



LIVED EXPERIENCE OF LONG COVID

Session 4
15:30 – 17:00

Hosted by: Ipsos & NHS England

[#PatExp](#)

[#LongCovid](#)



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**WHO WE ARE AND
WHAT WE DO**



Patient
Experience
Network



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Ipsos and NHS England Long COVID patient experience research

Lived experience event

Michelle Gray, Laura Tuhou,
Kate Duxbury

25 July 2023



Overview of the research programme

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 three 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.

The survey was in field between 22 April and 27 April 2022. A total of **1,828 respondents** completed the survey.

Strand 4

The objective of Strand 4 was to provide an in-depth understanding of adult patients' experiences of NHS Post-COVID 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 services.

This presentation provides an overview of the **overall findings** of this research across Strands 1-4, with a focus on communications.

Three previous reports covered the findings of Strands 1 and 2, Strand 3, and Strand 4, with a further summary report bringing together the findings across the strands, providing more detail on the themes outlined in this presentation.

What we'll cover in this presentation

Increasing awareness and knowledge about Long COVID

Providing better advice on the NHS website and helping people to self-manage their symptoms

Providing more information during the wait for a first appointment

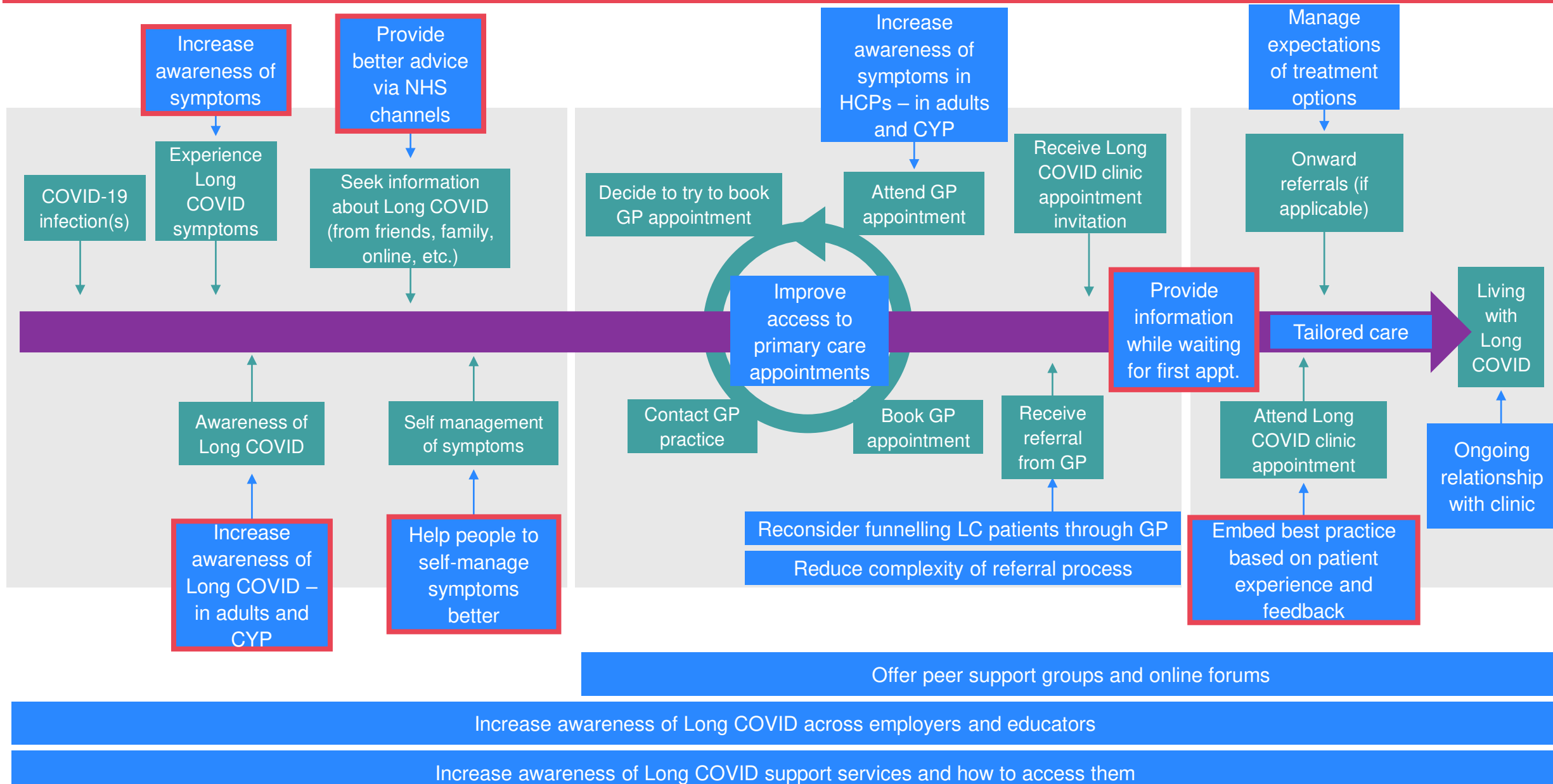
Embedding best practice based on patient experience and feedback

Making NHS information easily accessible in a variety of formats

The Long COVID pathway

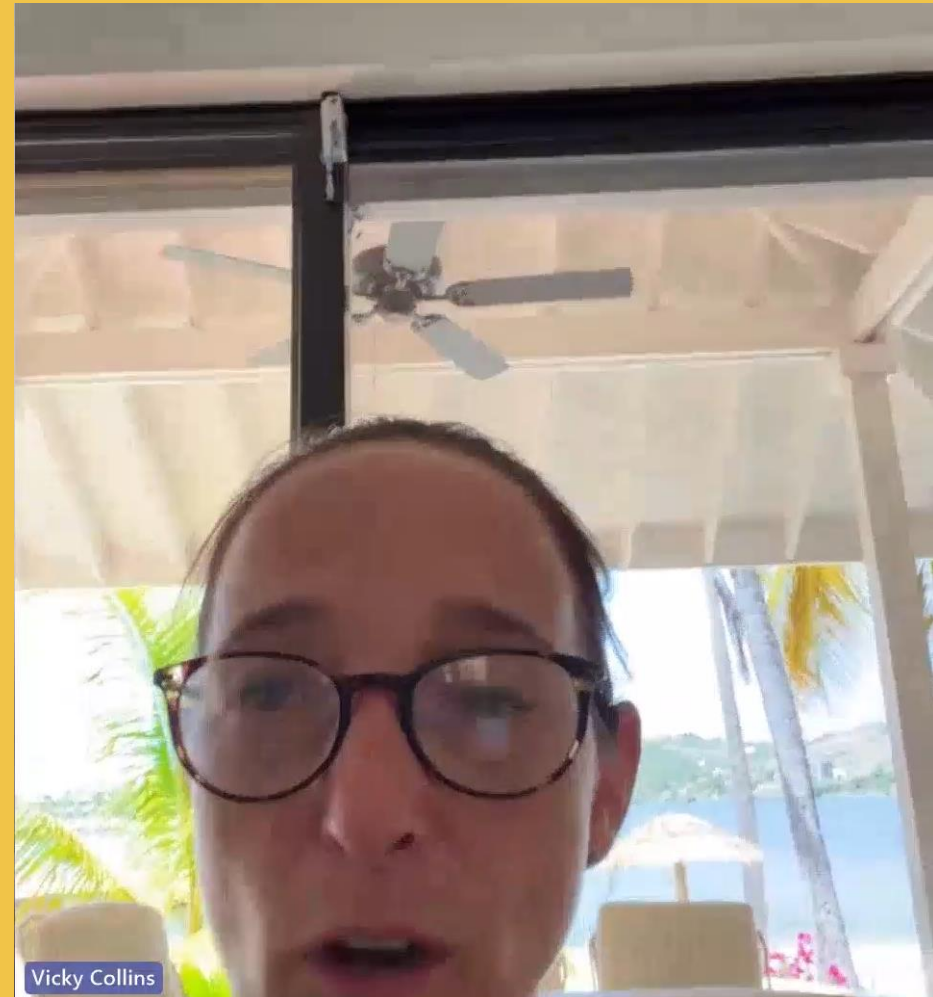
Review care pathway from perspective of health inequalities

Comms: (1) Develop comms in partnership with patient groups, including CYP. (2) Disseminate information via variety of channels.



Lived Experience

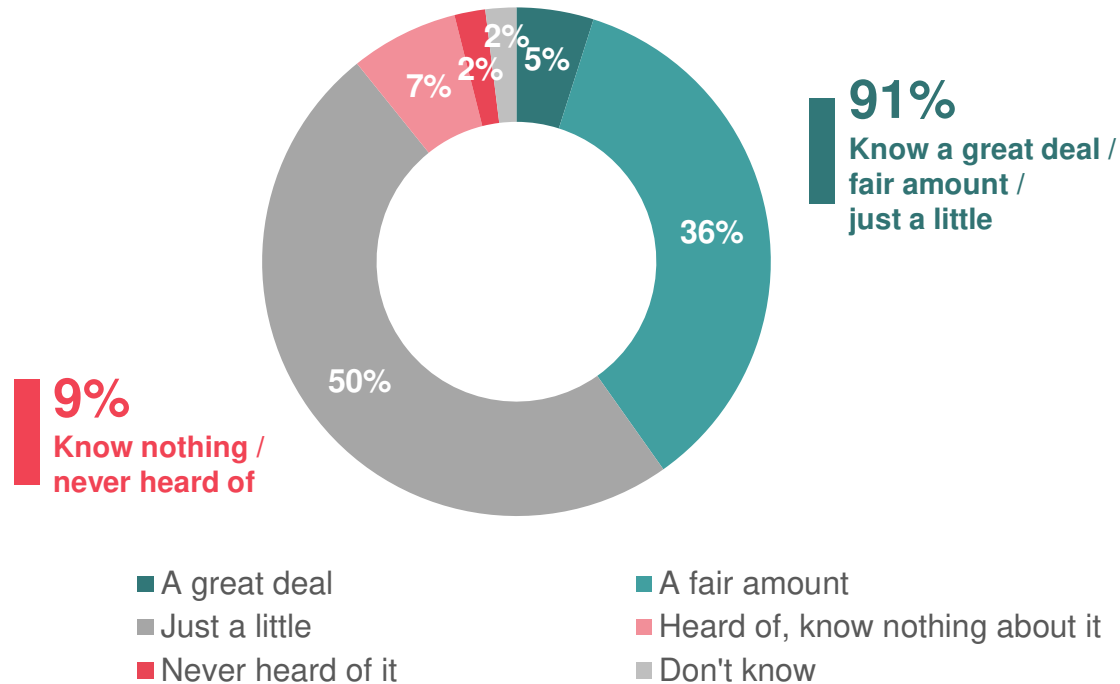
- Vicky is one of the lived experience partners who were involved in this project
- Both Vicky and her daughter Hannah have experience of Long COVID and accessing care



Increasing awareness and knowledge of Long COVID as a condition

Generally, the public have some knowledge about Long COVID, albeit often knowing just a little, and with variation between groups

Q. How much if anything, would you say you know about Long COVID?



Although 91% know something about Long COVID, this includes 50% who say they know 'just a little'

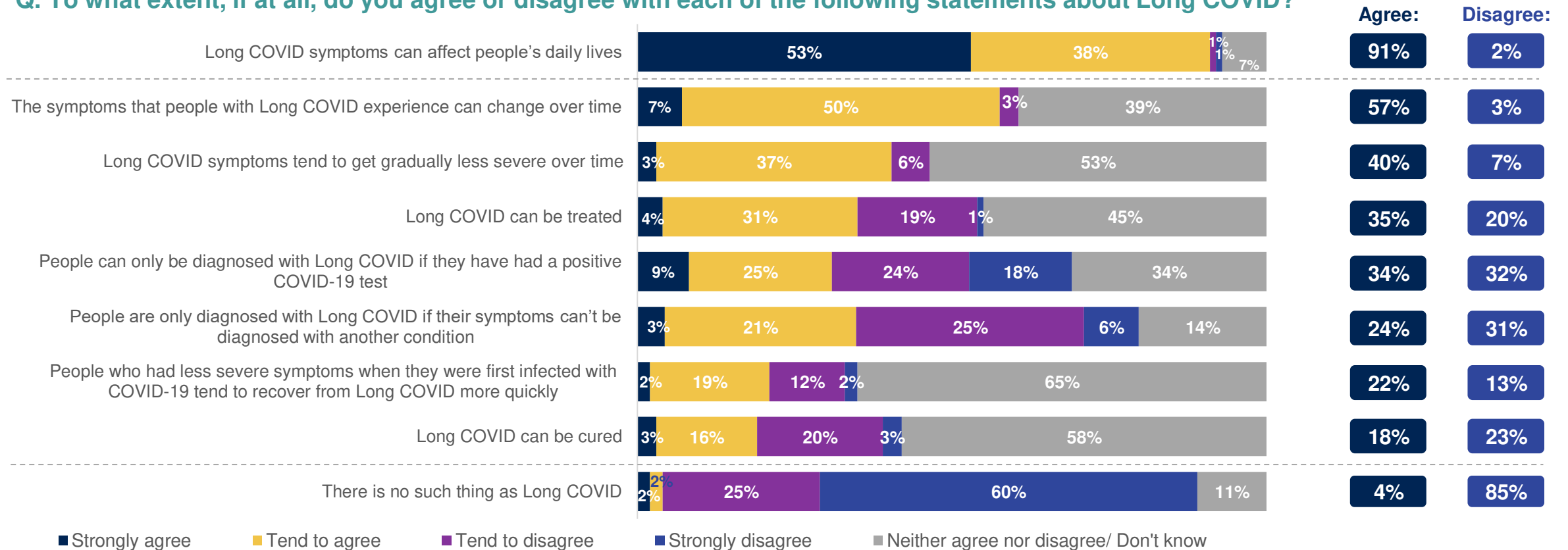
And knowledge is lower among some groups, for example:

- People from **ethnic minority backgrounds** (79%)
- People living in **the most deprived areas** (84%)

Base: All participants n=1828. Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

There is widespread agreement that Long COVID symptoms can affect people's daily lives

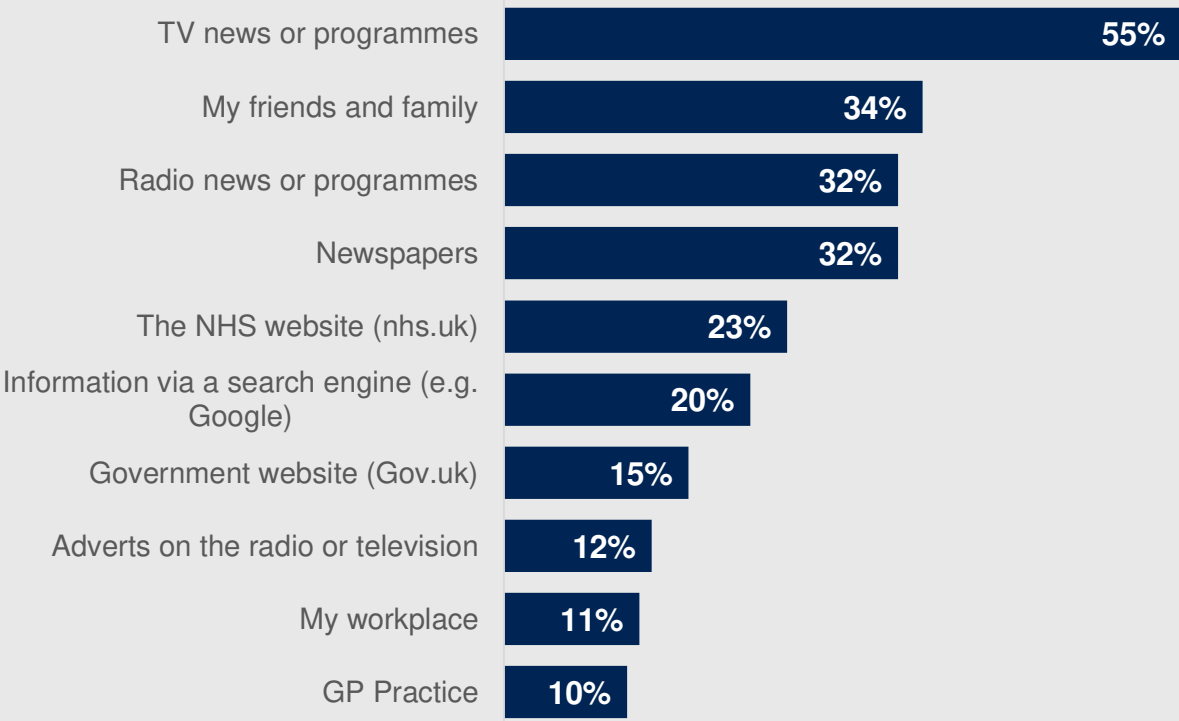
Q. To what extent, if at all, do you agree or disagree with each of the following statements about Long COVID?



Base: All participants who know at least a little about Long COVID n=1679. Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022

The public are currently hearing about Long COVID from sources such as TV news or programmes

Q. From which of the following sources, if any, have you heard or seen information about Long COVID?



Base: All participants (1828). Conducted online via KnowledgePanel UK between 22 April and 27 April 2022



Low awareness and misunderstandings about Long COVID are barriers to accessing care

How Long COVID symptoms progress or evolve

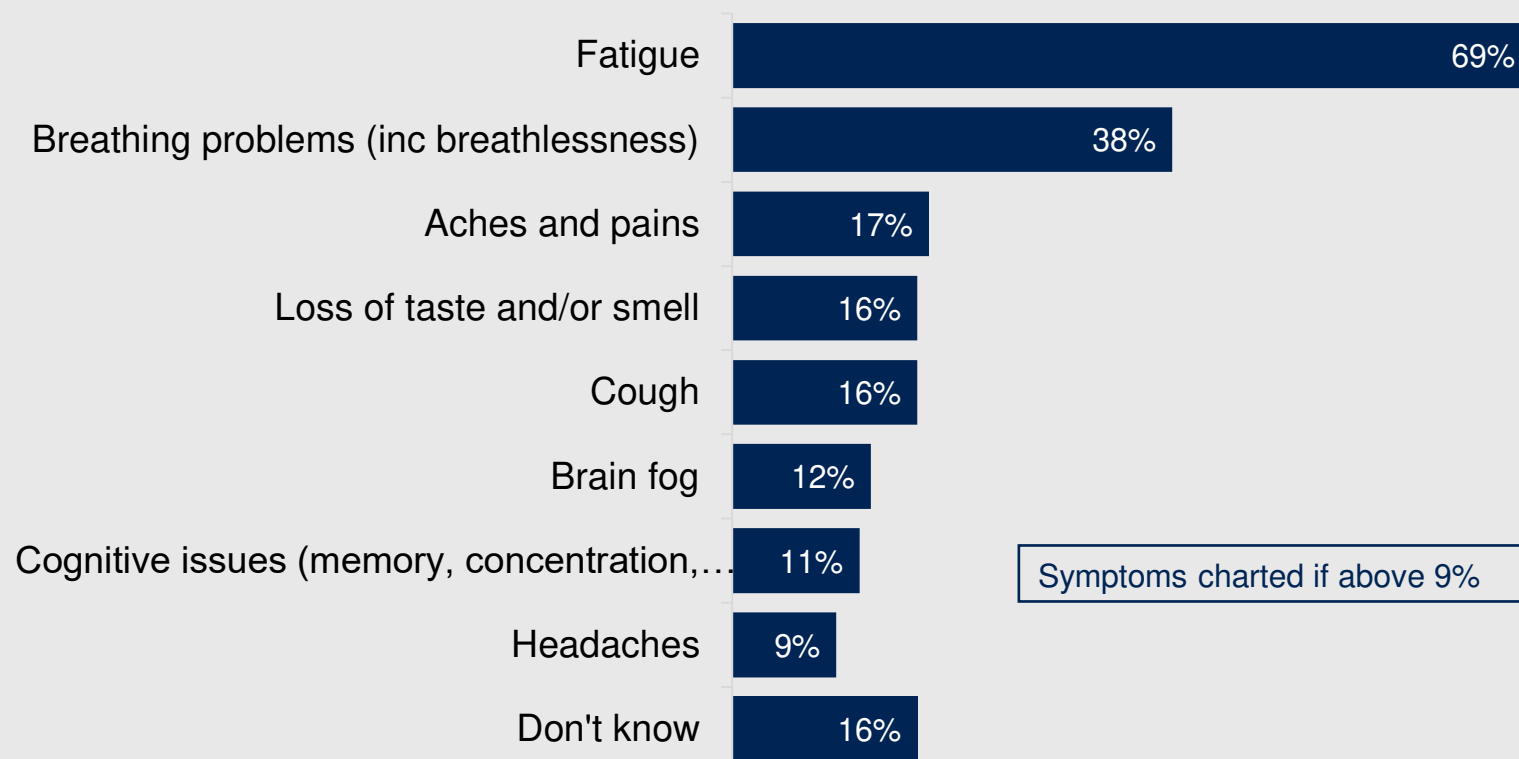
Although people generally understand that Long COVID affects people's daily lives, there is uncertainty over how the symptoms progress/evolve; how Long COVID is diagnosed; and whether or not the severity of the COVID-19 infection is linked to the severity of Long COVID.

Whether or not Long COVID can 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).

Raising awareness of Long COVID symptoms, in particular, may prompt people to seek help

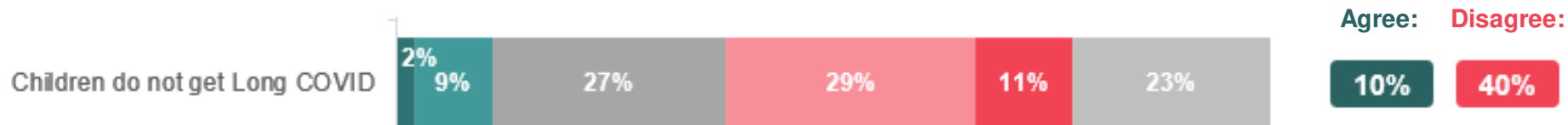
Q. As far as you know, what are the symptoms of Long COVID? (*unprompted*)



“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**

It is also important to increase public awareness about Long COVID in children and young people

- Messaging from public health and the government in the earlier stages of the pandemic had **minimised the risk to children**.
- They felt this led to a **perception that only adults could develop Long COVID**.



“ I remember at the time, seeing Dr Jenny Harris on the TV, saying, 'Kids don't get COVID. They're more likely to get hit by a bus.'” **Parent of CYP aged 17**

“ 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.” **Parent of CYP aged 14**

“ He knows this is his childhood going, and he wants his childhood. He loves life, he wants his time at school, he wants to be with friends, he wants to learn, he wants to be in the classes. So he knows he's not going to get this part of his life back, and it's like, when is he going to get better? How is he going to get better? Who's going to make him better? Who's going to help him to get his life back? Because that's what we need - we need people to be bothered, and not just push people away and say, 'Well, that's it, go and live a new disabled life.’” **Parent of CYP aged 15**

Increase healthcare professionals' knowledge and awareness of Long COVID symptoms

This will help to improve public confidence in healthcare professionals and their ability to treat Long COVID

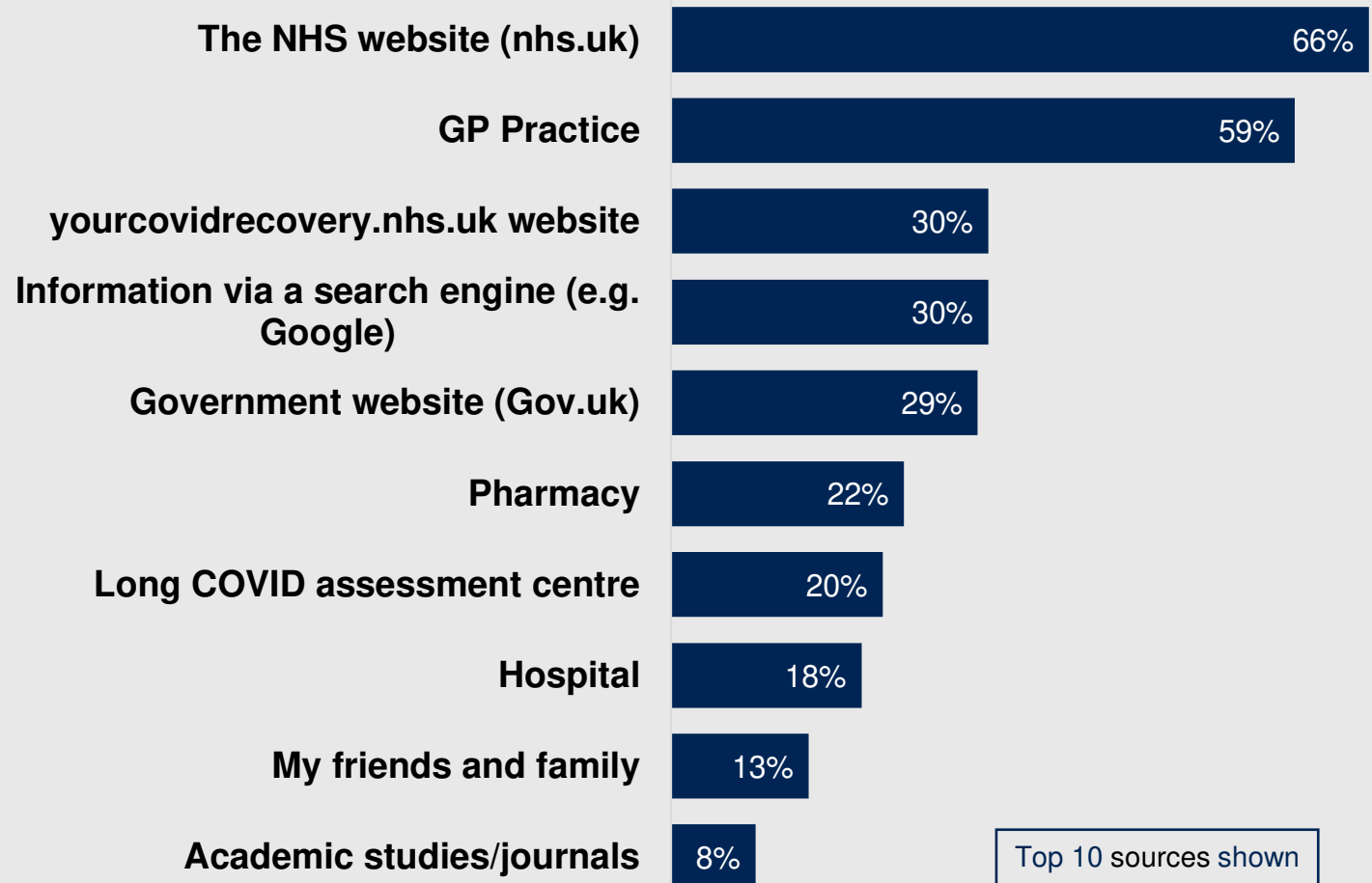
- Increasing awareness and knowledge among **health professionals** likely to have **first contact** with individuals experiencing Long COVID.
- Including **new information about symptoms and emerging treatments**.
- And in particular that it is **not necessary to wait until 12 weeks** post-infection to seek care.

“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**

Providing better advice via NHS channels and helping people to self-manage symptoms better

The public would first look to the NHS website or their GP practice for information from the NHS if they thought they may have Long COVID

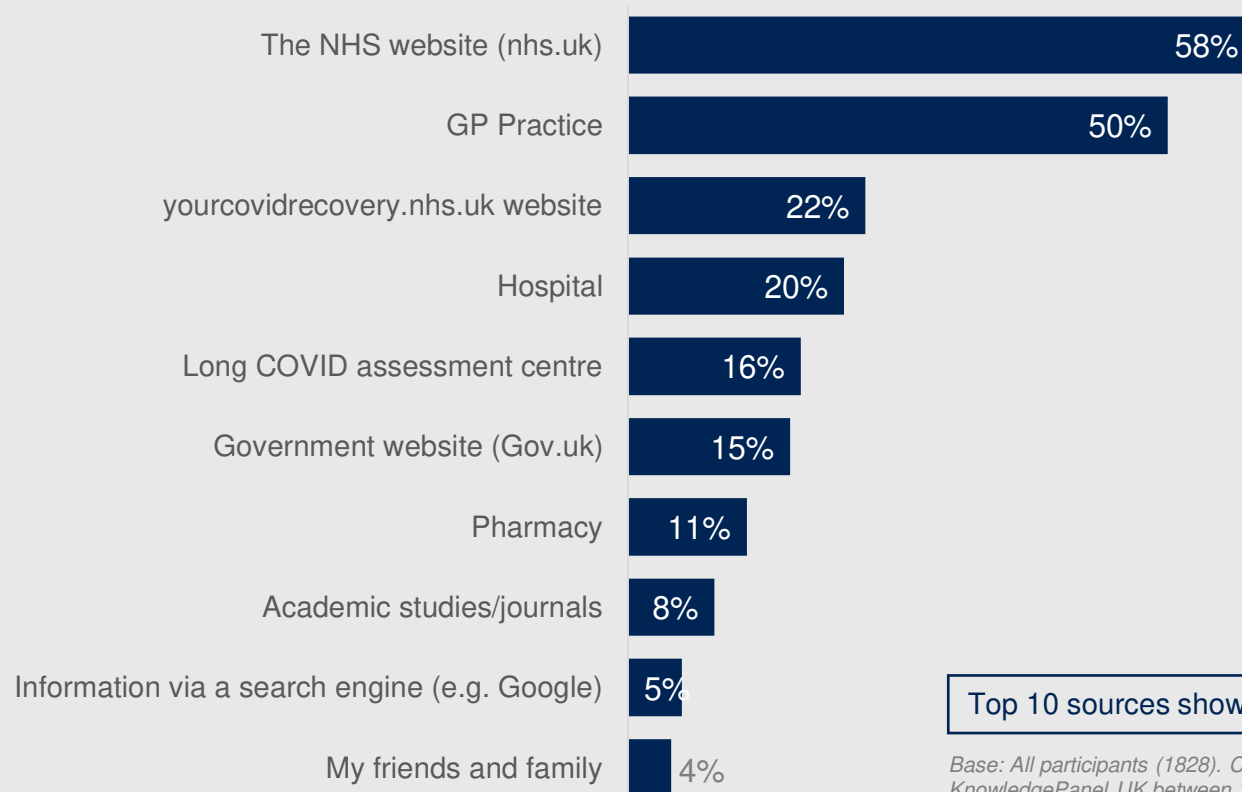
Q. If you thought you may have Long COVID, from which of the following sources, if any, would you look for information about Long COVID?



People trust the NHS website and their GP Practice most for information on Long COVID

These are trusted far more than any other source of information

Q. Which of the following sources, if any, would you trust most for information about Long COVID?

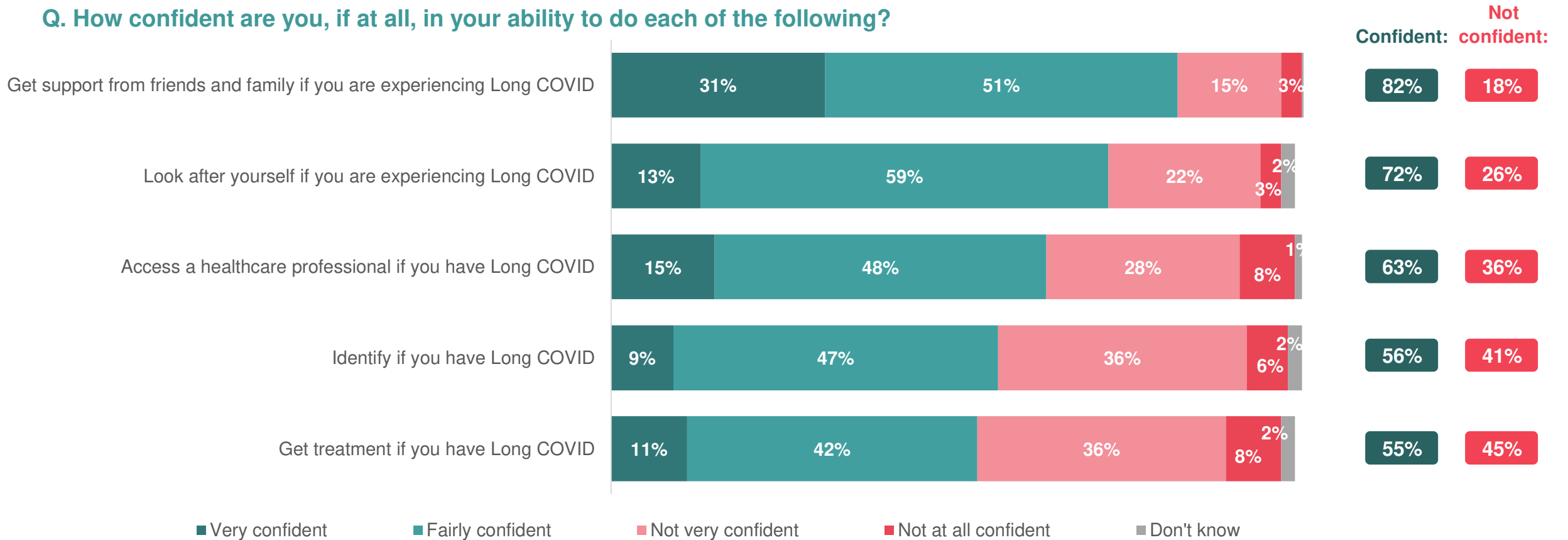


Top 10 sources shown

Base: All participants (1828). Conducted online via KnowledgePanel UK between 22 April and 27 April 2022

Significant minorities are not confident that they could identify if they have Long COVID or get treatment for it

Q. 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 (1679). Conducted online via KnowledgePanel UK between 22nd April and 27th April 2022



And the qualitative research shows that existing NHS information sources are not currently meeting the public's needs

Gaps in content

Existing NHS and UK government sources were perceived to focus on the acute phase of a COVID-19 infection rather than ongoing symptoms.

Lack of awareness

There is a lack of knowledge about what support was available for people with Long COVID, or how to access it.

Information availability

Participants struggled to find relevant information about Long COVID through NHS sources, so they looked elsewhere.



There could've been some sort of supporting documentation that came with it, you know? 'In the event of, you know, you suffering from Long COVID, this is what you can do to help.' Or, 'This is what to look out for if you believe that you do have it,' things like that, you know? Just a bit of guidance and support.”

These factors lead to an increased risk to the public

There are serious implications of NHS sources not meeting the public's needs, as non-NHS sources are likely to be unregulated, and may be incorrect, misleading, or dangerous

- Some 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." **Male, 56, White British, Living in a deprived area**

Clear guidance from the NHS would help improve knowledge and reduce anxiety for people with Long COVID

When people had (or suspected) Long COVID, they were especially interested in resources about:

- Prognosis
- Likely timeframes
- Where to go for help
- What to expect
- How to self-manage

“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-19. What is the process?” **Strand 4 participant**

In particular, the public should be made aware of:

Which organisation(s) are responsible for services

Options for self-managing their symptoms

Up-to-date information about treatment and support options

Pathways to accessing those organisations, so that eligible patients can be referred more smoothly

And there is a need for more proactive communications to share information with people with Long COVID who may be at greater risk of experiencing health inequalities

Advocates representing people who aren't able to prioritise health suggested:

Utilising **community outreach systems** that already exist

Proactively reaching out to some groups of the population

Encouraging **more handholding from advocates and peers** to enable people with Long COVID to access support

In order to reach out into communities where health is not a priority, it is important to **communicate symptoms in a variety of ways** – e.g. video/audio as well as written materials

Provide information while waiting for first appointment

Once patients have been referred to a Long COVID clinic, it is important to provide support while they wait for a first appointment

Having access to support and information during this waiting period could improve patients' overall experiences

This could include:

Support from
primary care

Using the
Living With
app earlier in
the pathway

Signposting to other support, for
example mental health services,
peer support, or self-management
tools

Lived Experience



Facilitating communication between patients (for example through support groups) could help patients feel less isolated

It is also important to manage patients' expectations

This helps to ease patients' anxiety about the process, but also to help make sure they do not attend their first appointment expecting a 'cure'

An explanation of **what Long COVID is**, and the **wide range of symptoms** they may experience

The **types of tests and investigations** they may be offered

An **estimate of when** they can expect to have their first appointment

What they can expect during their first appointment

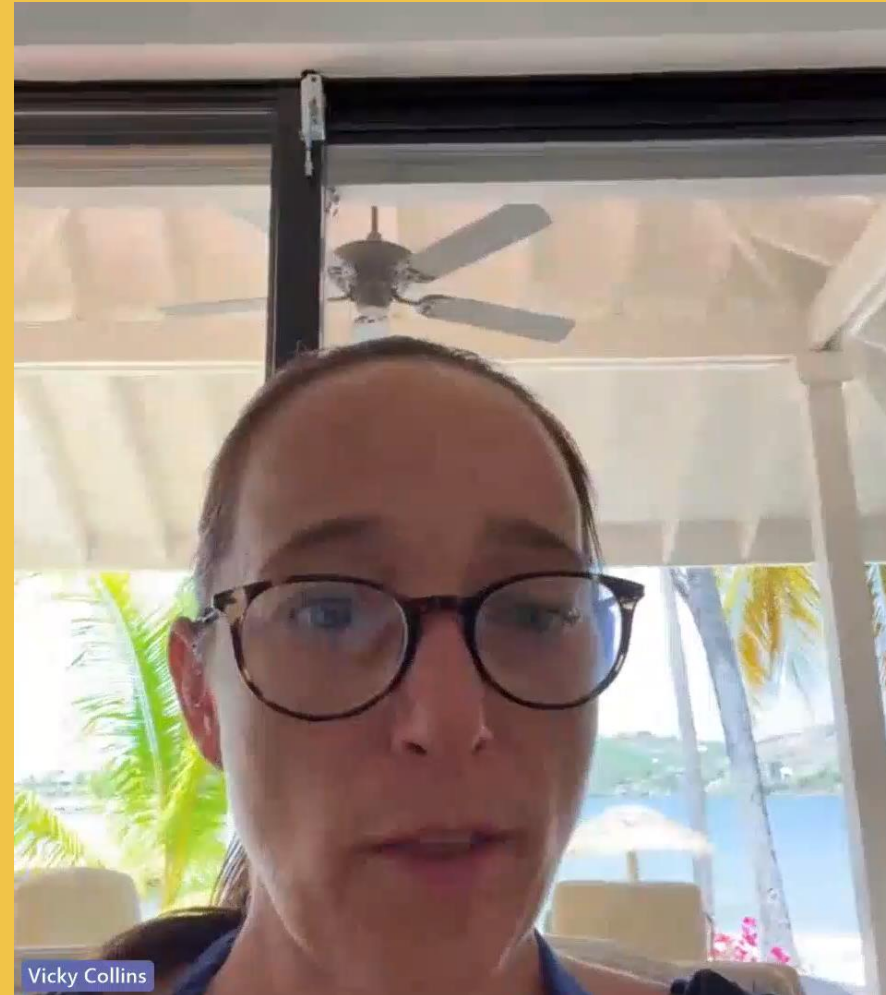
The **range of treatments** available for symptoms

Details of **who to contact** if needed

Signposting to any support available to them while they wait

Lived Experience

- Communication issues around notes and medical records
- Feeling 'on your own' due to lack of follow up post discharge



Embed best practice based on patient experience and feedback

Ensure treatment centres provide accessible and useable advice

An **initial call** with the Long COVID clinic was very well received, as an opportunity to find out more and for patients to ask questions.

Provide **advance warning** of appointments and paperwork patients need to complete.

“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?’”

Tell patients **what they can expect** at appointments, and **how long** they will last.

“I thought I was going at 09:30...and then I thought I’d be out at 10. So I didn’t plan for a three-hour appointment.”

Offer **further guidance and support** with self-management for some patients.

Lived Experience

- Lack of clarity around what the purpose of the service is (assessment vs. treatment)
- Lack of consistent knowledge of Long COVID across healthcare professionals



**NHS information
should be easily
accessible and in a
variety of formats**

Advocates asserted that some people in groups they represent struggle to know where to look for help

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

“ The last study showed 50% of people experiencing homelessness had severe literacy issues. I think that in itself is a barrier. We have seen an awful lot of people come through where English isn't their first language... accessing [services for] Long COVID, or any other health services - that's been a massive barrier.” **Evolve Housing and Support**

“ A lot of families that we see actually can't afford broadband and internet connectivity. So we tend to work with one of our corporate partners, Vodafone, so that we can support people in that way, and give that access to information. So, there's a group around there, in terms of poverty.” **Barnardo's**

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

Materials should be developed in partnership with patient groups

- **Develop communications in partnership** with people who have Long COVID
- **Involve a diverse audience** (including children and young people)
- Provide materials in a **variety of formats**
- Disseminate information **via multiple channels** to enable access for vulnerable people and those from deprived backgrounds

“ 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

Summary

Increasing awareness and knowledge of Long COVID as a condition

Providing better advice on the NHS website and helping people to self-manage their symptoms

Providing more information during the wait for a first appointment

Embedding best practice based on patient experience and feedback

Making NHS information easily accessible in a variety of formats

Breakout groups

Groups 1 & 2: Plan a comms campaign to increase public awareness of symptoms, self-management and where to go for help.

Groups 3 & 4: Discuss how information to raise awareness of Long COVID and/or how to manage symptoms and access health services can be disseminated into under-served groups. Through which channels?

Groups 5 & 6: Discuss what support and information could look like once people have been referred to a Long COVID clinic and are waiting for their first contact.

Please can each group be prepared to share a couple of key points from your discussion when we reconvene

BREAKOUT ROOMS

Main Room	
First Name	Surname
Camille	Alexis-Garsee
Deta	Almond
Nisreen	Alwan
Sarah Akhtar	Baz
Sarah	Baz
Jodie	BCU
Sumina	Begum
Andrea	Bell
Vicky	Betts
Derwena	Bowsher
Tricia	Bradbury
Emma	Brazier
Bridgett	Broughton
Eden	Byrne
Donna	Clutterbuck

Click Breakout Room 1	
First Name	Surname
Vicky	Collins
Gill	Davis
Paloma	Diaz Estevez
Emma	Dillon
John	Dunning
Kate	Duxbury
Alex	Evans
Alice	Faux - Nightingale
Katherine	Flanagan
beth	Fletcher
Jenny	Gaunt
Robin	Gorna
Michelle	Gray
Pam	Hancock
Bethany	Hawthorne

Click Breakout Room 2	
First Name	Surname
Nicki	Hodson
Sharon	Hui
Kate	Hunt
stacey	Hunter
Michelle	Hutton
Bilal	J
Victor	Jeganathan
Martin	Joinson
sam	knight
Pamela	Lawi
Fiona J.	Leggat
Ana	Leite
sally	longley
Joanne	Loughlin-Ridley
Tim	Lucas

Click Breakout Room 3	
First Name	Surname
Alice	MacLean
Sarah	Markham
Claire	Marshall
Sammie	McFarland
Claire	McWilliams
Ghazala	Mir
Natasha	Munoz
Carol	Munt
Michael	Natt
Mandy	Neophytou
Julie	Newell
Fiona	Newlands
Victoria	Newton
Aimee	Nixon
Susan	Nyandoro

BREAKOUT ROOMS

Click Breakout Room 4

First Name	Surname
Margaret	O'Hara
Moh	Okrekson
Nikhyta	Patel
Nicky	Payne
Colin	Pidgeon
Rosie	Pidgeon
Harriet	Pinel
Mary	Rankin
Jules	Rhodes
Jackie	Robinson
Jackie	Robinson
Martin	Rogers
Tracey	Ryan
Nathan	Samuels
Colin	Sandiford

Click Breakout Room 5

First Name	Surname
Naila	Shadi
Joanne	Smallman
Felicity	Smith
Nikki	Smith
Gemma	Smith
Nina	Smyth
Carly	Snowball
Emma	Solway
rebecca	spilsbury
abi	stothard
David	Sunkersing
Michael	Suter
Louise	Sutton
Roxanne	Talbot
Lisa	Till

Click Breakout Room 6

First Name	Surname
Emma	Tucker
Laura	Tuhou
Sudharma	Weerakkody
Charlotte	Welch
Victoria	Welsh
Ann	Westcott
Sarah	Weston
Cervantee	Wild
Jo	Worsfold

Thank you.

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NHS England's #StartWithPeople Learning and Support Offer

...to drive improvement, set national approach to supporting and developing people, empower local leaders to make decisions

Self-service resources

Self-service resources via [NHS England website](#) & [#StartWithPeople](#) Future NHS page to support implementation of [NHS England » Working in partnership with people and communities](#) statutory guidance

[Introduction to working with people & communities](#) via Futurelearn

Targeted learning & support for practitioners at NHSE and in systems

[#StartWithPeople webinars](#) and virtual events

Supporting learning programmes offered locally including [Local Trainer Community of Practice](#)

For support with involving people with a learning disability and autistic people read <https://www.england.nhs.uk/learning-disabilities/about/get-involved/> contact engage@nhs.net or follow @NHSability

Support for Patient and Public Voice (PPV) Partners

[Resources and learning to support PPV Partners](#) incl:

- [PPV Partner Welcome Pack](#)
- [PPV Partner network](#)
- [Mandatory and optional elearning modules](#)
- [Developing Influence & Impact in your role as a PPV Partner training course](#)
- [Citizens Advice Bureau helpline](#) for advice on payment
- Supply of devices to support [Digital Inclusion](#)
- [Recruitment opportunities](#)

Expert networks of policy makers and practitioners

ICB People and Communities Leads Network (and thematic working groups)

Arms-Length Bodies Forum

NHS England forums incl:

- Engagement Managers Community of Practice
- Engagement and Equality Champions
- Regional Leads Network

Building awareness of good practice through digital and social media

#StartWithPeople Newsletter

Twitter: #StartWithPeople @NHS Citizen

[Working in Partnership with People and Communities Podcast](#)

[People and Communities Blogs](#)

**For advice & support, contact us at:
england.engagement@nhs.net**

NHS England's Bitesize Guides to Patient Insight

A series of short guides to help providers and commissioners understand the use of patient insight better and to use it effectively in delivering local services.

[NHS England » Bite-size Guides to Patient Insight](#)

- Insight – what is already available
- How and when to commission new insight and feedback
- Writing an effective questionnaire
- Building greater insight through qualitative research
- Seeking feedback in distressing or highly emotional situations
- Helping people with a learning disability to give feedback
- The National Patient Reported Outcome Measures (PROMS) programme

**For advice & support, contact us at:
england.insight-queries@nhs.net**