Diversity in Data - Ethnicity coding standards working group

Recommendations towards an ethnicity data collection framework

Community and expert input received through our working sessions 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.

Based on the discussions and focus groups held during the past year, 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 (ONS). Below we outline a proposed set of specific recommendations for discussion at the next meeting:

Recommendation 1. Agreement around terminology and definitions to use in the context of using ethnicity data is needed. It is recommended that the ONS terminology is adopted widely across organisations to ensure consistency.

Recommendation 2. Reporting and capturing information about ethnicity is a legal requirement in NHS settings. While acknowledging that ethnic groups are not homogeneous, it is recommended that standardised ethnicity categories such as the ONS 18 categories are adopted nationally, across the four nations. As previously suggested [iv], it is recommended that all research and new routine data should collect and report at a minimum of five levels and when possible use 9.

Recommendation 3. Processes across NHS Trusts differ in the way ethnicity data is collected such as use of recording templates or use of outdated ethnicity codes. A standardised process of data collection should be implemented across NHS Trusts. National standardised data collection protocols and use of standardised ethnicity categories that can be harmonised across sectors would reduce this variation. (In line with recommendation in report on 'Ethnic health inequalities' report by Kings Fund).

Recommendation 4. It is recommended that ethnicity data collection should be based on self-reporting, using official classifications of ethnicity.

Recommendation 5. 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 6. Collection of wider determinants of health (such as deprivation, religion, language) and individual characteristics should be sought to enrich completeness of information to tackle health inequalities.

Recommendation 7. Data linkage would help enrich the information needed for a given purpose, therefore efforts to ensure system interoperability between settings should be made in line with upcoming requirements for NHS secure data environments.

Recommendation 8. 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. 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.

The working group will convene again on **18th January 2023** (1-2pm) via Zoom, to discuss a first draft of this set of recommendations. A final version of these recommendations will be presented at one of the next Alliance Board meetings for approval. It is expected that these recommendations will inform practice across Alliance member organisations. If you are interested in participating in this group discussion please email ukalliance@hdruk.ac.uk and we will send you the joining details.

Alternatively, if you are unable to attend the meeting but would like to provide feedback on the draft recommendations, please email ukalliance@hdruk.ac.uk