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The HEALthy Brain and Child Development Study (HBCD) experience: Recruiting and retaining diverse families in a longitudinal, multi-method early childhood study

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A B S T R A C T

The HEALthy Brain and Child Development (HBCD) Study, a multi-site prospective longitudinal cohort study, will examine human brain, cognitive, behavioral, social, and emotional development beginning prenatally and planned through early childhood. Given its aim to examine the impact of adversity and protective factors on children's outcomes, the recruitment and retention of families who have a wide diversity in experiences are essential. However, the unfortunate history of inequitable treatment of underrepresented families in research and the risks with which some participants will contend (e.g., substance use) makes their recruitment and retention in social science and neuroscience research particularly challenging.

This article explores strategies that the HBCD Study has developed to recruit and retain participants, including marginalized, underserved, and hard-to-reach populations, capitalizing on the extant literature and the researchers' own experiences. In this paper, we address strategies to recruit and retain families within HBCD, including: 1) creating experiences that engender trust and promote relationships; 2) maintaining connections with participants over time; 3) ensuring appropriate compensation and supports; 4) considerations for study materials and procedures; and 5) community engagement. The implementation of these strategies may increase representation and inclusiveness, as well as improve the quality of the resulting data.

1. Introduction

The HEALthy Brain and Child Development (HBCD) Study, a multi-site prospective longitudinal cohort study, will examine human brain, cognitive, behavioral, social, and emotional development beginning prenatally through early childhood (Nelson et al., 2024). HBCD will be the largest longitudinal study on early brain and child development in the United States, aiming to enroll over 7000 families across 27 recruitment sites. The HBCD Study will include a socioeconomically and racially/ethnically diverse sample of participants from the general population, a sample of participants who used substances during their pregnancy, and a sample of participants with similar socioeconomic experiences without substance exposure (Volkow et al., 2021).

Given the comprehensive and longitudinal scale of the HBCD Study, the National Institutes of Health funded multiple 18-month planning grants for its implementation, which included considerations for study design, protocol development and the legal and ethical context for the implementation of the study (Volkow et al., 2024). This planning process permitted opportunity to examine the feasibility of the larger study and more rapid implementation of study protocols as elements of the design and study elements were developed. The depth and breadth of assessments included in the HBCD is extensive and there are multiple visits planned within the child's first five years of life (see Timeline Fig. 1 for a summary of the first four planned visits); the HBCD is currently in the second year of a multi-year recruitment window (Nelson et al., 2024).

HBCD's scale calls for extensive efforts regarding recruitment and retention for the long-term success of the study. This is especially true

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regarding the inclusion of participants experiencing adversity, who are often underrepresented in neuroscience research. These families may be members of communities that have been treated inequitably and unethically by the research community (Scharf et al., 2010), making them understandably hesitant to engage in neuroscientific, longitudinal research like the HBCD.

Ensuring adequate representation of diverse populations in public health research has been recommended by the National Institutes of Health for 30 years (Mastroianni et al., 1994). Drawing samples from different social and geographic areas with substantial numbers of historically underrepresented groups is crucial for ensuring generalizability, validity, reliability, and reproducibility of findings (Dotson and Duarte, 2020; Green et al., 2022; Yancey et al., 2006). The lack of a diverse sample could lead to denying excluded groups health benefits of research participation (Rogers, 2004), the inability to offer health innovations to subgroups in the population (Albain et al., 2009), and the failure to identify and understand groups with the highest risk factors for illness (Singh, 2012). Researchers continue to encounter challenges in recruiting and retaining participants from socially diverse groups (Desai, 2020; Green et al., 2022; Shaghaghi et al., 2011). Exploring these challenges and suggesting strategies to enhance the representation of diverse groups in science is essential for eliminating systematic disparities in health (Matsuda et al., 2016).

This manuscript summarizes the work of the HBCD Recruitment, Retention, and Community Engagement Workgroup (WG-RRC) and explores barriers and strategies to recruit and retain a population with wide diversity of lived experiences for the HBCD Study, capitalizing on the extant literature, researchers' own experiences in prior studies, and lessons learned from HBCD pilot visits and the main study. We address multiple strategies to engage families within HBCD, including: 1) creating experiences that engender trust and promote relationships; 2) maintaining connections with participants over time; 3) ensuring appropriate compensation and supports; 4) considerations for study materials and procedures; and 5) community engagement.

1.1. *HBCD recruitment, retention, and community engagement workgroup (WG-RRC)*

HBCD Study decisions are informed by the efforts of numerous workgroups, overseen by the HBCD Consortium Administrative Core (HCAC). The Recruitment, Retention, and Community Engagement Workgroup (WG-RRC) was formed to support community engagement efforts and the recruitment and retention of diverse populations. Like other HBCD Workgroups, WG-RRC is led by two co-chairs and includes HBCD investigators from across sites who have expertise in community engagement and/or research experience with special populations involved in HBCD. Bi-weekly workgroup meetings are held to discuss issues related to participant recruitment, engagement, and retention; develop guidelines for study sites in these areas; support the development and revision of participant-facing communications, infographics, and study materials; develop suggestions for working with Community Advisory Boards (CABs); and discuss strategies for retention of study staff. Members of WG-RRC also provide periodic trainings to study staff and investigators and have supported HBCD to develop data elements to track sources of recruitment across study sites.

Further, the WG-RRC supports the efforts of the newly developed HBCD Metrics Support Team (MST), which has an overarching goal to ensure that the HBCD Consortium achieves its recruitment goals (i.e., 7200 participant dyads). With representation from the WG-RRC, the MST reviews the progress of each site in meetings its recruitment goals overall, and with respect to certain sub-groups (e.g., participants from diverse backgrounds and those with substance use histories). Members of the WG-RRC who recruit in similar contexts (e.g., rural) and have been successful in meeting their individual sites' recruitment goals are paired with sites experiencing challenges in recruitment; they provide support and share best practices to enhance sites' recruitment practices. Representatives from sites with successful recruiting strategies also share their effective strategies on Consortium-wide calls and meetings.

2. The HBCD experience

In early meetings, WG-RRC coined the term "The HBCD Experience"

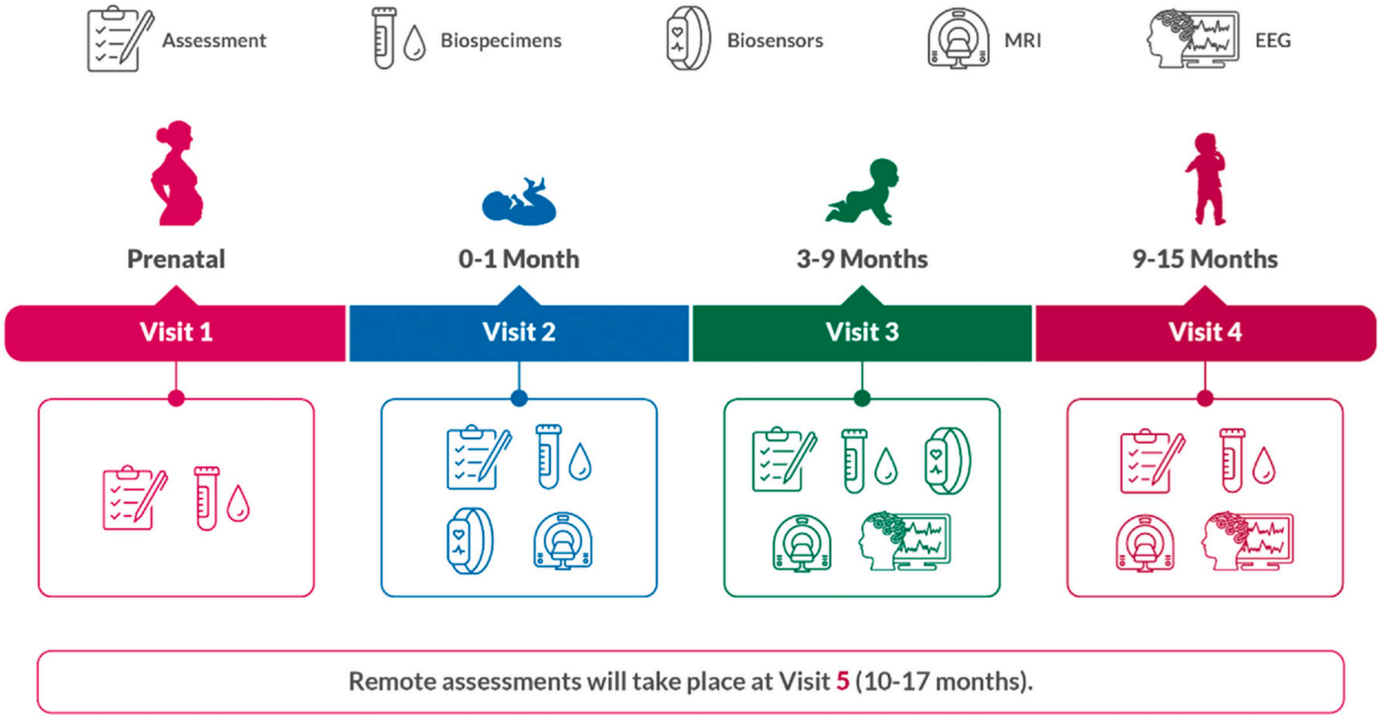

Fig. 1. HBCD study timeline.

to describe a research environment that participants find meaningful, supportive, and nurturing. Caregivers and children are made to feel special as participants in this study, and family members are welcomed and affirmed. The spaces in which data collection occurs are family centered, appealing, and comfortable. The concept of "The HBCD Experience" has been pervasive throughout WG-RRC discussions and applies to participants' experiences along the continuum of recruitment, engagement, and retention.

The HBCD WG-RRC has focused on the importance of connection when engaging families in the research experience. Recruitment specialists begin informal discussions about being engaged in research and focus primarily on building relationships with potential participants. Once a connection is established, they share information about the where (i.e., location of the study and reducing travel barriers), what (i.e., explaining study procedures and addressing safety concerns), when (i.e., schedule of data collection), and why (i.e., research purpose and benefits for participant and broader population) of study participation.

Following recruitment, research staff create a culture that fosters research engagement and retention. HBCD has developed a set of core values, including creating an environment that promotes dignity and respect where families feel safe and valued (Values – Healthy Brain and Child Development Study, 2022). Staff are flexible, welcoming, non-judgmental, kind, and considerate of potential barriers that families might face. Research personnel receive ongoing training in verbal and non-verbal behaviors that support connection, including being fully present and patient, active listening, tuning in to non-verbal communication, supporting families through discomfort, and being empathic.

To elevate the "HBCD experience", HBCD staff incorporate a trauma-informed approach in their engagement of participants (Substance Abuse and Mental Health Services Administration, 2023). HBCD staff, in particular study navigators (see paper in this volume by Hillard et al., 2024), have been trained to: 1) realize the impact of trauma on study participants; 2) recognize the signs and consequences of trauma in study participants; 3) respond to participants with empathy and engage them with mental health intervention if desired; and 4) resist re-traumatization of participants by being transparent and supportive with respect to study procedures. The principles of a trauma informed approach pervade the "HBCD Experience", including a physically and psychologically safe research environment; research staff who are trustworthy and transparent; a supportive, collaborative, and empowering approach to data collection (e.g., deferring to parents about the where and when of study visits); and support to research staff so that they do not experience secondary trauma (e.g., professional development experiences, reflective staff meetings, mindfulness experiences, staff self-care activities).

Moreover, HBCD sites have created comfortable physical research environments for families. HBCD research spaces are designed to feel as much like home as possible through welcoming families at the door, addressing basic needs (e.g., snacks, drinks, baby supplies), and providing a comfortable space (e.g., comfortable furniture and space for infant feeding, child-friendly space with books/toys). The HBCD WG-RRC also recommends "light touches" with families (e.g., sending cards for holidays and birthdays), providing research related incentives that are meaningful to children's developmental stages (e.g., onesies with HBCD logo, diapers, developmental resources), and creating positive data collection experiences (see Table 1). Although the study is not an intervention, each team has developed resources and referrals lists for families when needs are identified. Community engagement has also been encouraged to promote participant recruitment and retention (see specific strategies in Community Engagement section).

2.1. *Staff competencies that support relationship building*

A key component for recruiting and retaining underserved populations is having quality and effective research staff (Corbie-Smith et al., 2007; Leonard et al., 2003). Staff should have the skills to ask sensitive questions, to uphold participants' confidentiality, and to understand and respond appropriately to questions or concerns about study elements. They should be trained and supported to balance both building relationships and maintaining appropriate boundaries with participants (Leonard et al., 2003).

Recruiting and retaining underserved populations requires culturally sensitive research staff, who can constructively relate to and understand others' perspectives (Kumpfer et al., 2002). This is crucial for relationship building as it ensures an environment of trust. The use of regular training, supervision and role-playing regarding health inequities can aid in building a more culturally sensitive research team (Goff et al., 2016). Because it is nearly impossible for staff to be "culturally competent" for all cultures, HBCD has invested time and effort into training activities for research teams that promote "cultural humility" and the importance of respecting and learning from participants' cultures (Fisher-Borne et al., 2015; Taani et al., 2020).

Ideally, HBCD research teams include individuals with diverse backgrounds, experience working with particular study populations,

Table 1
Support for participants.

Before Study Visits
Ensure that participants have a good understanding of the study using recruitment materials to provide authentic information about the study
Ask participants what would make them feel more comfortable participating in the study (e.g., safety, time and location of visits, in-person, or virtual visits)
During Study Visits
Aid families who have other children who come along by providing child care, entertainment and activities for older siblings; have toys, books, movies, coloring books, and other child-centered materials available
Provide snacks and drinks to families during daytime visits and/or a meal/dinner to participants who bring their babies to an MRI in the evening
Provide family-friendly spaces (e.g., lactation room or space for participants to feel comfortable feeding their babies, changing table, crib and/or pack and play, bottle warmer, baby gear; television showing family-friendly clips)
Have diapers, wipes, and other baby essentials available for use during visits
Provide appropriate compensation for each visit
Give practical objects with study branding (e.g., an MRI-safe onesie or t-shirt with logo)
Provide transportation support - calling medical Ubers to transport families to the visit and providing car seats for the infant to use
Think about where families will park and providing clear/easy directions and facilitate transport to study visits when parking is difficult/remote
Consider providing a hotel room for caregiver and baby if the MRI is late and it will be difficult for them to travel back home that same evening
Reassure families when best efforts at data collection are not met
Between Study Visits
Provide referrals to community organizations to address concrete and psychosocial needs, including infant needs (e.g., diapers, wipes, and formula/milk bank; social services and mental health supports)
Maintain a resource closet with donated items (clothes, diapers) for moms to access/take
Create a "light touch" schedule to help families feel like they are always part of the study (e.g., informal communication via texts and cards; small gifts; visit reminders; newsletters)
Celebrate when an infant is born with a small gift
Send condolences if an infant or family member dies (e.g., card; resource list for grief-related services)

and a commitment to having a long tenure with the study (Taani et al., 2020). Staff from underrepresented groups should be supported with resources and mentorship, as they serve as the voices of participants and may contribute to establishing culturally responsive research protocols. Partnering with community groups who share cultural practices with potential participants can be helpful, as well as including fathers and other family members in study processes. This is particularly important when working with groups who have experienced adversity and stigma.

2.2. *Recruiting, engaging and connecting with participants*

Recruiting and retaining families in HBCD requires attention to the principles delineated as key to the HBCD experience. HBCD sites are using a variety of active and passive methods for recruiting participants. In addition to recruitment through typical methods used for individuals in pregnancy (e.g., obstetrics offices, nutrition services, prenatal classes), sites use a variety of recruitment opportunities tailored to their individual contexts. Recruitment occurs through partnering with early childhood community and social service agencies (e.g., WIC, home visiting, early childhood care and education programs), and through substance use treatment programs. HBCD sites have also recruited through community events for families with young children, including for health and healthcare (e.g., safety baby showers), infant clothing consignment events, children's library events, and fairs. HBCD has developed language to be used on social media platforms and sites are also using traditional print media advertising in their recruitment efforts. The HBCD will actively monitor recruitment compared to site enrollment goals and review sources as recorded with participant screening. The WG-RRCE and HCAC will provide additional support to recruitment sites to be responsive and shift their focus should recruitment fall short of enrollment goals.

Numerous strategies are used to maintain contact and engagement with research participants including: intensifying retention strategies during baseline and follow-up procedures (Lankenau et al., 2010); sending visually appealing reminder flyers; implementing "light touches" such as sending birthday and holiday cards, and awarding certificates of participation (Leonard et al., 2003); implementing active, in-person contact (Yancey et al., 2006); and using technology (King et al., 2014). For longitudinal studies, the careful tracking of participants is critical. In HBCD, study staff collect detailed participant contact information including phone numbers, email addresses, home addresses, and social media handles at the first visit. They also gather names and contact information for participants' family members, friends, and/or other close personal connections who could help locate the participant if the study team loses touch. At every follow-up visit, the team reviews and updates information on participants and close contacts.

Staying connected to participants *between* visits is a crucial aspect of retention in a study of this scope. As seen in Fig. 1, the period between the enrollment visit in the 2nd trimester of pregnancy and the neonatal visit is lengthy (Nelson et al., 2024). Since attrition can be high during the early postnatal period as families adjust to their children's births, multiple strategies to promote retention are implemented during this time. Staff conduct several "light touches" leading up to the birth, including required pregnancy check-ins (starting at 34 weeks gestation) to connect with the participant, obtain updates on the pregnancy, and to offer resources to families. Study sites vary in the ways they engage with families after birth (e.g., phone calls, congratulations cards, small gifts, home visits), but all are encouraged to connect with families during this time.

"Light touches" are planned to continue throughout the study. HBCD-branded materials were developed by the Communications, Engagement, and Dissemination Work Group (WG-CED) to promote study retention, including birthday, seasonal, and holiday cards that can be personalized and hand-addressed; visit reminder appointment cards; texts and emails for keeping in touch and reminding families of upcoming visits; and periodic newsletters with study updates and information of interest to families (Cole et al., 2024). A variety of materials were created to offer at the time of the visit, such as "Junior Scientist" participation certificates and MRI-safe onesies and T-shirts. The HBCD Study logo and other images are available to study teams in developing site-specific retention materials; sites are encouraged to consider family composition, cultural preferences, and other children, partners, and family members in tailoring and sharing these materials. Descriptions and exemplars of study materials are provided in the WG-CED article in this volume (Cole et al., 2024).

Whereas this is an observational study and benefits to participants are limited, the HBCD Study is committed to the ethical treatment of participants in the study. As outlined in the paper by the HBCD Ethics, Legal, and Policy Workgroup in this issue (Kingsley et al., 2024), the return of study results to participants was carefully considered. Each study site has identified a clinician and referral sources for all clinically actionable findings that would be returned to families. There is evidence that providing this support and information should promote family engagement and feelings of connection with the study overall (Lewis et al., 2021). Further, as the study progresses, participants will receive a "refresher" about the components of the study delineated in the original consent, as well as an updated version of future protocols (changes to the protocol would require re-consenting). This update would include a reminder of the voluntary nature of the study and that participants can opt-out of specific measures/assessments should they desire.

The use of technology has become increasingly important to connect with families over time (Baggett et al., 2009; Barry et al., 2019; Cardoso et al., 2020). Although demographic disparities in online access exist, mobile devices are commonly used, primarily among lower-income families with high school education or less (Anderson, 2015), thereby increasing the utility of technology in the recruitment and retention of hard-to-reach populations. Text messaging, phone calls, and emails represent important strategies for retention and may be used for data collection (Bonevski et al., 2014; Maher et al., 2010). The WG-RRC developed a standard operating procedure for recruitment sites suggesting at least three attempted contacts with study participants using these strategies, noting that it is important to vary attempts by day and time and communication modality. Social media platforms have become more popular for recruitment and retention due to their expansive reach and use (King et al., 2014; Thornton et al., 2016). To be accessible to participants, many sites have project-specific email addresses and phone lines.

HBCD Study staff are encouraged to be persistent and use various, creative methods for contacting participants over time. They reach out with phone calls, texts and/or emails multiple times and vary their attempts by time of day, day of the week, and format. If these methods are not successful, postal mail (with return service request), social media outreach, and even a home visit are suggested. Other methods for locating participants may include general internet searches, state public records, and participants' alternative contacts. Like with recruitment, the HBCD will actively monitor retention of study subjects and is currently planning a protocol to recruit to replace participants who are lost to follow-up (Si et al., 2024).

2.3. *Compensation and supports for participation*

Compensating study participants for their time, effort, and the cost of transportation is standard in research, and is even more critical for underserved, hard-to-reach populations (Corbie-Smith et al., 2007; Garcini et al., 2022). Research documents that respondents increase their participation if they were paid $50 or more (Western et al., 2016). Cash reimbursement is especially beneficial because it can help participants with immediate, concrete needs (Yancey et al., 2006). Research has shown that increasing the compensation at each study assessment increases participant retention and motivates them to stay in the study (Goff et al., 2016). Other compensation that addresses participants' concrete needs, such as diapers/pampers, is also being used in HBCD. While adequate compensation is critical, researchers should be careful not to make the compensation so high that it is an undue inducement (Permuth-Wey and Borenstein, 2009).

Because of the multiple, lengthy visits that HBCD entails, participants may be compensated $600 or more during a single year. Compensation at $600 or more per year requires institutional reporting to the US Internal Revenue Service, which provides notice of potential tax liability for participants (Waltz et al., 2023), therefore most institutions in HBCD require that participants provide their social security numbers. The WG-RRC has expressed concern for families with immigrant or lower-income backgrounds, for whom this taxable income may be detrimental to retention (i.e., families who worry that this additional income would make them ineligible for public supports). Therefore, the WG-RRC has encouraged sites to track compensation and inform families when their compensation will meet federal income reporting requirements. Sites have used a variety of mechanisms to reduce the likelihood that families would earn enough in compensation to create tax liabilities, including allowing participants to choose non-monetary compensation (e.g., diapers) or delaying compensation into the following calendar year. One institution has agreed to pay the tax liability for study participants, and another gave permission to refrain from requesting social security numbers.

In addition to monetary and non-monetary compensation, HBCD Study sites have made accommodations to support participation in laboratory visits. These include offering flexible scheduling for study visits, such as evening and weekend visits and scheduling around lengthy commutes. A recent study of HBCD sites (Zgierska et al., 2024) documents that most sites offer transportation assistance for families, which includes reimbursement for personal transportation and/or the use of paid public transit, taxis, ridesharing services, and leasing vehicles specific for study use. Sites have also provided car seats for families when in transit. Given that MRIs are lengthy and occur when children are sleeping, HBCD sites also provide entertainment and toys for siblings in the family, snacks and meals for families, and hotel stays and reimbursements for families with long commutes.

2.4. Data collection materials and procedures

Study materials, procedures, and measures can impact successful recruitment and retention efforts, especially for participants from underserved populations. Brannon et al. (2013) proposed making a document that includes pictures and brief sentences to maximize understanding of the study and procedures. Numerous materials were developed for HBCD with the goal of promoting understanding, authenticity, and transparency regarding study goals, timelines, study procedures, and family commitment. WG-RRC strongly promoted the use of a 5th-6th grade reading level (8th grade maximum) for all written communication and data collection materials to ensure understanding of those who may have learning differences, lower levels of education or literacy, or whose first language differs from the language of the materials (Goff et al., 2016).

Since both English and Spanish speaking participants are enrolled in HBCD, an HBCD Spanish Language Committee was created to ensure that all materials were translated appropriately (e.g., use of validated translated instruments, forward/back translation; review by bi-cultural/bi-lingual individuals). Because the study includes methods that might be negatively perceived by certain racial/ethnic populations due to historical experiences, it is critical to clearly explain the methods and potential risks in multiple modalities (e.g., words, pictures, video, role play), to have community members validate that these methods are safe, and to offer opportunities to experience the methods prior to the data collection. The HBCD Diversity, Equity, and Inclusion workgroup (WG-DEI) reviews all data collection materials and makes recommendations to ensure that measures and materials are appropriate for all study participants (T. M. Murray and Slopen, 2024).

The WG-RRC worked with the Communications, Engagement, and Dissemination Workgroup (WG-CED) to support the development of a host of HBCD-branded materials to promote study identity and support recruitment efforts (Cole et al., 2024). These materials include images that include representation from a range of families (e.g., caregivers and infants are racially and ethnically diverse, represent diverse family configurations and caregivers), have been translated into Spanish, and were developed to be readable for families with differing levels of education. Further, the HBCD provides a wealth of family-friendly information on the national and site-specific websites, including infographics and videos to support family understanding of study procedures. The WG-RRC reviewed and provided feedback on all these materials to ensure that the language was understandable and appealing, and expressed gratitude for participants' time and commitment to the study.

Ideally, data collection should be conducted flexibly, with the convenience of the participant paramount (Goff et al., 2016), and researchers should budget for multiple attempts to get one data collection visit completed. Although many HBCD assessments require participants to come to the research space (e.g., MRI, EEG), if at all feasible, research teams should be open to alternative locations for some aspects of the visits, as successful data collection is more likely to occur in venues that are more convenient for the participants (e.g., homes, community centers). Staff ask participants about their preferences (e.g., time and day of visits) on how they would like the visit to occur, especially for longer visits that are split across multiple days. Sites are encouraged to be as flexible as possible if participants cannot take off work or will not be paid for leave and offer visits on evenings and weekends to accommodate schedules.

In HBCD, questionnaires and interviews are administered at most visits, some completed during in-person visits, and some sent to participants by email to complete at home. It is important to ensure that instructions and survey items are understandable, and to order surveys in a way that makes sense to participants (e.g. grouping by topic, child vs parent-focused, common response options). Some questionnaires/interviews require that staff ask items verbally; staff should offer to read any or all questionnaire items if the participant has difficulty reading or prefers the assistance. Given the range of participant technology and reading skills, it is important that study staff are available to help participants access remote surveys and to complete surveys verbally over the phone.

As discussed, research staff are trained to effectively conduct interviews, promote participant comfort, and navigate potential challenges, which is critical for promoting retention while collecting high quality data on sensitive topics. The WG-RRC developed best practices for successful interviewing in HBCD that are consistent with the HBCD Experience (e.g., developing positive rapport, utilizing lay language, maintaining a non-judgmental stance). Active listening becomes crucial, especially when participants disclose sensitive information. It is important for research staff to be attentive to signs of discomfort and reluctance to share information. Staff should reassure participants of the confidentiality protocols in place, emphasizing the commitment to uphold their privacy.

Because research on underserved populations tends to be deficit-focused and assess participant risks, WG-RRC strongly promoted the use of resilience-based measures, and measures that assess experiences of racism and structural inequities. Questionnaires and assessments that focus on protective factors of vulnerable and stigmatized groups help participants feel that they are not being criticized and can lead to discussions related to hope and a positive future (Poehlmann-Tynan and Eddy, 2019). Participants may also provide feedback on the constructs assessed and report on content that they perceive is missing.

2.5. Community engagement

Community engagement is a critical aspect of recruiting and retaining underserved participants in longitudinal research. Community partners may serve families who are eligible for HBCD and can scaffold their recruitment in the study. They may also provide services for study participants who express a need and willingness to obtain community supports. Collaborating with community partners allows researchers to respond to community needs and expectations, create a culture that is accepting of participant beliefs and values, and integrate the HBCD project into the fabric of the local community.

Community Advisory Boards (CABs) serve to strengthen community involvement through bringing together community partners, sharing information and planning efforts for the HBCD project, and providing feedback on best practices in recruiting/engaging participants and project data collection and dissemination of results. Each HBCD Study site is required to develop a CAB with the goal of ensuring that participants are recognized, honored, and respected, and facilitating research planning, participant engagement, and study improvement. Each HBCD site has recurring meetings with their local CAB and was strategic in recruiting key partners that represent participant backgrounds. CAB members have been drawn from local medical clinics, substance use treatment facilities, early childhood education settings, community health centers, mental health programs, home visiting programs, and child welfare organizations. Although CAB members vary across sites, members represent local agencies working with participants, community leaders, and professionals with an understanding of supporting families within the community. Some CABs include pregnant individuals and parents from HBCD communities, although some sites have developed separate Parent Advisory Boards (PABs). CABs provide study sites with locally appropriate feedback on study procedures and participant-facing materials and promote community partnerships that allow warm handoffs for families to appropriate service providers.

Each site was funded to hire a Study Navigator, an important community outreach strategy utilized in HBCD. Study navigators can be persons with lived experience (e.g., substance use or other adversities), or can be community health workers, social workers, or other helping professionals. They identify resources for study participants, including concrete resources (e.g., diaper/food banks), and psychological resources (e.g., parenting programs, mental health services, drug treatment programs) (Hillard et al., 2024). Because of their unique roles, study navigators are provided with intensive support at the site and consortium levels.

3. Inclusion of underrepresented families

3.1. Families with diverse racial and/or ethnic identities

To guarantee representativeness and inclusiveness of participants in HBCD, it is necessary to understand specific barriers and devise strategies for recruitment and retention of diverse populations. Understanding the complex interaction of socioeconomic, environmental, political, and various cultural experiences, as well as race, ethnicity, nativity, and preferred language, is crucial when recruiting and retaining diverse families in a research study (Evans-Campbell, 2008; Green et al., 2022; Shaghaghi et al., 2011; Yancey et al., 2006). HBCD is focused on understanding the unique characteristics of these populations and simultaneously their heterogeneity. As such, HBCD has addressed language, cultural, and socioeconomic differences, historical mistrust of and exclusion from science and healthcare systems, reducing stigma, and protecting participant interests and information (Lovell et al., 2023; Phillips et al., 2011 Sowemimo, 2023; Vaughan et al., 2023; Farquhar et al., 2014).

To overcome recruitment challenges, culturally sensitive practices are being implemented by the HBCD Study. For Spanish-speaking families, the study uses participants' preferred language, hires research staff who are bilingual and bicultural from diverse backgrounds, utilizes services from a professional translation company, creates recruitment and retention materials customized for different communities, and identifies idioms of particular regions (Neelotpol et al., 2016; Silveira, 2014; Quay et al., 2017). Additionally, it is beneficial to promote a greater understanding of population heterogeneity by differentiating race, ethnicity, and culture when recruiting (e.g., Black American, African, and Caribbean immigrants), connecting with community and religious leaders as liaisons, recruiting and collecting data in sites trusted by and integrated into specific communities (e.g., Head Start, Health clinics for Latin or Black communities), and implementing appropriate measures for confidentiality (Gilliss et al., 2001; King et al., 2010; Lovell et al., 2023; Adynski et al., 2023; Laveaux & Christopher, 2009). Moreover, trust can be enhanced by building relationships with family doctors, creating space for involving other family members, and providing families with other study benefits (e.g., presentations, child development information) (Adynski et al., 2023; Laveaux & Christopher, 2009; Quay et al., 2017; Bakhireva et al., 2020). Other strategies include providing reimbursement for transportation costs and promoting flexible research timelines, being sensitive to issues related to immigration (e.g. social security numbers, fear of deportation) and cultivating respectful in-person recruitment by prioritizing human contact and real connections (Adynski et al., 2023; Quay et al., 2017; Kanaya et al., 2019; Gilliss et al., 2001).

While considering these barriers and implementing these strategies for recruiting and retaining the HBCD families, it is essential to recognize and respect unique cultural contexts and preferences of each specific group. HBCD staff acknowledges experiences of historical and structural racism in Black and African American communities in the U. S., stemming from slavery and segregation, such as racism in science and health services (Sowemimo, 2023; Lovell et al., 2023; Vaughan et al., 2023). Another group-specific example is considering familismo/colectivismo/machismo as cultural concepts that shape social interactions and decision-making within the Hispanic/Latino community, including gender roles (Calzada et al., 2013; Arciniega et al., 2008). American Indian and Alaska Native communities have higher health risks due to factors such as limited access to education and health care systems, living in isolated locations, poverty, experience of historical trauma due to colonization, and exposure to environmental hazards (Bakhireva et al., 2020; Evans-Campbell, 2008; Burns et al., 2021), and have a historical context of marginalization, forced migration, and mistreatment by the U.S government (Jones 2006; Burns et al., 2021; Mello & Wolf, 2010).

Finally, it is essential to understand the intersectionality of multicultural and multi-racial families to ensure recruitment and retention of a diverse population (Green et al., 2021; Shaghaghi et al., 2011; Yancey et al., 2006; Evans-Campbell, 2008). To prevent generalization and promote an understanding of the intersection of multiple contexts (e.g., Latin American U.S. born English or Spanish speaker, Latin American foreign born Spanish speaker), a multifaceted approach is required. This involves a deep comprehension of racial/ethnic/cultural heterogeneity, as well as recognizing and respecting multi-racial origins and multicultural identities. Such engagement efforts ultimately contribute to promoting inclusivity and representation in the HBCD Study sample, and to recruiting and retaining all underrepresented and marginalized populations (Green et al., 2021; Doston and Duarte, 2020; Shaghaghi et al., 2011).

3.2. Families in rural and urban settings

HBCD sites exist in urban, suburban, and rural areas, which should be reflected in recruitment and retention strategies. Underserved inhabitants of rural areas are a NIH-designated US health disparity population. Addressing the barriers faced by rural participants will facilitate obtaining a nationally representative research sample and conducting research that benefits underserved rural populations. As with other marginalized groups, building relationships is especially important for participants from rural communities. Rural participants may have less trust in research due to the lack of previous experiences with research, apprehension of community outsiders, and fear of sensitive information being disclosed to their often closely integrated communities (Kim et al., 2021; Rudolph et al., 2017; Sutherland & Collins, 2012). Trust can be built through creating relationships with respected individuals and organizations in the communities and having research staff trained in the culture and values of these communities (Kim et al., 2021).

Participants may face different burdens while participating in the study depending on where they live. Although urban and rural participants may face transportation burdens, the resources they need to help manage these burdens may vary. Urban participants may struggle to arrive at study visits on time due to traffic and reliance on public transportation. Scheduling visits during times with less traffic and providing participants with a rideshare service may help ease this burden (Grape et al., 2018; Leavens et al., 2019). Rural participants may have to travel far distances to study sites. HBCD sites are using travel compensation and offering transportation to help ease this burden (Zgierska et al., 2024). Study sites are also arranging for participants to stay in hotels during longer study visits (Zgierska et al., 2024).

Rural participants may also lack internet coverage. Having study staff bring a hotspot or use their phones' hotspots during at-home data collection visits would help overcome this barrier (Lim et al., 2011). Sites may also create a list of places with available public Wi-Fi in enrollment counties for the completion of virtual questionnaires. However, it is important to consider participants' confidentiality risks when using public Wi-Fi and to ensure participants are in a private space to answer sensitive questions and their electronic connection is secure. Because HBCD sites enrolling rural participants may have most of their participants outside of their site's local area, creating a list of resources from areas adjacent to the research site will help to ensure all participants are connected to services.

4. Families experiencing adversity

A principal aim of HBCD is to examine the impact of adversity on young children's brain and behavioral outcomes, thus, recruiting and retaining families experiencing adversity is crucial to this study. Poverty is a major adverse context that is more likely to occur during early childhood and has more pernicious effects if experienced during this developmental phase (Harden & Slopen 2022; Le Menestrel & Duncan, 2019). Participants from lower-income backgrounds, with lower levels of education, and that are younger are less likely to remain in longitudinal studies (Price et al., 2016). Therefore, as Langer et al. (2021) assert, intensifying the strategies delineated in the previous sections is necessary for family retention. In particular, the following strategies should be prioritized: community engagement; reducing data collection burden through transportation, child care, and flexible scheduling; being transparent and maintaining connections with participants; tracking recruitment and retention of participants; and individualized, continuous improvement strategies for non-respondents (Flores et al., 2017; Griffith et al., 2020). Participants experiencing forms of adversity beyond poverty require special recruitment and retention strategies, such as those delineated below for participants with histories of substance use and child welfare involvement/transitions in care.

4.1. Parental substance use

Given the goal that 25 % of HBCD's sample will have used substances during pregnancy, it is critical that recruitment and retention strategies be developed with an understanding of the implications of substance use for pregnant persons and families with young children (Boutin-Foster et al., 2013). Although the rates vary by substance, substance use in pregnancy has been identified as a public health problem (Patrick et al., 2017). Further, maternal substance use is highly correlated with maternal depression (Pentecost et al., 2021) and history of trauma (Racine et al., 2021). Participants using substances may exhibit shame and stigma surrounding use, unstable and/or violent living situations, fear of being penalized for use, and mistrust of research and medical personnel (Bright et al., 2022; Hillard et al., 2023). Other barriers to be addressed include participant tendency to hide their behaviors because of stigma and confidentiality concerns, compromised physical health and mental health, as well as living in residential treatment programs and related time constraints (Barnett et al., 2021; Hillard et al., 2023).

It is important that the study protects sensitive data about a person's involvement with illicit drugs or possible criminal behavior and ensures participants that data collected will be confidential (Worth et al., 2023). The HBCD uses the NIH Certificate of Confidentiality and has been designed with great consideration of ethical and legal risks to participants (Kingsley et al., 2024). Like with other families, there is the need for flexibility regarding the timing of data collection (e.g., rescheduling the visit if the participant felt sick, connecting medical and research visits). Flexibility regarding the format of the data collection session is also critical (e.g., phone, in-person, in their homes, in their treatment centers). Due to the instability in the lives of many persons using substances, HBCD sites will use technology to track parents as a retention strategy, such as search tools, public records, and social networking sites (Worth et al., 2023). For longitudinal studies like HBCD, it is critical to have extensive contact information, including of the participant and other persons who would know how to locate the participant. Additionally, multiple attempts at contacting participants for data collection visits should be made, including phone calls, texts, mailings, in-person visits, and contact at treatment centers (Worth et al., 2023).

The HBCD-Study Navigator workgroup (WG-SN) has provided training to staff to increase overall understanding of substance use and stigma (Hillard et al., 2024). These trainings have highlighted the importance of staff being trustworthy, empathetic, and nonjudgmental to build rapport and relationships with participants who use substances. Study navigators can establish linkages with recruitment sources that can refer participants with substance use (Young et al., 2022). Further, they can support participants' recoveries, by providing peer support (if they have substance use lived experience) and identifying substance use treatment resources (Hillard et al., 2023).

4.2. Families experiencing child welfare involvement and children's transitions in care

In longitudinal research with young children, and their families, especially those exposed to multiple family and environmental adversities such as parental substance use, researchers may be engaged with the child welfare system. Researchers are typically mandated reporters, requiring any team members to report suspected child abuse or neglect, given that they are faculty or staff at an institution of higher education, are health care professionals, or work for child-serving institutions (Becker-Blease & Freyd, 2006; Pietrantonio et al., 2013). This issue is particularly important for infancy researchers because infants are more susceptible to child maltreatment victimization than children of any other age (Administration for Children and Families, 2024).

To ensure that researchers address this issue appropriately, they should attend trainings regarding child maltreatment reporting and child welfare services in their local jurisdictions (Allen, 2009). To inform HBCD sites about the child welfare system, the Consortium sponsored a 1.5 day workshop on the implications of families' child welfare involvement for the study that all sites were required to attend. Multiple consortium-wide and site-specific training activities have been implemented to address child protection/welfare issues as the study has progressed. Additionally, HBCD's Transitions in Care workgroup developed a Child Welfare SOP as well as established other measures and processes to ensure follow-up of children who became involved in the child welfare system.

Further, sites were encouraged to consult with their local Institutional Review Boards (IRBs) or other research compliance entities regarding disclosure of reporting requirements in consent forms and reporting procedures in local jurisdictions. HBCD research teams have each devised explicit protocols for mandated reporting (e.g., who should make the call, when the call should be made, whether the parent should be informed). It should also be noted that the HBCD Study also considered the racial and ethnic disparities of referrals into the child welfare system (Thomas et al., 2023) and has made considerable efforts to train study teams and staff about racial and ethnic biases. For example, each member of the HBCD Study has completed mandatory training in on unconscious bias that was developed by the National Research Mentor Network (Murray and Slopen, 2024). Further, given that families who may be considered for child protection reporting tend to have higher levels of contextual risk, HBCD sites have developed resources and community connections for referring families to services.

The WG-RRC has recommended that local child welfare personnel be members of CABs. Such partnerships between HBCD researchers and child welfare personnel may increase the likelihood of retaining children and parents who become engaged in the child welfare system (e.g., children in foster care). Fortunately, there is research that suggests that child protection referral may not lead to significant study attrition in studies of children and parents (Knight et al., 2006). Given the HBCD sampling frame regarding prenatal substance exposures and other risk factors common to families involved in child welfare (Meinhofer and Angleró-Díaz, 2019), a key contribution of the HBCD Study is to follow children who experience one or more transitions in care, whether it is to foster care or an informal placement. Although most transitions to nonparental care are temporary and involve informal placements with kin (Radel et al., 2016), child welfare involvement is common. Because of risk factors and potentially different life trajectories (Murray et al., 2020), it is imperative to follow children in all their nonparental placements, including informal and formal care.

5. Concluding remarks

Careful attention to recruitment and retention is essential to ensure that neuroscientific studies are representative of the diverse populations of the U.S. It is arguably more important in HBCD, which is a longitudinal study that aims for 50 % of its participants to have experiences of adversity. The HBCD WG-RRC has identified multiple strategies for recruitment and retention through creating an HBCD experience that prioritizes relationships with and validation of families' unique experiences. Although the study is still in its early stages, research staff training and utilization of these approaches have resulted in the recruitment and early retention of a diverse group of families. Indeed, at this early point in enrollment, sites are successfully enrolling families from diverse racial and ethnic backgrounds (54 %) and with substance use in pregnancy (34 %). These milestones bode well for meeting long-term study aims and provide compelling evidence for sustaining the intensive recruitment and retention strategies recommended by the HBCD WG-RRC. It is our hope that HBCD will be an exemplar of how to conduct a neuroscientific study that is representative of the diverse families and experiences of children in the United States.

CRediT authorship contribution statement

Brenda Jones Harden: Writing – review & editing, Writing – original draft, Methodology, Investigation, Funding acquisition, Conceptualization. **Lorraine M. McKelvey:** Writing – review & editing, Writing – original draft, Funding acquisition, Conceptualization. **Julie A. Poehlmann:** Writing – original draft, Conceptualization. **Renee C. Edwards:** Writing – review & editing, Writing – original draft. **Florencia Anunziata:** Writing – review & editing, Writing – original draft. **Lana Beasley:** Writing – review & editing, Writing – original draft. **Melissa Bomberger:** Writing – original draft. **Oziomachukwu Chinaka:** Writing – original draft. **Sheila De La Cruz:** Writing – original draft. **Micaela Parkinson:** Writing – original draft. **Kelly Gurka:** Writing – original draft.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Data statement

This article does not include any data.

Declaration of Competing Interests

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