, friends, family, like literally everything." [Aged 23, P46]

There are also social impacts for those who do not have a diagnosis of Long Covid, but who experience physical effects of SARS-CoV-2. The young person below, for example, was told by their GP they had Long Covid but was also told that they did not meet the criteria for care at a Long Covid Clinic. They describe how the ongoing symptoms of chronic fatigue are a 'strain on relationships':

"My physical health [...] is so like unpredictable [...], especially if I like make plans and then I have to like cancel last minute, or not like having the energy [...]. I think like people found that quite difficult. And I found it like frustrating as well, like finally felt able to make plans with people, and then like it came around to it, and I didn't want to let people down, but I didn't feel up to it. So, that definitely has been like quite straining on my relationships." [Aged 20, P45]

Long Covid and pandemic impacts create a 'looping effect'

Young people living with Long Covid are **having to navigate the combined physical and social impacts of Long Covid alongside contending with the broader social and mental health impacts of the pandemic**. This creates a **'looping effect'**, where the **physical impact of Long Covid, and social impacts of illness and of pandemic feed into each other and deepen the challenges experienced over time**.

As one young person describes, **impacts of Long Covid extend into, and entangle with, mental health challenges**:

"I never had any kind of struggles with mental health before I got Long Covid, prior to 2020 [...]. Depression, I've definitely struggled with that, just because I'm constantly in the house, like feeling really rubbish every day, which takes its toll after 3 years. And I have virtually lost everything that I previously like held as my identity. So yeah, it's a big life shift, and I think you'd be superwoman not to have some sort of mental health challenges that come with it." [Aged 17, P4]

When appreciating how SARS-Cov-2 and the early years of the pandemic have enduring effects which affect young people's lives now, **we must give particular attention to how Long Covid amplifies and extends illness and pandemic experiences.**

Here, a young person emphasizes how physical symptoms linked to SARS-Cov-2, other health conditions, and social and economic insecurity **can all come together**, in a 'looping effect', including in uncertain ways, to **make the future more precarious**:

"I don't know whether it would be Long Covid but I do wonder because [...] I do find my sort of mental stamina is less [...]. I think the thing that's difficult for me is that I get things like brain fog and body pain and fatigue in extremes because of fibromyalgia [...]. It just sort of I think underscores all the things that care leavers already face like not having the bank of mum and dad [...] somewhere to run to [...]. I always try and have my own back and carve out the future that I best can [...]. There is that fear of what if my health like physically or mentally gets in the way of that, and I can't work for a little while, or I'm not giving it 100%." [Aged 23, P10]

This 'looping effect' illustrates the importance of providing holistic care for children and young people in response to pandemic as well as in response to illness linked to SARS-CoV-2. Whilst Module 8 of the Covid Inquiry is largely orientated around the mental health impacts of pandemic on young people, there are important and potentially under-reported physical impacts that also warrant attention. Policy responses need an integrated approach given how the physical and social impacts of both pandemic and of illness combine to create a precarious situation.

3 Not being heard

There is clear evidence that young people experiencing long-term effects from COVID-19, including Long Covid, felt they were not being heard during the early years of the pandemic.⁸ Young people experiencing Long Covid describe themselves as **being "dismissed", as well as "gaslighted"**. Many say that their illness symptoms – especially of fatigue and brain fog – were **trivialised or not taken seriously** by helping professionals, and often **misinterpreted as anxiety or worry**. Young women, for instance, describe how they were treated as if being "dramatic", "anxious", and "hysterical". There is evidence of young people's lived experiences being discounted and doubted. Here is one example:

"I remember being sat in this doctor's office and honestly being near tears, because I was like 'I'm not being believed [...] she's not trying to help [...] you can see she's not even believing me' [...]. I still remember that day and being so like distraught when I came out because I thought no-one was ever going to believe me, and maybe this was my fault". [Aged 17, P4]

Young people explained that part of the reason why they are not being heard is because **care systems are fragmented**. A common experience is **being bounced around** by different services; an experience which can be exacerbated in the case of Long Covid:

"My GP did a referral [...]. And then Long Covid Clinic couldn't take me on [...]. I was referred to Respiratory Clinic, and Respiratory Clinic said it's a Long Covid issue [...]. I seemed to just be like, going back and forth, and no-one really wanted to like take me on [...]. I do think if I had like an official label of Long Covid, then I would be offered more support." [Aged 20, P45]

Young people who were not being taken seriously by medical services, or who felt their illness was being trivialized or misinterpreted, also **felt the need to hide the impact of being chronically ill on their mental health**:

“I’ve been really, really reluctant to mention anxiety, even the word to doctors because I’m kind of terrified that they’ll hear me talk about anxiety and think that everything that I’m displaying is anxiety, like the heart palpitations and the breathlessness when I’m like “no, they are symptoms in and of itself, they are not anxiety related” [...]. We eventually had to bring it up [...]. I’ve put off going on anxiety meds all these years because I was so scared and I think they would have really helped if I’d gone on them earlier.” [Aged 17, P4]

The **mental health impacts of illness and of pandemic in some cases are going undeclared** so as not to undermine young people’s efforts to get their Long Covid and ongoing physical illness taken seriously:

“I think a lot of people avoid [talking about mental health] entirely. Just because they don’t wanna, you know, I think it’s hard if you know your body, and you know that something’s physically wrong with you. But you can’t prove that unless they do the tests, but then sometimes to get them to do the tests, you kind of have to present yourself in a certain way.” [Aged 2, P8]

There is a **failure to see health linked to COVID-19 and the pandemic as multifactorial**,⁹ which means that young people’s **care becomes fragmented**:

“Every time we went and mentioned Long Covid they just seemed to be like, “Ah yes, it’s in your head, it’s anxiety, go away.” We didn’t mention it this time, and we just focused on that [subclinical hyperthyroidism] [...]. As soon as you don’t mention it, they’re like, “Okay, well we can treat this problem, then we can treat that problem” [...]. If they actually saw it as the one big problem, they might be able to actually help people more or quicker, because they can see that something has to be triggering everything”. [Aged 18, P23]

The **prominent narrative in the early years of the pandemic that young people are relatively unaffected by SARS-CoV-2 has made it difficult for young people experiencing ongoing related illness to be taken seriously by medical professionals**:

They actually said to me in hospital that kids don’t get Covid, like not Long Covid, just the virus. [...] I was hospitalised in August 2020 for 4 days, I had a rash, I fainted, I was sick, I had a temperature of 40 degrees for 5 days, I [...] was on a drip, they didn’t know what was wrong with me at all, I had every test under the sun. I had brain scans because they were questioning whether I’d had a stroke. I had nausea, I nearly fainted twice in the hospital. [...] it was just them constantly running tests and being like well we don’t know what’s wrong with you. [Aged 17, P7]

Still not being heard

Importantly, the early pandemic **experiences of not being heard, of not being believed, and of having difficulties in navigating fragmented care systems, have not gone away**. This is especially the case for young people living with Long Covid. This can create a **situation of exhaustion**, exacerbated by post-viral chronic fatigue itself. Being told repeatedly by medical professionals that “you are the expert” can become felt as a form of “negligence”. There comes a point when young people may even give up on seeking formal care. Here is one such example:

“It wasn’t like I was constantly exhausted all the time or whatever and then I had Covid [...]. There is a distinct difference between like my fatigue levels, like my muscular levels now,

and things like that [...]. I've basically stopped doing that [going to the doctor] over the past year. I've got to the point now I can't be arsed with them anymore. I'm being generally bluntly honest there. I've got pushed back so many times for different things or the whole [pause], there's nothing there to support you." [Aged 25, P29]

Many young people feel that **the lessons of the early pandemic years are not being learnt**. For those still experiencing health issues related to COVID-19, **government and institutional policies which emphasize a 'return to normal'** – for instance, by undoing protections like face-masking or slowing down efforts to introduce HEPA filters into school, work and health care environments¹⁰ – further **extend the sense of not being heard** and of not being taken seriously. This can lead to frustrations and feelings of social injustice whilst living with Long Covid:

"Institutions and schools and governments want people back in the offices [...]. It goes back to the media peddling of "They're just lazy, they don't want to get in, they're just anxious" [...]. They don't want to test [for COVID-19] because if they test they'll figure out we're not anxious, so then we have to be at home, so then they'd have to actually set something up for us. But they don't want to because it costs money [...]. They've got air filters in the Houses of Parliament, you know, at the World Economic Forum [...], but when it comes to schools they'll never do it [...]. My own school, even after the school, you know, wore masks in communal spaces for a year and a half, but the headteacher still doesn't know what they do. No wonder people with Long Covid are being picked on for trying to keep themselves safe when the general public literally have no idea what any of these things do." [Aged 17, P7]

The circulation of 'return to normal' narratives also have wider social impacts to young people's lives, including its influence on popular views which can lead to bullying:

"They sort of say loudly to their friends, 'Oh, why's he wearing a mask'? Or, 'Take off the mask, it's 2024!' [...]. 'Covid's over', you know, which is really difficult [...]. A lot of people don't want to be told that it's still a thing, because for them they had to not go to cafes and go to the cinema and you know, wear a mask, and so I think a lot of people just don't want to kind of think that it's still around [...]. Especially with the sort of messaging from the Government about it, that they as good as said it was over, and there was no cautions needed. And so I think the one thing that I'd really like would be for more people to be educated about Covid and Long Covid and to understand." [Aged 16, P27]

This illustrates how young people's ongoing experiences of chronic ill health following COVID-19 can be minimised by government policy and surrounding narratives which seek to place the pandemic and SARS-CoV-2 in the past.

4 Informal care is vital yet fragile

The lack of formal health care and support available¹¹ means that **young people and their carers have pieced together informal networks to try to fill the gaps of fragmented and broken care systems**. Here is an example:

"I've been like in and out of A&E without any like support really [...]. I was just dismissed with like no answers like whatsoever [...]. They didn't even mention Long Covid as a possibility, so everything that I know about my health is because I've researched it and like discovered myself [...]. Facebook groups was my introduction to the fact that there was so

many people that also were struggling with this [...]. Once I saw these people were telling their stories about what they have, and what supplements they've taken, or what results they've had from the doctor and things, I was able to like figure it out that way." [Aged 25, P73]

Informal care is **vital but itself fragile**. Many parents and carers, for instance, have had to take time off from work in order to care for their loved ones, which has created **financial and other pressures for households**:

"It's felt a lot, like me and my parents, so my mum and dad, against the world. Like we've had to fight for healthcare, and schools and stuff [...]. My mum has also taken like a lot of sick leave and she's probably going to take early retirement [...]. She's basically my full-time carer now [...] I need like meals cooked for me, I need my like, all my washing and my bed, and stuff like pretty much everything done for me [...]. Obviously her work has taken a huge hit [...]. It's just been, I think hugely stressful for them, and hugely upsetting for all of us." [Aged 17, P4]

Sometimes the absence of available support means there's no other option but to try and find ways to self-finance their care, even when money is tight. The young person, below, for example, talks about how her family had to finance her wheelchair:

"When I came out of hospital there was absolutely no help for us at all [...] We got no help from anyone for a wheelchair [...]. My parents were both on furlough at the time, so we ended up having to put a wheelchair on the credit card for me, just a basic one. It was about 100 quid, but it was still debt, because the local GP said they wouldn't help me." [Aged 17, P7]

The challenges of seeking out or providing care can make life precarious for young people and their families. A common theme is that young people talk of **the "exhausting" efforts of trying to access healthcare, education, or financial support, which can feel like "a constant battle"**. Here, for instance, a mother of a young person reflects on their efforts to seek accommodations at college in light of their son's chronic fatigue and other illness effects of Long Covid:

"The second year at college, they basically said, 'we don't think you are medically fit, we suggest you withdraw' [...]. I did write quite a long email, wasn't it, and said that they hadn't followed their policies and procedures but unfortunately I had pneumonia at the time, so I didn't actually fight too much that one." [The mum of P66 [aged 19]]

At times **the constant fight to seek accommodations or care can end up becoming a 'losing battle'**:

"I needed bloods taken [...]. We [P4 and parents] requested them done at home and we were denied because apparently I don't qualify as housebound [...]. I can't leave the house other than to go to hospital appointments in a wheelchair and even then it's hard [...]. We ended up having to go to the hospital [...]. Every day is still a fight [...]. We had to like go back and forth for months trying to get them to do it, and eventually just gave up." [Aged 17, P4]

The **fragilities of informal care within families becomes especially acute when multiple family members are navigating Long Covid illness and are in need of care**. This creates a sense of household **precarity**, linked to the reduced capacity to work and earn, as well as the challenges of the family to provide informal care to one another:

“The impact on the family life has probably come from my dad having to stop work [...]. We’ve been on benefits for a bit [...]. My mum’s got a job as well but yeah, three kids [...]. We’re getting by, yeah, not swimmingly, but we’re getting by [...]. It was a bit more uncertain in between the time when work stopped paying dad’s sick pay and when mum got a job [...]. She’s had to do a lot more obviously without dad being as able as he was, she had to do quite a lot more of the general stuff, like around the house and taking us to everything we do.” [Aged 17, P15]

Young people in this situation also have the additional responsibility of caring for family members whilst navigating their own health and wellbeing linked to the pandemic. Here, a young person living with Long Covid is talking about caring for his mum who also has Long Covid:

“If she’s feeling particularly fatigued I, I’ll make her drinks, I’ll make her food. She wears compression stockings but, so I have to, she can’t get them off on her own so I have to take those off for her every day [...]. I help her make dinner in the evenings, I wash up with my sister in the evenings.” [Aged 16, P27]

The challenges of providing informal care to family members overlaps with precarities elsewhere, feeding into the looping effects of physical and social impacts of pandemic described above. As one young person describes, the need to pace himself in light of Long Covid, his experience of becoming a carer for his mum, and the experience of family breakdown during lockdown all looped in together:

“My mum at the time got diagnosed with Stage 2 or 3, I can’t remember, breast cancer [...]. I was doing a lot of the caring for her alongside my studies and everything, and it was a lot of overextending myself more than I probably should have [...]. Me dad [...] had spent from around the time she first got ill he’d started going on online dating, had a bit of a second life and the second she got the all clear he left her. [...] around the time I had Long-Covid is around the time they split up, so it was quite, it was like a double whammy, so it was quite heavy-going at points because both of them were trying to get me to act like a personal therapist.” [Aged 22, P43]

The informal care young people receive, including within families, is also made precarious by **a common narrative, especially in the early days of the pandemic, that positions young people as relatively unaffected by COVID-19.** Here, a young people living with Long Covid talks of breakdown within their family, and specifically with their father, linked to differences in view about the risk and impact of re-infection within their home:

“I had to try and explain to my dad, while literally not even being able to sit up, like what he needs to do [...]. [Getting reinfected] is hard, because he doesn’t wear a mask when he’s out, like me and my mum [...]. He doesn’t truly understand like how hard Long Covid has been for me” [...]. We still live with my dad, but he doesn’t get involved, because he doesn’t really believe that I’m like that ill, which is shocking because you literally see me every day, you’re kidding, anyway... [We] just stay separate, we just keep to ourselves, which sounds awful because we’re living in the same house, but we just like, if you’re not going to get involved, don’t get involved then, that’s fine, you have it your way.” [Aged 17, P7]

The lack of understanding of illness experience that is encouraged by government narratives, can limit access to care and support within young people’s households:

“My dad relationship is shaky [...]. For the first year, I wouldn’t say he was very supportive, no, he didn’t really understand my condition, and he didn’t really even try and ask me about

it. He just sort of thought I was lying and wanted to get out of school, and I'm like "I'm not, I like school, but I can't go in." [Aged 18, P23]

The **sense of dismissal, and of not being heard, that young people describe of their attempts to seek care from services** early in the pandemic (See Section 1 above) **runs parallel with a more generalised narrative which undermines or belittles young people's experiences of ongoing illness**, especially Long Covid. Informal care becomes difficult to navigate in the face of such persistent scepticism:

"Some people when they see young people who are practically healthy, externally look healthy, if you try bring, or mention Long-Covid they kind of go "Ooh, you look perfectly healthy, what are you on about? There's nothing wrong with you. Why are you saying you've got that?" [...]. I've definitely had conversations with family and relatives where my experiences with Long Covid are kind of "Oh it can't be that bad, you know, it can't be that bad."'" [Aged 18, P23]

This illustrates how informal care is vital but fragile. Part of the fragility is brought about by weak infrastructures for Long Covid support and care for young people¹² which combine with a lack of recognition of how COVID-19 can impact the physical health of children and young people.¹³

Lessons for the COVID-19 Inquiry

The COVID-19 Inquiry seeks to learn from the early years of the pandemic in order to improve future responses. The Inquiry is looking back at young people's experiences of SARS-CoV-2 and the pandemic and in doing so, actively places the pandemic in the past. Our study is showing that **COVID-19 and the pandemic need addressing in the present**. This is because **there are enduring multiple impacts linked to SARS-CoV-2, the pandemic, and Long Covid, which affect young people's everyday lives in lasting ways**.

The evidence we have summarised above highlights four points of learning for the Inquiry.

Long Covid amplifies pandemic impacts

Long Covid has multiple consequences in relation to young people's physical and mental health as well as social life. At the same time, **the multiple impacts of the early years of pandemic have not gone away**. They continue to shape young people's lives today and into the future, and can be life-changing. In the experience of Long Covid, **there is a 'looping effect' where the ongoing physical, social, and mental health impacts of illness and of pandemic intersect and make each other worse**. This makes the ongoing impacts of SARS-CoV-2 and the pandemic **especially pronounced for young people experiencing Long Covid**. There are many other young people who describe persistent symptoms from SARS-CoV-2 who are not diagnosed with Long Covid. These young people describe how the uncertainty of their persisting symptoms can **amplify and extend** the multiple physical as well as social impacts of SARS-CoV-2 and the pandemic in ways which **make their everyday lives and futures more precarious**.

Long Covid makes futures precarious

It is important therefore to recognise how SARS-CoV-2, Long Covid and the pandemic produce **distinct multiple impacts in relation to both physical health and social life**, which **endure** for young people. In addition to health, the intersections of physical illness with the pandemic have created **precarious futures** for young people in relation to work, education, societal inclusion, as well as family and social life. Future policies need to prevent young people's physical and mental health being seen as separate or in opposition. Policies need to acknowledge the multiple impacts that the pandemic can have on young people in the immediate and long term.

Young people do not feel heard

Many young people, especially those experiencing long-term and lasting impacts of SARS-CoV-2 and pandemic, **feel that their experiences are inadequately heard**, including by helping professionals and care systems. A key learning from the early years of the pandemic is that **the voices and experiences of young people with Long Covid went unheard, with care and support fragmented**, and with care systems lacking the capacity, as well as expertise, to respond to the multiple (physical, mental and social) needs of affected young people. There is a danger that policy efforts seeking to 'return to normal' fail to properly learn from the early years of the pandemic, or even extend their failures, if we do not learn from how young people's lived experiences of Long Covid have been left unheard.

Informal support is vital yet fragile, and on its own not enough

In the face of fragmented care systems in the early years of the pandemic, **networks of informal care have played a vital role** in supporting young people with Long Covid. Informal care has also **enabled young people's illness experiences to be validated and for young people to be heard**. They continue to do so now. Young people themselves, as well as their immediate significant others, are critical actors in creating opportunities for informal care and support. This is especially the case given the instability and limits of formal service responses. While vital, **informal care networks are fragile**, in large part because they rely heavily on those most affected by illness. A systemic and sustainable care response cannot, and should not, rely on informal care and support to 'plug gaps' where there is inadequate provision. A key learning from the early years of the pandemic for the future is the **need to create capacity and infrastructure for the provision of social support for young people that goes beyond formal service settings** and that is part of a **synergistic and systemic sustainable care response**.

Conclusion

The above four points of learning from the Covid Made Long research project emphasise the ongoing and lasting effects of the COVID-19 pandemic and persistent COVID-19 symptoms in young people's lives.

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For more information

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