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Co-Producing the International Pediatric Oncology Exercise Guidelines (iPOEG) Toolkit with End-Users

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The international Pediatric Oncology Exercise Guidelines (iPOEG) support physical activity among children and adolescents affected by cancer. Knowledge translation efforts are needed to ensure that those who will use and/or benefit from the iPOEG have access to it. This mixed-methods study followed co-production principles as guided by an integrated knowledge translation approach within the Knowledge to Action (KTA) Framework, to engage end-users (i.e., professionals and patients/caregivers) to: (1) identify the types of resources needed; (2) co-produce an iPOEG brand; (3) co-produce resources and content; and (4) co-produce dissemination plans to distribute the iPOEG Toolkit (i.e., resources and content). End-users indicated requiring resources such as posters, infographics, social media posts, and videos, and co-created resource content covering quick tips to get active and movement-related education and information. Generated strategies to disseminate the iPOEG Toolkit included: (1) academic presentations; (2) brief education sessions and facilitated discussions to different end-user groups; (3) engaging champions from different end-user groups; (4) emails and email reminders; (5) mainstream news outlets (e.g., newspaper, magazines, or segments on the television [i.e., local news]); and (6) social media. Co-production of the iPOEG Toolkit and dissemination plan were guided by two phases within the KTA framework to build tools that can promote the reach of the iPOEG, ultimately increasing physical activity in this population.

Introduction

Annually, 300,000 children and adolescents are diagnosed with cancer worldwide (Steliarova-Foucher et al., 2017). Although treatments continue to improve, up to 90% of children and adolescents affected by cancer experience negative physical (e.g., decreased strength, fatigue, pain) and psychological effects (e.g., anxiety, depression) both during and after treatment (Bitsko et al., 2015; Brinkman et al., 2016, 2018). Physical activity (PA) is safe and may mitigate some of the negative effects, while promoting benefits among children and adolescent affected by cancer during (Grimshaw et al., 2016; Rustler et al., 2017) and after treatment (Runco et al., 2019). Further, increased levels of PA may decrease the risk of morbidity and early-mortality (Scott et al., 2018). Despite the benefits that PA may offer, most children and adolescent affected by cancer remain inactive (Antwi et al., 2019), and several barriers (e.g., time, treatment, cancer- and treatment-related side effects) preclude many from starting or maintaining PA during and beyond treatment (Götte et al., 2014).

As a step towards supporting greater PA in this population, the international Pediatric Oncology Exercise Guidelines (iPOEG) were developed (Wurz, McLaughlin, Lategan, Chamorro Viña, et al., 2021). The iPOEG is based on the best available evidence [i.e., reviews and experimental articles; Wurz, McLaughlin, Lategan, Ellis, et al. (2021)] and consensus development amongst expert opinion using the Delphi process (Falzarano & Zipp, 2013) with 131 experts from 23 countries (Wurz, McLaughlin, Lategan, Chamorro Viña, et al., 2021). The iPOEG includes four guideline (i.e., how much/how to engage in PA) and five recommendation statements (i.e., how to tailor PA) (Wurz, McLaughlin, Lategan, Chamorro Viña, et al., 2021). The iPOEG statements are general and overall suggest that moving more is beneficial for children and adolescents affected by cancer. The iPOEG served as a foundation for more recently published guidelines from Network ActiveOncoKids (Götte et al., 2022).

While traditional academic outlets (i.e., conference presentations, manuscripts) have been used to disseminate the iPOEG, these outlets alone are insufficient to promote PA for children and adolescents affected by cancer. Indeed, these outlets are unlikely to reach the key end-users [i.e., children and adolescents affected by cancer, caregivers, healthcare providers (HCPs), qualified exercise professionals (QEPs), and community-based organizations (CBOs)] who can use or benefit from the information in the iPOEG. This inaccessibility and resulting lack of information disseminated to those who need it is an issue that is often-cited as the ‘17-year gap’ between knowledge and implementation (Munro & Savel, 2016).

Moving evidence into the hands of end-users, as part of the knowledge translation process, is critical. Visual knowledge translation projects are one way to present key findings from traditional academic outlets to end-users in visually and linguistically appropriate and appealing ways (Garcia-Retamero & Cokely, 2017; Kaufmann & Ramirez-Andreotta, 2019). In this context, visual knowledge translation projects could include posters, brochures, or infographics (i.e., resources) that distill information to support PA among children and adolescents affected by cancer. Notably, visual knowledge translation projects can be done with meaningful end-user involvement through a process known as co-production (Smith et al., 2022), an increasingly recognized component of integrated knowledge translation [iKT; Field et al. (2014)]. Therefore, the purpose of this study was to develop the iPOEG Toolkit, a compendium of resources that present the iPOEG guideline and recommendation statements in user-friendly ways. Specifically, the research team worked with end-users to: (1) identify the types of resources needed; (2) co-produce an iPOEG brand; (3) co-produce resources and content; and (4) co-produce dissemination plans to distribute the iPOEG Toolkit (i.e., resources and content).

Methods

The Knowledge to Action (KTA) framework, which outlines steps required to generate knowledge and then move to implementation, guided this study (Field et al., 2014). The KTA framework has been recognized by many organizations, including the Canadian Institute of Health Research as a relevant framework to be used to guide knowledge translation (KT) initiatives with end-users (Field et al., 2014). Furthermore, the KTA framework provides guidance through two distinct components: (1) knowledge creation; and (2) action cycle, both of which include multiple phases to help close gaps between research and practice. Specifically, the first two phases of the of the action cycle in the KTA framework were used within an iKT approach (Kothari et al., 2017). iKT is more broadly defined as the meaningfully

involvement of end-users throughout the research process, and is essential to help amplify end-users' voices (Slattery et al., 2020). iKT is a type of co-production that is recognized by the Canadian Institutes of Health Research as one way to engage end-users through the process of generating knowledge collaboratively (Parry et al., 2015; Reed et al., 2020), which was utilized throughout the study. Finally, this study used a concurrent mixed-methods design (Castro et al., 2010). This study was approved by the Health Research Ethics Board of Alberta Cancer Committee (HREBA.CC-19-0491) at the University of Calgary.

Participants

Potential participants self-identified as a member of one of two end-user groups: (1) professionals (defined as a healthcare providers [HCPs; broadly defined as any HCP treating children and adolescents affected by cancer, including oncologists, nurses, child life specialists, physiotherapists, and occupational therapists], qualified exercise professionals [QEPs; defined as having specific cancer and PA knowledge, gained through training and/or clinical experience (including clinical exercise physiologists, personal trainers, and yoga instructors), and potentially involved in delivery of PA to children and adolescents affected by cancer], and community-based organizations [CBOs; defined as a representative of an organization that offers programs and/or services to children and adolescents affected by cancer on- or off-treatment, and/or their family], or (2) patients/caregivers (i.e., children and adolescents affected by cancer defined as individuals currently between the ages of 8-21, being affected by cancer, and being on- or off-treatment, and caregivers defined as individuals with a child/adolescent that they are caring for affected by cancer between the ages of 5-21, who may be currently on- or off-treatment. In their role as a caregiver, participants may have identified as a parent, guardian, and/or grandparent). Participants were eligible to participate in the study regardless of how many years they self-identified as a member of one of the two end-user groups.

End-users were recruited from September 2020 - December 2020. HCPs were recruited via study team contacts and snowball sampling from the two children's hospitals in Alberta, Canada (Alberta Children's Hospital, Stollery Children's Hospital). QEPs were recruited internationally via study team contacts and snowball sampling. CBOs were recruited from across Canada through study team contacts and/or generic internet searches (further described elsewhere). Patients/caregivers were recruited from an email request via the Kids Cancer Care Foundation that asked patients/caregivers if they were interested in participating in a study to help contribute to the development of resources to promote PA among children and adolescents affected by cancer.

Sample Size

To foster rapport, leverage different perspectives, and take into consideration pragmatic restrictions (based on the study team's knowledge of the field), five to seven participants from each end-user group were expected to be recruited for this study, with a subsample of at least two from each end-user group agreeing to take part in the focus groups. Recruitment of participants was largely guided by pragmatic considerations, including time constraints, anticipated restrictions recruiting during COVID-19, and enhanced ability to facilitate iterative communication and feedback among smaller groups (Slattery et al., 2020).

Procedures

Systematic searches (September 2020) were used to identify existing PA resources for children and adolescents (for both healthy and chronic disease populations) following guidelines for scoping reviews (Tricco et al., 2016) and environmental scans (Hatch & Pearson, 1998). To ensure the most comprehensive scan possible, over 1,000 systematic searches using keywords covering the end-user groups (e.g., child, adolescent, caregiver, healthcare exercise specialist, organization), diagnoses (e.g., cancer, chronic condition), PA (e.g., PA, exercise, movement), and resources (e.g., brochures, posters, education) were performed in Google and Google Scholar (see [supplementary file 1](#)) These findings informed the worksheets and semi-structured interviews that were completed by the end-users.

After providing informed consent online, all participants completed a survey collecting personal (e.g., age, location) and additional information (e.g., role in end-user group, years in current role) to describe

the sample. From November 2020 to April 2021, professionals completed two worksheets and took part in one focus group. The first worksheet and focus group sought to identify the types of PA resources and content desired. Professionals who consented to participate in focus groups, but were unable to attend, were provided a supplementary worksheet in lieu of the focus group, where they were asked similar questions to the focus group question guide. The second worksheet presented versions of developed resources and content, and end-users were asked to identify potential dissemination strategies. Both worksheets included closed- and open-ended questions to better understand the types of PA resources and content for the iPOEG Toolkit. See [supplementary file 2](#) for all worksheets.

Based on our limited ability to recruit patients and caregivers due to the impacts of the COVID-19 pandemic on clinical settings and resultant restrictions on research activity, the decision was made post hoc to modify the data collection strategy and engage in 1:1 and dyad, semi-structured interviews with this patient/caregiver group. The interviews took place April 2021. During these interviews, participants were asked to identify potential resources and content, to review the iPOEG brand and resources, and identify potential dissemination strategies.

Throughout, as data were collected from professionals and patients/caregivers, it was reviewed by EM, AW, and SNCR and then collated and shared with the design specialist. The design specialist then drafted different versions of the iPOEG brand, posters, and infographics that incorporated the input from end-users. These versions were reviewed by the research team who determined the priority items for changes to the resources and content based on co-production principles ([Hatch & Pearson, 1998](#); [Smith et al., 2022](#)), including the number of end-users who requested the change, the significance of the change to the end-users, and additionally if the request aligned with the iPOEG mission, guideline, and recommendation statements.

Data Analysis

Data analysis occurred throughout as a concurrent mixed-methods project ([Castro et al., 2010](#)). Descriptive statistics (i.e., mean, frequencies) were computed in SPSS Statistics (Version 26) to analyze quantitative data from sociodemographic surveys, and closed-ended responses to online worksheets. Open-ended responses to online worksheets and focus group and interview transcripts were managed in Microsoft Excel (Version 16.48). Interviews and focus groups were transcribed verbatim and managed in NVivo. Open-ended responses and interviews and focus group transcripts were analyzed using conventional content analysis, which was led by EM and reviewed by AW and SNCR ([Hsieh & Shannon, 2005](#)). Conventional content analysis was an inductive approach, wherein the study team did not employ predetermined categories when analyzing the data, but rather allowed the category names to be derived from the data.

Results

Systematic Searches

Examples of existing PA resources identified via the systematic searches can be found in [supplementary file 1](#). The resources identified (e.g., posters, brochures, infographics) provided a starting point for engaging with end-users. Prior to the focus groups with professionals, end-users were sent a document with existing PA resources for different populations identified during the systematic searches to give them an idea of what the iPOEG Toolkit resources could potentially look like.

Participant Characteristics

Thirty-six individuals across the three end-user professional groups took part in this study. Given the impact of the pandemic on recruitment and research activities, only one adolescent, and two caregivers participated in interviews, thus representing very limited perspectives from the patients/caregivers group. Tables 1 and 2 show the characteristics of professionals and patients/caregivers, respectively, while Table 2 outlines how many end-users participated in each component of the iPOEG Toolkit co-production. In general, most professionals were QEPs (n=26; 72%) and had been in their role as a professional for >10 years (n=17; 47%). The adolescent was 17 years old from Alberta, was off-treatment, and was in

high school. The caregivers were 46- and 57-year-old mothers who were both from Alberta, one of whom completed a graduate degree and the other completed a professional graduate degree.

Table 1. Sociodemographic Survey Results for Professionals (n=36)

	Healthcare providers (n=9)	Qualified exercise professionals (n=22)	Community-based organizations (n=5)
Age (years)	40.8 (SD = 8.4)	36.5 (SD = 6.3)	46.6 (SD = 10.7)
Role in End-User Group (n)			
Oncologist	1		
Nurse	3		
Physiotherapist	2		
Occupational therapist	1		
Other (e.g., therapist assistant)	2		
Currently offer programs/classes for children and/or adolescent affected by cancer		20	
Previously offered programs/classes for children and/or adolescent affected by cancer		2	
Currently offer programs/services for children and/or adolescent affected by cancer and their families/ caregivers			4
Previously offered programs/services for children and/or adolescent affected by cancer and their families/ caregivers			1
Years Identified with End-User Group (n)			

	Healthcare providers (n=9)	Qualified exercise professionals (n=22)	Community-based organizations (n=5)
Location (n)			
0-5 years	1	5	0
6-10 years	3	5	2
10+ years	5	12	3
Alberta	9		
Australia		8	
Canada		3	
Chile		1	
Finland		1	
Germany		4	
Italy		5	
Ontario			4
Saskatchewan			1
Highest Level of Education (n)			
High school	0	1	
Undergraduate degree	5	2	2
Graduate degree	2	10	1
Professional graduate degree	2	9	0
Other (e.g., college diploma, some university education)	0	0	2

Table 2. End-User Involvement in iPOEG Toolkit Co-Production

	Healthcare providers (n=9)	Qualified exercise professionals (n=22)	Community-based organizations (n=5)	Patients (n=1)	Caregivers (n=2)
Worksheet 1	8	19	5		
Focus group 1	7	8	2		
Worksheet in lieu of focus group	1	7	2		
Worksheet 2	5	17	4		
Interviews				1	2

Worksheet 1 with professionals

[Supplementary file 3](#) provides the results from worksheet 1, including the rank order of resources based on end-users needs and preferences. Although the order in which resources were ranked varied across professional end-user groups, opened-ended responses suggested that professionals desired patient-facing resources including posters, infographics, brochures, and videos, and find these to be useful because they could share them with their patients, clients, or members in print form or via email.

Focus groups with professionals

[Supplementary file 3](#) presents findings from the focus groups and supplementary worksheet in lieu of the focus group. Across end-user focus groups, professionals reiterated the worksheet findings, that they specifically wanted iPOEG Toolkit resources and content that they could then share with children and adolescents affected by cancer. They emphasized the need for quick, eye-catching resources and content for the children and adolescents affected by cancer and their families, including posters, infographics, and quick tip videos on how to engage in more PA. At this time, professionals did not request educational resources for themselves. Professionals also discussed the importance of having a website where the resources could be housed, or where individuals could go for more information about PA and the iPOEG Toolkit specifically.

Worksheet 2 with professionals

[Supplementary file 3](#) provides the results from worksheet 2. Overall, end-users were pleased with the posters and infographics that had been developed for children and adolescents affected by cancer. The professionals felt that the resources and content were visually and linguistically appropriate and were memorable. End-users suggested minor changes to include more images with boys and adolescents who were bald, to be more representative of the target population.

Interviews with patients/caregivers

Across the interviews, the adolescent and caregivers liked the posters and infographics that had been developed. Specifically, the adolescent felt that the variation between the child-facing and adolescent-facing resources was appropriate for the age groups. Feedback highlighted that patients/caregivers desire

resources that are in both print and online to enhance accessibility, and that these resources provide information about the importance of PA and the practicalities of ‘how to move more’. The adolescent had feedback to make the images more vibrant. Participants also suggested additional resources that would be useful, such as educational videos featuring children and adolescents affected by cancer discussing the importance and impact of PA, and an app to house the iPOEG Toolkit.

Finalized iPOEG Brand

Based on the co-production process, the finalized logo included a person in free, fluid movement within a circle, as represented by the ‘O’ in the iPOEG name. The iPOEG slogan was finalized as ‘Move More’, consistent with messaging of the iPOEG guideline and recommendation statements to support PA (Wurz, McLaughlin, Lategan, Chamorro Viña, et al., 2021). Typography (i.e., font) were chosen and finalized based on end-user feedback to be ‘fun’, yet ‘professional’. Finally, finalized colours included variations of greens and blues, that were based on suggestions from professionals that these colours are ‘calm’, ‘encouraging’, and ‘attractive’. See [supplementary file 4](#) for the finalized iPOEG brand.

Finalized Preliminary Resources and Dissemination Strategies

The final preliminary resources compiled included four child-facing posters, three adolescent-facing posters, six child-facing infographics, three adolescent-facing infographics, and three poster templates, which can be found on the [Health and Wellness Lab website](#). It is acknowledged that further engagement with a range of patients (ages, cancer types), must occur in order to address any unmet needs, given the lack of patient engagement in the current study due to COVID-19 pandemic-related restrictions. Thus, ongoing work within our pediatric exercise oncology program (i.e., IMPACT, NCT04956133, Gilliam et al., 2011) is including feedback on materials. This will be reflected in updated documents on the [Health and Wellness Lab website](#).

In addition to these preliminary outputs, six dissemination strategies to move the iPOEG Toolkit into the hands of various end-users were identified by both professionals and patients/caregivers. These strategies included: (1) academic presentations to educate healthcare providers and other end-users about the benefits of PA and how to promote PA to their patients; (2) brief education sessions and facilitated discussions with different end-user groups (e.g., healthcare providers, qualified exercise professionals, community-based organizations); (3) engaging champions from different end-user groups to promote the iPOEG and PA among their colleagues; (4) sending emails and email reminders to various end-user groups; (5) utilizing mainstream news outlets (e.g., newspaper, magazines, or segments on the television [i.e., local news]); and (6) posting infographics and movement tips on various social media platforms (e.g., Instagram, Twitter, Facebook, Tiktok) to reach unique end-user groups. The iPOEG Toolkit includes initial resources that will be amended over time.

Discussion

The purpose of this study was to co-produce the iPOEG Toolkit with end-users by: (1) identifying the types of resources needed; (2) co-producing an iPOEG brand; (3) co-producing resources and content; and (4) co-producing dissemination plans to distribute the iPOEG Toolkit (i.e., resources and content). The result was an iPOEG brand consisting of a logo, slogan, font, and colours to create consistency throughout the resources in the preliminary iPOEG Toolkit. All resources can be found on the [Health and Wellness Lab website](#). Both professional and the patient/caregiver end-users identified the need for posters and infographics for children and adolescents affected by cancer that included content from the iPOEG guideline and recommendation statements. In addition, a multi-pronged dissemination plan, with six unique strategies, were identified to inform future dissemination efforts that will target professionals and families impacted by cancer.

Notably, the resources identified by all professional end-users, as well as by the patient/caregivers, were child- and adolescent-facing. This stands in contrast to prior work, which has reported that HCPs desire their own education and information to talk to their patients about strategies to manage their disease (Kime et al., 2020). HCPs are ideally suited for supporting their patients through behaviour change (Vallis et al., 2018), and the iPOEG Toolkit resources designed as patient-facing (vs for the HCP) may facilitate conversations and provide a tangible resource to promote ‘moving more’.

Although few researchers have described using an iKT approach with multiple end-user groups (Glowacki et al., 2019; Leask et al., 2019; Tomasone et al., 2020), the value in building tools that are valuable across end-user groups is compelling. Over five months, 39 end-users were recruited and contributed to the co-production process. While including representatives from different end-user groups who have different needs and perspectives through co-production is more time-consuming and can be complex to ensure all voices are heard, it is important to help move evidence to practice (Slattery et al., 2020). In the current study, we faced substantial restrictions, in particular in engaging with the patient/caregiver group. Despite repeated outreach attempts, we were unsuccessful in reaching children and adolescents affected by cancer and caregivers who were interested in participating in this study. As such, concerted efforts will be made to engage these end-user groups in ongoing work (Gilliam et al., 2011), which will allow us to continue to build on these preliminary resources.

The iPOEG adds to other PA guidelines (e.g., [Canadian Society of Exercise Physiology 24-Hour Movement Guidelines for Children and Youth](#)) developed for children and adolescents, and provides additional population-specific guidelines and recommendations to support the unique needs and considerations for children and adolescents affected by cancer. As pediatric exercise oncology evidence grows, the iPOEG guideline and recommendation statements will be updated, as will the iPOEG Toolkit. This is especially important in terms of gathering input from the patient population, including younger and older children at different stages of their cancer journey.

While this study had several strengths, including involvement of end-users within an iKT approach, co-production with a design specialist, and engaging varied end-user groups, it is limited by the sample of n=3 for patient/caregivers. Specifically, despite numerous outreach attempts, no children affected by cancer were included and only one adolescent engaged in our co-production process. While consensus on the final iPOEG Toolkit across all stakeholders groups engaged within this project lend preliminary support to this work, children and adolescents affected by cancer will continue to be engaged within our ongoing exercise work (Gilliam et al., 2011) to update the resources and ensure their relevancy across patient populations.

Conclusions

It is hoped that the co-produced preliminary iPOEG Toolkit will enhance the likelihood of translating recently generated evidence to practice within the field of pediatric exercise oncology. The Toolkit is available on the [Health and Wellness Lab website](#), and will continue to reflect updates as further feedback is generated in particular from children and adolescents with cancer, and will be used to support translation efforts.

Additional Information

This study was approved by the Health Research Ethics Board of Alberta Cancer Committee (HREBA.CC-19-0491) at the University of Calgary. This is part of ongoing work within a pediatric exercise oncology program (registered clinical trial; NCT04956133; <https://clinicaltrials.gov/ct2/show/NCT04956133>).

Contributions

All authors have read and agreed to the published version of the manuscript.

- Conceptualization: Emma McLaughlin, Amanda Wurz, and S. Nicole Culos-Reed
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- Data collection: Emma McLaughlin; data analysis, Emma McLaughlin
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- Visualization: Emma McLaughlin, Amanda Wurz, Gregory MT Guilcher, Jennifer Zwicker, and S. Nicole Culos-Reed; supervision, S. Nicole Culos-Reed

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Data and Supplementary Information

Data and supplementary material accessibility supporting documents can be found as supplementary data files at <https://doi.org/10.17605/OSF.IO/HK8EA>.

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