

Implementation, Policy and Community Engagement Research Article

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Views and experiences of youth participants in a pediatric advisory board for human subjects research

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Abstract

Introduction: Community Advisory Boards (CABs) are typically comprised of adult community members who provide feedback on health-related, adult-focused research. Few, if any, CABs comprised of youth participants exist. In 2019, a Midwest medical center recruited a diverse group of 18 11–17-year-old community members to a Pediatric Advisory Board (PAB) to provide feedback on the recruitment and involvement of minors in research. **Methods:** Semi-structured interviews with $n = 12$ PAB members were conducted to understand their experiences and views on participating in the PAB. Parents ($n = 7$) were interviewed separately to assess the congruence of views on PAB membership between parents and their children. Interview transcripts were qualitatively analyzed to identify iterative themes. **Results:** PAB members thought the PAB addressed an unmet need of soliciting feedback from youth to develop age-appropriate study materials and to understand potential concerns of young participants. While PAB members expressed interest in the research topics presented by researchers, a few members indicated barriers to full participation, including lack of self-confidence, anxiety, and discomfort sharing opinions in a group setting. Parents supported their child's PAB participation and hoped it would help them build confidence in developing and sharing their opinions in ways that were meaningful for them, which PAB members largely reported occurring over their period of involvement. **Conclusion:** Findings from a novel Midwest PAB indicated benefits to PAB members. While contributing to pediatric research planning by providing feedback on recruiting youth and improving study protocols, they gained confidence in providing opinions on biomedical research and developed their scientific literacy.

Introduction

Children are considered a vulnerable research population because of their inability to provide legal or ethical consent to participate in research [1,2]. Yet, children's research participation is necessary to advance pediatric medicine [3]. In 2015, pediatric research (ages 0–17) only represented 6% of new interventional clinical trials, even though this age group makes up about 25% of the US population [4]. Underrepresentation of children in clinical trials leads to limitations in evidence that supports clinical interventions, which in turn hinders treatment decisions in pediatric populations [4]. This trend has been exacerbated during the COVID-19 pandemic; between February 1 and April 11, 2020, only 30 of 275 COVID-19 interventional clinical trials were open to any patients younger than 18 years, although this number appears to be increasing with the completion of adult study arms [5]. This will have implications for when children may be able to receive SARS-Cov-2 vaccines. Specifically, the CDC has delayed the recommendation of vaccination in children under 16 years until additional clinical trial data is collected in children and adolescents [6].

In adult populations, many institutions have implemented Community Advisory Boards (CABs) to provide community engagement in biomedical research design and promote alignment with community priorities. The role of CABs is frequently multifaceted and may involve providing input on health needs in the community and gaps in existing research to address them; identifying emerging research topics (e.g., COVID-19) and populations of interest; and providing specific feedback on

individual human subjects research projects' recruitment, consent, study design, and implementation. Engaging with CABs can also help initiate and maintain bidirectional dialogue and co-learning in academic–community partnerships [7,8]. Some children's hospitals have advisory boards for patient advocacy or study-specific pediatric CABs formed by researchers. Very few, if any, CABs are designed to engage youth members to advise pediatric research more generally.

To address this gap, our NIH-funded Center for Clinical and Translational Science (CCaTS) and Special Population Program created a Pediatric Advisory Board (PAB) comprised of 18 diverse 11–17-year-old community members to provide feedback on the participation and involvement of minors in research. To our knowledge, this is one of the first CABs created to advise research involving minors within the NIH-funded Clinical and Translational Science Award (CTSA) consortium. The purpose of this study is to understand PAB members' views on, and experiences with, participating in the PAB and offering advice to researchers regarding health research involving minors. We also explored the perceived benefits to PAB members and to researchers. Parents of PAB members were also interviewed to assess their perspectives on their child's experiences with participation in the PAB.

Materials and Methods

Pediatric Advisory Board (PAB)

The formation and implementation of the PAB is described in detail in a companion manuscript [9]. Briefly, the PAB was formed in 2019 with 18 members (9 female and 9 male) aged 11–17 years; 73% were from an underrepresented racial/ethnic minority group. The members were recruited in the community by the adult PAB coordinator based on their interest in joining. The PAB coordinator did not assess or select potential members based on their prior clinical research experiences or clinical experiences with health or disease. PAB members were told they had an opportunity to provide researchers with feedback on studies involving youth. There was no expectation of service duration but that the PAB coordinator would check in annually to see if the youth was able and interested in continuing. The PAB coordinator who is bilingual (Spanish and English) facilitated all meetings. Beginning in April 2019, PAB meetings were held on a quarterly basis. Meetings were initially held in person, then by video conference following the inception of the COVID-19 pandemic. Members attend meetings without their parents present. The first two PAB meetings provided an introduction and training on human subject's research, research ethics, the research process, and vulnerable populations. The second and all subsequent meetings included one researcher presentation covering a range of health topics and diseases from youth depression to marijuana use and types of studies ranging from qualitative and observational research to clinical trials. Following a brief researcher presentation on their study and protocol, PAB members are asked to provide feedback on recruitment materials and procedures, and study implementation. Moreover, PAB members have the opportunity to directly engage with researchers and raise study-specific questions and discuss research topics of interest to them and their peers.

Participants

PAB members and their parents/guardians were recruited via a verbal announcement and a recruitment flyer distributed by the PAB coordinator at a PAB meeting. The PAB coordinator then

contacted the members and parents to verify their interest and inform potential participants that declining would have no impact on the member's participation in the PAB. For those expressing interest, a follow-up telephone call and text message were sent to members and parents/guardians to confirm the interview. Prior to the start of the interview, the researchers obtained oral consent from the parent on behalf of their child and/or themselves, and oral assent from the PAB members. The study was approved by Mayo Clinic's Institutional Review Board.

Procedures

Researchers with expertise in community-engaged research, bioethics, and special populations research developed a semi-structured interview guide that explored domains of personal experience with the PAB and practical suggestions for improvement in the design of pediatric research. Interviews were conducted from February 2020 through April 2020. Except for one interview conducted by phone, PAB member interviews were conducted in person. Members were given the option to be interviewed individually or in dyads with another PAB member; two interviews comprised youth dyads. Parents/guardians were interviewed separately, either in person or by phone. All interviews were conducted by one or two researchers and recorded with the permission of the participant. Interviews lasted an average of 17 min (range: 12–24 min) for parents and 29 minutes (range: 19–47 min) for PAB members. No incentives were provided for participation.

Data Analysis

Audio files of the interviews were professionally transcribed. Transcripts were entered into the software program NVivo 12 for qualitative analysis. Consistent with principles of iterative grounded theory-based methods, the research team developed two codebooks, one for PAB member interviews and one for parent/guardian interviews, using $n = 3$ transcripts each for initial analysis of consistent themes [10]. After finalizing the codebook, the remainder of the interviews were coded to consensus by two researchers.

Results

Demographics

Of the $n = 18$ PAB members and parents contacted to participate in this study, 12 PAB members and 7 parents completed an interview. Table 1 displays the participant demographics. Those completing the interview were similar to the overall group of PAB members with an average of 14 years of age (range: 11–17) and half were female. Racial/ethnic diversity was higher among those interviewed (84% from underrepresented minority groups vs. 73% overall).

Interview Themes

Attitudes regarding providing feedback to researchers

While many members joined the PAB on their parent's recommendation, they expressed understanding of the importance of the PAB as an opportunity to provide feedback. PAB members reported feeling that adults often do not sufficiently take adolescent opinions into consideration.

Table 1. Participant demographics

	PAB members <i>n</i> = 12	Parents <i>n</i> = 7
Age (years)	14.4 ± 1.7	41.6 ± 5.5
Grade		
Middle school	4	-
High school	8	-
Gender		
Male	6	1
Female	6	6
Race/Ethnicity		
Black/African Ancestry/African-American	2	0
Latinx/Hispanic	2	2
Caucasian/White	2	4
South Asian	1	1
More than one ethnicity	5	0

PAB, Pediatric Advisory Board.

"It's just . . . I feel adults don't really take kids or young people seriously at all, and it's kind of just always been that mentality."

– Female member, 14 years old

Responses from older members of the PAB implied that adults have greater power than children, along with more resources to make impactful changes with the information they have.

"Cause a lot . . . my friends and I, we talk a lot about controversial issues all the time and . . . but we don't get to talk to anybody of higher power who can actually listen and use that information."

– Female member, 17 years old

When parents were asked why their children were interested in participating in the PAB, their answers mirrored those of their children. Many reported that their children seemed proud to be a part of a larger community and feeling that their opinions carried weight and were valued.

"I think that getting that pride of being able to do something like that and be involved in something that's part of the [academic medical center] is a big deal to him and being able to see that and his opinion can change lives."

– Mother, 38 years old [Son, 12 years old]

Experiences of PAB members

PAB members reported varying levels of comfort when providing feedback to researchers. This was highly dependent on how social or extroverted they judged themselves. Self-reported introverted or quiet members reported feeling anxious or intimidated at first, where extroverted members were more comfortable speaking their minds. However, many of the introverted members who felt discomfort, in the beginning, reported feeling more comfortable as the sessions continued.

"I mean I don't really see a way to make it more comfortable other than over time . . . It was weird at the very beginning 'cause we didn't really know them; it was kinda like strangers. And so after time, I guess, you can get to know each other . . ."

– Male member, 15 years old

Benefits of the PAB

Benefits to members

PAB members and their parents/guardians saw many benefits to adolescent participation in the PAB. Most (*n* = 9) members reported that the PAB helped improve their knowledge about science and research. Younger members especially emphasized this.

"Just straight-up knowledge of stuff that is there and just what I could learn more about some things. It just interests me in other things that I could be interested in . . ."

– Male member, 12 years old

Several (*n* = 4) high school-aged PAB members and parents of high school-aged members (*n* = 2) found the PAB to be a resume or college application builder.

"Yeah, so she is super interested in going into a science field, and one of the selling points for me to get her to be interested in coming to PAB was that it would be on her resume when she grows up, like in her college resume, and then also that she would get to see firsthand, way before some of her other peers, what research looks like, and that eventually as a student or even if she goes into your field, she is gonna have to either do her own research or she is gonna have to lead research, and so for her to understand this process will be really beneficial for her in the future."

– Mother, 36 years old [Daughter, 15 years old]

Four parents saw the PAB as a tool to build their child's confidence and engage them in critical thinking, where parents with middle school-aged children reported that their children were especially proud of their participation.

"Oh yeah. Builds his confidence for sure. He likes getting paid to do something and to tell people that he works at [academic medical center]. Yeah, I don't . . . I think that . . . and it teaches him responsibility and understanding new things, and he gets to help people, and he knows that, and he really likes that he's . . . by what he's doing is helping others, and I think that that's part of what builds . . . makes him want to talk, which is awesome that it's helping other kids too."

– Mother, 38 years old [Son, 12 years old]

Benefits to researchers

PAB members unanimously agreed that the PAB brought a new point of view to researchers who conduct pediatric studies.

"It's a new point of view that they don't always get to hear 'cause this is a really new thing to have kids actually bring in their input, so that's a huge benefit."

– Female member, 14 years old

Several (*n* = 4) PAB members speculated that their feedback would help researchers refine their clinical protocols, especially with regards to recruitment.

"It's hard when you hear all of these words and you wanna know more about [research], but all of a sudden it feels like you can't be part of it, so I think it's important that the PAB is there to be like, well we don't understand this part, but if you can make that easier to understand, then people who are actually going through this don't have to feel like only their parents can be part of it."

– Female member, 15 years old

Echoing their children, parents reported that having their children participate in the PAB would bring a new perspective to their research. Further, the feedback provided can also help train doctors and scientists to treat children as active participants in informed medical decision-making as well.

"Well, I think it sheds light on what's in the minds of these young people and how they wanna receive information regarding their health or medical issues or medical situations."

– Mother, 41 years old [Daughter, 13 years old]

Research in Adolescents

Barriers to research participation

A majority ($n = 9$) of PAB members reported little to no awareness of research in adolescents prior to the start of the PAB; a few were surprised to learn the breadth of pediatric research as they thought medical research mostly happened in adults. Others rationalized it, citing that because children are medically treated, research must occur in children and adolescents, too. A couple of members expressed hesitancy about pediatric research, displaying concern for the comfort of child participants.

"I was kind of surprised . . . well . . . kind of surprised because . . . the kids might be nervous."

– Male member, 12 years old

Half of PAB members ($n = 7$) reported safety as a primary concern for adolescents in research. Other concerns frequently mentioned were privacy and child assent, where PAB members wanted to ensure voluntary participation of youth in research, not simply forced into it by parent/guardians or adults.

"Well, I know that kids aren't fully developed, so it could hurt that, or it could just make them do worse. Also, they're younger so they might not understand fully what is going on."

– Female member, 13 years old

Suggestions for improving recruitment

PAB members who participated in this study suggested that researchers must convey material in ways that adolescents can understand. They reported that unclear recruitment fliers and explanations make kids nervous when considering participation in research. They felt that addressing recruitment efforts to adolescents directly would be more effective.

"That sometimes it's confusing . . . They could explain it shorter, but with still the same descriptions and details that there are."

– Female member, 13 years old

Second, when recruiting, PAB members expressed a need for the researcher to consider adolescent emotions. While research protocols may be self-explanatory to adult researchers, adolescents will perceive certain things differently and may have different emotional responses. PAB members recognized that not all children participating in research are healthy and that some experimental treatments may look or sound scary, but are potentially beneficial. As such, PAB members recommend appealing to these children by explaining that their participation might help other kids like them.

In response to questions about the likeliness of their friends participating in research, most PAB members responded that their friends would be interested in participating in studies in topics that they're interested in or qualitative studies, such as the present one, where they can interact and provide feedback. They suggested that clearly explaining the link between the topic of the proposed research and the interests of potential participants would increase engagement.

Discussion

To our knowledge, this is one of the first PABs to engage youth members for bidirectional conversations with researchers with the goal of enhancing pediatric research participation. Previous PABs and pediatric research networks have been reported, but are either focused on clinical experiences or do not incorporate the voices of children, relying instead on parents, child health advocates, and pediatric specialists to guide and protect youth

research participants [11–13]. In this study, we share the experiences and insights of adolescent PAB members and their parents on the benefits of participating in the PAB and providing feedback on research studies involving youth participants. Our findings demonstrate that PAB participation is an empowering experience for members, generating feelings that their feedback on pediatric research is heard and valued; however, several challenges persist regarding PAB cohesion and robust participation from all members.

Implications of PAB Membership

PAB members reported that the PAB was an opportunity to gain scientific knowledge and build college applications or resumes. For many participants, the PAB was their first introduction to professional research and scientific projects. Parents of PAB members expressed that the PAB was a tool for their kids to engage in critical thinking and gain confidence in forming and expressing their own opinions. Often, adolescents spend significant time as an observer, especially evident in settings such as medical appointments or school meetings, where their parents are present. Participants suggested that PAB acted as a platform for adolescents to form opinions and express themselves on their own terms within a safe and regulated environment.

The PAB members who participated in this study were both gender and racially diverse and brought unique opinions to the PAB. However, this diversity is not a reflection of the reality of science, technology engineering, and math (STEM). The participation of underrepresented minorities in STEM is low despite recent initiatives, which is driven primarily by the lack of representation in current practitioners. Faculty of color only represent 20% (9% Asians or Pacific Islanders, 6% African-American, 4% Latinx, less than 1% American Indian or Alaska Native) of employees at the US degree-granting institutions [14]. Initiatives like the PAB may help address some of these disparities by increasing early exposure to science and medicine in adolescent populations and creating a pipeline for the next generation of diverse biomedical researchers. This is in line with previous findings that implementing a science curriculum at an earlier age may better prepare youth to pursue STEM careers [15,16].

Research Benefits and Implications

Pediatric researchers can benefit from utilizing PABs by soliciting feedback on their protocols and recruitment strategies from adolescents who may represent their target population. But to receive helpful feedback when utilizing PABs, the PAB members, and by inference, the target research population must be interested in the research being presented. The most enthusiastic and detailed descriptions of study feedback were in regard to study topics members felt were directly relevant to their peers; determining how to best present feedback to generate youth feedback may be a challenge to presenting researchers.

Minors are historically underrepresented in the development of the research that translates into their medical care [4]. Through mechanisms like the PAB researchers can potentially increase adolescent research participation by learning how to better explain their projects to minors in meaningful ways that they understand. A strength of PAB members is their ability to directly empathize with the potential child and adolescent research participants, considering how they might perceive study interventions and their potential fears and concerns. This is information that might not be directly obtained from youth research participants themselves,

given their developmental status and/or the power differential inherent in child-adult interactions, especially those that are perceived as authority figures. This information may be valuable to researchers not only in the development of recruitment materials, but also in the assent process and the enhancement of participant comfort.

As discussed in greater detail in our companion manuscript (under review), educational sessions were initially offered to provide a base level of knowledge for all members. While PAB members felt their contributions to the research process to be valuable, additional evaluation is needed to determine whether the presenting researcher found their comments were helpful to study development or implemented in their study design. Additionally, many members were unable to discuss their contributions at PAB sessions in-depth, suggesting continuing education on the research process, as well as future PAB topics, may improve feedback quality and enhance member education for those pursuing a STEM-related field. The developmental stage of PAB members may also influence their ability to offer salient responses to researcher questions and/or freely participate in the discussion, with typically older members better able to express their views. Continuing education targeted toward the developmental stage (e.g., middle school vs. high school) and the offer of alternative modalities of feedback (e.g., written vs. oral) may help less comfortable members build confidence.

Challenges and Critical Appraisal

The strengths of this study include an in-depth understanding of adolescent experiences and the perceived benefits of a PAB. While adolescent study participants were racially and ethnically diverse, parent participants primarily identified as Caucasian and female. Those who participated in this study were active community members and were more likely to participate in research and provide feedback on their experiences. Less outgoing PAB members, and PAB members and parents whose first language was not English, were less likely to participate. Although, the first two PAB meetings were dedicated to providing participants with a background in the scientific method and research structure, the young age of many PAB members meant that there was also a learning curve for members to understand research and how to provide meaningful feedback. Two PAB members stated they had prior experience participating in a research study and one participant's parent worked in clinical research, however, their responses were similar to other participants. PAB members were interviewed nearly a year after their first PAB meeting. Different feedback might be expressed if participants were interviewed after having served for a longer time and thus having had more experiences in providing feedback to researchers. Moreover, we did not assess the views of researchers or the impact of PAB feedback on recruitment or pediatric engagement with studies.

Future Directions

We need to understand more about how the PAB feedback influences subsequent research and institutional capacity for pediatric research. Future studies will assess if researchers perceive the PAB feedback as valuable, as well as the impact of PAB feedback on how researchers use the feedback to modify their recruitment materials and study implementation and dissemination. Another key metric of the potential impact of PAB feedback is on the

success of pediatric research recruitment, especially of those from diverse and under-resourced backgrounds.

Additionally, using exit interviews and longitudinal follow-up of PAB members we will collect data on barriers to participation; whether the quality of advice to investigators improves over time; long-term benefits to participants of PAB membership (e.g., improvements in science literacy); and whether PAB participants intend to or succeed in entering STEM-related fields.

Based on participant feedback, the research team also intends to incorporate more team-building exercises and ice breakers at the beginning of PAB sessions. These will address barriers to participation by quieter PAB members and welcome new PAB members into the larger group. We hypothesize that increasing the comfort levels of PAB members through building familiarity between members and the research staff will help adolescents feel more comfortable in voicing their opinions.

Conclusion

Qualitative findings from a novel Midwest PAB found that the PAB allows its members to contribute to pediatric research planning by providing feedback on the recruitment of youth and how to improve study protocols. The PAB also provides a means for its members to develop confidence in providing opinions on biomedical research and developing scientific literacy. Parents of PAB members agree that serving on the PAB builds confidence and scientific knowledge and is of benefit to members.

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