

Feasibility Study for a

National Female Genital Mutilation Data Collection

Final Report

Publication Information

Feasibility study to establish a national Female Genital Mutilation (FGM) data collection

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Contents

| | |
|---|-----------|
| EXECUTIVE SUMMARY | 5 |
| PROJECT TEAM MEMBERS | 6 |
| <i>FGM/C Project Steering Committee</i> | 6 |
| <i>Family Planning NSW FGM/C Project Team</i> | 6 |
| 1. ABOUT FAMILY PLANNING NSW | 7 |
| 2. ABOUT THE FEMALE GENITAL MUTILATION PROJECT | 8 |
| <i>Background</i> | viii |
| <i>Feasibility study to establish FGM data collection</i> | viii |
| 3. FINAL ACTIVITY REPORT | 9 |
| 4. FEASIBILITY OF A FEMALE GENITAL MUTILATION/CUTTING DATA COLLECTION | 13 |
| 4.1 <i>FGM/C data collection literature review</i> | 13 |
| 4.2 <i>FGM/C online survey report</i> | 18 |
| 4.3 <i>In-depth interviews and consultations</i> | 26 |
| 4.4 <i>Review of FGM/C data collection in Australia</i> | 31 |
| 4.5 <i>FGM data collection trial in Family Planning NSW</i> | 35 |
| 5. PROPOSED FEMALE GENITAL MUTILATION/CUTTING DATA COLLECTION IN AUSTRALIA | 38 |
| 5.1 <i>Summary of findings</i> | 38 |
| 5.2 <i>Proposed data collection on FGM/C in Australia</i> | 39 |
| 6. ESTIMATING FEMALE GENITAL MUTILATION/CUTTING PREVALENCE IN AUSTRALIA | 43 |
| 6.1 <i>Literature review</i> | 43 |
| 6.2 <i>Estimation of FGM/C prevalence in Australia</i> | 44 |
| 7. APPENDICES | 49 |
| 7.1 <i>Terms of Reference Project Steering Committee</i> | 49 |
| 7.2 <i>Terms of Reference Project Team</i> | 51 |
| 7.3 <i>Online survey form</i> | 53 |
| 7.4 <i>Perinatal National Minimum Dataset (NMDS) 2011–2012 items</i> | 63 |
| 7.5 <i>FGM/C Phrase-bank</i> | 64 |
| 7.6 <i>FGM/C Conversation Flowchart</i> | 66 |
| 7.7 <i>Health fact sheet A: Urinary tract problems</i> | 67 |
| 7.8 <i>Health fact sheet B: Sexual function issues</i> | 68 |

| | |
|--|----|
| 7.9 Health fact sheet C: Psychosocial issues | 69 |
| 7.10 Health fact sheet D: Other reproductive health issues | 71 |
| 7.11 Health fact sheet E: Obstetric issues | 73 |
| 7.12 Health fact sheet F: Menstrual disorders | 75 |
| 7.13 Health fact sheet G: Clitoral and vulval problems..... | 76 |

Executive Summary

This report represents a comprehensive summary of the **Feasibility study to establish a national Female Genital Mutilation/Cutting (FGM/C) data collection** funded by the Australian Government Department of Health under the Health System Capacity Development Fund (HSCDF) from July 2013 to December 2014. The project consisted of 2 major components:

1. Feasibility of a FGM/C national data collection, which entailed a review of existing literature on FGM/C data collection, a national online survey, in-depth interviews and consultations, and a review of existing data collections in Australia.
2. Estimating FGM/C prevalence in Australia, which involved a review of existing literature on estimating FGM/C and the application of the most appropriate method to estimate FGM/C prevalence in Australia.

Summary of recommendations

- Health professionals should undertake FGM/C continuing professional development to be more effective in communicating with women affected by FGM/C, to understand the health consequences and management of FGM/C, and to accurately collect information. Appropriately skilled and confident health professionals would substantially contribute to the collection of robust and reliable FGM/C data.
- Adequate funding should be provided to facilitate appropriate training for service providers, as well as the ongoing costs associated with a data collection system.
- Funding bodies should support the institution of mandatory collection and reporting of FGM/C data to the territories' and states' health departments. This information is relevant for government and policy makers to establish and maintain the services required to support women who are affected by, or are at risk of, FGM/C. Specifically;
 - Primary and secondary health care services should include FGM/C data collection and should be encouraged by their funders to collect information relating to FGM/C
 - Mandatory FGM/C data collection should be instituted in antenatal, gynaecological and obstetric wards in tertiary health care services
 - Tertiary health care services should provide FGM/C annual reports to their territory's or states' Ministry of Health
- Proposed data items relating to FGM/C should be collected and reported consistently across all states and territories using the same data item definitions. Data items should be registered to the Australian Institute of Health and Welfare (AIHW) Metadata Online Registry (METEoR)
- FGM/C related procedures should be delineated from current Medicare Benefits Schedule Items 35533 and 35534
- General practitioners, nurses, midwives and allied health workers should be informed about appropriate referral pathways for the variety of physical and psychological health implications of FGM/C. A network of expert health professionals, appropriately skilled in the particularities of FGM/C should be easily accessible, and adequately publicised
- The National Perinatal Minimum data set should include information on FGM/C and information should be included in the AIHW Australia's Mothers and Babies report
- FGM/C related information should be included in the domestic violence and sexual assault screening in primary health care services, which some states have implemented

Ann Brassil
Chief Executive Officer
Family Planning NSW

Project Team Members

FGM/C Project Steering Committee

Dr. Mary Stewart – Family Planning NSW Medical Education Coordinator, Chair

Anne Stuart – Family Planning NSW Director Planning, Education and International Programme

Robyn Wardle – Family Planning Northern Territory CEO

Vivienne Strong - Representative from NSW Education on FGM

Lynne Jordan/Catherine James – Representatives from Family Planning Victoria

Odette Tewfik - Representative from Family Planning Queensland

Dr. Nesrin Varol - Representative from University of Sydney

Susie Nanayakkara – Representative from Auburn Hospital

Jane Estoesta – Family Planning NSW Director Monitoring, Evaluation and Research Operations

Kathy Gerwald – Family Planning NSW Manager Education

Pippa Markham – Family Planning NSW Project Officer Evaluation – Research, Monitoring and Evaluation

Amy Zhong – Family Planning NSW Project Data Officer – Research, Monitoring and Evaluation

Family Planning NSW FGM/C Project Team

Jane Estoesta – Director Monitoring, Evaluation and Research Operations, Chair

Anne Stuart – Director Planning, Education and International Programs

Dr. Mary Stewart – Medical Director

Pippa Markham – Project Officer Evaluation – Research, Monitoring and Evaluation

Amy Zhong – Project Data Officer – Research, Monitoring and Evaluation

Kevin McGeechan – Statistician

Kathy Gerwald – Manager Education

Michelle Wicky – Project Officer – Education and Training

1. About Family Planning NSW

Family Planning NSW is the leading provider of reproductive and sexual health services in NSW. We are experts in the areas of contraception, pregnancy options, sexually transmissible infections (STIs), sexuality and sexual function, menstruation, menopause, common gynaecological and vaginal problems, cervical cancer screening, breast awareness and men's health.

We have five fixed clinics in NSW (Ashfield, Fairfield, Penrith, Newcastle and Dubbo) and use innovative partnerships to deliver services in other key locations across the state with more than 28,000 client visits annually. We also provide Family Planning NSW Talkline 1300 658 886, a confidential telephone and email information and referral service, connecting our expertise to people and communities across NSW.

We provide information and health promotion activities, as well as education and training for doctors, nurses, teachers and other health, education and welfare professionals.

As an independent, not-for-profit organisation, we recognise that every body in every family should have access to high quality clinical services and information, and we provide a safe place for people to talk about their most intimate and personal issues.

Our services are targeted to communities, including people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander backgrounds, refugees, people with disability, young people, people from rural and remote communities and lesbian, gay, bisexual, transsexual and intersex (LGBTI) people.

We respect the rights of our clients to make choices about their reproductive and sexual health and we treat each and every person with respect, dignity and understanding.

2. About the Female Genital Mutilation Project

Background

In April 2013, Family Planning NSW was invited by the Australian Government Department of Health and Ageing to submit a proposal to support action on Female Genital Mutilation (FGM) under the Health System Capacity Development Fund (HSCDF). The aims of the proposal were to undertake awareness raising, education and training, and/or evidence building activities in relation to FGM.

Family Planning NSW submitted two FGM project proposals in May 2013:

1. Scoping and development of a FGM continuing professional development program for doctors, nurses, and other related service providers
2. Feasibility study to establish a national FGM data collection

Family Planning NSW was successful in the two grant submissions. In July 2013, the Commonwealth represented by the Department of Health and Ageing commissioned Family Planning NSW to implement the two FGM projects.

This report covers the “Feasibility study to establish a national FGM data collection” project.

Feasibility study to establish FGM data collection

There is no national information or reporting on the number of women who have experienced FGM in Australia or the psychosocial, health or workforce impact for these women and their families. This precludes an understanding of localities where the prevalence of FGM may be concentrated. Such information is essential for community engagement, policy development, health system planning for primary prevention of FGM and the management and support of women living with FGM.

The feasibility study included the following components:

- a) Establishment of a steering committee, with appropriate representation
- b) Gaining ethics approval if required
- c) Consultation with stakeholders including community based and cultural organisations, non-government organisations, government departments and professional organisations involved in care and education regarding the potential scope, existing data and key information needed to monitor FGM
- d) Review of existing data collections and international best practice for monitoring FGM
- e) Estimate of FGM prevalence in Australia
- f) Development of a draft FGM data collection tool and pilot in Family Planning clinics
- g) Assessment and report on research and pilot findings

The project is funded from July 2013 through to December 2014.

3. Final Activity Report

| Report Details | | | |
|---------------------|--|-----------|------------------------|
| Flexible Fund Name: | Health System Capacity Development Fund | | |
| Organisation Name: | Family Planning NSW | | |
| Activity Name: | Feasibility Study For a National Female Genital Mutilation Data Collection | | |
| Duration: | From Date: | July 2013 | To Date: December 2014 |

| Project Summary |
|--|
| Please insert the Activity details from the Agreement into the space below. This should include the aim, objectives and methodology of the Activity, as well as the target group if applicable |
| <p>Aim: To trial the feasibility of a national FGM data collection system and estimate the prevalence of FGM in Australia.</p> <p>Activities:</p> <ul style="list-style-type: none"> • Establish a steering committee, with appropriate representation • Gain ethics approval, if required • Consult with relevant stakeholders, including in regard to existing data and the potential scope of a national data collection • Review existing data collections and international best practice for monitoring FGM • Estimate FGM prevalence in Australia • Develop a draft FGM data collection tool and pilot in Family Planning clinics • Assess and report on research and pilot findings • Report on the project, as specified at E: Reporting, including: <ul style="list-style-type: none"> - Details of the methodology used in delivering the project - Evidence of consultations with relevant organisations and stakeholders. - Evidence of successful delivery of project |

| Overall Project Outcomes |
|---|
| What has the activity achieved and how has this contributed to the stated objectives? |
| <p>Activity 1: <i>Establish a steering committee, with appropriate representation.</i></p> <p>A Steering Committee and an internal Family Planning NSW Project Team were established to oversee the planning and implementation of the project (see Appendices 1 and 2 - Terms of Reference). The Steering Committee reports to the Family Planning NSW Chief Executive Officer (CEO) and the Executive team.</p> <p>The Steering Committee is comprised of a diverse range of knowledgeable individuals with extensive professional experience in the area of Female Genital Mutilation, provision of women's health services and FGM data collection. The Steering Committee convened quarterly.</p> <p>Membership of the Steering Committee:</p> <ul style="list-style-type: none"> - Director Monitoring, Evaluation and Research Operations, Family Planning NSW - Education Manager, Family Planning NSW - CEO, Family Planning Victoria - Two Project Officers , Family Planning NSW - Clinical Nurse Specialist, Auburn Hospital - Medical Education Coordinator , Family Planning NSW |

- Manager, NSW Education Program on FGM
- Director Planning, Education and International Program, Family Planning NSW
- Project Coordinator, Multicultural Women's Health (FGM), Family Planning Queensland
- Clinical Senior Lecturer, University of Sydney and Gynaecologist and Laparoscopic Surgeon Royal Prince Alfred Hospital, Sydney
- CEO, Family Planning Northern Territory

The Project Team established to oversee the project is comprised of key Family Planning NSW staff members. This team met monthly to review project progress.

Membership of the Project Team:

- Director Clinical Services/Medical Director
- Director Monitoring, Evaluation and Research Operations
- Education Manager
- Two Projects Officers
- Medical Education Coordinator
- Medical Officer Education
- Statistician
- Director Planning, Education and International Program
- Nurse Education Coordinator

A Project Officer was appointed to oversee the survey of FGM data collection occurring among doctors, nurses and other service providers; conduct a desk review of international best practice on FGM; estimate FGM prevalence in Australia and write reports.

Activity 2: *Gain ethics approval, if required.*

Ethics approval was sought through a number of Human Research Ethics Committees (HRECs) nationally, for both the online surveys and semi-structured in-depth face to face and telephone interviews.

Submissions were made to:

- Family Planning NSW HREC in line with organisational protocol
- South Eastern Sydney Local Health District (SESLHD) HREC as lead HREC in order to gain access to hospitals
- Additionally, a number of Site Specific Applications were sought after SESLHD HREC approval was granted, including Western Sydney Local Health District (WSLHD) and South Western Sydney Local Health District (SWSLHD), in line with service known to be accessed by women who have had FGM
- Northern Territory Department of Health and Families as well as Menzies School of Health Research in order to interview clinicians who work in public hospitals
- Additional approval was sought through Research Governance Officers at sites in other states, and a number of information briefings were provided in order to gain access to these sites

Activity 3: *Consult with relevant stakeholders, including in regard to existing data and the potential scope of a national data collection.*

Consultations with relevant stakeholders were carried out in various ways:

- i. Collaboration with organisations who are/were involved in existing FGM projects such as Family Planning Victoria; NSW Education Program on FGM, Auburn Hospital; University of Sydney; University of Sydney Technology (UTS); Royal Women's Hospital; Melbourne University; Australian Colleges of Nursing and Midwives, Multicultural Centre for Women's Health; Family Planning Queensland and Family Planning Northern Territory. Five partners were invited to be a member of the Project Steering Committee. Other partners shared their FGM resources, literature reviews and outcome of their FGM projects. Partners also contributed to the success of the national online FGM survey by identifying stakeholders who could potentially complete the online survey.

- ii. Design, launch and analysis of a national survey on Feasibility of FGM/C national data collection. Respondents were asked questions about their experience with clients/patients who have had FGM/C; previous training about FGM/C; current FGM/C data collection and views about FGM/C data collection. Two hundred and thirty two responses were received, with representation from all States and Territories, and from the three professional target streams: doctors, nurses and other service providers. (See Section 4.2 – Survey report).
- iii. Completion of 31 semi-structured in-depth interviews exploring health workers' experience with clients/patients who have FGM/C, and their views regarding FGM data collection. We achieved near equal representation of the three professional target streams: doctors, nurses and other service providers. All interviews were transcribed, analysed and synthesised into key recommendations to guide the development of a FGM/C data collection tool (see Section 4.3 – In-depth interviews report).
- iv. Consultations with representatives from African communities living in NSW, Directors of Refugee Centres, clinicians from NSW, Melbourne, Western Australia, Queensland, Victoria and ACT to assess existing data collection and potential scope of a national data collection.
- v. Consultations with relevant experts residing overseas including a Belgian based demographer, a statistician working in South Africa, a FGM/C researcher based in the United States of America (USA), and a number of authors of relevant journal articles. These stakeholders were contacted to understand methodologies used to estimate FGM/C prevalence in their countries.
- vi. Attendance at FGM/C presentations and workshops in Sydney to establish networks and to become aware of FGM/C activities within Australia.
- vii. Attendance at the Public Health Association Conference in Melbourne in November 2014 to share findings of the project and to meet partners face to face.

Activity 4: *Review existing data collections and international best practice for monitoring FGM.*

- i. Literature review of relevant journal articles and reports related to FGM/C data collection (See Section 4.1 – Literature Review of Data Collection report).
- ii. Desk review of existing FGM/C data collection in Australia (See Section 4.4 – FGM/C Review of existing data collection in Australia report).

Activity 5: *Estimate FGM prevalence in Australia*

- i. Literature review of relevant articles and reports related to FGM/C prevalence.
- ii. Teleconference meeting with an obstetrician & gynaecologist at Royal Women's Hospital in Melbourne to verify whether FGM prevalence work has been conducted there.
- iii. Teleconference meetings with a demographer in Belgium, a statistician in South Africa, a FGM/C researcher from the USA and email correspondence to authors of journal articles to discuss methodologies and data used in estimating FGM/C prevalence in their countries.
- iv. FGM/C prevalence in Australia estimated based on Australian Bureau of Statistics (ABS) census and birth data and the World Health Organisation (WHO) FGM/C prevalence in countries with high FGM/C (See Section 5 – FGM/C prevalence in Australia report).

Activity 6: *Develop a draft FGM/C data collection tool and pilot in Family Planning clinics.*

The feasibility of FGM/C data collection was trialled in all Family Planning NSW clinics from November 2013 to date (See Section 4.5 – Family Planning NSW FGM data collection trial report and Section 5 Proposal for FGM/C data collection).

Activity 7: Assess and report on research and pilot findings.

- Report on the project, as specified at E: Reporting, including:
 - o Details of the methodology used in delivering the project
 - o Evidence of consultations with relevant organisations and stakeholders.
 - o Evidence of successful delivery of project

All activities stipulated in the grant agreement have been completed and all outcomes achieved. Proposed national data collection and summary of recommendations are presented in Section 5. Support for these recommendations is crucial to the achievement of a national FGM/C data collection in Australia. Family Planning NSW seeks endorsement and funding from the Australian Government Department of Health to achieve a national data collection in Australia to assist women who have, or at risk of, FGM/C.

FGM/C data collection is now incorporated within the Family Planning NSW routine data collection. Family Planning NSW is also managing the “Development of a nationally consistent data collection on Family Planning Organisation (FPO) Services” and FGM/C data items are being considered and will be informed by the results of this trial.

What were the most successful aspects of the Activity?

Building a national FGM/C informal network, through engagement with stakeholders in the in-depth interviews and the sharing of resources.

The data collection through both the survey and semi-structured, in depth interviews was successful across all states and territories, as well as the three professional streams of doctors, nurses and other service providers. This could be attributed to the efforts of the Project Steering Committee members, stakeholders and Family Planning Organisations’ Chief Executive Officers in promoting engagement and participation across a broad spectrum of health workers.

Collaboration with Ms Susie Nanayakkara, a Clinical Nurse Specialist at Auburn Hospital, and her inclusion on the Steering Committee / advisory group was very useful as she has extensive experience as an educator at Auburn Hospital antenatal clinic and considerable expertise in FGM data collection.

Based on the findings of the FGM/C data collection trial in Family Planning NSW clinics, FGM/C data collection is not possible where clinicians lack knowledge and understanding of FGM/C. Family Planning NSW was also funded by the Australian Government Department of Health for a project to “Scope and develop a FGM continuing professional development program (CPD) for doctors, nurses, and other related service providers”. The FGM CPD trial was delivered to relevant Family Planning NSW staff to raise awareness and understanding on FGM/C issues and appropriate referral pathways. After attending the FGM CPD trial, clinicians felt more confident in discussing FGM/C issues with clients and confirmed their confidence in collecting information relating to FGM/C.

What challenges to achieving the Activity, if any, objectives did you encounter and how did you address them?

There is currently a lack of data on the prevalence of FGM/C in Australia and little information on the impact of FGM/C on the lives of women living in Australia. FGM/C prevalence was estimated using data from the ABS.

Obtaining ethical approval across multiple sites, states and territories, and from a variety of Human Research Ethics Committees delayed the commencement of the data collection needs assessment, including the survey and interviews. Given the limited time frame, this proved challenging. Staff were only interviewed where Site Specific Agreement approval was obtained.

What did the Activity fail to achieve, and why?

All the intended milestones of the project were fulfilled.

Please describe any differences between the Implementation of the Activity and the approach detailed in the Agreement, and provide reasons for these differences.

Ethical approval for data collection took longer than originally estimated, and the provided Implementation Plan reflects the adjusted schedule. All activities have been on schedule subsequently.

4. Feasibility of a Female Genital Mutilation/Cutting Data Collection

With increasing numbers of girls and women immigrating to Australia from countries which practice female genital mutilation or circumcision (FGM/C), health services and service providers require adequate information to address the psychosocial and medical needs of women who have experienced or are at risk of FGM/C. While some in house data collections exist in services scattered across the country, currently there is no consistent, national data collection, which in turn means a lack of clarity on the prevalence of FGM/C, as well as the needs of girls and women affected by FGM/C in Australia.

FGM/C has received increased attention in the media in recent years, leading to greater awareness of this cultural practice. FGM/C occurs across many cultures for various reasons, with the current literature offering very little support for the many reasons why FGM/C is conducted. In fact, the current literature indicates that FGM/C is in numerous ways harmful for females^{1, 3-5, 7-8, 11-13}. Additionally, studies show that the incidence of FGM/C can be correlated to the education level of the parents^{4, 6, 9, 11} and area of residence within a high prevalence country^{10, 11}.

The aim of the current study was to assess the feasibility of FGM/C data collection in Australia. The establishment of a robust and nationally consistent FGM/C data collection system will be a useful addition to our field of health and medical research, allowing researchers a better understanding of the prevalence of FGM/C in Australia and enabling policy makers, service planners and clinicians to assess implications for health service delivery.

4.1 FGM/C data collection literature review

Background

This section summarises the outcomes of the review of literature on FGM/C. The purpose of this review was to determine whether there were any FGM/C data collections in Australia and internationally, and if so, what methods had been employed to collect the data. The literature review also identified individual authors that were later contacted regarding FGM/C data collection.

Literature search method

In order to scope the feasibility of establishing a FGM/C data collection, a literature search to identify any existing FGM/C data collection in other countries was conducted. The search revealed a lack of published peer reviewed FGM/C literature and policy papers from an Australian perspective. However, much of the literature concerning the collection of FGM/C data from within FGM/C affected countries can be translated to an Australian setting, as the prevalence of FGM/C in Australia is related to patterns of immigration. FGM/C is now evident globally, and not limited to the 29 high prevalence countries identified by The United Nations Children's Fund (UNICEF) and World Health Organisation (WHO)¹⁵⁻¹⁶.

PubMed was selected as the primary search database as it is the most up to date literature search database and includes citations from both Medline and Scopus. The following search terms were used: 'FGM' 'FGM/C', 'female genital mutilation', 'female genital cutting', and 'data collection'. The terms were used on their own and in a variety of combinations using the Boolean operators AND and OR to maximise our search results.

A five year custom date range was chosen for our search to net a current and up to date picture of FGM/C globally and in Australia. The search for literature was conducted between January 2008 and December 2013.

A preliminary search without filters was conducted to gauge the scope of existing literature. The preliminary search netted 320 articles. A review of the abstracts found many identified articles were outside of the five year custom date range.

Additional filters were employed to further refine the search, which reduced the number of articles for review to 161. Other filters used included: 'English only articles' and 'human subjects only'. The filter 'English only' was applied to the search, but as FGM/C is largely occurring in non-English countries, the exclusion on the basis of English only results may have limited the parameters of the search.

These articles were reviewed by a single reviewer to prevent any discrepancies in culling of articles. Of the 161 articles, 13 papers were found to be suitable for in-depth review. All others were excluded on the basis of lack of relevance to the topic at hand. Exclusion criteria included publications on FGM/C and human rights, medical consequences, religion and the law.

Findings

The articles that were culled for review had a common theme of collection of FGM/C data in high prevalence countries using various methods. Methods of collection included using national data collections such as the Demographic Health Survey (DHS) and Multiple Indicator Cluster Survey (MICS) question modules^{1,3,6-7,9,13}, physical examinations^{5,12}, focus groups, in-depth interviews^{4,8} and pre-tested surveys¹⁰⁻¹¹. These articles highlighted factors that influence the decision for a child or woman to undergo FGM/C, for example, FGM/C was found to be highly correlated with a lack of education^{4,6,9,11}. Additionally, the review of literature also highlighted the work that needs to be done to facilitate data collection, for example, forming education groups within high prevalence communities to better educate the women in those communities¹¹.

Of the 13 articles reviewed, six relied solely on the DHS/MICS reported data^{1,3,6-7,9,13}, one used multiple data sources⁵, two used focus groups or in-depth interviews^{4,8}; two crosschecked reporting of FGM/C with physical examination^{5,12}; one used a pre-tested school based survey, and the remaining study used a social media based survey^{2,10,11}.

Dubourg (2011) used DHS survey data, immigration data and birth register data from the Federal Directorate General for Statistics and Economic Information (DGSIE) in her study. The study also took into account asylum seekers using data from the Federal Agency for the Reception of Asylum Seekers (Fedasil)⁷.

Yoder (2013) used DHS survey data to estimate FGM/C prevalence of 28 high prevalence countries. Studies by Al-Khulaidi (2013), Rahlenbeck (2010), Dalal (2010) and Afifi (2010) also solely relied on DHS survey data for their analyses^{1,3,6,9,13}. The studies found that attitudes towards FGM/C were changing amongst the elder generation^{3,4,6,8}, and a decline in FGM/C could be seen within the younger age groups⁹. Dalal (2010) noted that women who resided in urban areas and had post-secondary education were more likely to support the discontinuation of FGM/C. Afifi (2010) studied ever-married women and found those who were already married had less inclination to support the discontinuation of FGM/C, even though they were aware of FGM/C's health complications¹.

Bjalkander (2013) also used DHS data but applied physical examinations to cross-check the presence of FGM/C in the reported cases, allowing for verification of the data collection process, creating a more robust study design⁵. Yasin (2013) also conducted physical examinations of the study participants, but used a structured, interviewer-administered questionnaire in place of population level self-administered questionnaire. The use of an interviewer-administered questionnaire may increase the reliability of the results compared to self-reported data from DHS¹².

Tamire (2013) used a cross sectional quantitative survey method to gauge the FGM/C prevalence in Southern Ethiopia. The survey was self-administered to a small sample in the Hadiya zone of Southern Ethiopia. The study found that while FGM/C prevalence was high in the region, not many supported the practice and the odds of being cut was higher (2.04 & 1.84 respectively) if the parents had completed less than secondary school level education¹¹. Shaer (2013) also used surveys to investigate the prevalence of FGM/C amongst internet users in the Middle East. The survey utilised, The Global Online Sexuality Survey, was distributed through paid advertising over social media networks, and results indicated that FGM/C was significantly higher in rural regions than in urban residences (78.7% and 47.4% respectively). Whilst the reach is infinite using the internet, there is an increased chance of bias and errors as the survey population is skewed to those using social media¹⁰.

Alo (2010) on the other hand used focus groups and in-depth interviews to probe whether attitudes regarding FGM/C were changing in Nigeria. A random sampling design that covered six states of south west Nigeria was used. The in-depth interviews and focus groups found FGM/C to be deeply rooted in their traditional identity; even though participants knew of the associated health complications, many were not willing to support the discontinuation of this cultural practice. Amongst those that supported the discontinuation, the majority were educated, suggesting that education may improve women's status and help eradicate the practice⁴.

Johnsdotter (2009) also utilised in-depth interviews to gauge the attitudes towards FGM/C amongst the Ethiopian and Eritrean immigrants in Sweden and those in the home country. The in-depth interviews found that immigrants in Sweden were firmly rejecting all forms of FGM/C and saw no meaning in upholding the custom⁸. The use of in-depth interviews and focus groups allowed researchers to delve deeper into the issue and gain a better insight into the current situation in Nigeria.

Table 4.1 Coverage of specific FGM/C topics in DHS surveys 1989-2002

| Survey | Ever heard of FGM/C | Occurrence of FGM/C for respondent | Occurrence of FGM/C for daughter | Support for FGM/C | Why continue FGM/C | Benefits of FGM/C | Required by religion | Medical problems |
|--------------------------|---------------------|------------------------------------|----------------------------------|-------------------|--------------------|-------------------|----------------------|------------------|
| Sudan (northern) 1989-90 | | | | x | x | | | |
| Cote d'Ivoire 1994 | | x | | | | | | |
| CAR 1994-95 | | | | x | x | | | x |
| Egypt 1995 | x | x | x | x | x | | x | x |
| Eritrea 1995 | | x | x | x | x | | | x |
| Mali 1995-96 | | x | x | x | x | | | |
| Tanzania 1996 | | x | | | | | | |
| Yemen 1997 | x | x | x | x | x | | | x |
| Niger 1998 | x | x | x | x | x | | | |
| Kenya 1998 | | x | x | x | x | | | |
| Cote d'Ivoire 1998-99 | x | x | x | x | x | | | |
| Burkina Faso 1998-99 | x | x | x | x | x | | | |
| Nigeria 1999 | | x | x | x | x | | | |
| Guinea 1999 | x | x | x | x | | x | x | x |
| Egypt 2000 | x | | x | x | | x | x | x |
| Ethiopia 2000 | x | x | x | x | | | | |
| Benin 2001 | x | x | x | x | | x | x | x |
| Mali 2001 | x | x | x | x | | x | x | x |
| Mauritania 2000-01 | x | x | x | x | | x | x | x |
| Eritrea 2002 | x | x | x | x | | x | x | x |

Source: <http://dhsprogram.com/pubs/pdf/CR7/CR7.pdf>

Discussion

To assess the feasibility of FGM/C data collection in Australia, a literature review was conducted to gauge what information was currently available, and whether any publications were in an Australian setting.

As noted above, of the articles reviewed, none were Australian, although the information and data from these studies may be translatable to the Australian context. It is, however, less robust and reliable to use data from a different context and extrapolate to our setting than having a custom FGM/C data collection system appropriate to an Australian context.

Of the 13 articles reviewed, the majority relied on DHS & MICS data to gain an insight into the FGM/C situation in their respective countries^{1,3,6,9,13}. It has been noted that the sole use of self-reported surveys, especially using DHS & MICS FGM/C modules, may result in unverified conclusions because the question modules may not be sufficient in gathering enough detailed information needed to gauge the prevalence^{5,7,13}. Thus the accuracy is severely compromised as researchers cannot follow up or verify such claims.

DHS & MICS surveys are not conducted annually and questionnaires vary with different regions¹³. Thus it is important to keep in mind that each region uses a differently designed DHS questionnaire and that the questionnaires used may vary slightly between them. In several studies, the DHS data analysed was rather outdated, and in one study was dated back as far as 1994^{3,7}. These data therefore may no longer be representative of the current situation at the time of publication of the article. The inclusion and comparison to population level data such as birth registers and immigration data may perhaps give a better estimation.

FGM/C is more linked to ethnicity than to nationality, and with the influence of migration, the collection of FGM/C data may not capture the entire affected population as the majority of the studies estimate population based on nationality, meaning second generation individuals at risk of FGM/C and who are born outside of high prevalence countries may have been missed⁷.

Dubourg (2010) highlighted that studies don't generally account for asylum seekers or people who are staying in a country illegally. Dubourg noted that FGM/C is often prevalent in countries with a high number of asylum seekers, thus affecting the reliability of estimating the prevalence of FGM/C outside of high prevalent countries⁷.

The phrasing of the questions in both surveys and interviews is important in obtaining quality responses. The use of the term "cutting" may not be feasible as some women don't perceive that they have been cut, but rather that they have undergone a cultural process¹. In the DHS surveys, questions paraphrase the term "cutting" with terms such as "circumcision", "sewn closed" and "nicked"¹⁴.

As mentioned above, the questionnaires vary slightly by region, and with that, the study methods also differed, with some studies sampling the entire female population and others sampling married women only^{1,3,6,9,13}. Thus the data collected is not comparable and the results can only be used as a general indicator.

In the studies by Bjalkaner (2010) and Yasin (2010), the self-reported data was cross-checked with data derived from physical examinations. Although associated with many practical, ethical and privacy considerations that need to be addressed before data can be collected, physical examinations were found to be a reliable proxy for the self-reported data^{5,12}.

Limitations

Evident from this review, worldwide data collection of FGM/C prevalence information is broadly dependent on population based DHS/MICS data^{1,3,6,9,13}. This method of data collection is difficult to verify in terms of reliability, and it is thus preferable for researchers to employ complementary methods of data collection, such as utilising in-depth-interviews and focus groups.

FGM/C has recently drawn more interest in both academic and media spheres. It is therefore possible that additional pertinent articles may have been published in the last year and were not apparent at the time of the current literature search.

Finally, only one reviewer conducted and culled the literature, and it is possible that this may have led to subjective conclusions.

Conclusion

While FGM/C continues to gain more public attention, more funding is also needed to facilitate the increasing amount of work needed to be done in this area. The establishment of a FGM/C data collection system is essential to identifying the gaps in current information. A minimum data set should be established for the above purposes

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4.2 FGM/C online survey report

Background

This section summarises the outcome of the Training and Data Needs Analysis on FGM/C online survey. The purpose of this survey was to investigate the experiences of clinicians and other health service providers with regards to providing services for women affected by FGM/C. This survey also asked information about existing and potential FGM/C data collection from February to March 2013.

Methods

The survey included 31 questions consisting of both open and close ended questions (Appendix 7.3). Data items collected include information about the survey respondents and their experience with clients or patients who have FGM/C, attendance to FGM/C training or continuing professional development, current and potential FGM/C data collection, common presenting problems and service or treatment provided to a client related to FGM/C. The survey was piloted internally by Family Planning NSW's clinical staff prior to implementation and dissemination. Members of the FGM/C Project Steering Committee, Family Planning Organisation staff, and other relevant stakeholders were asked to nominate health practitioners within their networks to undertake the survey. An email was sent to individuals inviting them to complete and forward the survey link to relevant individuals in their networks.

Ethical approval to conduct this survey was obtained from the Family Planning NSW Human Research Ethics Committee and the South East Sydney Local Health District Human Research Ethics Committee.

In order to encourage responses and to increase engagement, participants were given the incentive to enter a lucky draw for two \$100 Family Planning NSW Bookshop vouchers.

Responses and data collected were exported to Microsoft Excel. SPSS version 19 and Microsoft Access 2010 were used to generate tables and crosstabs for a more in-depth analysis of the results.

Results

Of the 232 health professionals who completed the survey, the majority were female (Table 4.2). Half of the respondents were working in NSW (50%), with Victoria (16%) and Western Australia (12%) having the next highest response rates. A great majority (62%) worked in urban areas followed by regional (23%) and rural (7%). Respondents comprised of nurses (31%), doctors (22%), social worker/psychologist/ counsellor (16%) and midwives (9%).

Table 4.2 Profile of survey participants

| Gender | No. | % |
|---|------------|----------|
| Female | 205 | 90% |
| Male | 23 | 10% |
| Not reported | 1 | 0% |
| State/Territory | | |
| New South Wales | 116 | 50% |
| Victoria | 38 | 16% |
| Western Australia | 29 | 12% |
| Northern Territory | 13 | 6% |
| South Australia | 13 | 6% |
| Queensland | 8 | 3% |
| Australian Capital Territory | 7 | 3% |
| Tasmania | 4 | 2% |
| Not reported | 4 | 2% |
| Workplace area | | |
| Urban | 144 | 62% |
| Regional | 54 | 23% |
| Rural | 16 | 7% |
| Remote | 8 | 3% |
| Worked in more than 1 area | 8 | 3% |
| Not reported | 2 | 1% |
| Position | | |
| Nurse | 73 | 31% |
| General practitioner and specialist | 52 | 22% |
| Social worker, counsellor and psychologist | 36 | 16% |
| Midwife | 22 | 9% |
| Management , health administration, coordinator | 19 | 8% |
| Health promotion / education provider | 13 | 6% |
| Multicultural, refugee and community worker | 11 | 5% |
| Researcher, policy officer and other | 4 | 2% |
| Not reported | 2 | 1% |

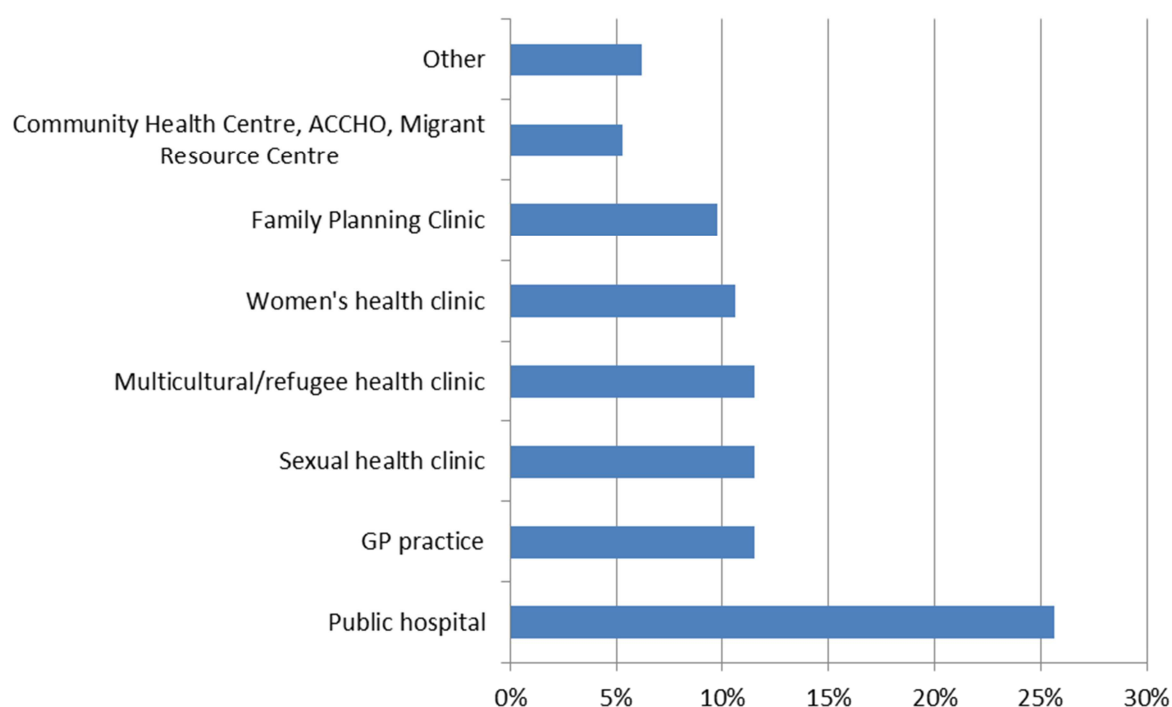
Table 4.3 Estimated number of clients who have had FGM/C in the last five years by position

| Position | 0 | 1-9 | 10-49 | 50-100 | 100+ | Total with experience | % with experience |
|--|--------------------|--------------------|--------------------|------------------|------------------|-----------------------|-------------------|
| Nurse | 32 | 27 | 5 | 3 | 1 | 36 | 32% |
| General practitioner and specialist | 25 | 20 | 5 | | 1 | 26 | 23% |
| Social worker, counsellor and psychologist | 16 | 14 | 3 | | | 17 | 15% |
| Midwife | 3 | 10 | 4 | 2 | 1 | 17 | 15% |
| Management, health administration, coordinator | 10 | 1 | 1 | 3 | | 5 | 4% |
| Health promotion / education provider | 3 | 5 | | 1 | 1 | 7 | 6% |
| Multicultural, refugee and community worker | 2 | | 3 | | | 3 | 3% |
| Researcher, policy officer and other | 2 | 1 | | | | 1 | 1% |
| Total | 93 (45%) | 78 (38%) | 21 (10%) | 9 (4%) | 4 (2%) | 112 | |

Of the 232 health professionals, 112 reported they have seen women who had FGM/C in the past five years (Table 4.3). Most of the clients were seen by nurses (32%), doctors (23%), midwives (15%) or social workers, counsellors and psychologists (15%).

Forty-five per cent of respondents stated they have not seen a client affected with FGM/C in the past five years while 55% have seen between one to 400 clients.

Figure 4.1 FGM/C clients presenting to which organisations



More than 25% of respondents who have seen women affected by FGM/C worked in public hospitals. Other health professionals worked in a general practitioner (GP) practice, sexual health clinics, multicultural/ refugee clinics, women's health clinics and family planning clinics (Figure 4.1).

Attendance at training or continuing professional development in FGM/C

Amongst our survey respondents, close to half (46%) indicated that they had received some training or continuing professional development related to FGM/C (Table 4.4).

Table 4.4 Attendance at training or continuing professional development

| | No. | % |
|--------------|-----|-----|
| Yes | 106 | 46% |
| No | 97 | 42% |
| Not reported | 29 | 13% |

Of those 106 who have attended training, 75% of them have seen FGM/C clients in the past five years.

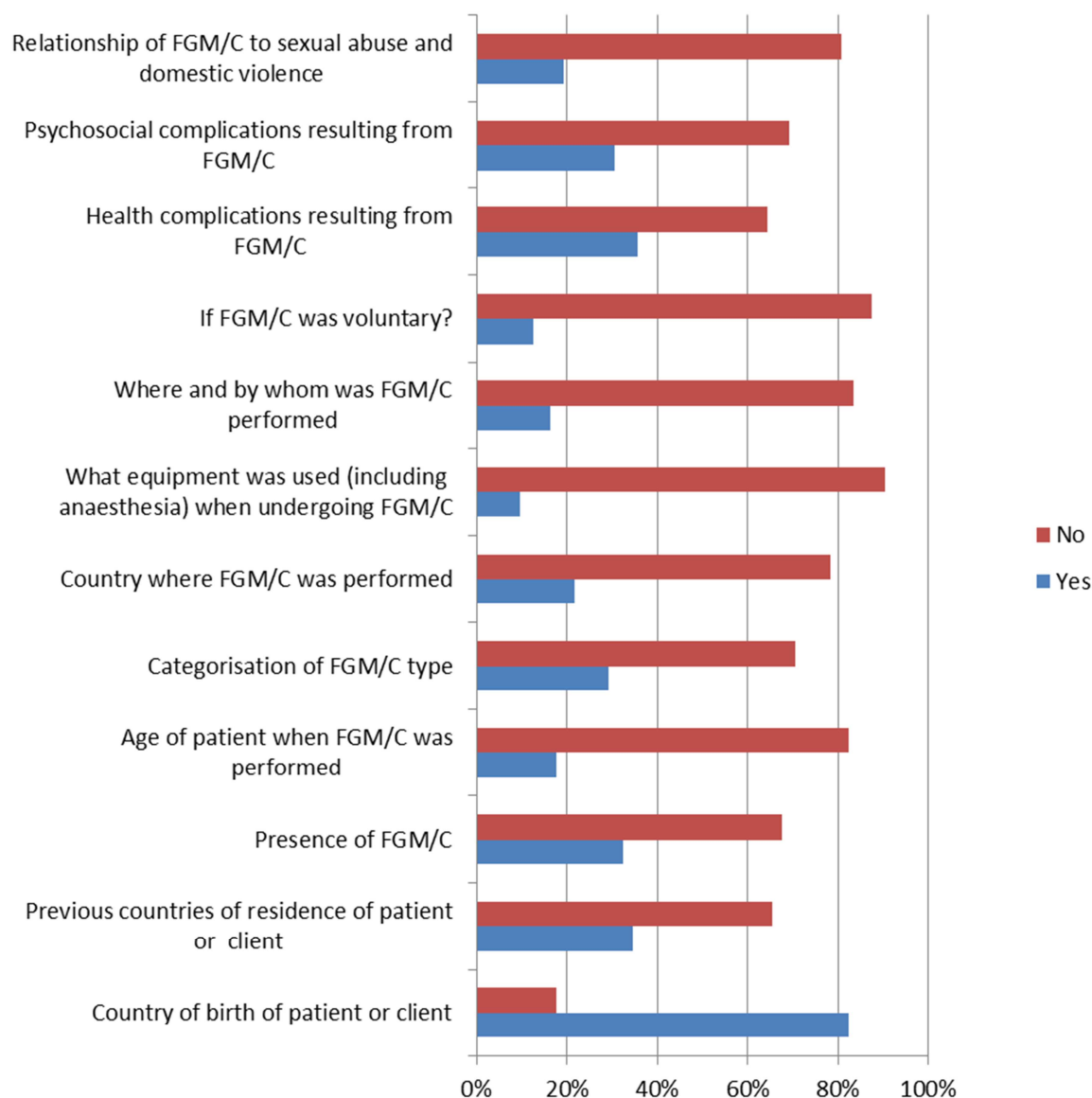
Of those 97 who indicated that they had not received any FGM related training, 68% saw FGM/C clients in the past five years.

FGM/C data collection

Current data collection

The country of birth of women is currently being collected in public hospitals/clinics and non-government organisation (Figure 4.2). Although not broadly disseminated, the in-house, custom collections of FGM/C related data do exist in public hospitals and in some clinics. This data includes presence of FGM/C, type of FGM/C, health and psychosocial complications that result from FGM/C. The data items least frequently collected include equipment used when undergoing FGM/C, if whether FGM/C was voluntary, where it occurred, and by whom.

Figure 4.2 FGM/C related data currently collected

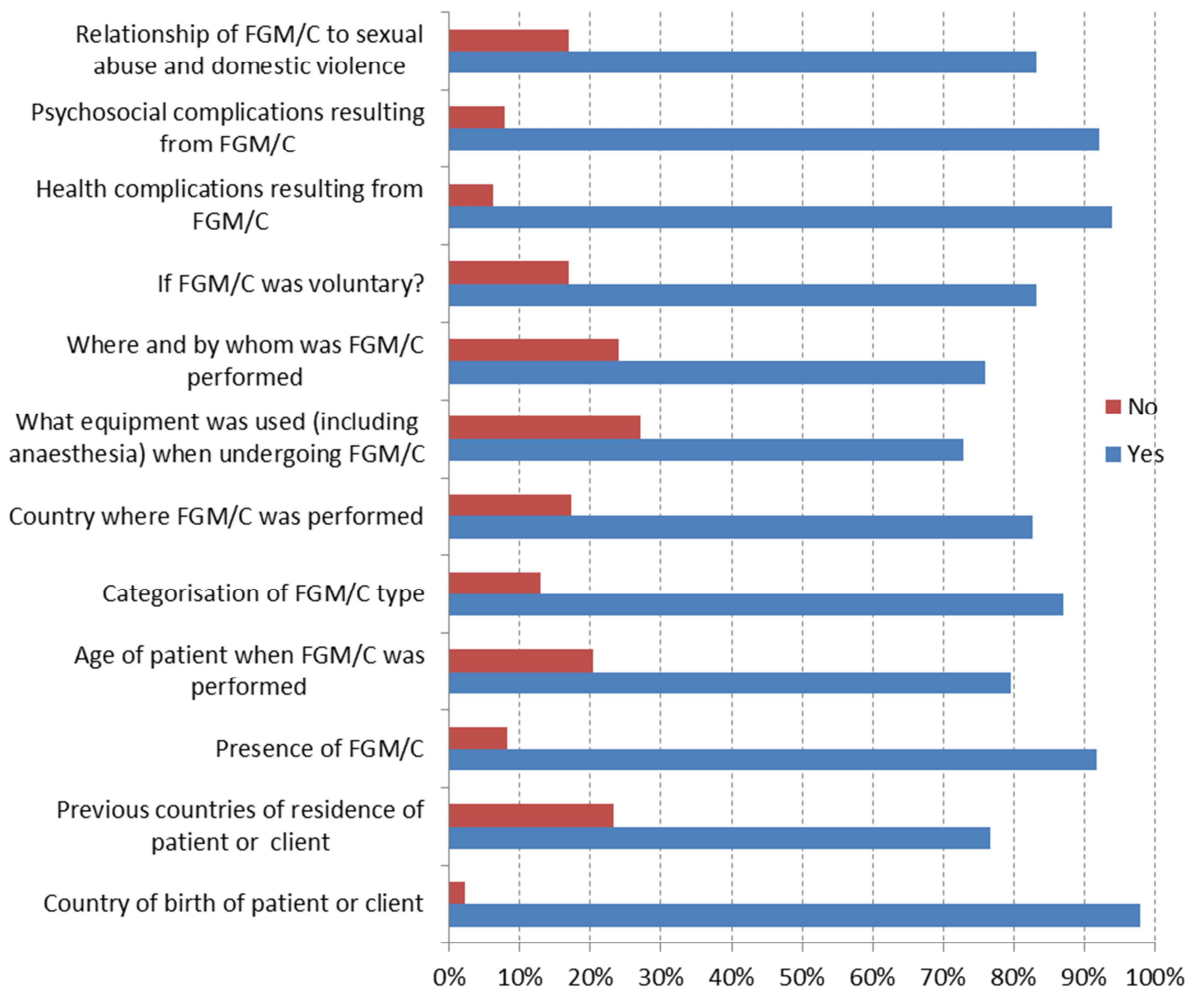


Current FGM/C data is collected as part of clinical note taking and for client clinical care. Data is not used for data reporting and quantitative data analysis. Some hospital databases have the facility to collect FGM/C related data but recording is not mandatory.

Potential FGM/C data items

Figure 4.3 shows that the majority of respondents would like to have more FGM/C data collected in the future. Almost all health practitioners agreed that the country of birth is an important data item, as with the presence of FGM/C, and psychosocial and health complications related to FGM/C. Other aspects of FGM/C such as when and where the procedure was performed and whether the procedure was voluntary were also deemed important for data collection.

Figure 4.3 Potential data to be collected



Respondents also suggested that the following FGM/C information should be discussed during consultation:

- Whether the clients have plans to continue with the cultural practice
- Knowledge of Australian laws
- Knowledge of health care services available to women especially to those from high prevalent countries
- Whether they have had gynaecological consultations and examinations
- Views on de-infibulation and/or re-infibulation after childbirth

Commonly presenting problems when first encountering a client affected by FGM/C

Respondents reported that women presented with FGM/C related health issues and complications during clinic consultations. These health issues include vulval pain, urinary tract infections, dyspareunia, birth complications (many cases are discovered at the time of birth), dysmenorrhea, post-partum complications, incontinence, psychological issues and antenatal issues.

Respondents reported that some women have difficulty initiating conversations with health practitioners due to language barriers and cultural differences. Women affected by FGM/C were also reported to be reluctant to disclose any information regarding FGM/C, especially when an interpreter or husband are present, decline pap tests and sexual health check-ups and lack knowledge about Australian laws and available health services.

Treatments or services provided to a client or patient related to FGM/C

Survey results indicate that doctors, nurses and midwives offer various services to women affected by FGM/C such as cervical cancer screening (pap tests); sexually transmissible infections (STI) checks and treatment; advice

on contraceptive use and pregnancy, FGM/C reversal or infibulation and discussion about common gynaecological issues.

Women were also referred to specialists (gynaecologists or obstetricians) for health complications associated with FGM/C; social work services and counselling in relation to stigma and impact on mental health; and antenatal clinic for antenatal support, counselling, birth planning and information regarding legislation.

Other comments regarding data collection in FGM/C

Collecting FGM/C data as part of routine health data collection gives rise to a number of issues. Respondents to the survey highlighted that, in order to collect robust data, it is imperative that service providers are well trained in sensitive and appropriate consultation techniques for communicating with FGM/C affected women.

Respondents have also noted that health practitioners should not be too intrusive or discriminatory with their tone, so that girls and women do not feel uncomfortable. To overcome this, both clients and health practitioners should be adequately prepared. They also believe that there is not enough information, resources, training and support available to them.

To record quality, reliable data for future work and policy, streamlining of FGM/C data collection as a nation is essential. Survey respondents have also noted privacy of data collection is often neglected; privacy is of paramount importance so that women who come to seek help have consented to data collection and the data collected is de-identified and is of restricted access.

Quotes from respondents:

"I would like to know practical strategies for approaching and discussing FGM with clients in my context, namely, screening interview/health assessment without ongoing therapeutic relationship with the client."

"I would like the confidence to raise the issue with women - I got some quite mixed messages in the only training I had about whether it's appropriate to talk with women about this; the idea seemed to sit between being non-judgemental but also clear about it being wrong and illegal - it has left me feeling somewhat unsure as to how and when to raise it with women."

"I would simply like to have more knowledge about this so if/when I do come across a client I know how to go about this consult in a professional and informed manner."

"Important to think about the language we use with clients. Having heard a group of refugee women saying they preferred and felt more respected by the word cutting rather than mutilation I think it is very important that we get the language right. Wrong language can shut down communication in this area. Also only women I worked with as a midwife who had experience this, would only be seen by female staff including doctors."

"Follow up counselling must be offered. No information sharing with colleagues unless in the women's best interest. Availability of picture aids for anatomy and childbirth."

"The difference between what we may like to know and what is essential to know. For example asking about the age someone was 'cut' may bring up feelings of guilt in a client, you know, as if it was their fault."

"Data collection is great but the clinical relationship remains the most important aspect and I am concerned that some of the questions may be unintentionally judgemental – e.g. did you consent, are you a victim of domestic violence or sexual assault?"

"Wouldn't want it to be too intrusive or outside relevance of service being offered."

"Really needs to be a push that all states collect this data. That this data is identified correctly and not just listed under a section which includes gynaecological procedures (this is occurring in some states)"

"Making FGM/C questions mandatory/routine when taking history."

"It would be good for a national body to develop a basic tool that could be used to collect data from all states. Basic information listed first and then other more refined information later - getting all of their information on the list above would be ambitions but worth attempting - at a National level."

“Needs to be included in systems like midwifery data obstetric data collecting, relevant hospital and community data collection systems, for example, electronic medical records, CHIME etc.”

Limitations

Our survey reach was the greatest in NSW as the majority of our contacts are based in NSW. Responses from other states were comparatively low and this could be attributed to the snowballing methodology used in the survey dissemination. This survey was distributed nationally to general practitioners in Australia using the THINKGP newsletter, which substantially increased our reach to this group.

As with any internet based survey, there is the limitation that the respondents reached are those who have access to a computer and the internet and we may have excluded those who are not accustomed to online surveys.

As was raised by a number of clinicians, and our consultations with affected communities, FGM/C is not seen as a health issue by many affected women, especially the older generations, and so some individuals are not disclosing their FGM/C experience to health practitioners.

Conclusion

It is feasible to develop a nationally consistent FGM/C data collection in Australia. Our respondents attested that FGM/C data is currently collected by a number of health professionals in a variety of locations, but that collection is *ad hoc*, and often up to an individual health professional. Some clinicians record this information in data items specifically assigned to collect FGM/C data, but most of the time information is written in clinical notes for the purpose of client clinical care rather than data reporting.

There is a critical need for health professionals to attend FGM/C continuing professional development training to be more effective in communicating to women affected by FGM/C to understand its health consequences and management, and in order to accurately collect information. Appropriate skills and confidence in this topic would contribute highly to robust and reliable FGM/C data collection.

General Practitioners, nurses, midwives and allied health workers should be informed about appropriate referral pathways for the variety of physical and psychological health implications of FGM/C. A network of expert health professionals, appropriately skilled in the particularities of FGM/C, should be easily accessible, and adequately publicised.

Finally, funding bodies should support the mandatory collection of FGM/C data collection and data reporting to territories' and states' health departments should be instituted. This information is relevant for government and policy makers to build an infrastructure to support women who are affected by, or are at risk of, FGM/C.

4.3 In-depth interviews and consultations

Background

The purpose of undertaking a broad range of in-depth interviews with health practitioners working in sexual and reproductive health was to scope what FGM/C related data are currently collected. Along with the literature review, the results from these in-depth interviews informed Family Planning NSW in determining the feasibility of a nationally consistent data collection system for FGM/C information.

Ethics

Ethical approval was obtained from the Family Planning NSW Human Research Ethics Committee (HREC) and the South Eastern Sydney Local Health District HREC. Appropriate Site Specific Agreements (SSAs) were also obtained.

Methods

A list of key health practitioners who were deemed relevant to our project was built through Family Planning NSW's existing network and through word of mouth recommendations. All participants were sent an information sheet and a consent form prior to the interview. The interviews were conducted either face to face or by telephone. A semi-structured questionnaire was developed and used as a guide for all interviews.

Interviews were recorded for transcription purposes. Once interviews were complete, files were transcribed and de-identified in line with formal ethical requirements. Transcribed interviews were thematically analysed to extract out themes and quotes from the respondents.

Several authors of papers identified through the literature review were contacted for further advice and to discuss and refine the study methodology^{8,16}. Our list of consultations also included health practitioners and researchers in the field, both across Australia and internationally.

Findings

Table 4.6 Profile of in-depth interview participants

| | |
|--|-----------|
| Number of interviews conducted | 31 |
| Total duration (minutes) | >700 mins |
| State and Territory | |
| Australian Capital Territory | 1 |
| New South Wales | 13 |
| Northern Territory | 2 |
| Queensland | 2 |
| South Australia | 2 |
| Tasmania | 1 |
| Victoria | 7 |
| Western Australia | 3 |
| Total | 31 |
| Professional role of interviewee | |
| Nurse/midwife | 11 |
| Doctor | 10 |
| Other service provider (e.g. refugee/immigrant service worker/counsellor/education provider) | 10 |
| Total | 31 |

Near equal representation between the three professional key streams of target participants was achieved (Table 4.6). The number of interviews conducted gave us a vast amount of information from a range of different viewpoints.

While a large proportion of Family Planning NSW's contacts are based in NSW, substantial effort was put into ensuring that we received views from across the country.

In-depth interviews

A national, consistent collection of FGM/C data would provide a better idea of the current FGM/C situation. As highlighted by a respondent, theoretically, FGM/C data collection should be as recordable as any other health issue such as hypertension and diabetes. However, given the sensitivities around culture, privacy and ethical considerations of examining women, there are still many barriers to FGM/C data collection^{2, 7, 11-13, 14-15}.

The in-depth interviews with health practitioners revealed details as to what data items are currently collected and a range of views on what information should and should not be collected. Additionally, barriers to data collection in the Australian health system were discussed.

Certain themes were identified from the data through thematic analysis. Some of the key points included being more vigilant about presence of FGM/C and having healthcare services tailored to individuals from high prevalence countries, the need for funding and training of staff^{5,9,14,18} and the data items that should be included in the FGM/C data collection system.

There was a general consensus that health practitioners should be more vigilant about FGM/C amongst their clients and that indirect or prompting conversations may allow the clients to divulge more information. As FGM/C has many known complications, it is important that health services are tailored to better address these specific needs.

One of the key messages that was expressed by the majority of participants was that health practitioners and community health staff need to be more proactive in their FGM/C related work. For example, researchers and staff members could approach and assess the needs of specific communities instead of waiting for women to approach health organisations for help.

Another key message from the interviews was the view that adequate funding and staff training, as well as developed and managed protocols for data collection need to be put in place in order to collect the relevant data items and to facilitate quality data^{5,9,14,17,18}.

Respondents also noted that FGM/C national data collection should extend beyond basic demographic data items, with suggested variables including, but not limited to, medical history such as FGM/C type and related complications, de-infibulation, childbirth outcomes and options, as well as sexual function. Additional items covering information such as when and where FGM/C was done, views on FGM/C and their attitude towards FGM/C were flagged for data collection.

The World Health Organisation (WHO) and United Nations Children's Fund (UNICEF) have released multi-country statistics on FGM/C, commonly referred to in estimates of prevalence. A number of interviewees reflected that these statistics should be taken with caution when looking at prevalence in Australia, as through extrapolation, the reliability of the data may be compromised^{18,19}. The figures reported internationally may not directly translate to the Australian context, as prevalence in Australian immigrant groups may be substantially demographically different from FGM/C affected groups in countries of origin. From currently available data, rural and remote areas of high prevalence countries seem to be of higher FGM/C prevalence^{2, 6, 8, 11-13, 15-16}, meaning prevalence within a country may also vary, further reinforcing the need to be cautious with national prevalence rates.

Respondents from the interviews also agreed that low prevalence in other countries and smaller cultural groups should not be overlooked, as there is evidence that FGM/C occurs in a number of countries or cultural groups that have not received substantial attention due to the relatively low prevalence compared to other groups¹⁶.

Finally, many respondents had the view that FGM/C data should be coordinated nationally to allow the collection of representative data. Some of the suggested possible points of data collection included maternity services, community health centres and hospitals.

- **Effect of culture**

Respondents noted that some women affected by FGM/C do not view the procedure as harmful, but rather as a cultural practice inherent to personal beliefs¹⁰, making it difficult to identify suspected cases of FGM/C and to develop strategies to appropriately address the needs of women affected by FGM/C. Respondents also reported that some women affected by FGM/C are relatively uninformed about the practice as well as the health and legal consequences that follow^{4, 7, 11, 13}.

Some of the views expressed that represent the issues around cultural sensitivities and strong views about FGM/C included:

“FGM/C is a cultural practice that needs to stop, it is awful” and “education into the Australian culture and the legalities is an important aspect of living in Australia”.

“Yes there’s a huge cultural component that everyone has to be aware of”

- **When and where FGM/C was carried out**

A number of participants expressed the need for data collection on where and when the procedure was undertaken in order to inform researchers about FGM/C prevalence and which age groups are most at risk. This will also inform researchers and health practitioners about the feasibility and usefulness of a robust data collection system dedicated to FGM/C.

“I think it is important to know when and where the cutting took place.”

“Many of them get cut before they are 15, data collection has to capture that”

- **Medical consequences**

Many women who have been affected by FGM/C face physical and psychological effects, some of which are life-long. These effects are frequently socially harmful for both the individual and their families^{2, 7, 9, 11, 13, 15-16, 19}.

“I’ve seen patients who have had some awful consequences of FGM/C”

“Women can have trouble giving birth, so birth outcomes data should be collected”

- **Views on FGM/C and whether it should be continued**

As the population becomes more knowledgeable and aware of FGM/C^{4, 7, 11, 13}, many women, especially those in the younger generations realise the consequences of the cultural procedure and are drifting away from the traditional views linked to FGM/C. Research has shown that many women who have undergone FGM/C would not have undergone the procedure today nor would they continue this cultural practice in future generations^{3, 4, 10}.

“It is important to know what the girls think of the procedure.”

“We should pay more attention to the younger generation as they too are at risk of FGM/C”

“We should also ask what the younger generations think of FGM/C.”

“Culturally it was very, very difficult to suggest that FGM/C shouldn’t be practiced, because it was very widespread and there was almost nothing we could do about it.”

“They need to know that there is surgery to reverse the procedure”

- **Additional items that should be part of the data collection system**

A number of suggested data items were raised in the interviews, showing how much more work needs to be done in establishing a robust FGM/C data collection system here in Australia. Forming partnerships was seen as the best approach in creating a streamlined data collection system that is nationally consistent. Data items of interest raised by respondents included a range of clinical but non-medical data, such as items on sexual function and psychosocial impacts.

“Would be good to have some sexual functions outcome data”

“Data on psychosocial outcomes would be nice”

“Perhaps we should collect some data on complications, menstruation and sexual problems as well as any emotional/ psychological impact”

“if you are looking at developing something nationally, whether there’s a way to have a specific focus on some of that clinical component in terms of managing FGM/C”

- **Settings for feasible data collection**

In addition to training and adequate funding, the settings in which data collection is collected plays a major role in determining the quality and type of data that is collected⁹. As mentioned above, many cases of FGM/C are discovered when women present for birthing or FGM/C related health consequences. Thus hospitals, such as antenatal care departments would be a feasible setting to collect such data.

“Certainly in maternity when they’re admitted, and in the birth suites, there is capacity to collect data then, but its hit and miss, it’s not accurately recorded. But certainly in the clinic that we have, she collects all that data.”

“When you don’t have that resource, I believe it’s much more difficult.”

“In hospitals, in women’s health services, in community health centres’

Limitations

Many cases of FGM/C in Australia are discovered when a woman accesses the health system for childbirth or at times where women present themselves due to health issues and complications. Therefore the cases that are recorded may not fully represent the Australian population who have undergone FGM/C.

The interview reach was far greater in NSW than in the other states. Additionally, given the current lack of coordination of FGM/C services nationally, it is possible that a number of key services and individuals working in FGM/C, with valuable insights, have not been encountered in this project.

FGM/C has only recently received broader attention in Australia, and thus many cases of women being affected by FGM/C may go unrecorded due to lack of knowledge or ability to identify or communicate about FGM/C, and with virtually no formal data collection it is currently not feasible to gauge the entire FGM/C situation in Australia.

Conclusion

Training health professionals is a pivotal part of establishing and maintaining a robust data collection system, particularly in eliciting information on sensitive topics like FGM/C^{5,9}. Staff need to be adequately trained so that they are skilled in collecting relevant data and in communicating with clients^{5,14}.

In order to facilitate proper training for staff, it is important that adequate funding is available, including the ongoing costs associated with the data collection system^{9,18}.

Establishing a robust national FGM/C data collection system is an important step in gaining a clearer picture of the extent and impacts of FGM/C in Australia. The in-depth interviews have provided valuable additional information that make FGM/C data collection feasible.

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4.4 Review of FGM/C data collection in Australia

Background

This section outlines the findings of the review of existing data standards, definitions, published reports and hospital data systems in the Australian setting. Findings of this review will assist in the assessment of the feasibility of a Female Genital Mutilation/Cutting national data collection in Australia.

Method

Published data reports and data standards from the Australian Institute of Health and Welfare (AIHW), Medicare Benefits Schedule (MBS), Australian Bureau of Statistics (ABS) and hospital data collections were reviewed to ascertain if FGM/C data collection exists in Australia.

Results

Australian Institute of Health and Welfare (AIHW) Metadata Online Registry (METeOR)

METeOR is Australia's repository for national metadata standards for health, housing and community services statistics and information.

Searching on METeOR using words such as "female genital mutilation", "female genital cutting", "genital cutting", "cutting" and "circumcision" was performed. There was only one data element related in any way to "female genital mutilation". The data element is called "Type of health or health related function". This item is defined as the type of activities or programs with a health or health related function provided by an organisation. This item is not related to client or patient data collection.

Medicare Benefits Schedule (MBS)

The MBS is a listing of Medicare services subsidised by the Australian Government. The MBS is managed by the Australian Government Department of Health (DoH) and is administered by the Department of Human Services (DHS).

An MBS online search was conducted using the words "female genital mutilation", "female genital cutting", "mutilation", "cutting" and "circumcision".

There were four items related to "circumcision" (MBS items 30653, 30656, 30659, 30660), but all related to circumcision of men. One item (MBS item 30663) relates to haemorrhage, or arrest of, following circumcision requiring general anaesthesia. MBS item 30663 is not suitable to collect FGM/C information as it is hard to ascertain if haemorrhage was due to a female or male circumcision.

While Item 35533 is used to cover the surgical repair of female genital mutilation, this item is also intended to cover major congenital anomalies of the uro-gynaecological tract which are not covered by existing MBS items, and is thus not a precise means of collecting information specific to FGM/C surgical repair.

Australian Bureau of Statistics (ABS) published reports

Review of published ABS census and health survey reports was conducted from 2001 to 2014 to assess whether FGM/C related issues were included. Australia is receiving an increasing number of migrants from countries where the practice of FGM/C is customary, however, questions relating to FGM/C data were not included in census and surveys. This is supported by the lack of information on estimated FGM/C prevalence in ABS reports.

Hospital clinical data systems

In 2005, a new database called ObsteriX was introduced in a few hospitals in NSW such as in Auburn Hospital, to replace a host of local hospital databases to track and manage detailed maternal and neo-natal information.



The ObsteriX database provides a space to record the type of FGM/C and whether the women had de-infibulation. The definition of the types of FGM/C was derived from WHO and include the following:

- Type 1 – Clitoridectomy: partial or total removal of the clitoris (a small, sensitive and erectile part of the female genitals) and, in very rare cases, only the prepuce (the fold of skin surrounding the clitoris)
- Type 2 – Excision: partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (the labia are "the lips" that surround the vagina)
- Type 3 – Infibulation: narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the inner, or outer, labia, with or without removal of the clitoris
- Type 4 – Other: all other harmful procedures to the female genitalia for non-medical purposes, e.g. pricking, piercing, incising, scraping and cauterising the genital area

Types 1 and 2 are classified as "Minor Grade" and Types 3 and 4 as "Major Grade".

Data collection is not mandatory, however, which leads to underreporting of FGM/C.

Some doctors and nurses who have had FGM/C training are recording FGM/C related information in patient's medical notes. Medical notes are encrypted to ensure confidentiality of information. Data managers are unable to extract data due to data encryption. Clients who have had FGM/C can only be identified during clinical audits.

Other hospitals in Australia use a variety of clinical data systems, but in-depth staff interviews were not conducted due to lack of Ethics Committee - Site Specific Agreement approvals in the short time frame of the project. It is inferred that, like the other hospitals interviewed, items relating to or amenable to collection of FGM/C information are available in their clinical data systems, but collection is not mandatory

Australian Institute Health of Welfare (AIHW) Australia's Mothers and Babies reports

A review of AIHW Australia's Mothers and Babies reports was carried out to determine whether there is any information relating to FGM/C. The AIHW Perinatal National Minimum Data Set collects mother's country of birth, aboriginality, smoking status and other relevant information but data relating to FGM/C is not collected.

Data for the AIHW Mothers and Babies reports are extracted from states and territories' hospitals obstetrics databases. While information about FGM/C may be available in some hospitals, data collection is very poor and the information is not reliable.

Family Planning NSW Training and Data Needs Analysis on Female Genital Mutilation/Cutting (FGM/C), February 2014

In February 2014, Family Planning NSW administered a national online survey relating to "Training and Data Needs Analysis on Female Genital Mutilation/Cutting (FGM/C)". A total of 232 responses were received, with representation from all states and territories, and from the three professional target streams: nurses, doctors and other service providers.

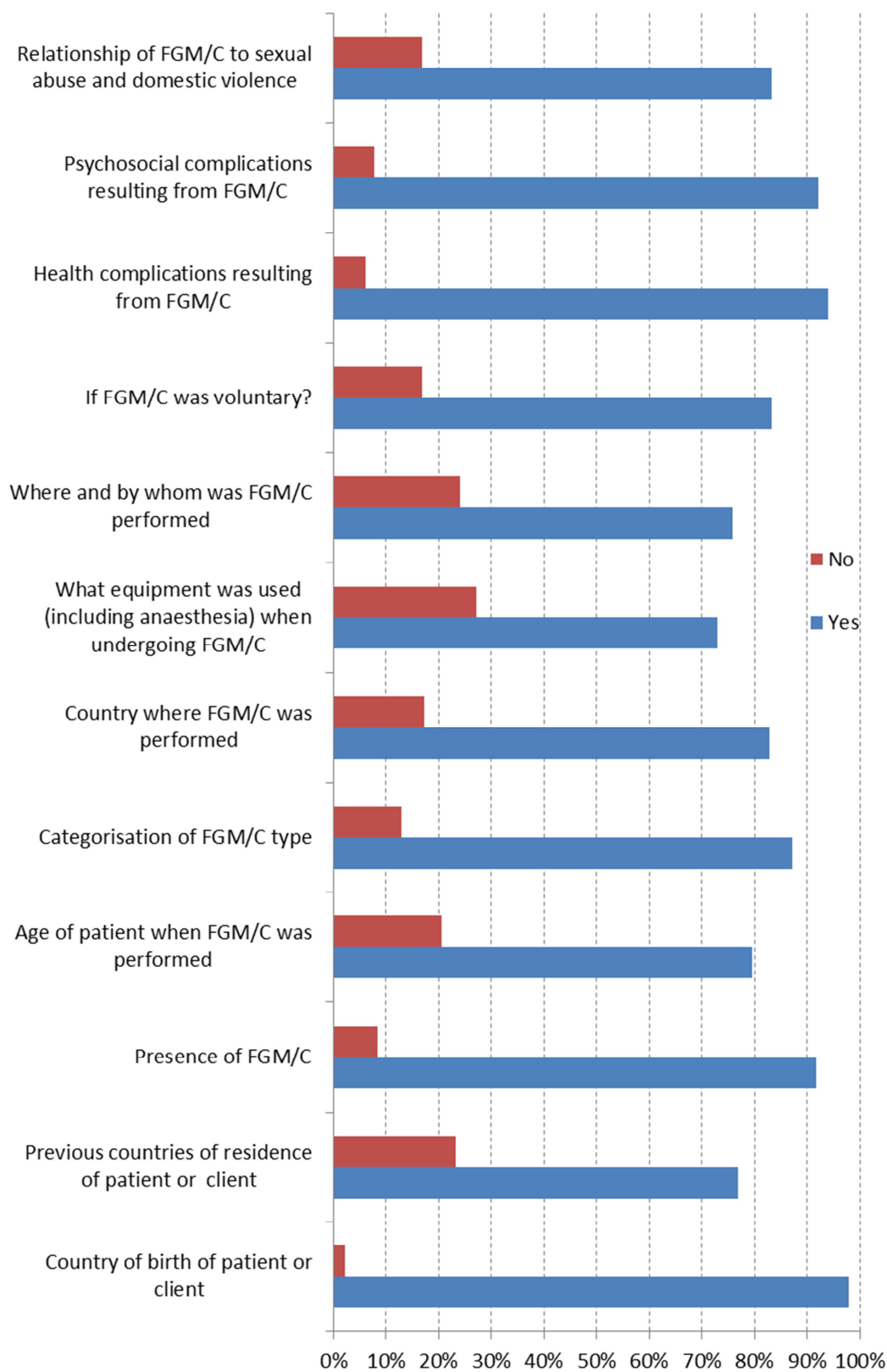
A question was asked as to whether collection of data relating to FGM/C currently exists in their practice. The majority of respondents (82%) reported country of birth as one of routinely collected data. Information about FGM/C was collected by antenatal clinics and FGM/C education providers (Figure 4.4).

Recommendations

It is proposed that:

- FGM/C type should be added to the Australian Institute of Health Welfare Meta data online Registry (METEoR). FGM/C types should be consistent with the World Health Organisation classification system
- The separation of FGM/C related operations from current Medicare Benefits Schedule Items 35533 and 35534
- Mandatory FGM/C data collection should be instituted to all hospital's antenatal clinics/wards
- Tertiary health care services should provide FGM/C annual reports to their states or territories' Ministry of Health
- The National Perinatal Minimum data set should include information on FGM/C so national data reporting is possible.

Figure 4.4: Information currently collected by online survey participants



Source: Family Planning NSW Training and Data Needs Analysis on Female Genital Mutilation/Cutting (FGM/C), February-March 2014

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4.5 FGM data collection trial in Family Planning NSW

Background

This section describes the outcome of the FGM data collection trial in Family Planning NSW clinics from November 2013 to date. It was planned that findings will be used to assess the feasibility of a national FGM data collection in Australia and to understand client's presenting problems, health related issues and available referral pathways.

Method

Family Planning NSW uses an electronic clinical data system called "Medical Director" to record client's medical notes. As part of the organisation's routine data collection, client's date of birth, country of birth, language spoken at home, migration status, year when client arrived in Australia, address, highest qualification and employment status are collected. Other standard information collected includes interpreter use, height, weight, smoking status, obstetric history, and other important clinical data used to manage client's clinical care.

The feasibility of FGM data collection was trialled in all Family Planning NSW clinics from November 2013 and is ongoing. The term "FGM" was adopted at first to be consistent to the word used by the Australian Government Department of Health. To assess whether FGM was discussed during the clinic consultation, a Female Genital Mutilation (FGM) tick box was added to the clinic visit form. All Family Planning NSW clinicians were advised by email of the inclusion of the FGM/C field in the clinic visit form and to collect this information as appropriate. This initiative was also discussed during the Family Planning NSW Clinical Update day in November 2013.

It was intended that the tick box will identify clients who have had FGM. Their medical records will be reviewed to understand presenting problems and health related issues. Findings will be used to define a FGM data collection tool.

Results

Review of FGM data collection, June 2014 (phase 1)

A review of the Family Planning NSW FGM data collection was conducted after 8 months, in June 2014. From November 2013 to June 2014, Family Planning NSW clinicians did not report any instances of discussing FGM with a client. In July 2014, a meeting with the FGM Clinical Nurse Specialist from Auburn Hospital was held to review the lack of FGM consultations. The FGM Clinical Nurse Specialist indicated that the lack of reported consultations may not be indicative of numbers of affected women, but rather due to factors affecting disclosure. As a result of these discussions, a FGM in-service training was scheduled to raise clinician's awareness and understanding of FGM and to discuss FGM referral pathways.

Intervention 1: Three hour in-service training, August 2014

The FGM Clinical Nurse Specialist delivered a three hour in-service training session on 6 August 2014 at the Family Planning NSW Fairfield clinic. This clinic was chosen because it represents the focus of Family Planning NSW Culturally and Linguistically Diverse (CALD) activities; more than 60% of the clients attending the clinic were born overseas. Three nurses, two doctors, one social worker, two data officers, one Health Promotion Officer and the Fairfield Centre Manager attended the in-service training. Four clinicians actively participated in the discussion and were very keen to develop a better understanding of:

- The types of FGM
- Consequences of FGM
- Methods by which to identify women affected by, or at risk of, FGM
- Appropriate FGM referral pathways

Family Planning NSW clinicians in attendance at the training reflected on the lack of reported consultations involving women affected by FGM. The clinicians indicated that there were instances of women affected by FGM attending the clinic, but this had not been reported through the client visit form, as the woman's reason for clinic attendance was related to other reproductive & sexual health issues, and there was no specific discussion of FGM during the consultation. The participating clinicians also expressed the belief that the discussion of FGM should be initiated by the client, not the clinician, as it is an issue very personal to the woman. Clinicians were motivated by respect for the woman's privacy and culture and a desire for the woman to maintain trust and confidence in the services provided by Family Planning NSW. The clinicians were concerned that the relationship with the client may

be jeopardised by raising such sensitive issues and the woman may be unwilling to return to the clinic. Improvement on FGM data collection was also discussed as part of the in-service training. Suggestions include:

1. Adding the word "Cutting" to the term "Female Genital Mutilation" within the client visit form and for all other references or documentation.
2. Moving the term Female Genital Mutilation/Cutting from "Other reproductive health issues" to "Gynaecological" within the client visit form.

The possibility of mandatory FGM/C data collection in Family Planning NSW was debated. Clinicians expressed their concerns about mandatory collection. Firstly, Family Planning NSW clinicians are not regarded as FGM/C experts and secondly, there is a specific FGM/C clinic in Sydney at Auburn Hospital where women can be referred to address FGM/C issues. Clinicians also suggested that if mandatory FGM/C screening is initiated, it should include all women. Clinicians felt that it is discriminatory to only screen women who were born in or came from countries with high FGM/C prevalence.

After the in-service training, doctors and nurses confirmed that their understanding of the types and health complications of FGM/C have increased and that they felt more confident discussing FGM/C matters to clients.

Action based on review of FGM/C data collection

The Family Planning NSW clinic visit form was changed to reflect the above suggestions. The Female Genital Mutilation / Cutting item in the electronic visit form was amended and placed within the Gynaecological data collection. Implementation of the revised clinic visit form was completed in October 2014.

Intervention 2: Trial of the newly developed Family Planning NSW FGM/C continuing professional education program for health professionals

Family Planning NSW was also commissioned by the Australian Government Department of Health to scope and develop a FGM/C continuing professional development (CPD) program for health professionals. The development of the first draft module was completed in September 2014. To raise awareness on FGM/C and to improve data collection, the course was trialled in Family Planning NSW Fairfield clinic on 15 October 2014. Juliana Nkrumah, President of the African Women's Association was invited as one of the trainers.

The evaluation of the course was very positive with participants making comments such as:

"This is a new area of learning for me. It was presented in a way that you can use and apply in practice"

"Very interactive / an eye opener"

"Well done excellent training"

"This has increased my knowledge/awareness"

Evaluation of FGM/C data collection, November 2014 (phase 2)

A review of the Family Planning NSW Fairfield FGM/C data collection was conducted at the end of November 2014.

From August to November 2014, Family Planning NSW clinicians did not report any instances of discussing FGM/C with a client.

In reviewing the lack of reporting, staff advised:

- They felt more confident in discussing FGM/C related matters to clients after they have attended the three hours in-service training in August and the FGM/C CPD workshop in September
- Women who have had FGM/C do not usually seek medical attention to family planning clinics
- Women usually attend Family Planning NSW clinics for their routine pap test, contraception advice, gynaecological and pregnancy advice
- Since the completion of the training, the four core clinical staff have not seen any client who have had FGM/C
- Staff agreed that any instances of FGM/C or risk of FGM/C will be reported to the data collection form if they see a client who had FGM/C or at risk of FGM/C

Despite quality control and training, there have still not been any reported cases of women affected by FGM/C at the clinic. We can be confident now that this is unlikely solely due to inappropriate communication around the issue with clients.

Discussion

Collecting FGM/C data in a primary health care setting similar to family planning clinics was not successful at the first phase of the trial because doctors and nurses lacked the understanding and confidence required to appropriately discuss FGM/C related matters with clients. After undergoing two FGM/C workshops, clinicians are confident in discussing this topic and agreed that instance of FGM/C will be reported through data collection if they see a client who has been affected by FGM/C.

Female Genital Mutilation/Cutting is a standing item in the Family Planning NSW clinic visit form. It is planned that all Family Planning NSW clinicians will attend the FGM/C CPD for health professional training in 2015. It is hoped that data collection in Family Planning NSW will improve as a consequence of improved knowledge and training of our clinical staff, particularly around communication about FGM/C. Additionally, increased community awareness that Family Planning NSW staff are educated about FGM/C may lead to increased attendance and/or disclosure by women affected by FGM/C at our clinic sites.

Complications relating to FGM/C are considered major gynaecological issues and primary care clinicians will refer these cases to a gynaecologist or, in the case of the Sydney area, to Auburn Hospital and in the case of Melbourne, to Royal Women's Hospital. It is also appropriate to collect data from FGM/C specialist clinics and hospitals such as these in order to build a picture of FGM/C prevalence in the area.

Family Planning NSW was also commissioned by the Australian Government Department of Health to develop the Family Planning Organisations (FPOs) data dictionary. This project will be completed in June 2015. Items on Female Genital Mutilation/Cutting will also be added to Family Planning Organisations (FPO) minimum data set. The FGM/C CPD for health professionals training will also be offered to other FPO staff across Australia. Consequently, it is hoped that FGM/C data collection in FPO will improve.

Reference

<http://www.hcn.com.au/Products/Medical+Director>

5. Proposed Female Genital Mutilation/Cutting data collection in Australia

Background

This section brings together the findings regarding the feasibility of data collection from the literature review, national online survey, in-depth interviews and consultations with relevant FGM/C experts around Australia, review of existing FGM/C data collection in Australia and the trial of FGM/C data collection at Family Planning NSW clinics. These outcomes are followed by recommendations for a proposed data collection, including how and where data should be collected.

The World Health Organisation (WHO) emphasises that a key means of eliminating FGM/C is to build evidence through generating knowledge about the causes and consequences of the practice, how to eliminate it, and how to care for those who have experienced FGM/C.

Collection of FGM/C data at a community education session is not recommended due to privacy and confidentiality reasons. The data collection trial found that few women disclose their FGM/C experiences during or after a community education session. Recording of FGM/C data could be informal and women must be referred to a primary, secondary or tertiary health care provider for appropriate clinical assessment and further client care.

Primary care refers to the work of health professionals who act as a first point of consultation for all patients within the health care system. Professionals in this area would usually include a primary care physician, such as a general practitioner, family physician or those physicians working in Refugee Health Services, Immigrant/Migrant Health Services, Women's Health Services, Family Planning clinics and/or other primary health care services.

Secondary care refers to the health care services provided by medical specialists and other health professionals who generally do not have first contact with patients, such as gynaecologists and obstetricians.

Tertiary care is specialised consultative health care, usually for inpatients and on referral from a primary or secondary health professional, in a facility that has personnel and facilities for advanced medical investigation and treatment, such as a tertiary referral hospital.

5.1 Summary of findings

Data collection literature review

While FGM/C continues to gain more public attention, more funding is also needed to facilitate the increasing amount of work needed to be done in this area.

The establishment of a FGM/C data collection system is essential in identifying the gaps in service provision, thus a minimum data set should be established. Once a minimum data set is established in Australia, a clearer insight of FGM/C in Australia will emerge.

Online survey

It is feasible to develop consistent FGM/C data collection in Australia. Respondents of the online survey attested that FGM/C data is currently collected by a number of health professionals in a variety of locations, but that collection is *ad hoc*, and often dependent on an individual health professional.

There is a critical need for health professionals to attend FGM/C continuing professional development training to be more effective in communicating to women affected by FGM/C to understand its health consequences and management, and in order to accurately collect information. Appropriate skills and confidence in this topic would contribute highly to robust and reliable FGM/C data collection.

General practitioners, nurses, midwives and allied health workers should be informed about appropriate referral pathways for the variety of physical and psychological health implications of FGM/C. A network of expert health professionals, appropriately skilled in the particularities of FGM/C, should be easily accessible, and adequately publicised.

Finally, funding bodies should support the mandatory collection of FGM/C data collection and data reporting to territories' and states' health departments should be instituted. This information is relevant for government and policy makers to build an infrastructure to support women who are affected by, or are at risk of, FGM/C.

In-depth interviews and consultations with relevant FGM/C experts around Australia

Training health professionals is a pivotal part of establishing and maintaining a robust data collection system, particularly in eliciting information on sensitive topics like FGM/C. Staff need to be adequately trained so that they are skilled in collecting relevant data and in communicating with clients.

In order to facilitate proper training for staff, it is important that adequate funding is available, including the ongoing costs associated with the data collection system.

Establishing a robust national FGM/C data collection system is an important step in gaining a clearer picture of the extent and impacts of FGM/C in Australia. The in-depth interviews have provided valuable additional information that make FGM/C data collection feasible.

Review of existing FGM/C data collection in Australia

FGM/C national data collection is feasible in Australia. Some hospitals are currently collecting information of FGM/C in their antenatal and obstetrics databases, however, it is not mandatory. These data items such as the FGM/C type should be added/registered to the Australian Institute of Health Welfare Meta data online Registry (METeOR) and should adopt the classifications and definitions recommended by the World Health Organisation. Funders should institute a mandatory collection to all hospital's antenatal wards and FGM/C annual reports should be provided to states' or territories' Ministry of Health. The National Perinatal Minimum data set should include information on FGM/C so national data reporting is possible.

All surgical repair of female genital mutilation should be separated from the current Medicare Benefits Schedule Items 35533 and 35534.

FGM/C data collection in Family Planning NSW

The trial conducted at Family Planning NSW indicated that a FGM/C data collection is feasible in primary and secondary health care, as long as appropriate training is provided. Female Genital Mutilation/ Cutting is a standing item in the Family Planning NSW clinic visit form. All Family Planning NSW clinicians will attend the FGM/C CPD for health professionals training in 2015. It is hoped that data collection in Family Planning NSW will improve as a consequence of improved knowledge and training of our clinical staff, particularly around communication about FGM/C. Additionally, increased community awareness that Family Planning NSW staff are educated about FGM/C may lead to increased attendance and/or disclosure by women affected by FGM/C at our clinic sites.

Complications relating to FGM/C are considered major gynaecological issues and primary care clinicians will refer these cases to a gynaecologist or, in the case of the Sydney area, to Auburn Hospital and in Melbourne, the Royal Women's Hospital. It is also appropriate to collect data from FGM/C specialist clinics and hospitals such as these in order to build a picture of FGM/C prevalence in the area. Family Planning NSW was also commissioned by the Australian Government Department of Health to develop the Family Planning Organisations (FPOs) data dictionary. This project will be completed in June 2015. Items on Female Genital Mutilation/Cutting will also be added to FPOs minimum data set. The FGM/C CPD for health professional training will also be offered to other FPO staff across Australia. Consequently, it is hoped that FGM/C data collection in FPOs will improve.

5.2 Proposed data collection on FGM/C in Australia

It is recommended that data definitions set by the Australian Institute of Health and Welfare Metadata Online Registry (METeOR) be used to ensure consistency of data collection and reporting across Australia. Those data items not currently in METeOR should be registered.

The following data should be collected as part of routine data collection (Table 5.1).

Table 5.1 Proposed FGM/C data items and definitions

| Data item | AIHW METeOR Reference Number or Recommended definition | Relevance |
|------------------------------|---|---|
| Country of Birth of Mother | 459973 | Can be used as an indicator or flag as to whether client came from a high FGM/C prevalence country |
| Address | 286620 | Can be used to identify Local Government Areas where there is a high prevalence of FGM/C in Australia |
| Main language spoken at home | 460125 | Can be used as an indicator or flag as to whether client came from a high FGM/C prevalence country |
| Interpreter service required | 304294 | Important to break language barrier between client and clinician Important to plan health care support |
| If women have had FGM/C | Yes or No | Important to plan health care support |
| If Type of FGM/C | <p>Use World Health Organisation classification and definition</p> <p>Type 1 - Clitoridectomy: partial or total removal of the clitoris (a small, sensitive and erectile part of the female genitals) and, in very rare cases, only the prepuce (the fold of skin surrounding the clitoris)</p> <p>Type 2 - Excision: partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (the labia are "the lips" that surround the vagina)</p> <p>Type 3 - Infibulation: narrowing of the vaginal opening through the creation of a covering seal. The seal is formed by cutting and repositioning the inner, or outer, labia, with or without removal of the clitoris</p> <p>Type 4 -Other: all other harmful procedures to the female genitalia for non-medical purposes, e.g. pricking, piercing, incising, scraping and cauterising the genital area</p> | Important to plan health care support |

| | | |
|--|---|--|
| De-infibulation performed | Yes or No | To determine how many women have been infibulated Important to plan health care support |
| Health complications resulting from FGM/C | Urinary tract problems Dysmenorrhea Pelvic Inflammatory Disease (PID) Dyspareunia Cervical cancer screening (Pap smear) Sexual function Other, please specify _____ | Important to plan health care support |
| Psychosocial complications resulting from FGM/C | Emotional, relationship and sexuality concerns Domestic violence Sexual assault Mental Health concerns Other, please specify _____ | Important to plan health care support |
| Referral to doctor or specialist | General Practitioner Gynaecologist Obstetrician Surgeon Uro-gynaecologist Continence nurses Physiotherapist Counsellors Psychologist Other, please specify _____ | Important to plan health care support |
| Referral to institution | Public Hospital Family Planning clinics Women's Health clinics Multicultural/refugees clinic Community Health Centre Other please specify _____ | Important to plan health care support |
| Does client have plans to continue with the cultural practice? | Yes/No | Important to plan community education activities |
| Does client understand Australian laws relating to FGM/C? | Yes/No | Important to plan community education activities |
| Year arrived in Australia | DD/MM/YYYY | Essential but not mandatory Important to determine if FGM/C performed after migrating to Australia and to |

| | | |
|---|--|-----------------------------|
| | | monitor trends |
| Age of patient when FGM/C was performed | | Essential but not mandatory |
| Country where FGM/C was performed | | Essential but not mandatory |
| If FGM/C was voluntary? | | Essential but not mandatory |

Recommendations

It is suggested that:

- All proposed items related to FGM/C should be registered with the Australian Institute of Health Welfare Metadata Online Registry (METEoR)
- General practitioners, nurses and other health professionals should attend FGM/C continuing professional development training to increase their FGM/C awareness, knowledge of FGM/C referral pathways and improve their data collection ability
- Mandatory FGM/C data collection should be instituted to antenatal, gynaecologist and obstetrics wards in tertiary health care service using the proposed data collection above
- Tertiary health care services should provide FGM/C related reports on an annual basis to state and territory Ministries of Health
- Primary and secondary health care services should include FGM/C data collection and should be encouraged by their funders to collect information relating to FGM/C using the proposed data collection and definition above
- Separation of FGM/C related operations from current Medicare Benefits Schedule Items 35533 and 35534
- FGM/C related issues should be incorporated into the domestic violence and sexual assault screening in primary health care service, of which some states have implemented.

6. Estimating Female Genital Mutilation/Cutting Prevalence in Australia

Background

There are no published estimates of the prevalence of FGM/C within Australia. A literature review was carried out to assess methods that have been used to estimate FGM/C prevalence in other countries and to determine the feasibility of applying these methods to estimate the FGM/C prevalence in Australia.

6.1 Literature review

A review of the literature was undertaken to identify articles which reported on the following topics:

- Prevalence of FGM/C
- Spatial distribution of FGM/C in high prevalence countries
- Reporting of FGM/C data

PubMed databases, which include the Medline and Scopus databases, were searched. PubMed was the database of choice as it has the greatest number of indexed articles and contains the most up to date articles.

The following search terms were used: FGM, FGM/C, female circumcision, female genital mutilation, prevalence. The search was restricted to articles published in English. Additional articles were also identified through discussion with experts in the field.

There were 280 articles published between January 2008 and December 2013 that met the initial search criteria. Two hundred and four articles were excluded as their focus was either human rights, medical consequences, religion or the law. The abstracts for the remaining 76 articles were reviewed and 14 papers were found to be eligible for a full review.

Findings

Among the selected articles, nine reported on countries with high prevalence (mainly countries in Africa)^{1, 2, 6-8, 10, 12, 15, 16} and five reported on countries with low prevalence (Belgium, United Kingdom, the Netherlands and Australia)^{3-5, 9, 11}.

The majority of studies carried out in high prevalence countries derived their estimates from the Demographic and Health Surveys (DHSs) and Multiple Indicator Cluster Surveys (MICSs). These surveys were designed to provide a national picture of a large number of health issues and determinants, although not all DHS/MIC surveys included questions on FGM/C. Cluster sampling was used to select households and women from the selected households completed a questionnaire.

Among the studies carried out in low prevalence countries, one undertaken by Dubourg³ estimated the prevalence of FGM/C by applying the rate of FGM/C in high prevalence countries to the number of women born in these countries but resident in Belgium. A similar approach was taken by the study carried out in the Netherlands.⁵ Other authors based their estimates on surveys of midwives⁹ or obstetricians¹¹.

Several factors were identified as being related to FGM/C prevalence such as ethnicity, geographic location, socioeconomic status and education^{1, 7, 8, 12}. It was also reported that there was a shift towards milder types of FGM/C (type I and II) in recent years¹⁰.

Limitations of the methods for calculating FGM/C prevalence

The DHS/MIC surveys relied on self-report of FGM/C status. Only one study examined whether such self-report was accurate² and it found that the presence of FGM/C was accurately reported but not the FGM/C type.

The DHS/MIC surveys ranged in size from 5005 to 11375. Such sample sizes were adequate for providing estimates of FGM/C prevalence in the high prevalence countries however in countries with lower prevalence (e.g. Australia, Belgium, Netherlands), and clustering of FGM/C within particular groups, surveys of individual women would have to be many times greater.

Another limitation of the DHS/MIC surveys was that they generally provide a national picture however as noted above the prevalence of FGM/C can vary within a country due to a number of factors such as geographic location, ethnicity, socioeconomic status and education.

The surveys of medical staff (obstetricians and midwives)^{9, 11} relied on these staff being able to identify FGM/C, accurately classify FGM/C and recall the number of cases seen. The survey of midwives in the Netherlands found that they may be underreporting FGM/C as many were not specially trained, meaning they may not enquire or may miss the milder forms of FGM/C⁹.

The studies carried out in Belgium and Netherlands^{3, 5} combined data from the DHS/MIC surveys of high prevalence countries with data on the number of women living in Belgium/Netherlands but who were born in, or whose parents were from, these high prevalence countries. This approach then has the same limitations as those that apply to the DHS/MIC surveys but also has additional limitations. These include whether the prevalence estimates obtained for the country of origin are applicable to the women who have migrated to the country of residence. As FGM/C prevalence is known to vary by a number of factors this may, or may not, be the case.

6.2 Estimation of FGM/C prevalence in Australia

Based on the limitations described above it was determined that the method applied in Belgium and Netherlands was the most feasible method for estimating the prevalence of FGM/C in Australia given the limited time and resources.

Data sources

The prevalence of FGM/C in the countries Benin, Burkina Faso, Cameroon, Central African Republic, , Chad, Côte d'Ivoire, Djibouti, Egypt, Eritrea, Ethiopia, Gambia, Ghana, Guinea, Guinea-Bissau, Iraq, Kenya, Liberia, Mali, Mauritania, Niger, Nigeria, Senegal, Sierra Leone, Somalia, Sudan, Tanzania Togo, Uganda and Yemen was obtained from the latest DHS or MIC survey conducted in that country. The earliest survey took place in 2002 and the latest in 2013 with 17 of the 29 surveys taking place in 2010 or later³. Prevalence was obtained for the age groups 15-19, 20-24, 25-29, 30-34, 35-39, 40-44 and 45-49. These data were provided by Dr Dominique Dubourg, Institute of Tropical Medicine, Antwerp, Belgium.

Data was obtained from the Australian Bureau of Statistics on the estimated resident female population of Australia for the years 2009 to 2013 by country of birth and five year age group.

Methods

The prevalence of FGM/C in each country and five year age group were multiplied by the number of women living in Australia for the corresponding country of birth and five year age group to provide an estimate of the number of women with FGM/C. The figures were then summed across all age groups and countries to provide an estimate of the total number of women with FGM/C who were resident in Australia. The calculations were carried out for each of the years 2009 to 2013. The prevalence of FGM/C for the age group 15-19 was applied to females aged under 15 as prevalence data were not available for all age groups in all countries. Similarly, the prevalence of FGM/C for the age group 45-49 to females aged 50 or over.

Results

The estimated total number of women with FGM/C in Australia in 2013 was 48505. Women born in Egypt made up the highest proportion of women with FGM/C in Australia (40%), followed by women born in Sudan (20%) and Ethiopia (9%) (Table 6.1). The countries of birth with the highest estimated proportion of women with FGM/C were Somalia, Guinea, Egypt, Djibouti, Eritrea, Sudan, Sierra Leone and Mali.

Table 6.1: Estimated prevalence of FGM/C in Australia by country of birth, 2013

| Country of birth | Estimated number of women with FGM/C | Per cent of estimated total with FGM/C | Estimated proportion (%) of women from country of birth with FGM/C |
|------------------|--------------------------------------|--|--|
| Benin | 1 | 0 | 2 |
| Burkina Faso | 7 | 0 | 70 |
| Cameroon | 2 | 0 | 1 |
| Cote d'Ivoire | 94 | 0 | 35 |
| Djibouti | 74 | 0 | 93 |
| Egypt | 19215 | 40 | 94 |
| Eritrea | 1678 | 3 | 91 |
| Ethiopia | 4196 | 9 | 76 |
| Gambia | 38 | 0 | 76 |
| Ghana | 100 | 0 | 4 |
| Guinea | 369 | 1 | 95 |
| Iraq | 2528 | 5 | 9 |
| Kenya | 2715 | 6 | 32 |
| Liberia | 1107 | 2 | 66 |
| Mali | 9 | 0 | 87 |
| Mauritania | 15 | 0 | 76 |
| Nigeria | 664 | 1 | 27 |
| Senegal | 46 | 0 | 27 |
| Sierra Leone | 1614 | 3 | 88 |
| Somalia | 3723 | 8 | 98 |
| Sudan | 9883 | 20 | 89 |
| Tanzania | 295 | 1 | 15 |
| Togo | 7 | 0 | 5 |
| Uganda | 24 | 0 | 2 |
| Yemen | 103 | 0 | 38 |

Women of reproductive age (15 to 49 years) accounted for over half (57%) of the estimated total of women with FGM/C in Australia in 2013 (Table 6.2). Approximately a third (35%) of the estimated total were aged over 50 and 8% were aged under 15.

Table 6.2: Estimated prevalence of FGM/C in Australia by age group, 2013

| Age group | Number of women with FGM/C | Per cent of estimated total with FGM/C | Age specific prevalence per 1000 women |
|-------------|----------------------------|--|--|
| 0-4 | 372 | 0.8 | 0.5 |
| 5-9 | 1249 | 2.6 | 1.8 |
| 10-14 | 2288 | 4.7 | 3.4 |
| 15-19 | 2830 | 5.8 | 4.0 |
| 20-24 | 3709 | 7.7 | 4.6 |
| 25-29 | 4528 | 9.3 | 5.3 |
| 30-34 | 4521 | 9.3 | 5.5 |
| 35-39 | 4277 | 8.8 | 5.5 |
| 40-44 | 3915 | 8.1 | 4.7 |
| 45-49 | 3676 | 7.6 | 4.8 |
| 50-54 | 3172 | 6.5 | 4.1 |
| 55-59 | 2979 | 6.1 | 4.2 |
| 60-64 | 2844 | 5.9 | 4.5 |
| 65-69 | 2669 | 5.5 | 4.9 |
| 70-74 | 1702 | 3.5 | 4.3 |
| 75 and over | 3774 | 7.8 | 4.5 |

In the five years from 2009 to 2013 the estimated number of women with FGM/C in Australia increased by 11%, from approximately 43000 to over 48000 (Table 6.3). Approximately 40% of the estimated total increase was attributable to increasing numbers of women who had been born in Ethiopia and Somalia. The estimated prevalence of FGM/C increased by only 4% over the five years, 2009 to 2013, due to the increasing population of Australia.

Table 6.3 Estimated prevalence of FGM/C in Australia, 2009 to 2013

| Year | Estimated number of women with FGM/C | Prevalence per 1000 women |
|------|--------------------------------------|---------------------------|
| 2009 | 43643 | 4.0 |
| 2010 | 45534 | 4.1 |
| 2011 | 45865 | 4.1 |
| 2012 | 47335 | 4.1 |
| 2013 | 48505 | 4.2 |

Limitations

There are a number of limitations to the method applied to estimate prevalence of FGM/C in Australia as discussed in the studies overseas that have applied similar methods. The authors of this report have:

- assumed that the prevalence of FGM/C reported in each country-specific survey provides a reasonable estimate of the prevalence of FGM/C of women born in these countries but is a resident of Australia. The validity of this assumption is dependent upon women resident in Australia being representative of women residing in the country of birth across factors such as region of birth within a country, ethnicity, religion, educational and socioeconomic status as the practice of FGM/C is known to vary with these factors. Without further comparisons between women residents in Australia with women residents in their country of birth it is not possible to say whether the assumption is reasonable or not. It may only be valid for some countries but not others.
- used the latest prevalence estimates of FGM/C from the countries of origin, however some of these estimates are over ten years old and may not reflect current practices in these countries
- not accounted for the age at which women arrived in Australia. FGM/C is most commonly performed before a child's 15th birthday hence alternative assumptions could be applied for women who arrived before or after the age of 15. For example, women who arrived after the age of 15 could be assumed to have undergone FGM/C whereas women who arrived before the age of 15 could be assumed to be "at risk". However, it is possible that families intending to migrate to Australia arrange for their child undergo FGM/C before leaving their country irrespective of the child's age
- assumed that women who were not born in the countries listed, but whose parents were born in these countries, have not undergone FGM/C. It is possible that these women may have undergone FGM/C or be at risk of FGM/C
- not reported on the prevalence of different types of FGM/C, the accuracy of recording type in the DHS/MIC surveys is questionable. The prevalence of the different types is known to vary by country and also within countries. Women with different types of FGM/C would have different needs with regards to health, and other, services.

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7. Appendices

7.1 Terms of Reference Project Steering Committee

Family Planning NSW

FEMALE GENITAL MUTILATION (FGM) STEERING COMMITTEE

TERMS OF REFERENCE

| | |
|------------------------|---|
| CHAIR: | Family Planning NSW Medical Education Coordinator |
| RESPONSIBLE TO: | CEO |
| REPORTS TO: | Executive |

CONTEXT

The FGM Steering Committee has been established to oversee the following project based activities funded through Department of Health and Ageing grants:

- FGM Continuing Professional Development
- Feasibility study for national FGM data collection

OBJECTIVES

The objectives of the FGM Steering Committee are to:

1. provide direction and support to the FGM Project Team and others engaged or working to support these projects to ensure that outcomes align with the Family Planning NSW vision and values
2. Provide advice on key stakeholders to contact for the training needs analysis and input into the competency and course development recommendations
3. Provide advice on key stakeholders to contact regarding potential scope, existing data and key information needed to monitor FGM
4. Oversee progress of the projects to ensure contracted deliverables are completed on time to the standard expected
5. Support the project and of exploring options of involvement upon project establishment in development of education materials and national data collection
6. Identify any risks arising during the course of the projects to ensure the that project objectives are met
7. Identify other projects to ensure minimal duplication and maximise coordination

REPORTING REQUIREMENTS

The minutes of FGM Steering Committee meetings will be reported to the Family Planning NSW Executive.

FREQUENCY OF MEETINGS

The FGM Steering Committee shall meet once quarterly or as the need arises.

7.2 Terms of Reference Project Team

Family Planning NSW

FEMALE GENITAL MUTILATION (FGM) PROJECT TEAM

TERMS OF REFERENCE

CHAIR: Director Monitoring, Evaluation and Research Operations

RESPONSIBLE TO: Executive

REPORTS TO: FGM Steering Committee

CONTEXT

The FGM Project Team has been established to progress and monitor two projects funded through Department of Health and Ageing grants including:

- FGM Continuing Professional Development
- Feasibility study for national FGM data collection

OBJECTIVES

The objectives of the FGM Project Team are to:

1. provide a reference point where issues affecting the progress of the funded projects can be reviewed and addressed
2. monitor progress of the funded projects to ensure objectives outlined in the respective project plans are delivered on time
3. ensure that current reproductive and sexual health evidence is accessed and applied
4. ensure that staff engaged in the projects have appropriate orientation to Family Planning NSW project management procedures and access to appropriate resources
5. provide support to the Project Officers engaged in the funded projects
6. identify and manage any risks arising during the course of the projects to ensure the that project objectives are met.

REPORTING REQUIREMENTS

The minutes of Project Team meetings form part of the records of the projects and will reported to FGM Steering Committee.

FREQUENCY OF MEETINGS

The Project team shall meet once a month initially and then at a frequency appropriate to the issues arising.

7.3 Online survey form



Family Planning NSW Training and Data Needs Analysis on Female Genital Mutilation/ Cutting (FGM/C)

Introduction

Female Genital Mutilation or Cutting (FGM/C) is the partial or total removal of the external genitals of a female for non-medical reasons.

The purpose of this survey is to assess the training needs of doctors, nurses and other service providers regarding FGM/C and also to assess what FGM/C related data are currently collected.

The results from this survey will be used to assist Family Planning NSW in designing a continuing professional development course and also to determine the feasibility of a nationally consistent data collection system for FGM/C information.

This survey will take approximately 15 minutes. At the end of the survey you will be able to enter a lucky draw to win a \$100 gift voucher to use at the online Family Planning NSW Bookshop.

Your responses to this survey will be anonymous. Any personal information you voluntarily submit for the purpose of the lucky draw will be kept separate from the survey responses.

Please do not provide any identifying information about your clients or patients in your responses to this survey.

We have received ethics approval to conduct this survey from the Family Planning NSW Human Research Ethics Committee and the South East Sydney Local Health District Human Research Ethics Committee. If you have any concerns with respect to this survey, please contact Mathew Halliday, Ethics Officer, Family Planning NSW on 02 8752 4348 or ethics@fpnsw.or.au or the Prince of Wales Ethics Secretariat, on 02 9382 3587 or RSOESLHD@sesiahs.health.nsw.gov.au

By clicking on next, you indicate that you have read this information and agree to participate in this survey.

Thank you for your participation.

Demographics

1. What is your gender?

- Male
- Female
- Other

2. Which best describes the organisation you work for?

- Family Planning clinic
- Public hospital
- GP practice
- Women's health clinic
- Sexual health clinic
- Multicultural/refugee health clinic
- Migrant resource centre
- Refugee resource provider
- Other (please specify)

3. Which best describes your position at this organisation?

- Doctor – GP
- Doctor – other than GP
- Nurse
- Midwife
- Social worker
- Psychologist
- Refugee worker
- Multicultural worker
- Family worker
- Community worker
- Health promotion / education provider
- Counsellor
- Other (please specify)

4. What state or territory do you live in?

5. Which of the following best describes your workplace location?

- Urban
- Regional
- Rural
- Remote

Experience

In this section we ask about your experience with clients or patients who have had FGM/C.

6. How many clients / patients would you estimate you have had in the past 5 years that have had FGM/C?

7. How many female clients / patients would you estimate you have had in the past 5 years that were from high FGM/C prevalence countries?

(High prevalence countries include, but are not limited to: Burkina Faso, Djibouti, Egypt, Eritrea, Ethiopia, Gambia, Guinea, Mali, Mauritania, Sierra Leone, Somalia, North Sudan)

Previous training in FGM/C

In this section we ask about previous training you may have had in FGM/C.

8. Have you received any training or continuing professional development in FGM/C?

- Yes
- No

Previous training in FGM/C

9. Where did you receive this training?

10. How much training did you receive?

Number of

hours:

11. What form did the training take?

- Face to face
- Online
- Combined face to face and online
- Other (please specify):

12. Who was the training aimed at? (tick all that apply)

- Doctors
- Nurses
- Allied health workers
- Community workers
- Not sure
- Other (please specify):

13. Overall, how useful was the training for your work?

| | | | |
|--------------------------|--------------------------|--------------------------|--------------------------|
| Not useful | Somewhat useful | Very useful | Extremely useful |
| <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

14. Have you used the knowledge from this training in your work?

- yes
- no

15. What were the best aspects of the training?

16. What were the worst aspects of the training?

Information sources

In this section we ask about where you would look for information about FGM/C?

17. If you had a client with FGM/C and wanted additional information, where would you most likely seek it?

- A training or continuing professional development course
- A colleague
- Internet search
- Government recommended guidelines
- Other recommendations (e.g. Cochrane review)
- Journal articles
- Book
- I would not seek further information
- Other (please specify):

FGM/C content - Knowledge and skills

In this section we would like your views on the potential content and delivery method of a FGM/C continuing professional development course.

18. Do you think these topics should be included in a continuing professional development course on FGM/C?

| | yes | no |
|--|-------------------------------------|-------------------------------------|
| Definitions and classification of FGM/C | <input type="radio"/> | <input type="radio"/> |
| Countries where FGM/C is commonly practiced | <input type="radio"/> | <input type="radio"/> |
| How FGM/C is practiced? | <input type="radio"/> | <input type="radio"/> |
| Cultural issues related to FGM/C | <input type="radio"/> | <input type="radio"/> |
| Physical consequences, complications and risks | <input type="radio"/> | <input type="radio"/> |
| Psychosocial consequences, complications and risks | <input type="radio"/> | <input type="radio"/> |
| Relevant guidelines and laws in Australia | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| Mandatory reporting requirements | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |
| Referral pathways | <input checked="" type="checkbox"/> | <input checked="" type="checkbox"/> |

Contraception and FGM/C

Common communication barriers between women with FGM/C and health professionals

FGM/C and history taking

FGM/C and physical examination

FGM/C and clinical practice in pregnancy, labour and post-partum

FGM/C and cervical cancer screening

Identification of girls and women who may be at risk of having FGM/C

Counselling skills for women who have had FGM/C

19. Please list any FGM/C topic areas or skills that were not covered above that you think should be included in a FGM/C continuing professional development course?

20. Which format would you prefer for a continuing professional development course on FGM/C?

- Face to face
- Online course – text format
- Online course – webinar format
- Combined face to face and online
- A printed paper resource with self-directed learning
- Journal club

Please provide any comments to further explain your response:

21. Is there anything else you would like to mention regarding continuing professional development in FGM/C that we may not have covered?

Accreditation and comments

22. How much would it positively influence your decision to enrol in a FGM/C continuing professional development course if it were accredited for professional points or credit?

- A lot
- Somewhat
- Minimally
- Not at all

Please provide any comments to further explain your response:

23. Which of the following bodies would you gain professional development points from?

- Royal Australian College of GPs (RACGP)
- Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)
- Australian College of Nurses (ACN)
- Australian College of Midwives (ACM)
- Australian College of Rural and Remote Medicine (ACRRM)
- Not eligible
- Other (please specify):

RACGP accreditation points

24. For FGM/C related continuing professional development, which RACGP category would you be more likely to participate in?

- Category 1: Active Learning Module – minimum 6 hours [women’s health points]
- Category 2: Minimum 1 hour

Please provide any comments to further explain your response:

FGM/C data collection

In this section we ask you about FGM/C data collection.

The following is a list of information that may be collected about your patients or clients.

Please indicate whether the following information is currently collected in your workplace, and whether you think the information should be collected.

25. Please indicate whether you currently collect the following information for patients or clients in your workplace:

| | yes | no |
|--|--------------------------|--------------------------|
| Country of birth of patient or client | <input type="checkbox"/> | <input type="checkbox"/> |
| Previous countries of residence of patient or client | <input type="checkbox"/> | <input type="checkbox"/> |
| Presence of FGM/C | <input type="checkbox"/> | <input type="checkbox"/> |
| Age of patient when FGM/C was performed | <input type="checkbox"/> | <input type="checkbox"/> |
| Categorisation of FGM/C type | <input type="checkbox"/> | <input type="checkbox"/> |
| Country where FGM/C was performed | <input type="checkbox"/> | <input type="checkbox"/> |
| What equipment was used (including anaesthesia) when undergoing FGM/C? | <input type="checkbox"/> | <input type="checkbox"/> |
| Where and by whom was FGM/C performed? | <input type="checkbox"/> | <input type="checkbox"/> |
| If FGM/C was voluntary? | <input type="checkbox"/> | <input type="checkbox"/> |
| Health complications resulting from FGM/C | <input type="checkbox"/> | <input type="checkbox"/> |
| Psychosocial complications resulting from FGM/C | <input type="checkbox"/> | <input type="checkbox"/> |
| Relationship of FGM/C to sexual abuse and domestic violence | <input type="checkbox"/> | <input type="checkbox"/> |

26. Please list any information on FGM/C that is collected but isn't mentioned above?

27. Please indicate whether you think the following information *should* be collected for your patients or clients:

yes no

Country of birth of patient or client



Previous countries of residence of patient or client



Presence of FGM/C



Age of patient when FGM/C was performed



Categorisation of FGM/C type



Country where FGM/C was performed



What equipment was used (including anaesthesia) when undergoing FGM/C



Where and by whom was FGM/C performed?



If FGM/C was voluntary



Health complications resulting from FGM/C



Psychosocial complications resulting from FGM/C



Relationship of FGM/C to sexual abuse and domestic violence



28. Is there any other FGM/C information you think *should* be collected?

Additional information on data collection

In this section we ask for some details about your experience with clients or patients with FGM/C.

Please skip these questions if you have not encountered FGM/C in your work.

29. What are the commonly presenting problems for first encountering a client or patient's FGM/C?

30. Please describe any service or treatment you have provided to a client or patient related to FGM/C.

31. Is there anything else regarding data collection on FGM/C that you would like to comment on?

Lucky draw

32. If you would like to be entered in to a lucky draw for a chance to win a \$100 gift voucher to use at the Family Planning NSW Bookshop (<http://www.fpnsw.org/categories/Bookshop/>) please enter your email address below.

(Please note that we will separate your email from your response upon initial viewing of the survey results and your email address will be in no way associated with your responses).

Email address:

If you have any queries or concerns about this survey, please contact Mathew Halliday, Family Planning NSW Executive Ethics Officer (ethics@fpnsw.org.au or 02 8752 4348). If you require any further information or have any questions about the project, please contact Pippa Markham, Family Planning NSW Project Officer (pippam@fpnsw.org.au or 02 8752 4223).

For further information about FGM/C, please see:

[Family Planning Victoria Service Coordination Guide](#)

[NSW FGM Education Program Brochure](#)

[RANZCOG FGM/C general information](#)

[Australian College of Midwives and Australian College of Nursing joint project on FGM learning resources](#)

Thank you very much for participating in our survey!

7.4 Perinatal National Minimum Dataset (NMDs) 2011–2012 items

| Data element name | METeOR identifier |
|--|-------------------|
| Birth event—birth method, code N | 295349 |
| Birth event—birth plurality, code N | 269994 |
| Birth event—birth presentation, code N | 299992 |
| Birth event—labour onset type, code N | 269942 |
| Birth event—setting of birth (actual), code N | 269937 |
| Birth event—state/territory of birth, code N | 270151 |
| Birth—Apgar score (at 5 minutes), code NN | 289360 |
| Birth—birth order, code N | 269992 |
| Birth—birth status, code N | 269949 |
| Birth—birth weight, total grams NNNN | 269938 |
| Episode of admitted patient care—separation date, DDMMYYYY | 270025 |
| Establishment—organisation identifier (Australian), NNX[X]NNNNN | 269973 |
| *Female (pregnant)—number of cigarettes smoked (per day after 20 weeks of pregnancy), number N[NN] | 365445 |
| *Female (pregnant)—tobacco smoking indicator (after twenty weeks of pregnancy), yes/no code N | 365417 |
| *Female (pregnant)—tobacco smoking indicator (first twenty weeks of pregnancy), yes/no code N | 365404 |
| *Person—area of usual residence, geographical location code (ASGC 2009) NNNNN | 426285 |
| *Person—country of birth, code (SACC 2008) NNNN | 370943 |
| *Person—date of birth, DDMMYYYY | 287007 |
| *Person—Indigenous status, code N | 291036 |
| *Person—person identifier, XXXXXX[X(14)] | 290046 |
| *Person—sex, code N | 287316 |
| *Pregnancy—estimated duration (at the first visit for antenatal care), completed weeks N[N] | 379597 |
| *Product of conception—gestational age, completed weeks N[N] | 298105 |
| **FGM/C status | |
| **FGM/C type | |

Note: * Existing Perinatal NMDs items
 ** Proposed items to be added to Perinatal NMDs

Source: Australia's mothers and babies 2011. <http://meteor.aihw.gov.au/content/index.phtml/itemId/426735>

7.5 FGM/C Phrase-bank

Phrase-bank: how to start conversations about FGM/C

INTRODUCTION

- I need to ask you a lot of questions about your health. Some of them are very personal and you may find them a bit embarrassing. I ask everyone who comes to the clinic these questions.

HISTORY TAKING RELATED TO FGM/C WITH MOST COMMON PRESENTING ISSUES

Urinary tract infection

- What you are describing sounds like a urinary tract infection. Have you had one of those before? How often?
- When you urinate how long does it take?
- Do you mind if I examine you today to find out why you are getting these infections?

Painful periods

- Does your mother or sisters (where relevant) have this pain as well?
- Tell me about your periods – how does the blood flow?
- How many days do you have periods for?
- I would like to examine you to find out what is happening with your periods. Is that ok with you?

Pain with sex – needs to be addressed with extreme sensitivity

- When did you get married?
- You said you have been having pain - can you describe the pain to me?
- When do you get the pain?
- I would like to examine you to find out why you are having this pain. Is that ok with you?

Pap smear

- Have you had a pap smear before?
 - If yes; how did that go? What was your result?
 - If no, as with all women, explain the process and show the woman a speculum.
- Most women find having a pap smear a little uncomfortable, but not painful. Before we start, I need to ask if you have had any female genital cutting as this may affect what type of test I use today.

HISTORY TAKING RELATED TO FGM/C IN PREGNANCY (NOT NECESSARILY RAISED AT FIRST CONTACT)

- (Ask all the general history, medical history, obstetric history first)
- Now, I need to ask you some questions about circumcision.
- We work closely with a clinic that specialises in the care of women who have been circumcised and can refer you to that service if needed.
- Have you been circumcised?

STARTING THE CONVERSATION ABOUT FGM/C WHEN IT HAS BEEN OBSERVED ON EXAMINATION

- I noticed when I was examining you that you have been circumcised
- Some women have difficulties with urination or painful periods – do you experience anything like that?

STARTING THE CONVERSATION ABOUT FGM/C AND HEALTH CONSEQUENCES

- Many women who have undergone circumcision have problems with their health (select some relevant health problems as examples).
- Circumcision does not have any benefits. In fact, it is the cause of many health problems.
- As a (doctor/nurse/social worker) I strongly recommend against future circumcisions because of the health problems it can cause. It is also illegal to perform circumcisions in Australia.
- Of course, I am happy to help you manage your health problems today and in the future.

STARTING THE CONVERSATION ABOUT FGM/C WHEN THE CLIENT SEEMS UNSURE ABOUT WHAT FGM/C IS

- I am not sure if this is relevant to you. In some communities babies, girls or women undergo a ceremony or operation in which the external part of the female genitals is cut and may be partially or fully removed.
- You may know this as circumcision, female genital cutting or another word from your language.
- Do you know if this has happened to you?

STARTING THE CONVERSATION ABOUT FGM/C AND THE LAW

- What do you know about the laws around female circumcision in Australia?
- In Australia it is illegal. It is illegal to perform any type of circumcision on babies, girls or women even if they consent to this procedure, it is still illegal. It is also illegal to take someone to another state or country to perform circumcision.
- Circumcision has been made illegal because it causes harm and can result in health problems.

STARTING THE CONVERSATION ABOUT FGM/C RELATED TO COUNTRY OF ORIGIN

- I notice you are from (country), do you know about circumcision?
- I see you are from (country). I have some experience in working with women from (country) and some have been circumcised. Have you been circumcised?
- I understand that in some countries female genital cutting is common. Have you had any female genital cutting?

Guiding principles for conversing with women about FGM/C

1. Show respect
2. Shift from the broad to the specific
3. Seek consent
4. Explain

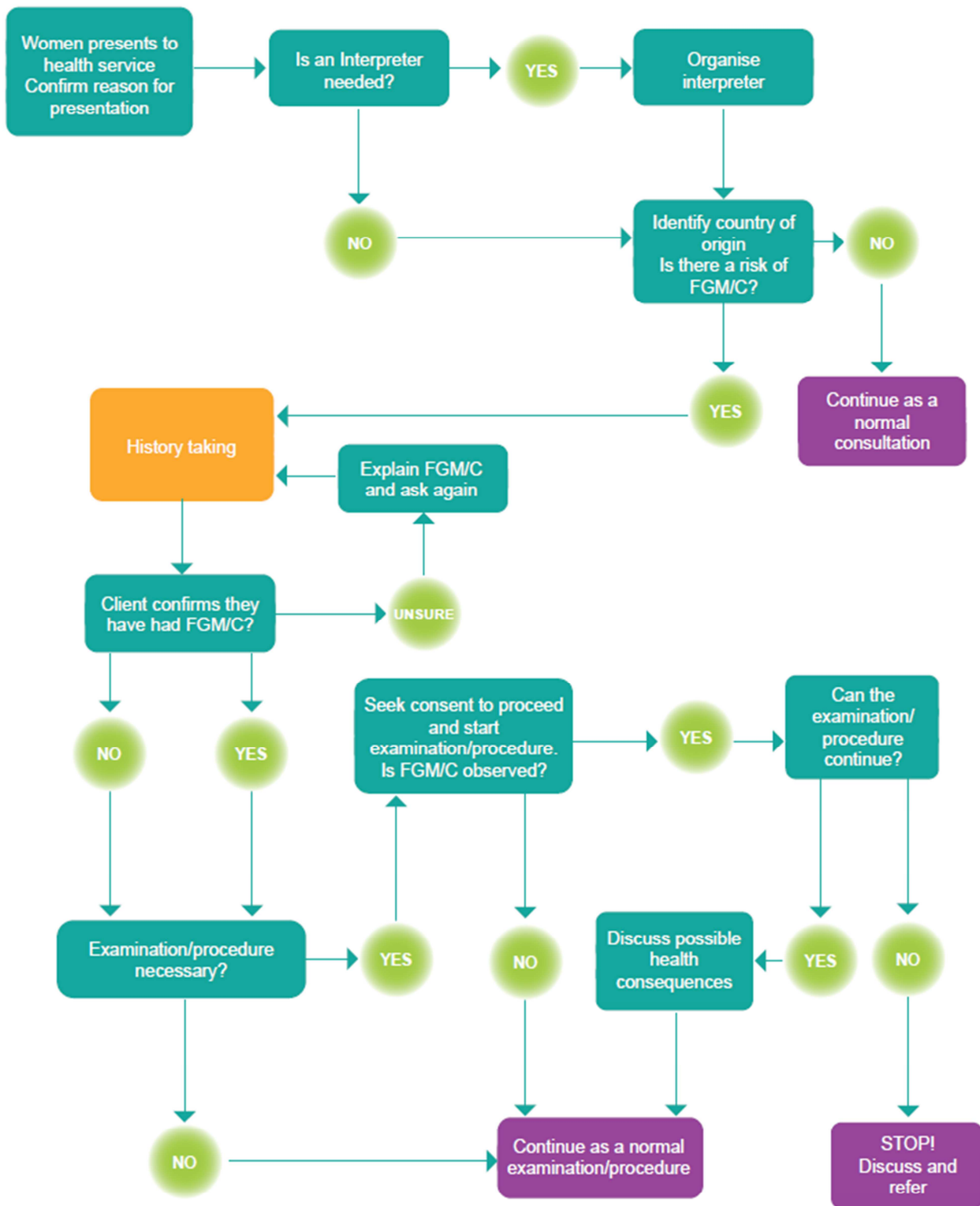
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7.6 FGM/C Conversation Flowchart

Conversation Flowchart



7.7 Health fact sheet A: Urinary tract problems

FGM/C Fact Sheet

Urinary tract problems

Page 1 of 1



Examples of urinary tract problems

- Recurrent urinary tract infections (UTIs) - due to urinary stasis or obstruction. Many women with infibulation (type III) have recurring UTIs and it is a common reason for women to present at health services
- Urinary incontinence due to urethral damage, fistula formation and over-distended bladder
- Voiding difficulties due to urethral damage, scarring or obstruction (e.g. can take up to 20 minutes to urinate, which client may view as normal)
- Dysuria
- Chronic urinary obstruction
- Hydronephrosis (with renal impairment) secondary to urethral injury and urinary tract obstruction
- Urethral vaginal fistula as a result of injury to the urethra or obstructed labour

Assessment

- Use professional interpreters as necessary. Telephone interpreters may be used if an interpreter is not available <http://www.tisnational.gov.au>
- Assess the woman (or girl) for urinary symptoms: urinary infection, recurrent urinary infection, difficulty with urination, urinary incontinence and urethral vaginal fistula remembering that it is possible that these problems may or may not be related to FGM/C
- Frequency of urinary problems may be an indicator of ongoing health issues related to FGM/C
- Assess the type of FGM/C

Management

- Recurrent UTIs: MSU and assess the need for antibiotics and prescribe according to guidelines. Continence: determine type of incontinence and make referrals accordingly
- Start a discussion regarding health issues and FGM/C (as indicated)
- Counsel the woman regarding the possible need for deinfibulation (as indicated)
- Assess renal function if concerns about possible hydronephrosis

Referrals

- Surgeon (urogynaecologist) (in the case of a fistula)
- Continence nurses and physiotherapists
- Women's health physiotherapists (often attached to maternity units)
- Well Women's De-infibulation Clinic at Royal Women's Hospital in Melbourne or High Risk Midwife Clinic at Auburn Hospital, Sydney
- Physician if concern about renal function

Resources

1. Continence Foundation of Australia Helpline <http://www.continence.org.au/pages/national-continence-helpline.html>
2. Continence resources in a range of languages <http://www.continence.org.au/other-languages.php>

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7.8 Health fact sheet B: Sexual function issues

FGM/C Fact Sheet

Sexual function issues

Page 1 of 1



Examples of sexual function problems

- Aparenia (absence or impossibility of sexual intercourse resulting in non-consummation) due to obstruction, painful scar tissue or vaginismus (involuntary vaginal muscle spasm)
- Dyspareunia (pain with sex) due to small vaginal openings or painful scar tissue around the vagina
- Vaginismus with or without introital scarring
- Impaired sexual response and enjoyment

Assessment

- Use professional interpreters as necessary. Telephone interpreters may be used if interpreter is not available or appropriate <http://www.tisnational.gov.au>
- Assess difficulties with sex
- Assess the type of FGM/C

Management

- Start a discussion regarding health issues and FGM/C (as indicated)
- Counsel the woman regarding the possible need for a deinfibulation (as indicated)
- Clients may require a sensitive approach to education on sexual positioning and use of lubricants to minimise pain or trauma during sex

Referrals

- Well Women's De-infibulation Clinic at Royal Women's Hospital in Melbourne or High Risk Midwife Clinic at Auburn Hospital, Sydney
- Psychosexual counsellors or psychologists who specialise in sexual health issues; often based in sexual health clinics or privately. Sex therapists can be found at <http://www.assertnsw.org.au/>
- Gynaecologists

Resources

- Overview of dyspareunia including treatment options <http://jeanhailes.org.au/health-a-z/sex-sexual-health/painful-sex-dyspareunia/>

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7.9 Health fact sheet C: Psychosocial issues

FGM/C Fact Sheet Psychosocial issues

Page 1 of 2



Examples of psychosocial problems

Emotional, relationship and sexuality concerns:

- Low self-esteem
- Psychological impact of physical issues and/or pain
- Psychological impact of infertility
- Unexplained physical symptoms e.g. back pain or headaches
- Guilt and shame
- Grief and loss
- Relationship problems
- Avoidance or fear of sexual relations due to trauma or pain
- Relationship problems secondary to sexual problems
- Fear of intimacy
- Body image concerns since settlement in Australia

Mental Health Concerns:

- Anxiety or depression symptoms or disorders
- Post trauma symptoms or disorders which might include:
 - Flashbacks: repeated intrusive memories or nightmares of the initial event (these may be triggered by gynaecological or obstetric procedures)
 - Blackouts: periods of memory loss or unconsciousness
 - Nightmares
 - Hypervigilance

Assessment

Use professional interpreters as necessary. Telephone interpreters may be used if an interpreter is not available
<http://www.tisnational.gov.au>

A psychosocial assessment is a process to identify current wellbeing from an individual, social, cultural, mental and physical well-being perspective. Some aspects to explore will include:

- Current well-being
 - Emotional
 - Self perception
- Family and support networks
- Relationship issues
 - Perceived impact of FGM/C
 - Sexuality
 - Communication
- Mental health signs and symptoms
 - Low mood
 - Anxious thoughts
 - Nightmares
 - Sleep disturbance
 - Changes in appetite
 - Intrusive thoughts
 - Repetitive behaviours/thoughts
 - Flashbacks
 - Avoidance

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Management

For clients presenting with signs of a mental illness (as listed above) you can refer to their GP for an assessment and development of a GP Mental Health Treatment Plan. This can provide access to Psychiatrists and Allied Health providers under the Better Access initiative for up to ten sessions per calendar year. Bulk bill services may be available via prior negotiation. For further information: www.health.gov.au/internet/main/publishing.nsf/.../mental-ba-gpsamp.

If you require information and support about the range of symptoms being presented you can contact the Transcultural Mental Health Service to gain clinical support and/or identify suitable referral options.

Referrals

- Transcultural Mental Health Service (NSW) 1800 648 911
www.dhi.health.nsw.gov.au/tmhc/
- Psychologists and Social Workers with experience working with CALD clients, cognitive behaviour therapy and trauma informed practice
 - <http://www.psychology.org.au/findapsychologist>
 - <http://www.aasw.asn.au/find-a-social-worker/search>
 - Social work or Psychology Department in your local Hospital or Community Health Centre
- Each state has specialised services that provide counselling for people who have undergone torture and trauma. Women experiencing psychological issues as a result of FGM/C may have counselling at these services. Services have multiple languages and are very experienced in using interpreters. Details of each service can be found at <http://fasstt.org.au/members/>

Resources

- http://www.fgmnationalgroup.org/psychological_aspects.htm
- <http://www.beyondblue.org.au/resources/for-me/multicultural-people>

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7.10 Health fact sheet D: Other reproductive health issues

FGM/C Fact Sheet

Other reproductive health issues

Page 1 of 2



Examples of other reproductive health problems

- Pelvic inflammatory disease (PID) as a result of obstruction of vaginal secretions due to occlusion of the vaginal opening (in women who have had type III) or due to the presence of primary stones in the vagina (calculi of urinary salts as a result of urine pooling in the vagina) or vaginal stenosis
- Contraception choices may be limited
- Infertility
- Difficulties with cervical screening

Assessment

- Use professional interpreters as necessary. Telephone interpreters may be used if interpreter not available or appropriate <http://www.tisnational.gov.au>
- Assess the type of FGM/C

Management

- PID: provide antibiotics for PID. Avoid giving women diagnosed with PID general information as this usually implies that a sexually transmissible infection is involved and this may not be the case for women affected by FGM/C
- Offer a range of contraception options that meet her needs in terms of culture, religion, social practices and any physical limitations she may have due to FGM/C. For example a diaphragm, vaginal ring, female condom or IUD may not be easily manageable or suitable depending on type of FGM/C
- Infertility: confirm with the client that she is able to have sex with her husband/partner and understands the role of penetrative sex and the fertile days in her cycle. Start the discussion regarding the need for more tests to determine the cause of infertility. Provide an overview of what fertility clinics can offer and the possible need for de-infibulation in order for specialists to carry out testing

- Provide patient education on cervical screening (bearing in mind some women come from countries with little or no preventative health). The proposed new National Cervical Screening Guidelines will likely incorporate the use of self-collected HPV DNA testing for under-screened women. For women who have infibulation consideration could be given to offering a high vaginal swab for HPV DNA testing as initial assessment of the need for further investigations (cytology/colposcopy) (thereby negating the need for a speculum examination initially). However HPV DNA testing is currently not Medicare rebated and is expensive
- Start a discussion regarding health issues and FGM/C (as indicated)
- Counsel the woman regarding the possible need for de-infibulation (as indicated)

Referrals

- Well Women's De-infibulation Clinic at Royal Women's Hospital in Melbourne or High Risk Midwife Clinic at Auburn Hospital, Sydney
- Fertility clinics: ideally seek out services that have experience in working with CALD clients (including use of interpreters and FGM/C where possible). Public clinics or bulk billing private clinics can provide free or low cost services for patients

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Resources

1. Contraceptive Choices National fact sheet <http://www.shfpa.org.au/sites/shfpa.drupalgardens.com/files/201308/SHFPA%20National%20Factsheet%202013%20Contraception.pdf>
2. Family Planning NSW translated fact sheets http://www.fpnsw.org.au/topic_factsheets.html?ID=69&TYPE=QUEUE&KEYWORD=4D756C746963756C747572616C&TYPE=AUDIENCE&BYDSND=TEXTU
3. Female Genital Mutilation: A student's manual (2001) Family Planning Method and type of FGM/C p75 http://www.who.int/gender/other_health/Studentsmanual.pdf
4. Female genital mutilation: Information for Australian health professionals (1997) Pelvic examinations and pap tests p48-49 http://www.ranzcog.edu.au/documents/doc_download/481-female-genital-mutilation-fgm- booklet.html.
5. NSW Health Multicultural Health Communication Service translated fact sheets. Including: Infertility: http://www.mhcs.health.nsw.gov.au/publicationsandresources#-eng&b_start=0&c1=Fertility Contraception: http://www.mhcs.health.nsw.gov.au/publicationsandresources#-eng&b_start=0&c1=Family+planning

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7.11 Health fact sheet E: Obstetric issues

FGM/C Fact Sheet Obstetric issues

Page 1 of 2



Examples of obstetric problems

Antenatal issues

- Urinary tract issues can be intensified during pregnancy
- Obstructed miscarriage for women with type III

Intrapartum care

- Additional pain
- Increased susceptibility to urinary problems and difficulty with catheterisation
- Difficulty for health professionals performing vaginal examinations
- Difficulty carrying out birthing interventions such as augmenting labour or use of foetal scalp electrodes
- Episiotomies and third or fourth degree tears
- Obstructed labour
- Higher chance of having a caesarean sections due to lack of staff knowledge around FGM/C, inability to use vacuum cap or forceps for delivery or obstructed labour

Postpartum care

- Post-partum haemorrhage
- Potential for body image disturbance as woman adjusts to her new post-birth, post- deinfibulation body

Assessment

- Use professional interpreters as necessary. Telephone interpreters may be used if interpreter is not available or appropriate <http://www.tisnational.gov.au>
- Take a sensitive and detailed history from women presenting to obstetric services
- Assess the type of FGM/C
- Continuity of care is essential for women affected by FGM/C so that they get access to the information and care they require throughout their pregnancy and post-natally. Caseload midwives or midwives working in group practice are well placed to provide this care.
- FGM/C is a category B in the Australian College of Midwives Incorporated (ACMI) guidelines. Early referral to obstetrician to build rapport, assess the patient and formulate a plan for delivery.

Management

- Conduct antenatal screening including blood born.
- Regular monitoring for urinary tract infections in pregnancy and at delivery.
- Over the course of the pregnancy formulate a detailed birth plan including a discussion on de-infibulation: what it involves, where the procedure is performed, the importance of health care providers being able to access the cervix before and during labour, what to expect after de-infibulation, and laws surrounding reinfibulation (this is illegal in Australia).
- Discuss the health consequences FGM/C in pregnancy and labour. For example, women who have undergone FGM/C may be at higher risk of third and fourth degrees tears or caesarean sections.

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- Provide women with options and be mindful that she may take time to make decisions as she may need to discuss this with her husband and family.

Referrals

- Senior caseload midwives or group practice midwives based at a level two or three hospital
- Large tertiary hospitals that have experience in providing care for women affected by FGM/C: Auburn Hospital in Sydney, The Women's Hospital in Melbourne
- Well Women's De-infibulation Clinic at Royal Women's Hospital in Melbourne or High Risk Midwife Clinic at Auburn Hospital, Sydney

Resources

1. Policy, Guidelines and Procedure Manual: Female Genital Mutilation – Maternity <https://thewomens.r.worldssl.net/images/uploads/downloadable-records/clinical-guidelines/female-genital-mutilation-maternity.pdf>
2. RANZCOG fact sheet has a good summary on pregnancy www.ranzcog.edu.au/doc/female-genital-mutilation.html
3. Many maternity wards have an in-house training course for midwives

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7.12 Health fact sheet F: Menstrual disorders

FGM/C Fact Sheet

Menstrual disorders



Examples of problems with menstruation

- Many women with infibulation (type III) have problems with menstruation and it is a common reason for women to present at health services
- Vaginal scarring and narrowing of the vaginal opening can result in congestion of blood, dysmenorrhoea and potentially retrograde menstruation. There may be associated endometriosis
- Young women may present with amenorrhoea and/or abdominal swelling due to vaginal obstruction, haematocolpos (accumulation of menstrual blood in the vagina), and/or haematomata (retention of blood in the uterus)

Assessment

Use professional interpreters as necessary. Telephone interpreters may be used if interpreter is not available or appropriate <http://www.tisnational.gov.au>

Assessment of menstrual problems:

- Type of FGM/C
- Marital status (as a culturally appropriate method of asking about sexual activity). Remembering, not all women will fit this stereotype and may have sexual relationships without being married
- Menstrual history including menarche, cycle, dysmenorrhoea, heavy menstrual bleeding/flow (clots, flooding), duration of bleeding

Management

- Normalise that many women (regardless of FGM/C) experience menstrual pain and discuss medications/techniques to manage this
- Consider commencing hormonal contraception eg the oral contraceptive pill or contraceptive injection to reduce menstrual blood. Careful consideration must be given to cultural acceptability of these methods and the woman's desire to get pregnant
- Pregnancy testing may be indicated

- Refer women for ultrasound (specify that this is not to be a trans-vaginal ultrasound, depending on the type of FGM/C)
- Start a discussion regarding health issues and FGM/C (as indicated)
- Counsel the woman around the possible need for de-infibulation, (highlighting this does not relieve dysmenorrhoea in all cases) or refer them to a service where this need will be addressed

Referrals

- Gynaecologists
- Family Planning clinics
- Reconstructive surgeons
- Well Women's De-infibulation Clinic at Royal Women's Hospital in Melbourne or High Risk Midwife Clinic at Auburn Hospital, Sydney

7.13 Health fact sheet G: Clitoral and vulval problems

FGM/C Fact Sheet

Clitoral and vulval problems

Page 1 of 1



Examples of clitoral and vulval health problems

- Clitoral neuroma resulting in pain
- Vulval abscess due to wound infection or embedded suture if labia has been sewn together
- Chronic vulval pain
- Vulval and vaginal scarring/keloid formation
- Vulval inclusion, sebaceous or dermoid cysts
- Vulval ulcers due to the formation of urea crystals in urine trapped under scar tissue
- Bleeding due to recurrent trauma

Assessment

- Use professional interpreters as necessary. Telephone interpreters may be used if interpreter is not available or appropriate <http://www.tisnational.gov.au>
- Examine the woman (or girl) for clitoral and vulval conditions – most women will need to be reassessed by a specialist
- Assess the type of FGM/C

Management

- Infection: assess the need for antibiotics and prescribe according to guidelines
- Referral to a gynaecologist, general surgeon or reconstructive surgeon may be indicated to manage cysts or abscesses
- Start a discussion regarding health issues and FGM/C (as indicated)
- Counsel the woman regarding the possible need for deinfibulation (as indicated)
- Clients may require a sensitive approach to education on sexual positioning and use of lubricants to minimise pain or trauma during sex

Referrals

- Gynaecologists/ general surgeon
- Reconstructive surgeon
- Well Women's De-infibulation Clinic at Royal Women's Hospital in Melbourne or High Risk Midwife Clinic at Auburn Hospital, Sydney
- The Australian and New Zealand Vulvovaginal Society have a list of specialists with an interest in vulval disorders. These specialists do not necessarily have experience with women affected by FGM/C but may be able to manage the vulval conditions. <http://www.anzvs.org/clinics.html>

Resources

1. Management of vulval abscesses <https://www.thewomens.org.au/health-information/vulva-vagina/vulva-vagina-problems/abscesses/>
2. List of specialists produced the Australian and New Zealand Vulvovaginal Society <http://www.anzvs.org/clinics.html>

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