



Long Covid Report 2024



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Thank you to all the citizens, groups and stakeholders that took part in the engagement activity.

Section 1. Executive Summary

Organisations reported that 106 Long COVID Community Awareness events took place prior to the reporting deadline, with some further events yet to take place. Six events were held online and 100 in-person.

The organisations reported that across all events, there was a total of 3347 attendees. Some events had as little as a single attendee, with the largest number of attendees at a single event being 200.

in raising awareness of Long COVID and its symptoms, of what to do if people have Long COVID, and awareness of the Post Covid Syndrome Service (and, to a lesser extent, confidence in accessing the service). The events had less of an impact on attendee's likelihood of getting vaccinated, but a number of those attendees were already fully vaccinated and increasing vaccinations wasn't the main focus of the events.

People involved in this project were also very positive about the effectiveness of the method of learning as this helped them gain more information around Long COVID and the available resources.

Organisations felt that partnering with medical professionals was of particular benefit to the attendees, with several organisations noting that they had appreciated the expertise offered by the BCHC Post Covid Health Inequalities Project Coordinator.

Recommendations

1

BCHC to utilise community locations/ premises for future health awareness and similar projects.

4

BCHC to ensure its information is in several languages wherever possible, and work with its communities to spread key health messages.

BCHC to further promote the Post Covid Syndrome Service.

5

BCHC to increase its representation at future health awareness events such as those that occurred during this project.

2

6

BCHC to ensure that, whenever possible, longer lead times are provided with community-based projects to help organisations engage with underrepresented groups and communities that aren't within their usual scope.

3

BCHC to stipulate that a collaborative partnership approach is taken in future funded projects of a similar nature.

BCHC to consider similar community engagement events that focus on trust of its services. communities that aren't within their usual scope.

7

Section 2. Context



Introduction & Background

Birmingham & Solihull Post Covid Syndrome Service (PCSS) started in January 2021 and was one of the first Post Covid Assessment Services established in England. Birmingham Community Healthcare NHS Foundation Trust (BCHC) is the lead provider supporting patients aged 16 onwards. The service provides patients with a physical, cognitive and psychological assessment, working in collaboration with other services to support a system-wide approach to support patient treatment.

Following the 2022/23 BCHC Long COVID Project, further funding was assigned to a new programme of activity, detailed within this report.

The key aims of this year's programme were to:

Reduce Long COVID health inequalities in underserved populations - focussing on ethnicity and disability.

Raise awareness of Long COVID symptoms and self-management.

Increase awareness of BCHC PCSS and how to access services.

Develop collaboration with the wider health and social care sector via engagement activities.

BCHC provided funding for 31 Voluntary, Community, Faith and Social Enterprise (VCFSE) organisations/groups across Birmingham and Solihull to help work towards these aims, utilising at least three engagement events either in person or online. Running alongside these community events, BCHC provided funding for Primary Care Practices across Birmingham and Solihull to help tackle increasing health inequalities and improve health literacy in relation to Long COVID, by undertaking a population health project through engagement and health promotion within their communities. Statistics relating to this activity have not been included in this report.

The aims of these engagement activities were to:

Help tackle health inequalities in relation to Long COVID, with a particular focus on people from minority ethnic backgrounds and people with disabilities or learning disabilities.

Enable collaboration with the wider health and social care sector and health professionals as part of undertaking engagement activities (i.e., GP practice staff, social prescribers, VSC, BCHC staff, Primary Care Networks).

Raise awareness of Post Covid (Long COVID) symptoms and self-management.

Increase the awareness of the Post-Covid Syndrome (Long COVID) service at BCHC and how to access this service.

Methodology

Each of the 31 organisations facilitated at least three engagement events within their community. Organisations asked attendees from each of their three engagement sessions to complete a survey detailing the impact of the event. The organisations were also asked to complete a final narrative report discussing the successes, barriers and themes that were seen within each of their communities.

Ten semi-structured interviews were conducted with staff from the VCFSE organisations as well as primary care staff.

This report summarises the results from these reporting mechanisms.

Section 3. Engagement Event Feedback



Events

In total, there were 106 events held, 100 in person and six online, with a reported total of 3347 attendees. This section of the report looks at the responses from the surveys collected from these events.

There were 1599 total survey respondents gathered from 97 of the Long COVID events.

The reasons for there being 1599 respondents out of a total 3347 attendees include: people choosing not to complete the survey, some organisations not returning completed surveys, and some large events (the largest being for up to 200 people) making the process of surveying people too challenging.

On average, there were 16.5 respondents per event where surveys were collected, but there were some organisations who reported much higher respondent numbers:

Building lives together: 114, across 3 events

CIRFLA: 134, across 3 events

GRIOT-ONE: 158, across 3 events

Moseley Muslim Community Association: 101, across 3 events

PAWA: 149, across 5 events

Attendee Demographics

The demographics of all respondents to event surveys are shown below.

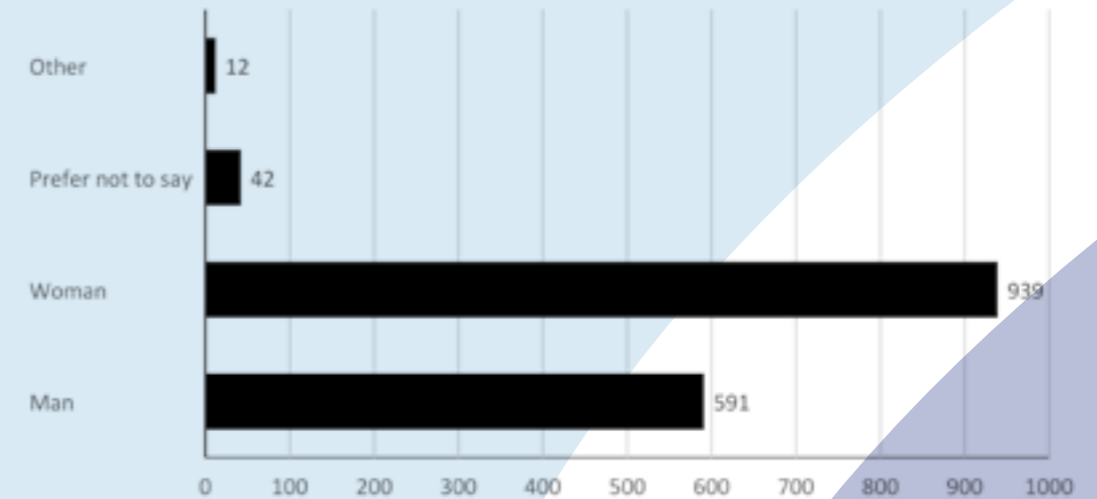
Ethnicity

The full breakdown for every ethnic group is shown below. There were seven individuals who did not answer this question. The most represented groups were Asian or Asian British – Pakistani (327), Black or Black British – African (310), Asian or Asian British – Bangladeshi (247), and White – English, Welsh, Scottish, Northern Irish or British (195).

Ethnicity	Percentage
White - Roma	0.3%
White - Irish	1.1%
White - Gypsy or Irish Traveller	0.1%
White - English, Welsh, Scottish, Northern Irish or British	12.6%
White - Any other White background	1.3%
Other ethnic group - Arab	3.3%
Other ethnic group - Any other ethnic group	1.2%
Mixed or multiple ethnic groups - White and Black Caribbean	2.3%
Mixed or multiple ethnic groups - White and Black African	1.1%
Mixed or multiple ethnic groups - White and Asian	1.4%
Mixed or multiple ethnic groups - Any other Mixed or multiple ethnic background	2.2%
Black or Black British - Caribbean	9.3%
Black or Black British - Any other Black background	1.5%
Black or Black British - African	20.8%
Asian or Asian British - Pakistani	21.1%
Asian or Asian British - Indian	5.9%
Asian or Asian British - Chinese	0.8%
Asian or Asian British - Bangladeshi	14.8%
Asian or Asian British - Arab	0.1%
Asian or Asian British - Any other Asian background	1.7%

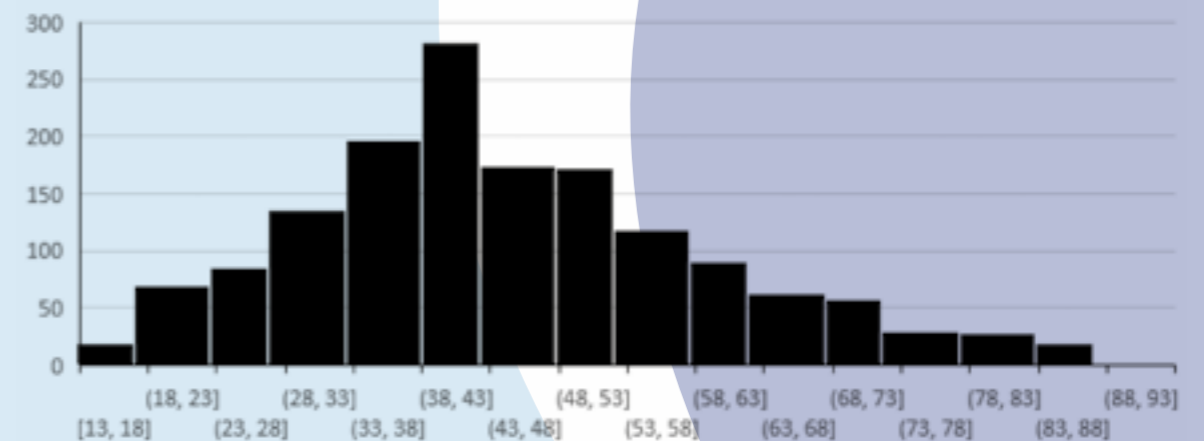
Gender

The majority of the survey respondents were women (939 respondents, or 60.8%) rather than men (591 respondents, or 38.3%). 42 respondents (2.7%) preferred not to say, and 12 respondents (0.8%) were of another gender. 15 people did not respond.



Age

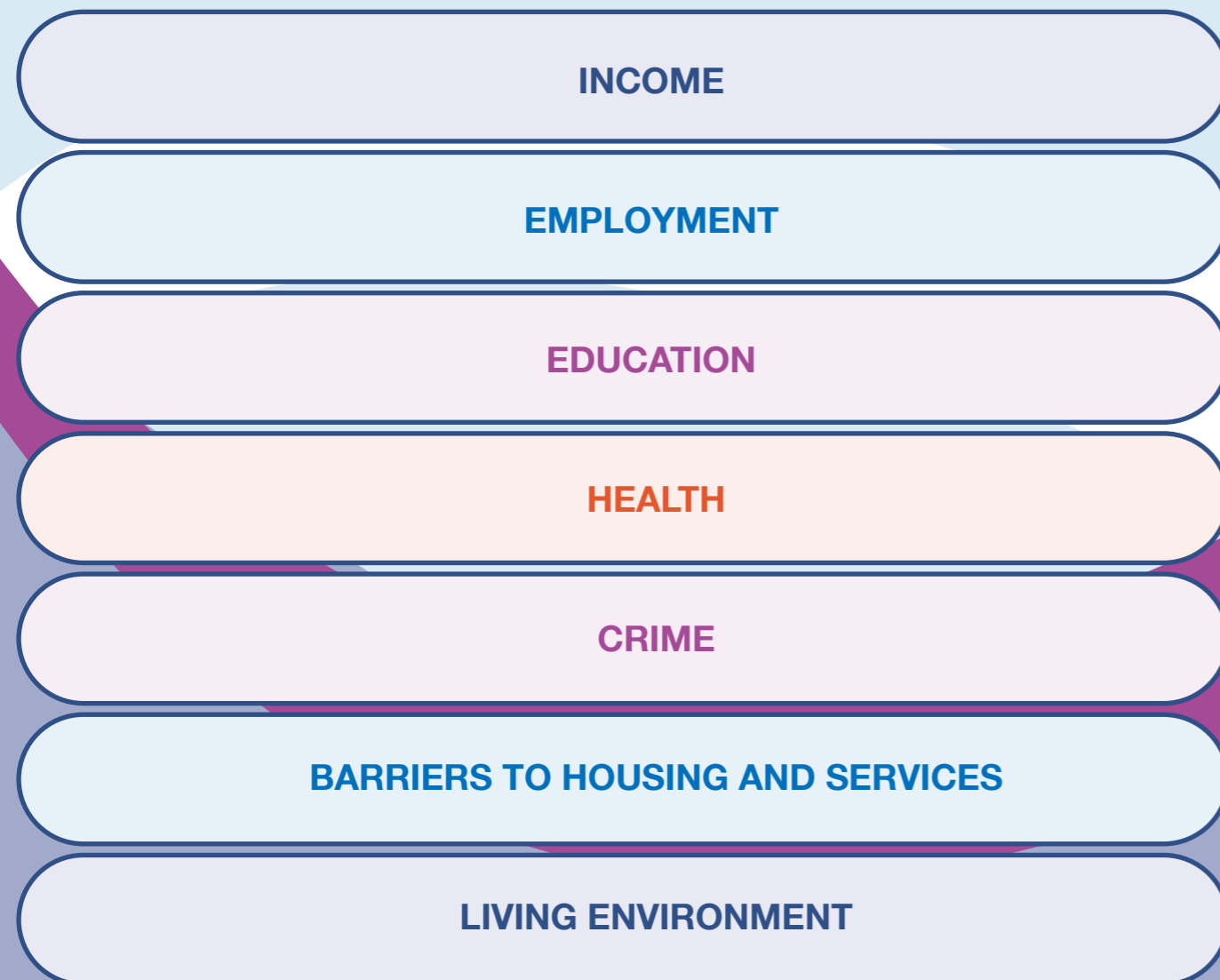
The oldest respondent was 93 years old, and the youngest was 13 years old. The average age across all respondents was 43 years old. 52 respondents did not respond to this question. A histogram showing the full distribution of ages is shown below:



Deprivation

Of all the survey respondents, 269 didn't provide their postcode, and 1184 gave postcodes in the correct format – a large number gave only partial postcodes or declined to answer. 1101 of the 1184 postcodes were successfully matched to the Index of Multiple Deprivation (IMD) decile for Birmingham – 83 could not be matched through the index tool. This gives us an insight into how many people living in deprived areas were engaged with through the events. The Indices of Deprivation (IOD) 2019 are the Government's official measure of deprivation for English local authorities and neighbourhoods. The Index of Multiple Deprivation (IMD) is based on 39 separate indicators, organised across seven sub domains of deprivation which are combined and weighted to calculate the Index of Multiple Deprivation 2019.

These indicators are:



More information on how the IMD relates to Birmingham, can be found [here](#).

Relative to deprivation (as measured using the 2019 IMD), the engagement events were skewed slightly towards more deprived areas. For example, across the city as a whole, only 43.1% of people live in areas which are in the most deprived decile of areas in the country, whereas of the attendees at engagement sessions, 49% were from the most deprived decile. Across the city as a whole, 14.2% of people live in areas which are in the top 50% most privileged areas nationally, but of attendees at engagement events only 12% were from the top 50% most privileged areas.

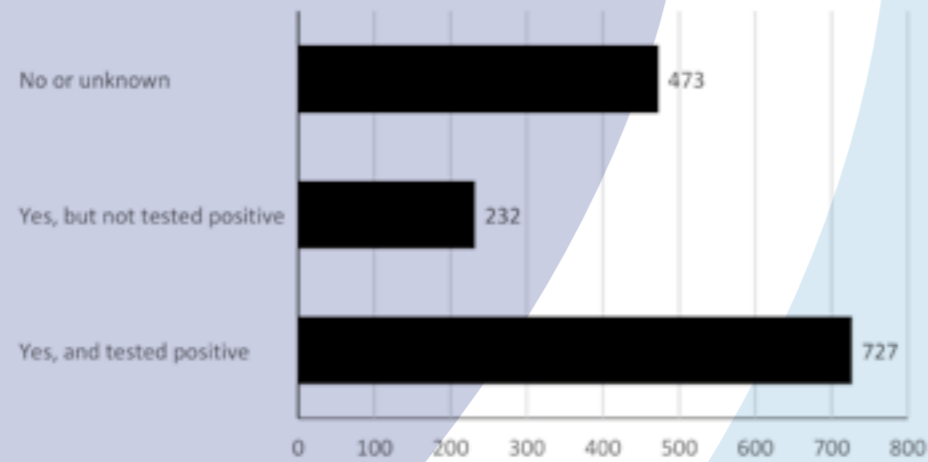
IMD Decile	Survey Respondents (count)	Survey Respondents (%)	Citywide (%)
1	534	49%	43.1
2	155	14%	12.2
3	112	10%	10.6
4	88	8%	11.4
5	81	7%	8.5
6	22	2%	4.4
7	55	5%	6.2
8	7	1%	1.6
9	26	2%	1.3
10	21	2%	0.7

This indicates that overall, the engagement events were effective at targeting the most deprived areas in the city, and demonstrates representation from all the IMD deciles.

COVID History

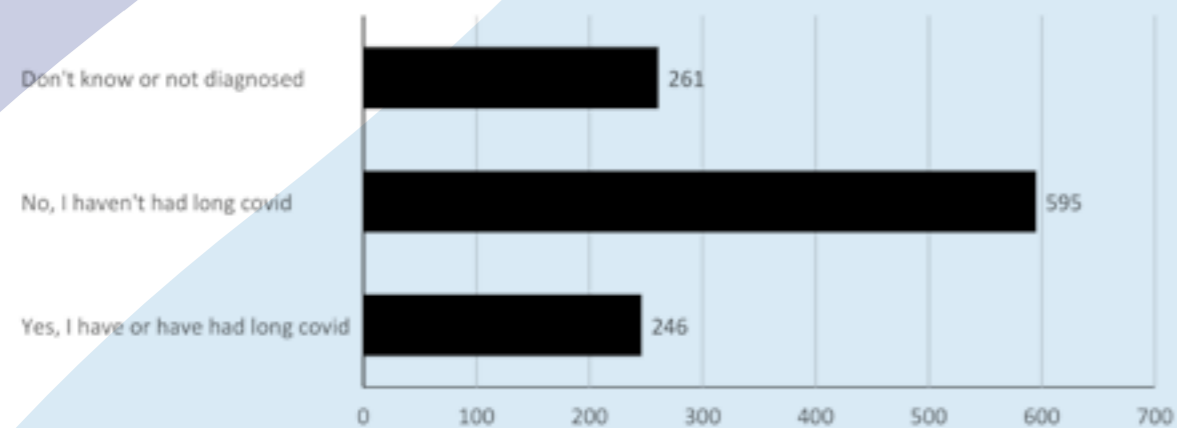
Have you had COVID?

Of all the respondents, 473 (34%) said that they hadn't had COVID or didn't know if they had. 232 respondents (16.7%) said they had had COVID but hadn't tested positive, 727 (52.2%) said they had tested positive. 167 people did not respond to this question.



Have you had Long COVID?

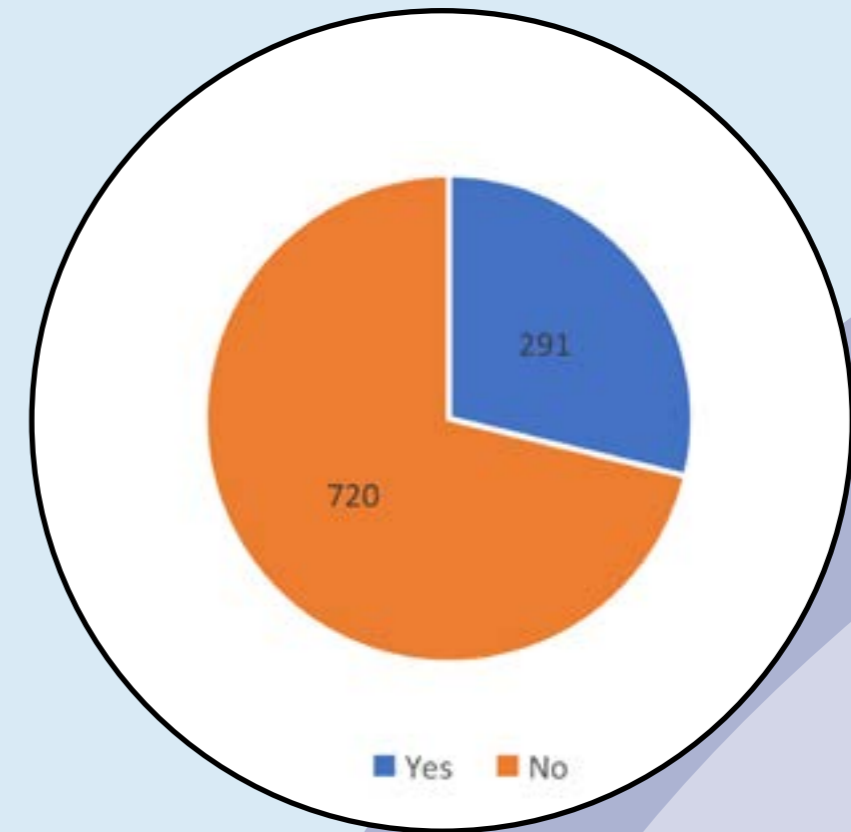
Of all respondents, 595 (55.8%) said they hadn't had Long COVID, 246 (23.1%) of respondents said they'd had/have Long COVID, and 261 (24.5%) said they didn't know or were undiagnosed. 497 individuals didn't respond.



Of all those who said they'd had COVID (959 respondents), 151 (15.7%) didn't respond about whether they'd had/have Long COVID.

Have you been to other Long COVID events?

Of all respondents, 720 people (71.5%) had not been to other Long COVID events, and 291 (28.9%) respondents said that they had been to other Long COVID events. 588 people didn't respond to this question.



Of the 291 individuals who had been to other Long COVID events, most had been to one other event (31.3%), some had been to two (14.8%), 5.2% had been to three events, 1.4% went to four. One individual had been to nine events, and another had been to 10 or more events.

Event Impact

Attendees at events were asked seven questions about the effectiveness of the event they attended, which are shown below.

A small number of organisations reported negative results – particularly in the first question around whether events had raised their awareness of Long COVID and its symptoms. This seemed at odds with the overall positive response to the question about whether the events had been effective as a method for learning about Long COVID.

We were not able to follow up with all the organisations, but we checked with those who had shown a large number of negative responses to the following questions:

Has this event affected your awareness of Long COVID and its symptoms?

Has this event affected your awareness of what to do if you have Long COVID?

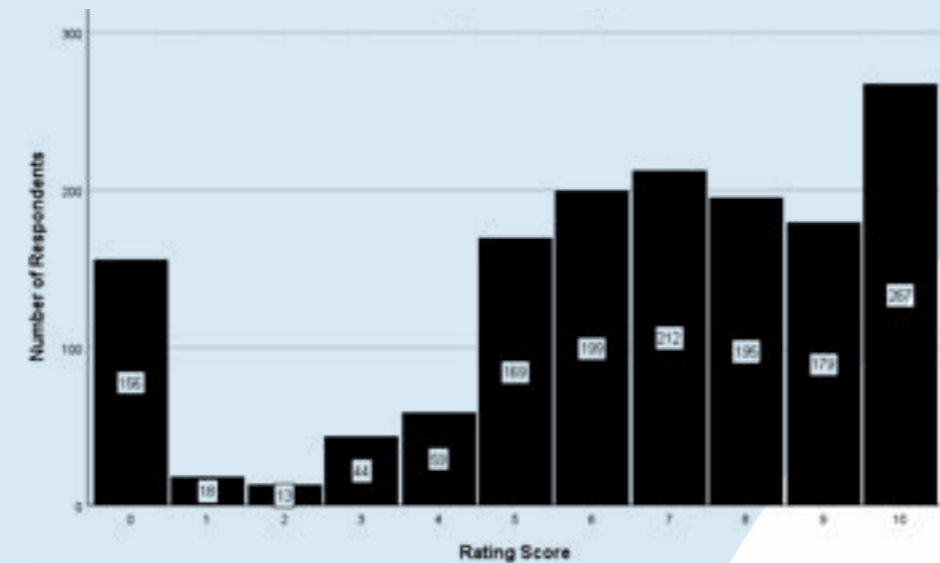
CIRFLA said that their participants hadn't heard about Long COVID before attending the events and learned about it for the first time during their attendance, suggesting their responses were perhaps reflective of their overall feeling of lack of knowledge on the subject, rather than not learning anything at the events.

Both PAWA and GRIOT ONE felt their participants didn't fully understand the questions, hence why they gave negative answers. Nevertheless, they felt that participants had found the events useful and insightful.

All questions were asked on an 11-point scale from 0 to 10, with anchors at 0, 5, 10, and which stated - much less confident/aware, no change, and much more confident/aware respectively. Any result above a 5 can be interpreted as a positive impact.

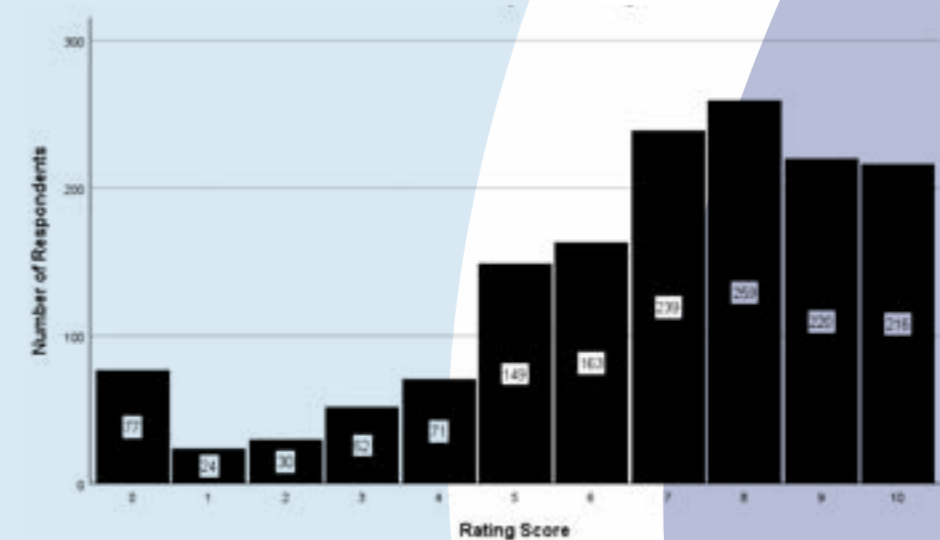
Has this event affected your awareness of Long COVID and its symptoms?

The average (mean) response rating overall was 6.5, with a middle value in the data (median) of 7, suggesting that events did increase awareness of Long COVID in general (as mentioned above, a discrepancy can be seen in the 156 responses of zero):



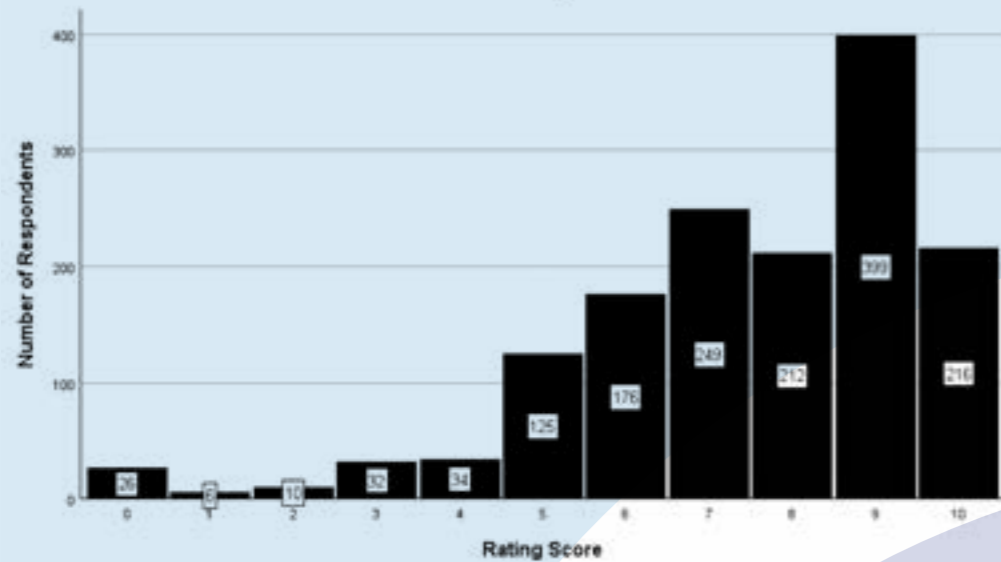
Has this event affected your awareness of what to do if you have Long COVID?

Across all respondents, the average (mean) impact reported of the event on awareness of what to do if you have Long COVID was 6.8, with a median of 7. The full distribution of responses is shown below (again, with a discrepancy responding zero):



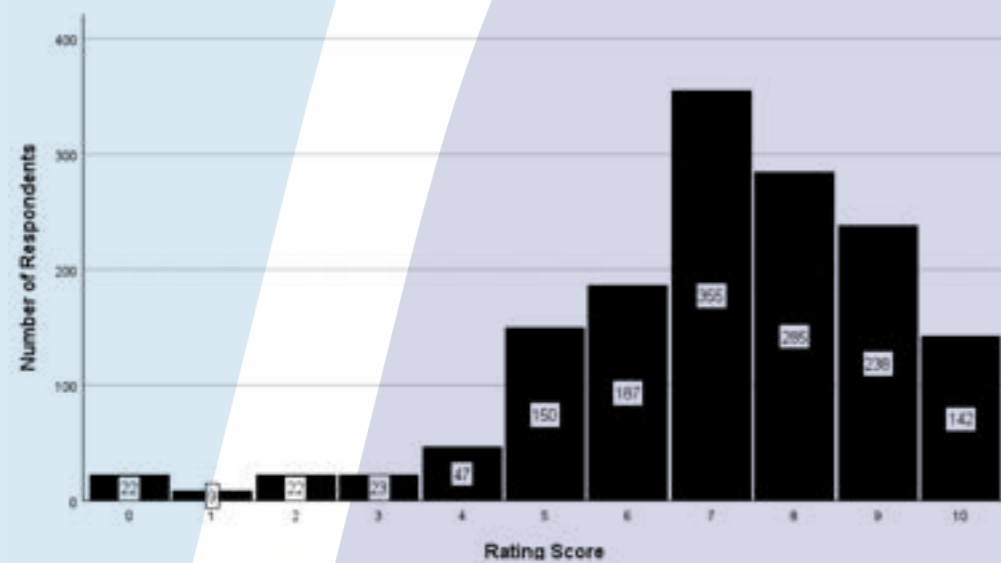
Has this event affected your awareness of the Post Covid Syndrome Service (PCSS)?

Across all respondents, the average impact of events on awareness of the PCSS was 7.5 (with a median of 8). Full distribution of responses shown below:



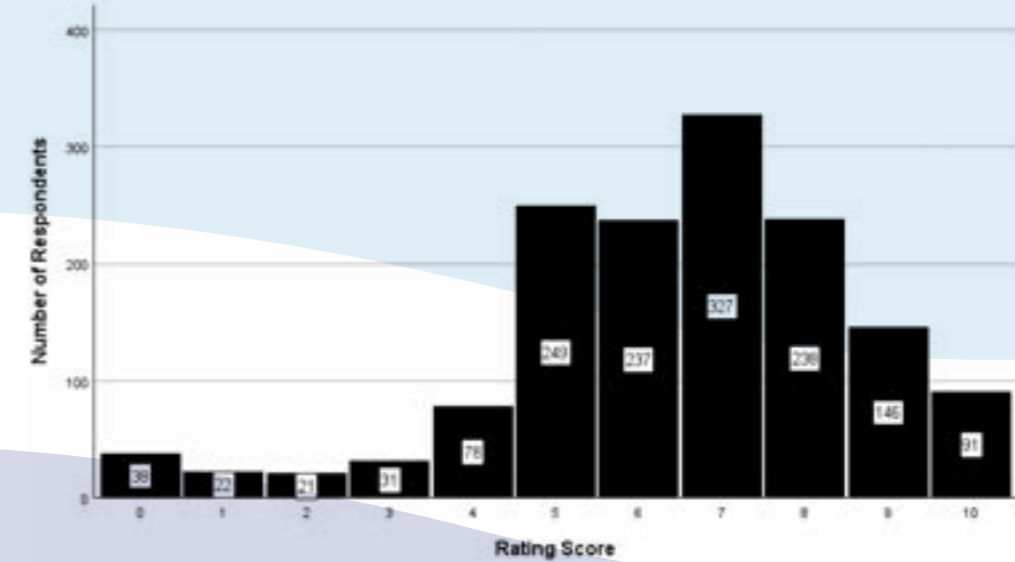
How has this event affected your confidence accessing the PCSS?

Across all respondents, the average impact the events had on confidence accessing the PCSS was 7.1 (median of 7). Full distribution of responses shown below:



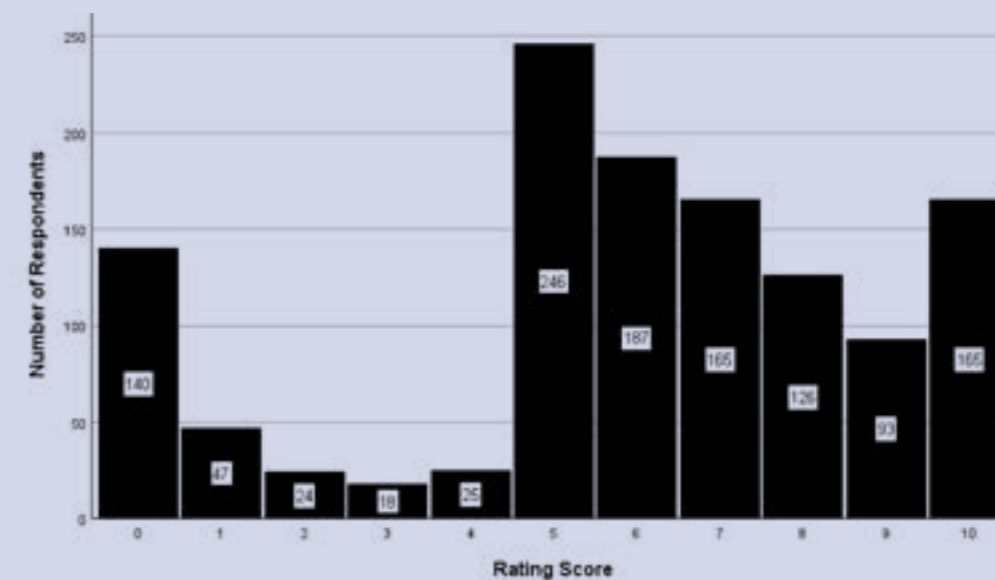
How has this event affected your trust in the NHS in general?

Across all respondents, it was reported that the events increased trust in the NHS in general, with an average response of 6.5 (median 7). Full distribution of responses shown below:



Has this event affected your likelihood of getting vaccinated?

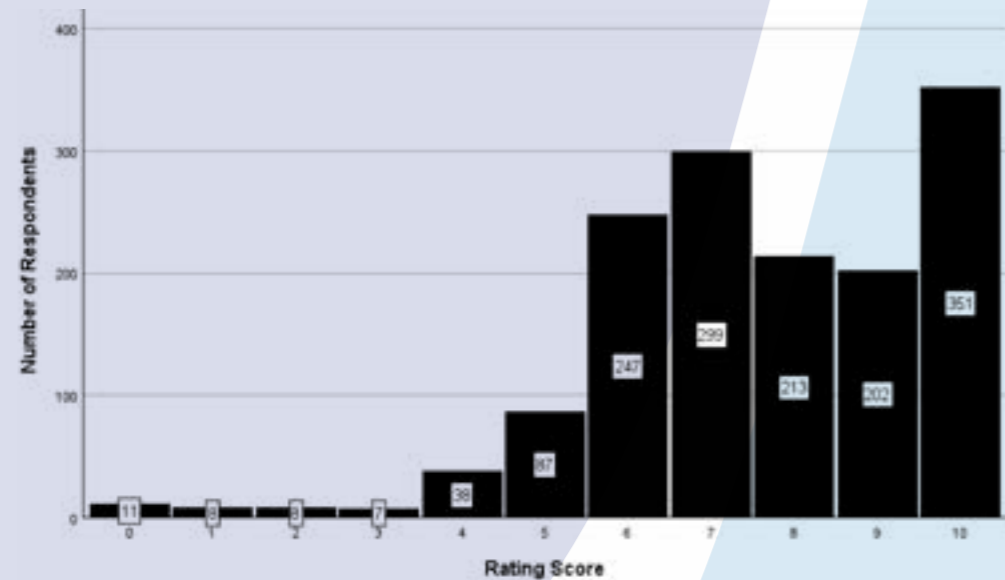
Across all respondents, there was an average response of 5.9, and a median response of 6 to this question – showing the events did slightly increase people’s likelihood of getting vaccinated. Full distribution of responses for this question shown below:



Was the event an effective method of learning about Long COVID?

Respondents were asked to rate how effective the event had been overall as a method of learning about Long COVID from 0 (very ineffective) to 10 (very effective). The average response overall was 7.6 (with a median response of 8).

The full distribution is shown below:



As mentioned above, some respondents said the events had negative results in other areas (i.e. awareness of Long COVID, and what to do if you have Long COVID), but still said that the event was overall an effective way of learning about Long COVID. This perhaps indicates that respondents misinterpreted some of the earlier questions about event impact.

Further Comments

The event survey also gave the attendees the opportunity to comment on four further areas of interest:

1. When thinking about health services in general - what are the main barriers to effective communication?

The main response here was around language and translation of advice and information into different languages, as well as patients misunderstanding 'medical jargon' used by health services. The phrase 'cultural barrier' came up multiple times.

"In a multilingual society, a major barrier to effective communication arises when healthcare providers and their patients do not share the same first language".

"Language barriers between health care staff and the patient might lead to incorrect assessments, inappropriate care for the patient and risk of misdiagnosis."

There were also several references to waiting times for appointments, and effectiveness of appointments/support:

"Appointment issue, very hard to get one."

"Appointments not long enough to gather holistic view and all symptoms and issues when accessing primary healthcare."

2. When thinking about health services in general - what does 'trust' mean to you, and how could it be improved?

Several responses here focused on the importance of honesty and transparency with communities, alongside ensuring patients feel they are being listened to:

"Being compassionate, spending appropriate time with patients, demonstrating active listening, and helping to advise and resolve the patient's needs."

"Trust means reliability and effective communication."

"Ask for positive feedback on physicians who are doing well and use them as advocates/allies in improving trust and experience."

Some responses again mentioned long waiting times and difficulties getting access to healthcare professionals, which consequently impacts on trust:

"GP's should be available to see more patients, waiting time should be reduced to at least 4-6 weeks not months."

"I trust the NHS but I can't get appointments when unwell."

There were a very high number of responses referencing the importance of cultural understanding, and how this can affect trust with patients:

"Proper care requires recognition and acceptance of the other's culture, ethnicity and race."

"The entire care team can deliver better care if they have empathy, ask what patients prefer (language, for example) instead of assuming, and create a nonjudgmental environment."

There were also some positive comments demonstrating some respondents felt they could trust their healthcare provider:

"I go to the GP for everything. I am a widowed mum and I worry a lot about my health and my sons. My GP is very good and always makes time for me."

3. What could BCHC provide that it isn't providing at the moment?

Most of the responses here stated that people would like more community-based events like the ones they attended, both on Long COVID and its symptoms, as well as other topics.

"More sessions like this throughout the year on different topics raising awareness not only on Long COVID but things like flu season etc."

"Peer support for those who have Long COVID - to promote health literacy around Long COVID and its symptoms."

Attendees also mentioned the importance of easier access to support, and more support being in-person.

"Face to face support like this."

"Having access to health professionals when needed, i.e. shorter waiting lists etc."

"I think that services are good when they are provided but more services need to be available as many people are suffering with health issues."

There were also several comments stating that respondents felt the service was 'fine' and there was nothing else BCHC needed to offer them.

4. What further activity would you like to see regarding Long COVID?

The responses here demonstrated a desire for continued efforts designed to increase awareness of Long COVID via events, media, resources such as information packs, and group and individual sessions, with support from healthcare professionals. Many expressed the desire for support to manage the condition at home or in the community, without needing to go through their GP. Overall, it was clear people wanted more resources and more awareness-raising activities that would be accessible to all.

“More awareness workshops about services on offer by the NHS to help people to get back to ‘normal’ life as soon as possible.”

“Different ways to get information, not all computer or written.”

“More advice and keep testing everyone so people have better knowledge to self-treat themselves at home before going to see GP.”

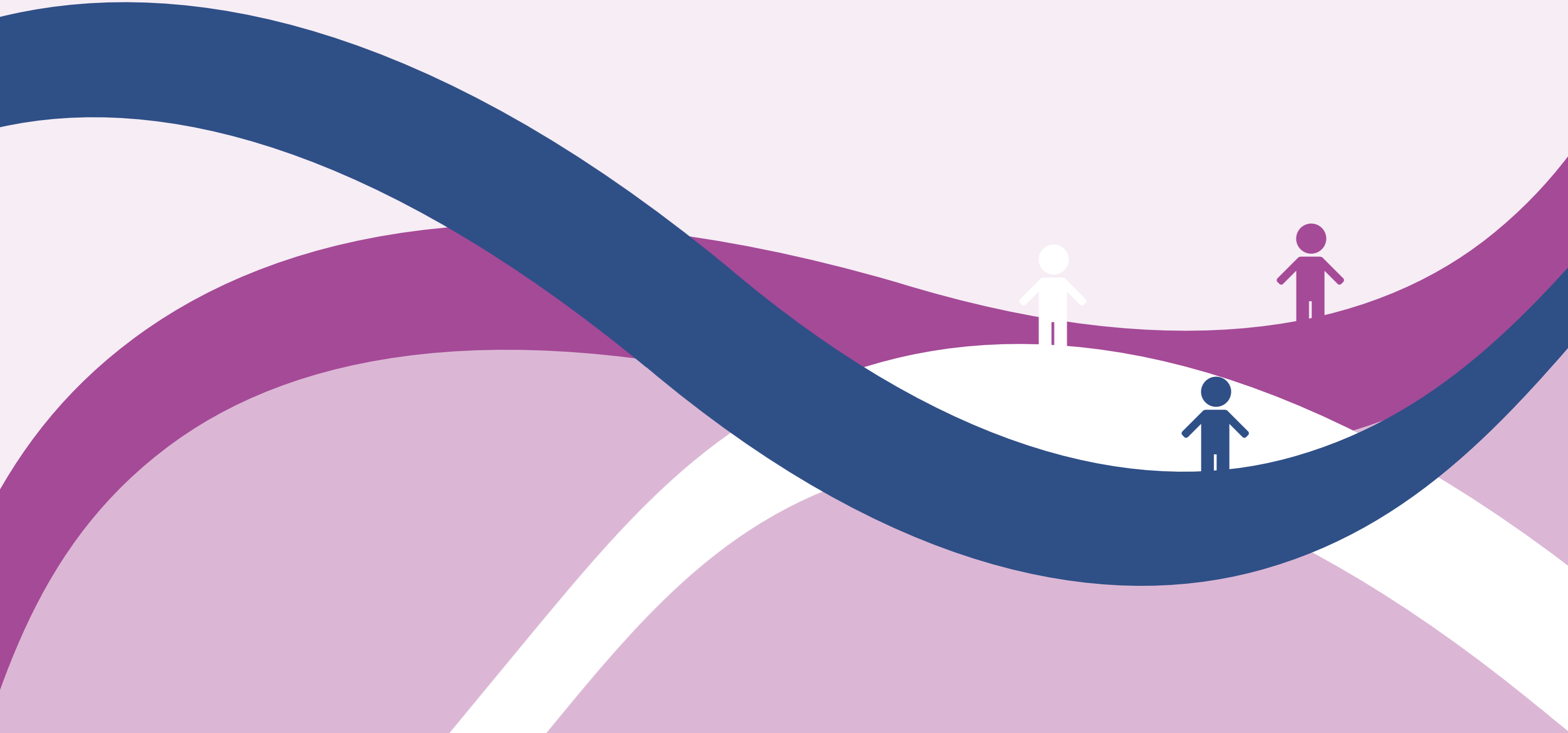
“To continue with Long COVID events so everyone is aware of symptoms and where to go to get help from and help each other.”

Section 4.

Organisational Feedback

All 31 organisations submitted a final report detailing their views on the impact of their awareness events, with seven interviews taking place to garner further detail.

Events were extremely varied in their content, ranging from engagement activity focussed solely on Long COVID and its effects, to organisations that utilised walking groups, dance sessions, art classes or Tai Chi to link Long COVID into overall wellbeing.



How successful do you believe your engagement activity was, and what support did you provide to ensure effective engagement at your events?

As was found in the 2023 engagement activities, most organisations felt that the events went well and had a good level of attendance (although there were some outliers, with two events attended by just one attendee and three events attended by more than 200).

Events that took place in person were felt to be more successful than the small number of events that were held online. A number of organisations also felt that it was beneficial to embed the Long COVID engagement within community events that were already scheduled to take place. Organisations' reasons for this were: people already being committed to attend the pre-arranged meetings, making attendance almost certain; attendees wouldn't have to pay for public transport a second time (to attend an event they had already committed to, as well as a standalone Long COVID event); and Long COVID wasn't felt to necessarily be enough in its own right to entice people to engage in an event.

“We organised the project as a walk because we're trying to do a walk as a physical activity, as well as talking to people. Everybody in the community centre, in the church, everywhere we passed through, we tried to talk about Long COVID. They were thinking about the physical activities, but in the meantime, we were talk to them about the Long COVID”.

Several organisations also provided refreshments, and where necessary, some organisations also provided one-to-one conversations with individuals away from the main event. This allowed for complex information to be given at the attendee's speed as well as any fears of stigma from contracting COVID could be discussed in a more private setting.

Organisations spoke about how they were able to strike up new partnerships with other local organisations or health practitioners that weren't previously known to them. This led to more effective events that were often co-hosted, promoted more widely via a joined up approach, and hopefully developing a legacy of collaboration beyond the funding's timeframe.

What barriers to engagement did you see and what was done to remove barriers when identified?

As mentioned above, the language barrier was the most common issue identified throughout this project. This is frequently raised as a common barrier to engagement with services, and something that community organisations support with on a regular basis. Where organisations identified this as an issue, interpreters were used to ensure attendees could understand and engage. The Long COVID presentation provided by BCHC for each of the organisations to use at their events was also raised as an effective tool to break down barriers of language and aid those who have difficulties in reading, as organisations stated that the presentation was visual and interactive.

Exposure to false information around COVID was also raised as a barrier to engagement, as well as people now wanting to move on from COVID and not think of it as an issue that still exists or a priority in their life. Where this was the case, combining Long COVID into existing meetings was seen as a good method to increase engagement.

Finally, digital exclusion (people not being able to access the internet or related apps) was raised as something that acts as a barrier to attendance from certain people within the community. As with last year's programme, this was one of the reasons that so many organisations facilitated their events in-person and not online.

“I think all the barriers that we expected to come across, we overcame them. Things like language barriers, we planned beforehand. One of my colleagues, he has a hearing impairment. We assumed that there will be other members who will have hearing impairments, so we got things like mics and speakers, just to accommodate everyone. We ensured that the buildings that we were using were wheelchair-friendly so people could access the buildings. Little things like that, it really does make a difference and it sets a good environment and atmosphere for when you do deliver and present your events. I think every barrier that we did overcome, we talked about it beforehand”.

Were you able to engage with the target demographics (people with disabilities, including learning disabilities, people from minority ethnic groups)?

Most organisations felt that they were able to engage with the target demographic.

Some organisations mentioned that they didn't engage as well as hoped with minority groups that they weren't already engaging with. This was overcome to some extent by partnership working, but a greater lead time to the project would have been beneficial as time is required to engage with people outside of normal organisational networks, especially those that might not trust the NHS or be sceptical around Long COVID. It was felt that organisations working together was the key to engaging those underrepresented groups, with several organisations hoping that the links created during this programme would go on well after the project ends.

"We tried a Facebook campaign because we thought, "Okay, let's see how that might work." What turned out is when we partnered with our online community networks, that was much more effective".

The Polish community and the Yemeni community were mentioned specifically as groups that were more hesitant to engage with Long COVID advice and information. This was both with the community in general as well as their community leaders. It was felt that further events such as those provided through this funding would eventually bridge gaps with those communities, but this was seen as a long term issue and not something that could be done with as a 'quick fix'. A number of organisations also ensured that they selected venues with good access for those with disabilities to try to remove physical barriers to attendance.

What methods did you use to engage with the target groups? Was this as successful as hoped?

As mentioned earlier, this year's project focused on collaborative working, and organisations found this a fruitful method of engagement and enabled them to further their reach.

Organisations were therefore able to engage with people that they wouldn't normally reach through their existing channels. Some organisations co-located their events at partner locations with better access or where the target demographic felt more comfortable. However, as with last year's events, the main method of engagement was through existing structures with their established communities. Most of the organisations found this the most practical way to engage with people, as they already had trusted relationships in place which in many instances helped engage people that may have been reluctant to do so with this topic. A number of organisations also mentioned the fact that they collaborated with medical specialists (sometimes directly via BCHC), and this made a real difference for a number of those attending. This lack of specialist knowledge was seen as a barrier during last year's events and something that was appreciated by this year's organisations and attendees.

"...The pharmacist knew his stuff. He knew the community, so he could explain from a medical point of view. He could understand the community perspective, and just his general manner wasn't like a GP staring at you through the spectacles. It was opening and engaging".

There was a specific effort to move away from advertising the events solely online, as it is known that certain communities wouldn't discover the events through this means. Therefore, posters were used in GP surgeries, post offices, community centres and other locations that targeted those that may benefit from these events. Organisations also ensured that the three events were on different days of the weeks and at different times, to allow those with commitments to hopefully attend at a time that was suitable to them.

How has your activity helped to reduce health inequalities in relation to Long COVID?

A number of organisations felt that simply reaching out and engaging with underrepresented communities was going some way to helping to reduce health inequalities. It was felt that actively reducing the barriers faced by these communities, tailoring the information and how that information was accessed, and providing clear and thorough NHS advice could increase engagement with health services moving forwards.

“When we did get feedback from our participants, they were like, “We want more sessions”. They don’t just have to be about Long COVID, they can be about anything, or they can be about any new service that has come out in the NHS.”

Organisations also commented on the fact that following these events, a number of attendees had contacted their local health providers and sought help for Long COVID and other health issues, something they may not have done without this initial engagement.

As mentioned previously, the fact that a health professional attended some events was seen as extremely positive and a crucial factor in reducing health inequalities. Attendees spoke of how they appreciated that expertise being available at the event, and how it made them feel more likely to approach NHS services in the future due to how approachable the NHS representative was.

Organisations stated that without this proactive approach to disseminating information, many of the attendees would never have had the opportunity to learn about Long COVID through regular means, and in turn, the other associated health and wellness information that was provided at many of the events.

What themes, issues and questions were raised by attendees at your engagement events relating to Long COVID?

The themes, issues, and questions raised by attendees at the engagement events mainly related to the general lack of understanding of what Long COVID is and concerns about access to healthcare. Many participants expressed that they were unaware of Long COVID and shared their worries about difficulties in accessing GPs and not being taken seriously by health professionals when they did seek medical help. Attendees asked host organisations about religious and cultural issues with the vaccine and shared their experiences of stigma and discrimination related to Long COVID, particularly within their own communities. Attendees were also keen to understand how culturally sensitive approaches to healthcare could be improved.

“They don’t want to say in the community that they’ve got Long COVID because some people don’t believe in it. They don’t believe Long COVID is real”.

Attendees frequently asked about how general healthcare and lifestyle choices could aid in recovery from Long COVID and boost immunity, therefore removing the need to access their GP – which was something they reported as being very difficult to do.

As with last year’s events, one of the main themes was lack of trust in the NHS in general. Questions were also asked about the lack of translated information and how people were supposed to access information if it was only produced in English.

These events sought to engage with underrepresented groups, and it’s to be expected that these communities would also have limited trust in services that have historically failed to engage with them. However, there was positive feedback about the events, and the clear efforts made by BCHC to better engage underserved communities.

How have you collaborated on this project?

Collaboration with health professionals (such as pharmacists and GPs) was seen as a huge positive for this year's project, and something that was raised regularly at last year's events as something that was lacking. Co-location of events was also seen to be an effective partnership approach, including GP practices, schools, faith-based centres and libraries amongst others. The BCHC representative was mentioned positively by a number of organisations, with their collaboration being invaluable to both answer specific health-based questions as well as break down barriers around trust with the NHS in general.

"She (BCHC representative) explained herself, and she was very approachable, her rapport was really good. They said that she wasn't too much. They said, if they knew that people in hospitals were like that, they'd probably engage more. I think they have a stigma that people are a certain way".

Organisations spoke about how planning the events with partners was also extremely useful, as it opened up different approaches that wouldn't necessarily have been thought of without this joint approach, such as: using culturally sensitive methods, finding suitable locations, and focussing on certain sectors of the community that were known to be underserved in this area. They also thought a joint approach to dissemination of the information would ensure a wider audience, with one organisation utilising a community radio station to broadcast one of their events.

Organisations spoke of their plans to continue their relationships with those they have worked with, with examples given of joint funding bids now being planned.

When thinking about health services in general - what are the main barriers to effective communication for you and your clients, and what can be done to overcome such barriers?

As with other areas of this report, language was seen as the main barrier to effective communications. Organisations felt that it was crucial that all NHS communication was available in the languages of the community, so those within that community felt seen and heard. It was also felt that the NHS could utilise specialist media such as Asian news channels, local radio that broadcasts in specific languages, and existing social media channels that already target communities using their own language.

"It's getting the right people in that are going to listen. They don't feel that they're being listened to. That's what we're hearing in my team going around, that they don't feel listened to".

As well as foreign language translations, it was felt that simplifying messages and communications was important if the NHS was to reach more communities. Organisations spoke of the need for the removal of complex language, and to try to make things more straightforward.

Lack of trust was seen as a barrier to communication. It was felt that consideration should be given to training representatives or champions in the community that already have the trust and relationships that the NHS can't always guarantee. This role could potentially assist in adding to culturally specific communication avenues that the NHS lacks. More events such as those discussed in this report were also seen as an effective method to build trust, especially when the NHS are represented.

When thinking about health services in general - what does 'trust' mean to your clients, and how could it be improved?

Several organisations felt that health services (and the staff from those services) being seen within community spaces where the public were already comfortable would be beneficial to improving trust. This would enable organisations such as BCHC to work in tandem with community organisations that had already built up trusting relationships with people that don't necessarily have the same level of trust in health services. Without that presence in the community and effort to reach out, many thought that trust would be very difficult to repair or rebuild.

The consistent message of difficulty accessing health care, and a local GP specifically, was also seen as a factor in reducing trust over time. People felt that if they can't be listened to by the GP, then they don't have a voice, and it has therefore led to a breakdown in trust.

There are also perceived inequalities in service delivery with concerns about unequal access to healthcare and information in general, undermining trust in the system as a whole. Again, incorporating culturally sensitive approaches to healthcare was seen as something that could improve the situation, showing those from underserved communities that they are being seen and heard. This would involve healthcare providers demonstrating an understanding of the cultural norms, beliefs, and values, and adapting their practices accordingly.

"When it comes to things like health issues and health inequalities, there is a deficit in the amount of sessions that are provided on raising awareness on, for example, diabetes in the community or raising awareness on high blood pressure in Asian communities. There is a deficit there. When there is a session related to health, people do attend. It's just that there's such less opportunities out there, in these areas".

Trust with the NHS was also seen as something tied into the wider situation of certain geographic areas and certain communities being underserved in general. This was seen as an issue that spans generations and would therefore require a joined-up approach to tackle.

When thinking about health services in general - what could Birmingham Community Healthcare NHS Foundation Trust (BCHC) do to reduce health inequalities in your area?

Organisations felt that if BCHC could take the comments from this and the previous report on board, then that would begin to reduce health inequalities locally. Organisations suggested that BCHC could continue its presence in the community, building on the work that was done as part of this project. BCHC should continue this approach for other common health issues, providing further drop-in sessions and regular liaison with community leaders that could initiate this process, along with the aforementioned community champions.

"They didn't know about the post COVID syndrome service. They didn't know about these things. They're saying it's good. They're not saying it's bad, they say it's good. It's just not promoted in their areas".

Organisations also spoke about working with other agencies to create an integrated health care model for underserved neighbourhoods. This could utilise the skills and relationships that already exist in the communities through the organisations that were commissioned to undertake this project.

Training staff to be culturally aware was seen as something that would need to happen if services were to improve. It was thought that this, once more, could be done in partnership with community organisations that hold that knowledge base.

Further activity around self-medication/self-support and preventative measures were raised. It was felt that BCHC could improve the information and advice that would help people help themselves relatively quickly and cheaply. Poor health literacy was seen as commonplace, but the community would like to know more about such areas as nutrition, wellness and exercise/healthy living.

Section 5. GP Feedback

Running alongside the community engagement events, BCHC are working with five medical centres to help tackle increasing health inequalities and improve health literacy in relation to Long COVID. These medical practices are reporting their data directly to BCHC, and figures aren't discussed within this report.

Interviews took place with five members of staff across three centres to determine their views of how this aspect of the project was progressing.

Staff felt that it was difficult engaging patients in this Long COVID research, with little appetite to get involved and therefore uptake was less than expected. Medical centres had initially targeted the information and engagement opportunities at particularly vulnerable groups as well as those from underrepresented ethnic communities. However, due to a lack of uptake, one centre opened up their engagement more widely across patients from the centre.

They also partnered with a Long COVID expert in Berkshire which resulted in a 'Myth-Buster' session that was uploaded onto YouTube. The patient engagement activity has also led to a peer-to-peer support group being established that will continue after this project ends, so although the update was limited, there are now resources that will last beyond the life of the project.

Another centre identified Black and minority ethnic and learning disability patients who had previously tested positive for COVID and sent them a questionnaire around whether they had Long COVID or any of its symptoms. However, they only received three responses and therefore limited progress was made. They then opened up the approach to any patients that had COVID, or were at high risk of having COVID. This approach identified another 26 Black and minority ethnic and learning disability patients, from which 20 had COVID reviews done with a medical practitioner.

Kingsbury Road Medical Centre and Coventry Road Medical Centre also partnered with a clinical pharmacist specialising in diabetes. It was felt that due to the COVID lockdowns, diabetes was going untreated and linking COVID and diabetes information would help with patient overall wellness. They ran a 12-week course discussing different dietary topics starting with diabetes then moving onto fat, carbohydrates, sugars, protein, processed foods, exercise and weight management.

Again, attendance at these sessions wasn't as high as hoped, but those that did attend gave extremely positive feedback.

The medical centres were unsure as to why engagement wasn't as high as hoped, but thought that it was to do with people wanting to move on and forget about COVID, or not understanding that their current health problems may well have been linked to Long COVID.



Section 6.

Summary & Lessons Learnt

3347 people were reported as attending the events, a 59% increase on last year's figure. This increase in number of attendees has been the result of more organisations being involved in this project as well as some events being particularly well attended (some with over 200 people). Further events have also been scheduled after the deadline for organisational reporting, so the total number of attendees will increase.

27% of attendees stated that they had a disability, with a number of organisations using locations and partnerships to make their events more accessible. It was mentioned by several organisations that disability is often underreported, so its felt that the figure of 27% is an absolute minimum. As mentioned earlier in this report, the engagement sessions were also effective at targeting the most deprived areas in the city, which are those generally seen as being the most underserved.

As with last year's project, the vast majority took place in person, with only four organisations utilising online meetings.

The feedback detailed throughout this report indicates that the events have been effective in raising awareness of Long COVID and its symptoms, of what to do if people have Long COVID, and raised awareness of the Post Covid Syndrome Service. Attendees also thought that the nature of the events and how they were shaped were an effective method of learning.

The events haven't been quite as effective in improving trust in the NHS in general, but this is to be expected as the primary purpose of the events was to concentrate on Long COVID and not trust. BCHC could consider hosting similar events in the future to focus solely on trust within their services if this was an area of priority.

The feedback from the event surveys and feedback from the organisations suggest the primary concern within the communities relating to awareness of Long COVID is a lack of language appropriate information. Linked to this is culturally aware messaging in a location that people feel comfortable and can easily access. This project has, in the short-term, effectively overcome these barriers through working with the community organisations who spoke to the attendees in their own language, in familiar locations that attendees felt comfortable in.

Another clear benefit that this year's events had was the attendance of the BCHC Post Covid Health Inequalities Project Coordinator at several events. They were named by several organisations as being particularly impactful at breaking down barriers with attendees around speaking with NHS staff.

Regarding the legacy of the project, several staff at the organisations felt that they now had a broader level of knowledge of Long COVID and would feel comfortable speaking with their communities about Long COVID after this project comes to an end. A number of attendees also spoke about how they would take the information back to their family, meaning that the learning from the events may have a ripple effect, with impact felt by a larger figure than the number of attendees alone.

“

I previously had COVID and even today I am feeling the effects of Long COVID which includes incontinence and fatigue. I attended a few of the Long COVID events. Before then I was not aware of any Long COVID support that was available. Now I have a better idea of what to say to my GP and also the self-help hints on the website. The events I attended did help me to be more aware of how living a healthy lifestyle can help me to stay well and how to boost my immunity. I found the events motivating because I realised I wasn't alone, and I am not imagining suffering from Long COVID. As a consequence of attending these events I now feel like there are others who understand, and I have changed my lifestyle according to advice given from the Long COVID sessions, which are blossoming into improvements.

”

Attendee





Case study 1

KIKIT Pathways to Recovery

The attendee, a female in her 40s from an ethnic minority background, had discussed how she had been experiencing persistent symptoms of Long COVID following the information provided within the workshop. Despite seeking medical support, she felt frustrated and overwhelmed by the lack of understanding and support she experienced from the healthcare provision she was accessing. Feeling isolated and unsure of where to gain support, she expressed that she was hesitant to participate in the workshop out of fear that her concerns would not be addressed or understood. Having a trusted relationship with her child's teacher encouraged her to attend by explaining the expertise of culturally sensitive support provided by KIKIT.

During the discussion following the workshop, she stated that she felt empowered and supported by connecting with others who shared similar experiences of Long COVID. By hearing the stories and seeing the information present on the BCHC website, it helped her realise that she was not alone in her struggles and that her symptoms were valid and worthy of attention giving her the ability to manage her and her children's condition more effectively.

She also expressed her appreciation for the workshop being so culturally sensitive by providing her with multi-lingual support via a leaflet and facilitators. By attending the workshop and having the information and access to resources available to her, she now felt she was more confident in accessing healthcare services by being more equipped to communicate her needs to healthcare providers.



Case Study 2

Building Lives Together (BLT)

At the “Beyond the Challenge” event in February, an individual, who had been grappling with the lingering effects of Long COVID, participated in a unique storytelling concept crafted by BLT’s Culture Development Officer. Through the expressive artistry of the dance artist, she was able to connect on a profound level with the challenges she faced, both physically and emotionally, due to Long COVID. The storytelling through dance offered a holistic perspective that resonated with her, offering her a sense of validation and empowerment in her journey towards recovery.

During the interactive dance session, she found solace and renewed vitality as she engaged in physical movement and expression.

As a result of her participation in the “Beyond the Challenge” event, she felt inspired to seek further support, connect with peer groups facing similar challenges, and actively engage in her healthcare journey towards managing Long COVID.

The event served as a platform for fostering understanding, empathy, and connection among individuals affected by Long COVID, highlighting the importance of holistic support and community engagement in addressing health challenges.



Case study 3

Inner Transformation

This attendee recently took retirement from her NHS job due to medical conditions. She has been going through challenging times with her mental and physical health, and suffers with Long COVID. She attended the event with an open mind and enthusiasm, so she got a lot out of it. She was pleased to hear that the NHS were doing their utmost to support people with Long COVID, and taking part in my nutrition talk, doing the light cardio, resistance training and yoga has lifted her spirits.

She has now taken up a regular yoga class local to her, has improved her diet and is more mobile and healthier.

“Doing the Long COVID event is one of the best things I have done for a long time”.



Case study 4

Moseley Muslim Community Association

Prior to the session an attendee had informed us that her son had tested positive for Covid and hadn't recovered from it well, and since then it had been a real struggle in managing his symptoms and care. He found it difficult to breath when carrying out activities such as walking up the stairs or going to the corner shop, and would often develop mild chest pain and shortness of breath which was never an issue before. As a mother she was keen to find classes and activities for him to become more active. Since there wasn't a lot of information about Covid, she felt helpless.

The session gave her more knowledge and educated her on Long COVID and the services she could access. This led to her booking an appointment with the GP and arranging initial investigations. She was happy that her son's symptoms were taken seriously and the doctor at her surgery arranged an appointment for chest x-rays for her son. The GP also informed her about the Post Covid Syndrome Service which she was shocked about as she never believed she would have been able to access it for her son. The impact the activities had on this lady and her situation allowed her to be confident and have trust in the system and these new services.



Case study 5

Neema Women Community

Our attendee is a widow who lives with her disabled son in the Balsall Heath area. She has been his carer for his whole life. She caught Covid in 2020, and since then has suffered multiple health problems. She is not fit for work and struggles with services in her local community. She struggles to reach out for help as she speaks Swedish, Arabic and very limited English. She has attended our group sessions in the mosque for Arabic speakers ever since. When delivering our engagement event, she became interested in the different support available for people affected by Long COVID. With the help of her caseworker, this attendee:

- Was supported to attend a GP appointment to request a referral to the Post Covid Syndrome Service.
- Was supported with registration for local physical activity organised by a local organisation for Arabic speakers (weekly walking sessions).



Case study 6

Salus Fatigue Foundation

I had Covid in December 2022/January 2023 and was unwell. Some days I tried to get up or down the stairs and had to just stop part way. I was falling asleep at the table when I ate. My head was confused and foggy, I struggled to sleep. But because I didn't have respiratory issues, I didn't think it was Long COVID. I attended some of the workshops and took on board advice that helped me with managing the fatigue related aspects. It was really helpful to hear from one of Salus' health practitioners who had also had Long COVID, and she was already putting into practice self-care measures around nutrition. I looked at the online support from BCHC as outlined by Salus in their event and dipped into some of their resources.



Case study 7

Smartlyte Communities CIC

This attendee is a mother in her 40s with three young children.

She attended the Long COVID workshop held at her local GP surgery.

Her husband got Covid recently and had not fully recovered and was always complaining of being very tired and always coughing and 'just doesn't seem to be getting better.' She did not realise it could be Long COVID and just thought he was recovering, but it could be a long recovery. But having come along to the workshop and learnt about the symptoms, she realised he has Long COVID. She was able to search about Long COVID symptoms on the BCHC and NHS website and learn more about the self-help available. She felt confident in taking the information back home and sharing it with her husband. It will also help when approaching his employer if he needs extra support whilst recovering.

She felt empowered with the knowledge she gained from the Long COVID workshop. Armed with information about the symptoms and self-help options available, she was able to support her husband in a more informed way. She understood the importance of proper communication with his employer to ensure he receives the necessary support during his recovery.



Case study 8

Solihull Parent Carer Voice (SPCV)

The individual who is a carer for their child with additional needs, had a processing disorder and learning difficulty.

Through the engagement events, we were able to discuss how Long COVID was specifically affecting them. We were able to provide a glossary of terms so that the written information was more accessible. We also printed the relevant information sheets so we could annotate and highlight as we went through them to tailor them to the individual. We were able to practice some of the techniques, such as deep breathing exercises, giving the individual confidence in being able to replicate those techniques. This highly personalised approach proved successful in engaging the individual and empowering them to continue in their recovery in a way that felt manageable and relevant.



Case study 9

Bold Actions

The attendee, a woman in her 40s, had a mild case of Covid a few years ago. While she recovered from the initial illness, she felt that she still experienced some symptoms that the GP had not completely treated (such as fatigue and occasional shortness of breath).

She decided to attend our local Long COVID awareness session at Heaven Gate Centre. Through interactive sessions, we explored the symptoms, shared self-management strategies accessible online, and emphasised the readily available support services for managing Long COVID symptoms.

She learned about the wide range of Long COVID symptoms and their potential to persist for months or even years. The lived experiences shared by other attendees resonated with her, making her realise she wasn't alone. The session also presented information on various self-management tips and treatment options.

However, the attendee remained sceptical. While she acknowledged the challenges faced by Long COVID sufferers, she remained unconvinced about the need for further support. She felt she could manage her symptoms on her own and worried that relying on existing support and her previous bad GP experience might hinder her recovery.



This highlights the challenges in Long COVID awareness within some ethnic minority groups in Birmingham, such as:

- **Destigmatisation:** Community members scepticism reflects a persistent stigma around Covid and Long COVID.
- **Self-management vs. specialist support:** There is hesitancy to seek professional help, despite the potential benefits.
- **Uncertainties about NHS Support:** Community members still have reservations about the effectiveness of specialist support due to negative experiences of GP services.

Her case highlights the importance of tailored support for Long COVID sufferers. While awareness sessions can be a starting point, some individuals might require additional support to overcome their scepticism and connect with available healthcare resources.



Case study 10

Colebridge Trust

This attendee was socially active, in part-time work but suffering, thinking of resigning due to the impact on her mental health from chronic pain and discomfort. She had been experiencing chronic pain and had medical investigations, but had no formal diagnosis. Following a Long COVID Awareness session, she arranged a follow up appointment with her GP and was referred for a specialist consultation, as the appointment identified a potential problem relating to her immune system.

She felt that the Long COVID workshop prompted her to think more about her health, and this was the catalyst for feeling confident enough to approach her GP to ask about Long COVID. This, in turn, resulted in more investigations into her illness.

By feeling that she was being listened to, there was a positive impact on her mental health, and she has been able to sustain her employment.



What we do?

Our aim is to lead and support high quality research and evaluation with, for and about the Voluntary, Community, Faith & Social Enterprise Sector.

We offer

Research about things that affect the sector and the communities we serve.

Evaluation of the services, projects, and organisations - supporting you to clearly evidence your impact.

We are committed to delivering high quality, timely and relevant research and evaluation that is useful and helpful to the sector. As part of this commitment, we offer a range of free events to bring people together in a 'research space' - including our quarterly 'Space to Think' sessions, webinars aimed at supporting a more 'research ready' sector, network events, training, and face to face codesign events.

Working in partnership with the VCFSE, public sector, academic and non-academic research institutions and Community Researchers we have developed strong networks across Birmingham of people keen to share resources, intelligence and information that can help inform and support practitioners working across the sector.

Our extended offer also includes consultancy support developing and implementing organisational values and values-based interviewing.

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