healthwatch Hertfordshire

Tackling Ethnic Health Inequalities: Learning from Black and Asian Community Leaders

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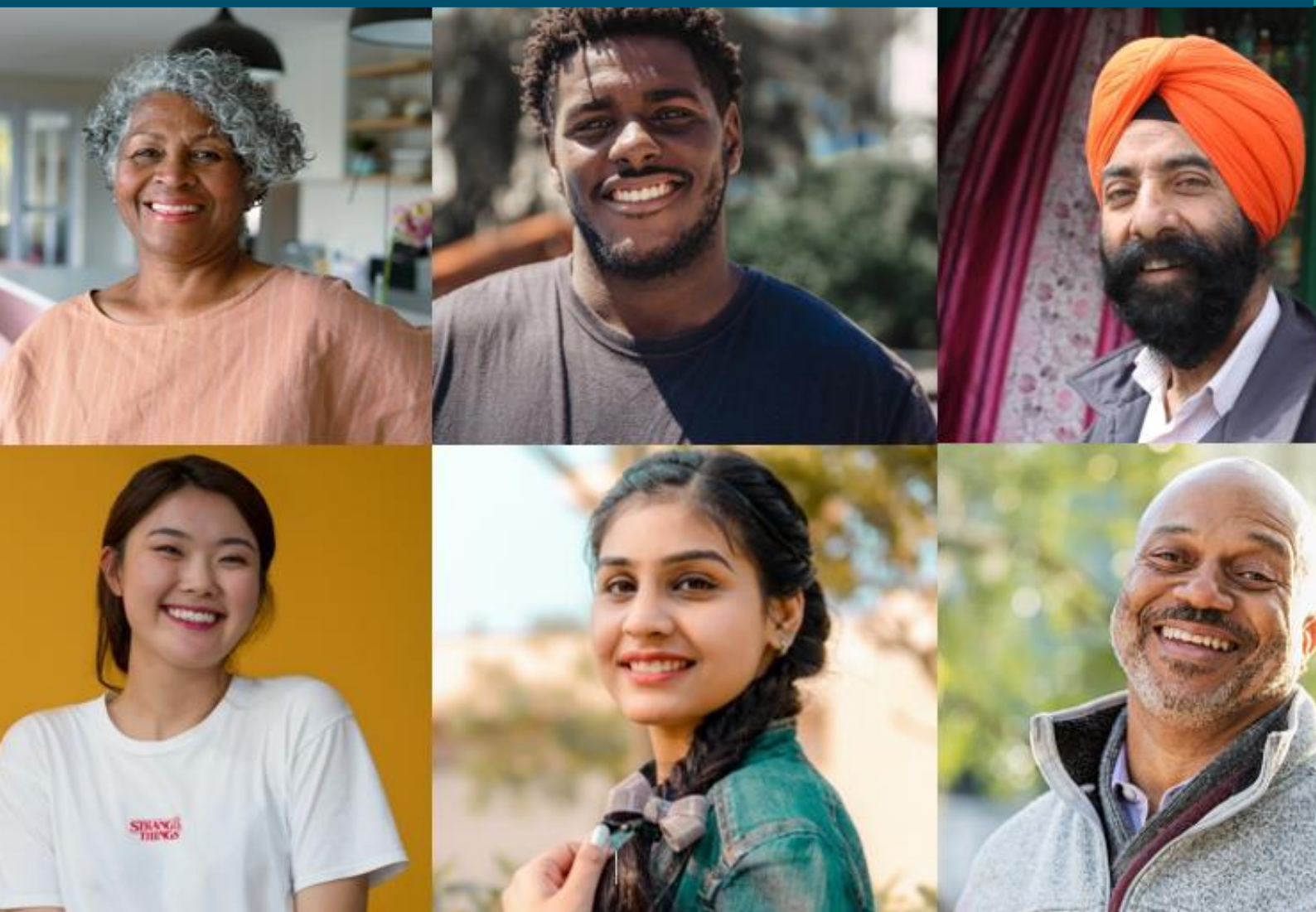


Executive Summary

What we found

- A deep mistrust in government and healthcare bodies, resulting in less involvement or engagement from Black and Asian communities on issues relating to healthcare.
- Feelings of being undervalued or concern about not being treated equally or fairly by healthcare professionals and local government.
- A feeling that Black and Asian communities are only engaged with when it suits the needs of the NHS or local government. Community leaders instead wanted more meaningful engagement, that demonstrates a longer-term commitment to listening and building trust.
- Experiences of areas with lower Black and Asian populations being ignored.
- That one size does not fit all. Community leaders stressed the damage of homogenising lots of different groups, cultures and communities into the term 'BAME'.
- That quick simple solutions for complex issues don't work. Community leaders stressed the importance of designing interventions from a place of understanding.
- Representation matters – leaders discussed the lack of representation of Black and Asian communities, especially in leadership positions. This means that individuals sometimes have nowhere to take their concerns and are unsure their concerns will be heard if they do.
- Linked to the point above, leaders also talked about the complexity of representation. They highlighted that the use of Black and Asian celebrities encouraging vaccine uptake lacked credibility for a lot of people that didn't share the same lived experience as a celebrity. This resulted in the counterproductive effect of people feeling that the vaccine was being forced upon them.

How it made a difference

- We submitted evidence collected from this work to local councillors at the Black Asian Minority Ethnic (BAME) Health Inequalities, Health Scrutiny Topic Group. We focused on the lack of cultural competence within local healthcare services and the need for a system-wide approach for tackling ethnic health inequalities. Recommendations were made to healthcare providers by Hertfordshire County Council's Health Scrutiny Committee, and we continue to work with them to ensure these recommendations are taken forward.

- Our work with the Ethnic Minorities Inequalities Group, made up of NHS, Council and Voluntary sector groups is ongoing. The group was initially established to address vaccine confidence within communities, but now has a broader role of addressing health inequalities through community interventions where possible. Here, we have been sharing our knowledge and evidence on how best to engage with different communities and the importance of using a tailored approach.

- Our findings have fed into the Hertfordshire and West Essex (ICS) Health Inequalities Workstream to support with the development of a good practice engagement model to ensure the community voice is heard.

A message from our Chief Executive

Engagement with Black and Asian communities plays a crucial role in tackling ethnic health inequalities. Over the past year, we have built strong relationships with community leaders, who have highlighted how, to be effective, engagement needs to be continuous, meaningful and culturally sensitive and recognise the diversity both between and within communities.

We continue to build on our partnerships with community leaders informing our upcoming research: "Making Local Healthcare Equal for All" which explores Black and Asian Hertfordshire residents' views towards, and experiences of, local healthcare services.

We are pleased to share this learning with our NHS and VCFSE partners so they can better engage with Black and Asian communities, and help to improve services and tackle ethnic health inequalities.

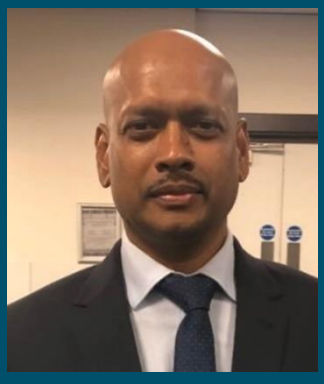
We wish to particularly thank the community leaders who participated in this research. We look forward to continue working together as we strive to make healthcare equal and more inclusive.

Geoff Brown, Chief Executive

A message from our community partners

"Healthwatch Hertfordshire's communication, interaction and work has been to the highest standard and should form the template for working with the Black community in the future for other organisations. It's clear that they were informed on some issues on our community specifically, before first contact, practically inputting what they learn from Black Voice Letchworth, other groups and their own investigation, then putting it into practice. This approach built a sustainable relationship of trust between us, making it a joy to be part of our partnership."
Micaelia Clarke, Chairperson, Black Voice Letchworth

"It is a great privilege to work with Healthwatch Hertfordshire. You come at the right time, and address the right people, especially with the work with ethnic minorities who were greatly impacted both during and following COVID. Health inequalities are very important going forward, as immigration to the UK is increasing and we have a responsibility to make people feel at home. That's what equality is all about. As the Chief Executive of One Vision, I've been working very closely with Healthwatch Hertfordshire as there is a lot of work to be done. I want to add that the team, including Geoff, have great experience and a great interest in addressing health inequality. We are going in the right direction together."
Enoch Kanagaraj, Chief Executive, One Vision



About Healthwatch Hertfordshire

Healthwatch Hertfordshire (HwH) represents the views of people in Hertfordshire for health and social care services. We provide an independent consumer voice for evidencing patient and public experiences and gathering local intelligence with the purpose of influencing service improvement across the county. We work with those who commission, deliver, and regulate health and social care services to ensure the people's voice is heard and to address gaps in service quality and/or provision.

Background

In February 2021, we launched a survey exploring over 1,800 Hertfordshire residents' views towards, and experiences of, the COVID-19 vaccine.

At the same time, local and national concern started emerging about the disparities in vaccine uptake between different ethnic groups. However, the majority of respondents to our survey were White British, meaning the data we had collected could not explain the differences in uptake.

In response, we began targeted work with Black and Asian communities to firstly aid understanding of the factors that influence vaccine confidence within these communities, but also crucially, ensure that these groups' concerns could be better heard in future discussions on topics of inequality or disparity.

This report details what we learnt from the stakeholders we engaged with and how this learning can inform engagement with Black and Asian communities across the Hertfordshire and West Essex Integrated Care System (ICS).

Aims

- To establish the key concerns of ethnically diverse communities in Hertfordshire relating to the COVID-19 vaccine.
- To understand how we can best engage with Hertfordshire's ethnically diverse communities; what facilitates or hinders engagement?
- To share what stakeholders told us to help inform and improve vaccine delivery and information provision from local health and social care services.
- To share what stakeholders have told us to help inform local services on how they can best engage with ethnically diverse communities.

Methodology

Firstly, we carried out a literature review to establish key barriers and concerns at a national level that were preventing people from having the COVID-19 vaccine. The literature evidenced how mistrust in the government and public bodies stemmed from both historical

treatment as well as present-day inequalities which impact a person's lived experience of accessing and using healthcare. Key historical examples of mistreatment within the medical field include the Tuskegee scandal, in which hundreds of African American men had syphilis left untreated as part of an experiment, and the 'father of modern gynaecology' forcibly using Black female slaves to further his work without the use of anaesthetic.

Modern-day inequalities largely centre around disparities in health outcomes between different ethnic groups. For example, Black women are 4 times more likely to die in pregnancy and childbirth than white women (MBRRACE, 2021) and Black men are disproportionately detained under the Mental Health Act (Mind, 2019).

The COVID-19 pandemic has both highlighted, and worsened, such inequalities, with ethnically diverse groups being disproportionately negatively impacted. This has further deepened the mistrust people have in the healthcare system and the feeling that the healthcare system was not built for them.

The findings from this literature review were used to inform our approach to stakeholder consultation.

As part of the stakeholder consultation exercise, we reached out to 43 small, medium and large community groups. This was important to make sure we could try to hear from as many people as possible, from different backgrounds, and hear a variety of perspectives at a local level.

In particular, One Vision, Black Voice Letchworth and St. Albans Islamic Centre took part in multiple rounds of engagement, including a stakeholder event. With these groups, we collaboratively discussed findings, future research topics and opportunities for working together.

This work began in Spring 2021 and has continued throughout the year. It has been built into future work on unequal treatment.

Key Findings

Terminology

Stakeholders discussed the importance of using respectful and accurate terminology. The term 'BAME' was viewed particularly negatively, with stakeholders emphasising that the term inappropriately homogenises ethnically diverse groups and fails to distinguish between the diverse histories, challenges and stories of people of diverse ethnic groups by grouping all non-white people in one category.

Stakeholders also felt the term 'ethnic minority' was problematic, as it implies that the views and experiences of different ethnic groups hold less value than the majority.

Another term that was discussed was 'vaccine hesitancy'. At the time of engagement, this term was being used commonly by organisations and in media, with a particular focus on how Black and Asian groups in particular were 'vaccine hesitant'. However, discussions with stakeholders highlighted that this term over-simplifies concerns, and does not account for the huge impact that ethnic inequalities and discrimination have on people's trust and confidence in a new vaccine.

Complexity of Communities

Stakeholders stressed the importance of understanding the complex nature of communities and ethnic groups, and ensuring that any engagement takes this complexity into account. They emphasised that different groups have their own histories, experiences, practices and opinions, meaning there cannot be a 'one-size-fits-all' approach to the challenges that different ethnic groups face.

For example, the need to have choice and control over accepting the COVID-19 vaccine stems from different places for different ethnic groups. Black groups tend to relate choice and control to historical treatment and long-standing issues of mistrust, while for some faith groups, choice and control is about ensuring that the vaccine doesn't compromise their religious beliefs.

We also found that whilst Asian communities tended to have concerns that could be addressed through myth-busting and information provision (such as transparency around vaccine ingredients), Black communities tended to want trust building to be built into conversations with health professionals and for their concerns to be heard without judgment – meaning that engagement in relation to the COVID-19 vaccine would need to be specific to each group.

Additionally, stakeholders talked about the importance of variation within, as well as between communities, and the impact of intersectionality. Intersectionality between race, religion, culture, gender, and age, amongst other factors, means that there are sub-groups within ethnic groups that have their own unique experiences, views and feelings.

For example, one stakeholder talked about how people will often refer to the 'Black community' although opinions and concerns differ greatly between Black Caribbean and Black African groups, and then again between more specific nationalities.

Another example was where one stakeholder noted how the matriarchs of South Asian families may be more likely to be concerned with their family's health than their own, which can contribute to a lack of engagement with healthcare services. Again, this emphasises the importance of taking a tailored approach and addressing a group's specific concerns.

Statistics vs lived experience data

Stakeholders discussed the overreliance of statistical data and the lack of lived experience data that is collected amongst Black and Asian communities, both locally and nationally.

Furthermore, stakeholders recognised that Black and Asian communities will naturally make up smaller percentages of the county's populations, meaning statistical data often does not hold huge value when considering the concerns of these communities. This is worsened when looking at localities or towns which were not very ethnically diverse - stakeholders gave examples of places within Hertfordshire with smaller numbers of Black and Asian residents and how difficult it was to get views and concerns on the agenda, recognised or valued.

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Representation of Communities

When recognising the variation across and within groups, it is perhaps unsurprising that stakeholders felt that group representation is not always accurate or sufficient. For example, stakeholders felt that ethnically diverse MPs and celebrities endorsing the COVID-19 vaccine do not truly represent the lived experience of most people within an ethnic group, with one stakeholder noting that Black celebrities lack credibility in the eyes of Black communities due to differences in lived experience. More frustrating than this was where organisations called for one person to represent all groups that come under the term 'BAME'.

Similarly, stakeholders discussed how community leaders can also not be seen as representatives of an entire community, again, due to them being unable to represent everybody's own lived experience. Stakeholders stressed that they themselves could not be seen as representatives, and instead, emphasised the value of hearing from as many people as possible during engagement activities to ensure that everybody's opinion can be acknowledged and respected.

A lack of sufficient representation was linked, in part, to a lack of ethnically diverse people in leadership roles, and the importance of these leaders being well-known and easily recognisable.

People from different ethnic groups want to see visible advocates for their issues and concerns so that they can see that they're being valued and looked after. Leaders of these communities also need to be known so that they can use a platform to influence and bring about change. For this reason, leaders need to be seen by both the community and the system.

Trust and Continuous Engagement

Trust

Underpinning concerns with the COVID-19 vaccine, as well as a lack of general engagement, is a deep mistrust in governmental and public bodies, and an anger at ethnic inequality. Stakeholder discussions highlighted that this is felt particularly strongly by Black communities.

Mistrust arises from different places for different groups, and it is important to understand this and be mindful of this when engaging with different communities. For Black communities, mistrust in the government, and institutions such as the NHS, are often attributed to institutional racism and historically poor treatment. The fact that these issues are historical and/or systemic demonstrates that initiatives aimed at Black African and Black Caribbean communities need to be broad with a long-term focus, rather than offering a tokenistic 'quick fix' to a specific issue, such as confidence levels in the COVID-19 vaccine.

The importance of building trust is particularly significant in light of the COVID-19 pandemic, during which mistrust has grown deeper for many communities. Stakeholders expressed frustration at the fact that specific ethnic groups were not on the Joint Committee of Vaccination and Immunisation vaccine priority list despite having higher infection and mortality rates.

Continuous Engagement

Stakeholders talked about how best to build trust and make community members feel more valued. The focus here was on the importance of continuous engagement with all communities. Stakeholders talked of how people and ideas constantly evolve and change, and how crucial things can be missed if continuous engagement is not happening. Organisations and initiatives need to be responsive and sensitive to change to ensure the long-lasting success of any initiative.

However, it is important to stress that continuous engagement also includes engaging with communities on a whole range of issues; not just concerns that are specific to particular ethnic groups. Stakeholders felt that their respective communities are often not engaged with, and often, people feel that there is no point in getting involved with work due to feeling that their contributions are not valued.

Another key element to this theme was the need for real change to result from communities' participation in engagement activities, and for communities to be kept informed of the

impact their voice has had. For many groups, trust decreases when organisations use their feedback but do not share the outcome. By not sharing feedback, communities do not see how their participation has made any positive change and this acts as a barrier to future engagement. Stakeholders therefore discussed how important it is to monitor changes that have happened as a result of people sharing feedback, and that there is a need to make sure communities are kept up to date with changes at all times.

Continuous Engagement: Practicalities

The ways in which organisations engage with communities, and work to build and maintain trust, will largely determine the success or failure of any engagement or initiative. In terms of factors that hinder engagement, stakeholders talked of how information on various topics is often provided in 'white spaces'. This can be a barrier to engagement with Black and Asian people who may not frequent these spaces and receive their information through different channels than the White British population, meaning it is important that engagement takes places in 'safe spaces' where people feel comfortable.

Similarly, stakeholders told us that more effective engagement should be with specific groups, rather than addressing multiple ethnic groups in one sitting. This is because community members are likely to feel more comfortable in their own group and more able to share their views and opinions freely, but also recognises that what is important to one group may be less important to another. This again emphasises previous points discussed of there being no 'one-size-fits-all' approach.

Another significant challenge for continuous engagement is that often, staff of community groups are volunteers who facilitate these groups out of good will. Staff earn a living through employment elsewhere, and so they are restricted on how much they can do and achieve within the community group. Organisations need to be aware of this when engaging with groups, and make sure that they respect people's time and, where possible, put measures in place to alleviate such constraints.

Stakeholders also discussed the difficulty in getting funding and resources for their community groups due to their focus not *traditionally* being viewed as a priority. This can make outreach and engagement particularly difficult, as even if community organisations are onboard with an engagement piece, they themselves may be unable to reach their communities without additional support.

Conclusion

It is clear that for engagement to be successful, communities need to be at the heart of engagement, and there needs to be a better understanding of the intricacies and complexities of different ethnic groups to allow for cohesive, collective action towards making change happen.

This work highlights the importance of working with communities directly to understand how best to value them and their contribution.

Crucially the work highlights the importance of continuous engagement and engagement that is not only driven by statutory agendas. These approaches ensure not only that people's views and experiences are valued but that statutory organisations are committed to understanding the communities they serve in depth, as well as re-building and/or building trust.

Impact of the Work

Learning for Healthwatch Hertfordshire

Based on the learning from this research, we have made changes to the language and terminology we use when talking with and about different ethnic groups and inequality.

Examples of terms we no longer use are the terms 'BAME' and 'Vaccine hesitancy' and we encourage our statutory partners to do the same through our work with them.

Where appropriate, we are committed to being more specific to the groups and the people we are talking to or referencing. This is learning that we have also taken forward in our communication strategies, by using terminology and imagery that is reflective of the groups we are trying to reach.

Importantly we continue to work with our stakeholders to keep testing our research methods and communication strategies and share this learning across the healthcare system. Thank you again to our stakeholders for their valuable insight.

Next Steps in our Research

Conversations with stakeholders were hugely insightful and covered a range of topics in great detail. However, the impact of health inequalities, not just on engagement and trust, but on people's lives, was highlighted as the most important research for us.

This stakeholder engagement has informed a subsequent piece of research, titled: 'Making Local Healthcare Equal for All'. The aim of this piece of work is to understand how Black and Asian communities view and experience local healthcare services, and whether they believe them to be understanding of, and responsive to, their ethnic, cultural and/or religious needs. This research will result in recommendations we send to local health and social care leaders to ensure there is equality and inclusivity in local NHS services. This report is due to be published in Summer 2022.

Learning for the Wider System

We regularly update our partners across the county on the feedback and intelligence we are receiving, and help the system to implement change to make sure that people's voices can make a difference.

Along with other community and voluntary sector partners, we submitted evidence to local councillors regarding ethnic health inequality at the BAME Health Inequalities Topic Group.

We presented evidence on a lack of cultural competence, a deep mistrust and the need for a broad, system-wide approach. A number of recommendations were made and we will ensure we hold the system to account as we move forward, to make sure these recommendations are implemented. The full report, presentations and responses from organisations can be found here.

We regularly attend the 'Ethnic Minorities Inequalities' Group where we continue to work in partnership to share intelligence and cohesive action across local NHS and county organisations. This group was initially set up to focus on increasing vaccine uptake in ethnically diverse communities. We shared knowledge on how to best engage with communities on the vaccine and contributed evidence supporting various initiatives, including vaccine pop-up clinics in typically non-white spaces, a need for education webinars, and again highlighted the importance of a broad focus on inequalities rather than targeted approaches. We will continue to work with this group as its remit widens to cover ethnic inequalities more broadly, rather than simply focusing on vaccine uptake.

In addition to sharing findings through groups and partners, our findings have fed into the Hertfordshire and West Essex Integrated Care System (ICS) Health Inequalities Workstream. Our contribution will aid the development of a good practice model for ensuring communities are engaged with and that their contributions are valued.

We also highlighted to local council leaders, stakeholder's concerns that community organisations are often ran by volunteers, and that they often give up considerable amounts of there time whilst struggling with finances and resources. As a result of intelligence provided by us and other partners, the Health Protection Board set up a funding pot for small organisations and community groups to apply for small grants to help maintain services that have been negatively impacted by COVID-19. This went a great way in making sure community groups could keep running, at a time of great need.