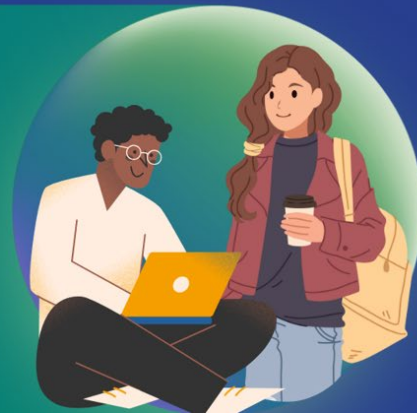


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Study Design Pre-Meeting June 9 and June 12, 2025

Participants

External Experts

Allison Aiello – Columbia University
Chia-Chen Yang – Oklahoma State University
Cristiane Duarte – Columbia University
Genevieve Dunton – University of Southern California
Jane Waldfogel – Columbia University
Jennifer Silk – University of Pittsburgh
Lauren Gaydosh – University of North Carolina – Chapel Hill
Megan Patrick – University of Michigan
Sheila Castaneda – Naval Health Research Center

ABCD Expert

Hugh Garavan – University of Vermont

Planning Team

Bethany Deeds – National Institute on Drug Abuse (NIDA)
Elizabeth Hoffman – NIDA
Elizabeth Powell – National Institute on Alcohol Abuse and Alcoholism
Lindsay Pool – National Heart Lung and Blood Institute
Michael Charness – US Department of Veterans Affairs

Summary

The study design group discussed a variety of best practices, lessons learned, challenges, and considerations for the study design of the future. The group emphasized the need to continue the conversation around study design to ensure strategy development is effective and efficient.

Best Practices for Retention & Lessons Learned

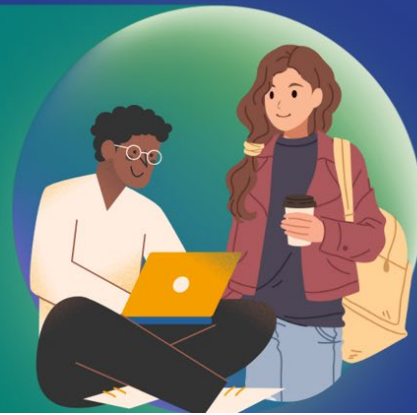
Communication & Value: Young adults are increasingly interested in receiving regular and meaningful updates on the progress of the study and incremental outcomes. Participants are motivated by a sense of giving back and want to understand how their data influences policy or science. Being able to communicate impact and value of participation via newsletters or research updates will be crucial to retention. Conversely, participant ownership (e.g., transitioning from parental enrollment to participant ownership) will be

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important to consider, ensuring participants see the relevance of the study and value to their own lives.

Accessibility: As participants become more mobile, may have technological limitations, or as their personal responsibilities increase (e.g., family, career, health), the study should consider flexibility in scheduling, communication, and response requirements. During the planning phase, it will be helpful to hear young adults share what makes the study most accessible for them. Finally, incorporating gamified elements (e.g., streaks, hidden emojis, small prizes) can increase engagement, especially for EMA and survey completion. Incentives must be accessible (e.g., digital payments), but research design should consider avoiding overly accessible incentives that would lead to “one-and-done” participation.

Challenges

Experts highlighted increasing difficulty in maintaining contact with participants due to frequent moves, changing email addresses, and opt-outs. Thus, multimodal communication (e.g., text, email, mail, phone) is necessary and there may be IRB requirements around frequency of contact. Texting is often most effective for young adults, but participants should be able to opt-in to their preferred mode of communication. Along those lines, not all participants prefer or have access to online surveys; some are more responsive to in-person or paper options. Experts noted that mode transitions (in-person to online) can result in loss of participants and stated that offering multiple modes can help recover lost respondents. Finally, clear instructions, easy-to-navigate surveys (for laptop, tablet, or mobile) will minimize participant burden. Each of these considerations may assist with continually declining response rates.

In the current environment, participants are increasingly concerned about their personal data remaining protected. Participants will benefit from built rapport and clear communication around data protections.

Balancing Innovation and Efficiency

To provide flexibility to participants, experts noted an emphasis on hybrid data collection, maintaining in-person assessments for critical measures (e.g., brain imaging), but shifting other assessments to remote/online where possible, or identifying opportunities to invite participants to a regional/national location for in-person assessments. Additional flexible data collection methods include passive data collection (e.g., smartphone sensors), at-home biosample kits, video calls for onboarding (helps build rapport), and potential for smartwatch-based EMA. Experts noted that passive data collection generates large volumes of data and may require a plan for backend processing.

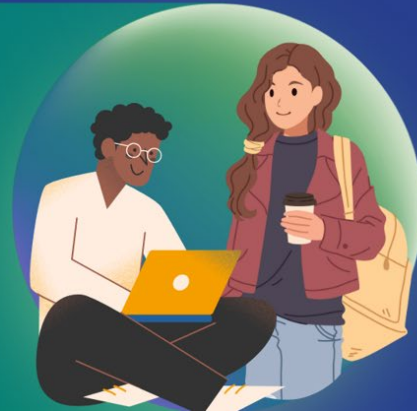
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Discussing an Open Cohort Model

While an open cohort can help address gaps (e.g., underrepresented groups or education levels) and aid in retention by recruiting through social/family networks, this sampling strategy could introduce clustering or nesting in the data. The group recommended prioritizing longitudinal follow-up of the existing cohort, especially for core measures (e.g., brain imaging), over expanding the cohort unless there is a clear scientific rationale.