ELSI Workshop June 24, 2019

All of Us Program Data

Where we are and what is to come

All of Us RESEARCH PROGRAM | The Future of Health Begins With You

National Institutes of Health

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Outline

- *All of Us* Scientific Framework
- Current data types
- Data Browser walkthrough
- Future data types
- Data lifecycle
- Researcher Workbench preview

All of Us Scientific Framework = Enable Research That Will:

I. Increase wellness and resilience, and promote healthy living

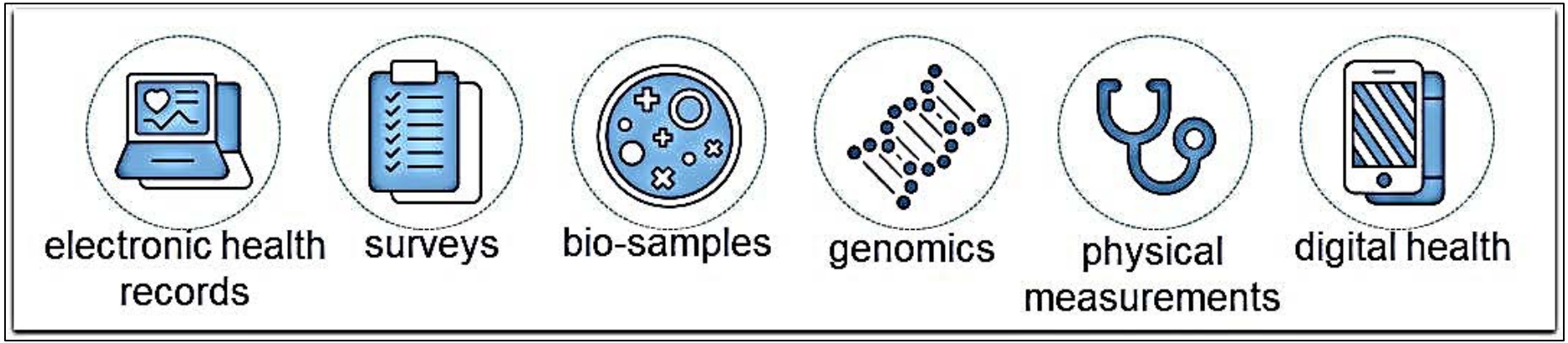
II. Reduce health disparities and improve health equity in underrepresented in biomedical research (UBR) populations

III. Develop improved risk assessment and prevention strategies to preempt disease

IV. Provide earlier and more accurate diagnosis to decrease illness burden

V. Improve health outcomes and reduce disease/illness burden through improved treatment and development of precision interventions

Current *All of Us* Data Types



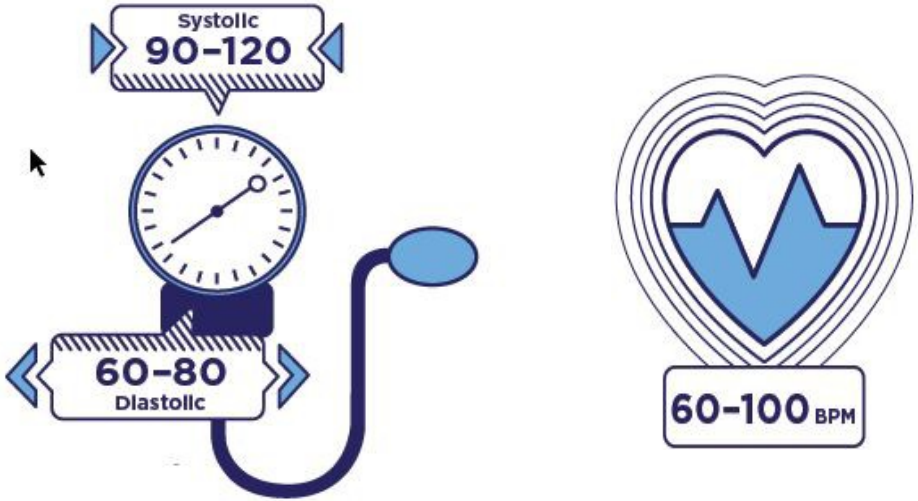
Participant Provided Information

- **Current surveys**
  - The Basics *(demographics, employment, income, contact information)*
  - Overall Health *(general health, daily activities, and women's health)*
  - Lifestyle *(tobacco, alcohol and recreational drug use)*
  - Health Care Access and Utilization *(access to and use of health care)*
  - Family Health History *(medical history of immediate biological family members)*
  - Personal Medical History *(current and past medical conditions, approximate age of diagnosis)*
- **Upcoming surveys**
  - Mental Health *(personality, mental health condition diagnosis, depression, suicidality, adversity/trauma, assault, specific disorders)*
  - Social Determinants of Health *(optimism, social and emotional support, loneliness, perceived stress, discrimination, social status, food insecurity, neighborhood disorder, religion/spirituality)*
  - Diet *(food/eating behavior)*

Participant Provided Information

- **Physical measurements**
  - Height
  - Weight
  - BMI
  - Waist circumference
  - Hip circumference
  - Blood pressure
  - Heart rate
  - Heart rhythm status
  - Wheelchair use
  - Pregnancy

(These apply to everyone.)

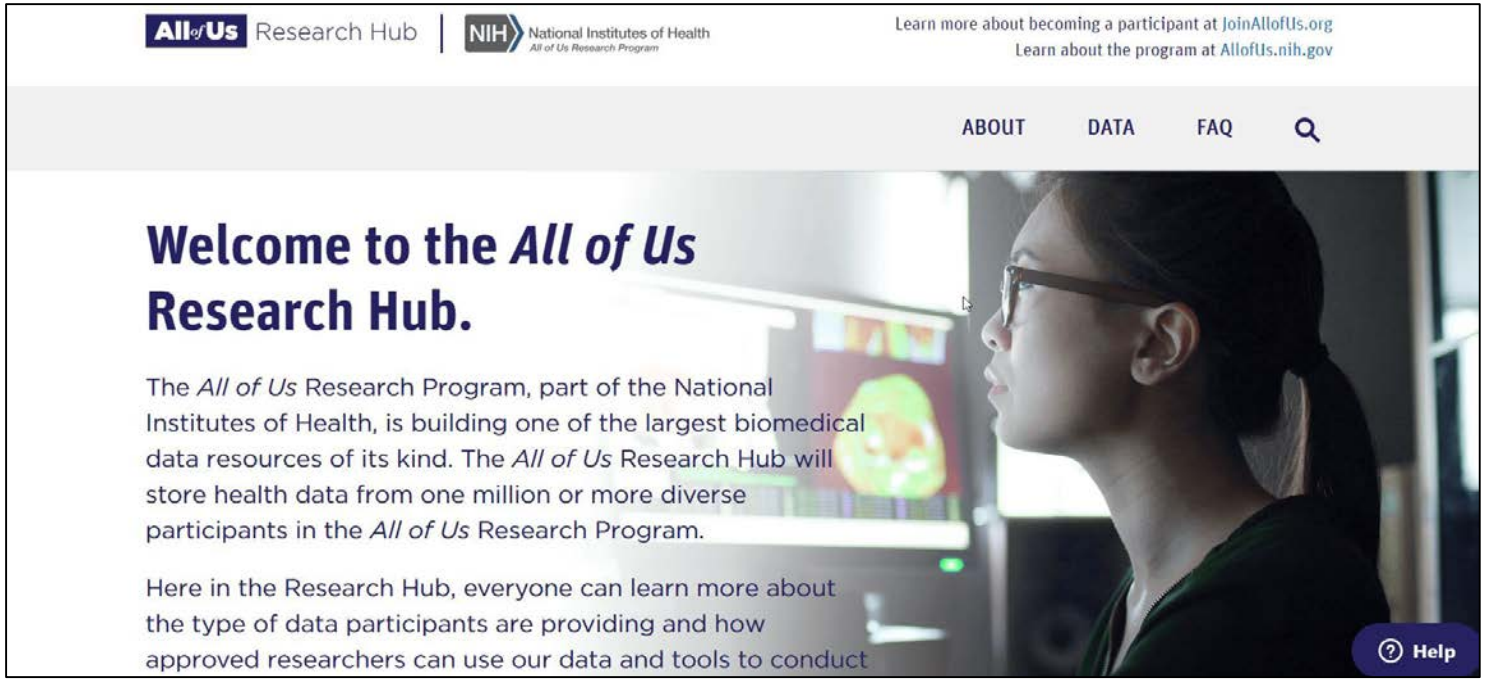


Electronic Health Records

- **Current**
  - Labs
  - Measurements
  - Conditions
  - Procedures
  - Drugs/medications
  - Visit type
- **Future**
  - Notes
  - Images *(CT, MRI, etc.)*

DATA BROWSER DEMONSTRATION

www.researchallofus.org



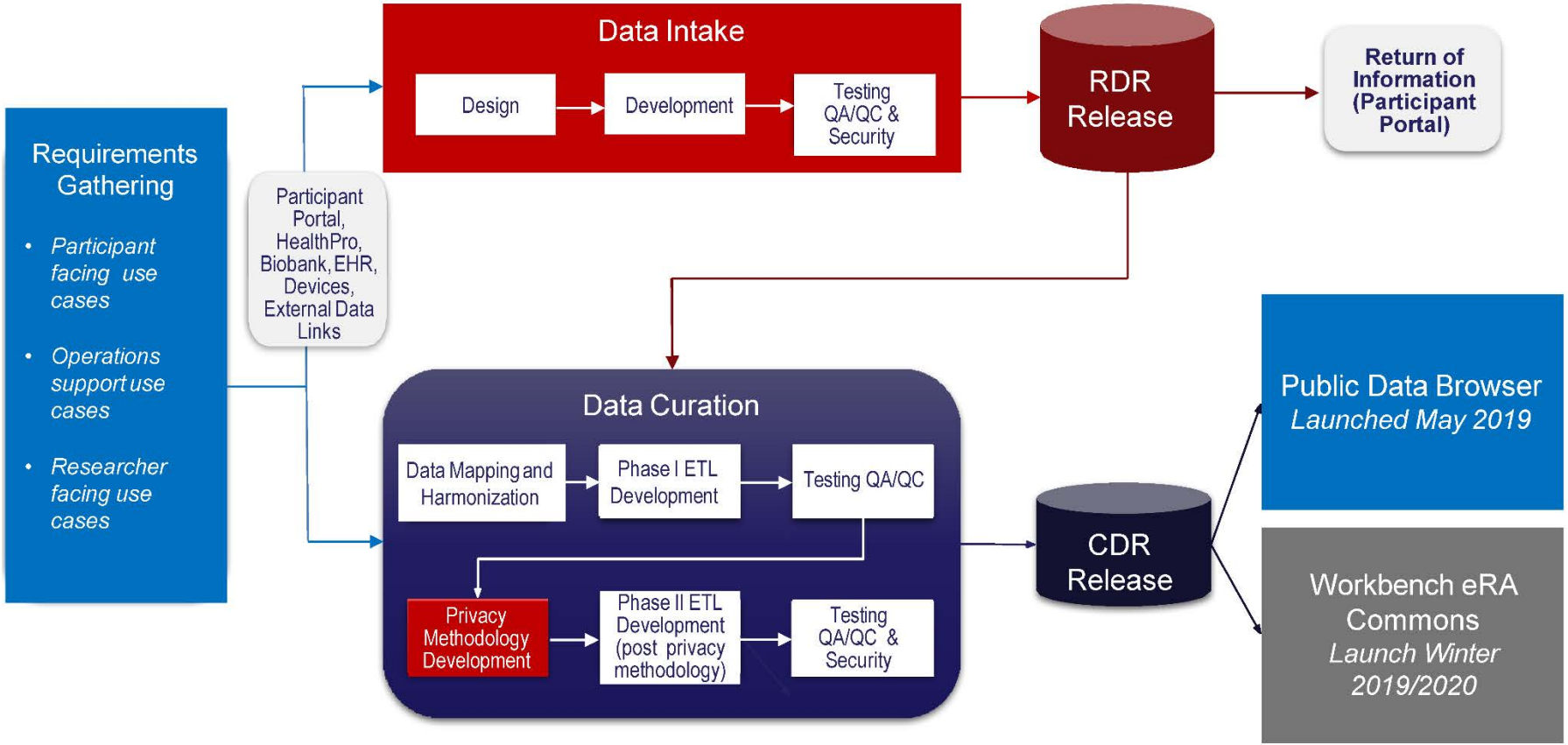
Other Data Types

- **Bring Your Own Device (BYOD)**
  - Fitbit *(>2500 users, data has been collected but not available to researchers yet)*
- **Apple Health Kit** *(on hold)*
- **External Data**
  - Mortality data (National Death Index)
  - Cancer registry data (NAACCR)

Biospecimens

- **Genomics – *All of Us* Array *(in progress)***
  - Captures more than 1.8 million sites
  - Supports association studies using common and rare variations across the genome
  - Includes clinically actionable variation in the genome (ClinVar)
  - Includes variants influencing drug transport, metabolism, elimination
- **Salivary Pilot *(in progress)***
  - Direct Volunteers
  - Samples processed at Biobank and stored until ready for genotyping
- **Assays *(proposed)***
  - HbA1c
  - CBC
  - Heavy metals
  - Pesticides + creatinine

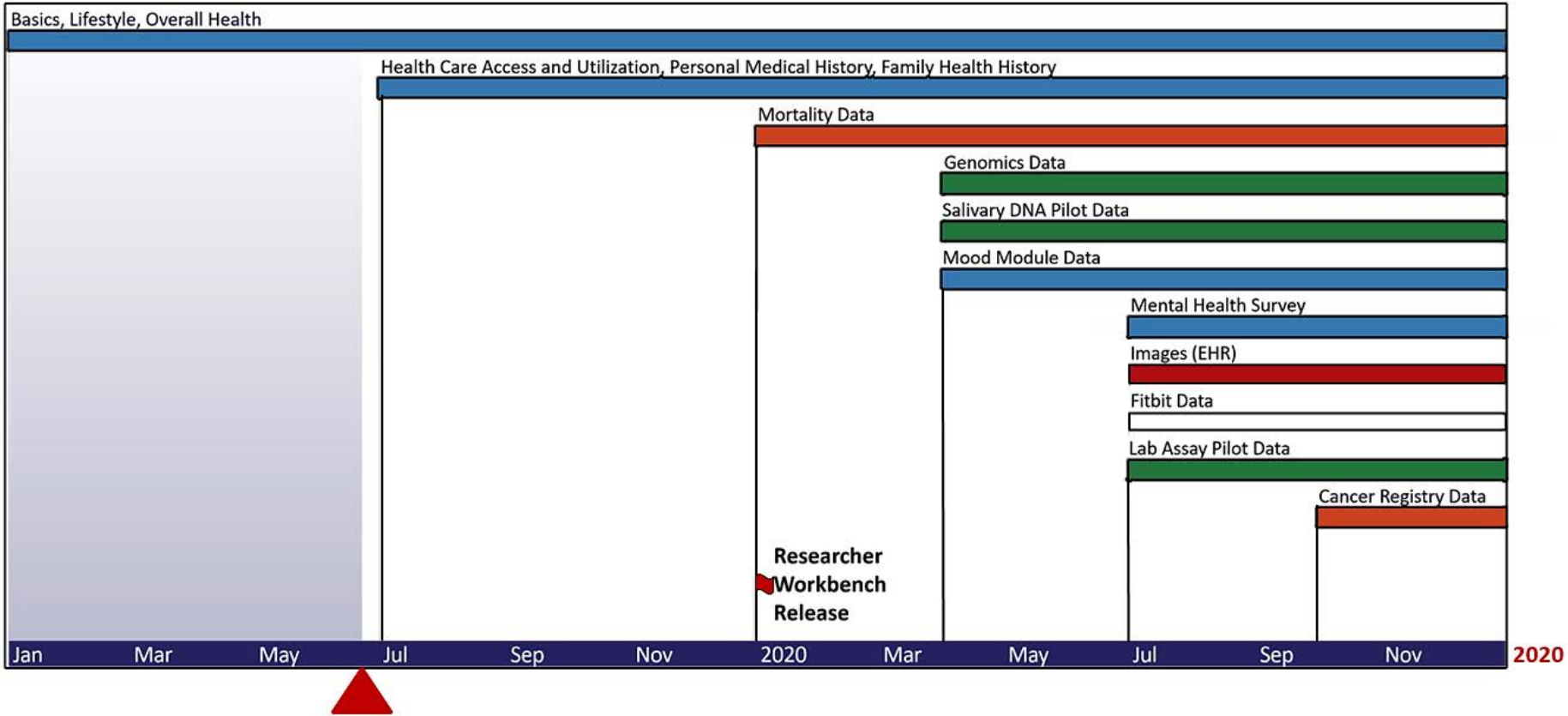
New Data Types Lifecycle



All of Us Research Data *(expected to grow by launch or shortly after)*

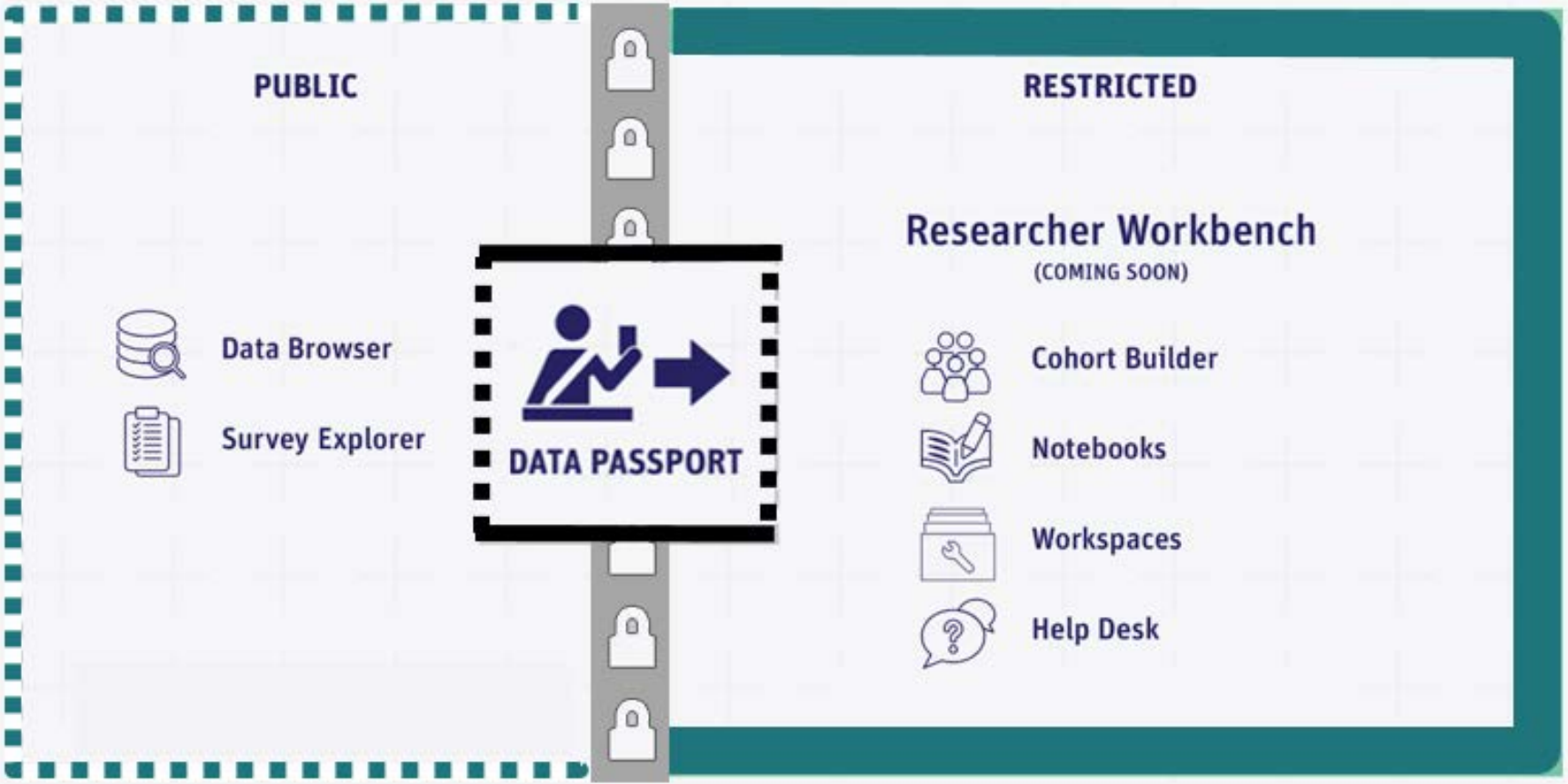
Data Type	Method	Specification	Expected *N* at launch
Blood pressure, heart rate, height, weight, BMI, hip and waist circumference, wheelchair use and pregnancy status	Physical Measurements	Baseline	>160,000
Sociodemographics, self-assessment	PPI Survey	Baseline	>200,000
Lifestyle, self-assessment	PPI Survey	Baseline	>190,000
Overall health, self-assessment	PPI Survey	Baseline	>190,000
Personal medical history, self-assessment	PPI Survey	Baseline	>30,000
Family medical history, self-assessment	PPI Survey	Baseline	>30,000
Health care access and utilization, self-assessment	PPI Survey	Baseline	>30,000
Electronic Health Record Data (diagnoses, drug exposures, lab measurements, and/or procedures)	EHR	Quarterly	>110,000

Research Dataset Timeline *(incorporation into the CDR)*



All dates and order of new data types are tentative and subject to change

Coming This Winter: Powerful Tools for Collaborative, Reproducible Science



Custom Tools for Exploring and Selecting Subsets of *AoU* Data

All of Us RESEARCHER WORKBENCH NON-PROD/SYNTHETIC DATA

Workspaces › Workspace A

Jeremy Chen

ABOUT | DATA | ANALYSIS | PUBLISH | Curated Dataset v. 1

Data

The Data Tab is the gateway to all Workbench tools and All of Us Research data that will help you complete your research project. Here, users can build a cohorts of participants, select concept sets of interest and build analysis-ready tables from the two called datasets.

Cohorts

A "Cohort" is a group of participants that researchers are interested in. The cohort builder allows you to create and review cohorts and annotate participants in a researcher's study group.

Concept Sets

Concepts describe information in a patient's medical record, such as a condition they have, a prescription they are taking or their physical measurements. Subject areas such as conditions, drugs, measurements etc. are called "domains". Users can search for and save collections of concepts from a particular domain as a "Concept set" and then use concept sets and cohorts to create a dataset, which can be used for analysis.

Datasets

Datasets are analysis-ready tables that can be exported to analysis tools such as Notebooks. Users can build and preview a dataset for one or more cohorts by selecting the desired concept sets and values for the cohorts.

Recent data

DATASET — Diabetes Meds
Research purpose lorem ipsum dolor sit amet consectetur iscing velit...
Last changed: 12:15 PM

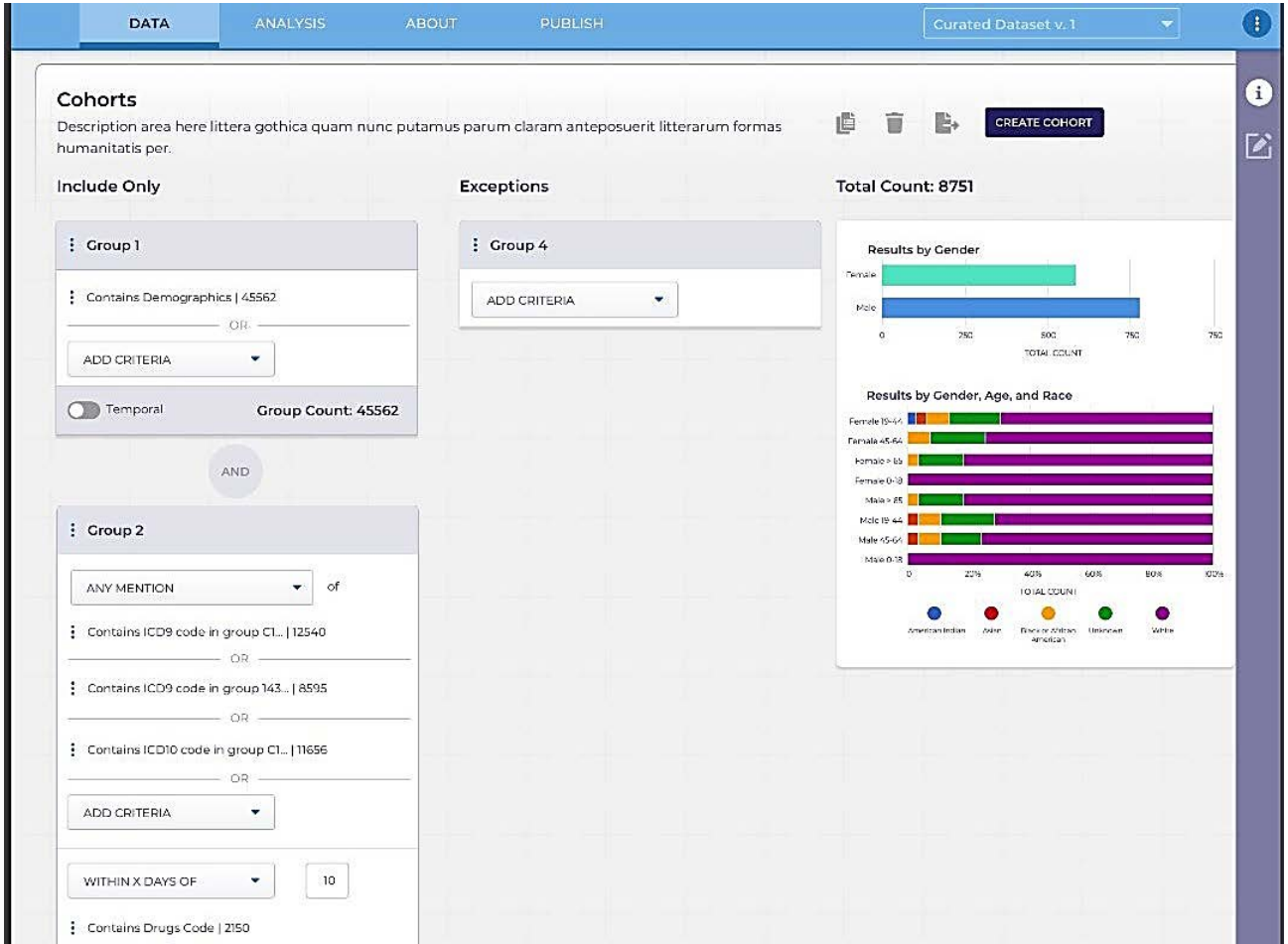
COHORT — All AoU Participants
Research purpose lorem ipsum dolor sit amet consectetur iscing velit...
Last changed: Mar 24, 2019

COHORT — Diabetes Case 1
Research purpose lorem ipsum dolor sit amet consectetur iscing velit...
Last changed: Mar 22, 2019

COHORT — Diabetes Case 2
Research purpose lorem ipsum dolor sit amet consectetur iscing velit...
Last changed: Mar 21, 2019

Data Type	Name	Owner	Last Changed
COHORT	Diabetes Control Group	Keri Wolf	Mar 19, 2019
CONCEPT SET	Demographics	Keri Wolf	Mar 1, 2019
CONCEPT SET	Physical Measurements	Karthik M	Feb 6, 2019
CONCEPT SET	Measurements	Helen Sullivan	Feb 1, 2019
CONCEPT SET	Vitals	Keri Wolf	Dec 24, 2018

Intuitive, Advanced Tool for Building Cohorts of Participants



Search Interface for Identifying Medical Concepts of Interest

ABOUT | DATA | ANALYSIS | PUBLISH | Curated Dataset v. 1

Concept Sets

Nonummy nibh euismod tincidunt ut laoreet dolore magna aliquam erat volutpat ut wisi enim ad.

Metformin

Standard concepts only

Learn more about OMOP domains

Conditions 10,859	Drugs 4,504	Measurements 2,911	Procedures 3,549	Demographics 1,203	Visits 7,350	Domain Descriptions

Showing top 100 of 4,504 Drugs

Name	Count
Drugs used in diabetes	102,456
Insulin and analogues	54,785
Blood glucose lowering drugs, excl. insulins	21,012
Biguanides Metformin	51,045
Sulfonylureas	12,874
Alpha glucose inhibitors	11,986
Thiazolidinediones	6,789

ADD TO SET

Point and Click Interface for Creating Analysis-ready Datasets

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Datasets

Build a dataset by selecting the variables and values for one or more of your cohorts. Then export the completed dataset to Notebooks where you can perform your analysis.

Select Cohorts

Cohorts

- All Aou Participants
- Diabetes Case 1
- Diabetes Case 2
- Diabetes Control Group

Select Concept Sets

Concept Sets

- Demographics
- Physical Measurements
- Measurements
- Vitals
- Drugs

Values — Select All

- Race
- Ethnicity

Drugs

- DRUG_CONCEPT_ID
- DRUG_CONCEPT_NAME
- DRUG_CONCEPT_CODE
- DRUG_VOCABULARY_ID
- DRUG_EXPOSURE_START_DATE

Preview Dataset A visualization of your data table based on the variable and value you selected above.

SAVE DATASET

Demographics | Drugs

Participant ID	DRUG_CONCEPT_ID	DRUG_CONCEPT_NAME	DRUG_CONCEPT_CODE	DRUG_VOCABULARY_ID
12345	201235	Acetohexamide	5645415	Vocab value
12346	88451	Chlorpropamide	545856	Vocab value
12347	117456	gliclazide	650210	Vocab value

Jupyter Notebooks for Powerful, Interactive Data Analysis

All of Us Research Program — Researcher Workbench

Workspaces > Phenotype Notebooks > Notebooks >

Major Depressive Disorder

Joseph DiPaolo

jupyter Major Depressive Disorder Last Checkpoint: Last Thursday at 4:36 PM (unsaved changes)

File Edit View Insert Cell Kernel Navigate Widgets Help Snippets — Trusted — Python 3

Run — Code

Contents

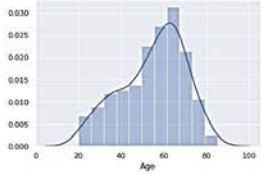
- Major Depressive Phenotype
  - 1. Find Concept IDs
    - Condition Concept IDs
    - Drug Concept IDs
      - Simple drug pull
      - Complex drug pull
    - Procedure Concept IDs
  - 2. Select participants with condition
  - 3. Select participants with drug exposure
    - Simple drug pull
    - Complex drug pull
  - 4. Select participants with procedure
  - 5. Select participants with PPI data
  - 6. Final results
  - 7. Cohort Breakdown
    - Gender Breakdown
    - Race Breakdown
    - Hispanic Breakdown
    - Age Breakdown

```
        WHEN DATE_DIFF(CURRENT_DATE(),DATE(CDR_DF.birth_datetime), DAY)/365 < 86 THEN '76-85'
        ELSE '86+' END) AS Age_Bracket,
    CAST(SUM(Simple_DF.Simple) AS NUMERIC) AS Simple,
    CAST(SUM(Complex_DF.Complex) AS NUMERIC) AS Complex,
    CAST(SUM(CDR_DF.CDR) AS NUMERIC) AS CDR

FROM
    CDR_DF
    LEFT JOIN Simple_DF ON CDR_DF.person_id = Simple_DF.person_id
    LEFT JOIN Complex_DF ON CDR_DF.person_id = Complex_DF.person_id

GROUP BY Age_Bracket

ORDER BY Age_Bracket ASC

""".format(simple_cohort_PIDs_subquery, complex_cohort_PIDs_subquery),
dialect = "standard")
```

In [124]:
```
display(age_table)
print("\n\n")

sns.distplot(age['Age'])
```

	Age_Bracket	Simple	Complex	CDR
0	0-17	None	None	2
1	18-25	11	11	12162
2	26-35	27	27	24268
3	36-45	35	35	22501
4	46-55	49	48	26219
5	56-65	75	74	32051
6	66-75	55	54	24564
7	76-85	18	18	8768
8	86+	None	None	904

Out[124]: <matplotlib.axes._subplots.AxesSubplot at 0x7f22fd3ccc50>



In [ ]:

Tools and Services for Research Support

- **Help Desk**
  - General & technical support
  - Community forums
  - Knowledge base
- **Training Materials**
  - Tool user guides
  - Instructional videos
  - Data model tutorials
  - Workspaces w/ example analyses
  - Reusable “code snippets”
- **Data Dictionary**
  - PDF as part of detailed data documentation
  - Integrated directly within Workbench tools

Thank you