COVID-19: Your Experience Matters Update Document



COVID-19 in Central West London:

How the pandemic has impacted Black, Asian and Minority Ethnic people in Westminster





"It would have been better if vulnerable families were given more consideration at the beginning of this. No one knew who to turn to. GPs could have made a list of all their carers and reached out to them to give them local support."

Local mum, Westminster





an independent organisation for people who use health and social care services. We have been speaking to NHS service users in **Westminster** about how COVID-19 has affected them and their families.

Impact of COVID-19 on Westminster

Since March 2020, we have been asking our local communities in Westminster and Kensington and Chelsea about how they have been affected by the COVID-19 outbreak, and the measures responding to them.

The COVID-19: Your Experience Matters survey was developed to capture the broadest range of experiences, from general wellbeing to the direct impact, and many other changes to your experiences of health and social care.

This survey will be an ongoing project for us, with the results shared regularly, to reflect the changing face of the pandemic and its response in Westminster.

Impact of COVID-19 on BAME communities

14 people completing the survey (14%) identified their ethnicity as BAME. This document is a short summary of the key themes and issues that have been raised by this group so far, and precedes a more detailed summary and analysis, which will be shared over the coming weeks.

As a charity that works in two of the most diverse boroughs in the country, we take seriously the importance of representing the full spectrum of views from our communities.



We remain committed to working with local BAME and migrant groups, in addition to gathering their experiences through this survey, so that their voices are central to discussions about improving local health and social care.

Who shared their experiences with us?



Knowing about the people involved in our study helps us to analyse their experiences through the COVID-19 (Coronavirus) pandemic.

This report compares the experiences of local Black and Minority Ethnic (BAME) people with that of their White or White British (W/WB) counterparts, to note any differences or areas of potential inequality. As the BAME case size (14) is relatively small, we only report on variations of 10% or more, with both positive and negative trends taken into account.

Five people identified as a carer, and one as a parent. Three have a disability and we record two for both a mental health and long term condition.

On employment, three people state they are unemployed while the rest are either in some form of employment or are retired. One of the respondents said they were a student.

Four (29%) of the BAME respondents to this study identified as **Asian/Asian British**.

Three (22%) identified as Arab.

Three people identified as Mixed.
Two people, identified as Black
British and two as Other.



Two (14%) of the BAME respondents to this survey identify as **men**.



12 (86%) identify as **women.**



Just over two thirds of people in this sample (10 people) are aged between 35-54.

In the rest of this sample, one person was in the 25-34 age group, one in 65-74, one in 75+ and one not stated.



Inequalities: What our results so far tell us about the disproportionate impact of COVID-19 on people from BAME backgrounds in Westminster



Inequalities



When compared to their White British counterparts, BAME respondents in Westminster were:

Inequalities at a glance*



More likely to be on the shielding list, and to be overlooked or missed.



Twice as likely to use the GP and more likely to use the pharmacy.



More likely to have appointments cancelled or changed and more likely to delay treatment.



More likely to experience mental health difficulties.



Less able to 'easily' understand information.



Less able to remain indoors, and to socially distance when out.

Found it easy to understand information



28% of BAME

of BAME respondents

78%

of White respondents.



Experienced changes to care provision



21%

of BAME respondents 3%

of White respondents.

respondents.

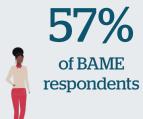
Required help with basic care needs



6%

of White respondents.

Delayed seeking treatment



19%

of White respondents.



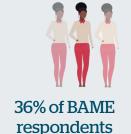
Inequalities*

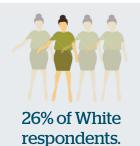


There were noticeable differences between White and BAME respondents to the Your Experience Matters survey

Used a food bank

On shielding list

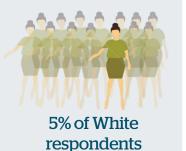






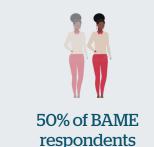


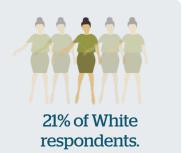






Wellbeing impacted

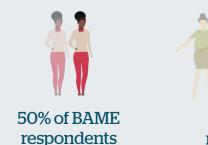


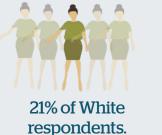


Using mental health services



Appointments cancelled





^{*}The images here illustrate a rounded up/down **proportion** of responses. The BAME results here are from the same 14 respondents as the rest of this document.

The issues you shared with us in the Your Experience Matters Survey.



1. Health and Services

Around 80% of those who consider themselves to be vulnerable have not registered with the Council for support.

21% of people from BAME backgrounds
have used food banks, compared with
just 3% of White or White British
respondents (see *Inequalities* page).

The pharmacy and GP were the most utilised services. BAME respondents were twice as likely to use the GP and more likely to use the pharmacy than White counterparts.



BAME respondents were **more likely to be on the shielding list, and were also to be overlooked or missed**, than their White or White British counterparts (see Inequalities on p12 for more detail).

Delays to treatment

BAME respondents were more likely to experience cancelled appointments and service changes. They were also more likely to delay their own treatment (compared to

"Two very important hospital appointments for my children were cancelled in March and April. We were not offered alternative appointments!"

"Initially no dental services were available. I had an abscess that required treatment. I was turned away by St Mary's but seen at UCLH."



Care Needs

White respondents).

BAME households, according to our survey responses, were more likely to have a basic care need. The respondents who had care needs noted that the levels of support for these needs had been severely reduced (more detail on carers and their needs on the following page).

"I am a full time carer of two disabled children, I feel I need more help."

2. Hearing from Carers

Four BAME respondents said they, or the person they care for, receives help with things like getting up, getting dressed or getting out.

Changes to care received

We asked carers if they felt they were getting the support needed. **Young carers and those with several children indicate that support is lacking,** with one parent particularly critical of their GP. One person is appreciative of family and wider support networks.

"Need more help, especially for young carers."





Changes to dental services

One parent commented that the lack of dental treatment for their son is causing real discomfort - throughout the household.

One person, turned away by a hospital later secured urgent dental treatment at another.



"He is becoming very challenging because of the lockdown and because we could not update his epilepsy medication or help him with [his] severe tooth ache.

[His] challenging behaviour meant that we could not find any help from carers or care centres who could cope with him or meet his needs. His school is still closed. He is not getting home education because he is in too much pain from his tooth. This is affecting all our lives!"

"Two very important hospital appointments for my children were cancelled in March and April... no support is offered to us at all."

Scaled back support: case studies

Restricted services exacerbating challenging behaviours

In one experience, we heard from a parent of a child with epilepsy that obstacles to collecting medication has had a direct negative impact: the child's behaviour deteriorated, which in turn made carers reluctant to offer support. The closure of schools further limits support options for often vulnerable children.

Lack of communication exacerbating anxiety

The same parent said that communication from the hospital about her daughter's brain tumour 'suddenly stopped', causing anxiety.

Barriers to accessing support

A parent with health conditions finds it difficult to also care for the daughter, who has complex needs, following a sudden lack of support. The parent also says that the registration process for social care support was 'very hard'.

One parent, whose daughter has multiple complex needs, worried that all support had been withdrawn.

"It's not as it should be. I used to have 4 hours of personal care a day but the carer left because of the pandemic.

After 40 days without any help I called social services to get help.

The help is not enough because I have my self health problems and I'm the one who's looking after my daughter for 24 hours and she lost all her support and respite."

"My daughter with cerebral palsy, mental health and challenging behaviour has lost all her therapists"

"I have a mixed-need household. Looked at individually, maybe it wouldn't be seen as vulnerable, however managing 4 children with minor to significant needs it is. I'm concerned there isn't the right support available and judgement."

3. Mental wellbeing and relationships



Half of people reported impact on their emotional and mental wellbeing. Parents with vulnerable children found it especially difficult to cope. Those with hobbies or strong social networks were notably more resilient.

"I am very aware of my emotions. At first watching the news all day created a lot of anxiety. I had to learn to moderate it to only watching it once a day or less and did gardening, exercising, doing something with my children or house work."

Impacted mental wellbeing and use of support

We asked people to what extent, they feel that changes have impacted on their emotional and mental wellbeing. **Seven people (50%) indicate it has changed 'a lot' or a 'great deal'** - this is more than double the proportion from White or White British responses, at 21% (see the *Inequalities* page for more comparisons).

"I try to find mental help as well, they only said that they are very busy.

I only had two to three sessions. Then that's it."

Causes and coping mechanisms

Many people express worry and stress about the welfare of their family, with some feeling 'very bad' both mentally and physically. Some say news has contributed towards anxiety.

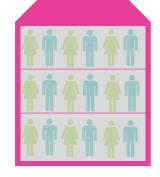
One person, worried about income and finding it difficult to access benefits comments on inadequate levels of mental health support - at a time of extreme difficulty.

Other people are better able to cope with emotions and mental health - in all such cases distractions, such as hobbies or socialising are extremely important.

"I attend meetings via video conferencing, plus I fill in lots of surveys daily. So I'm happy on the whole as I am keeping mental fatigue at bay!"

Wider determinants

Unsanitary and 'cramped' living conditions increased risk and discomfort for participants in this survey.



4. Personal Relationships



We asked people to describe how the changes have affected their personal and family relationships.

3.1. Parents and Children

Earlier in the report, we identified how parents with reduced levels of support have found themselves in difficult and deteriorating circumstances. Relationships are inevitably strained, especially for those missing out on much needed, even essential treatment and care. The most vulnerable families also appear to be the most affected. Some parents are appreciative of peer support.

"I value the support from other parents going through the same situation." "We are a close family and it has only made us appreciate each other more."

3.2. Partners

Just one person comments about their partner, with concern expressed about risk at work.

"Thaven't been able to see my partner and I'm very concerned about him as he has a job which puts him at risk."

3.3. Family and Friends

In household relationships, experiences reflect all parts of the emotional spectrum. Some people feel tense, snappy and irritable, while others feel closer and more appreciative, than before.

While friends and relatives are missed, some are more adept than others at staying in touch, with online virtual meetings cited.

We asked people how they keep in touch - popular methods include phone and text messaging, social media (such as WhatsApp) and video meetings (such as Zoom).

"Not being able to go into my mum's home has been difficult for us both. Not being able to see my sisters, nephews and niece has also been challenging." "I chat with members of my family near and far daily via FaceTime."

"I become very irritable. I've lost four friends already."



5. Housing and Environment

When asking people about their ability to remain indoors, just over half (eight people) consider it to be 'easy' or 'very easy'. Four people (29%) find it 'very difficult', this compares with 6% of people from White backgrounds.

Parents who care for vulnerable children, particularly those with neurological and mental health conditions, find it especially difficult to leave the house. We also hear about poor and unsanitary living conditions, with examples including leaks and a lack of space.

6. Social Distancing

"The houses, streets and shops in our area are quite close and small. It has sometimes been difficult when I'm shopping."

We also asked people about their ability to maintain social distancing when making 'essential trips', with six people (43%) finding it 'easy' or 'very easy'. 35% consider it 'difficult' or 'very difficult', compared with 13% of White respondents.

One person finds the 'condensed local environment' of small and tightly packed streets and shops a challenge, while another says his son, with a learning disability does not understand the concept of social distancing.

7. Personal Finances

When asking people about their financial situation, half (seven people) indicate no change. Three people say it has significantly reduced, while two report that it has increased. Nobody has experienced a complete loss of income, while 14% have had to seek financial support.

Welfare benefits, namely increased and decreased payments, were mentioned a lot. Some people are thankful at being able to work from home, or to save money on travel expenses. One person who does need financial support does not know who to contact.

"I'm asking but I don't know how to get the right financial support and from where."



8. Information

Just a quarter (three) of respondents found it easy to understand the available information about the COVID-19 outbreak. This compares with 78% of White respondents.

This also indicates a key difference between BAME communities in Westminster and those in Kensington and Chelsea. In the Kensington and Chelsea sample of this survey, the inverse was true, with three quarters of people from BAME groups finding it easy to understand the available information about the COVID-19 outbreak.

This is a reminder of the limitation of acronyms such as 'BAME' as it does not represent the diversity of different backgrounds within the term. It also reminds us to not treat the Bi-Borough as one entity, but to explore the differences between the two neighbouring areas.

Online support

The internet was cited as a popular source of information among respondents, with some also using the phone often. One person felt that not having a computer limits their access.

"Other families with children who have the same needs like my son were sent a letter! My son also has ASD, ADHD and Epilepsy which makes him even more vulnerable."

"Because I don't have a laptop and don't know how to get support."

Support groups

A large number of people value information from support groups. The <u>Make it Happen</u> parent's group was cited by the respondents who care for children with complex needs.

Healthwatch Central West London has been conducting focus groups with different community groups, including Make it Happen, who work with under-represented communities. We will be sharing our findings from these discussions in future reports.



Healthwatch Central West London (HWCWL)

Healthwatch was established under the Health and Social Care Act 2012 to understand the needs, experiences and concerns of people who use health and social care services.

We deliver the statutory Healthwatch provision for Kensington & Chelsea and Westminster, and we previously delivered this work for Hammersmith & Fulham. Our research and local engagement puts local people's views at the centre of decision making about health and social care.

We make this happen by:

Helping to improve the quality of local health by sharing what people need from their care with those who commission, run, and make decisions about NHS and social care services.





Contact us



If you would like to contact HWCWL about this report, or about our other research and local engagement in Westminster, you can get in touch with us here:

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Phone:

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Email:

info@healthwatchcentralwestlondon.org

You can add your voice to this ongoing survey here: https://www.surveymonkey.co.uk/r/YourExpMatters

You can request a paper version of the survey via any of the contact details above.