The All of Us Research Program:

The future of health begins with you

Dr. Dara Richardson-Heron
Chief Engagement Officer and Scientific Executive, All of Us Research Program
Polling Question

We are interested in understanding how familiar you already are with precision medicine. We want to know what kind of background you have and how we can increase your knowledge to best work together.

 hätte Screen: How familiar are you with precision medicine?

- Not familiar
- Somewhat familiar
- Very familiar
precision medicine: the right treatment for the right person at the right time
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 to analyze 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
Polling Question

We are interested in understanding how familiar you already are with the *All of Us* Research Program. We want to know what kind of background you have and how we can increase your knowledge to best work together.

- **On Screen: How familiar are you with the *All of Us* Research Program?**
  - Not familiar
  - Somewhat familiar
  - Very familiar
What is the *All of Us* Research Program?

- **Rich, Longitudinal Resource**: Deliver a national resource of deep clinical, environmental, lifestyle & genetic data from 1 million participants who have consented & are engaged to provide data on an ongoing, longitudinal basis (10+ years!)

- **Diversity of Participants**: Reflect the broad diversity of the U.S.—all ages, races/ethnicities, sex, gender, SES, geographies, & health status—by over-recruiting those underrepresented in biomedical research

- **Diversity of Researchers**: Build the tools & capabilities that make it easy for researchers from community scientists to premier university labs to make discoveries using the data & biosamples and through ancillary studies with the cohort
Two Methods of Enrollment

DIRECT VOLUNTEERS

HEALTH CARE PROVIDER ORGANIZATIONS
<table>
<thead>
<tr>
<th>Potential Activities Asked of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Enroll, Consent and Authorize EHR</strong></td>
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<tr>
<td>• Recruiting 18+ years old initially; plan to include children in 2019</td>
</tr>
<tr>
<td>• Online, interactive consent</td>
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<tr>
<td>• Includes authorization to share Electronic Health Record (EHR) data</td>
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<tr>
<td><strong>Answering Surveys</strong></td>
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<tr>
<td>• Three initial surveys: The Basics, Overall Health &amp; Personal Habits</td>
</tr>
<tr>
<td>• Additional surveys will be released on an ongoing basis.</td>
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<tr>
<td><strong>Physical Measurements</strong></td>
</tr>
<tr>
<td>• Blood pressure</td>
</tr>
<tr>
<td>• BMI</td>
</tr>
<tr>
<td>• Heart rate</td>
</tr>
<tr>
<td>• Height</td>
</tr>
<tr>
<td>• Hip circumference</td>
</tr>
<tr>
<td>• Waist circumference</td>
</tr>
<tr>
<td>• Weight</td>
</tr>
<tr>
<td><strong>Provide Biosamples</strong></td>
</tr>
<tr>
<td>• Blood (or saliva, if blood draw is unsuccessful)</td>
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<tr>
<td>• Urine specimen</td>
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<tr>
<td>• Biosamples will be stored at the program’s biobank</td>
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<tr>
<td><strong>Wearables and Digital Apps</strong></td>
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<tr>
<td>• Share data from wearable fitness devices, starting with FitBit</td>
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<tr>
<td>• Share data about mood &amp; cardio-respiratory fitness through integrated apps</td>
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<tr>
<td>• More integrations to come</td>
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</table>

*Based on diverse sampling and capacity

**Pilots under development: richer EHR data, health apps, fitness wearables, and return of genetic info**
core values
1. Participation is **open** to all.

2. Participants reflect the rich **diversity** of the U.S.

3. Participants are **partners**.

4. Trust will be earned through **transparency**.

5. Participants will have **access** to their information.

6. Data will be accessed **broadly** for research purposes.

7. Security and privacy will be of **highest** importance.

8. The program will be a catalyst for positive **change** in research.
The *All of Us* Approach to Participation

Participants in the *All of Us* Research Program will be true partners—not patients—in the research process.

- Involved in program development:
  - What *data* we collect
  - What *lab analyses* we do
  - What *research* is conducted
  - How data is *returned*
Trust will be earned through robust engagement and full transparency.
Disenfranchisement and Historical Abuses
Minorities make up 38% of the U.S. population.

Minority population will rise to over 56% of overall population.

Minority enrollment in clinical trials <10%

Underrepresented in biomedical research: populations include dimensions of race and ethnicity, as well as age, sex, gender, sexual orientation, income, education, geography, access to care and disability.
“Diversity in science is science done well. You need diversity in the research, diversity in who is being studied and diversity in the people doing the science. Otherwise you become an echo chamber – everyone looks and sounds just like us.”

- **Sam Oh, PhD, MPH**, epidemiologist and researcher at UCSF Center for Genes, Environment and Health.

<table>
<thead>
<tr>
<th></th>
<th>For the 31 drugs which populations are most at risk for the cancers treated?</th>
<th>For the 31 drugs how often was each population the largest group represented in clinical trials?</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td><img src="chart1.png" alt="Chart" /></td>
<td><img src="chart2.png" alt="Chart" /></td>
</tr>
<tr>
<td>Black</td>
<td><img src="chart1.png" alt="Chart" /></td>
<td>None</td>
</tr>
<tr>
<td>Similar Risk</td>
<td><img src="chart1.png" alt="Chart" /></td>
<td>None</td>
</tr>
<tr>
<td>Other</td>
<td>None</td>
<td></td>
</tr>
</tbody>
</table>

*Note:* Drugs are labeled “Similar Risk” if black Americans are at least 60 percent as likely as white Americans to be diagnosed with the cancer treated.

Source: UCSF News Center; UCSF
Polling Question

Now that you’re more familiar with the connections between local, public health and precision medicine, we would like to understand if precision medicine connect to any current effort of you or your health departments. Please indicate if you believe that precision medicine might have implications for the work of you or your health department as noted below:

On Screen: Precision medicine has implications for my work.
- Agree
- Disagree
- Unsure
The *All of Us* Approach to Diversity

Reflecting the country’s rich diversity to produce meaningful health outcomes for communities historically underrepresented in biomedical research.

- Develop a **national network of Health Care Provider Organizations (HPOs)** with incentives & methods to reach most diverse people & places
- Create an **innovative network of Direct Volunteer partners** to reach at least 90% of where all people live, within 20-45 minutes
- Build a **network of national & local Community Partners** to help build lifelong, trusted relationships with key communities & areas in the country
- Drive programs that **lead the way** for diverse communities to participate
All of Us Research Program Consortium

DATA AND RESEARCH CENTER
Big data capture, cleaning, curation, & sharing in secure environment
Vanderbilt, Verily, Broad Institute

BIOBANK
Repository for processing, storing & sharing biosamples (35+M vials)
Mayo Clinic

PARTICIPANT TECHNOLOGY SYSTEMS CENTER
Web and phone-based platforms for participants
Vibrent Health

PARTICIPANT CENTER / DV NETWORK
Direct volunteer participant enrollment, digital engagement innovation & consumer health technologies
Scripps Research Institute (with multiple partners)

HEALTHCARE PROVIDER ORGS NETWORK
HPOs with clinical & scientific expertise, enrollment & retention of participants
30+ regional medical centers, FQHCs, VA, and future awards to grow network

COMMUNICATIONS & COMMUNITY NETWORK
Communications, marketing & design expertise; engagement coordination & community partners network
Wondros, HCM, 29 community partner organizations, and future awards to grow network
All of Us Consortium Members

DV Network
(Direct Volunteers)

- Scripps Translational Science Institute
- National Blood Collaborative
- Aetna
- Walgreens
- BlueCross BlueShield

HPO Network
(Health Care Provider Organizations)

- DXC Technology
- Quest Diagnostics
- EMSI Health
- WebMD

RMCs

- California Precision Medicine Consortium
- Northwestern University
- UC San Diego Health
- UC Davis Health
- UC Irvine Health
- UC Health
- UCSF
- Cedars-Sinai
- University of Arizona

Illinois Precision Medicine Consortium
- Partners HealthCare
- NorthShore University Health System
- Rush University Medical Center
- Essentia Health
- Baylor Scott & White Health
- SPECTRUM HEALTH

New England Precision Medicine Consortium
- Partners HealthCare
- Brigham Women's Hospital
- University of Massachusetts Medical School
- Columbia University Medical Center

Trans-American Consortium for the Health Care Systems Research Network
- NewYork Presbyterian
- Well Cornell Medicine
- University of Arizona
- University of Pittsburgh

New York City Precision Medicine Consortium
- NYC Health + Hospitals
- New York Presbyterian
- Mount Sinai

Southern All of Us Network
- University of Alabama
- University of North Carolina
- University of Mississippi
- LSU Health

SouthEast Enrollment Center
- University of North Carolina
- University of Georgia
- Florida State University
- Virginia Commonwealth University

All of Us, Wisconsin
- Marshfield Clinic
- BloodCenter of Wisconsin

University of Arizona
- The University of Arizona
- Banner Health

University of Pittsburgh
- University of Pittsburgh
- UPMC

FQHCs (Federally Qualified Health Centers)
- Cherokee Nation
- Jackson-Hinds Community Health Center
- Rural Health Care of Alabama
- Hawaii Pacific Health

VA Medical Centers
- VA
- U.S. Department of Veterans Affairs

Communication & Engagement

- WONDROS

Platform Development
- Scripps Translational Science Institute
- Sage
- Broad Institute
- verily
All of Us Community and Provider Partner Network
All of Us Journey

2017-2018

2018-2019

Past Stops

Upcoming Stops
Partnership Between *All of Us* and NLM

**All of Us**  
*Research Program*

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**NIH**  
**NLM**

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**Community Education**  
**Community Engagement**  
**AoU Learning Platform**
The promise of *All of Us* for participants, health care providers and researchers.
What is the Promise for Participants?

- An opportunity to **fight disease** and improve the health of future generations.

- The opportunity to **be part of a movement** to make our health care more precise, more personal and more effective.

- The opportunity to **ensure that your community is included** in the studies that may lead to new understanding and new treatments.

- An **opportunity to learn** some of your own health indicators and get your own data.

*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** with research partners and reviewers.
- The chance to learn from the program’s pilots and experiments and **leverage innovations** for other studies and cohorts.

As with most studies, we are collecting, evaluating and curating initial datasets; availability in 2019.
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 responses 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 (EHRs) 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!
where
are we now?
Where Are We Now? Where Are We Headed?

**Present**

- >160,000 people registered to begin the participant journey
- >94,000 participants have completed all elements of the core protocol
- ~75% of current participants self-identify as belonging to one or more populations that have been historically underrepresented in biomedical research
- ~50% are from racial and ethnic minority groups

**Future**

- **Broadening inclusion** to additional demographics
- Expanding **linguistic support** for non-English or Spanish speakers
Join Us!

help@joinallofus.org

joinallofus.org/together | @AllofUsResearch | #JoinAllofUs

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