A PARTICIPATORY RESEARCH PROJECT:

Exploring the views and experiences of Black and South Asian communities in the UK on patient data and its uses

SUMMARY REPORT

Diverse voices on data

CLEARVIEW RESEARCH

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Authors and Acknowledgements

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About Us

ClearView Research (ClearView/CVR) is an audience insight and strategy agency. We are specialists in working on research, evaluation and engagement projects with young people, minority ethnic groups, culturally diverse communities, people with protected characteristics and those who often go unheard. We are committed to ensuring that our work is always inclusive and equitable. We strive to ensure that all our participants enjoy the research process and find it accessible, engaging and empowering. We ensure that their voices are central in the materials (e.g. reports and frameworks) that we produce. **We work best with organisations who give a damn and want to make a genuine impact.**

We are proud to be:

- **An MRS company partner** that upholds and acts in a manner compliant with the strict ethical and rigorous rules contained in the MRS Code of Conduct.
- **A Certified B Corporation,** which is a certification only awarded to organisations that exemplify the highest standards of social corporate responsibility, transparency and accountability. Our Impact Business Model is recognised for its intended design to create positive outcomes for all our stakeholders and address community-oriented challenges. Our standards and values serve as a foundation for social, economic, environmental and governance best practices for businesses. We exist not just for profit but to benefit all people, communities, and the planet.

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Understanding Patient Data aims to make the use of patient data more visible, understandable and trustworthy for patients, the public and health professionals. Based at the Wellcome Trust, the programme seeks to bring transparency, accountability and public involvement to the way patient data is used.

Find out more about our work at **www.understandingpatientdata.org.uk**

Project Background

The Covid pandemic has seen poorer health outcomes for Black and South Asian people, drawing attention to existing health inequalities. It has also exposed the frequent gaps in patient health records on ethnicity and on clinical information and social determinants of health, such as blood pressure and smoking status.[1,2,3] As a result, policy focus on collecting more patient ethnicity data to deliver more equitable outcomes and vaccination coverage during the pandemic has increased. However, Understanding Patient Data felt that to create lasting change, it is important first to understand the reasons behind data inaccuracy and incompleteness.

We, in partnership with Understanding Patient Data, undertook a qualitative research study to examine the views and experiences of people from Black and South Asian communities in the UK on how their patient health data is collected and used and their aspirations for how this should be done in the future. The objectives of this project were the following:

- To explore Black and South Asian peoples' thoughts on health data collection and use, why health records are often incomplete or incorrect, and what aspects of data collection and use matter to them.

- To understand what it means to be represented: peoples' perceptions of benefits or risks when it comes to being included or not included in health data collection.

- To gain insight into the particular questions, concerns, sensitivities and aspirations that people from Black and South Asian backgrounds have concerning the collection and use of data in their health records.

Methodology and Approach

Approach

Our approach was designed to gain deep insights into Black and South Asian people's thoughts on patient data collection and use. This included collecting insights into why health records are often incomplete or incorrect, what it means to be represented in data, and the concerns, sensitivities, and aspirations for the future that people from these communities have for the collection and use of the data in their health records.

ClearView sought to engage a range of people from Black and South Asian communities across the UK to discuss their thoughts and experiences concerning patient data. This was done through exploration labs facilitated by ClearView and by community research, both of which are methods developed by ClearView as participatory ways of engaging people in research.

Like focus groups, exploration labs are discussion groups where participants are encouraged to explore their thoughts and ideas through group discussion. While some structured questions were asked as part of this project, space was given for dynamic interaction and group discussions, and people often took the lead in progressing the discussions.

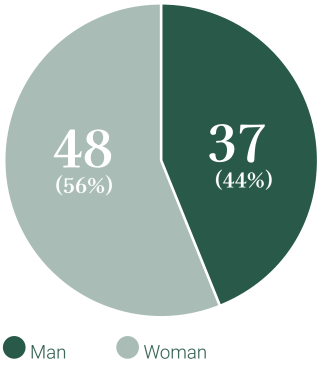
Community research involves upskilling a group of community or peer researchers in research methods, design, research bias, community engagement and data analysis and actively partnering with them to design, conduct, analyse, report, and disseminate the research as equal partners within the research team. Both community researchers and exploration lab participants were paid for their time and contributions.

Participant Profiles

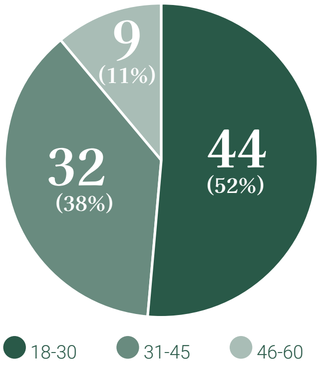
A total of 321 people participated in this research, including the eight community researchers. Of these, 85 participated in the ClearView-led exploration labs, while 228 participated in the peer-led community research. Further details of the demographic profiles for both the exploration labs and community research are included below.

Exploration labs

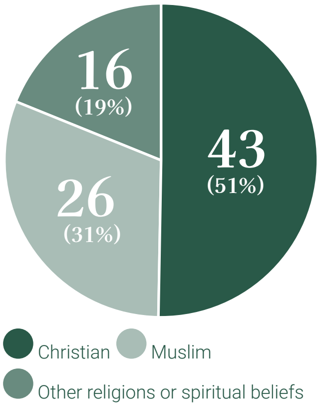
Gender



Age



Religion



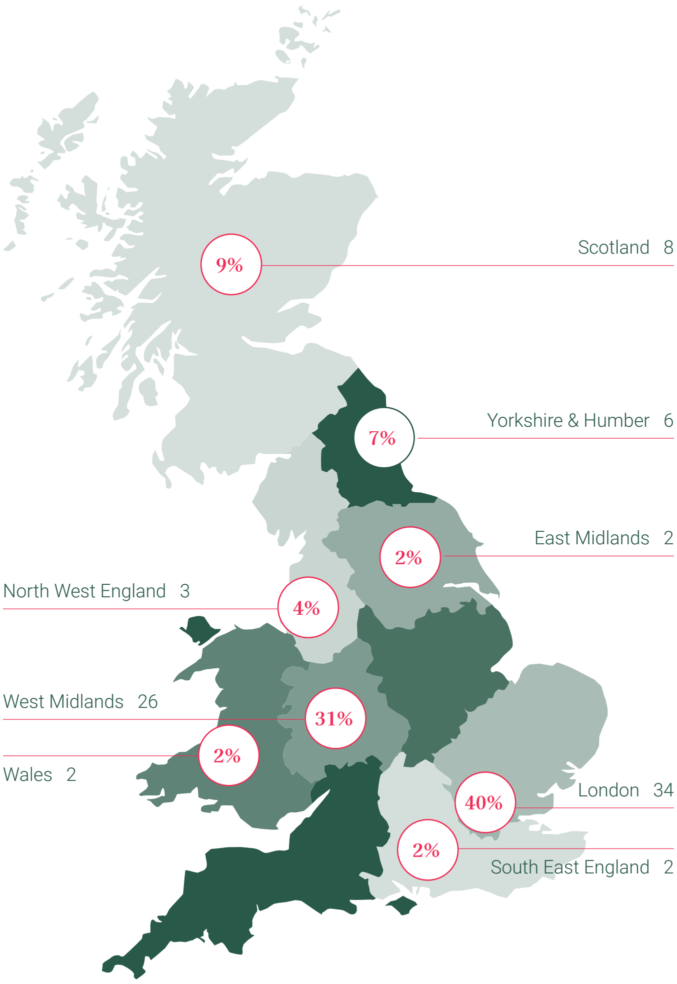
Ethnicity

Black - African	37%	31
Black - Caribbean	18%	15
Any other Black background	1%	1
Asian - Pakistani	15%	13
Asian - Bangladeshi	11%	9
Asian - Indian	7%	6
Asian - South East Asian	2%	2
Any other Asian background	2%	2
Mixed - Black Caribbean and African	2%	2
Mixed - White and Black Caribbean	0%	0
Mixed - White and Black African	4%	3
Mixed - White and Asian	0%	0

Education level

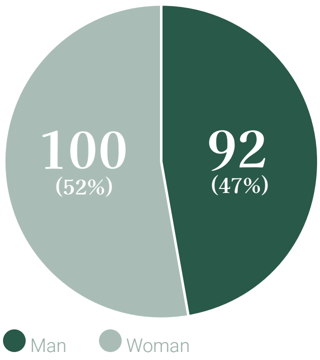
Post Doctorate / fellow or equivalent	1%	1
Master's degree or equivalent	12%	10
Bachelor's degree with honours	40%	34
Non-honours bachelor's degree	4%	3
Teaching qualification (not degree)	2%	2
Higher National Diploma or equivalent	6%	5
Higher National Certificate or equivalent	1%	1
Other technical, professional or higher qualification	5%	4
A-levels or equivalent	18%	15
GCSEs or equivalent	6%	5
No formal qualifications	2%	2
Other	4%	3

Geographic Location

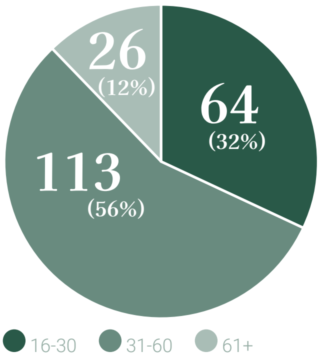


Community research

Gender*



Age*



Ethnicity	%	Total
African	1%	2
Arab	1%	1
Asian	5%	10
Asian - Pakistani	1%	1
Asian/African	1%	1
Bangladeshi	14%	26
Bengali	2%	3
Black African	19%	35
Black African/Caribbean	1%	1
Black British	1%	2
Black British African	1%	1
Black Caribbean	2%	3
British Bangladeshi	1%	1
British Pakistani	1%	2
Ghanaian	6%	11
Indian	15%	28
Iranian	1%	1
Mauritius	1%	1
Nigerian	2%	4
Pakistani	24%	44
South African	1%	2
Trinidad	1%	1

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* The percentages for ethnicity, age and gender for the community research participants are based on the total number of participants who felt comfortable sharing this information with the community researchers.

Exploration labs

We conducted a total of 11 exploration labs engaging 85 participants over three months from October to December 2021. Exploration labs for this project lasted approximately 70 minutes and were led by one of the ClearView Team, while another member of the ClearView team took notes. All exploration labs began with a set of questions to get a better understanding of the participants' existing knowledge of patient data. Then they were shown an infographic providing a detailed explanation of how patient data is collected and used, as seen in Figure 1. This allowed us to establish the group's existing level of understanding before confirming the details of what currently happens, to avoid any confusion for the rest of the discussion about what is meant by patient data and how it is collected and used.

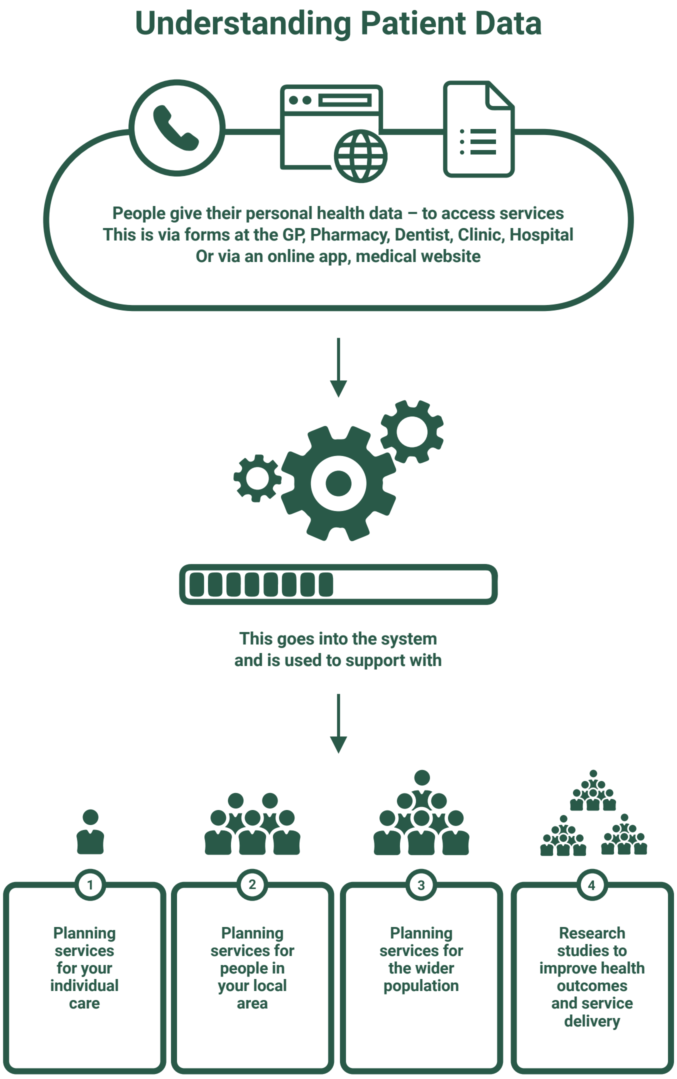
Community research

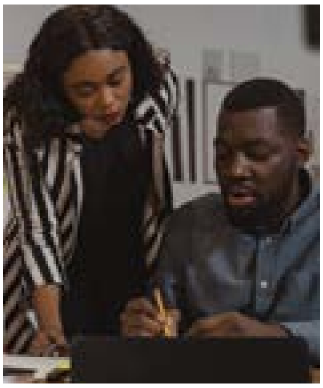
In addition to the exploration labs, we facilitated peer-led community research. Where the exploration labs achieved a depth of engagement and insight, the community research insights brought a breadth of experience.

We trained eight community researchers from Black and South Asian communities in our Peer Research Education Programme. The programme focuses on research and engagement in the community and includes modules on research design, research methods, fieldwork approaches, community engagement, analysis, and reporting. Following the training, we worked closely to assist the community researchers in designing their research questions and methods, recruiting participants, and engaging with their local communities. Each community researcher spoke with a minimum of 20 people in their community.

We also worked closely with the community researchers to inform the discussions in the exploration labs and worked with the group to sense-check the research findings at the end of the process. This enabled us to contextualise the findings properly, represent them correctly and frame them sensitively and appropriately.

Figure 1: Infographic for Exploration Labs and Community Research





Recruitment strategy

We used a combination of convenience and quota sampling to recruit participants for this study. In convenience sampling, participants are selected based on their availability and willingness to participate. Quota sampling then involves recruiting people from specific groups with predetermined characteristics, in this case, gender, age, and ethnicity. This method comes with the risk of missing the views or experiences of certain groups of people who do not tend to volunteer to participate in research. However, we counteracted this by using a number of our sampling approaches and techniques, including community research and snowball sampling.

This tried and tested approach results in high-quality participation, interest, and commitment to our research projects. It has also helped us to build relationships of trust with a large number of communities, organisations, and individuals across the UK.

Study Limitations

It is important to note that although the insights in this report reflect the lived experience and reality of the people who took part in the research, our findings cannot be generalised to represent the wider population of all people from Black and South Asian communities. This is a qualitative piece of research that should be used to gain a broader understanding of the views and experiences of people from Black and South Asian communities to complement broader quantitative research and future service delivery.

We examined the final transcripts from the exploration groups and the data collected by the community researchers to identify any important differences in how participants from different demographic groups, for example, age, gender, ethnicity, or religion, differed in their views and experiences of how patient data is collected and used. For the most part, we identified no substantial differences in the views or experiences of people from these different groups. However, as it was not one of the objectives of this research, we acknowledge that there may be differences in the views and experiences of different demographic groups that are not picked up in this type of research design, qualitative group discussion. Further research using interview or quantitative techniques could prioritise examining differences in the views and experiences of different demographic groups.

Key Findings

We summarised this research into 7 key findings:

1. Black and South Asian communities generally understand what is meant by patient health data (or information) but there are gaps in knowledge about the collection and uses of patient data.

2. Many people from Black and South Asian communities have low levels of trust in the NHS and are concerned about how their data will be protected.

3. Black and South Asian communities believe that data can be used to improve health outcomes in their communities, but they do not see this happening in reality.

4. Black and South Asian communities have had negative experiences of the healthcare system and fear that sharing their data will lead to racial discrimination and poorer health outcomes.

5. Black and South Asian communities want to be informed about how their data is/will be influencing research, design, and planning of healthcare services.

6. Black and South Asian communities report that local services do not reflect local needs.

7. ‘Tick box’ options are inadequate for collecting data on race and ethnicity.

1. Black and South Asian communities generally understand what is meant by patient health data (or information) but there are gaps in knowledge about the collection and uses of patient data.

The research shows that there is a gap in the understanding of how patient data is used for people from Black and South Asian communities across the UK. Most of the participants we spoke with during this research had a clear understanding of what patient data is and how or where it is collected. However, when it came to the different ways their patient data is used, many of the participants felt confident that they were fully informed about where their data is shared and used but were then surprised when they saw that it could be used for purposes well beyond their individual care, or even their local services. This shows that, even for those who feel confident about what patient health data is, there may be gaps in their understanding.

2. Many people from Black and South Asian communities have low levels of trust in the NHS and are concerned about how their data will be protected.

Many of the participants also spoke about being nervous when it comes to sharing their personal data with the NHS. The reasons behind this limited trust include:

- People’s confidence in the competency or willingness of the NHS to protect their data is limited.
- Little visibility of improvements to health outcomes for people from Black and South Asian communities means little social trust in the system.
- Negative experiences, or hearing stories about others’ negative experiences, such as racial profiling, bias, or outright discrimination damages trust.
- No feedback about how their data is leading to positive change and improvements in services and treatments for people in their communities means people doubt if this is the reality.

Some of the participants expressed fears that the NHS would willingly share their data with third-party organisations that they would prefer not to have access to their data (such as insurance companies). They were concerned that the NHS would not be able to protect their data from being accessed by unapproved people or companies, for example, due to data breaches.

3. Black and South Asian communities believe that data can be used to improve health outcomes in their communities, but they do not see this happening in reality.

Most of the participants who took part in the research said that while they believed, in theory, that providing data could help improve services they did not feel this was happening. Some of the participants even went so far as to say they believed the healthcare needs of Black and South Asian communities were not a priority in research and service design.

These accounts highlight that while most have no problem in providing their data and believe that it could improve the services on offer to Black and South Asian communities, some are still sceptical that it will result in benefits to their communities due to the lack of action and progress apparent in recent years. This challenges the narrative that people from Black and South Asian communities are reluctant to share their data but shows rather that they feel let down due to their experiences and observations.

4. Black and South Asian communities have had negative experiences of the healthcare system and fear that sharing their data will lead to racial discrimination and poorer health outcomes.

We also discovered that many of the participants had also either had negative experiences with the NHS themselves or had heard negative stories from close friends and family. This left these patients feeling nervous about providing their ethnicity or other demographic data in the future for fear of being discriminated against. Many of these participants described how their local services do not properly take their race, ethnicity, culture, or religion into account when delivering treatment and care, resulting in poor care and generating further distrust in the system. The history of discrimination experienced by people in Black and South Asian communities in the UK is compounded by these negative experiences and results in a growing distrust that can be seen at a local and a national level.

5. Black and South Asian communities want to be informed about how their data is/will be influencing research, design, and planning of healthcare services.

When it comes to their views on how data is collected and used, this distrust is amplified as the participants reported they never see positive outcomes from sharing their data. Many of the participants spoke about how they never hear about what happens with their data after they share it.

They expressed that they would like to know more and would be interested to see what is discovered in research that uses their data. The few participants who had participated in specific consented health research studies and were informed of the findings afterwards reported positive views of the research and said that they would be happy to share their data similarly again. This highlights the importance and usefulness of feedback loops as a way of recognising the value of the data someone is providing. Similar feedback loops to those used in consented research studies could be used for research using routinely collected data, and this could improve patients' understanding and involvement in their patient data collection and use.

However, it is not enough to report the findings of research using patient data; it is also essential to take action to improve care and services based on those findings. The lack of evidence of real change and the practical benefit of sharing their information discourages participants from continuing to share it and can lead to inaccurate or limited data collection. To build trusted relationships with Black and South Asian communities, the NHS and the wider health system will need to show that they are willing to take research findings and turn them into real action to improve care and services for people in these communities.

6. Black and South Asian communities report that local services do not reflect local needs.

Most of the participants also expressed that they did not feel their local services reflected the needs of their communities. We heard stories about how the limited knowledge of healthcare professionals has led patients to believe they are not seen as important or a priority. These participants described situations where a lack of appropriate medical and cultural knowledge meant they did not receive a suitable diagnosis, treatment, or care. This lack of knowledge and understanding from healthcare workers is reflected in other research studies, including research work that ClearView has conducted and the National Cancer Patient Experience Survey, where respondents who were Black reported having to visit the GP more often than their White counterparts to get a referral for a cancer diagnosis.[4,5] Numerous examples were given by people from Black and South Asian communities who either had difficulty getting a diagnosis because their symptoms appear differently due to the colour of their skin, or whose healthcare professionals did not know how to treat their condition because they did not have the relevant medical knowledge (such as in many sickle cell cases).

Furthermore, participants expressed how a lack of accessible information resources, especially translated content, showed how little local services adapt to meet their communities' needs. If local services cannot even meet the communication needs of their local community, they feel there is not much chance of greater adaptations, such as more culturally informed services.

7. 'Tick box' options are inadequate for collecting data on race and ethnicity.

Many of the people who participated in this research spoke about the challenges they face when providing data about their identity. Participants described how the forms they use to provide their data, both paper and online, provide only limited options to respond to questions about their identity (including questions on race, ethnicity, culture, and religion). This means that for some participants it was difficult to respond honestly to the question as none of the options describes their identity accurately. This also leaves them feeling excluded or unseen. Forms can also be confusing to people who do not speak English or who did not grow up in the UK, as often they will not have seen these types of questions or categories previously. This highlights the interesting challenge of collecting identity-based data, as categorisations tend to be socially constructed (i.e. meaning different things to different people). This means that when collecting data on individuals' identities, the healthcare system needs to do so considerately and respectfully.

One way to avoid the limited nature of forms for providing detail about complex topics such as identity would be to provide the information verbally, through a conversation with a healthcare professional which would necessarily include reflections on knowledge, attitudes and practices that may be relevant to health. However, none of the participants could recollect having a conversation of this type, and one participant, who works within the NHS, even reported that they have witnessed colleagues taking shortcuts when recording this type of information, preferring the use of collective or overarching categories, over recording more detailed and specific data. The important point to note here is that this specific level of detail, that accurately represents an individual's identity, is necessary if we are truly interested in the genetic, cultural, and experiential impact of ethnicity. Detailed information is key, both for an individual's healthcare and to inform and improve treatment and services for minority communities. If this data is not correctly recorded, then it cannot be used to support an individual's care or be used as data in research to inform improvements to care and services for the future.

Conclusions

Most of the people who participated in the research study were, despite the challenging experiences many have faced, optimistic about what could be done to improve how their data is used in the future.

Many of the participants spoke about how improving the cultural and medical knowledge of healthcare professionals and encouraging more diversity in both healthcare and data analysis, could lead to great improvements in both treatments and services for people from Black and South Asian communities across the UK.

However, they also pointed out that to achieve real change, trust between these communities and the system and the individuals within the system will need to be improved. They were mostly hopeful that this trust could be achieved, but this will require a commitment to anti-racist and anti-prejudiced practice, and a feedback loop that communicates back to communities the research findings and the actions taken to create positive change.

ClearView Recommendations for Policy and Practice

Based on our findings from both the exploration labs and community research and our experience and knowledge in this area, we have provided some recommendations for UPD, healthcare professionals and the wider health sector to move forward.

1. Healthcare professionals need the resources and training to be equipped to have conversations with Black and South Asian people about what patient health data is and how it is used.

The varying levels of understanding of how patient data is used and its links to service design observed in our research suggest there is a lack of standardisation around how health professionals approach these conversations and whether they have them at all. Coupled with reports from some NHS employees who participated in our exploration labs that suggest NHS staff do not always correctly record demographic details such as ethnicity, this shows that healthcare staff may not feel comfortable talking about topics such as ethnicity and may even not understand the importance of patient data themselves.

Healthcare professionals should feel empowered to communicate information around patient data and understand the importance of having patient data conversations with patients from Black and South Asian backgrounds.

Training and resources will give healthcare professionals the necessary communication and interpersonal skills to explain, reassure and respond to queries from Black and South Asian patients. It will also encourage them to make these conversations a priority during appointments or treatment. Training and resources should equip healthcare professionals with the skill and cultural literacy to communicate information to patients from this demographic effectively for them to make informed decisions about their data.

2. Research is needed to find a new, more inclusive method to collect identity information, including race and ethnicity so that patients can more easily and accurately provide this information.

There is evident dissatisfaction with the options available to Black and South Asian communities when indicating their race and ethnicity on forms while accessing health care and treatment. Participants mentioned that this is worsened by limiting and overgeneralised drop down and 'tick box' options that only allow one selection to be made.

The health sector should look both within and outside itself to identify best practices for categorising different combinations of race and ethnicity. Understanding different approaches, challenges and solutions will bring the health sector a step closer to finding methods that meet the needs of Black and South Asian communities.

If Black and South Asian communities are to provide accurate and meaningful information to shape local services, then the sector must adopt more equitable and empowering categorisations that capture their varied identities.

This should always be accompanied by free text options to allow patients from Black and South Asian backgrounds space for self-identification, should other available options not suffice.

We do not underestimate the complexities that may arise in the process but recognise that unless this challenge is addressed, issues with incomplete, inaccurate or missing data collection will persist. This in turn leads to health services holding unrepresentative patient data and so being unable to provide appropriate services that meet the needs of the communities they serve.

3. People from Black and South Asian communities should be involved in decisions about what research and improvement, involving their data, is being prioritised.

This recommendation addresses the issues raised during this research project of a lack of trust in data-sharing, doubts around how data is used, and whether it benefits Black and South Asian communities. Participants do not feel that they see any action being taken to improve care and services based on key areas that are important to their communities.

Like recommendation 1, beyond explaining the intentions of data-gathering, the health sector should update Black and South Asian communities on how the data they have gathered has been used to improve services. This requires a timely and transparent feedback loop so people from Black and South Asian communities can witness the benefits to their communities. Not only does consistent communication build trust but it allows Black and South Asian communities to hold health services to account.

However, it is just as important that these communities are involved in and consulted on how specific research questions are prioritised. Participants expressed that they would like to know more and would be interested to see what is discovered in research that uses their data.

Gaining a better understanding of the views of these communities on the current priorities and objectives of research using their data and working with these communities to develop an informed list of priorities is a key area of research that should be considered for the future.

The appetite to engage in data collection and be involved in shaping research should suggest to the NHS that improving data quality and representation and healthcare outcomes for Black and South Asian communities can be achieved using effective community engagement and partnership models. By involving people from Black and South Asian communities in decisions that impact data quality, representation, and health outcomes, they can begin to influence directly how their communities are impacted.

4. Health data should be used to ensure better and more appropriate representation in datasets and for research into conditions that disproportionately affect people from Black and South Asian backgrounds to improve health outcomes.

When healthcare providers are serving their local communities, especially those with a high population of people from Black and/or South Asian backgrounds, they need to ensure they are delivering services that reflect conditions that are prevalent within those communities, such as sickle cell and thalassaemia.

So, it is vital to produce enough research about conditions that disproportionately affect these communities and disseminate it amongst healthcare professionals at all levels. When this information is not available there can be fatal consequences.

It is negligent when people from Black and South Asian communities are left untreated or maltreated due to gaps in medical knowledge or misleading guidance on how to treat people from these communities. Therefore, more research should be done to understand why these needs are not being met. It is essential to determine if better or more accurate collection of patient health data or better use of this data in the design and planning of local services is needed so people from Black and South Asian communities can receive high-quality and appropriate health care.

However, if research is being conducted but improvements in health outcomes are not seen in practice, then conversations around patient health data will continue to frustrate and concern Black and South Asian communities, straining their relationship with the whole healthcare system. When changes are made to services, treatments or care based on evidence using patient data, these changes and the evidence behind them should be communicated to patients. This will open the lines of communication between patients and decision-makers, helping patients to understand how their data is impacting the services available to them and their communities. Opening these lines of communication also holds the NHS accountable as it means they have to provide the evidence behind their decision making.

5. The NHS must commit to eradicating racial and ethnic discrimination, which affects the way patient data is collected and used.

The NHS must demonstrate that they understand how important discrimination is as an issue. They should do this through an explicit commitment to eradicating racial discrimination and introduce success metrics to monitor progress against this commitment.

Acknowledging the role of racial and ethnic discrimination in the collection and recording of patient health data requires that the health care system recognises the part it plays in the lack of representative data being collected, rather than assuming that patients from these communities are hesitant to provide their data. Over the past two years, society has begun having more honest conversations about systemic racism and prejudice across sectors in the UK, which includes healthcare and medicine.

Beyond public discussion, healthcare services should develop specific, ambitious goals and actions to fill gaps in patient health data that lead to poorer health outcomes for people from Black and South Asian communities. Recommendations 1, 2, 3 and 4 are all underpinned by the need for the sector to eradicate racial and ethnic discrimination from patient health data collection and use. Ambitious as these goals and objectives need to be, the healthcare service must ensure that they are accompanied by realistic short-term targets so benefits can be experienced now, by current patients from these communities, rather than promises for future improvements that may never be realised.

References

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1. Nafilyan, V. et al. (2021) Ethnic differences in COVID-19 mortality during the first two waves of the Coronavirus Pandemic: a nationwide cohort study of 29 million adults in England. Accessed 14 March 2022. https://www.medrxiv.org/content/10.1101/2021.02.03.21251004v1
2. Williamson, E. et al. (2020) OpenSAFELY: factors associated with COVID-19-related hospital death in the linked electronic health records of 17 million adult NHS patients. Accessed 14 March 2022. https://www.medrxiv.org/content/10.1101/2020.05.06.20092999v1.full
3. Implementing phase 3 of the NHS response to the COVID-19 pandemic. NHS Publication (2020). Accessed 14 March 2022. https://www.england.nhs.uk/wp-content/uploads/2020/08/implementing-phase-3-of-the-nhs-response-to-covid-19.pdf
4. ClearView Research, (2022 – in press). Blood Cancer Patient Experience for Black, Asian, and ethnic minority patients. Blood Cancer Alliance.
5. National Cancer Patient Experience Survey. https://www.ncpes.co.uk/2019-national- level-results/. Accessed 1 February 2022.

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