Engagement Strategies for Creating a Research-Informed Community
The Precision Medicine Initiative (PMI)

A federal effort launched in 2015.

**MISSION:** To enable a new era of medicine through research, technology, and policies that empower participants, researchers, and providers to work together toward development of individualized care.
Genes + Environment + Lifestyle = Health Status
Precision Medicine in Real Life
Right treatment for the right person --

- Prescription Eyeglasses
- Insulin Pump
- Blood Transfusions
- Hearing Aid
One-size fits-all medicine

Stratified medicine

Stratification
Patients are grouped by:
- Disease
- Subtypes
- Demographics
- Clinical features
- Biomarkers

Personalisation
- Patient individual:
  - Preferences
  - Clinical features
  - Medication history
  - Environment
  - Behaviours & habits
  - Biomarkers

Precision medicine
The future of health begins with you
Overview of All of Us Research Program
The cornerstone of the larger Precision Medicine Initiative—led by the National Institutes of Health

The program will start by collecting data from sources that will include:

- Health questionnaires
- Electronic medical records
- Physical measurements
- Biospecimens (blood and urine samples)
- Mobile/wearable technologies
- Environmental data

Data types will grow and evolve with science, technology, and trust.
Scientific Opportunities

- Be able to measure **estimates of risk** for a range of diseases
- Study how genes affect a person's response to medicine = **pharmacogenomics**
- Discover **biological markers** that signal increased or decreased risk of developing common diseases
- Develop **solutions to health disparities** in people from different backgrounds, education, ethnicities, etc.
- Use **mobile health technologies** to get real-time body measures and environmental exposures
- **Empower study participants** with data and information to improve their own health
- Open the door for more **clinical trials**
How to Join *All of Us*

- Complete informed consent online or on smartphone
- Complete 3 surveys about lifestyle habits, overall health, and demographics
- Visit to enrollment center to provide physical measurements
  - Height, weight, blood pressure, heart rate, hip and waist circumference, blood and urine samples
- Participants receive $25 compensation and future return of results
All of Us Pennsylvania Community Engagement Strategies

- Consistent presence at community health fairs, festivals, and conferences
  - Tabling displays
  - Lunch and Learn staff education

- Partnering with community leaders and agencies
  - Churches, libraries, non-profits, YMCAs, FQHCs, and more

- Mobile clinic team to reach communities with barriers to access
National Network of Inaugural Partners

- **National Partners**
- **Regional Medical Centers**
- **FQHCs**
- **Community Partners**

**San Francisco General Hospital Foundation**

**Vanderbilt Univ. Medical Center, with Broad & Verily (Data and Research Center)**

**Southern All of Us Network**

**University of Arizona (w/Banner Health)**

**California Precision Medicine Consortium**

**San Ysidro Health Center**

**California Precision Medicine Consortium**

**University of Pittsburgh**

**Illinois Precision Medicine Consortium**

**Mayo Clinic (Biobank)**

**Trans-American Precision Medicine Consortium**

**All of Us, Wisconsin**

**University of Arizona**

**Scripps Translational Science Institute (Participant Center)**

**Wondros**

**FiftyForward**

**Eau Claire Cooperative Health Center**

**Cherokee Health Systems**

**SouthEast Enrollment Center**

**HCM**

**Community Health Center, Inc.**

**New York City Precision Medicine Consortium**

**All of Us, Wisconsin, SouthEast Enrollment Center**

**Federal Partners: White House, HHS, NIH, ONC, HRSA, VA, USDS**

**Vibrent (Participant Technology Systems Center)**

**National Alliance for Hispanic Health**

**Delta Research and Educational Foundation**

**Inaugural Partners**
- **Mayo Clinic**
- **University of Arizona (w/Banner Health)**
- **New York City Precision Medicine Consortium**
- **New England Precision Medicine Consortium**
- **Trans-American Precision Medicine Consortium**
- **San Francisco General Hospital Foundation**
- **Community Health Center, Inc.**
- **San Ysidro Health Center**
- **All of Us, Wisconsin**
- **Vanderbilt Univ. Medical Center, with Broad & Verily (Data and Research Center)**
- **Southern All of Us Network**
- **Wondros**
- **FiftyForward**
- **Eau Claire Cooperative Health Center**
- **Cherokee Health Systems**
- **FQHCs**
- **Regional Medical Centers**
- **Community Partners**

**Funding Sources**
- **Federal Partners:** White House, HHS, NIH, ONC, HRSA, VA, USDS
- **Vibrent (Participant Technology Systems Center)**
- **National Alliance for Hispanic Health**
- **Delta Research and Educational Foundation**
Methods for identifying those who are at risk before disease strikes.

Analytical tools for predicting which prevention strategies will work best for which patients.

Screening methods that can identify early signs of disease before symptoms emerge.

Diagnostic methods for identifying subtypes of disease that may look the same on the surface but respond very differently to treatment.

Tests that can identify disease carrier status for prospective parents.

Devices for managing diseases and for tracking and guiding recovery.
Barriers to participating in research

I’m interested but…
- Researchers aren’t honest about their intentions.
- Researchers aren’t honoring my right to privacy.
- Researchers aren’t personable.
- Researchers make me feel more like a patient and less like a partner.
- Researchers don’t provide explanations for rejections from studies.

Solutions for Overcoming Barriers:
- Invest time in building trusting, long-term relationships
- Accommodate participants’ needs
- Be prepared to participate - equally, honestly, and deeply
- Make research relevant to participants
- Work with a community liaison who knows population well
The *All of Us* and NNLM Partnership
National Network of Libraries of Medicine

Regional Medical Libraries (RMLs)

- Greater Midwest Region (GMR) at University of Iowa
- Middle Atlantic Region (MAR) at University of Pittsburgh
- MidContinental Region (MCR) at University of Utah
- New England Region (NER) at University of Massachusetts
- Pacific Northwest Region (PNR) at University of Washington
- Pacific Southwest Region (PSR) at University of California Los Angeles
- South Central Region (SCR) at University of North Texas
- Southeastern/Atlantic Region (SEA) at University of Maryland

National Offices (Institution)

- DOCLINE Coordination (UMD)
- Evaluation (UW)
- Public Health Coordination (UMass)
- Training (Utah)
- Web Services (Pitt)
Why Public Libraries?

The Opportunity for Libraries

40% of health outcomes are influenced by socioeconomic factors.

- Education
- Employment
- Income
- Family & Social Support
- Community Safety

Libraries are in a unique position to bring together the people, programs, and partners necessary to make health information and services accessible to everyone.

URL for Health Happens in Libraries
Health Information in Public Libraries

When community members don’t have access to health information, services, and technology, they

- Use fewer preventative services
- Know less about chronic disease management
- Are hospitalized more often
- Report poorer health statuses

Almost 3 in 4 say libraries help people find the health information they need.

42% of those who have gone online at a library using its computers, internet connections, or Wi-Fi have done so for health-related searches.
Activities and Outreach

1. Training opportunities on NLM’s trusted consumer health information
2. Funded projects supporting community library and health organizations
3. Making community connections
Training Support Examples
Funding and Programming Support Examples

Air Quality Awareness Week begins April 29th
Learn more about your environmental health in ToxTown (toxtown.nlm.nih.gov), a resource of the National Library of Medicine.

NNLM Reading Club Selection Guide: Family Health History

National Family Health History Day
Americans know that family history is important to health. A recent survey found that 96 percent of Americans believe that knowing their family history is important. Yet, the same survey found that only 33 percent of Americans has tried to gather and write down their family’s health history.
Partnerships

1. Public Library Association
2. Collaborative Summer Library Program
3. *All of Us* Consortium Members
4. *All of Us* Journey
Collaborations with *All of Us* Research Program

- **All of Us Journey**
  - Host the Journey at an event
  - Volunteer

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Collaborations with *All of Us*

- Presentation and Classes
- Amplifying messages
- Connection to *All of Us* partners
- Raise awareness through National Health Observances
- Discussing *All of Us* in health programs
Contact Us

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