

Increasing diversity in neuroimaging research: Participant-driven recommendations from a qualitative study of an under-represented sample

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ABSTRACT

Enhancing the generalizability of neuroimaging studies requires actively engaging participants from under-represented communities. This paper leverages qualitative data to outline participant-driven recommendations for incorporating under-represented populations in neuroimaging protocols. Thirty-one participants, who had participated in neuroimaging research or could be eligible for one as part of an ongoing longitudinal study, engaged in semi-structured one-on-one interviews (84 % under-represented ethnic-racial identities and low-income backgrounds). Through thematic analysis, we identified nine relevant research practices from participants' reports, highlighting aspects of their experience that they appreciated and suggestions for improvement: (1) forming a diverse research team comprising members with whom participants can interact as equals; (2) increasing accessibility to research by providing transportation and flexible scheduling; (3) providing family-oriented spaces; (4) enriching the campus visits to include optional on-campus activities to connect with the University; (5) developing safe strategies to accommodate participants with tattoos during the MRI; (6) incorporating engaging and interactive tasks during neuroimaging sessions; (7) providing small gifts, such as a picture of one's brain, in addition to financial compensation; (8) sharing research findings with the research participants; and (9) fostering long-term bidirectional relationships. The findings may be used to develop best practices for enhancing participant diversity in future neuroimaging studies.

1. Advancing strategies to increase participant diversity in developmental neuroscience

In recent years, there has been a growing emphasis on increasing participant diversity in neuroimaging research, particularly for studies examining the influence of social contexts on brain development (Arredondo et al., 2022; Garcini et al., 2022). The field is beginning to acknowledge and make efforts to elucidate how human brain development occurs within bio-ecological systems shaped by the evolving histories of individuals, families, and communities impacted by structural inequalities in broader societal contexts (Vélez-Agosto et al., 2017). Yet, one of the most utilized sampling strategies for neuroscience research

has relied heavily on recruiting nonrepresentative convenience samples, which may perpetuate the prolonged exclusion of individuals from historically marginalized communities (Falk et al., 2013; Green et al., 2022). Discussions of the implications of the lack of diversity and the reliance on convenience sampling in neuroimaging studies have highlighted that such shortcomings can lead to an incomplete representation of society's demographics (Ricard et al., 2023). This, in turn, potentially threatens the applicability and generalizability of research findings and hampers our understanding of how diverse experiences impact brain development (Dumornay et al., 2023).

Although recent neuroimaging studies have attempted to use stronger sampling approaches (e.g., probability sampling, survey weights) to

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increase the representation of individuals with historically excluded identities and experiences, these individuals continue to be under-represented (Gard et al., 2023). This challenge is not unique to neuroimaging; broader biomedical research has also faced difficulties in engaging individuals from under-represented backgrounds, often due to issues related to the inaccessibility of participation and low trust between researchers and participating communities (El-Galaly et al., 2023; Kennedy et al., 2007). However, these challenges are further exacerbated in neuroimaging research, as MRI studies require individuals to physically enter a closed-bore MRI machine for an extended period. Despite the documented safety, the risks associated with neuroimaging technology are often misunderstood by the public (Goldberg, 2007; Luechinger, 2023). Additionally, some individuals may be hesitant to participate due to anxiety from being in a tight, enclosed space (i.e., claustrophobia) (Thorpe et al., 2008). Moreover, a problematic history of pseudo-neuroscience being used to justify racist and other marginalizing policies (Branson, 2017; Majeed, 2021) may lead those with experiences of marginalization to be skeptical of the value of neuroimaging research, thereby affecting their willingness to participate (Ashford et al., 2022). Thus, the use of neuroimaging as a necessary element in developmental neuroscience research may bring additional challenges in recruiting individuals from historically under-represented demographics (Habibi et al., 2015).

As a means of addressing these issues, researchers are beginning to provide insights into strategies aimed at enhancing participant diversity in developmental neuroscience. These strategies particularly focus on engaging participants from communities with a persistent history of under-representation, often due to biased recruitment strategies against their ethnic-racial identities or socioeconomic backgrounds (Weng et al., 2020). Strategies include reducing barriers to participation, such as accommodating participants' schedules, providing transportation, and offering free babysitting during visits (Arredondo, 2023; Garcini et al., 2022). However, the existing body of work consists primarily of recommendations driven by theoretical guidelines, which include principles and values to inform decision-making and rely mainly on empirical data from neighboring fields without input from participants who have actually participated in neuroimaging studies, nor from those that could be invited (and may or may not be willing to participate – a key population of interest). Thus, while these studies provide valuable recommendations grounded in strategies applicable across disciplines, they lack the direct voices of neuroimaging participants and thus may miss important strategies that participants value. Additionally, there is also a notable gap in the literature regarding strategies for retaining under-represented participants in longitudinal neuroimaging studies, which are crucial for studying the developing brain.

An effective method for gathering empirical data relating to participants' firsthand perspectives is through qualitative data collection, typically achieved by conducting in-depth interviews that utilize open-ended questions (Fereday and Muir-Cochrane, 2006). This approach encourages participants to offer nuanced, non-linear responses from various perspectives, enabling researchers to gain deeper insights beyond the single-word responses typically found in self-reported surveys (Kamal, 2019). In collecting qualitative data, our aim was to gather participants' views to identify strategies to enhance participant engagement. We formulated our recommendations based on participants' reports, encompassing both past research experiences and suggestions for future improvements. We conducted this work with participants from the Future of Families and Child Wellbeing Study (FFCWS), a birth cohort population-based sample of youth born in large U.S. cities. Thus, all of our participants had experience in a 20-year longitudinal study and either had experience with a neuroimaging visit or were prospective participants for future neuroimaging visits. This combination is important as it provides feedback from actual participants who have participated, as well as participants who were being asked to participate (which allowed us to get input from participants who could have decided not to participate – a key population of

interest).

2. Background information on our study

The Future Families and Child Wellbeing Study (FFCWS; $N = 4898$) collected demographic, health, and behavioral data from families at birth of a child between 1998 and 2000, and followed up at ages 1, 3, 5, 9, 15, and 22 (most recent wave of data collection occurring in 2024), with a 3:1 oversampling for non-marital births, from children born in 20 large U.S. cities (Hardi, Goetschius, Tillem, et al., 2023; Reichman et al., 2001). Due to this sampling strategy and the demographics of large American cities, 42 % of mothers reported a household income of \$25,000 or less, and 61 % reported an income of \$50,000 or less at baseline (Reichman et al., 2001). The majority of parents were from under-represented demographic groups: among mothers, 48 % identified as Black, 27 % as Hispanic, and 4 % as other, while among fathers, 49 % identified as Black, 28 % as Hispanic, and 4 % as other. In collaboration with the FFCWS, the Study of Adolescent Neural Development (SAND first wave; $N = 237$) followed up with the subsample of the cohort at age 15–17 (mean age 15.8) from 2014 to 2017 and subsequently at age 21–24 between 2019 to present (now called the Study of Adolescent to Adult Neural Development; SAND second wave; $\sim N = 500$). The first wave of SAND (mean age 15.8) collected MRI data from a subsample of youth and parents from nearby cities (Detroit, Toledo, Chicago) (Gard et al., 2021; Goetschius et al., 2019; Hein et al., 2020). Additionally, extensive surveys, clinical interviews, discussion tasks, and biological measures (e.g., hair, saliva) were collected (Doom et al., 2022; Guzman et al., 2024; Hardi et al., 2024; Hardi, Goetschius, McLoyd, et al., 2023; Hein et al., 2020; Peckins et al., 2020). Based on the demographics of the cities sampled for SAND, participants in the neuroimaging study at age 15 identified primarily as Black (76 % as Black, 6 % as Hispanic), and 54 % reported a family income below \$40,000 (Hardi et al., 2022). The first wave of SAND (mean age 15.8) involved youth and their primary caregiver traveling to the University of Michigan for a 6–8 h in-person study session and a 1-h MRI scan. During the fMRI acquisition, there were two tasks: (1) Emotion Face Processing (Goetschius et al., 2019; Hein et al., 2018, 2020) and the (2) Monetary Incentive Delay (Murray et al., 2023). During structural and diffusion imaging (Calabrese et al., 2022; Goetschius et al., 2019; Hardi, Goetschius, Tillem, et al., 2023; Hein et al., 2018), digital shorts were played. A resting-state data was also collected (Goetschius et al., 2020). In the second wave of SAND, participants also completed a similar battery of MRI scans at age 21, along with other participants from other cities included in the FFCWS who were recruited into the study (Fig. 1).

The SAND provided the following accommodations for the participants for the neuroimaging visit at age 15. First, complimentary transportation was arranged for all participants. Local participants (i.e., within an approximately a 2-h driving distance) were picked up from their homes and dropped off afterward using a university-owned vehicle displaying the campus logo. If participants opted to drive themselves, the study reimbursed them for gas and parking expenses. For those residing outside a two-hour driving radius, the lab arranged transportation via bus, train, or plane, and provided pickup from the stations using a university-owned vehicle with campus branding. Additionally, a complimentary hotel room was provided for participants traveling from longer distances. Childcare was provided to youth and their primary caregivers to accommodate them bringing their children.

3. Qualitative data collection

In 2021, individuals who participated in the FFCWS (either as the participant or their primary caregiver), whether or not they had participated in the SAND, were invited on a rolling basis to engage in a one-on-one, semi-structured interview (range from 15 min to one hour) to answer 13 open-ended questions. The interviews were completed using a video conferencing platform in a video call format due to COVID-

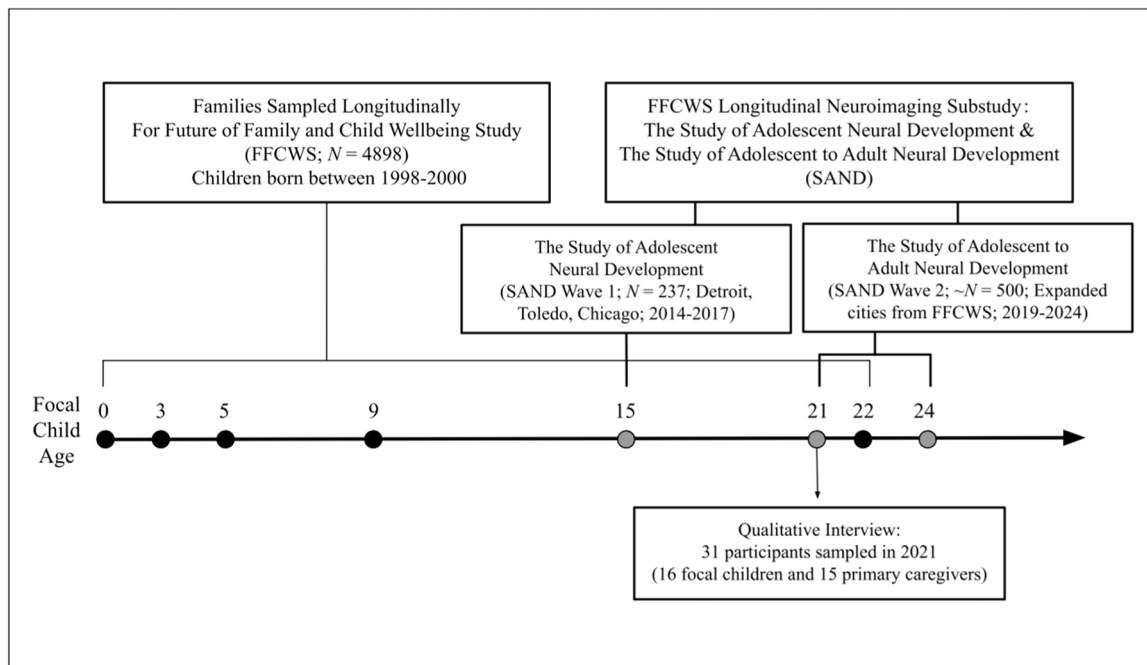


Fig. 1. Study Timeline.

19. The University of Michigan Health & Behavioral Sciences Institutional Review Board (IRB) approved the study procedure with 40 individuals were contacted, and 31 (77.5 %) consented to be interviewed and to be video recorded. The recommended sample size for a qualitative study is, on average, 20 and no more than 50 (Vasileiou et al., 2018). Thus, our sample size falls within the recommendation guidelines ensuring adequate richness and complexity of data.

Out of 31 participants, 84 % ($n = 26$) were from under-represented communities (74 % identifying as Black [$n = 18$], 10 % Hispanic/Latinx [$n = 3$], 3 % Asian [$n = 1$], or 3 % multiracial [$n = 1$]), and/or low socioeconomic status (45.2 % from families below 250 % of the poverty line [$n = 14$]). Fifty-two percent identified as female. Participants were recruited from midwestern cities, including Detroit ($n = 13$), Indianapolis ($n = 6$), Milwaukee ($n = 6$), Toledo ($n = 3$), Chicago ($n = 2$), Pittsburg ($n = 1$). Of the 31 participants, 16 young adults had been followed since birth as part of the FFCWS, and 15 adults/parents had participated as primary caregivers in FFCWS visits. Sixteen participants (6 young adults; 10 primary caregivers) participated in the SAND neuroimaging study (and thus were from Detroit, Toledo, or Chicago) when the young adults were 15–17 between 2014 and 2017. Fifteen participants (11 young adults; 4 primary caregivers) were from families that had participated in the FFCW since their birth (1998–2000) and were eligible to participate in the SAND's upcoming age 21–24 visits but had not yet been invited to participate (young adults only; at this point participation was paused during COVID).

The interview team was led by a Ph.D. candidate in Clinical Psychology at the time who is a Black American male in his late-20s. In addition, five other team members (one undergraduate, two post-undergraduate research staff, and one clinical psychology Ph.D. candidate who are White American females in their early-to-mid-20s, and one undergraduate who is Black American female in her early-20s) conducted the one-on-one interview. Before the team started conducting interviews, the leader of the interview team facilitated a lab-wide, two-part workshop on diversity, equity, and inclusion. The workshop covered several topics, including a session on how individual positionality can influence scientific research, as well as strategies for continuously improving the lab environment in alignment with the values of diversity, equity, and inclusion.

During the interview session, participants were asked 13 open-ended

questions (Supplemental Table 1), with the questions varying based on whether they had completed the neuroimaging portion in the past or were prospective participants for the upcoming neuroimaging study. In our effort to create informative interview questions that effectively capture participants' past experiences and input for future studies, the research team—comprising members with diverse racial-ethnic backgrounds and gender identities and positionalities (research assistants, graduate students, and principal investigators)—collaborated to brainstorm, draft, review and finalize the interview questions. The interviews were conducted in English. Interviewers used verbal cues to establish a more natural conversation with the participants and were instructed to provide open-ended responses as well. They asked follow-up questions if a participant's response was unclear and reiterated questions when clarification was needed.

4. Process for extracting participant-driven recommendations using qualitative data

The transcription process involved three iterations and was carried out by eight team members, which included undergraduate students and post-baccalaureate research assistants (One Asian female, one Asian American female and six White American females in their early-to-mid-20s). To ensure systematic and consistent transcription quality, all transcription team members involved in transcription received standardized training before commencing the process. This training was carried out by a Ph.D. candidate with a Masters degree in Social Work working toward a doctoral joint degree in Social Work and Developmental Psychology (Asian American female in her early 30 s) and one of the principal investigators of the study (White American male in his mid-40s with a Ph.D. in Sociology), prior to the start of the process. Please note that both the Ph.D. candidate and the principal investigator had prior experiences with qualitative research. Following the training, transcription processes involved two steps: initial transcription via auto-transcription of Zoom audio recordings, followed by transcription team members checking the transcription line by line while watching the Zoom video recording. Eight transcribers were organized into three teams, with each team assigned 10–11 interviews for both the initial and second rounds of transcription. In the workflow, Transcriber A from each team first transferred the automated closed captions generated by

Zoom into a Word document. They then meticulously reviewed and edited these captions while playing back the original interviews in a video format. Subsequently, Transcriber B from the same team reviewed the interviews, cross-referenced, and corrected the edits made by Transcriber A. Throughout this process, both transcribers used the "track changes" feature in Word to document their modifications to the original Zoom captions. Finally, the third and final round of transcription was conducted by the remaining two transcribers, who confirmed transcription accuracy and endorsed all revisions made during the process. The final transcriptions captured all spoken words, nonverbal cues, and interruptions during the interviews. Speakers were labeled as 'P' (Participant) and 'I' (Interviewer).

The transcriptions were coded by two research team members involved in the transcription process (an undergraduate Asian female in her early 20 s and a Ph.D. candidate who is an Asian American female in her early 30 s). Using thematic analysis, they identified patterns in participants' responses (Bhattacharya, 2017; Braun and Clarke, 2006). Specifically, participant-driven recommendations were developed through an abductive process (Timmermans and Tavory, 2022), combining deductive (i.e., drawing from existing literature and hypotheses) and inductive (i.e., emerging insights from research assistants' experiences and interactions with participants) approaches. Although quantitative research emphasizes replicability, qualitative research prioritizes the identification of multiple themes across participants' responses (Vasileiou et al., 2018). Therefore, while we provide the number of participants contributing to each theme in this paper, we acknowledge the differing epistemological priorities in qualitative and quantitative research (Small, 2009). In our analysis of the qualitative data, our emphasis was not solely on quantifying how many participants expressed a particular viewpoint but rather on extracting a wide range of insights that reflect the characteristics of their experiences as research participants. In sum, the paper focuses on interview content that amplifies participants' diverse voices in ongoing discussions about increasing diversity in developmental neuroscience.

The process for thematic analysis began with line-by-line coding, identifying key phrases from participants' speech using the highlight feature in the Word document. These phrases were then condensed into codes, categorized based on shared meanings, then grouped into overarching themes. The first coder independently created the codebook with themes using a Word document, and then the second coder checked for accuracy. To ensure inter-rater reliability, in cases of discrepancy, the coders revisit the original transcript and reach a consensus through multiple discussion sessions. The codebook went through several revisions with updated themes. Subsequently, the finalized themes were recorded on the digital copies of transcriptions. Once the themes were established, the coders identified appropriate quotes that best represented each theme. We went through this process to ensure clarity and consistency in themes (Fereday and Muir-Cochrane, 2006). All quotes were identified using a non-identifiable ID system. The first word indicates whether the interviewee was a caregiver ("Caregiver") or who has participated as a child ("Youth"). The second word represents whether the interviewee participated (or was the caregiver of a participant) in the neuroimaging study ("Neuro") or only participated in the non-neuroimaging portion of the study and is invited to participate in a future neuroimaging study ("FutureNeuro"). The numbers, ranging from 1 to 31, were randomly assigned to the interviewees.

5. Participant-driven recommendations to increase diversity in neuroimaging participants

5.1. Overview

Our analysis revealed nine themes. The themes were grouped into participant-driven recommendations for (1) pre-visit, (2) during the visit, and (3) post-visit. Two recommendations pertain to the pre-visit period: 1. Form a diverse research team comprising members with

whom participants can relate and interact as equals; 2. Increase accessibility to research by providing transportation and flexible scheduling. Five recommendations emerged as relevant during the visit: 1. Provide family-oriented space and experiences; 2. Enrich the campus visit to include optional on-campus activities to connect with the University; 3. Develop safe strategies to accommodate participants with tattoos (above the shoulder) during the MRI; 4. Incorporate engaging and interactive tasks during neuroimaging sessions; 5. Provide small gifts in addition to financial compensation. Finally, two recommendations related to the time after the visit: 1. Share findings with the research participants; 2. Foster long-term bidirectional relationships (Table 1).

5.2. Pre-visit

5.2.1. Form a diverse research team composed of members with whom participants can relate and interact as equals

Several participants ($n = 17$) believed that the diversity within the research team is important. One participant (Youth-Neuro14) noted that it was helpful to see that "[the interviewers/research team members] were not too far in age [because] they understood where [the participant] was coming from." Another participant (Youth-FutureNeuro27) said that "having [researchers with] the same ethnicity and race [would make it] easier [to participate]." Participant Youth-FutureNeuro27 also shared that researchers asking for preferred names and pronouns is important, especially for those belonging to LGBTQ+ communities. Caregiver-FutureNeuro19, who identified as a Hispanic caregiver and described herself as not fluent in English, shared that offering a space to speak a language other than English can make research more accessible to participants: "If [the research team has] somebody that speaks my language, it will be better [because it would] help me to address [my thoughts] in my language." Participants shared that researchers should have qualities such as being "personable" (e.g., Caregiver-Neuro7, Youth-Neuro11), "informative" (e.g., Caregiver-Neuro6, Youth-FutureNeuro22), and "welcoming" (Caregiver-Neuro6, Youth-FutureNeuro25). Potential participants in the neuroimaging study suggested that "disrespectful" behavior (e.g., Youth-FutureNeuro21, 24), lack of communication or clarity (e.g., Caregiver-FutureNeuro20, Youth-FutureNeuro29), and "not receiving compensation" (Youth-FutureNeuro30) could potentially contribute to negative experiences. Furthermore, Participants also wanted researchers who are "listening" (Caregiver-Neuro3) and "do not look down at [participants]" (Caregiver-FutureNeuro17). Another participant (Youth-FutureNeuro28) wished for interactions to feel more like a "friendly conversation" rather than an "interrogation":

"[Researchers should] not pressure [participants] when [they] do not want to speak about [certain topics]... It is hard to express your feelings [to] even the people you know and [even] more [so to] people you do not really know. [Allowing participants to] talk [with] freedom [can] just let out whatever emotion [they have]" (Youth-FutureNeuro28).

5.2.2. Increase accessibility via complimentary transportation and flexible scheduling

Participants ($n = 8$) reported that complimentary accommodations, such as transportation and flexible scheduling, are key elements to make the study more accessible. Participant Youth-Neuro23 highlighted that "get[ting] to travel" and "study provided transportation" were the primary reasons for them to recommend participating in the future study to a friend. Further, Participant Caregiver-Neuro3 reinforced that it "was good that it didn't take up a lot of our time during the day." Similarly potential participants of the neuroimaging study ($n = 4$) expressed the importance of researchers being mindful of the time commitment required. They noted that the visit length should be easy to "fit into [their] schedule" (Youth-FutureNeuro21, 28):

Table 1
Participant-driven Recommendations and Possible Steps for Implementation.

	Participant-driven Recommendations	Possible Steps for Implementation
Pre-Visit	Form a diverse research team comprising members with whom participants can relate and interact as equals	<ul style="list-style-type: none"> • Create diverse research teams that reflect participant demographics and lived experiences. • Ask for participants' preferred names and pronouns. • Provide a space where speaking in a language other than English is welcomed.
	Increase accessibility to research by providing transportation and flexible scheduling	<ul style="list-style-type: none"> • Provide complimentary transportation and lodging for participants to travel to research sites. • Ensure the duration of the visit is flexible and considerate of participants' schedules.
During Visit	Provide family-oriented space and experiences	<ul style="list-style-type: none"> • Do not unnecessarily separate children from their caregivers, and if absolutely needed, receive consent from both caregivers and their children. • Have educational resources on parenting available. • Provide childcare support for children during visits. • Offer developmentally appropriate items (toys, video games, laptops) for children and youth to use while they wait. • Provide optional on-campus experiences, such as campus tours and athletic events. • Develop strategies to safely include participants who have been more likely to be ineligible for neuroimaging studies, such as individuals with specific types of tattoos (e.g., above the shoulder, different inks, not done by professional artists, older tattoos) and those with various hairstyles (e.g., wigs, curly, coily, or kinky hair). • Add interactive and gamified approaches to the fMRI tasks.
	Enrich the campus visit to include optional on-campus activities to connect with the University Develop safe strategies to accommodate participants with tattoos (above the shoulder) during the MRI	<ul style="list-style-type: none"> • Show appreciation for participants' contributions with small gifts, such as a picture of their brain, a certificate of participation, and/or University or study-branded "swag" (e.g., t-shirts, stickers)
	Incorporate engaging and interactive tasks during neuroimaging sessions Provide small gifts, such as a picture of their brain, in addition to financial compensation	<ul style="list-style-type: none"> • Make research findings available to participants through personal communication methods (email, physical mail, newsletters, and text messages) and public platforms (social media, websites, expert-led discussions, and broadcasts). • Collaborate with community organizations and policy makers to implement proposed solutions based on research findings.
Post-Visit	Share research findings with the research participants	<ul style="list-style-type: none"> • Establish human connections with participants by asking about their backgrounds and sending birthday cards. • Include opportunities during the research for participants to give
	Foster bidirectional communication	

Table 1 (continued)

Participant-driven Recommendations	Possible Steps for Implementation
	feedback on what topic and questions they believe are important to be asking about.
	"If [the visit] is too long, it's not good for anyone involved because people would want to rush through it, and then the data won't be accurate... Being bombarded [with] interviews can be kind of overwhelming..." (Youth-FutureNeuro27).
5.3. During the visit	
5.3.1. Provide family-oriented space and experiences	
Participants ($n = 10$) appreciated that their visits entailed experiencing a safe space for the whole family. One mother (Caregiver-Neuro6) highlighted the importance of treating the family as one entity:	
"My fear was, 'I hope they do not ask me to just give [my daughter] to them, and they take her off to a separate room to ask her questions or do whatever.' Thankfully, it was never an issue... parents were there with the children" (Caregiver-Neuro6).	
Others valued acquiring new parenting skills; one mother (Caregiver-Neuro3) noted that she had started asking her child the same questions from the survey that the research team had asked her about her family's daily life, attempting to foster open communication with her children regarding their emotions. Concurrently, a few primary caregivers ($n = 3$) expressed a desire to receive additional parenting resources (in addition to the existing resource packets provided by the research team) on educating parents about "different ways of disciplining kids" (Caregiver-Neuro10), providing guidance on "the right socialization for children and parents" (Caregiver-Neuro9) and offering "programs and education on parenting" (Caregiver-Neuro9).	
Primary caregivers who accompanied their children's visits emphasized the importance of providing childcare support for children of all age groups during the visit. Many research participants brought not only the focal youth but also their siblings. Furthermore, some focal youths were also parents and brought their young children along. While primary caregivers appreciated that research team members provided toys for younger children (Caregiver-Neuro2), they suggested, "Teenagers have less patience, and we wish there was something to help with that" (Caregiver-Neuro9). While the research team provided video games and movies for older youth, an individual who previously participated as a teenager suggested that access to "laptops" would be helpful to occupy them (Caregiver-Neuro2).	
5.3.2. Enrich the campus visit experiences by offering optional on-campus activities	
Young adults that participated in the neuroimaging tasks ($n = 6$) appreciated the opportunity to travel to a university campus and foster a connection to the academic institution. Though our team had anticipated that traveling to the university could be a barrier for participants, none of our neuroimaging participants explicitly expressed that traveling to the university campus was inconvenient. One participant recalled their excitement about visiting the campus as a teenager to participate in the neuroimaging study:	
"I was like, this is super cool ...like all the movies ...like science for college... I love that I get to go to Michigan to see the researchers; I think when I came back, that was just a huge thing, especially when you are in high school. It is like, 'Hey, I got to go on a paid trip...' and [classmates were] like, oh my gosh, I want to go [too]... It was just a sweet gig. Everybody was like, that is super great" (Youth-Neuro16).	

While all youth participating in the neuroimaging tasks enjoyed traveling to the university campus, a few including their caregiver ($n = 3$) particularly underscored their wish for more on-campus activities during future visits. They suggested adding optional activities like a campus tour (Youth-Neuro13) or attending a football game (Caregiver-Neuro5) to enrich their overall experience and foster a more personal connection with the campus.

5.3.3. Develop safe strategies to accommodate participants with tattoos during the MRI

Because there is a small possibility that tattoos contain trace amounts of metal, their presence may prevent individuals from being able to participate in MRI studies. In SAND, tattoos above the shoulder are a major criterion for restricting participation. One participant (Youth-Neuro14), now a young adult, expressed disappointment about his inability to participate in scanning as a teenager due to the MRI facility's policy prohibiting scans for individuals with tattoos above their shoulders. This issue continued to arise in the second wave of data collection wave (2019–2024); out of a total of 113 participants who were ineligible for the MRI, 76 % were disqualified due to tattoos on their face, head, or neck. Note that this policy may be specific to the University of Michigan neuroimaging facility, as other facilities have experience with neuroimaging with participants with tattoos above the shoulder (Lohner et al., 2022). We are presently working to resolve this situation.

5.3.4. Incorporate engaging and interactive tasks during neuroimaging sessions

Participants who had engaged in neuroimaging enjoyed interactive fMRI tasks that resembled computer games. Four participants who underwent the scanning spontaneously mentioned their fMRI experiences as the reason for recommending participation in our neuroimaging study to their friends (Youth-Neuro11, 12, 15, 16). Participants from the neuroimaging study emphasized that undergoing the MRI was a "very fascinating" (Youth-Neuro15) experience that they "really liked" (Youth-Neuro15). As MRI scans are often limited and expensive, participants considered these experiences meaningful and valuable (Youth-Neuro11, 15). Moreover, the interactive fMRI tasks utilized during scanning made the neuroimaging procedures enjoyable, as they saw the tasks as being like "games" (Youth-Neuro15, 16). A youth who did not participate in the neuroimaging visit made a similar comment, "Incorporating game elements, modules, or ways to earn points or achievements [would make the research study] more fun and [help] time pass quickly" (Youth-FutureNeuro26).

5.3.5. Give small gifts in addition to financial compensation

One participant (Youth-Neuro15) highlighted that receiving a picture of their brain was a unique souvenir from an unusual experience that they appreciated. Meanwhile, another participant, who was a primary caregiver (Caregiver-Neuro3) hoped to receive a "letter [as the] proof of participation in the study," as they were "very proud of doing [the neuroimaging study]" and wanted to frame and display the certificate on the wall. Outside of the neuroimaging tasks, two participants also mentioned that simple gestures, such as receiving birthday cards each year, can have significant impacts (Caregiver-Neuro3, Youth-FutureNeuro29).

5.4. Post visit

5.4.1. Share findings with the research participants

Participants ($n = 26$) believed researchers should give back to the community by "spread[ing] knowledge in society [and] letting people learn directly from [them]" (Youth-Neuro11). Thus, participants ($n = 24$) urged researchers to collaborate with community organizations and the government to implement proposed solutions based on research findings:

"More researchers can help bring society together... To help us all be one, at peace, and not be so divi[ded]... I feel like researchers can bring so much to the world. They can cause change[s] in how we think, what we are doing, and help us, you know, build [society] together" (Youth-Neuro15).

In addition, all of the participants desired tangible outcomes from their involvement and hoped their participation would lead to social action. They identified that sharing the research findings can be a meaningful first step toward enacting social change:

"I want to see the fruits of my participation. [I would] very [much] appreciate getting the results back in the future... I think that will definitely be useful. Studies don't have to be limited to scientists. If they found something good ...I would want the whole world to know" (Youth-FutureNeuro21).

When asked about their preferred methods of receiving information, twenty-one participants favored more personal communication methods such as email (e.g., Caregiver-Neuro9, Youth-FatherNeuro24), physical mail (e.g., Youth-Neuro13, Youth-FatherNeuro30), newsletters (Caregiver-Neuro4) and text messages (e.g. Youth-FatherNeuro23, 27). In contrast, sixteen preferred receiving information through public platforms such as social media (e.g., Caregiver-Neuro8, Youth-FatherNeuro28), websites (e.g., Youth-Neuro14, Caregiver-FutureNeuro20), expert-led discussions (e.g., Caregiver-Neuro2, Caregiver-FutureNeuro18), and broadcasts (Caregiver-Neuro1), believing these methods could benefit both themselves and a broader audience. One participant (Youth-FatherNeuro27) proposed including hard copies of research information with compensation payments to inform participants about ongoing discussions.

5.4.2. Foster long-term bidirectional relationships

Participants expressed that recognizing them as vital partners in the research study is critical to motivating their engagement over a long period. One way to demonstrate this partnership is by ensuring participants feel cared for as human beings. During interviews, one participant became emotional: "[The researchers] let me know that they were there for me... it was a wonderful experience... and really makes me feel special" (Caregiver-Neuro3). While none of the participants explicitly stated which aspect of the research specifically made them feel supported, some participants ($n = 5$) shared similar experiences in which study participation provided them with strong emotional support (Youth-FutureNeuro31, 29). In this case, note that these visits included research aspects like a psychiatric interview by trained and experienced interviewers, which could be a potential venue for feeling emotional support via listening to the participants past experiences. A few participants ($n = 2$) shared that they felt deeply valued when researchers knew their families' names and personal backgrounds (Caregiver-Neuro7, Caregiver-FutureNeuro17). Conversely, engaging with different recruitment teams over time led to confusion and disengagement (Youth-FutureNeuro23).

Our participants valued the current longitudinal study's approach of avoiding researchers solely contacting participants for data collection without subsequent contact. However, they suggested improvements for a more continuous interactive dialogue and voiced a strong desire to participate in all stages of the research. Most participants ($n = 18$) wanted to stay "informed and educated" (Caregiver-Neuro4) throughout the research process and sought to foster a two-way exchange by integrating their perspectives into research studies. Specifically, when asked about future research topics they wish us to study, participants suggested studying parent-child relationships and parenting (Caregiver-Neuro3, Youth-Neuro13), mental health issues (Caregiver-Neuro4, Youth-FutureNeuroP29), demographic influences on health (Caregiver-Neuro5), coping skills (Caregiver-FutureNeuro19), the effect of child abuse and school bullying, and gang violence (Caregiver-Neuro3, Youth-Neuro13).

6. Implications and conclusion

This perspective paper presents nine participant-driven recommendations for enhancing participant diversity in future neuroimaging studies. Our work complements several published theoretical guidelines (Garcini et al., 2022; Green et al., 2022) by leveraging qualitative data directly from participants in neuroimaging settings. While our empirical findings align well with recommendations from previous theoretical guidelines, our work also identifies areas for further consideration that have not been explicitly or consistently addressed in previous literature.

The two recommendations for research ahead of the visits have been consistently suggested in published theoretical guidelines for improving accessibility to research participation among members of marginalized and under-resourced communities. These include forming a diverse research team composed of members with whom participants can relate and interact as equals (Green et al., 2022; Hattery et al., 2022) and increasing accessibility to neuroimaging lab visits by providing complimentary services around transportation (Arredondo, 2023; Glover et al., 2023), flexible scheduling (Glover et al., 2023; Greene et al., 2016), and creating a welcoming space for speaking in languages other than English (Cross et al., 2024). Additionally, the recommendation to provide family-oriented spaces during the visit aligns with previous work highlighting the importance of offering childcare and child-friendly activities during lab visits (Garcini et al., 2022). Hence, while these are not unique recommendations for working with neuroimaging samples, they are foundational strategies to employ when making efforts regarding participant diversity in research broadly.

The recommendation in regards to formulating a diverse research team aligns with strategies grounded in the cultural humility framework (Garcini et al., 2022; Yeager and Bauer-Wu, 2013), such as respecting participants' positionality, refraining from assuming their identity and viewing research participants as equal partners (Burger et al., 2023; Danso, 2018; Wilson and Neville, 2009). This framework promotes diversity by addressing power imbalances between researchers and participants, creating an equitable and inclusive environment (Foronda et al., 2016). As an example, in our research team, this cultural humility framework extended beyond direct interaction with participants to planning the research itself by identifying overlooked needs of the participants. For instance, researchers of color on the team highlighted the need to sensitively consider the impact of hair when scanning, such as the use of wigs or having curly, coily, or kinky hair. These factors can marginalize members of Black communities from participating in neuroimaging studies, as the hair might potentially exceed the dimensions of the head coil and/or participants might want/expect different accommodations for their hair when participating (Louis et al., 2022).

Moreover, our participants provided several perspectives that complement existing recommendations to diversify neuroimaging participants. First, while theoretical literature suggests using portable scanners to reduce potential barriers (Garcini et al., 2022), among our participants who underwent neuroimaging, visiting the university for MRI appointments was not perceived as a barrier. They valued personal engagement with the university environment, and moreover, both the focal youth/young adults and primary caregivers expressed a desire for additional activities to maximize their time on campus, such as campus tours and athletic events. Further, our findings show that the youth participants (age 15–17) enjoyed scanning, as it included interactive computer game-like tasks that were developmentally appropriate for their age group. This finding suggests the recommendation for employing enjoyable tasks that target the specific age group of the sample (Garcini et al., 2022; Greene et al., 2016; Raschle et al., 2009). Furthermore, our youth participants noted that receiving photos of their brains was a special gift.

Another critical area to consider for increasing accessibility, which, to our knowledge, has not been mentioned in previous guidelines geared to developmental neuroscience research but noted by our participants, is the desire for those with specific tattoos (i.e., above the shoulder,

acquired more than seven years ago, not done by professional artists, or potentially include metal in link) to participate in neuroimaging study. Based on the number of participants who could not participate in scanning and their explicit expression of disappointment, tattoos may be an emerging methodological limitation in neuroimaging studies, at least at our neuroimaging site. Tattoos have become increasingly prevalent, marking a significant shift in societal perceptions (Krutak, 2015; Roggenkamp et al., 2017). Specifically, tattoos are now seen as personalized expressions of marginalized identity (Sims, 2018) and healing from trauma (e.g., sexual trauma, loss of loved ones) (Crompton et al., 2021; Maxwell et al., 2020), particularly among youths and young adults (Cortez, 2013). Therefore, excluding individuals with tattoos above the shoulder may risk removing a significant portion of potential participants with experiences of marginalization and/or trauma (Krutak, 2015; Roggenkamp et al., 2017). Moreover, a recent study reported that among the 5000 participants in their neuroimaging study, none of the individuals with face or neck tattoos showed adverse events during scanning ($n = 130$) (Lohner et al., 2022). While preliminary findings must be replicated, careful and evidence-informed updates regarding scanning individuals with tattoos in safe ways are indicated, especially when working with adolescents and young adults from marginalized backgrounds.

Lastly, our two recommendations for post-visits – sharing findings with the research participants (Adderley-Kelly and Green, 2005; Yancey et al., 2006) and cultivating long-term research-participant partnerships (Adderley-Kelly and Green, 2005; Wilson and Neville, 2009) – align with previous recommendations. Furthermore, our participants underscored the importance of fostering two-way partnerships between research participants and the research lab grounded in a community-engaged framework to reduce the "helicopter research approach" (i.e., researchers approaching the population solely for data collection purposes without subsequent contact) (Burger et al., 2023; Wilson and Neville, 2009). Community-engaged frameworks, such as Community-Based Participatory Research (CBPR), emphasize equal partnership by actively involving both community participants and academic researchers at various stages of the research process (Collins et al., 2018). While a full discussion of CBPR's role—beyond simply engaging communities for research purposes—in developmental neuroscience is outside the scope of this paper, an increasing body of literature provides frameworks for using CBPR to include diverse populations in neuroimaging research (La Scala et al., 2023). Specifically, CBPR can facilitate a greater interdisciplinary collaboration and engagement with higher-risk populations that have been historically underrepresented in biomedical research (Leve et al., 2024). Neuroimaging research teams can further strengthen their work with children, young adults, and families from historically under-represented communities by inviting them to hear their feedback and committing to share research findings with them periodically and outside of the time in which they are being asked to participate. Participants wanted to stay informed and see the "fruit" of their contribution. Hence, shifting from the traditional one-way flow to a more interactive dialogue will enhance the partnerships with the community (Adderley-Kelly and Green, 2005; Burger et al., 2023; Weng et al., 2020).

It is important to consider this study within the context of its limitations, including potential biases such as recall and recruitment bias. For instance, 11 participants reported difficulties recalling exact details from past research interactions during their interviews. Additionally, individuals with positive experiences in previous studies may have been more motivated to participate in this interview-based study, while those with negative experiences may have opted out during recruitment. Lastly, we recognize that each researcher's positionality shapes their worldview, influencing selection of interview questions, approach to thematic coding, and interpretation of the data. Similarly, the positionality of interviewers may have affected social dynamics during interviews, potentially influencing participants' responses.

To advance developmental cognitive neuroscience research, ongoing

efforts are needed to develop participant-driven recommendations to enhance participant diversity by increasing engagement among historically under-represented groups. While our list is not exhaustive, it offers several meaningful guidelines for creating tangible action steps for future research (Table 1). Our findings show that efforts to increase participant diversity through better engagement with neuroimaging research participants may require both significant changes to the research lab, such as implementing a structure to foster two-way communication between the lab and the participants, as well as smaller actions that can have a big impact, such as giving participants brain photos. Our work, along with invaluable future contributions from others in the field, may provide empirical evidence for implementing best practices in neuroimaging studies and will continue to offer a roadmap for enhancing diversity among neuroimaging participants, especially from historically under-represented groups in developmental cognitive neuroscience research.

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CRediT authorship contribution statement

Colter Mitchell: Writing – review & editing, Supervision, Resources, Methodology, Funding acquisition. **Luke W Hyde:** Writing – review & editing, Supervision, Funding acquisition. **Edward D Huntley:** Writing – review & editing, Resources. **Vonnie C McLoyd:** Writing – review & editing, Resources. **Isaiah Sypher:** Writing – review & editing, Resources, Data curation. **Fernanda L Cross:** Writing – review & editing, Supervision, Resources, Methodology. **Sunghyun Hong:** Writing – review & editing, Writing – original draft, Project administration, Methodology, Formal analysis, Conceptualization. **Kefan C Wu:** Writing – review & editing, Writing – original draft, Validation, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Christopher Monk:** Writing – review & editing, Writing – original draft, Supervision, Project administration, Investigation, Funding acquisition, Conceptualization.

Declaration of Competing Interest

The authors report no declarations of interest.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.dcn.2024.101474](https://doi.org/10.1016/j.dcn.2024.101474).

Data availability

Data will be made available on request.

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