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Canberra

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Contents

Summary

Information is limited on the prevalence of female genital mutilation/cutting (FGM/C) in Australia and the health-care needs and service use of girls and women who are affected. A preliminary estimate, based on available data, suggests there could be over 50,000 women and girls living in Australia who may have undergone FGM/C. This estimate is based, however, on several assumptions and data limitations.

This report identifies and discusses what relevant data sources exist in Australia, the potential service contexts in which data are (or could be) captured, and what steps might be taken to improve their systematic collection.

The barriers and limitations inherent in collecting data on a sensitive and complex issue such as FGM/C limit the prospects for improving routinely collected data at a national level; however, there are some opportunities to enhance and develop data, particularly relating to service provision.

The National Hospital Morbidity Database (NHMD) is one national data source providing some information on FGM/C. This report presents data from the NHMD from 2015–16 to 2017–18 on the 477 episodes of admitted patient care where FGM/C was recorded as relevant to the care a patient received (primarily related to childbirth).

This is the second report on FGM/C in Australia published by the Australian Institute of Health and Welfare, the first being *Towards estimating the prevalence of female genital mutilation/cutting in Australia* (AIHW 2019a).

1 Introduction

Female genital mutilation/cutting (FGM/C) refers to all procedures involving partial or total removal of the external female genitalia, or other injury to female genital organs (such as stitching of the labia majora or pricking of the clitoris) for non-medical reasons (WHO 2018a). The main types of FGM/C, as classified by the World Health Organization (WHO) are described in Box 1.1; these types range in severity.

Box 1.1: Four main types of FGM/C

Type 1—clitoridectomy: partial or total removal of the clitoris and/or the prepuce (fold of skin surrounding the clitoris)

Type 2—excision: partial or total removal of the clitoris and the labia minora (inner folds of the vulva), with or without excision of the labia majora (outer folds)

Type 3—infibulation: narrowing of the vaginal orifice with the creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris

Type 4—other: all other harmful procedures to the female genitalia for non-medical purposes, such as pricking, piercing, incising, scraping and cauterisation (WHO 2018a).

FGM/C is a complex cultural practice that varies by factors such as time, ethnicity and geography. The reasons it is practised include preparing for marriage and adulthood, preserving socially accepted values related to femininity and modesty, ensuring a woman's fidelity, and for subjective aesthetic reasons (WHO 2018b). FGM/C has no basis in religion (AMWCHR 2014; WHO 2018a) and is practised by ethnic groups of many faiths.

FGM/C is almost always performed on girls aged 0–18. For the vast majority of girls, it is performed by the age of 15, and for many before the age of 9 (DHS 2018; UNICEF 2018a).

International health and welfare agencies and Australian governments view FGM/C as an abuse of human rights and children's rights, and as a complex form of violence against women (AIHW 2018a; COAG 2011; UN 1948, 1979; UNICEF 1989; UN Women 2017). Practising FGM/C in Australia or arranging for FGM/C to occur overseas for a girl who is an Australian resident is illegal and considered a form of child abuse.

Box 1.2: Note on terminology

Different terms can be used when discussing FGM/C. In some contexts, the word 'cutting' is preferred to reflect the importance of using non-judgemental terminology, especially within practising communities. In other situations, the term 'mutilation' is preferred so as not to diminish the impacts of the practice and to emphasise its human rights aspect. In this report, the term 'female genital mutilation/cutting' is used, acknowledging both perspectives. The term '(female) circumcision' has not been used because 'circumcision' is a term more commonly associated with males and may be associated with only the less invasive forms of FGM/C.

For further guidance on terminology, see the publication *Respectful dialogue: a guide for responsible reporting on female genital cutting* (AMWCHR 2014).

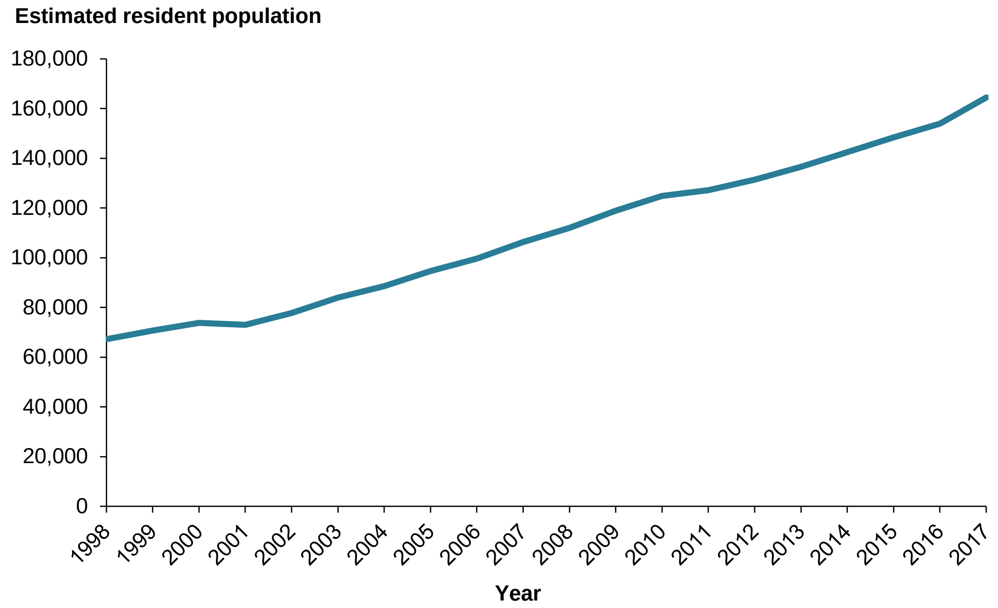
Prevalence of female genital mutilation/cutting

The United Nations and the WHO estimate that, worldwide, over 200 million women and girls alive today have undergone FGM/C. An analysis of prevalence estimates from household and health surveys in 29 countries where FGM/C is practised showed that, between 1990 and 2017, the prevalence rate among girls aged 0–14 fell in some areas and rose in others (Kandala et al. 2018). However, even where large drops in prevalence rates have been observed, rising birth rates could mean the actual numbers of girls and women with FGM/C may still be increasing.

The Australian Institute of Health and Welfare (AIHW) has estimated that about 53,000 women and girls currently living in Australia but born elsewhere have undergone FGM/C (AIHW 2019a). This estimate was calculated by combining available international FGM/C prevalence rates by country with Australian migration data. This methodology has several major limitations, such as the assumption that the populations that have migrated to Australia are representative of the survey populations used to generate the international prevalence rates. Nevertheless, the estimate does provide a theoretical count of the potential number of women and girls living in Australia who may have undergone FGM/C.

In Australia, the rate of migration from 30 countries where FGM/C is known to be practised rose an average of 5% per year between 1998 and 2017—from about 67,000 in 1998 to about 164,500 in 2017 (Figure 1.1). This may mean that the number of women and girls with FGM/C could continue to rise in the future in Australia. Figure 1.1 presents data on the estimated number of females living in Australia who were born in one of the 30 countries known to practise FGM/C. This incorporates data for the 29 countries for which data were used to estimate the Australian prevalence rate as well as for Indonesia, a notable contributor to immigration in Australia, and a country in which it is estimated half of all girls aged 0–11 have undergone FGM/C (2013 figures, from UNICEF 2016).

Figure 1.1: Estimated number of females living in Australia who were born in one of 30 countries known to practise FGM/C, 1998–2017



Note: Data included for the following countries of birth: Benin, Burkino Faso, Cameroon, Central African Republic, Chad, Côte d'Ivoire, Djibouti, Egypt, Eritrea, Ethiopia, (The) Gambia, Ghana, Guinea, Guinea Bissau, Indonesia, Iraq, Kenya Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leone, Somalia, Sudan (north), Tanzania, Togo, Uganda, Yemen.

Source: AIHW analysis of data from ABS 2018.

Practising or arranging for FGM/C in Australia

Unlike for some other studies (for example, Dubourg et al. 2011), the Australian FGM/C prevalence estimates did not include a separate estimate of the number of girls who may be considered at risk of FGM/C. Girls considered at risk are those born in Australia to parents from countries in which FGM/C is practised and girls who came to Australia before the traditional age of cutting in their culture. The latter group was included in the Australian prevalence estimates; the former was not.

As noted, practising FGM/C in Australia or arranging for FGM/C to occur overseas for a girl who is an Australian resident is illegal under state and territory laws. To date, there have been two legal cases in Australia relating to FGM/C legislation. However, because FGM/C is a deeply ingrained expectation in some cultures, families living in Australia can feel pressure from extended family either here or in their country of origin to have their daughters undergo FGM/C.

There is some evidence that FGM/C has occurred to a very small fraction of the at-risk population in Australia (see chapters 2 and 5 of this report); in general, though, it is considered that migration, especially to a low-prevalence country such as Australia, is a major driver for abandonment of FGM/C (Johnsdotter & Essén 2016). This cultural shift away from FGM/C was shown in a study carried out in Melbourne that found that young women, in particular, from backgrounds where FGM/C is traditionally practised are very strongly opposed to FGM/C for their daughters (Vaughan et al. 2014).

Health consequences of FGM/C

FGM/C has no health benefits, and there is no medical justification for it (WHO 2018a). In the short term, it can cause pain, haemorrhage (bleeding), shock, urination problems, swelling, infection, psychological trauma and, in rare cases, death.

It is assumed that almost all girls and women in Australia with FGM/C had the procedure before they arrived here. Hence, the potential burden of ill health in Australia resulting from FGM/C is generally related to longer term health problems, some of which may be chronic issues requiring lifelong management. These health problems may, in turn, increase the risk of secondary chronic conditions and reduced quality of life.

The potential long-term health consequences of FGM/C that are most common are listed in Box 1.3. According to the meta-analysis of 185 empirical studies on FGM/C by Berg et al. (2014), evidence is strongest for increased risk of menstrual problems, childbirth complications, genital infections and urinary tract infections.

Some of these consequences are less likely to occur in a high-resource country such as Australia than in low-resource countries (for example, the risk of maternal and infant death). It is not known what effects living in Australia may have on most of the long-term consequences of FGM/C and the associated patterns of health service use by affected women and girls. These effects may be positive (as a result of greater access to required services) or negative. For example, there is some evidence that women have had negative psychological consequences after receiving care by health professionals untrained in FGM/C (Murray et al. 2010; Ogunsiji 2016).

Box 1.3: Potential long-term health consequences of FGM/C

Childbirth complications—FGM/C is associated with an increased risk of Caesarean section, post-partum haemorrhage, episiotomy, difficult delivery, obstetric tears/lacerations, instrumental delivery, prolonged labour, and extended maternal hospital stay. The risks increase with the severity of FGM/C.

Chronic pain—tissue damage and scarring may result in trapped or unprotected nerve endings, causing chronic pain.

Genital infections—these may include, for example, bacterial vaginosis—an imbalance of the bacteria in the vagina that may cause abnormal discharge, itching or odour.

Menstrual problems—obstruction of the vaginal opening may cause painful menstruation (dysmenorrhea), irregular periods and difficulty in passing menstrual blood, particularly for women with Type 3 FGM/C (see Box 1.1).

Perinatal risks—childbirth complications can result in a higher incidence of infant resuscitation at delivery, stillbirth and neonatal death.

Potential need for further surgery—deinfibulation, a procedure to re-widen the vaginal orifice to have sex, give birth or relieve other health consequences of FGM/C (usually Type 3) may be required. In Australia, deinfibulation is often performed during antenatal care or during labour, but can be done at any time. Reinfibulation by an Australian health-care provider is not legal, although some women may request it.

Psychological problems—some studies have shown an increased likelihood of mental health issues such as anxiety disorders and depression. Some of these issues may stem from the physical consequences of FGM/C directly (for example, chronic pain) or indirectly (for example, in migration contexts, psychological problems may be caused by feeling stigmatised by members of the majority culture with little understanding of FGM/C).

Reproductive tract infections—these may cause chronic pain in the back or pelvis.

Scar tissue complications—scar tissue from FGM/C can continue to spread to surrounding areas and can result in pain, itchiness and inflammation.

Sexual health problems—removal of or damage to the clitoris and other genitalia may cause difficulties with sexual desire, pleasure, penetration, lubrication and orgasm; painful sex; and prompting of traumatic memories of the FGM/C procedure.

Urinary tract infections (UTI)—damage to the urethra by FGM/C puts girls and women at an increased risk of repeated urinary tract infections. UTIs are a very common effect of FGM/C and make urination painful; if not treated, infection can spread to the kidneys, potentially resulting in renal failure, septicaemia and death.

Sources: Berg et al 2014; Elnashar & Abdelhady 2007; Johnsdotter & Essén 2016; WHO 2019.

Perception of long-term health consequences

FGM/C is a collective term that describes a range of interventions that vary in severity and in their potential health consequences. Some women with FGM/C may not perceive the health issues arising from FGM/C as being particularly problematic. There is some evidence that long-term health consequences related to FGM/C may be seen as a normal part of being female, especially in communities where prevalence of FGM/C is high. This outlook is reflected in a study by Jacobson et al. (2018) on women with FGM/C who generally considered themselves healthy in spite of pain and discomfort throughout their adult lives.

The Melbourne-based study by Vaughan et al. (2014) found that age, sexual activity and motherhood affected the extent and type of FGM/C-related physical impacts that women reported. Young women who were not sexually active were more likely to report no health impacts, instead categorising issues such as uncomfortable periods and recurrent urinary tract infections as normal and minor. Younger women were more likely than older women to cite psychological impacts of FGM/C; these included traumatic memories of the cutting event and various issues in making the cultural shift to a non-FGM/C practising country, especially when the cultural expectation for FGM/C from the country of origin may still be strong. Older women focused more on the physical consequences of FGM/C, particularly complications with pregnancy and childbirth, sexual function and sexuality.

Both of these studies found that many of the FGM/C-related impacts identified by health professionals were not seen as priorities by women with FGM/C, especially in the period after migration when other issues relating to resettlement in a new country take precedence.

Purpose of this report

Relatively little is known about the health-care needs and usage patterns of health services by girls and women in Australia with FGM/C. Better understanding of FGM/C in Australia is important, particularly because of the:

- likelihood of high prevalence rates in some communities and the potential for the rate to rise due to migration trends
- potential impact on a female’s physical, reproductive and psychological health throughout her life
- complexity and intersectional nature of FGM/C in Australia (that is, those with FGM/C in Australia may face discrimination or disadvantage stemming from multiple roots; for example, age, sex, race and social class).

The purpose of this report is to explore what data on FGM/C exist in Australia, the potential contexts in which data are (or could be) captured, and what steps might be taken to improve their systematic collection. Increasing what we know, and the quality of that information, may help in the following areas:

- prevalence—adding evidence-based data with which to evaluate the accuracy of existing modelled estimates
- service provision—ensuring the delivery and evaluation of appropriate health care and social support to those with FGM/C who need it
- prevention—stopping FGM/C occurring to girls living in Australia.

Information on FGM/C in Australia, gathered systematically over time, could support the evaluation of the impact of initiatives such as service delivery improvements and prevention strategies.

The content of this report has been informed by consultation with a range of stakeholders within the AIHW and with external experts in the field (see Acknowledgements). A snowball methodology was used to identify stakeholders where initial contacts led to further contact and consultation with others.

Note on female genital cosmetic surgery

This report is predominantly about FGM/C; however, female genital cosmetic surgery (FGCS) is relevant to the discussion of some data sources described in Chapter 4. The Royal Australian College of General Practitioners (RACGP 2015) defines FGCS as:

> …non-medically indicated cosmetic surgical procedures that change the structure and appearance of the healthy external genitalia of women, or internally in the case of vaginal tightening.

There are a number of parallels between FCGS and FGM/C. Two of the main distinctions between them, however, are the age at which the procedure is performed and the ability for the person undergoing the procedure to give consent.

The report of the Attorney-General's Department *Review of Australia's female genital mutilation legal framework* (AGD 2013) noted a division in public discourse between FGCS and FGM/C, even though FGCS 'may involve procedures that are technically very similar to those defined in the [FGM/C] legislation' (2013:9). This technical similarity not only means a lack of clarity in the legal status of FGCS, but also presents issues for distinguishing between potential FGM/C and FGCS in some of the data sources discussed in this report.

2 Australian evidence base on FGM/C data

Research on FGM/C in Australia has been conducted mostly in hospital maternity or paediatric service settings. *Towards estimating the prevalence of female genital mutilation/cutting in Australia (*AIHW 2019a) contained an overview of the recent literature published in Australia on FGM/C, which reveal that many of the health-care needs of women who have undergone FGM/C often focus on pregnancy and childbirth. This chapter summarises selected publications from that overview that are most relevant to the availability and quality of population-level FGM/C data in Australia.

Family Planning NSW report on FGM/C data collection

The report *Feasibility study for a national female genital mutilation data collection* (Family Planning NSW 2014) made publicly available in 2019, presented information gathered from surveys and interviews with more than 230 health and social care professionals (mostly doctors, nurses, midwives, psychologists and social workers), 48% of whom reported having seen a woman with FGM/C in the previous five years. The study described the extent to which FGM/C data were routinely collected and the nature of these data collections, finding that:

- there were in-house custom collections of FGM/C-related data in public hospitals and some non-hospital clinic settings (for example, family planning clinics)
- most FGM/C information was collected for clinical care reasons in the form of clinical notes; broadly speaking, data were not being used for reporting and quantitative analysis
- some hospital databases are able to collect FGM/C-related data, but recording is not mandatory
- where FGM/C data are collected, the more frequently collected data items were:
    - presence of FGM/C
    - type of FGM/C
    - health and psychosocial complications resulting from FGM/C
    - country of birth (although the report notes that ethnicity would be more informative information)
    - age.

The report's recommendations relating specifically to data included:

- encouraging the collection and reporting of FGM/C data in primary, secondary and tertiary health-care settings, with mandatory reporting by some antenatal, gynaecological and obstetric wards at a state/territory level
- enabling identification of FGM/C-related claims on relevant Medicare Benefits Schedule (MBS) items
- developing suggested FGM/C metadata items for national endorsement and registration in the AIHW Metadata Online Registry (METeOR)
- adding an FGM/C item to the National Perinatal Minimum Data Set

- adding FGM/C to domestic violence and sexual assault screening in primary health-care services.

These ideas are further discussed in other sections of this report.

Maternal health studies

Studies conducted in maternity settings provide some of the most detailed information about FGM/C Australia. The studies described below from the maternal health literature are of particular relevance to FGM/C data.

Study of maternal health outcomes

Varol et al. (2016) compared the obstetric outcomes of women with and without FGM/C who gave birth between 2006 and 2012 at a Sydney hospital where staff have FGM/C expertise. Of a total study population of more than 9,000 women, 196 (between 1.8% and 2.3% each year) were recorded as having FGM/C.

The study illustrates that the health-care needs of a woman may vary depending on the type of FGM/C she has, highlighting the importance of clinicians being able to reliably identify FGM/C by type. Of the 196 women with FGM/C in this study, 33% had type 1, 33% had type 2 and 26% had type 3; the type was recorded as ‘unknown’ for 6.6% of the women. The women with FGM/C had similar obstetric outcomes to women without FGM/C, except for a higher risk of first and second degree perineal tears and Caesarean section, although the Caesarean sections were not found to be due to FGM/C. Perineal tears were more common among women with type 3 FGM/C.

The study design does not enable us know to what extent the obstetric outcomes for women with FGM/C were because the hospital’s staff had a relatively high level of knowledge and experience in FGM/C compared with staff at other hospitals.

The study by Varol et al. (2016) explicitly acknowledges the role of data systems for the recording of accurate information, describing two information systems in place at the study’s hospital: ObstetriX and the Midwives Database.

The ObstetriX information system is used across New South Wales (and in other jurisdictions in Australia) for managing maternal and neonatal information and has specific fields in which to record the presence and type of FGM/C. Data in the ObstetriX data set were entered by midwives at two time points: after their first visit with a woman and following their first visit with a woman after birth.

The Midwives Database is specific to the maternity ward at this hospital and can be used by clinicians to record more detailed information on conditions such as FGM/C. For example, details of deinfibulation procedures may be recorded here.

The quality of information in the ObstetriX data set varied over time, capturing 14% of all FGM/C cases recorded in either the Midwives Database or ObstetriX in 2006 and 90% in 2012.

Other studies in maternal health settings

Gibson-Helm et al. (2014) studied records for over 2,100 African-born women giving birth at three hospitals in Melbourne between 2002 and 2011. One of the main aims of the study was to compare maternal health and pregnancy outcomes of women according to whether the women were refugee or non-refugee migrants to Australia. It found that 78 (3.6%) women in the study had FGM/C recorded, the vast majority of whom (73, 94%) were born in humanitarian source countries and were therefore likely to have been refugees.

Regarding maternal health outcomes, the study suggested that rates of perineal trauma may be higher for women with FGM/C, though this was not statistically significant.

A survey by Moeed & Grover (2012) of Royal Australian and New Zealand College of Obstetricians and Gynaecologists doctors and other FGM/C program workers found that 82 (21%) respondents had been asked to re-suture a woman with FGM/C after giving birth and two (0.5%) had been asked to perform FGM/C.

Paediatric studies

Investigation of issues related to FGM/C in children in Australia has also occurred in paediatric settings.

Zurynski et al. (2017) published results of a survey of paediatricians, where, of over 1,000 respondents, 23 (2.3%) reported having seen at least one child with FGM/C in the previous five years of their practice in Australia, with a total of 59 children with FGM/C seen. Most (90%) were identified via refugee screening and were born overseas; however, three (19%) were born in Australia, two of whom had undergone FGM/C in Australia and one in Indonesia. Of the 59 cases recorded in the study, health problems relating to FGM/C were reported in eight cases for girls with FGM/C types 1, 2 and 3. The health problems reported included problems with urination, painful periods, genital inflammation and irritation, sexual and fertility problems, chronic pain and psychological problems.

The 2016 survey by Sureshkumar et al. of Australian paediatricians' knowledge, attitudes and clinical experiences of FGM/C found that 50 (10%) of almost 500 respondents had seen FGM/C in girls at some time in their career, 16 of whom had seen a total of 59 girls with FGM/C in the previous five years. Of the 16 respondents with more recent experience with FGM/C, several specialised in refugee health, obstetrics, urology or child protection.

Data sets in other countries

Routine national data collection on FGM/C in high-resource countries is relatively rare, although, since 2015, the National Health Service in England has collected data for the Female Genital Mutilation Enhanced Dataset (FGMED) (NHS Digital 2018a, 2019). Data submission is mandatory for services, including hospitals, mental health services and general practices, resulting in quarterly published statistical reports. The goals of the collection are both to safeguard girls at risk of FGM/C and to present national prevalence data.

Information collected includes the age of the girl or woman, whether the FGM/C was newly recorded for her or was a repeat recording, country of birth, length of time in England, area of usual residence, whether repair procedures were undertaken, number of daughters, and country and age at which the FGM/C occurred. Cases are typically reported in midwifery, obstetrics and gynaecology settings.

In 2017–18, the FGMED recorded 9,490 attendances for 6,195 girls and women where FGM/C was identified, or a procedure related to FGM/C was undertaken. To date, over the three years for which data are available, data on 16,265 girls and women with FGM/C have been recorded in the FGMED (NHS Digital 2018b).

3 Key questions about FGM/C

Accurate information about the health and wellbeing of the Australian population is valuable for many reasons, including improving clinical care, planning and providing services, and designing and implementing prevention strategies to mitigate the risk of ill health and disadvantage.

This chapter identifies information about FGM/C at a national level that would be most useful to know. The key questions posed, which draw on existing frameworks for assessing data sources for long-term health conditions (for example, obesity; see AIHW 2019b), are divided into three information areas—prevalence, service provision, and prevention—although some questions apply to more than one area. Answers to these questions provide an information base on which to assess existing or potential data sources. The assessment is presented in Chapter 4.

Prevalence

The primary question about prevalence is:

- **How many girls and women living in Australia have FGM/C?** Basic prevalence information is key to forecasting the demand for services (including planning of services) to meet that demand. Present prevalence figures for Australia are based on modelled estimates that have methodological limitations (AIHW 2019a).

  Prevalence information may also be useful for prevention purposes—that is, providing more information about the potentially ‘at risk’ population of girls living in Australia with a close family member (for example, mother or sister) with FGM/C (a known risk factor).

Secondary questions about prevalence, especially relating to socio-demographic differences within the total population with FGM/C, may include:

- **How many and what proportion of girls and women with FGM/C:**
  - **have each type of FGM/C?** Type of FGM/C can be related to severity of health conditions and therefore what services may be required. For example, a woman with Type 3 FGM/C may require deinfibulation to give birth
  - **are in various age groups?** Knowing the age of a girl or woman with FGM/C can help to predict health-care needs (for example, the number of women of child-bearing age)
  - **have common ethnicities?** This information can be used to improve cultural appropriateness in service delivery. Some service providers may also use ethnicity to help decide whether to initiate a conversation about FGM/C to find out if the patient or client is receiving the services or health promotion information they may need; however, this approach risks missing many women with FGM/C. Asking every patient if she has a history of genital surgery or cutting when it is clinically relevant to the service encounter may be a more reliable and objective approach. Often information on country of birth, and to a lesser extent language(s) used, act as proxies for ethnicity, which is not a commonly collected data item
  - **use a language(s) other than English?** This information is primarily used to meet the language needs of patients or clients; for example, providing interpreters or written health promotion materials in relevant languages; however, in this context, this information may also serve as an indicator of ethnicity

  - **live in various geographical areas of Australia?** This information helps in providing services where they are most needed.

Service provision

Understanding more about the service use patterns relating to FGM/C is useful for improving many aspects of service provision. The primary questions here are as follows:

- **Which and how many services are women and girls with FGM/C receiving and why?** Recording this type of information is routine at a national level in some areas of the Australian health system; for example, for hospitals admissions. However, in other areas, it is not routinely collected or is collected at a local or establishment level.
- **What potentially beneficial services are women and girls with FGM/C forgoing and why?** These include services directly related to the health impacts of FGM/C, and/or indirectly associated with FGM/C. For example, are cervical screening rates equivalent between women with and without FGM/C?

Secondary questions such as those that follow might seek more information about the services received, health conditions being treated, or service providers:

- **How many/what proportion of:**
  - **services provided were for various procedures/interventions?** For example, repair of a perineal tear after childbirth
  - **services provided are associated with various diagnoses?** For example, urinary tract infection or childbirth.

Prevention

Some evidence suggests that the risk of girls in Australia undergoing FGM/C is small, due to factors such as migration itself, changing community attitudes and Australian prevention initiatives (Johnsdotter & Essén 2016; Vaughan et al. 2014). The general lack of evidence of FGM/C's occurring in Australia or being arranged from Australia (except for a small number of reported cases) could be seen as evidential support for this view. However, because the practice is criminalised in Australia, it is possible that it is continuing within some families in secrecy.

Some key questions relating to the prevention of FGM/C include:

- **How many girls/women are at risk of FGM/C in Australia?** This question relates to prevalence as this information is usually calculated in the international literature (sometimes based on modelled estimates) as the number of daughters a woman with FGM/C has (for example, Dubourg et al. 2011).
- **Where are girls at risk living in Australia?** Again, linked with prevalence, answers to this question would enable prevention initiatives to be implemented in areas likely to have maximum impact.
- **At what age was a girl or woman cut?** This information may be useful to gauge the age range at which girls become most at risk within a family or community. Theoretically, it could lead to discovering some girls who had been cut after arrival in Australia.
- **In which country was a girl or woman cut?** The country where a girl is cut may be different from her country of birth. This may be more relevant in refugee contexts, where a girl may be born or have spent long periods in a transit country. This information may be useful in understanding these demographic patterns.

- **How many and what proportion of families and individuals:**
  - are being informed about FGM/C in the Australian context, including:
    - the legal and socio-cultural status of FGM/C in Australia?
    - the short-term and long-term health risks of FGM/C?
    - how to access support for a girl at risk?
  - have the opportunity to discuss FGM/C with relevant service providers (for example, refugee health service providers, primary care providers) after the initial resettlement period (for example, within the first year of resettlement), and in what service settings do these discussions occur?

This information would be useful for measuring over time the effectiveness of prevention strategies and health promotion initiatives.

4 FGM/C data in Australia

This chapter identifies, describes and, where possible, evaluates the data sources that:

- exist and currently contain FGM/C data
- exist and could contain FGM/C data with future development work
- are being developed and may be a potential future source of FGM/C data.

The word 'data' in this context mostly means the codified information in large data sets kept primarily for administrative purposes (for example, population-level health statistics, resource allocation) rather than for clinical purposes. However, we have also considered smaller information sources that may exist at, for example, the clinic level, kept predominantly for patient or client care purposes.

The list of data sources was compiled from a number of sources:

- consultation with stakeholders both within the AIHW and with external experts in the field (see Acknowledgements)
- consideration of the service pathways for women with FGM/C to identify possible points of contact with services and therefore potential data collection opportunities
- information from published literature.

Barriers and limitations to data collection

There are many barriers and limitations to collecting FGM/C information that overlay all existing and potential data sources. The factors listed below may restrict opportunities to collect FGM/C data in the first place, or limit the quantity or quality of data that can be collected when an opportunity does exist. Many of these factors relate to the sensitivity and complexity of FGM/C that make recording and collating good quality data, and then interpreting those data, an enterprise that requires specialised professional training for both clinicians and data specialists.

Patient/client-centred factors

Women/girls may not seek services or avoid certain types of health-care interventions because they:

- may not know that they have had FGM/C. If the procedure was done when a girl was very young and there are cultural taboos around discussing it, a girl or woman may not know she has had FGM/C, especially for the less severe forms
- do not experience, or do not perceive that they have, FGM/C-related health problems
- are not aware of the services that exist or may lack knowledge about how to access these services; for example, deinfibulation services in outpatient clinics
- are unwilling to talk about FGM/C, or lack the confidence or knowledge to talk about it—this may also depend on who may be accompanying the woman or girl at a health consultation
- do not feel culturally safe to discuss FGM/C (possibly because of previous negative experiences with service providers) or they may not feel comfortable discussing FGM/C in the presence of an interpreter

- may not feel comfortable discussing FGM/C in the presence of another family member (although the converse effect could also be true if the family member encouraged the discussion).

Service provider factors

Service providers may not:

- identify culturally or clinically appropriate times to discuss FGM/C within the service encounter or pathway. This includes not mentioning the topic when it is clinically relevant, as well as discussing the topic in a culturally inappropriate or disrespectful way or when it is not clinically relevant. Several health-sector stakeholders we consulted affirmed the importance of collecting FGM/C data within appropriate contexts, both at a broad level (for example, service encounters where experience of FGM/C may be directly relevant, such as maternity services) and within a service interaction or service pathway (for example, raising the subject only once a level of rapport and trust is established)
- be adequately trained or skilled in discussing FGM/C in a culturally and clinically appropriate way. Previous studies confirm that improvements to clinical education are still needed in Australia (Dawson et al. 2015; Turkmani et al. 2018)
- have enough appropriately trained staff with whom patients feel sufficient rapport to discuss FGM/C. For example, some women may prefer a female caregiver
- have enough appropriately trained staff who can accurately identify the presence or type of FGM/C. This may be for a range of reasons, such as lack of training or skills in discussing FGM/C or in identifying FGM/C via examination. Where information is collected through discussion, the limitations of any self-reported information would apply. Where an examination is conducted, the evidence of FGM/C may be so subtle that it is difficult to determine if it has occurred
- have the clinical skills or knowledge to provide appropriate treatment or referrals for FGM/C-related health-care needs
- record FGM/C in patient notes, or record it accurately with the appropriate level of detail, or record it in an format suitable for routine collection
- have provided adequate and culturally appropriate interpreter support where required, resulting in poor communication between a woman or girl and the service provider.

Existing data sources containing FGM/C information

Currently, there are only a few existing data sources that contain information on FGM/C in Australia. These vary in terms of completeness, and may overlap. The data sources are:

- National Hospital Morbidity Database (NHMD)
- Medicare Benefits Schedule (MBS)
- general practice aggregated data sets
- hospital clinic-level data
- refugee health services data
- child protection agency data.

These data sources are now discussed in terms of factors such their purpose, coverage and main limitations. Then the extent to which each can provide information on the key areas of prevalence, service provision and prevention (outlined in Chapter 3) is assessed.

National Hospital Morbidity Database

The NHMD is a comprehensive database with records for all episodes of admitted patient care (hospitalisations) from essentially all hospitals in Australia. The information it provides on admitted patient care includes demographic information (such as age, sex and country of birth), as well as data on diagnoses of patients and the procedures they underwent.

Data are supplied annually by state and territory health departments to the AIHW for compilation. The data required are specified in the Admitted Patient Care National Minimum Data Set (see metadata for 2017–18 at https://meteor.aihw.gov.au/content/index.phtml/itemId/641349).

In the NHMD, a record is included for each separation (or hospitalisation), not for each patient, so a person with multiple separations in the reference year would have multiple records. A separation is an episode of care, which is usually a total hospital stay (from admission to discharge, transfer or death), or a portion of a hospital stay starting or ending in a change of type of care (for example, from acute care to rehabilitation).

The NHMD records include information on principal diagnosis and any additional diagnoses, currently coded using the International Statistical Classification of Diseases and Related Health Problems, 10th Revision, Australian Modification (ICD-10-AM) (see Chapter 6). A principal diagnosis is that established after study to be chiefly responsible for occasioning an episode of admitted patient care. An additional diagnosis is a condition or complaint either coexisting with the principal diagnosis or arising during the episode of admitted patient care.

Since 2015–16, a diagnosis code specifically relating to FGM/C (Z91.7—*Personal history of female genital mutilation*) has been available and recorded in the NHMD. The Z91.7 code is used as an additional diagnosis only when FGM/C is considered to affect patient management for another (principal) diagnosis—for example, childbirth. Therefore, the NHMD cannot indicate the total number of hospitalisations involving girls and women with FGM/C. For example, if a woman with FGM/C was admitted to hospital for a heart attack, there might be no clinical reason to record the FGM/C, even if it was known.

Although the data have several limitations (see Chapter 5), this diagnosis code enables admitted care hospitalisations where FGM/C is identified as affecting care received during the hospitalisation to be analysed, and to be documented and coded as such. NHMD data on FGM/C from 2015–16 to 2017–18 are presented in Chapter 5.

Medicare Benefits Schedule data

Medicare is Australia's universal health insurance scheme. It provides patients with:

- free treatment as a public patient in a public hospital
- free or subsidised treatment by practitioners such as general practitioners, specialists, dentists, optometrists and other allied health practitioners for clinically relevant services listed in the MBS.

The MBS data set contains information on the subset of these services that are claimed and processed through Medicare. These include most visits to a general practitioner, certain specialists and allied health professionals, and hospital care for private patients in a public or private hospital. It does not include data on services provided to public patients in public hospitals and services provided in public outpatient or emergency departments of public hospitals.

The MBS data cannot generally be used to describe the condition or problem being treated because there is no information about diagnosis. There is, however, information about procedures and one of those explicitly mentions FGM/C.

MBS item number 35533 is used for claims for:

Vulvoplasty or labioplasty, for repair of:

a) female genital mutilation; or

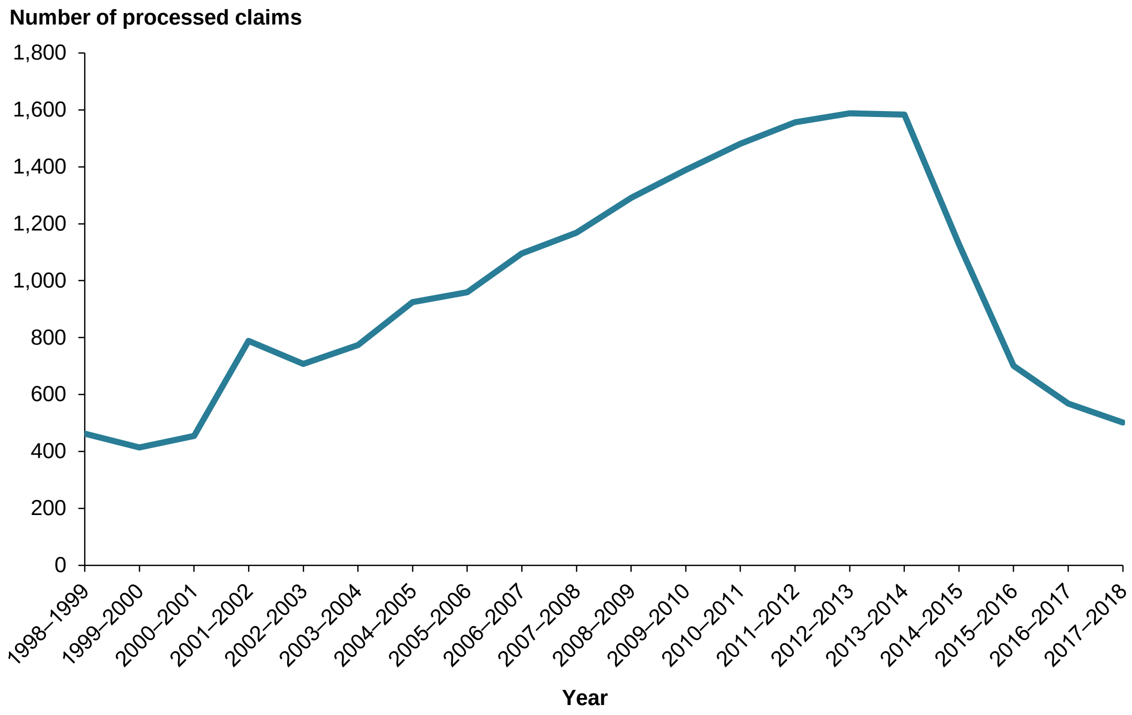
b) an anomaly associated with a major congenital anomaly of the uro-gynaecological tract.

As this code combines two reasons for the procedure, there is no way of using the MBS item alone to discern whether the procedure being claimed was related to FGM/C or to a congenital anomaly.

Trends in claims for vulvoplasty/labioplasty

Figure 4.1 shows the trend in the number of claims for item 35533 over the 20 years to 2017–18. The Royal Australian College of General Practitioners, in noting that the increase in claims for this item during this period was not accompanied by an associated rise in congenital or acquired disease conditions that may necessitate this procedure, attributed the rise to an increasing interest in FGCS (RACGP 2015; see also Simonis et al. 2016).

Figure 4.1: Number of MBS claims processed for item 35533, 1998–1999 to 2017–18



Source: Department of Human Services, 2019.

Since 2013–14, the number of MBS claims for item 35533 has decreased sharply, with just 502 recorded in 2017–18. However, the potential socio-cultural and other factors that may have driven the previous increases in MBS claims may not have changed. Rather, it is possible that these surgeries are now happening in parts of the health system not covered by the MBS and/or because claims for FGCS are not being submitted to Medicare due to the tightening of eligibility criteria for this item. In November 2014, application for FGCS was restricted to genuine medical cases involving FGM/C and major congenital anomalies (see also section headed 'Vulvoplasty' in Chapter 5).

At the same time, a new item (35534) (Department of Health 2014) was added to the MBS for vulvoplasty or labioplasty for 'localised gigantism' causing substantial functional impairment. The explanatory note (then TN.8.126) for this item specifically stated that ‘Medicare benefits are not payable for non-therapeutic cosmetic services’. Item 35534 required prior approval of the Medicare Claims Review Panel and medical evidence, such as a detailed clinical history, was previously required to accompany claims for the item. Since item 35534 was introduced to the MBS in 2014, up to 30 June 2018, there have been a low number of claims processed for it.

On 1 November 2018, changes were made to items 35533 and 35534 and the accompanying explanatory notes became TN.8.123 (Department of Health 2019). The Medicare Claims Review Panel was dissolved and the item descriptors were amended. The criteria for item 35534 was changed to ‘labium extending more than 8 cm below the vaginal introitus’. Since these changes, the Department of Health is monitoring trends in claims for these items in consultation with the medical profession.

General practice aggregated data sets

Many of the health conditions associated with FGM/C are likely to be dealt with in general practice. Routine cervical screening conducted in general practice provides a potential clinically appropriate opportunity to raise and discuss other gynaecological or sexual and reproductive health issues, including FGM/C.

Currently, there is no national source of data to provide a comprehensive understanding of the patient’s journey and experiences within the primary health-care system, including their reason for an encounter with a clinician, or their diagnosis, treatment and outcomes. This is a well-known data gap in the Australian health system; however, data collections are emerging to help fill it. Examples include MedicineInsight and POLAR (Population Level Analysis and Reporting)—data collections that contain de-identified information from a number of contributing practices (including reason for visit, diagnoses and patient demographics), and which could provide relevant data.

MedicineInsight, managed by the independent not-for-profit organisation NPS MedicineWise, is a longitudinal general practice data set that, in 2017–18, covered 6.6% of practices, 14% of general practitioners and 9.2% of general practitioner encounters in Australia; its coverage is growing. In 2017–18, MedicineInsight held records on 13% of regular patients, 2.7 million patients and 13.8 million general practice encounters. A preliminary search of the data set found that it contains 59 records where FGM/C is explicitly recorded in the medical history.

POLAR is a data collection provided and governed by participating Primary Health Networks and Outcome Health (a not-for-profit organisation) as the data custodian. It contains data from general practices across Victoria and New South Wales and is expanding. The data set currently contains longitudinal data from 1,000 practices (12% of practices in Australia) and 6 million unique patients.

Hospital clinic-level data

Hospital-based clinics or units such as outpatient clinics specialising in FGM/C and maternity and paediatrics units hold FGM/C data, however what data are collected and the collection methods used are not standardised between hospitals and may not be standardised within clinics or hospitals.

Hospital outpatient clinics

Our consultations and related work—for example, by Family Planning NSW (2014)—shows that clinical expertise in FGM/C tends to cluster in particular areas within state/territory health services (particularly in maternity units) that serve areas in major cities where women with FGM/C are more likely to live. Three hospitals in Australia are particularly well known for their expertise in managing issues associated with FGM/C: Auburn Hospital in Sydney, the Royal Women's Hospital in Melbourne and the King Edward Memorial Hospital in Perth (Varol et al. 2017). These hospitals regularly treat non-admitted patients as well as admitted patients with FGM/C.

The Royal Women's Hospital in Melbourne, for example, runs an FGM/C outpatient clinic one morning a fortnight, delivering services that include deinfibulation procedures for type 3 FGM/C. Although these clinics keep detailed patient records of the services provided, unless the service involves hospital admission (such as for childbirth), information on diagnoses and procedures is not captured in any current national non-admitted patient data set. This makes data from these types of clinics a potentially valuable source of data in the future.

Hospital maternity unit settings

Maternity services are provided in a range of settings, including general practice (discussed earlier), community health clinics and hospital maternity units that offer both admitted care (for example, for childbirth) and non-admitted care (for example, for antenatal care). Maternity service settings are one of the most clinically appropriate in which FGM/C information can be collected. Much of the published literature on FGM/C in Australia has been based on hospital maternity unit settings, and it is within these maternity services that the majority of clinical knowledge about FGM/C can be found in Australia (see Chapter 2).

While some service settings (such as general practice and community health clinics) may or may not be used during the period covering antenatal care, birth and postnatal care, most women are admitted to hospital when they give birth. This is one reason why admitted patient data from hospital maternity units is one of the most informative data sources on FGM/C. Another reason is national data coverage—certain information from all Australian hospital maternity units becomes part of national data collections such as the NHMD and the National Perinatal Data Collection (NPDC) on maternal and perinatal statistics (which does not currently include FGM/C data). However, there is not yet equivalent national data sets for general practice, community health, or non-admitted patient data that could capture information across all these settings (although the NPDC may contain some information collected during antenatal care visits in some jurisdictions).

Routine screening for FGM/C

Some maternity units in some of Australia's major cities have begun to routinely collect FGM/C data for use at a unit level for all patients, irrespective of a patient's ethnicity. These units have introduced a routine question into their antenatal screening questionnaires. They also have care pathways in place if the patient self-reports having FGM/C, including a physical examination, which is usually at a later point in the care pathway when more information can be collected.

In other maternity units, FGM/C data are collected on a case-by-case basis, relying more on the discretion of individual staff providing the service than on a routine question during antenatal screening. Information about a woman's country of birth is often used as the trigger for a care provider to ask about FGM/C; however, there are limitations with this approach, given that FGM/C is often related more to ethnicity than country of birth (UNICEF 2018b).

In some cases, due to some of the barriers and limitations discussed in Chapter 4, FGM/C may not be discussed at all and is discovered during an examination, or sometimes not until during labour.

Information management

A range of electronic information management systems are used across maternity units in Australia, including ObstetriX, Cerner and other more custom-built databases. Some are used at a state/territory level and may include specific basic FGM/C-related data fields such as presence of FGM/C and type. The extent to which these fields are present and accurately used across the country, however, is not known—although Varol et al. (2016) did study the accuracy of FGM/C data at one hospital (see Chapter 2).

As well as the higher level maternity information systems discussed earlier, some units keep other computerised records that can record FGM/C information in more detail—for example, the Midwives Database described by Varol et al. (2016) (see Chapter 2).

Some jurisdictions have initiatives to aggregate data from more than one hospital to inform service and policy improvement initiatives. This may be particularly beneficial in the case of FGM/C, where numbers of FGM/C-related service interactions may be low at individual hospitals.

Paediatric settings

Information on children with FGM/C seen by paediatricians is kept at a clinic, unit or hospital level. There is currently no routinely collected national data that specifically target specialist paediatric health care in Australia, although other national data sets may include children within their scope (for example, the NHMD includes those children who were admitted as hospital patients). Many centres also do not have centralised electronic medical records, limiting retrospective data collation and analysis.

The Australian Paediatric Surveillance Unit (APSU) is a national resource, set up in 1993 to facilitate active surveillance of low-prevalence health conditions in children. The APSU data collection methodology is survey-based—a monthly email to around 1,350 clinicians elicits reports of new cases of selected conditions being studied through the APSU. When a new case is reported, further de-identified information is solicited via a brief questionnaire. The APSU has conducted work in the area of FGM/C before (Zurynski et al. 2017) and could be a viable potential source of data on FGM/C in children in the future.

Refugee health data

Although only a small proportion of Australia’s migrant intake each year is for humanitarian reasons, extrapolation of the findings of Gibson-Helm et al. (2014) (see Chapter 2) suggests that the majority of women in Australia with FGM/C may come from asylum seeker/refugee backgrounds. Following arrival in Australia, refugees and humanitarian entrants are eligible for a voluntary health assessment paid for by Medicare. In some states/territories, specific jurisdictional services provide this short-term health assessment while, elsewhere, health care for newly arrived refugees is provided by mainstream general practice, community health centres or small non-government organisations (Phillips et al. 2011).

Some refugee health screening services run by jurisdictions in Australia now ask about both male and female circumcision as a routine question during all initial interview-based health assessments; others raise the topic only with some interviewees. Questions may relate to whether interviewees have FGM/C, and to family attitudes towards FGM/C for their children. Women reporting health conditions related to FGM/C are usually referred to relevant primary or secondary health-care services, and girls with FGM/C are referred to a paediatric gynaecologist. At least one jurisdiction automatically refers all daughters of women with FGM/C to a paediatrician specialising in migrant health, regardless of their self-reported FGM/C status. Counselling on the health impact of FGM/C and on relevant Australian legislation is also undertaken routinely by some specialist paediatric and general refugee health services when a history of FGM/C is disclosed.

Blanket screening provides an opportunity for service providers to inform the interviewees that FGM/C is not an accepted practice in Australian culture and is not permitted under

Australian legislation. Routine discussions around FGM/C foster engagement in challenging clinical discussions in a non-judgemental and de-stigmatising way, increasing patient rapport and engagement. In some cases, childrens and family services departments are notified where girls are considered to be at sufficiently high risk of FGM/C (in accordance with state/territory FGM/C reporting pathways).

Currently, there are no national data sets from this type of jurisdiction-led refugee health service context, although some FGM/C data are kept at a local level and paediatricians seeing refugee children with FGM/C were included in the scope of a targeted APSU survey on FGM/C.

Child protection data

When FGM/C is detected or suspected in a girl aged under 18 and there is reason to believe it may have been performed or arranged in Australia, mandatory reporting rules apply to members of certain professional groups, including doctors, nurses, teachers and police. This means they must report the matter to state/territory child protection authorities, making those agencies potential sources of data on FGM/C.

The AIHW’s consultation with child protection authorities from all jurisdictions in Australia revealed that there are a very small number of FGM/C cases reported to child protection authorities across the country, some of which are found after investigation to be substantiated.

Child protection services assess and intervene only in cases where there is an acute or imminent risk to the girl. As such, the majority of girls who may be deemed ‘at risk’ because family members have FGM/C are not necessarily engaged with child protection services, but with either refugee-specific services or primary care services. Girls who arrive in Australia having already had FGM/C are also not necessarily routinely linked to paediatric/adolescent gynaecology services or child protection services.

Ability of existing data sources to answer key questions

In Chapter 3, the key FGM/C information areas of prevalence, service provision and prevention were identified. This section assesses the extent to which each data source described so far in this chapter can provide answers in those three areas, keeping in mind the barriers to collecting data outlined elsewhere in this chapter that overlay all types of FGM/C data collection.

Prevalence

No existing data sources can provide national-level prevalence data on FGM/C. The only existing source of data with potential to collect prevalence data for a proportion of the ‘at risk’ population would be the refugee health services run by jurisdictions. These data would be limited to new arrivals to Australia who enter under humanitarian arrangements and who volunteer for a health check. Such a data source would require substantial resources to engage with services providers to ensure that the data were being collected in a consistent manner and recorded systematically in a way that allowed their routine reporting.

The sensitivity of the subject of FGM/C makes it inherently difficult for population-level data to be collected accurately. Internationally, data on prevalence have been collected via population health surveys. While the Australian Bureau of Statistics conducts surveys such as this on the health of Australians, and there are other surveys such as the Australian

Longitudinal Study on Women's Health, space and time restrictions of these surveys precludes collection of information on relatively low prevalence conditions. Surveys targeting participation from particular migrant populations in Australia may be the most practical way to substantiate national FGM/C prevalence estimates in Australia. A survey such as this would not result in routine data collection, but could be conducted periodically to provide regular estimates.

Service provision

There is some limited information on service provision—both nationally and/or setting specific—from existing data sources in admitted hospital care, general practice, maternity services, FGM/C outpatient clinics and paediatric clinics. However, most of these data sources are underdeveloped, either in terms of coverage (for example, general practice data) and/or the feasibility of collection at an aggregate level in a standardised form. As well, there are no data sources designed to collect detailed data on the mental health and sexual health consequences of FGM/C.

The NHMD (covering episodes of admitted patient care) is the only routinely available national data source. However, its impact is restricted: an annual average of only 159 hospitalisations with FGM/C were recorded from 2015–16 to 2017–18. Its limitations include its scope to one section of the health system (and for selected patients only who may have relevant admissions, and only where the FGM/C impacts on the care required). Nevertheless, it is possible to analyse NHMD data by variables, including diagnoses, procedures, country of birth, age, area of usual residence, socioeconomic status and service provider to gain a broader profile of hospitalisations involving women or girls with FGM/C; these analyses are presented in Chapter 5.

Prevention

Estimating the size of the population at risk of FGM/C is a key task with regard to prevention. In other low-prevalence countries where the presence of FGM/C is largely a consequence of migration, this information is mostly derived from modelled estimates of the number of daughters of women born in countries known to practise FGM/C (for example, Dubourg et al. 2011 in Belgium). In England, however, the FGMED routinely collects data on at-risk girls directly from girls and their families (including when a female baby is born) as part of its stated objective of safeguarding at-risk girls from FGM/C. Items included in the data set include whether information has been given to the family on the illegality and health consequences of FGM/C.

In Australia, an existing data source with the potential to provide information on prevention of FGM/C is refugee health data, which could possibly yield information on the numbers of girls deemed at risk of FGM/C, as well as associated demographic information. These data may also include details on the extent to which clients are given information about FGM/C in the Australian context to ensure migrating families are aware of the relevant legal and cultural expectations in Australia.

Other existing data sources with potential to collect FGM/C data

There are other data sources which, although they do not currently hold data on FGM/C, could have future relevance. These are described here.

National Perinatal Data Collection

The NPDC is a population-based cross-sectional collection of data on pregnancy and childbirth. It comprises a mandatory set of standardised data items (the Perinatal National Minimum Data Set), a set of additional standardised data items for supply if available (the Perinatal National Best Endeavours Data Set), and some additional data items that are voluntary to supply and may not have associated national standards.

The data are based on births reported to the perinatal data collections in each state and territory in Australia. Midwives and other birth attendants complete notification forms for each birth, using information obtained from mothers and from hospital or other records.

The development of a data item relating to FGM/C was considered by the National Maternity Data Development Advisory Group in 2013. While the issue was recognised as important, FGM/C was not included in the final list of priority data items.

Australasian Maternity Outcomes Surveillance System

An alternative potential data source to the NPDC may be the Australasian Maternity Outcomes Surveillance System (AMOSS), for which FGM/C could be included as a studied condition. AMOSS combines a clinical and population health approach to describe rare pregnancy and childbirth-related health conditions. Data are collected from maternity units with more than 50 births per year across Australia and New Zealand. Conditions studied by the AMOSS have an estimated incidence of fewer than 1 in 1,000 births per year. NHMD data show that FGM/C is recorded in 4 in 10,000 childbirth hospitalisations (see Chapter 5 for further analysis of NHMD data)

Future data opportunities

Two potential future data sources for FGM/C information are the secondary-use data from the My Health Record (MHR) system and the National Primary Health Care Data Asset. Both data sources are in the early stages of development, so they are only briefly described here. It is not possible to say at this stage to what extent these data sources will be able to yield information relevant to women and girls with FGM/C.

My Health Record

MHR is an online summary of a person’s health information over their lifetime, including their diagnoses, clinical notes, diagnostic test results, medications and Medicare claims history. Service providers across many parts of the health-care system (including general practice, allied health, outpatient, inpatient and emergency department services and pathology services) can contribute data if they are registered to participate in the MHR system, run software that conforms with it, and if the patient/client has not requested omission of the information from their MHR record. It is the first national person-centred digital health record data set in Australia that has the potential to allow analysis around the full set of health services received by a person.

As at 31 January 2019, the participation rate for MHR was 90%, with a national opt-out rate of 9.9%. Over 15,000 health-care provider organisations are registered with the MHR system, including general practitioners, pharmacies, and pathology and diagnostic imaging services. The AIHW is working closely with the Department of Health and the Australian Digital Health Agency to assess how data in the MHR system can be used for research and public health purposes, while preserving the privacy and security of data it contains.

Because FGM/C is a health issue that can be relevant across many areas of the health service, MHR may be of particular benefit for women in terms of receiving more appropriate and better quality services. For example, if FGM/C is recorded in a woman's record during pregnancy, when she later presents for menstrual problems at her general practice, the general practitioner may be able to immediately consider whether the condition is related to FGM/C. This increases the opportunities for FGM/C to be recorded as a relevant condition in the data record.

National Primary Health Care Data Asset

The National Primary Health Care Data Asset, initially comprised of sets of aggregate data, is being developed by the AIHW to provide collated, nationally consistent activity data from general practice and other primary health-care settings. Aggregated data sets from general practice described elsewhere in this chapter and content from MHR may feed into the National Primary Health Care Data Asset and may be a future source of information on FGM/C.

Data integration

Integrating existing data sources allows information to be connected that relates to, for example, the same people or health conditions across different data sources. This offers the opportunity to examine multiple service use and longer term outcomes for patients, providing a more complete picture of FGM/C in Australia. Well-developed methods of data integration (also known as data linkage) exist, with appropriate privacy controls, to bring data together to provide a better understanding of care pathways and the outcomes of care.

The AIHW is accredited as a Commonwealth Integrating Authority, allowing it to undertake data linkage involving Commonwealth data under enhanced security processes and protocols.

Linked data sets may enable research to be conducted on the journeys of patients through different parts of the health system where evidence of FGM/C is recorded. For example, there may be an opportunity for FGM/C-related records from the NHMD to be linked to records for vulvoplasty claims on the MBS, potentially enabling some distinction to be made between MBS vulvoplasty claims for FGM/C and for congenital abnormality reasons (see Chapter 4).

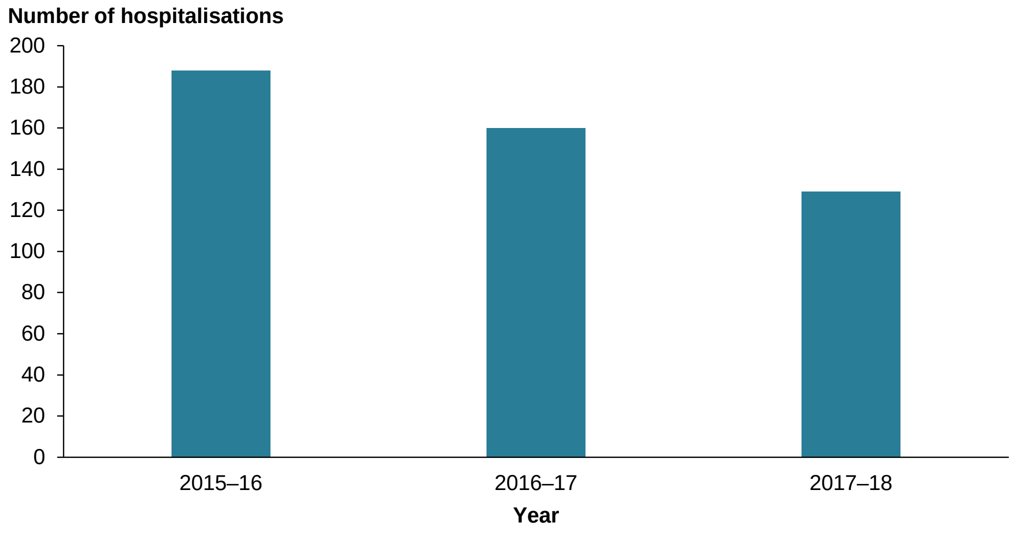
5 Hospitalisations data from 2015–16 to 2017–18

Further to the information in Chapter 4 describing the NHMD, this chapter presents information on admitted patient care provided in Australia's hospitals for the three years from 2015–16 to 2017–18 where FGM/C was relevant to the care received and was recorded as an additional diagnosis, supplementary to a principal diagnosis (such as childbirth). In this chapter, data for the three years (2015–16 to 2017–18) have been combined due to the low numbers of hospitalisations in the single years, however single-year data are presented in Appendix B.

From 2015–16 to 2017–18, 477 of the 32 million hospitalisations in Australia had the ICD code Z91.7 *Personal history of female genital mutilation* recorded as an additional diagnosis in the hospital record—an average of 159 per year. This figure may include multiple hospitalisations for the same person (for example, if a woman gave birth and then had a subsequent admission for a related condition where the diagnosis was also noted) or where a person was transferred from one hospital to another during an episode of care.

Figure 5.1 shows a decline in the number of hospitalisations recorded over these three years. Reasons for this variability are not known; however, the drop in 2017–18 may have been affected by a change in a relevant coding standard that year (see Chapter 6).

Figure 5.1: Hospitalisations with FGM/C recorded, 2015–16 to 2017–18



Note: Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 Personal history of female genital mutilation), so was considered to affect the care provided to patients during the hospitalisation.

Source: Table B1.

Hospitals reporting FGM/C in the NHMD

From 2015–16 to 2017–18, 67 hospitals recorded at least one hospitalisation where Z91.7 *Personal history of female genital mutilation* was recorded as a diagnosis. Six hospitals recorded over 50% (241) of the 477 FGM/C hospitalisations each year. These six hospitals each recorded between 23 and 79 hospitalisations over the period. The remaining 61 hospitals each recorded between 1 and 15 hospitalisations.

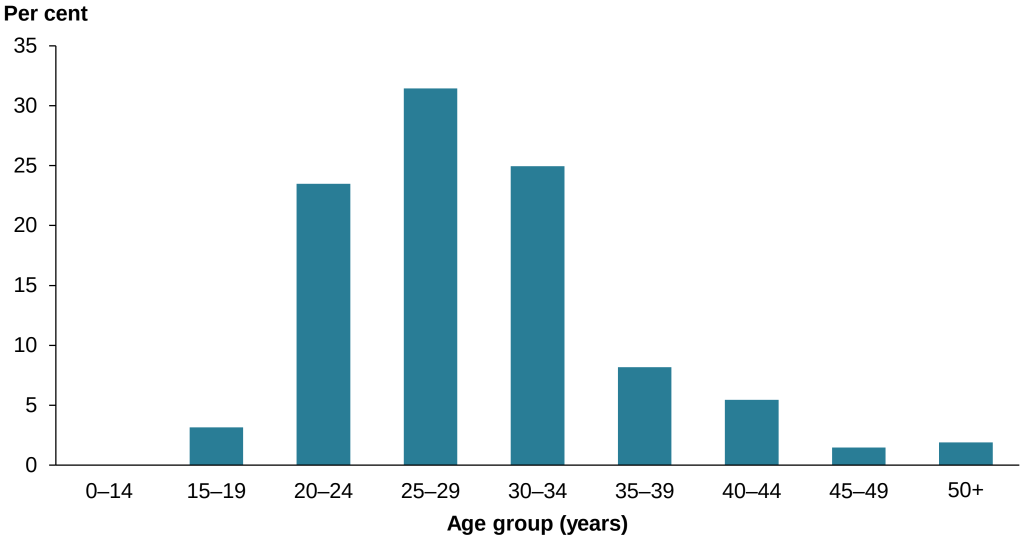
Patient demographics

In this section, the characteristics of hospitalised patients recorded as having FGM/C are described in terms of their age, country of birth, and the remoteness and socioeconomic status of where they live.

Age

From 2015–16 to 2017–18, about 80% of the hospitalisations where FGM/C was recorded were for women aged 20–34 (Figure 5.2). This relates to the predominant associated principal diagnosis of childbirth, with women in this age group making up the majority of those giving birth. There were no hospitalisations for girls aged under 15 where the FGM/C code was recorded.

Figure 5.2: Percentage of hospitalisations with FGM/C recorded by age group, 2015–16 to 2017–18



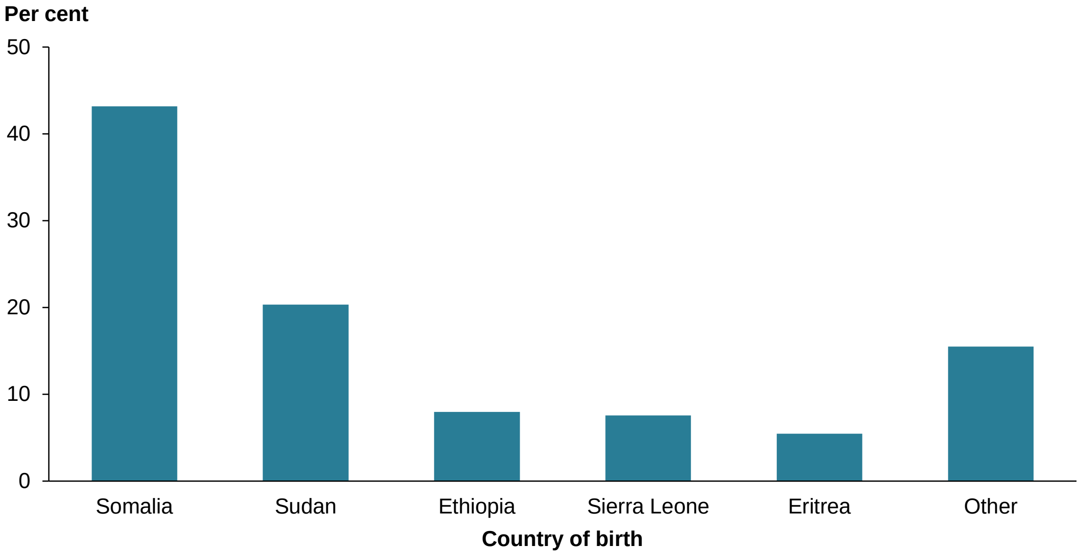
Note: Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 *Personal history of female genital mutilation*), so was considered to affect the care provided to patients during the hospitalisation.

Source: Table B1.

Country of birth

Patients with a hospitalisation in which FGM/C was recorded from 2015–16 to 2017–18 came from 25 countries. Each year, Somalian-born women accounted for over 40% of hospitalisations in which FGM/C was recorded, with Sudan being the second most common country of birth (Figure 5.3). During these three years, 9 women with a hospitalisation for which FGM/C was recorded had Australia recorded as the country of birth. It is not known to what extent this may be due to potential data quality issues with country-of-birth data in the NHMD. This may be of particular relevance where countries' names and borders change over time (for example, in 2011, South Sudan became a separate country from Sudan). It could also include women who underwent FGM/C in Australia before it was criminalised here (most states and territories drafted legislation in 1998 or soon after) (AGD 2013).

Figure 5.3: Percentage of hospitalisations in which FGM/C was recorded, by country of birth, 2015–16 to 2017–18



Notes

1. Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 Personal history of female genital mutilation), so was considered to affect the care provided to patients during the hospitalisation.
2. 'Other' includes Australia, Djibouti, Egypt, Guinea, Indonesia, Iraq, Kenya, Liberia, Malaysia, Mauritania, Nigeria, Qatar, Saudi Arabia, Senegal, South Sudan, Singapore, Sri Lanka, United Arab Emirates, and where country of birth was not stated or missing.

Source: Table B2.

Remoteness area and socioeconomic status

The majority of hospitalisations were for girls and women living in *Major cities* (91%), and 44% of hospitalisations were for girls and women living in the areas of lowest socioeconomic status.

See Appendix A for detail on methods used in analysis by remoteness area and socioeconomic status.

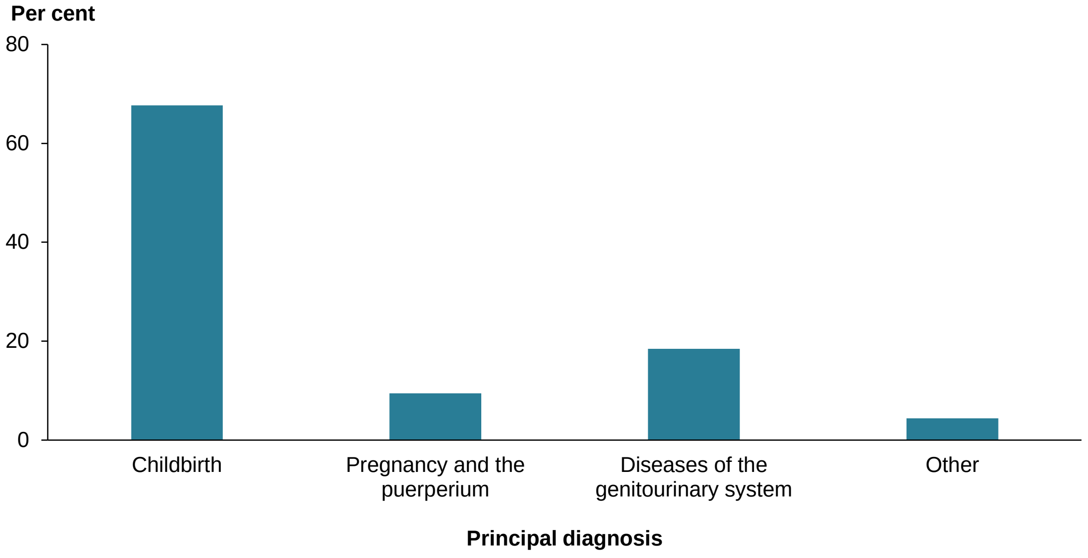
Diagnoses and procedures

This section provides analysis of the principal diagnoses recorded for hospitalised patients where FGM/C was also recorded (as an additional diagnosis), and explores the procedures or treatments that were given to them while they were hospitalised.

Principal diagnosis

The majority (368, 77%) of hospitalisations where FGM/C was recorded were for a principal diagnosis relating to *Childbirth* (defined as the delivery of at least one live or stillborn baby) or *Pregnancy and the puerperium* (the period of about six weeks following childbirth, during which a woman adjusts mentally and physically to motherhood and/or non-pregnancy life). The next most common reason for hospitalisation was for genitourinary system problems (88, 18%) (Figure 5.4).

Figure 5.4: Percentage of hospitalisations in which FGM/C was recorded, by principal diagnosis, 2015–16 to 2017–18



Notes

1. Hospitalisations where FGM/C was recorded as a diagnosis *(Z91.7 Personal history of female genital mutilation)*, so was considered to affect the care provided to patients during the hospitalisation.
2. ICD-10-AM principal diagnosis codes for the categories stated were: O80–84 (*Childbirth*), all other O codes (*Pregnancy and the puerperium*), and N00–77 for *Diseases of the genitourinary system.*

Source: Table B3.

Non-childbirth-related hospitalisations

From 2015–16 to 2017–18, 65 of the 88 records in which FM/C had been recorded with a principal diagnosis indicating genitourinary disease, were for a principal diagnosis of *Other specified non-inflammatory disorders of the vulva and perineum.* The remaining 23 recorded 17 other genital-related principal diagnoses, including vulvar cysts, abscesses and ulcers, and menstrual pain and abnormalities.

There were 21 hospitalisations for 18 other principal diagnoses not related to *Childbirth*, *Pregnancy and the puerperium* or *Diseases of the genitourinary system*.

Childbirth-related hospitalisations

From 2015–16 to 2017–18, 913,320 childbirth hospitalisations were recorded in Australia. FGM/C was recorded as a diagnosis relevant to the care provided in 331 (0.04%) of hospitalisations.

The vast majority of women born in the 30 countries known to practise FGM/C who gave birth in Australia from 2015–16 to 2017–18 did not have a diagnosis of FGM/C recorded—only 1.3% of childbirth records for women born in those countries had FGM/C recorded as a diagnosis. This may be for several reasons, which include the following: only a proportion of those women have FGM/C, FGM/C was not relevant to the care they received, or FGM/C was not identified or documented or coded.

Procedures and additional diagnoses for childbirth-related hospitalisations

Along with the principal diagnosis, additional diagnoses and procedures performed are also recorded for a hospitalisation. Procedures in the NHMD include:

- surgical (operating room) procedures, non-operating room procedures (for example, dialysis)
- procedures of a patient-support nature (for example, patient transportation)
- other interventions (for example, physiotherapy and other allied health interventions).

Additional diagnoses are for conditions or complaints that affected the patient's treatment and/or care during the episode; they may have been present on admission to hospital or arose during the hospitalisation.

International literature shows links between FGM/C and an increased risk of the following selected procedures and additional diagnoses: Caesarean sections, episiotomy, obstetric tears/lacerations, post-partum haemorrhage, and prolonged second stage of labour (see Box 1.3). Within NHMD records where the principal diagnosis was childbirth (see Appendix A for diagnosis and procedure codes used), we looked for evidence from the Australian context that supports these findings.

Caesarean sections

Caesarean section is one of the obstetric complications described in the international literature on FGM/C (for example, Banks 2006). However, for the three years 2015–16 to 2017–18, the NHMD shows lower Caesarean section rates for women where FGM/C was recorded (65 procedures; 20%) than for other women hospitalised for childbirth across all three years of data (314,708 procedures; 35%).

Caesarean section rates vary according to many factors, including orientation of the baby (for example, breech presentation), maternal age and health factors, whether the birth occurs in a private or public hospital and whether the mother has had a previous Caesarean section. The data presented here do not provide information on the extent to which (if any) FGM/C plays a role among these factors.

Other procedures and diagnoses

Table 5.1 presents data on the frequency with which selected procedures and diagnoses were recorded for non-elective Caesarean childbirth hospitalisations where FGM/C was, and was not, recorded as relevant to the care. These procedures and diagnoses relate to obstetric complications found in the international literature to be commonly associated with FGM/C (see Chapter 1). Knowing the type of FGM/C associated with each procedure or diagnosis would be valuable to better interpret these data.

Hospitalisations that involved an elective Caesarean were excluded from this analysis on the basis that women who do not go into labour are not at risk of the diagnoses and procedures related to vaginal deliveries, or to attempted vaginal deliveries that become delivery by emergency Caesarean section. The exception is the post-partum haemorrhage category, which may also occur in women who had an elective Caesarean section.

The data show consistency between years for the hospitalisations in which FGM/C was not recorded; however, the rates for the hospitalisations in which FGM/C was recorded show more volatility, likely due to the low number of hospitalisations where FGM/C is recorded. As a result, the data in this table should be interpreted with caution. They are presented here mainly to illustrate the fact that, although the NHMD may be Australia's best current systematically collected data source for FGM/C, it has notable data quality limitations in this context.

Table 5.1: Childbirth hospitalisations including selected additional diagnoses and procedures with and without FGM/C, 2015–16 to 2017–18

	FGM/C		Non-FGM/C	
Additional diagnoses and procedures	**Number**	**%**	**Number**	**%**
Episiotomy	185	61.3	136,612	18.6
Other immediate post-partum haemorrhage and Delayed and secondary postpartum haemorrhage	39	12.9	91,315	12.4
First-degree perineal laceration during delivery	38	12.6	84,913	11.5
Second-degree perineal laceration during delivery	65	21.5	184,610	25.1
Prolonged second stage of labour	18	6.0	44,412	6.0
Labour and delivery affected by abnormality of maternal pelvic organs	121	40.1	5,195	0.7
Maternal care for abnormality of vulva and perineum	73	24.2	344	<0.1
Total childbirth hospitalisations	**302**	**. .**	**735,669**	**. .**

. . not applicable

< less than

Notes

1. Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 Personal history of female genital mutilation), so was considered to affect the care provided to patients during the hospitalisation.
2. Hospitalisations including an elective Caesarean section procedures were excluded. Elective Caesarean sections were identified in records that recorded one or more of the following procedures codes: 16520-00—*Elective classical Caesarean section,* 16520-02—*Elective lower segment Caesarean section,* 16520-04—*Elective Caesarean section, not elsewhere classified.*

Vulvoplasty

Vulvoplasty is a procedure used to repair some types of FGM/C, but it is also conducted for other reasons, including for congenital or acquired anomalies and FGCS. Vulvoplasty was recorded in 33 (6.9%) records of patients with a diagnosis of FGM/C and in 3,767 (<0.1%) records where there was no diagnosis of FGM/C.

An average of 164 different principal diagnoses were associated with vulvoplasty each year from 2015–16 to 2017–18. The data show a wide variety of reasons that women without FGM/C recorded have vulvoplasty. The three most common principal diagnoses associated with vulvoplasty where FGM/C was not recorded were *Hypertrophy of vulva* (35–37% in the three years 2015–16 to 2017–18), *Other specified non-inflammatory disorders of the vulva and perineum* (9.3–11.1%), and *Other plastic surgery for unacceptable cosmetic appearance* (4.7–7.3%). Vulval hypertrophy is when one or both of the labia are larger than usual. Potential health consequences include discomfort, psychological problems and genital hygiene issues (Healthdirect 2019).

The most common principal diagnosis among women with FGM/C recorded who had vulvoplasty was *Other specified non-inflammatory disorders of vulva and perineum* (20 hospitalisations; 61%).

Limitations of the analysis

Several limitations should be considered when interpreting the analysis of hospitalisation data in this chapter and Appendix B—these limitations have to do with the counting unit, the scope of analysis, clinical diagnosis and coding, and the quality of country-of-birth data.

Counting unit

Several different counting units are used in this report. Some data are a count of procedures, some of diagnoses and some of hospitalisations. Where data are a count of hospitalisations, these are a count of hospital separations, not a count of individual patients. As a high proportion of FGM/C hospitalisations involved childbirth, it is likely that most of these episodes would be for different patients across a 12-month reference period, but it is possible that some double-counting of people has occurred across the three-year period.

Scope of analysis

The hospitalisation data in this report are for admitted patients only. Data for patients attending outpatient departments or emergency departments are not presented.

This is relevant as deinfibulation—a procedure to reverse some types of FGM/C—is generally done in outpatient departments; for example, at the nurse-led outpatient African Women's Clinic at The Royal Women's Hospital in Melbourne (RWH 2018). As most childbirth occurs in admitted hospital care, the coverage of FGM/C hospitalisations that involve childbirth is likely to be more complete.

Coding rules stipulate that diagnosis codes should reflect conditions that affected the management and care the patient received in the hospitalisation. As a result, the hospitalisation data in this report are likely to be an underestimate of all hospitalisations involving girls and women with FGM/C in the reference period. For example, if a woman with FGM/C was admitted to hospital for a heart attack, there might be no clinical reason to record the FGM/C, even if it was known.

Coding and clinical diagnosis

The quality of diagnosis coding may vary across hospitals. The diagnosis code used to identify hospitalisations in scope (Z91.7 *Personal history of female genital mutilation*) was introduced for use in hospitals from 1 July 2015. Before then, another code (Z90.7 *Acquired absence of genital organs*) was used as an additional diagnosis code if FGM/C was considered to affect patient management, and was documented in the hospital record.

The AIHW conducted a detailed analysis on the Z90.7 code in the NHMD for 2016–17 and 2017–18 and found that the likelihood of its being used for FGM/C in those years was low. This was because the age profile, country-of-birth profile, diagnoses and procedures were markedly different from those of the Z91.7 code.

Further information on the overall quality and comparability of the coded data at a state and territory level can be found in the AIHW's publications on admitted patient care for 2015–16, 2016–17 and 2017–18 (AIHW 2017, 2018b, 2019c, respectively).

The reliability and validity of clinical coding also depend on accurate clinical assessment in hospitals. Limited clinician experience and/or awareness of FGM/C might result in FGM/C being unrecognised, and so not reported in the medical record. There is evidence to suggest that only a minority of Australian paediatricians have had clinical experience with and/or education about FGM/C (Sureshkumar et al. 2016). A study of the accuracy of recording of FGM/C in Switzerland in 2010–2012 found that FGM/C was not recorded in more than one-third of medical records, despite its being present (Abdulcadir et al. 2014).

Data on types of FGM/C have not been looked at in this report, as the type of FGM/C cannot be separately identified through ICD-10-AM codes used to describe episodes of admitted hospital care. Studies reviewing hospital-based clinical databases—such as specific obstetric databases in Australia (Varol et al. 2016), England (Hodes et al. 2016) and Switzerland

(Abdulcadir et al. 2014)—have found that the accuracy of data recorded on FGM/C type is generally poor.

6 Role of data classifications and metadata

Good quality standardised data is underpinned by good quality data classification and metadata standards. This chapter outlines relevant FGM/C data classifications used in Australia and internationally, and describes METeOR, Australia’s online national metadata standards registry for health information.

ICD/ACHI/ACS classification system

Diagnosis and procedure data in the NHMD (describing all episodes of admitted patient care) are coded to ICD-10-AM and the Australian Classification of Health Interventions (ACHI), respectively. The Australian Coding Standards (ACS) is an accompanying resource that provides guidance on how to use ICD-10-AM and ACHI codes. This ensures that clinical coders use the classifications in a nationally consistent way when recording information from patients’ clinical notes in hospital databases.

Together, the ICD-10-AM, ACHI and ACS form a classification system for recording in a standardised way health conditions and interventions in Australia. All hospitals in Australia use this system to report to several national mandatory data sets, including the NHMD—Australia’s database on hospital admissions—and the National Perinatal Data Set. This classification system is also used in other clinical and research settings.

Governance

As of 1 July 2019, the body responsible for the management and ongoing development of the classification system in Australia is the Independent Hospital Pricing Authority. This classification system is a part of the WHO Family of International Classifications, and the ICD-10-AM and ACHI are based on corresponding international versions developed by the WHO. More information on the governance of the ICD-10-AM/ACHI/ACS can be found at https://www.ihpa.gov.au/what-we-do/ar-drg-classification-system.

History of FGM/C codes and standards

The classifications and coding standards are regularly reviewed and updated; there have now been 11 editions of the ICD-10-AM and ACHI. These updates can result in changes to the comparability of data (over time) recorded in the NHMD in relation to specific health conditions and interventions; this has happened in the case of FGM/C. The history of FGM/C classification codes and standards is as follows:

- 2000–01 (ICD-10-AM, 2nd edition) to 2014–15 (ICD-10-AM, 8th edition): the ACS 1435 coding standard directed coders to assign the code *Z90.7 Acquired absence of genital organ(s)* where a history of FGM/C was documented
- 2015–16 to 2016–17 (ICD-10-AM, 9th edition): coders were directed by ACS 1435 to code Z91.7 *Personal history of female genital mutilation*, following the guidance given in Box 6.1.

Box 6.1: ACS coding standard 1435 (ICD-10-AM, 9th edition)

Admission for repair of FGM

Assignment of the principal diagnosis code will be dependent on the documentation. However, N90.8 *Other specified non-inflammatory disorders of vulva and perineum* would be the preferred code when there is nonspecific information about the reason for repair. An additional diagnosis code of Z91.7 *Personal history of female genital mutilation* should also be assigned.

Code the documented procedure, for example, 35533–00 [1294] *Vulvoplasty*.

Admission for treatment of a condition/problem associated with FGM

Assign the appropriate code for the condition, for example, urinary tract infection N39.0 *Urinary tract infection, site not specified,* with an additional code of Z91.7 *Personal history of female genital mutilation*.

Pregnancy affected by FGM

Assign O34.7 *Maternal care for abnormality of vulva and* perineum and other relevant codes from ‘Chapter 15 Pregnancy, childbirth and the puerperium’ with an additional code of Z91.7 Personal history of female genital mutilation.

Note: Documentation of FGM should not be coded unless meeting the criteria above and/or meeting the criteria for additional diagnoses (see ACS 0002 *Additional diagnoses*).

- 2017–18 to 2018–19 (ICD-10-AM, 10th edition): the ACS 1435 coding standard was deleted. Education to coders was to not add additional codes to describe a disease/condition without a specific coding standard and there was no coding standard covering Z91.7. (The *Personal history* coding standard, ACS 2112, covered only codes within the Z85–Z87 range.) These changes combined may have affected the Z91.7 code being assigned.
- 2019–20 (ICD-10-AM, 11th edition): as of 1 July 2019, the ACS has once again includes a specific example (in ACS 0002) relating to the use of code Z91.7 *Personal history of female genital mutilation*. The example from ACS 0002 is provided in Box 6.2.

Box 6.2: Example 31 from ACS coding standard 0002 (ICD-10-AM, 10th edition)

A young woman was referred by her GP for deinfibulation of her vulva due to female genital mutilation (FGM) at 5 years old.

Principal diagnosis: Other specified non-inflammatory disorders of vulva and perineum

Additional diagnosis: Personal history of female genital mutilation

In this example, a code for the personal history of FGM is assigned, as it is relevant to the intervention (deinfibulation of vulva) being performed in the current episode of care.

Note: This example is provided to support the reporting of female genital mutilation (FGM) within the National Plan to Reduce Violence against Women and their Children 2010–2022.

ICD-11

The ICD-10-AM is the Australian modification of the WHO’s ICD-10 classification system. It will remain in use for several more years while Australia considers the implementation of the next generation of the International Classification of Diseases and Related Health Problems (ICD), the ICD-11. The ICD-11 was endorsed by World Health Assembly in April 2019.

As opposed to the ICD-10, which provides only one code for all types of FGM/C, the ICD-11 provides codes for the four main types of FGM/C and for sub-types within those four types:

- Type 1: Vulvar abnormality caused by partial or total removal of the clitoris and/or the prepuce (clitoridectomy)
  - Type 1a: Removal of the clitoral hood or prepuce only
  - Type 1b: Removal of the clitoris with the prepuce
  - Type 1, unspecified.
- Type 2: Vulvar abnormality caused by partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision)
  - Type 2a: Removal of the labia minora only
  - Type 2b: Partial or total removal of the clitoris and the labia minora
  - Type 2c: Partial or total removal of the clitoris, the labia minora and the labia majora
  - Type 2, unspecified.
- Type 3: Vulvar/vaginal abnormality caused by narrowing of the vaginal orifice with a covering seal, as a result of cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)
  - Type 3a: Removal and apposition of the labia minora
  - Type 3b: Removal and apposition of the labia majora
  - Type 3, unspecified.
- Type 4: All other harmful procedures to the female genitalia for non-medical purposes; for example, pricking, piercing, incising, scraping and cauterization.
- Female genital mutilation, unspecified.

Adopting the ICD-11 standards for use in Australia in the future could increase what we know about FGM/C in Australia; however, this depends on decisions made for implementation—for example, whether the full ICD-11 would be adopted and in what way, or whether an Australian modification would be implemented.

The quality of the data may also depend on other factors such as training to ensure clinicians can accurately diagnose the type of FGM/C, and that clinical coders are educated in how to interpret clinical notes using a more detailed level of coding in data systems.

SNOMED-CT

SNOMED-CT (Systematized Nomenclature of Medicine-Clinical Terms) is an international standardised clinical terminology designed for use by physicians and health-care providers to document electronic clinical health information. It is one of the major terminology solutions endorsed by the Australian Digital Health Agency for use in MHR data. It includes the codes relating to FGM/C shown in Box 6.3.

The versions of SNOMED-CT from other countries; for example, England, include codes on *Deinfibulation of vulva* and *Deinfibulation of vulva to facilitate delivery*, which are not included in the Australian version at present.

It is also worth noting that *Ritual female circumcision* is represented as a SNOMED-CT procedure, although any person recording this as a procedure in Australia would be recording a criminal offence. It could be that this code originates from a time before legislation outlawing FGM/C was enacted in Australia.

Ensuring that metadata relating to FGM/C in individual classification systems are kept updated, are specific enough to provide quality information, and can continue to be mapped across settings, between countries and to each other may be a future area for development for relevant metadata custodians.

Box 6.3: SNOMED-CT-AU codes relating to FGM/C

Condition codes for:

- Female genital mutilation
- Type 1 female genital mutilation
- Type 2 female genital mutilation
- Type 3 female genital mutilation
- Type 4 female genital mutilation

Situation code for:

- History of female genital mutilation

Procedure codes for:

- Discussion about female genital mutilation
- Provision of written information about female genital mutilation
- Ritual female circumcision

Finding (clinical observation, assessment or judgment) code for:

- At risk of female genital mutilation
- Female genital cutting

METeOR metadata

METeOR is Australia’s online repository for national metadata standards for the health, community services and housing assistance sectors (see meteor.aihw.gov.au). Managed by the AIHW, METeOR provides access to a wide range of nationally endorsed data definitions and tools for creating new definitions, based on existing components that have already been endorsed. Metadata sets are often created by a technical working group comprising members with both clinical and information management expertise and that is affiliated with a relevant national data committee.

The metadata standards recorded in METeOR are agreed for one of several purposes. They can provide information about:

- data that are agreed to be reported as part of a national minimum data set; for example, the Admitted Patient Care National Minimum Data Set, which forms the basis of data reported to the NHMD
- additional data items that are not agreed for national reporting, but can be reported on a ‘best endeavours’ basis as part of a National Best Endeavours Data Set
- data elements, or sets of elements, that may be registered in METeOR as a National Best Practice Data Set—that is, as a set of data items recommended as best practice and available to any service providers that wish to collect relevant information, and which could support the sharing of comparable data in the future.

As at June 2019, there are no current metadata standards in METeOR specifically relating to FGM/C. Opportunities to redress this are discussed in Chapter 7.

7 Future directions for improving data on FGM/C in Australia

This report shows that national information readily available on FGM/C in Australia is limited. The best source of routinely available data is that related to hospital admitted patient care. Even in that data source (the NHMD), however, the data are limited to women and girls admitted to hospital whose FGM/C had an impact on the care provided.

There are a few other service delivery data sources, although these are generally not currently available nationally, routinely and/or with sufficient specificity to provide information to understand related service use patterns. Furthermore, they offer fewer opportunities for the collection of data on national prevalence and prevention.

Although most data sources containing FGM/C information are undeveloped at a national level, some have potential to be developed into viable data sources in the future. This chapter discusses some potential ways in which FGM/C data in Australia could be improved. It draws on information presented in previous chapters, noting that the success of any FGM/C data development is likely to be associated with how well it is integrated with synchronous improvements in overcoming the general barriers and limitations to FGM/C data collection (see Chapter 4).

This approach represents an incremental approach to data improvement. Small improvements to do with available data would improve awareness of the issue among health service providers and the broader community. This, in turn, could support further efforts to improve services and further data collection.

The suggestions, although informed by consultation with stakeholders, are the views of the AIHW. Systematic consultation on the suitability, feasibility and relative priority of these suggested ways forward (with national data and other governing committees, service provider representatives, women’s and migrant health consumer representatives and others) was outside the scope of this report; however, it would be needed if any of these suggestions were pursued in the future.

Potential data set development opportunities

Improvements/further development of existing data sources

A number of data development activities on existing data sources could be pursued to improve the availability of data on women and girls who have experienced FGM/C. These data sets are outlined in Chapter 4 of this report but are summarised below for further consideration by decision makers.

Validation of FGM/C childbirth data in the NHMD

Our analysis of the NHMD data showed that about 99% of women born in 30 countries known to practise FGM/C who gave birth in Australia from 2015–16 to 2017–18 did not have a diagnosis of FGM/C recorded as a diagnosis. Further research of the robustness of the FGM/C diagnosis code in the NHMD would help to validate the NHMD as a data source for FGM/C in Australia.

Medicare Benefits Schedule data

The current claim item number relating to vulvoplasty or labioplasty (item 35533) captures cases where a female undergoes this procedure, related to either FGM/C or a congenital anomaly. Amending the item number to distinguish between these cases could be considered; this would provide better data for an FGM/C-related procedure.

Hospital outpatient clinic data

States and territories currently report on non-admitted patient care provided by public hospitals. This covers care provided in outpatient clinics, and involves reporting episode-level data for patients where available, and aggregate clinic-level information in other cases. However, the data as currently collected do not allow for identification of FGM/C, as they provide no information on the health condition for which patients are treated, nor procedures performed.

Opportunities to improve the data collected could be explored, though these may be limited where treatment is not provided through a specialist clinic, or where symptoms are not specific to FGM/C.

National Perinatal Data Collection

As noted previously, the NPDC is potentially one of the most relevant data collections for FGM/C data given that there is strong clinical relevance, and opportunities to identify cases. The development of data on FGM/C was previously considered by the National Maternity Data Development Project Advisory Group, but was not included on the final list of priority data items at that time. The committees could be asked to reconsider this in the future, perhaps as better data from other sources begin to become available, and if a clear purpose for the data could be articulated, including an understanding of how they would be used to improve the health of affected women.

Including data about FGM/C within the NPDC as a non-mandatory component could be considered in the first instance. This would provide an opportunity for reporting by those jurisdictions, or health services, that collect additional data routinely for data items not required to be reported against by all services/jurisdictions.

Condition-specific surveillance data

As well as the routine data sources already outlined, some existing data sources could potentially provide data intermittently or on an ongoing basis. These include the Australian Paediatric Surveillance Unit, which has collected information on FGM/C previously, and the Australian Maternity Outcomes Surveillance System. In both cases, funding to investigate specific research questions would be required.

Potential new data sources

As well as the existing data sources described earlier which differ in the extent to which they currently identify cases of FGM/C and provide associated information, we also identified some emerging data sets and some potential new areas for further investigation in terms of data set creation.

Emerging data sets

Emerging data linkage and integration opportunities, the development of a National Primary Health Care Data Asset and MHR will provide opportunities for enhanced FGM/C data in the future. These data sources will have limitations; however, they could provide considerable significant further information on FGM/C in Australia, as well as opportunities to understand whether services use patterns of females with FGM/C are different from those of a comparable population (for example, whether women and girls who have had FGM/C may be missing out on services such as cervical screening, and antenatal care opportunities).

These data sources should be monitored and reconsidered in the future for their relevance in providing information about women and girls who have experienced FGM/C.

Refugee health services

Some stakeholder consultations emphasised that targeted data collection was more likely to be successful than data collection that occurs in sectors where fewer affected women and girls are seen. This makes the data being collected more relevant to the service provider. Service providers are more likely to know how to conduct further discussions with patients, and to be confident in their ability to respond with appropriate care and/or referral pathways.

Our consultations identified that one area in which information about experience of FGM/C may be collected routinely is through refugee health services. In these contexts, it may be relevant to ask patients about a range of health issues and, if done routinely as part of general health screening, questions about FGM/C may be more acceptable to patients.

Currently, health services for refugees and asylum seekers are organised in different ways across different states and territories. Further consultation would be needed with relevant government agencies to understand what data are currently collected, whether this is done routinely (although our consultations indicated that this is the case in at least one area), and whether it could be captured in a way that supports routine reporting. What other data should be reported as part of a potential data set would also need to be considered, which may include broader health and welfare issues.

The major limitations would be that refugees comprise only a small proportion of the migrant intake, and not all will opt to use these specialised services for a range of reasons. Nevertheless, this area of the health sector provides the greatest potential for new data.

Feasibility of a dedicated national FGM/C data set

Based on information available and consultations undertaken for this project, it is considered that an FGM/C-specific national minimum data set on FGM/C is not currently feasible in the Australian health service context.

One of the main factors limiting the viability of such a data collection (on top of those barriers identified in Chapter 4) is the diverse nature of the health service professionals that may need to report data to the collection (who work across multiple sectors in the health system), and the different workforce arrangements that exist in Australia (including across public and private sectors). Factors such as these can affect the ability to consult with service providers who may be required to supply data, and affect the governance arrangements for such a collection. In turn, these issues can affect completeness and the quality of the data provided.

An alternative to a national minimum data set is a national best practice data set—that is, one not mandated by agreement for collection but recommended as best practice. These best practice data standards could then form the basis of a data collection—to which the contribution of data would be voluntary. Clinics already regularly collecting FGM/C data (for example, maternity units, outpatient FGM/C clinics, and refugee health clinics) may choose to contribute data to such a data set. A national best practice data set is sometimes used for piloting to gauge the feasibility of a new data set where a more formal commitment to participation by data providers is required.

If any type of national data set on FGM/C in Australia were to be pursued in the future, it would need to have a clear statement of purpose, and be positioned within a clear policy and service delivery context. The level of resources required to establish and maintain such a collection would need to be shown to be appropriate relative to potential benefits at a national level.

Suggested metadata development opportunities

Good quality metadata ensures what is being measured is clearly defined and optimised for comparability. This section discusses ways in which FGM/C metadata could be enhanced.

METeOR standards

Creating national metadata on FGM/C within the METeOR metadata registry would enable users of local, regional or state information systems to record data using nationally standard definitions and data items. This is one of the first steps in most data development initiatives, with metadata often created by a technical working group under the auspices of a data committee. Involving potential future data providers with clinical and information management system expertise in developing metadata can increase the participation rate by data providers in voluntary data collections.

There may be value and interest in firstly creating, metadata for one of the types of national data sets described above (for example, a national best practice data set). This would enable service providers across various settings already collecting FGM/C data to use the same set of core data items to support standardising the range of FGM/C data routinely collected. This would potentially enable informal data comparisons (for example, within a jurisdiction) or support reporting under more formal data collection arrangements.

Enhancing classifications standards

Classification standard systems such as the ICD-10-AM/ACHI/ACS and SNOMED-CT should continue to be updated by relevant classification system data committees in ways that make it possible for clinicians and clinical coders to accurately record FGM/C to a level of detail useful for service provision decision making. Adding the type of FGM/C to the ICD diagnosis codes may provide more detailed information on FGM/C.

Ensuring codes from different classification systems can be mapped to each other will be a task inherent in developing emerging linked and integrated data sources that will bring together data using different classification systems.

Supporting prerequisites to data development activity

Given the complex social, clinical and contextual issues around collecting FGM/C information, stakeholders were clear that there are several prerequisites to any data collection on this topic—particularly relating to education and the need for clear care pathways.

Continuing to improve education and awareness

The lack of education and awareness of FGM/C (including among health service providers and affected women and girls and their communities) can be a barrier to collecting data and to further understanding of the issue.

Qualitative studies have repeatedly found that, in many health-care settings, clinical staff are not sufficiently informed about FGM/C to accurately identify it and to provide appropriate, culturally safe treatment and support to women who need it. Stakeholders strongly echoed this view throughout the consultations. Any investments in data systems may need to be balanced with investment in education and awareness to support the provision of complete and good quality data. Hence, it is suggested that further investment in improving education/awareness of FGM/C is a prerequisite to improving the quality of FGM/C information.

Clinical care pathways

Some stakeholders also emphasised the need to ensure that there are clear clinical and referral pathways for women and girls who are identified as having FGM/C where needed. This is to ensure a coordinated approach to any health-care needs that have arisen, or may arise, in relation to FGM/C, to support health-care providers in responding to the issue, and to support good quality data collection. Clinical care guidelines relating to FGM/C do exist within some services. These may need to be made more broadly available, especially if data collection requirements resulted in greater identification of cases, or in health service contexts where the health service provider was not adequately trained in issues associated with FGM/C.

Appendix A: Additional notes on data analysis

This appendix provides a brief summary of some aspects of the analysis methods used in Chapter 5.

Analysis by remoteness

The remoteness of an area is described by the Australian Bureau of Statistics' Australian Statistical Geographical Standard, and is based on physical distance to the nearest urban centre, and its population size. Remoteness areas are *Major cities, Inner regional, Outer regional, Remote* and *Very remote*.

In this report, data were analysed by the remoteness areas: *Major cities, Inner regional, Outer regional*, and *Remote*/*Very remote*.

Analysis by socioeconomic status

Data on socioeconomic position are defined using the Australian Bureau of Statistics' Index of Relative Socio-Economic Disadvantage (IRSD).

The IRSD is one of four indexes compiled by the Australia Bureau of Statistics, using information collected in the Census of Population and Housing. It represents the socioeconomic conditions of geographic areas, by measuring aspects of disadvantage such as low income, low educational attainment, high unemployment, and jobs in relatively unskilled occupations.

Areas can be ranked by their IRSD score. The IRSD describes the population living in the 20% of areas with the greatest overall level of disadvantage as 'living in the lowest socioeconomic areas' or the 'lowest socioeconomic group'. The 20% at the other end of the scale is described as the 'living in the highest socioeconomic areas'. The IRSD reflects the average socioeconomic position of the population of an area; it does not show how individuals differ from each other. Analysis was done based on the socioeconomic status of areas defined using the IRSD.

Episodes involving childbirth

Episodes involving childbirth were identified where one or more of the following ICD-10-AM diagnosis codes or ACHI procedure codes from the 9th edition for 2015–2017 and the 10th edition for 2017–18 were recorded in a record:

- Delivery codes O080–O84
- Outcome of delivery code Z37
- Caesarean section procedure codes 1652000, 1652001, 1652002, 1652003, 1652004 and 1652005.

This definition includes deliveries that resulted in single or multiple, still or live births. For this reason, it provides a count of episodes involving childbirth, not a count of births.

More information about the NHMD can be found in the data quality statement available in the appendixes of the AIHW's admitted patient care publications for 2015–16, 2016–17 and 2017–18 (AIHW 2017, 2018b, 2019c, respectively).

Appendix B: Data tables

Table B1: Hospitalisations with FGM/C recorded(a), by age group, 2015–16 to 2017–18

	2015–16		2016–17		2017–18		Total	
Age group (years)	**Number**	**%**	**Number**	**%**	**Number**	**%**	**Number**	**%**
0–14	—	—	—	—	—	—	—	—
15–19	7	3.7	n.p.	n.p.	n.p.	n.p.	15	3.1
20–24	41	21.8	39	24.4	32	24.8	112	23.5
25–29	62	33.0	41	25.6	47	36.4	150	31.4
30–34	49	26.1	42	26.3	28	21.7	119	24.9
35–39	16	8.5	13	8.1	10	7.8	39	8.2
40–44	8	4.3	12	7.5	6	4.7	26	5.5
45–49	n.p.	n.p.	n.p.	n.p.	n.p.	n.p.	7	1.5
50 and over	n.p.	n.p.	7	4.4	n.p.	n.p.	9	1.9
Total	**188**	**100.0**	**160**	**100.0**	**129**	**100.0**	**477**	**100.0**

n.p. not published because of small numbers, confidentiality or other concerns about the quality of the data

— nil value

Note: Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 *Personal history of female genital mutilation*), so was considered to affect the care provided to patients during the hospitalisation.

Source: AIHW NHMD.

Table B2: Hospitalisations with FGM/C recorded(a), by country of birth, 2015–16 to 2017–18

	2015–16		2016–17		2017–18		Total	
Country of birth	**Number**	**%**	**Number**	**%**	**Number**	**%**	**Number**	**%(b)**
North Africa and the Middle East								
Sudan	42	22.3	35	21.9	20	15.5	97	20.3
Other, North Africa and Middle East(c)	n.p.	n.p.	7	4.4	n.p.	n.p.	13	2.7
Sub-Saharan Africa								
Somalia	83	44.1	69	43.1	54	41.9	206	43.2
Sierra Leone	16	8.5	9	5.6	11	8.5	36	7.5
Ethiopia	19	10.1	5	3.1	14	10.9	38	8.0
Eritrea	6	3.2	11	6.9	9	7.0	26	5.5
Liberia	5	2.7	n.p.	n.p.	n.p.	n.p.	11	2.3
Other, Sub-Saharan Africa(d)	5	2.7	17	10.6	7	5.4	29	6.1
Other	n.p.	n.p.	n.p.	n.p.	10	7.8	15	3.1
Unknown	n.p.	n.p.	n.p.	n.p.	—	—	6	1.3
Total(b)	**188**	**100.0**	**160**	**100.0**	**129**	**100.0**	**477**	**100.0**

n.p. not published not published because of small numbers, confidentiality or other concerns about the quality of the data

— nil value

(a) Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 Personal history of female genital mutilation), so was considered to affect the care provided to patients during the hospitalisation.

(b) Total might not equal the sum of individual cells due to rounding.

(c) Includes Egypt, Qatar, Saudi Arabia and United Arab Emirates.

(d) Includes Guinea, Kenya, Nigeria, Senegal, and Southern and Eastern Africa, not elsewhere classified.

Source: AIHW NHMD.

Table B3: Hospitalisations with FGM/C recorded(a), by principal diagnosis, 2015–16 to 2017–18

	2015–16		2016–17		2017–18		Total	
Principal diagnosis(b)	**Number**	**%**(c)	**Number**	**%**(c)	**Number**	**%**(c)	**Number**	**%**(c)
Childbirth	118	62.8	121	75.6	84	65.1	323	67.7
Pregnancy and the puerperium	21	11.2	10	6.3	14	10.9	45	9.4
Diseases of the genitourinary system	43	22.9	22	13.8	23	17.8	88	18.4
Other(d)	6	3.2	7	4.4	8	6.2	21	4.4
Total	**188**	**100.0**	**160**	**100.0**	**129**	**100.0**	**477**	**100.0**

(a) Hospitalisations are those where FGM/C was recorded as an additional diagnosis (Z91.7 *Personal history of female genital mutilation*), so was considered to affect the care provided to patients during the hospitalisation.

(b) Principal diagnosis information is grouped by ICD-10-AM chapters (broad diagnosis groups).

(c) Total might not equal the sum of individual cells due to rounding.

(d) 'Other' refers to other ICD-10-AM chapters. Hospitalisations included had a principal diagnosis in the following chapters: *Mental and behavioural disorders*; *Symptoms, signs, and abnormal clinical and laboratory findings, not elsewhere classified*; *Injury, poisoning, and certain other consequences of external causes*; *and Factors influencing health status and contact with health services*.

Source: AIHW NHMD.

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Abbreviations

ACCD	Australian Consortium for Classification Development
ACHI	Australian Classification of Health Interventions
ACS	Australian Coding Standards
AIHW	Australian Institute of Health and Welfare
AMOSS	Australasian Maternity Outcomes Surveillance System
APSU	Australian Paediatric Surveillance Unit
FGCS	female genital cosmetic surgery
FGM/C	female genital mutilation/cutting
FGMED	Female Genital Mutilation Enhanced Dataset
ICD	International Classification of Diseases and Related Health Problems
IRSD	Index of Relative Socio-Economic Disadvantage
MBS	Medicare Benefits Schedule
METeOR	Metadata Online Registry
MHR	My Health Record
NHMD	National Hospital Morbidity Database
NPDC	National Perinatal Data Collection
POLAR	Population Level Analysis and Reporting
SNOMED-CT	Systematized Nomenclature of Medicine-Clinical Terms
UTI	urinary tract infection
WHO	World Health Organization

Glossary

additional diagnosis: A condition or complaint either coexisting with the **principal diagnosis**, or arising during the episode of admitted patient care, episode of residential care, or attendance at a health-care establishment. The Australian Coding Standards for the ICD-10-AM specify that an additional diagnosis should be interpreted as conditions that affect the care provided in terms of requiring commencement, alteration, or adjustment of therapeutic treatment; diagnostic procedures; and/or increased clinical care and/or monitoring. METeOR identifier: 588981.

admitted patient: A patient who undergoes a hospital's admission process to receive treatment and/or care. This treatment and/or care is provided over a period of time, and can occur in hospital and/or in the person's home (for hospital-in-the-home patients). METeOR identifier: 268957.

Australian Classification of Health Interventions (ACHI): A classification developed by the Australian Consortium for Classification Development. The 9th edition was used for the 2015–16 and 2016–17 procedures data for **admitted patients** in Australian hospitals and the 10th edition was used for 2017–18.

deinfibulation: The practice of cutting open the sealed vaginal opening in a woman who has had type 3 female genital mutilation/cutting to allow intercourse or to facilitate childbirth.

hospitalisation: Synonymous with **separation**—that is, an episode of hospital care that starts with the formal admission process and ends with the formal separation process. An episode of care can be completed by the patient's being discharged, transferred to another hospital or care facility, or dying, or by a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute to rehabilitation).

International Classification of Diseases (ICD): The World Health Organization's internationally accepted classification of diseases and related health problems. The 10th revision, Australian modification (ICD-10-AM), is currently in use in Australian hospitals for **admitted patients**.

non-admitted patient: A patient who does not undergo a hospital's formal admission process. There are three categories of non-admitted patient: emergency department patient; outpatient; and other non-admitted patient (treated by hospital employees off the hospital site—includes community/outreach services). METeOR identifier: 268973.

outpatient: See **non-admitted patient**. METeOR identifier: 268973.

prevalence: The number or proportion (of cases, instances, and so forth) in a population at a given time.

principal diagnosis: The diagnosis established after study to be chiefly responsible for occasioning an episode of admitted patient care, an episode of residential care, or an attendance at the health-care establishment. METeOR identifier: 588987.

procedure: A clinical intervention that is surgical in nature, carries a procedural risk, carries an anaesthetic risk, requires specialised training, and/or requires special facilities or equipment available only in an acute care setting. METeOR identifier: 589101.

puerperium: The time after childbirth, lasting about 6 weeks, during which the anatomical and physiological changes brought about by pregnancy resolve, and a woman adjusts to the new or expanded responsibilities of motherhood and non-pregnancy life.

separation: An episode of care for an **admitted patient**, which can be a total hospital stay (from admission to discharge, transfer, or death), or a portion of a hospital stay beginning or ending in a change of type of care (for example, from acute care to rehabilitation).

Separation also means the process by which an admitted patient completes an episode of care, either by being discharged, dying, transferring to another hospital, or changing type of care.

separations: The total number of episodes of care for **admitted patients**, which can be total hospital stays (from admission to discharge, transfer, or death) or portions of hospital stays beginning or ending in a change of type of care (for example, from acute to rehabilitation) that cease during a reference period. METeOR identifier: 327268.

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This report discusses existing and potential data sources on female genital mutilation/cutting (FGM/C) in Australia, identifying opportunities to enhance and develop systematically collected data collections. Data from one national data source, the National Hospital Morbidity Database, are presented, showing that 477 hospitalisations with an FGM/C diagnosis were recorded from 2015–16 to 2017–18.

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