THE CONVERSATION

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Why Scotland needs to fund long COVID rehabilitation now

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BBC Scotland reporter Lucy Adams explored the symptoms and challenges of her own long COVID for Panorama, BBC/Panorama, Author provided (no reuse)

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The world is 19 months into COVID-19 and <u>more than 4m people have died</u>. Many countries have rising death rates and desperately require COVID-19 vaccination supplies. Others, including the UK, are benefiting from high vaccination uptake and decreasing deaths.

But fewer deaths do not equate to fewer cases. While in England <u>collective measures</u> to limit the spread of COVID-19 have been jettisoned, the number of infections across the UK as a whole is still <u>rising</u>.

It is now clear that increases in COVID-19 cases will result in growing numbers of people experiencing symptoms of varying degrees following their initial infection. A <u>recent study</u> found that 38% of people with COVID-19 had at least one enduring symptom 12 weeks later – a condition known as <u>long</u>. <u>COVID</u>.

Long COVID presents in many different ways. In a <u>recent survey</u> of COVID support groups, people who had either confirmed or suspected COVID-19 said that after six months their most common symptoms included fatigue, worsening of symptoms after very little activity and difficulty in thinking clearly – also known as "brain fog".

Responses to long COVID

Long COVID affects people's ability to go about their daily lives. In another <u>recent UK survey</u> respondents stated that it affected their family life (71%), ability to work (80%), ability to look after their families (39%) and their finances (36%).

Almost half of respondents were working reduced hours, with 22% being unable to work at all. As a result, <u>people living with long COVID</u> are increasingly calling on governments to provide appropriate assessment, rehabilitation and economic assistance to support their recovery.

To date, the four UK governments have responded differently to this condition. In December 2020 the Westminster government, responsible for health in England, <u>launched a network</u> of specialist multidisciplinary long COVID assessment centres. In June 2021 it extended these to include specific centres for <u>children and young people</u>.

In the same month, the Northern Ireland government announced the <u>establishment of similar</u> <u>centres</u>, while the Welsh government announced a £5m recovery plan, including a self-care <u>app</u> and a new <u>referral pathway</u> to help GPs guide patients with long COVID through existing services.

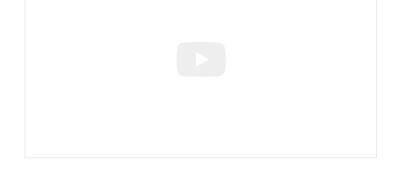
In August 2020 the Scottish government published a high-level COVID-19 <u>recovery and rehabilitation</u> <u>framework</u>. But so far it has not provided any financial support for the development of specific centres – as England and Northern Ireland have – or strengthened existing care services and pathways – as Wales has done.

Instead, recognising that little is known about how to best assess, treat and rehabilitate people with long COVID, the Scottish government has <u>funded nine research projects</u> totalling around £2.5m.

More recently, a further <u>£19.6m</u> of <u>National Institute of Health Research</u> (NIHR) funding has also been awarded to universities across the UK to help diagnose and treat long COVID.

Responding to a question following a recent <u>briefing</u>, Scotland's first minister Nicola Sturgeon stated that people with long COVID should attend their GP, who will refer them to relevant services. Our own <u>research</u> conducted earlier this year found that every territorial NHS health board in Scotland was providing rehabilitation services, in different ways, for these long COVID patients.

But while some Scottish COVID-19 <u>treatment pathways</u> and <u>dedicated services</u> have been developed, they are not universally available nor supported with additional funding. As a result, many health professionals and people with long COVID appear unaware of what services are available. Anecdotal evidence suggests that referrals for long COVID rehabilitation in several Scottish health boards are lower than anticipated.



What can be done?

UK-wide <u>guidelines</u> on managing the long-term effects of COVID-19 recommend that multidisciplinary rehabilitation teams should support people's recovery. But rehabilitation services have often been perceived as <u>neglected and sometimes disjointed</u>.

Long COVID has highlighted some of the limitations of these pre-existing systems. The <u>latest Scottish</u> <u>government figures</u> estimate that between 46,000 (0.7% of the population) and 110,000 (1.9%) people were estimated to experience long COVID in Scotland. Even if only a small proportion of these people were referred to existing rehabilitation services as currently funded, these services would quickly become overwhelmed. Additional funding is required to support the foreseeable surge in demand and the training required to upskill staff.

The jury is out as to whether specialist clinics or integration within existing services will prove to be most effective for people requiring long COVID rehabilitation. But, as has been <u>argued elsewhere</u>: "In the face of a pandemic the search for perfect evidence may be the enemy of good policy."

In other words, in situations such as this, it is best not to wait for the highest levels of evidence about "what works" before intervening – especially in cases such as long COVID where some forms of rehabilitation already exist for people who present with similar symptoms. This approach is known as the "<u>precautionary principle</u>". In these circumstances, research – which remains essential – and practice best proceed hand in hand.

It is time for Scotland to embrace the precautionary principle in long COVID rehabilitation and act – even without definitive evidence of what is best. Investment to scale up and publicise existing specialist and integrated long COVID rehabilitation would enable people to receive much-needed help and support.

Researchers like us – working in close collaboration with health and social care services and people living with long COVID – are well placed to evaluate these different forms of rehabilitation as they are made available, and we can develop and recommend how best to implement these services as they emerge.



Scottish Government UK government COVID-19 Long COVID

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