

Bridging the Gap to Youth Representation in Health Research: the Alberta Youth Health
Advisory (AYHA)

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Plain English Summary

An ongoing challenge in healthcare is involving youth in decision-making regarding health-system related issues that directly and indirectly affect them. Specifically, in Alberta, Canada, there has remained a lack of an established, province-wide platform to meaningfully engage with youth and use their perspectives to inform future directions. Research studies repeatedly demonstrate that youth involvement in healthcare initiatives and research design increases their effectiveness and adaptability, while also reciprocally benefiting the youth by promoting autonomy. In order to fill this gap in the province, the Alberta Strategy for Patient Oriented Research (AbSPORU) Patient Engagement Team created a provincial youth advisory titled the Alberta Youth Health Advisory (AYHA). This commentary paper outlines the development process, operations, and impact of AYHA. The advisory aimed to provide an empowering platform for youth in Alberta, allowing them to share their perspectives in a safe medium and connecting them to researchers in the field of youth health. Youth also found that their personal and professional growth was enabled through opportunities including research information sessions, conferences, and more. Altogether, AYHA has been reported to inform youth-related researchers and healthcare professionals on how to improve their approaches while also benefiting the youth involved in the advisory.

Abstract

Background: Recently the use of youth advisories has increased, and research shows that youth advisories benefit youth and researchers reciprocally. To address the lack of youth perspective in health research and policy making in Alberta, the Alberta Support for Patient Oriented Research Unit (ABSPORU) Patient Engagement Team, created the Alberta Youth Health Advisory (AYHA). In this commentary we address the creation of the advisory, main motives & objectives, the extent to which it empowered youth voices, and the importance of including youth voices in health research.

Methods & Results: The main motivations & objectives for creating AYHA was to increase youth representation in health research, provide for youth a platform to express their voices without judgement, provide youth professional development opportunities, and empower them to engage in health research. In order to gauge on the impact of the council on the youth, 10 advisory members volunteered to participate in iterative Zoom sessions to answer 5 prioritized questions. Key themes on youth perspectives were then extracted from their response. Members shared how participating in AYHA prepares and empowers youth to engage in health research and can lead to creating adults that are better equipped and more involved in health research and policy making. AYHA empowers youth to collectively influence change within the health system by providing a platform for youth perspectives to be shared with health experts and researchers.

Conclusion: The Alberta Youth Health Advisory is a successful model for a youth advisory group. It provides youth with agency to influence health research and policy by enabling youth to lead the direction the advisory takes & connecting youth with researchers to enable them to influence health research and policy making. AYHA also builds youth professionally through capacity building sessions and conferences. In all, youth become empowered leaders. Overall, AYHA provides a framework for creating a successful advisory, and is effectively filling the gap of youth representation in health research.

Keywords

Patient Oriented Research, Youth Engagement, Youth Advisory, Health Research, Policy Making, Patient Advisories, Youth Centered Research, Youth Council, Health Advisory

Background on previous youth health advisories

Historically, youth involvement in decision- and policy-making has been limited; however, today, it is an area of active research to understand how youth engagement can be increased in decision making. In 1989, the United Nations member states devised a structure for youth

advisories to include youth in decision making.^{1,2} However, the use of youth advisories varies across geographical space, and field of interest.¹ Chan et al. conducted an environmental scan of youth advisories & their structure, which found 40 advisory groups, most often associated with hospitals, non-profit organizations, researchers, youth service hubs, and local community governments.³ The main purpose of these advisories is primarily to provide feedback on services and interventions produced for youth.³ While advisories are beneficial in gathering feedback on services and interventions targeted towards youth, which enhances the relevance of these services and interventions, these advisories may not give youth decision-making power.^{3,4} Few advisories include youth in leadership and actively involve them in decision-making on the advisory. When Arunkumar et al. created a youth advisory to advise their own research teams they found that youth needed to be involved in every aspect of the research project as co-researchers and partners and be in equal control of the directions the advisory took as non-youth members.¹

Limited number of health or research advisories across Canada are youth-led and allow youth to lead the changes they would like to see.³ Adult-led youth advisories face challenges of tokenism, adultism, and struggle to create a trust based adult-youth relationship that would allow youth to express their opinions freely.^{1,2,5} Reviews conducted on youth advisories and their structure recommend the need for training—of both adults who organize, recruit and facilitate youth advisories, and training of youth to equip them with skills and capacity needed to lead an advisory.^{2,4,6} It is important to recognize and platform youth voices and concerns, as current and future stakeholders in their communities and healthcare systems. They make up a substantial fourth of the world's population, and investing in their health at early stages leads to improvements in the present and later generations.⁷ Their unique perspectives and experiences contribute fresh insights, leading to lasting solutions.⁸ This is recognized by global organizations, including the World Health Organization (WHO) and United Nations International Children's Emergency Fund (UNICEF), who outline the importance of involving youth in their personal health, as well as public

health.⁹ The United Nations Conventions on the Rights of the Child outline the right of youth to express their views freely, and to ensure that those views are considered by policy-makers and decision-makers.¹⁰ In including their voices, decision-makers can make progress towards policies and practices that align with youth needs and aspirations.

Youth participation in community, policy, and health advocacy provide mutual benefit to all parties involved. Their lived experiences serve as valuable insights for researchers and their outlook on their futures provide policy-makers a sense of direction.¹¹ In return, their engagement leads to empowerment and agency, affirming their autonomy and the idea that they have a voice in matters related to their health.¹² Youth participation in health promotion also leads to skill development and community belonging, factors that are fundamental to navigating the complex transition to adulthood.¹² Researchers, policymakers, and organizations can promote a participative culture, leading to increased civic engagement and positive outcomes for youth-oriented collaborative research processes, social connection, and community contributions.^{11,12} One of the most widely reported benefits youth have from being involved in advisories is an increase in confidence, decision-making skills, and empowerment.^{1,3,5} In addition, it increases relevance and accuracy of youth centered research.⁴ Thus, engagement in youth advisories not only improves research quality and policy-making, it reciprocally benefits youth as well.

About AYHA

The Alberta Youth Health Advisory was created to address the lack of representation of youth voices in health research and policy. The Alberta Strategy for Patient-Oriented Research Patient Engagement Team (AbSPORU PE) provides a platform for youth voices and allows youth to benefit from the youth-led experience. AYHA strives to ensure that youth from different demographics can advocate for prevalent concerns in healthcare. This commentary will demonstrate how the Alberta Youth Health Advisory has benefited and impacted the youth involved, the main motivations & objectives for creating this advisory, the extent to which it has empowered youth voices, and the importance of including youth perspectives in healthcare. Our

ultimate goal is to facilitate an appreciation and understanding of the importance of youth advisories and a greater extent of youth advisory formation internationally.

The Alberta Youth Health Advisory (AYHA) is an initiative of the Patient Engagement Team at AbSPORU, led by Dr. Maria Santana and coordinated by Tiffany Barbosa.

In March 2022, community leader Thompson Luu was invited to meet with Dr. Santana and Tiffany for the initial discussion on creating the AYHA. By April 2022, the AYHA Terms of Reference (TOR) were developed, aligning with the core values of the PE Team at AbSPORU. Compensation guidelines from PE AbSPORU were considered, providing a \$25 gift card to AYHA members who attended meetings.

A recruitment strategy was carefully crafted, targeting youth aged 15 to 25, with considerations for diversity, ethno-cultural background, gender, neurodiversity, and representation from both urban and rural Alberta. The interview structure was established as an “informal conversation.” It was also decided that monthly virtual meetings would be held via Zoom.

The first recruitment took place in spring 2022, selecting eight members through interviews from Calgary, Edmonton, Lethbridge, and Lac La Biche. Thompson Luu served as the first AYHA Chair, and University of Calgary student Farwa Naqvi was invited to co-facilitate the monthly meetings. Melissa Broadbent was later selected as a co-chair.

Together, Melissa, Thompson, and Farwa did remarkable work in facilitating and engaging with the members. However, Melissa resigned from her co-chair position to focus on starting her own business, and Youssef Elezzabi was then offered the leadership opportunity as a co-chair.

Due to a lack of participation, attendance, and commitment from the members, the coordinator decided to form a new group and initiated a fresh recruitment process in summer 2023. The interview structure remained largely the same, with some additions, such as asking specifically about lived experiences with the health system and network connections. We also emphasized the importance of participation as a mandatory requirement.

The Alberta Youth Health Advisory currently consists of 17 members. Over the past year, we have seen significant growth in our members by providing them with a voice and offering additional opportunities both inside and outside the advisory. These opportunities included calls for leadership as a co-chair (with a 6 to 12-month commitment), Currently, Ifrah Anjum and Ayush Jha serve as AYHA co-chairs. Thompson was offered the role of Support Coordinator, helping to facilitate the smooth transition to the new co-chairs and taking on additional responsibilities.

The AYHA co-chairs also provide updates and represent youth voices at the Albertans4Health-Research Collaborative Council every three months.

These opportunities also include invitations to participate in working groups, and the chance to engage with and share within their networks in health research. Members are also invited to attend and/or present at conferences and to participate in community events to increase their visibility.

Working groups offer members another opportunity to take an active role in research studies, which can even lead to publications.

As a part of the meetings structure, the members choose different topics of interest, allowing the coordinator, support coordinator, and co-chairs to plan the monthly meetings accordingly. Health experts are routinely invited to share information and perspectives on these selected topics and after their presentations, they engage in discussions to hear the youth members' perspectives. By leading to open-ended group discussions that gather youth perceptions, the insights are used to advise policymakers and other interested professionals within and outside of the Alberta Strategy for Patient Oriented Research Support Unit (ABSPORU). Some health experts that have attended an AYHA meeting include Dr. Simone Lebeuf a pediatrician specializing in teen & adolescent health; and nutrition services team from Alberta Health Services (Heather Osmond, Mervin Leibel, Caroline McCauley, Jaclyn Klukach, Adina Shafi, and Danielle Todd).

The Patient Engagement Team of ABSPORU also supports capacity-building sessions to help youth enhance their knowledge and research skills. These sessions allow youth to develop their skills to conduct patient oriented research. Furthermore, other opportunities include presenting on a conference panel for the NorthWest SPOR Collaborative Forum. Presenting at conferences offers opportunities for members to develop leadership and communication skills. Interested members are invited to co-present at provincial forums, (i.e. the NW SPOR Collaborative Forum, Better Together: Patient Oriented Research conference) where they share the advisory's purpose and insights with researchers and healthcare providers, while also engaging in networking.

Members of the advisory came into the meetings with the same goal of making a difference, and all the opportunities provided by being on the AYHA allow them to expand on their interests while continuously contributing to society. Through AYHA, a diverse group of youth are brought together and their diverse perspectives allow the advisory to ensure outcomes are as influential to society as possible.

Research Process

To address the commentary's main priority, iterative sessions over Zoom meetings were conducted with all advisory members invited. Of the total of 17 members, 10 members participated. The AYHA decided to base this commentary on five prioritized questions that would facilitate discussions relating to the goal of this commentary. Members of the advisory openly suggested questions that would align with the goal of the commentary. Voting was conducted to narrow down to the top five questions. The five questions this commentary will discuss are: what were the main motivations & objectives for forming the AYHA, how does the advisory ensure an accurate representation of Alberta's youth demographics, why is it important to include youth voices in healthcare, what was the personal growth of members since joining the AYHA, and to what extent does a youth health advisory empower and grant agency to youth.

Advisory members participated in a round-table discussion to answer the five questions. To ensure everyone's voices were heard members were placed in breakout rooms with five people in each room. Within each breakout room, members took turns answering the five questions and answers were documented on a shared Google Document. After 20 minutes of discussions the advisory members reconvened from the breakout rooms and shared their answers collectively. A record of prominent themes that arose in response to these questions was retained, merged, and are presented below.

Results

What were the main motivations and objectives for forming the AYHA?

The creation of a health advisory focused on Albertan youth was inspired from multiple different motives. Firstly, youth are highly underrepresented in research pertaining to youth. Creating a youth focused advisory can remedy the underrepresentation of youth voices. Additionally, youth need a platform that allows them to express their ideas safely, without repercussion or judgment. An advisory also allows researchers and policy makers to have an avenue for ensuring health policies align with the needs of youths and their ideas. In addition, the advisory was intended to provide youth with professional development and capacity building. The advisory we aimed to create would be inclusive and representative of youth in Alberta. This would allow youth to discuss topics from a youth lens, while also improving their awareness and understanding of different perspectives on current health issues and research processes.

How does the advisory ensure an accurate representation of Alberta's youth demographics?

The Alberta Youth Health Advisory strives towards accurate representation of Albertan youth perspective by utilizing a diversity-focused recruitment approach. Youth between the ages of 15-25 are actively engaged in the advisory with the recognition that those in high school, pursuing post-secondary, or entering the workforce may have different experiences when it comes to the youth transition from adolescence to adulthood. Geographical location also plays a part in the selection process, with most of the representation constituting youth from the main metropolitan centers of the province, Calgary and Edmonton. Further efforts are being made to recruit participants from rural areas, as their healthcare experience may differ from those in urban or suburban communities. Individual background and context also factor into selection decision-making, as the advisory is made up of various ethnic, religious, and immigrant backgrounds, as well as those in potentially marginalized groups, including the neurodiverse and those who identify in LGBTQ2I+ groups. In particular, recruitment efforts have been made to recruit those with Indigenous backgrounds, as their experiences with the healthcare system may differ significantly from non-Indigenous individuals.

Though AYHA seeks to represent Albertan youth voices and concerns by recruiting a heterogenous group of individuals, it should be recognized that the advisory may not fully reflect the entire demographic makeup of Alberta's youth. Demographics in AYHA were not deliberately matched to reflect population demographics within Alberta and due to the nature of having an advisory of limited size, many common or marginalized voices within the province may not be represented within the advisory.

Why is it important to include youth voices in healthcare discussions?

A fundamental purpose of the AYHA is to promote youth involvement in healthcare discussions to better represent the diversity of Alberta. Though youth make up a significant

portion of the population, they often lack the forum to contribute to change. This may lead to bias in decision making and research, as youth perspectives are being represented by others, rather than shared directly. Youth face unique health conditions that adults may not face, necessitating representation to properly evaluate the experience. Even in conditions that equally impact youth and adults, the effect on youth may differ. Youth are also impacted by different policy issues than adults, further justifying their involvement in decision making. Creating policy for the purpose of serving youth without considering direct accounts of their lived experiences may lead to misrepresentation and poor resolution of the concern. Even though each adult was once a youth, their lived experience may differ significantly based on the political, social, and scientific climates at the time. Social media, for example, significantly impacts youth in a way that other generations have not experienced. Beyond the importance of representing their perspectives, youth involvement in health care decision making promotes skill development for later life. This trickle-down effect may result in more informed adults that are better equipped for and more likely to engage in healthcare research and policy making.

What was the personal growth of members since joining the AYHA?

Since joining the advisory, the members reported that they have experienced substantial personal growth; in particular, they report having developed their capacity to understand and address health-related issues that are prevalent amongst Albertan youth today. Many participants reported an enhanced awareness of health-related challenges, finding that the discussions enabled them to hear perspectives that they would not otherwise come across in their day-to-day lives. This improved the youth's ability to identify disparities within healthcare. In addition to this broadened exposure, members found that they developed lifelong skills such as communication, leadership, research, and networking. They found these to be developed through the discussion-based nature of the meetings, which also fostered a heightened sense of agency and

responsibility; to reflect critically on the barriers to adequate healthcare that still exist for youth and use this as determination to keep making change.

To what extent does a youth health advisory empower and grant agency to youth? (for benefits and empowerment)

A youth health advisory empowers and grants agency to youth by enabling them to collectively influence change within the health system and policy on a larger scale than individual efforts could achieve. Through active participation in the advisory, youth develop communication and advocacy skills in a setting that is both relaxed yet formal. Such an environment allows the youth to engage directly with subject-area experts who actively listen to their perspectives and are willing to implement their suggestions in practice or convey them to higher levels of decision-making, all while simultaneously imparting the expert opinions in the discussion to enhance youth education in subject areas. This process not only facilitates the long-term implementation of youth ideas but also fosters a sense of ownership and responsibility, transforming youth from passive recipients of public policy into active, empowered decision-makers.

Conclusion

Youth health advisory groups are effective in engaging youth as equal stakeholders, ensuring their voice is heard in matters affecting youth healthcare access and outcomes. Youth, defined as those aged 15–25, represent a critical transitional period in life, encompassing both adolescence and early adulthood. AYHA exemplifies a successful and impactful youth advisory group, offering youth a broad range of opportunities in health research and policy, serving as a model for replication in diverse global contexts. Looking ahead, AYHA will continue to target maximum youth engagement, broaden the scope of personal and professional development opportunities for members both internally and externally, and further expand its activities (within

the advisory and with external stakeholders) and network to improve its impact on policy making and healthcare practices.

Appendix

List of Abbreviations

AbSPORU PE – Alberta Support for Patient Oriented Research Unit Patient Engagement Team

AYHA – Alberta Youth Health Advisory

WHO – World Health Organization

UNICEF – United Nations International Children’s Emergency Fund

Declarations

Ethics Approval and Consent to Participate:

N/A

Consent for Publication:

N/A

Availability of Data and Material:

Data available upon request to the authors

Competing Interests:

None Declared.

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Authors’ contributions:

YAE proposed the initiative. IA, AJ, TL, JK, HK, SP, TG, YAE, MA, TT, SL AYHA members who answered the priority questions and were involved in brainstorming the priorities of the commentary. IA, AJ, TL, SP, TG, YE, JK, are AYHA members who wrote the manuscript draft. HK and JK lead and organized the research project. SA, TB, MS reviewed and edited the manuscript. MS is the primary investigator. All authors reviewed and approved the final copy of the manuscript.

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NOT PART OF COMMENTARY

Table 1: List of Health Experts who presented and engaged in discussion with youth regarding different health topics, and list of capacity building sessions hosted by ABSORU PE Team.

Meeting	Presenter	Topic
Health Experts Invited to Present at Monthly Meeting		
September 2023	Dr. Simone Lebeuf, a pediatrician specializing in teen & adolescent health with an interest in sexual and reproductive health.	Sexual and Reproductive Health
May 2024	Heather Osmond Hoover, Registered Dietitian. Heather is a Population Public	Nutrition

	Health Dietitian in Nutrition Services, Alberta Health Services	
November 2024	Nutrition Services Team, Alberta Health Services: Heather Osmon Hoover, Mervin Leibel, Caroline Mcauley, Jaclyn Klukach, Adina Shafi, Danielle Todd.	Developing nutrition literacy resources for youth.
Capacity Building Sessions Hosted by ABSPORU PE Team Members		
February 2024	Sadia Ahmed & Farwa Naqvi	An Introduction to Health Research
March 2024	Sadia Ahmed	How do research projects and papers unfold?
April 2024	Matt Luzentales-Simpson	Research Ethics