
Building Community-Based Participatory Research Partnerships with a Somali Refugee Community

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Background: The U.S. has become home to growing numbers of immigrants and refugees from countries where the traditional practice of female genital cutting (FGC) is prevalent. These women under-utilize reproductive health care, and challenge healthcare providers in providing culturally appropriate care.

Purpose: This study examined Somali immigrant women's experiences with the U.S. healthcare system, exploring how attitudes, perceptions, and cultural values, such as FGC, influence their use of reproductive health care.

Methods: A mixed-method community-based participatory research (CBPR) collaboration with a Somali refugee community was conducted from 2005 to 2008 incorporating surveys, semi-structured focus groups, and individual interviews. Providers caring for this community were also interviewed to gain their perspectives and experiences.

Results: The process of establishing a partnership with a Somali community is described wherein the challenges, successes, and lessons learned in the process of conducting CBPR are examined. Challenges obtaining informed consent, language barriers, and reliance on FGC self-report were surmounted through mobilization of community social networks, trust-building, and the use of a video-elicitation device. The community partnership collaborated around shared goals of voicing unique healthcare concerns of the community to inform the development of interventional programs to improve culturally-competent care.

Conclusions: Community-based participatory research using mixed-methods is critical to facilitating trust-building and engaging community members as active participants in every phase of the research process, enabling the rigorous and ethical conduct of research with refugee communities.

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History of Somali Refugee Resettlement in the U.S.

The number of African-born immigrants to the U.S. increased 142% (from 363,000 to 881,300) between 1990 and 2000.¹ After the onset of civil war in 1991, thousands of Somali refugees have resettled in the U.S., making them the single largest African refugee group to enter this nation.^{1,2} Based on 2008 estimates by Columbus and Franklin County, Ohio, officials, there are 35,000–80,000 Somali immigrants and refugees residing in central Ohio,³ making it the nation's second largest Somali concentration, second only to Minneapolis, Minnesota.² This population con-

tinues to grow daily because of secondary migration from other parts of the country and from Canada.

Compared with other African immigrants, Somalis have low rates of literacy and English fluency and lower SES.^{1,4} They are less likely to be insured or have a regular source of care.^{5–8} In addition, they have been the least likely to receive a health evaluation or Pap smear in the past year.⁸ Somali women are also at increased risk of adverse pregnancy outcomes, for reasons that are only beginning to be understood.^{9–12}

The enduring social turmoil and political and economic uncertainties in Somalia will likely continue to generate additional refugees and asylum seekers. Relatively little is known about Somali immigrants. A better understanding of their situation may be directly applicable to future similarly disadvantaged refugee and immigrant populations.²

Female Genital Cutting

Female genital cutting (FGC), known as female genital mutilation (FGM) or female circumcision (FC), is an ancient tradition dating as early as 200BC during the Pharaonic era of Ancient Egypt.¹³ Predating Islam, the origins are cultural rather than religious, as it is practiced by Muslims, Christians,

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and Jews,¹⁴ and is not restricted to any particular ethnic or religious sect. Beliefs surrounding the practice of FGC include a rite of passage into womanhood, ensuring social acceptance and marriageability, preserving virginity, and protecting a woman's family honor. FGC is seen as defining a woman's livelihood and future as a wife and mother. In these societies, circumcision is performed out of love and to conform to longstanding social and cultural norms. Therefore not circumcising one's daughter is equivalent to condemning her to a life of isolation.¹⁵

Female genital cutting has been the subject of increasing legislation and worldwide educational campaigns,¹⁶ which have led to a considerable decline in its prevalence over the last 25 years. Approximately 100–140 million women worldwide have undergone a form of FGC,¹⁷ and each year, 3 million girls are at risk for the procedure.¹⁸ In Africa, approximately 91.5 million girls and women aged over 9 years are currently living with FGC,¹⁸ with an estimated 3 million at risk of undergoing FGC every year.¹⁹ Various types of FGC have been documented in 28 countries in sub-Saharan Africa, and in some countries throughout Southeast Asia and the Middle East, as well as other countries.¹⁷ In the U.S., 228,000 women and girls are either living with the results or are at risk of undergoing FGC.²⁰

Eighty-five percent of all forms of FGC comprise Type I/II, which entails partial or total removal of the clitoris, prepuce, labia minora and/or labia majora; 15% comprise Type III,¹⁷ which involves narrowing of the vaginal orifice with creation of a covering seal by cutting and appositioning the labia minora and/or the labia majora, with or without excision of the clitoris. Recent immigration and refugee resettlement from countries where Type-III FGC predominates (i.e., Somalia) have resulted in a rapid surge of girls and women with this type throughout North America and Europe. Somalia has among the highest rates of FGC of any country, with prevalence as high as 98%.¹⁷

While women with FGC have been found more likely than those without to experience adverse obstetric outcomes, with the risks increasing with more extensive FGC,²¹ a growing body of evidence suggests that in the West, FGC may not be as important a cause of obstetric morbidity among immigrant women as once perceived.^{22,24–28} Validated measures of assessing the socio-cultural context of immigration, traditional health beliefs, and practices on health-seeking behavior and healthcare utilization do not yet exist for African immigrant populations with FGC. It is worth evaluating factors such as verbal miscommunication, distrust, refusal of care, fear of pain, and anxiety; which may contribute to their sub-optimal health outcomes.²²

Community-Based Participatory Research

Mixed-method research designs are critical to working with refugee populations as it creates strategies for

moving research forward using existing tools while simultaneously gathering information to improve or change those tools based on qualitative research, thus contributing to increasingly valid studies.²⁹ Community-based participatory research (CBPR) is defined as a collaborative approach to research that equitably involves community members, organizational representatives, and researchers in all aspects of the research process whereby partners contribute unique strengths and shared responsibilities to enhance understanding of a given phenomenon and the social and cultural dynamics of the community, and integrate the knowledge gained with action to improve the health and well-being of community members.³⁰ CBPR using mixed-methods has emerged as a crucial strategy in partnering with refugee communities, particularly when working with vulnerable populations less commonly researched who uphold cultural standards that diverge from Western philosophies and values.²⁹

An overarching set of integrating principles became the building blocks of the CBPR partnership with the Somali community. These key principles: (1) recognized the community as a unit of identity, (2) built on strengths and resources within the community, (3) facilitated collaborative partnerships in all phases of the research, (4) integrated knowledge and action for mutual benefit of all partners, (5) promoted a co-learning and empowering process that attended to social inequalities, (6) involved a cyclical and iterative process, (7) addressed health from both positive and ecologic perspectives, and (8) disseminated findings and knowledge gained to all partners.³⁰

These guiding principles were fundamental to the success of this community-based endeavor which evaluated socio-cultural determinants of health-seeking behavior and barriers to healthcare utilization among African-born immigrants in an attempt to understand healthcare issues facing underserved, minority, refugee, and immigrant populations in the U.S. This article provides a description of the evolution of a collaborative partnership with a Somali refugee community in Columbus and identifies the challenges, the successes, and the lessons learned through CBPR.

Methods

Community Dialogue

The Midwest Network on Female Genital Cutting (MWNFGC) was formed in 2005 as a collaboration of health professionals, representatives from community-based organizations, refugee resettlement agencies, and immigration law experts across the Midwest, working together to identify the growing needs of immigrant and refugee populations of girls and women affected by or at risk for FGC in Minneapolis, Columbus, and Chicago. The MWNFGC fosters ongoing dialogue across communities and institutions aimed to improve cultural competency and healthcare delivery. Through the MWNFGC,

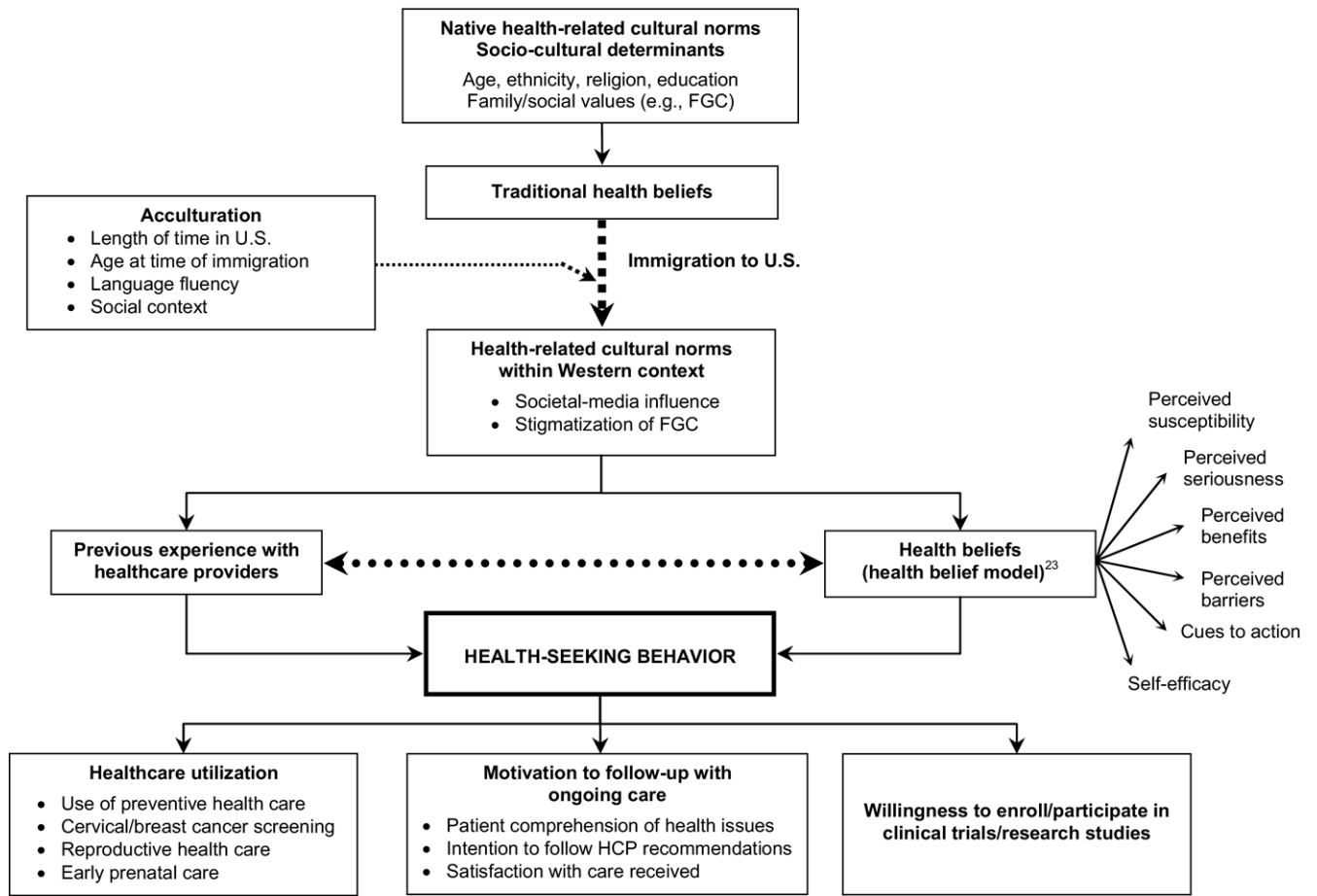


Figure 1. Conceptual framework
FGC, female genital cutting; HCP, healthcare provider

dialogue began in September 2005 with a local Somali community organization and researchers in Franklin County. This dialogue consisted of a series of community meetings which led to a partnership with The Columbus Immigration Resource Center (CIRC), a health consultancy and advocacy organization that seeks to improve health for immigrants and refugees. Through CIRC, the Refugee and Immigrant Women's Health Initiative (RIWHI) was created, and brought together key individuals from the state public health department, local academic institutions, healthcare providers, and the Somali community to form a team to address the healthcare needs of Somali refugee and immigrant women.

Conceptual Framework

A conceptual framework (Figure 1), became the basis of this mixed method approach. Immigrant women's traditional health beliefs are explored to determine how socio-cultural norms and values influence their perception of health. The role of acculturation is examined as it influences how one adapts to health-related cultural norms upon immigration to a Western context. Finally, the interplay of Western cultural norms, with one's previous experiences with health care providers, and health beliefs,²³ are further examined as they inform one's health-seeking behavior, specifically one's health care utilization, motivation to follow-up with ongoing care, and willingness to participate in research studies.

Study Design

This mixed-method approach utilized descriptive and exploratory strategies through iterative methodologic triangulation to garner rich, in-depth information on perceptions and motivations for healthcare utilization and health-seeking behavior among Somali refugees incorporating screening health surveys, in-depth semi-structured focus groups, and individual interviews with Somali women, as well as interviews with local healthcare providers who care for the Somali community.

Somali women aged >18 years, who resided in Franklin County were eligible to participate, with the goal of obtaining a representative community sample of 500 women through purposive and snowball sampling techniques. The screening survey comprised 69 questions covering socio-demographics, health status, reproductive health care, experiences with healthcare providers, and self-reported FGC status³¹; it was developed with the aid of Somali community representatives, health and social service providers, and items adapted from standardized instruments.³²⁻³⁵ The qualitative arm entailed five semi-structured, in-depth focus groups (composed of 30 women aged 18-90 years) using a video-elicitation device through the film *Tahara*,³⁶ and 18 individual interviews, to further explore the socio-cultural dynamics of FGC. Fourteen providers identified through specialty-specific public websites of centers, clinics, and hospitals serving Somali women, were

also interviewed to garner their experiences caring for this community.

Results

Partnership Development and Community Mobilization

The presented results delineate the process involved in establishing a community partnership with the Somali community using CBPR methods. From November 2005 to May 2007, a series of meetings was held with the RIWHI Community Advisory Board (CAB) both in Columbus and in Ann Arbor, Michigan, to determine the specific aims of a collaborative partnership. Over this 18-month period, the research design was constructed, reviewed, revamped in an iterative fashion, and ultimately agreed on by all members of the collaborative team. All survey instruments, interview guides, and informed consent documents were translated into Somali, and accuracy and face validity of the translated versions verified via pilot-testing in round-table discussions with volunteer respondents and trained bicultural medical interpreters. The final documents were approved by the appropriate IRB.

The mobilization of support and the strength of community social networks were invaluable to the success of the community partnership. Recruitment relied exclusively on word-of-mouth, face-to-face communication. From the inception of the community meetings, it was determined that telephone contact, posted fliers, or letter mailings would be an ineffective strategy. Instead, the support and strength of community networks was mobilized through well-known and highly respected local community members who were trained to serve as our interviewers/interpreters. Through these networks, Somali interviewers traveled between and within various neighborhoods that comprised large concentrations of Somali residents using word-of-mouth dissemination to generate interest and to garner participation and support. Word-of-mouth spread as women increasingly embraced our efforts and were eager to participate in the collaborative effort. Mobilization of community social networks enabled the team to surpass its recruitment goal by completing 515 surveys.

Building Trust

Among the successes in this endeavor was the time invested in building trust with the community and bringing their voice and involvement into all aspects of the partnership. Initially, there was considerable distrust among community members, which was more profound among longstanding residents as compared to newly-arrived refugees. Since the 1991 civil war erupted in Somalia, close-knit Somali refugee communities in the West have struggled to uphold positive memories of their homeland and culture amidst nega-

tive media attention and stigma. They feared that study participation may further polarize and exploit their community by negatively portraying their culture.

The Somali interviewers themselves, who were highly respected members of the community, had to walk a very fine line between being considered an “insider” versus an “outsider” by their own community in regards to their involvement in the collaborative effort. Over time, this challenge was surmounted, as trust was built with key Somali community leaders within local neighborhood social networks, who remained intricately engaged in every aspect of the planning, design and implementation of this collaborative partnership. The team was unified around a common theme of bringing attention to the various health challenges facing the community. Further, internal clan conflicts among ethnic Somalis were avoided as our collaborative effort involved a diverse group of Somali women that crossed many ethnic and tribal affiliations. Based on insight from the CAB, all interviews were conducted by an all-female team in women’s homes where participants felt more comfortable, were surrounded by familiar faces, and were in an informal, nonthreatening environment. Women remarked how the image of the Somali flag, printed on the cover of the screening survey, imbued a sense of identity and belonging.

Through this strategic partnership, the community and research team were cohesively aligned behind similar goals. This strategy proved to be particularly advantageous in this community, which is often stigmatized, vulnerable, distrustful, and reluctant to participate in formalized studies using traditional research methods. Further, the trust engendered through referrals made within the Somali community network of neighbors, acquaintances, family members, and peers enabled our team to gain entry into a close-knit social network that might otherwise have been impenetrable.

Conducting the Surveys and In-Depth Interviews

All survey interviews, while available in written format in both English and Somali, were orally administered via face-to-face interviews by trained female bilingual and bicultural Somali interviewers. However, only the first 17 surveys were actually conducted using the Somali version, as it became readily apparent that the interviewers were more comfortable administering the English version of the survey, while conducting the verbal interchange of questions and responses in Somali. Notwithstanding, the Somali version remained available for use as a reference for any questions of clarification.

For the focus group sessions, a traditional Somali meal was served, after which women viewed *Tahara*,³⁶ which served as a springboard for in-depth discussion. The film was well received and viewed quite positively by the Somali community. It was in Arabic (with English subtitles), and was neither judgmental nor culturally

demeaning. While it highlighted the practice of FGC, it showcased a culture other than Somalis, which women still identified with, and drew on the similarities and differences during the discussions. The group dynamics engendered in this setting, aided by the video-elicitation device, offered a rich depth of insight unmatched by the individual interviews or surveys alone.

In stark contrast to the focus groups wherein women were lively, animated, often all talking at once, and bolstered by the comments of others in the room, the individual interviews, which were aimed to ascertain more specific childbirth experiences, were more calm and subdued, in that women appeared more conscious of the audio-recording device and computer-based note-taking by the research assistant, and gave more guarded responses. It was later disclosed to the research team that some women feared repercussions, wherein any information disclosed would be reported to the government or immigration services and result in their loss of governmental assistance or deportation. This notion may have prompted socially-desirable and politically-correct responses rather than the truth.

Disseminating the Results and Sustainability

The preliminary findings of the gathered data were shared and discussed with members of the research team as well as with the Somali community. As a result, RIWHI has remained an active initiative through CIRC, and offers health referral services for Somali women and their families, facilitates access to healthcare services, including prenatal and reproductive health care in partnership with local healthcare providers, and distributes health information materials. In addition, statewide efforts through an Immigrant and Refugee Women's Health Initiative have organized health fairs, and brought together local ethnic organizations with state and local agencies to strategize ways of improving healthcare access and services to refugee communities. Somali women have been empowered and found a voice through which they can advocate their needs to the wider community.

Discussion

This is the largest study to date in the literature of African-born immigrants in the U.S., which incorporates a community-based, mixed-methods approach to examine socio-cultural determinants of health-seeking behavior and healthcare utilization. Our objective was to establish a dialogue with a Somali community, and to share the experiences and strategies used in the development and implementation of a CBPR effort to assess the unique healthcare needs of Somali women. A crucial aspect of this research endeavor was the partnership and engagement of community members in every stage of this process. Consequently, we surmounted incredible challenges, engendered trust, and

developed a respectful and successful dialogue, which enabled our collaborative success.

Limitations and Lessons Learned

There were many lessons learned not only in the successes achieved with this community partnership, which greatly enhanced our ability to surpass our recruitment goal, but also in the limitations, namely the ethical challenges of obtaining informed consent, reconciling language barriers, and relying on women's self-reported FGC status.

Informed Consent

The process of informed consent initially heightened distrust, as women were reluctant to sign the informed consent documents, as it was feared to be a form of self-identification. To overcome this challenge, the IRB subsequently provided a waiver of written/signed informed consent, wherein documentation of verbal consent obtained through an interpreter was sufficient. Precedents have already been established,^{29,37,38} given the sensitive nature of the information obtained during interviews, as refugees fear written consent as a possible means of identification, are often averse to signing "official-looking" documents, and have varied literacy levels.

The practice of obtaining *written* consent may be problematic in certain refugee communities, as orally-based cultures may assign higher value to verbal consent, and the presentation of a multipage document may be irrelevant, inscrutable, or perceived as intimidating.²⁹ Further, decisions may be made based on the best interests of a group rather than an individual, and there may be gender-based and/or familial hierarchies between a woman and her spouse, community elders, or other authorities in positions of power, wherein cultural traditions dictate an unquestioning respect and obliged acquiescence to participate in research. Even when community leaders are utilized to help enroll refugees in a study, there is the possibility of coercion due to an inability to refuse the request of a respected elder/leader. Moreover the validity of informed consent is further complicated when refugees arrive from countries whose governments violated human rights through coercive tactics. Fear of deportation or a desire to achieve legal status may lead a refugee to feel forced to participate, despite being told that a study is "voluntary." Hence conducting studies involving refugee communities may necessitate educating IRBs on cultural nuances that may fall outside the boundaries of Western values of individual autonomy, self-determination, and freedom inherent to the concept of informed consent.

Language Barriers

Somalia has a strong oral culture; the Somali written language is relatively new, becoming a Latin script in

1972.³⁹ Since the onset of civil war in Somalia in 1991, literacy in the Somali language has remained quite low. Hence language barriers persisted despite the use of interpreters and the translation of all documents into Somali. For instance, translating the documents from English to Somali was challenging as many English words, particularly some medical terminology were not available in the Somali language. Further, sensitive words describing genitalia or other reproductive functions were deemed culturally inappropriate and even offensive. To overcome this barrier, during the study design, each translated item was iteratively and meticulously examined to ensure that the context accurately captured its English interpretation. Further pilot-testing ensured the accuracy of the question construction, wording, and length, as well as the cultural appropriateness of the instruments.

Despite these efforts, the Somali interpreters were more comfortable administering the survey via oral translations of the original English text rather than using the translated Somali version. This has been documented in the literature, as cultures possessing strong oral traditions rely heavily on the flexibility and nuance of speech for effective communication. Using translated or back-translated documents, while accepted as best practice within cross-cultural research, may be inappropriate for certain cultural groups as it could lead to a loss of nonverbal nuances while giving the appearance of being more accurate than oral translations from the original English text.²⁹ Despite this challenge, every effort was made to work with the Somali interpreters to ensure that the orally translated terms and concepts reflected words culturally appropriate for use by all members of the Somali community regardless of educational or literacy level.

Reliance on FGC Self-Report

Most studies examining FGC have relied on women's self-reports of FGC status rather than clinically-verified examinations. However self-reported FGC status has consistently proven inaccurate as there is considerable under-reporting of the extent of FGC, as well as large variations in the level of agreement between self-reported descriptions and clinically observed types of FGC.^{40–44} Further, the reliability of clinical observation can be limited by natural anatomical variations and difficulty in estimating the amount of clitoral tissue under an infibulation (Type-III FGC).¹⁷ Due to the nature of this research collaboration being entirely community-based, clinical exams were not feasible. The socio-cultural perceptions of FGC were of greater concern, as they influence women's health beliefs and health service use.

An alternative method was devised to ensure the validity of women's self-report by using an illustrated anatomic guide—RAINBO[®] FC/FGM Full Color Quick Reference Chart,³¹ as a visual verification of self-reported FGC status. During the initial piloting, women

were very interested in viewing this guide. However, once incorporated into the surveys administered to the general community, the guide was viewed as offensive. Our Somali interviewers reported that women felt images of female genitalia were being “flashed all over Columbus.” This strategy was abandoned, and the guide was used only by women who specifically requested to view these images. Nonetheless, we believe the validity of self-reported FGC status remained intact for women with infibulation, as women consistently described their circumcision scar with easy accuracy, using such phrases as: *I am like a wall*, or using a zipping motion with their fingers moving across their lips to describe their infibulation.

During the focus groups in women's homes, the illustrated guide³¹ was eagerly viewed with intense curiosity. Women gathered around to ask questions regarding female anatomy and FGC-related sequelae long after the focus group sessions had concluded. It appears that the sense of privacy and security engendered among familiar, women-only peers during the focus groups, created an atmosphere where women felt comfortable and unabashed in viewing the diagrams and asking intimate questions.

Next Steps

The next steps entail completing the ongoing data analyses of the surveys, in-depth focus groups, and individual interviews, and disseminating findings not only through peer-reviewed publications, but also through local Somali community organizations, healthcare institutions and stakeholders. Future interventions will aim to improve health outcomes through capacity-building and partnership of these community organizations with local healthcare institutions, to enable the development of culturally-competent clinical guidelines and training protocols that are informed by the needs of the community. There is an increasing need for innovative strategies to improve community partnerships and effectively frame shared goals and priorities. The key lessons learned in this process of establishing community-based collaborative partnerships will not only enhance awareness of the healthcare needs of Somali women, but can also be exemplified in approaching other newly arrived, marginalized and vulnerable refugee and immigrant populations in the U.S.

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