



# MAINE COMMUNITY AND CLINICAL PERSPECTIVES ON FGM/C

*Honor our Bodies, Educate our Community, Respect our Heritage (HER) Initiative*



## ACKNOWLEDGMENTS

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### **Community Health Worker's reflections on the Report...**

*"About the FGC report compiled by Michelle and her team to me sounds scientifically very good as it describes the clinical, geographical and lastly details the clinical and community surveys done by MAIN. For me it is a reminder of what we have done and shared with others but for those who will hear the first time about FGC and those who will evaluate our HER grant I think they will find valuable information about what we accomplished till now."*

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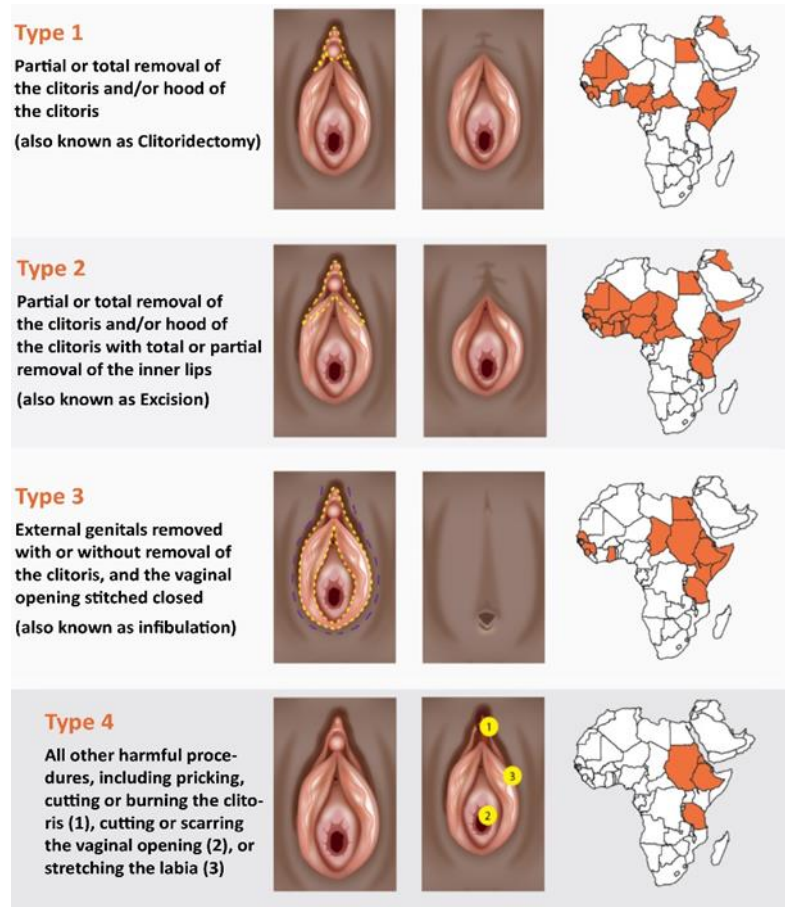
## FEMALE GENITAL CUTTING

### Defining FGM/C

**Female Genital Mutilation, Modification, Cutting, or Circumcision (FGM/C)** refer to any procedure that involves the partial or total removal of external female genitalia or any injuries inflicted on the female genitalia for non-medical purposes (World Health Organization, 2008). Typically, FGM/C is performed between infancy and 14 years old and is carried out by female community elders (United National Children's Fund, 2013). Worldwide, there are more than 200 million women and girls alive today who have experienced FGM/C (UNICEF, 2017).

There are four levels or types of FGM/C that vary in severity; these can range from pricking the clitoris to the complete removal and modification of the clitoris, labia, and vaginal opening. FGM/C varies internationally and is culturally specific in that different practices are more common among certain cultures. The clinical terminology for each type of FGM/C is as follows: (1) Type 1 is referred to as Clitoridectomy; (2) Type 2 is called Excision; (3) Type 3 is referred to as Infibulation; and (4) Type 4 is classified as Other. Diagrams and descriptions pertaining to each of these types of FGM/C, as well as the countries where each type is more commonly practiced, are detailed in Figure 1.

**Figure 1. Types of FGM/C**

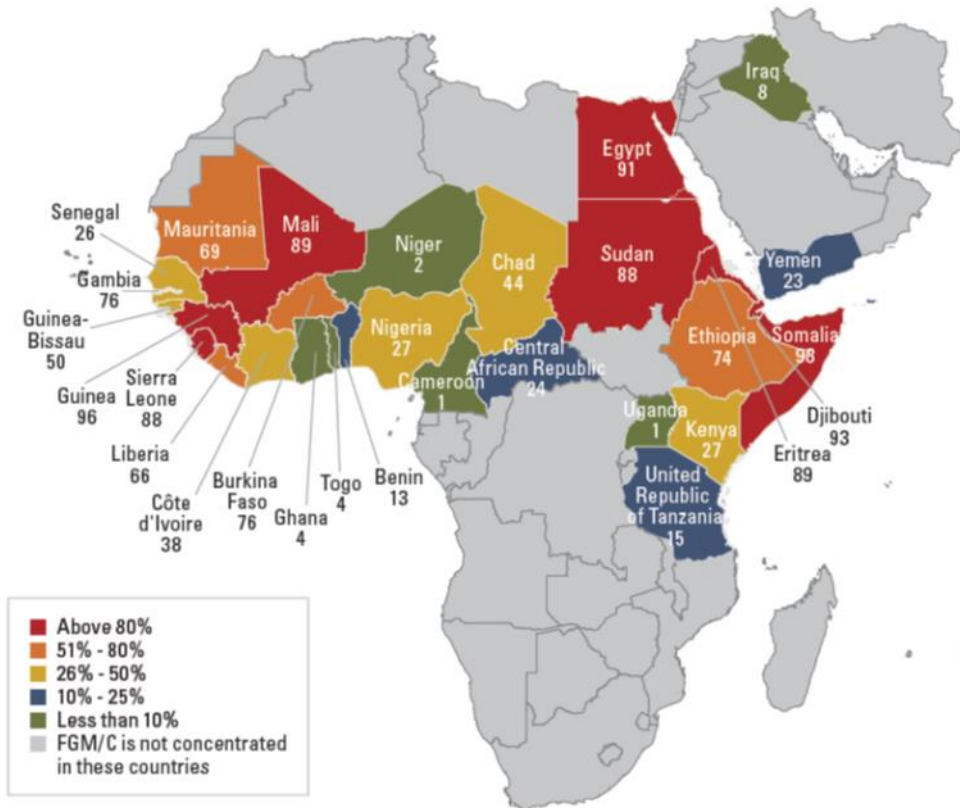


Source: Adapted from (Viva la Vulva, University College London, 2015).

**Prevalence of FGM/C**

**International prevalence.** FGM/C is a practice performed in many countries throughout Africa, Asia and the Middle East, with the highest prevalence in Egypt, Sudan, Somalia, Eritrea, Djibouti, Mali, Guinea, and Sierra Leone (United National Children's Fund, 2013). Figure 2 shows geographical representation of the international prevalence of FGM/C in countries where it is most-commonly practiced.

**Figure 2. International FGM/C Prevalence, % of 15 – 49-year-old females who have experienced FGM/C**



Source: (United National Children's Fund, 2013).

**The prevalence of FGM/C in immigrant and refugee populations in the U.S. is unknown.** There are no data that indicate how many women and girls arrive in the U.S. having experienced FGM/C or how many girls are taken out of the U.S. to undergo FGM/C in a country where it is still legal, commonly referred to as “vacation cutting.”

The Centers for Disease Control and Prevention (CDC) reported that approximately 513,000 women and girls in the U.S. were at risk of FGM/C or its consequences in 2012, which was more than three times higher than earlier estimates, based on data from 1990 (Goldberg, et al., 2016). The CDC’s report was based on estimates of risk – not prevalence – and their analysis was based on the prevalence of FGM/C in the countries where it is practiced (Goldberg, et al., 2016). These estimates focus on potential risk based on the estimated number of women and girls living in the U.S. who were born in a country or lived with a parent born in a country that practiced FGM/C. The report does not differentiate between the women who are at risk in the U.S. and women who have experienced FGM/C prior to arriving in the U.S.

The reported increase in the number of women and girls living in the U.S. who are at risk for or who have experienced the consequences of FGM/C (when compared to earlier years) is due to the rapid growth in the number of immigrants from FGM/C practicing countries living in the U.S. (Goldberg, et al., 2016).

**The prevalence of FGM/C in Maine.** Similar to the national landscape, there are no data on the prevalence of FGM/C in Maine.

## Ending FGM/C

FGM/C is already illegal in 24 of the 29 countries where the procedure is heavily practiced; there is an international movement to further its illegality (United National Children's Fund, 2013). In 2012, the United Nations General Assembly adopted the *Intensifying global efforts for the elimination of female genital mutilations* resolution to demonstrate the international political community's commitment to the elimination of FGM/C (United National Children's Fund, 2013). However, decrees and legislation restricting FGM/C have not eliminated the practice in many countries, including Djibouti, Egypt, Guinea, Somalia, and Sudan, where women are still experiencing FGM/C (United National Children's Fund, 2013).

**FGM/C in the U.S.** In the U.S., it is illegal to perform FGM/C on a female child younger than 18 years of age or to take the child out of the U.S. to undergo FGM/C.

**Eradicating FGM/C by 2030.** Internationally, the eradication of FGM/C by 2030 has been included as a target in the United Nations Sustainable Development Goals (SDGs), which were adopted by 193 UN member states in 2015 (End Violence Against Girls: Summit on FGM/C, 2016). In addition, various international treaty entities are committing to join their treaty implementation with the SDGs to support the global elimination of FGM/C. Some of these treaty entities include: Committees on the Convention on the Elimination of Forms of Discrimination Against Women (CEDAW), the Convention on the Rights of the Children (CRC), and the Protocol on the African Chapter on Human Peoples' Rights on the Rights of Women (Maputo Protocol) (End Violence Against Girls: Summit on FGM/C, 2016).

**U.S. National Initiatives.** On a national level, a number of sentinel events have occurred in the past several years that have helped to develop the U.S. framework for FGM/C-related policy initiatives:

*Vacation cutting included as a U.S. criminal offense.* In 1996, the U.S. Congress passed several pieces of legislation regarding FGM/C and its illegality in the U.S. and in September 1996 FGM/C became a criminalized practice in the U.S. as part of the Illegal Immigration Reform and Immigrant Responsibility Act of 1996 (Illegal Immigration Reform and Immigrant Responsibility Act of 1996, Title 18, United States Code, §116, 1996). The law determined that anyone who performs FGM/C on a person under the age of 18 years old would be subject to a fine and could face up to five years in prison. In 2013, an amendment to this 1996 immigration legislation was included in the National Defense Authorization Act for Fiscal Year 2013 that also criminalized "vacation cutting" (National Defense Authorization Act for Fiscal Year 2013, Pub. L. No. 112-239, 126 Stat. 1632, 2013).

*GAO provided recommendations for Executive Action regarding FGM/C.* In 2016, the U.S. GAO conducted an audit of the federal government's national efforts to combat FGM/C. The resulting report offered a number of recommendations to various U.S. agencies for executive actions to raise public awareness of the legal ramifications and health effects of FGM/C in the U.S., particularly among visa recipients (i.e. immigrants, refugees, asylum seekers, etc.). Most notably, these recommendations included developing plans for agency-wide approaches to providing national education and outreach (United States Government Accountability Office, 2016).

*Office of Women's Health, Health and Human Services issued a funding announcement focused on FGM/C.* The 2016 funding announcement solicited applications for a community-centered health care and prevention projects to implement strategies that: (1) address the gaps or problems in the FGM/C related health care services for women living in the U.S. who have experienced FGM/C; and (2) address prevention of FGM/C of girls living in the U.S. who are at risk for having the procedure conducted in the U.S. or for being sent to another country to undergo the procedures.

*End Violence Against Girls: Summit on FGM/C.* On December 2, 2016, Equality Now, Safe Hands for Girls, the U.S. Institute of Peace, and the U.S. Network to End FGM/C hosted the first End Violence Against Girls: Summit on FGM/C with funding from the Human Dignity Foundation and Wallace Global Fund. The overall goal of the summit was to encourage multi-sectoral discussions on FGM/C and support the elimination of the practice by 2030 by: (1) sharing best practices; (2) learning from women who have experienced FGM/C; and, (3) increasing coordination and collaboration across sectors (End Violence Against Girls: Summit on FGM/C, 2016).

**A comprehensive approach to eliminating FGM/C is most effective.** The elimination of FGM/C is unlikely when anti-FGM/C initiatives are perceived by the community as a critique and attack on culture and values driven by outsiders (World Health Organization, 2010). International evaluations suggest that reinforcing positive cultural values can be more effective (Denison, 2009), as can supporting community dialogue aimed at finding ways to signify a girl's "coming of age" without cutting (Masho SW, 2009). Research suggests that implementing multi-component approaches to FGM/C interventions have been most effective. These multi-component approaches typically consist of four components: (1) enacting and enforcing laws that prohibit FGM/C; (2) working with the communities affected by FGM/C; (3) increasing cultural sensitivity; and (4) providing education and outreach to protect girls living in the U.S. from FGM/C (World Health Organization, 2008).

There is a need for increased and higher quality education on FGM/C across sectors. This education must be developed in collaboration with community groups and it should focus on risk assessment and prevention. A comprehensive approach builds partnerships with affected communities so that healthcare professionals can be allies in improving appropriate services and create mechanisms for health sector engagement (End Violence Against Girls: Summit on FGM/C, 2016). FGM/C is a practice based on cultural and societal norms – eradicating the practice begins with changing these norms, attitudes and behaviors through education and information.



## Caring for Women and Girls Who Have Experienced FGM/C

Countless complications are associated with FGM/C, ranging from acute pain to death. Approximately 15% of women and girls who have experienced FGM/C develop these negative consequences (El-Shawarby & Rymer, 2008). In the short term, excessive bleeding during the procedure and shortly after is one of the most common complications of FGM/C, representing 25% of the reported complications (Hearst, 2013). Women who have experienced FGM/C are at an increased risk for various types of infections and obstructions (Little, 2015). Additionally, common long-term medical consequences of FGM/C include: scar tissue formation, menstrual problems, and childbirth challenges (Little, 2015). Aside from physical complications, many women who have experienced FGM/C suffer from chronic psychological issues, including anxiety, depression, phobias, and post-traumatic stress disorder (Little, 2015). Given the various complications that may arise, clinical care for women and girls who have experienced FGM/C is essential.

## The HER Initiative

In 2016, the Maine Access Immigrant Network (MAIN) received federal funding to implement an initiative aimed at decreasing the risk of FGM/C for girls living in Maine; and, to decrease the gaps in clinical services for women who have experienced FGM/C, with particular focus on safe birthing experiences. The HER Initiative: Honor our Bodies, Educate our Community, Respect our Heritage (HER) - is a community-led program implemented in Maine's cities of Portland and Lewiston.

Progress within the HER Initiative moves at the speed of trust, and the relationships with community members and clinical providers are the foundation of the Initiative's success. MAIN and Partnerships For Health (PFH) have a four year history of community engagement and involvement in multiple health-focused evaluations, including FGM/C.

Over a three-year period, the HER Initiative has and will continue to: (1) develop a peer education program; (2) facilitate HER neighborhood conversations; (3) promote clinical best practices; and (4) expand community-clinical linkages in Portland and Lewiston. The HER Initiative has several achievable benchmarks: identify gaps in FGM/C-related healthcare services; develop tools and resources that peer-educators can utilize to engage in intercultural and inter-generational conversations; create a social marketing campaign; and produce an inventory of lessons learned throughout the Initiative.

## Need for Evaluation

Internationally, it has been recognized that successful FGM/C-related strategies must address social norms, attitudes, and behaviors as well as build clinical competency, raise clinician awareness, and promote collaboration. Given the dearth of local information, evaluation is required to provide a baseline of clinical and community attitudes, behaviors, and perceptions regarding FGM/C.

## METHODOLOGY

The purpose of the coordinated, culturally-sensitive, community-based-participatory evaluation was to collect data that would provide a baseline from which the impact of the HER Initiative could be compared. In addition, it is envisaged that the methodology and results will contribute to the local and national conversation and research agenda regarding FGM/C.

**Study Design.** The evaluation followed a fixed mixed-method, with quantitative priority using a convergent parallel design. It relied primarily on the quantitative methods (i.e. quantitative priority), but also used qualitative methods complementarily for elaboration, enhancement, illustration, and clarification. PFH, the lead evaluator, received expedited Institutional Review Board approval (Solutions IRB Protocol #2017/03/05) prior to the implementation of the evaluation.

### Community-Driven Approach

To ensure cultural sensitivity and linguistic appropriateness throughout the evaluation process, PFH employed a community-driven approach to the evaluation that engages the community throughout the evaluation process. This process included making members of the community an integral part of the evaluation team and using their knowledge, expertise, input, and feedback to guide all evaluation stages. HER Initiative staff and members of the community partnered during the evaluation to incorporate the community’s voice into the development of the overall evaluation questions; instrument design; data analysis plan; interpretation of findings; reporting and broad dissemination.

Through this process, the HER Initiative was able to design and implement an evaluation that was culturally sensitive, linguistically appropriate, inclusive, and comfortable for the community. This process allowed for community buy-in and evaluation capacity building, but more importantly, this approach ensured that the evaluation was guided by the community and for the community.

### Data Collection

**Instruments.** Three data collection instruments were developed: (i) the Community Knowledge, Attitudes, and Perceptions Survey (Community Survey); (ii) the Birthing Patient Satisfaction Survey (Birthing Survey); and (iii) the Clinical Knowledge, Attitudes, Practices, and Skills Survey (Clinical Survey).

Criteria for inclusion and exclusion are shown in Table 1.

**Table 1. Participation inclusion and exclusion criteria**

|                         | INCLUSION CRITERIA   | EXCLUSION CRITERIA  |
|-------------------------|--|---|
| <b>Community Survey</b> | Adult (18 years +) men and women from countries where FGM/C is practiced.                          | <ul style="list-style-type: none"> <li>• Persons under the age of 18.</li> </ul>                              |
| <b>Birthing Survey</b>  | Adult (18 years +) women who have given birth in Maine and whose original country practiced FGM/C. | <ul style="list-style-type: none"> <li>• Persons unable to understand the evaluation requirements.</li> </ul> |
| <b>Clinical Survey</b>  | Healthcare providers who provide pre- and / or post-natal care at health systems in Maine.         | <ul style="list-style-type: none"> <li>• Persons unable to provide consent.</li> </ul>                        |

*Community and Birthing Surveys.* The Community and Birthing Surveys were paper-based and implemented by trained community members. To ensure standardization and full consent, each survey included a recruitment script, consent script, consent teach-back prompts and consent form. The consent script and teach-back prompts helped the survey administrator provide a summary of the consent process and address questions. The survey respondent then verbally confirmed their understanding of the study and consent process by ‘teaching back’ their understanding using their own words. After signing the consent form, respondents were able to choose their preferred mode (verbal or written) and language (English, Somali, Arabic, or French). Respondents were provided with a tote bag as a token of appreciation for participating in the survey.

*Clinical Survey.* The Clinical Survey was electronic and targeted medical professionals who are part of the pregnancy and birthing process, e.g. obstetricians, women’s health nurses and nurse practitioners, etc.

**Training, Implementation and Oversight.** All surveys were implemented simultaneously.

*Community and Birthing Surveys.* Ten community members, the majority of whom were skilled Community Health Workers at MAIN, received comprehensive data collection training and support to administer the Community and Birthing Surveys. The data collection process included weekly check-ins to monitor progress, collect anecdotal narratives, and problem solve challenges as they arose.

In May 2017, the surveys were implemented in Portland and Lewiston. At the request of the community, the data collection period was extended by a month as data collectors wanted to continue the discussion on FGM/C and thought that the surveys ignited conversations. As a result, a total of 403 respondents completed the Community Survey and 55 women completed the Birthing Survey by June 30, 2017. Collectively, this far exceeded the initial target of 60 completed surveys.

*Clinical Survey.* The Clinical Survey was distributed electronically (via SurveyMonkey) in May 2017 through hospitals and state associations including the Maine Nurse Practitioners Association, Central Maine Medical Center, Maine Chapter of the American Congress of Obstetricians and Gynecologists, Maine Medical Center, and St. Mary’s Health System. This broad distribution ensured that all interested medical professionals were given an opportunity to participate in the evaluation. This collaboration was made possible through the Daniel Hanley Center for Health Leadership. A total of 76 respondents completed the Clinical Survey. This exceeded the target of 60 surveys.

*Community Conversations.* In addition to the quantitative surveys, the Evaluation Team participated in and co-facilitated a number of community events and presentations where personal narratives and discussion topics were gathered to supplement the quantitative results. These events included: World Café-style discussions with female members of the immigrant and refugee community; facilitated discussions with community men; a Community-Clinical Forum; and presentations of preliminary survey results to some of the major health systems in Maine.

## Analysis and Triangulation

Once both the clinical and community databases had been cleaned, the data collectors were presented with the raw data and asked for their initial reflections and thoughts. Three presentations of the preliminary findings were given to communities and three to health systems. At each presentation, the audience was asked to contextualize the results, identify surprises, and reflect on unanswered questions. These discussions were used to refine the analysis plan. This reflective, iterative process ensured community buy-in, deepened the understanding of the results, and ensured appropriate interpretation.

Descriptive and summary statistics were undertaken on respondents' demographics and FGM/C-related knowledge, attitudes, and perceptions. To deepen the analysis, PFH compared results by key indicators, including: gender, age, and FGM/C status for the community respondents; and, area of specialization, years of experience, and county for the clinical respondents. The statistical significance of these comparisons was determined by conducting independent samples proportion difference z-tests using SPSS.

For most survey questions, respondents had the option of selecting "Agree", "Disagree", "Neutral", or "I don't know". In addition, respondents were allowed to leave any question blanks. Therefore, resulting percentages in the analysis will not always add up to 100%.

The qualitative data gathered during community discussions, forums and presentations was used to triangulate the quantitative analysis and feedback on the preliminary survey results. Given that most qualitative notes were gathered during discussions, forums and presentations that took place in four different languages, no verbatim responses were collected.

# CLINICAL PROVIDERS' FGM/C KNOWLEDGE AND ATTITUDES



13.5% were not familiar with FGM/C



85.5% did not believe that FGM/C only happens in Africa



66.7% believed women undergo FGM/C for social acceptance



92.6% did not believe that women want to undergo FGM/C



85.5% FGM/C causes sexual dysfunction in women



76.5% FGM/C can lead to fistula formation

### Clinical Providers

A total of 76 clinical providers responded to the survey representing 14 of 16 counties in Maine. The majority of respondents practiced in the Portland (57.9%) and Lewiston (6.6%) areas where the highest concentrations of immigrants live. Almost all (97.4%) respondents were female which reflects the trend that medical professionals who specialize in female reproductive healthcare are predominately female. Providers specialized in obstetrics and gynecology (33%), family medicine (32%) and maternal child health nursing (32%). The remainder identified as psychiatry, internal medicine, urgent care, and other.

While approximately half (47%) of the clinical respondents reported over 15 years of professional experience in their area of specialization, a quarter (26%) had 5 years or less of experience. The amount of professional experience was important when considering educational exposure to FGM/C evidence.

### Clinical Experience with FGM/C

Statewide, 59% of providers reported that, in the last year, less than 5% of the patients they saw had experienced FGM/C. Sixteen percent of providers, most from Portland and Lewiston, reported that between 5 and 25% of the patients they saw in the last year had experienced FGM/C.

### Clinical Knowledge

The majority (67.6%) of clinical respondents reported that they were slightly familiar with FGM/C, having learned about it through reading journal articles (48%) and / or attending presentations (19%).

However, 39% of clinical respondents reported that they have not received any FGM/C-related education during their medical career. This knowledge gap was evident in the large amounts of “I don’t know” responses to a series of myth and fact statements about FGM/C, as well as some common medical consequences of FGM/C. These results are summarized in Table 2.

**Table 2. Identifying FGM/C-related myths, facts and medical consequences among clinical providers**

|  | RESPONSES (n=69) |       |              |
|--|------------------|-------|--------------|
|  | MYTH             | FACT  | I DON'T KNOW |
| <b>MYTHS</b>   |                  |       |              |
| FGM/C is a religious practice.   | 44.1%            | 35.3% | 20.6%        |
| FGM/C is only practiced in counties in Africa.   | 85.5%            | 1.5%  | 13.4%        |
| Men have increased sexual pleasure with women who have undergone FGM/C.                        | 60.9%            | 4.4%  | 34.8%        |
| FGM/C is never carried out by trained healthcare professionals.                                | 30.4%            | 26.1% | 43.5%        |
| *Providers are required to report on any patient who have evidence of FGM/C.                   | 31.9%            | 11.6% | 56.5%        |
| FGM/C is comparable to male circumcision.  | 79.7%            | 7.3%  | 5.8%         |
| FGM/C always affects the number of births a woman can have.                                    | 58.0%            | 2.9%  | 33.3%        |
| Female sexual dysfunction is <u>not</u> a common consequence of FGM/C.                         | 85.5%            | 2.9%  | 7.3%         |
| FGM/C does <u>not</u> result in difficulties during childbirth.                                | 73.9%            | 2.9%  | 15.9%        |
| When performed correctly, FGM/C will <u>not</u> have negative, long-term medical consequences. | 69.6%            | 0.0%  | 20.3%        |

|  | RESPONSES (n=69) |       |              |
|--|------------------|-------|--------------|
|  | MYTH             | FACT  | I DON'T KNOW |
| <b>FACTS</b>   |                  |       |              |
| There are different types of FGM/C.  | 1.5%             | 76.8% | 21.7%        |
| FGM/C exists in America.   | 0.0%             | 88.4% | 11.6%        |
| *Providers are required to only report on girls younger than 18 who have evidence of FGM/C.  | 14.5%            | 30.4% | 55.1%        |
| The practice of FGM/C is a federal offense.  | 10.1%            | 23.2% | 66.7%        |
| FGM/C can lead to fistula formation.   | 1.5%             | 76.5% | 19.1%        |
| FGM/C increases the risk of sexually transmitted diseases / infections.  | 37.7%            | 15.9% | 36.2%        |
| *The survey failed to clarify whether the statements referred to reporting in electronic health records or mandatory reporting. These findings should therefore be interpreted with caution. |                  |       |              |

### Increasing Provider Knowledge

In discussions between clinical providers and community members, female members of the immigrant and refugee communities expressed that, if doctors don't know much about FGM/C, they should be transparent with their patients and should also try to learn more about the procedure so they can provide quality care. Almost all (98.6%) clinical respondents were interested in learning more about FGM/C.

### Clinical Attitudes and Perceptions

The majority (87%) of clinical respondents viewed FGM/C as a form of violence and believed that it was unnecessary (87%) and should not be practiced (91%). Almost all (92.8%) believe that women did not want to undergo FGM/C but did for a multitude of reasons, including: socio-cultural acceptance (66.7%); prevention of pre-marital sex and / or promiscuity (65.2%); initiation into womanhood (59.4%); and ensuring a woman is "clean" (52.2%).

Clinical respondents were divided on their beliefs regarding FGM/C as a form of intentional child abuse with 30.4% believing parents knowingly abuse their daughters by encouraging FGM/C and 26.1% disagreeing.

### Clinical Care of Women Who Have Experienced FGM/C

In a conversation with clinical providers from one health system, the providers reported that the clinical community is currently focused on determining best practices and improving cultural competencies regarding the treatment of women with FGM/C. There is interest in including FGM/C as a topic for Grand Rounds at a major medical center and potential for setting up lunch-and-learn sessions or training for the clinical community on providing quality care and treatment for women who have experienced FGM/C.

When determining a plan of action for care and treatment, members of the immigrant and refugee communities felt it was important for clinical providers to consider their patients' past care and treatment, even if past methods were not practiced in the U.S.

In discussing the results, members of the immigrant and refugee communities indicated that even if a clinical provider does not fully understand FGM/C or the cultural beliefs behind the practice, they should be respectful. Some women who have experienced FGM/C may remain supportive of the practice. Additionally, women who have experienced FGM/C may choose to forgo doctor-recommended procedures to medically reverse their FGM/C. Clinical providers should be respectful of these decisions, even if they don't fully understand or agree with them.

### System for Treatment and Care

The majority of clinical respondents (59.4%) reported that the healthcare facility for which they work does not have any policies and / or practices in place for treating women who have experienced FGM/C. Many have policies that support the linguistic and cultural diversity of their patients. This includes having interpreter services available (42.2%) and guidelines for cultural sensitivity (37.5%).

Almost a third (32.8%) of respondents reported having some sort of policy or practice in place specifically regarding the clinical care and treatment of women who have experienced FGM/C. These healthcare systems may serve as models for other facilities.

### Documenting FGM/C in Patient Electronic Health Records

In conversations with clinical providers, activities are underway to systematically document FGM/C in patients' electronic health records (EHR). Currently, when a clinical provider sees a pregnant woman who has experienced FGM/C, they try to include some of the following information as a text field in the EHR: the level of FGM/C; what the woman's post-delivery plans are (e.g., does she plan to have any kind of vaginal reconstruction); and what does the woman want her body to look like.

The clinical community is hopeful that all health systems will adopt a systematic approach of documenting FGM/C in their patients' files and eventually, all patients' records will be linked through EHR systems. Members of the immigrant community believe this would be helpful as well. They believe that FGM/C status should be asked about in patients' initial visit and should be incorporated into medical records/files so that patients do not have to discuss their FGM/C with each new provider.

### Provider and Client Conversations

Eighty-five percent of clinical respondents believed it was important to discuss FGM/C with their patients, but recognized that women may not trust providers or fear immigration/ legal ramifications. This may also lead to many women not seeking medical care.

Community women reported that they feel more comfortable speaking with female doctors and nurses about their circumcision.

Women who have experienced FGM/C said that they are often afraid to bring it up with their doctor and would find it helpful if their doctor asked about their circumcision in a respectful way. For example, clinical providers can ask, "It looks like you may have had a procedure. Would you like to talk about it?"



Both community and clinical participants believed that doctors and their patients should engage in conversations about FGM/C and learn more from each other. There was general agreement that clinical providers may not be experienced in discussing FGM/C and may need the patient to be the guide and help her provider understand.

Even if a woman has experienced a “minor” level of FGM/C or if the woman’s circumcision does not cause any concern for medical consequences, women would still appreciate their doctors asking about it. The doctors will know during any examination that the woman has experienced some type of procedure, so they should acknowledge that to their patient.

In general, community women preferred the procedure to be referred to as “circumcision,” because it implies that the procedure is not always a choice for the woman. According to these community women, the term “mutilation” implies that a woman is not ‘complete’ or ‘whole’ because of her circumcision.

# EXPERIENCE OF CHILDBIRTH AMONG WOMEN WHO HAVE UNDERGONE FGM/C



## Community Mothers

A total of 55 women, living in Portland or Lewiston, completed the Birthing Survey. Table 3 describes the demographics of the respondents. The majority (67.3%) of respondents had experienced FGM/C in their home country. The remaining third (32.7%) had not experienced FGM/C.

**Table 3. Demographic characteristics of women completing the Birthing Survey**

|                           | AVERAGE<br>(MEAN) | MODE | MEDIAN | RANGE   |
|---------------------------|-------------------|------|--------|---------|
| Age                       | 36.3              | 35   | 35     | 21 - 57 |
| Number of children        | 4                 | 3    | 3      | 1 - 10  |
| Number of births in Maine | 2.4               | 1    | 2      | 1 - 8   |

## Prenatal Care

Culturally, many women do not perceive pregnancy as a medical condition and therefore do not seek prenatal care (Institute of Medicine (US) Committee to Study Outreach for Prenatal Care, 1988). It was therefore surprising that the majority of women (96.4%) reported regular medical visits during their pregnancy. Having undergone FGM/C did not impact their use of prenatal care [FGM/C: 97.3%; no-FGM/C: 93.3%].

FGM/C had a significant ( $p=0.03$ ) impact on a woman’s pregnancy experience. Three quarters of women who had not undergone FGM/C had a very positive experience, while less than half (40.5%) of women with FGM/C had a very positive experience. In addition, women who had experienced FGM/C were more likely to have a negative pregnancy experience [FGM/C: 2.7%; no-FGM/C: 0.0%].

### KNOWLEDGE

22.2% thought their doctor had a good understanding of FGM/C

### ATTITUDES

72.2% said their doctor made them feel comfortable

67.6% said their doctor made them feel at ease and respected during physical examinations and discussions

### PRACTICES

33.3% spoke to their doctor about their FGM/C

28.6% discussed with their doctor how their circumcision may affect their delivery

54.1% received information from their doctor to prepare for childbirth

35.1% said their doctor told them what to expect when giving birth

27.0% worked with their doctor to create a birthing plan

The majority of women, who had experienced FGM/C, reported that their doctors made them feel comfortable (72.2%), and at ease and respected during their physical examination (67.6%). Many (54.1%) received information from their doctors to prepare for childbirth and some (35.1%) reported having conversations with their doctor about what to expect when giving birth. Approximately one-in-four (27.0%) pregnant women who had experienced FGM/C worked with their doctor to create a birthing plan.

Unfortunately, only a third (33.3%) of women who had experienced FGM/C spoke to their doctors about FGM/C and even fewer (28.6%) engaged in a discussion about how their circumcision may affect their delivery. The perceived knowledge of the doctor may be a contributing factor to the lack of dialogue as only 22.2% of women thought their doctor had a good understanding of FGM/C.

## Birthing

During the community discussions, many women voiced concern over the perceived high rates of C-sections among immigrant women. This appeared to hold true for the women who have experienced FGM/C with 56.8% reporting a vaginal birth and 43.2% a C-section. However, among women who had

not undergone FGM/C, the rates of C-sections appear similar to the statewide average of 29.4% (National Center for Health Statistics, 2017).

FGM/C did not impact on the overall experience of childbirth.

The majority (56.8%) of women who had undergone FGM/C reported having the type of delivery she expected (i.e., C-section or vaginal birth) and viewed it, overall, as a positive experience (78.3%). Most (80.6%) felt cared for by the hospital staff and many (60.0%) reported that the hospital staff helped them understand the delivery process.

Two-in-five women (43.2%) believed that their FGM/C led to challenges during the delivery process and 29.7% felt that the hospital staff did not keep the mother’s opinion in mind when addressing these challenges. This may, in part, be due to the perceived lack of knowledge and understanding of the impact of FGM/C on delivery: only 21.6% of women felt that the hospital staff had a good understanding of the impact of FGM/C on delivery.

 **KNOWLEDGE**

21.6% thought the hospital staff had a good understanding of the impact of female circumcision on delivery

 **ATTITUDES**

80.6% felt cared for by the hospital staff  
59.5% overall, had a positive birthing experience

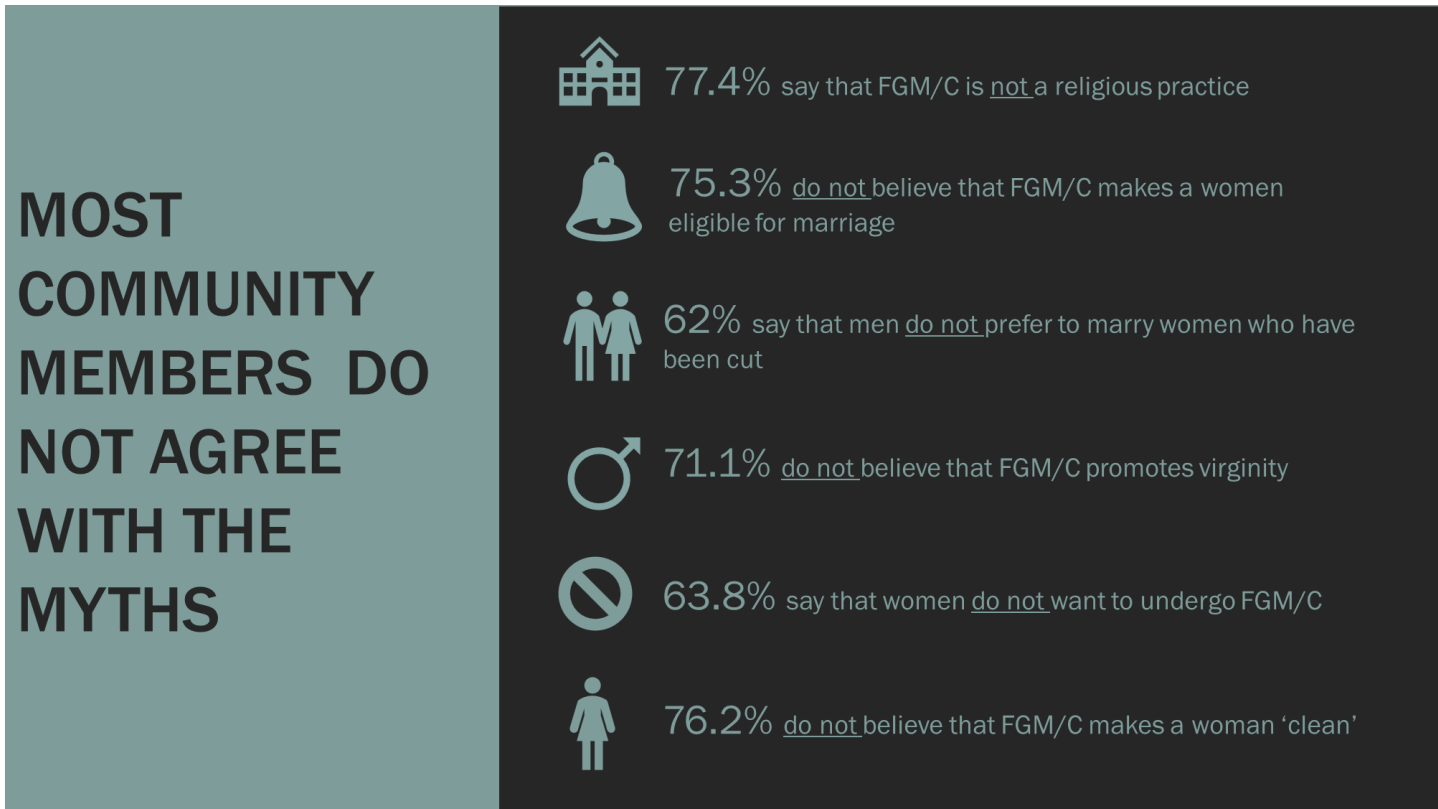
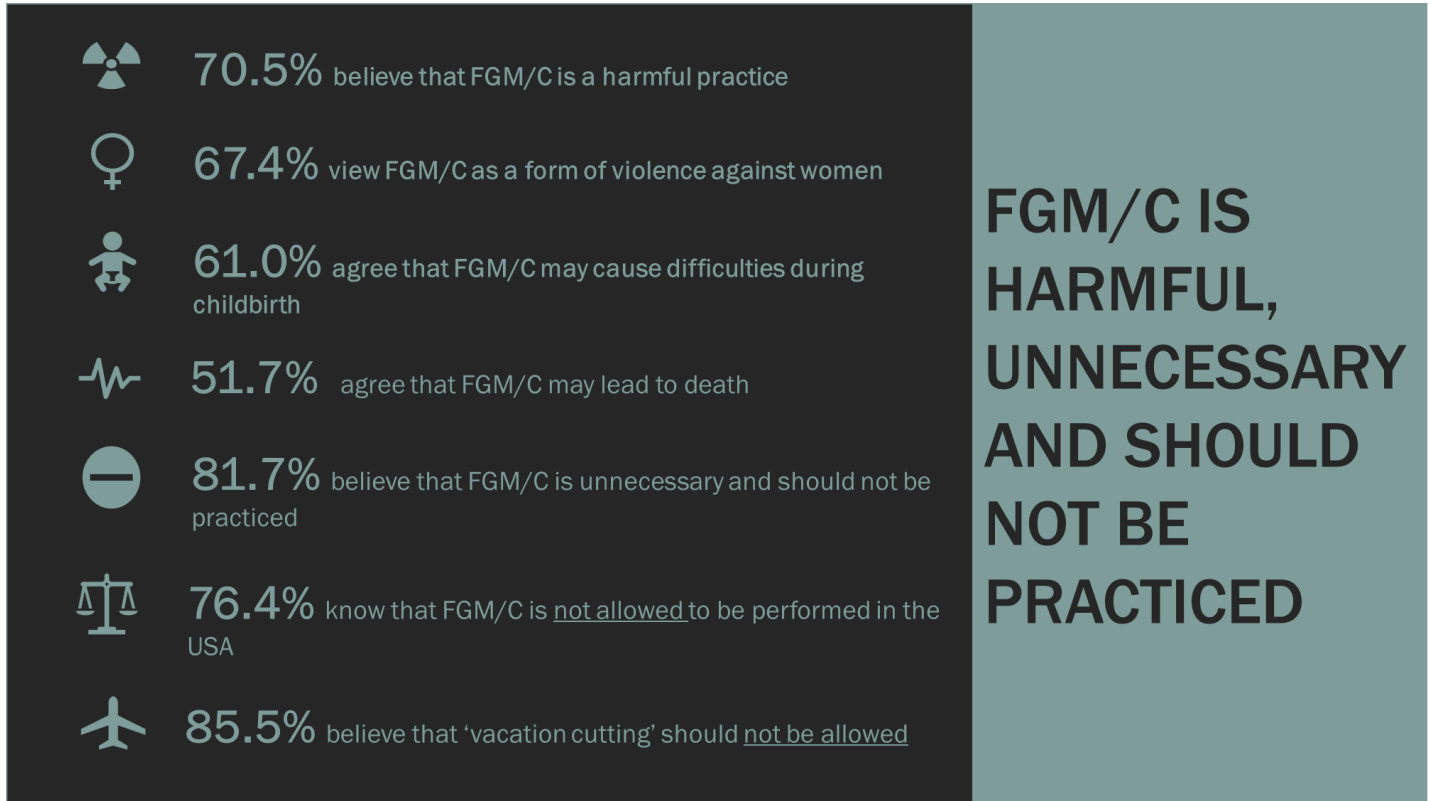
 **PRACTICES**

56.8% had the type of delivery she expected  
60.0% reported hospital staff helping them understand the delivery process  
43.2% believed their circumcision led to challenges during the delivery process  
35.1% said the hospital staff addressed the birthing challenges while keeping her (the woman's) opinions in mind

During community reflections on the survey results, the women emphasized the need to *not* assume that medical professionals were familiar with birthing processes for women who had undergone FGM/C or that they were prepared for complications that may arise. However, they cautioned against generalization and highlighted that FGM/C does not always lead to complications and it was important to consider the type of FGM/C a woman has undergone and the amount of scar tissue she has. When presenting the preliminary survey data to women in the community, the group discussed how exactly FGM/C may cause issues or complications during childbirth.

# COMMUNITY FGM/C KNOWLEDGE AND ATTITUDES





## Community Members

Men and women from immigrant communities showed an unexpected eagerness to complete the survey. In total, 403 people in Portland and Lewiston completed the survey. Table 4 provides a summary of their country of origin, age, religious practice, and marital status.

**Table 4. Demographic characteristics of women and men completing the Community Survey**

|   | WOMEN     | MEN     |
|---|-----------|---------|
|   | (n=248)   | (n=146) |
| Respondents   | 62.9%     | 37.1%   |
| Average age (Range: 18-75)  | 34.7      | 39.1    |
| Average length of time in the USA (Range: 1 month – 44 years)   | 8.5 years | 6 years |
| <b>Marital Status</b>   | (n=248)   | (n=145) |
| Ever married (includes widows/widowers)   | 61.7%     | 71.0%   |
| Single, never married   | 38.3%     | 29.0%   |
| <b>Country of Origin</b>  | (n=245)   | (n=146) |
| Somalia   | 35.1%     | 30.8%   |
| Democratic Republic of Congo  | 12.2%     | 21.9%   |
| Djibouti  | 14.7%     | 13.0%   |
| Iraq  | 10.6%     | 6.2%    |
| Other (Rwanda, Sudan, Angola, Burundi, Ethiopia, Jordan, Kenya, Pakistan)   | 27.4%     | 28.1%   |
| <b>Religious Practice</b>   | (n=247)   | (n=146) |
| Christian   | 21.1%     | 37.0%   |
| Islam   | 77.7%     | 63.0%   |
| <b>Experienced FGM/C</b>  | (n=242)   | N/A     |
| Yes   | 47.2%     | N/A     |
| No  | 49.6%     | N/A     |
| Respondents were able to skip questions or select “prefer not to answer”, resulting in percentages that may not add up to 100%. There were 9 respondents who did not provide their gender. The above percentages have excluded these respondents. |           |         |

## The Practice of FGM/C

Collectively, community women and men believe that FGM/C is harmful (70.5%) and a form of violence against women (67.4%). Most respondents thought the practice was unnecessary, and should no longer be practiced on children in their country of origin (81.7%) or through vacation cutting (85.5%).

The survey results reflect the conversations with community women, many of whom stated that they would not subject their daughters to FGM/C because they don’t want their children to experience the pain they went through when they were cut.

In discussions with clinical providers and community men, it was suggested that men’s perspectives on FGM/C change based on their role as a husband, father, uncle, etc. They proposed that men’s marital status might have an influence on their perceptions of FGM/C. However, the survey results did not support this hypothesis. Rather, the survey results found that men’s age was a better predictor of their attitudes and beliefs about the practice. Men between the ages of 18 and 34 years old were more likely than older men to agree with the cultural myths around FGM/C.

### Mental Health Consequences of FGM/C

There is a statistically significant difference ( $p = 0.003$ ) between men and women who believe FGM/C causes depression and other psychological problems. While almost two-thirds (63.9%) of women believed depression and other psychological problems can be a result of FGM/C, less than half (48.2%) of men held the same opinion.

Community women were surprised by this survey finding and questioned how a woman would know to attribute her psychological problems to FGM/C – particularly if she had no recollections of the procedure. These discussions continued in the community-clinical forum where it was acknowledged that mental health distress could result from many aspects associated with trauma, including anxiety on a woman’s wedding night when she was expected to have sex with her husband, and body dysmorphia.

### Physical Health Consequences of FGM/C

There was recognition from both men and women that FGM/C can cause difficulties during childbirth such as complications (61.0%), excessive bleeding (50.8%), and even death (51.7%).

Women spoke about debilitating menstrual pain and problems urinating. There was confusion about fistulas and the need and manner in which episiotomies were performed during childbirth. Additionally, both women and men of the community were often unsure about the common medical consequences of FGM/C; for every survey question regarding the physical health consequences of FGM/C, at least 1 in 5 community members reported that they did not know. Table 5 summarizes the community’s perspectives on the physical health consequences of FGM/C.

**Table 5. Physical health consequences of FGM/C**

| FGM/C MAY LEAD TO...   | RESPONSES |          |              |
|--|-----------|----------|--------------|
|  | AGREE     | DISAGREE | I DON'T KNOW |
| Difficulties during childbirth.  | 61.0%     | 11.5%    | 21.5%        |
| Excessive bleeding during childbirth.                                    | 50.8%     | 13.4%    | 28.8%        |
| Painful sexual intercourse for women.                                    | 58.9%     | 10.8%    | 24.2%        |
| Problems with urination and menstruation.                                | 61.8%     | 11.3%    | 21.9%        |
| An increased number of female infections.                                | 50.3%     | 15.8%    | 27.6%        |
| An increased risk of spreading sexually-transmitted diseases/infections. | 40.5%     | 22.0%    | 31.1%        |
| Infertility.   | 33.7%     | 26.1%    | 32.9%        |
| Death.   | 51.7%     | 18.7%    | 24.3%        |



### FGM/C as a Religious Practice

Most (77.4%) community respondents did not support the myth that FGM/C is a religious practice. Female community members (82.8%) were more likely to reject the myth than their male counterparts (69.0%). Additionally, around 1 in 5 male community members (19.0%) believe that FGM/C is a religious practice, depending on the type and / or level of FGM/C.

This myth was discussed in detail during the community-clinical forum. Community women pointed to evidence that FGM/C is a cultural (not religious) practice stating that it predates Islam and that many non-Muslim majority countries practice FGM/C. However, there was discussion that, though the religious teachings of Islam do not promote FGM/C, the scripture does reference a religious practice that may be misinterpreted as FGM/C.

### FGM/C Makes a Woman Clean and Promotes Virginity

The majority (76.2%) of community respondents did not believe that FGM/C makes a woman ‘clean.’ In some cultures, community members believe that women are not ‘clean’ or considered ‘feminine’ if they have not experienced FGM/C.

Respondents’ gender, age, and experience of FGM/C influenced their belief in this myth (Table 6). There was a statistically significant difference ( $p = 0.004$ ) between women and men who debunk the myth with 68.3% of men and 81.3% of women reporting that they do not believe that FGM/C makes a woman ‘clean’. Younger men (18-34 years) were statistically more likely to believe in the myth than older men ( $p = 0.034$ ). Women who have experienced FGM/C were more likely, than those how had not, to believe that FGM/C makes a woman ‘clean’ ( $p = 0.000$ ).

**Table 6. Gender, FGM/C Experience, and Age impact on belief in myth: FGM/C makes a woman clean**

| FGM/C MAKES WOMEN CLEAN |                     |                     |                   |                     |                         |                     |
|-------------------------|---------------------|---------------------|-------------------|---------------------|-------------------------|---------------------|
|                         | GENDER              |                     | FGM/C EXPERIENCE  |                     | MALE AGE                |                     |
|                         | Women<br>(n=246)    | Men<br>(n=142)      | FGM/C<br>(n=115)  | No-FGM/C<br>(n=123) | 18 – 34 years<br>(n=58) | 35+ years<br>(n=82) |
| Disagree                | <b><u>81.3%</u></b> | <b><u>68.3%</u></b> | 73.0%             | 91.1%               | 60.3%                   | 74.4%               |
| Agree                   | 6.5%                | 12.7%               | <b><u>13%</u></b> | <b><u>0%</u></b>    | <b><u>19.0%</u></b>     | <b><u>7.3%</u></b>  |

Bolded and underlined results indicate a statistically significant difference between data points.  
 “I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%.

Similar to the belief that FGM/C makes a woman clean is the perception of the need to ensure a woman remains a virgin until she is married (Table 7). The majority (71.1%) of community members do not believe that FGM/C promotes virginity. While men, particularly younger men, were more likely to support the myth, the differences were not statistically significant. However, there was a statistically significant difference ( $p = 0.002$ ) between women who have experienced FGM/C and those who have not.

**Table 7. Gender, FGM/C Experience, and Age impact on belief in myth: FGM/C promotes virginity before marriage**

| FGM/C PROMOTES VIRGINITY BEFORE MARRIAGE |                  |                |                     |                     |                         |                     |
|--|------------------|----------------|---------------------|---------------------|-------------------------|---------------------|
|  | GENDER           |                | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|  | Women<br>(n=245) | Men<br>(n=145) | FGM/C<br>(n=116)    | No-FGM/C<br>(n=122) | 18 – 34 years<br>(n=59) | 35+ years<br>(n=84) |
| Disagree                                 | 73.1%            | 69.0%          | 70.7%               | 77.0%               | 66.1%                   | 71.4%               |
| Agree                                    | 13.1%            | 17.2%          | <b><u>19.9%</u></b> | <b><u>6.6%</u></b>  | 22.0%                   | 13.1%               |

Bolded and underlined results indicate a statistically significant difference between data points.  
 “I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%.

During community discussions, women understood this difference as a way of justifying or making sense of having undergone the procedure.

### FGM/C and Marriageability

While collectively, most (75.3%) community members did not believe that FGM/C makes a woman eligible for marriage, 13.3% of men and 6.0% of women did (Table 8). This difference is statistically significant ( $p = 0.01$ ). While the age of men did not significantly impact on the belief in the myth, the experience of FGM/C was significant. Women who have experienced FGM/C were more likely to agree with the myth than those who had not ( $p = 0.00$ ).

**Table 8. Gender, FGM/C Experience, and Age impact on belief in myth: FGM/C makes a woman eligible for marriage**

| FGM/C MAKES A WOMEN ELIGIBLE FOR MARRIAGE |                    |                     |                     |                     |                         |                     |
|---|--------------------|---------------------|---------------------|---------------------|-------------------------|---------------------|
|   | GENDER             |                     | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|   | Women<br>(n=247)   | Men<br>(n=142)      | FGM/C<br>(n=116)    | No-FGM/C<br>(n=124) | 18 – 34 years<br>(n=59) | 35+ years<br>(n=85) |
| Disagree                                  | 77.7%              | 73.2%               | 67.2%               | 87.1%               | 67.8%                   | 74.1%               |
| Agree                                     | <b><u>6.0%</u></b> | <b><u>13.3%</u></b> | <b><u>19.9%</u></b> | <b><u>6.6%</u></b>  | 15.3%                   | 10.6%               |

Bolded and underlined results indicate a statistically significant difference between data points.  
 “I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%.

As FGM/C is not largely considered a requirement for marriage, the majority of men also indicated that they did not prefer to marry women who have experienced FGM/C (Table 9). Sixty-two percent of community members do not believe that men prefer to marry women who have been circumcised, with 68.3% of men and 59.1% of women. However, nearly 1 in 5 of both men (18.6%) and women (18.2%) do believe that men hold this preference. 20.3% of men between the ages of 18 and 34 and 16.7% of men over the age of 35 believe that men prefer to marry women who have experienced FGM/C. This difference was not statistically significant.

However, women who had experienced FGM/C were more likely than those who had not to support the myth ( $p = 0.000$ ).

**Table 9. Gender, FGM/C Experience, and Age impact on belief in myth: Men prefer to marry women who have undergone FGM/C**

| MEN PREFER TO MARRY WOMEN WHO HAVE UNDERGONE FGM/C |                  |                |                     |                     |                         |                     |
|--|------------------|----------------|---------------------|---------------------|-------------------------|---------------------|
|  | GENDER           |                | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|  | Women<br>(n=247) | Men<br>(n=145) | FGM/C<br>(n=116)    | No-FGM/C<br>(n=124) | 18 – 34 years<br>(n=59) | 35+ years<br>(n=84) |
| Disagree   | 59.1%            | 68.3%          | 45.7%               | 72.6%               | 66.1%                   | 70.2%               |
| Agree  | 18.2%            | 18.6%          | <b><u>37.1%</u></b> | <b><u>1.6%</u></b>  | 20.3%                   | 16.7%               |

Bolded and underlined results indicate a statistically significant difference between data points.  
 “I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%.

When the data on eligibility for marriage was shared with community women, they were surprised that the results showed that such a small percentage of men believed that FGM/C makes a woman eligible for marriage. They felt that the men in their community still believe that FGM/C protects virginity, which is considered a female prerequisite for marriage. Many suggested that some men may need to feel that their ego is boosted on their wedding night by having to penetrate a woman who has experienced FGM/C.

The majority (73.7%) of community members do not believe that FGM/C leads to a more trustworthy marriage (Table 10). Gender did not impact significantly on these findings. Female perspectives on this statement varied based on whether the woman had experienced FGM/C ( $p=0.000$ ). Men between the ages of 18 and 34 were significantly less likely to dispel the myth, compared with men of ages 35 and older ( $p=0.03$ ).

**Table 10. Gender, FGM/C Experience, and Age impact on belief in myth: FGM/C leads to a more trustworthy marriage**

| FGM/C LEADS TO A MORE TRUSTWORTHY MARRIAGE |                  |                |                     |                     |                         |                     |
|--|------------------|----------------|---------------------|---------------------|-------------------------|---------------------|
|  | GENDER           |                | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|  | Women<br>(n=244) | Men<br>(n=143) | FGM/C<br>(n=116)    | No-FGM/C<br>(n=122) | 18 – 34 years<br>(n=58) | 35+ years<br>(n=83) |
| Disagree                                   | 73.8%            | 74.8%          | 65.5%               | 82.0%               | <b><u>65.5%</u></b>     | <b><u>81.9%</u></b> |
| Agree                                      | 10.7%            | 14.7%          | <b><u>19.8%</u></b> | <b><u>0.8%</u></b>  | 20.7%                   | 9.6%                |

Bolded and underlined results indicate a statistically significant difference between data points.  
 “I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%.

### FGM/C and Sexual Pleasure

Over half of community members (57.6%) do not believe that FGM/C controls female sexual pleasure. Women and men differed slightly on this perspective, with 55.1% of women and 62.5% of men reporting that FGM/C does not control female sexual pleasure (Table 11). Only the experience of FGM/C significantly impacted on respondents’ belief in the myth.

**Table 11. Gender, FGM/C Experience, and Age impact on belief in myth: FGM/C controls female sexual pleasure**

| FGM/C CONTROLS FEMALE SEXUAL PLEASURE  |                  |                |                     |                     |                         |                     |
|--|------------------|----------------|---------------------|---------------------|-------------------------|---------------------|
|  | GENDER           |                | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|  | Women<br>(n=243) | Men<br>(n=144) | FGM/C<br>(n=114)    | No-FGM/C<br>(n=121) | 18 – 34 years<br>(n=59) | 35+ years<br>(n=83) |
| Disagree   | 55.1%            | 62.5%          | 50.9%               | 62.0%               | 57.6%                   | 66.3%               |
| Agree  | 22.6%            | 16.7%          | <b><u>35.1%</u></b> | <b><u>9.9%</u></b>  | 22.0%                   | 12.0%               |
| Bolded and underlined results indicate a statistically significant difference between data points.<br>“I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%. |                  |                |                     |                     |                         |                     |

The majority of community members (67.3%) disagree with the myth that FGM/C allows men to have more sexual pleasure (Table 12). There were gender and experience of FGM/C differences.

Men were more likely to agree with the myth than women ( $p = 0.02$ ). A woman’s FGM/C status played a large role in her perspective on male sexual pleasure, with more women who had experienced FGM/C believing that men have more sexual pleasure with a woman who has experienced FGM/C.

**Table 12. Gender, FGM/C Experience, and Age impact on belief in myth: Men have more sexual pleasure with a woman who has been circumcised**

| MEN HAVE MORE SEXUAL PLEASURE WITH A WOMEN WHO HAS BEEN CIRCUMCISED  |                    |                     |                     |                     |                         |                     |
|--|--------------------|---------------------|---------------------|---------------------|-------------------------|---------------------|
|  | GENDER             |                     | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|  | Women<br>(n=246)   | Men<br>(n=145)      | FGM/C<br>(n=116)    | No-FGM/C<br>(n=123) | 18 – 34 years<br>(n=59) | 35+ years<br>(n=84) |
| Disagree   | 64.6%              | 73.1%               | 69.8%               | 62.6%               | 69.5%                   | 75.0%               |
| Agree  | <b><u>6.1%</u></b> | <b><u>13.1%</u></b> | <b><u>11.2%</u></b> | <b><u>0.8%</u></b>  | 16.9%                   | 10.7%               |
| Bolded and underlined results indicate a statistically significant difference between data points.<br>“I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%. |                    |                     |                     |                     |                         |                     |

### Talking About FGM/C

Aligned with many other community FGM/C perspectives, the majority of community members (68.3%) believe it is important to talk about FGM/C in the community, with 67.4% of men and 69.4% of women sharing this perspective on community dialogue. Age did not significantly impact on these findings. FGM/C status had a statistically significant impact on women’s perspectives. Women who have experienced FGM/C were more likely to believe that it is important to talk about FGM/C in the community ( $p=0.002$ ).

**Table 13. Gender, FGM/C Experience, and Age impact on belief in statement: It is important to talk about FGM/C in the community**

| IT IS IMPORTANT TO TALK ABOUT FGM/C IN THE COMMUNITY   |                  |                |                     |                     |                         |                     |
|--|------------------|----------------|---------------------|---------------------|-------------------------|---------------------|
|  | GENDER           |                | FGM/C EXPERIENCE    |                     | MALE AGE                |                     |
|  | Women<br>(n=245) | Men<br>(n=144) | FGM/C<br>(n=117)    | No-FGM/C<br>(n=122) | 18 – 34 years<br>(n=58) | 35+ years<br>(n=84) |
| Disagree   | 21.6%            | 22.2%          | 17.9%               | 26.2%               | 20.7%                   | 23.8%               |
| Agree  | 69.4%            | 67.4%          | <b><u>76.9%</u></b> | <b><u>63.1%</u></b> | 69.0%                   | 66.7%               |
| Bolded and underlined results indicate a statistically significant difference between data points.<br>“I don’t know” and “neutral” responses are not presented which may result in totals not equaling 100%. |                  |                |                     |                     |                         |                     |



# DISCUSSION

## Clinical Providers

In general, the Clinical Survey highlighted that there are some knowledge and practice gaps among clinical providers in Maine regarding FGM/C. Clinical providers expressed some uncertainty around the state-mandated reporting requirements as they relate to FGM/C. In discussions and research presentations to clinical providers, it became clear that Maine lacks FGM/C-related resources and reporting guidelines for clinical providers. Providers are not sure who to ask questions to or which state office / agency to turn to for guidance on the topic. When approached with questions, Maine agencies directed the clinical providers to the federal level, who then referred them back to the state-level agency. This infrastructural confusion presents itself as a barrier to providing quality care and FGM/C-related competency in a clinical setting.

The HER Initiative Evaluation Team found similar concerns on the national level through discussions with the Department of Justice and Federal Bureau of Investigation.

Reporting aside, the HER Initiative discussions with clinical providers highlighted an immense interest in clinicians learning more about FGM/C and building potential partnerships with the community. Providers expressed that they would like to work with community members to determine how to make women feel more comfortable in their doctors' offices and how to best start the conversation about FGM/C.

## Mothers Who Have Given Birth in Maine

The Birthing Survey highlighted the important and sometimes overlooked challenge of providing culturally sensitive and respectful clinical care to women during pregnancy and childbirth. In general, women from the immigrant and refugee communities, those who have experienced FGM/C and those who have not, had positive perspectives on the pregnancy and birthing experiences in Maine. There was no direct correlation between women's FGM/C status and the type of delivery she experienced (C-section vs. vaginal birth). Additionally, women's FGM/C status did not appear to have a significant impact on women's overall birthing experiences or interactions with doctors and nurses during labor and delivery.

However, women who had experienced FGM/C were less likely to have had a positive labor experience. Only 1 in 3 women had discussed their circumcision with their doctors during their pregnancy and childbirth process. Most women reported that their doctor did not provide them with information on what to expect or how to prepare for childbirth, or adequately prepare them for their labor or address the challenges that arose during childbirth.

## Community Members

Collectively, members of the immigrant and refugee communities in Maine do not support the practice of FGM/C. The Community Survey results showed that the community sees FGM/C as a harmful and unnecessary practice that should no longer happen. In various discussions, community members suggested that FGM/C is irrelevant in the culture of today's society – there are other ways the community can carry out their cultural traditions. Though the community as a whole is against the practice of FGM/C, there are still community members who tend to cling to this cultural tradition of the past.

Most notably, men between the ages of 18 and 35 years old were the population of community members who were most likely to believe the commonly held myths about FGM/C, particularly the myths surrounding marriage and sexuality. Clinical providers and community members both postulated that these young men might be experiencing a sense of cultural push and pull. On the one hand, they are a younger, typically progressive group who do not necessarily hold the myths to be true for themselves (i.e. a young man may not require that his future wife be circumcised or will choose not to circumcise his daughter). But on the other hand, these young men may hold a close relationship with the elders of their family who have instilled a cultural loyalty in them, pushing them to hold on to traditional perspectives regarding FGM/C.

In addition, community women who experienced FGM/C while they were living in their home countries were more likely to agree with common FGM/C myths related to cultural acceptance, marriage, and sexuality. In community discussions, women suggested that FGM/C is often forced upon women by grandmothers and community elders. Without the ability to choose what happens to their bodies, many women feel powerless when it comes to FGM/C. Therefore, they may cling to the common cultural beliefs that FGM/C makes women clean or that men prefer to marry women who have experienced FGM/C as way to justify the practice that was forced on them and to cope with the trauma of the experience.

## Future Direction

**Priorities.** Based on the results of the surveys, and various community and clinical conversations, community members worked with clinical providers at a Community-Clinical Forum to determine the following top-six actions steps to take within the next year to continue the community-clinical FGM/C conversation:

1. Involve the community in clinical education, training, and conversations on FGM/C.
2. Involve clinical providers in community discussions on FGM/C.
3. Leverage new and existing relationships to bring the concerns of the community to clinical providers and hospitals.
4. Create and widely disseminate educational materials on FGM/C that can be used to start the FGM/C conversation between clinical providers and their patients.
5. Incorporate FGM/C-related education into schools through health courses and nurse-led education.
6. Facilitate more national-level conversations on FGM/C, starting with sharing with family and friends how the conversation is going in Maine.



**Continuing Community Conversations.** By keeping the community dialogue open and continuing to dispel community myths and misunderstandings about FGM/C, the HER Initiative strives to let the survey results and community members guide the shift in community attitudes and perceptions around FGM/C.

**Social Marketing.** Based on these age-related findings, the HER Initiative Evaluation Team will develop a social marketing campaign and messaging campaign to target young men between the ages of 18 and 35 in the immigrant and refugee communities of Portland and Lewiston. Through discussions with community members, men this age often struggle to find a safe place to ask questions about dating, women, sexuality, and marriage. The HER Initiative hopes to build an anonymous platform through which men and women, though specifically young men, can ask their questions and share their perspectives to inform the greater community discussion on FGM/C.

**Education.** The results of the Clinical Survey indicated that there is room for improvement in providing care to women with FGM/C for clinical providers in Maine, but the results of the Birthing Survey suggest this knowledge gap may be particularly evident in pregnancy and birthing. These results may inform future HER Initiative programming to: (1) provide targeted education to clinicians on labor and delivery considerations with FGM/C; and, (2) provide resources and education to community members on how to start the FGM/C conversation with their OB/GYN.

## LIMITATIONS

The community-driven evaluation model presents some inherent limitations. The strong community engagement required may have impacted the external validity and resulted in the findings not being generalizable to other communities or settings.

The development of all data collection tools was based on existing literature and evidence-based surveys. However, the HER Initiative surveys were modified to meet the needs of the neighborhood and clinical communities of Maine. In doing so, certain traditional questions were omitted for ethical and / or pragmatic reasons. For example, women were not asked to identify the type of FGM/C they had experienced. Likert scales were used extensively in the surveys. In an attempt to maintain consistency, some statements were worded as double negatives. These statements may have been confusing for respondents and may have impacted on their responses. Finally, all surveys were self-reported and therefore the influence of social desirability cannot be excluded.

Due to sample sizes, some variables were not included in cross tabulations. This included country of origin, length of stay in the U.S., and hospital where the community women gave birth. The impact of this exclusion in the usability of the findings was seen as less than the risk of unintended consequences.

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