

Recommendations towards an ethnicity data collection framework

Community and expert input received through our working sessions in 2022 and 2023 indicated that complete, detailed and accurate ethnicity data are necessary for clinicians, researchers and policymakers to understand disease outcomes and causes, and to provide insights into the management of care in minority populations. However, the completeness and accuracy of ethnicity data within health and social care and routine data sources can be poor and varies across settings. This could be due to inconsistent practices in data collection, missing information in electronic health records (HER) data sources and partly to a lack of understanding of the importance of data collection or reluctance for staff to ask for data, or for people to provide sensitive information.

While the use of categorisations to describe ethnicity, among other demographic characteristics, might be a controversial concept as definitions of individual characteristics do not adequately describe the cultural, social, and religious aspects, they are needed to enable comparable and scientific studies to address health inequalities and deliver care.

While progress has been made in recent years, especially due to the COVID-19 pandemic highlighting the need to explore health inequalities, more work is needed to ensure consistency of approaches to collecting and recording ethnicity data across different healthcare settings in the UK.

Based on the discussions and focus groups held during the past two years, the Alliance recommends that a national framework and relevant guidelines should be implemented to ensure consistent capture of ethnicity records and use of ethnicity coding standards as recommended by the Office for National Statistics.

Below we outline a proposed set of recommendations, that will be discussed in a final in-person working session and will be published online later this year.

Recommendation 1: Purpose

Collection and recording of complete, accurate and high-quality data around ethnicity and other determinants of health is crucial to ensure reliability of research and scientific insights.

It is recommended that collection of ethnicity data as well as wider determinants (such as - socio-economic status, religion, language) and individual characteristics should be sought consistently across the health and social care sectors to enrich the completeness of information to tackle health inequalities.

Recommendation 2: Standardisation.

Reporting and capturing information about ethnicity is a requirement in many healthcare settings. While acknowledging that ethnic groups are not homogeneous, agreement around terminology, definitions and coding standards is needed. To ensure consistency, it is recommended that:

- ethnicity data collection should be based on self-reporting, using official classifications of ethnicity.

- standardised ethnicity categories such as the ONS 18 categories are adopted nationally, across the four nations.
- all research and new routine data should collect the highest possible level and report at a minimum of five levels and when possible higher levels depending on disclosure control and appropriateness to the study or research question.

Recommendation 3: Communication and transparency.

High quality and reliable research based on use of routinely collected data is strictly dependent on patients providing accurate information for purposes beyond direct care and understanding why this data is collected.

A concerted effort should be made across the healthcare system to ensure the positive value of using data for research and innovation for societal benefit is widely articulated and communicated.

Recommendation 4: Training.

Healthcare professionals play a key role in data collection. But there is some reluctance or lack of knowledge about the importance of data collection.

It is recommended that standard guidance is distributed across NHS settings for healthcare professionals to consider in their interactions with patients. Staff training for standardisation of recording to address barriers such as lack of time to explain why data collection is important would also be needed. Training material and guidance should be developed with input from ethnic minority public contributors.

Recommendation 5: Linkage.

Evidence suggests that combining data from different sources and linking data assets can help enrich the information needed for a given purpose. This is also true for recording of ethnicity data. It is recommended that to enable effective data linkage efforts should be made to ensure system interoperability between settings, and in line with upcoming requirements for NHS secure data environments.