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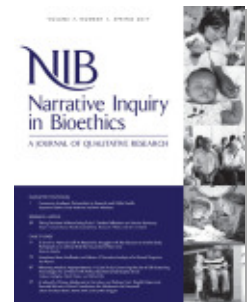
## Reflections on Cultivating Community-based Participatory Research Partnerships with the Afghan Immigrant Community

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Some collaborations showed to be stronger and longer-term than others. I also learned how structural and institutional impediments can continue to negatively affect Hispanic immigrant health, even when all the ‘right’ local partners are aligned. We cannot change the exorbitant cost of health care or somebody’s documentation status, for instance.

Our study interventions emphasized the importance of communicating with and across participants, volunteers, providers, organizational representatives, and research team members. This is time-consuming but helps clarify roles and responsibilities, which ultimately can help the quality of the partnerships and the outcomes. Providing comprehensive health and social service coverage for all Hispanic immigrants is challenging, though information about services available, how to navigate systems (health care, education, e.g.), and a healthy lifestyle can make positive impacts in the health and wellbeing of underserved Hispanic immigrants.

I feel privileged to have had the opportunity to work with an outstanding team and a wide variety of community partners, and to continue to be involved with MAPPR as part of their CAB. Being part of all steps of the research process taught me the strengths and complexities of CBPR, and shaped me as a community-engaged scholar. It provided a foundation for new community–academic partnerships in my dissertation, postdoctoral fellowship and beyond. I hope other graduate students are provided similar hands-on training and mentorship.

**Acknowledgements.** I would like to thank the community members that participated as part of the research, the MAPPR team, members of the Community Advisory Board and all other community partners.

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## Reflections on Cultivating Community-based Participatory Research Partnerships with the Afghan Immigrant Community

Mehra Shirazi

### Background

Using a community-based participatory research (CBPR) approach, we describe the process of a first-time campus–community partnership between UC Berkeley School of Public Health and the Afghan Coalition in California.

**Objectives:** We reflect on lessons learned in cultivating a unique community health partnership to provide a preliminary understanding of how Afghan immigrant women view their breast health, and to determine and assess their barriers to breast cancer screening. This story will emphasize the importance and challenges of (1) negotiating equitable collaborative relationships, (2) recruitment and retention of participants by community members and ways to overcome cultural and language barriers, (3) training of community members, and (4) data dissemination.

### Conclusion

Conducting meaningful community partnerships should be driven by a social justice agenda where community has control over the production of knowledge and engaged in all phases of research. There is also a need for transparency and mutual agreement around roles and responsibilities where researchers take on facilitative roles and do not attempt to control the research process.

These are the reflections of the first community/campus partnership between the Afghan Coalition of Alameda County, CA and the UC Berkeley School of Public Health in an effort to provide a preliminary understanding of how Afghan women view their breast health. This was done through in-depth semi-structured interviews conducted with non-English speaking first-generation immigrant Afghan women above the age of 40. This narrative aims to describe the experience of engaging in community–academic partnerships that brought forth essential information pertaining to the breast health

screening practices of Afghan women which then led to a five-year breast health education intervention program funded by the National Institute of Health.

*My mother, my sister, my aunt, my daughter . . .*

In telling their stories, the women were speaking about their struggles, their pain and resilience. They painted an accurate picture of breast cancer in their communities, which remained a subject considered taboo in Afghan culture. It was clear this was more than a “make sure everyone gets a pamphlet” intervention. No intervention was going to work unless it was a part of the community itself; not for them or about them or even from them. In a refugee community struggling against the label of terrorist as the United States entered its second decade of war in Afghanistan, information and access to preventative healthcare, including breast cancer screening, was minimal. And the stories kept coming.

*My niece, my daughter-in-law . . .*

Working with the Afghan community of Alameda County, CA, the largest Afghan refugee population in the United States, two-thirds of whom are female, meant we were approaching a long-established community with its own politics, social and cultural norms, and community leaders. It can be easy, and expedient, to paint broad circles in the name of increased access, but it was clear that previous research on immigrant Muslim women and breast cancer hadn't addressed the scope of what we were facing. The women here were less literate, unaware of screening recommendations, and hampered by their immigrant status, cultural valuation of female modesty, and a necessary wariness of any dealings with officialdom in the age of the “War on Terror” wherein the community was consistently approached for informants.

*My mother-in-law, my cousin, my wife . . .*

Establishing any partnership is part act of faith and part extended learning curve, but the development of a true partnership across culture, language, religion, and deep societal mistrust required more

than good intentions. The high rates of breast cancer anecdotally reported in the population, as well as the lack of access to care still faced by an established community (mean residence in the US was 16 years) pointed to the need for a culturally based intervention program to establish and address attitudes toward breast cancer screening among a population with limited English language usage, high rates of illiteracy in any language, cultural concerns around female modesty, and limited access to healthcare providers. Two groups, from the UC Berkeley School of Public Health and the community via the non-profit Afghan Coalition came together for a pilot study and the goal of developing a sustainable community based intervention project.

A Community Advisory Board (CAB) was established to develop research questions, partner in the data collection, and development of future intervention programs. The CAB) was representative of the Afghan community and consisted of local community leaders, elders, nurses, teachers, breast cancer survivors, and community health advisors invited by the Afghan Coalition. Transparency, roles, budget, and procedures were all collectively agreed upon and written into the grant proposal to avoid conflict or confusion at a later date. While this process was lengthy, particularly in the eyes of the University partners who were not fully enmeshed in the community politics and behind the scenes negotiations necessary, it did ensure community buy in.

*The importance of tea in Afghan culture cannot be overstated. If this project was going to go anywhere it would go there on the strength of the tea.*

They come in. Suddenly, all your academic notions of cultural relevancy and community participatory research become very real. Our partnership made our plans for a project design that would foster a warm and inclusive atmosphere possible. The multi-lingual interviewers, the careful recruitment of a broad cross section of the community, the careful attention to religious and cultural norms, remembering to provide childcare; it all begins to fade into the narrative of women's stories. Our community partnership model helped contextualize our research within the historical and political

context of women’s lives—as refugees, as woman headed households, as trauma survivors, and as members of an incredibly close–knit tribal culture that has rebuilt a community as outsiders. Our community researchers were trained to conduct interviews both to overcome literacy issues and to make this project a truly shared experience. There was extensive follow up built into the project design to maximize retention. We wanted our partnership to have time to build on the conversations started over tea because that trust was the foundation for community–based intervention. Academic timetables being what they are the pace could feel particularly laborious at times, but the room built into our project, and funding, for talk was an essential part of its success.

And it was the stories that stuck. Women were interviewed one–on–on in one of several possible languages. As the tea flowed so did the stories. Some were unsurprising—trouble with transportation and a lack of interpreters—and others were more nuanced. By centering religion (the community 99.9% identifies as Muslim), we opened the doors to deep discussions of philosophy and identity, their community, and their role in Afghan life. These women viewed their bodies as divine gifts and felt a deep responsibility to care for them and do everything they can to be healthy and beat disease—a contrast to a more fatalist attitude we often expect to find in deeply religious communities in the West. Additionally, particularly as the US presents such a negative view of gender relations in Muslim societies, it was essential that we understand that our partners viewed their health as essential for the survival of the family and, by extension, the community. From this we began to build our intervention strategies.

*“Islam doesn’t say we can’t go to a man doctor but I am Afghan and my culture says it’s not right”*

One of the most powerful things to come out of our partnership was the development of intervention programming for men. Afghan culture is so often portrayed as profoundly segregated, and it initially seems counter–intuitive that in an attempt to empower women in their healthcare interactions

we needed to focus on men as well. However, the community’s men serve as guardians, gatekeepers, and links to the outside world; ninety percent of the women interviewed indicated that they were reliant on a male relative for transportation, coordination of appointments, and, more tellingly, as decision makers for women’s health screening decisions. Our partnership was with the community, not only the women, and a variety of outreach programs to men—primarily focusing on general health and the link between women’s health and the health of the community—were initiated. Without full partnership and the use of community–based participatory research this essential aspect of an effective intervention program could have been missed.

*“. . . to listen to a woman and to let her tell you what is bothering her. To not just ignore her and make her feel small”; “. . . to be gentle, and caring’ and ‘Talk to her, explain everything . . .”*

There are, of course, challenges to any partnership. When working cross culturally they serve to highlight the vastly different ways in which communities and cultures approach problems and make decisions. This project, by definition had to have a level of flexibility, which can be difficult when working with academic publishing timelines and grant reporting. We found the project to be a long–term process requiring patience and flexibility. Additionally we had to address clarity, even when speaking the same language, in a project operating with a minimum of three languages (English, Farsi, and Dari). As the academic partners it was essential that we move slowly and build trust in a community with a level of paranoia when faced with ‘official’ sources, both from their experiences in Afghanistan and the ongoing exploitation of the community by US agents looking for informants. As outsiders we were also working in a community with several waves of immigration experiences and complex social and cultural hierarchies of which we knew little. In this case face–to–face interactions through culturally meaningful ways such as ‘tea parties’ proved to create a welcoming and warm environment that paved the way for sustainable trusting relationships.

The development of Afghan Women's Breast Health Program required extensive negotiation, flexibility, and constantly open communication, and from it grew a trusting relationship that allowed us all to address a serious concern from a sustainable place; and was an education in the development of long-term, effective programming on both sides of the partnership. Several of our early participants have been hired as health facilitators, and programming continues to focus on a holistic model of individual and community health. The community partners knew that this was their program that was benefitting their community, and that ownership was a powerful motivator.

**Acknowledgements.** This narrative is intended as a composite of the work done by our partnership, particularly Rona Popal executive director of the Afghan Coalition, Joan Bloom of UC Berkeley Public Health, Aida Shirazi of UC Berkeley, and the women of the Afghan community who shared their stories with us.

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### **Be Careful What You Wish for: A Community–Academic Student Partnership Story**

Trina C. Salm Ward, Mary C. Mazul,  
Martha L. Barry, and Amy E. Harley

#### **Background**

Milwaukee, Wisconsin is a unique Midwestern city. Situated on the western shore of Lake Michigan and the southeast corner of the state, it is Wisconsin's largest city. Milwaukee has a reputation for a diverse culture, cuisine, music, higher

education, and an incredible park system. These attributes make it a desirable city for over a half a million people in the Midwest. However, while steeped in rich history and culture, the city has some significant issues. While many urban cities in the United States suffer with racial tension and disparities, Milwaukee is considered one of the most segregated US cities and unfortunately has the largest racial disparities in some major health outcomes. One of the most significant disparities is in our infant mortality rate with African American babies dying at a rate nearly three times that of White babies.

In the fall of 2009, two doctoral students, Salm Ward and Mazul, enrolled in a newly formed public health course entitled Social and Environmental Justice in Public Health at the University of Wisconsin–Milwaukee taught by a public health professor, Dr. Harley. One student, a Master-prepared social worker and the other a Certified Nurse Midwife, joined together to complete a project assignment. The project consisted of designing a research proposal and presenting it to a community partner for feedback. The aim of this project was to provide students with the experience of engaging community partners in research. At the time, both students were involved in the Milwaukee Fetal/Infant Mortality Review (FIMR) committee and were vested in improving birth outcomes for African American babies. The FIMR data indicated that a much larger percentage of African American mothers received less than adequate prenatal care. The students were interested in understanding African American women's perceptions of prenatal care, including perceptions of racial discrimination, with the long-term goal of informing prenatal care providers.

The students created a proposal to undertake a qualitative study that would investigate the prenatal care experiences of low-income African-American women in Milwaukee with special interest in experiences of discrimination. They chose the YWCA Southeast Wisconsin (the YWCA) because of its mission to eliminate racism and the services the agency provided in the community with African American families and childbearing women,