Experiences of long COVID

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healthwatch
in Sussex

Introduction

Our rationale for exploring experiences of Long COVID

Healthwatch gather people's views of health and social care services in Sussex and make sure they are heard by the people in charge.

Long COVID is a new and evolving condition brought on by the contraction of a COVID-19 infection. The precise causes are not clear, and its impacts can vary significantly from person to person. This can create issues for diagnosis, treatment and management of the condition.

Given that more than 500,000 people across Sussex have contracted COVID-19, this will affect the wellbeing of some of our population, both now and in the future. Our research was focused at better understanding the scale and nature of long COVID locally so we could inform the provision of appropriate and effective support for those with the condition.

Our aims were to:

1. Raise awareness of long COVID amongst the public, commissioners and practitioners.
2. Capture a snapshot of people's experiences of long COVID, including their symptoms and the impact these had on their lives.
3. Understand how effective the support for long COVID is in improving people's quality of life to-date.
4. Identify how support for people with long COVID could be developed and improved.

Context

What is Long COVID?

Long COVID commonly refers to symptoms that continue for more than four weeks after a suspected coronavirus (COVID-19) infection, which are not explained by something else.

Long COVID symptoms vary significantly, but the Office for National Statistics reports the most common as being: fatigue, shortness of breath, difficulty concentrating and muscle ache.

The National Institute for Health and Care Excellence (NICE) recommendation gives the following clinical definitions:

1. **Ongoing symptomatic COVID-19**: signs and symptoms of COVID-19 from four to 12 weeks
2. **Post COVID-19 syndrome**: signs and symptoms that develop during or after COVID-19 and continue for more than 12 weeks and are not explained by an alternative diagnosis.

Both clinical definitions are commonly referred to as **'long COVID'** by lay people.

How common is Long COVID?
In February 2023, the Office for National Statistics reported that an estimated 2 million people living in private households in the UK (3.1% of the population) were experiencing self-reported long COVID.

A comparable proportion of the 1.72 million people living in Sussex would equate to approximately 51,600 people experiencing long COVID locally.

Context

Support for Long COVID

National response to Long COVID

In July 2022, NHS England announced an update to the NHS Long COVID Plan with a focus on deploying the £90 million committed by the NHS for long COVID services in 2022/23.

As part of this refresh, the update identified the progress made against the 10 key actions set out when the Plan was initially published in 2021-22. This includes the co-ordination of care by post-COVID clinics and rehabilitation pathways.

Support for long COVID in Sussex

In Sussex, the Post-COVID Assessment and Support Service (PCASS) is provided by the NHS to support those experiencing long COVID. Patients (aged 18+) need to be referred to this service by a healthcare professional, in order to rule out any underlying health conditions first. A separate service supports those aged under 18.

It is made up of a multi-disciplinary team that provides holistic support for people with ongoing long COVID symptoms who are referred to the service by their GP or another healthcare professional. It offers advice, self-management strategies and access to appropriate resources. The service has developed extensively since it was first introduced, and it is continuing to evolve to meet the needs of local people.

The service is delivered by East Sussex Healthcare NHS Trust and Sussex Community NHS Foundation Trust for people experiencing symptoms for four weeks or more. As of the end of February 2023, the PCASS service has received and treated 3,414 people. The waiting list for patients to be seen for an initial assessment is under six weeks and within the national target.

Other support exists through health and care professionals as part of the wider health system, community and voluntary organisations and via peer-to-peer and self-help networks in the community and via social media.

Tell us about your experience of Long COVID in Sussex

If you have experienced ongoing symptoms because of COVID-19, please complete our short survey and tell us:

- What the impact of Long COVID has been on you?
- Whether health and care services met your needs?
- How you feel support could be improved?

Complete our survey:

https://www.surveymonkey.co.uk/r/HWiSLongCovid2022

Healthwatch is the public watchdog for those using health and social care services in Sussex.

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What we did

Our methodology

During August and September 2022, Healthwatch East Sussex, West Sussex and Brighton & Hove ran a public survey to gather resident's experiences of long COVID.

The questions were developed through reviews of existing long COVID research, and in collaboration with the Sussex long COVID Communications and Engagement working group (including PCASS staff).

Our survey was widely distributed through our newsletter, bulletins, social media, staff, volunteers and partner networks. This included long COVID peer-to-peer networks and fora.

Paper versions were available, with staff available to complete the survey online or over the telephone.

94 responses were received by the 25th September deadline. 42 in East Sussex, 38 in Brighton & Hove, 13 in West Sussex and 1 from outside Sussex.

This report summarises their experiences and identifies our findings and recommendations.

Please note that the percentages shown in this report are a proportion of all 94 respondents to the survey unless stated otherwise.

What we heard – Our key findings

- We heard that **long COVID symptoms varied widely**, and most respondents reported experiencing **more than one symptom**.
- The **most common long COVID symptoms** people experienced were **fatigue/extreme tiredness, brain fog and muscle/joint pain**.
- **Fatigue/extreme tiredness** was the **most common severe impact of long COVID**, making it difficult or impossible to do normal activities.
- Whilst **42.6% respondents experienced improvements** in their long COVID symptoms, for nearly a quarter (22.3%) they had got worse.
- **Long COVID impacted on the mental health** of 4 out of 5 respondents, with a third of them reporting a severe impact. The most common effects were **low mood, anxiety and insomnia**. Some experienced **depression**.
- Nearly half of respondents (46.8%) reported **a severe impact on their quality of life** as a result of long COVID symptoms.
- The most **common negative impacts** were on **physical wellbeing, stopping people doing things they enjoyed** and undertaking **key household tasks**.
- The long COVID support rated as **most helpful** were self-help, websites, GPs and the PCASS service. Those rated as **least helpful** were GPs, Hospital specialists and self-help/websites.

What we heard – Our key findings

- **Awareness of the PCASS service is relatively low**, with only a third of all survey respondents being aware of its existence.
- Of those seeking to use/using the **PCASS service**, **81.5% rated it as very helpful/helpful,** but only 50% identified that it improved their quality of life.
- **Challenges with obtaining referrals to PCASS** were identified as:
  - **a lack understanding of COVID symptoms and pathways for support**
  - **limited awareness of long COVID and PCASS amongst healthcare professionals**
  - **challenges in accessing timely appointments to primary care and onward referrals**
  - **delays in diagnostics and tests which may hinder long COVID diagnosis**
- The **long COVID symptoms of PCASS services users improved at a greater rate** than those for non-PCASS users (50.0% vs 40.3%), although a higher proportion indicated that they got slightly/much worse (31.8% vs 19.4%).
- Nearly half of our 94 respondents **(43.6%) were dissatisfied or very dissatisfied with local long COVID support** in Sussex. Only 10.6% were satisfied or very satisfied.
- The three most identified forms of long COVID support people wanted to see were **a dedicated long COVID clinic** (65.3%), **improved information for health professionals** (53.3%) and **improved information for the public** (44.%).

The impacts of living with long COVID

What you told us about symptoms…

How long COVID has affected you

Respondents told us they experienced a wide-range of physical symptoms. Most align with the common symptoms of long COVID reported by the Office for National Statistics and others. A breakdown of their symptoms is presented overleaf.

The **most common long COVID symptoms** our respondents experienced were:

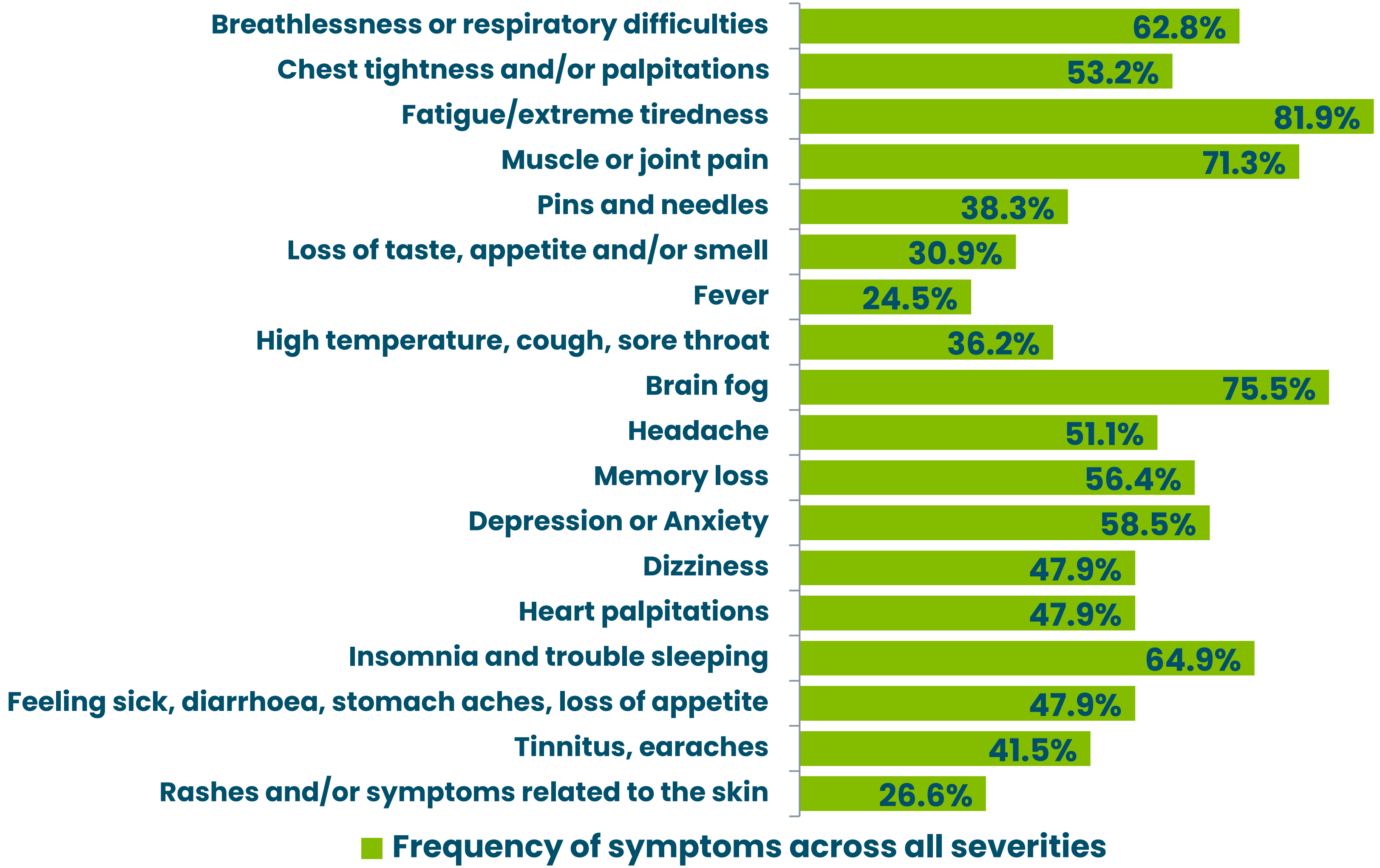
1. **Fatigue/extreme tiredness** (81.9%)
2. **Brain fog** (75.5%)
3. **Muscle or joint pain** (71.3%)

It is important to acknowledge that most respondents identified experiencing multiple symptoms due to long COVID. These also varied in frequency and severity.

We asked about the impact of long COVID symptoms on people's lives. They told us:

- **Fatigue/extreme tiredness (33.0%)** was the most common **severe impact** (makes it difficult or impossible to do normal activities)
- **Brain fog (39.4%)** was the most common **moderate impact** (makes it difficult to do normal activities)
- **Heart palpitations/Feeling sick (both 33.0%)** were the most common **mild impact** (does not stop me carrying out normal activities)

Which symptoms of long COVID are you experiencing, and what is their current impact on you?



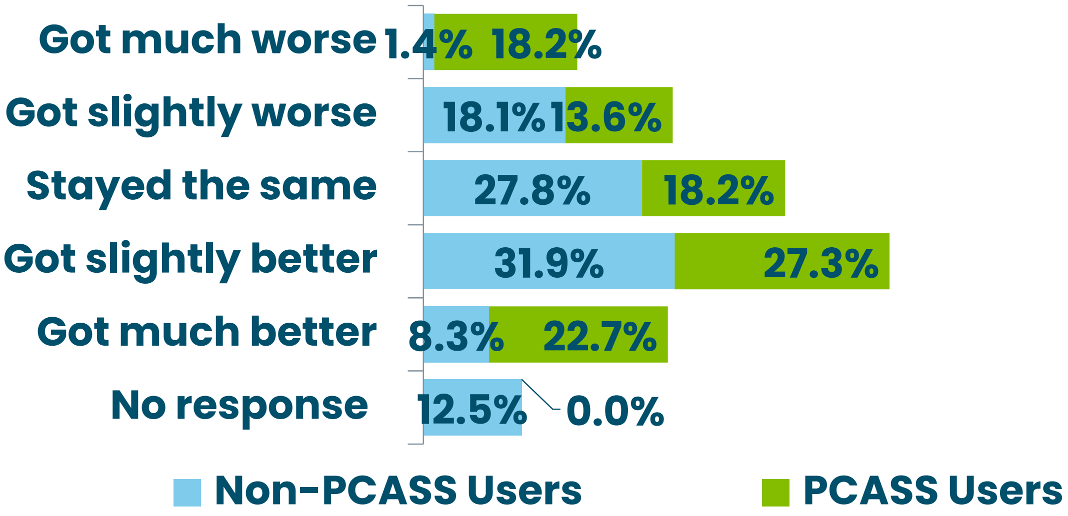
What you told us about symptoms…

How long COVID has affected you

When asked, **42.6%** respondents indicated that their **long COVID symptoms** got **slightly/much better**, **25.5% had stayed the same** and **22.3% got slightly/much worse**.

Overall, have your symptoms of Long COVID stayed the same or changed, either for the better or the worse?

Please tick one option only



Of the 22 people who had used the PCASS service:

50.0% got slightly/much better

18.2% had stayed the same

31.8% got slightly/much worse

Of the people who had **not** used the PCASS service:

40.3% got slightly/much better

27.8% had stayed the same

19.4% got slightly/much worse

What you told us about physical symptoms

“Loss of voice if talk for nearly ten minutes. Lose voice if talk intermittently if talk for 30 minutes. Mouth burns at night and tongue turns white - recovers to normal during daytime. Leg cramps at nighttime.”

“Hoarse voice - severely restricts talking. Photophobia - only comfortable with curtains closed. Frozen shoulder for 18 months - severe pain and restriction. Sore blurry eyes.”

“Severe pain behind eyes. Sensation of feeling there is something in my eye all the time. Eye(s) feel sore. Light sensitivity. Affects my well being and as I have a lot of screen time at work it becomes more aggravated.”

“Post exertional malaise. Affects me about 3 hours after anything mentally or physically strenuous for up to 2 days. Eyesight has deteriorated rapidly Loss of social engagement due to brain fog.”

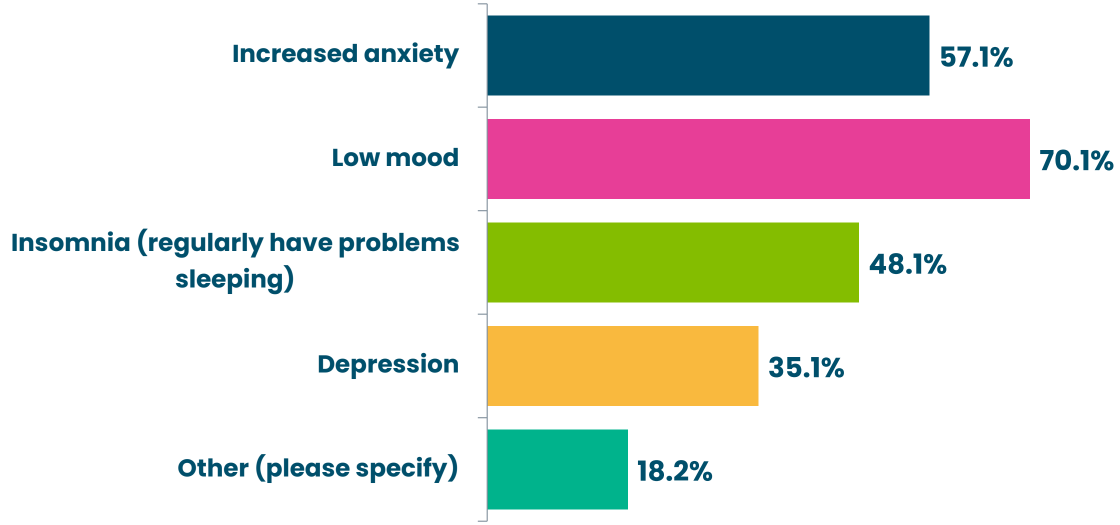
“I get the shakes - which may be described as palpitations? - usually when having a crash and particularly tired. It comes on often when dealing with people, such as talking, especially so to strangers or in busy places.”

What you told us about physical symptoms

What you told us about symptoms…

We asked about the impact of long COVID on mental health

If living with Long COVID has impacted on your mental health, please tell us in what way?
Please tick all that apply



77 of our 94 respondents (81.9%) indicated that living with **long COVID had impacted on their mental health**.

This took a variety of forms, with people often experiencing more than one mental health impact.

The **most common impact** was respondents reporting **Low Mood**, but approximately half also reported **anxiety** and **insomnia.**

Approximately a third (35.1%) identified suffering from **depression** due to living with Long COVID.

When asked about the overall impact of long COVID symptoms on their **mental health**, **37.2%** respondents indicated **a severe impact**, **30.9%** a **moderate impact** and **22.3% little or no impact.**

What you told us about emotional health

"Gone from feeling fine and able, to feeling weak and frail, not being able to pick up and hug my son, not being able to exercise, unexplained mood dips and bouts of fatigue plus not knowing if it's a lifelong thing ."

"Hopelessness, resigning to the idea that I will now never recover."

"Always wanting to sleep."

"Financially more precarious leading to anxiety about future."

"Unable to do activities loved previously."

"Feel a lot more stressed and tired as working is much harder."

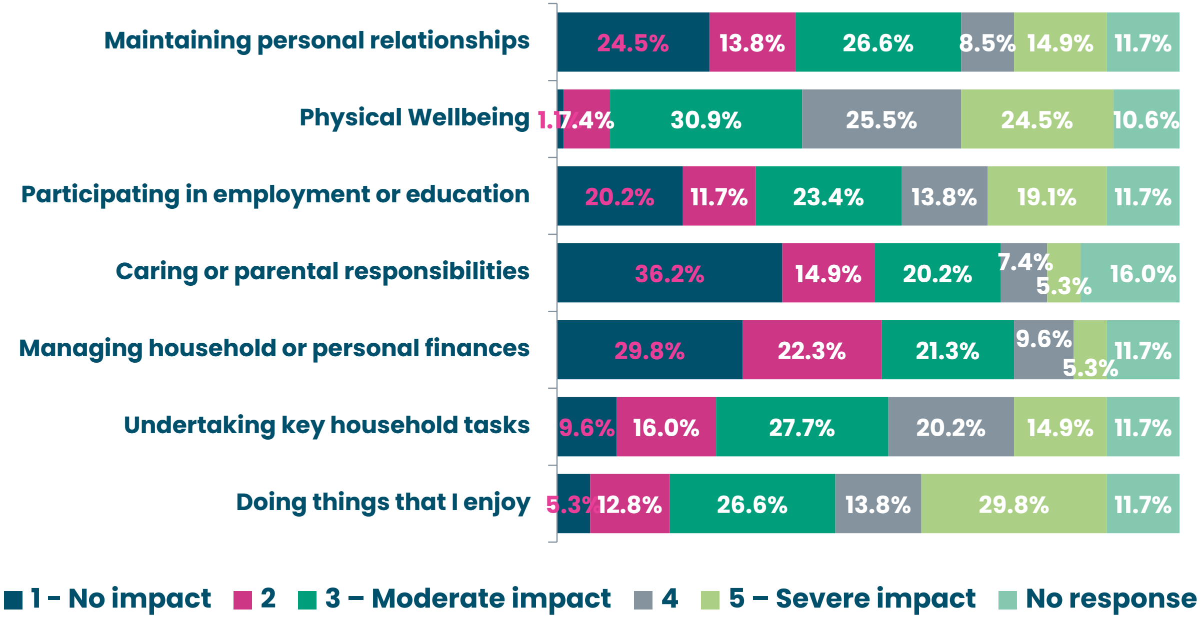
"Very jumpy and nervous (never used to be)."

"Periodic despair that will never be well again."

What you told us about symptoms…

We asked about the impact of long COVID and its symptoms

Please tell us about any negative impacts that living with Long COVID has had on the following areas of your life:
Please tick as many as apply to you



Long COVID symptoms may impact on people in different ways, depending on their make-up and severity.

The most common **severe negative impacts (rated 4 and 5)** of long COVID identified by respondents related to:

1. **Physical wellbeing** (50.0%)
2. **Doing things people enjoy** (43.6%)
3. **Undertaking key household tasks** (35.1%)

When asked about the overall impact of long COVID symptoms on their **quality of life**, **46.8%** respondents indicated **a severe impact**, **34.0%** a **moderate impact** and **8.5% little or no impact.**

Accessing support for long COVID

What you told us about support for Long COVID

Where have you sought support and how helpful did you find it?

We asked all 94 of our survey respondents about the long COVID support they had accessed or used, and how helpful they had found it. A summary of responses received is presented overleaf.

The long COVID support most rated as **Helpful/Very Helpful** were:

1. **Self-help**(52.1%)
2. **Websites**(48.9%)
3. **Your GP**(34.0%)

*The **PCASS service** was the fourth most common response (23.4%), which is broadly in line with the proportion of respondents we heard from who had used this service.*

The long COVID support most rated as **Unhelpful/Very Unhelpful** were:

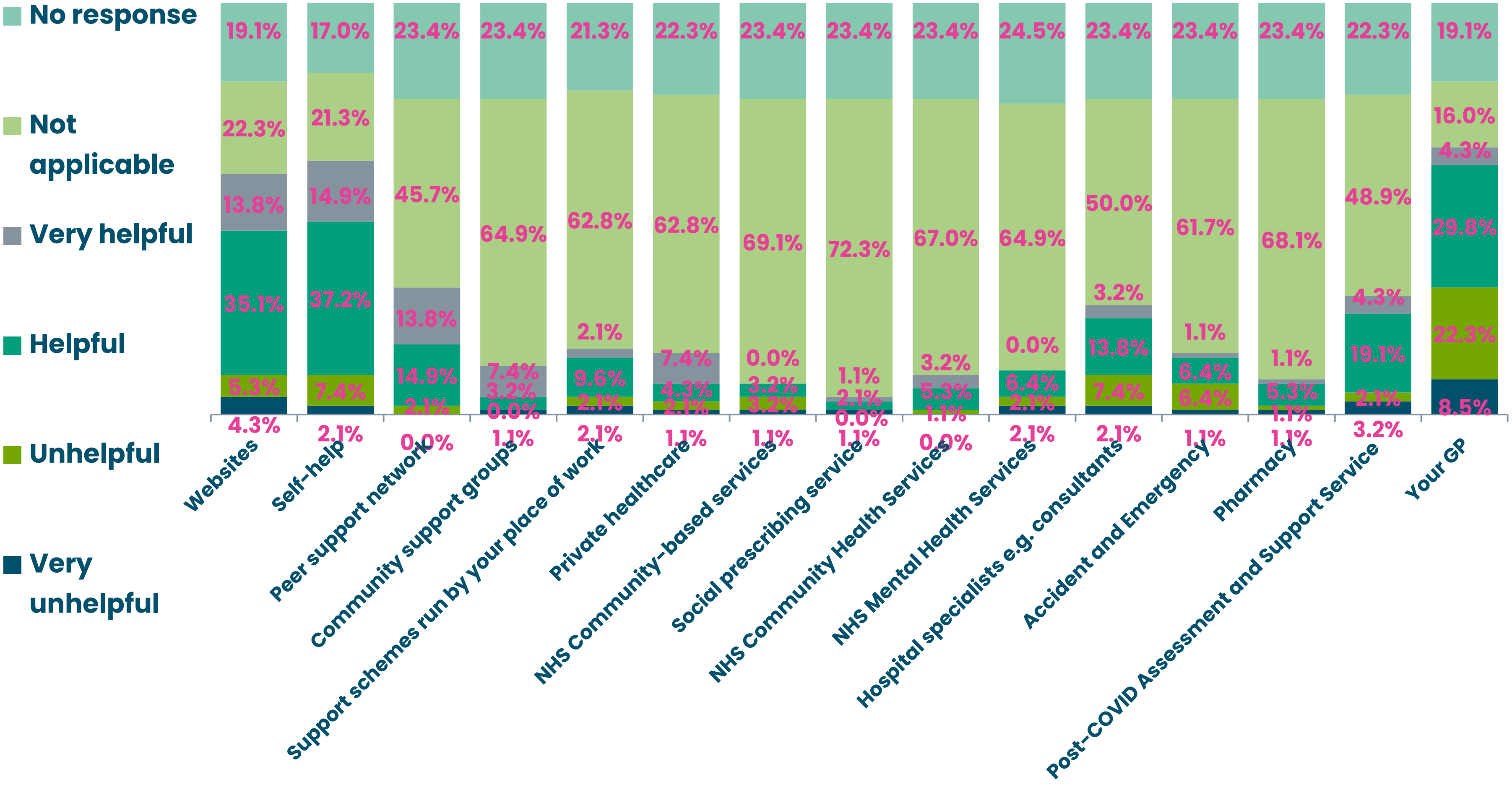
1. **Your GP** (30.9%)
2. **Hospital Specialists** (9.6%)
3. **Self-help/Websites** (both 9.6%)

It is important to acknowledge that the appropriateness of support may reflect respondent's symptoms, pre-existing conditions and their expectations.

When asked, **43.6% of all survey** respondents were **dissatisfied/very dissatisfied** with local long COVID support, with only **10.6%** being **satisfied/very satisfied**.

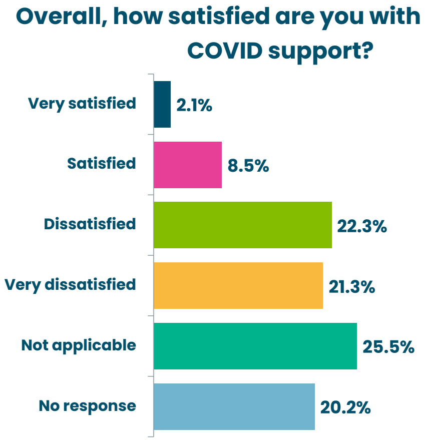
If you have sought support for long COVID, where from and how helpful did you find it?

Please tick all that apply



What you told us about support for long COVID

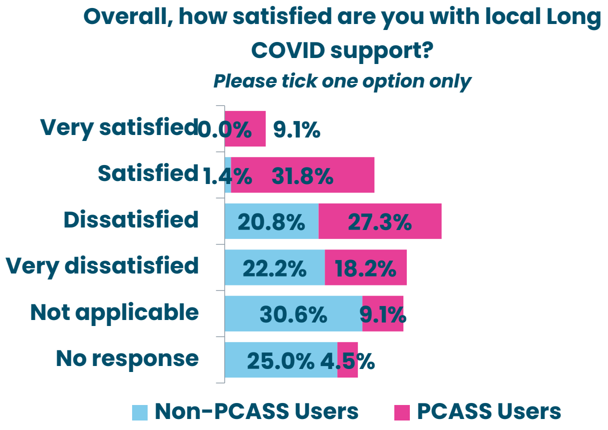
Overall, how satisfied are you with local long COVID support?



Of our 94 survey respondents:

10.6% were satisfied/very satisfied with local long COVID support

43.6% were dissatisfied/very dissatisfied with local long COVID support



Of the 22 respondents who had used the PCASS service:

40.9% were satisfied/very satisfied

45.5% were dissatisfied/very dissatisfied

Of the 72 respondents who had **not** used the PCASS service:

1.4% were satisfied/very satisfied

43.0% were dissatisfied/very dissatisfied

What you told us about support for long COVID

Where have you sought support and how helpful did you find it?

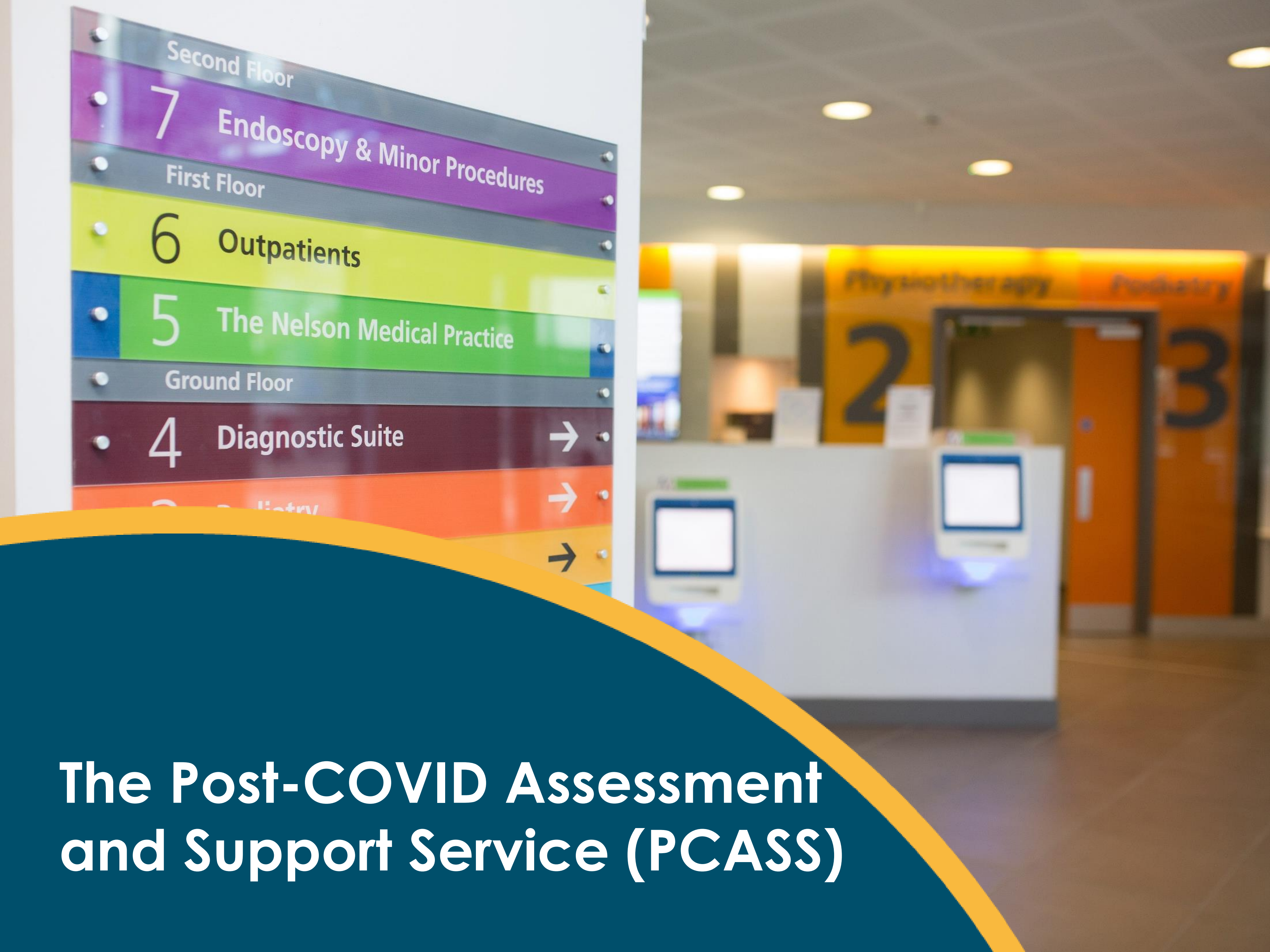
We asked all respondents about the long COVID support they had accessed or used, and how helpful they had found it.

Helpful/Very Helpful

- 72.7% of the 22 people managing to access the Post COVID Assessment and Support Service (PCASS) rated it as Very helpful/Helpful in responding to their symptoms.
- Peer support and engagement was identified as particularly valuable, especially that provided through social media channels and online fora.
- Websites were useful in helping understand more about long COVID and in finding local support, but respondents recognised issues in identifying robust information.

Unhelpful/Very Unhelpful

- Issues with health services and professionals [largely primary care staff] included: challenges in obtaining timely access to primary care appointments as a gateway to other support; perceptions that they had a limited understanding of long COVID symptoms and a limited awareness of PCASS and other support mechanisms amongst some non-PCASS staff.
- Whilst valued, only half of the PCASS service users we heard from indicated that it had improved their quality of life. It was often felt not to be sufficiently holistic or long-term.



The Post-COVID Assessment and Support Service (PCASS)

Post-COVID Assessment and Support Service

Awareness of PCASS

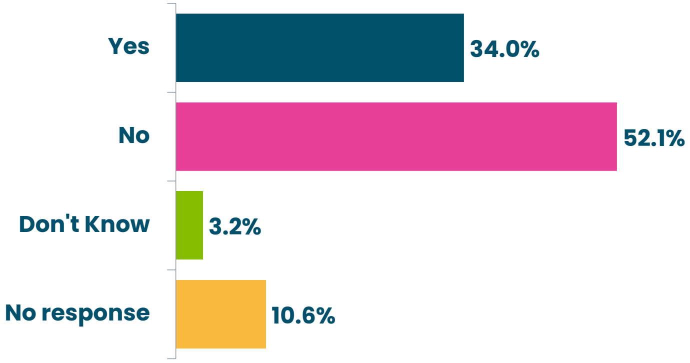
Of our 94 survey respondents, only a third (32) had heard of the Post-COVID Assessment and Support Service (PCASS).

Of those who had been referred to PCASS (22), approximately three-quarters (16) indicated they had been aware of it before they were referred.

These responses suggest awareness of PCASS may not be particularly high amongst the public, and this may extend to the health, care and wellbeing practitioners responsible for signposting or referrals. Sussex Health and Care has a comprehensive action plan in place to raise public and practitioner awareness.

However, referral rates may be higher where patients and practitioners have a greater awareness of it.

Have you previously heard of the Post-COVID Assessment and Support Service (PCASS)?



Of those respondents we heard from who had been referred to the PCASS service:

- 11 were from Brighton & Hove (out of 38 survey respondents from this location – 28.9%)
- 7 were from East Sussex (out of 42 survey respondents from this location – 16.7%)
- 4 were from West Sussex (out of 13 survey respondents from this location – 30.8%)

Please note that this figures indicate response rates and are not intended to be indicative of PCASS promotion or referral rates by place.

Post-COVID Assessment and Support Service

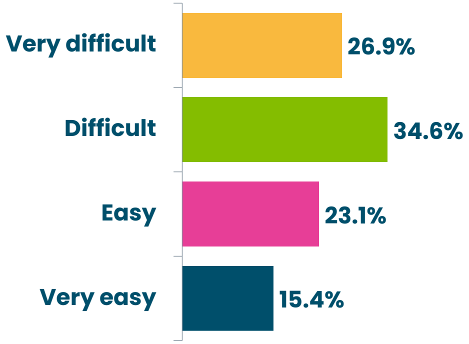
Access to PCASS

26 people told us about their experience of getting a referral to the Post-COVID Assessment and Support Service (PCASS).

Of these :

- **61.5%** felt it was **Very difficult/Difficult**
- **36.4%** felt it was **Very easy/Easy**

How easy or difficult did you feel it was to get a referral to the Post-COVID Assessment and Support Service (PCASS)?



Barriers to accessing the PCASS service were identified by respondents as including:

- A perceived **lack of awareness of long COVID symptoms** and **pathways for support** amongst healthcare professionals
- **Limited awareness of the PCASS service** amongst primary care practitioners
- Challenges in **timely access to appointments**, especially primary care
- Some **delays in diagnostics or tests** being carried out and results being received

Delays in referrals for PCASS had led some respondents to access alternative support, including paying for private diagnosis and treatment.

Barriers to accessing PCASS

"I had to push for my GP to do it she was reluctant for some reason. She never really believed me about my long covid and gave me some advice that made my symptoms even worse. It took her ages to actually refer me to the clinic. So pleased she finally did it."

"If this is the long covid clinic, I asked my GP to refer but they didn't know it existed then when they finally did (under duress) they failed to tell me for 5 months that the lc [LONG COVID] covid clinic had said they couldn't see me until they'd taken my bloods…in the end my private neurologist had to get involved."

"I tried to contact my GP about it several times and was not able to get through - I was referred by a nurse in the practice due to my difficulties breathing."

"Once I reached 12 weeks post COVID it was clear I had reached the next step on the plan and the GP knew what to do with me."

"…those in the frontline GPs, A and E consultants failing to recognise or be clued up on long Covid . it was going to a specialist that enabled progress."

Post-COVID Assessment and Support Service

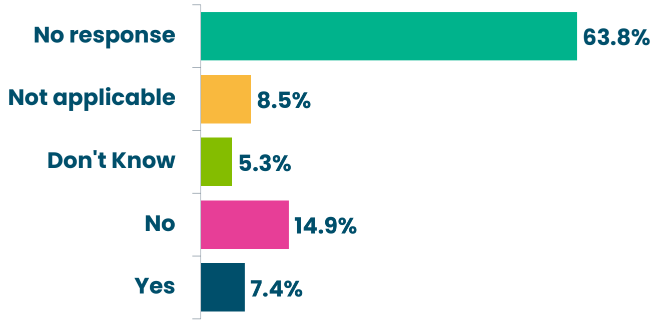
Support for Long COVID

Seven survey respondents to our survey (7.4%) told us that they had a request for a referral to the Post-COVID Assessment and Support Service (PCASS) declined.

The reasons provided included:

- Lack of awareness of the PCASS service amongst health and care professionals
- Not meeting the PCASS eligibility criteria
- Offered other support before a PCASS referral might be made
- Required further tests first
- GPs resisted or declined a referral
- Declined referral due to incomplete referral submission but accepted at subsequent attempt.

If applicable, have you had any request for a referral to the Post-COVID Assessment and Support Service (PCASS) declined?



> *"My first GP didn't really believe me about my long covid and took me several appointments for me to persuade her to refer me. She was reluctant saying 'you'll be waiting ages and it won't be worth it, sure you'll be fine by then'. I pushed her to do it and they got back to me within a few weeks."*

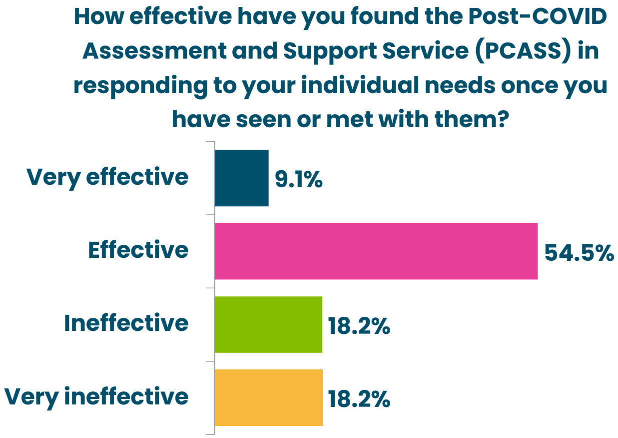
Post-COVID Assessment and Support Service

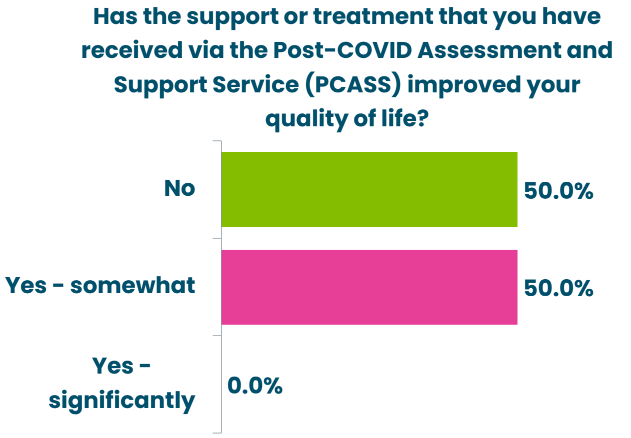
Support for Long COVID

Of the 22 respondents we heard from who had been referred to the PCASS service:

- **63.6%** rated its ability to respond to their individual needs as **Very effective/Effective**
- **36.4%** rated its ability to respond to their individual needs as **Very ineffective/Ineffective**

20 of the 22 PCASS service users we heard from (90.9%) rated the information and resources it had provided as Very easy/Easy to understand.





Half of the 22 users (50.0%) of the PCASS service we heard from told us that the support and treatment they had received had improved their quality of life ‘somewhat’.

However, 50% indicated that the support and treatment had not improved their quality of life.

Positive experiences of PCASS

"It was good to see I was not alone, and the support would be most useful to users."

"Supportive and made request to GP for further testing as chest pain/breathlessness exists after 21 months."

"Excellent. This service made a significant impact in my wellbeing in actively trying to support."

"Very useful. A shame that this multidisciplinary referral model hasn't be used for other health conditions."

"I finally felt understood and believed and was referred for testing."

"I had 2 phone consultations with a very helpful OT, who provided comprehensive written advice and asked my GP to refer me to the ME/CFS service."

"Generally ok. Though it does lean to the therapeutic talking treatments as opposed to solid physiological examination."

Negative experiences of PCASS

"Telephone assessment who referred me on to websites. Follow up chest appointment has taken 18 months."

"I was hoping for some kind of ongoing support, mentor, treatment services, but what I got was just advice I already knew."

"I haven't found it has made any difference to my experience of long covid."

"To be honest, I felt like I was as useful to them as they were to me! I already had a lot of information on things like pacing, therapeutic rest, and nutrition. The things the service talked with me about were reassuring - they confirmed for me that I was doing the right things already. They referred me to ENO Breathe, which was a good experience too, but I don't feel like either of those things were what has helped me slowly slowly regain my health."

"They still have not made contact with me I've currently been waiting 5 months - I have chased it up twice via my GP surgery but had no response."

"They told me what I knew that I had extreme fatigue and told me what I had already found out from the internet."

Post-COVID Assessment and Support Service

Support for Long COVID

We asked respondents who has used the PCASS Service for their views on any changes they felt would improve it now or support its evolution moving forwards. They identified:

- **Raising awareness** of the PCASS service amongst the public and health practitioners and clarifying in more detail what it can and cannot offer. Greater highlighting of its role in providing information and referring to services rather than offering treatment itself.
- **Simplifying the referral process** (format and timescale) so people can get access to PCASS as soon as possible and it is easier for GPs to refer them.
- **Face-to-face appointments** where appropriate, and the provision of video appointments as an option alongside phone calls.
- **A long COVID clinic** where more robust examinations and testing can be carried out by specialist clinicians on those most severely affected by Long COVID, either in terms of impact or duration of their symptoms.
- **Longer-term support** for those experiencing long COVID symptoms for extended periods of time.
- **A holistic approach to people's needs** which considers people's wider needs and support referrals and signposting to other aspects of support e.g. finances, mentoring, peer networks.

Preferred forms of long COVID support

Preferred support for Long COVID

Which services or follow-up assistance and care would be most helpful in meeting your long COVID related needs?

We asked all 94 survey respondents about their preferences for support which would help meet their long COVID needs. A breakdown of the responses received is provided overleaf.

The three most identified forms of long COVID support that people would like to see were:

1. **A dedicated long COVID clinic** (65.3%)
2. **Improved information about long COVID for health professionals** (53.3%)
3. **Improved information about long COVID for the public** (44.0%)

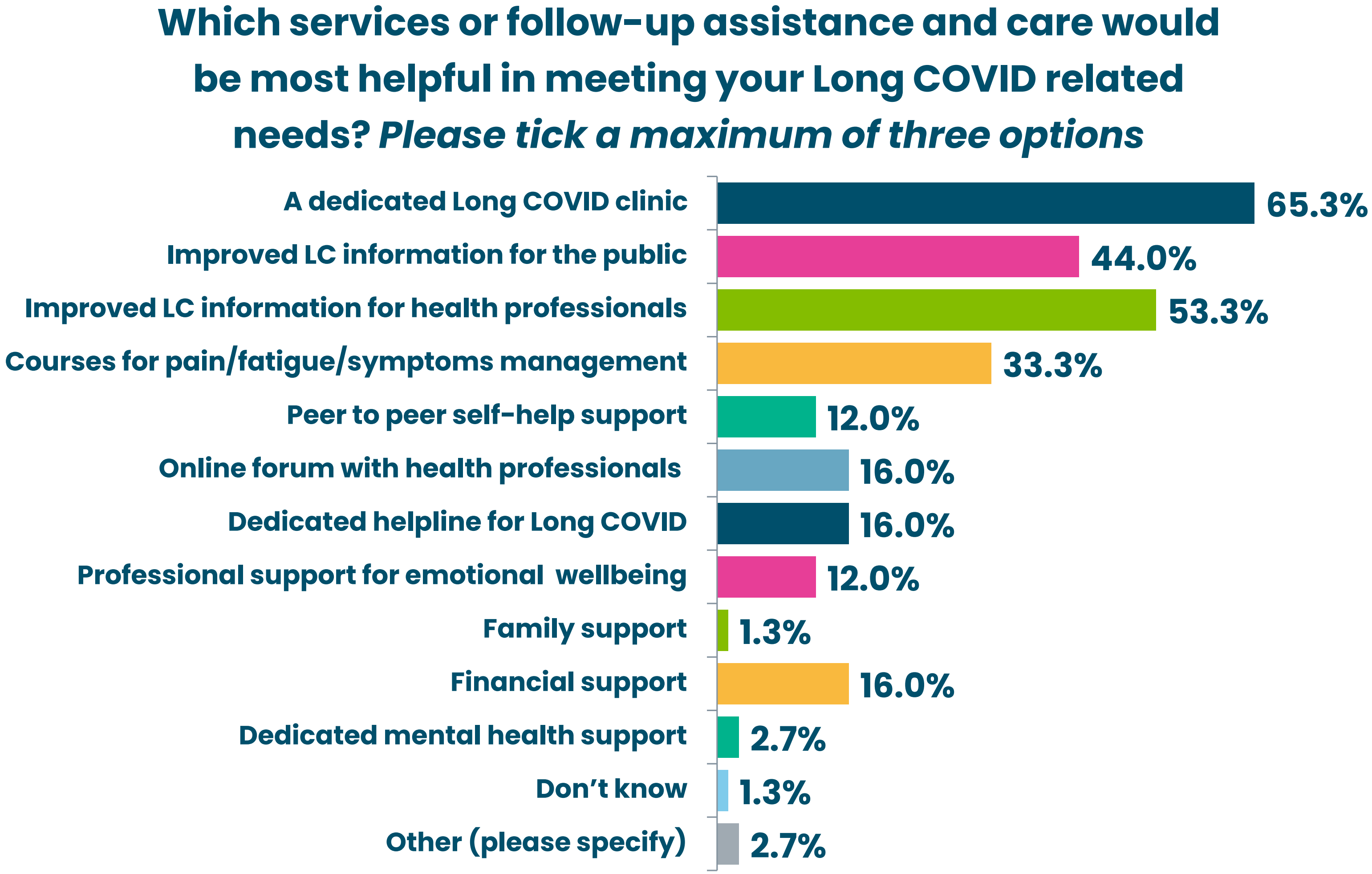
A third of respondents (33.3%) identified a preference for **courses for pain/fatigue/symptom management.**

Other responses also identified the need for improved access to information related to Long COVID, such as a **dedicated long COVID helpline** (16%), or an **online forum** to facilitate discussions with health professionals (16%).

16% of respondents indicated that **financial support** was needed to help people manage with reduced incomes whilst experiencing the symptoms of Long COVID.

When asked, **41.5%** respondents were **Very likely/Likely** to participate in a peer support group for long COVID if one were established, with **30.9%** being **Very unlikely/Unlikely**.

Preferred support for Long COVID



Effective support for long COVID

In your opinion how could the support for those with long COVID be improved?

Respondents told us about the effectiveness of the different forms of support for long COVID and how they felt it could be improved.

Some responses replicated suggestions for PCASS (see slide 28). The three key issues most regularly highlighted by respondents to the whole survey included:

1. **Greater awareness, understanding and recognition of long COVID** across the whole health and care system but especially in primary care, and by other public sector organisations e.g. local authorities, government departments and agencies.
2. **Dedicated support** for those experiencing significant or debilitating impacts as a result of long COVID symptoms. This should include assistance beyond the treatment or management of physical symptoms, for example, additional wellbeing support.
3. **Flexibility of support** and a recognition that each person may experience long COVID differently, and that this may change over time. This may include providing access to support mechanisms over an extended period and providing access to different services at different points in the journey.

Whilst not a solution in its own right, **peer-to-peer support**, both face-to-face and virtual, was valued as it allowed people to share experiences without any fear of stigma. This support was also holistic in nature and allowed the sharing of information on symptoms, treatments as well as advice on employment, finances etc.

Effective support for long COVID

"Long covid is very different for everyone - for some breathing is an issue. For others, fatigue and autonomic dysfunction is an issue. Any service needs to reflect these differences. It also needs to be so much more than the 'your covid recovery' booklet."

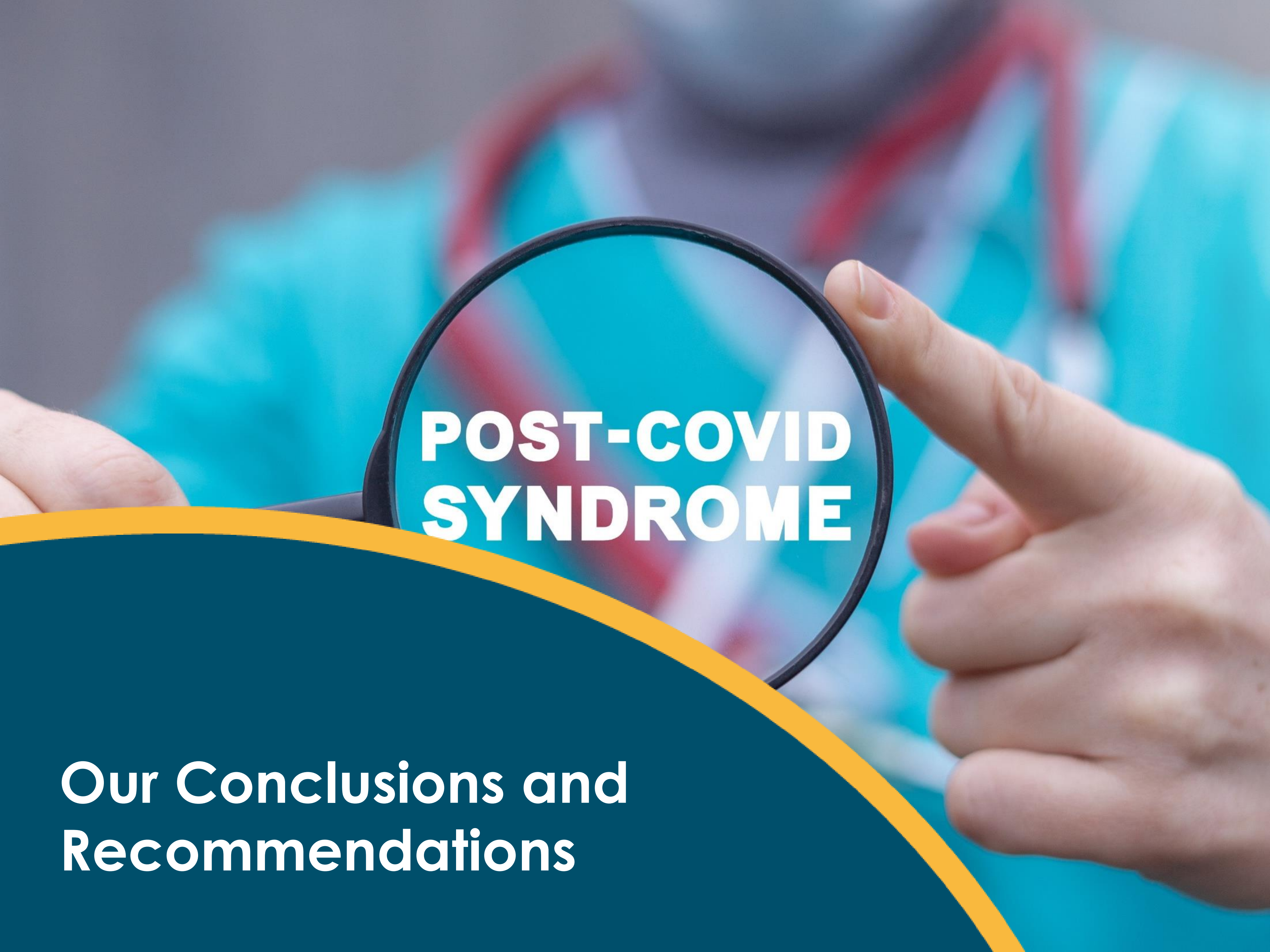
"Recognition that our symptoms are many, real although not medically proven, come and go and fluctuate for no reason and not all of us maintain progress. Provide face to face support and continuity."

"I liked the idea of long covid support clinics which would at least help with the feelings that you are going mad."

"Financial. Having Covid and Long Covid as a freelance worker has completely ruined me. There's no support to pay mortgages and little otherwise."

"More information for GPs - each GP surgery should have a long covid expert. More resources for long covid clinics."

"More clinics addressing physical and mental health, education of Healthcare professionals and public. Dedicated well funded and prompt services."



Our Conclusions and Recommendations

Conclusions

Complexity of long COVID

Our findings indicate that long COVID is a complex theme. We heard that people experience diverse symptoms and these have wide-ranging impacts on their physical and mental wellbeing, as well as wider effects on their lives such as work and finances. Tailoring treatment and support can therefore be complicated. Lower rates of COVID testing may also be impacting on links between ongoing symptoms and COVID 19 infections.

Some people experience severe long COVID symptoms over extended periods of time, which can be problematic to respond to as there is currently no long-term dedicated mechanism available to support them. We heard frustration that there appeared to be limited recognition of this, and that local responses to long COVID felt rather more rigid and piecemeal, than holistic, flexible and co-ordinated.

Awareness of long COVID

Whilst public awareness about long COVID appears to be increasing, it still seems relatively low, and this may hinder people in seeking a prompt diagnosis or support, especially where symptoms are diverse, change over time or are masked by an existing condition. Similarly, anecdotal responses suggest that awareness and understanding of long COVID amongst some health professionals (especially in primary care) is variable, leading to mixed experiences in receiving diagnoses, tests or additional support, including referrals to the Post Covid Assessment and Support Service (PCASS).

Challenges in accessing services and barriers in securing a diagnosis have led some people to focus on self-help and peer-to-peer support. Respondents identified that this provided an ability to secure emotional support, as well as greater awareness of treatments that may be outside the scope of those offered through the NHS.

Conclusions

Local support for long COVID

Responses to our survey indicated that a majority of people were not happy with the effectiveness of the support available locally for Long COVID.

PCASS is a key local response to long COVID which provides valuable and effective support to many, but not to all, especially where needs were complex or longer-term. Its effectiveness also appears to be hindered by a reliance on other services for referral and for delivery of the treatment and support.

It is still early days in the provision of responses to Long COVID, but consideration should focus on how to provide a flexible and diverse package of support, which is able to respond to their physical and mental wellbeing, but also to assist them in living with and managing Long COVID, especially on an ongoing basis.

More could be done to improve the quantity, quality and accessibility of information provided to the public and health professionals around Long COVID. In parallel, action should be taken to expand self-help resources, including non-NHS services, and to expand dedicated expertise, especially amongst primary care services.

Long COVID support moving forwards

Many of our findings are addressed in headline terms by the updated NHS Long COVID Plan published in July 2022 which clarifies the need for improved awareness and education about Long COVID, improved clinical pathways and patient support and the need to acknowledge the impact of long COVID on every aspect of people's lives.

NHS Sussex and other members of The Sussex Integrated Care System (ICS) should consider our findings within this context and in evolving and implementing the support for long COVID locally.

Recommendations:
Sussex Integrated Care System (ICS)

1. Awareness of long COVID needs to be significantly increased amongst the public and professionals. Diverse communication channels, local networks and engagement with local stakeholders should be used to raise and sustain this awareness. Messaging should focus on clarifying how-to: recognise symptoms, self-manage impacts and to get support.

2. Commissioners should ensure that robust training, information and support should be provided to primary care clinicians on Long COVID, including its symptoms, impacts, treatment and local support pathways (including PCASS) with the aim of appropriately identifying and supporting people potentially experiencing long COVID. An emphasis should be placed on achieving consistency in diagnosis and referral to long COVID support services.

3. Commissioners should ensure that support for long COVID is holistic and able to cater for people with diverse or non-traditional symptoms. This may include the provision, resourcing or co-ordination of alternative forms of assistance for those experiencing long COVID. For example, a dedicated long COVID clinic, development of peer support groups, or further support for Primary Care Networks (PCNs) in co-ordinating long COVID responses.

4. The ongoing development of locally tailored self-help resources linked to long COVID is required. A central repository of robust, accessible and appropriate information should be made available and promoted to support symptom awareness, self-management and access to support, but also wider impacts of long COVID on people's lives e.g. debt, employment advice. These should be made available publicly, through PCASS and via GPs.

Recommendations: Post Covid Assessment and Support Service (PCASS)

5. Work should be undertaken on an ongoing basis to increase and sustain awareness of the local long COVID support available amongst primary care professionals, especially GPs. This could include regularly communicating uptake of PCASS, service development and positive feedback and outcomes to GPs and Primary Care Networks.

6. A 'lay review' of the public-facing information on the PCASS service should be undertaken to assess its quality, clarity and accessibility. Patient Participation Groups could play a role here.

7. 'Long COVID' event(s) or training session(s) could be organised to bring together different professionals, services and stakeholders to share experiences and inform local provision.

8. Information and signposting for community activities, peer support and other non-NHS services which may assist with long COVID management or recovery should be regularly reviewed to ensure that they are up-to-date and accessible.

9. Feedback should be regularly captured from users of the PCASS service in order to ensure the service is meeting their needs, delivering appropriate outcomes and that their experience of accessing and using the service is consistent. This information should be used to inform the provision of both PCASS and other long COVID support.

10. Evolution of the PCASS service should closely consider patient and user preferences, including a desire for face-to-face interaction with health professionals (long COVID clinics) and assistance with peer-to-peer support (facilitation, signposting, resourcing).

Recommendations

Public Health Teams

11. Public health teams should monitor data around the prevalence and nature of long COVID within the Sussex population on an ongoing basis, in order to support NHS commissioners and providers in tailoring long COVID support to the appropriate communities and socio-demographic groups.

12. Public health teams could explore the potential for a ‘deep dive’ into long COVID in Sussex with the goal of better understanding its symptoms and impacts at a local level, and informing the provision of appropriate responses.

Healthwatch

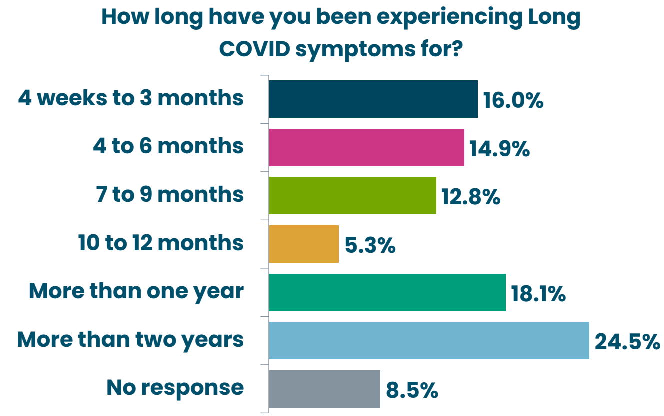
13. Healthwatch should liaise with NHS Sussex to explore the scope for capturing feedback from health professionals on their experiences of long COVID diagnosis and referral processes.

14. Local Healthwatch should monitor public and patient feedback on long COVID (including use of the PCASS service) in Sussex and share experiences with commissioners and providers to guide to the provision of equitable and accessible services.

15. Local Healthwatch will share insight and reports on long COVID with Healthwatch England and contribute to a national repository of intelligence on this theme.

Who did we hear from?

Characteristics of our respondents



90 respondents completed the survey on their own behalf, with four on behalf of other people (none as carers).

76.6% of respondents indicated they had received a positive COVID-19 test result, but 19.1% had not.

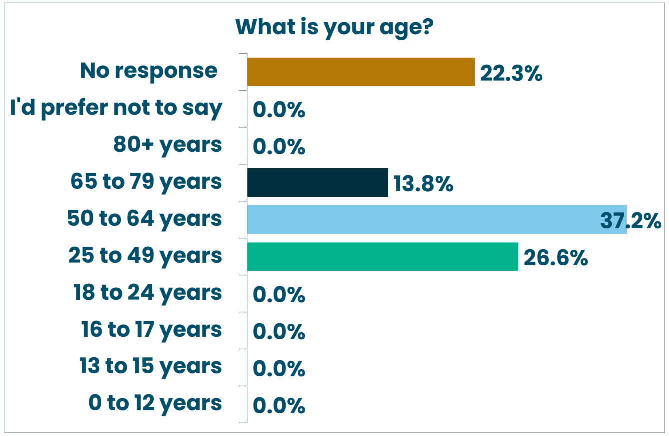
Approximately a third of those responding (37.2%) had a disability or long-term health condition before they contracted COVID-19. The most common of these were long-term health conditions (19.1%) or physical or mobility impairments (9.6%).

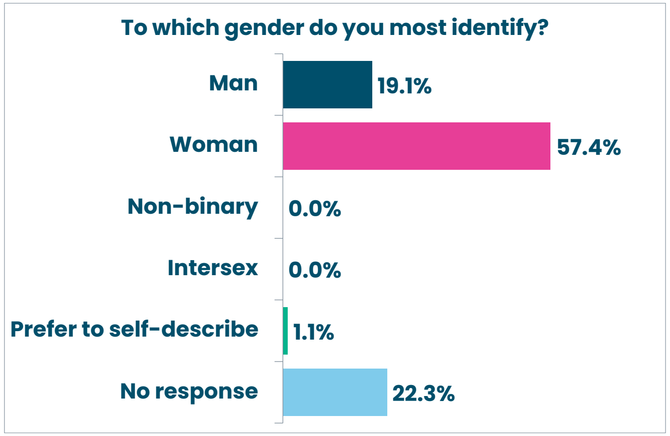
48.9% of our respondents had experienced long COVID symptoms for a year or less,18.1% for between one and two years and 24.5% for more than two years.

Just over a third of the people we heard from had been (36.2%) had been formally diagnosed with long COVID by their GP.

Who did we hear from?

An equalities breakdown of our 94 respondents is provided below:





- 0.0% respondents were aged under 18, 63.8% were between 19 and 64 with 13.8% over 65. 22.3% *did not respond*.
- Most respondents identified as a woman (57.4%).
- 76.6% respondents had the same gender identity as the sex they assigned at birth.
- 61.7% identified their sexual orientation as Heterosexual/Straight, with 5.3% as Bisexual.
- 66.0% identified as White: British / English / Northern Irish / Scottish / Welsh, with 6.4% as an 'Other' White background.
- 33.0% respondents identified as having 'No religion', 27.7% respondents were Christian and 6.4% 'Preferred not to say'.
- 42.6% were married, 14.9% were single and 7.4% were co-habiting.
- 0.0% were currently pregnant, breastfeeding or had given birth in the last 26 weeks.
- 57.4% had a disability.
- 14.9% were carers.

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healthwatch

Post COVID Assessment and Support Service (PCASS)

Addendum to Healthwatch report – March 2023

The public and community

You said:

- Awareness of long COVID needs to be significantly increased amongst the public.
- There should be a lay review of public facing information to assess its quality, clarity and accessibility including information and signposting for community activities and non-NHS services.

We did:

- The programme has used a variety of communications and engagement strategies to increase public awareness of the pan Sussex long COVID services, centred around the symptoms to watch out for and how to get support. This includes continually updating our patient facing websites, creation of an explainer video, a podcast and use of social media. Resources have been produced such as posters, leaflets and digital screens for patient facing areas. Materials we have made for patient facing areas are on the Sussex Health and Care website.
- We have dedicated public involvement professionals completing engagement work and we have two community ambassadors who have supported our service for 14 months, adding the patient perspective to the programme of work. We are planning a Patient Reference Group which will add the voice of patients with lived experience. Volunteer readers check all our communications, and we also have translations and easy read versions of all documents available. The chairs of Sussex's Patient Participation Groups have all been consulted and updated on the service developments.
- We are working on targeted social media messaging for underserved groups and to target specific demographics according to location and age. An enhanced Spring campaign is planned for more public involvement, as winter pressures ease.

Services

You said:

- Support for Long COVID should be holistic and able to cater for people with diverse or non-traditional symptoms, including alternative forms of assistance for long COVID such as a dedicated long COVID clinic.
- Feedback should be regularly captured from users of the PCASS service to ensure the service is meeting their needs.
- The PCASS service should closely consider patient and user preferences, including a desire for face-to-face interaction with health professionals (Long COVID clinics) and assistance with peer-to-peer support (facilitation, signposting, resourcing).
- A central repository of robust, accessible, and appropriate information should be made available and promoted to support symptom awareness, self-management, and access to support, but also wider impacts of Long COVID on people's lives e.g. debt, employment advice. These should be made available publicly, through PCASS and via GPs.

We did:

- PCASS is a therapy led service, based on need, rather than a medical model, using a holistic, personalised approach. Immediately after referral patients are given a waiting well pack with bespoke tailored self-management advice and material and advised of their appointment date for their initial assessment. Waiting times from referral to initial assessment are currently four weeks, within the national target of six weeks. This assessment can last up to one hour and is designed to identify the requirements that the patient has, then further personalised support is flexibly designed for the patient to suit their specific needs. Everyone has a choice between a video or phone call. The patient would then usually have a three-month period of self-management, aiming to put the agreed measures in place. At the three month follow up, if people still need further help, they are offered options to join four rehabilitation pathways, which are breathlessness, cognition, vocational support (to assist with return to work and employment issues) and fatigue. This is all underpinned with psychological support to aid understanding and acceptance of their condition and support them to improve. Most therapies can be offered virtually, in groups or 1:1 depending on the clinical need. Patients can move between the pathways in a flexible and coordinated way, supported by a care coordinator, which is important due to their often complex symptoms. There is no one-size-fits-all and personalised approach is maintained at all times.
- A dedicated care coordinator supports the patients as they navigate through the service, as they often remain within it for many months taking advantage of the different therapies. They also signpost to Social Prescribing Link Workers in primary care who can help facilitate and signpost patients with wider aspects of people's lives such as debt management, housing etc.
- Feedback is collected at every patient contact through formal outcome measures and from general feedback, which is reviewed and acted upon by the clinical teams. The service has been set up with a 'personalised' approach with a patient focus on 'what matters to me?' All

aspects of feedback are reviewed and acted on as part of a process of continual improvement.
- Patients will have a 3-month review and a final review at discharge. Following this, Patient Initiated Follow Up (PIFU) allows their case to be kept open for a further three months if they need further advice and support and want to refer back in.
- Feedback on patients' experience is sought through the Friends and Family Test and smart surveys. Due to limited responses, two additional health confidence questions are asked at every interaction and responses captured. The services are implementing a scale called C19-Yorkshire Rehabilitation Scale to collect enhanced information for further service feedback as a part of continuous improvement.
- All qualitative feedback is reviewed by both teams and actions are taken as a process of continual improvement.
- We are constantly reviewing whether there are any further holistic, flexible, and co-ordinated therapies that we can offer to patients to support them more widely.
- We understand that peer support is very powerful for sharing experiences and support regarding symptoms, treatments, as well as advice on employment, finances etc. We are considering a Sussex wide self-management peer support offer for all patients with long term conditions.

Professionals

You said:

- Robust training, information, communication, and support for PCNs should be provided to primary care clinicians to achieve consistency in identifying symptoms, providing self-management support, diagnosing, supporting and referring to long COVID support services.
- Increase and sustain awareness of long COVID support to primary care regarding service uptake and development and positive feedback and outcomes.

We did:

- PCASS, set up in January 2021, is a dedicated, therapy led clinic for long COVID with strong clinical leadership and medical oversight from a service GP and Respiratory Consultant. The programme team has collaborated closely with primary care throughout, gaining feedback on processes, which have been adapted accordingly and improved.
- Using our experience and evidence from treating nearly 3,500 patients over 2 years, we have been running a continuous internal communications campaign to promote symptom recognition and increase referrals, including webinars, briefings, bulletins, case studies, circulation of data and information to advertise the service to General Practice staff and additional roles, such as social prescribing link workers, as well as secondary care. We have also connected with wider stakeholders such as the Voluntary and Community Sector, Borough councils, Public Health and Citizens Advice, for example. We have been able to create some communication tools to be used in a wide range of media for professionals

shared on our intranet sites. Two years on, we are now able to share patient outcomes, which are positive.

- We are working with the NHS England team who are championing wider research through the Office of National Statistics data to complete ‘active case finding’ to find the people that are not coming forward into the service.
- We are thinking creatively as to how we can increase access to the service based on our experience to date.

Public Health

You said:

- Public health teams should monitor data around the prevalence and nature of Long COVID within the Sussex population on an ongoing basis, in order to support NHS commissioners and providers in tailoring Long COVID support to the appropriate communities and socio-demographic groups.
- Public health teams could explore the potential for a ‘deep dive’ into Long COVID in Sussex with the goal of better understanding its symptoms and impacts at a local level and informing the provision of appropriate responses.

We did:

- We have liaised with the Public Health team with the aim of working with them in a complementary way on health promotion initiatives for long COVID.
- We are working with Public Health Intelligence specialists to identify GP encounter data with long COVID SNOMED codes, via the Sussex Integrated Dataset, comparing this to data from our services to seek further intelligence on impacts at a local level.

For further information, please contact charlotte.rogers12@nhs.net, Long COVID Programme Manager, Sussex Health and Care.