

# Long COVID Peer Support

Project Evaluation 2022-23



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### Case Study: Mel, Service User

Mel first got Covid back in January 2021. She first attended the online workshop before signing up to the fortnightly support group sessions. She had attended a group before, but was still struggling with major fatigue, a lot of pain and a range of other strange symptoms. Mel's whole body was impacted, and she wasn't really able to go out anywhere. *"My mental health was shot to pieces, I was open to trying anything that would help me get better and get new ideas."*

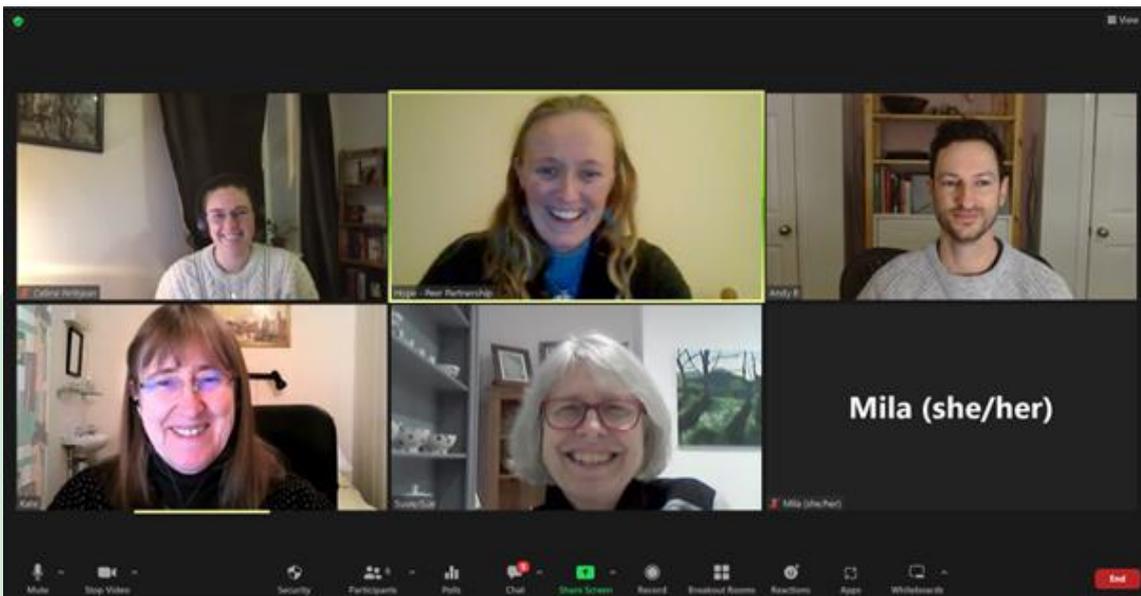
Mel found the sessions to be a safe space where she could talk about what was going on and *"everyone knew where you were coming from."* She didn't feel like she had to make any kind of effort – *"You didn't have to say things all the time. Sometimes it was just about hearing from other people and then you couldn't help but join in."* For Mel, the sessions felt relaxed and cosy. *"I used to look forward to it".*

Over the sessions, Mel mentioned the group was a great place to share tips and borrow strategies from one another. *"We all picked up helpful things from each other."* For Mel, the sessions were also a place where you were validated in what you were going through - *"The group also gave you a kind of courage."*

The group developed a strong bond. *"Having the connections made it easier to talk about stuff. We didn't want the sessions to end...So now we have set up our own little group. We don't all always meet up, but we're there - you can put something in the chat and someone will answer you."* Mel's experience of the peer support sessions has been very positive, and she mentioned how glad she was to have attended the sessions – *"I always recommend the service to my GP – people need to know where they can go and do these things...it was a lovely thing to do."*

## The Peer Partnership Long COVID Peer Support Programme

We partnered with Sirona care and health's Long COVID Single Point of Access to launch peer support for people living with Long COVID in February 2022. This service has been designed to provide information, affirmation and reassurance to people feeling frustrated, isolated, and unsure of their future due to having a diagnosis of Long COVID, and uses workshops and support groups to improve knowledge, confidence, and ability to cope with the condition.



71

Number of workshop participants

37

Number of Support Group Participants

7

Number of Peer Facilitators

720

Capacity of Service

## Peer Workshops



## Peer Workshops

We are providing peer facilitated Long COVID workshops. These two-and-a-half hour sessions support participants to explore Long COVID and how it affects them on a holistic basis.

In these workshops participants discuss their experiences of Long COVID symptoms, explore the impact it's having on their daily lives, and discover what kind of support and coping strategies are available. These sessions include a healthcare professional who provides participants with up-to-date information about living with Long COVID. Our peer facilitators provide the opportunity for participants to talk about their situation and the medical information alongside others going through similar circumstances. The aim of these workshops is to support increased knowledge, confidence, and ability to help cope with living with Long COVID.

Capacity for 24 workshops

12 Workshops Delivered

97 Registrations

71 Attendees

## From Our Workshop Participants

*These workshops have been one of the best things I have done for my Long COVID.*

*I'm so grateful for the opportunity to share and listen with other people on a similar journey.*

### Comments from workshop attendees:

*"A big 'Thank you' to the facilitators for your time and energy - I'm finding this peer service a godsend after months of being adrift and isolated with this condition, it's been really helpful to be validated and to find a supportive group."*

*"Just hearing about others' experiences has been invaluable"*

*"Thank you. It's really valuable, meeting other people in a similar situation to validate how I am feeling and having a forum to talk about how I am and to have something to attend and get up and dressed for - I happened to be having a low day and it's made my day that bit better than it would have been otherwise."*

*"I really valued meeting others with Long COVID and felt I am not alone at all. I had never met anyone else with Long COVID until today."*

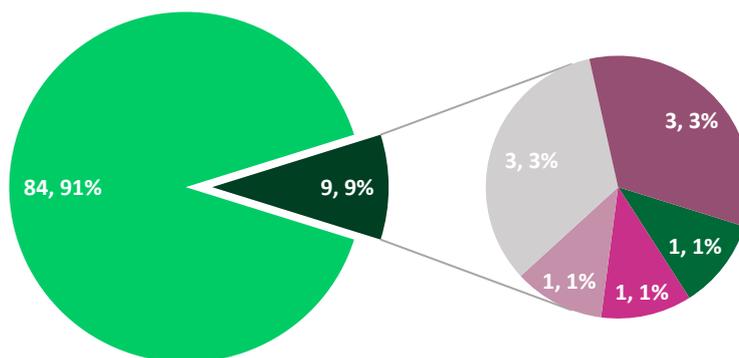
*"I can't think of one thing I would change about these workshops. I thoroughly enjoyed the approach, expertise of the leaders, really first class. I valued the flexibility of the leaders, allowing for a little diversity, making the workshop unique to each group. Loved the entire approach."*

*"Being able to express myself, my feelings, symptoms, or concerns without feeling embarrassed or fearing to be judged by others was the best thing about this workshop. I felt listened to and they were all so understanding and supportive."*

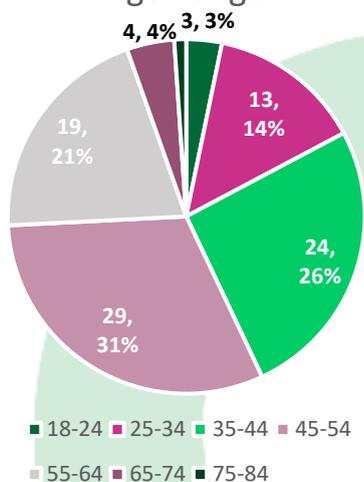
## Workshop Participant Demographics

### Ethnicity

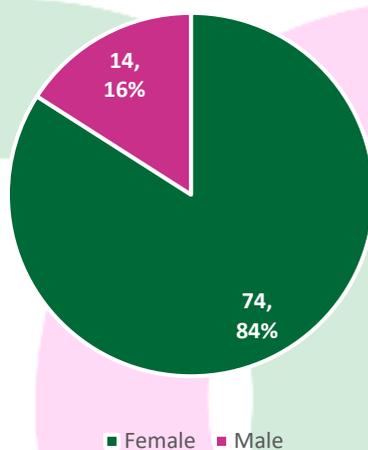
- Asian
- Black/Black British
- White British
- White Irish
- White Other
- Prefer not to say



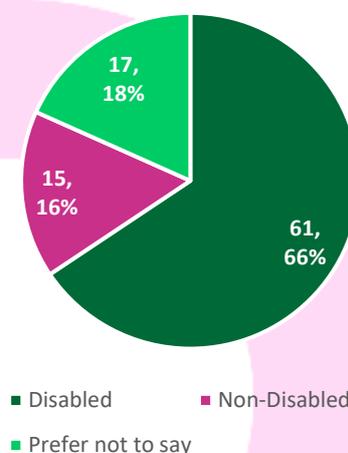
### Age Range



### Gender



### Disability Status



## Case Study: Jim, Service User



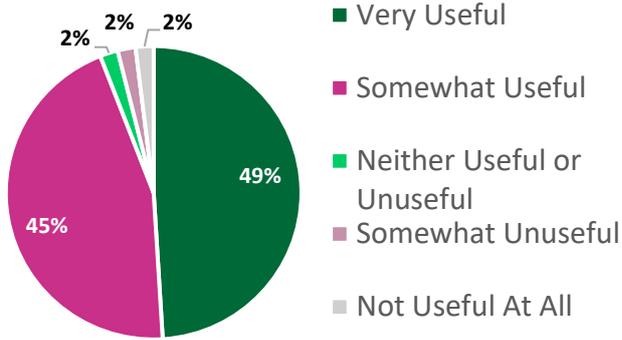
Jim first got covid in September 2020 and has attended both our workshop and an online support group.

Before accessing peer support Jim experienced very little support for his Long COVID. *“At the time, it felt like there was very little help out there.”* Before attending the workshop, Jim didn’t know anyone else with Long COVID. Through the sessions getting to meet other people personally who also had Long COVID made *“the world of difference. I went from being the only person on the planet this has happened to, to knowing actually there are other people, and there are ways of making this not so bad.”*

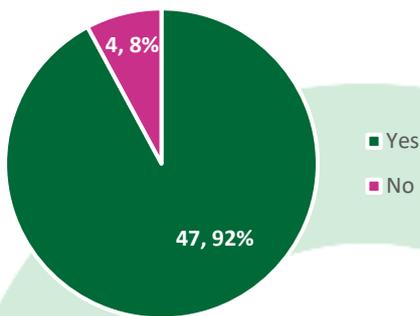
For Jim, *“the sessions were a safe place where we recognised each other’s struggles- but they were more than just getting together for a moan.”* The sessions provided *“a place to reflect how we were doing, but also learn about some of the positives, some ways that were working, and ways forward.”* For Jim the support group became a space once every couple of weeks which he felt he *“didn’t otherwise have.”*

Jim found the peer element of the sessions to be very important. *“It made a huge difference that the people running it were in the same position as me. I can’t imagine how it would have worked otherwise. It brought a kind of equality to the space – we were all on the same wavelength, there was a genuine understanding.”*

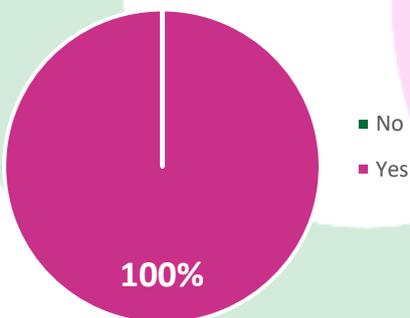
### How useful was this workshop?



### Did you feel heard?



### Would you recommend this service to others?

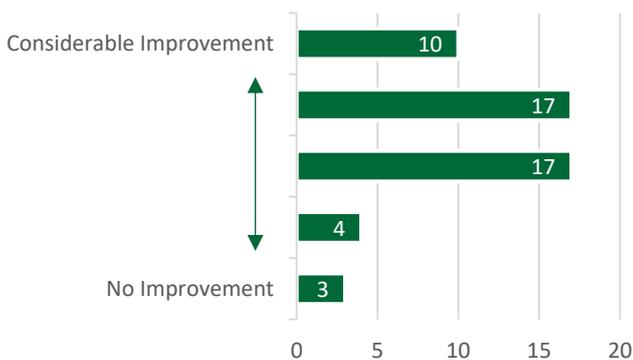


## Workshop Feedback

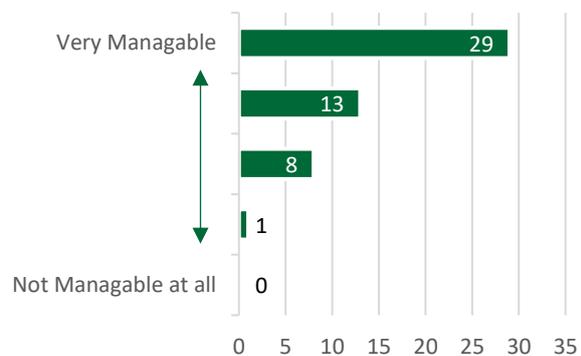
We evaluate these workshops through feedback from participants to an online or paper form following workshop sessions. We ask the following questions:

1. How useful was it for you to have attended this workshop?
2. From attending this workshop, how has your understanding of Long COVID improved?
3. What have you taken from this workshop that may help you manage living with Long COVID?
4. Did you feel that there were enough breaks?
5. Did you feel this workshop provided you with a space to be listened to and heard?
6. How could this workshop be improved?
7. Would you recommend this support to someone else in the same position as you?

### Understanding of Long COVID



### Was your workshop manageable?



## Support Groups



### Support Groups

We are providing Long COVID support groups. Each Support Group runs for 6 sessions over a 12-week period. These two-hour sessions provide a space to discuss Long COVID, checking in with participants on how they are doing, and giving up-to-date information on various aspects on how to manage living with the condition, including coping strategies such as pacing, occupational therapy and how to discuss their situation with friends, family, employers, and health care professionals.

The aim of these support sessions is to reduce the isolation that living with Long COVID can create, and support participants knowledge, confidence, and ability to cope with the condition in an empathetic, reflective, and person-centred way.

Capacity for 12 support groups

7 support groups Delivered

50 Registrations

37 Attendees

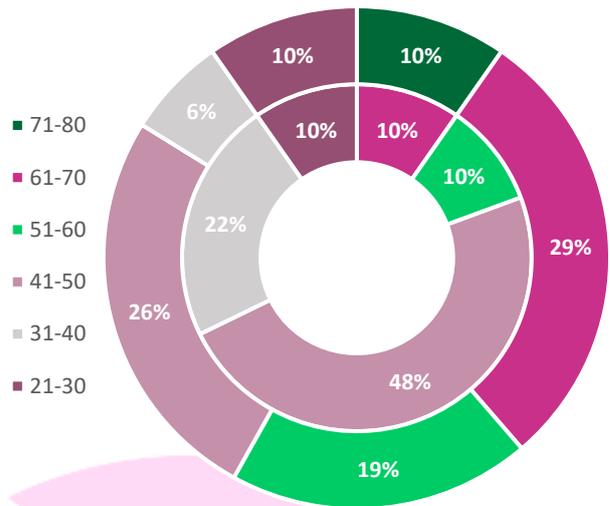
## LTCQ-8 Results

The LTCQ-8 is a self-reported outcome measure for assessing the overall impact of living with long-term health conditions. It asks 8 questions and provides a score out of 100. A higher score equals a higher health-related quality of life.

Our results show:

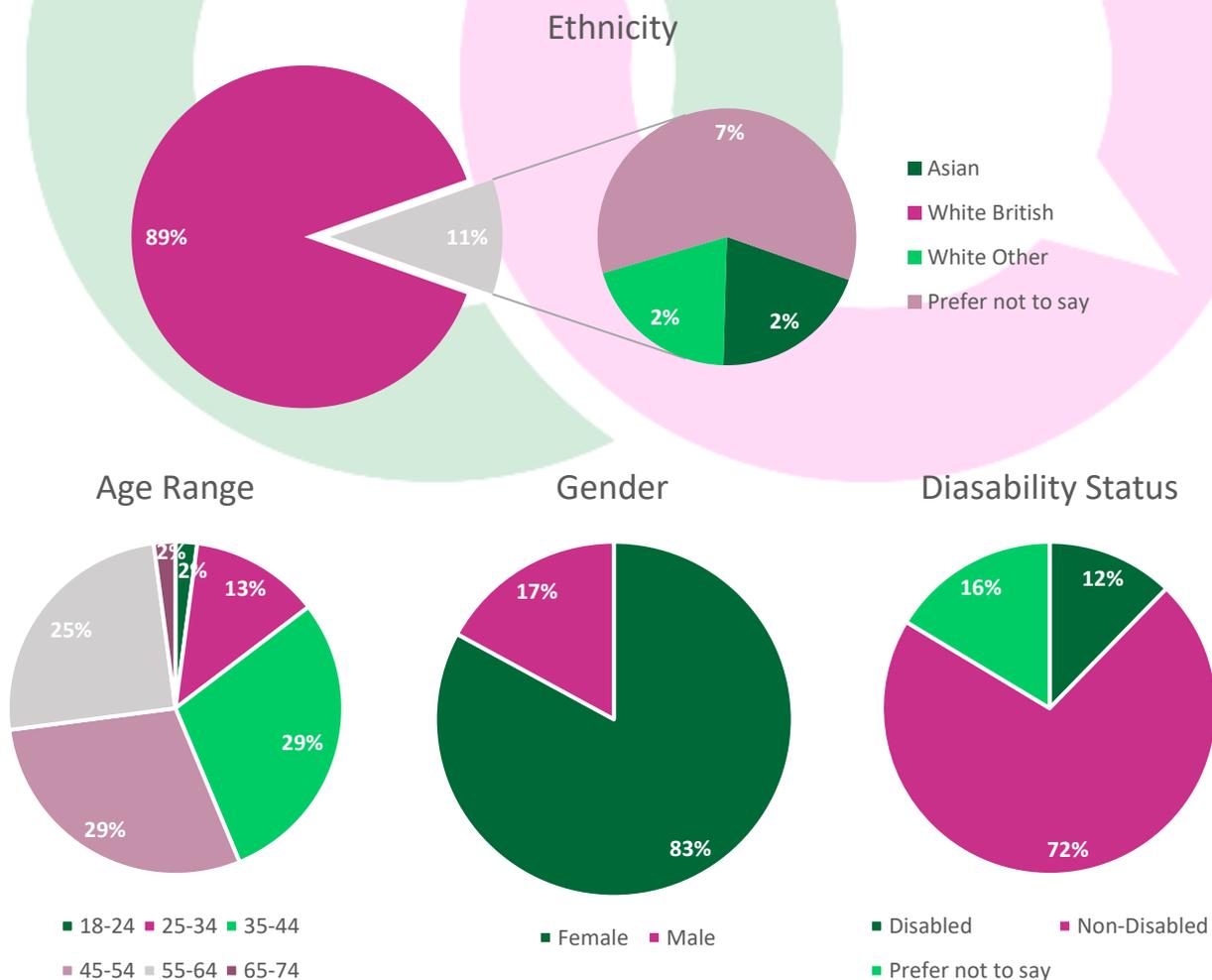
- **84%** of participants saw a positive increase in their LTCQ-8 scores
- **58%** of participants saw a 10% increase or greater
- Before mentoring, **83%** of participants were below 50. This halved following support to **42%**

These results show a significant positive contribution by support groups in self-reported feelings in how participants feel their health condition impacts them.



Inner ring = before support  
Outer ring = after support

## Support Group Demographics



## From Our Support Group Participants

### Comments from Support Group attendees:

*"I think the support groups are great. It's been a lifesaver"*

*"Thank you for providing this service and treating us with compassion and acceptance. It helps so much to have my experience validated."*

*"The support group has been a revelation and without this safe space to discuss our condition and learn from others, I really think I was heading for a breakdown."*

*"Instead of feeling adrift, I've gained the understanding that I may have a new and different future, and need to plan for and pace myself"*

*"It really has been helpful to have something to look forward to, meet with others and know I'm not alone, and that we are all facing similar challenges. Discussing managing my symptoms has been so valuable as it otherwise can feel so overwhelming. I have been feeling quite isolated since developing long covid and being unable to work. Meeting with friendly people has made such a difference."*

*"It should be the case that everyone is offered this sort of support, as I feel it has helped me mentally. I wasn't in a good space at all before attending my support group. More support groups like this are needed."*

*"This support has been invaluable and enabled a much better understanding of the condition. The workshop at the beginning was incredibly helpful in providing a clear medical view, and it's so good to get ongoing support through the group."*

*"The group has made me feel less alone. Being with others who are in the same position is reassuring as they completely understand what it's like. There has also been a good sharing of things to try, including supporting my mental health as well as my physical. Practical tips, website links or findings from researching studies or articles has been helpful to learn from. Having a laugh and sharing jokes despite our situations has been very therapeutic too. "*

If you were to pick one thing you found most useful from attending these sessions what would it be?



## Our Mentors

*Much of the knowledge and expertise required to self-manage long-term conditions is not held by professionals, but by people with experience of the condition. Peer-based approaches can be a powerful tool in building people's capabilities to manage their health. (Kings Fund, 2018)*

Our mentors are the backbone of our service, and we could not do what we do without them. Our peer mentor volunteers go through comprehensive training to prepare them to mentor and are provided with regular group supervision when they are providing support. Our mentors are trained in:

- Motivational Interviewing and Active Listening
- Goal Setting and Action Planning
- Boundaries, Confidentiality and Safeguarding
- Reflective Practice



### Thank You Awards

Two of our mentors, Nick and Sue, accepted a Thank You award from Eastside Community Trust on behalf of all the mentors on our Long COVID service in 2022.

Between our seven mentors, they have supported over 100 people through workshops and support groups throughout Bristol, North Somerset, and South Gloucestershire, to explore and maintain their physical and mental health whilst living with an uncertain condition.

Without the passion and dedication of our mentors, and their willingness to support others despite their own Long COVID symptoms, services such as this simply couldn't exist.

## Case Study: Celine, Service User & Peer Support Volunteer



Celine first got covid in March 2020, she has had a long turbulent journey with her health since - facing relapse after relapse, time off work and a second covid infection in Spring 2022, which wiped her out completely for another 2 months. Despite her GP being understanding, there wasn't much they could do. She had already been sick for 2 years and it had completely changed her life.

Following referral to Sirona, Celine attended the first in-person workshop in February 2022. This was the first time Celine had left the house in a month. *"It was that important for me to go – I knew I would prefer to take a few hours now even if I crash later".* For Celine one of the most important things about the session was *"To realise my symptoms were experienced by other people – there are other people in Bristol, who are here and physically real, that have this. It can be so isolating otherwise'."*

After this Celine joined our online support groups. The group provided an important space to talk about Long COVID without having to continually explain, justify, or worry about how other people were perceiving it *"it's very different expressing your situation to someone who shares the experience"*. Celine has experienced a shift in how secure she feels in talking about her situation. The group helped Celine explore her perception of her own condition, and her position on it. *"I am the expert of my own condition"*. Through conversations in the group, she felt more able to express her condition with others, and Celine kept in touch with other members. *"We ended up creating a WhatsApp group and exchanging emails and have recently organised a couple of meet ups. We are sharing stuff positive or negative, and it's quite nice... we now have this kind of little community. I've met some friends, who are on completely different paths of life than me and that's really nice."* For Celine this has been a very positive takeaway.

Celine became part of our peer volunteer team in September 2022 and is facilitating support groups. Her experience of having received support from the program makes her ideal to be someone who now provides the support. *"Volunteering with the group is interesting and feels like it is really making a difference for people."* So far, Celine has enjoyed various parts of what it means to be a volunteer. *"The team is great...the training was excellent... the supervision sessions are really interesting – it helps me in other roles I have in my life too or dealing with my own relationship with Long COVID"*. Celine feels the programme is *"well run and well structured. As a volunteer it is easy to facilitate the sessions"*. For Celine, *'the quality of how the programme is run, the training, and the support given on variable levels'* has been key – and something we are glad she is happy to be a part of, and we are very happy to have her with us.



# Development Points

## Service User Development Feedback

In November we held a focus group for 10 people who had been through our peer support workshops and support groups and used the results to create a questionnaire that was sent to all previous service users.

From this service-user feedback we discovered:

### Contact with others living with Long COVID

The main thing people valued from both workshops and support groups was being able to meet other people with the condition and have their feelings and experiences validated by others in a similar position. This has supported participants to feel less isolated and alone.

### The biggest benefit to using our service

Respondents informed us that they found it more manageable to manage symptoms when finding out other people struggle to do this too. The support offered has provided a place to talk about their struggles with managing their symptoms where people understand - so they don't have to justify/explain worry about how they will be received and has helped affirm that they do not need to feel like they are failing when they struggle to do daily activities.

### Ease of access

100% of responses said it was easy to sign-up to the service once they received their referral letter from Sirona. Some respondents said they would like more options of times and online/in-person formats.

### Additional Workshops for specific Topics

Respondents would like further one-off workshops. The favoured topic areas of these workshops were:

1. Long COVID and Employment – Focussing on talking to employers about Long COVID and how to advocate for reasonable adjustments in the workplace,
2. Long COVID and Benefits – Focussing on what benefit entitlements participants may have and how to access them,
3. Friends and Family Workshops – Provided to friends, family members and carers, to explore what they may need to consider to support those living with Long COVID

### Ongoing Groups

Respondents would like some continuation of support. There was split between preference for continuation of existing groups, which could be self-administered, and for ongoing monthly drop-in sessions accessible for anyone who has used services.

## Data Informed Development Feedback

### Feedback Forms

Our feedback from workshop and support group participants has been almost universally positive, with 100% of participants who completed feedback forms saying they would recommend this service to others, even when they had critiques of certain elements of the programme. Workshops participants feel the service is easy to access, sessions are manageable despite Long COVID symptoms, they felt heard in the sessions, and that the sessions have improved their knowledge of Long COVID. The feedback would suggest that the workshops have been successfully designed and implemented for their intended purpose. Our

support groups have seen 81% of attendees report an improvement in their LTCQ-8 scores, and 42% showing an improvement of over 10%.

## Demographics

Our demographics report shows a need to concentrate offers of support in particular demographics. There is very significant underrepresentation in both workshops and support groups, with no more than 2% of participants being from non-white ethnicities. There is no evidence to suggest that those from diverse ethnic backgrounds have significantly lower rates of Long COVID, so it will be important to focus development of support in meeting the needs of patients from Black African, Black Caribbean, South Asian, and South-East Asian communities.

Male participants are also underrepresented in services, with a ratio just below 1:6. Further exploration should be made into the impact this has on male participants experience of support. Consideration should be given a for single-sex group to see if this could increase male participation.

## Access and referrals

Our [google analytics data](#) shows that we are not reaching or converting sufficient numbers of patients referred to Sirona Long COVID Single Point of Access into registration to workshops and/or support groups. We can see from the data that there are peaks of visits to our referral pages throughout the year, likely coinciding with Long COVID Clinic referral letter mailouts, but these fall significantly short of the numbers needed to take advantage of the available capacity of the service. The service currently has the capacity to fulfil the original stated goal of providing 24 workshops, able to support up to 360 participants, and 12 structured peer support groups, able to support up to 240 participants, for a full capacity of 600 participants annually. In order for this service to provide best value for money, the referral processes to the service and the content of information and websites should be reviewed to ensure ease of access and attractiveness of service.

## Recommendations for Service Development

1. Based on the success of the workshop format, but considering the number of referrals in, we would propose to replace 25-50% of newly diagnosed workshops with topic specific workshops, including Long COVID and Employment workshops and Long COVID and Benefits workshops. This would allow for the Newly Diagnosed workshops to continue, but also for specific topic workshops based on areas that service-users have informed us that they struggle with. This would also have the benefit of reducing the time commitment of Health Care professionals in the service, who would be replaced with employment or benefits specialists, to be drawn from either Jobcentres or third sector organisations with expertise in these areas.

### Considerations

- a. Will this still allow for enough variation of workshop times (daytime/evening/weekends)
  - b. Will we find sufficient support from additional specialists in employment and benefits?
2. The service needs to reach out into specific communities to ensure that they are supported through the services available. This should include targeted recruitment of volunteers from these communities to ensure that potential participants feel that advice is culturally sensitive and so that they see themselves represented in the support that is on offer. This will require partnership with community organisations across Bristol who represent those communities currently underserved by our service provision.

### Considerations

- a. Are there sufficient numbers and community recognition to justify this move?
  - b. Will we be able to effectively engage these communities?
3. We propose to trial a man only workshop and support group to explore and identify if this would increase the numbers accessing our services.

### Considerations

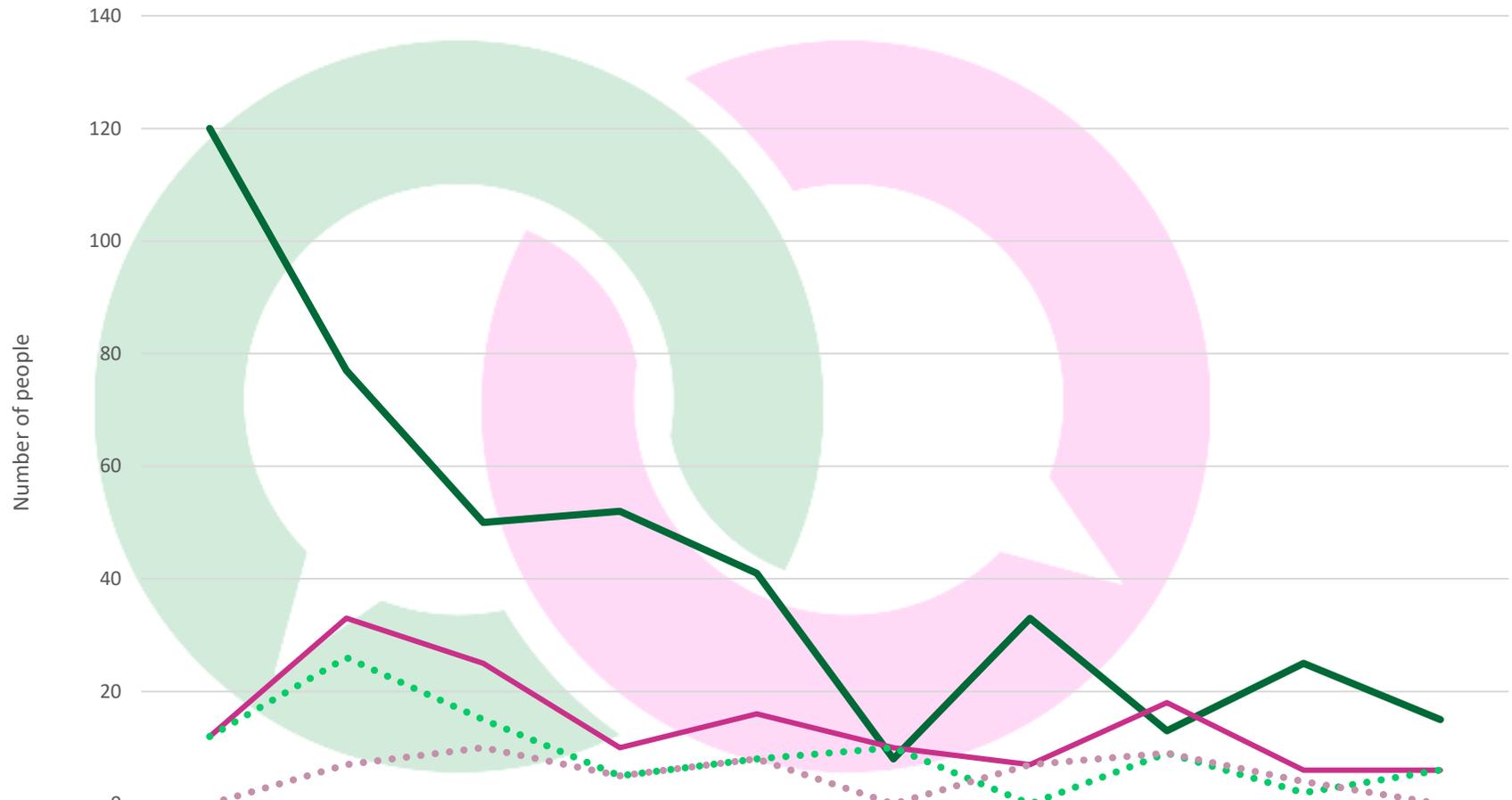
- a. Is there actual demand for this?
  - b. Will we also run female only sessions?
4. Referral processes should be reviewed to make accessing the service easier. This could include:
- a. Opening referrals to workshops at an earlier stage of diagnosis,
  - b. Allowing direct referrals from Primary Healthcare and social prescribers,
  - c. Follow-up offers of service to those lost to care, who may have previously been referred to and offered services from the SPA but have not accessed interventions. Follow-up may encourage them to take up services that will improve their situation.
  - d. Providing information about services electronically, via email, as opposed to written and posted letters. Our experience in supporting Homerton Long COVID Clinic has shown significantly higher and quicker take-up of workshop spaces when provided with an email with a clickable link, removing a significant barrier to access.

### Considerations

- i. Will this cause problems with differential diagnosis?
  - ii. Will primary care actual refer?
  - iii. Will follow-up cause increases in the number of referrals to other services that are already at capacity?
  - iv. Is there the infrastructure in place to communicate with patients via email?
5. Promotion of service should be improved, with public adverts of the service, including clarity on referral pathway. In addition, new materials should be developed for both public and referrers, including:
- a. A public version of this evaluation,
  - b. A video of the service, featuring mentors and service-users,
  - c. Updating of webpage,
  - d. Promotion via social media, local newsletters, radio appearances and event attendance (Such as CAAFI Clinics).

# Google Analytics – Web Page Visits and Registrations to Service

Registrations for Service



	March	April	May	June	July	August	September	October	November	December
Registration Page Visits	120	77	50	52	41	8	33	13	25	15
All Registrations	12	33	25	10	16	10	7	18	6	6
Workshop Registrations	12	26	15	5	8	10	0	9	2	6
Support Group Registrations	0	7	10	5	8	0	7	9	4	0

## Registrations, deliveries and attendances

Registered	143
Attended	108

Workshops	Total to date	In-Person	Online	Q4 21/22	Q1 22/23	Q2 22/23	Q3 22/23	Q4 22/23
Scheduled	26	10	16	3	9	9	5	0
Delivered	12	4	8	2	6	2	2	0
Registered	97	36	61	15	54	11	17	0
Attended	71	25	46	12	38	9	12	0

Support Groups	Total to date (TTD)	In-Person (TTD)	Online (TTD)	Q4 21/22	Q1 22/23	Q2 22/23	Q3 22/23	Q4 22/23
Scheduled	7	0	7	0	3	2	2	0
Delivered	7	0	7	0	3	2	2	0
Registered	46	0	46	0	22	15	9	0
Attended	37	0	37	0	18	11	8	0
Completed	22	0	22	0	2	9	3	0