

Experiences of long COVID in Sussex

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1 Context and aims

1.1 Background

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

As part of a programme of activity to explore the 'restoration and recovery' of health and care services after the COVID-19 pandemic, the three Sussex Healthwatch (Brighton & Hove, East Sussex and West Sussex) sought to better understand the longer-term impacts of COVID-19 infections, including people's experiences of support in managing ongoing symptoms and the wider impacts on their day-to-day lives.

Our research was focused on 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.

We were particularly keen to learn about its impact on people's everyday lives, their experiences of engaging with health and other support services and their views on what effective support for those with long COVID could or should look like.

1.1.1 What is long COVID?

Long COVID is a relatively new and evolving condition brought on by 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. It can also have wider effects on people's livelihoods and day-to-day lives, and as such presents challenges for the NHS, other services and wider society.

Long COVID commonly refers to symptoms that continue for more than four weeks after a confirmed or suspected coronavirus (COVID-19) infection, which are not explained by something else. More detail on long COVID and commonly recorded symptoms are set out in Appendix 1.

Given that more than 600,000 people across Sussex have contracted COVID-19, it is likely that long COVID will affect the longer-term wellbeing of at least some of our population, both now and in the future.

The [Post-COVID Assessment and Support Service](#) (PCASS) has been established to support those experiencing ongoing symptoms of a COVID infection for more than four weeks. Further details of the service's role, who delivers it in Sussex and how it operates are set out in Appendix 2.

1.2 Context to our research

This report presents the findings from the second of a two-part engagement exercise exploring the experiences of long COVID on people's lives.

In March 2023, Healthwatch [published its findings](#) from the first-part, which were the results from a Sussex-wide public survey on people's experiences of long COVID undertaken in late 2022.

Our phase one long COVID survey heard the following:

- Long COVID symptoms vary widely, and many people experience more than one symptom. Fatigue/extreme tiredness was the most common severe impact, making it difficult or impossible to do normal activities.
- The mental health of four out of five of our respondents was affected by long COVID, with a third of these reporting a severe impact. The most common effects were low mood, anxiety and insomnia.
- Nearly half of the people we heard from (46.8%) reported a severe impact on their quality of life because of long COVID symptoms, with changes including severe restrictions on mobility, extreme fatigue, loss of employment and a need for regular carer support.
- The Post-COVID Assessment and Support Service (PCASS) delivered by the NHS in Sussex (established in 2021) was viewed as helpful by a majority of those referred to it, but public and practitioner awareness of it needs to be raised, as does long COVID more generally.
- The three changes most respondents wanted to see were a dedicated long COVID clinic with clinicians providing COVID-19 specific treatment (rather than referral to mainstream services via PCASS), improved information for health professionals and improved information for the public about long COVID.

This second research activity involved undertaking qualitative engagement to explore the themes and issues raised above in more detail, particularly on the impacts on people's lives and experiences around managing their symptoms and accessing support.

We used semi-structured interviews (via phone) to engage with a small cohort of individuals who had completed the Healthwatch in Sussex long COVID survey and who had given permission to be contacted for further follow-up.

1.3 Our aim and objectives

Our aims were to:

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

2 Methodology – What did we do and how?

2.1 Our approach

A total of 46 respondents to our long COVID public survey indicated a willingness to participate in follow-up conversations to explore their views and experiences in more detail: 23 from Brighton & Hove, 16 from East Sussex and 7 from West Sussex.

We used semi-structured interviews to engage with 16 of the survey respondents who had shared their details and provided consent for us to contact them. Seven were from Brighton & Hove, six from East Sussex and three from West Sussex.

Follow-up interviews focused on two main cohorts, those who have used the Post-COVID Assessment and Support Service (PCASS) service and those who have not. We interviewed seven individuals who had used the PCASS service, and nine individuals who had not.

We gathered experiences of people with a breadth of experience of long COVID and treatment pathways, including those requiring support from the PCASS service, seeking support from Primary Care, receiving support in the community and those who had never reached out and who were managing symptoms on their own.

2.2 Our lines of enquiry

Our lines of enquiry were developed using the findings from our long COVID survey, as well as through discussions with colleagues at NHS Sussex, including those responsible for commissioning and delivering the PCASS service.

We focused on exploring several *golden threads* with both cohorts of interviewees, including:

- Symptoms and impacts on physical and mental wellbeing
- Ease of diagnosis with long COVID (if applicable)
- Support sought and accessed from health, care and other services
- Effectiveness of any long COVID support accessed/used

- Preferences for changes or developments to long COVID support.

In addition, PCASS users were asked:

- Their experience of referral and access to the PCASS service
- About differences it has made to their long COVID symptoms/quality of life
- How they feel the service and/or support may be improved locally.

2.3 The interview process

Interviews were conducted via phone during May 2023 by two experienced Healthwatch volunteers. Participants from the survey were contacted and their willingness to be interviewed were confirmed, with a preferred date/time organised for the interview to take place.

Each volunteer only engaged with one cohort, one with PCASS users and the other with non-PCASS users. A standard set of questions were used to guide the discussions with each cohort to maximise uniformity in the approach, but flexibility on follow-up questions was provided to allow for a detailed discussion of themes.

Further details of the specific interview questions used for each cohort are set out in Appendix 3.

Responses and comments from each interviewee were recorded and uploaded to a digital survey platform on an anonymised basis to safeguard the anonymity of the interviewees during data collation and analysis.

We sought to engage with a cross-section of individuals with a mix of gender, age, and place of residence. However, to an extent this was governed by those willing to participate. A summary of interviewees headline characteristics is below:

Brighton & Hove	East Sussex	West Sussex
7	6	3

Aged 25 to 49	Aged 50 to 64	Aged 65 to 79
7	6	3

Man	Woman	Self-identify
7	8	1

3 Key findings and themes

3.1 Impacts of living with long COVID

3.1.1 Quality of life

We heard about the extent to which the ongoing effects of a COVID infection affected people's lives. Nearly everyone we spoke to self-identified the severe impacts of long COVID on them, both directly on their physical health, but also the wider knock-on effects on their day-to-day lives (including their household, family and employers), both of which regularly had an impact on their mental wellbeing.

Often, our interviewees were themselves shocked by the scale of the effects and legacy of COVID-19 on them. Changes included restriction in their ability to work and occupy appropriate employment, undertake basic household tasks, and engage in social, cultural and physical activities that contribute to fulfilling lives.

Several interviewees described the impact as 'life changing', highlighting how significantly their lives had altered, with several going from fit and extremely active individuals to people whose ability to live engaging, dynamic and varied lives was now restricted.

3.1.2 Physical wellbeing

People told us how their physical wellbeing had been fundamentally changed by long COVID. Several had been severely affected, going from extremely fit and active individuals able to run, walk and exercise regularly, to the point where these were no longer activities they could pursue. Increased fatigue and reduced mobility were common themes identified by participants.

Interviewees described feeling 'old before their time', due to a combination of factors such as rapid fatigue, lack of energy, breathlessness and forgetfulness. Some also experienced joint/nerve pain, inflammation, lack of balance and 'brain fog' which impacted their ability to complete tasks or communicate effectively.

Nine interviewees identified some level of improvement since they had initially contracted a COVID-19 infection, five that things had remained the same and two that

their symptoms had got worse. However, it is important to note that only one interviewee indicated that they were 'back to normal', with all the others indicating being left with ongoing effects, which in some cases were severe and debilitating.

One interviewee indicated they had become formally classified as 'disabled' since contracting COVID, although it wasn't always clear in all cases whether COVID was the sole cause. One had secured Personal Independence Payments [PIP]. Due to the effects on their mobility, two individuals had successfully obtained a 'Blue badge' which supported their ability to access services, but they still had to alter their behaviour in response to their physical limitations. These same individuals were also pursuing PIP applications.

However, we also heard from those whose symptoms were not deemed sufficiently severe or impactful to meet the thresholds required for a 'Blue badge' or support through financial benefits, yet who were still severely affected. In part this may be due to symptoms such as fatigue and brain fog potentially being more challenging to quantify than direct physical effects, especially if these fluctuate over time.

3.1.3 Mental wellbeing

As well as the physical effects, we also heard about the negative impact on people's mental wellbeing. Various drivers were identified for this: anxiety about getting medical help and support when required; concerns over day-to-day living; the effects of social isolation; concerns over finances and employment and an inability to participate in activities people previously enjoyed.

A frequent concern was not knowing how long symptoms would continue and if and when they would change. For some, the severity of their symptoms fluctuated over time, whilst for others they had experienced progressive improvements, but they were still ongoing.

Because of symptoms such as breathlessness, reduced mobility, fatigue and brain-fog and their impacts on many tasks regarded as 'normal', this also raised anxiety in people's ability to complete them. For example, interviewees highlighted getting tongue-tied or struggling to communicate, in addition to physical challenges.

A key source of anxiety and concern for many related to mixed levels of awareness and recognition amongst health professionals, other professionals, employers and wider society about the existence, impact and legacy of long COVID. This affected people's confidence when seeking to communicate the issues they faced and obtain support, with concerns that 'long COVID' wasn't always viewed on a par with other illnesses or syndromes.

3.1.4 Employment and Job Security

A significant effect of long COVID for many interviewees was on their job and therefore their levels of income.

We heard that the ongoing effects of COVID had led several people to have to change their employment, either at their employer's request or because of a recognition of changes in their own circumstances.

One person told us they had lost their job, four had reduced their working hours (often from full to part-time), three had changed their job and others had asked for more flexible forms of working, such as working more varied or reduced hours, or working from home.

A respondent told us that their income had halved because of the changes they had to make in their employment due to long COVID. Others had reduced outgoings, and one had taken in a lodger to generate additional income.

Several interviewees commented on the benefits of working from home and working more flexibly, which allowed them to manage symptoms such as reduced mobility or increased fatigue.

Some employers had been flexible in responding to people's changing circumstances and allowed changes to their roles and working patterns, but others had been less able to accommodate appropriate changes due to the nature of the jobs involved. In both cases, interviewees still felt there was a job to do to inform and educate employers about long COVID, its impacts on employees and the support that could be provided.

3.1.5 Home life and day-to-day living

For some people, the impacts of long COVID and changes in personal circumstances created a reliance on family, friends and carers to offer support with day-to-day activities such as home maintenance, DIY and chores. This was most common where their mobility was affected, or where they experienced extreme fatigue in response to physical tasks.

Changes to individual's physical wellbeing also had knock-on effects on their mental wellbeing, as they were no longer able to undertake the physical activities they enjoyed, further limiting opportunities for social interaction and engagement. Interviewees described feeling isolated as a result.

We also heard about the impacts on people's self-esteem and pride where they were forced to seek financial and other forms of support, particularly where levels of independence had been high previously.

3.2 Experiences of health and care services

3.2.1 Diagnosis with long COVID

One of our lines of enquiry was whether people had been diagnosed with long COVID and what their experience of engaging with health professionals to obtain a diagnosis had been. This would help us understand how quickly people were getting access to support, and how prominent long COVID is as an illness in healthcare practitioners' awareness.

Our interviewees highlighted mixed experiences in relation to experiences of diagnoses, and more detail is set out below. Four people told us they obtained a relatively quick diagnosis and referral for support, whilst twelve experienced needing to see NHS healthcare professionals repeatedly, long wait times or needing to pay for a private diagnosis. Seven individuals identified ongoing symptoms after a COVID infection but no formal diagnosis of long COVID.

Of the seven interviewees who had been diagnosed with long COVID and referred to the Post-COVID Advice and Support Service (PCASS), three identified a quick and efficient diagnosis: one by a respiratory nurse at a GP practice; one through a hospital diagnosis after being taken to hospital with chest pain; and the other through self-diagnosis as a health professional and subsequent colleague referral.

Of the other four, three experienced issues in obtaining diagnoses by GPs, obtaining these after repeated visits and in some cases patient-led requests for referral. In one example, an individual paid privately to see a Neurologist who subsequently diagnosed long COVID and made the referral to PCASS.

Of the nine interviewees who had not accessed PCASS: five had seen their GP about their symptoms but had not been diagnosed with long COVID; two identified that their GPs were dismissive of their symptoms being linked to long COVID; one had been relatively easily diagnosed but it had taken three months to get the GP appointment and they were offered no advice or PCASS referral post-diagnosis and one interviewee had subsequently been referred to PCASS but they weren't aware that they had been diagnosed with long COVID.

Some interviewees expressed frustration where they felt they clearly had common symptoms of long COVID and had consciously asked whether this may be the cause during appointments, only to have this overlooked or dismissed, especially if they were subsequently diagnosed at another appointment or via another means (alternative healthcare professional).

3.2.2 Barriers to long COVID diagnosis

Based on our interview feedback, barriers to long COVID diagnosis include:

- Challenges in obtaining timely access to primary care appointments.
- Mixed levels of awareness of long COVID symptoms amongst healthcare professionals, including different practitioners at the same service.
- Reduced likelihood of a long COVID diagnosis where symptoms are mixed, and where people have other long-term or severe conditions, especially where these exhibit similar symptoms to long COVID.
- Limited information and advice on management of long COVID symptoms and potential support pathways (including NHS and non-NHS) being offered to those exhibiting common long COVID symptoms.

3.3 Information and Support for long COVID

We asked interviewees which forms of long COVID information and support they had accessed, and how useful they have been in supporting them.

3.3.1 Self-help

It was common amongst those we spoke to for individuals to have researched and explored long COVID themselves, even where they received support and information from services. Some people had then subsequently pursued other forms of treatment.

One interview highlighted that they had benefitted from privately funded acupuncture, Pilates and osteopathy sessions which had been beneficial in helping them manage their symptoms.

One individual used a counsellor who supported them with their increased anxiety and they identified their input as 'essential to their recovery'.

3.3.2 Social Media and websites

Social media (Facebook and Twitter), podcasts and websites were identified by several interviewees as being useful sources of information, particularly those shared by other individuals exhibiting similar symptoms of long COVID about the responses they found which they had adopted, and which had eased their symptoms.

These sources were also identified as reassuring in that they indicated that others were experiencing similar symptoms and circumstances, which made interviewees feel that they were not alone in dealing with long COVID.

One person we heard from identified that participating in regular meetings with people in similar circumstances had allowed the sharing of information and enabled mutual support to be provided to each other, and they had valued this.

However, people did acknowledge that it was often challenging to identify what information was robust and of use to them, both from websites and that shared by others in fora and meetings.

None of the interviewees that we spoke to explicitly identified that they were aware of or had used the NHS 'Your COVID Recovery' website.

3.3.3 Gaps in long COVID support

Several interviewees identified that they had found it challenging to identify additional long COVID support and information. In part, as they were not clear what was available and because they did not necessarily know what they were looking for. Even those that did, highlighted the difficulty in seeing the 'wood for the trees' given the scale and diversity of COVID-related information available.

Interviewees didn't highlight or raise with us that they were aware of or had used the 'Your COVID Recovery' website.

Five interviewees indicated that they had not accessed peer support, and that they were largely reliant on that offered to them directly by friends and family.

Three of the individuals we spoke to from the non-PCASS user cohort identified that they were unaware of the PCASS service (at the time of interview), including what it offered and how it operated. Whilst understandable if they have not been referred due to not having a long COVID diagnosis, however, the lack of awareness also means that they are potentially unable to pro-actively explore a referral with their GP or another healthcare professional.

4 Experiences of the Post-Covid Assessment and Support Service (PCASS)

4.1.1 Support received via PCASS

Interviewees told us that they had received a diverse range of support after being referred to the PCASS service. This reflects the varying impacts of long COVID and the array of responses that the PCASS is able to bring to bear in response.

This included:

- Referrals for: auto-immune appointment at a hospital; occupational therapy support; respiratory rehabilitation; speech and language therapy; Ears, Nose and throat [ENT]; Cardiology.
- Psychological management support.
- Energy and Pacing patient group.
- Support with employment and benefits advice (Personal Independence Payment [PIP] application).
- Online group discussion sessions with other PCASS referees.
- Follow-up phone calls from PCASS to check on individuals' status and wellbeing.

4.2 Effectiveness of PCASS support

Feedback from the interviewees who had been referred to PCASS was largely positive about the experience, and generally identified that the service had helped them for a range of reasons, including:

- Recognising that long COVID existed, with a feeling that if a dedicated service did not exist that it was unlikely that people would have received such extensive support.
- PCASS staff being understanding of people's experiences of long COVID, which they identified may be at odds with their experience of other healthcare professionals, employers and wider society.
- Support to engage with employers about individual needs and returning to work, including writing to employers to highlight individual's diagnoses and needs.
- Referrals to other health services and support mechanisms.

One interviewee described how their use of the PCASS service had enabled them to 'gain control of their long COVID, rather than it being in control of them'.

We did ask interviewees whether based on their experience of using the PCASS service they had any preferred changes or improvements which may be beneficial moving forwards. They identified a range of options, including:

- Preference for a holistic service with specialist in-house medical expertise focused on long COVID, rather than a service that referred to others, and was reliant on their awareness and understanding of long COVID.
- Greater continuity in the PCASS professionals that referred individuals engaged with so that there may be greater 'case' management.
- Improved waiting times in the services 'referred to', as some can be have long waits.
- Access to psychological support in addition to mental health support [it should be noted that the respondent identifying this was scheduled to access psychological support, but had yet to do so].

4.3 PCASS as a virtual service

The PCASS service is a 'virtual service' as it does not deliver physical clinics, and we sought to explore whether this was viewed positively by users or if they felt that this had in any way been detrimental.

A majority of the PCASS users we interviewed were supportive of the focus of the PCASS service being virtual, identifying that those with long COVID symptoms were likely to prefer not to have to travel if it could be avoided, it minimised risks of other infections, it was becoming 'the norm' for many health services and as long as appointments dates/times were kept to then it generally wasn't a problem.

One interviewee did indicate that they were aware that long COVID support (with multi-disciplinary teams) was provided on a face-to-face basis in other areas, which they would have preferred and they indicated that it was a 'postcode lottery' to have mechanisms operating differently in different locations.

4.4 Changes or improvements to long COVID support

Interview participants identified a range of changes or improvements that they felt would be beneficial in improving long COVID support. These included:

- A more joined-up approach to gathering people's experiences, both in terms of the impacts of long COVID on them (both on their health and wider knock-on impacts) and the successful responses to help raise awareness of long COVID. Respondents felt there was a focus on physical symptoms, but not always on the effects these had on people's wider lives.
- Increased awareness amongst wider society of the existence and impact of long COVID with a focus on highlighting its prevalence, as well as the diversity and extent of its effects on people. It is far more complex than people 'feeling tired'.
- Greater awareness amongst employers of the potential effects of long COVID, with improved understanding and flexibility in supporting people with ongoing COVID symptoms to remain in employment through adaptations and discussion.
- Improved awareness amongst all public services, but especially those related to financial, debt and employment support, about the prevalence of long COVID so that support can be appropriately adapted to cater for those experiencing it.
- Greater acknowledgement amongst GPs that long COVID exists as a condition and that there are clear pathways for NHS support (PCASS) that people can access, as well as social prescribing and other alternatives. Improved access to timely primary care appointments, as well as continuity with the same healthcare professional and/or improved record keeping were also flagged.
- Clarity early in the referral process about what the PCASS can and cannot offer, in order to manage user expectations, and minimise disappointment or frustration.
- Development of a specialist 'long COVID service' able to have in-house clinical/medical expertise linked to 'long COVID' with a desire for multi-disciplinary clinics able to offer dedicated and tailored support for those with long COVID.
- Consideration for people to have the opportunity to self-refer or to have a lighter-touch referral mechanism to the PCASS service, which may minimise the risk of any intentional or unintentional gatekeeping by healthcare professionals.

5 Case Studies

To illustrate the personal impacts of long COVID on people's lives, we have developed some brief case studies from our interviewees summarising how they have been affected, what support they have accessed and their aspirations moving forwards.

5.1 Case Study 1: Jane

Jane [name changed] was massively impacted by long COVID, going from a fit and active person, who walked and cycled regularly and went on camping trips to someone who now describes themselves as 'significantly disabled'.

Whilst not yet aged 60, Jane described how her life has changed dramatically, feeling 80 on a typical day and 90 on a bad day. She is now only able to walk for 6 minutes with the aid of a walking stick and needs support from a carer to make the bed and empty the bins. She has sold her beloved camper van.

Until recently, Jane has never had the need to claim any benefits, but now receives Personal Independence Payments (PIP).

Jane is worried about her employment. Before contracting long COVID she worked face-to-face in her job, but since contracting long COVID has been working from home. Her employer wishes her to return to working face-to-face and she is worried about her ability to do this and fears she may be dismissed on health grounds. If she loses her job, she may not get another job and is likely to be reliant on benefits.

Access to the PCASS service was fast and efficient, with a quick referral from her GP in April/May 2021. She appreciated the help and support received (via telephone), especially having someone 'listen and believe you'. The PCASS service provided advice and referred Jane for a cardiology appointment, but the wait time for the appointment was 10 months.

Jane valued the support PCASS offered but was frustrated it only offered telephone support and referrals to other services. Her preference was for a service that provided treatment for long COVID, indicating that in other locations people receive face-to-face appointments with direct access from dedicated multi-disciplinary teams.

On reflection, Jane felt that initial appointments for long COVID should be undertaken at a hospital-based 'one-stop shop' where necessary tests and referrals can be completed, and this could also support ongoing support on a dedicated basis.

5.2 Case Study 2: Alison

Alison (name changed) first contracted COVID-19 three years ago and every day since has been severely affected by its ongoing impacts. The main effect has been extreme fatigue which has limited her ability to participate in activities that used to feature strongly in her life, such as cycling which was her main form of transport.

One of the impacts of long COVID is she is no longer able to work full-time, but her employer has been very understanding and flexible in supporting her to continue in her job. Whilst severely affected, Alison is not eligible for disability benefits, which combined with her reduced working hours has severely affected her finances and she still faces monetary challenges. To help, she has taken on a lodger to generate additional income.

Alison initially found getting a diagnosis for long COVID to be relatively simple, receiving this quickly from her GP after a couple of months of ongoing COVID symptoms. However, some barriers were faced after moving house, as her new GP highlighted that a long COVID diagnosis was not on her medical records. This combined with a need for additional tests [to aid a referral] and healthcare professionals repeatedly asking if she was seeking a long COVID 'diagnosis' has made her feel frustrated and not believed.

A referral to the PCASS service was received in January 2023, with two online meetings subsequently undertaken. Alison described it as comforting and reassuring to have a conversation with someone 'who gets it', reminding her that she is not alone, not 'making it up' and it has a real impact on her life.

Whilst not the same as a face-to-face meeting, virtual consultations (via video) undertaken as part of the PCASS referral were helpful and convenient. However, Alison met different people each time and would have preferred continuity through meeting the same person.

Alison's key message is that long-term conditions such as long COVID may not be obvious to others, however, this doesn't mean that they are not impactful and may mean that they are unable to manage or to work.

5.3 Case Study 3: James

James (name changed) has been very severely affected by long COVID and he describes it as 'life changing'. Whilst he continues to work, largely out of necessity, he has had to radically reduce the amount he works and working still feels like a significant struggle. He doesn't socialise anymore as he feels unable to do so, and his life consists of 'eat, sleep, rest and work a bit'.

The symptoms that James experiences include severe fatigue, which also leads to brain fog once the tiredness takes effect, making it hard to complete tasks that might otherwise be simple to undertake. This means he must stop activities once the fatigue kicks in. The other symptom is pain in his legs which affects his mobility.

His diagnosis for long COVID was provided by a respiratory nurse at the GP practice, who then referred him to the PCASS service for support, and he was contacted promptly. He received phone support from the PCASS service and participated in four/five online group discussions with others experiencing Long COVID.

Whilst sharing of experiences and views with others affected by long COVID is valuable, James felt that a lot of the advice received he was already aware of. Technology used in virtual meetings also hindered some people's ability to engage in discussions, and face-to-face options may be useful for some, even if virtual meetings are generally more accessible and flexible.

James no longer has ongoing contact with PCASS, and he is now trying to manage his COVID symptoms which he still experiences on a day-to-day basis.

The change that James would most like to see is a greater understanding and wider awareness in the community of long COVID.

He reflects that people simply think that you are tired or lazy, but they don't appreciate the full effects it has, and that if it were simply a case of will power then there is nothing he'd like more than to use this to combat the symptoms.

5.4 Case Study 4: Elizabeth

Elizabeth (name changed) has contracted COVID-19 twice, and whilst not formally diagnosed with long COVID has been experiencing ongoing symptoms which have greatly impacted on her life.

After contracting COVID-19, Elizabeth was left with very little energy, with energy levels that fluctuate regularly, meaning it is difficult to plan what to do and when, and it can leave her with blocks of two or three weeks at a time when she feels particularly unwell. She now must plan her time carefully to ensure she does not overdo things. Since catching COVID, she has stopped going out as she lacks the energy to do so.

Whilst Elizabeth is learning to cope, the fluctuations in energy levels have been hard to deal with, as one day things aren't too bad, and on others she is forced to spend the day in bed. She finds it especially frustrating not to be able to undertake the tasks or activities that she did before COVID.

Until now she has self-managed her condition and has found that changing her diet has been helpful in making her feel better. She hasn't sought out or accessed any forms of peer support or wider engagement with others, highlighting that even if they are helpful, she doesn't feel they are appropriate for supporting her needs.

Elizabeth has spoken to her GP about her symptoms, but this hasn't led to a long COVID diagnosis and therefore no referral for support from the PCASS service, or receipt of any wider advice or support with the ongoing symptoms. She acknowledges that she does have some symptoms and a medical history which may have made a diagnosis of long COVID more challenging.

In supporting the recovery of those experiencing long COVID, the greatest change that Elizabeth would like to see is an acknowledgement by GPs that the condition exists, and that people with these symptoms should be taken seriously.

At the moment, she doesn't feel that this is the case, but people know their own body and their concerns and should be acknowledged and appropriately responded to.

5.5 Case Study 5: Bernard

Bernard (name changed) found that the greatest effects after contracting COVID-19 were on his mental wellbeing and cognitive ability. Things that were second nature before the infection now needed to be learned again, and he had also had to learn new skills such as controlling his breathing to help manage his symptoms, including anxiety.

Whilst still experiencing feelings of anxiety, he has learned techniques that help to lessen the severity of their effects and reduce the frequency with which they occur. He is grateful that his job allows him to work from home and reduces the stress and triggers that having to go to work might generate.

Bernard saw his GP about his symptoms after a long wait for an appointment. Whilst there were no explicit barriers to being diagnosed with long COVID by his GP, they did not then refer him to the PCASS service, nor did they seem to sufficiently understand long COVID in a way that allowed them to provide appropriate tailored advice and support.

Consequently, he feels he has had to independently learn to do things differently and think differently. He has focused on self-learning about his own body and sought to have reasonable expectations of his capability. He regards himself as still being fragile but more in control, finding his own boundaries, and setting reasonable expectations about what he can now achieve.

No NHS services were used by Bernard to aid his recovery, which largely focused on self-learning. In addition, he identified two other forms of as being key in managing his circumstances. Firstly, a local counsellor was identified as essential in helping him understand and manage his symptoms. Secondly, support from friends and social media peer networks have helped with the sharing of information and experiences, especially feeling that you are 'not alone'.

Bernard's message for improvement in long COVID support would be that employers need to change their attitudes and not pressure people to work excessive hours or to return to work too soon.

Lots of work needs to be done to raise awareness that long COVID exists and alter people's attitudes to the extent and scale of its impacts.

6 Conclusions

Given that COVID infections continue to occur in Sussex and are likely to for some time to come, it is important that the feedback gathered from those experiencing ongoing symptoms and effects from COVID is used to inform the response put in place to support them.

The findings from our interviews, broadly align with those identified from our phase one [long COVID survey](#), identifying similar themes around the diagnosis, impacts and responses to long COVID.

It is clear from the experiences captured through both Healthwatch engagement exercises that the responses to long COVID need to go beyond an initial diagnosis and the provision of short-term support with physical and mental wellbeing, as people require ongoing support to deal with the longer-term health-related effects as well as the wider impacts on their lives such as employment, finances and day-to-day living.

Therefore, responses to long COVID should not be the sole responsibility of NHS or health services, but instead should form part of a joined-up system-wide approach that is able to flexibly respond to and cater for the varying needs that people have.

Increased awareness of long COVID, acceptance of its existence, and statutory and other services adapting and supporting those with long COVID in a similar way to people with other severe or debilitating illnesses are important factors to consider when working towards this goal.

6.1 Impacts of long COVID

Whilst variable in severity and nature, most of the people we heard from told us that long COVID had a significant impact on their lives, both on their physical and mental health, as well as affecting their day-to-day activities, jobs, quality of life and wider wellbeing.

Some people had experienced improvements in their health since developing long COVID, others had learned to adapt and manage their symptoms, but overall many remained adversely affected at some level, requiring ongoing medical or therapeutic support, as well as help from friends, family and carers with day-to-day living.

The diverse range of physical and mental symptoms of long COVID, make it challenging to deliver a single comprehensive response by any one organisation or service. Instead,

a flexible response able to tailor treatment, advice, referral or signposting appropriately is required across the Sussex healthcare system, but also across public and community services.

6.2 Awareness of long COVID

Our respondents indicated that awareness of long COVID still appears relatively low amongst the general populace, employers, in statutory services, and remains variable between different health and care services and practitioners. This includes its prevalence, symptoms and severity. This has several potential knock-on impacts.

Firstly, it can inhibit people's awareness of long COVID and the fact there is support available, potentially limiting the number of people engaging with a healthcare professional about their symptoms, thereby reducing onward referrals to PCASS and support services.

Secondly, a variable understanding of long COVID and the support available amongst healthcare professionals, including PCASS, social prescribing and self-help, means people may receive inconsistent diagnoses, advice or referrals for support. In some cases, this may not be provided even where explicitly requested, leaving people without support or to manage until a diagnosis or referral is made.

Thirdly, different levels of understanding amongst the wider public, employers and service providers can affect how people with long COVID are perceived and dealt with. Whilst they may be aware of the syndrome and its common symptoms such as fatigue and breathlessness, they may be unaware of its severity or other less visible symptoms. This may lead to long COVID sufferers experiencing a lack of empathy, as well as inadequate support in dealing with the direct and indirect effects on their lives.

6.3 Support for long COVID

We heard that the support sought and/or accessed by those experiencing ongoing COVID symptoms was often quite mixed. In part, this appears to reflect the two different cohorts we engaged with, rather than factors such as gender, societal group or location.

This appeared reliant on individuals' own awareness, understanding and COVID symptoms and treatment, as well as the awareness of any healthcare professionals they engaged with about the syndrome and the available treatment and support.

Responses from our interviewees suggest that a potential bottleneck remains in accessing support for long COVID due to the main route for long COVID referrals being

through primary care, which potentially leads to GPs being 'gatekeepers', affecting the consistency of experience and uptake.

Those accessing the Post COVID Assessment and Support Service (PCASS) were often referred to it by healthcare professionals aware of and able to diagnose long COVID symptoms, or through their own awareness of long COVID and/or PCASS which had led them to request a referral through a healthcare practitioner.

Where professional or personal awareness of PCASS and other forms of NHS support were lower, we heard that people utilised a diverse range of support mechanisms, including paying for private therapies and treatments, researching and managing their own symptoms and participating in peer groups (face-to-face and via social media) to support them. Due to the diversity of responses identified and variety of options used by everyone it is challenging to identify the benefits that may be directly applicable to others.

Given we heard that both recipients of long COVID support and those who had not received a formal diagnosis or referral to PCASS were self-managing their symptoms, the provision of, or signposting to, robust, accessible and NHS endorsed 'self-management' information would appear to be a potentially valuable aspect of support. The multitude of both NHS and other websites and sources of information related to long COVID do not currently make it clear to identify which sources to use.

Outside of the direct physical impacts, our interviews highlighted that employment is one area of people's lives that is often significantly impacted by long COVID, especially where those developing long COVID have full-time roles, active or mobile occupations or their job has less flexibility in how and when it can be undertaken.

Supporting people contracting long COVID with robust information they can provide to their employer about symptoms, suitable adaptations and support with flexible working may be valuable in raising awareness and allowing people to remain in their jobs. This may include the provision of correspondence from health practitioners or the PCASS service (if applicable) directly to employers, explaining that people had developed long COVID and highlighting potential adaptations and changes.

Similarly, the provision of, or signposting to appropriate employment, benefits, debt advice and support may be useful in helping people to manage their changing circumstances and reduce the direct and indirect effects on them.

6.4 The Post COVID Assessment and Support Service (PCASS)

We provided those we had interviewed who had not used the PCASS service with details, and many people indicated that would access the information and explore whether it may be able to support them.

Those we interviewed who had used the PCASS service were generally positive and happy with their experience, identifying that the service was responsive after initial referral, staff were friendly and engaging and that the support offered was tailored to their needs and generally beneficial. It was also good to have a single service or point of entry for anyone experiencing ongoing COVID symptoms.

It is challenging for any single service to meet people's diverse needs, especially where they vary extensively as in the case of long COVID. Perhaps the greatest limitation of the PCASS service identified by interviewees is that it is not itself a direct deliverer of all support or treatment. This can mean that PCASS is judged by the performance and effectiveness of other healthcare providers, over which it may have limited influence.

7 Recommendations

The March 2023 [report](#) of the findings from our long COVID survey identified 15 recommendations for the Sussex Integrated Care System, the PCASS service, Public Health teams and Healthwatch in Sussex to support ongoing responses to long COVID.

In summary, these proposed:

- Supporting greater awareness of long COVID, both in the wider populace and within health and other public services, with the goal of enhancing recognition, diagnosis and increased access to information, advice, support and treatment.
- Ongoing training, information and support for healthcare professionals, but especially primary care clinicians to enable diagnosis of long COVID as early as possible, with a focus on consistency and speed of referral to PCASS.
- Consideration to be given to dedicated clinics and 'long COVID' clinicians within the PCASS service in Sussex, so as to provide specialist long COVID support directly and holistically, rather than through referral to mainstream healthcare services.
- The PCASS service regularly capturing patient preferences and feedback to ensure that it meets user's needs and evolves in line with any changing trends. This should be supported by triangulating data and insight alongside NHS, Public Health and other services so responses to long COVID are appropriately designed and delivered.

Our interviews have identified similar themes to our survey findings, so we believe those first-phase recommendations (see Appendix 4) are consistent with, and continue to apply to our findings from this second phase.

We do not intend to replicate them again here in full, but wish to draw attention to several themes where ongoing focused responses to long COVID may be valuable.

Sussex Integrated Care System (ICS)

- Recognition of the need for a system-wide response to long COVID, which supports increased awareness, rapid diagnosis and referral to PCASS and other appropriate services, tailored support and the provision of non-health related information and advice e.g. employment, debt, benefits.
- Engagement with employers (ICS members) and business representatives (e.g. Chambers of Commerce, Federation of Small Business etc.) to raise awareness of long COVID, recognise its impacts on employees and encourage flexibility.

NHS Sussex/Healthwatch

- Increased promotional activity and communication to raise public awareness of long COVID symptoms, impacts and how to access NHS advice and support. This should include other public services, employers, schools, as well as advocacy, community and voluntary sector organisations.
- Continued awareness raising with primary care health practitioners of long COVID and the PCASS service offer and benefits to service users to support consistent diagnoses and reduced barriers to identification and referral. This should be regularly updated to outline new information on symptoms and treatments, and seek to keep messaging fresh and varied.

Post COVID Assessment and Support Service (PCASS)

- Ongoing development and adaptation of the PCASS service informed by regularly capturing and reviewing user and independent feedback and exploring best practice from long COVID responses in other areas.
- Review of the strands of support offered to people experiencing an acute COVID-19 infection, and those living with and managing long COVID on an ongoing basis.
- Engage with PCASS service users, patient groups and patient advocates to support the development of long COVID communications in a range of accessible formats, to ensure that content is appropriate for those who may find it more challenging to understand health information.
- Internal review to assess whether more could be done to support people in communicating long COVID status and support needs to employers, and in accessing employment, debt and benefits support and advice.

Healthwatch

- Continued sharing of feedback on long COVID and experiences of the PCASS service with NHS Sussex to inform ongoing learning and service development.

8 Appendix 1: Context on long COVID

8.1 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 laypeople.

8.2 How common is long COVID?

In March 2023 [the latest release], the Office for National Statistics [reported](#) that an estimated 2 million people living in private households in the UK (approx. 3% of the population) were experiencing self-reported long COVID not explained by something else. This is approximately 1.2 percentage points higher than comparable data from December 2021.

A comparable proportion of the 1.72 million people living in Sussex would equate to approximately 50,000 people experiencing long COVID locally.

9 Appendix 2: 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, 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.

10 Appendix 4: Interview questions

10.1 Questions asked of users of the Post-Covid Assessment and Support Service (PCASS)

1. What impact has Long COVID had on you?
2. Tell me more about your situation and how are you coping at the moment?
3. If applicable, how did you get diagnosed with long COVID?
4. Can you tell us about your experience of getting referred to the PCASS service?
5. When (month/year) did you get referred to the PCASS service?
6. What support did you receive through the PCASS service?
7. How did using the PCASS service help you?
8. How do you feel about the PCASS service being predominantly virtual?
9. If you could make one change to improve the PCASS service, what would it be?
10. What needs to change to make the experience of those recovering from long COVID better?
11. Would you be willing to participate in a Patient Experience Group to support NHS Sussex in responding to long COVID?
12. Are you willing to give consent for Healthwatch East Sussex to use your comments as follows:
 - Anonymised quotes and comments Y/N
 - Anonymised case studies Y/N

10.2 Questions asked of those with no experience of the Post-Covid Assessment and Support Service (PCASS)

1. What impact has Long COVID had on you?
2. Tell me more about your situation and how are you coping at the moment?
3. If applicable, how did you get diagnosed with long COVID?
4. What information or advice have you accessed about long COVID, and how useful has it been for you?
5. Is there anything you haven't been able to find out about?
6. What forms of support for long COVID, if any, have you used?
7. Have you used any forms of peer support?
8. Are you aware of the PCASS service offered by the NHS to support long COVID?
9. What support has been most useful and least useful during your illness and recovery from long COVID?
10. What needs to change to make the experience of those recovering from long COVID better?
11. Would you be willing to participate in a Patient Experience Group to support NHS Sussex in responding to long COVID?
12. Are you willing to give consent for Healthwatch East Sussex to use your comments as follows:
 - Anonymised quotes and comments Y/N
 - Anonymised case studies Y/N

11 Appendix 3: Recommendations from Phase One research

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.

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).

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.



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