CASE STUDY

SEPTEMBER 2024

See the full case study **HERE**

How health and care systems can improve ethnicity data collection to help combat inequality

Ethnicity data are used in the UK to improve or target services more effectively and to inform efforts to address health inequalities and discrimination amongst historically disadvantaged or underrepresented populations [1, 2].

There is recognition that the quality of the data used to inform these efforts needs to be improved. Here, we discuss an example of current efforts in the East of England to address this problem with regards to patient ethnicity, as well as some of the challenges in having good-quality data.

Starting in Autumn 2023, the Performance and Analytics team at the Cambridgeshire and Peterborough NHS Foundation Trust (CPFT) initiated a project to improve the recording of ethnicity data in their Trust, noting that NHS England had started a programme to investigate mental health inequalities and ethnicity.

Initially, the team investigated ethnicity data quality, noticing that the data they supplied to NHS England varied in quality. While CPFT scored highly nationally on data quality, the team noted marked variance in ethnicity data recording across clinical departments.

To improve the recording of ethnicity data, the team developed an analytics dashboard powered by PowerBI (see Figure 1) allowing the children's mental health services clinical teams to view their own rates of ethnicity data completion compared with other teams. The Performance and Analytics team ran meetings and workshops to educate staff about the importance of collecting ethnicity data to help combat health inequalities. Finally, the team was dependent for this work on a central post in children's services that helped to liaise among different clinical teams regarding the importance of collecting ethnicity data.

We cannot create policies to address problems that we cannot identify.

These interventions helped to reduce incidences of 'not stated' ethnicity from 18% in mid-2022 to less than 5% at the end of 2023.

The recent scoping review and qualitative study with stakeholders highlighted institutional and societal challenges to improving data pathways. This is an important obstacle to combatting health inequality:

The study flagged important barriers to effective data collection, including but not limited to poor design of digital fields for categories like ethnicity, poor communication between systems within a care institute, and low patient trust in the purposes of data collection and use. The burden of information governance rules and related costs may also prevent effective data collection — further highlighting the importance of senior-level understanding and buy-in around these issues.

Participants flagged several mechanisms for improving data quality with the most frequent including data linkage and staff training programs, but standardisation and senior-level buy-in were also cited (Figure 2).

Figure 1: Sample PowerBI dashboard showing ethnicity data completion rates between departments among children, young people, and families
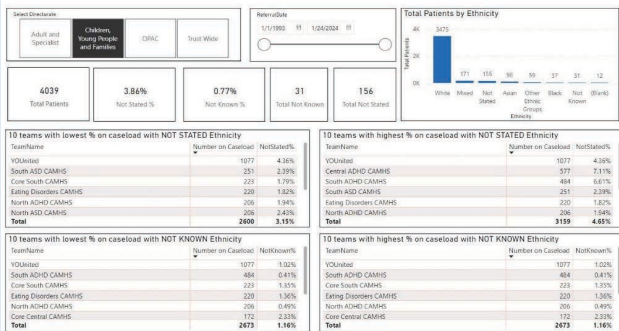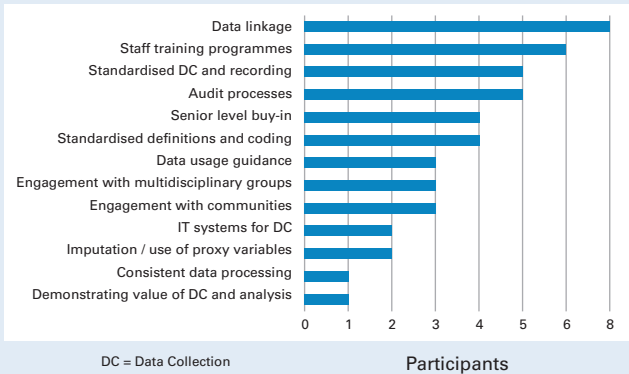
Figure 2: Mechanisms to improve data quality that were raised by qualitative study participants

DC = Data Collection

Participants

Some professionals did not fully understand health inequality and the implications of poor data collection and our review showed that the particular importance of ethnicity data collection is not widely understood. Crucially, some clinical and administrative staff do not feel comfortable asking patients about sensitive information like ethnicity.

As part of the qualitative interviews, it was suggested that there should be standardised national guidance and frameworks to support action along the pathway. These might include, for example, developing a shared understanding of health inequalities and best practices in demographic categorisation, especially around ethnicity.

References

1. Ruth Robertson, et al., Ethnic Health Inequality and the NHS. Driving progress in a changing system. 2021, NHS Race and Health Observatory: Online England. p. 6.

2. Mathur, R., et al., How do we collect good-quality data on race and ethnicity and address the trust gap? Lancet, 2022. 400(10368): p. 2028-2030.

3. Moorthie, S., et al., A Scoping Review of Approaches to Improving Quality of Data Relating to Health Inequalities. Int J Environ Res Public Health, 2022. 19(23).

4. NHS Foundation Trust, M.S.E. Health Inequality and Anchor Programme report. 2023; Available from: https://www.mse.nhs.uk/search?term=ethnicity+inequality&searchType=document https://www.mse.nhs.uk/download.cfm?ver=21756

Contact: For enquiries, please contact Louise Lafortune, Lead of Population Evidence and Data Science Research Theme. Email: ll394@cam.ac.uk

Cambridge Public Health is an Interdisciplinary Research Centre of the University of Cambridge. We aim to build connections between researchers, foster collaborations and conduct research that improves the health and wellbeing of populations.

www.cph.cam.ac.uk