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# Characterisation and Management of Children and Young People Referred to a Paediatric Tertiary Post-COVID Service

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A B S T R A C T

**Purpose:** Post-COVID condition (PCC) emerged following the 2020 coronavirus pandemic and required rapid service development to manage affected patients. This evaluation describes the demographics, medical background, management and six-month outcomes of children and young people with PCC-related symptoms referred to one specialist tertiary service between June 2020 and August 2022.
**Methods:** Data were retrospectively collected from referral information and medical notes.
**Results:** 176 patients (61% female) aged 6–18 years were referred, with a mean 8.2 PCC-related symptoms impacting on functioning (97%) and school attendance (86%). 10% patients had an autistic spectrum disorder diagnosis, above the ~2% national prevalence, while rates of atopy and mental health were similar to national prevalence. 59% patients were managed in specialist tertiary clinics by clinicians with input from allied health professionals. At 6 month review, 40/73 patients reported improvement in their daily functioning, with 30/73 reporting no change and 3/73 reporting functional deterioration. School attendance increased over 6 months for 43/67 patients, with 12/67 reporting no change and 4/67 reporting reduced school attendance.
**Discussion:** Patients referred for PCC-related specialist input have significant functional impairment and challenges accessing education. More than half of those seen in specialist clinics showed

**IMPLICATIONS AND CONTRIBUTION**

This evaluation details the demographics, management and six-month functional outcomes of a large regional cohort of children and young people with significant post-COVID condition symptoms referred to a specialist clinic. It expands on available data and outlines the symptom time course and trajectory for patients with significant functional impact.

**Conflicts of interest:** The authors have no conflicts of interest to disclose.

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functional improvement and increased school attendance over 6 months, while a subgroup had persistent symptoms. This suggests that the service model is beneficial for this complex patient group overall, although needs to be resourced for longer input for some. Further work is needed to understand the variability in presentation and symptom course.


Following the 2020 emergence of acute symptomatic infections caused by the novel severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2; COVID-19), a proportion of those infected have experienced persistent health and well-being sequalae of COVID-19 infection. This has been termed post-COVID syndrome/condition or Long COVID [1]. This manuscript will use the term post-COVID condition (PCC) throughout, as defined by the World Health Organisation as 'the continuation or development of new symptoms 3 months after an initial SARS-CoV-2 infection, with these symptoms lasting for at least 2 months with no other explanation' [2]. Symptoms can be wide-ranging and fluctuating in nature and can include fatigue, post-exertional malaise, brain fog, headaches, breathing difficulties, gastrointestinal issues, sore throats, muscle pain, or weakness, fevers, nausea, mood changes, rashes, dizziness, and cognitive blunting [3–5]. Reported incidence and prevalence of PCC vary widely, with broad estimates suggesting 1%–5% of young people are impacted [6,7]. Symptom severity varies widely and some patients experience a significant impact on their daily functioning and ability to participate in their usual social, recreational, educational, and self-care activities [1,8,9].

The emergence of PCC required prompt action by to address concerns around end organ involvement and management of complex and poorly understood symptoms. In England, a standardised referral process for children and young people (CYP) was developed. Between June 2020 and April 2021 patients were referred to the University College London Hospitals adolescents with complex conditions (UCLH TRACCS) service. In April 2021, the Pan-London Post-COVID CYP service was established as one of 15 planned national services [10].

The Pan-London Post-COVID CYP service incorporates a multidisciplinary team including doctors from multiple specialties, together with allied health and social care professionals [11] from multiple London NHS Foundation Trusts including UCLH, Imperial College Healthcare, Evelina London Children's Healthcare as part of Guys and St Thomas' (ELCH), South London and Maudsley and Great Ormond Street Hospital for Children. The service operates a 'hub-and-spoke' model and accepts referrals from secondary care paediatricians (for CYP $<$16 years) or general practitioners (16–18 years) meeting criteria for likely PCC and impaired daily functioning.

Each referral is discussed at a virtual meeting between the referrer and the Pan-London multidisciplinary team and a personalised action plan is formulated for either (1) continued self-management supported by the local paediatric/primary care service with verbal and written advice from the tertiary specialist team; (2) in-person specialist PCC interdisciplinary team clinic review for those with severe symptoms in need of specialist input; or (3) referral to alternative services as appropriate. In-person clinics were established at UCLH (https://www.uclh.nhs.uk/our-services/find-service/children-and-young-peoples-services/post-covid-service-children-and-young-people) and ELCH (https://www.evelinalondon.nhs.uk/our-services/hospital/post-covid-19-assessment-service/overview.aspx), with broadly overlapping models of care offering assessment and specialist tailored management in collaboration with the local paediatrician/primary care practitioner. CYP are assigned to either the UCLH or ELCH based on residential address.

To date, there are limited published data detailing the clinical course and outcomes of CYP with PCC symptoms after specialist tertiary clinic management. This evaluation describes the characteristics of CYP with PCC referred to a tertiary specialist paediatric service and outlines the functional outcomes after 6 months of those CYP managed by the specialist team.

## Methods

This project is a retrospective evaluation of CYP aged 0–18 years with post-COVID symptoms referred to the UCLH TRACCS service (June 2020–March 2021) and the Pan-London Post-COVID service (April 2021–August 2022). Data were collected for referred patients at initial presentation from referral letters, medical notes and modified International Severe Acute Respiratory and emerging Infection Consortium working group questionnaires [12] (only after April 2021). Data included demographic information (age, sex, ethnicity, residential postcode), past physical and mental health conditions, symptoms during acute SARS-CoV-2 infection, symptoms at referral and indicators of daily functioning. Previous atopic illness or neurodiversity were specifically identified in view of previous data linking chronic urticaria, allergic rhinitis and attention deficit hyperactivity disorder with PCC symptoms [13]. Diagnoses included in the umbrella term neurodiversity included autistic spectrum disorder (ASD), attention deficit hyperactivity disorder, sensory processing disorder, dyslexia, dyscalculia, dyspraxia, and tic disorders.

Three daily functioning indicators were included. First, a categorical functional impairment score was assigned to each patient based on the National Institute for Clinical Excellence guidance for myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome (ME/CFS) [14]. Categories include where an individual's functional impairment is mild (able to care for themselves and likely to still be in education but with limitations to their activities), moderate (reduced mobility and restrictions of all their activities of daily living), severe (only be able to undertake minimal daily activities, and may be unable to leave the house without significant after-effects) and very severe (restricted to bed and dependent on care; See Table S1 for full detail). Second, reported school attendance was categorised as not attending school in person, attending half the week or less, attending more than half the week, full-time in person attendance and being home-schooled. Third, a self-reported global wellness score was collected where patients were asked "How would you rate your overall health out of 100 over the last month

**Table 1**
Showing key demographics and background medical history for all patients referred to the Pan-London Post-COVID service, by the multi-disciplinary team meeting outcome (in-person clinics vs. local management)

| | All referrals | In person clinic | Local management |
|---|---|---|---|
| Number of patients[a] | 176 | 104 | 48 |
| | Mean ± SD | Mean ± SD | Mean ± SD |
| Age (years) | 13.0 ± 2.6 | 12.8 ± 2.4 | 12.8 ± 2.8 |
| | n (% of patients) | n (% of patients) | n (% of patients) |
| Sex assigned at birth | | | |
| Female | 107 (61%) | 62 (60%) | 29 (60%) |
| Male | 68 (39%) | 42 (40%) | 19 (40%) |
| Data not available | 1 | 0 | 0 |
| Ethnicity | | | |
| Asian/Asian British | 12 (7%) | 8 (8%) | 3 (6%) |
| Black/African/Caribbean/Black British | 3 (2%) | 1 (1%) | 2 (4%) |
| Mixed/multiple ethnic groups | 15 (8%) | 7 (7%) | 6 (13%) |
| White | 122 (69%) | 71 (68%) | 35 (73%) |
| Other ethnic group | 11 (6%) | 9 (9%) | 0 |
| Data not available | 13 | 8 | 2 |
| IMD quintiles | | | |
| 1 (lowest) | 14 (8%) | 9 (9%) | 3 (6%) |
| 2 | 31 (18%) | 23 (22%) | 4 (8%) |
| 3 | 49 (28%) | 24 (23%) | 16 (33%) |
| 4 | 37 (21%) | 25 (24%) | 9 (19%) |
| 5 (highest) | 41 (23%) | 22 (21%) | 14 (29%) |
| Data not available | 4 | 1 | 1 |
| Any previous medical history | | | |
| Yes | 125 (71%) | 80 (77%) | 33 (69%) |
| No | 43 (24%) | 20 (19%) | 15 (31%) |
| Data not available | 8 | 4 | 0 |
| History of atopy | | | |
| Yes | 72 (41%) | 48 (46%) | 18 (38%) |
| No | 101 (57%) | 56 (54%) | 30 (63%) |
| Data not available | 3 | 0 | 0 |
| History of neurodivergence | | | |
| Yes | 30 (17%) | 21 (20%) | 4 (8%) |
| No | 143 (81%) | 83 (80%) | 44 (92%) |
| Data not available | 3 | 0 | 0 |
| History of mental health condition | | | |
| Yes | 38 (22%) | 26 (25%) | 7 (15%) |
| No | 135 (77%) | 78 (75%) | 41 (85%) |
| Data not available | 3 | 0 | 0 |

All percentages are rounded to the nearest percent.
There were no significant differences in demographics or background medical history between the groups ($p > .05$).
SD, standard deviation.
[a] 17 patients were not discussed at the Pan-London multi-disciplinary team meetings and 7 patients were referred to alternative specialist services and are not displayed here.

where 100 is completely well?" This is a routinely collected clinical measure and originally developed as a method to record overall health in ME/CFS [15,16]. It is a similar measure to the widely used EQ-5D-Y visual analogue score [17] but is asked verbally rather than written to suit the needs of this patient group. Patients are asked to provide a score for their previous month rather than 'now' as in the EQ-5D-Y as it is recognised that their wellbeing can vary substantially across different days and can be significantly impacted by travelling to the clinic setting.

Follow-up daily functioning scores were collected after approximately 6 months (based on the closest appointment between 4 and 9 months) for those seen at in-person clinic. Follow-up wellness scores were only collected for CYP attending the UCLH in-person clinic.

Data were analysed in R. Ethnicity was coded using Office of National Statistics categories [18]. Index of multiple deprivation (IMD) quintiles for each CYP were generated using residential postcode as a proxy for socioeconomic status. Dichotomous variables were compared using Chi-squared tests, ordinal variables were compared using Mann-Whitney U-tests, and continuous variables were compared using t-tests. Within-participant change parameters were calculated for self-reported functional impact, school attendance and wellness, and differences in progress based on baseline function was compared where there were sufficient data. The project was registered at UCLH as a service evaluation in March 2022. Formal ethical review was not required for this retrospective evaluation based on UK NHS Health Research Authority guidelines.

## Results

### *Baseline demographics*

176 CYP aged 6–18 years (mean 13 years) were referred between June 2020 and August 2022 (Table 1) including 21 patients referred to the UCLH TRACCS service prior to the Pan-London

**Table 2**
Showing functional scores and number of PCC-related symptoms for all patients referred to the Pan-London Post-COVID service, by Pan-London multi-disciplinary team meeting outcome (in-person clinics vs. local management)

| | All referrals n (% of patients) | In person clinic n (% of patients) | Local management n (% of patients) |
|---|---|---|---|
| Number of patients | 176 | 104 | 48 |
| Initial functional impairment score | | | |
| No impairment | 4 (2%) | 0 | 4 (8%) |
| mild impairment | 95 (54%) | 56 (54%) | 32 (67%) |
| moderate impairment | 37 (21%) | 26 (25%) | 5 (10%) |
| severe/very severe impairment | 13 (7%) | 11 (11%) | 2 (4%) |
| Data not available | 27 | 11 | 5 |
| Initial school attendance | | | |
| Not attending | 27 (15%) | 19 (18%) | 4 (8%) |
| Half attendance or less | 66 (38%) | 48 (46%) | 12 (25%) |
| More than half attendance | 37 (21%) | 17 (16%) | 18 (38%) |
| Full time attendance | 21 (12%) | 8 (8%) | 10 (21%) |
| Home school | 3 (2%) | 1 (1%) | 0 |
| Data not available | 22 | 10 | 4 |
| | Mean ± SD (Range) | Mean score ± SD (Range) | Mean score ± SD (Range) |
| Initial wellness score | 36 ± 22 (0–95) | 31 ± 20 (0–80) | 49 ± 21 (20–95) |
| Data not available | 66 | 27 | 22 |
| Number of PCC symptoms | 8.2 ± 3.8 (1–19) | 9.5 ± 3.7 (1–19) | 6.8 ± 3.2 (2–17) |
| Data not available | 5 | 2 | 0 |

SD, standard deviation.
All percentages are rounded to the nearest percent.

Post-COVID service being established. 107 patients (61%) were female. 69% CYP were of White ethnicity (compared to 54% across the Greater London population; Figure S1a), with 7% being Asian/Asian British (21% across Greater London) and 2% being Black/African/Caribbean/Black British (14% across Greater London).

Patient's residential postcodes were evenly spread across IMD quintiles 2–5, with fewer patients residing in the most deprived IMD quintile 1 areas. This contrasts with the regional Greater London population, where nearly half of residential neighbourhoods are in the 2 most deprived IMD quintiles (Figure S1b).

At referral 71% of patients had a previous medical history including 42% with atopy, 17% neurodiverse patients and 22% with a previous or current mental health condition (Table 1). Of neurodivergent patients, 18 had ASD (10% of total sample), 5 had attention deficit hyperactivity disorder, 4 had dyslexia, 3 had sensory processing disorder, 2 had dyspraxia and 3 had tic disorders (some patients had more than one diagnosis).

### *Differences between patients seen at in-person specialist clinics compared to local services*

Of the 176 patients referred, 104 (59%) were seen at in-person clinic while 48 (27%) had ongoing local care (Figure S2). Three patients were initially triaged to local care and were subsequently rereferred and directed to in-person clinics. Referrers for 17 patients did not attend the Pan-London multidisciplinary team meeting, while 7 patients were referred to other tertiary services after discussion including to respiratory, cardiology, ear, nose and throat, infectious diseases and complex adolescent clinics. Comparing CYP referred to in-person clinics to those continuing with local care, there were no differences in age ($t = 0.09$, $p = .9$), sex ($X2 = 0.01$, $p = .9$), IMD quintile distribution ($U = 2{,}034$, $p = .2$), or background medical history.

Patients reported a mean 8.2 PCC-related symptoms (range 1–19 symptoms). No patients required hospital admission during their acute SARS-CoV-2 viral infection. 54% CYP had mild functional impairment, with 21% having moderate and 7% having severe or very severe functional impairment (Table 2). 53% of patients referred were either not attending school or were attending half the week or less (Table 2). Mean wellness score at referral was 36/100 (data were missing for 66 CYP). These functional indicators were not associated with age or sex.

Patients triaged to in-person clinics reported more symptoms (9.5 vs. 6.8; $t = 4.5$, $p < .0001$), lower school attendance at initial assessment ($U = 1{,}299$, $p < .001$), more severe functional limitations ($U = 2{,}585$, $p = .001$) and lower wellness scores (31/100 vs. 49/100; $t = 3.9$, $p < .001$) than those where ongoing local care was advised.

### *Symptom profiles of patients at initial in-person clinic assessment*

Patients seen at in-person clinics ($n = 104$) reported a mean 9.5 current PCC-related symptoms (Table 2). Number of symptoms was not associated with baseline demographics or previous medical problems. Almost all CYP (96%) reported fatigue, with the next most common symptoms being brain fog (83%), headache (80%), mood disturbance (72%), sleep disturbance (64%), shortness of breath (57%) and abdominal pain (50%) (Table S2). Anosmia was reported by 25% CYP.

Patients with past mental health problems and neurodiverse patients were less likely to report PCC-related sleep disturbance than other CYP (mental health conditions: 42% vs. 72%, $X2 = 6.2$, $p = .01$; neurodiversity: 43% vs. 70%, $X2 = 4.4$, $p = .04$). Neurodiverse patients were less likely to report mood changes (48% vs. 78%, $X2 = 6.4$, $p = .01$). Patients with pre-existing atopy were less likely to report rash symptoms (10% vs. 32%, $X2 = 5.9$, $p = .02$) but more likely to report anosmia (35% vs. 16%, $X2 = 4.2$, $p = .04$) than those without atopy. There were no other associations between symptoms and background medical problems.

More severe functional impairment recorded in clinic was associated with weakness ($X2 = 12.6$, $p = .002$) and anosmia ($X2 = 8.6$, $p = .01$) symptoms. Only 20% CYP with mild functional

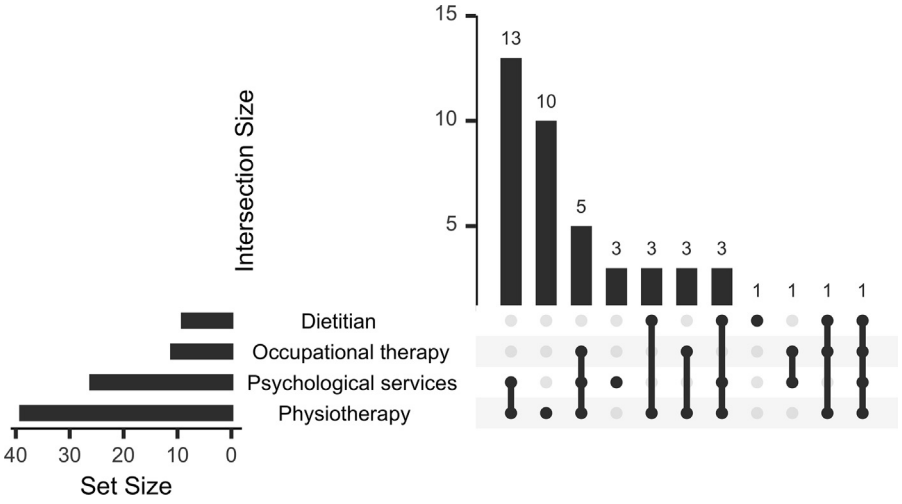


**Figure 1.** Showing an upset plot detailing the allied health professionals seen by patients as part of their in-person clinic management. The total number of patients seeing each allied health service is represented on the left horizontal bar plot (set size). Each possible combination of professionals is represented by the dot and line plot along the bottom of the figure, while the top vertical bar plot represents how often each combination occurred in the patient population (intersection size). In total 44/54 patients seen in the UCLH IDT clinic received input from allied health professionals including physiotherapy, occupational therapy, psychological services and dietetics.

impairment at baseline reported symptomatic weakness, whereas 31% with moderate functional impairment and 73% with severe/very severe functional impairment reported weakness. There were no other associations between symptoms and extent of functional impairment at the time of initial assessment.

*Management offered*

The 104 patients seen in UCLH or ELCH clinics were managed by senior clinicians (consultant or senior registrar paediatrician, consultant child, and adolescent psychiatrist or paediatric nurse consultant) with a multidisciplinary team. Over 6 months of in-person clinic management, 33/54 CYP in the UCLH cohort were advised to commence medication including melatonin (n = 18), antihistamines (n = 14), vitamins and supplements (n = 12), gastrointestinal-related medications (n = 8), and amitriptyline (n = 6) (see Table S3 for full list).

In the UCLH in-person clinic cohort of 54 CYP (ELCH data were not available), 81% received management input from allied health professionals including physiotherapy (72%), occupational therapy (20%), psychological services (46%), and dietetics (17%). 14/54 patients saw one of these allied health professionals, with 30/54 patients accessing 2 or more different allied health professionals (Figure 1). Forty-four onward referrals were made for 26 patients from this cohort of 54 CYP, including multiple referrals for 11 CYP. Referrals were most commonly to subspecialist paediatric cardiology (n = 10), gastroenterology (n = 8) and respiratory (n = 7), with additional referrals to neurology, neurosurgery, rheumatology, endocrinology, genitourinary, mental health, audiovestibular medicine, pain, acupuncture, podiatry, and transition teams.

*Six-month follow-up of in-person clinic cohort*

*Functional impairment.* Six-month follow-up functional impairment scores were available for 78/104 in-person clinic patients. CYP with missing data did not show any differences in demographics or initial functional impairment scores from those with follow-up data. There was an overall improvement in function across the group, with 29/78 (37%) CYP having no functional impairment, 28/78 (36%) having mild functional impairment, 16/78 (21%) having moderate functional impairment, and 5/78 (6%) having severe impairment at six-months follow-up.

Of 73 CYP with initial and six-month functional impairment scores, 55% improved by at least one functional category, with 41% remaining in the same category and 4% showing a deterioration in function by one category (Figure 2). There was no difference in the proportion of CYP whose functional impact score improved compared to those where it was unchanged ($X^2 = 0.9$, $p = .6$; there were insufficient patients whose function deteriorated to include in the analysis). Change in functional impairment was not correlated with baseline characteristics, medical history, or specific symptoms at presentation.

*School attendance.* Six-month follow-up school attendance data were available for 79/104 patients. There were no differences in demographics or initial school attendance for the group with missing follow-up data from those with follow-up data. Of these, 31/79 CYP reported full-time school attendance at follow-up, with 20/79 attending school more than half the time, 16/79 attending half the time or less, and only 5/79 not attending school at all. A further 7/79 CYP were being home-schooled.

Of 67 CYP with school attendance data for initial and six-month follow-up clinics (home-school CYP at either time point were excluded) 63% had increased school attendance at follow-up, with no change in attendance reported for 22% and reduced attendance reported for 6% (Figure 3), while 7% CYP reported full time school attendance at both timepoints. Comparing CYP attending school less-than full time at baseline, there was a trend that those who were attending half the time or less or not attending at all were more likely to show improvement in school attendance at 6 month follow-up compared to

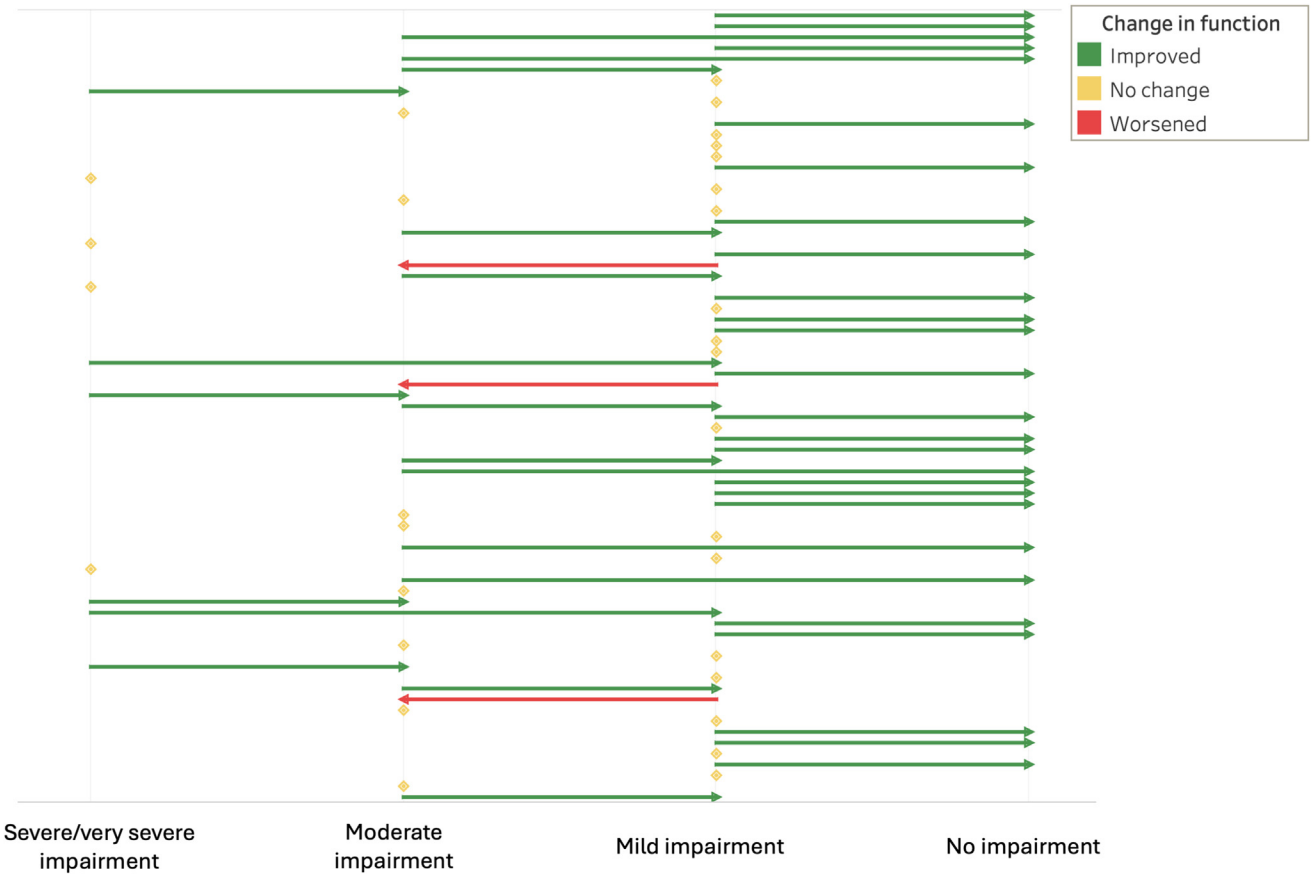


**Figure 2.** Showing patients' levels of functional impairment at the initial in-person clinic and at 6 months follow-up the 73 patients with complete data. Start of arrows represents initial functional impairment category, arrow head represents functional impairment category at 6 months. Green arrows 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.

those attending more than half the time, although this did not meet statistical significance ($X^2 = 6.0$, $p = .051$). School attendance was not associated with baseline characteristics or previous medical history.

*Wellness scores.* Follow-up wellness scores were only available for 23/104 patients, all seen at the UCLH site. Neurodiverse CYP were less likely to have a follow-up wellness score recorded ($X^2 = 4.6$, $p = .03$) The mean wellness score at six-month follow-up was 61/100 (range 10–100). Of the 22/104 CYP with wellness scores at initial assessment and six-month follow-up, the mean improvement in wellness score was 31 points. 20/22 CYP reported increased wellness scores, with one patient reporting no change, and one patient reporting a decrease in wellness score.

## Discussion

Our data describe the baseline characteristics, symptoms, functional impairment and management of the first 176 patients with PCC-related symptoms referred for tertiary specialist input to a regional post-COVID service between June 2020 and August 2022, based on routinely collected and recorded clinical data.

In keeping with other data sources, our records show a higher number of females than males being referred to the service [19,20]. There were no sex differences in baseline demographics or functioning of those referred. Most commonly, patients were 12–15 years of age, reflecting that PCC-related symptoms are more prevalent in adolescents than younger children [21]. The referrals showed a higher percentage of White patients, and lower percentage of Asian and Black patients, than the regional population. A smaller proportion of referred patients came from the lowest IMD quintile than would be expected based on regional data, despite data suggesting that PCC-related symptoms are more prevalent in patients of low socioeconomic status [22,23]. This difference may reflect variations in symptom prevalence but is likely also influenced by factors including access to health services, potential barriers to diagnosis, onward referral from secondary paediatric or primary care services, and the intersection between socioeconomic status and ethnicity in the population [24]. It suggests that this specialist service may not be reaching particularly CYP vulnerable groups and further work is needed to ensure that access to these specialist clinics is equitable to the whole population they serve [25], Nearly 60% of patients referred to the Pan-London service met the criteria for in-person clinic management by a tertiary specialist team. As expected, these patients had more symptoms and greater functional impairment than those who continued to have local management. No patients referred were found to have severe end organ complications of SARS-CoV-2 infection e.g. myocarditis. While the proportion of CYP referred with a history of atopy

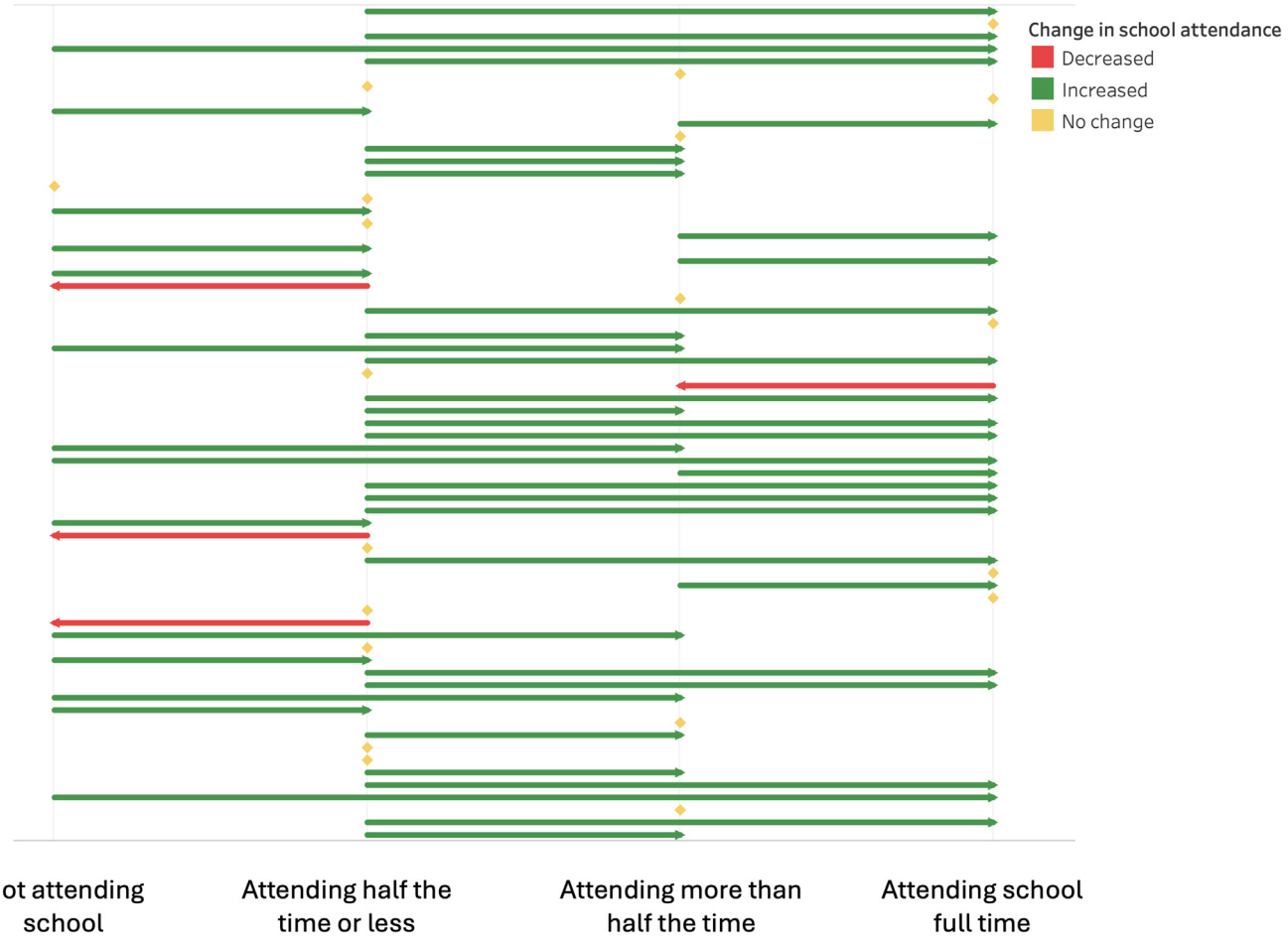


**Figure 3.** Showing patients' school attendance at the initial in-person clinic appointment and 6 month follow-up appointment for the 67 patients with complete data. Patients who reported primary home schooling at either timepoint (n = 8) are excluded. Each horizontal line represents one patient. Green arrows represent increase in school attendance over 6 months, red arrows represent decrease in school attendance. Yellow diamonds represent patients who had no change in their attendance over 6 months.

or a mental health condition were in keeping with estimated regional prevalence rates, the proportion of patients referred to clinic who have a confirmed ASD diagnosis (10%) is much higher than population estimates of ~2% [26,27], and may not capture all those with symptoms, only confirmed diagnoses. Further work should be undertaken to explore whether the high ASD prevalence in our CYP population with PCC-related symptoms is seen across similar clinics.

A high proportion of patients seen at in-person clinics received individual allied health professional input in addition to the group sessions offered to all patients referred to the service of targeted activity management and psychological support, cognitive function, sleep and nutritional advice, and parents/carer support. The commissioned service had more physiotherapy than occupational therapy time included (5:2 ratio) which likely influences the numbers of CYP seen by each therapist. Offering coordinated care with input from relevant health professionals is central to the Pan-London Post-COVID service model. Understanding the multidisciplinary support needed to manage the ongoing needs of CYP with complex symptoms is critical as our understanding of PCC management continue to develop.

Sixty-one percent of patients were started on medication in clinic including prescriptions to support sleep, pain, cardiac or gastrointestinal symptoms. There were a high number of referrals to a range of other specialists. The diversity of referrals emphasises the heterogeneity of PCC-related symptoms, while the large number of onward referrals may reflect the profession's initial uncertainty regarding PCC sequelae, including the potential for end-organ damage and the management of dysautonomia, and may be expected to change as our understanding of PCC develops. Further work and clinical trials are needed to develop additional treatment options, particularly to support autonomic dysfunction.

Six-month functional outcomes were variable, with more than half of in-person clinic patients reporting functional improvement, but many others reporting the same level of functional impairment. Only a small number of patients report worsening impairment after 6 months which can positively reinforce that many CYP experience improving symptoms after developing PCC. However, these functional categories are broad, not linear in severity and may include a diverse set of limitations. Therefore, although individuals may stay in the same functional

impairment category, their symptoms may change, and symptoms and function may show some improvement or deterioration but not sufficient to 'move' categories. There was no association between baseline functional impairment severity and progress over 6 months in our cohort.

Only 25% patients referred to the Pan-London Post-COVID service were attending school at least half of the week, emphasising the functional impact of PCC on this cohort at a critical point in their educational journey. At 6 months follow-up, nearly 60% patients showed improved school attendance. There was a trend to this being more likely for those who were attending school half the time or less at baseline compared to those attending more. This may reflect symptomatic improvement enabling a young person to manage the physical, cognitive and socioemotional demands of school, but also may reflect the role of the specialist healthcare team in liaising with schools to support personalised plans for flexible managed reintegration to education. School attendance does not in itself provide evidence that CYP are accessing learning and maximising school attendance may not necessarily be the primary focus of care where activity levels need to be manged. Future qualitative and quantitative evaluations and research are needed to understand how to maximise access to education and learning including online and home-based resources and reduce the impact of significant adolescent illness on long term opportunities and goals.

Our data represent a large patient cohort seen in a novel Pan-London post-COVID service at a time when the symptom profile, pathogenesis and optimal management were poorly understood. This evaluation helps characterise patients attending our service and captures their functional progress. Based on our analyses, there were no clear features at presentation in terms of demographics, symptoms, or functional impairment that predicted whether individual young people would show significant functional improvement over 6 months. Future work investigating the impact of individual treatment factors are needed to understand the mechanisms by which improvements in function occur.

While there are many strengths to our service evaluation, there are also limitations to this work. The symptoms captured on the International Severe Acute Respiratory and emerging Infection Consortium were based on self-report and were considered present or absent. This means we cannot capture 'severity' of individual symptoms and do not have objective measurements to track change over time, and instead have an overview impact of symptoms on functioning and well-being. The wellbeing score used in this study is commonly used in our clinical practice but has not been formally validated against other measures of subjective wellbeing. At the time of data collection, COVID tests were not consistently available and the criteria used to diagnose PCC in young people were broad. The Pan-London multi-disciplinary team triaged each referral to ensure that the service was appropriate for their needs, the clinic cohort presented is diverse and heterogenous and contains some diagnostic uncertainty. There continues to be uncertainty about the pathophysiology of PCC and its potential overlap with ME/CFS with COVID as a precipitating event, and it is not clear how much our data are specific to PCC and can be generalisable to other cohorts. Follow-up data were retrospectively analysed from routinely collected clinical data so are limited to features considered clinically relevant during appointments, particularly reviewing persisting symptoms, rather than documenting the presence/absence of potential symptoms. This limits our evaluation of broader functional outcomes rather than individual symptom level changes. Follow-up data are only available where patents attend clinic, meaning that missing data may not be random.

Two key areas of the service that could not be evaluated using available data were understanding the views of patients, families and carers, and understanding the management and outcomes of patients managed locally after their initial Pan-London multidisciplinary team review. Future work aiming to address these gaps through both further service evaluation and formal research projects is being undertaken and will be complemented by plans to consider how other equivalent services nationally and internationally operate and how their patient populations compare with our own.

### *Conclusion*

Our data represent a large cohort of young people requiring tertiary referral for PCC-related symptoms to a Pan-London service. The evaluation highlights the significant functional impact and effects on accessing educational provision suffered by moderately and severely affected patients with PCC-related symptoms. Our data demonstrate that more than half of patients seen in our specialist tertiary clinics showed functional improvement and increased school attendance over 6 months, while a subgroup had persistent symptoms without improvement. This suggests that the service model is beneficial for this complex patient group overall, but demonstrates the ongoing need for support via specialist services. Further work is needed to understand the variability in presentation and symptom course, and to explore underlying causes and potential further treatment options.

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## Supplementary Data

Supplementary data related to this article can be found at https://doi.org/10.1016/j.jadohealth.2025.01.026.

## References

[1] Behnood SA, Shafran R, Bennett SD, et al. Persistent symptoms following SARS-CoV-2 infection amongst children and young people: A meta-analysis of controlled and uncontrolled studies. J Infect 2022;84:158–70.

[2] World Health Organization. Post COVID-19 condition (long COVID). 2022. Available at: https://www.who.int/europe/news-room/fact-sheets/item/post-covid-19-condition. Accessed November 6, 2023.

[3] Simpson F, Lokugamage A. Counting long covid in children. The BMJ. October 16, 2020. Available at: https://blogs.bmj.com/bmj/2020/10/16/counting-long-covid-in-children/. Accessed June 26, 2023.
[4] Newlands F, Goddings AL, Juste M, et al. Children and young people with long COVID—comparing those seen in post-COVID services with a non-hospitalised national cohort: A descriptive study. Children 2023;10:1750.
[5] Pinto Pereira SM, Shafran R, Nugawela MD, et al. Natural course of health and well-being in non-hospitalised children and young people after testing for SARS-CoV-2: A prospective follow-up study over 12 months. Lancet Reg Health Eur 2023;25:100554.
[6] Toepfner N, Brinkmann F, Augustin S, et al. Long COVID in pediatrics—epidemiology, diagnosis, and management. Eur J Pediatr 2024;183:1543–53.
[7] Johnston R, Sonnappa S, Goddings AL, et al. A review of post COVID syndrome pathophysiology, clinical presentation and management in children and young people. Paediatr Respir Rev 2025;53:14–22.
[8] Brackel CLH, Noij LCE, Vijverberg SJH, et al. International care programs for pediatric post-COVID condition (long COVID) and the way forward. Pediatr Res 2024;96:319–24.
[9] Gonzalez-Aumatell A, Bovo MV, Carreras-Abad C, et al. Social, academic, and health status impact of long COVID on children and young people: An observational, descriptive, and longitudinal cohort study. Children (Basel) 2022;9:1677.
[10] NHS England. NHS sets up specialist young people's services in £100 million long COVID care expansion. 2021. Available at: https://www.england.nhs.uk/2021/06/nhs-sets-up-specialist-young-peoples-services-in-100-million-long-covid-care-expansion/. Accessed June 26, 2023.
[11] Wacks M, Wortley E, Gregorowski A, et al. Fifteen-minute consultation: Managing post-COVID-19 syndrome (long COVID) in children and young people. Arch Dis Child Educ Pract Ed 2024;109:29–34.
[12] Sigfrid L, Maskell K, Bannister PG, et al. Addressing challenges for clinical research responses to emerging epidemics and pandemics: A scoping review. BMC Med 2020;18:190.
[13] Merzon E, Weiss M, Krone B, et al. Clinical and socio-demographic variables associated with the diagnosis of long COVID syndrome in youth: A population-based study. Int J Environ Res Public Health 2022;19:5993.
[14] National Instiute of Clinical Excellence (NICE). Myalgic encephalomyelitis (or encephalopathy)/chronic fatigue syndrome: Diagnosis and management. 2021. Available at: https://www.nice.org.uk/guidance/ng206. Accessed November 6, 2023.
[15] Viner R, Gregorowski A, Wine C, et al. Outpatient rehabilitative treatment of chronic fatigue syndrome (CFS/ME). Arch Dis Child 2004;89:615–9.
[16] McKenzie R, O'Fallon A, Dale J, et al. Low-dose hydrocortisone for treatment of chronic fatigue SyndromeA randomized controlled trial. JAMA 1998;280:1061–6.
[17] Wille N, Badia X, Bonsel G, et al. Development of the EQ-5D-Y: A child-friendly version of the EQ-5D. Qual Life Res 2010;19:875–86.
[18] Office of National Statistics (ONS). Ethnic group, national identity and religion. 2021. Available at: https://www.ons.gov.uk/methodology/classificationsandstandards/measuringequality/ethnicgroupnationalidentityandreligion. Accessed June 26, 2023.
[19] Bai F, Tomasoni D, Falcinella C, et al. Female gender is associated with long COVID syndrome: A prospective cohort study. Clin Microbiol Infect 2022;28:611.e9-611.e16.
[20] Sylvester SV, Rusu R, Chan B, et al. Sex differences in sequelae from COVID-19 infection and in long COVID syndrome: A review. Curr Med Res Opin 2022;38:1391–9.
[21] Miller F, Nguyen DV, Navaratnam AM, et al. Prevalence and characteristics of persistent symptoms in children during the COVID-19 pandemic: Evidence from a household cohort study in England and wales. Pediatr Infect Dis J 2022;41:979.
[22] Pfaff ER, Madlock-Brown C, Baratta JM, et al. Coding long COVID: Characterizing a new disease through an ICD-10 lens. BMC Med 2023;21:58.
[23] Khullar D, Zhang Y, Zang C, et al. Racial/ethnic disparities in post-acute sequelae of SARS-CoV-2 infection in New York: an EHR-based cohort study from the RECOVER program. J Gen Intern Med 2023;38:1127–36.
[24] Raleigh. The health of people from ethnic minority groups in England. The King's Fund. May 17, 2023. Available at: https://www.kingsfund.org.uk/publications/health-people-ethnic-minority-groups-england. Accessed November 14, 2023.
[25] Neale FK, Armstrong EJ, Cohen JM, et al. How fair is our service? Evaluating access to specialist paediatric care. Arch Dis Child 2019;104:1105–7.
[26] O'Nions E, Petersen I, Buckman JEJ, et al. Autism in England: Assessing underdiagnosis in a population-based cohort study of prospectively collected primary care data. Lancet Reg Health Eur 2023;29:100626.
[27] Roman-Urrestarazu A, van Kessel R, Allison C, et al. Association of race/ethnicity and social disadvantage with autism prevalence in 7 million school children in England. JAMA Pediatr 2021;175:e210054.