

All of Us Research Program

FIBCO Virtual Community Health Fair

Thursday, February 25, 2021

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All of US
RESEARCH PROGRAM

The *All of Us* Research Program



#joinallofus

All of Us Anthem Video

(image links to 30-second
version of video on
YouTube; open notes
section for links to 15- and
90-second versions)



What is the NIH *All of Us* Research Program?



The
Future of
Health Begins
With You

The *All of Us* Research Program is a historic, longitudinal effort to **gather data from one million or more people** living in the United States to **accelerate research and improve health**. By taking into account individual differences in **lifestyle, socioeconomic, environment, and biology**, researchers will uncover paths toward delivering **precision medicine – or individualized prevention, treatment, and care – for all of us**.



“All of Us is among the most ambitious research efforts that our nation has undertaken!”

NIH Director Francis Collins, M.D., Ph.D.

The *All of Us* Research Program is part of the broader Precision Medicine Initiative.

Kinds of Questions this Resource May Help Answer

How can we prevent the chronic pain that affects more than 100 million people across the U.S. each year?

Or develop better pain medicines that aren't addictive?

Or develop better treatments for diabetes, which affects almost 10% of Americans—or prevent diabetes altogether?

Or slow or even stop different kinds of dementia?

Or develop more cancer cures that will work the first time, so we can skip painful trial-and-error chemotherapy?

Or drive local disparities interventions that work sustainably?

Understand the whole person: example data types that *All of Us* may collect

Environmental

- Highway proximity
- Chemical exposures
- Air pollution
- Water quality
- Weather
- Occupational hazards
- Zip code

Biological/Clinical

- Metabolomics
- Mental health
- Medications
- Electronic health records
- Proteomics
- Genomics
- Microbiomics



Social

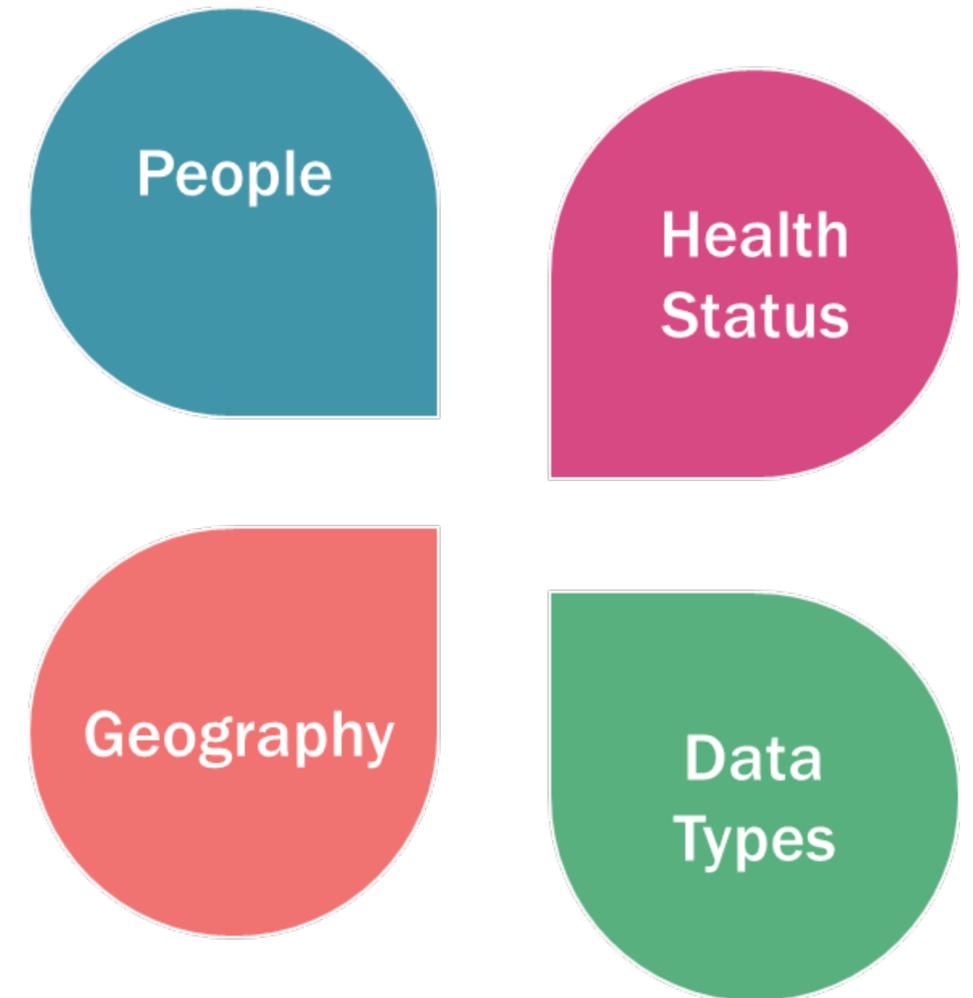
- Upbringing
- Education level
- Family structure
- Stress
- Literacy level
- Access to care
- Financial means
- Size of social network
- Religion

Behavioral

- Exercise
- Eating
- Drinking
- Self-report
- Drug usage
- ADLS
- Smoking history
- Routines

Innovative Aspects of *All of Us*

- ◉ **Diversity at the scale of 1 million people:** demographically, geographically, medically, and especially those underrepresented in biomedical research
- ◉ **Diversity of data types collected longitudinally:** clinical, environmental, genetic, behavioral, socioeconomic
- ◉ **Focus on participants as partners:** included in governance, invited to co-invent systems and give input into the science, choice to receive all data and information back
- ◉ **National, open resource for all:** open to the public and all researchers, open source software & tools



All of Us learns from and partners with other large research programs; sharing knowledge and data is key!

What is the promise for participants?

- An opportunity to help **fight disease** and improve the health of future generations.
- A chance to **learn about your own health**, including personalized risk factors or exposures.
- The ability and choice to **access your own data**, including increasingly rich health records.
- An opportunity to **ensure that your community is included** in the studies that lead to new understanding and new treatments.
- A chance to **learn about additional research opportunities** that may interest you.
- The choice to **meet others like you**, perhaps even joining some of them to propose & do research.



This is a long-term relationship and the value to participants (and researchers) will grow over time.

What is the promise for researchers?

- ◉ The opportunity to **save time and resources** and **accelerate your research breakthroughs** by leveraging:
 - A **rich resource of data**, including biospecimens and increasingly robust electronic health records.
 - A **longitudinal dataset** that will follow participants as they move, age, develop relationships, get sick, and try treatments.
 - A **diverse cohort of participants**, including people both healthy and sick, from all walks of life and all parts of the country.
 - Both raw data and data that is already **cleaned and curated**.
 - **Robust computing and analytic tools** to support complex data analyses in a **secure data environment**.
 - A group of **engaged participants** who may be eager to participate in ancillary studies.
- ◉ The ability to easily **share workspaces and analyses** with research partners and reviewers.
- ◉ The chance to learn from the program's pilots and experiments and **leverage innovations** for other studies and cohorts.



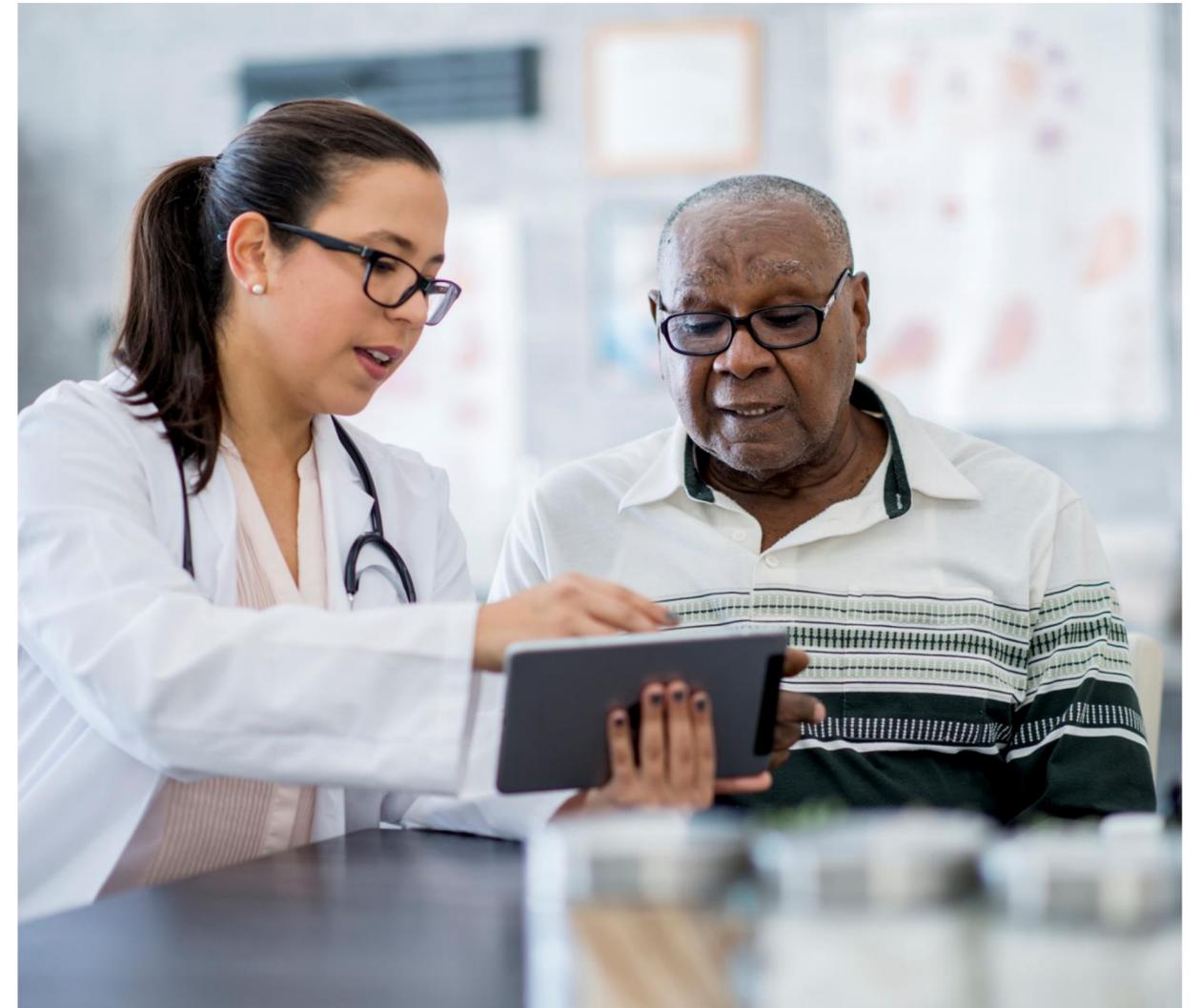
NIH's *All of Us* Research Program returns first genetic results to participants

The National Institutes of Health's All of Us Research Program has begun to return genetic results to participants who have donated biosamples for research. This reflects the program's priority to give back information to its research volunteers. Initially, participants can choose to receive...

As with most studies, we are collecting, evaluating, and curating initial datasets; availability this winter.

What is the promise for providers?

- Over time, **increased scientific evidence and improved guidelines** to enable precision medicine opportunities for more people and conditions:
 - Better understanding of the **impact of environment and lifestyle factors** on health.
 - Increased knowledge of differences in risk factors and response to treatments among **diverse populations**.
 - More information on the development of conditions that will allow for **earlier detection**.
 - Deeper understanding of different conditions that may allow for **better stratification**.
- Innovations that may make it easier to **share electronic health records** with other providers and patients.
- New knowledge to help address **health disparities**, increase **patient engagement**, and understand the usefulness of **consumer health devices and apps**.



Help accelerate medical breakthroughs by sharing information about *All of Us* with your patients!

What are the potential activities asked of participants in the current protocol?



Enroll, Consent and Authorize EHR

- Recruiting 18+ years old initially; plan to include children later
- Online, interactive consent
- Includes authorization to share Electronic Health Record (EHR) data



Answering Surveys

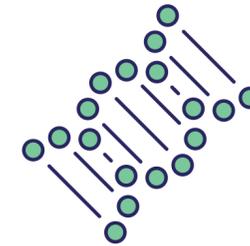
- Six initial surveys: The Basics, Overall Health, Personal Habits, Health Care Access & Utilization, Family Medical History, Personal Health History
- Additional surveys will be released on an ongoing basis.



Physical Measurements*

- Blood pressure
- BMI
- Heart rate
- Height
- Hip circumference
- Waist circumference
- Weight

**Based on diverse sampling and capacity*



Provide Biosamples*

- Blood (or saliva, if blood draw is unsuccessful)
- Urine specimen
- Biosamples will be stored at the program's biobank

**Based on diverse sampling and capacity*



Wearables and Digital Apps

- Share data from wearable fitness devices, starting with FitBit
- Share data, such as cardio-respiratory fitness, through integrated apps (coming soon)
- More integrations under development

Pilots under development: richer EHR data, health apps, fitness wearables, and return of genetic info

Current consortium members (beyond community partners)

DV Network (Direct Volunteers)



Biobank



Communication & Engagement



HPO Network (Health Care Provider Organizations)

RMCs

California Precision Medicine Consortium

Illinois Precision Medicine Consortium

New England Precision Medicine Consortium

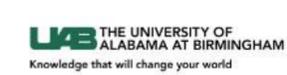
Trans-American Consortium for the Health Care Systems Research Network

New York City Precision Medicine Consortium

Southern All of Us Network

SouthEast Enrollment Center

UC San Diego Health



All of Us, Wisconsin

University of Arizona

University of Pittsburgh

FQHCs (Federally Qualified Health Centers)

VA Medical Centers



Platform Development



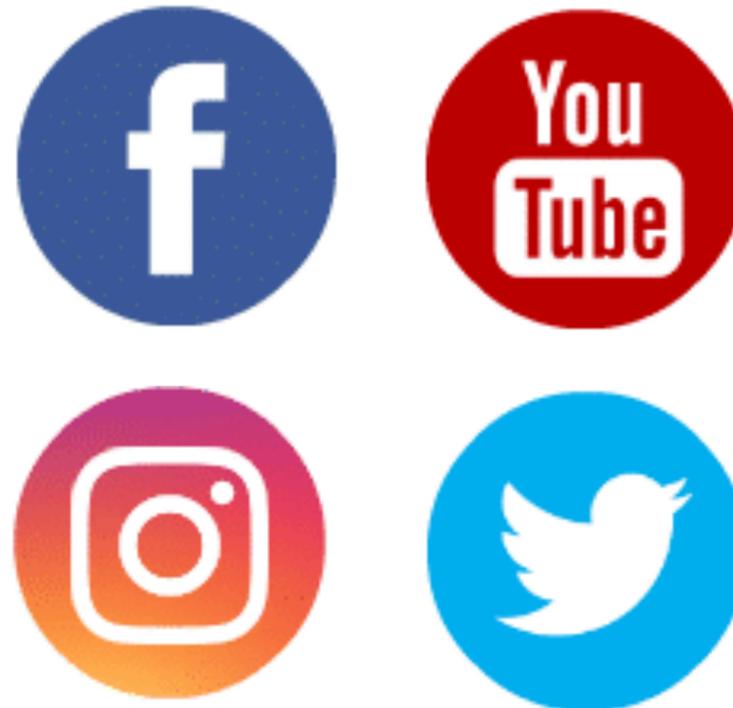
Genomics Infrastructure



All of Us Community and Provider Partner Network



Thank you!



National Institutes
of Health

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ResearchAllofUs.org

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#JoinAllofUs

AllofUs.nih.gov