

Translating Research into Practice: Using Women's Health Needs Study Data to Inform Local Community-Based Efforts

May 31, 2024

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Women's Health Needs



STUDY

Introduction

This brief highlights how community partners spearheaded wide-ranging dissemination strategies to share findings from the Women's Health Needs Study (WHNS) back to their local communities and inform their programs and services. WHNS was a one-time survey on women's health care experiences and needs, as well as their experiences on female genital mutilation/cutting (FGM/C). WHNS surveyed US women from countries where FGM/C is practiced. The study took place from November 2020 to June 2021 in four metropolitan areas in the United States (Atlanta, Minneapolis, New York, and Washington, DC) with input, collaboration, and support from community-based organizations.

Key Findings from WHNS

WHNS collected data from 1,132 women. WHNS found that:

- ▶ more than half of respondents reported experiencing FGM/C.
- ▶ more women with FGM/C reported health concerns compared to women without FGM/C, including problems with childbirth, reproductive health, sexual health, and mental health.
- ▶ over half of women with FGM/C felt comfortable discussing their experience with their health care provider, but only a third have done so.
- ▶ nearly all women believe the practice should be stopped, and most believed that the practice can cause health problems later in life.

Additional information on study methodology and findings is available on [NORC's Project Page](#).

Between September 2020 and May 2024, NORC at the University of Chicago (NORC) engaged with various community partners (Exhibit 1) to disseminate findings from the WHNS in ways that reflected the needs and preferences of local communities.

Exhibit 1: Community Partners Participating in Dissemination of WHNS Findings

Organization	Description
Amani Women Center (AWC)	AWC provides culturally tailored programs and services that empower and contribute to the economic security, spiritual, mental, and physical well-being of refugees and immigrant women. AWC disseminated WHNS findings via sister circles, worked with local doulas to create a training tool for offering care to women who have experienced FGM/C, and have identified pathways to medical care for women who have experienced FGM/C.

Organization	Description
International Institute of Minnesota (IIMN)	Founded in 1919, IIMN offers New Americans quality services that support their journey to stability and success. IIMN's comprehensive offerings include refugee resettlement, English education, workforce and leadership development, college preparation and immigration and citizenship assistance. IIMN is a diverse team of knowledgeable and encouraging advocates, ready to welcome refugees and immigrants. IIMN helps New Americans rebuild their lives while pursuing their personal and professional goals.
Sauti Yetu Center for African Women (Sauti Yetu)	Sauti Yetu provides services to low-income and immigrant African women in the greater New York City area and nationally. Sauti Yetu focuses on several topics, including FGM/C, violence against women and girls, early forced marriage, and reproductive justice. The organization also provides services for community members in crisis and recently immigrated community members who are becoming acclimated to the area.

Key Dissemination Approaches

Community partners disseminated WHNS findings in culturally responsive ways. This section describes some of the dissemination activities that community partners undertook to ensure that findings reached communities impacted by the study findings.

Community Partner Convenings and Data Parties

NORC convened a series of community partner meetings in which they:

- Conducted “data parties” to collectively interpret key data points from the study, understand the context behind these data points, and assess what information would be most helpful to community partners.¹
- Discussed the type of dissemination products would be most useful for community partners for dissemination. For example, NORC developed data briefs that summarize WHNS findings on background characteristics, reproductive preventive healthcare behaviors; and reproductive, sexual, and childbirth health concerns by FGM/C experience and type. In addition, NORC developed a brief on interpreter use and preferences. These briefs are available to community partners for their internal use to inform their programs and services.
- Listened to partner updates on their dissemination, activities, needs, opportunities, and lessons learned, allowing partners to hear and learn from each other.

Questions that Informed Discussion in Community Data Parties

- ▶ What are the implications of these findings for your community?
- ▶ Where are key areas of need based on these findings? What are major areas of concern?
- ▶ Where are there opportunities for dissemination, education, and prevention messaging to address some of the concerns highlighted in the findings?
- ▶ Based on the findings, what are some key prevention messages?
- ▶ Are these the right key takeaways? What other key takeaways might be worth including?
- ▶ How have you all summarized these findings with your communities?
- ▶ What misinformation topics or “data” are most prevalent, from what you have seen? Do you believe that these data help to counter these topics?
- ▶ What would be helpful to come next based on these findings?

Infographics

In response to community partner requests for a plain language study product that they could share with community members and other key partners in their community, NORC developed an infographic that aggregated findings from the WHNS study. NORC worked with community partners to discuss which data points from the survey would be most helpful for their work. Community partners also reviewed draft infographic layouts and weighed in on NORC translated WHNS infographics into all languages in which the study was available. NORC worked with a certified translation vendor to conduct the initial translations of the infographics, and then worked with community partners who reviewed the translations for accuracy prior to dissemination.

- ▶ **Aggregate infographic** (English, Amharic, Arabic, French, Oromo, Somali, Tigrinya)
- ▶ **Regional infographics:** NYC, Atlanta, Washington, D.C., and Minneapolis. Infographics are available [here](#).

In response to community partner requests, NORC also developed regional infographics that described findings by geographic region. NORC also developed data briefs that summarize WHNS findings on background characteristics, reproductive preventive healthcare behaviors; and reproductive, sexual, and childbirth health concerns by FGM/C experience and type.

“A woman held my hand and asked us to please continue to educate people using the WHNS infographic. We’re also happy to [have our] workshop participants learning more about FGM/C and sharing this information with family abroad. I am sad the project is coming to an end, but [our organization] will continue to have case management and services to provide to our community.”

– Community Partner

Women's Health Workshops and Community Conversations

Community partners convened culturally responsive and trauma-informed small group workshops and conversations around specific topic areas. The conversations helped disseminate WHNS findings, gather frequently asked questions, information, and resources to support community needs, and build rapport within the community while also providing opportunities for families to discuss FGM/C.

- ▶ Community partners conducted at least **25** workshops, community conversations, and sisters circles.
- ▶ These convenings reached at least **275** participants.

AWC held 12 health workshops and sister circles with women in the community on: FGM/C and period health, birth control, mental health, reproductive health, and sexual health. Sister Circles are integrated programs that promote healing and economic empowerment by teaching sewing, offering crisis management and mental health support, and access to safety net resources and services. During these workshops and sister circles, AWC co-facilitated these workshops with medical providers and other subject matter experts, depending on the topic area. The workshops discussed information about the context of FGM/C and health and legal consequences of FGM/C. These workshops and sister circles were available in multiple languages. Sauti Yetu held three community conversations, two in English and French, with women in the community. IIMN held at least 10 women's health workshops with women impacted by FGM/C in Somali and Oromo to disseminate WHNS findings. These discussions focused on sharing WHNS findings and discussing how these data relate to women's experiences with FGM/C. Women discussed their different experiences with FGM/C, gender and cosmetic surgeries, and misconceptions regarding FGM/C.

Some community partners noted that, for many participants, this was their first-time discussing women's health and FGM/C. Community partners noted that sharing this information through a trauma-informed, culturally attuned lens allows the community to hold sensitive conversations together and discuss implications for reproductive and mental health care. Critical to this work is community partners providing safe spaces for these conversations and for community members to develop tools to think critically about WHNS findings.

"I really enjoyed working with the community. Something that touched me is knowing that we are providing a space for women to talk about their experiences, which was not acceptable to talk about in public before. I met people who thought they were the only ones who experienced this because they did not speak to family about it before being married. It was hard to provide space to discuss side effects and they did not have space to talk. I am inspired by how brave these women are in talking about it. These conversations have been inspiring to be part of – they have raised awareness; women want to spread information back to their home countries... Right now, our team works with impacted women, and we need to continue this valuable work."

– Community Partner

Social Media Campaign

Sauti Yetu created a social media campaign to dispel many of the misconceptions around FGM/C by providing information from an accurate resource – the WHNS study. Sauti Yetu has been sharing social media content via Instagram, given that is a highly-used platform that allows for quick digestion of small videos and reels. They can easily share these videos to community members who might not use Instagram but are active on other platforms such as WhatsApp. In addition to sharing WHNS findings, one of the goals of these videos is to clear up misconceptions around FGM/C and further inform the community conversations.

Most Reached Posts

- ▶ All WHNS! Why Do We Call It FGC? Video (73 reaches, 101 plays)
- ▶ # Women & Girls Affected Worldwide (47 reaches)
- ▶ Immediate Complications of FGC (47 Reaches)

“We have taken the findings from the WHNS back to the community. From the beginning of the study, we knew this was something vital, that this study has an impact that reaches farther than service or medical providers. For us working with people every day, we know they are some of the best educators for their communities, and they do this every day.”

– Community Partner

In addition, Sauti Yetu invited NORC to participate in an Instagram Live session, “Understanding Research with Sauti Yetu & NORC,” focused on informing African immigrant women and families and client communities that partner with Sauti Yetu about strategies for interpreting and applying research findings in personal and professional settings and better understanding how community-based organizations and their partners combine scientific evidence with first-hand experience to provide culturally-attuned services.

Provider Trainings and Other Health Care Resources

Community partners integrated WHNS findings into various resources and materials.

- IIMN produced a set of training materials for dissemination to local communities. They developed a set of slides for a one-hour PowerPoint presentation that includes basic information about the cultural background/context of FGM/C, health, and legal consequences of FGM/C, and local and national WHNS CDC data on FGM/C prevalence. The audiences for this training are health care professionals and law enforcement agencies. Community partners used findings to develop and host trainings for health care professionals and law enforcement agencies. They also shared translated copies of infographics and integrated findings from the infographics into posters and pamphlets

to create awareness of health consequences and local resources with community centers, mosques, grocery stores, etc.

- AWC used findings from their health workshops and sister circles discussion from these workshops to develop a frequently asked questions (FAQ) document that they will share with women in the community. They are also using findings from the workshops and sister circles to work with doula organizations to develop a tool that will inform how doulas provide care to women who have experienced FGM/C, including the FAQ document. AWC hosted two sessions with doulas and organizations that work with doulas to share WHNS findings and inform this work.
- Both AWC and IIMN have engaged with women in the community to develop pathways for health care services for women with FGM/C. Both organizations have identified health care providers in their areas that provide services like surgeries or who can support women who have undergone FGM/C and make referrals to those services for women in their community who request it.

Co-presenting in Webinars and Conferences

NORC and community partners also collaborated on sharing WHNS findings more broadly.

- NORC, AWC, and Sauti Yetu collaborated on a two-part webinar with End FGM/C network. The two-part webinar included a presentation of findings from the WHNS study and community partner perspectives on engaging with the study to disseminate findings to their local communities.
- NORC and AWC also co-presented on how community partners are using WHNS findings to inform local community efforts at the American Association of Public Opinion Research (AAPOR) annual conference in May 2024.

► [Two-part webinar with End FGM/C Network:](#)

- Part 1: Findings from the Women's Health Needs Study
- Part 2: Community Partner Perspectives on the Women's Health Needs Study

Conclusion

Community engagement in dissemination can lead to a deeper understanding of research findings, ensure that findings reach community members who are invested in the results in a culturally attuned manner, and enhance trust between communities and researchers.²

Engagement of communities specifically in the dissemination phase of research is vital as:

“Community members deserve access to the knowledge they have made possible through participation or other forms of engagement in the study... [it] creates opportunities to explore the

implications of research findings from a local perspective... [it] allows providers to implement findings immediately and locally, potentially reducing the gap between research and practice... [and it fosters] dialogue with those most affected by a given health issue... aid[ing] in developing culturally relevant interventions.”³

WHNS is one of the first studies that investigated the health care needs, access, and beliefs of women who have experienced FGM/C in the United States. These findings can help to inform communities and health care providers of the needs of women with FGM/C and provide data for evidence-based public health strategies to address these needs. AWC, IIMN, and Sauti Yetu were critical partners in delivering WHNS findings to their respective communities. These partners created culturally attuned, trauma-informed workshops and programs for women who have experienced FGM/C. Avenues like community conversations can empower women to begin discussing the practice of FGM/C culturally within their family units. Social media is also a powerful tool to combat misinformation, particularly around sensitive topics such as FGM/C. A well-designed social media campaign can better inform community conversations and serve to educate others about FGM/C.

Overall, two-way dialogue in dissemination between researchers and community partners results in findings that are well-grounded in community perspectives, strengthens community-researcher partnerships, builds trust, and builds the capacity of both researcher and community partners to better engage in research efforts and translate findings into practice.⁴

“In a way, this work has given us a way to discuss FGM/C with folks and incorporate the lessons learned into different spaces. We have learned so much from having that experience. Before the project, the conversation was limited. Now we have data and can provide high level information on these experiences women have shared. This helps to us identify patterns and have something to compare to; it is a baseline. None of this is new, but the ability to be able to see traction with the resources available and to get the word out on different ways to address FGC... now it is a community-centered approach, when it was only a one-person story before. We are forever grateful, to develop resources together and not just build movement from one person’s story.”

– Community Partner

¹ Better Evaluation. 2022. Data Party. Available at: <https://www.betterevaluation.org/methods-approaches/methods/data-party#:~:text=A%20data%20party%20is%20a%20time-limited%20event%20of,the%20data%20mean%20and%20the%20implications%20for%20action>

² McDavitt B, Bogart LM, Mutchler MG, Wagner GJ, Green HD Jr, Lawrence SJ, et al. Dissemination as Dialogue: Building Trust and Sharing Research Findings Through Community Engagement. *Prev Chronic Dis* 2016;13:150473. DOI: <http://dx.doi.org/10.5888/pcd13.150473> Available at: https://www.cdc.gov/pcd/issues/2016/15_0473.htm

³ Ibid.

⁴ Ibid.