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# Recruitment of hard to contact, hard to engage child populations in clinics and schools

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ABSTRACT

Recruiting children with chronic disease or subgroups of children (low income, obese, specific ages, types of cancer) from clinics and schools for research studies may be particularly difficult. While some have deemed such groups as hard to reach, these groups may be more accurately described as either hard to contact or hard to engage. This is not because children are unknown to the school or clinic but because the researcher's ability to communicate directly with targeted children prior to enrollment is limited. The purpose of this paper is to describe barriers and possible strategies for recruiting hard to contact or hard to engage subgroups of children. Barriers identified in recruiting these children were: naïve to research, communication style and technology, parent/guardian burden, parental conditions and concerns, child stressors and distractions, and research setting. Possible strategies include: pre-consent education, information sheets about study, identifying preferred method of communication, meaningful and appropriate incentives, coordinating recruitment visit with regularly scheduled clinic appointments or school schedule, demonstrating research equipment, informing staff about research study, negotiating creatively for space for research, and emphasizing confidentiality of data. Consideration of barriers to recruitment and utilization of strategies to counteract these barriers is critical to the success of a study involving subgroups of children.

## 1. Introduction

Recruitment of participants is essential to the success of any prospective research study. This may be particularly difficult when recruiting children with chronic diseases (e.g., sickle cell disease (SCD), cancer, diabetes), conditions such as attention-deficit/hyperactivity disorder (ADHD), or subgroups (obese, low income, specific ages, specific type of cancers) from clinics or schools. While some have deemed such groups as 'hard to reach' (Cooper, Levay, Lorenc, & Craig, 2014; Shaghaghi, Bhopal, & Sheikh, 2011; Steinman, Hammerback, & Snowden, 2015), these groups are more accurately described as either hard to contact or hard to engage (Sinclair & Alexander, 2012). Recruiting subgroups of children may be especially difficult given that they are hard to contact even in sites where a researcher has access, not because the children are unknown to the clinic or school but because the researcher's ability to communicate directly with targeted children is limited. Since contacting the children is difficult and involves interaction with the parents/guardian, it is also hard then to engage the children in the research. The purpose of this paper is to describe barriers and possible strategies for recruiting hard to contact or hard to engage subgroups of children. Examples from the authors' studies with these subgroups of children are used as exemplars (Table 1) to illustrate barriers and strategies.

## 2. Barriers

Barriers identified in previous studies of hard to engage populations are: decreased access (Kauffman et al., 2013), conflicts with parental employment (Lebensburger et al., 2013), mistrust of researchers (Kaiser et al., 2017; Lebensburger et al., 2013; Steinman et al., 2015), costs of participation (Kaiser et al., 2017), transportation challenges (Lebensburger et al., 2013; Wallace & Bartlett, 2013), participant burden due to research study oversaturation (Powers, 2007), lack of on-site research space (Mishna et al., 2012), and difficulty in contacting parents for consent (Lamb et al., 2001; Mishna et al., 2012). Some lesser-known barriers identified in our studies fall within seven domains: naive to research, communication style and technology, parent/guardian burden, parental conditions and concerns, child stressors and distractions, and research setting (Table 2). Some barriers were unique to the population or research setting, sometimes causing delays in the early stages of recruitment and the overall duration of the studies.

### 2.1. Naive to research

Not being aware of the research process on the part of parents and/or children was evident in some studies. Parental characteristics, such as age, income, and cultural background, may influence participation, and low-income parents are less likely to consent (Boccia et al., 2009). Parents often did not discuss participation with their children prior to the consenting process. For this reason, children sometimes refused to participate as was evident in the ADHD (Gray, 2017) and SCD (Soistmann & Rice, 2017) studies. In addition, some child participants gave assent based on parental encouragement rather than understanding study requirements or having the desire to participate. This was particularly apparent in the ADHD (Gray, 2017) and cancer survivor (Johnson, 2016) studies. Understanding who could give consent

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**Table 1**
Exemplar studies with hard to reach, hard to contact children.

| Study | Population(n) | Setting | Recruitment Strategies/Incentives (IRB approved) |
|---|---|---|---|
| Sleep hygiene and ADHD (Gray, 2017) | Child (Kaiser, Thomas, & Bowers, 2017; Lebensburger et al., 2013; Mishna, Khoury-Kassabri, Gadalla, & Daciuk, 2012; Powers, 2007; Wallace & Bartlett, 2013)/parent dyads or triads (n = 27) | Schools, clinics | Face-to-face meetings with principals; Flyers, Phone calls, Parental Letters, School social media Meetings with ADHD support groups<br>Incentives (Cooper et al., 2014): Child-restaurant gift card, Parents-gift card |
| Factors that influence blood pressure (Rice, Turner-Henson, Hage, et al., 2017) | Child (Kauffman et al., 2013; Shaghaghi et al., 2011; Sinclair & Alexander, 2012)/parent dyads (n = 56) | Head Start Centers | Flyers; Face to face meetings with parents; Collaboration with Directors; Communication with teachers<br>Incentives (Cooper et al., 2014): child – developmentally appropriate book, parent - cash |
| Prepubertal children diagnosed with type 1 diabetes for at least 1 year (Davis, 2017) | Child (Boccia, Campbell, Goldman, & Skinner, 2009; Kaiser et al., 2017; Lamb, Puskar, & Tusaie-Mumford, 2001; Mishna et al., 2012; Powers, 2007; Wallace & Bartlett, 2013)/mother dyads (n = 30) | Pediatric endocrinology clinic | Calls, texts, letters, flyers, referrals from health care providers<br>Incentives (Cooper et al., 2014): Cash for mothers, toys/games for child, restaurant gift card to use during break in data collection |
| Stress, sleep disturbance and fatigue in SCD (Soistmann & Rice, 2017) | Child (Boccia et al., 2009; Gray, 2017; Lamb et al., 2001; Mishna et al., 2012; Powers, 2007; Soistmann & Rice, 2017; Wallace & Bartlett, 2013)/parent dyads (n = 30) | Hematology clinic | Telephone calls (1 week prior and 1 day prior to clinic appointment), chart/schedule review, referral from provider<br>Incentives (Cooper et al., 2014): Cash given to the child participant and to the parent to compensate time and travel |
| Stress, fatigue and sleep in CNS cancer survivors (Johnson, 2016) | Child (8–12)/parent dyads (n = 21) | Neuro oncology clinic | Provider referral<br>Clinic roster review<br>Incentives (Cooper et al., 2014): Retail gift cards both child and parent |

was sometimes problematic and delayed recruitment, especially if the legal guardian was not a parent. Negative parental perceptions of informed consent language can influence participation in studies so it was important to clarify risks and benefits of participating in research studies (Cico, Vogeley, & Doyle, 2011).

### 2.2. Communication style and technology

The added layer of interacting with school or clinic personnel and the methods and devices used to communicate with parents (in person, telephone, email or text) can affect recruitment. Contact with parents or guardians prior to contacting potential child participants is required in all studies with children; however in school and clinic-based studies, researchers must communicate with school officials or clinic personnel before approaching parents and/or children (Davis, 2017; Gray, 2017; Johnson, 2016; Rice et al., 2017; Soistmann & Rice, 2017). Communicating information about the study either physically in waiting rooms/lobbies or on social media or websites requires approval and assistance by clinic and/or school officials adding to the time of the recruitment process.

Accessing parents and guardians by telephone, text, or email proved difficult (Davis, 2017; Gray, 2017; Johnson, 2016; Rice et al., 2017; Soistmann & Rice, 2017). Telephone issues included out of service phone numbers and voice mailboxes, parents not answering because incoming number was not familiar or answering and not having time to talk. Challenges also arose with text and email. Messages were returned because email addresses/phone numbers were not current or texting service not available (Rice et al., 2017; Soistmann & Rice, 2017).

Security concerns and regulations also affect how researchers communicate with parents. In some cases, clinic sites have security regulations that require parental consent and registration to communicate by email or text. In other instances, sites (Johnson, 2016; Soistmann & Rice, 2017) require researchers to obtain a secure e-mail address to communicate with staff or patients regarding appointment times and initial screening details (e.g. age and diagnosis).

Similar difficulties arise with the use of the electronic medical records (EMR). A researcher may have access to a participant's chart from a clinical, ethical, or institutional review board perspective, but logistically cannot log in because he/she does not have access. Staff have to log in and obtain data for researchers, adding burden to staff members and delaying researchers. This was particularly true for the clinic-based studies (Davis, 2017; Johnson, 2016; Soistmann & Rice, 2017).

### 2.3. Parent/guardian burden

Parents and/or legal guardians of children with chronic conditions (e.g., SCD, diabetes, ADHD) or who have survived serious illnesses such as cancer, may be experiencing financial difficulties making participation in research difficult (Johnson, 2016). These difficulties may be compounded by the large geographic catchment area of medical centers, causing many families to travel long distances for clinic visits (Johnson, 2016). To help families avoid an extra trip to the clinic, the consenting appointments were often coordinated with a scheduled appointment which decreased trips but increased the length of time at the clinic, further burdening families (Davis, 2017; Johnson, 2016; Soistmann & Rice, 2017).

### 2.4. Parental conditions and concerns

Chronic conditions of the parent or guardian and parental concerns about the child participating in research can also influence recruitment. For example, parents with ADHD may have trouble keeping scheduled recruitment appointments (Gray, 2017). In other instances, the focus of the research (e.g., maternal depression (Soistmann & Rice, 2017)) may make parents less inclined to participate. Other parental concerns that may cause reluctance include time commitment to participate in the research (Davis, 2017), the invasiveness of study procedures such as blood draws (Rice et al., 2017) or the use and storage of the child's biological samples (Davis, 2017; Rice et al., 2017). In addition, fear of inadvertent disclosure of confidential information to school or clinic personnel, evident in the ADHD (Gray, 2017) study, can preclude some parents from enrolling their child in research.

### 2.5. Child stressors and distractions

Worry regarding procedures, tests, schedule disruptions, missed extracurricular activities or school exams, and effects on school performance may influence a child's willingness to enroll and participate in

**Table 2**
Barriers and Strategies Parent/Child Recruitment.

| Theme | Barriers | Strategies |
|---|---|---|
| Naive to research | Parents not preparing their child for participation | Pre-consent education for child and parents (Davis, 2017; Gray, 2017). |
| | Child refusal due to lack of information | Information sheet about study purpose, procedures and requirements of parents and child (Davis, 2017; Gray, 2017; Soistmann & Rice, 2017). |
| | Determining legal guardianship for consent | Confer with staff to determine legal guardian. |
| | Parental concern regarding invasive study procedures; storage and use of biological samples | Providing simple demonstrations of specimen collection and storage (Soistmann & Rice, 2017). |
| Communication style and technology | Parental access to texting, email, phone | Identify preferred method of communication early and obtain permission to communicate in that manner (Davis, 2017; Gray, 2017; Soistmann & Rice, 2017). |
| | Parental permission and response to mail | Provide business card with study title and researcher contact information (Boccia et al., 2009; Soistmann & Rice, 2017). |
| | Security/regulation of electronic communication related to research including social media recruitment | Keep text information to a minimum (Davis, 2017; Gray, 2017). |
| | | Review institutional regulations regarding electronic communication. |
| | Participants not responding to/answering unknown incoming phone numbers | Suggest participants add the researcher as a "contact" in their personal electronic device. |
| | Inability to obtain current mailing address | Update parent contact information at each encounter. |
| Participant Burden | Large geographic catchment area of medical centers and clinics can present financial and travel difficulties | Meaningful and appropriate incentives linked to the mission of the research setting or the purpose of the research (Davis, 2017). |
| | Coordination of family/researcher schedules | Coordinate research appointment with regular clinic visits (Davis, 2017; Soistmann & Rice, 2017). |
| | | Bundle data collection to decrease time commitment; allow home data collection if appropriate (Davis, 2017; Gray, 2017). |
| Parental conditions and concerns | Parental disclosure of their own diagnosis of ADHD, depressive symptoms during the research process. | Emphasize confidentiality of parental data disclosed as part of research process (Davis, 2017; Gray, 2017). |
| | Parent conditions impacted ability to participate and keep appointments | Adjust consenting procedures to accommodate parental conditions (Boccia et al., 2009). |
| | Worry regarding time commitment/stigma/disclosure of child diagnosis | Ensuring that text messages do not include specifics about child diagnosis or other health information (Gray, 2017). |
| Child stressors and distractions | Worry regarding procedures, tests, schedule disruptions, missed extracurricular activities or school exams, and effects on school performance | Allow parents to use familiar terminology to allay child's concerns (Davis, 2017). |
| | | Avoid recruiting and consenting on the same day as intensive medical studies or school exams (Soistmann & Rice, 2017). |
| | Parent fears projected to children (fingerstick) | Explain procedure with parents and allow them to stay with child during procedure (Davis, 2017; Rice et al., 2017). |
| | Child lack of knowledge of measurements/procedures | Demonstrate equipment and use puppets to explain procedures (Davis, 2017). |
| Research Setting | Using non-research personnel to assist with logistics of studies | Educate staff about goals of research and the research procedures (Davis, 2017; Soistmann & Rice, 2017). |
| | Academic calendar coordination | Obtain academic calendar and school activities calendar prior to recruitment (Gray, 2017). |
| | Shared space | Be aware of space limitations and negotiate creatively for space for recruitment and consent (Davis, 2017; Soistmann & Rice, 2017). |
| | Lack of access to medical records | Obtain credentialing to have a separate login for database access to medical records, etc. (Davis, 2017; Soistmann & Rice, 2017) |
| | Lack of access to a clinic/school schedule prior to the day of recruitment effort | Identify a staff contact to relay information about updated schedule (Soistmann & Rice, 2017). |
| | Missed appointments/school absences | Ensure correct family contact information Plan for return visits for recruitment if absent or inclement weather (Davis, 2017). |
| | | Continuous contact with staff about schedule updates (Soistmann & Rice, 2017). |
| | | Develop an inclement weather plan. |

research (Soistmann & Rice, 2017). Children may also feel stigmatized if participation requires them to be a part of a special subgroup such as children with ADHD (Gray, 2017) or being obese. Parents may withhold consent because they do not want (Johnson, 2016; Powers, 2007) to further stress children with participating (Davis, 2017; Rice et al., 2017; Soistmann & Rice, 2017).

### 2.6. Research setting

Researchers are highly dependent upon stakeholders in clinics and schools for assistance in recruitment. The assistance can increase staff workload, potentially without compensation or dedicated time (Rice et al., 2017). Additionally, staff may not agree with the research procedures, aims, or outcomes (Sullivan-Bolyai, Bova, Deatrick, et al., 2007). Even without active assistance in recruitment, staff may have to coordinate data collection around existing clinic and diagnostic appointments or class schedules. In addition, limitations in space may contribute to difficulty obtaining buy-in from staff in schools and clinics and cause a lack of privacy for consenting or data collection (Davis, 2017; Johnson, 2016; Soistmann & Rice, 2017).

Other unforeseen circumstances related to the research site can affect the rate of recruitment and enrollment. Long travel distance, natural disasters and inclement weather causing school closures and families cancelling appointments can challenge coordination of recruitment visits (Davis, 2017; Rice et al., 2017; Soistmann & Rice, 2017). In the preschool study, some recruitment visits were cancelled three times due to weather (Rice et al., 2017). In addition, low clinic volume and/or changes in systems such as the implementation of a new EMR system can influence recruitment (Davis, 2017; Soistmann & Rice, 2017).

## 3. Strategies

### 3.1. Naïve to research

Family naivety of the research process, including knowledge about

informed consent and assent may vary. Strategies to address families' research naivety include providing a summary about the study to children and parents/guardians by mail or email prior to consent. Simplified information sheets outlining the research process, as well as the consenting process (informed consent, assent), help to clear up confusion or misunderstanding. Clear and concise information on the risks, costs and benefits, considering parental characteristics (e.g., income, cultural background, literacy) will aid the parents in the decision-making process (Boccia et al., 2009; Cico et al., 2011; Nabulsi, Khalil, & Makhoul, 2011).

Parents naïve to the research process should be educated on the research process, including the informed consent process and assent process. Investigators should promote shared decision making between the parent(s) and child, as well as using developmentally appropriate language, taking into account the child's cognitive development, maturation, and previous experiences respecting the child's emerging autonomy (Katz et al., 2016). For example, when obtaining assent from a school-age child, the researcher should not assume literacy level, and read aloud a statement that asks the child to verbalize yes or no about joining the study, letting them know that they can quit the study at any time; it is up to them.

The informed consent is a process in which investigators should use non-value laden language in consent documents, taking into account parental perceptions (Cico et al., 2011), allowing adequate time for an exchange of information, and providing adequate time for parents to comprehend the consent form (Boccia et al., 2009; Nabulsi et al., 2011). In the parent consent process, investigators should explain key scientific terms in lay language and standard informed consent components (e.g., mandatory child abuse/neglect reporting, and payment of research related injuries, costs, etc.). Further, they should, allow parents the time to comprehend the benefits to the child, and discuss a realistic, non-inflated view of the risks (Johnson, Leek, Drotar, et al., 2015; Nabulsi et al., 2011). For example, research that includes painful procedures needs to include a discussion of the relevance of the procedures to the child (Nabulsi et al., 2011). In addition, researchers can spend time during telephone screening interviews explaining how consent and assent will be obtained, detailing what data collection will involve, and determining who can consent for the child (i.e., parents and/or legal guardian) (Davis, 2017; Rice et al., 2017).

Along with research staff contacting potential participants, it is helpful for familiar clinic or school personnel to reach out to parents and children. Previous studies have noted parent and child participants are mistrustful of researchers at some stages of the research process (Barakat, Patterson, Mondestin, et al., 2013; Blom-Hoffman et al., 2009; Branson, Davis, & Butler, 2007; Kaiser et al., 2017; Lebensburger et al., 2013; Steinman et al., 2015). Having familiar staff introduce the idea of research, perform some education about the research process, or introduce the researcher could build trust between family and researcher (Johnson, 2016; Soistmann & Rice, 2017). However, investigators should be aware of the possibility of coercion or acquiescence, and emphasize that the participation decision will have no effect on their relationship with the site.

### 3.2. Communication style and technology

Since a primary barrier is lack of communication, strategies to improve communication between researchers, parents, and children are vital. Identification of a preferred communication method (e.g., phone, text, email, in person), best times for communication, and verification of contact information early in the recruitment process can facilitate efficient communication between researcher and participants. Obtaining a separate, dedicated telephone line with a local area code specifically for research or printing business cards with researcher contact information may also be beneficial as was noted in the SCD study (Soistmann & Rice, 2017). Mitchell and colleagues (Mitchell, Schwartz, Alvanzo, et al., 2015) report success in study retention rates by using participants' cell phones for voicemail and text messages.

Researchers may also consider initially meeting participants face-to-face in a location familiar to and safe for the participants such as the clinic, the child's school, or a public library (Gray, 2017). While meeting in-person, researchers can give families the phone number or address from which research communication will come, thus easing doubt about the veracity of the researcher or mistrust of unfamiliar calls or mail. Subsequent communication can then be conducted through text messages or email if participants so desire. Care in these communications must be taken to only refer to meeting times and locations in unsecure text messages and not to include information about the study or the children's diagnosis (Mitchell et al., 2015).

### 3.3. Parent/guardian burden

Strategies for easing parent/guardian burden must be flexible and respectful of families' schedules, time and finances. If families travel considerable distances to meet a researcher, incentives such as gas gift cards or cash may help to cover travel costs. Researchers may also provide incentives (ex. videos, games, books) that could make car travel with a child more pleasant (Johnson, 2016). Strategies that demonstrate consideration of families' busy schedules include scheduling recruitment and consent procedures to coincide with a clinic visit (Davis, 2017; Johnson, 2016), prior to the start of the school day (Rice et al., 2017), or on weekends (Davis, 2017). In addition, providing restaurant gift cards sufficient to feed the adult and child while they are participating in a research study, recruiting and collecting data at locations convenient for the participants or via telephone can decrease participant burden (Davis, 2017). Other researchers have used such strategies as allowing parents to bring non-participant siblings along on study visits to decrease need for alternate childcare or setting up valet parking (Nicklas et al., 2016). Recognizing the many demands on families' time and attention can create an empathetic bond between researcher and family and predispose the families to participate in the study.

### 3.4. Parental conditions and concerns

Parent conditions such as ADHD (Gray, 2017) and depression (Davis, 2017) and parental concerns about their child's right to confidentiality may affect willingness to participate in research. To address parent conditions, researchers should emphasize the confidentiality of the parent data and, if necessary, adjust the consenting process to accommodate parent conditions. In the ADHD study, the researcher emailed a copy of the consent to parents so they would have time to review before the consent visit (Gray, 2017). To counter parent concerns about confidentiality, researchers may consider recruiting and obtaining consent and assent away from the school or clinic setting or after normal operating hours. Also, continuously ensuring confidentiality by reminding parents that data collected are not identified by names and will not be shared with staff unless the IRB protocol dictates (such as in times of regulatory audits or risk for suicidality) may be helpful.

Providing simple demonstrations or videos of how specimens will be collected may help alleviate parental fears and facilitate recruitment. Ensuring parents that a trusted member of staff, such as a clinic nurse or teacher, or they themselves can be present during procedures may also help alleviate anxiety and make them more likely to enroll (Rice et al., 2017), Decreasing child burden in the research, such as collecting data over several days, may make parents more likely to consent for child participation. This was particularly helpful in decreasing child burden in the school setting while not requiring extra parental trips to the school (Rice et al., 2017).

### 3.5. Child stressors and distractions

Meaningful and thoughtful incentives for the child may be

beneficial to decrease stress and provide distraction during the study consent/assent appointment (Schoeppe, Oliver, Badland, Burke, & Duncan, 2014). These incentives, including developmentally appropriate games, books, and/or snacks, can be used to entertain children and/or siblings while the family learns about the study or signs consent/assent. Another strategy to reduce child anxiety of unknown research procedures is to let the child handle research equipment or use a mannequin to demonstrate research procedures. If possible, the researcher should also consider letting the parent stay with the child for the duration of study procedures. Finally, the researcher should be aware of school schedules and planned clinic procedures to decrease child anxiety and burden. These strategies were instrumental in recruiting children in the diabetes (Davis, 2017), preschool (Rice et al., 2017), and SCD (Soistmann & Rice, 2017) studies.

### 3.6. Research setting

Partnerships with gatekeepers and parents are vital to the success of research studies involving children from special populations. Since school or clinic staff may be affected by the research process (either directly or indirectly), early contact with staff members is helpful (Soistmann & Rice, 2017). Researchers must be flexible, aware of scheduling constraints, and willing to assist and involve gatekeepers who provide access to potential participants.

School and clinic staffs (e.g., nurses, teachers, secretaries, etc.) may assist in identifying potential study participants without being considered 'engaged in research.' Individuals engaged in research must adhere to the standards imposed by their local Institutional Review Board (IRB) that monitors and approves the research. Individuals engaged in research are defined as those who, for research purposes, intervene or interact with human participants or obtain individually identifiable private information (NIH, n.d.; NIH, 2015).

Potential participants may ask the staff about expectations and it is helpful if the staff is aware of study details, including what is expected, the process of data collection, timing of procedures, where data collection will occur, and who is responsible for collecting data. In the preschool study, staff often were asked about the study and were able to provide information (both oral and written) to parents who subsequently enrolled their children (Rice et al., 2017). Working around the clinic appointment, perhaps by having potential participants arrive early for consent/assent, may decrease staff burden making staff more open to the research and assisting with recruitment. Similarly, to decrease the challenge of limited clinic space, it might be helpful to complete the consent/assent process once the child/family is in an exam room or private area of the waiting room (Davis, 2017; Johnson, 2016; Soistmann & Rice, 2017).

Since most clinic settings have moved to the EMR system, it has become increasingly difficult for researchers to access medical records in research settings. While some staff members are able to share information about potential participants with the researcher, this often becomes burdensome for staff and presents various legal challenges. Obtaining access to the EMR with an individual user ID and institutional credentialing can remedy this situation (Johnson, 2016).

Investigators should also consult their IRB with regard to using the clinic staff in screening EMRs, as this may be considered engagement in research.

In addition to providing incentives to children and parents, incentives for clinics and schools are beneficial and may increase staff buy-in. Incentives for schools may include donation of classroom materials, gift cards, and help with writing grants (Alibali & Nathan, 2010; Powers, 2007). Other incentives for both schools and clinics may include providing educational presentations and/or food and snacks in the teachers'/staff lounge (Alibali & Nathan, 2010; Rice et al., 2017).

## 4. Conclusions

Inclusion of hard to contact/hard to engage child participants in research is necessary in order to address research questions related to these groups. Recruiting subgroups of children from clinics and schools may be difficult. Identifying barriers and specific strategies to overcome barriers in these child research settings can be instrumental in successfully recruiting child participants.

## Declarations of interest

None.

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