



The health data gap for Black and South Asian people: How can improvement play a role?

Q community webinar



Agenda

12:30 - **Welcome and introductions**

12:35 - **Understanding Patient Data context**

12:40 - **Liberating Knowledge Findings**

12:50 - **Panel reflections**

13:00 - **Q&A**

13:25 - **Closing Remarks**



Speakers



Emily Jesper-Mir

Strategy and Engagement Manager
- Digital Equity at Understanding
Patient Data



Rebecca Asher

Strategy and Engagement Manager
- Digital Equity at Understanding
Patient Data



Daphne Amevenu

Director of Amevenu Ventures LTD
and Associate of Liberating
Knowledge

Panelists



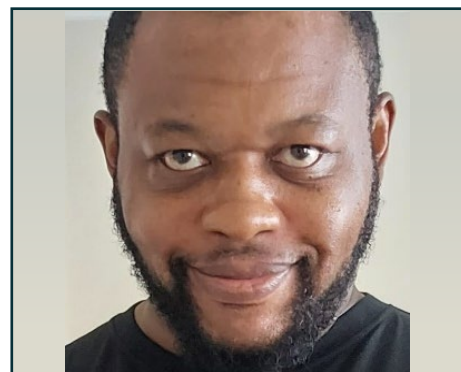
Professor Winston Morgan

Researcher in toxicology and clinical biochemistry, teaches Pharmacology, Biochemistry, Biochemical Science and Medical Physiology at University of East London



Reema Patel

Leads deliberative engagement at Ipsos directing the Global Science Partnership. Cofounder of the Ada Lovelace Institute



Stephen Quashi

Carer and works for an LGBTQ+ organisation supporting, Black, Asian and Ethnic Minority people over 50

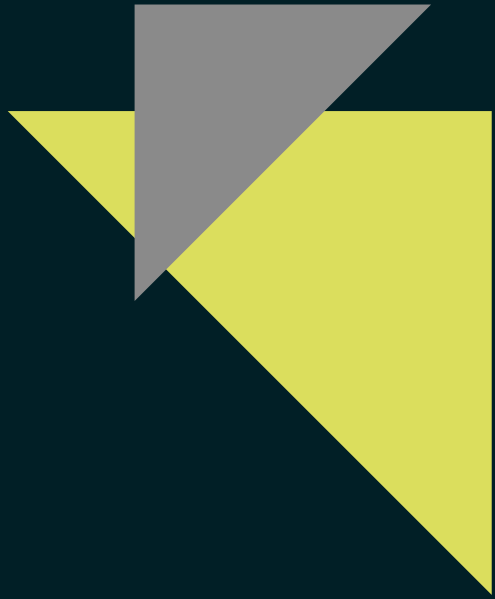


Sabrina Phillips

Director of Lambeth Living Well Network Alliance and a Mental Health nurse, working in South London & Maudsley NHS Foundation Trust



Understanding Patient Data Context



Liberating Knowledge Findings

LK worked with UPD to understand the root causes of patient data inequalities

Liberating Knowledge worked with Understanding Patient Data to build on insights generated from previous work conducted by ClearView Research

- **Qualitative research** explored the perspectives of healthcare workers on the following:
 - why patient data is less complete for patients from Black and/or South Asian backgrounds
 - barriers that hinder good data practice and possible solutions that would make it easier for the workforce to collect and use data more effectively
 - Aspirations for how the NHS routinely collects and uses patient data to improve health outcomes
- **Quantitative research** aimed to survey a representative sample, exploring the key themes that emerged from ClearView Research's work, to measure the extent to which the views that surfaced were shared among Black and South Asian communities.

Engagement with healthcare workers (1)

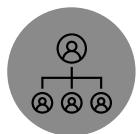
We conducted **5 focus groups and 7 interviews with 37 healthcare workers** to explore their perspectives of the barriers and enablers to data collection:



Lack of confidence to describe the purpose and use of data that is not used in their role



Resource and time pressures impacts staff's ability to prioritise data collection and to hold conversations with patients about their data



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 were a barrier



Concerns about the 'trustworthiness' of the NHS from Black and South Asian communities, including healthcare workers, given past harms

'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

'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 and sex not disclosed

Engagement with healthcare workers (2)



Mixed views on whether staff believed that Black and South Asian communities are 'hard to reach'. Some agreed while others shared that investing time to build trust led to good engagement



Those from minoritised ethnic groups were more likely to understand the **importance of being represented in data to support efforts to tackle health inequalities**



Some suggested health inequalities were a consequence of individual level and biological factors rather than due to structural inequalities of healthcare systems and wider society



A **common desire for the NHS to be more ambitious** about how it approaches improvement in collection and use of patient data



Innovative ideas proposed such **as giving more control to people and communities over their data** and the insights generated from them

'We must lean on the people in the communities who are well respected, and who people do listen to.'
Clinician/Researcher,
White Other, Female

'I think one of the key advantages with collecting data is that you make sure that service provision is equitable.'
Psychologist, Black British (Caribbean), Male

Key findings from survey

3,273 respondents from wide range of backgrounds

- **High levels of engagement in health-related information** amongst survey participants
- Survey respondents across all backgrounds **trust the NHS with their personal data**
- **People from all ethnicities** have similar levels of engagement with health information and **have a willingness to share personal data**
- **Only one in five respondents** had a conversation with a healthcare worker about how their data is used
- **Black and South Asian respondents have both greater concern about the impact of discrimination** against them and their communities when sharing their data as well as **greater hope** that sharing data can reduce likelihood of discrimination
- Conversations with NHS staff **increased willingness to share personal data** and a broader understanding of its use
- Most respondents want to **learn about how health data is used** ahead of health consultations; written formats and conversation preferred

Black and South Asian communities are not more reluctant to share their personal data

- **Similar levels of comfort** sharing most types of data with the NHS across all ethnicities
- **High levels of engagement across all ethnicities** indicating that gaps in data for Black and South Asian communities may not be due to a lack of interest or engagement
- This supports 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**

Reframing narratives about trust

- **Lack of trust** is often cited as a factor that influences the willingness of Black and South Asian communities to share their data
- We need to **reflect on where the power lies to shift the dynamic between institutions and communities**
- The NHS needs to demonstrate to communities that they are **'trustworthy'**
- This should be done **instead of locating the issue of distrust** within Black and South Asian communities
- This may potentially **lead to better relationships** and opportunities to work collaboratively to tackle health inequalities

The burden of tackling health inequalities rests on people with lived experience

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

Now is the time to ensure staff are equipped to close the gap in patient data

- **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 to tackle health inequalities
- Given the positive impact of having a conversation between healthcare workers and patients about data usage, and yet the low frequency of this happening, there needs to be **more space created for these conversations**
- 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

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
2. Consider **developing a race equity framework for physical health services** that draws on 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**
5. Equip healthcare workers with **tools to hold meaningful conversations about data**
6. **Regularly share the learning from equalities work** with the community, healthcare workers and the wider professional and scientific community

Recommendations

7. Maximise opportunities 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 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



Panel Reflections



Q&A

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.



**Understanding
Patient Data**



About Liberating Knowledge

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.

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Closing Remarks