# <u>UK-Malaysia joint statement at Joint</u> <u>Committee</u>

News story

UK-Malaysia Officials agree to elevate Joint Committee on Trade and Investment Cooperation to a ministerial level engagement



On Thursday 3 November 2022, the UK and Malaysia convened the second Joint Committee on Trade and Investment Cooperation in London. The first Joint Committee meeting was hosted virtually by Malaysia in 2020.

His Majesty's Trade Commissioner for Asia Pacific, Natalie Black CBE, cochaired the meeting alongside Deputy Secretary General (International Trade) for the Ministry of International Trade and Industry (MITI) Malaysia, Mr Hairil Yahri Yaacob.

In recognition of the importance of the trading relationship, the meeting also formalised the intent to elevate the Joint Committee to a Ministerial led Joint Economic Trade Committee (JETCO). The new JETCO will help to promote and enhance trade, investment and economic cooperation linkages, including addressing trade barriers affecting business between the two countries. The first meeting of the UK-Malaysia JETCO is expected to be held in autumn next year.

At the meeting of the Joint Committee, the UK congratulated Malaysia on its ratification of CPTPP. The UK provided an update on their accession status and Malaysia presented on the benefits of CPTPP when it enters into force for Malaysia on November 29, 2022. The CPTPP will increase the potential for further trade between the UK and Malaysia, contributing to the shared prosperity of both countries through the creation of new opportunities for businesses and investors.

The meeting also brought together six working group co-leads to report on the progress of their bilateral cooperation in agreed priority areas. In addition, there were presentations from the UK on teacher training and on Malaysian sustainable palm oil initiatives.

# <u>Civil news: opportunity in new year</u> <u>for civil contract work</u>



Providers interested in working on our extended 2018 civil contracts will be able to apply for face to face work in the new year.

### Why is this happening now?

Since announcing in October 2022 that we are extending 2018 civil contracts, we have received expressions of interest from organisations. They have indicated that they would welcome the opportunity to apply for work on the 2018 civil contracts.

### What will happen next?

We are now working on our approach to allow tender applications for work on the extended contracts. We will publicise information on the process for making applications in the new year, 2023.

### Further information

Extension of civil contracts until 31 August 2024

Published 3 November 2022 Last updated 7 November 2022 <u>+ show all updates</u>

1. 7 November 2022

Clarification that all suitably qualified legal practitioners will be welcome to apply for work on extended 2018 civil contracts.

2. 3 November 2022

# <u>COVID-19 testing in a deprived local</u> <u>authority: Hackney, London</u>

### **Executive summary**

This case study describes the obstacles experienced by Hackney Council and public health team in supporting testing, as well as some of the local responses implemented to overcome these challenges.

The following themes emerged.

<u>Coronavirus (COVID-19) testing hesitancy</u> is often linked to the financial and practical impacts of self-isolation.

In an effort to support disadvantaged communities, Hackney Council has established a close cooperation with voluntary and community services. According to interviewees, third sector organisations have been an effective channel to build engagement within the most deprived wards.

<u>Digital exclusion</u> has been identified by Hackney's public health team as a significant barrier to testing.

Digital exclusion may result from either digital poverty or a lack of technological skills. Local initiatives to tackle digital exclusion have included offering 'no-appointment' testing and developing non-digital channels, such as telephone helplines.

A persistent <u>lack of understanding of COVID-19 transmission and the benefits</u> <u>of testing</u> has been described as one of the difficulties experienced by Hackney Council in promoting testing.

Interviewees attributed the lack of understanding or awareness around COVID-19 to low levels of literacy and education, language barriers and untailored communication materials.

<u>Mistrust and disengagement</u> were described as one of the barriers to testing and vaccination among disadvantaged groups.

According to interviewees, an apparent lack of trust in government and official bodies within these groups can result in lack of engagement in local and central authorities' initiatives. The public health team in Hackney has addressed this issue through collaborating with third sector organisations and the Community Champions, who have played a key role in disseminating information to residents who might not access it through mainstream channels.

Another reported barrier to increasing testing rates was the <u>lack of granular</u> <u>analyses of socio-demographic and test and trace data</u> conducted locally.

This has been described as a hindrance to the effectiveness of testing services in Hackney. A more detailed examination of local data would allow more targeted interventions.

The most salient aspect of Hackney's response to the pandemic was to establish <u>close cooperation with the third sector</u>.

This helped to reach and engage residents in more deprived areas of the borough.

### About this report

Hackney is one of London's most deprived boroughs (1) and a highly ethnically diverse local authority. In this qualitative study, we explore the challenges faced by Hackney public health team to develop and promote COVID-19 testing. We also describe some of the local initiatives implemented to address identified barriers to testing.

This study is presented as follows: section 2 sets the research context including Hackney's socio-demographic profile, its level of deprivation, COVID-19 mortality rates and available testing services. Section 3 describes the barriers to testing reported by Hackney public health team during in-depth interviews. Section 4 outlines the local responses put in place to address these barriers. Finally, we conclude this paper with some general recommendations.

In this report, the terms 'disadvantaged' and 'deprived' are used interchangeably to refer to groups or individuals experiencing socio-economic hardship.

### Methodology

This qualitative study draws on in-depth interviews with 4 key members of the Hackney public health team in March and April 2021. Interviewees are cited as Participant A, B, C or D.

Each interview was conducted remotely (via telephone or videoconference), audio-recorded and lasted between 50 and 60 minutes. Prominent themes were identified across the 4 interviews using bottom up thematic analysis. Interviews provided valuable insights into the barriers experienced by stakeholders in the local authority in developing and promoting testing during the COVID-19 pandemic. Additionally, we used quantitative evidence from NHS Test and Trace data management systems to determine levels of testing in Hackney and describe the local context.

This study was conducted in line with government social research guidance  $(\underline{2})$  and research participants provided informed consent before data collection.

This report was reviewed and approved by the research participants.

The report was completed in July 2021.

### Study limitations

While much can be learned from a case study, findings from one locality are not generalisable  $(\underline{3})$ . This research draws on a small sample of participants who shared their personal experiences of developing and managing testing services within their local authority.

This study focuses on barriers to testing as reported by the local authority and does not involve any direct insight into the experiences of residents.

With these limitations in mind, the purpose of the present case study is not to generalise results to the wider population. Instead, it highlights some of the potential challenges faced by local authorities during the pandemic.

### Hackney socio-demographic and equality profile

This section describes Hackney's demographic and socio-economic profile and provides data on COVID-19 mortality rates and testing services.

### A young population

The London borough of Hackney has an estimated total population of 281,000 residents with an almost 50:50 male to female ratio. It has a relatively young population with a quarter of its residents under 20. The proportion of people between 20 and 39 years is 40% and those aged over 55 make up only 16% of the population. The median age in Hackney is 32, compared to 35.8 in London and 40.4 in the UK overall ( $\underline{4}$ ).

### The sixth most ethnically diverse borough in London

Hackney is a culturally diverse area, with well-established Caribbean, Turkish, Kurdish, Vietnamese and strictly orthodox Charedi Jewish communities. A large group of more recently arrived residents include people from Europe, North and South America, Australasia and African countries (<u>5</u>).

The borough's increasing diversity currently marks it out as the sixth most ethnically diverse borough in London. Table 1 gives the proportion of Hackney's population in different ethnic groups, using data from the 2011 census.

Hackney's White British ethnic group represents 36% of its total population, compared with 45% for London and 80% for England. The second largest ethnic group in Hackney is the African/Caribbean/Black British group (23%), among which Africans – more particularly, the Nigerian community – are the largest group within this category. Kings Park and Chatham wards both fall within the top 20 wards in England with the highest numbers of Nigerian residents. The third largest ethnic group in Hackney is Other White (16%) which has shown a 60% increase since 2001. Hackney has large and long-established Turkish, Kurdish and Turkish-Cypriot communities who fall within the Other White ethnic category and total 6% of the population. Other White residents also include the second largest Charedi Jewish community in Europe, as well as a large proportion of people from Eastern European countries, particularly Poland.

### Table 1. Ethnic groups in Hackney

| Ethnic group   | 9 <sub>0</sub> |
|--|----------------|
| White English/Welsh/ Scottish/Northern Irish/British   | 36.2%          |
| White: Other White                                     | 16.2%          |
| Black/African/Caribbean/ Black British: African        | 11.4%          |
| Black/African/Caribbean/ Black British: Caribbean      | 7.8%           |
| Other ethnic group: Any other ethnic group             | 4.6%           |
| Black/African/Caribbean/ Black British: Other Black    | 3.9%           |
| Asian/Asian British: Indian                            | 3.1%           |
| Asian/Asian British: Other Asian                       | 2.7%           |
| Asian/Asian British: Bangladeshi                       | 2.5%           |
| White: Irish   | 2.1%           |
| Mixed/multiple ethnic group: White and Black Caribbean | 2.0%           |
| Mixed/multiple ethnic group: Other Mixed               | 2.0%           |
| Asian/Asian British: Chinese                           | 1.4%           |
| Mixed/multiple ethnic group: White and Black African   | 1.2%           |
| Mixed/multiple ethnic group: White and Asian           | 1.2%           |
| Asian/Asian British: Pakistani                         | 0.8%           |
| Other ethnic group: Arab                               | 0.7%           |
| White: Gypsy or Irish Traveller                        | 0.2%           |

Source: 2011 census

### **Religious** profile

Thirty-nine percent of Hackney's residents are Christian. This is a lower percentage than the figures for London (48%) and England (59%). Hackney has a higher proportion of people of the Jewish and Muslim faiths than London and England.

### Level of deprivation

The 2019 Index of Multiple Deprivation (IMD) ( $\underline{6}$ ) shows that Hackney is the London borough with the highest proportion of lower super output areas (LSOAs) within the most deprived 10% nationally (11% of its LSOAs). It is also the 78th most deprived local authority out of 339 in England. Hackney ranks particularly highly on the child poverty index (41%, the third highest in London), as well as poverty and isolation among older people ( $\underline{7}$ ).

The job density in Hackney – that is, the ratio of total jobs to population aged 16 to 64 - is 0.77, compared to 1.03 for London and 0.87 for the UK ( $\frac{8}{2}$ ). In March 2020, 10% of Hackney's working age population claimed out-of-work

benefits, the highest rate among all London boroughs. The number of out of work benefit claimants in Hackney is particularly high and there is a high level of in-work poverty. Hackney also has the highest rate of working-age adults who have no qualifications: 11% compared to 7% for London overall.

In addition to a high level of unemployment, the city has a difficult housing market, with rent for an average one-bedroom dwelling in Hackney standing at 61% of median pre-tax pay, one of the highest ratios in London. The borough also has one of the highest rates of households in temporary accommodation (26.8 households per 1,000 compared to an average of 16.6 across London) ( $\underline{9}$ ).

The high level of deprivation in Hackney is reflected in a lower life expectancy than the London average, especially for males, whose average life expectancy at birth is 78.8 years compared to 80.5 for the whole of London (5).

### Wealth disparities within Hackney

Like other boroughs across East London, Hackney has undergone a process of gentrification (10) – the influx of more affluent people and businesses resulting in an increase in property values and the displacement of earlier, usually poorer residents. Gentrification is a factor in disparities in the local authority and has impacted local community dynamics by creating concentrations of more established, poorer, and mostly ethnic minority groups (notably Caribbean, Vietnamese, Charedi Jewish, Turkish/Kurdish), particularly in south and west Hackney. The more recent demographic includes an incoming of wealthier middle class able to afford the private housing market. The disparities, perceived by some residents as having created '2 Hackneys', have led to increasing tensions which were further exacerbated over the course of the lockdown, as ethnic minorities were disproportionately affected by COVID-19 (11).

A total of 16 neighbourhoods in Hackney are among the 10% most deprived in England, including, among others, Wick Streets bordering on the River Lea, parts of Clapton, Manor House and Hoxton. More affluent areas in Hackney include Haggerston, Victoria, Dalston, Lordship and Hackney Central where average private property prices have passed the £500,000 mark. Wealth disparities within the borough were reflected in the COVID-19 prevalence rates during the first and second waves of infections, more deprived areas having been more severely hit.

### **COVID-19** in Hackney

### COVID-19 mortality and positivity rates in Hackney

Hackney was especially hard-hit by high COVID-19 mortality rates at the onset of the pandemic (ranked third of all local authorities in England between 1 March and 31 April 2020) (14). Comparison with the 5-year average mortality rate for City and Hackney (see Figure 1) provides an indication of how the pandemic has affected mortality locally. The figure is a column chart with the Y-axis presenting the time period between March 2020 and February 2021 and the X-axis representing the number of deaths. The light green columns represent deaths arising from causes other than COVID-19, the dark green columns represent deaths due to COVID-19, the orange line represents the average deaths measured between 2015 and 2019. After a sharp increase in COVID-19 related deaths between March and mid-May 2020, mortality rates went back to levels similar to the number of deaths in Hackney over the past 5 years. In January 2021, the borough experienced a second wave of COVID-19 deaths, which was lower than the peak in April 2020.

# Figure 1. Mortality rates in Hackney and City between March 2020 and February 2021

Source: ONS

### Intra-borough variation of COVID-19 positivity rates

Data on prevalence of COVID-19 during the highest peak of the first wave of infections, week of 7 April 2020, and during the second wave, November 2020, shows differences across wards, with the highest number of cases in Brownswood, Homerton, and Hoxton West. These 3 wards have a higher proportion of residents in social housing, lower levels of qualifications and a more ethnically diverse population, relative to the borough averages. Generally, higher positivity rates have coincided with higher levels of deprivation.

### Available COVID-19 testing services in Hackney

COVID-19 testing capacity has been increasing consistently across the UK since March 2020. The first symptomatic test centre located in Hackney was launched in September 2020 and testing capacity in the borough was built up gradually.

Hackney Council has also been running local test and trace operations complementing the national system. Drawing on local data, Hackney Council staff have been offering guidance to local residents regarding contact tracing and self-isolation (<u>15</u>).

### Reported barriers to testing in Hackney

This section describes some of the challenges in increasing and promoting COVID-19 testing in the local authority. According to interviewees, the high level of deprivation and the multitude of ethnic backgrounds found in parts of Hackney contributed to shaping the borough's experience and management of the COVID-19 pandemic.

# Inability to self-isolate if tested positive – financial and practical impact of self-isolation

Interviewees reported that the main barrier to testing within disadvantaged groups was the concern of having to self-isolate following a positive COVID-19 test. Reluctance towards getting tested was, therefore, not directly

related to testing itself, but to a range of financial and practical considerations linked to self-isolation. For many disadvantaged residents, self-isolation had a direct impact on remuneration and repeated periods of self-isolation may be a threat to their employment security. Other practical concerns included caring responsibilities for children and older relatives.

It's not only the financial issues that are the problem. Some people are not going to lose money, but they are concerned that, especially if they've been through several periods of selfisolation, if they've been someone's contact, they may be concerned about their job. There are a lot of barriers for people. And there are some other practical issues, like we did a survey recently, and they found out that some people only had 2 days' worth of food in the house. People had pay as you go gas and electric meters. So, if your gas runs out in the middle of your ten days, you're supposed to just stay at home in the cold? Or how are you going to go and top it off?

### (Participant A)

Self-isolation means people can't budget because they get universal credit once a month and they can only manage little and often. They can't ask somebody to go to the shops for them. They don't have those resources or maybe they feel uncomfortable doing that. So, if they're told if you take this test, you'll have to self-isolate for 10 days...

#### (Participant B)

#### Lack of awareness of available support from central and local authorities

Where practical support during self-isolation was available from the council, it was noted that residents were not always aware of it. For instance, vulnerable people may not have known about the one-off financial support of £500 for workers who would lose earnings as a result of self-isolation. Moreover, some parents and guardians on a low income may have been unaware that they were also eligible to a £500 payment when taking time off work to provide childcare where their child had to self-isolate.

Participant A described how a lack of understanding of the role of local authorities and the available support network may contribute to residents' reluctance to getting tested for fear of having to self-isolate:

When they talk to someone from Test and Trace, they ask, "Do you need any help?" and they say, "Yeah," they put them in touch with their local council. Well, their local council wasn't going to look after their mother who lives 30 miles away. So, not everyone understands the system well enough to know that they can call other councils or to say to their local council, can you contact that council because their mother is on her own and blah blah do you know what I mean?

(Participant A)

### **Digital exclusion**

Interviewees reported that a large proportion of Hackney residents did not have access to reliable broadband or to a technological device that would allow them to easily book a COVID-19 test or simply look for relevant information on testing. Participant A summed up the challenges faced by digitally excluded groups as follows:

A lot of people in Hackney who, to use the jargon, are in digital poverty, don't have good access to the internet, or they don't have a device that would enable them to do the booking very easily. So, a lot of our residents, for example, wouldn't be at home with broadband. But they might have a smart phone, but then, to do the booking online, how much of their data are they going to have to use to do that? A lot of people also don't have those all-inclusive plans, they're on these pay as you go phones and so that actually becomes a very expensive undertaking just to book a test.

(Participant A)

With the rollout of home testing, digital exclusion remains one of the main challenges to increase testing within certain communities:

For example, the Charedi community, really still struggle registering kits. And because of digital divide and their cultural and religious observance, doesn't include access to the Internet for many people. And there are quite a number of pockets of deprivation in the north of the borough.

(Participant B)

# Lack of understanding of COVID-19 transmission and the benefits of testing

A prominent theme across all interviews was a perceived persistent lack of understanding around COVID-19 transmission and the benefits of testing. This was said to remain a significant barrier to testing within deprived areas:

People are struggling to understand why. If you think of the COM-B model\*, in health psychology and behavioural insight, you have opportunity, capability and motivation. We have lots of opportunity

and capability now. Brilliant. But if people don't want to use them...

(Participant B)

\*The COM-B model proposes that there are 3 components to any behaviour: capability (C), opportunity (O) and motivation (M).

As described by interviewees, lack of understanding may be partly attributed to low literacy, education and English proficiency rates, commonly found in the most deprived areas. One interviewee reported a high level of confusion around the objectives and benefits of rapid testing, and how it can coexist with vaccination.

I think the key element, and this is what I'm banging my head about, it's basically, we don't have strong enough comms from central government on rapid testing and getting people to understand why it's necessary. I was on a call this morning with a colleague and he said I don't understand why we need to test twice a week. So, I tried to explain the infection curve with the incubation period and level of infectiousness.

(Participant B)

One of the problems we have, at the moment, is that people don't really get rapid testing. They don't get why it's twice a week, they don't get why if they've had the vaccine, they need to do a rapid test. They just don't get it. It doesn't matter if we do a 3page spread in the Hackney Gazette. Some people won't see it. It's not penetrating enough.

(Participant B)

### Lack of trust and engagement

Lack of trust in central and local authorities has been reported as a noteworthy, although less significant, obstacle to testing in disadvantaged communities.

You've got to understand that those structural inequalities are built on years and years of having, of people feeling they can't trust the government, that they can't trust any institutions. They're always marginalised and things are difficult to navigate, whether it is DWP, or trying to get a job, or anything, trying to maintain housing. These are just built in how people relate to you.

(Participant B)

### Access to test sites

According to both test uptake data and the interviews, lack of access to test sites was a substantial barrier to testing at the earlier stage of the pandemic. Regional centres requiring substantial road travel from the borough were incompatible with Hackney's low car ownership rate: only 35% of households in the borough own a car (<u>16</u>). As Participant A said, "When the testing started to develop the more local offer, that was an enormous improvement".

Figure 2 below is a line chart demonstrating uptake of testing over a particular time period with the area below the line coloured in. The X-axis represents the time periods over which appointments for testing were made and the Y-axis represents a measure of the number of tests performed per capita which has been measured over an average of 14 days. The results show a consistent rise in first rapid testing – lateral flow test (LFT) – uptake in Hackney, with a sharper rise since mid-December 2020, coinciding with the appearance of the LFT site in the borough.

Figure 2. Time series LFT uptake per capita, Hackney residents, 1 September 2020 to 28 January 2021

Source: NHS Test and Trace data management system

### Lack of suitable spaces for test centres

Finding adequate spaces to establish testing sites, in accordance to standard operating procedures, was challenging for the local authority. While they have endeavoured to set up test centres in locations that would both be most convenient to disadvantaged residents, and address high infection rates, they were not always able to do so. For example, it was essential for the local public health team to set up the third local test site (LTS) in the north of the borough in order to address high COVID-19 prevalence within pockets of deprivation. Sandford Court, located in a housing estate, was selected, as the only available space in the area. The site was apparently unpopular and test uptake remained low.

And the third one (LTS) we put in the north of the borough, in Sandford Court. And the only place we could put it was in right the middle of a housing estate. That was unbelievably bad. And to be fair, it looks awful, and you can totally see why residents felt really upset about that. Basically, it was the only space that we had... eventually, the Hackney Borough Command Centre, did the brilliant job of finding the Arriva Bus Garage that we now use.

(Participant B)

Moreover, they argued that establishing testing in the wrong setting has had a negative impact on residents' trust in the local authority's ability to manage the pandemic.

It's your building block in everything you do. If you mess up and no one can trust you, you've completely started off on the wrong foot.

(Participant B)

Sandford Court LTS was later replaced with what was reportedly seen locally to be a more suitable location.

### Limited data on communities' geographical distribution

While local authorities and NHS Test and Trace have made important efforts to strategically set up testing sites to provide an adequate coverage of all communities, their work was reportedly hindered by a lack of granular understanding of the geographical distribution and testing rates of various ethnic and religious communities. For instance, and as previously described, the Other White Other ethnic group in Hackney includes a large Turkish community, the largest Charedi Jewish community in Europe, Gypsy travellers, as well as a high number of residents from Poland and South America. Our interviewees suggested that the existing local data did not allow them to locate these different groups and offer more targeted communication and testing services.

Our data isn't showing us at ward level, by ethnic group. We might get age, but we don't get by ethnic group. But also, it's very broad ethnic groups. That's so generic. We've got at least 12 different African communities, not to mention the South American communities. And then 'Other', we've got the Charedi Jewish community, the Turkish community, but they're not the same. How do we know what's going on with the Gypsy community for example? Where should the pop-up clinic be located? And it's hard to communicate with people if you don't know where they are.

(Participant A)

Additionally, interviewees report the absence of detailed local test and trace data that would allow them to identify communities or areas where contact tracing is low.

We input that data into CTAS\* to then lose it, and not understanding the wider picture. It's then difficult for us to target particular groups and have more targeted initiatives. After people get a rapid test, what do they do? What things could we do to make sure that they are more likely to engage with test and trace and share their contacts? (Participant D)

\*CTAS stands for Contact Tracing and Advisory Service, the national IT system for recording information about people who have tested positive for COVID-19 and their contacts.

### Local initiatives addressing barriers to testing

In this section, we describe local initiatives implemented by the Hackney public health team in response to the barriers to testing they identified. While we do not provide any evaluation evidence of the effectiveness of these interventions, we report interviewees' rationale for these measures and their perceptions of their potential impact on the community.

### Collaborating with the third sector

Members of the local public health team described the council's collaboration with Hackney Voluntary and Community Services (HVCS) as key in reaching disadvantaged and disengaged groups in Hackney.

### Building trust and engagement through a bottom-up approach

Interviewees described the council's close cooperation with third sector organisations as an assets-based approach that draws on both local government resources and those of the voluntary and community sector. This bottom-up approach was intended, among other objectives, to support testing among residents in the borough's most deprived areas. According to Participant B, this has led to a positive 'ripple effect' in the community.

In December 2021, COVID-19 funding made available to the local authority allowed the council and public health team to offer grants to third sector organisations and train volunteers on a range of topics including health and safety measures, the availability of testing, how to access testing, the contact tracing system, available support during self-isolation, as well as effective communication and signposting.

As part of their effort to engage with local communities, Hackney Council and public health team launched a Community Champions Programme with the aim of communicating important public health messages to vulnerable residents, through trained volunteers and frontline staff. Participant D described the initial objective of the programme as follows:

In the beginning... it's very diverse in Hackney, the aim was to reach some of these communities, so the focus was on test and trace. That was our initial insight, that's why we looked at this. Because people were not understanding it, the test and trace system, didn't know what it meant, didn't know, you know, any sort of financial support. There was confusion, if you remember the beginning, especially for our population that are quite far from mainstream services. (Participant D)

The Community Champion programme was open to a variety of people with an active interest in helping the community.

If you're a champion, you could be working within a voluntary organisation, you could equally be someone who's working in the council, or just volunteering in the borough or just have an active interest. So, it's kind of a combination of these different things under one umbrella.

### (Participant D)

As a result of the programme, 110 public health community champions have been trained and deployed across 53 different local VCS organisations, expanding the local authority's capacity to provide information and support to disadvantaged groups. Each Community Champion covered a given neighbourhood or street, and had, therefore, a deep understanding of the experiences and challenges of local residents. Community Champions were reported to have played a key role in disseminating information on COVID-19 testing to residents who might not have access to information through mainstream channels. This included adults with learning disabilities, residents with a low level of literacy and those who need messaging translated into their native language.

Other interviewees saw the work of the Community Champions as paramount in building relationships of trust with the most vulnerable groups.

People don't know where to go. So, the Community Champions have become some sort of an independent but trusted source of information. And that's really important, especially where there are structural inequalities and people are not sure who they can trust.

#### (Participant B)

Furthermore, interviewees report that Community Champions have provided them with valuable insight into effective methods to communicate with local communities. One interviewee explained how volunteers had been systematically consulted before the production of communication materials.

We check our communication with them before we produce something new. For example, bubbles, people didn't understand that, especially our Turkish community. So, we made a new poster specifically for this, which we translated into Turkish. And also, our ambition is getting champions to share their resources a bit more. (Participant C)

### Third sector support with self-isolation

HVCS associations and Community Champions had organised an integrative support system that included aid to vulnerable residents during self-isolation.

We have a very strong food network which has been absolutely outstanding in its response, being able to, if somebody literally has no food, they will have a food parcel delivered to them for as long as they need it. It's been an unbelievable response from our community and voluntary sector.

(Participant B)

All interviewees report that self-isolation support provided by the third sector may have contributed to overcoming some of the practical barriers to testing.

### Tackling digital exclusion

Interview participants described the following initiatives put in place to address digital exclusion: walk-in testing, non-digital channels and practical support from Community Champions.

### Walk-in testing

Throughout the pandemic, walk-in testing was offered to all test sites during specific time slots. According to one interviewee, walk-in testing was popular among more disadvantaged residents.

We then looked at people who would book online and some people who don't have digital access. There's going to be language barriers. People will be quite anxious, people won't necessarily understand what's being asked of them, they won't understand that they were supposed to have booked. But it's more important that people turn up and get tested.

(Participant B)

While there has not been a formal impact evaluation of walk-in testing in the area, interviewees believed that it may have contributed to a higher uptake in some of the more deprived and ethnically diverse wards, such as Hackney Wick. Figure 3 demonstrates uptake of LFT by different ethnicities over time. Figure 3 is a line graph with different ethnicities represented by different colours of lines, the X-axis represents the time period over which testing appointments were made and the Y-axis represents uptake over a 14 day rolling average. Between the end of February and late April 2021, in Hackney Wick,

LFT uptake increased from 17% to 34% of total LFT testing within the African and Caribbean group, and from 4% to 8% for the Asian group.

Figure 3. Time series LFT uptake by ethnicity for Hackney Wick residents (1 December 2020 to 28 March 2021)

Source: NHS Test and Trace data management system

#### Non-digital channels (helplines)

The Hackney public health team had also implemented pragmatic solutions to support the Charedi Jewish community, in which use of the internet is limited due to both digital poverty and cultural practice. They set up a helpline linking callers directly to one of the test sites from which test operatives can assist them with registering their tests. The local authority was working towards establishing a local service with the sole purpose of recording test results for residents.

The next step is to set up a local service that will just record results for people. For the Charedi community, it's still difficult to record results. They can call the number and someone will record the results for them. We need to look at how we'll do that.

#### (Participant B)

Interviewees reported that another pragmatic solution to deal with digital exclusion had been to support the most disadvantaged residents through the Community Champion Programme. Community Champions had helped vulnerable residents with accessing the NHS Test and Trace website, booking tests on their behalf and acting as a trusted person to receive a notice.

### **Providing tailored and accessible information**

Interviewees said that a significant aspect of Hackney Council's work to support testing in the community had been the production of information materials adapted to the socio-demographic characteristics of its residents. They believed that better engagement could be achieved through information formats tailored to areas with low literacy rates and high linguistic variety. According to Participant B, a year into the pandemic:

Many people still don't understand how this virus gets transmitted, and we need to equip people with basics: How does this thing spread? Why do we test twice a week? Getting vaccinated doesn't mean you don't need to take a test.

### (Participant B)

Rather than providing information on testing as an isolated service,

interviewees highlighted the need to adopt an integrated approach to information materials demonstrating "how behaviours are linked, why they are beneficial to them, how they can apply them to their lives." (Participant B). Interviewees suggested the use of short information videos shareable through social media such as WhatsApp.

If there was like, an animation, saying the 'beat the COVID curve' or something, and a short video that could be shared on WhatsApp and social media. Some sort of visualisation, that allow people to say, 'Oh yeah now I understand.

#### (Participant B)

Things are still quite hard for Community Champions to take the sort of information that's been nationally produced and share it with the community. We're not really thinking in the minds of our residents. It's not a WhatsApp format, it's in a PDF, it's long, there's lots of bullets. Gov.uk guidance is not really accessible to our community. To be honest they won't look there. If you had a place on the website where you click and say, 'Right, you can send it to yourself in a WhatsApp,' that you could share those messages is one way to sort these things out. We need to put ourselves in the shoes of the Champions.

### (Participant C)

Interviewees reported that, with the rapid rollout of home and community testing, Hackney Council had directed significant effort into communication around regular asymptomatic testing. They highlighted the importance of communication aids, translated into languages spoken in the local community, and which can be easily distributed through community champions.

Community collect, the home kits are really brilliant. Well done to central Government to work with Innova to adapt their LFTs for home use. There's a comms campaign coming out soon from central Government about testing, that will be very helpful. The more they can produce, communication aids, in different languages, in different format, that we can share through community champions, social forums.

### (Participant B)

For us, the priority now is to make sure they become their own experts, training, swabbing aids, stuff like that [...] we now need to support the understanding about rapid testing, about registering the kits, going to the helpline, and so on... (Participant B)

### Conclusion

This case study shares the 'on the ground' experience of public health teams and highlights the complexity of being able to reach out to a diverse population, many of whom are vulnerable and at higher risk of adverse health and socioeconomic outcomes of COVID-19. A key learning is the potential value of collaboration with the third sector as a channel to engage disadvantaged and under-represented groups. Hackney Voluntary and Community organisations, alongside Community Champions, were seen to have played an essential role in disseminating public health messages and assisting vulnerable residents with testing and self-isolation. They were seen to have helped combat the issues of digital exclusion, language barriers, and misinformation and to have contributed to building strong relationships with local communities.

The case study highlighted complexities of a local public health response combining COVID-19 vaccination and testing. Participants described the need to provide accessible information on the link between testing and vaccination. They reported a high degree of confusion within the community around the need to continue testing while the COVID-19 vaccine is being rolled out. Their solution was to offer a one-stop information service linking testing, social distancing, self-isolation and vaccination.

### References

- 1. London Councils: Indices of Deprivation 2019
- 2. <u>GSR Professional Guidance Ethical Assurance for Social and Behavioural</u> <u>Research in Government</u>
- 3. Yin, RK (2009). '<u>Case study research: Design and methods, Fourth Edition</u>.' Thousand Oaks, California Sage
- 4. ONS mid-2020 population estimates by local authority
- 5. Equality and Diversity facts and figures for Hackney
- 6. English indices of deprivation 2019: technical report
- 7. Leeser, R (2019) Indices of Deprivation 2019 Initial Analysis
- 8. Labour market profile, via Nomisweb

9. <u>Social housing in Hackney: Have your say on how we allocate homes and</u> <u>support people in housing need</u> (2020)

10. Lees, Loretta (2019). '<u>Gentrification, displacement, and the impacts of</u> <u>council estate renewal in 21st century London</u>'

11. Bear and others. (2020). 'A Right to Care: The Social Foundations of Recovery from COVID-19.' London: LSE monograph

12. Data from Ministry of Housing, Communities and Local Government

13. National Housing Federation

14. ONS Deaths involving COVID-19 by local area and socioeconomic deprivation: deaths occurring between 1 March and 31 May 2020

- 15. 'Hackney and City step up to boost local test and trace efforts'
- 16. RAC Foundation from 2011 Census

# <u>COVID-19 PCR: home-testing experience</u> of blind and partially sighted people

The PCR Home Test Service (HTS) was first rolled out for key workers in April 2020 and expanded to the wider population by May 2020. As part of the UK NHS Test and Trace programme, HTS was launched as a means of improving accessibility by capturing those who were unable to get to a test site, were shielding or self-isolating, had mobility issues, lived in rural areas or had physical or mental impairments.

### Home PCR test process

The process for carrying out a home PCR test was as follows:

- 1. Order a PCR test kit online or call 119 (0300 303 2713 in Scotland).
- 2. Read instructions before opening the test kit.
- 3. Locate a priority post box or use courier collection (assistance via 119, NHS Scotland helpline).
- Register PCR test kit to obtain results (you will need a 10 digit order ID plus 11 character test kit barcode plus 13 character barcode on the prepaid label).
- 5. Ensure kit components are present and undamaged.
- 6. Wash hands then perform swab of throat and nostril, insert swab into the plastic tube.
- 7. Insert sample tube into zip-lock bag then insert this bag into biohazard bag.
- 8. Assemble the returns box, insert biohazard bag and apply security seal.
- 9. Return the test sample via the returns route identified previously.
- 10. Receive result via email and text or call 119 (NHS Scotland helpline).

NHS Test and Trace strives to deliver services that are accessible to all users. A one-size-fits-all approach cannot be adopted as different groups within the population may require responses more tailored to their specific needs. HTS was quickly recognised as being a suitable alternative to in person testing for people who are blind and partially sighted (BPS). According to the Royal National Institute of Blind People (RNIB), figures from 2017 show there are approximately 350,000 people registered as blind and partially sighted in the UK. However, even this cannot be considered a homogeneous group of individuals as they display a wide variation in visual abilities and circumstances which can be influenced by the severity of sight loss and age of onset, to name but a few. Furthermore, these numbers only reflect those who have been in some contact with health and social care services and as such, there may be more than 2 million people currently experiencing some form of sight loss.

Home self-testing is not straightforward for BPS people, particularly if they live alone. In order to continually monitor and improve the service offered by NHS Test and Trace, 2 user experience evaluations were undertaken in collaboration with voluntary sector partners in May 2020 and in February 2021 respectively. The first aimed to understand the end-to-end experience for BPS participants, from ordering a test kit to receiving a result, and to identify the range and depth of challenges to home testing. The second sought feedback from BPS participants on some bespoke assistance incorporated in response to the first evaluation. This report describes the 2 evaluations, summarises their findings and describes how services have been adapted to support service BPS users.

### User experience evaluation I

In the first evaluation, the RNIB helped to recruit 29 BPS people using their established communication routes. The ease with which these individuals were able to access and complete home PCR testing through the live service was then monitored. Participants agreed to researchers observing them by video throughout the process. Researchers did not intervene or offer advice to participants at any stage of the process so as not to undermine the holistic experience of the service. Individuals could use whatever visual aids were normally available to them, including help from a sighted individual, assistive technology or devices. Additional feedback was garnered by interviews conducted by the research team. Participants partaking in the evaluation all stated that they were asymptomatic for coronavirus (COVID-19) so that anyone unable to complete and return the test would not be at a disadvantage clinically.

The group comprised:

- 23 individuals who were severely sight impaired since birth or for more than 20 years
- 4 who had developed a severe impairment within the last 20 years
- 2 individuals who had experienced partial sight loss from birth or for more than 20 years

### **Evaluation I feedback**

BPS people want to complete the test independently without having to rely on friends and family. People expect the call centre to be able to assist with a broad range of issues across the user journey. Feedback provided at different stages of the process are highlighted below.

#### Before the test

The GOV.UK platform is in general well suited to serve most BPS people.

However, finding and reading barcode numbers for registration and courier pickup was almost impossible for participants to complete without assistance.

#### Preparing for the test

Digital text only instructions would be preferred by most BPS participants.

The flow of the instruction document should support people in preparing for the test.

Instructions should describe the objects by their tactile qualities as well as provide enough information to understand the purpose of each object.

#### Taking the test

Accidental contamination of the test kit was the main concern for participants.

Identification of some kit components was challenging without assistance.

The swab test was considered unpleasant but intuitive for participants to carry out

#### Packaging the test

Complex manual activities like sealing the biohazard bag and especially folding the box were very hard to complete for most of the participants.

For returning the test, participants liked having the option to choose between the post box and courier pick up.

#### After the test

Arranging courier collection was difficult or impossible for most participants to do unaided because it required them to be able to read the number on the Royal Mail label, therefore returning the sample through a postbox was the only viable option.

Participants didn't have a strong preference between receiving the results by text or by email.

### Additional feedback from participants

Concerns were raised regarding possible accessibility issues for BPS people who are less confident with using, or do not use technology.

Difficulties reading barcode numbers generated the highest risk for BPS people not to engage with the test

Going back and forth between different platforms, browsers or devices, and navigating between apps such as SeeingAI and the registration portal, proved very difficult.

### User experience evaluation II

User engagement identified a series of issues which impacted accessibility and from this work, improvements were identified. HTS sought to redress accessibility issues and proposed modifications underwent a second round of evaluations. The introduction of a new support service for this BPS user group would also be examined.

The scope for evaluation was as follows:

- A trial of a live video assistance service with trained support specialists from the 119-call agent population, using the Be My Eyes smartphone app. This supported participants to carry out the end-to-end home testing process via a free, live one-way video call.
- A trial of improvements to the packaging design of the returns box. Participants either received an easier to assemble flatpack design or a preassembled box.
- 3. <u>An online portal on GOV.UK</u> providing alternative formats of home testing instructions including HTML text only, Easy Read and accessible PDF formats.
- 4. Improved instructions with enhanced descriptions for a sample of participants who were testing the redesigned flatpack returns box.
- 5. Improvements to general accessibility and usability of online services.

NHS Test and Trace continued its association with RNIB but the partnership was now expanded to include the Macular Society, Visionary and the Thomas Pocklington Trust. The role of the voluntary sector partners again proved invaluable in a number of areas. They were part of the delivery team and contributed to decision-making in determining the research approach and delivery of the study. In addition, they led a training session for 119 call agents ahead of the trial of the live video assistance service regarding best practice for communicating with people with sight loss. The voluntary sector partners appraised the guidance document and the script used by these 119 agents, as well as contributing to the trial Be My Eyes app content.

As before, communications raising awareness of this evaluation were distributed by the voluntary sector partners through various channels. Ninety-eight BPS participants were enrolled by dedicated NHS Test and Trace team members:

- 72% of participants classed themselves as being severely sight impaired or blind
- 43% stated their eye condition had been present from birth
- a further 24% had been affected for most of their lives

### **Overview of participants**

The following gives background information on the makeup of the participants

(for a graphic representation of this data see Figure 1, below). Registered as blind and partially sighted Yes, severely sight impaired or blind -72%Yes, sight impaired or partially sighted - 18% Yes (unspecified) -9%No - 1% Proportion of life with an eye condition From birth - 43% Most of my life - 24% Recently or within last few years - 14% Around half my life - 10% Less than half my life - 9% Cause of eye condition Retinitis pigmentosa - 75% Diabetic retinopathy - 8% Glaucoma - 7% Cataracts - 5% Age-related macular degeneration -3%Other - 2% Gender Female - 56% Male - 44% Ethnic group White - 93% Asian or Asian British - 4% Black, African, British or Caribbean - 2% Another ethnic group - 1%

### Devices and internet use

"I'm comfortable using the internet completely independently" - 43%

"I can use the internet to do most things independently" - 42%

"I can use the internet with support from someone else" -11%

"I don't use the internet or someone else always uses the internet for me" – 3%

Figure 1. Overview of participants

There was a generational divide in the use of technology, with younger BPS people much more likely to be using the internet, a computer or a smartphone, compared to older people. It has been reported that <u>less than one in 3 BPS</u> <u>people</u> feel able to make the most of new technology. Although some non-digital means were used, most of the recruitment for this study was organised via social media and other digital channels, indicating some degree of digital literacy was prevalent amongst the participants. As such, 85% of the study group described themselves as being comfortable using the internet completely independently or were able to use the internet to do most things independently. All participants were made aware of the specialist support available through live video assistance as part of the enrolment process. Once again, participants were able to use whatever visual aids were normally available to them.

### **Evaluation II outline**

Participants were placed into 2 groups to examine different aspects of the service.

The first group was asked to confirm and expand on the original insights. There were 10 participants, each was interviewed for one to 1.5 hours for their feedback on a range of topics including digital exclusion.

The second group was asked to provide feedback on their experience of the improvements. This group was further split by the different approaches used to gather feedback:

In Group 2A, there were 10 participants who were interviewed about their experience of ordering a home test kit. They were then observed whilst they used the test kit and were interviewed afterwards to describe their experience. This group was provided access to the trial Be My Eyes service so that their organic, unprompted use of this support could be understood. Observation and interview sessions lasted from one to 2 hours.

In Group 2B, 9 participants were observed as they ordered and subsequently used the home test kit; they were interviewed after each observation to describe their experience of each step of the process; this group was provided with access to the trial Be My Eyes service, and they were actively

encouraged to try and critique it at each stage of the process. Each observation and interview session lasted one to 2 hours.

In Group 2C, 69 participants were asked to complete the end-to-end home testing process without being observed and were then asked to complete a survey to provide feedback about their experience of the process as a whole. This group was provided with access to the trial Be My Eyes service so that their organic, unprompted use of this support could be understood.

Feedback was also provided from the specialist team of 119 call centre agents, who provided the trial live video assistance service via the Be My Eyes app.

Half of the participants from each group (2A, 2B and 2C) were sent a preassembled returns box to use. The other half from each group received a redesigned, easier-to-assemble flatpack design. The participants from group 2C who received the flatpack box were also emailed an additional set of instructions which had been produced by the RNIB. These included more haptic, tactile descriptors throughout, and feedback was sought to assess if they were suitable for wider use.

### **Evaluation II feedback**

The sections below highlight the experience of participants as well as identify areas where the service could be improved.

#### Live video assistance via Be My Eyes

Half of the participants made use of the trial Be My Eyes service, and their experience regarding the quality of assistance provided was overwhelmingly positive. Many felt they wouldn't have been able to complete the home test without assistance via Be My Eyes. Having someone patiently provide step-bystep verbal guidance throughout the process helped provide participants with reassurance and reduce their anxiety. Using Be My Eyes allowed the 119-call agents to address any challenges experienced by individual users, offering a more tailored support service which wouldn't otherwise have been possible.

Participants reported that live video assistance was especially helpful for kit registration, with the agents being able to locate and read the test kit barcodes on their behalf, as well as discussing their local postal options and talking them through how to assemble the returns packaging. Participants in the second evaluation also provided feedback on how a live video assistance service should be more widely communicated among people with sight loss. For example, emphasis should be given to the fact that the 119 call agents providing assistance are actually specially trained NHS Test and Trace staff, and not the volunteers who are generally associated with Be My Eyes.

Participants advised that potential users should be informed that the support offered can be flexible depending on their requirements, for example, support can be provided throughout the whole home testing process, or just to assist at specific, smaller key stages such as barcode reading. Live video assistance call agents can arrange courier bookings and also provide clear guidance on postage timings and wider context for test results.

Be My eyes was routinely available as part of the Home PCR Test Service to all who required it.

### Improved flatpack returns box

Although some participants were able to assemble the flatpack box with support via live video assistance, it often took longer than participants and advisers thought it should take, required repeated instructions to achieve assembly and was sometimes the cause of frustration. There was also uncertainty from participants as to whether their attempts to self-assemble boxes were robust enough to protect the sample during shipping. Attaching the security seal often proved problematic due to difficulties removing it from its backing. Furthermore, the security seal sometimes got lost when opening the kit package, or it was misidentified as a small piece of paper or part of the test kit delivery packaging because of its texture.

There was general agreement from participants that a pre-assembled returns box or another simpler packaging design would be more usable for shipping samples.

Home PCR tests now contain an easier-to-assemble flatpack box.

### GOV.UK portals and guidance pages

Following feedback from Evaluation I, alternative formats of PCR home test instructions were available on GOV.UK. Having a wide choice of formats was important to satisfy individual preferences and needs. Formats that were highlighted by participants as being most useful included:

- audio only and video instructions with audio description
- PDF and text only (HTML)
- hard copy large or giant print booklet
- digital and hard copy braille
- Easy Read

This feedback supports the continued provision of a variety of formats, both digital and hard copy. Participants provided general feedback regarding the navigation and ease of use of the GOV.UK portals, including the compatibility and usability of the ordering and registration portals when using assistive technology, such as screen readers. Participants also provided feedback regarding where they would expect to find support services, including alternative formats of instructions, signposted across the digital journey.

### Those with sight loss without digital access

Throughout the duration of these trial periods, further modifications were added to the service, which proved beneficial to this community and the public at large. Those who are unable or have no access to digital platforms including email, internet or mobile phones can access PCR testing via the 119 service.

### Pain point mapping - taking the test

The following describes the response rates from the 69 participants in group 2C to each step of the testing process. The percentage of users who found a step challenging is shown in brackets. Under each step are given some personal responses expressed by group members. This data is conveyed in graphic form in Figure 2.

### Before the test

Opening the home test kit (17% of users found this step challenging)

"No obvious tear point. I was concerned opening the kit through brute force might damage something."

Identifying the parts of the kit (20% of users found this step challenging)

"I was concerned about making sure I got everything right and did not want to feel items and contaminate them despite washing my hands as instructed."

"After having read the enhanced instructions carefully a number of times, I was able to identify each piece of the kit without help."

### Prepare for the test

Using the instructions (45% of users found this step challenging)

"I found it rather confusing as I did not have instructions in a format I could read."

"The instruction booklet was not accessible. The font size was too small, the contrast of colours was very poor."

Registering the kit (55% of users found this step challenging)

"Several long codes which are not easily accessible for someone with little or no vision."

"Spent more time doing the kit than actually doing the test."

"I was put off by how complicated the initial opening and registration processes seemed."

Choosing how to send the sample back (23% of users found this step challenging)

"Maybe a pro tip which is concentrated on reassuring you that it is perfectly OK to utilise the [courier] collection service if it would be in any way difficult for you to get a specialised post box."

#### Take the test

Collecting the swab with the sample (42% of users found this step challenging)

"Something is needed to make the swab easier to feel through the wrapper – the difference between the 2 ends is very slight and the risk of getting hold of the wrong end is very high."

"Making it more obvious where to snap off the stick."

Putting the swab into the tube (32% of users found this step challenging)

"The tube is quite narrow and it would be easy to miss the opening and accidentally touch your hand or the side of the tube hence contaminating the sample."

Sealing the plastic bag (17% of users found this step challenging)

"I wouldn't have realised the absorbent pad was part of the kit, I thought it was just a bit of packaging."

"For those with little or no sight at all, this yellow strip coud be made to feel more tactile." (The yellow strip to seal the plastic bag.)

#### Package the test

Packaging the sample (41% of users found this step challenging)

"It was like doing a jigsaw with no instructions and no picture — that's what it's like for blind or partially sighted people doing the test."

Attaching the label (22% of users found this step challenging)

"Replace the origami box with a different kind of return packaging that does not need to be built."

"Label needs a 'peel easy' section that can be felt (that's to say, is obvious) as I struggled to take it off the backing (which I could barely distinguish as the edging was so small)."

#### After the test

Sending back the sample (14% of users found this step challenging)

"If I'm not ill it would be easy."

Pain point mapping: taking a test

Figure 2. Responses from group 2C highlighting challenging steps

### User feedback and engagement

Although these evaluations of user experience were small in scale, they were important in identifying possible barriers to home PCR testing within the BPS community. Feedback gained from these studies, as well as from other sources, has been used to implement service improvement.

The customer feedback survey and the Be My Eyes management dashboard are regularly reviewed to identify further opportunities for continuous improvement, both to the home PCR testing route but also to other services within home testing and across all of NHS Test and Trace where relevant.

Figure 3 shows images of the contents for kits issued as part of the first evaluation and kits available for BPS individuals as of summer 2021. Table 1 lists the components for these kits.

Figure 3. Image of Home PCR test kits, summer 2020 (left) and July 2021 (right)

Table 1. Table listing components of PCR test kits, then and now

| Home PCR test kit summer 2020               | Home PCR test kit July 2021   |  |
|---|---|--|
| 24-page printed instruction<br>booklet      | <pre>12-page printed instruction booklet.<br/>Also available in alternative formats (both<br/>digital and hard copy).<br/>Formats include: easy read, large and giant<br/>print, Braille, audio, and 12 different<br/>translations of the easy read instructions<br/>for non-English speakers</pre> |  |
| Flatpack box requiring<br>customer assembly | Easier-to-assemble flatpack box   |  |
| Biohazard bag                               | Single leakproof bag  |  |
| Zip-lock bag                                |   |  |
| Swab  | Swab  |  |
| Plastic tube containing<br>liquid           | Plastic tube containing liquid  |  |
| Security seal to close the<br>box           | Security seal to close the box  |  |
| Absorbent pad                               | Absorbent pad   |  |

Overall, the voluntary sector partners have welcomed the service modifications as likely to improve accessibility and the experience for the community they represent. The Home Test Service, as well as the programme more broadly, continues to work in close collaboration with these and other voluntary sector partners, seeking out their expert opinion to help us identify and drive service improvements.

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## <u>COVID-19 LFD: self-testing experience</u> of blind and partially sighted people

Early in 2021, the home test service was launched by the Department of Health and Social Care to improve access to COVID 19 testing. Exploration of the challenges of PCR home tests faced by those who were blind and partially sighted (BPS) led to the introduction of alternative Instruction For Use (IFU) media formats and the introduction of Be My Eyes live video assistance to help this group of people carry out a PCR self-test more independently.

The requirement for widespread asymptomatic testing using lateral flow devices (LFDs) led to calls from all stakeholders involved in PCR home test improvements to ensure the existing support is extended to aid BPS people in carrying out rapid lateral flow self-tests as independently as possible.

A small-scale pilot was conducted by the UK Health Security Agency (UKHSA) to examine the effectiveness of the current live video assistance service delivered via Be My Eyes app in enabling BPS people to perform COVID-19 selftests using rapid lateral flow test kits. The test kit chosen to be used in this pilot was one that was widely available for home self-testing and involved nasal-only swabbing with pre-filled sample extraction tubes. These 2 features were believed to simplify the process for BPS people by removing the need for throat swabbing and for filling the sample extraction tube with buffer.

Experiences gathered from BPS participants and Be My Eyes agents would help UKHSA to make informed decisions on introducing service adjustments as part of its ongoing drive to meet equality and accessibility requirements.

There were 2 main elements in determining the effectiveness of this approach:

- collecting user feedback from BPS individuals to understand and recommend where improvements are needed to the LFD live video assistance and to the test instructions
- collecting feedback from the Be My Eyes agents to understand their experiences of supporting BPS participants through the LFD journey

Eliciting suggested improvements to the test kit was not a primary aim of the pilot.

### Participant enrolment

The Blind and Partially Sighted Stakeholder Forum, convened by UKHSA, meets regularly to discuss a variety of topics, with a focus on access to testing technologies. This Forum has allowed UKHSA to gain valuable insights into the difficulties experienced by BPS people in their day-to-day lives. Recruitment of volunteers for the pilot was conducted in collaboration with voluntary sector partners involved in this Forum. Volunteers interested in taking part in the pilot were asked to complete a questionnaire which allowed the selection of individuals with a diverse range of demographic characteristics including the conditions underlying their sight loss. The questionnaire was devised by members of the UKHSA Inclusive Design Team within the Customer, Communications and Innovation directorate, and then tested and reviewed by the voluntary sector partners to ensure the terminology used was suitable as well as verifying the survey format was accessible for various assistive technologies. The voluntary sector partners then used their existing social media networks to inform and facilitate recruitment of suitable participants for the pilot.

Eight candidates were selected. They varied in age between mid-twenties to over 60 with 2 being male and the remainder female. Six were registered as severely sight impaired or blind, one was registered as sight impaired or partial sighted and one was not registered as sight impaired. The project team hypothesised that this last individual may have been unable to register their vision loss status through official channels as a result of the pandemic, but this could not be confirmed. All participants considered themselves to be either moderately or highly confident at using digital media but only 3 had previous experience of using Be My Eyes.

The 8 candidates had a range of vision loss types which included:

- idiopathic intracranial hypertension
- nystagmus optic atrophy
- macular telangiectasia Type 2
- bioptic glioma
- retinitis pigmentosa, and
- age-related macular degeneration

### User journey insights and observations

A summary of the testing process as well as an indication of difficulties experienced by users is presented in Figure 1. Levels of difficulty are colour-coded: green represents steps considered easy, yellow represents minor issues and purple represents major issues for participants. The figure describes each step of the testing process which is assigned an overall level of difficulty represented by a colour code and the opinions of each BPS user which are represented by a colour coded square. Below are the process steps and accompanying levels of difficulty:

- 1. User receives LFD test kit, overall score for this step was green (no issues), 8 users scored green.
- User prepares their test area, overall score for this step was yellow (minor issues), 3 users scored green, 4 scored yellow and 1 scored purple.
- 3. User checks test kit contents, overall score for this step was purple (major issues), 4 users scored yellow and 4 scored purple. Note, 1 participant withdrew from the pilot after this stage.
- 4. User peels seal off the top of the extraction tube, overall score for this step was purple (major issues), 3 users scored yellow and 4 scored purple.
- 5. User places filled tube into extraction tube holder, overall score for this step was yellow (minor issues), 1 user scored green, 6 scored yellow.
- 6. User identifies swab and opens the packet, overall score for this step was yellow (minor issues), 2 users scored green and 5 scored yellow.
- 7. User swabs both nostrils, overall score for this step was green (no issues), 5 users scored green, 2 scored yellow.
- 8. User transfers their sample from the swab to the extraction tube, overall score for this step was yellow (minor issues), 2 users scored green, 5 scored yellow.
- 9. User closes dropper tip of extraction tube, overall score for this step was green (no issues), 4 users scored green and 3 scored yellow.
- 10. User squeezes 4 drops of liquid onto the test cassette's sample well, overall score for this step was purple (major issues), 1 user scored green, 2 scored yellow and 4 scored purple.
- 11. User waits 15 minutes for result to develop, overall score for this step was green (no issues), 7 users scored green.
- 12. User interprets their test results, overall score for this step was green (no issues), 7 users scored green.
- 13. User reports their results, overall score for this step was yellow (minor issues), 5 users scored green, 1 scored yellow and 1 scored purple.
- 14. User understands the implications of their results, overall score for this step was green (no issues), 7 scored green.

### Figure 1. Participant experience of the LFD test process

Step1: Although users were provided with the test kits, this step was considered analogous with the real-world process of ordering and receiving a test kit online. No one reported any issues.

Step 2: Some participants mentioned issues relating to a lack of colour contrast between test kit items and their preferred test area surface.

Step 3: There was often confusion around test kit contents. The split between elements that are bundled together and those packaged separately was not intuitive. Component contrast was a common problem. Items packaged inside other items were often missed. Step 4: Of necessity the small foil cover on the vial is stuck on very firmly to minimise risk of contents spillage. Removing this foil can prove problematic even for people with standard vision level.

Step 5: Some users found the location of the vial holder hole in the box wasn't ideal.

Step 6: Be My Eyes agents were able to provide support for those users having difficulty in identifying the correct way to open the swab to avoid contamination.

Step 7: Users had few issues with swabbing the sample. The nasal only swabbing was generally considered as being easier than throat and nasal swabbing required for some other test kits.

Step 8: Users noted issues with aligning the swab with the extraction tube. Agents noted that some users took multiple attempts to insert the swab which could result in sample contamination.

Step 9: Some users encountered issues with closing the dropper tip. Due to the 2-handed aspects to this process, agents were often unable to view this stage.

Step 10: Most users encountered multiple issues applying the sample to the test strip. These included difficulties in being able to distinguish the sample well from the results well and determining whether the appropriate sample volume had been applied. Agents could not witness the number of drops applied by users with any degree of confidence.

Step 11: Users did not describe any issues with this waiting time and the requirement to call back the Be My Eyes service to interpret their results. Users noted no issues with speaking to different agents as part of any live service.

Step 12: Agents had no difficulty in viewing and confirming the test results received by users.

Step 13: Agents described some difficulties in viewing the codes required to register test results. Camera angle, environment lighting and device image quality all impacted on viewing the required information.

Step 14: No issues were noted by users in regard to understanding the implication of their test results and any next steps in the process.

### Experience summary

BPS participants and Be My Eyes agents described 3 main areas of difficulty using the test kit, identifying kit components, removing the foil seal from the extraction tube and ensuring the correct sample volume was added in the appropriate fashion to the sample well. Some of these difficulties were in part the result of the Be My Eyes agent being unable to adequately view the activities of the participant during particular steps. BPS participants experienced challenges in conducting the tests while holding their smartphone as some parts of the process required them to use both hands. This required them to prop up their cameras up by other means in unsuitable positions which limited the ability of the agent to observe and provide assistance.

Difficulties identifying kit components derived from a combination of how they were packaged and a lack of visual contrast and tactile differences between them. For example, items such as cassettes were individually wrapped whereas 7 days' worth of extraction extraction buffer tubes were contained together within a single package. Participants noted the process would prove easier if all the kit components required to conduct a single LFD test were packaged as 'sets' within the kit box. Even though agents had the benefit of having a kit in front of them to assist them in providing descriptive and directional language to participants throughout the testing process, the lack of colour contrast of some components sometimes proved problematic for users as well as agents. Concerns were noted by agents that tactile interaction with kit components by the user could lead to contamination of the test sample and invalidate results. Colour contrast issues were more pronounced if test areas with pale backgrounds were used. During the pilot, BPS participants were generally only advised about preparing and sanitising their chosen test area as well as hand washing. They did not receive prior advice in optimising their testing environment to help minimise colour contrast issues.

Further investigation of the difficulties experienced by BPS users when removing the foil lid revealed an issue in the manufacturing process that had affected the test kit batch used in the pilot. The machine attaching the foil lids was subsequently recalibrated, resolving the issue and may mitigate any future difficulties experienced by BPS people at this particular step.

In 6 out of the 7 completed tests, Be My Eyes (BME) agents could not confidently witness whether the correct number of drops had been squeezed into the LFD specimen collection well, nor whether contamination of this well or its contents had occurred via touch by the BPS participants. This step was the most challenging for BPS participants and BME agents and was a particular example where the users' difficulty was compounded by the difficulties for agents to direct suitable positioning of the BPS participants' cameras. However, despite these issues, the tests for the 7 BPS participants were all completed in as much as the LFDs displayed a line in the control line region.

### Improving existing service delivery

Due to a general anxiety about testing, multiple participants noted they would want to be reassured that their Be My Eyes agent had received appropriate training. Furthermore, both BPS participants and agents mentioned the usefulness of providing some key information for the caller prior to using the Be My Eyes service. These included having a hands-free setup for the BPS participants' smartphone or camera device using either a directional stand, tripod or some other suitable support. Additional information should be supplied about preparing the testing area and guidance about avoiding the use of white or pale testing areas. Using a coloured test area would increase the contrast between the white test components and test surface and make them more visible to both BPS participants and agents on the video link. It would also be useful to explain the end-to-end rapid lateral flow testing process to help set expectations. To this end, further agent training has been provided via briefings and agent scripts have been updated which should enable improvements to the Be My Eyes service and improve usability and confidence for users.

Since the soft launch of the service on 17 January 2022, followed by the full launch 10 days later, 247 calls were received up until 9 September 2022. Figure 2 describes the calls made to the Be My Eyes LFD support service with an additional breakdown of the numbers of calls and their level of satisfaction at the service provided.

### Figure 2. Reasons for calling the Be My Eyes LFD support service

| <b>Column1</b>                       | Number of calls | % Customer satisfaction |
|--------------------------------------|-----------------|-------------------------|
| Reporting a void LFD test result     | 10              | 50                      |
| Reporting a positive LFD test result | 38              | 100                     |
| Reporting a negative LFD test result | 122             | 96                      |
| Identifying LFD test kit components  | 14              | No data                 |
| Administering a home LFD test kit    | 61              | 91                      |
| Ordering a home LFD test kit         | 2               | 100                     |

Reasons for calling the service include:

- ordering a home LFD test kit 2 people called, who were fully satisfied
- administering a home LFD test kit 61 people called, satisfaction level of 91%
- identifying LFD test kit components 14 people called, no data as to the satisfaction of their service
- $\bullet$  reporting a negative LFD test result 122 people called, satisfaction level of 96%
- reporting a positive LFD test result 38 people called who were fully satisfied
- $\bullet$  reporting a void LFD test result 10 people called, satisfaction level of 50%

### Future developments

Investigations are actively proceeding for new test kit products to improve accessibility by reducing the need for liquid measuring and limiting the requirement for component identification and manipulation. However, there is no quick fix for this situation as any new products will have to be thoroughly tested and validated. Furthermore, processes are also being reviewed to consider how we can improve meeting customer needs by offering tailored journeys, based on their access needs.

Despite these service improvements and future aspirations, there may be some users that find existing testing solutions unsuitable for independent selfuse and require some form of physical assistance to perform a rapid lateral flow test successfully. However, we expect that many users will benefit from the introduction of Be My Eyes to support COVID-19 self-testing using rapid lateral flow tests.

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