Long COVID patient experience research

Summary report - Strands 1, 2, 3 and 4
March 2023

Kate Duxbury, Michelle Gray, Laura Tuhou, Rob Sinclair, Seps Sharafi

Contents

Executive summary

Introduction

With the increasing prevalence of Long COVID across the UK population, Long COVID presents the health service, and society more widely, with a number of challenges, particularly because it is a new condition.

Given the policy context, the Insight & Feedback Team at NHS England (NHSE) identified an urgent need for wide-ranging research to examine experiences and perceptions of Long COVID and Long COVID services, and commissioned Ipsos to conduct a research programme.

The research programme involved four strands, amongst four distinct audiences.

Strand 1 - **Enablers and barriers** to accessing care for Long COVID - A total of 37 semi-structured interviews with people living with Long COVID were conducted from three communities of focus who self-diagnosed as having Long COVID but had not accessed care or support from NHS Long COVID clinics regarding their condition.

1. Adults with pre-existing long-term conditions
2. Adults living in areas of deprivation
3. Children and young people

Strand 2 - **Enablers and barriers** to accessing care for Long COVID - This work comprised of 17 semi-structured interviews with representatives of advocacy organisations involved with supporting the lesser-served patient groups identified above. The work explored advocates' understanding of how Long COVID care might potentially differ between communities; as well as understanding the various challenges, or barriers, to accessing health services within these three specific communities.

Strand 3 - **Understanding public attitudes towards Long COVID** - The third phase of the research was a quantitative survey to measure awareness and perceptions of Long COVID across the wider population. This section of the project was conducted via Ipsos KnowledgePanel, and a total of 1,828 respondents completed the survey.

Strand 4 - **Patient experience of post-COVID services** - A total of 42 semi-structured interviews were carried out with adults who have Long COVID, all of whom had been referred to a Long COVID clinic. The objective of this strand was to provide an in-depth understanding of adult patients' experiences of NHS Post-COVID-19 services, to identify where services are working well and how they could be improved.

This executive summary presents the key implications that cross-cut the four strands.

Key implications

Increasing awareness of Long COVID – the condition itself and its symptoms, as well as the available support – will overcome some barriers to accessing services.

- Although awareness of Long COVID is generally high among the general public, there are some misunderstandings about Long COVID and differences in levels of knowledge between groups within the population. Increasing the general knowledge of Long COVID among the public, and particularly with groups where knowledge tends to be lower, would be beneficial so that people know when to seek help.

- Up-to-date guidance should be regularly provided to healthcare professionals who may have first contact with individuals experiencing Long COVID. In particular, it would be helpful to raise awareness (amongst both the public and healthcare professionals) that it is not necessary to wait until 12 weeks post-infection to seek care and support for Long COVID symptoms.

- Participants in the qualitative research strands generally had a low awareness of Long COVID services and/or how to access them. In addition, advocates reported very low or non-existent awareness of Long COVID services, making it difficult for them to signpost people to services.

- Knowledge about COVID-19 and Long COVID in children and young people was even less common, and a perceived lack of information about Long COVID from the NHS in relation to children and young people was reported.

Expanding and smoothing pathway access will help to lessen the barriers to accessing Long COVID services

- The current pathway relies on GPs, but GP availability and patient access to appointments are well-known challenges at present (across the board – not just in relation to Long COVID).

- A perceived lack of availability of GP appointments lowers public confidence in the ability of the NHS to care for people who have Long COVID, and this was enough of a barrier to deter some participants from trying to access care for Long COVID symptoms.

- The primary route into Long COVID services among participants was via a GP; this produces a perceived bottleneck however and places GPs in a ‘gatekeeping’ role, which impacts on how equitable and accessible Long COVID services are perceived to be.

- Vulnerable people from deprived backgrounds face additional barriers accessing and trusting healthcare professionals, so expanding the pathway to allow access via other routes may improve access to Long COVID services among these populations.

- Participants tended to find the referral process complex and time consuming, particularly in cases where they felt they had to chase or drive progress. If there is a way of streamlining the process – from the perspective of both patients and GPs – it could take less time, enable patients to access care and support for their symptoms more smoothly, and ease the workload for GPs.

Providing greater support throughout the patient journey will improve patient experience and satisfaction with Long COVID and other services

- The NHS is a trusted source of information for the public, who therefore look to the NHS to take a lead in the creation and dissemination of material regarding Long COVID. Clear guidance from such a trustworthy source would help improve knowledge and reduce anxiety when patients first develop symptoms or are first diagnosed. It might also encourage more people to seek out healthcare providers.

  Participants suggested that the NHS could produce specific guidance around Long COVID for patients in these early stages, informing people about what to look out for, including:

Prognosis

Likely timeframes for accessing Long COVID services

Where to go for help

What to expect from the Long COVID clinic, and during the wait for an appointment

How to self-manage

- Many patients mentioned that they were ‘self-managing’ their symptoms outside of the support structures of the NHS. People had experimented with lifestyle changes, and sought support from professionals outside the NHS, to enable them to cope with their ongoing symptoms, either because they had given up hope of finding a cure, or while they waited for treatments. Easily accessible information regarding how best to ‘self-manage’ would undoubtedly help these patients. But when possible, there should be opportunities for patients to ask questions specific to their conditions.

- Peer support groups and online forums provide an important source of fellowship and learning for people experiencing Long COVID, but misinformation is rife. If the NHS could facilitate, moderate, or otherwise try to influence the information provided in such groups to improve the quality of the discussion, it would be mutually beneficial to both the healthcare services and the patients themselves. The format (online vs in-person), duration and content is important to consider when setting up support groups.

Better meet the needs of patients with Long COVID by reviewing how services are set up (Strand 4 only)

- Many patients reported having to wait a long time to have their first appointment at the clinic, which was often coupled with a general lack of information about the Long COVID clinic.

- From referral through to discharge the Long COVID clinics should be providing as much communication as possible. Upfront information eases the concerns and anxiety of patients. Throughout their patient journey many participants felt in the dark about what was happening to them, or what support the clinic could provide. Patients expressed a wish for more information about the clinic, and it is also important to manage patients’ expectations of Long COVID clinics in advance of their first appointments by providing more information. Not having clear expectations sometimes added to patients’ anxiety or led to expectations that they would be ‘cured’ at the clinic.

- Where patients had an initial call prior to a more detailed assessment, this was an important moment in their journey and made them feel they would get the support they so desperately wanted to help manage Long COVID. If possible, this should be provided to all.

- Patients were often positive about their in-depth assessments. They described feeling a mixture of gratitude and relief following their initial consultation at the Long COVID clinic – particularly that their condition had a name and that others were also experiencing similar ongoing symptoms. Best practice for this appointment includes allowing enough time for the appointment, asking the patient detailed questions, listening, focusing on symptoms that are most important to the patient, and being clear about the support available and onward referrals.

- Some participants reported feeling exhausted and worn out from appointments (especially in-depth or lengthy appointments), and those who struggled with fatigue and brain fog reported struggling with completing paperwork. When designing services, it is important to keep the needs (and potential limitations) of patients with Long COVID in mind:

Consider how patients may be supported in telling their story, e.g., by putting together a timeline, or providing an aide memoire.

Consider the optimal length of an appointment/visit to the clinic, while acknowledging that patients appreciate the time spent with them.

Obtain information from patients in advance rather than during the appointment – giving them enough notice to complete the information while managing their energy.

Locate services in areas that can be fairly easily reached by patients.

Share information between services and departments to minimise duplication, helping to manage patients' energy.

Consider whether it might be possible for some tests to be completed more locally in advance of appointments.

- There was an expectation among patients that the Long COVID clinic would be able to provide them with tailored support. Patients felt severely let down when the guidance provided by the service felt too generic, or not relevant to them.

- The clinics should consider the policy around discharging patients. Many participants expressed a wish to maintain contact with the clinic, in case treatments developed or their conditions changed – rather than needing to obtain another referral.

Involve end users in the development of communications and use a range of formats and channels for dissemination

- Developing communications with people who have Long COVID will help to maximise the benefit of communications, by ensuring that it effectively communicates the information that they need.

- Involving a diverse audience in this development will help to ensure communications are accessible to a range of groups, including children and young people, those who may find it more challenging to understand health information, and those who require materials in alternative formats.

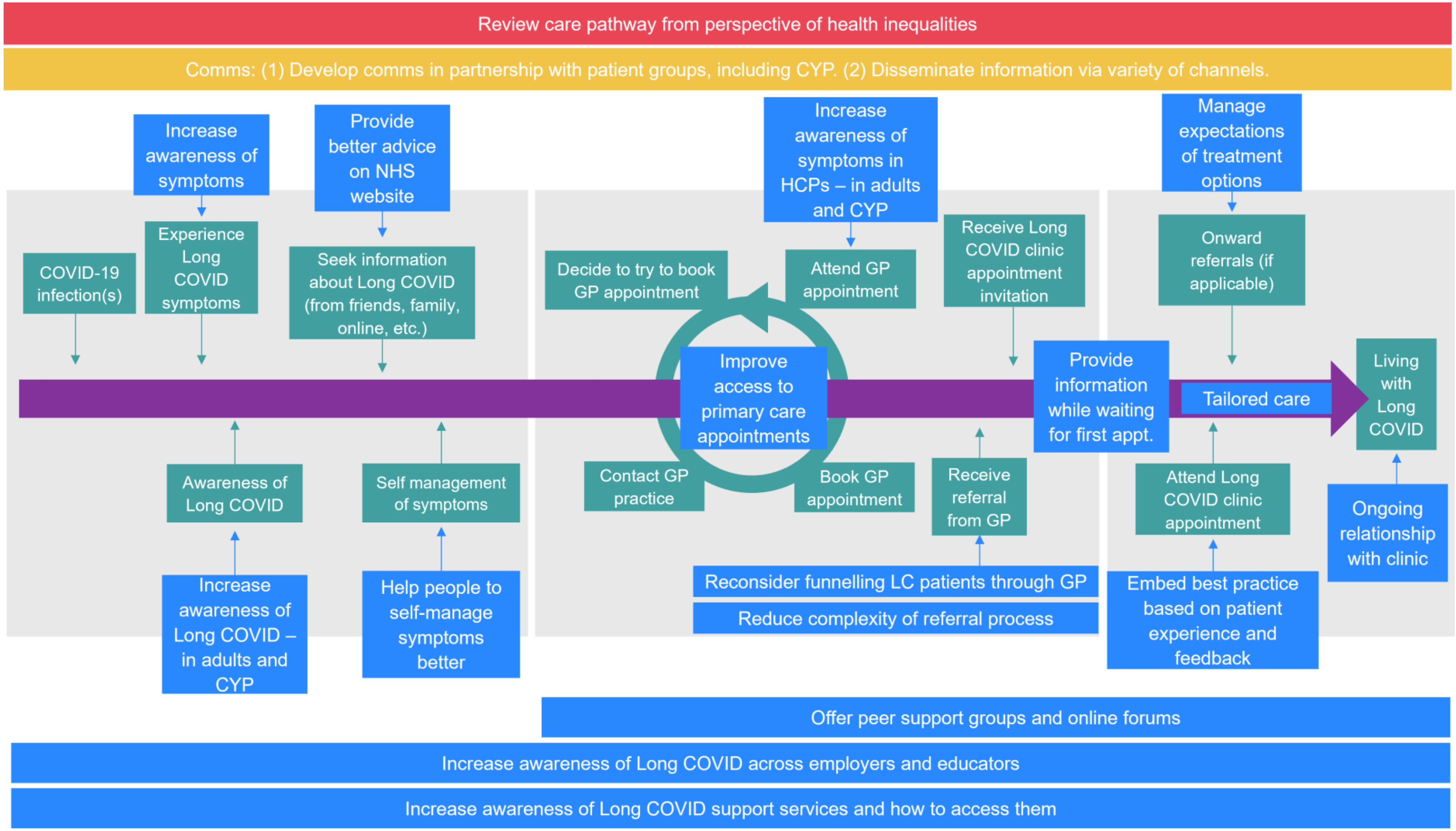
- Vulnerable people from deprived backgrounds face additional barriers trusting healthcare professionals – disseminating information via multiple channels will improve knowledge about and access to Long COVID services among these populations.

Review the pathway from the perspective of health inequalities

- The NHS could utilise already-existing support services that are not necessarily health focused (such as those in the voluntary and community sector) to help disseminate information about Long COVID and the services that are available to people who are unlikely to be able to prioritise looking into possible care, support or treatment options.It will be important to find ways to smooth the pathway for all patients, but especially those who are less able to navigate the health system and advocate for themselves.

- Offering greater guidance and support for people who may struggle to self-manage their symptoms would help more patients with Long COVID to manage their condition.
- Peer support services are a useful and welcome tool for people living with Long COVID – the NHS could encourage, support and do more to signpost to these services, so that more people with Long COVID have access to them (particularly where the NHS can work to ensure they are providing credible and safe information).

This flowchart below provides a summary of the Long COVID pathway, including key points of contact between patients and services, and – in blue boxes – suggestions for where improvements could be made.



1 Introduction

1.1 Background and context

With the increasing prevalence of Long COVID across the UK population, Long COVID presents the health service, and society more widely, with a number of challenges, particularly because it is a new condition.

According to Office of National Statistics (ONS) data, the prevalence of Ongoing Symptomatic COVID-19 and Post COVID-19 Syndrome, also known as 'Long COVID', across the UK population is increasing. As of 2 February 2023, an estimated 2.0 million people, over 3% of the population, living in private households self-reported having experienced it[1]. This is 1.2 percentage points higher than when comparing to the data obtained from 2 December 2021[2].

Long COVID is associated with a wide range of different symptoms impacting physical, psychological and cognitive health. Fatigue is the most common symptom reported as part of individuals' experience of Long COVID (71% of those with self-reported Long COVID), followed by difficulty concentrating (49%), shortness of breath (47%) and muscle ache (46%)[3]. It can, therefore, negatively affect one's quality of life, their ability to work, and/or attend education.

As a proportion of the UK population, the prevalence of self-reported Long COVID was greatest in people aged 35 to 69 years, females, people living in more deprived areas, those working in social care, those aged 16 years or over who were not working and not looking for work, and those with another activity-limiting health condition or disability[4].

---

[1] Matt Bosworth, Piotr Pawelek and Daniel Ayoubkhani. "Prevalence of Ongoing Symptoms Following Coronavirus (COVID-19) Infection in the UK: 2 February 2023." Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics. Office for National Statistics, February 2, 2023. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/2february2023.

[2] "Prevalence of Ongoing Symptoms Following Coronavirus (COVID-19) Infection in the UK : 2 December 2021." Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics. Accessed March 29, 2023. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/2december2021.

[3] Matt Bosworth, Piotr Pawelek and Daniel Ayoubkhani. "Prevalence of Ongoing Symptoms Following Coronavirus (COVID-19) Infection in the UK: 5 January 2023." Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics. Office for National Statistics, January 5, 2023. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/5january2023.

[4] King, D.A.and S. (2022) *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK: 3 November 2022*, *Prevalence of ongoing symptoms following coronavirus (COVID-19) infection in the UK - Office for National Statistics*. Office for National Statistics. Available at: https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/3november2022 (Accessed: March 29, 2023).

Given the policy context, the Insight & Feedback Team at NHS England (NHSE) identified an urgent need for wide-ranging research to examine experiences and perceptions of Long COVID and Long COVID services and commissioned Ipsos to conduct a research programme.

1.2 Overview of the project

The research programme commissioned by NHSE involved four strands, amongst four distinct audiences, outlined in Figure 1.1, and discussed in detail below. The research programme was guided by a Working Group which was comprised of professionals working in disciplines relating to health and social care and lived experience partners who were recruited to advise the project.

Figure 1.1: Overview of Long COVID research programme for NHSE

Strands 1 and 2

The objective of Strands 1 and 2 was to provide an in-depth understanding of the barriers and enablers to accessing Long COVID care, so that access to Long COVID services could be facilitated and improved. These strands had a specific focus on three lesser-served patient groups:

- Children and young people
- People with long-term health conditions
- People living in deprived areas

This work comprised 54 in-depth interviews, divided across individuals within the specific patient groups (Strand 1) and advocates working with these groups (Strand 2).

Strand 3

Strand 3 was a nationally-representative public survey conducted on the Ipsos KnowledgePanel, a random probability online panel.

The aim of the public survey was to provide an up-to-date understanding of public knowledge of, and attitudes towards, Long COVID.

Strand 4

The objective of Strand 4 was to provide an in-depth understanding of adult patients' experiences of NHS Post-COVID-19 services, to identify where services are working well and how they could be improved.

This strand comprised 42 in-depth interviews with adult patients who were using Post-COVID-19 services.

Strand 1: Enablers and barriers to accessing care for Long COVID

Certain subgroups within society are impacted more by COVID-19 or Long COVID, and in general, individual groups experience poorer quality care or greater challenges accessing care. In addition, existing evidence about Long COVID care is more readily available for some groups than others.

The objective of Strand 1 was to address this gap in understanding and to provide an in-depth understanding of the barriers and enablers to accessing Long COVID care. The work was undertaken so that access to services can be facilitated and improved.

A thorough review of existing research revealed a gap in existing understanding of lesser-served patient groups, and from these, the groups below were selected for specific focus in this strand of the research:

- Adults with pre-existing long-term conditions
- Adults living in areas of deprivation
- Children and young people

A total of 37 semi-structured interviews with people living with Long COVID were conducted from the communities of focus who self-diagnosed as having Long COVID but had not accessed care or support from NHS Long COVID clinics regarding their condition. As research **focused on three lesser-served patient groups** this means that the findings from this strand do not necessarily reflect the experiences of all people living with Long COVID who have not accessed a Long COVID clinic. For the specific demographic breakdown of the sample please see Appendix 3.

The interviews lasted on average **60 minutes** and were conducted via MS Teams or over the telephone, depending on the participant's preference. They took place between **23 August and 11 November 2022.** Participants received a financial incentive as a thank-you for taking part in the research.

Recruitment was achieved via two different approaches:

- People living with Long COVID were identified and recruited from the three communities of focus by a specialist recruitment agency.
- Advocacy organisations that took part in Strand 2 also supported with recruitment by sharing recruitment materials on their social media platforms.

Strand 2: Enablers and barriers to accessing care for Long COVID

Strand 2 of the research also aimed to understand the barriers and enablers to accessing Long COVID care. Working in conjunction with interviewing the patients themselves in Strand 1, Strand 2 of the research was undertaken with representatives of advocacy organisations involved with supporting the lesser-served patient groups already identified. The work explored advocates' understanding of how Long COVID care might potentially differ between communities; as well as understanding the various challenges, or barriers, to accessing health services within these three specific communities.

This work comprised of 17 semi-structured depth interviews, each lasting 30–45-minutes. The sample of advocacy organisations was identified in collaboration with the Working Group.

Interviews were conducted via MS Teams or over the telephone and took place between **18 July and 14 September 2022.** Strands 1 and 2 shared a report, delivered in January 2023.

Advocacy organisations were recruited to the project via leads obtained from the Working Group, organisation websites and their social media channels. For a list of the organisations represented in the research please see Appendix 3.

Strand 3: Understanding public attitudes towards Long COVID

The third phase of the research was a quantitative survey to measure awareness and perceptions of Long COVID across the wider population, including:

- Measuring public awareness and understanding of Long COVID, including its various symptoms.
- Capturing how people currently identify whether they are experiencing Long COVID and attitudes toward it as an illness.
- Ascertaining the actions that the public have taken/would take if they were experiencing Long COVID/symptoms and understanding potential enablers and barriers to seeking care and treatment for Long COVID.
- Collecting the experience of seeking and receiving treatment for Long COVID (from a small minority).
- Identifying any differences in experiences, knowledge and perceptions among different groups within the population.

This section of the project was conducted via Ipsos KnowledgePanel, a gold standard online random probability panel. The survey was in field between **22 April and 27 April 2022.** A total of **1,828 respondents** completed the survey.

For the sample breakdown, information about sample selection, and weighting please see Appendices 3 and 4.

Strand 4: Patient experience of post-COVID services

Strand 4 focused on gaining an in-depth understanding of individuals' experiences among those who have accessed NHS Long COVID clinics. The specific objectives of Strand 4 were to provide an **in-depth understanding of adult patients' experiences** of NHS Long COVID clinics; to identify where **services are working well** and how they **could be improved**; and to explore enablers to accessing Long COVID services.

To meet the aims and objectives of the strand, a total of **42 in-depth semi-structured interviews** were carried out with adults who have Long COVID, all of whom had been referred to a Long COVID clinic. These interviews lasted on average **60 minutes.**

As with the first two strands of the research, the interviews used tailored topic guides designed in collaboration with the project's Working Group, and reviewed and signed off by NHS England. The interviews were conducted by telephone or on Microsoft Teams, depending on the participant's preference.

Most of the recruitment was carried out via Long COVID clinics operating in England. Seven services were selected based on following factors, with the aim of having a mix of:

- Region
- Different models of care (for example, therapeutic and medical)
- Appointment format – remote, face-to-face, or hybrid
- Friends and Family Test (FFT) scores (where available) to include low scoring and high scoring clinics (as the only proxy available for indicating patient experience)

Recruitment materials were shared with patients at the clinics, with contact details provided for those who wanted to opt in.

This recruitment method was **supplemented with recruitment via social media:** notices were placed on Twitter and LinkedIn to ask people to get in touch with Ipsos if they had Long COVID and were receiving support for this via an NHS clinic.

All participants were screened, with soft quotas set on region, and existence of pre-existing health conditions. An additional quota on healthcare professional was set as fieldwork progressed, as many people opting-in to the research worked in a health setting. For the full demographic breakdown of the participants in this phase, please see Appendix 3.

The interviews took place between **15 September 2022 and 31 March 2023.** Participants received an incentive to thank them for their time. A post-interview information sheet providing support and advice resources was offered to people at the end of interview. The report for Strand 4 was finalised in March 2023.

1.3 About this report

Key implications explored in this report

This report focuses on six main implications that cross-cut the research strands. For further detail on any of the findings or the methodologies employed, please refer to the individual reports for each strand – to request access, please contact england.insight-queries@nhs.net.

The remainder of this report is structured as follows:

- Chapter 2 - Increase awareness of Long COVID – the condition itself and its symptoms, as well as the available treatments.
- Chapter 3 - Expanding and smoothing pathway access will help to lessen the barriers to accessing Long COVID services.
- Chapter 4 - Providing greater support throughout the patient journey will improve patient experience and satisfaction with Long COVID and other services.
- Chapter 5 - Better meet the needs of patients with Long COVID by reassessing how services are set up (Strand 4 only).
- Chapter 6 - Involve end users in the development of communications and use a range of formats and channels for dissemination.
- Chapter 7 - Review the pathway from the perspective of health inequalities.

Grey boxes provide summaries at the start of each chapter, and blue boxes highlight barriers.

Comparability between the strands

This report is intended to bring together the findings from across all four strands of the research programme. The work aims to highlight themes from across the strands. Nevertheless, it is important to note that the findings from each strand are not directly comparable, this is because each strand of the research was conducted with a different population. Strands 1/2 were focused on three specific communities of interest who had not accessed a Long COVID clinic, Strand 3 was a general public survey, and Strand 4 focused on those who had been referred to Long COVID clinics.

2 Increasing awareness of Long COVID – the condition itself and its symptoms, as well as the available treatments – will overcome some barriers to accessing services

This section explores awareness of Long COVID as a condition, as well as knowledge of support services. The research demonstrated that there is a need for awareness-raising about Long COVID and its symptoms, as well as the treatment and support that is available.

The main findings from this chapter are:

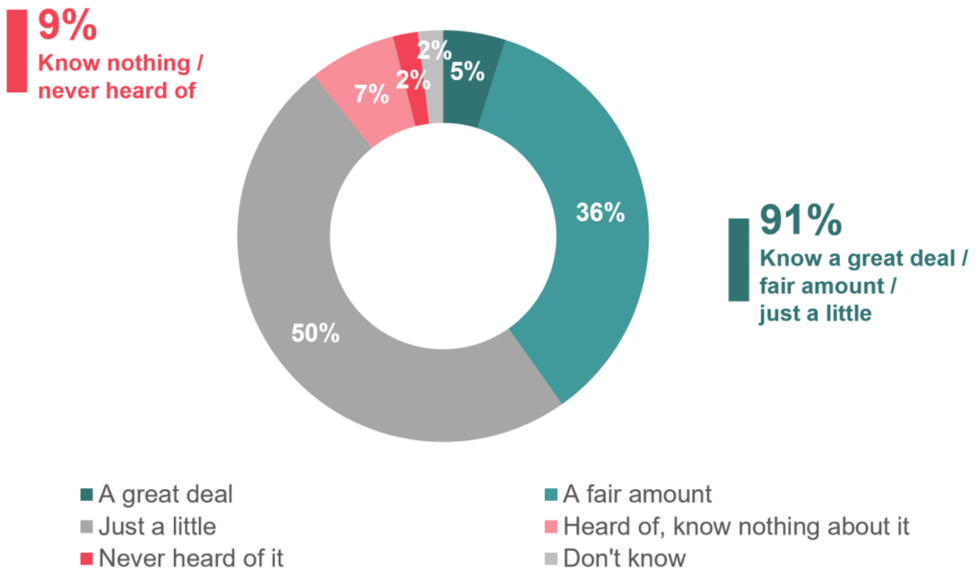
- Although awareness of Long COVID is generally high among the general public, there are some misunderstandings about Long COVID and differences in levels of knowledge between groups within the population. Increasing the general knowledge of Long COVID among the public, and particularly with groups where knowledge tends to be lower, would be beneficial so that people know when to seek help.
- Up-to-date guidance should be regularly provided to those likely to have first contact with individuals experiencing Long COVID, including healthcare professionals, employers, schools, advocacy organisations, and the charity sector. In particular, it would be helpful to raise awareness (amongst both the public and healthcare professionals) that it is not necessary to wait until 12 weeks post-infection to seek care and support for Long COVID symptoms.
- Participants in Strand 1 (those who had not accessed a Long COVID clinic) generally had a low awareness of Long COVID services and/or how to access them. In addition, advocates reported very low or non-existent awareness of Long COVID services, making it difficult for them to signpost people to services.
- Knowledge about COVID-19 and Long COVID in children and young people was even less common, and a perceived lack of information about Long COVID from the NHS in relation to children and young people was reported.

2.1 General knowledge and awareness of Long COVID and symptoms will decrease barriers to accessing care - public

Awareness of Long COVID as a condition

Results from the Strand 3 survey in Figure 2.1 showed that the majority of the public (91%) claimed to have some knowledge about Long COVID, although this included half (50%) who said they knew ‘just a little', indicating there was a self-perceived gap in more detailed knowledge. A small proportion of the public (just under one in ten, or 9%) said they had heard of but had no knowledge of Long COVID, or had never heard of it.

Figure 2.1: How much if anything, would you say you know about Long COVID?



Base: All participants (n=1,828). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

Awareness of some of the more nuanced information about Long COVID was low across the board. More than half of the public (56%) were confident they could identify if they had Long COVID, while 41% were not confident they would be able to do this. In addition, there were some misunderstandings about Long COVID, for example, 34% thought it could only be diagnosed if there had been a positive COVID-19 test, which may deter some people from presenting with symptoms. Further, around half of the public (51%) who said they knew at least a little about Long COVID were not aware before taking the survey that someone could be considered to have Long COVID if they had ongoing symptoms four weeks after COVID-19 infection.

There were also low levels of knowledge about how Long COVID is diagnosed, with three-quarters (74%) saying they did not know that Post-COVID Syndrome is diagnosed only where symptoms cannot be explained by any other condition, and nearly all (91%) saying they were unaware prior to the survey that there are two types of Long COVID (ongoing symptomatic COVID at 4 weeks, and Post-COVID Syndrome at 12 weeks).

Participants had found out about Long COVID through the media, from friends, family & colleagues, and from healthcare providers. Groups that were more likely to have knowledge of Long COVID included:

- People who had had three or more doses of the COVID-19 vaccine. These people were significantly more likely to report greater knowledge about Long COVID (93%) than those who had not had the vaccine, or had had one or two doses (81%); and

- People who had had COVID-19 were more likely to have some knowledge about Long COVID (93%) than those members of the public who had not had COVID-19 (88%).

Groups *less likely* to know about Long COVID included people from ethnic minority backgrounds (79% had at least some knowledge, compared with 91% overall), and those living in the most deprived areas of the country (84%, compared with 91% overall).

Those who caught COVID-19 later in 2021, and in 2022, were more likely to have known about Long COVID before contracting it. However, the public tended to believe that they were unlikely to experience Long COVID after having COVID-19 (41%), or were ambivalent about the likelihood of their experiencing it (26%).

In contrast, people with a long-term condition were more likely to think they may experience Long COVID themselves (27%, compared with 15% of those without long-term conditions).

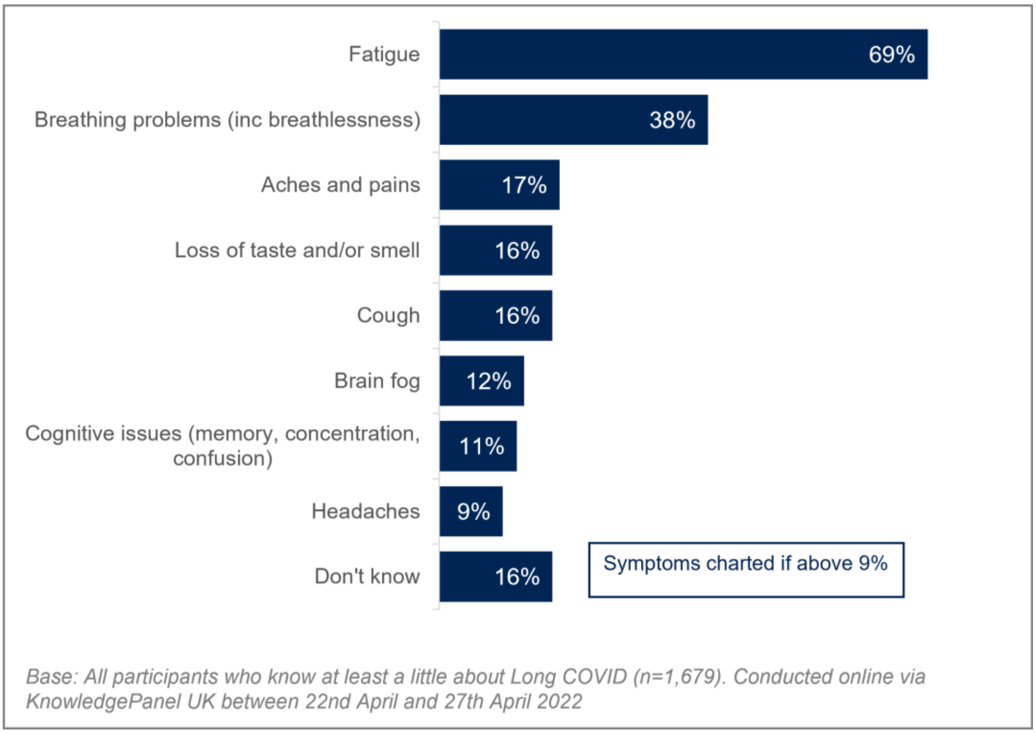
Awareness of Long COVID symptoms

Long COVID has a wide range of symptoms that can appear in various combinations. Some other health conditions have symptoms similar to Long COVID, which can make it extremely difficult to identify Long COVID as a separate condition, especially among people with other pre-existing health conditions. It is therefore important to raise awareness of the various symptoms of Long COVID, so that people can recognise when they are experiencing it.

> “I knew that the symptoms were very similar to the conditions I've mentioned previously: chronic fatigue; ME and fibromyalgia; and that possibly there could be some overlap. But because I had an existing condition that perhaps displayed the same symptoms, looking back, I probably attributed it to fibromyalgia rather than Long COVID.”
>
> **Strand 4 participant**

In the Strand 3 survey, Figure 2.2 shows around seven in ten of those who knew at least a little about Long COVID (69%) identified fatigue as a symptom of Long COVID unprompted. In addition, close to two in five (38%) mentioned breathing problems (including breathlessness) as a symptom. Many other symptoms were also cited. A further 16% were not able to identify any symptoms of Long COVID unprompted.

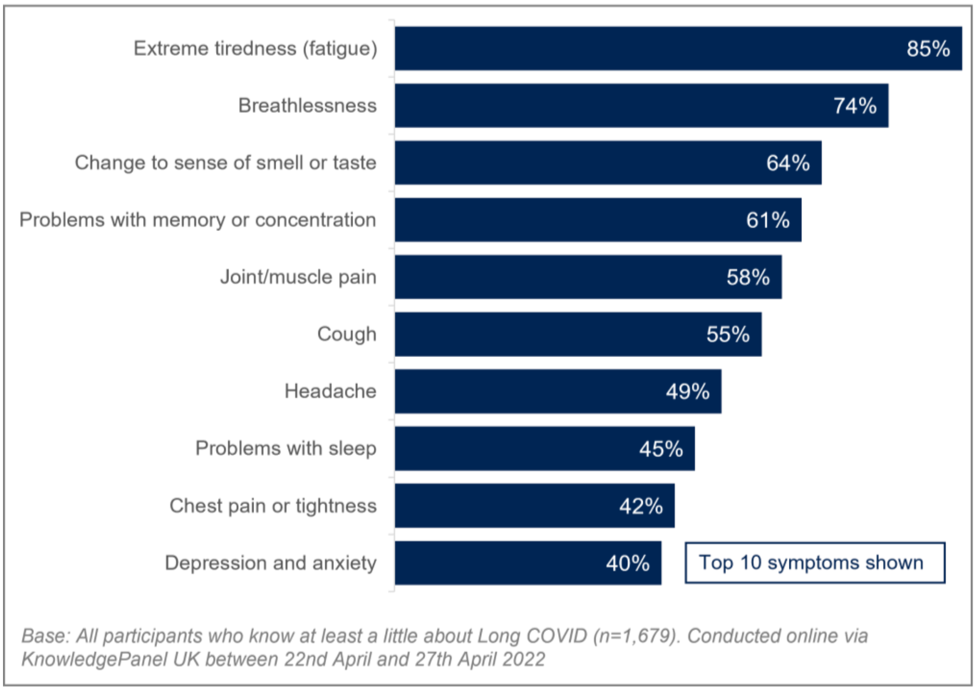
Figure 2.2: As far as you know, what are the symptoms of Long COVID? (unprompted)



Base: All participants who know at least a little about Long COVID (n=1,679). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

When presented with a list of symptoms, extreme tiredness was most commonly identified as a symptom of Long COVID (85%), followed by breathlessness (74%), as illustrated in Figure 2.3. While more than half identified other symptoms such as changes to the sense of smell or taste (64%) and problems with memory or concentration (61%), relatively fewer associated Long COVID with mental health conditions such as depression and anxiety (40%).

Figure 2.3: Looking at this list, which of the following, if any, do you think are symptoms of Long COVID?



Base: All participants who know at least a little about Long COVID (n=1,679). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

Across Strands 1 and 4 (qualitative research with those experiencing Long COVID), those who had COVID-19 early in the pandemic reported not realising that their ongoing symptoms were indicative of Long COVID, because there was low awareness across the population and the healthcare profession that such a condition existed. Those who developed Long COVID later in 2021, and in 2022, were more cognisant of the key symptoms to look out for, mentioning fatigue and brain fog in particular. However, levels of knowledge about Long COVID symptoms and signs were inconsistent across participants.

There are some specific communities that could benefit from targeted messaging:

- **Those who are experiencing Long COVID**: helping people better understand their condition, and feel more in control of their health; and improving people's knowledge of the possibilities for self-managing their symptoms and the support available for doing so.

- **Communities likely to experience health inequalities; people who are less likely to be engaged with health services; and groups with lower levels of trust in the government/NHS:** these populations are likely to benefit from messaging via non-NHS organisations such as charities that have already secured reach, access, and trust with the community. Partnering with organisations in the voluntary and community sector could improve the NHS's ability to reach minority populations and improve health outcomes.

2.2 Awareness of Long COVID amongst healthcare professionals can be more consistent

Participants reported a perception that healthcare professionals were in the dark about Long COVID for quite a while, so it was difficult to access information or help in environments where they expected to access knowledge and support.

> "My doctor said, 'I could send you [to the Long COVID clinic], but they'll do exactly the same as me'."
>
> **Strand 1 participant, long-term health condition**

Advocates, as well, expressed concerns that **GPs may be finding it difficult to recognise symptoms of the condition –** particularly as distinct from other illnesses/disorders. It was mentioned that GPs had attributed Long COVID symptoms to other (either pre-existing or new) conditions, both physical and mental, such as depression, anxiety and asthma. This was particularly the case for children and young people (see Section 2.4).

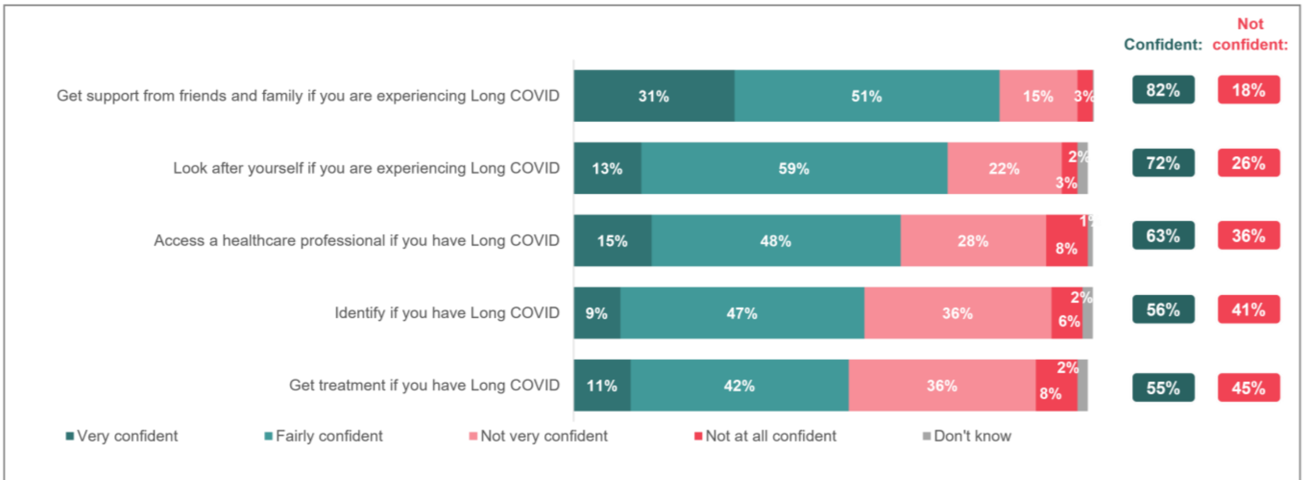
To mitigate these barriers the NHS should ensure that primary care health professionals, particularly those who may have **first contact** with individuals experiencing Long COVID such as GPs, nurse practitioners, pharmacists and clinicians working in urgent and emergency care, and paediatricians, **are kept up-to-date** in relation to Long COVID generally. This should include **new information about symptoms and emerging treatments –** which may help to avoid dissonance between providers and patients and enable quicker diagnosis.

It's also important to raise awareness among healthcare professionals that it is **not necessary to wait until 12 weeks** post-infection to seek care – this is particularly important given that participants tended to believe that their Long COVID symptoms could not be addressed by the NHS before the 12-week mark, and reported that GPs reflected and reinforced this view to them.

2.3 Awareness of Long COVID support services was low and people were unclear about how to access them

People generally had a low awareness of Long COVID services and/or how to access them. The Strand 3 survey results in Figure 2.4 show that, while the public often felt confident that they could manage issues arising from Long COVID themselves (72%), and that they would be able to get support from their friends and family (82%), they were less confident that they could get treatment for Long COVID (55%).

Figure 2.4: How confident are you, if at all, in your ability to do each of the following?



Base: All participants who know at least a little about Long COVID (n=1,679). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

The public were unclear about whether or not Long COVID could be treated or cured: only half of people who said they knew ‘a great deal’ about Long COVID believed it can be treated (52%). Around one-third of people who said they knew ‘a great deal’ about Long COVID (34%) thought that Long COVID can be cured (compared with 18% overall). These findings were reflected in the qualitative strands (1 and 4, with participants who were experiencing Long COVID), which identified that there was an expectation from some participants that a Long COVID clinic would be able to ‘cure’ them. This expectation often resulted in disappointment amongst strand 4 participants. Clear information provision and expectation management throughout the process – from presentation at primary care, to attendance at the Long COVID clinic – could help to alleviate this issue. **Communications and information provision should make it clear that there is a possibility of improvement from Long COVID symptoms (albeit not a cure), and encourage people to contact their GP practice or other healthcare provider;** there is potential for people experiencing Long COVID to have a better quality of life with care and support from health services.

Strand 1 participants (those from three specific communities reporting that they were experiencing Long COVID but had not been referred to a Long COVID clinic) reported having been **unable to find the information they needed on official UK government and NHS resources**, meaning that people did not realise that NHS care and support was available. Participants also expressed frustration that there may be NHS support available that they had not been told about or offered.

> “I've read about people going private, there are things they're doing. They're doing more tests, they're finding these little similarities in lots of people, like the blood clots and, you know, hyperimmune things going on... And I know in Germany, you know, they're screening for these blood clots and they're doing a lot for Long COVID in Germany. And I understand that there's no money that's really been put into the children side of it over here, for long-term COVID.”
>
> **Strand 1 participant, parent of young person aged 15**

There was a strong theme of 'not wanting to bother the NHS' among people who felt their symptoms were not 'serious enough' to warrant seeking help. But although some were coping by self-managing their symptoms, their quality of life could be improved by care and support from health services. This topic is covered in greater detail in Chapter 4.

Among the participants in Strands 1 and 4 (both strands including participants who were experiencing Long COVID) who caught COVID-19 towards the start of the pandemic, there was no awareness of Long COVID as a condition until later in the pandemic. Among these participants, there was a theme of 'just getting on with it' and 'adjusting to a new normal' while they were unaware that any NHS support was available.

Strand 2 interviews with advocacy organisations revealed that **awareness of Long COVID services among advocates was generally very low or non-existent.** Although a small number of advocates knew that Long COVID services existed, most did not know what was available and did not understand how Long COVID services fit into existing pathways to specialist services. The few who were aware of services were passing this information on to the people they support – that is, suggesting they contact their GP to seek referral to a Long COVID service. Long COVID services were also perceived by advocates as varying widely across the country in terms of both availability and breadth of service types, which was seen as unfair. Increasing knowledge amongst advocates of the support available would increase the chances of someone from an under-represented group being able to access services.

Suggestions for how the NHS could raise awareness included:

- One or multiple **public awareness campaigns**, encouraging those experiencing the symptoms of Long COVID to come forward for care. As part of this campaign some participants with Long COVID requested a **central point** (such as a website) where they could locate key information and find links to more specialised advice about the symptoms they are experiencing. Awareness of the '**Your Covid Recovery'** website, a potential 'central point', was typically very low, with few of the participants mentioning that they had found (or been directed to) the website – though it is possible that people may have visited the website without knowing (or recalling) it by that name. Those who had found the site felt it was more suited to people recovering from an acute COVID-19 infection, rather than living with Long COVID; as a result, the information provided did not 'chime' with their symptoms. Optimisations to this source of information could help support those looking for information.

In particular, the public should be made aware of:

- Which organisation(s) are responsible for services;
- Pathways to accessing those organisations, so that eligible patients can be referred more smoothly;
- Up-to-date information about the treatment and support options available; and
- Options for self-managing their symptoms (discussed in Chapter 4).

2.4 Awareness of Long COVID in children and young people was even lower

Knowledge about COVID-19 and Long COVID in children and young people was even less common. Participants with at least some Long COVID knowledge believed that adults were more likely than children (56%) to develop Long COVID, with 15% of respondents unsure. A perceived lack of information about Long COVID from the NHS, especially in relation to children and young people, led parents and caregivers to look elsewhere for information and advice. Parents and caregivers of children with Long COVID commented that public health messaging and messaging from the government in the earlier stages of the pandemic had played down the risk to children, by claiming that children were at low risk of becoming ill with COVID-19.

"The paediatrician's appointment was a disaster. He hadn't seen any children with Long COVID. He didn't know anything about Long COVID clinics. He'd never done a referral. He described [my child] as 'well,' because all the bloods were normal."

Strand 1 participant, parent of young person aged 14

Participants also expressed concerns that children and young people living with Long COVID, and their parents and caregivers, were not taken seriously by healthcare providers, and that their symptoms were often being dismissed as psychological disorders or attention-seeking behaviour.

"She got really bad chest pains in school. They had to take her to A&E and it was awful. And we just got basically told it was anxiety and, 'What are you doing here? There's nothing wrong with you.'"

Strand 1 participant, parent of young person aged 17

Again, to mitigate these scenarios, the NHS should ensure that primary care health professionals' who may have **first contact** with children and young people experiencing Long COVID such as GPs, nurse practitioners, pharmacists and clinicians working in **urgent and emergency care, and paediatricians** are educated about Long COVID in children and young people and are familiar with the children and young people **Long COVID syndrome pathway**, including Long COVID assessment and management options.

2.5 Low awareness of Long COVID amongst other institutions

Among Strand 1 and 4 participants of working age, there were some concerns about employers' lack of awareness of Long COVID, and the impact it could have on people's ability to go about their usual tasks (including work). In a small number of cases, employers were unwilling to change participants' hours or allow them to work from home, for example. **Participants suggested that increased information provision about Long COVID – both generally and targeted towards employers – could help to solve this and provide them with more support as they navigated life with Long COVID.**

Another issue raised by parents and caregivers was the lack of knowledge about Long COVID in children and young people among **educators.**

"[The school] kept saying that he should be back at school and, you know, they were convinced that, well, all the other children who've had COVID-19 were going back, why wasn't he going back? They need to accept that rest is the primary thing that [helps], and forcing children to go to school… fining parents for not sending their kids to school, getting social services involved [is making things worse]."

Strand 1 participant, parent of child aged 9

Parents and caregivers talked about having **little or no support from healthcare providers in explaining to schools/colleges that their children were too ill to attend,** with some receiving threats of legal action unless attendance improved. Parents and caregivers felt that schools and colleges also had limited awareness of Long COVID in children and young people, and in many cases were therefore providing little or no support.

“It feels like [the school] wants her in for their numbers, rather than anything else, because they're happy for her to go and sit in the inclusion area. And [for the] last term, she's been going in but she wasn't even given any work. So, I'm dragging her into school crying; they sit her in a room and she sits and draws in her book until it's time for me to come get her.”

Strand 1 participant, parent of young person aged 13

To help increase levels of support in places of education or work, the NHS could work with partners to improve communication with employers and schools to provide information about Long COVID so that people aren’t ‘punished’ for being ill.

3 Expanding and smoothing pathway access will help to lessen the barriers to accessing Long COVID services

This section explores barriers and enablers to accessing Long COVID services.

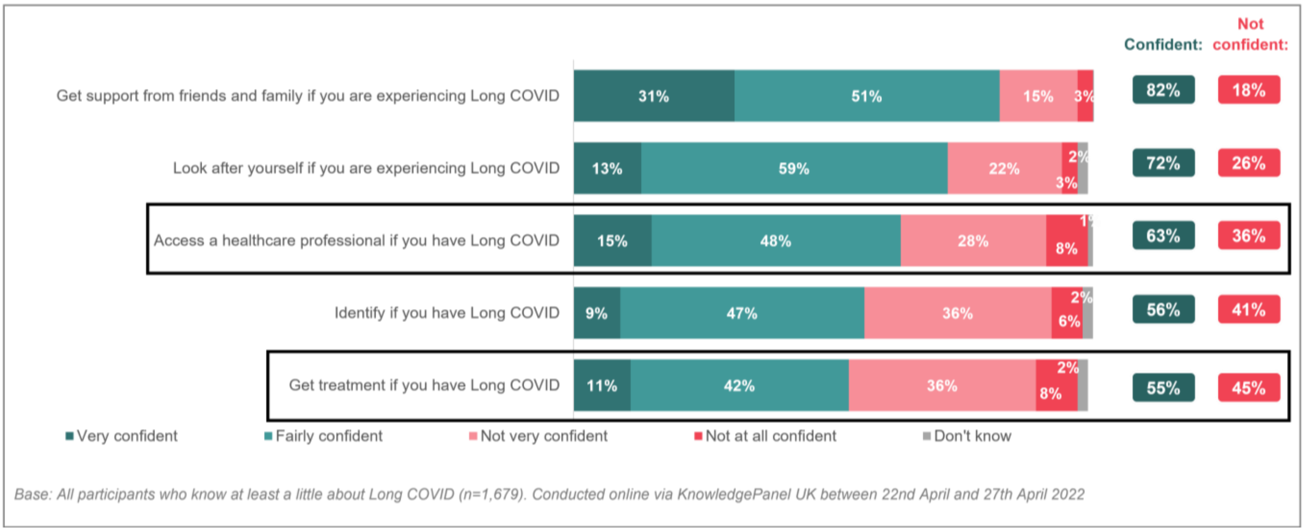
The main findings from this chapter are:

- The current pathway relies on GPs, but there is a perceived lack of availability of GP appointments. This lowers public confidence in the ability of the NHS to care for people who have Long COVID.
- The primary route into Long COVID services among participants was via a GP; this produces a perceived bottleneck however and places GPs in a 'gatekeeping' role, which impacts on how equitable and accessible Long COVID services are perceived to be.
- Vulnerable people from deprived backgrounds face additional barriers accessing and trusting healthcare professionals, so expanding the pathway to allow access via other routes may improve access to Long COVID services among these populations.
- Participants tended to find the referral process complex and time consuming, particularly in cases where they felt they had to chase or drive progress. If there is a way of streamlining the process, it could take less time, enable patients to access care and support for their symptoms more smoothly, and ease the workload for GPs.

3.1 Levels of confidence in accessing care and support varied widely

The Strand 3 survey showed that more than half of the public who knew at least a little about Long COVID felt confident about accessing care and support for Long COVID (Figure 3.1). However, a significant minority were not confident: more than a third of respondents who had at least a little knowledge about Long COVID said they were 'not confident' that, if they had Long COVID, they would be able to get treatment (45%) or access a healthcare professional (36%).

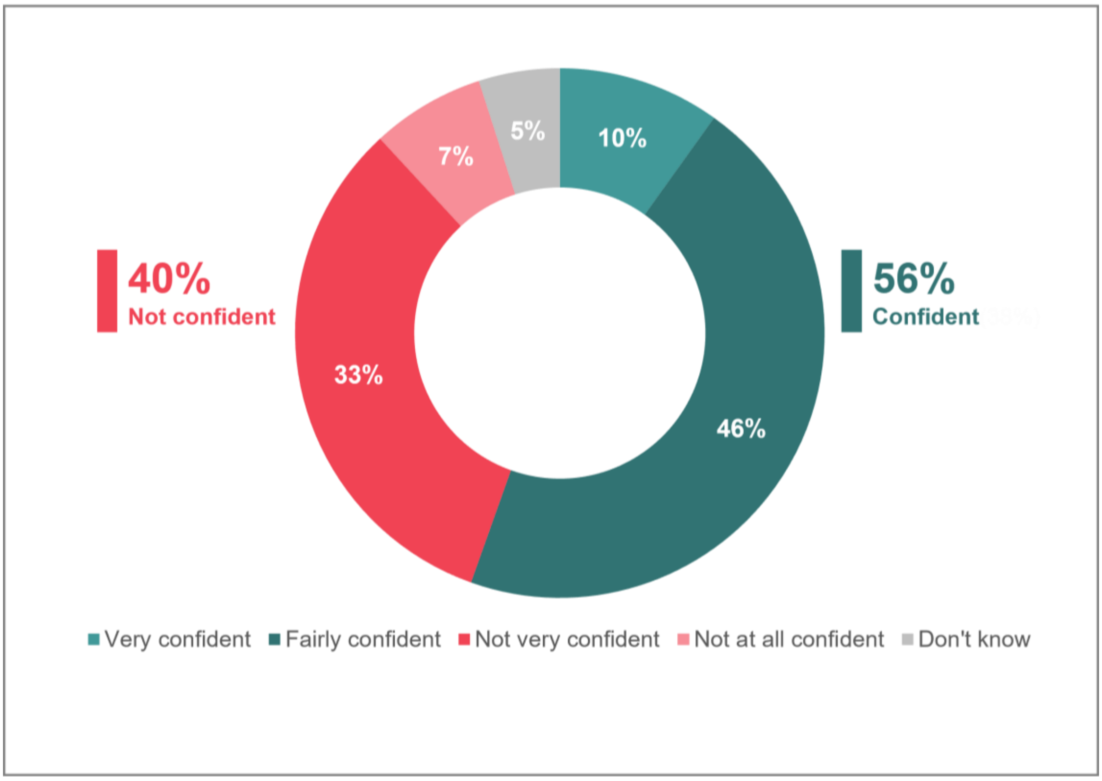
Figure 3.1: How confident are you, if at all, in your ability to do each of the following?



Base: All participants who know at least a little about Long COVID (n=1,679). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

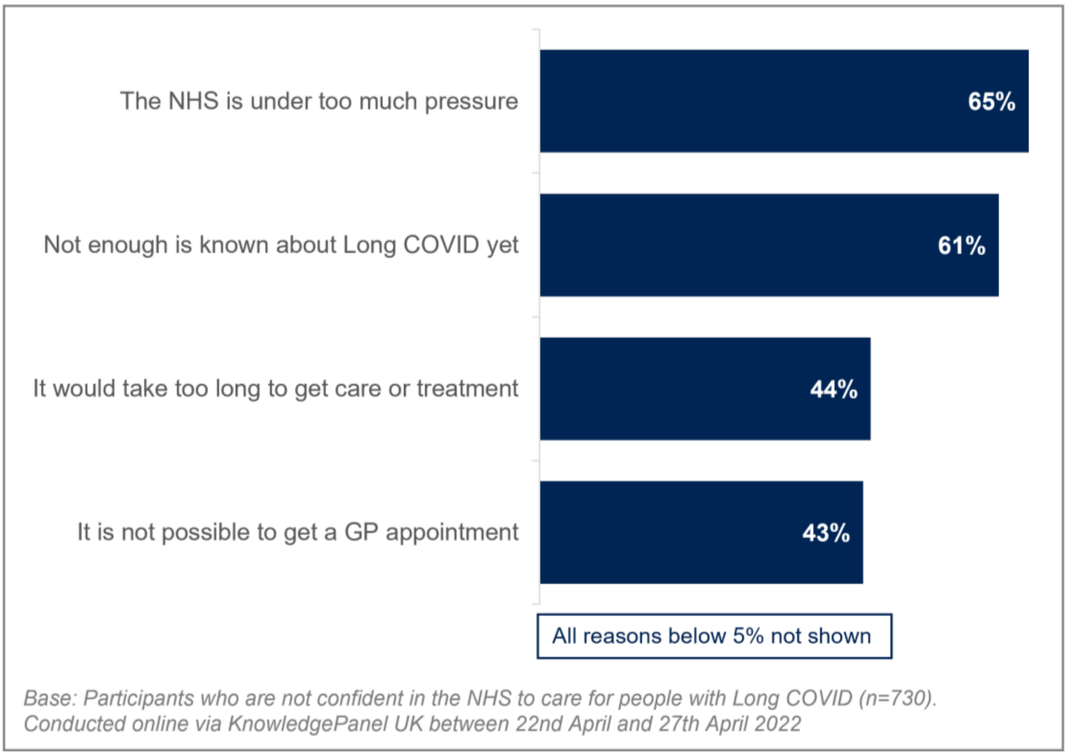
Confidence in the ability of the NHS, in general, to care for people with Long COVID was also low, with 40% ‘not confident’ in the NHS (Figure 3.2). **This figure was higher for people from ethnic minority backgrounds and people with long-term conditions.**

Figure 3.2: How confident are you, if at all, in the ability of the NHS to care for people who have Long COVID?



Among those with low confidence in the NHS to care for people who have Long COVID, reasons given (Figure 3.3) included the **NHS being under too much pressure** (65%), the **NHS having a lack of knowledge about Long COVID** (61%), it taking too long to get care or treatment (44%), and **difficulty getting a GP appointment** (43%).

Figure 3.3: You mentioned that you are not very/not at all confident in the ability of the NHS to care for people who have Long COVID. Why do you say that?



Base: Participants who are not confident in the NHS to care for people with Long COVID (n=730). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

3.2 Improving access to primary care appointments

Difficulty getting a GP appointment was a recurring theme across the qualitative strands, and was identified as a **main barrier to accessing Long COVID care by participants**. The GP was the first port of call for many of the participants across both strands – both for Strand 1 participants who were not referred onwards, and for patients in Strand 4 who had received care from a Long COVID service. Challenges accessing GP appointments were attributed by both groups of participants to a lack of appointments available, being unable to get through to a practice over the phone, and not being able to book an appointment with their preferred (or usual) GP.

> "I just think the difficulty in getting an appointment is just rubbish. I mean when I spoke to [the GP] she was absolutely lovely, but it's just so hard to get through and to get an appointment in the first place."
>
> **Strand 4 participant**

For some participants in Strand 1, difficulty accessing a GP appointment was enough of a (psychological and physical) barrier to deter participants from trying to access care for their Long COVID symptoms.

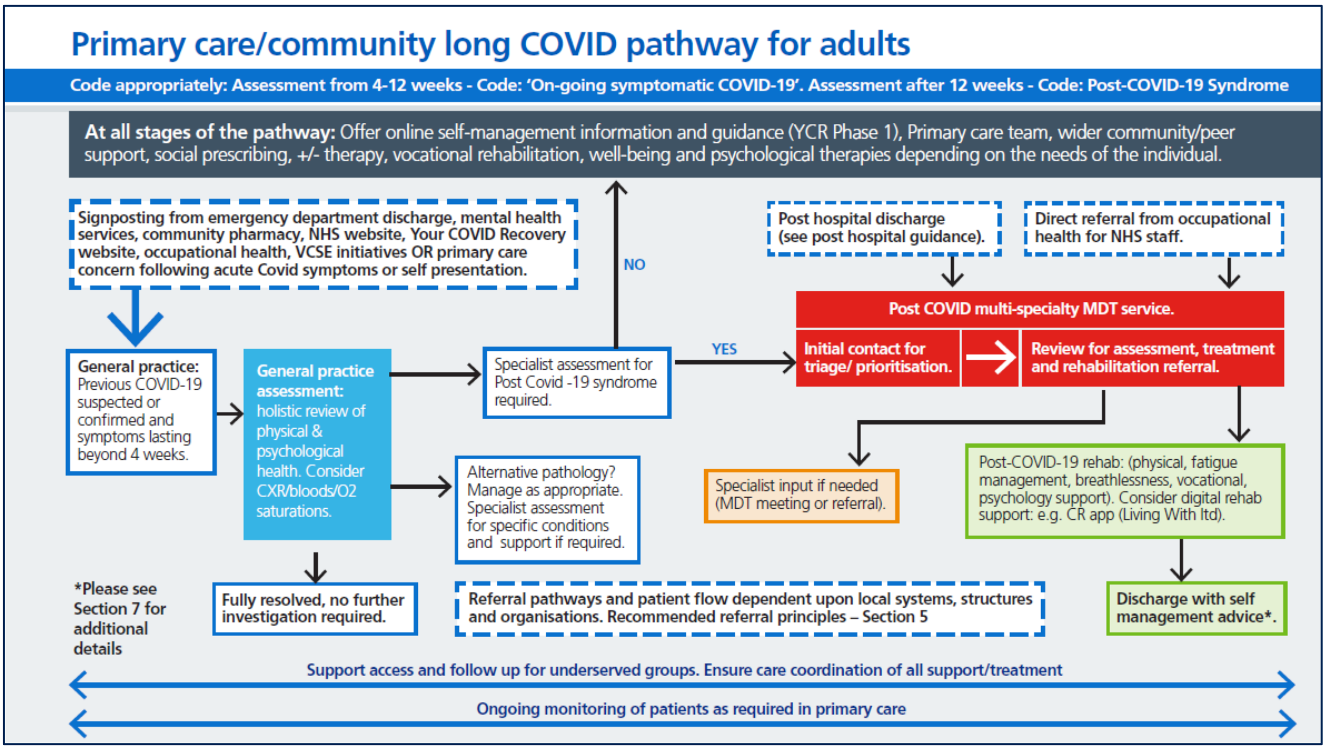
Participants also mentioned how **slow the process of getting an appointment** was, with many waiting weeks to access the service. It is important to try and improve access for patients to primary care appointments so patients can discuss their symptoms with a GP and be referred to further support, such as the Long COVID clinic, if they are eligible.

3.3 The role of the GP in the Long COVID pathway could be considered and the pathways streamlined or smoothed

Most participants in the research went to their GP as their first port of call after developing Long COVID symptoms. Although there were aspects of the service that participants valued, especially when they felt listened to and taken seriously, several **key issues** were identified by some participants during the research. Where participants perceived that they were not well supported by a GP, they pointed to what they saw as inappropriate advice, or felt that a GP had shown a lack of empathy.

The pathway was designed for GPs to play a pivotal role in diagnosing and funnelling eligible patients through to Long COVID services, as outlined in the NHSE adult pathway diagram below in Figure 3.4.

Figure 3.4: Primary care adult Long COVID pathway (source: NHSE)



This has led to a perceived bottleneck, and in some cases participants in Strand 1 felt that GPs were acting as overly **strict gatekeepers to services that might provide beneficial care**, treatment, or reassurance (although please note that since Strand 1 participants self-reported as having Long COVID, they may not meet the criteria for referral to a Long COVID clinic). Some patient participants across both groups (Strands 1 and 4) reported resorting to private healthcare in order to access tests that had been 'denied' by their GP.

"I'm just tired of being fobbed off, and whenever I do talk to these healthcare professionals about Long COVID it always ends up in an argument, because I'm just so wound up and frustrated inside."

Strand 1 participant, long-term health condition

It is also important to **review the referrals process** to identify if there is any way of streamlining it from the perspective of both patients and GPs, so that it takes less time and/or is less complex, and so that patients themselves do not feel like they need to drive the process. This might include the Long COVID services utilising an alternative pathway to GP referrals, to speed up the process.

Some participants (including all of Strand 4 participants – patients with Long COVID who had been referred to a clinic) went through an ‘exploratory’ phase with a GP while ascertaining the cause of the symptoms. Though participants tended to understand the necessity of eliminating other possible diagnoses, some participants (especially those in Strand 1) expressed frustration at having had to drive this process.

“It's a bit strange because I feel like I'm being the doctor sometimes. I'm, sort of, going, 'Oh I think we should look at this, because of that' and it's like, 'Yes, sure.' I'm like, I'd quite like it, really, if my doctor could come up with ideas, whereas that's not really the case.”

Strand 4 participant

The process of navigating symptoms and diagnostic tests was exhausting to those patients who had to drive the process, and it could result in a misdiagnosis and receiving treatment for another condition. For example, participants reported having been prescribed an inhaler for suspected asthma; betablockers for anxiety; or antidepressants. This was perceived as being unsuccessful and therefore unhelpful to smoothly accessing care for Long COVID. The variability in diagnostic tests and timeframes it took to complete diagnostic tests meant that access to Long COVID services was inconsistent.

Advocacy organisations representing people from deprived backgrounds (including children and young people and homeless people) highlighted the additional difficulties faced by vulnerable people when trying to access GP appointments. Advocates also identified issues around lack of trust regarding healthcare providers among marginalised groups; past negative experiences can lead to people feeling unsafe or not confident to contact a healthcare provider in a time of need. Expanding the referral routes could improve access to Long COVID services – for example, allowing specialists who already have a relationship with vulnerable patients to make referrals to the Long COVID clinic.

3.4 Patients found the Long COVID referral process difficult to navigate (Strand 4 only)

Once Long COVID was considered as a possibility by their GP, Strand 4 participants (all of whom had been referred to a Long COVID clinic) were typically asked to complete a range of diagnostic tests, the most common being blood tests and a chest x-ray, but others also reported having an ECG, a breathing test (spirometry) or an ultrasound. The referral process for the Long COVID clinic was described as complex: ‘clunky,’ with ‘long-winded’ questionnaires required.

“[It was a] very slow protracted process that referral…I had to fill out load of questionnaires, and then a series of tests.…It took about five weeks for the referral to actually leave the GP practice. Really clunky. The GP said it was the most complicated referral she’d done in her career.”

Strand 4 participant

In addition, the tests required for the referral often meant the patients had to travel to a hospital and spend time getting the tests completed, which could be difficult and exhausting for patients with Long COVID symptoms. This could be seen as a potential barrier to progressing along the pathway.

“I think it's actually quite a lot of effort to get those tests done, it wouldn't be if I was more well, but, yes, and it could be a barrier, I think, because obviously I'm very tired.”

Strand 4 participant

It would be worth considering locally how access to the tests that are needed to provide a diagnosis of Long COVID could be improved, or the process simplified, given the set of symptoms those with Long COVID can experience.

4 Providing greater support throughout the patient journey will improve patient experience and satisfaction with Long COVID and other services

This section focuses on how the NHS could provide greater support to those experiencing Long COVID.

The main findings from this chapter are:

- The NHS is a trusted source of information for the public, who therefore look to the NHS to take a lead in the creation and dissemination of material regarding Long COVID. Clear guidance from such a trustworthy source would help improve knowledge and reduce anxiety when patients first develop symptoms or are first diagnosed. It might also encourage more people to seek out healthcare providers.
- Many patients mentioned that they were ‘self-managing’ their symptoms outside of the support structures of the NHS. People had experimented with lifestyle changes to enable them to cope with their ongoing symptoms, either because they had given up hope of finding a cure, or while they waited for treatments. Easily accessible information regarding how best to ‘self-manage’ would undoubtedly help these patients. But when possible, there should be opportunities for patients to ask questions specific to their conditions.
- Peer support groups and online forums provide an important source of fellowship and learning for people experiencing Long COVID, but misinformation is rife. If the NHS could facilitate, moderate, or otherwise try to influence the information provided in such groups to improve the quality of the discussion, it would be mutually beneficial to both the healthcare services and also the patients themselves.
- This research identified several prominent barriers when it comes to patients receiving care. These include finances, time available, and also the severity of one’s condition.

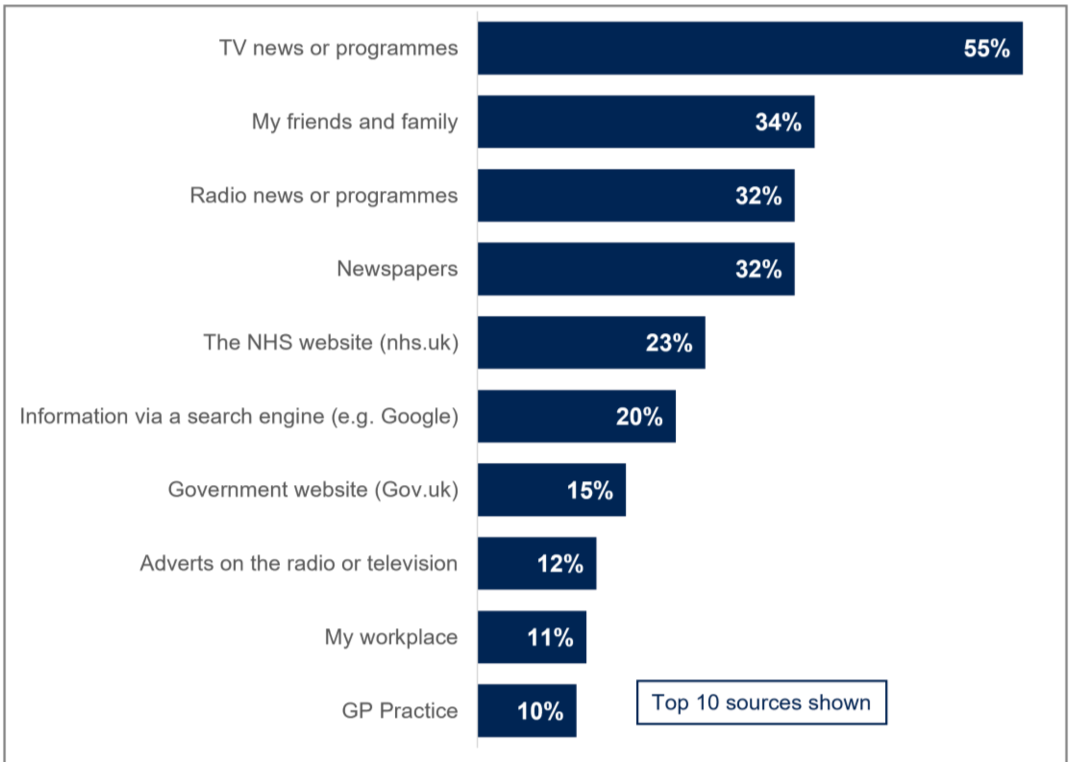
4.1 Providing support for those seeking information about Long COVID could help to improve knowledge and reduce patients’ confusion and anxiety

As noted in the research, particularly Strand 1 (with participants who had not been referred to a Long COVID clinic), even when participants were aware of Long COVID they often **struggled to access relevant information** through NHS sources. Participants typically started by looking online and/or speaking to their GP. Yet, awareness among GPs was perceived by participants to be variable (and much lower earlier in the pandemic than it is now), while online NHS and UK government sources were perceived to focus on the **acute phase of a COVID infection rather than ongoing symptoms.** This meant that participants did not always realise that help and support was available. The Strand 3 survey illustrated that nuanced information about Long COVID was therefore not widely known, even among those who considered themselves informed.

> “What we need is just more information. You know? We need more information – why does someone get Long COVID? What to do in those early weeks if you suspect you've got Long COVID. What is the process?"
>
> **Strand 4 participant**

When asked where they would look for information about Long COVID, the two most popular sources cited in the Strand 3 survey were the **NHS website** (66%) and **GP practice** (59%). This speaks to patients’ trust in the NHS; participants looked towards the services and staff for help and guidance **throughout their patient journey.** Nevertheless, the information provided **did not always meet their needs**. As a result, a high number of participants were forced to turn to **alternative sources** for support. Figure 4.1 shows that in the public survey, respondents were most likely to recall hearing or seeing information about Long COVID from **news sources (55%)** and **via friends and family (34%)**, rather than from the NHS or the government.

Figure 4.1: From which of the following sources, if any, have you heard or seen information about Long COVID?



Base: All participants (n=1,828). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

When researching the condition there were several key pieces of information that participants in the qualitative research strands who were experiencing Long COVID wanted to learn:

- **Prognosis** – whether they were likely to recover or not, and what partial recovery might look like.
- **Likely timeframes –** both for accessing any treatment they needed and for recovery.
- What to expect in terms of their **symptoms**.

- How to **manage their symptoms themselves**.
- Where to look for **further information, advice, and support**.

Participants suggested that the NHS could produce specific guidance around Long COVID: informing people about what to look out for; where to go for help; and when to get help. This could help those who are trying to learn more about their condition and symptoms. The NHS should ensure this information is easily accessible and available through a variety of formats for when people need it. (It is worth noting again at this point that there was little to no awareness among participants of the Your COVID Recovery website.)

Barriers to accessing information: Researching information on one's condition takes both time and effort. As a result of fatigue some patients were simply unable to do so. Others were unable to prioritise their health, as they had more urgent needs. This was particularly prevalent for those living in areas of deprivation, with advocates highlighting that these communities often have other, more urgent needs, and deprioritise health below things like housing and food – while others, such as single parents or carers, had others to look after.

4.2 Helping those 'self-managing' their symptoms could improve levels of satisfaction

Participants in both Strands 1 and 4 mentioned a variety of ways in which they were '**self-managing'** their symptoms, outside of the scope of the NHS.

> "So, I usually go online and start researching. Talk to friends, family, see if they have experienced something similar. I ask my friends and family as well…I'll try and call the GP if it gets worse. But as I said, it's impossible, there is a long wait, it's been really hard."
>
> **Strand 1 participant, long-term health condition**

In the first strand of research there were a number of participants who had yet to access Long COVID clinics, either through their own choice or because there were a number of barriers to accessing this care (summarised in Appendix 1). The fourth strand of the research observed that even among those patients who did access Long COVID clinics, often they had long wait times to receive care and support (both while they waited for their first appointment at the Long COVID clinic and after the initial assessment), and they reported not necessarily being provided with support sufficiently tailored to their needs. As a result, many participants had **developed their own strategies to self-manage symptoms** to enable them to cope.

Self-management techniques and support varied dependent on the individuals' symptoms, their resources, and the research they had conducted themselves. It was clear that some participants had learnt a lot about the bio-chemical science behind their condition and explored the latest academic research to try and improve their health.

> "I have looked at a lot of what other people do and use and related it back to my own symptoms and tried to marry that up with the data, and then, I try and run something for a month and see if it makes any difference to me. So, I've tried loads of things."
>
> **Strand 4 participant**

A small number of participants had resigned themselves to their symptoms being permanent, which had led to them not looking into treatment options. But participants across both strands of qualitative research with those experiencing Long COVID mentioned having found a range of **workarounds to enable them to cope with their ongoing symptoms**:

- **Emotional support:** Family/friends helping with daily tasks; peer support groups; mental health charities.
- **Lifestyle changes:** Support from employers/schools to change their work/school schedule; increasing or limiting exercise; changing their diet.
- **Support from professionals outside the scope of the NHS**: Privately funded psychotherapy; privately funded tests and scans; treatments provided by charities, such as oxygen therapy.
- **Medicating with drugs/supplements:** Alternative medicines; caffeine; CBD oil; vitamin injections; antihistamines.

Self-management techniques embraced by participants with Long COVID included drinking large quantities of coffee in an attempt to combat their fatigue and get through the day; or sleeping with multiple pillows to try to ease their breathing difficulties in a prone position. More extreme measures included having to stop their car part-way home from work to have a nap so that they could be more confident of getting home safely; and buying injectable vitamin B12 supplements online.

> “Somebody recommended me vitamin B12 injections. And I've been taking them for the last three or four months. Now, whether it's placebo or not, they do seem to have helped me. My memory has improved. But that never got mentioned to me by the NHS, that was just something I'd seen on the internet, and I was that desperate at the time, I thought, 'I'll give anything a try.’ So, I did, and I do think it has helped me.”
>
> **Strand 1 participant, living in a deprived area**

Barriers to accessing support: Participants were sometimes paying for supplements/therapy, so these were not available to all. They also require an individual to have a certain amount of knowledge and aptitude to research, identify or obtain additional support. This may be a further barrier.

4.3 Peer support groups and online forums provide an important source of camaraderie and knowledge

The benefits of **peer support groups** were mentioned many times across the participants from the different cohorts of this research: some participants were already engaging with groups on platforms like Facebook and felt positive about the emotional support they had received there. Such opportunities allowed participants to speak to people with similar conditions for emotional support, as well as sharing the latest research and different management techniques, and was something mentioned throughout the research by participants. Getting together with other people (virtually or in-person) with lived experience helped participants’ understanding of Long COVID and eased feelings of isolation. However, participants also mentioned that such sites had a large amount of unhelpful and potentially dangerous misinformation. It was suggested by some that the **NHS could facilitate similar peer support groups** to ensure information sharing is accurate and safe. It might also be helpful to consider how to communicate with patients about appropriate treatments and how they can judge the reliability of what they might read on the internet or hear via peer support groups.

"I'm not a fan of Facebook as a whole, but I do think where it does come into its own is in things like the Long COVID support group…you can sometimes just go on there and rant. So, I find that very useful. I think NHS should use that, not just Long COVID, but for multiple illnesses, especially chronic illnesses, because I think peer support is quite a powerful thing."

Strand 4 participant

"[Joining an online support group] has made life bearable; that has given us hope; it's provided support; it's provided sanctuary; it's enabled us to speak to people who have the same experience as us… and it puts things into perspective, and you no longer feel isolated and alone, albeit that it's a virtual community."

Strand 1 participant, parent of child aged 9

The NHS could partner with voluntary and community sector organisations who have services already in place that **offer help and support to people with other long-term conditions that have comparable symptoms to those of Long COVID.** If the NHS can tap into these resources, this could minimise unnecessary duplication of services and would help to reach into populations that might not otherwise access information.

4.4 Other forms of online support can also be useful, but have their limitations

Some Strand 4 participants, patients who had been referred to Long COVID clinics, mentioned having been referred to online support groups, workshops, or webinars. These were intended to provide patients with information about managing Long COVID. Online programmes typically lasted around six to seven weeks, with each week focussing on a different topic such as sleep, pacing and exercise, or fatigue. Of those who participated in these groups, some valued the insights into Long COVID; the hints and tips they provided about managing their condition; and hearing from other people with Long COVID, which helped them feel less 'alone.' However, participants identified some areas for improvement:

- Format and duration: Online formats were not appropriate for everyone. Participants described struggling to look at a screen for prolonged periods of time (because of the nature of their condition), and in some cases had to give up on the sessions.

- Tailoring: The content was not relevant for everyone, and participants said they would have liked the sessions to be more tailored around their needs. This was also frustrating for some participants who had done their own reading around their symptoms, and who therefore already had much (or even all) of the information offered to them by the Long COVIC clinic.

4.5 Providing support and information while people wait for their first appointment at a Long COVID clinic could improve patients' overall experience (Strand 4 only)

Research with participants who had been referred to a Long COVID clinic in Strand 4 highlighted improvements that can be made to the procedure to both streamline the process and make it less frustrating for patients.

Many patients reported having to **wait a long time to have their first appointment at the clinic**, this was after having already **struggling to be referred** in the first place. The wait time seemed inconsistent, with some only having to wait a few weeks, but for others it took up to 16 months.

This long wait was often coupled with a **general lack information** about the Long COVID clinic at the time of the referral being made, or what it would entail. Many patients expressed a wish for **more information about the clinic** and they also couldn't recall receiving any support from the clinic while they waited for their appointment. Participants described feeling 'lost' or 'alone' if there was no contact from the clinic, or support offered, for long periods of time.

It is worth considering what **further support can be offered to patients while they wait** for their referrals to the Long COVID clinics to come through. For example:

- Identifying what support primary care health professionals may be able to offer, or signpost patients to, so they can self-manage their conditions as far as possible while they wait.
- Using the Living With app at this earlier point in the pathway, since it was well-received by some participants.
- Identifying what other support patients can access, for example mental health services or peer support.

It is also important to **manage patients' expectations of Long COVID clinics in advance of their first appointment** by providing more information. Not having clear expectations sometimes added to patients' anxiety or led to expectations that they would be 'cured' at the clinic.

The type of information that would be helpful includes: an explanation of **what Long COVID is** and **what symptoms** people can experience; **what patients can expect** during their first appointment; the **types of tests and investigations** that patients may receive; the **range of treatments** available for the symptoms; **signposting to any support** available to them while they wait; an **estimate of when** they can expect to have their first appointment; and details of **who to contact** if needed.

5 Better meet the needs of patients with Long COVID by reassessing how services are set up (Strand 4 only)

This section explores patients experiences of the Long COVID clinics in the fourth strand of the research project.

The main findings from this chapter are:

- From referral through to discharge the Long COVID clinics should be providing as much communication as possible. Upfront information eases the concerns and anxiety of patients. Throughout their patient journey many participants felt in the dark about what was happening to them, or what support the clinic could provide. Patients expressed a wish for more information about the clinic, and it is also important to manage patients' expectations of Long COVID clinics in advance of their first appointments by providing more information. Not having clear expectations sometimes added to patients' anxiety or led to expectations that they would be 'cured' at the clinic.

- Where patients had an initial call prior to a more detailed assessment, this was an important moment in their journey and made them feel they would get the support they so desperately wanted to help manage Long COVID. If possible, this should be provided to all.

- Patients were often positive about their in-depth assessments. They described feeling a mixture of gratitude and relief to have their condition validated. Best practice for this appointment includes allowing enough time for the appointment, asking the patient detailed questions, listening, focusing on symptoms that are most important to the patient, and being clear about the support available and onward referrals.

- There was an expectation among patients that the Long COVID clinic would be able to provide them tailored support. Patients felt severely let down when the guidance provided by the service felt too generic, or not relevant to them.

- The clinics should consider the policy around discharging patients. Many participants expressed a wish to maintain contact with the clinic, in case treatments developed or their conditions changed – rather than needing to obtain another referral.

5.1 The first contact with a Long COVID clinic is an important point on the pathway and should focus on validating patients and easing their concerns

Participants tended to feel positive about their initial interaction with the Long COVID clinic. This was usually a call with someone (typically an administrator or nurse) to go through symptoms and book in an appointment. These calls worked well because they helped to ease participants' concerns; provided context about what they could expect from the Long COVID clinic; provided an opportunity to ask questions of someone with specialist knowledge of both the process and Long COVID itself; and demonstrated to the patient that they were still part of the process and had not been 'forgotten.'

However, some participants reported not having had one of these initial calls, and would have liked to. Incorporating these initial calls for all patients at Long COVID clinics would enhance patient experience.

"I felt really listened to; that I wasn't going a bit crazy; that other people were experiencing what I'm experiencing; and that [I wasn't] alone in that."

Strand 4 participant

Some **participants reported being given little or no advance warning** of appointments. This was challenging because symptoms can be more severe at different times in the day; and it can be difficult to recall symptoms spontaneously. Participants were worried that, as a result, they had been unable to give the caller a fully rounded picture of their condition. This could be prevented by giving patients advanced warnings of consultations, and tools to help them prepare such as a timeline to complete about their experiences or a list of questions that would be asked in the consultation.

"It was also hard to find energy to have a 30-minute conversation, and I didn't have the memory or cognitive power to give them the information they needed. So, I think I missed a lot."

Strand 4 participant

5.2 The next stage of interaction with the Long COVID clinic was also generally very well received. It is important the clinics build upon this.

In most cases, this initial call was followed by an **in-depth appointment** consisting of either:

- An **hour-long discussion** with a clinician (typically a doctor); or
- An appointment lasting a number of hours, where the patient would see **multiple people** (such as doctors, nurses, occupational therapists, physiotherapists, psychologists, etc.), and also **undergo tests** (for example, blood pressure, breathing assessments, active stand tests).

Having a one-to-one consultation with clinicians at this stage was **not universal**. In one case, a participant was simply asked to complete a questionnaire which was then reviewed by a group of clinicians before deciding about the possible care options. **They reported far less satisfaction with the process.**

As with the initial phone call (where that had taken place), it was important to patients to speak to someone who could **demonstrate knowledge** of Long COVID and its symptoms in order to validate their experiences, **reassure them** about their symptoms and rule out more serious conditions (potentially through further tests). Participants described feeling a **mixture of gratitude and relief** following their initial consultation at the Long COVID clinic – particularly that their condition had a name and that others were also experiencing similar ongoing symptoms.

"I think I was surprised about how thorough it all was, and how much time I was given. The initial appointment was over an hour, and that was a lot longer than what I expected they would give you."

Strand 4 participant

It is important to continue to embed the best practice that often led participants to have a positive and validating first appointment: **key features of best practice** in patient experience included allowing time for the appointment, asking detailed questions, listening carefully, focusing in on the symptoms most important to the patient, having clarity around the support on offer, and discussing the options for onward referrals and support.

“One of the questions that he asked was, 'If we could sort three of your symptoms what would they be?', which I thought was really important for me because it was almost like, 'Let's look at what I can offer for...', and that's what he did. So, the three things that I said to him, he automatically came back with answers about how we could sort that.”

Strand 4 participant

At this stage, for some participants, there was an expectation that these clinics would ‘cure’ them. **More upfront information regarding the purpose and scope of the clinics might help manage such expectations and not lead to patients feeling let down by the process.**

The **mode of this appointment** (face-to-face, phone, or video) varied depending on the set-up and design of each service. Patient satisfaction with these different modes also varied, as services were not always able to accommodate a patient’s preferred mode. Those with fatigue issues noted how difficult it was to make face-to-face appointments for example. One participant, for example, described developing a new symptom (localised muscle spasms) as a result of the strain this put on her body. Participants told us they would have **liked to have the ability to choose how they have this initial consultation.**

In addition, participants were not always told how long these initial assessment consultations would take. Some struggled to pace themselves throughout the day as a result, they reported feeling exhausted and worn out from the appointment.

Moreover, participants who struggled with fatigue reported struggling with completing paperwork ahead of the appointment – sometimes with a short timeframe to complete it. They also described having to answer similar questions multiple times ahead of appointments (for example, through multiple questionnaires).

“They called me the day before the clinic appointment and said, ‘There's a load of questionnaires that we'd like you to fill in in advance, could you please do them?’ … If I had been worse-off, it would have been a struggle for me to have done it in such a short timeframe.”

Strand 4 participant

Barriers to accessing support: Physical symptoms might prevent some participants being able to fully engage with the Long COVID clinics.

To mitigate the issues with fatigue and other physical symptoms that participants are experiencing as a result of Long COVID, clinics might wish to consider the following:

- Healthcare appointments can be very challenging for those experiencing common Long COVID symptoms such as brain fog, as well as for people with other conditions and disabilities that make it difficult for them to remember or communicate information. For example, repeating their stories to different clinicians, and remembering details. **Could services be redesigned with these needs in mind?**
    - If data sharing is not yet in place, or if clinicians need to listen to the information in the patients’ own words, consider how patients may be supported in this (for example, by putting together a timeline, or providing an aide memoire).

- Similarly, it can be difficult for people experiencing Long COVID to make and attend a scheduled appointment, in terms of cognition, time, and having the energy to attend. **Can the NHS rethink how best to support patients to navigate these challenges?** For example, it may be possible to support people experiencing brain fog via existing short-term memory clinics, rather than setting up new services.

- Consider the **optimal length** of an appointment/visit to the clinic and streamline them where possible, acknowledging that participants did also appreciate the time spent with them.

- **Locate services** in areas that can be fairly easily reached by patients.

- For appropriate aspects of patients' stories, **obtain information from them in advance** where possible rather than during the appointment – giving them enough notice to complete the information while managing their energy.

- Consider whether it might be possible for **some tests to be completed more locally** in advance of appointments.

- If possible, the clinics should give participants more time to fill in these forms, as well as share information between different departments to minimise duplication of information collection.

5.3 Ensuring that treatment in the Long COVID clinics best meets the needs of the individual patient is key to a positive patient experience

Although many of the participants were referred onto specialist teams to help with their condition, for a small group of patients this initial assessment was their only interaction with the Long COVID clinic. This group was typically provided with some further information on self-management but no further treatment. This often left them disappointed and frustrated because of their initial expectations of what the clinic can offer being so high.

Some patients accepted that advice on self-management was the best solution clinics could offer, given the absence of specific treatments for Long COVID. In some cases, participants were broadly positive about the wealth of information provided by the Long COVID clinics and felt that the advice they received from the Long COVID clinic had helped them to make changes to their day-to-day lives, and some had seen positive improvements.

"[The clinic has been] sending me these files and things to do in email: I'm doing them, and I'm finding that they are helping me…I'm finding them very therapeutic…my joints are not aching as much."

Strand 4 participant

Small-scale **goal setting** was one example of advice that some participants found valuable – building small goals around a patient's interests, to help them to feel like they were achieving more from each day than just the necessities of keeping themselves clean, fed, and rested. Some participants also mentioned the **Living With app** in this context as a useful tool for identifying small, actionable, concrete goals, which could enable people to measure and track their progress.

"This is specific small-scale goal setting to make you feel like you're doing something positive for good mental health. I used to walk at weekends and weekday – I can't do that anymore so they're helping me look for substitutions. I have found that helpful."

Strand 4 participant

However, **the Long COVID clinics' focus on self-management did not meet everyone's expectations,** particularly if it was not combined with referrals to other services or support. Information was not felt to be sufficiently tailored; it was 'too basic'. Because waiting times were long for the first contact with the Long COVID clinic, participants tended to have already done their own research to identify different self-management techniques, such as breathing or pacing exercises; and changes they could make to their diet, activities, sleep hygiene, etc. For these participants, much of the self-management advice from the Long COVID clinic felt repetitive and unhelpful. In some cases, the clinic had also provided some resources for self-management prior to their first appointment, so the value of this additional support at the appointment was limited.

Other reasons for Strand 4 participants' dissatisfaction with the focus on self-management included:

- The **heavy focus on rehabilitation** meant that participants felt **the underlying causes of their condition were not being addressed.**
- Participants would have liked more **hands-on demonstration** of some of the different ways they could go about managing their recovery.
- When people were not seeing any improvements in their symptoms (often after prolonged periods of time), despite putting some of the advice into practice, **they questioned whether the clinic had been able to help them at all.**
- Almost all participants reported the need for support to deal with the **mental health challenges** of Long COVID and did not feel self-management was an appropriate or adequate response to this need.

"I expected something a bit more physical to be dealing with how to build your muscle strength back up or, I don't know, how to cope with being tired. They probably don't know yet and that but, it would have been nice to have had a little bit more face-to-face information that way."

Strand 4 participant

It is important to explain to participants how the **self-management techniques** that they are being introduced to will help their symptoms to improve. This may help to soften the gap between patients' expectations of being cured and an outcome of needing to self-manage symptoms for gradual improvement.

A common way for information to be provided to patients regarding managing Long COVID was through **online support groups, workshops, or webinars**. These online programmes typically lasted around six to seven weeks, with each week focussing on a different topic such as sleep, pacing and exercise, or fatigue.

Participants valued the insights into Long COVID, the hints and tips they provided about managing their condition, and hearing from other people with Long COVID so they did not feel 'alone.' However, there were common areas for improvement that participants discussed, around:

- **Format and duration:** the online format was not appropriate for everyone – participants described struggling to look at a screen for prolonged periods of time (because of the nature of their condition), and in some cases had to give up on the sessions.

  "One of the things that I found which fatigued me massively was to be on video calls…it would just wipe me out for the rest of the day."

Strand 4 participant

- **Tailoring:** The content was not relevant for everyone, and participants said they would have liked the sessions to be more tailored around their needs. This was also frustrating for some participants who had done their own reading around their symptoms, and who therefore already had much (or even all) of the information offered to them by the Long COVID clinic.

> "The Zoom thing hasn't given us any information I didn't already know. Two of them really had nothing to with my type of symptoms. And the one I had been looking forward to was the dealing with the chronic fatigue and pacing, and really there was nothing there that I hadn't already looked up on the NHS website."

Strand 4 participant

It is therefore important that the Long COVID clinics review the format of support it provides to ensure they are suitable or identify where adjustments could be made.

5.4 Patients would appreciate an ongoing relationship with the Long COVID clinic, even after discharge, if possible

For those who had been **discharged** or had completed the treatment the clinic was able to offer them, there was some acceptance that there was nothing further the clinic could do, and the focus should now be on self-management. However, this was often coupled with **disappointment that the clinic was not able to do more for them**, often because of those initial expectations.

Even with this acceptance of the situation, participants in the research reported feeling 'stranded' or 'alone' once they had been discharged – because they didn't know who they could contact in future.

"I feel a bit stranded, as if I've been left on my own. So, they had that check-in, but I felt that check-in that they did, which is the first thing I've had in four months or so from them. It felt more like they were doing it, not really because they were interested in my symptoms, but more that it was doing it to tick boxes."

Strand 4 participant

It was suggested by some that there should be ways to **maintain contact with the clinic** on a more long-term basis, after discharge. Such opportunities would reassure patients that they have somewhere to go if symptoms got worse, or do not improve; and also allow the clinic to contact patients if other treatments become available as research develops.

"What I would like them to do now – offer patients to be kept on the list rather than discharged, so we can make contact with the clinic if we want to, and if there are things they can offer in terms of new treatments they can get in touch with them."

Strand 4 participant

The small number of patients who had been discharged and did feel that **the lines of communication with the clinic remained open tended to be far more positive**. For example, one patient reported getting 6-monthly check-in calls to see how their progress has been. Another reported being on Patient Initiated Follow-Up (PIFU), so that they could set up an appointment if they felt they need one. This type of approach would be preferable for patients to discharge, if it would be possible to roll this out more widely.

"[I asked], 'Can I call you if anything-, if I go really, really backwards, etc.?' And I remember them saying, 'Well, you are actually being discharged today, but if anything else happens then feel free to contact the Long COVID clinic, and they can re-refer you'."

Strand 4 participant

6 Involve end users in the development of communications and use a range of formats and channels for dissemination

This section looks at how information and communications about Long COVID could be designed, compiled, and disseminated to provide relevant and accessible information.

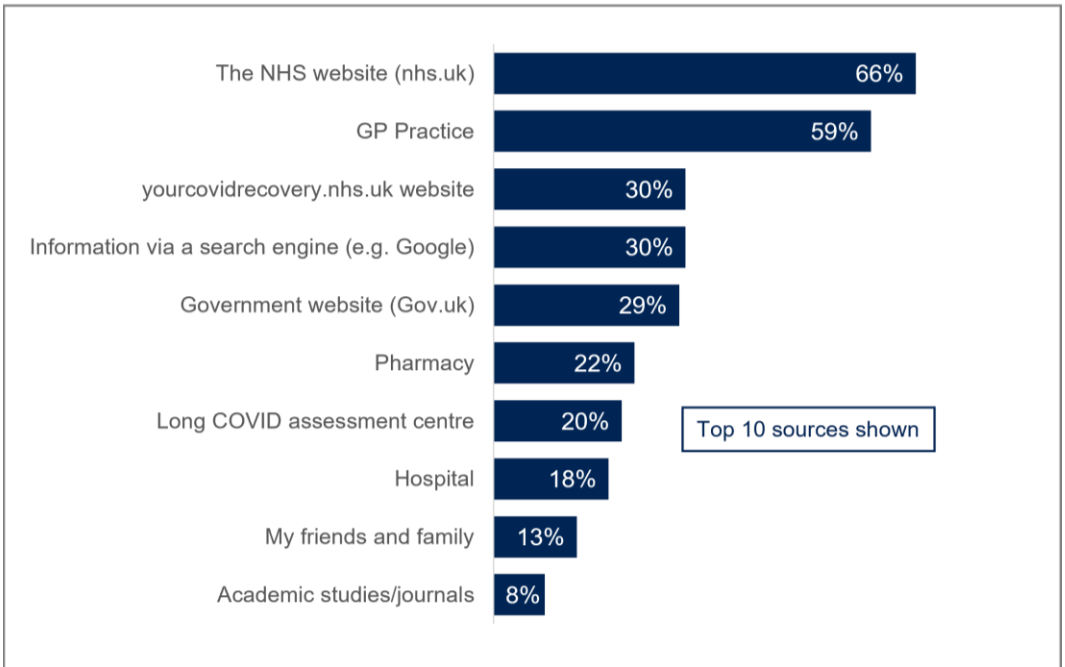
The main findings from this chapter are:

- Developing communications with people who have Long COVID will help to maximise the benefit of communications, by ensuring that it effectively communicates the information that they need.
- Involving a diverse audience in this development will help to ensure communications are accessible to a range of groups, including children and young people, those who may find it more challenging to understand health information, and those who require materials in alternative formats.
- Vulnerable people from deprived backgrounds face additional barriers trusting healthcare professionals – disseminating information via multiple channels will improve knowledge about and access to Long COVID services among these populations.

6.1 Confidence and trust in information provided by the NHS is high, but there are perceived limitations

In the public survey, Figure 6.1 shows that two-thirds (66%) said they would look for information on the NHS website if they thought they may have Long COVID, while around three in five (59%) said they would seek information from their GP practice. The next most common sources were websites, including via a search engine such as Google (30%) or on gov.uk (29%).

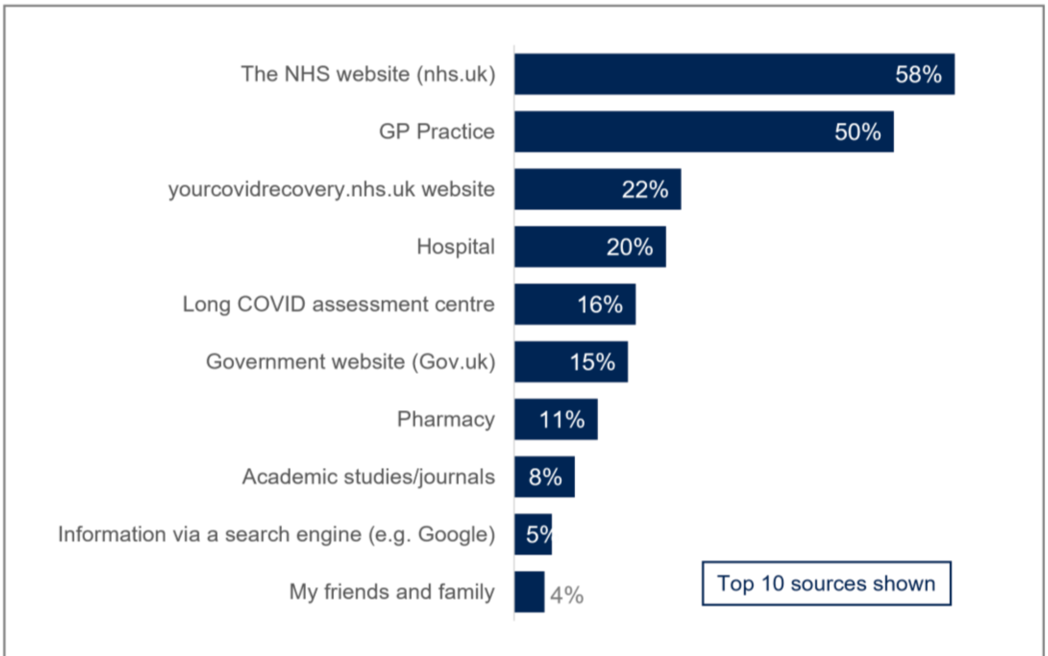
Figure 6.1: If you thought you may have Long COVID, from which of the following sources, if any, would you look for information about Long COVID?



Base: All participants (n=1,828). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

Additionally, as illustrated in Figure 6.2, almost three in five of the public (58%) said they would trust the NHS website most for information about Long COVID, while half (50%) would trust their GP Practice.

Figure 6.2: Which of the following sources, if any, would you trust most for information about Long COVID?



Base: All participants (n=1,828). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

In contrast, participants in Strand 1 were typically not satisfied with the information they received about Long COVID from the NHS online, and awareness of the NHS Your COVID Recovery website was very low. Participants wanted more information about the condition, and even participants from Strand 4, who had been referred to a Long COVID clinic and were receiving information from the Long COVID clinics, also reported seeking other forms of information such as different self-management techniques.

As a result of a perceived lack of information from the NHS, participants were relying on a range of other sources (as discussed in Chapter 4), which were often not regulated, and included sources such as online forums, Facebook groups, YouTube, and international (mostly US) news media. While participants were aware that information they found online may not be reliable, in the absence of what they felt was sufficient information and support from the NHS, many were still using these sources.

6.2 Development of materials should be done in partnership with patient groups

To make the information the NHS provides about Long COVID more relevant and helpful, Strand 2 advocates suggested developing communications with people who have Long COVID, which will help to maximise the benefit of communications, by ensuring that it effectively communicates the information needed.

Involving a diverse audience in development will help to ensure communications are accessible to a range of groups, including those who may find it more challenging to understand health information and those who require materials in alternative formats, such as people with learning disabilities; people who require Braille, BSL, large print, etc. At a minimum it is expected that GPs should provide a leaflet upon diagnosis, but this information should also be available on the NHS App and website, and in a letter.

> “I think the trouble is that people develop things with adults in mind, and then children's involvement is an afterthought. So, to me, the young people would look at [the Your COVID Recovery website] and think, 'I'm not looking at that.'”
>
> **Strand 2 advocate organisation**

Advocacy organisations pointed out that the existing resources are not accessible to **children and young people**; those who have different access needs; or who are **digitally excluded**. They suggested a range of principles to apply when designing content:

- For children and young people: produce information that is relevant for, and can be accessed by, children and young people and their parents/caregivers, again by involving them in the development of materials.
- Use diverse visuals: information leaflets and any campaign material should feature images of people who represent a wide range of ethnicities, disabilities, and ages.
- Use case studies: these demonstrate what Long COVID may feel like, are easier to engage with, and help people to feel less alone.

6.3 Dissemination of information should utilise a variety of channels and modes

Advocates also suggested that the NHS could utilise voluntary and community sector organisations and their existing reach into marginalised communities, to conduct proactive outreach and information sharing, as it is known that communications resonate most when from a person in a position of trust. In the public survey, those from white ethnic backgrounds were more likely to trust their GP practice (51%, compared with only 41% from ethnic minority backgrounds).

It is important to use a range of information formats and disseminate information via multiple channels (including audio and video, as well as written materials). Again, this will help to reach a broad audience base, including groups where communications may be more challenging such as those with specific accessibility needs, who are digitally excluded, or who otherwise would tend to engage less with their health and health services. Examples of channels that may help to achieve this include:

- Distributing resources via a range of organisations, such as charity shops, pharmacies, and libraries: these are located on high streets, have a lot of foot traffic, and can be a useful source of information accessible to a wide range of people, including those experiencing deprivation.
- Utilising the networks that the voluntary sector already has into communities that the NHS may traditionally find more challenging to reach and where trust may be lower, but where there are organisations with links into communities that already have a great deal of trust among the public.

“Wherever the emails were coming from to say that we were [COVID-19] positive, [communications about Long COVID could] be in line with that. [That would] show that there’s a process in place, so, you know, it’s the testing, the result, and then the aftermath of it… You know how when you get medicine it tells you how to use it, what the side effects could be, what to do if something goes wrong? I think something like that should have been in place, so you know what you’re looking at, rather than thinking, ‘Oh, my god, I’m going to die,’ going on to Google and reading just anything, and not knowing how much fact is in there.”

Strand 1 participant, living in a deprived area

7 Review the pathway from the perspective of health inequalities

The existing Long COVID pathway does not comprehensively meet the needs of some of those most likely to experience health inequalities. In this chapter we have identified some actions the NHS could take to address the ways in which the pathway is currently inaccessible or unnecessarily complex.

The main findings from this chapter are:

- Joining up NHS and other existing support services (such as those in the voluntary and community sector) could help to disseminate information to people who are unlikely to be able to prioritise looking into possible care, support or treatment options.
- Clear communication from the NHS about the parameters of support available through the service (and, if possible, clarity about what is not available) may help to manage patients' expectations.
- It will be important to find ways to smooth the pathway for all patients, and especially those who are less able to navigate the health system and advocate for themselves.
- Offering greater guidance and support for people self-managing their symptoms could make this a more effective option.
- Peer support services are a useful and welcome tool for people living with Long COVID – the NHS could encourage and support these services to ensure they are providing credible and safe information.

Certain groups within society are impacted more by COVID-19 and Long COVID; and in general, certain groups experience poorer quality care or greater challenges accessing care. Strand 1 (with people who have not accessed Long COVID services) in particular aimed to understand the perspective of some groups that experience health inequalities: adult participants in this strand had pre-existing long-term conditions, and/or lived in an area of deprivation. Levels of hope for the future were mixed among those in groups more likely to experience health inequalities. Those who were optimistic about their chances of improving pointed to improvements they had already experienced or treatments they were receiving. However, others were less hopeful due to not having seen any changes yet, or being sceptical about whether they would receive the medical help they needed. There was a theme of having adjusted to a 'new normal' repeated across interviews.

"I've kind of lost all hope as to when is all this going to end."

Strand 1 participant, long-term health condition

"The physical. Although my mental health, you know, it sounds a bit extreme, [but] I feel like it's been destroyed. But physically, the constant tiredness. Not being able to do other things I was doing prior to it. I feel like that life doesn't exist anymore."

Strand 1 participant, long-term health condition

> "I'm dreading what my September pay is going to look like. And I've already had to call my housing association, to let them know that if I don't pay rent next month, it's because of this, and now I've got to try and seek help through the housing benefit."

Strand 1 participant, long-term health condition

The findings of this research programme point to a number of places where inequalities in support, treatment and outcomes related to Long COVID may arise. A further review of the pathway from the perspective of health inequalities may help to address some of these areas, for example:

- Advocates for people experiencing deprivation highlighted that this population often have other, more urgent needs, and deprioritise health below things like housing and food. **Can the NHS utilise links with support services to disseminate information to people who are unlikely to be able to prioritise looking into possible care, support or treatment options?**
- Some patients are 'topping up' what they receive from the NHS with other diagnostics, support, and medication. **Clear communication from the NHS about the parameters of support available through the service (and, if possible, clarity about what is not available) may help to manage patients' expectations.**
- There is some suggestion that the pathway is not always smooth, meaning that patients who are better placed to advocate for themselves and to navigate the health service will be better able to secure referrals to Long COVID clinics and/or the support and treatment they need. **Are there ways in which the pathway could be smoother or less reliant on patients to advance?**
- Participants across the different strands suggested that the NHS could do more to **proactively signpost to support options** that could help those experiencing Long COVID, to reduce the burden on participants, which in turn would contribute to a reduction in health inequalities. **Can the NHS signpost to health charities, and extra support available in tandem to Long COVID services (for example, from other services)?**
- The emphasis on self-management assumes that patients have the level of knowledge and capability needed to follow these techniques. **Can further support be provided to some patients who struggle with self-management?**
- The value of peer support came through very strongly from participants across strands 1, 2 and 4. **Could NHS services encourage or support this in some way – for example, providing signposting to networks that the NHS considers credible and safe; or hosting/funding peer-support services directly?**

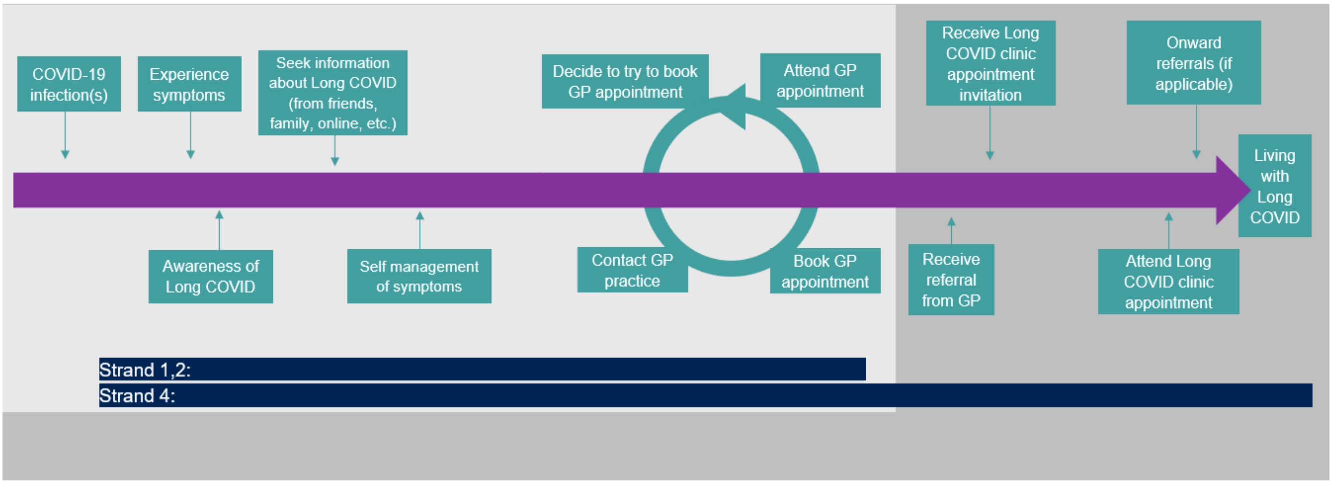
Appendix 1: Summary of barriers and enablers (S1/2)

Barriers	Enablers
Knowledge of Long COVID, and recognition of symptoms	**Increasing the general knowledge of Long COVID and its symptoms** among the public would be beneficial, so people know when to seek help. Using the relationships of trust that the voluntary and community sector already has with communities that are vulnerable or have lower awareness of Long COVID would help to disseminate information.
Capacity to prioritise health	Communications and information provision should make it clear that **there is a possibility of improvement** from Long COVID symptoms, that the **NHS provides support** to people experiencing Long COVID, and encourage people to contact their GP or other healthcare provider. Voluntary and community sector organisations can help to signpost people to services – and the NHS could signpost patients to other support that is available via the sector.
Knowledge of Long COVID treatment and support options	Ensuring that **GPs receive new information about symptoms and emerging treatments** may help to avoid dissonance between providers and patients.
Relationship with GP and other NHS services	**Rebuilding trust** between patients and healthcare providers by validating symptoms, looking at symptoms holistically, providing consistent advice and support, as well as maintaining communications with patients.
Access to GP / availability of GP appointments	Since participants reported that GP appointments are difficult to obtain, access to Long COVID services could **utilise an alternative pathway** to already-existing services and pathways.

Appendix 2: The care pathway

The care pathway

The diagram below represents a typical patient journey with key stages along the pathway.



Appendix 3: Breakdowns of Sample

Tables A.1 Characteristics of 37 participants taking part in Strand 1 in-depth interviews

Sex	Number of participants
Male	8
Female	29
Total	**37**

Age group	Number of participants
Under 18	9
18-34	6
35-49	14
50+	16
Total	**37**

Ethnic background	Number of participants
Bangladeshi	1
Black Caribbean	3
Indian	1
White and Black Caribbean	2
Other white background	2
Pakistani	2
White British	26
Total	**37**

Region	Number of participants
North	15
Midlands	9
London	7
South	6
Total	**37**

For Strand 1, recruitment of people living with Long COVID was managed by a specialist recruitment agency, Criteria Fieldwork. The sample for Strand 1 provided a breadth of perspectives as it secured representation from a mix of ethnic groups, and areas of England. There were some challenges in recruiting people with Long COVID within these specific groups of interest, particularly in relation to people from ethnic minority groups, men, and children and young people (and/or their parents and caregivers). This is reflective of the population that tends to seek help for Long COVID (namely white women), while research suggests that men and people from ethnic minority backgrounds are less likely to seek out help or treatment for Long COVID symptoms.

Tables A.2 Breakdown of organisation types for Strand 2

Focus of organisation	Number of participants
Housing/homelessness	4
Long-term conditions	7
Children and young people	5
Minoritised ethnic groups	1
Total	**17**

Figure A.1 Organisations who took part in Strand 2

Participating advocacy organisations

The logos below illustrate the advocacy organisations that participated in this research

Tables A.3 Sample breakdown for Strand 3 Survey (*n=1,828*)

Sex	
Male	48%
Female	51%

Age group	
16-24	13%
25-34	17%
35-44	16%
45-54	17%
55-64	15%
65-74	12%
75+	11%

Ethnic background	
Ethnic minorities (excluding White minorities)	13%
White (including White minorities)	86%

Region	
Northwest	13%
Northeast & Yorkshire	15%
Midlands	19%
London	15%
Southwest	10%
Southeast	16%
East	11%

Tables A.4 Characteristics of 42 participants taking part in Strand 4 in-depth interviews

Sex	Number of participants
Male	13
Female	29
Total	**42**

Age group	Number of participants
18-34	5
35-49	13
50+	24
Total	**42**

Ethnic background	Number of participants
Asian	2
White British	40
Total	**42**

Region	Number of participants
North	14
East of England	5
London	7
South	16
Total	**42**

For Strand 4, as mentioned previously in this report, recruitment was carried out via Long COVID clinics operating in England. This recruitment method was supplemented with recruitment via social media. All participants were screened, with quotas set on region, ethnicity, level of deprivation in the area in which they live, pre-existing conditions, and appointment mode (face-to-face or remote). An additional quota on healthcare professional was set as fieldwork progressed as many of the people opting in to the research worked in a health setting. Speaking to patients from across different stages of the pathway was prioritised. There were some challenges in recruiting people with Long COVID who were referred to a Long COVID clinic from ethnic minority groups and living in the most deprived areas; quotas on these were relaxed to ensure the overall number of interviews were reached. These challenges reflect the population that tends to be successful in accessing help for Long COVID (namely women and people from White ethnic backgrounds), while research shows people from ethnic minority backgrounds are less likely to seek help or treatment for Long COVID symptoms.

Appendix 4: UK KnowledgePanel Technical Notes

Recruitment to the panel

Panellists are recruited via a random probability unclustered address-based sampling method. This means that every household in the UK has a known chance of being selected to join the panel. Letters are sent to selected addresses in the UK (using the Postcode Address File) inviting them to become members of the panel. Invited members are able to sign up to the panel by completing a short online questionnaire or by returning a paper form. Up to 2 members of the household are able to sign up to the panel. Members of the public who are digitally excluded are able to register to the KnowledgePanel either by post or by telephone, and are given a tablet, an email address, and basic internet access (see further information below) which allows them to complete surveys online.

Conducting the survey

The survey was designed using a ‘mobile-first’ approach, which took into consideration the look, feel and usability of a questionnaire on a mobile device. This included: a thorough review of the questionnaire length to ensure it would not over burden respondents from focusing on a small screen for a lengthy period, avoiding the use of grid style questions (instead using question loops which are more mobile friendly), and making questions ‘finger-friendly’ so they’re easy to respond to. The questionnaire was also compatible with screen reader software to help those requiring further accessibility.

Sample and weighting information

This study was conducted on the KnowledgePanel between 22 April – 27 April 2022. In total 1,828 interviews were achieved with residents across England, aged 16+.

The KnowledgePanel is a random probability survey panel. Therefore, the KnowledgePanel does not use a quota approach when conducting surveys. Instead invited samples are stratified when conducting waves to account for any profile skews within the panel.

Stratification

The sample was stratified by education and country.

A total of 3,170 respondents were selected and invited to take part in the survey.

The selected sample was then reviewed on key demographics to ensure a balanced sample was selected for the survey.

A total of 1,828 respondents completed the survey, delivering a response rate of 58%.

Weighting

In order to ensure the survey results are as representative of the population of England as possible, the below weighting spec was applied to the data in line with the target sample profile.

Two members per household are allowed to register on the KnowledgePanel. Therefore, we employed a design weight to correct for unequal probabilities of selection of household members.

Calibration weights have also been applied using the latest population statistics relevant to the surveyed population.

Two sets of calibration weights are applied:

- Calibration weighting was applied using the following variables: Region and an interlocked variable of Gender by Age. Both use ONS 2020 mid-year population estimates as the weighting target.
- Demographic weights were then applied to correct for imbalances in the achieved sample; the data was weighted on: Education, Ethnicity, Index of Multiple Deprivation (quintiles), and number of adults in the household. Estimates from the ONS 2020 mid-year population estimates and Annual Population Survey were used as the weighting target.

The below tables present the weighting profile targets:

Age & Gender	Male	Female	In another way	Prefer not to say
16-24	6.69%	6.32%	0.18%	0.06%
25-34	8.38%	8.25%	0.06%	0.00%
35-44	7.76%	7.86%	0.12%	0.00%
45-54	8.23%	8.43%	0.00%	0.00%
55-64	7.29%	7.53%	0.00%	0.18%

Region	
North East	4.82%
North West	13.05%
Yorkshire And The Humber	9.79%
East Midlands	8.66%
West Midlands	10.48%
East Of England	11.05%
London	15.66%

South East	16.30%
South West	10.19%

Region	
1	20.00%
2	20.00%
3	20.00%
4	20.00%
5	20.00%

Education	
Degree level or above	30.05%
Below degree level	68.36%
Prefer not to say/Not Stated	1.60%

Ethnicity	
White	85.51%
Non-White	13.54%
Don't know/Prefer not to say	0.95%

Number of adults in the household (16+Pop)	Person Level
One adult	18.15%
Two or more adults	81.85%

Statistical reliability

The table below summarises the various figures based on a 95% confidence interval – that is they would apply 95 times out of 100 where results from a sample are being compared with entire coverage of the population or between subgroups.

For example, if the sample shows that 91% of people nationally say they know at least a little about Long COVID, we can be 95% confident that the result (had everyone been interviewed) would have been within around ±1.4 percentage points of this figure – that is, between 89.6% and 92.4% (based on a sample of 1,828).

	Result is at or near…		
	10% or 90%	30% or 70%	50%
Sample size	**±%**	**±%**	**±%**
1,828	1.4	2.1	2.3
1,500	1.5	2.3	2.5
1,000	1.9	2.8	3.1
500	2.6	4.0	4.4
300	3.4	5.2	5.7
100	4.1	9.0	9.8

Our standards and accreditations

Ipsos' standards and accreditations provide our clients with the peace of mind that they can always depend on us to deliver reliable, sustainable findings. Our focus on quality and continuous improvement means we have embedded a 'right first time' approach throughout our organisation.

ISO 20252

This is the international market research specific standard that supersedes BS 7911/MRQSA and incorporates IQCS (Interviewer Quality Control Scheme). It covers the five stages of a Market Research project. Ipsos was the first company in the world to gain this accreditation.

Market Research Society (MRS) Company Partnership

By being an MRS Company Partner, Ipsos endorses and supports the core MRS brand values of professionalism, research excellence and business effectiveness, and commits to comply with the MRS Code of Conduct throughout the organisation. We were the first company to sign up to the requirements and self-regulation of the MRS Code. More than 350 companies have followed our lead.

ISO 9001

This is the international general company standard with a focus on continual improvement through quality management systems. In 1994, we became one of the early adopters of the ISO 9001 business standard.

ISO 27001

This is the international standard for information security, designed to ensure the selection of adequate and proportionate security controls. Ipsos was the first research company in the UK to be awarded this in August 2008.

The UK General Data Protection Regulation (GDPR) and the UK Data Protection Act (DPA) 2018

Ipsos is required to comply with the UK GDPR and the UK DPA. It covers the processing of personal data and the protection of privacy.

HMG Cyber Essentials

This is a government-backed scheme and a key deliverable of the UK's National Cyber Security Programme. Ipsos was assessment-validated for Cyber Essentials certification in 2016. Cyber Essentials defines a set of controls which, when properly implemented, provide organisations with basic protection from the most prevalent forms of threat coming from the internet.

Fair Data

Ipsos is signed up as a 'Fair Data' company, agreeing to adhere to 10 core principles. The principles support and complement other standards such as ISOs, and the requirements of Data Protection legislation.

For more information

3 Thomas More Square
London
E1W 1YW

t: +44 (0)20 3059 5000

www.ipsos.com/en-uk
http://twitter.com/IpsosUK

About Ipsos Public Affairs

Ipsos Public Affairs works closely with national governments, local public services and the not-for-profit sector. Its c.200 research staff focus on public service and policy issues. Each has expertise in a particular part of the public sector, ensuring we have a detailed understanding of specific sectors and policy challenges. Combined with our methods and communications expertise, this helps ensure that our research makes a difference for decision makers and communities.