Engagement Priorities for the All of Us Research Program

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Overview – *All of Us* Engagement Priorities

- *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.
Core Values Mandated Engagement

1. Participation is open to all.
2. Participants reflect the rich diversity of the U.S.
3. Participants are partners.
4. Trust will be earned through transparency.
5. Participants will have access to their information.
6. Data will be accessed broadly for research purposes.
7. Security and privacy will be of highest importance.
8. The program will be a catalyst for positive change in research.
Comprehensive Engagement Strategy

● *All of Us* is engaging organizations across the U.S.
  • **Engagement Partners**: Trusted national and regional community organizations and health care provider organizations
    ● Increase awareness of *All of Us*; some educate providers

  • **Champions**: Community and health advocacy organizations
    ● Increase awareness of *All of Us*

Photo: CPGI meeting May 2019

Dara Richardson-Heron, MD
Chief Engagement Officer
All of Us Community and Provider Partner Network
Comprehensive Engagement Strategy

**Key Engagement Partners**

- HCM Strategies, LLC
- Delta Research and Educational Foundation
- FiftyForward
- National Alliance for Hispanic Health
- PRIDEnet (Stanford, formerly SFGH)
- Engagement leads at all enrollment sites
- Vanderbilt Engagement Core
Engagement ≠ Recruitment
Engagement is Distinct from Recruitment and Retention

Goal of Engagement: Involve stakeholder in some aspect of study selection, design, conduct or dissemination

Goal of Recruitment: Enroll in study

Goal of Retention: Keep participant in study until completion

Although the goal of engagement is recruitment, engagement often enhances recruitment and retention
The Recruitment Continuum

Awareness  Acceptance  Consent  Enrollment  Retention  Return of Results

Wilkins and Johnson 2016
Engagement: A bidirectional relationship/interaction that results in informed decision-making about matters that affect or have the potential to affect the stakeholder group.

Engagement requires trust, respect, and cultural humility

Leshner et al 2013; Michener et al 2012; Frank et al 2014; Krumholz 2012; Wilkins 2015
Why engage the communities?

There is no substitute for the lived experience.

Community members, health care consumers and patients provide unique and invaluable insights, which can make all aspects of care, research, and medical education more relevant, credible, and effective.
Engagement

........ varying terms used for engagement, but not all are created equal......
The history of community engagement

Increasing Level of Community Involvement, Impact, Trust, and Communication Flow

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: Develop connections.

Consult
- 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.

Outcomes: Optimally, establishes communication channels and channels for outreach.
Outcomes: Develop connections.
Outcomes: Visibility of partnership established with increased cooperation.
Outcomes: Partnership building, trust building.


Engagement prior to *All of Us* launch
Precision Medicine Initiative Pilot Community Engagement Studios (4/29/16 – 10/31/16)

- 77 Studios
  - 60 were part of the Pilot
  - 17 with FQHCs (CT, TN, SC, NY, MS, CA)

- 654 community members

- Avg 8.5 community members/studio

- 46% self-identified as a racial/ethnic minority

- 9% self-identified as a sexual or gender minority


Vanderbilt PMI Pilot Community Engagement Studios
77 Studios; N= 654; Racial/Ethnic Minorities: 46%
April 29, 2016 - October 31, 2016
Engagement prior to *All of Us* launch

September 2016 – National Community Partners meeting
Lead by: HCM Strategies and NYC Precision Medicine Consortium
Engagement prior to *All of Us* launch

Inaugural Steering Committee members
Selection process November 2016
Appointed early 2017

Patricia Butts  
Steve Mikita  
Karl Surkan
AoU Engagement Core– PI: Consuelo H. Wilkins, MD, MSCI

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 Research Program Engagement Core

Mission:
Engage “participants as partners” in the oversight, design, and conduct of the All of Us Research Program
All of Us Research Program Engagement Core

Specific Aims:
- Create infrastructure to fully integrate participants in all aspects of the research
- Identify and meaningfully engage diverse participants in governance
- Assess impact of engagement on research; develop metrics to inform All of Us as well as future large-scale research programs

Current Participant Partner Initiatives

- 4 Steering Committee Members
- 2 Executive Committee Members
- 2 Advisory Panel Members
- 30 Participant Ambassadors
- 8 Director’s Think Tank Members

Future initiatives
- Community Engagement Studios
- Participant Polling
# Participants as Partners: Multi-level Engagement

<table>
<thead>
<tr>
<th>Engagement Method</th>
<th>Role</th>
<th>Key Dates</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All of Us Steering Committee (n= 4)</strong></td>
<td>Member of All of Us Steering Committee; provides participant perspective</td>
<td>Selected 4/6/18</td>
</tr>
<tr>
<td><strong>All of Us Executive Committee (n= 2)</strong>*</td>
<td>Member of All of Us Executive Committee; provides participant perspective</td>
<td>Selected 4/6/18</td>
</tr>
<tr>
<td><strong>All of Us Advisory Panel (n=3)</strong></td>
<td>All of Us Advisory Panel; provides participant perspective</td>
<td>Selected 4/6/18</td>
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<tr>
<td>Participant Ambassadors (n=24)**</td>
<td>Participant representatives from each HPO and FQHC, four from VA and four from DV**; provide input in overall engagement</td>
<td>Panel established by 4/10/18**</td>
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</table>

*Two of the four participants on the Steering Committee will also serve on the Executive Committee.

**Participant Ambassadors from HPOs will form the initial panel. Participants from the VA and DV will be added by July 2018.
## Participants as Partners: Multi-level Engagement

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<tr>
<td>Director’s Think Tank (n= 5-7)</td>
<td>Community representatives provide critical feedback to shape new approaches, solve problems, and advance All of Us mission</td>
<td>Think Tank selected by 5/30/18</td>
</tr>
<tr>
<td>Community Engagement Studios (n= 8-10/studio)</td>
<td>Panels of participants convened to provide specific-input; one-time commitment.</td>
<td>Convened on demand, for specific input.</td>
</tr>
<tr>
<td>Participant polling (n= 500+)</td>
<td>Participants invited via portal to provide feedback, answer questions. Polls will require 5-10 minutes.</td>
<td>Goal: first invitation July 2019 ongoing invitations</td>
</tr>
<tr>
<td>Peer mentors and participant speakers (n= 10)</td>
<td>Prior members of Steering Committee, Advisory Panel, or Think Tank; provides peer guidance to new members;</td>
<td>Begin identifying potential participants 7/1/2018</td>
</tr>
</tbody>
</table>
2018 Engagement Core Timeline

Jan-Feb
- Engagement Core launched, Call for Participant Partner & Ambassador nominations (HPO & RMC)
- Participant Partners selected & announced

March
- Call for Director’s Think Tank nominations

April
- One-on-one calls with Participant Partners to clarify roles & assess needs

May
- Orientation & meeting with leadership for Participant Partners on SC, EC, AP
- Begin participating in SC, EC, AP meetings

June
- Call for DV/VA Ambassador nominations, selected & announced; Director’s Think Tank members selected & announced

July
- Advisory Panel & Participant Ambassador orientation
- Director’s Think Tank meetings begin Aug

Aug-Sep
- Participant Ambassadors monthly meetings

Oct-Dec
- In-person Retreat in Oct
- Dec work group onboarding, participant led project planning begins
- Director’s Think Tank meeting October

24
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.
Participants as Partners
Steering Committee, Executive Committee, Advisory Panel

- Steering Committee: 4; 2 of which also serve on Executive Committee; 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 top candidates
  - 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 Ambassadors

- Participate in monthly meetings
- Help identify ways to make the program relevant to participants by identifying challenges, barriers and opportunities
- Serve on Governance Committees/Boards/Task Forces
- Provide feedback and input on *All of Us* activities and priorities
- Deliberate on issues presented from the *All of Us* Research Program
- Suggest new activities, including participant led projects
<table>
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<tr>
<th>Governance Group</th>
<th>Participant Ambassador</th>
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<tr>
<td>Participant Evaluation and Assessment Board</td>
<td>Lottie Barnes and Gus Prieto</td>
</tr>
<tr>
<td>Omics</td>
<td>JD Bean</td>
</tr>
<tr>
<td>Special Populations Committee</td>
<td>Miguel Flores and Hugo Campos</td>
</tr>
<tr>
<td>Participant Provided Information (PPI)</td>
<td>José Iraheta</td>
</tr>
<tr>
<td>Science</td>
<td>Keisha Bellamy</td>
</tr>
<tr>
<td>Committee on Access Privacy and Security (CAPS)</td>
<td>Vilma Velez and Evelyn Ortiz</td>
</tr>
<tr>
<td>Electronic Health Records Committee</td>
<td>Tyrone Thigpen and Ana Pavon</td>
</tr>
<tr>
<td>Incident Notification Board (INB)</td>
<td>Michael Miller</td>
</tr>
<tr>
<td>Publications Board</td>
<td>Beth Rubinstein</td>
</tr>
<tr>
<td>Resource Access Board</td>
<td>Karen Wall and Marilyn Roman</td>
</tr>
</tbody>
</table>
Director’s Think Tank

● **Purpose**
  - Small group of mid-level professionals from 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
Conceptual Framework Engagement in Precision Medicine. Adapted from Wallerstein and Duran by Menon, Szalacha, Cohn, Watson, Wilkins 2017
Questions?
## A comprehensive approach to evaluating engagement

<table>
<thead>
<tr>
<th>Aim</th>
<th>Successful Processes</th>
<th>Successful Outcomes</th>
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| Establish the infrastructure to fully integrate participants and advocates into the governance and oversight of the All of Us Program. | • Engaged a representative sample of Program members in the nomination, selection, onboarding, mentoring and succession planning for the outcomes  
• Provided appropriate compensation for representatives  
• Ensured equitable opportunities to participate that account for time and effort of representatives | • Appointed participants and advocates to key positions through a participatory process  
• Established and implemented an on-boarding plan for appointees  
• Developed a succession plan for alternate and renewal appointments |
| Facilitate ongoing input from diverse participant representatives to enhance the design, implementation, and use of the All of Us Program. | • Jointly identified engagement strategies and populations  
• Engaged expert advisors to identify individuals from underrepresented groups to participate in activities  
• Ensured equitable opportunities to participate that account for time and effort of representatives  
• Provided appropriate compensation for representatives  
• Implemented course-corrections as necessitated | • Established and implemented onboarding plan  
• Implemented engagement of individuals from pool of diverse representatives in activities such as input on protocols and communications  
• Implemented process for convening panels to assist with language translations; and providing feedback on tools, processes and applications. |
| Assess the impact of participant engagement on All of Us Program design, conduct, and use, and on participant representatives, advocates and partner organizations. | • Consistently measured engagement over the 5 years.  
• Track changes to the Program based on engagement of participant representatives and partner organizations  
• Provided compensation for representatives  
• Measured the expectations of engagement of the Program team and participant representatives  
• Measured changes in capacity & personal development for participants, researchers, and organizations | • Documented positive impacts (such as higher trust, culturally-congruent protocol processes) on the Program and participant representatives,  
• Developed and disseminated a tool-kit for engagement plans for future endeavors such as the All of Us Program.  
• Documented that expectations and aspirations were met for Program staff |