

# Data opportunities in perinatal mental health screening

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# About

National guidelines recommend that all women are screened for signs and risk factors of mental health conditions during the perinatal period. This report explores, for the first time, perinatal mental health screening data from three state and territory health authorities and how these vary by maternal characteristics and behaviours, birth settings, and birth outcomes. It describes how efforts to improve reporting and targeted initiatives that improve outcomes for mothers and their families may be possible through data development and integration opportunities.

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Findings from this report:

- Currently, there are no national data about perinatal mental health screening, service use or outcomes
- State and territories are making progress to implement perinatal mental health screening data items
- In Qld, Tas and the ACT, 3 out of 4 women receive mental health screening during pregnancy
- Women are more likely to be screened if they are under 25, are First Nations women or give birth in a public hospital

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# Summary

For many women, having a baby is an exciting time. But for some, pregnancy and the first year of their baby's life (together known as the perinatal period) can be a challenging experience. While it's normal to sometimes experience ups and downs due to the challenges of adjusting to parenthood, having a perinatal mental health condition is different - it is more severe and will usually not improve without treatment.

Mental health, and social and emotional wellbeing are important aspects across a person's lifespan (NMHC 2022). Poor mental health may affect all Australians at times, both directly and/or indirectly, and vary in severity, persistence, and impact (Productivity Commission 2020).

Depression and anxiety are common perinatal mental health conditions experienced during the perinatal period with impacts ranging from mild to severe. Other severe mental health conditions, such as schizophrenia and bipolar disorder, are less common but have high comorbidity with other mental health conditions and are associated with a range of adverse outcomes (Highet et al. 2023). Mental health conditions during the perinatal period are common, affecting an estimated 1 in 5 mothers and can have serious effects on the health and wellbeing of women, their babies and families. In 2019, the two most common perinatal mental health conditions, depression and anxiety, are estimated to have cost Australia \$877 million from increased health care costs associated with increased service use, and productivity losses from reduced economic participation (Highet et al. 2023; PwC Consulting Australia 2019).

National guidelines recommend that all women are screened for signs, symptoms and risk factors of mental health conditions during the perinatal period, to help ensure women receive timely support and treatment (Highet et al. 2023). However, currently, there are no national data about perinatal mental health screening, service use or outcomes.

Data about the mental health of parents in the perinatal period are collected by a range of health services, government and nongovernment organisations, mostly as a by-product of delivering maternity services. This information is not collected consistently across Australia, with differences in how, when and if screening occurs. At present, only Queensland, Tasmania and the Australian Capital Territory provide perinatal mental health screening data to the National Perinatal Data Collection (NPDC). Previous research indicates that the proportion of mothers receiving mental health screening has increased over time but has highlighted particular cohorts that have been underrepresented, such as Aboriginal and Torres Strait Islander (First Nations) women, women born overseas, single or separated women, private patients and older mothers (Moss et al. 2020; San Martin Porter et al. 2019).

This report focuses on perinatal mental health screening and explores, for the first time, *Antenatal mental health screening status* and *Total EPDS score* data from three state and territory health authorities and how these vary by maternal characteristics and behaviours, birth settings, and birth outcomes. It describes efforts to improve data collection and reporting to build a national picture about perinatal mental health screening that can inform the development and evaluation of policies, services and initiatives to better support mothers and their families.

#### Quick facts

In Queensland, Tasmania and the ACT:

- 3 out of 4 women received mental health screening during pregnancy
- Women were more likely to be screened if they were aged under 25, were First Nations women, smoked or gave birth in a public hospital
- Mothers aged under 20 were three times as likely to have a screening score indicating risk of depression, compared with mothers in their 30s or above

Source: NPDC 2020 and 2021 (AIHW 2021a).

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# What is perinatal mental health?

Perinatal mental health generally refers to the social and emotional wellbeing of a woman from the time of conception through to the baby turning 12 months old.

A perinatal mental health diagnosis is different from the 'baby blues', which occurs for approximately 80% of women between three and five days after birth. The baby blues can leave women feeling very distressed and/or emotional in the early days following the birth but will normally disappear within a few days without treatment, however ongoing symptoms may be a sign of a mental health condition (COPE 2021).

Mental health conditions are the leading cause of disease burden in Australian women of child-bearing age (15 to 44 years) (AIHW 2022b), and the perinatal period is considered to be a time of increased risk. Perinatal mental health conditions include those that present symptomatically as they would at other times of a woman's life (including depressive and anxiety disorders, schizophrenia, bipolar disorder and borderline personality disorder), in addition to perinatal period-specific disorders such as psychological birth trauma and postpartum psychosis (Highet et al. 2023). Many women experience changes in their mental health during this period - women with a current or previous mental health condition may be at increased risk of worsening symptoms or relapse, while other women may experience symptoms for the first time (Highet et al. 2023).

Poor perinatal mental health has a significant impact on the woman and can also have a long-term impact on her baby. Mental health conditions during pregnancy have been associated with adverse obstetric and pregnancy outcomes, such as premature birth, independent of mental health-related medication use (Adane et al. 2021; Jarde et al. 2016; Mitchell and Goodman 2018). Perinatal mental health conditions are also associated with poorer child and adolescent development, including increased risk of poorer cognitive development, emotional problems and externalising behavioural difficulties (such as attention deficit hyperactivity disorder) (Rogers et al. 2020; Slomain et al. 2019; Stein et al. 2014). The relationship between having a perinatal mental health condition and the long-term outcomes for the baby is complicated, and may be due to a mix of genetic, epigenetic (how environmental influences and experiences affect a person's genes) and environmental factors, including through effects on parenting practices and mother-infant attachment (Rogers et al. 2020; Slomain et al. 2019; Stein et al. 2014).

Key risk factors for developing a perinatal mental health condition include a history of mental illness, history of abuse or intimate partner violence, limited social support and lower socioeconomic status (Bayrampour et al. 2018; Bedaso et al. 2021; Míguez and Vázquez 2021; Yang et al. 2022). Other risk factors may include poor sleep quality (Ladyman et al. 2021), and experiencing psychological childbirth-related trauma (Ayers et al. 2016; Kranenburg et al. 2023; Loxton et al. 2021). Conversely factors such as personal resilience, positive childhood experiences and social support have a protective effect against perinatal mental health conditions and can mitigate the effects of some risk factors (Atzl et al. 2019; Carlin et al. 2021).

# How common are perinatal mental health conditions?

Anxiety disorders are the most common mental health conditions in the perinatal period, with prevalence estimates ranging from around 10% to 20% of mothers (Dennis et al. 2017; Fawcett et al. 2019), and this often co-occurs with depression (Falah-Hassani et al. 2017). It is estimated that perinatal depression affects around 10% of mothers in high-income countries, and that prevalence is considerably higher in low- and middle-income countries (Woody et al. 2017). Research indicates rates of depression and/or anxiety tend to be higher during pregnancy compared with the first year after birth, and that having depression or anxiety during pregnancy is associated with postnatal depression and anxiety (Dennis et al. 2017; Liu et al. 2021; Underwood et al. 2016). It is estimated that childbirth-related post-traumatic stress disorder (PTSD) affects from 3% to 5% of mothers (Grekin and O'Hara 2014; Heyne et al. 2022).

Mental health conditions such as schizophrenia, postpartum psychosis (which includes symptoms such as hallucinations, delusions, mood swings, confusion and changes in behaviour), and bipolar disorder are less common but can have a significant impact on the health and wellbeing of women and families (Jones et al. 2014; Masters et al. 2022; VanderKruik et al. 2017).

# What about fathers and other parents?

Traditionally the focus of perinatal mental health research has been on the mother who gave birth. There is increasing evidence that fathers, partners and other non-birthing parents or guardians, such as adoptive parents and step-parents, can also be affected by poor mental health during the perinatal period experiencing perinatal depression and depressive symptoms, anxiety disorders, and suicidal thoughts (Anthony et al. 2019; Cameron et al. 2016; Darwin et al. 2021; Giallo et al. 2023; Leach et al. 2016; Mott et al. 2011). For more information, see <u>Key information gaps</u>.

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What is perinatal mental health and psychosocial screening and why is it important?

- On this page
- Screening for perinatal mental health and psychosocial risk and protective factors
- Perinatal mental health screening and identifying risk of suicide and intentional self-harm
- <u>When are women screened?</u>
- What treatment and support services are available?
- Why is national collection of perinatal mental health screening data important and what data are available?

# Screening for perinatal mental health and psychosocial risk and protective factors

Perinatal mental health and psychosocial screening involves asking women a series of questions about their current and past emotional and social wellbeing, to detect signs, symptoms and risk factors for having or developing a mental health condition. This can be done as part of routine pregnancy (antenatal or prenatal) and postnatal care by midwives, obstetricians, and other health care providers.

The <u>iCOPE screening platform</u>, developed by the Centre of Perinatal Excellent (COPE), includes the questions from the EPDS and ANRQ and enables automated clinical scoring; it delivers timely reports to clinicians and patient record systems.

Perinatal mental health screening is an important tool to identify at-risk women who may benefit from further support and formal mental health assessment. Perinatal mental health conditions are underdiagnosed during routine pregnancy care without routine screening (Willey et al. 2020).

Screening may take the form of a questionnaire with defined response options or may comprise of open-ended questions discussed with a health care provider. Screening is usually undertaken using pen and paper and more recently through digital tools such as the iCOPE digital perinatal mental health screening platform.

Mental health and psychosocial screening tools that have been validated are perceived as credible by health professionals, provide a framework for initiating conversations with mothers about sensitive topics and improve diagnosis and timely access to care (Willey et al. 2020). There are several established and validated screening tools that are recommended by the Australian clinical practice guidelines for mental health care in the perinatal period (National guideline) (Highet et al. 2023), which are routinely offered to women during pregnancy and in the postnatal period in Australia and aim to detect different aspects of mental health and psychosocial risk:

- Depression risk is most commonly screened for using the Edinburgh Postnatal Depression Scale (EPDS) but may also be screened for using other tools such as the depression module of the Patient Health Questionnaire (PHQ-9), the Whooley Questions, the Kessler Psychological Distress Scale (K-10) and the Depression, Anxiety and Stress Scale (DASS). Perinatal mental health screening tools specific for First Nations women have also been developed including Part 1 of the <u>Kimberley Mum's Mood Scale</u> (KMMS), <u>Baby Coming You Ready?</u> (BCYR) and the Mount Isa Depression Scale.
- Psychosocial risk factor screening is commonly conducted using the Antenatal/Postnatal Risk Questionnaire (ANRQ/PNRQ) or <u>SAFESTART</u> psychosocial questions. Other tools include the ANRQ-Revised (ANRQ-R) (Reilly et al. 2021), Part 2 of the KMMS and BCYR. These screening tools ask about a range of psychosocial risk factors, including the mother's mental health history, social support system and if they are experiencing or have ever experienced abuse or family violence. *Note* Family violence is a psychosocial risk factor that is not specifically asked by the ANRQ. To bridge this gap, the iCOPE screening platform, which includes the ANRQ, asks additional questions relating to perceptions of safety, and problems with drugs and alcohol within the relationship.
- Anxiety risk is commonly determined through the anxiety-related items in the depression and psychosocial risk factor screening tool used. The Generalised Anxiety Disorder 7-Item Scale (GAD-7) may also be used.
- Protective factors: Exploring and amplifying strengths and protective factors raised by a person may be a more effective way to promote mental health, rather than trying to reduce risk factors (KMMS 2023). For example, social support has been found to play a role in protecting against perinatal depression (Milgrom et al. 2019) and childbirth-related PTSD (Ayers et al. 2016). Current research in Queensland is exploring the role of protective factors and potential benefits of their inclusion in perinatal mental health screening tools such as the iCOPE screening platform.

It should be noted that scoring high on a perinatal mental health screening tool does not represent a diagnosis.

Clinical screening tools allow health care providers to gather information about a patient to identify potential risk factors, and enable clinical decision-making to provide support, formal mental health assessment and referral.

Risk factors may be identified:

• by specific item(s) in the tool – for example, answering 'Yes' to the ANRQ question 'Have you ever been sexually or physically abused?' identifies a *history of abuse*.

- by a combination of items in the tool for example, responses to items in the EPDS are scored from zero to 3, and a combined score of 5 or higher for the items 'I have blamed myself unnecessarily when things went wrong,' 'I have been anxious or worried for no good reason,' and 'I have felt scared or panicky for no very good reason,' identifies a risk of anxiety.
- by overall score for example, a total score for all items in the EPDS of 13 or higher identifies a risk of depression.
- by more than one tool for example, both the ANRQ and EPDS have items that may identify a risk of anxiety.

Refer to the <u>Glossary</u> for more information about terms and clinical tools. This report focuses on mental health and psychosocial risk factor screening, which can also include screening for family violence. For more information about family violence data see <u>Family</u>, <u>domestic and sexual violence</u>: National data landscape 2022.

### Perinatal mental health screening and identifying risk of suicide and intentional self-harm

#### Where to find help and support

The AIHW respectfully acknowledges those who have died or have been affected by suicide or intentional self-harm. We are committed to ensuring our work continues to inform improvements in both community awareness and prevention of suicide and self-harm. This page discusses suicide and presents material that some people may find distressing. If this report raises any issues for you, <u>support services</u> can help. Crisis support services can be reached 24 hours a day.

- Lifeline Call 13 11 14
- Text (SMS) 0477 13 11 14
- Online chat

Mindframe is a national program supporting safe media coverage and communication about suicide, mental ill health and alcohol and other drugs. Resources to support reporting and professional communication are available on the <u>Mindframe website</u>.

#### Visit Suicide & self-harm monitoring for information on suicide and self-harm data.

Suicide and intentional self-harm are complex issues and can have multiple contributing factors. Screening for mental and psychosocial risk factors plays an important role in providing timely support, further assessment and follow-up for women. In a study of women giving birth in Western Sydney between 2006 and 2016, women reporting intimate partner violence at their first antenatal care visit were more likely to have an EPDS score above 13, to have had a history of anxiety and depression, or to have had thoughts of self-harm (Dahlen et al. 2018). Further assessment is recommended for any women who report thoughts of self-harm on the EPDS, regardless of total EPDS score (Highet et al. 2023). Experiencing one or more psychosocial risk factors does not mean a person will experience suicidal behaviours, and most people experiencing psychosocial risk factors will not experience suicidal behaviours (AIHW 2023).

While most individuals with a mental health condition do not report suicidal behaviours, suicidality is more prevalent for people with a mental health condition compared to those without (AIHW 2022d). In the 2007 National Survey of Mental Health and Wellbeing, almost 3 in 4 people exhibiting suicidality (72%) reported a mental health condition in the preceding 12 months (ABS 2008). Research indicates that individuals with a diagnosed mental illness such as borderline personality disorder, psychotic disorders and severe perinatal depression are at increased risk of suicidality and intentional self-harm (Cantwell et al. 2011; Kroger et al. 2011).

Death by suicide was the leading cause of death for women in Australia aged 15-44 between 2011 and 2020 (ABS 2013, 2014, 2015, 2016a, 2016b, 2017, 2018b, 2019, 2020, 2021) and was one of the leading causes of maternal death in Australia, accounting for 10% of maternal deaths (20 women) between 2011 and 2020 (AIHW 2022c). Maternal death is defined as the death of a woman while pregnant or within 42 days of the end of pregnancy, irrespective of the duration and outcome of the pregnancy.

Research indicates the risk of death by suicide may be even higher between 43 and 365 days after the end of pregnancy. In Queensland between 2014 and 2019, 31 of the 130 deaths during pregnancy and up to 1 year postpartum (24%) were by suicide of which 27 (87%) occurred after 42 days postpartum (Queensland Health 2018, 2020, 2022).

Mental health screening is a critical tool for the early identification of women at risk of suicide, and can reduce the risk of perinatal suicide if supported by strong referral pathways that connect at-risk mothers to accessible mental health care and support (Chin et al. 2022).

For further information see: <u>Australia's mothers and babies: Maternal deaths</u> and <u>Suicide & self-harm monitoring</u>, and refer to the <u>Glossary</u> for more information about terms used.

If you or someone you know needs help, contact:

- Lifeline on 13 11 14 (lifeline.org.au)
- Perinatal Anxiety & Depression Australia (PANDA) National Helpline on 1300 726 306 (panda.org.au)
- Suicide Call Back Service on 1300 659 467 (suicidecallbackservices.org.au)

#### When are women screened?

National guidelines recommend all women are routinely screened for depression and psychosocial risk factors at least twice during pregnancy and twice during the first year after birth (Highet et al. 2023).

In practice, women may not be routinely screened, or may be screened multiple times across a range antenatal and postnatal mental health settings (Figure 1). Health care is provided in many ways during and after pregnancy, depending on the woman's health care needs, personal preference, individual circumstances and where they live. Settings include public hospitals, private hospitals, antenatal clinics,

maternal and child health services, local primary health care services, Aboriginal Community Controlled Health Services and outreach home visits. While there are national guidelines, there are differences across state and territories and health settings in how, when and if women are screened for perinatal mental health and psychosocial risk factors.

Although perinatal mental health screening has increased over time, research indicates that some groups have historically been underrepresented including First Nations women, women born overseas, single or separated women, private patients and older mothers (Moss et al. 2020; San Martin Porter et al. 2019).

# Figure 1: Services where women may be offered perinatal mental health screening, noting potential data sources and funding sources

# Perinatal mental health screening settings

Perinatal mental health screening settings include:

- Public hospital admitted patient<sup>(a)</sup>
- Public hospital outpatient services, including antenatal clinics and maternity, child and family health services
- Private hospital admitted patient<sup>(a)</sup>
- Out-of-hospital care by allied health workers, including psychologists and other allied mental health workers
- Out-of-hospital care by medical practitioners, including general practitioners, obstetricians, and other specialists. Includes some maternity and family practices, Aboriginal Health Services and endorsed midwives and nurses working in private practices in a collaborative arrangement with a medical practitioner

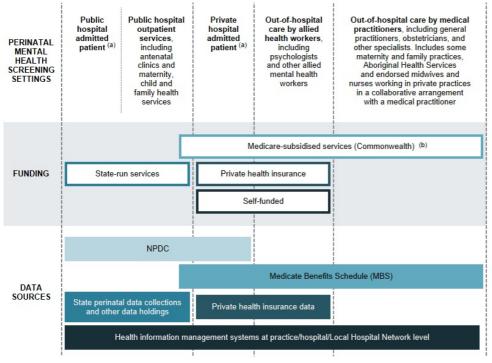
#### Funding

- State funding covers public admitted patient and outpatient services.
- Medicare subsidised services include out-of-hospital care by medical practitioners, and some public outpatient services, private hospital services and out-of-hospital care provided by allied health workers<sup>(b)</sup>.
- Private health insurance funds some private hospital care, and out-of-hospital care provided by allied health workers.
- Some private hospital care, and out-of-hospital care provided by allied health workers is funded by the patient.

#### Data sources

Potential data sources include:

- the NPDC for public hospital settings.
- State and territory perinatal data holdings for state funded services.
- The Medicare Benefits Schedule (MBS) for MBS subsidised services.
- Private health insurance data for services funded by private health insurance.
- And local hospital network/hospital/practice level health information management systems (HIMS).



#### Notes:

(a) Hospital admission includes admissions related to pregnancy and childbirth, as well as specialised mental health inpatient services. Local referral pathways may exist to ensure the mother receives appropriate care including screening at the right time. Screening for mental health risk factors, for example with the EPDS, may not be needed in these circumstances due to other processes being in place to assess the patient's mental health.

(b) In 2021-22, 11% of all outpatient (non-admitted) service events in public hospitals were covered by the MBS.

# What treatment and support services are available?

Data and discussion about the availability and efficacy of treatment and support services are out of scope for this report but a useful report to refer to is the AIHW's <u>Resources for supporting psychosocial health in pregnancy</u> for details of clinical guidelines, screening tools and information about services for supporting psychosocial health during pregnancy. There are also a range of treatment and support services provided by private providers like General Practitioners (GPs), as well as Primary Health Networks (PHNs), state and territory government agencies, and non-government organisations. Mothers may also receive support for mental health and psychosocial issues through more general <u>crisis and support services</u>.

# Why is national collection of perinatal mental health screening data important and what data are available?

Consistent, nationally collected perinatal mental health screening data helps build the evidence about women's exposure to risk and protective factors, presentation patterns (before, during and after pregnancy), and health outcomes for mothers and babies across Australia. It enables targeted initiatives, service coordination and delivery, and further research and evaluation to ensure that women and families receive the care they need when they need it, particularly for priority population groups.

# Mental health and family violence Perinatal NBEDS items

The AIHW started investigating the feasibility of including antenatal mental health and family violence screening data in the NPDC in 2010. The NPDC includes the Perinatal National Minimum Data Set (NMDS), a collection of mandatory data items that state and territory health authorities have agreed to supply, and the Perinatal National Best Endeavours Data Set (NBEDS), a collection of data items that are not mandated for national collection but for which there is a commitment to provide data nationally on a best endeavours basis. Several antenatal mental health and family violence data items were developed and refined in consultation with subject matter and data experts between 2013 and 2019. Voluntary implementation of the following four mental health and family violence data items commenced July 2020 through the <u>Perinatal NBEDS 2020-21</u>:

- 1. Antenatal mental health risk screening status (METEOR identifier 733468)
- 2. Indication of possible symptoms of depression at an antenatal care visit, Edinburgh Postnatal Depression Scale (EPDS) score (METEOR identifier 704384)
- 3. Presence or history of mental health condition indicator (METEOR identifier 622450)
- 4. Family violence screening status (METEOR identifier 733542).

State and territory health authorities are working to implement the four voluntary mental health and family violence Perinatal NBEDS items into their perinatal data collections, and the AIHW is working with them to refine specifications (where required) and progress the items to the mandatory Perinatal NMDS. Data about the postnatal period after discharge are out of scope for the NPDC.

# Perinatal Mental Health pilot

The AIHW is working with state and territory health authorities to develop the Perinatal Mental Health pilot (PMHp), a novel collection of de-identified screening data from public antenatal and postnatal maternity health services. This project is piloting the collection of de-identified clinical data for research purposes in a faster way, compared to traditional data flow pathways, by collecting data through a range of sources:

- the Centre of Perinatal Excellence's (COPE) implementation of the iCOPE screening platform to Australian public maternity hospitals and other settings
- existing perinatal mental health data supplied directly from state and territory health authorities.

The PMHp is being established as Local Hospital Networks (LHNs) and state and territory health authorities confirm their interest to participate. The PMHp aims to complement and potentially support the refinement of the NPDC, by collecting data that is currently out of scope for the NPDC.

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# Initial findings

This report describes initial insights from the implementation of data collection on mental health and family violence screening in Australia.

# Mental health and family violence Perinatal NBEDS items

Queensland, Western Australia, Tasmania and the Australian Capital Territory (ACT) supplied antenatal mental health and family violence screening data for both the 2020 and 2021 birth cohorts.

This report focuses on antenatal EPDS screening status and score for the state and territory health authorities that contributed data for these items (Queensland, Tasmania and the ACT):

- Antenatal mental health risk screening status (Yes, Not offered, Declined)
- Indication of possible symptoms of depression at an antenatal care visit (total EPDS score).

Analysis has not been presented for the following data items:

- Presence or history of mental health condition indicator (Yes, No) due to high levels of variation between state and territory health authorities and health services in the criteria used to record the data item. Standardising how data are collected for this item would improve its reliability as an indicator and enable further analysis.
- Family violence screening status (Yes, Not offered, Declined) due to the small number of state and territory health authorities currently providing data for this data item.

Table 1: Overview of state and territory health authorities that supplied the mental health and family violence data items, 2020 and 2021

Data item	Qld	WA	Tas	ACT	Per cent of mothers from supplying state and territory health authorities <sup>(a)</sup> with a stated result <sup>(c)</sup> (%) 2020	Per cent of mothers from supplying state and territory health authorities <sup>(a)</sup> with a stated result <sup>(c)</sup> (%) 2021	Per cent of all mothers <sup>(b)</sup> with a stated result <sup>(c)</sup> (%) 2020	Per cent of all mothers <sup>(b)</sup> with a stated result <sup>(C)</sup> (%) 2021
Antenatal mental health risk screening status	1	\$	\$	\$	96.5%	96.8%	33.8%	33.9%
Indication of possible symptoms of depression at an antenatal care visit, total EPDS score	\$		1	1	75.7% (99% of women with an Antenatal mental health risk screening status of 'Yes')	75.3% (99% of women with an Antenatal mental health risk screening status of 'Yes')	18.3%	18.1%
Presence or history of mental health condition indicator	1		1	1	100%	100%	24.1%	24.0%
Family violence screening status	1		1		99.6%	99.6%	21.9%	21.9%

Notes:

a. Supplying state and territory are indicated by the check mark for each item.

- b. All mothers includes all mothers from all states and territories in the NPDC.
- c. Stated results exclude mothers with 'Unknown', 'Not stated/inadequately described' or missing results. For instance, for the total EPDS item, stated results include a score of 0 to 30.

Source: AIHW analysis of the NPDC, 2020 and 2021.

Detailed information on completeness, accuracy and other aspects of data quality for the NPDC is in the data quality statement. Additional detail about the NPDC is in the Availability of perinatal data.

The AIHW continues to engage and consult with technical and subject matter experts from state and territory health authorities to determine next steps to improve the consistent collection of these data items. See Data opportunities for more information.

#### Initial findings - details

As part of the Perinatal NBEDS (NPDC), the AIHW received data for the data items Antenatal mental health screening status and Total EPDS score from Queensland, Tasmania and the ACT for 2020 and 2021, and found:



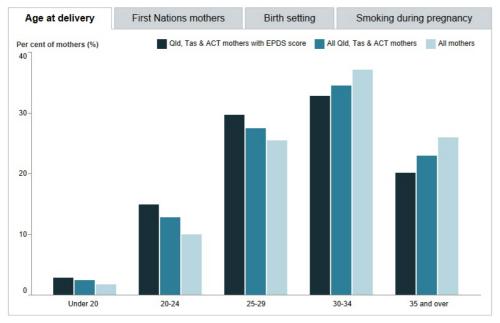
- Of the 145,137 mothers who gave birth in these states and territories, 109,547 (75%) received antenatal mental health screening with a recorded EPDS score during their pregnancy.
- The remaining mothers were either not offered screening (20%), declined screening (0.7%), received antenatal mental health screening but did not have an EPDS score recorded (0.8%) or their screening status was not stated (2.7%).

#### Who was more likely to be screened?

There were differences in some characteristics between women who had an EPDS score recorded and all women who gave birth.

• For example, compared with all mothers who gave birth in Queensland, Tasmania and the ACT, women with a recorded EPDS score were more likely to be aged under 25, give birth in a public hospital, report smoking at any point in their pregnancy, or were First Nations mothers.

Figure 2. Maternal and pregnancy characteristics of all mothers, mothers who gave birth in Queensland, Tasmania and the Australian Capital Territory, and mothers with an EPDS score, 2021 and 2022.



Note: Percentages are calculated after excluding records with 'Not stated' or missing values for the variables of interest

Source: AIHW analysis of the National Perinatal Data collection (2020 and 2021) ttps://www.aihw.gov.au

#### Who was more likely to be identified as at risk?



8% depression Overall, 7.6% of mothers with a recorded EPDS score were assessed as scoring 13 or above, indicating a high risk of depression and/or anxiety.

Of the women with a recorded EPDS score during their pregnancy:

- a higher proportion of mothers aged under 20 years scored 13 or above (20%), compared with 9.0% of mothers in their 20s, and 5.9% of mothers aged 30 and over
- scored 13 or above, indicating a high likelihood of a higher proportion of mothers who smoked at any point during pregnancy had a score of 13 or above (17%), compared with mothers who did not report smoking at any point (6.3%)
- a higher proportion of mothers who gave birth in public hospitals scored 13 or above (8.2%), compared with mothers who gave birth in a private hospital (3.9%)
- a higher proportion of mothers who had 3 or more previous live births scored 13 or above (9.9%), compared with 7.6% of first-time mothers and 7.2% of mothers who had 1-2 previous live births. A similar pattern was observed by parity with a higher proportion of mothers who had experienced 3 or more previous pregnancies scoring 13 or above (9.9%) compared with 7.6% of mothers experiencing pregnancy for the first time, and 7.2% of mothers who had experienced 1-2 previous pregnancies.

#### Birth outcomes for at-risk mothers

The causes of adverse pregnancy outcomes, such as stillbirth or pre-term birth, are complex. Adverse birth outcomes are associated with a range of factors that may also be associated with higher EPDS scores, including previous experience of trauma, complications during pregnancy, smoking, and social disadvantage. Associations between adverse birth outcomes and scores of 13 or above on the EPDS do not imply a causal relationship. Despite this, there may be an opportunity to further explore the relationship between birth outcomes, perinatal mental health screening results, and common contributing factors as more data become available.

In the data currently available, for women with a recorded EPDS score during their pregnancy:

- a higher proportion of mothers who subsequently had a pre-term birth (less than 37 weeks gestation) scored 13 or above during pregnancy (11.2%), compared with 7.4% of mothers who subsequently gave birth to their babies at term (37 to 41 weeks).
- a higher proportion of mothers who subsequently had a stillbirth scored 13 or above during pregnancy (11.8%), compared with 7.6% of mothers who had all live births for the pregnancy.

#### Interpreting the data

Scoring high on the EPDS is not a diagnosis of mental illness, it is an indication that the woman may have experienced depressive and/or anxiety symptoms in the past 7 days. Interpreting a high EPDS score as a diagnosis would likely overestimate antenatal depression prevalence (Lyubenova et al. 2021). The total EPDS score is one measure that clinicians can use to understand when women may be at heightened risk of poor mental health and may need further assessment, support and follow up. Similarly, factors associated with a higher EPDS score provide some insight into what cohorts of women may require more support through targeted services, policies or programs.

This report explores data from three states and territories who have implemented the perinatal mental health screening data items in the Perinatal NBEDS/NPDC. This report includes NPDC data for women giving birth in Queensland, Tasmania and the ACT only. This is the first perinatal mental health screening data to be assessed as being suitable for reporting, providing a case study to demonstrate the insights to be gained from reporting perinatal mental health screening data. Data from other state and territory health authorities will be available progressively as national implementation of the Perinatal NBEDS continues.

A higher proportion of women who had an EPDS score recorded had demographic and health factors which have been associated with a higher risk of perinatal depression, compared with all mothers in the three supplying state and territory health authorities and nationally. As such, results are not generalisable nationally.

Variation in EPDS response rates and scores may be due to a range of factors, such as the willingness of women to disclose their concerns and symptoms, and the cultural appropriateness of the EPDS for the woman. The NPDC also only collects data for one occasion of screening per woman, even if they were screened multiple times during pregnancy. Screening uptake and results may also have been affected by the COVID-19 pandemic shutdowns and service disruptions. However, the impact of the pandemic cannot be examined because the collection of these NPDC data items only began in 2020 and the date of screening is not collected.

See Key information gaps and Data opportunities for further information.

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# Availability of perinatal data

To date, there is no national data about perinatal mental health screening, service use or outcomes. Data about the mental health of parents in the perinatal period are collected by a range of health services, Australian Government and state and territory government agencies, and non-government organisations, mostly as a by-product of delivering maternity services. The range of settings has implications for the ease with which comparable data can be extracted and collated into a national data collection.

A number of existing data collections currently offer some insight into perinatal mental health, including the:

- National Perinatal Data Collection (NPDC)
- National Maternal Mortality Data Collection (NMMDC)
- Medicare Benefits Schedule (MBS).

In addition, large-scale longitudinal studies also provide insight, including the Australian Longitudinal Study on Women's Health survey.

Data relating to the mental health of mothers are also routinely collected in national hospital, hospital emergency department, and pharmaceutical data collections, however data linkage would be required to identify women in the antenatal and postnatal period.

# National Perinatal Data Collection

The NPDC is Australia's authoritative source of data about pregnancy and childbirth. Each state and territory health authority maintains its own perinatal data collection about births in its jurisdiction and provides an annual standard extract of the data to the AIHW for national collation. Work to include antenatal mental health data in the NPDC commenced in 2010, and in July 2020, three antenatal mental health data items and one family violence screening data item were introduced as part of the voluntary Perinatal NBEDS:

- Antenatal mental health risk screening status (Yes, Not offered, Declined)
- Indication of possible symptoms of depression at an antenatal care visit (total EPDS score)
- Presence or history of mental health condition indicator (Yes, No)
- Family violence screening status (Yes, Not offered, Declined).

The Perinatal NBEDS is not mandated for national collection but there is a commitment to provide data nationally on a best endeavours basis. State and territory health authorities are at different stages in implementing the data items for a variety of reasons. Four state and territory health authorities supplied at least one of the four data items for both the 2020 and 2021 birth cohorts (<u>Table 1</u>). For further information, see <u>Data opportunities</u>.

# National Maternal Mortality Data Collection

The National Maternal Mortality Data Collection (NMMDC) is a national data collection of maternal deaths (up to and including 42 days postpartum, irrespective of the duration or outcome of the pregnancy). The NMMDC includes data on if the death was caused by suicide, if mental health screening was offered, complications in the pregnancy and up to 42 days postpartum (including *Mental health illness*) and pre-existing conditions (including *Mental health illness*).

# **Medicare Benefits Schedule**

The MBS data collection contains information on services that qualify for a benefit or subsidy and for which a claim has been processed. It includes two antenatal and three postnatal obstetric items that require the claiming GP or obstetrician to offer a 'mental health assessment' to the patient. Between 2018 and 2022, the number of these antenatal services claimed per year decreased, from around 121,000 services in 2018 to around 101,000 services in 2022. Use of the postnatal items has increased steadily per year, from around 37,900 services claimed in 2018 to around 59,900 services in 2022 (Figure 3).

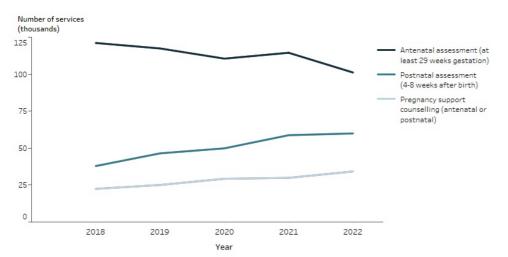
Medicare subsidises antenatal and postnatal services delivered in the community and to admitted private hospital patients by GPs, midwives, specialists and some allied health workers. This does not include services provided to public hospital patients, including antenatal clinics run by public hospitals. It is currently unknown what proportion of antenatal and postnatal services this represents.

The MBS also includes items for non-directive Pregnancy Support Counselling provided by GPs, other eligible medical practitioners (not including specialists or consultant physicians), psychologists, social workers and mental health nurses to patients who are pregnant or 1 year postpartum. Pregnancy support counselling does not need to relate to a patient's mental health and can be used to discuss any pregnancy related concerns such as parenting, health, relationship and financial concerns. Use of these services has steadily increased, from around 22,500 services claimed in 2018 to 34,200 services in 2022 (Figure 3). These services were provided to patients out of hospital, and the bulk were provided by GPs (96% of services in 2022).

Figure 3: Number of Medicare-subsidised perinatal mental health-related services, by service type, 2018 to 2022 In 2018 there were 121,078 MBS funded services for antenatal assessment (at least 29 weeks gestation).

In 2019 there were 117, 385 MBS funded services for antenatal assessment (at least 29 weeks gestation).

In 2020 there were 110,502 MBS funded services for antenatal assessment (at least 29 weeks gestation). In 2021 there were 114,467 MBS funded services for antenatal assessment (at least 29 weeks gestation). In 2022 there were 101,136 MBS funded services for antenatal assessment (at least 29 weeks gestation). In 2018 there were 37,882 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2019 there were 46,451 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2020 there were 49,829 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2020 there were 49,829 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2021 there were 58,712 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2022 there were 59,917 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2018 there were 22,429 MBS funded services for postnatal assessment (4-8 weeks after birth). In 2019 there were 22,429 MBS funded services for pregnancy support counselling (antenatal or postnatal). In 2019 there were 25,069 MBS funded services for pregnancy support counselling (antenatal or postnatal). In 2020 there were 29,256 MBS funded services for pregnancy support counselling (antenatal or postnatal). In 2021 there were 29,866 MBS funded services for pregnancy support counselling (antenatal or postnatal). In 2021 there were 29,866 MBS funded services for pregnancy support counselling (antenatal or postnatal). In 2021 there were 34,197 MBS funded services for pregnancy support counselling (antenatal or postnatal).



Note: Results are by date of processing. Antenatal items include items 16590 and 16591. Postnatal items include items 16407, 91851 and 91856. Pregnancy support counselling items include 4001, 792, 81000, 81005, 81010, 93026, 93029, 92136, 92137, 92138 and 92139.

Although the antenatal items have existed since 2004, these items were updated in November 2017 to require the medical practitioner to offer a mental health assessment (previously it was at the discretion of the medical practitioner). The postnatal items requiring an assessment to be offered were introduced from November 2017.

Source: AIHW analysis of Medicare Benefits Schedule item reports. Sourced on 23 October 2023.

It should be noted that the MBS claims data does not include information about if or how the woman was screened (that is, the tools used) or the outcome of the mental health screening - the selected antenatal and postnatal items only tell us that the woman has been 'offered' a mental health assessment. In addition, this is likely to be underestimated, as GPs and obstetricians might provide similar services under different 'general' MBS items (for example, item 23), or a mental health-specific item that is not specific to women in the antenatal or postnatal period.

As such, while the MBS claims data can give an indication of the number of women being offered perinatal mental health screening in out of hospital settings, or to private admitted patients of public and private hospitals, its use for monitoring perinatal mental health is limited without linkage to another data source that identifies women in the antenatal and postnatal period.

# Surveys and longitudinal studies

There are several large scale and ongoing surveys and longitudinal studies in Australia that provide insight into perinatal mental health screening and outcomes (<u>Table 2</u>), including:

Table 2: Overview of Australian surveys and longitudinal studies related to perinatal mental health

Mothers

Study

Perinatal mental health scope In scope cohort

Representativeness

Australian Longitudinal Study on Women's Health (Loxton et al. 2021)	Mothers were asked: 'For your most recent pregnancy, were you asked any questions by a midwife, GP, child health nurse or other professional about your emotional wellbeing? (e.g., given a questionnaire to complete)'.	1973-78 cohort: Across the 2009 to 2018 surveys (aged 31 to 42), 1,180 women reported giving birth in the three years before the survey. 1989-95 cohort: Across the 2017 and 2019 surveys (aged 22 to 29), 1,083 women reported giving birth in the three years before the survey. Perinatal mental health related questions were not included in the 2020 survey but may be included in future years.	<ul> <li>1973-78 cohort: Randomly sampled from the Medicare database in 1996. Women from rural and remote areas were oversampled to support analysis of this group.</li> <li>1989-95 cohort: Recruited by traditional methods (referral, print and commercial media) and social media/marketing campaigns in 2013. Women with tertiary education were overrepresented, and women from non-English speaking backgrounds were underrepresented.</li> </ul>	
Australian Genetics of Depression study (Kiewa et al. 2022)	Women with self-reported perinatal depression were asked about symptom onset and prior depression history.	2,261 women with perinatal depression with a prior depression history. 878 women with perinatal depression with no prior depression history.	Women with major depression were recruited during 2016- 2018. The Australian Genetics of Depression Study cohort is mostly young and well- educated and may not generalise to the entire population.	
The Mothers' and Young People's Study (Brown et al. 2021)	Mothers and offspring are given a range of mental health and behavioural measures.	2003-2005: Over 1,500 first- time mothers and their first- born children from pregnancy to age 18.	Women were recruited from six Melbourne metropolitan hospitals between 2003-2005. Younger women (aged 18-24 years) and women born overseas in non-English speaking countries were underrepresented.	
Fathers				
Study	Perinatal mental health scope	In scope cohort	Representativeness	
Ten to men: Australian Longitudinal Study on Male Health (AIFS 2021a, 2021b, 2021c, 2021d)	Patient Health Questionnaire 9 (depressive symptoms, no assessment of anxiety or stress). Age of child is not recorded, and no questions specific to mental health during the perinatal period.	Wave 1 (2013/14): 7,458 fathers to children under 18. Wave 2 (2015/16): 205 new fathers since Wave 1 (5,648 fathers to children under 18). Wave 3 (2020/21): 3,403 fathers to children under 18.	Low response rate (35% of eligible males). Sampling not conducted in remote and very remote areas while inner and outer remote areas were oversampled.	
21-item Depression, Anxiety, Men and Parenting Pathways (MAPP) Study (Macdonald et al. 2021) Study al. 2021) Study (Macdonald et al. 2021) Study (Macdonald		Wave 1: 241 fathers to 421 children. Waves 2 and 3: 67 new fathers and 156 new births. 44 new fathers identified after wave 3 completion. Waves 4 and 5: in progress.	Small sample size (608 men aged 28-32 when recruited between 2015 and 2017), although fairly representative.	

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# Key information gaps

The majority of available data are about antenatal mental health screening of mothers conducted by state and territory-funded services, which only covers a segment of the perinatal mental health screening occurring across the country.

Data about mental health and psychosocial screening are collected in antenatal and postnatal settings such as hospitals and GP clinics through the course of providing care to patients. These data are stored within the health setting's clinical information system, and may be electronic or paper-based. The ease of which this information can be extracted varies, due to the way data are collected and stored, legislative remit, and resource constraints.

Key information gaps include:

- postnatal mental health screening, which generally occurs through primary health care or Maternal, Child and Family Health Services
- psychosocial risk factor screening and anxiety screening in the antenatal and postnatal period
- repeat screening
- perinatal mental health screening of private patients and of mothers in non-hospital settings such as by GPs, other primary health care workers, and obstetricians
- data for population groups that may be at higher risk, such as First Nations parents, Culturally and Linguistically Diverse (CALD) parents, parents who identify as Lesbian, Gay, Bisexual, Trans and Gender Diverse, Intersex, Queer or other (LGBTIQ+), and parents with disabilities
- fathers and other non-birthing parents
- protective factors in the perinatal period
- relationship between physical and psychological birth trauma and perinatal mental health.

# First Nations communities

First Nations people are an important priority population as they typically have poorer health outcomes including higher rates of adverse pregnancy and birth outcomes (AIHW 2021b), high prevalence of mental illness and suicide (Martin et al. 2023), and higher experiences of intimate partner violence and child abuse and neglect compared to non-Indigenous Australians (AIHW 2022a).

Current research generally suggests that the standard English version of the EPDS is not culturally appropriate for First Nations mothers, however some health care professionals have expressed mixed perceptions on its suitability (Chan et al. 2021). Alternative screening tools have been or are being developed specifically for First Nations women, such as the Kimberley Mums Mood Scale (KMMS), Baby Coming You Ready? (BCYR) and the Mount Isa Depression Scale (MIDS). Expanding data collections to include these screening tools that have been culturally adapted and validated (such as the KMMS) or specifically developed for First Nations people (such as BCYR), may improve representation of First Nations women in the data and result in higher quality data about the perinatal mental health of First Nations women.

# Culturally and Linguistically Diverse (CALD) communities

Migrants, refugees and asylum seekers are a diverse population, and as such estimates of the prevalence of perinatal mental health conditions and other psychosocial risk factors vary widely (Eastwood et al. 2021; Stevenson et al. 2023; Sullivan et al. 2020). People from CALD backgrounds may have different levels of social support in Australia, have different levels of language proficiency, may be recovering from pre-migration trauma, and may have experienced or continue to experience discrimination and other stressors such as employment difficulties and insecure visa status (Sullivan et al. 2020).

How mental health is expressed, understood and stigmatised differs across cultures. Women's responses to screening and help-seeking behaviours may be influenced by mistrust of their health care provider or translator, language and translation issues, perception of stigma, and different cultural norms about emotional expression (Firth et al. 2022; Skoog et al. 2022). This has implications for how mental health data are collected and interpreted clinically and for research: for instance, lower EPDS cut-off scores are recommended when screening women from CALD backgrounds to account for this (Highet et al. 2023).

Providing screening in a woman's preferred language improves their understanding of questions being asked in the tool (Willey et al. 2020). Research indicates that women feel more able to answer sensitive questions truthfully when they can complete screening by themselves, by using a translated paper or digital screening tool, however the presence of an interpreter is still valuable for clarifying the meaning of questions and providing support when speaking to health professionals (Willey et a. 2020).

Accurately identifying CALD populations is a challenge for many data collections, including the NPDC which currently collects country of birth (AIHW 2022e). Collecting other variables such as language, English proficiency, and year migrated to Australia, will support understanding of the perinatal mental health of CALD populations, including allowing recommended culturally relevant cut-off scores to be accounted for when analysing data.

# LGBTIQ+ childbearing parents

Childbearing parents who identify as LGBTIQ+ may face unique mental health risks during pregnancy and following childbirth, including stigma, discrimination, difficulty accessing inclusive services for fertility, antenatal, birthing and postnatal support, and challenges related to gender identity. Emerging research suggests the prevalence of perinatal mental health conditions in LGBTIQ+ childbearing parents may be higher than cisgender heterosexual mothers (Kirubarajan et al. 2022). It is currently not possible to identify LGBTIQ+ parents in national data collections, however this is a potential area for exploration in the Perinatal Mental Health pilot (see <u>Data opportunities</u>).

#### Fathers and other non-birthing parents

Fathers and other non-birthing parents can also experience poor mental health and social and emotional wellbeing during the perinatal period.

It is estimated depression affects between 5% and 10% of fathers during this period (Cameron et al. 2016; Mazza et al. 2022; Paulson and Bazemore 2010), and anxiety affects around 5% to 15% of fathers (Leach et al. 2016). It is estimated that paternal depression co-occurs in around 1% to 3% of mothers and fathers (Mazza et al. 2022; Smythe et al. 2022). Paternal depression during the perinatal period is associated with an increased risk of long term emotional, behavioural and social difficulties in children, independent of maternal perinatal depression (Gentile and Fusco 2017). There are limited data about the prevalence of perinatal mental health conditions in other non-birthing parents and guardians, including adoptive parents, step-parents, and non-birthing LGBTIQ+ parents.

At present, there are limited data available about perinatal mental health screening and outcomes of fathers in Australia, and even scarcer data available on other non-birthing parents. Addressing and measuring the mental health and wellbeing needs of fathers and other parents requires a tailored approach noting cultural differences in parenting roles, and differences in when and how parents interact with the health system. Signs of mental health conditions can also display differently in men, with symptoms such as irritability, aggression and risk-taking behaviours not captured by the EPDS (Kennedy and Munyan 2021). The EPDS has been used to screen fathers using a lower cut-off score, however evidence for which cut-off score is mixed (Kennedy and Munyan 2021). The ANRQ has recently been adapted for men (Highet et al. 2023), and work is underway to adapt other screening tools for fathers, such as BCYR.

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# Data opportunities

In 2022, under the <u>National Mental Health and Suicide Prevention Agreement, Bilateral Schedules</u> (Bilateral Schedules) between state and territory health authorities and the Australian Government were developed to support the enhanced collection and reporting of perinatal mental health data from public antenatal and postnatal care settings, and the provision of perinatal mental health data to the AIHW (Commonwealth of Australia 2022). This work builds on efforts that commenced in 2010 with extensive consultation with subject matter and data experts, and supports the National Perinatal Depression Initiative which recommended nationally consistent perinatal mental health data also supports the delivery of woman-centred continuity of care and improved outcomes and experiences for women and their families (COAG Health Council 2019).

Despite challenges, there are a number of developments and opportunities underway to harness these data:

- Perinatal NBEDS items
- Perinatal Mental Health pilot
- Data linkage
- Primary health care data development

# Mental health and family violence Perinatal NBEDS items

State and territory health authorities are at different stages of implementing the four mental health and family violence Perinatal NBEDS items, for a variety of reasons. Data quality, comparability, and universal coverage are required before the data items can progress to become mandatory as part of the Perinatal NMDS.

The AIHW is undertaking extensive stakeholder engagement with state and territory health authorities through the Perinatal Mental Health Jurisdictional Data Working Party (Working Party) to understand the challenges experienced in implementing and collecting these data items, and to ensure that these data items are fit-for-purpose and a priority for jurisdictional and national data development. For example, for the Perinatal NBEDS *Presence or history of mental health condition indicator* data item, Working Party members are considering how analysis of PMHp data, which includes the self-reported mental health history from the ANRQ and SAFE START Psychosocial questions, could provide evidence to improve the consistency and comparability of the data collected.

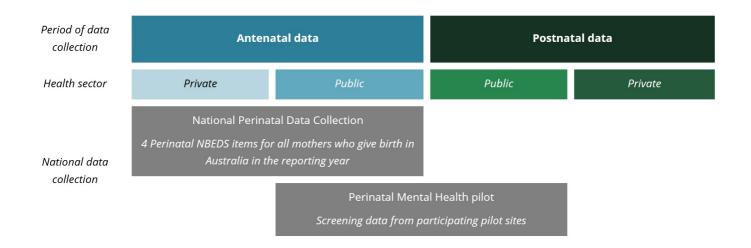
Each state and territory health authority's perinatal data collection, which feeds into the NPDC, is typically sourced from data collected by midwives or other birth attendants shortly after the mother has given birth. Data may also be sourced from information that has been previously electronically captured through the woman's antenatal care. At present there is limited capacity to collect additional mental health-related items in the NPDC. Data about the postnatal period after discharge are out of scope for the NPDC.

# Perinatal Mental Health pilot

The Perinatal Mental Health pilot (PMHp) is a novel collection of de-identified screening data sourced from public antenatal and postnatal maternity health services. In mid-2023, the AIHW received the first tranche of PMHp data from South Australia's Northern Adelaide Local Health Network (NALHN). Analysis is underway including sharing service-level data back to NALHN through the AIHW's Perinatal Portal, a secure platform to share perinatal data and insights with perinatal service providers.

The PMHp will grow iteratively in scope and coverage over time, as state and territory health authorities and health services commit to contributing their public antenatal and postnatal maternity service data. The AIHW has received interest from Queensland and New South Wales (NSW) to participate in the PMHp. As such the PMHp is a small but growing sample of the antenatal and postnatal mental health screening occurring across Australia. The PMHp aims to complement the NPDC (**Figure 4**), by collecting data that is currently out of scope for the NPDC, such as postnatal data and psychosocial risk factor screening data from participating pilot sites.

Figure 4. Scope of the National Perinatal Data Collection and Perinatal Mental Health pilot



The PMHp will trial a new way to collect and report perinatal mental health screening data. Noting that screening practices differ across the country, the PMHp has a flexible scope, with ongoing AIHW ethics approval to collect a broad range of data including:

Symptoms of depression and anxiety Edinburgh Postnatal Depression Scale (EPDS)

Psychosocial questions Antenatal/Postnatal Risk Questionnaire (ANRQ/PNRQ) SAFE START First Nations screening tools Kimberley Mum's Mood Scale (KMMS) Baby Coming You Ready? Mount Isa Depression

Patient demographics

Age, usual residential area, Indigenous status, if born in Australia or not Occasion of screening variables

Language of screening, and when screening occurred (incl. if patients are screened multiple times)

# Key areas for investigation

The PMHp will provide valuable insights about variation in perinatal mental health screening uptake and the prevalence of psychosocial risk factors by maternal age, socioeconomic level, Indigenous status, geographic region, and language, and changes over time; these insights will inform clinical decision making and benchmarking progress. For example, the PMHp will enable analysis of:

- All EPDS scores (not just the total score): This will provide insights in relation to whether patients report thoughts of self-harm (Question 10), and their anxiety risk (EPDS questions 3, 4 and 5, and ANRQ questions relating to trait anxiety and perfectionism), noting further investigation is needed to assess the validity of the anxiety items (Austin et al. 2022; Smith-Nielsen et al. 2021).
- When and how screening is conducted: To inform interpretation of these data, the PMHp is seeking to collect data from all occasions of screening, including how many weeks pregnant or postpartum the woman was at the time of screening. This will allow exploration of the patient journey through contact points with maternity services by considering factors including repeat screening, whether women were screened in both the antenatal and postnatal periods, differences between initial and subsequent screens, and whether at-risk patients (EPDS score 13 or higher) received follow-up screening within the recommended period.
- Presence or history of mental health condition indicator data item: Analysis of PMHp data will also support efforts to improve this data item in the Perinatal NBEDS.
- **Psychosocial risk factors** refer to prior mental health history, availability of support systems and feeling safe with their partner, experiences of abuse, alcohol or other drug concerns, and experience of giving birth and parenting. Collecting these data will provide a fuller picture of women's perinatal mental health and build understanding of the different tools used to conduct psychosocial risk factor screening across the country.
- Protective factors interact with risk factors and are relative to the individual and their psychological, social, environmental, and cultural needs. Improved understanding about risk factors of mental health conditions through screening in the perinatal period, will help improve understanding about protective factors, such as social support, physical activity, and coping strategies before and after childbirth, as well as positive mother-infant interaction.
- Priority populations such as First Nations people and CALD communities, particularly as mainstream approaches may not be the most suitable for these populations. The iCOPE screening platform includes First Nations-specific screening tools and is available in 24 languages other than English. By collecting the language of screening, it will allow recommended lower cut off scores to be accounted for when analysing the data. The AIHW is also exploring opportunities to include perinatal mental health screening of fathers and other non-birthing parents which the iCOPE screening platform facilitates.

# Data linkage

Data linkage is a process that combines information from multiple data collections to tell a richer story than would be possible from a single data source. This maximises the utility of existing data sources and minimises the burden and cost of collecting additional data.

There is potential, with relevant approvals, to link the NPDC to other health and welfare related data collections. This will build an understanding about patterns of mental health care use by women before, during and after pregnancy, and health outcomes for mothers and babies. For example, linking the NPDC to:

- MBS will provide insight into use of mental health-related Medicare subsidised services, including from GPs, psychiatrists, psychologists and other allied health workers
- PBS will provide insight into use of mental health-related prescription medications
- Hospital admitted patient data will provide insight into hospital admissions for mental health and intentional self-harm
- Hospital ED will provide insight into mental health-related ED presentations
- Community mental health data will provide data about women treated in specialist community and hospital-based outpatient care services provided by state and territory governments. These are collectively referred to as community mental health care (CMHC) services and contribute data to the Community Mental Health Care National Minimum Data Set (CMHC NMDS). The CMHC NMDS does not include data from non-government funded community services such as not-for-profit organisations.
- Mortality data will provide data about women who die by suicide in the postnatal period, beyond 42 days after birth. Linkage with the above data sources, will also provide insight into mental health service use and medication use by these women, compared with women who have not died by suicide.

These insights will inform service planning and policy, to help ensure women and families get the care they need, when they need it.

#### Development of primary health care data

GPs and other primary health care providers play a key role in the delivery of antenatal and postnatal mental health screening, referral and care. As noted earlier, MBS data offers limited insight into the delivery of these services and patient outcomes, without linkage to other data collections.

There are information gaps in primary health care data that make it difficult to understand a patient's journey through the health care system. A variety of clinical information systems are used in primary health care settings, and there are also different tools for extracting data from these systems, which can make it difficult to collate data into a national collection.

There are a number of large-scale projects underway to improve the availability of primary health care data, and it may be possible to leverage these projects to give insight into the screening and management of perinatal mental health conditions in general practice, particularly for women in the postnatal period:

- The AIHW is developing a <u>National Primary Health Care Data Collection</u> (NPHCDC), with an initial focus on general practice activity data. The AIHW has consulted across the primary health care sector and is now working collaboratively with PHNs to conduct small-scale data demonstration projects. The goal of these projects is to generate a comprehensive overview of the current state of general practice data in Australia. The first data demonstration project commenced in 2023 and is focused on general practice data on dementia. A long-term aim is for the NPHCDC to be linked with other datasets in the national data linkage system.
- NSW's Lumos is a state-wide program linking GP data with public and private hospital admitted patient, non-admitted patient, ambulance, cancer and cause of death data. Data linkages are performed twice per year, and after each linkage participating GPs and PHNs receive a customised report about their patients. As of October 2022, all NSW PHNs and more than 600 general practices were participating in Lumos. The program has been funded through the Commonwealth Health Innovation Fund (NSW Health 2022).
- The University of Melbourne, in partnership with general practices, has developed <u>Data for Decisions</u>, a collection of de-identified general practice data. In 2020, there were approximately 3.5 million de-identified patients in the dataset and around 80 million patient visits.

#### Next steps for perinatal mental health screening data

Evidence about perinatal mental health is essential to inform the development and evaluation of policies and to help plan, deliver and coordinate targeted services and initiatives. Perinatal mental health data are currently disparate and fragmented, and this report highlights there is currently no single solution. To produce a meaningful national picture, a multipronged, iterative approach is needed that builds on existing systems and works in tandem with the delivery of quality health care.

The various data development initiatives described in this report will improve evidence about perinatal mental health in Australia. Amplified by Australian stories of perinatal mental health experiences, future reporting of state and territory efforts, including data gained from the PMHp and data linkage, will improve our picture of the needs of mothers and families, so they receive the mental health support they need.

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# **Technical notes**

# Terminology

#### Sex and gender terminology

This report uses the terms 'woman', 'women', 'mother' and 'mothers' to mean females who were pregnant or gave birth. 'Woman' and 'women' typically refers to groups of people aged 18 years and over; however in this report, people who were pregnant or gave birth aged less than 18 are included.

It is acknowledged that this report includes people who do not identify as women or mothers, and that individual parents and families may use different words to those used in this report. This may include transgender men, intersex people, non-binary and gender diverse people.

#### **First Nations terminology**

The AIHW uses 'First Nations people' to refer to Aboriginal and/or Torres Strait Islander people in this report.

#### Data sources

#### National Perinatal Data Collection

Analysis in this report uses data from the National Perinatal Data Collection (NPDC) for 2020 and 2021, including voluntary mental health screening items contributed by states and territories under the 2020-21 and 2021-22 National Best Endeavours Data Set (NBEDS).

See Availability of perinatal data for more information about what perinatal data are available in the NPDC and NBEDS.

See Australia's mothers and babies for more information on how data are collected for the NPDC and its structure.

#### Methods

#### Cohorts

Analysis in this report and supporting data tables presents maternal and pregnancy characteristics of:

- all mothers who gave birth in Australia between 2020 and 2021
- all mothers who gave birth in Queensland, Tasmania and the Australian Capital Territory

and the maternal and pregnancy characteristics, and EPDS screening results for:

• all mothers who gave birth in Queensland, Tasmania and the Australian Capital Territory and had a recorded antenatal mental health screening result.

#### **Missing data**

Proportions, percentages and rates for maternal characteristics exclude cases where the variable of interest is missing, recorded as not stated, or is inadequately described.

New South Wales, South Australia, Western Australia, and the Northern Territory did not supply data on the use of assisted reproductive technologies to the NPDC for 2020-2021.

New South Wales and Western Australia did not supply data on *previous pregnancies resulting in live birth* and *previous still birth* to the NPDC for 2020-2021.

New South Wales did not supply data on *alcohol consumed during first 20 weeks* and *alcohol consumed after 20 weeks* to the NPDC for 2020-2021.

States and territories that did not supply data for specific data items are excluded from the calculations for all mothers.

#### **Multiple births**

Where a pregnancy resulted in multiple births (twins, triplets, and so on), birth setting and gestational age from the first birth are reported. Where any birth resulted in stillbirth, birth outcomes are reported as 'any stillbirth'. Birth outcomes are reported as 'all live births' where all babies were live born, regardless of subsequent survival or death in the perinatal and postnatal periods.

#### Remoteness

This report uses the Australian Statistical Geography Standard (ASGS) Remoteness Structure which classifies geographical areas based on their relative access to services.

Remoteness Areas are assigned to the smallest statistical geography unit in the ASGS, Statistical Area 1 (SA1), describing an area with a population of between approximately 200 and 800 people.

This report uses ASGS Remoteness Areas mapped to the Statistical Area 2 (SA2) of mother's usual residence. As Remoteness Areas are assigned at the SA1 level, which aggregate to form SA2s, some SA2s include more than one Remoteness Area. For mothers in an SA2 containing more than one Remoteness Area, counts of mothers were proportionally assigned based to Remoteness Areas based on the estimated percentage of persons in each Remoteness Area within the SA2.

In this report, remoteness is not reported for mothers not usually resident in Australia or where the mother's SA2 or state of usual residence was not stated, inadequately described, was unable to be mapped to a Remoteness Area, or was in a territory other than Northern Territory or Australian Capital Territory. Table 3 shows the number of mothers for whom remoteness is not reported.

#### Table 3: Mothers excluded from remoteness reporting by state and territory of baby's birth

State of baby's birth	N (%)
New South Wales	1,582 (0.8)
Victoria	162 (0.1)
Queensland	64 (0.1)
South Australia	33 (0.1)
Western Australia	1,221 (1.9)
Tasmania	_
Northern Territory	4 (0.1)
Australian Capital Territory	1 (0.0)

See the <u>Australian Statistical Geography Standard (ASGS): volume 5 - remoteness structure</u>, July 2016 (ABS 2018a) for further information on Remoteness Areas.

#### Socioeconomic areas

The Socio-Economic Indexes for Areas (SEIFA) summarises a range of variables to rank geographic areas of Australia according to relative socio-economic advantage or disadvantage. This report uses the 2016 Index of Relative Socioeconomic Disadvantage (IRSD) developed by the Australian Bureau of Statistics for use at Statistical Area Level 2 (SA2), defined geographic areas generally containing between 3,000 and 25,000 people.

The IRSD is a summary measure for a geography area and describes the average level of disadvantage in that area. Socio-economic advantage and disadvantage varies at the individual level within each SA2. A SEIFA rank does not apply to an individual but summarises characteristics of the geographic area such as income and opportunities in education and employment.

This report uses SEIFA quintiles, five approximately equal sized groups ranking geographic areas from the least advantaged (Q1) to the most advantaged (Q5). Mothers are classified into SEIFA quintiles based on their SA2 of usual residence.

In this report, SEIFA scores are not reported for mothers not usually resident in Australia or where the mother's SA2 or state of usual residence was not stated, inadequately described, was unable to be mapped to a SEIFA score, or was in a territory other than Northern Territory or Australian Capital Territory. Table 4 shows the number of mothers for whom SEIFA is not reported.

#### Table 4: Mothers excluded from SEIFA reporting by state and territory of baby's birth

State of baby's birth	N (%)
New South Wales	1,701 (0.9)
Victoria	204 (0.1)
Queensland	66 (0.1)
South Australia	272 (0.7)
Western Australia	1,263 (1.9)
Tasmania	_
Northern Territory	25 (0.3)
Australian Capital Territory	317 (2.6)

See Socio-Economic Indexes for Areas (SEIFA), Australia, 2016 (ABS 2018c) for further information on SEIFA.

# Maternal country of birth

Country of birth is recorded using the Standard Australian Classification of Countries (SACC) a four-digit hierarchical structure classifying countries into major and minor groups country. Mothers born in Australia are identified using the minor group and country codes for Australia and its external territories (11, 1101, 1102 & 1199).

#### Gestational age

Gestational age uses the number of completed weeks of pregnancy at the time of birth. In this report, mothers were classified as *pre-term* if they gave birth at between 20 and 36 completed weeks of pregnancy, as *at term* if they gave birth between 37 and 41 weeks, and *post-term* if they gave birth at 42 or more completed weeks of pregnancy.

# Age-standardisation

Age-standardised rates enable comparisons to be made between populations that have different age structures. Data tables for this report include age-standardised rates using direct standardisation, in which the age-specific rates are applied to a constant population.

Age-standardised rates in supporting data tables use the June 2001 Australian female estimated resident population aged 15-44 as the reference population using five-year age groups. Limited 10-year age groups were used for some characteristics due to small numbers (Table 5).

Age-standardised rates are not reported for post-term births due to small numbers.

#### Table 5: Age groups used for age standardisation, by maternal characteristic

Characteristic of mother or pregnancy	Age groups
Alcohol consumed after 20 weeks,	15-24, 25-29, 30-34, 35-39 and 40-44
Parity,	
Previous live births,	
Previous stillbirth	
Birth setting,	15-19, 20-24, 25-29, 30-34, 35-44
Remoteness Area	
Birth outcomes,	15-24, 25-29, 30-34, 35-44
Use of assisted reproductive technology	
Alcohol consumed during first 20 weeks,	15-19, 20-24, 25-29, 30-34, 35-39 and 40-44
Diabetes during pregnancy,	
Indigenous status,	
Gestational age,	
Hypertensive disorder during pregnancy,	
Mother's country of birth,	
Multiple births,	
Pre-pregnancy BMI,	
Socioeconomic status (SEIFA quintile),	
Smoked after 20 weeks,	
Smoked at any point,	
Smoked during first 20 weeks	

#### References

Australian Bureau of Statistics (ABS) (2018a) <u>Australian Statistical Geography Standard (ASGS): volume 5 - remoteness structure, July 2016</u>, ABS, Australian Government, accessed 26 September 2023.

ABS (2018c) Socio-Economic Indexes for Areas (SEIFA), Australia, 2016, ABS, Australian Government, accessed 26 September 2023.

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# Glossary

**ANRQ:** The Antenatal Risk Questionnaire (ANRQ) is a 12-item questionnaire used to address key domains of psychosocial health that have been shown to be associated with increased risk of perinatal mental health morbidity (e.g., depressive or anxiety disorder) and less optimal mother-infant attachment. The ANRQ can be self-completed or administered by the clinician and can be used during pregnancy or postnatally.

antenatal: The period covering conception up to the time of birth. Synonymous with prenatal.

**antenatal care:** A planned visit between a pregnant woman and a midwife or doctor to assess and improve the wellbeing of the mother and baby throughout pregnancy. It does not include visits where the sole purpose is to confirm the pregnancy. Also known as an antenatal visit.

**anxiety disorders**: A group of mental disorders marked by excessive feelings of apprehension, worry, nervousness and stress. Includes generalised anxiety disorder, obsessive-compulsive disorder, panic disorder, post-traumatic stress disorder and various phobias.

birth trauma/traumatic birth: Includes births, whether pre-term or full term, which are physically traumatic (for example, instrumental or assisted deliveries or emergency caesarean sections, severe perineal tears, postpartum haemorrhage) and births that are experienced as traumatic, even when the delivery is obstetrically straightforward (NICE 2020), and thus may include **psychological birth trauma**. The Australian Longitudinal Study on Women's Health defines traumatic birth experiences as emergency caesarean, labour lasting more than 36 hours, emotional distress during labour, or stillbirth (Loxton et al. 2021).

data linkage/linked data/data integration: Bringing together (linking) information from two or more data sources believed to relate to the same entity, such as the same individual or the same institution. The resulting data set is called linked data. In this report, data linkage is used to bring together information from datasets that indicates a population of interest (such as people with dementia) with other datasets that include information on other characteristics or service usage.

**de-identified:** A process that involves the removal or alteration of personal identifiers, followed by the application of additional techniques or controls to remove, obscure, aggregate, alter and/or protect data so that they are no longer about an identifiable (or reasonably identifiable) individual.

**depression:** A mood disorder with prolonged feelings of being sad, hopeless, low and inadequate, with a loss of interest or pleasure in activities and often with suicidal thoughts or self-blame.

**depressive disorders:** A group of mood disorders with prolonged feelings of being sad, hopeless, low and inadequate, with a loss of interest or pleasure in activities and often with suicidal thoughts or self-blame.

**EPDS:** The EPDS is a 10-item questionnaire asking women how often they have felt certain ways in the past 7 days. For example, for the item 'I have been able to laugh and see the funny side of things,' women are asked to choose between responses; 'As much as I always could,' 'Not quite so much now,' 'Definitely not so much now,' and 'Not at all.' Responses to EPDS items are scored between zero and 3, and a total score of 13 is regarded as a flag for possible depressive symptoms requiring follow up.

family violence (or family and domestic violence): Violence between family members as well as current or former intimate partners. Can include acts of violence between a parent and a child. Family violence is the preferred term used to identify experiences of violence for Aboriginal and Torres Strait Islander people as it encompasses the broad range of extended family and kinship relationships in which violence may occur.

fetal death (stillbirth): Death, before the complete expulsion or extraction from its mother, of a product of conception of 20 or more completed weeks of gestation or of 400 grams or more birthweight. Death is indicated by the fact that, after such separation, the fetus does not breathe or show any other evidence of life, such as beating of the heart, pulsation of the umbilical cord or definite movement of voluntary muscles.

First Nations: Person of Aboriginal or Torres Strait Islander descent who identifies as an Aboriginal or Torres Strait Islander.

general practice: general practice includes fully qualified general practitioners. Physicians in training are normally excluded.

general practitioner (GP): A medical practitioner who provides primary comprehensive and continuing care to patients and their families in the community.

**mental health**: A state of wellbeing in which the person realises their own abilities, can cope with normal stresses of life, can work productively and can contribute to the community. Mental health is the capacity of individuals and groups to interact with one another and their environment in ways that promote subjective wellbeing, optimal development and the use of cognitive, affective and relational abilities. Different cultural groups may prefer to use other terms to describe mental health, such as 'social and emotional wellbeing' (Everymind 2020).

mental health condition/mental illness (or mental health disorder/mental disorder): A clinically diagnosable disorder that significantly interferes with an individual's cognitive, emotional or social abilities. The term covers a spectrum of disorders that vary in severity and duration, including **anxiety disorders**, affective disorders (such as **depression**), psychotic disorders and substance use disorders. The terms mental illness and mental disorder are often used interchangeably.

midwife: A person who is trained to help women in childbirth.

**mood (affective) disorders:** A set of psychiatric disorders, also called mood disorders. The main types of affective disorders are depression and bipolar disorder. Symptoms vary by individual and can range from mild to severe.

non-Indigenous: People who have indicated that they are not of Aboriginal or Torres Strait Islander descent.

parity: Number of previous pregnancies resulting in live births or stillbirths, excluding the current pregnancy.

**perinatal:** Pertaining to or occurring in the period covering pregnancy and the first year of birth. Note - this differs from other AIHW reports where perinatal is used to mean 'pertaining to or occurring in the period shortly before or after birth (usually up to 28 days after)'.

plurality: Number of births resulting from a pregnancy.

**postnatal/postpartum:** Pertaining to or occurring in the period immediately after birth and the first year after birth. The terms postnatal and postpartum are often used interchangeably however explicitly, *postpartum* refers to the woman and *postnatal* refers to the baby. This differs from other AIHW reports where these terms are used to mean 'pertaining to or occurring in the period immediately after birth lasting 6 weeks.'

postpartum psychosis: Acute cute psychotic episode arising in the early postnatal period.

**post-traumatic stress disorder (PTSD):** The development of a set of reactions in people who have experienced a traumatic event that might have threatened their life or safety, or others around them. Examples of traumatic events can include war or torture, serious accidents, physical or sexual assault, or disasters. A person who has PTSD can experience feelings of helplessness, horror or intense fear. Childbirth-related PTSD relates to a person's response to their birthing experience.

Pre-term birth: Birth before 37 completed weeks of gestation.

**Primary health care:** These are services delivered in many community settings, such as general practices, community health centres, Aboriginal health services and allied health practices (for example, physiotherapy, dietetic and chiropractic practices) and come under numerous funding arrangements. Expenditure on primary health care includes recurrent expenditure on health goods and services, such as on medical services, dental services, other health practitioner services, pharmaceuticals and community and public health services.

**Primary Health Network (PHN):** An administrative not-for-profit organisation set up under the Australian Government Primary Health Networks Program to commission primary care health services:

- to meet the identified and prioritised needs of people in their administrative health region
- to provide practice support to general practitioners
- to integrate health services, including coordinating with local hospitals, to improve operational efficiency and provide a better experience for patients.

**Private hospital:** A privately owned and operated institution, catering for patients who are treated by a doctor of their own choice. Patients are charged fees for accommodation and other services provided by the hospital and by relevant medical and allied health practitioners. The term includes acute care and psychiatric hospitals as well as private freestanding day hospital facilities.

**Private patient:** A person admitted to a private hospital, or a person admitted to a public hospital who decides to choose the doctor(s) who will treat them or to have private ward accommodation - this means they will be charged for medical services, food and accommodation.

**protective factors:** These are actions a person can take to reduce the negative impact of issues like mental health conditions and delayed developmental outcomes in children. They may strengthen a person's ability to cope with difficult circumstances and may include actions before and after childbirth such as physical activity, healthy nutrition, social support, and supporting mother-infant interaction.

**psychological birth trauma:** May result from a traumatic birth and be experienced by both birthing and non-birthing parents following a birth.

psychosocial: Involving both psychological and social factors that impact on health and wellbeing.

**psychotic disorders:** 'A diverse group of illnesses that have their origins in abnormal brain function and are characterised by fundamental distortions of thinking, perception and emotional response.' (Slade et al. 2009).

**public hospital:** A hospital controlled by a state or territory health authority. In Australia, public hospitals offer free diagnostic services, treatment, care and accommodation to all eligible patients.

**public patient:** Patients who are admitted to hospital at no charge and are mostly funded through public sector health or hospital service budgets.

**risk factors:** Any factor that represents a greater risk of a health disorder or other unwanted condition or event. Some risk factors are regarded as causes of disease; others are not necessarily so. Along with their opposites (**protective factors**), risk factors are known as determinants.

stillbirth: See fetal death (stillbirth)

suicide, suicidality, and intentional self-harm: Suicide - An action taken to deliberately end one's own life; Suicidality - a term that encompasses suicide plans, attempts and ideation; Intentional self-harm is deliberately causing physical harm to oneself but not necessarily with the intention of dying.

For additional terms, refer to the Glossary in Mothers & babies.

#### References

Everymind (2020) <u>Reporting suicide and mental ill-health: a Mindframe resource for media professionals</u>, Everymind, accessed 8 August 2023.

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# Notes

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For more information see <u>State and territory perinatal collections</u>.

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# Data

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# **Related material**

For information about the physical health of mothers and babies see:

• Australia's mothers and babies

For more information on family, domestic and sexual violence see:

- Family, domestic and sexual violence: National data landscape 2022
- Family, domestic and sexual violence data in Australia

# **Related topics**

• <u>Mental health</u>

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