Expert Report for the UK Covid-19 Public Inquiry

Module 8 - Children and Young People

Long COVID in Children and young people

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Author statement

We confirm that this is our own work and that the facts stated in the report are within our own knowledge. We understand our duty to provide independent evidence and have complied with that duty. We confirm that we have made clear which facts and matters referred to in this report are within our own knowledge and which are not. Those that are within our own knowledge we confirm to be true. The opinions we have expressed represent our true and complete professional opinions on the matters to which they refer.

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Preamble

1. Elizabeth Whittaker is a Professor of Practice in Paediatric Infectious Diseases and Immunology, MB BAO BCh MRCPCH DTM&H PhD.

2. In 2020 she was a consultant in paediatric infectious diseases at Imperial College Healthcare NHS Trust in London where she was the clinical lead for high consequence infectious diseases in children. She was the Convenor of the British Paediatric Allergy Infection and Immunity Group. She was invited to be a member of the Expert Review Group for COVID for the Royal College of Paediatrics and Child Health (RCPCH). In these roles, she was responsible for the writing and dissemination of national guidelines on the management of Covid-19 in children. In April 2020 she led the publication of the first paper describing the emergence of a post SARS-CoV-2 multisystem inflammatory condition, and she became involved in national and international research in the field of post Covid-19 conditions. This led to inclusion in the NIHR Funded Long COVID in Children and Young People (CLoCK) research team. In October/November 2020, she was asked by NHS England to lead a task and finish group to establish services for children with persistent symptoms following SARS-CoV-2 infection. Working closely with colleagues including Terry Segal, she co-led these services for three years, sharing learning nationally and internationally through webinars, teaching, guidelines and publications.

3. Dr Terry Segal is a paediatric consultant with a special interest in adolescent medicine and paediatric endocrinology, MbChB, FRCP. She has worked in the field of complex adolescent work, including fatigue conditions such as chronic fatigue syndrome (ME/CFS) and functional conditions since 1999 and has been an adolescent consultant since 2007 at University College London Hospital (UCLH). She was convenor of RCPCH affiliated young person's health special interest group (YPHSIG) 2018-2021. She is joint lead for Transition and developmentally appropriate healthcare for UCLH and previously North Thames Paediatric Network. She led the Treatment and rehabilitation of adolescents and children with complex conditions at University College London Hospitals NHS Trust (UCLH) for many years, before becoming Clinical Director for adolescent specialties in CYP division at UCLH in 2020. She was invited to join the NHS England run task and finish group in November/December 2020 to establish services for children with persistent symptoms following SARS-CoV-2 infection. Working closely with colleagues including Elizabeth Whittaker, she co-led these services for 4 and a half years, sharing learning nationally and internationally through webinars, teaching, guidelines and publications. She jointly set up the pan London Post COVID service in 2021, the largest in England, where she continues to work clinically to support young people and their families with post Covid-19 conditions,

together with a multidisciplinary team. She was appointed CYP representative for the national Post COVID society in 2024. She has published several peer-reviewed articles on post Covid-19 conditions and was included in the NIHR Funded CLoCK research team. She is currently working on publishing the 3 year follow up data for the Pan London Post COVID service.

4. This is an addendum report to that provided by Professors Christoper Brightling and Rachel Evans on Modules 2 [INQ000280198] and 3 [INQ000421758] of the UK Covid-19 Inquiry.

How Long Covid usually presents in children

5. Long Covid (LC) in children and young people (CYP) is a condition that is caused after infection with SARS-CoV-2 virus. It presents heterogenously and over 200 symptoms have been reported across nine body systems. The National Institute of Health Research (NIHR) funded Long Covid in Children and Young People (CLoCk) study showed that 27.6% of SARS-CoV-2 test-positive children and young people had three or more physical symptoms 6 months post test vs 15.9% of test-negative children and young people. In this study, test positive means they had a positive SARS-CoV-2 test and test negative means they have not had a positive SARS-CoV-2 test. Although the diagnosis of Long Covid does not require a confirmed episode of SARS-CoV-2 infection, testing at the time of this study was commonplace, and isolation with symptoms normal practice. However, some of those who did not have a positive test may have had an asymptomatic episode of SARS-CoV-2 infection and not been tested. The most commonly reported symptoms are fatigue, headache, sleep disturbance, cognitive dysfunction ('brain fog'), abdominal pain, nausea, myalgia (muscle aches) or arthralgia (joint aches), post-exertional malaise, and symptom exacerbation, congested or runny nose, cough, chest tightness or pain, loss of appetite or weight, disturbed smell or anosmia, and rash. Mood is commonly affected. Tics and functional neurological disorder (FND) have been noted. Some patients' mobility is affected, and they become 'newly-disabled' and reliant on a wheelchair for mobility, or in the worst cases bed bound. Multiple and fluctuating symptoms are a hallmark of the condition. This list of symptoms is not exhaustive and many other symptoms have been reported in the literature. Importantly, an impact on daily functioning is a key factor in diagnosis and can be debilitating (for example impacting educational attendance, mobility, self care, homelife or friendship relationships). Some patients are very severely affected, and unable to conduct activities of daily living (such as self care), have reduced mobility, and are unable to speak for more than a few minutes. Of the patients coming to NHS services, most likely reflecting the severe end of the spectrum of Long Covid in children and young people, the majority were attending less than 50% of school and many were out of all education.

6. Children and young people presenting with LC often present similarly to myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) and in addition, there appear to be different patterns of symptoms (ways that it affects individuals), as seen in ME/CFS. For example, some have headaches and tiredness, others have abdominal symptoms such as nausea and pain and others have muscle and joint pains. The median age of LC appears to be lower (13 years) (Goddings, 2025) than ME/CFS (13-15 years) (Rowe, 2017), however it is possible that delayed diagnosis of ME/CFS is a confounding factor. Symptoms that may distinguish LC from ME/CFS include shortness of breath, chest pain, rashes and other skin complaints, anosmia/parosmia (abnormal or absent sense of smell) and Covid toes (chilblain-like painful lesions). Over the past 5 years, symptoms such as the rashes, shortness of breath and Covid toes have reduced, and the clinical picture is more similar to ME/CFS. Early as yet unpublished findings from the world's largest study into the genetics of ME/CFS (Decode ME, 2025) pinpointed eight regions of the human genome that were substantially different in people with an ME/CFS diagnosis compared to those without the illness. The discovery suggests that several variants of genes commonly found in the population raise the risk of developing the illness, though many people will carry the variants and never acquire the illness. Their findings suggest that both immunological and neurological processes are involved in the genetic risk of ME/CFS. While many symptoms are similar, the researchers found no genetic link between ME/CFS and Long Covid.

7. There has been an emerging international recognition that these patients commonly suffer from autonomic nervous system dysfunction, such as postural orthostatic tachycardia syndrome, or benign tachycardia, explaining postural symptoms, dizziness, and palpitations. The mechanisms for this are not well understood and include a direct effect of the pathological processes on the autonomic nervous system, or possibly fatigue induced immobility over time.

8. Unlike adults, end organ damage (acute pulmonary embolism, myocarditis and cardiomyopathy, venous thromboembolic event, acute and unspecified renal failure) is rarely/uncommonly seen, and there are very few patients with sequelae of hospitalisation due to severe SARS-CoV-2 infection causing disease (Covid-19). Children and young people may experience impact on a number of body systems including the neurological, endocrinological, autonomic nervous systems.

Presentation differences by age group

9. The mean age seen in the Pan London CYP LC service (and consistent with ages reported by other NHS services) was 13 years (range 6-18 years), with clusters of younger children

aged 9-10 and older adolescents. The youngest child presenting to the NHS services was 6 years of age and we do not have clinical experience of caring for patients younger than this. However, in the literature, a recent study comparing symptoms in 472 children 5 years of age and under who had SARS-CoV-2 infection, with those not known to have SARS-CoV-2 infection, identified that 14% and 15% of children who had SARS-CoV-2 infection aged <2yrs and 3-5yrs respectively, had persistent symptoms that could be consistent with LC. They reported distinguishable patterns in both age groups, (such as poor appetite, trouble sleeping, wet cough, dry cough, stuffy nose for infants/toddlers, and daytime tiredness/sleepiness/low energy and dry cough for preschool aged children), distinct from those seen in older children and adults (Gross, 2025). Ongoing follow up of this cohort will hopefully provide further clarity on the long-term impact on their developmental progress. This study highlights the importance of raising awareness with primary care and paediatric colleagues, and indeed all health professionals and appropriately investigating persistent symptoms in children of all ages. There are always challenges in assessing young children who are either non-verbal or unable to articulate their symptoms and listening to parents or carers who are advocating on their behalf is key.

Comparison to other chronic post-viral conditions

10. In April 2020, a cohort of children were identified, initially in England, then internationally, presenting with a novel multisystem inflammatory syndrome 2-6 weeks following SARS-CoV-2 infection. This was known as Paediatric Inflammatory Multisystem Syndrome Temporally associated with SARS-CoV2 (PIMS-TS, named by the RCPCH, UK), Multisystem Inflammatory Syndrome in Children (MIS-C, named by the US Centre for Disease Control (CDC)) and Multisystem Inflammatory Disorder in Children and Adolescents (named by the World Health Organization (WHO)). They presented with symptoms similar to Kawasaki disease (fever, rash, red mucosa (eyes, lips, tongue), lymphadenopathy), but also with marked abdominal pain, and concerningly 50% had multiorgan failure, myocardial dysfunction and shock requiring critical care support. Blood markers showed profound inflammation. The median age at presentation was 9 years (Whittaker, 2020). At 6 month follow up of patients with PIMS-TS, the biochemical and clinical inflammation had resolved, there was minimal functional impairment, echocardiogram (heart scans) had normalised, but in some cohorts, 20% reported emotional difficulties, although 98% were back in full time education (Penner, 2021). Overall although PIMS-TS was severe during the acute phase, most recovered quickly and had reassuring longer term prognosis. Although a very tiny proportion of children and young people with PIMS-TS/MISC have persistent symptoms, these have not been associated

with end organ damage, and in particular cardiac investigations (Echocardiography, MRI heart) normalise within a few months of admission.

11. Kawasaki disease is a multisystem inflammatory condition that predates Covid-19 and presents in younger children (median age 2.7 years). Although shock is described in some children with Kawasaki, this occurs more rarely than in children and young people with PIMS-TS. In addition, there were other differing biochemical features to PIMS-TS in a study comparing large groups of children with PIMS-TS, Kawasaki, and another inflammatory shock condition called Toxic Shock Syndrome (Whittaker, 2020). It is most likely that Kawasaki disease follows a viral or bacterial infection, but as the children likely present after they have cleared the infection, it is very hard to say what the trigger was. It is possible that SARS-CoV-2 may be one of the triggers of Kawasaki disease. The long-term complication of Kawasaki Disease, coronary artery aneurysms (CAA; swelling of the walls of blood vessels in the heart), which occurs in up to 25% of patients who are not treated, is not a feature of PIMS-TS or Long Covid. Although some children with Kawasaki disease develop CAA, these are usually asymptomatic, but can cause heart attacks later in life (Jone et al, 2024).

12. The difference between Long Covid and PIMS-TS/Kawasaki disease is the very high levels of inflammation that can be measured with blood tests in PIMS-TS/Kawasaki disease. We have not seen measurable raised inflammatory markers in patients with Long Covid. In addition, the majority of patients with PIMS-TS and Kawasaki disease make a full recovery without persistent symptoms. There have been a paucity of mechanistic studies of Long Covid in children and young people which may demonstrate inflammation not measured by current routinely available laboratory investigations, such as are emerging in adults (Liew et al, 2024).

13. Some children with LC are diagnosed with postural orthostatic tachycardia syndrome (PoTs) - it seems that SARS-CoV-2 infection may be a trigger or exacerbate pre-existing symptoms. PoTs is when your heart rate increases very quickly after getting up from sitting or lying down, often making you feel dizzy or lightheaded, and can include other symptoms such as headache. The pathogenesis is unclear and treatment is largely supportive, with the minority requiring medical management. PoTS is under the umbrella of autonomic nervous system dysfunction, which also includes diagnoses such as postural hypotension (low blood pressure) or tachycardia (fast heart rate).

14. Distinct from LC, in the first year of the pandemic, there was a suggestion that SARS-CoV-2 infection triggered Type I diabetes mellitus (T1DM) in children. In a recently published meta-analysis (taking all of the published studies on this topic and analysing all of the data

together) it was shown that the risk of new-onset T1DM following SARS-CoV-2 infection in children and adolescents was 42% (95% CI 13%-77%, p = 0.002) higher compared with non-Covid-19 control groups (Rahmati et al, 2023). The risk of developing new-onset T1DM following SARS-CoV-2 infection was significantly higher (67%, 95% CI 32%-112%, p = 0.0001) in children and adolescents between 0 and 11 years, but not in those between 12 and 17 years (RR = 1.10, 95% CI 0.54-2.23, p = 0.79). A RR or relative risk of 1 means it is no different from the comparison group, as it goes above 1, the risk gets greater. However, it was noted that the higher risk for developing new-onset T1DM following SARS-CoV-2 infection only exists in studies from the United States (RR = 1.70, 95% CI 1.37-2.11, p = 0.00001) but not Europe (RR = 1.02, 95% CI 0.67-1.55, p = 0.93). Furthermore, this group found that SARS-CoV-2 infection was associated with an elevation in the risk of diabetic ketoacidosis (DKA) in children and adolescents compared with non-Covid-19 control groups (RR = 2.56, 95% CI 1.07-6.11, p = 0.03) (Rahmati et al, 2023).

15. It is possible that SARS-CoV-2 infection accelerates the progression of disease in children with presymptomatic T1DM - as has previously been described with other viruses, such as enterovirus. This may be through the induction of islet cell autoantibodies (attacking proteins or antibodies, against the cells in the pancreas that make insulin) in children who are already predisposed through their HLA genotype (a genetic pattern that increases the risk for autoimmunity, but does not mean you will definitely get it). It is not clear why there is a difference between the US and European data. The risk for diabetic ketoacidosis may be partly related to delays seeking medical attention and challenges accessing healthcare during lockdowns.

The developmental impact of Long Covid in children

16. Adolescence is a crucial period of development and includes biopsychosocial changes such as puberty and growth, development of complex abstract thought, pruning of the frontal cortex and experimentation in order to learn and develop, and separation from parents and core family towards peer groups and relationships. These three areas are intertwined, for example, if you are house bound, this impacts experimentation and results in persistent parental dependence compared to a typical healthy adolescent, which affects development of separation and independence skills. In the NHS clinical cohort, which is likely to reflect the more severe end of the spectrum of illness, with higher number of symptoms and more severe symptoms than those in the CLoCK study, 75% of children and young people were attending education less than half the time, and 20% were out of education completely (Goddings, 2025). This impacts both educational attainment and development, and worryingly contributes to the development of 're-entry phenomena'

associated with anxiety which many struggle to overcome to return to education. Decreased social interaction, despite social media contact with friends, impacts on experiences and social development of adolescents.

17. The pandemic and its restrictions negatively impacted adolescent mental health at a population level and in our opinion impacted many children at an important developmental period (for a full consideration of the mental health impacts of the pandemic, please see the Module 8 Mental Health expert report, INQ000587958). This included an increase in referrals to and presentations at children's mental health services from April 2021, with increasing demand for eating disorder services being a particular problem (INQ000587958). For some children and young people with neurodevelopmental conditions however, lockdown was a welcome relief from the pressures of school and socialisation and the need to 'mask' to fit in. For some of this cohort, re-entry into education was particularly challenging. Around England CAMHS services are hugely oversubscribed, and hence children and young people were unlikely to get the support they needed. Effects on mental health were increased when children and young people presenting with Long Covid faced clinicians who minimised symptoms or did not understand Long Covid, delaying or preventing the necessary support.

18. In some cases, it can be difficult to distinguish between LC and the impact of lockdown, missed school, school re-entry, anxiety and neurodevelopmental conditions. The pandemic has highlighted the urgent need for educational settings to be appropriately resourced to support all children, particularly those with possible or diagnosed neurodevelopmental disorders.

19. In terms of children <5 years with symptoms consistent with LC, as above, developmental follow up is pending, although it may be expected that poor sleep and fatigue is likely to interfere with normal learning and development. However the impact of lockdown on this cohort, with or without LC needs elucidating. For information on the developmental impacts on children under the age of five please see the expert report on Child Development (INQ000587957).

The functional impacts of Long Covid on children

20. Observational data from our NHS services has demonstrated significant functional impact of LC in children, largely secondary to fatigue and brain fog. This includes normal activities of daily living such as showering and self-care, school attendance, participating in interests, concentrating and keeping up with schoolwork, sports and exercise. This functional impact has a spectrum (measured using the NICE ME/CFS severity score).

21. In the first 176 patients referred to the service, 60% were mildly affected, 28% were moderately affected, 10% were severely affected and 2% very severely affected (Goddings, 2025). In comparison with those who met the definition of Long Covid and were SARS-CoV-2 test positive in the NIHR funded research study of LC in children (CLoCK), Children and young people attending the pan London post COVID service experienced a higher number of symptoms and were more likely to report problems with daily functions such as mobility, self-care and usual activities (Newlands, 2023). In addition, those attending the NHS services had significantly higher SDQ impact scores, indicating the symptoms were causing greater impairment and more distress. See Figure 1. It is probably not surprising that those who sought healthcare were experiencing a higher number of symptoms and difficulties than the group identified from a community study, who may or may not have sought healthcare.

22. Table explaining severity of symptoms of ME/CFS used for Long Covid.

Mild ME/CFS	People with mild ME/CFS care for themselves and do some light domestic tasks (sometimes needing support) but may have difficulties with mobility. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often have reduced hours, take days off and use the weekend to cope with the rest of the week.
Moderate ME/CFS	People with moderate ME/CFS have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work or education, and need rest periods, often resting in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed.
Severe ME/CFS	People with severe ME/CFS are unable to do any activity for themselves or can carry out minimal daily tasks only (such as face washing or cleaning teeth). They have severe cognitive difficulties and may depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed and are often extremely sensitive to light and sound.
Very severe ME/CFS	People with very severe ME/CFS are in bed all day and dependent on care. They need help with personal hygiene and eating, and are very sensitive to sensory stimuli. Some people may not be able to swallow and may need to be tube fed.

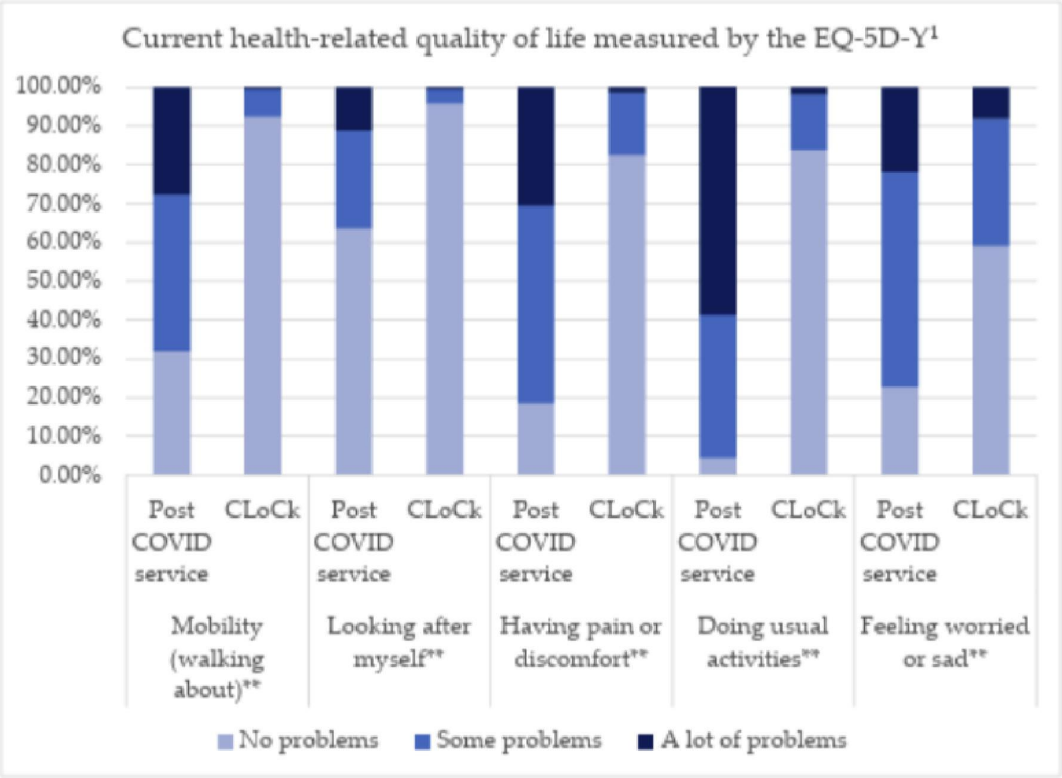

Figure 1. Current health-related quality of life measured by the EQ-5D-Y. [1] NB: The number of participants in the PCS varies due to missing data from 91 to 92. ** Significant difference between PCS and CLoCk sample at $p < 0.001$.

Figure 1 Comparison of quality of life of clinic patients v CLoCK patients

23. On review at 6 month follow up, 40/73 patients reported improvement in their daily functioning, with 30/73 reporting no change and 3/73 reporting functional deterioration. This is in keeping with the outcomes from other services nationally, where between 60-70% appeared to make meaningful progress, but the numbers in the ‘no progress’ or ‘deteriorating’ groups were variable with some services reporting higher numbers deteriorating. Figure 2 illustrates the change in each patient of function.

24. On review at 6 month follow up, 6% were in the severe category, 21% moderately severe, 36% mild and 37% no impairment.

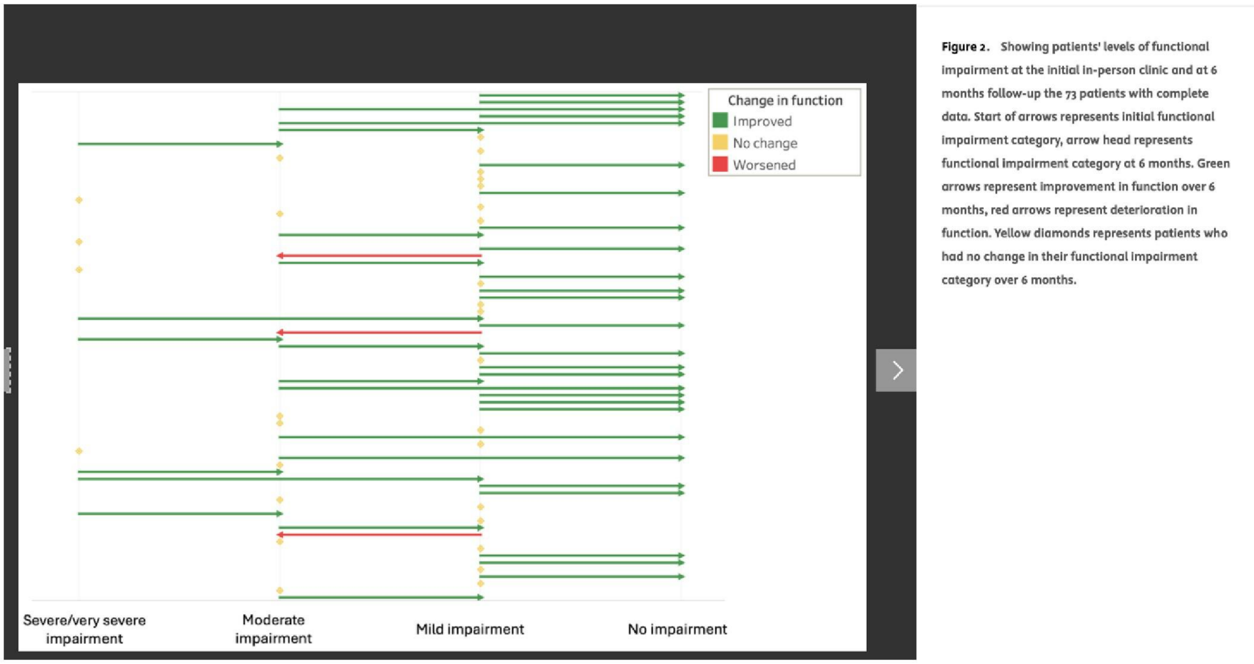

Figure 2. Showing patients' levels of functional impairment at the initial in-person clinic and at 6 months follow-up the 73 patients with complete data. Start of arrows represents initial functional impairment category, arrow head represents functional impairment category at 6 months. Green arrows represent improvement in function over 6 months, red arrows represent deterioration in function. Yellow diamonds represents patients who had no change in their functional impairment category over 6 months.

Figure 2. Patients' levels of functional impairment at initial clinic and at 6 months follow up

25. Fatigue and post exertional malaise and brain fog, and inability to tolerate noisy light environments interfere with ability to attend school for children and young people with LC and ME/CFS. This is well recognised in ME/CFS. When assessing children and young people with poor school attendance, Crawley et al found that 1% of school children, and 34% (50/146) of those missing significant amounts of education (>20% absence over a 6 week period) fulfilled criteria for ME/CFS (Crawley, 2011). One of the criteria for being accepted into the LC multidisciplinary face to face clinics after discussion at the virtual MDT, was attending less than half time in school. Patients who just managed to attend school at the expense of all other activities were also accepted. School attendance is not always a reliable marker as some children and young people have no choice but to attend school, even if not well enough, due to parental work commitments. Overall, 15% of patients were entirely out of school and education, 38% were attending half time or less, with 21% attending more than half time and 12% attending full time. Similarly, at follow up at six months, there was an improvement in school attendance in 63% (43/67) patients, with stable attendance for 22% and reduced attendance in 6% of patients.

26. Despite evidence showing that approximately two thirds of children and young people make a significant and meaningful improvement, in the NHS services, the remaining third remain static and 5-10% deteriorate. Being unwell for many months or years results in secondary problems in terms of deconditioning and the emotional and mental impact of being out of

normal social and independent environments. A subset of approximately 5% of patients in the NHS services were so severe they needed to have regular inpatient admissions. There were no specific predictive factors identified to distinguish which children and young people would improve, stay the same or deteriorate. In the CLoCK study, the proportion of children and young people meeting the definition of Long Covid decreased over time, suggesting progressive improvement in symptoms with time (Stephenson, 2024). One of the limitations of this study is attrition over time, however they maintained a 40.7% response rate at 24 months and it remains the most comprehensive study to date.

27. It is important for schools to be informed about the diagnosis of LC so that personalised advice such as flexible reduced attendance plans and educational health care plans can be created to address specific needs such as modified physical activities or rest breaks.

Prevalence of Long Covid in children

28. Of the 943 children & young people in England in the NIHR funded CloCK study with a positive SARS-CoV-2 PCR test recruited between September 2020-March 2021 who reported at every time point:

    28.1. 233 (25%) of these fulfilled Long Covid definition at 3 month follow up.

    28.2. 135 (14%) of these continued to fulfil Long Covid definition at 6 months.

    28.3. 94 (10%) of these continued to fulfil Long Covid definition at 12 months.

    28.4. 68 (7%) of these continued to fulfil Long Covid definition at 24 months.

29. Therefore, 68 (7%) fulfilled the LC definition at 3-, 6-, 12- and 24-months. It is not possible to easily extrapolate from this to the general population or the 0.25 million teens who originally tested positive September 2020-March 2021 because this 943 are a self-selected group (the response rate to the original approach to teenagers was 13% and less than half of those responding initially stayed in the study for all 2 years). However, if it was extrapolated, this would equate to 17,500 children and young people aged 11-17 years old with persisting problems 2 years on from September 2020-March 2021 when they originally tested positive for SARS-CoV-2. This is of the same order of magnitude as the ONS study below, which used completely different methods but had a similar initial response rate to our 13% and included all of the UK.

ONS Data (as of March 2023)

30. An estimated 1.9 million people in private households (people of all ages including adults) in the UK (2.9% of the population) were experiencing self-reported Long Covid as of 5 March 2023. Of those, around 9 in 10 (92%) first had (or suspected they had) Covid-19 at least 12 weeks previously. Over two thirds (69%) reported experiencing LC symptoms for at least one year. Over one third (41%) reported experiencing symptoms for at least two years. ONS estimated that 37,000 11-16 year olds and 22,000 2-11 year olds across England had symptoms for more than 12 weeks after Covid-19 infection (ONS, 2023).

CYP NHS data

31. Up to October 2023, NHS England recorded >1400 referrals were made to CYP post COVID services in England, with 3588 <17 year olds being coded as Post COVID syndrome in primary care. The numbers were likely higher than this as there are known inconsistencies with coding mechanisms. In the past 18 months, the Pan London post COVID service was the largest service in England (based on reporting to NHS England) having received 507 referrals in total to date and the referral pattern seen there was reflected across the UK. The numbers of referrals reached a peak in May 2022 (Figure 3) and referral numbers have declined in 2025. It is likely that numbers are declining for several reasons such as the virus likely causing fewer infections, those who are infected are not testing, and with the closure of Long Covid services and reduced awareness amongst referrers of which services are open, they are then presenting to paediatricians and ME/CFS services instead of Long Covid services. The UCLH ME/CFS service Treatment and rehabilitation of adolescents and children with complex conditions service (TRACCS) are getting referrals that should have gone to the Pan London post COVID service, and diverting them. However, NHS services continue to receive referrals of children and young people who have likely new LC or have been affected for years.

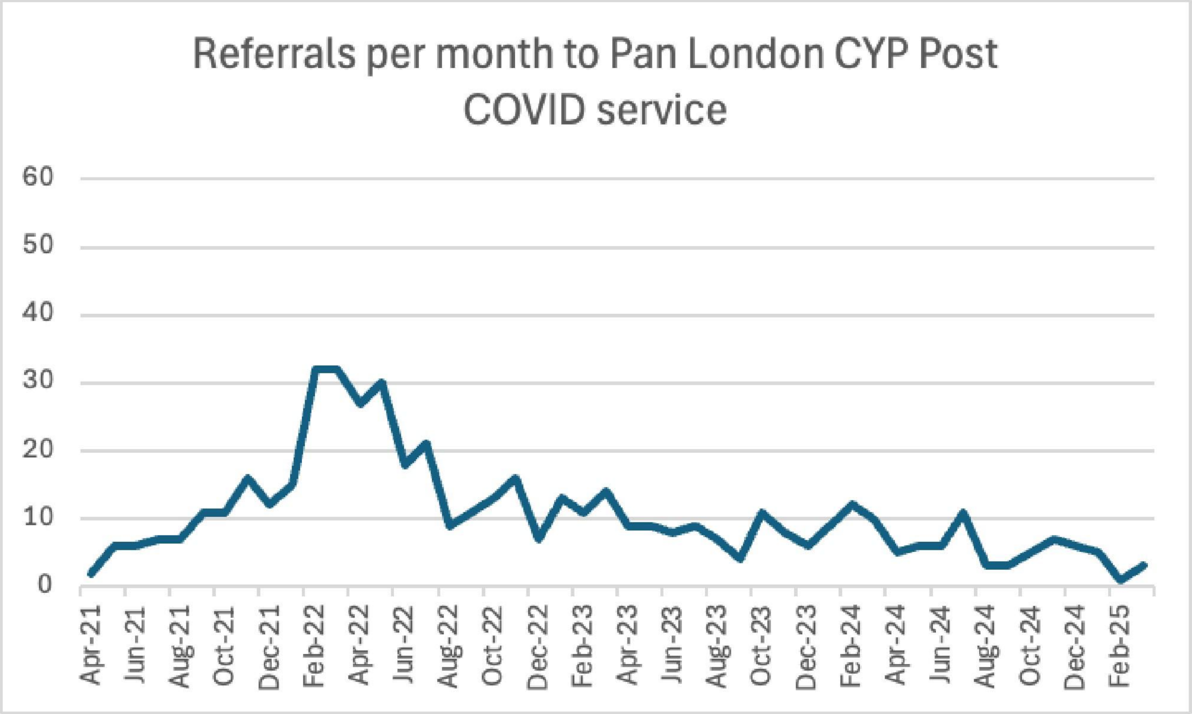

Figure 3 Number of referrals per month to the Pan London service over time April 2021-February 2025.

32. On review of the UCLH clinical service's experience of symptom duration, using discharge as a surrogate for recovery,[1] of a cohort of 117 followed up for up to 3 years, in total, 62% were discharged, with a median duration of care of 12 months. However this does include 50% of patients who had only been in the service for less than a year. Taking the 2021 cohort alone, at a review point of 3 years follow up, 93% were discharged as their symptoms had mainly resolved and they had regained usual activity/school attendance. 56% of this 2021 cohort were discharged at 24 months. Figure 4 shows the amalgamated 2021-2022 cohort. The lower rate of discharge at 24 months for 2022 cohort is likely to reflect the more severe cases taken on during the peak referral period in 2022. Figure 5 shows this by year of initial assessment.

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[1] Discharge follows major resolution of symptoms and return to school/normal activity. This study highlights that almost half of patients from the 2022 cohort are still significantly suffering at 24 months.

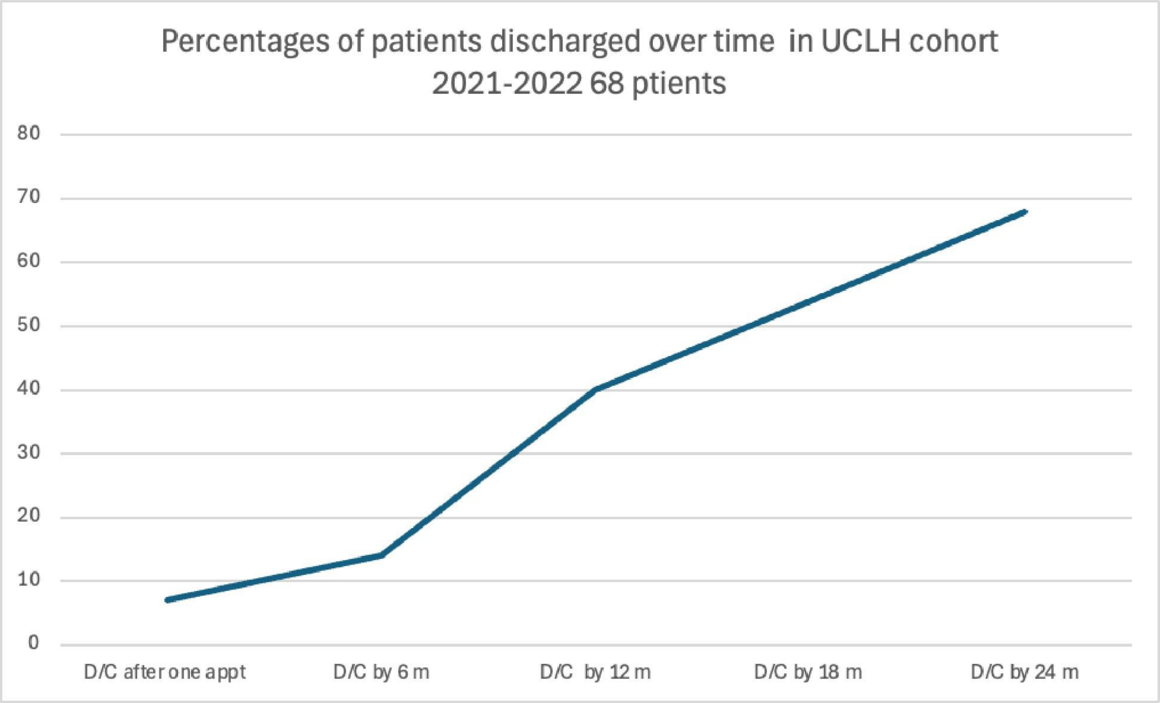

Figure 4 Discharge percentage over time for CYP seen in UCLH clinical services in 2021-2022

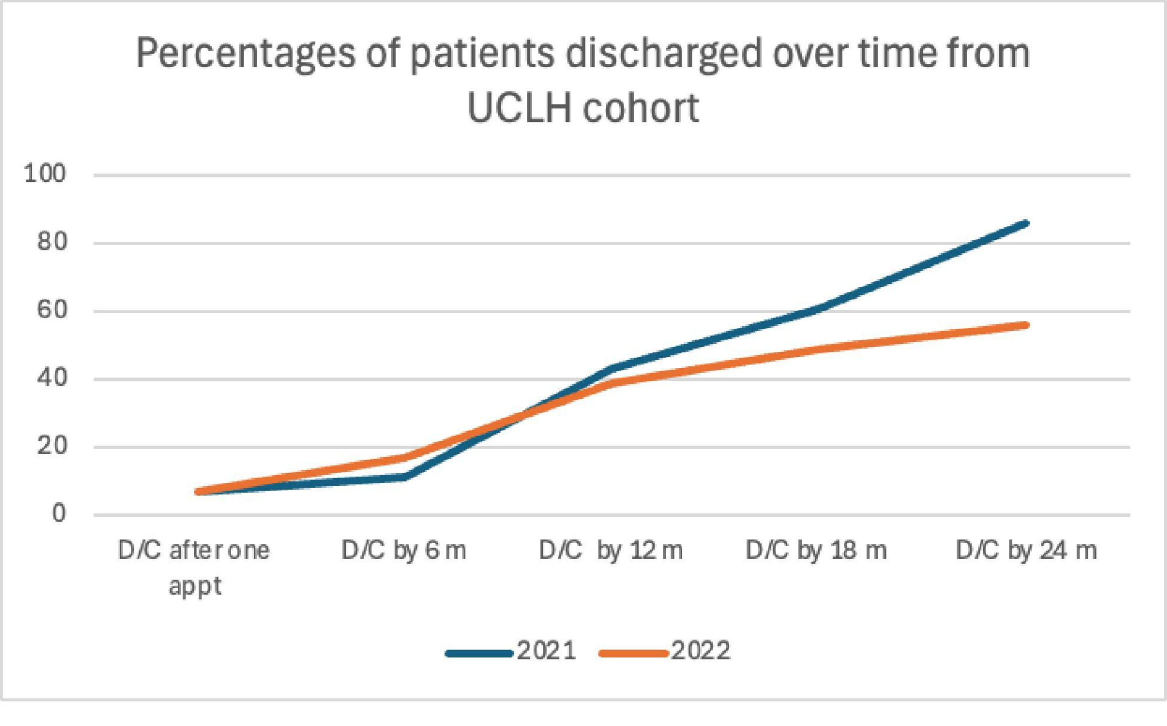

Figure 5 Percentages of patients discharged from service over time for patients accepted in 2021-2022 to UCLH service broken down by year

33. Of those that have not yet been discharged, 50% are within the first 12 months of their management. Twenty-six (22%) have been under the care of the service for 2 years. Of these 22%, 10 (39%) improved then relapsed, 7 (27%) remained the same, 4 (15%) improved partially and maintained, one got worse and one got worse then started to improve. Symptoms causing the main challenges for those still seen at 2 years in clinic were fatigue (10/26), nausea (3/26), anxiety (5/26), migraines/headaches (5/26), brain fog/difficulty concentrating (5/26), constipation (3/26), dizziness (9/26), nosebleeds (2/26) and abdominal pain (2/26). Other main symptoms were low mood, stress, palpitations, pains in arms and legs, cramps, joint stiffness, and poor appetite. In terms of school attendance of this group who remain in follow-up at 2 years, a third are showing slow improvement, a third fluctuating and a third worsening attendance.

34. Anecdotal comments from other service leads in England were that the younger group (8-12 years) were more complex and took longer to recover.

35. Attendance and support in schools have been shown to be key to individual children and young people's experience and recovery. There was no standardised approach for the management of return to school for children and young people with LC across different educational settings, and this led to differences in the experience, support and recovery that individual children and young people experienced. Some children and young people report a battle with school to support the young person, requiring them to provide evidence of diagnosis, and failing to instigate activity management and support them to remain connected with education. Some practitioners and families reported that educational settings did not believe in LC and were dismissive of the need for a supportive return to education.

Reported prevalence of Long Covid in children from minority ethnic groups, those with other illnesses and those with neurodevelopmental conditions

36. Despite Black and ethnic minority groups being disproportionately impacted by Covid-19 as evidenced by increased infection, hospitalisation, multiorgan dysfunction and mortality rates in adults and children (Smyth, 2022), estimates of LC in adults are not higher in these populations. CLoCK study data (Stephenson, 2024) shows there was little difference by ethnicity in children and young people meeting the definition of Long Covid. Non white children and young people were much less likely to be vaccinated against SARS-CoV-2. Symptoms or their impact did not differ by vaccination status, but the number of children and young people vaccinated remains low and most children and young people had already

had SARS-CoV-2 prior to vaccination being available so it is not possible to definitively state whether vaccination is protective for Long Covid or not. CLoCK also showed that LC was more common in older than younger children and young people and more common in the most, compared to the least, deprived centile. In a 3 year prospective cohort study in Italy, they reported that vaccination was associated with a lower risk of LC at 3, 6 and 12 months for older children and a lower risk of reinfections (Camporesi, 2024).

37. The pan London NHS service ethnicity data shows over-representation of white British and a lower number than expected Black (40% less) and Asian (50% less) backgrounds compared to London ethnicity data. Less deprived groups are also overrepresented, leading us to wonder why more deprived children and young people from minority backgrounds were not accessing the LC NHS Services. This may be due to a relatively lower number having impairment, less help-seeking, a lack of awareness amongst schools and professionals or a reflection of the health inequalities faced by some populations in accessing healthcare. There is also a possibility of discrimination and black and ethnic minority children may be less likely to be diagnosed and may be less likely to be believed. Although in some services the deprivation index was reflective of the clinic population, in other services this was reversed.

38. Studies have shown an association between LC and pre-existing health conditions (Atchison, 2023). Some studies report that children and young people with LC were more likely to have been severely symptomatic and required hospitalisation with their known episode of SARS-CoV-2 (Merzon, 2022). In addition, children with LC were significantly more likely to have a previous history of ADHD, chronic urticaria, and allergic rhinitis (Merzon, 2022). NHS Services clinical data from the Pan London service showed 74% of those referred to the MDT and 80% of those seen in person at the clinic had a pre-existing medical condition (Goddings, 2025). For example, 42% of those referred had a history of asthma, eczema or allergy – just above the top end of the estimated population prevalence of 10-40%. 22% had previously documented mental health concerns such as low mood or anxiety in keeping with a reported prevalence of 18-22% in children and young people and a reminder that prior mental health issues are not more prevalent in children and young people with Long Covid than the general population.

39. In keeping with reports from CYP service leads from around England who concur that neurodiversity is common in the LC cohort and poses significant diagnostic and management challenges, the Pan London service (UCLH and Evelina clinics) overall found that there was an overrepresentation of neurodevelopmental issues in their cohort. In contrast to a population prevalence of between 3-10%, 17% of referred patients had a

confirmed neurodevelopmental diagnosis (including 10% with autistic spectrum disorder (ASD), 3.5% had ADHD, others had sensory processing disorder, dyslexia, dyspraxia or tic disorder). A possible neurodevelopmental diagnosis was suspected in the UCLH and Evelina clinics in a further group. Looking at those seen at the Evelina clinic alone, where the clinical lead is a psychiatrist and has an interest in this area, there was a higher rate of autistic spectrum disorder, with 20 (17%) of 122 consecutive patients reporting an existing diagnosis and a further 33 (27%) having a suspected ASD diagnosis (either waiting for assessment or with clinic presentation in keeping with ASD and a first or second degree relative with known or suspected ASD). The gender ratio of those with a pre-existing neurodevelopmental diagnosis showed a female to male ratio of 2:1 which is a significantly different gender ratio from the general population of those with ASD. The proportion of patients referred to the Pan London clinics with a confirmed diagnosis of autism was 10% which is far higher than the population estimates of 2% (O'Nions, 2023) and is in keeping with the experiences of other post Covid-19 services in England. The reason for this overrepresentation is not clear yet but will be important to explore and understand.

A brief timeline of the emergence and recognition of Long Covid in children, and the provision of specific healthcare services for these patients in England.

40. The first report in the literature was a preprint on the 2nd November 2020 detailing 5 Swedish children with persistent symptoms following SARS-CoV-2 infection (Ludvigsson, 2020). The TRACCS team at UCLH had been receiving referrals of children and young people with ME/CFS and other symptoms associated with SARS-CoV-2 from at least September 2020. The CLoCK team prepared draft applications for the NIHR Funding call in November 2020. The first meeting with clinical stakeholders from multiple specialities and allied health professionals with NHS England (London) regarding a Local and then National service for children with persistent symptoms was on the 24th November. An NHS England task and finish group was convened on the 8th December with further meetings over the following month culminating in a national workshop at the end of January 2021. NHS England London incorporated children attending the ME/CFS services at UCLH into the post COVID assessment policy with a small budget for CYP until the national CYP budget was confirmed to fund the proposed 15 MDT paediatric services.

41. The first version of the NICE guidance (NG188) for Long Covid in adults and children was released on 18th December 2020.

42. The NHS England guidance for Post COVID Syndromes assessment clinics was released in April 2021 and this incorporated advice around services for CYP for the first time. This included a recommendation for an early, holistic, medical assessment to identify need for specialist input, organ impairment and supportive care for the wide range of symptoms that can significantly impact quality of life. This guidance included the patient pathway, referral routes to primary and then secondary care, and onwards to the post-Covid specialist clinics. A virtual multi-disciplinary team meeting for the discussion of best management of patients with a referring clinician and local support was recommended, with the more severe cases being seen in multidisciplinary clinics. In addition, it highlighted the importance of data collection and incorporation of research from the beginning, including close working with ISARIC and the NIHR Funded CLoCK study.

43. Subsequently a national webinar presenting the model for the clinics was held in May 2021. The London service was formally open to referrals from mid-April 2021 and 15 CYP Long Covid hubs were announced as part of the NHS England strategy for Long Covid with a hub and spoke format in July 2021. There were different models for each MDT service, as some built on existing ME/CFS services, and others were set up from scratch. As part of the development of NHS England services, a series of patient resources were also developed (leaflets and videos) by the CYP NHS England LC taskforce workstream and these were then shared on 'Your COVID Recovery' website. Information regarding assessment and referral pathways was disseminated to primary and secondary care via webinars and email.

44. In May 2021 following the webinar, NHS England supported a CYP post Covid clinical network which met twice monthly to collate numbers and share good practice, experience and plans, as well as to update the national guidance, keeping it as a living document as learning changed with experience over time. Although 14 services were finally funded and established, there remained geographic gaps, particularly in areas such as the Southwest of England where the population density is lower and paediatric services more widely spread out.

The provision of services in Wales, Northern Ireland and Scotland

45. We have concentrated this report on England primarily, as we were working with NHS England.

46. To our knowledge, no formal services for children and young people with LC were established in Northern Ireland. There was no dedicated Long Covid service for children in

Wales. Adferiad (recovery programme) was not solely for Long Covid, nor was it ring-fenced for children and based on their reports only 2 children and young people accessed these services for LC Support in 2023, and none in 2022. There were no formal services for children and young people with LC in 6 of the 9 health boards in Scotland. In these areas as well as Wales and Northern Ireland, referrals were managed by the general paediatric services with different funding streams and community pathways in different regions. This can make it difficult for healthcare providers to understand the best way to support children and young people with LC. England-based services such as the Pan London service have provided remote support to some patients and their paediatricians from Scotland and Ireland. This remote support is helpful to the named local paediatrician who may not have the specialised expertise. The support may be somewhat helpful to the patients, however its effectiveness is likely to be limited by the inability to manage face to face appointments with the MDT.

The delay in the recognition of Long Covid in children, compared to adults

47. The delay in recognition of LC in children and young people compared to adults is likely to be multifactorial. Although persistent symptoms in children and young people following SARS-CoV-2 infection are relatively common, severe symptoms with significant impact on functioning and activities of daily living are relatively uncommon. Rarer presentations are harder to identify and may take longer to be recognised.

48. This was confounded by lockdowns and school closures as children were out of school and not functioning as normal, school absence and persistent symptoms may not have been picked up through usual pathways of education and healthcare.

49. As well as there being a delay in the collective realisation that Long Covid affected children due to the reasons explained above, there was likely also a minimisation and 'disbelief' by some HCPs. Invisible disabilities are recognised as challenging for people to understand, and hence disabled children and young people may not be believed. Some children's symptoms were thought to be due to other reasons than Long Covid, such as mental health presentations, or symptom exaggeration, or 'school refusal' and some Long Covid diagnoses were dismissed. Additionally some clinicians labelled parents (affected by the pandemic) as 'anxious' and 'hypervigilant' and assumed exaggeration of their children's symptoms, again refuting Long Covid diagnosis and therefore support. This non-belief caused a huge amount of additional distress for children, young people and families, as it made the process of trying to get help even more difficult, and in some cases impossible.

The symptoms of what is now well understood to be associated dysautonomia took time to be understood and be recognised and in some cases the fast heart rate was put down to anxiety, or deconditioning.

50. The presenting symptoms are non-specific and the prevailing message that children were less affected by Covid-19, i.e. less likely to experience hospitalisation, severe acute infection/disease and death, may have led to an overall neglect of 'non-severe' symptoms. Furthermore, accessing routine primary care appointments in general and especially in person was challenging for many families across the country.

51. In 2021, following the formal NHS England webinar to present the model for the services, our teams continued to raise awareness of Long Covid in children. It was clear that some families were struggling to get recognition of the condition from health and education settings. We worked with RCPCH, ESPID (European Society of Paediatric Infectious Diseases), WHO (World Health Organisation) and BMJ (British medical journal) to advocate for recognition and appropriate support and management for these children and young people. Our team worked with integrated care board (ICB) champions and GP partners across London to raise awareness to paediatricians and GPs and information on referral pathways, which was likely replicated across England. Our team has published widely, presented at a variety of conferences, created podcasts for health professionals and worked with NHS England and WHO to create resources to support health care professionals to recognise children and young people with this condition. Resourcing of the services did not include funding for this type of work, which was largely done in 'free time'. Both Long Covid and other similar but distinct conditions such as ME/CFS have struggled to gain recognition, and awareness and education about these conditions to health and allied care professionals and those in education continues to be important.

The impact of lack of specialist services for children

52. NHS Post Covid Services for CYP in England were commissioned to be set up at speed, and this relied on multidisciplinary team members with appropriate expertise being available to add some sessions of work. This precluded anyone who was already working full time. Services that already had fatigue services were more able to flex and add a post Covid workstream. Some services who had an interest set up at speed. It would potentially have been helpful for the UK pandemic planning to have anticipated the impact from the long-term sequelae of SARS-CoV-2 on children and young people, from the known impact of long-term sequelae of previous coronaviruses.

53. The Post Covid services in England met monthly which was helpful to share ideas, compare outcomes and learn together. Colleagues from Scotland, Northern Ireland and Wales were invited and welcome to join these meetings. NHS England shared results of the assurance report in December 2023 and reported that:

53.1. Most of these NHS England funded services are accepting referrals from both primary and secondary care.

53.2. Most of these NHS England funded services provide a full holistic assessment.

53.3. The majority of NHS England funded CYP hubs MDTs include: consultants, physiotherapists, occupational therapists and psychology.

53.4. The multidisciplinary team model has been working well in most of the NHS England funded hubs.

53.5. Most of the NHS England hubs have reported positive outcomes where outcomes were recorded and reviewed.

53.6. Sharing resources, training materials etc may help to support teams with vacancies.

53.7. Some of the NHS England funded Post Covid services would like further support with recruitment, notably with therapies and psychology.

53.8. There have been problems accessing timely and well-resourced rehabilitation in the community due to a lack of resource locally.

53.9. Some of the NHS England funded Post Covid services would like the facilitation of discussions for ongoing support with ME/CFS as this is not resourced everywhere.

53.10. A clinical forum for complex cases and shared practice would be helpful.

54. Insecurity and uncertainty around continuity and the short-term nature of funding of NHS England funded services, meant some services were unable to recruit appropriate staff and sadly this allowed some services to close to referrals, and follow up of patients.

55. One Allied Health Professional (AHP) remarked: "*The short term nature of funding and the often last minute decisions have been incredibly challenging to work with and often disproportionately affected nursing and AHP staff. We are not sure the impact on staff has ever been truly recognised or acknowledged. This continues, with a lack of ongoing clarity on the future of services. Nationally [in England], it's clear that this has led to closure of*

many services, increasing existing regional variation. It is essentially now a postcode lottery as to whether a CYP with post-COVID symptoms can access ongoing care."

56. Once funding moved from centralised to localised provision for NHS England services in April 2024 there was no clear direction about how to manage the complex patients. There was uncertainty as to which of these services would remain funded and this led to a reduction in the number of CYP LC services to 9 services from the original 14. For example, one LC service, who had set up an excellent service with a highly-expert and connected team had job insecurity for many months/years and were unable to continue taking referrals and supporting children and young people with LC.

57. There was an over-reliance on good will in people working above and beyond to set up and provide these services. Many were able to build on existing services, but smaller services had to be established from scratch. Prediction of need was impossible when the money was first allocated which meant that some smaller services had the same funding allocation as bigger busier services with a resulting lack of equity.

58. A key area of challenge was delivery of Allied Health Professional (AHP) input in the community. The NHS services identified that rehabilitation was crucial to support return to activities for these children and young people with LC, and lack of resource for AHP in the community meant this was often impossible to deliver near the patient. There exists chronic under-resourcing of AHP for children and young people in London and across England. Services developed innovative solutions to optimise the efficiency of their teams to overcome this, including group online therapy sessions and webinars.

59. From the outset, there was an ambition to collect outcome data. The NHS England task and finish workstreams that were set up to ensure accurate data collection were only resourced for the first 18 months and there was no financial or technical support to support local data collection by the MDT services consistently. A novel software platform, ELAROS, was endorsed by NHS England, but unfortunately there were large and unexpected procurement delays of up to a year for each trust. The process of establishing these services has highlighted that streamlining routine data collection should be an urgent priority for the NHS. Measuring outcome data accurately is key from a clinical governance perspective to understand if care is effective, and if not, to learn how to improve care and hence outcomes for the affected population.

Research

60. An ambition was to include research from the start. The NIHR Funded CLoCK study into prevalence was the greatest success, however despite submission of multiple grant funding applications exploring mechanisms and outcomes, many of these were rejected. An NIHR funded study exploring the immunology of LC included children, but has yet to report. A brain and body MRI study is ongoing for children. In London, there was an Action Medical Research funded study "Connecting breath and mind: Development of an online holistic treatment programme addressing mental health in children and young people with Long-COVID". The UCLH NHS team attempted to add older children and young people (>12 years) into adult recruiting studies with limited success. Although families were extremely keen to be enrolled in studies there were limited opportunities to offer them.

Transition of care between paediatricians, GPs and adult services

61. A common issue for children and young people is the gap between paediatric services and adult services into which those young people aged 16/17 often fall. This was an age group who were particularly affected by LC, but for whom the referral pathways were unclear. The plan for primary care assessment and referral to secondary care for more specialised comprehensive clinical assessment and investigations to rule out other conditions was unsuccessful, as most paediatric services do not see children and young people aged 16 and over. However adult services also would not take the referral from primary care. To meet this need, a new pathway of direct referral from primary care to the MDT was created. The challenge of this was then in delivery of care if they did not meet the threshold to be seen in person by the accepting LC service.

Private practitioners

62. The model of care was supportive within the post Covid service. Naturally patients and their families wanted access to investigational treatments, particularly as so many were discussed in social media and other platforms. The post Covid service was reluctant to offer investigational treatments outside of a research/trial basis and there was no clear pathogenesis or basis for the use of potentially dangerous treatments (for example anti-coagulation).

63. In our experience, some private practitioners offered appointments to families, performing costly and sometimes invasive investigations without diagnosis. This resulted in children and young people seeing multiple specialties, such as review by neurology, immunology, cardiology and gastroenterology for example, but without effective treatment. This

heightened anxiety for the child and family as they underwent more and more tests without appropriate supportive care and planned management of symptoms. Some private practitioners prescribed unlicensed treatment to children and young people, including those with a high-risk side effect profile such as triple anticoagulation, plasmapheresis, hyperbaric oxygen treatment. The informed use of unlicensed treatments may be necessary in paediatric practice and it is not unlawful. However, it is good practice to only use them following advocation by a respectable, responsible body of professional opinion, that is they should be part of national guidelines following consensus expert opinion if there is no evidence base for their use. The majority of paediatricians, and most relevantly those who were seeing the majority of children and young people with Long Covid, did not and do not recommend the use of these treatments. Furthermore, they were not included in adult guidelines, nor recommended for use by the adult services or professional bodies. In addition, there are no international guidelines recommending their use. The GMC would suggest that the prescriber should be satisfied there is sufficient evidence or experience of using the medicine to demonstrate its safety and efficacy (GMC, 2021). The vast majority of those nationally and internationally caring for this cohort do not feel there is sufficient evidence or experience of using these treatments, and that the risks may outweigh the benefits. Finally, the use of these treatments was concerning as it undermined the NHS services who would not provide such treatments.

64. The impact of the lack of specialised services across the 4 nations has meant there are large geographical gaps where likely tens of thousands of children and young people across the UK (based on ONS data) have been deprived of the benefit of specialised input and large numbers remain very unwell, housebound and out of education.

Hoped for 'legacy' for post infective conditions services

65. Patients including children and young people with post infective conditions existed before and after the Covid-19 pandemic, and continue to need input. The legacy that was hoped for was better services and support for children and young people with post infective symptoms and conditions, and diagnoses such as ME/CFS where this was not available nationally prior to the pandemic. Local services are essential due to the debilitating nature of these conditions precluding lengthy geographical travel, and the far-reaching effects of lack of management on education, development and mental health. Unfortunately, due to the closing of services where there was no other provision in most areas, there is a lack of service support nationally. Decommissioning of specialist LC services has been very detrimental to children. The provision for children and young people with LC and ME/CFS is a 'post-code lottery' with hugely variable services, many far from ideal due to lack of

interested/experienced paediatricians and other specialists and AHP support. There is no structure to develop disease modifying treatment. A recent International ME/CFS Conference 2025 – “Understand, Diagnose, Treat” took place in Berlin, organised by the Charité Fatigue Center in collaboration with the ME/CFS Research Foundation. The consensus amongst the experts was that there is great overlap in pathology and effects between ME/CFS and LC, that disorders of the autonomic nervous syndrome such as PoTS are common to both, that the underlying pathophysiology is increasingly well understood, that there are advanced clinical trials that appear to be showing significant results that will take us from the current situation of offering rehabilitation and psychological support to a future of using combination medications to treat these conditions. Other European countries are developing their services nationally whereas in England (and the other devolved nations) there is no central plan or structure and our children and young people with these devastating, long term conditions will be neglected through being unable to access appropriate diagnoses or treatment.

66. We have missed opportunities to maintain and strengthen a network of expert teams across England to continue to support these children and young people who are unwell, and out of education. This will continue to affect their development, attainment and productiveness and functioning in society as a whole.

List of figures

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Brightling C E, & Evans, R A. An expert report on the treatment of Long Covid	INQ000421758
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