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Appendix F

Pregnancy loss before 20 weeks' gestation (including miscarriage): topic overview and data strategy

Caution: Some people may find parts of this content confronting or distressing, including content relating to pregnancy loss and termination of pregnancy. Please carefully consider your needs when reading the following information.

F.1 Topic overview

Background

The following topic overview is a summary of the key data gaps based on findings from literature reviews, data scoping and stakeholder consultation activities. Section F.2 identifies existing data sources and options for new data collection.

Pregnancy loss before 20 weeks' gestation (including miscarriage) (abbreviated to 'pregnancy loss') is a common reproductive health experience that can have significant physical, emotional, and psychological impacts on all individuals involved in the pregnancy (Farren et al. 2016; Farren et al. 2018; Farren et al. 2020). For the purposes of this work program, pregnancy loss is defined as the unplanned loss of a pregnancy before 20 weeks' gestation. In stakeholder consultations, the term 'pregnancy loss' was preferred to miscarriage as it encompasses all forms of pregnancy loss before 20 weeks' gestation, for example, ectopic pregnancy and molar pregnancy, in addition to miscarriage (AIHW Stakeholder Consultations 2025). The term 'miscarriage' includes complete, incomplete, missed, threatened and recurrent miscarriage (as defined by RANZCOG 2025). The AIHW will use both 'miscarriage' and 'pregnancy loss' where appropriate, reflecting the terminology used in the literature or data sources being referenced. Where 'miscarriage' is used, it is intended to align with the original source material or clinical coding, while 'pregnancy loss' will be used to refer to the broader spectrum of pregnancy loss experiences.

Estimates of miscarriage prevalence vary widely due to inconsistent definitions and data collection methods, with studies suggesting rates between 16% (aggregated European and North American data) to 34% (Australian data) (Quenby et al. 2021; Richters et al. 2022). One study found that 22% of people who had experienced miscarriage reported two losses, and 16% reported three or more (Richters et al. 2022). Despite its prevalence, pregnancy loss remains under-recognised in health data, policy, and service planning in Australia, with no routine, nationally consistent collection or reporting of data on pregnancy loss prevalence, recurrence, or quality of care.

Australian survey data suggests that young people, individuals in their late 30s and 40s, those with lower levels of educational, and individuals with disabilities are more likely to report experiencing miscarriage (Hure et al. 2012; Jean Hailes for Women's Health 2020). Higher rates of miscarriage have also been observed among women with fewer live births, those who smoke, and those who have experienced prolonged infertility (Hure et al. 2012). Biological and environmental factors such as embryonic defects, endometrial health, and exposure to pollutants have also been associated with increased miscarriage risk (Huang et al. 2020; Quenby et al. 2021).

Stakeholder consultations and published research have highlighted a range of barriers to appropriate care and support for pregnancy loss at all stages of the conception, pregnancy and pregnancy loss journeys:

- During conception and pregnancy, limited access to dedicated early pregnancy assessment services (EPAS), particularly in rural and remote areas, can delay timely care. Stigma around disclosing pregnancy during the first trimester may also prevent individuals from seeking support, contributing to isolation and distress in the event of pregnancy loss (AIHW Stakeholder Consultations 2025).
- Unclear and inaccessible guidance for individuals on clinical pathways to follow in the event of pregnancy loss prevent individuals from accessing the support they require.
- Limited training and support for health professionals in providing trauma-informed, culturally safe care and mental health support following pregnancy loss have been associated with higher levels of anxiety, depression and post-traumatic stress (Farren et al. 2016; Farren et al. 2018; Farren et al. 2020).
- AIHW stakeholder workshops identified significant barriers to tissue collection and karyotyping, particularly outside of major metropolitan hospitals, which can limit understanding of the causes of pregnancy loss and potential value of future reproductive care and intervention (AIHW Stakeholder Consultations 2025).

Priority populations

Understanding experiences of different groups within the population is necessary to inform policy and ensure equitable healthcare outcomes in Australia, including in relation to access. Recognising the intersectionality among different population groups is also important to understand the complexity of these experiences.

The following priority populations have been identified through the stakeholder consultation process and literature review in relation to pregnancy loss, but this is not intended to be an exhaustive list. Identifying priority populations affected by pregnancy loss is challenging due to the absence of comprehensive national data on who is experiencing pregnancy loss and how they access care. A full list of priority populations considered within the framework and data strategy is available in the Sexual and Reproductive Health Monitoring Framework and Data Strategy document, Section 2.5.

First Nations people

First Nations individuals experience higher rates of stillbirth, an experience correlated with pregnancy loss, in part due to barriers in accessing culturally safe and appropriate care (Kilcullen et al. 2022; AIHW Stakeholder Consultations 2025). AIHW consultations identified that some First Nations people wish to complete their pregnancy loss on Country in alignment with their cultural values. If the individual is living in a remote or rural area without a health service nearby, they may be required to travel far from home and community during a time of grief and vulnerability.

People living in regional, rural and remote areas

People living in regional, rural and remote areas face challenges in accessing early pregnancy care. The absence of dedicated EPAS in these areas means many people must travel long distances to receive diagnosis, treatment and support, which can increase distress and delay care (AIHW Stakeholder Consultations 2025).

People with low health literacy in relation to mental health

People with low health literacy in relation to mental health, and particularly those who are culturally and linguistically diverse, including recent migrants, may not recognise or seek help for emotional distress following pregnancy loss, resulting in unaddressed grief, anxiety, or trauma (AIHW Stakeholder Consultations 2025). For people from culturally and linguistically diverse backgrounds, this is further hampered by barriers in accessing culturally safe and appropriate care.

Critical data gaps and priority areas for data development

Through the literature review and consultation process, the AIHW identified 5 overarching data gaps relating to pregnancy loss in Australia, along with a series of priority areas for data collection and development to begin to address these.

Table F.1 Critical data gaps and priority areas for data development

Data gap	Priority for data development
Disaggregated[1] national data on pregnancy loss prevalence	Collate national data on pregnancy loss prevalence disaggregated by type (e.g. miscarriage, ectopic, molar), gestational age, recurrence, and demographic characteristics (including priority populations and geography)
Access to and quality of care (e.g. where and when individuals seek care, wait times, service availability)	Monitor the availability of pregnancy loss services, including the number and distribution of EPAS Collect data on care pathways and pregnancy loss management, including: • alignment with current clinical guidelines • wait times for assessment in emergency departments and EPAS and surgical management in hospital settings Identify and monitor health professional knowledge and practices, including training in trauma-informed and culturally safe care
Mental health outcomes following pregnancy loss (e.g. grief, anxiety, post-traumatic stress disorder, depression)	• Monitor mental health outcomes following pregnancy loss • Monitor referral to, availability and uptake of mental health support and grief counselling following pregnancy loss
Health literacy	Measurement and monitoring of pregnancy loss health literacy, disaggregated, and the accessibility of accurate and appropriate (culturally, linguistically, practically) information.
Significant overlap between pregnancy loss and termination of pregnancy (abortion) in data collections	Data collection to allow counts of procedures for pregnancy loss as distinct from termination of pregnancy.(a)

NOTE: Where "disaggregation" is used, this is referring to disaggregation by geographic and demographic characteristics, including regarding all priority populations listed in Section 2.5 of the monitoring framework.

a) Stakeholder consultations identified the separation of MBS item numbers for pregnancy loss and TOP procedures as a priority for data development. As the MBS is not designed to provide explicit data on reasons or causes for procedures, expanding the level of detail for pregnancy loss and TOP procedures would be at odds with the purpose of the MBS. The AIHW will explore alternate methods of collecting distinct counts of pregnancy loss and TOP procedures

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[1] Age, geographic region (patient, provider, pharmacy) – LGA, SA3, PHN, state, remoteness, ethnicity, language spoken at home, sexual orientation, gender identity, household income, disability type (e.g. autism), socioeconomic status, migrant status, residency/visa/Medicare status, homelessness, provider type (nurse, general practitioner etc.)

Additional data gaps

The following data gaps were also identified but deemed, through the consultation process, to be of a lower priority for data development at this time:

- Data collection regarding genetic status of conceptus (euploid versus aneuploid), and access to and advice on genetic testing options.
- Differentiating between pregnancy loss caused by chromosomally abnormal embryos (aneuploid) and those involving chromosomally normal (euploid) embryos is critical for understanding pathophysiological causes and informing future care.
- Karyotyping can be valuable, particularly for people with recurrent pregnancy loss or those not undergoing IVF, but routine testing for all may not be economically or clinically justified.
- Data collection regarding environmental exposures, including geocoding and other approaches to capture information on air quality, water quality, heavy metals.

F.2 Data strategy for pregnancy loss before 20 weeks’ gestation (including miscarriage)

The context and scope of each section of this table is described in Appendix J.

Priority area for development	What to monitor (areas of measurement) [(a)]	How to measure it [(b)]	Potential data sources	Current status [(c)]	Options for development of existing data sources	Options for new data collections: establish a new collection or standardise and collate existing data	MF domains, subdomains and outcomes
Collate national data on prevalence of pregnancy loss disaggregated by type, gestational age, recurrence, and demographic characteristics.	National annual pregnancy loss incidence. Disaggregation by type of pregnancy loss. Gestational age at pregnancy loss. Recurrent pregnancy losses experienced and their frequency. Disaggregation by priority population. Disaggregation at lowest reportable geographic level.	National surveys National register Health records	Australian Longitudinal Study on Women’s Health Australian Study of Health and Relationships National Hospital Morbidity Database (NHMD)	Very limited / fragmented - refer to Appendix J Requires significant development	Explore additional analysis of national administrative data collections (e.g. NHMD). Strengthen/improve disaggregated data in national collections.	**National survey:** Develop an ongoing nationally representative SRH survey. **National Register:** Develop a national register (completion by health care providers), with potential for data linkage. **Primary health care data:** Explore feasibility of using the national primary health care data collection (once available).	2.1; 2.3

Priority area for development	What to monitor (areas of measurement) [(a)]	How to measure it [(b)]	Potential data sources	Current status [(c)]	Options for development of existing data sources	Options for new data collections: establish a new collection or standardise and collate existing data	MF domains, subdomains and outcomes
Monitor the availability of pregnancy loss services.	Number and locations of early pregnancy assessment services (EPAS). EPAS opening hours. Distance travelled to access EPAS. Availability (and uptake) of genetic testing options.	Service mapping	No data currently exist	No data currently exist	n.a.	**Suggestions:** - Explore feasibility of developing geo-mapped database of healthcare providers and data on service availability and accessibility. - Explore scope and content of the National Audit of EPAS, when available	6.1; 6.2; 6.3 9.5
Collect data on care pathways and pregnancy loss management, including for complications.	Identify sequential encounters with the health system associated with the same event, disaggregated by patient demography, geography and pregnancy loss type. Wait times for assessment in emergency departments and EPAS.	National surveys National register	No data currently exist	No data currently exist	n.a.	**National survey:** Develop an ongoing nationally representative SRH survey. **National Register:** Develop a national register (completion by health care providers), with potential for data linkage. **Primary health care data:** Explore feasibility of using the national primary health care data collection (once available).	4.2; 4.3 5.1; 5.2 7.1; 7.2 O10

Priority area for development	What to monitor (areas of measurement) [(a)]	How to measure it [(b)]	Potential data sources	Current status [(c)]	Options for development of existing data sources	Options for new data collections: establish a new collection or standardise and collate existing data	MF domains, subdomains and outcomes
Identify and monitor healthcare provider knowledge and practices.	Awareness of clinical guidelines. Pregnancy loss management in alignment with current clinical guidelines. Availability and uptake of training in trauma-informed and culturally safe care.	Workforce (nurses, midwives, doctors) surveys Clinical audits Patient experience surveys Participation in professional development training	No data currently exist	No data currently exist	n.a.	**Primary health care data:** Explore feasibility of using the national primary health care data collection (once available). **Workforce survey:** Explore the value of developing a national audit of healthcare providers or workforce survey.	8.1 9.1; 9.4 10.3; 10.4 17.1 O22
Identify and monitor healthcare provider knowledge and practices.	Self-reported quality of care, service-level barriers to uptake of medical/ surgical management encountered, and level of trauma-informed and culturally safe care.	National survey	No data currently exist	No data currently exist	n.a.	**National survey:** Develop an ongoing nationally representative SRH survey.	3.1 4.1 O5; O13; O14; O15
Monitor mental health outcomes following pregnancy loss (including partners).	Self-reported mental health outcomes (anxiety, depression, post-traumatic stress disorder) after experiencing pregnancy loss.	National survey	No data currently exist	No data currently exist	n.a.	**National survey:** Develop an ongoing nationally representative SRH survey.	O2; O3; O4

Priority area for development	What to monitor (areas of measurement) [a]	How to measure it [b]	Potential data sources	Current status [c]	Options for development of existing data sources	Options for new data collections: establish a new collection or standardise and collate existing data	MF domains, subdomains and outcomes
Monitor referral to, and/or availability and uptake of mental health support and grief counselling following pregnancy loss (including partners).	Referrals to mental health services, community services organisations, and advocacy/research bodies.	Health records (e.g. primary care, MBS codes, hospitalisations, specialist services)	No data currently exist	No data currently exist	n.a.	**National Register:** Develop a national register (completion by health care providers), with potential for data linkage. **Primary health care data:** Explore feasibility of using the national primary health care data collection (once available) - number of referrals to mental health support and number of referrals completed.	5.2 6.1; 6.2; 6.3
Measure and monitor pregnancy loss health literacy.	General public knowledge and awareness of: • all possible pregnancy outcomes, • pregnancy loss types and definitions, prevalence, risk factors and protective factors, and • when and where to seek health care for pregnancy loss. Disaggregation by priority populations and geography.	National survey	No data currently exist	No data currently exist	n.a	**National survey:** Develop an ongoing nationally representative SRH survey.	1.1

Priority area for development	What to monitor (areas of measurement) [(a)]	How to measure it [(b)]	Potential data sources	Current status [(c)]	Options for development of existing data sources	Options for new data collections: establish a new collection or standardise and collate existing data	MF domains, subdomains and outcomes
Measure and monitor the accessibility of trustworthy and appropriate (culturally, linguistically, practically) information resources.	Presence and use of trustworthy information: • in various formats (text, audio, video), • in language, • that is culturally appropriate, and • in plain English. Provision of accessible information by healthcare providers.	National surveys Resource audit	No data currently exist	No data currently exist	n.a.	**Suggestions:** • Partnerships with existing organisations for data collection and review of existing data. • Qualitative research studies to understand cultural safety, inclusiveness, and complaints experiences. • Explore options to evaluate/audit information resources available.	1.2

Note: The focus of this work is on addressing gaps in information and data and to not duplicate work currently being undertaken or in development.

(a) The aim is to report priority populations for all areas of measurement where possible. This includes age, geographic region (patient, provider, pharmacy) – LGA, SA3, PHN, state, remoteness, ethnicity, language spoken at home, sexual orientation, gender identity, household income, disability type (e.g. autism), socio-economic status, migrant status, residency/visa/Medicare status, homelessness, provider type (nurse, general practitioner etc.).

(b) In the absence of comprehensive prevalence/primary data, multiple supplementary data sources may need to be used.

(c) 'Very limited/fragmented data' indicates that only one or two data points/questions are available in the current source; whereas 'Partially available' means that it includes data that could partially answer some of the priority areas for development but still requires significant development/expansion. Refer to Appendix J for a summary of existing national data sources that capture some SRH data across the initial priority areas.

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Sexual and Reproductive Health Monitoring Framework and Data Strategy

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