

Engaging Youth in Bladder Health Research: Perspectives from a National Consortium's Young Women's Health Council

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ABSTRACT

Engaging community stakeholders is increasingly an expected component of health-related research. This paper describes the development and implementation of a Young Women's Health Council (YWHC) within the context of a multicenter research consortium focused on the emerging field of bladder health from the perspective of its members. The principles of mutual benefit and social exchange direct the council's activities. To participate in the YWHC, members, ages 13-21 years, must be attentive to communications from facilitators and actively participate in bimonthly 90-minute Zoom meetings during which they provide input on research activities. YWHC members gain valuable knowledge, skills, and motivation for personal health and health careers and take pride in contributing to the research. Although the YWHC positively impacts both the young women and the research consortium, there remain areas for improvement. Recommendations are presented for fostering meaningful community engagement with youth in research initiatives.

KEYWORDS:

Bladder health, Community engagement, Adolescent and young adults, Youth advisory board, Community perspective

INTRODUCTION

Engaging community stakeholders as a means of improving research questions, design, findings, and ultimately the impact of the study is increasingly expected of researchers.¹⁻⁶ Youth participatory action research, in which youth are engaged as advisors, has been recognized as an approach to liberatory research (YPAR).⁷ While it is increasingly common to engage youth in community driven research studies, we found no examples in the literature of their participating specifically in large national research consortia. The voices of young people are particularly needed to inform research on risk and protective factors that may influence adolescent health or health trajectories over the life course.⁸ This manuscript describes young women's experiences developing and participating in a youth advisory board (YAB) embedded in a large, national federally funded research consortium.

The Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium is a transdisciplinary scientific network, consisting of nine geographically diverse research centers and a Scientific and Data Coordinating Center, established by the National Institute of Diabetes and Digestive and Kidney Diseases in 2015 to conduct research on bladder health and prevention of lower urinary tract symptoms (LUTS) in girls and women.⁹ PLUS established the Young Women's Health Council (YWHC) in 2019, institutionalizing youth voices and perspectives across the multi-institution research consortium operations to guide research efforts and to build youth's capacity as researchers.¹⁰ The timeline of these activities is in the appendix.

This manuscript was developed in close collaboration between PLUS researchers and the YWHC members through intentional discourse arising during council meetings. As a part of our council

ethos, facilitators regularly check-in with members on ways to improve and what our greatest strengths are. Through these discussions, council members expressed that the work we do as the YWHC is meaningful and we conceptualized creating an academic paper to provide tips and inspiration for other researchers that are interested in replicating our efforts. YWHC facilitators sent out a survey to the group to elicit the perspectives of the council as well as which members were interested in joining the writing group for this manuscript. YWHC member authors are indicated by their affiliation. This manuscript was developed through discourse with all council members, a qualitative review of quality-improvement surveys completed by the council, and collaborative meetings with the writing group. Some sections of this manuscript were written by YWHC members. These are indicated in the headers as “Member Perspectives” and are written in first person. Others were developed by YWHC Facilitators and PLUS investigators, in collaboration with YWHC members. These are indicated in the headers as “Joint Perspectives.”

BACKGROUND

Who are We? (Member Perspectives)

The YWHC is a coalition of young women, ages 13-21 years, from across the United States who serve as the Youth Advisory Board (YAB) to the PLUS Consortium. We meet bi-monthly via video chat to learn about, discuss, and provide feedback on various components of the PLUS research on women's bladder health. Drawing on our lived experience, we give researchers more direct knowledge of the stakeholders that PLUS aspires to reach.

Purpose and Intention (Joint Perspectives)

The YWHC was established to integrate the voices of young women into PLUS’s research. The

YWHC is one branch of PLUS's community engagement efforts, which strengthen the relationship between researchers and communities and ensure that the consortium takes the perspectives of community members into account when designing research.¹¹ PLUS implemented the YWHC with the intention of creating a bidirectional and mutually beneficial relationship between the council members and investigators. The YWHC provides input on elements of PLUS research that includes adolescents and young adult women as research participants, ensuring this work is relevant and resonant to the community. In the spirit of reciprocity, PLUS incorporates educational activities and opportunities for growth into each meeting, with an emphasis on leadership experience, research knowledge, skills-building, and exposure to careers in public health and health care. The YWHC is co-facilitated by two members of the PLUS research staff under the counsel of PLUS investigators with expertise in community-engaged research.

COMMUNITY ENGAGEMENT APPROACH

Recruitment of YWHC Members (Joint Perspectives)

PLUS allots two YWHC slots per research center. PLUS is comprised of nine universities across the United States, with representation of the West Coast, East Coast, Midwest and the South. At the inception of the YWHC, each center was provided with documents produced by members of the PLUS Community Engagement team which outlined the YWHC purpose and suggested procedures to support recruitment efforts using their existing community engagement mechanisms, relationships, and investigator networks. These are living documents that evolve with the YWHC.

YWHC membership includes young women aged 13-22, with a mean age of 17.3 (SD 2.5) and a median age of 18. Recruiting across the research center locations and across adolescence ensures that the YWHC includes a geographically and age diverse member pool. The coordinators at each site developed their own promotional recruitment materials and procedures for reviewing and selecting members, which allowed for the necessary flexibility of recruiting across different communities at the start. Recently, as we have iterated the recruitment strategy for the YWHC with input from the original members, we implemented a brief nomination application for the sites to complete that also allows for self-nomination of members. This two-question application elicits the reason for interest in the council and a summary of the nominee's background, including skills and expertise.

Meeting Logistics (Member Perspectives)

The YWHC uses interactive online tools to help coordinate and run meetings. These tools were selected based on discussion between us and facilitators. Since the YWHC is composed of participants in different time zones, the co-facilitators identify regular meeting times based on maximum availability as assessed via online poll.

YWHC meetings are conducted virtually via Zoom. YWHC meetings originally occurred once per month to establish rapport among members and now occur every two months for 90 minutes. Between meetings, we communicate with the facilitators through email and GroupMe, a group texting application. We find these methods help us maintain a professional but approachable line of communication between ourselves and the facilitators. YWHC members are compensated with a \$50 gift card per meeting.

Meeting Content (Joint Perspectives)

Each YWHC meeting is designed to accomplish two goals: supporting the professional development and education of YWHC members and contributing to PLUS research. Each meeting is divided into three main portions:

Community building activities and ice breakers: Meetings begin with games or themed questions to foster connection and trust among the council members, facilitators, and guest speakers (typically PLUS investigators).

Educational Activities: Each meeting incorporates an educational element for members that is designed to foster professional development, expose members to careers in healthcare and research, or build the capacity of the council to deal with increasingly complex research tasks. These activities are designed with reciprocity in mind – the members learn skills and are exposed to concepts that align with their interests (as solicited on regular quality-improvement surveys) and are applicable beyond their involvement in the YWHC. As the YWHC members gain more sophisticated understanding of research practices, PLUS can request deeper involvement in the consortium’s research.

During most meetings, a PLUS investigator gives a 20-minute talk about a career in science, bladder health, or research. These talks have included topics such as community-based participatory research, journeys to careers in the medical field, research study design, tools in research, and research publication. In one meeting, a YWHC member who worked with Planned Parenthood shared her expertise by giving a talk on sexual health, stretching her presenting and communication skills. Additionally, meetings can include activity-based learning such as group discussions about women’s health topics, designing mock-research

studies, and brainstorming responses to questions using digital collaboration tools such as Google JamBoards. These activities intentionally build on each other and increase in complexity from meeting to meeting. For example, in an early meeting, a PLUS investigator presented on qualitative and quantitative research methods, a later meeting shared findings from PLUS research, and another meeting focused on issues in women's bladder health. After these activities, the YWHC provided input on common language summaries that describe the findings from published PLUS research studies for lay audiences. The educational activities built the capacity of the council to serve as a bridge between PLUS investigators and community members, improving dissemination efforts.

Research Input and Guidance: The YWHC facilitators liaise with PLUS investigators to determine which aspects of PLUS research would benefit from our input. The YWHC has provided feedback on the wording of survey instruments, common-language research dissemination products, research-related social media posts, recruitment materials, study instructions for participants, and more.

The YWHC facilitators routinely collect feedback from members through anonymous, quality-control surveys and group discussions that are used to inform meeting agendas and facilitation practices.

Communication Between YWHC and PLUS (Joint Perspectives)

There are three main avenues for communication between the YWHC and PLUS Consortium: de-identified meeting notes that are shared with the PLUS Consortium, direct conversation during meetings, and anonymous surveys. Notes from YWHC meetings that include feedback on

PLUS research are relayed to the relevant working group(s) (i.e., Dissemination Committee, Recruitment and Retention workgroup, Diversity, Equity and Inclusion task group), and YWHC facilitators report back to the council members about how their input was used. Additionally, the PLUS investigator guest speakers communicate how the YWHC has contributed to the progress of their research. The PLUS Consortium also periodically collects anonymous survey data to evaluate the broad impact of the YWHC on its members.

RESULTS

Benefits to YWHC Members (Member Perspectives)

Learning about PLUS's history and attending guest talks from experts has helped us explore our interests in science and medical fields.

[The YWHC] has made me realize that the work that public health specialists do is beneficial to an extremely wide audience, which lines up wonderfully with my goals for my future career. (Age 16, University of California San Diego)

I now know more about bladder health and am more curious to discover other parts of my health that I have overlooked. Being in YWHC has made me more passionate about the representation and research of female bodies. (Age 18, Washington University)

It's [the YWHC] offered me a place to share my opinions and perspectives as a young woman and feel that I can have an impact on research. I've also learned about various careers in medicine that I didn't know existed. (Age 18, University of Michigan)

Connecting with presenters has exposed us to topics and interests to pursue down the road and taught us about the value and reality of research.

I've gained knowledge about bladder health and the research process. (Age 21, University of Alabama at Birmingham)

I have widened my perspective to consider more people and their needs, and I have learned more about what goes into conducting an extensive study. (Age 18, Washington University)

Besides educational benefits, the YWHC helps us hone our collaboration skills and build community with our peers.

Because this group is made up of young women around the same age from all over the country, I have been able to listen to others' opinions and views, whether they are similar or completely different. (Age 18, Washington University)

As a participant in the YWHC, I have learned invaluable lessons about women's health and the research that goes into it. Additionally, I have been put in contact with women who I otherwise would have never met; this has allowed me to have contacts in other parts of the country should I need them. Lastly, this is a leadership opportunity like none other. (Age 16, University of California San Diego)

Providing input on research practices and contributing to productive meetings pushes us to use a diverse set of skills. For instance, offering feedback requires us to explain the reasoning behind our opinions to PLUS researchers and extrapolate, based on our experiences, how to best support

good research. Clearly conveying our thoughts has become easier with more meetings. Furthermore, we have learned to cultivate an open-minded and safe community that allows members to share personal experiences or controversial ideas.

Benefits to the PLUS Consortium (Joint Perspectives)

The YWHC has provided specific feedback to the PLUS consortium spanning elements of the research process such as recruitment methods, phrasing of questions on novel research instruments, and common-language dissemination products. For example, on review of drafts of bladder health surveys designed for adolescents, the YWHC shared that their peers may interpret questions about well-being as equivalent to questions about health and recommended adding and provided examples to specify the questions for younger audiences. Additionally, collaborating on the development of a common-language dissemination product of a PLUS publication, the YWHC recommended changing the format of the document from a flyer to a brochure and altering to the text to make the language more inviting and accessible to their peers. This included recommendations such as moving away from expressions such as “Toileting Behaviors”, towards terms like “Bathroom Habits” and presenting the data in a narrative format. They also shared potential distribution venues that would reach adolescents more effectively, such as social media. The youth guidance complements feedback PLUS receives from other community engagement mechanisms to ground research activities.

DISCUSSION

How to Improve the YWHC (Member Perspectives)

The YWHC has evolved since its inception, yet there remain areas for improvement. Our ability

to create a strong sense of community is limited by our bimonthly virtual meetings. Offering ways to connect offline or more regularly could support greater sense of connection to each other and responsibility to our shared goals. Additionally, many of our activities include group discussions which may result in groupthink. To avoid this, facilitators could incorporate some opportunities to review materials independently. Expanding YWHC recruitment to further diversify membership could help ensure that our feedback reflects the range of youth involved in PLUS' studies.

Recommendations (Member Perspectives)

Although there is no single correct way to foster community engagement, we offer several suggestions for researchers interested in starting YABs.

Diversity in Recruitment:

Recruiting members from diverse backgrounds is key to elicit a variety of ideas and perspectives. We recommend that researchers focus on recruiting members who are underrepresented in research. This may require reaching out to community members through non-traditional channels such as identity-based associations, student societies, or social media communities. In the early stages, recruitment for the YWHC was done through existing relationships between sites, principal investigators, and the community. While this was useful when getting started, it may have limited the diversity of participants. YWHC member recruitment has since been adapted to include a nomination process where potential members can be nominated by PLUS investigators, current YWHC members, or self-referred. Prospective members are asked to share their background, primary identities, and motivations for joining the YWHC.

Facilitation:

It is also important to find leaders for the council who foster a comfortable space and help youth understand the research they are guiding. The YWHC facilitators ensure that youth feel comfortable through community norm and goal setting discussions, bonding activities such as personal icebreakers and birthday acknowledgements during meetings, and remaining accessible after the meetings for one-on-one conversations as necessary. Comfort within the YWHC was built overtime as we got to know one another. Effective and consistent facilitators can help ensure that time is spent productively and that questions are appropriately tailored. It is also essential that facilitators create a non-judgmental space where participants can express their opinions. Offering multiple ways to participate can help people voice their thoughts. This is relatively simple in virtual meetings, where participants can privately message their opinions to group leaders. However, one can also use other methods to collect feedback during in-person meetings, such as brainstorming maps and sticky notes.

Compensation and Reciprocity:

Researchers should compensate YAB members. YWHC members are compensated with online gift cards. Offering compensation makes participation more feasible for individuals who might otherwise have to prioritize paid work, increases commitment, and demonstrates that youth contributions are valued. If offering monetary compensation is not possible, consider other forms of compensation, such as training or resume-building activities. Other ways to increase buy in from members include highlighting the importance of the YAB and demonstrating the effects of their suggestions. To determine which form of compensation is preferred by your members, offer

them options and allow them to pose their own suggestions while remaining transparent about what is possible.

Consistent Communication:

Researchers who interact with YABs should be responsive to their members. The YWHC uses a combination of email and messaging app communication that we discussed and agreed upon. Different groups will require different structures and guidelines to be effective research advisors. Whether members want more frequent shorter meetings or fewer long meetings, what they want to learn about, and how they'd like to engage will vary by group. YWHC members share their interests and suggestions for meetings through anonymous quality-improvement and reflective surveys. There is no 'one size fits all' approach, and the most straightforward method to determine the needs of your group is to ask and remain open to feedback.

This exploration of the experiences of youth on a YAB for a large national research consortia provides insight into the conditions in which youth can optimally be engaged in an advisory role in a large national complex study. We found it's not just about building and providing space but rather about valuing the unique, diverse assets youth bring and maintaining a respectful, trusting co-learning environment so that youth experiences and priorities can be deeply understood.

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Prevention of Lower Urinary Tract Symptoms (PLUS) Research Consortium

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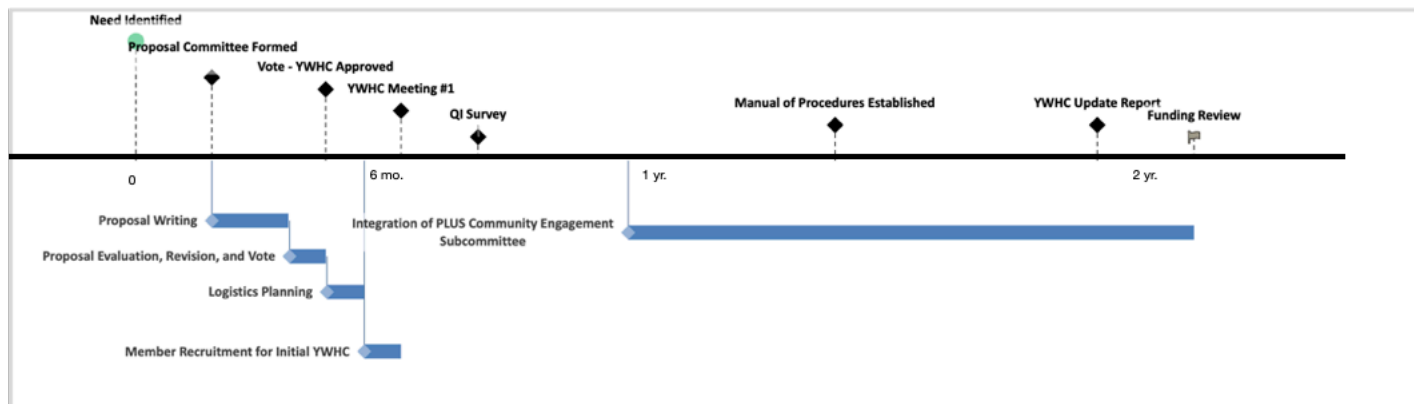
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Appendix 1A: Timeline of the YWHC

PROGRESS IN COMMUNITY HEALTH PARTNERSHIPS: RESEARCH, EDUCATION, AND ACTION (PCHP). FORTHCOMING. ALL RIGHTS RESERVED.



Appendix 1B: Table and Description of Milestones

Timeline Event	Description
Need Identified	Need for the Youth Council is expressed in the Adolescent Bladder Health Initiative (ABHI) group by experts in adolescent health.
Proposal Writing	The ABHI team prepares a proposal for consideration by the PLUS consortium to formally establish a Youth Council to help guide the research involving adolescents as subjects.
Proposal Evaluation and Revision	The ABHI team communicates with the PLUS consortium and adapts the YWHC proposal into the final version.
Vote – YWHC Approved	After numerous discussions and proposal iterations, the PLUS Consortium approved the initiative.
Logistics Planning	<ul style="list-style-type: none"> - Establish team roles and meeting times - Hire Two Facilitators - Set timeline for meeting - Develop recruitment guidance - Determine and test online meeting technology - Plan meeting formats and initial research support tasks
Member Recruitment for Initial YWHC	<ul style="list-style-type: none"> - Guidance on purpose and inclusion criteria for members provided to the sites - Sites nominate 2 members and connect them with YWHC Facilitators
YWHC Meeting #1	First YWHC meeting occurs with a focus on introductions, community building, and

	introduction to the goals and activities of the YWHC. Members share their perspectives on group norms and values.
Integration of the PLUS Community Engagement Subcommittee	- Additional members of PLUS with interest in Community Engagement join leadership to guide the YWHC This team develops a formal manual of operating procedures to codify the YWHC
Manual of Operating Procedures Established	
QI Survey	- On a bi-meeting basis, an anonymous Quality Improvement survey is sent to YWHC members to elicit feedback on what can improve the meetings and what topics they would like to learn about
YWHC Update Report to the PLUS Consortium	To update the larger consortium about the activities of the YWHC, we created video testimonials from YWHC members that shared their experiences as a part of the group and a summary of the research activities that the YWHC provided feedback on and were adapted accordingly.
Funding Review	YWHC is re-established as a formal arm of the community engagement efforts in PLUS, with dedicated funding allocated from the