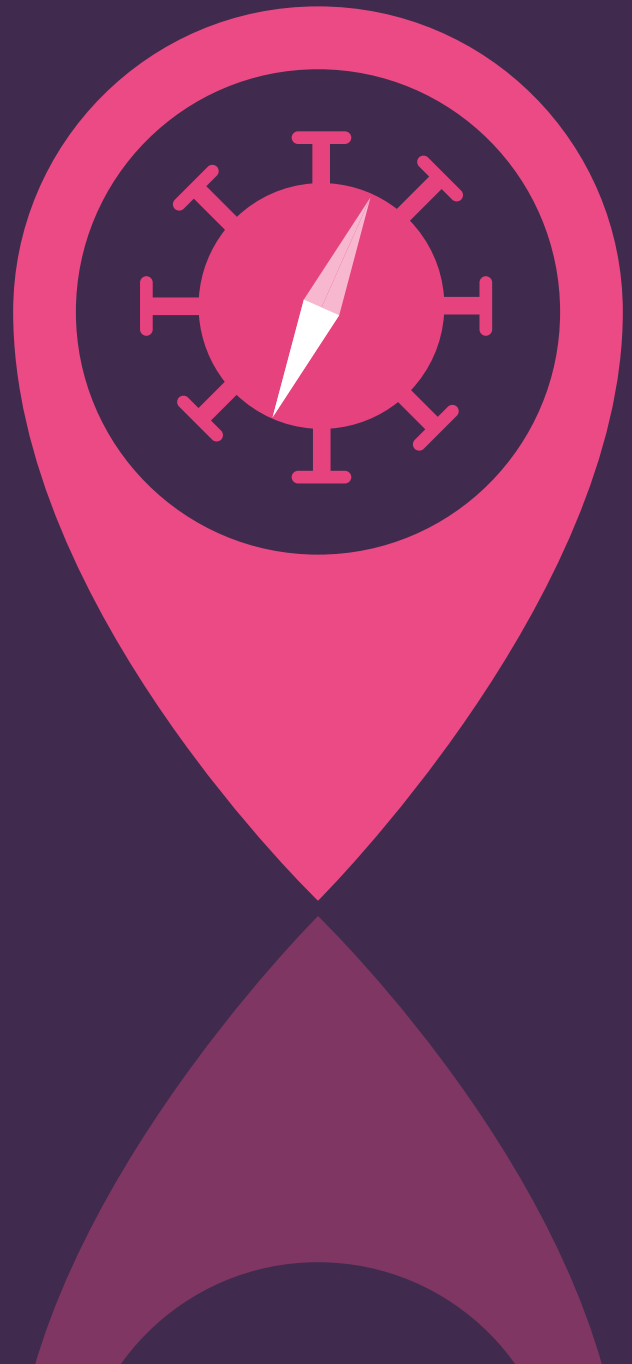


Navigating the Long Haul:

Understanding
Long Covid
in Northern
England





Authors

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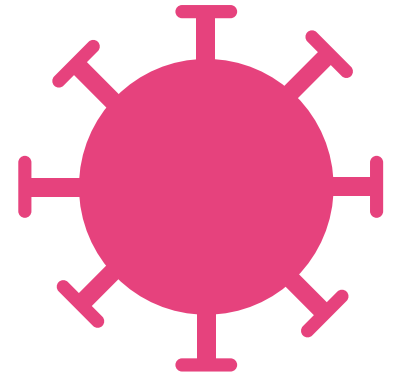
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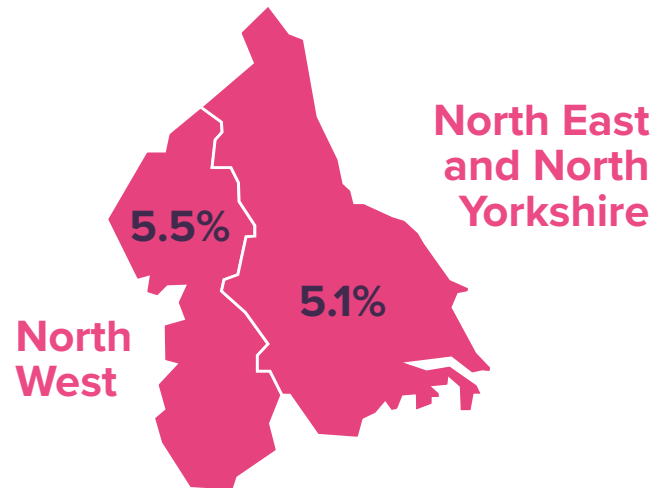
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SECOND SUMMARY

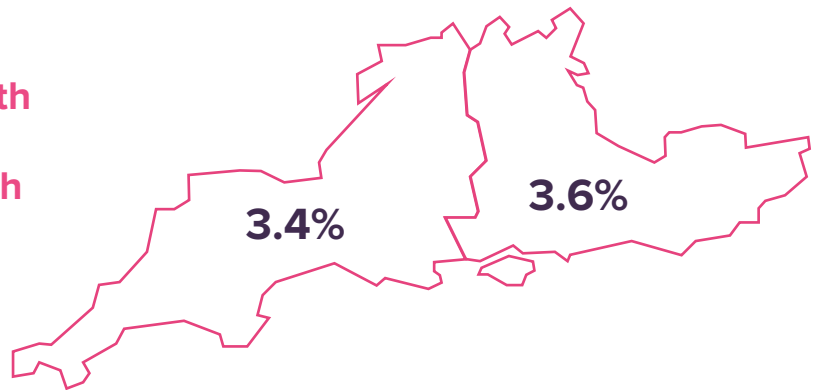


KEY FINDINGS

North-South divide



The regions with the lowest prevalence were the South West (3.4%) and the South East (3.6%). The average for England as a whole was 4.4%.



The North East, Yorkshire and the North West had some GP practices where the prevalence rate was at least .

North

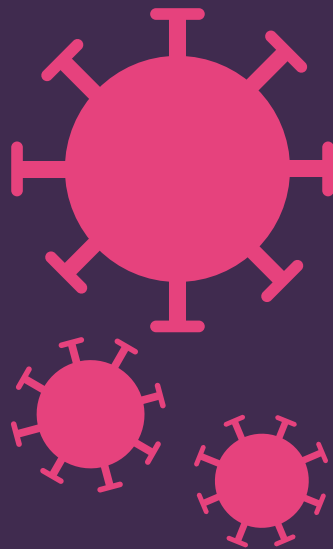
1.9million

people in England were experiencing a myriad of self-reported Long Covid symptoms as of March 2023, according to the Office for National Statistics (ONS).

79%

of people who self-reported Long Covid symptoms said it has had a negative impact on their day-to-day activities.

There is considerable evidence of socioeconomic inequalities in Long Covid in the North East and Yorkshire, where rates in the most deprived groups (8.3%) were 5.2 percentage points higher than in the least deprived areas (3.1%).



While many employers in the North provide support for Covid-19, this is specified on an acute basis, rather than in response to Long Covid/post Covid illnesses.



Only three out of 10 northern employers contacted offered a specific rehabilitation package to employees living with Long Covid despite the high prevalence in the region.

The prevalence rate in the most deprived decile (6.3%) was nearly twice that in the least deprived decile (3.3%).

The most deprived areas in the North had higher Covid-19 mortality rates than equally deprived areas in the rest of England, indicative of 'deprivation amplification' where the negative health effects of local deprivation is worsened for those living in deprived regions.

Recommendations

Research funders should prioritise biomedical research into Long Covid to establish accurate diagnostic tests, understand the illnesses' pathophysiological mechanisms and develop treatments.

Research into the impact of known social determinants of health and their relationship with Long Covid should be undertaken.

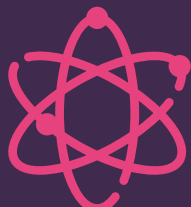
Learning from overlap with other post-viral conditions such as myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) should be harnessed during Long Covid research and further funding into these conditions should be allocated to assist with treatment and future pandemic preparedness.

The relationship between disability figures, sex and Long Covid should be the basis of further research.

Priorities for government:

Government should develop programmes for employers to support members of their workforce with Long Covid.

A government consultation with Long Covid patients should be undertaken to better understand their condition and to implement care plans to facilitate rehabilitation and management of the condition.



Our previous research has demonstrated that the Covid-19 pandemic hit England unevenly with disproportionate effects for health, wealth and service provision in the North of England (Scott et al, 2024; Bambra et al, 2022; Munford et al, 2021). The North experienced significantly higher mortality rates, in both Covid-19 and all-cause, than the rest of England across the whole 13 months of pandemic lockdowns (Bambra et al, 2023). This adds to mounting evidence demonstrating worsening regional inequalities in mental wellbeing, hospital pressure, and vaccination uptake, as well as in unemployment and economic inactivity (Bambra et al, 2023; Bambra et al, 2022; Munford et al, 2021). Recent analysis indicates that the most deprived areas in the North had higher Covid-19 mortality rates than equally deprived areas in the rest of England, indicative of ‘deprivation amplification’ whereby the negative health effects of local deprivation is exacerbated for those living in more deprived regions (Bambra et al, 2023; Munford et al, 2022).

Nevertheless, despite a growing Covid-19 evidence base, some of which has explored ‘Long Covid’, there has been little examination of how prolonged Covid-19 signs and symptoms may have implications for population health and wealth, particularly in terms of more deprived regions - such as areas within the North East and North West. This introductory chapter provides background on what we know so far about Long Covid, the potential inequalities in Long Covid and the social and economic impacts that those experiencing Long Covid face.

Long Covid – What do we know so far?

Long Covid is a patient-made term first used by Elisa Perego to summarise her experiences of long-term Covid illness, characterised as cyclical, progressive and multiphasic (Callard and Perego, 2021). The hashtag #LongCovid was created on Twitter on the 20th of May 2020 and within the space of a few weeks, it started being used by an increasing number of individuals who were experiencing continuing symptoms of Covid-19 even after recovery (Garg et al., 2021).

National Institute for Health and Care Excellence (NICE) guidelines have been updated to reflect the possibility of having Covid-19 symptoms post-recovery and divides Covid-19 infections into three different phases: “acute Covid-19”, “ongoing symptomatic Covid-19” and “post-Covid-19 syndrome”. The umbrella term “Long Covid” can thus apply to both “ongoing symptomatic Covid-19 and “post Covid-19 syndrome” (Shah et al., 2021). Whilst we recognise that other terms exist, here we use Long Covid as an umbrella term, and one which encompasses other terms such as ‘Long-Haul Covid Patients’.

‘Long Covid’ is now defined in UK clinical guidelines, by NICE, as “signs and symptoms that continue or develop after acute Covid-19. It includes both ongoing symptomatic Covid-19 (from 4 to 12 weeks) and post Covid-19 syndrome (12 weeks or more)”. Estimating Long Covid prevalence has been limited considerably by heterogeneity and fluctuations in reported symptoms, signs and sequelae; as well as heterogeneity in study designs, follow-up durations, and measurement methods (Ziauddeen et al, 2022). To this end, Barker et al (2022) have described Long Covid as having ‘unwieldy clinical boundaries’.

Globally, however, it is anticipated that 65 million people worldwide are impacted by Long Covid as of January 2023, a figure based on an estimated global rate of 10% of infected people, extrapolated from an overall Covid-19 prevalence rate of 651 million documented cases (Davis et al, 2023). Other estimates suggest that more than 17 million people across the World Health Organisation (WHO) European Region may have experienced Long Covid during the first two years of the pandemic (2020/21). Meanwhile, one recent systematic



review placed global Long Covid prevalence to be as high as 45% of Covid-19 survivors, regardless of hospitalisation status, defined as those who experienced a range of unresolved symptoms at 4 months (O’Mahoney et al, 2023).

As of March 2023, according to the Office for National Statistics (ONS), an estimated 1.9 million people in England were experiencing a myriad of self-reported Long Covid symptoms; with very little published prevalence data available after this point. 79% of these individuals stated that Long Covid has had a negative impact on their day-to-day activities, with fatigue being named as the most experienced symptom, and over half reporting reduced functionality in their everyday activities, which resulted in their inability to return to work, with one study suggesting quality of life to be affected more than in the case of some cancers (Brehon et al, 2023; Burton et al, 2022; Walker et al, 2023; Callan et al., 2022; Kingstone et al., 2020; Ladds et al., 2021; Rushforth et al., 2021).

Thus, Ziauddeen et al (2022) reported that, amongst their participants, symptoms of exhaustion, cognitive dysfunction, shortness of breath, headache, chest pressure/tightness, and muscle aches dominated, with 86% scoring four or above on the Fatigue Severity Scale. Other reported symptoms include dyspnoea, post-exertional malaise, cognitive dysfunction, compromised quality of life, reduced capacity for self-care, altered smell and taste, myalgia, cough, and diarrhoea, as well as single and/or multiple organ impairment and significant impacts upon mental wellbeing, all of which can persist for weeks and months after initial infection (Garg et al., 2021; Carfi et al., 2020; Lopez-Leon et al., 2021; Davis et al., 2020; Ziauddeen et al, 2022).

Responding to Long Covid

As of May 2023, Covid-19 no longer officially constitutes a global health emergency of international concern and, over three years after initially being instated, Covid-19’s alert status was downgraded to ‘an established and ongoing health issue’ – an endemic disease (McGowan and Bambra, 2022). However, whilst the WHO have outlined concerns in relation to the long-term dangers posed by Long Covid, this decision creates a striking dissonance with the position of Long Covid patient groups and researchers, which is that Long Covid represents a “mass disabling event” and that its threat to health and wealth is still ongoing (Lowenstein, 2022; Ireson et al., 2022). Meanwhile, there remains little evidence-based treatment

for Long Covid with clinical guidance and the English health system response to date instead focused upon symptom management.

General practice is the first point of contact of the NHS for Long Covid patients and NHS England announced a five-point plan in October 2020 to support those experiencing Long Covid (see Box 1.1), followed up by formal publication of Long Covid: The NHS Plan in June 2021. A report on progress published in July 2022 highlighted, amongst other actions: (1) the establishment of 90 post Covid services, with an estimated foot fall of 60,000 people; (2) an increase in the recording of people with Long Covid at primary care level in England allowing for more consistency in referrals; and (3) monitoring/publication of data relating to inequalities in referral, access and wait times in order to aid transparency and performance improvement (NHS England, 2022). Nevertheless, the care of patients with Long Covid has the potential to significantly increase workload burden for general practices (Hutchinson et al, 2022). Despite the establishment of an enhanced service contract intended to support general practice workforce planning, training needs and infrastructure for Long Covid (NHS England, 2021), analysis of recent data has demonstrated that the funding formula used for the Long Covid enhanced services fails to take into account deprivation or geographical difference with, for example, the North-East receiving just 54% of the funding per Long Covid case of the South-East (Hutchinson et al, 2022).

Lived Experiences of Long Covid and Inequalities

A recent systematic review and meta-analysis demonstrated that certain demographics (such as age and sex), pre-existing comorbidities and having experienced severe Covid-19 (previous hospitalization or ICU admission) were associated with increased risk of Long Covid, whilst vaccination played an important protective role (Tsampasian et al, 2023). Similarly, Shabnam et al (2023) identified that people aged 35 to 69 years, women, people living in more deprived areas, those working in social care, those aged 16 years and over who were not working and not looking for work, and those with another activity-limiting health condition or disability have a higher risk of developing Long Covid.

Meanwhile, by examining regional trends, Bambra et al (2023) have recently argued that England has experienced several ‘parallel pandemics’ of poor mental health and increased anti-depressant usage, increased hospital pressure and a greater burden of Long Covid – an unequal legacy of the pandemic, all of which have adversely impacted the North of England. Whilst most research has focused on the clinical characteristics of Long Covid, a smaller, emergent field of qualitative and quantitative research has focused on the lived experiences of Long Covid sufferers (Ireson et al., 2022; Ladds et al., 2021; Callan et al., 2022; Kingstone et al., 2020; Buttery et al., 2021; Ladds et al., 2021; Taylor et al., 2021). Most of this literature coalesces within the broad themes of uncertain trajectories; loss of identity; impacts upon mental health and wellbeing; and experiences of stigma, all of which play a key role in being able to access care, support and services, both formally and informally (Fang et al, 2023; Macpherson et al, 2021).

Extant research has explored the fluctuating, uncertain and non-linear nature of Long Covid, which does not appear to follow a chronological path from symptom onset to recovery, and which takes a significant toll on emotional, social and physical health (Burton et al, 2022; Callan et al, 2022; Schiavi et al, 2022). Thus, in a study conducted by Ladds et al, participants described themselves as being “trapped in a cycle of small improvements followed by setbacks which were physically and emotionally stressful, with no clear prospect of full recovery” (2021:4). Meanwhile, Brehon et al (2023) have described this experience as an episodic relapsing-

Box 1.1: NHS England’s original 5-point plan to support Long Covid Patients

- 1 A rapid guideline produced in collaboration with the National Institute for Health and Care Excellence (NICE), Scottish Intercollegiate Guideline Network (SIGN), and Royal College of General Practitioners (RCGP).
- 2 Publication of two themed reviews on Long Covid and commissioning of £18.5 million in research funding to focus on Long Covid evidence gaps.
- 3 Establishment of a Long Covid Taskforce, bringing together NHS clinicians, academics and patient representatives.
- 4 Establishment of dedicated, multidisciplinary post-COVID-19 assessment clinics within each Integrated Care System (ICS).
- 5 Launch of an interactive rehabilitation platform — ‘Your COVID Recovery’.

remitting “rollercoaster”, whilst work conducted by Ireson et al (2022) defined experiences of Long Covid as ‘life changing’. In this sense, the experiences of those experiencing Long Covid may overlap with the experiences of those experiencing myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) (Komaroff and Lipkin, 2023). Meanwhile, other studies have unpacked important consequences for identity and sense of self. For example, Loft et al (2022) and Spence et al (2023) have drawn on the concept of biographical disruption to illustrate identity conflicts faced by those experiencing Long Covid, and the long-term challenges this poses to people’s social and emotional selves. In doing so, Spence et al (2023) problematise the notion that we can all simply ‘return to normal’ now that Covid-19 no longer officially constitutes a ‘global health emergency’.

Whilst there remain only a small number of studies exploring people’s experiences of Long Covid, those that do have highlighted how experiences have been poorly understood, minimised or trivialised and how sufferers may feel invisible or unheard, leading to the need to search for validation, justice and recognition. For example, Ireson et al (2022) argue that those experiencing Long Covid are frequently disbelieved or not taken seriously, resulting in epistemic injustice and both internal and external stigma; whilst Pantelic et al (2022) found that the majority of people with Long Covid are experiencing some form of stigma, with 95.4% experiencing at least one type at least ‘sometimes’, and 75.9% experiencing it ‘often’; prevalence of stigma was also higher in those reporting a clinical diagnosis of Long Covid.

In addition to potential inequalities in who has Long Covid (and how severely and how long), as with other chronic conditions, it is possible that Long Covid itself leads to other social and economic inequalities. Studies from multiple countries have demonstrated that Long Covid is linked to an increased likelihood of not working. For example, within a recent umbrella review, almost 50% of primary studies reported some degree of Long Covid related social and family-life impairment, long absence periods off work, adjusted workloads, and loss of employment (Nittas et al, 2022). It is estimated that 27,000 working-age adults in the UK are inactive because of their Long Covid symptoms as of July 2022 (Ayoubkhani et al, 2024). Data collected as part of a joint report by the Trades Union Congress (TUC) and Long Covid Support also found that 1 in 7 respondents (14%) had lost their job because of reasons connected to Long Covid whilst two thirds of respondents (66%) said they had

experienced one or more types of unfair treatment at work (Ceolta-Smith et al, 2023). Further, Lunt et al (2022) highlighted that only 15% of their participants had been able to fully return to work whilst Brehon et al (2022) identified that, in a small sample of workers (n=80), only 43 (53%) returned to work. Like Hung et al (2024), they recommend that outcomes would likely improve with increased availability of modified duties and timely, tailored rehabilitation.

Likewise, The Institute for Fiscal Studies (IFS) further demonstrate that people who are more likely to live in social housing, to have been claiming benefits before the pandemic, and who are in poverty are more likely to develop Long Covid (Waters and Wernham, 2022). The IFS go on to show that 10% of those who develop Long Covid (compared to similar individuals who do not have Long Covid) stop working, with sufferers generally going on sick leave (rather than losing their jobs, or becoming unemployed altogether). Therefore, on average, the total number of hours worked reduce by about 2.5 hours per week and earnings by £65 per month (6%), or £1,100 per person who drops out of work. Meanwhile, in the same report the IFS also state that their estimates suggest that if the prevalence and severity of Covid-19 remain at the current levels, the aggregate impact to the economy is equivalent to 110,000 workers being off sick. Similarly, Reuschke and Houston (2023), using estimates of cumulative prevalence of Long Covid, activity-limiting Long Covid in the working-age population and of economic inactivity and job loss resulting from Long Covid, demonstrate that cumulatively 2.9 million people of working age (7% of the total) in the UK have had, or still have, Long Covid. They also highlight that, since the beginning of the pandemic, economic inactivity due to long-term sickness has risen by 120,900 among the working-age population, whilst an estimated 80,000 people have left employment due to Long Covid.

Nevertheless, little qualitative research has specifically, directly and with depth explored the relationship that Long Covid has with employment and economic inactivity, the latter of which has risen sharply, post-pandemic and cost of living crises, according to recent ONS data, and at a sharper level in deprived regions. As of September 2023, the unemployment rate in North East England remains 5.2%, an estimate which falls just short of the highest unemployment rate estimate in the UK for the North West (5.3%) and remains much higher than the national average of 4.3%. Similarly, few studies have sought to understand people's experiences of Long Covid through the lens of inequality and marginalisation, and we still know very little about how Long Covid has been



experienced regionally. An extensive evidence base has repeatedly demonstrated that Covid-19 disproportionately affects certain groups and populations. This phenomenon has been described as a “syndemic pandemic”, whereby Covid-19 exacerbates existing forms of inequalities, particularly along socio-economic, geographical and ethnic axes (Bambra et al, 2020). Thus, it isn't a huge extrapolation to suggest this may be mirrored in Long Covid impact, like de Leeuw et al who have stated “communities that were already struggling before the pandemic will suffer more from infection and will be devastated interminably from the ongoing cascade of social (e.g., work and employment, housing and service access, disability support) and health (exacerbating chronic suffering and comorbid conditions) consequences” (2022: 222).

This Report

This report examines regional differences in rates of Long Covid, the relationship between socioeconomic deprivation, the impact of the illness on sufferers lives and how employers manage the condition. It was commissioned by Newcastle upon Tyne Hospitals NHS Foundation Trust and was conducted as part of the ‘COVID Recovery Analytics’ project, to understand the impact of Long Covid on the health, wellbeing and employment prospects of adults living in northern England. In doing so, this study aimed to contribute to the existing literature on Long Covid, as well as providing a timely and relevant analysis of the economic repercussions of Long Covid in the North East of England. It represents a partnership between the Northern Health Science Alliance, Healthworks, Middlesbrough Council and the Northern NIHR Applied Research Collaborations (ARCs; North East and North Cumbria [reference: NIHR200173] and Greater Manchester [reference: NIHR200174]. The rest of this report examines different facets of Long Covid as follows:

Chapter 2 uses nationally representative data to examine the prevalence of Long Covid at national (England), NHS Region, and GP practice-levels. We show that the national prevalence of Long Covid in 2022 in England was 4.4%. We also demonstrate regional inequalities with a clear North-South divide: regions with the highest prevalence were the North West (5.5%) and the North East and Yorkshire (5.1%). The regions with the lowest prevalence were the South West (3.4%) and the South East (3.6%).

Chapter 3 explores people's experiences of living with Long Covid in North East England. Our analysis highlights that Long Covid is a multi-layered and complex condition with repercussions that extend beyond the physical and mental health symptoms of the illness into other parts of people's lives, including their sense of self and professional identity. Changes in professional identity and lack of a strong support network led most participants to experience social isolation and exclusion. Interviewees were also now having to navigate the social, physical and psychological complexities of disabled living, a situation seemingly exacerbated by the actions of employers who did not adjust to the needs of employees with Long Covid.

Chapter 4 attempts to understand the policy and practice responses of employers to Long Covid using data obtained from 162 public sector employers under the Freedom of Information (FOI) Act. This dataset suggests that only a small proportion of employers have responded to the specific challenge of Long Covid. In this sample, we identified few instances of innovative, new or tailored sickness absence policy and found that many employers were not specifically recording Long Covid related absences.

Finally, **Chapter 5** reflects on what is needed to support the health and wealth of people experiencing Long Covid. It suggests ways forward for local, regional and national policy makers in local authorities, national government and the NHS.

Summary of key points

- The national prevalence of Long Covid in 2022 in England was 4.4%
- Regionally, there were striking inequalities and a clear North-South divide. The regions with the highest prevalence were the North West (5.5%) and the North East and Yorkshire (5.1%). The regions with the lowest prevalence were the South West (3.4%) and the South East (3.6%).
- The prevalence rate in the most deprived decile (6.3%) was nearly twice that in the least deprived decile (3.3%).
- Practice level prevalence rates indicated the existence of many hot spots of high prevalence in the Northern Regions. Although there were also hot spots of high prevalence in other regions too. Hotspots of high prevalence map closely to hotspots of underlying deprivation.
- The ten GP practices with the highest prevalence of Long Covid were all in the Northern regions. Both the North East and Yorkshire and the North West had some practices where the prevalence rate was at least 20%.
- There was considerable evidence of socioeconomic inequalities in Long Covid within the North East and Yorkshire, where the prevalence rate amongst the most deprived groups in this region were 5.2 percentage points higher than in the least deprived parts of the North East and Yorkshire
- There was no evidence of within region inequality within the North West region.

Introduction

This chapter uses nationally representative data to examine the prevalence of Long Covid. In particular, it considers inequalities based on NHS Commissioning Region and area-level deprivation. It also considers whether within region inequalities exist, as well as between region inequalities.

Data

The key data source is the General Practice Patient Survey (GPPS) [1], using data collected during 2022. The survey is distributed by post to over two million people annually by Ipsos on behalf of NHS England. It is sent to a sample of patients registered at each general practice in England and includes questions on, health, primary health care use, socioeconomic characteristics, and health-related quality of life (HRQoL). Importantly, in 2022, the survey contained a question

specific to the existence of symptoms of Long Covid. The data used in this study is available online.[2] Here, we use practice-level information. Individual-level data can be accessed via a data sharing agreement with NHS England, although that was not the focus of analysis here.

National prevalence of Long Covid from the GPPS

The key question for the analysis presented here, asked to all respondents, is “Would you describe yourself as having “Long Covid”, that is, you are still experiencing symptoms more than 12 weeks after you first had Covid-19, that are not explained by something else?” The first row of Table 2.1 summarise the results for the whole of England, where 4.4% of the population responded that they thought they did have Long Covid symptoms.

Subsequent rows summarise the results by each of the seven NHS England Commissioning regions. Nationally, in England, 7.3% of people were not sure if they had Long Covid symptoms; a sizable percentage.

Prevalence of Long Covid by NHS Commissioning Region

Figure 2.1 summarises the ‘yes’ responses graphically. We take ‘yes’ responses to be a proxy for the prevalence of Long Covid by different NHS regions. The North West had the highest prevalence of Long Covid (5.5%), followed by the North East and Yorkshire (5.1%). The Midlands and London both had prevalence rates above the English average (both were 4.8%). The East of England had a prevalence rate below the English (3.9%). The two NHS regions with the lowest prevalence were the South East (3.6%) and the South West (3.4%).

Regionally, there was much variation in the percentage of people who were not sure if they had Long Covid symptoms. London had the highest percentage of people who were not sure (8.6%) and the North West had the second highest percentage (8.2%). The South West had the lowest percentage (5.6%). The pattern in ‘not sure’ is similar to that observed in the ‘yes’ category.

Table 2.1: Responses to the 2022 GPPS 2022 question “Would you describe yourself as having “Long Covid”, that is, you are still experiencing symptoms more than 12 weeks after you first had Covid-19, that are not explained by something else?”

Table 2.1: Responses to the 2022 GPPS 2022 question “Would you describe yourself as having “Long Covid”, that is, you are still experiencing symptoms more than 12 weeks after you first had Covid-19, that are not explained by something else?”

	Yes	No	Not sure	Prefer not to say
England	4.4%	87.3%	7.3%	1.0%
East Of England Commissioning Region	3.9%	88.4%	6.9%	0.8%
London Commissioning Region	4.8%	85.0%	8.6%	1.6%
Midlands Commissioning Region	4.8%	86.3%	7.7%	1.2%
North East And Yorkshire Commissioning Region	5.1%	86.1%	7.8%	1.0%
North West Commissioning Region	5.5%	85.3%	8.2%	1.1%
South East Commissioning Region	3.6%	89.5%	6.3%	0.7%
South West Commissioning Region	3.4%	90.4%	5.6%	0.7%

Notes: Green shading indicates at least 10% below the English average; Red shading indicates at least 10% above the English average; Amber shading indicates within 10% of the English average.

Prevalence of Long Covid by GP Practice-level Index of Multiple Deprivation (IMD) decile

It is possible to merge information on the average area-level deprivation scores of the catchment areas of each General Practice within England, using data from Office for Health Improvement and Disparities (OHID) Fingertips[3]. We combine this data with GPPS data to obtain the prevalence of Long Covid by area-level deprivation, as measured by the Index of Multiple Deprivation (IMD). IMD is the most commonly used measure of area-level deprivation in England.

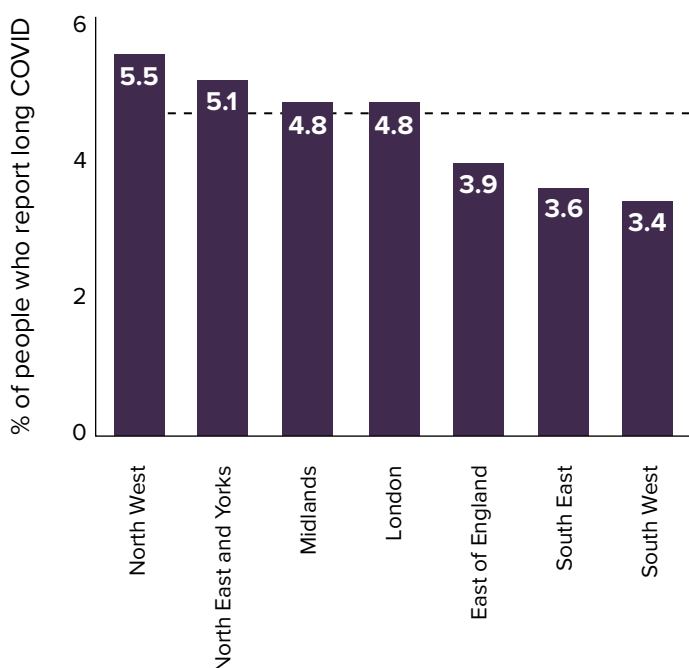
It produces a ranking of areas in England based on relative local scores for: income, employment, health, education, crime, access to services and living environment.[4] To obtain IMD scores and ranks for GP catchment areas, population weighted average score of lower-layer super output areas (LSOAs) within each catchment area were calculated. Each GP practice was then ranked from 1 (least deprived) to 6,649 (most deprived). For ease, we split deprivation into deciles, ranging from 1 (least deprived 10% of GP practices) to 10 (most deprived 10% of GP practices).

Figure 2.2 presents estimates of the prevalence of Long Covid by deprivation decile from the GPPS. There is a monotonic relationship; that is, on average, the more deprived, the higher prevalence of Long Covid. The prevalence rate in the most deprived decile (6.3%) is almost double that in the least deprived decile (3.3%).

Prevalence of Long Covid at GP Practice-level

Figure 2.3 presents prevalence estimates for Long Covid based on the catchment areas of each GP practice within England. To obtain this, practice-level data from the GPPS were matched to GP catchment area data reported by NHS Digital.[5] Practice level prevalence rates (Figure 2.3) indicate the existence of hot spots of high prevalence in the northern Regions. There are also hot spots of high prevalence in other regions too, although they seem to cluster more in the North of England.

Figure 2.1: Estimated prevalence of Long Covid by NHS Commissioning Region



Note: the dashed black line in the average value across England (4.4%)

Within NHS Region inequalities in Long Covid

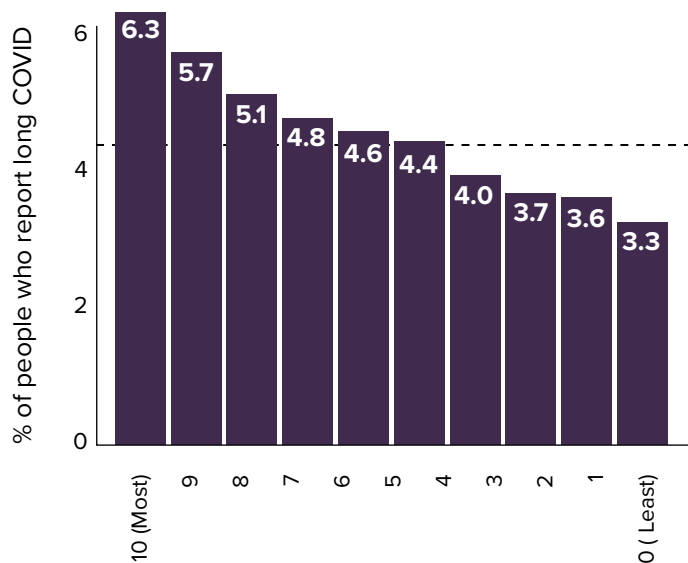
Earlier parts of this chapter have demonstrated that there are regional inequalities in the prevalence of Long Covid. On average, the prevalence is much higher in the North of England (NHS Commissioning regions in the North West and the North East and Yorkshire) than in the South of England. There are also inequalities by deprivation decile, with more deprived areas experiencing higher levels of Long Covid prevalence.

Here we explore how much within-NHS Region inequality there is. We do this using the slope index of inequality (SII). This measures differences in health outcomes between the most and least deprived parts of a population. It is included in the NHS Public Health Outcomes Framework to measure health inequalities.[6] We calculate the SII for England as a whole, as well as for each of the seven NHS Commissioning Regions and compare them to examine which region(s) has the greatest within-area inequality.

The SII in Long Covid prevalence for England as a whole was 4.83 (95% CI: 3.39 to 6.26), indicating that the (average) prevalence of Long Covid in the most deprived parts of the country is estimated to be 4.8 percentage points higher than that in the least deprived parts of the country (Table 2.2). However, when we examine the SII by region, there is a lot of heterogeneity. The NHS Commissioning Region with the highest SII is the North East and Yorkshire (Table 2.2). The SII in the North East and Yorkshire is 5.21 (95% CI: 1.73 to 8.69), indicating that the (average) prevalence of Long Covid in the most deprived parts of the North East and Yorkshire is estimated to be 5.2 percentage points higher than that in the least deprived parts of the North East and Yorkshire.

Interestingly, the NHS Commissioning Region with the lowest SII was the North West, who had a SII of 0.28 (95% CI: -2.62 to 3.18). In the North West, as the confidence interval contains zero, there is no evidence that the most deprived parts of the North West had a higher Long Covid prevalence than the least deprived parts of the North West. This would indicate that although the North West

Figure 2.2: Estimated prevalence of Long Covid by Index of Multiple Deprivation (IMD) decile



Note: the dashed black line in the average value across England (4.4%)

had the highest Long Covid prevalence on average, there was no evidence of inequalities within the North West. In the North East and Yorkshire, however, there was strong evidence of both between and within inequality.

Apart from the North East and Yorkshire, the only other NHS Commissioning Regions that exhibited within regional inequality were Midlands (SII=3.24; 95% CI:0.25 to 6.22) and London (SII=4.05; 95% CI: 0.89 to 7.21). There was no statistical evidence of within region inequalities in the East of England, the South East, or the South West.

Conclusion

We identified a clear North-South divide for Long Covid rates. The regions with the highest prevalence were the North West (5.5%) and the North East and Yorkshire (5.1%). The regions with the lowest prevalence were the South West (3.4%) and the South East (3.6%). The average for England as a whole was 4.4%. There is considerable evidence of socioeconomic inequalities in Long Covid in the North East and Yorkshire, where rates in the most deprived groups (8.3%) were 5.2 percentage points higher than in the least deprived areas (3.1%). The ten GP practices with the highest prevalence of Long Covid were all in the North. The North East, Yorkshire and the North West had some practices where the prevalence rate was at least 20%.

[1] <https://www.gp-patient.co.uk/>

[2] <https://www.gp-patient.co.uk/SurveysAndReports>

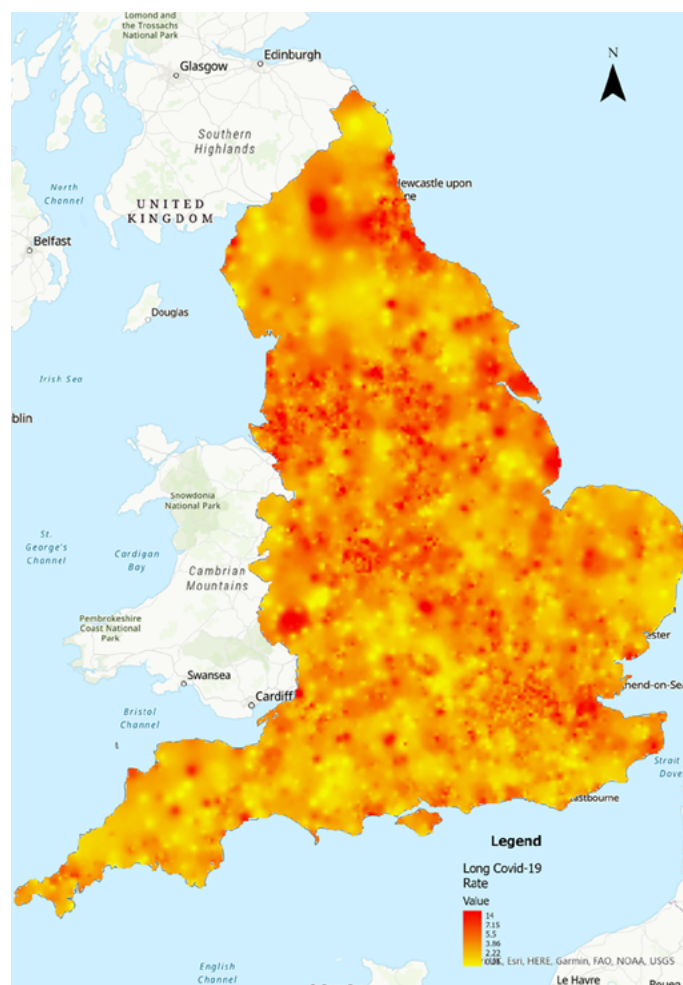
[3] <https://fingertips.phe.org.uk/profile/general-practice/data#page/9/gid/2000005/pat/167/par/E38000021/ati/7/are/G81090/iid/93553/age/1/sex/4/cat/-1/ctp/-1/yr/1/iid2/848/age2/168/sex2/4/cat2/-1/ctp2/-1/yr2/1/cid/4/tbm/1/page-options/cin-ci-4>

[4] Department for Communities and Local Government (2019) English Indices of Deprivation 2019, available from: <https://research.mysociety.org/sites/imd2019/about/>

[5] <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/gp-data-available-through-sdcs>

[6] <https://fingertips.phe.org.uk/profile/public-health-outcomes-framework>

Figure 2.3: Practice-level estimates of the prevalence of Long Covid, based on GP catchment areas



The 10 GP practices with the highest prevalence of Long Covid were all in the North. Three were in the North East and Yorkshire and seven were in the North West. Both the North East and Yorkshire and the North West had practices where the prevalence rate was at least 20%.

Table 2.2: Slope Index of Inequality (SII) for England and each of the seven NHS Commissioning Regions

	SII	p-value	95% CI		
ENGLAND	4.83	<0.001	3.39	to	6.26
North West Commissioning Region	0.28	0.85	-2.62	to	3.18
North East And Yorkshire Commissioning Region	5.21	<0.001	1.73	to	8.69
Midlands Commissioning Region	3.24	0.03	0.25	to	6.22
London Commissioning Region	4.05	0.01	0.89	to	7.21
East of England Commissioning Region	3.02	0.17	-1.31	to	7.35
South East Commissioning Region	3.46	0.16	-1.35	to	8.26
South West Commissioning Region	0.58	0.83	-4.63	to	5.80



Summary of key points

- Long Covid encompasses physical, cognitive and mental impairments, with brain fog, fatigue, breathlessness, low mood, and depression being listed as the most common symptoms.
- The severe impact of Long Covid's symptoms significantly hampered participants' lives, impeding their capacity to work and carry out routine activities.
- Long Covid sufferers experienced a degree of social isolation, which was exacerbated by a lack of effective communication with non-ill individuals. Women seemed better equipped to cope with the social isolation that living with a chronic and invisible illness brought into their lives.
- Long Covid had a significant impact on working life and employment prospects. Most participants had been demoted, fired, forced to resign or switch to part-time work because of Long Covid. Dissatisfaction with employer's support, lack of compassion, and emotional repercussions were common themes throughout our interviews.
- The connection between Long Covid and employment extends beyond financial impact. The inability to perform one's job can have a significant impact on someone's emotional wellbeing and sense of self.

Introduction

Long Covid is often described as a confusing illness, with numerous and varied relapsing and remitting symptoms, which lead its sufferers to a heavy sense of loss and stigma (Ladds et al., 2021). The impact of this condition has been widely discussed both in medical and sociological literature (Garg et al., 2021; Carfi et al., 2020; Lopez-Leon et al., 2021; Davis et al., 2020; Callan et al., 2022; Kingstone et al., 2020; Ladds et al., 2021; Rushforth et al., 2021). However, these works have not fully addressed the repercussions that Long Covid might have on the health, wellbeing and education and employment prospects of the people living with this condition.

In Chapter 2 we identified regional variation in prevalence rates for Long Covid, with the North East and Yorkshire experiencing one of the highest prevalence rates across England. Moreover, we observed considerable evidence of socioeconomic inequalities existing within the North East and Yorkshire, where the prevalence rate amongst the most deprived groups in this region were 5.2 percentage points higher than in the least deprived parts of the North East and Yorkshire. In this chapter, we use narrative interviews with adults in North East England and public engagement workshops to better understand how Long Covid has impacted their social, emotional, physical and financial lives.

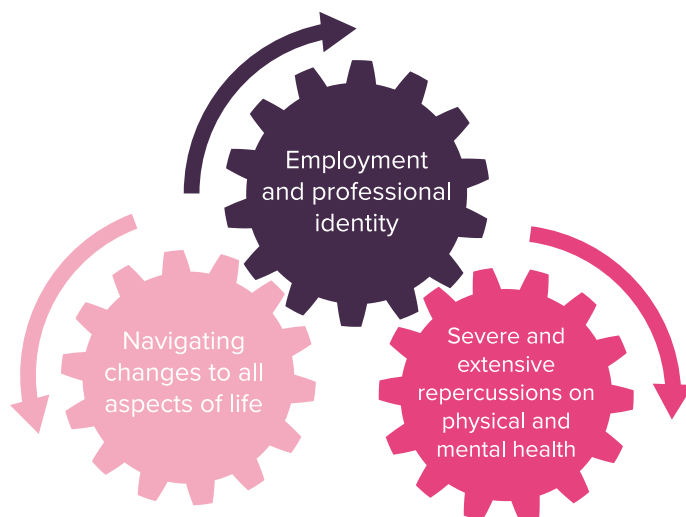
Methods

We conducted narrative interviews with 13 people who have experienced or continue to experience Long Covid between November 2022 and January 2023. We also held two public engagement workshops comprising six people in each workshop (with nine different people in total). The first workshop was held in December 2022 whilst the second was held in June 2023.

Long Covid was threaded through all aspects of day-to-day life for our interviewees and public representatives, making it impossible to work and live in the ways in which they did pre-infection. Our analysis of the data yielded three overarching themes which are unpacked in the sections which follow.

Throughout these sections, we use quotes from our interviewees to contextualise our findings. To safeguard the anonymity of our interviewees, pseudonyms have been used. Our findings are also summarised visually in Figure 3.2 below.

Figure 3.2: Thematic Map of Qualitative Data



"I couldn't think, I couldn't listen to the radio. I couldn't read, I couldn't watch TV" - The impact of Long Covid on physical and mental health

Although we did not set out to focus on the clinical aspects of this condition, Long Covid symptoms were discussed at length during our interviews. This is due to the extensive and impactful ways in which Long Covid has changed the lives of our participants. The range of symptoms that participants experienced encompassed physical, cognitive and mental impairments, with brain fog, fatigue, breathlessness, low mood and depression being named as the most common experienced symptoms. Most participants were severely impacted by the physical symptoms of Long Covid, and debilitation associated with Long Covid impacted on the ability of interviewees to work and perform everyday tasks. For example, 'Claire', a mum of three, reported that she was experiencing symptoms so severe that she feared for her life:

"At one point, more than once, I was surprised to wake up the next morning. I felt like I was having stroke-like symptoms, the pressure in my head. I couldn't move enough to either call for my children or to reach for my phone to get help. I think I lost consciousness. The next morning, I was like, I can't believe I'm waking up. I wrote my end of life wishes and told my kids what to do if I didn't make it". (Claire)

Most participants showed signs of cognitive dysfunction or 'brain fog' during our interviews, where they would either ask the interviewer to repeat the question or they would stop mid-sentence because they lost their train of thought. They narrated a myriad of examples of how this impacted upon them in their day-to-day lives, particularly in social settings. In the following extracts, 'Sarah' and 'Isla' – two women in their early 40s – discuss episodes of cognitive dysfunction that had happen to them since developing Long Covid:

"I tried to go for coffee with my sister when I was still recovering. When I was around people, I was just bumping into people, I was struggling to order what I wanted. When I got to the front of the queue I couldn't remember, properly, what to order. Even though I was just ordering a hot chocolate or a cup of tea or something, I just couldn't get my words out". (Sarah)

"I had a cognitive test a few weeks ago, and one of them was to join numbers then letters, then numbers, then letters, in ascending order. And they gave me the pen, and I knew the order of numbers and letters, that was no problem. What I didn't know was how to put the pen on the piece of paper to join the lines. And I sat there and thought, "Okay, I don't know how to do it." And that happens quite a

lot. I just don't know how to do something". (Isia)

Alongside physical and cognitive sequelae, most interviewees had been significantly affected by the psychological repercussions that Long Covid had brought into their lives. Low moods, depression and frustration often emerged in the stories that we collected. In particular, Long Covid was described as a condition where physical and mental health are indiscernible, in the sense that the psychological symptoms are often exacerbated by physical ones and, as a result, Long Covid sufferers had to battle both physical and mental health at the same time. In the following extracts, 'MK' – a 57-year-old man – and 'Leanne' – a 43-year-old woman – share similar views on the psycho-physical entanglements of Long Covid:

"My physical symptoms have had a knock-on effect on my emotional, my psychological well-being, my cognitive functions. And it's very difficult, I think, for me to separate now, if you look at some Long Covid symptoms and if you look at symptoms of depression, there's this overlap happening". (MK)

"I've been an absolute mess with it, because it just messes with your head. I'm 43, and to feel like even walking up the stairs to go to the bathroom, and then you're wiped out for however long. If you have a shower and just... To be a healthy-ish, fit woman, and then to suddenly just wake up and just not... This thing just not doing what you want it to do. It just completely messes with your head". (Leanne)

Nevertheless, the tangible impact that Long Covid had on health – from mobility to mental health, to ability to perform day-to-day tasks – constitutes a necessary but insufficient explanation of their suffering. To fully appreciate the extent of this condition's impact on the lives of Long Covid sufferers, we also need to consider the changes that people needed to navigate their social, cultural and emotional worlds.

"I do not resemble that human beforehand in every aspect of life" - Navigating social life with Long Covid

Social isolation – perceived or otherwise – formed a considerable part of most participants' stories. Here, "perceived social isolation" refers to a mismatch between an individual's social needs and the perceived ability of their social environment to fulfil their social needs (Hawkley & Capitanio, 2015). Our participants reported having a strong support network and a number of people – mainly spouses, children, close family members and friends – who have supported them during their Long Covid journey. Nevertheless, their stories also contained elements of loneliness, aloofness and detachment from their social life and peers. Their social environment, at times, was perceived to offer inadequate social support and, as a result, they felt detached from it:

"A lot of people, friends, have kind of dropped off the map. Because I think you get to a point where they're like, "Are you okay?" and I just don't even know how to answer it anymore, I just go, "Yes." And obviously I've got a few close friends that have really stuck by me and done the most lovely things to keep my spirits up, and keep checking in. But it just feels very detached. [...] You just feel detached a little bit, because these things have happened. But you've missed things that have gone on in their life and you're suddenly just not part of it. You feel really... I mean detached..." (Leanne)

This social isolation appeared to be the result of two concomitant factors: the disabling nature of Long Covid, which actively prevented Long Covid sufferers from partaking in social interactions; but also the self-imposed restrictions that participants placed upon themselves in order to avoid potentially awkward social interactions.

As outlined earlier in this report, Long Covid manifests as a number of physical and cognitive symptoms, particularly fatigue, breathlessness, post-exertional malaise and brain fog. As such, one of the reasons participants in our study experienced social isolation was due to their (physical) inability to participate in social interactions:

"It's incredibly isolating because you physically often cannot leave the house at all. If you do, you need help in a wheelchair or you might be able to walk a little amount, but then this post-exertional symptom exacerbation gets you the next day or up to 72 hours later. I couldn't walk across a room. Even this time last year I could not walk across a room. Sometimes I could walk across the room. I remember it was November last year I had to get someone to sit me in my wheelchair to get me across the room to go to the toilet. It's incredibly isolating, particularly if you live on your own". (Claire)

The above extract captures the complexities of navigating social spaces when dealing with the physical symptoms of Long Covid. Claire – a once active woman who used to cycle 13 miles a day on her commute and is now registered disabled and a wheelchair user – found herself unable to leave the house and therefore experiencing the social isolation that comes from not being able to interact with other human beings in a public space. It is worth noting that most of our participants experienced Long Covid at a time when there were still government-mandated restrictions. As such, the inability to socialise in private dwellings meant that participants were deprived of a significant part of their social life. For example, 'Louise' and 'Budkis' found themselves unable to use physical exercise as a pillar of their socialisation – as they did pre-infection – and, as a result, are now reporting a diminished social life:

"I was a member of the tennis club here... I don't do that anymore, and that was part of my social life. I was a member of a running club, I don't do that anymore. And that was kind of social as well... And even though I've kept in touch with a few people, you're not in the loop really, so you kind of drift- I've drifted off from quite a few of those sorts of social circles. So yes, I think my social life is not as good as it was, because it was tied into quite a lot of activity that I used to do". (Louise)

"My social life was going to meet lovely people at the gym... I enjoyed that, but that's been taken away from us. And as I say, that was four times a week. It was a big part of my life, and there's a void there now... Because I have no joy in life now. If you could split my personality, pre-COVID to now, it's black and white, white being pre-COVID, and it's just black... I do not resemble that human beforehand in every aspect of life. I've been out three times since June, twice to my occupational health therapist and once for my daughter's birthday. I've missed funerals, I've missed social gatherings, everything. I don't go out anymore". (Budkis)

The physical symptoms of Long Covid were only partially responsible for the participants' inability to take part in social interactions. Another contributing factor was the fear of judgment that they might experience in public spaces. For some, even when they were physically fit enough to navigate social settings, they preferred to refrain from doing so, suggesting that those experiencing Long Covid were negotiating both felt and enacted stigma. Enacted stigma refers to the negative attitudes, beliefs and behaviours that are directed towards individuals or groups who are seen as different or deviant (Scambler, 2004). This can take the form of physical, verbal or nonverbal aggression, exclusion or discrimination. Felt stigma, on the other hand, is the internalisation of negative attitudes and beliefs about oneself that are caused by enacted stigma (Scambler, 2004). Individuals who experience felt stigma often feel ashamed, inferior and powerless, and may experience depression, anxiety, low self-esteem and a lack of social

support (De Zola et al, 2020; Gray, 2002; Lawrence et al, 2022; Scambler, 2004; Ziersch et al, 2021). Our participants, at times, appeared to prefer to shy away from potentially harmful social interactions perhaps exacerbating their sense of social isolation. In the quotes that follow, 'Sarah' and 'Budkis' manifest a degree of reticence in engaging in social outings:

"A lot of people, I haven't seen in a while, they keep messaging, "Do you want to go for a coffee, do you want to do this, do you want to do that?" I've just had to keep putting them off and putting them off and say, "I'm still not feeling very well." I think a lot of people have just got a bit fed up with me now, just thinking, "Oh, well she probably just doesn't want to hang out or something." It's really difficult to explain to people, so I think people have got a bit fed up. They might not have said it, necessarily, to my face but I think people have got fed up with the fact that I'm just a bit absent in life at the moment." (Sarah)

"The anxiety, the coughing. I find it embarrassing now because coughing is very much associated with Covid, and when I've been out and I'm coughing, I get looked at and stared at. And probably paranoid on my behalf, I'm thinking, "People are thinking he should be inside." I plan things with friends and then two days beforehand, I just cancel, and that's the way of my life now. My daughter does most things for us now, and I don't want her to. She's young, she's 20." (Budkis)

Social isolation was exacerbated by a lack of effective communication. Specifically, our participants found it difficult to fully express to others what it felt like to have Long Covid, both because they did not know how to have these conversations with their family and friends, but also because they believe that there was a specific incommunicability that pertained to their experiences. For example, 'Russ' and 'Louise' reported having solid and supportive relationships with their close family members and yet, the perception of being poorly understood by them dominates their narratives:

"People don't understand it. Even my wife and my mother-in-law, who is close to me, they see what effect it's having on me. They don't understand it, and they don't understand the impact of the pain. Unless you've had pain, and prolonged pain, and then are on the drugs for this pain, I don't think you can understand it, if I'm honest". (Russ)

"My mum and dad were great. But then extended family, sometimes they were like, "Oh, are you not better yet?" or, "What's the matter?" I would say, "I've got this awful brain fog," and they'll go, "I forget things as well." And you'd say, "Well it's kind of different to that. I know what normal forgetting things are, or losing your words." They'd be like, "Oh, I do that all the time," and you think, "No, it's not what you think it is." And it's quite hard to explain to some people what's going on in your head. So I think it's much better now". (Louise)

This inability to effectively share symptoms and experiences with other non-ill individuals is a characteristic that Long Covid sufferers appear to share with other populations experiencing chronic illness (Årestedt et al., 2014). Further, the incommunicability of their condition was experienced so strongly by our participants, that some of them wished they had a visible illness or injury just so that other people would understand that they were in fact ill:

"If I had cancer, I don't think I would have the same regard. You know, if I had hepatitis, I don't think I would have the same regard". (MK)

"If you broke your arm, most people can kind of understand how that feels. But I had no idea, the fatigue, the exhaustion, what that

felt like when your body takes over". (Leanne)

Meanwhile, despite continuing to experience social isolation and subsequent feelings of detachment, women who took part in our study tended to report having a livelier social life than their male counterparts, both before and after contracting Long Covid. Whether it was through volunteering, being part of a choir, a fitness group or other interest-based groups, women reported having a stronger and larger support network than men.

As a result, they seemed better equipped to cope with the social isolation that living with a chronic and invisible illness brought into their lives. In the following extracts, 'Lainey' and 'Isla' – respectively, 67 and 43 years old – provide examples of their lively social life and how it revolved around shared interests, such as choir singing, theatre acting and swimming:

"So there's a group of about 10 women. We're all very friendly and we went. We've all stuck together and gone to a new choir. So we're all together, but this term was Christmas carols. So I've been going along and learning them because I love socialising with them, and they've been very, very supportive because we've all got problems. [...] They say, "How are you today?" and we sort of help each other and we've got a group, a WhatsApp group, and we all send each other messages, "How are you doing?" and everything." (Lainey)

"...my theatre friends, they're lovely, and whenever I still- because my little one goes to the theatre group, I used to be part of. So, I see them, and we chat. But that's how it always was anyway. We would always be together rehearsing for those shows. So, I'm not in those rehearsals anymore. So, that's there. My swimming club, they're lovely. A couple of them have been around a couple of times" (Isla)

On the other hand, men expressed feelings of isolation to a higher degree, both because they lacked a strong support network outside the family and because they didn't want to be perceived as a burden.

Men also expressed visible emotion during their interviews and disclosed being excluded by their social groups. For example, one participant was removed from his gym private Facebook group because he could no longer take part in their activities, whereas another was excluded from his son's Scouts WhatsApp group as the parents of the other children were concerned about his ability to safely drive.

"For the sake of my wife and my daughters, I expend an enormous amount of energy to be present, to be positive. I don't cry when anyone else is around. I do that when I'm on my own, either when I go for a walk or if I'm in the bathroom by myself. They are already worried about me, so I don't want them to worry anymore". (MK)

The above and below quotes exemplify a common pattern amongst the men who took part in this study, i.e. the difficulties that they often encountered in sharing emotional experiences. Scholarly literature on gender roles, masculinity and emotions has already amply discussed how societal expectations and entrenched gender norms can play a significant role in diminishing the likelihood of men engaging in discussions around painful emotions (McNess, 2008).

This is what Messner (1997) termed "the costs of masculinity". These difficulties in expressing and sharing emotional experiences – particularly experiences of vulnerability, grief, loss and pain – have been linked to a detrimental impact on men's depression and other mental health issues (de Boise & Hearn, 2017).

The experiences of the men who took part in this study align with what the wider literature suggests, i.e. that societal norms



demanding job. As a result, his manager encouraged him to resign:

“Like I’ve said to work, you need to either make a call on my future... He says, “Well, you can resign.” I said, “Well, I’m not resigning. It’s as simple as that. I’m not resigning.” I said, “If I resign, I won’t get anything off the government.” And don’t get me wrong, I’ve never been in that situation, but the more I’ve thought about it...” (Budkis)

Instead of resigning and making himself voluntarily unemployed, ‘Budkis’ decided to use some of his pension to sustain his costs. As he had already been without a pay for several weeks prior to our interview, he had also decided to stop paying into his pension scheme and was using his savings to get by. Meanwhile, ‘MK’ had decided to resign from a teaching assistant position. Due to the physical symptoms of Long Covid, they did not feel that they had enough energy to perform this job at the best of their abilities:

“When I got Covid at the time, I was furloughed. But previously, I worked in schools... I was thriving in it. I was doing so well. I was busy. I was enjoying myself. And there is no way at the current state that I’m at that I could return to that. And several times I’ve said, “Oh, yeah, I can do this, I just need to want to do it,” and I have no doubt that if I were to go back to that sort of work, the level of engagement and energy and exertion and focus... I also have brain fog, of course, I’m afraid... well, not just afraid, I’m convinced that if I went back to it, I would not be able to do it, not just to do it as effectively... I could not, I will not go into a school and then halfway through the day have to tap out, because then what happens to these children and young people, that it’s my assignment to be with them, to work with them. You know, it’s not fair. It’s not right. It’s not good. You shouldn’t do this unless you’re ready to do it the whole way”. (MK)

Similarly, ‘Leanne’, another teaching assistant, who had numerous conversations with Occupational Health (OH) and Human Resources (HR) managers, was informed during an employment tribunal that it was not possible to make reasonable adjustments to ease her return to work and, as such, her contract had to be terminated:

“I just felt so ashamed of losing my job. Because I had never been sacked or anything. And I know I wasn’t sacked, but I’ve never lost a job. And it couldn’t be helped, and they couldn’t keep paying me. So something had to happen. It’s just the way it went. But yes, I miss working...” (Leanne)

Most of our participants had been demoted, fired, forced to resign or switch to part-time work because of debilitating physical, cognitive and psychological impairments of Long Covid. When asked if they felt that they had been adequately supported by their employers in their Long Covid journey, as well as their return to work, a few participants – namely those on high-end and skilled jobs – depicted a scenario of support, such as phased returns to work:

“My employer, they couldn’t have been better to me really. They’ve been so helpful, flexible and responsive” (Claire)

However, most participants expressed a level of dissatisfaction with the ways in which their employer supported them. In particular, they felt that not enough humanity and compassion had been showed to them at such a difficult time in their life and, at times, this culminated in participants not feeling believed by their employers.

Some felt guarded when talking with HR representatives, line-managers and OH specialists, as if the interactions that took place were aimed at being punitive rather than supportive. This happened regardless of the type of employment or level of seniority, with the exemplar narratives below from ‘Isla’, ‘Sarah’ and ‘Leanne’ resembling one another despite working in very different professions at very different stages in their career:

of masculinity can inhibit men from expressing vulnerability in conversations with their loved ones.

“I don’t want to become a burden” (Budkis)

“I just felt so ashamed of losing my job” - The impact of Long Covid on employment and professional identity

In the previous sections, we explored the impact that Long Covid can have on both physical and mental health, as well as the disruption that it can cause to an individual’s social life. Another significant theme that emerged from our research concerns the impact that Long Covid has had on the working life and employment prospects of Long Covid sufferers. Most of our respondents – all except one – were of working age and employed when they first contracted Covid-19. For some of our participants – namely those that were self-employed, on precarious employment and those who identified as working class – employment insecurity brought financial instability.

The extent of how participants were affected by Long Covid in their employment varied in terms of the severity of their symptoms but also the length of their time away from work. In fact, some participants were able to return to work within a few weeks, while others had been on (self-defined) long-term sick leave. The latter had faced significant consequences as a result of their long-term sick leave, including termination of employment, resignation, being in-work but receiving no pay and, in some cases, they were waiting for their employers to decide whether they were going to terminate their contracts. ‘Budkis’, a 62-year-old man, had found himself too debilitated both physically and mentally to carry out his physically

“The worst thing they did, to be honest, was they arranged for a catch-up, which I thought meant they were coming to see how I was. And they said they’d pop by my house because they knew it was difficult for me getting out, and they came here. And they looked really uncomfortable, and I knew something was up. Because these were my peers. So, they weren’t my boss... I was level with these guys. And they looked really uncomfortable, and then they said, “There’s no way to say it. We just need to say it. You don’t have a place here anymore”... And I was like, “We haven’t done the occupational health assessment yet. You haven’t even asked me how am I”... they said, “We’ll support you with ill health retirement, or you’re dismissed on ill health grounds, straight away. It’s up to you.” (Isla)

“Because I’d been off sick for so long and it was still a new job... the first week back, I had to go to a meeting in front of a panel to discuss whether they were going to extend my probation or not or whether I was going to be let go... I didn’t want to ask for any adjustments or anything because I was just worried about keeping my job at the time. That was all just a bit upsetting and stressful... they decided to extend my probation by three months and then, after three months, I got signed off my probation so now that’s not a concern... But it was for the first three months. For those first three months, I didn’t want to rock the boat, I just wanted to show willing and try my best and not cause any more fuss”. (Sarah)

“I think I didn’t realise until after work finished how much of a pressure the Zoom meetings were, because you were having to- “Well, we spoke to you two weeks ago, are you any better?” ... Because there were three of them on. Every time, there was the manager and somebody else and somebody from occupational health- I can’t remember what department they were in. But it’s almost you have to be very careful of what you were saying because I felt like they were - not wanting to trip you up, but what I said last time and how I was feeling could be completely the opposite to this time”. (Leanne)



Some of our participants were able to stem financial losses, both because they were able to access savings or because themselves and/or their partners were in a stable and high-income job.

Nevertheless, their stories emphasised that even where there was no financial impact from employment inactivity, there were emotional repercussions. The following extracts exemplify the mental toll brought on by not being able to rely on one’s professional identity:

“...it’s not the wage that we’re missing, it’s the satisfaction, the worth of earning.” (MK)

“My mental health was shot with not being at work. I hated just being, basically, in the world that I was in” (Russ)

Isla’ was on the verge of losing her professional registration at the time of interview because she was unable to work due to Long Covid. She was offered early retirement, but as she was only 42 years old at the time, the offer did not seem appealing and reaching her own long-time career goal was so meaningful to Isla that it became entangled with her own sense of self:

“I cried a lot over that... as long as I can remember, that’s what I’ve wanted to do, and it is very much part of how I define myself... what’s my identity if that’s not? That kind of helping people, all the things I have done... The hardest part has been the response from my work. Because it felt like my home. They were my family, and it felt like such a betrayal, and to not be wanted.” (Isla)

At a time of great turmoil – brought on by the physical, cognitive, psychological and social challenges of living with Long Covid – most participants found themselves unable to tap into their professional identity in order to give meaning to their lives, with detrimental impacts to their mental health and wellbeing. This suggests that the connection between Long Covid and employment might be about much more than just earning an income. The inability to perform one’s job can have a significant impact on someone’s emotional wellness and sense of self (Waddell and Burton, 2006).

Conclusion

Long Covid encompasses a broad array of physical, cognitive, and mental impairments, with common symptoms including brain fog, fatigue, breathlessness, low mood, and depression. These symptoms collectively impose a significant burden on the lives of individuals affected by this condition, as they severely restrict Long Covid sufferers’ ability to engage in daily activities. However, the profound impact of Long Covid extends beyond the complexities of living with the symptoms associated with a chronic and invisible illness. Our research suggests that Long Covid sufferers often find themselves grappling with a sense of social isolation, which is exacerbated by the difficulties in effectively communicating their experiences to those without lived or living experience.

Long Covid’s detrimental effects also extend to the realm of employment, where the majority of participants faced adverse consequences – e.g. demotion, termination, or the need to transition to part-time work – due to the limitation caused by this condition. The lack of adequate support from employers, coupled with a perceived lack of compassion, emerged as recurrent theme in our interviews, compounding the emotional toll experienced by those affected. However, it is essential to recognise that the impact of Long Covid on employment transcends mere financial concerns. The inability to perform one’s job can have a profound effect on an individual’s emotional wellbeing and sense of self. This underscores the need for comprehensive support systems and increased awareness to address the multifaceted challenges posed by Long Covid.

Summary of key points

- Only three out of 10 of northern public sector employers contacted offered a specific rehabilitation package to employees living with Long Covid despite higher prevalence in the region.
- While many public sector employers in the North provide support for Covid-19, this is specified on an acute basis, rather than for Long Covid/post Covid illnesses.
- Differences in recording methods meant that statistical comparisons across organisations regarding number of employees experiencing Long Covid and number of working days lost to Long Covid absence were not possible. Further, a sizeable proportion of public sector organisations collected Covid-19 related absence only and could therefore not be specific about instances of Long Covid.

Introduction

In previous chapters we demonstrate both regional variation in Long Covid prevalence and that, for those with lived experience, Long Covid is a multi-layered and complex condition with repercussions that extend beyond the physical and mental health symptoms of the illness into other parts of people's lives, including their sense of self and professional identity. In this chapter, we use publicly available data obtained via FOIA requests to better understand policy and practice responses of public sector employers to Long Covid.

Methods

FOIA requests were made to 164 public sector employing organisations (Local Authorities, NHS Trusts and Universities) across the North of England (defined as North West, North East and Yorkshire & Humber) in December 2022 requesting details of employment policy and practice adjustments in response to Long Covid. All requests were submitted through and responses managed by the website "What Do They Know" (www.whatdotheyknow.com).

Numerical and narrative data received were extracted and summarised on:

1. The proportion of public sector organisations that had a standalone policy detailing how they support managers and employees on the issue of Long Covid
2. The proportion of organisations that had amended another existing policy detailing how the organisation will support managers and employees on the issue of Long Covid.
3. Details of specific rehabilitation package(s) available to staff experiencing Long Covid (other than signposting to standard NHS care)
4. How many employees have notified the organisation that they have been diagnosed with Long Covid (between 1st January 2020 and 31st December 2022)?
5. How many days have you lost as an organisation due to formally diagnosed Long Covid (between 1st January 2020 and 31st December 2022)?

Response Rate and Policy Responses to Long Covid

Responses were received between December 2022 and May 2023. 162 organisations responded to our request, a response rate of 98%. Of those that responded, 157 organisations (97%) sent some or all information requested; with remaining organisations sending a holding response only or a response to indicate that this information was not held. Importantly, information was not sent in standardised



formats making it difficult to extract, interpret and synthesise. Therefore, data presented is designed to present a contextual and descriptive picture only and we acknowledge the need for further research in this area.

Of those organisations who sent some or all information requested (n=157), the majority (n=149; 95%) did not have a standalone policy detailing how they support managers and employees on the issue of Long Covid. Some organisations provided additional contextual details. Thus, several identified that, whilst no standalone policy had been created, they had created guidance for managers and staff (though falling short of a formal policy), had adhered to their pre-existing policy on managing long-term absence and/or had adhered to guidance provided by NHS England in relation to Covid absences and Long Covid.

A smaller proportion of organisations indicated that they had issued a standalone policy in relation to Long Covid (n=6; 3%), whilst one organisation (1%) did not respond to this query and for one final organisation (1%) the response was unclear. Similarly, a high proportion (n=120; 76%) indicated no changes to existing policies. Reasons provided for this included: adherence to guidance provided by NHS England, adherence to broader long-term sickness policies only, temporary changes during the pandemic in response to Covid-19 illness which had now ceased rather than been maintained; issuing manager guidance and/or guiding principles but not formal policy; and signposting to GPs and support groups.

Further, even where responses stated they had revised an existing policy (n=30; 19%), some policies still did not specifically mention Long Covid or mentioned acute Covid-19 infection only. However, several organisations indicated they had adapted 'Living with Coronavirus Guidance', had added the condition to their OH guidance booklet or had specific risk assessments for individuals suffering from Long Covid. Remaining respondents (n=7; 5%) gave no definitive answer or did not respond to this question at all.

Details of Specific Rehabilitation Offered

Forty-seven responding organisations (30%) indicated that they had designed and offered specific rehabilitation packages in response to Long Covid. Policies and practices outlined included:

- referrals to clinicians
- physiotherapists
- NHS Covid Hubs and local Long Covid Clinics
- psychological/counselling referrals
- peer support groups
- phased return to work periods
- adjusted duties and redeployment
- extended sick pay
- career breaks
- support through the Access to Work scheme.

A larger proportion of organisations (n=104; 66%) indicated they had developed no specific rehabilitation packages for Long Covid. Nevertheless, at times it was difficult to determine whether rehabilitation described - regardless of answering yes/no - was specific to Long Covid or open to all employees from responses we received. Thus, most responding organisations - regardless of whether they felt they had created tailored rehabilitation packages - stated referral to OH and/or Employee Assistance Programmes as their primary pathway and suggested that circumstances would need to be assessed on a case-by-case basis to determine the need for reasonable adjustments.

Others outlined that they treated cases of Long Covid in much the same way as any other long-term condition. Remaining respondents (n=6; 4%) gave no definitive answer or did not respond to this question at all.

Number of Employees Diagnosed with Long Covid

Again, answers to both of these queries were reported differently across organisations due to differences in recording methods and due to the fact that we did not ask for any details on the size of the employing organisation inhibiting further statistical comparisons. For example, some organisations could only report on Covid-19 related absence and could not be specific about instances of Long Covid. Similarly, some employers defined Long Covid as Covid-related absence of over 21-28 days but with the recognition that this is not based on a formal diagnosis/definition of Long Covid and is therefore a simplistic calculation. Meanwhile, others reported the combined absences of those who had been diagnosed with

Long Covid, which had occurred since their initial Covid infection, but which included instances where Long Covid may have been a contributing factor as well as where it may have been unrelated. Nevertheless, 56 responding organisations (36%) reported that they did not record or hold data on the number of employees diagnosed with Long Covid. For those who did hold data, the minimum number of employees reported was 0; the maximum was 693.

Number of working days lost attributed to Long Covid

Sixty-four responding organisations (41%) reported that they did not record or hold data on the number of working days lost as a result of Long Covid illness. For example, one organisation stated that they did not record Long Covid specifically as an absence type but that this is recorded combined as part of the category of chronic fatigue and/or infections such as coughs and colds. For those who did hold data, the minimum number of days reported was 0; the maximum was 88,361.

Conclusion

Responding to staff experiencing Long Covid fell under the umbrella category of chronic illness for most employing organisations contacted, with many using pre-existing measures and support initiatives designed for long-term absence. Further, a sizeable proportion of organisations collected Covid-19 related absence data only and could therefore not be specific about instances of Long Covid.

However, comparing this data to the narratives of those experiencing Long Covid suggests that the ways in which employers currently respond to Long Covid absence does not appear to represent the needs of those experiencing Long Covid who illustrated non-linearity of their symptoms, the need for tailored non-judgemental support, recognition of the detrimental impact upon their professional identity and flexible patterns/working spaces.

We reinforce our recommendation that there is a need for comprehensive support systems, nuanced absence reporting systems and increased awareness to address the multifaceted challenges posed by Long Covid. Government should develop programmes for employers to support members of their workforce with Long Covid. Further, a government consultation with Long Covid sufferers and employers should be undertaken to better understand their condition and to implement care plans to facilitate rehabilitation and management of the condition.



Recommendations

Research funders should prioritise biomedical research into Long Covid to establish accurate diagnostic tests, understand the illnesses' pathophysiological mechanisms and develop treatments.

Research into the impact of known social determinants of health and their relationship with Long Covid should be undertaken.

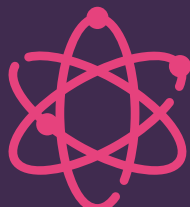
Learning from overlap with other post-viral conditions such as myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) should be harnessed during Long Covid research and further funding into these conditions should be allocated to assist with treatment and future pandemic preparedness.

The relationship between disability figures, sex and Long Covid should be the basis of further research.

Priorities for government:

Government should develop programmes for employers to support members of their workforce with Long Covid.

A government consultation with Long Covid patients should be undertaken to better understand their condition and to implement care plans to facilitate rehabilitation and management of the condition.



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