

# Amplifying adolescent and emerging adult voices: Development of a pediatric-to-adult transition research advisory council

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## ABSTRACT

**Background:** Adolescents and emerging adults (AEA) with chronic health conditions may face numerous challenges when undergoing the transition from pediatric to adult health care. Despite the need for engagement with AEA in health research, little is known about how researchers operationalize this engagement. In an effort to enhance transparency in the practices of patient engagement, this commentary details the process of developing a pediatric-adult transition-specific youth advisory council in Alberta: the Transition Research Advisory Council (TRAC).

**Objectives:** We provide an overview of AEA engagement in health research and detail TRAC's recruitment and onboarding strategies. Moreover, TRAC members provided reflections on their motivations and experiences during the onboarding process.

**Key recommendations:** This commentary provides key recommendations for AEA council development, emphasizing equity, diversity, and inclusion principles, optimizing compensation plans, adopting an iterative engagement approach, fostering capacity-building and mentorship, and promoting empowerment in decision-making.

## 1. Introduction

The transition from pediatric to adult health care is a challenging time for adolescents and emerging adults (AEA), associated with adverse health outcomes, increased hospitalizations and emergency room visits.<sup>1,2</sup> A team of multidisciplinary stakeholders including researchers, clinicians, and administrators located in Alberta, Canada, are dedicated to developing and testing interventions focused on improving transitions from pediatric to adult care.<sup>3</sup> Samuel et al. are leading a province-wide Transition Navigator Trial, the largest pragmatic, randomized controlled trial evaluating the effectiveness of a patient navigator intervention for youth with chronic conditions transitioning to adult healthcare.<sup>3</sup> Given this team's commitment to advancing the field of pediatric-adult transitions, AEA voices are needed to ensure their

priorities are being addressed.

There is a paucity of literature on the experiences of researchers conducting meaningful engagement with AEA who have chronic health conditions. Hawke et al., 2020 sought to identify experiences, needs and knowledge gaps of researchers in engaging AEA in health research.<sup>4</sup> The study highlighted a predominant barrier to such engagement, with 45.2% of respondents citing a lack of practical knowledge on how to engage youth effectively.<sup>4</sup> Additionally, 44.0% expressed uncertainty about preparing youth for research participation, and 33.3% were unsure about the ethical considerations of involving youth in research.<sup>4</sup> Another relevant study by Faithfull et al., 2019 explored barriers and enablers to meaningful AEA participation in mental health research, revealing a "know-do" gap where researchers lacked practical skills.<sup>5</sup> Specifically, this study concluded that, "Participants in this study

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expressed the desire to hear about how their colleagues were approaching youth participation...These papers should be co-written with youth researchers, and young people should be encouraged to write about their own experiences of participatory research".<sup>5</sup> As such, it is imperative that researchers and AEA share their experiences of participatory research.

Therefore, the main objective of this commentary is to provide the operational details on the development of the Transition Research Advisory Council (TRAC): a provincial AEA advisory council in Alberta, Canada focused on transitions from pediatric to adult healthcare. This article, co-authored by TRAC members, begins with an overview of patient engagement in health research and key considerations for engaging AEA in health research. A particular focus is placed on AEA advisory councils in Canada to understand how this demographic is currently being engaged in health research. The logistic process of developing the TRAC is then detailed to provide insights on recruitment strategies, onboarding procedures, and addressing the principles of equity, diversity, inclusion, and accessibility within the council's operation. Finally, recommendations for AEA council development are outlined based on our experiences and learnings.

## 2. Engaging AEA in health research

Patient engagement across all stages of health research provides opportunities for understanding patient priorities, increasing the uptake of evidence into practice, and improving healthcare outcomes.<sup>6-9</sup> Engagement with patients who are AEA, in particular, provides opportunities for skill development, peer mentorship and self-perceived importance.<sup>10,11</sup> At the core of patient engagement in research is the importance of recognizing and valuing patients' lived experiences and expertise.<sup>6,8</sup>

There are certain considerations for ethically engaging AEA in research given their stage of development and the potential roles of caregivers in AEA's lives at this time.<sup>4,12</sup> The stage of emerging adulthood, in particular, is a time when individuals are actively assuming more responsibility for their healthcare decisions, managing their condition, and navigating new relationships, education milestones, and career prospects.<sup>13,14</sup> Furthermore, growing evidence suggests possible benefits and clinical relevance of engaging patients, particularly AEA, in forming developmentally appropriate research questions, accessible and practical outputs, and capacity building.<sup>4,6-8,12</sup>

Conducting meaningful engagement with patients who are AEA in health research requires resources, time, training, and flexibility.<sup>6,15</sup> A clear understanding of degree of possibility and desired engagement from the perspectives of both researchers and patient partners can lead to meaningful engagement and clear role allocation. It is imperative that practical approaches are taken at the outset of planning a patient-engaged research study. This includes setting aside time for the iterative process of identifying and adapting to the unique needs of the young adults involved (e.g., identifying goals for patient involvement, rapport-building, developing multiple avenues for AEA to contribute their perspectives based on their interests and preferred methods).<sup>16</sup> Successful engagement approaches provide adequate training to patient partners and researchers, ongoing support to build relationships, and compensate patient partners for their time and expertise.<sup>8</sup> Therefore, incorporating a compensation plan from the outset will allow for ease of implementation. Particularly for AEA, it is important to consider multiple forms of compensation that would be most beneficial to them, including but not limited to, a selection of gift cards, cash, volunteer hours, and/or reference letters.<sup>17</sup>

### 2.1. Diversity in patient engagement

Diversity in patient engagement necessitates that barriers to engagement are minimized so that people of varying backgrounds, abilities, ethnicities, and genders, have the opportunity to meaningfully

participate.<sup>6,18,19</sup> This requires identifying and addressing potential barriers within health research structures to support the long-term involvement of all people. For example, some individuals may experience difficulty articulating themselves in a group setting, impacting their ability to contribute meaningfully to discussions.<sup>18,19</sup> Additionally, the shift towards virtual engagement methods highlights the importance of computer literacy.<sup>19</sup> Reynolds et al., 2021 implore researchers to go beyond recruiting people from diverse backgrounds and reflect on the research system's barriers to inclusion including the impact of lower socio-economic backgrounds, ethnic minorities, and lower levels of literacy.<sup>19</sup> For instance, addressing issues like uncompensated time spent engaging with researchers can serve as a pivotal step in removing barriers to inclusion.<sup>8,19</sup> Engagement opportunities should therefore have the wherewithal to be flexible, responsive to the needs of those being engaged, and amplify the voices of people with varying health experiences within the research team.<sup>18,19</sup> The needs and preferences of patients should be considered and valued because incorporating these preferences fosters patient-centered care,<sup>20</sup> empowers them in decision-making,<sup>8,21</sup> enhances relevance and applicability of the research,<sup>8,22</sup> and promotes positive health outcomes.<sup>8,23</sup>

### 2.2. Power dynamics in patient engagement

Power dynamics inherently exist when engaging with patients, and these are exacerbated when the patient demographic is AEA.<sup>6,12</sup> Recognizing and addressing power dynamics between researchers and patients is imperative because it fosters genuine collaboration, especially within the AEA demographic.<sup>6,8</sup> Heffernan et al., 2017 discuss the importance of reciprocal learning when working with youth, wherein all parties involved have expertise and everyone takes on the role of a learner.<sup>24</sup> Fostering an environment of mutual growth and capacity building helps develop meaningful partnerships and allows for improved engagement.

### 2.3. Current state of AEA engagement in Canada

Chan et al., 2021 conducted a thorough environmental scan to identify research and health-related youth advisory councils in Canada.<sup>25</sup> They identified 40 groups, with the majority of these groups focusing on mental health. Sixteen of these groups (40%) were focused on research advisory activities.<sup>25</sup> Of the 13 group representatives interviewed to learn more about youth engagement in health, none of the groups provided monetary compensation to AEA; however, reference letters and volunteer hours were offered.<sup>25</sup> The ages of members ranged from 9 to 35 years.<sup>25</sup> Key findings from this environmental scan indicate the need for youth involvement in the development process to ensure relevancy and effective engagement.<sup>25</sup> A gap was identified in terms of training resources for new members; however, Chan et al. advised against "overtraining" members.<sup>25</sup> The authors noted it is crucial that members' authentic experiences are understood.<sup>25</sup>

To understand the current landscape of youth engagement in Canada, we conducted an environmental scan to identify transition-specific AEA advisory councils. Specifically, published articles, grey literature, and websites were identified using search terms of "adolescent health transition advisory council", "youth engagement in healthcare transition", "pediatric to adult healthcare transition councils", "young adult patient advisory groups Canada", "transition-specific youth advocacy organizations", "healthcare transition support for adolescents", "adolescent health advisory boards", "transition-specific patient engagement initiatives", "young adult healthcare transition programs", "pediatric to adult healthcare transition initiatives". Three transition-specific AEA advisory councils were identified through this scan. Details of these councils including age of members, goals and local context are provided in [Table 1](#).

Studies emphasize the importance of rigour and dedication when undertaking patient-engaged research studies, and upholding the

**Table 1**  
Transition-specific patient advisory councils in Canada.

Council Name	Membership	Goal (s)	Local Context
<b>READY2Exit Young Adult Research Partners (YARP)</b> - established in 2021 <sup>1,2</sup>	Five young adults aged 18-30 with lived/living experience in the health and/or mental health systems in Canada	Project-specific research partner group formed to collaborate on a doctoral project focused on the readiness and experiences of adolescents with co-occurring health and mental health issues exiting pediatric services	Alberta, Canada: Doctoral research project within the Faculty of Social Work, University of Calgary. YARP engagement takes place virtually through monthly meetings.
<b>Sibling Youth Advisory Council (SibYAC)</b> - established in 2018 <sup>3</sup>	Six young adults aged 21-27 years who have siblings with a chronic health condition or disability	SibYAC formed as a research partner in a doctoral study, primarily for the purposes of developing an integrated knowledge translation strategy	Ontario, Canada: Doctoral research project within the School of Rehabilitation Science, McMaster University
<b>Transitions of Care Committee</b> <sup>4</sup>	Youth and young adults with lived experience in transitioning to adult care, parents and caregivers, pediatric and adult health care providers, and community partners based in Atlantic Canada	To inform transition of care practices at the Izaak Walton Killam (IWK) Health Centre	Based at the IWK Health Centre, affiliated with the IWK Transitions of Care Program. Monthly meetings held.

responsibility of trust.<sup>6,8</sup> Understanding the implementation specifics on developing a transition-specific advisory council will help develop practical ways of approaching patient engagement in health research that account for the nuances of this unique demographic.<sup>4</sup> Therefore, it is imperative to share the operational details of developing an AEA research advisory council to guide the practical steps for patient engagement with this age group.<sup>8,12</sup>

### 3. Development of provincial transition research advisory council (TRAC) in Alberta

#### 3.1. Purpose of TRAC

The impetus for the TRAC arose in February 2021, with the

identification of the crucial need for an AEA advisory council dedicated to research in pediatric-adult care transitions. The research team envisioned developing a council to bridge the gap between researchers and those with lived/living experiences. The purpose of TRAC was to engage with AEA on ongoing research studies in Alberta focused on pediatric-adult transitions. Key tasks for TRAC members included providing input on interview guides, setting priorities for research, and contributing to knowledge translation outputs.

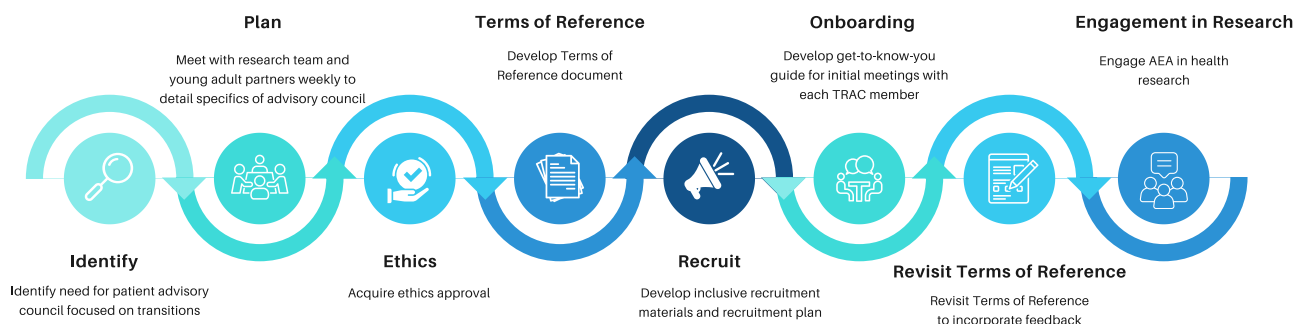
#### 3.2. Planning process for developing the TRAC

The overall process of developing the TRAC is outlined in Fig. 1 and TRAC members' reflections on onboarding, recruitment, and research processes are highlighted in Table 2.

Existing literature on best practices for developing an AEA advisory council was consulted prior to the TRAC's formation. Our team held bi-weekly planning meetings for six months prior to the first meeting of the council. Next, research ethics board approval was obtained from the Conjoint Health Research Ethics Board at the University of Calgary (REB-18-0751) for the development and operation of the council. During research team meetings following ethics approval, we developed comprehensive goals for the TRAC, created AEA-friendly and inclusive recruitment materials, and a Terms of Reference (ToR) document to clarify our guiding values, roles, and responsibilities. Successful engagement approaches provide adequate training to patient partners and researchers, ongoing support to build relationships, and compensate patient partners for their time and expertise.<sup>2</sup> Recognizing compensation as a key pillar of patient engagement in health research, project budgets included funds for compensating AEA according to the Alberta Strategy for Patient-Oriented Research (SPOR) Support Unit's guidelines.<sup>17</sup> In addition to compensation via electronic gift cards, TRAC members were provided options for volunteer hours, reference letters, mentorship opportunities, and co-authorship to honour their contributions once onboarded.<sup>6</sup>

#### 3.3. Development of a terms of reference (ToR) document

Based on a review of publicly available ToR documents for similar councils across North America, relevant headings, and areas of focus for an AEA advisory council ToR were developed. A combination of prior experience with advisory council facilitation, and reflective discussions allowed our team to consolidate topics to be covered within a draft ToR document for the TRAC. Key areas for the draft included: an overview of the TRAC's purpose and vision, roles and tasks for TRAC members, guiding principles, our commitment to inclusivity, accessibility and reciprocal learning, confidentiality, and compensation (Supplement). Key roles and tasks for TRAC members included refining recruitment materials to enhance AEA-friendliness, offering feedback on preliminary study findings, co-developing qualitative interview guides, and priority setting for future research. Logistics of TRAC involvement, including meeting schedule, length of membership commitment, and



**Fig. 1.** The overall process of developing the TRAC.

**Table 2**  
Reflections from TRAC members about the recruitment process, onboarding process and overall patient engagement in transition-related projects.

Recruitment process	Onboarding process	Overall patient engagement in transition-related projects
<p>“Utilizing various streams of recruitment for TRAC ensured a wide range of individuals would see the recruitment materials, and potentially see them more than once. Having the materials forwarded from previous patient engagement organisations, provided an extra level of trust regarding the information presented and the goals of TRAC with the recruitment materials. The visual aids and inclusive language was a critical component that exemplified the organizing team’s commitment to EDI within the group. Non-judgemental and plain language was employed contributing to the comprehension of materials for all ages and abilities. While COVID-19 was a factor in virtual recruitment, it increased its accessibility.”</p> <p>“Recognizing the harms that research has imposed on vulnerable populations, such as AEA, direct statements of the team’s EDI commitments were critical to communicating that the TRAC would be a safe(r) space to contribute lived/living experience. Additionally, while Zoom was used due to COVID-19, a virtual advisory council increased the accessibility of TRAC by providing closed captioning and other accessibility features.”</p> <p>“I wasn’t able to be part of my youth advisory council after serving for years because I was over the age of 21. However, I still wanted to advocate for youth within health care. TRAC provided me with that opportunity to continue doing so as an older AEA.”</p>	<p>“TRAC was different from than other advocacy groups I had been part of. During onboarding, I met with a coordinator who asked me something along the lines of “What would you like to get out of this?” This question initially perplexed me; in my experiences, I felt that advocating for others was the sole focus of these groups. I felt valued as a member of TRAC, because it was made clear that I was gaining something out of this experience. I could develop skills I could use in my career or other endeavours, while advocating for AEA.”</p> <p>“Standardized questions regarding accommodations was a critical component to feeling welcome and safe within the group. Previous stigma regarding disabilities or learning disabilities has prevented me from voicing the accommodations I require to participate to the best of my ability. The team’s willingness to make adjustments and listen to their AEA members provided a more inclusive environment.”</p> <p>“Intentionally asking council members about their accommodations emphasized the team’s commitment to EDI. The healthcare system, and particularly the process of transitioning in and of itself, has been largely inaccessible for myself as an Autistic person. The TRAC team’s commitment to accessibility was definitely a positive step forward to creating a more inclusive transition experience for youth in the future.”</p>	<p>“Patient engagement is an essential component to developing and conducting research that patients feel benefit other patients and improve the overall system. As a member of TRAC, I felt I was able to appropriately guide researchers on questionnaires to ensure the language conveys the correct message to the patient. The opportunity to be a member of TRAC and contribute to academic research has provided me with a newfound appreciation for the academic process and rigour. This process has been instrumental in my desire to further pursue research projects and activities to benefit more patient populations.”</p> <p>“The perspectives of patients experiencing intersectional oppressions (such as myself- disabled, racialized, and female), are often undervalued or excluded in health research. This is particularly important as intersectional identities contribute increased barriers to a successful transition from pediatric to adult care. As a researcher myself, recent movements towards patient-centred and peer-led research, such as TRAC, are a considerable asset to the field.”</p> <p>“I felt heard and valued as a member of TRAC. I appreciated TRAC’s utilization of open-ended questions to understand the barriers affecting AEA. We collaboratively provided input on projects to improve their accessibility and appropriateness.”</p>

**Table 2 (continued)**

Recruitment process	Onboarding process	Overall patient engagement in transition-related projects
		<p>“TRAC provided a social component for AEA to create connections with likeminded people going through similar changes in life.”</p> <p>“Comfort among AEA allowed for ideas to be shared freely.”</p> <p>“Components of the meetings were designed to lessen formality and thus divide between researcher and AEA. For example, attire worn by all attending was often casual. Additionally, the ratio of AEA to researchers present in meetings was consistently higher for AEA.”</p>

communication, were also included. The working document was reviewed by different members of our team and revised for AEA-friendliness and accessibility.

**3.4. Recruitment strategies: commitment to equity, diversity, and inclusion (EDI)**

Diversity in patient engagement necessitates that barriers to engagement are minimized so that people of varying backgrounds, ethnicities, races, genders, religions, and abilities have the opportunity to meaningfully participate.<sup>7</sup> Engagement opportunities should therefore be flexible, respond to participants’ needs, and amplify the voices of people with varying health experiences within the research team.

EDI principles guided the development of the recruitment materials and the eventual council.<sup>26-28</sup> Our commitment to EDI began with the voices represented on the research team, which was then organically reflected in the work generated by this team. We are mindful that our team is also missing important voices, and as such, it was imperative to continually assess and reflect on questions like: Who are we engaging? What does it mean to have diverse voices? How are we mitigating barriers to provide equality of opportunity? Meaningful engagement necessitated capturing the nuanced and intersectional perspectives of people with varying diseases, disorders, backgrounds, and identities. One of the strategies implemented for engaging diverse AEA was creating intentionally inclusive recruitment materials by using gender-neutral language and visuals of people from various backgrounds and abilities. One member’s reflections in Table 2 highlighted the impact of having a direct EDI statement on recruitment posters: “Recognizing the harms that research has imposed on vulnerable populations, such as AEA, direct statements of the team’s EDI commitments were critical to communicating that the TRAC would be a safe(r) space to contribute lived/living experience.”

While efforts were made to increase diversity in TRAC, demographic information beyond age and gender identity was not collected. In the development of councils in the future, we encourage researchers/advisors to have discussions about collecting demographics at the outset of partnerships and to co-design surveys for doing so. We suggest group decisions be made about what information members are comfortable disclosing/having published.

Restrictions due to the COVID-19 pandemic required that all recruitment and onboarding meetings be held virtually. Therefore, a virtual snowballing approach was used for sampling, wherein we

reached out to existing organizations to share our recruitment materials on their social media platforms and via email.<sup>8</sup> These organizations included the Alberta SPOR, Alberta Children’s Hospital’s Child and Youth Advisory Council, Stollery Children’s Hospital’s Youth Advisory Council, and Patient and Community Engagement Research. Materials were also shared via the TNT social media (X and Instagram) accounts, which were re-shared by other organizations, expanding the reach and by contacting parents/youth who had already expressed interest in becoming involved in future transition-related projects.

Based on experiences of the research team’s prior engagement with AEA, we recognized the importance of ease of access to contact the research team. Traditionally, the recruitment process requires individuals to reach out to the research team via email; however, drafting an email may be an added barrier. Therefore, a Google Form was created, which only required one’s name and contact information, and the research team could subsequently reach out to interested AEA. The option to contact the research team via email was also provided. We acknowledge the limitations of recruiting for and operating an advisory council virtually, as this approach may exclude individuals who lack stable internet access or are not technologically savvy. Given rural and Indigenous communities are disproportionately affected by internet connectivity issues<sup>29</sup> future engagement efforts should more intentionally and thoughtfully consider how to garner the perspectives of AEA within these communities.

Recruitment occurred from May-July 2021. We received expressions of interest to join the council from 11 individuals via email and 21 individuals via the Google form. In order to include individuals who had begun the transition process or begun the process, our initial inclusion criteria for this council were AEA aged 16–25, or their siblings/caregivers. We received several responses from AEA over the age of 25 years who expressed their interest in joining the council to provide their expertise. Specifically, they stated that they had aged out of existing youth advisory councils but had since gained important perspectives that transition research would benefit from. The literature has a lack of consensus as to the ideal age range to include when engaging AEA. Our team brainstormed the pros and cons of the age ranges: The collaboration process may be hindered if power dynamics develop within the group due to wide age ranges. Alternatively, having a wide age range may allow for mentorship opportunities within the council. Therefore, we expanded the age range for this council to include those aged 16–35.

We also noted that many of the AEA who reached out to us are participating in multiple research advisory councils. While it is a great strength to have AEA who understand the process of research, it is vital to be mindful of incorporating new voices and perspectives. There are often barriers that prevent some AEA from engaging in research, such as disease-specific concerns, compensation, or lack of awareness of patient engagement in research.

Finally, while our recruitment material invited AEA, siblings, and caregivers to contact us, we only received responses from AEA and siblings of AEA with lived/living experiences. This was likely due to the platforms we utilized for advertisement. Overall, we recruited 15 (based on our project budget) AEA aged 16–35 years old, with lived/living experiences of pediatric-adult health and/or mental health service transition(s) or siblings of AEA with healthcare transition experiences.

### 3.5. Onboarding interviews

Following an expression of interest, prospective council members were invited to an informal onboarding phone or Zoom call, based on each AEA’s preference, with one or two members of our research team based on scheduling/availability. An onboarding ‘get-to-know-you’ guide was used to structure a call with prospective council members. This consisted of 5–7 informal questions used to explore motivations, interests, skill development, and preferred meeting times.

During the first few onboarding interviews, we noted that some AEA requested specific accommodations to support their involvement such as

sending out materials to their helper, ensuring large fonts on PowerPoint presentations, and sending out meeting materials in advance of the meetings so that members have time to read it. Recognizing the potential barrier of asking for accommodations, we incorporated a question in the interview for all prospective members to proactively identify needs and preferences to improve engagement and participation. This was well-received as noted by one member (Table 2): “Standardized questions regarding accommodations was a critical component to feeling welcome and safe within the group. Previous stigma regarding disabilities or learning disabilities has prevented me from voicing the accommodations I require to participate to the best of my ability. The team’s willingness to make adjustments and listen to their AEA members provided a more inclusive environment.” During onboarding interviews, some members expressed that they were more comfortable with sharing their ideas via the chat function on Zoom and may prefer to keep their cameras turned off. The importance of keeping a live transcript was also stated. Being mindful of the competing commitments for AEA, it was essential for the research team to be flexible about the timing of meetings and send out meeting materials (e.g., Powerpoint slides, agendas) ahead of time due to processing speed or learning disabilities. These onboarding interviews provided a valuable opportunity to engage AEA in the early stages and played a pivotal role in refining our engagement strategies. Through these interactions, we gained insights that helped identify potential barriers to engagement, allowing us to implement creative solutions to address concerns effectively.

This was an iterative learning process wherein we learned to reach people in equity-deserving communities and identify who we had missed. It was important to avoid a tokenistic approach when incorporating EDI in patient-engaged research. Rather than checking boxes to show who we included, it was critical to reflect on *who was not* included, *why* they were not included, and *how* we could include them.

When we asked about AEAs’ motivations for joining TRAC in the onboarding interviews, we noticed similar answers appear across interviews. We anonymously recorded prospective members’ responses and grouped these according to underlying concept to illuminate shared patterns related to motivations. We shared these groupings with TRAC members in early meetings to foster a collective sense of purpose and vision. Members’ motivations, with the number of members who expressed similar motivations, are summarized in Table 3. In line with the motivations expressed by our AEA members during the onboarding interviews, engagement opportunities for TRAC members were thoughtfully developed to cater to their interests and needs. For example, we offered opportunities for expanding knowledge about health research by delivering presentations on different research methods.

In advance of our first TRAC meeting, a working draft of the ToR was emailed to TRAC members, and the guiding principles of the council were discussed at our first meeting. We invited TRAC members to provide their feedback and suggestions on the ToR document, either via email or during the meeting, however, the council approved this document with no changes.

**Table 3**  
Members’ motivations for joining TRAC.

Members’ motivations for joining TRAC	Number of members who expressed the motivation
Build capacity in leadership, conducting health research and receive mentorship for post-secondary schooling (e.g., graduate school applications)	7
Seeking mentorship and/or connection with others who have gone through the process of transition	5
Advocating for and with AEA	5
“Make sure other people don’t have the same experiences”	4
Aged out of existing youth advisory councils	1

### 3.6. Engagement in research

To date, we have had over 10 consultations with TRAC wherein the members have provided valuable feedback on recruitment materials, input on interview guide questions, recommendations for AEA-friendly and accessible content for AEA mental health, feedback on how to best engage AEA participants for other councils, ideas on how to effectively present data on research posters and evaluated knowledge translation materials for social media. TRAC members have also conceptualized topic ideas for mental health-related videos and co-created a briefing note for healthcare professionals on how to improve the transition between pediatric to adult healthcare. Currently, TRAC members are engaged in various health research projects with the TNT, which are in the analysis and writing stages.

The considerations highlighted in Section 2 of this commentary were helpful in building a rapport with the TRAC members and creating an environment that fostered rich discussions. One member's reflections showed that there were other aspects of the meetings that helped create a comfortable setting and mitigate potential power dynamics (Table 2): "Components of the meetings were designed to lessen formality and thus divide between researcher and AEA. For example, attire worn by all attending was often casual. Additionally, the ratio of AEA to researchers present in meetings was consistently higher for AEA."

### 4. Conclusion and recommendations

It is imperative that practical approaches are taken at the outset of planning a patient-engaged research study, especially for the unique AEA demographic. Ultimately, the onus is on the researcher to find and address context-specific barriers to meaningfully engaging AEA in health research. In Table 4, we provide recommendations that are actionable and generalizable for AEA council development. The experiences shared here provide valuable guidance for fostering robust engagement strategies and further advancing patient-centered research initiatives.

In conclusion, the development of the TRAC in Alberta represents a crucial step toward amplifying the voices of AEA undergoing the transition from pediatric to adult healthcare. This commentary underscores the significance of meaningful patient engagement in health research and details the operational aspects of establishing TRAC, encompassing recruitment strategies, EDI principles, and onboarding procedures. The insights gleaned from TRAC's development shed light on the complexities and necessities of engaging AEA in research, emphasizing the importance of flexibility, understanding power dynamics, and embracing diverse perspectives.

#### Ethics in publishing

This research has been approved by the University of Calgary Research Ethics Board REB16-2561.

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#### CRedit authorship contribution statement

**Mica Pabia:** Writing – original draft, Formal analysis. **Sarah Mooney:** Writing – original draft, Formal analysis. **Paul Siska:** Writing – original draft, Formal analysis. **Laurel Ryan:** Writing – review &

**Table 4**

Recommendations for AEA Council Development.

VOICE: Recommendations for AEA Council Development	
Value diversity and inclusivity	Prioritize diversity in recruitment and engagement strategies, ensuring inclusive recruitment materials with gender-neutral language and diverse representation of patients from different backgrounds and abilities. Foster inclusivity by proactively identifying accommodation needs and creating an environment that respects and amplifies diverse perspectives.
Optimize compensation plans	Develop comprehensive compensation plans, including monetary and non-monetary forms of acknowledgement (e.g. volunteer hours, reference letters), fostering recognition for AEA contributions in ways they value.
Iterative engagement approach	Implement an iterative engagement process that accommodates evolving needs, preferences, and feedback from AEA council members. Create flexible engagement models that adapt to different communication styles and preferences.
Capacity building and mentorship	Create opportunities for capacity building and mentorship within the council, enabling knowledge exchange among different age groups and empowering AEA to develop leadership skills in research and advocacy.
Empowerment in decision-making	Foster a culture of shared decision-making within the council, enabling AEA members to actively contribute ideas, shape agendas, and co-create initiatives. Encourage meaningful participation in decision-making processes, allowing AEA to take ownership of their involvement and impact within the healthcare research landscape.

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#### Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

#### Data availability

No data was used for the research described in the article.

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## Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at [doi:10.1016/j.hctj.2024.100058](https://doi.org/10.1016/j.hctj.2024.100058).

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