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

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Disclaimer

The views and opinions expressed in this presentation are those of the individual presenter and do not necessarily reflect the views of the Clinical Trials Transformation Initiative (CTTI) or the U.S. Food & Drug Administration (FDA).



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

All of Us
RESEARCH PROGRAM

The
Future of
Health Begins
With You

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



demographics

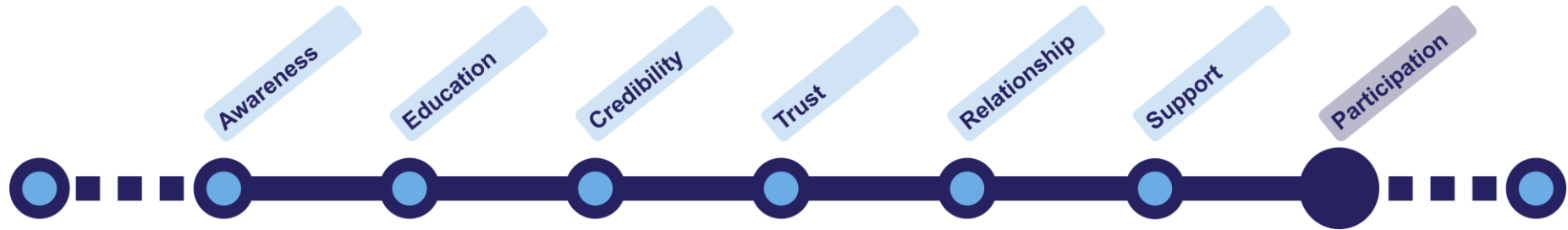
health status

geography

data types

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)

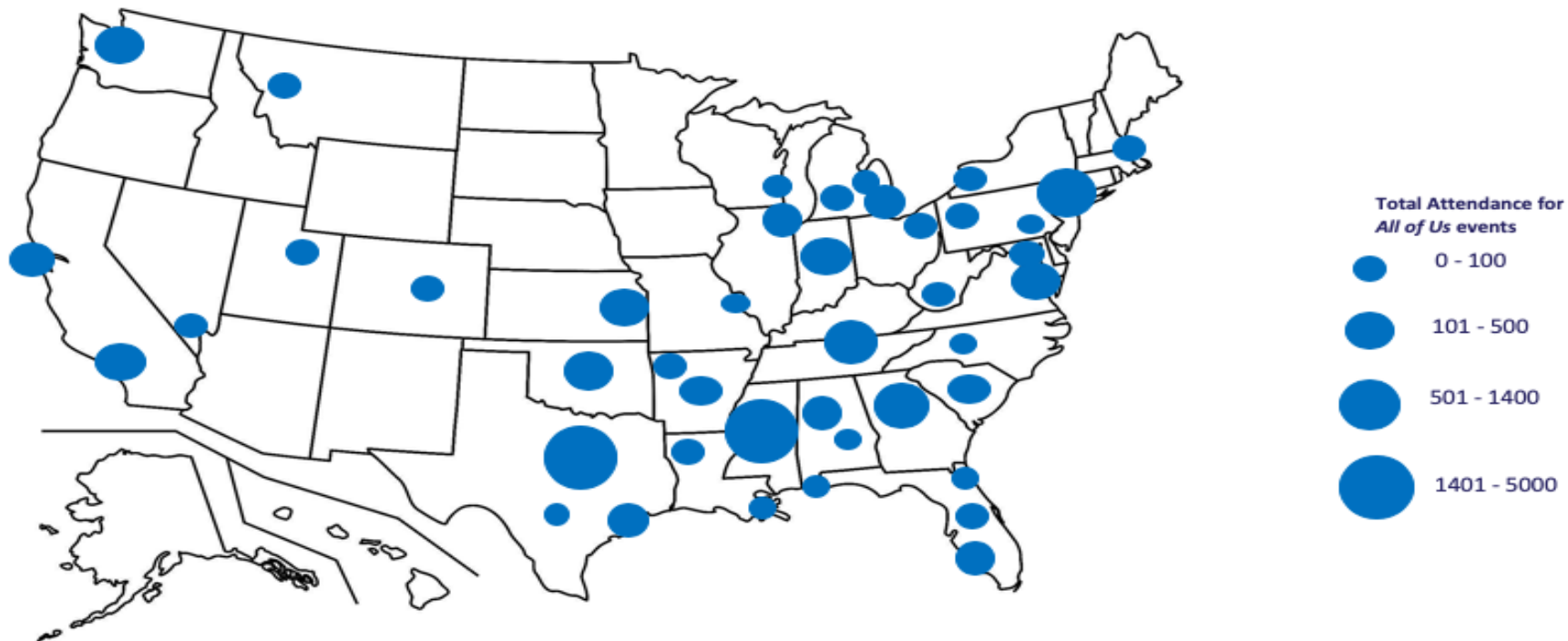
- Network of trusted community messengers who can engage communities in an authentic and impactful way
- Focused on **education and awareness** of *All of Us* within their communities



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

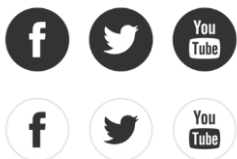
Since 2016, our team has cultivated relationships with community and provider organizations to garner support for the program at launch and beyond to help increase awareness of *All of Us* and the importance of participating in research in communities across UBR populations.

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**

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