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Minutes by Mohor Sengupta (IQ Solutions)

Participant List (Note: Not all participants attended the in-person meeting.)

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EXECUTIVE SUMMARY

The Adolescent Brain Cognitive Development (ABCD) Study is the largest longitudinal study of brain development and child and adolescent health in the U.S., having enrolled nearly 12,000 youth and assessed them repeatedly throughout adolescence into early adulthood. The goal of the ABCD Study is to elucidate developmental trajectories (brain, cognitive, social, emotional, academic) and the myriad factors (e.g., genetic, biological, environmental, social) that influence those trajectories. Of note, the study was designed to understand risk and resiliency factors for substance use and mental health, their interactions, and their impact on long-term outcomes. As a result of its open science model, the ABCD program has resulted in more than 1,500 papers being published to date by investigators within and outside the ABCD consortium.

Participants who joined the study as 9–10-year-olds are now in the 16–19-year age group – when one would start to see the emergence of substance use disorders and mental illness. Therefore, it is a critical juncture to evaluate how best to move the study forward to ensure it can realize its full potential. The goal of this meeting was to inform the next phase of the ABCD study by understanding critical domains to capture, identifying broad elements of the study design, discussing the role of current sites in ongoing studies, talking about the appropriate frequency for imaging, neurocognitive evaluation, etc., and considering what proportion of the information should be acquired in person versus remotely.

Key areas that emerged from the meeting included understanding the social context and transitions occurring at this stage of life; identity development; agency, self-efficacy, and sense of purpose; and the quantity, diversity, movement, and quality of social networks. With respect to substance use and mental health, understanding the environmental factors, context, and motivations for substance use; harmful patterns of use and functional impairment; preciseness of timing of substance use and mental illness; the changing landscape of substance use; stress and coping mechanisms; loneliness; and the nature and source of substance use/mental health treatment would be critical to capture. In the physical health domain, the focus was on nutrition and physical activity; sexual health; sleep; perception of health and well-being; pain and fatigue; as well as cardiovascular health, and respiratory and liver function. The discussions about neurocognition and neuroimaging emphasized the need to maintain modalities and tasks that are in the current protocol for longitudinal consistency. However, there were recommendations to include more complex cognitive tasks, tasks of reward reactivity, stress paradigms, and social decision-making both inside and outside the scanner. Potential new imaging modalities included electroencephalography (EEG) and naturalistic movie-based scanning.

Discussions about study design focused on measurement issues such as balancing longitudinal consistency and new measures; remote data collection and Ecological Momentary Assessment (EMA); the use of wearables; and obtaining qualitative data such as from personal narratives. Retention discussions highlighted the use of social media; automated dashboards for scheduling and notifications; compensation/incentives; and providing feedback to participants. Finally, the importance of data confidentiality, stringency in the level of access to data, and handling data ethically emerged as resounding areas of critical emphasis from program staff and participants alike.

During and up to one week following the meeting, NIDA received public comments on these topics as well. Forecasts for the next phase of grant applications were published in June. The Notices of Funding Opportunities are estimated to be published in February 2026, with the earliest start date for the next phase being April 2027.

DAY 1 – July 21

Agenda

- **Welcome/Opening Remarks**
 - Nora D. Volkow, National Institute on Drug Abuse (NIDA)
 - George F. Koob, National Institute on Alcohol Abuse and Alcoholism (NIAAA)
 - William Klein, National Cancer Institute
- **Overview of ABCD and Charge to the Panel**
 - Gayathri J. Dowling, NIDA
 - Bethany Deeds, NIDA
 - Michael E. Charness, Harvard Medical School/Boston University
- **Panel Discussion with Young Adults**
 - Jaden Chan, *ABCD Study* Participant Advisor
 - Sara Parthemer, *ABCD Study* Participant Advisor
 - Kissairy Guareño Peña, *All of Us* Participant Ambassador
 - Adriana Mares, *All of Us* Participant Ambassador
- **Social Health and Environment**
 - Laura Thomas, National Institute of Mental Health (NIMH)
 - Leah Somerville, Harvard University
 - Julianne Holt-Lunstad, Brigham Young University
 - Genevieve Dunton, University of Southern California
- **Neurocognition**
 - Elizabeth Hoffman, NIDA
 - Leah Somerville, Harvard University
 - Jennifer Pfeifer, University of Oregon
 - Jungmeen Kim-Spoon, Virginia Polytechnic Institute and State University
- **Substance Use and Mental Health**
 - Elizabeth Powell, NIAAA
 - Jungmeen Kim-Spoon, Virginia Polytechnic Institute and State University
 - Kenneth Leonard, University at Buffalo
- **Physical Health**
 - Kim LeBlanc, NIDA
 - Abbi Lane, University of Michigan
 - Genevieve Dunton, University of Southern California
 - Holly Gooding, Emory University
 - Sara Vasilenko, Syracuse University
- **Closing Remarks**

Welcome/Opening Remarks

Nora D. Volkow, NIDA

Dr. Volkow opened the meeting and noted that the ABCD Study[®] started in 2016. However, the work on the ABCD project started before that, when experts came together to help design a study of brain development trajectories in children as they transition into adolescence. The program initially joined forces with the National Institute on Alcohol Abuse and Alcoholism (NIAAA) and the National Cancer Institute (NCI) to focus on understanding developmental trajectories, risk and resiliency factors for substance use, and the impact of substance use on development at this very important period of transition. Support for the study then grew to encompass priorities for 10 NIH Institutes, Centers, and Offices and the Centers for Disease Control and Prevention. At the time, discussions also took place around the value of open access data. The openness of data access has been instrumental in the enormous success of the ABCD program.

As the project moves to its next phase, the participants will be in the 19–20-year age group – where one would start to see the emergence of substance use disorder and mental illness. The project leaders and researchers are invested in studying this very crucial period in the life of the participants.

It is likely that moving forward, the funding for the program may not be at the level it was before. The project is cognizant of the challenges that may be imposed to continue successfully. Dr. Volkow encouraged attendees to think about ways in which the project can be more efficient in securing its survival into the future.

Dr. Volkow thanked the project leaders for their heroic effort, the staff from the institutes that came together for the partnership, Dr. Gaya Dowling, the Director of the ABCD program, the project investigators, and Dr. George Koob, without whom the alliance with NIAAA would not have happened.

George F. Koob, NIAAA

Dr. Koob thanked Dr. Volkow for brainstorming this endeavor. He noted that according to the National Consortium on Alcohol and Neurodevelopment in Adolescence (NCANDA) study, the ages of 25 to 34 are the peak for alcohol intake, alcohol misuse, binge drinking, and alcohol use disorder in the U.S. population. The NCANDA study, which laid the foundation for the ABCD Study, has shown that youth who initiate heavy drinking have altered trajectories of brain development. The ABCD Study has collected biological samples that may help us understand how alcohol affects the body in addition to its interaction with the brain. For example, alcohol-associated liver disease cases are growing the fastest in the 20-30 age group.

Research from ABCD and NCANDA suggests that early life experiences, such as adverse childhood events, emotional neglect, and violence (ABCD findings) and easy home alcohol access, less parental control, and traumatic brain injury (NCANDA findings) influence alcohol use later in life. NIAAA supports advancing research on alcohol misuse in adolescents and young adults. Some of its efforts are to

understand how early life experiences influence the brain stress circuitry, and if dysregulation of the brain's negative reinforcement systems is linked to substance use in young adults, among other areas of interrogation.

Dr. Koob applauded the fruitful collaboration between NIDA and NIAAA and thanked everyone associated with the effort. He shared some findings from recent ABCD publications.

William Klein, National Cancer Institute (NCI)

Dr. Klein thanked the attendees and welcomed the opportunity to discuss science at this meeting. He shared some recent publications that emerged from the ABCD Study, several of which have overlapping interests with research at NCI, such as sex-specific trajectories of adolescent brain development and behavioral health in relation to family environments, and longitudinal associations between screen time, physical activity, and sleep duration with BMI in U.S. youth, among others.

Forty to fifty percent of cancer cases are related to modifiable risk factors, several of which are being measured in the ABCD Study, including physical activity, sedentary behavior, sleep, obesity, and substance use. Although there are NCI-funded epidemiological cohorts, they start at a much later age than when ABCD recruited. Therefore, there is much to learn about cancer risks in a cohort that starts so young.

Dr. Klein spoke about the cancer control continuum, which starts with etiology, and goes on to understand prevention, treatment, and finally survivorship. The continuum is not linear. Because of advanced treatment options, people often do not stay for life in the survivorship group and may go backward in the continuum and develop a new cancer altogether, whether it is a secondary cancer or a relapse. Currently, cancer survivorship is not a 1- or 2-year duration, but a 30- or 40-year one, necessitating thoughts about the earlier parts of the cancer control continuum, some of which involve behaviors such as substance use, diet, sleep, obesity, physical activity, sun protection, and social media.

The ABCD Study may provide the opportunity to understand where participants might be in this continuum, especially in the case of pediatric cancer. The ABCD Study would add a dimension of behaviors that people are engaging in that may be a projection to future cancer development – for example, alcohol use in youth that could have a relation to breast and colorectal cancer, both of which are being diagnosed at earlier ages.

Dr. Klein ended his talk with an invitation to submit research applications to NCI.

Overview of ABCD and Charge to the Panel

Gayathri J. Dowling, NIDA

Dr. Dowling provided a brief overview of the ABCD program. The ABCD Study is a longitudinal study of about 12,000 youths, including about 2,000 twins and triplets, from ages 9–10 through adolescence into early adulthood. The study assesses factors that influence individual brain development and other trajectories and functional outcomes.

Dr. Dowling reminded the group of the original research objectives of the study as a point of reference for the discussions during the meeting. The research objectives of ABCD are to develop individual developmental trajectories (e.g., brain, cognitive, emotional, academic); develop national standards for healthy brain development; study how physical activity, sleep, screen time, sports injuries, and other factors affect brain development; investigate the role and interaction of genes, environment, and experiences on development; examine factors that influence the onset, course, and severity of mental illnesses; understand how mental health is related to substance use; and study the interrelation of substance use with developmental outcomes.

ABCD participants were enrolled between 2016 and 2018. In fall 2025, the ABCD program will start its 10th year (9-year follow-up) of data collection. The current protocol involves annual in-person visits (with biennial imaging visits) and mid-year touchpoints by phone or online. ABCD covers a broad array of domains such as physical health, mental health, substance use, social health and environment, neuroimaging, and neurocognition, all of which will be discussed at the meeting. In addition, discussion of the role of biospecimens, novel technology, and geocoded data will cut across each of these domains at the meeting.

The ABCD program is proud that it has retained 95 percent of its participants. While participants may miss visits, through persistent outreach, many of these participants return to the study. More than 7,000 participants have never missed a visit. About 10,000 participants have missed at most two visits.

Recently, NIDA launched the NIH Brain Development Cohorts (NBDC) Data Hub along with the ABCD 6.0 data release, which includes data up to the six-year follow-up visit. ABCD also has a Biospecimen Access Program for investigators around the world to do additional analyses. Because of the open science model, the ABCD dataset has been used in more than 250 grants and more than 1,500 publications to date – 60 percent of which are from groups that are not affiliated with the ABCD Study. ABCD publications are already being cited in clinical guidance documents, demonstrating its value for public health.

Bethany Deeds, NIDA

Dr. Deeds provided an estimated timeline for the next phase of the ABCD Study. A concept clearance presentation was held in May 2025. Two forecasts were published in June 2025. The expert panel meeting was held on July 21–22, 2025. The Notice of Funding Opportunity (NOFO) is expected to be published in February 2026. Estimated application submission due date would be May 2026. Application review and council approval would take place through late 2026 and early 2027. The earliest start date would be April 2027.

ABCD was accepting public comments, including attachments. They could be sent through NIH Videocast or directly to AdolescentBrain@nih.gov. Comments would be accepted until July 29, 2025.

Michael E. Charness, Harvard Medical School/Boston University

Dr. Charness emphasized that the group is envisioning a continuation of ABCD, not a new developmental study of early adulthood. The proposed work should take full advantage of the current ABCD cohort and further the aims of ABCD.

The scope of this meeting was to envision the major aims of the next 10 years of ABCD, to understand the critical domains to capture, to identify the broad elements of the study design, to discuss the role of current sites in ongoing studies (considering that participants are now embarking on a more mobile phase of their lives and may move away from their current sites), to talk about the appropriate frequency for imaging, neurocognitive evaluation, etc., and to consider what proportion of the information should be acquired in person versus by virtual evaluation. Specific neuroimaging tests, imaging sequences, and fMRI tasks were out of scope of the meeting.

Dr. Charness indicated that ABCD may not be funded as robustly in the next 10 years as it has been so far. Therefore, the meeting would need to discuss the most important questions that must be answered to achieve the promise of ABCD. It will be important to suggest study designs for three contingencies: low, moderate, or full funding.

Dr. Charness thanked the program staff, the attendees, and the ABCD participants.

Key Panel Discussion with Young Adults

Jaden Chan, ABCD Study Participant Advisor

Sara Parthemer, ABCD Study Participant Advisor

Kissairy Guareño Peña, All of Us Participant Ambassador

Adriana Mares, All of Us Participant Ambassador

Moderated by Traci Murray, NIDA

What are some issues impacting young adults that should be considered in the next phase of the study?

- Sleep
 - Sleep health was not covered to the extent it should have been, considering how it affects the functioning of young adults.
 - Poor sleep affects many of the other issues that ABCD is interested in studying. Therefore, sleep health and chronic sleep deprivation in young adults are important topics to consider.
- Coping mechanisms
 - In the context of mental health, it is important to ask if cycles of coping mechanisms, i.e., how people process difficult life events as they age, develop in a healthy way.
 - Greater understanding of how the youth deal with change and transitions would be useful.
- Prevention of acute and chronic illness - The cancer continuum of care is an important aspect to study.
- Social media and environmental risk factors.
 - Social media data could provide useful correlation with some of the endpoints and outcomes.

- How many sites are visited per day, what time of day they are visited, and how much time is spent on each site may be useful social media data.
- Social media usage and the purpose of usage may vary with different groups, so it is important to account for that difference.

What recommendations do you have to make data collection less burdensome?

- Keeping in-person visits shorter and having more online methods of participation would be important considerations for retention.
- Apps offer convenience and time management to young adults and are a good way to regularly remind them of their participation in the study.
- Apps are also more interactive and will keep participants more interested in the program.
- An app would make participants feel more involved on a regular basis.
- Consistent, short surveys would result in a higher retention rate than a survey of a couple of hours.
- Reasonable time and resources for participants to complete their assessments.
- A few questions would be okay, but a longer survey or anything over 5 minutes may be too much for multiple times per day.
- The option to pause a survey and complete it at another time could be helpful to many participants.
- Having questions that are not based on your situation at that specific moment would allow participants more flexibility in answering the questions later. It also allows you to think about the question more.
- Some in-person surveys would be good but not for a 3-hour time block.
- Flexible timing of response.
- Adding incentives would be helpful.
- Frequency matters if you are looking for sustainability.

Can you discuss your comfort level with sharing social media and other sensitive data with the study?

- Data privacy
 - Any data of participants' social media use must be protected. Clauses about data privacy and steps to prevent data breach must be clearly indicated in consent forms.
 - Transparency of what data are being captured by the program and the ability to prevent apps from tracking data are important factors to consider.
- Social media tracking
 - Social media tracking would connect more with the social environment part of the study.
 - Data privacy is particularly important when it comes to tracking social media activity.

What would make you continue to participate in the study?

- Contributions to science
 - Participants should feel invested in the program. They should feel that they are contributing to something bigger than themselves for them to continue to be part of the program.

- With 12,000 ABCD participants, it may appear that your data is a small percentage of it, but when that data is shared in a consistent manner, it makes a participant feel motivated that they are contributing to something bigger.
- The knowledge that your data can benefit many people in the future is a motivation to continue participation.
- Information about how participation may help the research.
- Return of results
 - Survey responders should be given a clear idea of what answering the survey would mean for them.
 - Information about what the participant might learn about their health from the data.
- Communicating impact of the research
 - Release of information about what the data has been used for and who the data may be helping, are important for participants to be aware of.
 - It is important for participants to know what the program finds from their data, specifically if that information could potentially be relevant to them.
 - The *All of Us* program sends emails with updates and new findings.
 - Emails/questionnaires/information from the ABCD program from time to time would be welcome.
- Sense of community
 - As participants, the connection with each other is the yearly visit and the half-year survey. A social media app would be useful for maintaining contact with other participants.
- Resources
 - Information about access to care and other resources, such as community and mental health care, would be useful for young adults that do not yet have health insurance or financial stability.
 - Lesson guides designed as apps and games.
- Opportunities to engage in research
 - It would be good for ABCD to create opportunities for involvement in the study after the role as a participant has concluded. Providing opportunities for those who want to continue their careers in this subject would be beneficial.
 - The *All of Us* study has used the *Researcher Workbench* that enables participants to cross collaborate.
 - Investing in internships for the participants and identifying and helping those participants who are interested in health sciences would ensure their continued participation. In that way, participants can see the arc of development in their own careers.

Social Health and Environment

Overview – Laura Thomas, NIMH

Dr. Thomas presented a brief overview of the topic. The social environment includes physical, chemical, and other environments. Some of the key considerations discussed were how social connection includes structure, function, and quality of relationships; the importance of self-report measures for socioeconomic outcomes and more objective approaches to understand them; using Ecological

Momentary Assessment (EMA) for capturing day-to-day emotional and social variability; capturing the time of transition into independence for young adults; and understanding experiential diversity.

Panelists

Leah Somerville, Harvard University

Julianne Holt-Lunstad, Brigham Young University

Genevieve Dunton, University of Southern California

Moderated by Gaya Dowling and Michael E. Charness

Social Context in the Transition to Adulthood

Transitions

- Higher education
- Military
- Employment
- Parenthood
- Insurance status

Relevant social contexts/settings

- Intimate partners
- Living circumstances
- Work environment
- Parents/families
- In person interactions
- Messenger apps
- Gaming platforms (e.g., non-face-to-face socializing)

Focus areas

- Identity development - Understanding who a person is in relation to their values, morals, and belief systems. This process occurs in the social world through learning and being influenced by others.
- Timing and nature of transitions
- Launching into independence and managing oneself, with the caveat that this is a transition period and there is variability in what independence looks like.
- Agency and self-efficacy
- Finding a sense of meaning and purpose, constructing goal directed behaviors
- Subjective social well-being and resilience
- Issues of work stress, work-life balance, and adverse childhood events
- Reluctance of face-to-face social interactions (enabled by social media and technology) even though they feel positive about it afterwards.
- Commitment, involvement, and satisfaction of relationships
- Social context for substance use behavior
- Social interactions/networks
 - Quantifying social interactions and networks, changes in social networks, and their dynamic interactions

- Network diversity, as we see evidence of more homogenized networks
- Movements in and out of relationships
- Intergenerational networks
- Subjective value of social connections may be more important than quantity - people's social environments may or may not be reflected in quantifying social interactions or learning about the kinds of social interactions without getting into what they mean for that person.
- Various types of engagements meet different types of needs. Being thoughtful about not treating all interactions as equal is helpful.

Measurement Considerations

- Many validated measures were developed before digital means of engaging socially existed.
- Tradeoff between the breadth of the measures and the detail needed to ensure the validated items adequately capture the required elements.
- Capture the changing landscape of the social environment, and engagement of people through digital means. It is not just about measuring what is happening digitally, but we may gain interesting and more comprehensive ways of assessing social connections than we can through self-reports.
- Sentiment analyses of social media usage (but not everyone uses social media)
- Ecological Momentary Assessment (EMA)
 - To capture who an individual is with and where they are, which would not be continuous data streams, the responder would not be identifiable, but the data could give granular contextual information.
 - Capture stress and emotion when a person is being pushed toward heavy drinking.
 - The psychometrics within the EMA could be a challenge, but there is good developmental work in that area. There are some repositories, for example, on Open Science Framework.
- Consider multiple levels of data for a nuanced picture - An EMA study of people's social interactions over several days suggested that their perceptions of interactions in the moment were less predictive than how they felt about that person normally.
- Passive monitoring through mobile devices that can recognize each other, rather than tracking participant interactions directly. Participants would just have to indicate who they were near, and the mobile device of the person they are interacting with would be recognized in subsequent interactions. Passive monitoring presents a low burden on participants.
- Qualitative analysis
 - Narrative data (including about their social experiences) with open-ended prompts (e.g., tell the story of their life over the last year in 5 minutes) is very cost-effective. Natural language processing can do a semi-objective analysis of someone's subjective experiences.
 - Privacy protection – Participants would be prompted to mask the identities of other people; would only share higher-level themes/rich summary measures rather than the actual narratives.

Neurocognition

Overview – Elizabeth Hoffman, NIDA

Dr. Hoffman summarized the key considerations from the premeeting. There is recognition that the current battery captures substance use risk and resilience reasonably well at multiple levels of influence, such as environmental, peer, and families. The premeeting also discussed the need for continuity and innovation as the study moves to the next phase. Several key areas of impact were identified, such as the value in construct consistency across neurocognition and neuroimaging measures over time and reducing participant burden. Finally, some notable gaps were identified, such as reward learning contingencies over time, measures for cognitive flexibility and adaptive learning, and social decision-making.

Panelists

Leah Somerville, Harvard University

Jungmeen Kim-Spoon, Virginia Polytechnic Institute and State University

Focus areas

- The Rey Auditory Verbal Learning Test gives good data and has strong literature suggesting sensitivity to cannabis use.
- Retain some toolbox tests. There are toolbox tasks that can be done remotely.
- Learning and memory (including working memory)
- Visual and spatial skills can get down to five measures.
- New tasks that better engage more complex cognitive operations, such as abstract reasoning and social decision-making
- Behavioral computational tasks (e.g., ultimatum games), social decision-making, and more complex measures of executive functioning
- Cognitive processes such as reward reactivity, inhibitory control, and stress paradigms may be important for substance use decisions.
- Consider more nuanced measures to capture the subtle shifts in cognition impairment.

Measurement Considerations

- Measurement consistency is important as participants move into young adulthood, especially prefrontal cortex functioning that continues to develop until the late twenties.
- Consider more developmentally sensitive measures. Measures such as environment reaction time and intra-individual variations across performance can offer the glimpse of continuous developmental processes
- Consider heterotypic continuity – where underlying mechanisms may remain unchanged, but the phenotypic manifestation may change
- Administer adolescent and young adult measures at the same time to see overlap between the constructs being measured
- NIH Toolbox tasks may not vary significantly in young adults that do not have significant psychopathology but still important to measure impacts of substance use
- Short, gamified tasks used in the EMA framework (Robb Rutledge of Yale University) could be coupled with EMA data captured for other tasks to see how the domains potentially talk to each other.

- To tease apart developmental changes or cognitive improvements with age versus practice effects, one could assess whether parents accomplish the tasks as well as the youth do at the same intervals. Prioritize measures that show the most variance over time.
- There is low likelihood for a task to capture the momentary challenge of deciding to engage in substance use, as multiple complex factors affect the process.
- It is challenging to do well in stress tests because of the individual variability of how someone responds to the induction of a mood/state.
- A new measure does not have to be part of a new longitudinal battery.
- Remote data collection
 - Working memory and cognitive flexibility can be assessed remotely but not inhibition task, as that measures the reaction time.
 - Need a platform that can be accessed from a variety of devices and provides metadata.
 - The National Longitudinal Study of Adolescent to Adult Health (*Add Health*) used TestMyBrain for remote cognitive assessments. It captures the device, screen type, and operating system, and has a lot of metadata on reaction time.
 - A subset of participants was administered both the NIH Toolbox and TestMyBrain.
 - The domains chosen for TestMyBrain were working memory, executive functioning, and processing speed.
 - Testing neurocognitive constructs that fluctuate intra-individually day to day, such as inhibitory control, could then be combined with EMA.
 - Prolific platform for cognitive tasks.
 - Strategies to improve data quality include attention checks built into the tasks and elaborate instructions at the beginning about setting up their environments, with the option to call a research assistant before moving on with the tasks.
 - Different groups will be more or less likely to do things online. It may be important to have some subgroups do tasks in-person.
 - Potential concerns about data quality for children with ADHD doing tasks without being observed by study staff.
 - Potential concerns about remote cognitive testing if the youth are intoxicated or otherwise impaired.
 - Potentially randomly select a sample for remote assessments in the next phase so they aren't self-selected, to disambiguate the effect of remote from self-selection.

Substance Use and Mental Health

Overview – Elizabeth Powell, NIAAA

Key considerations that came from premeeting discussions were the frameworks to be considered: stress model, interactions of individual vulnerabilities and environmental stressors, and motivational and contextual models to inform assessment. Among measurement priorities, considerations were adjusting measures in the mental health and substance use spaces to be relevant for young adults – involving categorical and dimensional factors, family history and personality, substance use patterns, biospecimen collection/ toxicology, and technology to understand resilience, such as screen time and social media. The premeeting also discussed minimizing participant burdens by consulting parent or youth advisory boards for feedback, using remote or hybrid data collection, and targeted sampling for

intensive measures. Finally, there were discussions around ethical sensitivity in protocols to ensure inclusivity and representation.

Panelists

Jungmeen Kim-Spoon, Virginia Polytechnic Institute and State University
Kenneth Leonard, University at Buffalo

Discussion

Theoretical Models

- Stress report model
- Motivational models of substance use
- Social development models – social interactions that may influence people to use substances or refrain from using them
- Diathesis-Stress model
- Deaths of Despair hypothesis – *Add Health* question about life expectations, particularly whether a participant expects to live beyond 35, is predictive of socioeconomic status, substance use behavior, and premature mortality.
- Ecological perspective – Considerations should be at a higher level from one’s immediate contexts of community and neighborhood to policies and accessibility of accommodating opportunities at school.

Focus Areas

- Environmental factors, contexts, and the motivations for young adult use.
- The Alcohol Use Disorders Identification Test (AUDIT) makes sense from the validity standpoint and in the perspective of harmonization with a lot of other data.
- Educational attainment and occupation have shown significant implications for substance use behavior, morbidity, and mortality.
- Harmful patterns of use, rather than just use
- Harmful use can be quite different in different groups. Therefore, the interaction between the vulnerability and the phenotype may also be variable.
- Substance market is changing rapidly, and people may not know what they are using.
 - The hemp product market is unregulated, and hemp contains intoxicating cannabinoids.
- Most adolescent studies define use in terms of frequency; whereas adult studies define it based on problems and functional impairment
- Distinguish between recreational and medical use
- Cannabis dose – consumers are not knowledgeable and systems don’t make it easy to be aware of doses; could ask about their confidence in the composition of their intoxicating products
- Cannabis source
- Simultaneous use is important because it is deliberative, as opposed to same day use, which may be because of opportunity
- Stress and substance use are strongly correlated. It would be interesting to know if therapy or participation in certain groups helps people relieve stress
- Future orientation and future discounting in relation to substance use

- Constructs on optimism and self-affirmation, which have measures predictive of various outcomes.
- Financial stress and food insecurity
- Preciseness of the timing to understand the relationship between substance use and mental health
- Caution against relying only on EHR data for substance use/mental health
- Capture major diagnoses, maybe not through the EHR.
- Family history (parental drinking and substance use),
- Adverse childhood events
- Social media could provide a good dataset to tease out appropriate and problematic substance use.
- Nature/source of substance use/mental health treatment
 - Many students prefer to seek care in their college because that information will not be reported in their EHR (so that it does not affect their future employment).

Measurement Considerations

- Consider the number of optimal month intervals to follow up on with the balance of participant burden.
- A combination approach of a shorter period intense follow-back, a diary approach, or a random snapshot approach.
- Concern about under-reporting. Self-reported substance use gets better (as compared to toxicology) as participants get older.
- Objective measures
 - DNA methylation, in relation to smoking tobacco
 - Blood spots can be used to objectively quantify alcohol use for past weeks or months.
 - Wearables (patches to measure at interstitial level; wristbands to measure at skin level) to measure alcohol, cannabis, glucose, lactate, etc.
- Medication inventory, especially in the context of treatment disruption in depression, anxiety, and ADHD, when people may go through insurance and health care provider transitions.
- Pharmacy record linkage, which is a harmonized database at an individual level and doesn't necessarily rely on the EHRs.
- With HBCD going into the second trimester, and ABCD continuing, there is the opportunity to draw the arc of typical development from birth to age 27. We can bifurcate this into two paths – one for people who do not have severe substance use issues to disrupt normal development and the other for people for whom it would be important to understand how they deviate structurally and functionally from the former group.
- It is possible to follow the pathways by having different assessments triggered when participants report on different substance use levels. A similar approach can be deployed in other domains as well.

Physical Health

Overview – *Kim LeBlanc, NIDA*

Some of the key considerations that came out of the premeeting discussions were about measures to continue from ABCD's first phase. Some of them were objective (biospecimen assays, wearable devices) and some were subjective assays (questionnaire) of diet and nutrition, sleep, sexual and reproductive health, physical activity, cardiovascular health, and social determinants of health. New areas to consider are measures and modes of assessment that are validated and/or are particularly relevant for emerging adults and new biospecimen collection or analysis, body composition, and early predictors of chronic diseases.

Panelists

Abbi Lane, University of Michigan

Genevieve Dunton, University of Southern California

Holly Gooding, Emory University

Sara Vasilenko, Syracuse University

Focus Areas

- Nutrition
 - Apps
 - The Million Veteran Program uses Walter Willett's Fast Food Questionnaire, which feeds into a database
 - At low funding levels of funding, food frequency types of measures (NCI's Fat Screener and Fruit and Vegetable Screener).
 - With more funding, 24-hour recall dietary assessment linking it to NDSR software or contracting with other entities.
 - ASA24 dietary assessment is self-administered
 - With still higher funding, newer digital devices, such as a digital EMA currently in development that captures added sugar and saturated fats from the diet.
 - A sub-study in UNC had participants log every meal with a picture of the food and beverage from a week.
 - NCI has an entire branch focused on diet so that could be available to consult. Research is moving more toward eating patterns and timing.
- Physical activity
 - The Modified Activity Questionnaire performs better in terms of sedentary behavior and objective measures than the IPAQ; also assesses aerobic activity and strength training
- People who weigh themselves frequently will maintain their weight better. Therefore, questions like how often do you weigh yourself, do you keep track of your food, etc., could have predictive value.
- Cardiovascular health
 - Eight metrics, all of which are collected and should continue to be collected. That will allow longitudinal tracking to observe the emergence of cardiovascular health issues.
 - Pulse wave velocity is a gold standard for measuring arterial thickness, which is a precursor to heart disease, cognitive dysfunction, renal disease, and vision loss. Pulse pressure from a blood pressure machine is a surrogate for arterial thickness and could be considered as a measure.
 - Alternatives to BMI as risk factors of obesity. Waist circumference may be a measure to consider.
 - Endothelial dysfunction could be measured as precursors to cardiovascular disease.

- Consider some contextual environmental factors that could influence these biomarkers of health, such as air pollution and PFAS exposure, which could be achieved by wearable devices.
- Cortisol, C-reactive protein, or other inflammatory cytokines could be useful to gather from saliva.
- Respiratory function
 - Long-term impacts of vaping cannabis on lung health.
 - Spirometry poses a low research burden, but participants do not like doing this test.
- Liver function
 - Growing number of people in their twenties are developing nonalcoholic steatosis.
 - Based on obesity and metabolic disorders, it is important to screen liver function in this age group.
 - Growing number of children with fatty liver disease
 - Sedentary lifestyle and ultra processed diet are impacting fat metabolism.
- Sexual Health
 - Early non-intercourse sexual behaviors.
 - As more participants become sexually active, relationships with their sexual partners, sexually transmitted infections (STIs),
 - History of exposure to pornography, current use of pornography, sexting, receiving unwanted pictures
 - Attitudinal measures, such as interest in being in a sexual relationship, sexual and relationship expectancies, consequences and desire for sex.
 - Social norms in the peer group
 - HIV knowledge, testing, and prevention behaviors are important to assess.
 - Pregnancy
 - Gestational awakening, preterm birth, preeclampsia, amount of lactation
 - For any intergenerational cohort, we need to constantly screen samples for pregnancy. Since asking about pregnancy is sensitive, it may be best to work with the HBCD project to figure out a good way to do that.

Remote Measurement

- *Add Health* has done some self-collections of samples. They use a company called ExamOne. Participants can select if they can get their labs in another location, apart from their home. It is easy to do and costs less than a phlebotomist visiting the house. But they lose on the volume we can collect from individuals.
- Physical measurements and sample collection for DNA is done onsite in the *All of Us* program. Participants have the option to go to a lab such as Quest to give their sample, or have collection tools sent to their homes.
- During the pandemic, participants were mailed measuring scales and blood pressure cuffs and were scheduled into a time when the research team remotely worked with them to get the readings.

Prioritization

- At a lower budget
 - Lipids
 - HbA1C

- C-Reactive Protein
- Blood pressure
- Pregnancy
- Urine collection (if not for assays now then for the future for renal diseases that we may see in his cohort)
- Lung function
- Dietary screener
- Physical activity self-report
- Sleep (duration, time to sleep onset and sleep quality, night-to-night variability school start time),
- Perception of their health and well-being (opportunities to harmonize with the ECHO program)
- Pain
- Fatigue
- Higher budget
 - Vascular thickness
 - Distal capillary tests
 - Heart rate variability
 - Liver function studies
 - Endothelial function
 - Intergenerational study (being able to follow the next generation).

Day 1 Recap and Closing Remarks

Michael E. Charness, Harvard Medical School/Boston University

Dr. Charness thanked the attendees for a rich discussion. He indicated that the day 1 discussions offered a rich preliminary envisioning of what the next 10 years of ABCD might look like. In its first phase, ABCD has achieved a great task of exhaustively characterizing a cohort of children through a decade, starting at age 9-10. The participants were characterized in the domains of mental health, childhood experiences, exposures, screen time, etc. The program conducted neuroimaging and performed detailed neurocognitive and psychiatric assessments. The program survived through a pandemic, successfully retaining almost all participants.

The ABCD program has presented a cohort of developing youth who now offer the program the opportunity of deeper understanding of how the information coalesces into outcomes when the group matures into adulthood. The program aspires to understand a lot more of this cohort's phenotypes and outcomes by the time they are 30.

In a way, ABCD strives to be a version of the [Framingham Study](#) in its quality of understanding conditions across generations. The outcomes that researchers learn from the ABCD program is intended to be generalized to the entire country. This group will play an important role in shaping the vision of how to take what ABCD has accomplished and will accomplish by the time it concludes and moves forward in a way that realizes the vision and promise of ABCD.

Dr. Charness summarized key areas that the program could pursue further: sleep, coping mechanisms, navigating personal and digital environments for social interactions, and finding the right spot for

continuing studies by being cognizant of the cohort's available time for the program as they step into the next decade of their lives. The program recognizes that the participants prioritize their sense of purpose when opting to be in the study and hopes to find opportunities for those who are interested in the work of the program to remain involved with it in addition to their capacity as participants.

An important take-home message for the program is that it needs to measure not only the structure but also the function and quality of relationships, which is a challenge to accurately analyze because of the prevalence of social media interactions. The goal of this meeting is not to come up with measurements but with the framework. When the study is funded, it will be the goal of the grantees to come up with measures.

We have approached this study at a time when trust in science is at a low point. The program understands the importance of being mindful of this when it comes to asking participants to disclose information about themselves and their relationships, with the additional understanding that it is not easy to pinpoint how technology would evolve in a few years' time. One of the major goals of the program is to understand the roles of experience and social environment in the development of mental health and substance use disorders, not only of the participants but also of those who become their partners in life or at the moment, as they heavily influence participants.

The questions that need answers are measuring the quality of social relationships, understanding what gives meaning and purpose, what are the goal-directed behaviors related to social interaction, with the understanding that the participants' social lives and geographical locations may rapidly evolve in the next decade. The program is aware of the transient nature of social relations it intends to capture, for which it needs to understand its approach to the information that EMA will provide. There was a desire from this meeting to learn about social interactions in participants' lives from qualitative short narratives of their lives and learn about agency and self-efficacy.

Important measures are commitment, satisfaction with relationships, measurements of intimacy, measures of career success, understanding temporary digital interactions, collecting basic demographic information, measures of social well-being, measures of loneliness, social and emotional supports, and neurocognition.

Measures that may not be in continuity with ABCD but valuable in helping determine outcomes are social decision-making, virtual versus in-person determination of all the measures, toxicology mismatches, measures of drug use, and early predictors of disease.

Gayathri J. Dowling, NIDA

With a study as broad as ABCD, the program needed to bring together expertise along several dimensions, which was evidenced by the discussion during the first day of the meeting. Dr. Dowling provided a preview of Day 2 of the meeting and thanked the group for attending the meeting.

Traci Murray, NIDA

Dr. Murray thanked all attendees and videocast viewers. She encouraged the latter group to submit their comments using the live feedback form or directly send comments to AdolescentBrain@nih.gov for the program to incorporate them into the planning phase.

DAY 2 – July 22

Agenda

- **Welcome Back**
- **Imaging**
 - Elizabeth Hoffman, NIDA
 - Sarah Yip, Yale University
- **Study Design**
 - Bethany Deeds, NIDA
 - Lauren Gaydosh, University of North Carolina at Chapel Hill
 - Genevieve Dunton, University of Southern California
 - Christiane Duarte, Columbia University
 - Lindsay Pool, National Heart Lung and Blood Institute
- **Final Thoughts from Young Adults**
- **Summary/Next Steps**
 - Michael E. Charness, Harvard Medical School/Boston University
- **Closing Remarks**
 - Nora D. Volkow, NIDA

Welcome Back

Traci Murray, NIDA

Dr. Murray welcomed back the attendees and thanked the planning team, Deloitte, and IQ Solutions for their roles in bringing the meeting together. She indicated that the deadline for public comments would be July 29, 2025.

Michael E. Charness, Harvard Medical School/Boston University

Dr. Charness reminded the attendees that by the end of the meeting the plan is to emerge with a framework and a set of concepts. The meeting would conclude with the summary that captures everyone's priorities.

Imaging

Overview – *Elizabeth Hoffman, NIDA*

Dr. Hoffman described the protocol for neuroimaging, which runs for 2–2.5 hours and is administered every other year. There are T1 and T2 structural imaging and a diffusion MRI protocol, a 20-minute resting state fMRI, and three different tasks for fMRI.

Some of the key considerations that emerged in the premeeting discussions were prioritizing the maintenance of backwards compatibility and data quality; utilizing task-based neuroimaging; considering naturalistic movie-based scanning for richer and better quality data, and greater participant engagement; considering the potential reduction of predictive power by reducing resting state data; and considering more intentional study design, such as subsampling imaging tasks or distributing scans across ages, staggering task intervals, and collecting more detailed data from smaller cohorts if resources are limited.

Panelist

Sarah Yip, Yale University

Focus Areas

- There is a compelling argument to repeat the existing protocols in the next phase. Brain development may slow down but it never finishes.
- Keeping some consistency in the functional task data would be important. Changing the task may potentially diminish the power of the dataset.
- Having robust measures of brain structure and function at this age range when substance use is diversifying and rising is another unprecedented opportunity for this stage.
- Naturalistic movie-based scanning
 - Open-ended, which provides future ways to analyze it, but shouldn't replace resting state MRI
 - Movie watching is a task; should not be treated as resting state; they answer different questions

- Complicated to perform - Use existing movie, harmonization, copyright issues, emotional content, language, potential biases, etc.
- Does not allow modelling events of interest as with task-based imaging – it gives the same stimuli but in an environment of very less motion in the participants.
- Concomitantly obtain EEG along with resting state fMRI to identify information on developmental trajectories that can be deployed in the clinic
- Decision-making under emotional stress, or social processing, or cognitively challenging tasks.

Measurement Considerations

- We should aim to have at least two scans within the twenties. One of those scans could be what we are already doing.
- Divide the cohort in half and give one group the existing protocol and the other the new protocol.
- MRI contraindications – increase in face/neck tattoos that could impact representativeness of the study.
- Some data acquisitions that we consider do not have to be repeated but could be one-offs.
- Staggering the samples for imaging would be a potential design consideration to cover the pattern of development; could have implications for demographic representativeness.
- Link data from wearable devices that will provide a lot of rich information, such as heart rate and respiratory variability, and sleep architecture, with brain imaging.
- We would want to get a comprehensive resting state scanning protocol.
- The scan and survey durations have shown a high satisfaction rate among participants. The MRI scan length is doable, especially since they are spread out.

Study Design

Overview – *Bethany Deeds, NIDA*

Key considerations from the premeeting were the value of communication – regular updates and demonstrating the impact of participation that motivate young adults; accessibility – flexible scheduling and communication methods, including gamified elements, can improve engagement; challenges – maintaining contact – frequent moves and changing contact details make it hard to keep in touch; data protection – participants need reassurance about the security of their personal data; balancing innovation and efficiency; hybrid data collection – combining in-person and remote assessments, with innovative methods like passive data collection and at-home kits, can offer flexibility; and possibility of an open cohort model and the longitudinal follow-up of the existing cohort that preserves core measures like brain imaging is critical.

Panelists

Lauren Gaydosh, University of North Carolina at Chapel Hill

Genevieve Dunton, University of Southern California

Christiane Duarte, Columbia University

Lindsay Pool, National Heart, Lung, and Blood Institute

Measurement Considerations

- EMA can be used to understand day-to-day or moment-to-moment processes and can also characterize something about the participants that could be used for future predictive purposes. While the latter is suited for ABCD, the moment-to-moment measurements are perhaps more suited for other studies with specific contexts.
 - Various health outcomes occur at different timescales. Need a core set of constructs that might fluctuate rapidly, as EMA cannot be administered too often – 4 days was seen as optimal in some observations.
 - Catch the interplay of mental health and substance use, for example by asking a question about mood and following that up several hours later with a question about substance use.
 - It may narrow down the quality of the data if you are only asking for a construct on a subsequent survey if something occurs in the first survey.
 - Frequency
 - For the younger age group, frequent reminders may be reminiscent of parents.
 - Delivery is important to how we communicate the reminders. Three times a day may be a sweet spot. A shorter check-in time may be optimal for time management and the data that the program needs.
 - If there are follow-up questions, people can often lie to the survey to avoid the follow-up question.
 - There could be burst type questions – 30 seconds to 2 minutes
 - There could be core modules that would go to everybody and subset modules which could go to certain participants only.
 - If our interactions with participants are going to be lower, a much more sparse sampling of mood and substance use may be needed for validation.
 - The type of responses could impact how often participants would respond (e.g., a visual analog slider (across a scale) may be a good way to interact).
- Mind Lamp is a relatively cost-effective platform for remote data collection.
- Wearable data, like heart rate variability is indicative of stress response. These measurements would be useful for measuring stress reactivity.
- Moving to mobile REDCap would be relatively easy. It may be easy to move to the mobile phone version of REDCap.
 - The REDCap link could be opened on any device; therefore, we do not have to have an app to have a device-based REDCap.
- Qualtrics – survey design is easy and there is a choice of the device the user wants to use. There are data to suggest that the majority prefer mobile devices.
- An app that posts participants' physical measurements and sends reminders to get their physical measurements done. The app could also track diet and nutrition, among others.
- Some assessments, such as those relying on performance may be challenging to do on phones.
- Subset groups for particularly intensive measures
- Providing choices to participants might help with engagement. However, then we need a strategy to mitigate bias
- Gamification built into the apps to make it more interesting
- In terms of imaging, it is better to collect high-quality data from a smaller number of people than subpar data from everyone.

- Have a subset of core measures that we can measure often across participants. It may be useful to include some shorter, self-report measures that people can complete at home to track fluctuations and ordering of constructs, which can be correlated with the imaging measures.
- Exposome (measuring the totality of all environmental exposures) can be linked geographically and help cast a wide net.
- Biospecimen collection
 - Unclear how much the savings would be gained by collecting remotely compared to participants being at a place with a phlebotomist onsite.
 - The Tasso device is a reasonable option for remote collection and allows more frequent collection, but the tradeoff is a reduction in the volume of blood collected.
 - It is likely that participants would not want to come for in-person tests if remote biospecimen collection is enabled.

Balancing longitudinal consistency and new measures

- Review publications to identify the most frequently used measures to aid in prioritization
- Focus on processes that are most relevant for this developmental stage as opposed to broadening an assessment battery that is novel
- If the ability to add new measures is limited, consider allowing independent researchers to apply for grants to add measures.
- Need a survey protocol that is ready for deployment in the event of a mass disaster in a specific geographical area. This will help increase the relevance of ABCD.

Consolidating Sites

- Participants who would be less likely to get to a site that is further away may be the more vulnerable individuals, those with higher clinical severity, or potentially less financial resources.
- Part of the reason retention has been excellent in ABCD is the relationship the sites have with the participants. We are likely to damage that relationship if participants must now go to a different site or are entirely remote.
- GenAI analysis suggested that 72 percent of people stay within 100 miles from the research site.
- It could be disruptive, expensive, and potentially biasing if sites are reduced.
- Across sites, imaging can be done but it is ideal to have the same person at every site at the same scanner.

Retention

- Texting is a low-cost way to stay in touch with participants but has rules. Texting can also be used as a maintenance approach. Collecting consent now could be useful as participants move in the future.
- Social media is also a good way to keep in touch.
- A dashboard for scheduling and notifications to help participants self-monitor their engagement.
- Reexamine incentive structure
- Strategy for non-response follow-ups. You may lose people with the push to web, and they will have different characteristics from the people who effortlessly move to web from in person. *Add Health* selects a sub-sample of non-respondents for in-person non-response follow-up and tries to get them back in person.

- Reporting data back to participants is a great idea. This could be an important retention tool because it would enable participants and parents to see the longitudinal trajectory.
 - If you go down that route, choose variables that participants would not be able to measure themselves or get from their doctor's office.
- Data transparency has been an incentive for participants. The *All of Us* program makes it possible to choose what results you want to get.
- In this age group, communication and the way you word things is very important. Everything is about approach. Information that goes back to participants should blend with their age group.
- Participants would like to see how they fall among the whole cohort based on their self-reports. If you include data centered around people in your area or people that have some things in common with you, a lot of people will benefit from that.
- Would getting results back change behavior?
 - It depends on the data received. If it is data on chronic illnesses or conditions that have the potential to manifest in future, that would matter a lot. It may have opposite effects on participants, with some choosing not to see that data.

Partnering/Harmonizing with Other Studies

- The Human Connectome Project (HCP) is now complete. It has 1,325 unique participants ages 5–21. A lot of the domains of data collection in HCP were harmonized with ABCD, so that dataset is available for partial harmonization.
- Enrolling ABCD participants into the *All of Us* program will offer ABCD integration with EHRs and other data sources.
- Other countries are exploring such large-scale projects, which could potentially offer an avenue for protocol harmonization.
- The NCANDA study and a European study called IMAGEN are relevant datasets
- MoBA, a Norwegian study, is enriching itself with more imaging and harmonized phenotypes.
- The Healthy Brain Network from the Child Mind Institute also has resting state fMRI data.
- Offspring of the participants could enroll into ECHO or HBCD, which starts at an earlier age, and they could start the ABCD protocol when they are 9 years old.

Managing Large Volumes of Data

- There are standards for compression and storage and metadata for these kinds of data, such as the kinds of data ABCD is collecting, the sampling rate, the period of time that you are going to be tracking the data, etc.
- Each type of wearable device has developed in its own way to store and access data more efficiently. There is use of automated workflows for extracting certain kinds of curated indices from the data.
- Could use tabularized summary data and different levels of access.
- Some companies in Europe are using data donation to distill data down to usable constructed measures, which help with processing large volumes of data and with data transparency.
 - Florian Keusch has the datadonationscience.de domain.
 - NIMLAS (Network for Innovative Methods in Longitudinal Aging Studies).

Privacy Considerations

- Need to think about the overall climate of trust in science, which continues to be a major concern among young individuals.
- Video explanations of consent process would help participants understand privacy controls.
- Being transparent and saying everything up front will make participants comfortable and trusting of the study.
- There is a need for a balance of what data can be acquired and whether it will be acceptable to participants.
- When tracking social interactions, personal identifiers should be concealed.
- Older participants may tend to be more cognizant about the consequences of being tracked than their younger counterparts, and the former may not be as readily permissive of it.
- Participants would include their friends and family in the context of confidentiality of information.
- There may be group-level differences in comfort level with tracking, such as between sociodemographic groups.
- While what we do now is acceptable, it may not be sufficiently acceptable 5 years from now, as technologies evolve. We should be honest about what confidentiality may look like. There is a concern about where we will be in the future regarding confidentiality and what we should communicate with participants.
- The utility and added value of the data collection should be balanced against the potential risk.

Community Engagement

- The *All of Us* program has a monthly participant ambassador advisory committee where issues and feedback are exchanged.
 - Community-level participant groups are structured around several different themes (age groups, if people work for *All of Us*).
 - There are Zoom and in-person meetings every 2–3 months where participants offer feedback to the program specialist on the site.
 - Staff are not part of the advisory committees to avoid conflicts of interest.
- Participants go through community partners when giving feedback. Community partners then share that feedback with the national *All of Us*.
 - Participants do not get incentives to join participant advisory groups.
 - Incentivizing the participant advisory groups may be useful for getting different voices about the project.
- Opportunities for immediate feedback from participants.
- Feedback relevant to communications, such as infographics, is obtained from participants in the community-level advisory groups.
- Participants are interested in getting involved with other people in the study
 - Social media is a large form of communication, if not the largest. Participants might be inclined to join online communities.
 - Participating in a study like this may help restore trust in science.

Final Thoughts from Young Adults

Jaden Chan, ABCD Study Participant Advisor

Sara Parthemer, ABCD Study Participant Advisor

Kissairy Guareño Peña, All of Us Participant Ambassador
Adriana Mares, All of Us Participant Ambassador
Moderated by Traci Murray, NIDA

What discussions stood out to you the most during the meeting?

- Everyone's commitment toward understanding the viewpoints of young adults and in keeping the program active.
- The discussions around various topics, including participant burden.
- The resilience the program showed through the pandemic.
- How data-rich the imaging and other assessments are and that the project aims to close a gap in pediatric data.
- How the program is interested in collaborations across institutions, agencies, and countries.
- By including us as participant ambassadors, you are not losing the human touch.
- Involving participant narratives stood out the most to me and AI narratives will give a lot of data.
- How this study is future oriented, and it is growing up as we do.
- You are building a community, too. There are a lot of young adults who have ADHD (almost 23 million). There is a lot of pending research, especially in women. Not only does ADHD affect scholarly life but also social and emotional development. There is a lot of potential for this study.
- I want to thank everyone for the careful consideration you are putting into this program. I liked how you are brainstorming to refine the study, in light of potentially lower funding in the next phase. It was very useful to know about samples, surveys, and biospecimens, and how they are used and planned to be used in the future.

What is one good thing about plans for the study?

- I love the app plan. The app would serve as one place to do many things. Transparency will help participants engage with the program. The program may want to ask more participants what they think, maybe do a mini survey.
- I like the fact that you are open to exploring AI and technology, and open to collaboration with other studies. It is good to see that reproducibility is important in this study.
- Thank you for taking our feedback into account. There was a really interesting discussion about younger children. I liked the naturalistic movie imaging, and I feel it will give younger participants a good first impression of the study.
- I like that the program is thinking about what would keep young adults engaged.

What is one point where we could improve?

- The program may want to think about helping participants transition into adulthood. Mini sessions for participants would be a good platform for people to give their opinions about various aspects of the program.
- I would emphasize the importance of privacy, especially when you involve people who were originally not participants.
- Getting data from parents would be important with keeping in mind that there are participants whose parents don't know much about the study. That may be a point to think about if you want to involve people that may interact with the participants' social environment.

What are a few more interesting or engaging parts of the assessment protocol?

- Incorporating games
- I like the imaging process, and the staff are very accommodating and provide all the information I need.
- I like the fact that the program is evolving as participants are evolving in their lives.

What are a few unengaging parts of the protocol?

- The full-day sessions may be a lot, hybrid visits may be a good idea.

Name a few things that will help you in the next step of your lives and career.

- Conducting college readiness events would be helpful.
- Provision of opportunities for people to get involved in the study as staff.

What else should we be thinking about?

- Because of budget, you may want to invest in invested individuals. Quality data is important, even if it means a reduction in participant numbers.
- Something that we have to explain to participants is how you store data samples and keep them private.
- Show participants a bit of what the project does in terms of the work.
- The program should have provision of follow-up care after return of results, which can be a very critical and vulnerable moment for some participants.
- Community building would be a good next step. Instilling a sense of responsibility and common confidence about the transition of adolescence to adulthood would also be good.

Summary/Next Steps

Michael E. Charness, Harvard Medical School/Boston University

Dr. Charness provided a high-level summary of the meeting. ABCD is at least two studies – first, of the normal trajectory of development, which combined with HBCD will give some picture from birth until the endpoint of development; and second, study of the interplay of experience, environment, genetics, and outcomes in the late teens and twenties. Therefore, the program should be rigorous in determining the final phenotypes to be confident of the outcomes and capture data in a credible, reliable, and reproducible way across all sites.

There were data that were not obtained when participants started the protocol and which may now need to be obtained. The program needs to conceptualize what the current imaging technology will allow the program to do 10 years from now to look at the final structure and function of the brain at age 29. The same is true for neurobehavioral assessments or cognitive evaluation and the determination of psychiatric phenotypes using rigorous methods.

Participation in the next phase is essential. It is important to know what will be acceptable to participants in the next phase of ABCD in terms of what the program will ask them and how it will ask them.

Dr. Charness said to the participants that the project respects their motivation and reasons for involvement, and it owes them information in return. He thanked the attendees for the extraordinarily rich and informative discussion.

Gayathri J. Dowling, NIDA

Dr. Dowling thanked everyone, especially the young adult participants. ABCD has been a huge undertaking and there are many challenges ahead – the more brains that can be put to it, the better it will be. Dr. Dowling thanked Dr. Murray for pulling together the 2-day meeting.

Closing Remarks

Nora D. Volkow, NIDA

Dr. Volkow thanked all attendees and the participants for attending the meeting. She acknowledged the importance of hearing the voice of the community that ABCD is studying. The project is unprecedented in allowing us to understand the basics of how the human brain develops in one of the most consequential stages of life. As part of the NIH mission, the responsibility of projects is to drive science to develop knowledge, and to promote health with that knowledge and understand and prevent mental illnesses, substance use, and other conditions. When ABCD was started, the project emphasized the power of sample size that would enable the understanding of cannabis exposure to various mental health outcomes, particularly psychosis. The required sample size was 10,000 individuals. While the project was predicted to be important, it has turned out to have an enormous impact at many levels.

The project wanted to generate models that are not completely categorical. Dr. Volkow strongly resonated with the observation of a participant to engage the most with those participants who have been the most invested in the study, as that will lead to more careful evaluation. However, the power of the sample size is important, as a fraction of the number of participants will develop physical and mental health conditions in the future. It will have a tremendous value to go backwards into a person's brain developmental trajectory and gain insights from there when they develop a psychiatric disorder in the future. The project has the unprecedented opportunity to do so in the next decade when most of the psychiatric diseases emerge in the age group of the participants. The important question is to create a protocol that will allow the project to achieve its aim with the cognizance that budget is going to be limited.

Dr. Volkow emphasized being more proactive about securing additional funding. One way is collaboration with institutes that can share the expenditure but have also given the project scientific input. The project needs to explore more avenues of collaboration. The pandemic provided an opportunity for others to recognize the value of ABCD and ultimately provide additional resources. The RECOVER project aims to understand the effects of long COVID in terms of developmental trajectories of people who were infected or vaccinated versus those who were not. The ABCD project needs flexibility to maintain its objectives moving into the future.

ABCD participants are now entering their twenties, and there is a big opportunity to interest them in science, to get the knowledge from them on how to quantify the degree of networks and impact of those relationships, and to create forums where the project can encourage people to analyze data. As funders and investigators, there is the need to be mindful of maintaining the flexibility in the program to enable the program to identify susceptibility to mental illnesses and understand what systems are affected in the brain.

Dr. Volkow emphasized the importance of confidentiality, stringency in the level of access to data, and handing data ethically. The program has the opportunity to generate an imaging story with deep phenotyping that can help back-and-forth translation to benefit a larger number of people.

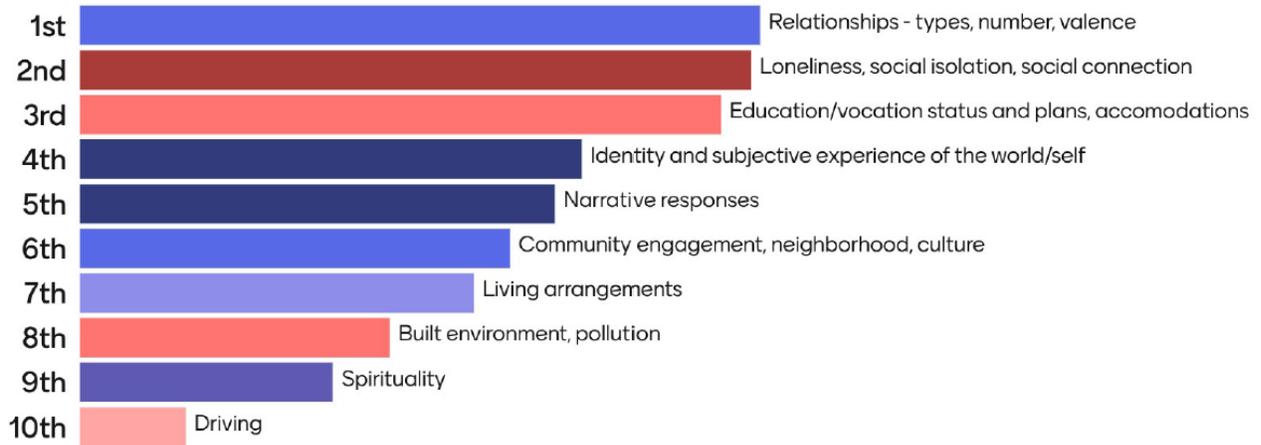
Dr. Volkow once again thanked the young adult participants and welcomed them to consider analyzing ABCD data if they were actively interested in research.

Appendix - Results from Topic-Specific Attendee Poll

At the end of the meeting, attendees were asked to rank recommendations that came out of each session and provide any elements they felt should be added. Those results are outlined below.

Social Health and Environment

Critical Elements

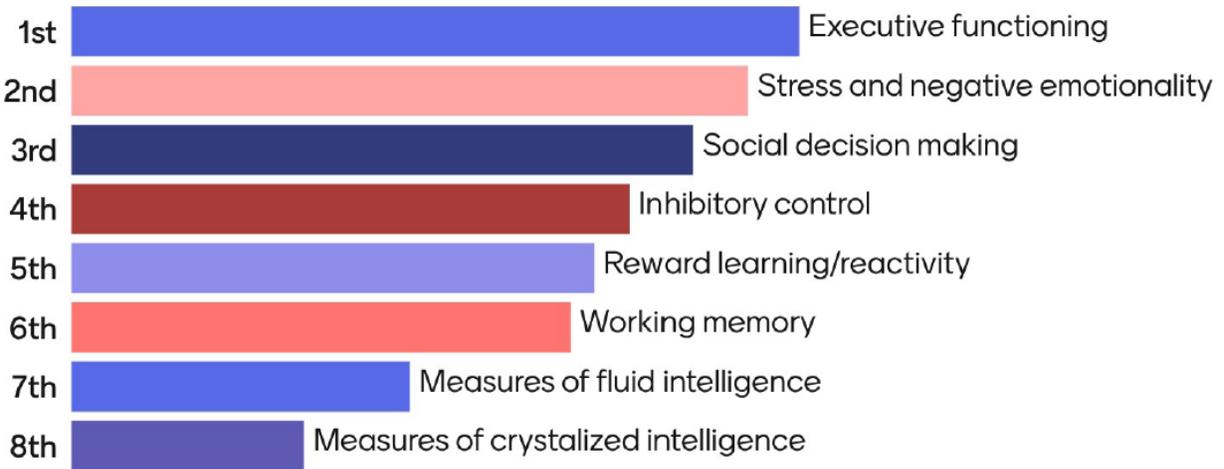


Potential Elements



Neurocognition

Critical Elements

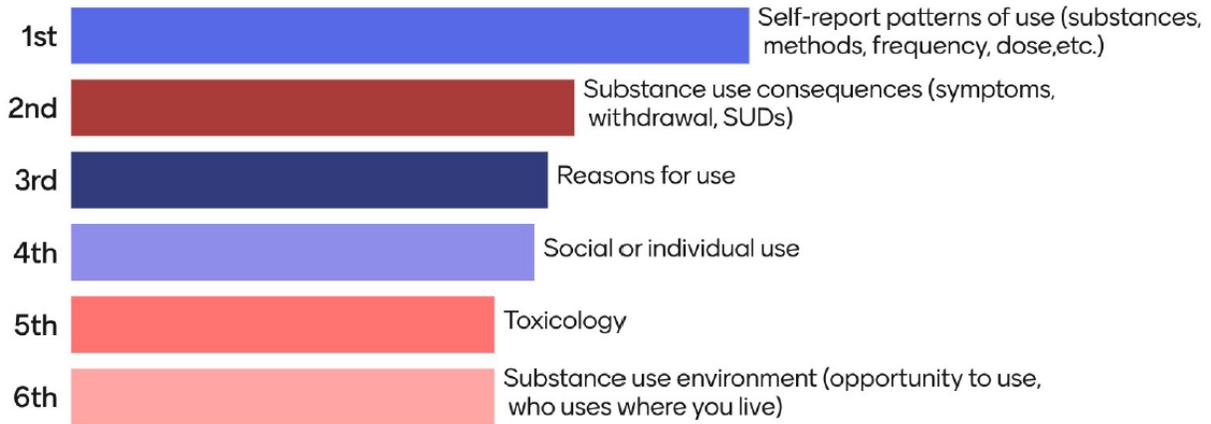


Potential Elements



Substance Use

Critical Elements

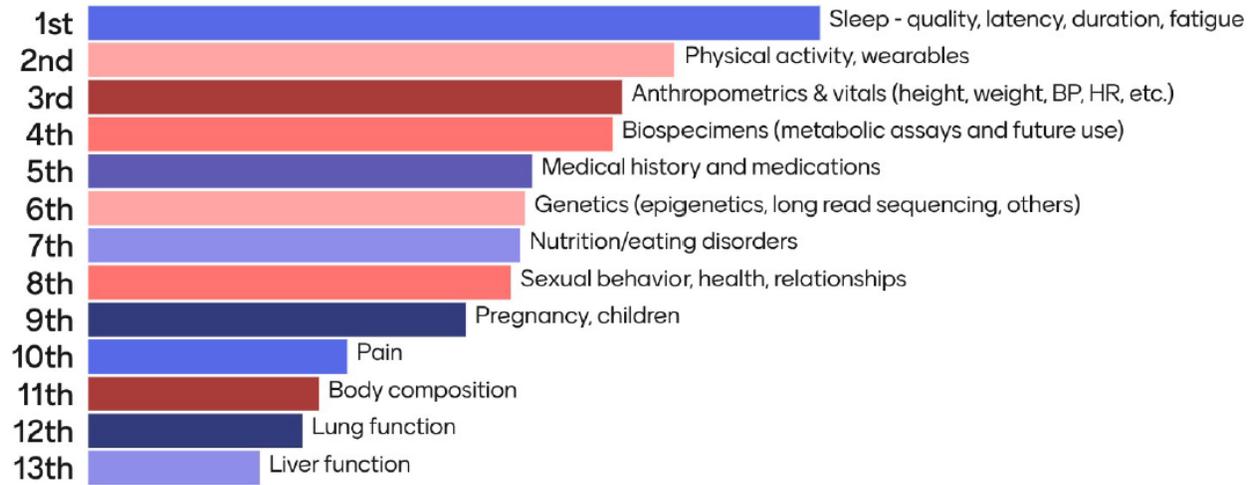


Potential Elements



Physical Health

Critical Elements

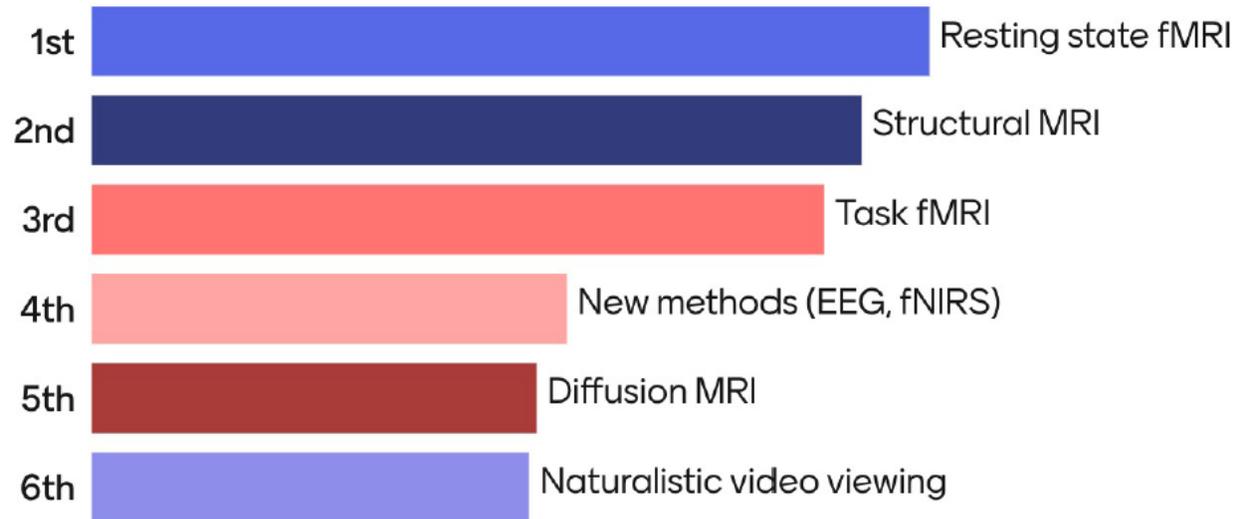


Potential Elements



Neuroimaging

Critical Elements



Potential Elements



Other Important Measures or Considerations

Great opportunity to add EMA	agree on the need to get high quality data, even if it's from fewer participants	How to retain the boys	Social network
Keeping large diverse study population	Health behaviors	Privacy in participant data, especially considering the amount of data collected on each person over time.	EMA
Human touch (narratives, feedback, events with participants)	Measuring a sense of belonging	Computational behavioral tasks	politics & religiosity
Participants opinions will always be of greater value	Moral reasoning; types of adult responsibilities	Support of ancillary studies to obtain important and detailed data in subsets	Condensed high quality data
Reinforcing activities	Retaining participants and continuity of measures re most important for developmental lens	wearables for environmental exposures	Development of social emotions and how they are relating to memory of evocative events, social encounters, etc (narratives and imaging)
Continue to stay on the cutting edge of communication technology (e.g., apps, hybrid approaches); explore increased advisory involvement from the aging sample	laws	It is critical to understand AI and tech as a ubiquitous part of life and how it influences brain and cognitive development. Socially and cognitively	Qualitative measures with AI assistance to analyze
Social networks and interactions	Resilience, callous and unemotional traits, schizophrenia questionnaire		