

All of Us The Precision Medicine Initiative
RESEARCH PROGRAM Initiative

All of Us Research Program
Make a Difference for Generations to Come:
The Future of Health Starts with You –

Monica Toquinto, Director of Programs
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Presenter

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Presentation Objectives

- 1) Provide an overview of the *All of Us* Research Program
- 2) Learn how the differences between us can help create different types of treatments
- 3) Answer your questions about how to participate

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Kinds of Questions this Resource May Help Answer

- How may we prevent the chronic pain that affects more than 100 million people across the U.S. each year?
- Or may slow or potentially stop different kinds of dementia?
- Or may help researchers develop more cancer cures that will work the first time, so we may skip painful trial-and-error chemotherapy?
- Or may develop pain medicine that potentially may not be addictive?
- Or may develop better treatments for diabetes, which affects almost 10% of Americans—or may potentially prevent diabetes altogether?
- Or may drive sustainable interventions that may support health equity?

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What is precision medicine?

1. Precision medicine is health care that is based on you as an individual.
2. It takes into account factors like where you live, what you do, and your family health history.
3. Precision medicine's goal is to be able to tell people the best ways to stay healthy. If someone does get sick, precision medicine may help health care teams find the treatment that will work best.

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The All of Us Research Program

- The cornerstone of the larger PMI – led by the NIH.
- One million or more volunteers, reflecting the broad diversity of people who live in the U.S.
- Volunteers key to success as they will provide information on their own unique health an ongoing basis.
- This information will benefit thousands of research studies throughout the

Opportunities for communities that historically have not been represented in biomedical research studies

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Who Can Participate?



- ❖ People 18 years old or older.
- ❖ People who live anywhere in the U.S.
- ❖ People of every race, ethnicity, sex, gender, and sexual orientation.
- ❖ Participants can be healthy, or can have a long-term health issue.
- ❖ Participants don't have to speak English to join. Enrollment materials in Spanish and advisors will help Spanish-speaking volunteers.
- ❖ No health insurance is required.

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What might participants be asked to do?

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
- Consent to get DNA Results

Answering Surveys

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

Physical Measurements*

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

*Based on diverse sampling and capacity

Provide Biosamples*

- Blood (or saliva, if blood draw is unsuccessful)
- Urine (optional)
- 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
- More integrations under development

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How to join - Roadmap

- Learn about the program.
- Talk with family, friends, or health care provider about your interest in joining.
- Decide to join the *All of Us* Research Program, enroll, and give your consent.
- Agree to share your electronic health records.
- Answer health-related questions.

- Have physical measurements taken
- Give blood and urine samples.
- Update your health and lifestyle information from time to time.
- If eligible, take part in new research projects.
- Participants may not, if they withdraw, have access to the data they give to the program.

Pilots in development: complete EHR data, health applications, wearable devices that track physical activity and genetic return of results.

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Remember...

Top ten things to know:

1. Participation is free.
2. Participant do not need to change providers
3. Enrollment will not interfere with the way patients receive care from their current health care team.
4. Participants will be asked to complete online surveys about their health history, lifestyle habits, and environment.
5. Participants may be asked to provide access to their electronic health records.
6. Participants may be asked to visit a partner site to have basic physical measurements taken and to provide blood and urine samples. If they do so, they will receive \$25 for their time.
7. The program has rigorous safeguards in place to protect data security and participant privacy.
8. The program may last for 10 years or more.
9. Participants may withdraw at any time.
10. Participants will have access to their own data and summarized results from across the program.

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All of Us Research Program

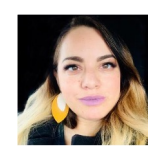


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Enroll and Consent

- 1. Create an account**
 - Email address and password.
 - Cell phone number
- 2. Fill in the enrollment and consent forms**
 - Learn about the research program and the consent process.
 - Answer questions about the program.
 - Electronically sign to complete the consent process.
 - Takes 18-30 minutes
- 3. Complete surveys and provide biosamples.**



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Join Now!


All of Us
You have the power to drive health research. Without you, it won't be All of Us.


Sign in

Your Address Or Phone Number

Account

Sign Up







Scan code to access the website on your phone or visit:
joinallofus.org/juntos

Use this QR code in cilles with HPO

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Join Now!






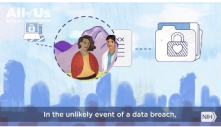

Scan code to access the website on your phone or visit:
joinallofus.org/todos

Use this QR code in cilles with DV Partners

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All of Us – Consents

1. Consent for enrollment
1. Electronic Health records
1. Return of genetic results

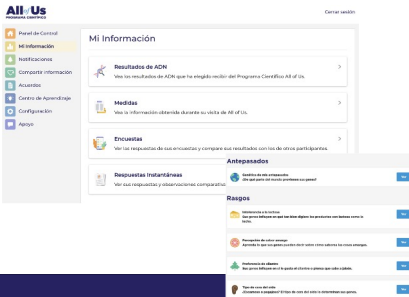




If possible, you can show a short video (less than a minute). This is the All of Us consent for DNA analysis: <https://www.youtube.com/watch?v=IGAAGWOPoM>

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All of Us Participant Portal

- Participant information
- Consents for joining the program, electronic health records, and return of DNA results
- Notifications
- Learning Center



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Providing Biosample

- Option 1: Salvia (send by mail)
- Option 2: Blood and urine(kit is received by mail and taken a local lab)

KEEP THIS CARD FOR YOUR RECORDS
If you like to track your research, use your QR code tracking number below. It is a code that links the participant to their own data throughout the life.

MAILING INSTRUCTIONS
Follow the instructions provided in the Data Collection Kit to collect your samples. This kit also contains the kit for Biosample Storage.

	SALIVA	BLOOD & URINE
Provide your DNA	X	X
Allows measuring of lab results like cholesterol and blood sugar levels.		X
Can be collected without an appointment	X	
Option to receive ancestry and track information	X	X
Option to receive health-related information based on your DNA		X



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What information will we share with you?

We expect to share information about:

- Your ancestry** (where your family comes from)
- Your traits**, such as why you might love or hate cilantro
- Whether you may have an increased risk** of developing a particular health condition
- How your body might react** to certain medications
- Other health-related information**

We plan to use many different methods to check your DNA for information. You may get some DNA results sooner than others.

It will take some time to get your DNA results. Some participants may not get their DNA information for a few years.

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How to get your DNA results from All of Us

- 1 Create an All of Us participant account and complete the "Consent to Join the All of Us Research Program".
- 2 Agree to share your electronic health records (EHRs) with All of Us.
- 3 Go through the Consent to Get DNA Results in your All of Us account. At the end of that consent, tell us if you want to get your DNA results.
- 4 Complete The Basics survey.
- 5 When invited to do so, make an appointment to provide blood, urine, and/or saliva samples.*
- 6 Go to your appointment and provide the samples to All of Us so that we can study your DNA.
- 7 Keep your email and/or mobile phone number up-to-date in your All of Us account to get important updates about your DNA results.

Then make sure to check your All of Us account for messages. When we are ready to generate a specific type of results from your DNA, we will send you a message about how to get those results.

**Note: A blood or saliva sample is needed to study DNA.*

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What if I need help understanding my results?

All of Us will provide educational materials that help explain DNA results.

If you still have questions after reviewing those materials, you will be able to contact a genetic counselor through the [CCR for Latinos](#). To do so, log in to your All of Us account or call our Support Center at (844) 842-2855.

Joinallofus.org/juntos

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Communication from All of Us Research Program – My Medical Minutes

MY MEDICAL MINUTES All of Us

Septiembre del 12 de septiembre

¡Now regístrate un minuto!


¡This Register Minute! ¡Ahora sí, te registras! ¡En minutos!

¡Read the Latest Newsletter!

All of Us by the Numbers

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Questions?



Nuestra Salud

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