# A Community-Academic Partnership to Explore and Address Cancer Disparities in Southwest Chicago Arab Americans

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## ABSTRACT

**Background.** Despite the need to consider multiple sources of evidence to guide locally and culturally relevant interventions, few studies have documented the process by which evidence is *integrated*.

**Objectives.** We leveraged a community-academic partnership to describe a participatory approach to integrating community and academic sources of evidence to inform cancer programming priorities in the Arab American (ArA) community in Southwest Chicago.

**Methods.** Informed by Intervention Mapping, this study comprised three phases led by community and academic partners: 1) qualitative assessment of cancer-related priorities through eight focus groups with 48 ArA community members, 2) a focused literature review to identify models of cancer interventions implemented with ArAs, and 3) integration of focus group and literature review findings and development of a strategy for a community-based cancer program administered by the community partner.

**Results.** Focus groups revealed attitudes and beliefs across the cancer control continuum. The literature review highlighted two cancer interventions utilizing education, community health workers, and patient navigation components.Through facilitated discussions with community partners, we integrated community and academic sources of evidence to develop a comprehensive cancer program plan that is informed by the data we generated as well as our community partners' preferences and organizational capacity.

**Conclusions.** Our participatory approach for integrating community and academic sources of evidence generated a locally-relevant strategy to address cancer burden in the ArA community in Chicago. We discuss the benefits and challenges of utilizing this approach in intervention development.

**KEYWORDS**: Arab Americans, cancer disparities, community-based participatory research; Intervention Mapping; evidence-based public health

## Introduction

Cancer disparities seem refractory to the advances in cancer research, pointing to a breakdown in the translation of research to practice.[1,2] Accelerating the adoption of evidence-based strategies necessitates the weaving of different forms of evidence, namely the peer-reviewed literature and contextual data from real-world settings.[3] The latter can be obtained through community engagement approaches, which ~~can~~ build an infrastructure for multidirectional knowledge transfers between researchers and diverse community, clinical, and public health partners.[4–6] These approaches prioritize "home-grown" interventions that reflect the communities' unique contexts, leverage their knowledge and capacity, and ensure decision-making around health interventions is aligned with the local context.[3,4]

Several intervention development frameworks have emphasized community assessments as a precursory step to intervention development (e.g., Intervention Mapping [IM], PRECEDE-PROCEED).[7,8] Through these assessments, interventionists can gain foundational knowledge of the priority issues within the target communities and select intervention strategies that are aligned with the community's priorities, culture, context, and capacity.[7,8] Multiple community-based cancer interventions with racial/ethnic minorities have incorporated a community assessment component to guide intervention development.[9,10] Given the multilevel etiology of cancer disparities, including multiple stakeholders' perspectives in the community assessment can help clarify determinants at different levels of influence. For example, community members may discuss individual-level factors, while community leaders can provide complementary information on healthcare barriers and community-level resources.[11–13]

The next stage translates the foundational knowledge gained through community assessments into responsive interventions. Community participation at this stage ensures that the proposed intervention balances the knowledge of researcher (i.e., scholarly literature and evidence-based strategies) and the knowledge of the community (i.e., real-world experiences and perspectives), to design an intervention that can achieve the desired outcomes, while being feasible and acceptable.[7,8,13–16]

Community engagement approaches are also applicable to the research aspect of intervention development. Mullins et al.[17] referred to a “continuous engagement” strategy, for shared ownership of research decisions and processes and shared credit for research successes. In the context of cancer disparities, this strategy would entail community participation to determine which cancer topics are prioritized, frame research questions within the locally-relevant determinants, determine best approaches to data collection, ensure data interpretation is plausible given the community’s intimate knowledge of how context and culture may influence cancer outcomes, and facilitate dissemination of results to the broader community, and use these results to inform action plans.[17]

Although community involvement is frequently leveraged in cancer disparities intervention research and health disparities research overall, the specific processes are rarely described and documented. A review of cancer interventions revealed that while most community assessments highlighted multilevel determinants of cancer burden, most interventions prioritized individual- or interpersonal-level strategies, without justifying how programming decisions were made and whether and how community partners’ voices were centered in the decision-making process.[18] Therefore, opening the “black box” of community intervention planning, including challenges of reconciling community and academic evidence and lessons learnt, could provide a useful model for integrating multiple sources of data and partner perspectives in intervention development.

The present study is led by a community-academic partnership and grounded in community-based participatory research principles (CBPR; Table 1);[19,20] it exemplifies one participatory approach to integrating community and academic sources of knowledge toward intervention development. We apply our participatory approach in a case study focused ~~We focus~~ on cancer disparities among Arab immigrants and US-born Arabs, hereon referred to as Arab Americans (ArA). ArAs face high rates of rare cancers (e.g., thyroid, liver, brain);[21–23] and great late stage diagnoses,[24,25] and are more likely to die from common cancers (e.g., breast, lung) compared to whites.[26] Importantly, ArAs have been historically invisible in national and local health registries due to their inclusion in the white racial category.[27] This misclassification obscures their unique health outcomes and determinants, thus making community-engaged local assessments particularly important to drive research priorities and intervention development. This study has two overarching goals: 1) to document the participatory process of integrating community and academic expertise and 2) to describe findings from our case study which aimed to explore cancer-related programming priorities in the ArA community in Chicago.

## Methods

Our case study focused on the cancer-related priorities as well as cultural and contextual realities of the ArA community residing in Southwest Chicago. The geographic boundaries for our case study were defined by our community partners to align with their programming catchment area. The case study was also bound by the preferences and organizational capacity of one community-based organization (i.e., our community partner).[28] Using an adapted IM protocol,[7] we explored cancer-related concerns of our priority community using a three-phase approach ~~comprised three phases~~ led by community and academic partners (Figure 1): 1) focus groups to determine priorities for a cancer intervention by exploring ArA community members' cancer beliefs (IM step 1: needs assessment)~~;~~ 2) a focused literature review to identify models for community-based cancer interventions with ArAs (IM step 3: theory-based intervention methods); and 3) facilitated discussions between community and academic partners to integrate focus group and literature review findings and develop a strategy for a community-based cancer program (IM step 4: program plan). All methods and materials were approved by the University of Illinois at Chicago Institutional Review Board.

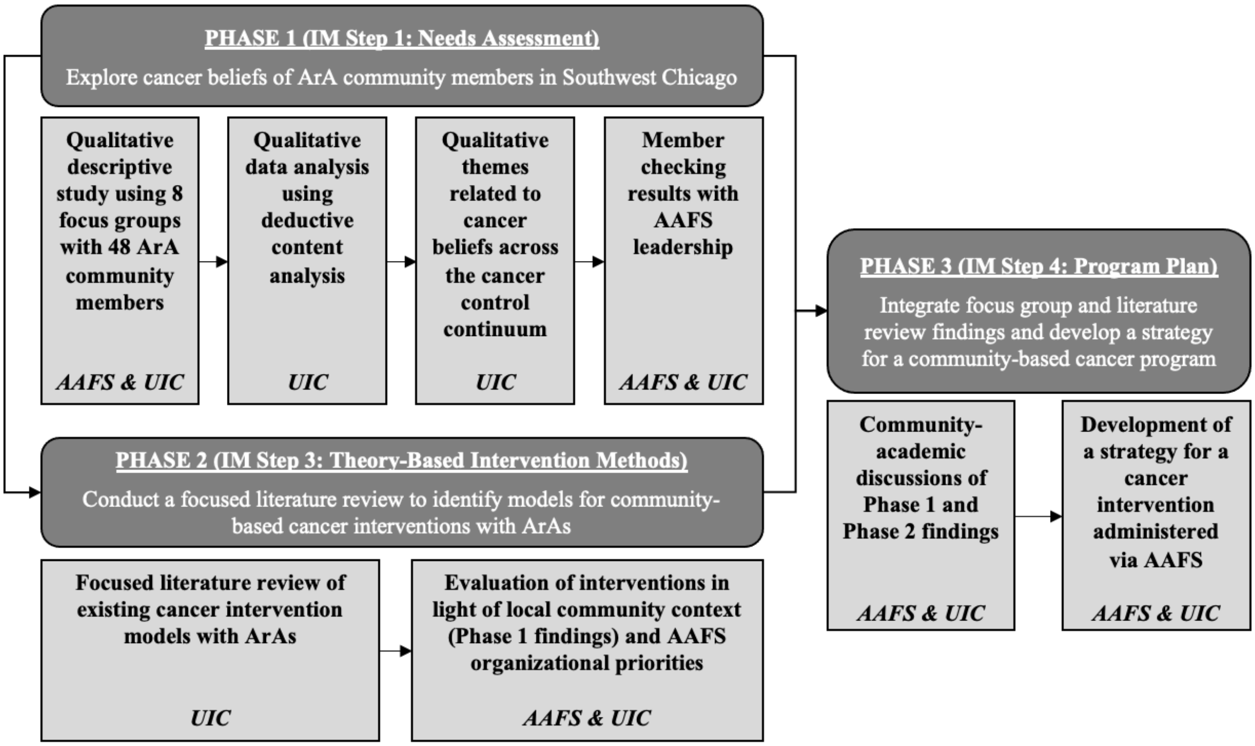

**Figure 1.** Study design: three-phase study informed by Intervention Mapping

## Study team

The study team combines two organizations: the University of Illinois at Chicago (UIC) and the Arab American Family Services (AAFS); both teams are included as co-authors of this manuscript. Informal discussions between UIC researchers and AAFS' co-directors (Shalabi [IS] and Taha [NT]) were initiated in 2016: Chebli (PC) and Abboud (SA), Arab/Arab American researchers and co-authors, were interested in understanding the local landscape of community-based organizations in Chicago and met with multiple agencies serving the ArA communities. AAFS co-directors were especially interested in addressing their client population's health needs, given their embeddedness in their communities and knowledge of persistent health concerns as well as their background in social work and psychology. A joint decision was made to collaborate on health research projects. Our partnership formally started in September 2017, with a collaborative, community-driven effort to assess health priorities among ArA community members (n=200) residing in Southwest Chicago, AAFS's catchment area. Methods and findings ~~Details~~ from the collaborative community health assessment ~~of this community~~ are detailed ~~available~~ in Zayed et al.[29] Notably, half of surveyed participants identified cancer as a top community health priority, sparking our interest in exploring this issue together. This led to joint submissions to funding opportunities and research collaborations to further understand and address the multilevel determinants of health in ArAs in Southwest Chicago.

*AAFS* is a nonprofit social service agency founded in 2001, serving communities in the South Suburban Chicagoland area, with a focus on the ArA community. AAFS delivers in language, culturally tailored direct assistance through safety net case management, immigration services, and community health education programs. AAFS is also engaged in policy advocacy to protect immigrants, undocumented, and deportable communities.

The *UIC* study team includes researchers in the field of community-based participatory research, qualitative methodologies, cancer disparities in underserved communities including ArAs, and intervention development.

## Procedures

### Phase 1: Focus groups to explore ArA community members' cancer-related beliefs

Phase 1 was part of a larger qualitative descriptive study led by the senior author (SA) and AAFS to identify community-driven health priorities. Qualitative description is a pragmatic qualitative research approach that is typically less interpretative than other qualitative methods.[30,31] Its purpose is to *describe* participants' perceptions of a specific phenomenon and to stay as close as possible to the data and participants' own language. This approach is most suitable for needs assessments and to inform development and tailoring of interventions, which are consistent with our study goals. We used convenience sampling and snowballing methods to recruit community members from AAFS's client population and their social networks respectively. Interested community members contacted the study team to be screened. To be eligible, they had to: 1) be first-generation immigrants (foreign-born and living in the US) or second-generation immigrants (born in the US to foreign-born parents), 2) self-identify as Palestinian, Jordanian, Iraqi, or Yemeni (i.e., the most prevalent Arab nationalities in Chicago, 3) be 18 years or older, 4) be currently residing in the Chicagoland area, and 5) be able to speak Arabic or English.

Eligible participants attended same-gender focus groups facilitated by bilingual study staff (PC, SA) in a private office at AAFS. Focus groups included 4-6 participants and lasted approximately 90 minutes. The focus group guide included prompts to explore factors at the individual, interpersonal, healthcare, and structural levels that shape beliefs (i.e., knowledge, perceptions, misconceptions) around cancer risk and cancer risk factors within the community. ~~Sample~~ The list of questions included: "What have you heard about cancer prevalence in the Arab American community?"; "Who do you think is at greater risk of having cancer?"; and

“How do you compare Arabs to others in the US with regard to risk for cancer?”. Participants received $30 incentives.

**Analytical approach**

Focus groups were audio-recorded, translated verbatim and transcribed by a bilingual member of the study team, and uploaded onto Dedoose, a qualitative analysis software. The two bilingual authors (PC, SA) facilitated focus groups, debriefed and compared notes after each session, then reviewed the transcripts to verify the translation accuracy. The analysis was performed by the first author (PC) who had didactic training in qualitative research methods and pragmatic experience with senior faculty; PC was supported in the analysis by the senior author (SA) who is a qualitative researcher. The first author (PC) led a predominantly deductive content analysis using an a priori codebook informed by the cancer control continuum[2,32] and the National Institutes of Health Centers for Population Health and Health Disparities multilevel model for health disparities.[1] Inductive codes were also allowed to emerge from the data, especially to further nuance findings within each pre-determined category. The primary coder (PC) met regularly with the senior author (SA) to discuss the analysis by randomly selecting sections of transcripts, examining how codes were applied, and resolving any disagreements in code interpretation, thereby fostering coding reliability. This approach to reliability is valid and indeed common, especially in early-career contexts wherein a sole researcher must be responsible for most of the coding.[33] The primary coder then grouped similar concepts into categories illustrating the emerging themes, which were organized by stage of the cancer control continuum (i.e., etiology/prevention, detection/diagnosis, and treatment/survivorship) and level of influence (e.g., individual, interpersonal, healthcare, and structural). After coding was completed, peer debriefings with community partners (IS, NT) were conducted to evaluate the analyses and interpretations given their firsthand knowledge of the priority population.

## Phase 2: Literature review of community-based cancer interventions with Arab Americans

AAFS expressed interest in leveraging patient navigators or community health workers in their programming to ensure the intervention "lives" in the community. Therefore, we focused on identifying community-based cancer interventions that incorporated these approaches. Our partners were also adamant that the interventions be implemented with ArA populations to ensure alignment with cultural needs and norms and increase the likelihood of replicability in the Chicago context. Phase 2 of the current study was a focused literature review to identify interventions that align with our community partner's priorities. Databases we explored included PubMed, EMBASE, CINAHL, and Google Scholar, with no restriction on date of publication to maintain a purposefully wide scope. Key words that guided the search included different variations of the following key concepts: "Arab American", "intervention", "cancer control", and "patient navigation". Next, we mapped out the cancer belief themes addressed by these interventions and contrasted them with the identified cancer beliefs from our focus groups, to determine the appropriateness of the interventions.

## Phase 3: Integrating findings from focus groups and the literature to inform AAFS' cancer program strategy

The UIC team developed infographics of focus group and literature reviews findings (see Appendix for a sample infographics) and disseminated it to AAFS co-founders (i.e., co-authors IS, NT). The purpose of the infographic was to summarize and simplify the rich and complex data generated from Phases 1 and 2 into a clear, concise, and accessible visual. In March 2020, the UIC and AAFS teams initiated their strategic discussions which were informed by data from both the focus groups and the literature review. The preliminary goals of these discussions were to: (1) evaluate the suitability of the identified cancer interventions; (2) identify AAFS' programming priorities based on their capacity and the community needs; and (3) examine the feasibility of these programmatic priorities by outlining existing assets and needs. The discussions were audio-recorded, summarized by the UIC team, and shared with AAFS as a reference for future meetings.

## Results

### Phase 1: Focus groups findings on cancer beliefs in ArA community members

*Leveraging academic-community partnerships in research processes*

On the day of focus groups, some community members were apprehensive about audio-recoding the discussions, citing their fear of wiretapping for surveillance purposes. Having both the study purpose and team members "endorsed" by AAFS had a significant impact on alleviating these concerns. All individuals agreed to continue their participation.

Demographic characteristics of the 48 focus groups participants are provided in Table 2. Emergent themes with illustrative quotes organized by the stage of cancer control and level of influence are presented in Table 3.

*Beliefs related to cancer etiology and prevention*

Participants identified various risk factors (e.g., smoking, stress, US environmental factors) and protective factors (e.g., healthy Arabic diet) related to cancer incidence. Regardless of these factors, some participants believed that cancer was unavoidable or predetermined by God's will. Cases from their social network were used to support their beliefs; for example, participants cited family members who adopted healthy lifestyles but were still diagnosed with cancer as evidence of the unavoidability of cancer.

*Beliefs related to cancer detection and diagnosis*

Most participants perceived few benefits to cancer screening, stating that screening was not necessary without symptoms and similarly, that asymptomatic cancer cannot be detected with screening. In parallel, most reported several barriers to screening at intrapersonal, cultural, and structural levels: fear of cancer and cancer screening, absence of norms promoting preventive care, lack of knowledge about recommended screening guidelines, and healthcare costs and lack of health insurance. Healthcare providers appeared to be major sources of knowledge and cues to action, serving as women's main source of information and referrals for female-specific cancer screenings (e.g., mammography). In contrast, men were unable to accurately define any screening guidelines, including for male-specific cancer (e.g., prostate cancer).

*Beliefs related to cancer treatment and survivorship*

Cancer treatment and survivorship beliefs seemed determined by experiences within participants' social networks. Cancer mortality, rather than survivorship, dominated the discussions: the expectation was that a cancer diagnosis is a death sentence, based on their previous experiences with cancer.

### Phase 2: Patient navigation and community health worker cancer interventions with ArAs documented in the literature

Our literature review identified two community-based cancer interventions with ArAs that integrated either patient navigation or a community health worker component. The Arab

American Breast Cancer Education and Referral program (AMBER) offers breast cancer educational workshops in community settings and patient navigation assistance to cancer screening and treatment.[34] The Kin Keeper cancer prevention program uses community health workers to deliver breast and cervical cancer education in participating women's homes.[35] Descriptions of the interventions, including cancer belief themes addressed, are presented in Table 4. Both interventions implemented community engagement strategies for intervention development, through a community advisory board in AMBER[34] and a formal community-academic partnership in Kin Keeper.[36]

### *Beliefs related to cancer etiology and prevention*

Knowledge of cancer risk factors was addressed in both interventions through community informed and culturally tailored education. AMBER's implementation was preceded by formative focus groups with the community[37] and the Kin Keeper breast and cervical cancer curriculum was adapted by interviewing ArA community members.[36] Cancer predestination was a common theme, suggesting that tailoring and delivery of the interventions were responsive to these beliefs. Additionally, educational sessions in both interventions were facilitated by linguistically congruent staff (AMBER) or community health workers (Kin Keeper) to address language barriers.

### *Beliefs related to cancer detection and diagnosis*

The primary purpose of Kin Keeper was to improve breast and cervical cancer screening knowledge.[35] Although the intervention reported significant improvements in knowledge, implications on screening uptake were unclear. In addition to raising awareness of breast cancer, the AMBER intervention model provided referrals to free/affordable breast cancer screening, language assistance during appointments, and support to other services, such as insurance and transportation.[34]

*Beliefs related to cancer treatment and survivorship*

AMBER spanned the entire cancer continuum, including cultural competency training to healthcare staff and support for ArA women with breast cancer through treatment and survivorship. Specifically, AMBER held monthly support groups for ArA women diagnosed with breast cancer. Kin Keeper did not address cancer treatment and survivorship.

**Phase 3: Developing AAFS' cancer program strategy**

In response to findings from focus groups, the literature review, and AAFS's programmatic priorities and firsthand knowledge of the community, the UIC and AAFS teams developed a strategy for a community-based cancer program to be implemented by AAFS. This program would have four major components. First, trained community health workers would deliver a comprehensive culturally and linguistically tailored educational cancer curriculum that includes cancer etiology (diet, smoking, stress, environmental factors, predetermination); diagnosis and detection (fear, fatalism, knowledge, misconceptions); and treatment and survivorship (e.g., chemotherapy side effects; beliefs based on social networks' lived experiences). Second, ArA healthcare providers will be engaged and serve as major sources of information and cues to action. Third, patient navigation will address healthcare access (e.g., cost, insurance) throughout the cancer continuum in partnership with healthcare organizations and cancer assistance programs. Finally, a support group for cancer patients/survivors will be established to disrupt the cancer mortality narrative. Program components are summarized in

Table 5. Below, we provide a detailed description of each component, needs, and existing capacity.

*Program scope and openness to academic-community partnerships*

AAFS emphasized that they have long adopted a "one-stop-shop" model for their organization and are committed to applying it to their cancer programming as well. As one community partner reflected:

> *"We can't just educate people without giving them resources or next steps and keeping them hanging. That has resonated with me because, fine, you've provided me with a mammogram then what good is it if I can't find what's my next step after a mammogram if I'm positive and I have breast cancer. Which hospital do I go for free screening? For follow up? Who's my doctor? Where do I get support for this? Because I feel now alone. You've kind of opened a Pandora box without giving me any help."*

Given this and the multilevel factors of cancer uncovered in focus groups, AMBER's systems-oriented approach was selected to ensure comprehensiveness and continuity of services. Funding and funding sustainability were the main challenges to this approach, evidenced by previous unsuccessful grants applications. The UIC study team's grant-writing experience, specifically in the context of CBPR, was considered a resource.

*Planned educational components regarding cancer etiology and prevention beliefs*

Cancer and general health knowledge misconceptions~~,~~ identified in focus groups~~,~~ underscored the need for continuous education that spans the cancer control continuum, including diet, smoking cessation, and stress management. The conveniently located and spacious AAFS office was viewed as ideal for educational workshops. AAFS emphasized that education should be accessible to lay community members, citing low literacy or English language proficiency in vulnerable sub-groups as impetus. The UIC study team's expertise in developing health promotion materials in Arabic was viewed as an asset.

### *Cultural component regarding cancer etiology, prevention, detection, and diagnosis beliefs*

Cultural factors and cultural tailoring were recurrent themes in the focus groups and the interventions from the literature, respectively. As a result, cultural adaptation of the educational curriculum was prioritized. For example, the curriculum should incorporate ArA cancer survivors' stories to shift the narrative from cancer mortality to survivorship. AAFS believed they have the organizational capacity, both programmatic and staff, to administer a culturally congruent cancer intervention. Most important to them~~,~~ was to train community members (e.g., their staff and clients) as community health workers, similar to the Kin Keeper model.[35]

### *Beliefs related to cancer detection and diagnosis: a focus on healthcare access and structural barriers*

AAFS indicated that formal partnerships with healthcare organizations (e.g., community clinics, hospitals) are needed to facilitate access to cancer care across the continuum and address barriers. AAFS lamented the abundance of Arab medical providers in clinical settings, contrasted with their minimal presence in the community setting, stating, *"It's like they don't exist in the community"*. They suggested leveraging their leadership role in the community to engage these providers~~,~~ as a strategy to address knowledge misconceptions and overcome mistrust in healthcare institutions.

### *Partnerships to address cancer treatment and survivorship*

AAFS recognized that a comprehensive cancer intervention should be anchored in a network of partnerships, stating, *"We don't have to provide everything ourselves, we just have to know what resources are available to our community"*. Cognizant of their community's socioeconomic challenges, AAFS stressed the importance of identifying and referring supportive services to ArA patients with cancer (e.g., financial assistance, childcare, transportation). Therefore, hiring a care coordinator was seen as essential to compile an inventory of assistance programs administered through health departments, foundations, and other relevant entities. Finally, given cancer stigma which was apparent in the focus groups and through their daily interactions with the community, AAFS was interested in convening a support group for ArA patients with cancer, as per the AMBER intervention.

## Discussion

This study is an example of a community-academic partnership spanning the continuum of CBPR, from defining the problem to community action planning in the context of cancer disparities in the ArA community in Southwest Chicago. Our work highlights a participatory approach through which multiple sources of knowledge can be integrated from research to action.

Our community assessment in Phase 1 demonstrated the benefits of original qualitative data collection in identifying the cancer beliefs specific to our local ArA community. These beliefs are aligned with past ArA research on cancer etiology (diet, smoking, stress, environmental factors, predetermination); detection and diagnosis (fear, fatalism, healthcare access, providers as major sources of knowledge/cues to action); and treatment and survivorship (chemotherapy side effects; beliefs based on social networks' lived experiences).[37,43–45] Yet, it should be noted that this literature is heterogeneous; not all articles reported each of these factors. Consequently, our original work identified the beliefs that were most important to our community.

The literature review in Phase 2 demonstrated the value of reviewing extant academic literature to identify existing cancer programs adapted to ~~for~~ ArAs. A common characteristic was the delivery of culturally tailored educational content, highlighting the importance of academic-community partnerships in the past. In terms of available models, few programs addressed cancer etiology (e.g., diet, smoking cessation, stress management). Both identified programs targeted detection, namely in terms of fear, fatalism, and knowledge; notably, this was not through providers, as we found in the focus groups, but through community health workers and navigators. Only one program addressed treatment and survivorship and associated factors. AMBER was also the only model to intervene on healthcare access and supported patients throughout the cancer care continuum.[34] Overall, the programs provided useful models that could be adapted to the Chicago Southwest context.

Program planning through the strategic community-academic discussions ~~with AAFS~~ in Phase 3 demonstrated the ~~feasibility~~ benefits of a participatory approach to integrating multiple sources of knowledge. Overall, existing organizational and community capacity, as well as partnership with the UIC study team were viewed as assets. Our work demonstrates the various factors contributing to decisions and action planning. The most important prerequisites were sustained funding, hiring and training staff, and building a network of multisectoral partners, to ensure access to care and support across the cancer control continuum. Although action planning discussions were informed by data from focus groups and the literature review, they were also influenced by the community organization’s values, preferred intervention approaches, commitment to provide comprehensive services, and firsthand knowledge of their priority population. Despite significant funding implications, AAFS asserted their commitment to deliver holistic programs that span the cancer control continuum. Based on the joint capacity of academic and community stakeholders, we devised a strategic plan that addresses factors identified in focus groups through a comprehensive program informed by elements of the AMBER and Kin Keeper programs.

Our study demonstrated several benefits and advantages to academic-community partnerships. During the focus groups discussions (Phase 1), participants' suspicions around voice recording were appeased by our partnership with AAFS. This is consistent with other studies documenting ArAs' mistrust in institutions[38] and reluctance to sign consent forms.[37,39] Of note, two members of the UIC study team (PC, SA) identified as Arab. Whereas their congruent identity may have facilitated communication and familiarity with the community, it did not automatically grant them acceptance.[40] This distrust is exacerbated by the current sociopolitical climate, wherein ArAs are systematically targets of heightened surveillance and racial discrimination.[41] Our foundational partnership with AAFS imparted credibility and trustworthiness on the UIC study team. In the literature review (Phase 2), we documented how community engagement and partnership supported the interventions, including development, recruitment, and implementation of educational activities in community sites. In the action planning discussions (Phase 3), the AAFS-UIC partnership leveraged the strengths, experiences, and capacity of academic and community stakeholders to develop priorities for a community-based cancer program.

Despite these documented benefits, our participatory approach also poses inherent challenges. As previously stated, community participation is often incorporated in needs assessments yet less commonly documented in decision-making around intervention strategies. The academic team might favor intervention strategies that are strictly "fundable" (i.e., prioritize funding agencies agendas) while community partners prioritize "what works" given their knowledge of their communities. The inherent caveat in community-academic evidence integration is the balancing act required to allay these equally valid considerations. In our case study, the intervention plan is comprehensive, thus addressing all identified community needs, yet requires significant funding to realize. In subsequent partnership discussions, these limitations were conveyed along with the requisite infrastructure needed to be built pre-funding (e.g., partnership consolidation between AAFS and healthcare organizations). Relatedly, our approach is time- and resource-intensive. In instances where rapid assessments may be needed to respond to grant announcements or urgent health crises, this systematic approach may not be feasible. It is worth noting, however, that community-academic partnerships and related capacity for research can be flexible and adapted to respond to diverse health needs.

In reflecting on “what it took” to engage with the ArA community in an authentic way and to apply a participatory approach to integrate community and academic evidence, the study team proposes “THIQAT” (trust, in Arabic), with each letter signifying one fundamental rule of engagement. T is for *Trust*, a prerequisite to all community-engaged research but especially important with ArAs, a marginalized minority group bearing the brunt of anti-immigration and Islamophobic rhetoric. Trust was essential for both building and sustaining the community-academic partnership as well as collecting locally relevant evidence from community members. The latter was especially challenging given the sensitive and stigmatized nature of cancer in the ArA community[46]: community members had to trust the researchers to open up and share authentic reflections on cancer. This process was made possible by the extent to which community members trust community partners who “vouched” for the researchers’ bona fides. H is for *Heed*, which entails listening to community partners and members and valuing their knowledge and expertise. Community partners were deeply engaged in and contributed to the three phases of our study, thus ensuring that our evidence-based decision-making was context-specific and from multiple sources of evidence.[3] I is for *Involve*, or to seek and sustain community participation in all aspects of the research to align project findings and decisions with the local context. Q is for *eQuity*, both promoting it within the partnership dynamics and orienting the partnership towards health equity goals. Our community partners have reported instances of inequitable collaborations with academics, which tainted their view of health research and required academic partners to demonstrate their commitment to equity (e.g., through ad hoc technical assistance, staff trainings, frequent meetings and visits, dissemination of findings). A is for *Action*, or ensuring the partnership is committed to translate evidence into action that can benefit the community. This commitment served to reinforce trust between partners through a demonstrated dedication to serve the ArA community. Lastly, T is for *Transparency*, requiring all partners to acknowledge and clarify their respective priorities, continuously recognize their biases, and resolve disagreements openly. The THIQAT rules of engagement build on the principles of CBPR and demonstrated value of community participation in identifying locally relevant problems, devising locally relevant solutions, and participating as active decision-makers in intervention implementation and evaluation. To claim the promise of THIQAT, researchers must not only engage with communities authentically, but also commit to documenting challenges, successes, and lessons learned of academic-community partnerships in scholarly publications to build the evidence base for community participation in intervention development.

## Limitations

This study has several limitations. First, we used convenience-based sampling to recruit focus group participants from AAFS' client population, and although we did find similarities in cancer beliefs with other ArA studies, we cannot generalize our findings to the broader ArA community in Chicago and beyond. However, our primary purpose was to generate actionable data specific to AAFS' community. Second, we sought the perspective of one community organization and did not have a community advisory board, which may skew our interpretations and action plan to align with AAFS' priorities. Third, our program plan does not include specific and measurable program objectives; however, our purpose in this study was to develop a preliminary program strategy on which to build future work.

## Conclusions

In this study, we presented a case study of a community-academic partnership wherein we employed a participatory approach to integrate community and academic evidence to identify cancer programming priorities for the ArA community in Southwest Chicago. Engaging in community participatory approaches with the ArA community was an iterative process that required a commitment to equitable partnerships and intentional community participation. Leveraging local community knowledge through community assessments and partnership ensured that study findings were locally relevant and actionable

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**Table 1. Application of Community-Based Participatory Research (CBPR) Principles in the Community-Academic partnership**

| CBPR Principle | Application of the CBPR Principle in the Community-Academic Partnership |
|---|---|
| Recognize the community as the unit of identity | The Arab American community in Southwest Chicago is the unit of identity and is engaged as a partner.<br>Cultural norms and beliefs and explored and centered in intervention development. |
| Build upon community strengths and assets | The project goals were shaped by the community partners' deep knowledge of their community.<br>The strategic plan for the intervention emphasizes the community partners are "leaders" of the intervention and leverages community members as patient navigators to ensure the community is part of the solution. |
| Foster equitable partnership in all phases of research | The project goals aligned with the community partners' priorities.<br>Community partners were involved in all decision-making aspects of the research, including ideation, topic selection, reviewing data collection instruments, data interpretation, and integration of community and academic knowledge to create a strategic plan for a cancer intervention. |
| Facilitate co-learning and capacity building for all partners | The community partners contributed their deep knowledge of the local community context while academic partners contributed their research and institutional resources.<br>The strategic plan for the cancer intervention leverages existing assets within community and academic partners. |
| Balance knowledge generation and action | Data collection was geared towards intervention development.<br>The project culminated in a strategic plan for a cancer intervention which addresses barriers/challenges identified through research. |
| Explore locally relevant multilevel determinants of health | Cancer was identified as a community concern through community listening sessions and a community health assessment.<br>Cancer disparities were conceptualized as the result of locally relevant multilevel determinants which were clarified through research. |
| Engage in systems and intervention development through a cyclical and iterative process | Community and academic partners met regularly to agree on project priorities and conduct and jointly make project-related decisions. |
| Disseminate research findings to all partners and engage partners in broader dissemination | Research findings were disseminated to community partners through infographics.<br>Community and academic partners are both co-authors on this manuscript. |
| Plan for sustainability | Partners are committed to seek funding to pilot test the cancer intervention (plans on hold because of COVID-19). |
| Openly address issues of race, ethnicity, racism, and social class, and embody "cultural humility" | Academic partners engaged in reflexivity exercises regularly to ensure their assumptions and biases are surfaced and not interfering with authentic partnership building. |
| Ensure research rigor and validity while broadening research validity | Intervention priorities were shaped by both community and academic knowledge equally. |

**Table 2.** Sociodemographic Characteristics of Focus Group Participants (*n* = 48)

| | |
|---|---|
| Age (years) | |
| <40 | 17 (35%) |
| 40+ | 31 (65%) |
| Gender | |
| Male | 17 (37%) |
| Female | 29 (63%) |
| Marital status | |
| Married | 33 (69%) |
| Not married | 15 (31%) |
| Educational attainment | |
| High School or less | 33 (69%) |
| Some college or more | 15 (31%) |
| Household income | |
| <$30,000 | 31 (78%) |
| $30,000 or more | 9 (22%) |

**Table 3.** Emergent Themes and Illustrative Quotes of Cancer Beliefs by Cancer Control Stage and Levels of the Cancer Disparities Multilevel Model

| Cancer control stage | Cancer beliefs | Multilevel determinants of cancer beliefs |
|---|---|---|
| **Cancer etiology and prevention** | ***Diet is a protective factor***<br>“Americans’ food consists of hamburger and McDonalds because the woman and man work, and their only choice left is McDonalds. They don’t have the choice of eating except from outside. This is why they have the highest rate of people with cancer. Look at Arabs, they are the last people to have cancer.” – Man, Focus Group #1<br>“Is there anything that a person can do to prevent cancer? A good diet.” – Woman, Focus Group #6 | Individual knowledge and misconceptions |
| | ***Smoking and stress are risk factors***<br>“But the main reason I believe that cancer is spread in the younger population is because they smoke and drink.” – Man, Focus Group #7<br>“Maybe bad habits. Like smoking. My grandpa was a smoker and the consequences started later in his life, towards the end. He got lung cancer and he died because of smoking. So maybe your aunt had a bad habit in regard to her stomach and same with the leukemia.” – Woman, Focus Group #6<br>“I think that the main thing that causes cancer is too much stress and pressure. There are rich people that, as the saying goes, "eat with a golden spoon" and who are provided with the best quality foods and still get cancer. Personally, I hear that the people who always took care of themselves the most are the ones that get cancer.” – Woman, Focus Group #8 | Individual knowledge and misconceptions<br>Social networks’ lived experiences |
| | ***Unavoidable environmental factors can cause cancer***<br>“The food is not healthy. Most of what people eat comes out of a can. The preservatives found in it is very bad for the body. So, there is a lot of people reuse store containers when they were supposed to throw them away.” – Woman, Focus Group #6<br>“There is also an additional point to add. Arabs have been exposed to a lot of bombings.” – Woman, Focus Group #8<br>“[There are more cancers] because of the technological advances. The ozone layer that God put for us to protect us is being destroyed and we get nuclear waves without knowing.” – Man, Focus Group #7 | Individual knowledge and misconceptions<br>Structural factors (environment and mistrust of US institutions) |
| | ***Cancer is unavoidable or predetermined by God’s will***<br>“I don't think it matters much what type of lifestyle you lead. Because my aunt never smoked yet she got cancer.” – Woman, Focus Group #6<br>“Maybe in the end it's just from God. Of course, it is, but there's also a cause. Bad lifestyle choices.” – Woman, Focus Group #6<br>“[Cancer] is something you can't really prevent. We have a saying in Palestine: "Anything received by God is beautiful." I want to tell you about my experience even though it's a bit private. I was surprised when I went to the doctor for a check-up and he tells me that I might have cancer. The reasons for cancer are unknown. Why was cancer not around in the past?” – Man, Focus Group #7<br>“My dad had cancer. but I don’t know how he got it because he was a healthy person. Always ate right and exercised and was mentally healthy, no stress.” – Woman, Focus Group #8 | Cultural norms (e.g., fatalism)<br>Social networks’ lived experiences |
| **Cancer detection and diagnosis** | ***Knowledge misconceptions about cancer screening***<br>“They used to tell me to go do the mammogram test. I used to tell them that I don’t have a problem so why should I go? Praise God, we don’t have anyone in the family [who has cancer], and I don’t have any symptoms that show me that I might have something.” – Woman, Focus Group #5<br>“Cancer, specifically, can’t be discovered by a regular check-up. You know that if you want to test it, you’ll need a biopsy from that certain place. Am I right or not? […] Nobody goes to the doctor and tells him that I want you to check up for cancer in all my body. There is nothing like that unless you complain about things and you tell them to check it. Then, they will do tests and they will follow on that step by step and in the last stage, they will find the cancer.”– Man, Focus Group #1 | Individual knowledge and misconceptions |
| | ***Fear of cancer diagnosis as a barrier to cancer screening***<br>“I have a problem of fear. Because they discovered that I have a problem in my breast in an early stage. The doctor told me that we have to do screening for the colon after 40. So, she [the doctor] told me, “When should I schedule an appointment for you?” I told her not to. She told me, “Why?” I told her, “Because I came to you and had nothing with my breast, and you got me out with something in it. I am afraid that you will dig up things that I don’t want.” – Woman, Focus Group #5 | Cultural norms (e.g., health-seeking behaviors) |

| | | |
|---|---|---|
| | ***Cultural norms as barriers to cancer screening***<br>"I think that the Americans have less cancer than us [Arabs] because they take care of themselves. They exercise and do constant check-ups. Us Arabs have to be close to death to agree to go to the doctor. That's why they have fewer medical problems." – Woman, Focus Group #8<br>"For all of us Arabs, generally nobody goes to the doctor unless they feel like there is something wrong. No Arab goes periodically to the doctor to do tests." – Man, Focus Group #1 | Cultural norms (e.g., health-seeking behaviors) |
| | ***Healthcare factors (insurance, language) are barriers to cancer screening***<br>"Not it's not laziness [preventing Arabs from accessing cancer screening], it's because their English isn't that good. He [hypothetical Arab man] goes to the doctor and doesn't understand a thing. I have a college education and I had checkups done for a couple months and I never understood what the doctor was saying. […] I understood cancer and none of the other things. There's also the headache of insurance and what it covers and what it doesn't, it's exhausting." – Man, Focus Group #7 | Healthcare system<br>Structural factors |
| | ***Healthcare providers recommending cancer screening facilitates uptake***<br>"Yes, of course, the community accepts cancer screenings. My doctor asked if I was over 40, and then he said that I needed to do cancer screenings. And he did that every year. Yes, they keep reminding you of it." – Woman, Focus Group #6<br>"A good doctor would do all the tests every 3 months to be sure." – Man, Focus Group #7 | Healthcare system |
| **Cancer treatment and survivorship** | ***Cancer treatment is equated with its severe side effects***<br>"We hear of it [cancer] but not a lot. My sister-in-law had her breast removed. We hear of it the same as any other disease." – Woman, Focus Group #6<br>"Some people have their hair fall out because of the chemotherapy. When they stop treatment, it grows back. I know of a teacher who had all her hair fall out, she showed me. And after 2 months she passed away." – Woman, Focus Group #6<br>"Cancer you have 3 or 4 years then you're gone. You get chemical substances, you get it to your head. You will lose your hair and your eyelashes he is treated by the chemicals. Even if he denied, you can see it in his pictures." – Man, Focus Group #1 | Individual knowledge and misconceptions<br>Cultural norms (e.g., fatalism)<br>Social networks' lived experiences |
| | ***Cancer diagnosis is equated with mortality***<br>There are a lot [of cancer cases in the Arab community]. My mom died from cancer, breast cancer. My aunt also died from breast cancer, same thing." – Woman, Focus Group #2<br>"It looks like diabetes is more spread than cancer. But diabetes, we don't feel like it's that serious and I'll tell you why. We see it as something we can live and cope with, but when you hear about someone having cancer you know that they aren't going to live that long. That's why. There isn't a single home that hasn't experienced cancer." – Woman, Focus Group #6<br>"My nephew […] got cancer in the liver. He passed away." – Woman, Focus Group #8 | Individual knowledge and misconceptions<br>Cultural norms (e.g., fatalism)<br>Social networks' lived experiences |

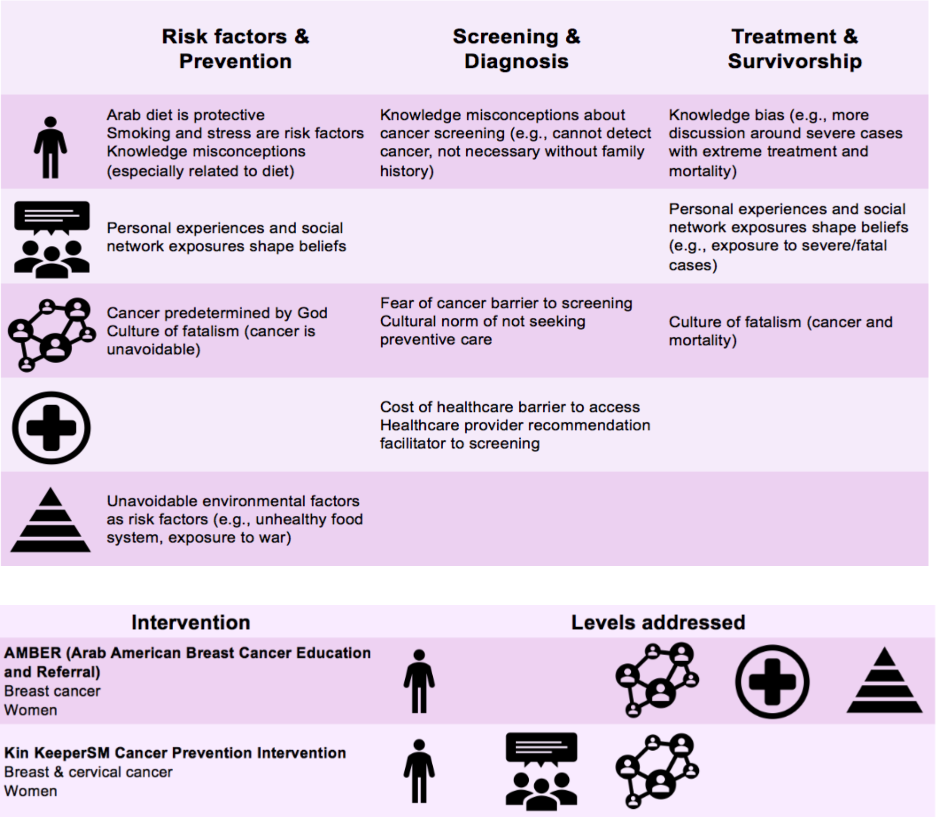
**Table 4.** Inventory of Cancer Programs with Arab Americans Documented in the Literature

| Program name | Cancer site(s) | Cancer control stage(s) | Community engagement strategy | Theoretical/Conceptual framework | Program components | Shared cancer themes addressed |
|---|---|---|---|---|---|---|
| Arab American Breast Cancer Educational and Referral program (AMBER)<br>*New York*<br>**(Ayash, 2011)** | Breast cancer | Etiology<br>Detection/ diagnosis<br>Treatment/ survivorship | Relationships with eleven organizations, mosques and churches<br>Community Advisory Board<br>Implementation at community sites | Community-based participatory research<br>Patient navigation model | Culturally- and linguistically congruent education<br>Cultural competency training to healthcare staff<br>Patient navigation<br>Support group | Knowledge misconceptions about cancer screening through education<br>Fear and cultural barriers to cancer screening through education and patient navigation<br>Addressing healthcare barriers (language, insurance) through patient navigation<br>Addressing structural barriers through patient navigation<br>Cancer equated to mortality address through support groups |
| Kin Keeper$^{SM}$ Cancer Prevention Intervention<br>*Michigan*<br>**(Williams, 2009)** | Breast & cervical cancer | Etiology<br>Detection | Community-academic partnership with Arab-serving community organization | Ecological model (with a focus on the family environment)<br>Community Health Workers model | Culturally- and linguistically congruent education<br>Home-based/family-based education<br>Trained Community Health Workers | Knowledge misconceptions about cancer screening through education |

**Table 5.** Strategic Plan for Community-Based Cancer Program with Program Priorities and Feasibility Factors

| Data source driving action planning | Program component | Program objective | Cancer control stage | Existing capacity/assets | Needs |
|---|---|---|---|---|---|
| Findings on multilevel determinants (Phase 1)<br>Models from cancer programs inventory (Phase 2)<br>AAFS commitment to one stop approach | Comprehensive community-based cancer program | **Overall goal:** Facilitate ArAs' access into, and navigation through the cancer control continuum | Etiology<br>Detection<br>Treatment<br>Survivorship | UIC team's experience with identifying and applying for funding opportunities | Sustainable funding<br>Program staff (e.g., program coordinator who will develop resource inventory and build relationships and support case management) |
| Findings on knowledge gaps (Phase 1) | Develop and deliver accessible educational content in Arabic | Increase knowledge of cancer (e.g., nutrition education) and correct knowledge misconceptions (e.g., screening benefits) | Etiology<br>Prevention<br>Detection<br>Treatment<br>Survivorship | UIC team's experience with health promotion and educational content development<br>Office space for workshops | Funding to print materials |
| Findings on prevailing cultural norms and harmful cancer beliefs (Phase 1)<br>Models from cancer programs inventory (Phase 2)<br>AAFS experience with the community | Cultural tailoring of content | Address cultural barriers to cancer control (e.g., fatalism, lack of access to preventive care) | Etiology<br>Detection<br>Treatment<br>Survivorship | AAFS leadership and staff experience with the community and knowledge of cultural context<br>UIC team's health promotion and content development experience | Participation of ArA cancer survivors<br>Expertise of ArA healthcare providers |
| | Trained community health worker as patient navigators | Address cultural barriers (e.g., fatalism, lack of access to preventive care)<br>Address mistrust in healthcare/institutions by making community a part of the solution<br>Overcome language barriers in healthcare | Etiology<br>Detection<br>Treatment<br>Survivorship | AAFS staff<br>AAFS domestic violence clients who need employment<br>AAFS relationships with the community at large | UIC team's training experience<br>Community volunteers for pilot testing |
| | Cancer support group | Overcome cancer stigma and isolation of cancer patients | Treatment<br>Survivorship | AAFS's office space<br>AAFS's relationships with ArA cancer survivors<br>AAFS's relationships with ArA providers | Arabic-speaking group facilitator<br>Buy-in/participation from ArA cancer survivors |
| Findings on access to healthcare and mistrust of institutions (Phase 1)<br>Models from health intervention inventory (Phase 2) | Linkages to free/affordable care (cancer detection, diagnosis, and treatment) | Address logistical barriers to care (e.g., insurance, cost) | Detection<br>Treatment<br>Survivorship | Community trust in AAFS<br>New partnership with large healthcare organization (details kept confidential because | Leverage ArA healthcare providers' expertise<br>Partnerships/MOUs with healthcare organizations (e.g., community clinics, hospitals) |

| | | | | | |
|---|---|---|---|---|---|
| AAFS commitment to one stop shop approach | | | | agreement is being finalized) | |
| Models from cancer programs inventory (Phase 2)<br>AAFS knowledge of their community's socioeconomic challenges | Referrals to supportive resources across the cancer control continuum | Provide continued support from screening to survivorship | Detection<br>Treatment<br>Survivorship | Existing relationships with foundations | Catalogue resources across the cancer control continuum<br>Partnerships with local and national assistance programs |



| | Risk factors & Prevention | Screening & Diagnosis | Treatment & Survivorship |
|---|---|---|---|
| 🧍 | Arab diet is protective<br>Smoking and stress are risk factors<br>Knowledge misconceptions (especially related to diet) | Knowledge misconceptions about cancer screening (e.g., cannot detect cancer, not necessary without family history) | Knowledge bias (e.g., more discussion around severe cases with extreme treatment and mortality) |
| 💬 | Personal experiences and social network exposures shape beliefs | | Personal experiences and social network exposures shape beliefs (e.g., exposure to severe/fatal cases) |
| 🕸 | Cancer predetermined by God<br>Culture of fatalism (cancer is unavoidable) | Fear of cancer barrier to screening<br>Cultural norm of not seeking preventive care | Culture of fatalism (cancer and mortality) |
| ⊕ | | Cost of healthcare barrier to access<br>Healthcare provider recommendation facilitator to screening | |
| ▲ | Unavoidable environmental factors as risk factors (e.g., unhealthy food system, exposure to war) | | |

| Intervention | Levels addressed | | | | |
|---|---|---|---|---|---|
| **AMBER (Arab American Breast Cancer Education and Referral)**<br>Breast cancer<br>Women | 🧍 | | 🕸 | ⊕ | ▲ |
| **Kin KeeperSM Cancer Prevention Intervention**<br>Breast & cervical cancer<br>Women | 🧍 | 💬 | 🕸 | | |

**Appendix:** Example of infographics disseminated to community partners ahead of Phase 3 discussions