

D.1 Topic overview

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 D.2 identifies existing data sources and options for new data collection.

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 and PCOS, or their cause may be unknown. People may also have symptoms that are unrelated to the menstrual cycle phase, such as pelvic pain, which may indicate an underlying menstrual disorder or condition. Table D.1.1 shows the complex cross-over between selected menstrual disorders, symptoms and underlying conditions.

Menstrual disorders, symptoms, and underlying conditions can interfere with life activities, reduce quality of life, and impact fertility. They may change over the life course and can alleviate after a person experiences menopause.

For the first phase of the SRH work program, the topic focuses on the menstrual disorders, symptoms, and underlying conditions highlighted in green. These include:

- Heavy menstrual bleeding (HMB), including iron deficiency and iron deficiency anaemia
- Pelvic pain, including dysmenorrhea
- Endometriosis and adenomyosis
- Polycystic Ovary Syndrome (PCOS).

Future phases of the work program may be expanded to include other menstrual disorders, symptoms and related conditions.

Table D.1.1 Selected menstrual disorders, symptoms and conditions

Menstrual disorders and symptoms	Endometriosis	Adenomyosis	PCOS	Uterine fibroids
Abnormal Uterine Bleeding (AUB): absent (amenorrhea) or infrequent bleeding	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
AUB: Irregular cycles	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
AUB: Heavy menstrual bleeding (menorrhagia)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Pelvic pain	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Dysmenorrhea (painful periods)	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>
Fertility issues	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>	<input checked="" type="radio"/>
Mental health conditions	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Hirsutism, acne and female pattern hair loss	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Weight gain	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Insulin resistance	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Pregnancy complications	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>
Pain during or after sex (dyspareunia)	<input checked="" type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Note. This table lists some of the commonly reported menstrual disorders, symptoms, and conditions. An individual may experience some, or none, of the menstrual disorders and symptoms listed. Menstrual disorders may be caused by other conditions or may have no identifiable cause. Some conditions frequently co-occur.

Background

HMB, including iron deficiency and iron deficiency anaemia

HMB (also known as menorrhagia) is the most common type of abnormal uterine bleeding (Shapley et al. 2004). It is defined as 'excessive menstrual blood loss which interferes with a woman's physical, social, emotional and/or material quality of life. It can occur alone or in combination with other symptoms' (ACSQHC 2024a; Committee on Adolescent Health Care 2019). Prevalence estimates, utilising linked survey data and administrative health data, demonstrate HMB is common among Australian women. It increases with age and is most common in the late pre-menopause and perimenopausal phases of life, found to affect 32% of women by the age of 48 years (Wilson et al. 2025).

Stakeholder consultations also identified iron deficiency and iron deficiency anaemia, a condition related to HMB and endometriosis (Gete et al. 2024). This was reported as a common reason for presentation to primary care. Iron deficiency and anaemia can affect cognitive and physical performance (Bruner et al. 1996; Camaschella 2015).

Pelvic pain, including dysmenorrhea

Pelvic pain is very common among Australian women, with 47% of women (aged 18 years or older) reporting they had experienced pelvic pain in the last 5 years in 2023 (Jean Hailes 2023).

Pelvic pain includes dysmenorrhea, often referred to as period pain. Dysmenorrhea can be due to menstruation alone, called primary dysmenorrhea, or because of an underlying cause, called secondary dysmenorrhea (Christensen 2024; Committee on Adolescent Health Care 2018). Dysmenorrhea has been estimated to affect almost three quarters of school and university aged women internationally (Armour et al. 2019).

Endometriosis and adenomyosis

Endometriosis is a chronic, inflammatory, gynaecological disease where tissue similar to the lining of the uterus is found outside of the uterus (RANZCOG 2025). It is the most common condition underlying dysmenorrhea in adolescents (Committee on Adolescent Health Care 2018).

Robust prevalence estimates, utilising linked survey data and administrative health data, indicate endometriosis is common in Australia (AIHW 2023). Endometriosis diagnosis increases with age, until middle age (AIHW 2023). By age 44-49, the cumulative prevalence of clinically confirmed and suspected endometriosis among women born between 1973-78 in Australia is 14% (AIHW 2023).

More women are being diagnosed with endometriosis at younger ages. At 31 years old, 6.9% of women born between 1973-78 had been diagnosed with endometriosis, compared to 9.2% of women who were born between 1989-95. This may be due to increasing awareness (AIHW 2023).

Adenomyosis is a closely related condition where tissue similar to the lining of the uterus grows in the muscle layer of the uterus (Healthdirect 2024). It can occur on its own or with endometriosis, the two conditions often co-occur (RANZCOG 2025). Compared with endometriosis there is less research and guidance regarding adenomyosis (RANZCOG 2025). The epidemiology of adenomyosis is difficult to ascertain: study designs are often reliant on hysterectomy for diagnosis (Upson & Missmer 2020), and diagnostic codes are combined with endometriosis (AIHW 2023).

Polycystic Ovary Syndrome (PCOS)

PCOS is a multi-system condition, which can cause abnormal uterine bleeding. It has metabolic, reproductive, psychological and dermatological features (Teede et al. 2023). PCOS is common, affecting around 1 in 10 women (March et al. 2010, Bozdag et al. 2016) and is the second highest contributor of non-fatal burden from reproductive and maternal conditions (AIHW 2024).

Barriers to care for people experiencing menstrual disorders, symptoms and related conditions

Stakeholder consultations and published research have highlighted a range of barriers to appropriate care and support for people with menstrual disorders, these include:

- Healthcare pathways to diagnosis and treatment of endometriosis and PCOS can be long and complex, with inadequate information provision upon diagnosis (AIHW 2023; Armour et al. 2020; O'Hara et al. 2022, Gibson-Helm et al. 2017; Gibson-Helm et al. 2014). People can experience long wait times for referrals and specialists (such as gynaecologists) and may have difficulty advocating for appropriate referrals and diagnostic testing (AIHW Stakeholder Consultations 2025). These delays can impede timely interventions and can impact fertility outcomes (Moss et al. 2021).
- Lack of consistent standardised definitions and diagnostic criteria limits the ability to report accurate prevalence estimates and understand how many people in Australia are affected, and if prevalence is higher among some populations.
- Training for general practitioners (including during medical school and residency) and other healthcare providers on menstrual disorders is minimal. This leads to a lack of awareness and ability to diagnose and treat menstrual-related conditions (AIHW Stakeholder Consultations 2025).
- Low health literacy. There is a lack of education on menstrual disorders and awareness of abnormal menstrual symptoms among the general population and symptoms are often normalised (AIHW Stakeholder Consultations 2025).
- Parents may hold values or stigma relating to contraceptives. They may have limited knowledge of their use for management of menstrual disorders, symptoms or underlying conditions. This may prevent children in their care from being able to utilise hormonal contraceptives for management of menstrual symptoms and conditions (AIHW Stakeholder Consultations 2025).
- Geographical barriers and service access, particularly for First Nations, and culturally and linguistically diverse people who face additional barriers such as language barriers and access to culturally appropriate services and information (AIHW Stakeholder Consultations 2025).

- Lack of coordination between primary care, emergency care, and specialty services, leading to fragmented care (AIHW Stakeholder Consultations 2025).
- PCOS is often overlooked in prenatal care, despite increasing risk of pregnancy complications (AIHW Stakeholder Consultations 2025).
- Menstruation is stigmatised in many communities, and people do not feel comfortable talking about their menstrual symptoms, limiting help-seeking behaviour, particularly for certain populations (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 were identified through the stakeholder consultation process and literature review in relation to menstrual disorders, but this is not intended to be an exhaustive list. 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

- The rates and impact of menstrual disorders among First Nations people is unknown, however existing limited research indicates there may be higher rates of PCOS among some groups (Boyle et al. 2012).
- Stakeholders identified connecting First Nations people with information about menstrual disorders as a barrier to care. There is no Australian research on beliefs and menstrual health practices of First Nations people (Ciccia et al. 2023).
- There are lower rates of hospitalisation for endometriosis among First Nations people (AIHW 2023). This could be indicative of inadequate access to health services.

People living in regional, rural and remote areas

People with menstrual disorders living in rural and remote areas may have difficulty accessing, or be unable to access, best-practice care. For example:

- There are known inequities in access to best-practice care of HMB between regional and other areas. This is demonstrated in consistently higher rates of hysterectomy and lower rates of endometrial ablation, which represent the final treatment and preferred earlier treatment options for HMB, respectively (ACSQHC 2024b).
- There are lower rates of hospitalisation for endometriosis among people living in remote and very remote areas and living in lowest compared to highest socioeconomic areas (AIHW 2023).

Young people

- In adolescents, dysmenorrhea can interfere with life activities and education (Armour et al. 2019; Parker et al. 2010). It can negatively impact performance and concentration in the classroom, and lead to absence from school or university (Armour et al. 2019).
- Young people may not be aware of what symptoms are abnormal and when they should seek care.
- Young people have limited autonomy in their care, decisions can be mediated by parent's knowledge and values, such as of hormonal contraceptives (AIHW Stakeholder Consultations 2025).
- It is very common for young people to present to general practitioners with iron deficiency and iron deficiency anaemia related to HMB (AIHW Stakeholder Consultations 2025).

People who are culturally and linguistically diverse, including recent migrants

- An Australian study indicates that the prevalence of pelvic pain may be higher among women who spoke a language other than English at home (Jean Hailes 2023).
- Consideration of healthcare service availability also needs to recognise socio-cultural barriers, such as taboo, access to trusted female GPs, or prior negative experience with health services (Henry et al. 2020).

People with comorbidities

- Stakeholders noted a lack of data and research on the comorbidities of mental health and menstrual disorders, and mental health service usage (AIHW Stakeholder Consultations 2025).
- Stakeholders noted that conditions such as uterine fibroids, adenomyosis and PCOS frequently co-occur among people with endometriosis, but better data is needed to understand these and other comorbidities (AIHW Stakeholder Consultations 2025).

LGBTQIA+ people

- Stakeholder consultations identified that transgender men and some gender diverse people (assigned female at birth) may find menstruation and bleeding cause gender dysphoria. Health care professionals and pathways should be safe and affirming (AIHW Stakeholder Consultations 2025).
- Stakeholder consultations identified that transgender men may experience higher rates of menstrual disorders than cisgender women (AIHW Stakeholder Consultations 2025).

People with disabilities and/or who are neurodivergent

- Differences in experiencing and communicating pain, challenges with interoception, and higher pain thresholds can be barriers to receiving care for people with intellectual disabilities and people with autism (AIHW Stakeholder Consultations 2025).
- Data is needed on menstrual disorders and related conditions among people with lifelong disabilities (AIHW Stakeholder Consultations 2025).
- There is a lack of data on people with disabilities intersection with fertility care and reproductive justice (AIHW Stakeholder Consultations 2025).

Critical data gaps and priority areas for data development

A review of the literature and stakeholder consultations has identified the most significant data gaps relating to menstrual disorders, symptoms and related conditions in Australia. These findings have informed the following priorities for data development to address these gaps.

Table D.1.2 Critical data gaps and priority areas for data development

Data gap	Priority for data development
Comprehensive national data on prevalence of menstrual disorders and comorbidities over time.	<p>Collate data on prevalence, including primary care data, to strengthen and disaggregate¹ national estimates for endometriosis and HMB over time. Data on comorbidities of menstrual disorders and frequency of co-occurring conditions (e.g. endometriosis and adenomyosis).</p> <p>Collate data on prevalence to establish disaggregated national estimates for adenomyosis, iron deficiency and iron-deficiency anaemia, pelvic pain, dysmenorrhea, PCOS, and comorbidities.</p>
Impacts of menstrual disorders on quality of life.	Measure and monitor the impact of menstrual disorders on relationships, daily activities, performance/attendance at school and work, and mental health.
Use of hormonal contraceptives for management of symptoms and conditions, and other forms of symptom management, over time.	<p>Capture data on use of hormonal contraceptives and other symptom management.</p> <p>Capture data on acceptability of hormonal contraceptives for the management of symptoms and conditions.</p>
Health literacy over time.	<p>Measure and monitor health literacy relating to abnormal symptoms of menstruation, particularly among young people and parents.</p> <p>Measure and monitor awareness and accessibility of trustworthy and appropriate sources of information on menstrual disorders and related conditions.</p>

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.)

Data gap	Priority for data development
Time taken to diagnosis and treatment/management of menstrual disorders and related conditions, over time.	Collect data differentiating between age at first noticing symptoms, first seeking care, diagnosis (suspected and confirmed), and treatment or management of symptoms.
Access to and quality of care (e.g. where and when individuals seek care, wait times, service availability).	<p>Monitoring the availability of and geographical distribution of services including Endometriosis and Pelvic Pain Clinics (EPPCs).</p> <p>Monitoring wait times for assessment in EPPCs and other specialists; diagnostic tests and surgeries in hospitals.</p> <p>Collect data on care pathways and menstrual disorders management.</p> <p>Capture data on barriers to seeking or accessing care.</p>
National data standards.	Develop national data standards that reflect diagnostic criteria to inform consistent data collection.
Healthcare provider capability, capacity, and wellbeing/support.	<p>Monitor training provided for GPs and other healthcare providers on menstrual disorders and related conditions.</p> <p>Measure and monitor healthcare provider confidence diagnosing and treating people with menstrual disorders and related conditions.</p> <p>Measure and monitor alignment to care standards and clinical guidelines.</p>
Costs associated with menstrual disorders.	Identify and monitor costs to individuals associated with menstrual disorders and accessing healthcare services, tests, procedures, and medications.

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.

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:

- Validated tools for diagnosis and consistent coding.

D.2 Data strategy for menstrual disorders, symptoms and related conditions

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 ^(c)	Current status ^(d)	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 data on prevalence, including primary care data, to strengthen and disaggregate national estimates for endometriosis and HMB over time.	Proportion of people with confirmed and suspected endometriosis.	Health records (primary care, hospitalisations, specialist clinics, diagnostic imaging reports)	ALSWH MBS	Partially available - refer to Appendix J	Expand/add questions to national surveys/ longitudinal studies	National survey: Develop an ongoing nationally representative SRH survey.	2.1; 2.2; 2.3
	Proportion of people with HMB.	Medicare records Insurance/private health claims Longitudinal cohort studies National surveys National registries Data linkage Data tracking apps	PBS Hospitalisations and ED				

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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
Data on comorbidities of menstrual disorders and frequency of co-occurring conditions (e.g. endometriosis and adenomyosis).	Proportion of people with multiple menstrual disorders or related conditions, or comorbidities, disaggregated by conditions and comorbidities.	Health records (primary care, hospitalisations, specialist clinics, diagnostic imaging reports) Medicare records Insurance/private health claims Longitudinal cohort studies National surveys National registries Data linkage Data tracking apps	ALSWH MBS PBS Hospitalisations and ED	Partially available - refer to Appendix J	Expand/add questions to national surveys/longitudinal studies. Explore data linkage opportunities (National Health Data Hub) Explore additional analysis of national administrative data collections	National survey: Develop an ongoing nationally representative SRH survey. Primary health care data: Explore feasibility of using the national primary health care data collection (once available). Pharmacy data: Explore feasibility of establishing an ongoing national pharmacy data collection.	2.1; 2.2; 2.3

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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 data on prevalence to establish disaggregated national estimates for adenomyosis, iron deficiency and iron-deficiency anaemia, pelvic pain, dysmenorrhea, PCOS, and comorbidities.	Proportion of people with adenomyosis, iron deficiency and iron-deficiency anaemia, pelvic pain, dysmenorrhea, or PCOS and comorbidities.	Health records (primary care, hospitalisations, specialist clinics, diagnostic imaging reports) Medicare records Insurance/private health claims Longitudinal cohort studies National surveys National registries Data linkage Data tracking apps	ALSWH MBS PBS Hospitalisations and ED ANZARD Intergenerational Health and Mental Health Study (National Health Measures Study)	Very limited / fragmented - refer to Appendix J	Expand/add questions to national surveys/ longitudinal studies. Explore additional analysis of National administrative data collections (e.g. PBS, mental health services). Explore data linkage opportunities (National Health Data Hub).	National survey: Develop an ongoing nationally representative SRH survey (priority populations, geography). Primary health care data: Explore feasibility of using the national primary health care data collection (once available). Pharmacy data: Explore feasibility of establishing an ongoing national pharmacy data collection. Other suggestions: Explore potential of diagnostic imaging reports and pathology data.	2.1; 2.2; 2.3

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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 impact of menstrual disorders on relationships, daily activities, performance/ attendance at school and work, and mental health.	<p>Self-reported interference of menstrual disorders and related conditions with a person's daily life e.g. absences from work or school, performance at work or school, relationships, participating in activities.</p> <p>Self-reported quality of life and psychological distress using validated tools.</p>	<p>National surveys</p> <p>Data tracking apps</p>	<p>Longitudinal Study of Australian Children</p> <p>Periods, pain and endometriosis (PEPP talk) survey</p>	Very limited / fragmented - refer to Appendix J	<p>Expand/add questions to national surveys/ longitudinal studies.</p> <p>Explore data linkage opportunities.</p> <p>Explore analysis of existing data collections from national surveys.</p> <p>Explore NECST endometriosis registry.</p>	National survey: Develop an ongoing nationally representative SRH survey.	O1; O2; O3; O4
Capture data on use of hormonal contraceptives and other forms of symptom management.	<p>Self-reported reasons for use of hormonal contraceptives.</p> <p>Reasons for presenting to primary care, diagnosis and prescriptions.</p> <p>Use of other forms of symptom management (e.g. pain relief medications, acupuncture, tranexamic acid).</p>	<p>Health records (primary care, hospitals, MBS)</p> <p>National surveys</p> <p>Pharmacy/ prescription data</p>	Hospitals data	Very limited / fragmented - refer to Appendix J	N.A.	<p>National survey: Develop an ongoing nationally representative SRH survey.</p> <p>Primary health care data: Explore feasibility of using the national primary health care data collection (once available).</p> <p>Pharmacy data: Explore feasibility of establishing an ongoing national pharmacy data collection.</p>	<p>6.1</p> <p>8.1</p> <p>O4; O5</p>

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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
Capture data on acceptability of hormonal contraceptives for the management of symptoms and conditions.	Self-reported acceptability of hormonal contraceptives for the management of symptoms and conditions.	National surveys	No data currently exists	No data currently exists	N.A.	National survey: Develop an ongoing nationally representative SRH survey.	3.1 15.1; 15.2 05; 012; 013
Measure and monitor health literacy relating to abnormal symptoms of menstruation, particularly among young people and parents.	Self-reported awareness of abnormal symptoms.	National surveys	Periods, pain and endometriosis (PEPP talk) survey	Limited and requires significant development	Explore analysis of existing data collections from national surveys.	National survey: Develop an ongoing nationally representative SRH survey.	1.1
Measure and monitor awareness and accessibility of trustworthy and appropriate sources of information on menstrual disorders and related conditions.	Self-reported knowledge of appropriate sources of health information.	National surveys	No data currently exists	No data currently exists	N.A.	National survey: Develop an ongoing nationally representative SRH survey.	1.2 12.1; 12.2; 12.3; 12.4 15.1; 15.2

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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
Collect data differentiating between age at first noticing symptoms, first seeking care, diagnosis (suspected and confirmed), and treatment or management of symptoms.	Summary statistics of first noticing symptoms, first seeking care, diagnosis (suspected and confirmed), and treatment or management of symptoms.	Health records (primary care, hospitalisations, specialist clinics) Medicare records Insurance/private health claims Longitudinal cohort studies National surveys National registries Data linkage Personal data tracking applications	ALSWH MBS PBS Hospitalisations and ED	Very limited / fragmented - refer to Appendix J	Expand/add questions to national surveys/ longitudinal studies. Explore data linkage opportunities (National Health Data Hub). Explore feasibility of using data tracking apps such as QENDO to monitor symptoms and Healthcare service usage.	National survey: Develop an ongoing nationally representative SRH survey. Primary health care data: Explore feasibility of using the national primary health care data collection (once available).	4.2 5.1; 5.2 O16; O17
Monitoring the availability of and geographical distribution of services including endometriosis and pelvic pain clinics (EPPCs).	Number, location and distance to closest EPPCs.	Service data	EPPCs	No data currently exists	Explore data collected by federally funded SRH services.	Suggestions: Explore feasibility of developing geo-mapped database of EPPCs and data on service availability and accessibility.	4.3 6.2; 6.3

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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
Monitoring wait times for assessment in EPPCs and other specialists; diagnostic tests and surgeries in hospitals.	Wait times for appointments, tests, surgeries.	Health records (primary care, hospitalisations, specialist clinics)	National Elective Surgery Waiting Times Data Collection (NESWTDC) database EPPCs	Very limited / fragmented - refer to Appendix J	Explore additional analysis of national administrative data collections (elective survey wait times). Explore data collected by federally funded SRH services.	Suggestions: <ul style="list-style-type: none"> Explore analysis of National Elective Surgery Waiting Times Data Collection data. Explore data from EPPCs. 	4.2 O16
Collect data on care pathways and menstrual disorders management. Capture data on barriers to seeking or accessing care.	Use of pelvic pain and endometriosis clinics and patients accessing these clinics and link data with other services. Patients and appointments related to menstrual disorders and related conditions in primary care including EPPCs, allied health and fertility services, and diagnostic services. Referrals to diagnostic services (eg. blood tests, ultrasounds), specialists, allied health and fertility services. Data on patient care pathways including use of allied health and fertility services, and outcomes.	Health records (e.g. primary care, hospitalisations, diagnostic and imaging reports, specialist services) Medicare records Patient experience surveys Data tracking apps Data linkage	Evaluation of EPPCs ANZARD	Very limited / fragmented - refer to Appendix J	Explore data linkage opportunities (National Health Data Hub).	National survey: Develop an ongoing nationally representative SRH survey. Primary health care data: Explore feasibility of using the national primary health care data collection (once available). Other suggestions: <ul style="list-style-type: none"> Explore feasibility of ANZARD data. Explore potential of diagnostic imaging reports and pathology data. 	5.1; 5.2 6.1 7.1; 7.2 9.1; 9.2; 9.3; 9.5; 9.6 O5; O7

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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
Establish national data standards for menstrual disorders and related conditions, for use across settings to facilitate consistent data collection and reporting.	Data consistency, accuracy, comparability.	Audit existing guidelines, standards and definitions	No data currently exists	No data currently exists	Establish data standards for consistent data collection. Improve coding / develop standardised definitions/use standard diagnostic codes.	Workforce survey: Explore the value of developing a national skills/training audit of healthcare providers. Suggestions: Establish or work within an existing national working group.	13.3 14.2
Monitor training provided for GPs and other healthcare providers on menstrual disorders and related conditions.	Scope and quality of formal training and professional development available which addresses menstrual disorders and related conditions. Uptake of professional development which addresses menstrual disorders and related conditions.	Training and skills audit	No data currently exists	No data currently exists	N.A.	Workforce survey: Explore the value of developing a national skills/training audit of healthcare providers.	10.3; 10.4 11.1
Measure and monitor health care provider confidence diagnosing and treating people with menstrual disorders and related conditions.	Self-reported healthcare provider confidence diagnosing and managing menstrual disorders and related conditions.	Workforce surveys	No data currently exists	No data currently exists	N.A.	Workforce survey: Explore value of undertaking a nationally representative workforce survey.	10.3; 10.4 11.1

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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 alignment of treatment of menstrual disorders and related conditions with care standards and clinical guidelines.	Self-reported health care provider awareness of validated tools for diagnosis, coding standards, care standards and guidelines.	Health records (e.g. primary care, hospitalisations, diagnostic and imaging reports, specialist services)	ACSQHC reporting on HMB rates of endometrial ablation and hysterectomy	Very limited / fragmented - refer to Appendix J	Explore additional analysis of National administrative data collections (e.g. PBS).	Workforce survey: Explore value of undertaking a nationally representative workforce survey.	5.1
	Monitor rates of first line and subsequent interventions for menstrual disorders and related conditions over time, where guidelines and hierarchy of therapies exist.	Medicare records	MBS		Explore data linkage opportunities (National Health Data Hub).		Pharmacy data: Explore feasibility of establishing an ongoing national pharmacy data collection.
	Diagnoses of menstrual disorders referring to and meeting criteria of relevant validated diagnosis tools.	Workforce surveys	PBS				11.1
			Hospitalisations and ED			Primary health care data: Explore feasibility of using the national primary health care data collection (once available).	17.1
							O17

Priority area for development	What to monitor (areas of measurement) ^(a)	How to measure it ^(b)	Potential data sources ^(c)	Current status ^(d)	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 costs to individuals associated with menstrual disorders and accessing healthcare services, tests, procedures, and medications.	Direct costs of menstrual disorders and related conditions - out-of-pocket costs incurred by patients to access services and treatment.	Health records (e.g. primary care, hospitalisations, specialist services)	AIHW Disease expenditure database and the AIHW Health Expenditure Database (HED)	Very limited / fragmented - refer to Appendix J Requires significant development	Explore data linkage opportunities. Explore additional analysis of National administrative data collections (e.g. health expenditure data).	Pharmacy data: Explore feasibility of establishing an ongoing national pharmacy data collection. Suggestions: Explore feasibility of data linkage opportunities.	4.1 O6
		Medicare records	ANZARD				
		Insurance/private health claims	MBS PBS				
		Pharmacy/prescription data	Hospitalisations and ED				
		Health expenditure data					
		Registries					
		Data linkage					

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) Only nationally representative data collections with established time-series data are included in this table (see the section 4.1. Data sources assessment criteria for more information). Other data sources out-of-scope for this table, that may be considered for future research include: Genetic Variants, Early Life Exposures and Longitudinal Endometriosis Symptoms study (GELLES), MadeHER: Origins and Impacts of Menstrual Disorders and Pelvic Pain, MCRI Longitudinal Study of Teenagers with Endometriosis, Period and Pelvic Pain (LongStePPP), The Endometriosis Management Plan Project (ENDO-MP), the 45 and Up study, ACT Survey of Women’s Health, and Victorian Women’s Health Survey.
- (d) ‘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.



TO LEARN MORE
click here

See the full report

Sexual and Reproductive Health
Monitoring Framework and Data Strategy



Australian Government
**Australian Institute of
Health and Welfare**

A I H W

