

All of Us Includes Disability



An Introduction to the *All of Us* Research Program

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American Association on Health and Disability

- Reduce Health Disparities
- Advocate for Community Inclusion
- Promote Full Accessibility
- Integrate Disability into Public Health Agenda
- Advance Knowledge Translation & Disability Research



AAHD Mission: To promote health and wellness for people with disabilities

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



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!”

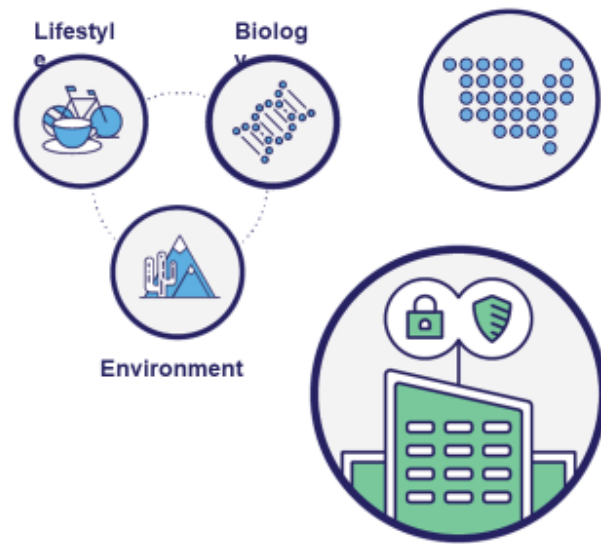
NIH Director Francis Collins, M.D., Ph.D.

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What is precision medicine?

Precision medicine is an emerging approach for disease treatment and prevention that takes into account individual variability in lifestyle, socioeconomics, environment, and biology.

It is a radical shift in how each of us can receive the best care possible based on our unique makeup.



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The Cost of Imprecise Medicine



Patients

- Health care is often targeted to the average patient, not the individual
- Health problems can take years to unravel, with significant trial and error



Providers

- Not enough research to draw on for clinical evidence, especially in diverse populations
- Medical records scattered in different places
- Not enough time for analysis one patient at a time








Researchers

- Enormous time and cost spent building IT systems vs. doing research
- Siloed data resources and funding opportunities
- Challenges acquiring large sample sizes
- Slow translation of data into knowledge

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POTENTIAL ACTIVITIES ASKED OF PARTICIPANTS

 Enroll, Consent and Authorize EHR	 Answering Surveys	 Physical Measurements*	 Provide Biosamples*	 Wearables and Digital Apps
<ul style="list-style-type: none">• Recruiting 18+ years old initially; plan to include children in 2019• Online, interactive consent• Includes authorization to share Electronic Health Record (EHR) data	<ul style="list-style-type: none">• Three initial surveys: The Basics, Overall Health, & Personal Habits• Additional surveys will be released on an ongoing basis.	<ul style="list-style-type: none">• Blood pressure• BMI• Heart rate• Height• Hip circumference• Waist circumference• Weight	<ul style="list-style-type: none">• Blood (or saliva, if blood draw is unsuccessful)• Urine specimen• Biosamples will be stored at the program's biobank	<ul style="list-style-type: none">• Share data from wearable fitness devices, starting with FitBit• Share data about mood & cardio-respiratory fitness through integrated apps• More integrations to come
		<p><i>*Based on diverse sampling and capacity</i></p>	<p><i>*Based on diverse sampling and capacity</i></p>	<p><i>Coming soon</i></p>

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What is the promise for participants?

- An opportunity to help **fight disease** and improve the health of future generations.
- An opportunity to **ensure that your community is included** in the studies that lead to new understanding and new treatments.
- The choice to **meet others like you**, perhaps even joining some of them to propose & do research.



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

JoinAllofUs.org/GO

Direct Volunteers are encouraged to visit JoinAllofUs.org/GO or to download the app (with white background) for iOS or Android to learn about the program and register to create an account.

Learn More



JoinAllofUs.org



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