Creating a pediatric advisory board for engaging youth in pediatric health research: A case study

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Abstract
Youth are an understudied population requiring additional safeguards when participating in research. Their input is necessary to facilitate participation and interest in studies. To address this, Mayo Clinic established one of the first pediatric advisory boards (PAB) comprised of 18 diverse youth aged 11–17. The PAB members participated in quarterly meetings (in person and then by video conference with the advent of COVID-19) where they provided feedback to researchers on recruitment strategies, study materials, and procedures. The PAB meetings fostered bidirectional conversations with researchers on several health research topics, including mental health. Youth advisory boards can promote engagement in pediatric research.

Introduction
Youth are considered as a vulnerable population that requires additional protections to participate in human subjects research studies, such as providing assent and parent/guardian’s consent [1]. Many studies document recruitment strategies on how to engage youth in research studies in the study planning process [2–4]. However, many pediatric studies have low enrollment in clinical trials [5]. Greater youth participation in research study design, implementation, and interpretation might improve the quality and success of pediatric research by increasing engagement with the research team, providing age-appropriate study materials, and assessing comprehension of participation and risk/benefits [6]. In response, our NIH-funded Center for Clinical and Translational Science (CCaTS) developed one of the first pediatric research advisory boards (PAB) to overcome the knowledge gap in how to engage youth as meaningful partners in pediatric research.

A community-engaged research framework facilitates collaborative partnerships between academic researchers, community members, and patients who have shared interests or are connected geographically and have the same overall goal of increasing wellness [7]. A common platform for community engagement is the use of community advisory boards (CAB). CABs are typically comprised of adult patients and/or community members who advise investigators on research projects, including review of study materials and feedback on special considerations or risks/benefits to participants. CABs foster bidirectional conversations between investigators and community members [8]. Existing Mayo Clinic CABs have demonstrated success in addressing the health needs of the communities across the enterprise (Arizona, Florida, and Minnesota) [9]. However, to our knowledge, the creation of CABs that feature adolescent voices for pediatric research has not been reported in Clinical and Translational Science.

Our PAB was created with four primary goals: (1) designing pediatric research that represents the major health concerns of youth, (2) respecting the ability of youth to assent for research, (3) providing health benefits for youth through research, and (4) providing feedback to Mayo Clinic investigators on pediatric studies. This report describes the process of establishing the PAB at Mayo Clinic.

Methods
Setting
Rochester, MN USA.
PAB Member Recruitment

Based on our experience with adult CABs, we aimed for 20 youth to join the PAB. The PAB coordinator was in charge of recruiting youth as members, with the goal of achieving a well-balanced diversity of age, gender, and ethnicity. Potential youth members were identified through existing relationships and referrals, as well as recommendations from established community partners with the Community Engagement Program team, including our adult CAB. Locations of recruitment included African-American churches, a youth-sponsored bike club, and a homeschooling network. Given the comparatively large immigrant population in our catchment area, we also engaged community liaisons to help communicate with parents/guardians of these potential PAB members. The project was explained in ongoing conversations with the youth and their parents/guardians. The PAB coordinator reached out to youth recommended by other stakeholders to gauge their interest before official invitations were distributed.

Interested adolescents were given personalized invitations to be part of the Mayo Clinic PAB. Once a parent/guardian’s consent was obtained, invitations were either mailed or hand-delivered in December 2018. Youth provided assent to participate in the PAB. Parents/guardians were asked to submit authorization for use of the youth’s image and video and co-sign a W-9 form for remuneration. The PAB members were paid $25 for each session they attended and a meal was provided.

Training

Prior to giving feedback to researchers, PAB members were trained in the research process, human subject research, research ethics, and vulnerable populations. The first meeting in April 2019 was an introduction to the PAB members and staff. It also involved a presentation about the research process and special populations. The second meeting held in May 2019 focused on human research training and a speed information session with scientists. The July 2019 meeting involved learning about research ethics, vulnerable populations, and a researcher presentation. After human subjects research training in the initial sessions, the researchers presented their material of interest on July 2019, October 2019, and January 2020.

Meeting Structure

In contrast to the traditional CAB structure, the team decided that the PAB would not have a Chair because of uncertainty that youth would be comfortable volunteering for this role. Instead, the PAB coordinator facilitated the meetings. Subsequently, there has been discussion of instituting a youth co-Chair for members who feel more confident or comfortable.

The PAB was established with quarterly meetings with the potential for expanding the frequency of meetings depending on the need of PAB members and researchers. Parents were not present at PAB meetings. All of the PAB meetings had a set agenda. The meetings were initiated with welcome and roundtable updates by the PAB coordinator with the PAB members. The speaker was then introduced, proceeded with their research presentation, and had an open discussion with the PAB members. The speakers were invited to come earlier to socialize with the PAB members if they were interested. Detailed minutes were taken at each meeting.

Table 1. Demographics of pediatric advisory board

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Black/African Ancestry/African-American</td>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>White/Caucasian</td>
<td>4</td>
<td>27%</td>
</tr>
<tr>
<td>Hispanic/Latinx</td>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>More than one (±2)</td>
<td>5</td>
<td>33%</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Education Level</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Elementary</td>
<td>2</td>
<td>13%</td>
</tr>
<tr>
<td>Middle school</td>
<td>3</td>
<td>20%</td>
</tr>
<tr>
<td>High school</td>
<td>10</td>
<td>67%</td>
</tr>
</tbody>
</table>

Results

Demographics

A total of 19 invitations to be part of the PAB were sent. All were accepted except one due to a work conflict. Our recruitment goal was reached with 9 girls and 9 boys aged 11–17 joining the PAB. All lived in Olmsted County or surrounding communities. Demographic information was missing for three members including one who moved out of the catchment area (Table 1). Quarterly PAB attendance ranged from 13 to 18 members with the exception of the January 2020 session which had 5 members.

Feedback

The topics of each of the first five meetings of the PAB are presented in Table 2. Two of the three investigators were initially presented to the PAB specialized in pediatrics and the other in adolescent psychology. The PAB provided feedback to speakers such as comments to help increase awareness of research studies for adolescents. Some examples included how to direct research flyers or letters to the adolescent’s interest and not their parents. PAB members provided suggestions of locations to advertise research studies and to conduct focus groups. Many of the sessions were bidirectional with members advocating for health concerns in their age group, including mental health and vaping. Other examples are listed in Table 2.

Table 2. Researcher presentations

<table>
<thead>
<tr>
<th>Presenter</th>
<th>Audience and Focus</th>
</tr>
</thead>
<tbody>
<tr>
<td>Investigator 1</td>
<td>Research on mental health and vaping</td>
</tr>
<tr>
<td>Investigator 2</td>
<td>Research on adolescent psychology and substance use</td>
</tr>
<tr>
<td>Investigator 3</td>
<td>Research on nutrition and physical activity</td>
</tr>
</tbody>
</table>

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Given the lack of precedent for the PAB model, there were initial challenges, including education of the PAB members to establish a base of knowledge from which to provide feedback. To understand members’ experience, a study was conducted to assess initial challenges and build upon the successes of the PAB. Despite achieving gender and racial/ethnic diversity of members, there is a need for more Asian representation on the board. We aim to include youth who do not identify within traditional gender roles. In time, we hope to address this as future spots are made available on the PAB.

### Future Directions

The PAB continues to meet quarterly and has transitioned to a video conferencing format following COVID-19 guidelines. Currently, there is a waiting list for membership. Future directions include transitioning of graduating PAB members into the Mayo Clinic CAB or future inclusion as an observer. Feedback can include helping researchers adapt to continue researching during these unprecedented times. PAB members could take more active roles in the entire research process such as initiating their own research projects on their topics of interest.

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### Disclosures

The authors have no conflicts of interest to declare.

### Ethical Statement

The creation of the PAB did not require IRB protocol but we received parent/guardian’s consent and youth’s consent.

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