Issues paper:

Improving National Data Systems for LGBTIQ+ Health: the ABS 2020 Standard

Executive summary

- Consistent collection of data relating to sex, gender, sexual orientation and innate variations of sex characteristics is essential to improve the health and wellbeing of LGBTIQ+ people in Australia.
- The Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020 (2020 Standard), developed by the Australian Bureau of Statistics (ABS), is a nationally consistent framework for collecting this data.
- Inconsistent or absent data collection contributes to the invisibility of LGBTIQ+ populations within health, social and administrative systems, limiting evidence-based policy and service delivery.
- Implementation of the 2020 Standard will improve data quality, strengthen monitoring of health inequities, support preventive health planning and enable more inclusive and effective services.

Background

Data is critical for shaping health policy, service planning, funding allocation and population health responses. LGBTIQ+ populations have been largely invisible within Australian datasets due to gaps and inconsistencies in the collection of information about sex, gender, innate variations of sex characteristics and sexual orientation. This information is needed to identify health disparities, monitor trends, evaluate interventions and design responsive services.

The 2020 Standard[1] developed by the ABS provides nationally consistent guidance for collecting and reporting this information. The Standard was developed through extensive consultation and represents an important step towards improving visibility and evidence-based policy.

For the first time in the 2026 Census, Australians aged 16 years and over have been asked questions relating to sexual orientation and gender. While this is a significant development, the absence of a question relating to people born with variations of sex characteristics and the restrictions on data collection about younger LGBTIQ+ populations highlight the continued challenges achieving comprehensive data.

Key issues

Many national datasets do not consistently collect information relating to sexual orientation, gender and innate variations of sex characteristics. This is often the result of data systems that have historically been structured around binary categories, limiting their ability to accurately capture the experiences of LGBTIQ+ people, particularly those who are non-binary.

As a result, LGBTIQ+ people are often absent from population health monitoring, service planning and evaluation processes. This limits the ability of governments, Primary Health Networks and service providers to understand the scale and nature of health inequities experienced by these populations, identify local service gaps and allocate resources effectively.

For example, gaps remain within national suicide monitoring, preventive health datasets, aged care systems and primary healthcare data collections. These gaps contribute to reduced understanding of disparities in mental health, chronic disease, healthcare access and experiences of discrimination. They can also make it more difficult for community-led organisations to demonstrate unmet need and advocate for investment sufficient to address health inequities.

Impacts on health and wellbeing

Data gaps have direct implications for health and wellbeing

LGBTIQ+ populations experience disproportionately high rates of psychological distress, suicidality and barriers to healthcare. The Private Lives 3 national survey found significantly poorer mental health outcomes among LGBTIQ+ people compared to the broader population, particularly for trans and gender-diverse people.

Without consistent data collection, these inequities can remain poorly understood or insufficiently prioritised. When populations are not counted or recognised within systems, it can contribute to exclusion, reduced trust in institutions, and lower confidence that services will be safe and inclusive.

Data gaps can reinforce a cycle of invisibility. Where intake forms, registration systems and other service-level data collection do not include appropriate questions, services may assume they have few or no LGBTIQ+ clients. This can reduce focus on inclusive service design, workforce capability, communication practices and quality improvement, further limiting the visibility of LGBTIQ+ populations and their needs.

Some organisations and jurisdictions have adopted elements of the 2020 Standard, while others continue to use outdated, inconsistent or non-inclusive approaches. This inconsistency creates challenges for comparability across datasets and limits the ability to analyse national trends. It can create confusion for staff and service users, particularly where terminology or collection methods differ between systems.

Inclusion of people born with variations of sex characteristics

Despite the inclusion of variables relating to innate variations of sex characteristics in the 2020 Standard, data on people born with innate variations of sex characteristics remain largely absent from data systems. This contributes to a lack of visibility, and persistent misunderstanding of this population and its distinct health, human rights and service needs. People born with innate variations of sex characteristics are a distinct population whose experiences and health needs cannot be assumed to mirror those of other LGBTQ+ populations.

The absence of reliable data means people born with innate variations of sex characteristics can be overlooked, mischaracterised or inadequately considered in health research, policy development and service planning. It also contributes to broader public and institutional misunderstandings, making it more difficult to develop informed and effective policy responses. Consistent data collection is necessary to improve understanding of health outcomes, healthcare experiences and service needs, and to support evidence-based policy, program design and public understanding.

The exclusion of a question on innate variations of sex characteristics from the 2026 Census is a missed opportunity to address longstanding gaps in visibility, evidence, understanding and accurate representation. Without improved data collection, the specific and at times unique health and service needs of people born with variations of sex characteristics will continue to be poorly understood and inadequately addressed.

Policy considerations

Implementation of the 2020 Standard can raise practical questions regarding privacy, question design, data quality and perceived administrative burden. These considerations are common to many forms of demographic data collection and require careful implementation and clear communication.

The 2020 Standard was specifically developed to support respectful, voluntary and statistically robust data collection. It recognises the importance of privacy, self-identification and context-specific implementation. Consistent with the Standard, collection should be undertaken only where relevant, with individuals able to choose whether to disclose this information, and with appropriate safeguards to protect privacy and confidentiality.

In some contexts, public discussion about sex, gender and sexual orientation is politicised. This can create additional challenges for the collection and use of demographic data, particularly where debates question the legitimacy of LGBTIQ+ populations. However, data collection is a public health and equity measure consistent with established approaches to identifying population needs, monitoring outcomes and addressing health inequities.

Effective implementation of the 2020 Standard requires more than updating forms, databases and data collection systems. Safe, respectful and meaningful collection depends on workforce training, privacy protections, community engagement, clear guidance and consistent practices across organisations and jurisdictions. Standardised data collection can reduce duplication across systems, support linked data environments, enable consistent reporting, and improve evaluation of funded programs and services.

Various jurisdictional and national organisations, including the ABS and Australian Institute of Health and Welfare (AIHW), have developed practical implementation approaches consistent with the 2020 Standard. Community-led organisations also have expertise in culturally safe data collection and service delivery that is vital to successful implementation.

Policy alignment

Implementation of the 2020 Standard aligns with key national strategies, including:

- National Action Plan for the Health and Wellbeing of LGBTIQA+ People 2025–2035[2] supports priorities on data, research and policy.
- The National Health and Medical Research Council (NHMRC) and the Department of Health, Disability and Ageing joint Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research[3] requires use of the ABS 2020 Standard in NHMRC funded research.
- National Preventive Health Strategy 2021–20304 emphasises the role of high-quality data in reducing health inequities, improving population health outcomes and supporting preventive health action, including early identification of health risks, targeted interventions, program evaluation and monitoring of outcomes.
- Many national strategies recognise the need to improve data, monitoring, accountability and evaluation, such as the National Women's Health Strategy 2020-2030[5], National Mental Health and Suicide Prevention Plan[6], National Drug Strategy 2017–2026[7], National Men's Health Strategy 2020-2030[8], National Suicide Prevention Strategy 2025–2035[9], Australia's Primary Health Care 10 Year Plan 2022–2032[10] and National Action Plan for the Health of Children and Young People 2020-2030[11].

Adoption of the 2020 Standard will strengthen the evidence base for policy development, service design and resource allocation. It will support preventive health by enabling earlier identification of emerging health risks, more targeted interventions, monitoring of vaccination uptake and cancer screening participation, evaluation of chronic disease prevention initiatives, and assessment of preventive mental health programs.

While most national strategies acknowledge data limitations, including the lack of disaggregated data, they do not have specific actions to support consistent collection, limiting capacity to measure outcomes and target interventions effectively. Consistent implementation of the 2020 Standard would provide a practical mechanism to address these widely recognised data gaps.

Recommendations

1. Require Commonwealth-funded health and social service datasets to adopt the 2020 Standard, with implementation timelines, reporting requirements and ongoing monitoring of uptake and compliance.

2. Integrate compliance with the 2020 Standard into national data governance frameworks and funding agreements.

3. Include questions relating to people born with variations of sex characteristics in future Census and national data collection processes, supported by strategies to achieve understanding and data quality.

4. Prioritise adoption of the 2020 Standard within primary healthcare, mental health, aged care, suicide prevention and preventive health systems.

5. Fund and deliver national guidance, workforce training and privacy protocols to support safe and consistent implementation, including funding to support community-led organisations to lead or co-design implementation of the 2020 Standard.

6. Provide targeted funding to support health and social service organisations to update data systems, implement the 2020 Standard and undertake associated workforce development activities.

7. Fund research and evaluation activities that use the 2020 Standard to improve understanding of LGBTIQ+ health and wellbeing outcomes, and support implementation of the NHMRC Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research.

8. Recognise consistent data collection as core health system infrastructure for reducing health inequities experienced by LGBTIQ+ populations.

Delivery of these recommendations requires coordinated action across Commonwealth, state and territory governments, reflecting their different responsibilities for healthcare funding, workforce development, service delivery and data systems.

References

This paper draws on peer-reviewed research, government reports, community-led evidence and policy documents. These references are selected key sources that are useful for further reading.

Amos, N., Lim, G., Buckingham, P., Lin, A., Liddelow-Hunt, S., Mooney-Somers, J., Bourne, A., 2023. Rainbow Realities: In-depth analyses of large-scale LGBTQA+ health and wellbeing data in Australia. ARCSHS.

Australian Bureau of Statistics, 2021. Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020.

Department of Health and Aged Care, 2024. National Action Plan for the Health and Wellbeing of LGBTIQA+ People 2025-2035. Department of Health and Aged Care, Canberra, Australia.

Statement on Sex, Gender, Variations of Sex Characteristics and Sexual Orientation in Health and Medical Research [WWW Document], 2024. National Health and Medical Research Council. URL https://www.nhmrc.gov.au/research-policy/gender-equity/statement-sex-and-gender-health-and-medical-research (accessed 9.27.24).

Australian Institute of Health and Welfare. Australia's health 2024: data insights and health system overview. AIHW, Canberra.