



Australian Government
Australian Institute of
Health and Welfare

AIHW



Appendix J

Data strategy and national data sources by priority topic

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.

J.1 Data strategy by priority topic

Data strategies have been created for each of the 5 priority topics, noting there is significant crossover in the data sources that are proposed.

Appendices [D](#), [E](#), [F](#), [G](#) and [H](#) (Sections D.2, E.2, F.2, G.2, H.2) summarise priority areas for data development identified during stakeholder consultations and literature reviews and include the following:

- **Priority area for data development:** priorities for data development to address the data gaps identified in the topic overview reports (Appendices [D](#), [E](#), [F](#), [G](#) and [H](#)).
- **What to monitor (areas of measurement):** the type of information required to monitor the priority areas for development.
- **How to measure it:** the data collection mechanisms that could be used to monitor the priority areas for development.
- **Potential data sources:** whether data sources exist that could be used for reporting existing SRH data or through enhanced analysis.
- **Current status:** a high-level summary of data currently available in existing data sources. Section J.2 presents a summary of existing national data sources that capture some data across the initial priority topic areas. Often the data collected or reported is limited and the collections would require significant development to enable comprehensive monitoring of the priority areas for development. However, there may be some additional information that could be obtained from these collections through additional analysis.
 - 'Very limited/fragmented data' indicates that only one or two data points/questions are available in the current source.
 - 'Partially available' means that it includes data that could partially answer some of the priority areas for development but still requires significant development/expansion.
- **Options for development of existing data sources:** indicates if an existing data source could be expanded or linked with other data sources to address some of the priority areas for development; or could include additional or different analysis than previously reported (disaggregated by different data items or analysed in further depth).

The AIHW notes that expanding existing national surveys to any large extent is often impractical due to the significant number of new questions that would be required, which can require removal of other items with implications for continuity and monitoring over time.

- **Options for new data collections: establish a new collection or standardise and collate existing data**
 - New data collections are proposed where either no data currently exists, or it is not feasible to use existing data sources to address the current priority areas for development due to the significant amount changes that would be required. Suggestions are proposed for establishing new data collections or standardising and collating existing data and include five main suggestions (refer to sections 4.3 and 4.4 of the [SRH Monitoring Framework and Data Strategy](#) for further details):
 - an ongoing nationally representative SRH survey
 - an ongoing national pharmacy data collection
 - a national register on pregnancy loss before 20 weeks' gestation
 - a national workforce survey and/or skills and practice audit
 - standardising and collating national healthcare data and other service-level data collection(s).
- **Monitoring framework domains, subdomains and outcomes**
 - Shows the relationship of the priority areas for development and the links to domains, subdomains and outcomes specified in Monitoring Framework (see section C.2 of [Appendix C](#) for numbering of domains and subdomains).

J.2 National data sources by topic

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
Survey: Cohort (Longitudinal)						
Australian Longitudinal Study on Women's Health (ALSWH)	Approximately every 3 years, 4 cohorts, initial collection 1996. National.	Diagnosis and treatment (Condition specific - Endometriosis, Pelvic Pain, PCOS, Fibroids, Timeframe) Medications (Type) Age at diagnosis Surgical Intervention (Endometrial ablation, Hysterectomy) Menstrual Description (Premenstrual tension, Irregular, Heavy, Dysmenorrhea) Help seeking behaviour (Presentations to healthcare provider, Satisfaction)	Usage (By contraceptive type, Duration, Condom Use, Reason) Sterilisation (Male, Female) Coercion (Interference, Pressured) Fertility intentions and desires (Trying to become pregnant, IVF) Help seeking behaviour (Presentations to healthcare provider)	Prevalence (Number) Coercion (Pressured) TOP reason (Medical, Personal)	Pregnancy (Number) Miscarriage prevalence (Number) Ectopic pregnancy prevalence (Number) Live births (Number) Stillbirth (Number) Infertility (Current or previous problems, Male, Female)	MHT usage (Duration, Brand) Menstrual status (Menstruation status, Age at first period, Cessation, Age at cessation, Regularity) VMS Presence (Night sweats, Hot flushes) Surgical Intervention (Hysterectomy, Oophorectomy) Help seeking behaviour (Presentations to healthcare provider, Satisfaction) Non-reproductive Health conditions Lifestyle Behaviours (Alcohol, Smoking, Weight) Workplace absenteeism, presenteeism
Longitudinal Study of Australian Children (LSAC)	Every 2 Years, initial collection: 2004. National.	Menstrual status (Age at first period, Regularity) Menstrual Description (Premenstrual tension, Heavy, Dysmenorrhea) Absenteeism (School, Work, Social, Sports) Pelvic Pain (Days in past 12 months)	Usage (By Contraceptive Type, Reason) Fertility intentions and desires (Trying to become pregnant, Avoiding, Neither trying nor avoiding)	Pregnancy outcome (TOP) TOP reason (Medical, Personal) Social Circle Awareness (Others knowledge of TOP occurring)	Pregnancy (Number) Pregnancy outcome each pregnancy (Stillbirth, Miscarriage, Ectopic)	No data

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
Survey: Cross-sectional						
Household, Income and Labour Dynamics in Australia (HILDA)	Annual, initial collection: 2001. National	No data	Usage (By contraceptive type) Sterilisation (Male, Female) Fertility intention and desire (Timing, Desire, Gender preference)	No data	No data	No data
Jean Hailes National Women's Health Survey	Annual, initial collection: 2015. National. 2023 Survey looks at menopause and menstrual disorders. 2024 Survey looks at TOP and contraception.	Menstrual status (Regularity) Menstrual Description (Heavy, Dysmenorrhea) Absenteeism (School, Work, Exercise) Social impact (Relationships, Wellbeing) Help seeking behaviour (Presentations to healthcare provider, Experience, Comfort) Pelvic Pain (Presence, Impact, Absenteeism) (2023)	Usage (By contraceptive type, History) Fertility intention and desire (Pregnancy avoidance, Family planning) Satisfaction (Current contraceptive method) Pain (Contraception insertion) Accessibility (Physical, Preferred, Barriers, Capacity for correct use) (2024)	Pregnancy (Ever, Unplanned) TOP prevalence (Once, More than once) TOP method (MTOP or STOP) Fertility intentions and desire (2024)	No data	Leave Provision (Desire, Comfort using, Attitudes) Menstrual Status (Menstruation status, Cessation, Age at cessation) Surgical Intervention VMS Presence (Night sweats, Hot flushes) Absenteeism (School, Work, Exercise) Social impact (Relationships, Wellbeing) Help seeking behaviour (Presentations to healthcare provider, Experience, Comfort) (2023)
The Australian Secondary Students and Sexual Health Study (SSASH Study)	Approximately every 5 years, initial collection: 1992. National.	No data	Usage (By contraceptive type, Reason) School Sex Education (Prevalence, Trust, Quality)	No data	No data	No data

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
The Australian Study of Health and Relationships (ASHR)	Three data collections: 2001-02, 2012-13 and 2023-24. National. 23-24 data has not yet been finalised. Information based off ASHR3 as prior surveys outdated.	No data	Usage (By contraceptive type) Coercion (Sexual, Reproductive) School Sex Education (Content) Stealthing (Condom removal without consent)	TOP prevalence (Number) Gestation TOP method (MTOP or STOP) Coercion TOP service location (Location, Distance one-way, Out-of-state) TOP access (Cost, Ease)	Live births (Number) Miscarriage prevalence (Number) Ectopic pregnancy prevalence (Number) Infertility (Trying 12+ months, Help-seeking) Stillbirth (Number)	No data
Periods, Pain and Endometriosis (PEPP talk)	National for private schools, partial coverage of schools. NSW, ACT and NT state schools do not participate	Assessment (PIPPA) tool (Pain, Interference, Absenteeism) Help seeking behaviour (Presentations to healthcare provider or emergency department for periods and pelvic pain) Health literacy (Knowledge of endometriosis, tools for pain management, general health)	No data	No data	No data	No data
Intergenerational Health and Mental Health Study (including the National Health Study, National Health Measures Survey)	NHS survey - approximately every 3 years, nationally representative sample NHMS (includes NATSIHMS) - Blood and urine samples	Chronic conditions (Endometriosis) Blood and urine samples (Iron studies)	TBC	No data	No data	No data

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
Ongoing National Administrative datasets						
National Congenital Anomalies Data Collection (NCADC)	Information on congenital anomalies including both live and stillbirths and patient (mother) characteristics including Indigenous status and remoteness. 20+ weeks gestation data only.	No data	No data	Pregnancy outcome TOP (>20 weeks gestation) due to congenital anomaly	No data	No data
National Perinatal Data Collection (NPDC)	Information on terminations of pregnancy from 20 weeks' of gestation National data are not currently available. Termination of pregnancy flag is only provided by 4 jurisdictions. 20+ weeks gestation data only.	No data	No data	TOP numbers TOP reason	TBC	No data

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
National Perinatal Mortality Data Collection (NPMDC)	Information on all stillbirths and neonatal deaths up to 28 days post-birth in the state and territories, and patient characteristics including Indigenous status and remoteness. 20+ weeks gestation data only.	No data	No data	TOP numbers TOP reason	TBC	No data
Medicare Benefits Scheme (MBS)	Information on claims made for government subsidised services (including Professional attendances, Diagnostic imaging services, Therapeutic procedures, Pathology services, Miscellaneous Services). Medicare eligible people only.	Ultrasound Laparoscopic resection Hysterectomy Myomectomy Polypectomy Iron studies Other services	LARC insertion Sterilisation (Male and Female)	Pregnancy counselling Ultrasound STOP procedure	Ultrasound Pregnancy loss management Human chorionic gonadotrophin (HCG) test	Menopause health assessment

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
Pharmaceutical Benefits Scheme (PBS)	Information about claims processed for government subsidised (PBS) scripts (medicines) and payments, patients (including closing the Gap co-payment eligibility), prescribers and dispensing pharmacies. Medicare eligible people only.	Some oral contraceptives, hormonal IUDs, iron infusions, tranexamic acid, Metformin, Goserelin, Ryeqo, Visanne, and other various medications	Some oral contraceptives, injectables, hormonal IUDs, and implants	MTOP medicines (MS-2Step)	TBC	Some MHT formulations and brands
National Hospital Morbidity Database (NHMD)	Episode-level records from admitted patients in public and private hospitals including patient characteristics, diagnoses, length-of-stay, procedures and funding source.	Hysteroscopy Endometrial ablations Hysterectomy And other admissions with diagnosis of menstrual disorders and related conditions LARC insertions for menorrhagia, dysmenorrhoea etc	LARC insertion Sterilisation	STOP procedure	Curettage and evacuation of uterus with diagnosis of miscarriage and other PL	No data

Data Source	Description	Menstrual disorders	Contraception	Termination of pregnancy	Pregnancy loss including miscarriage	Perimenopause and menopause
National Elective Surgery Waiting Times Database (NESWTDC)	Information on waiting lists for publicly funded surgeries (clinical urgency, intended procedure, reason for removal from a waiting list, surgical speciality, waiting time (at removal), patient characteristics including indigenous status).	Hysteroscopy Endometrial ablations Hysterectomy And other surgeries	Sterilisation	Curettage and evacuation of uterus	Curettage and evacuation of uterus	No data
National Non-admitted Patient Emergency Department Care Database (NNAPEDCD)	Information on presentations to public emergency departments not resulting in an admission, including reasons for presentations, principal diagnosis, wait time and patient characteristics.	Endometriosis Menorrhagia Menstruation (irregular) Abnormal uterine bleeding Dysmenorrhoea	Contraceptive management IUD insertion, reinsertion, removal Implant insertion, reinsertion, removal	Ectopic or molar pregnancy MTO Failed abortion attempt Complications following abortion	Missed abortion Spontaneous abortion (complete) Spontaneous abortion (incomplete)	No data
National Health Workforce Dataset	Information on the demographic and employment characteristics of healthcare providers.	Information on general workforce (provider classification and broad type of specialty) and location (state, MMM area, principal work setting).				



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Sexual and Reproductive Health
Monitoring Framework and Data Strategy



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