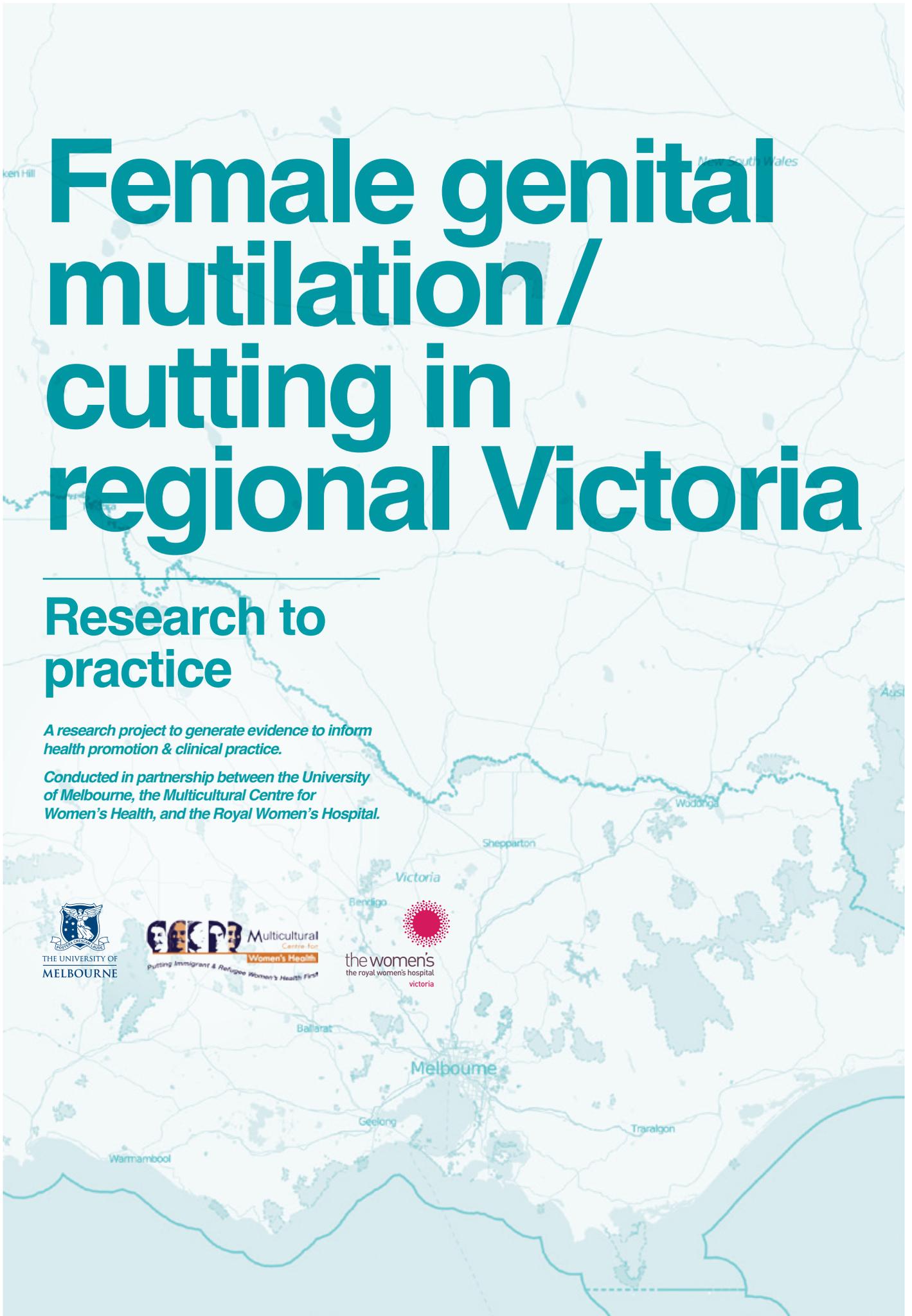


# Female genital mutilation / cutting in regional Victoria

## Research to practice

*A research project to generate evidence to inform health promotion & clinical practice.*

*Conducted in partnership between the University of Melbourne, the Multicultural Centre for Women's Health, and the Royal Women's Hospital.*





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# Acknowledgements

This report summarises findings from a research to practice project conducted by a team comprising researchers from the Centre for Health Equity (Melbourne School of Population and Global Health) and Melbourne Law School at the University of Melbourne; the Royal Women's Hospital; and the Centre for Multicultural Women's Health. The project was conducted in consultation with regional health and resettlement service providers, and members of the Kenyan, South Sudanese, Sudanese and Togolese communities living in the regional Victorian centres of Ballarat, Geelong, Latrobe (including Moe, Morwell and Traralgon) and Shepparton.

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# Executive Summary

Female genital cutting (FGC, also known as female genital mutilation, or FGM) is a practice that involves the partial or total removal of the external female genitalia for non-medical reasons. FGC does not have any health benefits, but may have significant short- and long-term consequences for the physical and mental health of women and girls.

There are approximately 35,000 people living in Australia who were born in one of the 29 countries where FGC is traditionally practiced (Costello et al. 2013). While most people migrating from countries where FGC is concentrated settle in metropolitan cities, a small proportion resides in regional and rural Australia. Available evidence suggests that the occurrence of FGC anywhere in Australia is rare, including in regional centres (Moeed & Grover 2012). However little is known about the health service needs and experiences of women and girls who are already affected by FGC prior to settling in regional areas. There is also little information available about the FGC-related knowledge, attitudes and skills of health service providers working in regional centres.

This report describes a community-engaged research-to-practice project aimed at generating evidence to strengthen support for girls and women living in regional communities who have health needs associated with FGC. The research underpinning this report was conducted in regional Victoria, but has relevance for policy makers and regional service providers nationally.

The project aimed to build evidence that could strengthen the capacity of service providers to meet the FGC-related health needs of women and girls in regional Victoria. Specifically the project engaged with community members and service providers in Ballarat, Geelong, Latrobe Valley and Shepparton to explore:

- community and service provider knowledge;
- community and service provider attitudes in relation to FGC;
- community health service needs and experiences in relation to FGC;
- capacity of service providers to meet community needs in relation to FGC; and
- the most appropriate strategies for building regional service provider capacity to provide FGC-related care to women from affected communities in regional Australia.

The project team conducted interviews and focus group discussions with 51 community members and 14 service providers from across regional Victoria. Data generated were analysed thematically.

## Key findings

Participating community members had **high levels of knowledge** in relation to the health consequences of FGC. Overall, communities also had high levels of awareness that Victorian law prohibits FGC, though some community members were not aware that taking daughters overseas for the purpose of FGC was also illegal.

Consistent with recent research in metropolitan Melbourne, participating communities reported that FGC was a **practice in decline**. Most participants were against the practice, although there was active community debate about abandonment of the practice in a least one recently arrived group.

While many African diaspora community members living in regional Victoria were not affected by FGC, some newly resettled **women and families are affected by the practice** and have FGC-related health needs including in relation to sexual and reproductive health, and the impact of FGC on sexuality and relationships. This finding was in contrast to the perception of health service providers, who held the view that FGC had minimal impact in regional Victorian centres.

Regional service providers rarely see women presenting for FGC-related care, and incidental discovery of the practice is also uncommon. This contributes to service providers' perception that FGC is not an important issue for regional communities. However, **screening for FGC is inconsistent across the state**. There are opportunities to strengthen screening for FGC through both refugee health assessment processes and in the antenatal setting.

Women from recently resettled communities face challenges accessing sexual and reproductive health care, including FGC-related care, that are exacerbated by the **limited availability and inadequate use of interpreters**. The limited use of interpreters by service providers has been identified as a particular issue in regional health services in previous studies, and this research project confirmed community members' access to interpreters is an ongoing problem.

The research team's initial intention to develop and pilot a professional development initiative for service providers in regional Victoria was proved inappropriate by the data. **Professional development needs are highly varied across the state**, with some service providers having undertaken professional development in relation to FGC previously and the current impact of the practice being variable across centres. No single approach was indicated. However all service providers interviewed indicated they were interested in having more information about FGC and the client groups in their particular location. Therefore the findings of this project will be widely disseminated to policy makers and regional service providers, including through community feedback meetings.

Participating community members indicated that they had **unmet health education needs**. In some settings this included FGC-related education, but was certainly not limited to this issue. All community groups requested community-based education in relation to sexual and reproductive health more broadly (including contraception), and breast and cervical cancer screening. The research team have allocated resources from this project to provide community education sessions in the language of community members' preference, and will liaise with regional service providers regarding ongoing health education needs identified by communities after these sessions. Service providers raised mental health and intimate partner violence as priority health issues for migrant communities in regional centres, and further research is indicated in these areas.

The variability in how FGC impacts on the health of women from diverse cultural groups in regional Victorian centres reinforces the need for careful and respectful health needs assessment of each newly settled community. This is relevant not just to policy and programs in Victoria, but to service providers working with immigrant and refugee communities in regional centres across Australia.

# 1. Introduction

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This report describes a community-engaged research-to-practice project aimed at enhancing support for girls and women who have health needs associated with female genital cutting (FGC, also known as female genital mutilation, or FGM) and who are living in regional Victoria. By building upon a model of community engagement and participation originally designed and implemented with FGC-affected communities in metropolitan Melbourne, this project has engaged communities and health practitioners about FGC-related health needs and experiences in regional Victoria.

As migration and resettlement patterns continue to evolve, regional Victoria has become home to sizeable communities from the 29 countries where FGC has traditionally been practiced. Approximately 35,000 people who live in Victoria were born in one of the 29 countries where FGC is traditionally practiced, and around 6% (1169 people) of these reside in regional areas. Present trends suggest that this figure will continue to grow (Costello et al 2013); over the period 2006 – 2011, the number of people living in regional Victoria who were born in countries where FGC is traditionally practiced doubled. Communities from countries where FGC is traditionally practiced are also growing in regional centres outside Victoria, in particular in New South Wales.

It is anticipated that knowledge generated through this project will inform evidence-based workforce training and education initiatives capable of addressing the needs of service providers working with communities affected by FGC living in regional Victoria and in regional centres nationally.

## *A note on terminology*

Female genital mutilation (FGM) is the term most commonly used by the United Nations and other international agencies to describe all practices that “involve partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons” (WHO, UNICEF, UNFPA, 1997). For over 20 years the World Health Organization (WHO) and the Inter-African Committee on Traditional Practices Affecting the Health of Women and Children have recommended using the term ‘female genital mutilation’ to emphasise that the practice is harmful and a violation of the rights of women and girls. ‘Female genital mutilation’ and ‘FGM’ is used in Australian legislation. However the term FGM can be offensive to women who have experienced the practice but do not consider themselves to be mutilated, and it can also be a barrier to engaging communities where female circumcision is traditionally practiced.

Our previous experience with affected communities in inner Melbourne confirmed that some community members may use, and be comfortable with, the term ‘FGM’ (Vaughan et al. 2014). However, we found that this term can be uncomfortable and offensive to many members of the community. ‘FGM’ was perceived by many to be a polarising term, and requests for researchers and service providers to use alternative language were felt to have been ignored in the past. The practice may be described by community members with a variety of terms including FGM, FGC (female genital cutting), female circumcision, and words in their mother tongue that most directly translate to ‘cut’ or ‘circumcision’. For the purposes of this report, the acronym FGC is used – other than when directly quoting respondents or source documents. The research team acknowledges the diversity of experiences among girls and women who have undergone the practice, and in how they may identify and interpret their experience. We recognise in turn the limitations of any one term adequately capturing these diverse perspectives and experiences.

## What is FGC?

The World Health Organization (WHO) classify female genital cutting into four major types, as described in the table below (WHO 2014, UNICEF 2013):

World Health Organisation Classifications	
<b>Type I</b>	<b>Clitoridectomy:</b> partial or total removal of the clitoris and/or the prepuce (the fold of skin surrounding the clitoris). Some practising communities refer to this type as <i>sunna</i> (Arabic for 'tradition' or 'duty')
<b>Type II</b>	<b>Excision:</b> partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora. There is considerable variability in the form and degree of cutting within this type
<b>Type III</b>	<b>Infibulation:</b> 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. Usually the cut edges of the labia are stitched together (infibulation), resulting in near complete covering of the urethra and vaginal orifice. This must be reopened for sexual intercourse and childbirth (deinfibulation)
<b>Type IV</b>	<b>Other:</b> all other harmful practices to the female genitalia for non-medical purposes, e.g. pricking, piercing, incising, scraping and cauterising the genital area. Nicking the genitalia to draw blood, without removal of tissue or permanent alteration of genitals, is sometimes called 'symbolic circumcision'

Female genital cutting does not have any health benefits. All of the practices described above involve removing or injuring normal, healthy female genital tissue. This interferes with the natural functions of girls' and women's bodies (WHO 2014). FGC can have significant short- and long-term consequences for the physical and mental health of girls and women.

## Health consequences of FGC

Short-term consequences of the practice include pain, shock, bleeding, and infections. Some of these consequences can result in death. Longer-term health consequences can include dermoid cysts and abscesses, chronic pelvic infections, recurrent urinary tract infections, increased risk of complications during childbirth (including association with higher caesarean section rates, increased risk of haemorrhage and tears), negative psychological consequences, and sexual problems (WHO 2011). Risk of longer-term complications increases with the severity of the cutting and subsequent scarring. It should be noted that some women report no adverse consequences.

## Where and why is FGC practiced?

FGC is most commonly practiced in 29 countries in Africa (in a belt of countries from the Atlantic coast to the Horn of Africa/East Africa) and the Middle East (Yemen and Iraq). Cutting practices across and within these countries are highly diverse, as is prevalence – with estimates of the percentage of women and girls who have experienced the practice ranging from 1% in Uganda up to 98% in Somalia (UNICEF 2013). FGC is also known to occur in some countries in Asia (including countries with large populations now living in Australia, for example India, Indonesia and Malaysia) but it is unknown how common this is, or how many women and girls are affected (WHO 2011).

# 1. Introduction

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In most practicing communities, FGC is regarded as a cultural tradition, something that is expected for girls and women, and as a social obligation to the community (usually other members of the same ethnic group). It is perceived that the majority of girls in the group are circumcised and that families, and the girls themselves, may be subject to community sanction if daughters are not cut. That is, in many communities, FGC can be defined as a *social norm* meaning “it is difficult for individual families to stop the practice on their own” (UNICEF 2013, p.15). A social norms perspective highlights the role of the collective in making change, rather than seeing responsibility for elimination of FGC lying solely with individuals or individual families.

In some communities prevalence of FGC is associated with place of residence (with FGC being more common in rural areas) though this is not consistent across countries and cannot be seen as a causal association. FGC is usually less common in households that are relatively wealthier and where mothers have had more education, though again there is some variability across countries and data need to be interpreted with caution (UNICEF 2013).

## **Current Context in Regional Victoria**

Families from countries that traditionally practice FGC began settling in Australia in notable numbers in the late 1980s. Migration to regional and rural areas has increased rapidly over the last decade, with the support of both state and federal governments. The federal government *Report of the Review of Settlement Services for Migrants and Humanitarian Entrants* (DIMIA 2003) is credited with stimulating renewed impetus for regional and rural settlement nationwide (McDonald et al. 2008). Federal commitments in the 2004-2005 Budget aimed at doubling refugee settlement in regional areas by 2005-2006, and government support for regional resettlement has continued since this time.

New South Wales is the largest settlement area for humanitarian entrants to Australia, having received 31% of the nation's total over the past five years. A significant number of these new arrivals have settled in regional areas, and include families from countries that traditionally practice FGC (Refugee Council of Australia, 2014). Victoria settles the next largest number of humanitarian entrants, having received 29% of the nation's total over the past five years. Humanitarian entrants from African source countries have made up a significant proportion of people recently resettled in Victoria, with the peak in African humanitarian entrants to the state occurring in 2004-2005 (DEECD 2011). People from Sudan/South Sudan made up the largest group of humanitarian migrants to Victoria over the period 1996-2008, with entrants from Ethiopia and Somalia making up the 7th and 8th largest groups of humanitarian migrants respectively over the same period (DEECD 2011).

In Victoria, Regional Humanitarian Resettlement Pilots began in 2006-2007 with support from all three levels of government (McDonald et al. 2008). There are continued efforts to directly resettle new humanitarian entrants in regional Victoria, consistent with government policies encouraging regional development and aimed at addressing regional skills and population shortages. Secondary migration also sees families who were initially settled in city areas choosing to resettle in regional areas either through formal programs or in order to access affordable housing and better work opportunities (Victorian Multicultural Commission 2008). People from countries where FGC was traditionally practiced may also reside in regional areas as skilled migrants and as international students.

Several studies have investigated the impact of these demographic trends on regional health services in Victoria. A study of the impact of Regional Resettlement Pilot Programs on health services in Shepparton and Ballarat observed that overall local health systems adapted well, with program viability depending as much on government funding as “the intensive planning, co-ordination, flexibility and dedication of the individual health care providers” (ECCV 2011, p.6). The authors observed that general shortfalls in regional health provision, such as the lack of GPs in some regional centres, converged with the unique health needs of many resettling community members, and that many humanitarian entrants (in particular) faced difficulty accessing health services once they were no longer eligible for assistance from settlement services. Other studies around the health needs of newly arrived people in regional Victorian settings have highlighted the need for a social model of health; ensuring processes for consulting and engaging communities; and well-integrated planning and accurate research to support service delivery (McDonald et al. 2008; ECCV 2011).

# 1. Introduction

In 1998 the Victorian Department of Health established the Family and Reproductive Rights Education Program (FARREP) as the primary response and prevention point for women and communities affected by FGC. FARREP aims to work with communities that practice FGC in order to strengthen their knowledge about the practice and support changes to attitudes, with the aim of preventing the occurrence of FGC; increase access to sexual and reproductive health services by women and girls from affected communities; and to build capacity of health services to respond to the health needs of women affected by or at risk of FGC (Department of Human Services 2009). At this time FARREP services are only available on a regular basis in metropolitan Melbourne.

## Limited evidence about the impact of FGC in regional settings

A long-standing challenge facing health service providers in countries where migrants from FGC practicing communities now reside, has been the absence of reliable data on the prevalence of the practice. However available data were recently drawn together in a comprehensive compilation of the current statistics across affected countries, *Female Genital Mutilation/ Cutting: A statistical overview and exploration of the dynamics of change* (UNICEF 2013).

Of particular relevance to this report are the data in this UNICEF (2013) report specific to Sudan, Kenya and Togo – countries of origin for community participants in this project. The current estimated prevalence of FGC for women aged 15-49 years in Sudan is 88%, Kenya is 27% and Togo is 4% (UNICEF 2013, p. 26). It should be noted that many migrants from 'Sudan' now resident in regional Victoria are actually from South Sudan. As a new country there is no reliable FGC data for South Sudan, but the prevalence of FGC in the country is thought to be considerably lower than in its northern neighbour,

although FGC certainly occurs in parts of South Sudan.

These national level data mask the substantial variability that exists in cutting practices within countries (between different ethnic groups and between rural/urban areas). While the prevalence of FGC is low to moderate in Togo and Kenya, it is very high for particular ethnic and cultural groups within those countries (with FGC prevalence in parts of Kenya, for example, over 80%). Data on the specific groups that regional Victorian migrants come from is unavailable.

It should also be noted that using national level prevalence measures to estimate the number of girls at risk in destination countries for migration "overestimates the true risk to girls from countries where there has been a decline in FGM/C prevalence" (UNICEF 2013, p.23), and that researchers have found that parents' intentions to circumcise their daughters decline after migration (see, for example, Morison et al. 2004, Johnsdotter et al. 2009, Gele et al. 2012). Attitudes towards FGC also appear to be changing in the countries of origin most relevant to this report (UNICEF 2013).

Review of the Australian literature highlights a number of documents relating to the impact of FGC in Melbourne and other metropolitan centres in Australia. These include publications relevant to clinical practice (Bayly et al. 1997; Bayly 2002; Ogunsliji et al. 2007; Jordan & Neophytou 2013), the clinical experiences of women affected by FGC (Knight et al. 1999; Murray et al. 2010), and African women's reproductive health more broadly, including discussion of FGC (for example Allotey et al. 2001; Allotey et al. 2004). In 2012 Moeed & Grover surveyed health workers to investigate whether FGC was being performed in Australia, and found there was no evidence of health professionals performing FGC (though they noted

that people other than registered health practitioners may be doing so).

In 2012-2013, the research team conducted the largest study focused specifically on the impact of FGC in Australia to date, in conjunction with members of the Eritrean, Hararian, Oromo, Somali and Sudanese communities of Carlton, Collingwood, Fitzroy, Flemington, North Melbourne and beyond. This study, focused on inner Melbourne, found evidence of a substantial generational shift towards abandonment of FGC. However the study also found that women who had already experienced FGC prior to arrival in Australia often faced ongoing negative consequences in relation to sex, pregnancy and childbirth, and mental wellbeing. Women's experiences with FGC-related services in inner Melbourne had improved over the last decade, but care was inconsistent with not all service providers having the appropriate cross-cultural communication and clinical skills to address women's health needs.

While health services in metropolitan Melbourne can draw on research evidence to inform their policy and practice, very little is known about the health service needs and experiences of women and girls affected by FGC prior to moving to regional Victoria, and who may require access to health care that is responsive to the lasting impacts of the practice. The FGC-related knowledge, attitudes and skills of health service providers working in regional Victoria are unknown, and it is unclear whether service providers are able to meet the needs of women and girls now living in regional centres. The lack of information about the impact of FGC in regional Australia was raised as a concern at the National Summit on FGM held in Canberra in 2013. This project has sought to address these knowledge gaps through locally grounded research in four Victorian regional centres (Ballarat, Geelong, Latrobe Valley and Shepparton).

# 2. Methods

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The aims of this project were to identify the FGC-related service needs prioritised by affected communities living in Victorian regional centres, and to build evidence as to the training, education and professional development required for service providers working in regional Victoria to be able to meet these needs. As this project was not trying to establish prevalence or incidence of FGC, but was rather interested in people's experiences, attitudes, perceptions and needs, a qualitative approach was used. This project built on the research team's experience of community-based research in relation to FGC (see Vaughan et al. 2014), with a strong focus on building relationships with local service providers and community members prior to data collection.

The project focused on the four local government areas (LGAs) in regional Victoria that are home to the largest communities from countries where FGC has traditionally been practiced (Costello et al. 2013): City of Greater Geelong, Greater Shepparton City, Latrobe City and City of Ballarat. It should be noted that available data, distilled from census data on country of birth, may not accurately reflect the impact of FGC on particular communities living in regional communities. 'Country of birth' cannot capture the enormous variance in FGC prevalence and practices across countries and between different cultural groups (UNICEF 2013). However, these data provide the best guide to potential impact of FGC in regional communities that is available to researchers, policy makers and service providers at this time.

## **Aims and objectives**

The project aimed to identify the health service needs of communities affected by FGC and living in regional Victoria, and to inform evidence-based strategies for building the capacity of service providers to meet these needs. Specifically the project engaged with community members and service providers in Ballarat, Geelong, Latrobe Valley and Shepparton to explore:

- community and service provider knowledge (including knowledge of the short and long term consequences of FGC);
- community and service provider attitudes in relation to FGC (including views on the role and meaning of FGC and whether and how perspectives change and/or differ over time – for instance between cultural, generational and professional groups);
- community health service needs and experiences in relation to FGC;
- capacity of service providers to meet community needs in relation to FGC; and
- the most appropriate strategies for building regional service provider capacity to provide FGC-related care to women from affected communities in regional Australia (including a review of existing resources, and in consultation with relevant professional associations and service provider peak bodies).

## **Recruitment**

### *Recruiting community members*

Health, settlement and other service providers who were actively engaged with culturally and linguistically diverse communities were contacted to obtain referrals to community members, with a process of snowballing of contacts often set in place. Individuals willing to be 'contact persons' for the project, either in their capacity as a service provider or as an active community member, were identified in this manner. Contact persons were provided with project information to share with community members, and would liaise with communities about their preferred meeting arrangements (eg: language preferences and child care needs) should they wish to participate. In each regional centre, recruitment targeted members of the three largest cultural communities from countries where FGC is traditionally practiced, as identified in the available data (Costello et al. 2013).

### *Recruiting service providers*

The research team identified service providers willing to participate in the project by drawing on the networks of the Multicultural Centre for Women's Health and the Royal Women's Hospital, and through referrals from locally-based organisations with well-developed networks in their communities. These organisations included the women's health service operating in each LGA and the University of Melbourne Centre for Excellence in Rural Sexual Health in Shepparton. Service providers were contacted by email and, on occasion, directly by telephone. If they were interested in participating, they were invited to nominate interview dates and times most convenient for them, at which point written consent was obtained. Service providers who wished to support the project but who felt they had limited experience with FGC often suggested alternative contacts within their local service networks.

## 2. Methods

Recruitment involved extensive communication with service providers and community members, and was a more time consuming process than anticipated, resulting in considerable delays to project implementation. For example, in the case of one city, recruitment involved contacting relevant people at four general practices; four community health and settlement service providers; the local council; the local public hospital; an institute of research; a local ethnic society; a multicultural council; as well as individuals in the community. The challenges of communication and recruitment were compounded by the part-time employment arrangements of both members of the research team, and service providers in many regional organisations.

### Reflections on recruitment

Recruitment of members of communities affected by FGM/C proved to be quite challenging in this project. One of the primary obstacles to recruitment of community members lay not in a lack of community members' interest, but in the limits of the research team's networks – as accentuated by our remote (metropolitan) location. The project is indebted to all service providers and 'contact persons' who facilitated opportunities for women's participation. Community members were usually quite willing and interested to participate once the opportunity was presented, with community members approached by the research team rarely (if ever) declining to be involved. However, two community contact persons reported finding it difficult to find available and interested participants, at which time the research team identified alternative avenues for reaching communities in those areas.

The team was quite reliant upon service providers (particularly those working in refugee and migrant health and settlement services) to link us with community members. In many cases, service providers reported having limited

contact with relevant community groups as they had resettled in Australia more than five years ago, and were therefore no longer eligible for assistance through resettlement services. In other instances, assumptions made by service providers as to what is sensitive and relevant for communities shaped how opportunities for women's participation in the project were made available. Early conversations with some community health and settlement service providers revealed their impression that regional communities are not impacted by FGC, though this was not supported by data collected during the project. Women *are* affected by the practice, and are living in those regional centres where service providers' view that the issue was not relevant was expressed most strongly. Some service providers indicated that FGC had never been raised by community members, and against the backdrop of their enduring community relationships, felt that this implied community members were unaffected by the practice. Other service providers were uncertain whether and how FGC might be acceptably broached with the communities they served. Concerns about the sensitive nature of FGC were expressed alongside frustration, particularly in one location, that local communities were 'researched out' or that their area was 'the pilot place for everything'. These statements may have reflected concern about the skills and intentions of the researchers as outsiders, but also reflect the strong desire among service providers to protect their good relationships with local communities.

The research team acknowledge the considerable investment service providers had often made in building strong and respectful relationships with communities, and that these could be jeopardised by 'inflicting' unknown researchers upon communities – particularly given that the team were not local and wanted to investigate a potentially sensitive topic. However, the team did not anticipate the length of time

it would take to build the trust of service providers in *addition* to the time required to build relationships with community groups (which was anticipated).

### Data Collection

#### Community members

Data collection was based on the model of engagement devised through consultations with communities affected by FGC in metropolitan Melbourne (Vaughan et al. 2014). From these consultations the research team understood that potential participants often appreciate a choice between private interviews (sometimes with friends or relatives present) and focus group discussions. However, in this particular project, community members recognised the challenges associated with data collection in regional centres and primarily elected to participate through focus groups, minimising the complexity of logistical arrangements and maximising the opportunity for participation by as many community members as possible. Our past experience suggested that focus groups work best when they bring together women of the same age, language and cultural group, and every reasonable effort was made to promote these arrangements in this project. The focus groups held in one regional centre (Lalor) were a notable exception, as they were formed around friendship circles and brought together different cultural and language groups. While this introduced new shades of complexity to the discussion (with affected and non-affected women wishing to highlight different health priorities), participants with experiences of FGC were not inhibited from sharing their needs and experiences and were in fact supported in doing so. Another notable exception brought elder and younger women together in a discussion that highlighted the generational nature of changing sexual and reproductive health perspectives.

## 2. Methods

Focus groups were conducted by a member of the research team and interpreter arrangements were made as required and according to community preferences. On some occasions interpreters were known to participants, and on other occasions they were sourced through a Melbourne-based agency. While this project primarily focused on collecting the views and experiences of women, in Shepparton a contact person indicated that men in the area also wished to participate in the project, and it was felt appropriate to welcome all interest in the project. While work commitments precluded more men from participating in the data collection, an interview was held with one man at this site.

Focus group discussions ran for approximately 1.5 hours. Permission was sought to audio record each interview and discussion, and this was granted on almost all occasions. Notes were always taken in case of audio failure, and were the primary source of data when permission to record was declined (2 focus groups). Group discussions took place in a variety of community meeting rooms nominated by participants or identified in consultation with a contact person.

### *Service providers*

Service provider interviews were conducted by a member of the research team, in English, and ran for approximately 45 minutes. Interviews were conducted at a time and place of each participant's convenience (usually their place of work), and most interviews were held face-to-face. Scheduling constraints meant that two interviews were conducted by telephone, and consent was obtained by email.

### *Participants*

Over 50 community members participated in 9 focus group discussions. A higher concentration of focus groups in one regional centre reflects the particularly strong support the project received from a local community organisation. In addition, 15 health service providers participated in interviews with three to four participants being interviewed in each of the regional centres.

### **1. Community Member Focus Groups and Interviews**

LGA	Community Group	Participants
<b>BALLARAT</b>	Togolese Women	5
<b>BALLARAT</b>	South Sudanese (Nuer) Women	6
<b>LATROBE</b>	Sudanese (Nubian) & South Sudanese (Nuer) Women	9
<b>LATROBE</b>	Sudanese (Nubian) & South Sudanese (Nuer) Women	8
<b>GEELONG</b>	South Sudanese (Nuer) Women	8
<b>SHEPPARTON</b>	South Sudanese (Dinka) Women	5
<b>SHEPPARTON</b>	Sudanese (Nubian) & South Sudanese (Dinka) Women	7
<b>SHEPPARTON</b>	Kenyan Women	2
<b>SHEPPARTON</b>	Male community member	1
<b>Total Community Participants</b>		<b>51</b>

### 2. Service Provider Interviews

LGA	Service providers	Participants
BALLARAT	Medical Consultant; (Former) Community & Refugee Health Worker; and GP	3
LATROBE	Midwife; (Former) Community & Refugee Health Worker; Community Health Worker; and GP	4
GEELONG	Medical Consultant; Sexual Health Practitioner; Refugee Health Practitioner; and two GPs	5
SHEPPARTON	Medical Consultant; Senior Midwife; and Community Development Worker	3

#### Data analysis

Where interviews and group discussions were digitally recorded, these recordings were transcribed verbatim. For the two focus groups for which there was no audio, the facilitator expanded upon their notes to type up a full account of the discussion as soon as possible after the event. All transcripts and notes were subjected to thematic analysis. Through reading and re-reading of the transcripts the research team developed a list of codes and clustered these into key themes. All data were coded, with NVivo software used to facilitate this process. Research team members reviewed the coded data and revised the list of identified themes that form the basis of this report.

#### Ethics

A number of ethical issues were considered in the design and implementation of this project. Steps were taken to ensure privacy and confidentiality for participants during data collection with focus groups being facilitated with groups of people from the same cultural community, as much as possible and in accordance with participant wishes. Where participants indicated that they would prefer to participate in an interview, rather than a group discussion, this was accommodated.

Participation was voluntary, with all participants having the opportunity to read and discuss the project's plain language statement and consent form (translated as appropriate) – with and without a researcher being present – prior to providing written consent to their participation in the project.

Research questions were designed so as to avoid being personally intrusive. Community members were asked about their awareness of FGC, their views on the role and meaning of FGC in their cultural community, and about their health-service experiences related to FGC. They were not specifically asked about their own experience of FGC, or their intention with regard to circumcision of their daughters or granddaughters. Some participants chose to share their personal story (of circumcision prior to coming to Australia, for example), and were not prevented from doing so. However the plain language statement emphasised that this was not the purpose of the research, and the question guides used in focus groups and interviews were carefully designed to minimise the potential for unintended disclosure.

At the beginning of each focus group or interview participants were reminded that should researchers form a reasonable belief that a child or children were at risk of FGC, researchers would then have a mandatory duty to report this to the Department of Human Services. This information was also included in the plain language statement. Participants were also reminded that disclosure of any information to suggest a health practitioner had performed FGC might oblige researchers to notify the Australian Health Practitioner Regulation Agency of the conduct. There was no occasion that required mandatory reporting during the project.

This project was approved by the Human Research Ethics Committee at the University of Melbourne.

# 3. Findings

Findings of the data analysis will be presented in relation to regional Victorian community members' knowledge in relation to FGC; the role and meaning of FGC for communities now living in regional Victoria; perceptions of community members and service providers in relation to the impact of FGC on women's health and wellbeing; the current health service responses to FGC; professional development for service providers in relation to FGC; and the other health priorities of participating communities that were identified through the research process.

## 3.1 Local knowledge of FGC and its consequences in regional Victoria

### Community members' knowledge

#### Knowledge of the law

Echoing the research team's recent findings among communities in inner Melbourne (Vaughan et al. 2014), most community members demonstrated both awareness and acceptance of Australian law.

*"Yeah she said ah the circumcision in Australia, she said you not allowed to, even to take your child back home"* (Interpreter for community member, Shepparton)

The illegality of taking children abroad for circumcision was specifically mentioned by many, but a small number of participants were unaware of this aspect of the law and sought more information around this. Community members were also aware that FGC was illegal in most countries of origin.

Community members described Australian legislation, and legislative reform in home countries, as contributing to change in social norms relating to FGC. However it was also clear that legislative efforts were most effective when combined with public health education (particularly about the negative health consequences of the practice) and service delivery.

*"From the broadcast from TV, from newspaper, and yeah, everybody's talking about it's bad, not to do it"* (Interpreter for community member, Latrobe)

#### Knowledge of the health consequences

Participants similarly demonstrated sound awareness of the health consequences associated with FGC. Women who had undergone the procedure themselves, or who had formerly been midwives, demonstrated the greatest knowledge of potential health consequences.

*"When it heal, it's really bad, even when you have to pee, and when you have period, it's really hard"* (Interpreter for community member, Shepparton)

*"When the woman has a baby, it has to be cut before the baby's coming out and after that they have to stitch it"* (Interpreter for community member, Shepparton)

All participants were from countries known to traditionally practice FGC. However some women were from cultural groups within those countries who do not traditionally circumcise their daughters. Women who did not belong to traditionally practicing cultural groups, or who had not grown up 'back home', often saw the focus group discussions as an opportunity to extend their understanding of the legal and health implications of the practice, and group discussions were often characterised by an exchange of information. Participants in one group

spoke openly about the impact of FGC on their own health, sharing this with women in the same group discussion who were not affected by the practice. Health knowledge was also attributed to health promotion campaigns in home countries, as well as to knowledge gained through migration experiences.

*"So we had this project on this circumcision, female circumcision from Sudan, because a lot of woman affected for- been affected by this, a lot of side effects, and people die because of the- so we heard from before we come here"* (Interpreter for community member, Latrobe)

FGC was frequently discussed in terms of the practices known by participants as 'sunna' and 'Pharaonic' (corresponding roughly to types I and III in the WHO classifications), and focus groups often involved participants providing detailed descriptions of the different types of procedure to each other. Participants' conversations emphasise the importance of health workers understanding the enormous variance in FGC practices, and that health workers need to be able to elicit information about a woman's experience (and potential needs) without referring to the WHO classifications that most women were unfamiliar with and found puzzling. Participants suggested that the use of visual diagrams may aid this conversation.

*"They don't tell us which form of circumcision. You don't get told. It's done in secret. If you ask you can't be told. Something not to discuss"* (Community member, Shepparton)

*"If you ask [affected women] 'how was it done?' they can tell you, but not what type of circumcision... They can explain what skin is removed... If you ask 'how was it performed?' they will tell you"* (Community member, Shepparton)

### 3.2 Role and meaning of FGC for communities now living in regional Victoria

#### A practice in decline

There was general consensus among community members who participated in this project that their communities had already abandoned FGC, or that it was a practice in decline. Most community members expressed the view that FGC was something that 'shouldn't be done'. Participants linked legislative reform and public health campaigns in their home countries to attitudinal change both 'back home' and in Australia. Representations of FGC in film were cited by some as influential, as was the education provided by some church groups. Migration to the Australian context was considered to be a key factor in changing attitudes, including a desire to observe Australian law and to 'live as other people live'.

*"It's changed, nobody been doing it in Australia"* (Interpreter for community member, Shepparton)

*"I know everybody was born into an already existing culture and they practice whatever is in their culture but they [community members] realise that they all cultural things are not right and all of them are not wrong, so they to you know, see what the, the bad one, get rid of the bad one, and keep the good ones"* (Community member, Shepparton)

Abandonment of FGC represents a rapid generational shift. Community members spoke of not wishing their daughters to suffer as they had, and of children who now choose for themselves.

*Interpreter: I have seven years old daughter and when we ask her... she said "I will not do it myself, I don't like it".*

*Interviewer: A seven year old says this? (Interpreter: Yeah) (Participant: Yeah) Oh wow, so she knows about it? Yep. How does she know?...*

*Interpreter: We discuss about it at home, back Sudan also they bring it the TV and they know the meaning of course and they ask 'what is this?' and they explains for them*

(Interpreter for Community member, Latrobe)

While the overall representation of FGC from community members was one of a practice in decline, abandonment of FGC remains a contested issue for some regional Victorian families. Some groups shared stories of parents taking children home to be circumcised and their concern about these families facing legal repercussions on their return to Australia, with some enquiring about the penalties for such actions. No identifying details of these cases were shared by participants, and the stories appeared to be exchanged as edifying anecdotes. Others referred to resisting pressure from families in home countries to bring their daughters home for the procedure, but saw the declining relevance of FGC 'back home' as further diminishing its value in Australia.

*"People back home they will still call us and say 'no you have to bring the kids back and do this and this' and I said to her, to them, 'no this is not the time I can do these things to my kids because I don't think it's right'"* (Community member, Shepparton)

*"She said these people they shouldn't be doing it still because it's abandoned even back home they abandoned, why are they still doing it even in Australia?"* (Interpreter for community member, Shepparton, responding to the suggestion of children being taken abroad for FGC)

One woman felt that parents living in her city 'still consider doing it to their girls' despite fearing the law. She spoke of a friend who was afraid of being circumcised. The friend, who belonged to a non-African cultural group, felt unable to seek help because she did not want her parents to get into trouble. Disclosure of this information made the participant feel uncomfortable and she declined to speak further, potentially illustrating how mandatory reporting requirements can inhibit community members' access to FGC-related support. In addition, this exchange reinforces the importance of further efforts to engage non-African communities (including those from Iraq, Malaysia and Indonesia) where FGC may be practiced. Very little is known about the impact of FGC on women from practicing cultural groups from these countries, including within diaspora communities.

#### Meanings of FGC

Community members described FGC as a cultural practice or tradition dating back many centuries. The rationale for FGC was most often described as curtailing female sexual desire and sexual activity, but was sometimes attributed to a Pharaonic decree. The 'Pharaonic' form of FGC was seen to predate 'Sunna'. Practices described as 'sunna' (type I FGC, or clitoridectomy) were sometimes linked to notions of 'cleanliness' or 'purity'. Participants described how in the past FGC was seen to protect a woman's virginity and, in a context where virginity before marriage was highly valued, her marriageability.

## 3. Findings

Non-conformity could compromise a woman's marriageability as well as a family's social standing. Women's stories emphasised not only how non-conformity was censured, but also how community celebration and reward (in the form of social inclusion) worked to perpetuate FGC through the generations.

*"[At the time of marriage] If you [were] used by another man, any, they can know and if you didn't use by another man everyone will be happy, everyone will cry even... Then everyone will be happy, then the man's side will have the cows killed, the woman's side will have cow killed, everyone in an area will be happy and dance and say 'yeah, she's a girl, she's you know never used' and it's really good and nice thing in that sort of culture"* (Interpreter for community member, Shepparton)

The role and meaning of FGC differed among participants from affected communities, as well as for those from cultural groups with no tradition of genital cutting. Participants from groups for whom FGC was not a traditional practice had primarily negative associations with the practice.

Surprisingly, differences in personal perspectives and experiences did not inhibit discussion on those occasions when women from affected and non-affected cultural groups came together in the same focus group discussion. However on one occasion it became apparent that discussions could become antagonistic. For instance, should FGC be described in relation to cleanliness, this could be perceived to imply a standard by which women from other communities were judged to be unclean.

*"But if you ask them are you circumcised, they said yes but you [are] not. They feel like you didn't have the good, you know the good thing, in your life. For us as a group, as a Sudanese or South Sudanese and with other group, they feel like they are better than us because they have that sort of thing"* (Interpreter for community member, Shepparton)

Members of affected communities emphasised that FGC is not a religious obligation, and indicated that disassociation of FGC from religion was important. Indeed, education provided by some churches and religious leaders was felt to have helped drive change. The sentiment that women were created whole by God or Allah was expressed often and was reportedly a key message in public health campaigns in countries of origin.

*"I'm sure, I'm sure it is not religious, cos even religion doesn't like it.... in Koran there is a term that it says that we create a human being in a good condition, in a beautiful, yeah, we create him beautifully so no need to adjust"* (Interpreter for community member, Latrobe)

Participants from traditionally non-practicing cultural groups associated the procedure with the (different) religion of practicing groups however, which is potentially a source of conflict and misunderstanding between the two groups. This is a particularly relevant consideration when bringing groups from Sudan and South Sudan together for discussion of FGC.

### 3.3 Impact of FGC in regional Victoria

#### *Impact on women's health*

Early conversations with community health and settlement service providers revealed a widely held impression that regional communities were not affected by FGC, but this impression was not always supported by conversations with community groups themselves. There were discrepancies between some service providers' impression of the impact of FGC, and community members' experiences. Participants in Ballarat and Geelong indicated that their communities did not traditionally practice FGC (though this should not be taken to suggest that there are no women affected by FGC living in those centres, with findings being limited to those groups who participated).

Discussions with women and men in Shepparton and Latrobe (across Moe, Morwell and Traralgon), however, showed that FGC does affect a number of women and families from a range of cultural groups.

*"[FGC] Services are relevant. They need to be there"* (Community member, Shepparton)

*"I think it's really very interesting because when, if you are talking about the [female] circumcision in our community, [it] is affecting both side, men and women"* (Community member commenting on the impact of FGC on family and intimate relationships, Shepparton)

Community members often spoke about the impact of FGC on women's health in general or non-personal terms. When participants volunteered information about the impacts of FGC on their own health while living in Victoria, they shared a range of experiences: of both smooth and difficult labours, of cysts and infections, and of being unable to undergo a pap smear. In most instances, participating women seemed able to navigate the Australian health system to source the FGC-related care they required, both prior to and after settling in regional areas.

*"And she said the first child she had in Australia, they brought her Egyptian girl, doctor, in Royal [Women's] hospital. She came and asked her 'are you circumcised or not'. And she said 'yes' and then she couldn't have a baby until until when they cut her. They cut her and she had a baby then they stitched it back. But the rest of the other kids they just coming out normal"* (Interpreter for community member, Shepparton)

*"I went to Melbourne for this check-up [a pap smear] and the lady or the doctor she couldn't enter the instrument to check so she send me to Monash hospital, but I couldn't go there, I didn't want to go... So maybe they will open or they make operation"* (Interpreter for community member, Shepparton)

### Impact on women's sexuality and relationships

Some participants emphasised that of all consequences of FGC that they experienced, their greatest concern was diminishment of sexual feeling. One participant spoke of being able to deliver a child, but of being unable to 'feel', and wanting this to be taken seriously by health services. Speaking candidly about the impact of FGC on their sexual experience, participants sought information on the availability of 'medicine for that', and expressed hope that this project would leverage attention to what they regarded as a priority health concern.

*"It's very hard to have babies only. And you don't have any feeling, you don't have, you don't enjoy anything, very hard"* (Interpreter for community member, Latrobe)

*"In the research, you have to put a big title that the Sudanese woman here or in Sudan, there is no feeling... Yeah, when you put this big title it means generally, um, those who had this circumcise they don't have feeling, you put this one, maybe they will try to find some treatment for this or solution, they will talk about it"* (Interpreter for community member, Latrobe)

The impact of FGC for women and couples, and in turn families, was emphasised by a male participant who linked this impact to the mental health of each partner, to conflict within families, and to marital breakdown or separation affecting children (though not in isolation from other stressors). Having witnessed as a child the circumcision traumas experienced by his older sisters, the participant opposed FGC and understood how women's sexuality can be affected by the procedure. His account of the tension men experience in reconciling their understanding of the practice's impact on their partners, with their desire for their partners to be more responsive and engaged during sex, was underpinned by sorrow.

*"Nobody's going to do something about it [the impact of FGC on women's sexuality] and, ah, it's really very sad. And what I hope is the generation that's coming after us, they should be able to, you know, to enjoy their life in the right way as, you know, as a human can do. But for, for us it's already gone and it's something that is broken and we are to going to fix it [by ensuring our children are not circumcised]. Yeah"* (Community member, Shepparton)

### Frequency of FGC presentation

Almost all service providers reported that they had seen very few presentations, or none, of FGC in their regionally-based professional practice.

*"No I haven't seen – since I've been in Geelong I don't think I've seen a woman who's had female circumcision"* (Medical consultant, Geelong)

*"That's why I say I haven't seen them, because when I do pap smears the genitalia looks normal"* (GP, Geelong)

Among those service providers who reported having seen women with FGC, most described having seen one or two cases at most during their time practicing in a regional area. These cases tended to be minor types of FGC and rarely presented complications in terms of the woman's care.

*"The ones that we have seen, which have been very, very minor, um, we've managed"* (Senior midwife, Shepparton)

A Geelong service provider's role included development of protocols and guidelines to manage increasingly common health care presentations, with requests for new guidelines coming from staff providing obstetric and gynaecology services. During her time in this role she had never received a request for the development of a

protocol concerning FGC. She therefore felt that cases of FGC were rarely seen at the hospital, or that if FGC were seen it posed few issues for the care of women who had been circumcised.

*"We didn't have any need to formalise any process there was no... you know circumstances of uncommon things start showing up because of migration patterns or what have you... There was certainly never any request for a guideline... Uncommon, or if there was female circumcision, it was of such a minimal, a minor type that it wasn't impacting at all on, you know, the women who were presenting with it as obstetrics and gynaecology patients"* (Medical consultant, Geelong)

Several service providers spoke of having seen cases of FGC in their previous practice either in metropolitan areas of Australia or in other countries. One service provider noted that she had seen a number of cases of FGC among Somali and Sudanese women as part of her previous practice in New Zealand, but since being based in Shepparton she had seen only one presentation. Another service provider spoke of having seen women who had experienced FGC in metropolitan Melbourne but never in other communities, including Geelong where she was currently practicing.

*"I've seen lots when I was working in Brunswick with the Somali community you know, over ten years ago... I haven't seen any cases in other communities, and I've seen a lot of refugees, people from a lot of refugee communities in Geelong and Colac as well, Sudanese, um, Liberian, People's Republic of Congo, Khmer people from Burma, people from Afghanistan and Pakistan and Iran um and I'm not aware of any cases of um female genital mutilation in any of those communities"* (GP, Geelong)

One GP based in Geelong proved to be

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an exception in that he did occasionally see women with FGC in the context of performing pap smears on affected women. The clinic in which he practiced saw high numbers of refugee patients and he described his clinic as, 'the largest clinic that deals with the refugee population in Geelong'.

*"When I do my pap smears I notice that bits and pieces are missing... look, because I'm male doctor, so, I don't do many pap smears on ethnic women, but on the odd occasions that I do them um I notice that, especially on the Sudanese, South Sudanese"* (GP, Geelong)

While the majority of service providers saw few or no women with FGC in the course of their professional practice, several spoke of anticipating a future rise in the number of FGC cases seen as the demographics of their regional communities changed over time.

### Service provider perceptions surrounding frequency of FGC presentations

Service providers felt that major forms of FGC would be easy to identify and wondered whether their perception of the low rate of FGC in their regional centre might be due to the difficulty of detecting minor forms of FGC during physical examination.

*"Sometimes the procedure is done very young and if it is, if there's nothing very more than a flick of skin or something taken then it can be very easily missed, the area can be reformed very, to a point that it would be difficult to tell"* (Medical consultant, Shepparton)

A number of service providers reported that they did not regularly perform physical examinations on women as part of their role. These providers felt that this may be a factor in why they had seen so few cases of FGC.

*"Like when I initially see kids for a pregnancy test etc or an STI screen, the majority of the time that's gonna be a urine screen so I don't have a reason, unless you're symptomatic, I don't actually have, um, any real clinical reason to do an examination in the pelvic area"* (Sexual health practitioner, Geelong)

Some service providers had limited knowledge about which cultural groups might be more likely to be affected by FGC, and were unsure whether the women they generally saw in their practice were from community groups that practiced FGC. Some service providers also wondered whether these groups actually practiced FGC as frequently as they had been led to believe.

*"My impression is they're [women patients] not from the cultural groups that had the major infibulation type procedures. Or even any at all"* (Medical consultant, Geelong)

*"It's not that we don't see them [women from countries where FGC is most concentrated], because we do see them, but it just may be that their region they've been in just hasn't been practising it to the level that one would think, or one has led, made to believe"* (GP, Ballarat)

When asked if women may choose to travel to metropolitan areas to access maternity care, service providers had little if any knowledge of this being the case. However, it was recognised that women affected by FGC may actively seek practitioners they know to have FGC-related knowledge and experience, or who share similar cultural backgrounds. Another wondered if clients might like to keep FGC-related care separate from their general care.

*Interviewer: So do you think, do you think we should be wondering if people are travelling to Melbourne for services, um, around childbirth?*

*Service provider: I wouldn't be surprised. They've onl- they've got no choice here, because they won't be privately insured almost universally. So they can only come here [to the public hospital] (Medical consultant, Ballarat)*

*"Sometimes it actually works the opposite. It's like they know their GP but they're not really happy for him or her to know that, you know, the genital area or have the genitals examined"* (GP, Ballarat)

## 3.4 Current health service responses to FGC in regional Victoria

### Current FGC screening practices

FGC screening practices were inconsistent and patchy across the state. Some service providers did not engage in routine FGC screening, nor did routine FGC screening occur within their service. Other service providers did screen for FGC or felt that routine screening for FGC occurred within their wider service (including through the Refugee Health Assessment process). It should be noted that while 'circumcision' is listed as a prompt on the Refugee Health Assessment form, not all practitioners asked about FGC during refugee health screening.

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Despite inconsistent screening, there was a strong feeling from service providers that it would be beneficial to women's maternity care if FGC were identified in the earlier stages of pregnancy rather than at the time of giving birth. This would allow for the opportunity to engage in surgical intervention if needed and would reduce potentially serious complications occurring at the time of delivery.

*"So the problem is that if there is labour where the diagnosis hasn't been made the potential for damage is enormous particularly if, well it's going to be their first babies almost inevitably. If there's quite a degree of scarring then it can be a lot of trauma, urethral trauma and vaginal trauma and vulval trauma and bleeding which can be difficult to control at the time, so ideally it's best to assess before they have their baby. If a surgical corrective procedure can be done beforehand that's ideal"* (Medical consultant, Ballarat)

In some instances service providers had adapted screening practices to changing patient demographics. For example, service providers described routine screening for FGC as taking place within the hospital at Shepparton. Midwives routinely asked about FGC when taking an antenatal history of women from African backgrounds (but not from other, eg. Iraqi, communities). These questions had been added to their history-taking out of recognition of the significant numbers of refugee and migrant women residing in their area as well as a need to prevent complications by identifying FGC in the early-stages of pregnancy.

Some service providers felt that women from countries where FGC is traditionally practiced should be screened to assess if they were affected, because it opened dialogue around the issue and provided an opportunity for service providers to educate and inform women about their options. Other service

providers questioned whether women from FGC practicing communities should be routinely screened given the low incidence in their regional area and the barriers that service providers perceived to be associated with asking about FGC.

*"So my issue is, should it be part of the routine, is the need out there so great that we need to work out how we ask those questions? Given that in the clinic we've got possibly a husband with a wife, the interpreter is from the local community that they don't want to tell"* (Sexual Health Practitioner, Geelong)

Some service providers felt that women should only be asked about FGC if it had direct relevance to their health care, for example when providing maternity care. Others felt that it would only be viable to integrate FGC-screening opportunities within their consultations if screening tools and referral pathways were available to support this (and it should be noted that clinical software programs such as Medical Director do not include codes for FGC to be recorded in patient files).

*"It's sort of need to know basis, you know? Does any other caregiver need to know about this? No. So therefore, it's part of a kind of ritual technique, ritual procedure that's happened, that isn't impacting on their health because that's sort of, I suppose, the way we'd pragmatically look at it"* (Medical consultant, Geelong)

*"I never asked the patient whether it is circumcised or not, because it is I mean, here in Australia we are not involved, and here in Australia it is no need to document that one so, what the benefit that I ask her unless there is some complaint related to the health condition apart from that"* (GP, Latrobe)

### **Factors influencing service provider identification of FGC and delivery of FGC-related care**

One of the most common difficulties service providers described as hindering them identifying women affected by FGC, was the need to work through interpreters when providing care to women who may be affected. Service providers in regional areas face particular difficulties engaging interpreters, especially given the limited availability of interpreters for specific languages.

Some service providers felt that regional GPs often did not use interpreters when consulting with patients for whom English was not their primary language, leading to frequent misunderstandings.

*"I'd say 'well, what did the doctor say?' 'I don't know' I'd say 'so did they have an interpreter?' 'No.' So furiously I would ring up patient's clinic and the poor girls at reception would say 'I told the doctor, I told so-and-so that she'd need an interpreter and they would say 'oh we'll just see how we get on', and wouldn't book it in"* (Community & Refugee Health Worker, Ballarat)

*"Some doctors wouldn't even use interpreters, so I had no idea how they would even know what was the problem if they didn't use interpreters. And a lot of the people say yes yes yes -but they don't even know, they're just saying yes because they think you know"* (Midwife, Latrobe)

Service providers felt that interpreters in regional centres often lacked an understanding of medical terminology. Both service providers and community members perceived confidentiality as being undermined by the small pool of people providing interpreter services. Being able to source a female interpreter for consultations with women about particularly sensitive issues such as FGC was perceived as necessary but sometimes difficult to achieve.

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*“So we often have to use phone interpreters because either the person, the interpreter we’ve gained, is a community member ... [This] more happens in the kind of termination situation, so I’m extrapolating to other you know intimate and confidential discussions... Because often these are small communities and they’ve – in regional areas there’s small communities and therefore they will be known to that, to that interpreter so it’s difficult to maintain that professional integrity” (Medical consultant, Geelong)*

One of the most common difficulties service providers described was not knowing how to broach the subject of FGC with women, and feeling discomfort about asking women whether they had experienced FGC. There was a perception among service providers that this was a particular issue for GPs and male service providers who may be especially concerned about causing offence.

*“Most people find it very confronting and an easier choice just to leave it be and see whether you can discover it on examination... I think it’s a sensitive topic. I think in particular male gynaecologists and obstetricians may find it difficult to ask the question” (Medical consultant, Shepparton)*

Service providers also felt that identifying FGC and providing FGC-related care was difficult because, even when asked directly, women may not necessarily disclose their experience, either out of a lack of awareness of what had happened to them or fear of the repercussions (including judgement from service providers).

*“It’s not a stock standard question I would ask the majority of my cohort anyway, um, and whether or not they would own up to it, or be aware of it even being different” (Sexual Health Practitioner, Geelong)*

Building a relationship of trust with women was seen as the best way to facilitate women’s disclosure of FGC, and being able to provide continuity of care was seen as central to establishing trust.

*“If someone’s seeing someone different all the time there’s no way, um, people are gonna provide information to someone randomly without building up that rapport and trust. There’s, there’s just no way in the world that anyone’s gonna open up about anything” (Midwife, Latrobe)*

Despite the fact that a number of service providers were frequently involved in a woman’s pregnancy care, no one provider was directly responsible for FGC screening. In order to ensure that FGC-related complications were identified and managed in the early stages of pregnancy, there was a perception that a single service provider needed to take on a case-manager type responsibility. That is, being both a liaison person for the woman as well as the coordinator of a host of service providers and interpreters.

*“It’s very time consuming... they have to know about the appointments, they’ve gotta know why they’re having the appointment, the physio’s gotta be involved, the obstetrician’s gotta be involved. Everyone’s gotta - there’s gotta be all the interpreters, there’s, there’s lots of things involved ... But unless you have someone there that knows the person and brings everyone together, it’s just not gonna work” (Midwife, Latrobe)*

There was a general feeling that the onus of responsibility for FGC identification should rest with service providers. It was seen as unreasonable to expect a refugee or migrant woman to always understand the relevance of FGC to her medical care. Language barriers, fear of repercussions, and a lack of understanding of the Australian health care system further reduced the likelihood of her disclosing FGC without prompting.

*“Because the woman can’t just go along and say here I am, this is my problem, this is what I need done, because she’s new to the whole thing, she doesn’t know the language, she doesn’t know the health system” (Midwife, Latrobe)*

#### **Community members’ experiences of health services and unmet service needs**

Despite the challenges described above, in most instances, participants reported feeling satisfied with the FGC-related health care they had received in Victoria, both in Melbourne and in their present regional setting. Participants felt it was important to see service providers who were knowledgeable of health needs specific to FGC, and women’s stories often reflected an ability to navigate local health service contexts in order to identify appropriate providers. One woman spoke positively of the care she received when giving birth at the Royal Women’s Hospital prior to settling in Shepparton, while others indicated they had been able to find services locally when required – at Traralgon Hospital for instance. Women spoke of consulting community and word-of-mouth networks, and described receiving GP referrals to appropriate providers for FGC-related needs.

A preference for seeing female service providers was expressed by some, though a service provider’s language and cultural background were often of equal or greater consideration. Many women preferred Arabic-speaking doctors for both their familiarity with FGC-related health needs and for ease of communication.

*Interviewer: And how, how do you find a female doctor who speaks your language? Is it word of mouth, asking around? ....*

*Interpreter: An Iraqi woman told them about her*

*(Interpreter for community members, Latrobe)*

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“What I know is Monash [Medical Centre], there is somebody who knows about this. And my sister in law when she have her baby, so she has to go to Monash hospital because they know about it. There is somebody there special who knows about it” (Interpreter for Community member whose sister chose to travel to Monash Medical Centre to access FGC-related services, Latrobe)

Communication was one area in which experiences and needs varied. When asked if women would feel comfortable to raise FGC with their GPs, responses were mixed. Some women spoke of feeling confident to seek FGC-related care in a candid and proactive way, and most indicated they would feel comfortable if their GPs were to initiate a conversation about FGC. This included women from cultural groups that did not traditionally practice FGC, who stated that they would not mind being asked. However, some women emphasised the deeply personal nature of sexual and reproductive health and felt that women may feel shy or uncomfortable discussing FGC with their GP. Community members concurred with service providers’ in stating that trust would facilitate discussion of FGC.

One woman spoke of actively seeking pregnancy information and advice from older African women (not necessarily of the same cultural group), rather than antenatal service providers, when pregnant with her first child in Australia. Her experience of routine antenatal questioning around FGC illustrates that how questioning is approached can have a big impact on women’s experience. Describing sexual and reproductive health issues as very private for women of her cultural group, the participant spoke of feeling ‘shocked’ when hospital staff inquired if she was circumcised. She emphasised that it was important to tell patients why the question might be posed, as there will be ‘more cooperation’ if women understand the reason for staff interest:

“If women understand we will be happy”. She emphasised that FGC should not be one of the first questions asked either.

*“I felt really bad. I asked myself what sort of question are you asking?... I didn’t know why she was asking me. I felt bad in my heart. I didn’t expect to be asked... I prayed that I did not meet that woman again the process of my pregnancy... GP was better. He never asked me this question... Everything was friendly [at the hospital], but they asked me”* (Community member, Shepparton)

The use of visual aids during questioning was recommended, rather than simply questioning women about the ‘types’ of FGC they may have experienced. While women could usually speak easily about FGC in their first language, they were often unfamiliar with English anatomical terminology like ‘vagina’ and ‘labia’. Community members also felt that service providers needed to develop more awareness of the context in which women may have been circumcised. Community members felt service providers were unaware of the impact of their (negative) attitudes towards FGC. One participant, who said that staff looked ‘surprised’, ‘worried’ and ‘astonished’ on hearing her circumcision status summarised that “The attitude is not good”.

*“They should be more aware that people are different... It was a fashion, they [parents] had to do it, it was not illegal. The age of my mothers, the age of my sisters, it was legal”* (Community member, Shepparton)

*“I experienced it myself. I have a cyst [related to circumcision]. And they make me an operation, there was lots of group of doctors, and they surprised or they wonder ‘how do this woman’? So there was a lot of questions, ‘how do I have a baby’? So it was a lot of questions at that time”* (Interpreter for community member, Shepparton, referring to care received in Traralgon)

As described above, some women identified diminished sexual pleasure as their priority FGC-related health need. This was something not currently being addressed by service providers in any of the regional centres. Participants with health information needs around FGC, particularly in relation to sexual feeling, or who felt shy raising other FGC-related issues with their GP, expressed interest in community-based information sessions for women such as those provided by FARREP workers in metropolitan areas.

In every focus group conducted women expressed the need for more information on pap smears. It was noted that some women who were affected by FGC felt apprehensive about the procedure and were also unsure of what the procedure entailed, suggesting a clear health education need.

Community education around FGC more broadly was also seen as having ongoing value. A male community member in Shepparton wondered why FGC-related information was not available in GP waiting rooms:

*“[Women] go to the clinic. How many posters put up [about FGC]? That one is not. It’s just if you go to the clinic, washing hands, and all those things... [FGC information] is not promoted”* (Community member, Shepparton)

Participating women suggested educating a female representative from each cultural community, so that knowledge may reach all the various cultural groups; holding education programs for community members by working closely with trusted local people; and delivering education to children as educators of parents and families.

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### 3.5 Professional development for service providers in relation to FGC

#### Previous experience with FGC professional development

Almost half of the service providers interviewed had previously undertaken professional development (PD) in relation to FGC. Those who had undertaken some form of PD in this area, spoke favourably about their experience. Despite seeing few or no presentations of FGC, some service providers felt that it was an area in which they should have some knowledge so that they were prepared should this issue arise in the course of their professional practice.

*"We did because we felt that it could be something that we may come up against and we felt that it was better to be prepared rather than to be on the back foot...it was good opportunity for us to be able ask the hard questions"* (Senior midwife, Shepparton)

For others, PD was undertaken as part of an effort to become more 'culturally aware'. For example, one service provider spoke about how a newly arrived patient presenting with syphilis prompted their service to consider the specific issues that might be of importance to different cultural groups, and how best to address the barriers to providing health care to diverse groups of people.

*"It was then I thought, ok, I've got to find out what I need to do that's culturally appropriate. I don't want to be putting anyone offside, and so it was all just a big learning curve and that's when we got the FGM people in as well to help us learn about that, and the whole team participated"* (GP, Ballarat)

Others engaged in a process of self-education in order to be better informed about FGC.

*"I 'spose just because I was dealing with people from, um, you know non-English speaking backgrounds... this subject would just come up sometimes, not from the client but for your own education, self-education that you'd just start to look into it yourself. And then you'd just see documentaries and you know that would make you start to think"* (Midwife, Latrobe)

Service providers spoke about the pride they felt in expanding their knowledge about FGC and other cultures, as well as PD meaning that they felt prepared to address FGC-related health concerns should they arise in their professional practice.

#### Service providers' professional development needs in relation to FGC

There was a general feeling among many service providers that despite seeing few presentations of FGC in their regional communities, PD in relation to both the practice and broader issues affecting the health of immigrant and refugee women would be beneficial. It was seen as important to keep the momentum up with training so that staff responses to potential issues related to FGC were proactive rather than re-active.

*"It still should be on the radar because it's not gonna disappear one hundred percent and... I think it's just one of those things in women's health that, you know it's like you [also need to consider] under-screened and unscreened pap tests for women from those groups, always keep the momentum there, I think that's important"* (Sexual Health Practitioner, Geelong)

Staff turnover and new graduate practitioners entering services also meant that it was important for services to engage in regular PD to ensure that all staff were aware of issues that may arise in their clinical practice.

Several service providers talked about the importance of gaining a better understanding of cultural contexts. Rather than simply focusing on FGC, service providers preferred a broader approach to learning about other cultures and cultural practices that may directly impact on the health of people from different cultural backgrounds.

*"You know raising the cultural awareness. Like I used to go as part of my role as a Refugee Health Nurse to the midwives, trainee midwives at the women's unit, just to give them a special knowledge of what the refugees, who is a refugee. You know just letting them know, refugee health, life and tell them what to expect because they will be surprised when people react the way they do and they will wonder why are they doing that. Just to raise the cultural awareness, it would be good"* (Community & Refugee Health Worker, Latrobe)

In terms of PD focusing specifically on FGC, service providers felt it would be useful to develop skills to assist them in identifying women who may have experienced FGC.

*"If they're pregnant, what is the risk? Are they low risk are they high risk? Where do we stratify them? Where are going to be the problems? When you've got female infibulation, which particular groups are we looking at where we might be getting into trouble"* (Medical consultant, Ballarat)

Service providers who did not routinely screen women for FGC in their current practice felt it would be useful for any future PD to include helping them with specific questions that they could ask of women from FGC practicing communities. Many service providers were unsure how to sensitively question women about FGC

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and were fearful of giving offence and jeopardising the therapeutic relationship. This was seen as especially significant in regional locations where women did not have many other service providers to choose from.

*"We can't afford to put them off side when we first meet them because it colours the rest of their visits to this hospital. And in Melbourne they can hospital and doctor shop but they haven't got the luxury here of doing that... So we've gotta be perfect every time"* (Medical consultant, Ballarat)

A number of service providers suggested that PD to build clinicians' skills in relation to FGC should look at FGC screening being built into pap test history taking, along with screening for other sensitive issues that may also be an issue for these women, such as interpersonal violence.

*"There's some very, ah, defensive behaviours or with women with pap smears. So that's why I'm wondering about how I can, what I could say, for instance how I could change the way that I approach or talk to people when I do pap smears. It might be an occasion when I can screen for that [FGC] and domestic violence... The issue for me is how to deal sensitively in history taking and examination for people who may have been traumatised in the past in one way or another including genital mutilation"* (GP, Geelong)

Several service providers expressed a desire for the development of a protocol to guide their practice in relation to FGC (noting that these already exist in some regional services). PD that provided service providers with resources to access and utilise in the event that a woman presented with FGC-related complications was also seen as valuable. The de-infibulation clinic at the Royal Women's Hospital was perceived as an important resource on this issue and service providers believed that the awareness of the clinic should be promoted. Some of the service

providers involved in this project were not aware of this service.

*"We need to be able to at least have a contact where we can ring or refer a patient like this to an area where there's expertise... For us, as a peripheral unexperienced unit, we need an ability to be able to say this is who we ring, this is where we go, this is what the protocol is"* (Medical consultant, Ballarat)

### Preferences in relation to professional development

Ideally, service providers felt that PD should be provided to a broad range of practitioners who may potentially deal with women from FGC-affected communities. This was seen to include maternity care providers, GPs, community health nurses, and family planning providers.

Regional service providers preferred that PD be conducted locally and face-to-face. Making trips to metropolitan Melbourne for PD activities was perceived as logistically difficult for those with family commitments and the cost of these trips was often prohibitive. Locally-based PD had the benefit of maximising the number of staff who could participate.

*"They [organisation providing PD] actually did the first program in Geelong and then they came to Ballarat for our program so they kind of travelled Victoria. It was like a travelling circus. So they came to us and that was really good because that was done in the clinic here, so as staff members we just had to down tools and cross off a couple of hours from our day and go and do it and then come back to work kind of thing"* (GP, Ballarat)

Some service providers felt that running PD activities at community health centres was a convenient way of targeting community health nurses. In addition, PD through tertiary institutions

responsible for training new health care professionals as well as PD through health professional membership and registration bodies, was also suggested by service providers.

*"I think um, possibly the RANZCOG doing a little bit more with both GP level and our fellow level teaching and training on it. Having teaching modules, having de-infibulation conferences, talking about it, bringing speakers from other parts of the world to talk about it, those would be learning experiences"* (Medical consultant, Shepparton)

Some service providers also appreciated the flexibility of online PD and felt that this would be their preferred format.

While a number of service providers expressed a desire for PD in FGC and related areas, some service providers did not feel that PD in the area of FGC was necessary. This was largely due to the infrequency of FGC presentations and FGC related-complications that they had witnessed in their own professional practice.

*"I think you'd probably get really poor uptake of it because people would think 'oh I probably should but you know I haven't come across it yet' ... There's so many things every day that you would see ten thousand of and feel like you'd need to have a great knowledge of, but I would imagine it would be so rare that people would probably – no, I think most people would be thinking 'I never see it'"* (Community & Refugee Health Worker, Ballarat)

Several service providers described feeling confident that they would be able to identify and manage women with FGC should they present at their service. They were aware of the resources in this area and felt confident that they would be able to access these resources should they need additional support.

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*“Truly, you know, the centres of excellence like the Women’s have you know a process, that a guideline process. We can easily tap into that, that’s no problem at all. So therefore you know, if it ‘oh my goodness they’ve got that’, look, have a look, there it is, beautiful, we can do that. So it’s not, there won’t be a long lead time into acting on it once it’s there”* (Medical consultant, Geelong)

*“There’s certainly an awareness that, that it’s out there and we could be confronted with it in any single day. I think that our obstetric team are comfortable in handling and managing a situation should it arise given our cultural demographic”* (Medical consultant, Shepparton)

There was also a feeling that even if service providers had only a basic knowledge of FGC, they should be able to draw on their other skill sets such as their knowledge of anatomy in order to respond appropriately to complications related to FGC.

Those service providers who felt PD in relation to FGC was not necessary at the present time noted that it was an area that may require greater attention in the future. The changing demographics of their regional areas and the potential for greater numbers of women from FGC-affected communities moving into these areas meant that it may be necessary for service providers to up skill in the future.

*“[If] a big group of women from Somali all of a sudden come to the area you’d kind of go right, now we need to you know pay attention to this cos you know that’s a high incidence, um, area for the more significant forms”* (Medical consultant, Geelong)

### 3.6 Other health priorities for participating communities

#### Addressing miscommunication with service providers

The importance of building trust and rapport in health care relationships was highlighted by community members in Ballarat, who acknowledged that community members may be cautious to share information with service providers unless a relationship is established.

*“The culture we come from is very complex in a way. We don’t give information. Like if you go to the street and somebody’s asking you ‘what is your name?’, oh you may think ‘why, why she need my name?’ So it hard to get information unless you trust the person”* (Community member, Ballarat)

Conversely, members of another cultural community in Ballarat were concerned that service providers may withhold information from them as clients. Community members felt that health professionals did not always fully disclose patients’ diagnosis and treatment options, and they attributed this to a perceived assumption among health professionals that they were poor and could not afford treatment.

Reflecting on this apparent misunderstanding, one service provider reported that health professionals often give ‘not much forethought’ to a patient’s existing medical knowledge and language needs – preferring to ‘see how we go’ rather than routinely arrange an interpreter. Patients may be informed of their condition (such as arthritis) but not understand the information given, and this may result in considerable stress for the client. Community members reported that interpreters were often not used, and that sign language was relied upon instead. One service provider

observed that while some general practices have adopted protocols for using interpreters, the relatively small number of families using these services can mean that protocols don’t gain traction or get lost in staff changes. Provision of interpreters was especially low in the case of specialist referrals and the local hospital.

*“DHS guidelines, you know you must provide an interpreter for consent, for information about surgery, for information about a diagnosis... [but] the staff would say they didn’t know how to look up. It was all on their intranet. Some staff didn’t know how to use their intranet, didn’t know they had an intranet! Some staff said ‘no they’re very expensive; we’re not allowed to use them’. They had no idea that each hospital received funding particularly for interpreter services”* (Community & Refugee Health Worker, Ballarat)

The perception among some community members that treatment advice was withheld may also stem from a lack of discussion around how a condition may be managed in the long term. Many women report chronic back pain, for instance, who then may doubt they’re being taken seriously by their doctors when advised to swim.

*“The girls couldn’t see how that would be the right treatment you know swimming in the pool, so hydrotherapy, which is what they needed to do, they needed to do often but they couldn’t think that that’s what was [going to help]”* (Community & Refugee Health Worker, Ballarat)

*“They’d have people in and teach them exercises without an interpreter and the person’s got no English and a bad back.... Physiotherapy... you’re teaching them exercises to prevent the worsening of an injury and to increase your capacity to perform in your daily living and you do it by sign language”* (Community & Refugee Health Worker, Ballarat)

### Women's health information

Community members consistently expressed strong interest in opportunities to access women's health information through community education sessions, including information on pap smears, breast checks, contraception and fertility, as well as vitamin D and iron. Participants saw information on these topics as being important for their own health and wellbeing, as well as for their children's. The issues identified by women were quite consistent across community groups, and were often in line with those identified by service providers. Participants were also very consistent in how they would like to access information, preferring an opportunity to attend community education sessions with other women from their communities.

*"Like information, yeah [in a] group, and we need to know more of the, about the women's health, yeah. Even how you connect with your girls at home you know about, about period, if it's coming, after how long will be terrible, something like this will be good"* (Community member, Shepparton)

Pap smears were identified as a key health priority by almost all community groups, though information needs did vary. Participants spoke of hearing about pap smears on TV and radio but of not understanding the procedure's purpose or intention; of not knowing how to go about getting a pap smear; and of not knowing what the procedure actually entails. Female GPs were often preferred, though women may see a female GP and still prefer to defer their pap smear 'til next time' because they feel shy or uncertain about the procedure. Participants in Ballarat and Geelong said they would like a reminder system for keeping pap smears up-to-date. In Shepparton, participants spoke positively about a community information session on pap smears run by a community worker in the past, and

suggested that inclusion of pap smear information on the agenda of future health sessions would serve to increase attendance.

*"And the pap test, it is good but we need to know more information about that, because we need to know why, why it is important"* (Community member, Ballarat)

*"Sometimes it's not in the culture. You rather be checked out when you giving birth, you know. It's hard for you to go to the doctor. Like me I don't specially do it, because I find it – I don't go and do it. I did it once, and I never did it again because it's not comfortable for you to do it... But sometimes if you get a male doctor it's kind of 'no, I'll do it next time, you know'... If you know you're late for pap smear you have to go and be checked up, cos they don't remind you when to be checked up, but you have to remind yourself, when and where to be checked up"* (Community member, Geelong)

Women in Geelong and Ballarat stated that they would like more information around contraception, including an interest in knowing their options; in understanding the side effects of different contraceptive methods (which symptoms may be attributed to contraception and how they can be minimised); and in how to use contraception effectively (with one woman reporting an unplanned pregnancy while using Implanon). When GPs did not use interpreters, consultations around contraception were difficult and women were not able to make informed decisions. Women also wanted information that would assist them to provide contraceptive advice for their daughters and sons.

Not all participants were at ease with conversations around contraception, and it was apparent that for some women, contraception may be a more sensitive issue than FGC. This is in contrast to the assumptions of many

service providers who tend to address contraception directly, while perceiving FGC to be a sensitive issue. Older participants felt that young women should manage their fertility without contraception, as they had done when they were young and contraceptive options were not available. Some younger women in Shepparton did not 'agree' with contraception, but felt that more information could be valuable. From their perspective, information about contraception would not attract people from the community, as opposed to pap smear education, which they felt would motivate many to come.

Furthermore, some women in Shepparton expressed fertility rather than contraceptive concerns; they expressed concern for women who are unable to fall pregnant but who may feel pressure from family members to do so.

*"These people do need a lot of information, women like this, yeah, because some of the women just tried a lot of doctor [looking for help]... A lot of women here confused about what is going on here, what happened. Some people say maybe the food is no good, some people say maybe the water, some people say maybe the weather, some people say maybe something [else]"* (Community member, Shepparton)

### Other health issues

Vitamin D and iron were identified as health priorities by cultural groups in Ballarat and Geelong. Local community members were not aware of the Vitamin D clinic that had been established in Ballarat and participants in Geelong were also unsure of their service options. Interest in dietary information was expressed by participating groups in Ballarat and Latrobe.

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*“You coming to different culture, you eat different things, people are not aware of health foods, what’s good for children they don’t know. Ah the first time that I came I can eat a lot of chocolates and lollies and everything, but then I don’t know what is good for my son so he’s drinking a lot of Coca Cola”* (Community member, Ballarat)

In addition to chronic back and joint pain, older women highlighted the mental health impacts associated with being separated from children and loved ones back home, while worrying for their safety.

*“They’re not healthy, they bored, so tired. Because they’re not happy in this country. Because they miss their children. Cos their children they’re in Africa. And now a lot of things going on the war and everything. They could not sleep. They cannot do anything... they think of one thing. That’s what they think. It’s really difficult”* (Interpreter for community member, Geelong)

#### **Priorities identified by service providers**

Service providers perceived that sexual and reproductive health, intimate partner violence, vitamin D deficiency, diabetes, and issues related to mental health and trauma, were of equal or greater importance than FGC for the health of immigrant and refugee women in regional communities.

There was a perceived need for greater attention to the sexual health education of women, particularly younger women, from refugee and migrant communities. Many service providers felt that these women had limited understanding of their body, contraception, and sexually transmitted infections. Contraception and the prevention of unplanned pregnancy was frequently mentioned as service providers’ primary concern,

particularly for younger women. There was a perceived need to target young people within immigrant and refugee communities and provide them with education about contraception to counter myths and misinformation circulating in some communities.

*“We took the box of every form of contraception from the sexual health clinic to her [young refugee’s] house, and she had a reason why every single one of them was going to cause her imminent death. The IUD was going to move up and get into her brain and then she would die. The pill was going to do all sorts of things and then she would never bear a baby again and then she would die”* (Community & Refugee Health Worker, Ballarat)

There was also a concern that because contraception was not used, women turned to terminations as a solution for unplanned pregnancy.

*“You know termination’s not a contraception, um, and there has been a couple of girls over the years that have had two plus terminations um that I’ve been directly involved with”* (Sexual Health Practitioner, Geelong)

Service providers felt that long-acting reversible contraception (LARC) options were not offered as frequently as they should be to women within these communities. LARC was viewed as a good option for those women for whom the stigma and shame surrounding contraceptive use could inhibit uptake.

*“I had one recently, a young Sudanese women who wanted when she had a termination, she was seventeen years old and was keeping it quiet from her family, with the termination she requested to have her Implanon put into a place where she couldn’t be seen, into her thigh...[if] any other community members or church*

*members saw that she had an Implanon in her arm, she would be in trouble. So I for the first time I had to put an Implanon in someone’s inner thigh, so that they could keep it completely...confidential”* (Medical consultant, Geelong)

Service providers also discussed discrepancies between the attitudes of parents and children in relation to unplanned pregnancy. Providers spoke of instances where parents wanted their daughter to continue with an unplanned pregnancy while their daughter aspired to a different outcome.

*“Access of these younger women particularly to unplanned pregnancy care, um, is a tricky thing you know because...there’s often quite a discrepancy between the daughter and the mother about whether to go on with the pregnancy. And so often the parents are very anti-abortion, quietly so, so if they, and can’t understand why they wouldn’t just go on and have the baby. You know sixteen, seventeen year olds who want to complete their schooling and have a different life trajectory in mind”* (Medical consultant, Geelong)

Attempting to influence community attitudes by raising awareness of alternative life trajectories for women such as the pursuit of education and training, and engaging in paid employment, was seen as an important unmet need for these communities.

The promotion of both breast and cervical screening was seen as important among refugee and migrant communities. There was a perception that women’s awareness of the availability of these tests may be low, and that these aspects of health were often low on the priority list when women were being processed to enter the country.

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*“Yeah I think with the female health it would be good to try and encourage or raise awareness on issues like um breast cancer, which is already there but to empower them to have the guts to go and have it done for themselves”* (Community & Refugee Health Worker, Latrobe)

*“Oh smear tests. They don’t know anything about it. I presume once they’ve arrived and been processed that most of the major health problems like you know tuberculosis, the serology for infectious diseases and HIV and syphilis, and these sort of things have been sorted out. Um, but of the more basic needs with the contraception, cervical dysplasia routine sort of screening, that sort of thing, ah I think would probably be lacking”* (Medical consultant, Ballarat)

### **Need for specialised SRH services**

Offering sexual and reproductive health services to refugee and migrant communities within one service was seen as preferable, due to their specialised needs and their need for resources such as interpreters. Having comprehensive sexual and reproductive health services located in one setting was also seen as the ideal approach for women who may have trouble navigating a fragmented health system.

The issue of intimate partner violence (IPV) within migrant and refugee communities was frequently raised by service providers, with many stating that this should be a primary area of concern. There was a strong perception that this was a significant and largely unaddressed problem among these communities. Service providers raised concerns about physical, emotional and sexual abuse, as well as sexual coercion in relation to minors. This was generally perceived to be a more significant issue for women than FGC.

*“So I would say that if you’re working with health professionals here, I’d think domestic violence, sexual health, those things are far bigger than FGM”* (Community & Refugee Health Worker, Ballarat)

Service providers wanted to know how to sensitively screen women from these communities for IPV, and felt this to be a professional development priority. Community education targeting IPV, with a particular focus on what was acceptable and unacceptable behaviour in Australia, was also seen as desirable.

*“Probably around relationship and family violence in the ethnic population, yeah, and the migrant populations and this probably needs to be priority. Especially it’s educating the newly arriving men about how to treat women and what’s normal and what’s expected, because, um, there’s two different things between what’s normal in their country and what’s normal here. And usually woman are subject to physical and mental abuse and, um, they regard that as a normal behaviour which is not. So I guess educating the new arrivals about these issues”* (GP, Geelong)

Service providers acknowledged that women’s fears for their own safety and that of their family members, as well as fears of being ostracised from their community were significant barriers to women’s disclosure of IPV. Finding a way to address these barriers was seen as important.

Other community health priorities raised by service providers included concerns around Vitamin D deficiency within some migrant and refugee populations, with the Vitamin D clinic in Ballarat having been established in response to an identified need within these communities. Diabetes was perceived as another health priority. Poor diets and a lack of healthy food choices were seen to contribute to this issue.

*“Diabetes in the migrant population is pretty significant than some other populations, and I think quite a lot of it is easy access to high carbohydrate foods. They’re coming through the settlement and the first thing they see is McDonald’s and Hungry Jacks and everything else, food that’s cheap, it fills the belly, feels good”* (Medical consultant, Shepparton)

Mental health and trauma-related issues were also raised as important health priorities. Service providers acknowledged that refugees often had frequent and unaddressed experiences of grief, trauma and loss.

*“I still think mental health and wellbeing is still an area that’s needs some work. There’s a lot of grief and loss associated with the tragic circumstances over in Sudan at the moment... When most of our community have identified that there’s been losses of close relatives and that they’ve lost, you know, villages that have been destroyed and cattle and everything’s been destroyed. Our families here are sending money across and some have still not found those family members, and they don’t know whether they’re dead or alive”* (Community & Refugee Health Worker, Latrobe City)

# 4. Implications for FGC-related care in regional centres

## **Assumptions and misunderstandings**

The data presented above suggest that assumptions held by both service providers and, to a lesser degree, community members, may hinder the delivery of FGC-related health care in some regional Victorian centres. In some settings, service providers strongly perceived that FGC did not affect immigrant and refugee communities that had settled in their region. This perception was based on the infrequency of FGC presentation, in a context of positive relationships between service providers and communities. However, some community members in these settings reported that FGC was an issue for them (and in at least one setting, an issue of active and current debate).

Some providers assumed that if a woman does not mention FGC, then it is not present and/or affecting her health. Affected women described both an unwillingness to raise the topic, and sexual and other health problems that may be present. Both providers and women were seeking to avoid unnecessary discomfort and distress, with the effect of not addressing an important health concern. This suggests that providers need to be assisted with education about ways to raise the subject of FGC in a sensitive and non-threatening way.

Service provider assumptions as to what was and was not a 'sensitive' issue for community members may also impact upon the delivery of care. While many participating community members described FGC as personal and private, and something not normally discussed, many were amenable to health service providers raising the issue with them if this was done carefully, respectfully and with an explanation of why this information might have implications for their health care (i.e. if women knew why the question was being asked). On the other hand, service providers generally did not see contraception and fertility as sensitive topics but some community members did. The data suggest the need for careful and respectful provider-patient communication about all issues relating to sexual and reproductive health including, but not limited to, FGC. This careful communication seemed to be hindered in many instances by the limited use of interpreters in regional centres.

Previous research has identified that limited use of interpreters by health practitioners is a major shortcoming of service provision for regional migrant communities (McDonald et al. 2008; ECCV 2011). There are particular constraints that regional service providers face when using interpreters. The pool of registered interpreters in communities is small, particularly for some language groups, and it may not be possible to attain the services of an

interpreter of the same gender as the patient, who is also not known to the patient. This raises concerns, for both service providers and patients, about the confidentiality of the consultation and the appropriateness of the interpreter if the consultation is about a potentially culturally-sensitive topic (which may include FGC, but could also include sexual and reproductive health more broadly, and issues to do with mental health or intimate partner violence). In such circumstances it is incumbent upon the service provider to ask the preference of the patient with regards to how to proceed, and to respect their wishes. This negotiation can be difficult for service providers who may have heavy workloads and tight time constraints (for example, overloaded GPs in regional centres), and may contribute to the 'let's see how we go without an interpreter' approach. Negative experiences with phone interpreters may also deter service providers from exploring that option (and it is recognised that phone interpreters can be less than ideal, particularly for sensitive topics).

The challenges for regional service providers in using interpreters are recognised. However data generated during this *project* suggest that improving the availability and use of interpreters in regional settings should be a priority for improving delivery of care, including FGC-related care, to immigrant and refugee women in regional Victoria.

## 4. Implications for FGC-related care in regional centres

### **'One size' does not fit all communities or all service providers**

The initial intention of this project was to use the data presented above to develop and evaluate a pilot workforce education and training initiative across the four regional centres. However, this intention was based on the research team's assumptions about the potential impact of FGC in regional Victoria (based on conversations with stakeholders in the sector at the National Summit on FGM in Canberra in early 2013, and available 'country of birth' data collated by Family Planning Victoria and RMIT, see Costello et al. 2013). While it is clear that FGC is an important issue for some women and families in some regional centres, it is also clear that the impact of the practice is highly varied across the state with the variability in service needs identified not lending itself to any one particular pilot initiative.

It is clear, however, that there is a need for careful assessment of the broader sexual and reproductive health needs, including of the potential impact of FGC, of communities newly arrived in regional areas. Assumptions cannot be made as to whether 'African women' will be impacted by FGC, based on their country of birth or religion.

During this project and our recent inner Melbourne work (Vaughan et al. 2014), service providers and some community members would often make the blanket statement that 'the South Sudanese don't practice FGC'. While FGC prevalence data for South Sudan is not yet available, there is reason to

believe that at least a small to moderate proportion of women and girls in the newly independent country will be affected by the practice. Five of the six countries bordering South Sudan are considered to be countries where FGC is concentrated, with prevalence in these nations ranging from very low in Uganda (1%) to very high in Sudan (88%). It is clear that FGC practices and prevalence among particular ethnic and cultural groups extend across national boundaries (UNICEF 2013; see map of regions within countries p. 32). Authoritative statements made by service providers and others that 'the South Sudanese do not practice FGC' ignores the cultural diversity within the country, and in fact makes it very difficult for those South Sudanese women who may have experienced FGC to say so. It is clear from this project that some women and their families who identify as South Sudanese do have health needs in relation to FGC, and that abandonment of FGC is an issue of ongoing debate for some recently arrived communities.

In our inner Melbourne research we found evidence of substantial generational change towards abandonment of FGC, with the majority of community members and community leaders now being against the practice (Vaughan et al. 2014). This was also true for communities living in regional Victoria who participated in this project, however recently arrived and less established groups were more likely to express ambivalence about abandonment of the practice and it was clear that in at least one centre this is a current and ongoing community debate. This reinforces the need for careful local

assessment of new arrivals' knowledge of FGC (in relation to its health consequences and the law), attitudes towards the practice, and health service and education needs. Screening for FGC during initial refugee health assessments, and potentially during antenatal care, would begin this process of building a better picture of local FGC education and service needs.

Collection and analysis of the data generated by this project confirmed that no 'one size fits all' approach to FGC-related professional development would be appropriate across regional Victorian sites, or for individual service providers in these locations. Practitioners' need for professional development in relation to FGC, and their perceptions of this need and subsequent interest in professional development, varied considerably. However it was clear that all service providers would appreciate more information about the impact of FGC in their communities, and about existing services and resources that they could draw on or refer to (such as the Deinfibulation Clinic at the Royal Women's Hospital, and the *Service Coordination Guide and Care Plan Flow Chart* developed by Family Planning Victoria, see Jordan & Neophytou 2013). Therefore a priority of the research team is to disseminate project findings, along with a list of available resources (many of which are available online), to regional service providers.

## 4. Implications for FGC-related care in regional centres

The diversity of actual FGC-related need across regional Victoria, as well as the real and perceived variability in need for professional development of service providers across the state, has implications for policy makers and regional service providers across Australia. There is a need to avoid assumptions and to engage in careful contextual assessment of the potential impact of FGC on all communities resettled in regional centres. This assessment must be based on trust, include addressing women's broader sexual and reproductive health priorities, and consider the potential impact of the practice on groups historically neglected in relation to FGC. In the context of the recent demographics of humanitarian entrants to Australia, this should include consideration of the potential impact of FGC on resettling Iraqi communities. Overall prevalence of FGC in Iraq is less than 10%, however prevalence among Kurdish communities from some northern regions of the country is over 50% (Yasin et al. 2013). While FGC in these groups most commonly involves type I procedures (that are less likely to result in long term health consequences), women may still experience ongoing health needs arising from the procedure's psychological impact and impact on sexuality.

It is clear the social norms underpinning FGC are affected by migration, with attitudes supporting the practice changing over time in a new country (Morison et al. 2004; Johnsdotter et al. 2009; Gele et al. 2012; Vaughan et al. 2014). This suggests it is important to target FGC-related education and awareness raising to newly arrived communities, many of whom are now being directly settled in regional centres throughout Australia.

### **Addressing other health priorities**

Across all data generated by this project, the greatest concurrence between service providers and community members was with regard to the leading health priorities for women from countries that traditionally practice FGC. While community members sometimes saw FGC as a higher priority for their health and wellbeing than did service providers, the two groups of participants agreed that sexual and reproductive health and 'women's health' more broadly were high priorities.

Breast and cervical cancer screening (in particular pap smears) were repeatedly raised as health needs that were under-addressed for these groups. Participating community members often did not understand that the pap smear test was a screening tool for cervical cancer, and had poor understanding of what the procedure actually (physically) involved. Women affected by FGC reported particular concerns, and discomfort, in relation to pap smears. Participants from the community were very keen to have more information about pap smears, preferably presented to community groups as part of interactive health education sessions.

Community members and service providers agreed that contraception and managing fertility were high health service priorities. However, the two groups did not always agree with how fertility should be managed and what the contraception priorities should be, with community sensitivity in this area suggesting that the potential for misunderstandings is high. Data suggest that community members often have a poor understanding of contraception options and side

effects, with many myths being identified. However younger women did express a need for discreet, effective contraceptive choices.

Community members and service providers also agreed that Vitamin D deficiency, diabetes, healthy diets, chronic back pain, and mental health were important health priorities. In some instances health service providers had developed specific services in response to these issues, however community members were sometimes unaware that these services existed. This suggests a need for outreach education and awareness raising with communities, with providers being unable to rely on community members 'coming in'. In some places it is difficult for community members to 'come in' to health services, in particular GPs, because of an overall shortage of service providers in regional centres.

Intimate partner violence was raised as a priority by health service providers, but not particularly by community members. This may reflect the sensitive nature of the topic, but suggests this is a potential priority for future research.

## 4. Implications for FGC-related care in regional centres

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# 5. Support for interventions

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While the data suggest our initial plan for a pilot professional development initiative across regional Victoria is not appropriate, the research team have initiated a number of activities in response to the research findings:

- **Support for community education sessions:** Participating community members in all four centres requested women's health education sessions. Women in both Shepparton and the Latrobe Valley requested specific information in relation to FGC, its impact on health and sexuality, information to support abandonment of the practice, and FGC-related services (including the Deinfibulation Clinic at the Women's). Women in all sites requested more information on breast and cervical screening, with most also interested in more information on contraception. Community members expressed a desire to receive this health information and education in their first language, and in a group format. Therefore the project will allocate resources to support experienced bilingual health educators from the Multicultural Centre for Women's Health to travel to regional Victorian centres to conduct specific women's health education sessions with participating groups. It is anticipated that these health education sessions will take place in the first quarter of 2014-2015 (when one of the key bilingual health educators returns from leave).
- **Dissemination of research findings to service providers and participating communities in regional Victoria:** This research report will be disseminated (in electronic and hard copy) to participating service providers and participating communities in September 2014. Participants (community members and service providers) will be invited to a community feedback meeting, to be held in September/October 2014 in each site depending upon participant interest
- **Linking participating service providers with existing resources:** The research team have begun developing a list of existing resources for service providers in regional Victoria, including pathways for referral to the Deinfibulation clinic at the Royal Women's Hospital. A number of other activities funded by the Health System Capacity Building Fund FGM Support Targeted Round have involved collating available resources and development of 'clearing house' functions. As results of these activities become available, the research team will be able to disseminate relevant findings to service providers along with the findings from this project.

## 5. Support for interventions

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# 6. Conclusion

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This report presents findings from a research project that aimed to assess the impact of FGC on women and girls now living in regional Victoria, with a view to identifying appropriate strategies for developing the capacity of regional health service providers to respond to FGC-related health needs.

This study is the first of its kind, specifically focused on the impact of FGC in local government areas in regional Australia. Findings were generated through engagement with community members and service providers in the regional Victorian centres of Ballarat, Geelong, Latrobe Valley and Shepparton. These regional centres are home to various cultural communities that have resettled from countries that traditionally practice FGC, including Sudan, South Sudan, Kenya and Togo. FGC prevalence and practices vary enormously across these countries of origin, and this was reflected in the diverse impacts of FGC on women and families now living in regional Victoria.

Some women living in some regional centres are affected by FGC, and experience ongoing impacts on their health, sexuality and relationships. Other women from countries that traditionally practice FGC are unaffected by the practice, but identified a range of other sexual and reproductive health needs. Community members are, overall, positive about the services available to them in regional Victoria, but report ongoing challenges relating to communication, availability of interpreters, and unmet health education needs (including, but certainly not limited to, FGC-related information needs).

The FGC-related professional development needs of regional service providers also vary considerably across the state, with some but not all service providers having undertaken professional development activities in this area in the past. All service providers interviewed were interested in more information about the impact of FGC on the regional centre where they worked, and in having more information about existing resources and services that they can draw upon to provide FGC-related care.

This is encouraging as possibly the most problematic issue identified in the study is the mismatch between providers' beliefs about the lack of FGC-affected women in their area, and the reality of resettlement patterns and the needs of affected communities. This perception needs to be corrected in order for practitioners to have the motivation to develop the skills and confidence to ask patients about their experience of FGC and its effects, an area of inquiry that is acknowledged to be difficult and sensitive.

Community members and service providers agreed that a range of other health issues were important priorities for African diaspora communities now living in regional Victoria. These included sexual and reproductive health (including access to contraception), breast and cervical cancer screening, Vitamin D deficiency, diabetes, chronic back pain and mental health. Service providers also perceive intimate partner violence as impacting negatively on the health of immigrant and refugee women living in their communities.

FGC is a practice that may have long-term consequences for health. It is also a practice that is unfamiliar to many health service providers working in regional (and metropolitan) centres in Australia. As patterns of migration and settlement continue to evolve, it is likely that more people will settle in regional Australian centres from countries that traditionally practice FGC. These include migrants from countries often neglected in responses to FGC, such as Iraq. It is therefore important that research, to assess the FGC-related needs and experiences of new arrivals to regional Australia, is accompanied by evolving health policy and programs that support the careful and respectful assessment of the specific health needs of each newly arrived community. Through this ongoing assessment, the professional development of health service providers can be tailored to meet the emergent needs of women and families resettled in regional centres Australia wide.

## 6. Conclusion

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