### **NIHR** Applied Research Collaboration East of England

# CASE STUDY

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

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#### What is ethnicity and why do we collect this information?

Commitment to reducing population health inequalities is obligatory for NHS England and Integrated Care Systems (ICS). This relies on good-quality data to understand local community needs and monitor existing services about access, experience, and outcome.

'Ethnicity' has no agreed definition, though it is a mechanism used for categorising individuals based on shared geography, language, and culture, amongst other features. As these factors are critical social determinants of health, information on ethnicity helps us to understand and address socially driven inequalities. For example, 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, however, recognition that the quality of the data used to inform these efforts need 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. Moreover, we place these efforts within the context of our recent scoping review [3] and qualitative study [4], which highlighted best practices for creating effective data pathways across the health service. Lastly, we note that the challenges discussed are not restricted to ethnicity data and can be applied to other data of interest concerning equity, such as gender and sexual orientation.

#### The case study: Improving ethnicity data capture

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 variation in ethnicity data recording across clinical departments. In some cases, ethnicity data were rarely missing, though some clinics within the Trust did not record these data effectively.

To improve the recording of ethnicity data, the team developed an analytics dashboard powered by PowerBI to show the coverage of ethnicity data recording in children's mental health services.

The PowerBI dashboard (see Figures 1 and 2) allowed clinical teams to view their own rates of ethnicity data completion, which drew clinical teams' attention to their own missing data — and how their completion rates compared with other teams. Moreover, 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. This allowed for liaising among different clinical teams regarding the importance of collecting ethnicity data.

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

Figure 1: Sample PowerBI dashboard showing ethnicity data completion rates between departments among children, young people, and families



Figure 2: The PowerBI dashboard displays a decrease in 'Not Known Ethnicity' from mid-2022 through late 2023 in one dataset



Broadly, the team noted that barriers to improving ethnicity coding across services can include:

- Individuals collecting ethnicity data may not understand why it is important to do so. In cases of high rates of staff vacancy and because staff turnover is high, it is difficult to maintain understanding of and interest in this need.
- GP and hospital services can sometimes refer to one-another about whose job it is to record ethnicity data.
- Many people within the Trust may not understand the data chain, and therefore are unsure of who should be recording such variables.
- The initial improvement was largely due to a focused staff member intent on influencing data recording behaviours, and relaxing this intent may reduce compliance.

#### The broader context: Challenges highlighted by our research

This team's experience highlights both behaviours that can promote ethnicity data collection improvement and the barriers to doing so continuously. Our recent scoping review and qualitative study with stakeholders highlighted institutional and societal challenges to improving data pathways. This is an important obstacle to combating health inequality: we cannot create policies to address problems that we cannot identify.

In our scoping review, we discovered that distal initiatives, such as upstream approaches, would be helpful. For example, mandating and prioritising ethnicity data collection can improve data quality. Relatedly, the Equity Act 2010 and Quality and Outcome Frameworks have significantly affected the completeness of ethnicity data [3]. The more comprehensive actions include support by senior-level leaders ("senior level buy-in"), staff training on the importance of data, guidance on data use, citizen engagement, and training on analysis. We outline these and other best practices that should be implemented widely to improve data quality in Table 1.

Table 1: Summary of best practices for improving data quality across the care pathway

Theme	Point in the Data Pathway	Actions
Distal factors	Upstream of data collection and analysis	<ul> <li>Mandating data collection</li> <li>Legal safeguards to ensure non-discrimination</li> <li>Legislation incentivising data collection</li> <li>Prioritisation in policy</li> </ul>
Wider actions to make improvements in data collection	Preparing for data collection	<ul> <li>Achieving senior-level buy-in organisations involved in data collection</li> <li>Engagement activities with citizens, patients, and communities</li> <li>Staff training programmes on purpose and mechanisms for data collection</li> <li>Developing guidance on how data can be used</li> <li>Demonstration of the value of data collection and analysis for organisations</li> </ul>
Data collection instruments, systems, and standardisation	Data collection	<ul> <li>Using multidisciplinary groups to inform data collection instruments, systems and standardisation</li> <li>Creating standardised definitions and coding practices across organisations</li> <li>Improving granularity of data fields</li> <li>Developing standardised processes for collecting and recording data</li> <li>Developing audit processes to monitor data quality aspects</li> <li>Creating IT systems to facilitate data collection</li> <li>Periodic revision of definitions and categories</li> </ul>
Methodological approaches to improve data quality and accuracy	Data analysis	<ul> <li>Linking with other data sources</li> <li>Use of proxy variables</li> <li>Imputation</li> </ul>

Our recent qualitative study based on interviews with professionals working in the local health and care system — "stakeholders" — built upon the findings from our scoping review. Participants flagged several mechanisms for improving data quality. These most frequently included data linkage and staff training programs, but standardisation and senior-level buy-in were also cited (Figure 3 overleaf).

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





Furthermore, some organisations have prioritised the collection of standard variables and neglected others, particularly ethnicity. Some suggestions made in our qualitative interviews were to have 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.

Relatedly, our scoping review and qualitative 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.

#### References

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