

# Accessing Long Covid support in Sheffield

November 2024

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## How we have presented the data in this report

This report is based solely on what people have told us through interviews and community research. It is based on two sets of data:

- **21 in-depth interviews** with people with Long Covid and their carers
- **Community research insights** gathered by voluntary organisations through our Long Covid Community Grants Programme

The interview findings form the main body of the report, whilst the community research insights are presented to highlight specific themes.

**The community insights are highlighted in green boxes throughout this report.**

We have spoken directly to individuals and groups who have self-identified their heritage. When we refer to what they told us, we name their heritage directly. We also refer to the wider ethnically diverse groups of people who live in Sheffield. It has not been possible to represent everyone and we appreciate that there are complexities when trying to find common terms that include everyone.

We would like to name the groups in Sheffield that we refer to when we talk about inequalities in our city, and to whom we generalise in our recommendations. We hope this provides both clarity and transparency to our approach and promotes inclusivity.

The self-defined, ethnically diverse communities that we have worked with and heard from are included in Appendix 4.

In order to protect the privacy and maintain the confidentiality of the individuals who contributed to this report, all names have been changed.

## About Healthwatch Sheffield

We are here to help adults, children and young people influence and improve how services are designed and run. We are completely independent and not part of the NHS or Sheffield City Council.

We collate the feedback you give us so that we can make evidence-based recommendations to the organisations that design, pay for, and run our local services.

## About Voluntary Action Sheffield

VAS' purpose is to support people, communities and the Voluntary and Community Sector (VCS) to lead positive change. We do this by focusing on:

1. Building, hosting and nurturing strong inclusive and effective partnerships to develop positive social change.
2. Supporting leadership and capacity in communities and the voluntary sector.
3. Creating volunteering and other opportunities for people that are most marginalised.
4. Supporting access and empowerment in the next generation of leaders.
5. Being a good employer and a well-run organisation, which cares for our people and resources.

## Acknowledgements

This project would not have been possible without:

The funding and support of Sheffield Teaching Hospitals NHS Foundation Trust and NHS South Yorkshire Integrated Care Board (ICB)

The Long Covid Project Steering Group

The Community organisations that took part in the grants programme

A huge thank you to all of you with Long Covid who took the time and energy to speak to us and share your experience

# Summary

This summary outlines the key findings and recommendations of the Long Covid Project by Healthwatch Sheffield and Voluntary Action Sheffield from October 2022 to September 2024.

We wanted to explore people's experiences of Long Covid and understand the barriers affecting those who are currently under-represented in Long Covid services in Sheffield, particularly those from our ethnically diverse communities as well as those with lower socio-economic means.

This report is based on 21 in-depth interviews with people with Long Covid and their carers. In addition, our grants programme connected with 440 people in diverse communities to gather their experiences and insights about Long Covid. The data produced by the community groups is presented in this report alongside the key interview findings.

Our findings suggest that people with Long Covid face significant challenges in managing their condition and overcoming barriers to healthcare. We have outlined these for general practice, hospital care and Long Covid specific services.

People told us about how they managed their condition and looked for sources of advice and information in their communities and online. They also told us about the impact of Long Covid on their mental health, work and personal lives.

The report also includes several sections where we spotlight the insights from the community research that emphasises specific areas of interest. We have also indicated areas for improvement for particular services as well as case studies that bring people's experiences to life.

We have made a number of key recommendations to commissioners and providers of services for people with Long Covid, based on what they have told us. These address the challenges faced by people with Long Covid and aim to improve services and guide future strategies.

# Introduction

## Background

The global Covid-19 pandemic, driven by the SARS-CoV-2 virus, has had a profound effect on many people's lives, their wellbeing as well as health and social care services.

As early as May 2020, the term "Long Covid" was being mentioned by patients in the UK who shared their experiences of persistent symptoms following infection of Covid-19.<sup>1</sup> This patient-led awareness played a crucial role in initially bringing attention to the issue and patient-led advocacy groups have continued to be a driving force in shaping the response to Long Covid in the UK.<sup>2</sup>

The National Institute for Health and Care Excellence (NICE) defines Long Covid as "signs and symptoms that develop during or after an infection consistent with Covid-19, which continue for more than 12 weeks and are not explained by an alternative diagnosis". Despite this formal definition, many people with Long Covid have faced challenges in obtaining an official diagnosis, often relying on self-identification based on their persistent symptoms.<sup>3</sup>

As of March 2024, an estimated 2 million people living in England and Scotland reported that they were experiencing Long Covid symptoms.<sup>4</sup> There is evidence that the impact of this condition on people's lives is profound and the wider social and economic consequences are both significant and complex.

The Covid-19 pandemic had a disproportionate impact on people from ethnically diverse groups, revealing and amplifying existing health and social inequalities. Members of ethnically diverse groups have experienced higher infection rates,

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<sup>1</sup> Covid-19: What do we know about "long Covid"? BMJ 2020; 370

<https://doi.org/10.1136/bmj.m2815>

<sup>2</sup> McClymont, G. (2021). The Role of Patients and Patient Activism in the Development of Long COVID Policy. <https://doi.org/10.17863/CAM.75505>

<sup>3</sup> Al-Aly, Z., Davis, H., McCorkell, L. et al. Long COVID science, research and policy. Nat Med 30, 2148–2164 (2024). <https://doi.org/10.1038/s41591-024-03173-6>

<sup>4</sup> ONS: Self-reported coronavirus (COVID-19) infections and associated symptoms, England and Scotland: November 2023 to March 2024

more severe outcomes, and greater socioeconomic impacts compared to the wider population.<sup>5</sup>

Despite the disproportionate impact on ethnically diverse groups, both national and local data indicate that these communities are under-represented among those being referred to Long Covid services.<sup>6</sup>

In Sheffield, the South Yorkshire Long Covid Programme board<sup>7</sup> was established to develop and deliver Long Covid services in accordance with national guidelines. It included a number of different clinical and commissioning services, all of which aimed to make sure that services for people with Long Covid were joined up and that people were supported in their rehabilitation and recovery. The programme board worked at speed and in consultation with patients, to deliver a new, complex service design.<sup>8</sup>

January 2021 saw the opening of the Long Covid Rehabilitation Hub based at Sheffield Teaching Hospitals NHS Foundation Trust. Developed as a new specialised service, it was designed to support individuals experiencing persistent symptoms of Long Covid. The Long Covid Rehabilitation Hub offers a multidisciplinary approach to care, combining expertise from various healthcare professionals to address the complex and varied needs of patients.

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<sup>5</sup> The King's Fund 2023 <https://www.kingsfund.org.uk/insight-and-analysis/long-reads/health-people-ethnic-minority-groups-england>

<sup>6</sup> Smyth, N et al: People from ethnic minorities seeking help for Long Covid: a qualitative study. British Journal of General Practice 28 May 2024;

<sup>7</sup> The Board was a system wide collaboration charged with the delivery of a NICE compliant Long Covid offer for the Sheffield population.

<sup>8</sup> Carolan, C et al, 2021: Long Covid Programme Evaluation. Sheffield Teaching Hospitals. Sheffield Clinical Commissioning Group.

## Why did we do this work?

Healthwatch Sheffield were commissioned by the Sheffield Teaching Hospitals to work with groups and individuals to increase the understanding of:

- The experiences of people living with Long Covid
- The experiences of people accessing care and support for Long Covid
- The barriers to accessing support and gaps in support
- What would lead to better outcomes for people

At the same time, the South Yorkshire Integrated Care Board<sup>9</sup> were interested in developing the role of the Voluntary and Community Sector (VCS) to know how to connect to and support individuals with Long Covid. They funded Voluntary Action Sheffield to:

- Explore what work is already happening in the VCS relating to Long Covid
- Understand the challenges for organisations in this work
- Hear from VCS organisations about the experiences of people they support, including an understanding of barriers to getting the right support for people living with Long Covid

The two different commissions came together and developed into the Long Covid Project. This had a focus on:

- Involving people with experience of Long Covid as the experts in this work
- Groups currently under-represented in the demographics of people attending Long Covid services, particularly those from ethnically diverse communities and those with lower socio-economic means.

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<sup>9</sup> The SY ICB is responsible for funding, planning and coordinating healthcare services across South Yorkshire with the aim of improving overall health outcomes, reducing health inequalities, and ensuring efficient use of resources. <https://southyorkshire.icb.nhs.uk/>



## What did we do?

The Long Covid project undertook a wide range of activities overseen by a cross-sector Steering Group.<sup>10</sup>

### We interviewed 21 people

We conducted **21 in-depth, semi-structured interviews** with people living with Long Covid and their carers, to help us understand their experiences. These interviews helped us bring people's stories to life for people planning and delivering Long Covid support services.

### Who we spoke to through interviews



15 had a formal diagnosis of Long Covid through their GP

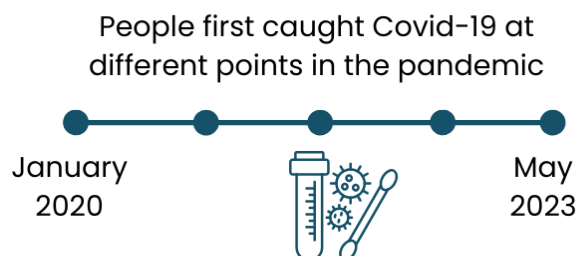


4 hadn't been formally diagnosed, but self-identified as having Long Covid



2 were carers of people with Long Covid

What is your ethnicity?	
White British	12
Pakistani	4
African Caribbean	2
Black British	1
Other Asian British	1
Other White	1



Two thirds (14) were women; one third (7) were men



3 interviewees were disabled:  
2 had physical disabilities  
1 had a learning disability



Interviewees ranged from 28 to 72 years old

<sup>10</sup> See Appendix 3 for a full description of Steering Group membership

## We ran a community grants programme

Our community grants programme worked with **15 community organisations**<sup>11</sup> and spoke with **440 people** (not all of whom had Long Covid), from backgrounds who were under-represented in Long Covid services. These conversations highlighted what the gaps were in Long Covid information locally and nationally.

The community grants programme funded local voluntary organisations to undertake 3 types of activity with their communities.



### 3 stage grants programme



Community research to **understand the barriers and the needs** that people have when trying to access support for Long Covid.



Further rounds of funding in the community grants programme supported organisations to produce a total of **21 information resources** about Long Covid in a variety of formats and languages.



Organisations delivered the information resources to approximately **20,000 people** living in Sheffield.

Amongst many of the community resources developed by the programme, the project produced a **Long Covid Information Video**<sup>12</sup> for use in waiting areas across NHS facilities including hospitals, clinics, GP surgeries, and any other healthcare settings where patients wait for appointments or treatments.



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<sup>11</sup> See Appendix 4 for a full list of participating organisations

<sup>12</sup> <https://tinyurl.com/53zahz84>

## Who we spoke to through the grants programme



Our grants programme heard from a wide range of people from ethnically diverse communities



We heard from people who told us they were homeless, and others who were asylum seekers



People belonged to different faiths; Muslim, Christian, and Hindu



Some people said they had disabilities, learning disabilities, or mental health issues



### How?

Workshops, questionnaires, interviews, focus groups, and conversations



### Where?

In neighbourhoods, on the street; at community centres, drop-ins, and events; at health centres; by telephone and email



# Findings

## Life before Long Covid

We asked the people that we spoke to tell us a little bit about their life prior to their infection with Covid-19. Their descriptions provide a rich snapshot of a moment in time – the activities and ambitions as well as the comfortable everyday routines and challenges that life presents. Everybody was getting on with living their life in their own way.

It paints a picture of a varied group of people, most of whom were in employment and who were physically active – whilst a couple were training to run a half marathon or cycling 10 miles a day, others enjoyed a more leisurely stroll to their local mosque for prayers and socialising. We also spoke to people with both physical and learning disabilities who were engaged in their communities.

The variety of work that people were engaged in was also wide ranging. We spoke to company directors, academics, taxi drivers, freelancers and NHS nursing staff, as well as a couple of people who whilst retired from work, were still engaged in a variety of community projects.

## Experiences of Covid-19

Most of the people that we spoke to had contracted Covid-19 in 2020. They have all now been living with Long Covid for approximately three years, they often refer to themselves as ‘Long Haulers’.

When talking about that initial infection, some hadn’t given it much importance – they said they’d had worse illnesses in the past:

*“It wasn’t the worst illness I’ve ever had but then I never improved” Sam*

Others had a very traumatic experience of infection and were initially hospitalised for varying periods of time with serious conditions and consequences:

*“I was unconscious for 34 days... Afterwards I know that I’ve been in hospital... I don’t know where they put me to sleep or I went in coma. But for after 34 days I’ve kept on machines. You know, on various breathing apparatus and whatever and my lungs and everything collapse, kidneys, everything” Hamza*

## Covid safety and public information

Many people spoke about a lack of public recognition and awareness of Long Covid. They felt that it is not acknowledged or taken seriously enough by health services, the public or the media, leaving them feeling isolated and overlooked.

People with Long Covid were concerned about being re-infected with Covid, particularly when attending appointments in healthcare settings as they felt that these don't implement appropriate precautions to limit cross-infection.

The fear of being re-infected with Covid was serious enough to stop people going into public spaces and is a barrier to accessing health care services.

*"I don't feel safe going to the doctors at the moment because it's the place where all the sick people are and there's no health precautions in the place that you're supposed to go to get better. You know, it's very frustrating"* Julia (carer)

*"It feels like living in a sort of parallel universe. I guess where no one's describing that Long Covid exists. It's impacting people. It just doesn't seem to be taken seriously or come up in the media or just anywhere really. There's just a few people online who speak to each other, who found themselves in strange situations who are sort of, removed from public life"* Adam

### Community insights: A lack of awareness and information

There was little knowledge or understanding of Long Covid amongst many of the under-served<sup>13</sup> community groups we spoke to. Those with significant barriers such as language support needs\* were particularly lacking in information about Long Covid and the support services available.



Women of South Asian heritage who attended open sessions about Long Covid in Sharrow, Darnall and Tinsley identified two main awareness and information gaps:

- They didn't have any knowledge or understanding of what Long Covid was.
- They weren't aware of any support services for people with Long Covid.

*"A client lost her husband due to Covid and she was still suffering from symptoms but due to losing her support, she didn't know how to reach out for help or where to go"* Project worker at Roshni

\*People with **language support needs** were not only those that need translated materials and interpreting services to understand information and be able to communicate. It also includes those who do not read or write in their first language, and for whom translated materials may not be enough.

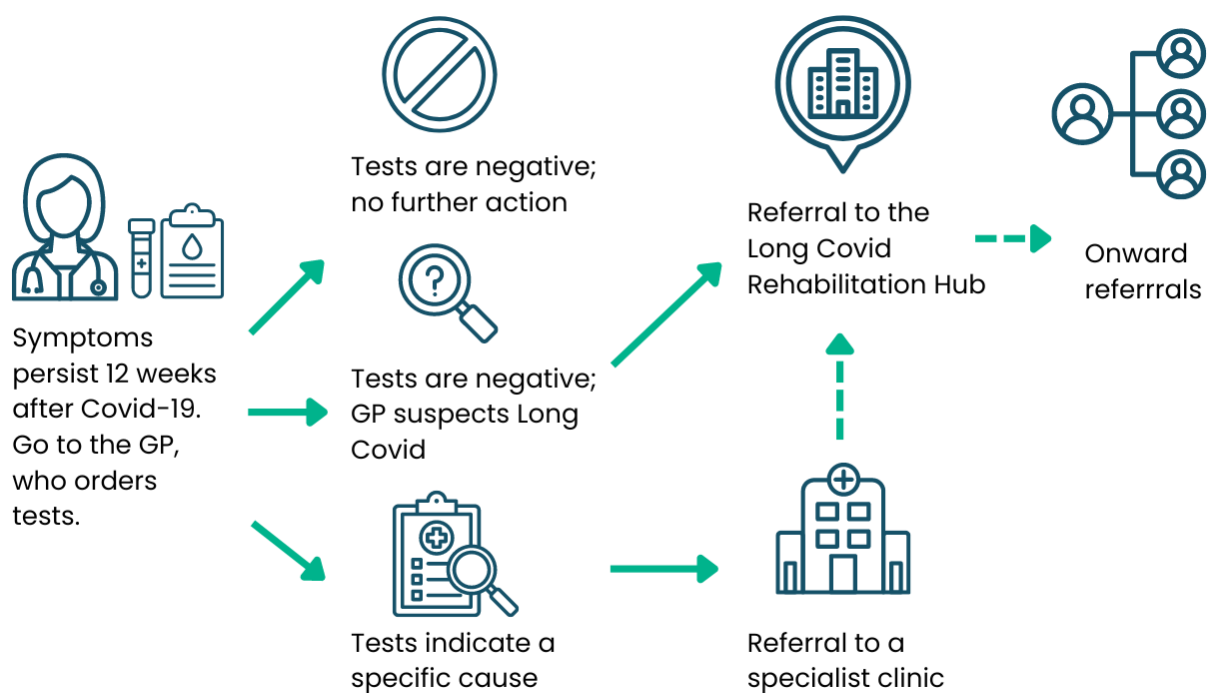
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<sup>13</sup> An under-served community is one which is not adequately provided with enough help or support - their services or facilities may not be of a high enough quality.

# Experiences of health services

## The journey through the services

In Sheffield, the GP has been placed at the centre of the Long Covid journey. They are the first port of call for what is defined as 'a diagnosis of exclusion' – which means that it is only when other possible causes for the symptoms have been ruled out – that a patient may get a diagnosis of Long Covid.



A number of medical tests may have to be completed with the appropriate specialists in order to rule out any other causes for the symptoms. Once all investigations have been done and there is no other diagnosis – then the GP may make a referral to Long Covid specialist services. In Sheffield this is the Long Covid Rehabilitation Hub.

# General practice

People spoke of the difficulties in accessing support from GPs. These issues are not exclusive to people with Long Covid, but they place a significant barrier for those who need multiple appointments and who have limited energy. The following barriers are those that people identified:

## Difficulty booking appointments

Almost everybody spoke of the difficulty in getting to see their GP, the frustration with the appointment system as a whole, and of the challenges that this causes when having to book multiple appointments:

*"The GP appointment system needs to change... being in a queue and being asked to call at 9 or 8.30 in the morning is really hard for people with Long Covid particularly, because I'm often sick in the morning and can't sit on the telephone waiting, and calling later in the day isn't a solution either because you're still number 28 in the queue" Justine*

*"I had an infection so I called my GP. They didn't pick up [so] I went there because I was waiting for 40 minutes in the queue. [They] didn't pick up the phone again, they said I had to book an appointment on the phone. I took the phone out my pocket and rung them, and she asked why I was standing there. I said it's because you didn't pick up the phone, and I can see that you're free and still don't pick up the phone. This has been going on for a few years now. I don't like the GP" Fatima*

## Telephone appointments do not work for everyone

There were mixed opinions on the use of telephone appointments. Some found the experience of trying to communicate with their GP practice stressful and disappointing:

*"I'd phone up for something and I didn't even get to speak to my GP, they'd pass messages from reception and then get back to me. And I just thought it was just disgusting. I felt it was just it was extremely poor. And then I just thought to myself and other people must be going through this thing, must've lost their jobs and things" Kyla*

Others found it frustrating that a telephone appointment was not available to them:

*"I'd called initially to ask for a phone appointment and just had a massive run around with a receptionist who refused to give a phone appointment. Said he [partner] wasn't down on their system as housebound. So she'd got appointments, but she wouldn't give them to me" Julia (carer)*

## Short appointments for complex conditions

It was often difficult for people with Long Covid to understand what was happening to them or know how to describe their symptoms. People spoke of a multitude of confusing symptoms that varied in frequency and for which they found the limited appointment time insufficient.

*"I've had 38 symptoms so far and sometimes one goes away and two days later something else really weird crops up and you're thinking is that my imagination" Justine*

*"I can't imagine if you are struggling to articulate how you're feeling about something because it's new or you don't know the words, trying to do it with [a GP] who's constantly looking and thinking 'I want to spend time with you, but I've got six or seven different appointments that I need to come in' and that's if you can even get an appointment in the next few weeks to even to do that" Olive*

*"The symptoms were more profound at certain points, similar to Chronic Fatigue Syndrome, but didn't always make sense, I kept symptom diaries to try to understand the triggers" Sam*

## Administrative barriers and delays

Many people spoke of the administrative barriers and delays in their journey with Long Covid.

This included the **emotional and physical toll** of this challenging process, and dealing with receptionists who felt unhelpful. When feeling very unwell, they would have to navigate the various appointments and tests as well as the delays and cancellations:

*"I got told there are these things that I have to do. I had to go to the hospital for a chest X-ray that was at the Northern General. So, I did that. And then I had to go for an ECG at Nether Edge hospital. Went and did that. I had to book an appointment at the surgery to get my bloods done. Did that. So, they were like*



*additional hoops to have to jump through when you're already really struggling just to stay in work. So, I did all of that and then months and months went by... probably 6-7 months, didn't hear anything from anybody. Rang the GP and said have you actually made this referral? Because I've not heard anything?" Kiara*

They also spoke about frustrations of having to follow up **lost forms and referrals**. As Long Covid is a diagnosis of exclusion, a GP needs to order a bundle of tests before the referral can be made to the Long Covid Rehabilitation Hub. This has been a source of frustration and delays as the system loses forms, orders the wrong tests and people find their referrals returned, marked as incomplete:

*"Then we did get referred through and then Long Covid hub were like, well, you're missing these tests. You need to confirm these things before we accept you because you need to rule out other things, make sure it is Long Covid. So just a lot of a lot of delays and disconnect. Yes, and confusion" Adam*

*"Like they just lost forms, they just didn't do tests and they didn't explain processes to us, so like once they'd got all the information or we thought that all the information, the form just like sits somewhere and it can sit there for weeks waiting to be emailed, I think is the process which just strikes me as absolutely wild that that happens" Julia (carer)*

People spoke of not having the energy or organisational skills to **advocate and follow up delays** in referrals and administration, this means that they can fall through the gaps:

*"There's no way I would have been able to just chase up all those admin things and logistics with like how tired I am. I probably would have just fell through the cracks I reckon, if my partner hadn't chased it up" Adam*

People also said the complexity of managing various medical appointments and referrals is **exhausting**, particularly for those suffering from fatigue and brain fog:

*"As you can see from that big pile of paperwork, it's so hard to keep track of it, and I keep trying to write it all down, but I think what I do is write a bit down and then forget about it and then I write more somewhere else" Caroline*

## Difficulty in getting a diagnosis

People said that diagnosis of Long Covid has been important for them for two main reasons:

- It provides them with access to services such as the Long Covid Rehabilitation Hub
- It supports them at work

There were many reasons why people found it difficult to get a diagnosis of Long Covid.

### 1. Those with complex pre-existing health conditions found it difficult to get a diagnosis

As Long Covid is a diagnosis of exclusion, people with pre-existing health issues often struggle to convince doctors that their symptoms are due to Long Covid.

*“About 20 years ago, when I was in my late teens, I had ME. And [GP] said ‘Ah, your ME’s come back.’ And I was like ‘what?’ No, it hasn’t this is not what this is, this is devastating... this isn’t anything like my experience of ME. The symptoms that I’m having aren’t the same, apart from I’m knackered, but it’s tired in a different way. And it was it was just a constant battle of speaking to the doctor trying to get something sorted out and trying to get referred and nothing really happening”*  
Caroline

### 2. Professionals had a lack of awareness and understanding of Long Covid

People reported that their GPs had a lack of awareness and understanding of the nature of and criteria for a diagnosis of Long Covid, they often had to refer them to the NICE guidelines<sup>14</sup> written for the condition.<sup>15</sup>

The lack of testing early in the pandemic meant that some people were unable to provide a positive test. Others had tested negative despite experiencing symptoms of Covid-19. **The lack of a Covid positive test result posed a barrier with those GPs who thought they needed one to start the process of diagnosis.**

*“At this point, it was 6 weeks after I became infected, and I called the doctor to say that I thought I have Long Covid. The GP said ‘You haven’t tested positive so you don’t have it’. I asked him if he’d seen the NICE guidelines saying that people can have Covid, even if they don’t test positive. And I asked him if I could be referred to the Long Covid hub and he said: ‘No, you need a positive test result for that.’ And I again referred him to the guidelines, which said you don’t need a positive test result”*  
Justine

People felt that GPs had **a limited knowledge of the symptoms of Long Covid**. They did not fully understand the nature of Long Covid and how symptoms can vary between individuals. The cycles of symptoms that come and go and the varied

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<sup>14</sup> The National Institute for Health and Care Excellence (NICE) produces evidence-based recommendations in the form of guidelines for health and care in England and Wales. They help health and social care professionals to prevent ill health, promote good health and improve the quality of care and services.

<sup>15</sup> <https://www.nice.org.uk/guidance/ng188> (last updated 25<sup>th</sup> January 2024)

experiences of recovery needed to be understood and communicated to people with Long Covid.

*“Another bulletin that needs to be going out [to GPs] is the relapsing and remitting nature of Long Covid, because there are some expectations out there that you are going to recover more quickly than you are. I know that this information changes all the time, but we have a cohort of [year] 2020 people who are not recovered, a huge cohort, so there needs to be some awareness about that” Justine*

Many believed it was reasonable that medical professionals were not fully informed about the evolving guidelines and diagnostic criteria in the early days of the pandemic. However, they also felt this should not have prevented a serious consideration of their health concerns.

*“It was the end of April 2020. So, to be fair, the information coming out was very new and the GPs at that point were pretty overwhelmed. I didn’t see them face to face. They weren’t doing face to face appointments. So the antibiotic prescribing was over the phone and the request for the Long Covid referral was over the phone” Justine*

*“I didn’t feel that the GP was kind of really taking it seriously. Now I know that he didn’t really understand, he didn’t know – nobody knew. But I didn’t feel very supported” Caroline*

We heard that those who had the confidence and were in a position to self-advocate could sometimes push through to get the support that they needed, but for others this was much more difficult.

*“It was my own lack of understanding that stopped me challenging some of these attitudes” Sam*

## Not being believed

People expressed frustration at encounters with GPs who would **not believe them or take their symptoms seriously**:

*“The doctors didn’t believe me because they had a very narrow idea of what Long Covid looked like. When I went and said all these things are happening, these musculoskeletal things... brain fog, this raging tinnitus, this burning sensation, you know, they were just like ‘oh It’s the menopause” Kiara*

*“One GP asked me if it was all in my head” Sam*

*“Professionals need to be a bit more open to listening and not speaking quite so much. And taking people seriously, I don’t have any history of factitious disorder. You know, I wouldn’t make something up. Quite the opposite. I don’t go to the*

*doctor's enough, you know, I tend to deal with things on my own. But when I do go, I don't expect it to be treated like somebody who has got a factitious disorder. You know, there were very real symptoms. They were very disturbing experiences for me, especially with somebody who's already got pre-existing conditions both with my lungs and with you know, my disabilities. I just felt the response was utterly dreadful" Kiara*

People told us of their frustration that GPs play a key role in diagnosing and managing the Long Covid pathway. When GPs are doubtful or unsupportive, they said that it makes dealing with this confusing and exhausting condition even harder."

*"I find that if I ask certain questions they [consultants] go 'Oh I don't know, you need to speak to your GP'. My GPs have been quite sceptical. There's been times when I've had a conversation with the GP and he's just been so unsupportive that I've burst into tears because I'm just at the end of my tether with it" Caroline*

**When their experience of Long Covid is dismissed by a health care practitioner, people said this has a significant impact on their health and wellbeing:**



- It can make it challenging to manage their own wellbeing
- It can make them hesitant to seek help
- Their inability to self-advocate might stop them getting the treatment they need

## **Barriers to referrals to Long Covid services**

All of the barriers that people experienced at the beginning of their journey – the difficulties getting a diagnosis, the dismissiveness and the lack of awareness – have made it difficult for them to get referrals to the Long Covid Rehabilitation Hub.

**Out of the 19 people with Long Covid that we spoke to, only 12 had been referred to and attended appointments at the Long Covid Rehabilitation Hub.**

**This means nearly one third had never been to the Hub.**

Of those who had, very few people had a referral to The Hub suggested to them by their GP. For most of them, they not only had to suggest the referral, but also advocate for themselves by insisting on it or facilitating the process by providing the information.

The barriers in general practice that people described to us affected their ability to obtain a referral to Long Covid services:

- GPs **did not know how to make referrals** to Long Covid services, so people with Long Covid had to find out how the referral system worked and guide them.

*“I had to really fight for my GP to refer me to the Long Covid Hub and he really struggled to work out how to do it – It was me that was finding out for him how to do his job. So I had to learn how they go about referring people... If those things were trained out, then that would have made a big difference”* Caroline

- Some GPs **questioned the value of referring to Long Covid services**. When the patient didn’t insist, they were not given a referral and so they were left to go home to self-manage.

*“Well I said ‘what can be done, what are the options? What treatments do you have for Long Covid?’ And they were like ‘it’s just this [the Long Covid Rehabilitation Hub] and you have to do lots and lots of tests’. They sounded sceptical and I sounded sceptical too. And I think they seemed quite happy to just let me not do it...”* Simon

- Needing **support** to get a referral:

*“When I spoke to the psychologist over the phone, she asked me if I’ve been referred to Long Covid Hub, and I said I’ve asked my doctor, but I’ve been told no, because they’re treating my symptoms. And then she said, OK, leave it with me. And then she advised my GP and then they referred me finally”* Fatima

## Community Insights: Barriers and under-representation

People spoke of the **trauma** of hospitalisations and of the multiple deaths in their communities during the Covid-19 pandemic. They said it’s important that we acknowledge **the impact of the pandemic on our diverse communities and the lack of mental health services to support those affected during this time.**



Diverse communities identified **barriers** that people experience when accessing healthcare services:

- **Socio-economic and language barriers** that lead to unequal access to healthcare and varying levels of understanding among different communities.
- Healthcare environments often lack **cultural representation and a welcoming atmosphere**, which can discourage people from seeking the medical care they need.

People also spoke of the **value of local knowledge, community projects, and diverse cultural practices** and how they contribute to overall well-being, as well as the importance of **including and learning from diverse health communities.**

## Importance of believing patient concerns

There were a couple of instances where people had a positive experience in which they felt supported and understood by their GP, as a result of which – all the necessary tests were completed in order to have a referral to the Long Covid Rehabilitation Hub.



*“Thankfully, my GP was really nice and actually listened to me and suspected that it was likely Long Covid, although I wasn’t quite at the 12 week point then, she said by the time she’d sent me for I think it was a chest X-ray, ECG and bloods, which a Long Covid clinic needed. Once we got them back, I’d be at about 12 weeks anyway, and if I was still struggling, which she assumed I would be, then she could forward it on. And then she confirmed (after I’d had all them tests) that she was sending it to the Long Covid clinic” Grace*

## What people said they wanted

Many people with Long Covid expressed that they simply wanted their healthcare practitioners to show they believed them, sometimes all that was needed were small, supportive actions:



*“Listening and acknowledging, because people need to be validated that this is real” Justine*

*“I think a little bit of understanding and empathy would have gone a long way, to helping me ‘cos I felt like I was going mad. I felt like, am I making this up? Is this really happening to me? Of course, it’s really happening, but when you’re in it, you forget who you were before. When you’re experiencing what you’re experiencing for such a long period of time you forget what normal is until you’ve come out of it and thought ‘Ohh yeah. Bloody hell I was really, really ill’. And just some validation would have been good” Kiara*

## Spotlight on NHS plan for improving Long Covid services<sup>16</sup>

North Central London (NCL) is using part of its funding for Long Covid services to support Long Covid GP leads in each borough.

These GPs take part in community meetings to ensure that GP services play a key role in planning care and that health records are easily accessible to the team treating each person. Public health teams have also reviewed how GP practices record and refer people with Long Covid, helping these GPs identify which practices need more support and when to refer patients to Long Covid services.



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<sup>16</sup> [July 2022: The NHS plan for improving Long Covid services](#)

# Hospital Care

For people with Long Covid, experiences with hospital care typically meant that:

- They had spent time in **Intensive Care Units**
- They had been referred for tests and evaluations at **Outpatient clinics**
- An ambulance had taken them to **A&E** because their symptoms required urgent care

They spoke to us about their personal experiences, the challenges they faced, and also of the difficulties of communication within the system.

## Traumatic experiences of hospital admissions

A few of the people that we spoke to experienced secondary care through A&E admissions, usually in an ambulance. These experiences can be broken down into two categories:

- Those who were initially admitted during the early stages of the pandemic and spent time in an Intensive Care Unit (ICU). People spoke of the trauma that has stayed with them to this day.

*“The fear is horrific. People do not realise what it was like in there. You didn't know if you were gonna survive or not. And that fear to go upstairs [to ICU]. Got to a point where at night I was shaking. And I would panic and I was crying, screaming, shouting and you know, it took me ages to, you know... even now sometimes... you know... there's sometimes you wanna cry” Omar*

*“He was traumatised by his stay, he became very depressed and kept asking doctors if he could leave as it was affecting his mental state. The mental health team came to talk to him which helped, but it wasn't provided in his language” Interpreter to Bilal*

- Those who have been admitted to A&E numerous times due to the severity of their symptoms.

*“My experience of going to A&E was horrendous, they actually told my partner that I walked out of the hospital, I had been there over 12 hours. I was basically unconscious on a bed and they said to him ‘oh no she's not here anymore, she's been discharged, she's gone’. He had to check my location on my phone, which showed that I was still in A&E... They'd lost me basically, so yeah it was really horrible” Caroline*

## Difficulty navigating hospital services

For many people, the Long Covid journey consisted of multiple referrals to a variety of different specialists and this caused a number of difficulties.

The main challenges for patients trying to navigate a system that they are unfamiliar with, was the lack of coordination and communication between consultants, administrative systems and departments with whom they were trying to get an appointment or treatment.

People spoke of the **lack of integration of medical records**.

*"It feels like none of them kind of talk to each other. I would expect the medical records and systems to integrate so that it's easier for someone to get a holistic view of what 's going on. I find so many of them [consultants] are so dismissive, and it's just really hard work to manage" Caroline*

There were **difficulties in scheduling appointments with specialists** due to the unavailability of appointments and cancellations causing delays. People said that this is particularly challenging when these are inter-dependent and patients have to coordinate them themselves. Many people spoke about the frustrations of referrals getting lost in the system.

*"My GP lost one of the referrals. We spent 4 months chasing up the appointment and I was told that it's up to the patient to chase up the appointment, so it's up to me to go back to the GP not the Long Covid Hub. And my physio tried to get into the computer system to chase the appointment, but she said 'I can't do it. The hospital computer system is separate from SystemOne, that GPs use. So you'll need to go back to your GP'" Justine*

The **lack of coordination and communication** between professionals and departments was a source of frustration for many. People spoke of having to repeat and justify themselves and felt that there was no one that was looking at their case as a whole.

*"Then I'll see a consultant and they'll say 'Why are you in a wheelchair?' And then you have to explain it to them and it's just so off-putting, you know. You feel like you're having to justify yourself all the time" Caroline*

*"Each department deals with the problem he goes in with but they're not connecting the dots" Lucy (Carer)*

The difficulties of navigating a confusing system were compounded by having to manage the information and advice given to them.

*"There is no matching up of information, it's uncoordinated and the advice is inconsistent" Sam*



## Areas for improvement: Learning with patients

People with Long Covid need a comprehensive, person-centred approach that improves knowledge and a better understanding of the condition.



### Listening consultations

Many people spoke of going to appointments with consultants and GPs where they didn't feel listened to and where there wasn't enough time to describe the complex symptoms.

*"It's like it's a quick, a quick appointment, you know, quick, you tell them quickly and they just, you know, skills and then give you they don't really put their whole effort in to try and really dig down at the problem, you know deeply"* Hamza



### Sharing knowledge

People with Long Covid often felt that they had more information about the overall condition than the healthcare practitioners that they spoke to.

*"Another thing that me and the other people in my group have experienced a lot, is that we are actually in a position of educating the clinicians. Now of course I don't mind that, because to a certain extent it's different for everybody so they need the information from you"* Justine



### A collaborative approach

Many said that more research on Long Covid is necessary and that a joint approach between people with Long Covid and clinicians is an important step to enhancing understanding of the condition.

*"Healthcare professionals need to take a proactive, transparent and collaborative approach with their patients"* Disability Sheffield

*"[Long Covid] Needs more research and understanding from the medical professionals"* Sheffield ME and Fibromyalgia Group



# Long Covid specific services

In Sheffield, Long Covid specific services are delivered by the Long Covid Rehabilitation Hub, as part of Sheffield Teaching Hospitals. This service opened in January 2021 and began taking referrals that same month.

The offer at the Long Covid Rehabilitation Hub has developed over the period of time that it has been running. The experiences that are described here represent people's stories which span from January 21 to May 23. Out of the 19 people with Long Covid that we spoke to, 12 had accessed the service – for those that didn't, a number of barriers to access were described which are set out on page 19.

## The Long Covid Rehabilitation Hub ('The Hub') in the patient journey

Within the first year of the pandemic, as people were beginning to recognise the existence of Long Covid, they started to search for Long Covid services. Many of the people that we interviewed had signed up to participate in research programmes both at Sheffield Hallam University and other national centres to help them connect with others and learn more about the condition.

## Expectations of the Long Covid Rehabilitation Hub

People had varied expectations about what the Hub would offer them. The lack of information available to patients before being referred to the service led to confusion, as many had assumed the service would perform specific tasks.

People indicated that they thought the Hub would:

- Provide a Long Covid **specialist** service that would undertake medical assessments and provide ongoing support, insights and treatment. Instead people felt that there was an absence of medical intervention, with an emphasis on the management of the condition instead of treatment.

*"But when I got there it was a bit of shock. Because they were like, 'oh, we don't do any medical treatment... that's not a service we provide. If you need some sort of medical treatment [you need to go] back to your GP'. So, I was kind of a bit confused as to why I was trying to go there in the first place"* Adam

Many people expressed a dissatisfaction with a rehabilitation approach that focuses on supporting the patient to live with the condition instead of a clinical

approach to diagnostics and treatment. The **clinical approach** focuses on diagnosing and treating the condition itself, the **rehabilitation approach** focuses on helping the individual live as fully and independently as possible despite the condition.

- Provide **coordination** within a centralised service that would manage the complexities of referrals to specialists, coordinate the appointments and review available treatments.

*“At my surgery no one keeps tabs on all these referrals and no one kind of connects the dots so I'd much rather have a specialist hub in the centre with consultants who are connected to the hub who can offer a multidisciplinary approach, and actually talk to each other about, you know, what's going on with me rather than this way that it works at the moment”* Caroline

- Provide clear **information** about what the service offers the treatment options.

*“I know there are doctors at the Hub but I don't know, or there's a clinical team. I don't know what their role is. I think it would be good if it was more obvious to patients the process of going through the Hub and what they can actually do and offer you. Because there was an expectation certainly with my case that you know oh they'll be able to sort you out because they're the specialists and actually they're not”* Caroline

## Experiences of the Long Covid Rehabilitation Hub

For some, their arrival to the Hub was a positive experience. After the challenges of diagnosis and referral they spoke of **a sense of relief** at having reached a service they felt would understand and support them.

Taking part in group sessions with others was found to be an important part of managing Long Covid. This **peer support** offered a valuable comfort to many people we spoke to.

*“I got the diagnosis and then I went to the Hub. It was clear. And I think that was what was so enlightening and comforting... and all the people there was exhibiting it and saying I've got this, I've got this, which was exactly what I was saying and you think. Ohh it's OK. I know what I've got now. And maybe not I know what to do because I'm not infectious. But I can pace now. I can learn how to pace properly and that'll work better for me”* Barbara

People were pleased with the **practical support** they received for making changes at home, like using aids and adaptations. They emphasised the importance of having early assessments by Occupational Therapists to help with daily needs.

*“I think it was good. I think the occupational therapist being involved was really good... having that point of contact is quite good”* Helen

## Case study: A journey with good support



Maria was diagnosed with Covid in January 2022. She had two weeks off sick before returning to her job at the Hospital. Two months later, after her manager noticed her severe breathlessness, Maria was prompted to visit her GP, who suspected Long Covid and referred her for diagnostic tests.

Within three weeks Maria had her referral to the Hub and was booked in for some telephone consultations with the therapists. She was referred to various specialists, including cardiology for palpitations, respiratory physiology for sleep studies, and eventually occupational health for a phased return to work. Throughout her journey, Maria experienced challenges accessing psychological support, relying instead on a counselling service available to her through her work as a healthcare worker.

Maria's experience with the Hub has been quite comprehensive, with the Hub taking the lead in coordinating her care rather than her GP. A healthcare worker at the Hub also provided support for fatigue management, including home assessments and arranging aids and adaptations like a perching stool.

Despite being discharged whilst her care was managed by other services, Maria was able to re-connect with the Hub when she needed support for her mood and psychological well-being. She found the group sessions offered by the service might have been more helpful at the beginning of her journey and helped her prepare for the mental health challenges associated with Long Covid.

In terms of ongoing care, Maria has upcoming appointments with the Hub to address her fatigue and stress management needs, and she plans to inquire about specific therapies like vagus nerve stimulation that have been beneficial for others but haven't been mentioned to her by the Hub.

She appreciates the support she has received from the Hub and feels fortunate to have been able to access their services despite the challenges posed by her Long Covid symptoms.

## Areas for improvement

### An initial assessment that considers the health of the disability community before Long Covid

We spoke to people who were disappointed to find that the initial assessment questionnaire on arrival at the Hub, which asked for information about pre-existing conditions and abilities and how Covid-19 had affected them, did not consider the health and abilities of the broader disability community. They expected that the

assessment process would include a more comprehensive examination of their physical capabilities and disabilities.

*"I got the letter through explaining asking me to tell them what was happening, you know where I was before and where I am now, but that I couldn't fill in. I just couldn't fill the letter in because I'm already disabled. I was disabled before, but [the questionnaire] was coming from a point that you didn't have any disabilities or any problems whatsoever before"* Kiara

*"It was just a form that just asked you the subjective questions. Things like how well do you feel on certain, most days. It's a bit like the one they use for PIP. It was very subjective, actually, that form because I remember filling it in initially and thinking to myself because there's all this middle ground and I didn't know whether to fill in it's most days, is it today? And I actually think the things says today or something like that. So I filled it in first and I thought 'No, this doesn't make any sense' so then I did it based on how I've been feeling"* Olive

### **Provision of support during the referral process**

Waits of six months in getting the first appointment after referral were not unusual, while the Hub was developing its service offer. People spoke of a frustrating lack of contact during this period, where they felt they had been left to cope on their own.

*"And then the Long Covid clinic referral went in sometime in that year. And you know, it took absolutely ages for somebody to come back to me. And it was just like, well, what's the point? What is the point in this?"* Kiara

### **Lack of treatment explanation**

Many people mentioned being referred to an online breathing programme run by the English National Opera (ENO Breathe). This specific referral was challenging for many because they did not understand why they had been referred to it. The lack of an explanation made people feel that their condition was not taken seriously.

*"I did feel that it became a blanket referral because clearly my issue was not what the, you know, ENO project had dealt with. So I did get angry having sat in two sessions and then thinking, you know, I'm taking the session away from someone. Blanketly sending people there is another issue. Really figuring out if an Opera House project is going to help when somebody's life has completely fallen apart. It's a very middle-class referral, although the funny thing about when you're in the community of ENO project, it's just so not"* Olive

### **Improved accessibility of courses and materials**

Many people attended sessions provided by the Hub on topics to help them manage symptoms such as fatigue, as well as classes on things like stress management. Whilst some people found these useful, there was a variation in how

suitable the course materials were for people with conditions (such as brain fog or fatigue) that make it difficult for them to be actively engaged over a period of time or causes them to crash after the activity.

### Need for a person-centred service

Some people felt that the response to their situation was met with a generic response and that the service needed to understand and address the unique challenges faced by the individuals with Long Covid.

*"I was just like... I think I need more like specific advice that I can actually, you know, take on because like all the advice you're giving me is not relevant to my situation. It's like I don't have the capacity to do the things you're describing anyway"* Adam

### Case study: Challenging referrals

Sam had her first appointment at the Hub in November 2021. In total, she had three appointments and received three referrals from the Hub.



The first referral was to a breathing program run by the English National Opera, which Sam found frustrating and chose not to pursue.

The second referral was for a rehabilitation exercise program with Nuffield Health. However, by this time Sam found that she was pregnant and although she had disclosed this early in the referral process, it was only when she went for her first session that they told her that she couldn't participate, due to her pregnancy.

The third referral was for the Chronic Fatigue Service, but by then, Sam was disillusioned and disengaged, so she didn't attend.

Sam felt that she hadn't been offered any meaningful treatment options to address the symptoms and difficulties she was experiencing. She was very dissatisfied with the referrals she was offered and decided that her time and energy were better spent learning how to manage her condition on her own.

*"I'm trying to manage all of these things it's virtually impossible. It's really hard work. As someone who's maybe on their own or who doesn't understand, or a child, or an older person. I don't know how they do it and I know someone [who] said that they haven't been referred to the Hub I think because he said it was a bit too much. And I completely appreciate his perspective because, you know, it's not what I think, we hoped it would be"*

# Cross-cutting themes

## The need to self-advocate

People told us how difficult it had been for them to get the care they need. They had either had to firmly advocate for themselves, insisting on referrals and following these up, or had others – mostly partners, do it on their behalf.

Some people spoke of all the requests that they had made for information regarding things like test results. Others told us of their ‘battles’ and having to ‘fight’ to be heard.

*“I asked for a blood test. I had to go to the GP and request the blood test and then they sent me to Hallamshire Hospital. And I went to get it done. And when I requested again to go back to have a breakdown of the results, the receptionist said, ‘oh, you’re fine’ but I wasn’t fine, I really was declining” Alesha*

*“It was just a constant battle of speaking to the doctor trying to get something sorted out and trying to get referred and nothing really happening” Caroline*

Many spoke of a system in which it is difficult for people to have a voice, and in which you need to be strong and articulate to be heard in order to get what you need.

*“I really feel like people that are not able to advocate for themselves, who don’t have the support of someone who can do that. I feel like they’re gonna get lost. [Partner] doesn’t think he would’ve got through to the Long Covid clinic on his own. I advocate for people all the time and it was hard, so I don’t know how people have Long Covid or just people who, you know are not used to navigating these systems can manage it” Julia (carer)*

*“And so when you’re going in to the situations that are just really challenging. How on earth are you supposed to fight for yourself?” Olive*

The struggle to self-advocate was felt by everyone, including those people that we spoke to who worked as professionals in healthcare.

*“Calling my GP became stress-invoking. It was just awful and I just felt so disappointed that I couldn’t advocate for myself and I’m usually really good at that. And it was, it was just horrible, it was horrible, being in that situation and [GP] just did not understand” Kyla*

People from under-represented ethnic and linguistic backgrounds faced additional hurdles in their access to healthcare due to language barriers and lack of confidence in advocating for themselves. The need to be assertive and strongly advocate for themselves was mentioned by most of the people we spoke to from diverse backgrounds.

*"I've had to fight really hard and advocate on my own behalf... So I've had conversations with doctors who've gaslight me about things, doctors who have not taken things seriously, or who thought I was more stupid than I am. I recently had a conversation with at the same surgery with a Doctor who was using an outdated methodology of calculating kidney disease, which was based on colonialism and racism, which is no longer being used"* Olive

*"It's tough. And I am quite confident. So I do wonder what other African Caribbean, non-white people where English is not their first language, and the less confident - what they face. It does worry me"* Alesha

## Communication and training needs of healthcare professionals

Many of the difficulties that people spoke about centred around communications with healthcare providers.

People felt that they **weren't listened to**. They want person-centred care that treats them as individuals. The difficulties in explaining the symptoms of Long Covid and the uncertainty surrounding the nature of the condition, means that people need medical professionals to listen to them and engage with their concerns.

*"We are actually in a position of educating the clinicians to a certain extent, it's different for everybody so they need the information from you. But a lot of what we're doing is giving them basic information. So there's two or three articles that we're always digging out the links to and giving to other people in the group because they go into their GP or they go into one of the specialists and they say: 'They're there denying my symptoms, they're saying they're not real, they're saying it's something else, they're saying it's psychological' - that happens a lot - 'They're saying it's anxiety'"* Justine

People want a **holistic, person-centred approach** to their care in which they could have more in-depth conversations with healthcare professionals and be treated with respect.

*"Start off by treating that person as a person. The treatment is based on an average. We accept that, but the care you give them can be personalised and we also know that half of treatment is care, it's how you respond to someone. And it's something that you know that you can do and I know there are many healthcare*



*professionals who would love to spend more time doing that, but the system is the system” Olive*

*“I think I could have benefited from maybe a longer conversation, maybe some more probing questions into my health and well-being because I did know something was not quite right, but I just kept. Yeah, I just didn't wanna not continue to advocate for myself. I hear so many stories where people that keep getting shoved out of the door and then they've actually got something internally wrong with them and they've just never known. So I just didn't want to kind of let myself windle away when I know that I'm not how I'm normally feeling and I couldn't really, I didn't really know” Alesha*

# Self-management

## The importance of trying different strategies

The experience of having Long Covid has affected people in different ways, and so the personal resources that people have sought or developed to manage themselves and their lives, have also varied.

For some people, the most significant personal strategy was to learn how to manage their lives in a different way. This could include understanding how pacing<sup>17</sup> could help them on their day to day or joining a group of people with similar experiences.

The main theme was that people had to keep trying to find something that worked for them.

*"It's just a case of trial and error, and it's hard to kind of get your head around why some things work for some people and not for others. It's just a case of trying things"* Caroline

### Community insights: Sub-Saharan Africa

Two voluntary organisations working mainly with people from Sub-Saharan Africa spoke to 60 members of their communities, including some who were asylum seekers and others who were homeless.



People spoke about self-management because of the barriers they experienced when accessing healthcare services. They mentioned the difficulties in getting appointments, but also spoke about how language, poverty, traditional approaches to health as well as their experience of racism – continue to affect their engagement with healthcare providers.

*"Because I can't speak good English, they don't listen to me, say 'No interpreter today'. Next is, I receive prescription of medication that I don't know why I should take"* Abena

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<sup>17</sup> Pacing is a strategy used to self-manage fatigue. It involves balancing activity and rest to avoid overexertion and prevent "crashes" or exacerbation of symptoms. The aim is to break tasks into smaller, manageable parts, interspersed with regular rest periods. This way people can hope to maintain a consistent level of activity without overwhelming their energy reserves.

*"Not easy to get appointment, I'm tired and these symptoms comes often and am worried, but what can I do? My English not good. I don't bother anymore"* Palesa



*"I don't think the NHS can help. It's difficult to see the doctor and if they give a prescription, I don't have the money to buy"* Chike

They reported that there were a number of factors that influenced their relationship with the medical establishment, these are primarily related to:

- A prevailing lack of trust in the quality of care that they might receive



*"We don't know why Black people were dying more here. They should tell us first. Why did many Black people not die in Africa with no vaccines, but they died here? I will try other things first – I don't trust the help now. There was no help during the pandemic"* Dakarai

- A widespread use of home remedies and African traditional medicine (including ginger, lemon, cannabis, apple cider vinegar and eucalyptus oil)



*"I do the steaming with Vicks. We used to do it back home. It helps when I feel breathless. I also make ginger and lemon tea – everyone uses it, I learnt from WhatsApp groups. People didn't have vaccines at home, they just used other things like guava leaves, eucalyptus and other leaves and herbs – I don't know their names in English"* Zaire

- A hesitancy to seek statutory help among asylum seekers



*"He is a failed asylum seeker who fears seeking help when ill as he's worried the healthcare provider will call police on him"* Project worker

## Prior long-term illness helps people understand

People with previous experience of long-term illness found that they had tools with which to understand how to manage their Long Covid.

*"With the ME, I was told to do graded exercise therapy, which I did and I was put back and was bed bound for two years so there's no way I would do that. Because of having ME for so long, you know the language, you know what comments to make, you know the trigger words"* Barbara

*"I've had long term health conditions most of my entire life, and many of them have been life and energy-limiting, so I've had to kind of pace myself, so I understood about pacing, but I never understood it from a fatigue point of view. So mostly it was a pain point of view that I was dealing with"* Olive

## Community insights: Organisations working with people with Long Covid



Darnall Wellbeing (DWB) and the Sheffield ME, Fibromyalgia and Long Covid Group (SMEFG) are two groups in Sheffield who are working with people with Long Covid. They joined together to survey their members. Altogether they heard from 48 people with Long Covid from across their communities.

### The barriers to accessing support included:



- A lack of information about available support options
- Financial barriers\*
- Time constraints or scheduling conflicts
- Mobility or transportation issues
- Language or cultural barriers
- Negative social stigma
- Long Covid symptoms and/or physical health
- Poor mental health

### What support did people want?

- The need for mental health support was frequently mentioned in relation to adjusting to a 'new self' and how the illness had transformed their lives.
- People wanted something more specific and dedicated to the condition than was on offer through Talking Therapies
- A holistic approach to their healthcare with longer GP appointment times so that more than one symptom can be discussed at each visit.
- People wanted follow-up and support post-discharge from the Long Covid Rehabilitation Hub



*"I've now been discharged from Long Covid Hub as they have nothing else to offer. I'm still struggling but there doesn't seem to be anything else"* Survey respondent

*"There is a lack of follow up from the Long Covid Hub. When requesting additional support or services from the hub, I was asked to wait so not to 'overwhelm' me with appointments. I explained that there was no risk of overwhelm but was still discouraged from more care - to date, I am still waiting"* Survey respondent

## How did they want this support?

- People mostly wanted face to face support. This was mainly because language support needs are easier to work with in person and because many in the community are digitally excluded in terms of resources and/or skills.
- Those that felt they benefitted from online support said that it fitted better with their working patterns and was an option for those times when they didn't feel well enough to attend in person.
- The response to peer support groups was varied across the two communities. Some people at DWB mentioned that they had been to support groups in the past and had not found them helpful, or that they felt they might bring the group down when they're in a negative mood. The community in SMEFG however felt that peer support was important to them.



\* People in both groups were struggling with the cost of living. Many had a reduced income due to losing a job and/or partners taking on caring responsibilities.

People said they struggled with:

- a) Knowing what Government support they were eligible for, e.g. PIP (Personal Independence Payment) and Blue Badges
- b) Getting help with completing the process of applying for financial support (due to language issues, learning difficulties, general comprehension) as well as filling in the forms to best reflect their experience



## The importance of voluntary organisations

Most people had contacted organisations based in the voluntary sector for advice or support, whether it be for specific advice and information or to join a support group. Other than the NHS, people looked to specialist national organisations for people with Long Covid as well as for local resources provided by community organisations.

*"One of the things I will say to people when they have a particular health condition is find out if there's a charity that supports it because the charities are always amazing, they would break it down and they will give you support. Some of them even have their own counsellors" Olive*

*"I ended up speaking to someone from Frontline 19 who were offering like free counselling type sessions for people who are affected by Covid and that really helped, it was just trying to like frame things and put it into like perspective. And that helped a bit because I just got into such a rut that I was just completely fed up" Grace*

## Using online resources to understand their condition

Most of the people that we spoke to had turned to the internet to connect with others, look for information that might help them understand their condition and find sources of support. The online communities have been a great source of reassurance for many. These informal peer support networks made people feel recognised and less alone.

*“Just like understanding that other people are going through the same thing, and sharing frustrations and advice and tactics, and celebrations. Like if [my partner] drove me out to the Peak District and we’ve had a nice picnic, I feel those people understand why that’s good” Adam*

*“Facebook was my saviour because I found the Long Covid support group really early on, and it was like, it was just ‘Thank you, God’, because I just felt I’d found this group of people that were, a lot of them were professionals like myself. They weren’t people that had got a factitious disorder, like I’d been made to feel at the GP surgery” Kiara*

However, the online groups did not work for everyone:

*“The Facebook group was full of very depressed people and reading everything made me very agitated. People also gave me unsolicited advice, for example when I asked about the brain fog because it was agitating me, they diagnosed me with anxiety and started telling me how to manage my panic attacks. It was frustrating” Barbara*

# Impact of Long Covid

## Mental health

### Impact of Long Covid on existing mental health difficulties

A couple of the people that we spoke to had existing mental health difficulties prior to developing Long Covid. One person told us how they had spent a lot of time developing techniques that would help them manage their everyday life:

*“But post Covid, I couldn’t do that anymore. And there were loads of other techniques that I’ve learned, they just didn’t work. What seems to have happened is I’ve got a factory reset on my ADHD. That’s what it felt like. Like it just got back to standard settings and I was gonna have to relearn all these techniques” Simon*

Those who have experienced mental health difficulties in the past told us that their new symptoms were different to what they had known before. Alarmingly, both of the people that we spoke to about the change in their mental health, mentioned having suicidal thoughts as something they had never had prior to developing Long Covid.

*“I really noticed that I was very low, like I was incredibly low. I’ve had three periods of depression in my life that really have been quite traumatising [but now] I’ve been feeling very down and suicidal for the first time in my life... It felt sort of alien, it felt like something, my thought processes changed” Simon*

*“My depression and anxiety did get worse, I had suicidal thoughts. There have been nights in the dark winter where I left the house, just roaming in the streets nearby, my husband looking for me on the street and then after a couple of hours I got back home. I don’t know why I did it or what happened” Alesha*

## Mental distress caused by the impact of Long Covid

People spoke about the impact of Long Covid symptoms on their mental well-being, particularly when the symptoms appeared unexpectedly or were prolonged, which led to feelings of anxiety and frustration.

They also spoke of the trauma and the depression that they felt through feeling isolated and vulnerable. The fear and uncertainty about the future, together with the physical pain and limitations imposed by Long Covid also contributed to their mental distress.

*"My anxiety is directly related to the unexpectedness of the symptoms"* Justine

*"I feel kind of like I am appropriately upset, you know, not like this is a mental health problem. This is like a bad situation. And, you know, I'm frustrated and upset and angry about it in ways that don't feel unhealthy"* Adam

*"Isolation can be so debilitating and that can lead to anxiety and depression"*  
Barbara

*"I've been to A&E three or four times, twice in an ambulance, it's been quite traumatic"* Caroline

## Lack of resources and support

For those that have the money to pay for it, access to mental health support in the form of talking therapies has been invaluable.

*"I have a therapist that I was seeing anyway and she's amazing and I feel like had I not had that support I would be in a much worse place"* Caroline

For others, previous experience of using statutory mental health services have made them hesitant to access further services or engage in any medical interventions:

*"Generally you have to jump through a lot of hoops, you do a lot of work and you get nothing. Often you will get no treatment, sometimes you will get bad treatment. It's vanishingly rare to get any kind of support that you genuinely find useful. Often you will be getting the kind of support where you are required to take an air of positive thinking to see it as useful, rather than it actually being useful"*  
Simon

Many felt that they would benefit from counselling, but the six-week limitation on sessions offered through the NHS Sheffield Talking Therapies was a source of frustration. Some people thought that it undermined the good that could come out of it, and so did not access the service as a result.



*"The problem with everything is that they're time-limited because they're all so resource-light. I mean what is the point of six sessions? You're just getting to the point where you trust someone and then they're having to say – 'I can't help you'"*  
Olive

## **The stigma of mental health**

There were a number of people who spoke about the stigma surrounding mental health within their community – a sense of shame, disapproval, or discrimination associated with mental health problems.

People mentioned a lack of awareness, understanding, or acceptance of mental health conditions, making it difficult for people to talk about or seek help for their mental health struggles.

*"People don't [understand] because you take people at face value nowadays. So they don't realise, they just see you as you are. Like I say, the people saw me. Nobody knows about me. Nobody knows. I remember one thing is mental health itself is a stigma in the Asian community nobody talks about it. A woman can be depressed, yeah. A man can't be depressed. You understand? Well, that's the reality of life"* Omar

# Work and finances

Everybody that we spoke to had had to make adjustments to their working life during the course of their illness. Those that were able to, had taken early retirement, whilst others had managed to transition into roles where they had some level of autonomy over their working conditions. Some people had lost their jobs as a result of their illness.

Managing brain fog, post-exertional malaise and the unpredictability of symptoms had an impact on people's **physical and mental abilities** to carry out paid employment.

*"I couldn't stand all day. I couldn't stand for half the day. You know. I can't stand for longer than half an hour anyway, so I don't know how people work in shops. I don't know how people work in healthcare, the fire service or, you know, I really don't know how people do it"* Caroline

People told us how their **cognitive difficulties** and an **inability to concentrate** affected their ability to carry out their job:

*"I really wanted to get back to work and in financial services. You have to keep up to date with your CPD [Continuing Professional Development] and I found that really hard because I can't focus on anything. So, I can't do like calculations and Excel and all that stuff. I get so confused I just can't do what I could before"* Caroline

People also spoke of the impact of losing their work on their **personal and professional identity**. A nurse who has been working in the NHS for the last 19 years told us of the impact that Long Covid has had on her as she was about to lose her career:

*"Next year I will be receiving my 20 year award which I don't think it's going to happen now I'm going to lose my registration for nursing soon... The registration you have to revalidate every three years and for that you have to have 450 hours of practice, which of course I haven't done and I'm still not suitable to go back to work... that means that the profession that I've loved, always since I was a child, I'm going to lose that now. So that is my identity and that's the only thing I know so that's quite upsetting and scary"* Fatima

People who could work, spoke of the importance of having a working life as a **positive focus** in an otherwise disrupted existence:

*"I feel like it's a real important outlet like. Yeah, I do think I do feel like I probably would feel much worse if I didn't have [job] I guess what I'm saying is that I'm trying to focus on things that are positive still in my life. Yeah, but yeah, I am still, I am still very sad and angry and upset about the situation, you know, frustrated"*  
Adam

## The need for support in the workplace

The first step to getting support in the workplace is to have a **formal diagnosis** with which to communicate the condition to employers. As discussed earlier, this has not been a straightforward journey for many of the people that we spoke to.

Delays in assessments and lack of a clear diagnosis creates challenges for people with Long Covid in the workplace.

*"[With a diagnosis] I think there might have been more sympathy in the workplace environment"* Alesha

### Areas for improvement: Support in the workplace

People spoke about what they needed in their workplace:

- The importance of **flexible working arrangements** to support people to stay in work. Where people had flexibility in how and when they worked, they were able to accommodate their working time and to fit around their symptoms:

*"I'm very fortunate not just because of the flexibility of income but because of the flexibility of the hours, so I can pick and choose. I'm better in the mornings so I try to do my work in the morning and then spread other stuff slowly throughout the day"* Caroline

- Return to work policies that understand the nature of relapsing-remitting conditions and **the need for flexibility** when people have fluctuating symptoms. People with Long Covid may need advocacy when discussing their return to work plans and associated reasonable adjustments:

*"There needs to be that awareness about how to make that kind of reasonable adjustment and also awareness that the reasonable adjustment may have to change week to week"* Justine



- The importance of **understanding and supportive management**:

*"I mainly rested and got time off work. I have a very sympathetic line manager who believed in Covid and never questioned any of it. I was very fortunate"* Sam



- Employers that have **good information and policies**, particularly those small organisations with limited resources who can find it difficult to fully support people in the workplace:

*"I think workplaces generally aren't always very good at supporting people and don't always have the information to do that either. I think particularly in a sector with such small organisations, there's not a HR department, everybody's doing so many different jobs. It does just make it a bit more difficult"* Helen



- **Information and support** that can provide clarity around what individuals can request from employers:

*"A bit of information about what I can ask for. I know there's pages about for employers and stuff on the NHS website, but for me, I think that would've been quite good. A big part of my life that it's affected is my work life"* Helen



- **Covid-safe working policies** that include testing and sickness pay so that people who are actively infected can stay at home until they are no longer infectious:

*"The policy is as it is now, which is to come into work if you have Covid and so we didn't have sick pay at that job. So, you know, the incentive is pretty strong for people to come into work and spread Covid around."* Adam



- The **categorisation of Covid-related illness in sickness records** would help further the understanding of Long Covid in the workplace, legitimise the condition and lead to better support for employees:

*"I think it would have been a real benefit and it could have been at least on the online system rather than it looks like I've just been off sick and I don't know when I've, you know there wasn't any, there wasn't a sort of reason that was tangible that I could express"* Alesha



## Community insights: Fir Vale Community Hub

Fir Vale Community Hub work with a local community which includes an extensive Roma population. They used their community channels to speak about Long Covid to 80 people from groups such as the Roma Network as well as mental health and women's groups.



People reported how their precarious working conditions were a barrier to accessing support:

- They were not testing themselves for Covid because poorly paid working conditions and lack of sick pay meant that they couldn't take **time off work**.
- **Zero hour contracts** affected their ability to attend and manage healthcare appointments as they could not make commitments ahead of time.

## The financial impact of Long Covid

The people that we spoke to had a range of financial circumstances. Whilst a few had the funds and the support at work to help them through the changes in their personal circumstances, for most people, having Long Covid has meant reduced income.

They spoke of the challenges of applying for benefits and the need for specific guidance and support.

*"One thing that we've been putting off is applying for PIP for [partner] it just seems like such an enormous emotional task that we're almost certainly going to fail, at least initially"* Julia (carer)

*"I have been able to buy my way through some of this – I get taxis everywhere"*  
Sam

# Relationships and social life

## The importance of personal support and understanding

Some people had a range of support from their partners, this could be with things like household tasks or with emotional or financial support. They spoke about how this helped alleviate some of the burdens brought on by the illness.

*"I have a lot of support from my partner. So they've taken on like, you know, all the housework, cooking, cleaning, that sort of stuff. It's like driving me places if I need or want to go somewhere, a lot of like logistics as well... just managing things like that"* Adam

## The strain on relationships and family dynamics

In many cases, living with Long Covid has put a strain on relationships and family dynamics and made it difficult to develop new ones. Some individuals experienced shifts in their relationships with children or spouses due to their illness, leading to feelings of guilt or strain.

*"You know, in my relationship, it was just really hard to for me just being constantly ill. [They] Not understanding what the reality of what I was experiencing"* Kiara

## The need for social support and understanding

People spoke about how the lack of understanding or support from friends and family members has been challenging. Misunderstandings about the severity and impact of Long Covid have strained friendships, leading to disagreements and feelings of isolation.

*"I've been a bit disappointed actually with the support that I've had from [friends] Yeah, I think I felt like fairly let down. I still have the relationships and the friendships, but it's not the support that I thought that I would get. I guess this is not a sort of acute event like a breakup or the pregnancy it's, you know. It's just it's ongoing for a really long time"* Julia (carer)

# Caring responsibilities

We spoke with two people who were carers for their partners with Long Covid, as well as others who discussed the caregiving responsibilities of people close to them. Additionally, some of the individuals with Long Covid we spoke to were also carers for other family members.

Many of the concerns that carers have are similar to those voiced by the people they support, but carers also face additional challenges of their own.

Carers spoke of a sense of **isolation and lack of support networks** for those in the age groups that are not at either the younger or older ends of the scale. They said that it has been difficult to connect with others in similar situations and with similar needs and circumstances.

*"I get the sense especially from like walking around that [carers] event and from their sort of photographs, you know, people are a lot older. And there seems to be like young carers, which you know I'm way too old for a young carer. But I'm also not in my 60s and beyond. I don't know where those [my] people are. So yeah, I didn't want to go to the walk and talk thing and the other things didn't seem [appropriate]" Julia (carer)*

## Case study: Caring with a learning disability

Peter has Long Covid and a visual impairment and his wife Lucy is his carer, she has a learning disability. Lucy spoke to us about how hard it is to get health professionals to listen to her and take her seriously, and how difficult this makes her job as a carer for her husband:



*"As a carer it's hard enough, but it's also even harder for someone who's a carer who's got a learning disability to get listened to"*

*"It annoys me that people who are carers with learning disabilities don't get the support as certain people who have got learning disabilities who are patients. Sometimes, especially in my situation, it's important for the carer to understand as well. I need to understand it as well, so I can support my husband and keep him out of hospital"*

One of Lucy's main difficulties when dealing with health services is the accessibility of information, both spoken and written:

*"It's like people think that because I've got a learning disability, that I'm stupid, and I'm not. You just need to explain things in a way that I understand. They sent us this booklet, and it was 20 pages and in small font so I couldn't read it at all. So I asked them if they could either send it back out in large print or an easy read version, and they went 'Sorry, we don't do it in large print and we don't have an easy read process'"*

Lucy believes that if information was made accessible for people with learning disabilities, it would benefit everyone else, especially when it came to things like understanding instructions and taking medication:

*"As we move forward, we need to make sure that every bit of information is accessible for everybody"*



# Recommendations

## For Primary Care

- Ensure that GPs have all the information they need on the service offer and referral process to the Long Covid Rehabilitation Hub and illustrate this through the use of patient stories. This could be shared during protected learning initiatives, rather than through bulletins.
- Provide training for healthcare professionals on how to recognise and manage cases of Long Covid – with updated and easily accessible information, particularly around diagnostic criteria and the relapsing and remitting nature of the condition.
- Building on the work of some existing Primary Care Networks, to develop the role of a dedicated care-coordinator within the healthcare setting who understands the patient's story and coordinates referrals and treatments accordingly. This would streamline the process and improve patient outcomes.
- Trialling new systems to manage booking appointments with the GP – to better suit people with chronic conditions for whom early mornings are often more difficult.

## For Sheffield Teaching Hospitals NHS Foundation Trust (Long Covid Rehabilitation Hub)

- Create an accessible resource detailing the approach and full range of services available at the Long Covid Rehabilitation Hub – ensuring patients have a comprehensive understanding of what to expect and how to access available support.
- Consider implementing a self-referral option to the Long Covid Rehabilitation Hub. Allowing patients to directly access the care they need without needing a referral from a GP. This would help to overcome some of the barriers in primary care and so improve accessibility.
- Continue the approach of community outreach that supports people to understand the Long Covid service offer and promotes accessible information about the condition.
- Provide a supporting role to client's application for PIP and/or other welfare benefits, to confirm diagnosis and impact of condition.

## For the Sheffield Health and Care Partnership

- Promote and support further public information campaigns about Long Covid which are based in healthcare settings and are accessible to a variety of communities. Local resources are available in Sheffield that can be utilised for this purpose.
- Public information campaigns need to be accompanied by Covid safety measures that aim to reduce the risk of transmission and make people with Long Covid feel safe enough to attend healthcare appointments.
- Build on the work of the Long Covid project to apply the principles of inclusion and community engagement for the development and delivery of services addressing long term conditions.
- Invest in strengthening community connections to support the reduction of health inequalities and create a more equitable healthcare system.

## For NHS South Yorkshire Integrated Care Board

- Strategic commissioning decisions should actively involve individuals with Long Covid in the planning process and explore innovative approaches to meet their needs (see North Central London case study on page 21)

## For Sheffield Health and Social Care NHS Foundation Trust

- There is a need for the provision of comprehensive and compassionate mental health support that addresses both the psychological and physical aspects of their condition.
- Review the current offer from Sheffield Talking Therapies to better meet the needs of people with Long Covid to address the complexities of experiences and the length of time the support is available.

## For the Integrated Care Partnership and the Health and Wellbeing board

- Drive the health care system to work with employers to develop and implement good practice around supporting people with Long Covid in the workplace (see Support in the workplace on page 42)

## For the Department for Health and Social Care and the National Institute for Health Research

- Allocate additional resources and attention to research on Long Covid to better understand its underlying mechanisms, symptoms, and long-term impacts. There is a need to invest in inclusive large-scale studies with both patient and interdisciplinary collaborations to identify effective treatments and rehabilitation strategies.

# Appendices

## APPENDIX 1 – Membership of the Long Covid Steering Group

- 5 People with Long Covid attending in a personal capacity (names withheld)
- Voluntary and Community Sector organisations:
  - Darnall Well Being
  - Sheffield ME and Fibromyalgia Group
  - Shipshape
  - Fir Vale Community Hub
  - SOHAS (Sheffield Occupational Health Advisory Service)
- Sheffield Teaching Hospitals – Long Covid Rehabilitation Hub
- Sheffield City Council – Public Health
- Sheffield Hallam University
- Voluntary Action Sheffield/Healthwatch Sheffield

## APPENDIX 2 – Organisations participating in the Long Covid Community Grants programme




- Aspiring Communities Together
- Darnall Well Being
- Disability Sheffield/Sheffield Voices
- Element Society
- Firvale Community Hub
- Flower Estate Family Action
- Hope and Dignity Hearth
- Israac
- Life after Crisis
- Parson Cross Community Development Forum
- Reach Up Youth

- Roshni
- Sheffield Flourish
- Sheffield ME and Fibromyalgia group
- United Women Affiliation

## APPENDIX 3 – People’s self-defined ethnic heritage

Afghani	Eritrean	Rwandan
African Caribbean	Indian	Slovakian
Asian	Iraqi	Somali
Asian British	Kurdish	South African
Bangladeshi	Libyan	White British
Black African	Malawi	White Canadian
Black Caribbean	Nigerian	Yemeni
Burundian	Pakistani	Zimbabwean
Congolese (DRC)	Roma	

Healthwatch Sheffield  
The Circle, 33 Rockingham Lane  
Sheffield, S1 4FW

 [www.healthwatchsheffield.co.uk](http://www.healthwatchsheffield.co.uk)  
 Call: 0114 253 6688 Text: 0741 524 9657  
 [info@healthwatchsheffield.co.uk](mailto:info@healthwatchsheffield.co.uk)

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Healthwatch Sheffield is committed to providing a quality service.

Every three years we perform an in-depth audit to ensure we meet this high standard.