

Adults and Public Health Policy and Scrutiny Committee

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Title:	Healthwatch report: People's experience during the COVID-19 pandemic
Report of:	Healthwatch Westminster
Cabinet Member Portfolio	Adults and Public Health (as listed at www.westminster.gov.uk/cabinet)
Wards Involved:	All
Policy Context:	COVID-19
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1. Executive Summary

The paper provides a summary of the experiences of local people through the Covid 19 pandemic as captured from March 2020 onwards. A variety of methods and channels have been used to gather these insights with an additional focus on young people and local BAME communities.

3. Background

Key themes from the work are those of fear and anxiety about the virus itself alongside its knock on impact to peoples every day lives; their contact to family friends and society, employment and the limitations of their home environment.

The Committees attention is drawn to the views shared on the challenges of a digital offer as well as the mis information circulating about Covid.

With the focus on vaccine distribution and uptake there has been considerable joint working of the Local Authority, NHS and Voluntary Community Sector, this is increasingly reaching into local communities.

Healthwatch Central West London – what residents are telling us about their experiences of COVID-19

1. Introduction

This document outlines what Healthwatch Central West London has been hearing from local people through our community engagement in RBKC and Westminster.

In line with a directive from Healthwatch England we continue to prioritise:

- a) providing clear and accurate information and advice to local people and
- b) gathering feedback from local people about their needs and experiences in relation to COVID-19 and other services.

Since March 2020 we have been carrying out extensive community engagement, hearing from our residents about their experiences of information, support and services subsequent to the first wave of COVID-19. This was initially through a digital survey and more recently has been through focused discussion groups and paper survey.

We sought to hear the experiences of seldom heard groups to understand the indirect, wider health determinant impact of lockdown and social distancing on residents.

This paper presents some of the key themes that have emerged from our discussion groups, wider community engagement activity, Young Healthwatch engagement with young people, and our partnership work with the National Institute for Health Research.

2. Coronavirus – Your Experience Matters discussion groups

Method for engagement

Surveys

We use open, free answer survey questions to find out about the lived experience of local people. We do this so that we can better understand common themes in people's experiences or identify exceptions that might otherwise be missed.

Discussion groups

Our group discussions bring together small groups of people who come from similar backgrounds or who have common experiences to discuss specific topics of interest. This is a form of qualitative research.

We ask group members about their lived experience – this might be in relation to things like using a specific type of service or what it is like to live with a particular health condition. We base our questions on what people have already told us through our general engagement on health and care services locally, or from what we are hearing through one of our surveys.

In the discussions, we encourage group members to reflect together on the experiences that they are sharing with each other as well as respond to the questions that the facilitator asks.

Across both surveys and discussion groups, looking at 'what' people tell us (the content), helps us see the breadth of their experiences.

Noticing 'how' they talk about their experiences (emotive language for example), helps us better understand what this has been like for them and often uncovers hidden nuances that might not otherwise have been apparent.

This type of research can help us understand more about why people make the choices they make, how they prefer to get support, and where there might be gaps. It can also enable us to identify groups of people with shared characteristics, for example age or ethnicity, who are finding it more difficult to get support.

This can help organisations that commission or provide services, such as the NHS or local councils, to better plan, design and run services that are good quality and meet the needs of local people.

Who were we speaking to?

We held a focus group with six members of LEGS, an organisation that provides exercise groups, led by physiotherapists, for people who have had a stroke or who live with a neurological condition.

Workers from the French African Welfare Association (FAWA), carried out 23 telephone interviews based on our survey questions, with 23 of their members. FAWA offers a range of support, help and services for French-speaking African communities in London.

Breathe Easy Westminster adapted our Coronavirus – Your Experience Matters survey to ask their members and other people in Westminster about their experiences of accessing healthcare through July to September 2020. They received 75 responses. Breathe Easy Westminster is a British Lung Foundation support Group, whose primary aim is to provide support and information for people living with a lung condition and those who look after them

What were the key takeaways from what we heard?

Digital exclusion

From listening to patients over the last few months we have had a number of discussions around the use of technology. Using technology has provided a serious challenge to some, while others have been able to adapt more easily. Ultimately, as long as we are living with COVID-19 restrictions, a balance needs to be struck. Support and arrangements for those who may be otherwise excluded from services need to be provided in systems which also allow those who can engage virtually to do so.

From listening to members from LEGS, we heard that a lack of access to, and understanding of new technologies presented a significant barrier for support and engagement. Participants expressed frustration that they felt excluded from access to treatment or engagement because of a lack of access to, or understanding of, new technology.

We heard that, in many cases, technological solutions did not provide an adequate replacement for existing arrangements. Unfamiliarity with technology, or a lack of access to it, can have knock-on effects. Feelings of stress, isolation and uncertainty were frequently reported by participants when asked about their use of technology during this period.

During the session one participant told us that

“I am using Zoom now, through LEGS, but [my physiotherapist] is using something called Attend Everywhere. I am not young, so using all this new technology is very stressful for me.”

This echoes what we have heard through our engagement over the past months: **it is not just access to technology that can present a barrier to receiving help and support; feeling confident using technology is important too.**

However, some participants in the session did tell us that in certain situations technology has been used well as a replacement for physical meetings and appointments. One participant, for instance, told us that,

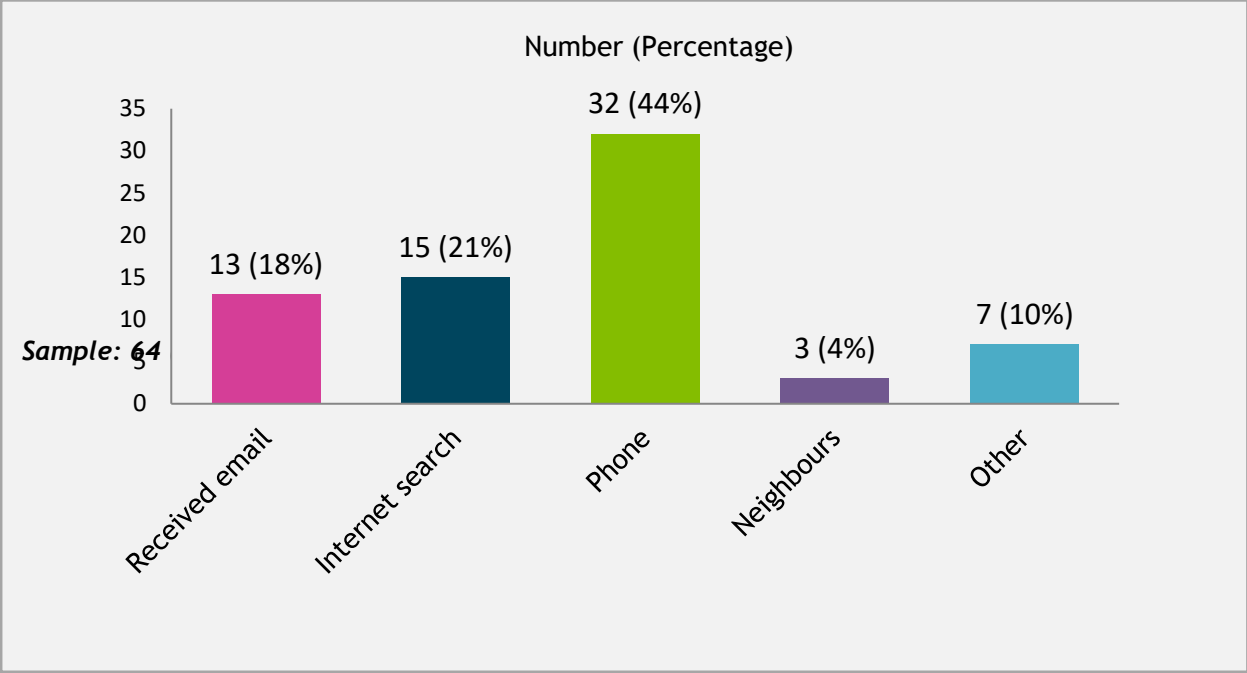
“phone consultations with a GP could be quite good, as you can get things down on the phone which can be useful at the time.”

They added that “video calls are a great improvement to phone calls.”

There certainly is scope for good use of technology in health and social care provision. In our session with LEGS, those who were already well equipped and confident in using technology tended to be the most positive. Encouraging those who can use technology to do so, can help reduce the strain on health and social care providers, reduce face-to-face interaction, and possibly make some appointments, like initial GP consultations, less time consuming for patients and doctors.

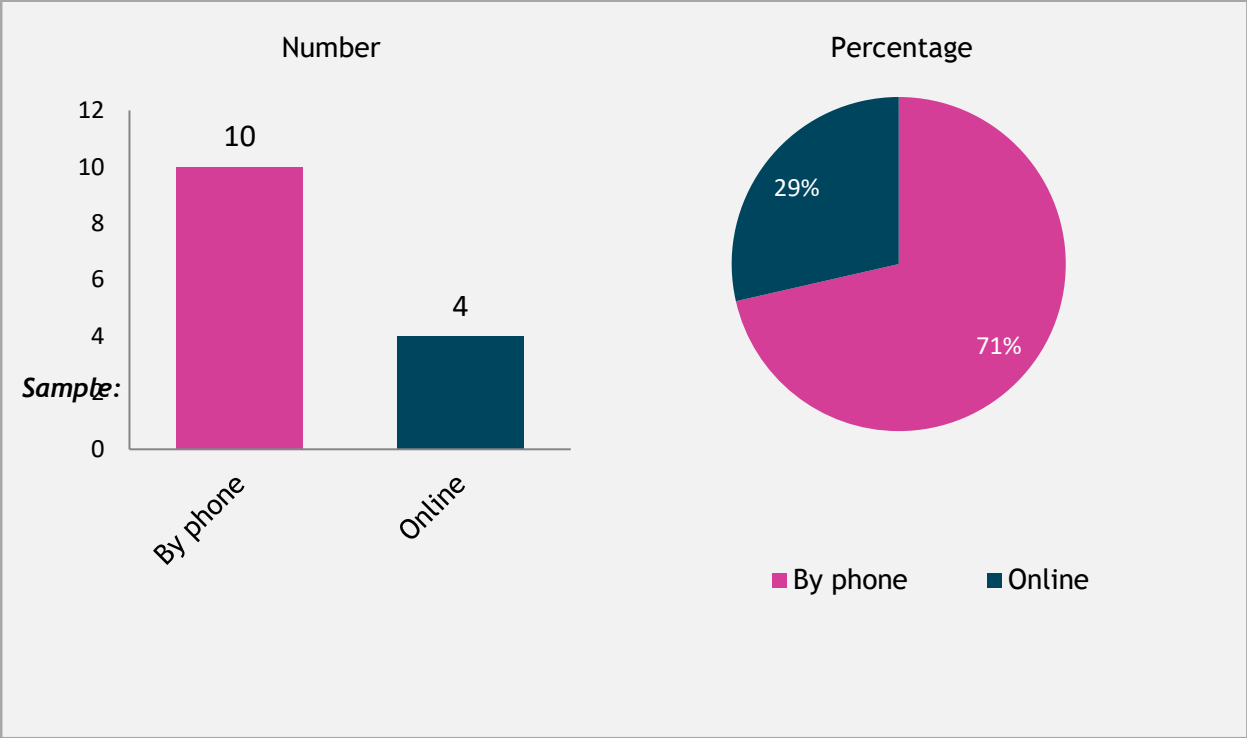
Provision for those who do not or cannot use technology needs to remain a vital part of all health and social care services. From our survey with Breathe Easy we heard that in response to a question on how they managed to find the support needed, the phone was significantly the most popular method of seeking support (44%). Only around a fifth of respondents (21%) searched the internet while a similar number (18%) received emails.

Q5. How did you manage to find the support needed?



Likewise, in response to how people had contacted 111, of the 14 people who had used this service, 10 had done so by phone and only 4 online.

Q7. How did you contact 111?



This has been a major recurring issue that has been reflected across our work and suggests that it is not just about a lack of access to technology; it is also about a lack of confidence in using it. Many people have said that technology proficiency has been assumed to some extent by service providers, and that this has caused them to be excluded, for a variety of reasons. Many of the people we have spoken to us are very reliant on friends, family and carers for support.

Mental health concerns

Almost everyone we have spoken to has told us their mental health had been affected during the period of lockdown. We have heard about feelings of loneliness, anxiety, fear and panic. People have told us they worried that this period would have long-term effects for their mental health and their relationships with others.

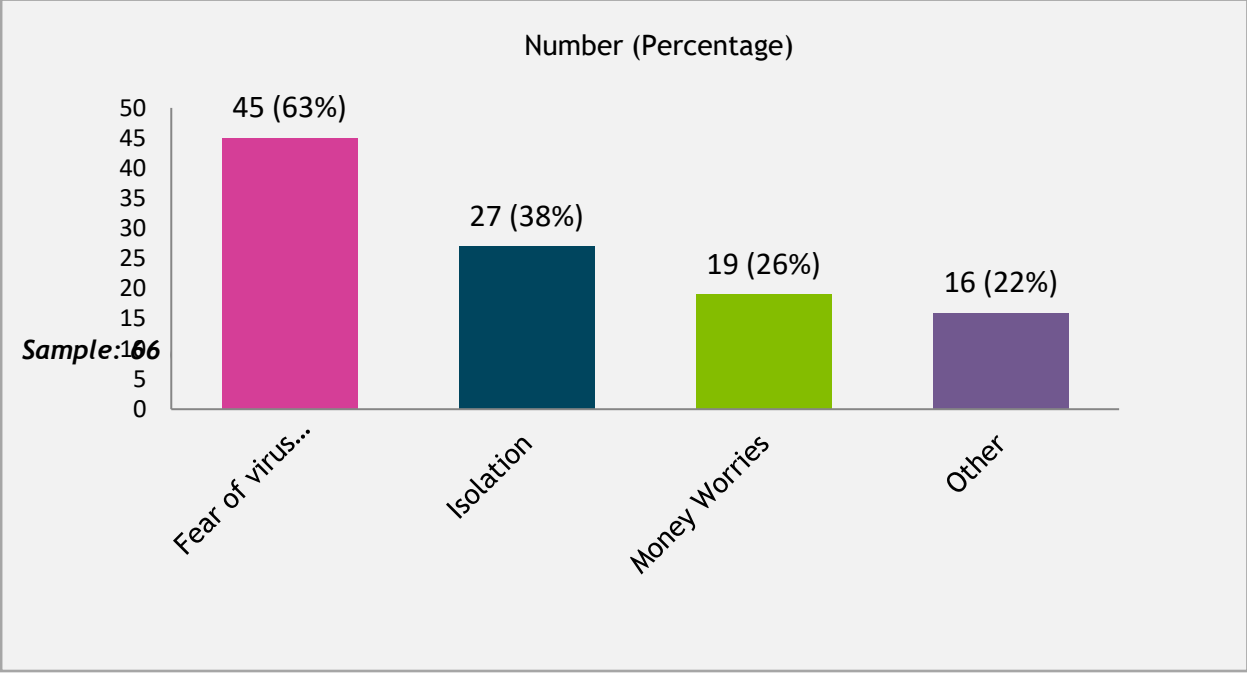
One person from FAWA said she felt frightened as she lives alone. She said that although she has a sister and a brother in the UK, both live outside London. She said the news made her fear for her life. She told the interviewer that she constantly thought about her son, who was stabbed 14 years ago in Hammersmith. She said she thought she would die alone in the house because evil people took her boy away from her.

Another person we spoke to through FAWA said self-isolation affected him badly. He said he found himself sometimes screaming at home because of the anxiety, often for

no reason at all. He told the interviewer that he is waiting for an appointment with a psychiatrist.

The Breathe Easy survey asked people about the causes of their stress over the period:

Q28. What are your main causes of stress?



The largest cause of stress, by some margin (63%) was fear of contracting the virus. Lesser but still significant causes included isolation (38%) and money worries (26%). 22% of respondents cited a wide range of 'other' indicators.

The data here is largely similar to what we have been told across our engagement work. Fear of catching the virus has been the major worry of most of the people we have spoken to. The difficulties of isolating, and fear over money, have been other recurring issues.

A further issue highlighted in our engagement with LEGS, which is likely to become relevant again later this year, were worries over leaving lockdown and the safety of leaving the house once the country begins to open up.

What has really stood out in what we are hearing from residents is how many people have noted minor deteriorations in their mental health. This is going to have an impact in the present time but will potentially also have longer term impacts on residents' wellbeing into the future.

Stigma and alternative information

This was a major, and very important, finding from our work with FAWA. Some participants told us about the stigma attached to contracting COVID-19. One

participant talked of the social stigma of having family members who have died from COVID-19.

For instance, one participant in our engagement work with FAWA told us that she still suffers from stigma as people say that her husband died of COVID-19. She said other people say she killed her husband, which is not true.

We also learnt from our engagement with FAWA of the prevalence of alternative information shared via WhatsApp. This information often suggests false, alternative treatments which have no scientific and empirical background.

One person we spoke to, for instance, told us that her friend or relative who is her primary source of information on COVID-19 forwards her other people's personal recommendations. Some of the videos she received discussed drinking your own urine each morning as a cure for COVID-19. The participant said that she and her children did that for four days.

She said she believed that Bill and Melinda Gates will introduce vaccinations and that they would be dangerous for her family. She said she trusts traditional cures instead.

Although this was only really present in the work from FAWA, it is important to mention. We were told of a stigma associated with contracting coronavirus, and also of the fake remedies and conspiracies shared via WhatsApp. This, coupled with a lack of trust in 'official' channels of information, presents a problem that needs highlighting and addressing.

Next steps

Publications on our findings from each of these discussion groups, surveys and interviews will be available in November 2020. This will include recommendations for addressing some of the difficulties that we heard from people

We are continuing to engage with local residents, and we are currently planning further discussion groups to hear more from BAME communities.

3. Young people's mental health survey - Initial Findings Reports

<https://healthwatchcwl.co.uk/young-healthwatch-westminster/>

The role of education

From our outreach work, young people have talked about their frustration at how the pandemic was handled in schools and have called for clearer messaging from teachers and beyond, including for further provision for mental health first aid-trained staff and peers. Young people we have spoken to have reported feeling 'hopeless' and 'lost' over their futures.

Mental health

Through our survey for young people we heard examples of a stigma relating to the term 'mental health' and confusion around what it means - it is often conflated with 'mental illness' and we are hearing that young people are uncomfortable talking about it in many instances.

In our survey, we listed 8 services and a worrying 35% of respondents had not heard of any of them, suggesting that more work is needed to educate young people on the local and national mental health support that is available (in school and out of school). Of our survey respondents, only 40% had heard of CAMHS and the positive impact it can have. Young people have told us that access should be reviewed, including the referral system.

From our outreach we have found that young people do not know that their GP can support them anonymously with their wellbeing, or they feel disinclined to contact them, suggesting that more comprehensive campaigns to address this, primarily in school would be useful.

Body image and social image were found to be two of the most stressful parts of young peoples' lives in our survey, reminding us that young people continue to have other stresses in their lives that have been added to by COVID-19.

From our survey we found that young people from BAME backgrounds have been disproportionately affected by COVID. Our survey revealed that one quarter of young people from BAME backgrounds had reported losing a member compared with only 7% of those from non-BAME backgrounds, which will have implications for how to offer support in the present time and into the future.

Next steps

We are continuing our engagement with young people, including providing opportunities for them to speak directly to experts about their concerns, through webinars in partnership with Connecting Care for Children at Imperial College Healthcare Trust and Kooth. We are now exploring how to roll this approach out more widely to reach more young people through partnerships with schools.

4. 2020 Vision: Your Experience Matters – Shaping the Westminster Borough Plan workshop

This Zoom workshop was attended by 55 **patient representatives**, healthcare professionals, **commissioners** from CLCCG and representatives from **local community groups** and the **voluntary sector**.

It included opportunities for participants to:

- hear about the detail of the Westminster Borough Plan
- contribute their experiences through an open discussion and breakout sessions
- make suggestions for next steps in engagement.

Jules Martin, Managing Director of CLCCG presented the latest version of the Borough Plan. Healthwatch CWL presented people’s experiences reported to us through our survey and focus groups.



A visual recording of the workshop has been shared in a blog on our website and through social media

The common feeling from the workshop was that the Coronavirus pandemic has magnified pre-existing problems within the healthcare systems such as the need for better **communications** and how the **lack of integration** of services makes it harder to get the care they need.

Participants also highlighted the need for **behavioural changes** to keep people safe and a greater focus on **prevention** to keep people well in the anticipation of a second wave.

Specific concerns were also raised about **vulnerable** groups of people, as well as support for those who are **digitally excluded**.

What people said on the day

There were many examples where people said that they got the support and care that they needed – including a patient who had been very ill with COVID-19. However, there were many issues raised that Central London CCG will be able to use to ensure that their Westminster Borough Plan meets the needs of residents.

Integration of services

“For 3 years we have been told we are sharing information and we are in safe hands and they can get access to files if anything happens. Social care knows nothing of what is happening”

“I hope in my lifetime, I will be able to comfortably walk into, or call, or go online, to a doctor or consultant just by clicking my name and birthdate and access my records.

Can they briefly look at my background that might affect the new issue I am coming in with?"

Communications

"I know more about the cycle lanes than I know about the GP"

Prevention and behavioural change

"The lower-paid workers are mainly women. A lot of the BAME community. They have to work 3-4 jobs to pay their expenses and financial burdens, and they were the most failed, because in the care homes, they're having to go from job to job"

Shielding, people with long-term health conditions and those identified as vulnerable

"Vulnerable people are still vulnerable. You don't become un-vulnerable all of a sudden"

"Having delays in appointments for conditions that have been with them for some time that have been affected by COVID. COVID is being used as an excuse and long-term illnesses are getting worse"

Digital access and digital exclusion

"There are people who really can't cope with a phone conversation. The NHS needs a more flexible approach to assess it. The GPs know their patients, they can do it easily, so they can sort out when it's necessary to have face-to-face appointments, rather than a blanket approach of Digital First for everybody"

"What I am trying to highlight is even with the long-term health plan of what's been outlined is for people to have options, and if CCGs could design services that smoothly provide those options on how people engage with services, that would be great"

5. General engagement

We have continued to hear from residents about their experiences of accessing healthcare and two themes have begun to emerge that we would like to draw attention to – access to primary care and oral health.

Engagement in primary care

GP Medical Contracts require all GP practices to engage with their patients and work together to improve services for all registered patients. We have been supporting GP practices in RBKC and Westminster with setting up and establishing their Patient Participation Groups (PPGs) to meet this requirement.

During the first lockdown many GP practices suspended their PPG activities. However, NHS England informed GPs in July 2020, that they should restart practice-based patient engagement and advised to move PPG activities online.

We contacted PPG members in August/September asking how their PPGs are doing.

Our findings show that are very few GP practices continued to collaborate with their PPG throughout the lockdown to ensure effective communication with practice patients and offering mutual support.

Most PPG members reported that their practice meetings have stopped and that communication with practice staff is very difficult or non-existent.

“The PPG has ceased to function during the months of the pandemic, and I am not even aware of how the practice has coped. I've had one telephone consultation with Dr that wasn't very satisfactory but that may be more to do with the coronavirus situation than the fault of the practice... “

This PPG Chair from this practice has now resigned from duties and this is not an isolated case.

In addition, we have received no evidence that patient engagement is happening at Primary Care Network level.

We recognise that GP practices are under a lot of pressure, arguably even more now than at the beginning of the pandemic. However, patients are also feeling more anxious, frightened, unsafe and, in many cases, misinformed. Many patients delayed seeking help during the first wave of COVID-19 and now they are seeking help with more complex and more urgent issues.

Our concern is that if communication and engagement with patients does not improve, pressures, anxiety and hostility will increase on both sides. We have met with the CQC inspectors who asked for our advice how to monitor patients' engagement in GP practices as they are also concerned that this is not happening.

To support GP practices in both boroughs, we are offering access to digital engagement tools: Zoom and SurveyMonkey platforms. We will continue to monitor the situation and offer support and encouragement for GP practices to meet their patient engagement requirements.

Initial findings from our paper surveys

We are focusing on hearing from people who do not have access to, or who choose not to use, digital platforms, to hear their views and experiences of the Coronavirus and to support them access the right information to find the help they need. Our volunteers and partner organisations are supporting us to distribute these to residents. We have also targeted people living in sheltered accommodation, to ensure that we are hearing their experiences.

To achieve this, we produced:

- **Paper copies of the Coronavirus: Your Experience Matters survey** with **free-post** envelopes.
- **Free-post postcards** for people that want to send us only a comment.
- **Paper copies of resource packs** with useful contacts for support such as health, mental health and finances

We are beginning to receive completed responses and are in the process of analysing them. The main themes that we are picking up are:

- Confusion regarding messaging from the Government
- Many respondents report finding it difficult to stay indoors due to their housing conditions, as well as, feeling isolated and lonely
 - People living in cramped conditions, with no balcony or outdoor space.
 - Loneliness, however some are able to keep in contact with friends and family over the telephone
- Some people experienced cancelled GP appointments
- Annoyance at other people not socially distancing or wearing a mask
- Reasons for not using technology include:
 - It is too expensive
 - Don't know how to use it.
 - Not used to it.
- Majority of respondents so far have told us, 'things could have been better if we had lockdown much sooner and there was more testing available'.

Oral health

During the first lockdown, many Dental Practices temporary closed their practice. Residents told us through our 'Your Experience Matters' survey that they were not able to make appointments with their dentist and that they did not know where to go.

Following our request for more information for patients, WLCCG created an information leaflet explaining how to access urgent dental health. This leaflet was adopted by the NW London and shared with the General Dental Council.

However, COVID-19 created a backlog for routine and urgent dental care treatment.

In September – October, patients have been telling us that they are not able to get appointments with NHS dentists. We have also found that many NHS Dentists will only deal with urgent care needs and that routine appointments are suspended.

We are hearing similar experiences from other local Healthwatch across England. If this is not addressed, this will become more acute in near future.

More information is needed to publicise routes to NHS urgent dental care and more support is needed for patients who are looking for appointments with NHS dentist.

6. Partnership with National Institute for Health Research Workshops on BAME communities and COVID-19 vaccines

In September 2020, we worked in partnership with the National Institute for Health Research to gain a better understanding of why people from Black, Asian, and Minority Ethnic (BAME) groups were less likely to participate in health research than people from White communities. We focused in particular on vaccines trials and COVID-19.

We held three focus groups with FAWA, Positive Network, and WAND. We have a further focus group planned for November with People Arise Now.

Across the three focus groups there were many reoccurring themes, the main themes can be grouped into two groups, Communication and Knowledge.

Communication

Across the focus groups communication, particularly from the Government brought up feelings of distrust and confusion. Unclear messaging with regards to the outbreak and vaccinations fuelled these feelings. However, during the conversations there was some underlining notes of continual distrust of the government. An alternative avenue to receiving information that was mentioned was receiving information from the NHS as a trusted source.

Members of some focus groups, noted that a way of getting information into the community was by going into schools whilst being mindful of not targeting BAME communities.

Knowledge

Lack of knowledge regarding COVID-19 and vaccines was a major concern for all participants. Participants felt that there should be better understanding of the virus, vaccinations, research trials within communities. Participants suggested that improved communication from the Government or a trusted body such as the NHS, would people to participate in the research and share this with their peers.

The prominent questions that participants felt needed answering were:

- What is the virus and how does it affect people?
- Why are BAME communities most effected?
- What are vaccinations and how do they work?
- What are the possible side effects of vaccines?
- Vaccines normally take many years to develop, so why is this vaccine is being created in a few months?
- Do we know the long-term effects of the vaccine and COVID?
- Does the vaccine effect those with comorbidities adversely?

Although the focus groups were focused on gaining a better understanding of the thoughts and feelings from the local BAME communities, it was also a space for participants to have some of their questions answered and to ease a few of their concerns.

Towards the end of the meetings possible solutions to counter misinformation and to improve communication were discussed, the prominent points were:

- immunity in the community
- equipping local leaders with the correct information, so that they can pass it on within their community
- putting information within the community such as, in schools and pharmacies

Healthwatch Central West London (HWCWL) will continue the work of listening, engaging and sharing the experiences of local people. We are pleased to be working with the local authority public health, adult social care and communities department as well as NHS colleagues to ensure that this evidence is reaching and supporting decision makers.

Further information, reports and resources are available on the Healthwatch Central West London website <https://healthwatchcwl.co.uk/>