Australian Government
Australian Institute of Health and Welfare

How to tell the story: a strategy for monitoring sexual and reproductive health data in Australia

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About

This Data Strategy presents a practical approach to strengthening sexual and reproductive health data in Australia. It identifies priority data gaps and actions to improve monitoring across 5 initial topics: menstrual disorders, symptoms and related conditions; contraception; pregnancy loss before 20 weeks' gestation; termination of pregnancy; and perimenopause and menopause. The strategy supports better evidence for policy, service planning and health system improvement. It is a companion report to Bringing focus: a monitoring framework for sexual and reproductive health in Australia.

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Key findings

- There is no comprehensive national picture of sexual and reproductive health in Australia
- Large national data gaps exist across sexual and reproductive health, including prevalence, outcomes and care pathways
- Improving sexual and reproductive health data requires better use of existing data, linkage and new collections
- A stronger focus on priority populations is needed to understand equity in care and outcomes

Summary

Sexual and reproductive health is important for general health and wellbeing. It affects all of us, at every stage of life. It covers physical and mental health as well as social wellbeing and education and workforce opportunities.

The Australian Government provided funding in the 2024–25 Federal Budget for the AIHW to develop a National Sexual and Reproductive Health Monitoring Framework (the Framework), a data strategy, and to develop reporting. Currently, there is no national source of data that allows sexual and reproductive health and care in Australia to be comprehensively understood.

Having timely and reliable information on sexual and reproductive health will help to inform policy and improve health outcomes. This is important for policymakers, service delivery planning, health service providers, researchers, peak bodies, advocates and consumers.

The AIHW released a draft of the Framework and the Data Strategy for consultation in 2025. The feedback was reviewed and incorporated in this final Data Strategy. The Framework covers the full scope of sexual and reproductive health.

This companion data strategy initially focuses on the following 5 priority topics:

- menstrual disorders, symptoms and related conditions (including endometriosis)
- contraception
- pregnancy loss before 20 weeks' gestation (including miscarriage)
- termination of pregnancy (abortion)
- perimenopause and menopause.

These were selected based on current policy priorities, recent government inquiries and on areas where the largest national data gaps were identified.

Many additional topics were raised during the public consultation and stakeholder engagement processes. These are not excluded from the program for this work. Rather, the initial scope of work is only the start, reflecting a staged and pragmatic approach to data development. The Data Strategy will evolve over time to reflect the dynamic nature of sexual and reproductive health for all people in Australia, subject to resourcing, feasibility, the evolving data landscape and future government priorities. The Framework and Data Strategy have been designed to support additional priority topics to be added in future or progressed by other organisations, including where complementary data collections, research programs or reporting arrangements already exist.

This data strategy sets out a plan to collect and report sexual and reproductive health data. It proposes to improve the quality and availability of this information in 6 ways:

- **Use existing data sources and collections**: priority will be given to maximising the use of existing national data collections wherever feasible through enhanced analysis, and improved disaggregation for priority populations.
- **Further develop existing or planned data collections**: by collaborating with owners of existing data collections to add questions or modules to existing surveys, or data items to existing collections; develop data standards or improve data extraction from existing systems.
- **Collate service-level data sources**: aggregate state and territory health services data and other service-level data sources; collate measures and develop data standards where there are clear benefits and where they are supported by data providers.
- **Use linked data assets**: for in-depth analysis to undertake more complex and targeted analytical projects to answer complex questions about care pathways, patient journeys and sexual and reproductive health outcomes
- **Establish new data collections**: 4 new data collections are proposed (National Sexual and Reproductive Health Survey; National Pregnancy Loss Register; Sexual and Reproductive Health Pharmacy Data Collection; Health Care Provider Workforce Survey).
- **Incorporate qualitative data**: including case studies, and consumer and patient feedback.

The development of the Framework and Data Strategy is a discrete piece of work led by the AIHW in consultation with stakeholders. This strategy outlines a broad set of potential actions reflecting the scope and complexity of sexual and reproductive health data in Australia. It identifies priorities, opportunities and key considerations to inform future decision-making and support improved monitoring – not only by the AIHW and the Australian Government, but across the sector.

The actions presented are indicative and not exhaustive. Their value, priority and sequencing will be refined through ongoing consultation with subject matter experts, data custodians and stakeholders. The Data Strategy is designed to be flexible and to evolve over time to reflect changes in policy priorities, emerging evidence and the data landscape, including new or improved data sources.

About this data strategy

There is currently no comprehensive picture of sexual and reproductive health in Australia. This Data Strategy sets out a practical approach to strengthening the evidence base by identifying critical data gaps and a staged plan to data development. It complements Bringing focus: a monitoring framework for sexual and reproductive health in Australia (the Framework), which outlines what should be measured to understand sexual and reproductive health in Australia. Together, they support consistent, evidence-based monitoring of sexual and reproductive health to inform policy, service planning and decision-making.

The initial priority topics are:

- menstrual disorders, symptoms and related conditions (including endometriosis)
- contraception
- pregnancy loss before 20 weeks' gestation (including miscarriage)
- termination of pregnancy (abortion)
- perimenopause and menopause.

These 5 topics were selected based on their public health significance and limited national data and agreed in consultation with the Australian Government Department of Health, Disability and Ageing. They respond to policy priorities and data-related recommendations from:

- the *Senate inquiry into universal access to reproductive healthcare*
- the *Senate inquiry into issues related to menopause and perimenopause*.

The Data Strategy focuses on addressing key data gaps by using or strengthening existing data sources where feasible and establishing new data collections where necessary. It prioritises approaches that maximise the use of available data, minimise duplication, and support integrated analysis to inform policy, service delivery and system improvement.

The Framework and Data Strategy are designed to evolve over time, reflecting emerging evidence, improvements in data availability and changing stakeholder needs.

Key themes identified during the public consultation

The draft Framework and Data Strategy were available for public consultation from 17 September to 16 November 2025. The AIHW then engaged in further targeted consultation with priority population and community groups, state and territory departments, and Primary Health Networks (PHNs).

Table 1 details the key themes identified throughout the public consultation and the actions taken to address feedback received.

Table 1: Key themes identified and actions taken to address consultation feedback

Key theme	Action taken
The intention to improve sexual and reproductive health data was strongly and broadly supported, but there were concerns it is too ambitious	An implementation plan has been added to the Data Strategy that shows: • short-term actions that are achievable with existing data and funding • medium and longer-term development that will require enhancement or linkage of existing data, or that will depend on new collections or future resourcing.
Strengthen equity, increase emphasis on priority populations and explain how under-represented groups will be included	A dedicated section on priority populations has been added to the data strategy. It includes more information on why these are a priority, which data sources are likely to support disaggregation and where gaps are expected to remain.
The dual approach of optimising existing data and developing new collections was supported	The rationale for proposing new data collections has been strengthened, including outlining: • the strengths and limitations of proposed collections • the way in which they would address identified data gaps • the unique value and opportunities that establishing new collections would provide.
Data linkage was strongly supported, although this needs to be more clearly explained	A plain language example using data linkage has been added, including how linkage of hospital, Medicare Benefits Schedule (MBS) and Pharmaceutical Benefits Scheme (PBS) data could be used, together with other data collections, to examine care pathways and to understand outcomes.
Including service mapping and access measures was strongly supported	The AIHW will prioritise service mapping and access measures, particularly for time critical services such as termination of pregnancy and pregnancy loss care. This will include addressing priority data gaps related to service availability, geographic distribution and timely access to preferred care.
There were concerns about the reporting burden on clinicians and services	Enhancing existing collections will be prioritised where possible, particularly for workforce and primary health care data to minimise reporting burden on providers. It is proposed to use data extracted from existing infrastructure wherever possible to reduce the need for manual reporting. Piloting is recommended before national implementation, showing how data will be collected or used and consulting with those impacted (for example, PHNs, service providers) on the feasibility and timing of implementation.
The project scope needs to be clearer, particularly where additional topics are requested	Additional topics identified through consultation have been recorded as potential future priority areas. Many are included in Chapter 2 of the Framework. Given the breadth of sexual and reproductive health, it is not feasible to address all priorities at once and additional topics may be included in future stages of work by the AIHW or other organisations. Cross-cutting issues, such as fertility and infertility (including involuntary childlessness), will be addressed within the existing 5 priority topics where appropriate.

How this strategy will include priority populations

In this section

The Framework and Data Strategy recognise the importance of equitable access to sexual and reproductive health care and outcomes.

A range of social, cultural, geographic and structural factors influence differences in people's access to services and their experiences of care and health outcomes. It is essential to clearly identify these differences to inform policy, service planning and resource allocation.

Stakeholders emphasised the importance of ensuring that priority populations are clearly reflected in how sexual and reproductive health data are collected, analysed and reported. This section responds to that feedback by strengthening the focus on equity, while recognising the limitations of currently available data sources.

For the purposes of this strategy, priority populations include people who face greater barriers in accessing sexual and reproductive health services or who experience poorer sexual and reproductive health outcomes.

Priority populations are not mutually exclusive. Many people experience multiple forms of disadvantage, which can compound barriers to care and impact outcomes. Where data allow, the Data Strategy will support analysis that considers these intersecting factors.

These priority populations were identified through literature reviews and the consultation process. They include (but are not limited to):

Aboriginal and Torres Strait Islander (First Nations) peoples

First Nations peoples may experience greater severity and complexity of symptoms (for example, higher rates of underlying health conditions can increase symptom severity and make management more complex), as well as barriers to treatment, timely diagnosis and culturally safe care. National data are limited and vary across jurisdictions. Where possible, the strategy will report data disaggregated by Indigenous status. Limitations related to identification, coverage and data quality will be clearly stated.

Through this strategy, the AIHW is committed to implementing the Framework for Governance of Indigenous Data and its 4 guidelines: working in partnership with First Nations peoples, building data-related capabilities, providing knowledge of data assets, and building an inclusive data system.

Leadership from and partnership with Aboriginal Community Controlled Health Organisation (ACCHOs) are essential to improving sexual and reproductive health data for First Nations peoples.

People with disability

People with disability can face challenges in accessing care and being involved in decisions about their care. They may need extra support to recognise health issues and get the right treatment.

Existing data sources rarely capture disability status, or do not do so consistently. Disability status will be reported where feasible and limitations clearly stated.

Culturally and linguistically diverse people (including migrants and refugees)

People from culturally and linguistically diverse backgrounds may face language barriers and cultural differences that make it more difficult to navigate the health system and access culturally safe care. Existing data sources provide limited capacity for disaggregation by cultural and linguistic background. Reporting will be undertaken where feasible and limitations clearly stated.

People ineligible for Medicare

People without access to Medicare may experience financial and system barriers and have reduced access to affordable health care. This population is poorly captured in administrative data sets. The data strategy will acknowledge these limitations and explore alternative data sources as they become available.

Lesbian, gay, bisexual, transgender and queer people and people with innate variations of sex characteristics and other sexuality or gender diverse people (LGBTQIA+ people)

LGBTQIA+ people may have distinct sexual and reproductive health needs that are not well reflected in existing data. Most national data sets do not capture information on sexual orientation, gender diversity or diversity of sex characteristics. LGBTQIA+ people may also find it difficult to access respectful and appropriate sexual and reproductive health care. Reporting will use inclusive language and clearly note data constraints.

People living in rural and remote areas

People living in rural and remote areas may have reduced access to sexual and reproductive health services and experience delays in diagnosis. Geographic disaggregation will be prioritised where data allow. Results will be interpreted in the context of service availability.

People experiencing family, domestic and sexual violence and coercion

People experiencing family, domestic and sexual violence, including reproductive coercion and abuse, may face barriers to accessing safe, timely and appropriate sexual and reproductive health care. These experiences can affect decision-making, autonomy and health outcomes across the life course. Available data are limited and inconsistent across national data sources. Reporting will be undertaken where feasible, with limitations clearly stated, and will aim to interpret these experiences within broader social and health contexts.

The Framework includes the full scope of priority populations for inclusion in the monitoring of sexual and reproductive health (including people living in closed settings and people living with chronic and/or complex health needs).

While the initial focus is on the individual, it's important to note that a person's sexual and reproductive health conditions and experiences may also affect their partner and family. For example, a person's sexual and reproductive health condition may affect their daily functioning and wellbeing and the care and support they need from partners and families. Decisions and experiences may also involve partners and families. Data on these impacts are limited because most national data collections focus on individuals accessing care. Initial reporting will therefore focus on individual experiences, with opportunities to better understand impacts on partners and families explored over time.

Data coverage and gaps for priority populations

Information on most priority populations is not well collected in existing data sources, and comprehensive reporting will initially be limited due to gaps in available data. Many priority populations are poorly identified in national data sets; others are under-represented due to service access, reporting practices or data collection settings. Some priority populations are not explicitly sampled in surveys, which limits how well the results represent them.

Table 2 outlines the level of coverage for priority populations across national data sources that capture some sexual and reproductive health information.

Table 2: Coverage of priority populations in national data collections

Priority population	Coverage
Aboriginal and Torres Strait Islander (First Nations)	Medium
Culturally and linguistically diverse	Medium
Experiencing family, domestic and sexual violence and/or coercion	Low
Experiencing socioeconomic disadvantage, including those not in education, employment or training	Medium
Have innate variations of sex characteristics	Low
Ineligible for Medicare, including those on temporary work visas such as Pacific Australia Labour Mobility (PALM) scheme and international student visas	Low
Lesbian, gay, bisexual, queer, and asexual	Medium
Living in closed settings, including prisons, detention centres and residential rehabilitation centres and others restricted within the justice system	Low
Living in insecurity, including unstable housing or experiencing homelessness	Low
Living in regional, rural and remote areas	Medium to High
Living in residential aged care or specialist disability accommodation	Low
Living with chronic or complex health conditions and/or needs	Medium
Living with disability	Medium
New arrivals, including recent migrants and refugees	Low
Neurodivergent	Low
Older (aged 50 and over)	High
Transgender and gender diverse	Low
Sex workers	Low
Young (under 25 years)	High

Notes:

1. High coverage: collected in most national data collections.
2. Medium coverage: collected in some national data collections (for example, may not be routinely collected in administrative data, but captured in surveys or cohort studies).
3. Low coverage: little to no coverage. Includes populations not routinely collected or identified in national administrative data collections and populations for which data collection is difficult to reach or sample reliably for surveys.

Where possible, and subject to inclusion in data sources and data quality, data will be disaggregated by characteristics such as age, state or territory, geographic region (including remoteness), Primary Health Network (PHN), finer geographic areas (such as postcode, local government area or statistical area), Indigenous status and gender.

Over time, the data strategy will support targeted data development activities that:

- enhance existing collections to better identify priority populations
- explore new data collections where gaps cannot be addressed through existing sources.

Improving identification, coverage and reporting in relation to priority populations will require a combination of approaches, including:

- strengthening and applying standard national classifications and data standards
- using data linkage to improve coverage (for example, linking survey and administrative data)
- partnering with priority populations to improve data collection

- incorporating qualitative data where appropriate
- being transparent about data limitations, including gaps in coverage and data quality.

This transparency supports appropriate interpretation of findings and helps guide future data development priorities.

Progress will depend on feasibility, data quality, governance arrangements and resourcing. Equity will be a consideration in decisions about where new investment in sexual and reproductive health data is likely to have the greatest impact.

Data gaps and data development

The following sections summarise the key data gaps and priorities for data development for the initial 5 priority topics:

Menstrual disorders, symptoms and related conditions

Contraception

Termination of pregnancy (abortion)

Pregnancy loss before 20 weeks' gestation, including miscarriage

Perimenopause and menopause

These are informed by stakeholder input and findings from a data landscape and literature review.

Menstrual disorders, symptoms and related conditions

This topic includes menstrual disorders, some of their underlying causes, and associated symptoms. Menstrual disorders are disruptions to the menstrual cycle. These include abnormal uterine bleeding, such as heavy menstrual bleeding, and painful periods (dysmenorrhea) (Munro et al. 2018). Some menstrual disorders may be due to underlying chronic conditions, such as endometriosis or polyendocrine metabolic ovary syndrome (PMOS, formerly known as polycystic ovary syndrome), or their cause may be unknown.

People may also have symptoms unrelated to the menstrual cycle phase, such as pelvic pain, which may indicate an underlying menstrual disorder or condition. The scope of this current work program includes heavy menstrual bleeding, iron deficiency and iron deficiency anaemia, dysmenorrhea, endometriosis, adenomyosis, PMOS, uterine fibroids, premenstrual distress (including premenstrual dysphoric disorder) and pelvic pain. Future phases of the work program may be expanded to include other menstrual disorders, symptoms and related conditions.

A review of the literature and stakeholder consultations identified 9 critical data gaps relating to menstrual disorders, symptoms and related conditions in Australia, along with a series of priority areas for data development to start addressing these gaps (Table 3). These gaps and priority areas for data development have directly informed the development of the Data Strategies for the 5 Priority Topics.

Table 3: Menstrual disorders, symptoms and related conditions: critical data gaps and priority areas for data development

Data gap	Priority areas for data development
1. Comprehensive national data on the prevalence of menstrual disorders, symptoms, conditions and comorbidities over time	a. Strengthen national estimates for endometriosis, uterine fibroids and heavy menstrual bleeding (particularly among priority populations). b. Establish national estimates for adenomyosis, iron deficiency and iron-deficiency anaemia, pelvic pain, dysmenorrhea, PMOS and premenstrual distress (including premenstrual dysphoric disorder). c. Improve data on comorbidities of menstrual disorders and related conditions, including the frequency of co-occurring conditions (for example, endometriosis and adenomyosis).
2. Impacts of menstrual disorders, symptoms and related conditions on quality of life, mental health and sexual and reproductive health outcomes	a. Measure and monitor impacts on mental health, relationships, daily activities, attendance and performance at school and work. b. Measure and monitor impacts on sexual and reproductive health outcomes (for example, infertility and ability to reach desired family size) and how these outcomes affect mental health and quality of life.
3. Access to and quality of care (for example, where and when individuals seek care; wait times; service availability)	a. Monitor availability of, and geographic distribution of, services. b. Monitor wait times for specialist services, diagnostic tests and procedures. c. Collect data on diagnosis and management care pathways. d. Monitor patient's reported experiences of care.
4. Use and acceptability of therapies for menstrual disorders, symptoms and related conditions	a. Capture data on how menstrual disorders, symptoms and related conditions are managed and treated. b. Capture data on patient acceptability of different therapies for menstrual disorders, symptoms and related conditions.
5. Health literacy	a. Measure and monitor health literacy relating to abnormal menstrual symptoms, particularly among young people, parents and LGBTQIA+ people. b. Measure and monitor awareness of, and access to, trustworthy and appropriate sources of information.
6. Time taken to diagnosis and treatment, or management of menstrual disorders and related conditions	Collect data that differentiate between age when symptoms first noticed, age when first seeking care, age when diagnosed, and age when symptoms were treated or managed.
7. Health care provider knowledge, training and confidence	a. Monitor training provided for general practitioners and other health care providers. b. Measure and monitor health care provider confidence in diagnosing and treating menstrual disorders, symptoms and related conditions. c. Measure and monitor alignment to care standards and clinical guidelines.
8. Costs associated with menstrual disorders, symptoms and related conditions	Identify and monitor costs to individuals for health care services, tests, procedures and medications in relation to menstrual disorders, symptoms and related conditions.
9. National data standards	Develop national data standards and consistent diagnostic criteria to support consistent data collection.

Additional data development priorities

Developing validated diagnostic tools and using consistent coding are required to improve data quality for menstrual disorders, symptoms and related conditions. These will support more consistent identification of symptoms and conditions in relevant data collections, enabling improved monitoring of this topic.

Developing validated diagnostic tools and implementing consistent coding approaches are broader system-level activities that are beyond the scope of the current work program and would require collaboration with clinical experts, data custodians and other stakeholders.

References

Munro MG, Critchley HOD, Fraser IS and FIGO Menstrual Disorders Committee (2018) 'The two FIGO systems for normal and abnormal uterine bleeding symptoms and classification of causes of abnormal uterine bleeding in the reproductive years: 2018 revisions', *International Journal of Gynaecology and Obstetrics*, accessed 15 July 2025. https://doi.org/10.1002/ijgo.12666

Contraception

Contraception is the act of preventing pregnancy using pharmaceutical, procedural or behavioural methods (Bansode 2023). Contraception is primarily used to prevent pregnancy, but some methods are commonly used for other purposes such as menstrual management and treatment of certain health conditions. Other specific methods, such as condoms, can provide protection against sexually transmitted infections. Unless otherwise specified, 'contraception' in this topic refers to contraception methods and devices used for any reason, including and beyond pregnancy prevention.

A review of the literature and stakeholder consultations identified 6 critical data gaps relating to access to contraception in Australia along with a series of priority areas for data development to start addressing these gaps (Table 4). These gaps and priority areas for data development have directly informed the development of the Data Strategies for the 5 Priority Topics.

Table 4: Contraception: critical data gaps and priority areas for data development

Data gap	Priority areas for data development
1. Comprehensive national data on contraception use. Limited capacity to disaggregate information to understand reasons for contraceptive use (including pregnancy prevention, menstrual disorder management, STI prevention)	Monitor contraception use, including by type and reasons for use.
2. Provider capacity and service delivery for contraception, particularly long-acting reversible contraception (LARC)	a. Monitor the geographic distribution of contraception prescribers and services by method and prescriber or service type. b. Monitor the number, proportion, type and distribution of health care providers trained and actively delivering LARC insertion and removal, and permanent contraception services.
3. Health care provider knowledge, training and confidence	a. Monitor training provided for general practitioners and other health care providers. b. Assess health care provider knowledge and prescribing practices, including alignment with contraception and clinical guidelines.
4. User out-of-pocket cost and government expenditure	Monitor out-of-pocket costs and government expenditure on contraception products and services, including PBS-subsidised and private prescriptions, emergency contraception and MBS-subsidised services.
5. Patient access, autonomy, and quality of contraception care	a. Monitor patient autonomy and agency in contraception decision-making, access and use. Identify barriers (to provision and uptake) where preferences are unmet. b. Monitor access to pain relief during LARC insertion and removal procedures. c. Track wait times for LARC insertion and removal procedures, and permanent contraception procedures. d. Evaluate the prevalence and impact of reproductive coercion and abuse in relation to contraception, including screening practices, and effects on contraception use.
6. Health literacy	a. Measure and monitor contraception health literacy. b. Measure and monitor access to trustworthy and appropriate (culturally, linguistically, practically) information resources.

Additional data development priorities

The following data gaps were also identified but were considered to be out of scope for data development at this time:

- reproductive coercion and abuse response protocols and available supports
- condom sales, and trends in community availability
- contraception counselling across care settings, and health care provider type
- length of time using the contraception method, including LARC
- contraception consultation and procedure wait times in non-hospital care settings.

References

Bansode OM, Sarao MS and Cooper DB (2023) *Contraception*, StatPearls [Internet]. Treasure Island (FL): StatPearls Publishing, accessed 20 May 2026.

Termination of pregnancy (abortion)

Termination of pregnancy (TOP), or abortion, involves intentionally ending a pregnancy by removal or expulsion of the embryo or fetus and the placenta from the uterus. It involves either:

- taking medications before 9 weeks' gestation (medication termination of pregnancy or medication abortion), or
- undergoing a procedure (surgical termination of pregnancy or surgical abortion).

A review of the literature and stakeholder consultations identified 4 critical data gaps relating to access to TOP in Australia, along with a series of priority areas for data development to start addressing these gaps (Table 5). These gaps and priority areas for data development have directly informed the development of the Data Strategies for the 5 Priority Topics.

Table 5: Termination of pregnancy (abortion): critical data gaps and priority areas for data development

Data gap	Priority areas for data development
1. Comprehensive national data on TOP (abortion), disaggregated by method, gestation, and patient and provider demographic and geographic characteristics[(a)]	a. Routinely link, collate and publish disaggregated TOP prevalence data in a timely way, including improved reporting by method and gestational age. b. Describe and monitor geographic accessibility of TOP care.
2. TOP accessibility across priority populations, including access to choice of methods	a. Collate data on barriers to TOP care. b. Monitor ability to access preferred method and aspects of TOP care (provider type, service type, model of care, service location, pain relief). c. Identify and monitor out-of-pocket costs associated with accessing TOP care in Australia. d. Record self-managed and unsafe abortion attempts.
3. Routine measurement and monitoring of patient experiences, quality of care and complication rates	a. Monitor patient experiences, both within and before contact with the health care system. b. Monitor quality of TOP care (including stigma, obstruction and conscientious objection, and complication rates) with the lowest feasible geographic disaggregation across provider types.
4. Understanding of provider capability, capacity and wellbeing or support	Identify and monitor health care providers delivering appropriate TOP care, including: a. Whether health care providers have undertaken formal training. b. Health care provider confidence and capacity in offering TOP care. c. Service and systems-level factors influencing provider capability, capacity and wellbeing.

(a) Stakeholder consultations identified clearer separation of procedures for TOP – as distinct from pregnancy loss in administrative data collections – as a data development priority in future or new data collections.

Additional data development priorities

The need to develop national data standards for termination of pregnancy was identified as an additional priority area for development. Developing data standards would support more consistent identification of abortion in relevant data collections, enabling improved monitoring and reporting.

Pregnancy loss before 20 weeks' gestation, including miscarriage

Pregnancy loss is the loss of a pregnancy before 20 weeks' gestation. It is associated with the non-viable development, spontaneous death, or passing from the uterus of an embryo or fetus before a gestational age that is compatible with life outside the uterus.

This topic includes:

- loss of pregnancies located within the uterus (miscarriage)
- loss of pregnancies located outside the uterus (ectopic pregnancy)
- pregnancies that can be identified by a positive chemical pregnancy test, but which do not develop into a viable pregnancy (biochemical, anembryonic, and molar pregnancy).

A review of the literature and stakeholder consultations identified 4 critical data gaps relating to pregnancy loss before 20 weeks' gestation in Australia, along with a series of priority areas for data development to start addressing these gaps (Table 6). These gaps and priority areas for data development have directly informed the development of the Data Strategies for the 5 Priority Topics.

Table 6: Pregnancy loss before 20 weeks' gestation: critical data gaps and priority areas for data development

Data gap	Priority areas for data development
1. Disaggregated national data on pregnancy loss prevalence[(a)]	Collate national data on prevalence of pregnancy loss disaggregated by type, gestational age, recurrence and care setting.
2. Access to, and quality of, pregnancy loss care (where and when individuals seek care, waiting times, service availability)	a. Monitor the availability of, and access to, pregnancy loss services across all stages of pregnancy loss (assessment, diagnosis, management and bereavement), including waiting times, costs and care pathways. b. Monitor quality of pregnancy loss care across all stages (assessment, diagnosis, management and bereavement), including complications. c. Monitor health care provider confidence and capacity to provide pregnancy loss care.
3. Impacts of pregnancy loss on quality of life	Measure and monitor the impacts of pregnancy loss on mental health, and wellbeing, social experiences and relationships, daily life, and long-term health.
4. Health literacy	a. Measure and monitor health literacy on pregnancy loss. b. Measure and monitor the accessibility of trustworthy and appropriate (culturally, linguistically, practically) information resources.

(a) Stakeholder consultations identified clearer separation of procedures for pregnancy loss – as distinct from termination of pregnancy or other reasons in administrative data collections – as a data development priority in future or new data collections.

Additional data development priorities

Additional data gaps identified through the consultation process but assessed as lower priority for data development include information related to causes of pregnancy loss (especially recurrent pregnancy loss), such as access to and advice on genetic testing following pregnancy loss, and environmental exposures (for example, air and water quality, and exposure to heavy metals).

References

Prigerson HG, Maciejewski PK, Reynolds CF, Bierhals AJ, Newsom JT, Fasiczka A, Frank E, Doman J and Miller M (1995) 'Inventory of complicated grief: A scale to measure maladaptive symptoms of loss', *Psychiatry Research*, 59(1-2):65–79, doi:10.1016/0165-1781(95)02757-2.

RANZCOG (The Royal Australian and New Zealand College of Obstetricians and Gynaecologists) (2025) 'Miscarriage', *Patient Information*, ranzcog.edu.au, accessed 24 June 2026

Perimenopause and menopause

Menopause occurs when the reproductive capacity of a person ceases, signified by the absence of a menstrual period for one year.

Perimenopause is the phase leading up to, and just after, the final menstrual period. Perimenopause usually starts in a person's 40's but can start earlier or later. Oestrogen and progesterone fluctuate during this time, causing changes to menstrual period frequency and regularity, and many start experiencing a combination of physical, emotional or mental health symptoms. Perimenopause typically lasts for 4 to 6 years, however, can last between 2 and 10 years.

The average age of menopause in Australia is 51; however, early menopause or premature ovarian insufficiency (POI) affect approximately 1 in 15 people born with ovaries (Department of Health, Disability and Ageing 2026). Early menopause is when menopause occurs before age 45. Early entrance into menopause can be associated with different or varying intensities of symptoms and can amplify risks to health and wellbeing. POI is when menopause occurs before age 40 and is typically attributable to underlying medical or genetic conditions which may impact reproduction (Jean Hailes for Women's Health n.d). Medical treatment or surgery can also cause early or premature menopause, which is known as medically induced menopause (Department of Health, Disability and Ageing 2026).

A review of the literature and stakeholder consultations identified 8 data gaps relating to perimenopause and menopause in Australia, along with a series of priority areas for data development to start addressing these gaps (Table 7). These gaps and priority areas for data development have directly informed the development of the Data Strategies for the 5 Priority Topics.

Table 7: Perimenopause and menopause: critical data gaps and priority areas for data development

Data gap	Priority areas for data development
1. Use of menopausal hormone therapy (MHT) in Australia, including costs, accessibility and barriers to access	Monitor access to and use of MHT across Australia to: • understand reasons for its use • identify barriers to its use • improve understanding of access to and use of MHT among priority populations • monitor costs and affordability of MHT use.
2. Experiences of perimenopause and menopause, including symptom severity and duration, and impact on quality of life	Collect national data that consistently monitors perimenopause and menopause symptoms, including: • severity and duration • impacts on daily activities, relationships, mental health and other health conditions • variation in symptoms and severity by population groups.
3. Impact of perimenopause and menopause on workforce participation and engagement	Collate data on impacts of perimenopause and menopause on workforce engagement and absenteeism (separate to other mid-life stressors), particularly in female-dominated industries (for example, nursing, teaching, early childhood).
4. Relationship of perimenopause and menopause with health and wellbeing across the life course	Identify and monitor the impact of reproductive conditions and other health conditions on experiences of perimenopause and menopause.
5. Health care provider knowledge, training and confidence to support people presenting with perimenopause- and menopause-related health needs	Identify and monitor health care providers delivering appropriate care, including: • evidence of providers having undertaken formal training on perimenopause and menopause • confidence and capacity of health care providers to treat or manage symptoms • knowledge and attitudes of providers about MHT and menopause.
6. Availability and accessibility of services for perimenopause and menopause care	a. Collate national data on access and service provision, including wait times to access specialist menopause services and out-of-pocket costs to access services. b. Monitor geographic distribution of health care providers and specialist services.
7. Experiences of early menopause, premature ovarian insufficiency and medically induced menopause	Collate national data on early menopause, premature ovarian insufficiency and medically induced menopause and monitor changes over time with respect to: • relationships with other health conditions (including associated reproductive conditions) • age of onset.
8. Health literacy	a. Measure and monitor health literacy on perimenopause and menopause. b. Measure and monitor access to trustworthy and appropriate (culturally, linguistically, practically) information resources.

Additional data development priorities

The following data gaps were also identified but were considered a lower priority for data development at this time:

- determine how culture, language and background influence understandings of perimenopause and menopause and how people do or do not access health care services, considering:
  - cultural safety
  - cost and opportunities for subsidies
  - stigma and attitudes
- identify the physical and psychosocial needs of people experiencing early menopause, premature ovarian insufficiency and medically induced menopause
- measure awareness of clinical guidelines and monitor alignment to care standards and clinical guidelines
- monitor the number of workplaces with supportive policies (for example, menopause leave)
- determine the impact of perimenopause and menopause on income, superannuation and finances.

References

Department of Health, Disability and Ageing (2026) *Perimenopause,* DHDA website, accessed 17 June 2026.

Jean Hailes for Women's Health (n.d) *Medically induced menopause*, Jean Hailes for Women's Health, accessed 18 June 2026.

Identifying data sources and data availability

Data sources for each of the priority topic areas for data development were identified through a structured review of available national data collections.

The following factors guided the selection of existing data collections for the data strategy:

- geographic coverage (preferably national, or feasible to expand across all or most jurisdictions)
- representativeness of the target population, including priority populations and service providers
- frequency (how often the data source is updated and whether past or future collections enable ongoing monitoring or time-series analysis)
- inclusion of at least some relevant sexual and reproductive health data elements or items.

Future data development work will also consider data sources as appropriate for use and development based on:

- potential for data linkage
- ethics and consent processes
- privacy issues
- ability to access data
- governance and data transmission arrangements
- data ownership
- costs.

Data sources will be assessed against the AIHW and Australian Bureau of Statistics (ABS) data quality framework.

Data collections not included were those that:

- are one-off studies (that is, they will not be repeated)
- lack sufficient coverage
- are not representative of the target population
- have small sample sizes that cannot be generalised to the Australian population.

However, relevant data items from these data collections may be used as examples during new data development, including to support comparability and use of validated questions. For example, questions and/or methodologies used in several state-level population health surveys could inform the development of a national survey.

Data sources used in this strategy include national administrative data sets and collections, linked data assets, state and territory administrative data sets and collections, data from service providers, and survey data with national coverage. Smaller surveys, including those conducted at a jurisdictional level, are out of scope as they cannot be combined for national coverage.

Potential data sources

The tables below present the data sources that were considered for the initial scoping phase of sexual and reproductive health data (by collection type and in alphabetical order).

These data sources will either be:

- included for initial analysis and reporting, or
- are currently being explored to determine their suitability for monitoring against the areas of measurement identified in the data strategies for each topic.

Tables 8 to 10 also include data sources currently under development that will be considered for future reporting once available for analysis.

National administrative data sets

Table 8: National administrative data sets

Data source	Included, exploring or future	Brief description
My Health Record	Future collection	Digital health record which stores a patient's key health information. Coverage dependent on provider participation and data upload. Quality and accessibility of data still being assessed.
National Congenital Anomalies Data Collection (NCADC)	Exploring	The NCADC is a national data collection on babies with a congenital anomaly. Includes births (both live births and stillbirths) with a diagnosed congenital anomaly. Includes terminations of pregnancy due to a congenital anomaly (from 20 weeks' gestation). May under-count due to variation in diagnosis and reporting practices.
National Elective Surgery Waiting Times Data Collection (NESWTDC)	Included	The NESWTDC is a national administrative database which holds episode-level information on patients added to or removed from elective surgery waiting lists managed by public hospitals. Excludes private sector activity and people who do not enter waiting lists. Limited to procedures classified as elective. Does not capture most priority populations.
National Health Expenditure Database (NHED) and Australia's Disease Expenditure database	Exploring	The NHED stores data from the Australian National Health Account, which is derived from more than 50 data sources capturing health spending across individuals, some private sources, and governments. The Disease Expenditure Database contains estimates of expenditure by ABDS group and are derived from the NHED. Limited to diseases included in the ABDS; disease expenditure is only an indicator of the use of health system resources. Limited capacity to link spending to individual outcomes, specific populations or sexual and reproductive health conditions.
National Hospital Morbidity Database (NHMD)	Included	The NHMD holds data on procedures, diagnoses and stays of patients admitted to hospitals in Australia. Excludes primary care and most outpatient services. Limited to recorded diagnoses, procedures and dependent on coding quality. Does not capture most priority populations.
National Medicine Record (NMR)	Future	The NMR is proposed to provide a complete picture of a patient's medicines history using existing digital health capabilities like electronic prescribing, the Active Script List and My Health Record.
National Non-Admitted Patient Emergency Department Care Database (NNAPEDCD)	Exploring	The NNAPEDCD holds data on patients seen in the emergency department, without further admission. Limited to emergency department presentations; variable coverage and completeness across jurisdictions.
Nationally Notifiable Diseases Surveillance System (NNDSS)	Exploring	The NNDSS holds notification data on 70 nationally notifiable diseases. There are several notifiable diseases included that may be of relevance to the topic of pregnancy loss. These include sexually transmitted infections, gastrointestinal diseases and vaccine preventable diseases. Linked NNDSS data is not currently available.
National Perinatal Data Collection (NPDC)	Exploring	The NPDC is an administrative collection that includes data for some jurisdictions on termination of pregnancy and previous pregnancy loss. Coverage of these data items varies by jurisdiction. Does not capture most priority populations.

National Perinatal Mortality Data Collection (NPMDC)	Exploring	The NPMDC holds information on stillbirths and neonatal deaths in Australia, including timing, causes, and investigations. Limited to fatal outcomes and small numbers restrict detailed analysis.
National Primary Health Care Data Collection (NPHCDC)	Exploring/ future collection	The NPHCDC (forthcoming, not yet complete) will include information collected during primary health care interactions (see Further develop existing or planned data collections for more details). The data quality and coverage are unknown at this stage.
National Public Hospital Establishments Database (NPHED)	Exploring	The NPHED is a national administrative database which holds information on public hospital resources including beds, staff and specialised services, revenue and recurrent expenditure. Does not include patient-level data and excludes private hospitals.
Non-Admitted Patient Unit Record Database (NAPUR)	Exploring	The NAPUR holds episode-level data on non-admitted patient service events in public hospital outpatient clinics. Excludes private outpatient services and primary care; variations in quality and completeness across jurisdictions.
Pharmaceutical Benefits Scheme (PBS) and Repatriation Pharmaceutical Benefits Scheme (RPBS)	Included	The PBS holds information on dispensing of government subsidised medicines in Australia. Excludes private prescriptions not subsidised and over-the-counter medicines. Reporting outpatient/discharge/day-only prescriptions for NSW/ACT is not available. Data on pharmacist prescribing is currently unavailable. Does not confirm if medicine was taken. Limited demographic data captured. The RPBS is subsidised by the Department of Veterans' Affairs and provides a range of pharmaceuticals and wound dressings at a concessional rate for eligible veterans, war widows/widowers and their dependants.
Private sexual and reproductive health service and training data	Exploring	Private sexual and reproductive health service data includes service provision data from not-for-profit organisations, and from private clinics. Fragmented, not routinely collected nationally; lacks standardisation.

Surveys: cross-sectional and longitudinal studies

Table 9: Surveys: cross-sectional and longitudinal studies

Data source	Included, exploring or future	Brief description
Australian Longitudinal Study on Women's Health (ALSWH)	Included	ALSWH is a nationally representative longitudinal cohort study conducted about every 3 years. Collects geographic information and demographic information on Indigenous status, sexual orientation, disability, and CALD variables, but is not fully representative of priority populations.
Australian Perimenopause and Menopause Study (A-PaM)	Future collection (under development)	The A-PaM study will be a longitudinal study that aims to identify and evaluate the impacts of perimenopause and menopause on health and wellbeing (it will be codesigned with the community). Data are not yet available; scope still under development.
Australian Study of Health and Relationships (ASHR)	Exploring	ASHR is a nationally representative cross-sectional study of sexual health behaviours and relationships conducted about every 10 years. Collects some demographic information but is not fully representative of priority populations; latest data not yet available.
Australian Survey of Secondary Students and Sexual Health (SSASH)	Exploring	SSASH is a national survey that asks about knowledge, behaviour and educational experiences related to sexual health and wellbeing. Limited to those aged 14–18; not representative of priority populations.
Australian Women's Midlife Years (AMY) Study	Exploring	AMY is a national cross-sectional study of women aged 40–69 years, across different stages of the menopause transition. Excludes younger populations and other genders and focuses on a specific life stage.
Australia's Disability Strategy Survey (ADS Survey)	Exploring	The ADS Survey collects data on attitudes towards people with disability, to support reporting on Australia's Disability Strategy 2021–2031. Limited information collected on sexual and reproductive health and focuses on attitudes rather than health outcomes.
Growing up in Australia: Longitudinal Study of Australian Children (LSAC)	Exploring	LSAC is a nationally representative, longitudinal study of Australian children and their families. Limited SRH content and participants currently represent younger adults only.

Household, Income and Labour Dynamics in Australia (HILDA) Survey	Exploring	HILDA is a household-based nationally representative longitudinal survey which includes an occasional rotating fertility module. Limited sexual and reproductive health specific content.
Jean Hailes National Women's Health Survey (NWHS)	Included	The NWHS is an annual cross-sectional survey with a sample of approximately 3,500 women each year. The survey focuses on a different health topic each year, reflecting current information needs. Since 2023, the NWHS has recruited nationally using representative sampling techniques and periodically collects relevant sexual and reproductive health data. It does not support time series analysis but can be used as initial/proxy data to temporarily fill critical data gaps. Collects some demographic information but is not representative of priority populations.
Medical Training Survey (MTS)	Exploring	The MTS is an annual national survey that collects information from doctors-in-training on their education and training experiences, including workplace culture, wellbeing and access to learning opportunities. It is not designed to capture clinical practice or service delivery in sexual and reproductive health. Response rates are quite low, further limiting use, but may be useful as a supplementary source that provides insight into capability, skills and confidence.
National Health Measures Survey	Exploring	The NHMS is a nationally representative survey with biological samples taken for information on biomarkers of chronic disease and nutrition. Conducted periodically; small sample limits disaggregation of data.
National Health Survey (NHS)	Included	The NHS is a nationally representative household survey. It collects information on self-reported health status, long-term health conditions, health behaviours and use of health services. It can be used to estimate the prevalence of some sexual and reproductive health conditions however detail is limited, and the survey is not designed to comprehensively capture sexual and reproductive health conditions. Sample size may be too small for detailed analysis of less common conditions or disaggregation for priority populations.
National Health Workforce Dataset (NHWDS)	Exploring	The NHWDS includes information on the demographics and employment information for registered health practitioners in Australia, based on their Australian Health Practitioner Agency registration and a voluntary workforce survey. It supports workforce monitoring but has limited capacity to identify sexual and reproductive health specialisations or advanced training.
Periods, Pain and Endometriosis (PPEP talk)	Exploring	PPEP talk is a questionnaire accompanying a national endometriosis school education program. Sampling over-represents independent schools with no public schools captured in some states. Limited to participants in a specific program. Limited coverage of priority populations.
Survey of Disability, Ageing and Carers (SDAC)	Exploring	The SDAC is a nationally representative household survey. It collects information on people with disability, older people and carers, including data on long-term health conditions, functional limitations, need for assistance and use of support services. SDAC is the preferred data source for reporting disability prevalence. Limited sexual and reproductive health detail.

Other data sources

Table 10: Other data sources

Data source	Included, exploring or future	Brief description
AUSLARC trial (AUSLARC) is led by Sexual and Reproductive Health Australia, in partnership with The Royal Australian College of General Practitioners	Exploring	AUSLARC provides scholarships for Implanon and intrauterine device training to reduce financial and geographic barriers to long-acting reversible contraception (LARC) training. AUSLARC trial contains training data, including post-training survey data.
Australian and New Zealand Assisted Reproduction Database (ANZARD)	Exploring	ANZARD is a clinical quality registry with information on all assisted reproduction cycles in Australia and New Zealand. Limited to people who access fertility treatment; does not capture fertility experiences outside of clinical treatment.

Healthdirect	Exploring	Healthdirect is a national virtual health service that provides telephone and online health information. It captures data on call volumes, reported symptoms, triage outcomes and referral pathways, and can provide insights into service demand and help-seeking behaviour, including for sexual and reproductive health. It has limited clinical information and is not designed for diagnosis or confirmed conditions. In addition, the National Health Service Directory is a national directory of health services and practitioners.
Jurisdictional Abortion Notification Systems (ANS)	Included	ANSs have been established in some jurisdictions. Variations in coverage, definitions, and data quality across jurisdictions. Some data requires jurisdictional approval. Limited priority populations data in some ANS.
Long-acting reversible contraception (LARC) Centres of Excellence	Exploring	Australian Government-funded services that provide contraceptive counselling, LARC insertion and removal services, and health professional training. Potential source of data on access to contraception services, service utilisation, workforce training and geographic variation in service provision. Centres were only established in 2026 and routine data collections or reporting arrangements are yet to be determined.
Medicare Urgent Care Clinics (UCC)	Exploring	Medicare UCCs provide bulk-billed urgent care services for conditions and illnesses that are episodic and not immediately life-threatening. Limited to Commonwealth-funded clinics and focused on episodic care only. Limited historical data and excludes state-based urgent care centres and people who do not consent to their visit information being shared. UCC data are currently being explored therefore data quality and coverage are unknown at this stage.
MedicineInsight	Exploring	A general practice (GP) data set that contains de-identified, patient-level data extracted from participating general practices. It is not nationally representative as it is limited to participating clinics but may provide insights into prescribing and patient care patterns. Variations in data quality and completeness.
Qendo	Exploring	Qendo is an application for tracking symptoms, treatment, and management of endometriosis, pelvic pain, and other related conditions. Large number of users in Australia. App-based, self-selected sample. Limited representativeness and standardisation.

Note: other data sources may become relevant over time, such as new data collections or enhanced existing data collections, or as additional priority topics are added.

Excluded data sources

Several additional data sources were identified or suggested by stakeholders through the consultation process. These are listed alphabetically in Table 11 along with a brief rationale for their exclusion.

Table 11: Currently excluded data sources

Data source	Rationale for exclusion
45 and Up Study	Currently excludes younger populations[(a)] and is not nationally representative – NSW only.
Endometriosis and Pelvic Pain Clinic (EPPC) Minimum Dataset	Sample not representative, not suitable for population monitoring or monitoring care pathways as it only measures a small proportion of contact with specific health services.
The Grollo–Ruzzene Foundation Young Women's Health Study	Not nationally representative (only 3 Eastern states) and ongoing monitoring of trends is not possible (cross-sectional one-off study conducted in 2016–17) but will be considered for reporting contextual or supplementary information.
Longitudinal Study of Teenagers with Endometriosis, Period and Pelvic Pain (LongStePPP)	Small sample size, may be valuable for analyses of risk factors, interventions and outcomes, but (due to small sample size) not suitable for population monitoring or monitoring care pathways.
MenoDoctor Survey	The MenoDoctor Survey was a one-off survey which allowed participants to self-select. As such, there may be bias.
National Endometriosis Clinical and Scientific Trials (NECST) Registry	Registry for endometriosis and pelvic pain. Not nationally representative, small sample size.
Personality and Total Health (PATH) Through Life Study	Not nationally representative, ACT and surrounding regions only.
RAINE Study	Not nationally representative, Western Australia only. Small sample size (less than 3,000) making it less generalisable to people living in Australia.
Survey of Women's Health in the ACT	Not nationally representative, ACT or surrounding region only. Participants also self-select and as such, there may be bias.
SWASH survey of lesbian, bisexual, queer and other non-heterosexual identifying women engaged with LGBTIQ communities	Not nationally representative.
Victorian Women's Health Survey	Not nationally representative, Victoria only.
VITAL registry	Currently excluded as it's not nationally representative. Participants also self-select and there may be bias. May be explored for future reporting.
Women's Healthy Ageing Project (WHAP)	Not nationally representative, Metropolitan Melbourne region only.

(a) Intended to be expanded to younger age groups (18 and up); may be explored in future reporting due to large sample size.

Key strategies

The Data Strategy proposes to improve the quality and availability of sexual and reproductive health information through 6 key strategies:

- use existing data sources and collections
- further develop existing or planned data collections
- collate service-level data sources
- use linked data assets
- establish new data collections
- incorporate qualitative data, including case studies and consumer and patient feedback.

Use existing data sources and collections

The AIHW recommends prioritising the use and optimisation of existing data collections to make best use of available information and minimise reporting burden on health care providers and services. Using existing data sources provides a timely and cost-effective way to strengthen sexual and reproductive health reporting. Enhanced analysis can generate new insights into health outcomes, experiences and care pathways that are not available through routine reporting alone, while improved disaggregation can support better understanding of priority populations and health inequities, where feasible.

The existing data sources to focus on initially for analysis and reporting are listed in the section 'Potential data sources'. However, these collections were not necessarily designed to meet sexual and reproductive health information needs. They may lack key data items, have gaps in coverage, or provide only limited information on experiences of care and priority populations. Existing data should therefore be used alongside other data sources and, where needed, further developed (as outlined in the next strategy) or complemented by new data collections.

Further develop existing or planned data collections

In this section

This section describes data sources that could be developed to improve the quality, relevance, and coverage of sexual and reproductive health data for the initial priority topics.

This may involve working with data custodians to:

- add new data items
- expand survey modules, or
- improve data extraction and use from existing systems.

This approach builds on established infrastructure and supports more consistent and comparable data over time, while minimising the burden on data providers.

Changes to existing collections can be complex. Constraints may include competing priorities, governance arrangements and the need to maintain consistent time series. Opportunities to add new data items are often limited, and changes may take time to implement and deliver results. Hence, development of existing or planned collections will be targeted and undertaken alongside other strategies to address priority data gaps.

National administrative data

National administrative data are routinely collected as part of health services and government programs.

They include information recorded during patient care and service use such as:

- hospital records
- MBS services claimed
- PBS data.

These data support national monitoring of service use, procedures and treatments over time. They provide broad population coverage and are collected routinely, allowing trends to be monitored. However, they are not necessarily designed for population health monitoring. Coverage and data quality can vary, and they may lack clinical detail, as well as information on patient experiences and priority population groups.

National administrative data collections that contain some sexual and reproductive health data, and which are currently being explored, are included in Table 8.

Survey data and longitudinal studies

Survey data and longitudinal studies collect information directly from people about their health, behaviours and experiences. These data include information not available in administrative data, such as experiences of care and the experiences of people who do not seek care. They can support analysis of changes over time, particularly where surveys are repeated. However, surveys rely on self-reported information and may be affected by recall and reporting biases. They may also have limited sample sizes for some population groups or conditions and are typically collected less frequently than administrative data.

Some large-scale surveys in Australia include sexual and reproductive health questions relevant to the priority topics and may be used to report prevalence. In some cases, they can also act as proxy measures or provide context where high-quality, nationally representative data are not available. These surveys may help to fill part of a data gap – such as indicating prevalence for a condition or experience – but cannot address all data needs. They can be used until more comprehensive, nationally representative data sources are available.

Survey relevance was assessed by reviewing the most recent questionnaires. Surveys that repeat relevant sexual and reproductive health questions over time have been included to support ongoing monitoring. Relevant surveys currently being explored are listed in Table 9.

Opportunities will be explored to expand existing collections by adding data items or through data linkage. However, filling priority data gaps will likely require substantial development across multiple data collections and topics. It is often not feasible to add a large number of new questions to existing surveys because of constraints on survey length and the need to maintain time series. In many cases, existing questions must be removed to accommodate new content. Survey design decisions sit with data custodians and their relevant governance and advisory groups.

Developing a new survey focused on sexual and reproductive health may be a more effective way to fill many data gaps and incorporate additional priority topics (see National Sexual and Reproductive Health Survey).

National Primary Health Care Data Collection

The lack of nationally consistent primary health care data to support effective population health monitoring, research, policy and planning is well recognised. The AIHW is leading work to fill this gap by developing a National Primary Health Care Data Collection (NPHCDC).

Much sexual and reproductive health care is provided in general practice and community-based settings that are not well captured in existing administrative data sets. The NPHCDC presents an opportunity to understand sexual and reproductive care in primary care settings.

The NPHCDC aims to establish consistent governance, standards, data collection, quality processes, and reporting across the primary health care sector. Initially, it will focus on collecting, analysing and reporting general practice data, with a view to developing and incorporating other primary health care areas (including nursing, Aboriginal Community Controlled Health Organisations and allied health) as soon as practicable.

The lack of nationally agreed and implemented data standards is a major barrier to the availability of comprehensive, high-quality primary health care data.

The AIHW, Primary Health Networks (PHNs) and data extractors are working together on a number of demonstration projects as part of the NPHCDC. These projects test general practice data through assessing data quality, coverage and analytical value prior to national implementation approaches, and harmonising general practice data across extraction systems including aligning clinical terminology and classifications.

The AIHW will continue to undertake demonstration projects focused on sexual and reproductive health to explore how primary health care data can improve the visibility of selected sexual and reproductive health conditions, management and care pathways, while recognising data limitations.

These demonstration projects provide a practical way to:

- explore priority sexual and reproductive health data gaps
- refine data definitions and counting rules
- assess fitness for purpose.

Evidence from recent projects indicates that this staged approach:

- supports shared learning with PHNs and data partners
- informs future data standards and governance
- reduces risk by focusing early investment on areas of highest value.

Further information on the NPHCDC, governance framework, data standards and demonstration projects is available on the AIHW website.

National Primary and Acute Care Data Linkage Project

This project is a partnership by all Australian, state and territory government health departments; the AIHW; Primary Health Networks; general practice; and Aboriginal Community Controlled Health Organisations. It developed a proposal to link de-identified data from general practices with other health data, to improve understanding of patients' journeys across the health system. It is subject to funding; cost-sharing arrangements are being discussed with states and territories.

My Health Record

My Health Record (MHR) has the potential to provide longitudinal sexual and reproductive health information from multiple care settings.

MHR contains a range of clinical documents, including:

- shared health summaries
- pathology and diagnostic imaging reports
- prescription and dispensing information
- hospital discharge summaries
- specialist correspondence.

Internal scoping has identified potential use cases focused on understanding patterns of presentation, diagnosis and management for selected sexual and reproductive health conditions and symptoms across care settings and over time. Currently, MHR data are not available for research or public health purposes. Under the *My Health Records Act 2012*, secondary use for research and public health requires specific governance arrangements to be established, including an independent data governance board, with the AIHW as the legislated data custodian.

Australian Burden of Disease Study

The Australian Burden of Disease Study (ABDS) produces estimates of the health impact of more than 200 diseases and injuries on the Australian population, including the proportion attributable to selected modifiable risk factors. A separate study produces burden of disease estimates for First Nations populations. The ABDS draws on data from multiple data sources to estimate incidence, prevalence, severity and mortality for included conditions.

The latest study (Australian Burden of Disease Study 2024) includes several sexual and reproductive health conditions, such as STIs, endometriosis, infertility and early pregnancy loss. The 2026 study, planned for release in December 2026, is expected to expand coverage to include menstrual cycle disorders and termination of pregnancy.

The ABDS will be a key data source for outcome measures within the sexual and reproductive health work program going forward.

Australia's Disease Expenditure Database

Australia's Disease Expenditure Database provides estimates of health system spending by condition, age group and sex. It includes expenditure on hospital services, primary health care and referred medical services. The database uses the ABDS condition groups and provides estimates for 'well care', including family planning.

The database captures spending from all funding sources across the health system, including state and territory governments, private health insurance and out of pocket payments by individuals. Estimates are derived from multiple data sources, including the National Hospital Morbidity Database and the Health Expenditure Database.

These data could be used to:

- examine spending on sexual and reproductive health conditions and 'well care' across a person's life and over time
- assess how costs are distributed between government, private health insurers, and individuals, including where care disproportionately relies on private insurance or out-of-pocket payments.

Standardise existing data and establish data standards

A data standard is an agreed way to collect and record information so that it means the same thing wherever used. It sets out how data items are defined, coded and reported. For example, it can define how a condition is recorded or how a service is counted.

Establishing national data standards for sexual and reproductive health would support the use of consistent terminology, definitions and coding across primary, tertiary, public and private health settings. This would enable more accurate, comparable and complete data to be collected. Standardised data elements and classifications systems (such as the International Classification of Diseases and Related Health Problems, 10th Revision – ICD-10 and ICD-10-AM):

- reduce variability
- improve data quality
- support linkage across data sets
- enable consistent monitoring of trends, equity and outcomes.

This consistency strengthens the evidence for policy, service planning and research, and supports targeted interventions to improve health outcomes.

Transition to ICD-11

The anticipated transition to ICD-11 across health and care systems in future will enable better data capture of the 5 priority topics with the expanded and new content available in the ICD-11. These include a new chapter for *Conditions related to sexual health* and a restructure and expansion of the categories to reflect current clinical knowledge and terminology for *Diseases of the female genital system*, *Menopausal or perimenopausal disorders* and *Abortive outcome of pregnancy*.

ICD-11 also has a capability of linking related or associated conditions together in a way not possible in ICD-10 (-AM).

An ICD-11 classification capability assessment is currently being undertaken by the AIHW for the 5 initial priority topics to gain more understanding of how ICD-11 can improve and expand data reporting capabilities.

Australian Clinical Data for Interoperability

The Commonwealth Scientific and Industrial Research Organisation (CSIRO) is developing the Australian Clinical Data for Interoperability (AUCDI). This task focuses on developing data groups and data elements that reflect clinical care (patient care) requirements for data entry, use and sharing, including for sexual and reproductive health. AUCDI aims to make the collection, sharing and reuse of clinical information more consistent across tiers and sectors of Australia's health system.

Collate service-level data sources

In this section

This strategy includes collating service-level data sources, including information from state and territory health services, to improve understanding of access to care, service availability and variation across Australia. Sources may include data from specialised services and jurisdictional systems, such as abortion notification collections, where available. This could provide more detailed and timely insights into service delivery, and support more geographically specific reporting, particularly where national data are limited.

However, service-level data are often not standardised across jurisdictions and may vary in coverage, definitions and data quality. Access may also be constrained by governance arrangements, as not all data are available or approved for national reporting. As a result, collation of service-level data is proposed where feasible and alongside other data sources to support consistent national reporting.

State and territory health services data

State and territory organisations that provide specialised sexual and reproductive health services are important sources of data and often also contribute to workforce training and research.

Administrative data from these services could provide insight into access to care for priority populations, including people without access to Medicare. Other aspects of access, such as acceptability of care, could be explored through patient experience surveys or workforce surveys.

Five states and territories currently operate notification systems for terminations of pregnancy completed by health care practitioners. These systems are not standardised, and not all notifications data are accessible or approved for reporting. However, they include some patient and geographical information and provide important insights into termination of pregnancy prevalence, type, gestation and patient characteristics.

Standardising and consolidating these data sets could provide more detailed insights and disaggregation not available from PBS, MBS and hospital data.

Other service-level data sources

Data from service providers and other sources could be standardised and collated, particularly in relation to reasons for service delivery and services provided. The AIHW has identified some types of service provider data that could be considered (for example, workforce training data from programs such as Long-acting reversible contraception (LARC) Centres of Excellence), detailed in Potential data sources.

Use linked data assets

Data linkage refers to the bringing together of information from more than one source that relates to the same person. This allows researchers to tell a bigger story than analysing data from just one source. For example, comparing the data on women who received the HPV vaccination with data on women who developed cervical cancer provided strong evidence that overall, the vaccination was effective in reducing cervical cancer.

This strategy includes using linked data assets to provide a more complete picture of people's use of services and health outcomes. By linking information over time, these assets support analysis of care pathways, including how people access and move through the health system.

This approach enables more detailed and policy-relevant insights than can be obtained from a single data source and can improve understanding of patterns of care and outcomes.

This strategy includes undertaking more in-depth analysis and targeted analytical projects to answer complex questions about care pathways, patient journeys and sexual and reproductive health outcomes.

A range of data linkage assets are held or being developed by the AIHW and other data linkage authorities, including the ABS.

Key data assets that could provide greater insights into sexual and reproductive health include:

- the AIHW's National Health Data Hub (NHDH), a data asset that draws together core administrative health, disability, welfare and aged care data sets
- the ABS's Person Level Integrated Data Asset, a secure data asset that combines information on health, education, government payments, income and taxation, employment and population demographics (including the Census) over time.

Understanding care pathways, symptoms and outcomes related to endometriosis: an example of how data linkage could be used

Linking hospital, perinatal MBS and PBS data with primary health care and other data could show how people with symptoms consistent with endometriosis move through the health system over time.

Linked data could help to show:

- when people first seek care for symptoms of endometriosis
- how often they see different health professionals
- whether symptoms are managed in primary care or lead to hospital admission
- how long it takes to receive a diagnosis of endometriosis, and the factors associated with faster diagnoses
- what treatments are provided, such as medicines or surgery, and the association with certain health outcomes
- what are the fertility experiences and outcomes, such as use of medically assisted reproduction, live births, pregnancy loss or involuntary childlessness
- what are the longer term impacts on health and wellbeing.

Linking hospital data across different types of care also allows related pregnancy outcomes to be analysed. For example, analysis could examine whether people with endometriosis are more likely to experience pregnancy loss, and what care they receive before and afterwards.
Data linkage is complex and requires strong governance, privacy protections and technical infrastructure. Access to linked data may be limited by approvals, data availability and data quality, and linked data may still be constrained by the scope and limitations of the original data sources. As a result, it is recommended that data linkage be undertaken where feasible and alongside other data sources to support robust and appropriate interpretation of findings.

Establish new data collections

In this section

A new data collection may need to be established where no suitable data exist, where there are a substantial number of identified information gaps or where it is not feasible to adapt existing sources to address priority data gaps without substantial changes.

Four new data collections are proposed:

- National Sexual and Reproductive Health Survey
- National Pregnancy Loss Register
- Sexual and Reproductive Health Pharmacy Data Collection
- Health Care Provider Workforce Survey.

New collections can capture information that is not available in administrative or service level data, such as experiences of care, unmet need and outcomes across the broader population.

This approach supports more comprehensive and nationally consistent reporting over time, particularly for areas where current data are limited or do not exist. However, establishing new data collections requires considerable time and resourcing as well as governance arrangements, including those to do with privacy, consent and data quality.

National Sexual and Reproductive Health Survey

A National Sexual and Reproductive Health Survey, conducted every 3 years, has been identified as a key data development activity.

A national survey enables comprehensive, consistent and comparable data collection across multiple sexual and reproductive health topics, in a single data collection. This makes it a cost-effective approach to address a large number sexual and reproductive health data gaps. In contrast, smaller, targeted studies do not necessarily support population-level or time-series insights for ongoing monitoring, though may be cheaper to conduct.

A national survey could support monitoring over time of a large breadth of sexual and reproductive health priority topics and data gaps for men, women, trans and gender diverse people in Australia, to inform and evaluate policy.

Types of information to be collected include (but are not limited to):

- prevalence and severity of symptoms, conditions and events (including pregnancy loss)
- comorbidities with sexual and reproductive health conditions, including other chronic conditions/disease
- preferences and use of sexual and reproductive health-related products, services or treatments
- affordability, availability and quality of care
- unmet need in relation to sexual and reproductive health products, services or treatments
- sexual and reproductive health literacy
- health-seeking behaviours
- impacts on economic productivity, quality of life and a person's physical and mental health
- fertility intentions, outcomes and impacts on family planning, including involuntary childlessness
- stigma in sexual and reproductive health care.

It would be developed in consultation with experts and stakeholders, including government and non-government organisations, academic and research experts, consumer and lived experience groups, community organisations and priority populations.

A self-report survey would enable data to be collected from people who do not seek health care. This would be particularly valuable for people who have experienced pregnancy loss or symptoms related to menstrual disorders, perimenopause and menopause, but who have not had contact with a health care service.

The survey would be designed to be representative of the Australian population and different geographic areas. It would aim to improve representation of key priority populations such as multicultural communities and First Nations peoples. Some priority populations, however, are unlikely to be well-represented or face barriers to accessing this type of survey (such as people experiencing homelessness).

The survey could be designed to monitor sexual and reproductive health issues relevant to policy, including:

- the *National Women's Health Strategy 2020–2030*
- the *National Men's Health Strategy 2020–2030*
- the *National Action Plan for the Health and Wellbeing of LGBTIQA+ People 2025–2035*
- other strategies, including but not limited to National strategies for bloodborne viruses and sexually transmitted infections
- government responses to the Senate inquiry into issues related to menopause and perimenopause and the Senate inquiry into universal access to reproductive healthcare.

The survey cannot replace hospital data, primary care data, pharmaceutical data or other administrative and clinical data. New collections would be developed in a staged way and used alongside existing data sources, where feasible, to address priority data gaps.

Key activities to develop a National Sexual and Reproductive Health Survey

Development of a National Sexual and Reproductive Health Survey would involve staged implementation across design, testing, delivery and reporting as detailed in Table 12.

Table 12: Key activities to develop a National Sexual and Reproductive Health Survey

Key activity	Steps required
Establishment	• establish a technical advisory group and subject matter expert working group • undertake consultations with stakeholders and community organisations to co-develop survey content and confirm priority topics and areas for measurement • review survey methodologies used in jurisdictional, national and international surveys, including collection modes, sampling approaches and strategies to improve response rates and representativeness.
Survey development	• finalise survey content and agree on methodologies for piloting • undertake qualitative and cognitive testing, including focus groups and in-depth interviews • test the validity and reliability of the survey instrument and refine the questionnaire • obtain ethics approval to establish the collection, confirm survey content and support engagement with priority population groups.
Testing and finalisation	• conduct a pilot study and prepare a pilot report for consultation with the advisory group and the Department of Health, Disability and Ageing • refine the survey methodology and questionnaire based on pilot findings • undertake a tender process and establish contractual arrangements with a fieldwork provider.
Delivery and analysis	• undertake survey fieldwork • analyse data and report preliminary results • release initial outputs, including reports or dashboards • prepare a confidential unit record file for external researchers.
Ongoing improvement	• evaluation and refinement prior to subsequent survey waves • ongoing consultation with stakeholders and priority populations • linkage with the National Health Data Hub to enhance analytical capability.

National Pregnancy Loss Register

There is no routine national collection and monitoring of pregnancy loss information in Australia. Existing data sources provide only a partial view of pregnancy loss and associated care, as described in Pregnancy loss in Australia: a data scoping study.

A National Pregnancy Loss Register would draw on and link existing administrative and/or clinical data sets containing data items relevant to pregnancy loss.

Data sets under governance development (such as My Health Record) and undergoing pilot processes (such as the National Primary Health Care Data Collection) are also in scope for future linkage. The register would be similar in concept to the AIHW COVID-19 Register, with the important addition of a self-report arm.

A national register would provide greater visibility of care occurring for pregnancy loss before 20 weeks' gestation beyond hospital data, to include primary care and community service organisations.

This would support improved insights into:

- pregnancy loss prevalence, types and gestation
- clinical information, including associations with other (reproductive) health experiences and outcomes
- contact with the health system and care pathways, including counselling and supportive care
- quality of care and waiting times
- disaggregation by patient, provider and service characteristics and geography, as well as future data linkage opportunities.

A register that links across multiple data collections is particularly relevant given the broad range of conditions associated with pregnancy loss, and the important role of primary and community care pathways for pregnancy loss. A linked register is an efficient way to obtain improved insights into pregnancy loss before 20 weeks' gestation, as it avoids placing extra burden on health care providers and services by automating data collection. Further, it reuses data that already exist.

Data on experiences of care and support for pregnancy loss currently rely on separated research and community organisation surveys. The self-report arm of the register would collect new data, allowing data on experience and outcomes to be collected from people who:

- engage only with primary care (with linkage to their corresponding administrative and/or clinical data with consent)
- have no contact with the health system in relation to their pregnancy loss.

Key activities to develop a National Pregnancy Loss Register

Development of a National Pregnancy Loss Register would involve staged implementation across governance, data collection, data linkage and reporting as detailed in Table 13.

Table 13: Key activities to develop a National Pregnancy Loss Register

Key activity	Steps required
Establishment	• obtain ethics approval • establish advisory arrangements to guide design and implementation • define core pregnancy loss data items and dataset specifications • develop data sharing and collaboration agreements.
Testing and data development	• a primary care demonstration project in partnership with selected Primary Health Networks (PHNs), including consultation with providers and opt-out arrangements • development of a My Health Record use case, including data specifications, quality assessment and initial analysis • development and testing of a self-report mechanism, including question design, cognitive testing and identification of appropriate collection methods.
Expansion, rollout and data linkage	• expansion of the primary care project across additional PHNs • rollout of an opt-in self-report mechanism • integration of data from primary care, My Health Record and other sources into a linked data asset, including development of a shared set of core pregnancy loss data items • development of feedback mechanisms for participating PHNs.
Delivery, analysis and ongoing improvement	• routine reporting from administrative and self-reported data • comprehensive analysis using linked data • development of resources to support the use and interpretation of linked pregnancy loss data.

Sexual and Reproductive Health Pharmacy Data Collection

A national aggregate collection of pharmacy data would improve monitoring of access to sexual and reproductive health medications. As well as data on PBS-subsidised prescriptions and sales, the collection would include data on private or non-subsidised and off-label prescriptions and sales that were not recorded in national administrative data sets. This extra data would support monitoring of the use, affordability and geographic accessibility of sexual and reproductive health related medications and commodities over time. These data would provide important evidence to inform and evaluate policy.

The AIHW is exploring a pilot project to assess data quality, feasibility, supply mechanisms, governance and ethics of such a collection. Development of the National Medicines Record will be monitored to prevent duplication.

Key activities to develop a Sexual and Reproductive Health Pharmacy Data Collection

Development of a Sexual and Reproductive Health Pharmacy Data Collection would involve staged implementation across design, testing and delivery as detailed in Table 14.

Table 14: Key activities to develop a Sexual and Reproductive Health Pharmacy Data Collection

Key activity	Steps required
Establishment, testing, refinement	• establish advisory arrangements • refine data request including consultation around medications for inclusion, data specifications and frequency of data (e.g. monthly, quarterly, annual) • establish streamlined data analysis and regular reporting • data analysis and regular reporting.
Delivery, analysis and ongoing improvement	• refine data request including consultation around medications for inclusion and data specifications • data analysis and regular reporting.

Health Care Provider Workforce Survey

A Health Care Provider Workforce Survey would help to monitor the provision of sexual and reproductive health care, including:

- self-reported sexual and reproductive health literacy
- training in, and provision of, culturally safe and trauma-informed care
- confidence in diagnosis, treatment, prescribing, procedures, screening and other care practices, where relevant
- barriers to providing sexual and reproductive health care
- workplace culture and supports for the provision of sexual and reproductive health care.

It could include an audit of skills and training and assess whether health care providers are working to their full scope of practice, including their ability to perform the activities and responsibilities for which they are educated and trained, and legally authorised, to undertake. Such a survey could provide insight into whether practice aligns with clinical guidelines, and/or how conscientious objection affects practice (or the role of conscientious objection).

Key activities to develop a Health Care Provider Workforce Survey

Development of a Health Care Provider Workforce Survey would involve staged implementation across design, testing and delivery as detailed in Table 15.

Table 15: Key activities to develop a Health Care Provider Workforce Survey

Key activity	Steps required
Establishment	• establish advisory arrangements to guide survey design and implementation • undertake consultations with stakeholders to develop survey content and confirm priority topics and areas for measurement • review survey methods used in similar surveys.
Survey development	• finalise survey content and methods for piloting • undertake pilot testing, including focus groups to inform survey topics, questions, language and terminology • develop the questionnaire and undertake cognitive testing of survey questions • obtain ethics approval to establish the collection and confirm survey content.
Testing and finalisation	• refine the survey methodology and questionnaire based on testing • undertake a tender process and establish contractual arrangements with a fieldwork provider.
Delivery and analysis	• undertake survey fieldwork • analyse data and report initial findings • release initial outputs, including reports or dashboards.

Benefits and limitations of proposed new data collections

Table 16 summarises the rationale for each of the 4 proposed new data collections and outlines their potential strengths and benefits. It also documents limitations, including development timeframes, resource requirements, data quality and comparability issues, reporting burden on services, and governance and privacy considerations.

Table 16: Benefits and limitations of proposed new data collections

New data source	Benefits and strengths	Limitations and contingencies
National Sexual and Reproductive Health Survey (repeated at regular intervals, for example, every 3 years)	Nationally representative; includes priority populations not captured in other collections (including trans and gender diverse people, people who do not access health services, migrants and people without access to Medicare). Supports monitoring over time for many sexual and reproductive health topics (not only the 5 initial priority topics) and enables tracking of trends and changes over time. Provides information on sexual and reproductive health topics either not captured, or poorly captured, in existing administrative and clinical data sets. Enables consistent, comparable national reporting across multiple priority topics using a single data collection. Provides data on experiences, behaviours, needs and outcomes that cannot be measured through existing health system data. Responds directly to strong and consistent stakeholder feedback on the need for a national sexual and reproductive health survey.	Has cost and resourcing requirements. Some priority populations would still not be captured through a survey and ensuring representative samples of small groups may not be possible. May have limited statistical power for rare outcomes or small population groups, even with oversampling. Some disaggregation may not be possible due to data quality or to maintain confidentiality. Relies on self-reported data, which are subject to reporting biases and interpretation of questions. Requires careful management of participant burden and sensitivity.
National Pregnancy Loss Register / linked data asset	Nationally representative when fully established, drawing on national data sets such as hospitals collections. Reduces clinician burden, with no requirement for additional manual data entry. Lower cost, by using existing data. Can be accessed for government policy development and reporting as well as for research purposes. Has a self-report option that allows: • capture of data from people who engage only with primary care or do not engage with the health system for their pregnancy loss • collection of data items not available in existing administrative or clinical data sets. Can be linked to administrative data sets to obtain insights on patient care pathways and care experiences over time.	The register relies on existing data items, which may have their own limitations. There may be potential variability in data accuracy due to differences in coding practices across administrative data sets. The timeliness of reporting may be affected by delays in the availability of some administrative data sources. The self-report option coverage may be limited, as it relies on awareness of, and voluntary completion by, individuals (and would require promotion). It is subject to governance arrangements and funding.

Sexual and Reproductive Health Pharmacy Data Collection	Includes data on all prescriptions dispensed by panel pharmacies and is not limited to PBS-subsidised prescriptions. Can allow data to be disaggregated by PBS status, enabling the visibility of off-label and private prescribing. Enables quantification of over-the-counter product sales, such as emergency contraception. Provides proxy data to support the estimation of out-of-pocket costs across prescription and over-the-counter products.	Pharmacy panel data do not include all retail pharmacies in Australia. The collection does not capture products supplied directly to clinicians or clinics. The collection has reporting limitations where dispensing quantities are low. The collection is subject to governance arrangements and funding.
Health Care Provider Workforce Survey	Would fill a major evidence gap in sexual and reproductive health care relating to workforce capability and capacity, which was raised consistently by stakeholders across most priority topics. Could capture self-reported confidence, knowledge and experience in diagnosing and managing sexual and reproductive health conditions and identify awareness of, or lack of, validated tools, clinical guidelines and care pathways. Supports workforce planning and service capacity by enabling assessment of whether health care providers are working to their full scope of practice. It could also identify gaps in skills and training and support targeted investment in education, training and professional development programs. Would improve understanding of quality and consistency of care and may contribute to identifying unwanted variations in care. Would allow assessment of workforce capability to provide culturally safe and inclusive sexual and reproductive health care.	Relies on self-reported data, which would be subject to recall and social desirability bias. May have a low completion rate, or response rates may vary by profession, setting or region. Adds to the clinical/health care provider reporting burden, which the AIHW is trying to minimise. Requires sensitivity in questions relating to confidence, skills and conscientious objection. Subject to governance arrangements and funding.

Incorporate qualitative data

Quantitative data alone cannot fully capture people's experiences of sexual and reproductive health. This is particularly relevant where data are limited and where access to, and quality of, care vary across population groups.

Qualitative data provide important context to:

- help explain observed patterns
- identify emerging issues
- highlight areas where quantitative data are not yet available.

Qualitative data describe people's experiences, views or behaviours, rather than measuring them with numbers. They are often collected through interviews, surveys, observations or written feedback (for example, people describing barriers to accessing services).

Quantitative data are measured or counted information, using numbers. They show how many, how much, or how often something happens and can be analysed using statistics. They are often collected through administrative records (for example, the number of people who used a service).
As part of sexual and reproductive health reporting, the AIHW will incorporate qualitative data (including case studies and consumer and patient feedback) alongside quantitative data, where appropriate. These data will be used to highlight lived experiences of people accessing sexual and reproductive health care, particularly those from priority populations, and to help identify service barriers and areas for future data development.

Case studies

Case studies may be included in sexual and reproductive health reporting to show how sexual and reproductive health services, policies or programs operate in different settings. These may help to illustrate variation in service delivery across jurisdictions or regions, or to highlight innovative or emerging approaches that have been effective in delivering sexual and reproductive health care.

Case studies could also provide examples of pathways through the health care system and across the life course in relation to sexual and reproductive health experiences, impacts and outcomes.

Consumer feedback and lived experience

Consumer feedback and information on lived experience are essential to understand the impacts of sexual and reproductive health conditions, events and services on the individual, and their partners or families. These perspectives support more inclusive and meaningful interpretation of findings and ensure that the experiences of priority populations are reflected in reporting.

How the Data Strategy will be implemented

In this section

The AIHW has developed an implementation plan for the Sexual and Reproductive Health Data Strategy that distinguishes between short-, medium- and longer-term actions; it provides a staged approach to the development of data. It recognises the capacity of data providers (such as jurisdictions, Primary Health Networks and other service providers), funding constraints and data readiness.

Implementation plan

The development of the Framework and Data Strategy is a discrete piece of work led by the AIHW in consultation with stakeholders. This Data Strategy outlines a broad set of potential actions reflecting the scope and complexity of sexual and reproductive health data in Australia. It identifies priorities, opportunities or key considerations to inform future decision-making and support improved monitoring—not only by the AIHW and the Australian Government, but across the sector.

The implementation plan does not commit that the AIHW will deliver all proposed activities. Table 17 outlines key strategies to consider in developing sexual and reproductive health data and indicates:

- what can be progressed in the short-, medium- and longer-term
- key activities involved to progress strategies
- the dependencies of successful implementation.

Implementation principles

Implementation of the Sexual and Reproductive Health Data Strategy will be guided by the following principles:

Use existing data first: prioritise the use of existing national data collections through enhanced analysis, improved reporting, and data linkage.

Minimise burden on services: data development will seek to reduce burden on clinicians, services, Primary Health Networks (PHNs) and jurisdictions by prioritising data extracted from existing infrastructure and alignment with current reporting processes.

Test approaches first: new approaches will be tested through pilots, demonstration projects or use-case analyses before considering broader implementation.

Focus on equity: equity and priority populations will be considered at each stage of the implementation, including for decisions about data sources, disaggregation and reporting.

Collaborate and consult: ongoing engagement with jurisdictions, PHNs, data custodians and community representatives will be essential to feasibility, quality and trust.

Be transparent about limitations: implementation efforts will be transparent in outlining constraints relating to resourcing, data quality, consent, and governance arrangements.

Table 17: Key strategies, activities and dependencies of implementation plan

Time frame / phase	Key strategy	Key activities	Dependencies
Short term (in progress)	Use existing data sources and collections	Analyse existing data collections to strengthen disaggregation for priority populations where feasible. Analyse and report sexual and reproductive health data items that have not been previously published. Analyse existing national data sets to produce baseline reporting aligned to the Framework.	Data custodian approvals and data-sharing arrangements.
Short term (in progress)	Develop existing data: initial service mapping	Undertake targeted, low-burden service mapping using existing publicly available sources.	Availability of location information on sexual and reproductive health providers and services (by urban, regional and remote areas). Jurisdictional collaboration.

Short term (in progress)	Establish new data collections: Sexual and Reproductive Health Pharmacy Data Collection	The Sexual and Reproductive Health Pharmacy Data Collection will initially be piloted over 6–12 months for a selection of priority topics and potentially published in the first or second phase of reporting. If successful, it will be expanded to other sexual and reproductive health priority topics in the medium term.	Assessment of data quality and suitability. Data governance, privacy and consent arrangements; data custodian and data sharing agreements. Resourcing to establish ongoing collection. Monitoring development of the National Medicines Record to prevent duplication.
Short to medium term	Develop existing data: expand existing collections	Collaborate with data custodians to add or further develop questions, data items or modules to existing surveys or other data collections.	Data custodian agreement; continuity of collections or data items to enable monitoring over time.
Short to medium term (in progress)	Develop existing or planned data collections: pilot primary health care demonstration projects	Progress primary care data demonstration projects in partnership with PHNs and data extractors, harmonisation of data and expand participation by PHNs.	Data governance arrangements; PHN approvals and data extraction agreements; data harmonisation; development of infrastructure.
Short to medium term	Further develop existing data: standardise existing data and establish data standards	Develop and pilot data standards and definitions for selected sexual and reproductive health concepts and conditions; establish expert advisory groups or seek expert advice.	Jurisdictional and PHN engagement, collaboration and approvals; stakeholder and service provider engagement.
Medium term	Use linked data assets	Conduct targeted priority data linkage projects (such as using hospital, MBS and PBS data in the National Health Data Hub) to examine care pathways and outcomes.	Data linkage governance and ethics approvals; resourcing; technical feasibility and data quality assessments.
Medium term	Collate service-level data source: pilot with selected jurisdictions, PHNs or service providers	Identify service providers, PHN and jurisdictional data sources for collation and reporting; assess coverage; review definitions; develop data standards.	Data custodian agreement and data sharing arrangements; privacy consent and governance requirements.
Medium term	Establish new data collections: Health Care Provider Workforce Survey (pilot)	Pilot survey to show value and feasibility.	Workforce capacity and willingness to participate; resourcing.
Medium term	Develop planned data collections: National Primary Health Care Data Collection	Continue exploring the use of primary health care data to address specific sexual and reproductive health data gaps (including data quality, coverage and analytic value), while informing future data standards, governance and collection design.	Expand participation, data harmonisation; data quality assessments; completeness of records, including diagnoses fields.
Longer term	Establish new data collections: National Sexual and Reproductive Health Survey	Develop a nationally representative sexual and reproductive health survey, including design, testing, expert advisory arrangements; full roll-out and reporting, and added to the National Health Data Hub.	Resourcing; tender process to select fieldwork provider; ethics approval; governance arrangements.
Longer term	Establish new data collections: National Pregnancy Loss Register	Progress development of National Pregnancy Loss Register, in consultation with jurisdictions, PHNs, service providers and data extractors. Pilot in a selection of PHNs or regions to show value and feasibility.	Resourcing; ability to automate data extraction and progress of a NPHCDC.
Longer term	Develop existing data sources: My Health Record	Demonstration projects to test feasibility, data quality and fitness for purpose once access pathways are established.	Governance arrangements; funding decisions. Data fields may have different completion rates and depend on uptake and infrastructure developments in different areas.
Longer term	Expand existing data linkage assets	Integrate new collections, such as the National Sexual and Reproductive Health Survey, into the National Health Data Hub.	Ethics approval; strong data governance, privacy and consent arrangements.

Note: this roadmap will be refined as work progresses and through ongoing consultation around priorities, opportunities, resourcing and sequencing.

How data will be used

The Framework and Data Strategy together are designed to deliver regular analysis and reporting that is useful to policymakers, service planners and providers in evidence-based decision-making.

Aligned with the Australian Government Data and Digital Government Strategy, reports will be delivered through a 'digital by design' approach, with accessible web-based outputs that support the development of consistent national monitoring over time (Australian Government 2023). This approach allows for timely updates as data become available and at least annually. Outputs will present what can be measured using available data, with clear information about data limitations, including gaps in coverage, quality and disaggregation.

As presented throughout the Data Strategy, the initial focus of sexual and reproductive health reporting is to establish a nationally consistent evidence base for the 5 identified priority topics. For each topic, outputs will align with the areas of measurement and reflect the identified data gaps and priorities for data development.

In the short term, the AIHW's sexual and reproductive health monitoring and analysis outputs will include:

- accessible, web-based reporting for the 5 priority topics, aligned to areas of measurement
- clear information on what can be measured using available data, including limitations in coverage, quality and disaggregation
- enhanced analysis of existing data, including improved presentation and, where feasible, data linkage.

In addition, the AIHW will remain responsive to emerging government priorities and time sensitive stakeholder needs through targeted or bespoke analysis.

Staged approach to delivery

This reporting model will evolve alongside the work program, with the AIHW initially focused on maximising the value of existing data. A staged approach ensures timely and useful evidence is available to inform policy and service delivery while longer-term data development progresses.

The data strategies for each priority topic provide a practical pathway for development. Not all activities will be undertaken at the same time or by the AIHW. The priority, sequencing and value of actions will be refined through ongoing consultation with subject matter experts, data custodians and stakeholders.

Short-term priorities

Current funding for sexual and reproductive health data spans 3 years (2024–25 to 2026–27). However, many activities extend beyond this period, with most significant data development requiring medium to longer term investment.

Short term activities focus on what can be progressed within the next 6–18 months. These indicate both available data and early development priorities, including data that may be included in the first or second annual sexual and reproductive health report.

Expansion of analysis and reporting over time

As the work program progresses, analysis and reporting can expand in scope and depth to incorporate new data sources and additional topics. This may include more detailed and disaggregated data, with secure access where appropriate to meet the needs of data providers, jurisdictions, PHNs, services and policymakers. This may include access to more localised and granular data, as well as feedback mechanisms to support quality improvement.

How the work program will be overseen and updated

The AIHW intends to regularly review and update the work program to reflect:

- emerging sexual and reproductive health issues
- evolving data needs and stakeholder priorities.

This oversight will support a responsive and evidence-based approach to data development, analysis and reporting.

The AIHW will continue to work in partnership with communities and stakeholders (including people with lived and living experience) to guide the design, interpretation, analysis and reporting of sexual and reproductive health data. This work will include ongoing collaboration with non-government organisations, consumer groups, sector peak bodies, clinical networks and community-controlled organisations, supported by regular feedback processes and clear progress updates.

To support ongoing oversight and engagement, additional structures will be established. These will include:

- **the Sexual and Reproductive Health Stakeholder Collective**, which will provide insight into health, service use and community experiences and contribute to the design, analysis and presentation of data to inform how sexual and reproductive health data are interpreted and reported. Members will be appointed for a fixed term through expression of interest.
- **the Sexual and Reproductive Health User Experience Forum**, which will provide input on terminology, framing and presentation of data for new or substantially revised reporting. Representation will be sought across stakeholder groups through invitation and expression of interest.
- **topic-specific expert advisory panels**, which will provide clinical and technical advice to guide data development, interpretation and reporting for specific topics. Panels will be established as needed and will operate for a defined period.
- **data committees**, which will provide expert technical advice and support consultation and collaboration with data providers and custodians when establishing new data collections.

See the AIHW website and sexual and reproductive health subscriber notices for information on engagement opportunities. Stakeholders can also contact srh@aihw.gov.au for further information.

The AIHW welcomes ongoing engagement to support rigorous, accurate and inclusive reporting on sexual and reproductive health in Australia.

Data privacy and security

Protecting the privacy and confidentiality of individuals and service providers is a core responsibility of the AIHW. All data collected, held and reported under the sexual and reproductive health data strategy will be managed in accordance with the *Australian Institute of Health and Welfare Act 1987*, the *Privacy Act 1988*, the Australian Privacy Principles, and relevant state and territory legislation.

The AIHW applies strong governance, technical and procedural controls across the full data life-cycle, including data acquisition, storage, analysis and reporting. These controls are designed to minimise the risk of identification, misuse or unauthorised access, particularly for sensitive sexual and reproductive health information and for small or potentially identifiable populations.

The Five Safes framework will be applied to manage privacy, confidentiality and secure access throughout the data life-cycle.

All sexual and reproductive health data activities will operate within the AIHW's broader data governance framework, which provides oversight of ethical use, privacy, security and data quality. Governance arrangements include formal data sharing agreements, ethics and privacy assessments where required, and oversight through internal governance committees and project-specific advisory groups.

The AIHW is committed to streamlining data access for external users in line with governance, privacy and confidentiality, and security requirements.

How to measure the success of the Framework and Data Strategy

Success of the Framework and Data Strategy will be reflected in improved availability, quality and use of sexual and reproductive health data over time.

This includes:

- increased coverage of priority topics and priority populations
- enhanced use of existing data
- delivery of new or improved data and analyses.

Success will also be demonstrated by the extent to which data support policy, service planning and system improvement, and by the ability of the monitoring approach to adapt to emerging priorities and stakeholder needs.

Adding more topics in the future

The Data Strategy focuses on 5 priority topics. Additional topics were raised during public consultation and stakeholder engagement as important for future consideration. These are not excluded from the sexual and reproductive health work program. Rather, the initial scope reflects a staged and pragmatic approach to data development. Where relevant, additional topics will also be explored as cross-cutting issues within existing topics.

The Data Strategy is designed to evolve over time to reflect the dynamic nature of sexual and reproductive health for all people in Australia, subject to resourcing, feasibility, the evolving data landscape and future government priorities. Additional priority topics may be added in future or progressed by other organisations, including where complementary data collections, research programs or reporting arrangements already exist. Refer to *Section 2 Sexual and reproductive health is complex* of the Framework for examples of the wide range of conditions and experiences that sexual and reproductive health encompasses.

References

Australian Government (2023) *Data and Digital Government Strategy: The data and digital vision for a world-class APS to 2030*, Australian Government, Canberra.

Technical notes

Table 18: Abbreviations

Term	Description
ABDS	Australian Burden of Disease Study
ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ALSWH	Australian Longitudinal Study on Women's Health
ANZARD	Australian and New Zealand Assisted Reproduction Database
A-PaM	Australian Perimenopause and Menopause Study
ASHR	Australian Study of Health and Relationships
AUCDI	Australian Clinical Data for Interoperability
CSIRO	Commonwealth Scientific and Industrial Research Organisation
ICD-10	International Classification of Diseases and Related Health Problems, 10th Revision
ICD-11	International Classification of Diseases, 11th Revision
LARC	long-acting reversible contraception
LGBTQIA+ people	lesbian, gay, bisexual, transgender and queer people and people with innate variations of sex characteristics and other sexuality or gender diverse characteristics
LSAC	Longitudinal Study of Australian Children
MBS	Medicare Benefits Schedule
MHR	My Health Record
MHT	menopausal hormone therapy
NHDH	National Health Data Hub
NPHCDC	National Primary Health Care Data Collection
PBS	Pharmaceutical Benefits Scheme
PHN	Primary Health Network
PMOS	polyendocrine metabolic ovary syndrome
RPBS	Repatriation Pharmaceutical Benefits Scheme
SDAC	Survey of Disability, Ageing and Carers
SSASH	Australian Survey of Secondary Students and Sexual Health
STI	sexually transmitted infection
TOP	termination of pregnancy
UCC	Urgent Care Clinic(s)

Notes

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Authorship

This report was authored by the AIHW Sexual and Reproductive Health Unit, including (in alphabetical order): Sayler Allen, Shivali Amin, Cathy Claydon, Deanna Eldridge, Quinn Guy, Kate Johnston-Ataata, Nafiseh Khalaj, Susan Manners, Brooke Petzke, Lucy Stackpool-Moore, Nellie Thomson and Kari Vallury. Contributions by Adrian Webster are gratefully acknowledged.

Related material

Resources

Sexual and reproductive health – Data strategies for the 5 priority topics

Resource
PDF 900kB

Summary: a strategy for monitoring sexual and reproductive health data in Australia

Resource
PDF 639kB

Bringing focus: a monitoring framework for sexual and reproductive health in Australia

Resource

Pregnancy loss in Australia: a data scoping study

Resource

Related topics

- Sexual & reproductive health
- Women's health