



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

[www.lgbtiqhealth.org.au](http://www.lgbtiqhealth.org.au)  
[info@lgbtiqhealth.org.au](mailto:info@lgbtiqhealth.org.au)  
02 7209 6301  
ABN 45 138 151 569

## Submission to the Community Affairs Legislation Committee regarding Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024

### 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, National Preventive Health Strategy, National Men’s and Women’s Health Strategies, and the National Mental Health and Suicide Prevention Plan<sup>1-5</sup>. The release of the National Action Plan for the Health and Wellbeing of LGBTIQ+ People 2025–2035<sup>6</sup> 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 status, cultural and racial diversity, age, disability, socioeconomic disadvantage, and geographic isolation.

### Contact

Name: James Zanotto  
Position: Policy, Research and Communications Director  
Email:  
Phone:

---

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 comment on the proposed amendments to the My Health Record (MHR) system, particularly the initiatives to enable "sharing by default" for pathology and diagnostic imaging reports and to remove the seven-day delay for consumer access. While these changes are aimed at improving healthcare access and coordination, they present significant privacy and safety concerns for LGBTIQ+ populations. These concerns must be addressed to avoid exacerbating existing disparities in health outcomes for these populations.

## Key concerns

### 1. Privacy and autonomy risks

LGBTIQ+ people, particularly trans and gender diverse people, intersex people, sex workers, and people who use drugs, face heightened risks of stigma, discrimination, and safety breaches. Automatic uploading of sensitive health data to the MHR system, such as pathology results for blood-borne virus testing or hormone levels, could unintentionally disclose personal information to healthcare providers or third parties, violating privacy and exacerbating mistrust. This concern is especially critical given that privacy and access controls within the MHR system serve as the primary risk mitigation strategy under the "sharing by default" mandate.

### 2. Impact on access to healthcare

LGBTIQ+ populations have historically faced barriers to healthcare, including fear of discrimination and previous experiences of medical trauma. Sharing by default may discourage individuals from seeking necessary care, particularly for stigmatised health issues, if they fear breaches of confidentiality.

### 3. Digital inclusion and accessibility challenges

Many people within LGBTIQ+ populations, particularly those in rural or remote areas, older LGBTI people, and LGBTIQ+ people with disability, face challenges in accessing and navigating digital systems like MHR. Limited digital literacy and infrastructure mean they may be unaware of their ability to restrict access to sensitive records.

### 4. Mistrust in digital health systems

Existing research highlights low levels of trust in digital health systems among LGBTIQ+ populations, driven by experiences of stigma and discrimination. The shift to a "sharing by default" model risks deepening this mistrust, further hindering engagement with healthcare services.

## Recommendations

To ensure the proposed amendments support equitable health outcomes while safeguarding privacy, LHA recommends:

### 1. Opt-out and informed consent

- Introduce mechanisms allowing consumers to opt out of the automatic upload of specific types of pathology or diagnostic imaging results to their My Health Record. While consumers currently can request that certain results not be uploaded at the point of collection, this recommendation refers to establishing a broader and

ongoing mechanism to allow users to restrict specific categories of sensitive results.

- Require explicit, informed consent before enabling the automatic upload of sensitive health information and ensure patients are informed about how to restrict access through privacy settings.

## **2. Comprehensive privacy controls**

- Develop targeted education campaigns to empower LGBTIQ+ populations to navigate MHR privacy settings and raise awareness of their right to request information not to be uploaded at the point of collection. This should include practical guidance tailored to diverse needs, such as those who are trans or gender diverse, and intersex people.
- Simplify privacy settings to allow users to restrict access to specific records or individual healthcare providers.

## **3. Safeguards against discrimination**

- Mandate healthcare providers to adopt anti-discrimination training specific to LGBTIQ+ populations, ensuring they use sensitive health data responsibly.
- Establish clear accountability measures for inappropriate access or misuse of sensitive health data. While accountability mechanisms already exist, it is critical to provide clear guidelines for consumers on what constitutes misuse or inappropriate access, along with clear complaints processes. Additionally, a distinction should be made between inappropriate access and appropriate access that results in misuse of information or discrimination.

## **4. Alignment with the 2020 standard**

- Incorporate the Australian Bureau of Statistics' 2020 Standard for Sex, Gender, Variations of Sex Characteristics, and Sexual Orientation Variables into MHR updates to ensure data collection and sharing respect LGBTIQ+ diversity.

## **5. Trust-building initiatives**

- Collaborate with LGBTIQ+ community-controlled organisations to co-design and implement measures that address the unique concerns of these populations.
- Regularly evaluate the impact of the "sharing by default" model on healthcare access and outcomes for LGBTIQ+ people.

## **Conclusion**

The Health Legislation Amendment (Modernising My Health Record – Sharing by Default) Bill 2024 offers opportunities to enhance healthcare coordination and patient empowerment. However, to achieve these goals equitably, the concerns of marginalised populations, including LGBTIQ+ people, must be prioritised. By adopting the recommendations outlined above, the government can ensure the proposed changes promote both health equity and trust in the digital health system.

LGBTIQ+ Health Australia remains committed to supporting the implementation of inclusive healthcare policies and would welcome further consultation on this matter.