

# 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 healthcare providers about FGM/C.<sup>1-3</sup>

This tool was created by a team from RTI International, John 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 the tool. **All questions are optional.**

1. Select which form is right for you (options also available Arabic and French):
  - **General medical visit form** (shorter form with fewer questions)
  - **Comprehensive women's healthcare form** (more questions specific to women's and girl's 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 the 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. *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. *Journal of Immigrant and Minority Health*, 21, 954-964. 4 <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. *Journal of Immigrant and Minority Health*, 23(1): p. 45-53. doi: <https://doi.org/10.1007/s10903-020-01018-1>

This tool was produced by RTI International under award 15POV-21-GK-00654-NONF, awarded by the Office for Victims of Crime, Office of Justice Programs, U.S. Department of Justice. The opinions, findings, and conclusions or recommendations expressed in this resource are those of the contributors and do not necessarily represent the official position or policies of the U.S. Department of Justice.



# PATIENT SELF-ADVOCACY: GENERAL MEDICAL VISIT FORM

This form is for people who have experienced **female genital mutilation/cutting (FGM/C)** to use with healthcare providers during **general medical visits** (such as urgent care, emergency room, women’s health checks, well-child visits, and primary care visits). 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 would like to have an interpreter at this visit.  Yes  No

I prefer female clinicians only.  Yes  No  No preference

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

Yes  No  No preference

My top priorities for this visit are \_\_\_\_\_

Please select if you experience any of the following symptoms or concerns (check all the apply):			
Repeated urinary or vaginal infections	<input type="checkbox"/>	Flashbacks, anxiety, depression related to FGM/C	<input type="checkbox"/>
Pain urinating (peeing)	<input type="checkbox"/>	Fear of discussing FGM/C with medical providers	<input type="checkbox"/>
Difficulty with urination or fully emptying the bladder	<input type="checkbox"/>	Fear of not being “normal”	<input type="checkbox"/>
Pain with periods	<input type="checkbox"/>	Fear of childbirth	<input type="checkbox"/>
Pain with sex	<input type="checkbox"/>	Fear of telling my partner that I am cut	<input type="checkbox"/>

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

I would also like you to know:

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

WHO Clinical Guide



US Eng FGM/C Network



FGM/C Visual Reference and Learning Tool



Pediatric Guide to FGM/C

