

# The *All of Us* Research Program and Public Libraries

## Engagement Strategies for Creating a Research-Informed Community



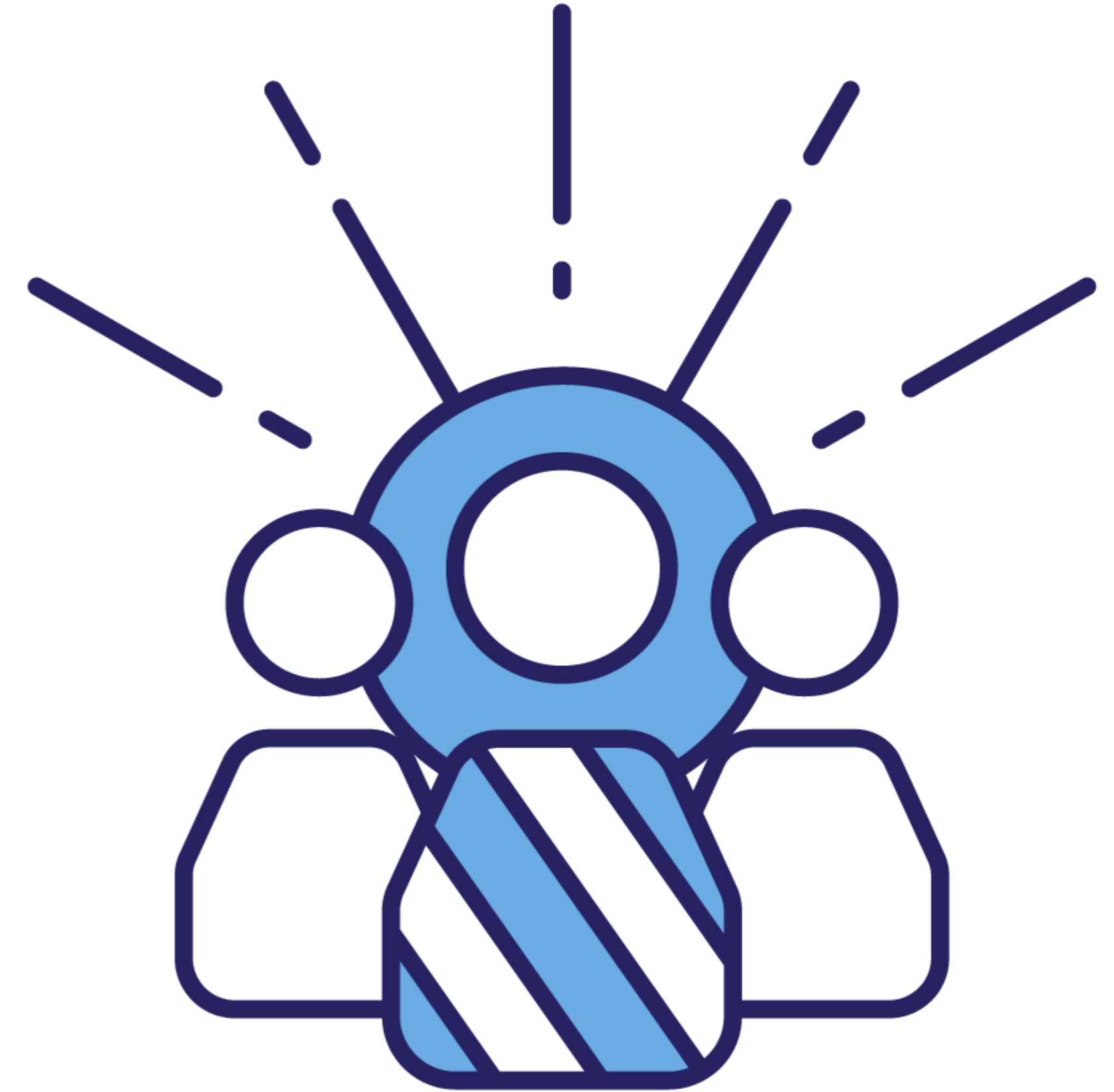
National Institutes  
of Health

# The Precision Medicine Initiative (PMI)

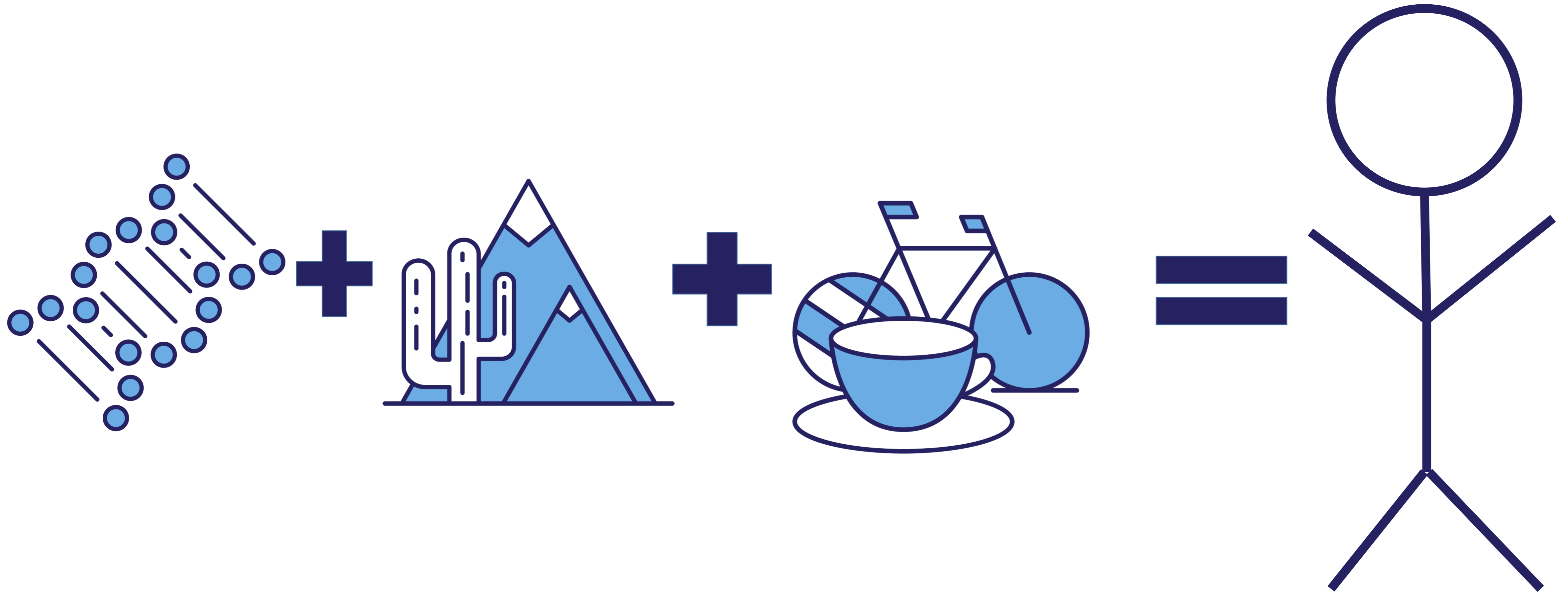
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A federal effort launched in 2015.

**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



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# 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**

**Precision medicine**



**Stratification**

Patients are grouped  
by: Disease  
Subtypes  
Demographics  
Clinical features  
Biomarkers



**Personalisation**

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



**Precision medicine**





**The future  
of health  
begins  
with you**



**All of Us**  
RESEARCH PROGRAM



# Overview of *All of Us* Research Program

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

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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

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- 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 different populations, such as 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*

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- 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***

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- 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

FQHCs (Federally Qualified Health Centers)

VA Medical Centers

*All of Us*, Wisconsin

Marshfield Clinic  
University of Wisconsin School of Medicine and Public Health  
Medical College of Wisconsin

Banner Health

JACKSON HENRY  
TUSKIGEE UNIVERSITY  
UNTSVILLE HOSPITAL  
HRHCare

## Communication & Engagement

HCM STRATEGISTS

## Platform Development

VANDERBILT  
UNIVERSITY

# Barriers to participating in research

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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.

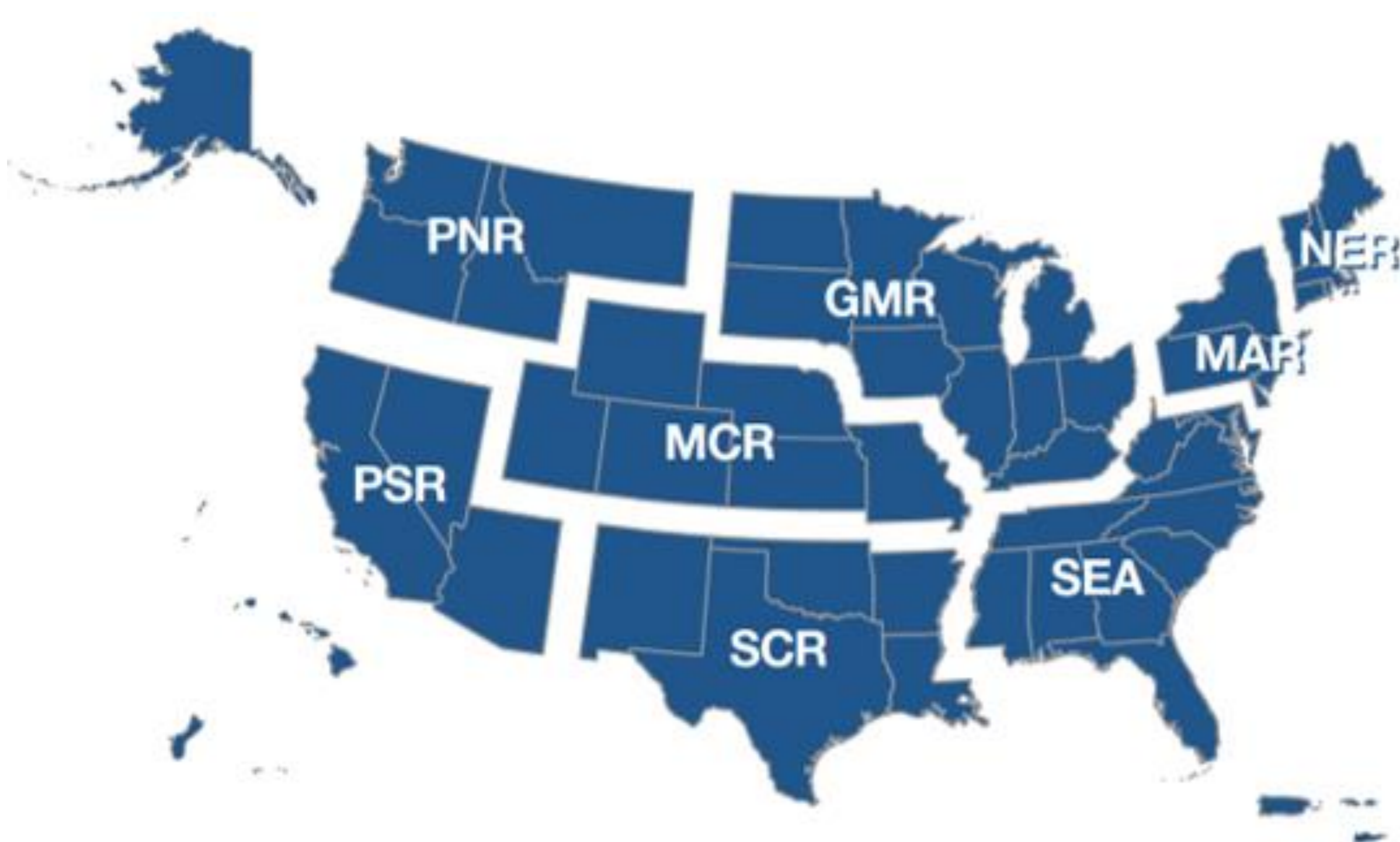
Solutions for Overcoming Barriers:

- 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

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# 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](https://nnlm.gov/all-of-us)

# Why Public Libraries?

## THE OPPORTUNITY FOR LIBRARIES



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

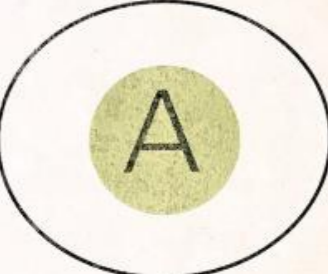
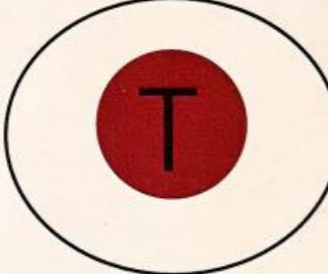
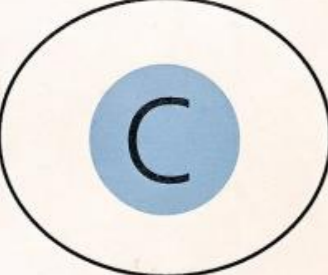
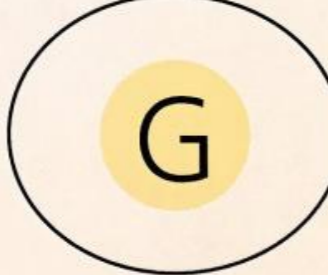
1. Training opportunities on NLM's trusted consumer health information
2. Funded projects supporting community library and health organizations
3. Making community connections

# 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**  
RESEARCH PROGRAM

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](http://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

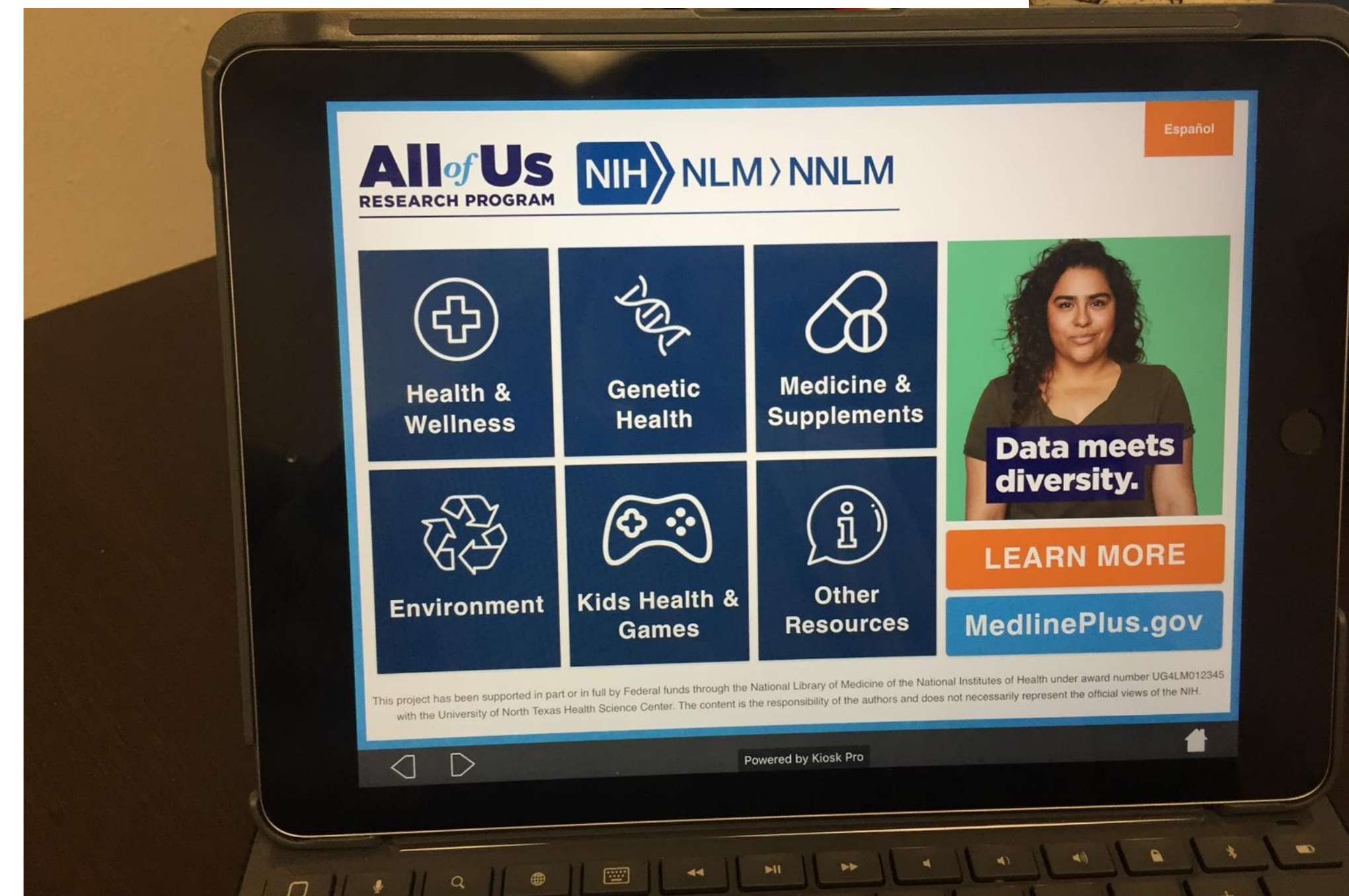


## NNLM Reading Club Selection Guide: Family Health History

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.



# 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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[nnlm.gov/mar](https://nnlm.gov/mar)

[nnlm.gov/all-of-us](https://nnlm.gov/all-of-us)

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#JoinAllofUs