Creating safer and more useful health data systems for sexuality and gender diverse people in Australia

Project report and recommendations

2026

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Graphic summary: How can we build safer and more useful health data systems for sexuality and gender diverse people in Australia?

Aim and methods

We aimed to generate new insights for policy on health data systems and the needs and rights of sexuality and gender diverse people

We used qualitative research methods with community members and healthcare providers in NSW, Queensland and Victoria

We conducted narrative interviews with 25 key informants and 64 gender and sexuality diverse community members

We facilitated nine co-analysis workshops (49 participants)

Key findings

We found weak engagement with health data systems

Healthcare provider misunderstanding and lack of confidence with gender diversity reduces trust in health data systems

Health data systems can reduce the privacy and autonomy of people living with HIV

Community members ...

... seek queer affirmative providers to reduce risks and optimise benefits of health data systems

... see health data as their own and for the benefit of their care; they do not support uses outside of personal health care and research

... see that consent procedures for health data can be coercive and meaningless

... favour granular consent for different kinds of health information coupled with transparency and accountability on the part of other users

Recommendations

Address the blind spot in national health data policy for LGBTQA+ people

Improve clarity on who uses health data and for what purposes

Improve clarity regarding data ownership and consent

Strengthen policy on data rights, social justice and inclusion

Establish standards in data management for LGBTQA+ people

Mobilise upstream education on gender diversity and health data systems

Ensure data protection in HIV care

Examine health data system scientific and practical inflexibility

Establish transparent tracking of health data use

Establish accountability for misuse of health data

Build sector capacity to take action

Funding, researchers and advisors

This project was funded by the Australian Research Council (DP230100245).
Researchers and reference group: Ellen Sargent, Bernard Gardner, Daniel Reeders, James Gray, Mish Pony, Richard Keane, Andrew Heslop, James Hamlet and Kath Albury.

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INTRODUCTION

This report summarises the findings from sociological research on health data systems and the experiences and expectations of gender and sexuality diverse people – including lesbian, gay, bi+, transgender and gender diverse, queer and asexual people (LGBTQA+) – and their health care providers and advocates.

We wrote this report for decision-makers, practitioners and LGBTQA+ health and rights advocates to provide them with analyses and insights from the project to inform their work. We hope that the report can be placed into dialogue with key policies and research outputs used to shape healthcare for LGBTQA+ people. Our research can be read as part of the response to the recent backlash against inclusive and rights-based social progress, which aim to diminish the justice and safety of excluded groups. The insights and recommendations herein reflect the needs, views and wishes of LGBTQA+ people and their care providers, but they also illuminate social justice and ethical data practices for all those who face prejudice and discrimination. LGBTQA+ data rights serve all people and societies, and we expect that our research findings will contribute to best practice approaches to inclusion and safety in data systems beyond LGBTQA+ healthcare settings.

The project informing this report drew on key informant and community interviews combined with workshops to deepen insights on the interview findings. In the first stage of the project, key informant interviews were conducted with physicians, clinic managers, health data system designers, LGBTQA+ healthcare and rights advocates and other decision makers in Queensland, NSW and Victoria. These interviews ensured that the experiences and needs of care providers and other professionals were incorporated into the research and helped inform the community interviews and workshops.

In the second stage of the project, we conducted interviews with LGBTQA+ community members, most of whom lived in Queensland, NSW and Victoria in metropolitan, regional and rural settings. A small number of participants joined the research from the ACT, SA and Tasmania due to social networking. Participants were selected to ensure diverse genders, sexualities and ages and the intersections of those. We were able to document participant experiences of gender affirmation, HIV and sexual health care, alongside other considerations including mental health, neurodiversity, surgery, weight management, pain management, and chronic illnesses such as diabetes.

To help synthesise the interview findings and reflect on action pathways, in the third and final stage of the project we conducted workshops with national and local LGBTQA+ health advocates, physicians, decision-makers and community members. The workshops involved presenting selected interview findings to workshop participants to guide deeper discussion to reflect on policy settings and standards of practice for safer and more useful health data.

This project was funded in 2023 by the Australian Research Council and led by researchers from the School of Social Sciences at Monash University, the Centre for Social Research in Health at UNSW Sydney, and the School of Public Health at the University of Queensland. The project was assisted by a reference group comprised of individuals from national and state-based community agencies involved in LGBTQA+ healthcare advocacy, research and rights: Health Equity Matters, National Association of People with HIV Australia (NAPWHA), Scarlet Alliance, Queensland Positive People, Queensland Council for LGBTI Health, Positive Life NSW, Living Positive Victoria, ACON and Thorne Harbour Health.

CONTEXT

Summary

- Data-led medicine is growing in investment and complexity
- Australia's electronic patient record system (My Health Record) has faced implementation challenges and criticism
- LGBTQA+, gender diversity and HIV advocacy groups have expressed concern regarding the privacy protections linked with My Health Record and similar products
- National health data policy settings partially address LGBTQA+ health data needs and sustain a narrow (data access) concept of inclusion
- Mistrust of the uses of personal health data and data systems inhibits LGBTQA+ engagement
- Lack of understanding and prejudice regarding sexuality and gender diversity and related identity concerns erode trust in health data systems and therefore their administrative and scientific utility
- LGBTQA+ health data are subject to an exposure/erasure duality; they have the potential to 'expose' LGBTQA+ people to harms related to visibility and lack of privacy in unsafe health systems, but systems also often 'erase' LGBTQA+ people through lack of inclusion or recognition

Healthcare and data

Healthcare is saturated with technologies and procedures that collect and depend on health data. These include electronic health records, accounting systems used to manage healthcare businesses, computer-assisted triage, electronic notations made by providers, and technology used to transfer diagnostic results and communicate with patients.

Globally, governments and corporations are investing in the creation and expansion of health data systems and often justify these as necessary for patient safety, economic efficiency, personalised care and the discovery of knowledge. The WHO has outlined that investment in digital health will help to achieve Universal Health Coverage (World Health Organization, 2021). The European Commission has also invested in its eHealth programme as the basis for economic rationalisation and the integration of healthcare across the European region (European Commission, 2012). At the same time, the EU has rigorous data protection regulations that seek to protect European citizens, for example, mandating that data must be managed to prevent

> discriminatory effects on natural persons on the basis of racial or ethnic origin, political opinion, religion or beliefs, trade union membership, genetic or health status or sexual orientation. (European Union, 2016 paragraph 71)

To meet this standard, the EU data protection regulations prohibit third party use of personal data unless particular conditions apply, including consent and the 'vital' interests of the individual (European Union, 2016). Australia's Privacy Act 1988 also makes provision for the protection of sensitive information, including sexuality and health status (Office of the Australian Information Commissioner, n.d.).

A central feature of data-led healthcare is the publicly accessible electronic patient record. These databases capture patient and clinical information in online technology environments that allow for

forms of patient participation. *Sundhed.dk* is the Danish system established in 2003 (Mahnke, 2025). The Swedish system, *Journalen* (Hägglund & Scandurra, 2022), was established in 2012. In the UK, the National Health Service supports the *GP health record* for patients (Turner et al., 2023).

In Australia, there is a national system called My Health Record (MHR) accompanied by state-based systems (Australian Digital Health Authority, 2023b):

- Single Digital Patient Record, New South Wales
- Health Information Exchange, Victoria
- Integrated electronic Medical Record (ieMR), Queensland
- Digital Health Record, Australian Capital Territory
- Electronic Medical Record, Tasmania
- Territory Kidney Care, Northern Territory

From a healthcare user point of view, then, health data systems are considerably complex. Evaluations of health data systems have also identified significant challenges for the effective use of electronic patient records, including: the time imposed on medical practitioners (Bloom et al., 2021; Hertzum et al., 2022; Turner et al., 2023), the emergence of the unintended effects of patient access, such as confusion with medical terminology (Turner et al., 2023), and uncertainty-related anxiety (Mahnke, 2025).

Australian policy milestones

Several policy milestones in Australia help to explain the background of our research. These include policies related to the implementation and revisions of health data, national health data and health strategies and the impact of the COVID pandemic.

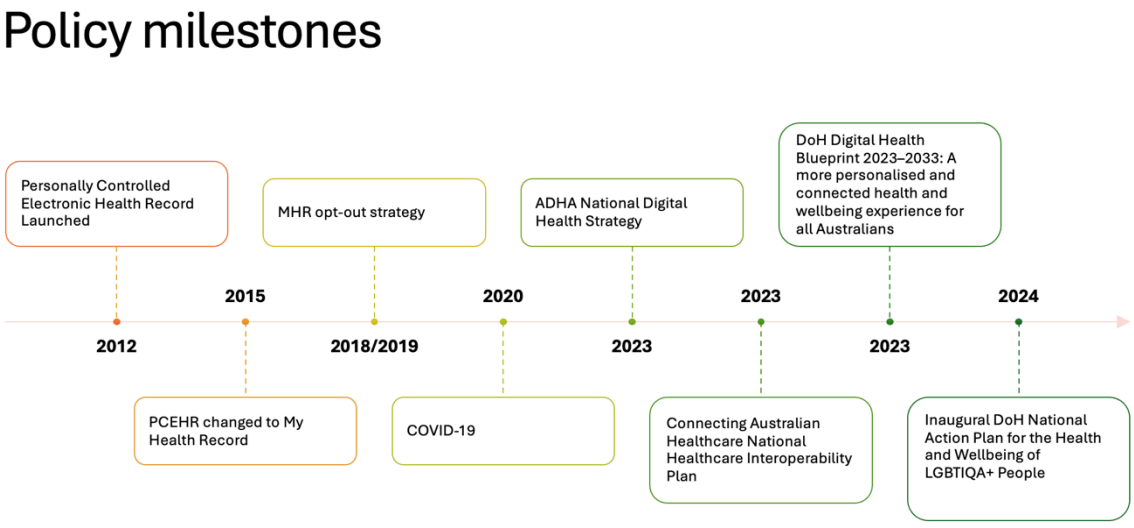


Figure 1. Policy milestones in Australia, from 2012

2012 Personally Controlled Electronic Patient Record (PCEHR)
PCEHR, Australia's initial nationwide system, was launched in 2012 with the objective of enabling patients to engage with their own healthcare (Pearce & Bainbridge, 2014). The project was justified in terms of the benefits of 'personalised care', to rationalise use of resources and improve safety.

2015 My Health Record (MHR)
MHR replaced PCEHR and captures data about diagnoses, treatments, and health outcomes, among other biomedical details. MHR is significant because it is one of the main ways in which members of the general public can engage with health data.

2018/2019 My Health Record: 'stay in' or 'opt out'
Inadequate participation in PCEHR and MHR led the Commonwealth government to institute a publicised and time limited 'opt-out' phase in 2018/2019 (Duckett, 2019; Thompson, 2018). During this period, Australian citizens were invited to opt out of MHR if they wished. Financial incentives were offered to community-based primary care clinics to encourage physician participation. The stay in or opt out approach was controversial because practical and ethical challenges remained unresolved, including risks to privacy, autonomy and public trust (Duckett, 2019; Thompson, 2018). Community advocates cautioned that sexuality and gender diverse people should consider legal advice that their MHR data may not be protected from third party uses, for example, by insurance companies, police and commercial entities (Living Positive Victoria, 2018; Scarlet Alliance, 2018).

2020 COVID-19
Public health responses to the COVID pandemic created some impetus for expanding health data systems. Telehealth, e-scripts, app-based contact tracing, for example, were employed by public health authorities to support social distancing, promote testing and diagnosis and to manage vaccination programmes. COVID is said to have accelerated the adoption of digital health technologies (Fang et al., 2022).

2023 National Digital Health Strategy (ADHA)
The first national digital health strategy addresses MHR in combination with other forms of digital healthcare (Australian Digital Health Authority, 2023b). The strategy document explains and justifies the digital health approach and makes some passing reference to the needs of sexuality and gender diverse people. The strategy is organised around four pillars: enabling citizens and health professionals to use digital health; person-centredness; inclusion; and that healthcare should be data-driven. Incorporating an inclusion pillar is encouraging for the development of LGBTQA+ affirmative data, but the strategy restricts itself to notions of inclusion as digital accessibility. This way of formulating inclusion makes it seem like it is secondary to the rollout of digital health systems rather than a founding principle for health data system design. Importantly, the management of patient consent for the use of their data is referred to the Interoperability Plan (see below).

2023 Connecting Australian Healthcare: National Healthcare Interoperability Plan (ADHA)
The interoperability plan (Australian Digital Health Authority, 2023a) complements the national strategy and explains how health data should be shared easily across all health systems to support increased efficiency and quality of care. Consent is explained as the means to ensure ethically sound access to data. Gender and HIV care are not discussed in the plan, illustrating that the management of sensitive patient information in general is only indirectly addressed in the policy.

2023 Digital Health Blueprint 2023-2033 (DoHAC)
The Commonwealth Department of Health and Aged Care (2023) Digital Health Blueprint outlines key assumptions for the strengthening of healthcare through the personalised control thought to be produced in digital health systems. The Blueprint gives emphasis to human rights and inclusion, with particular reference to these key population groups:

- Aboriginal and Torres Strait Islander people(s)
- people in remote and rural locations
- culturally or linguistically diverse groups
- LGBTIQA+ people
- people in socioeconomically disadvantaged circumstances
- those with limited access due to disability, age, skills or choice

The priority groups named in the policy document provide an important starting point for fine-grained, inclusive digital health care.

2024 National Action Plan for the Health and Wellbeing of LGBTIQA+ People (DoH)
Australia's first action plan for LGBTIQA+ people (Department of Health and Aged Care, 2024) is a policy landmark. In relation to health data, the Action Plan recommends the following:

- Improve collection, disaggregation and publication of LGBTIQA+ data across health and wellbeing datasets
- Ensure data is used routinely in policy and planning activities
- Promote and facilitate research that builds the evidence base and addresses knowledge gaps

The national digital health policies discussed above make some, often cursory, reference to the needs of sexuality and gender diverse people. The National Action Plan for the Health and Wellbeing of LGBTQIA+ People acknowledges the importance of digital data for healthcare. However, national digital health policy and LGBTQIA+ health policy need to be linked more explicitly to provide guidance for the creation of safer, more useful and equitable health data for sexuality and gender diverse people.

Commercial health data

Private enterprise is a powerful driver of health data. Commercial interest in health data is strong and numerous biometric technologies are available for consumers (Lupton, 2018). General practice clinics use patient record systems supplied and managed by corporations, which may store data offshore. Consumers regularly use apps to book their consultations and subscription based personal health records are available outside of government systems (see for example, MyIHR.com).

Effective policy and communications regarding health data will need to acknowledge the importance of commercial systems and the complexities that arise when these are combined by patients with national and state-based systems.

Queer affirmative health data

An important background theme for this project is the scholarship on what can be termed 'queer affirmative' health data. In the following, we highlight key themes in this scholarship and their implications.

Queer data

Kevin Guyan's book, *Queer data* (2022), is an important resource for researchers and policymakers building and using health data systems. Guyan posed the book as an account of his work in diversity, equity and inclusion (DEI) for the university sector in Scotland and more broadly, as a framework for addressing the ethical and epistemological assumptions and blind spots that can limit the quality and use of knowledge about LGBTQA+ lives. Guyan argues that partial or uncritical collection of data about the lives of sexuality and gender diverse people can lead to problematic and antagonistic assumptions (Guyan, 2022). Collecting data that does not benefit LGBTQA+ people or simply to enhance the public image of institutions is potentially abusive. Unless data is used to hold decision-makers to account for their actions, it may do very little to enhance the lives of LGBTQA+ people.

Epistemic injustice

The conceptual framework of epistemic justice (Fricker & Jenkins, 2017) is also useful for developing perspectives on LGBTQA+ health data systems. This framework melds perspectives on social exclusion and prejudice with reflection on the knowledge generation practices used in research and policy. Data may expose LGBTQA+ people to ways of knowing about their lives that sustain prejudice and therefore further ignorance about lived experience. In addition, silencing patients through prejudice or failure on the part of health services to accept patient testimony with regard to their health data can also lead to harmful ignorance. Moreover, some exposures may also constitute erasures, for example, when disclosure of sexuality or gender identity leads interlocutors to make inaccurate assumptions and/or ignore nuances that matter to the discloser. For example, trans people may find that medical practitioners misunderstand their gender affirmation needs (Fricker and Jenkins 2017) because medicalised language of gender and identity excludes – or worse, discredits – lived experience.

Trust in Digital Health: UNSW survey and key informant interviews

In 2020, researchers at the Centre for Health Social Research published a report from the Trust in Digital Health study (Holt et al., 2023; Newman et al., 2020) comprising surveys with the general population and members of priority populations nominated in national blood borne viruses and STIs strategy – people with HIV, trans and gender diverse people, sex workers, and gay and bisexual men – along with key informant interviews representing these priority populations, to document knowledge and practices regarding MHR and related digital health systems. Priority populations were more likely to have opted out of MHR and less likely to share personal information with healthcare providers, compared with the general population. Among their recommendations, the report authors advocate for,

> "…significant reforms in system design, in community consultation processes, and in the policy and legal contexts that shape the everyday lives, rights and wellbeing of these communities" (page 1).

Analysis of the key informant interviews with found that the benefits of MHR were anticipatory, while the potential harms were viewed as concrete and tangible (Smith et al., 2023). The analysis emphasised that community consultation regarding MHR with marginalised communities had not been undertaken and that there were concerns about privacy and consent regarding digital health data. The authors therefore recommended community consultation and meaningful involvement of priority populations was needed to improve data system design, thereby promoting trust in and the use of health data technologies.

Prejudice and stigma influence sharing personal information in healthcare

Prejudice linked with sexuality and gender diversity constrains willingness to share personal information with healthcare providers, with implications for health data. For example, a scoping review of qualitative research on transgender and male sex workers (Brookfield et al., 2020) reported that experienced or felt prejudice led transgender and male sex workers to be selective about what they shared with whom in clinical contexts. In another study, lesbian women nominated the hetero-norms exhibited by practitioners as a reason to avoid disclosures (LaVaccare et al., 2018). One in three transgender people in the US reported negative experiences in healthcare (Kronk et al., 2022). A survey of MSM in Aotearoa/New Zealand found that while a majority (63.1%) were comfortable with reporting their sexual orientation in the national census, a sizeable minority remained cautious. Practitioners providing care for people living with HIV and hepatitis C (Lenton et al., 2025) reported that the medical record systems that they used in their everyday clinical practices mobilised social and medical stigma. As these researchers detailed, notes made by one practitioner can be uncritically repeated by others in the patient's records. Reductive coding schemes wedge patients into pigeon-holes that medicalise their identities. For example, use of the term "HIV patient" in a patient record identifies them in terms of their HIV diagnosis and minimises personhood.

Loss of privacy in tension with the need for visibility

For gender and sexuality diverse people, health data systems come with the dual problem of privacy and visibility. Sharing sensitive information may expose LGBTQA+ people to loss of privacy, prejudice from healthcare workers and employers, and scrutiny by police and insurance companies. In parallel, however, hetero-norms, and transphobia in health data may erase the lives of LGBTQA+ people and exclude them from the possible benefits of participating in health data systems (Guyan, 2022).

Some researchers and advocates argue that sexuality and gender identity information must be collected to properly serve LGBTQA+ communities (Grasso et al., 2019; Lau et al., 2020; Saxby & Hammoud, 2025; Streed et al., 2020; Waite & Denier, 2019; Westbrook et al., 2022). Yet, uncritical collection of personal data can expose LGBTQA+ people to abuse. In South Korea during the COVID-19 pandemic, geospatial contact tracing apps made it possible to track attendance at LGBTQA+ venues, outing LGBTQA+ people in ways they seek to avoid (Guyan, 2022). This tension between the rights of LGBTQA+ people to be free from discrimination but also to have optimum healthcare is a central theme for this project.

AIM AND RESEARCH QUESTIONS

This project aimed to develop sociological insights into the safety and utility of digital health data for sexuality and gender diverse people by addressing the following research questions:

> *What social, cultural, identity, trust and medical factors influence participation in digital health data systems?*
>
> *What do personal experience narratives reveal about the safety and utility of digital health data systems for sexuality and gender diverse people?*
>
> *What strategies do individuals employ to address the benefits and drawbacks of digital health data?*
>
> *How could digital health data systems be enhanced to better serve and protect sexuality and gender diverse people?*

METHODS

This report summarises findings from qualitative, sociological research consisting of interviews and co-research workshops with key informants and LGBTQA+ community members in Queensland, NSW and Victoria. The interviews generated personal experience narratives on health data systems to enable us to address our research questions. The workshops were used to advance the analysis of interview narratives with the assistance of key informants and community members. Data collection was conducted between 20 December 2023 and 19 March 2026.

Samples and recruitment

We used purposive criteria to select key informants and community members for interviews.

Key informant interviews

We developed a list of relevant community organisations, gender, HIV and sexual health care services, physicians, clinic managers, policy makers and other decision makers, from Queensland, NSW and Victoria. With input from the project's reference group, we established a master list of N=73 agencies and individuals, who were all approached; n=25 agreed to an interview. Key informants expressed a high degree of expertise and engagement with health data and its implications for LGBTQA+ people. We note that it is likely that individuals not interested in LGBTQA+ healthcare did not contribute.

The interviews were conducted via Zoom using a conversational and iterative method. Interviewees were asked to reflect on: the health data technologies used in their work, including patient records such as MHR; how disclosure of sensitive patient information is managed; the importance of personal data for healthcare; and trust in health data and related issues.

Community interviews

To recruit interviewees, we blended purposive selection criteria and maximum variation, that is, diverse genders, sexualities and ages in metropolitan, regional and rural parts of Queensland, NSW and Victoria. We also sought out participants who used health services, including for gender affirmation, HIV treatment and sexual health care. We used social networking, news and social media, and assistance from health agencies to recruit participants (see recruitment materials below). During recruitment we

used a short Qualtrics questionnaire to help us select participants and minimise risks of 'fraudulent' participants (Drysdale et al., 2023). We interviewed 64 participants from Queensland (n= 23), NSW (n= 23), Victoria (n= 13) and other states and territories (n = 5). Of these, 27/64 resided outside the metropolitan areas. Interviewees were offered a gift card ($50) as compensation for their time.

We were able to recruit across the age range from 18 years and up (see Table 1). This wide distribution helped us to explore ageing related engagements with health systems. During interviews, we asked participants to provide their gender and sexual identities, as summarised in Table 1 (Note that some opted for more than one gender identity).

Table 1. Community interviewee age groups, gender and sexual identities

Age group	18-29 years	30-39 years	40-49 years	50-59 years	60-69 years	70+ years
Number of interviewees	17	15	12	9	5	6

Gender identity	Non binary	Gender non conforming	Agender	Gender queer	Trans woman	Trans femme	Trans man	Trans masc	Cis woman	Cis man
Number of interviewees	12	2	2	4	2	3	3	1	11	27

Sexual identity	Lesbian	Gay	Bisexual+	Asexual	Queer+
Number of interviewees	7	21	15	3	12

Interviewees described diverse engagements with LGBTQA+ communities and networks, intersected by age/generation, location of residence and time in Australia. For example, metropolitan interviewees accessed queer affirmative healthcare services wherein disclosure of sexuality was mostly not an issue. Many regional and rural interviewees provided stories of strategic disclosures or avoidance of some services and social settings due to lack of safety or allyship.

The participant group also reported a wide range of experiences of health care systems. In particular, 14/64 interviewees referred to seeking and/or having undertaken gender affirmation care with related implications for trust in health data and medicine more generally. In relation to HIV, 18/64 interviewees discussed their HIV treatment and 4/64 referred to accessing PrEP. Many of our interviewees (n= 48/64) spoke of chronic conditions that required them to interact with health systems, including: mental health care; support for neurodiversity; pain management; weight management; diabetes; and immune-related conditions. The interviewees were predominantly Australian born (51/64) and tertiary educated (35/64 held a bachelor's degree or higher).

In the Zoom and in person exploratory interviews, participants were asked to

- describe their health status and engagement with health data technologies, including MHR
- discuss the MHR opt out period, if they recalled it
- discuss their expectations of service providers when they disclosed sensitive information
- reflect on their strategies for sharing information and having data recorded

- discuss what health data was used for and how it should be managed
- reflect on trust and circumstances when it worked and when it failed, including in relation to health records
- describe experienced or felt prejudice in healthcare, if relevant

Where appropriate and because the interviews were mostly online, we asked interviews to 'walk through' a health data app they used. Most commonly, MHR was opened and discussed. Notably, many interviewees reported that they had not opened MHR prior to the interview, or had not opened it recently.

Workshops on findings and action pathways
The workshops involved selecting specialist topics or populations to enable collaborative discussion, and to deepen insights by presenting workshop participants with quotations from key informant and community interviews. Workshop participants and topics were selected in response to our analysis of the key informant and community interviews. We presented community interview fragments in the workshops to stimulate the discussions.

We approached key informants and community agencies to access participants. Nine in person or Zoom workshops were conducted with 49 participants in: Victoria (gender care providers and advocates; HIV care providers and advocates; decision-makers including managers and CEOs); New South Wales (NSW) (members of Rainbow Families x 2, gender diverse people); Queensland (sex workers x 2, people living in rural and regional communities). Workshop participants were offered a gift card ($100) for their time commitment.

Workshop topics included generic themes and related interview materials combined with themes and materials matched to the composition of the workshop participants. The workshop specific questions were designed locally in Queensland, NSW and Victoria to draw out themes relevant for the workshop participants. The generic and specific topics and questions can be found in Table 2 and 3, respectively.

Ethics
The interview and workshop participants provided written informed consent as approved by the research ethics committees at Monash (ID: 38644, 12 July 2023), ACON (26 September 2023) and Thorne Harbour Health (12 October 2023).

Analysis
Interviews and workshop voice files were transcribed verbatim and inputted into NVivo to organise data for thematic analysis. Workshop Padlet files and summaries were also downloaded and included in the coding and analysis. To establish themes, sub-samples of interview and workshop transcripts and downloads were independently coded by members of the research team. These codes were then combined and applied to the remaining materials, using constant comparison and refutational logic to deepen and nuance the themes. In addition, mini-life history narratives were prepared for all the community interviews.

Table 2. Workshop generic topics and questions

Generic topic name (NSW, VIC, QLD)	Generic topic explanation	Topic question(s)
Engagement	Most community interviewees reported low engagement with health data and were not clear about their purpose. We asked workshop participants if engagement should be promoted and if so how.	*Is it important to promote engagement with health data? How could it be done?*
Personal control	Community interviewees reported that they preferred to have personal control over the use of their data, transparency regarding who used it and to be able to edit data. However, the policy and clinical justification for health data collection and use was often said to be tied to the accuracy and indelibility of data. We asked participants to discuss the tension between personal control and assumptions about data integrity.	*What is your view on health data ownership and the potential for missing data?*
Exposure/erasure	Health data systems present a dilemma for sexuality and gender diverse people living with heteronormative biases and blind spots. Shared data can expose people to prejudice and data systems can also be constructed in ways to exclude and erase sexuality and gender diversity. We asked workshop participants for their views on how to manage this dilemma.	*How can we navigate this tension so that health data are safe and useful for LGBTQA+ people?*
Synthesising questions	To complete the workshop, we posed a provocation by asking participants to discuss the fundamental question of the purpose of health data and whose needs are met by them. We also asked participants to identify methods of promoting safer and more useful health data, if appropriate.	*In your own view, what is the purpose of health data, like MHR?* *How can these systems better serve LGBTQA+ people?*

Table 3. Workshop specific topics and questions.

Workshop specific topic name	Workshop specific topic explanation	Topic question(s)
Gender care (VIC)	Misunderstanding and lack of confidence with gender diversity and data was a prominent theme. We asked gender care providers and advocates to consider how gender awareness and skills could be addressed.	*What are your views on misgendering and how it could be addressed?*
HIV care (VIC)	People living with HIV indicated that sometimes the privacy of their personal information compromised their care and trust. We asked HIV care providers and advocates how data systems could be strengthened to promote privacy.	*How could data privacy issues be addressed for people living with HIV?*
Decision makers (VIC)	In our workshop with decision makers and managers we explored health data management to consider possible solution pathways.	*What are your responses to these challenges for health data management?*
Sex work (Queensland)	We conducted online and in person workshops with people in the sex work industry and health advocates. We therefore posed sex work specific questions to better understand experience of sharing personal information and related issues of safety and trust.	*When and how do you want your sex working status recorded? In what context do you want that information shared with other health providers?* *What strategies do you use to keep yourself safe in the digital health space? Are any of these informed by or related to sex work?*
Rural and regional (QLD)	Queensland has sizable regional and remote communities spread over a large geographic area. For this reason, we conducted a workshop with LGBTQA+ community members to explore the interview materials and deepen knowledge and understanding of LGBTQA+ healthcare and data needs outside metropolitan settings.	***We found that many of our participants described the particular context of regional/ rural localities when describing their healthcare and using digital health. Have a look at these quotes. Do they speak to your experiences? Is there anything else around the regional/ rural context that is missing? Thinking about your regional/ rural context:*** • ***What do you think of the online digital healthcare space?*** • ***How do you navigate finding and using online digital healthcare providers?*** • ***What does good online digital healthcare look like for you?***
Parenting (NSW)	LGBTQ+ parents indicated that procreation and parenting intersected with health data systems. We therefore held an online and in person workshops to explore these issues in more depth. The questions asked for experiential narratives on navigating health data systems for themselves and their children and how this could be strengthened.	*How are your personal views on health data influenced by your role as a parent or caregiver?* *What hopes and fears do you have, as a parent or caregiver, for the way that your children interact with health data now and into the future?*
Gender diversity (NSW)	In NSW, we conducted a workshop with trans and gender diverse people to explore health data issues. This workshop considered what we had learned from interviews and analysis, while also supporting reflection on whether developments in other countries were impacting local views and decisions.	*Are changes in global politics influencing your thinking and decisions about the security of your own health data in Australia now?*

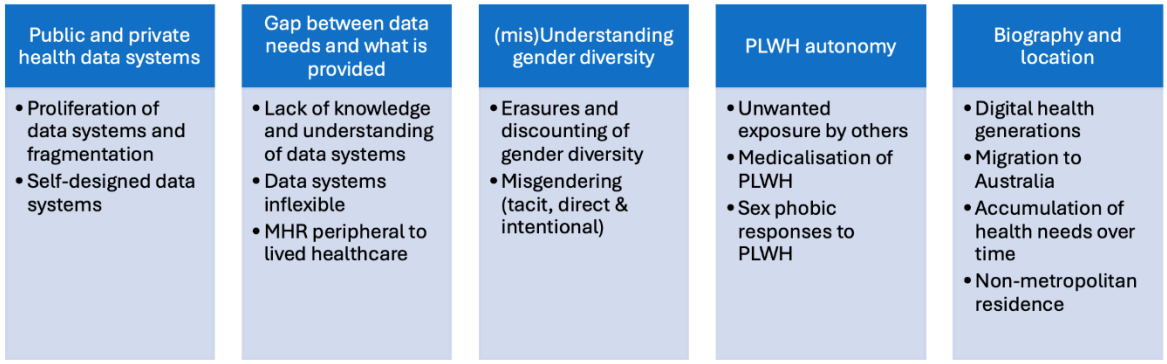
FINDINGS

What social, cultural, identity, trust and medical factors influence participation in digital health data systems?

Summary

- Community members generally lack understanding of health data operation and how their data are used
- Community members were mainly disengaged from MHR
- Inflexible, absent and misused gender codes erode trust and decrease engagement
- HIV codes in data systems can trigger homo-, sex- and disease-phobia in the wrong contexts
- LGBTQA+ community engagements with, and trust in, health data complexly intersect with age, generation, migration history and metropolitan/regional/rural residence

Themes



Public and private health data

Many community interviewees reported that they had used a great variety of digital health technologies. We counted over 30 brand names and types mentioned across the study data including: booking and communication systems; information recording systems apart from MHR; and biometric trackers. Some reported specific uses of private, fee-for-service systems that recorded information about neurological conditions in case of an emergency, for example, if they were unconscious and unable to communicate with paramedics and police. Others used biometric devices to monitor menstruation and blood sugar, for example. We also collected stories from individuals who gave up using these technologies due to lack of interest, unclear benefit and anxiety related to constant prompts from apps. We also noted that some interviewees had very limited or no engagements with any digital health technologies.

These complexities raise several issues about the use of digital health systems: individuals combine use of public and private health data systems; use changes over time; not everyone is enthusiastic and skilled; and enthusiasm wanes overtime. Inclusive policy needs to focus on more than simply whether an individual accesses digital healthcare. Effective and inclusive policy settings need to acknowledge the private-public mix and how individuals assemble their own blend of health data systems that change overtime.

Gap between data needs and what is provided

A prominent theme in health data narratives was a mismatch between what community members and their care providers wanted and needed and what health data systems were able to provide. There were several elements to this mismatch: a lack of understanding on the part of community members; friction in clinical settings produced by data; and the time and resource costs of these systems. MHR often figured in these narratives. Importantly, most interviewees reported limited use of MHR. During interviews some participants attempted to open MHR online. In these situations, some interviewees found that they could not access MHR, had opened Medicare instead, or reported that this was the first time they had looked at the portal and were surprised to see what was uploaded and what was missing.

Many community interviewees reported that they did not know what health data systems were used for. They were unable to explain health data in any detail and created somewhat generalised accounts in interviews. Prompted by discussion with us, many surmised that health data systems were used to manage personal care and research:

> Interviewer: Do you trust health data systems?
> Comm 24: I guess part of what's gonna make that difficult to answer is, clearly, I don't really know what health data systems are. Let's just be honest about that. But I have a sense that there's data moving around that is identifiable and that is hopefully used for me. And then there's other data moving around that's hopefully used for the good of me and my community in general or whatever. (Comm 24, NSW rural/regional, 50-59 years, cis woman, lesbian, chronic illness)

Interviewees were also unclear about the benefits of participating in health data systems. Some interviewees suggested that they were useful as a memory aid for their healthcare experiences and hoped that the systems would benefit their own care. One interviewee recalled that two hospitals shared their data when they were transferred to undergo a major surgery, although the informant did not witness the records themselves.

Key informants working in clinical settings endorsed health data systems such as MHR in principle but found that they were generally not useful. The time cost produced by health data was noted by our informants in line with previous research (Bloom et al., 2021; Hertzum et al., 2022; Turner et al., 2023). Healthcare providers shared accounts which highlighted the mismatch between patient lives and health data systems.

> … I find anyone who comes to see me for gender-affirming, hormone care, who also wants to transition hormonally, [are] so educated. Like, so educated around their own health and what's going on, so they're wanting to use these services. And then they come up against [inflexible data]. A lot of them will decide not to use the health record because it doesn't fit their needs. So that does mean that you can sometimes get fragmentation of care when I think, in another world, they would use the health record because these are people who I find are so self-empowered, in some ways. (KI04)

We asked community interviewees if they recalled the MHR 'opt out' period in 2018/2019 and how they responded. Responses varied from 'no' and vague recall to more definite memories. Participant

stories were also recorded of those who were too young in 2018/2019 or not in the country. Reasons provided for opting out included living with HIV and fear of exposure, because their GP advised them to, and privacy concerns. Community interviewee 62 provides an opt-out narrative and signals that this position has weakened into resigned acceptance:

> Comm 62: When the My Health Record program came out, there was a lot of discussion about privacy and stuff like that. And like I've been a regular attendee down at [HIV support service] and, because of my HIV status and stuff, I wasn't really happy to have that information going onto My Health program. I even spoke to my GP and he said he wasn't going onto My Health Record. I really got influenced a lot by the people at [HIV support services] so I just thought, "Look, I've kept this private."
> [later]
> Interviewer: So, did you opt out of My Health Record?
> Comm 62: I did, yep. I'm at an age now where I'm starting to think it really doesn't matter and they might as well know. Like the government knows everything about me anyway. [Laughs] (Comm 62, VIC metro, 70+ years, he/him, bisexual, chronic illness, PLWH)

For those who recalled they did not opt-out of MHR, reasons included, managing complex health conditions, gender affirmation care, and not having considered opting out. In this fragment, the interviewee explains that they saw benefits in staying in MHR:

> I very consciously opted to have all of my stuff uploaded on there … I mean I don't think it kind of came into my scope until maybe 2019, 2020, when it was like starting to be more available, I think, once it had really properly entered the public domain. But, by that point, I was having a lot of health issues and so I was seeing a GP and a few different people at the hospital. So, I was like, "It's probably easier for them to all be uploading everything on there." (Comm 25, NSW outside metro, 18-29 years, cis man, queer, chronic illness)

Key informant narratives on MHR underlined the mismatch between its potential and their experience:

> I use it [MHR] very little. I don't have any overall objection to it, the concept was good, the execution's been abysmal because it's so unfriendly and ungainly to use. I was on a committee once, years ago, that had some kind of contribution to the setting-up of this. And what I was told is that the reason the format is so abysmal is that this was the sort of lowest common denominator between all of the different softwares that were gonna have to talk to each other. (KI07)

Health data systems, and most particularly MHR, do not appear to align with the specific ways in which lives are lived or clinical practices engaged with. Increasing knowledge and understanding of digital health among the general public is unlikely to be effective if it is not useful for healthcare users or healthcare providers. This seems especially the case for MHR.

Understanding gender diversity

These mismatch issues flowed into the context of gender affirming care, where they intersected with lack of understanding on the part of the health system as a whole. Interviewees described experiences

of asserting their identities but finding that this was not always supported. In this example, Comm 29 relates a story of a consultation where information about gender identity was ignored:

> … the curtain was pulled back, three other physios came in and then the physio who was seeing me sort of started talking about me and using she/her pronouns repetitively. And I kind of said after that encounter, 'cause I didn't wanna do it in front of the other physios 'cause I feel like I'd rather call people in and have a private chat rather than … 'Cause I feel like that's when the most kind of people tend to be most open to educational moments. And that's how I really like when people call me in or like have a private chat. But, you know, whatever mode they wanna use. But, and then I basically said to that physio, "Oh, yeah, I'm just letting you know I'm a non-binary person. I use they/them pronouns." And the physio said, "Yeah, I saw that you were non-binary on the form." And so I think when you do give that data to people, doctors don't actually do anything about it. (Comm 29, NSW metro, 30-39 years, non binary, bisexual, no disclosed illness)

As in this example, many non-binary and trans interviewees were disappointed and frustrated by their encounters with health professionals in relation to the use of stated gender markers and a general lack of regard for the specificity and the security of their health data. For these reasons, to the extent that they were able, interviewees sought out experienced, trustworthy services and providers to minimise problems.

HIV autonomy

Another prominent theme was the management of HIV serostatus data. Similar to non-binary and trans interviewees, people living with HIV reported that they selected services and providers who could be trusted for their expertise and affirmative practice. Outside of these settings, however, problems arose. For example, in this interview fragment, Comm 60 narrates a clumsy intervention from a provider:

> Comm 60: I used to have all of my GP stuff go through the HIV clinic but if I just needed a quick script, I'd go to the place around the corner. And one doctor had said one day, "I hope you're wearing condoms." I said, "Absolutely not. I'm absolutely not doing that." And she goes, "Well, you need to have safe sex." And I said, "Yeah, well, I am in my own way. I take my medication and that's having safe sex, so you need to educate yourself." And that was like conversation that would have happened like 10 years ago versus, yeah, a conversation which like you wouldn't really have with someone at the HIV clinic these days …
> Int: So, how did that come up in the conversation?
> Comm 60: I think, she'd just seen it on the system and just mentioned it matter-of-factly. (Comm 60, VIC metro, 40-49 years, cis man, gay, chronic illness, PLWH)

This story highlights how a health data system triggered a discriminatory response from a healthcare provider. It illustrates a form of data-led medicalisation combined with a crude application of public health assumptions and lack of understanding regarding sexual practices and HIV prevention. We see this as just one example of how easily personal health data (in this case, HIV status) can be circulated, misinterpreted and misapplied in paternalistic ways.

Biography and location

Health data engagements were shaped by features of life history that included generation, residence and migration to Australia. The qualitative interviews suggested generational differences regarding these engagements. For example, some interviewees were teenagers during the 2018/2019 MHR opt out period and had no recollection of the LGBTQA+ community debate about health data privacy and misuse. Interviewees living in rural and regional areas reported caution with regard to the disclosure of potentially compromising health data due to the interconnected social networks in small communities. Informants newly arrived in Australia commented that it took some time to navigate the health system and understand their rights with regard to health data. For some, a deep lack of trust of governments in other countries coloured their experiences in Australia. Others focussed on the strategic management of personal information to optimise eligibility for residency status.

What do personal experience narratives reveal about the safety and utility of digital health data systems for sexuality and gender diverse people?

Summary

- Community members adopt and combine different risk approaches to the safety and dangers of health data
- Risk fatalism may contribute to lack of engagement
- Health data systems are primarily viewed as providing a personal benefit for healthcare and valuable for research and evaluation of health services
- Community members reject commercial and police use of health data
- Common consent mechanisms used in health data are recognised as somewhat meaningless and coercive

Themes

Community interviewees adopted a variety of positions regarding the safety and utility of participating in health data systems. Some adopted the view that health data afforded them and their communities no or minimal risks. Others considered health data to never be safe, whilst others provided fatalist narratives that assumed that risks could not be prevented. These positions on health data risks should not be interpreted as an evaluation of community perception of health data system risk; our sample is opportunistic and methods are qualitative and therefore do not allow for inferences about all LGBTQA+ people. Policy and communications will need to address each of these positions to strive for trust in the safety and utility of health data.

A key theme in the interviews was a tension between beneficial, altruistic uses of health data for LGBTQA+ communities and commercial and other forms of exploitation of health data. Most commonly, interviewees endorsed third party uses for their own health and for LGBTQA+ people, but not by private enterprise.

The interviewees also discussed consent for third party uses of their data, which is an important element of national policy in Australia (Smith et al., 2023). Consent was seen as valuable for asserting some control over risks, but it was also compromised due to lack of understanding of how health data could be used by third parties or when consent was forced onto people in some circumstances.

No or minimal risk

Comm 08 provided an example on the minor risks posed by health data:

> I mean I don't love the idea of [my health data being shareable]. And that's my instinct but then I have to think about what actual, malicious uses of this data are there. And I can't think of anything too terrible, so I'm not like overly concerned. I would still rather that they didn't do that [share data with third parties] but like I'm not like concerned for my immediate safety about it. (Comm 08, NSW metro, 18-29 years, gender queer, bisexual, chronic illness)

"Not overly concerned" was a common theme in no/low risk narratives on third party uses.

Risk aversion

In contrast, Comm 38 made reference to harms related to sensitive information:

> I think there's like it's a really big pros and cons list of it can both be really helpful to be able to see your own health history and have that like online data if you need it and if like, you know, if someone has to call an ambulance, being able to see your health thing, like allergies and whatever. But also there is still the possibility of that information being leaked and sold, and tracked, and whatever on-line. And there's always like dodgy people that want information for whatever, and the same reason. And particularly from like a queer and maybe more specifically trans standpoint of the possibility of that information being leaked is possibly dangerous; particularly, if it has personal identifiers on it. (Comm 38, QLD rural/regional, 18-29 years, non binary, asexual, chronic illness)

Comm 38 noted that sharing health data could be helpful in emergency settings, but that without protections, health data risks could also proliferate.

Risk fatalism

This tension between the benefits of health data and its risks led some to adopt the fatalistic view that harms cannot be resisted:

> I've never been concerned about third-party marketeers having my information; generally, because if you're on the internet in any form they have that information already. I obviously do not want the government giving my information to third parties — specifically, like, you know, marketing firms and selling off, you know, our data in those ways — but I'm of the belief they sort of already have it. It wouldn't stop me using the services. It's a weird line to draw but I'm sort of realistic of the fact, you know, I'm on Facebook. I'm on everything like that. They've already got everything. (Comm 42, QLD rural/regional, 18-29 years, cis woman, bisexual, chronic illness)

Other interviewees modified and nuanced these differing risk positions. There is, therefore, no evidence for a single approach to risk or simplistic no risk/risk split. Rather, interviewees crafted approaches that fitted their own circumstances, previous experiences and expectations.

Third party uses

Use of health data for personal clinical care was accepted as was its use by third parties for medical research and the evaluation of health systems. Commercial, insurance and police use of data were ruled out by our interviewees, though some adopted the fatalist view that assumed that the information was already in circulation. Importantly, some interviewees responded to the third-party use question by

expressing lack of understanding, underlining, therefore, the more general sense in which health data do not much intersect with lived experience. This comment from Comm 31's interview captures the resigned acceptance that third party uses of health data are inevitable:

> Interviewer: And your sort of thoughts on any third-party use?
> Comm 31: It happens and there's really not a lot you can do about it, so … yeah.
> Interviewer: And any thoughts on how or what could be done to make digital health technologies safer?
> Comm 31: I think it's as safe as it can be. Unfortunately, the hackers out there are just getting smarter and smarter each time, so … So, yeah, I think it's as safe as it can be. Unfortunately, you've just gotta take into account the dishonest people in the world that think they can make money out of it. (Comm 31, QLD rural/regional, 50-59 years, cis man, gay, chronic illness, PLWH)

(un)Consent

We use the term (un)consent to draw attention to the partial or forced quality of interviewee narratives on the value of informed consent for third party uses of their data. Consent was seen as a means to safeguard data and assert control over further use. However, consent was questioned because interviewees did not have oversight of how their data could be used in the future. Consent was constrained in the sense that to withhold it could jeopardise access to technology and, by extension, services. Comm 57 explained how they managed the constraints of consent and possible misuse of personal information:

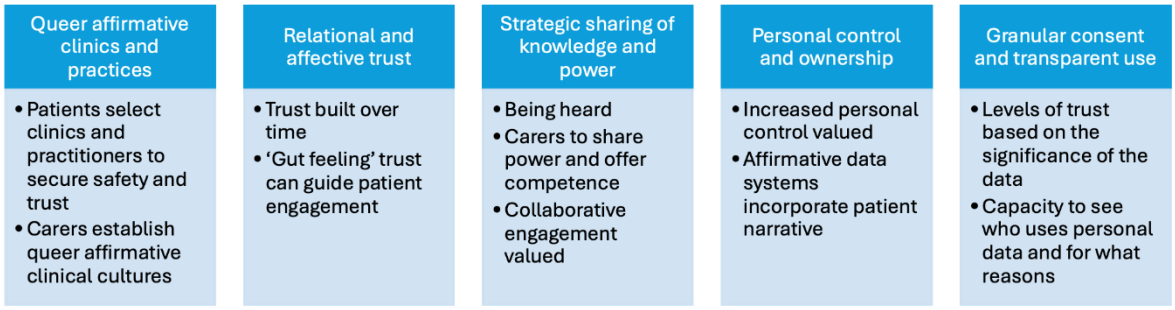
> I mean one of these things that's becoming increasingly apparent is, yes, there's all these privacy statements and what have you around technology but, at the end of the day, if you don't accept, you don't have access, right? And, if you choose not to opt into your Samsung phone's way of working, then you don't have a phone that's functional. Same with iPhone. It's the same with my Samsung watch and all that sort of stuff. So, you have to make concessions and I would have to say, honestly, I don't fully understand what my data's being used for, what's being collected and why. I can only speculate that it's for marketing purposes, it's for X, Y and Z. I always take the view, and I don't know whether it's the right way or the wrong way to do it but I always try and use pseudonyms, different date of births, different email accounts and all that sort of stuff to try and minimise the trackability of my data. But I'm sure there's ways that they get around that. (Comm 57, QLD metro, 40-49 years, cis man, gay, chronic illness, PLWH)

What strategies do individuals employ to address the benefits and drawbacks of digital health data?

Summary

- LGBTQA+ affirmative health care and gender and HIV sensitive services help community members to optimise the benefits and moderate the harms of health data
- Trust in healthcare and data has a pronounced affective quality traced into social cues and 'feelings'
- Collaboration and power sharing recognised as the ideal framework for the collection and application of useful health data
- Community members see that they own their health data and benefits their personal healthcare
- Data ownership flows into a granular, tiered approach to consent and transparency with regard to the other users of the individual's health data

Themes



Interviewees provided extensive examples of the ways in which health data could be managed to benefit them and to reduce drawbacks. Choosing LGBTQA+ affirmative clinics and providers reduced the risks of misgendering, exposure of HIV serostatus and inappropriate disclosure of other sensitive attributes of identity and healthcare. Sharing personal information was enacted carefully and gradually to ensure that providers were LGBTQA+ affirmative. Trust was not limited to reasoned action as affective 'gut feeling' linked to social cues and continuity were also important for interviewees. Granular consent for access to personal data was favoured alongside transparency about the use of personal data by others.

LGBTQA+ affirmative clinics and practices

LGBTQA+ community-led and affirmative primary care services and gender, HIV and sexual health clinics exist in Australian capital cities and regional settings. Health and gender care advocacy agencies and informal networks provide advice for LGBTQA+ people seeking services. Interviewees reported that they made extensive use of these services and that they valued them. As indicated in this interview fragment, LGBTQA+ oriented healthcare settings were seen to possess the needed skills for effective and safe management of personal data:

> Interviewer: Is there any sense in which you feel your data or information about you or your sexuality, whatever, is safer at [name of clinic]?
> Comm 01: Well, that's a good question and perhaps, subliminally, I do feel it's safer. But, actually, perhaps not so much safer as in, you know, things might get out. But, rather, I think

> it's more … it's used more fruitful in assessment and diagnosis, in just seeing what's going on. I think that kind of the nuance of LGBTI healthcare needs in individuals is perhaps better understood by a practice that has a focus on it. Whereas, when you're in a revolving door of the CBD GP, it's like 'tick the box' as part of the assessment process. (Comm 01, VIC metro, 50-59 years, cis man, gay, PrEP)

It is likely that access to LGBTQA+ affirmative healthcare services helps LGBTQA+ community members to mitigate prejudice and secure trusting relationships, both of which are important for the safe and useful management of health data. Indeed, narrative on negative experiences was linked with encounters outside of LGBTQA+ affirmative healthcare, for example, in hospitals and with consultants.

Relational and affective trust

Interviewees noted that trust in health was interpersonal and affective. For this reason, health data were managed to minimise disruption of trust relations. Significantly, trust was holistic in the sense that it included a sense of security under conditions of uncertainty with regard to health and gender care, as Comm 29 made clear:

> Yeah. I think kind of like the embodied feeling of trust for me would be, like a positive experience would be my current clinical psychologist. So, he actually has experience with supporting gender-diverse people, trans and gender-diverse people with gender-affirmation stuff, and the trust was built, I think, to get to that point where I could sit there and feel relaxed and sort of ease into the chair rather than sitting up straight and being nervous, for instance, which would be one embodied manifestation of lack of trust for me. The way that he sort of built up that trust was I sort of saw on their website they indicate pronouns and that kind of thing. (Comm 29, NSW metro, 30-39 years, non binary, bisexual, no disclosed illness)

Strategic sharing of knowledge and power

Interviewees provided nuanced examples of how they shared sensitive information. There was no sense of a universal approach that worked across settings. In contrast, interviewees spoke of sharing personal information according to their assessment of the clinic, the provider and other social factors. They also recognised that sharing information was a relation of power in the sense that sharing too much with the wrong person could reduce their autonomy and compromise their rights. As Comm 47 explained, collaboration is the quality of effective healthcare:

> I mean I kind of have as a baseline, I'm already a pretty open … And especially like this clinic is pretty good, so I knew the likelihood was that he was gonna be fairly good. But, also, I think a huge part of it was that he was willing to treat me. And I think I told him that this is what I would demand, "This is what I demand and, if you can't do it, I will find someone else." It was like, "I expect to be treated as a collaborative partner in my healthcare and as an expert." Like, "You do not know more than me about my life and my existence and my health. You can help me and I expect for this relationship to be like collaborative, not, you know, you are not the expert in me." (Comm 47, QLD metro, 18-29 years, non binary & trans femme, bisexual, chronic illness)

Personal control and data ownership

Personal control over access to health data was a prominent interviewee theme. For example, Comm 59 explains how health data could seek personal consent for use of the data, whenever it was accessed by another person:

> Wouldn't it be cool, you know, when you get a notification? It's like when you forget password and then they'll send you a code. It's the same thing. That would be great if you then give a consent and give the code and then they can access it sort of thing. I think that's awesome, 'cause that would provide you with more security and it also gives you more ownership over the data, right? Like it still stays in your control and you're getting to choose when and how people access it instead of it being totally out of your control and ownership as soon as someone else records it. [later] The data still belongs to me … … Even if they wanna use it just for the slightest whatever bit but, at the end of the day, it's my personal thing … … For example, like I would say STI testing. If I got an infection or like gonorrhoea and then that information comes up somewhere else, then, how would I feel about that? (Comm 59, QLD metro, 18-29 years, gender queer, queer, PLWH)

Granular consent and transparent use

Interviewees recognised that health information needed to be recorded and shared to optimise their healthcare, but also wanted to avoid needless and potentially harmful disclosures. They proposed that health data should be subject to tiered consent approaches that harmonised access for clinical benefits and protection of sensitive information. Some interviewees also wanted to have information about who had accessed their data and for what reason. Comm 46 reflected on this balanced approach in this way:

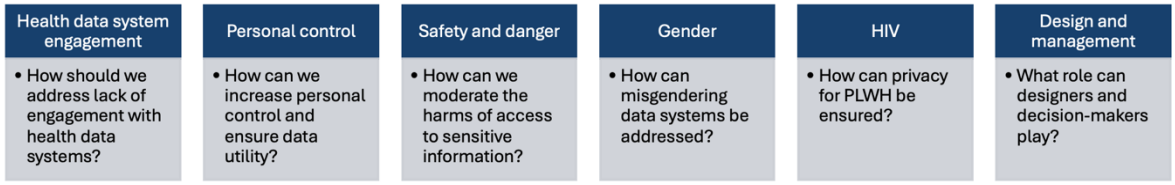
> Interviewer: And how ideally would you like healthcare providers to respond to the information that you're sharing?
> Comm 46: That it's private like everything that we share, or that I've been led to believe is how they're meant to deal with our information. And I think some information should be understood as sensitive and should even be in systems with some kind of like spoiler feature, do you know? … .. So it's not visible to everybody.
> Interviewer: It sounds like when you disclosed that you were non-binary to the GP, you would have liked them to check whether you want that recorded in the system. Whether you wanted your future referrals and just your general sort of file to reflect that or not. You would have liked that choice.
> Comm 46: Definitely. More of a conversation around consent for information and more of an understanding of how that is managed. (Comm 46, QLD metro, 30-39 years, non binary, bisexual, chronic illness)

How could digital health data systems be enhanced to better serve and protect sexuality and gender diverse people?

Summary

- Lack of LGBTQA+ community engagement and understanding of health data can be addressed by building clarity and awareness on the purposes and uses of data and how these benefit the individual and their carer
- Increased personal control is likely to support trust and engagement
- 'Upstream' interventions and resources are needed to improve data safety for sexuality and gender diverse people, and people living with HIV
- Social justice approaches to gender diversity and HIV, for example, can help to strengthen engagement, safety and trust
- Policy and practice need to promote accountability for misuse of data

Themes



We conducted workshops with LGBTQA+ community members, health advocates, physicians, managers and decision-makers to help digest interview materials and develop potential action pathways for safer and more useful health data systems. The workshops considered key, general themes from the analysis (engagement, personal control, safety & danger), and particular concerns in relation to gender and HIV care, parenting, sex work, and living in rural and remote communities.

Health data system engagement

As noted above, there was little evidence of day-to-day engagement with health data systems among community members and knowledge about them was not well developed. Providers could see value in health data but recognised that they were sometimes troublesome and time consuming. We asked workshop participants to consider if and how engagement could be developed. There was general endorsement that health data systems had the potential to be helpful for providers and community members, but considerable development of awareness, knowledge, skills and resources was needed to make them work. As this participant noted, too, promotion of community engagement needs to communicate clearly on how their identities and sensitive information are protected and what the benefits are likely to be:

> To promote engagement with health data to LGBTIQA+ people, the sense of privacy and individual benefit would need to be clearly outlined. Our communities have a long history of stigmatisation in healthcare settings and many people are cautious or accidental misgendering from health data records. (VIC Gender care workshop)

Personal control

Workshop participants recognised that community members wanted increased personal control over their data and 'to own' it, as noted above. Participants also acknowledged that personal control over data might lead to missing data if information was withheld through personal choice. However, they also noted that engagement with health data systems and trust in them would be supported by personal control, as this fragment makes clear:

> Giving the individual more control in accessible ways to choose what is shared where, in what way. Access to the data so we can change it if we need to. When I say giving it, like the individual more control, like, like seconding the point around like we need, as community members, need more information so we understand what our choices are and then can enact them. And, in actual fact, like that would allow us to then choose like what, like, "Am I wanting to share with this doctor what is real and true right now?" (QLD Regional workshop)

Participants involved in diagnosis and prescribing pointed out that missing data would not be a problem for them because: data sets are commonly partial and become out- dated; patient records do not stand in for the *in vivo* clinical consultation.

Safety and danger

A central issue in the design of health data systems is that encoding personal information is often justified in terms of improved patient safety, but these data also have the potential to generate harms for LGBTQA+ people in the form of breach of privacy, misuse and prejudice. Community members and their providers are aware of this tension, which shapes how they think and feel about consent, disclosure and third-party uses of data. Participants adopted a realist position on this tension and noted that harms for community members and their care providers were not eradicable, but needed to be carefully managed to mitigate them.

In this fragment from a workshop, the participant explained how health data systems was enmeshed with clinical, legal, commercial and other interests:

> The next issue is to know why the notes are written. The patient thinks that notes are for their care. The health professional may agree with that but also want to protect themselves legally in what is recorded and not recorded. The practice owner wants notes taken in a way that favours practice accreditation. Medical malpractice insurers want comprehensive notes but taken in a way to minimise liability. At times third parties such as insurance companies and employers may be able to subpoena notes, or exert pressure to release notes by denying insurance cover or payment of claims if notes are withheld. This is problematic in situations in which a client with an insurance claim does not want certain data released to an insurer, but the insurer has subpoenaed all notes. In the UK insurers cannot request sexual health data, but Australia does not have that protection in place. Notes should in general only contain information about the specific patient, however often family history data and some information about offspring are included, such information could subsequently compromise confidentiality. (VIC Gender Care workshop)

These and similar comments from the workshops pointed to the need for robust 'upstream' regulation of health data that account for consent, privacy and the sensitive nature of some personal information.

Gender

As noted above, concerns about the security of health data are linked to a perceived and experienced lack of understanding of gender identity and gender affirmation, which in turn reduces trust, willingness to engage and therefore the utility of these systems. Workshop participants agreed that healthcare sector-wide awareness and skills building is needed to address (mis)gendering and protections for LGBTQA+ people:

> So, for instance, accessing someone's My Health data and to have it, "Oh, that person is trans and, therefore, I'm going to treat them differently. I am a clinician in emergency department." And, as P1 has mentioned, we do experience stigma and you're probably also familiar with—What is it?—the broken, trans, broken-arm syndrome which is like- they're like: "Oh, it's because of your hormones." Because, while what we want is clinicians to understand these biases so that they just don't put it on, on our transness, when we access this care, this type of care. (NSW gender diversity workshop)

HIV

Felt and actual HIV status disclosures that impacted the autonomy and wellbeing of people living with HIV was a key theme of interviews and workshops. Though people living with HIV are well served by LGBTQA+ affirmative and HIV support services, outside these settings negative data-related experiences underlined the need for increased and more effective management of HIV and other sensitive personal information. As one participant noted, social justice mandated that people living with HIV be afforded both privacy and respect:

> I am not sure if these are privacy concerns so much as they concern what I would describe as the 'data social contract' that governs the risk/benefit calculus that goes on around all these data, practices and cultures. If a person is participating in HIV care and in so doing protecting public health via U=U, the state on behalf of the public should be protecting them from discrimination in insurance, employment, and (at the very least) from stigma in healthcare settings. (HIV care workshop)

Design and management of health data systems

Workshop participants were asked to nominate how health data systems could be designed to better serve LGBTQA+ communities. A participant from a decision-maker workshop provided this framework that synthesised the discussion:

> Things that may improve things:
> - clarity on what is actually captured and what isn't at the point of care
> - clarity on training provided and safeguards in place
> - a framework for LGBTQA+ digital health safety and inclusion
> - being able to easily change incorrect entries, including a central spot for gender and name etc to be affirmed
> - being able to easily escalate stigmatising entries
> - being easily able to opt out and opt in (Decisionmaker workshop – Padlet)

RECOMMENDATIONS

1. Address the blind spot in national health data policy for LGBTQA+ people
National policy settings for the development of health data systems acknowledge LGBTQA+ people's data needs but lack the detail suggested in our research. Similarly, national policy on the health needs of LGBTQA+ people makes sparse reference to the nuances of data-led healthcare, as we have explored. These two policy domains, therefore, unwittingly create a policy blind spot for the health data needs of LGBTQA+ people. Bridging policy is needed to ensure that Australia's approach to data-led healthcare accommodates LGBTQA+ people, in line with the findings of our research. National LGBTQA+ health data policy should be developed in consultation with sexuality and gender diverse communities, their advocates and care providers HIV and sexual health services, and gender affirmation services, as we did in our research. Consultation should also be widened to include First Nations and variation of sexual characteristics advocacy and support services, drug and alcohol services and other LGBTQA+ oriented services as appropriate. National policy could help drive change in relation to the points noted below.

2. Improve clarity on who uses health data and for what purposes
LGBTQA+ communities reported that health data systems were not well understood, particularly regarding the use of health data outside of personal healthcare settings. As in other research in Australia and internationally, LGBTQA+ communities were not highly engaged with My Health Record. This lack of understanding and engagement despite continued and expanding development of health data systems can be construed as an alienation of the health rights of LGBTQA+ people. The purposes of using health data outside of individual healthcare need to be more precisely specified and monitored. This information should be shared with individuals, advocates and providers to strengthen consent procedures and sustain trust in healthcare services and the more general administration of the data-led governance of Australian society.

3. Improve clarity regarding data ownership and consent
Members of LGBTQA+ communities were active and informed about their own healthcare and regard their own health data as a personal possession. Commercial health data reinforce this sense of data ownership. Consent was seen as a way of exercising ownership and therefore a vital means of engaging with the third-party use of data. Meaningful and granular (tiered) consent was linked with improved trust in health data systems, and the appropriate use of personal health data. In line with point 2, above, policy and practice frameworks need to be explicit about data ownership so that individuals can establish their rights and responsibilities in the management of data systems. Consent procedures need to be meaningful for the individual to promote trust and engagement.

4. Strengthen policy on data rights, social justice and inclusion
Inclusion is an important policy agenda but how to apply it meaningfully and productively to health data for LGBTQA+ people is an emerging agenda. Our research demonstrated that healthcare services for sexuality and gender diverse people, HIV and sexual health services and LGBTQA+ affirmative practitioners have crafted inclusive practices valued by members of LGBTQA+ communities. LGBTQA+ affirmative design of inclusive policies and practices is likely to benefit trust, engagement and the utility of health data for LGBTQA+ communities and beyond.

5. *Establish standards in data management practices for LGBTQA+ people*
Our research documented the day-to-day action of individuals, advocates and providers navigating the rollout of health data systems and the healthcare needs of LGBTQA+ people. LGBTQA+ health data management practices exist and are most effective when they are particular to social, clinical and medical contexts. Sharing these insights across the health system would advance effectiveness and enable the development of standards to help monitor and evaluate data-led healthcare. Standards would also promote accountability and therefore healthcare for LGBTQA+ people. We note that EU data regulation prohibits the use of personal data (sexual orientation, health status) unless criteria are met, including robust consent and the benefit for the individual (European Union, 2016). Similarly, prohibitions on poor quality use of data have been recommended to protect health data for all groups (Hoeyer, 2023). Australia policy settings may be strengthened by a similar approach.

6. Mobilise upstream education on gender diversity and health data systems
Understanding gender identity and gender affirming care and how to apply that knowledge in the use of personal health data is another important agenda. Gender diverse community members and their care providers reported that practices were evolving and inconsistent, possibly due to lack of understanding and confidence. Gender aware data management practices, including the prevention of misgendering, need to be adopted and encouraged across Federal, state, metropolitan and regional and rural health systems, to support providers and promote trust and engagement among community members.

7. Ensure data protection in HIV care
HIV positive serostatus remains subject to forms of prejudice and related expressions of homo-, sex- and disease-phobia, though many gains have been made over the course of the pandemic. Coding of HIV in health data may trigger medical paternalism and other forms of mistreatment. Some people living with HIV report these impacts as minimal while others find them distressing and view them as compromising their healthcare. Data that identifies the individual as living with HIV (or other data that can lead to such inferences) need to be considered in light of these social and health impacts. It follows that sequestration of these kinds of data would help to moderate negative effects. This approach is likely to be valuable for other medical diagnoses and identities that attract prejudice.

8. Examine health data systems scientific and practical inflexibility
Flexibility with regard to the encoding of identity markers, including gender identity and pronouns, were valued by our research participants as a means to exercise ownership, secure trust and promote engagement. Inflexibility in engagements with health data systems were therefore sources of frustration for community members and unhelpful for providers seeking to build trust. We understand that data attracts some scientific value when group and timewise comparisons are made and that, to do so, data codes need to be comparable. However, data (in)flexibility needs to be examined to harmonise the needs of community members and their care providers with scientific requirements. We are not convinced that data science should be inflexibly applied in healthcare, particularly as the benefits for LGBTQA+ individuals and communities are yet to be fully clarified and realised, if they ever will be.

9. Establish transparent tracking of health data use
LGBTQA+ community members endorsed the view that tracking who uses their data would promote trust and engagement. Access to information about other users/uses of data would be consistent with points 2 and 3 (above). Transparency may also deter misuse.

10. Establish accountability for misuse of health data
Related to transparency, clarity for individuals on how to make complaints about possible data misuse was endorsed in workshops. Health data systems need to incorporate mechanisms for individuals to register concerns and meaningful responses need to be resourced and supported.

11. Build sector capacity to take action
Interviews and workshops highlighted the need for resources so that healthcare providers, community advocates and LGBTQA+ community members can gain understanding of health data systems and take action on the implications for LGBTQA+ people. Resources could include: documentation of best practice; skills development opportunities particularly with regard to the communication and coding of sensitive information; workplace adjustments to support health data systems management; and agreed safety standards for different settings.

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REFERENCES

Australian Digital Health Authority. (2023a). Connecting Australian Healthcare. NATIONAL HEALTHCARE INTEROPERABILITY PLAN 2023–2028, Sydney.

Australian Digital Health Authority. (2023b). National Digital Health Strategy 2023-2028, Sydney.

Bloom, B.M., Pott, J., Thomas, S., Gaunt, D.R., & Hughes, T.C. (2021). Usability of electronic health record systems in UK EDs. *Emergency Medicine Journal,* 38, 410.

Brookfield, S., Dean, J., Forrest, C., Jones, J., & Fitzgerald, L. (2020). Barriers to Accessing Sexual Health Services for Transgender and Male Sex Workers: A Systematic Qualitative Meta-summary. *Aids and Behavior,* 24, 682-696.

Drysdale, K., Wells, N., Smith, A.K.J., Gunatillaka, N., Sturgiss, E.A., & Wark, T. (2023). Beyond the challenge to research integrity: imposter participation in incentivised qualitative research and its impact on community engagement. *Health Sociology Review,* 32, 372-380.

Duckett, S. (2019). Australia's new digital health record created ethical dilemmas. *Healthcare Management Forum,* 32, 167-168.

European Commission. (2012). Communication from the Commission to The European Parliament, The Council, The European Economic and Social Committee and The Committee of The Regions. eHealth Action Plan 2012-2020 - Innovative healthcare for the 21st century.

European Union. (2016). Regulation (EU) 2016/679 of The European Parliament and of The Council of 27 April 2016 on the protection of natural persons with regard to the processing of personal data and on the free movement of such data, and repealing Directive 95/46/EC (General Data Protection Regulation). European Union.

Fang, M.L., Walker, M., Wong, K.L.Y., Sixsmith, J., Remund, L., & Sixsmith, A. (2022). Future of digital health and community care: Exploring intended positive impacts and unintended negative consequences of COVID-19. *Healthcare Management Forum,* 35, 279-285.

Fricker, M., & Jenkins, K. (2017). Epistemic Injustice, Ignorance, and Trans Experiences. In A. Garry, S. Khader, Serene, & A. Stone (Eds.), *The Routledge Companion to Feminist Philosophy* pp. 268-278). New York Routledge.

Grasso, C., Goldhammer, H., Funk, D., King, D., Reisner, S.L., Mayer, K.H., et al. (2019). Required Sexual Orientation and Gender Identity Reporting by US Health Centers: First-Year Data. *American Journal of Public Health,* 109, 1111-1118.

Guyan, K. (2022). *Queer Data : Using Gender, Sex and Sexuality Data for Action*: Bloomsbury.

Hägglund, M., & Scandurra, I. (2022). Usability of the Swedish Accessible Electronic Health Record: Qualitative Survey Study. *JMIR Hum Factors,* 9, e37192.

Hertzum, M., Ellingsen, G., & Cajander, Å. (2022). Implementing Large-Scale Electronic Health Records: Experiences from implementations of Epic in Denmark and Finland. *International Journal of Medical Informatics,* 167, 104868.

Hoeyer, K. (2023). *Data Paradoxes: The Politics of Intensified Data Sourcing in Contemporary Healthcare*: MIT Press.

Holt, M., MacGibbon, J., Smith, A.K.J., Broady, T.R., Davis, M.D.M., & Newman, C.E. (2023). Knowledge of Australia's My Health Record and factors associated with opting out: Results from a national survey of the Australian general population and communities affected by HIV and sexually transmissible infections. *PLOS Digital Health,* 2, e0000200.

Kronk, C.A., Everhart, A.R., Ashley, F., Thompson, H.M., Schall, T.E., Goetz, T.G., et al. (2022). Transgender data collection in the electronic health record: Current concepts and issues. *Journal of the American Medical Informatics Association,* 29, 271-284.

Lau, F., Antonio, M., Davison, K., Queen, R., & Devor, A. (2020). A rapid review of gender, sex, and sexual orientation documentation in electronic health records. *Journal of the American Medical Informatics Association,* 27, 1774-1783.

LaVaccare, S., Diamant, A.L., Friedman, J., Singh, K.T., Baker, J.A., Rodriguez, T.A., et al. (2018). Healthcare Experiences of Underrepresented Lesbian and Bisexual Women: A Focus Group Qualitative Study. *Health Equity,* 2, 131-138.

Lenton, E., Seear, K., Farrugia, A., Lemoh, C., Cama, E., Nourse, G., et al. (2025). Health-Related Stigma: The Affordances of Electronic Health Management Systems in the Production of Structural Stigma. *Sociology of Health & Illness,* 47, e70043.

Living Positive Victoria (2018). Should people living with HIV register for My Health Record? Online document accessed 15 April 2019.

Lupton, D. (2018). *Digital Health: Critical and Cross-disciplinary Perspectives*. Abingdon: Routledge.

Mahnke, M.S. (2025). Affective gaps in eHealth communication: Exploring patient experiences with health data on the eHealth platform sundhed.dk. *Health,* 0, 13634593251374317.

Newman, C., MacGibbon, J., Smith, A., Broady, T., Lupton, D., Davis, M., et al. (2020). Why trust digital health? Understanding the perspectives of communities affected by BBVs and STIs in AustraliaSTIs Australia. Centre for Social Research in Health, UNSW.

Office of the Australian Information Commissioner. (undated webpage). Australian Privacy Principles, https://www.oaic.gov.au/privacy/australian-privacy-principles, accessed 4 March 2026.

Pearce, C., & Bainbridge, M. (2014). A personally controlled electronic health record for Australia. *Journal of the American Medical Informatics Association,* 21, 707-713.

Saxby, K., & Hammoud, M.A. (2025). Setting the standard: no LGBTI+ health equity without data equity. *Medical Journal of Australia,* 222, 52-52.

Scarlet Alliance. (2018). My Health Record Information Brief for Sex Workers, Newtown, NSW. Online document accessed 15 April 2019.

Smith, A.K.J., Davis, M.D.M., MacGibbon, J., Broady, T.R., Ellard, J., Rule, J., et al. (2023). Engaging Stigmatised Communities in Australia with Digital Health Systems: Towards Data Justice in Public Health. *Sexuality Research and Social Policy,* 20, 1220-1231.

Streed, C., Grasso, C., Reisner, S.L., & Mayer, K. (2020). Sexual orientation and gender identity data collection: Clinical and public health importance. *American Journal of Public Health,* 110, 991-993.

Thompson, A. (2018). Human Rights Commissioner says My Health scheme should be opt-in. The Age, 24 July.

Turner, A., Morris, R., McDonagh, L., Hamilton, F., Blake, S., Farr, M., et al. (2023). Unintended consequences of patient online access to health records: a qualitative study in UK primary care. *British Journal of General Practice,* 73, e67.

Waite, S., & Denier, N. (2019). A Research Note on Canada's LGBT Data Landscape: Where We Are and What the Future Holds. *Canadian Review of Sociology/Revue canadienne de sociologie,* 56, 93-117.

Westbrook, L., Budnick, J., & Saperstein, A. (2022). Dangerous data: Seeing social surveys through the sexuality prism. *Sexualities,* 25, 717-749.

World Health Organization. (2021). Global strategy on digital health 2020-2025, Geneva.

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