Improving national reporting on diabetes in pregnancy

Technical report

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Summary

Diabetes affecting pregnancy can be pre-existing diabetes (that is, type 1, type 2, or other types of diabetes), or might arise as a result of the pregnancy (gestational diabetes), and has serious implications for the health of mothers and babies.

This report:

- identifies and describes national data sources available for monitoring the effects of diabetes during pregnancy on mothers and babies
- identifies current data gaps and alternate data sources for monitoring outcomes associated with diabetes during pregnancy
- explores the feasibility of data linkage to improve the monitoring of outcomes.

Data sources to monitor the impact of diabetes during pregnancy

Data on diabetes in pregnancy are available from various data sources in Australia, all of which have strengths and weaknesses. Three data sources provide data at the national level:

- The National Perinatal Data Collection (NPDC) is a national population-based collection of data on pregnancy and childbirth. The data collected within the NPDC identify women who gave birth and were found as either having pre-existing diabetes or gestational diabetes during pregnancy, as well as outcomes of these mothers and their babies around the time of birth.
- The National Hospital Morbidity Database (NHMD) is a collection of episode-level records from the Admitted Patient Care National Minimum Data Set. It contains information on episodes of care for admitted patients in hospital (pregnant women and babies), and includes demographic, diagnostic, outcomes, interventions and procedural information.
- The National Diabetes Services Scheme (NDSS) is an initiative of the Australian Government, administered with the assistance of Diabetes Australia. The NDSS provides information and support services, and delivers diabetes-related products at subsidised prices to people with diabetes. Within the NDSS, the National Gestational Diabetes Register (NGDR) was established to help women who have had gestational diabetes manage their future health. It contains demographic and some treatment information for women with diabetes.

Other data sources provide information at the state and territory level, or for specific population cohorts, but are not sufficient for exploring the Australian national context.

Improving national reporting

The NPDC is a useful data set to assess the outcomes of mothers and babies affected by diabetes during pregnancy. It enables mothers with diabetes in pregnancy to be identified, and the impact of diabetes on the health of these mothers and their babies to be assessed.

But some factors limit the use of the NPDC in looking at the impact of maternal diabetes on the health of mothers and their babies, including:

- the inability of some states and territories to distinguish between types of diabetes
- differences in data collection methods across jurisdictions.

The NHMD contains information about episodes of care for patients in hospital, including pregnant women and babies. But the inaccuracy of recording diabetes type, and changes in the coding of diabetes limit the use of data from the NHMD for reporting outcomes and complications by pre-existing diabetes type.

The NDSS and NGDR contains demographic and some treatment information for women with gestational diabetes, but are not designed to capture pregnancy-related information outside of gestational diabetes status. As such, they cannot be used to assess pre-existing diabetes in pregnancy, or supply information on pregnancy-related complications or outcomes.

Data required to monitor the impact of diabetes in pregnancy, and fill current knowledge gaps are not available in any one data set, but a more comprehensive data set could be obtained by linking multiple data sets containing information on mothers and babies.

Linking a national data set that has a robust record of births in Australia and diabetes in pregnancy status with other data sets containing information on health service use and treatment would provide a more comprehensive data set.

1   Introduction

1.1 Background

Diabetes affecting pregnancy can be pre-existing (type 1, type 2, or other types of diabetes) or might arise as a result of the pregnancy (gestational diabetes).

It can have immediate, short-term and long-term implications for the mother and her baby (HSCRG 2009). The type and severity of complications differ according to the type of diabetes experienced in pregnancy.

Monitoring diabetes during pregnancy provides important information on the impact of diabetes during pregnancy, and its complications, including how diabetes affects the health of mother and child (HSCRG 2009; Negrato et al. 2012).

This information can help policymakers assess the impact of diabetes during pregnancy, and build the evidence base needed to develop prevention and management programs that improve the care of mother and babies affected by diabetes in pregnancy.

This report discusses the need for monitoring pregnancies affected by diabetes, and the maternal and perinatal outcomes associated with diabetes in pregnancy. It extends on the 2010 AIHW *Diabetes in pregnancy: its impact on Australian women and their babies* report, and discusses the value and limitations of national data sources currently available for undertaking such a task.

This report also identifies current data gaps, alternate data sources for monitoring outcomes associated with diabetes in pregnancy, and possible data linkages to improve national monitoring of pregnancies affected by diabetes.

An accompanying report with population-level data on mothers with diabetes in pregnancy, and outcomes for mothers and babies using the National Perinatal Data Collection (NPDC) is available at https://www.aihw.gov.au/reports/diabetes/diabetes-in-pregnancy-2014-2015/contents/summary.

1.2 Structure of the paper

This chapter provides background about diabetes in pregnancy, providing information about the:

- effects of diabetes in pregnancy for mothers and their babies
- importance of monitoring diabetes in pregnancy
- data sources currently available for monitoring pregnancies affected by diabetes.

Chapter 2:

- discusses existing data gaps
- identifies potential data sources to fill data gaps
- assesses the feasibility of linking data sets to report on these data gaps.

1.3 What is diabetes in pregnancy?

Diabetes in pregnancy—whether pre-existing diabetes (diagnosed before the pregnancy or first detected during pregnancy) or arising during pregnancy as gestational diabetes—increases the risk of serious complications in both mother and child (WHO 2014).

Pre-existing diabetes can be type 1, type 2, or other types of diabetes. Other types of diabetes are relatively uncommon, and most typically related to certain conditions and syndromes.

Box 1: Types of diabetes in pregnancy

Type 1 diabetes

Type 1 diabetes is an autoimmune disease, which destroys the cells in the pancreas that produce insulin. It usually has an onset in childhood or early adulthood, but can be diagnosed at any age. People with type 1 diabetes need insulin replacement to survive.

Women with type 1 diabetes are advised to achieve strict control of blood glucose levels before and during pregnancy, and to be screened for diabetes complications before conception (McElduff et al. 2005).

Type 2 diabetes

Type 2 diabetes, while involving a genetic component, is largely preventable, and associated with a later onset.

Modifiable risk factors that can lead to type 2 diabetes include physical inactivity, poor diet, being overweight or obese, and tobacco smoking. It is the most common form of diabetes in the Australian population. But type 1 and type 2 are less common than gestational diabetes among pregnant women.

People with type 2 diabetes produce insulin, but do not produce enough, and/or cannot use it effectively. Type 2 diabetes can be managed with changes to diet and exercise, oral glucose-lowering drugs, non-insulin injectable, glucose-lowering medications, insulin injections, or a combination of these.

Women with type 2 diabetes are advised to strictly control blood glucose levels before and during pregnancy, and to be screened for diabetes complications before conception.

In addition, hypoglycaemic agents (except for metformin) commonly used to treat type 2 diabetes should be ceased, and insulin therapy should be introduced before and during pregnancy to achieve optimal glucose control (McElduff et al. 2005; RACGP 2016). Antihypertensive medications should also be reviewed, and statin use should be ceased either before pregnancy or when pregnancy has been confirmed.

Gestational diabetes

In uncomplicated pregnancies, the natural development of insulin resistance due to an increase in hormones and other pregnancy-related factors are not fully understood (Kampmann et al. 2015).

Gestational diabetes is a form of diabetes that develops when the woman is unable to produce insulin to compensate for the increase in insulin requirement during pregnancy (Farrar 2016).

This form of diabetes is characterised by glucose intolerance of variable severity, with onset or first recognition during pregnancy (Nankervis et al. 2014). Mostly, glucose intolerance develops during the second or third trimester of pregnancy, and usually disappears after the baby is born. But it can recur in later pregnancies.

Some cases of gestational diabetes are managed with changes to diet and exercise alone, and some might require pharmacological treatment, such as insulin, to manage the condition.

(continued)

Box 1 (continued): Types of diabetes in pregnancy

Various factors can increase a woman's chance of developing gestational diabetes, including:

- previous gestational diabetes

- previous elevated blood glucose level

- ethnicity—South and South-East Asian, Aboriginal or Torres Strait Islander, Pacific Islander, Maori, Middle Eastern, or non-Caucasian African women are at greater risk than other women

- age—women over 40 are at greater risk than younger women

- family history of diabetes mellitus

- pre-pregnancy obesity (body mass index of more than 30 kg/m^2)

- previously having a high birthweight baby (greater than 4,500 grams)

- polycystic ovarian syndrome

- medications the mother is taking, including corticosteroids or antipsychotics (Nankervis et al. 2014; Nankervis et al. 2018).

New information about the relationship between hyperglycaemia in pregnancy and perinatal outcomes led to the formulation of revised recommendations for the diagnosis of gestational diabetes in 2013 (Nankervis et al. 2014).

The new criteria recommended that a diagnosis of gestational diabetes be made if 1 or more of the following blood glucose levels are elevated:

- fasting glucose of 5.1 mmol/L or more

- 1-hour glucose 10.0 mmol/L or more

- 2-hour glucose 8.5 mmol/L or more.

Changes to the diagnostic criteria lowering the threshold for diagnosing gestational diabetes were anticipated to increase the number of women diagnosed with gestational diabetes (IADPSG 2010; Nankervis et al. 2014).

1.4 The impact of diabetes in pregnancy

Diabetes in pregnancy is associated with an increased risk of adverse pregnancy outcomes, including obstetric and neonatal complications (morbidity and mortality) (HSCRG 2009; Owens et al. 2015; Sacks et al. 2015). Adverse effects associated with diabetes in pregnancy can be:

- short term—including those characteristics, outcomes, conditions and interventions that can be seen during pregnancy, labour, and shortly after birth
- longer term—such as the development of type 2 diabetes in mothers with gestational diabetes during pregnancy.

The complications and adverse outcomes experienced by mothers and their babies differ between the different types of diabetes (pre-existing diabetes and gestational diabetes) during pregnancy. This is likely due to the different causes and effects of each diabetes type.

Gestational diabetes

The lack of insulin to compensate for the increases in insulin required and to maintain blood glucose in the normal range during pregnancy results in maternal hyperglycaemia (high blood sugar levels).

Maternal hyperglycaemia results in excessive blood glucose being transferred to the fetus. This can cause the baby to produce excessive amounts of insulin that stimulate fetal growth and result in complications, such as macrosomia (high birthweight of more than 4,000 grams), shoulder dystocia, and hyperbilirubinemia (Kampmann et al. 2015; Mayor 2017). These complications can, in turn, increase the risk of caesarean section delivery and obstetric complications, such as birth trauma and injury (Kampmann et al. 2015).

Pre-existing diabetes

In pregnant women with pre-existing diabetes, type 1 or type 2 diabetes, some diabetes related complications such as diabetic retinopathy and nephropathy may appear or have accelerated progression if they are already present (Kulshrestha & Agarwal 2016). Multiple factors can contribute to this including the presence of complications prior to pregnancy, long duration of diabetes, coexisting hypertension, rapid improvement of glycaemic control in early pregnancy and possibly pregnancy-related growth factors (Vargas et al. 2010).

Babies born to mothers with either pre-existing type 1 or type 2 diabetes have an increased risk of congenital anomalies, macrosomia, stillbirth, respiratory distress, and hypoglycaemia (Reece 2012).

Studies have shown that the increased risk of stillbirth or congenital anomalies of the spine, heart, and kidney can result from exposure to high blood glucose levels during the period of fetal development in the first trimester of the pregnancy. But the mechanism by which this occurs is not known (Negrato et al. 2012; Reece & Homko 2000).

Outcomes differ by diabetes type

Studies have shown that women with pre-existing type 1 and type 2 diabetes during pregnancy experience different maternal and perinatal outcomes, and are more likely to be adversely affected during pregnancy than those with pregnancies complicated by gestational diabetes (Murphy et al. 2017; Owens et al. 2015).

The risk of adverse outcomes is progressive, with increasing glycaemia (HSCRG 2009; Owens et al. 2015; Sacks et al. 2015; Visser & de Valk 2015).

Women with pre-existing diabetes are more prone to interventions and adverse outcomes during pregnancy, labour, and delivery. They also have higher rates of chronic hypertension, pre-eclampsia, pre-term delivery, failed induction of labour, and caesarean section than women with gestational diabetes (Fong et al. 2014).

In addition, for women with pre-existing diabetes, diabetes-related complications can develop or progress, including kidney and ophthalmic complications (Kulshrestha & Agarwal 2016).

Some studies have shown that babies of mothers with pre-existing diabetes are at an increased risk of adverse outcomes, including congenital anomalies and stillbirth when compared with babies of mothers with gestational diabetes (Fong et al. 2014).

The risk of adverse outcomes, such as congenital anomalies, were lower in pregnancies complicated with gestational diabetes than for those with pre-existing diabetes, as hyperglycaemia generally appears later in pregnancy (Åberg et al. 2001).

Several studies have compared the outcomes of mothers with pre-existing type 1 and type 2 diabetes, but results have been conflicting. Studies have shown that the outcome is generally similar, if not worse, in pre-existing type 1 diabetes (Balsells et al. 2009; Knight et al. 2012; Murphy et al. 2011).

Recent studies found that women with pre-existing type 1 diabetes were at a higher risk of pre-eclampsia, pre-term delivery than women with pre-existing type 2. Babies of women with pre-existing type 1 diabetes were also at an increased risk of adverse outcomes, including neonatal hypoglycaemia, macrosomia, stillbirth, and congenital anomalies than babies of women with pre-existing type 2 diabetes (Murphy et al. 2017; Owens et al. 2015).

The difference in outcomes is likely due to unstable blood glucose levels and the microvascular burden of a longer duration of diabetes in women with pre-existing type 1 diabetes (Gonzalez-Gonzalez et al. 2008; Owens et al. 2015).

Longer-term outcomes

Diabetes in pregnancy has also been associated with an increased future risk of other chronic diseases for both mother and baby.

Pregnancies complicated by gestational diabetes have an increased future risk of recurrent gestational diabetes in subsequent pregnancies, and progression to type 2 diabetes (Daly et al. 2018; Getahun et al. 2010).

The recurrence rate of gestational diabetes in Australia was estimated to be 35% (Moses 1996). A recent systematic review of population-based studies across the world have showed that the risk of gestational diabetes in subsequent pregnancies is about 48% (Schwartz et al. 2015). Women who have gestational diabetes are also at high risk of developing cardiovascular diseases in the future (Burlina et al. 2016; Daly et al. 2018).

The effects of diabetes in pregnancy on fetal development might result in an intergenerational cycle of diabetes. Children of mothers with diabetes in pregnancy are at increased risk of developing childhood metabolic syndrome, obesity, impaired glucose tolerance, and type 2 diabetes (Clausen et al. 2007; Kim et al. 2012; Zhao et al. 2016).

Rates of type 2 diabetes incidence have been shown to be substantially higher in children of mothers with pre-existing diabetes in pregnancy than those of mothers with gestational diabetes or without diabetes (Dabelea & Crume 2011).

1.5 Monitoring diabetes-related pregnancy complications

Why monitor diabetes in pregnancy at the population level?

Diabetes during pregnancy should be monitored, because it has serious implications for the health of mothers and babies. Outcomes associated with diabetes in pregnancy are not regularly monitored at the Australian national level, and the scope of the issues and their impact are unclear. Regular reporting on national data is essential to:

- understand and reduce the impact of pregnancy-related diabetes complications
- plan for and provide specialised management of treatment services for those most affected
- identify population groups at higher risk to tailor prevention and treatment strategies
- monitor the impact of prevention and management programs over time
- determine the best way to allocate public health resources.

What should be monitored?

Reducing the impact of pre-existing diabetes in pregnancy and gestational diabetes is an important goal of the Australian National Diabetes Strategy 2016–2020.

Providing a comprehensive data set to monitor the health of mothers and babies is essential to assess the impact of current and future work in reducing the effects of diabetes during pregnancy.

Comprehensive population monitoring of pregnancies affected by diabetes needs national data to assess:

- the number of pregnancies affected by diabetes by age of mother
- the number of maternal short-term and long-term (for example, development of diabetes and cardiovascular disease in women with gestational diabetes) complications associated with diabetes during pregnancy
- the number of short-term (for example, stillbirths, admission to special care unit/neonatal intensive care unit and congenital anomalies) and long-term complications (for example, childhood metabolic syndrome and obesity) associated with diabetes during pregnancy
- the difference in outcomes for women with diabetes developed during pregnancy (gestational) compared with women with pre-existing diabetes before pregnancy, and the differences in impact for different pre-existing diabetes types
- the impact of glycaemic control on outcomes for women with diabetes during pregnancy
- the impact of health service use on outcomes for women with diabetes during pregnancy
- the impact of pharmacological intervention on diabetes-related pregnancy complications
- differences by various sociodemographic characteristics, including Indigenous status, ethnicity, socioeconomic areas, and remoteness areas.

National data sources for monitoring

The 3 sources providing data on diabetes in pregnancy at the national level are the:

- National Perinatal Data Collection (NPDC)
- National Hospital Morbidity Database (NHMD)
- National Diabetes Services Scheme (NDSS).

These data sources are administrative data sets designed to collect information primarily for administrative purposes, so might not always be suitable for monitoring complex health issues and for some research.

Other data sources provide information at the state and territory level, or for specific population cohorts, but are not sufficient for exploring the Australian national context.

The strengths and limitations of each of the 3 national data sources are described in this section, and summarised in Table 1.1. The potential of using other data sources for future reporting and data linkage opportunities are explored further in Chapter 2.

National Perinatal Data Collection

The NPDC began in 1991, and is a collaborative effort by the Australian Institute of Health and Welfare (AIHW) and state and territory health departments. It is a national population-based cross-sectional collection of data on pregnancy and childbirth.

Data are based on births reported to the perinatal data collection in each state and territory in Australia. Midwives and other birth attendants, using information obtained from mothers and from hospital or other records, complete notification forms for each birth. A standard de-identified extract is provided to the AIHW annually to form the NPDC.

The scope of the collection is all births (live births and stillbirths) in Australia in hospitals, birth centres, and the community, where gestational age is at least 20 weeks or birthweight is at least 400 grams. In Victoria and Western Australia, births are included if gestational age is at least 20 weeks, or, if gestation is unknown, birthweight is at least 400 grams.

The NPDC includes information about:

- the sociodemographic characteristics (age)
- maternal diabetes status
- antenatal care
- interventions (for example, induced labour, caesarean section, and resuscitation)
- conditions of pregnancy (for example, hypertension)
- labour and delivery of women who gave birth
- the outcomes for the babies (for example, stillbirth).

This enables the incidence of pre-existing diabetes in pregnancy and gestational diabetes to be calculated, and provides information on associated adverse maternal and perinatal outcomes around the time of birth for different population groups (such as Indigenous status, socioeconomic areas, and remoteness areas).

Limitations

Pre-existing diabetes status during pregnancy has been recorded as a maternal condition, and gestational diabetes as an obstetric complication in the NPDC since 1991. But the data items were not standardised for most of this time, and provision to the NPDC is not mandatory.

As a result, definitions and methods used for data collection vary across jurisdictions. In 2014, a voluntary standard for data items on diabetes status and type of diabetes during pregnancy was introduced to improve data quality and availability. But due to these changes, data from 2014 onwards are not comparable with earlier years.

Diabetes status may be recorded through paper-based perinatal forms, in electronic systems, or in medical chart notes, which may be coded using the International Classification of Diseases and Related Health problems, 10th Revision, Australian Modification (ICD-10-AM). The ICD-10-AM is regularly revised, with each new edition updating the classification of disease and rules around how data are coded. The collection of diabetes information has been affected by these coding changes.

Data on diabetes status in Victoria are not currently collected in a format comparable with the specifications for the NPDC, and some jurisdictions are currently unable to distinguish between the pre-existing diabetes types.

The National Perinatal Data Development Committee continues to work to improve the availability and quality of information on maternal diabetes during pregnancy.

Reporting of some pregnancy-related outcomes—such as eclampsia, antepartum haemorrhage, postpartum haemorrhage, and complications of the puerperium—is also voluntary, and might not be provided by all jurisdictions.

While standards are in place for several of these data items, there remain differences in definitions and methods used for data collection across jurisdictions. These outcomes also cannot be assessed for comparison across maternal diabetes types, due to the small numbers of recorded cases of women with pre-existing diabetes, and the differences in the definition of these outcomes across jurisdictions.

For more information, see the NPDC data quality statement available at http://meteor.aihw.gov.au/content/index.phtml?itemId/693978.

Enumeration of pregnancies affected by diabetes

In the 2-year period 2014–2015, about 45,000 pregnancies affected by gestational diabetes, and 4,700 pregnancies affected by pre-existing diabetes were identified in the NPDC. Data on diabetes status in Victoria are not collected in a format comparable with the specification for the NPDC, and have been excluded from the results presented in this report.

Age distribution

The peak age of women who gave birth was 30–34. Mothers with pre-existing diabetes and gestational diabetes were more likely to be older (30 and over) than those without diabetes.

Indigenous status

Indigenous status was not stated for about 1% of mothers, regardless of diabetes status (pre-existing diabetes, gestational diabetes, and no diabetes) on the NPDC. About 12% of mothers who gave birth with pre-existing diabetes, and 8% of mothers with gestational diabetes identified as being Aboriginal or Torres Strait Islander on the NPDC.

National Hospital Morbidity Database

The NHMD is a compilation of episode-level records from the Admitted Patient Care National Minimum Data Set in Australian hospitals, which is maintained by the AIHW.

Diagnostic information relevant only to the current episode of care—including conditions or disorders that affect the treatment received by the patient during the episode—is included. The collection comprises comparable state and territory hospitalisation data.

The NHMD allows differentiation between diabetes types, using ICD-10-AM codes. These data are episode-based, and do not equate to individuals. Data supplied for diagnosis and procedure can be used to determine an episode of care related to pregnancy, and where diabetes is recorded as a principal or additional diagnosis, using codes from the ICD-10-AM.

The 2 sets of diabetes codes in the ICD-10-AM that identify diabetes in pregnancy status are:

- diabetes 'E-codes' in Chapter IV *Endocrine, nutritional and metabolic disease*
- diabetes in pregnancy 'O-codes' in Chapter XV *Pregnancy, childbirth and the puerperium*.

Although individual women who give birth in hospital cannot be identified across multiple admissions, each outcome of delivery can be correlated to a unique pregnancy, as the delivery code are assigned only once for each birth.

The NHMD also captures information about pregnancies that have been terminated or have resulted in a miscarriage before 20 weeks, which are not captured on the NPDC.

Limitations

ICD-10-AM coding changes for the diabetes 'E-codes' in Chapter IV *Endocrine, nutritional and metabolic disease* have affected the ability to monitor trends or report outcomes by pre-existing diabetes type using data from the NHMD.

Transition between ICD editions has resulted in differences in how pre-existing diabetes was recorded, only when it had a direct relationship with the principal reason for the episode of care, or when it might be recorded as an additional diagnosis in any hospitalisation. As a result, it is difficult to compare data for pre-existing diabetes-related hospitalisations over time.

Coding changes between 2010 and 2012 also resulted in a lower capture of diabetes-related hospitalisations, which affects the ability to report by pre-existing diabetes type using the NHMD. These coding changes did not affect the diabetes in pregnancy 'O-codes' in Chapter XV *Pregnancy, childbirth and the puerperium*. Data quality issues and data gaps are further explored in Chapter 2.

Babies affected by maternal diabetes can be identified with ICD-10-AM Chapter XVI *Certain conditions originating in the perinatal period* codes P70.0—*fetus or newborn (with hypoglycaemia) affected by maternal gestational diabetes*, and P70.1—*fetus or newborn (with hypoglycaemia) affected by maternal diabetes mellitus* in the NHMD.

Using the P70 codes and any additional diagnoses reported on the records of the babies will provide information on the impact of maternal diabetes on babies. But the codes are not able to comprehensively identify all babies born to mothers with diabetes, as they only identify babies affected by maternal diabetes, and not all babies born to a mother with diabetes will experience complications.

Linkage of maternal records (with characteristics such as diabetes status during pregnancy) and baby records in the NHMD will provide information about the complications not linked with the maternal diabetes status for comprehensive analyses of the impact of maternal diabetes on babies at a national level.

Enumeration of pregnancies affected by diabetes

In the NHMD, individuals cannot be identified across separate hospital separations. But each episode of care with an outcome of delivery can be considered a unique pregnancy, as the code for delivery is assigned once for each birth. It is possible that some women will give birth more than once in the 2-year period analysed in this report, and a unique pregnancy might represent the same mother giving birth at different periods.

About 66,300 pregnancies affected by gestational diabetes, and 4,600 by pre-existing diabetes were recorded on the NHMD in 2014–2015. Mothers with diabetes, especially pre-existing diabetes are likely to experience complications during pregnancy and delivery, and are more likely to have hospital births than births at home or in the community (RACGP 2016). This is likely to influence the number of pregnancies affected by diabetes identified in the NHMD.

Age distribution

The peak age of women who gave birth was 30–34. Mothers with pre-existing diabetes and gestational diabetes were more likely to be older (30 and over) than those without diabetes.

Indigenous status

Indigenous status was not stated for about 1% of mothers, regardless of diabetes status (pre-existing diabetes, gestational diabetes, and no diabetes) on the NHMD. About 12% of mothers who gave birth with pre-existing diabetes, and 4% of mothers with gestational diabetes identified as being Aboriginal or Torres Strait Islander on the NHMD.

National Diabetes Services Scheme

The NDSS, which began in 1987, is an initiative of the Australian Government administered with the assistance of Diabetes Australia. It delivers diabetes-related products at subsidised prices, and provides information and support services to people with diabetes.

Registration is free and open to all Australians diagnosed with diabetes with a valid Medicare card. More than 1.3 million Australians diagnosed with diabetes have been registered with the NDSS (Diabetes Australia 2018).

Within the NDSS, the National Gestational Diabetes Register (NGDR) was established in 2011 to help women who have gestational diabetes manage their health into the future. It provides reminders for follow-up diabetes screening, and healthy lifestyle information, to reduce their risk of developing type 2 diabetes. The NGDR data are also captured in the NDSS database.

The NDSS and NGDR provide information:

- to calculate the incident and prevalent number of women with gestational diabetes at the national level in a given time period
- to calculate the number of women having a repeat diagnosis of gestational diabetes in a given time period
- about the method of treatment, such as insulin treatment for women with gestational diabetes.

Diabetes Australia have provided regular snapshots of the NDSS every 3 months since December 2013, which can be used to assess the total number of women with gestational diabetes (newly registered cases and recurrent cases).

Limitations

The NDSS and NGDR are not designed to capture pregnancy-related information outside of gestational diabetes status. As a result, it cannot be used to assess pre-existing diabetes in pregnancy, or supply information on pregnancy-related complications or outcomes.

Ongoing linkage to other data sources is required to obtain clinical information about pregnancy status and pregnancy-related complications and outcomes for women with gestational diabetes and pre-existing diabetes.

The incidence of women diagnosed with type 2 diabetes, or type 1 diabetes, following a previous diagnosis of gestational diabetes, can be sourced from the NDSS database by matching identifiable demographic information available on the records. However, linking the newly diagnosed records with the records for gestational diabetes is difficult due to the structure of the database.

While the NDSS registration form contains fields related to the applicants' country of birth, languages spoken at home, and Aboriginal and Torres Strait Islander origin, it is not mandatory to complete these fields.

Women with gestational diabetes may choose not to report or reveal their Indigenous status as Indigenous Australians when they register with the NDSS. Indigenous women with gestational diabetes may also choose to access some diabetes-related products directly through their local community-controlled Indigenous health services.

As a result, the number of women with gestational diabetes who have a culturally and linguistically diverse or Indigenous background on the NDSS and NGDR might not reflect the total population of these women.

Enumeration of pregnancies affected by diabetes

About 64,000 pregnancies affected by gestational diabetes were registered on the NDSS in 2014–2015 (Diabetes Australia 2018). About 10,000 women were recorded as having a repeat diagnosis of gestational diabetes in this period.

Registration with the NDSS is voluntary and motivated by the need for access to subsidised diabetes consumables, information, and support services. This might positively influence the number of women with gestational diabetes registered on the NDSS.

Age *distribution*

The peak age of women who gave birth was 30–39 (Diabetes Australia 2018).

Indigenous status

Indigenous status was not stated for 7% of mothers with gestational diabetes on the NDSS. About 3% of mothers who gave birth with gestational diabetes identified as being Aboriginal or Torres Strait Islander on the NDSS (Diabetes Australia 2018).

Considerations for reporting on diabetes in pregnancy

All 3 national data sources (NPDC, NHMD, and NDSS) provide data on diabetes in pregnancy, but the suitability of these data sources for reporting on the impact of diabetes in pregnancy nationally varies across the data sources.

The NHMD provides national data on pregnancies affected by diabetes, and some complications and interventions. Data from the NHMD enable new cases of gestational diabetes in Australia over time to be identified.

While, the NHMD allows for the differentiation between pre-existing diabetes types using ICD-10-AM codes, changes to the ICD-10-AM coding, and the accuracy of recording diabetes type have an impact on the ability to report complications by diabetes type from the NHMD (AIHW 2014; Knight et al. 2011).

Compared with the other data sources (NHMD and NDSS), the NPDC provides comprehensive data for assessing the short-term impact of diabetes in pregnancy on the health of mothers and babies.

But national data for all pregnancies affected by diabetes are not available for reporting, as data on diabetes status in Victoria are not currently collected in a format comparable with the

specifications for the NPDC, so are excluded when reporting on the impact of diabetes in pregnancy.

Data are also not currently of sufficient quality to assess diabetes type at the national level, as some jurisdictions are unable to distinguish between pre-existing diabetes types. Before 2014, information for diabetes type were provided, but varied across jurisdictions, so data cannot be compared with data collected after 2014.

The NDSS allows the number of women with gestational diabetes to be identified at the national level, including the number of women having a repeat diagnosis of gestational diabetes, and provides information about the number of women who are using insulin therapy as the method of treatment for their condition.

But the NDSS cannot be used to assess pre-existing diabetes in pregnancy, or be used to assess pregnancy-related complications or outcomes.

Table 1.1: Summary of national data sources for monitoring diabetes in pregnancy

Data source	What can be reported?	Capture of women with diabetes	Can be used to capture information about pregnancy-related complications or outcomes	Limitations
NPDC	• Number of women with diabetes during pregnancy. • Characteristics and outcomes of mothers and babies affected by diabetes during pregnancy.	Women who have pre-existing diabetes or gestational diabetes during pregnancy.	Yes	• Due to the differences in the definition of diabetes status across jurisdictions, national analyses by diabetes type are not currently possible. • Data for Victoria are not currently available according to the specifications for the NPDC. • Due to the small number of recorded cases of mothers with pre-existing diabetes, and differences in the definition of outcomes across jurisdictions, reporting of some pregnancy-related outcomes—such as eclampsia, antepartum haemorrhage, postpartum haemorrhage—are not possible. • Recording of diabetes and diabetes types has changed over time, which affects trend analysis.
NHMD	• Number of episodes of care with a diagnosis of diabetes and a birth outcome. Each episode of care with a birth outcome can be considered a unique pregnancy. • Characteristics and outcomes of mothers affected by diabetes during pregnancy.	Women who have pre-existing diabetes or gestational diabetes during pregnancy.	Yes	• Maternal records with characteristics such as diabetes status are not linked to baby records, and comprehensive analyses of perinatal outcomes by diabetes type are not currently possible. • Changes in ICD-10-AM coding affects trend analysis. • Lack of completeness of the documentation of diabetes types affects the reporting by diabetes type from the NHMD.
NDSS and NGDR	• Number of women with gestational diabetes, demographic characteristics, and information related to use of insulin as a method of treatment.	Women who have gestational diabetes during pregnancy.	No	• Information about pregnancy status, complication, and outcomes is not available. • Unable to assess pre-existing diabetes status in pregnancy.

2 Improving national reporting

This chapter outlines current data gaps, alternate data sources, and possible data linkages that could be used to improve reporting at the national level on pre-existing and gestational diabetes in pregnancy, as well as short- and long-term outcomes for mother and child.

2.1 Data gaps

The NPDC contains information about the diabetes status of women who gave birth, and associated adverse maternal and perinatal outcomes around the time of birth.

While it is a useful data source, the current information on maternal diabetes that it contains has several limitations, including the inability of some states and territories to distinguish between types of diabetes, and differences in data collection methods across jurisdictions.

Data from the NHMD can be reported by pre-existing diabetes types to determine the varying level of risk, and the differences in adverse complications for women with pre-existing type 1 and type 2 diabetes. But changes to coding standards for coding diabetes-related hospitalisations, and the lack of completeness of coding diabetes types limit the use of data from the NHMD over time.

There is also a lack of comprehensive national data to monitor the longer-term impact of diabetes in pregnancy on mothers and babies, and the treatment and care received by the mothers during pregnancy.

Recording diabetes diagnosis

There are problems with how well diabetes diagnoses are recorded in administrative data sources.

The capture of diabetes hospitalisations on the NHMD has varied across years, depending on the ICD-10-AM Australian Coding Standards for the coding of diabetes, particularly the diabetes 'E-codes' in Chapter IV *Endocrine, nutritional and metabolic disease* from clinical documentation (AIHW 2014).

In the 6th edition of the ICD-10-AM (used between July 2008 and June 2010), changes were made to the diabetes coding standard, where conditions were only being recorded when there was a direct cause and effect relationship, or when a related complication was being treated (IHPA 2017). This resulted in a lower number of hospitalisations with an associated diagnosis of diabetes being recorded in the NHMD (AIHW 2014; Knight et al. 2011).

Further changes to the diabetes coding standard for classifying diabetes under the 7th edition of the ICD-10-AM (used between July 2010 and June 2013) resulted in further decreases in the number of hospitalisations with diabetes diagnoses recorded in 2009–10 and 2010–11 (AIHW 2014; IHPA 2017).

In March 2012, the National Health Information Standards and Statistics Committee endorsed a change to the Australian Coding Standard ACS0401 under the ICD-10-AM 7th edition from July 2012 onwards (IHPA 2017). The change was that when diabetes was documented, it should always be coded, resulting in an increase in the number of diabetes hospitalisations recorded.

Coding changes are likely to have had an impact on the number of complications reported from the NHMD during this time, especially for the small population of women with pre-existing diabetes during pregnancy.

The way that diabetes status is recorded in the NPDC varies by state and territory perinatal data collections. Information about diabetes status may be collected from paper-based perinatal forms, electronic systems, and medical chart notes. This information may be coded according to ICD-10-AM codes, and affected by the ICD-10-AM coding changes.

Data for diabetes status exclude Victoria, where information about diabetes is not collected in a format comparable with the specifications for the NPDC. Due to changes in the definition of diabetes status in the NPDC in 2013–2014, data on diabetes status from 2014 onwards are not comparable with earlier years.

Other administrative data sources only capture people when they register voluntarily for specific services and/or access to subsidised products to manage their condition, such as the NDSS. Since the establishment of the NGDR, the number of women registering with the NDSS has increased over time.

Reporting by diabetes type

Research has shown that maternal and perinatal outcomes differ between mothers with type 1 diabetes and mothers with type 2 diabetes (Murphy et al. 2017; Owens et al. 2015), but this distinction is not currently available in the NPDC for all jurisdictions.

The NPDC identifies mothers with pre-existing diabetes, with gestational diabetes, and without diabetes in pregnancy. Changes to the recording of diabetes type in 2014 has resulted in some state and territory perinatal data collections providing information on diabetes type, but the completeness of this data is inconsistent across jurisdictions.

Using only pre-existing diabetes without further information on type is enough to detect differences in adverse effects that might relate to the presence of diabetes at conception (pre-existing diabetes), but loses important information on the varying level of risk and treatment requirements for women with these different forms of diabetes.

In the 2010 AIHW *Diabetes in pregnancy: its impact on Australian women and their babies* report, NPDC data were supplemented by data from the NHMD, including data on additional outcomes not available in the NPDC, and data on pre-existing diabetes type (AIHW 2010).

The NHMD allows diabetes types to be differentiated using ICD-10-AM codes. But this is affected by various factors, including:

- the quality of information gathered during admission
- the quality of communication between patients and clinicians
- clinicians' training and experience with diabetes
- missing documentation
- transcription errors
- the quality of coding documentation and experience of clinical coders (O'Malley et al. 2005).

The coding of diabetes type in the NHMD rely on diagnostic approaches used by health professionals, which could also result in misclassification (Wild et al. 2016).

Symptoms of type 1 and type 2 diabetes are similar, particularly in young adults, and the diagnosed diabetes type, and subsequently coded diabetes type are not always correct (Stone et al. 2010).

Linked Fremantle Diabetes Study Phase II and hospitalisation data showed that, of all hospitalisations where diabetes was coded, the type was accurately coded for:

- 78% of hospitalisations for type 1 diabetes
- 96% of hospitalisations for type 2 diabetes
- 24% of other/unspecified forms of diabetes (T Davis & W Davis, Fremantle Diabetes Study, 2018, pers. comm., 6 March 2018).

Treatment and control measures

Comprehensive data on diabetes-specific treatment and type of care received by women during pregnancy are not available from current national data sources used to monitor pregnancies affected by diabetes. These data items have been recently added to the NPDC, but data are not yet of sufficient quality for reporting.

For women with diabetes during pregnancy, maintaining optimal glycaemic control can reduce the risk of maternal and perinatal complications, birth trauma, early induction of labour, and needing a caesarean section (HSCRG 2009; Owens et al. 2015).

Clinical guidelines for the management of pre-existing diabetes during pregnancy recommend maintaining optimal blood glucose levels, optimising weight gain, monitoring existing complications and the development of new diabetes complications and reviewing insulin therapy (Negrato & Zajdenverg 2012).

The guidelines recommend that women with gestational diabetes are managed through dietary adjustments, optimising the rate of weight gain, blood glucose monitoring and insulin therapy if required. Strict self-monitoring of postprandial glucose levels is also important during pregnancy (Negrato & Zajdenverg 2012).

Data on fasting blood glucose, self-monitoring of postprandial glucose levels, and glycated haemoglobin (HbA1c) testing by gestational age would enable assessment of the impact of treatment strategies to meet targets, and complications associated with the spectrum of blood glucose control.

The availability of data to track treatments (health service use and pharmacological interventions) received by women with diabetes during pregnancy would also enable an assessment of whether treatment interventions meet current clinical guidelines, and of the impact of treatment and care received on the occurrence of maternal and perinatal complications in women with diabetes.

Trend analysis

Comparison with the 2010 AIHW *Diabetes in pregnancy: its impact on Australian women and their babies* report is only possible for a small number of outcomes, due to method changes in collecting information about diabetes status. Results for some complications by diabetes status were also only previously available from the NHMD.

Trend analysis by diabetes status is difficult, due to issues with data comparability over time. The changes in the method for collecting information about diabetes status or diabetes type described in Section 2.1 influences the way data can be analysed by diabetes type over time from the NPDC.

Similarly, the ICD-10-AM coding changes summarised in the section about *Recording diabetes diagnosis*, and the factors described in the section about *Reporting by diabetes type* that influence the accuracy of recorded diabetes type, affect comparison of data from the NHMD over time.

Several factors might also influence the trends reported for gestational diabetes. In particular, changes in the diagnostic pathways, which resulted in more women being tested, and changes to the diagnostic criteria for gestational diabetes, which were recommended in 2013.

Adoption of the recommended changes to the diagnostic criteria have been implemented to varying degrees, and at different times across jurisdictions, and this might influence the trends observed over time (Flack & Ross 2016). Due to these changes, comparing gestational diabetes incidence over time is problematic.

Longer-term complications

Due to the lack of data availability, long-term complications of diabetes in pregnancy for the baby have not been assessed at a national level.

The longer-term complications of diabetes in pregnancy for both mother and baby are of great interest to researchers. But these complications might not become evident for many years, and current data sources do not allow for long-term follow-up of mothers and their babies after a pregnancy affected by diabetes.

Mothers with gestational diabetes have an increased risk of developing type 2 diabetes and cardiovascular diseases (Burlina et al. 2016; Daly et al. 2018; Getahun et al. 2010). The NDSS records where women change from gestational diabetes to type 2 diabetes, but issues with women being re-registered with new diagnosis information prevent these data from currently being used for this purpose. Data from the NHMD are episode-based, so, without data linkage, it is not possible to assess longer-term maternal outcomes.

Longer-term complications for children born to mothers with diabetes might include increased risk of childhood metabolic syndrome and obesity, impaired glucose tolerance, autism, impaired cognitive development, and type 2 diabetes (Camprubi Robles et al. 2015; Kim et al. 2012; Xu et al. 2014; Zhao et al. 2016).

Some congenital anomalies associated with maternal diabetes during pregnancy are also not clinically detected at birth, and are diagnosed later in life (Reece 2012). Identifiable variables—for example, name and address—are not available on the NPDC and NHMD for linkage to other data sources such as deaths records and congenital registries to assess longer-term health implications for mother and baby.

2.2 Alternate data sources

Several data sources are available in Australia to monitor gestational diabetes and pre-existing diabetes in pregnancy, and associated short-term maternal and perinatal complications.

These data sources have been looked at in this report for their potential to fill data gaps in national data sources that monitor diabetes in pregnancy, including determining pre-existing diabetes (type 1 or type 2) during pregnancy, and assessing longer-term complications from diabetes in pregnancy.

Other data sources at the state and territory level, or for specific population cohorts, provide excellent data on maternal and perinatal complications by diabetes types.

The Northern Territory and Far North Queensland Diabetes in Pregnancy Clinical Register includes all women with any type of hyperglycaemia in pregnancy and collects antenatal data and maternal, perinatal and neonatal information from medical records following birth, as well as biomedical data such as OGTT or HbA1c results (Maple-Brown et al. 2019; Diabetes in

Pregnancy Partnership 2017). Data from the Northern Territory Diabetes in Pregnancy Clinical Register allows for the assessment of short-term complications.

Cohort studies such as The Australian Longitudinal Study on Women's Health and The Raine Study contain information required to assess longer-term complications, such as the development of type 2 diabetes in mothers and children affected by diabetes during pregnancy, neonatal death, or death of child (ALSWH 2017; The Raine Study 2018).

The Pregnancy and Adverse Neonatal Diabetes Outcomes in Remote Australia longitudinal observational study is a comprehensive data source with antenatal data, diabetes type, and birth, maternal, perinatal, and neonatal information, as well as medical records (Maple-Brown et al. 2013). These data could be used to assess short-term maternal and perinatal complications during pregnancy, labour, and delivery, as well as longer-term health implications for mother and children.

The Medicare Benefits Schedule (MBS), Pharmaceutical Benefits Scheme (PBS), and NHMD could provide data on health services and pharmacological treatments used, and on hospital treatments during pregnancy. These data sources would enable treatments and care pathways to be described if data can be linked to women with diabetes who have given birth.

Table 2.1 presents a brief overview of the data sources, data variables available, and strengths and limitations of the data.

Table 2.1: Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
PBS	Administrative (national)	The PBS provides subsidised access to necessary medicines for Australians, and includes information related to dispensing medicines through pharmacies and other health services.	Claims for a prescription for medications, including insulin and oral glucose-lowering medicines subsidised through the PBS.	No	No	Captures data on treatments (pharmacological interventions) received by women before, during, and after pregnancy.	Information about diagnosis and maternal and infant outcomes are not captured on the PBS. The PBS can only provide information by linkage to another data collection that records diabetes type.

(continued)

Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
MBS	Administrative (national)	Medicare provides access to Australian Government-subsidised medical and hospital services listed through the MBS.	Claims for a diabetes-related health services, including pathology tests, other tests (HbA1c testing in pre-existing diabetes where the patient is pregnant, oral glucose tolerance test, oral glucose challenge test), general practitioner visits, diabetes cycle-of-care items, and allied health services.	No	No	Captures data on care received (health services use) by women before, during, and after pregnancy.	Data on diagnosis, maternal characteristics and outcomes, and infant outcomes are not captured on the MBS. This information can only be obtained by linkage to another data collection that records diabetes type. The majority of pregnant women with pre-existing diabetes would be attending specialised services, and care provided for these women might not be captured on the MBS. The MBS has no specific code to differentiate between gestational diabetes or pre-existing diabetes.

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
Australian Longitudinal Study on Women's Health For more information about the data source, see: https://www.alswh.org.au/publications-and-reports/technical-reports	Longitudinal survey (cohort study)	Women were selected from the Medicare database in 1996, and invited to participate in the project for at least 20 years. The study assesses the women's physical and mental health, sociodemographic factors, use of health services, and life stages (such as childbirth).	Maternal variables such as self-reported diabetes status, pregnancy status, parity, plurality, premature birth, stillbirth, labour (induced), caesarean section, and hypertension. Infant variables such as birthweight, admission to special care/neonatal intensive care, death within 1 month and after 1 month, status and neonatal death.	Yes—based on self-reported diabetes type.	Yes	Able to track longer-term complications such as neonatal death or death of child.	Survey-based data collection that provides population estimates. Data based on self-reporting information are likely to be inaccurate. Data for additional maternal and infant outcome measures of interest are not available (for example, length of hospital stay, gestational age and Apgar score, and resuscitation).

(continued)

Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
		About 58,000 women in three cohorts were included in the study, aged: • 18–23 (born 1973–78) • 45–50 (born 1946–51) • 70–75 (born 1921–26). Each cohort has been surveyed about once every 3 years. A more frequent, shorter survey was introduced in 2011 for the oldest cohort.					

(continued)

Table 2.1 (continued): Other potential data sources

Northern Territory and Far North Queensland Diabetes in Pregnancy Clinical Register For more information about the Diabetes in Pregnancy Clinical Register , see: http://www.dipp.org.au/	Clinical register	The Northern Territory Clinical Register was established in 2011 by the Northern Territory Diabetes in Pregnancy Partnership. The Far North Queensland Diabetes in Pregnancy Register was established in 2016 by the Northern Territory and Far North Queensland Diabetes in Pregnancy Partnership. All women with any type of hyperglycaemia in pregnancy are eligible for inclusion in the Diabetes in Pregnancy Clinical Register. Participants give informed verbal consent to be included on the Clinical Register. Consent is obtained by their referring health practitioner who completes a written form at the time of referral (Kirkham et al. 2017; Maple-Brown et al. 2019).	Demographic variables: age, ethnicity and location of residence. Maternal variables: diabetes type, Body Mass Index, presence of hypertension, smoking or alcohol use, gestational age and results of the oral glucose tolerance test (OGTT) or HbA1c (no OGTT data for women with pre-existing type 2 diabetes and no HbA1c data for women with gestational diabetes). Variables collected from medical records after birth: diabetes medication in third trimester, location and mode of delivery, gestational age, birth weight and birth complications (Maple-Brown et al. 2019).	Yes	No – captures data on short-term maternal and infant outcomes	Captures data that allows for the number of women with diabetes in pregnancy, and the health implications for mother and baby to be monitored. Collects biomedical data such as OGTT and HbA1c results and diabetes medication used in third trimester.	Jurisdictional clinical register/study.

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
Pregnancy and Adverse Neonatal Diabetes Outcomes in Remote Australia (PANDORA) longitudinal observational study The aim of the PANDORA study is to: • monitor the rates of diabetes in pregnancy in the Northern Territory.	Longitudinal (observational) study	PANDORA is a longitudinal study that includes all women on the Northern Territory Diabetes in Pregnancy Clinical Register who have consented to participate in the study (Maple-Brown et al. 2013).	Maternal/paternal ethnicity, Indigenous status, family history of diabetes, medications, smoking/alcohol status in pregnancy, antenatal care, socioeconomic status, education, and language. At birth—baby's body fat, circumference measure, limb lengths, and skin-fold thickness, and measurement of glucose, c-peptide, lipids, adiponectin, and leptin. Maternal follow up—6-week postpartum tolerance test results from women with gestational diabetes, rates of diabetes, and assessment of metabolic and cardiovascular risk at 12 and 24 months. Routine growth assessments of babies.	Yes	Yes	Able to monitor the number of women with diabetes in pregnancy, and the health implications for mother and baby. Captures data on short-term maternal and infant outcomes and longer-term health implications for children affected by maternal diabetes during pregnancy.	Jurisdictional clinical register/study. PANDORA is a consent-based study, and does not capture all Northern Territory women with diabetes in pregnancy.

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
• report demographic, clinical, biochemical, anthropometric, and socioeconomic factors that contributed to key maternal and neonatal outcomes associated with diabetes in pregnancy • monitor relevant clinical outcomes for mothers and their babies (Maple-Brown et al. 2013).		The PANDORA cohort at birth comprises of 1,140 Northern Territory women with and without diabetes in pregnancy and 1,170 babies (Lee et al. 2018). Consent is sought to collect the child's medical and pathology records until the child reaches the age of 12, and further consent is sought for ongoing follow-up from medical records until the age of 20.					

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
The Raine Study	Cohort study (longitudinal)	The Western Australian Pregnancy Cohort (Raine) Study cohort was established between 1989 and 1991 to determine how events during pregnancy and childhood influence health in later life. About 2,900 pregnant women entered the study, and 2,868 live births were recruited into the cohort. Follow-up assessment of the cohort has been done at birth, and ages 1, 2, 3, 5, 8, 10, 14, 17, 18, 20, and 22. The age 22-year cohort review started in 2016.	Diabetes status of mother. Babies/children long-term outcomes— obesity, developmental stages, Denver developmental screen test (cognitive and behavioural problems), education, health service use, and cardiovascular health.	No	Yes—some longer-term complications for children affected by diabetes in pregnancy.	Captures data on longer-term health complications for children and adults affected by maternal diabetes during pregnancy.	Data on pre-existing diabetes type is not captured on the data set. Cohort study that provides population estimates.

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
Victorian Congenital Anomalies Register Congenital anomalies registers or data set that collect information on congenital anomalies are available in other jurisdictions. But the information and method for collecting information varies across the different jurisdictions.	Registry	Collects information on all congenital anomalies for live births, stillbirths, and terminations of pregnancy. The register also collects information about congenital anomalies for children aged up to 6.	Maternal data— postcode, date of birth, method of prenatal diagnosis, country of birth, Indigenous status, maternal medical conditions, obstetric complications, complications of labour birth and postnatal, procedures and operations, type of labour, presentation, method of delivery. Child data—hospital of birth, date of birth (termination), sex, birthweight, plurality, rank, condition of birth (termination before or after 20 weeks, stillbirth, live birth), date of death, Apgar score, time to establish respiration, resuscitation methods, neonatal morbidity.	No	Yes	Captures data on congenital anomalies not currently captured on the NPDC. Also contains data on congenital anomalies detected after birth, and diagnosed later in life.	Maternal diabetes information is not captured on the Victorian Congenital Anomalies Register.

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
The Longitudinal Study of Australian Children	Longitudinal survey (cohort study)	Australia's first nationally representative longitudinal study of child development. The study is following 2 cohorts of children who were selected from across Australia. The B (baby) cohort was aged 0–1 at the start of the study (born between March 2003 and February 2004). The K (kindergarten) cohort was aged 4–5 at the start of the study (born between March 1999 and February 2000).	Maternal variables—diabetes status during pregnancy, antenatal visits. Babies short-term outcomes—gestational age, preterm birth, Admission to a neonatal intensive care unit or special care unit. Child longer-term outcomes—diabetes status, age when diabetes was diagnosed, severity of diabetes, and emotional, school, and social functioning.	No	Yes	Captures data on longer-term health complications for children, by maternal diabetes during pregnancy.	Data on pre-existing diabetes type is not captured on the data set. Cohort study that provides population estimates.

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Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
National Assessment Program—Literacy and Numeracy (NAPLAN) data	Administrative	In Australia, national minimum standards have been developed for reading, writing, spelling, language conventions (grammar and punctuation), and numeracy for students in Years 3, 5, 7, and 9. Achievement against these standards is assessed annually through the NAPLAN. Australian Curriculum and Assessment Reporting Authority holds the national de-identified NAPLAN data.	Demographic characteristics—date of birth, sex, Indigenous status, language background, parental occupation, and parental education. Results from the NAPLAN test—name of test, year level, participation, test achievement score, percentile, and national achievement band.	No	Yes—developmental outcomes.	Captures data on longer-term complications, such as developmental outcomes and school functioning.	Maternal diabetes information, pregnancy-related complications, and short-term implications for mothers and babies are not captured by the data set.

(continued)

Table 2.1 (continued): Other potential data sources

Data source	Type of data source	Description	Data variables available	Can be used to report on maternal and infant outcomes by pre-existing diabetes type (type 1 or type 2)	Can be used to track long-term complication of diabetes in pregnancy for both mother and baby	Strengths	Limitations
		Data with identifying information such as student identification and name for linkage is held by the test administration authorities in each state and territory.					

Potential for data linkage

Data linkage offers the opportunity to improve data for monitoring the number of women with pre-existing diabetes and gestational diabetes during pregnancy, and for assessing short- and long-term health implications for mothers and babies at the national level.

Previous sections have highlighted the data sources available in Australia that can be used to monitor the number of women with pre-existing diabetes and gestational diabetes during pregnancy and the limitations with these data sources. The data required to monitor diabetes and fill current knowledge gaps are not available in any single data set, but a more comprehensive data set could be obtained by linking multiple data sets containing information on mothers and babies.

Data linkage to assess pregnancy issues at a national level must have a robust record of births in Australia. The primary gaps identified with the NPDC and NHMD have been the lack of completeness of data available for diabetes status, and reliability of assessing diabetes type.

But the completeness of diabetes information in the NPDC is improving, with the introduction of a voluntary standard for data items on diabetes status and type of diabetes during pregnancy to improve data quality and availability.

The National Perinatal Data Development Committee is working on improving the quality of data, and on including the data items on diabetes status and type of diabetes during pregnancy to the Perinatal National Minimum Data Set.

The NDSS offers a secondary data source to help confirm both diabetes status and diabetes type for women who are registered with the scheme. Linking the NDSS with the NPDC or NHMD would increase the likelihood of capturing diabetes diagnosis for pregnant women.

The AIHW is working with the Department of Health and state and territory health authorities to create the National Integrated Health Services Information (NIHSI) Analysis Asset. This will contain de-identified data from 2010–11 onwards from:

- admitted patient care services (in public and private hospitals, where available)
- emergency department services and outpatient services in public hospitals for all participating states and territories
- MBS
- PBS
- Repatriation Pharmaceutical Benefits Scheme
- residential aged care facilities
- National Deaths Index.

Incorporating data into the NIHSI Analysis Asset will be staged, and will depend on when the required data are received.

These de-identified data will initially be available to selected analysts nominated by the data providers—state and territory health authorities, the Department of Health and the AIHW.

It is anticipated that other users will be able to apply for access to the NIHSI Analysis Asset, or to data extracted from it, provided their proposed use of the data complies with the AIHW Ethics Committee–approved purposes for the NIHSI Analysis Asset.

These include:

- chronic disease management—patterns of service provision
- accessibility and effectiveness of services contributing to the management of chronic conditions
- policies and programs designed to reduce the incidence and severity of disease and injury.

As identifiable variables are not available on the NPDC, it cannot be linked internally or with other data sources. But individual perinatal data collections can separately supply the information needed for data linkage. The AIHW is working on a linkage project following this method (see case study in this section).

Additional information can be gained from linking data sets with a robust record of births in Australia, and diabetes in pregnancy status, with other data sets such as the MBS and PBS, which can help assess the type and effectiveness of treatment strategies.

The MBS and PBS offer insight into the health services—such as those provided by general practitioners and allied health professionals—and pharmacological treatment used during pregnancy.

Linked hospital data would also provide a more complete picture of hospitalised treatment throughout pregnancy. Ideally, data on glycaemic control could be identified, and linked with pregnancy-related data sources.

Information about fasting blood glucose levels, postprandial glucose monitoring and HbA1c results would enable the impact of treatment strategies to meet targets, and complications associated with the spectrum of blood glucose control to be assessed. But no linkable data source is currently available to achieve this at the national level.

Currently, small cohort and longitudinal studies have the information to assess longer-term complications, and could provide additional and/or specific information about longer-term complications, including congenital anomalies detected after birth, developmental and behavioural outcomes, development of metabolic syndromes, and obesity and diabetes in children and adults.

But currently, no national data source assesses this, and national data sources might not be appropriate for tracking longer-term outcomes.

Linkage of individual perinatal data collections to hospital data, deaths data, NAPLAN data, and congenital anomalies registers have the potential to provide detailed data for a small cohort to assess these longer-term outcomes.

The linkage of the perinatal data collection to hospital admitted data collection to report on congenital anomalies has been developed in Queensland (Howell 2009). If expanded at the national level, this could describe some longer-term health complications of diabetes in pregnancy.

The linkage of multiple data sets containing information on mothers and babies will require relevant ethics committee approvals, in consideration of relevant legislations such as the *Australian Institute of Health and Welfare Act 1987* and the *Privacy Act 1988.*

Case study: linked perinatal data set project

The AIHW is currently working on a project linking perinatal, births, and deaths data sets to look at the differences in birth and health outcomes, including infant and child mortality between Indigenous and non-Indigenous Australians.

The project linked 3 types of data sets from each jurisdiction—the perinatal, registered births, and registered deaths data sets. Agreement to provide data were sought from relevant state and territory data custodians before starting.

The Data Integration Services Centre at the AIHW linked and merged the data. Unit records of the perinatal, registered births, and registered deaths data sets, over 2003–2011, were linked to create a national linked perinatal, births, and deaths data set. This approach gave data custodians control over how their data are linked, while maintaining privacy and data confidentiality.

The results of the analysis of the linked perinatal data set will help policymakers develop policies and programs, and deliver services to address adverse infant and child health outcomes, including infant and child mortality, particularly, among the Aboriginal and Torres Strait Islander population.

2.3 Conclusion

Diabetes affecting pregnancy has serious implications for the health of mothers and babies. The complications associated with diabetes in pregnancy are not regularly tracked at the national level, and the scope of the issues and their impact are unclear.

Regular reporting on national data is essential to understand and formulate prevention and management programs that reduce the impact of pregnancy-related diabetes complications, and assess the impact of prevention and management programs over time.

A comprehensive data set to monitor diabetes during pregnancy, and the effects on mothers and babies across Australia is essential.

Three national data sources (NPDC, NHMD, and NDSS) provide data on diabetes in pregnancy at the national level. At this time, the NPDC is considered the most comprehensive data set available to assess the short-term impact of diabetes on mothers and babies, including those characteristics, outcomes, conditions, and interventions that can be observed during pregnancy, labour, and shortly after birth.

Strengths of the NPDC include that it is a useful data source that captures information on pregnancy-related complications and maternal and perinatal outcomes. While data from the NPDC allows for an assessment of pregnancy-related health, several factors limit the use of data from the NPDC to look at the impact of maternal diabetes on the health of mothers and their babies.

National data for all pregnancies affected by diabetes are not available on the NPDC, as data on diabetes status in Victoria are not collected in a format comparable with the specification for the NPDC, so are excluded when reporting on diabetes in pregnancy.

The collection of information about diagnosis of diabetes types varies across jurisdictions, with jurisdictions being unable to distinguish between pre-existing type 1 and type 2 diabetes. This means that data are not of sufficient quality to report on outcomes and complications by diabetes type.

The NDSS allows the number of women with gestational diabetes to be identified at the national level, can be used for assessing trends over time, and can also be used to assess the number of women having a repeat diagnosis of gestational diabetes.

The NHMD provides national data on pregnancies affected by diabetes, and offers another data source for assessing trends for gestational diabetes. But ICD-10-AM coding changes and the accuracy of recording diabetes type affects the ability to report on the number of pregnancies affected by diabetes, and complications by pre-existing diabetes type.

Data linkage of a national data set that has a robust record of births in Australia with other data sets containing information on health service use and treatment will provide a more comprehensive data set to assess the short- and long-term impact of diabetes in pregnancy on the health of mothers and their babies, and fill an important information gap.

Given the complex relationship between the complications and adverse outcomes reported, future work investigating the effects of diabetes in pregnancy could explore the inter-relationships of these complications through pathways and multivariate analyses.

This will contribute to the evidence base, so that prevention and management programs can improve the care of mothers and babies, in line with the guidance provided by the Australian National Diabetes Strategy 2016–2020 under Goal 4 to 'reduce the impact of pre-existing diabetes and gestational diabetes in pregnancy'. Accurate data on the impact of diabetes in pregnancy on the health of mothers and children will also enable continued reporting of

indicators outlined in the Implementation plan for the Australian National Diabetes Strategy 2016–2020.

Acknowledgments

Abbreviations

AIHW	Australian Institute of Health and Welfare
Apgar	appearance, pulse, grimace, activity, and respiration
HbA1c	glycated haemoglobin
ICD-10-AM	International Classification of Diseases and Related Health Problems, 10th Revision, Australian modification
MBS	Medicare Benefits Schedule
mmol/L	millimoles per litre
NAPLAN	National Assessment Program Literacy and Numeracy
NDSS	National Diabetes Services Scheme
NGDR	National Gestational Diabetes Register
NHMD	National Hospital Morbidity Database
NIHSI	National Integrated Health Services Information
NPDC	National Perinatal Data Collection
OGTT	Oral glucose tolerance test
PANDORA	Pregnancy and Neonatal Diabetes Outcomes in Remote Australia
PBS	Pharmaceutical Benefits Scheme

Glossary

Aboriginal or Torres Strait Islander: A person of Aboriginal and/or Torres Strait Islander descent, who identifies as an Aboriginal and/or Torres Strait Islander. See also **Indigenous**.

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

Apgar score: Numerical score used to indicate the baby's condition at 1 minute and at 5 minutes after birth; 0–2 points are given for each of 5 characteristics—heart rate, breathing, colour, muscle tone, and reflex irritability. The total score is 0–10.

birthweight: The first weight of the baby (stillborn or live born) obtained after birth (usually measured to the nearest 5 grams, and obtained within 1 hour of birth).

caesarean section: A method of birth in which a surgical incision is made into the mother's uterus via the abdomen to directly remove the baby.

data linkage: A statistical procedure in which identifying information contained in 2 or more data sets is compared to determine matching records—for example, the same individual or the same institution. This can provide more information about the entity, and, in certain cases, provide a time sequence, helping to tell a story, show pathways, and perhaps unravel cause and effect. Synonymous 'record linkage' and 'data integration'.

cardiovascular disease: Any disease of the circulatory system—namely, the heart (cardio) or blood vessels (vascular). Includes heart attack, angina, stroke, heart failure, and peripheral vascular disease. Also known as circulatory disease.

diabetes: A chronic condition in which the body cannot properly use its main energy source, the sugar glucose. This is due to a relative or absolute deficiency in insulin, a hormone that is produced by the pancreas and helps glucose enter the body's cells from the bloodstream and then be processed by them. Diabetes is marked by an abnormal build-up of glucose in the blood, and it can have serious short- and long-term effects. For the 3 main types of diabetes, see **type 1 diabetes**, **type 2 diabetes** and **gestational diabetes**.

diabetic nephropathy: Disease of the capillaries of the glomeruli resulting from diabetes.

diabetic retinopathy: Damage to the blood vessels of the retina resulting from diabetes.

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.

gestational age: Duration of pregnancy in completed weeks, calculated from the date of the first day of a woman's last menstrual period and her baby's date of birth, or calculated via ultrasound, or derived from clinical assessment during pregnancy or from examination of the baby after birth.

gestational diabetes: A form of diabetes that is first diagnosed during pregnancy (gestation). It might disappear after pregnancy, but signals a high risk of diabetes occurring later on.

glucose: The main sugar that the body uses for energy. Glucose is a simple sugar that comes from the breakdown of carbohydrates in the diet, as well as from the breakdown of glycogen (the storage form of glucose) in the liver. The body requires the hormone insulin to use glucose properly.

high birthweight: Weight of a baby at birth that is more than 4,500 grams.

high blood pressure/hypertension: Definitions vary, but a well-accepted definition is from the World Health Organization (WHO)—a systolic blood pressure of 140 mmHg or more, or a diastolic blood pressure of 90 mmHg or more, or where the person is receiving medication for high blood pressure.

hyperbilirubinemia: An elevated level of the pigment bilirubin in the blood.

hyperglycaemia: High blood glucose (sugar) level.

hypoglycaemia: Low blood glucose (sugar) level.

incidence: The number of new cases (of an illness or event, and so on) occurring during a given period.

Indigenous: A person of Aboriginal and/or Torres Strait Islander descent, who identifies as an Aboriginal and/or Torres Strait Islander. See also **Aboriginal or Torres Strait Islander**.

induction of labour: Intervention to stimulate the onset of labour.

insulin: A hormone produced in the pancreas that helps glucose to enter body cells for energy metabolism.

insulin resistance: A condition in which insulin works inefficiently.

International Statistical Classification of Diseases and Related Health Problems: The World Health Organization's internationally accepted classification of death and disease. The 10th Revision (ICD-10) is currently in use.

kidney disease: Kidney disease is caused by damage to small blood vessels in the kidneys leading to the kidneys becoming less efficient or failing altogether. Kidney disease is much more common in people with diabetes than in those without diabetes. The disease is caused by damage to small blood vessels, which can cause the kidneys to be less efficient, or to fail altogether. See also **diabetic nephropathy**.

maternal age: Mother's age in completed years at the birth of her baby.

morbidity: Ill health in an individual, population, or group.

mortality: Death.

neonatal death: Death of a live-born baby within 28 days of birth.

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.

plurality: Number of births resulting from a pregnancy.

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

resuscitation of baby: Active measures taken shortly after birth to assist the baby's ventilation and heartbeat, or to treat depressed respiratory effort, and to correct metabolic disturbances.

stillbirth: See **fetal death (stillbirth)**.

type 1 diabetes: A form of diabetes mostly arising among children or younger adults, marked by a complete lack of insulin and needing insulin replacement to survive.

type 2 diabetes: The most common form of diabetes, occurring mostly in people aged 40 and over, and marked by reduced or less effective insulin.

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List of tables

Related publications

This report, *Improving national reporting on diabetes in pregnancy*, is accompanied by a *Diabetes in pregnancy 2014–2015* bulletin. The bulletin presents the latest population-level data on mothers with diabetes in pregnancy, and outcomes for mothers and babies using the National Perinatal Data Collection.

It is available at https://www.aihw.gov.au/reports/diabetes/diabetes-in-pregnancy-2014-2015/contents/summary.

The following AIHW publication relating to diabetes in pregnancy might also be of interest:

- AIHW (Australian Institute of Health and Welfare) 2010. Diabetes in pregnancy: its impact on Australian women and their babies. Diabetes series no. 14. Cat. no. CVD 52. Canberra: AIHW.
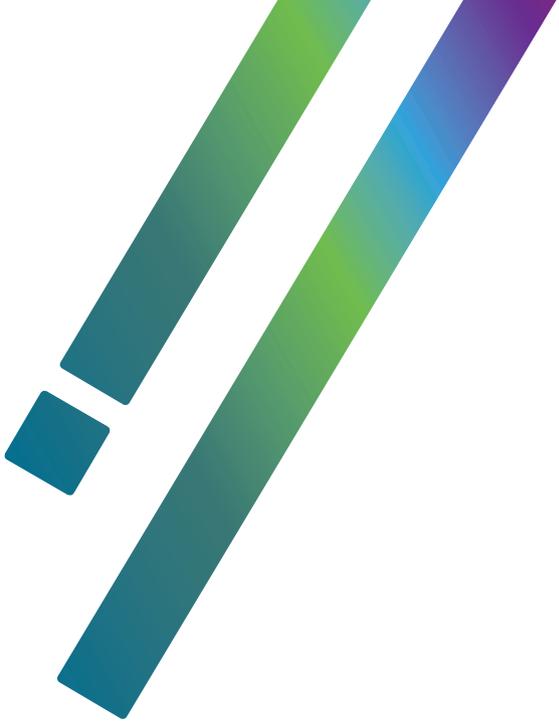
Monitoring diabetes during pregnancy provides important information on the impact of diabetes during and after pregnancy on the health of mother and child. This report:

- describes national data sources available for monitoring the effects of diabetes during pregnancy on mothers and babies

- identifies current data gaps, alternate data sources for monitoring outcomes associated with diabetes in pregnancy, and possible data linkages to improve national monitoring of pregnancies affected by diabetes.

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