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Reaching, Educating and Engaging Diverse Communities: All of Us Research Program Case Study

Ronnie Tepp,
Principal, HCM Strategists
Disclaimer

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All of Us
RESEARCH PROGRAM

Mission:
To accelerate health research and medical breakthroughs, enabling individualized prevention, treatment and care for all of us.
Coincident with advancing the science of medicine is a changing culture of medical practice and medical research that engages individuals as active partners—not just as patients or research subjects.

We believe the combination of a highly engaged population and rich biological, health, behavioral, and environmental data will usher in a new and more effective era of American healthcare.

-- Precision Medicine Initiative (PMI) Working Group Report to the Advisory Committee to the Director, NIH, September 17, 2015
All of Us Mission and Objectives

Nurture relationships with one million or more participant partners, from all walks of life, for decades.

Our mission
To accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us.

Deliver the largest, richest biomedical dataset ever that is easy, safe, and free to access.

Catalyze a robust ecosystem of researchers and funders hungry to use and support it.
All of Us Research Program Core Values

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.
A Transformational Approach to Diversity
HCM’s framework: The Participant Engagement Journey

- Start at point of relevance
- ‘Inside out’ strategy
- Digital/non-digital tools and experiences
- Multiple touchpoints
The Value of Participating in *All of Us*

- **An opportunity to learn** some of your own health indicators and get your own data

- An opportunity to **fight disease** and improve the health of future generations

- The opportunity to **ensure that your community is included** in the studies that may lead to new understanding and new treatments

- The opportunity to **be part of a movement** to make our health care more precise, more personal, and more effective
Value is Different for Each Community and Person

- Help improve the health of your children, grandchildren, and future generations
- Ensure that your local community is included
- Learn about your own health
- Choose to access your data
- Learn about additional research opportunities
Right Messenger + Right Tool = Strong Value Statement

- Materials are passive
- People are engaging
- Provide trusted messengers with a variety of tools and they are able to localize a national program to resonate with the target audience
Community & Provider Gateway Initiative (CPGI)

- Network of trusted community messengers who can engage communities in an authentic and impactful way.

- Focused on education and awareness of All of Us within their communities.
CPGI Network (as of February 2019)
Snapshot of activities (August 2018-February 2019)
Generating activity around National launch: May 2018
National Network of Community and Provider Organizations

Since 2016, our team has cultivated relationships with community and provider organizations to garner support for the program at launch and beyond to help increase awareness of All of Us and the importance of participating in research in communities across UBR populations.

Types of organizations include:

- Patient/Disease/Research Advocacy
- Community-based
- Minority serving
- Faith-based
- Provider trade associations
- Professional Societies
Activities in Support of Launch (Non-CPGI, Non-funded, May – July 2018)

71 Community and Provider organizations completed an activity at launch in support of All of Us*.

Social Media: 39

Email distribution: 16

Blog/website/other: 5

Webinar: 1

In-person activity/meeting presence: 8

Champions Program: 26

*some organizations engaged in more than one activity
Key takeaways:

- Don’t be confined by traditional stakeholders
- Think creatively about partnerships
- Use a variety of engagement models
- Give your partners space to define value