

WHAT IT MEANS TO BE SEEN:

# Closing gaps in patient data for Black and South Asian communities



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## Authors and Acknowledgements

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- United We Rise UK

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### About Us

Liberating Knowledge is a research agency who focus on creating and curating knowledge that has the potential to address systemic injustices. We platform the voices of marginalised communities so they can lead on the issues that affect their lives. Working alongside our associates and communities we identify innovative solutions by holding space for our collective creativity and imaginations to run free.

### About Understanding Patient Data

Understanding Patient Data (UPD) 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](http://www.understandingpatientdata.org.uk).



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# Executive Summary

Patient data is essential for providing high-quality healthcare for all and is used in a variety of ways from giving individual care to health service planning for a local geography. In addition to medical information, patient records can include additional information such as ethnicity, employment status, and housing situation. This information can help healthcare decision makers assess how social determinants impact health and then deliver appropriate initiatives. Incomplete patient records for minoritised groups, including minoritised ethnic groups, exacerbate health inequalities.

The Nuffield Trust found an increase in 'not known', 'not recorded,' and 'other' ethnicity codes in English hospital datasets, limiting ethnicity-related data analysis. They also found that people who identify as Black and South Asian are more likely than White people to be incorrectly labelled as 'Other' leading to an overrepresentation of people categorized as 'Other,' whilst simultaneously underrepresenting those from mixed and "specific ethnic groups." However, the report was unable to conclude whether this result was due to a change in peoples' self-identification or if it was assigned by a practitioner or healthcare worker, based on an assumption of their ethnicity.<sup>1</sup>

Detailed patient data sets can be used by policy makers and leaders of healthcare systems and organisations within the UK to uncover where inequalities arise and who they affect. The NHS created the [Health Inequalities Improvement Dashboard](#)<sup>2</sup> to help healthcare workers understand who needs what type of support in their area. It's crucial to understand why some patient data is missing to tackle the root causes that hinder Black and South Asian patient data collation. This will support efforts to tackle health inequalities.

We worked with Understanding Patient Data (UPD) to conduct engagement with healthcare professionals and a public survey to explore the barriers to patient data collection for people from Black and South Asian backgrounds. We also wanted to understand what solutions there are to tackle these barriers. Our work builds on [Diverse Voices on Data](#)<sup>3</sup>, a qualitative research study commissioned by UPD from ClearView Research, to examine the views and experiences of people from Black and South Asian communities on how their patient health data is collected and used.

We started our work by conducting several focus groups with healthcare professionals and supplemented them with interviews where some backgrounds were underrepresented. The survey results were collected by an external market research and insights agency. Whilst we had good representation from Black and South Asian communities, our research had some limitations with marginalised groups within these communities not being represented. We did not have sufficient respondents from LGBTQ+ communities to gain insights into views from this population. In addition, we had limited respondents from older Black and South Asian backgrounds.



## Key findings from engagement with healthcare workers

Through the focus groups and interviews we conducted with healthcare staff, we gained the following insights:

- There is a good understanding of the breadth of data collected by the NHS. However some staff were less confident about describing why data is collected or how it is used when they are not responsible for using the data in their role.
- Resource and time pressures impacts staff's ability to prioritise data collection and to hold conversations with patients about why their data is collected and how it is used.
  - Participants also shared barriers and enablers of using IT, such as having more ethnicity categories to reduce selection of 'other' and the challenge of IT systems having mandatory fields which staff may populate with 'not answered' or similar options when under time pressure.
- Staff felt that a lack of people in leadership roles who are committed to tackling bullying, institutional racism and health inequalities and who are from Black and South Asian communities was also a barrier to collecting patient data.
- Some staff also referred to a concern from Black and South Asian communities about whether they can trust the NHS given past harms, expressing that they personally held these concerns as members of these communities.
- Whilst some respondents expressed that Black and South Asian communities are hard to reach, others did not agree with this view, sharing instances where through investing time to build trust, they and others were able to improve understanding of the usage of patient data and collection of it.
- The level of understanding of the consequences of gaps in patient data for Black and South Asian communities varied across healthcare workers. Those from minoritised ethnic groups were more likely to understand the importance of being represented in data to support efforts to tackle health inequalities. Others didn't recognise this importance and saw health inequalities by ethnicity as having a biological basis rather than the structural inequalities of healthcare systems and wider society.
- There were innovative ideas proposed such as the NHS being more radical in how it thinks about data ownership and giving more control to people and their communities over their data and the insights generated from them. Overall, there was a common desire for the NHS to be more ambitious about how it approaches improvement in collection and use of patient data.



## Key findings from public survey

- The majority of survey respondents have high levels of engagement in health information which may be reflected in their willingness to participate in the survey. There was no difference in the level of engagement based on ethnicity.
- We found that respondents from all ethnic groups were willing to share most types of personal data with the NHS. All respondents were less comfortable sharing financial information with the NHS. Only 3% of survey respondents didn't trust the NHS with their personal data, reflecting high levels of trust in the NHS amongst our survey respondents.
- We noted some variations in views based on ethnicity with people who are Black and South Asian respondents were more likely to believe that incomplete data from members of their community will impact their care as compared to people who are White. They were also more likely to believe that gaps in their data would lead to a worse quality of care for people in their community.
  - There was also slightly greater concern that personal data about their children would be used to discriminate against them, compared to White respondents.
- Only one in five respondents reported having a conversation with a healthcare worker about how patient data is used showing the need for much greater engagement by the NHS with the public regarding collection and use of patient data.
  - People who are older, lower earners and with less education are less likely to have had a conversation compared to those who are older, higher earners and more educated.
- When people reported that they had a conversation with NHS staff, there was a significant impact on increased willingness to share personal data and a broader understanding of the use of patient data including the benefits.
- Most respondents shared that they wanted to learn about how health data is used before an appointment. They wanted this information provided in either an NHS setting (GP practice, health centre or hospital) or via a website. A conversation and written forms of information were the preferred ways of sharing how health data is used.

Findings from our research challenge the view that Black and South Asian communities are more reluctant to share their personal data compared to other communities.

- We saw the same levels of comfort sharing most types of data with the NHS across all ethnicities.
- Respondents reported high levels of engagement across all ethnicities indicating there isn't an issue regarding interest and engagement within Black and South Asian communities.
- This builds on the findings in the Diverse Voices in Data report that Black and South Asian communities are willing and interested in sharing data.
- Hiding behind the narrative that some communities are 'hard to reach' perpetuates the assumption that the responsibility to take action rests with minoritised groups rather than with the NHS.



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Lack of trust is often cited as a factor that influences the willingness of Black and South Asian communities to share their data.

- Rather than focusing on the distrust Black and South Asian communities may have of institutions, we encourage NHS organisations to think more critically about how they can make themselves trustworthy organisations for all communities.
  - Focusing on this particularly for those who are most impacted by health inequalities may potentially lead to better relationships with these communities and opportunities to work collaboratively to tackle health inequalities effectively.
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## The burden of tackling health inequalities rests on people with lived experience.

- We found challenges in engagement from White people with significant time required to recruit sufficient White healthcare workers to the focus groups.
- Insights from the survey suggested less concern for potential discrimination for minoritised ethnic communities by White respondents. Also, healthcare workers shared that they observed less engagement from senior leaders who are not from minoritised backgrounds in tackling health inequalities.
- To make progress in tackling health inequalities and to reduce gaps in patient data, it is imperative that all staff see addressing inequalities as their responsibility, particularly influential and senior decision makers.



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With the strong spotlight on tackling health inequalities, now is the time to ensure staff have the tools, knowledge, and confidence to have good conversations with the public to close the gap in patient data collection for Black and South Asian communities.

- To make progress on tackling the patient data gap, NHS staff need to be supported to understand why it's important to have complete data and the potential of using data to improve services and reduce health inequalities.
  - Given the positive impact of having a conversation, and yet the low frequency of this happening, there needs to be more space created for these conversations.
  - There is a greater focus on health inequalities, with Integrated Care Systems being tasked with tackling them and the disparate impact of COVID-19 also starkly highlighting the issue.
  - It is important to share with communities how data collected from them is used in planning and research. This would avoid an extractive relationship where information is shared but no benefit is seen.
  - This research surfaced unique insights that help us to begin to dispel myths and think about practical actions to move forward. We have set out recommendations for decision-makers and frontline staff to make progress towards closing the data gap for Black and South Asian communities.
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## Recommendations

- 1** Create the conditions for systemic change to enable the following recommendations to be delivered by accelerating efforts to eradicate racism within the NHS. This should include developing the cultural and racial capability of the workforce.
- 2** Consider developing a race equity framework for physical health services that draws on the approach used for the Patient and Carer Race Equality Framework in Mental Health services.
- 3** Secure the support and commitment of senior leaders to improve data practices, embed inequalities work and create space for staff to innovate within the NHS.
- 4** Actively challenge 'hard to reach' narratives that encourage the perception Black, Asian and minoritised communities are disengaged or unwilling to share their patient data.
- 5** Equip healthcare workers with the tools to hold meaningful conversations about data: explore more innovative approaches that provide engaging 'bite-size' learning material targeted at healthcare workers.
- 6** Regularly share the learning from equalities work, that has been driven by data insights, with the community, healthcare workers and the wider professional and scientific community.
- 7** Maximise opportunities presented by integrated working to meaningfully engage and resource Black and Asian-led VCSE organisations to involve local communities.
- 8** Develop system wide protocols to routinely collect equalities data, disaggregate it by the protected characteristics and use an intersectional approach to analysis.
- 9** Work with racially minoritised communities and the Unified Information Standard for Protected Characteristics teams to expand the ethnicity categories used by the NHS.
- 10** Invest in research that takes an intersectional approach to explore the health experiences of Black and South Asian communities.
- 11** Embed an antiracist approach to data collection, analysis, dissemination and use which will include enabling staff to apply an equity/social justice lens to their work.

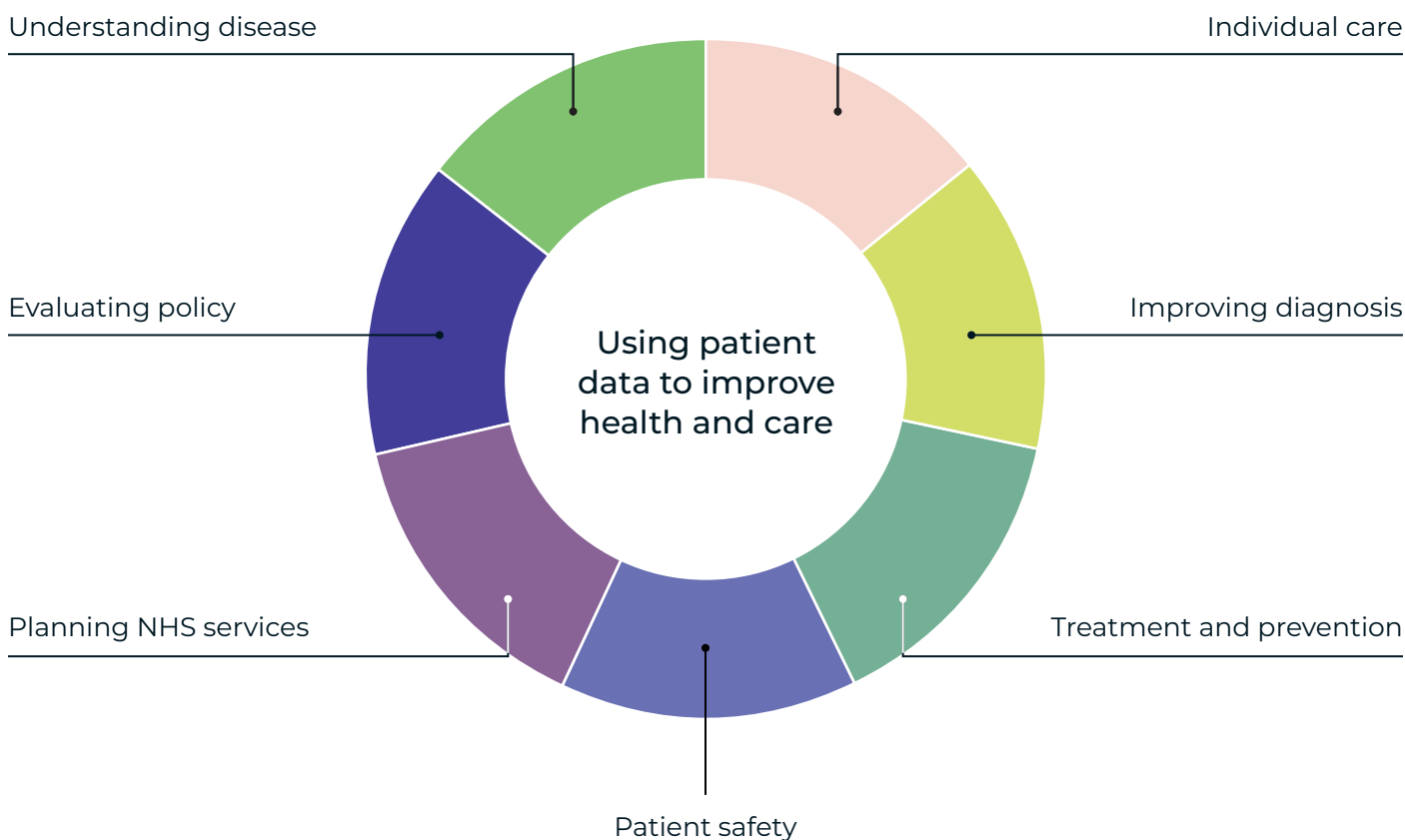
# Background



Patient data is essential for providing good health care

Patients using the NHS are routinely asked to provide and update sensitive information including biometric data and medical histories during interactions with the system, such as initial registration with a GP or attending a hospital appointment. This information, which we'll refer to as patient data, is essential for providing high quality and appropriate healthcare for all and is referenced by healthcare professionals when making decisions about an individual's care. For example, patient records will have information about medication allergies which will inform healthcare professionals unfamiliar with the patient's history to avoid using certain medication. Data can also be used to understand why some groups are more likely to develop particular diseases and the best approach to prevent these illnesses or treat them. The figure below by Understanding Patient Data provides further examples of uses of patient data. <sup>4</sup>

Figure 1: Examples of how patient data is used to improve health and care



Patient data includes information such as contact information, religion, education, ethnicity and sex. It can give insights about the wider aspects of a person's identity and life which can help decision makers in healthcare assess how social determinants impact health and work with relevant public agencies to deliver appropriate initiatives. This is recognised by the UK Government in the Data Saves Lives strategy<sup>5</sup> which positions accurate data as 'vital for managing population health' in the new 'place-based health and social care systems'. The strategy states the importance of data being broken down into known 'indicators of disparities' such as ethnicity, age, economic status and disability amongst many others so agencies can accurately identify the ways in which these impact people across various demographic groups, and how to tackle these disparities through clinical and policy interventions.

In an effort to reduce inequalities the NHS and other statutory providers are exploring the opportunities offered through the increased centralisation of data and through data linkage. This is an area of interest within Children's Services.<sup>6</sup> On the one hand it has the potential to assist systems to make smarter choices by directing resources and support where it is needed the most. However, due to systemic racism these approaches can cause and exacerbate harms and this is of particular concern for parents from Black and other racially minoritised communities.<sup>7,8</sup>

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Minority ethnic or racially minoritised communities are people from groups that have been 'minoritised through social processes of power and domination rather than just existing in distinct statistical minorities'.<sup>9,10</sup> We use these phrases interchangeably in recognition that people from these communities who live in the UK are also members of a global majority i.e. ethnic groups that collectively make-up 89% of the global population.<sup>11</sup>



**Incomplete patient records for people from minoritised ethnic communities contribute to challenges in tackling health inequalities**

There are ongoing challenges of routine data collection with records often being incomplete for people from minoritised ethnicities, particularly those who are Black and South Asian. The Nuffield Trust conducted research that showed across English hospital datasets, there was an increasing use of the 'not known', 'not recorded' and 'other' ethnicity codes which limits ethnicity related data analysis.<sup>1</sup> They also found that Black and Asian communities are more likely to be coded as 'Other'. Patients in the most deprived decile were the least likely to be assigned a valid ethnic group and the number of patients coded as the 'other' ethnic group increased with deprivation. The disparities in the COVID-19 pandemic impacting minoritised ethnic communities required analysis of patient records and other information to understand the reasons for this.<sup>12</sup> Due to gaps in data such as ethnicity not being recorded on death certificates, more sophisticated data analysis was required (data linkage).

The Core20PLUS5 framework developed by NHS England seeks to accelerate action to reduce health inequalities.<sup>14</sup> There are five clinical priority areas which have been identified through analysing patient data from routine as well as research studies. Maternity care is one of the priority areas because there is evidence that women

from poorer backgrounds are more likely to die in childbirth. Similarly, South Asian and Black women are also more likely to die in childbirth compared to White women.<sup>15,16</sup>

Small studies with health and care staff found that there is a discomfort amongst staff in asking patients for ethnicity data suggesting this is an issue to address within the workforce.<sup>13</sup> Given the correlation between deprivation, ethnicity and worse health outcomes, these issues are likely contributing to sustaining and even potentially further widening inequalities.



### **There are efforts to tackle the impact of incomplete patient data for minoritised ethnic communities**

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To provide care that tackles health inequalities, insights from good quality patient data can begin to uncover where health inequalities arise and who it affects across various communities. This information provides a guide to develop tailored initiatives to ensure communities receive the required care. The NHS has created the [Health Inequalities Improvement Dashboard](#)<sup>2</sup> to provide all healthcare workers using data with what they need to inform practical action and understanding of who needs different types of support in their area.

Other system actors are using their expertise to tackle the impacts of incomplete patient data. NHSX (now part of NHS England) is collaborating with the Health Foundation to fund artificial intelligence and data-driven technologies projects that better meet the needs of minoritised ethnic communities.<sup>17</sup> Four projects were awarded £1.4 million in total and they will report findings in 2023 - 2024. Health Data Research UK (HDR UK) are leading an alliance of organisations in support of their shared objective of capturing 'Diversity in Data'. The alliance has an ethnicity coding working group which explores the opportunities and challenges of how ethnicity data can be used in research.<sup>18</sup> The Wellcome Trust is funding research led by the Office for National Statistics (ONS) which assesses the quality of ethnicity classifications in data collection and across existing datasets. They are also funding research delivered by the Race Equality Foundation exploring the barriers to collecting ethnicity data in healthcare settings. The Patient and Carer Race Equality Framework<sup>19</sup> emerged from the independent review of the Mental Health Act. A key focus of this organisational competency framework is embedding good data practice within Mental Health Trusts as part of wider efforts to address mental health inequalities for racially minoritised groups. Many of these initiatives are at the early stages of delivery but it will be useful for the wider health system to learn from the good practice that emerges.



## We need to understand root causes of incomplete patient data records for Black and South Asian communities

As important as it is to create solutions to minimise health inequalities, it is also essential to understand the reasons for these gaps in patient records.<sup>20</sup> This insight will streamline efforts to develop solutions that tackle the root causes that hinder comprehensive collation of patient data for Black and South Asian communities. There are some assumptions about why these gaps exist, including lower trust from these communities due to past and ongoing harm in healthcare.<sup>21-27</sup> For example, the discrimination Black women experience within maternity services has more recently gained visibility within the media and the health system. FiveXMore, an organisation that advocates for Black women throughout their pregnancies and after childbirth, conducted research where Black women reported that the care they received was negatively impacted by inappropriate assumptions about their bodies. There was a shared experience of healthcare staff refusing or being reluctant to offer pain relief due to assuming they had a higher pain threshold.<sup>15,16</sup>

Although the public may have some understanding of the importance of data and the value sharing data may have for research purposes, people still express reservations about the risk of data breaches and the data being misused.<sup>21-25</sup> Other explanations that are put forward to explain health inequalities and inequities within datasets include that communities from Black, Asian and minority ethnic communities are hard to reach or engage.<sup>26,27</sup>

Communities may also have concerns that their data may be shared with other agencies which may present a risk to them or their families.<sup>28</sup> For example, in 2017 NHS Digital had a Memorandum of Understanding with the Home Office which permitted the Home Office access to patient data including non-clinical information which has subsequently been subject to legal challenge and was withdrawn in 2018. In 2019 The Independent<sup>29</sup> newspaper reported that data sharing was still taking place despite claims that it had been abolished the previous year. Such policies and practices significantly compromise trust from communities who are marginalised and can have a detrimental impact on their health outcomes as people are more likely to be hesitant to access preventative health services.<sup>30</sup> Similarly, the Metropolitan Police's Gangs Matrix<sup>31,32</sup> and the Government's Prevent agenda<sup>33</sup> have received a lot of criticism for being institutionally racist and their approach to data sharing affecting people's access to other public services.



## Project background

As part of Understanding Patient Data's commitment to prioritise public engagement with people whose concerns about health data have gone unheard, they commissioned a multi-stage project to explore the views of Black and South Asian communities. The first stage of the project was delivered by ClearView Research with the following objectives:



**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: Exploring peoples' perceptions of the benefits or risks of 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 about the collection and use of data in their health records.



# 321

people were engaged by the ClearView Research team which included peer researchers from Black and South Asian backgrounds

ClearView Research conducted community engagement with 321 people led by their team and peer researchers from Black and South Asian backgrounds. The engagement produced rich insights which identified several key findings including low levels of trust in the NHS, low levels of awareness about how the NHS uses patient data and the observation that insufficient effort is made to ensure all races and ethnicities are represented in the data collation process. Despite the reservations people from these communities may have, they still expressed a willingness to share their data with the NHS.

The present study aimed to build upon the insights generated by ClearView Research. Firstly, it explored the perspectives of healthcare workers on why patient data is less complete for patients from Black and or South Asian backgrounds, the barriers that hinder good data practice and possible solutions that would make it easier for the workforce to collect and use data more effectively. It also explored their suggestions for how the NHS could use data to improve service provision and the health outcomes of Black and South Asian communities.

The second part of the study aimed to survey a representative sample, exploring the key themes that emerged from ClearView Research's qualitative research to measure the extent to which the views that surfaced were shared among Black and South Asian communities.

The learning from ClearView Research's work and the present study have been used to inform the co-design process to develop:

- Closing the gap in patient data for Black and South Asian communities : A guide for healthcare workers <sup>34</sup>
- Closing the gap in patient data for Black and South Asian communities : A guide for NHS leaders and policy professionals <sup>35</sup>

These resources will assist healthcare workers to hold meaningful conversations with patients and carers about how their data is collected, used and stored.



# Methodology and Approach

## Research design

The study adopted an exploratory mixed methods approach which is well suited to researching complex issues. The qualitative phase of the research surfaced the views and experiences of healthcare workers through interviews and focus groups. The quantitative phase built upon the findings from the engagement work with healthcare professionals and the insights from ClearView Research by using a survey to gain insight into Black and South Asian communities views and aspirations for the use of patient data.

## Qualitative research with healthcare workers

The qualitative phase of this research project aimed to explore:



- Health professionals' knowledge and awareness of the purpose and use of patient data
- Levels of confidence to explain to patients and carers the purpose for data collection and how data is used and stored
- Experiences of collecting and using patient data when working with Black and South Asian communities including barriers and enablers
- Aspirations for how the NHS could routinely collect and use patient data
- Levels of awareness of the implications of not collecting patient data
- Levels of synergy between the findings from the ClearView Research's Diverse Voices on Data report and healthcare workers' beliefs around the barriers and enablers to improving data collection for Black and South Asian communities
- Examples of good data practice



## Participants

The study used a purposive sampling approach to engage a heterogeneous sample of healthcare workers with diverse experiences and perspectives. Participants were recruited through posts on social media (Twitter, LinkedIn and WhatsApp), via email using the research team and partners' networks.

Thirty-seven healthcare workers from diverse ethnic backgrounds (Asian/Asian British n=6; Black/Black British n=11; mixed n=3; White/White other n=9; Arab n=2; ethnicity not disclosed n=6) were recruited. Participants were aged between 25 and 63 years' old, 28 identified as female and 8 as male (1 participant did not disclose their sex). Professionally the sample consisted of people working from Band 2 to 9 within the NHS, across physical and mental health services in a range of roles including clinical, administrative, social care and research. They also worked across NHS primary, secondary care services as well as hybrid roles embedded jointly within the voluntary and statutory sector. Healthcare workers in London were heavily represented although the sample did include participants from East Sussex and County Durham.



### Approach

The perspectives of healthcare professionals on the barriers and enablers to data collection in Black and South Asian communities were explored through online focus groups (n=5) which lasted between 90 minutes and one hour and 48 minutes and eight interviews which lasted between 36 minutes and one hour and 28 minutes. The focus groups and interviews were recorded and transcribed verbatim. The transcripts were then analysed thematically using Quirkos software.

## Quantitative research with the public

The findings that were summarised in ClearView Research's report with Black and South Asian members of the public warranted further exploration to understand the extent to which these themes were echoed in a larger sample of people from these communities within the UK.

### Participants

A convenience sample of 3,273 participants were recruited to the study (figure 2). This cohort's age distribution was skewed, with younger age groups comprising the majority of responders. The relative lack of older respondents, especially among those over 71, is noteworthy. The majority of participants identified as White (n=849). However, there was good representation from respondents from the global majority within the sample (figure 5) who are often underrepresented in surveys. Within the sample, 814 people identified as Black, 215 people identified as Black mixed, 699 people identified as South Asian, 256 people identified as Asian – excluding South Asian, 112 people identified as Asian mixed and 219 people from other ethnic groups, 109 people preferred not to share their ethnicity.

The majority of survey respondents were made up of people who identify as female (n=1,948) and male (n=1,328). Female participants were often over-represented (figure 4). The cohort can be described as a healthy cohort as self-reported levels of good health were high (figure 13).

Although there is representation from respondents who identify as LGBTQ+, a high proportion of the sample identified as heterosexual (figure 11). Respondents largely identified as Christian (42.4%). Participants from this demographic were more likely to be from Black and White ethnic groups. The survey had representation from across the UK (figure 10). However, the dataset is distinctly London-centric with low levels of uptake from Northern Ireland and Wales (figure 9). Place of birth was overwhelmingly UK based for White (92.9%), Asian mixed (78.6%) and Black mixed (86.5%) respondents (figure 12). A lower proportion of minoritised groups were born in the UK: Black respondents (54.3%), South Asian respondents (59.7%) and respondents from other minoritised ethnic groups (58.9%). For Asian respondents (excluding South Asian respondents), 60.5% of respondents were born outside of the UK. A small proportion (1%) selected 'Prefer not to say'. The reluctance to self-disclose may be an indication of institutional mistrust and/or concerns held by people whose immigration status may be unsettled.

Within the cohort 63% of respondents had engaged in higher education (higher education below degree n=368, first degree n=1,043, postgraduate degree n=648), more than would be expected in the general population (approx. 35%). Similarly, the self-reported income levels were also higher which is likely to reflect the representation of London based participants which may have inflated average income levels. Figures 6 and 7 provide an overview of the educational attainment and income for the cohort.

## Participant Profiles

Figure 2: Ages of survey respondents

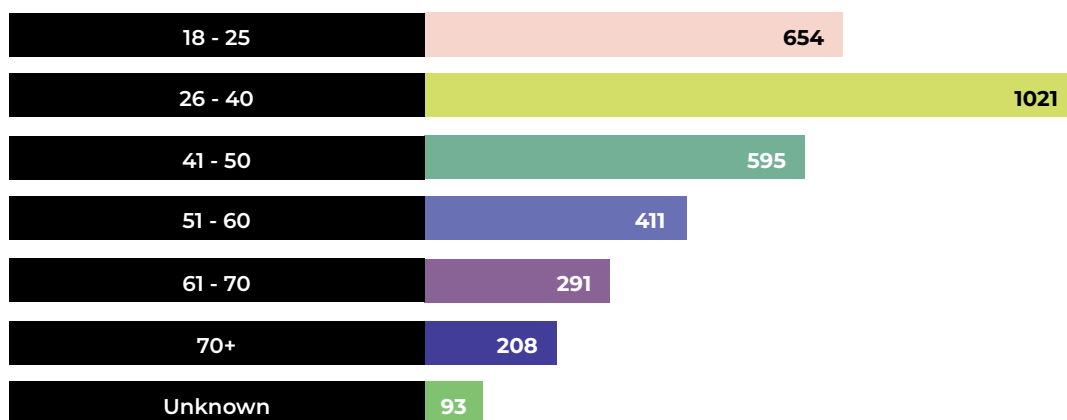


Figure 3: Age by ethnicity breakdown of survey respondents

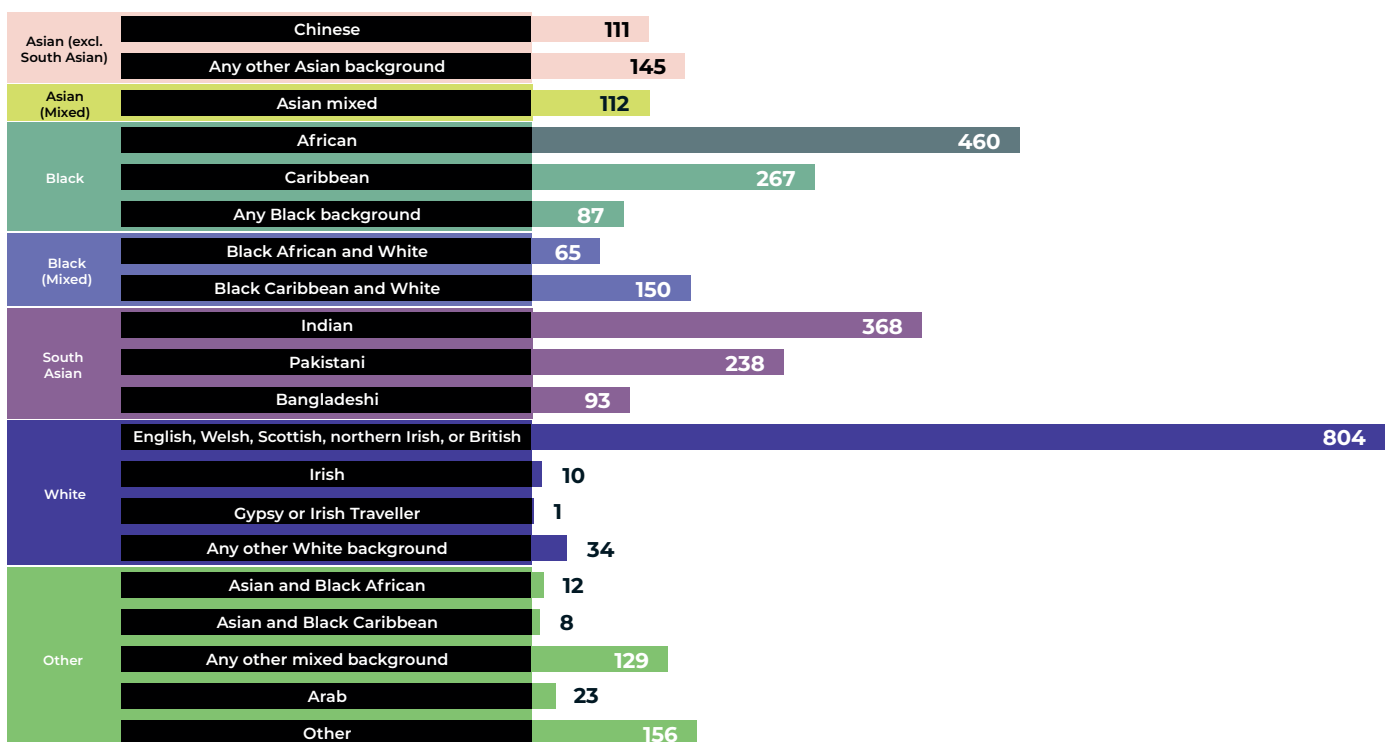


# Participant Profiles

**Figure 4:** Sex and ethnicity of survey respondents



**Figure 5:** Ethnicity breakdown of survey respondents



## Participant Profiles

Figure 6: Education level of survey respondents

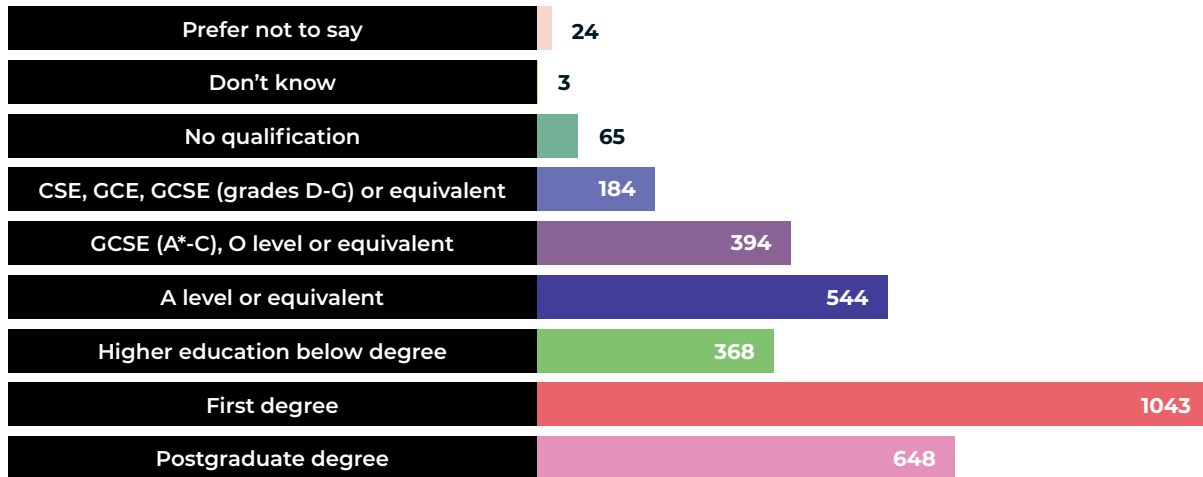
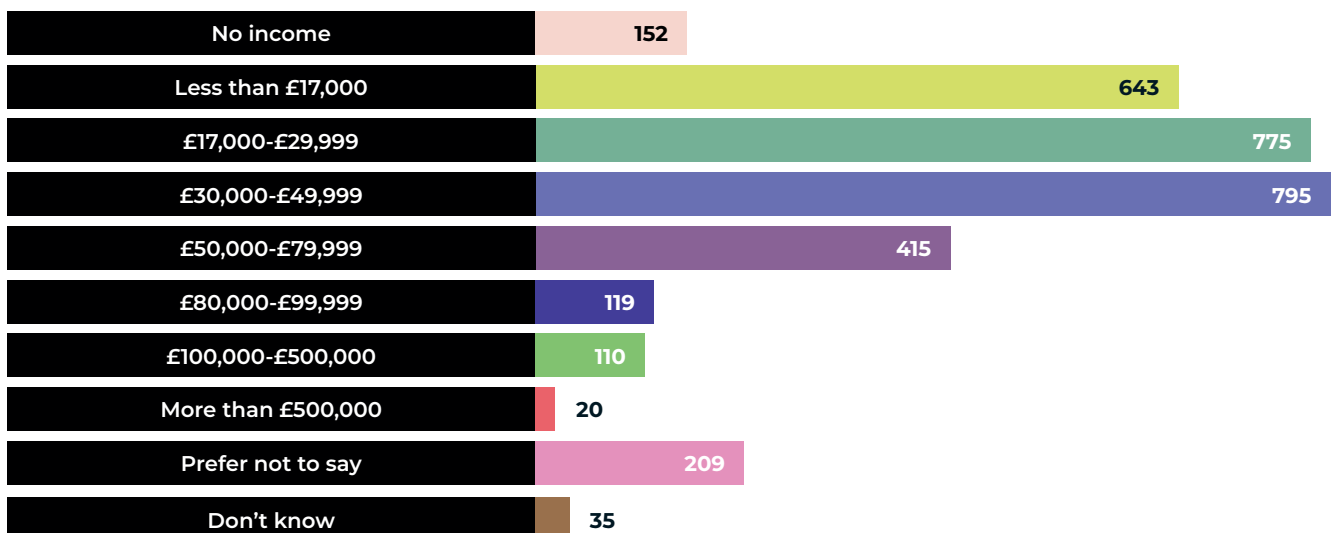
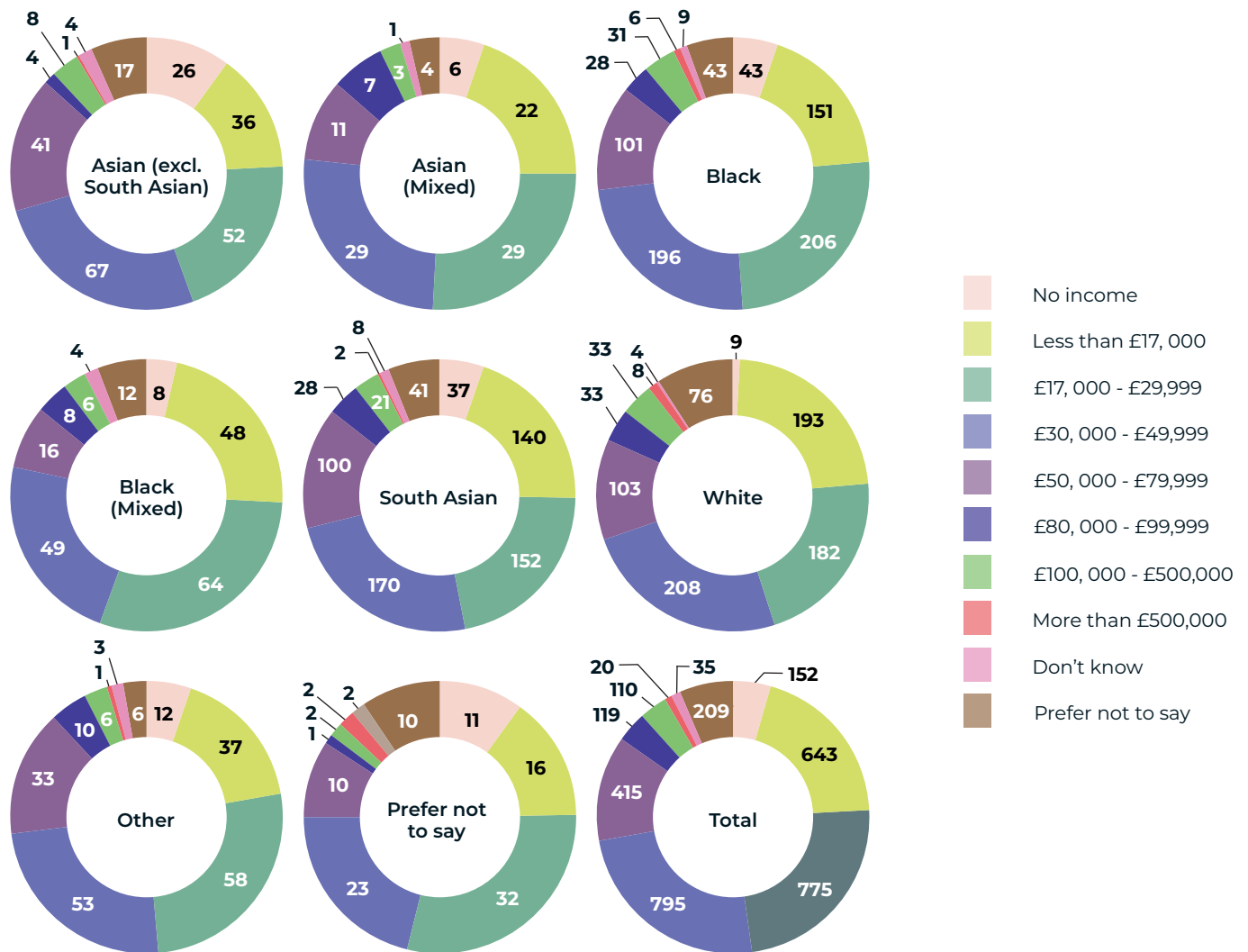


Figure 7: Income level of survey respondents

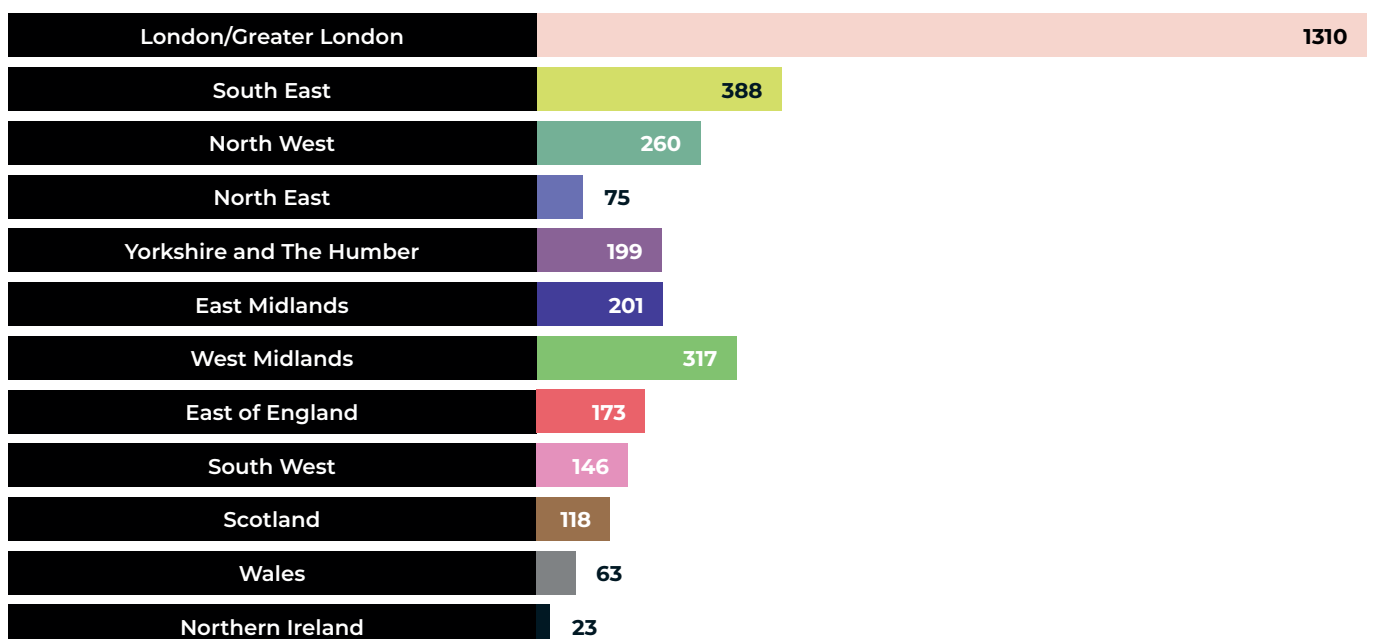


## Participant Profiles

**Figure 8:** Income by ethnicity breakdown of survey respondents



**Figure 9:** Regional split of survey respondents

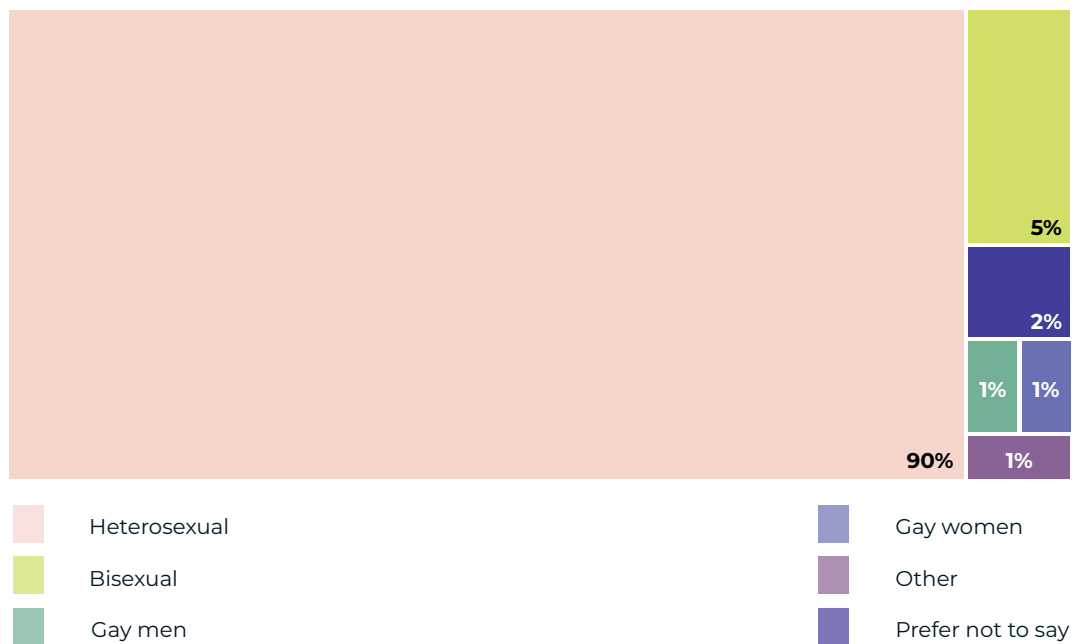


# Participant Profiles

**Figure 10:** Religion and ethnicity of survey respondents



**Figure 11:** Sexual orientation of survey respondents



## Participant Profiles

Figure 12: Place of birth of survey respondents

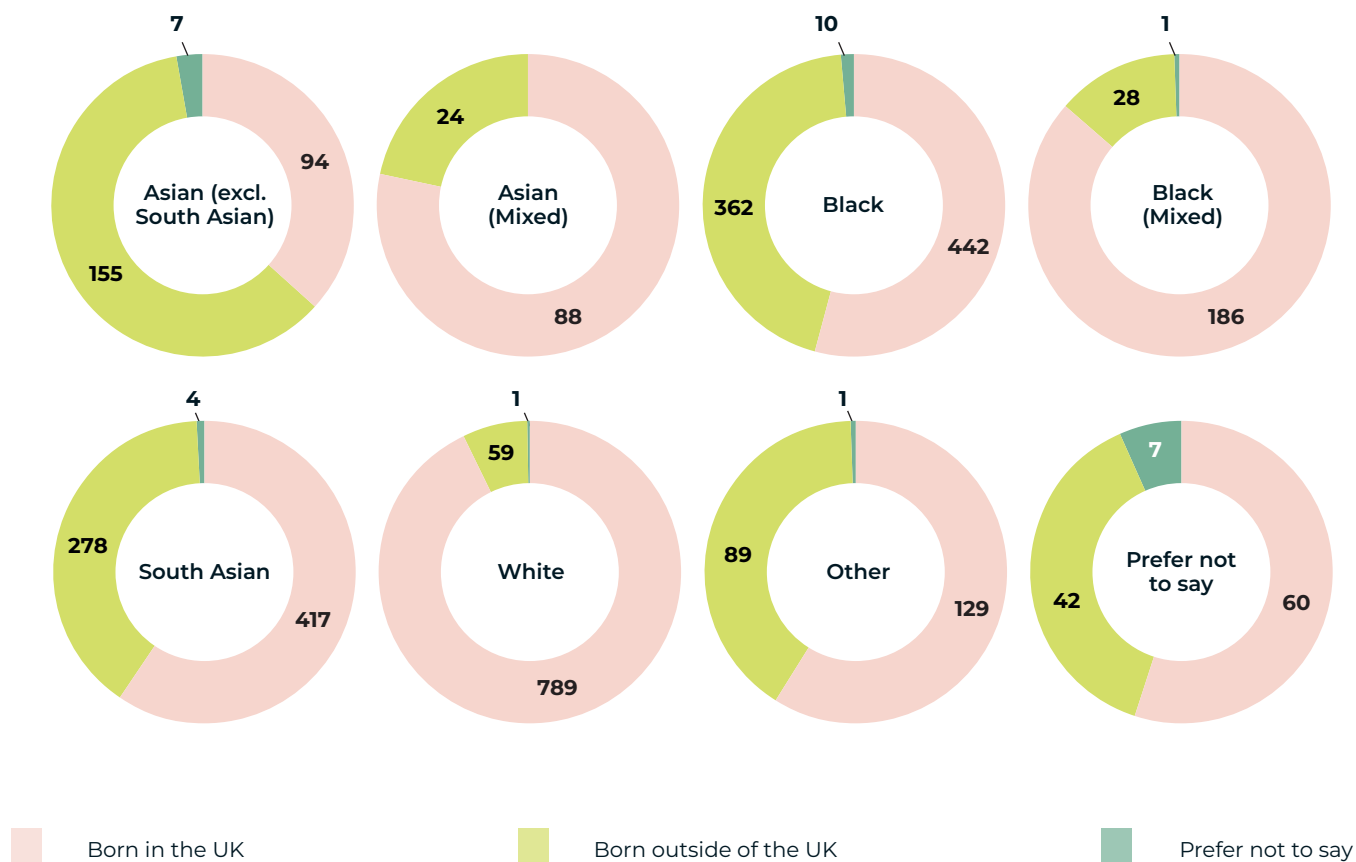
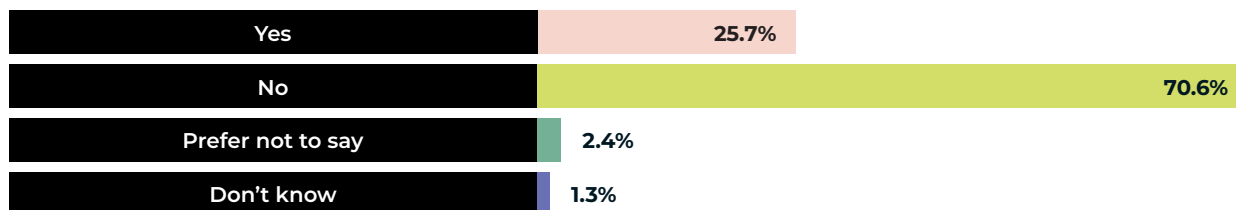


Figure 13: Health status of survey respondents

Do you have any physical or mental health conditions, illnesses or disabilities lasting or expected to last 12 months or more?








## Study strengths and limitations

The present study has several strengths and limitations that help to put the findings that have emerged into context and provides learning that can be applied in future research.

The qualitative phase produced rich data which benefited from the diverse sample that was selected to participate. It enabled the study to gain insight into the barriers and opportunities to improve data practice within the NHS across physical and mental health services. We gained insight into the contexts that healthcare workers operate in according to their grade which helped to tailor the recommendations that have been put forward. The findings have also been used to inform the development of resources to support frontline healthcare workers to hold informed discussions with patients about their data. Although it was not the intention of this study, the findings may not be representative of the experiences of healthcare workers across the NHS. However, the themes that emerged appear to reflect existing evidence. Despite the successful engagement of Black and, to some degree, Asian participants the study found it difficult to engage healthcare workers from White backgrounds. The research team found they had to put more effort and resources in to recruit participants. The team have reflected that the publicity may have focused heavily on addressing inequalities and some healthcare workers may have felt the study was not for them. Based on the themes that surfaced through the qualitative phase about White healthcare workers having concerns or lacking in confidence in talking about race, it is possible that they may have decided not to engage to avoid conversations that were likely to be centred around race and racism.

Although the survey had good representation from people from Black and South Asian backgrounds there are several limitations. There were low numbers of respondents from older individuals and those from lower educational and socioeconomic backgrounds, especially Black and South Asian people. The digital questionnaire may have been a barrier for older participants to be involved. We planned to engage people through face-to-face community events to overcome digital exclusion barriers, but this was limited due to time restrictions and cancellation of national and local events during September 2022. The options for participants to share their ethnicity limited our ability to conduct some analysis for people who identified as mixed White and Asian. They were not able to specify their Asian background e.g. White and Indian or White and Chinese. Given this, we were not able to explore the views of people who are mixed with a South Asian background which may have hidden a distinct experience.



Despite the option to disclose a non-binary or trans identity, none of the survey respondents identified as non-binary or transgender. In addition, the number of people who identified as lesbian, gay, bisexual or 'other' sexuality was too low to conduct analysis. Therefore, it is not possible to know if the findings in the study would be applicable to these groups. Similarly, there were several other groups that were also underrepresented in the present study. For example 25.7% of participants indicated that they had a long-term health condition. Therefore the findings from the study rest heavily on the views of people who may not have regular contact with the healthcare system. To help address this gap, future research should explore attitudes towards sharing patient data among older people, LGBTQ+, disabled, people living with long term conditions, refugee and asylum-seeking people from Black and South Asian communities to understand how to tackle data inequalities for these groups. To protect participants anonymity but provide some location information, we asked participants to provide the first three letters of their post code. Due to the partial information, we were not able to compare the level of deprivation of the survey participants against the general population. The index of multiple deprivation (IMD) ranks small areas within the UK from most to least deprived. <sup>36</sup>

There is a higher-than-average level of higher education amongst the survey respondents. This may be explained by educational opportunities being concentrated in London and the high proportion of London based survey respondents. Caution should be applied when extrapolating insights to the wider population about data literacy and engagement in health information which is likely higher amongst a more educated cohort. <sup>22</sup>



## Key findings from engagement with health professionals

This section provides an overview of the key themes that emerged from the interviews and focus groups.

### 01 Health professionals' knowledge and awareness of the purpose and use of patient data



Health professionals have good knowledge of the breadth of data collected by the NHS. They need to be more informed about why data that does not directly inform a patient's care is required. They are also less confident in describing why or how data they are not personally responsible for collecting in their role is used. A healthcare worker's level of confidence to hold conversations with patients about their health data is linked to their working knowledge of why and how the NHS uses data.

The healthcare workers who participated in this study were generally able to recall a wide range of data types collected by the NHS. They were also clear about the necessity to record clinical information to inform patient care and have the ability to keep patients informed (e.g. contact details). Health professionals expressed that they needed to be informed of the reasons why the NHS requests patients to provide data (e.g. relationship status, housing etc.) in situations where it is not immediately apparent how it relates to the care they receive.

They expressed higher levels of certainty when describing the purpose and use of data they were personally responsible for collecting or using and less confident in articulating why other forms of data were collected or used:



I think a lot of it is above my pay grade. I mean certainly the data that I collect I know how it's used. You have to reassure patients that the data is collected and won't be shared. I don't really know how it's used.

Practice Nurse, White British, Female

However, we found a direct correlation between the level of a participants' knowledge and their designation within the NHS. For example, people who worked in roles that involved service planning or research were well-equipped to describe how information they collected is used and stored:

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'Not everyone in the research team has access to the data. It's authorised, there are some people who are authorised to have access to specific types of data, and these people need to be trained. I work with women from high risk and highly deprived areas, and they are majority Black, ethnic minority, Asian, or 'other'. That's why I use that data. If I do have someone from that specific ethnicity then I will make my service bespoke to them, to their needs.'

Clinical Research Assistant, Arab, Female

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'I've worked in a research role where we also work with patients and we have focus groups like this to talk about what data we've collected, how we've collected it, and how we store it. I'm quite used to that experience, collecting the data at source and now talking about how you're going to use it either for direct care or for research, or for planning.'

Clinician, South Asian, Female

Participants highlighted that their lack of insight into data processes made it difficult to guide patients through the data collection process and ensure they were able to give informed consent when they shared data with the NHS:

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'I think it's hard to explain to a patient, if you yourself don't know what the purpose of these kind of data collection exercises are.'

Registrar, Asian British, Female



# 02

## Barriers to reducing inequalities in patient data for Black and South Asian communities



Healthcare professionals highlighted a range of barriers that may contribute to inequalities in data collection. These included a lack of awareness among staff about how the NHS uses patient data, difficulties in managing time and resource pressures, lack of access to technological solutions that could improve data collection and use, an absence of people in leadership roles focusing on addressing inequalities and an organisational hierarchy and work culture that tolerates bullying and institutional racism.

There are varied views amongst healthcare professionals about whether the perception that Black and South Asian communities are hard to reach is accurate. However, there is a recognition that language barriers may impact engagement, and communities question the motives of the NHS due to the harms they may have experienced within research and health services.

The health professionals we engaged described a range of barriers that may contribute to inequalities in data collection for Black and South Asian communities. The emerging themes included the level of trust that the workforce and communities had in the NHS, lack of professional curiosity, organisational culture, financial and time constraints.



## 2.1 Workforce and organisational challenges

### Trust in the NHS and lack of professional curiosity

Some participants described having high levels of trust in the NHS and the capability of their colleagues. One participant acknowledged that their level of confidence in their employer meant that they were unlikely to question the realities of current data practice:

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'I've got high levels of trust for some strange reason. I mean, how many people have you seen leave patient notes in Tesco's Weetabix aisle, you know? But I think there's something about showing how the data is being used for good, which I think can help build that trust.'

Senior Healthcare Manager, Asian British, Female

They recognised that the NHS made mistakes but felt the organisation ultimately contributed to the greater good. Participants also spoke positively of their colleagues and were acutely aware of the pressures that they faced:

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'If I see gaps in data, I don't assume that someone hasn't done their job, I think there is a reason.'

Junior Doctor, Black African, Male

However, there was some acknowledgement that some staff were negligent about data collection. This included miscoding information or suggesting that a patient has declined to provide information when they have not been asked.



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At times participants may not have used the term ‘racism’, but their narratives described key policies, processes, mental models and behaviours which indicated that institutional racism was likely to be a key factor. Others offered specific examples of how racism affected their work. It was suggested that the White majority senior leaders were less likely to be affected by the challenges that face Black and South Asian communities and therefore there was no impetus to transform services:

‘I guess it depends on who’s making the decisions as to why this data needs to be collected. I think, as we said before, you [referring to the Black female researcher] and I are going to be impacted by the results of this data. One of the reasons why I’ve agreed to have this conversation is because I want that impact, I want it to change. Maybe those that are making the decisions aren’t necessarily directly impacted. So, maybe the answers to the questions don’t really matter to them’

Anaesthetist, South Asian British, Female

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The participant also illustrated how her experience as an observer and participant in work programmes focused on addressing inequalities reinforced her view that these efforts were performative and lacked real impact:

‘They’ve been preparing this health inequalities project for at least a year, eighteen months. Now they’re going to the launch events, where they get people like me to sign up and my question to them was, ‘So, if health inequalities and this data is really important to you, does this information for patient consent come in any other language other than English?’ And unfortunately, the response was, ‘Oh. No’ I felt hugely disappointed because your preamble is saying, ‘Yes, it’s really, really important.’ But your outcome is, ‘It wasn’t so important that any of us had thought about it for the past eighteen months.’

Anaesthetist, South Asian British, Female



Participants were asked to provide an explanation as to why data on ethnicity is recorded inconsistently for people from Black and South Asian communities. Healthcare workers mentioned that some of their peers were hesitant to ask for some information due to perceived sensitivities and this sometimes led to options being selected on behalf of patients:

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“I think that there is a big thing about not being perceived as racist. People aren't letting the patient fill it out. People are guessing and not asking or communicating with them or completing it correctly’

Matron, White British, Female

Another healthcare worker from a Black background also related to this happening:

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‘People do it to me all the time, despite the way that I look, the way that I speak, they just assume that I'm Caribbean, and I'm not Caribbean.’

Head of Service, Black British, Female





Other health professionals suggested that people's discomfort arose as a result of having limited insight into other ethnic groups:



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“Could it be that people are not comfortable because they don't understand enough about those ethnic groups? So, for example on the system we've got one category for Black African, and we've got another category for Mixed African British. I wouldn't know what the difference is necessarily. If I have somebody with me and they tell me they're African, I wouldn't necessarily want to ask them the follow-up question, 'Yeah, but are you Mixed African?' They may think 'Why are you asking me this? What's it got to do with my healthcare?'

Data & Information Manager, White British, Male

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“When you ask the question 'what is your ethnic background?' As a White person sometimes you perceive that person might find it offensive. You don't want to offend people or upset people, and I think it's explaining why the data was being collected. That was the thing - it was not knowing how to do it.'

Practice Nurse, White British, Female

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However, this reluctance to ask people from minoritised backgrounds for information may also be influenced by the stereotypes people hold about these communities. The stereotypes can shape assumptions about what people will share and ultimately the services they can access:

“When I worked in A&E a few years ago in an alcohol liaison service the level of filling in these forms, for people from Asian backgrounds, was very low. When I had informal conversations with the nurses, who were mainly from ethnic minority backgrounds themselves, to try and get them to make sure that they asked every single patient, they said, ‘I’m not going to ask an Asian woman, who has come in with her husband, if she drinks alcohol. She’ll probably lie, and also, what if there’s any domestic issue?’. I was completely bemused by this, but that’s why they didn’t collect this kind of data, because of stereotypes. One person said ‘well, you know, they’re Muslim and they wear a scarf, so obviously they don’t drink.’

Senior Healthcare Manager, South Asian British, Female

This quote also illustrates that people who are likely to experience racism may also have internalised racist and biased beliefs, which shape the assumptions they make about certain groups based on their social identities. The example provided above brings with it a level of complexity that is explored in more detail within the discussion (page 78).



### Lack of representation from racially minoritised groups

Participants spoke about the importance of Black and South Asian people being represented in the workforce, as this was likely to impact the willingness of underrepresented communities to share their data:



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‘If we have more Black people in the workforce it puts me at a very comfortable position as I would give you my data without any hindrance. I wouldn’t think, ‘What are you going to use it for?’ So, I think one big enabler would be having Black people occupying key positions in health care.

Health and Social care worker, Black African, Female

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‘If we’re getting a Caucasian chap always out there, as a clinician, talking to ethnic minorities, trying to get them to come on board, it doesn’t always work. You need someone from the community, you need the engagement from people from the same ethnicity, to be able to build that rapport, to build that connection.’

Operations Manager, British Asian, Male

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And you don’t want a White, upper-class doctor that’s gone to a posh school to talk about, the social barriers to an audience of young Black guys, because really, he actually doesn’t understand. He might be very well-read and very well-educated, but deep down, he can’t ever put his feet in their shoes.’

Clinician/Researcher, Mixed South Asian, Female

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### Toxic workplace culture

Participants described how the hierarchical structure of the NHS and how the bullying culture that has been well documented manifests itself within their roles (38;39). They also discussed the personal cost it had on their experience of working within the NHS as well as the impact that it has on patient care. Within this study this appeared to be more pronounced for participants from Black and South Asian backgrounds. There was also evidence that the intersection of race and gender created a worse experience for women who experienced racism, classism, and misogyny:



‘As a trainee, if I would say something and my White peer would say something, he would be listened to, even though we said the same thing. He could be even junior to me. Now I see the difference because I am the Consultant. I don’t have the same battle that there used to be. So, now I have more energy to do things like this [referring to equalities and antiracism work].’

Anaesthetist, South Asian British, Female

Participants also highlighted that the mental models held by the workforce influenced the language that was used in consultations and shared their reflections on the need for culture change:

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“I’m thinking about the language that’s used within our practices and how that’s portrayed and how people are spoken to. If you come to one of my groups it’s very, very different to what we’re doing in surgery. What we’re talking about is changing a huge educational cultural history - so good luck. Good luck.’

Social Prescriber, White British, Female



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### Hiding behind narratives of the ‘Hard to Reach’

The participants we interviewed held opposing views on the belief that Black and South Asian communities are ‘hard to reach’. Whilst some represented communities in this way:

‘There are very deprived boroughs in the UK, in London. It’s very hard to recruit patients even with incentives in place, it’s still very hard.’

Research Manager, South Asian, Man

Others found patients to be open to participate in research or share their data:

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‘I do phone patients and I ask them for their participation all the time. You will not believe how cooperative they are.’

Clinical Research Assistant, Arab, Female

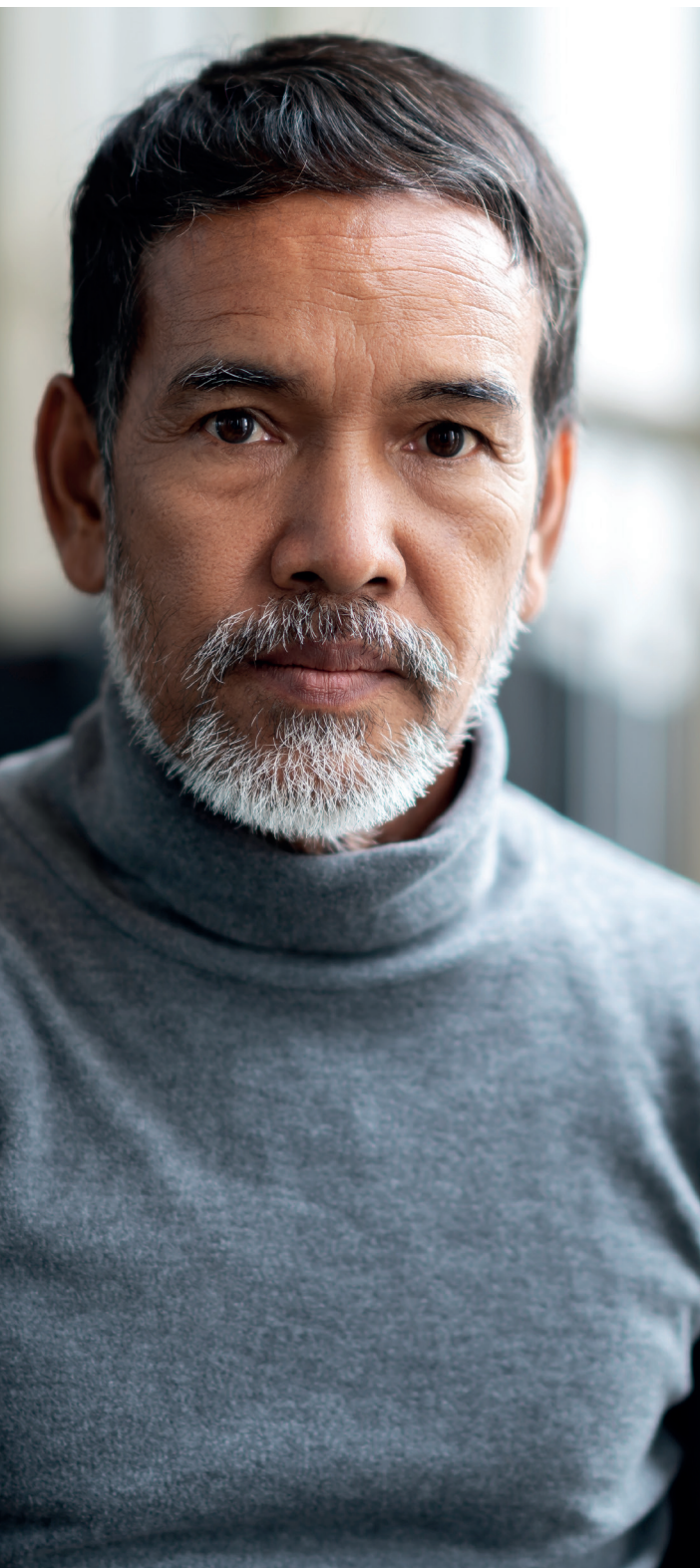
Others spoke about the challenges with engagement being exacerbated by the way the NHS works and the need for the organisation to change:

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‘I think where people get it wrong is that we need to adapt ourselves to meet that demographic group.’

Matron, White British, Female





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### **Data practices that stigmatise or exclude**

Healthcare workers who worked closely with marginalised groups, and were aware of systemic issues that shaped their experience of discrimination, expressed greater concern about the NHS's move towards data sharing and the risks that it may further marginalise:

'I deal with former prisoners and lots of people say, 'Please don't say I've been imprisoned.' The NHS can easily diagnose people and label people. You could have been in prison for whatever reason, and it could have been 30 years ago. It doesn't really need to be something that's passed on anymore but it is and then it creates problems and barriers for people'

Clinician/Researcher, White Other, Female

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These concerns also impact what healthcare workers felt comfortable recording in their attempt to safeguard their patients from harm.

'I feel very strongly that people are already profiled. So, I feel personally we must be very careful not to add to that profiling. We used to have a different way of holding data, that meant that basically only psychologists in my team could see the detail of my notes. But now everyone can see them, including physios and people who don't need to see what the person has said in their second year of weekly psychotherapy with me. Because of that I don't go into things that I think are not essential for people to know.'

Psychologist, White, Male



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However, the study also revealed that when data is available it may not be routinely screened to identify potential inequalities that are disadvantageous to racialised groups:

‘We don’t look at specific groups. We look at the overall picture of those patients admitted. So we don’t really classify them in terms of ethnicity. We just classify them according to how ill they are.’

Patient Safety, Asian British, Male

Similarly, another participant recalled a situation where they wanted to undertake a more granular analysis of the outcomes of racially minoritised groups. However, it was not possible as systems had not been set up to collect or analyse data by ethnicity. Nor were they able to get backing from senior leaders to implement the required changes.



## 2.2 NHS infrastructure

Participants spoke about how the infrastructure that supports the NHS may contribute to disparities. One participant pointed out patients were forced to select the 'other' category due to the limited ethnicity categories available on their systems:

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'South Asia and Africa are such big continents/ areas. Ticking Black Other is actually saying I'm Nigerian, I'm from Zimbabwe, I'm Ghanaian, I am proud of where I come from.'

Matron, White British, Female

The workforce spoke about the benefits and challenges presented by introducing technology to improve data collection and use of patient data. They welcome systems that would enable them to streamline their processes. Giving patients greater control over the information was thought to be a viable option to help improve data.

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'You need automation of some of that data collection. How many times are we collecting the same data? Your ethnicity's unlikely to change. So, if it's been recorded once, why do we need to keep recording it?'

Anaesthetist, South Asian, Female





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One participant observed that the introduction of a new system with mandatory fields was a helpful mechanism that made it easier to collect people's information:

“We couldn't book in a patient until we had that information, so we had to liaise all the time. Things are a lot better now, but the first six or seven months, or maybe more, we had to ask the patients about their ethnicity or their preferred language, and things like that.”

Administrator, Black African, Female

The healthcare workers we engaged had mixed feelings about how helpful mandatory fields were in maintaining the integrity of the data collected. Some expressed concerns that when working under pressure people may enter incorrect information to move to the next question or screen.



## 2.3 Individual and community-level factors

Participants also identified a range of factors categorised as individual and community-level factors. However, it is recognised that the areas to be discussed are linked with structural factors and any challenges are likely to be a consequence of those structures.

### Levels of trust in health services

Healthcare workers considered trust an important factor that influenced how willing Black and South Asian communities were to share their data. People were not always explicit about the underlying reasons that may have led to their distrust of the NHS. However, some referenced the negative experiences communities may face when accessing health services and others spoke of situations where services/institutions have caused harm:

A healthcare worker was also able to relate on a personal level with patients who may not wish to share data with health services as they did not trust that they would not be discriminated against:



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‘I think the previous stigmas and the unfortunate tales that happened before, does haunt some of our patients now.’

Operations Manager, Asian British, Male

‘Patients will think this is how the service has treated me, and there’s no way that they can rectify it, apart from them saying, “Sorry”. They’ll think, ‘Okay, what is the sorry going to do?’ There’s not going to be any change, because it’s already been done.’

Matron (Mental Health), Black British, Female

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‘Now I’m more informed about how data is used in the organisation that I work in. However, there have been times when I’ve filled in data and I’ve always left out my ethnicity. I don’t want anything to be held against me, being Black - or services being withheld.’

Head of Service (Mental Health), Black British, Female

‘I fear discrimination, that’s the reason why I don’t want to fill in forms, and everyone would literally be having that as a reason.’

Service Manager, Ethnicity not disclosed and sex unknown

‘Especially for failed asylum seekers and people that want to be under the radar. And what’s interesting is they think that the NHS are like the police, and we share data.’

Clinical Nurse Specialist, White Other, Female

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Interestingly, although the distrust of institutions was a prevalent narrative, participants reported that in their experience, patients were broadly open to sharing their data:

‘People have that trust, just like any other person. They would trust their healthcare professionals to make use of the information and guard it. In my workplace I have not encountered any issues collecting data from Black and ethnic minorities. They are happy to give their data because they need treatment.’

Doctor, Black African, Male

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This quote illustrates the transactional nature of sharing one’s data. In some respects, a patient who is sceptical about sharing their data will still need to provide enough information for their health needs to be met.

‘I don’t recall anyone having an issue. They just accept it, you know, I suppose you had to say it in a certain way.’

Administrator, Black African, Female

In general, participants from Black, South Asian and other minoritised backgrounds were less likely to report experiences where patients have refused to provide their information:

‘From my own personal experience, I wouldn’t say there has been any significant difference between the White population and the Black and ethnic minorities. People are just not interested in giving their time to surveys or getting data from them. And people get scared about what their data could be used for, that it could get into the wrong hands.’

Doctor, Black African, Male



# 03

## Consequences of missing patient health data



Levels of awareness of the consequences of gaps in patient data for Black and South Asian communities was mixed. Most people understood that data was needed to provide individual-level care. Healthcare workers were less aware of the wider impact. People from racially minoritised backgrounds were more likely to highlight the importance of being represented to reduce inequalities. Some healthcare workers appear to interpret the inequalities experienced by racially minoritised groups to have some form of biological basis rather than situating health inequalities in the context of wider structural issues.

Healthcare workers understood that data was required to support the care of individual patients and to assess if services were equitable:



'I think one of the key advantages with collecting data is that you make sure that service provision is equitable. So, that means that you're providing the service for everyone and not missing big chunks of the community. I think it's the only way you could really know if people are accessing services equitably is by looking at the data and then responding to that. So, if there are communities that are not represented in a certain type of therapeutic approach then we need to do something about it.'

Psychologist, Black British (Caribbean), Male



'Certain types of health needs or disease processes, there was a reluctance to collect their data because of fear of some sort of racism business. That's around sexual health, but thank goodness in the last ten, fifteen years it's been realised that we need to collect the data otherwise we can't look after patients.'

Clinical Nurse Specialist, Black British, Female

This quote echoes an earlier issue raised about workers and services being concerned that they will be seen as racist.

# 04

## Healthcare professionals' recommendations to improve how the NHS routinely collects and uses patient data



Health professionals' recommendations to improve how the NHS collects and uses patient data varied considerably. Some felt greater attention needed to be placed on reassuring patients of the benefits of sharing their data. Others were keen for the NHS to take advantage of technology to improve the standardisation of data collection. Some participants felt the NHS could be more radical in redistributing power to patients, so they had more control over their data and their communities directly benefit from the resources and insights generated through research and private partnerships. They shared existing examples of good practice that could fulfil their aspirations for how the NHS routinely collects and uses data.

Participants were invited to share their ideas about the things they felt would help to address inequalities in health data.





## Building trust

We heard several ideas about how to build the trust of Black and South Asian communities:



'If someone asks, 'Why are you collecting this data?' I feel that staff need to be skilled enough to explain why so there are no secrets. As a Black man I know that there's a lot of mistrust with mental health services in particular, and it's really important that the Black community is able to trust services. And the only way you can really trust services is if you can say, "This is how we're going to use the data - is that okay?" And if there are any objections then that could be talked about and explained. I think it's transparency.'

Psychologist, Black British (Caribbean), Male

'I think total disclosure and transparency, I think that would slowly start building trust, and you know, this transparency should be able to happen independently. It shouldn't be done through the NHS. You know, if we ask the NHS to send me a protocol, you can't guarantee that it's going to be done in a non-biased way. You want it to be done independently. There should be a governing body available for people to request whatever they want independently, with full transparency.'

Operations Manager, Asian British, Male

'I might not ask for people's data straight off. If you don't want to tell me your name and if you don't want to tell me your correct date of birth, don't. That's okay. Let's use whatever you feel comfortable with because we can always go back and update it. I'm prepared to put you on the system as this, and when you know me and when you trust me. A lot of people will turn around and say, 'You know that address I gave you a couple of months ago, it's actually incorrect. I live here.' I take a long time, because I don't think it should be rushed, and I don't think it should be a barrier to service.'

Clinician/Research, White Other, Female



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### **Holding conversations about data and building rapport**

Others emphasised the relational aspects of collecting data and the importance of building patient trust. Building rapport with patients is a skill that needs to be nurtured. One participant described how this is a skill she has honed for over 20 years.

‘It’s a very hard skill to learn and even now, when I go back to support my old ward, they will come and get me to do the difficult conversations because they are still not at that point. That’s a skill you develop in your career. It’s not something you get straight away.’

Matron, White British, Female

‘So I think that I have a good relationship and a good rapport with most patients.’

Practice Nurse, White British, Female

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### **Better communication about the importance of data to NHS staff**

The healthcare professionals we engaged felt that the NHS could do more to raise awareness of the importance of data among the workforce and within Black and South Asian communities:

‘I don’t know if they’re doing it already, maybe they can do some more advertisements and make staff, non-staff, patients aware that the data is there to help you, it’s there to help the NHS. We’re not collecting it for our personal use but it’s to help everyone.’

Administrator, South Asian, Female

‘The higher you go, the more you realise how important data is when you run a service.’

Nurse matron, White, Female



Many felt that staff are less motivated to collect data when they are not clear about its purpose or the impact that it might have. The workforce recognised that most of their colleagues wanted to make a positive contribution and therefore emphasising the difference their efforts will make in patient care and public health policy is likely to inspire people to collect data:

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‘Yeah, I do have experience with data collection. I receive data from different sites, so, some of them are very meticulous and they send the data complete from the first time. There are many people whose data is really good, and I don’t have any problem with the data that I get. Everything is complete, starting from demographics until the discharge of the patient until the follow up. Everything is perfect. So I do have a good experience with that, or a positive one.’

Clinical Research Assistant, Arab, Female

‘Ensuring that the patient or whoever you’re collecting the data from, understands fully why you’re collecting that data. That way, you know, they would be more likely to cooperate, and give you all the data that you require. They would even also ensure that it is accurate because if they do not understand then they could falsify it, they could give you false information and that can skew your data.’

Doctor, Black, Male





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Others described the benefits of introducing a feedback loop with staff teams to share the insights from the data they are collecting. When staff are able to understand the benefits (e.g. improved service delivery, cost savings etc.). They found that this motivated staff to improve data collection and embedded a culture of continuous learning and improvement:

My colleagues ran fellowships for clinicians, trainees, to code orthopaedic operations properly, and in that, they got to do other experiences, so build their clinical skill set. But what they found was, because they were coding more accurately, they were generating a greater income, which offset the cost of their salary, and then some.'

Anaesthetist, South Asian British, Female

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There was a strong feeling that mandatory e-learning was unlikely to be well received by healthcare workers:

'I'm sure there's lots of educational information around how the learner learns and retains information, mandatory e-learning modules are not one of them.'

Anaesthetist, South Asian British, Female





### **Learning from, and working with, other parts of the healthcare system and the voluntary sector**

Participants recognised that approaches to data collection and use were variable across the health system. One participant suggested that secondary health services could learn from primary care who were often better at recording ethnicity data:



‘Recording is done quite well in primary care.’

Registrar, South Asian British, Female

Others drew upon their experiences of working with communities and the voluntary sector to support their work:

‘And I think one of the things that I have learnt is the importance of accessing this community. I think it’s about speaking to them, having this focus group and representation - someone who knows the community really well. It can be in the same ethnicity as well, and letting them understand its importance, having that discourse really.’

Patient Safety Department, Asian British, Male

Leaders within the voluntary sector were considered to be conduits to engage communities and disseminate key messages:

‘We must lean on the people in the communities who are well respected, and who people do listen to, and who can talk the talk and walk the walk. I think a lot of people might trust giving information out to the NHS, but I think what they don’t trust is what happens to that information.’

Clinician/Researcher, White Other, Female

## Building technological solutions in partnership with the end users

Earlier in the report, we highlighted that technology could both support and hinder data collection and how the workforce engages with data. One of the issues that arose was that healthcare workers felt as though senior leaders had imposed new systems that were not fit-for-purpose. However, one participant described a time when his employer had co-designed a new system in partnership with clinicians and people who would have insight into how the system could be used:

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‘When they went live with [the new system], one of the key decisions they made was they wanted it to be clinically led. It was built from scratch based on people that understand the clinical workflows. And most of the people that were able to feed in from the patient care perspective, which turned out to be a really good decision.’

Data and Information Manager, White British, Male



## Standardising data collection and sharing across institutions

Participants were invited to share their recommendations to improve how the NHS collects and uses patient data. The suggestions put forward included better standardisation in data collection and opportunities to share data across institutions:

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'I would say the NHS is a very uniquely positioned organisation that spans the whole UK. In an ideal world, I'd want data to be collected such that it's harmonised across the country and across different hospitals and primary care and secondary care. That each hospital, or whatever, shouldn't work in silos.'

Doctor, South Asian British, Female

'The medical records are basically anonymised and put into a massive cloud that, people with the appropriate security and training, can go in there and query that data across the whole hospital without having access to actually who that patient is. They don't need to know that. They can analyse trends. Personally, I'd like to see the whole NHS go that way. All the data being sucked into a massive system.'

Data and Information Manager, White British, Male

This participant also added:

'Would there be some way in the future vision to get demographic stuff that is captured in a certain place? Have one place or source of truth that auto-populates everything else. We're a long way away from that at the moment but certain information that is captured really diligently and then feeds out to other systems.'

Data and Information Manager, White British, Male





### **Giving patients more ownership of their data**

Participants were invited to share their recommendations to improve how the NHS collects and uses patient data. The suggestions put forward included better standardisation in data collection and opportunities to share data across institutions:



'I think it would totally radicalise services for people to be able to, like, when you write your notes, the person sees it. I think that would be amazing in loads of ways. How would people write? People having a right to challenge things more accessibly may change this.'

Trainee Family Therapist, White, Non-binary

Others suggested a review of policies and processes with the goal of redressing the inequities Black and South Asian communities experience and extending the benefits that might emerge from sharing data. This was a particular focus when discussing NHS partnerships with research and private sector entities:

'I would like the NHS to look into how we can reimburse patients involved in clinical studies to provide a little bit more, rather than compensating their journeys and giving them some expenditure. With the data that we collect, there are hundreds and thousands of pounds that are invested and generated with selling data and using data in a research sort of way and I think maybe we should find a way of compensating our patients a little bit more.'

Researcher, Asian, Male

He went on to say:

'If we're going to encourage these folks to come along and provide support, I think they should get a fair deal out of this. You know, at the moment, you see a lot of people, they charge for their photos to be taken, footballers and celebrities, I think it should be the same for DNA and data, any samples. If you're sharing this and it's going to be passed on multiple times, you should get some sort of reimbursement and profit out of it.'

Operations Manager, Asian British, Male






# Key findings from the public survey

**There are high levels of engagement in health-related information amongst survey participants**

The present study explored the participants' levels of engagement with health information and its relationship with other aspects of the survey. Several of our hypotheses (Table 1) assumed that as engagement increased, other topics that were of interest to this study would also increase positively. A high proportion of respondents reported high levels of engagement in health-related information.

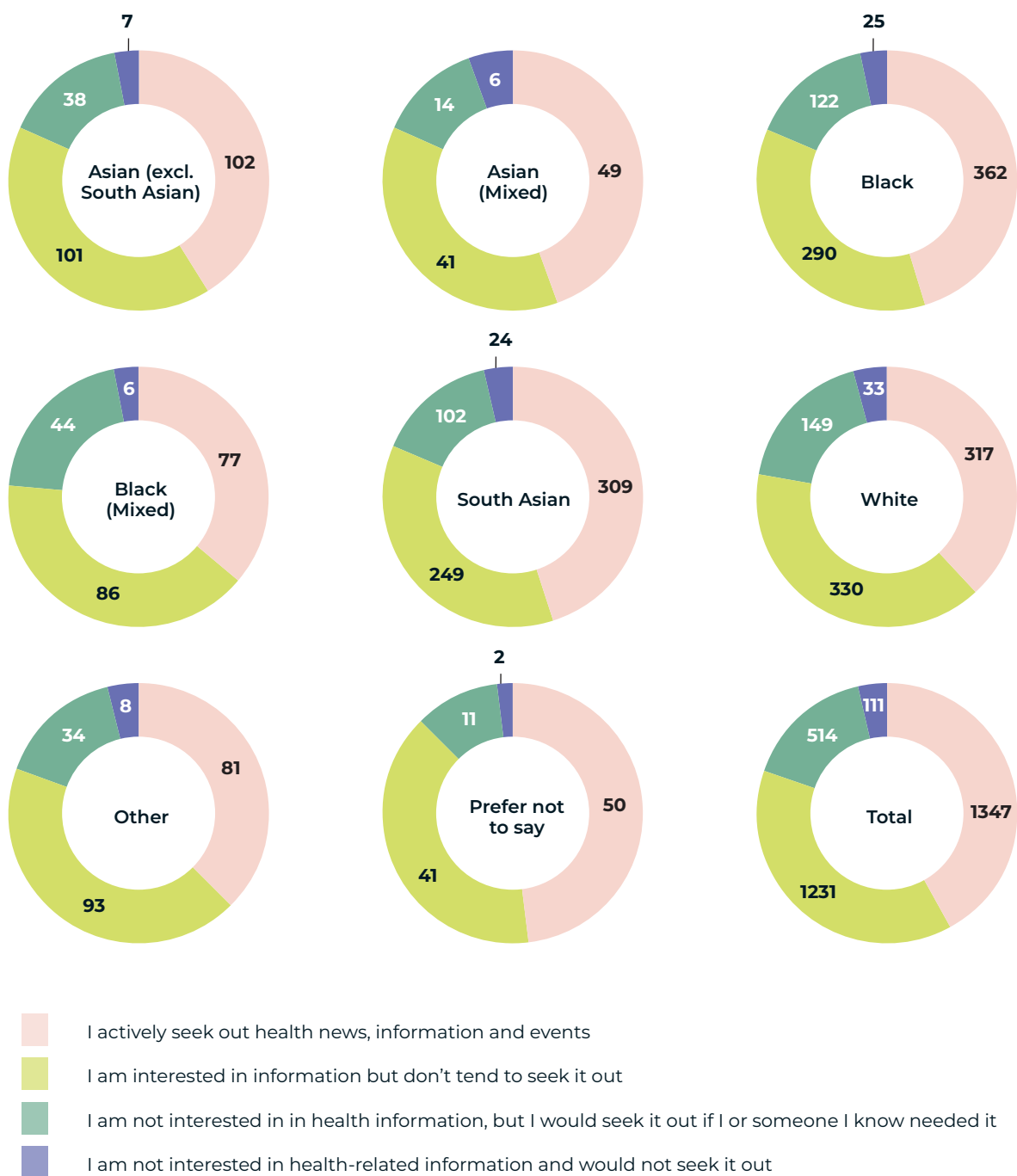


**Table 1:** List of hypotheses and expected survey insights

Hypothesis	Predictions
 <p>Engagement with health information is interrelated with trust in institutions and willingness to share health data</p>	<ul style="list-style-type: none"> <li>■ A person’s level of engagement with health information will be shown to increase as the following increases:               <ul style="list-style-type: none"> <li>• Their trust in institutions</li> <li>• Their willingness to share their patient data/their children’s data</li> <li>• The patient data types they are prepared to share</li> </ul> </li> <li>■ Reasons for trust/lack of trust in institutions will be shown to:               <ul style="list-style-type: none"> <li>• Differ between demographics where those most likely to experience marginalisation will have lower levels of trust in institutions and lower onward levels of willingness to share information</li> <li>• Differ based on whether respondents have had a conversation with a healthcare worker about how their data is used; this will impact willingness to share patient data</li> </ul> </li> <li>■ Low levels of trust in the NHS and supporting institutions will result in:               <ul style="list-style-type: none"> <li>• Less willingness to share personal data</li> <li>• Less willingness to share children’s data</li> </ul> </li> </ul>
 <p>The experience of being minoritised influences data literacy, scepticism and aspirations for data use</p>	<ul style="list-style-type: none"> <li>■ Drivers for comfort sharing data will be affected by demographic variables</li> <li>■ People who identify with minoritised identities are less likely to be comfortable sharing information about these identities</li> <li>■ Minoritised groups are more likely to express concerns over discrimination and/or sharing data across institutions as a key factor in not being willing to share information</li> <li>■ Preferences on how, where and when people want to learn about how their data is used will differ across demographic variables (e.g. age, ethnicity, migration history, location etc.)</li> <li>■ Aspirations about onward data use will vary across levels of engagement in health information and/or demographic variables</li> </ul>
 <p>Health engagement impacts levels of data literacy</p>	<ul style="list-style-type: none"> <li>■ People who are more engaged in health information are more likely to agree that there are negative consequences when health data is missing</li> <li>■ Levels of agreement or disagreement about the consequences of missing health data will be influenced by levels of trust in the NHS and institutions and/or demographic factors</li> </ul>

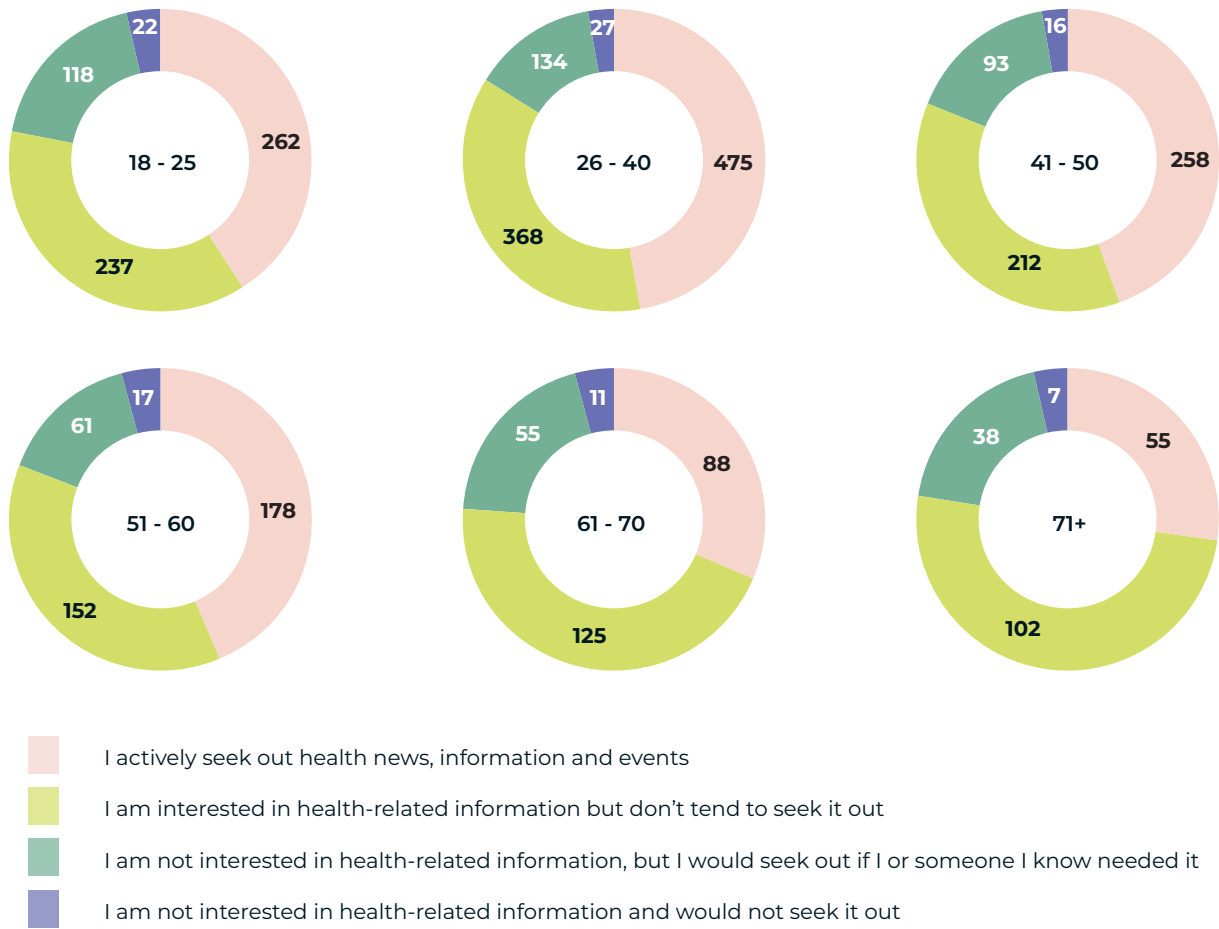
When considering engagement with health information across various ethnicities, there were no significant differences. Given that a higher proportion of respondents from minoritised groups within the sample are younger compared to White respondents, it may be that their views are being averaged out due to age. The breakdown of engagement across age groups shows decreasing engagement with age. Despite this, very few older respondents shared that they are not engaged at all with health information.

**Figure 14:** Engagement in health information across ethnicities <sup>40</sup>





**Figure 15:** Engagement in health information across age groups



## Survey respondents across all backgrounds trust the NHS with their personal data

We asked survey participants how much they agreed with the statement 'I am willing to share my personal data with the NHS' and to specify this for different types of data. Across all demographic variables, most respondents agreed or strongly agreed that they were willing to share their data with the NHS. An interesting trend within the data was an increased willingness to share personal data with age and absolute distrust decreasing with age. This may be because as people get older, they may be more likely to experience health issues and have increased interactions with the NHS. This is likely to increase the willingness to share personal data for the benefit of the person's care.

Whilst most respondents are willing to share their personal data, there is a higher proportion of White respondents who strongly agree or somewhat agree with the statement 'I am willing to share my personal data' at 85.1%. This is compared to 73.9% and 73.2% for Black and South Asian respondents respectively.

**85.1%**

of White respondents who strongly agree or somewhat agree **'I am willing to share my personal data'**

**V**

**73.9%**

and 73.2% of Black and South Asian respondents who strongly agree or somewhat agree **'I am willing to share my personal data'**


## There is a stronger relationship between engagement in health information and trust in public sector organisations as compared to trust in private organisations

We were interested to explore the correlations between levels of trust in various organisations accessing patient data and engagement. This was measured using Spearman's Correlation as detailed in the methodology. Results are always denoted between -1 (negative correlation) and +1 (positive correlation) to provide an indication of both the strength and directionality of the relationship. The closer the value is to 1 (+/-) the stronger the relationship between the variables being explored. To assess whether we can meaningfully conclude that the relationships under investigation are significant a p value of < 0.05 and below has been set.

We found that overall, there is a stronger correlation between engagement in health information and trust in public organisations as compared to private companies. The only group who did not reflect this trend were those with long term conditions, this is understandable as this group may have more to gain from trusting all organisations that could support with management of their health conditions. Generally, with age there was increasing trust in institutions as engagement in health information increased until age 60 (table 2 as an example) and 73.2% for Black and South Asian respondents respectively.

**Table 2:** Summary of Spearman correlation analysis for engagement and trust in NHS research organisations by age

Age range	Correlation	Significant / level of significance
18 - 25	0.09	p < 0.05
26 - 40	0.15	p < 0.001
41 - 50	0.11	p < 0.1
51 – 60	0.17	p < 0.001
61 – 70	0.17	p < 0.05
71+	0.069	Not significant p < 0.5



The limited correlation above this age is likely due to smaller sample sizes limiting the likelihood of seeing any strong trends. Across all types of organisations (except private companies), there was an increasing positive correlation between trust and engagement for Black respondents (Spearman's coefficient ranged from 0.1 – 0.18 with  $p < .001$  or  $.05$ ). For South Asian respondents, this positive correlation between trust and engagement was only significant for local councils (coefficient = 0.1,  $p < .05$ ), health-related charities (coefficient = 0.11,  $p < .05$ ) and NHS hospital trusts (coefficient = 0.076,  $p < .05$ ). For all organisations except local NHS organisations (women – coefficient = 0.094,  $p < .001$ ; men – coefficient = 0.056,  $p < .05$ ), there was a stronger correlation between engagement and trust for men (average coefficient = 0.125) when compared to women (average coefficient = 0.098) which is unexpected. Men are generally viewed to be less trusting of authorities.<sup>21</sup>

## **Ethnicity does not drive variations in the relationship between engagement with health information and willingness to share personal data**

We explored the relationship between engagement with health information with willingness to share data with the NHS. Our assumption was that people who are more engaged with health information would be more willing to share data with the NHS. As predicted, there was a positive correlation with willingness increasing as engagement levels rise. The main demographic variables that differentiate levels of engagement are income and education levels with much stronger positive correlation as income and education level increases (see Appendix).

Where there is a significant relationship, the correlation between level of engagement and willingness to share data does not change across ethnicities (see Appendix) which challenges the common assumption that people from minoritised ethnic groups are less willing to share data than their White counterparts.



## Reasons for trusting the NHS

- I understand how my data will be used
- It will help to improve services
- I will get the best care
- My data will be kept securely
- My data will be used for the purpose it was collected
- It will help to improve research
- My data won't be shared with other agencies or government departments (e.g. police, Home Office, local council) without my permission)
- Other
- None of the above
- Don't know
- Not applicable - I do not trust the NHS with my health data

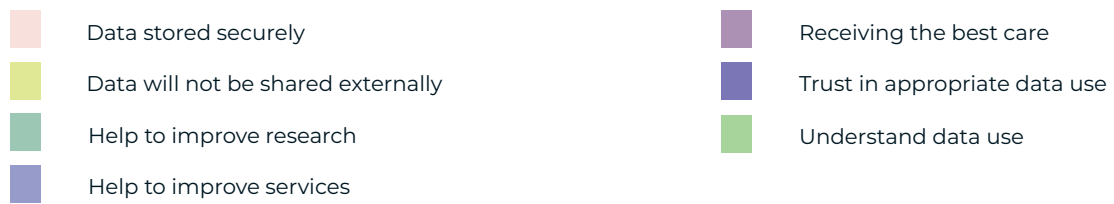
## Reasons for trusting the NHS

We asked survey respondents to select their top three reasons for trusting the NHS with their data and gave the option to choose not trusting the NHS. Out of 2,463 respondents, only 90 said they didn't trust the NHS with their data showing an overwhelmingly positive view of the NHS managing personal data. The reasons for trusting the NHS were similar across all demographic variables. We note there is a higher proportion of respondents above 60 (4%) who 'understand data use' compared to those under 60 (8.4%). This may be due to lower numbers of respondents in these age categories. Despite this, respondents' trust in the NHS to use their data appropriately was seen to increase with age. The most frequently selected reasons for trusting the NHS with their data included the improvement to care and services. Across all demographic variables, understanding of how data is used is the least selected option.

**Figure 16:** Reasons for trusting the NHS with health data by age

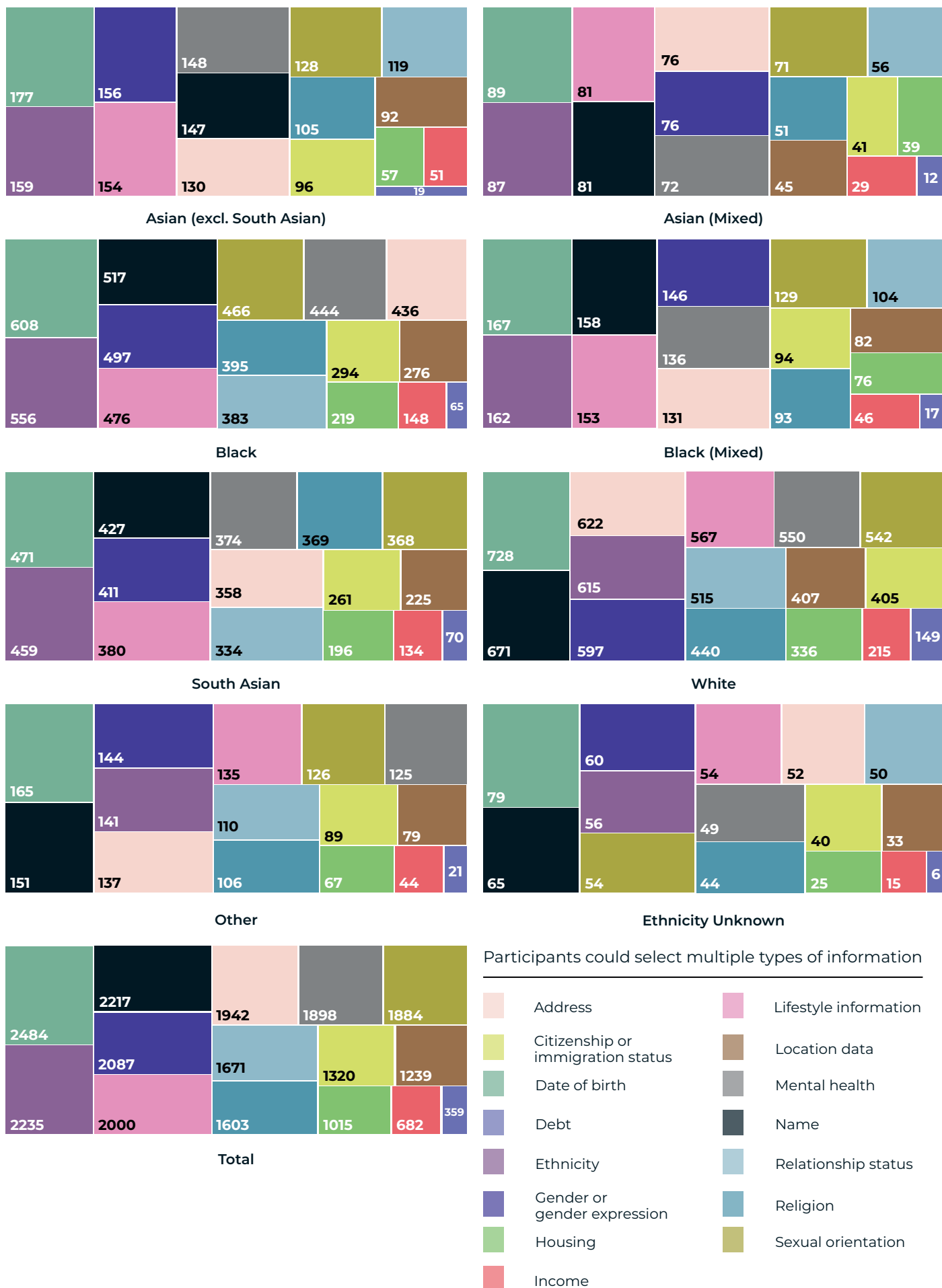


Respondents were able to choose up to 3 answers:



We also gauged respondents' level of comfort sharing various types of data. Across all ethnic groups there were no variations in the level of comfort respondents had when sharing various types of data. All groups expressed less comfort sharing their financial information (i.e. debt and income levels).

**Figure 17:** Types of information that participants are comfortable sharing with the NHS broken down by ethnicity



## Only one in five respondents had a conversation with a healthcare worker about how their data is used, despite this having a significant impact on willingness to share data

We found that only 19% of people have had a conversation with a healthcare worker about how their data is used. When analysing who has had a conversation by ethnicity, we see that 25.6% of Black respondents have had a conversation compared to 13.2% of White respondents (figure 18). We see that younger people are more likely compared to older people to have had a conversation (figure 19). Those who have higher levels of education and higher incomes are also more likely to have had a conversation about data (figure 20 and 21). Given the link between socioeconomic status and worse health outcomes, it is of concern that those who experience greater health inequalities are less likely to have had a conversation about patient data. For those who have had this conversation, there is a more equal distribution of increased comprehension about how patient data is used (figure 22). There is also an increased willingness to share patient data (figure 23) with 47.9% who are strongly willing to share their personal data after having a conversation with a healthcare worker about their data versus 40% who have not had a conversation. It seems that having a conversation with people about how patient data is used leads to an increased awareness of its various uses.

**Figure 18:** Ethnicity and conversation with healthcare worker

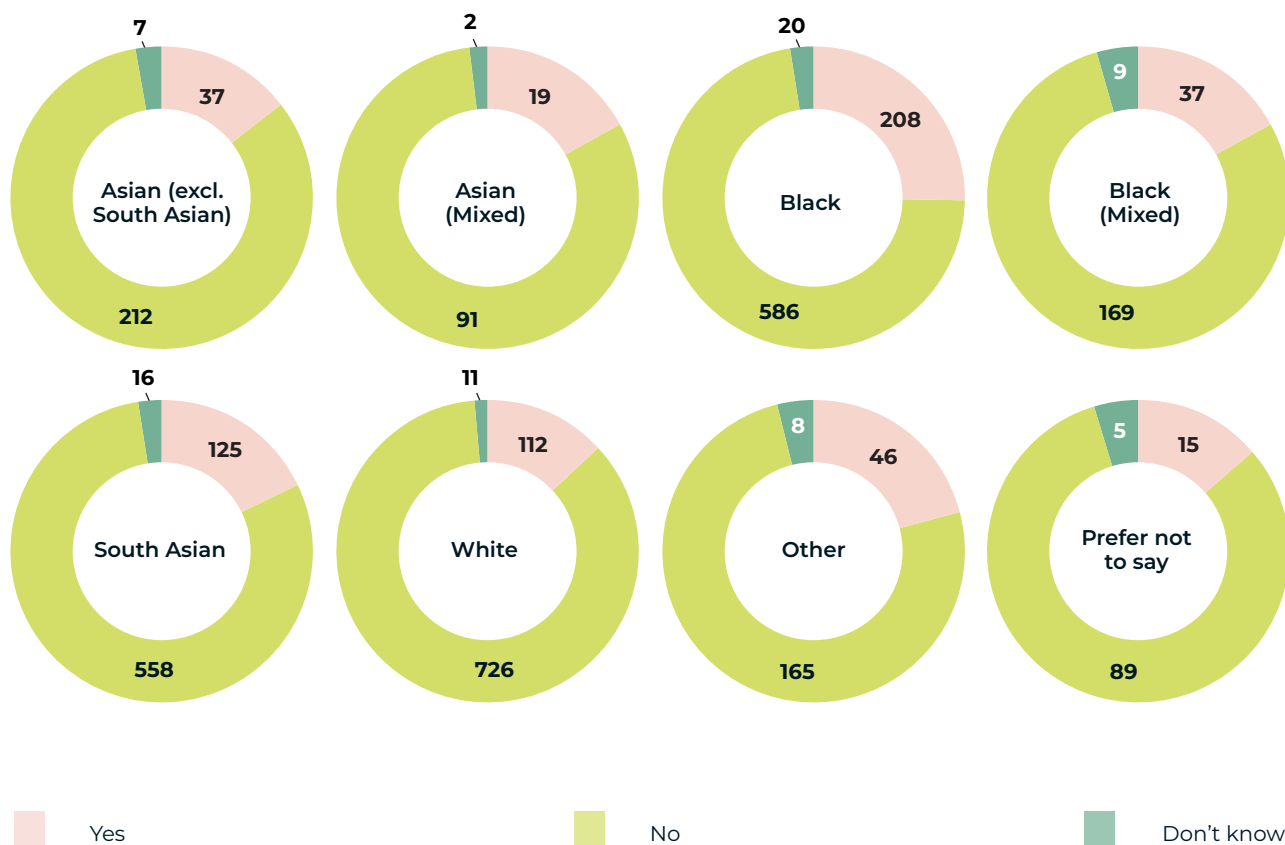




Figure 19: Conversation with healthcare worker by age

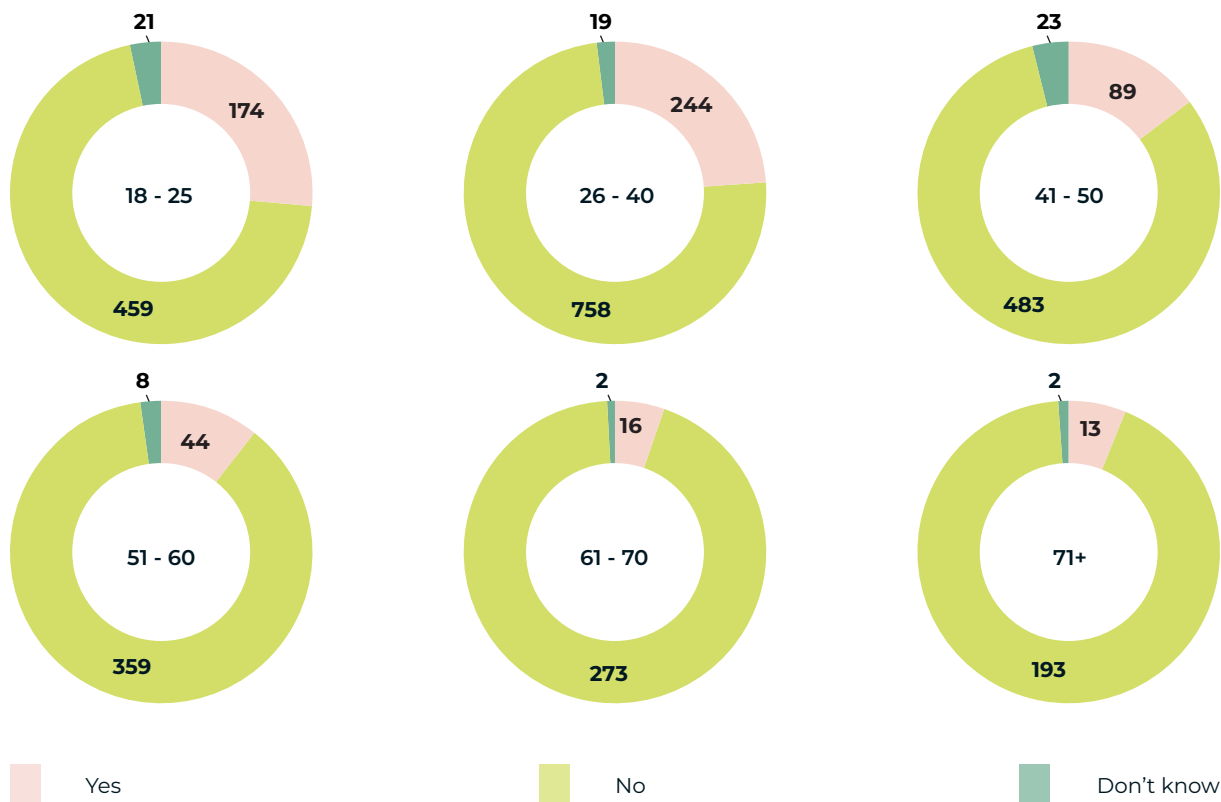
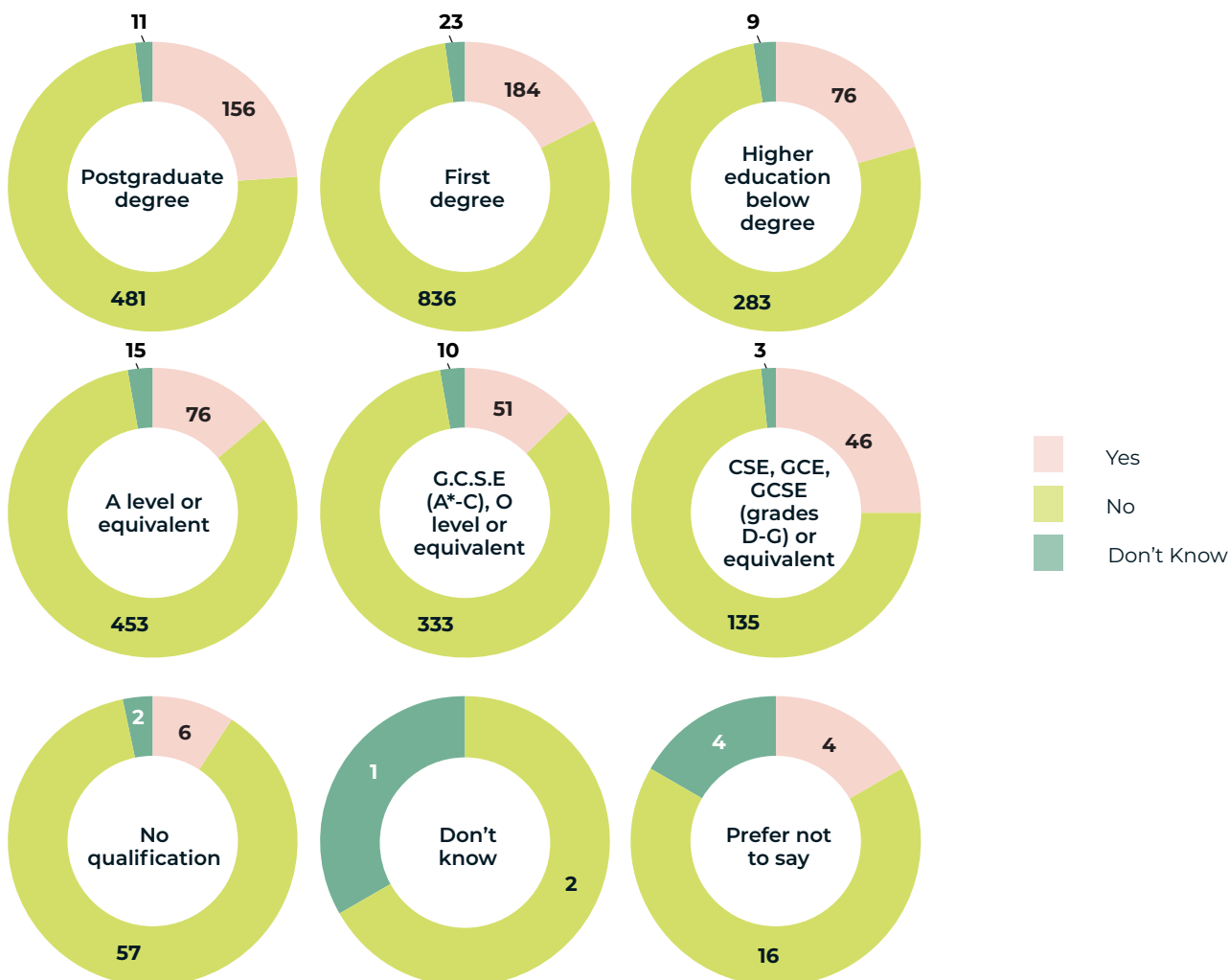
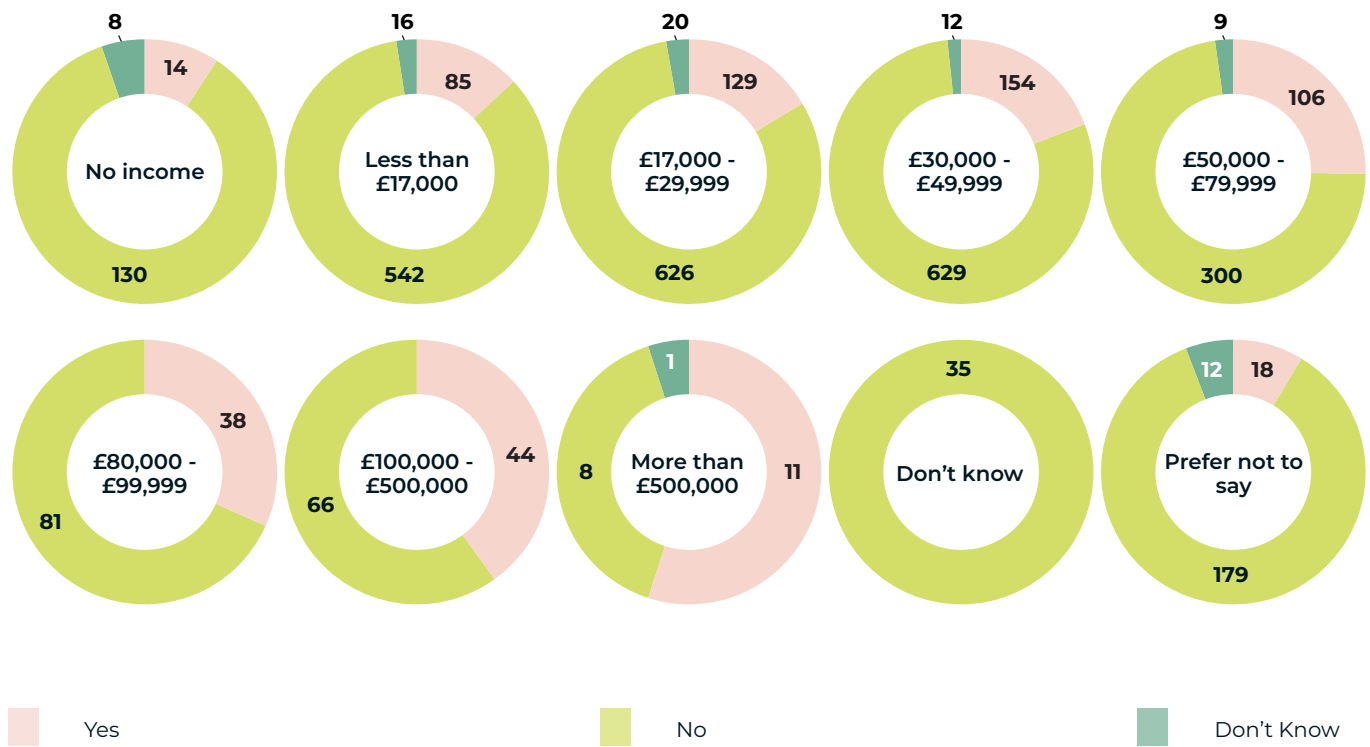


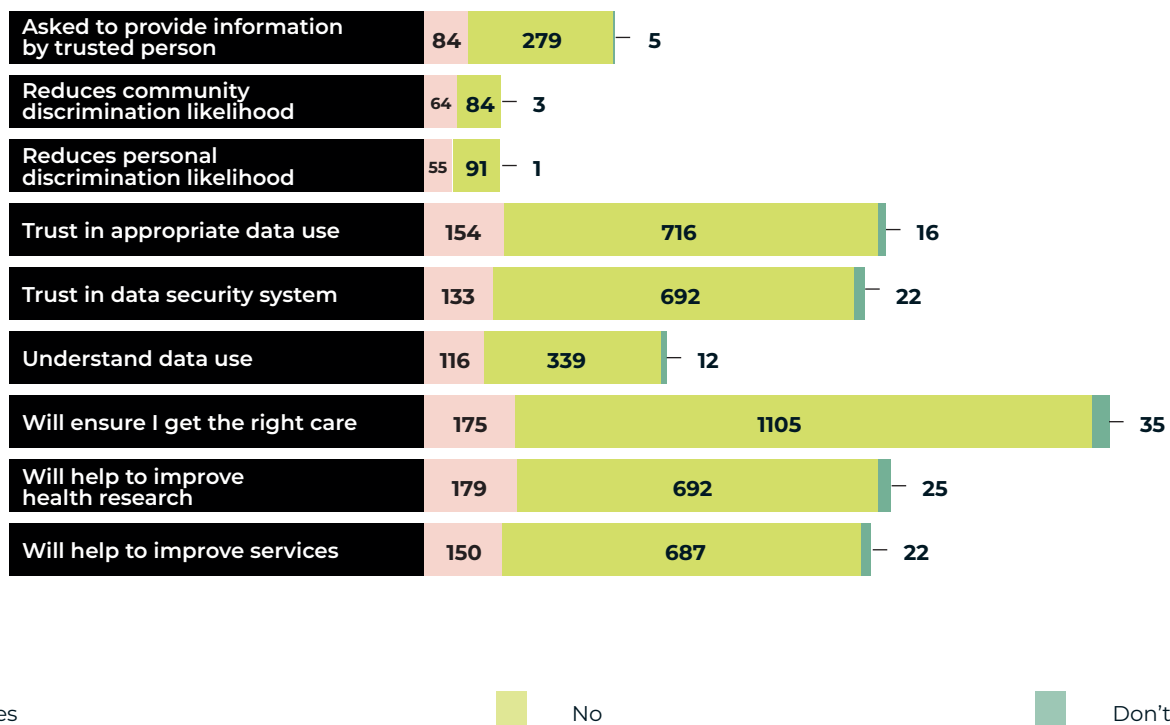
Figure 20: Conversation with healthcare worker by education



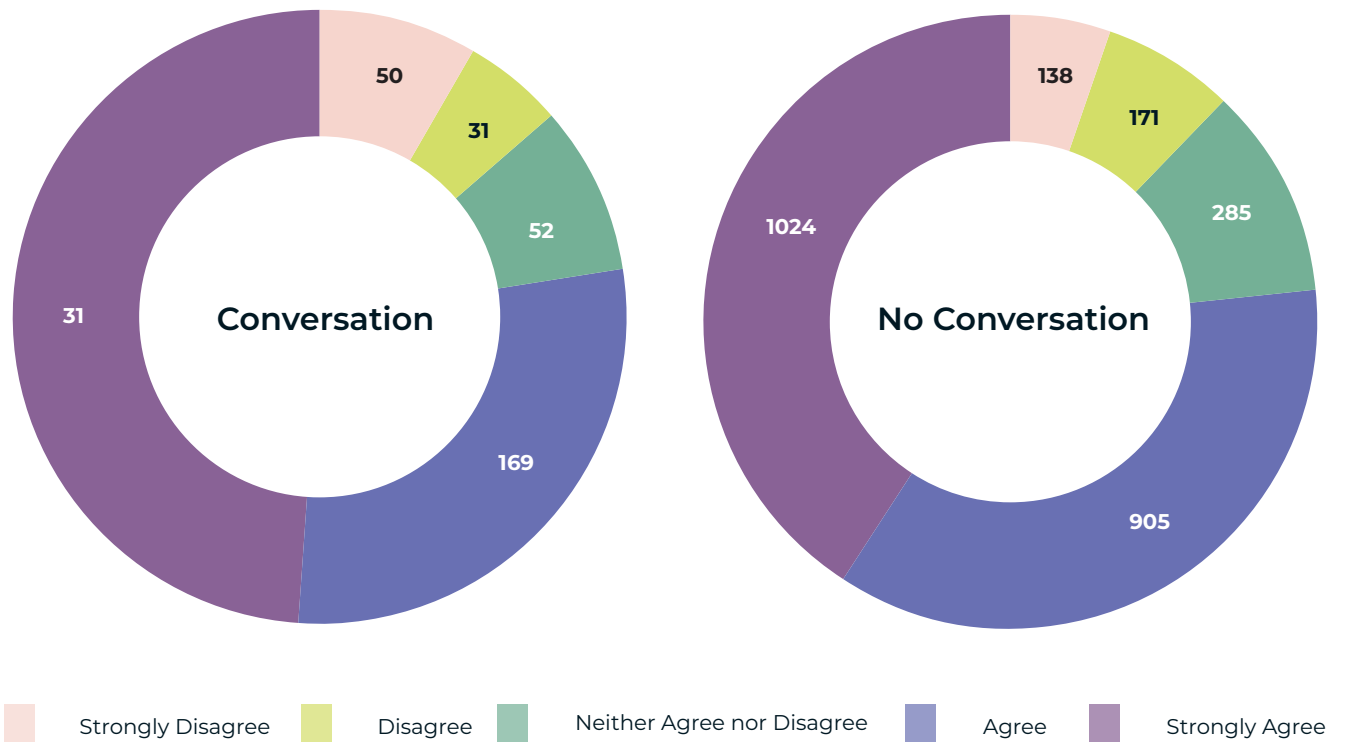
**Figure 21:** Conversation with healthcare worker by income



**Figure 22:** Reasons for sharing health data with NHS and whether respondents have had a conversation about use of patient data



**Figure 23:** Respondents willingness to share their personal data and whether they have had a conversation about use of patient data



## Black and South Asian respondents have greater concern about the impact of discrimination against them and their communities when sharing their data

When exploring the reasons for participants sharing data with the NHS, we noted a slight increase in respondents from minoritised ethnic backgrounds reporting that they thought that by sharing their data it might reduce discrimination for both themselves and their community members compared to White participants (table 4). This may appear to be a contradiction as the survey also highlighted that people from these communities had concerns that sharing their data could lead to experiencing discrimination. This is likely to reflect the conundrum faced by these communities where they are hypervigilant to the reality of the racist structures they navigate in their daily lives. At the same time they are aware that if their data is used in an unbiased way it could improve outcomes for them and their communities. We also found that aspirations for onward data use remain broadly the same regardless of ethnicity with 'find new treatments', 'improve services for all' and 'find better ways to diagnose illnesses' and 'ensure I get the care I need' dominating. That said, White respondents' disproportionately low reporting of data aspirations for improving services for Black, Asian and other minority users is of real interest, and concern (see figure 24).

**Table 4:** Proportion of respondents who think sharing data reduces discrimination for themselves and their community by ethnicity

<b>Ethnicity</b>	<b>% of respondents selecting sharing data reduces likelihood of personal discrimination</b>	<b>% of respondents selecting sharing data reduces likelihood of discrimination against community</b>
Black	3.5	3.1
Asian (mixed)	3.1	1.3
Other	2.9	4.0
South Asian	2.6	3.5
Asian (excl. South Asian)	2.6	2.1
Black (mixed)	1.9	2.6
White	1.6	1.3

**Figure 24:** Aspiration for use of patient data by ethnicity

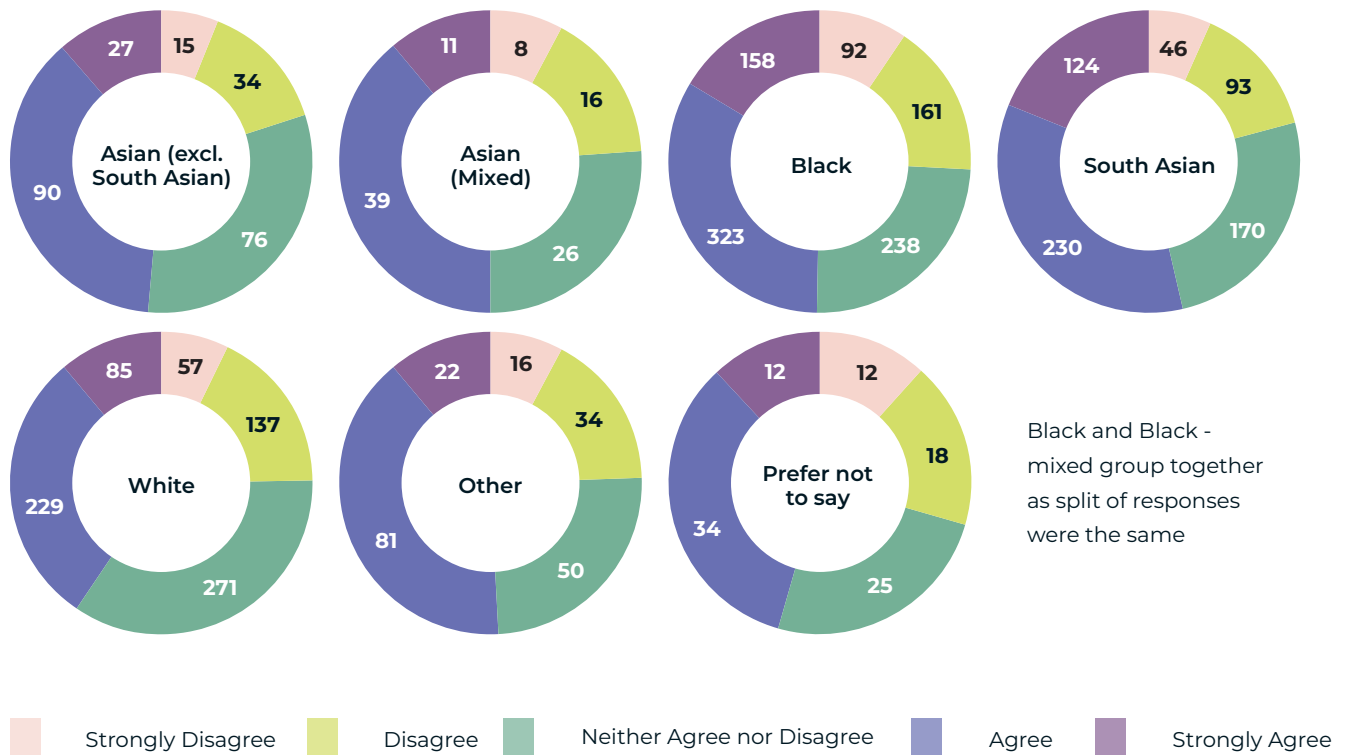


Black and Black - mixed group together as split of aspirations were the same. Aspirations for use of patient data: (Respondents could select up to 4 options)

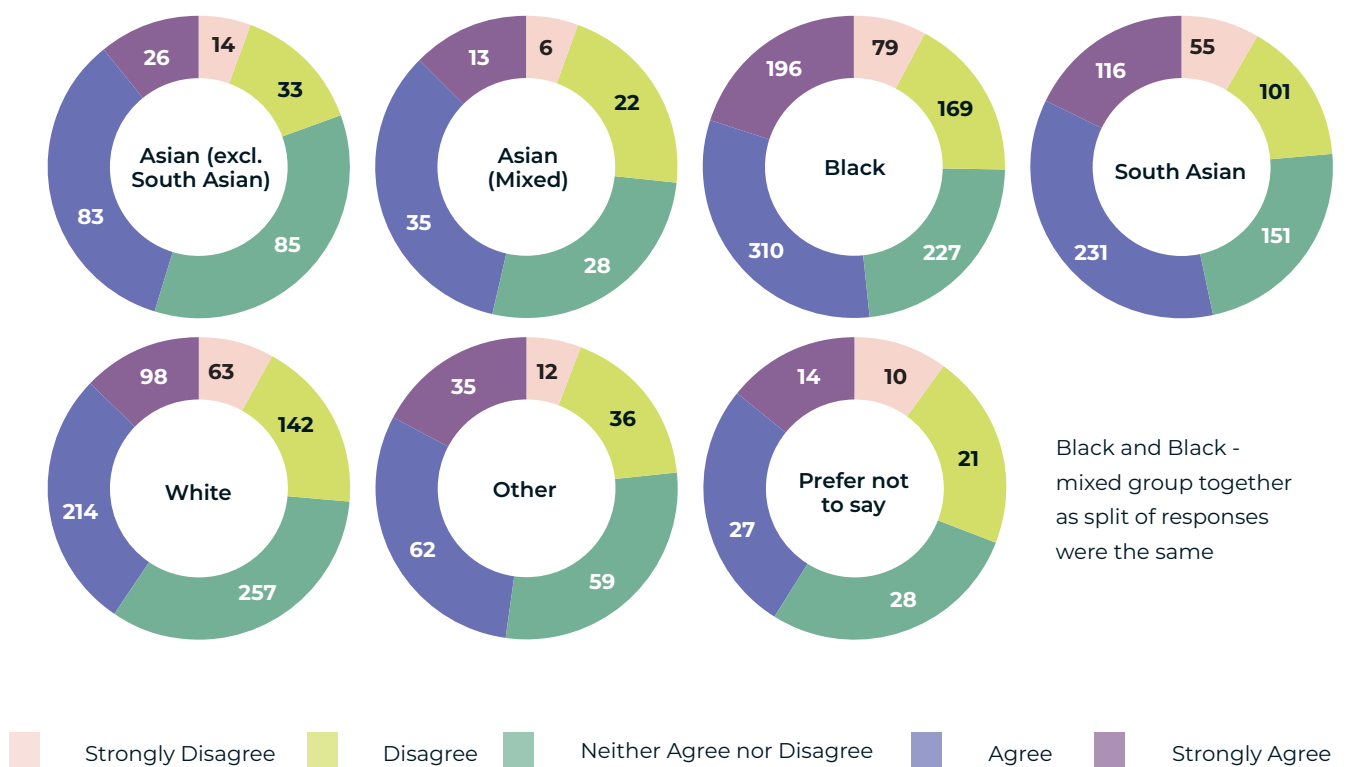
- Ensure I get the care that I need
- Find better ways to diagnose illnesses
- Find new treatments
- Improve services for all
- Improve services for Black, Asian and other minority communities
- Improve the health of communities with poorest health outcomes

We explored the perceptions of respondents about how incomplete data may impact care received by individuals and their communities. South Asian (19%) respondents are almost twice as likely to strongly agree with the statement that ‘if my data is incomplete, there will be worse quality of care for others in my ethnic group’ as compared to White respondents (11%) (figure 25). Black (20%), South Asian (18%) and people from other ethnicities (17%) are more likely to strongly agree with the statement ‘if data for others in my ethnic group is incomplete, there is worse quality of care for me respondents’ as compared to those who are Asian (Asian mixed – 13%, Asian excluding South Asian – 11%) and White (13%) (figure 26). These results suggest that people from minoritised ethnic groups are more likely to believe that incomplete data will impact their care as compared to people who are White.

**Figure 25:** Views of whether incomplete data may lead to worse quality of care for others in their ethnic group

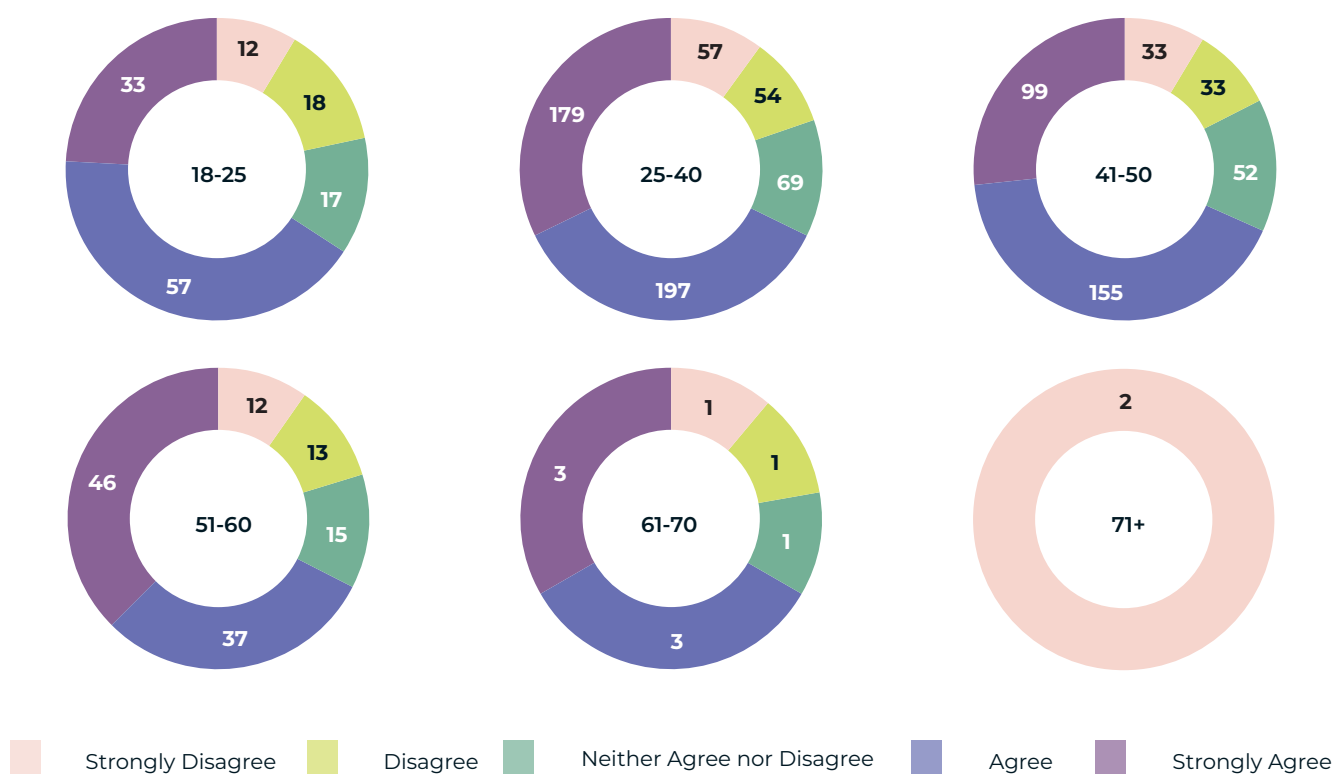


**Figure 26:** Views of whether incomplete data for others in your ethnic group, may lead to worse quality of care for respondents

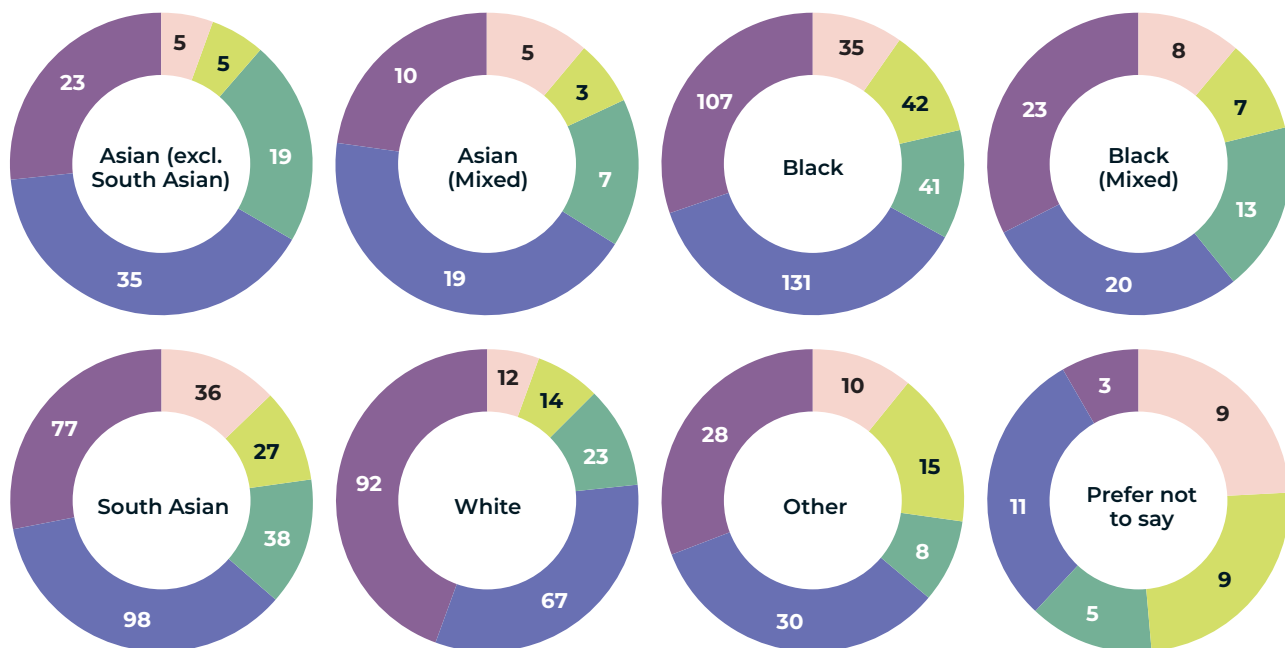


Ethnicity driven differences also influence views regarding sharing children's data. Overall, willingness to share children's data increases with age of the respondents. However, we see that when the responses are categorised by ethnicity there is less comfort amongst respondents from minoritised backgrounds. This may be a result of having more respondents from this background who are younger compared to White respondents and younger respondents being less willing to share their children's data as compared to older respondents. While the willingness to share data has a positive correlation with trust in an organisation, the strength of this relationship reduces when asked about sharing children's data (except for White respondents).

**Figure 27:** Willingness to share children's patient data by age



**Figure 28:** Willingness to share children’s information by ethnicity



Black and Black - mixed grouped together as split of responses the same.

Willingness to share child’s information

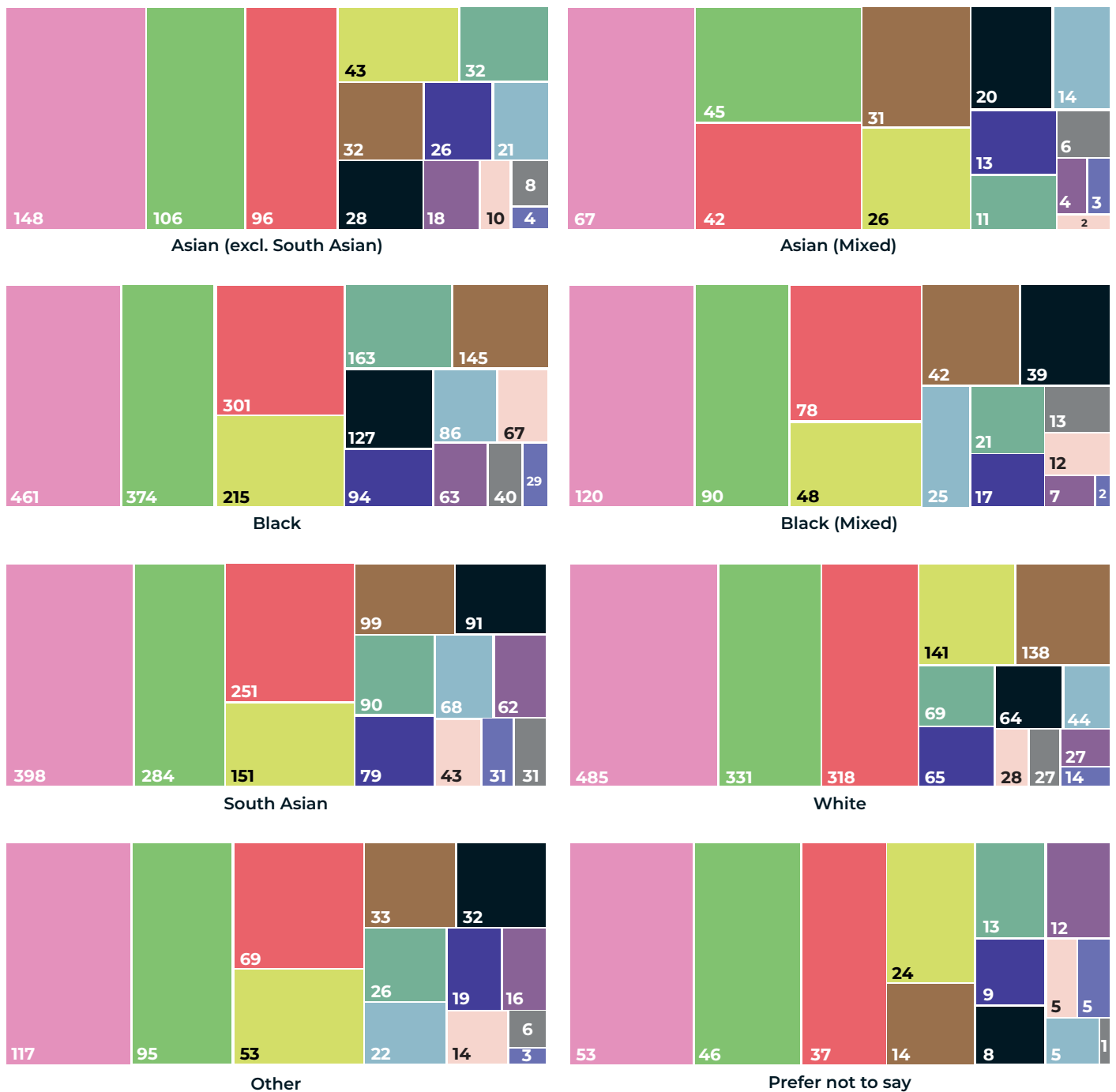
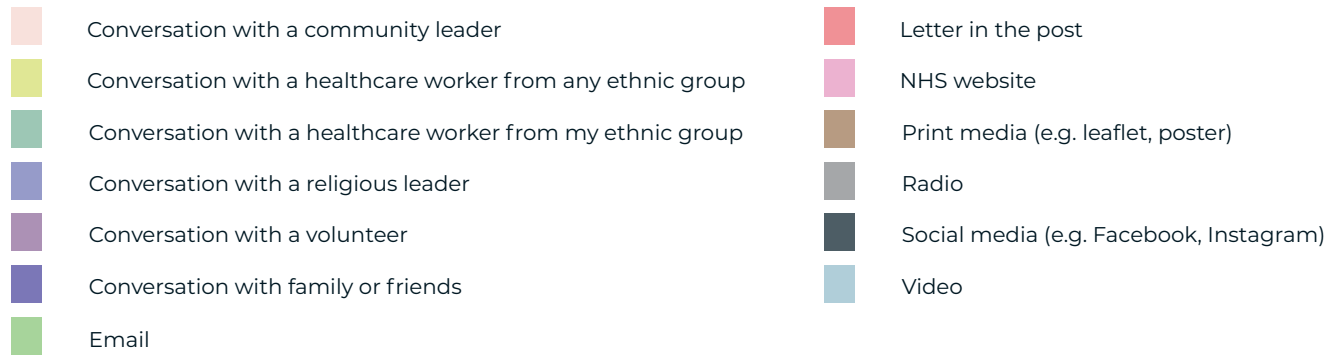


**Most respondents want to learn about how health data is used in a written form and ahead of health consultations**

We sought to understand respondents’ views on the best approach to sharing information about how health data is used. The most commonly selected approach across all ethnicities was to have information in writing. We see a marked preference for written material among White respondents which is likely due to the higher proportion of older respondents. People from South Asian backgrounds placed greater importance on the role of friends and family to support them when information is shared about how health data is used. After a written description, participants most frequently indicated they would prefer a verbal conversation with a healthcare worker or guidance on how to share data. The survey did not probe further on the nature or format of the guidance that would be agreeable to the respondents who participated in the study.

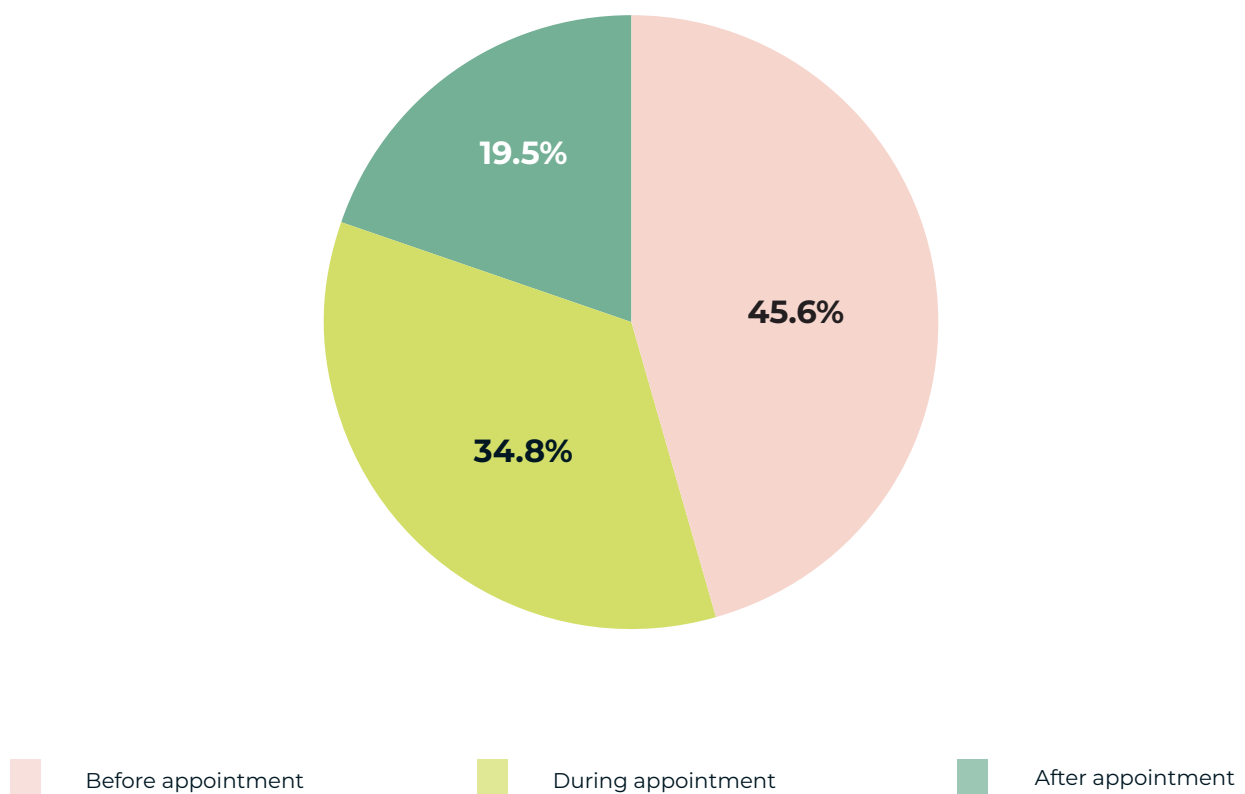


**Figure 29:** Preferences for how to learn about how data is used



Across all ethnicities, 45-50% of people would prefer to learn about health data prior to an appointment with a healthcare worker (figure 30). We were also interested to learn about the preferred venues or communication channels that participants would use to find out information about how their health data is used. Participants were able to select multiple options from a list of 14. Participants across all demographic categories most preferred to find out information at a GP surgery. The next three most preferred locations to access information about how patient data is collected and used by the NHS were in hospital, website and health centre. This correlates with the high levels of trust in the NHS reflected in previous questions. There is a second choice preference of how to learn about data via a website.

**Figure 30:** Preferences for when to learn about how health data is used

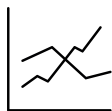




# Discussion

This section reflects on the insights surfaced from the qualitative and quantitative stages of this project. It considers the findings in the context of existing research and the wider social and political context and puts forward recommendations for future policy, research and practice to help reduce data inequalities for Black and South Asian communities in the UK.

The idea that people from Black and South Asian backgrounds are hard to engage and reluctant to share their health information is a widely accepted assumption within the health sphere.<sup>31,32</sup> Their perceived scepticism is attributed to experiences of discrimination, misinformation and lack of trust in institutions. However, the findings from this study lead us to question whether these explanations serve as justification for health systems to excuse data inequities for racially minoritised groups.



## Health engagement and willingness to share data

It is important to reflect on the close resemblance in engagement patterns across ethnicities. The prevailing view of under-engagement amongst ethnic minorities was not supported by the findings in this study. The level of engagement may have been influenced by the higher levels of education within the cohort given we see higher proportions of people being engaged who have completed a form of higher education. People who have no qualification show lower levels of engagement. It is also possible that the COVID-19 pandemic may have also contributed to increased levels of engagement across the board.

As there appears to be a relationship between the level of engagement in health information, trust in the NHS and willingness to share data it would make sense for the NHS to consider how they can effectively engage Black and South Asian communities in health information. It was beyond the scope of this study but gaining further insights into the types of health information valued by these communities will help the NHS to tailor their messaging appropriately. Partnering with the voluntary and community sector could help to further engage communities in conversations about health data.

The study highlighted that the drivers that would make respondents feel comfortable sharing data were similar irrespective of ethnicity, sex, and differing health status. Younger respondents showed a preference for digital information and older respondents preferred written material. The role of family and friends was more important for South Asian communities and people in higher income brackets. Respondents also indicated that they would value a government endorsed course to help them feel more comfortable sharing their data. This may be surprising due to perceived mistrust of institutions and would warrant further investigation to understand what communities would value from a government endorsed course. As highlighted earlier different demographics influence the way people want to engage in information. Whichever mode is selected, it is important that the information is provided in an accessible and culturally relevant format. This can be achieved by coproducing materials and an engagement strategy with communities who will be able to sense check key messages. It would also be helpful to seek out expertise to ensure that the messaging and approach taken upholds antiracist principles.



## Data Black and South Asian communities are willing to share

The COVID-19 pandemic highlighted how data collection on ethnicity is universally poor and it became apparent how these gaps hinder health systems ability to respond appropriately to the needs of Black, South Asian and minoritised communities. The healthcare workers involved in this research were acutely aware of the inequalities that were laid bare during the pandemic.

The reluctance of community members to self-identify is often offered as an explanation for the gaps that exist within data sets. This narrative also emerged in our discussions with healthcare workers. It is recognised that the situation is likely to be more complex than this explanation would suggest. However, if we only considered the findings from the present study and ClearView Research's *Diverse Voices on Data* report, this suggestion that there is reluctance to self-identify begins to unravel. The survey and *Diverse Voices on Data* report highlighted that people from racially minoritised groups were not reluctant to share information about their ethnicity. However, it is important to be mindful that some people may be hesitant about sharing their ethnicity or other information for fear of being discriminated against on the basis of their racial identity, which is a common experience for many people as they navigate social contexts in the UK.<sup>8</sup> In addition to this the survey also explored different types of data that people were prepared to share. Interestingly, respondents were open to sharing information that would ordinarily be regarded as sensitive such as mental health status which is often stigmatised. There were no significant differences between ethnic groups, but they all expressed an aversion to sharing financial information (income and debt).

These findings begin to disrupt assumptions that we often take for granted. It highlights that there are opportunities for the NHS and partners to work more effectively with patients and their carers to explore the most effective way to collect data that could help to advance the NHS ambitions to transform services. There is a need for a fundamental shift in mental models to prevent people and the organisations from hiding behind 'hard to reach' narratives.

If we return our attention to the collection of equalities data, a recommendation from the ClearView Research report highlighted that communities called for equalities monitoring forms to be expanded to enable people to be more specific about their ethnic identities. This was also reinforced in the qualitative phase of the present research where a healthcare worker had observed that patients had a sense of pride in their identity and wanted to self-define beyond high level census categories such as Black African or Asian British.

The interviews and focus groups also highlighted that some staff avoid asking patients the equalities questions or are making assumptions about a person's racial identity. Making a judgement about someone's ethnic identity based on their physical features is unethical, a sign of poor practice and risks compromising data quality. It appears that staff primarily from White backgrounds are concerned that they may be perceived as racist or may make a patient feel uncomfortable if they ask them to disclose their ethnicity. The qualitative phase indicated that this may be less of a barrier for staff from racially minoritised groups. However, it also highlighted that staff from non-White backgrounds may also hold assumptions about the types of data different groups are prepared to share and the norms that are associated with different cultures. Based on these assumptions healthcare workers may either under or overestimate risk or harm posed to or by a patient, which in turn may influence their decision to offer or withhold services. This indicates that staff from all ethnic backgrounds need routine orientation around cultural and racial awareness.



The project team found that White healthcare professionals were less likely to put themselves forward to participate. Extra time and resources were needed to get them engaged. The labour required to address health inequalities should not rest on the shoulders of staff and community members from Black, Asian, and other minoritised groups. Further work is required to understand why there may be a reluctance to engage in inequalities work. Ultimately the NHS needs to reinforce that engagement is not optional, the labour involved should not rest with staff from Black, Asian or other minoritised backgrounds but is in fact everybody's business.



## Motivations and aspirations for sharing data

Respondents' motivations for sharing their data remained broadly the same regardless of educational background, ethnicity, and health status. The primary reasons selected included finding new treatments, improving services for all, diagnosing illness, and enabling people to get the care they need.


The perspective of Black and South Asian respondents in the survey is consistent with the findings from the report produced by ClearView Research. People want to know that their data is being used to improve outcomes for their community and wider society. These drivers are important, and the NHS needs to streamline their messaging so people from racially minoritised groups can see how they are contributing to the greater good.



## The need for feedback loops

Engagement in health information was consistent across ethnicities and there was a clear relationship with respondents' level of trust in institutions and their willingness to share data. The findings show that the more engaged a person is in health information the more willing they are to share their information and to express trust in the NHS, other public institutions and health charities.

The qualitative phase of the present study highlighted the value in feeding back insights to the health care workers that have gathered the data. Seeing the benefits (e.g service improvements, improved patient outcomes, cost savings etc.) is likely to help people to understand how they contribute to the wider picture to reduce health inequalities. Similarly, the report by ClearView Research also highlighted that communities would value feedback on what happens to their data. They touched on the frustration Black and South Asian communities feel about the extractive relationship between them and the NHS and research institutions. People offer their time, clinical data and experiences, but they do not receive feedback about the outcome of their contribution. When we consider what motivates people to share their data, failing to keep communities informed is a missed opportunity to build relationships and the support of communities to continue to share their data. There is also value in sharing the learning of equalities work with communities and the wider professional and scientific community.



The qualitative phase of this study and Diverse Voices on Data report highlighted an opportunity for the NHS to devolve power to communities through their use of data. The NHS could adopt progressive approaches that would involve communities in supporting data collection, analysis, the sensemaking process, setting priorities for action and disseminating learning.

The ClearView community research found that Black and South Asian people had gaps in knowledge about how patient data is collected and used. Our survey results suggest this isn't unique to people who are from these backgrounds and is common across all groups. We assume those who have high levels of engagement are likely to have better understanding of various health matters if they are given greater exposure.

These feedback loops should be both data driven and informed so that inequalities are not further exacerbated. To be data driven risks overlooking communities who do not feature in a dataset or populations that are too small to be included in a meaningful analysis. A data informed approach on the other hand allows you to be guided by the data but also encourages services to consider the wider context. For example, a small population who are categorised as 'Other' may experience poorer health outcomes but this may be obscured by how they have been categorised in the data along with people from different ethnic groups. This can be mitigated by involving local communities to surface local intelligence about the health experiences of communities and using these insights can help to provide useful context and focus local priorities.

There is an opportunity for physical health services to learn from efforts to advance mental health equalities with the introduction of the Patient and Carer Race Equality Framework (PCREF). A key focus of this compulsory framework is to improve data quality and ensure communities are able to hold their local mental health trusts to account. Physical health and social care services should consider the learning that emerges from the implementation of the PCREF and explore the potential to adopt a similar framework.







## Reframing the role of trust

The assumed lack of trust that Black, Asian and minoritised communities have in institutions dominates health inequalities narratives. Interestingly this study contradicted this perspective as respondents overwhelmingly indicated that they trusted the NHS. This finding indicates that lack of trust in the NHS and other institutions may not be held universally within Black and South Asian communities and therefore we need to reframe the way we consider the links between trust and people's willingness to share their data. Firstly, it may be more helpful to consider the trustworthiness of an organisation rather than whether communities have trust in them. Reframing it in this way recognises that trust has often been broken by the actions of institutions.

Therefore, the responsibility lies with the NHS to demonstrate that they can be trusted. The study signalled some of the steps they could take to build confidence.

- Greater transparency about the purpose of collecting data and how it is used would be welcomed.
- A commitment to ensure that people's data will not be exploited in a way that causes harm.
- Communities would like assurances that their engagement will lead to tangible improvements in their access to services, their experience and health outcomes.
- The NHS also needs to make a visible improvement in addressing institutional racism within the organisation.

There are several indices that could explain the high levels of trust observed. The cohort was highly educated and recorded above average incomes. Therefore, they may be more likely to engage in health information and have higher levels of trust. Due to the privilege that is associated with their income and education levels, it is possible that these respondents are in a better position to advocate for themselves which may insulate them to a degree when interacting with the NHS.

People from Black and South Asian communities with multiple marginalised identities may hold a different position on trust in the NHS. It may be helpful to apply an intersectional lens when exploring how the trustworthiness of organisations is experienced across the intersections of ethnic and other social identities. For example, a service considered inclusive for people from Black African backgrounds born in the UK may have policies or approaches that could be harmful to Black African people who may be seeking refuge or asylum. Therefore, it may be reasonable to assume that there will be different perspectives on trust within ethnic groups based on their exposure to marginalisation.




## Being alert to the potential risks of sharing data

### **Risks of data sharing for children and families**

Overall respondents were more open to share their data with the NHS than their children's health information. Male respondents and the majority of White respondents had higher levels of comfort sharing information about their dependents. Conversely, women from ethnically minoritised backgrounds were more cautious and had concerns that information could be used to discriminate against their child and or community. Parents from racially minoritised backgrounds expressing concerns about sharing their children's data is consistent with previous research.<sup>78</sup> Due to differential sample sizes it is difficult to draw firm conclusions on why concerns about discrimination were less apparent for White respondents.

Considering this finding within the wider social and historical context offers some answers. Due to the patriarchal structure within UK society, mothers are more likely to have caregiving responsibilities. Therefore, they may be more nuanced when assessing potential contextual safeguarding issues. Mothers from Black and South Asian backgrounds may also be more vigilant regarding the potential harms of sharing data with statutory institutions due to their own racialised experience and awareness of the social injustices that confront their children. For example, adultification for Black children is of particular concern where vulnerable children are treated as adults. This means that institutions do not put an appropriate level of support in place which may make children more vulnerable and cause harm.<sup>39</sup> Parents from Black and South Asian backgrounds also experience discrimination within health and social care services. Engaging with health services can lead to the involvement of social care services and parents may have concerns that their children may be removed from their care. At times clinicians and social workers perceptions of risk can be disproportionate due to biases they hold. This can lead to the over representation of children within social services. It can also mean that children who require support are denied help.

White people are less likely to be exposed to the forms of discrimination that are commonly experienced by people from Black and South Asian backgrounds in health and social care services and within society more widely. Therefore, they may be less concerned about the potential consequences of sharing their children's data. However, this may not be the case for parents from White backgrounds who have children who are mixed race as they may witness the discrimination that their children may face. Other groups such as Gypsy, Roma and Traveller communities may also share similar concerns due to the discrimination they experience within statutory services.



When considering these findings, the NHS and other statutory organisations need to consider how their approach to collecting and using data is likely to impact communities differently and put plans in place to mitigate against potential harms.

- Implementing standards of recording information that is unbiased and refrains from feeding into stereotypes about different ethnic groups and cultures.
- Embedding reflective practice so staff can reflect on the content of their notes and explore assumptions and biases that may surface in their description of the patient, events that took place or perception of risk.

### **Risks of stigmatisation**

Concerns about sharing data was also surfaced by the healthcare workers of all ethnicities during the qualitative phase of the research. Their narratives not only spoke about historical events, but they also signalled to the way in which data sharing may have negative consequences for patients today and in the future. For example, assigning labels which are stigmatised and sharing data in a way that reinforces stereotypes.

With the move towards sharing data across services and agencies it is important for the NHS to be cognisant of the structurally racist context within which these improvements exist. It is imperative that context is considered to ensure that data is used for good and not weaponised as this will create and deepen health inequalities. The NHS can learn from the errors of other statutory bodies such as the Metropolitan Police who have used and shared data to support the Gangs Matrix<sup>31,32</sup> and Prevent agenda<sup>33</sup>, both of which disproportionately affect Black and South Asian communities and have created scenarios where people from these communities have been made vulnerable. Similarly, health services have also shared information about patients with the Home Office which has created vulnerabilities and or compromised a person's citizenship status.<sup>28-30</sup>






## The power of the conversation

Our data clearly shows the value for the NHS of having conversations with people to help them understand why their data is collected and how it is used. A conversation with a health professional increases people's willingness to share data with the NHS and broadens their understanding of the benefits of doing so and the consequences of missing data. Across all ethnic groups respondents expressed an interest in finding out about how patient data is used by the NHS in a healthcare setting or on a website before a consultation.

The survey suggests that these conversations are not taking place as frequently as they could be, with most respondents reporting that they were not able to recall any conversations on the issue with a health professional. The survey highlighted that some groups (i.e. older people on lower incomes, people with lower educational attainment) were more likely to report that they had not had a conversation with a healthcare worker. This was also highlighted in the qualitative phase of the study where healthcare workers identified that their peers were not speaking to patients or their carers about why their data is collected and used by the NHS. These findings also reinforce a recommendation that emerged from ClearView Research's report that healthcare workers need to be equipped to hold these conversations with service users.

Throughout our study it became apparent that there are several factors that may hinder these conversations from taking place. Firstly, healthcare professionals expressed that there were gaps in their knowledge about why data is collected and how it is used. It would be reasonable to assume that if a healthcare professional is not confident in this area, they will be less likely to initiate a discussion where they are unable to answer questions which may arise. The healthcare professionals we engaged called for better training and support. They were very clear about the need for resources that were engaging and easily digestible, including short videos. They expressed a real aversion to online mandatory training. There is an opportunity for the NHS to work with staff to identify more innovative learning approaches.

Secondly, there is a need for the NHS to improve the racial and cultural literacy amongst its workforce. This is consistent with wider issues the NHS is grappling with regarding bullying, harassment, and institutional racism. Lack of confidence in this area is likely to prevent healthcare workers from holding conversations with people from Black and South Asian communities through fear of offending them and or being perceived as racist. Without a good level of competence, the workforce are less likely to be able to hold conversations that may be sensitive. Investing in tackling institutional racism is likely to have a profound impact on the experiences of services users and carers from Black, South Asian and other minoritised groups. It will also enable the NHS to make strides in reducing health inequalities and creating an environment where staff thrive.



Thirdly, healthcare workers are also working under a great deal of pressure and collecting information on ethnicity and other types of data may not be considered an immediate priority when they are trying to attend to a patients' needs. The desire from communities to have conversations with a GP or health professional also needs to be met with a level of pragmatism. Staff within the NHS are under immense pressure and as highlighted in the our study, this is a barrier to holding these conversations. With the move towards more integrated health systems there is an opportunity for partners across the statutory and voluntary sector to consider how they can support the NHS by sharing responsibility for holding these conversations. It also needs to be noted that Black and South-Asian led organisations could provide an avenue to reach sections of the community who experience the poorest health outcomes.

Black and South Asian-led organisations are an asset for Primary Care Networks (PCN) and Integrated Care Systems (ICS) to support the involvement of communities in their work (e.g. data strategies, service design etc.). However, PCNs and ICSs need to be mindful of the systemic barriers organisations led by minoritised groups are likely to face. The chronic under investment in these organisations are likely to have an impact on their capacity. Therefore, the NHS and partners need to consider how they redirect resources to support their active engagement. There also needs to be greater recognition of the inherent power imbalance between communities, the VCSE and the statutory sector. Any partnership developed needs to be equitable and institutions should consider how they genuinely redress the power imbalance. This includes paying attention to the voices that are missing from the conversation, ensuring that the identities of the people who are making decisions that affect the lives of Black and South Asian communities reflect the communities the NHS serve, and working at a pace that facilitates deep and meaningful engagement.

There is no question that if the healthcare system wishes to achieve its ambition to reduce health inequalities, data quality needs to improve. Greater attention should be paid to the wider determinants of health. When considering the experiences of racially minoritised groups there is likely to be value in collecting data on patients' exposure to discrimination within health and social care services and wider society. The dialogue between patients and healthcare workers will become even more important as it may be unclear to patients how this information can help the NHS and their partners to improve services and population health. Senior leadership within the NHS need to be invested in efforts to address health inequalities and the infrastructure needed to support staff should be put in place in a timely manner. The NHS also needs to hold staff and commissioned services to account for upholding data quality standards.

## Recommendations

- 1** Create the conditions for systemic change to enable the following recommendations to be delivered by accelerating efforts to eradicate racism within the NHS. This should include developing the cultural and racial capability of the workforce.
- 2** Consider developing a race equity framework for physical health services that draws on the approach used for the Patient and Carer Race Equality Framework in Mental Health services.
- 3** Secure the support and commitment of senior leaders to improve data practices, embed inequalities work and create space for staff to innovate within the NHS.
- 4** Actively challenge 'hard to reach' narratives that encourage the perception Black, Asian and minoritised communities are disengaged or unwilling to share their patient data.
- 5** Equip healthcare workers with the tools to hold meaningful conversations about data: explore more innovative approaches that provide engaging 'bite-size' learning material targeted at healthcare workers.
- 6** Regularly share the learning from equalities work, that has been driven by data insights, with the community, healthcare workers and the wider professional and scientific community.
- 7** Maximise opportunities presented by integrated working to meaningfully engage and resource Black and Asian-led VCSE organisations to involve local communities.
- 8** Develop system wide protocols to routinely collect equalities data, disaggregate it by the protected characteristics and use an intersectional approach to analysis.
- 9** Work with racially minoritised communities and the Unified Information Standard for Protected Characteristics teams to expand the ethnicity categories used by the NHS.
- 10** Invest in research that takes an intersectional approach to explore the health experiences of Black and South Asian communities.
- 11** Embed an antiracist approach to data collection, analysis, dissemination and use which will include enabling staff to apply an equity/social justice lens to their work.

# Broader reflections and learning about conducting engagement work

This project has presented an opportunity to conduct engagement through a large survey of Black and South Asian communities and also speak to healthcare workers about engaging with patients from these communities. We have several reflections that can support others conducting similar projects.

**There's a tension in the standard approach of conducting anonymised surveys with seeking views from those from minoritised backgrounds.**

It's standard process to seek anonymity for respondents to large surveys partly to increase comfort in responses and to protect individual's privacy in line with common research practice and information governance considerations. Given minoritised communities are typically smaller, it can be challenging to maintain anonymity for people who identify with multiple minoritised communities. Seeking anonymity may not be the gold standard we seek and instead it's worth considering whether pseudonymity is appropriate in these circumstances. Doing so will allow people from smaller groups that may often not be a focus of research but who experience significant marginalisation and discrimination to share their experiences where there is comfort to do so. People in these groups may not want to be identified, so such risks should be shared to allow people to make an informed choice. Organisations supporting engagement work may want to consider being more open and critical of standard approaches and how they may need to be adapted to achieve the desired outcome whilst respecting the choice and privacy of individuals. To increase confidence in these approaches it could be helpful to partner with trusted organisations within these communities to improve levels of engagement.





### **To secure the views of those from multiple marginalised backgrounds, focused engagement approaches are essential**

Whilst the project was successful in recruiting a higher proportion of people from Black and South Asian communities who are the focus of the research, we did see a skewing of participants from larger populations within the UK with a high proportion of people from Christian backgrounds and mostly heterosexual people. There was also a high proportion of younger people. We attempted further focused engagement partnering with voluntary and community sector organisations who work with communities who experience multiple marginalisation. Whilst we didn't maximize the full potential of this approach on this project, we believe such approaches are essential in ensuring a diversity of views from minoritised communities are heard. Digital exclusion is more common amongst older people which likely contributed to lower numbers of respondents from this age group. People from multiple marginalised backgrounds may feel less comfortable disclosing personal information. Having an intermediary organisation with goodwill and existing trusting relationships is likely to increase comfort in sharing personal information and engaging with large scale surveys.

### **When partnering with small VCS organisations, proportionate agreements are required to reduce the burden of work**

Organisations that have strong connections with underrepresented communities are likely to be small organisations with limited staff capacity. To encourage their involvement with such work, we believe it's fair to provide financial resources to support their organisations and reduce the burden of unpaid work. Typically, this type of funding is provided alongside grant agreements with multiple requirements to be fulfilled before payment is made. It's important to consider adjusting typical agreements to be proportionate to the ask of small organisations as well as the capacity that exists within them. Setting expectations for them to fulfil multiple requirements for relatively small sums of funding creates a high burden of work which isn't necessarily proportionate to the level of risk involved. Poor compensation could reduce the likelihood of them engaging with this type of work and further marginalise underrepresented communities.





# Summary

Data is not neutral and contributes to the systemic injustices we see in healthcare and wider society. It plays an important role in what we know about human existence. It shapes the judgements and decisions we make in our daily lives, influences our behaviours and affects how we navigate the world. In the context of healthcare, data shapes who is seen and who is invisible, whose needs are met, overlooked or ignored. Although there is significant debate about how patient data is best collected and used in the public interest, most will not question that data has the potential to save lives. The findings from this study highlight that addressing the issue of data inequities is not an insurmountable task. Despite the potential harms that may come to Black and South Asian communities due to the mismanagement of data, the overarching message is that people from Black and South Asian communities are open to engaging in health information and to sharing their data. They have the desire for their data to make a positive contribution in improving the outcomes of their community and wider society. The key is how the system harnesses this energy. It will require some structural changes but what is clear is that these adjustments should not detract from what can be achieved.

Holding a conversation with a patient about their data has huge potential. Placing emphasis on addressing the factors that hinder the conversation from taking place will enable the NHS to make strides in visibility of Black and South Asian people in datasets. There are real opportunities for the NHS to think about how communities can be more involved in improving data collection, making sense of the data the NHS holds and shaping priorities which aim to prevent injury and disease as well as improving access, experience and outcomes for people who suffer the poorest health outcomes.

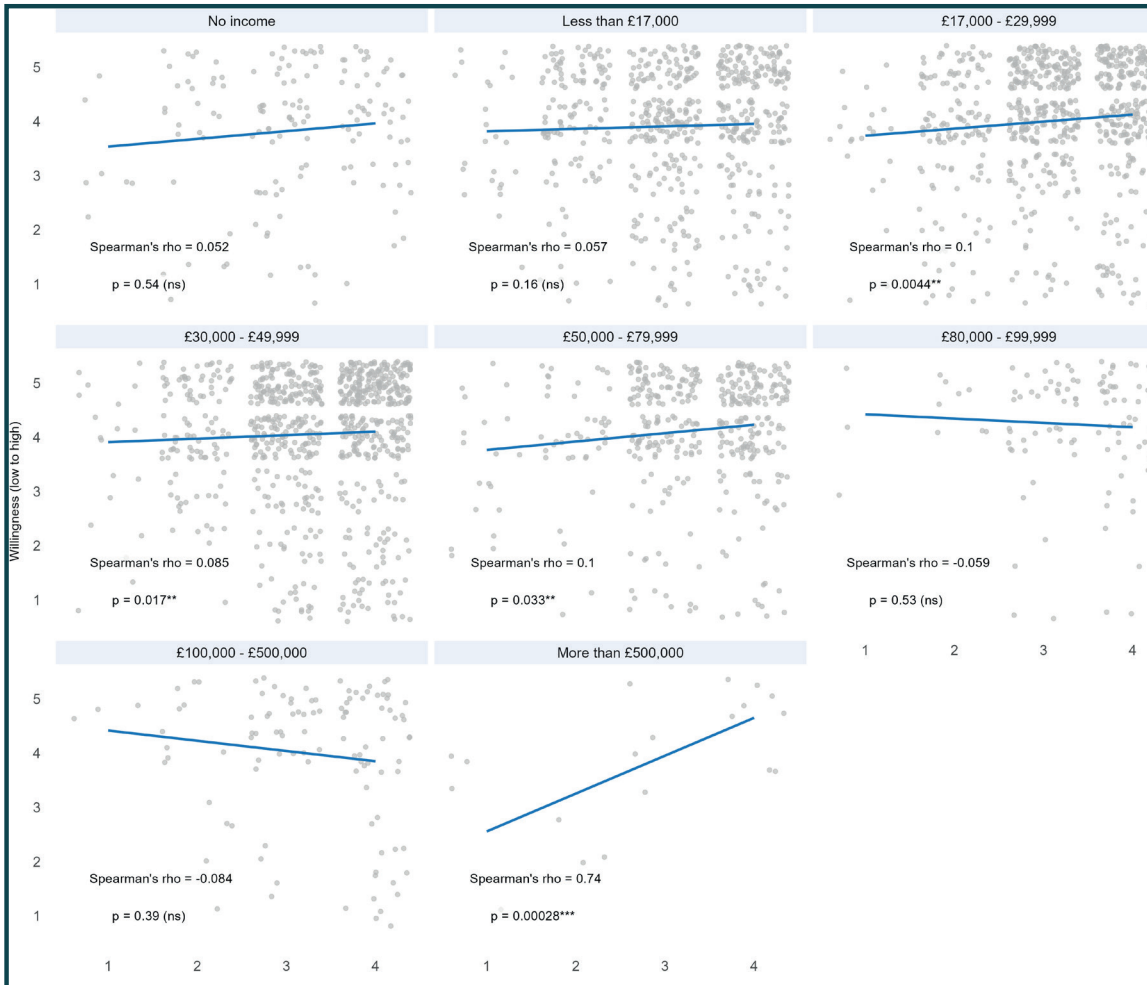
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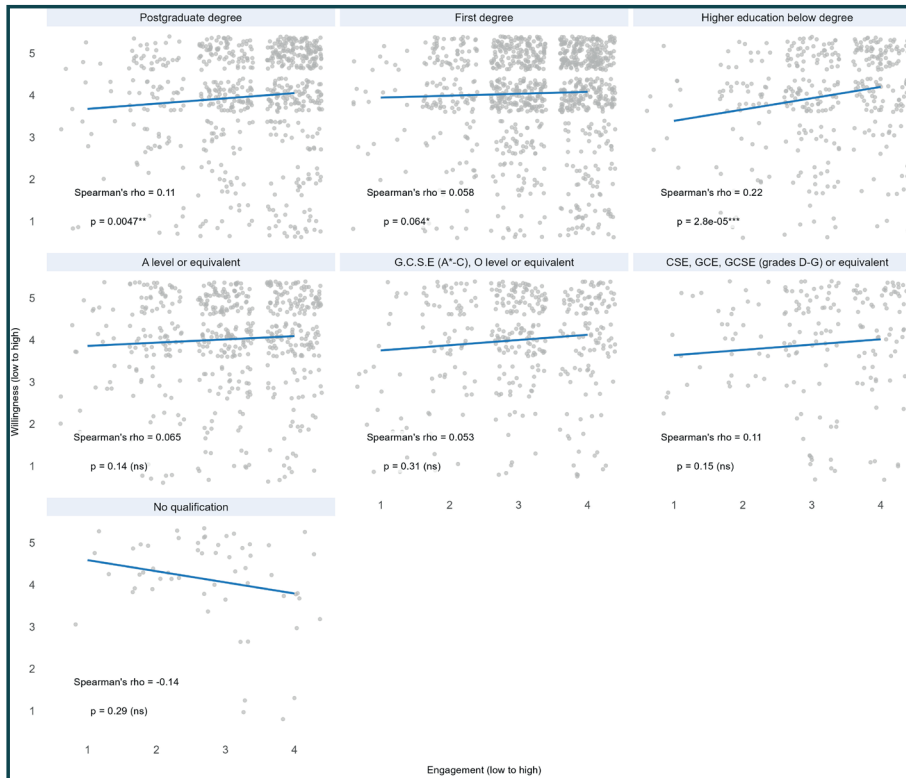
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# Appendix

Correlation between engagement with health information and willingness to share data by income



## Correlation between engagement with health information and willingness to share data by education



## Correlation between engagement with health information and willingness to share data by ethnicity

