

TORRANCE, N., GRANT, A., KENNEDY, C., DOUGLAS, F., SANTIAGO, V.H., SKÅTUN, D., ADAMS, N. and MACIVER, E. 2023. *Lived experience of long COVID in health workers in Scotland (LoCH study)*. Edinburgh: Chief Scientist Office [online]. Available from: <https://www.cso.scot.nhs.uk/wp-content/uploads/COVLTE2032report.pdf>

Lived experience of long COVID in health workers in Scotland (LoCH study).

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2023



RESEARCH

INFORMATION

Lived Experience of long COVID in Health Workers in Scotland (LoCH study)



AIMS

The Long COVID in health workers (LoCH) study investigated the lived experience of the longer-term effects of COVID-19 (long COVID) on professional and ancillary staff employed in the NHS across Scotland. We asked about their symptoms of long COVID, health and wellbeing, use of healthcare and self-management strategies, working in the NHS and about personal and household finances.



KEY FINDINGS

- Due to on-going symptoms of long COVID, both physical health and mental wellbeing were lower compared to the general population and overall, there was no significant improvement over the 6-month study period, in those who completed the online survey.
- Most participants were in work in the NHS but managing complex and dynamic symptoms, with periods of improvement and exacerbation. They engaged in a range of strategies to manage, such as rest, pacing, planning, and prioritising, with work prioritised overall. Many engaged with online long COVID support groups.
- Access to healthcare was limited, some engaged in persistently seeking healthcare and others understood options were limited and the single disease model of care did not fit their long COVID symptoms. For some individuals, access to specialist care was helpful in addressing specific symptoms.
- From the interviews, improvement in symptoms was often linked to: being believed by GP and/or at work; workplace adjustments (phased return, role, responsibilities, hours, location); and an acceptance they may never get better and/or engage in social activities they had done pre-Covid. The NHS long COVID payment enabled participants to work in a reduced capacity with usual pay, however, participants were concerned with when this would stop and the implications.



WHAT DID THE STUDY INVOLVE?

The study had three components:

1. An online survey of NHS workers with self-reported symptoms of long COVID. Recruitment was via online support groups, social media, and NHS boards' communications teams.
2. In-depth qualitative interviews were conducted with a sample of 50 NHS workers who had completed the survey. These individuals were selected to ensure a wide range of occupations, sociodemographic characteristics and severity of long COVID, and included nurses, doctors, allied health professionals, ancillary and administration staff.

Six months later, participants were invited to complete a follow-up survey and (if applicable) interview. We asked about symptoms, health related quality of life (HRQL), access and use of health services, impact on working lives, support, and household finances. Our advisory group (some with lived experience) helped raise awareness of the study and gave advice on study materials and interpretation of findings. 471 NHS workers completed the first survey and 302 the follow-up. 44 participants took part in the follow-up interviews.

3. Stakeholder workshops were held online with health professionals, policymakers, and people with lived experience to help inform the study's policy and practice recommendations.



WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

All participants experienced a wide range of dynamic and unpredictable symptoms. Fatigue, 'brain fog', breathlessness and pain were the most common. Both physical and mental wellbeing (HRQL) scores were below average, compared to the general population, at both time points and fatigue scores were high. Long COVID symptoms adversely affected the day-to-day activities of 84% of participants, with 32% reporting that these were "limited a lot" at 6-month follow-up.

For the majority (65%) long COVID resulted in periods of sickness absence, and 17% had never recovered enough to return to work. A fifth of participants had reduced their contracted works hours in the NHS and 60% were worried about their future financial situation. For 40%, their work duties had changed and these included working in a reduced capacity (phased return, role, responsibilities, hours, location). This is likely to place additional pressure on those working in their teams and the system more generally, so is likely to exacerbate the NHS staffing and wellbeing crisis. 35% were considering leaving or unsure about continuing in their NHS employment because of their long COVID symptoms.

All participants experienced improvement and exacerbation of symptoms (= episodes of sick leave for those working). These episodes were often triggered by reinfection and vaccinations but also unsuccessful returns to work, highlighting the importance of flexible workplace adjustments. Fear of re-infection was prevalent across the people interviewed. Current NHS occupational health policies (4-week phased return) are not practicable for dynamic and unpredictable conditions like long COVID. Almost a quarter were dissatisfied with the support received from their employer



WHAT WERE THE RESULTS AND WHAT DO THEY MEAN (2)?

At the first survey, 73% had contacted their GP practice, 38% had contacted Occupational Health and 30% sought advice from an NHS website, for their long COVID symptoms. Over a third (34%) had been to a hospital outpatient clinic, and 10% had been admitted to hospital. Overall satisfaction with health care received was low, with only 29% reporting that they were satisfied, and this was consistent at follow-up.

Participants expressed distress at not being believed at work, home and by their GP. Rest, pacing, planning, and prioritising were successful strategies to manage home life, social life, and work. Rest did not improve symptoms but provided temporary relief and time to plan and strategize activities. Participants prioritised work over other aspects of their life, feeling guilt for the implications of their absence/reduced contribution on colleagues, given the pressures the NHS was under at the time (in wave 3 of the pandemic for interview 1).

Participants reported a deep sense of loss of their usual function, sense of self, professional identity, and fear of what the future might hold. Often asking “will I ever get better?” In follow-up interviews, acceptance of this new health status was key to coping and in some instances improvement.

The NHS long COVID payment had been fundamental in enabling them to work in a reduced capacity without reduced pay but there were high levels of anxiety about when the payment would stop and the implications for them and their family financially (data collection stopped 2 months before this payment ceased in October 2022). A reduction in pay and job security will have resulted in additional stress and anxiety for those unable to meet their contractual obligations but the full implications are unclear. Long COVID has impacted on mental wellbeing and is likely to have longer-term implications on the NHS workforce.



WHAT IMPACT COULD THE FINDINGS HAVE?

- For NHS workers affected by long COVID the findings help with increasing awareness of their symptoms and experiences and it highlights the need for all NHS staff to be provided with more information to improve knowledge and promote better understanding around the condition.
- Long COVID is impacting on the health and wellbeing of NHS staff and is likely to exacerbate the workforce crisis. People need long-term support and flexible occupational health and human resources policies to enable them to be retained in or reintegrated into their NHS role in a useful capacity. This is likely to be applicable to NHS staff with other long-term conditions which impact physical and mental health and wellbeing.
- There is a need for flexible workplace adjustments to retain skilled NHS staff. Clinical pathways, particularly for primary care practitioners, are needed to help them provide long-term support for people living with long COVID including referral to appropriate specialist services.



HOW WILL THE OUTCOMES BE DISSEMINATED?

Our results will be shared with the long COVID policy team and the Long Covid Strategic network hosted by NHS National Services Scotland. Research findings have been already presented at national and international conferences. A summary of the main findings will be shared with the participants who indicated an interest in receiving them. A full report of the findings will be submitted to a peer reviewed academic journal for publication. Analysis of the different aspects from the study is ongoing.



CONCLUSION

Long COVID has had a significant impact on the lives of those NHS staff in Scotland suffering from these prolonged symptoms. Due to the variability and dynamic nature of symptoms, supporting the health and wellbeing of individuals, workplace support, and flexible policies are needed to help retain these NHS employees or to implement pathways to changes to their current role.



RESEARCH TEAM & CONTACT



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Additional Information

The project ended on 30th April 2023 and received £294,605 of funding from the Chief Scientist Office