

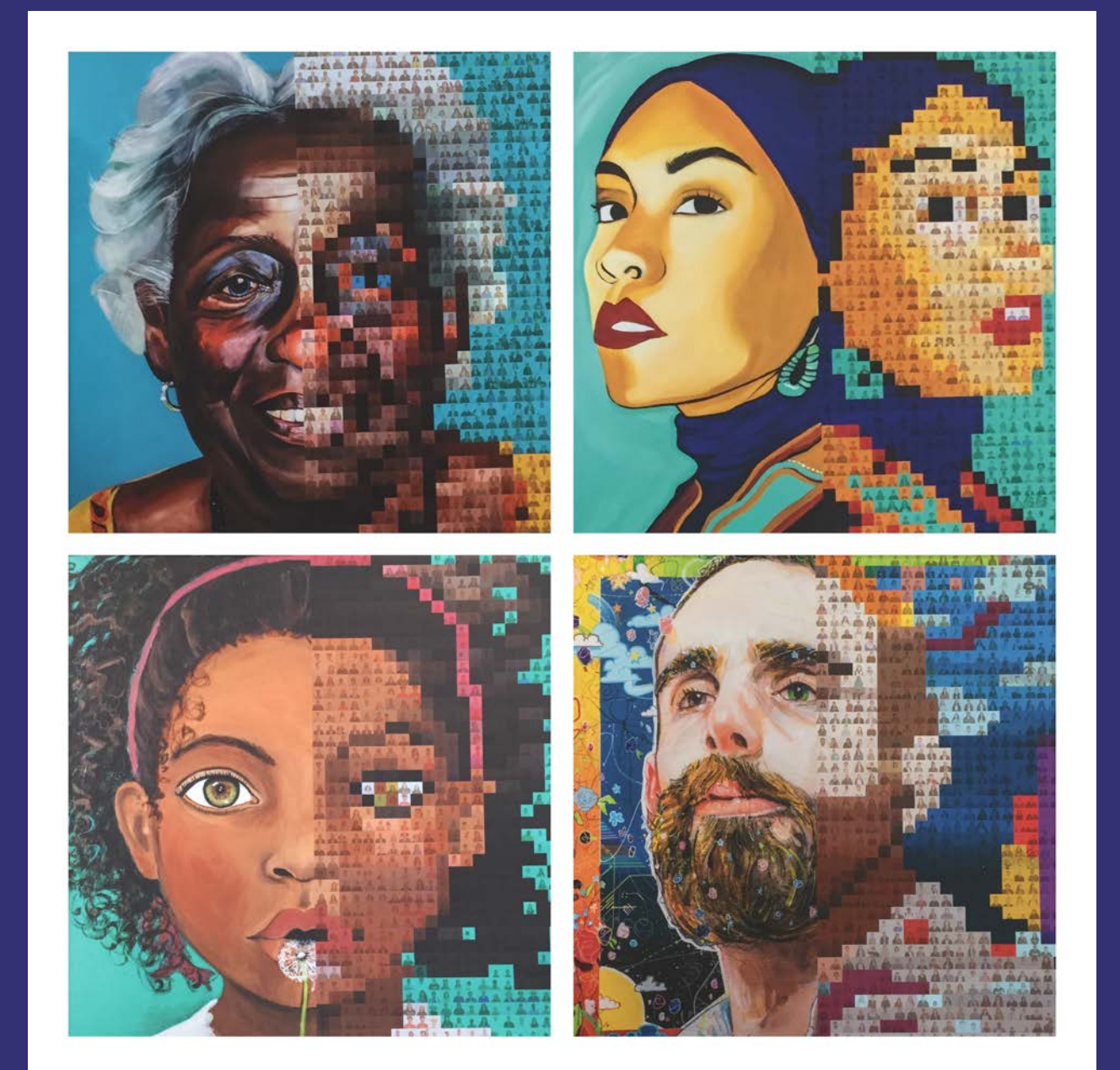
AoU Advisory Panel meeting  
July 10, 2019

# Participants as Partners in the *All of Us* Research Program

*Consuelo H. Wilkins, MD, MSCI*  
*Vice President for Health Equity*  
*Vanderbilt University Medical Center*

 [@DrCHWilkins](https://twitter.com/DrCHWilkins)

**All of Us**  
RESEARCH PROGRAM



# Overview

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- *All of Us* has a comprehensive approach to engaging participants, communities, health care providers, and other stakeholders.
- Engagement is distinct from recruitment and retention.
- Engaging **participants as partners** is expected to make the research more relevant to participants and communities and speed the translation of discoveries into practice.





## Engagement

*Involve stakeholders in study selection, design, conduct, and/or dissemination*



## Recruitment

*Enroll in study*



# The Recruitment Continuum



# *All of Us* Research Program Engagement Core

## *Mission:*

Engage “participants as partners” in the oversight, design, and conduct of the *All of Us* Research Program



# AoU Engagement Core

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**Consuelo H. Wilkins MD, MSCI**



**Karriem S. Watson, DHSc, MS, MPH**



**Laura Beskow, PhD, MPH**



**Elizabeth G. Cohn, PhD, RN**



**Alecia Fair, DrPH**



**Selena McCoy Carpenter, MEd**



**Juan Escarfuller, MA, MDiV**



**Kathleen Brelsford, PhD, MPH**



**Catherine M. Hammack, MA, JD**

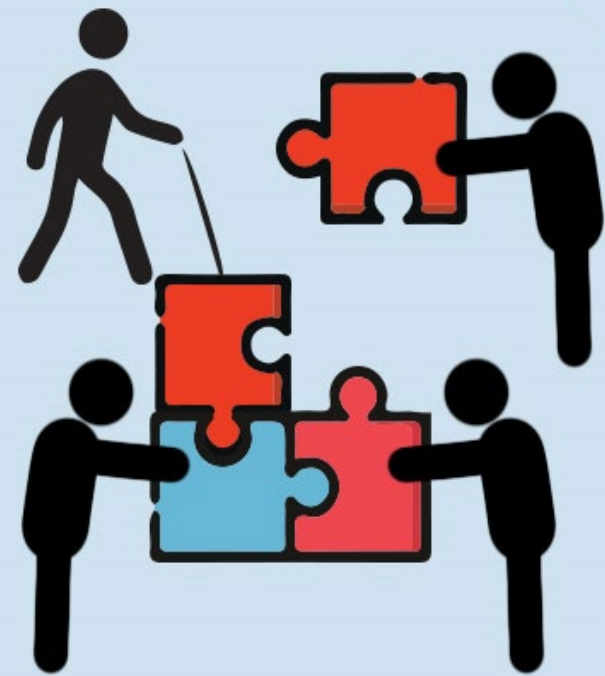


**Melinda Aldrich, PhD**

All core members are at Vanderbilt University Medical Center – except for Dr. Watson at University of Illinois in Chicago and Dr. Cohn at CUNY and Columbia.

# *All of Us* Engagement Core Aims

Create infrastructure  
to fully integrate  
participants in all  
aspects of *All of Us*



Identify and  
meaningfully engage  
diverse participants in  
governance

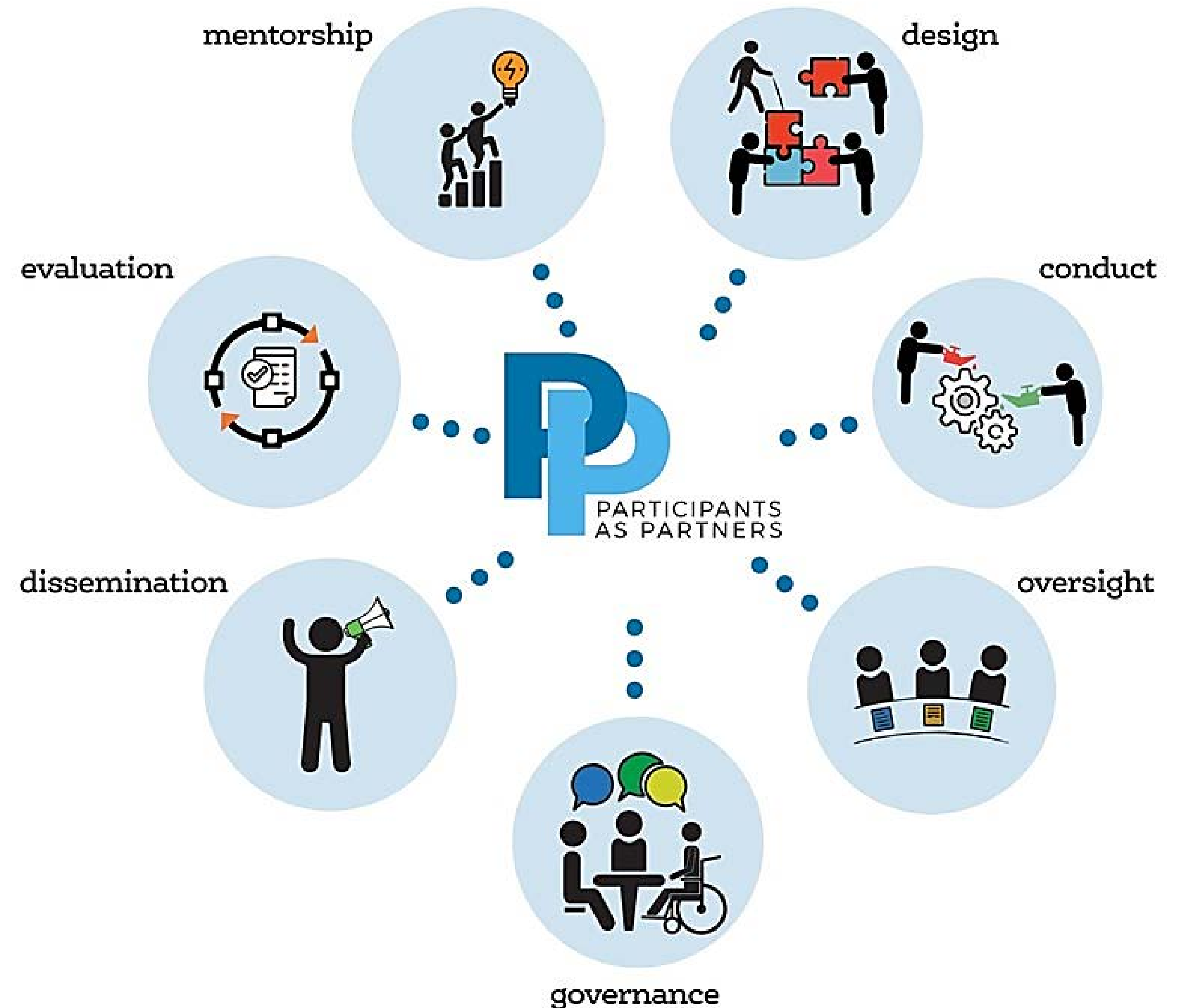


Assess impact of  
engagement in  
*All of Us* Research  
Program



# Engagement Core Guiding Principles and Domains

- Participants reflect the broad **diversity** of the US: geographic, racial, ethnic, gender, cultural, health status, and sexual identity.
- We provide **clear expectations and resources** to participate fully.
- We provide **communications and resources** based on participants' needs and preferences.
- Participant representatives receive **appropriate compensation** for their time.
- We use **engagement strategies** that are distinct from enrollment and recruitment, reflecting **mutual respect, trust, and cultural humility**.
- We **arrange travel and pay in advance** to reduce participants' burden.





# *All of Us* Research Program Engagement Core

## Current Initiatives

**Steering  
Committee**

**Executive  
Committee**

**Participant  
Ambassadors**

**Advisory  
Panel**

**Director's  
Think Tank**

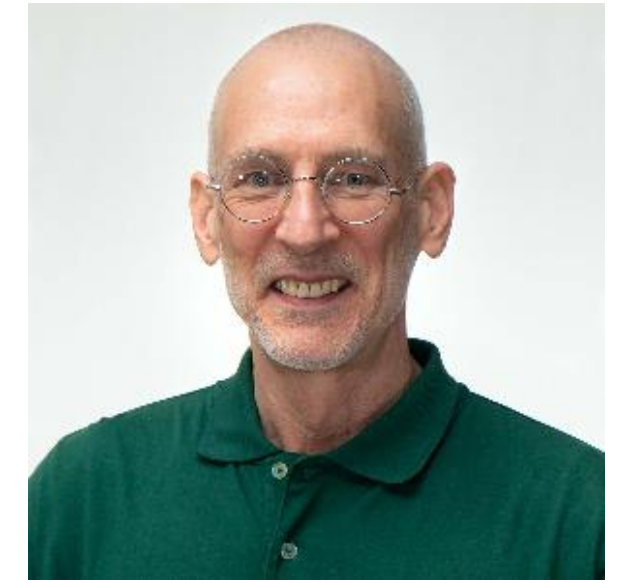
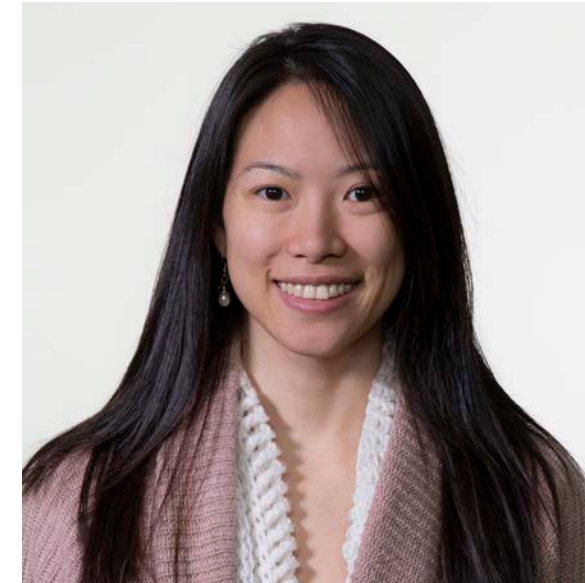
## Planned initiatives

**Participant  
Polling**

**Engagement  
Studios**

# Participants as Partners

## Steering Committee, Executive Committee, Advisory Panel



- Steering Committee: 4; Executive Committee 2; Advisory Panel: 2
- Full members – attend meetings, vote, etc.
- Selection Process
  - Announced in participant newsletter February 2018
  - Full participants self-nominated
  - Blind review of personal statements
  - Interviewed 15 participants
  - Selections prioritized to include diverse backgrounds



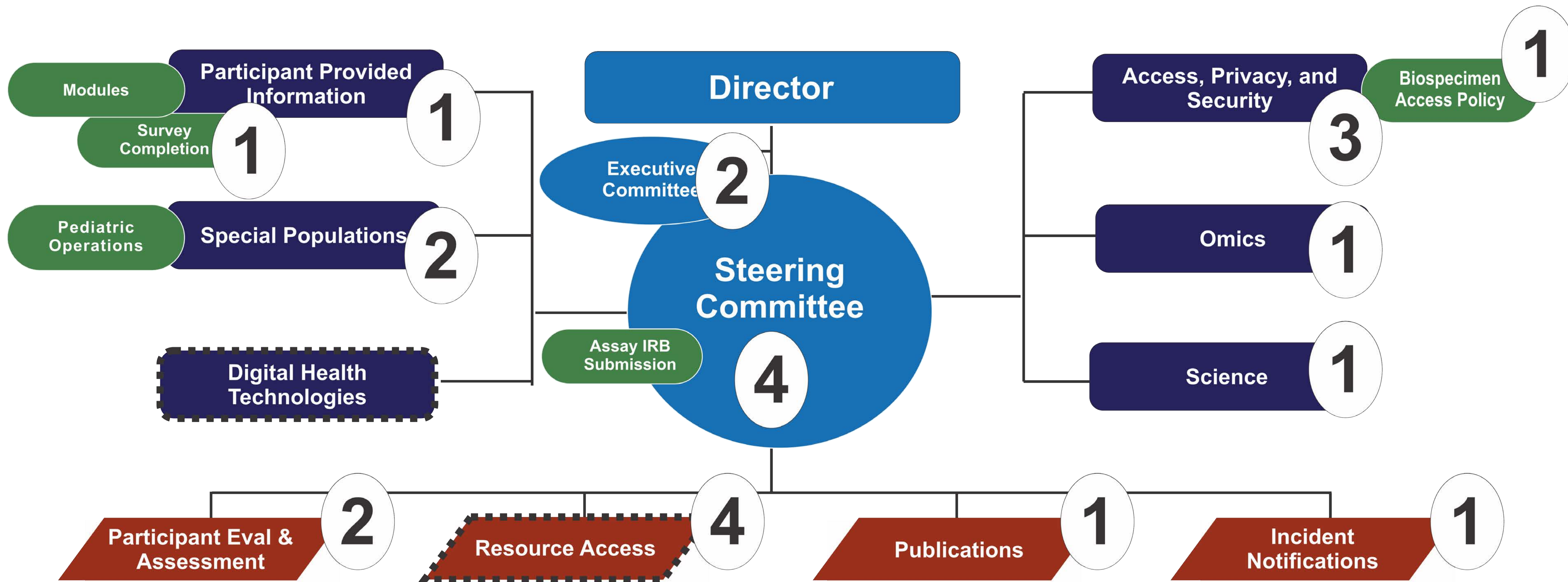
# Participant Ambassadors



- Individuals from 15 states: FQHCs (6), Health Provider Organizations (10), VA (3), DV (3)
- Nominated by engagement leads; from their respective Community and/or Participant Advisory Boards

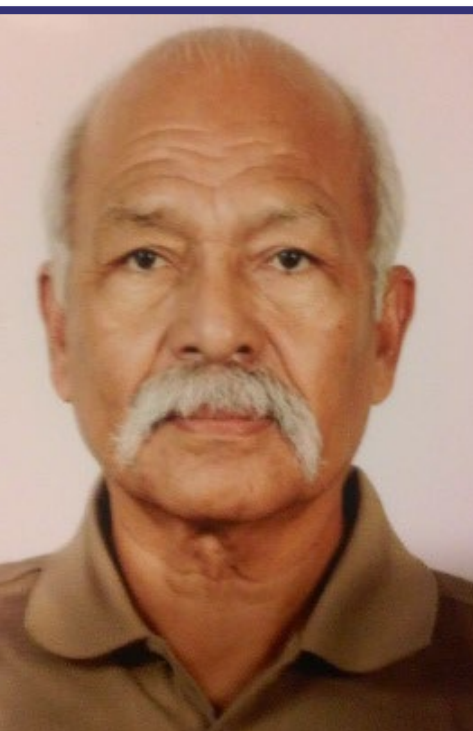


# Participant Partners in Governance





# Director's Think Tank

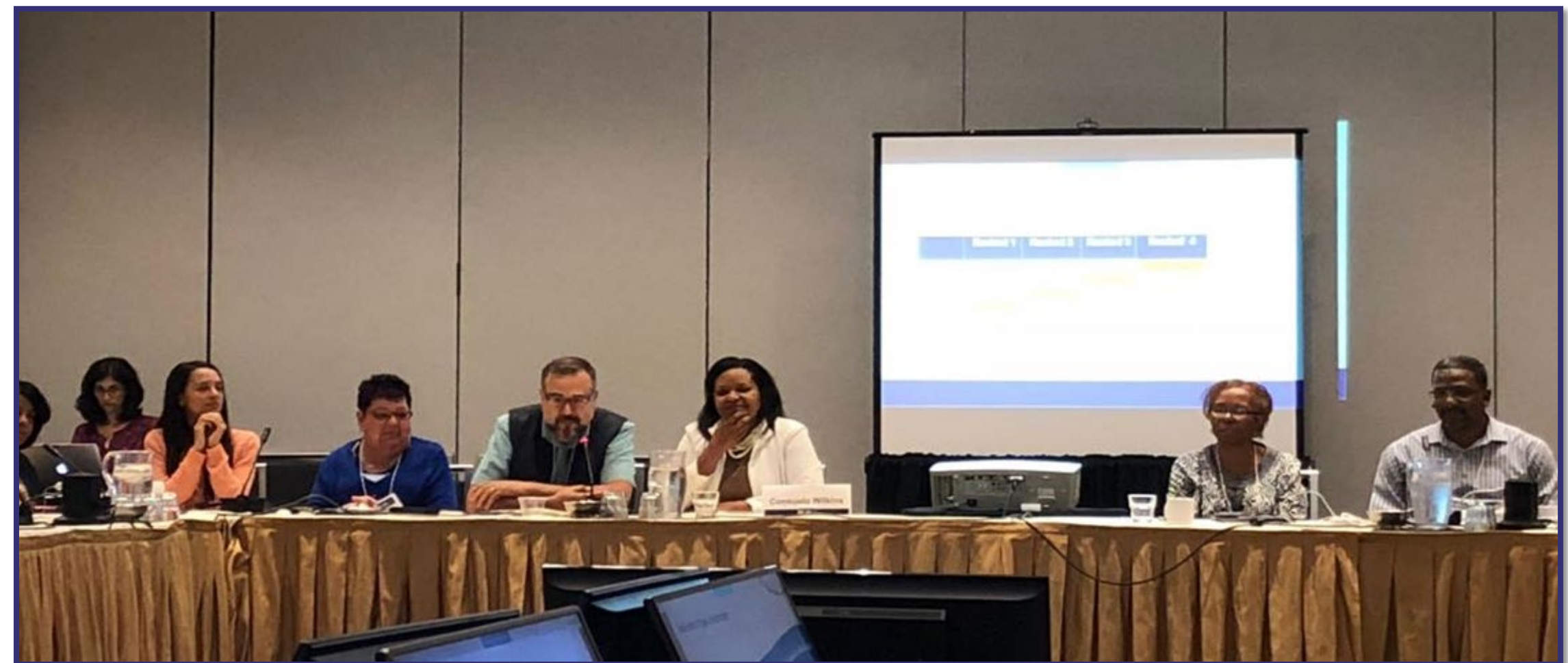


- Purpose
  - Small group of individuals who live in DC area to provide feedback directly to AoU leadership
  - Help shape new approaches
  - Overcome challenges
  - Advance AoU mission
- Selection Process
  - Engagement Core performed blind review of nominator's short essay
  - Nominees ranked with preference to diversity and experience with working with diverse populations



# October 2018

- Participant Partner Retreat
- Director's Think Tank in-person meeting
- Joint session with AoU Steering Committee





## Multi-pronged approach to evaluation: quantitative, qualitative, objective

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- Participant Partner evaluation of engagement
- Leaderships' evaluation of engagement
- Mentorship evaluation (Steering Committee)

- Assessing AoU leaders, researchers, staff readiness for engagement
- Assessing Working Group Chairs' perceived need for engagement

- Blind review of meeting minutes
- Tracking timestamp of when participants receive meeting materials
- Pre-post comparison of how documents change after engagement

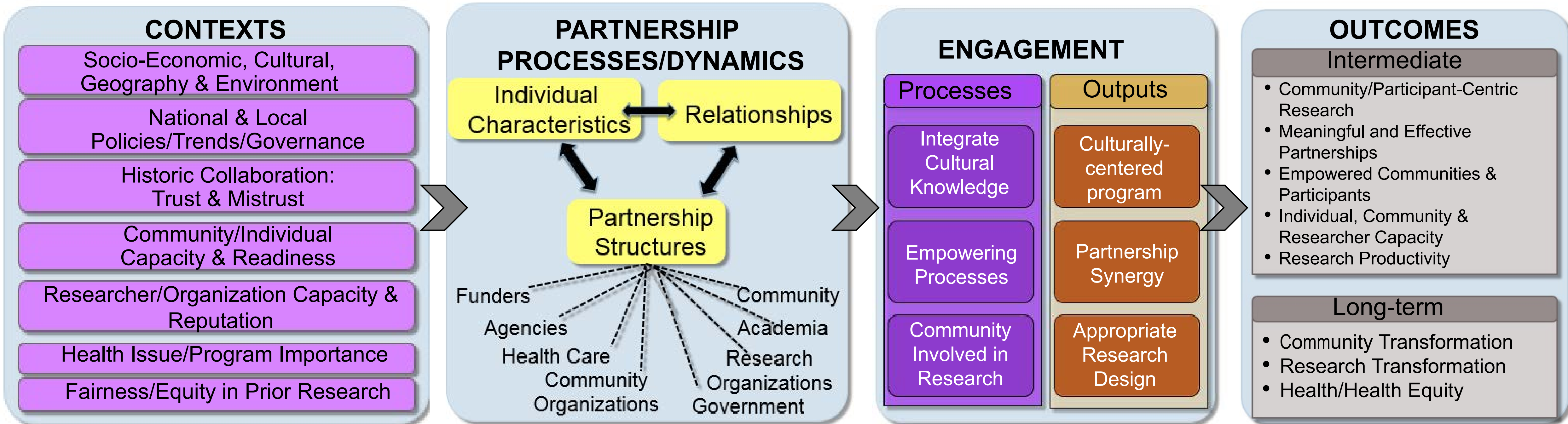
## 3-5 questions

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1. How can we ensure that perspectives of participants are proactively sought and considered at all levels of AoU?
2. When measuring the success of participant engagement, what are the most important outcomes to assess?
3. How can we work together to get researchers to value the science of engagement – not just the impact on recruitment/retention?

contact: [consuelo.h.wilkins@vumc.org](mailto:consuelo.h.wilkins@vumc.org)





CONTEXTS	PARTNERSHIP PROCESSES/DYNAMICS		ENGAGEMENT	OUTCOMES
<ul style="list-style-type: none"> <li>• Social-economic, cultural, geographic, political-historical, environmental factors</li> <li>• Policies/Trends: National/local governance &amp; political climate</li> <li>• Historic degree of collaboration and trust between researchers &amp; community</li> <li>• Community capacity &amp; readiness</li> <li>• Researcher/Organization: capacity, readiness, reputation</li> <li>• Perceived severity of issues or importance of program</li> <li>• Historic degree of fairness in use of information &amp; findings</li> </ul>	<p><b><u>Structural Dynamics:</u></b></p> <ul style="list-style-type: none"> <li>• Diversity</li> <li>• Formal Agreements</li> <li>• Real power/resource sharing</li> <li>• Alignment with principles</li> <li>• Length of time in partnership</li> </ul> <p><b><u>Individual Dynamics:</u></b></p> <ul style="list-style-type: none"> <li>• Core values</li> <li>• Motivations for participating</li> <li>• Personal relationships</li> <li>• Cultural identities/humility</li> <li>• Individual experiences</li> <li>• Individual beliefs, spirituality</li> <li>• Reputation &amp; trustworthiness of researchers/organization</li> </ul>	<p><b><u>Relational Dynamics:</u></b></p> <ul style="list-style-type: none"> <li>• Safety, fairness</li> <li>• Dialogue, listening &amp; mutual learning</li> <li>• Leadership &amp; stewardship</li> <li>• Influence &amp; power dynamics</li> <li>• Flexibility</li> <li>• Self &amp; collective reflection</li> <li>• Participatory decision-making &amp; negotiation</li> <li>• Integration of local/community beliefs to group process</li> <li>• Task roles and communication</li> </ul>	<ul style="list-style-type: none"> <li>• Processes that honor cultural knowledge, local settings and organizations; and use both academic &amp; community language</li> <li>• Empowering co-learning processes lead to partnership synergy &amp; trust</li> <li>• Community members involved in research activities leads to research/evaluation designs that reflect community priorities, needs &amp; preferences</li> <li>• Bidirectional translation, implementation &amp; dissemination</li> </ul>	<p><b><u>Intermediate Outcomes:</u></b></p> <ul style="list-style-type: none"> <li>• Policy changes: in academia &amp; communities</li> <li>• Effective partnerships and projects</li> <li>• Empowerment – multi-level</li> <li>• Shared power relations in research/knowledge democracy</li> <li>• Growth in individual &amp; community capacities</li> <li>• Researcher knowledge and attitudes</li> <li>• Research productivity: research outcomes, papers, applications, awards</li> </ul> <p><b><u>Long-Term Outcomes:</u></b></p> <ul style="list-style-type: none"> <li>• Community transformation: policies/programs/conditions</li> <li>• Research transformation: culture, teams</li> <li>• Optimal health/health equity</li> </ul>

**Conceptual Framework Engagement in Precision Medicine.** Adapted from Wallerstein and Duran by Menon, Szalacha, Cohn, Watson, Wilkins 2017

# A comprehensive approach to evaluating engagement

Table 5. Evaluation Plan: Indicators of Success

<i>Aim</i>	<i>Successful Processes</i>	<i>Successful Outcomes</i>
<p><b>Establish the infrastructure to fully integrate participants and advocates into the governance and oversight of the <i>All of Us</i> Program.</b></p>	<ul style="list-style-type: none"> <li>• Engaged a representative sample of Program members in the nomination, selection, onboarding, mentoring and succession planning for the outcomes</li> <li>• Provided appropriate compensation for representatives</li> <li>• Ensured equitable opportunities to participate that account for time and effort of representatives</li> </ul>	<ul style="list-style-type: none"> <li>• Appointed participants and advocates to key positions through a participatory process</li> <li>• Established and implemented an on-boarding plan for appointees</li> <li>• Developed a succession plan for alternate and renewal appointments</li> </ul>
<p><b>Facilitate ongoing input from diverse participant representatives to enhance the design, implementation, and use of the <i>All of Us</i> Program.</b></p>	<ul style="list-style-type: none"> <li>• Jointly identified engagement strategies and populations</li> <li>• Engaged expert advisors to identify individuals from underrepresented groups to participate in activities</li> <li>• Ensured equitable opportunities to participate that account for time and effort of representatives</li> <li>• Provided appropriate compensation for representatives</li> <li>• Implemented course-corrections as necessitated</li> </ul>	<ul style="list-style-type: none"> <li>• Established and implemented onboarding plan</li> <li>• Implemented engagement of individuals from pool of diverse representatives in activities such as input on protocols and communications</li> <li>• Implemented process for convening panels to assist with language translations; and providing feedback on tools, processes and applications.</li> </ul>
<p><b>Assess the impact of participant engagement on <i>All of Us</i> Program design, conduct, and use, and on participant representatives, advocates and partner organizations.</b></p>	<ul style="list-style-type: none"> <li>• Consistently measured engagement over the 5 years.</li> <li>• Track changes to the Program based on engagement of participant representatives and partner organizations</li> <li>• Provided compensation for representatives</li> <li>• Measured the expectations of engagement of the Program team and participant representatives</li> <li>• Measured changes in capacity &amp; personal development for participants, researchers, and organizations</li> </ul>	<ul style="list-style-type: none"> <li>• Documented positive impacts (such as higher trust, culturally-congruent protocol processes) on the Program and participant representatives,</li> <li>• Developed and disseminated a tool-kit for engagement plans for future endeavors such as the <i>All of Us</i> Program.</li> <li>• Documented that expectations and aspirations were met for Program staff</li> </ul>



# All of Us Engagement Core Aims

Create infrastructure to fully integrate participants in all aspects of the research



- Core
- Steering Committee
- Executive Committee
- Participant Ambassadors
- Advisory Panel
- Director's Think Tank

Identify and meaningfully engage diverse participants in governance



- Monthly meetings
- Participants voting members of SC and EC.
- Participant Ambassadors on 11 governance groups
- Continuous input and evaluation on AoURP processes, products and engagement experience.

**Specific Aim 3**  
Assess impact of engagement on research; develop metrics to inform *All of Us* as well as future large-scale research programs



- Readiness to Engage measure
- **Future Initiatives**
- Return of Results Survey
- Community Engagement Studios