

# Strategic Insights for the Growth and Sustainability of the *All of Us* Research Program

*All of Us* Reflection and Advancement Working Group Final Report

Russ Altman, MD, PhD  
September 12, 2024



**Pioneering Precision:**  
**Strategic Insights for the**  
**Growth and Sustainability of**  
**the *All of Us* Research Program**

**September 12, 2024**

*All of Us* Reflection and Advancement Working Group Report to the *All of Us* Research Program Advisory Panel

# Outline

- Creation of this working group
- Process and evaluation activities
- Summary of working group findings
- Open for Council questions and discussion
- [Council Vote to accept Working Group's report]

# Background

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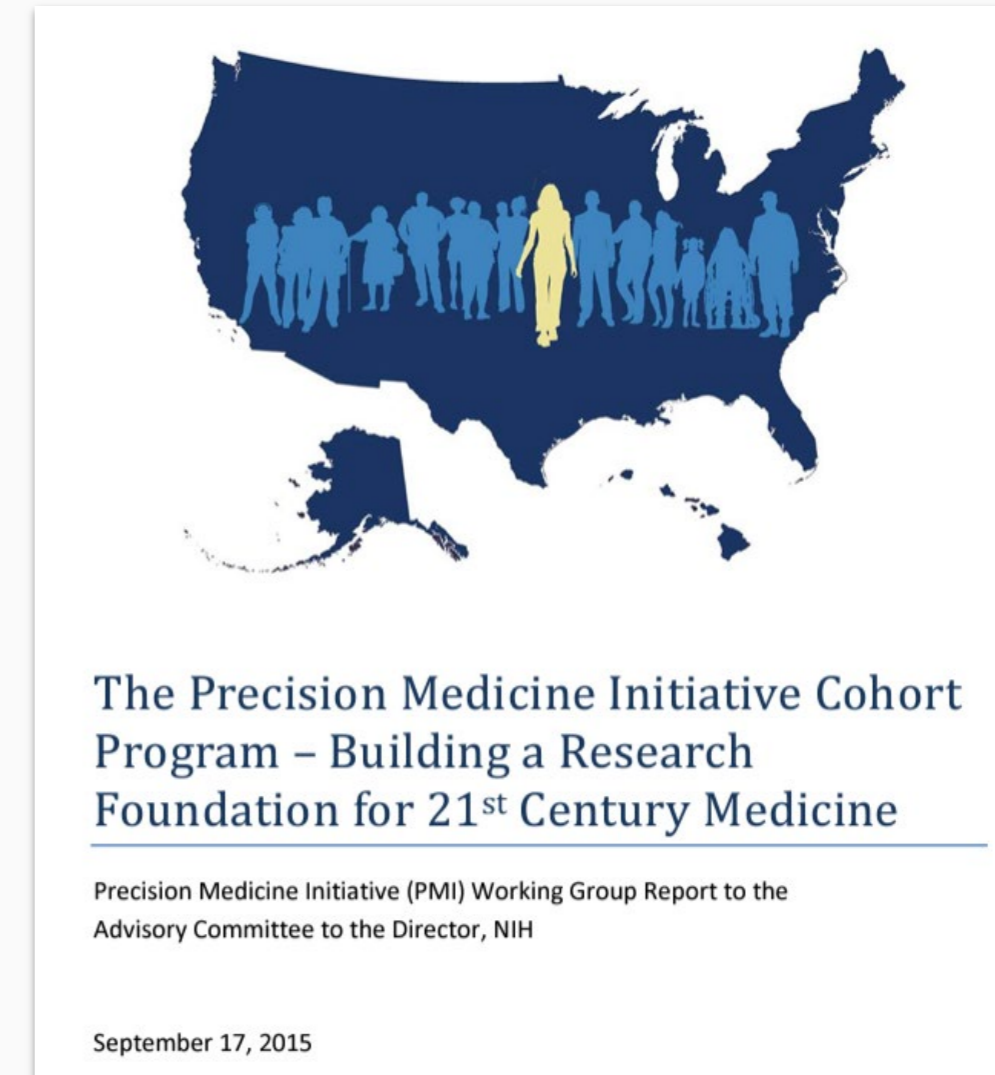
# Advisory Panel Mission

The [2015 PMI Working Group Report to the NIH ACD](#) recommended the creation of an [Independent Advisory Board](#) to provide external oversight.

## *All of Us* Advisory Panel's Objective and Scope:

- Provide feedback and vision and direction on *All of Us*
- Contribute to the program's strategic five-year goals and how they relate to the broader precision health ecosystem
- Review progress
- Help realize opportunities
- Be thoughtful advocates for the program's success

The panel will ensure at appropriate intervals that the vision continues to adapt to the evolving landscape of research, clinical practice, and participant engagement.



## Snapshot of Advisory Panel Impact To Date:

- Inspired & encouraged 2026 5-year goals
- Working Groups on:
  - Reflection and Advancement
  - Child Enrollment Scientific Vision
  - Tribal Collaboration
  - Data Quality & Completeness

# All of Us Advisory Panel Members

[Learn more here!](#)



Aaron Abend, MBA



Naomi Allen, D.Phil., MSc, BSc



Council of Councils Representative

Rhonda Robinson Beale, MD



New Member  
Participant Ambassador

Christina C. Bell Andrews, JD, MPH, MBA, MA



Russ B. Altman, MD, PhD



Wendy K. Chung, MD, PhD



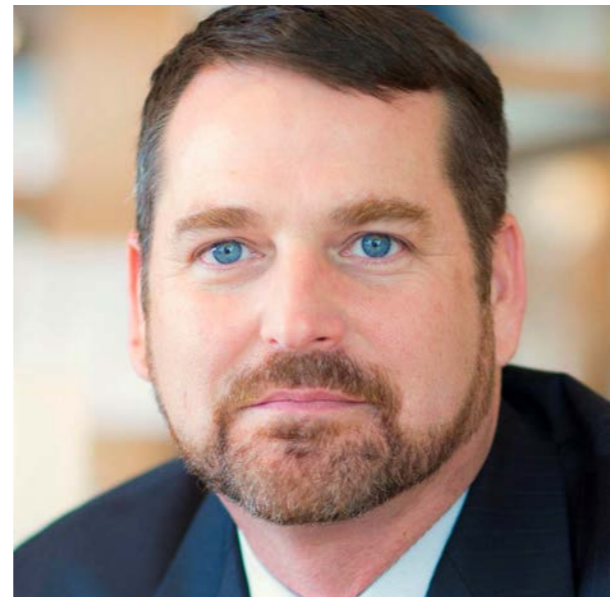
Marylyn DeRiggi Ritchie, PhD



Dontal Johnson, MD



James Lu, MD, PhD



Gary W. Miller, PhD



John Molina, MD, JD, LHD



Chris O'Donnell, MD, MPH

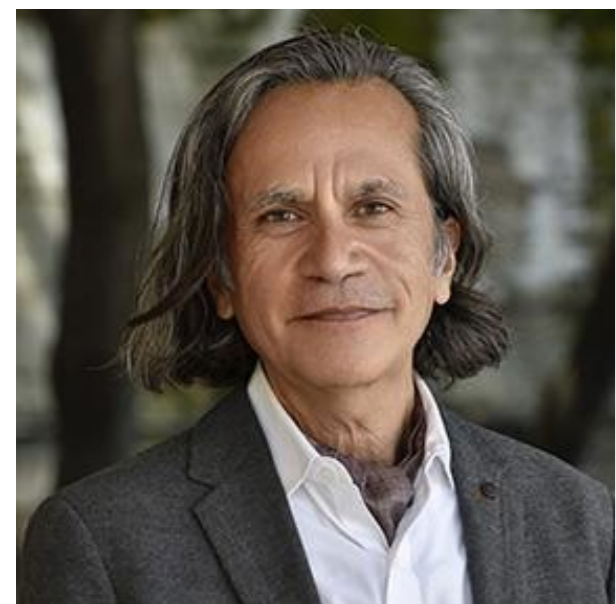


Elizabeth O. Ofili, MD, MPH, FACC



Participant Ambassador

Evelyn Ortiz



Jesus Ramirez-Valles, PhD, MPH



Former Council of Councils Representative

Scout, PhD, MA



Prashant Shah, MS



Hannah Valantine, MD, MRCP



Roberto Vargas, MD, MPH



Xiaobin Wang, MD, MPH, ScD

# Working Group Chair and Co-Vice Chairs



**Russ B. Altman, MD,  
PhD**

**Stanford University**

Kenneth Fong Professor of  
Bioengineering, Genetics,  
Medicine and Biomedical Data  
Science (and Computer Science,  
by courtesy)

Associate Director, Stanford  
Institute for Human-Centered AI

**Chair**



**Marylyn DeRiggi  
Ritchie, PhD**

**University of Pennsylvania**

Professor in the Department of  
Genetics, Director of the Center  
for Translational Bioinformatics

Associate Director for  
Bioinformatics in the Institute for  
Biomedical Informatics

Associate Director for Precision  
Medicine

**Vice Chair**



**Rhonda Robinson  
Beale, MD**

**UnitedHealth Group**

Senior Vice President, Mental  
Health Services

Deputy Chief Medical Officer,  
Mental Health Services

**NIH Council of Councils  
Liaison**

**Vice Chair**

# All of Us Reflection and Advancement Working Group

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**Purpose:** Assess the program's evolution, evaluating achievements, challenges, and opportunities for improvement and advancement since the national launch to shape the program's strategic plan towards maximizing its scientific impact leading up to 2031.

**Deliverable:** The Working Group developed a report to lay the groundwork for shaping the next iteration and extension of the *All of Us* strategic plan.

**Process:** Launched in April 2024, the Working Group conducted **five focused input sessions** with Advisory Panel members, program leadership, and subject matter experts to **discuss the program's progress, challenges, and opportunities.**

The Working Group evaluated **eight strategic questions** to guide the development and writing of the report, which was reviewed for accuracy by the program.

## Roster

### Chair and Vice Chairs

Russ Altman - Chair

Marylyn DeRiggi Ritchie - Vice Chair

Rhonda Robinson Beale - Vice Chair

### Members & Contributors

Aaron Abend

Naomi Allen

Wendy Chung

Gary Miller

Christopher O'Donnell

Evelyn Ortiz\*

Scout

Jesus Ramirez-Valles

Roberto Vargas

Prashant Shah

Hannah Valantine

Xiaobin Wang

Sadiqa Mahmood

Josh Mandel

Karen Wall\*

Elizabeth Rubinstein\*

*\*Participant Ambassador (Present and/or Past)*

# Strategic Questions

## Charting Progress (or Forging a Unique Path): Key Metrics and Program Differentiators

1. Given the vision outlined in the 2015 ACD Working Group Report, which key indicators or metrics best reflect the program's progress and success thus far?
2. What are the most important differentiators of the program? What is, or should be, *All of Us* uniquely positioned to achieve?

## Cultivating Established Trust: Future Growth Opportunities for *All of Us*

3. Where are the opportunities for growth or areas for improvement within the program?
4. How can the program amplify the trust established among diverse participants, expanding their engagement and leveraging their involvement and voices

## Ensuring Health Equity: The Current and Future Impact of *All of Us* as a National Resource

5. What is the impact of the *All of Us* Research Program and what are the best opportunities for it to change the equitable practice of medicine now and in the future?
6. As the program exceeds 800K participants, and 10K researchers, how should it focus future investments to sustain and grow as a vital national research resource?

## Envisioning the Future: The Sustainability and Longitudinality of *All of Us*

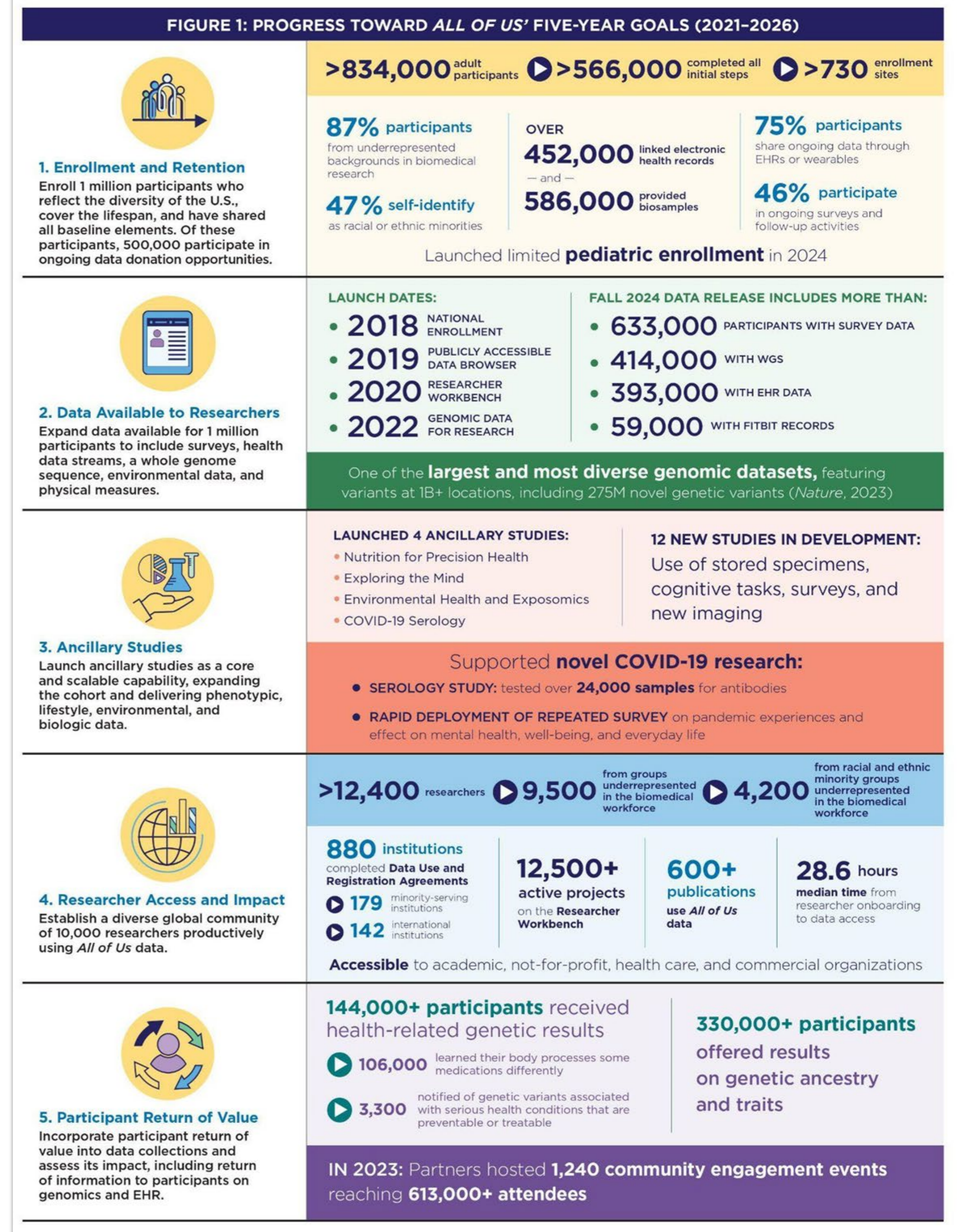
7. What prospective actions can *All of Us* take to minimize long-term infrastructure costs to taxpayers while improving overall efficiency and effectiveness?
8. How can *All of Us* strategically contribute to future cost savings for researchers within the scientific ecosystem, leveraging initiatives like the passport and cloud model?



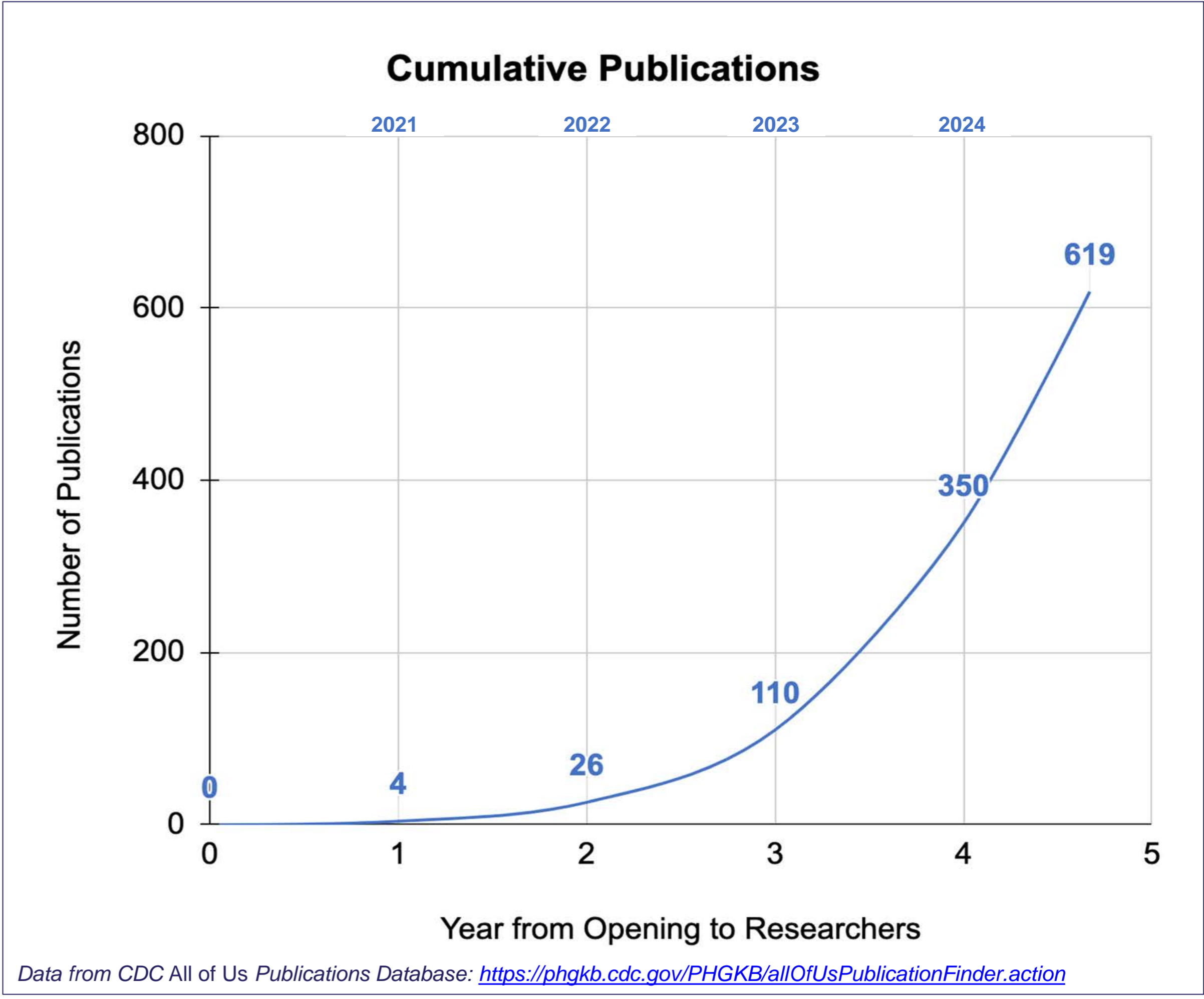
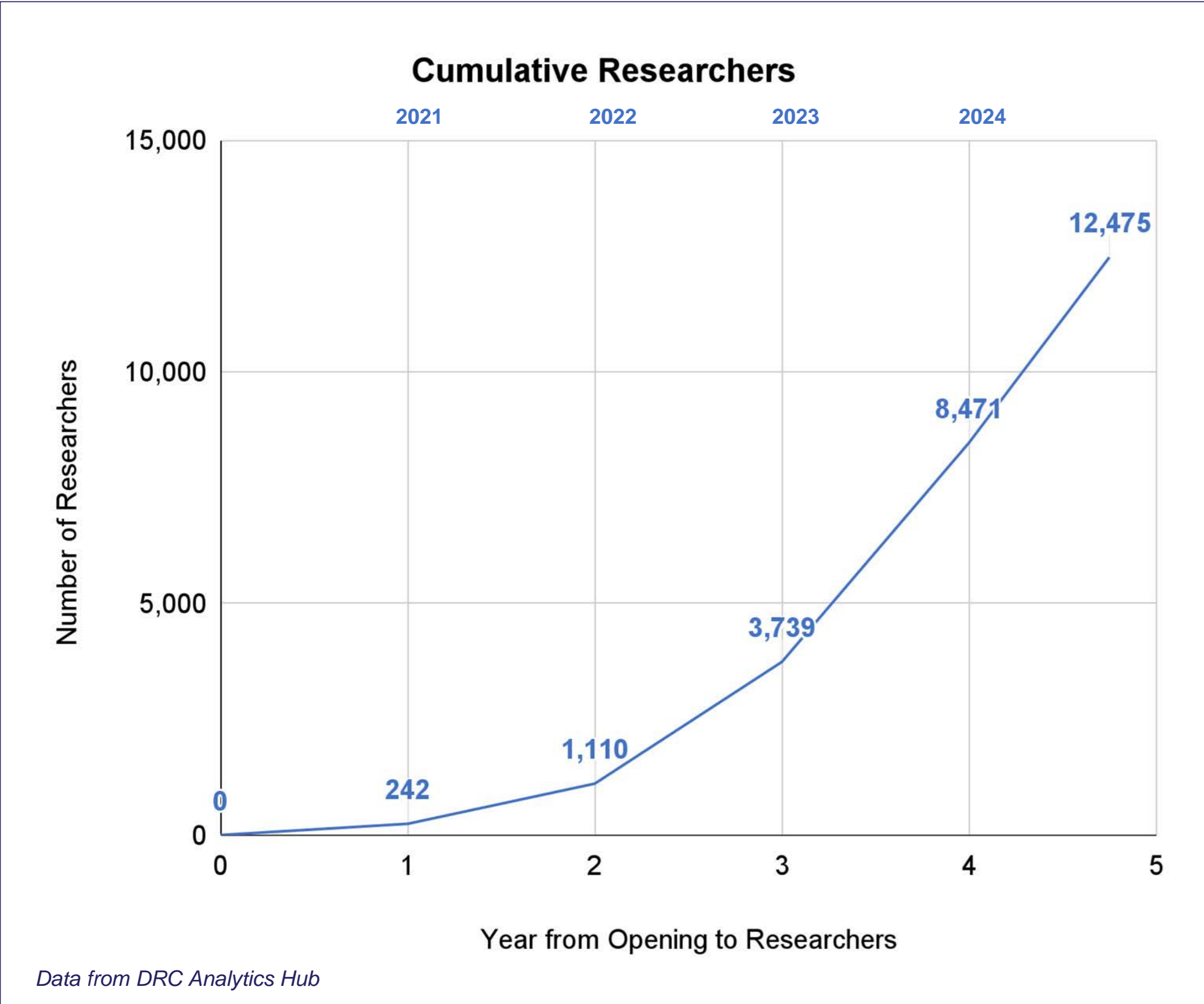
# Report Themes

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# Figure 1: Progress Toward *All of Us* Five-Year Goals (2021-2026)



# Figure 2 - Growth of Researchers and Publications



## Executive Summary *(slide 1 of 3)*

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1

- The primary strength is the **diversity** of the *All of Us* cohort – particularly among participants underrepresented in biomedical research
- Build and **engage** cohort

2

- Enrollment should continue to goal of **at least 1,000,000** participants
- Ensure that participants **engage, contribute, and take pride** in their participation and the resulting biomedical discoveries

3

- Add a **pediatric cohort** to observe health through the full life span
- Link to **family members in the cohort** (e.g., observe generational effects)

## Executive Summary *(slide 2 of 3)*

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4

- **Robust platforms** for intake and dissemination
- “**Buy vs. build**” decisions for better economics and flexibility
- Competitive awards and **evolving partners**

5

- Match diversity of cohort with **diversity of researchers** (and questions)
- Include: Academia, industry, payors, government, NGO, multiple disciplines

6

- **Build trust** with high-quality communications to participants, returning results
- Recruit participants into **collaborative, ancillary, supplementary** studies

7

- Become key research resource for **translational research** (with NIH ICs)
- Support research in **science of translation**
- Contribute core research results to **inform equitable healthcare**

## Executive Summary *(slide 3 of 3)*

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8

- Use *All of Us* for collaborative projects that **add data at low cost (or free)**
- Help NIH ICs **recruit cohorts from *All of Us* quickly and economically**
- **New research partners** for new data, new researchers, new questions

9

- In face of budgetary uncertainty, **stable core budget** and staff is key
- All decisions must be made with a 30+ year project horizon
- Clear ability to identify “must haves” and “nice to haves”

10

- *All of Us* should be a research arm for **national health emergencies** (e.g., Covid-19)
- **Build and test capabilities** with multi-institution collaborations in areas of ongoing health issues (opioids, dementia, obesity, depression, cancer, etc...)

# Reflections on Budget

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- Loss of stable funding threatens long-term intended outcomes for the country
- Budget pressure necessitates razor sharp focus, consolidation, strategic partnerships
- Maintenance of existing cohort (data and samples) is required under all circumstances

# Discussion

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## **Council Action:**

Vote to accept the Working Group's report

**Thank You!**