

Diversity in Data - Ethnicity coding working group

Workshop Report – 18th January 2023

On 18th January 2023, we held our third Diversity in Data - Ethnicity coding working group session, chaired by Ashley Akbari and Kamlesh Khunti. The session provided an opportunity for stakeholders working in this area to share their thoughts and feedback on a first draft of a set of recommendations to improve the capturing and recording of ethnicity data in the UK, based on community feedback and input received so far.

About 30 participants attended the meeting. At the start of the session Paola Quattroni, Head of Alliance Strategy & Engagement, gave a brief introduction to the Alliance, then Ashley Akbari and Kamlesh Khunti gave some background information about how the working group came about, a recap on the last 2 workshops and an overview of how this third session would run. An agenda can be found in Appendix.

Below we summarise the main points highlighted during the meeting.

Recommendation 1.

Agreement around terminology and definitions to use in the context of using ethnicity data is needed. It is recommended that the Office for National Statistics terminology is adopted widely across organisations to ensure consistency.

Summary of most common responses

- The key is CONSISTENCY.
- If using ONS classification it is important to consider which level should be the minimum acceptable (5-level or 18-level 2021 Census).
- Each of the devolved nations capture different categories therefore guidance on mapping across the devolved nations codes is needed as well as mapping historic records to the 2021 levels.
- Need to consider how to get wider buy in over the adoption of these codes more universally. Perhaps state all public sector organisations who collect ethnicity data?
- It was noted that some categories are missing (Arab, Japanese) and there is a need for further classification in the White group.

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.

Summary of most common responses

- 5-level categorisation is not suitable. Granularity in ethnicity categorisation is very important and data collection should reflect this. Feedback from ethnic minorities suggest aggregation of categories to levels such as White, Asian, etc is not acceptable, nor does it produce results that are easy to interpret or action.
- Need to clarify this wording. Primacy is placed on the 18 categories. What is the relevance of the recommended minimum levels of 5 and 9 where possible. Does this not undermine the importance of capturing the diversity of ethnicity? Using the 5 or 9 levels may not encourage use of the 18 levels.
- Current categories tend to centre around Census categories but are these the most useful for the types of analysis required to provide evidence to support actions to address e.g. inequality. Are the more detailed categories used by National Records of Scotland or NISRA better?
- Categorisation needs to be consistent across the four nations.

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).

Summary of most common responses

- Not just NHS Hospital Trusts (these don’t exist in Scotland). Important to standardise across all Primary and Secondary Care data and support linkage between data collected in other sectors.
- Who would be responsible for the harmonisation of these data? Consider also working with the Integrated Care Systems.
- Implementing these standards may be challenging due to changes required to IT systems which can be costly, take time, etc.
- Ethnic minority groups should be consulted when developing the standardised data collection process.

Recommendation 4.

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

Summary of most common responses

- The majority of the audience agreed that it is very important to allow patients to self-report. If data is not self-reported it leads to issues of data quality. However, in some settings (ie: A&E) it may not be possible for patients to self-report. Need guidance on what should be done in these instances.
- Many ethnic minority groups report that the ONS categories don't adequately represent them (insufficiently granular; moral injury from always being 'othered').
- Need to consider how we improve public trust so that individuals feel comfortable sharing their ethnicity data, and don't leave blank or select 'Other'.
- Will there be any recommendations on when and how (and how often) ethnicity data should be collected? Finding the right settings and methods and frequency is important. Asking patients repeatedly may lead to fatigue.

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.

Summary of most common responses

- The majority of the audience agreed that staff training is vital so they are able to clearly explain the reasons why the collection of health data is important (for public benefit). Staff also need training on how to accurately record ethnicity data.
- What more can be done to make the data collection process as easy and time-efficient as possible? Data collection is often clunky and difficult to record with systems that are not clear or easy to use. Guidance should also be provided to system suppliers.
- There needs to be full transparency about how patient data is used especially as there is a lot of misinformation, concern and distrust when it comes to data sharing.
- Information material also need to share with members of the public to explain the reasons why the collection of health data is important.

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.

Summary of most common responses

- The majority of the audience agreed that the collection of wider determinants of health is very important however, who should collect this data? Focus on data linkage as these other determinants are collected in other settings and harmonisation across four nations.
- Need separate categories for sex and gender identity. At present NHS data conflates gender and sex therefore transgender people are misrepresented. Not sure gender identity can have the same issues as ethnicity. Many public members do not agree with the categorisation of themselves.
- Keeping much of this information up to date will be challenging as it could change frequently e.g. occupation / employment status.

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.

Summary of most common responses

- Linkage with Census would improve data quality more rapidly than waiting for data collection procedures to be updated. Need to be transparent with patients when linking across datasets. However, back-end data linkage should not replace the need for improving data collection processes.
- Data linkage between primary and secondary care to reduce need to ask ethnicity on multiple occasions?
- There are practical constraints to data linkage – IT technicalities. Adherence to [FHIR](#) / [OMOP](#) or equivalent. Need for the NHS to adopt a standard across the systems.
- Need for speedier and streamlined approaches to linkage that allows broader uses for service improvement and research.

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.

Summary of most common responses

- This is largely an administrative task and doesn't need to directly involve clinicians who are overstretched. Need dedicated 'data clerks' to collect and input data or systems can be set up to collect these data routinely. There is also the use of Apps which could be expanded to collect this data in the comfort of their own home.
- Transparency, communication and education is key to getting 'buy-in' – communicate the success stories to the public, which help demonstrate why ethnicity data is valuable and how public health has been improved. COVID provides some good examples of the differential impacts. Information should be clear and accessible to lay persons in order to win trust.
- Need to include clinicians, healthcare workers and the public in these discussions, rather than just speaking to the research community.

AOB

- Who are the decision makers we should address this recommendation to? Is [PRSB](#) involved? Consult with [ICO](#).
- There has been a lot of work on this across a number of organisations e.g. NHS Race and Health, UPD, thus we need to coordinate and bring these all together.
- How would the implementation of recommendations be audited or reported on? Should it be?
- How regularly would these guidelines be reviewed?
- Should there be a supplementary strategy for who to target with the recommendations and how to target them? Can the Alliance help?
- Ideally patients should be providing this information directly into their medical records without involving clinicians or administrative staff.
- Should we survey GP practices to find out what's happening at point of recording. when ethnicity is recorded, by whom, how many times?
- Need to explore ways in which ethnicity data can be collected in an *ethical* way. Some groups might feel apprehensive about sharing this information for fear of being discriminated against.



Actions

The next working group session will be taking place **in-person**, on 24th May 2023 at the College Court Conference Centre in Leicester. The purpose of this meeting is for us to share the overall outputs from this series of workshops, and agree on a final set of recommendations and next steps, to be proposed at one of the next Alliance Council meetings in 2024. There will be presentations from individuals who have conducted their own research in this specialist field. More details to follow.

Appendix

Agenda

Time	Item	Lead and Slides
1pm	Welcome and introductions.	Paola & Chairs
1.05pm	Overview of draft recommendations	Paola & Chairs
1.15pm	Main Session – Discuss the 8 recommendations <i>Participants were asked to add feedback/comments to a Jamboard</i>	ALL
1.55pm	AOB and Close	

Outputs

[Video Recording](#) of the session