LGBTIQ+ HEALTH AUSTRALIA

Health and wellbeing for lesbian, gay, bisexual,
trans, gender diverse, intersex, queer and
other sexual orientation, gender and bodily
diverse people (LGBTIQ+)

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Submission: National Primary Health Care Data Collection Data Governance Framework Roadmap

About LGBTIQ+ Health Australia

LGBTIQ+ Health Australia (LHA) is the national peak organisation promoting the health and wellbeing of LGBTIQ+ people and communities. With a diverse membership spanning LGBTIQ+ community-controlled health organisations, community groups, state and territory peak bodies, service providers, researchers, and individuals, LHA is uniquely positioned to deliver national leadership in policy, advocacy, research, and capacity building.

A national focus on LGBTIQ+ health

LGBTIQ+ people are recognised as a priority population in key national strategies such as the *Primary Health Care 10-Year Plan*[1], *National Preventive Health Strategy*[2], *National Men's*[3] and *Women's Health Strategies*[4], and the *National Mental Health and Suicide Prevention Plan*[5]. The release of *the National Action Plan for the Health and Wellbeing of LGBTIQA+ People 2025–2035*[6] (National Action Plan) marks a historic step forward, delivering a comprehensive framework to address systemic health inequities and achieve better physical and mental health outcomes for LGBTIQ+ people across Australia.

Understanding experiences of LGBTIQ+ people

Despite these national strategies, LGBTIQ+ people continue to experience poorer health outcomes due to stigma, discrimination, prejudice, and abuse. LHA acknowledges the compounding barriers faced by LGBTIQ+ people with intersecting experiences, including Aboriginal and Torres Strait Islander people, cultural and racial diversity, age, disability, socioeconomic disadvantage, and geographic isolation.

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[1] https://www.health.gov.au/resources/publications/australias-primary-health-care-10-year-plan-2022-2032
[2] https://www.health.gov.au/resources/publications/national-preventive-health-strategy-2021-2030
[3] https://www.health.gov.au/resources/publications/national-mens-health-strategy-2020-2030
[4] https://www.health.gov.au/resources/publications/national-womens-health-strategy-2020-2030
[5] https://www.health.gov.au/resources/publications/the-australian-governments-national-mental-health-and-suicide-prevention-plan
[6] https://www.health.gov.au/resources/publications/national-action-plan-for-the-health-and-wellbeing-of-lgbtiqa-people-2025-2035

Introduction

LGBTIQ+ Health Australia (LHA) welcomes the opportunity to provide input into the development of the Data Governance Framework for the National Primary Health Care Data Collection (NPHCDC).

The development of a coordinated, national approach to primary care data is critical to improving population health planning, informing policy and ensuring that health services are responsive to the needs of all people in Australia.

Ensuring visibility of LGBTIQ+ populations in national data systems

A central objective of the NPHCDC is to address gaps in primary care data for population health planning and research. This objective cannot be achieved unless LGBTIQ+ populations are visible within the data. Historically, the absence of consistent data on sexual orientation, gender and variations of sex characteristics has resulted in significant evidence gaps, limiting governments' and health services' capacity to identify health inequities and respond effectively.

While the Framework recognises the importance of inclusion, consultation and representation in governance, it does not explicitly address the collection of these variables. This omission risks perpetuating the long-standing invisibility of LGBTIQ+ populations within national health datasets and limiting the capacity of the NPHCDC to deliver on its stated purpose.

These current gaps have practical consequences across the health system:

- At a local level, Primary Health Networks rely on high-quality data to plan, commission and fund services based on local population need. The lack of consistent data on LGBTIQ+ populations limits PHNs' ability to identify unmet needs, recognise service gaps and allocate resources equitably, increasing the risk that disparities remain unaddressed.
- At a national level, inconsistent data collection has also constrained the evidence base maintained by the Australian Institute of Health and Welfare, contributing to significant blind spots. The absence of LGBTIQ+ indicators in systems such as the National Suicide Monitoring System, despite well-documented disparities in mental health outcomes, illustrates the consequences of this invisibility.

Without a coordinated, national approach to data collection, these gaps will persist. Ensuring that LGBTIQ+ populations are visible within the NPHCDC is therefore foundational to its purpose and to improving equity, accountability and population health outcomes across Australia.

Recommendation: Implementing the Australian Bureau of Statistics 2020 Standard

LHA recommends that the Data Governance Framework explicitly require alignment with the Australian Bureau of Statistics Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables (2020)[7].

The Standard for Sex, Gender, Variations of Sex Characteristics and Sexual Orientation Variables, 2020 (2020 Standard) was developed to standardise the collection and dissemination of data across Australian governments. It provides a nationally agreed framework to ensure that data relating to sex, gender, variations of sex characteristics and sexual orientation are collected consistently, accurately and respectfully.

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[7] https://www.abs.gov.au/statistics/standards/standard-sex-gender-variations-sex-characteristics-and-sexual-orientation-variables/latest-release

Embedding the 2020 Standard within the NPHCDC would ensure consistency, comparability and data quality across jurisdictions and datasets. It would also support interoperability with other national data collections.

There is now a clear and consistent policy direction from the Australian Government to improve the collection and use of these variables across health and wellbeing systems. Examples of uptake include:

- The 2026 Australian Census will, for the first time, collect data on sexual orientation and gender for people aged 16 years and over. This represents a significant step towards improving national population data and demonstrates both feasibility and policy commitment.
- The National Health and Medical Research Council (NHMRC), alongside the Medical Research Future Fund (MRFF), now requires that sex, gender, variations of sex characteristics and sexual orientation are considered across all stages of funded research[8].

Taken together, these developments establish a clear expectation that these variables should be routinely and consistently captured across Australia's health and research systems.

The NPHCDC presents a critical opportunity to embed this consistency within national primary care data infrastructure. Embedding this alignment within governance settings, including data standards, data dictionary development and data quality processes, will support consistent implementation across contributing datasets.

Data quality, consistency and national comparability

The Framework identifies challenges relating to data quality, variation in clinical systems, and the need for standardisation across primary care data.

LHA supports this focus and notes that without standardised approaches to key variables, including those relating to sex, gender, innate variations of sex characteristics and sexual orientation, data will remain inconsistent and of limited utility for population-level analysis.

Embedding the ABS 2020 Standard within governance arrangements would:

- improve data quality and comparability across jurisdictions and systems
- support meaningful analysis of health outcomes for different populations
- reduce the risk of inconsistent or non-standard data collection practices

This is consistent with the Framework's objective of supporting nationally consistent primary health care data.

Governance and representation

LHA supports the establishment of governance structures that include representation from key stakeholders, including consumers and community representatives.

We recommend that consideration be given to including expertise in LGBTIQ+ health within governance arrangements, including through engagement with community-controlled organisations.

This would support:

- appropriate interpretation of data relating to LGBTIQ+ populations
- appropriate, safer and meaningful use of data
- alignment with community expectations and priorities

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[8] https://www.nhmrc.gov.au/research-policy/gender-equity/statement-sex-and-gender-health-and-medical-research

Privacy, trust and social licence

LHA supports the strong focus on privacy, de-identification and ethical use of data within the Framework.

At the same time, it is important to recognise that trust in data systems is shaped not only by technical safeguards, but also by whether people can see themselves reflected in the data and understand how it will be used to improve health outcomes and that their data will be protected.

Transparent communication about the inclusion and use of data relating to sexual orientation, gender and innate variations of sex characteristics will be important to maintaining public confidence and social licence.

Resourcing and implementation

LHA notes that the successful implementation of the NPHCDC will require investment in:

- data system development and integration
- workforce capability to collect, record and use data appropriately
- engagement with community-controlled organisations to provide lived-experience expertise

Additional resourcing will be critical to ensure that data collection is both accurate and meaningful, particularly for populations that have historically been underrepresented in health data.

Conclusion

LHA strongly supports the development of the NPHCDC and the establishment of a robust Data Governance Framework.

We emphasise that this initiative represents a foundational opportunity to improve the visibility of LGBTIQ+ populations within Australia's health data systems.

Embedding alignment with the ABS 2020 Standard within the governance framework will ensure that the collection delivers on its objective of supporting high-quality, nationally consistent data for policy, research and planning, and contributes to improved health outcomes and more equitable service planning for all people in Australia.