

Making lemonade out of lemons: an approach to combining variable race and ethnicity data from hospitals for quality and safety efforts

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Equity is one of the six core healthcare quality domains in ‘Crossing the Quality Chasm’, published by the Institute of Medicine in 2001.¹ While substantial quality measurement and improvement work has focused on improving safety, patient-centredness, timeliness, efficiency and efficacy (the other five domains), far less has focused on health equity measurement and improvement. This is in part due to limited adoption of standardised definitions of racial and ethnicities and therefore limited availability of high-quality data on race and ethnicity.² Having accurate data is a key first step in addressing health inequities, since what is measured influences what is done.³ There are substantial efforts to improve these data availability and quality by healthcare systems, nationally and internationally.² Currently, adequate efforts require several steps: the decision to collect data, ensuring the quality of data being collected, and reconciliation of race and ethnicity data across frequently non-standardised data collection systems.⁴ The study by Lyren and colleagues⁵ in this issue of *BMJ Quality & Safety* focuses on the third step, providing a replicable method to use race and ethnicity data while data standardisation efforts continue. Data collection and analytics are a core principle of advancing health equity, positioned within a larger framework to ultimately improve individual and population-level health.³

STUDY SUMMARY

Lyren and colleagues performed a secondary analysis of data from 25 children’s hospitals in the Solutions for Patient Safety network in the USA,⁵

to describe racial and ethnic disparities in safety events across the hospitals. In designing the study, the authors were confronted with the current reality of race and ethnicity data collection efforts—substantial variation.⁴ They describe four typologies of hospital-level data collection: (1) one race and ethnicity question (ie, Hispanic or Latino/Latina/Latine/Latinx ethnicity, hereafter Hispanic/Latinx to match study language) with a single response allowed; (2) one race and ethnicity question with >one response allowed; (3) separate race and ethnicity questions (ie, Hispanic/Latinx ethnicity plus race) *with* Hispanic/Latinx allowed as a race; and (4) separate race and ethnicity questions *without* Hispanic/Latinx allowed as a race. They developed a crosswalk for each typology, to translate responses across the typologies into a single set of analysable race and ethnicity categories for the study. This approach enabled the study analyses, which showed disparities by racial and ethnic groups in commonly used quality improvement (QI) metrics: central line-associated bloodstream infections (CLABSI) and unplanned extubations (UEs). Measuring inequity in safety outcomes is a necessary, though not sufficient, first step to addressing health inequities in hospital quality of care.

The authors’ approach follows current recommendations for reporting on race, ethnicity and language (REaL) data. Prominent journals’ reporting guidelines for REaL data include recommendations to report method of data collection (eg, self-report, staff report, electronic health record source, etc), rationale for selection of race and ethnicity categories,



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and rationale for comparator groups (to address the common and often unexamined practice of selecting white participants as a default normative reference group).⁶⁻⁸ The study authors note that all hospitals collected data via self-report, and the study uses the overall group as a comparator, rather than a specific racial or ethnic group.

METHODOLOGICAL INNOVATION

This study also provides a methodological innovation (the four typologies and crosswalk described above) which addresses two sources of ongoing discussion on current limitations of REaL data collection and analysis. The first is the collection of race and ethnicity, specifically around Hispanic/Latinx ethnicity respondents. The US Office of Management and Budget (OMB) standards for minimum data collection for those receiving federal funding explicitly recommend that race and ethnicity be collected separately, as in both typology #4 and the US census. However, evidence suggests that a substantial portion of Hispanic/Latinx respondents do not relate to the given race options,² which can lead to decreased response rates⁹ and can lead to respondents often choosing ‘some other race’.² The second ongoing discussion is how to gather, analyse and report on multiracial groupings. OMB standards require that respondents be allowed to check more than one race box. However, there is still a fundamental tension between small sample sizes if all combinations (up to 64) of multiracial groups are analysed and reported separately, versus placing all multiracial respondents into a monolithic box, as is commonly done in the USA. Notably, there are variations in standards in reporting REaL data internationally, with a recent European Commission report documenting some countries not collecting or reporting at all and others with a range of approaches reflecting political and historical contexts.¹⁰

The authors’ approach addresses, in part, both the issues of ethnicity and multiracial groupings, by including in the final crosswalk two relatively non-standard categories: multiracial (Hispanic/Latinx) and multiracial (non-Hispanic/Latinx). This approach has some advantages. These groupings create delineation within the poorly differentiated multiracial category. They also avoid creating two separate Hispanic/Latinx groups (those who choose ‘white’ and those who choose ‘some other race’) when those two groups may not have distinct self-perceived or socially constructed racial or ethnic identities.² Of note, dividing the multiracial group into these two categories resulted in adequate sample sizes for analysis, and identified the multiracial (Hispanic/Latinx) group as having >2 SD higher CLABSI rates than the overall group. However, the approach still results in substantial heterogeneity within each multiracial group. This can ultimately result in erasure when participants identify with ‘some other race’ or ‘other’ more than they identify with

Table 1 Ethnicity and data standards from the Office of Minority Health*

Ethnicity data standard	Categories
Are you Hispanic, Latino/a or Spanish origin (one or more categories may be selected)	
<input type="checkbox"/> No, not of Hispanic, Latino/a or Spanish origin	These categories roll up to the Hispanic or Latino category of the OMB standard
<input type="checkbox"/> Yes, Mexican, Mexican American, Chicano/a	
<input type="checkbox"/> Yes, Puerto Rican	
<input type="checkbox"/> Yes, Cuban	
<input type="checkbox"/> Yes, another Hispanic, Latino or Spanish origin	
Race data standard	
What is your race? (one or more categories may be selected)	
<input type="checkbox"/> White	These categories are part of the current OMB standard
<input type="checkbox"/> Black or African American	
<input type="checkbox"/> American Indian or Alaska Native	These categories roll up to the Asian category of the OMB standard
<input type="checkbox"/> Asian Indian	
<input type="checkbox"/> Chinese	
<input type="checkbox"/> Filipino	
<input type="checkbox"/> Japanese	
<input type="checkbox"/> Korean	
<input type="checkbox"/> Vietnamese	
<input type="checkbox"/> Other Asian	
<input type="checkbox"/> Asian Indian	These categories roll up to the Native Hawaiian or Other Pacific Islander category of the OMB standard
<input type="checkbox"/> Native Hawaiian	
<input type="checkbox"/> Guamanian or Chamorro	
<input type="checkbox"/> Samoan	
<input type="checkbox"/> Other Pacific Islander	

*From the US Health and Human Services Department Office of Minority Health, based on an examination of current federal data collection standards, adequacy of prior testing and quality of the data produced in prior surveys; consulted with statistical agencies and programmes; reviewed OMB data collection standards and the Institute of Medicine Report ‘Race, Ethnicity, and Language Data Collection: Standardization for Health Care Quality Improvement’ and built on its members’ experience with collecting and analysing demographic data.¹³ OMB, Office of Management and Budget.

the provided categories.^{2 11} In contrast, more granular subgroup analyses can uncover disparities that are otherwise hidden in aggregate analyses,⁹ and can lead to more actionable information for hospitals that serve high proportions of specific subpopulations.¹²

POSSIBLE ALTERNATIVE APPROACHES

Though the methodology to combine hospital race and ethnicity data in the study by Lyren and colleagues represents a substantial advance in data collection (compared with no REaL data collection), there are some possible alternative approaches. The US Health and Human Services Office of Minority Health suggests standardised categories that are more granular than the OMB minimum (eg, including options such as Asian Indian, Filipino, Chinese, Korean, rather than only an ‘Asian’ option).¹³ They also provide a crosswalk to roll up to OMB data standards so health systems can gather the granular data while also meeting the OMB standards (table 1).¹³ Finally, they provide item-ordering recommendations (asking ethnicity followed by race),

which evidence shows leads to higher response rates, particularly for Hispanic/Latinx respondents.^{13 14}

Though creating multiracial (Hispanic/Latinx) and multiracial (non-Hispanic/Latinx) groupings provides more nuance to the multiracial category overall, the multiracial population in the USA is growing substantially, increasing from 2.9% of the US population in 2010 to 10.2% in 2020.¹⁵ Greater nuance in describing the group will be important for quality and equity efforts. One approach, used by the National Health Interview Survey, is to ask respondents who choose more than one race which group they most identify with and then assign them to that group rather than a multiracial group. Another approach is to assign respondents who choose both a minoritised race and white race to the minoritised identity group, erring on the side of measuring their lived experience as more influenced by a minority identity than a white identity.¹⁶ A third approach, from the US Department of Housing and Urban Development, adds the four most frequently selected multiple-race combination in addition to the six OMB categories. This avoids reporting all 64 combinations while still capturing the most frequent multiple-race combinations. Another option would allow individuals to write in their identities. A 2006 survey had lower rates of missing values and categorisation for 'other' race when patients wrote in their own preferred racial and ethnic terms, with Hispanic/Latinx and multiracial/multiethnic individuals more likely than other groups to report preferring to use their own categories.⁹ Testing these above options in ongoing efforts can inform effective data collection standards for multiple-race populations, to facilitate health equity QI work.

Recent advances in artificial intelligence open the possibility of systems that can both gather individual preferred racial and ethnic terms, and also feasibly create aggregated data groupings as needed.¹⁷ Testing and validation would include collaborative work to develop multiracial categories that both honour multiple rich racial and ethnic identities and are amenable to data aggregation. Qualitative data and authentic community engagement provide critical contextualisation and enrichment of REaL data collection and analysis efforts.

IMPLICATIONS FOR QUALITY AND SAFETY EFFORTS

The issues of REaL data collection and use are particularly relevant to quality measurement and performance assessment. One purpose of equity performance assessment would be to identify health systems without health inequities or systems which successfully address health inequities, to identify lessons learnt and potential best practices. Lyren and colleagues were not able to assess hospital-level performance due to small sample sizes. This has been addressed in prior work by assessing performance over longer time

periods (7 years¹⁸ compared with the 18 months in Lyren and colleagues⁵). Longer measurement periods in QI efforts can delay detection of the effects associated with an equity intervention, due to long lag times between the intervention and a repeat measure to assess changes. While a longer time horizon is less preferable due to this lag, we would argue that a longer horizon is preferable to no comparative equity measurement. Alternatively, quality measures with a larger group of eligible populations (eg, birthing persons at a hospital, rather than the small number of those with central lines or on a ventilator)¹² increase the eligible sample size and thus can more likely identify equity variations over a shorter period.

Those who have not yet started collecting REaL may want to consider collecting data on social or structural determinants of health, in order to stratify performance by social risk rather than only REaL. Stratifying by REaL data identifies downstream impacts of structural racism and discrimination. Since upstream social and structural determinants of health drive inequity, looking at performance by social risk may be a more direct avenue to addressing health inequity.¹⁹ Hence, countries creating health equity data collection systems could consider gathering social risk data in addition to REaL data.

In summary, the methods that Lyren and colleagues use respond to the current state of data collection, and we have suggested specific areas for potential improvement in data collection and reporting. The authors discuss their CLABSI and UE findings in the context of systemic racism, the upstream cause of racial and ethnic inequities. It is important to note that inadequate data are also a symptom of systemic racism. While it is necessary but not sufficient to do so, addressing data inadequacy is possible. REaL data collection and analysis are a commendable and important first step to identify health inequities. Subsequent deeper work is needed to understand and address drivers, as part of health system efforts to advance health equity and ultimately improve outcomes for minoritised groups.³

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