

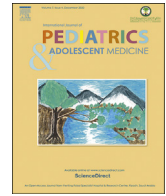
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Facilitators and barriers to the training and maintenance of young persons' advisory groups (YPAGs)

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ABSTRACT

Introduction: Increasing demands from public and private healthcare coupled with national initiatives in patient-oriented research has led to an increase in avenues to allow patients to be directly involved in research. In particular, the push towards participation of children and youth has resulted in the formation of pediatric patient advisory groups with broad partnerships and consultation requests across the globe. However, there is a lack of evidence to examine the challenges in formation and training of young persons' advisory groups (YPAGs) and management processes required thereafter.

Purpose and objectives: This study's purpose is to document YPAG formation and training protocols around the world, highlight common strengths, and evaluate pitfalls and challenges. The results from this study will subsequently inform the development of standardized training protocols for children and youth to be piloted globally.

Methods: In this study, 17 select YPAG team leaders from 7 countries were surveyed to determine current training techniques used within existing groups. 17 youth representatives and 16 team leaders were then interviewed to gather further qualitative data on facilitators and barriers that aid or prevent successful initiation and maintenance of these groups. Qualitative interview data was coded and analyzed using NVivo by two independent reviewers (SYC, VWLT). Any inconsistencies in thematic analysis was confirmed by a third reviewer (JB).

Results: The most common training topics include consent and assent (64.71%), clinical trials (64.71%), and patient safety (70.59%). There are significant discrepancies to the amount of training received by each team. Most YPAGs out of the 17 groups receive no formal training (58.82%) while training sessions in the remaining 7 groups vary in both duration and frequency. Collectively, meetings ranged from 15 minutes to 6 hours long, with the majority of team meetings being 2–3 hours long (58.82%). The most common training facilitators are a positive relationship with a local hospital (82.35%) and access to a dedicated team coordinator (64.71%). 70.59% of team leaders identified a lack of access to appropriate educational materials available as a drawback to the impact of their YPAG, making this the greatest common barrier.

Conclusion: Bringing children and youth to the forefront of paediatric trials and clinical research facilitates appropriate patient representation in subsequent research decision-making. There is an urgency to create and implement standardized protocols for the training of children and youth, especially in preparation for national and international research consultations. This low barrier framework may be of special interest to lower-middle-income countries who wish to encourage community participation in healthcare.

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1. Introduction

In recent years, emphasis on stakeholder participation has led to pediatric patient and family involvement in upstream healthcare processes. Examples include family partnership programs [1],

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shared decision-making during hospitalization [2,3], and education of medical students [4]. In particular, young persons' advisory groups (YPAGs), involving children and youth as active participants in transferring scientific knowledge from clinicians to young people have become increasingly more popular within academic institutions. YPAGs are an example of patient and public involvement (PPI) as it allows individuals from the patient and general population to have a voice in scientific research by advising on the needs of their demographic [5].

There are many purposes for the creation of YPAGs [6]. This includes but is not limited to providing feedback on hospital administration, consultations on community collaborations, and advising on research protocols. In this study, particular attention will be paid to YPAGs focused specifically on research involvement. Evidence suggests that individuals who are involved in PPIs feel empowered and valued, while researchers gain a greater understanding in their research area and develop better relationships within the community [5,7]. Young people are able to learn about the scientific process through their collaboration with researchers. In similar ways, researchers are able to seek opinions from young people, who are the target demographic of their studies, in order to improve application of research outcomes.

In 2015, a number of existing YPAG chapters dedicated to research collaborated to give rise to the International Children's Advisory Network (iCAN). The iCAN is focused on providing youth voice in paediatrics and aims to create positions for young people in both downstream local research consultations and upstream decision-making. Their mission is to foster greater global understanding about the importance of pediatric patient and caregiver voice in healthcare, clinical trials, and research.

The iCAN started with the collaboration of two chapters - based out of Hartford, Connecticut USA and Vancouver, BC Canada. Now with 19 international teams present in 7 countries around the world, the iCAN provides the much-needed youth input on research to international stakeholders such as independent physicians, regulatory agencies, and various pharmaceutical companies [8]. Each iCAN team consists of 10 to 20 youth, within the ages of 8–23 years. While the research focus of each group may vary, all chapters share a commitment to research and common activities of performing consultations, revising documents, and making direct recommendations on research protocols. Each team is led by a team leader trained in research methodology but whose role as staff in the hospital may range from clinical nurses and child life specialists to residents and physicians.

These YPAGs are especially beneficial for research groups around the world that do not have access to a local group at their hospital, academic centre, or community-based health care facility. However, while these exciting initiatives are taking place, there remains a lack of standardized protocols for children and youth involvement in research, especially in the area of group formation and training.

A knowledge gap in evaluation of the barriers of YPAG training leaves success dependent on the serendipitous selection of patient representatives, establishment of a strong guiding vision, maintenance of ongoing leaders, and engagement of staff to collaborate with the advisory group [9]. Current studies that look into the creation of YPAGs rely mostly on the use of surveys without extensive qualitative questioning and only pertain to one particular hospital or health care setting [7,10–12]. Furthermore, systematic reviews on shared decision making interventions in pediatrics conclude that the heterogenous conception of shared decision making and their impact on outcomes remains unclear [13].

This study aimed to determine how the healthcare and scientific community can better support these groups by establishing

effective training protocols to equip young people who are providing a voice for pediatric patient populations. The primary goal was to assess strengths and pitfalls in current training protocols used in YPAGs around the world to inform the creation of new international standardized training guidelines. The secondary goal of the study was to identify common themes in existing YPAGs regarding the facilitators and barriers for successful initiation and maintenance of these groups in their respective health care settings.

2. Methods

2.1. Materials

Mixed methods research methodology was used to investigate the strengths and limitations of Young Persons Advisory Groups (YPAGs), in order to understand the perspectives of team leaders and young persons who are involved in the training and maintenance of a YPAG. A semi-structured interview guideline was utilized for the 17 youth representatives and 15 team leaders and a peer-reviewed survey was developed from input from physician representatives from 16 YPAG teams globally.

2.2. Participants

This study involved both youth members and adult team leaders of YPAGs. Both adult team leaders and young persons were invited to participate in this study to represent their perspectives on training techniques in their YPAG. Recruitment was performed by sending emails to each YPAG team leader with an invitation for the team leader and a young person from their team to participate in the study.

A purposive sample of active YPAG team leaders ($n = 16$) and young person representatives, 8–21 years of age ($n = 17$) from 17 sites that are part of the International Children's Advisory Network (iCAN) participated in an individual semi-structured interview. Representation included the following sites: Albania, Bari, Canada, Ohio, Connecticut, Georgia, Illinois, Michigan, Houston, Florida, Kansas City, Barcelona, France, Liverpool, Brighton, Oxford, Edinburgh. Participants were included in the study if they are active members of a YPAG in the iCAN for at least one academic year (September–April) and are able to read and speak English.

YPAG team leaders ($n = 17$) from the iCAN were further invited to provide feedback through an online survey to provide logistical details about training in each team. The members of the iCAN who participated in this study represent six countries worldwide – Canada, United States, Spain, France, United Kingdom, and Italy. The remaining two teams in the network were created within the past 6 months and were not included as participants. By including the voices of young persons and adults in our study, we were able to compare and contrast their views to determine current facilitators and barriers to initiation, training, and maintenance of YPAGs around the world. Ethics approval was obtained prior to starting this study. Informed assent and consent were obtained from the participants and parents of young persons involved in this study respectively.

2.3. Data collection

Individual face to face, semi-structured interviews (Appendices 1, 2) were performed by three researchers (VWLT, SYC, JB) in-person during the annual iCAN Summit in Edinburgh, Scotland between July 5–10, 2018. Interviews were audio recorded along with notes made by the researcher. The interview examined the participants' perspective in formation, training and maintenance phases of

YPAGs. Interviews were transcribed by three researchers (VWLT, SYC, JB) and a team of five research assistants (HW, SK, LE, RO, JH). Brief survey questions were further disseminated to all iCAN team leaders to identify the facilitators and barriers in training their YPAG members. Only team leaders participated in the survey because it concerns logistical administrative processes to YPAG maintenance that youth participants are not involved in. All relevant subjective questions regarding youth-perceived facilitators and barriers were incorporated as part of qualitative interviews.

2.4. Data analysis

Interview data was summarized and tabulated according to key questions in the interview guide. The table was manually populated with responses from each team. Using inductive analysis, common details, themes, and patterns were identified among the teams. Common training facilitators and barriers were identified and coded. Responses from the team leader survey were also coded according to when they received training for certain topics - prior to youth members starting as advisors, during their time as advisors, prior and during their time as advisors, or if they received no training at all. Coded results were tabulated and quantified by the percentage of teams who receive training in each training topic (Table 1). Qualitative interview data was coded and analyzed using NVivo by two independent reviewers (SYC, VWLT). Any inconsistencies in thematic analysis were confirmed by a third reviewer (JB) and overseen by two pediatrician leads (SS, CT). Special care was taken so that researchers conducting interviews did not transcribe or code data from interviews they performed.

3. Results

The demographic of children and youth who are recruited into the 17 YPAGs range from 8 to 23 years old and different teams are comprised of varying proportions of patients to non-patients

(Figs. 1 and 2). 9 teams (52.94%) require young people to fill out an application in order to join the group, with KIDS Barcelona being the only team (5.88%) that conducts an interview with their applicants. The majority of the teams (52.94%) do not require a commitment contract to be signed by their members. Existing members naturally transition out of the group due to age-related circumstances such as moving away for work or further schooling. Those that do not are welcome to stay on as mentors.

There are significant discrepancies to the amount of training received by each team. 10 out of the 17 groups receive no formal training (58.82%) while training sessions in the remaining 7 groups vary in both duration and frequency. Collectively, meetings ranged from 15 minutes to 6 hours long, with the majority of team meetings being 2–3 hours long (58.82%). Liverpool's YPAG youth representative shares that they do not think training is not needed in their team because "[the youth] are lay people, they're not supposed to be doctors, they're supposed to be giving a young person's opinion". In contrast, Bari's YPAG dedicated their inaugural year entirely to training because their team leader believes that, "[the youth] do not have all the right competencies to do [consultations] yet because they still have to learn".

Within the core training topics, youth members received significantly more training both prior and during their membership in the YPAG in the fundamental principles of advocacy, patients as partners training, pediatric ethics, and consent and assent. Over 60% of teams trained their youth in these areas. In comparison, other training topics such as knowledge translation and qualitative and quantitative methods are topics discussed in training in less than 50% of all teams. These findings highlight the practical nature of research skillsets YPAGs deem useful. Six teams (35.29%) also received specific education on special topics, such as population-specific diseases and ten teams (58.82%) received targeted training on how to become youth research advisors on research projects (Table 1). Young people are trained by their team coordinator or leader, a parent, or senior youth member.

Table 1
Team leader survey results on current topics of training in YPAGs focused on research.

	Key Training						
	Qualitative methods (%)	Quantitative methods (%)	Knowledge translation (%)	Consent and assent (%)	Patient safety (%)	Clinical trials (%)	
Prior only	7.1	7.1	6.7	6.7	13.3	6.7	
During only	14.3	14.3	33.3	26.7	13.3	26.7	
Prior & during	7.1	7.1	0.0	40.0	33.3	40.0	
No training	71.4	71.4	60.0	26.7	40.0	26.7	
	Additional Training						
	Patients as partners (%)	Bench to bedside (%)	Safety and regulation (%)	Health systems operation (%)	Biotechnology (%)	Pediatric Ethics (%)	Advocacy (%)
Prior only	6.7	0.0	7.1	7.1	0.0	13.3	6.7
During only	33.3	7.1	14.3	14.3	46.7	26.7	33.3
Prior & during	26.7	28.6	35.7	0.0	0.0	26.7	33.3
No training	33.3	64.3	42.9	78.6	53.3	33.3	26.7
	Topical Training						
	Adolescent health (%)	Common sexual and reproductive health conditions (%)		Common mental health conditions (%)	Common children's health conditions (%)		
Prior only	6.7	0.0		0.0	0.0		
During only	26.7	14.3		26.7	26.7		
Prior & during	20.0	0.0		0.0	13.3		
No training	46.7	85.7		73.3	60.0		
Other							
Our team does not train our youth advisors prior to their involvement in the team			Our team does not train our youth advisors during their involvement in the team		Do you think your training is adequate?		
23.5%			11.8%		Yes No		
					58.8% 29.4%		

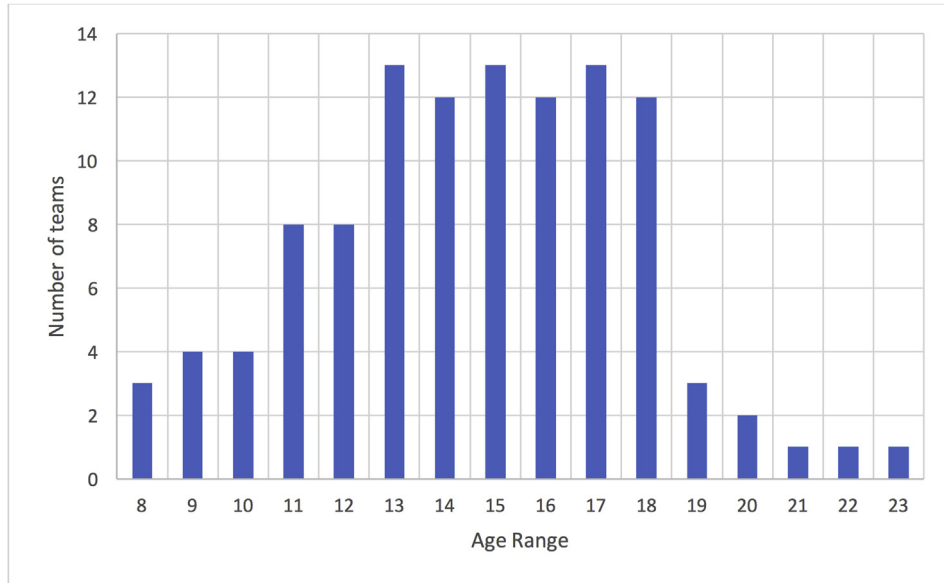


Fig. 1. YPAG Patient vs. Non-Patient Age Distribution.

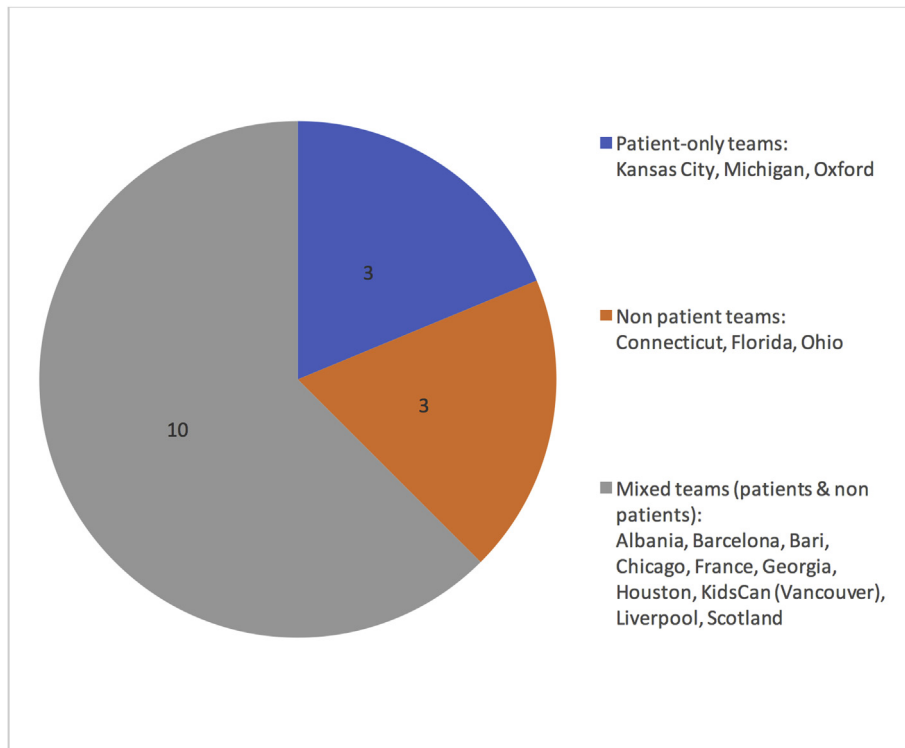


Fig. 2. YPAG Patient vs. Non-Patient Demographics.

There are a variety of methods to train members, in the format of online courses, such as the massive open online courses, modules, surveys, PowerPoint, videos, and paper hand-outs. The majority (58.82%) of teams report using self-made training or educational materials, or those made by their local hospital group. Teams find discussions to be the most effective delivery technique as youth have the opportunity to express their thoughts by engaging in discourse with their peers and presenters. While all materials presented is meant to be easily understood by the range of ages within a YPAG, younger participants benefit largely from small

group discussions where an older “buddy” can clarify questions and unpack scientific jargon. Parents are not invited to YPAG meetings so the “buddy” system is particularly helpful for groups with a larger age discrepancy amongst their members. Practical activities are enjoyable among teams, including interactive games and field trips to laboratories or hospitals.

3.1. Training facilitators

The greatest common training facilitator for most teams is a

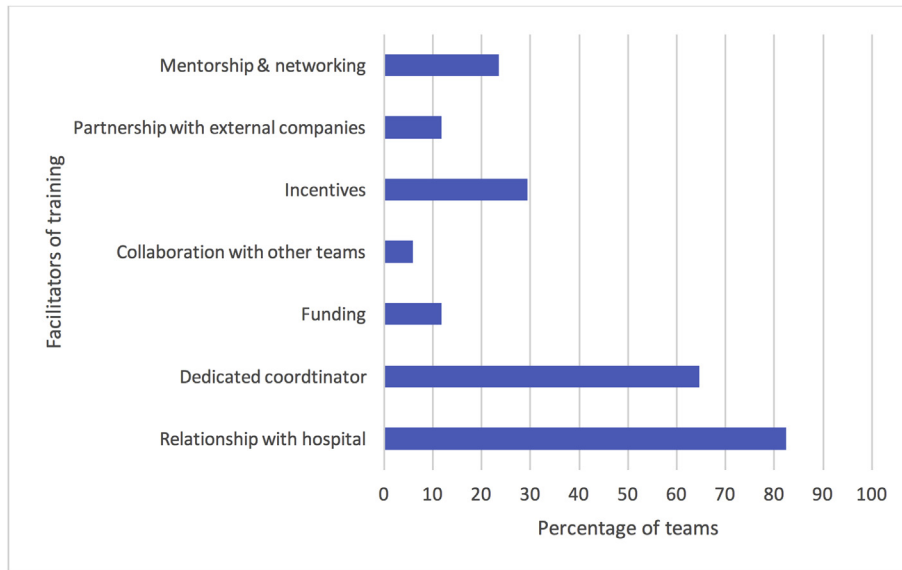


Fig. 3. Common training facilitators.

positive relationship with a local hospital (82.35%) and having a dedicated team coordinator (64.71%). Other facilitators include incentives for youth members in YPAGs. The specifics of these incentives varied from monetary compensation to opportunities such as mentorship and networking. Non-monetary incentives such as mentorship and networking opportunities were stated as highly common facilitators accounting for 29.41% and 23.53% of teams, respectively. Only 11.76% of teams identified funding and partnership with external companies as training facilitators. The least common training facilitator is collaboration with other teams, with 5.88% of teams ranking it as a resource in their training program (Fig. 3). While collaboration in general may be a benefit, it is recognized that geographic distribution and navigation of time zones serve as a barrier.

3.2. Training barriers

Teams recognize that the lack of training materials (52.94%) and

the lack of engagement from members (35.29%) are the major drawbacks to training-making these the greatest common training barriers among all teams (Fig. 4). When asked if the adult-level materials used were appropriate in Michigan’s YPAG ethics training, the team leader shared, “I would not say no ... I don’t think there was necessarily anybody [who] felt completely comfortable. There were probably still questions”. When asked specifically, 70.59% of team leaders identified a lack of educational materials that are available or suitable for their group.

The next most common barrier is the lack of engagement from members (35.29%). When asked what makes a training session engaging for youth, Georgia’s youth representative shared, “Um, depending on if the speakers are interactive or [if] the project we’re doing or reviewing is interesting. And ... active”. Oxford’s team leader shared their solution to increase engagement: “Rarely we will give a talk that is more than 10 min. We’ll talk for a bit and then we’ll do interactive games”. There is also pressing need to standardize the measurement of engagement within YPAGs as well as to measure

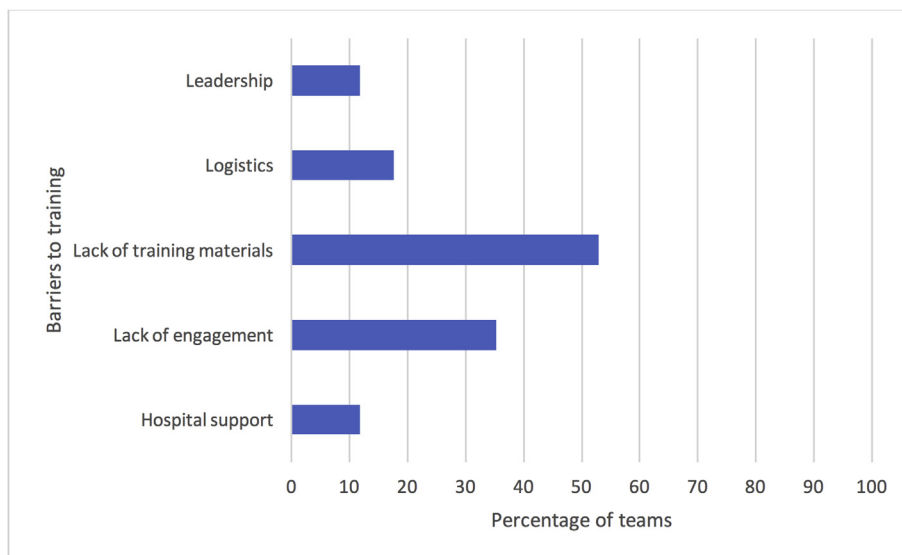


Fig. 4. Common training barriers.

the impact of training. None of the YPAGs surveyed currently have a system of evaluation. Team Scotland's team leader shares, "I think we just try to make them as engaging as we can. I suppose we never really surveyed our group ...". Team Oxford goes on to share that measurement of:

"any measurement of hard skills or soft skills gained would be great. Right now we just don't know how to evaluate this. So we are just sending them a lot of surveys saying 'hey do you like it?' which isn't well thought out. It would be nice if it was like a plan".

Logistical issues, which include travel to and from meeting locations and scheduling difficulties for members and presenters (17.65%) serve as another barrier as is the lack of hospital support and leadership (11.76%).

4. Discussion

The iCAN and other platforms that serve to highlight the voices of children and youth in paediatric medicine has increased over the last decade [8,14,15]. Patient-oriented research initiatives such as the Canadian Institutes of Health Research Strategy for Patient-Oriented Research (CIHR SPOR) [16] have contributed in part to the increased involvement of this demographic [17]. Demand from public and private healthcare sectors have also driven the development of patient engagement programs [18].

However, past models of youth engagement regardless of specificity to research, have been impacted by significant challenges. Gaw [3] reports factors such as youth age, emotional maturity, and education level creating difficulties for shared-decision making. A lack of open-ended involvement opportunities also create difficulties for patients and families to contribute to upstream hospital processes, much less research [3]. Furthermore, Tait et al. reported discordant research priorities between youth and parents [19]. Therefore, awareness of potentially conflicting information priorities between youth and parents when considering pediatric participation in research must be considered and youth interests must be prioritized.

In addition, spreading awareness of the benefits of patient involvement and creating socially supportive environments for shared decision making between pediatric healthcare providers and patients promotes a culture of support and encourages patient engagement [10,20]. Involving patients and their families in clinical and health services research can aid in the optimization of health care and outcomes [11]. YPAGs also appreciate opportunities to impact health care as it allows individuals to give back to the patient community [21]. By providing appropriate research skills training through the engagement of YPAGs, young people, patients, and parents can become invaluable collaborators in pediatric health care and services because of their lived experiences.

In contrast to common hospital-based administrative youth councils or teen advisory boards, the push towards youth participation in research specifically has resulted in both formal and informal partnerships between pharmaceutical industry and hospitals across the globe [22]. While there is need for public-private collaborations, and engagement of youth for national and international trials, there is a lack of standardized protocols for the development and training of YPAGs nor any quantifiable way to measure impact and adoption of youth opinion into upcoming or ongoing clinical trials and research. Data from 17 teams within the iCAN revealed a need to focus on a YPAG's collective purpose to inform demographic composition and engagement, as well as appropriate training protocols.

4.1. Collective purpose

Currently, YPAGs are engaged in diverse activities and programming both locally and globally [23]. However, the goals and purpose of a group determines its recruitment and engagement strategies and topics of training. There is an emerging need to clarify the goals and purpose of YPAGs prior to establishment and uptake of collaborations so that training and preparation of youth advisors are appropriate to the group's function. Using the iCAN as an example, some teams are involved in local initiatives at their regional hospital through fundraisers or educational visitations to nearby academic centers while others advise on national research consultations and global research projects. However, collective, multi-site, multi-country patient advisory groups such as iCAN are viewed as a much-needed resource for consultations on international trials or studies involving patients from diverse ethnic and cultural backgrounds. While the semi-autonomous nature of this governance model is advantageous in many ways, it has also contributed to varied onboarding and training process between youth in different groups. Training ranges from none, to extensive training on topics such as qualitative and quantitative research methodologies, knowledge translation and patient safety. Training timelines also vary from sessions completed prior to involvement to both formal and informal sessions offered along the course of a youth's involvement in the YPAG. Such diversity in the expertise of young advisors create difficulties and interrater inconsistencies when multiple teams come together for international collaborations emphasizing the need for systematic training protocols.

4.2. Demographic composition

In reciprocal fashion, a YPAG's demographic composition also largely affects their purpose and resulting training protocols employed in the group. A notable distinction in the demographic make-up of various YPAGs and their respective training protocols are found when comparing groups that are patient-specific with groups with non-patients, and mixed teams (Fig. 2). Patient-only groups trend towards shortened or absence of training protocols. Team leaders often do not want the youth in their group to be overwhelmed with additional materials for training while groups with non-patients tend to involve youth with intrinsic interest in healthcare and medicine who naturally wish to learn more about medical topics. Perhaps more importantly, patient-only groups place an added emphasis on youth contributing from their experience as patients with lived experience or a "child's perspective" and not as "expert patients" [24].

The "expert patient" is a phenomenon now becoming an area of contention amongst researchers who noticed that the same patients who start with only a basic knowledge of disease processes and hospital logistics are now experts not only in their subjective understanding of healthcare experiences but rather in administrative processes and hospital functioning bordering that of healthcare professionals [25]. A paradoxical observation was also noted that the "expert patient" fails to acknowledge the opinions of patients who are most in need [26]. This becomes an issue of tension within partnerships where youth are consulted on their understanding of patient documents and take-home materials such as consent forms and pamphlets on trials for experimental medication. It is arguably difficult for youth to artificially adopt a falsely inexperienced perspective after months or years of engagement in such YPAGs. In contrast, researchers who seek the opinion of youth for clinical trial methodology (e.g., coming in for three lumbar punctures per year instead of one) or involvement in participatory health research (e.g., consultations on designing protocols) require input from individuals that have more than a basic understanding

of medical language and the ability to understand the implications of complex medical procedures without necessarily having gone through the same process themselves. In this way, the composition of a YPAG affects its ability to provide relevant perspectives on research activities.

4.3. Training protocols

Current educational initiatives and training protocols that range in length, consistency, and materials contribute to challenges in global consultations and consistent advice and feedback to collaborators. While education is much broader in scope, training in this context is defined specifically as the acquisition of specific skill sets for application to ongoing or upcoming projects. This may include qualitative and quantitative methods, consent and assent, patient safety, and ethics. The majority of team leaders admit to a lack of educational materials available or suitable for their YPAG, and spend significant time and effort crafting their own training materials or inviting guest speakers. As such, there is a pressing need for the standardization of training materials for use across the globe. In acknowledgement and support for local groups to continue serving as resources for their local academic and hospital institutions, the consolidation and distribution of shared educational materials will be key in helping streamline existing resources.

For youth advisors to provide purposeful feedback pertinent to the diverse research projects they are consulted on, it is essential for YPAGs to incorporate training to guarantee a collective baseline of research knowledge. Current frameworks on training for similar groups operate on a case-by-case basis where youth are trained as collaborators arise [6,27,28]. These groups also focus on youth investigating their own research topics through participatory action research which differs from the service-based consultations performed by YPAGs focused on research *advising* – serving as a resource for clinicians and researchers. Furthermore, materials developed for adult participants in patient-oriented research may not be appropriate for children and youth, either in language or format of presentation. For example, authors VT and SYC underwent training for the CIHR SPOR program where a series of modules were delivered during 5-hour sessions over 2 days [16]. The sessions were didactic in nature and much of the wording was nuanced and difficult even for most adults to comprehend. The training series lacked engaging hands-on activities and group input was limited to round-table discussions.

There is shared benefit in training youth advisors about the research process [29]. A standardized training protocol among YPAGs around the world will ensure that all advisors are being adequately prepared for their role as advisors in a healthcare facility if their focus is on research advising. Furthermore, methodology for engagement can be gathered from youth engagement models outside of medicine [30,31]. Educating young people on foundational research methods, literature review and theme identification in conjunction with their past experiences as young patients, allows them to develop necessary research skills to be able to provide credible youth perspective into the provision and design of international research and policy [32].

4.4. Limitations

This article highlights the challenges and ongoing work within the iCAN specifically as an illustration of the possibility for replication and expansion of similar groups around the world. While the iCAN chapters span many cities and regions globally, there may be unmentioned issues faced by existing groups elsewhere that is not captured. Furthermore, this paper makes a particular focus on

YPAGs that are involved in research. Therefore, findings may not be applicable to all YPAGs. Our interviews were only able to elicit opinions from participants who read and spoke English which may have limited the range of answers gathered. The data collected is also a compilation of the opinions of team leaders and select youth representatives from each of these groups and may not reflect the opinions of all members within the YPAG. It is noted that many youth members, whether patients or non-patients, choose to join the YPAG because of an intrinsic interest in the health sciences, biasing them to put their best efforts towards most topics they are exposed to. Lastly, though the focus of this paper does not extend to include issues of sustainability and governance such as funding, leadership, and transition, we do not negate the fact that more research is needed in these areas.

5. Conclusion

The reality of the recognized inconsistency between different YPAGs around the world speaks to the range of regional needs these advisory groups strive to meet. While the impact of individual projects and the value they add to their community cannot be undermined, it is timely to acknowledge a growing interest for inter-country collaborations and the needed consultations that come alongside. To address this global demand, standardized protocols for the training of children and youth in consultations for paediatric clinical trials must be created and implemented. In conclusion of this article, the following categories are recommended as major considerations for training youth in the initiation and maintenance of YPAGs focused on research:

1. Ethics and patient safety – there is widespread agreement that training for all groups working with children in healthcare should include safety regulations and ethics. Specifics may differ per hospital administration, city, or federal guidelines. While care must be taken to standardize similar coverage in ethical and safety considerations, disparities in legalities between countries must be accounted for.
2. Core research competencies have been determined through evaluation of existing training priorities of YPAGs focused on research. Shared areas of emphasis include advocacy, patients as partners training, pediatric ethics, and consent and assent. Over 60% of groups receive training in these areas.
3. Region and topic-specific training –YPAG teams should be encouraged to engage in training specific to unique aspects of the demographic they serve. Examples include sexual health conditions, mental health, and demographic-specific children's conditions i.e. beta thalassemia.

Logistical assessments should be done to understand how YPAG training can best integrate into an existing institution's infrastructure and governance model. Furthermore, the establishment of key stakeholders through contractual agreements is an important aspect of collaborator management. Financial and administrative support will not be elaborated upon in this article. The YPAG model is adaptable to institutions with more or less administrative support and internal funding and this flexibility contributes to ongoing viability of a group and ensures future success.

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Ethical statement

Authors confirm that informed consent was obtained for experimentation with human subjects. The privacy rights of human subjects has been observed.

Declaration of competing interest

No conflicts of interest declared.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijpam.2019.10.002>.

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