Supporting recovery from Long COVID:

A digital care pathway

Pogo Digital Healthcare

Long COVID may well be the first condition to be named on social media, in May 2020 on Twitter (Callard F 2021). This simple term has now been widely accepted, by the World Health Organization (WHO) and the NHS among others, encapsulating the fact that COVID 19 symptoms can last a long time, with no clear understanding of its causes, or any way of predicting its duration.

This white paper summarises the published evidence of the impact of Long COVID on patients and their families, the economy, and health services. It examines the response of the health services in the UK to providing guidance for health professionals and support for patients. It also looks at how digital care pathways can be used to provide that support, giving details of NHS Lothian's pilot of a Long COVID digital pathway.

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What is Long COVID?

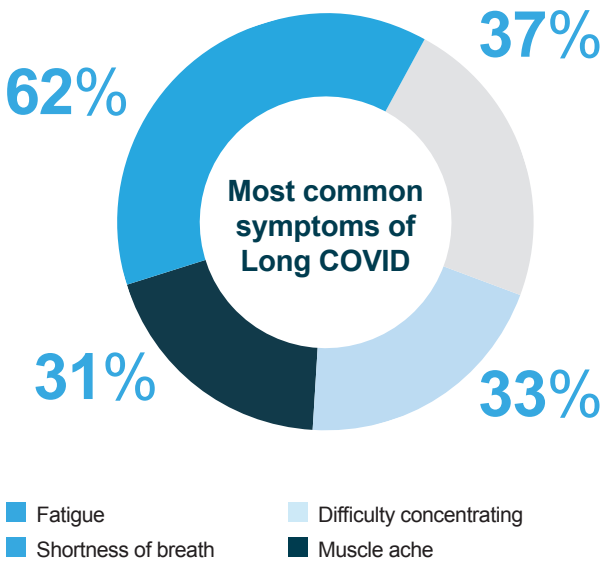
COVID 19 was first described as a respiratory disease, categorised by pneumonia severity. The focus for health care professionals at the start of the pandemic was very much on mortality. The discussion around Long COVID focuses on morbidity and reflects the fact that there can be many different aspects to the condition. It can be debilitating and have long-term effects on the people who experience it.

The NHS defines two forms of Long COVID:

- Ongoing symptomatic COVID: when COVID symptoms carry on for four to 12 weeks
- Post-COVID syndrome: when COVID symptoms carry on for over 12 weeks

The symptoms of Long COVID are varied. This can make it difficult both for patients to report, and for medical professionals to diagnose. The most common symptoms in those with self-reported Long COVID (ONS) are:

- fatigue (62%)
- shortness of breath (37%)
- difficulty concentrating (33%)
- muscle ache (31%)



> "Since there is no specific test for Long COVID and symptoms vary so widely, diagnosis can be a lengthy process"

However, one survey of 3,700 people found 205 different symptoms. A study of 2,550 people found an average of ten ongoing symptoms for each person (Davis et al 2021).

Since there is no specific test for Long COVID and symptoms vary so widely, diagnosis can be a lengthy process.

The time it takes for someone to recover from Long COVID also varies. The length of time a person is ill with Long COVID doesn't always link to how unwell they were when they had COVID 19, or whether they were in hospital.

Support for people with Long COVID can involve a range of services including GPs, consultants, nurses, physiotherapists, occupational therapists, and psychiatrists. This places substantial demands on how much time is available from these professionals, has a knock-on effect on waiting times for all patients and impacts NHS Budgets (BHF 2022).

Who Long COVID affects

As of 31 July 2022, an estimated 2 million people in the UK (3.1% of the population) said they were experiencing Long COVID (ONS 2022). Of these people:

13% reported they first had COVID 19 less than 12 weeks previously

83% reported they first had COVID 19 at least 12 weeks previously

45% reported they first had COVID 19 at least one year previously

22% reported they first had COVID 19 at least two years previously

Anyone can be affected by Long COVID, but ONS data shows that some groups are more likely to have it (ONS 2022). These are:

- people aged 35-69
- women
- those living in the most deprived areas
- people with disabilities or existing health conditions
- those working in health or social care

Impact of Long COVID

Impact on patients

Long COVID symptoms adversely affects the day-to-day activities of 1.5 million people (73% of those with self-reported Long COVID), with 384,000 (19%) reporting that their ability to undertake their day-to-day activities had been “limited a lot” (ONS 2022).

Impact mental health

Long COVID can negatively affect mental health. Studies have shown that a substantial proportion of Long COVID patients have symptoms of post-traumatic stress disorder (PTSD), anxiety and depression (Houben-Wilke et al 2022; Naidu et al 2021).

There are also public health implications for the management of people from ethnic minority groups suffering with Long COVID. People from ethnic minority groups have been shown to be more likely to get COVID 19 but their uptake of mental health services is generally low (Sze et al 2020).

> “Studies have shown that a substantial proportion of Long COVID patients have symptoms of post-traumatic stress disorder”

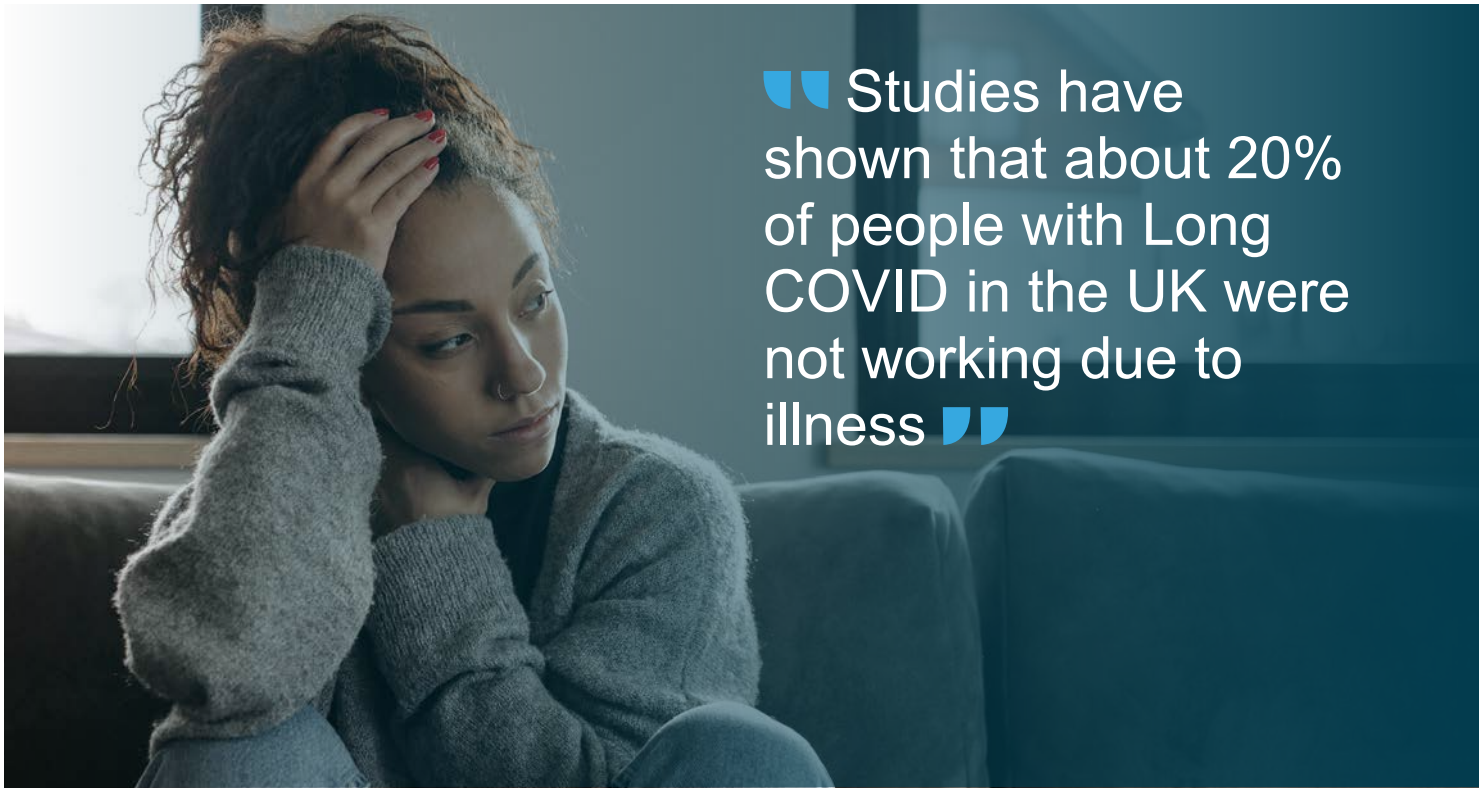
Impact on families

Long COVID has been shown to affect families negatively. The biggest impact was on family members “feeling worried”, followed by problems with family activities, feelings of frustration and sadness, poor sleep, and reduced sex drive. Many also reported an increase in family expenses (Shah et al 2020).

With women more at risk of Long COVID and at the same time largely bearing the burden of care in households, their wellbeing is often severely affected (Seedat and Rondon 2021). This can have a ripple effect on their families.

Impact on employment

Poor health and disability can significantly impact education, earnings, and employment (Jones and McVicar 2020). Since the pandemic, staff absences have risen sharply, contributing to substantial labour shortages (Westerlind et al 2021). Some Long COVID symptoms can severely hinder ability to work, such as post-viral chronic fatigue, cardiopulmonary symptoms, anxiety, and depression (Aiyegbusi et al 2021; Burton et al 2021).



Impact on the economy

Long COVID has a serious impact on people's ability to work. This may have significant economic consequences for them, their families and for society (Rajan et al 2021).

Studies have shown that about 20% of people with Long COVID in the UK were not working due to illness, and an additional 16-45% were working reduced hours (TUC 2021; Davis et al 2021). Long COVID is one of the main causes of long-term staff absence (Strauss and Smyth 2022).

Mothers of children under 12 were the group most likely to move from employed to not employed as a result of Long COVID (OECD 2021).

A much-reduced labour force can significantly impact the economy (Bach 2022).

Impact on health systems

The high prevalence of Long COVID in the UK puts an extra burden on the health system. According to the latest NHS England figures, waiting times have not improved much since last year (NHS England 2022).

COVID 19 patients discharged from hospital have markedly higher risks for rehospitalisation and death than the general population (Bhaskaran et al 2022; Menges et al 2021).

GPs face extra demand for their services as well, with 40% of COVID 19 patients in Zurich reporting at least one general practitioner visit related to COVID 19 after acute illness. A third of those who had not fully recovered did not seek further care, which may also have longer-term consequences on health systems (Menges et al 2021).

These findings emphasise the need for the timely planning of resources and patient-centred services for post-COVID 19 care.

Support plans: England, Scotland, Northern Ireland, and Wales

NHS England, Scotland, Wales, and Northern Ireland have all drawn up care pathways to tackle Long COVID (NHS England 2021; Scottish Government 2021; Dept of Health NI 2021; Welsh Government 2021). All pathways have been conceptualised based on the following principles:

- Personalised care: care focused on the individual.
- Multidisciplinary support and rehabilitation: a multidisciplinary team should tailor support and rehabilitation for the person, to enable the development of individual care plans for physical, mental and social needs.
- Supporting and enabling self-care.

The National Institute for Health and Care Excellence (NICE) published clinical guidance on managing the long-term effects of COVID 19 in December 2020.

There are now 89 post-Covid assessment clinics set up in England alone.

Digital self-management tools have also been provided through the Your Covid Recovery website.

NHS Lothian in Scotland is piloting a pathway involving a digital support tool called MyTailoredTalks for Long COVID.

Effectiveness of digital pathways

The use of digital technologies has transformative effects on how health systems achieve programmatic goals, deliver services, and run operations (WHO 2022).

Indeed, a number of digital health tools were made available during the pandemic, such as telehealth, smartphone mobile apps, machine learning and artificial intelligence (Alghamdi and Alghamdi 2022).

The NHS has also recognised the role of digitally enabled care. Digital transformation of health and social care is a top priority for the Department of Health and Social Care and NHS England (DHSC and NHS England 2021). Four key goals for improvement have been established:

- prevent people's health and social care needs from escalating
- personalise health and social care and reduce health disparities
- improve the experience and impact for people providing services
- transform performance

Digital health tools have several advantages that can help the NHS achieve these goals.

Digital health tools were an integral part of pandemic responses. They were used to support communication, aid monitoring, assist the continued provision of health services and ease transitions from pandemic-related restrictions (Williams et al 2022). New and emerging technologies can support flexible, tailored services that promote people's health, wellbeing, and their independence (Williams et al 2022).

They can tackle the huge challenges the sector faces by offering people timely access to physical and mental health services, helping them manage their own health and care (Williams et al 2022).

Patients may find it easier to access and understand their care when supported by digital tools. One study has shown that a digital recovery pathway can improve the care of ICU patients after discharge from hospital (Rose et al 2021). Clinicians are also happy to offer a modern and adaptable service (Atherton et al 2018).

Digital technologies have the potential to reduce pressure on the overstretched workforce, and to target disparities in access and outcomes (DHSC and NHS England 2022).

> "Patients may find it easier to access and understand their care when supported by digital tools"

They can help to shrink the sector's carbon footprint and improve its resilience to the effects of climate change and future pandemics (DHSC and NHS England 2022).

However, the use of digital tools in care pathways carries risks. It may result in additional consultations or generate data that must be processed, acted upon and stored safely. This can add to the already high workload that healthcare professionals face (Hammersley et al 2018; Marshall et al 2018; Grant et al 2019).

Digital inclusion

According to the US based National Digital Inclusion Alliance, digital inclusion refers to the activities necessary to ensure that all individuals and communities, including the most disadvantaged, have access to and use of information and communication technologies (ICTs). The use of digital health tools in care pathways can have many advantages, as explored above. However, it also runs the risk of excluding groups of people that do not engage with digital technology.

Evidence indicates that a range of personal, situational, and environmental factors can affect how people engage with digital technology. For example, a lack of access to equipment and internet services, or poor digital literacy. However, the most commonly reported reason for not being online is motivation, or a lack of willingness to engage with and use digital technology (NHS England 2022).

NHS England's Transformation Directorate recently commissioned research to help better understand the behaviours of people who lack the motivation or trust to use digital services in health and social care, even if they have digital access and could use them in theory.

The research was carried out by Basis Social, working in partnership with social change charity, the Good Things Foundation.

For members of the public, the main factors influencing motivation to use digital channels f or health and social care were:

- **Perceived effectiveness:** how digital can deliver the expected service (and outcomes) quickly and efficiently.
- **Feeling understood:** how digital can enable people to communicate their needs and to feel heard.
- **Providing control:** how digital can give people more control over the support they access through the NHS and social care system.
- **Confidence:** beliefs in personal capabilities to access and use digital channels to meet health and social care needs (Basis Social and Good Things Foundation 2022).

Lessons learned from the Lothian Long COVID pathway

Digitally enabled care pathways have the potential to ease the pressures on the health systems caused by COVID 19 and Long COVID. They also have the potential to enhance quality of care.

To understand how they may work in practice, it's useful to examine the Lothian Long COVID pathway being piloted and evaluated by NHS Lothian before potentially being implemented across other areas in Scotland.

The pathway was developed in partnership between people living with Long COVID, NHS Lothian, Chest Heart & Stroke Scotland (CHSS) and Pogo Digital Healthcare.

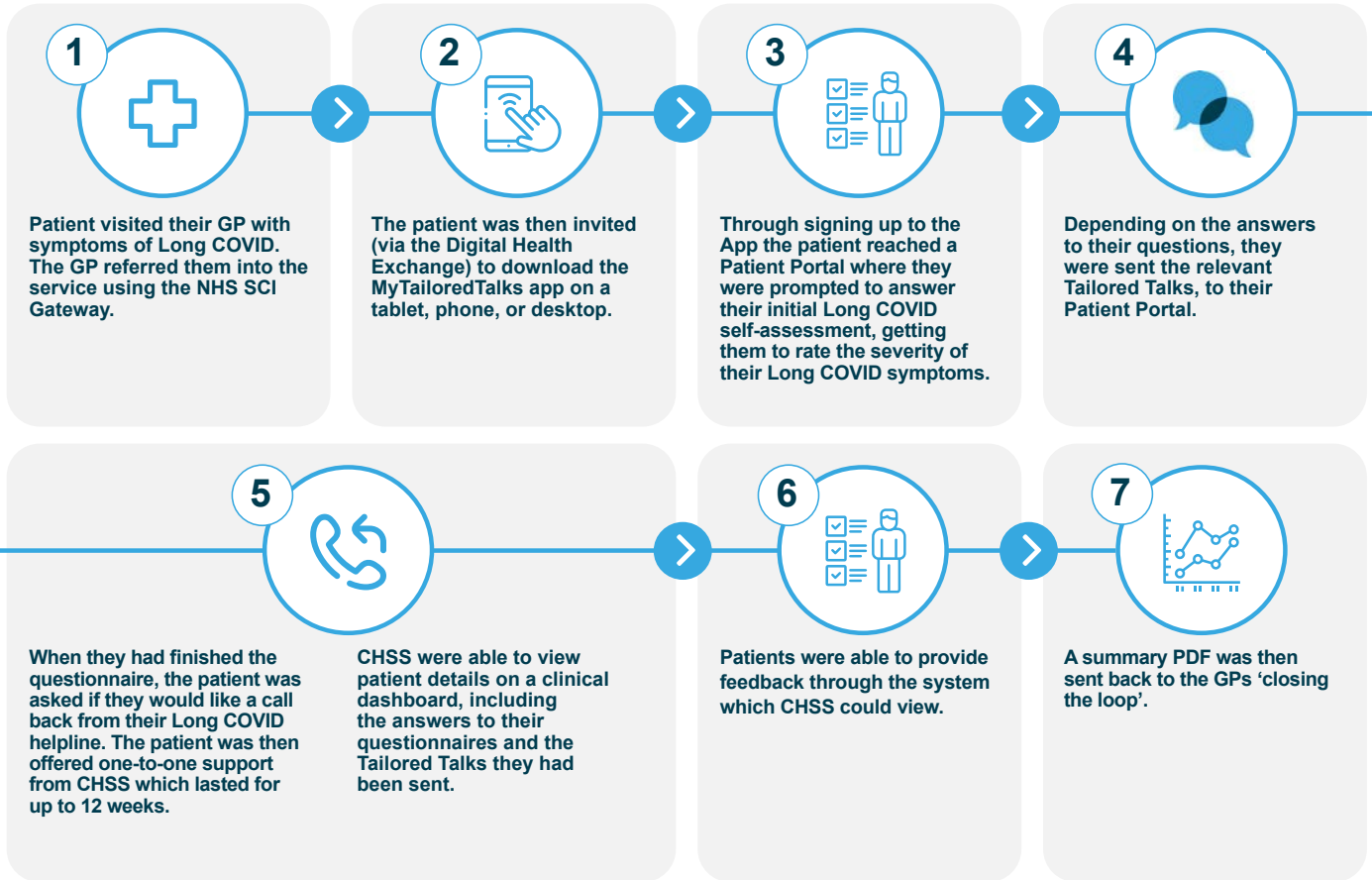
This pathway combined the following:

- GP referral onto a digital platform
- a self-assessment questionnaire
- personalised health information
- a helpline run by CHSS

Pathway aims:

- To provide a pathway of support, including digital information and advice via MyTailoredTalks, and support provided by a team of nurses and allied health professionals via the CHSS advice line.
- To promote self-management in recovery from Long COVID.
- To improve wellbeing and quality of life for people living with the impact of Long COVID.

The visual below illustrates the Long COVID Pathway and how patients access it:



An early review of the pathway was carried out by Senior Research Nurse Lucy Macdonald and NRS Healthcare Clinician Corrinne McCulloch. They completed 15 in-depth interviews with people who had been referred onto the pathway to understand how it was being used, its benefits and potential for improvement.

User responses to the digital support service

The digital support services offered by the Lothian Long COVID pathway were well-received by a majority of participants.

Most people:

- were positive about using a digital support service, and found it effective
- felt the digital support service could help them cope with Long COVID
- felt that digital support service met their expectations
- agreed that the service was delivered in the right way for them
- agreed that they saw value in the digital support service

> "Most people felt the digital support service could help them cope with Long COVID"

Insights into the effectiveness of the digital pathway

Registration: Overall people felt that it was easy and straightforward to sign up or join.

Varied use of MyTailoredTalks: Most people logged in several times to read their Tailored Talks. Some were suffering too much with Long COVID-related symptoms such as fatigue and brain fog to really engage with the content.

Self-assessment questionnaire: People felt that the self-assessment questionnaire covered most of the symptoms they were experiencing and that it was a good length. A few missing symptoms were highlighted, and some thought there was not enough detail.

"It was not that easy to rate symptoms. I kept going back to read them and rate them."

Length and content of the Tailored Talks: There were mixed views on this. Some felt that the length and wording was good and not too difficult to read. Others found that due to brain fog and lethargy they were unable to focus and read the slides.

"The talks were good and useful – they were about the right length and got to the point."

"The talks kind of solidified what I knew and had been looking up online."

Frequency of use: Most participants valued that they were able to go back at any point and re-read the information.

"Even if I could not concentrate at that point, I did go back to them."

Reassurance: Participants felt reassured by the talks. They helped them feel that they were managing their Long COVID correctly. They liked the "helpful reminders". Some said the language used was calming and reassuring. They also appreciated that the information came from the NHS.

"Good to have information directly from the NHS as it can be difficult to get solid information from the internet."

CHSS advice line: Participants valued the independent support, emotional support, reassurance, rapport, and general advice.

"I would particularly recommend the one-to-one conversations."

> "The talks were good and useful – they were about the right length and got to the point"

Potential improvements

The pilot flagged up some important learnings, which justify the decision to test early, iterate and retest.

One key finding is to consider the condition of the end user. Many of these patients were struggling with brain fog and found it difficult to read written content. They requested audio and video content instead. An early finding like this allows the content to be adapted quickly. They requested audio and video content assets, which are now integrated into MyTailoredTalks.

Users also requested the addition of positive stories about people recovering from Long COVID, regular updates on new research and more information about diet and vitamins. These requests highlight the importance of offering hope and agency to people struggling with a relatively new condition, the severity of which may be underestimated by many.

Overall, it is encouraging to see the digital Long COVID pathway met the needs of most participants. They understood the value of it and found it effective in a number of ways, while offering suggestions to improve the service. The results of the pilot and the patient feedback are now being used to improve the pathway for future use.

Conclusion

Digital channels offer the potential to make access to services more equal. They can help to remove some of the practical barriers faced by individuals and enable more effective targeting of clinicians' time and expertise to the people who are most likely to need support.

Digital tools and technology can also make it easier to measure the reach and impact of interventions, which will help services to continually improve, making sure that underserved populations are identified and supported.

A hybrid digital solution combining personalised information and real-time support provides a way to address the varied symptoms of Long COVID and the long-term aspects of the condition. Users of the Lothian Long COVID pathway particularly valued:

- knowing that the information came from the NHS, a trusted source
- the hybrid nature of support, starting with their GP or consultant
- the CHSS helpline, which gave them one-to-one support when most needed

To be both effective and inclusive, digital services must be designed to encourage behaviour change. The Behavioural Insights Team suggest using the EAST framework, making the service 'Easy, Attractive, Social and Timely' (BIT 2015). The results of the Lothian Long COVID pathway pilot show that supporting people with Long COVID can be done successfully with a hybrid digital pathway.

Given the numbers of people dealing with Long COVID and the time needed for recovery, using digital pathways is an important way to personalise support while freeing up clinicians' time and managing costs.

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