

The *All of Us* Research Program and Public Libraries

Engagement Strategies for Creating a Research-Informed Community

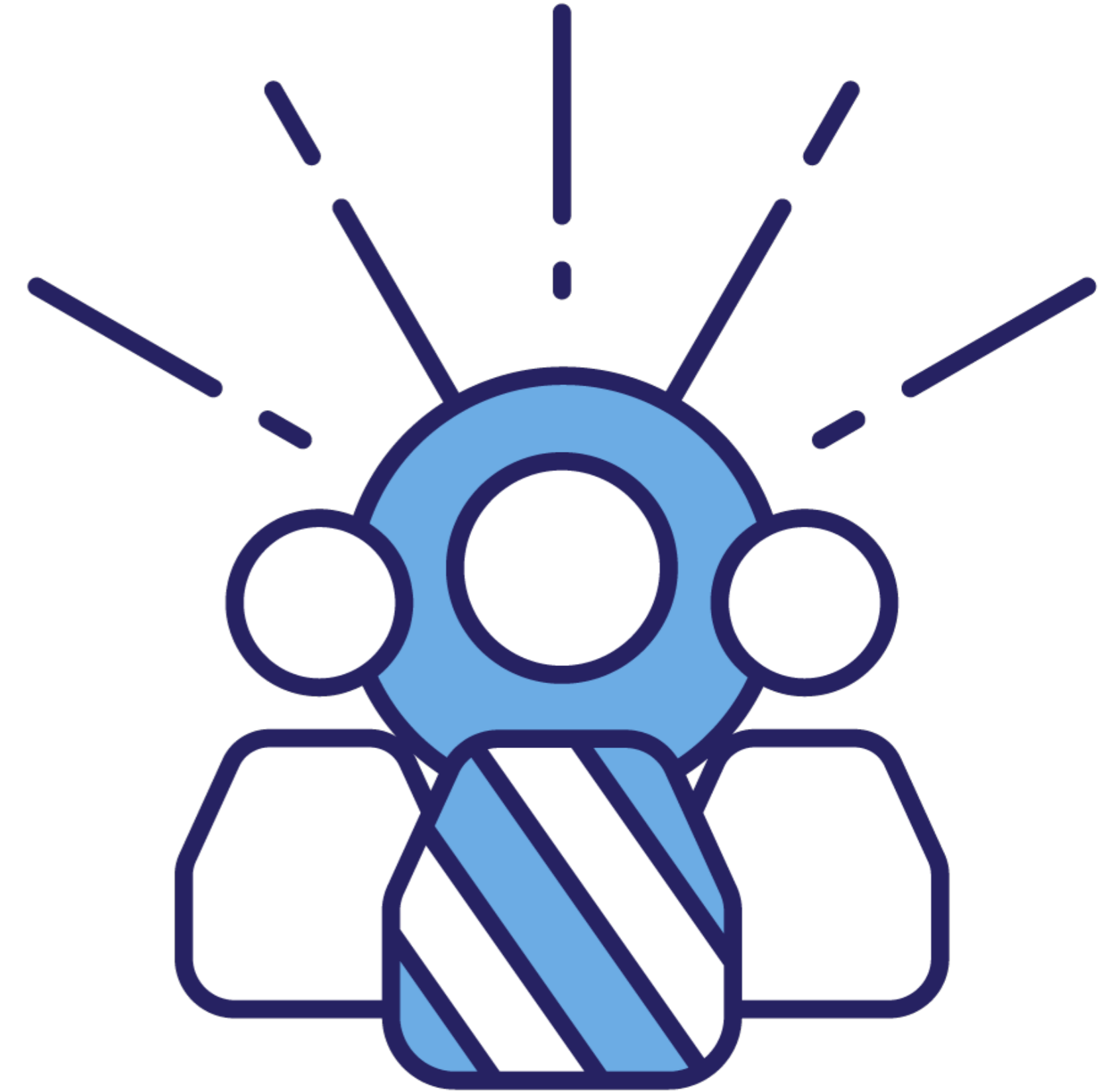


National Institutes
of Health

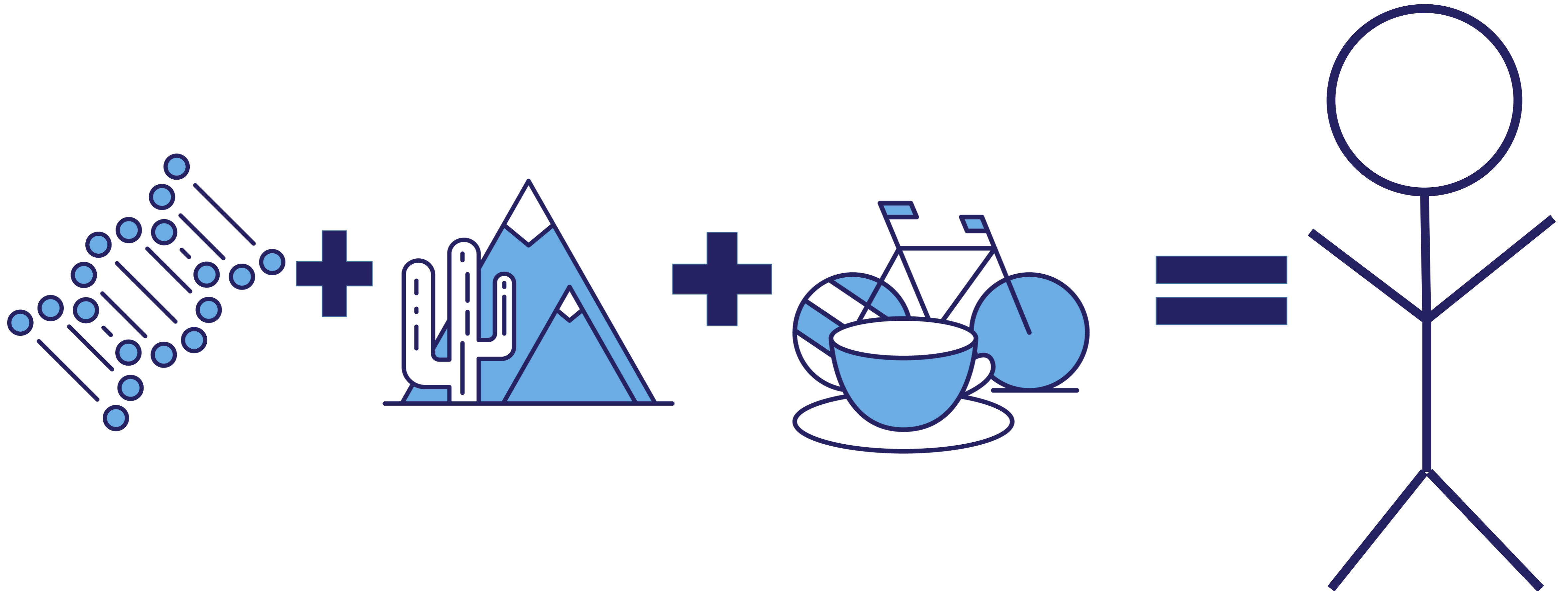
The Precision Medicine Initiative (PMI)

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

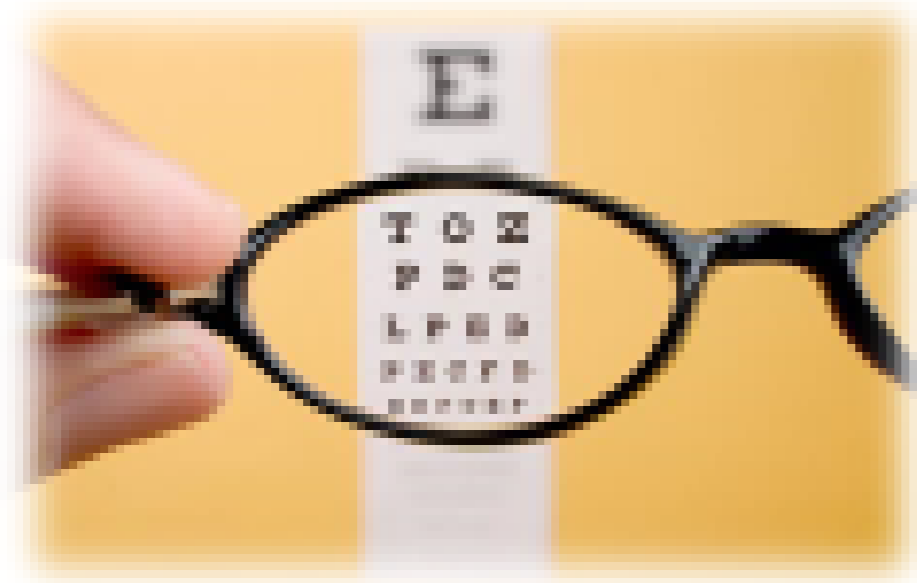


Genes + Environment + Lifestyle = Health Status



Precision Medicine in Real Life

Right treatment for the right person --



Prescription
Eyeglasses



Insulin Pump



Blood
Transfusions



Hearing Aid

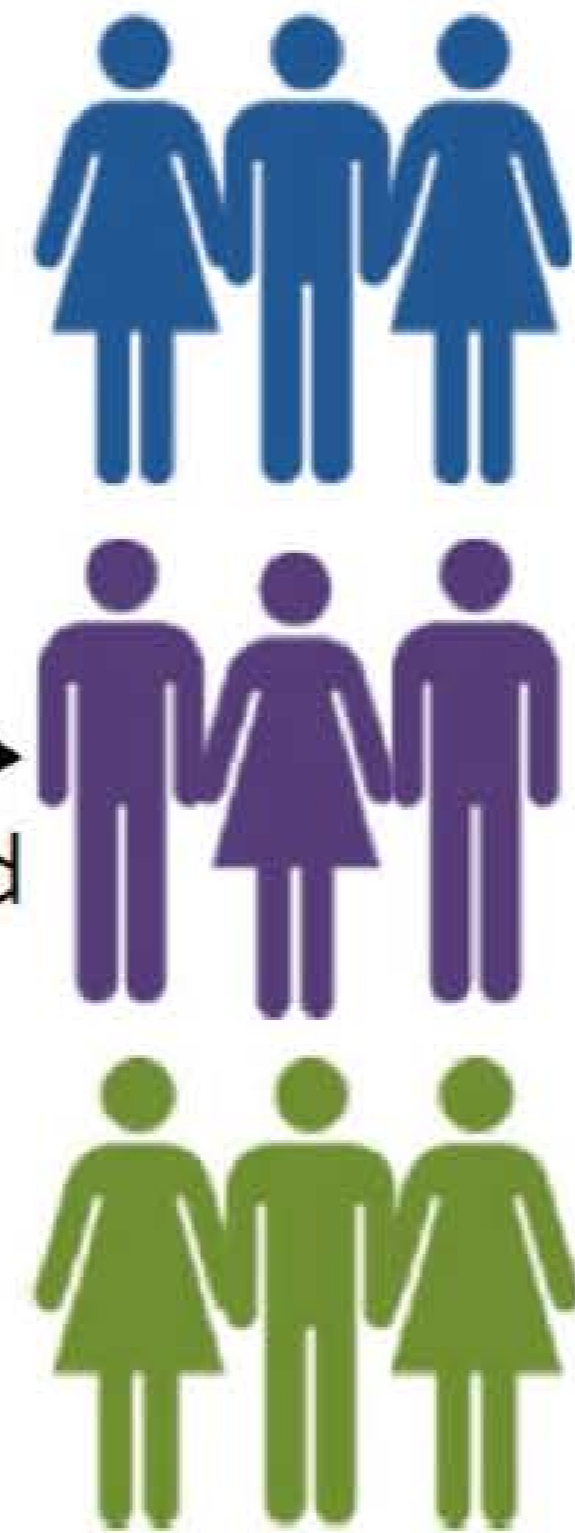
**One-size fits-all
medicine**



Stratification

Patients are grouped
by: Disease
Subtypes
Demographics
Clinical features
Biomarkers

Stratified medicine



Personalisation

Patient individual:
Preferences,
Clinical features
Medication history
Environment
Behaviours & habits
Biomarker

Precision medicine



Precision medicine





**The future
of health
begins
with you**



All of Us
RESEARCH PROGRAM



Overview of *All of Us* Research Program



***All of Us* Research Program Data**

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 education, ethnicities, etc..
- Use **mobile health technologies** to get real-time data on exposures
- **Empower study participants** with data and insights
- 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



Current Consortium Members

DV Network

(Direct Volunteers)



Biobank

HPO Network

(Health Care Provider Organizations)

RMCs

California Precision Medicine Consortium

Illinois Precision Medicine Consortium

New England Precision Medicine Consortium

Trans-American Consortium for the Health Care Systems Research Network

New York City Precision Medicine Consortium

Southern *All of Us* Network

SouthEast Enrollment Center

UC San Diego Health

U.C. DAVIS HEALTH Keck Medical Center of USC

UC Irvine Health

UC HEALTH UCsf
San Diego Blood Bank
Cedars Sinai

RUSH

THE UNIVERSITY OF ILLINOIS AT CHICAGO

RICHMOND HEALTH PROGRAM AND RESEARCH CENTER

Baylor Scott & White HEALTH

University of Wisconsin-Madison School of Medicine and Public Health

University of Arizona

University of Pittsburgh

Well Cornell Medicine

TUNTSVILLE HOSPITAL

TUSKIEGEE UNIVERSITY
Duke University Health Services

MOREHOUSE SCHOOL OF MEDICINE

All of Us, Wisconsin

Marshfield Clinic
UNIVERSITY OF WISCONSIN
University of Wisconsin School of Medicine and Public Health
MEDICAL COLLEGE OF WISCONSIN

Banner Health

FQHCs (Federally Qualified Health Centers)

JACKSON HENRY
GREENSBORO
HRHCare

VA Medical Centers

Communication & Engagement

HCM STRATEGIC SITE

Platform Development

VANDERBILT
UNIVERSITY

Barriers to participating in research

I'm interested but...

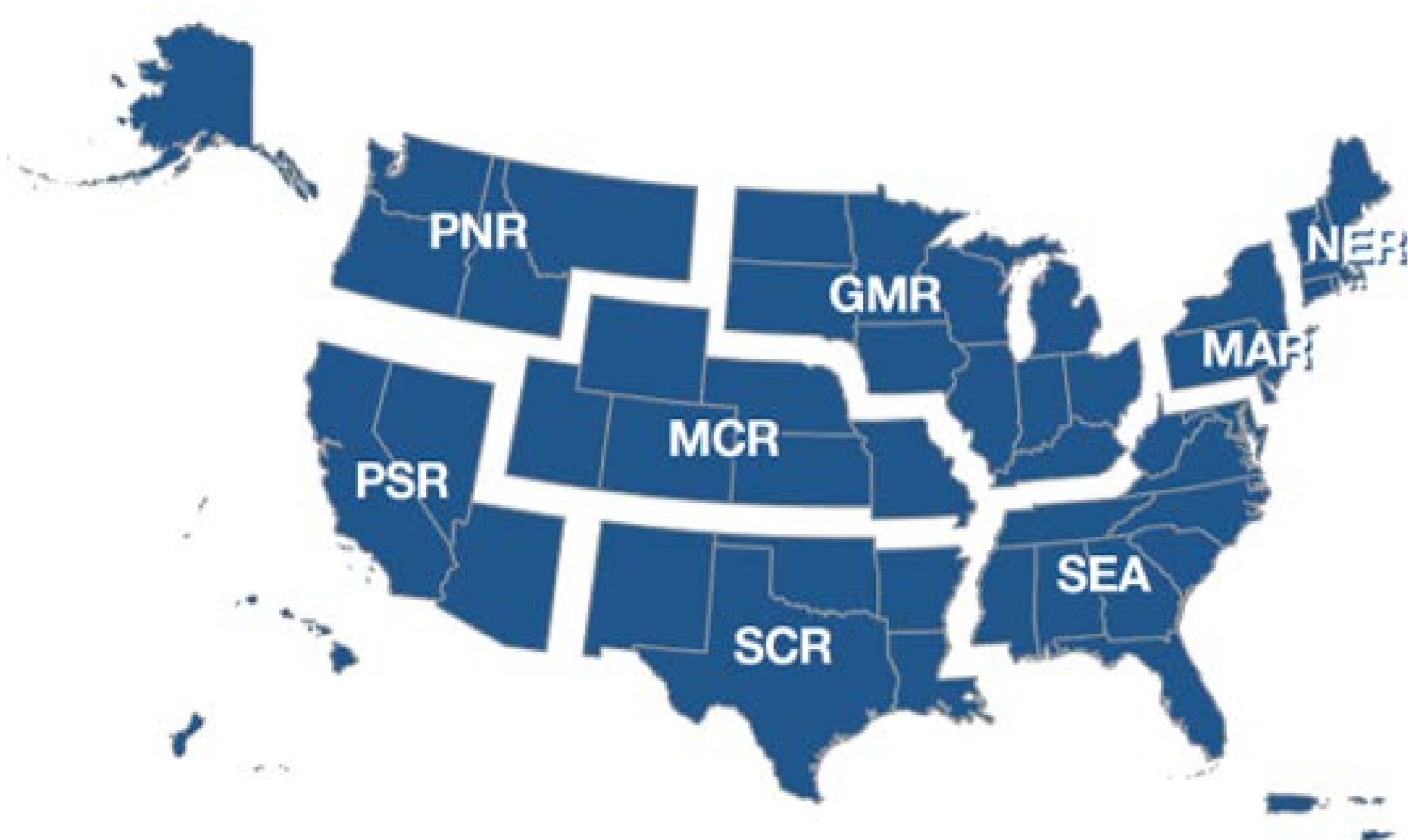
- Researchers aren't honest about their intentions.
- Researchers aren't honoring my right to privacy.
- Researchers aren't personable.
- Researchers make me feel more like a patient and less like a partner.
- Researchers don't provide explanations for rejections from studies.

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

National Offices (Institution)
DOCLINE Coordination (UMD)
Evaluation (UW)
Public Health Coordination (UMass)
Training (Utah)
Web Services (Pitt)

NNLM *All of Us* Community Engagement Network



U.S. National Library of Medicine
National Network of Libraries of Medicine

All of Us
RESEARCH PROGRAM

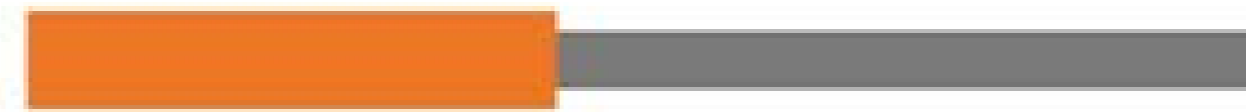
nnlm.gov/all-of-us

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

PEOPLE



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



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

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

NNLM *All of Us* Community Engagement Activities



Activities and Outreach

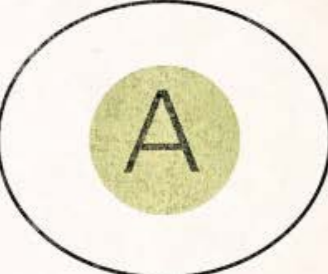
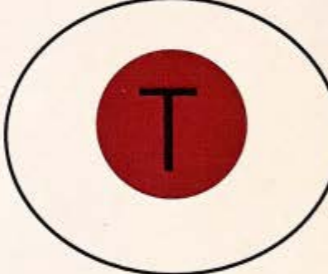
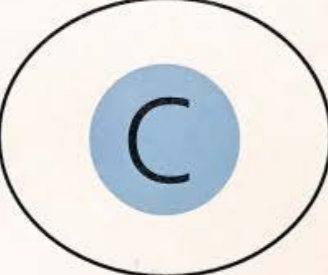
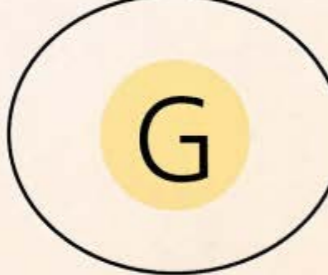
1. Training opportunities on NLM's trusted consumer health information
2. Funded projects supporting community library and health organizations
3. Making community connections

Training Support Examples



Sequence bracelets

DNA bases : pairing rules

	pairs with	
	pairs with	

DNA is made up of four units or 'bases', known as A,C,T and G.



Access to health insurance

For my future
Por mi futuro

All of Us
RESEARCH PROGRAM

Reliable access to health care and community support for mental health

For my future
Por mi futuro

All of Us
RESEARCH PROGRAM

empower people, compassionate, active healthcare system

For my future
Por mi futuro

All of Us
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mental health is supported

For my country
Por mi país

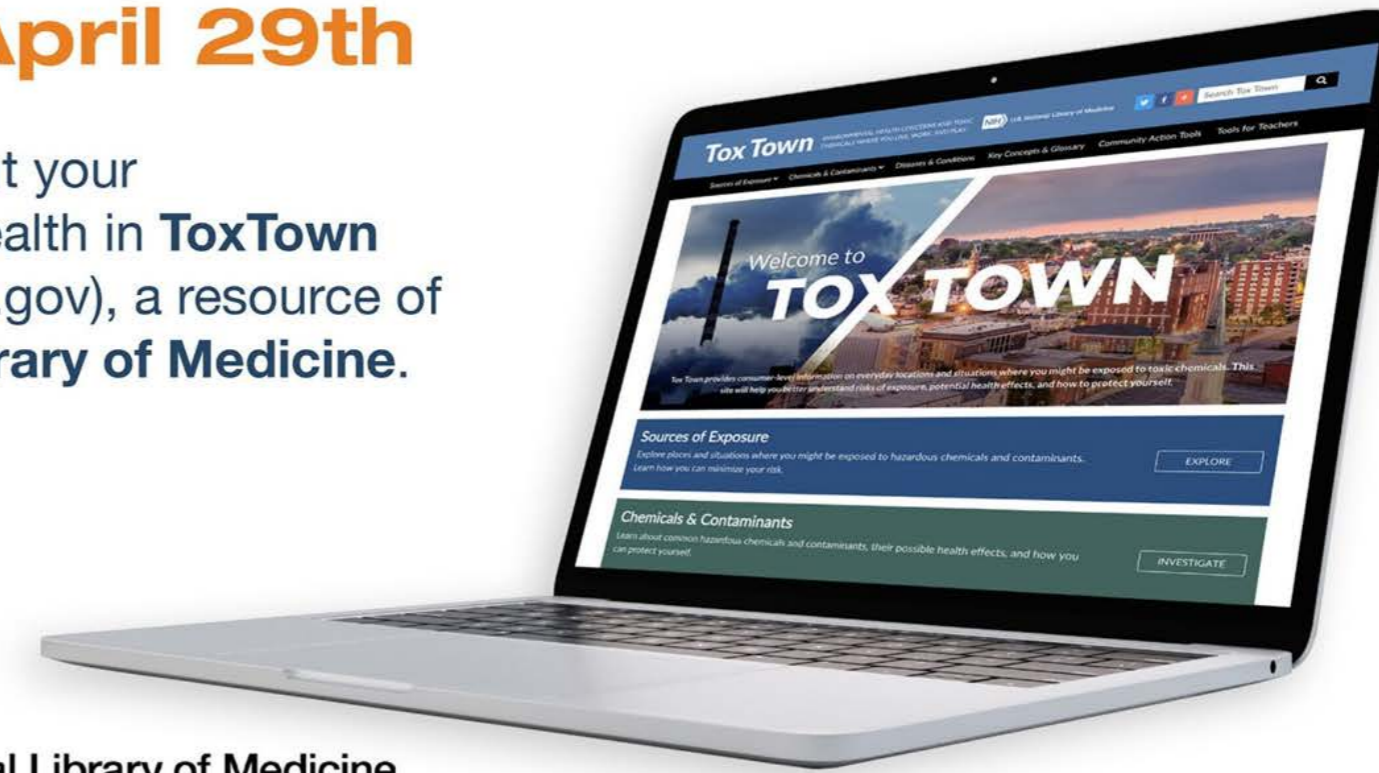


Funding and Programming Support Examples



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**.



NIH U.S. National Library of Medicine
National Network of Libraries of Medicine



NNLM Reading Club Selection Guide: Family Health History

About Family Health History | The Immortal Life of Henrietta Lacks | She Has Her Mother's Laugh | It's All Relative | Family Health History Resources

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.

All of Us RESEARCH PROGRAM | NIH | NLM | NNLM | Español

- Health & Wellness
- Genetic Health
- Medicine & Supplements
- Environment
- Kids Health & Games
- Other Resources

Data meets diversity.
LEARN MORE
MedlinePlus.gov

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NNLM *All of Us* Community Engagement Activities



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

2/11 – 2/17	Jackson, MS
2/18 – 2/24	Memphis, TN
2/25 – 3/3	Louisville, KY
3/4 – 3/10	Charlotte, NC
3/11 – 3/17	Raleigh, NC
3/18 – 3/24	Takoma Park/Baltimore, MD
3/25 – 3/31	Washington DC
4/1 – 4/7	Germantown, MD
4/15- 4/21	Philadelphia, PA
4/22- 4/28	Philadelphia, PA
4/29 – 5/5	New Brunswick & Newark, NJ
5/6 – 5/12	Bridgeport & Middletown, CT
5/13 – 5/19	Danbury & Stamford, CT
5/20 – 5/ 26	Boston, MA
5/27 – 6/ 2	Harrisburg, PA
6/3 – 6/ 9	Youngstown & Warren, OH
6/10 – 6/16	Columbus, OH
6/17 – 6/ 23	Cincinnati, OH
6/24 – 6/30	Dearborn & Detroit, MI
7/8 – 7/14	Grand Rapids, MI
7/15 – 7/21	South Bend, IN
7/22 – 7/28	Chicago, IL
7/29 – 8/4	Elgin, IL



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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#JoinAllofUs