All of Us Research Program Programmatic Update; a Glimpse of Mental Health Data in *All of Us*

ALL *of* **Us**
RESEARCH PROGRAM

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All of Us Research Program, NIH

October 5, 2020
NIMH Joint Alliance-Coalition for Research Progress Town Hall

NIH
National Institutes
of Health

Goals

- In the next 10 minutes I will share with you:
  - Brief Updates from the *All of Us* Research Program
    - Enrollment updates
    - COVID-19 priority areas
    - Overview of the COVID-19 Participant Survey (COPE)
  - Preliminary peeks at mental health data available in the *All of Us* dataset
  - Future plans for Mental Health Campaign

Enrollment Highlights

More than **357,000** participants have enrolled in the program, including more than **271,000** who have provided physical measurements and biospecimens.

Numbers as of September 10, 2020

100+ Funded Partner Organizations

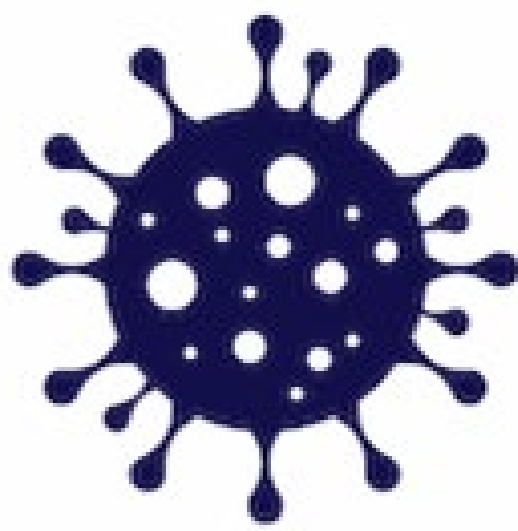**320+** Sites Collecting Samples and Measurements

50%+ Racial and Ethnic Minorities

80%+ Underrepresented in Biomedical Research

228,000+ Electronic Health Records

**277,000+** Biosamples

View our Data Snapshots

All of Us Response to COVID-19

- *All of Us* COVID-related activities:

    - **Digital enrollment and retention (in-person visits paused March 16 through July 13)**

    - **Self-report data through surveys (COPE Survey)**

    - Participant serum sample antibody testing (10k)

    - Standardize EHR information on COVID-19 symptoms, associated health problems, and the effects of different medicines and treatments. Over 4,000 participants who have shared their EHR have been tested for COVID-19.

    - *All of Us* is exploring a collaboration with Accelerate COVID-19 Therapeutic Interventions and Vaccines (ACTIV). ACTIV is a public-private partnership to develop a coordinated research strategy for prioritizing and speeding developments of the most promising treatments and vaccines.

All of Us publicly announced its activities surrounding COVID-19 on June 16.

(Digital) Enrollment and Retention
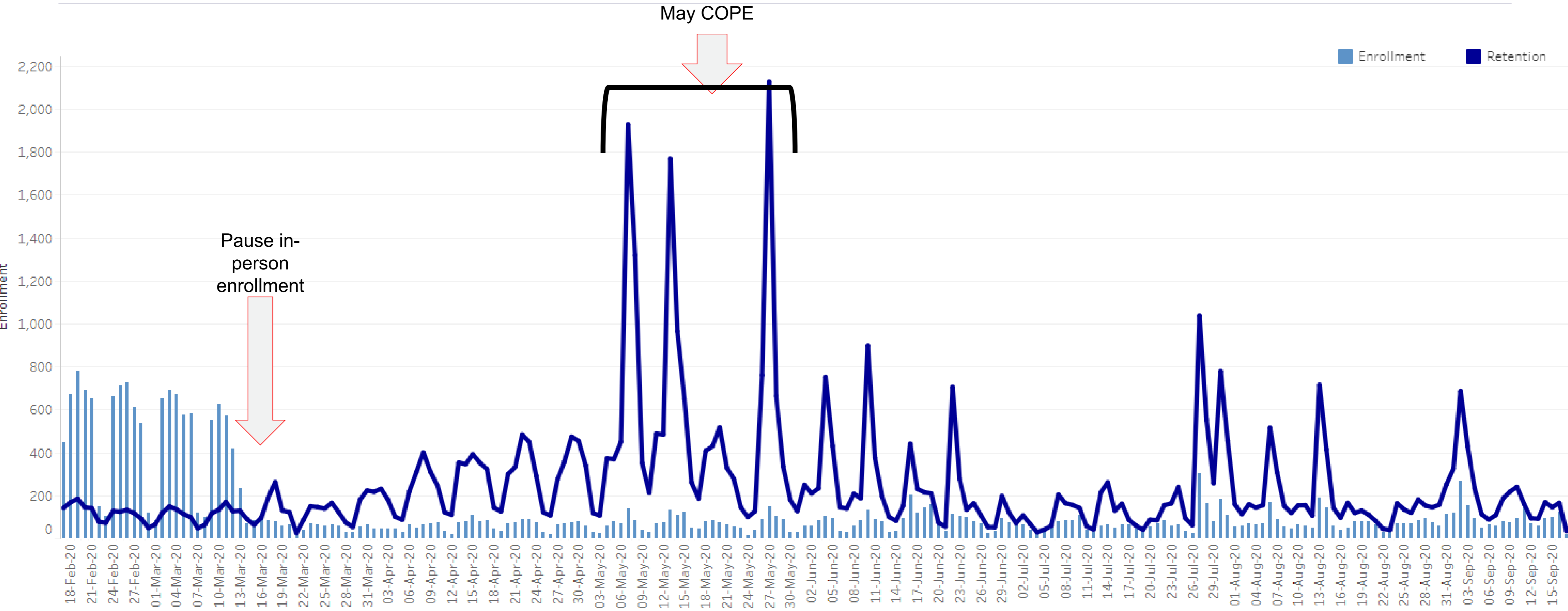
Digital retention spiked as enrollment dropped. COPE survey showed significant spikes.

Types of Mental Health Data available in the *All of Us* Dataset

NOW

1. **EHR**
   a. Conditions
   b. Drug Exposures
   c. Procedures (e.g. screening)

1. Survey Questions
   a. Personal Medical History
   b. Family Medical History
   c. COPE: anxiety, depression, suicide

https://databrowser.researchallofus.org/

Example of "Mood Disorder" in Data Browser

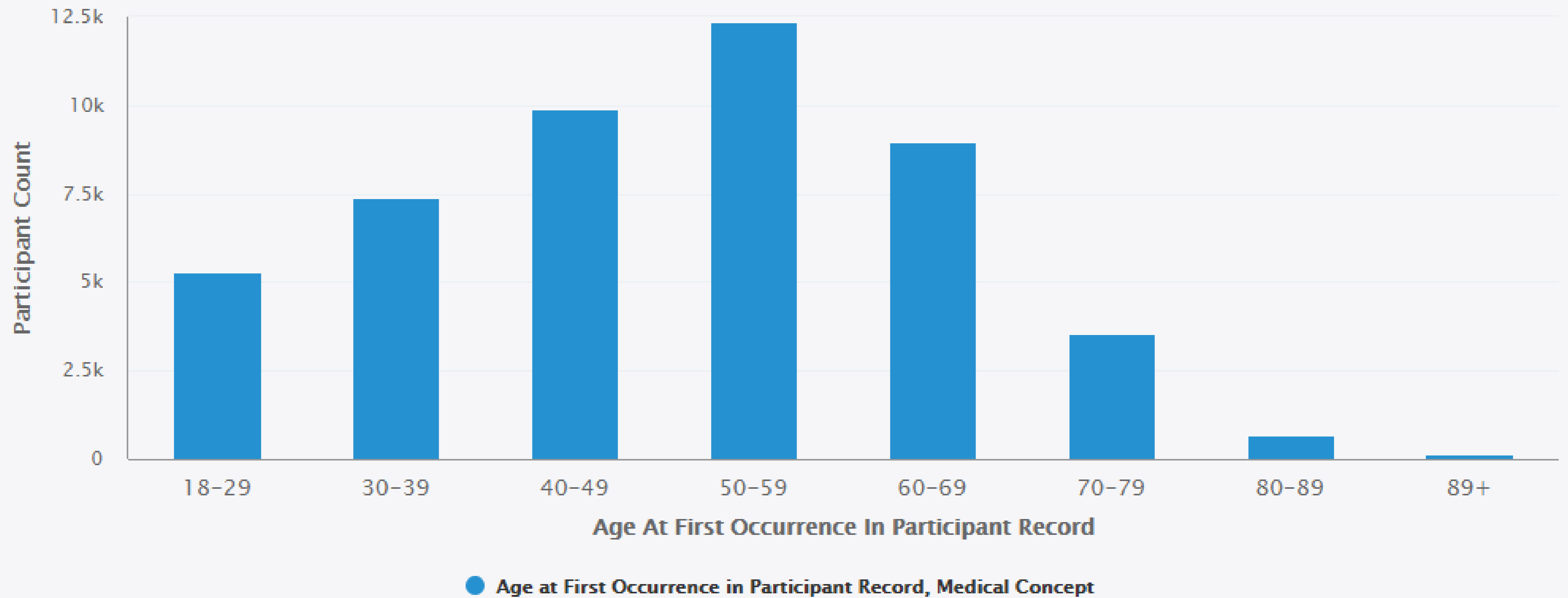23. Mood disorder   35,400   31.27%

Also Known As ⓘ

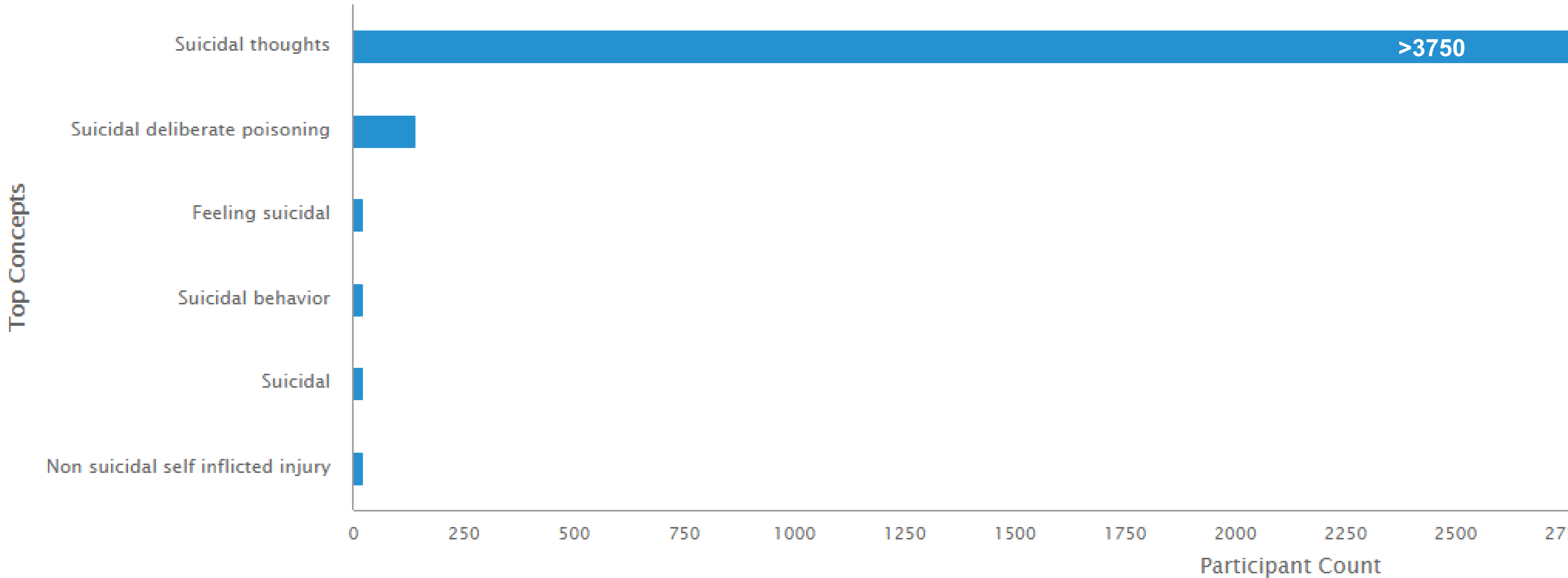Mood disorder (disorder), Affective disorder, Disorder of affect

Sex Assigned at Birth ⓘ   **Age** ⓘ   Sources ⓘ

● Age at First Occurrence in Participant Record, Medical Concept

over 35k adult participants with 'mood disorder' in EHR; https://databrowser.researchallofus.org/
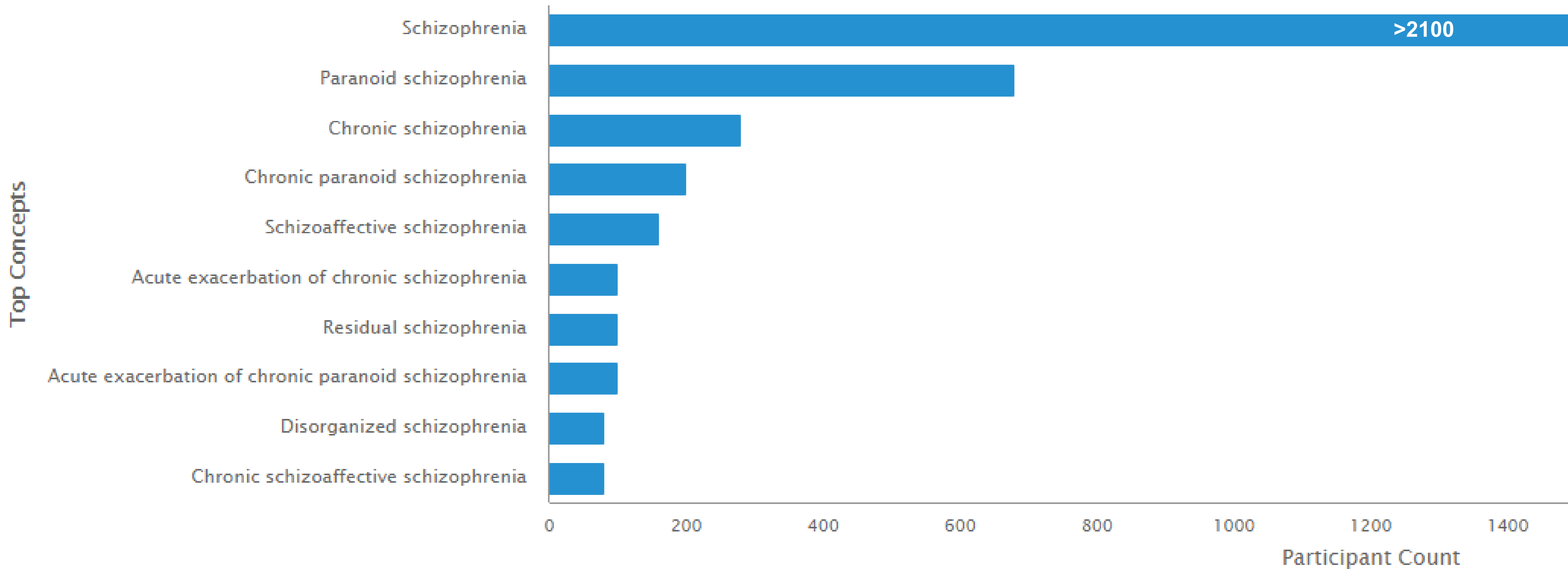
Example of 'Suicidal' in Data Browser

Top 6 Conditions by Descending Participant Counts ⌄

>3,750 participants with 'suicidal' in EHR

Example of 'Schizophrenia' in Data Browser

Top 10 by Descending Participant Counts ⌄

Diversity of EHR entries for 'schizophrenia'; https://databrowser.researchallofus.org/

COPE Survey Overview: May, June, July

◉ Mental health and well-being
- optimism
- general well-being
- generalized anxiety (GAD7)
- depression and suicidal ideation (PHQ9)
- perceived stress
- posttraumatic stress symptoms
- physical activity

◉ Social information
- social support
- loneliness
- resilience

◉ COVID-19 specific
- impact on work/childcare from COVID-19
- COVID specific symptoms and testing
- social distancing compliance
- impact of COVID-19
- coping with social isolation

◉ Basic information
- current employment
- health insurance coverage and selection

◉ Substance use
- alcohol use
- electronic nicotine use
- drug use

We focused on information we could not get easily from EHRs and could change in response to COVID-19.

Underrepresented in Biomedical Research (UBR) Completions of COPE

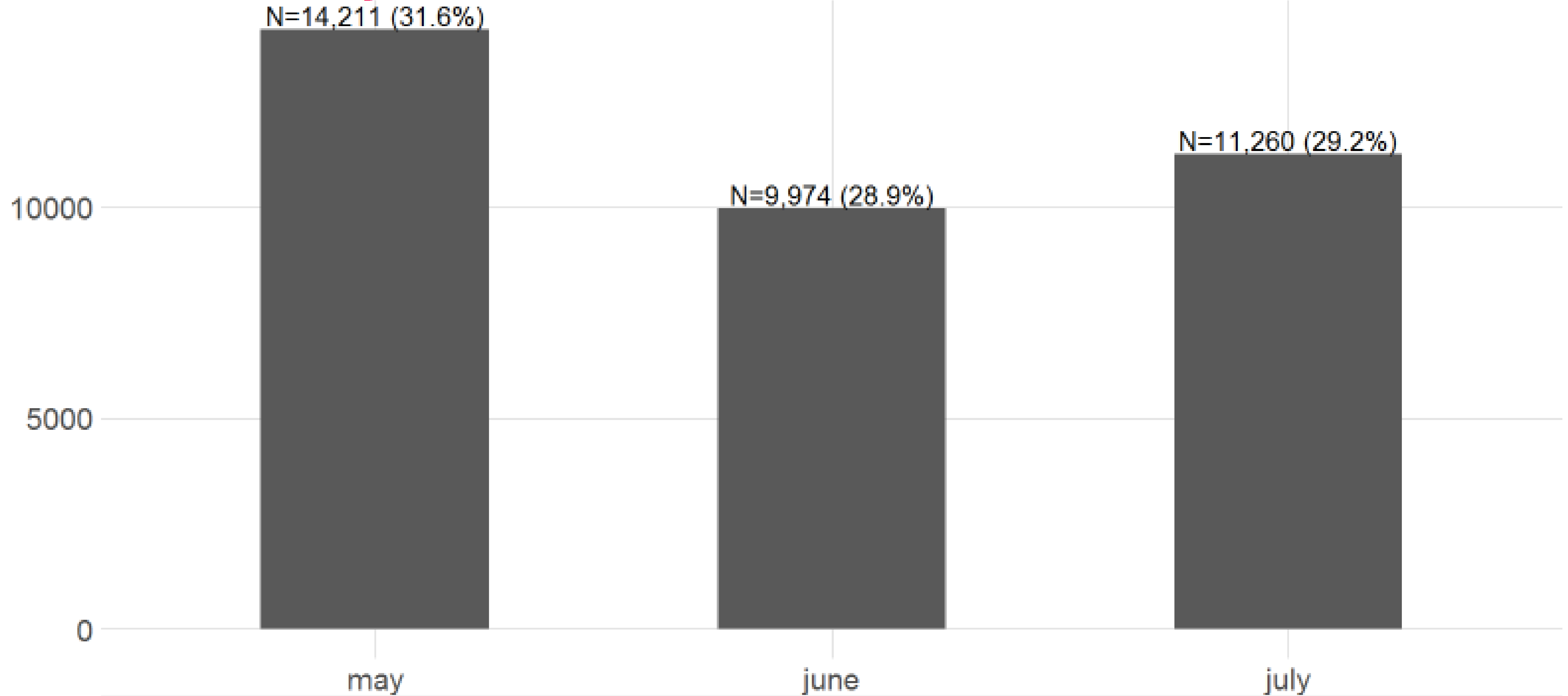**61%-63% of survey takers** belong to at least one **UBR category...**
Share of participants by UBR characteristic

AoU Forum | Sept 2020 | By Francis Ratsimbazafy
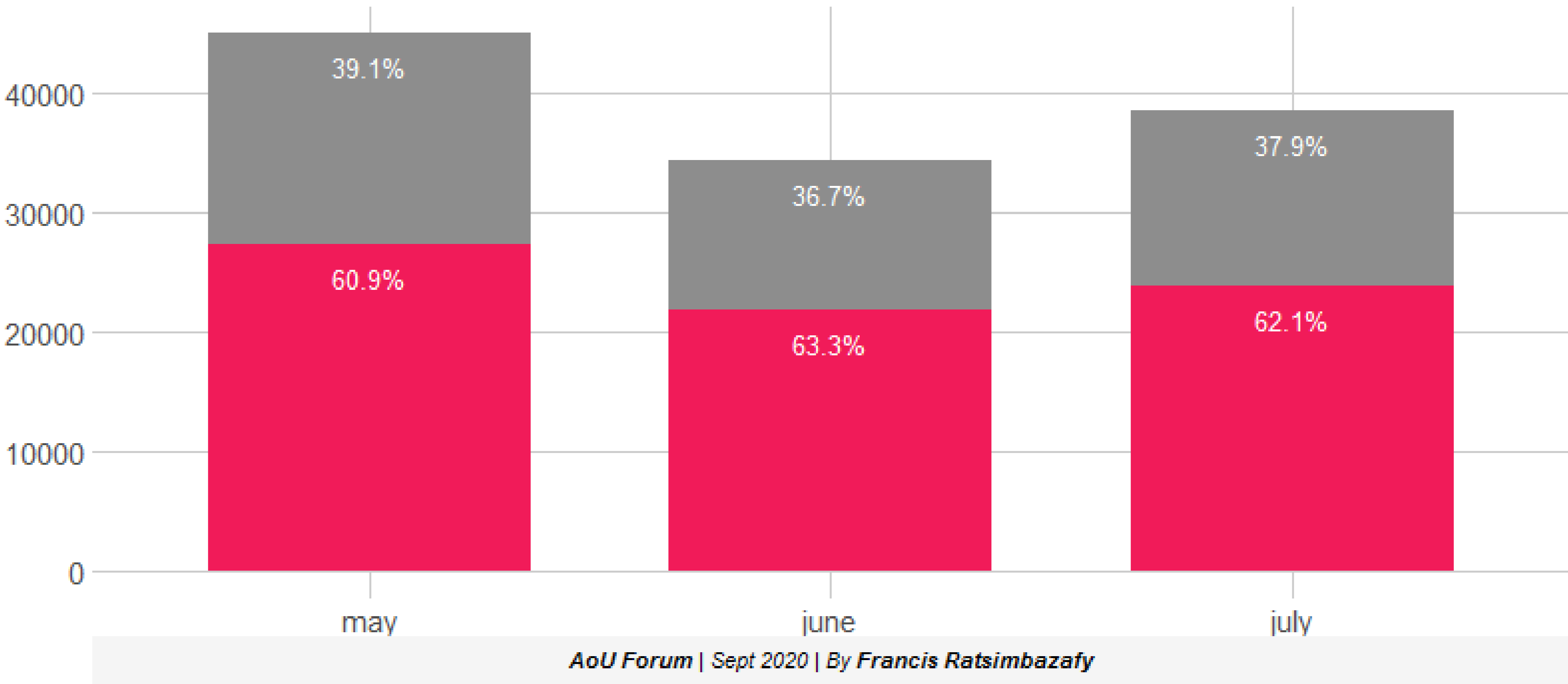
Approximately two thirds of participants who took the COPE survey each month were UBR in at least one category.

# Of the COPE Respondents, ~30% endorse anxiety or depression symptoms

~30% of survey takers endorse severe mental health conditions

N=14,211 (31.6%) — may
N=9,974 (28.9%) — june
N=11,260 (29.2%) — july

All of Us | Sept. 2020 | By Francis Ratsimbazafy

Suicide Prevention Message Over Time in COPE

The suicide prevention message popped up 7% of the time...

Count of participants with answers other than *Not at all* on *Thoughts being better off dead*

- may: N=3,005
- june: N=2,240
- july: N=2,608
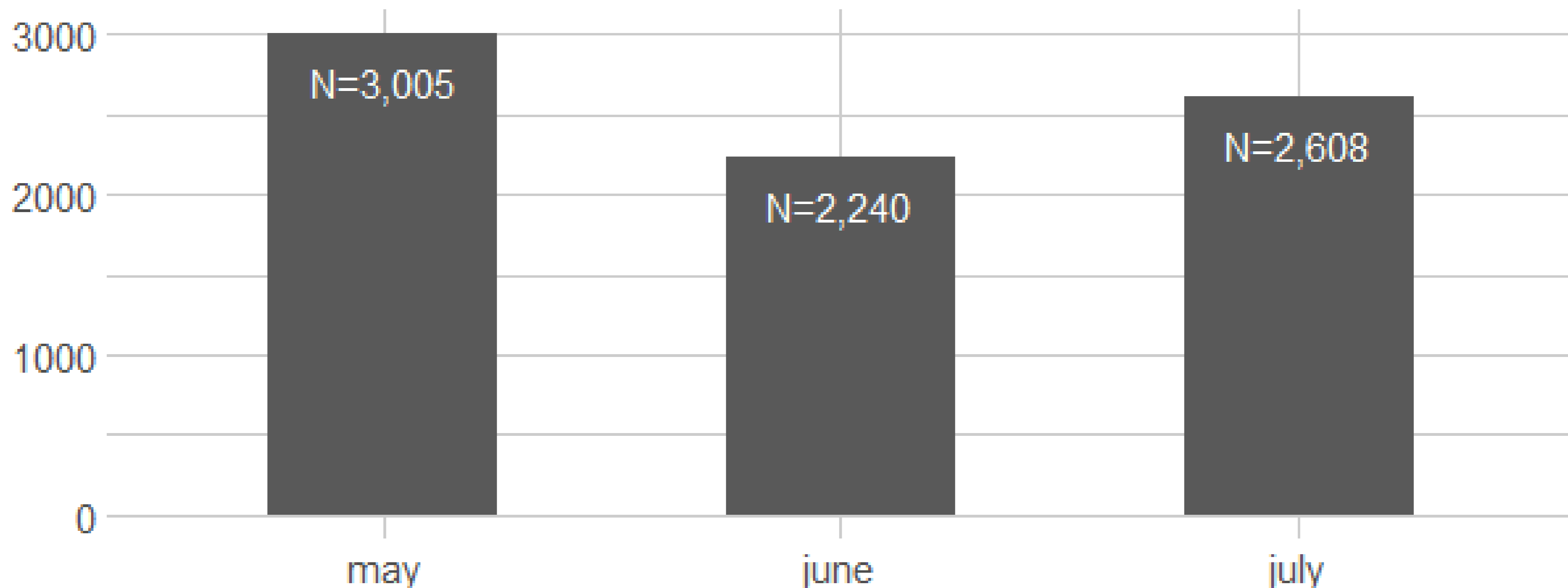
AoU Forum | Sept 2020 | By Francis Ratsimbazafy

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FUTURE

1. EHR
   a. Conditions
   b. Drug Exposures
   c. Procedures (e.g. screening)

1. Survey Questions
   a. Personal Medical History
   b. Family Medical History
   c. COPE: anxiety, depression, suicide
   d. **Mental Health and Well-being**

1. **Digital Health Technology**
   a. **Mood Module**

https://databrowser.researchallofus.org/

All of Us Mental Health Campaign Components

Mental Health and Well Being Survey

Mood Module
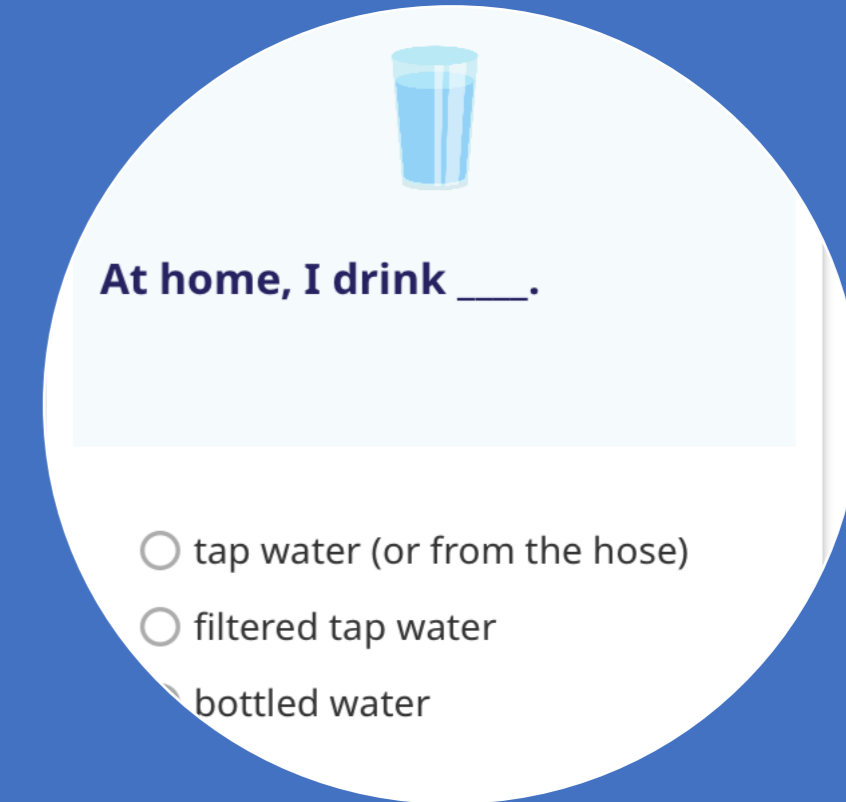
Snap Questions

Communications Relevant to Mental Health
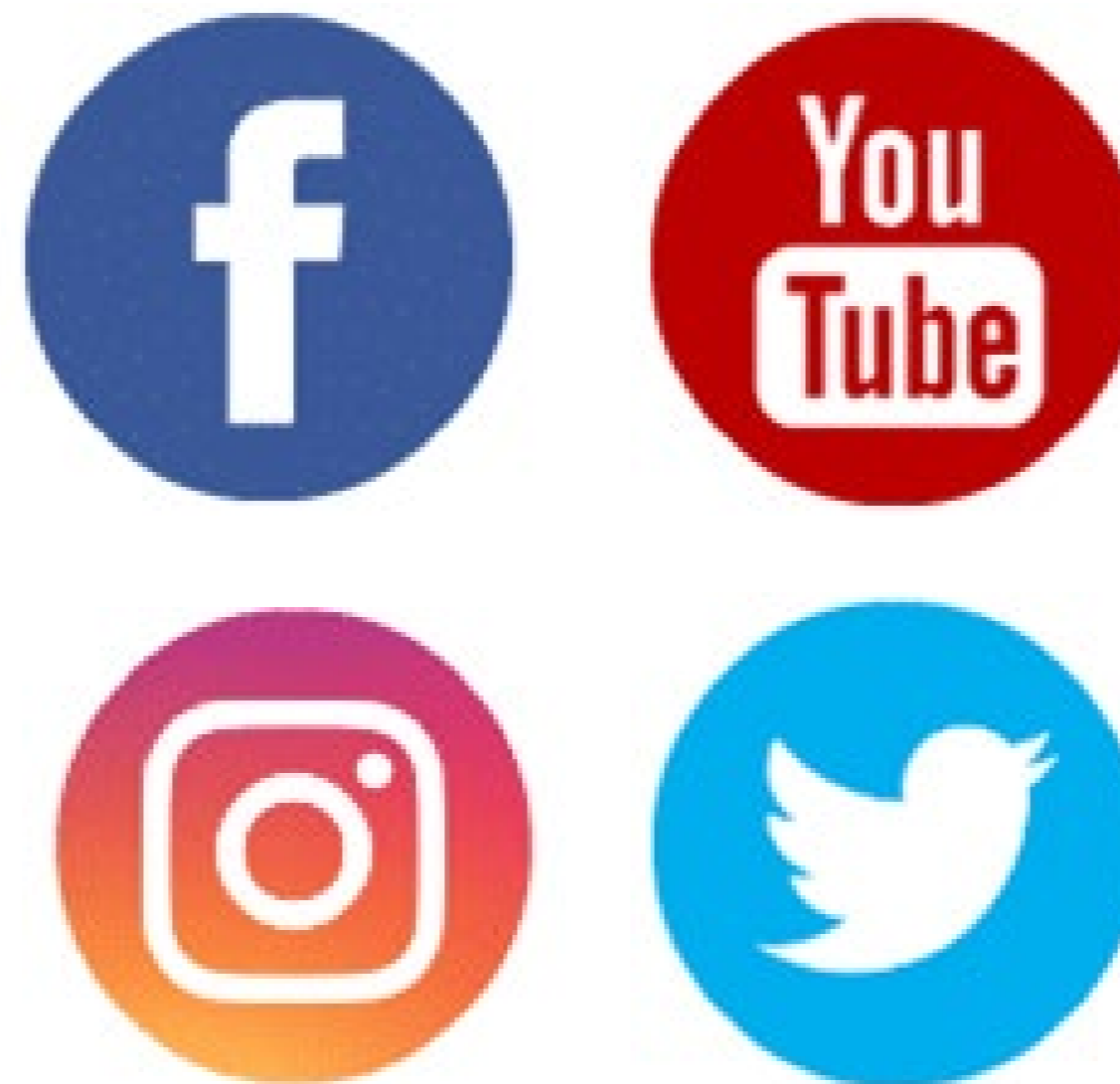
Pre-Campaign Awareness Evaluation

Post-Campaign Awareness Evaluation

Length of Campaign: 2-3.5 months

For more information…

ResearchAllofUs.org
(includes the Data Browser)
JoinAllofUs.org

@AllofUsResearch
#JoinAllofUs

AllofUs.nih.gov