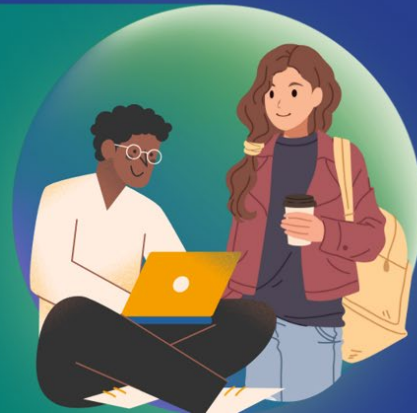


ABCD: Continuing the Arc of Development

July 21-22, 2025

9:00 AM ET

Virtual: <https://videocast.nih.gov>



Young Adults Pre-Meeting June 10, 2025

Participants

External Experts

Ariana Mares – All of Us Participant Ambassador

Kissairy Guareno Pena – All of Us Participant Ambassador

Planning Team

Elizabeth Hoffman – National Institute on Drug Abuse (NIDA)

Michael Charness – US Department of Veterans Affairs

Miri Gitik – National Institute on Alcohol Abuse and Alcoholism

Paul Burns – National Institute on Minority Health and Health Disparities

Traci Murray – NIDA

Summary

Young adults from the All of Us Research Program provided valuable input on the frequency of communications, mode of communication, and how participants are engaged for surveys, assessments, and compensation.

Engagement Successes and Lessons Learned

Young adult engagement is the foundation of the ABCD Study. Generally, young adults feel that transparency should be a core component of the program to ensure participants know they are a valued member. Feeling like a contributor rather than just a subject was motivating and fostered a stronger connection for young adults to the program. Personalized outreach plays a key role in retention. Phone calls and emails reminding participants about pending surveys or appointments were effective, and participants appreciated having flexibility in choosing their preferred communication methods, including texts, emails, and calls.

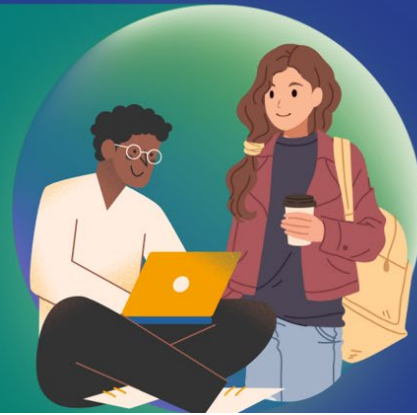
Some All of Us sites implemented feedback mechanisms, such as participant advisory groups, which allow for input on materials and processes. However, there was a noted gap in general feedback solicitation, as most input was gathered from those in ambassador or advisory roles rather than from all participants. Additionally, not all sites have bandwidth to contact participants, let alone collect feedback on how the program is performing. Thus, engagement strategies and resources differ by site which has led to inconsistent experiences among participants.

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Communications

Monthly program updates are sufficient, as more frequent communication could be overwhelming. However, they advised that the frequency should be flexible based on the importance of the information (e.g., urgent data changes or critical updates should be communicated immediately).

Young adults appreciate being able to choose their preferred mode of communication (text vs. email). There was strong interest in building an interactive participant portal (as social media is a passive means of communication), which would allow individuals to view updates, track actions, and engage in two-way communication with program staff. A forum or thread-based system for questions and answers with staff would be helpful and could prevent peer-to-peer data sharing.

Study Participation

Participants felt current compensation in the All of Us research program does not reflect the time, effort, or expenses involved, especially for long visits or those requiring travel. They recommended that payment be proportional to the length and complexity of the activity, with extra compensation for travel, family participation, and additional tasks. Transparent and fair compensation was seen as key to participant retention.

For Study activities, annual in-person visits were considered reasonable; more frequent sessions could be burdensome. Flexible remote options and travel support are important, especially for participants who move or live far from study sites. In-person requirements, like neuroimaging, should be clearly justified and compensated considering long visits and travel remain major barriers for young adults.

Written Input Following Pre-Meeting

Jaden Chan – ABCD participant

Sara Parthemer – ABCD participant

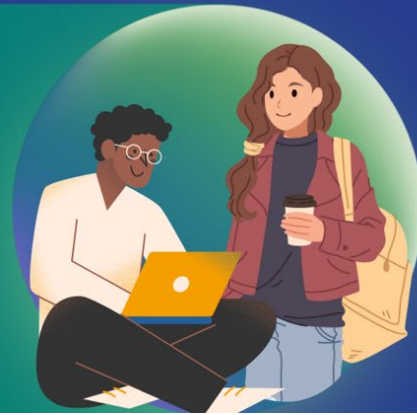
- I agree with the points about flexibility in communication and choosing when to come in. From my own experience, it's easier to fit into my schedule and figure out when it is best to go for the in-person section. I'd like to add my support behind an interactive participant portal, or a way to continue being active with the study. In the period between visits, I forget that I'm a participant in it and that I have to return the next year. Additionally, since the study is so widespread and has released multiple rounds of data, I think it would be interesting if there were more examples of the work done with that data, other than on the ABCD Study website (if that makes sense). The ABCD study*

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can serve as inspiration for other widespread studies and as an example of why research is important.

- I am a firm advocate of feeling like a contributor as opposed to a test subject, so including more transparency on what our data is being used for would be amazing. Especially for those of us interested in Health Sciences. :) I also love the idea of internships through the program.*
- Since some participants are unsatisfied by payment, it could be more specifically based on visit length and complexity (for travel, family involvement, or special tasks). Maybe other incentives as opposed to just money? Discounts or travel offers?*
- Consider the younger generations and the platforms they most often use. Maybe start a TikTok? This could offer ways to maintain the study's scientific data while also adding to its accuracy due to increased engagement.*