

# The All of Us Research Program



April 13, 2024

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Director of Health Equity

All of Us Research Program



# 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, we hope that researchers will one day uncover paths toward delivering precision medicine – or individualized prevention, treatment, and care – for all of us.

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

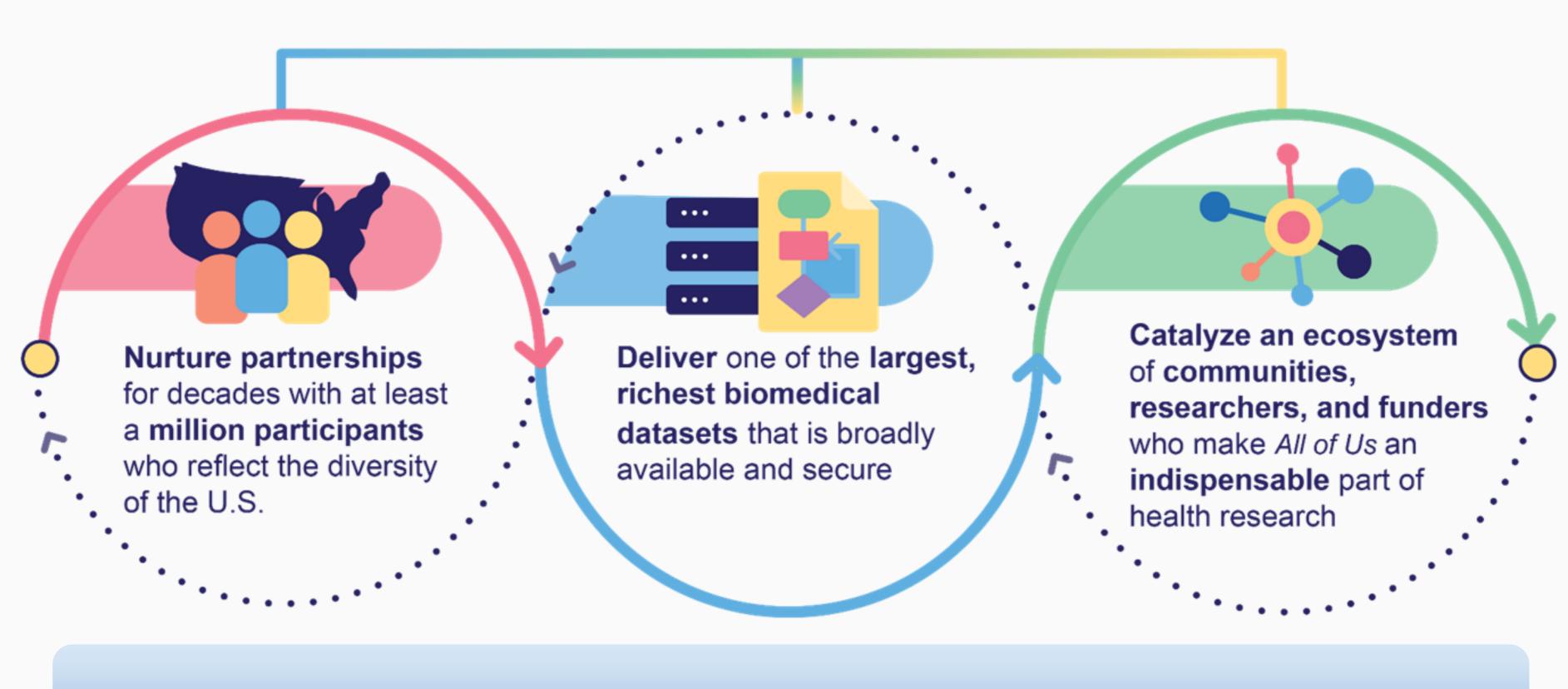


"All of Us is among the most ambitious research efforts that our nation has undertaken!"

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

# **Program Mission**

Accelerate health research and medical breakthroughs, enabling individualized prevention, treatment, and care for all of us



Integral to this mission is a commitment to health equity

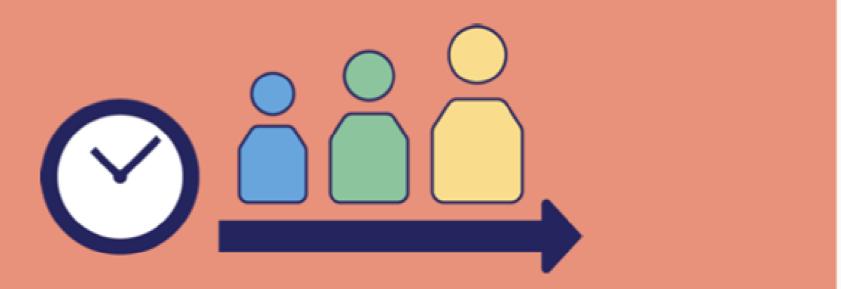
# **Enabling Research Discoveries that Drive More Precise Approaches to Care**

Engages people & communities who have been left out of medical research in the past



Combines biological factors and social determinants on a large, inclusive scale

Follows participants as they move, age, and grow



# Easily accessible

to any researcher with a secure internet connection



# Status of the All of Us Research Program (as of April 8, 2023)



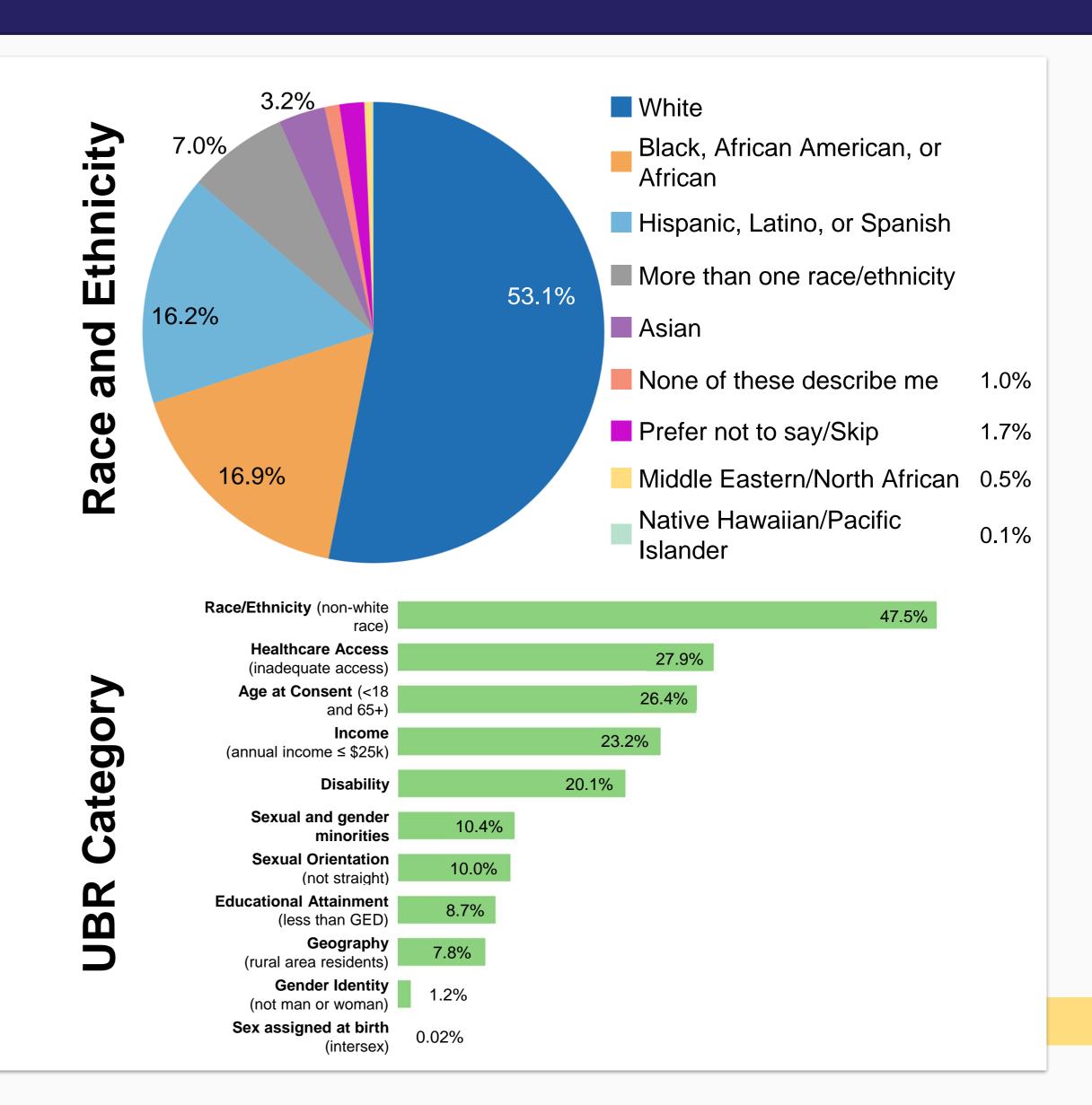
432,000+
Electronic Health
Records

539,000+

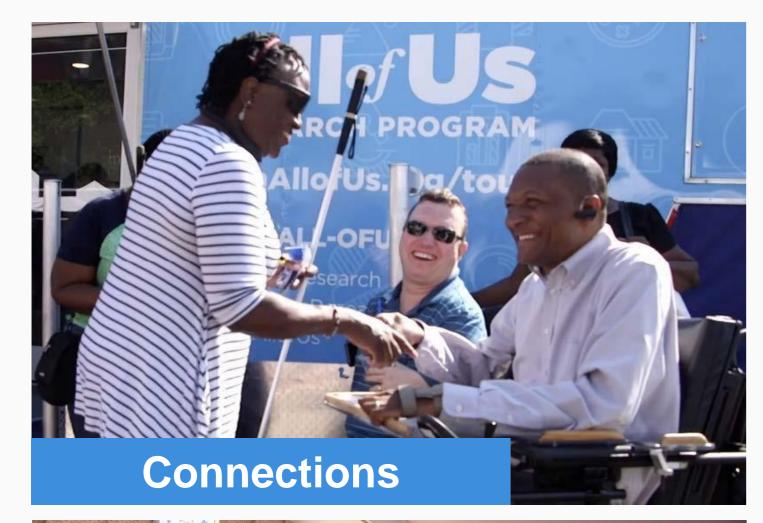
Participants who have completed initial steps of the program

557,000+

Biosamples



# **Engaging Communities Through Trusted Partners**





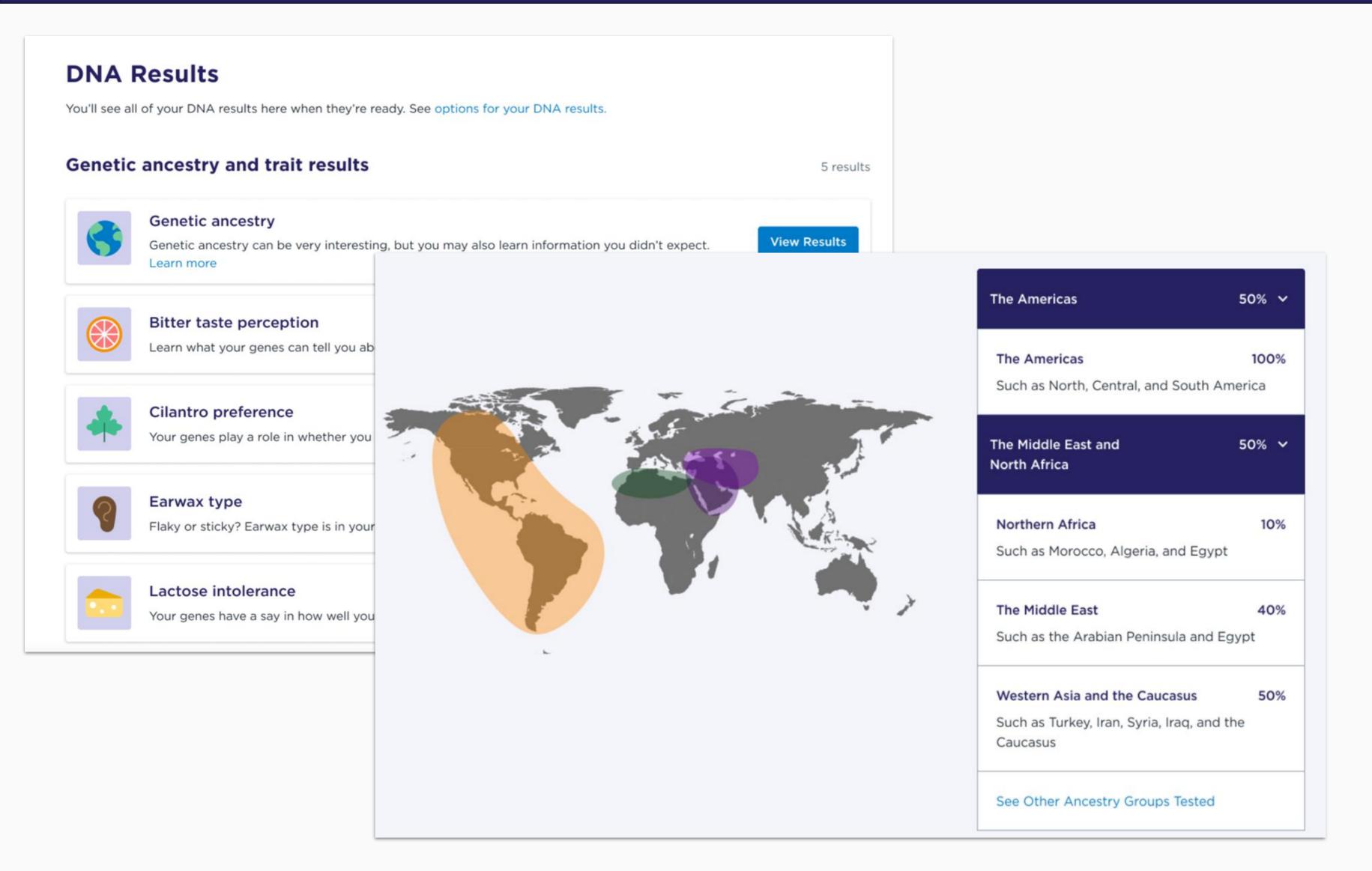




Education



# Genetic Ancestry and Traits (as of April 8, 2024)



297k+ participants were invited to receive their results

167k+ participants viewed their genetic ancestry results

170k+ participants viewed genetic trait results

## Genomic Health-Related Return of Results (as of April 8, 2024)

## **Hereditary Disease Risk**

All of Us currently looks for genetic variants in 59 genes associated with serious health conditions.



JANE DOE
DOB: January 1, 2000

Specimen: Whole Blood
Barcode: AOU 000 000 000 0002
Collected: January 1, 2022
Papert data: September 29, 2022

PESEADCH DESULT - Your doctor will need to confirm this result with a clinical test before using it in your care



#### Your result:

Something very important for your health was found in your *BRCA1* gene.

#### What does this mean?

- If confirmed by a clinical DNA test, this result means that you are more likely to get some types of cancers than other people.
- It does **not** mean that you have some types of cancers.
- It does **not** mean that you will definitely get some types of cancers.
- This result is important and should not be ignored.

#### IMPORTANT!

Genome Center: BCM

## Share this report with your doctor.

- This report comes from a research program, so it is
  a research result. Your doctor will need to confirm
  these results with a clinical DNA test before using
  them in your care.
- Do not change your medical care before this result is confirmed by your doctor.
- Results provided are from an investigational device. An "investigational device" is a device that is the subject of a clinical study.

## **Medicine and Your DNA**

All of Us analyzes seven genes that can affect how bodies metabolize medicines.



DOB:

Barcode: Collected:

RESEARCH RESULT — Your doctor will need to confirm this result with a clinical test before using it in your care.



#### **Medicine and your DNA**

Our genes affect how we respond to medicine.

They do that in many different ways. Some genes help move medicines to the right part of the body.

This test looked at a few of the genes in your DNA that can affect how medicines are used. The technical term for this kind of information is "pharmacogenetics."

What is this kind of information used for?

Pharmacogenetics: Medicine and your DNA
Genome Center: Broad Institute of MIT and Harvard, CLIA #22D2055652
Laboratory Director: Heidi L. Rehm, PhD, FACMG

Doctors and pharmacists use this kind of information when they consider why medicines work differently for different people.

**But doctors and pharmacists don't make decisions based on just DNA.** Some other important considerations can be age, weight, health, diet, and other medicines you are taking at the same time.

233k+ participants asked if they want health related results generated

101k+ participants viewed HDR results

97k+ participants viewed PGx results

# Data Tiered Access Levels Enable Discovery



Available to Anyone



Available to Registered Researchers

## **PUBLIC TIER**

### Public resources include:

- Data Snapshots: Aggregated, public-facing overviews of participant characteristics and data types
- Data Browser: Interactive preview into the All of Us dataset through public-facing aggregate data
  - Currently includes participant-provided survey responses, physical measurements, data from EHRs and wearables, and genomic data
- Survey Explorer: Details the questions included in each of the surveys
- Research Projects Directory: Descriptions of each research project within the Researcher Workbench

## RESEARCHER WORKBENCH

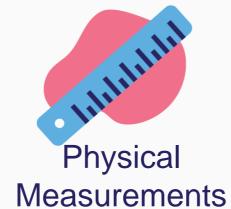
### REGISTERED TIER

Registered researchers can access in-depth data and a variety of research tools to conduct a wide range of studies.



Electronic Health

Records





## **CONTROLLED TIER**

Registered researchers with amended institutional agreements can access all of the data in the Registered Tier plus additional and expanded data types, including genomic data, real dates of health events, ICD codes, granular demographic data, and more.

Genomics

Health and

Lifestyle surveys

Data have been processed to protect participant privacy



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AllofUs.NIH.gov

JoinAllofUs.org

Research Allof Us.org

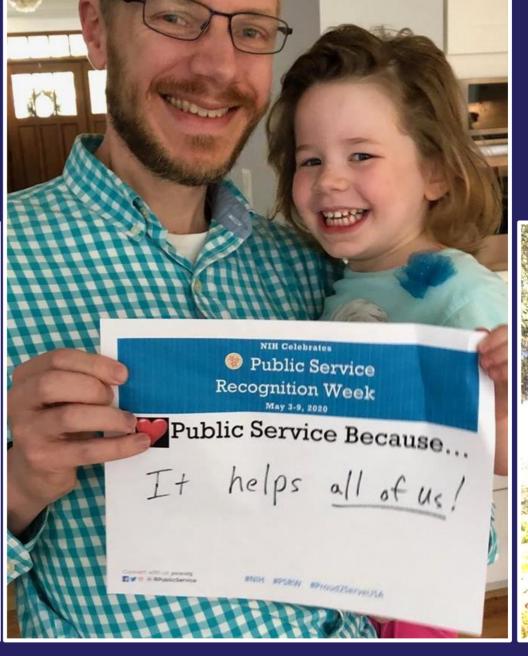




@AllofUsResearch
@AllofUsCEO
#JoinAllofUs









Thank you to our 785,000+ participants!