



Implementing a youth advisory board to inform adolescent health and medication safety research

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ARTICLE INFO

Keywords

Youth advisory board
Medication safety
Adolescent health
Pediatric population
Community-based participatory research

ABSTRACT

Adolescents are a crucial, yet underrepresented population for health service researchers to study. Nevertheless, youth are rarely included in the design, implementation, and evaluation of research. There is a lack of literature describing adolescents as advisors in health services research in pharmacy. The creation of a youth advisory board (YAB) provides a platform for youth to contribute to the design and implementation of research aimed at improving health and medication use in the pediatric population. This commentary describes the development, benefits, challenges, and lessons learned from the first YAB at the University of Wisconsin-Madison (UW) Collaborative Research on MEDication use & family health (CRoME) Lab alongside feedback from the youth members.

1. Introduction

In 2020, adolescents aged 12 to 18 made up 34% of the United States population, making them a critical population for health services research.¹ Nevertheless, youth voices are often underrepresented in the research process. Publications describing adolescents as research advisors are notably limited within the health services research in pharmacy literature.² One study that reviewed community-based participatory research (CBPR) publications found that only 15% of studies partnered with youth aged 18 years and under.³ Since community-engaged research facilitates partnerships between academic researchers and community members with shared interests in and goals of increasing wellness, it is critical to include youth voices in the research process.⁴ The creation of a youth advisory board (YAB) provides a platform for youth to contribute to the design and implementation of research aimed at improving adolescent health, medication use behaviors, and overall well-being.^{2,5}

Youth are an understudied and vulnerable population that require additional safeguards compared to the general adult population, such as the need for parental consent and additional Institutional Review Board (IRB) approval requirements when participating in research.⁶ In recent years, emphasis on stakeholder engagement has led to youth involvement in the research process. YABs have been increasingly utilized as

resources throughout the research process to facilitate study design and elucidate the research topic as it pertains to what matters to youth.^{7–9} Advisory boards allow everyday youth to have a voice in research and shape academic research to be more reflective of the needs of their target population.⁷ The utilization of a YAB presents a unique opportunity for researchers to gain multiple perspectives from their target population. In addition, youth input and feedback are necessary for building youth participation and interest in health services research.⁶

This commentary describes the process the Collaborative Research on MEDication use & family health (CRoME) Lab at the University of Wisconsin-Madison (UW) used for designing, recruiting, and developing a YAB to inform medication safety and adolescent health services research. The benefits and challenges faced with the first cohort of youth members, as well as member feedback, are discussed.

2. CRoME lab youth advisory board: mission and goals

The CRoME Lab's mission is to develop, implement, and disseminate novel methods for improving medication safety and health behaviors for vulnerable and underserved populations. Projects within the CRoME Lab share the common goal of applying community-engaged, collaborative, and transdisciplinary approaches to improving medication use and health outcomes for families through education, prevention, and

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<https://doi.org/10.1016/j.sapharm.2022.12.003>

Received 15 August 2022; Received in revised form 8 December 2022; Accepted 8 December 2022

Available online 13 December 2022

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intervention. A YAB was created to ensure that the CRoME Lab’s research aligned with the needs and interests of its target population. The YAB was formed to achieve three primary goals: (1) create a national sample of youth members to inform research projects, (2) support long-term investments in the professional development and mentorship of youth, and (3) provide an avenue for youth to be exposed to health services research and the healthcare field. The dual mission of the CRoME Lab’s YAB is to understand youth perspectives on the CRoME Lab’s research, provide adolescents with opportunities to explore the health science research process—inspiring and informing their future career and personal endeavors.

3. The value of a YAB in adolescent health and medication safety research

The importance of promoting excellent health and prevention education in adolescence cannot be overlooked. As such, there is the need for a more interdisciplinary and collaborative research process to ensure the creation and dissemination of new knowledge as well as innovative solutions to address adolescent health and medication safety issues.^{10,11} This approach will assist in identifying future research needs aimed at improving adolescent health and improving medication safety for youth. Moreover, studies have shown that the involvement of key stakeholders throughout a research process enhances the amount of relevant research and the uptake of these findings for improving health outcomes.¹²

YABs provide benefits not only to the youths but also to the research team in a reciprocal and synergistic manner. Engaging youth in adolescent health research through the creation of a YAB provides a platform for adolescents to advise and participate in research addressing health and medication use issues relevant to them and promotes CBPR practices.^{2,13} Youth participation in health research through community and YAB engagement facilitates their empowerment and helps young people gain leadership skills alongside other lifelong skills while providing feedback and ideas for addressing research needs to the research team.^{14,15}

4. Recruitment, selection, and membership

There are general factors that can be considered during the recruitment and selection process for members of a YAB. The number of members selected for a YAB may depend on the overarching goal of each researcher, the purpose of the YAB, the Lab’s capacity and composition. For example, a researcher who plans to engage youth in the research process, by providing training, and offering members opportunities to work with data and/or manuscripts, may want to recruit a smaller group of 5–10 members. If the researcher’s main goal is to create and foster relationships with youth, a group of 10–15 members may be more appropriate. Lastly, a multi-faceted project that requires a wide range of feedback and perspectives would benefit from a larger group of 15–30 members.

When recruiting YAB members, one should aim to recruit from a variety of avenues that will bring unique perspectives to the research. Recruitment of a YAB could take place via multiple avenues and various media to elicit participation from a diverse sample of youth. To obtain a diverse sample, it is important to think about recruitment strategies that may have worked in the past, such as school flyers and reaching out to parents, but also non-traditional methods such as social media, Black, Indigenous, and People of Color (BIPOC) listservs, community centers, and after school programs for at-risk youth. Another factor to consider is the length of a YAB membership. Examples of questions to consider when structuring membership guidelines are: Will members be a part of the YAB for as long as a project is running or definite terms? Will members have the option to join when it is convenient for them to give their best feedback? Will members be asked to leave after they have reached the age of 18?

To recruit a diverse national sample, the CRoME Lab reached out to

both Wisconsin-based community members and national email listservs. Recruitment began in February of 2021. Digital flyers were sent out via email announcements to faculty, students, and staff at the UW-Madison School of Pharmacy. Flyers were also distributed via word of mouth and national academic listservs. To be eligible to join the CRoME Lab’s YAB, interested youth had to be between the ages of 12 and 18, live in the United States and speak English. These criteria allowed for flexible recruitment of youth from a variety of backgrounds across the United States within the target age range. The recruitment email provided a brief description of the YAB including its purpose, goals, and benefits to members. Interested youths were asked to reach out to the research team via email. Parental or guardian consent was obtained for potential members who were under the age of 18 years old. Students were then asked to provide the lab with their resume, answer questions about themselves (Table 1) and why they wanted to be on the YAB as well as complete a short interview with a research team member.

Factors considered for the selection of YAB members included the interest of applicants’ research experience and career goals. Applicants were also asked about their commitment and willingness to give feedback on group research studies, share ideas, and availability of applicants to engage in YAB activities and meeting sessions. A total of 17 applications were received and reviewed by two members of the CRoME Lab research team. Of the 17 applicants that were interviewed, 14 youth made up the 2021 to 2022 CRoME Lab YAB cohort. Members were briefed on the expectations for the board, research ethics, and the policies of the CRoME Lab and UW School of Pharmacy to ensure confidentiality and professionalism throughout their tenure on the YAB. The demographic characteristics of the YAB members are listed in Table 2.

The CRoME Lab decided to have members commit to a one-year period, with an option to renew their membership if they are under the age of 18 or still in school. This timeline allowed youth to be engaged in research and make contributions to a project, but also allowed them to decide if they wanted to continue with the YAB or pursue other extra-curricular activities. This decision was modeled after the Social Media and Adolescent Health Research Team (SMAHRT) YAB in Wisconsin.²

5. YAB meetings

Working with a YAB requires regular communication and a consistent meeting schedule to maximize youth participation.¹⁶ Meetings were held quarterly: February, May, August, and November. The first meeting for the 2021 to 2022 YAB cohort was conducted in May 2021. To maintain membership status, members must attend three of the four quarterly meetings. Two meetings were held each quarter to accommodate the varied availability and time zones of YAB members. All meetings occurred virtually over Zoom and were facilitated by research specialists in the CRoME Lab. Meetings followed a specific agenda which included a professional development section, a research study feedback period, and time to answer questions and schedule the next meeting. Meeting topics ranged from public health to research ethics, and human

Table 1
YAB member sample recruitment questions.

Application questions	Why are you interested in being on the Youth Advisory Board? What skills or background make you a suitable candidate for the YAB? What are your career or educational goals? What are your strengths? And what are some opportunities for growth?
Interview questions	Take about 5 minutes to tell us about yourself, your previous jobs, volunteer activities, and/or leisure activities that might help you be a successful member to the Youth Advisory Board. Tell us why you believe you are the best candidate for this position. Tell us about your previous research experience (if applicable). What do you hope to get out of your time on this Youth Advisory Board?

Table 2
Demographic characteristics of CRoME YAB members (N = 14).

	Characteristics	Frequency	Percentage (%)
Gender	Male	3	21.43
	Female	10	71.43
	Nonbinary	1	7.15
Age (years)	12–15	4	28.57
	16–18	10	71.43
Race/Ethnicity	Asian	7	50.00
	Black or African American	2	14.29
	White	5	35.71
Education	Middle School	2	14.29
	High School	12	85.71
Geographic Location	Midwest	3	21.43
	Southeast	1	7.14
	Southwest	6	42.86
	West	4	28.57

subjects research, to presentations on the CRoME Lab's ongoing research. Professional development sessions included topics such as, how to create a resume or curriculum vitae, draft a research paper, and health career guidance. The professional development sessions offered YAB members the opportunity to interact with university pharmacy students and research staff of varying progression in their educational journeys, therefore, exposing YAB members to the variety of ways to progress in research settings. Time was also allocated for members to share ideas on research materials, data, and innovations (for example, gameplay, interview guides, and surveys). Each YAB member was asked to review and provide feedback on research projects and to share ideas promoting impactful research on medication safety and health behaviors for families and vulnerable populations like the pediatric population. Three members of the CRoME Lab's research team (the principal investigator (PI) and two research specialists that were trained by the PI on the best practices for working with youth and had experience conducting research with youth) led the quarterly meeting. All meetings lasted approximately 90 minutes (about one and a half hours). YAB members who participated in at least three out of the four quarterly meetings were compensated \$30. YAB members could email the CRoME Lab if they have questions, comments, or suggestions between meetings.

6. Feedback and benefits of the YAB

The meetings with YAB members and the CRoME Lab research team fostered a two way exchange of research ideas and expertise between youth members and the researchers. The research team valued the contributions of YAB members as community partners, that could provide a wealth of knowledge on issues related to medication safety and adolescent health based on their lived experiences. All YAB meetings were structured for youth members to share ideas using the popcorn approach (one participant speaks out loud and passes to another YAB member to speak) to engage all youth, ensure all voices were heard, and manage power differentials. The research team also set clear expectations at each meeting that it was important for all YAB members to voice their ideas. YAB members expressed interest in learning about the research process and the research team shared their expertise in technical aspects of conducting and leading research projects. During these sessions, the research team obtained youth feedback on improving recruitment materials and strategies for youth recruitment and retention for existing research projects. Accordingly, frequent interactions provided unique opportunities for YAB members to play a critical role in providing feedback on research conducted by the CRoME Lab. Feedback included recommendations on topics and research areas that could be of foremost importance to youth in the United States. YAB members also expressed the need for education on medication adherence, over-the-counter (OTC) medications use, pain relief medications, medication side effects, and drug resistance. Additional feedback aimed at improving patient-provider communication on medication usage

through counseling.

Numerous benefits to being part of a YAB were identified through end-of-year reflections. Significant benefits that were identified included networking, professional and career development, and being exposed to different research processes. At the end of the 2021 to 2022 year, YAB members were asked to share their experiences, benefits, future expectations, and learning goals through written reflection. Benefits shared by the YAB members are reported in Table 3. YAB members stated that they found their time serving on the YAB to be very rewarding and satisfying. Statements of the learning experience shared by YAB member participants are listed in Table 4. Most members were content with the current YAB proceedings and meeting agendas. Recommendations for improving future meetings included, firsthand research activities, and the addition of more interactive sessions with the CRoME Lab's researchers. Other topics included discussions on student life, the professional journey of healthcare professionals and researchers to provide more insight into their successes, challenges, and how those challenges were overcome. Future learning goals shared by YAB members included learning more about technical concepts in the pharmacy setting and research process, career paths in medicine and research, and education on drug abuse and correct medication usage.

7. Challenges of a virtual YAB

The creation of a YAB has its challenges. First, due to the COVID-19 pandemic, the CRoME Lab YAB was recruited and held in a virtual environment. While the lab was able to recruit a sizable advisory board, there is a need to explore other avenues for recruitment, such as social media, community centers, schools, and non-traditional recruitment methods. Second, while digital technology has allowed for communication to continue during the pandemic, it can be difficult for youth to share their opinions and bounce ideas around in a virtual environment, compared to an in-person setting. In the end-of-year reflections, members stated they initially faced the challenges when opening-up and sharing their experiences. However, this was overcome with time as members built their confidence and realized the value that they add to the team by sharing their experiences.

Another challenge that occurred was scheduling meetings. Because the CRoME Lab wanted a national sample of youth, the research team needed to work with multiple schedules across time zones. To accommodate everyone, the lab offered two meeting times per quarter. This solution allowed for more members to join overall; however, each meeting group was smaller than the size of the full group. In certain

Table 3
Summary of benefits from the CRoME Lab YAB members.

Benefits of Serving on the YAB
"The YAB program gave me the opportunity to meet other students and learn from their experiences and perspectives. I enjoyed getting to know other student leaders and hearing their experiences from other parts of the country." ... Participant 1
"The biggest benefit to participating in the YAB would have to be learning if I was really interested in pursuing a career in medicine, research, or something similar. Without participating in the YAB, I wouldn't have had the exposure I gained to different career paths or have a clear view about the process people undertook to do so." ... Participant 2
"I benefitted from being a part of the YAB since it helped me develop my leadership and teamwork skills and I learned about ways to careers in the sciences, which helped me." ... Participant 3
"From being on the YAB I gained knowledge on gaining research, exposure to speaking to adults in a field I am potentially going into, and I also benefited from setting up a Linked In account." ... Participant 4
"I really liked meeting with all the YAB members and mentors along with current Pharmacy students." ... Participant 5
"Through the YAB program, not only could I see a possibly futuristic view of what I in the future maybe, I was able to ask questions to help narrow my decision." ... Participant 6
"I like hearing other people's thoughts and questions on different topics because it gave me a perspective that I might not have seen otherwise." ... Participant 7

Table 4
Summary of learning experiences from the CRoME Lab YAB members.

Learning Experiences from the YAB
“Over the course of the last year, I’ve learned numerous things about the research processes and daily lives of people interested in medicine and who are currently taking steps toward their dream. The most rewarding and educational experience for me personally would have had to be working with other people who were also interested in medicine. As they gave feedback towards the lab, I was provided with thoughts and opinions from people of all different backgrounds and interests. It provided me with more insight and knowledge in the medical field I wouldn’t have known or even been aware of without joining the Youth Advisory Board.” ... Participant 1
“I learned about the research process and how to collaborate as a team to provide feedback.” ... Participant 2
“Over the past year, I have learned a lot about the medical/pharmacy field, including the different career paths in these industries.” ... Participant 3
“I learned the misuse of medication is trending higher among young kids and teenagers. Many teens are exposed to medication or offered medication, that may not be right for them.” ... Participant 4
“Over this past year on the Youth Advisory Board, I have had the privilege to see what a career in medicine would look like.” ... Participant 5
“This year I learned about the different perspectives of adults and adolescents on technology use. I also learned how to get into research after watching many researchers give presentations. I also learned more about the steps it takes to become a pharmacist and undergraduate research.” ... Participant 6
“I learned how different advancements in the medical fields can affect (either positive or negative) people around my age. I also learned a bit about what college is like for people who want to pursue a career that includes medicine and science.” ... Participant 7

meetings, this was beneficial as some members preferred to bounce ideas off each other, while others were very shy and did not offer much feedback. The challenges listed above should be considered when forming a YAB to optimize both the researcher’s and YAB members’ time and efforts.

8. Future directions and goals

The CRoME Lab YAB continues to meet quarterly over Zoom video conferencing. Currently, there are 15 members from across the United States. Feedback from YAB members helps researchers adapt to the needs of adolescents and continue researching youth-related health issues. Future directions include mentoring interested members and fostering opportunities for YAB members to get firsthand research experience. Research tasks for YAB members include feedback on research processes such as data collection, educational materials creation, or manuscripts. Moreover, based on the end-of-year responses, meetings will incorporate professional student speakers to share their process of applying to and navigating through pharmacy, medical, and graduate school. Whereas policy can often be restrictive towards the participation of adolescents, the formation of a YAB includes youth voices into the policymaking process—allowing for policies that represent realistic parameters for its target population. Through youth-informed science, health services researchers can disseminate more pertinent research to applicable policymakers and overall health services literature fostering a better fit between interventions, policies, and the youth they impact.

The CRoME Lab encourages other research labs to form their own YAB to help shape adolescent health-based research as well as get youth involved in research and healthcare. However, the creation, planning, and sustainment of a YAB would require a significant amount of effort and resources by researchers. One recommendation is to observe the functioning of a current successful YAB and inquire into the processes and resources needed to sustain the YAB. For the CRoME Lab, the PI’s effort was supported by a career development award and the SMAHRT YAB provided guidance for the structure and functioning during early stages of development. In addition, two other members of the CRoME Lab were involved in assisting with recruitment and managing other aspects of the YAB. Given the goals of the YAB in exposing youth to

health services research, the research team could benefit from efforts to increase greater participation of youth from underrepresented minorities. Although the CRoME Lab aimed to recruit a diverse national sample, some youth may still face barriers to participate (e.g., access to a computer device, stable/high speed internet to participate in zoom meetings, etc). Another potential limitation is that information was not collected regarding the health status of YAB members. Youth with chronic conditions and ongoing health or medication-related needs may have a different set of challenges and lived experiences than healthy youth. For example, youth dealing with chronic conditions that require medication might have different perspectives on medication adherence, self-management behaviors, engagement in their own care, care navigation, and planning for independence.

9. Conclusion

Health services research aims to improve the quality of health and overall well-being of youth; however, the participation of youth in its design, implementation, and evaluation is minimal. Thus, there is a need to maximize youth engagement in the design and implementation of policies and programs tailored to meet the needs and priorities of young people. The creation of a YAB has shown to be one of the channels through which youth can be meaningfully engaged in adolescent health research initiatives. The creation of a YAB amplifies youth voices and creates the opportunity for researchers, healthcare professionals, and policymakers to create relevant and effective initiatives that are tailored for youth.

Funding

This study was supported by KL2 grant KL2 TR002374-03 and grant UL1TR002373 to the University of Wisconsin Institute for Clinical and Translational Research by the Clinical and Translational Science Award program, through the National Institutes of Health (NIH) National Center for Advancing Translational Sciences. The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH. Sponsors had no further role in study design, data collection or analysis, or writing and submission.

Author statement

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Declaration of competing interest

All authors report that they have no financial disclosures and no conflict of interest.

Acknowledgment

The authors would like to thank Tyler McCarthy and Joanne Peters from the UW School of Pharmacy for assisting in editing the final manuscript. Lisa Szela from the UW School of Pharmacy for her help with the recruitment of the YAB, for leading meetings, for creating professional development materials for YAB members, and for championing the lab. The authors would also like to extend immense thanks to the YAB members for their participation.

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