

Setting the Stage: The Next Frontier of Mental Health Research Depends on Ecological Data

Webinar Questions & Responses

May 10, 2024

Q1: Dr Milham - How do you collect sensor-based data?

“We are using smartphone apps, and wrist-worn Fitbit like accelerometry devices capable of assessing physical activity and sleep.” – Mike Milham

Q2: Thank you to the panelist for informative information. Happy to be doing similar work in Africa using wearable devices among youths. Have the tools being used in the ABCD study been adapted in LMIC?

I am not aware of any studies in LMIC that are as expansive as ABCD. However, we are happy to share all of our protocols if you are interested in seeing how you might harmonize with us. – Gaya Dowling

Q3: Dr. Gaya in your study you are following participants over a decade. How have you managed attrition considering the vast data being collected that can result in fatigue?

Retention in the ABCD Study has been very good (96% have been retained). I attribute this to the sense of community that our research sites have created for participants. They were recruited from schools, which lended itself to having multiple families from the same school. I think having friends in the study helps with retention. Many sites hold annual events for participants (e.g., hockey game, ice skating) to build the sense of community. We also engage with them throughout the year with newsletters, birthday cards, seasonal cards. Finally, we are now developing infographics summarizing findings for the families and associated webinars where they can ask questions of the speakers to show them the value of participating in the study. – Gaya Dowling

Q4: Dr. Chamaraman - the Youth, Media & Wellbeing Research Lab has a youth advisory board. I'm curious if you've heard from youth themselves about these methodological challenges and the role of participatory methods might be in devising innovation systems of measurement?

Our youth advisory board consists of a group of 12-20+ year olds who are at different stages of their social technological development. They help co-create questions on longitudinal surveys that are timely for what they care about each year, based on language that is age-appropriate and relevant to their lived experiences in today's digital world. Besides measurement development and piloting, the YAB helps us interpret findings in ways that would not be possible without their insights and contexts to fill in gaps in our understanding from a researcher point of view. – Linda Charmaraman

Q5: Dr Ghosh mentioned moving from neuroscience to behavior. What data collection would support the documentation of this movement?

The data collection will have to acquire information at cells or circuit level and simultaneously acquire behavior through the lens of different sensors, potentially including the exposome. This is challenging as some of the recording techniques that collect cellular level information are invasive. The most common approach right now would be something like EEG or fNIRS that can measure certain aspects of brain activity continuously alongside other behavioral sensors. In some patients, for example those with deep brain stimulation electrodes, one could get closer to cellular or circuit activity. However, most of the omics work currency happens in ex vivo brain tissue. Thus connecting from cells to behavior remains a challenging problem. – Satrajit Ghosh

Q6: Are any of you trying to use this data to determine what medications are working for which mental health conditions? Prescribing medication is very hit or miss now and using big data could help inform medication management.

The ABCD Study does collect information on medications and mental health conditions so these analyses can be done with the available dataset. There have been some papers looking at ADHD meds and some other mental health conditions in the resources section. – Gaya Dowling

Q7: How could implementing youth led communities of practice help in these ecosystems' design and meaningful data collections and developing actionable and adaptive strategies?

We have translated our longitudinal research-based findings into actionable strategies through our digital wellbeing workshops. Co-designed for and by older youth who mentor their younger counterparts, the mission of these workshops is to enhance self-awareness, self-care, and social wellbeing in digital spaces. Through the years, we have learned from our youth that they are on their own journeys of self-discovery - what works is different depending on many contextual factors. We have learned to question our researcher assumptions that youth are all monolithic in their needs and boundaries - for instance, some are on a path toward trying to connect less often whereas others are aiming to find more meaningful connections. – Linda Charmaraman

Q8: If you are working with youth, how do you combat school policies and allowable technology in the building? How does this impact data collection if the tech is not being used all day?

In our studies we provide a letter to the parents to provide to the school to allow the child to respond at specific times of the day,,,generally lunch time, We also adapt the assessment schedule to people's daily schedules. – Kathleen Merikangas

Our ongoing EMA study only collects data before and after school hours. They are also allowed to pause an answer to a ping which will “snooze” until they are ready to respond when it is safe and allowable to do so (e.g., after driving, break from work, etc.). – Linda Charmaraman

The ABCD Study is not currently using EMA. We collect information about cell phone use through apps on their phones. We also have information on when they are in school so that people can look at the data in context. – Gaya Dowling

Q9: Can you speak to the intrusiveness of EMA as it relies on an individual's constant reporting and engagement with data input?

This is perhaps a function of how we communicate why EMA is collected, what is being done with it, and how it benefits/could benefit an individual. It may also be beneficial to understand how new technologies may allow adapting EMA collection at times when it's not intrusive, or to change the kind of collection to be very minimally intrusive (e.g. tapping on one's phone). The UI/UX is likely to become important in different settings (e.g., research, clinical/personal monitoring, etc.,). – Satrajit Ghosh

Q10: Someone needs to call out the social media companies for hoarding their enormous datasets, with insights into all users both collected and derived?

I do believe that there can be enormous benefits to independent researchers having access to big datasets to mine data that already exists. One of the key benefits would be to understand timing and frequency of use across different ages and stages of life. However, there are some practical limits to the knowledge gained in the end. For instance, there would be no data on what the user's habits, psychological states, or social networks were *before* they become a user on that particular platform - thus there is no "pre-test" - just a "post-test" which limits any analyses related to causal mechanisms. There would also be a lot of concerns over data privacy and confidentiality if the research dives into content created and consumed (rather than measuring screen time only, etc.). – Linda Charmaraman

Q11: What resources do you recommend on this topic — reports, blog posts or articles, etc.?

[Psychiatric Diagnoses and Treatment in Nine- to Ten-Year-Old Participants in the ABCD Study](#)

[Treatment of US Children With Attention-Deficit/Hyperactivity Disorder in the Adolescent Brain Cognitive Development Study](#)

[Evaluation of Attention-Deficit/Hyperactivity Disorder Medications, Externalizing Symptoms, and Suicidality in Children](#)

[Stimulant medications in children with ADHD normalize the structure of brain regions associated with attention and reward](#)

[Young Adolescents' Digital Technology Use and Mental Health Symptoms: Little Evidence of Longitudinal or Daily Linkages](#)
<https://www.so-me-study.org/about>

<https://www.nytimes.com/2023/11/09/opinion/phone-ban-teens.html>