


# Community-Engaged Approaches for Equitable Representation in Research

Namratha Kandula, MD, MPH  
Professor, Medicine and Preventive Medicine  
Northwestern University, Feinberg School of Medicine  
@NammiKan

NIH Workshop on Inclusive Participation in Clinical Research

# Disclosures

Namratha Kandula

I have no relevant financial relationships to disclose.

I receive funding from the National Institutes of Health.

# 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

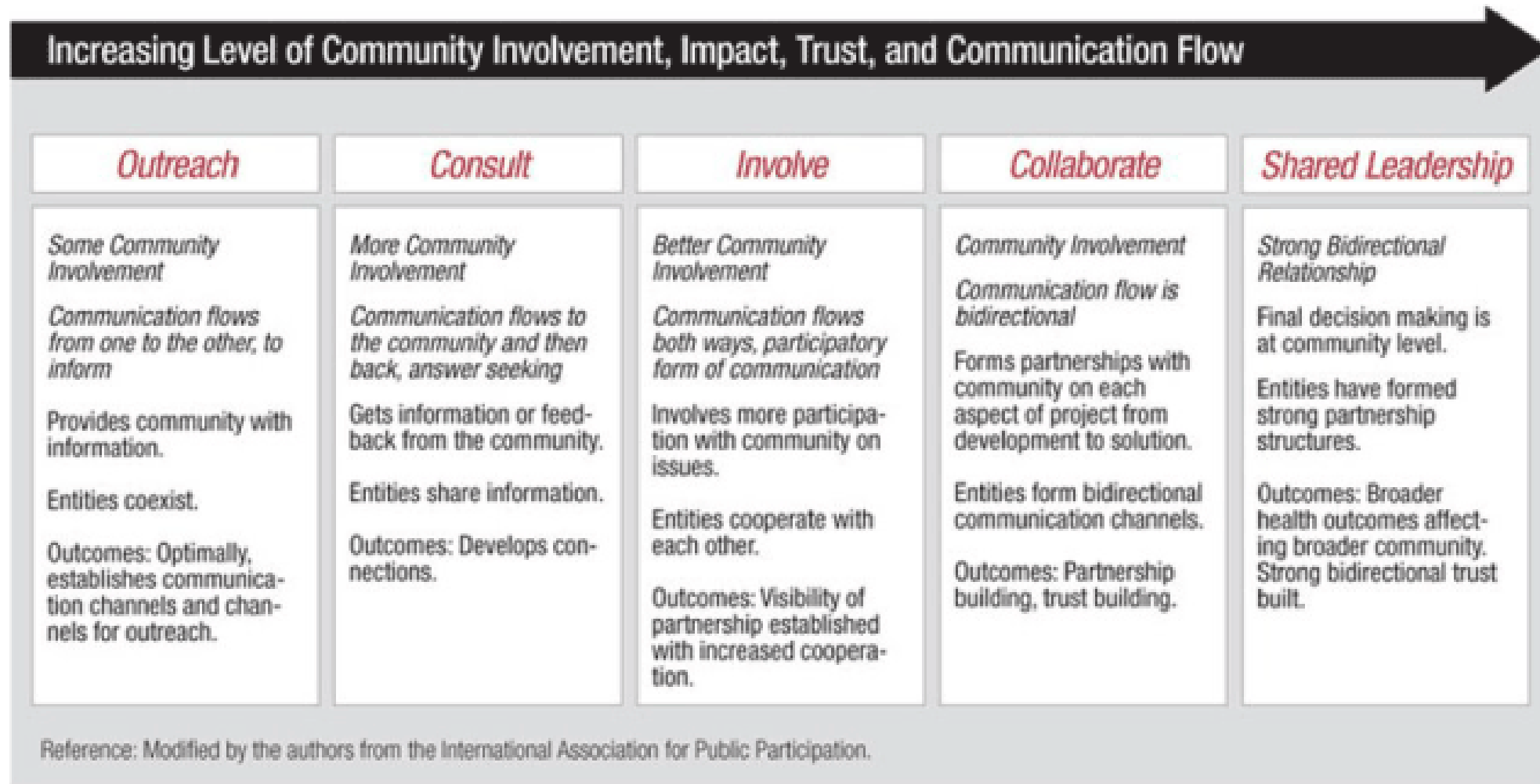
- **Access:** lack of healthcare access and transportation.
- **Awareness:** language, physicians don't communicate about opportunities.
- **Racism and discrimination:** less trust, concerns about surveillance, mismatched priorities and power.
- **Gender norms:** caregiving, stigma, and health beliefs.
- **Workforce:** cultural and linguistic competence of research team.

Study population should reflect 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



# Inclusion of Community and Clinical Co-investigators on Study Team

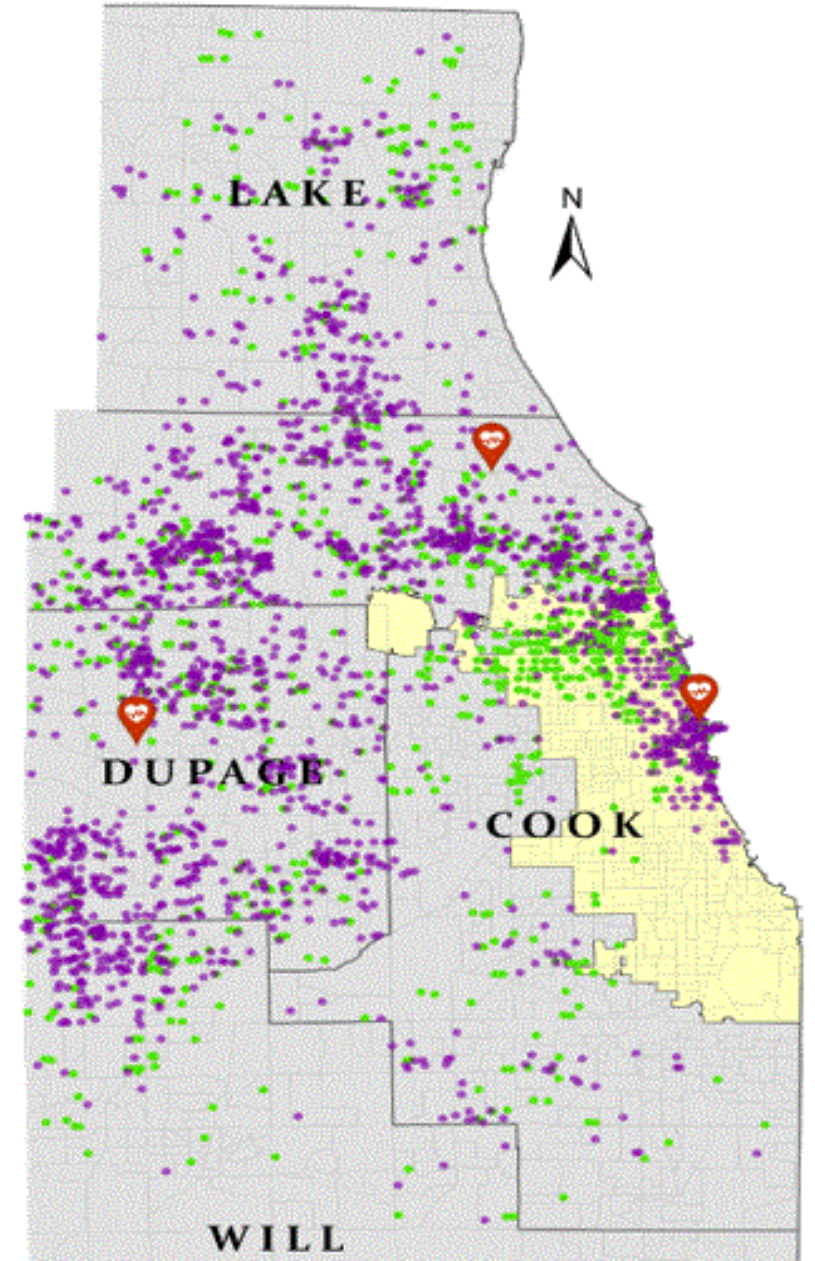
- Community Organizations
- Public Health Department
- Health System
- Park District
- School District



***“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.



Study Team, Summer 2022



# 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.

## Statistics

2x

South Asians 2x more likely to die of heart disease

23

MASALA research shows a BMI of 23 is overweight for South Asians

10 years

South Asians develop risk factors and coronary heart disease 10 years earlier than other groups

## WANT TO DO MORE?

Patients may be eligible to join our study if they are between the ages of 18-65 with two or more risk factors for heart disease.

These include: Hypertension, high cholesterol, pre-diabetes or diabetes, and overweight/obese.

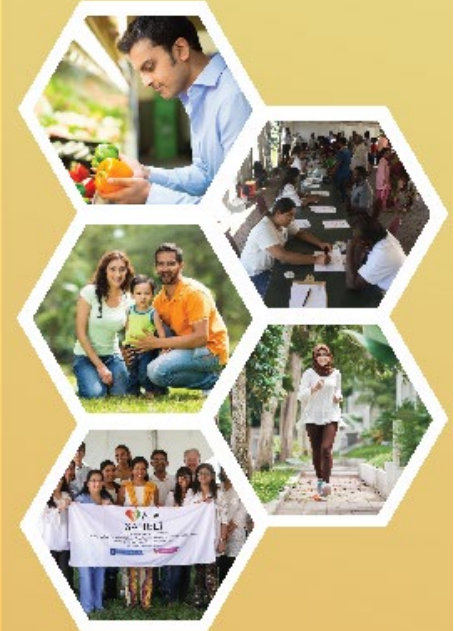
## CONTACT

Visit us at [sahellstudy.org](http://sahellstudy.org) or [masalastudy.org](http://masalastudy.org)

OR

Send us an email at [sahellstudy2@gmail.com](mailto:sahellstudy2@gmail.com)

We're on Instagram, Twitter, and Facebook!



## Understanding South Asian Heart Risk

*How you can make a difference*



# Translated Study Materials

- All participant facing materials are in most commonly spoken South Asian languages.
- English, Hindi, Urdu, Gujarati

**Northwestern University**



Study Title: A Multilevel Physical Activity Intervention for South Asian Women and Girls  
Northwestern University IRB# STU00211374  
Principal Investigator: Namratha Kandula MD, MPH



## દક્ષિણ એશિયનો એકસાથે સક્રિય

ગોરાઓ અને અન્ય એશિયન અમેરિકન જૂથોની સરખામણીમાં દક્ષિણ એશિયન સમુદાયમાં ડાયાબિટીસ અને હાઈ બ્લડ પ્રેશરનું જોખમ વધારે છે.  
સારા સમાચાર એ છે કે હૃદય રોગ અને ડાયાબિટીસ અટકાવી શકાય છે!

**સાથ શું છે?**

સાઉથ એશિયન્સ એક્ટિવ ટુગેથર (SAATH) એ 12 મહિનાનો સંશોધન અભ્યાસ છે જે સાંસ્કૃતિક રીતે યોગ્ય કાર્યક્રમ દ્વારા, સમુદાયો સાથે ભાગીદારીમાં, દક્ષિણ એશિયન મહિલાઓ અને છોકરીઓના સ્વાસ્થ્યને સુધારવા માટે સમર્પિત છે

**શું તમે છો...**

- શું તમે કામ પર અને/અથવા ખાલી સમય દરમિયાન નિષ્ક્રિય જીવનશૈલી જીવો છો?
- શું તમે 11-16 વર્ષની દીકરીની માતા છો?
- ભારતીય, પાકિસ્તાની, બાંગ્લાદેશી, શ્રીલંકન કે નેપાળી પૃષ્ઠભૂમિના?
- હાલમાં શિકાગો અથવા ઉપનગરોમાં રહો છો?

**આ અભ્યાસમાં રહેવાથી તમને કેવી રીતે ફાયદો થશે?**

સમૂહ વ્યાયામ વર્ગો

\$ 320 મેળવવાની તક

નવા મિત્રો બનાવો!

કોઈપણ કિંમત વગર આરોગ્ય તપાસ

સાથે ભાગીદારીમાં:

વધુ માહિતી માટે, કૃપા કરીને સંપર્ક કરો

[saathstudy@northwestern.edu](mailto:saathstudy@northwestern.edu)  
312-767-8747



QR Code:





# Ethnic Media Relationships

## THE MASALA STUDY

### مسالہ آپ کے دل کے لئے کیا کر رہا ہے؟

آپ کو کتنا معلوم ہے کہ آپ کی دل کی صحت آپ کی غذا، ورزش، اور دیگر عوامل پر منحصر ہے؟

**MASALA کیا ہے؟**

MASALA پہلی طویل دورانیے کی ریسرچ اسٹڈی ہے جس میں ایسے عوامل کی نشاندہی کی گئی ہے جو ساؤتھ ایشین لوگوں میں دل کی بیماری کا باعث بنتے ہیں۔ ساؤتھ ایشیاء سے تعلق رکھنے والے تمام لوگوں میں پاکستانیوں میں ذیابیطس، موٹاپے اور پانی گولیستول کی شرح سب سے زیادہ دکھائی دیتی ہے۔

**کون شامل ہو سکتا ہے؟**

- ایک پاکستانی شخص ہے۔
- انگریزی یا اردو بول اور پڑھ سکتے ہیں۔
- 40-84 کی عمر۔
- دل کے دورے یا فالج کی کوئی تاریخ نہیں ہے۔
- شکاگو یا اس پاس کے مضافات میں رہتا ہے۔

**مجھے کیسے فائدہ ہوگا؟**

- مفت کلینک کا دورہ اور لیب کے نتائج آپ کے ساتھ شیئر کیے جائے ہیں۔
- مفت لنچ کے ساتھ آپ کے وقت کے لیے \$100 گفٹ کارڈ۔
- ہسپتال کی پارکنگ کی توثیق کی جائے گی اور ادائیگی کی جائے گی۔
- اپنے دل کی صحت کے بارے میں جاننے کا موقع۔

[masalastudy@northwestern.edu](mailto:masalastudy@northwestern.edu)  
 (773) 548-2123  
[WWW.MASALASTUDY.ORG](http://WWW.MASALASTUDY.ORG)

Study Title: MASALA Exam II - Expansion  
 Northwestern University IRB # ST0002546  
 Principal Investigator: Namratha Kandula

ایک پاکستانی شخص ہے۔

انگریزی یا اردو بول اور پڑھ سکتے ہیں۔

40-84 کی عمر۔

دل کے دورے یا فالج کی کوئی تاریخ نہیں ہے۔

شکاگو یا اس پاس کے مضافات میں رہتا ہے۔

مجھے کیسے فائدہ ہوگا؟

مفت کلینک کا دورہ اور لیب کے نتائج آپ کے ساتھ شیئر کیے جائے ہیں۔

مفت لنچ کے ساتھ آپ کے وقت کے لیے \$100 گفٹ کارڈ۔

ہسپتال کی پارکنگ کی توثیق کی جائے گی اور ادائیگی کی جائے گی۔

اپنے دل کی صحت کے بارے میں جاننے کا موقع۔

[masalastudy@northwestern.edu](mailto:masalastudy@northwestern.edu)  
 (773) 548-2123  
[WWW.MASALASTUDY.ORG](http://WWW.MASALASTUDY.ORG)

## What Is Masala Doing For Your Heart?

**S**ahida Perveen--a Pakistani mother who immigrated to the US 15 years earlier--was only 55 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 69 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 a lack of research that investigate 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

are now trying to understand differences in heart health between the three largest South Asian subgroups in the US: Pakistanis, Bangladeshis, and Indians. When Abida 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 Kandula, MD, MPH, 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, 78, for example. Growing up in Pakistan, Hameed was involved in sports and worried little about his health. As he grew older, he saw

## THE MASALA STUDY

### WHAT IS MASALA?

MASALA is the first long-term, research study identifying factors that lead to heart disease in South Asians. Pakistanis appear to have the highest rates of diabetes, obesity, and high cholesterol among all South Asians.

### WHO CAN JOIN?

- Identifies as Pakistani
- Can speak and read English or Urdu
- 40-84 years old
- Has no history of heart attack or stroke
- Resident of Chicagoland and surrounding suburbs

### HOW WILL I BENEFIT?

- Free clinic visit and the lab results are shared with you
- \$100 gift card for your time along with a free lunch
- Hospital parking will be validated and paid for

## COMMUNITY ACROSS AMERICA

16 India Post      www.indiapost.com      January 26, 2018      Details on page 23

## Cultural strategies can combat heart disease among S. Asians

SURENDRA ULLAL

CHICAGO: Research shows that individuals of South Asian descent including Indians, Pakistanis, Nepalis, Bangladeshis and Sri Lankans are at high risk for heart disease. This is partly due to a lack of exercise and a

that use culturally appropriate strategies to lower heart disease risk in 'Desi' population. Namratha Kandula, MD, MPH and her team at Northwestern University in Chicago have partnered with Metropolitan

provide nutrition and health education, personalized exercises, stress management strategies, and group support geared to South Asians. In a talk with this paper, Dr. Kandula explained, "Our goal is to de-

# Social Media Toolkit for Community Partners



## Tweets from @SAAPRChicago

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](http://SAATHstudy.org)).

**Northwestern University**

Study Title: A Multilevel Physical Activity Intervention for South Asian Women and Girls  
Northwestern University IRB# STU00211374  
Principal Investigator: Naradha Kandula MD, MPH

**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!

1 17



# 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.