Beyond the Data: One Year On
Executive Summary

During the first wave of the pandemic it became apparent that COVID-19 exacerbated long standing inequalities in England across ethnic and socio-economic groups, disabled people, young people and care home residents. The publication of a national review by Public Health England (PHE) in June 2020 highlighted the extent of COVID-19 related inequalities, especially the unequal impact on Black, Asian and minority ethnic populations. The report provided recommendations on how to reduce the disparities exacerbated by COVID-19, which contributed to the drive of multi-disciplinary organisations to work in partnership to tackle health inequalities.

Since that time, action has been taken in London to implement these recommendations and minimise the health inequalities from COVID-19. Local government, the NHS, the Mayor and Greater London Authority (GLA) have worked with communities to help protect them from infection and its consequences, and most recently to roll out the vaccination programme. They have sought to do this by working with representative groups, communities and community leaders.

This engagement has contributed to better knowledge of London’s’ communities as well as a heightened understanding of the drivers of inequality they experience. Specifically, it highlighted communities’ views on structural racism, discrimination and vaccine hesitancy.

Implementing the recommendations from the Beyond the Data report and work across many organisations both public and private has made a difference. However, despite the action that was taken, and the deeper understanding of what risks communities faced, the second wave of the pandemic still showed that some Londoners, particularly those from ethnic minority communities, remained at greater risk of the harmful consequences of COVID-19. Some of these data are summarised below.

Throughout the last year, local authorities, the NHS, GLA and PHE have continued to engage and work with local communities to learn and adopt work across the city to tailor it to the lived experiences of Londoners and ensure that there was a targeted local approach to infection control and the vaccination programme.
To take stock of what communities in London felt has happened since the original PHE Beyond the Data Report was published, the London Health Equity Group organised a series of engagement events, led by a project team at PHE London. The events served not only to contribute to the existing body of knowledge on equity and health during COVID-19 but also to remain accountable to and ‘check-in’ with many of the groups who had helped craft the original report. Additionally, the engagement provided insights on communities’ experiences of health and care in relation to their identities more broadly. Crucially, this exercise served as an opportunity to gain community feedback on what priorities they wanted London to adopt going forward.

This report documents these community insights and reflections from strategic partners addressing health equity in London, community leaders and representatives, as well as co-ordinators of COVID-19 ‘champions’ programmes in the City.

Key messages to take from this work are that:

- London’s diverse communities are a source of great strength to the capital
- They rose to the challenge of working together during the pandemic, showing leadership, resourcefulness and resilience, without which the impacts of COVID-19 would have been a lot worse
- They were positive but wanted to have documented that they still experienced discrimination and stigmatisation, and the consequences of how the pandemic was managed had a profound negative impact for many.
- They want to be part of the solution for how London recovers from the impact of COVID-19.

Going forward, London’s strategic health and care partners must respond to community insights in a meaningful way that is accountable and collaborative. The need to work together is clear, to ensure London recovers in a way that leaves no-one behind and tackles inequalities in a multi-disciplinary, coordinated manner.
Background: London’s response to Beyond the Data

During the first wave of the pandemic it became apparent that COVID-19 exacerbated long standing inequalities in England across ethnic and socio-economic groups, disabled people, young people and care home residents. Pre-existing inequalities in social and economic conditions, otherwise known as wider determinants of health, contributed to the high and unequal death toll from COVID-19 in London, and throughout England.

In June 2020, a national review by Public Health England (PHE) led by Professor Kevin Fenton was published. It set out the scale of COVID-19-related inequalities with a particular focus on the impact on Black, Asian and minority ethnic populations. Extensive consultation across a range of organisations led PHE to make a set of recommendations on how to reduce the disparities in COVID-19 infection rates, hospitalisations and mortality, and to start addressing long standing issues that lay behind these inequalities. Moreover, the report sparked conversation about the wider determinants of health - the diverse range of social, economic and environmental factors which impact on people’s health – and contributed to the drive to work in partnership with multi-disciplinary actors to tackle health inequalities across the system.

Following London’s experience of the first wave of the COVID-19 pandemic and the publication of PHE’s Beyond the Data report the London Health Board, chaired by the Mayor, established a Health Equity Group. The group’s role is to provide oversight of work addressing COVID-19 health inequalities and support the delivery of strategies on the ground. In addition, a Health Equity Delivery group was formed to support operational delivery.

The Voluntary, Community and Social Enterprise (VCSE) sector
Community and voluntary organisations have provided much-needed help and resources to their local communities, as well in providing invaluable insights to ensure actions are tailored to all London’s rich and diverse communities. Many VCSE organisations have been stretched, facing reduced budgets and increased demands. In-spite of this they remain a crucial link between the broader health and care system, and its ability to take a place-based approach to addressing community needs in health improvement and protection.
**Local authorities**

Local authority teams have been instrumental in local outcome management and infection control, sharing insights and best practice across the city to maximise impact and operate as ‘one London’ with the region when needed. Boroughs built on their long history of tackling inequalities and forging close relationships with the communities they serve. Both social and financial support was offered to vulnerable people when they needed it to protect themselves and their families.

In many places culturally appropriate interventions and programmes were co-designed with local communities to stay safe, get tested and isolate when required. Boroughs have partnered with PHE London to ensure good infection control and the management of COVID-19 in care homes - with levels of infection in the second wave considerably lower than the first.

**The NHS**

The NHS has worked on key priorities to tackle inequalities in the context of COVID-19, with London’s five Integrated Care Systems taking forward ‘Beyond the Data’ recommendations across their sub-regions to reflect the equity implications on service delivery and workforce. In the past year, a Health Inequalities and Improvement team was established in NHS England to work across the region and with partners in the wider system to deliver against the commitments set out in the NHS Long Term Plan and deliver the NHS response to COVID-19. As ICSs begin to develop their strategies building a ‘place-based response’ is vital.

**HM Government, the London Mayor and the Greater London Authority**

At the London level, the Mayor and GLA have played an important role in communicating on behalf of and with Londoners, highlighting the cities unique qualities and approaches to protect population health. For example, after the first wave voluntary and community grassroot funding was awarded to improve reach into communities with lower uptake of testing, isolating and vaccination.

Prior to the public health sector reform, in October 2021 PHE played a key role in providing public health leadership, championing practical action to address the issues identified in Beyond the Data and support implementation of the recommendations that were made. PHE’s health protection teams have managed complex outbreaks of COVID-19, working in a range of settings including schools, universities, care homes to workplaces. PHE supported the vaccine programme by providing insight and support to tackling hesitancy in taking up the offer to be vaccinated that was manifest in certain groups. PHE has also provided surveillance, oversight and support to implementing the recommendations in Beyond the Data on behalf of
the Health Equity Group. It is anticipated that the Office of Health Improvement and Disparities (OHID) will continue to lead in addressing health inequalities and championing the work of its predecessor.

Cross-organisational action to tackle inequalities
Since late 2020, the NHS, working with boroughs, the Mayor, PHE London and a range of partners has led London’s vaccination programme - the largest of its kind in the country's history. It has been the most successful vaccination programme in London’s history. From the start, attention was paid to ensuring differences in take up and coverage of vaccinations were addressed. Targeted interventions were designed to encourage vaccination in hesitant groups working with a network of local champions from faith and community groups.

The removal of inter-organisational barriers combined with partnership work enabled action to protect the most vulnerable across the city, and at a locality level. For example, partnership work between London boroughs, the Mayor, GLA, NHS and the voluntary and community sector, led to 7,800 rough sleepers being placed in alternative accommodation to protect them from COVID-19. Social care needs arising from the pandemic were also met through close partnership working also and learning from the experience of the first wave.

This community involvement and a targeted local approach facilitated improved physical access to vaccinations, with centres across the city being set up in a variety of formats from buses to stadiums located close to communities and saw increased vaccine uptake.

COVID-19 related inequalities over the last year
Despite the scale of this commitment and action, it has been evident that since the publication of the Beyond the Data report and subsequent recommendations, COVID-19 has continued to have a disproportionate impact on different communities and many inequalities persist. These inequalities are presented in the companion report ‘Beyond the Data: One Year On, A Companion Narrative to Data and Literature’.

Analysis completed by PHE in this report highlights that, as the second wave of the pandemic took hold and progressed across the city, infections, hospitalisations and deaths were still higher in particular ethnic groups, the most deprived, those with a disability and different inclusion groups. In particular, people from Bangladeshi and Pakistani backgrounds suffered worse outcomes. Bangladeshis men were 5 times more likely to die compared to White British males and Bangladeshis females over 4 times more likely to die in comparison to White British
females. Black Caribbean and Black African people remained at higher risk of mortality compared to White British people, but these risks had reduced compared to the first wave. Though socioeconomic and other health factors contribute to the increased risk of COVID-19 deaths, even after taking into account of where people live, where they work and their health conditions, most Black and South Asian groups remained at higher risk of COVID-19 deaths in the second wave compared to White British people.7

Beyond the Data One Year On: stakeholder engagement

Methodology

Throughout the last year there has been extensive community engagement by boroughs, the NHS, GLA and PHE. This has helped direct a targeted local approach to managing infection rates and tailor the COVID-19 vaccination programme to London’s diverse communities. To supplement the insights gained from this work, the Health Equity Group arranged a series of stakeholder engagement sessions. These were to mark one year on from the publication of PHE’s Beyond the Data report and to return to those groups in London that had informed the original work. The objective was to understand their experience since its publication and the extent to which recommendations had been implemented, based on their experiences.

Specifically, the aims were to

(1) Give participants the chance to reflect on the impact of actions that had been taken locally to reduce COVID-19 health inequalities, and more recently vaccinate the most vulnerable
(2) Identify what communities felt should be prioritised in order to tackle these health inequalities.

Insight was gathered from nine community engagement sessions, three roundtables with a range of organisations, and one webinar. The community engagement sessions took place over a three-week period (between 16 June 2021 and 30 June 2021) online using Microsoft Teams with participants from community and faith groups, Lesbian, Gay, Bisexual, Transgender, and Queer or Questioning (LGBTQ+) groups, young Londoners and disability groups. Colleagues from local government, the NHS, GLA, London Councils, and Health and Wellbeing Board Chairs also joined the sessions. These were chaired by senior leaders from each community group. A total of 457 individuals took part.
In addition to the community engagement sessions, members of London’s HEG hosted a webinar to gain broader insights and reflections on the work. During the webinar, interaction was enabled using an interactive presentation software ‘Mentimeter’. A roundtable session was also held with system partners, existing networks hosted ‘One Year On’ meeting items to gather insights.

Recording and minuting of the webinar, roundtables and each community engagement session enabled the collection of key insights. Transcripts were produced and meeting notes summarised following each event to extract quotes and qualitative data for analysis. After each event, a post-event survey was shared with participants to gain additional insights. Key themes from survey findings were collated and considered within the content of the report. PHE also received written feedback from other community group representatives who did not attend an event. Data analysis was conducted using an iterative approach, which incorporated deductive and inductive methods to identify themes. This is similar to the use of thematic analysis in the original Beyond the Data report.

The webinar had speakers from key London health and care system partners including Public Health England; Greater London Authority; NHS England London; London Councils; and the University College London’s Institute of Health Equity. Presentations and discussions were focused on building back fairer, building trust and cohesion, supporting health and social care, and data and communication. Illustrated minutes are presented in the Figures below.

Three roundtable sessions were held. The first, a session with London’s Directors of Public Health organised in collaboration with the Association of Directors of Public Health London. The second a roundtable with London Councils Health and Wellbeing Board. A third roundtable discussion was held towards publication of the report with members of the HEG.

Live Illustration, a virtual graphic recording artists agency, was commissioned by PHE to produce illustrated minutes. These highlighted key themes that emerged from the webinar and community engagement sessions, with the purpose of making the reports more accessible to a wider audience and producing a tool which could be used in communications relating to ‘One Year Beyond the Data’.
Figure 1: Key messages from Beyond the Data webinar
PHE: BEYOND THE DATA
UNDERSTANDING THE IMPACT OF COVID-19 ON BLACK, ASIAN & MINORITY GROUPS

Q. GLOBAL IMPACT ON ETHNIC GROUPS & MINORITIES?
Q. HOW TO INCREASE HEALTH & EQUALITY WITHOUT DECREASING WEALTH?
Q. WAGES & RIGHTS ARE ON THE DECREASE
Q. NHS PLANS FOR LONG WAITING LISTS?
Q. MOMENTUM & PROGRESS AFTER PANDEMIC/LOCKDOWN?
Q. SUGICAL HUBS & PRIORITISING PATIENTS BY URGENCY

LIVE ILLUSTRATION.CO.UK
© GRAPHIC RECORDINGS. REPRODUCTION PROHIBITED.
PHE: BEYOND THE DATA
22/06/21
UNDERSTANDING THE IMPACT OF COVID-19 ON BLACK, ASIAN & MINORITY GROUPS

TRUST:

IMPROVING HEALTH & SOCIAL CARE SERVICES:
- Greater equity across society
- Social determinants of health
- Access & inclusion
- Communication
- Community engagement
- Employment opportunities

MEASUREMENT IS VITAL

TRUTH X CONSISTENCY X TIME = TRUST!

PARTNERSHIPS & REPRESENTATION
- Listening, co-production & support
- Diversity in thought, experience & requirements

LIVEILLUSTRATION.CO.UK

How to: Build back fairer & recover from COVID-19?
Findings from community engagement sessions

Impact of social and economic inequalities

Income inequality remains a challenge for communities. Some participants confirmed that despite the actions taken, the impact of social and economic inequalities remain a challenge. Not all Londoners were able to access the government’s furlough scheme, particularly those in insecure jobs, undocumented migrants or the newly self-employed. Although examples were shared that showed some organisations topped up furlough payments, the reality for many was that living on 80% of their salary was not enough to look after their families. Regardless of the government guidelines, many still had to work even with a diagnosis of COVID-19, as isolation would have had an unsustainable impact their income.

“In the first wave and for several months during the pandemic we were telling people to isolate if they had symptoms, and if they were, you know, in insecure employment it was very difficult for them to isolate because they didn’t have any income and patients told me point blank that they were not going to isolate because for them it was a choice between their lives and their livelihoods. When they had to pay rent and bills - they just couldn’t afford to take time off work and they had no income support at all”.

Doctor from the Muslim community

“Younger people are struggling to make ends meet… class and deprivation not talked about… middle class often in jobs where they can more comfortably work from home. The pandemic has been more difficult if you’re on furlough, zero-hour contracts, working in performing arts”.

LGBTQ+ community representative

“Not everybody had the opportunity to be furloughed. There were new businesses who had no access to funding, which had a detrimental effect on households”.

Muslim community representative

Economic inequalities experienced specifically by women were highlighted in several focus groups. There were examples of women who were working in part-time roles in sectors that had been adversely affected by the pandemic. In addition, women with children had the additional challenge of supporting their children through home-schooling.
“Women who contributed to the household income were affected, especially those in the retail industry had a big hit. We’re picking up the pieces now and it doesn't look good”.

*Muslim community representative*

The impact of job losses during the pandemic resulted in an increased demand for local food banks. Even with communities coming together to support the distribution of food packages, the reality of the loss of income meant travelling further to access affordable food.

“People such as myself who can't afford home deliveries had to go out more in person when supermarkets were the number one place during the pandemic where you are likely to actually contract COVID-19”.

*Disabled Londoners representative*

For faith organisations, the closure of places of worship presented the challenge of how to cover their overheads, as financial contributions in many cases were limited given job losses and limited income of many of their congregations during the pandemic.

**Living conditions**

Some participants highlighted the continued challenge of living conditions. With social housing lettings paused, those who were already in overcrowded accommodation had the additional challenge of home-schooling children, whilst working from home. Some participants also shared their concerns regarding the safety of parks and open space within their neighbourhoods, and the adverse impact this had on their wellbeing.

“People need space to relax and to recoup outside the four walls for their overcrowded houses. Vulnerable adults, women and children's health are seriously hindered by the lack of access to safer space in their neighbourhood”.

*Anonymous representative from post-event survey*

“A lot of disabled people like me are not in suitable accommodation so being stuck indoors while shielding and not having access to anything outside the home caused me a great distress and decline in my health”.

*Disabled Londoners representative*
The impact of job losses during the pandemic put several households at risk of homelessness. Some participants shared that although action was taken by the government to delay landlords from evicting tenants, there was a burden and concern about what would happen if enforced eviction orders returned. Others shared harrowing experiences of being thrown out of their homes because they had COVID-19, which not only had an adverse effect on their health and wellbeing but put others at risk of contracting COVID-19.

Vulnerable groups and populations
Concern for vulnerable groups was expressed in several focus groups. An increase in domestic violence towards women, LGBTQ+ communities and people with disabilities was highlighted by some participants who also noted the surge in the demand for helpline services.

“[We’ve] never had so many referrals for people wanting to access support for domestic violence and safeguarding”.

LGBTQ+ community representative

“Domestic violence went through the roof, and we were lucky to support women remotely. But in the first wave, faith organisations were forced to close so it was more challenging supporting at that time”.

Muslim community representative

During the second wave of the pandemic, higher case rates were observed in men from the Muslim community. Participants noted concerns regarding the continued inequalities this group experienced.

“We also saw in particular with faith communities that it was Muslim men in particular who are most likely to die from COVID-19 and the least likely to take up the vaccine, so we do have certain inequalities within faith communities”.

Muslim community representative
The inequity of access to financial support experienced by undocumented migrant workers and others with no recourse to public funds, who put their lives at risk by continuing to work, was highlighted as an issue.

“The worst hit in our community are the undocumented migrant workers, because in the process they didn’t have any social support because they couldn’t go into any furlough. I don’t get any recourse to public funds. Also, we have a lot of nurses and carers who have no recourse to public funds and when they get ill with COVID-19 (especially those working in the care sector) they only get statutory sick pay and that’s not enough to live on, so sometimes they are forced to go back to work even though they’re not fully recovered”.

Asian community representative

Some participants highlighted the challenges experienced by disabled Londoners in relation to access to support, and the reality that many are still experiencing difficulties accessing the services that they need.

“What we saw initially was that many support systems for disabled people collapsed very quickly. People who relied on social care support to live a normal life, many of them lost it. People really struggled to get food, to access health service. For some it still continues”.

Disabled Londoners representative

Bereavement and Loss

The impact of bereavement and the scale of loss were highlighted particularly amongst participants from the Black, Asian and faith communities. There were examples of families experiencing multiple losses, with many being unprepared for the financial burden of funerals and no will in place for their bereaved family members. Some participants expressed feeling unsupported at work as managers were not considerate towards staff needing to take compassionate leave on multiple occasions often leading them to ask, “How many times are you going to have bereavement leave?”

“So many friends and family were dying around us that we had to stop counting”.

Black community representative
Faith organisations played a key role in managing the trauma associated with the loss and grief due to COVID-19, and there were calls for more counselling support within a variety of settings.

**Impact of isolation**

For participants who were shielding, many shared how they felt left out and forgotten, as they were unable to have physical contact with anyone outside their home. Participants perceived there to be conflicting messages around those who were eligible to shield and those who could form household bubbles. They reported that this was very confusing and some shared that it had an adverse effect on their health.

**Digital Exclusion**

Many participants reflected on the value of being able to work from home and communicate with family and friends using virtual technology. For some however, digital exclusion was a concern. Participants shared that limited access to enough laptops in the home resulted in many families having to share single devices which proved to be a challenge in scenarios where children were home schooling and parents were also relying on the same device to work from home.

The impact of digital exclusion across the life course was recognised. Some participants, many of them being older Londoners, noted that they were unable to book appointments online due to poor computer literacy and had to rely on family members to do so (which often resulted in a delay). This affected the quality of their experience of health services. For example, with virtual GP consultations many found it challenging to articulate their health needs and didn’t have the technology to support video consultations or could not upload photo evidence to describe their ailments.

"*Some of our elderly users find it a bit difficult to book an appointment with the GP as it took some time to get appointments*."

*Black churches representative*

"*Online and remote appointments - They don't work for everybody and there are some people who don't have technology. There are people who do not or are not able to use it. But there are also people who are not able to communicate*."

*Disabled Londoners representative*
Although actions were taken by the government and the statutory sector to support children and young people with access to laptops and devices to support digital learning, some pointed out that the support was not timely and resulted in community organisations stepping in and having to use their own assets to support affected households.

**Community Support**

Formal and informal community support was one of the key actions taken to address some of the social and economic inequalities. There were examples of communities coming together to share food and support with shopping, where many noted long supermarket queues as a barrier. Other examples of community support included checking in on neighbours who were shielding and living alone and supporting families who were impacted by digital exclusion.

> “Mutual aid groups stared up because of lockdown…looking after those in the community [isolated, elderly, mental health concerns] led by LGBTQ+ communities for fellow community members [non-LGBTQ+ also]”.  
>  
> LGBTQ+ community representative

Participants recognised the strength and resilience of faith communities who continued to be a trusted source for support for many Londoners during the pandemic. Many also shared examples of engagement activities that supported wider communities beyond Londoners from specific faith groups.

> “The Jewish Council set up certain funds to support communities affected by job losses and ways to reach out to people locally (mobilising effort internally and externally)”.  

> “Temples supported with food parcels for all communities”.  
>  
> Faith communities’ representatives

It was echoed in several focus groups that some faith leaders felt “used” by the government and that the government’s recognition of the role faith leaders could play in building vaccine confidence was belated. The importance of resourcing communities was a major cross-cutting theme. Some participants highlighted that community organisations were operating on an already limited budget and that they felt the government needed to provide adequate funding to support the work that they do in mobilising communities.
“There was no consideration for British Sign Language (BSL). The community stepped in to support that. We didn’t receive any grants to do this, we did it because we were in crisis. Now we are coming out of this, I fear that the momentum that we have built is going to be lost”.

Muslim community representative

Londoners have experienced differential scales of social and economic impact from the COVID-19 pandemic. Having to deal with social isolation in some cases heightened by digital exclusion has been challenging.

The financial impact from job losses, being furloughed or having no recourse to public funds has been a widespread issue.

Formal and informal community support networks including faith organisations have been key to addressing some of the social and economic inequalities in the city.

Box 1: Summary of key findings from the impact of social and economic inequalities theme
Risk of exposure to and transmission of COVID-19

Across the focus groups, participants recognised the continued risk of exposure to and transmission of COVID-19. The role of community organisations helping with personal protective equipment (PPE) was highlighted. Despite the strong communication on social distancing measures to protect the nation and the NHS, the impact of these measures was experienced differently by communities.

Social distancing measures

There was an overwhelming sense of loneliness and loss experienced by not being able to celebrate life events with friends and family. From a faith communities’ perspective, such measures prevented certain religious practices from being carried out as not all religious activities can be practiced online.

“The main prayer that needs at least 10 men all physically in the same place is that said by mourners. This has given distress to many people especially at the time of a funeral and the following week as well as on the anniversary of the death”.

Faith communities’ representative

For disabled Londoners, social distancing measures had a negative impact on the ability to communicate, as the wearing of masks prevented the opportunity to recognise facial expressions. They also felt their independence was compromised, as they didn’t have access to the same level of support and were unable to benefit from visits. This had an exacerbating impact on their mental health.

“The independence of visually impaired people has been greatly compromised by social distancing, lack of assistance on public transport, removal of usual activities and opportunities to interact, also access to food, as very difficult to get access to online shopping impacts on health”.

Disabled Londoners representative

“People who rely on lip-reading not being able to do so. Just to be able to do the everyday things like go to the corner shop became incredibly difficult. Deaf and blind people rely on physical contact to do signing and guiding and so that became incredibly difficult”.

Disabled Londoners representative
Some participants from the LGBTQ+ community expressed a deep sense of loss from not being able to meet in environments that have often been a safe space for their community. Participants also reported that restrictions on travel resulted in people being unable to visit their usual health services, as many often travelled out of borough to meet their trusted health care professionals who were from the same community.

Young Londoners expressed feelings of judgement, as they were often highlighted in the media as “rule breakers” which didn’t reflect the actions of young Londoners who were adhering to the government guidelines. Young people also felt left out and that there was a lack of conversation on the specific impact of the pandemic on young people including how they were managing significant life events being cancelled – such as end of year exams, paused apprenticeship schemes and graduations.

“We feel like when young people got COVID it was dismissed, and we were expected to ‘get on with it’. We felt stigmatised for getting vaccinated last and received little praise for following guidance, staying at home and not seeing friends. Often, we were still trying to protect ourselves from COVID and the older relatives we lived with”.

Young Londoners representative

In relation to expecting and new mothers, some participants noted the impact of social distancing measures and their experience of accessing maternity services during the pandemic. For example, some participants expressed “feeling isolated” as they were unable to have the additional support from family members after giving birth.

Accessibility to vaccination and testing sites

Some participants expressed frustration regarding the location of the testing and vaccination sites. For many, this involved having to use public transport to travel to these locations and given their fear of exposure to COVID-19, this presented a significant barrier to accessibility. This was a particular concern raised by Londoners with disabilities.

“I remember fighting for test centres to be more local. They were mainly based in Canary Wharf, which is a no-go area for most residents, as you have to take public transport to get there. So, it was through listening to the community that helped to change that and allowed for more local test centres to be set up”.

Muslim community representative
Participants were critical of the initial location of the testing sites and said this fuelled pre-existing fear and scepticism.

“People were anxious and didn’t want to go for a test. They were even more anxious to jump on a bus to go into an area that they weren’t familiar with. It felt more focused to the privileged city workers and not for the community”.

Muslim community representative

Access to health services

There were mixed responses regarding accessibility to health services during the pandemic. Many expressed anger on perceived conflicting messages regarding contact with GPs earlier in the pandemic, such as being told not to contact GPs about the vaccine. This was a barrier for many; participants shared that their GP was their trusted source for information and that connection had been taken away, leaving them feeling excluded. Other barriers included the impact of extended waiting lists and being unable to get through to making telephone appointments.

Although participants were aware that health services were still in operation throughout the pandemic, many communicated that fear of contracting COVID-19 was a real concern and barrier to accessing services.

“We’ve (sexual health centre) been open the majority of the whole pandemic, providing care for patients, and we found that we’ve been seeing a lot more patients with non-sexual health related illnesses because people have found it difficult to get into their GPs at this time”.

Black community representative

“I see there’s a frustration in terms of patients having to wait a long time and even longer now to get appointments with their doctors. There are lots of patients with very serious symptoms, like chest pain or pain in the back of the legs. They just want to see the GP because at the height of the pandemic, everyone was really scared of going to the hospital for fear of contracting COVID-19”.

Muslim community representative

The way health practitioners communicated the level of risk of COVID-19 infection amongst people from Black, Asian and minority ethnic backgrounds, caused many participants to feel as if they were to blame and not wanting to access the support from health services.
Health Literacy

Health literacy was highlighted as one of the key enablers and barriers to accessing health services during the pandemic. For example, some noted that inability to community their needs or the required format prevented some patients, particularly the elderly and those who could not speak English, from accessing care.

“I am really shocked by the way my family have been treated. My parents do not speak English and social care were not bothered that there was no interpreter for my mother when my dad was trying to access care. They always went through me without making an effort to speak to them directly and they said, ‘you know, we try to communicate with them. We’ve been trained in communication. So basically, it’s their fault not being able to understand us’”.

Asian community representative

Across the focus groups, some participants were concerned about the limited support available for Londoners requiring support with accessing translators within health services. Participants reported that given their limited ability to communicate their health concerns, they felt at a greater risk of developing COVID-19.

“When COVID-19 happened, families couldn’t be there to support their loved ones through advocacy and that was hard for many particularly with language barriers, which is a big issue.”

Muslim community representative

Cultural appropriateness in relation to accessing health services was also highlighted by some participants. There was a call from participants for more diversity amongst health care staff, noting the usefulness of staff who could understand certain cultural nuances and health conditions experienced by certain communities.

“Universal services often don’t reflect Black lived experience…need more Black counsellors, psychologist that can be culturally sensitive to us… trauma goes way back, it needs identifying and dealt with”.

Black community representative

“There needs to be fair access in relation to meeting our needs as white doctors often do not get us”.

Asian community representative
“We need to be aware that health disparities are most likely going to increase once all of this is over. We have a huge backlog of NHS care that we need to deliver in terms of routine appointments”.

Muslim community representative

Protection for staff in frontline roles

Unequal treatment of staff was raised as a concern particularly amongst some participants from the Black and Asian communities. There were examples of health care agency staff being sent home from work, as they were considered “at risk of COVID-19”.

“I did a risk assessment at work and due to being 60 and due to my risk score, I was told more or less to pack my bags and go home and they will find some work for me to do. They never did in the end”.

Black community representative

It was acknowledged that whilst efforts were made to redeploy vulnerable staff to other parts of the organisations there were examples of staff in domestic roles, such as cleaners and security staff, who were not afforded the same level of support. It was noted that there were a number of instances where staff were made to continue to work despite their risk. Some participants expressed challenges around the impact of long COVID-19 symptoms and not having support from their managers.

“We have a number of people in the community who are suffering with long COVID-19 and we’re still fighting against employers who refuse to accept and offer support to staff”.

Asian community representative

Participants highlighted the reality for many frontline workers and not being able to isolate given that they lived within multi-generational family structures.

“We had key workers who were bus drivers and nurses living in households with three generations of households and so there wasn’t provisions for them to isolate within their homes. They had to go out to work and therefore they were at risk”.

Muslim community representative
The role of faith organisations was acknowledged in relation to their support with the provision of PPE for front line staff early in the pandemic when there were challenges with supply.

“It was astonishing that care home staff did not have enough PPE and the local Mosque’s helped to fund that”.

Muslim community representative

Availability of vaccines

Participants recognised the efforts made to engage with communities and build vaccine confidence, though some flagged that historic mistrust of pharmaceutical organisations had resulted in their delayed participation in the vaccination programme. Communications about the blood clot risk of the Astra-Zeneca vaccine also had an adverse effect on vaccine confidence, particularly in those who were already hesitant.

In relation to undocumented migrants, participants recognised the work to support communities to register with GPs and provide support with accessing the vaccine without fear of being reported to immigration authorities. However, participants also expressed dismay that such practices were not happening pre-pandemic.

“There wasn’t clarity in the beginning regarding the accessibility of vaccines for undocumented migrants, as they were not registered with a GP. So, this put them at a greater risk of contracting COVID-19 and resulted in a lot of lives being lost. This caused many of them to lose trust with these organisations and it is through the work we have been doing in the community that has helped to rebuild some of that trust”.

Asian community representative

“Imams have been really instrumental in helping to take the fear away from getting the vaccine, especially during Ramadan when people were due to get their 2nd doses”.

Muslim community representative
Experiences of different community groups vary, not least disabled Londoners who had their independence compromised and experienced heightened difficulty accessing health services during the pandemic.

The impact of long COVID-19 appears to be unclear, thus making it difficult for some employees to get the support they need.

London needs to do better at ensuring that no-one is left behind.

Box 2: Key messages from risk of exposure to and transmission of COVID-19 theme

Increased risk of complications and death from COVID-19

Impact of long-term conditions

Participants highlighted that more work is needed to support communications around the increased risk of complications and death from COVID-19, particularly amongst those with long-term conditions.

“[It’s the] second pandemic… [the LGBTQ+] community have lived through the AIDS epidemic, feels like another dangerous virus for over 50’s…[there is a] correlation between fear and trauma”.

LGBTQ+ community representative

“We’ve seen people who have not accessed healthcare in over a year who are now coming in during a time of crisis for concerns around chronic diseases which are linked with COVID-19 deaths. Sadly, people are now coming in with poorly controlled chronic diseases”.

Muslim community representative
In relation to vaccine hesitancy, participants with disabilities felt that there needs to be more consideration for those who may be suffering with chronic conditions. They also felt the additional impact of recovering from side effects from taking the COVID-19 vaccination should be considered.

“I think also there's been a lack of consideration of how disabled people with pre-existing conditions are going to cope with the physical effects of vaccination”.

Disabled Londoners representative

Mental health

Participants across the focus group raised concerns regarding the impact of the pandemic on the mental health of communities. There was acknowledgement that mental health and wellbeing services were already stretched prior to the pandemic and demand was high. Participants felt actions would need to be taken to ensure that adequate support is put in place to manage their mental health, considering the challenging time that communities across the life course have faced.

“[Loneliness] increased in the [LGBTQ+] community… lots of social spaces/safe spaces have gone [because of lockdown]”.

“It’s been harder to access support networks, [as well as] more referrals for mental health and suicide support”.

LGBTQ+ community representatives

From a workplace perspective, participants shared the impact of trauma experienced by frontline staff and how this affected their families.

“It's mainly the ethnic minority, African and Caribbean nurses who have been working on the front line and they carry right now a lot of trauma, a lot of hurt, a lot of pain. For a lot of our nurses, they live with their families and so they come home with trauma and that is obviously shared amongst the rest of the family members”.

Muslim community representative
Some participants from faith communities highlighted the challenges around managing the scale of the demand for support with mental health, and the reality of the time that will be required to address this.

“We’re seeing a mental health crisis as well, so the government needs to step up the efforts and work with community organisations better because we have a huge crisis that’s coming ahead of us”.

Muslim community representative

**Conflicting health messages**

Participants were critical of the official guidance and messages about the roll-out of the COVID-19 vaccination. Many criticised the fact that despite the increased risk of infection, severe symptoms and death, people from Black, Asian and minority ethnic backgrounds were not prioritised to be vaccinated earlier.

Social media played a key role in presenting conflicting health messages, as participants reflected on the contrast between what was being said publicly by health and government officials regarding the efficacy of the COVID-19 vaccine and what they had seen on videos that had been circulated on platforms such as WhatsApp.

“I only got my [vaccine] information about side effects from friends, general conversations and Instagram posts… the volume of these posts made me think there was some truth to the posts”.

Young Londoners representative

Participants from the faith community acknowledged the role of faith leaders in helping to build confidence by addressing misinformation and leading the way by sharing their personal experience of having the vaccine. Participants felt that more time and ongoing work with communities would be needed as conflicting health messages continue to be shared on multiple platforms.

“Many don’t listen to Government messaging – most of the people on TV are white and messages are in English”.

Asian community representative
“This fear is real (the mark of the beast), especially among the older church communities. What can church leaders and health professionals do to allay their fears?”

Black churches representative

“There is still a low take up rate in the Black community in Brent, despite pop-up vaccination centres in local areas, due to historic mistrust. It will take time”.

Black community representative

Co-production with communities

Participants reflected on the actions taken to engage with communities particularly with the COVID-19 vaccination programme. Participants congratulated the impact of community champions and their continued engagement with communities. One of the cross-cutting themes across the focus group was the need to continue to co-produce with communities on all aspects of public health and not just on the vaccination roll-out.

“The government started to lean on organisations such as Black Thrive, Croydon BME Forum to better understand the impact of COVID-19 on Black communities”.

Black community representative

Participants shared examples of great work that had been delivered to address inequalities but felt that lessons needed to be captured from the work and shared with others.

“There is so much work being done in the community to tackle inequalities, but not enough cohesion, so we don’t know what is going on. We need to start coming together as a community to strengthen the work that we do have”.

Black community representative

The COVID-19 champions programme, for example, was shared as an example of how the system could partner directly with communities working in ways that enable direct and informal communication and ongoing true co-production.
Racism, discrimination, stigma, fear and trust

The impact of racism and discrimination was one of the major cross cutting themes from the focus groups. Participants highlighted their lived experience of racism and discrimination in London.

Experience of staff working in health and care settings

In the workplace, there were examples of health and care workers who were subject to abuse from patients and their families who had requested that they didn't want to receive care from staff members from particular communities.

“Our colleagues in the Chinese community are probably getting some of the worst kind of publicity. In terms of hate crime, the Filipino nurses and carers are also getting it in the workplace because they are being refused by their clients”.

Asian community representative

Others shared challenges about the way risk assessments were carried out, which left many health and care staff from Black, Asian and minority ethnic backgrounds either without work or working in high-risk areas.

“There’s a lot of injustice, and especially when you see and hear stories about Caucasian nurses being put on the non-COVID-19 wards and our nurses being constantly put again and again on the front-line working long hours”.

Muslim community representative

Box 3: Key messages from the increased risk of complications and death from COVID-19 theme

Londoners are aware of the differential risks from COVID-19 and understand the need for the infection control measures that were in place. However, they feel the messaging for those with pre-existing conditions can be improved.

Londoners recognise the strength of the community champions and want to be part of co-producing interventions for their community.
There was an overwhelming acknowledgement that actions taken so far has not addressed structural racism and discrimination.

“Racism should be seen as a public health issue in order to deal with inequalities”

*Black community representative*

“I don’t think much has changed. As long as the institution is racist, the change will not happen. But we need to remove this from the structure of public services”

*Asian community representative*

“These disparities for health have happened for decades and they’ve never been addressed, and even in COVID-19 they still have not been addressed. The government spent lots of money on lot of things, but actually, why are we - the ethnic minority communities still worse off?”

*Muslim community representative*

**Feeling judged**

Participants noted the changes in attitudes and behaviour towards people from Black, Asian and minority ethnic communities. For many, unhelpful groupings of ethnicities under the umbrella of Black, Asian and minority ethnic (BAME) equated to “Blame” as participants felt that a lot of the media around COVID-19 gave the impression that there was something “wrong” with people from those communities who were disproportionately affected by COVID-19.

“I overheard my neighbour saying his friend was telling him to stay away from Asians because they’re the ones spreading the virus”.

*Asian community representative*

“I felt judged, as my nurse would say things like ‘don’t put on any more weight because of your risk of COVID-19’.

*Black Churches representative*
Some disabled participants shared examples of how they experienced an increase in rudeness and intolerance during the pandemic and were made to feel “abnormal”.

“I had the lovely experience one day of leaving my local supermarket during the vulnerable person shopping hour and as I left, the store manager yelled out to the security guard. Great, you can let the normal people in now”.

_Disabled Londoners representative_

Young Londoners shared experiences of being stereotyped for not following the rules and feelings of being judged by older generations when being out with friends.

“As young people we are judged by older people when we’re out with friends now. There is this stereotype that young people socialising is what is spreading COVID. This made me angry especially when I saw adults on the news in crowded places at beaches and watching football. All young people were generalised for the few who broke guidance”.

_Young Londoners representative_

**Barriers to accessing communications**

Some participants shared that although translation services are available in health care settings, they were limited during the height of the pandemic and were concerned about the lack of support for people for who could not speak English.

“Even if they have a translator, usually they don’t often find the translator that can translate the information into the language that they understand”.

_Disabled Londoners representative_

Some participants with disabilities felt that some of the infection control policies that were put in place created barriers to accessing communications and put them at a disadvantage.

“At the beginning of pandemic there were some policies that were implemented for infection control, but they had disproportionate impact on disabled people. For example, policy like not allowing visitors to be with the person, and we know that had huge negative impact on disabled people, especially those who need communication support because some people do use very specific ways of communication”.

_Disabled Londoners representative_
Cultural Appropriateness

Participants recognised the actions taken by system partners to address cultural appropriateness in relation to the vaccination programme and the impact that made on communities on building vaccine confidence.

“We did see uptake among ethnic minority communities triple between January – April and that was the result of huge partnership working between the NHS, Public Health England and community organisations. So, these organisations in the community were central to get messages across that were culturally sensitive, linguistically appropriate, contextually relevant. And that is why we saw this dramatic uptake in the vaccine”.

Muslim community representatives

Participants expressed the need for more actions to be taken to address cultural appropriateness within the health and care system. For example, it was noted that staff needed to be supported to better understand how to communicate effectively with patients from other cultures to ensure that they can fully address the health concerns raised.

“Need for people to be more culturally competent, especially around trans/gay rights. [Health] staff need to know how to speak to us and make us feel safe…Are staff asking the right questions? Do service users feel safe? Don’t want to ‘other’ people”.

LGBTQ+ community representative

“Ethnic minority communities are not a monolithic community. We have various nuances and diversities within those communities that we really need to understand to be able to deliver tailored health promotion messages”.

Muslim community representative
Trust

Trust remains a one of the dominant themes presented across the focus groups. Trust is influenced by events well beyond COVID-19 which anecdotally have a knock-on effect on willingness to engage with public sector organisations. Some participants highlighted the lack of trust towards health leaders and were critical of the sudden “concern” for communities given experiences of lack of support.

“People have lost trust with public health and not just because of COVID-19 and how it has been managed, but pre-existing health inequalities where people did not receive the right information, the right support and the right guidance”.

Muslim community representative

Participants reflected that rebuilding trust would take time and that there was a need for clarity and sustained commitment from health and care partners.

“There is still fear and mistrust within our communities. Tackling that mistrust will take much more work than a few workshops and activities here and there”.

Anonymous representative from post-event survey

Although changes in attitudes towards people from Black, Asian and minority ethnic communities have been acknowledged, Londoners call for structural racism and discrimination to be tackled. As long as institutions are racist, the required change will not happen.

The impact of cultural appropriateness on the vaccine uptake is acknowledged. Cultural appropriateness needs to be addressed throughout the health and care system.

Londoners recognise that rebuilding trust will take time. They want to see a clear and sustained commitment from health and care partners.

Box 4: Key messages from the racism, discrimination, stigma, fear and trust theme

The illustrated minutes below provides a summary of discussions during the community engagement sessions and the key themes identified.
Figure 4: Key messages from Beyond the Data community engagement sessions
Community priorities for action

The following is a summary of priority actions highlighted by communities in relation to how they would like local leaders and health services to work with them to address the issues raised across the focus groups.

Co-production with communities

The strength of community organisations needs to be acknowledged. They should be involved in decision making early on, as opposed to after strategies and interventions have been put in place. Co-production with communities needs to be prioritised as a solution to addressing health inequalities. The momentum of engagement with communities needs to continue beyond the roll-out of the COVID-19 vaccination programme and extended to include long term conditions and other social issues.

“Do not do anything without involving the communities, also must test interventions with communities”.

Muslim community representative

“Have people that look like me to help me”.

Black community representative

Participants from the faith community called for health and care partners to utilise the assets available within their communities, as they have a greater understanding of their communities; knowing what they want and how they would like information to be presented.

“Places of worship are a huge source of support and links to the Black, Asian and minority ethnic communities. This should be recognised and used”.

Faith community representative

Young Londoners called for greater opportunities and involvement in engagement events to inform services that are being developed for them. There is a call for delivery partners to recognise their influence and to ensure that young leaders are trained and empowered to cascade the right messages to their communities.

“Young people listen to young people, so we need to work on getting young people the right messages”.

36
“[Those leading the COVID-19 response should] youth-proof documents and messaging on COVID-19. [You could] just get local and national youth councils and scrutinisers involved because we’ve been doing this for a while and know what young people will and will not understand. For example, you could make WhatsApp-able documents that young people will read”.

Young Londoners representatives

Participatory research
In addition to co-production, communities want to be more involved in participatory research with system partners. Participants acknowledged the limited research in relation to specific health issues for some communities and the importance of being involved in research given historic experiences.

“We should be developing appropriate research involving black women that is able to demonstrate how institutional racism actually occurs within the NHS and looks at the experiences that they are having across the life course. It is happening to young women, women of childbearing age and older women. We all know that COVID-19 has shone a light on the inequity that exists”.

There was a clear emphasis for research to be led by researchers that reflect the communities that they are trying to engage.

“We need to capture the lived experience of different communities in relation to access to services and led by culturally competent staff. As too often this is led by people who do not have full understanding of the communities”.

“We need to get involved in research as black people. We need to work together to engage with the systems that affect us”.

Black community representatives

Creating services that reflect London’s diverse cultures
Communities called health and care partners to acknowledge that health services should reflect cultural nuances, ensure that services are staffed by practitioners who reflect the diversity of the population that they serve, and receive adequate training in culturally appropriate practice. The need to review existing interventions, as well as update culturally
appropriate resources was highlighted. In addition, participants felt that the need for a shift from unhelpful grouping of communities.

“You miss those cultural nuances when you lump people together under the umbrella of BAME. There are differences. The lived experiences of access to healthcare can be very different: from someone who is born in the UK compared to somebody who is new to the country and that needs to be considered”.

Anonymous representative

The need to resource community organisations

Participants highlighted that although the work of volunteers is to be celebrated, there is a need for community organisations to be better supported to make successful applications for sustainable funding, so they continue to support their communities.

“We can’t do the work without being resourced. The community champions and other volunteers are working so hard to support people to access health services and this needs to be backed with financial provision”.

Asian community representative

“We need to build on moving forward, but we need to be able to do it in a sustainable way. A lot of these community organizations, like mine are doing this in our own time on a voluntary basis and we have frontline jobs, and it was very busy. Partnership working in a sustainable way requires resources: human, technical and financial. Those need to be in place to have a meaningful change that is long lasting”.

Muslim community representative

Addressing discrimination and racism

The engagement highlights communities call for racism to be acknowledged as a public health issue. Communities are challenging health and care partners to commit to addressing structural racism and work to improve the experiences that Londoners from Black, Asian and minority ethnic communities face within the health and care system. For example, communities engaged called for a review of ‘Stop and Search’ measures and their disproportionate impact on certain communities. Crucially, there was a call for London’s health and care system partners to work with community organisations to start to rebuild that trust.
“There is an urgent need to dismantle institutional structural and systematic racism - things must change”.

“Healing hasn’t happened. Some services that are wishing to support the community are those that communities lack trust with due to historical discrimination”.

Black community representatives

Improve access to wellbeing services

Communities have called for further improvements to wellbeing services. Waiting lists for example, particularly in mental health services, emerged as a priority and concern. Communities are keen to ensure that service providers take on board feedback from patients regarding their challenging experiences of accessing health services during the pandemic and demonstrate a clear commitment to improving access and health outcomes for all communities.

“Poor experiences have been happening for decades”.

“We don’t want to go back to that kind of normality where we are still facing inequalities within health”.

Muslim community representatives

“Access to wider services…social care, education support etc… is much harder for Black parents… [We] have to fight at every step”.

Black community representative

Moving forward, communities want to be given more choice in relation to how they access health services and investment towards rebuilding relationships between health providers and patients.

“As things open up, I think the key issue is about offering people choice and not just returning to pre pandemic normal”.

Disabled Londoners representative
Data and Information sharing

Communities recognise the value of collecting data for the development of services but request greater transparency about how their data is used. Many remain hesitant to share information about their gender identity, sexual orientation, ethnicity and faith background given the discrimination that they have experienced and, in many cases, continue to experience. Public institutions should recognise some communities' perceptions of discrimination, and where these practices exist it is vital that relevant organisations take swift decisive action.

“[More] data capture needed on a local a level… but needs to be done in a safe way. Need to make it safe for people to disclose their sexual orientation and personal data… many people still ‘prefer not to say’. Don’t want to be minimised but are scared… stigma still exists”.

LGBTQ+ community representative

“How are we supposed to address inequality when we’re not even collecting the right data? We have no faith-based outcomes that are collected properly across the whole spectrum. So, we really need to look at the data that we’re collecting to reduce the gap”

Muslim community representative

Community priority actions illuminated through engagement activity with Londoners:

<table>
<thead>
<tr>
<th>Co-production</th>
<th>Involving communities, including young Londoners in co-production of interventions for the community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Participatory research</td>
<td>Research by researchers that reflect the community</td>
</tr>
<tr>
<td>Culturally competent care</td>
<td>Staffing of health and care services to reflect the diverse communities they serve</td>
</tr>
<tr>
<td>The need to resource community organisations</td>
<td>Adequate resourcing of community organisations to support their work</td>
</tr>
<tr>
<td>Addressing discrimination and racism</td>
<td>Acknowledge racism as a public health issue</td>
</tr>
<tr>
<td>Improve access to health care and wellbeing services</td>
<td>Londoners want better experience of health and care services</td>
</tr>
<tr>
<td>Data information and sharing</td>
<td>Londoners want greater transparency with how their data is used. They want collected data to be fit for purpose</td>
</tr>
</tbody>
</table>

Box 5: Key priority actions identified from the community engagement sessions.
**Limitations**

The focus groups provided a snapshot of the reflections from Londoners representing the city’s diverse demographic, social, cultural and economic characteristics. It is worth noting that participants were not asked to disclose personal demographic information about themselves or to disclose what part of London they came from.

Given the impact of social distancing measures it was not possible to engage with Londoners in a face-to-face context. This has inadvertently excluded Londoners unable to participate via digital platforms.

There was a small sample size of participants involved in the focus group sessions. From an analytical perspective, having a larger number of participants gives greater reliability to generalise the findings to London’s entire population. Nonetheless, our participants were reflective of the diverse communities in London.

Future research could assess the sub-regional differences of attitudes and perceptions of actions taken to address health inequalities following on from the recommendations highlighted in the Beyond the Data report.

**A commitment for change**

The Beyond the Data report from 2020 produced seven key recommendations (Appendix 1) and highlighted the areas where commitment, focus, and delivery at scale could make a significant difference in improving the lives and experiences of Black, Asian and minority ethnic communities. The engagement sessions conducted in 2021 highlight a need for further action to address inequalities and reduce the disproportionate impact of COVID-19 and other social determinants.

London’s health and care system leaders have gained better knowledge of real-life experiences of Londoners, acquired an increased understanding of inequalities and how structural racism and discrimination persists in the health system. London’s leadership is committed to addressing deep seated inequalities as the city recovers, to build back fairer, tackle long-standing injustices and improve the health and wellbeing of communities using local data and information to apply targeted action.
Key elements of the health and care partnership work include taking forward the Health and Care Vision as London works towards becoming the world’s healthiest city and a place where everyone has access to world class care. The refresh of the Mayor’s Health Inequalities Strategy implementation plan and progressing the recovery Missions are key to London’s progress.

The way insights, such as those collated in this report, are used will inform progress to rebuild trust with communities in COVID-19 recovery and beyond. The London Health Equity Group will aim to ensure that communities continue to be engaged in a meaningful way and commit to continuing to set the tone for health inequalities priorities for health and care partners in the city.

We will ensure that findings from this research are accessible to the broad and diverse range of communities who helped to bring it together. Moreover, we endeavour to ensure that the engagement exercises and partnership working unlocked during the pandemic are not lost, but rather built upon.
Appendix 1: Recommendations from Beyond the Data report

1. Mandate comprehensive and quality ethnicity data collection and recording as part of routine NHS and social care data collection systems, including the mandatory collection of ethnicity data at death certification, and ensure that data are readily available to local health and care partners to inform actions to mitigate the impact of COVID-19 on BAME communities.

2. Support community participatory research, in which researchers and community stakeholders engage as equal partners in all steps of the research process, to understand the social, cultural, structural, economic, religious, and commercial determinants of COVID-19 in BAME communities, and to develop readily implementable and scalable programmes to reduce risk and improve health outcomes.

3. Improve access, experiences and outcomes of NHS, local government and integrated care systems commissioned services by BAME communities including: regular equity audits; use of health impact assessments; integration of equality into quality systems; good representation of Black, Asian and minority ethnic communities among staff at all levels; sustained workforce development and employment practices; trust-building dialogue with service users.

4. Accelerate the development of culturally appropriate occupational risk assessment tools that can be employed in a variety of occupational settings and used to reduce the risk of employee’s exposure to and acquisition of COVID-19, especially for key workers working with a large cross section of the general public or in contact with those infected with COVID-19.

5. Fund, develop and implement culturally appropriate COVID-19 education and prevention campaigns, working in partnership with local Black, Asian and minority ethnic communities and faith communities to reinforce individual and household risk reduction strategies; rebuild trust with and uptake of routine clinical services; reinforce messages on early identification, testing and diagnosis; and prepare communities to take full advantage of interventions including contact tracing, antibody testing and ultimately vaccine availability.

6. Accelerate efforts to target culturally appropriate health promotion and disease prevention programmes for non-communicable diseases promoting healthy weight, physical activity, smoking cessation, mental wellbeing and Beyond the Data: Understanding the Impact of COVID-19 on Black, Asian and minority ethnic communities effective management of chronic conditions including diabetes, hypertension and asthma.

7. Ensure that COVID-19 recovery strategies actively reduce inequalities caused by the wider determinants of health to create long term sustainable change. Fully funded, sustained and meaningful approaches to tackling ethnic inequalities must be prioritised
Beyond the Data: understanding the unequal impact of COVID-19 in London one year on

Themes from community engagement findings

Increased risk of complications and death from COVID-19

- "We’re seeing a mental health crisis as well, so the government needs to step up the efforts."
  Muslim community representative

- "There is still a low (vaccine) take-up rate in the Black community... due to historic mistrust. It will take time."
  Black community representative

Racism, discrimination, stigma, fear and trust

- "I don’t think much has changed. As long as the institution is racist, the change will not happen."
  Asian community representative

- "I felt judged, as my nurse would say things like ‘don’t put on any more weight because of your risk of COVID-19.’"
  Black Churches representative

Social and economic inequalities

- "What we saw initially was that many support systems for disabled people collapsed very quickly... People really struggled to get food, to access health service. For some it still continues."
  Disabled Londoners representative

- "We’ve never had so many referrals for people wanting to access support for domestic violence and safeguarding."
  LGBTQ+ representative

Risk of exposure to and transmission of COVID-19

- "We have a number of people in the community who are suffering with long COVID and we’re still fighting against employers who refuse to accept and offer support to staff."  
  Asian community representative

- "We feel like when young people got COVID-19 it was dismissed, and we were expected to ‘get on with it.’"
  Young Londoners representative

What next

Londoners want to be part of the solution, not consulted as an afterthought.

Community Priorities for Action

- Designing services with Londoners that reflects diverse cultures
- Funding and support for community organisations
- Addressing discrimination and racism
- Improve access to wellbeing services
- Greater transparency about how your data is used

The report will be used to inform the work London needs to do to both live with COVID and to recover from the devastating impact of the pandemic in London.

For more information, please contact London.HEST@phe.gov.uk.

Glossary

Acronyms
COVID-19 – Coronavirus Disease 2019
GLA – Greater London Authority
LGBTQ+ – Lesbian, Gay, Bisexual, Transgender, and Queer or Questioning
NHS – National Health Service
PHE – Public Health England
PPE – Personal Protective Equipment
VCSE – Voluntary, Community and Social Enterprise
OHID – The Office for Health Improvement and Disparities
DHSC – The Department of Health and Social Care
BAME – Black Asian and Minority Ethnic*

*In line with the requests of community participants we have not used the acronymised version

Terminology
Inequality – an inequality is an unfair and avoidable difference between people or groups of people. Inequalities exist in health, income and other areas.

Monolithic – an organisation or system which is very large, without interesting differences and unable or unwilling to be changed

Mortality – death.

Stakeholder – a person, group or organisation that has an interest or concern in a given topic

Wider determinants of health - also known as social determinants. The diverse range of social, economic and environmental factors which impact on people’s health.
References


Acknowledgements

This work would not have been possible without the contributions of those provided valuable insights for this work. Many thanks to the focus group attendees who gave up their time to be involved in this research and for being open, honest, and sharing personal experiences. Also, to the wider communities who gave feedback.

This work was led by the London Health Equity Group which the London partners: Public Health England, NHS England, London Councils, The Mayor of London and The Institute of Health Equity. A steering group with representation from the partnership provided invaluable governance and support to this project. Many thanks also to webinar and roundtable panellists, attendees and co-contributors.