

PATIENT SELF-ADVOCACY TOOL

AN OVERVIEW

PURPOSE

Although people who have experienced female genital mutilation/cutting (FGM/C) may have unique healthcare needs, providers are often not familiar with how to ensure quality care for this population. This creates a difficult experience for providers and patients. In an effort to ensure respectful and evidence-based care, we created this tool to bridge the gap in communication between patients and their healthcare providers about FGM/C.¹⁻³

This tool was created by a team from RTI International, Johns Hopkins University School of Nursing, medical experts, and people from communities impacted by FGM/C. **Patients can use this tool during healthcare visits to educate their healthcare providers and advocate for their medical needs.**

Instructions for Patients

Individuals of any age may use this tool, but some content is more applicable to adults. Younger audiences may need support from a caregiver to complete this tool. **All questions are optional.**

1. Select which form is right for you:
 - **General medical form** (shorter form with fewer questions)
 - **Comprehensive women's healthcare form** (more questions specific to women's and girls' healthcare that may be useful for OB/GYN, women's well checks, urology, and more)
2. Complete the form prior to your visit (optional). Fill out the questions that pertain to you.
3. During the start of your visit, share the form with your healthcare provider.

Instructions for Healthcare Providers

- Become familiar with FGM/C using the resources provided on this form.
- Print and have copies of this form available for patients.

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References:

1. Fay, K.E., et al. (2022). United States' Obstetrician/Gynecologists' Readiness to Care for Women Affected by Female Genital Cutting. (Préparation des obstétriciens/gynécologues aux États-Unis pour la prise en charge des femmes ayant subi une excision). *Journal of Women's Health*, 31(3): p. 431-438. doi: 10.1089/jwh.2020.8622
2. Lane, J. L., Johnson-Agbakwu, C. E., Warren, N., Budhathoki, C., & Cole, E. C. (2019). Female genital cutting: Clinical knowledge, attitudes, and practices from a provider survey in the US. (Excision : connaissances cliniques, attitudes et pratiques issues d'un sondage de praticiens aux États-Unis). *Journal of Immigrant and Minority Health*, 21, 954-964. <https://doi.org/10.1007/s10903-018-0833-3>
3. Levy, A.T., et al. (2021). Provider Knowledge and Attitudes About Female Genital Mutilation/Cutting in Philadelphia. (Connaissances et attitudes des praticiens concernant l'excision/mutilations génitales féminines à Philadelphie). *Journal of Immigrant and Minority Health*, 23(1): p. 45-53. doi: <https://doi.org/10.1007/s10903-020-01018-1>

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PATIENT SELF-ADVOCACY TOOL: COMPREHENSIVE WOMEN'S HEALTHCARE FORM

This **comprehensive** form is for people who have experienced **female genital mutilation/cutting (FGM/C)** to use with healthcare providers during visits to address their FGM/C. This may include OB/GYN visits, women's well checks, urology, prenatal appointments, and more. Healthcare providers may review these answers to become more familiar with their patient's visit needs.

My preferred name is _____

I am from (name the country) _____

My preferred language/dialect is _____

The term I use for FGM/C is _____

My support system includes _____

I was about age _____ when FGM/C was performed. ☐ I don't know or remember

It was performed in a health facility. ☐ Yes ☐ No ☐ I don't know or remember

It was performed by a healthcare provider. ☐ Yes ☐ No ☐ I don't know or remember

I would like to have an interpreter at this visit ☐ Yes ☐ No ☐ No preference

I prefer female clinicians only ☐ Yes ☐ No ☐ No preference

I permit students and/or colleagues to be a part of a teaching experience during this visit.

☐ Yes ☐ No ☐ No preference

My top priorities for this visit are _____

The last time I discussed FGM/C with a healthcare provider, the experience was: ☐ Positive ☐ Neutral ☐ Negative
☐ I have never discussed this with a healthcare provider before

Please select if you experience any of the following symptoms or concerns (check all that apply)			
Repeated urinary or vaginal infections	☐	Flashbacks, anxiety, depression related to FGM/C	☐
Pain urinating (peeing)	☐	Fear of discussing FGM/C with medical providers	☐
Difficulty with urination or fully emptying the bladder	☐	Fear of not being "normal"	☐
Pain with periods	☐	Fear of childbirth	☐
Pain with sex	☐	Fear of telling partner about FGM/C	☐

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If an internal exam is part of today's visit, I prefer that you:

- ☐ Do not use a speculum
 ☐ Talk me through the process
☐ Do not attempt a bimanual exam (hands)
 ☐ Show me the tools you plan to use and describe my options (e.g., smaller speculum)
☐ Other _____

With respect to my FGM/C, I want to know more about:

- ☐ How my body was affected
 ☐ How to have sex without pain
☐ If/how I can be opened again
 ☐ Contraception/preventing pregnancy
☐ Best timing of being opened again
 ☐ How to get pregnant
☐ How to be treated for pelvic pain
 ☐ How to improve my sexual wellbeing
☐ How to treat painful periods
 ☐ How to talk to my partner about FGM/C and my body
☐ Other _____

I am interested in the following resources/information:

Your medical provider may not have all of these answers and resources readily available. Please see the QR codes below for additional resources.

- ☐ Emotional health counseling
 ☐ FGM/C support groups or community groups
☐ Impacts of FGM/C for my daughter or female relatives
☐ Legal implications of FGM/C for
 ☐ myself (e.g., asylum)
 ☐ my daughter or female relatives
 (Note: performing or facilitating FGM/C in the Australia or abroad is illegal)
☐ How to talk to my family about the Australian laws related to FGM/C
☐ Travel to a FGM/C prevalent country with my daughter or female relatives
☐ Other _____

Additional comments

Consider describing ways the provider can make the visit easier for you, your past experiences receiving medical care for your FGM/C, things you want them to know about your FGM/C, or any other concerns you have about your FGM/C.

To learn more about FGM/C, check out these additional resources

WHO Clinical Guide



National Education Toolkit for FGM/C Awareness



FGM/C Visual Reference and Learning Tool



Pediatric Guide to FGM/C

