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

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NIMH Joint Alliance-Coalition for Research Progress Town Hall
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 retention spiked as enrollment dropped. COPE survey showed significant spikes.
Types of Mental Health Data available in the *All of Us* Dataset

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

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

- Suicidal thoughts: >3750
- Suicidal deliberate poisoning: 100
- Feeling suicidal: 50
- Suicidal behavior: 25
- Suicidal: 10
- Non suicidal self inflicted injury: 5

>3,750 participants with ‘suicidal’ in EHR
Example of ‘Schizophrenia’ in Data Browser

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

- **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

- **Social information**
  - social support
  - loneliness
  - resilience

- **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.
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.
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
## 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
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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/](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

Length of Campaign: 2-3.5 months

Pre-Campaign Awareness Evaluation

Post-Campaign Awareness Evaluation

Campaign launch timeline is To Be Determined.
For more information…

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

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