All *of* Us
RESEARCH PROGRAM

The *All of Us* Research Program

NIH
National Institutes of Health

#joinallofus

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

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, socioeconomics, 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.

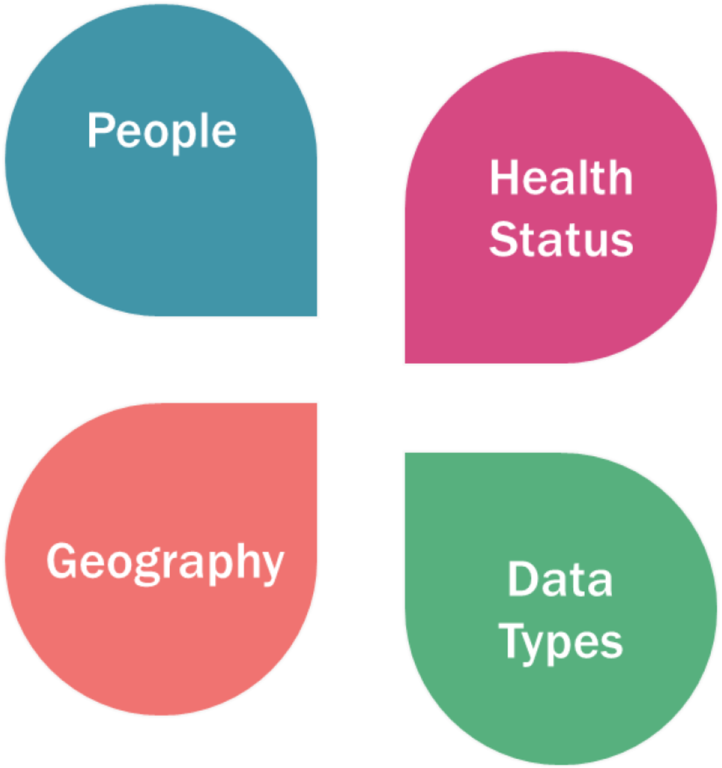
Innovative Aspects of *All of Us*

- **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!**

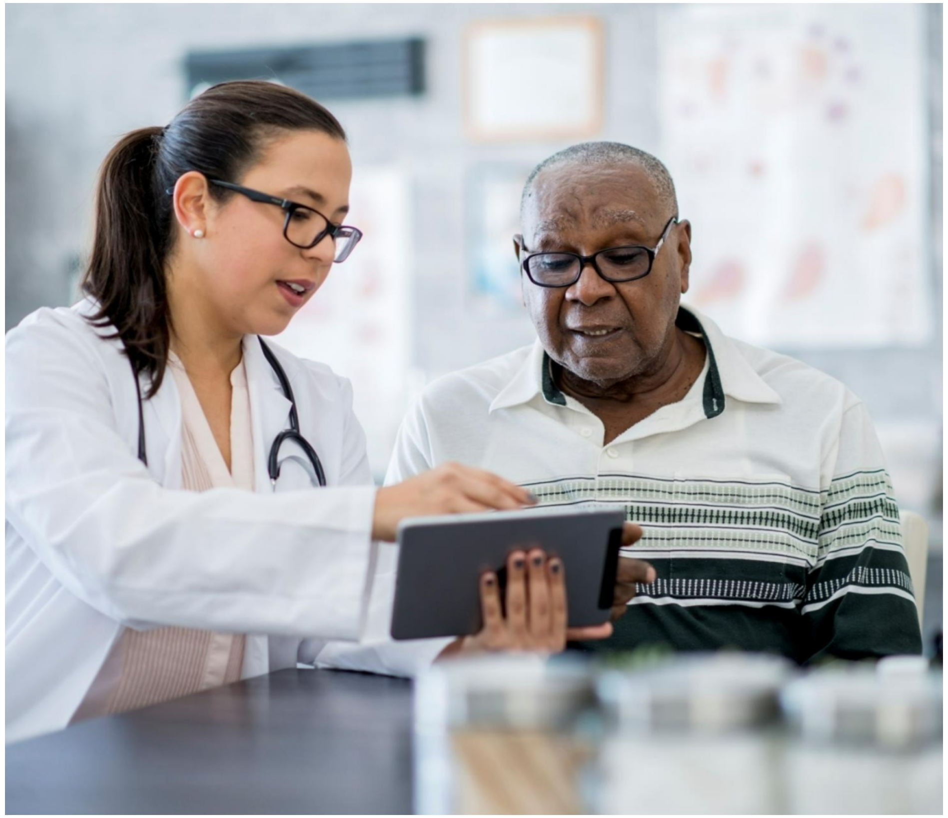
What is the promise for participants?

- 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 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 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.
  - 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.

Beta testing of our initial dataset and researcher tools will begin soon.

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

How will *All of Us* lead to discoveries?

Participants Share Data
Participants share health data online. This data includes health surveys and electronic health records. Participants also may be asked to share physical measurements and blood and urine samples.

Data Is Protected
Personal information, like your name, address, and other things that easily identify participants will be removed from all data. Samples—also without any names on them—are stored in a secure biobank.

Researchers Study Data
In the future, approved researchers will use this data to conduct studies. By finding patterns in the data, they may make the next big medical breakthroughs.

Participants Get Information
Participants will get information back about the data they provide, which may help them learn more about their health.

Researchers Share Discoveries
Research may help in many ways. It may help find the best ways for people to stay healthy. It may also help create better tests and find the treatments that will work best for different people.

Approach to Privacy and Security

- Guided by privacy, trust, and data security principles developed by experts with input from the public.
- Data warehouse is built with the most advanced security available.
- Experts have done and will continue to do rigorous security testing.
- Data is encrypted and direct identifiers are removed.
- Researchers must agree to a code of conduct before accessing the data.
- Participants’ preferences will be respected.
- Protected by a Certificate of Confidentiality.
- Committed to transparency in the event of a data

Safeguarding your identity and data to the best of anyone’s abilities is our most important responsibility.

Physician Champion Contact Information

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