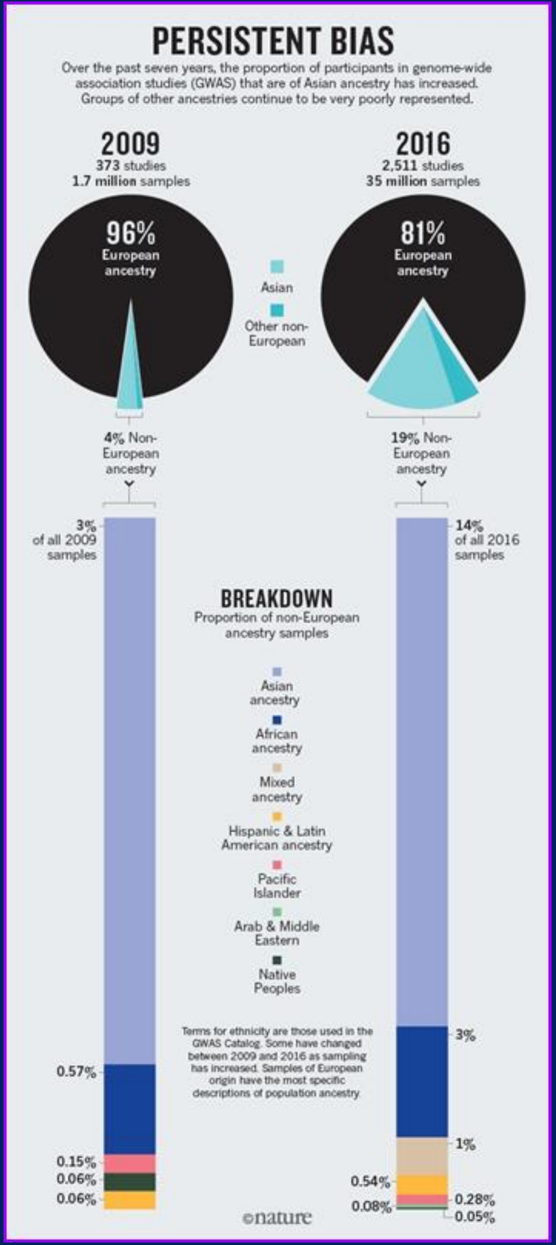
THE POWER OF COMMUNITY VOICE

Exploring Community Advisory Boards
Structure and Function in Translational Research
Fronters CTSI
Elizabeth Cohn, RN, PhD
Hunter College
City University of New York
March 9, 2023

Agenda for this session

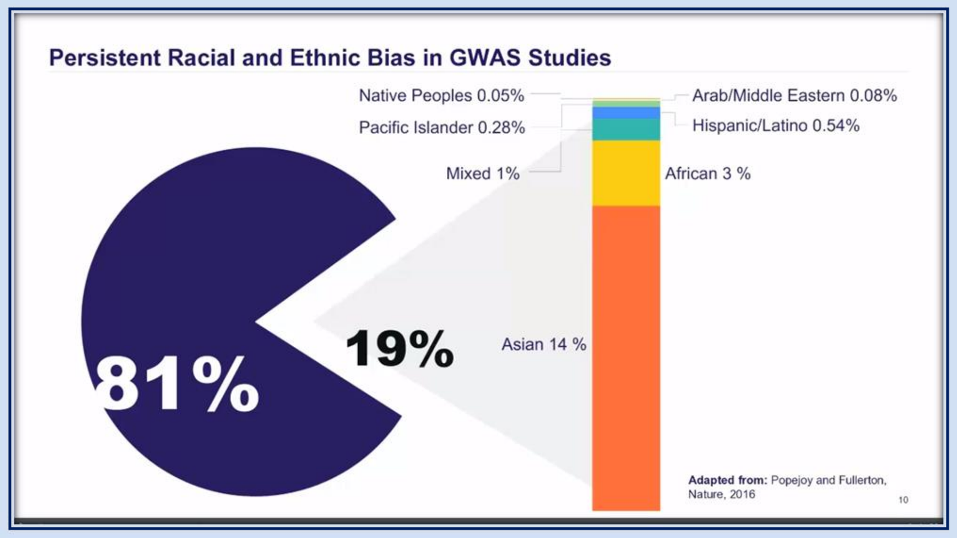
- Describe the purpose and power of Community and Participant Advisory Boards (CAB/PAB) as one method for amplifying and elevating the community voice.
- Explore 4 examples of CAB/PAB models in use in a single study, a department, a center grant and a national program.
- Discuss and provide examples of CAB/PAB template documents that can be adapted for local use.
- All board members discussed in this presentation are receive stipends for their service.



PERSISTENT BIAS

Over the past seven years, the proportion of participants in genome-wide association studies (GWAS) that are of Asian ancestry has increased. Groups of other ancestries continue to be very poorly represented.

Terms for ethnicity are those used in the GWAS Catalog. Some have changed between 2009 and 2016 as sampling has increased. Samples of European origin have the most specific descriptions of population ancestry.



Persistent Racial and Ethnic Bias in GWAS Studies

Adapted from: Popejoy and Fullerton, Nature, 2016

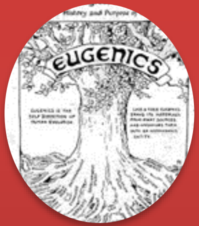
A persistent bias exists in Precision Medicine resulting in worsening of current health disparities.

There are legal, ethical and scientific mandates to address this inequity. These are issues of social justice.

Genomics for the world *NATURE* Bustamante, C. D., Burchard, E. G., De La Vega, F. M. (2011); 475 (7355): 163-165

Fullerton (2017) http://www.nature.com/news/genomics-is-failing-on-diversity-1.20759

Historical Context for Research Participation



1880-1900s
Eugenics

1932-1972
Tuskegee
Experimentation

FDA Law on Drug Safety

1939-1947
Nazi Human Experimentation

The Nuremberg Code

1948-1949
U.S. Public Health Service Sexually-transmitted disease in Guatemala

Declaration of Geneva

1951-1953
Henrietta Lacks
National Institutes of Health Human Subjects Policy

1956-1971
Willowbrook State School
Kefauver-Harris Amendments requiring Informed Consent.
45 CFR 46
Helsinki Declaration

1976-1995
Belmont Report

President's Commission

Common Rule

National Bioethics Advisory Committee

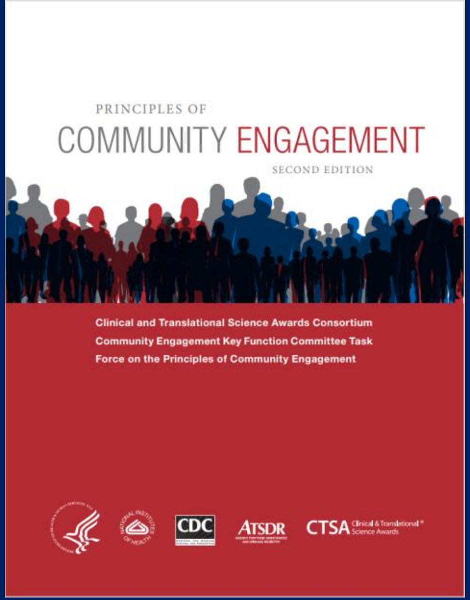
1990
Havasupai Tribe

Ethical issues in Disability Rights

https://history.nih.gov/about/timelines_laws_human.html
https://www.niehs.nih.gov/research/resources/bioethics/timeline/

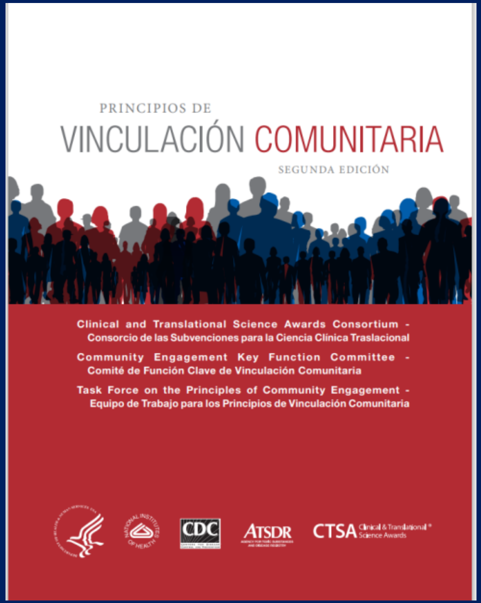
What's new in Community Engagement?
New Principles 3rd edition

- New Emphasis
- New Models
- New Frameworks
- New Partnerships and Importance
- 30th Year
- **All free**



PRINCIPLES OF
COMMUNITY ENGAGEMENT
SECOND EDITION

Clinical and Translational Science Awards Consortium
Community Engagement Key Function Committee Task
Force on the Principles of Community Engagement



PRINCIPIOS DE
VINCULACIÓN COMUNITARIA
SEGUNDA EDICIÓN

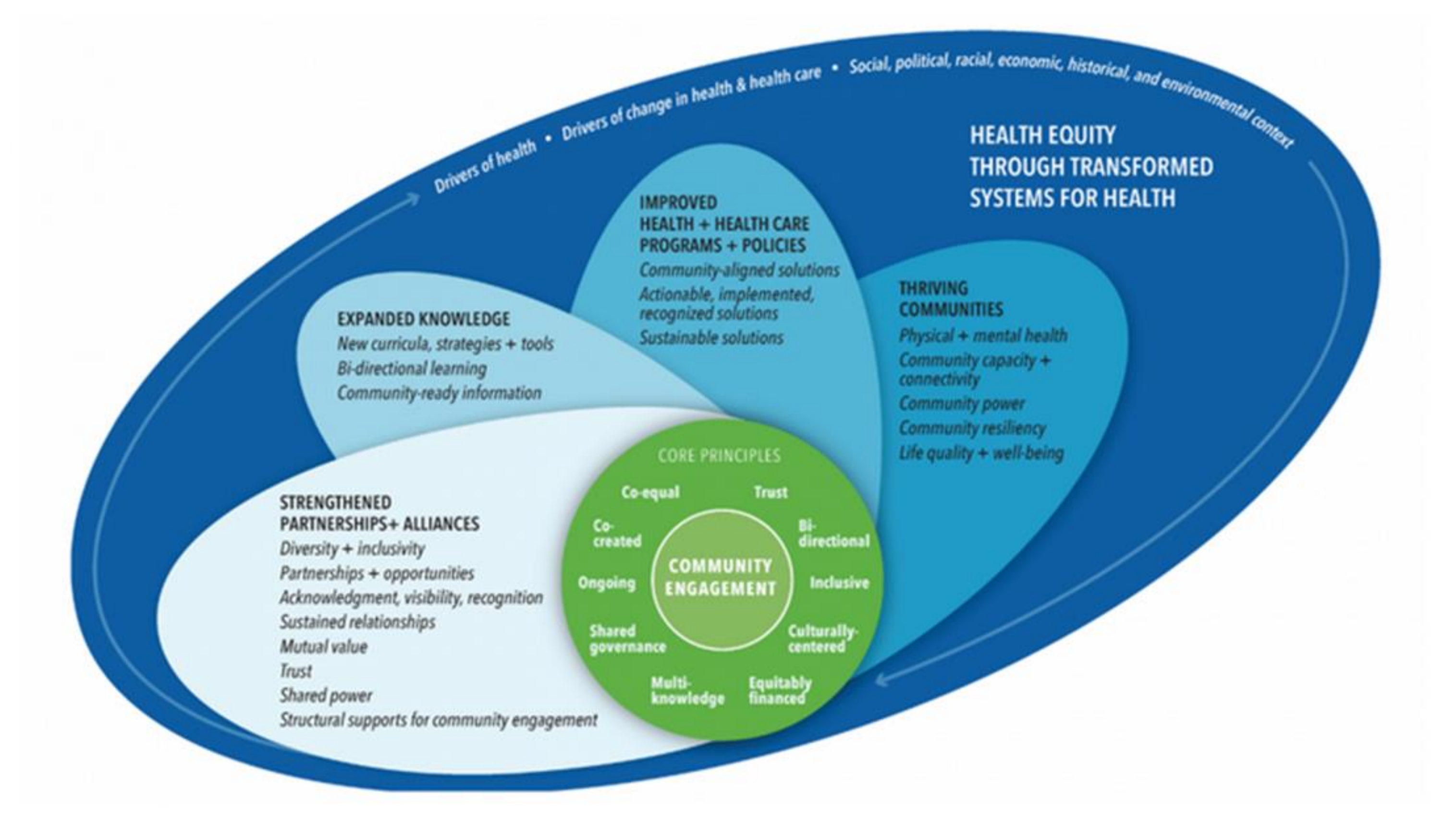
Clinical and Translational Science Awards Consortium -
Consorcio de las Subvenciones para la Ciencia Clínica Traslacional

Community Engagement Key Function Committee -
Comité de Función Clave de Vinculación Comunitaria

Task Force on the Principles of Community Engagement -
Equipo de Trabajo para los Principios de Vinculación Comunitaria

https://www.atsdr.cdc.gov/communityengagement/index.html

Models and Frameworks



Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies. 2022. Assessing Meaningful Community Engagement: A Conceptual Model to Advance Health Equity through Transformed Systems for Health. *NAM Perspectives.* Commentary, National Academy of Medicine, Washington, DC. https://doi.org/10.31478/202202c.

Why Stand Up a CAB/PAB

- Recent studies have cited the need to empower participants to be engaged as partners in research.[1,2]
- The strength of this approach includes increasing trust[3], deepening an understanding of cultural perspectives[3], strengthening the science and increasing generalizability[4], calibrating expectations[5,6], and ultimately improving the health of communities[7].

1. Yoshizawa *et al*: ELSI practices in genomic research in East Asia: Implications for research collaboration and public participation, *Genome Medicine* 2014 **6**:39.
2. Kaye, J. *et al*: From patients to partners: participant-centric initiatives in biomedical research. Nature Rev. Genetics 2012, **13**:371-373
3. Moodley, K., Singh, S. "It's all about trust": reflections of researchers on the complexity and controversy surrounding biobanking in South Africa. BMC Med Ethics. 2016 Oct 10;17(1):57.
4. Fullerton (2017) http://www.nature.com/news/genomics-is-failing-on-diversity-1.20759
5. Folayan M.O., Oyedeji K.S., Fatusi O.A. Community members' engagement with and involvement in genomic research: lessons to learn from the field. *Dev World Bioeth.* 2015 Apr;15(1):1-7. doi: 10.1111/dewb.12020. Epub 2013 Apr 17.
6. Etchegary, H, Green, J, Parfrey, P, Street C, Pullman, D. Community engagement with genetics: public perceptions and expectations about genetics research. *Health Expect.* 2015 Oct;18(5):1413-25. doi: 10.1111/hex.12122. Epub 2013 Aug 23.
7. Cohn E.G., Husamudeen M., Larson E.L., Williams J.K. Increasing participation in genomic research and biobanking through community-based capacity building. *J Genet Couns.* 2015 Jun;24(3):491-502. doi: 10.1007/s10897-014-9768-6. Epub 2014 Sep 18.

How Community and Participant Advisory Boards Strengthen Research

1. SCAN-MP ATTR Amyloid Boston Medical Center and Columbia University Irving Medical Center (NHLBI)
2. Department of Pediatrics at Columbia University Irving Medical Center (Institutional)
3. COMMUNITY Center of Columbia, Weill-Cornell, Hunter and PAGNY (NIMHD)
4. All of Us Research Program (Columbia University Medical Center, Weill-Cornell and Harlem Hospital, Health and Hospitals)

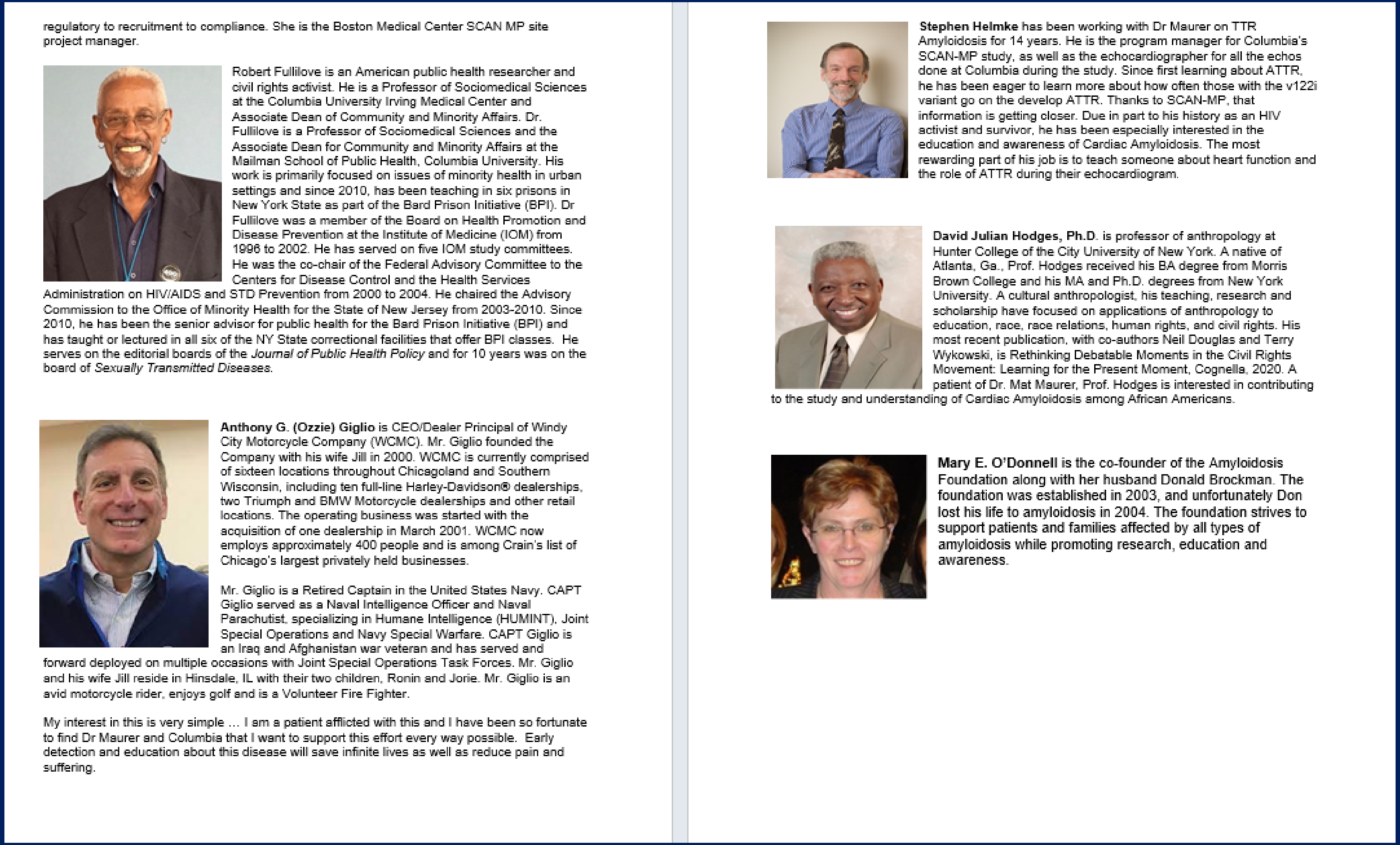
Screening for Cardiac Amyloidosis with Nuclear imaging in Minority Populations (SCAN-MP) Study

Community and Professional Advisory Board

March 11, 2022

SCAN-MP

Screening for Cardiac Amyloidosis with Nuclear imaging in Minority Populations



regulatory to recruitment to compliance. She is the Boston Medical Center SCAN MP site project manager.

Robert Fullilove is an American public health researcher and civil rights activist. He is a Professor of Sociomedical Sciences at the Columbia University Irving Medical Center and Associate Dean of Community and Minority Affairs. Dr. Fullilove is a Professor of Sociomedical Sciences and the Associate Dean for Community and Minority Affairs at the Mailman School of Public Health, Columbia University. His work is primarily focused on issues of minority health in urban settings and since 2010, has been teaching in six prisons in New York State as part of the Bard Prison Initiative (BPI). Dr Fullilove was a member of the Board on Health Promotion and Disease Prevention at the Institute of Medicine (IOM) from 1996 to 2002. He has served on five IOM study committees. He was the co-chair of the Federal Advisory Committee to the Centers for Disease Control and the Health Services Administration on HIV/AIDS and STD Prevention from 2000 to 2004. He chaired the Advisory Commission to the Office of Minority Health for the State of New Jersey from 2003-2010. Since 2010, he has been the senior advisor for public health for the Bard Prison Initiative (BPI) and has taught or lectured in all six of the NY State correctional facilities that offer BPI classes. He serves on the editorial boards of the *Journal of Public Health Policy* and for 10 years was on the board of *Sexually Transmitted Diseases*.

Anthony G. (Ozzie) Giglio is CEO/Dealer Principal of Windy City Motorcycle Company (WCMC). Mr. Giglio founded the Company with his wife Jill in 2000. WCMC is currently comprised of sixteen locations throughout Chicagoland and Southern Wisconsin, including ten full-line Harley-Davidson® dealerships, two Triumph and BMW Motorcycle dealerships and other retail locations. The operating business was started with the acquisition of one dealership in March 2001. WCMC now employs approximately 400 people and is among Crain's list of Chicago's largest privately held businesses.

Mr. Giglio is a Retired Captain in the United States Navy. CAPT Giglio served as a Naval Intelligence Officer and Naval Parachutist, specializing in Humane Intelligence (HUMINT), Joint Special Operations and Navy Special Warfare. CAPT Giglio is an Iraq and Afghanistan war veteran and has served and forward deployed on multiple occasions with Joint Special Operations Task Forces. Mr. Giglio and his wife Jill reside in Hinsdale, IL with their two children, Ronin and Jorie. Mr. Giglio is an avid motorcycle rider, enjoys golf and is a Volunteer Fire Fighter.

My interest in this is very simple … I am a patient afflicted with this and I have been so fortunate to find Dr Maurer and Columbia that I want to support this effort every way possible. Early detection and education about this disease will save infinite lives as well as reduce pain and suffering.

Stephen Helmke has been working with Dr Maurer on TTR Amyloidosis for 14 years. He is the program manager for Columbia's SCAN-MP study, as well as the echocardiographer for all the echos done at Columbia during the study. Since first learning about ATTR, he has been eager to learn more about how often those with the v122i variant go on the develop ATTR. Thanks to SCAN-MP, that information is getting closer. Due in part to his history as an HIV activist and survivor, he has been especially interested in the education and awareness of Cardiac Amyloidosis. The most rewarding part of his job is to teach someone about heart function and the role of ATTR during their echocardiogram.

David Julian Hodges, Ph.D. is professor of anthropology at Hunter College of the City University of New York. A native of Atlanta, Ga., Prof. Hodges received his BA degree from Morris Brown College and his MA and Ph.D. degrees from New York University. A cultural anthropologist, his teaching, research and scholarship have focused on applications of anthropology to education, race, race relations, human rights, and civil rights. His most recent publication, with co-authors Neil Douglas and Terry Wykowski, is Rethinking Debatable Moments in the Civil Rights Movement: Learning for the Present Moment, Cognella, 2020. A patient of Dr. Mat Maurer, Prof. Hodges is interested in contributing to the study and understanding of Cardiac Amyloidosis among African Americans.

Mary E. O'Donnell is the co-founder of the Amyloidosis Foundation along with her husband Donald Brockman. The foundation was established in 2003, and unfortunately Don lost his life to amyloidosis in 2004. The foundation strives to support patients and families affected by all types of amyloidosis while promoting research, education and awareness.

SCAN-MP - Community and Professional Advisory Board Objectives (CAB/PAB)

- We are very grateful for your willingness to participate in the CAP/PAB!
- The broad objectives CAB/PAB are that its members serve as:
  - An expert group – to share the study results and listen to perceptions from the community most affected
  - A connector -- to amplify the study findings, spreading awareness
  - A reflector -- to improve effectiveness of study efforts through individual observations and experiences

SCAN-MP

SCAN-MP's goal is to make patients with cardiac amyloidosis live longer and feel better

To change the course of transthyretin cardiac amyloidosis (ATTR) by early screening, diagnosis, and effective treatment leading to better outcomes and a longer life.

SCAN-MP

Reminder of Ground Rules

1. Speak up and speak out. We really want to hear from you. These meetings are best when you give us your thoughts and reactions.
2. Assume the best of intent—practice grace. Thoughts sometimes don't translate into words in the right way. We will tackle subjects such as race and disease, and concepts can tangle in real time. We all have everyone's best interest at heart.
3. We'll hold space about 10 minutes before the end of the meeting for those who haven't spoken. Put your name in the Chat or raise your hand on the zoom if you want to speak.
4. Medical Translations and Acronyms—I'll translate in the Chat but if we accidently use a word or phase that you aren't sure of, please just stop us or put a note in the Chat, we would be so disappointed to learn later if not all could follow the discussion.

SCAN-MP - Community and Professional Advisory Board Objectives (CAB/PAB) Agenda

- Brief Overview of Study (Drs. Ruberg and Maurer)
  - Progress to Date
- Yale Center for Clinical Investigation (Dr. Miller)
  - Cultural Ambassadors
- ATTR Friends and Family Tool (all)
- Open Discussion and Questions

SCAN-MP

Screening for Cardiac Amyloidosis with Nuclear imaging in Minority Populations (SCAN-MP)

- Prospective, cohort study (800 people total)
- Black and Hispanic subjects with heart failure
- Undergo cardiac testing
- Specific primary questions to answer:
    1. What proportion of people have ATTR-CA (prevalence)
    2. Do the inherited and non-inherited forms look different by testing performed? (phenotype)
    3. Are outcomes different between the inherited vs. non-inherited forms, older vs. younger, men vs. women, etc.

SCAN-MP

SCAN-MP is an important study that aims to reduce health disparities

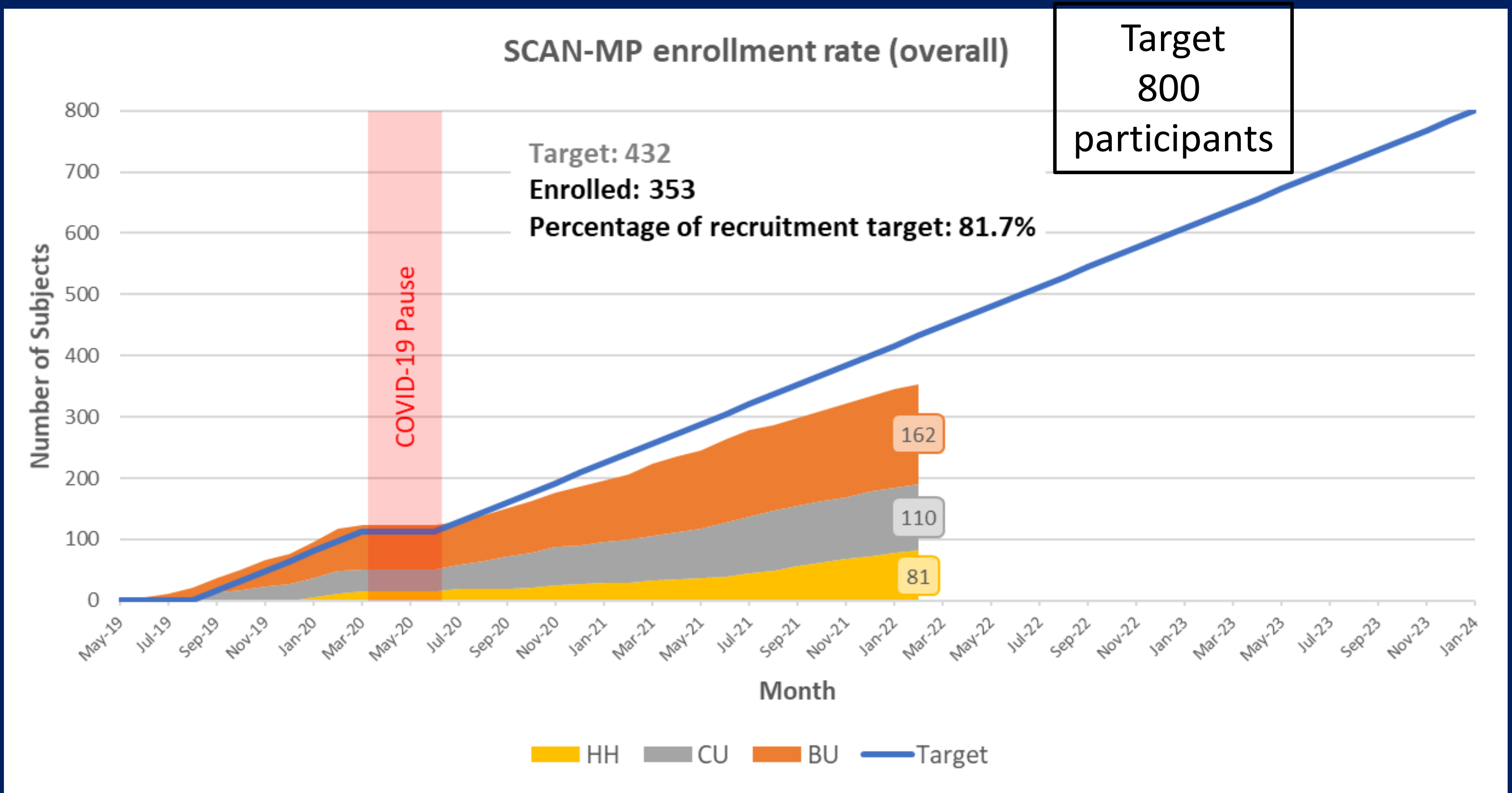
- Addresses an overlooked, underappreciated cause of heart failure which disproportionately afflicts Blacks and possibly Hispanics for which there are now treatments.
- Collects data that can be leveraged by FDA to change labeling and enable more widespread testing.
- Potential to change clinical approach and encourage earlier identification of disease at a time when emerging therapeutics have the greatest potential.

SCAN-MP

Performance sites

- Boston Medical Center
- New York
  - Columbia University Irving Medical Center
  - Harlem Hospital
- Yale University / Yale New Haven Hospital

SCAN-MP aims to recruit 800 participants and enrollment is ongoing



Target
800
participants

Target: 432
Enrolled: 353
Percentage of recruitment target: 81.7%

Center for Clinical Investigation
One Heart Initiative

One Heart Initiative

Community-guided, Precision medicine-based Cardiovascular Medicine Research Group

- Understand factors contributing to LVH/HF development communities in YNHHS
- Identify and treat ATTR-CA, HCM and other genetic cardiomyopathies
- Engage historically underrepresented minority communities

Awareness

How we plan to engage our Community
- Radio outreach/IG/TikTok - Tom Ficklin Show
- Newsletter and educational material distribution
- Young Ambassadors
- Church newsletters
- CA participation in Study Steering Committees

Analysis

Reaching out to the Community: Screening for LVH
- What: Identify patients with LVH and/or HTN
- Aim: triage to appropriate clinical care and/or investigations
- How: design and implement a Community-Partnered Cardiovascular Disease Research Program

Screening for CHF: SCAN-MP
- What: Evaluation of ATTR as cause of CHF in Black and Hispanic communities
- Aim: Enrolling 100 patients over 2 years In YNHHS clinics
- How: Standardized diagnostic and follow up approaches, funded by NIH

Who are we missing? Advanced Health Record Analysis
- **Alnylam:**
  - What: Artificial Intelligence to identify amyloid heart disease
  - How: AI identification followed by clinical assessment
- **Retrospective Screening YNHHS for LVH**
  - What: to screen patients for entry into prospective studies (Clinical trials, genetics, etc)
  - How: Utilize existing echocardiograms

Action

What will happen after screening:

Clinical trials
- CHF-->**SCAN-MP**
- AI identification of CA followed by clinical assessment-->**Alnylam**

Clinical navigators: HTN-->PCP and/or Cards referral

Pharmacological Treatment and monitoring
- Specialty Pharmacy access programs
- Treatment trials (**Flutemetamol PET study**)
- **Intellia** CRISPR V142I Phase III

V142I Biorepository: Explore variable penetrance
- Known V142I patients and family cascade screening

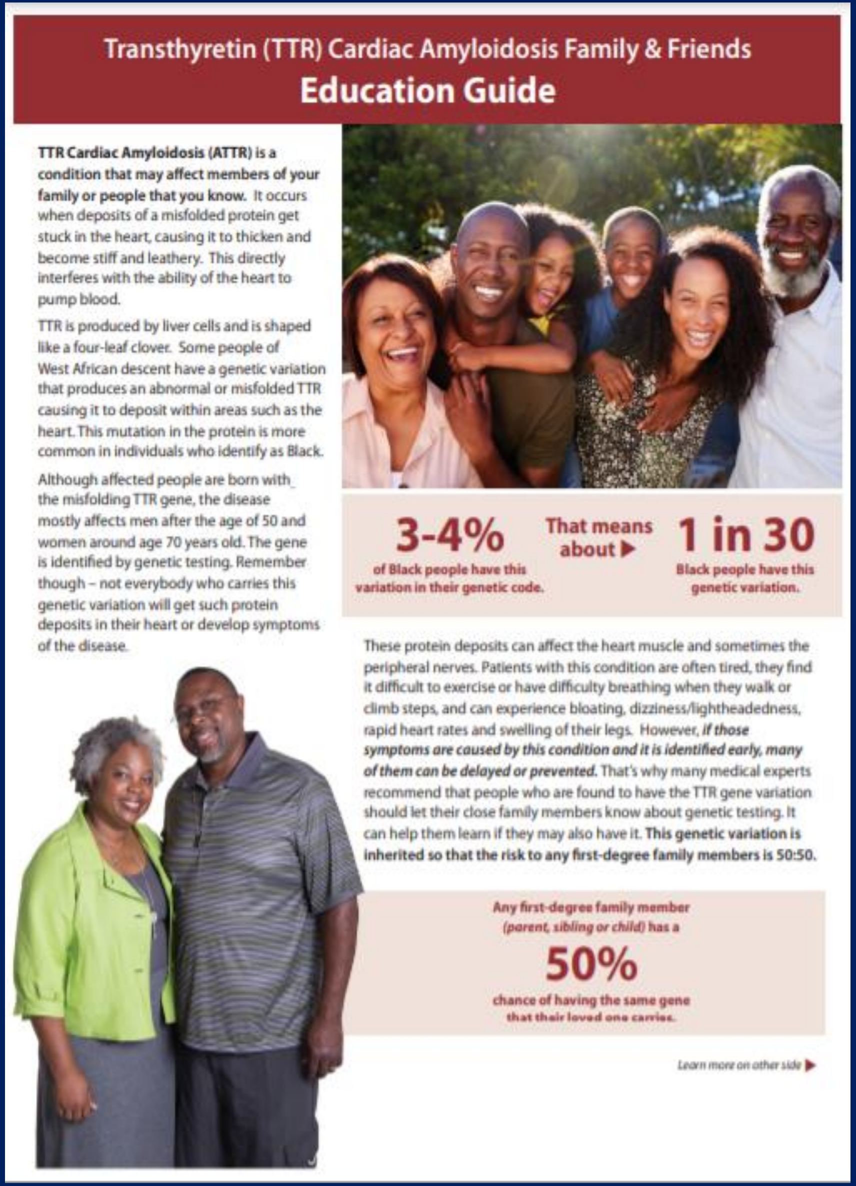
Advance

Circle back to Community
- Feedback system
- Report retrospective analysis results
- Prospective follow up include yearly phone calls

Abbreviations:
CA: cardiac amyloidosis
LVH: left ventricular hypertrophy
HTN: hypertension
ATTR: transthyretin amyloidosis
CHF: congestive heart failure

Reviewing our Homework:

1. What is the most important information you most want people to know about ATTR?
2. What questions do you have, especially if they are not answered by the flyer.
3. How do you see using this flyer, what would be the best way for us to provide it to you?
4. Is it clear how people can get more information or how they can take next steps?
5. What else should we add, do you think we should change some of the pictures or text?



Transthyretin (TTR) Cardiac Amyloidosis Family & Friends
Education Guide

TTR Cardiac Amyloidosis (ATTR) is a condition that may affect members of your family or people that you know. It occurs when deposits of a misfolded protein get stuck in the heart, causing it to thicken and become stiff and leathery. This directly interferes with the ability of the heart to pump blood.

TTR is produced by liver cells and is shaped like a four-leaf clover. Some people of West African descent have a genetic variation that produces an abnormal or misfolded TTR causing it to deposit within areas such as the heart. This mutation in the protein is more common in individuals who identify as Black.

Although affected people are born with the misfolding TTR gene, the disease mostly affects men after the age of 50 and women around age 70 years old. The gene is identified by genetic testing. Remember though – not everybody who carries this genetic variation will get such protein deposits in their heart or develop symptoms of the disease.

3-4%
of Black people have this variation in their genetic code.

That means about ▶

1 in 30
Black people have this genetic variation.

These protein deposits can affect the heart muscle and sometimes the peripheral nerves. Patients with this condition are often tired, they find it difficult to exercise or have difficulty breathing when they walk or climb steps, and can experience bloating, dizziness/lightheadedness, rapid heart rates and swelling of their legs. However, ***if those symptoms are caused by this condition and it is identified early, many of them can be delayed or prevented.*** That's why many medical experts recommend that people who are found to have the TTR gene variation should let their close family members know about genetic testing. It can help them learn if they may also have it. **This genetic variation is inherited so that the risk to any first-degree family members is 50:50.**

Any first-degree family member *(parent, sibling or child)* has a
50%
chance of having the same gene that their loved one carries.

Learn more on other side ▶

Transthyretin (TTR) Cardiac Amyloidosis Family & Friends **Education Guide**

Early identification of this genetic variation provides an opportunity to not only learn more about the disorder, but to diagnose it as early as possible. There are several effective therapies that can greatly reduce the chance of becoming very sick with this condition, or if they are already affected by the disease, to meaningfully slow down the progression of the disorder.

Get in the know

If you have learned that you are a person with this genetic variation, you may want to share that information with your loved ones, so that they too can learn about it early and prevent later damage. You can visit:

amyloidosis.org | **www.arci.org** | **www.amyloidosissupport.org**
to read the websites of the national amyloidosis organizations and learn more.

You may also visit the NIH website:
medlineplus.gov/genetics/condition/transthyretin-amyloidosis

Finally, you should call the medical center below that diagnoses and cares for people with ATTR, or find one near you at the website links:

amyloidosis.org/resources/#treatment-centers

arci.org/patients-and-caregivers/treatment-centers-clinical-trials

www.amyloidosissupport.org/amyloidosis_centers.html

Advisory Boards for Individual Studies
(Discussion and General Structure)

1. Charge the group and describe the study (if all participants, ask about their experience thus far)
2. Review where we are in the study progress and progression.
3. Have a group assignment related to the study that is at Board level: ie. This is a genetic mutation, so cascade testing of family members is a critical component to identification.
4. Create synergy between people, when possible, we have a newspaper publisher that reaching predominantly Black and African American Communities in Boston so we have pair them with a family who will write about their experience. In fact, an issue will be dedicated to this cause.
5. Leave extra time for discussion, response, reflection and questions.
6. Others with experience with CAB/PAB for individual studies?

Columbia

Columbia University
Department of Pediatrics

NewYork-Presbyterian
Morgan Stanley Children's Hospital

Columbia Children's Research Community Advisory Board

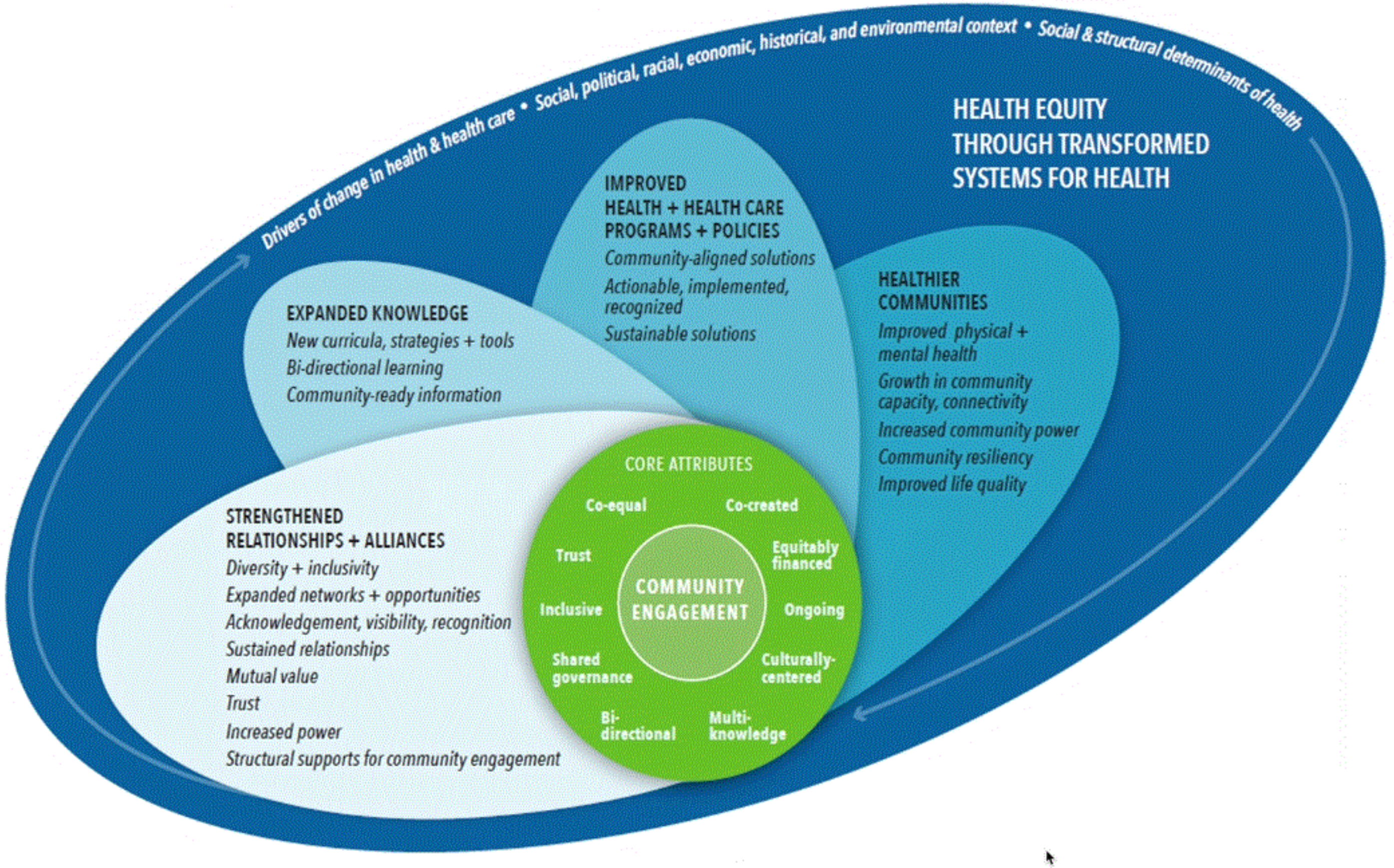
Dodi Meyer MD, Erika Berman-Rosenzweig MD, Elizabeth Cohn, NP, PhD, FAAN, Jesse Weiss MSN, RN

Why Engage Partners in research?

- Need to empower participants to be engaged as partners in research[1,2]:
  - Increasing Trust[3]
  - Understanding cultural and social perspectives[3]
  - Strengthening the Science[4]
  - Calibrating expectations[5,6]
  - Improving Health of the Communities[7]
- Required by many funding agencies[8]

National Academy of Medicine Model

A Dynamic Relationship: Community Engagement & Outcomes In Health And Health Care



See References[9]

Board's Mission Statement

Goal

- Improve Health of Communities

Aims

- Integrate the community voice
- Facilitate community engagement
- Promote community linkages

Process

- Created a board of professionals who live and work in the community
    - Providers represent a range of domains related to family health: Housing, Food, Mental Health, Schools, Perinatal Health, FBO, environmental justice, and local business
- Quarterly meetings in which researchers present their work
    - Prior to meetings, the board is provided with a summary of research + questions for the board to consider
    - Board members are reimbursed for their time

Leadership


Elizabeth Cohn, NP, PhD, FAAN


Dodi Meyer, MD


Jesse Weiss MSN, RN

Members


Génesis Abreu
Childhood Education/
Environmental Justice


Deni Alarcon, NP
School Nurse
Practitioner


Fajah Ferrer
Maternal-Child Health


Tiffany Lee
Faith Based
Organization


Angie Nuñez, MA, RDT, LCAT
Mental Health


Sarina Prabasi
Small Business Owner


Jannett Santana, LCSW
Mental Health


Gregory Silverman
Food Insecurity


Megan Wendt, LMSW
Housing Insecurity

Presentations and Collaborations

COVID-19 Mother Baby Outcomes (COMBO)

- Dr. Kelli Hall and Dr. Dani Dumitriu

Overview of Columbia University Department of Pediatrics

- Dr. Jordan Orange

Piloting a Pediatric Health Equity and Quality Dashboard and Implementation Roadmap

- Dr. Katie Nash

Letter of Support for Dr. Anna Penn and Division of Neonatology to join NICHD Neonatal Research Network

Next Meeting->Project GUARDIAN: Genomic Uniform-screening Against Rare Diseases In All Newborns/GENE Genetic evaluation of newborns

- Dr. Wendy Chung

References

1. Yoshizawa *et al*: ELSI practices in genomic research in East Asia: Implications for research collaboration and public participation, *Genome Medicine* 2014 **6**:39.
2. Kaye, J. *et al*: From patients to partners: participant-centric initiatives in biomedical research. Nature Rev. Genetics 2012, **13**:371-373
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8. Halladay JR, Donahue KE, Sleath B, et al. Community Advisory Boards Guiding Engaged Research Efforts within a Clinical Translational Sciences Award: Key Contextual Factors Explored. *Prog Community Health Partnersh*. 2017;11(4):367-377. doi:10.1353/cpr.2017.0044
9. Aguilar-Gaxiola S, Ahmed SM, Anise A, et al. Assessing Meaningful Community Engagement: A Conceptual Model to Advance Health Equity through Transformed Systems for Health: Organizing Committee for Assessing Meaningful Community Engagement in Health & Health Care Programs & Policies. *NAM Perspect*. 2022;2022:10.31478/202202c. Published 2022 Feb 14. doi:10.31478/202202c

Department Specific (Peds)

- Membership focused on a single populations (Peds).
- Research from the department can access this board for early input.
- First consultation for submission is paid for by the department.
- Supported within each grant that requires consistent feedback over the course of the grant.
- Strong affiliation and is cohesive because it is well defined.

National Program

Community & Participant Advisory Board Meeting

All of Us
RESEARCH PROGRAM

January 13, 2022
4:30 pm – 6:00 pm
https://columbiacuimc.zoom.us/j/94226307658?pwd=WU5ROEQxWFZ1aFJFMWx1cVB6RzVTdz09

NIH
National Institutes of Health

#JoinAllofUs

Agenda

- **Welcome** – Dr. Elizabeth Cohn
- **NIH National Engagement Announcements and Updates** – Dr. Elizabeth Cohn
- **NIH AoU Innovation Team Introduction and Strategy Preview Discussion** – Ashton Asbury and Daozhong Jin
- **"IMPACT Trial: Intervention to Improve Adherence Equitably" Presentation and Discussion** – Dr. Dawn Hershman and Dr. Ian Kronish
- **"*Are Genetics Your Destiny*" Genetic Counseling Module Presentation** – Nicky Delva
- **NYC Consortium Update** – LaKeisha Jones
- **Open Forum** – Team
- **Closing Remarks** – Dr. Elizabeth Cohn
- **Post – Meeting Technical Assistance Availability**

NIH National Engagement Announcements and Update

Dr. Elizabeth Cohn

All of Us RESEARCH PROGRAM

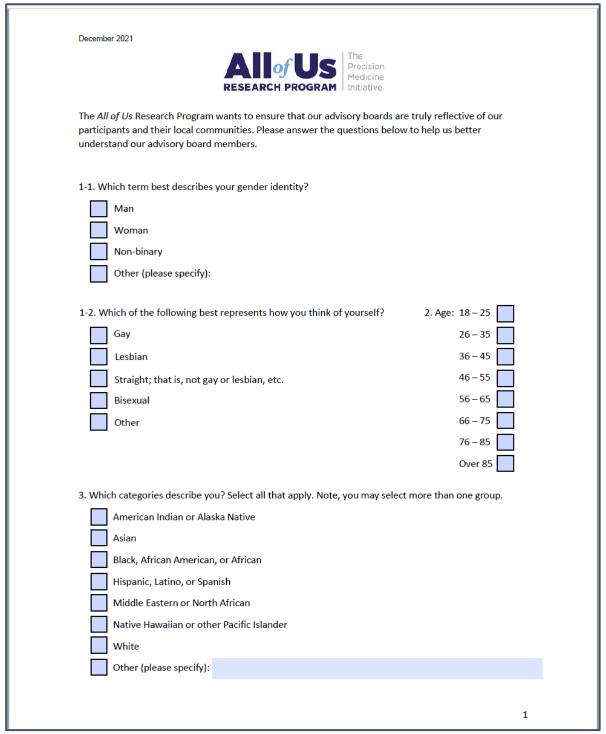
#JoinAllofUs

National Institutes of Health

NIH National Engagement Update

- **New Appointments**
  - Congratulations, Larry – National Advisory Committee Member
- **Ensuring Diverse Researcher Engagement Efforts and Outreach**
- **Social Determinants of Health Survey Reminder** – January 11, 2022
- **NIH AI and Ethics in Biomedical Research Microlab 2** – January 12, 2022
- **Upcoming Meetings and Presentations**
  - NIH NNLM Online Screening of FAUCI – January 27, 2022
  - AoU Virtual Face 2 Face Meeting – February 4, 2022
  - NIH Round Robin Engagement and Retention Series Presentation – March 18, 2022

Community and Participant Advisory Boards 2022 survey – Final submission opportunity – Today, January 13, 2022



December 2021

All of Us RESEARCH PROGRAM | The Precision Medicine Initiative

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1-1. Which term best describes your gender identity?

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2. Age: 18 – 25 ☐
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☐ White
☐ Other (please specify):

1

All of Us RESEARCH PROGRAM

NIH National Engagement Update

All of Us RESEARCH PROGRAM

NATIONAL GEOGRAPHIC | DOCUMENTARY FILMS

FAUCI

Film Screening & Conversation: "FAUCI"

To register, scan the code or visit bit.ly/FAUCInnlm

Jan. 27, 2022

Live Film Screening: 6 p.m. EST/3 p.m. PST
Conversation: 7:45 p.m. EST/4:45 p.m. PST
Film Available On Demand: Jan. 24-31, 2022

After the film, hear from longtime AIDS activist and survivor Michael Manganiello in a discussion about the importance of representation in medical research.

NIH National Library of Medicine
Network of the National Library of Medicine

CENTERLINK THE COMMUNITY OF LGBT CENTERS

CENTER ON 3656 N. HALSTED

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National Partnership Opportunity

Partner Interest form

Download FAUCI Flyer

Click to download the UPDATED Communications Toolkit!

All of Us RESEARCH PROGRAM | The Future of Health Begins With You

FAUCI Movie Screening Communications Toolkit

NIH National Institutes of Health

Pyxis Partners
December 2021

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NIH AoU Innovation Team Introduction and Strategy Preview

Ashton Asbury
Daozhong Jin

National Institutes of Health

All of Us RESEARCH PROGRAM

#JoinAllofUs

All of Us (AoU) Research Program: The Innovation Team

WHAT DOES THE INNOVATION TEAM DO?

The *AoU* Innovation Team **conducts market research and promotes strategic planning** so that the *AoU* leadership team has the **information and tools they need to make decisions and plan for the future of the program**. The Innovation team helps anchor research areas to the program's long-term goals and strategies to identify areas of growth and future consideration.

INNOVATION TEAM CORE FUNCTIONS:

Market Research & Assessment

- Conduct desktop research from databases and broader web searches to analyze similar health studies and broader industry trends
- Interview principal investigators of similar cohorts and industry SMEs to identify best practices

Strategic Planning

- Build key strategies in the form of playbooks, concepts, roadmaps, and frameworks
- Facilitate senior staff strategy brainstorming and strategy development through facilitated sessions and other tools

New Idea / Concept Testing

- Support testing of new ideas and concepts across the program via rapid prototyping and other tools
- Train individuals and teams across *AoU* on how to develop concepts

All of Us (AoU) Research Program: The Innovation Team

WHAT IS THE INNOVATION TEAM WORKING ON NOW?

**Long-Term
Data Strategy Refresh**

**Long-Term Enrollment
Strategy Refresh**

**Next Phase of Program
Development & Growth**

We look forward to pulsing this group for insights as we jumpstart strategic planning across these and other key program areas of the future!

IMPACT Trial: Intervention to Improve Adherence Equitably

Dr. Dawn Hershman
Dr. Ian Kronish

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All of Us RESEARCH PROGRAM

Are Genetics Your Destiny?

Nicky Delva

National Institutes of Health

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All of Us
RESEARCH PROGRAM

NYC Consortium Update

LaKeisha Jones

National Institutes of Health

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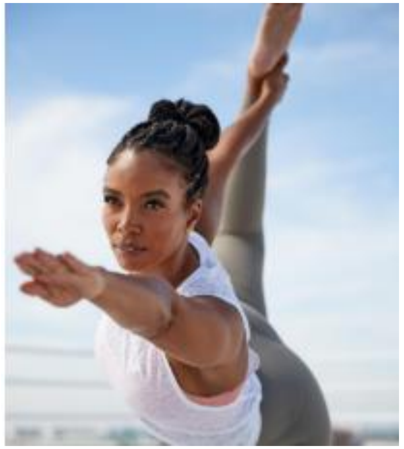
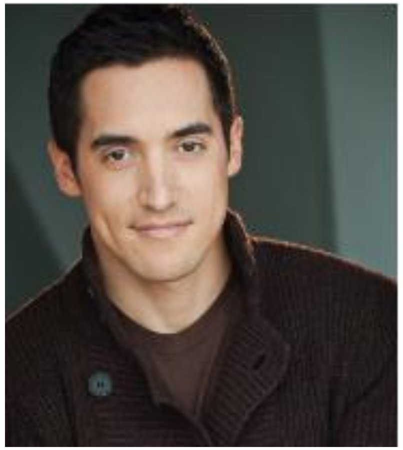
All of Us RESEARCH PROGRAM

Engagement





All of Us RESEARCH PROGRAM

SAVE THE DATE

Join us for the 2022
Spring Engagement Meeting

May 4th - May 5th

Wednesday 5/4 12 - 4 pm, ET
Thursday 5/5 12 - 4 pm, ET

Meeting Registration and Agenda will Follow

PYXIS

Contactless Tabletops – Available to NYC Consortium

Influencer Plan – Drive program awareness and enrollment by extending the reach of our message through local influencers (November "21 – May "22)

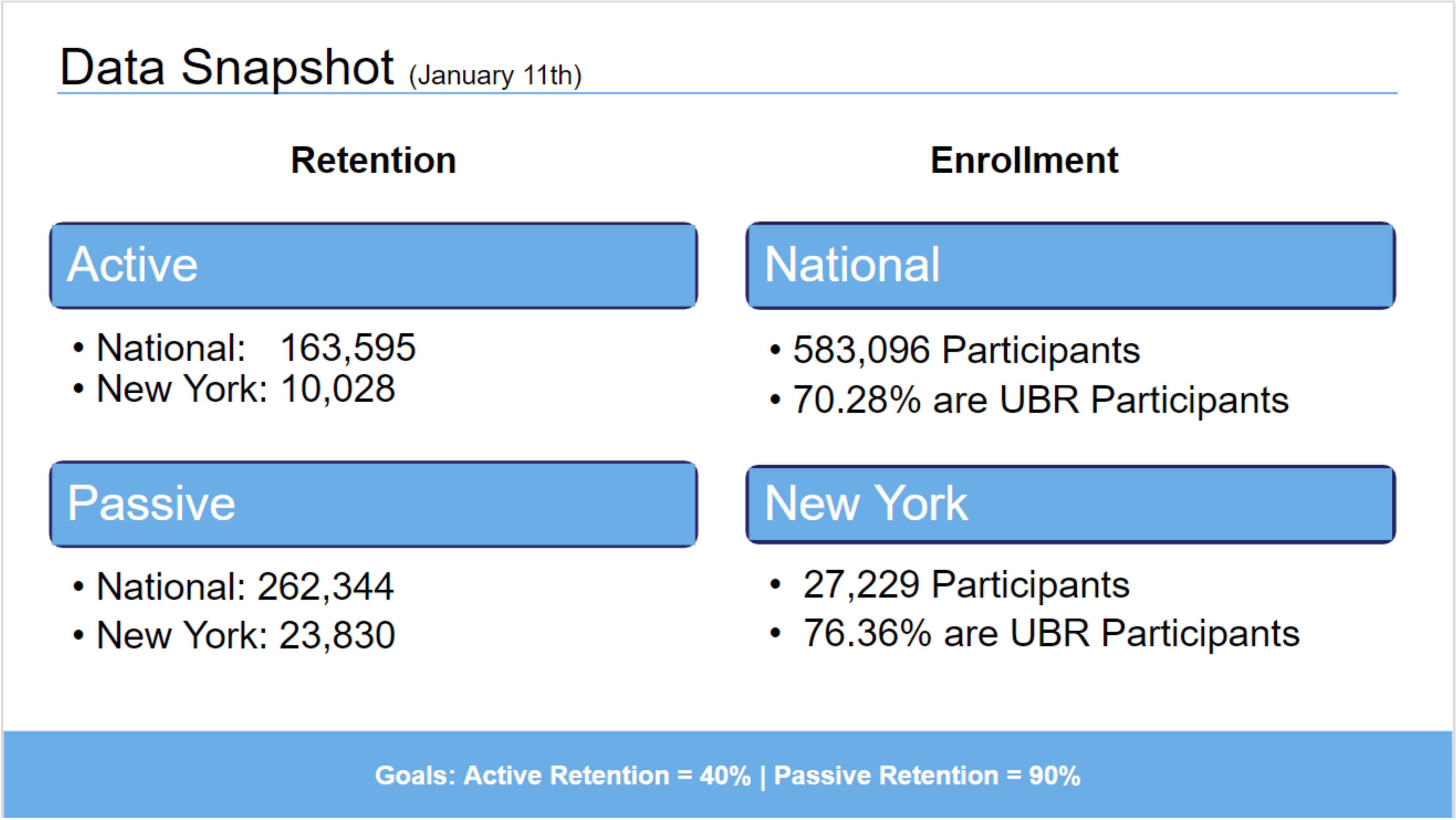
- Dr. Chelsea Jackson Roberts, Peloton Instructor: UBR: Black / African American
- Keahu Kahuanui, Actor: UBR: Native Hawaiian

Partner Search: Virtual event on black maternal health. If interested, please let me know by **Friday, January 14, 2022.**

PYXIS AoU Spring Engagement Meeting – May 4-5, 2022

COLUMBIA   Weill Cornell Medicine   NYC HEALTH+ HOSPITALS | Harlem   NewYork-Presbyterian

Retention and Enrollment



Data Snapshot (January 11th)

Retention

Active

- National: 163,595
- New York: 10,028

Passive

- National: 262,344
- New York: 23,830

Enrollment

National

- 583,096 Participants
- 70.28% are UBR Participants

New York

- 27,229 Participants
- 76.36% are UBR Participants

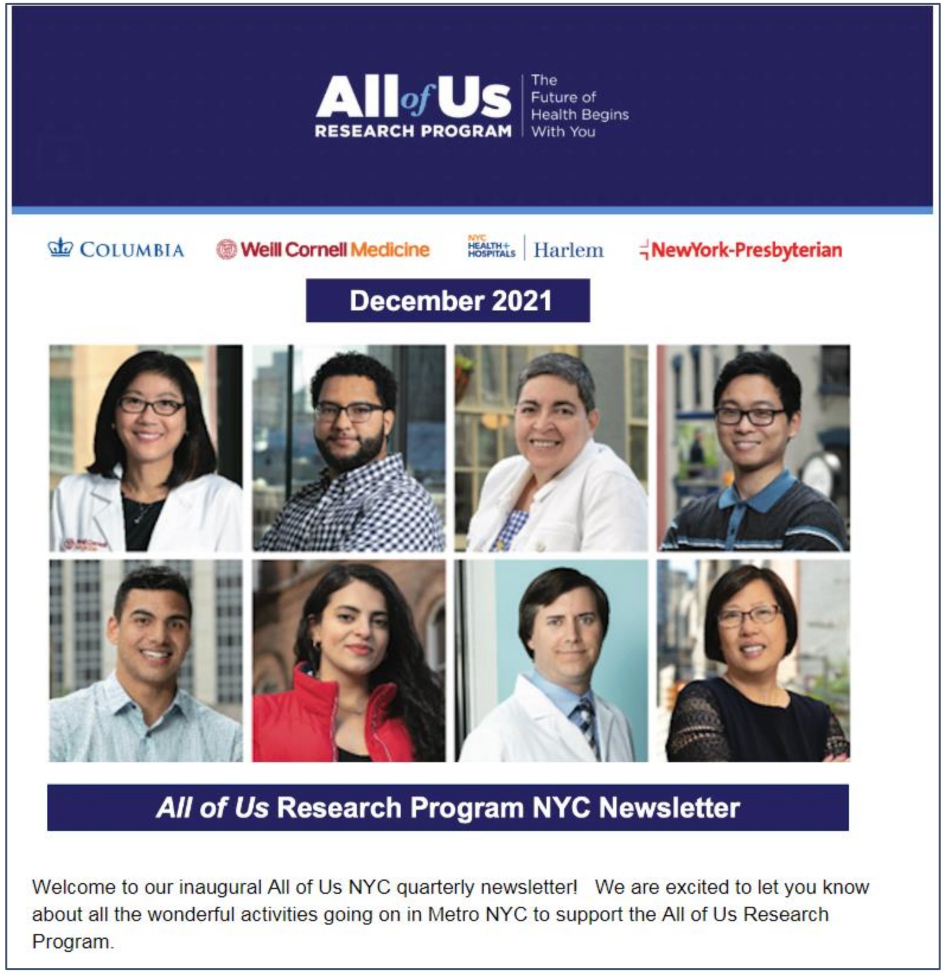
Goals: Active Retention = 40% | Passive Retention = 90%

COLUMBIA Weill Cornell Medicine NYC HEALTH+ HOSPITALS | Harlem NewYork-Presbyterian

All of Us RESEARCH PROGRAM

Communications

- **Welcome, Siobhan Gilbert**
    - Digital Marketing & Communications Lead, NYC Consortium
- **Inaugural NYC Consortium Newsletter**
- **Subway Ad Campaign**
    - 125th Street: A/B/C/D/2/3
    - 135th Street: 2/5
    - Columbus Circle-59th Street: A/B/C/D/1
    - Atlantic Avenue / Barclay Center: B/Q/2/3/4/5
    - Union Square: 4/5/6
    - Grand Central: Metro North: 4/5/6/7



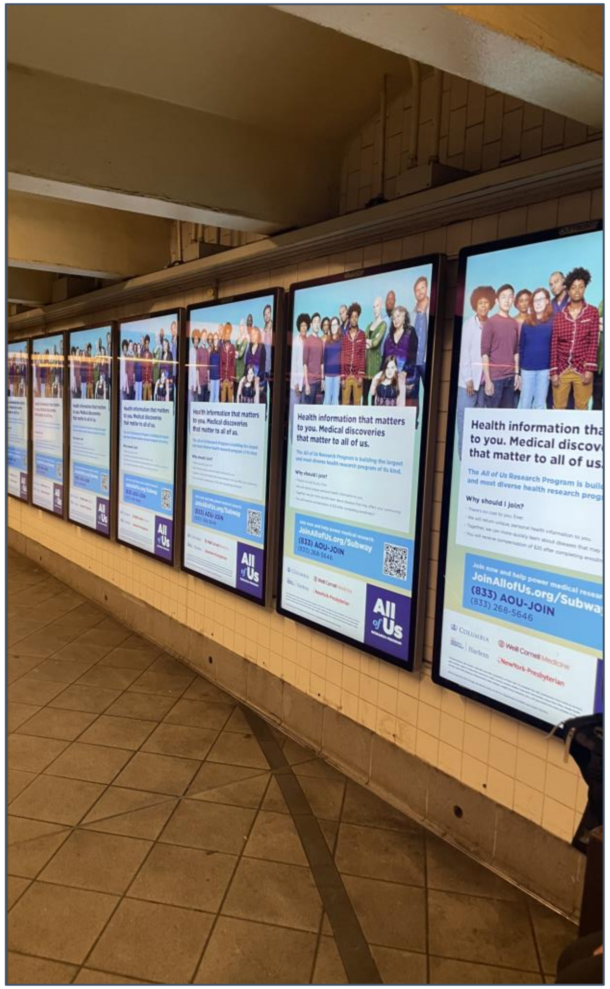
All of Us RESEARCH PROGRAM | The Future of Health Begins With You

COLUMBIA | Weill Cornell Medicine | NYC HEALTH+ HOSPITALS | Harlem | NewYork-Presbyterian

December 2021

All of Us Research Program NYC Newsletter

Welcome to our inaugural All of Us NYC quarterly newsletter! We are excited to let you know about all the wonderful activities going on in Metro NYC to support the All of Us Research Program.



COLUMBIA | Weill Cornell Medicine | NYC HEALTH+ HOSPITALS | Harlem | NewYork-Presbyterian

Open Forum & Closing Remarks

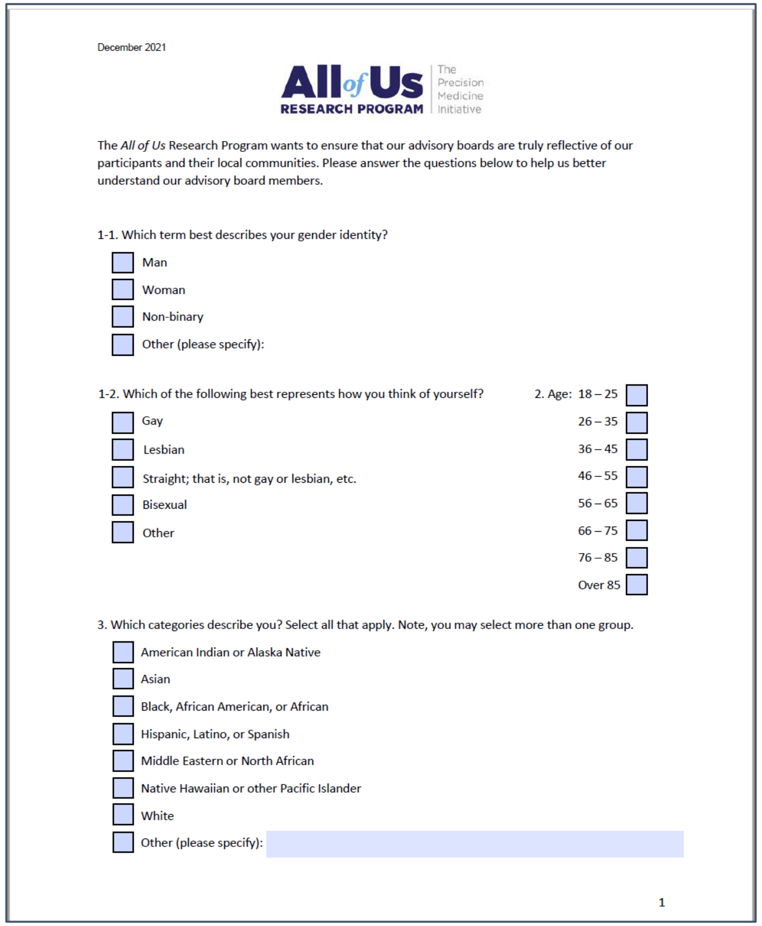
Dr. Elizabeth Cohn

#JoinAllofUs

All of Us
RESEARCH PROGRAM

Open Forum and Closing Remarks

- CPAB Demographic Survey: 7 Questions
- Troubleshooting – Technical Assistance Available
- Next Meetings: TBD
  - *April 21, 2022*
  - *July 21, 2022*
  - *October 20, 2022*



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All of Us
RESEARCH PROGRAM
The Precision Medicine Initiative

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COLUMBIA Weill Cornell Medicine NYC HEALTH+ HOSPITALS | Harlem NewYork-Presbyterian

Post-Meeting Technical Assistance Availability

LaKeisha Jones

#JoinAllofUs

COMMUNITY

Center to Improve Chronic Disease Outcomes through Multi-level and
Multi-generational approaches Unifying Novel Interventions and
Training for health equitY

COMMUNITY LINKING CAB MEETING

Columbia University

HUNTER

PAGNY
Physician Affiliate Group of New York, P.C.

Weill Cornell Medicine

Agenda

- Welcome!
- Introductions
  - Linking CAB members: Connection to the center and other CABs
  - COMMUNITY Center Overview
- Linking CAB purpose & Roles
- IDC Health Equity Scholar Research
  - Q&A and Feedback
- Reminders
  - Next meeting **May 25th, 2003 @ 5:30pm – 7pm**

COMMUNITY Linking CAB

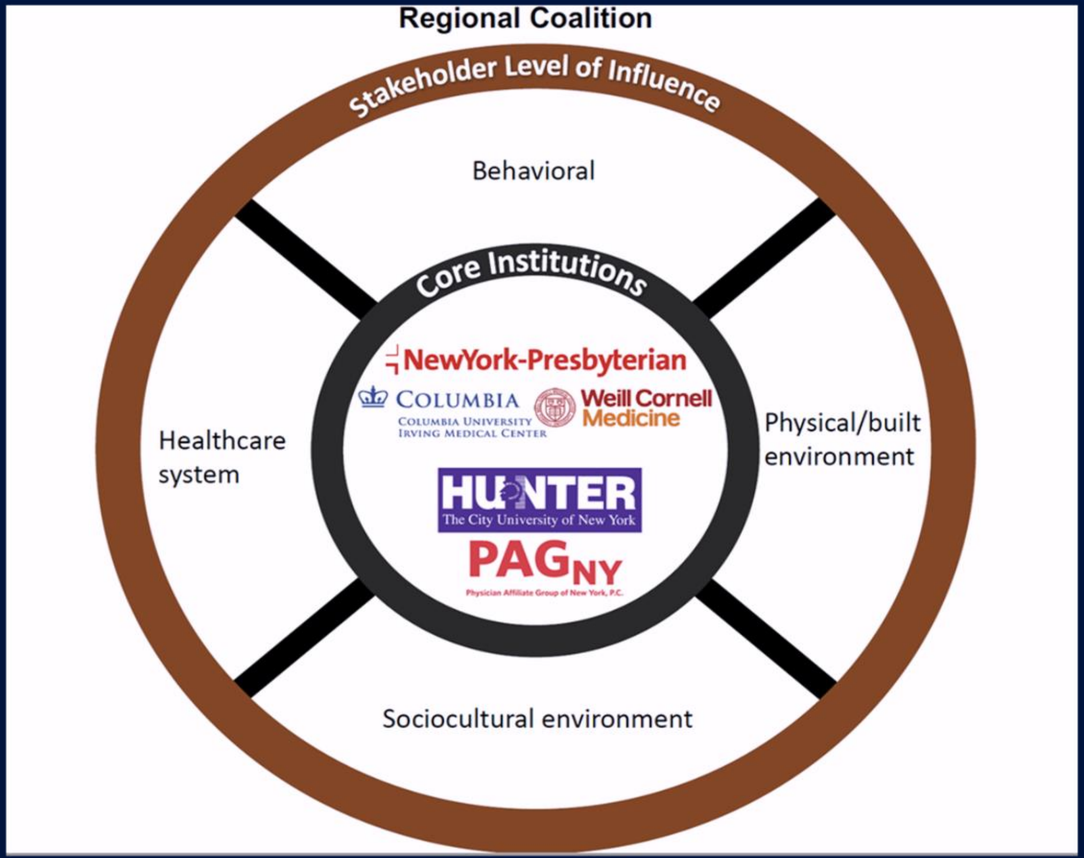
Nominated by Center PIs due to your expertise and connection to center activities/research

- Purpose: Collaboration, inform center activities, test out ideas to make NYC healthier and promote collective action to address the needs of those most affected by health inequities
- Role
  - Experts: provide insight, share knowledge and real-time reactions from communities most affected by health inequities
  - Connectors: advise community leaders and healthcare providers/researchers acting in the interest of those most affected by health inequities
  - Reflectors: provide feedback to COMMUNITY center researchers
  - Facilitators: bring recommendations to fruition

COMMUNITY Center Overview

The COMMUNITY Center brings together an interdisciplinary team of investigators, health care providers and community stakeholders to reduce health disparities in multiple chronic diseases in the New York City Region.

Our current research and interventions focus on **cardiovascular disease and cancer and their risk factors among Black and Latinx populations**



The COMMUNITY Center is one of 11 NIMHD funded centers addressing health disparities in chronic diseases in the U.S.

11 NIHMD Multiple Chronic Disease Disparities Research Centers

CHLA
Columbia
Hopkins
Rutgers
U.Arkansas
U.Chicago
U.Minnesota
UAB
UCLA
Vanderbilt
Wayne State

Columbia University
HUNTER
PAGNY
Physician Affiliate Group of New York, P.C.
Weill Cornell Medicine

HUNTER

Elizabeth Cohn **(MPI)**
RN, PhD
Professor of Nursing,
Associate Provost for
Research

PAGNY
Physician Affiliate Group of New York, PC

Maryanne Rivera
Director of Research
Operations for PAGNY

Weill Cornell Medicine

Erica Phillips **(MPI)**
MD, MS, Associate
Professor of Clinical
Medicine, Director,
Office of COE for the
Sandra and Edward
Meyer Cancer Center

COLUMBIA UNIVERSITY

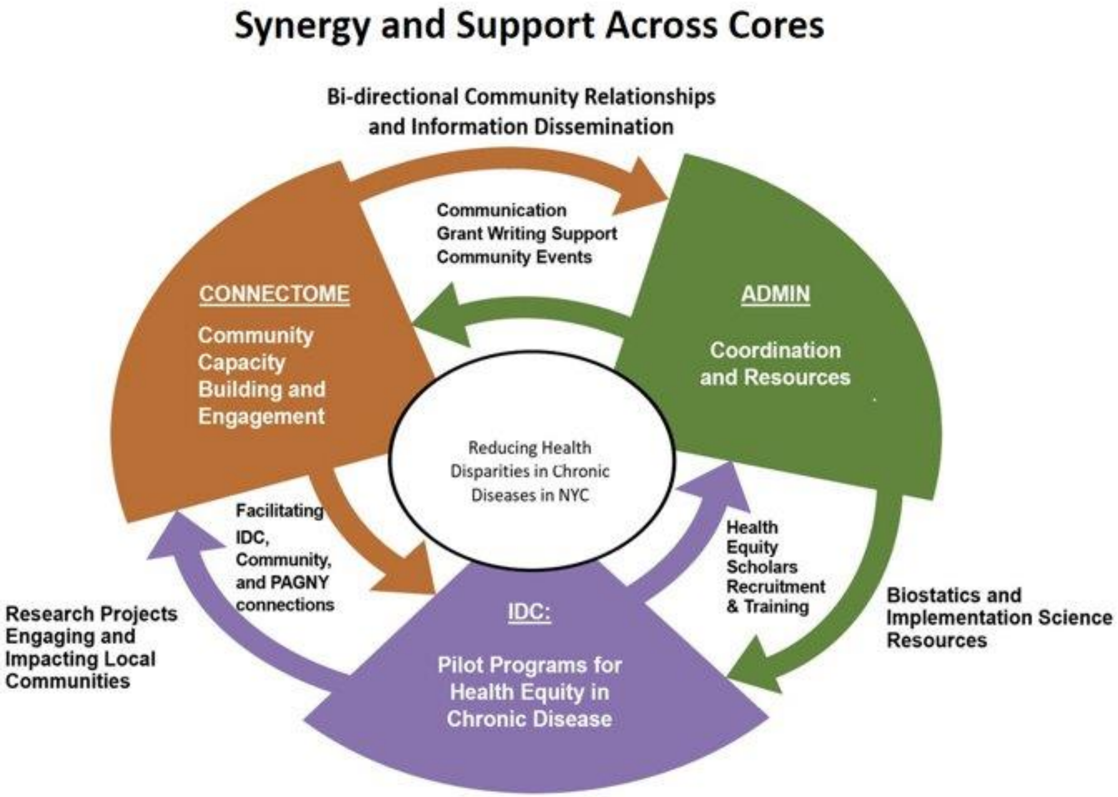
Dawn Hershman **(MPI)**
MD, MS, Professor of
Medicine and Epidemiology,
Director, Breast Oncology and
Population Science Program

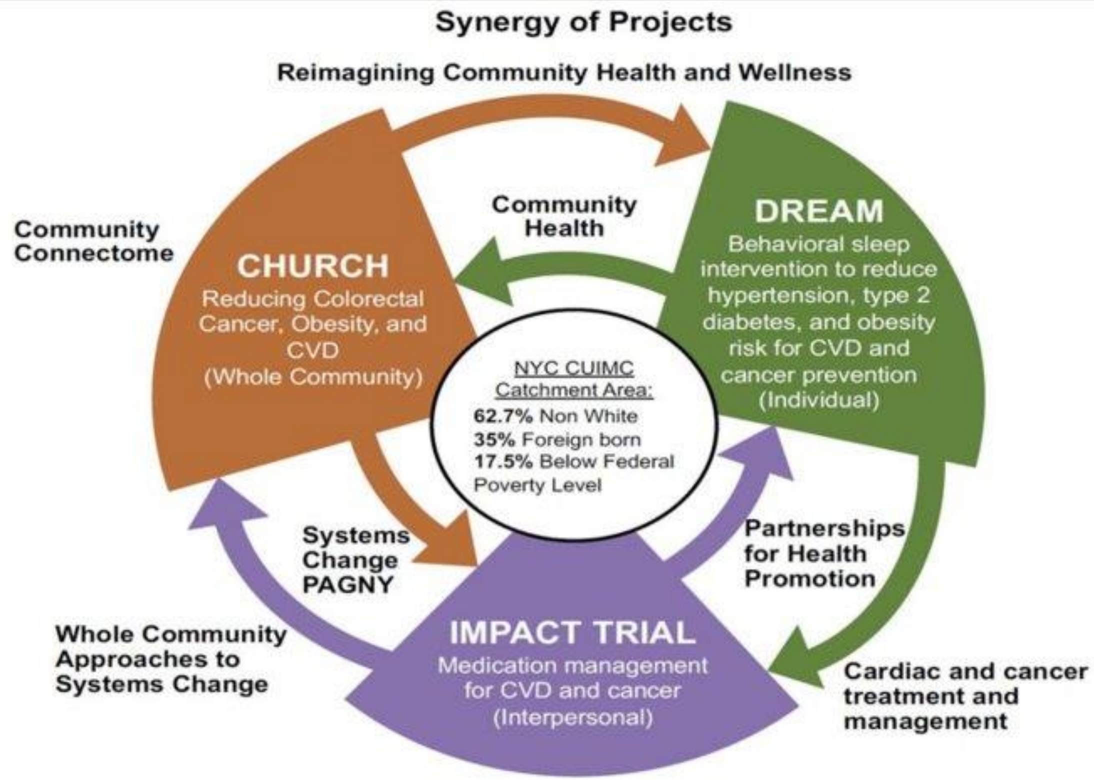
Daichi Shimbo **(MPI)**
MD, Professor of
Medicine, Co-Director
of the Columbia
Hypertension Center

Mary Beth Terry
(Contact MPI)
PhD, Professor of
Epidemiology, Director,
Office of COE at CUIMC
Cancer Center

Olajide Williams **(MPI)**
MD, MS, Professor and
Chief of Staff of the
Department of Neurology

Center Synergy and Collaboration





COMMUNITY CENTER RESEARCH

Dr. Olajide Williams & Dr. Sidney Hankerson

Dr. Dawn Hershman & Dr. Ian Kronish

Dr. Nour Makarem & Dr. Parisa Tehranifar

CHURCH:
Community **H**ealth workers
United to **R**educe **C**olorectal
cancer and CVD among
people at **H**igher risk

DREAM:
Addressing Sleep **D**uration,
Regularity, and **E**fficiency: **A**
Multidimensional Sleep
Health Intervention for
Reducing Disparities in
Cardiometabolic Disease

IMPACT:
Intervention to i**M**Prove
Adheren**C**e equi**T**ably, a trial
to support medication
management for people with
multiple chronic diseases

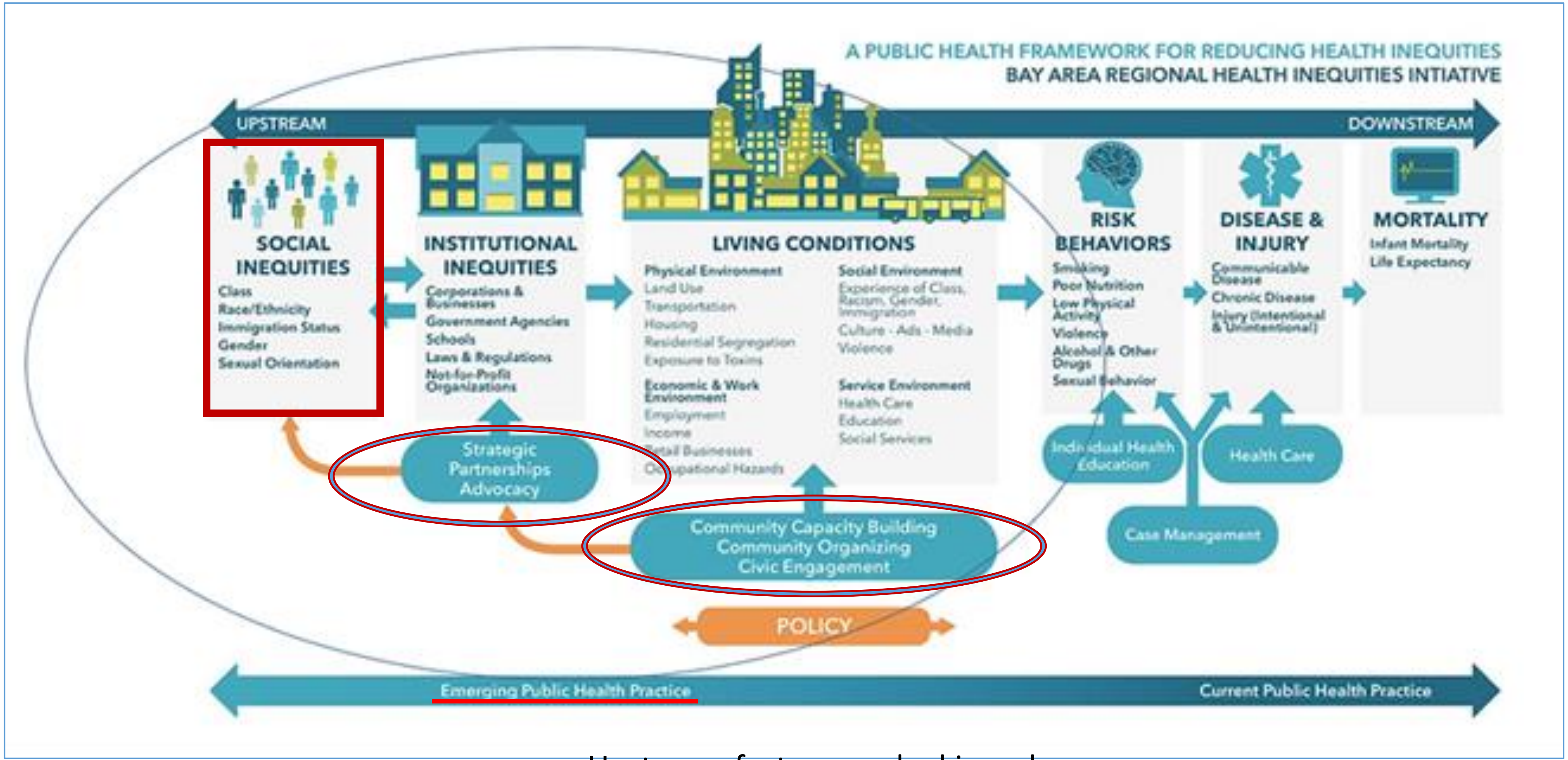
Columbia University HUNTER PAGNY Physician Affiliate Group of New York, P.C. Weill Cornell Medicine

COMMUNITY Center CONNECTOME
Vision & Mission

We aim to address systemic/structural racism (Upstream/Root causes)

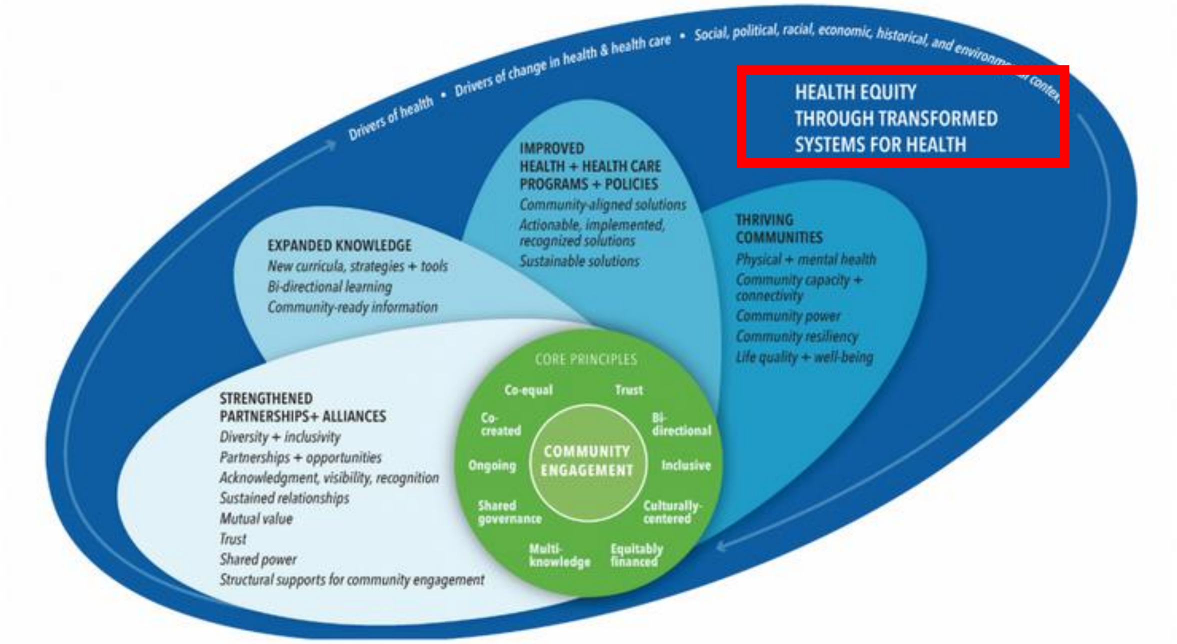
- By centering the voice of, and power-sharing with, community members
- Acknowledging, valuing, and listening to community organizations’ and members’ expertise
- Collaborating & Co-creating a culturally-responsive model of community-engagement that will inform implementation science, transform systems and achieve health equity

Addressing Upstream Factors that Impact Health



Upstream factors marked in red

Pathways to Health Equity



Capacity Building & Sustainability Programming

- BUILD grants
  - Funding Opportunities
- Skills-sharing & professional development
  - COMMUNITY Academy
- Strategic partnerships
  - COMMUNITY Linking CAB
  - COMMUNITY Stakeholder Meetings
  - COMMUNITY Conference/CHW Symposium (Fall '23)
  - COMMUNITY Health Equity Series (Fall '23)

Investigator Development Core: Health Equity Scholar Research

Pilot awards are intended to support:

Collection & analysis of new preliminary data to support a larger future study

Collection & analysis of additional data for a grant resubmission

Devika Jutagir, PhD
Asst. Attending Psychologist
Memorial Sloan Kettering Cancer Center
Asst. Professor of Clinical Psychiatry
Weill Cornell Medical College
COMMUNITY Center Investigator Development Core, Health Equity Scholar

Anita Gul, MD
NY Medical College/Physician Affiliate Group of New York
Memorial Sloan Kettering
COMMUNITY Center Investigator Development Core, Health Equity Scholar

COLUMBIA UNIVERSITY HUNTER PAGNY Physician Affiliate Group of New York, P.C. Weill Cornell Medicine

Discussion, questions and other experiences.