



# Female Genital Mutilation/Cutting: Challenges, Research Gaps, and Opportunities in a Hidden Population

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# Outline

- Historical/Cultural Overview
- Epidemiology
- WHO Classification Scheme
- Health Outcomes
- Challenges and Gaps in Care
- Emerging Evidence
- Research Gaps
- Legal & Ethical Controversies
- Health Policy & Research Directives



# **Historical/Cultural Overview and Epidemiology**

# **Female Genital Mutilation/Cutting**

**“Any procedure that involves partial or total removal of external female genitalia or other injury to female genital organs whether for cultural or non-therapeutic reasons.”**

# Female Genital Mutilation/Cutting

## Controversial Terminology:

Cutting

vs.

Mutilation

Jacoby, S. D., & Smith, A. (2013). Increasing certified nurse-midwives' confidence in managing the obstetric care of women with female genital mutilation/cutting. *Journal of Midwifery and Women's Health*, 58(4), 451–456. <https://doi.org/10.1111/j.1542-2011.2012.00262.x>.

World Health Organization. WHO Guidelines on the Management of Health Complications From Female Genital Mutilation. Geneva: WHO; 2016. <http://www.who.int/reproductivehealth/topics/fgm/management-health-complications-fgm/en/>.

**Respect for Girl**

**Family honor**

**Rite of passage**

**Status**

**Preserves virginity**

**Sense of belonging to a  
community**

**Custom or  
tradition**

# **Justifications for FGM/C**

**Fulfills  
religious  
requirement  
believed to  
exist**

**Helps  
cleanliness**

**Bad luck / evil spirits**

**aesthetics**

**Safer childbirth**

Nour, N. M. (2015). Female Genital Cutting : Impact on Women's Health, 1(212).

# Preconceptions



## Religious

Predates Abrahamic Religions (Judaism, Christianity, and Islam), however mistakenly linked to religion.

World Health Organization. WHO Guidelines on the Management of Health Complications From Female Genital Mutilation. Geneva: WHO; 2016. <http://www.who.int/reproductivehealth/topics/fgm/management-health-complications-fgm/en/>.

Female Genital Mutilation: Recognising and Preventing FGM. (n.d.). Retrieved August 8, 2017, from <https://fgmelearning.vctms.co.uk/trainingrecord/DashBoard.aspx?sessionID=37263788&digest=6395D390F1031E528C37F0B1DCF284A0B12172C9>

# FGC General Information

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- Age
- Trending to younger age of girls
- **Who Performs: often women (mothers, grandmothers, elders) who child respects and loves**



Image: Pexels.com

Nour, N. M. (2015). Female Genital Cutting : Impact on Women's Health, 1(212).

UNICEF. (2013). END violence against children, (December). Retrieved from <https://www.unicef.org/endviolence/>

United Nations Children's Fund. (2016). Female Genital Mutilation/Cutting: a Global Concern Unicef'S Data Work on Fgm/C Support for Data Collection Data Analysis and Dissemination. *Unicef*. Retrieved from [https://www.unicef.org/media/files/FGMC\\_2016\\_brochure\\_final\\_UNICEF\\_SPREAD.pdf](https://www.unicef.org/media/files/FGMC_2016_brochure_final_UNICEF_SPREAD.pdf)



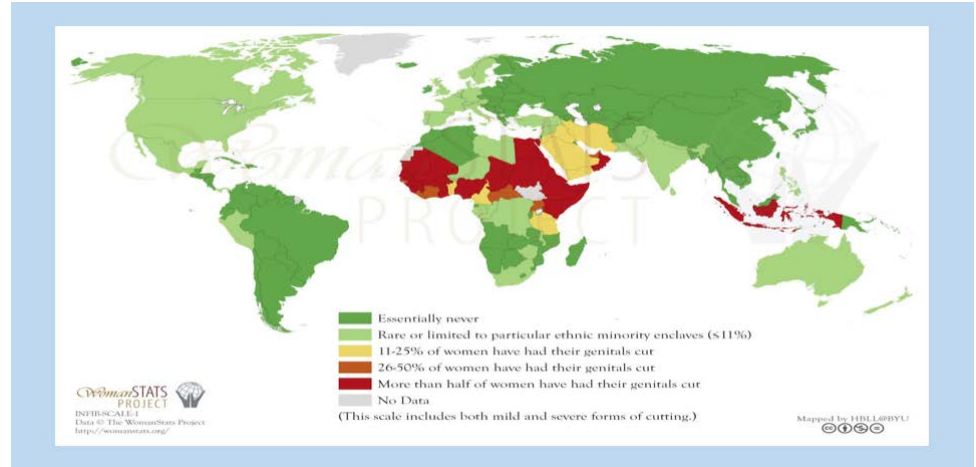
# World Prevalence

Countries of Origin

30 African Countries

South-East Asia

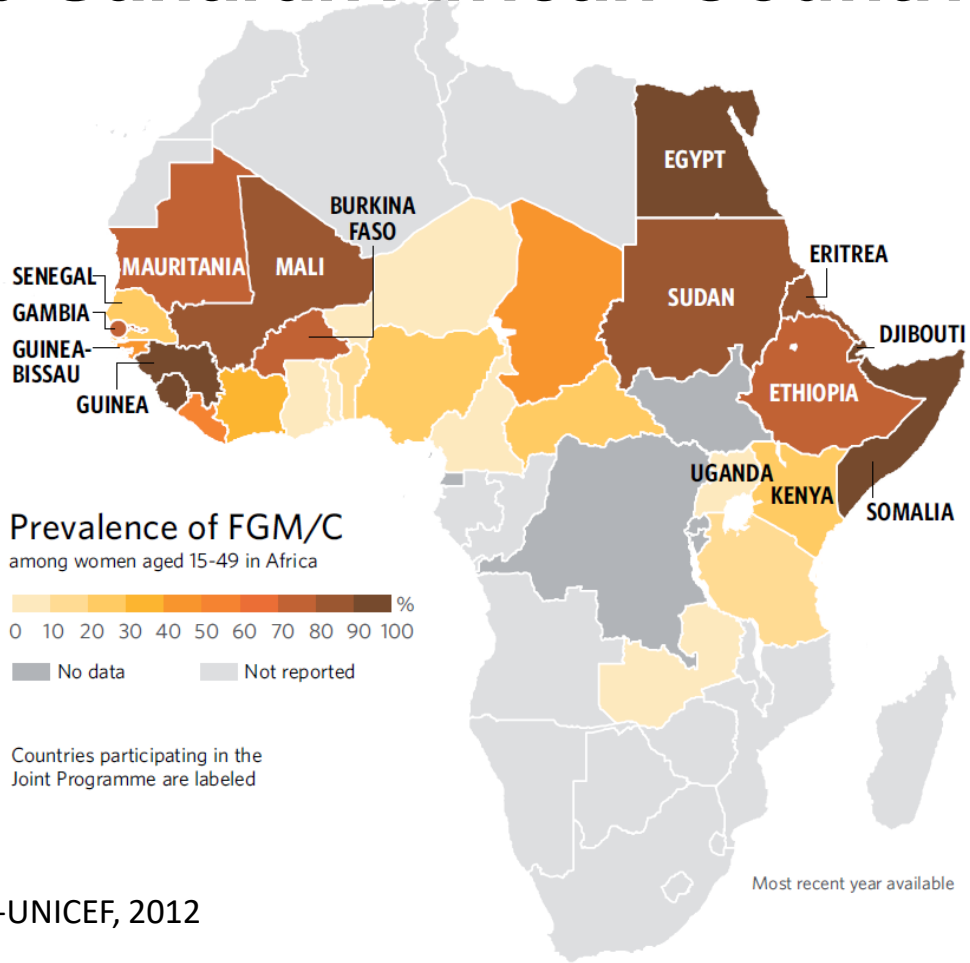
Middle East



World Health Organization. WHO Guidelines on the Management of Health Complications From Female Genital Mutilation. Geneva: WHO; 2016. <http://www.who.int/reproductivehealth/topics/fgm/management-health-complications-fgm/en/>.

UNICEF. (2013). END violence against children, (December). Retrieved from <https://www.unicef.org/endviolence/>

# Sub-Saharan African Countries Practicing FGM/C

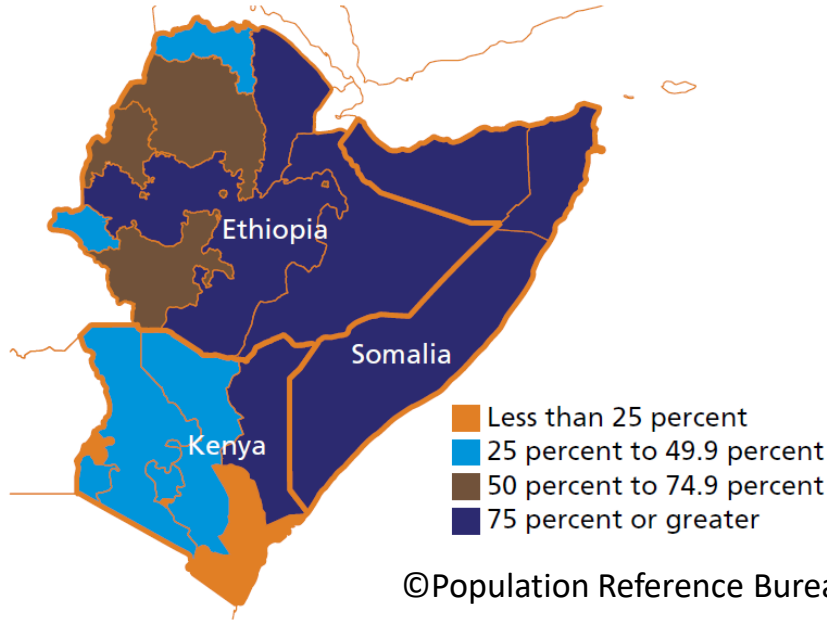


Prevalence of FGM/C in Africa among women aged 15-49.

- 90 to 100 percent: Guinea, Egypt, Somalia, Djibouti, and Sierra Leone.
- 80 to 90 percent: Mali and Sudan.
- 70 to 80 percent: Mauritania, Burkina Faso, Gambia, and Ethiopia.
- 50 to 60 percent: Liberia.
- 40 to 50 percent: Chad and Guinea-Bissau.
- 30 to 40 percent: Côte d'Ivoire.
- 20 to 30 percent: Senegal, Nigeria, Central African Republic, and Kenya.
- 10 to 20 percent: Benin and Tanzania.
- 0 to 10 percent: Ghana, Togo, Niger, Cameroon, Uganda, and Zambia.
- All other countries either did not have data or did not report data.

## Variations Within and Across Borders

Looking only at national prevalence rates can hide the regional variations within a country. FGM/C often reflects ethnicity or social interactions of communities across national borders.



©Population Reference Bureau, 2010

## Variations Within and Across Borders

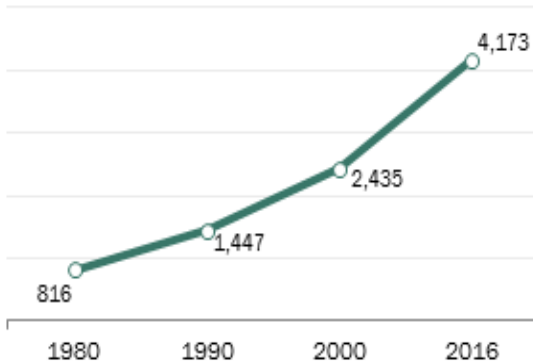
Looking only at national prevalence rates can hide the regional variations within a country. FGM/C often reflects ethnicity or social interactions of communities across national borders.

- FGM/C rates are above 75 percent in all of Somalia.
- FGM/C rates are 75 percent or higher in western Kenya, 25 to 49.9 percent in eastern Kenya, and less than 25 percent in southern Kenya.
- FGM/C rates are 75 percent or greater in western Ethiopia, 50 to 74.9 percent in most of eastern Ethiopia, and 25 to 49.9 percent in two small regions of Ethiopia (far eastern tip and the far northern tip).

# USA Prevalence

**Black immigrant population in the U.S. rose to 4.2 million in 2016**

*Total foreign-born black population in the U.S. in thousands*



Note: In 2000 and later, foreign-born blacks include single-race blacks and multiracial blacks, regardless of Hispanic origin. Prior to 2000, blacks include only single-race blacks regardless of Hispanic origin since a multiracial option was not available.

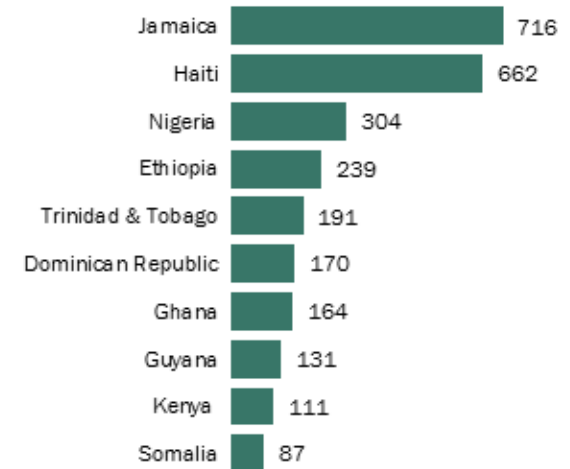
Source: Pew Research Center tabulations of the 2016 American Community Survey (1% IPUMS) and the 1980, 1990, and 2000 censuses (5% IPUMS).

**513,000** women and girls affected by or at risk of FGM/C in the United States

Goldberg, H., et al. (2016). *Public Health Reports*, 131(April), 340–347.

**Jamaica, Haiti, Nigeria are top birthplaces for black immigrants in the U.S.**

*Total foreign-born black population in the U.S., in thousands, 2016*



Note: Foreign-born blacks include single-raced blacks and multiracial blacks, regardless of Hispanic origin. Top 10 largest black immigrant groups shown.

Source: Pew Research Center tabulations of the 2016 American Community Survey (IPUMS).

Pew Research Center 1/24/2018.

Retrieved from: <http://www.pewresearch.org/fact-tank/2018/01/24/key-facts-about-black-immigrants-in-the-u-s/>

# USA Prevalence

FEMALE  
GENITAL  
MUTILATION  
/  
CUTTING  
FGM/C



**40%** OF WOMEN AND GIRLS  
AT RISK OF FGM/C LIVE IN FIVE METRO AREAS

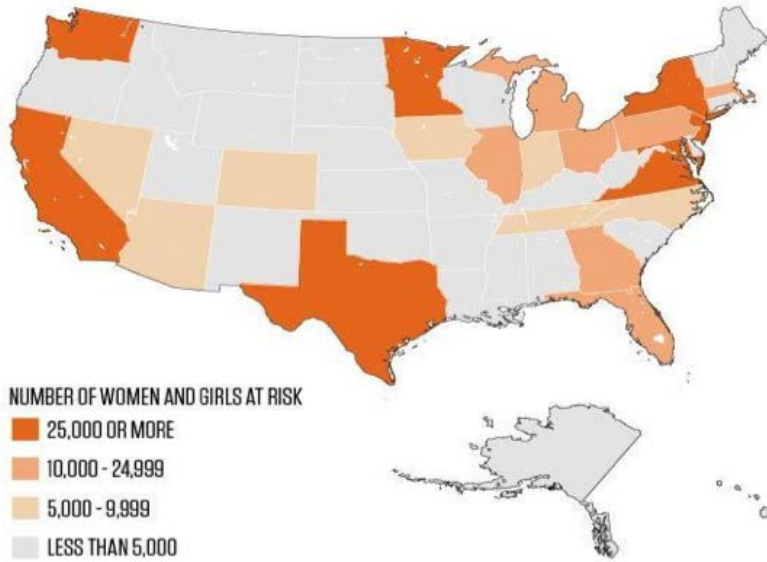
## TOP 5 METRO AREAS IN THE UNITED STATES

1. NEW YORK
2. WASHINGTON, DC
3. MINNEAPOLIS
4. LOS ANGELES
5. SEATTLE

Mather, M., & Feldman-Jacobs, C. (2016). Women and Girls at Risk of Female Genital Mutilation/Cutting in the United States. *Population Reference Bureau*. Retrieved from: <http://www.prb.org/Multimedia/Infographics/2015/graphics-us-fgm.aspx>

# USA Prevalence

THE NUMBER OF WOMEN AND GIRLS AT RISK OF FGM/C VARIES WIDELY ACROSS THE STATES.



Source: Population Reference Bureau, 2013 data.

THE NUMBER OF WOMEN AND GIRLS AT RISK OF FGM/C VARIES WIDELY ACROSS THE UNITED STATES.

Map of the United States showing the number of women and girls at risk of FGM/C by state.

- 25,000 or more: Washington, California, Texas, Minnesota, New York, New Jersey, Maryland, and Virginia.
- 10,000 to 24,999: Michigan, Illinois, Ohio, Pennsylvania, Massachusetts, Georgia, and Florida.
- 5,000 to 9,999: Nevada, Arizona, Colorado, Iowa, Indiana, Tennessee, and North Carolina.
- Less than 5,000: All other states.

Source: Population Reference Bureau, 2013 data.

Mather, M., & Feldman-Jacobs, C. (2016). Women and Girls at Risk of Female Genital Mutilation/Cutting in the United States. *Population Reference Bureau*. Retrieved from: <http://www.prb.org/Publications/Articles/2015/us-fgmc.aspx>

# **FGM/C Classification Schema**

# FGM/C WHO Classification Subtypes

- Type I: Partial or total removal of the clitoris and/or the prepuce (clitoridectomy)
  - Type Ia: Removal of the clitoral hood or prepuce only
  - Type Ib: Removal of the clitoris with the prepuce
- Type II: Partial or total removal of the clitoris and labia minora, with or without excision of the labia majora (excision)
  - Type IIa: Removal of the labia minora only
  - Type IIb: Partial or total removal of the clitoris, the labia minora and majora
  - Type IIc: Partial or total removal of the clitoris, the labia minora and majora
- Type III: Narrowing of the vaginal orifice with the creation of a covering seal by cutting and positioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)
  - Type IIIa: Removal and apposition of the labia minora
  - Type IIIb: Removal and apposition of the labia majora
- Type IV: Unclassified. All other harmful procedures to the female genitalia for non-medical purposes, for example, pricking, pulling, piercing, incising, scraping, and cauterization.

***\*Clitoris – only the glans or the glans with part of the body of the clitoris is removed.***



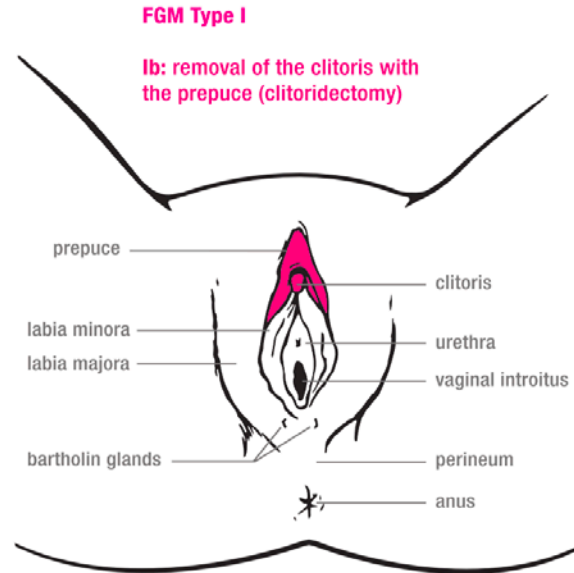
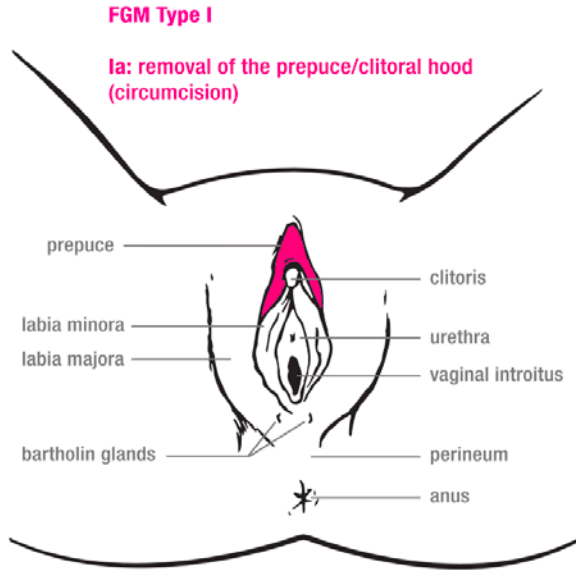
# WHO Classification of FGM/C

**Type I** Partial or total removal of the clitoris (clitoridectomy) and/or the prepuce

FGM Type 1:

Ia: removal of the prepuce/clitoral hood (circumcision)

Ib: removal of the clitoris with the prepuce (clitoridectomy)



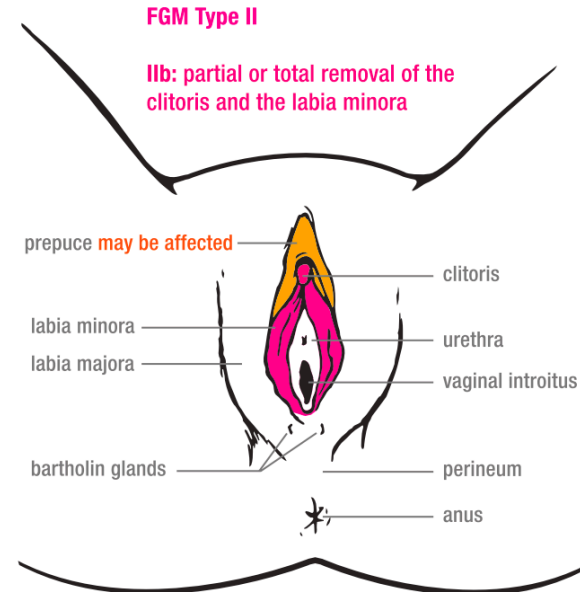
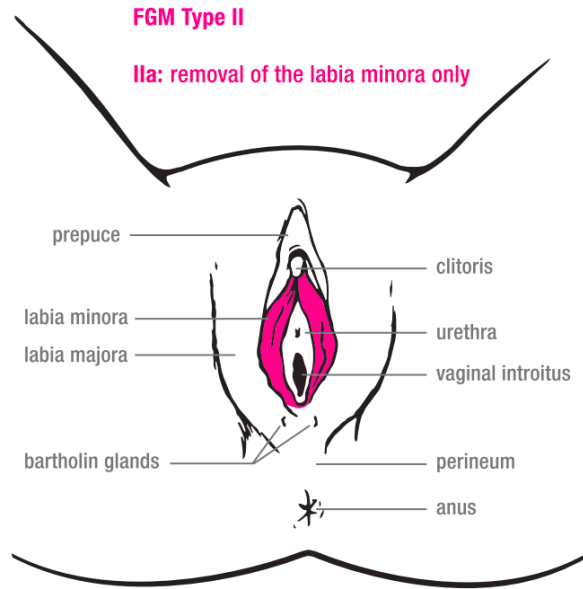
# WHO Classification of FGM/C

**Type II** Partial or total removal of the clitoris and the labia minora, with or without excision of the labia majora (excision)

FGM Type II:

IIa: removal of the labia minora only

IIb: partial or total removal of the clitoris and the labia minora



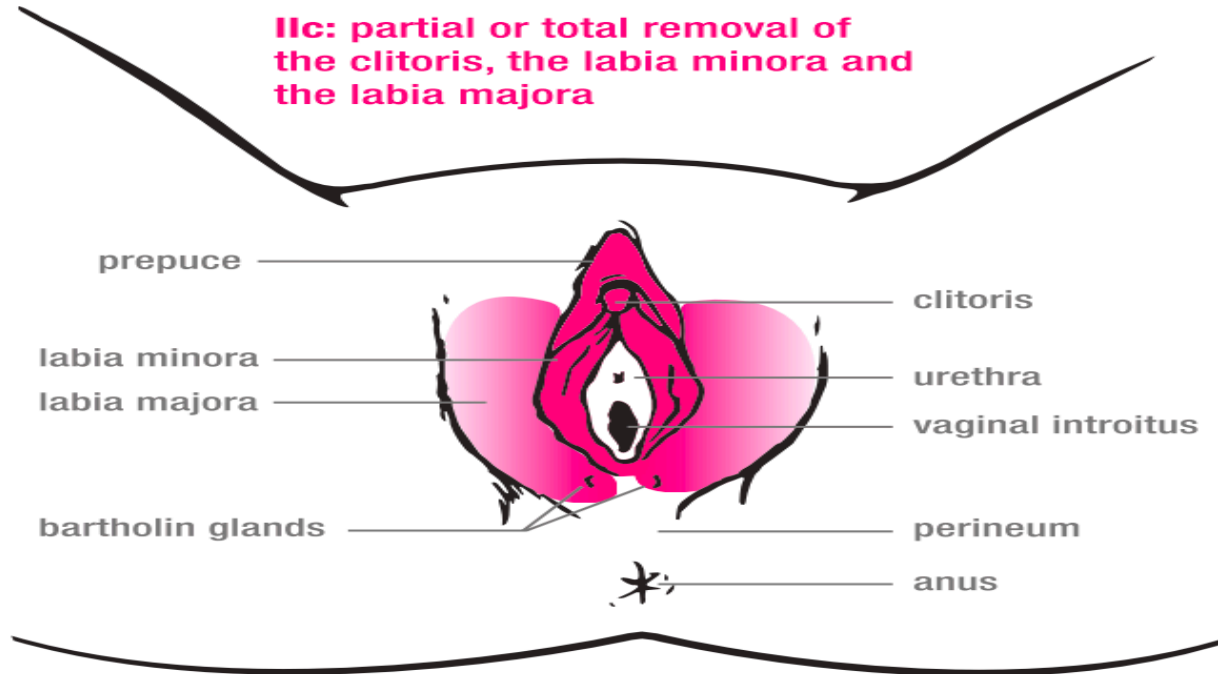
# WHO Classification of FGM/C

FGM Type II:

IIc: partial or total removal of the clitoris, the labia minora and the labia majora

## FGM Type II

**IIc: partial or total removal of the clitoris, the labia minora and the labia majora**



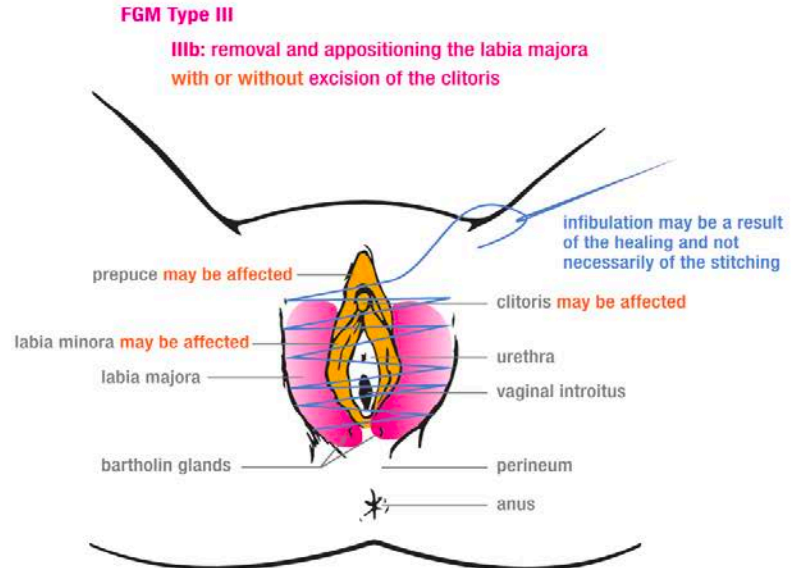
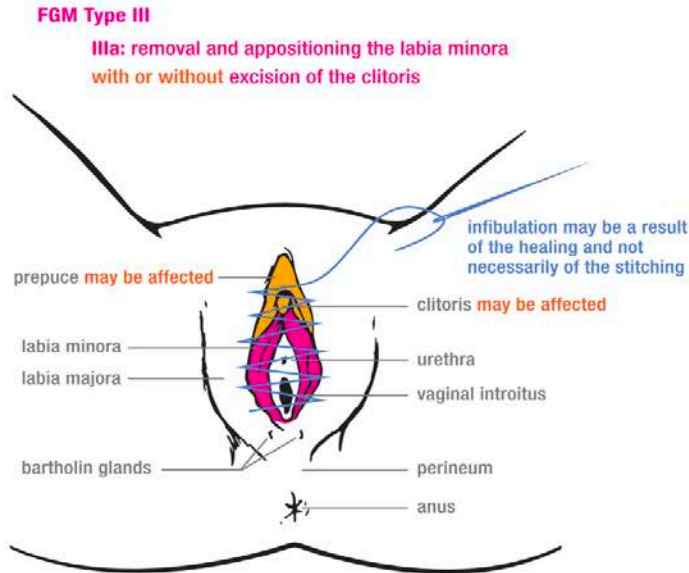
# WHO Classification of FGM/C

**Type III** Narrowing of the vaginal orifice with the creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris (infibulation)

FGM Type III:

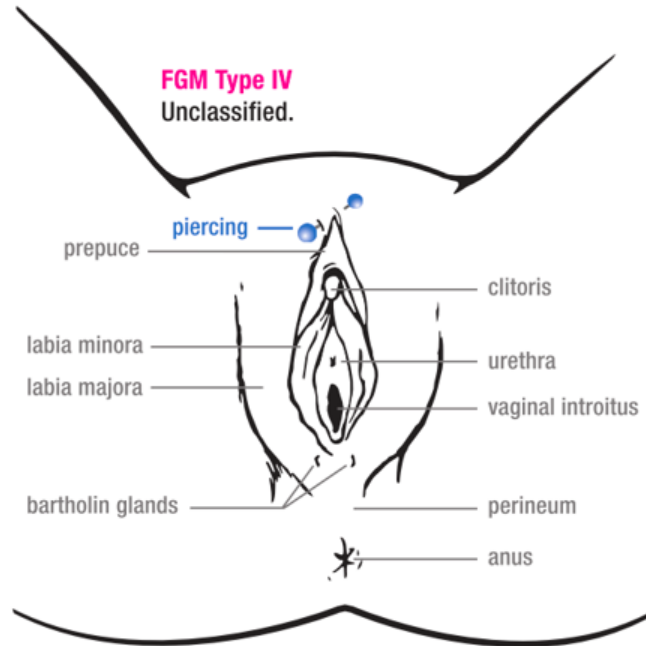
IIIa: removal and appositioning the labia minora with or without excision of the clitoris

IIIb: removal and appositioning the labia majora with or without excision of the clitoris



# WHO Classification of FGM/C

**Type IV** All other harmful procedures to the female genitalia for non-medical purposes, for example: pricking, pulling, piercing, incising, scraping and cauterization  
FGM Type IV Unclassified.



Abdulcadir, J., Catania, L., Hindin, M. J., Say, L., Petignat, P., & Abdulcadir, O. (2016). Female Genital Mutilation. *Obstetrics & Gynecology*, 128(5), 958–963. <https://doi.org/10.1097/AOG.0000000000001686>

# Health Outcomes

# Immediate Complications

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- Bleeding/Hemorrhage
- Infection: wound, septicemia
- Shock
- Fever
- Genital Swelling
- Urinary retention
- Tetanus
- Pain
- Death



Berg, R. C., Underland, V., Odgaard-Jensen, J., Fretheim, A., & Vist, G. E. (2014). Effects of female genital cutting on physical health outcomes: a systematic review and meta-analysis. *BMJ Open*, 4(11), e006316–e006316.

<https://doi.org/10.1136/bmjopen-2014-006316>

Reisel, D., & Creighton, S. M. (2015). Long term health consequences of Female Genital Mutilation (FGM). *Maturitas*, 80(1), 48–51. <https://doi.org/10.1016/j.maturitas.2014.10.009>

# Obstetric Complications

- Prolonged labor
- Vaginal lacerations
- Instrumental delivery
- Hemorrhage
- Episiotomy
- Cesarean Section
- Increased length of hospital stay
- Infant resuscitation



Berg, R. C., Underland, V., Odgaard-Jensen, J., Fretheim, A., & Vist, G. E. (2014). Effects of female genital cutting on physical health outcomes: a systematic review and meta-analysis. *BMJ Open*, 4(11), e006316–e006316.

<https://doi.org/10.1136/bmjopen-2014-006316>

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<https://doi.org/10.1016/j.maturitas.2014.10.009>



# Urogynecologic Concerns

- Genital tissue damage (scarring/keloids)
- Chronic vulvar or clitoral pain
- Chronic genital tract infections
- Dysmenorrhea
- Irregular menses
- UTI (often recurrent)
- Painful urination
- Cysts

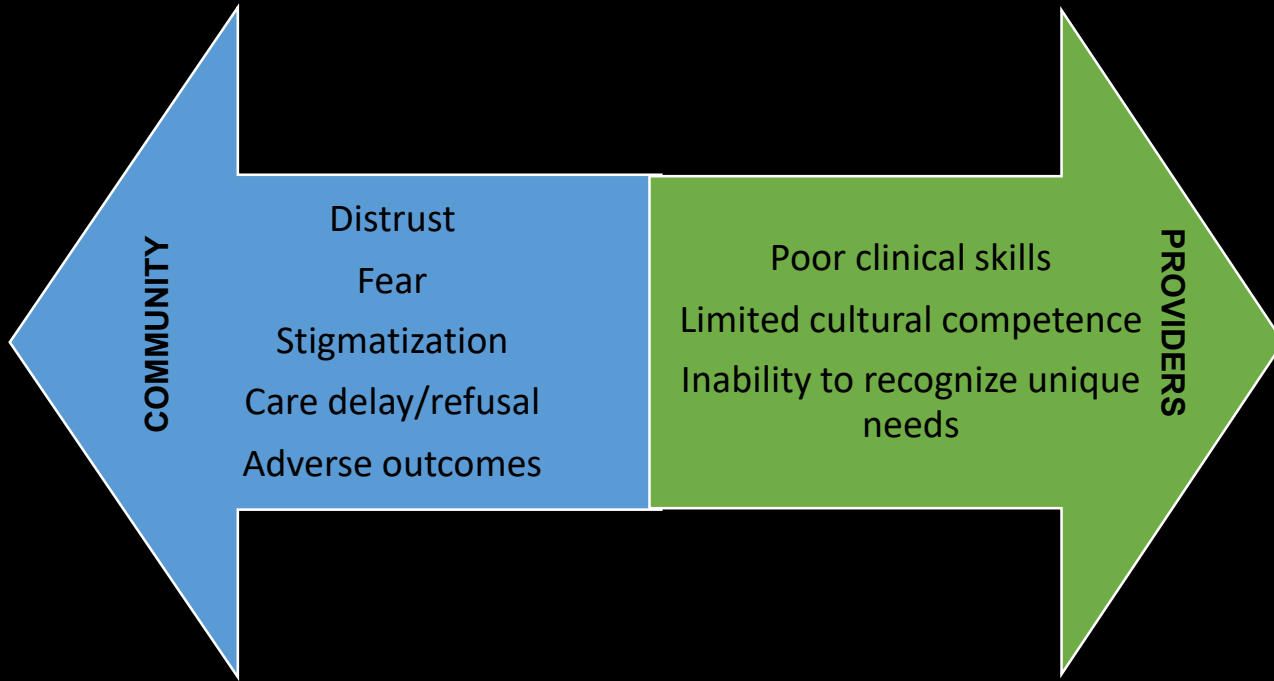
# Sexual Dysfunction

- Dyspareunia (pain during sex)
- Decreased sexual satisfaction
- Reduced sexual desire
- Infertility

# Mental Health Morbidity

- Post-traumatic stress disorder (PTSD)
- Anxiety Disorders
- Depression

# Challenges and Gaps in Care



# FGM/C diagnosis codes

*(Do not reflect current WHO Typology)*

FGM/C Diagnosis	ICD-9	ICD-10
Female Genital Mutilation, Unspecified	629.20	N90.810
Female Genital Mutilation, Type I	629.21	N90.811
Female Genital Mutilation, Type II	629.22	N90.812
Female Genital Mutilation, Type III	629.23	N90.813
Other Female Genital Mutilation	629.29	N90.818

# CPT Code Defibulation (*Not Specific to FGM/C*)

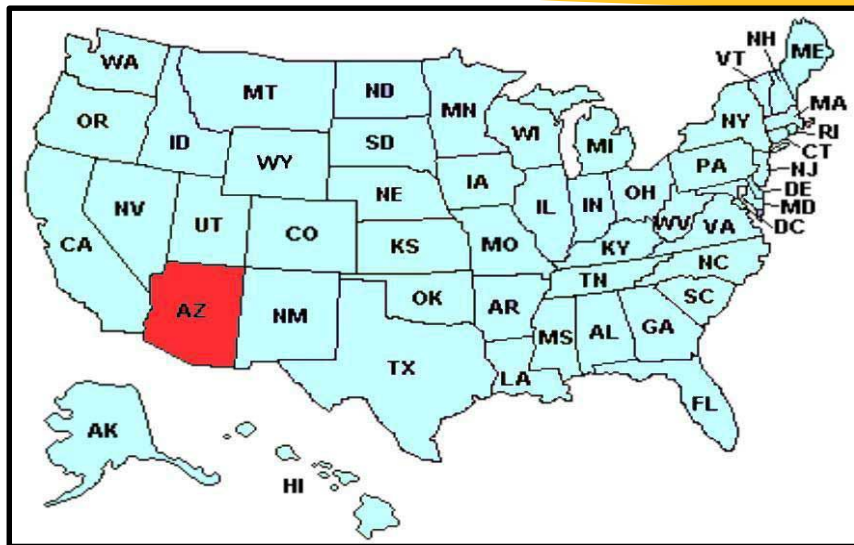
- **13131** Defibulation (general procedure code)  
Repair, complex procedures on the Integumentary System  
(*forehead, cheeks, chin, mouth, neck, axillae, genitalia, hands and/or feet*)
- **56441** Lysis of labial adhesions
- **56800** Plastic repair of introitus

*For complicated procedures, add the -22 modifier and document any additional physician work*

# Challenges in the Pediatric Context

- FGM/C constitutes child abuse in female minors
- Every state has mandatory reporting requirements
- Should Pediatricians perform universal GU exams?
  - If not, there's concern for racial/ethnic profiling
- FGM/C in Pediatric populations difficult to diagnose
- Providers unfamiliar with identifying FGM/C in pediatric populations
- Poor clinical documentation
- Vacation Cutting
  - Lack of clinical documentation of genital exam before/after travel
- Parental consent required

# FGM/C-Affected Populations in Arizona



Arizona  
7<sup>th</sup> largest Somalia-born population  
7,459 women/girls  
Robust community partnerships

Population Reference Bureau, 2013



Somalia  
98% FGM/C prevalence  
Type 3 FGM/C is most common  
Traumatic displacement

Shell-Duncan et al., 2016

# Research Gaps



# **Future Inquiry**



**Impact migration and acculturation**

**Optimizing obstetric outcomes**

**Psycho-sexual outcomes**

**Full spectrum FGC sub-types**

**Mental health outcomes**

**Validated metrics, cross-cultural  
equivalency**

**Ethno-cultural comparison groups**

**CBPR in current political climate**

# **Legal & Ethical Controversies**



# U.S. Timeline of Legislation



Congress passes  
**“Federal Prohibition  
of Female Genital  
Mutilation Act.”**



1996

“Transport for Female Genital  
Mutilation Act” (***Girls Protection  
Act***) protects female minors from  
being taken out of the country for  
FGM (***‘vacation cutting’***).



2013

HR 3317 – **SAFE Act (Stopping Abusive  
Female Exploitation Act of 2017)**  
unanimously passed the U.S. House of  
Representatives, increasing federal  
penalty to 15 years and urges states to  
employ mandatory reporting policies.



2017

Resolution passed by UN  
General Assembly  
**“Intensifying Global Efforts  
for the Elimination of Female  
Genital Mutilations”** –  
towards global legislation  
against FGM.



2012

**“Zero Tolerance for Female  
Genital Mutilation Act”**  
introduced to the House of  
Representatives urging  
Federal strategy to prevent  
and respond to FGM.



2015



## Michigan Doctor Is Accused of Genital Cutting of 2 Girls

By JACEY FORTIN   APRIL 13, 2017

A Michigan doctor has been accused of performing [genital cutting](#) on two 7-year-old girls at a medical clinic, in a case that federal officials believe to be the first prosecution under a law banning the brutal practice.

The doctor, Jumana Nagarwala, 44, was arrested on Wednesday on charges that she performed the genital cutting at an unnamed medical clinic in Livonia, Mich.; transported minors with intent to engage in criminal sexual activity; and lied to federal agents.



Dr. Jumana Nagarwala  
Henry Ford Hospital

According to a criminal complaint filed in federal court on Wednesday, Dr. Nagarwala performed the procedure on two girls from Minnesota who traveled to the clinic with their parents in February. The complaint also said that “multiple” other girls, including some from Michigan, may have been victimized between 2005 and 2007.

One of the girls told investigators that she thought she and the other girl had gone to the doctor because “our tummies hurt.” The other said the cutting procedure was so painful that she screamed and could barely walk afterward. She drew a picture of the room where the procedures were allegedly carried out, marking an “X” on

### RELATED COVERAGE



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# Dawoodi Bohra Federal Prosecution

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- ~ 1 million worldwide
- India, Pakistan, Sri Lanka, Europe, N. America, SE Asia, Australia
- Ismaili Shia Islamic sect
- Girls circumcised age 7 (*Khatna/Khafd*)
- ~100+ girls cut over 10 year period in Livonia, Michigan
- First federal prosecuted case in U.S. history since federal law passed in 1996

## **FGM law deemed Unconstitutional (11/20/18)**

- Most federal charges dismissed
- Interstate Commerce Clause
- Congress has no authority to enact FGM law
- Jurisdiction of States
- Gender Discrimination (*violates Equal Protection Clause of 14<sup>th</sup> Amendment*)
- Federal appeal likely

# Legal Status

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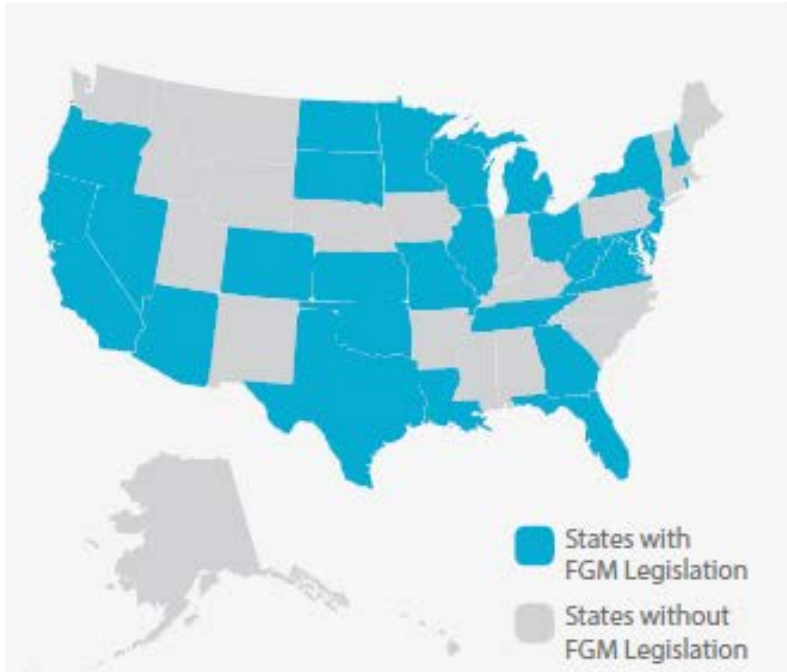
- FGM/C is a form of Child Abuse
- Child abuse/Sexual assault is prosecutable in every state
- Vacation Cutting
- Grounds for Asylum

## US Federal Statues

- **18 U.S. Code § 116(d) states:**
- *“Whoever knowingly transports from the United States and its territories a person in foreign commerce for the purpose of [female genital mutilation] with regard to that person that would be a violation of subsection (a) if the conduct occurred within the United States, or attempts to do so, shall be fined under this title or imprisoned not more than 5 years, or both.”*
- First passed in 1996, amended in 2013 to include transport out of country
- **8 USCS § 1374**
- US Immigration officials provide immigrants with info about severe physical and mental harm caused by FGM and legal consequences in US

## Current FGM/C Legislation by State

- 28 states have passed legislation
- Individual state laws vary in terms of:
  - Ban on Vacation Cutting
  - Inclusion of female minors and adults
  - Parents/Guardians penalized even if they did not perform actual FGM/C



States with FGM Legislation: California, Oregon, Nevada, Arizona, Colorado, Kansas, Oklahoma, Texas, Louisiana, Missouri, North Dakota, South Dakota, Minnesota, Wisconsin, Michigan, Ohio, Tennessee, Illinois, West Virginia, Maryland, Delaware, Virginia, Georgia, Florida, New York, New Jersey, New Hampshire, and Rhode Island.

# Ethical Controversies

- Iatrogenic Pathologization
- Genital Self-Image
- Ongoing Controversies
  - Female Genital Cosmetic Surgery (*Re-infibulation/Clitoral Reconstruction/Hymenoplasty*)
  - Human Right to Bodily Integrity/Genital Autonomy regardless of sex/gender (*female, male, and intersex children*)
  - Adult woman's right to choose



# Current Climate in USA

- Anti-immigrant/anti-refugee/anti-Muslim policies and initiatives can trigger hostility toward migrants (refugees, immigrants and asylum-seekers)
- Targeted vulnerable populations may experience perceptions of vulnerability, threat and psychological distress
- Negative health effects such as lower birth weight babies have been documented in Hispanic populations after large immigration raids, and in Arab-American women post-Sept 11<sup>th</sup>
- Women may not feel safe seeking public assistance or preventive and prenatal care

Williams, D. R., & Medlock, M. M. (2017). Health Effects of Dramatic Societal Events — Ramifications of the Recent Presidential Election. *New England Journal of Medicine*, 376(23), 2295–2299. <https://doi.org/10.1056/NEJMms1702111>

# **Health Policy and Research Directives**

# End Violence Against Girls: Summit on FGM/C

## *Healthcare Sector Working Group's Recommendations for Strategies to Respond to FGM/C in the U.S.*

- A. Provide high quality care to **affected women and girls**
- B. Provide high quality care to **those at risk** for FGM/C
- C. Work with collaborators, including affected teens and women, to **prevent FGM/C** in the U.S. and elsewhere
- D. **Expand research** on FGM/C, including, but not limited to:
  - 1) its prevalence in the U.S. and how the practice changes in the context of resettlement;
  - 2) its medical and psychological sequelae; and
  - 3) appropriate, evidence-based interventions.

# Multi-pronged strategy



# Community Engagement

- Community outreach/education
- Trust-building is paramount
- Bi-directional learning
- Engage multiple stakeholders
  - ✓ Men
  - ✓ Women
  - ✓ Youth
  - ✓ Elders
  - ✓ Religious leaders
- Ethnic Community-based Organizations
- Social Service Agencies (e.g., Refugee resettlement agencies)
- Schools, law enforcement, social work
- Economic empowerment, gender equity, intimate partner violence, stigma-reduction





# Optimizing FGM/C-related Clinical care



## Women/Girls

- Address Social Determinants of Health
  - Health Literacy
  - Distrust
  - Western vs Traditional health beliefs
  - Patient autonomy in decision-making
  - Stigma reduction
- Address structural barriers to care
  - Insurance coverage
  - Language barriers/Interpretation
  - Transportation
  - Gender concordance of staff
- Engage the Male partner/spouse/ father  
*(as appropriate)*

## Healthcare providers

- Sustained Provider Education
  - Appropriate clinical documentation/coding
  - Culturally sensitive counseling
  - Surgical skills competency (*within scope of practice*)
  - Culturally appropriate treatment paradigms
  - Ethical dilemmas
- Patient-Centered Multidisciplinary Care
  - Peds, OB/GYN, FM, Emerg Med, PA, CNM, NP, RNs
  - Psychiatrist/Psychologist
  - Sex therapist/Counselor/SW
  - Pelvic Floor Physical Therapist
  - Peer Mentor/Support/Community Advocate/Navigator

# Health Policy/Research



- Promote public-private partnerships (Federal/State/Local)
- Ethno-cultural specificity in data collection/tracking
- Validated instruments with cross-cultural equivalency
- ICD-10/ICD-11, CPT Procedural codes specific to WHO FGM/C Typology
- Library of educational photos/videos of FGC among pre-pubertal girls/adolescents
- Joint/Consensus Clinical Practice Guidelines across professional societies (ACOG, AAP, AAFP, ACNM, NASPAG)
- Design quality improvement metrics, track longitudinal outcomes
- Partnership across multi-center research sites within and across countries
- Ongoing Controversies
  - Female Genital Cosmetic Surgery (Re-infibulation/Clitoral Reconstruction/Hymenoplasty)
  - Human Right to Bodily Integrity/Genital Autonomy regardless of sex/gender (female, male, and intersex children)
- Address current U.S. political landscape/rhetoric: (Anti-refugee/Anti-immigrant/Anti-Muslim)

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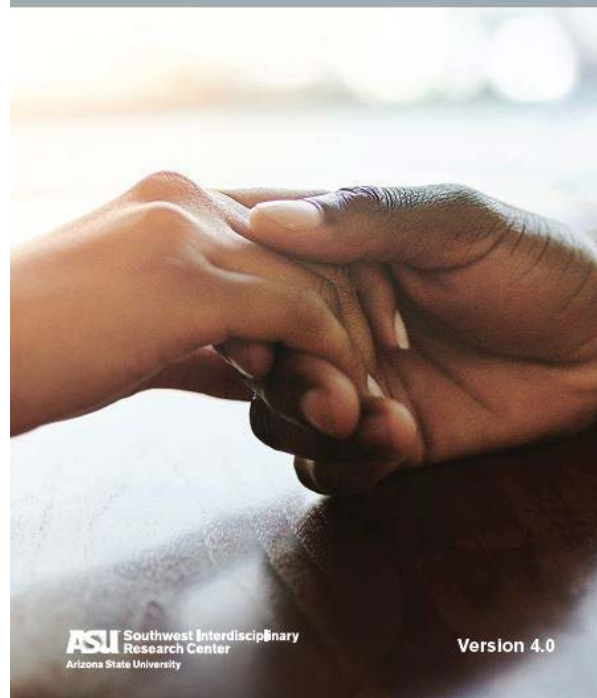
**John Keeney**

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Female Genital Mutilation/Cutting (FGM/C)

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# Thank You!

