



Department of Family Medicine
and Public Health Sciences

Arab/Chaldean Americans' Perspectives on Participating in Research: A MetroNet Study

Victoria Neale,
K Campbell-Voytal, F Dallo, A Hammad,
H Hamade, K Schwartz

Presented at NAAMA July 3, 2019

Introduction

Background: Participation of ethnically diverse populations is important for translating research into practice and extending generalizability.

Study Objective: Identify recommended strategies for recruiting & retaining Arab and Chaldean Americans into research studies.

Study Context

5 practice-based research networks (PBRNs) collaborated to develop recruiting strategies specific to local minority communities.

1. MetroNet: Detroit-area PBRN connected with the local Arab/Chaldean population.
2. New Mexico: Native American Navaho
3. Houston: Hispanic
4. San Francisco: Chinese
5. Dayton Ohio: African American

Methods

Approach to identify best practices for study recruiting:

- 1) Expert Panel (EP) interviews: Professional researchers
- 2) Key Informant (KI) interviews: Experienced recruiting Arab/Chaldean community members
- 3) Focus Groups: Arab and Chaldean community members

Expert Panel (EP) and Key Informant (KI) Interview Questions

- Describe your experience recruiting minority groups into research
- Describe processes that worked well
- Example when adaptation was needed?
- What are your recruiting 'best practices'?
- Recommendations for others?

4 Expert Panel (EP) Interviews

- Expertise in clinical and survey research

Expert Panel	Organization
James Galliher, PhD	American Academy Family Physicians National Research Network (AAFP NRN)
Heidi Guyer, MPH	University of Michigan Survey Research Center
Virginia Rice, PhD, RN	Wayne State University
Cheryl Wiese, MA	Group Health Research Institute (Seattle)

5 Key Informant (KI) Interviews

- Experienced recruiting members of the Arab/Chaldean community

Key Informant (KI)	Organization
Najah Bazy, BS, RN	Zane International (non-profit)
Mickey Eder, PhD	Chicago FQHC Network
Hiam Hamade, RN	Arab Community Center for Economic and Social Services (ACCESS), Dearborn
Linda Jaber, PharmD	Wayne State University
Anahid Kulwicki, PhD, RN	Florida International University,

Focus Group Questions

- What does research mean to you?
- What are your community's attitude toward research?
 - Is it easy to get participation?
- If somebody invites you to participate, what expectations will you have?
- Who are the people who should do research?
 - What is the role of community leaders?
- Recommendations for researchers seeking to recruit from your community

4 Focus Groups

- 2 FGs recruited through ACCESS
 - 1 Muslim men; conducted in Arabic (n=8)
 - 1 Muslim women; conducted in English (n=8)
- 2 FGs recruited through a Chaldean church
 - 1 Chaldean young people (mixed sex) (n=10)
 - 1 Chaldean older people (mixed sex) (n=10)

Focus Group Demographics

		M				
	N	US-born	Year in US	Age	Education (< H.S.)	Research Experience
		% (N)	Mdn (SD)	Mdn (Range)	% (N)	% (N)
Arab	16	13% (2)	10 (6.4)	42 (21-58)	44% (7)	0
Chaldean	20	30% (6)	18 (10.7)	35 (19-84)	50% (10)	20% (4)

Expectations of “Research Study”

- “We’re not taught to go out and do research”
- “Is it going to benefit me, what will come out of it, is what help me decide.”
- “Some people are afraid that research is used in the wrong way (to hurt some people)”
- “Most people are reluctant to speak about their problems and diseases”

Results: Researcher/University Reputation

- “Many universities do not have a good reputation. They need a community-based infrastructure so that patients can participate in community settings.”
- “There’s one other thing that the communities become keen about, as they get more educated; I don’t think they want to be chased down because of grant dollars.”
- “You participate and never hear about it. What’s the benefit? But if you don’t hear about it, I don’t think you will be encouraged to do it again.”
- “Build a relationship based on confidence between the researchers and the Arab community. The goal is not to collect information for a “security archive”. But to have cooperation and development.”

Results: Community Engagement

- "One agency spent \$25,000 on a study brochure, but they did not involve the community. When the community saw the brochure they went crazy. They made the agency destroy it and throw it in the garbage. We have to take time to involve the community in the process of writing the research grant."
- "Integrate with people even if you don't have a research study. Connect in religious holidays, let them know you understand the culture and outreach programs."
- "If it is on the phone, I am going to be honest, I don't like it...If friends are going, it kind of helps you make your decision a lot easier."

Results: Mediating Influences/Gatekeepers

- “It is better to convince the population through churches, mosques, hospitals, schools.”
- “If the doctor says it’s good research, good for your health, because doctors know what they are talking about.”
- “We listen to the religious leaders who can make decisions... and can say this research is OK for the followers of this faith to participate in.”
- “The only thing about going after an influential person is that our community segregates itself into groups”

Discussion

- Unique cultural themes foretell the possibility of competing needs and interests that interfere with or enable research participation.
- Trust was an over-arching theme but was recognized differently by each group. Addressing concerns with trust appears to be an early and recurring obligation across all phases of research

Conclusion

- Cross-cultural communication is enhanced by community-based participatory research (CBPR) strategies that emphasize the importance of establishing trust and using culturally competent teams and tailored practices to engage clinicians and communities.
- Clinical research has not traditionally used principles and strategies identified with a CBPR approach. Although time/resource intensive, these methodologies may improve research engagement and reduce health disparities in the long run.

Funding

This study was funded by the NIH National Center for Minority Health and Health Disparities (RC1 MD004692)

Principal Investigator: A.V. Neale