

The need for transparent reporting of ethnicity in health research

Alana B McCambridge

Dear Editor,
I read with interest a recent *New Zealand Medical Journal* issue (Vol. 137 No. 1598) and noted four articles reported health-related data characterised by ethnicity.¹⁻⁴ Ethnicity is a measure of cultural affiliation and is self-perceived, and people can identify with or feel they belong to more than one ethnic group.^{5,6} In New Zealand, ethnicity is of particular importance when considering the ethnic disparities in healthcare and health outcomes that persist. It is important that ethnicity is measured, analysed and reported as accurately and transparently as possible.

In two of the four articles that characterised their data by ethnicity in this issue, the authors described their ethnicity protocol. For example, Weatherall and colleagues' study on urinary incontinence used "total response ethnicity", which allows a person to identify with more than one ethnic group.⁴ Ethnicity data were grouped into Māori, Pacific, Asian, and European/Other. This means that an individual who identifies as Māori/Pākehā would be counted in both the Māori and the European/Other groupings, or an individual that identifies as Sāmoan/German/Pākehā would be counted once in the Pacific and once in the European/other groupings. Because this study has opted to combine European and "Other", an individual who identified as African would be grouped together with people who identified as European. Grouping of the "Other" category can sometimes be done to avoid small sample sizes; however, it can also make invisible some ethnicities. Total response ethnicity (also termed total response overlapping) allows for a more complete understanding of ethnicity, as individuals can self-identify with as many (or up to six) ethnicities they feel they belong to.⁵ However, as individuals can be counted more than once, the total denominator can be greater than 100% of the population, and overlapping data may obscure health disparities.

In contrast, Stedman and colleagues' study on paediatric type 1 diabetes used "prioritised ethnicity", which allocates people to a single

ethnic group based on a priority order, even if they identify with more than one ethnicity.³ The priority order, from highest to lowest, has been determined as: Māori, Pacific, Asian, Middle Eastern/Latin American/African (MELAA), Other, and European.⁵ Stedman and colleagues then grouped their data into four groups: Māori, Pacific peoples, Asian, and European/Other, omitting MELAA as its own grouping and combining European and Other together.³ The prioritised ethnicity protocol means that an individual who identifies as Tongan/Māori/Pākehā would be counted only as Māori, or someone who identifies as Sāmoan/Chinese would be counted only as Pacific. This can be problematic, as the prioritised order may not be representative of the ethnicity that an individual most strongly identifies with.⁵ The order biases the statistics to over-represent some groups and under-represent others, and the forced categorisation of a given ethnicity is incongruent with ethnicity being self-identifiable.⁵ As such, Stats NZ recognised the need to discontinue using prioritised ethnicity data protocols for official statistics.⁷ However, for certain analyses there may be a need to reduce people to a single ethnic group and the prioritisation protocol aims to give greater visibility to ethnic groups of particular importance to policy.⁵

Unfortunately, the articles by Garrett and Gray¹ on diabetes-related lower extremity amputations and Richly and Romero Ferrando² on anti-NMDAR encephalitis did not report their ethnicity data protocols. A lack of reporting about how ethnicity is measured and analysed in research limits the generalisability of findings.

Researchers who use data from New Zealand health databases need to be aware of potential issues with ethnicity data quality. There is substantial evidence indicating a lack of compliance with ethnicity protocols throughout the New Zealand health and disability system.⁸⁻¹⁰ Several barriers to compliance have been mentioned, such as IT systems and the range of systems in use, the cost of changing non-compliant systems, inadequate training and support in proper data collection and use and poor understanding of the rationale for

high-quality ethnicity data.^{9,11} Researchers who use ethnicity data from health databases or who collect ethnicity for original research must ensure they understand the ethnicity protocols and treat ethnicity with the same rigour as any other variable. Consistency in the analysis of ethnicity would also allow for better synthesis of the literature, as well as comparisons between studies and over time. Better coordination is needed across the entire health and disability sector, including health research, to drive the changes needed to improve the quality of ethnicity data.^{11,12}

The *New Zealand Medical Journal* should adopt

a policy that requires all publications to clearly state their ethnicity protocol. Journal policies play a significant role in shaping research practices and ultimately influencing the evidence base that informs healthcare practice and policies. Better transparency and guidance in the reporting of ethnicity data would help to more accurately represent issues and inform potential strategies to address ethnic disparities in health outcomes in New Zealand.

Sincerely,

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COMPETING INTERESTS

Nil.

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Editor's response to: The need for transparent reporting of ethnicity in health research

Frank Frizelle

Dear Alana B McCambridge,
Thank you for your letter to the editor on the need for transparent reporting of ethnicity in health research. I agree with your statement that in New Zealand (and elsewhere) "*Ethnicity is of particular importance when considering the ethnic disparities in health-care and health outcomes.*"^{1,2} As a consequence, how we report ethnicity is important. Your point about the different forms of reporting ethnicity, i.e., "total response ethnicity" versus "prioritised ethnicity", is well made. I agree that we (the *NZMJ*) should consider adopting a policy that requires authors to state their ethnicity protocol. I will discuss this with the other *NZMJ* editors and will try and develop a policy by the end of the year.

Thank you for bringing this to our attention.

With regard to your comment "*Researchers who use data from New Zealand health databases need to be aware of potential issues with ethnicity data quality,*"¹ I also agree. The *Journal* has reported repeatedly on the inaccuracy of ethnicity based on the National Health Index over the last 22 years (while I have been editor).^{3,4} It is, however, slowly improving with the attention being drawn to it from many sources. It is also outside the *Journal's* scope to alter this, other than making people aware of this and reporting the issue when people study it.

Frank Frizelle
Editor *NZMJ*

COMPETING INTERESTS

Nil.

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