The NNLM and *All of Us* Research Program Partnership: Transforming, Translating and Transcending Health Disparities Through Health Literacy

Michele Spatz, M.S.
NNLM All of Us Community Engagement Coordinator
NNLM PNR, University of Washington
Seattle, WA
Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in lifestyle, environment, and biological makeup. It is a radical shift in how each of us can receive the best care possible based on our unique characteristics.
Precision Medicine in Real Life

Right treatment for the right person

Prescription Eyeglasses
Insulin Pump
Blood Transfusions
Hearing Aid
Why now?

We have technologies that can collect and crunch huge amounts of data.

More people are engaged in their health, and can track and share their data — like steps and sleep.

We have a greater understanding of human genes.

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

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

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
Participation in the *All of Us* Research Program will be open to interested individuals. The program will reflect the rich diversity of America. Participants will be partners in the program. Trust will be earned through robust engagement and full transparency. Participants will have access to information and data about themselves.

Data from the program will be broadly accessible to empower research. The program will adhere to the PMI Privacy and Trust Principles and the PMI Data Security Policy Principles and Framework. The program will be a catalyst for innovative research programs and policies.
**All of Us Research Program Infrastructure**

**DATA AND RESEARCH CENTER**
Big data capture, cleaning, curation, & sharing in secure environment

*Vanderbilt, Verily, Broad Institute*

**BIOBANK**
Repository for processing, storing, and sharing biosamples (35+M vials)

*Mayo Clinic*

**PARTICIPANT TECHNOLOGY SYSTEMS CENTER**
Web and phone-based platforms for participants

*Vibrent Health*

**PARTICIPANT CENTER / DV NETWORK**
Direct volunteer participant enrollment, digital engagement innovation, and consumer health technologies

*Scripps Research Institute (with multiple partners)*

**HEALTHCARE PROVIDER ORGS NETWORK**
HPOs with clinical & scientific expertise, enrollment & retention of participants

*30+ regional medical centers, FQHCs, VA, and future awards to grow network*

**COMMUNICATIONS & COMMUNITY NETWORK**
Building public awareness and fostering relationships with community organizations.

*This is where public libraries fit.*
Important Website

http://www.joinallofus.org
All of Us Partnership with the National Network of Libraries of Medicine

nnlm.gov/all-of-us
Overview of the partnership between *All of Us* and NLM

The AoU/NLM partnership has three main components.

- **Community Education**
- **Community Engagement**
- **AoU Learning Platform**
Goals of the partnership between *All of Us* and NNLM

- To increase the capacity of public library staff to improve health literacy.

- To highlight libraries as a technology resource for participant engagement, particularly those in underserved communities affected by the digital divide.

- To equip public libraries and member organizations with information about the *All of Us* Research Program to share with their local communities.
Activities and Outreach

1. Professional development & training opportunities through NNLM’s free webinars [https://nnlm.gov/training](https://nnlm.gov/training)
2. Support for CHIS certification
3. Funding for health information outreach (nnlm.gov/funding)
4. Making community connections & providing programming support
Libraries meet people where they are

Libraries are “generally perceived as trustworthy and helpful…”

Libraries encourage discussion and exploration

Libraries serve all...
## All of Us Research Program Underrepresented in Biomedical Research (UBR) Populations

<table>
<thead>
<tr>
<th>UBR Description</th>
<th>Algorithm</th>
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<tbody>
<tr>
<td>Race/Ethnicity</td>
<td>Is reported and is Hispanic, Latino or Spanish; race is reported and identified as something other than White</td>
</tr>
<tr>
<td>Age</td>
<td>Under 18 or over 65</td>
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<tr>
<td>Sex</td>
<td>Assigned female or intersex at birth</td>
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<tr>
<td>Sexual and Gender Minorities (SGM)</td>
<td>Is reported and is not Man, or is different than participant-reported sex at birth; sexual orientation is reported and is not straight</td>
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<tr>
<td>Income relative to FPL</td>
<td>Is reported and below Federal Poverty Level</td>
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<tr>
<td>Educational Attainment</td>
<td>Is reported and is less than a high school degree</td>
</tr>
<tr>
<td>Geography</td>
<td>Zip code is reported and is contained in the list of rural zip codes (&gt;50% of population resides in a non-metro county and/or rural Census Tract)</td>
</tr>
<tr>
<td>Access to Care</td>
<td>Participant needed or needs any medical visit in the past 12 months or currently, but cannot readily use the health care system or could not pay for medical care as needed</td>
</tr>
<tr>
<td>Disability</td>
<td>Participant has a physical and/or mental disability</td>
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NNLM Reading Club & Book Club Kits
How Can Health Sciences Librarians Get Involved?

• Become an NNLM Network Member (if not already)
• Apply for funding to implement a health literacy project with a public library partner
• Facilitate an NNLM Reading Club book discussion
• Participate in an NNLM CE offering on genetics
• Listen to Dara Richardson’s MLA talk on *All of Us*
• Share *All of Us* information with your library patrons
• Other opportunities to come!
Questions?

- Learn more and get involved at: nnlm.gov/all-of-us

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NNLM PNR, University of Washington, Seattle, WA
Email: mspatz@uw.edu
https://nnlm.gov/pnr