



Disabled, discharged and disappearing from view

A snapshot review of Long Covid
services across the UK
Executive Summary, March 2025





Executive summary

Long Covid is a clinical syndrome characterised by persistent symptoms caused by a SARS-CoV-2 infection. It is a complex, chronic, multisystem condition that can be severely disabling (Al-Aly et al., 2024).

The Office for National Statistics (ONS) reported that, as of 7 March 2024, 2 million people in England and Scotland were experiencing self-reported Long Covid, representing 3.3% of the total population (ONS, 2024). This is approximately equivalent to the combined populations of Birmingham, Glasgow and Cardiff. Data from ONS Infection Surveys show that the prevalence of Long Covid has risen steadily between September 2021 and March 2024. (ONS, 2022a; ONS, 2023; ONS, 2024).

NHS England commissioned specialist Long Covid services for adults, children and young people (CYP). In the devolved nations, there was no central commissioning of specialist services, though some were established by individual regional health authorities.

Feedback from people with Long Covid suggests that some services are failing to meet existing commissioning guidelines. Additionally, anecdotal reports of service changes and closures have raised concerns about continued access to specialist Long Covid care.

To investigate this we:

1. Conducted an online nationwide survey of adults and CYP with Long Covid (n = 692; 510 adults, 182 CYP)
2. Submitted Freedom Of Information (FOI) requests to all relevant health authorities regarding the status of their Long Covid services
3. Conducted an analysis of local Long Covid referrals in 1 UK region using Derby and Derbyshire Integrated Care Board (ICB) as an exemplar
4. Present a case study describing the public consultation on proposed changes to Long Covid services in Derby and Derbyshire ICB

We found that...

Finding 01

Long Covid is driving high levels of disability.

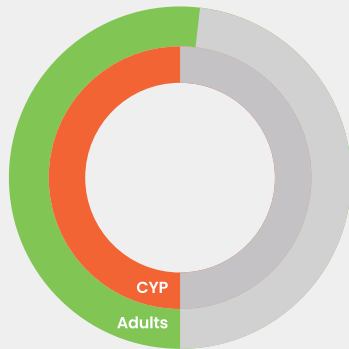
Over half of adults and CYP considered themselves disabled by the condition.

55%

Adults

50%

CYP



Finding 03

Specialist Long Covid services are falling short of NHS commissioning guidelines, which stipulate that services should be physician-led and require the option for in-person consultations.

Over a quarter of adults and CYP have received neither an in-person appointment nor a remote consultation with a healthcare professional.

28%

Adults

26%

CYP

Finding 02

Awareness of specialist Long Covid services remains insufficient amongst those with Long Covid.

Over a quarter of adults and three-fifths of CYP were not aware of any local specialist Long Covid services.

28%

Adults

61%

CYP

51%

Adults

28%

CYP

Finding 04

Many patients are not followed up or are discharged despite ongoing symptoms.

Half of adults and just over a quarter of CYP reported that they had been discharged despite still having ongoing symptoms.



Finding 05

Satisfaction with specialist Long Covid services is low but is higher than that for NHS services overall.

About half of adults (48%) and CYP (55%) reported low satisfaction levels with specialist Long Covid services. However, low satisfaction with the NHS was even lower among those who had not used specialist services compared to those who had (77% versus 55%). Similarly, CYP reported low satisfaction levels with the NHS, but there was little difference between those who had used specialist services compared to those who had not (67% and 69% respectively).



Finding 06

Specialist Long Covid service provision in the UK is already limited and is set to diminish further.

Some services have already closed, others are merging with local providers and many face the risk of closure unless funding is secured beyond March 2025.



Finding 07

Public consultation about specialist Long Covid service change is absent or tokenistic.

Only 6% of adults and 1.4% of CYP reported participating in public consultations and none felt that the outcomes met their expectations. Most respondents described these consultations as largely tokenistic.

Finding 08

Health authorities are underestimating the true demand for Long Covid care.

Some health authorities are using GP referral numbers to justify the closure or reduction of specialist Long Covid services. Our analysis shows that this is a woefully inadequate method to determine true demand for services.



Based on our findings, we make 8 recommendations:

- 1. Urgently reinstate national Long Covid surveillance.**
- 2. Reverse closures of NHS specialist Long Covid services for adults and children.**
- 3. Allocate sufficient, secure, ongoing funding for specialist Long Covid services.**
- 4. Restore national oversight of specialist Long Covid services to the DHSC.**
- 5. Establish a comprehensive Long Covid national research strategy led by a dedicated co-ordinating body.**
- 6. Evaluate and adopt gold standard Long Covid clinical practice nationwide.**
- 7. Implement a rolling programme of Long Covid healthcare professional education and training.**
- 8. Formally recognise and manage Long Covid as a disabling condition.**

Recommendations

01 Urgently reinstate national Long Covid surveillance

Urgent reinstatement of national surveillance via the ONS is essential to accurately measure the ongoing impact of Long Covid. Health authorities in England, Northern Ireland, Scotland and Wales should commit to using this national surveillance data to assess the true demand for Long Covid services across the UK, based on national prevalence data rather than relying solely on local GP referral figures. As our analysis of referrals in Derby and Derbyshire ICB shows, many individuals with Long Covid are not being referred to clinics, meaning referral data does not capture the full demand for services. Without national surveillance, the true burden of Long Covid will remain hidden and underreported, undermining efforts to make evidence-based decisions, allocate resources effectively and provide adequate support to those affected.

02 Reverse closures of specialist NHS Long Covid services for adults and CYP

NHS England and health authorities in Northern Ireland, Scotland and Wales must immediately act to reverse closures or reductions of Long Covid services. Preserving this network is critical, not only for meeting the specific needs of Long Covid patients, but also for retaining the accumulated expertise of the healthcare professionals involved.

03 Allocate sufficient, secure, ongoing funding for specialist Long Covid services

NHS England, alongside the NHS in Northern Ireland, Scotland and Wales must adequately fund Long Covid services for adults and children in proportion to the true demand, ensuring consistency in access, care outcomes and patient experience across the UK.

Funding should be explicitly ring-fenced for specialist Long Covid services, preventing the reallocation to other areas of healthcare. Funding must be matched to the prevalence of Long Covid and it should be part of a long-term financial commitment to ensure that services are not subject to short-term funding arrangements or to future cuts.

The lack of specific funding for paediatric Long Covid services in the NHS England operational planning guidance is unacceptable and must be addressed to ensure children also receive appropriate care.

04 Restore national oversight of specialist Long Covid services to the Department of Health and Social Care

National oversight of Long Covid services should be reinstated to the DHSC to ensure a co-ordinated and consistent approach to care across the UK. This oversight should involve verifying that Long Covid services adhere to NHS clinical commissioning guidelines. This system must also monitor

service use across different demographics and locations to identify gaps in provision and ensure that all individuals have equitable access to specialist Long Covid care. It should also include a centralised, publicly available system which should be established to map Long Covid services across the UK to improve transparency.

Additionally, Long Covid must be incorporated into any NHS long-term condition strategies, equivalent to the now-paused Major Conditions Strategy, to ensure long-term recognition and funding within broader healthcare planning (DHSC, 2023).

05 Establish a comprehensive Long Covid national research strategy led by a dedicated co-ordinating body

A national research strategy focused on Long Covid is urgently required to improve patient outcomes. Research funding should prioritise research into pathophysiology, diagnostics, clinical management, treatments and health services delivery. It should be supported by long-term government funding and led by a dedicated co-ordinating body to oversee a sustained, large-scale interdisciplinary research program. Meaningful patient involvement should be central throughout the entire research process, from planning to implementation.

06 Evaluate and adopt gold standard Long Covid clinical practice nationwide

A programme of clinical audit and research should be established to identify best practices for Long Covid services with regular updates to reflect the evolving evidence base, as understanding of the condition continues to develop. This programme should prioritise high patient

satisfaction, patient safety and clinical outcomes. Centres of excellence should be identified and serve as models for the wider healthcare system. The best practice model should also inform budget planning for the provision of specialist services.

07 Implement a rolling programme of Long Covid healthcare professional education and training

A national training programme in Long Covid clinical practice for healthcare professionals should be established. This programme should address both the career development of healthcare professionals and the embedding of core competencies for Long Covid care across all levels of the NHS. Training should be integrated into the NHS Core Skills Training Framework and included in pre-registration competencies for undergraduate and postgraduate education. Specific training programmes should be targeted at frontline staff and specialist care providers to ensure consistent, high-quality, safe, equitable and inclusive service design and care.

08 Formally recognise and manage Long Covid as a disabling condition

Many people with Long Covid experience significant and prolonged impairments that severely impact their ability to work, study and engage in daily life. These challenges align with the definition of a disability under the 2010 Equalities Act (Equalities Act, 2010). Official recognition of Long Covid as a disabling condition would ensure access to essential educational and workplace accommodations, social support and healthcare resources. Additionally, it would provide vital legal protections to guarantee access to these supports.

Conclusion

With more than 2 million people living with the condition across the UK, and the number continuing to rise, Long Covid is a national public health crisis. Many of those affected now consider themselves disabled due to persistent symptoms that adversely impact their ability to work, attend school, maintain relationships and engage meaningfully in daily life.

Specialist Long Covid services were established across England and in some regions of the devolved nations by 2022 but access remains inconsistent across the UK and many people with Long Covid still do not know these services exist. While some services provide high-quality care, others require improvement. The future of these services is uncertain, with funding cuts threatening to leave many patients without care after March 2025. Our findings from Derby and Derbyshire ICB indicate that relying solely on GP referrals to assess demand for these services is inadequate and likely severely underestimates the true number of people in need of specialised care. If other health authorities are using the same flawed approach, they may be making similarly misguided decisions to close these essential services. The closures of these services would not only deprive Long Covid patients of the specialised care they need, but it will also lead to the loss of the expertise healthcare professionals have accumulated.

Our findings suggest that Long Covid services are not meeting NHS commissioning guidelines and are failing in their statutory duty to involve the public in service development. We also found that satisfaction with NHS services for Long Covid remains generally low, though adults in our survey reported slightly higher satisfaction with specialist Long Covid services compared to NHS care overall. It is clear that healthcare professionals urgently require better nationally co-ordinated support to deliver effective, high-quality care.





The provision of Long Covid healthcare is hindered by a lack of actionable medical research and, where evidence exists, it has largely not been integrated into clinical practice across most of the UK. Even when people can access care, clinicians are often limited to offering symptom management-based care using treatments for conditions with similar symptoms. It is crucial to invest in research aimed at developing disease-modifying therapies for Long Covid and other IACCI to ensure their rapid implementation in clinical care.

The initial investment in Long Covid care primarily enabled signposting and basic support, but this is insufficient to meet the needs of those affected. Addressing the Long Covid crisis successfully will require a considerable increase in funding for specialist services but failing to provide high-quality care for Long Covid is ultimately a false economy. People with Long Covid will still seek healthcare, but if this care is inadequate it will waste both patient and clinician time and fail to improve health outcomes. As a result, many individuals risk remaining unable to return to work, education or caregiving responsibilities, at great cost to the economy and society. Investing in comprehensive Long Covid care will help to counteract these losses and bring long-term returns.

Failing to address the problem now will leave millions with a diminished quality of life and little prospect of improvement

There are concrete steps that can be taken to address these issues, outlined in our recommendations. These include: urgently reinstating national Long Covid surveillance; halting NHS Long Covid service closures and cutbacks; funding Long Covid services; restoring national oversight of Long Covid services at the DHSC; establishing a comprehensive national research strategy for Long Covid; evaluating and adopting gold standard Long Covid clinical practices; creating a programme of healthcare professional education and training; and formally recognising and managing Long Covid as a disabling condition.

Failing to address the problem now will leave millions with a diminished quality of life and little prospect of improvement, while further straining an already overstretched healthcare system and struggling economy. The UK government and healthcare authorities must acknowledge that people with Long Covid deserve the same high-quality care as those with other debilitating long-term conditions.

The choice is clear: either address Long Covid as the urgent public health crisis it is, or allow the UK healthcare system to abandon vast numbers of people. A national crisis of this scale demands a response of equal magnitude. We call upon the DHSC to recognise this reality and act.

