healthwatch Brent

# Effect of Covid-19 on Seldom Heard Communities in Brent


June 2020

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# 1. EXECUTIVE SUMMARY

## 1.1. Engagement

During June – September 2020 Healthwatch Brent staff carried out extensive community engagement, contacting, sourcing, listening and speaking to our residents about their experience of information, support and services subsequent to the first wave of COVID-19. With the lockdown measures being lifted and a push to return to work and school, we adapted our engagement methods to meet face to face with residents where possible while, also engaging digitally with communities that are seldom heard. This report follows on from the one presented to the Health and Wellbeing Board on 29 June 2020.

We used face to face, digital and telephone conversations and surveys to gather feedback from 584 residents with a focus on residents that were from hard to reach communities. In addition to the 584 residents engaged with during this period, Healthwatch Brent engaged with 270 people (including some key workers), 7 care homes and 10 organisations between April and May bringing the total of BAME and other Brent residents to almost 1000 individuals. We believe this is one of the largest samples collected by any Healthwatch team nationally and accurately reflects the challenges and realities of local people in one of the worst pandemics in modern times.

Due to the rise in digital engagement, views were gathered from those residents who had previously never engaged with us regarding their social or health care. This included the Sickle Cell community, South Asian people with HIV and, persons with complex learning difficulties amongst others where we partnered with The Advocacy Project to gain insight. Healthwatch Brent has taken a forensic look at insights from micro and macro resident groups. It is important to note that many residents occupy several categories i.e: what is the impact on a Caribbean person who also functions as an unpaid carer. Therefore, these categories should read in an intersectional context and views can be found in table 1 in the full report.

The COVID-19 BAME Public Health England report highlighted the direct effect of COVID-19 on Black, Asian, Minority Ethnic (BAME) populations. It was found that BAME communities are more at risk to suffer severe effects and, more likely to die once infected with COVID-19. It notes that the pandemic exposed and exacerbated longstanding structural inequalities that particularly affect BAME populations in the UK[1]. As Brent has been one of the worst hit boroughs by the pandemic[2] and, with 66.4% of the population of Brent coming from BAME backgrounds[3], Healthwatch Brent sought to look into their experiences of these often hard to reach populations to understand the indirect impacts of lockdown and social distancing to residents. We note that the COVID-19 landscape is continually evolving, this report needs to be read within this context.

## 1.2. Findings

Some of the key themes to emerge from these engagements have followed similar sentiments to our previous COVID-19 report and include

- Requests that information was available in easy-read and community languages, requests for translated information to be made available to key community leaders for dissemination
- Many were unable to access services and felt left out of council updates, due to a lack of digital resources
- Residents are becoming more aware of the digital divide between richer and poorer households
- Some members of the BAME community – particularly those with language barriers, mental health difficulties and mobility issues – fear they are being ignored and excluded from communications and interventions
- There are growing sentiments of mistrust with central services and therapies such as flu vaccines stemming from 'confusing' COVID-19 communication

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[1] PHE COVID-19 BAME report, June 2020 https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

[2] https://www.kilburntimes.co.uk/news/health/brent-has-highest-COVID-mortality-rate-in-uk-1-6704545

[3] Brent JSNA December 2014; https://www.brent.gov.uk/media/11085556/BrentJSNA-Health-and-Wellbeing-in-Brent-Dec-2014.pdf

- Commendations given to local pharmacies who can give a more hands on approach to residents
- Growing sentiments to delineate management and strategies applied to BAME populations; Asian Black and Middle Eastern communities are different and in turn have different needs
- Many praised Brent Council for the walk-in testing centre in Harlesden which they found convenient and easy to navigate
- Residents with learning disabilities noted delays to receiving COVID-19 test results and difficulty using self-administered test kits
- Some residents are experiencing food poverty and economic poverty and there are growing feeling of wariness for the future
- Some residents questioned the safety of hospitals and noted their concern and reluctance to attend routine treatment
- Families experiencing 'burnout' and anxiety due to the lack of respite, as family carers or home schoolers
- Social isolation and loneliness were concerns of many older residents and new parents
- Many praised the work of Brent councillors and found them to be supportive and proactive during this time

## 1.3. Next Steps

The following key themes were identified and proposed next steps are detailed below. We are keen to work with the Health and Wellbeing Board and our statutory and charity partners to develop our proposals going forward.

**'Frustrations about growing number of services going digital – unable to access services and many questions are left unanswered from service providers. Lack of trust in digital platforms.'**

***Older residents in Brent***

### Statutory and community partners next steps

**1a. Communication and Misinformation:** unable to access information due to national push towards relying on digitalised updates and the growing sense of digital exclusion; delays to routine treatments; fears regarding hospital admissions to and safety in hospital for non-COVID conditions and for ongoing information about the economic/employment situations, benefits and the continuation or not of current COVID food support schemes; misinformation about flu vaccines and growing sentiments of mistrust

Suggested next steps:

- Healthwatch Brent would welcome the use of different communication strategies to be used to engage with different BAME community groups – Asian populations should be managed differently from African or Caribbean populations. We welcome the opportunity to take this report to the next Brent CCG Governing Body and the Strategic Delivery Board and work with the team to cascade messaging down to local communities. Furthermore, we would like to present to work with NHS North West London to share our findings with the EPIC task force
- Brent CCG primary care department and Primary Care Networks to work with Healthwatch Brent to share clear consistent messaging on the benefits of the flu vaccine and target communications to at risk groups. We suggest working with community leaders to deliver information to dispel sentiments of mistrust in populations

**1b. Challenges to Mental Health and Wellbeing:** Challenges related to stress, anxiety and isolation are overriding themes that cut across all our engagement. Views were noted in relation to isolation in hospital; social isolation being experience by older residents; financial and employment security coinciding with the rising cost of care for dependants who are spending more time at home; heightened awareness of entrenched structural inequalities for BAME populations
Suggested next steps:

- Share findings with Central North West London mental health teams to understand how services have adapted to the pandemic
- HealthWatch Brent welcomes the opportunity to talk to local community-based community health providers to understand what services have been offered to residents. There is an awareness that most residents will not meet statutory assessment of needs but do in any case need access to mental health services to boost resilience. Healthwatch would like to share this report with these providers

**Minority group felt they did not want to put siphoned into the same bracket:**

**"I am not BAME, I am Asian so why am I put into one bracket when it comes to certain needs."**

***Asian resident of Brent***

### Healthwatch Brent Next Steps

**1c. Experience of BAME residents:** Following on from previous suggestions and given the challenges outlined above and recognising the urgency of the current situation, we propose to work with existing BAME Networks to learn from residents and communities about:

- working collaboratively with our communities, frontline staff and across the system to highlight lessons learned both in the immediate period and longer term – acknowledging that different communities require different strategies of engagement.
- identifying best practice and areas for improvement in connecting with communities and frontline staff to reduce inequalities and make a difference, both now and in the future

**1d. Healthwatch Brent Activity:** Due to the impact of COVID-19 on different communities, we propose that with our charity partners and the Health and Wellbeing Board, we examine and focus activity more specifically to:

- assess how COVID-19 impacts BAME communities particularly in council wards and estates with a disproportionate number of residents affected by the pandemic. Given the disproportionate death rates as well as the numbers of those tested positive for COVID-19 in Brent, we aim to proactively work with communities and partners as a starting point.
- gather the experiences of affected communities in the context of their everyday lives.
- determine what system and community responses need to be developed as a result. The resources produced can provide an evidence-base to hold 'listening' and 'change' conversations.
- consider whether there are lessons learned and new approaches that can be applied to other communities and the wider community going forward – particularly during the second wave during the autumn

As previously stated, secondary research into satisfaction, complaints and good practice could help identify key issues and further engagement could include: consideration of translation services in health and social care; advocacy services for in-patient and outpatient services and social care; increase trust or understanding of services within different communities; identifying challenges and barriers that have become embedded through the pandemic; and the impact of public health factors on residents' health and wellbeing.

## 2. INTRODUCTION

This report has been prepared by Healthwatch Brent, based on the experiences and views of residents as they live under the cloud of the pandemic whilst observing the government's instructions on saving lives and remaining alert. Healthwatch Brent engaged with Brent's diverse communities to gain a better understanding of the disease's impact. We used different techniques and methods to gain access to hard to reach and seldom heard groups.

The indirect implications of the pandemic and, by consequence, lockdown and social distance will continue to affect our most vulnerable communities who live with various comorbidities, for years to come. Brent has the highest number of furloughed workers in the UK[4] many of which come from already disadvantaged groups in wards with a significant population of furloughed workers such as the Harlesden. The longer-term socio-economic impact on already disadvantaged populations can and will be significant. This in turn will have a disproportionate impact on longer term health and wellbeing.

We have started to collate evidence, mindful of observing and maintaining social distance where necessary. These voices were captured using a range of online, virtual and digital techniques to engage with key hard to reach stakeholder groups. We engaged with wider resident communities and gathered their views of those accessing and using services. We relied on using digital media such as WhatsApp, phone-calls, and video messaging services to engage with support groups. Where possible we sought to maintain face to face contact with prominent community members and charity partners.

**'Social media activism has helped the youth express their views and raised awareness on COVID-19 landscape. Youth want to be consulted in planning of services and policies'**

***Young person in Brent***

[4] https://www.kilburntimes.co.uk/news/health/brent-central-highest-for-furloughed-workers-1-6728211

# 3. HEALTHWATCH BRENT APPROACH AND ACTION

## 3.1. Engagement Methods

Given the emergent nature of the short and long-term impact of COVID-19 on communities as well as the need for urgent action, North West London developed an approach to engagement working with patients, residents, communities and partners. These are set out below and have been utilised by the Healthwatch Brent team:

- Collaborative: Creating the space and facilitating conversations with and between individuals and organisations.
- Evidence-based & Person-centred: Ensuring a parity of esteem between the insight and experience of local stories and experiences and qualitative data / research evidence.
- Asset-based: Ensuring that the voices of communities and residents drive the work forward, ensuring that conversations are facilitated and reflect the wishes of those who participate in the work.
- Continuous and iterative: Constantly reviewing, evaluating and testing emerging themes so that they influence decisions in real-time.

## 3.2. Engagement Activity

Traditionally, Healthwatch has gathered the views of residents through surveys, face to face conversations, community stalls, briefings and e-communications. But, mindful of social distancing, we developed a safe programme which involved assessing, preventing, and mitigating risks by implementing the government's instructions at the time. We were also mindful that there was a risk of COVID-19 widening inequalities caused by digital exclusion. Digital exclusion is associated with social exclusion and poor health which, if not tackled, can result in a further increase in health inequalities.
Since the COIVD-19 pandemic and subsequent lockdown, we adapted our engagement methods to include:

- Joining and liaising with Mutual Aid groups being established across the borough
- Joining and liaising with ward and street-based WhatsApp groups
- Zoom meetings with residents and stakeholders
- Contacting care homes and carers by telephone to ask how they are coping
- Face to face engagement near places of worship, community socially distant events
- Conducting telephone interviews with community organisations and charity partners
- Promoting a survey in partnership with The Advocacy Project to find out if individuals with complex disabilities had access to digital media and whether they received enough support during the pandemic
- Participation in stakeholder webinars
- Collecting case studies and evidence from populations of Brent residents from youth, older aged, South Asians living with HIV, residents with Sickle cell, unpaid carers, homeless and migrant groups.

**'No recourse to public funds puts financial pressure on migrant key workers who could fall ill or get furloughed'**

***Migrant key worker in Brent***

The following table outlines the resident experience of access to services during and after the first wave the of COVID-19 pandemic. Healthwatch Brent has taken a forensic look at insights from micro and macro resident groups. These views are segmented to reflect sentiments received from resident populations. It is important to note that many residents occupy several categories i.e: can be a Caribbean person who also

functions as an unpaid carer. Therefore, these categories should read in an intersectional context.

**Table 1: Resident insight on the direct and indirect impact of the COVID-19 pandemic as a result of engagement with Healthwatch Brent**

| Resident category | Insights shared |
|---|---|
| Unpaid carers | • Lack of respite is taking toll on carers especially those looking after adults with severe disabilities<br>• Carers have complained about social and support workers ignoring their calls and/or not replying to their emails<br>• Carers are reluctant to attend hospital appointments as they are worried about catching COVID and passing it onto dependents<br>• Carers looking after older parents, or people with mental health issues such as dementia and complex learning difficulties have seen their dependents' mental health and cognitive skills deteriorate due to lack of stimulation or social isolation<br>• It is difficult for carers to home school children if one of the siblings has learning difficulties. This causes interruption and noise intrusions which break concentration. There is also a lack of privacy which may be due to cramped living conditions |
| BAME residents | • BAME community feel as though they are being ignored and are apathetic about engaging with authorities as their voices are often ignored<br>• Information from the Government/Council is not trusted and is confusing. BAME communities rely on their own local communities for COVID information<br>• Social distancing rules are difficult to adhere during bereavement periods, weddings, and other social events as this is the only time they get a chance to come out of social isolation<br>• Jobs losses or reduction in working hours has had a significant effect on earnings in households. Some have faced financial difficulty as their jobs were often within service industries which has been badly affected<br>• BAME residents expressed anger that there is no recognition of the difficulties faced by BAME key workers who are unable to work from home –they often use public transport which has added risks<br>• Minority group felt they did not want to put siphoned into the same bracket "I am not BAME, I am Asian so why am I put into one bracket when it comes to certain needs"<br>• Smaller localised communities are emerging where they are meeting in local parks, or volunteering for local charities |
| Young people and parents | • Anxiety about the future especially with further education and growing financial difficulties from home<br>• Anger and sense of injustice due to inequalities, especially from BAME youth communities<br>• Lack of digital equipment such as laptops which hinders the learning experience<br>• Nowhere to escape, especially if living in an unhappy or abusive home environment<br>• Social media activism has helped the youth express their views and raised awareness on COVID-19 landscape. Youth want to be consulted in planning of services and policies<br>• Young and new mothers lack vital support especially as they maintain social isolation. There is lack of support from maternity perinatal team, especially if the new mums are unable to speak English or lack digital skills to connect online |
| Homeless, migrant and undocumented workers | • Not enough protection for eviction, and displacement from housing |

| Resident category | Insights shared |
|---|---|
| | • No recourse to public funds puts financial pressure on migrant key workers who could fall ill or get furloughed<br>• There is exploitation of migrant workers in a jobs market, they may not get minimum wage and are unable to complain<br>• Reluctance to ask for help or understanding of how to access help. Call for Brent council to signpost debt advice especially those who have rent/council tax arrears |
| Older residents | • Reluctance to go to hospital and particularly use services in Northwick Park<br>• Frightened to leave homes, once they do maintain strict social distancing<br>• Very concerned about second wave, cost of winter fuel bills if stuck indoors<br>• Financially supporting relatives who have been hit by sudden job losses<br>• Lack of face to face GP contact raises frustrations<br>• Frustrations about growing number of services going digital – unable to access services and many questions are left unanswered from service providers. Lack of trust in digital platforms<br>• Personal hygiene and wellbeing is being neglected |
| Insight into NHS and social care services from residents | • GP support is insufficient for residents who lack digital skills<br>• Some GPs are advising patients to go to A&E when they phone for consultation which is causing panic<br>• Commendations given to local pharmacies who are able to give a more hands on approach when compared to GPs<br>• There is anxiety amongst cancer patients as there are delays in their treatment. Added strain on mental health as they shield. Cancellation to vital operations has had significant effect to those suffering and heightened feelings of anxiety<br>• Some residents are still not aware of testing centres within Brent despite being promoted by stakeholders and on social media<br>• Many don't want to see a break to routine care in a second wave |
| People living with Sickle Cell Disease | • Some people living with Sickle Cell Disease have been affected financially due to the pandemic and are unable to find alternative sources of income<br>• Still had to visit hospitals for regular transfusions and were very nervous about doing so |
| South Asian persons with HIV | • Heightened awareness of clinical vulnerability if infected with COVID<br>• Social stigma associated with being a person with HIV and being from a marginalised population<br>• Sense of community with other South Asian people with HIV – opportunity to partner with individuals to deliver localised messages |

Alongside the engagement work, the Healthwatch Brent Team worked with colleagues from The Advocacy Project to find out if individuals with complex disabilities had access to digital media and whether they had received enough support during the pandemic. It is generally accepted that people with learning disabilities face a higher risk of digital exclusion[5]. 15 people completed the survey, responses were recorded in free text to ensure participants were able to freely express their sentiments; these can be viewed in appendix 3 at the end of this report.

The questions were formulated to gain a better understanding of the impact of social isolation, digital access, and time management. The following questions were used:

1) **Social isolation/distancing -** How did clients cope with social isolation/social distancing?
2) **Digital access -** Did your client have access to the internet?
3) **Time management -** Were there more pressures on your time during the pandemic?
4) **Second wave -** If there was a second wave, do you think you would be able to cope better

[5] https://www.poverty.ac.uk/report-social-exclusion-disability-older-people/growing-problem-'digital-exclusion'

# APPENDIX 1: CASE STUDIES OF BRENT RESIDENTS DEALING WITH IMPACT OF COVID

## CASE STUDY 1: Elderly resident

Mrs M is a 76-year-old resident in a Housing Association and is finding it difficult to get workmen to fix a grab rail on the stairs leading to her flat on the 3rd floor. Since 2019, she has been in touch with the Housing Association to have the grab rails fitted, this will ensure that she is able to live independently as she was initially due to have a major operation of her spine. Despite the workmen taking the relevant measurements in 2019, no work has been carried out on the property. Due to COVID, her operation is delayed until the end of September. Mrs M has been trying to reach the Housing Association but to no avail and is extremely worried about her after care. She has no support and relies on her son who is also not in best of health.

Mrs M believes basic duty of care is being ignored and the pandemic is being blamed for all the shortcomings. The pandemic has exposed and heightened structural inequality and has further delayed her access to life changing services. To add to her anxiety, Mrs M's operation has had to be pushed back to a later date. Healthwatch Brent assisted her with writing an email to the Housing Association as she did not have the IT skills to send digital correspondence. She was also signposted to Age UK who could provide additional support.

## CASE STUDY 2: Single parent with 5 children

Ms F is of Somali and her command of the English language is limited; she has 5 children all under the age of 15. She is being supported by her friends and family for COVID updates and changes to other vital services. Ms F relies on access to welfare benefits and she expressed how difficult it is for her to feed her children during the lockdown especially as the food parcel service has been withdrawn. With schools shut over lockdown, her children are at home more often and require food. To this effect, Ms F has been relying on foodbanks fulfil her shortfall. Ms F is mentally exhausted as there is no time for herself as she constantly has to look after her children's needs. Additionally, she lives in a cramped overcrowded property which has poor internet connections that impacts her children's schoolwork.

## CASE STUDY 3: Migrant key worker

Mr & Mrs P are migrant workers from Philippines. Mr P works is a key worker in the NHS and Mrs P was working in the beauty industry. Due to lockdown, Mrs P lost her job and, as she had no recourse to public funds, they cannot afford to pay the rent on Mr P's earnings alone. To them, the pandemic has highlighted how excluded the migrant workers are from access to public funding, despite the contribution made by them through taxes. The couple are reliant on food banks and Mrs P is currently working as a domestic cleaner however, their combined income is insufficient. Mrs P is worried about the future, she believes it looks bleak if there is no support for migrant workers like herself and her husband. The couple is of an opinion that migrant workers must be given the same rights as British workers especially if they have been working and contributing to the British economy for a considerable time in a sector which has staff shortages such as the NHS.

## CASE STUDY 4: Elderly carer

Mrs L is a widow aged 75 years and up until last year she has been a carer for her 50-year-old son, Mr L, who has learning difficulties. Mr L was moved into a care home which he does not like. He complains that the staff are physically and emotionally abusive. Mrs L was upset at her son's care and worries for her son's mental health which has deteriorated due to his stay at the home. She has been trying to arrange a meeting with Mr P's support worker, but to no avail. Due to COVID-19, reviews are being delayed and Mrs L has to wait for a significant amount of time before discussing her son's case placing her son in an incredibly vulnerable

situation.  According to Mrs L, her son's support worker often ignores her messages or queries or generally takes long time to respond.

Taking matters into her own hands, Mrs L in a flurry of concern contacted other care homes to arrange a transfer for her son. One agreed on the condition his support worker made the arrangements.  Mrs L had to wait 2 weeks before meeting with the support worker, during this time she became increasingly worried and anxious that the place she found for her son would be given away.  Healthwatch Brent have referred Mrs L to Brent Carers Centre for additional support in securing better care for her son.

# APPENDIX 2: DIGITAL ACCESS FOR THOSE WITH COMPLEX DISABILITIES DURING THE COVID-19 PANDEMIC

Healthwatch Brent worked in partnership with The Advocacy Project, an organisation that supports clients with a range of complex disabilities to deliver this engagement. Our objective was to find out if individuals with complex disabilities had access to digital media and, whether they received enough support during the pandemic. The Advocacy Project collected information from vulnerable individuals and their carers; the questions were converted to easy read format by the team to ensure all individuals could participate in the questionnaire.

The questions were formulated so that we could gain a better understanding of attitudes pertaining to social isolation, digital access, and time management.

## Listening to people with complex disabilities

| Topic | Comments, Views & Experiences |
|---|---|
| **Social Isolation/Social Distancing**<br>*How did clients cope with social isolation/social distancing?* | ● I wear a mask and go out<br>● I feel safer now that I can wear my mask<br>● I now know what to do i.e. wear a mask, keep my distance from others.<br>● I was scared and frightened. I was scared it would spread to my local community. I was scared to go out as people may pass the virus onto me<br>● At first, I was scared as I did not know what to do so I stayed inside. I was crying every day<br>● I do not travel on the bus anymore I travel by taxi now if I have somewhere far to go<br>● I have had counselling during lockdown every week to help with my emotions<br>● Walking in the park really helped me<br>● Currently re-reading books as I missed be able to go to the library to get new books<br>● Day Centre activities stopped I accepted that this needed to be done as I was shielding<br>● Watching TV – daily broadcasts<br>● I felt vulnerable<br>● If there was a second wave, we should be all tested and PPE should be more readily available<br>● For a lot of the services I tried to access staff were furloughed. i.e. no library service. So, I did not seeing a doctor when I was unwell made which me feel isolated<br>● We coped well, we adapted to rules and regulation now we use PPE's when going out |

| Topic | Comments, Views & Experiences |
|---|---|
| **Internet / Digital Access**<br>*Did your client have access to the internet?* | ● Yes, I keep in contact with my family over the phone<br>● I found out all my information about COVID-19 on the news and with my support worker<br>● I do not use the internet as I do not have access to it<br>● No internet access so it is difficult to receive information. I get my information from the daily paper and daily news updates<br>● Independent living setting: I have access the internet via my phone so, if people want to contact my service user via email I can access this for them. Information regarding COVID-19 was sent via our head office i.e. posters were made available for the staff and residents. Otherwise there is no internet access here |
| **Time Management**<br>*Were there more pressures on your time during the pandemic?* | ● I stay at home a lot now<br>● I have been keeping myself busy with my colouring and cooking<br>● I am now going to the local shops during the quiet time<br>● I needed to buy lots of food to ensure that I did not have to go out as often<br>● Had nothing to do so became very lazy, otherwise would be out and about in the community on most days.<br>● Carers came in the morning promptly, so that kept my routine in the mornings as regular as it could be. But the evening became more difficult as the work times were changed as the carers were not working due to the COVID-19 pandemic. Therefore, I had new carers coming in and felt vulnerable.<br>● We keep the residents busy our aim was to keep everyone safe<br>● We only went out to walk for exercise locally<br>● I worked longer hours during this period to ensure that everyone is safe, and they felt comfortable |
| **Second Wave**<br>*If there was a second wave, do you think you would be able to cope better?* | ● I will continue having counselling<br>● Continuing to keep residents and ourselves safe<br>● Continuing to keep the residents busy with activities and in contact with their usual contacts via the phone<br>● Having internet would need to be advised via social service at this service |

## APPENDIX 3: THE ADVOCACY PROJECT

The Advocacy Project your voice your rights your choice

# My Health, My Choice – Covid 19 case study

### Background

John*, 62, has a learning disability along with other physical disabilities. John attends our User involvement service group – My Health, My Choice in Brent. John has been an active member of the group for 2+ years and is very keen for his voice and others to be heard regarding health and accessing services.

### Issue

John lives independently within the community in his own home and has support staff visit his home daily to support with day to day care duties.

However, during lockdown John felt isolated, he was unaware of the services available to him as a vulnerable individual. John does not have access to digital technology, so he must rely on others for information about services available in his community. John is finding this difficult as he is beginning to realise that most services are facilitated online.

Due to the nationwide Covid 19 lockdown, John stopped attending group sessions within the community and therefore his social circle become reduced and is spending more time at home not being very active. John is concerned about his health regarding weight gain and lack of exercise.

John's main concern was contracting the Covid 19 virus as he had different support staff entering his home daily and reached out to The Advocacy Project, via the 'My Health, My Choice' project to find out how to proceed with getting tested.

This was a difficult process for John due to his physical and learning disabilities, there was no reasonable adjustments such as 'easy read' literature made available for John regarding:

My Health, My Choice project provided John with the details to his local testing centre. John made his way to the centre and proceeded to have the test administered. John experienced that the NHS testing service in Harlesden is self-administered, meaning that the individual would test themselves using the testing kit.

- instructional direction
- opening of the packaging
- administering the test
- gaining his test results

John was unable to provide an email address to receive his results and was informed he would have to ring a dedicated telephone line along with a reference number to gain his results.

John has had a difficult experience with gaining his results as the 'test and trace' dedicated phone line **119** is computer operated. There is no human contact, therefore if you have a query you cannot get through to anyone to get your results.

John was unable to provide an email address to receive his results and was encouraged by the testing service to source one (either his own or a third party) to access the service.

## Process

We were able to gain access to this story of events by having regular contact with John to discuss health options, accessibility and services within Brent.

During our conversation, we were able to discuss why, where and what to expect for the testing process from the information provided by NHS.

John was very keen to get the test administered even though he was not displaying any symptoms, due to having many care workers entering his home. John was also keen to see if the service was accessible to people with learning disabilities and is eager to voice his experience.

We supported John with the experience by providing him with a telephone number, address of the location and discussed the process of testing. We offered to send through the literature of the NHS service in the post to which John stated he would be ok with the information provided. It was agreed once John completed the test, he would be in contact with us to communicate his experience.

## Outcome

The outcome of the test is still unknown John is unable to obtain his results, we also tried to contact the delegated telephone number and we were not able to talk with anybody regarding the difficulties to which John was experiencing and after all the options have been listed the phone line is cut dead. Therefore, John's initial goals have not been met using the NHS service.

John has stated that he feels 'let down' by the NHS testing service and he felt that 'it was not safe to give out personal information which are private to another person'. This is regarding the service manager suggesting that John provide an email address of someone else to gain his results. John feels that he should not have to do this being that he does has not have an email address.

It appears if you do not have a digital devices or accessibility, services are not catering to those who cannot access them or have enough knowledge on it use and purpose.

John is now weary about using the service in the future if he were to display symptoms if a second wave does shut down the community again.

## Systemic issues

The biggest impact experienced by John getting testing is the digital divide/isolation he is experiencing. John has said he will think about getting a 'tablet' or mobile phone but has stated

he would not know how to use it if he did. Also due to his physical disabilities, he would not be able to 'walk and have a mobile phone as my priorities are keeping my balance'. Therefore, John will require the support to use a digital device before purchasing one. Other service users have shared this same

viewpoint.

It would be beneficial for NHS services like this to provide an alternative accessible way for people without digital accessible to still be included, as John is still without his test results. Also, the staff on site at that testing centre should be available to support people who have identified as having a disability or those who appear to be struggling. In this case John did ask for help and was told the service is self-administered, this could be discrimination to those who are **vulnerable.** *identity changed for confidentiality.