Intro to Survey Data

Reference Guide & Resources

The Intro to Survey Data reference guide helps researchers understand the survey data within the *All of Us* dataset and its organization in the *All of Us* Researcher Workbench.

As you go through this reference guide, we hope you leave with a basic understanding of what types of surveys are available, how survey data are collected and organized, and more.

1. Survey development

The *All of Us* Research Program uses surveys as a way to collect participant provided information (PPI) directly from participants. The surveys are primarily designed to complement information collected from other sources such as electronic health records (EHRs) where information such as social, environmental, and behavioral determinants of health are routinely missing.

Surveys are developed and deployed following a methodical process which includes prioritization of scientific domains, content creation based on reviewing items from well-established studies and literature, pilot evaluation and refinement, and scheduled fielding.

2. Survey data collection

Surveys are administered to participants via the online, secure *All of Us* Participant Portal. Participants can complete surveys in English or Spanish. When a participant enrolls into the *All of Us* Research Program, participants are invited to complete three baseline surveys (The Basics, Overall Health, and Lifestyle), which include questions on basic demographic, health, and lifestyle information, which include questions on basic demographic, health, and lifestyle information.

The Basics	Overall Health	Lifestyle
The Basics survey asks basic demographic questions, including questions about a participant's work and home. *Note: Participants must complete The Basics survey before responding to additional surveys.*	The Overall Health survey collects information about a participant's overall health including general health, daily activities, and women's health topics.	The Lifestyle survey asks about a participant's use of tobacco, alcohol, and recreational drugs.

Additional surveys on other topics of interest are regularly developed and released for participants to complete as follow up surveys via the *All of Us* Participant Portal. Current follow up surveys include Health Care Access and Utilization, Personal and Family Health History, and Social Determinants of Health.

Health Care Access and Utilization	**Personal and Family Health History**	**Social Determinants of Health**
The Health Care Access and Utilization survey asks questions about a participant's access to and use of health care.	The Personal and Family Health History survey collects information about past medical history, including medical conditions and approximate age of diagnosis.	The Social Determinants of Health survey asks about the social determinants of health, including a participant's neighborhood, social life, stress, and feelings about everyday life.

Additional voluntary surveys were released to participants for completion during the coronavirus disease 2019 (COVID-19) pandemic. These optional surveys were released multiple times throughout the pandemic, so participants may have multiple data points for the same survey item if participants completed more than one iteration of the survey. *Note: Most of the content across survey versions are consistent, but some questions may differ slightly.*

COVID-19 Participant Experience (COPE) Survey	**Minute Survey on COVID-19 Vaccines**
The COVID-19 Participant Experience (COPE) Survey asks about the impact of COVID-19 on a participant's mental health, well-being, and everyday life. *Note: The COVID-19 Participant Experience (COPE) Survey was administered to participants multiple times from May 2020 to March 2021.*	The Minute Survey on COVID-19 Vaccines collects information regarding a participant's COVID-19 vaccination experience. *Note: The Minute Survey on COVID-19 Vaccines was administered to participants multiple times from June 2021 to March 2022.*

The *All of Us* Research Program continues to develop and deploy additional surveys to participants. To view current and planned surveys and learn about survey sources, browse the Survey Explorer on the *All of Us* Research Hub.

For aggregate-level survey data, visit the publicly available Data Browser. *Note: To protect participant privacy,* All of Us *has removed personal identifiers, rounded aggregate data to counts of 20, and included only summary demographic information. Individual-level survey data are available for analysis in the* All of Us *Researcher Workbench to registered researchers.*

3. Organization of survey data

Survey questions and answers are transformed into structural survey metadata and transmitted from the *All of Us* Participant Portal to the *All of Us* Data and Research Center via an artifact referred to as a "survey codebook."

The *All of Us* survey codebook was created using REDCap data dictionary format and contains not only survey content but also assigned variables (e.g., codes), branching logic, and field validation rules.

Codebook variables (e.g., source codes) are transformed during a "curation process," which includes

- Applying privacy rules to select data elements and structuring the raw survey response data according to the Observational Medical Outcomes Partnership (OMOP) Common Data Model's specifications for observational data.
- Uploading survey items and response variables into an *All of Us* specific "PPI" vocabulary via Athena, the online, browsable and downloadable OMOP repository.

Considerations for researchers
Researchers should be aware of each survey's content as well as content changes that have occurred over time when preparing to select survey data for their research project.

Eligibility criteria and survey completion status can also vary based on the type of survey (e.g., baseline or follow up). For more information on eligibility criteria for each survey and whether a survey is still being collected, read inclusion criteria in Introduction to *All of Us* Survey Collection and Data Transformation Methods.

Additional Resources

Below are additional, in-depth articles related to learning about the *All of Us* data, getting started in the Researcher Workbench, and analyzing data in the Workbench.

Learning the basics of the *All of Us* Surveys
All of Us survey data codebooks
The Basics: Baseline survey details and resources
Lifestyle: Baseline survey details and resources
Overall Health: Baseline survey details and resources
Personal and Family Health History: Follow up survey details and resources
Social Determinant of Health: Follow up survey details and resources
COVID-19 related survey series details and resources
Health Care Access and Utilization: Follow up survey details and resources
Frequently asked questions about surveys
Data curation process for the *All of Us* data

Getting started in the Researcher Workbench
Intro to the *All of Us* Researcher Workbench

About workspaces
Selecting participants using the Cohort Builder
Building a dataset with the Dataset Builder

Analyzing data in the Researcher Workbench
Overview of applications in the Researcher Workbench
Exporting and analyzing your data in the Researcher Workbench

If you have questions or need assistance, please contact us at **support@researchallofus.org**.