Setting the standard: no LGBTI+ health equity without data equity

To the Editor: As researchers with decades of experience in public health, and as proud members or allies of the LGBTI+ (lesbian, gay, bisexual, transgender, intersex, and other diverse sexual and gender identities) community, we express our deep concern about the handling of the collection of comprehensive data on LGBTI+ Australians in the 2026 census. Following significant community backlash from research groups, community organisations, the LGBTI+ community, and their allies, the discourse around capturing LGBTI+ identities within the 2026 census has seemingly resulted in a positive outcome for sexual and gender diverse Australians.[1] However, the inclusion of questions identifying people with innate variations of sex characteristics remains uncertain and unconfirmed.

The Australian Bureau of Statistics 2020 *Standard for Sex, Gender, Variations of Sex Characteristics, and Sexual Orientation Variables* (hereafter, the 2020 Standard) — a standard that has been rigorously tested with community and advisory groups and has already been implemented in national surveys — sets a clear precedent for comprehensive data collection.[2] However, despite this successful implementation and the recent endorsement of the 2020 Standard in all phases of health and medical research by the National Health and Medical Research Council and the Department of Health and Aged Care, the current approach to data collection in the 2026 census does not align with these guidelines.[3]

The robust and considered inclusion of the 2020 Standard in the census is crucial. This is because the inclusion of the LGBTI+ population in traditional population surveys has been inconsistent, incomplete or inappropriate.[4,5] Further, as these surveys are generally smaller probabilistic samples, results are often aggregated or incomplete (eg, grouping lesbian, gay and bisexual results together or omitting results for people with intersex variations).[2] This masks the significant heterogeneity and diversity within the LGBTI+ community and ultimately reduces our capacity to deliver the evidence base needed to help address persistent and, in some cases, widening LGBTI+ health inequalities.[6,7]

Research institutes across Australia have also advocated for the inclusion of these items, reflecting a consensus in the scientific community about their importance.[1] If we miss this opportunity, our next chance to include these items in the census will not arise until 2031, further perpetuating data inequities and limiting our ability to address disparities in LGBTI+ health outcomes.

We strongly urge the relevant government departments and data custodians to recognise the need for comprehensive, validated and consistent data collection of LGBTI+ identities such as those developed through the 2020 Standard. Ultimately, health equity is unachievable without data equity. The future of health equity depends on the informed actions we take today to ensure our data accurately reflects the diversity of the entire Australian population.

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