



RESEARCH

INFORMATION

The Long-COVID in Scotland Study (Long-CISS)



AIMS

The Long-COVID in Scotland Study (Long-CISS) aimed to identify the effects of COVID-19 on the health of people in Scotland. We wanted to find out how many people continue to be unwell after having COVID-19, what their symptoms are, and how it affects their lives. This is important to inform the nature and level of services required to support patients.



KEY FINDINGS

- At 6 months or more after symptomatic infection, 48% of participants reported not being fully recovered.
- The symptoms of long-COVID vary, but the most common are tiredness, headache, muscle aches/weakness, difficulty sleeping, and breathlessness.
- The risk of long-COVID is greater in people who had to be hospitalised for their COVID infection, women, people living in deprived areas and those with pre-existing health conditions (especially those with two or more chronic conditions), and absent following asymptomatic infection (i.e. when the individual had no symptoms of acute infection).
- The 'true' prevalence of long-COVID (percentage of people who had one or more current symptom with no alternative diagnosis) was 6.6%, 6.4% and 10.3% at 6-, 12- and 18-month follow-up. This takes into account other patient characteristics and the prevalence of current symptoms reported by people who did not have COVID-19 infection recorded.
- Interviews with participants living with long-COVID identified the devastating effect it has on lives, with detrimental impacts on finances, careers, relationships and mental health
- Repeat interviews 6 months later identified fatigue, breathlessness, and brain fog as common enduring symptoms and effective treatments are elusive.





WHAT DID THE STUDY INVOLVE?

Long-CISS used the Scottish polymerase chain reaction (PCR) test result database to identify and invite every adult in Scotland who had had a positive PCR test for COVID-19 and a comparison group of people who had a negative test only. 4,049,590 invitations were sent by SMS (text message). We included existing cases and added new cases as they occurred, and a total of 257,341 unique people participated fully. Study participants completed questionnaires at 6, 12, 18, and 24 month follow-up. We also linked this information to their routine health data on medications, hospital admissions and deaths.

Participants also consented, if they wished, to recruitment to the qualitative study. Forty-five people were interviewed; eighteen were reinterviewed 6 months later. Overall, we interviewed 24 men, 21 women with most aged 40 and over.

The University of Glasgow, College of Medical, Veterinary and Life Sciences PPIE (Patient and Public Involvement and Engagement) and COVID-19 PPIE groups contributed to study design, recruitment, and interpretation of results.



WHAT WERE THE RESULTS AND WHAT DO THEY MEAN?

Self-reported long COVID was very common. Following symptomatic infection 42% reported that they had only partially recovered and an additional 6% said they have not recovered at all. The condition was associated with worse quality of life, impairment across all aspects of daily living and a wide range of symptoms. However, the true frequency (taking into account individual characteristics and current symptoms in people who did and did not have COVID infection recorded) of long-COVID was much lower than the self-reported frequency. Apart from altered taste and smell, the symptoms of long-COVID are non-specific and therefore may occur irrespective of infection. Therefore, whilst 64.5% of the people in this study reported at least one symptom 6 months following SARS-CoV-2 infection, this was also true of 50.8% of those never infected. The 'true' prevalence of long-COVID (percentage of people who had one or more symptom that would not have occurred anyway) was 6.6%, 6.4% and 10.3% at 6-, 12- and 18-month follow-up.

Between 6- and 12-month follow-up the overall percentage of people with one or more symptom did not change, but there were changes in specific symptoms. Altered taste, smell and confusion improved over time in the post infection group when compared to the never infected group. Conversely, late onset dry and productive cough, and hearing problems were more likely following SARS-CoV-2 infection than among those never infected.

Interviews identified the devastating impact of long COVID on people's lives. Participants spoke about its catastrophic effects on finances, careers, relationships and mental health. The desire to have 'their life back' was universal. Recognising and attributing symptoms to long COVID was difficult for some, especially if they lived with other long-term conditions. Some female participants spoke of being unsure if they had long COVID or symptoms of the menopause. Many spoke of attempts of access healthcare as 'fragmented'. Some felt 'dismissed' by GPs; others described an arduous cycle of undergoing various investigations, receiving normal test results, organising more consultations and more tests, all adding to the burden of life with long COVID. This made some reluctant to seek further healthcare.





At follow-up interviews six months later a diverse picture emerged where for some symptoms had gradually improved while others experienced no improvement or worsening symptoms. Fatigue, breathlessness, and brain fog were common enduring symptoms. Worsening symptoms were sometimes attributed to a second COVID-19 infection. Mental health issues were more of a feature with the long-term aspect of long-COVID, and frustrations about a lack of treatment options, fuelling anxiety and depression. Effective treatment remained elusive – people were even more reluctant to consult after being previously dismissed by healthcare professionals or because previous consultations and investigations proved fruitless. An exception to this is treatment from physiotherapists, in the form of breathing exercises and advice on pacing to manage fatigue, which was well received.



WHAT IMPACT COULD THE FINDINGS HAVE?

- Prevalence estimates of people with long-COVID can inform service provision at a whole population level in Scotland.
- People's lives are seriously impacted, often for years. People need long-term support to help them deal with its impact, and to help them identify and navigate appropriate healthcare.
- Primary care practitioners require support, and services to which they can refer, in order to provide those living with long COVID the long-term support they need.
- Policies to support return to work and to mitigate the financial impacts of living with long COVID should be a priority.



HOW WILL THE OUTCOMES BE DISSEMINATED?

Our results are shared with the Scottish Government, NHS Scotland and PPIE groups. They are also disseminated through links with long COVID Scotland (a volunteer-led charity run by people living with Long Covid). Initial findings were published in a peer reviewed medical journal (<https://www.nature.com/articles/s41467-022-33415-5>) and shared through social media and a press release. Analysis is ongoing.



CONCLUSION

Long COVID is a significant health issue for the Scottish population, which varies in symptoms and severity. Patients require long-term support, and potential treatments explored.



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