ELSEVIER

Contents lists available at ScienceDirect

# Developmental Cognitive Neuroscience

journal homepage: www.elsevier.com/locate/dcn



**Next-Gen Tools** 

# Understanding barriers to adolescent participation in developmental neuroscience research

Emma Renwick<sup>a</sup>, Kristabel Stark<sup>b</sup>, Emily Tan<sup>a</sup>, Jenna Gonzalez<sup>a</sup>, Alexis Brieant<sup>a,\*</sup>

- <sup>a</sup> University of Vermont, Department of Psychological Science, USA
- <sup>b</sup> University of Vermont, Department of Education, USA

#### ARTICLE INFO

Keywords: Representation Qualitative Adolescence Methodology MRI

#### ABSTRACT

Increasing representation of youth in developmental neuroscience research is essential to elucidating neurobiological mechanisms of cognition, behavior, and mental health. However, the field faces critical challenges in optimizing recruitment strategies and reducing barriers to participation among underrepresented populations. To examine these challenges and identify solutions, we employed a qualitative approach to assess barriers to research participation among a sample of adolescents. Data were drawn from semi-structured online focus groups with adolescents in a rural area of the United States. The sample included 20 participants (ages 13–18 years, 65 % female). A subset of questions addressed interest in research participation and potential barriers, and data were analyzed using thematic analysis. Results indicated five key themes: transportation, time, safety, caregiver involvement, and other barriers. Many participants highlighted their reliance on caregivers for transportation, as well as concerns about the overall time commitment of research participation. Misconceptions about magnetic resonance imaging (MRI) contributed to adolescents' hesitancy to participate. Many of these barriers are relevant across research settings, but may be especially salient for youth in rural communities, a population often underrepresented in developmental neuroscience research. Based on the data, we offer potential solutions such as community outreach and education, fair compensation, and community-based partnerships.

# 1. Introduction

The field of developmental neuroscience has grown rapidly over the past several decades, yielding novel insights into the neurobiological mechanisms underlying youth cognition, behavior, and mental health. However, research samples to date have often underrepresented youth from minoritized and underserved populations and overrepresented White participants of high socioeconomic status (Green et al., 2022). Indeed, scientific research broadly has largely relied on western, educated, industrialized, rich, and democratic (WEIRD) samples (Henrich et al., 2010), overlooking the critical importance of participants with diverse identities for capturing the full range of variability in neurodevelopmental processes and mental health outcomes. There are many reasons for these sampling biases in developmental neuroscience and mental health research, including: 1) longstanding mistrust of scientists and academic institutions among marginalized groups due to histories of abuse and exploitation in research (Kibler and Brisco, 2006), 2) reliance on convenience samples drawn primarily from easily accessible populations (Nielsen et al., 2017), 3) logistical barriers to participation (e.g., transportation to collection sites, time commitment) (Woodall et al., 2010), and 4) methodological constraints that limit the inclusivity of study designs and recruitment strategies (Ricard et al., 2023)

Many of these challenges are relevant across different research settings; however, some may be especially pronounced for youth in rural communities. Youth from rural communities experience unique stressors, sources of adversity, and forms of marginalization relative to youth in urban contexts, which may contribute to distinct patterns of neurodevelopment and mental health outcomes. Despite evidence for variability in sociocultural contexts and developmental processes across youth from different geographic regions (e.g., Brieant and Burt, 2025), there remains a lack of developmental neuroscience research conducted with rural youth. Given that the majority of biomedical studies are conducted at universities and research centers in urban areas, rural communities have been drastically underrepresented in neuroimaging research (Feyman et al., 2020; Sterling et al., 2022). Further understanding the barriers to research participation faced by youth in rural as well as urban areas is imperative in order to gain a more holistic

<sup>\*</sup> Correspondence to: University of Vermont, 338 Dewey Hall, 2 Colchester Ave., Burlington, VT 05405, USA. E-mail address: alexis.brieant@uvm.edu (A. Brieant).

understanding of variability in youth development, and to offer researchers crucial insight into how to increase representation of youth in future research.

Barriers to ensuring representation in developmental neuroscience research are present across each stage of the research process, from study design to recruitment, data acquisition, and interpretation and dissemination of findings (Ricard et al., 2023). Careful planning in the earliest stages of study development (i.e., before data collection) is crucial to expanding access to participation, and recruitment strategies should be tailored to the population of interest and involve intentional outreach efforts. Neuroscience research has historically failed to recruit within rural communities and populations with diverse racial, ethnic, and economic backgrounds (Dhamala et al., 2025; Wu et al., 2024). Instead, studies have disproportionately relied on homogenous samples (primarily White middle-income youth) due to systemic measurement and sampling biases (Nketia et al., 2021). These biases compromise the external validity of the research, despite frequent assumptions of generalizability. Notably, the existing body of evidence in developmental neuroscience to date has been constructed almost exclusively on youth from urban or suburban settings, and it remains unclear whether many established findings would replicate among youth with different residential and sociodemographic backgrounds.

Although these challenges are increasingly recognized within the field and addressed in discussions of study limitations, there remains a pressing need for research that directly engages youth to better understand their perspectives on research participation and to identify concrete, community-informed strategies to promote more equitable opportunities for participation. Historically, when researchers recruit participants, youth voices and perspectives are rarely considered beyond their participation. Consequently, researchers may unintentionally design studies that lack appeal or do not feel inclusive to youth. While other disciplines have longstanding histories of community-engaged research, these practices have only recently been adopted in developmental neuroscience as a promising approach to reducing participation barriers, increasing representation, and enhancing the relevance and translational impact of research. A wide spectrum of communityengaged practices can be implemented to facilitate these goals (see Brown, 2022 and Parade et al., 2024 for relevant reviews). As one example, research teams can develop community advisory boards to solicit feedback and co-design studies (Moreno et al., 2021). Several developmental neuroscience research teams have developed strong models for advisory boards (e.g., La Scala et al., 2023). However, past work has almost entirely involved adult community members, and there are limited examples of youth advisory boards in developmental neuroscience. Hearing directly from youth about their lived experiences, motivations, and concerns about research involvement is crucial for understanding and reducing barriers to participation.

As the field has reckoned with issues of representation and equity in neuroscience research, there have been a growing number of commentaries and reviews addressing key challenges and proposed solutions. However, only one existing study (to our knowledge) has used a datadriven approach to understanding barriers and facilitators to developmental neuroscience research participation (Wu et al., 2024). In this study, a subset of participants (including a mix of caregivers and children from underrepresented racial or socioeconomic backgrounds) were recruited from the Future Families and Child Wellbeing Study. Through qualitative interviews and thematic analysis, nine participant-driven recommendations emerged, centered on topics such as transportation and scheduling, diversity of research teams, and incentives for participation. These findings offer valuable solutions for enhancing recruitment, engagement, and retention strategies in developmental neuroscience research. However, such studies have primarily sampled youth who were already enrolled in research studies, many of whom had prior experience participating in neuroimaging protocols. As a result, the perspectives of youth who may have declined participation (or who were never reached in the first place) remain largely unexplored.

Understanding the viewpoints of these individuals is critical for addressing systemic barriers to participation and for designing more inclusive research practices. Achieving this goal requires a proactive approach, engaging youth outside the context of ongoing studies to solicit their perspectives on neuroimaging research participation more broadly, including their potential concerns, motivations, and suggestions for improvement.

We assert that a first step in expanding youth research participation is to engage directly with youth themselves to better understand their perspectives, motivations, and concerns. To systematically examine these perspectives, characterize key challenges, and identify youth-centered solutions, we employed a qualitative approach to assess barriers to research participation among a sample of adolescents in a predominantly rural state in the northeast region of the United States.

# 2. Method

# 2.1. Study setting & context

Data were collected as part of a larger qualitative study, the Conversations About Resilience and Early-life Stress (CARES) study, which involved online semi-structured focus groups with adolescents in the state of Vermont (northeastern US). An online format was used to minimize barriers to participation, particularly for adolescents who resided in locations far from the university. We recruited youth from across the state to ensure the inclusion of rural community members. Vermont is the most rural state in the US, with over 60 % of the population residing in rural areas (U.S. Census Bureau, 2023).

The CARES Study included a list of specific open-ended questions to guide each session. The study protocol encompassed a broad range of topics, and facilitators allowed the conversation to evolve towards topics participants found most salient. Questions addressed topics including teen mental health, lived experiences of stress and adversity, sources of resilience, and barriers to participation in research. The questions were posed to all participants within each session and were worded such that participants could share personal experiences or subjective observations about adolescents more generally. The present study focuses on the final section of the interview, which was dedicated to questions about barriers to research participation and participants' willingness to participate in on-site research at our institution (see Appendix A for list of questions used in this analysis).

# 2.2. Participants

To be eligible for participation, adolescents had to be 13-18 years of age and currently residing or attending school in the state of Vermont. Twenty-one adolescents participated in the study; after data collection, we excluded one participant from analysis due to concerns about caregiver influence during the session, resulting in an analytic sample of 20 adolescents. Prior work suggests that 20 participants is the average recommended sample size required to reach saturation, the point at which gathering new data does not generate new information or themes (Vasileiou et al., 2018). In the final sample, participants ranged from 13 to 18 years of age (M = 15.50, SD = 1.47). Participants were asked to identify their sex assigned at birth, in addition to their self-reported gender identity; the sample included adolescents assigned male at birth (35%) and assigned female at birth (65%), with 30% self-identifying as transgender or non-binary. Adolescents primarily identified as White (75%) and Black or African American (20%); the remaining participants held other identities (withheld for confidentiality due to small sample size). Based on current U.S. Census data, the sample was representative of the state in which we conducted the research in terms of White and Black or African American participants, while the Hispanic or Latine community was underrepresented (U.S. Census Bureau QuickFacts, 2024). Participants identified their perceived socioeconomic positioning using the MacArthur Scale of

Subjective Social Status (Adler et al., 2000). This scale presents an image of a ladder with 10 rungs and the following description: "Think of this ladder as representing where young people stand in your school, neighborhood, or community. At the top of the ladder are the young people who have the highest standing. At the bottom are those who have the worst standing." They were then instructed to click on the rung that best represented their perception of their social standing. The average score within the sample was 6.37, which is above reported national averages (Cardel et al., 2018). Based on Rural-Urban Commuting Area (RUCA) and Core Based Statistical Areas (CBSAs) codes, the sample included a mix of adolescents from rural communities (32 %) and from urban communities (68 %).

# 2.3. Procedures

We used convenience sampling methods to recruit participants through three main channels: social media, distribution of information in schools, and posting physical flyers across the state. We compensated adolescent participants for their time with \$25 Visa gift cards. Prior to data collection, we obtained written informed consent from all adolescents who were 18 years of age. Written informed consent was obtained from the caregivers of adolescents < 18 years, as well as informed assent from the adolescents.

We conducted the semi-structured focus groups (and one interview) with a total of 21 adolescents. Trained research assistants facilitated the 8 groups (2–3 participants per session) and 1 interview (1 participant), each approximately 1 h in length. Sessions ranged from 41 min to 68 min, ( $M=51\,\mathrm{min}$ ). All sessions were held online via Microsoft Teams and were audio and visual recorded with the permission of participants. Following the focus group, participants completed a brief online demographic survey. All procedures were approved by the university's Institutional Review Board (IRB).

#### 2.4. Analytic approach

After each session concluded, it was transcribed orthographically using the automatic caption generation function through Microsoft Teams. Trained research assistants cleaned and corrected all transcriptions for accuracy. All raw data were then deidentified, and any identifiable personal information was redacted before analysis began. We began by extracting data related to our central research question: 'What are the barriers to adolescent participation in research?' This included participants' responses to six questions from the study protocol pertaining to participants' prior research experience and perceived barriers to research participation.

A subset of members from the author team, including a postbaccalaureate research assistant and two assistant professors, used thematic analysis to analyze the data (Braun and Clarke, 2006). Following standard thematic analysis procedures, we began by familiarizing ourselves with the data. We organized the questions and participants' responses by session number and read through all extracted data to familiarize ourselves with the responses, writing independent memos regarding potential codes that might help us sort the data. The team then met to discuss initial memos and inductive codes. Once we identified preliminary codes across all nine study sessions, we used inductive coding (i.e., coding based on the raw data without pre-determined categories) to organize the data and to examine emergent themes. Two of the authors developed the initial themes, then refined them in collaboration with a third author. We returned to the data to search for any disconfirming evidence (i.e., data points that contradicted the emerging themes), and to ensure that the selected themes captured all participants' voices. In this process, we noticed that there were many intersections among the themes and coded for these intersections across emergent themes.

#### 2.5. Efforts to increase trustworthiness and reliability

Throughout the research process, we engaged in various efforts to increase trustworthiness and reliability. We intentionally assigned undergraduate research assistants to conduct the focus groups so that the age difference between facilitators and participants would be minimal. We hoped that this would create an environment in which participants felt more comfortable engaging authentically and asking clarifying questions about the process if needed. Indeed, one participant (P11) indicated the age of the research assistants was a benefit, stating "... because you guys are kind of... [the] same age... for me going to lab, I would love to talk to someone that's the same age with me."

In addition, our research team included members with distinct positionalities in regard to the research topic, which provided us with a variety of lenses from which to interpret the data. Specifically, our team includes one post-baccalaureate and six undergraduate research assistants, an Assistant Professor of Education with expertise in qualitative research, and the lead investigator, an Assistant Professor in Developmental Psychology. Our team holds a wide range of diverse identities, varying across racial/ethnic, gender, and geographic backgrounds, with each team member providing their own unique perspective and positionality throughout the data collection and analysis process. Our team members are from diverse locations within the United States, all outside of the geographic area of our sample population. To ensure that all team members' perspectives were valued, we provided time for open discussion during weekly team meetings. As a team, we employed reflexivity throughout all study stages to remain conscious of our positionality and potential biases to minimize their effect. We created space for communication between team members during all phases of the study. We further aimed to increase trustworthiness and reliability by including as many direct quotes as possible within the findings reported below. Finally, we provided participants with an opportunity to review our initial findings to ensure that we represented their experiences and perspectives accurately. None of the participants requested changes to our interpretation of the data.

#### 3. Results

Most participants reported that they had never participated in oncampus research before; only one described having prior experiences as a research participant. When asked if they would be interested in traveling to campus to participate in future research, the majority (60 %) expressed that they would be interested (others responded maybe, not applicable, or did not directly respond to the question). Several participants expressed being motivated to participate in research as a social good. For example, P17<sup>1</sup> said, "I think yes, because mainly I feel like it's kind of like an important topic to... know about for other people, so like they have more knowledge to understand [and] to help others." Additionally, P9 stated, "I guess I would be because it's for a good cause." Another participant shared that participating in research would provide an opportunity to "see the college and the opportunity to take a look, if you wanna go" (P18). Despite their motivation to participate in research, youth described a variety of potential barriers to future participation. In the following sections, we provide a summary of these barriers, organized into five overarching themes: transportation, time commitment, safety, caregiver involvement, and "other barriers" (summarized in Fig. 1 and Table 1).

# 3.1. Transportation as a barrier

Many adolescents shared that transportation to the research site

 $<sup>^1</sup>$  Direct quotes are provided for transparency, but deidentified for confidentiality. For the purposes of reporting, each participant is assigned a number 1–20 and labeled as "P#" in text.

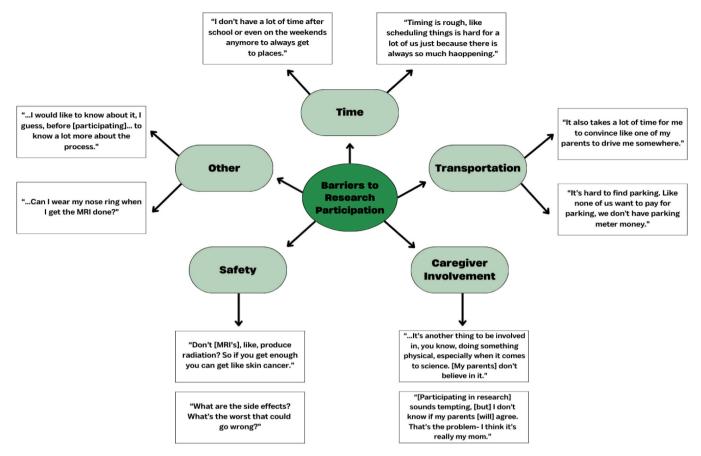


Fig. 1. Five primary themes identified through thematic analysis, including exemplary quotes from participants.

would be a barrier to their participation in research studies. For example, many participants highlighted their reliance on caregivers for transportation-P3 explained, "I can't drive, I am 14!" P16 stated, "It also takes a lot of time for me to convince like one of my parents to drive me somewhere," with another stating that a barrier for their peers would probably be "getting a ride" (P5). A few participants mentioned that the timing of the study would impact their ability to get transportation. For example, P6 explained, "If it was at the same kind of time as [this session, a lot of parents aren't just down to, you know, drop a kid off at this time." Similarly, P7 stated, "Unless it's a weekend, my parents wouldn't normally drive me over at this time [of day]." P16 also mentioned that they would participate "as long as it's on the weekend or something, not during the week, because I do not live in the area." Participants also mentioned financial costs or other barriers related to transportation; for example, P8 said, "It's hard to find parking. Like none of us want to pay for parking, we don't have parking meter money."

## 3.2. Time as a barrier

A second overall barrier was the time it would take to participate in research. This included concerns about the overall time commitment of research participation, scheduling of research activities, and time needed for transportation to and from the research site. Many participants emphasized that adolescents generally have busy schedules. P8 shared, "Timing is rough, like scheduling things is hard for a lot of us just because there is always so much happening." Another participant explained, "Also, just like extracurriculars, like I have a lot of stuff like after school." The same participant said, "I would want to [participate]. I'm just really busy so I don't know if I'd be able to" (P13). However, P15 noted that, "If a date is given to me a few months in advance or even a few weeks in advance, I'm pretty sure I could probably make it work." Likewise, P6 stated, "I'd be down for [participating]. I think your being

open to everyone's schedules is probably the best thing you could do. Just have flexibility on times and stuff." Participants also mentioned that the time it takes to travel, in addition to their already busy schedules, created a barrier. P16 said, "I don't have a lot of time after school or even on the weekends anymore to always get to places." P3 added, "It takes me an hour to get to [campus], so it would be 2 hours [of travel] to do a social experiment."

# 3.3. Safety concerns as a barrier

The third overall barrier was safety. Concerns regarding safety as a barrier to research participation primarily surfaced when adolescents were probed to consider participation in MRI research. We first asked youth if they had ever heard of MRI and if they knew how MRI worked. Of those who responded, fourteen had heard of MRI and three had not. One elaborated that they had heard of it through media; four had personal or familial experience. Few of the youth had a clear understanding of what an MRI is, and many emphasized their need for increased understanding of the technique before considering participation. Many had inaccurate perceptions of the function of MRI, indicating varying degrees of misinformation. For example, P3 said, "Don't they, like, produce radiation? So if you get enough you can get like skin cancer." However, one participant clearly and accurately defined the technique (P8).

Some adolescents were explicitly against participating in this type of research: P11 emphasized, "I'm really scared... so I will not offer [to participate]." Others expressed feelings of fear, for example: "That kind of stuff, just usually like freaks me out a little, just in general" (P13). Many had further questions about the safety of the technique. P17 asked, "Can the MRI radio waves cause anything?" When asked whether they would have concerns about participating in neuroscience research that uses MRI, there was significant variability in their responses. Many

**Table 1** Primary themes and suggested solutions.

| Theme   | Exemplar Quotes   | Possible Solutions *Relevant citations  |
|---|---|---|
| Time Challenges related to scheduling and time commitments involved in participating.                             | <ol> <li>"I would want to [participate]. I'm just really busy so I don't know if I'd be able to," (P13)</li> <li>"Timing is rough, like scheduling things is hard for a lot of us just because there is always so much happening." (P8)</li> </ol>  | <ul> <li>Provide childcare for other children during data collection.</li> <li>Ensure fair compensation.</li> <li>Emphasize the value and importance of their participation. This can be done both during participation as well as after, through clear dissemination of research findings.</li> <li>*Zgierska et al. (2024)</li> </ul>   |
| Transportation Issues with obtaining transportation to the research site.   | <ol> <li>"It also takes a lot of time for me to convince like one of my parents to drive me somewhere," (P16)</li> <li>"It's hard to find parking. Like none of us want to pay for parking, we don't have parking meter money." (P8)</li> </ol>   | <ul> <li>Provide compensation for travel expenses, including any parking costs</li> <li>Consider alternative imaging methods, such as functional near-infrared spectroscopy (fNIRs), that can be transported directly to communities to offer more accessible opportunities for participation.</li> <li>*Jasińska and Guei (2018)</li> </ul>  |
| Safety  Concerns about safety of research techniques, such as neuroimaging.                                       | <ol> <li>"Don't they, like, produce radiation? So if you get enough you can get like skin cancer." (P3)</li> <li>"What are the side effects? What's the worst that could go wrong?" (P18)</li> </ol>  | <ul> <li>Invest in creating valuable relationships with members of the community to increase trust and reduce various concerns.</li> <li>For example: attending local community events, educational outreach at high schools or parenting groups, accurately explaining potential risks and safety features of various research techniques.</li> <li>Acknowledge concerns and assure participants of relevant safety precautions.</li> <li>*Randolph et al. (2022); Wu et al. (2024)</li> </ul> |
| Caregiver Involvement Issues related to caregiver permission or assistance that may limit ability to participate. | <ol> <li>"It's one thing to go there and talk. It's another thing to be involved in, you know, doing something physical, especially when it comes to science. [My parents] don't believe in it." (P1)</li> <li>"I don't really live with like a stable parent or guardian, so I would have trouble with transportation," (P15)</li> </ol> | <ul> <li>Strive to build relationships with caregivers of potential participants.</li> <li>Create open dialogue for questions about risks and benefits of research participation.</li> <li>Minimize time and transportation burden.</li> <li>*La Scala et al. (2023); Reck et al. (2025)</li> </ul>   |
| Other Other limitations to research participation, such as uncertainty or logistical concerns.                    | <ol> <li>"Isn't [the machine] enclosed? Yeah, I think I'd be a little claustrophobic! I'd have anxiety about being stuck," (P14)</li> <li>"can I wear my nose ring when I get the MRI done?" (P16)</li> </ol>   | <ul> <li>Create nonjudgemental opportunities for participants to voice logistical concerns about study participation.</li> <li>In MRI studies, this may include concerns such as claustrophobia, jewelry removal, and the experience of being inside an MRI.</li> <li>Provide clear information about what to expect during study visits to give participants a sense of comfort and predictability.</li> </ul>   |

participants voiced apprehension about potential risks, for example, "What are the side effects? What's the worst that could go wrong?" (P18). However, other participants voiced little to no concern about participating in MRI research; for example, "If it doesn't cause cancer, I don't care." (P3).

# 3.4. Caregiver involvement as a barrier

Another overall barrier involved caregiver involvement. Many participants expressed that the involvement of their parent or caregiver may be a significant barrier to their research participation, for various reasons. Some of the adolescents mentioned that obtaining caregiver consent may be a barrier, even if they wanted to participate. For example, one participant voiced concern about their caregivers' belief and trust, or lack thereof, in science and research broadly: "It's one thing to go there and talk. It's another thing to be involved in, you know, doing something physical, especially when it comes to science. [My parents] don't believe in it." (P1). Additionally, caregivers' schedules and ability or desire to aid in the transportation of their children to participate in research was frequently mentioned. P15 stated, "I don't really live with like a stable parent or guardian, so I would have trouble with transportation 'cause the [bus system] is not great." P1 also explained, "I think my biggest problem would be cars and my parents because I kind of stay with my siblings."

# 3.5. Other perceived barriers

Participants expressed various other concerns about research participation that did not clearly fall within the other themes. This included logistical concerns, such as claustrophobia when participating in research using MRI. For example, P14 explained, "Isn't [the machine] enclosed? Yeah, I think I'd be a little claustrophobic! I'd have anxiety

about being stuck... I could probably do it, [but] I'd be anxious about it." Some of the participants had questions and concerns about the process of participating in research using MRI. For example, P6 asked, "...what's the duration of, you know, a session for one?" They also asked about accommodations during MRI, stating, "Are we able to listen to music ..." (P15) and "...can I wear my nose ring when I get the MRI done?" (P16).

Participants also expressed that not fully understanding how the research procedures worked would make them nervous to participate. For example, P19 explained, "I like to know about something before I [participate] especially if it's something like that... I would like to just know about it, I guess, before [participating]... to know a lot more about the process." Likewise, P20 clarified, "I just don't know much about [MRI research]. Which I think is kind of a big one in my opinion, since I don't really know what it is at all."

#### 3.6. Intersections across themes

The barriers that were described across the five themes had some clear intersections. The most prominent intersection occurred between the themes of transportation, caregiver involvement, and time. Many of the adolescents expressed that their transportation was dependent on their caregivers and their schedules. P19 said, "Yeah. For me, it's just like finding a time 'cause, my mom also has a busy schedule, and then also just transportation, finding a way to get there." Another participant noted, "My dad lives pretty close [to campus], so I can just go to his house...[but] he just has a very busy schedule" (P20). Additionally, for some participants, time, transportation, and caregiver involvement were inextricably linked, as they lived far enough away that it would require both the participant and their families to adapt their schedules. For example, P13 stated, "Yeah. I mean... like my parents wouldn't really be able to drive me for multiple days since it's like an hour and a half or two hours..."

#### 4. Discussion

Understanding youths' perspectives and concerns related to research participation is crucial to developing strategies to minimize barriers and increase representation. In this study, we explored adolescents' views on barriers to participation in developmental neuroscience research. Through qualitative thematic analysis of focus group and interview data with twenty youth participants, we identified five overarching themes: 1) transportation, 2) time constraints, 3) safety concerns, 4) caregiver involvement, and 5) other logistical concerns.

Our findings highlight the range of challenges that youth may face when considering whether to participate in developmental neuroscience studies. First, transportation and associated financial burdens were primary limitations to adolescent research participation. Participants described various contributing factors, including their inability to drive or access a vehicle, limited public transportation options, and the cost of parking. These logistical challenges are common in studies that require participants to travel to a designated research site, but pose particular difficulties for developmental neuroscience, where many leading methodologies (e.g., MRI, electroencephalography (EEG)) necessitate specialized equipment that is either immobile or challenging to bring to participants. Whenever possible, researchers should consider finding alternate methods of transportation for facilitating travel, such as bussing or compensating for taxi/car share services. Additionally, we recommend including funding in research budgets for supporting adolescents and families with associated costs of travel (e.g., gas per mile driven, parking) as a solution to this barrier.

Transportation-related factors may have been particularly salient in our sample, given that participants resided in a largely rural area with limited public transit options. Youth living in urban and suburban areas typically have more access to options such as public busses, metros, or reliable taxi and rideshare services. This is not the case in most rural areas of the US, and these factors have likely contributed in part to the underrepresentation of rural communities in biomedical research broadly (Feyman et al., 2020). Despite these challenges, there are successful models for developmental MRI research in non-urban areas of the US (e.g., Brody et al., 2017; Kim et al., 2013; Kim-Spoon et al., 2019). However, given the known barriers, future research may consider alternative imaging methods that can be transported directly to communities, such as functional near-infrared spectroscopy (fNIRs), which offers valuable opportunities for reaching rural communities and conducting in-field developmental neuroscience research (Jasińska and Guei, 2018).

The time commitment required to engage in research was also a common barrier voiced by adolescents. Adolescents have myriad demands on their time and attention, and are occupied by schoolwork, extracurriculars and hobbies, and socializing (Ferrar et al., 2013), and may find it difficult to prioritize research in their schedules. Thus, it is important for researchers to ensure flexible and varied scheduling options, working with participants and their families to minimize the effect of this barrier. Researchers can also identify ways to support families who are interested in dedicating their time to research participation; for example, providing childcare for non-participating children during data collection.

Despite certain limitations, MRI remains one of the leading methodologies for imaging the developing brain due to its non-invasive nature and high spatial resolution. Thus, we focused on adolescents' perceptions and knowledge of MRI. Safety concerns were a prominent theme that emerged, and many participants expressed uncertainty or apprehension related to MRI. While these concerns are understandable, they were largely driven by misinformation or misunderstanding. For example, several participants expressed concerns about adverse health effects. This is consistent with (albeit limited) prior empirical evidence that has illustrated heightened perceptions of risk associated with MRI. For example, in one study, 24 % of adult participants believed that MRI exposed people to radiation and 30 % were unsure (Kohlasch et al.,

2021). When asked if MRI was safe for children, over 40 % reported that it was not or that they were unsure. Communicating with youth and their families about the safety of research methods is vital for recruiting and retaining participants, especially those from underrepresented backgrounds. Thus, we recommend that researchers invest in community building and educational outreach in order to accurately explain potential risks and safety features of various research techniques, while creating valuable relationships with community members and potential future participants. For example, researchers may want to attend local community events and engage with families, with a focus on building trust and educating youth and caregivers about research methods such as MRI. These initiatives would also provide opportunities to discuss the other types of logistical concerns that adolescents in our study raised, such as claustrophobia, jewelry removal, and the experience of being in an MRI.

Developmental neuroscience research poses unique barriers given that the population of interest is typically minors. Not only are minors often reliant on their caregivers for transportation (as described above), but they require a caregiver's consent to participate. Our findings indicated that this may be a barrier, as caregivers may not have time or interest to facilitate participation or may have mistrust in science. Thus, it is critical to also facilitate multi-pronged engagement efforts that emphasize building relationships with caregivers of potential participants and adults in the community, in addition to youth, and work with them to minimize burdens and clarify the risks and benefits of research participation.

Our findings complement and build upon recent findings from Wu et al. (2024), who interviewed 31 participants from the FFCWS, a longitudinal study in large U.S. cities. In both studies, participants emphasized a need for representative research teams, scheduling and transportation accessibility, and increased educational information and resources for participants and families. Wu et al. highlighted additional findings, such as the perceived value of visiting the university campus, emphasis on creating a family-oriented environment, and importance of fostering bidirectional communication with participants and the research team. These themes were not represented in our data, likely in part due to the "research-naïve" nature of our participants. In contrast to Wu et al., none of the youth in our sample had ever participated in a neuroimaging study, and only one participant reported prior experience participating in research of any type. Thus, our findings emphasize the key barriers and opportunities perceived by those who are new to research participation, while also representing the voices of youth in more rural geographic areas. Together, the results from these two studies suggest a range of strategies that can be tailored to participants with varying backgrounds and levels of familiarity and experience with research.

Within the field of developmental neuroscience, there are emerging efforts to increase community engaged work to address many of these barriers. For example, the "Community Engagement and Education (CEEd) Core" out of the Masonic Institute for the Developing Brain (MIDB) at the University of Minnesota (UMN) employs a listening model to center community voices and build trusted relationships, and has codeveloped numerous programs with their community partners (Randolph et al., 2022). At the University of Georgia, the Building Resilience and Nurturing Children's Health (BRANCH) study is employing similar techniques within a predominantly rural population. In the early stages of this study, researchers have established a Family and Community Engagement (FACE) team, who lead engagement initiatives to foster positive and trusting relationships between the local community and the research team (Reck et al., 2025). On a larger scale, the national Adolescent Cognitive Brain Development (ABCD) Study has created a community advisory board of stakeholders, both young people and families, that work alongside researchers to create and disseminate research initiatives (Auchter et al., 2018). These models exemplify the value of enmeshed community liaisons that support high participant retention and quality data, while fostering long term relationships

within the community. Research teams should also consider using unique and engaging dissemination techniques to maintain relationships with youth community members and demonstrate the products of their research participation. For example, researchers can post informative graphics and short form videos via social media or publish developmentally appropriate articles in youth-focused outlets such as "Frontiers for Young Minds" (e.g., Broadhouse, 2019).

#### 4.1. Limitations and future directions

There are several limitations to our study that should be considered. First, while we recognize the value of targeted recruitment strategies that maximize representation from different groups, this study primarily relied on a convenience sample. While qualitative research often prioritizes "information-rich" cases over probability sampling (as is typically used in quantitative research), this approach does limit the generalizability of our findings. While we sought to elevate the experiences of rural youth, we did not exclusively recruit from rural zip codes and thus only about a third of the sample qualified as rural according to US Census Bureau metrics. However, the broader context of the study setting is predominantly rural, and the urban areas represented in our sample are quite small (i.e., small towns rather than large metropolitan areas). In ongoing and future quantitative research, we are working to implement a range of strategies that are known to enhance representation, including cultivating community partnerships, building trust with youth and their families, and engaging in reciprocity through efforts such as public dissemination, outreach, and education (Rowley and Camacho, 2015).

Second, the group format of the study may have impacted the results. We used focus groups as opposed to individual interviews to allow youth participants to feel more comfortable contributing to the conversation, reduce pressure to respond, and provide opportunity to build on each other's points. However, the group format may have also increased the likelihood of peer influence on their responses, and some participants may have felt more hesitant to share certain personal details with peers that they did not know. Offering varied modes of participation based on individual preferences may be a valuable opportunity for future work. Additionally, the focus group protocol questions were designed to be broad in order to be applicable to all participants. This may have limited our ability to probe specific differences between youth in more rural versus urban geographic areas. Future research will benefit from a more targeted approach with an exclusively rural sample to further explicate these unique experiences.

Third, the perspectives of youth in our study may differ in meaningful ways from youth in other contexts. While many of the experiences and concerns raised by youth in our geographic area of the northeastern United States may resonate broadly, communities are highly heterogeneous. Our study sampled youth in this particular geographic context and does not represent all populations and experiences. For example, our sample had a high proportion of femme and transgender/non-binary identifying participants. State-level demographics indicate a higher proportion of LGBTQ+ identifying individuals relative to most other areas in the United States, which may explain the high representation of this group within our sample (Williams Institute at UCLA School of Law, 2019). Further, subjective SES was slightly above national averages, and the barriers reported by participants in this sample may be different or exacerbated in a sample with greater socioeconomic disadvantage. Thus, we acknowledge that our findings and recommendations may not apply uniformly across youth in different settings and emphasize the importance of understanding the unique needs and concerns of each community and individual.

While these historical barriers in developmental neuroscience research have posed challenges, there is rich opportunity to implement new methodologies and research practices in future work. As one example, there is increasing emphasis on the importance of community-engaged research (CEnR) practices and applications in developmental

neuroscience (Foster et al., 2024). There are many ways to implement these practices, for example, through community based participatory research (CBPR), where researchers and community members share power and responsibility of research questions, the application of results, and the dissemination of findings. Within CBPR, partnerships are integral to the research process, and rely on reciprocal transfer of expertise between both parties that intends to create mutually beneficial relationships (La Scala et al., 2023). The inclusion of youth in CBPR practices promotes equity by integrating the voices of youth from underrepresented populations, which in turn generates more impactful research and representative findings (Offiong et al., 2023). Our findings highlight the need for trusted relationships with researchers, as adolescent participants emphasized that feeling comfortable with the research team had an impact on their willingness to participate and remain involved in the future. Our findings also emphasize the need for long-term engagement with young people and their communities. Researchers should allot resources specifically for building relationships within the community, as it can impact long term retention and support data interpretation within studies. For example, in addition to time spent within the community, researchers may want to create community advisory boards that take part in all stages of study development and execution, providing firsthand input. This includes community input on the interpretation of research findings, ensuring that results are properly contextualized. Increased uptake of these types of methods in developmental neuroscience would have benefits for both researchers and youth participants (McCarry, 2012) and facilitate new solutions to common barriers to research participation.

#### 5. Conclusion

Critical examination of barriers to participation in developmental neuroscience research represents an essential first step toward the development and implementation of youth-centered, equity-focused strategies. The findings from this study highlight several key areas where researchers might reduce participation burdens and concerns, including transportation, time, caregiver involvement, and safety. Proactively integrating strategies to address participation barriers within study design holds significant potential to advance a more inclusive developmental neuroscience. Such efforts may enhance the field's capacity to engage rural communities and minoritized populations, thereby broadening the representativeness and generalizability of research findings.

# CRediT authorship contribution statement

Emma Renwick: Writing – review & editing, Writing – original draft, Visualization, Investigation, Formal analysis, Data curation. Emily Tan: Project administration, Investigation, Conceptualization. Kristabel Stark: Writing – review & editing, Writing – original draft, Methodology, Formal analysis. Alexis Brieant: Writing – review & editing, Writing – original draft, Resources, Project administration, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. Jenna Gonzalez: Project administration, Formal analysis, Data curation, Conceptualization.

# Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used "ChatGPT by OpenAI" in order to improve clarity and readability of text. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

# **Declaration of Competing Interest**

The authors declare the following financial interests/personal

relationships which may be considered as potential competing interests: Alexis Brieant reports financial support was provided by National Institute of Mental Health. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Acknowledgements

We are grateful to the youth who participated in this study. We thank research assistants Alexa Divers, Rachel Lamb, and Avinabo Poddar for their contributions to this work. This work was supported by a grant from the University of Vermont Office of the Vice President for Research. AB is supported by 2L40MH131146–02.

# Appendix A

Protocol for facilitation of interview and focus groups.

| Question 1   | Have any of you ever participated in a research study with the University of Vermont before this one?  |
|--------------|--|
| Question 1.1 | If you don't live in Burlington, would you be interested in traveling here to participate in research that takes place on UVM's campus? Why or why not?          |
| Question 1.2 | What barriers would make it difficult to participate in research on UVM's campus?  |
| Question 1.3 | Have you ever heard of MRI? Does anyone know how it works?   |
| Question 1.4 | What questions or concerns would you have about participating in neuroscience research that uses MRI?  |
| Question 1.5 | What do you think psychologists and neuroscientists should focus on in their research with people your age? What topics do you think are most important and why? |

#### Data availability

Data are not posted publicly due to the small sample size and personal nature of the qualitative data transcripts. Data may be available upon request.

#### References

- Adler, N.E., Epel, E.S., Castellazzo, G., Ickovics, J.R., 2000. Relationship of subjective and objective social status with psychological and physiological functioning: preliminary data in healthy, White women. Health Psychol. 19 (6), 586.
- Auchter, A.M., Mejia, M.H., Heyser, C.J., Shilling, P.D., Jernigan, T.L., Brown, S.A., Dowling, G.J., 2018. A description of the ABCD organizational structure and communication framework. Dev. Cogn. Neurosci. 32, 8–15.
- Braun, V., Clarke, V., 2006. Using thematic analysis in psychology. Qual. Res. Psychol. 3 (2), 77–101. https://doi.org/10.1191/1478088706qp063oa.
- Brieant, A., Burt, K.B., 2025. The Protective Role of Community Cohesion Across Rural and Urban Contexts: Implications for Youth Mental Health. Adolescent Mental Health
- Broadhouse, K.M., 2019. The physics of MRI and how we use it to reveal the mysteries of the mind. Front. Young Minds 7, 1–7.
- Brody, G.H., Gray, J.C., Yu, T., Barton, A.W., Beach, S.R.H., Galván, A., MacKillop, J., Windle, M., Chen, E., Miller, G.E., Sweet, L.H., 2017. Protective prevention effects on the association of poverty with brain development. JAMA Pediatr. 171 (1), 46–52. https://doi.org/10.1001/jamapediatrics.2016.2988.
- Brown, N., 2022. Scope and continuum of participatory research. Int. J. Res. Method Educ. 45 (2), 200–211. https://doi.org/10.1080/1743727X.2021.1902980.
- Cardel, M.I., Tong, S., Pavela, G., Dhurandhar, E., Miller, D., Boles, R., Haemer, M., 2018. Youth subjective social status (SSS) is associated with parent SSS, income, and food insecurity but not weight loss among Low-Income hispanic youth. Obesity 26 (12), 1923–1930. https://doi.org/10.1002/oby.22314.
- Dhamala, E., Ricard, J.A., Uddin, L.Q., Galea, L.A.M., Jacobs, E.G., Yip, S.W., Yeo, B.T.T., Chakravarty, M.M., Holmes, A.J., 2025. Considering the interconnected nature of social identities in neuroimaging research. Nat. Neurosci. 28 (2), 222–233. https:// doi.org/10.1038/s41593-024-01832-y.
- Ferrar, K., Chang, C., Li, M., Olds, T.S., 2013. Adolescent time use clusters: a systematic review. J. Adolesc. Health 52 (3), 259–270. https://doi.org/10.1016/j. iadohealth.2012.06.015.
- Feyman, Y., Provenzano, F., David, F.S., 2020. Disparities in clinical trial access across US urban areas. JAMA Netw. Open 3 (2), e200172. https://doi.org/10.1001/ jamanetworkopen.2020.0172.
- Foster, J.C., Hodges, H.R., Beloborodova, A., Cohodes, E.M., Phillips, M.Q., Anderson, E., Gee, D.G., 2024. Integrating developmental neuroscience with community-engaged approaches to address mental health outcomes for housing-insecure youth: implications for research, practice, and policy. Dev. Cogn. Neurosci. 68, 101399.
- Green, K.H., Van De Groep, I.H., Te Brinke, L.W., van der Cruijsen, R., van Rossenberg, F., El Marroun, H., 2022. A perspective on enhancing representative samples in developmental human neuroscience: connecting science to society. Front. Integr. Neurosci. 16. https://doi.org/10.3389/fnint.2022.981657.
- Henrich, J., Heine, S.J., Norenzayan, A., 2010. The weirdest people in the world? Behav. Brain Sci. 33 (2–3), 61–83. https://doi.org/10.1017/S0140525X0999152X.

- Jasińska, K.K., Guei, S., 2018. Neuroimaging field methods using functional near infrared spectroscopy (NIRS) neuroimaging to study global child development: rural Sub-Saharan Africa. J. Vis. Exp. JoVE (132), 57165. https://doi.org/10.3791/57165.
- Kibler, J.L., Brisco, K., 2006. Evaluation of a brief questionnaire for assessing barriers to research participation. Ethn. Dis. 16 (2), 547–550.
- Kim, P., Evans, G.W., Angstadt, M., Ho, S.S., Sripada, C.S., Swain, J.E., Liberzon, I., Phan, K.L., 2013. Effects of childhood poverty and chronic stress on emotion regulatory brain function in adulthood. Proc. Natl. Acad. Sci. 110, 18442–18447. https://doi.org/10.1073/pnas.1308240110.
- Kim-Spoon, J., Deater-Deckard, K., Brieant, A., Lauharatanahirun, N., Lee, J., King-Casas, B., 2019. Brains of a feather flocking together? Peer and individual neurobehavioral risks for substance use across adolescence. Dev. Psychopathol. 1–14. https://doi.org/10.1017/S0954579419001056.
- Kohlasch, K.L., Cioffredi, L.-A., Lenninger, C., Stewart, E., Vatalaro, T., Garavan, H., Graham, A., Heil, S.H., Krans, E.E., Robakis, T., Rommel, A., Sullivan, E.L., Thomason, M., Potter, A., 2021. Factors associated with parent views about participation in infant MRI research provide guidance for the design of the healthy brain and child development (HBCD) study. Dev. Cogn. Neurosci. 50, 100986. https://doi.org/10.1016/j.dcn.2021.100986.
- La Scala, S., Mullins, J.L., Firat, R.B., Emotional Learning Research Community Advisory Board, & Michalska, K. J. (2023). Equity, diversity, and inclusion in developmental neuroscience: Practical lessons from community-based participatory research. Frontiers in Integrative Neuroscience, 16. (https://www.frontiersin.org/articles/10.3389/fnint 2022 1007249)
- McCarry, M., 2012. Who benefits? A critical reflection of children and young people's participation in sensitive research. Int. J. Soc. Res. Methodol. 15 (1), 55–68. https://doi.org/10.1080/13645579.2011.568196.
- Moreno, M.A., Jolliff, A., Kerr, B., 2021. Youth advisory boards: perspectives and processes. J. Adolesc. Health 69 (2), 192–194. https://doi.org/10.1016/j. jadohealth.2021.05.001.
- Nielsen, M., Haun, D., Kärtner, J., Legare, C.H., 2017. The persistent sampling bias in developmental psychology: a call to action. J. Exp. Child Psychol. 162, 31–38. https://doi.org/10.1016/j.jecp.2017.04.017.
- Nketia, J., Amso, D., Brito, N.H., 2021. Towards a more inclusive and equitable developmental cognitive neuroscience. Dev. Cogn. Neurosci. 52, 101014. https:// doi.org/10.1016/j.dcn.2021.101014.
- Offiong, A., Willis, K., Smith, B.D., Lewis, Q., Portee-Mason, D., Glover, D., Burton, M., Powell, T.W., 2023. Maintaining community-engaged research with young people in a virtual setting. Prog. Community Health Partnersh. Res. Educ. Action 17 (2), 329–337. https://doi.org/10.1353/epr.2023.a900213.
- Parade, S.H., Jennings, E., Huffhines, L., Rojo-Wissar, D.M., Caron, C., Berger, B., Stroud, L.R., Tyrka, A.R., 2024. Community-engaged research: bringing the science of developmental psychopathology into the real world. Dev. Psychopathol. 1–8. https://doi.org/10.1017/S0954579424001020.
- Randolph, A.C., Henry, A., Hewitt, A., Mejia, A.P., Sethuraju, R., DeJoseph, M., Fair, D. A., 2022. Creating a sustainable action-oriented engagement infrastructure—a UMN-MIDB perspective. Front. Integr. Neurosci. 16, 1060896.
- Reck, A., Holley, L., Bower, K., Whitaker, S., Hall, C., Brown, C., Oshri, A., 2025. Building trust in rural communities: recruitment and retention strategies in developmental science. Front. Public Health 13, 1586988.
- Ricard, J.A., Parker, T.C., Dhamala, E., Kwasa, J., Allsop, A., Holmes, A.J., 2023. Confronting racially exclusionary practices in the acquisition and analyses of neuroimaging data. Nat. Neurosci. 26 (1), 4–11.
- Rowley, S.J., Camacho, T.C., 2015. Increasing diversity in cognitive developmental research: issues and solutions. J. Cogn. Dev. 16 (5), 683–692. https://doi.org/ 10.1080/15248372.2014.976224.

- Sterling, E., Pearl, H., Liu, Z., Allen, J.W., Fleischer, C.C., 2022. Demographic reporting across a decade of neuroimaging: a systematic review. Brain Imaging Behav. 16 (6), 2785–2796. https://doi.org/10.1007/s11682-022-00724-8.
- The Williams Institute. (2019, January). LGBT demographic data interactive. UCLA School of Law. (https://williamsinstitute.law.ucla.edu/visualization/lgbt-stats/).
- U.S. Census Bureau. (2023). Urban and rural. U.S. Census Bureau. (https://www.census.gov/programs-surveys/geography/guidance/geo-areas/urban-rural.html).
- U.S. Census Bureau. (n.d.). QuickPacts: Vermont. U.S. Census Bureau. Retrieved March 18, 2025, from (https://www.census.gov/quickfacts/fact/table/VT/PST045224).
- Vasileiou, K., Barnett, J., Thorpe, S., Young, T., 2018. Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. BMC Med. Res. Methodol. 18 (1), 148. https://doi.org/10.1186/s12874-018-0594-7.
- Woodall, A., Morgan, C., Sloan, C., Howard, L., 2010. Barriers to participation in mental health research: are there specific gender, ethnicity and age related barriers? BMC Psychiatry 10 (1), 103. https://doi.org/10.1186/1471-244X-10-103.
   Wu, K.C., Hong, S., Cross, F.L., Sypher, I., McLoyd, V.C., Huntley, E.D., Hyde, L.W.,
- Wu, K.C., Hong, S., Cross, F.L., Sypher, I., McLoyd, V.C., Huntley, E.D., Hyde, L.W., Mitchell, C., Monk, C.S., 2024. Increasing diversity in neuroimaging research: Participant-driven recommendations from a qualitative study of an underrepresented sample. Dev. Cogn. Neurosci. 70, 101474. https://doi.org/10.1016/j. dcn.2024.101474.
- Zgierska, A.E., Gramly, T., Prestayko, N., Downs, D.S., Murray, T.M., Yerby, L.G., Howell, B., Stahlman, B., Cruz, J., Agolli, A., Horan, H., Hilliard, F., Croff, J.M., Consortium, the Heal. B. and C. D. (HBCD), 2024. Transportation, childcare, lodging, and meals: key for participant engagement and inclusion of historically underrepresented populations in the healthy brain and child development birth cohort. J. Clin. Transl. Sci. 8 (1), e38. https://doi.org/10.1017/cts.2024.4.