Community-Engaged Approaches for Equitable Representation in Research

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Community engagement is essential to improve diversity and inclusion in health research

- **Investment**: Community infrastructure, workforce, technologies to support research and for community benefit.

- **Focused**: Efforts focused on trust, anti-racism, transparency, and accountability.

- **Sustained**: Across the continuum and at every level of research.

- **Power**: Shifting power and resources to community priorities.
Goal

• Describe effective community engaged strategies for recruiting and retaining research participants from historically excluded and underrepresented groups.
Research Context

South Asian Healthy Lifestyle Intervention
Randomized Control Trial
549 South Asian Americans, 18-64 years
R01HL132978

South Asians Active Together
Randomized Control Trial
160 South Asian mother-adolescent daughter dyads
R01CA242520

Mediators of Atherosclerosis in South Asians Living In America
Cohort study
2000 South Asian Americans, 40-79 years
R01HL093009, R01MD016071
Barriers to Research Participation at the Intersection of Race, Class, Gender, and Immigration Status

- Racialized minority
- Immigration and legal status
- Language
- Underinsured and uninsured
- Lower income
- Women and girls
Barriers

- **Access**: lack of healthcare access and transportation.

- **Awareness**: language, physicians don’t communicate about opportunities.

- **Racism and discrimination**: less trust, concerns about surveillance, mismatched priorities and power.

- **Gender norms**: caregiving, stigma, and health beliefs.

- **Workforce**: cultural and linguistic competence of research team.
Study population should reflect the heterogeneity of South Asian Americans and include people with less access and higher burden:

- People from diverse backgrounds: country of origin, religion
- Immigrants
- Limited English Proficiency
- Low income
Formal and Informal Engagement Mechanisms with Different Levels of Engagement

Outreach
- *Some Community Involvement*
  - Communication flows from one to the other, to inform
  - Provides community with information.
  - Entities coexist.
  - Outcomes: Optimally, establishes communication channels and channels for outreach.

Consult
- *More Community Involvement*
  - Communication flows to the community and then back, answer seeking
  - Gets information or feedback from the community.
  - Entities share information.
  - Outcomes: Develops connections.

Involve
- *Better Community Involvement*
  - Communication flows both ways, participatory form of communication
  - Involves more participation with community on issues.
  - Entities cooperate with each other.
  - Outcomes: Visibility of partnership established with increased cooperation.

Collaborate
- *Community Involvement*
  - Communication flow is bidirectional
  - Forms partnerships with community on each aspect of project from development to solution.
  - Entities form bidirectional communication channels.
  - Outcomes: Partnership building, trust building.

Shared Leadership
- *Strong Bidirectional Relationship*
  - Final decision making is at community level.
  - Entities have formed strong partnership structures.
  - Outcomes: Broader health outcomes affecting broader community. Strong bidirectional trust built.

Reference: Modified by the authors from the International Association for Public Participation.
Inclusion of Community and Clinical Co-investigators on Study Team

- Community Organizations
- Public Health Department
- Health System
- Park District
- School District

“Collaboration to reduce cardiovascular health disparities in South Asians Americans through research, education, and advocacy.”
Range of organizations that serve South Asian across Chicago-metro area

• Urban and suburban concentration of populations.

• Community and clinical partners provide space for study visits and equipment.

• Hybrid study procedures: remote and in-person components.
Structure of the Study Team

- Academic and community experiences.
- Cultural and linguistic competence.
- 2 Community health specialists: embedded at community sites, trusted relationships and networks.
- Trained in research, recruitment, retention and intervention delivery.
- Training for the whole team: communication, respect, transparency, equity.
Community Advisory Board

• Input on recruitment materials and procedures.
• Connecting team to new recruitment venues and events.
• Advising on challenges.
• Disseminating recruitment fliers and social media messages.
• Sharing knowledge about engagement and advocacy.
• Interpreting and disseminating research results.
• Participating in manuscripts and presentations.

Community Advisory Board Meet and Greet, Fall 2021
Research 101: *What should you know about research?*

- Developed by the Community Advisory Board.
- Goal: Increase awareness and understanding about health research and *why participation matters*.
- Uses plain language and everyday life examples.
- Available for CAB members and study team to deliver in community settings.
- Presented by CAB co-chair at 2022 American Public Health Association.
Stakeholder Academic Stakeholder-Academic Resource Panels (ShARPs)

- Custom panels that bring together 8-10 community stakeholders with professional and/or personal expertise related to a research project.

- Feedback on adaptations that can improve research relevance, feasibility, and/or dissemination opportunities.

- Input on sensitive study measurements and questionnaires.

- Strategies for overcoming recruitment barriers for specific subpopulations.

- Marketing and social media messages.
Community Presentations and Tabling

• Health talks based on community needs and interests.

• Discussion groups.

• “Rethink your Drink” and Food Models.

• Distribute recruitment materials.

Talk at Palatine, IL Gurudwara 2019
Health system and clinician outreach

• Clinician facing pamphlets.

• Patient portals and mailings with physician endorsement.

• Brief presentations at clinician meetings by study PI and co-I.

• Funding for electronic health record queries and staff from health system to conduct patient outreach.
Translated Study Materials

• All participant facing materials are in most commonly spoken South Asian languages.

• English, Hindi, Urdu, Gujarati
Ethnic Media Relationships

What Is Masala Doing For Your Heart?

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nahida Perveen - a Pakistani mother who immigrated to the US 15 years earlier - was only 25 years old when she began to suffer from debilitating headaches. She was diagnosed with high blood pressure and high cholesterol and was prescribed blood pressure medication. When the pandemic hit, Mrs. Perveen contracted COVID-19 and passed away at the age of 60 due to heart failure. She is remembered by her five children.

Sadly, Mrs. Perveen is one of many individuals from the Pakistani American community who experience complications from heart disease in their prime adult years. People from South Asia (Bangladesh, India, Maldives, Nepal, Pakistan and Sri Lanka) comprise almost two-thirds of the world's patients suffering from heart disease. Though the impact of heart disease is high, there's lack of research that investigates heart issues in South Asian communities. Now, the National Institutes of Health has funded the MEDIATORS of Atherosclerosis in South Asians Living in America (MASALA) Study to add more participants of Pakistani background.

The MASALA Study began in 2010 and is now trying to understand differences in heart health between the three largest South Asian subgroups in the US: Pakistani, Bangladeshis, and Indians. When Aibha Usman, 56, was approached about joining the MASALA study, she readily agreed. She wanted to check her heart health and learn more about how she could prevent heart attacks through her diet and physical activity. She recalled that it was "a great experience," and she was able to get screening tests done through the study and learn more about her health.

Dr. Namratha Kanthula, MD, M Phil, a Professor of Medicine at Northwestern University, leads the study and encourages members of the community to participate in research. "The Pakistani, Bangladeshi, and Indian communities are often not represented in health studies, which can make it difficult to know the best prevention and treatment options for our communities," she said. It's crucial that Pakistani individuals participate in research to help current and future generations live healthier lives. Take Hameed Siddiqui, 79, for example. Growing up in Pakistan, Hameed was involved in sports and worried little about his health. As he grew older, he saw
diabetes at a younger age compared to many other ethnic groups. Due to their immigration status, culture and gender, SA women are at particularly high risk for these health conditions (SAATHstudy.org).

South Asians Active Together

The South Asian community has a higher risk of Diabetes and High Blood Pressure compared to Whites and other Asian American groups.

The good news is that heart disease and diabetes is preventable!
Retention

• Consider every element of the project from the perspective of a participant.

• Relationships and recognition

• Burden and benefit

• Ongoing communication

Retention postcard for follow-up visit in the SAHELI trial
Participant Perspectives about Research Participation

“Informed and healthy”
“Visible”
“More Awareness”
“Feel healthy and confident”
“Makes me feel safe...like I am in good hands”
“I feel the impact in our community”
“Fun as well as informative”
“Developed such a great friendship”
“Staff was really nice. They were mindful of my time and were flexible about it.”

MASALA cohort study community event, 2019
Gaps in Current Efforts and Knowledge to Diversify Clinical Research

• Sustained commitment and financial investments in community infrastructure to participate in research and community development.

• Comparative studies of different community engagement strategies to assess success.

• Impact of digital, decentralized health research on diversity and inclusion of excluded and underrepresented groups.

• Progress towards community led research.