

Including minority populations in research: we must do better

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Time, money and commitment are needed to increase the value of medical research — and to respect participants



Two articles in this issue of the *MJA* discuss the inclusion of minority populations in research. Stanaway and colleagues found that one in five recent clinical trials in Australia excluded participants with low English proficiency,¹ while Comino and her co-authors describe the responses of urban Aboriginal mothers to illness in their infants.²



Why does including minority populations in medical research matter? Firstly, we might sometimes expect treatment effectiveness to vary between ethnic groups. In Australia, where 19% of the population speak a language other than English at home,³ the systematic exclusion from clinical trials of participants who are not fluent in English may restrict the generalisability of research findings. There are parallels here with historical research practices

which assumed that findings of investigations in single white men could be directly applied to partnered, female, and minority populations.⁴

A second reason is that excluding minority populations means that they may neither benefit from the improvements that research might directly offer, nor be protected from treatments that harm them.⁵ The international debate about including women in clinical trials drew attention to related problems.⁶ Not offering some treatments to women because their effects have been investigated only in men restricts the potential benefits of research, and is also unfair. Just as importantly, offering a treatment to women that has only been tested in men can be dangerous. The outcome of the debate — recognition that we need to ensure that clinical trials include participants from all prospective patient groups — also applies to the inclusion of members of minority populations.⁷

A final reason for securing the participation of minority groups in research is a simple question of equity: excluding participants with low English proficiency is discriminatory, denying them opportunities available to other Australians, and which should be available to all, regardless of their ethnic or social background.



There may, of course, be good reasons for limiting the participation of minority groups in research, particularly when they are vulnerable to exploitation or coercion. The *National Statement on Ethical Conduct in Human Research* specifies that researchers need to explicitly enable participants from certain groups — including pregnant women, children and young people, people highly dependent on medical care, and Aboriginal and Torres Strait Islander peoples — to make informed choices, and to ensure they are not overly burdened as a result of their participating.⁸

How can researchers optimise the inclusion of minority groups in research? The article by Comino and colleagues, from the Gudaga Study, is grounded in best practice methods for undertaking research in Aboriginal and Torres Strait Islander communities. The Gudaga Study explicitly based its design and implementation on *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*.⁹ The *South Australian Aboriginal Health Research Accord* built on this foundation, providing examples of how research can be conducted most appropriately.¹⁰

These approaches to research undertaken in partnership with Indigenous Australians can be instructive for the conduct of research in other minority communities. It is not simply a matter of employing translators or recruiting staff fluent in community languages. As best practice in research involving Indigenous Australians has shown, increasing the participation of minority groups may require additional or new approaches to investigation.¹¹ For example, research questions should be developed in thorough and inclusive consultation with the participating community so that they are aligned with their priorities. Research methods must respect how minority communities build knowledge and interpret the world. High levels of involvement from research leaders and robust governance methods are important for building and maintaining trust. Including members of minority groups in research leadership teams can also help to

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translate the participants' understanding of health, health care, and research in the design and execution of the investigation. These practices help to ensure that research is relevant, acceptable to the participating community, accountable, and translational.

Time, money and commitment are needed if we are to appropriately include minority populations in research and to enable minority groups to make their own decisions about how, when and why they participate in research. Investigators will thereby be better positioned to avoid practices that have harmed minority groups in the past. All of this will contribute to better health outcomes and to greater self-determination for minority communities.

Acknowledgements: The Centre of Research Excellence in Aboriginal Chronic Disease Knowledge Translation and Exchange (CREATE) is funded by the National Health and Medical Research Council (APP1061242). The CREATE Methods Group is Odette Gibson, Kim Morey, Stephen Harfield, Elaine Kite, Karla Canuto, Karen Glover, Carol Davy, Edoardo Aromataris, Drew Carter and Annette Braunack-Mayer.

Competing interests: No relevant disclosures.

Provenance: Commissioned; externally peer reviewed. ■

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