Derby and Derbyshire
Integrated Care Board

Post (Long) COVID Service Review

Pre-engagement Report

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1.Summary of key findings of the report

Awareness and understanding

- There is a lack of awareness of the Post (Long) COVID Service with nearly 90% of people who have not used the service not being aware of it and 66% of people who have used the service not being aware of it before accessing.
- Just under 50% of people that do not use the services feel that they know what the symptoms are of Long COVID.
- 70% of people who attended the service felt they knew the symptoms of Long COVID prior to using the service.

Current service

- Nearly 70% of people rated the current service as good and above, 92% rated it as acceptable and above, and 8% rated it as poor.
- The key areas that people said worked well were treatment and care, the staff, communication, knowledge, support and understanding and the coordinated approach.
- The key areas people said needed improving were service/care coordination and pathways, communication, waiting times, education and research, care planning and personalisation and professionals understanding and diagnosis.
- 68% of people stated that they did not receive information while they were waiting to access the service and of these almost 80% said they would have found it useful. Key Information people said they would have found useful was: self-support information and initial advice, reassurance that they were in the system and not forgotten and what to expect from the service.
- Over 60% of people rated the communication as good or very good, with 82% rating it as acceptable and above, and 18% rating it poor.

Future service

People identified the most important things to them for the future of the Post (Long) COVID Service in Derby and Derbyshire were:

- Treatment, specialised care and diagnostics
- Service availability and accessibility
- Support and on-going care
- Education and awareness
- Empathy and understanding
- Research and up to date information
- Multi-disciplinary approach (hub model) and holistic approach

Health inequalities

The research suggests that people who need the Post (Long) COVID Service are not accessing it. This includes people living in deprived areas as well as some people from inclusion health groups. The barriers to accessing this service that may be faced by some of these people include:

- Low digital and health literacy
- Frequent moving
- Low trust in and/or trauma from services
- Knowledge about Long COVID
- Knowing to see their GP
- Trouble getting a GP referral
- Overlap of symptoms
- Problems getting to the clinic

National research

NHS England (NHSE) conducted national research in 2023. The key implications of the research were around the following areas:

- Increasing awareness of Long COVID – the condition itself and its symptoms, as well as the available support – will overcome some barriers to accessing services
- Expanding and smoothing pathway access will help to lessen the barriers to accessing Long COVID services
- Providing greater support throughout the patient journey will improve patient experience and satisfaction with Long COVID and other services
- Better meeting the needs of patients with Long COVID by reviewing how services are set up
- Involving end users in the development of communications and use a range of formats and channels for dissemination
- Reviewing the pathway from the perspective of health inequalities

Many of these key themes are echoed in this report on a local level for Derby and Derbyshire.

2: Definitions

Post (Long) COVID – Most people with COVID-19 feel better within a few days or weeks of their first symptoms and make a full recovery within 12 weeks, but for some people symptoms can last longer. This is called Long COVID or Post COVID-19 Syndrome. Long COVID is a new condition which is still being studied. Read more on the NHS England website.

ICB – Integrated care boards (ICBs) replaced Clinical Commissioning Groups (CCGs) in the NHS in England from 1 July 2022. NHS Derby and Derbyshire ICB is the NHS organisation responsible for planning to meet local health needs, allocating resources, ensuring services are in place to deliver against ambitions, and overseeing delivery of improved outcomes for their population. Find out more on the NHS Derby and Derbyshire website.

ICS – Integrated Care Systems (ICS) are partnerships of organisations that come together to plan and deliver joined up health and care services, and to improve the lives of people who live and work in their area. Read the NHS England website for more information.

NHSE – NHS England (NHSE) lead the NHS in England to deliver high quality services for all. Read more on the NHS England website.

Health inequalities – Unfair and avoidable differences in health across the population, and between different groups within society. These include how long people are likely to live, the health conditions they may experience and the care that is available to them. See the NHS England website for more information.

3: Introduction and background

The Derbyshire Post COVID Syndrome Assessment Clinic was launched in December 2020 to provide physical, cognitive, and psychological assessments to patients experiencing complex Post COVID Syndrome (Long COVID) symptoms.

In April 2022 the service was expanded to include rehabilitation hubs in the north and south of the county to manage patient symptoms. The rehabilitation offer includes support for breathlessness, chronic fatigue, occupational health, vocational and health psychology.

The Post (Long) COVID Service is provided by:

- Derbyshire Community Health Services (DCHS): lead on the assessment clinic and provide psychology and coordinator staffing within the rehabilitation hubs.
- University Hospitals of Derby and Burton (UHDB): lead on the south rehabilitation hub. Staffing includes occupational, physio, pulmonary rehabilitation, and chronic fatigue therapists.
- Chesterfield Royal Hospital NHS Foundation Trust (CRH): lead on the north rehabilitation hub. Staffing includes occupational, physio, pulmonary rehabilitation, and chronic fatigue therapists.

Why is a Service Review being done?

Since 2020/21 NHSE have provided annual non-recurrent funding to all Clinical Commissioning Groups (CCGs)/Integrated Care Boards (ICBs) to implement Post (Long) COVID services.

From January 2022 to February 2023 referrals into the service have averaged at 40 referrals every two-week period and peaked at 120 referrals in June 2022. However, from December 2022 to February 2023 there has been a downward trend in referrals to 25 every two-week period. This fall in referrals is in line with national trends.

The key challenges identified within the case for change include:

- Referrals: Since December 2022 there has been a downward trend in referrals from 20 per week to approximately 12 per week. This is in line with national trends.
- 2024/25 Funding: The ICB have been notified by NHSE that funding will be significantly reduced in 2024/25 due to the reduction in referrals across the region. This brings into question the financial sustainability of the service.
- Workforce recruitment and retention: Staff are aware of the financial and reduced demand challenges faced by the service for 2024/25. There is a risk that staff will start to look for alternative employment, destabilising the service in-year.

- Discharges and Patient Initiated Follow-up: There were 1000 patients on the caseload in April 2023 and this figure has been increasing monthly since December 2022. There is a risk that this caseload will carry over into 2024/25, impacting the efficiency of future service models.

If you would like further detail please see the Case for Change Document and/or the Summary of the Case for Change Document.

Service opportunities

The ICB has requested that an options appraisal and business case are developed to recommend a future service model for 2024/25. The options are required to consider and mitigate the key challenges identified. The aim is to gain approval on the recommended service model by February 2024. The implementation of the service changes will commence immediately following approval.

A monthly Operational Delivery Group is chaired by the ICB to support service delivery, embed NHSE guidance, and review performance. The membership of this group includes providers and patient representatives. Due to the key challenges identified, the group has started to consider and discuss future service model opportunities.

The initial service opportunities include:

1. Decommission the Post (Long) COVID Service (signpost www.yourCOVIDrecovery and existing services).

2. Enhance existing services to accommodate Long COVID patients.

3. Provide a nominal service based on the current model and review how this would look with reduced staffing and funding.

4. Develop a service that maintains the integrated and holistic approach that has been embedded in the service and additionally considers the opportunity to reduce service health inequity.

The formal options development and appraisal process will not commence until a pre-engagement exercise is complete.

Patient and public engagement

Throughout the month of September 2023 engagement activities took place across the city and count. The key areas that engaged on included:

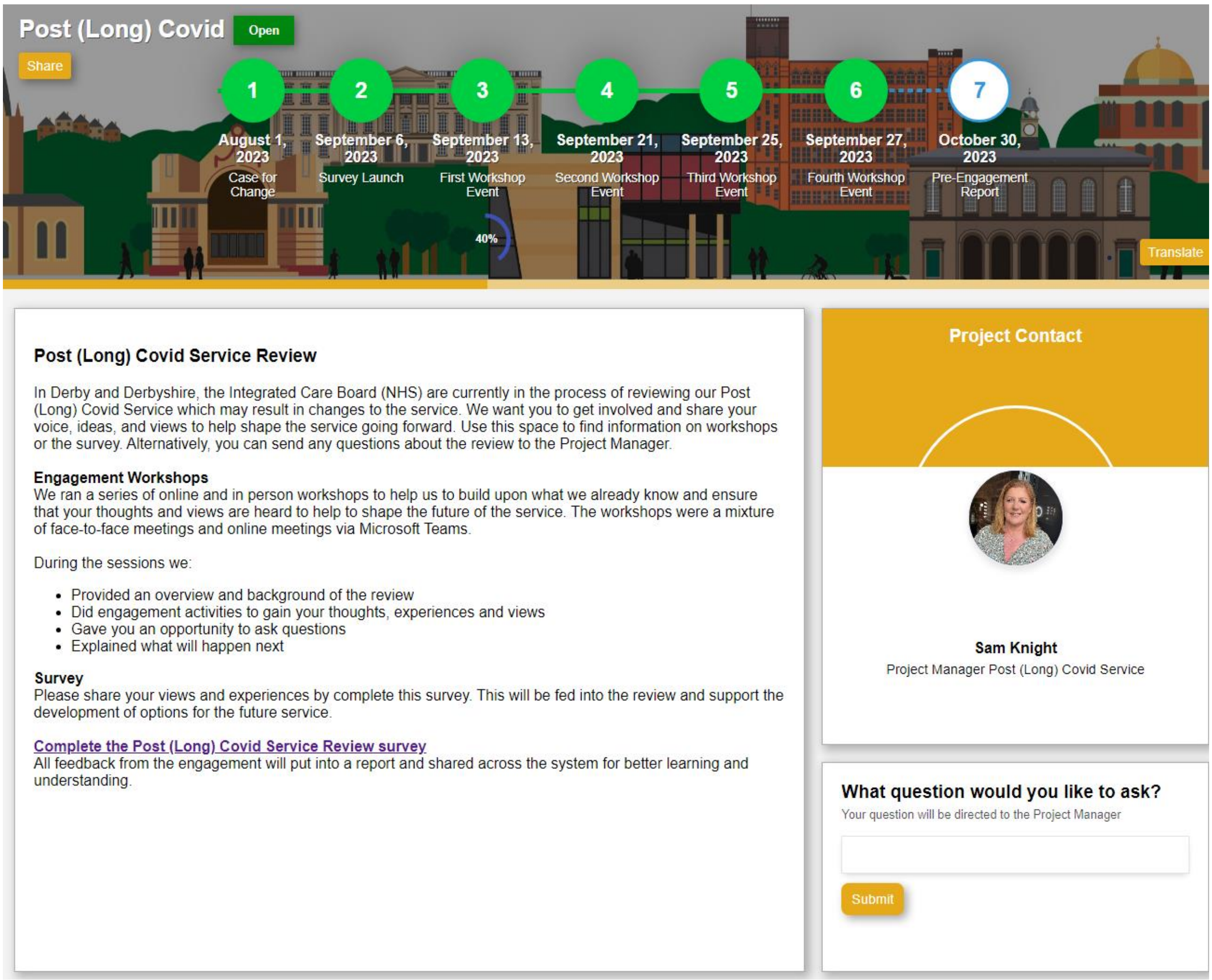
- People's knowledge of Long COVID and the Derbyshire Post (Long) COVID Service.
- People's experiences of the current service – what works well and what could be improved.
- What is important to people for the future service.

Methodology and Timelines

The methods of engagement included a survey and five workshops. The workshops included two virtual (online) workshops at different times of the day, and three face to face workshops across the north and south of the county. See the Engagement Approach for full details.

- The engagement programme has a tile on the Engagement Platform which was accessible from 23 August 2023. (Figure 1 – online engagement platform)
- The events were launched on 23 August 2023, so people were able to sign up for them, and were planned throughout September 2023.
- The survey was launched on 6 September 2023 until 30 September 2023.

Each of the events had a member of the Commissioning Team, a clinician representative and a member of Engagement Team present. 20 attended the face-to-face events (there was a mixture of patients, family members and carers), 24 people attended the online events, and 177 people completed the online survey. Demographics were only collected from the people who completed the survey. There have been other sources of feedback such as emailed experiences and social media feedback that has been added to this report.



Post (Long) Covid Service Review

In Derby and Derbyshire, the Integrated Care Board (NHS) are currently in the process of reviewing our Post (Long) Covid Service which may result in changes to the service. We want you to get involved and share your voice, ideas, and views to help shape the service going forward. Use this space to find information on workshops or the survey. Alternatively, you can send any questions about the review to the Project Manager.

Engagement Workshops
We ran a series of online and in person workshops to help us to build upon what we already know and ensure that your thoughts and views are heard to help to shape the future of the service. The workshops were a mixture of face-to-face meetings and online meetings via Microsoft Teams.

During the sessions we:

- Provided an overview and background of the review
- Did engagement activities to gain your thoughts, experiences and views
- Gave you an opportunity to ask questions
- Explained what will happen next

Survey
Please share your views and experiences by complete this survey. This will be fed into the review and support the development of options for the future service.

Complete the Post (Long) Covid Service Review survey
All feedback from the engagement will put into a report and shared across the system for better learning and understanding.

Sam Knight
Project Manager Post (Long) Covid Service

What question would you like to ask?
Your question will be directed to the Project Manager

(Figure 1 online engagement platform)

Health inequalities

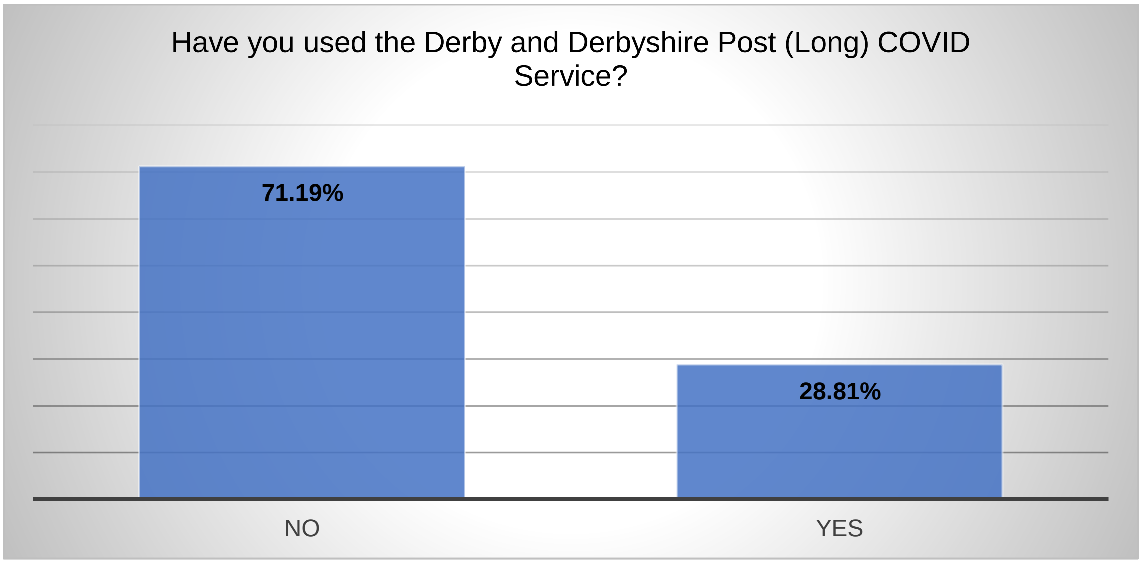
As of February 2023, in Derbyshire there has been a focus on understanding whether the people that need to use the service are using it.

From this work, it has been found that less people from areas of high deprivation are accessing the service. Work has been done to understand why this is and to make it easier for people to access the service. Targeted engagement was done with the survey in areas of high deprivation to understand what people's understanding of Long COVID is and if they were aware of the service.

The Research & Implementation Officer, who is funded by Health Inequalities money received from NHSE, has contributed to this report to identify the key barriers for people accessing the service from areas of high deprivation.

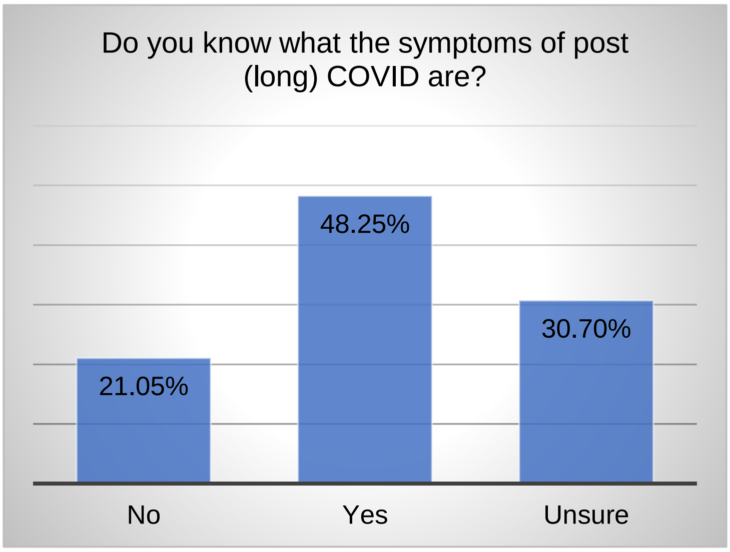
4: Feedback from the engagement

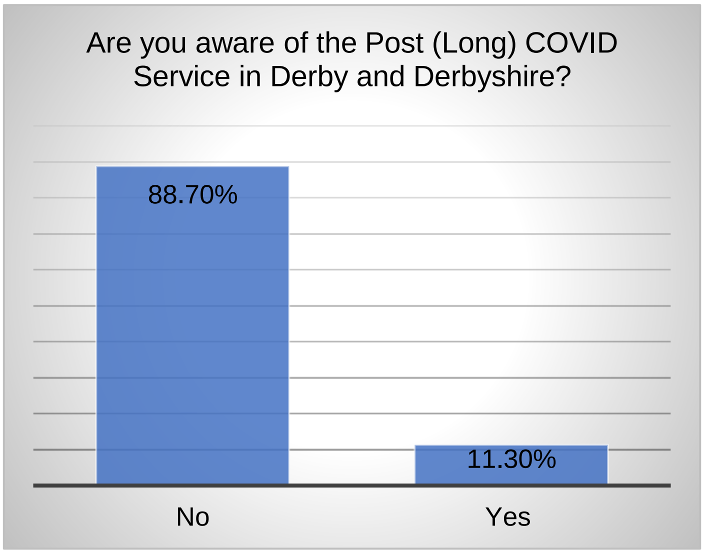
Within this section is all the feedback from the engagement events including the survey and the engagement workshops. 20 people attended the face-to-face events, 24 people attended the online events, and 177 people completed the online survey.



This question was on the survey only; 126 people had not used the service (71.19%) and 51 people had used the service (28.81%).

People that had **not** used the service were asked:

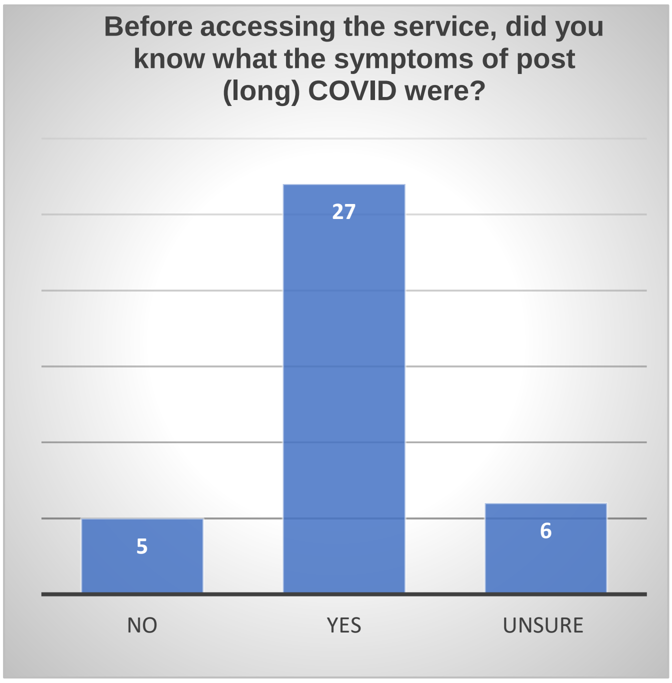


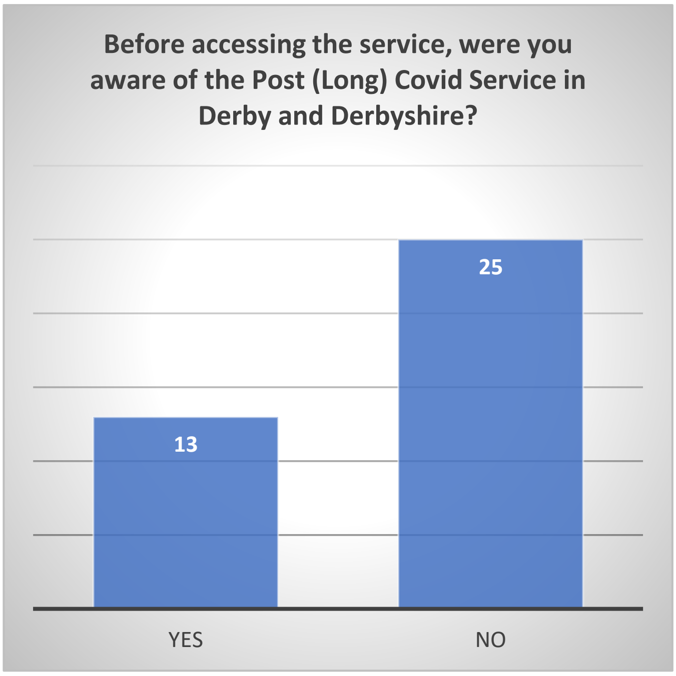


Just under half of respondents felt that they knew the symptoms of Long COVID.

Nearly 90% of people were unaware of the service. Of the people that were aware of the service they said they knew for the following reasons: online, social and local media, the NHS and other health services, individuals such as friends, patients, other professionals and through research.

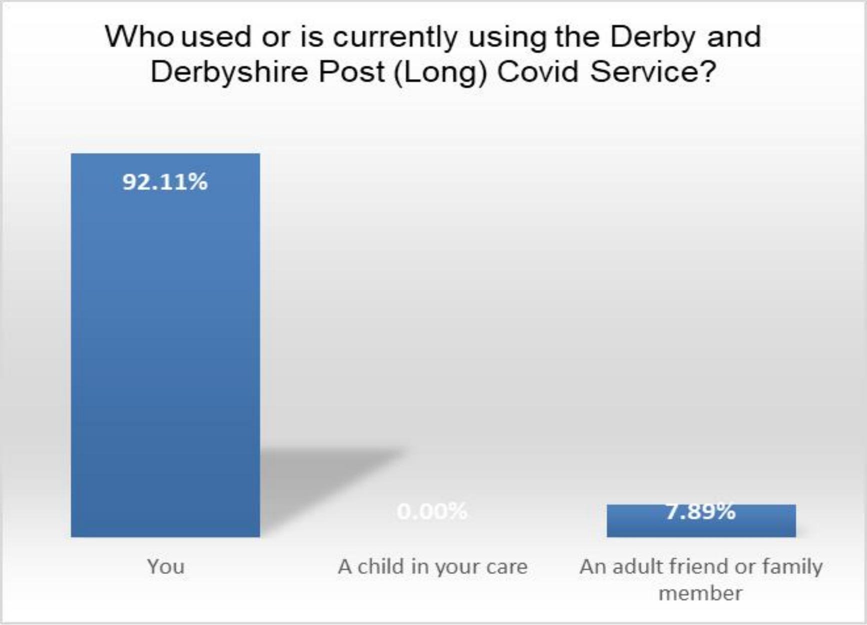
People who had used the services responded as below:



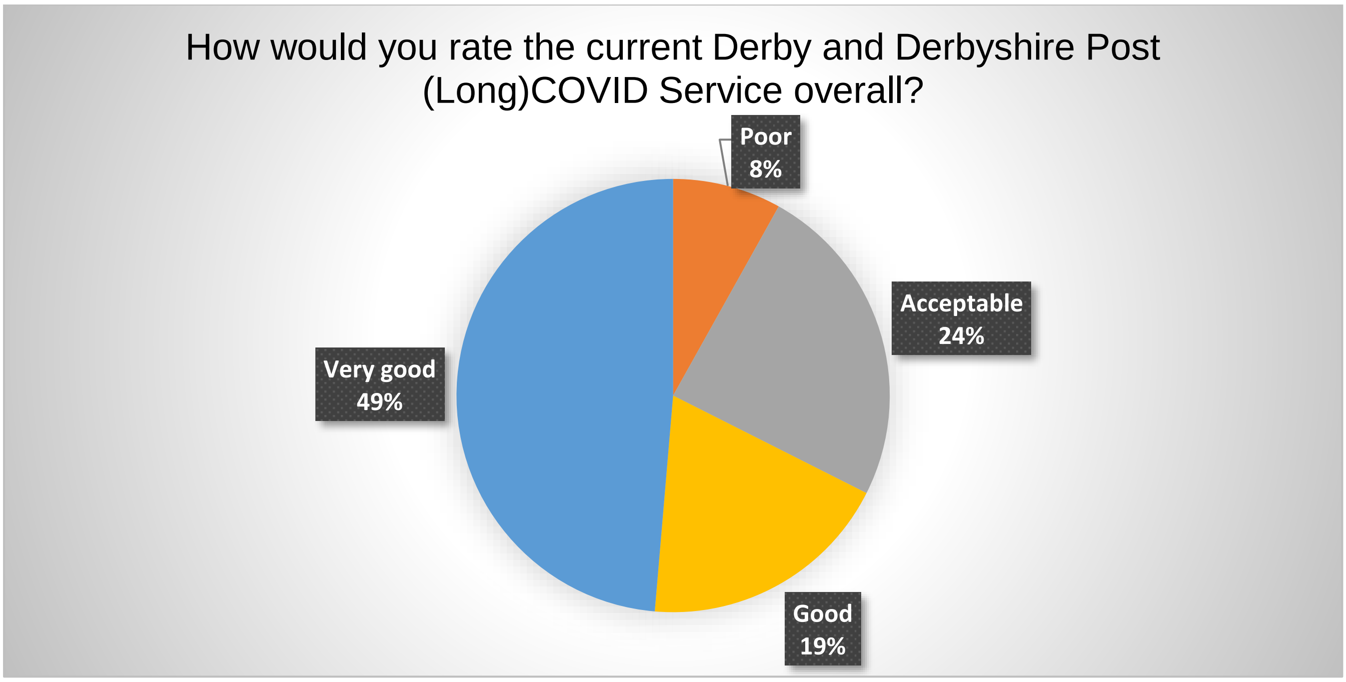


Over 70% of people who attended the service felt they knew the symptoms of Lost COVID prior to using the service and over 30% of people were aware of the service as well, though only a few people could recall where they first came across the service, which included, social media, online and a team meeting. Sixty-six percent of people were not aware of the service before accessing.

From the survey we asked who had used the service:



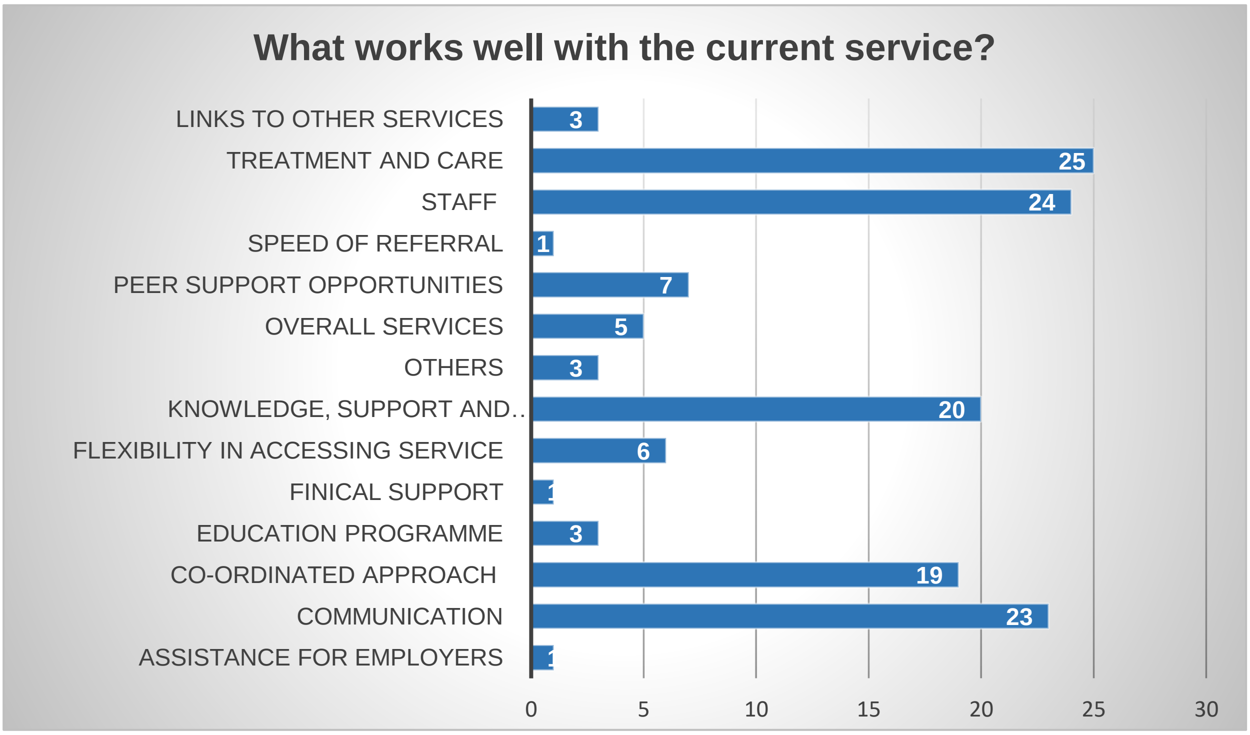
At the workshops the majority of people had used the service as well as people who were carers and family members.



Almost 50% of people who responded to the survey thought the service was very good and nearly 70% of people rated the service good and above. 92% rated the current service as acceptable and above, and 8% rated it as poor.

Current Patient Experiences

What do people think currently works well with the service?



All comments from the survey and workshops have been broken down and themed below.

The five main areas people spoke about were:

- **Treatment and Care** – mainly people spoke positively about the treatment and care they received. There were also mentions of positive experiences around psychological, chronic fatigue and physio services and the continual and regular support.

- **Staff** – staff were caring, knowledgeable, listened, friendly, understanding, encouraging and kind.

- **Communication** – in regards being able to contact staff easily, responses of emails, good communication amongst professionals and across services and that the service listened and was responsive.

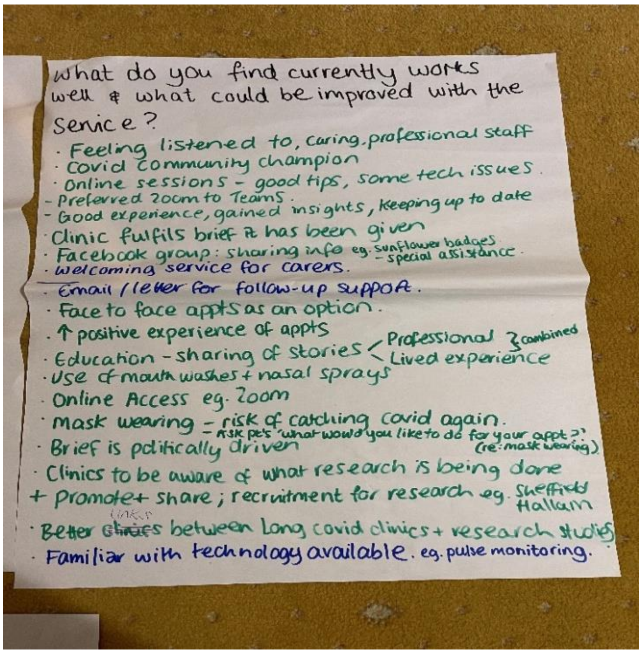
- **Knowledge, Support and Understanding** – around the advice, tips and information given. The service gave a people a greater understanding and was supportive.

- **Coordinated approach** – that the joined up working of the hub model gives a holistic and multi-disciplined approach that addresses all needs in one place and gives access to or referral to a specialist.

Other areas included:

- Flexibility in accessing the service – that there is a range of options on of how to access the service.
- Peer support opportunities – there are opportunities to link in with peer support groups such as a Facebook group and a support group.
- Overall services.
- Links to other services – signposting and linking to other services.
- Education programme.

Other fields spoken about were trying out new ideas, financial and employers support, and speed of referral.



What do you find currently works well & what could be improved with the service?

· Feeling listened to, caring, professional staff
· Covid Community champion
· Online sessions – good tips, some tech issues.
- Preferred Zoom to Teams.
- Good experience, gained insights, keeping up to date
· Clinic fulfils brief it has been given
· Facebook group: sharing info eg. sunflower badges – special assistance.
· Welcoming service for carers.
· Email / letter for follow-up support.
· Face to face appts as an option.
· ↑ positive experience of appts
· Education – sharing of stories < Professional } combined < Lived experience
· Use of mouth washes + nasal sprays
· Online Access eg. Zoom
· Mask wearing – risk of catching covid again.
– Ask pt's 'what would you like to do for your appt?' (re: mask wearing)
· Brief is politically driven
· Clinics to be aware of what research is being done
+ Promote + share; recruitment for research eg. Sheffield Hallam
· Better ~~clinics~~ links between Long covid clinics + research studies
· Familiar with technology available. eg. pulse monitoring.

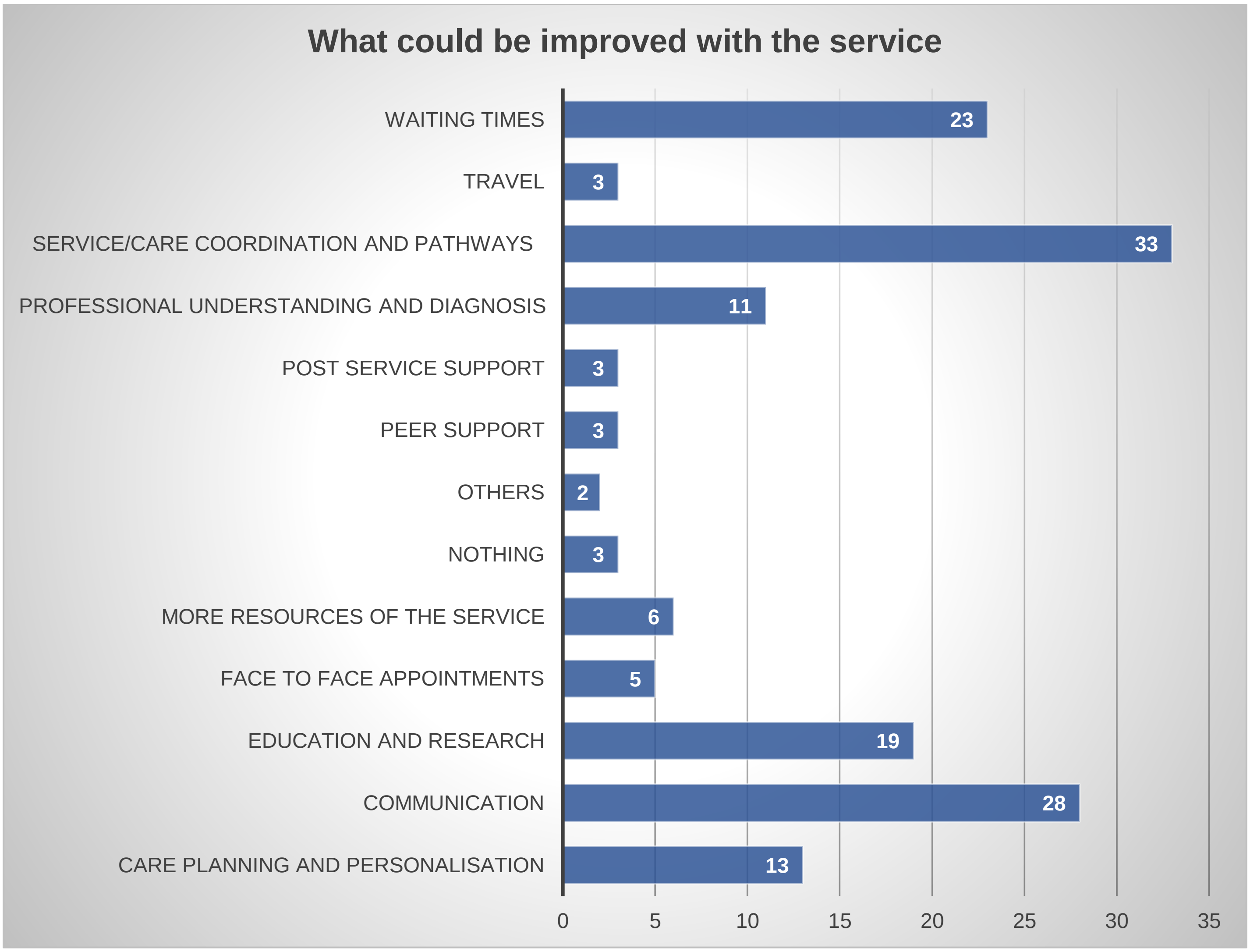
"The holistic approach the clinical and psychological care has worked well."

"Having contact details was great in terms of being able to contact the hub when needed."

"Giving information on chronic pain, chronic fatigue, workshop / group on chronic fatigue, referring to respiratory physiotherapy. Having one service where everything comes together."

What could be improved with the service?

All comments from the survey and workshops have been broken down and themed below.



Service/care coordination and pathways

- Service coordination – lost referrals, having to repeat lots of information, past from pillar to post, repetition of treatment, lack of coordination at assessment clinic and between services once referred.
- Appointments – set times/days, unable to do two appointments consecutively, lack of availability for people that work and follow up after appointment.
- Staffing – medical staff to attend to hub, one person to have responsibility over care, complex needs are meet need consultant.
- Pathways – unsure of service pathway, not being referred to a GP for every symptom and then referred to lots of different services.

Communication

- Improve information about: information while waiting to access the service, what service offers, what is the service pathway, peer support opportunities, other methods the service has in place to communicate with patients such as emailing or WhatsApp, information about new treatments and care, about potential risks and signposting.
- Clearer messaging around infection control messaging (mask wearing).
- Professionals – read patient information prior to appointment, contradicting opinions and better communication between professionals and ability to send information prior to appointment fatigue and memory flares.

Waiting times

- The main area people spoke about was waiting times to access the service.
- Other waiting time issues mentioned were waiting times between referrals, treatment and further investigations.

Education and research

- To improve the education, understanding and availability of services of Long COVID to GPs, the public, employers and hospitals.
- To increase research – links with research teams, signposting patients to research, unmet needs should be monitored, incorporate research into the service.

Care planning and personalisation

- Patients have a clear care plan with information around: their care plan pathway, who they are seeing, who they have been referred to, to be able to review their care plan.
- More personalised around: targeted holistic approach to appointments, advice, and symptom management. Having one staff member to go to and someone who knows the patient to present at meetings.

Professional understanding and diagnosis

- Need to standardise the approach to diagnosing and develop more diagnostic tools/assessments.
- The approach to Long COVID services are still linear but multiple symptoms occur concurrently.
- Lack of understanding of other associated conditions.
- Reliance of patients understanding their own condition when symptoms may include brain fog/chronic illness.
- To develop a clinical response to ‘living with COVID’.

Others

- There were other comments around wanting more face-to-face appointments, more general resources of the service, some in regard to more mental health support and employer support.
- To have a peer support group in the north/Chesterfield.
- Travel can be an issue to appointments.
- Discharge – concerns raised about being discharged when complex or no improvements but still being unwell, that people should be referred to other services or other considerations put in place.

"Now feel in limbo while I wait to be seen by ENT. Contact is infrequent and more of a catch up as opposed to meaningful intervention. Providing me with a clearly defined care plan would be useful, so I don't feel so lost."

"Would find it good if had a letter to say what services am on waiting list for and what happens next."

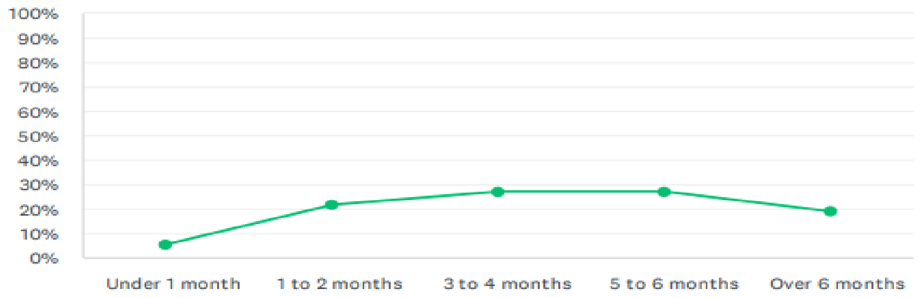
"It was unclear to me when I had been transferred from the assessment clinic to rehab clinic and I found this confusing and upsetting as I did not consider myself to be in a position to rehabilitate without further investigations. I requested further input from the assessment clinic but was told nothing more could be."

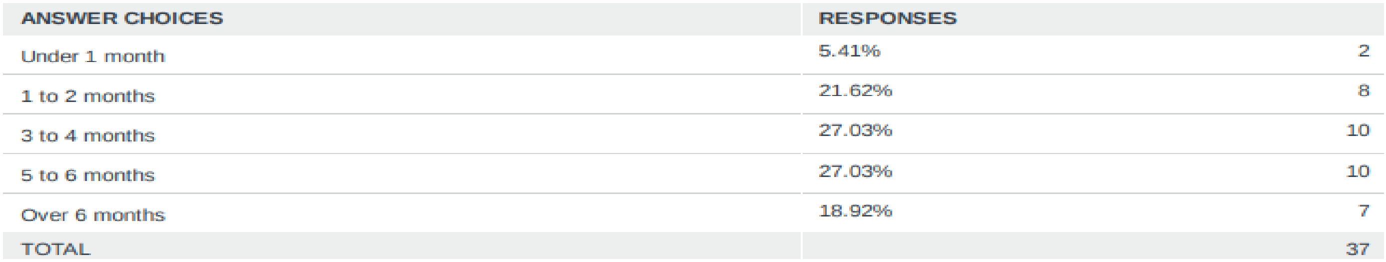
Do you think there is anything unfair about the current service?

Eight people made further comments to this question. These were regarding:

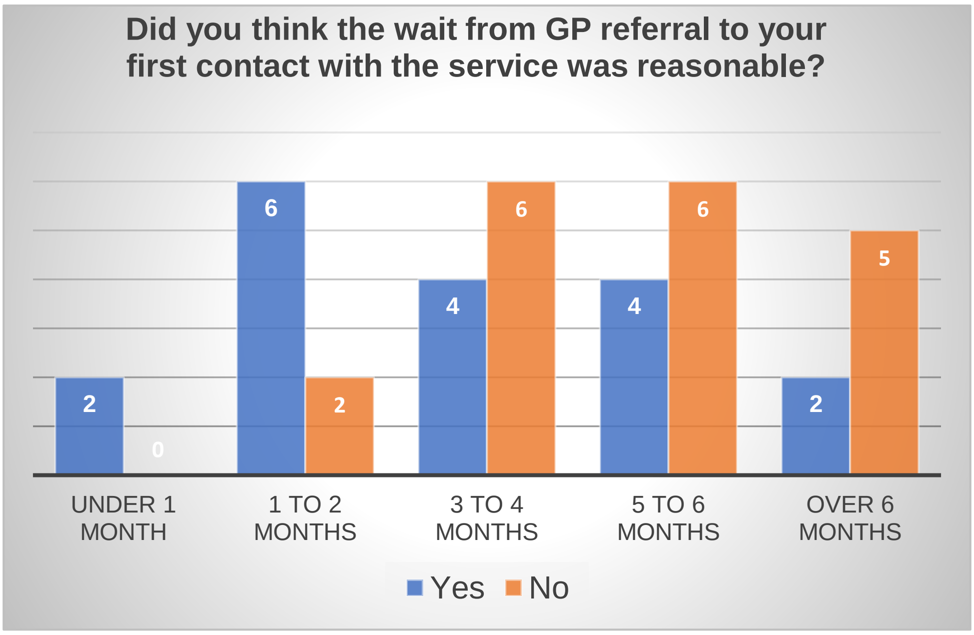
- No peer support in the North of the county
- Long waiting lists.
- Concerns over being discharged when still needing help and someone who was discharged and felt devastated.
- Concerns about services being reduced or closed.
- Lack of signposting to the service from GPs.

Roughly how long did you wait from GP referral to your first contact with the Derby and Derbyshire Post (Long) COVID Service?



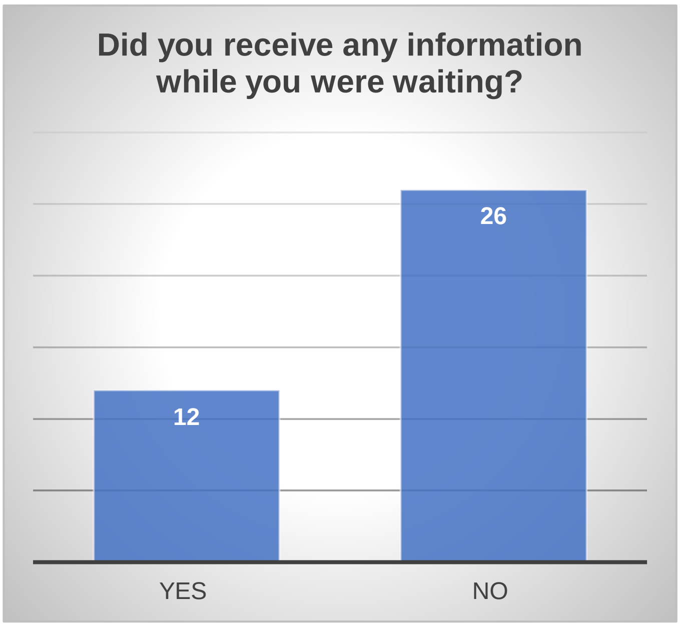


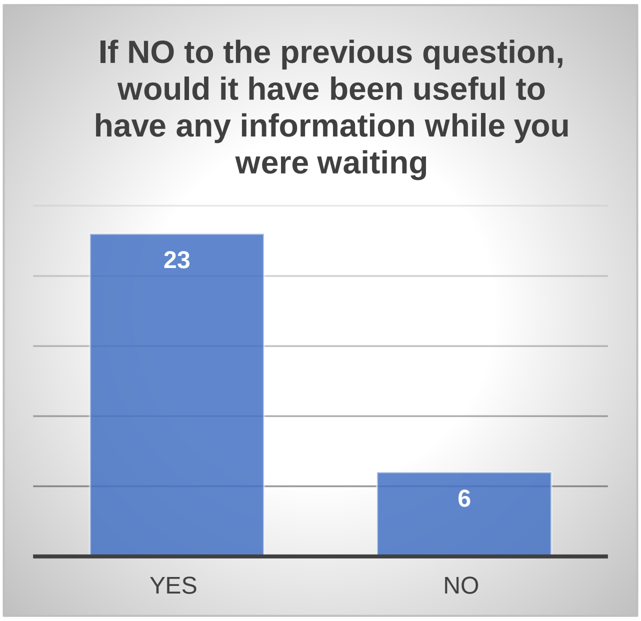
ANSWER CHOICES	RESPONSES	
Under 1 month	5.41%	2
1 to 2 months	21.62%	8
3 to 4 months	27.03%	10
5 to 6 months	27.03%	10
Over 6 months	18.92%	7
TOTAL		37



Waiting times ranged from 1 to over 6 months.

People had differing opinions in what they thought was a reasonable wait time. From the graph it shows that an increasing number of people felt that 3-4 months (and above) waiting time was unreasonable.





When asked for some examples of what information would have been useful, 23 people responded and the key themes were:

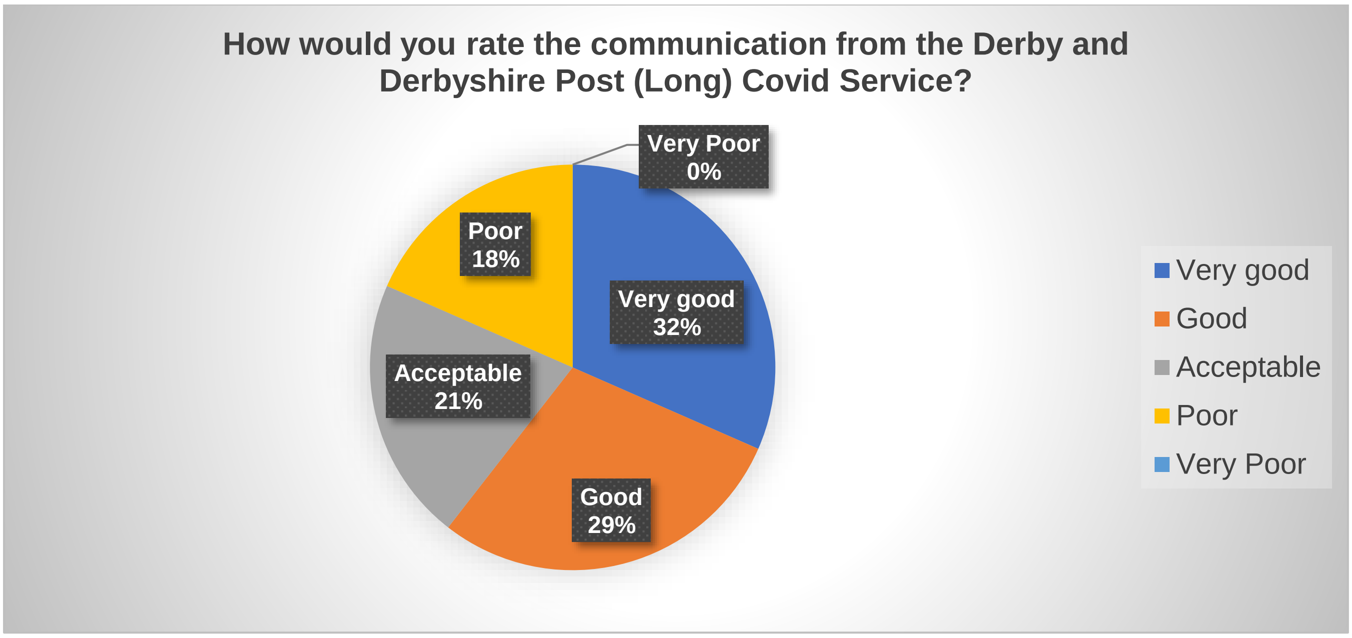
- **Self-support information and initial advice** – links to self-support such as YouTube, podcast, websites. Initial information about advice such as the importance of rest, pacing and what else was available to be tried.

- **Reassurance** – that they were in the system and not forgotten, someone to contact them and explain there was a waiting list and provided with rough waiting times.

- **What to expect from the service** – information such as how long the care will last for, what is the process of the assessment, groups and classes.

Other areas mentioned were:

- Escalation advice – what to do if things get worse or what to do if you are unable to care for yourself.
- Peer Support information – where to get peer support from.
- An explanation – what is Long COVID.
- Timed contact points – i.e. if not in the service within 3 months to re-contact and give reassurance.
- Research information.



Over 60% of people rated the communication as good or very good, and 18% rated it poor. People were asked why they gave this rating.

The main positive elements spoken about were:

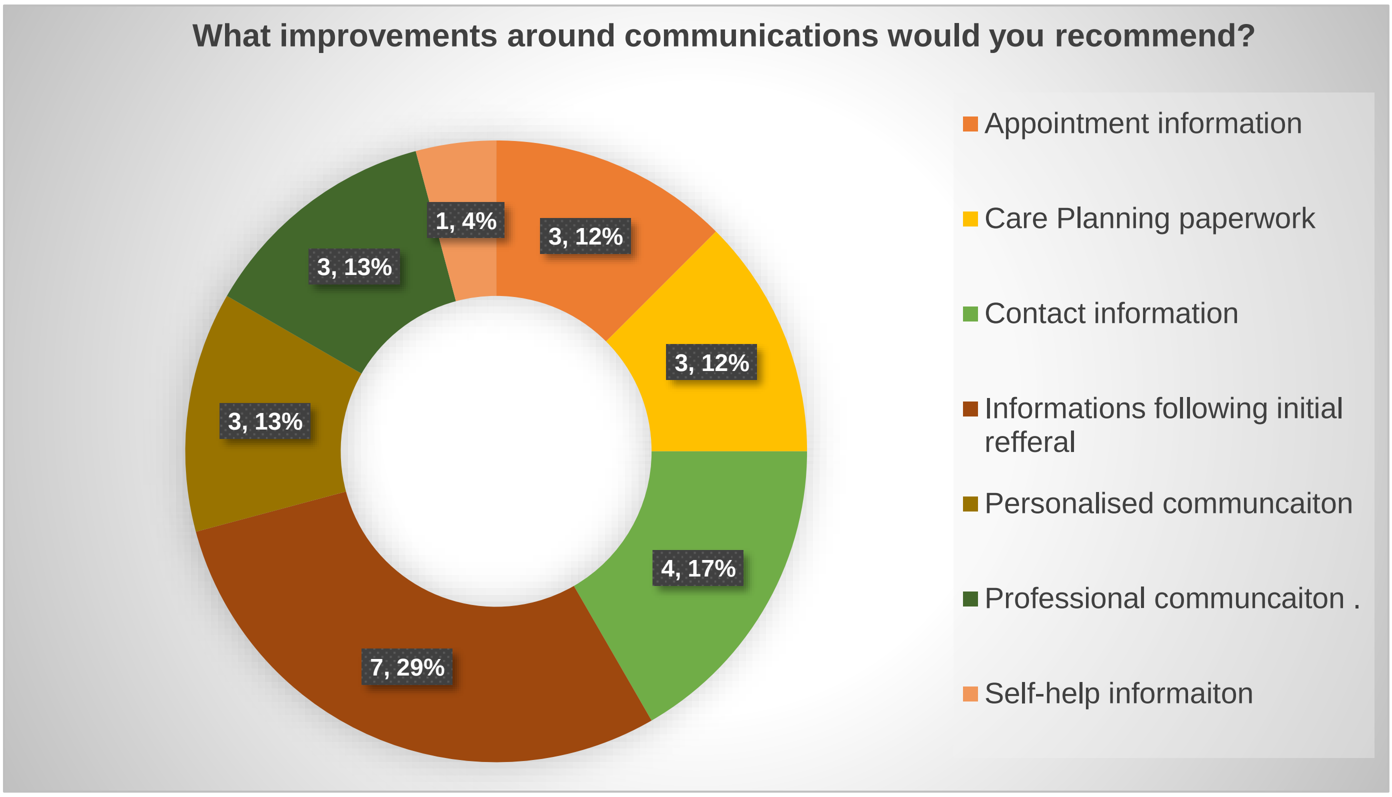
- **Responsive and Accessible Contact Channels** – regarding contact details information, promote replies to emails and phone and this being reliable.
- **Explanation and information given** – clear timely and informative.
- **Appointment information and Reminders** – text reminders and information given about appointments and the information following them.
- **Regular updates** – via emails and contacts.

Other positive areas mentioned were – staff in regard to listening and being encouraging to get involved, the Facebook group, and .sharing information between services around sending information to GP and individual comments around being contacted quickly following referral.

There are too few negative comments to draw key themes from but the following experiences were raised:

A few people had stated:

- They had received text message reminders for appointments but never received a letter.
- It takes too long to answer questions/queries, had to chase and some were never responded to.
- Individual comments around not being aware about follow ups/what happens next and a lack of information about this review.



(Comments have been broken down and themed)

The main area spoken about was:

Information following initial referral:

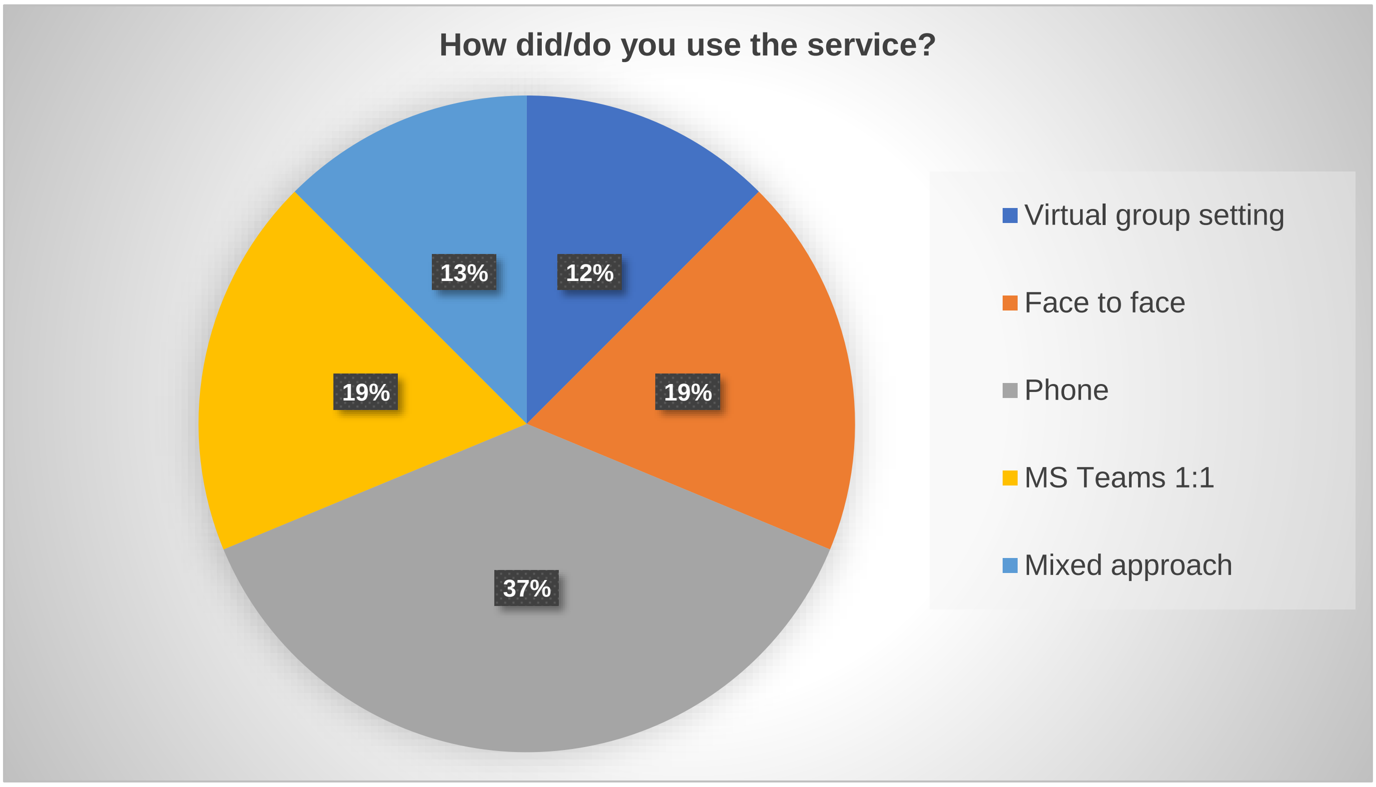
- How the service works.
- What to expect from the service and what it can offer.

Other areas spoken about were:

- **Contact information** – Useful contact list - telephone numbers and email addresses for the different professionals, when and how you can contact the team, phone operating times and responding to answer machine messages, if you get removed from the service, please alert the patient.
- **Personalised communication** – Practitioners following up verbal advice/information with an email - forget things, brain fog and struggle with processing information.
- **Professional communication** – More professional communication – talking to each (tiring repeating myself) staff communication to patient (1 person explained a negative experience with how they were spoken to), information to other professionals about Long COVID.
- **Care panning paperwork** – A care plan that collates all information in one place/document, who you have been referred to, who's involved in your care and evaluating methods – to see if health and symptoms are improving/getting worse.
- **Appointment information** – To be informed about next appointment (not waiting for months), more text reminders and notifications.

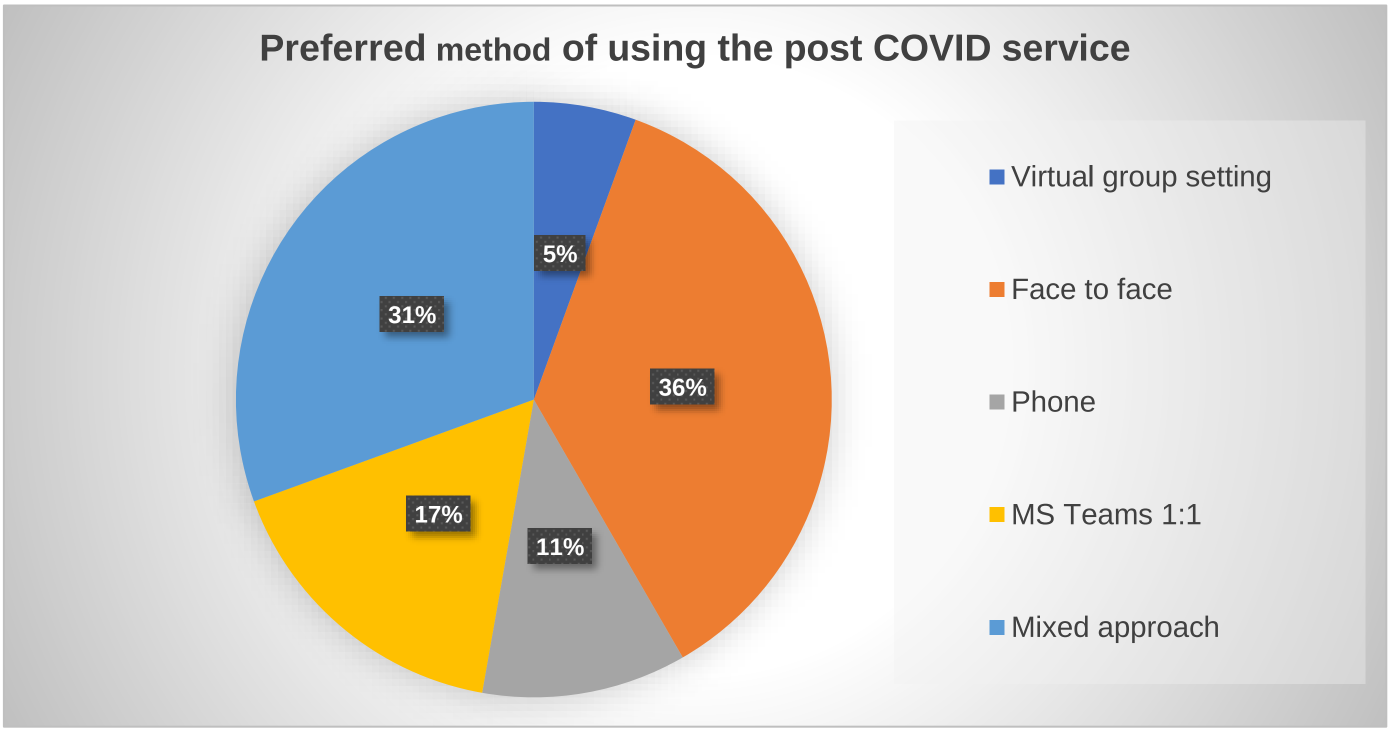
Individual comment around – self-help information. Send self-help information – pacing, energy management.

Access to the service



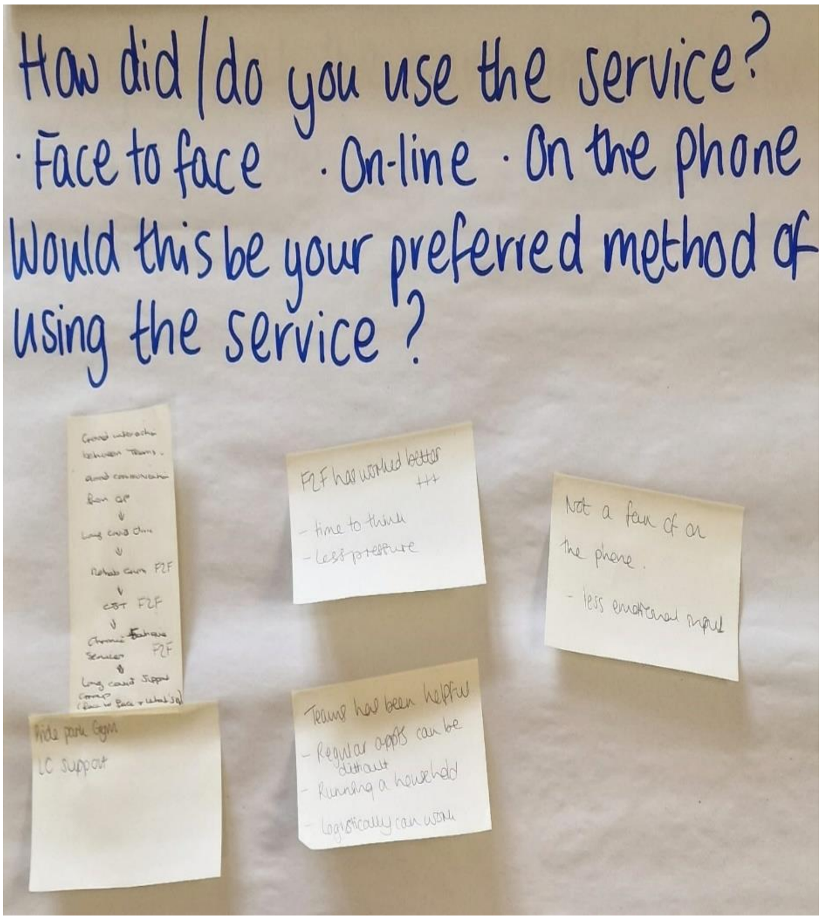
(Combined face to face and virtual workshop data)

Most people (46%) accessed the service via the phone, with 27% accessing the service via face-to-face appointments.



(*Combined face to face and virtual workshop data)*

Most people (36%) preferred face to face appointments, or a mixed approach (31%).

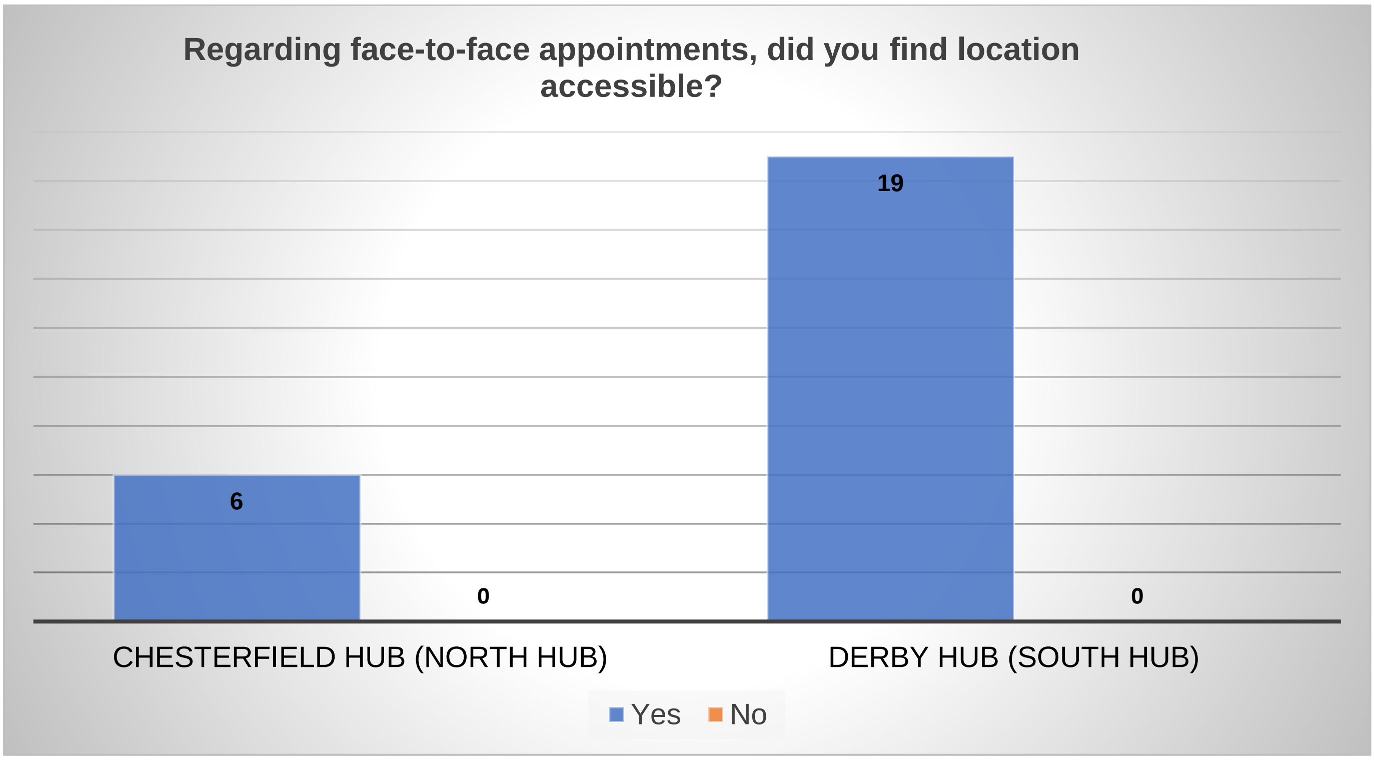


'I enjoy the phone conversations. I would've liked to be seen in a safe environment one or twice to check me over.'

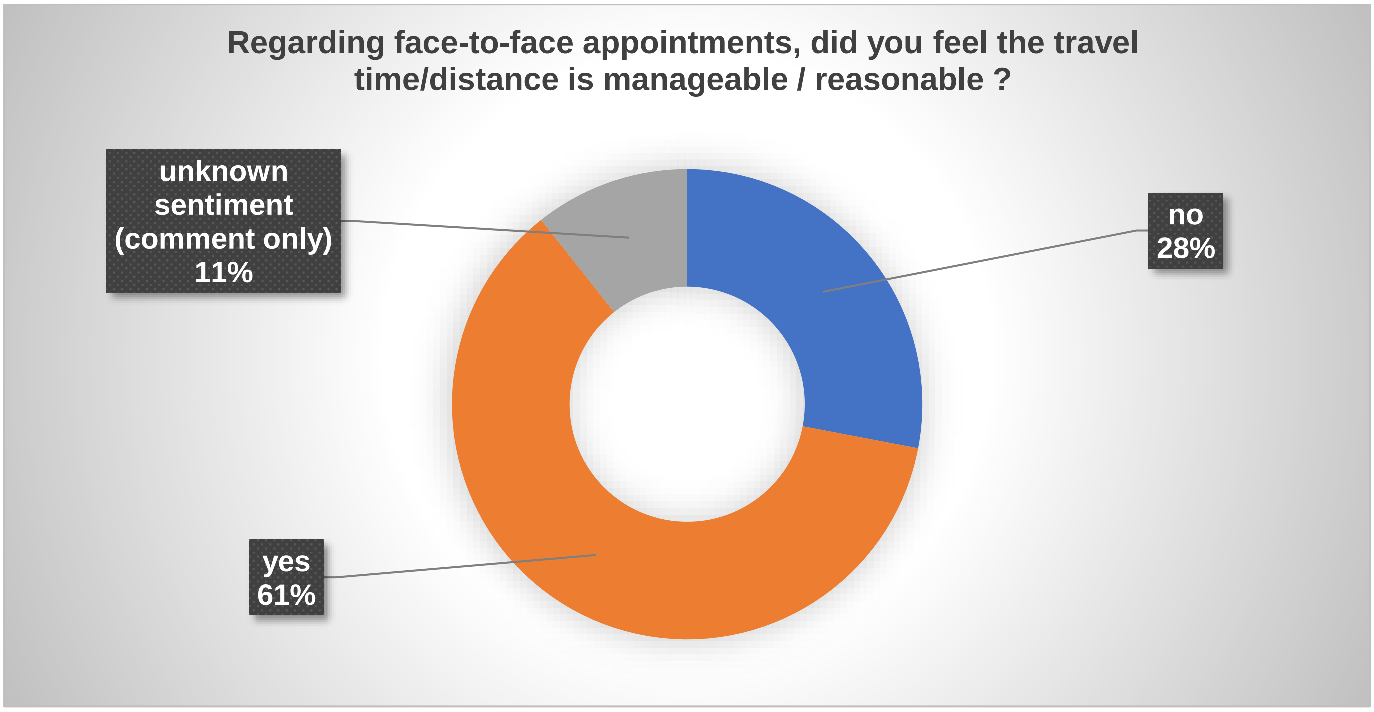
'Teams as too far to travel.'

'When I get given a choice (this isn't always the case), I would always choose Face to Face.'

'The options of telephone/online have been great as I'm often not well enough to drive to appointments.'



One-hundred percent of people who responded in the survey stated that they found the locations of the face-to-face appointments accessible.



Sixty-one percent of people felt that the time/distance to face-to-face appointments was manageable.

(During the face-to-face workshop deeper discussion happened around this question and some comments do not carry a sentiment and some comments were from a number of people but for the purpose of this report each comment has been counted once)

Comments that were given from the survey and the workshops were:

"Reasonable - lives close to the service venue."

Some comments from the workshops and from people who did not feel it was manageable raised issues such as:

- A local offer – would be nice to offer more local level service.
- The journey worsening symptoms or being exhausting.
- Being reliant on family/friends or taxis to travel.

"Travel distance worsened my symptoms."

"Ideally more local hubs."

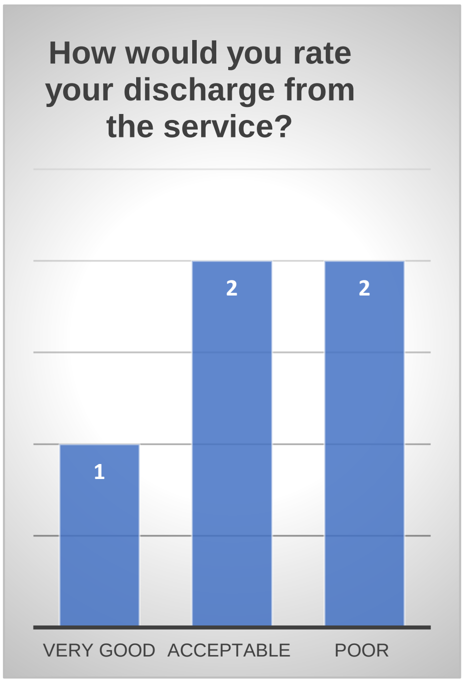
"It's over 30 mins travel time to the nearest venue and feels this can be too much sometimes."

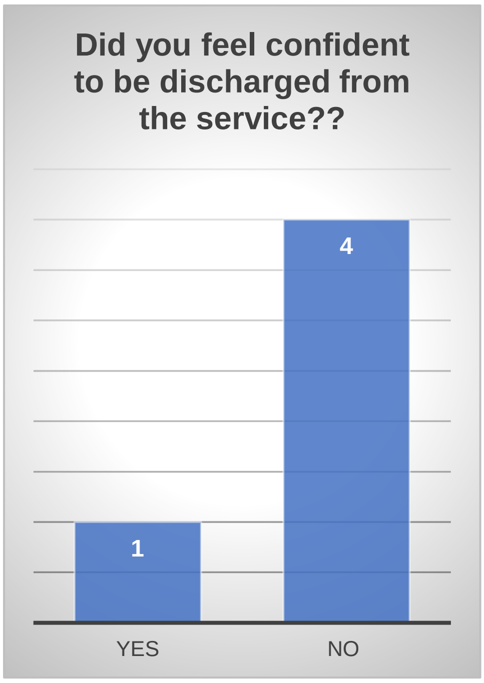
A few people also mentioned flexibility within the service around when they were unable to attend face to face appointments, that other methods were put in place to continue the appointment.

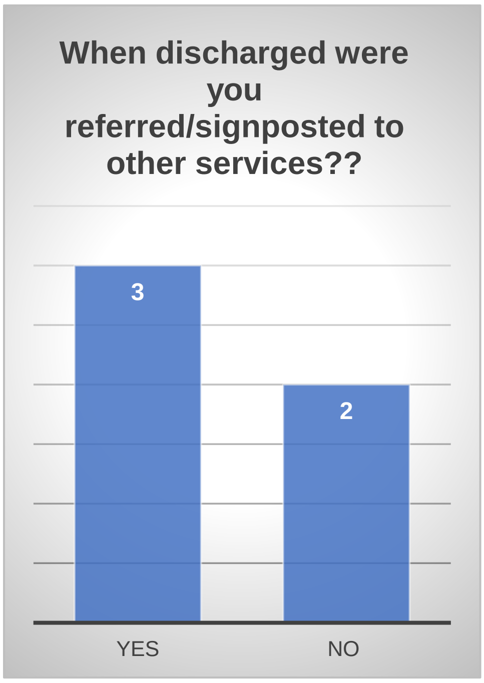
"But it was not always possible due to increasing fatigue levels so having option of telephone calls was great."

"Things were moved to teams if I was ever unable."

Discharge







There were only 5 people who have been discharged from the service so unable to collect themes but 4 of the 5 people did not feel confident to be discharged from the service.

What's most important to you when being discharged from the service?

The key areas and information that people spoke about being important to them when being discharged from the service were:

After service contact methods and information

Including:

- Direct contact details and method so people can seek advice and support.
- Escalation and worsening advice.
- Being able to be fast tracked back into the service when needed.

Other areas spoken about were:

- Referring to other services and having a long-term plan in place.
- Clear communication – regarding, being information that you are being discharged, be honest with prognosis and outcome, explain future risks and how to manage them. Have a discharged package.
- Being taught how to self-manage the condition – to understand methods and feel confident.
- Signposting and support information, such as peer support opportunities and employment support.

- To feel helped and see improvement in self.
- To be able to access boosters/treatments.
- To still be able to be learn about new updates around things such as new research or treatments.
- GP coding – so it is a diagnosis on their system – help to support patients e.g. for future financial support.

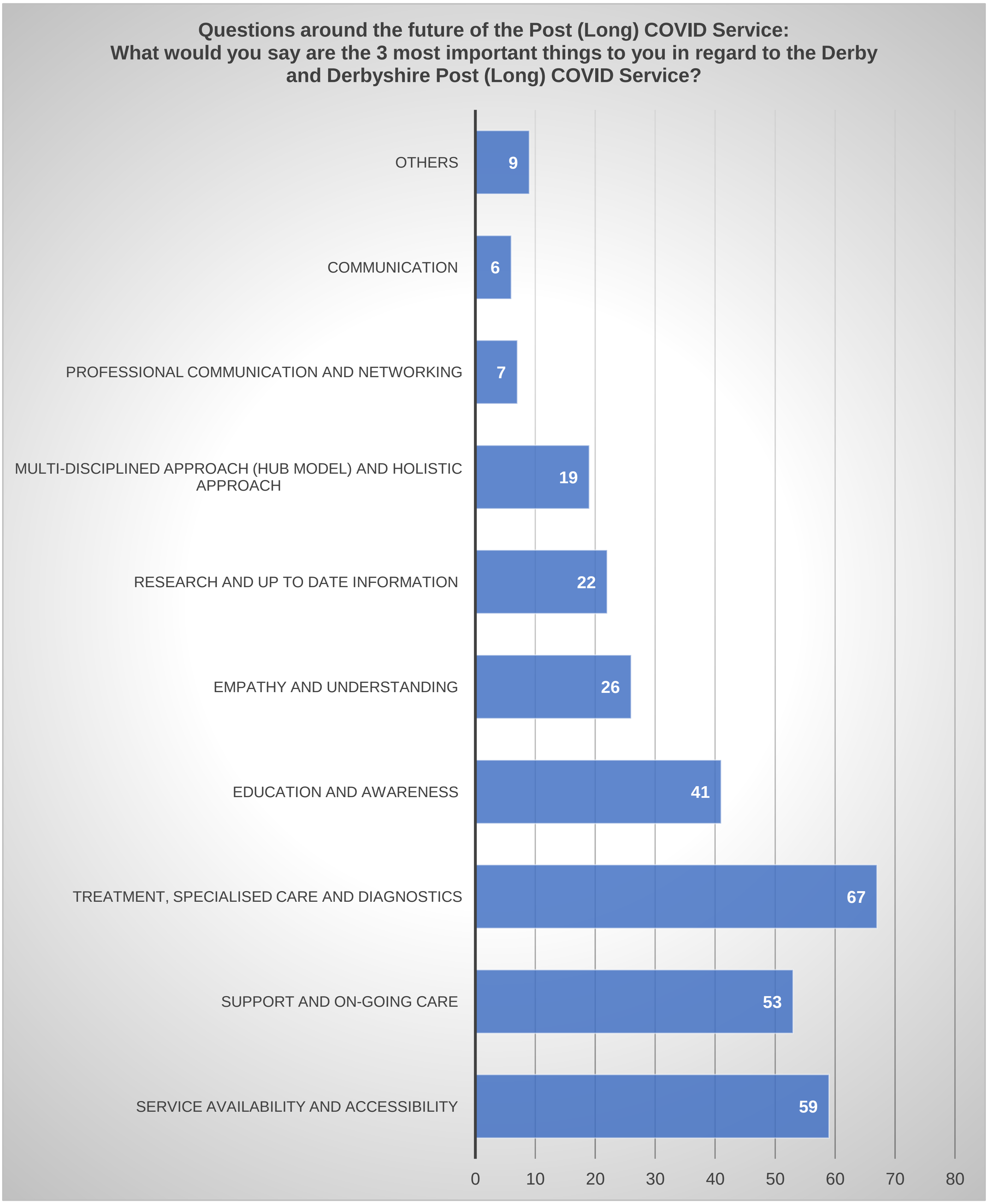
There were also concerns and comments raised in this section with regards to feeling that the service should not be discharging patients. Issues were raised around:

- This being lifelong condition with remitting/relapsing characteristics.
- That long term implications would be missed.
- Patients should have regular assessment.
- That it would be difficult to manage.
- People should not just be discharge as they don’t know what to do with you.

Future Service opportunities

Questions around the future of the Post (Long) COVID Service

(Comments from the survey and workshops have been broken down and themed below)



There was a wealth of responses for this question and more than three areas were highlighted. comments have been broken down and themed. The key areas people said were important to them were:

Treatment, specialised care and diagnostics

- That people have access to medical treatment, therapies, investigations, and diagnostics.
- Having treatment and advice that manages and improves symptoms.
- Refer to specialists such as cardiologist, fatigue specialist, psychology, rehab, physio, occupational health, other diagnostics/investigations.
- Time with experts and retain the specialist clinical knowledge of the staff and build on it in the future.

Service Availability and Accessibility

- The main things that matter to people were that there is service available and accessible.

Other areas mentioned around availability and accessibility were:

- Accessing options should still be available such as, face to face, phone calls and online.
- Access, waiting times and referrals to the service should be easier and shorter.
- To keep the current service.
- Individual mentioned drop-in clinics and geographic locations, in regard to providing outreach hubs so more people can access, access for patients in the High Peak area, having drop-in clinics for people with symptoms or for support services.

Support and ongoing care

That the service is supportive.

- That there is support for people. Including psychological support, support to reduce the feeling of isolation and feeling alone, support with employer, benefits and workplace.
- Peer Support services and signposting
- Ongoing support – in regard to long term support for a long term condition, contact information for support and advice following the service, being able to be fast tracked back in to the service and patient initiated follow up for 12 months.

Education and awareness

- Education and greater awareness in the public domain about the condition, symptoms, the service and how to be referred.
- Education to GPs about symptoms, the service and referral pathway.
- Better understanding of the condition and clarity on what the service offers.

(Four people completing the survey stated that they did not believe in the condition)

Empathy and understanding

- People feel listened to, understood, and treated with empathy.
- Reduce the feeling of isolation and feelings of not being believed.

Research and latest information

- That the latest research and up to date information are used for treatments and to understand the condition.
- People have access to trials, research, and information.
- Statistics are accurate and the service continues to develop.

Multi-disciplinary Team (hub model) and holistic approach

- Having a hub model, multi-disciplinary team (MDT), one place for all services: where the team are specifically focused on the condition and have the knowledge and experience to give the right care and advice that has a joined up holistic and personalised approach**.**

Other areas that people spoke about were:

- **Professional communication and networking** – To share good practice with other models and hubs, ability of professionals to communicate directly with each other, to link in with local teams such as Derby Uni (research)
- **Communication** – easily contactable and being open and honest.
- Others: Funding – to remain and be appropriate. Primary care – issues raised around access and referrals and suggestions of being able to do test and treatment at GP practice. Booster to be available, health monitoring apps, prevention, and involvement of patients within the improvement of services.

Do you have any initial thoughts about the potential opportunities to change for the future service?

During the engagement workshops members of the commissioning team talked through the initial opportunities to change which are:

1. Decommission the Post (Long) COVID Service (signpost www.yourCOVIDrecovery and existing services).
2. Enhance existing services to accommodate Long COVID patients.
3. Provide a nominal service based on the current model and review how this would look with reduced staffing and funding.
4. Develop a service that maintains the integrated and holistic approach that has been embedded in the service and additionally considers the opportunity to reduce service health inequity.

People were then asked for their initial thoughts. A summary is below:

Overall, there were lots of concerns and questions raised around all future opportunities:

- Opportunity 1 – Concerns raised about the website and this opportunity being inappropriate for someone with the condition.
- Opportunity 2 – Concerns raised around increased waiting times, lack of holistic and joined up approach.

- Opportunity 3 – Concerns raised about the increased waits, workloads, and reduction of service – that the impact would need to be fully understood. Positive comments regarding keeping the specialist knowledge.
- Opportunity 4 – Some positive comments about this being a progression of the service and keeping the experience of the team but concerns that it would reduce focus on specialism.

(Please note these are what people directly stated and are their initial thoughts)

Opportunity 1 feedback

- *Opportunity 1 - would just be on a waiting list +++, back onto waiting lists*
- *On line website is ok as an only thing, its not great and does not share a lot of information*
- *Not Opp. 1 - too many print outs, can't take it in or remember it*
- *Not Option 1 the national website is rubbish*
- *NHS site isn't useful. When you have brain fog it's hard to understand anything. Personal touch definitely needed*
- *The first was to close the service - there are a lot of people with Long COVID and they are suffering like those with stage 4 cancer. By removing the service you have to be honest with how much suffering it will create because they won't have any support and will be sent to a website. can you imagine being sent to a website for any other condition that wreaks so much suffering. This is wildly inappropriate.*
- *Feedback on points 1 and 3: Please please, please don't stop or run down the service! I can't think of anything worse than just being referred to a webpage and then on to (most likely) a GP. It's a serious, disabling illness and needs to be taken seriously. GP's aren't equipped for this — mine didn't believe in PoTS!!!*

Opportunity 2 feedback

- *Opportunity 2 - would just be waiting again, would keep asking why, increased time and increased travel, wouldn't cover all aspects*
- *Option 2 - not overwhelmed by having to wait for other rehab services due to the long waiting list*
- *Opp 2 - don't think it will work with just joining another long queue / joining lots of different queues e.g. cardiologist would just look at heart, not whole person. Fragmented.*
- *Option 2 if the hub model in use was kept. Noted that the waiting lists would be long to attend the other rehab specialist services and difficult to navigate for the patients. In addition, each speciality do not talk to each other.*
- *Option 2: Need to be careful with bundling in things like Physio around PEM*
- *My preferred option:2 - Develop existing services to meet the needs of Long COVID patients,*

Opportunity 3 feedback

- *Opportunity 3 - What is the knock on effect ? 'I want it (money) spent on things that matter to me'*
- *Opportunity 3 - concerned fatigue management would be reduced e.g. every 3 months not 2*
- *Needs to be transparency on impact opportunity 3 will have on patients*
- *Prefer option 3 and to consider running as 2 or 3 full days*
- *Opp 3 - concerns are that staff are really really busy now. Understand reasons for this opportunity but staff will have to work even harder for even less. Concerned waits will go up.*

- *Option 3 - would be favourite and then start to incorporate elements of Option 4 and understand how other rehab servcies could be included.*
- *Retain the service with reduced staffing. It is essential that the unique knowledge in the clinic is retained.*
- *3 - preferred - specialist service. Keep the expertise, specialism to come back to as required*
- *Definitely retain service*

Opportunity 4 feedback

- *Opportunity 4 - A natural progression of the service - weakness of this would be it would weaken the focus on the condition, reduce focus on specialism*
- *Opp. 4 - experience within the team*
- *Opp 4 - a more helpful way to move forward - all in one place regardless of whether you've had COVID or not especially if not testing for COVID any more*
- *Option 4 - as above for option 3 merge and incorporate services together.*
- *Option 4 is of upmost importance but none are good*
- *4 would be my preference, if not then 3 then 2*
- *Option 4 sounds a way forward but I'm probably biased but surely different chronic illness services could be combined*
- *My preferred option 4 - Develop a service that provides support for existing Long COVID symptoms and understand if other symptoms could be included in the programme.*

Combined opportunities preference and feedback

- *1,2 and 4 - think would be going away from specialists that understand the condition.*
- *2 and/or 4*
- *Options 2 or 4*
- *The most strategic way forward is to join as many existing services as possible and persuade other rehab services to take on LC patients. 2 and 4*

Other comments and questions were around:

- *Can see the relevance of linking symptoms 'cluster of symptoms'*
- *Consider virtual groups for age, men, etc - different options as options are currently limited.*
- *I found it's the coordination of the disciplines that seems to fall back to the GP who isn't a specialist, and there is a conflict of treatments.*
- *Assessments and diagnostics are a frustration*
- *Why have referrals decreased? Is it because GPs are not referring*
- *Why are all the options worse than what's there now? The need for people with Long COVID is increasing, not decreasing, so why is the plan to offer less?*
- *It would be a shame to reduce service/increase the waiting list again in future when it's worked so well but understandable if the need is less - could it also be ramped up again if needed?*

Other concerns that were raised: (themed from general comments)

- Majority of concerns were around the possibility of stopping or reducing the service in regard to:
    - The detrimental effects on physical and mental health it could have on people
    - Increased waiting times
    - Reduced funding and staffing but would reduce quality.
- Concerned about children becoming very sick as adults 'a sick generation'
- Digital exclusion
- Lack of financial support

Do you have any other comments about the service review?

'Any other comments' – Including some comments from 'Is there anything else we could consider' - Themes:(full comments in appendices)

How does the service evaluate itself?

It's not just about new referrals, it's about those who are currently using the service and still need help. Questions were raised around evaluating the service, the reputation of the service effecting referrals, do people feel recovered at discharge, are they offered follow up reviews, that symptoms fluctuate, need to look at long term support model.

What will people do without the service?

Lots of people feel the hub is still very much needed and changing it will let Long COVID sufferers down. Concerns raised around a lack of knowledge about the condition at primary care, having to be seen at multiply different services to address different conditions, increasing isolation and loneliness and a lack of emotional support.

Not enough awareness of the service or Long COVID

Areas spoken about were, training for professional/clinicians regarding Long COVID, about the service, making the public aware of service and symptoms to increase refers and reduce stigma. People feeling that they are not believed.

Positives about the service

Lots of positive comments regards the staff being compassionate and understanding, thorough in assessments, the hub being a lifeline, the support given.

Is there anything else we should consider (which do not sit in the themes above)?

Reduction in level of service rather than no service at all

- Reducing the frequency of the group/services, but still having support available.

- The fear is having nothing, so continue in some form or another.

Providing a service that deals with similar clusters of symptoms.

- E.g., fibromyalgia does not have its own service but presents similar issues.
- Understand the skill set of the staff and what they can offer.
- Pathway for the symptoms rather than the condition as there is no testing for COVID anymore.
- Consider undiagnosed patients who have these symptoms.

Look for research/use research/take up opportunities for research

- This Service needs to keep up with the science, new advanced diagnostics etc.
- At present a limited service is provided because the research isn't there yet, but it will come, and then people will need somewhere to get access to the new treatments.
- Linking up regularly with Dr Mark Faghy and his LC Research team at the University of Derby. Knowing that research is happening, what the researchers think is happening and why, and the ability to ask them questions is important.

Family/Carers

- A video that can be shared with family members, so they can understand the illness and the effect it has.
- The role of carers tends to be overlooked and they need particular understanding.

Groups

- Need a variety for diverse populations.
- A few comments about a group in the north, Chesterfield was mentioned. This has been promised but hasn't happened.

Look at cognitive aspects, not just physical

- No-one is looking at my brain 'I am not the person I was' 'I can't do things like I could'.

Your COVID Recovery

- NHS tool not shaped by lived experience.
- Your COVID Recovery isn't a service, it's a fob off. We hear a lot of complaints about YCR.
- I am livid that one of the options in the review is to signpost us to a website. How can this even be considered a viable option? I don't know of any other long-term condition where this would be considered. We need human interaction from people that understand our condition.

Use lived experience

- Please involve us.
- There is an underuse of people with lived experience.

Support for those on the waiting list

- It's very isolating for those first 6 months – being able to talk to others would help.
- Information pack.
- Access to the Facebook group.

5: Health Inequalities Report

This following report has been completed to look at the key barriers for people in areas of high deprivation around accessing the service.

Health Inequalities and public engagement: Whose voices are missing?

Introduction

Health inequalities are defined as 'the unfair and avoidable differences in health across the population, and between different groups within society' (NHSE, 2023). COVID-19 and Long COVID impacted our communities unequally (ONS, 2023). This highlighted and increased health inequalities (Mishra et al., 2021). Health inequalities can be driven by lots of different factors including:

- The impact of the wider determinants of health (e.g. how much money people have).
- Differences in health behaviours (e.g. smoking).
- Psycho-social factors (e.g. social support from friends and family).
- Unequal access to healthcare services.
- Different experiences of healthcare services.
  (The King's Fund, 2022)

To address health inequalities as part of the Derby and Derbyshire Post (Long) COVID Service, we asked three questions:

1. Who needs the service?
2. Who are we not seeing in the service?
3. What is getting in the way of some people accessing to the service?

Who needs the service?

A national survey on Post (Long) COVID suggested some groups self-report higher rates of the condition (ONS, 2023). These include:

- People living in more deprived areas.
- People aged 35 to 69 years.
- Females.

- People with another health condition or disability which impacts their day-to-day lives (ONS, 2023).

These survey findings suggest the service should be seeing more of the patients that fall into these groups.

Research finds health inequalities are linked to a number of factors. These include deprivation level, ethnicity, income, and inclusion health (The King's Fund, 2022). Inclusion health groups are groups which face more barriers to healthcare services. They are also more likely to have poorer health outcomes (NHSE, 2023). These include:

- People in contact with the criminal justice system.
- People with severe mental illness.
- Gypsy, traveller and boating communities.
- New migrants.
- People whose first language is not English (NHS England, 2023).

It was important to make sure that we were helping the people who needed our service the most, and the ones who face the most barriers to health.

Who are we not seeing in the service?

We used the Index of Multiple deprivation (IMD) to work out if we are helping the community equally. IMD looks at patients' postcodes to work out if they are living in a more or less deprived area of Derby and Derbyshire. We found that less than 1 in 5 patients who use the Post (Long) COVID Service live in the most deprived areas. This means we were seeing fewer patients from deprived areas than we expected. This data showed that there are some barriers to the Post (Long) COVID Service for people that live in the most deprived areas.

Table 1 shows rough numbers of local people from some key inclusion health groups and a rough number of these people who may have Long COVID. It is not clear from our data how many people from each group currently use the service.

Table 1 Inclusion health groups

	Population estimates in Derbyshire and Derby	**Difference in life expectancy relative to the UK average of 81 years (years)**	**Potential Long COVID cases in Derby and Derbyshire ***
People experiencing homelessness	1800	-34	55
Asylum seekers	4171**	Unknown***	26
People in contact with the criminal justice system	800	-25	25
Gypsy, Roma and Travelling communities	2800	-10	84
Severe mental health issues	9500	-20	280

*Potential cases based on the assumption 3% of a population may have Long COVID (ONS, 2023).

**Estimate based on total of 2022 (264,000) arrivals under Ukraine schemes, the Afghan relocation and resettlement schemes, arrivals in small boats, other resettled persons and arrivals on family reunion visas.
***No data found but it is reasonable to presume that is lower as they often can land into other population groups mentioned.

What may be getting in the way of some people accessing the service?

From the data it seems that there may be factors that are making it harder for some people to access the service. This includes people living in more deprived areas and from inclusion health groups. In the next section we look at our data and other research to think about why some people might find it harder to access the service.

Service location

The service has two hubs, one in Chesterfield and one in Derby city. Both of these areas are more deprived compared to other areas in the region. Figure 2 shows that both hubs are accessed by slightly more patients from these areas than we would expect (Derbyshire Observatory, 2023).

Figure 2 also shows that sometimes being nearer the hub does not help people from more deprived areas access the service. For example, both Bolsover and northeast Derbyshire are both near the Chesterfield hub; however, there are less patients than would be expected from Bolsover (more deprived) in the service. There are also more patients than would be expected from northeast Derbyshire (less deprived).

People who live in the High Peak (a less deprived area) are also less likely to access the service (Figure 2). This may be because of the long journey to the nearest hub in Chesterfield (particularly on public transport), as well as having more local healthcare services over the integrated care services border.

Overall, this data suggests that when hubs are in more deprived areas it may help people in the immediate area access the service. However, for people living in neighbouring deprived areas there may be access barriers, even if a service appears to be nearby. Research shows that public transport access can be a barrier to healthcare, particularly for people with lower incomes (Syed et al., 2013).

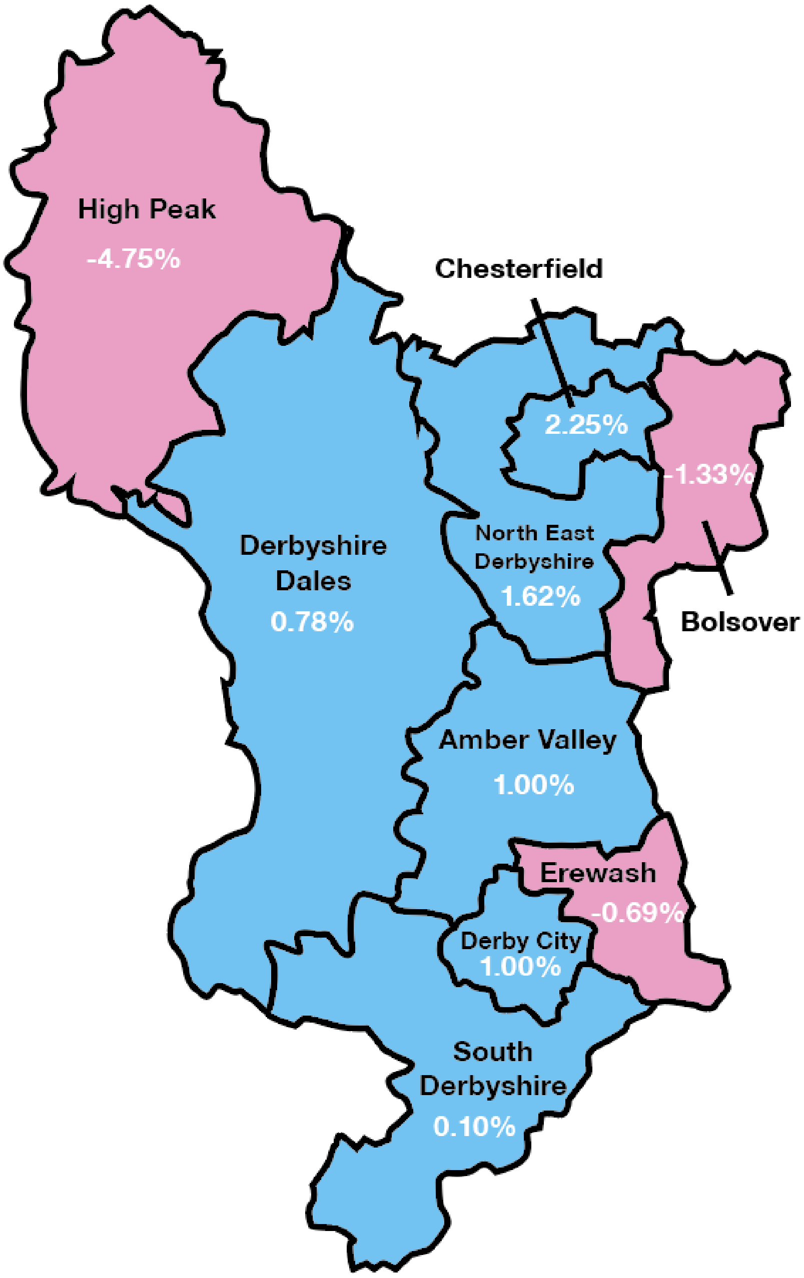


Figure 2 Difference in population in the area and representation within the service (red means the service intake is lower than expected)

Low digital and health literacy levels

The service also offers telephone and digital appointments. In Derbyshire, almost 1 in 10 residents do not have digital access. This is more common for people living in deprived areas (Derbyshire County Council, 2023; House of Lords, 2023). Research also shows people that use the internet less are often less aware of online and telephone healthcare service offers (Bryce et al., 2021). This may be the case for the Post (Long) COVID Service too.

Low health literacy levels predict poorer health (Public Health England, 2015). In areas of high deprivation health literacy levels are often lower. In Derby city and Bolsover over 65% of people are thought to have low health literacy and numeracy levels (Geodata, 2023). Low health literacy may stop people with Long COVID symptoms getting help. For example, research suggests in the general population many people still do not know much about Long COVID as a health condition (Bogale et al., 2023; UCL, 2023).

Frequent changes of address
Some inclusion groups experience barriers to the service because of moving often. For example, people in contact with the criminal justice system. There are two prisons within Derby and Derbyshire, Foston Hall and Sudbury Hall. Research into these prisons found there are barriers to healthcare services such as the Post (Long) COVID Service due to:

- It being hard to get in and out of prison for appointments, for both inmates and health care staff.
- Frequent changes of address.

Lack of trust in healthcare
Research shows that some groups experience barriers to healthcare services as a result of:

- Being highly traumatised.
- Having a lack of trust in 'officials'.
- Difficulties registering with a local GP.
- A lack of, or differing views about health.
- Compromised living situation and immigration status.
  (Refugee Council, 2023)

Feedback from the Derby and Derbyshire asylum seeker forum, and the Ukrainian centre in Derby city found that these barriers are relevant to some local residents.

GP referral route
All referrals to the service need to come through a GP. Difficulties in getting an appointment with a GP will be another barrier to the service (Healthwatch, 2022). It is also important to consider that Long COVID is a new condition, and because it's still changing, some GPs might not be confident about diagnosing it (UCL, 2023).

Overlap of symptoms
The group of symptoms that make up Long COVID can also look like other health problems, such as menopause, making misdiagnosis possible (Stewart et al., 2021). Research shows people with learning disabilities are also more likely to have their physical health symptoms overlooked and put down to other things (Rawlings et al., 2021).

Knowledge of Long COVID
The general consensus is that Long COVID is a condition which isn't well recognised by the public. A yet to be published internal survey showed that, of 2585 staff members of the Joined Up Care Derbyshire team, 11.84% (306 participants) said yes to the following question:

"Have you had COVID-19 more than 4 weeks ago and are still experiencing ongoing symptoms? The most common are: breathlessness, chronic fatigue, "brain fog", anxiety and stress."

Of those that said that they had, only 39% had been to their GP. This shows even those working within the system are not going to the GP when experiencing Long COVID like symptoms. It is therefore reasonable to presume that this percentage would be greater in the general population and even more pronounced in more deprived communities, where GP access is often harder. It is clear that public education is needed around this topic.

Summary

The research suggests that people who need the Post (Long) COVID Service are not accessing it. This includes people living in deprived areas as well as some people from inclusion health groups. The barriers to accessing this service that may be faced by some of these people include:

- Low digital and health literacy
- Frequent moving
- Low trust in and/or trauma from services
- Knowledge about Long COVID
- Knowing to see their GP
- Trouble getting a GP referral
- Overlap of symptoms
- Problems getting to the clinic

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6: National Patient Experience Research

Long COVID patient experience research summary report - Strands 1, 2, 3 and 4 March 2023

(key messages have been taken from the report in link above – further information about key areas in appendices)

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

The key implications that cross-cut the four strands are**:**

- Increasing awareness of Long COVID – the condition itself and its symptoms, as well as the available support – will overcome some barriers to accessing services.
- Expanding and smoothing pathway access will help to lessen the barriers to accessing Long COVID services.
- Providing greater support throughout the patient journey will improve patient experience and satisfaction with Long COVID and other services.

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

Prognosis

Likely timeframes for accessing Long COVID services

Where to go for help

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

How to self-manage

- Better meet the needs of patients with Long COVID by reviewing how services are set up .

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

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

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

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

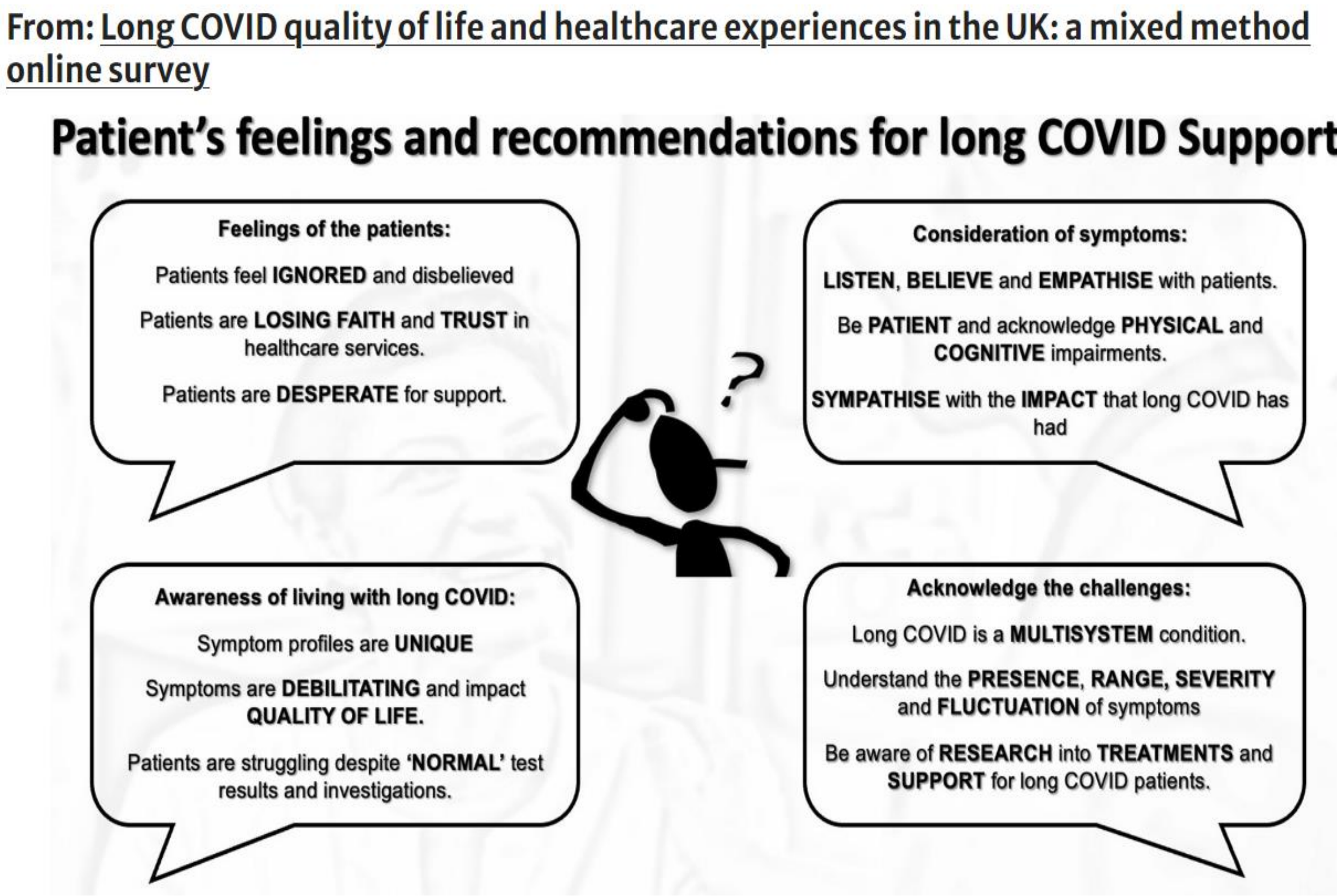
Share information between services and departments to minimise duplication, helping to manage patients' energy.

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

- Involve end users in the development of communications and use a range of formats and channels for dissemination.
- Review the pathway from the perspective of health inequalities.

Long COVID quality of life and healthcare experiences in the UK: a mixed method online survey

Derby University completed an online web-based survey designed using Patient and Public Involvement and Engagement (PPIE) to increase understanding of the lived experiences of Long COVID.



From: Long COVID quality of life and healthcare experiences in the UK: a mixed method online survey

Patient's feelings and recommendations for long COVID Support

Feelings of the patients:

Patients feel **IGNORED** and disbelieved

Patients are **LOSING FAITH** and **TRUST** in healthcare services.

Patients are **DESPERATE** for support.

Consideration of symptoms:

LISTEN, **BELIEVE** and **EMPATHISE** with patients.

Be **PATIENT** and acknowledge **PHYSICAL** and **COGNITIVE** impairments.

SYMPATHISE with the **IMPACT** that long COVID has had

Awareness of living with long COVID:

Symptom profiles are **UNIQUE**

Symptoms are **DEBILITATING** and impact **QUALITY OF LIFE.**

Patients are struggling despite **'NORMAL'** test results and investigations.

Acknowledge the challenges:

Long COVID is a **MULTISYSTEM** condition.

Understand the **PRESENCE, RANGE, SEVERITY** and **FLUCTUATION** of symptoms

Be aware of **RESEARCH** into **TREATMENTS** and **SUPPORT** for long COVID patients.

Results

Within the sample of 132 people living with Long COVID, the findings highlight that individuals are being severely impacted by their symptoms and are unable to or limited in participating in their daily activities, reducing quality of life. Long COVID places strain on relationships, the ability to live life fully and is detrimental to mental health. Varying health care experiences are described by participants, with reports of medical gaslighting and inadequate support received.

Conclusion

Long COVID has a severe impact on the ability to live life fully, and strains mental health. The appropriate mechanisms and support services are needed to support those living with Long COVID and manage symptoms**.**

It is clear that existing support mechanisms are ineffective, sporadic, and disproportionate and there is a clear need for bespoke services that address the complex and multifaceted nature of the disease.

7: Next steps

Involvement of patients and the public for the Post (Long) Covid Service review for the Pre-Engagement Report and development of a SWOT analysis (Strengths, Weaknesses, Opportunities and Threats).

A template will be provided as a basis for exploring the factors and recording the information and from the findings a discussion document will be written and then shared as part of the evaluation pack.

From the engagement events held, patients who have expressed an interest in further work to develop the service will be included in the next steps process, along with the two patient representatives who were recruited to work on the Post (Long) Covid Service and have been invited to attend the:

- **Pre-engagement Report session and details of the SWOT analysis** – this session will be used to discuss the findings from the pre-engagement work and share details of how to complete the SWOT analysis. The findings from this exercise will be included in the information packs for evaluation to aid panel decision making.

In addition, the Pre-engagement report will be shared with staff who have been actively involved in the development of the high-level options, the details of the report will be considered and incorporated into the models. The stakeholders will also be completing the SWOT analysis across the four options.

The evaluation panel will include representatives from patients and staff across the providers (Integrated Care System (ICS)) who are involved in the Post (Long) Covid Service.

The evaluation process and governance are to be led by the Integrated Care Board.

8: Demographic monitoring

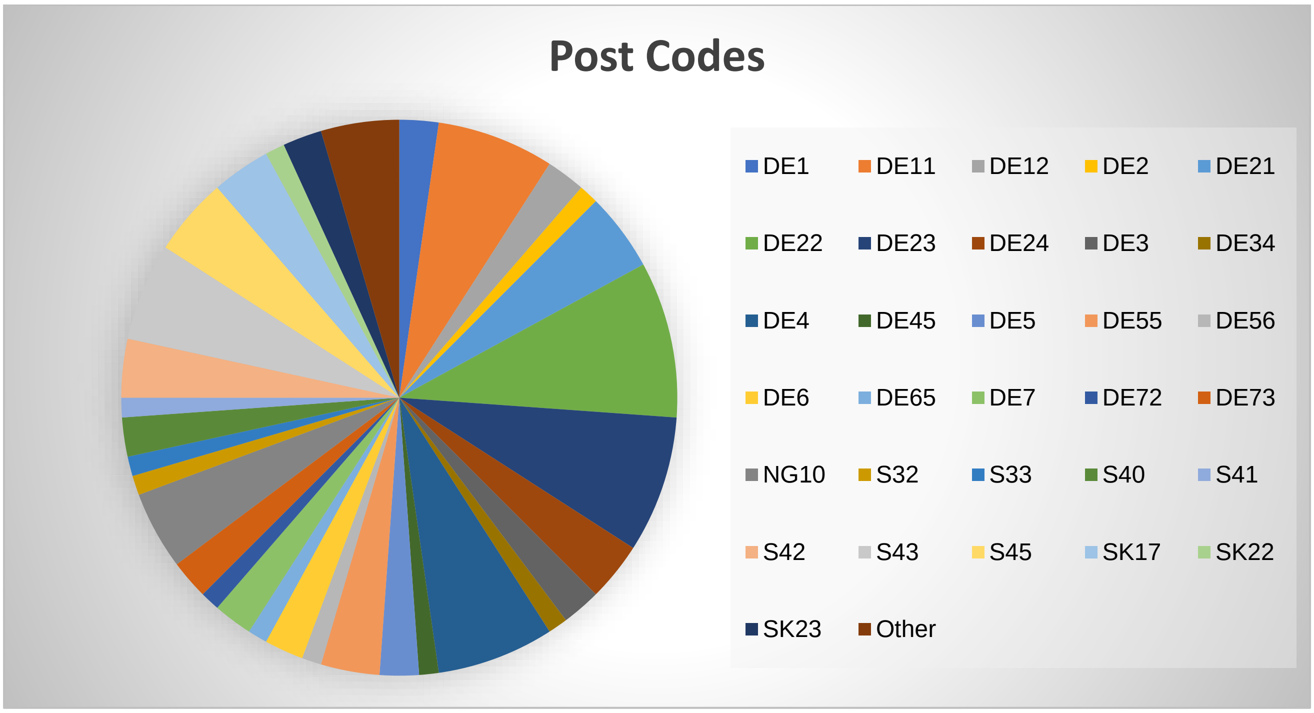
Demographics information and limitations to take into consideration

The following demographic information is taken from people who completed the survey. Of the 177 people that completed the survey 88 people completed it fully with 102 people partly answering the demographic questions.

After analysis, it is found that this section is not completely representative of those who have accessed the service or those who we would expect to access the service. There will be further work in future engagement to target a more representative sample.

The ethnicity, age and gender of respondents to the survey have been compared to the demographics of people who have accessed the service.

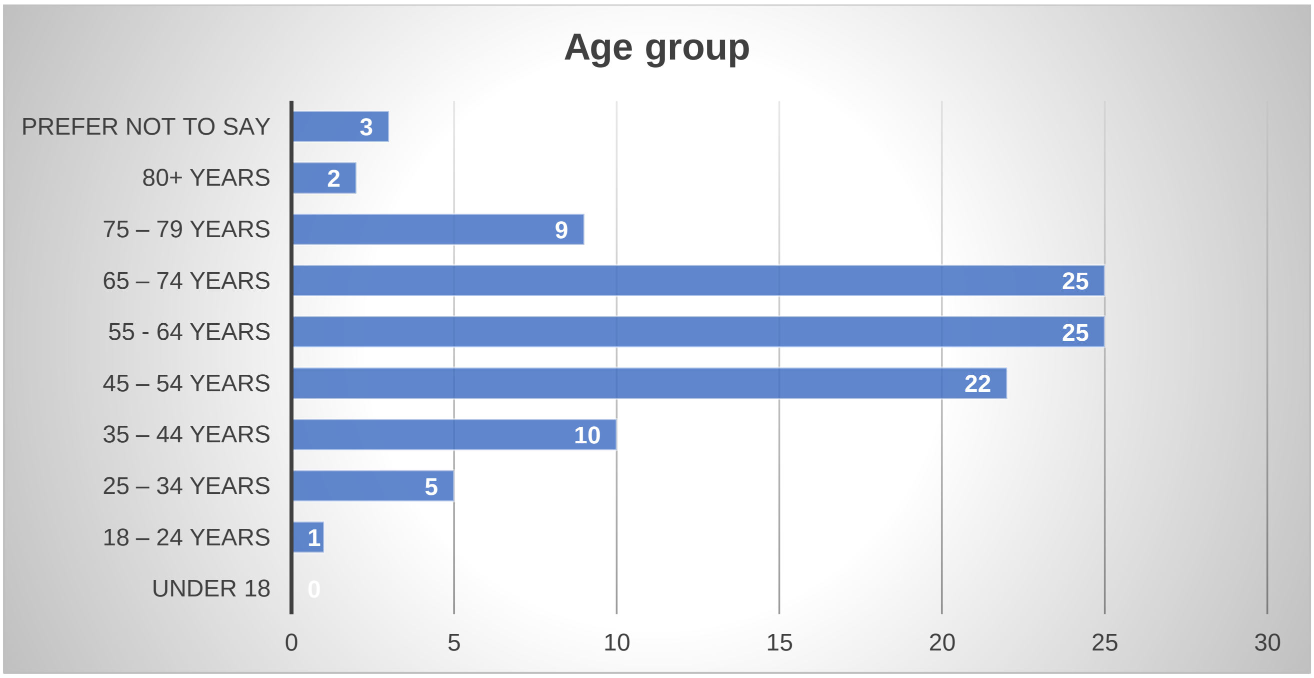
The demographic data is from the survey only.



Post codes: Areas of high deprivation

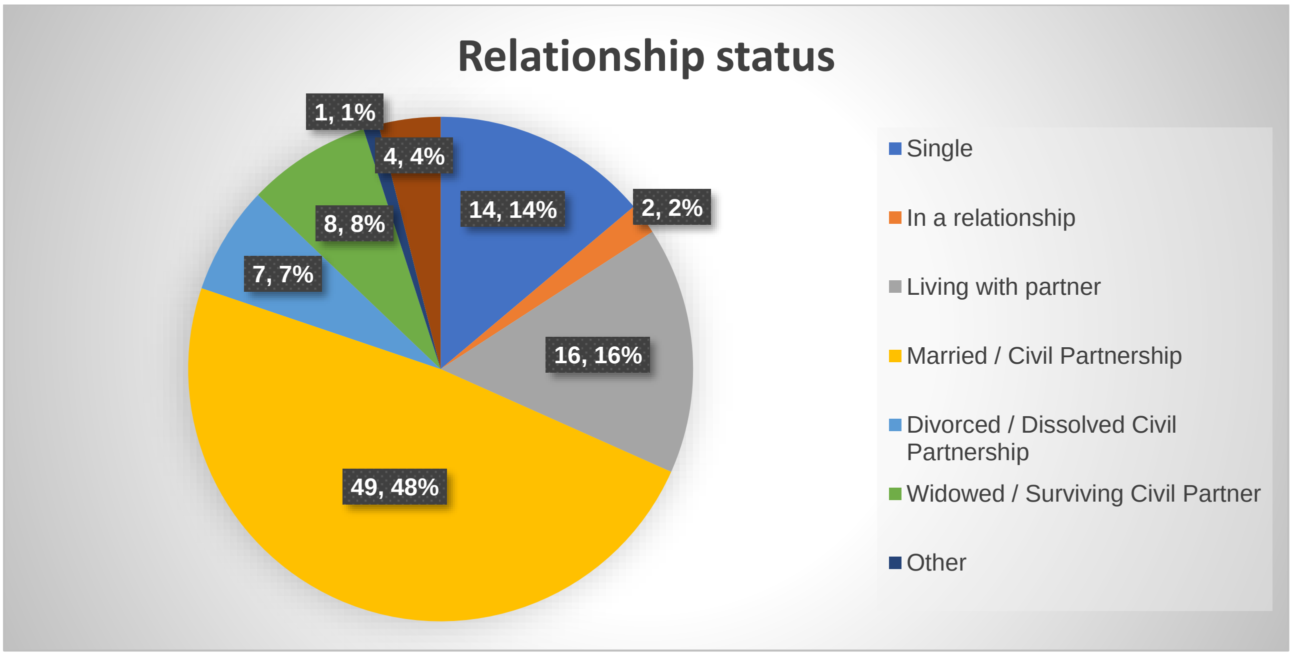
The approach for the survey was an open communication to everyone in Derby and Derbyshire. Areas of high deprivation were noted as an inequality and therefore, targeted messaging was done to encourage people from these areas to complete the survey. Key areas targeted included Chesterfield, Bolsover, Shirebrook, Clay Cross, Glossop, Hartington, Derby city, Swadlincote and Erewash.

Due to limitation in the data we are able to collect (first 4 letters of a post code) we are unable to seek full assurance that we have reached those from the highest levels of deprivation. We are able to see that a wide range of responses were given from across the county with the most common areas being Derby city (DE21, DE22 and DE23), Swadlincote (DE11), around Matlock (DE4), Long Eaton (NG10), Chesterfield (S40, S41, S42, S43, S45) and Stockport (SK43 and SK45).



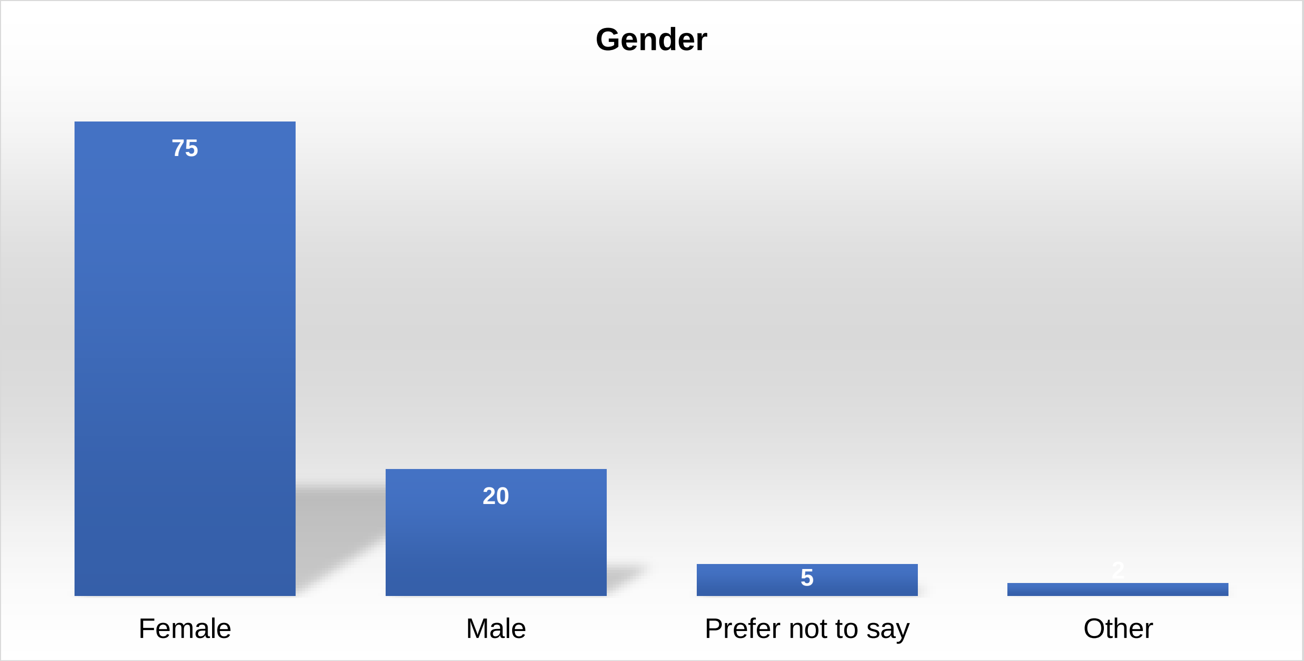
Age

Seventy percent of people accessing the service are aged between 35-44, 45-54 and 55-64. From those who completed the demographic data in the survey the number of people in these 3 age groups was 56% which means these key age groups is slightly underrepresented.



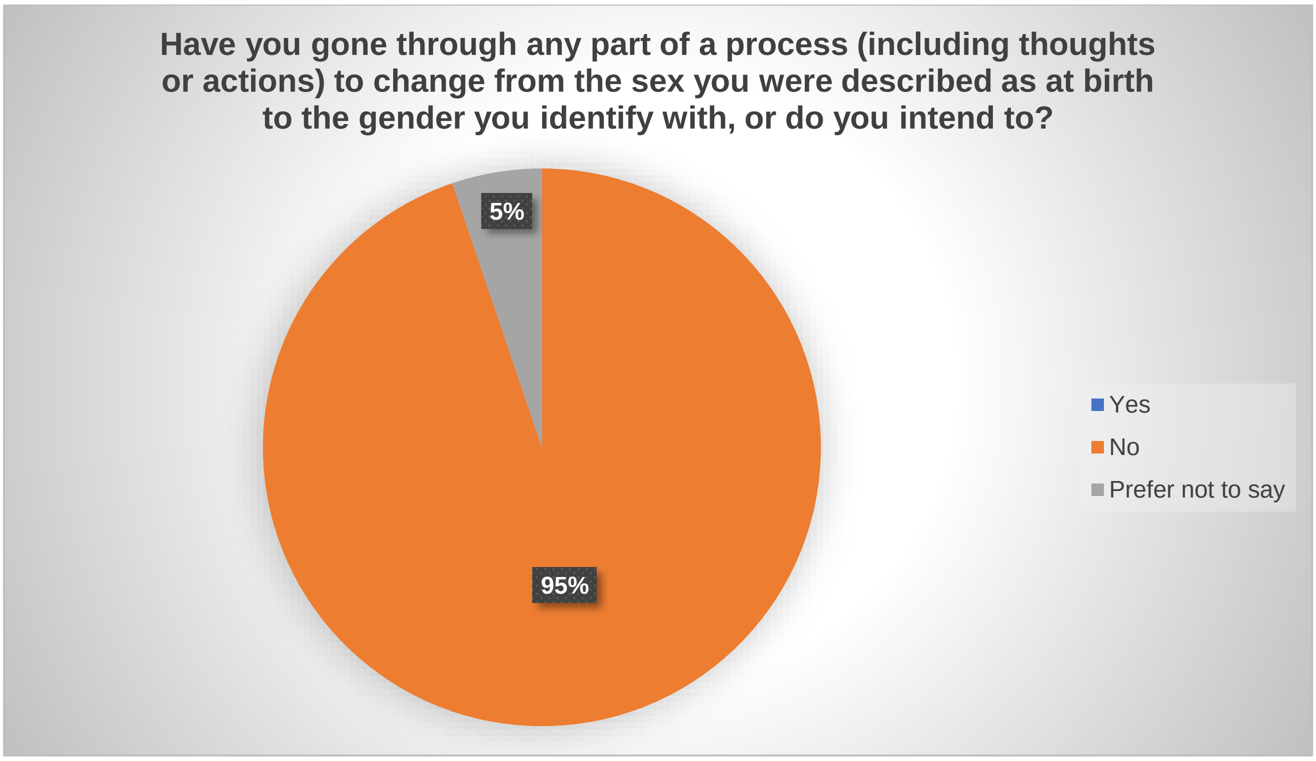
Relationship status

The majority of survey respondents were married (48.5%), living with partner (15.8%) or single (13.8%)



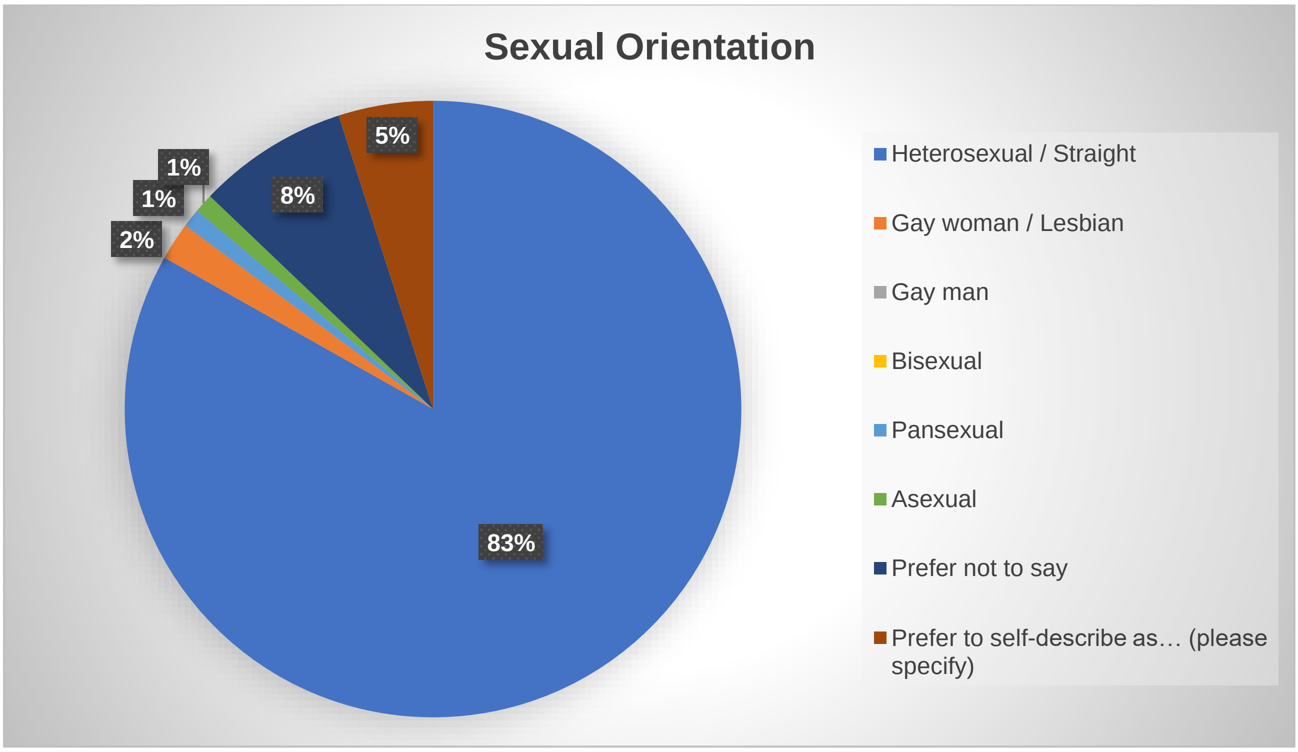
Gender

Female patients represent over 60% of referrals into the service. Of the people who completed the demographic data from the survey 77% were female which is an over representation of this gender.



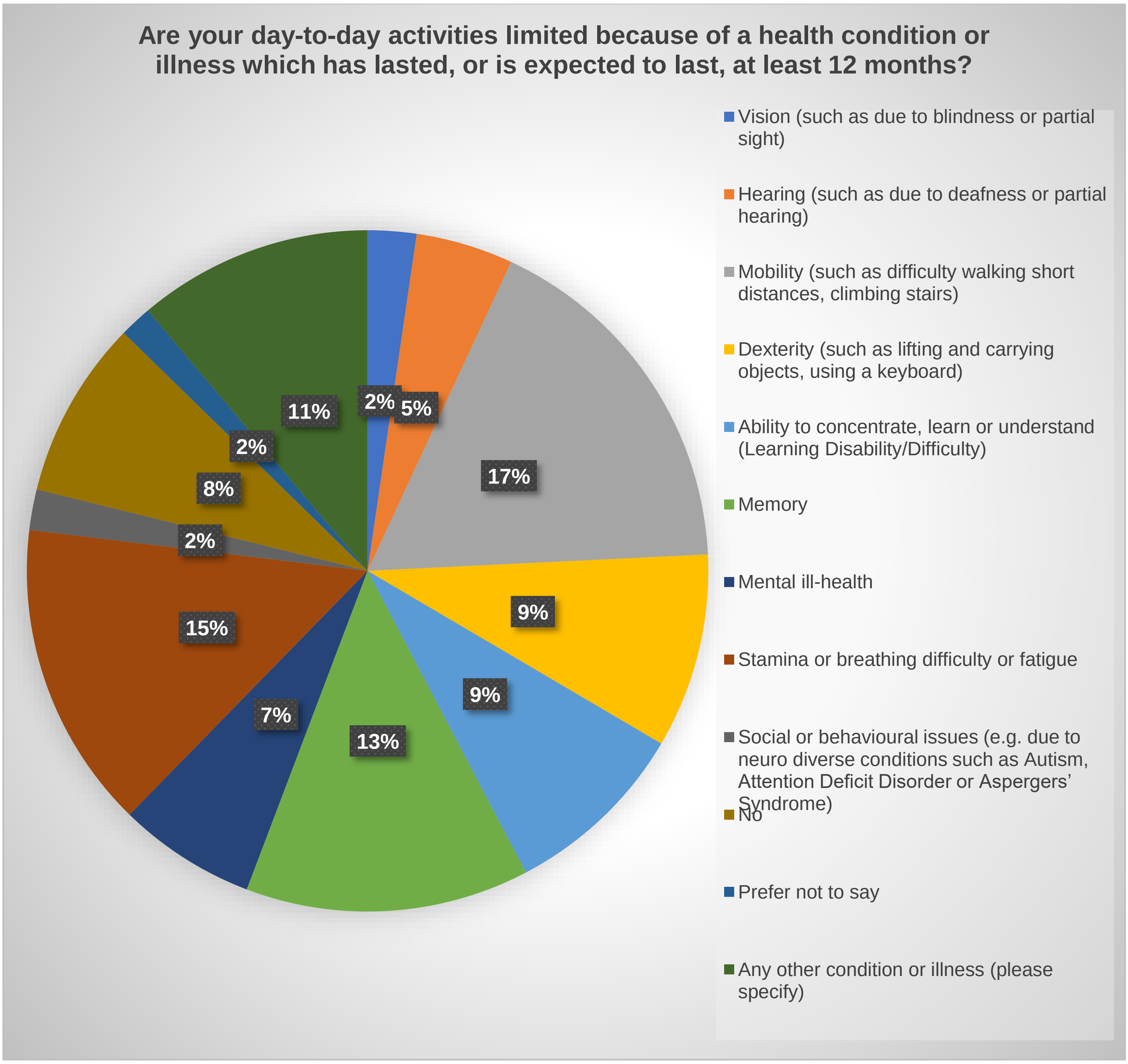
Gender reassignment

Ninety-one respondents (95%) said they had not gone through any part of the process of gender reassignment, none said yes, and 5 said they preferred not to say.



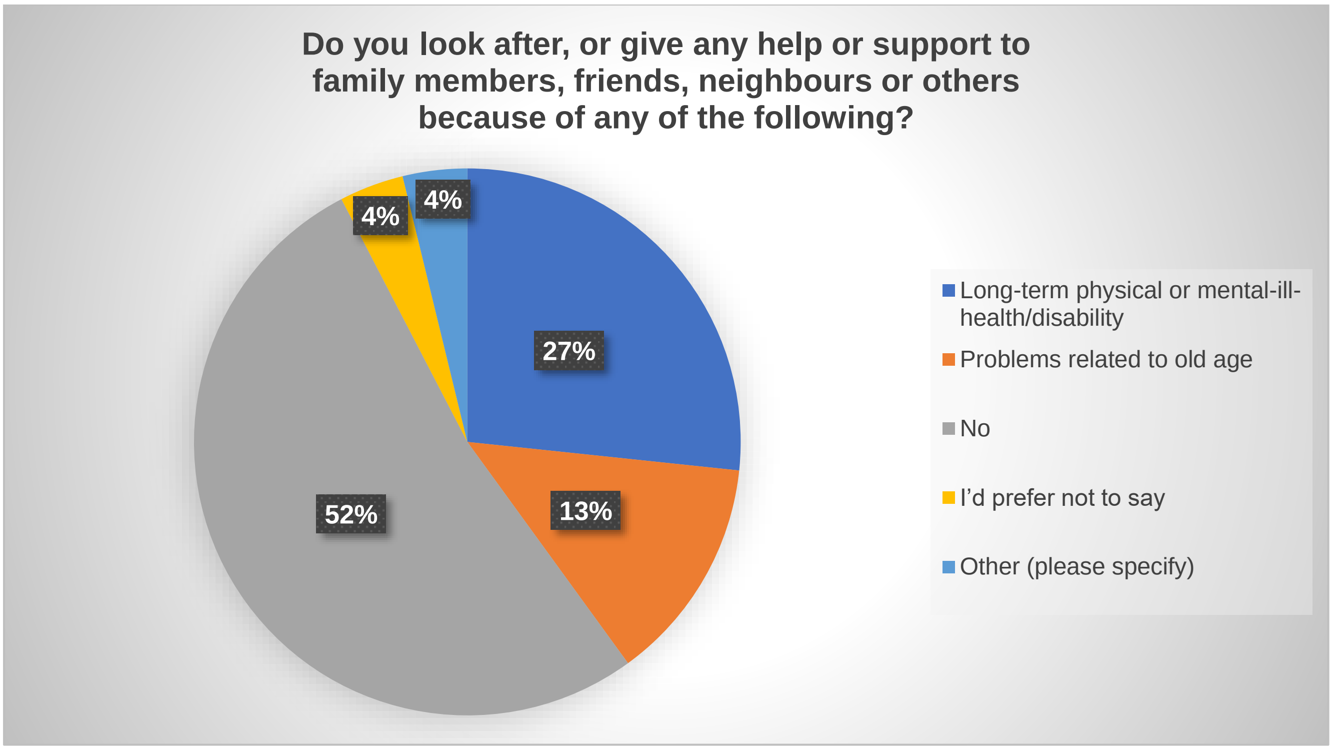
Sexual Orientation

Eighty-four respondents described themselves as heterosexual / straight, while 8 preferred not to say. 2 respondents described themselves as a gay woman / lesbian, 1 as pansexual, 1 as asexual, and 5 as other.



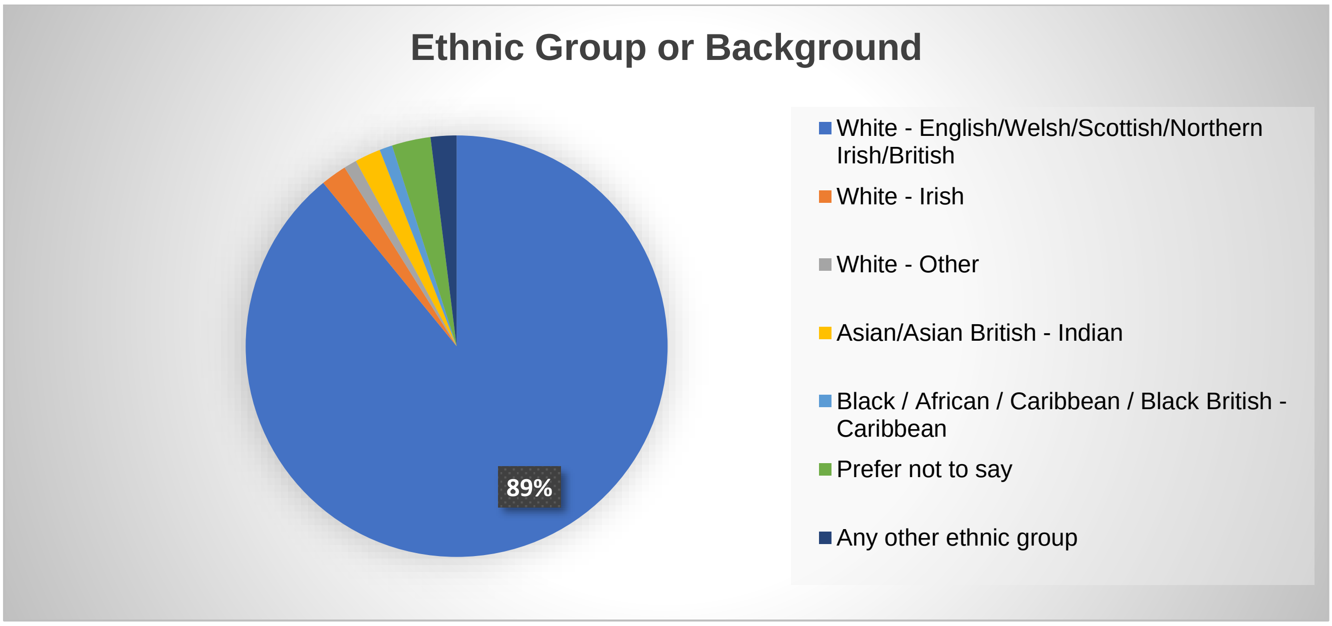
Day-to-day activity limitations

Forty-five percent of respondents said mobility was limited because of a health condition or illness, 38% respondents said stamina or breathing difficulty or fatigue was limited, 35% respondents said memory was limited, and 22% respondents said activities were not limited or preferred not to say.



Support to family members, friends, neighbours or others

Fifty-five (56.7%) respondents said they did not have to give support, 28 respondents said they supported someone with a long-term physical or mental-ill-health/disability, and 14 to problems related to old age.



Ethnicity

Eighty-five percent of referrals into the service are white British and 89% of people who filled out the demographic data from the survey identified as white British which is slight overly representative of this ethnic group.

9: Appendices

Any other comments about the service review?

'Any other comments' – Including some comments from 'Is there anything else we could consider'

How does the service evaluate itself?

It's not just about new referrals, it's about those who are currently using the service and still need help. Questions raised around evaluating the service, the reputation of the service effecting referrals, do be feel recovered at discharge, are they offered follow up reviews, that symptoms fluctuate, need to look at long term support model

- How does the service know that patients are getting better or worse?
- How does the service know that patients know the best way to care for themselves? – i.e., not from the internet, from professionals.
- Reviews are mixed in the Long COVID community for how helpful the service is, which could be why referrals are going down - improved services could change this.
- Are people offered follow ups or reviews?
- Do people feel fully recovered when you discharge them?
- Patients' symptoms can fluctuate and stick around for a long time.
- Need to look beyond an assessment and treatment model and develop longer term support and care. Needs will change over time.

What will people do without the service?

Lots of people feel the hub is still very much needed and changing it will let Long COVID sufferers down. Concerns raised around a lack of knowledge about the condition at primary care, having to be seen at multiply different services to address different conditions, increasing isolation and loneliness and a lack of emotional support:

- Without this service I worry that Long COVID will be dismissed and ignored. Not all GPs are knowledgeable about it. The mental and emotional support service and simply the recognition sufferers get from talking to professionals who believe and listen to their symptoms is often cited as a very positive aspect of Long COVID services.
- Without the service if you have chronic fatigue and chronic pain, you will need to be seen at different services.
- Without this service we would be lost and alone – it provides emotional as well as physical support to aid symptoms.
- Long COVID isn't going anywhere so the service is still needed.
- If this is wound down, I don't see what alternative would provide effective help. I struggled for around 10 months from infection to first real appointment with the service - nothing was helping me.
- We need more not less.

- I believe that the service is very necessary and will be required for a considerable time into the future, especially if people continue to experience the effects of Long COVID after even 'mild' COVID symptoms, as I did.
- It will be devastating if the service is ended.
- I haven’t seen mention in any written discussions or statements, of any other NHS services from where money could be diverted to keep the Post (Long) COVID Service going and enhanced! Current COVID cases seem to be on the up as Winter approaches, so the whole process of closing or reducing the service could be rather premature.
- If this service goes, I fear that all my medical/ pastoral support for my condition will go. I will be left with several health problems which I will not have a hub or medical contact to reach and will have to repeatedly make GP appointments and fight for my healthcare.
- Long COVID is still something that is a battle to access the right services or get appropriate understanding or up to date knowledge from other professionals. The clinic plays a key role in this.
- If these are closed, people like me will get forgotten about. My GP has no real understanding or compassion about my LC condition!
- People feel they are gaslighted in mainstream services.
- Patients are still living with Long COVID and as such still need to be supported with self-management strategies and dealing with the changes it's made to their lives. The Service gives people hope & comfort while they feel frustrated & deigned by society.
- It needs continuing because it has not gone away, we have no statistics (due to lack of testing), but this doesn’t mean it is not needed.
- LC sufferers need to be seen and heard. Am concerned that once funding is reduced or removed, we will become invisible and forgotten
- Living with Long COVID is exhausting. Dealing with a team that understand Long COVID assists that exhaustion massively. It is one less thing to worry about or have to fight for.

Not enough awareness of the service or Long COVID

Areas spoken about were, training for professional/clinicians regarding Long COVID, about the service, making the public aware of service and symptoms to increase refers and reduce stigma. People feeling that they are not believed.

- Training is needed for professionals/clinicians regarding Long COVID.
- Do all Clinicians/Professionals know about the service? Not everyone is getting a referral.
- Not enough information about the side effects of Long COVID, so people are unaware they have it. There would be more referrals if people were more aware.
- I think that there is still stigma. There needs to be more education of the wider community of the many ways Long COVID can present. This will reach more patients who need support and lead to more compassion in workplaces and elsewhere.
- GPs are ill equipped to support and have little knowledge.
- I have told a couple of people about the service who have now been referred by their GPs.
- Lots of comments saying they had not heard of this service.
- GPs are felt to be gatekeepers here and there is a feeling that they are not fully aware of the impact this can have.
- It is a real condition and people living with it have been disbelieved – feeling of gaslighting.

Positives about the service

Lots of positive comments regards the staff being compassionate and understanding, thorough in assessments, the hub being a lifeline, the support given.

- Staff have been so kind and compassionate and very thorough in their assessments.
- This hub is a lifeline for a condition which is still not well understood and multifaceted.
- This support made me feel believed and makes me feel I will be supported until I have ways to cope/ am better.
- With the support of this service, I have returned to my job, I still have daily health difficulties but know without this service I probably wouldn't have been able to accept and adjust my life to where I can resume working. Thank you to the professional compassionate team and ongoing care.
- All the staff I have met have been very supportive, understanding, friendly, welcoming, responsive and proactive.
- This service I feel is one of the most under-rated in the NHS, it provides a 1st class care for patients that is 2nd to none. I feel it has saved my life and without it I have no idea where I would be now. The doctors and other clinicians within this service are excellent.
- Yes. I believe this service has saved my life. I am an OT myself. I cannot work. I cannot walk the dog. I spend more time asleep than awake. I have no energy to go out anywhere or see friends. I cannot do housework. This disease has changed my life and I know realistically this is not likely to change. Without ongoing help from the Long COVID clinic I believe I would have given up and taken my life.

Long COVID patient experience research summary report - Strands 1, 2, 3 and 4 March 2023

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

The key implications that cross-cut the four strands are**:**

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

- Although awareness of Long COVID is generally high among the general public, there are some misunderstandings about Long COVID and differences in levels of knowledge between groups within the population. Increasing the general knowledge of Long COVID among the public, particularly with groups where knowledge tends to be lower, would be beneficial so that people know when to seek help.
- Up-to-date guidance should be regularly provided to healthcare professionals who may have first contact with individuals experiencing Long COVID. In particular, it would be helpful to raise awareness (amongst both the public and healthcare professionals) that it is not necessary to wait until 12 weeks post-infection to seek care and support for Long COVID symptoms.
- Participants in the qualitative research strands generally had a low awareness of Long COVID services and/or how to access them. In addition, advocates reported very low or non-

existent awareness of Long COVID services, making it difficult for them to signpost people to services.
- Knowledge about COVID-19 and Long COVID in children and young people was even less common, and a perceived lack of information about Long COVID from the NHS in relation to children and young people was reported.

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

- The current pathway relies on GPs, but GP availability and patient access to appointments are well-known challenges at present (across the board – not just in relation to Long COVID).
- A perceived lack of availability of GP appointments lowers public confidence in the ability of the NHS to care for people who have Long COVID, and this was enough of a barrier to deter some participants from trying to access care for Long COVID symptoms.
- The primary route into Long COVID services among participants was via a GP; this produces a perceived bottleneck however and places GPs in a 'gatekeeping' role, which impacts on how equitable and accessible Long COVID services are perceived to be.
- Vulnerable people from deprived backgrounds face additional barriers accessing and trusting healthcare professionals, so expanding the pathway to allow access via other routes may improve access to Long COVID services among these populations.
- Participants tended to find the referral process complex and time consuming, particularly in cases where they felt they had to chase or drive progress. If there is a way of streamlining the process – from the perspective of both patients and GPs – it could take less time, enable patients to access care and support for their symptoms more smoothly, and ease the workload for GPs.

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

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

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

Prognosis

Likely timeframes for accessing Long COVID services

Where to go for help

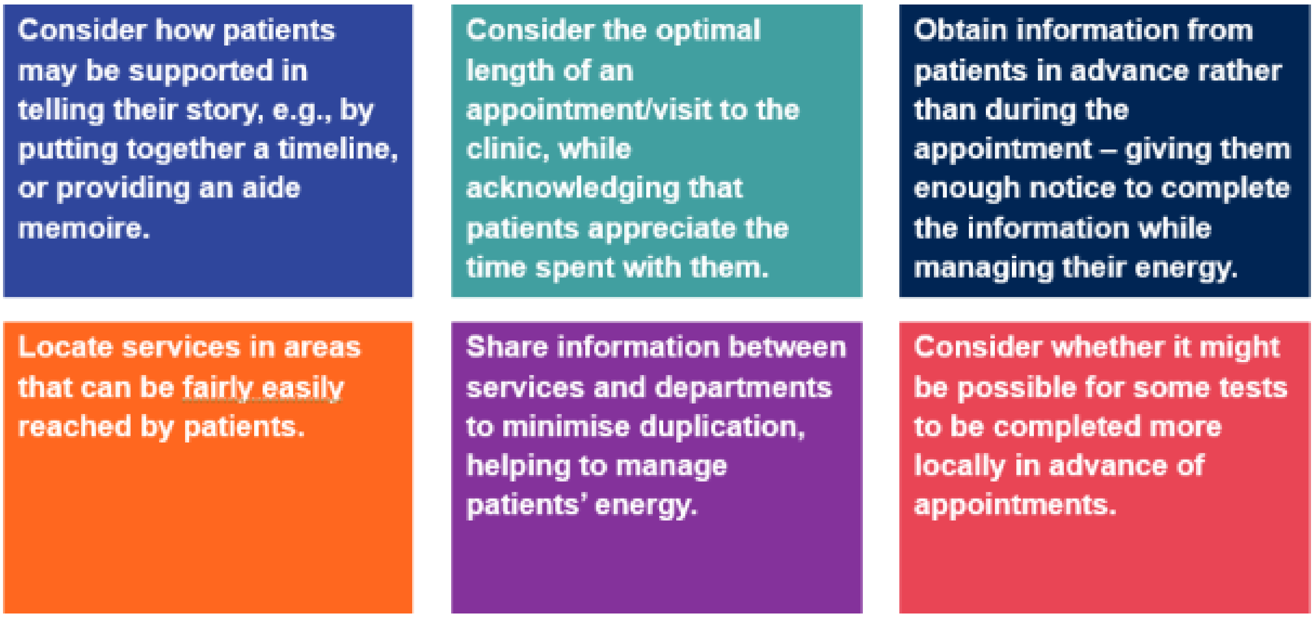
What to expect from the Long COVID clinic, and during the wait for an appointment

How to self-manage

- Many patients mentioned that they were ‘self-managing’ their symptoms outside of the support structures of the NHS. People had experimented with lifestyle changes, and sought support from professionals outside the NHS, to enable them to cope with their ongoing symptoms, either because they had given up hope of finding a cure, or while they waited for treatments. Easily accessible information regarding how best to ‘self-manage’ would undoubtedly help these patients. But, when possible, there should be opportunities for patients to ask questions specific to their conditions.
- Peer support groups and online forums provide an important source of fellowship and learning for people experiencing Long COVID, but misinformation is rife. If the NHS could facilitate, moderate, or otherwise try to influence the information provided in such groups to improve the quality of the discussion, it would be mutually beneficial to both the healthcare services and the patients themselves. The format (online vs in-person), duration and content is important to consider when setting up support groups.

Better meet the needs of patients with Long COVID by reviewing how services are set up

- Many patients reported having to wait a long time to have their first appointment at the clinic, which was often coupled with a general lack of information about the Long COVID clinic.
- From referral through to discharge the Long COVID clinics should be providing as much communication as possible. Upfront information eases the concerns and anxiety of patients. Throughout their patient journey many participants felt in the dark about what was happening to them, or what support the clinic could provide. Patients expressed a wish for more information about the clinic, and it is also important to manage patients’ expectations of Long COVID clinics in advance of their first appointments by providing more information. Not having clear expectations sometimes added to patients’ anxiety or led to expectations that they would be ‘cured’ at the clinic.
- Where patients had an initial call prior to a more detailed assessment, this was an important moment in their journey and made them feel they would get the support they so desperately wanted to help manage Long COVID. If possible, this should be provided to all.
- Patients were often positive about their in-depth assessments. They described feeling a mixture of gratitude and relief following their initial consultation at the Long COVID clinic – particularly that their condition had a name and that others were also experiencing similar ongoing symptoms. Best practice for this appointment includes allowing enough time for the appointment, asking the patient detailed questions, listening, focusing on symptoms that are most important to the patient, and being clear about the support available and onward referrals.
- Some participants reported feeling exhausted and worn out from appointments (especially in-depth or lengthy appointments), and those who struggled with fatigue and brain fog reported struggling with completing paperwork. When designing services, it is important to keep the needs (and potential limitations) of patients with Long COVID in mind:



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

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

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

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

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

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

- There was an expectation among patients that the Long COVID clinic would be able to provide them with tailored support. Patients felt severely let down when the guidance provided by the service felt too generic, or not relevant to them.
- The clinics should consider the policy around discharging patients. Many participants expressed a wish to maintain contact with the clinic, in case treatments developed or their conditions changed – rather than needing to obtain another referral.

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

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

Review the pathway from the perspective of health inequalities

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

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

NHS Derby and Derbyshire ICB would like to thank everyone that took part.