#### ORIGINAL RESEARCH



# The international Pediatric Oncology Exercise Guidelines (iPOEG)

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#### **Abstract**

Physical activity (PA) and exercise are safe and beneficial for children and adolescents affected by cancer. Yet, this population is not active enough to receive benefits. PA guideline and recommendation statements can support individual behavior and practice change. The purpose of this project was to develop the international Pediatric Oncology Exercise Guidelines (iPOEG), comprised of guideline and recommendation statements, to promote PA among children and adolescents affected by cancer. Guideline development procedures, stakeholder engagement strategies, and the Delphi technique were used. Four online surveys were distributed to the iPOEG network (n = 9 core team members, n = 122expert consensus committee members). Surveys included closed- and open-ended items informed by a literature synthesis and an in-person meeting. Responses were analyzed using descriptive statistics and content analysis. Consensus was defined as ≥ 80% agreement. Response rates to online surveys ranged from 82% to 91%. The iPOEG network agreed on four guideline and five recommendation statements, which highlight that movement is important for all children and adolescents affected by cancer. These statements are generic in nature as more research is still required to provide specific guidance on the frequency, intensity, time, and type of PA for this population. Nevertheless, the iPOEG statements represent available evidence and expert opinion, collectively suggesting that it is time for children and adolescents affected by cancer to move more.

#### **Keywords**

Childhood cancer, Physical activity, Delphi technique, Consensus

#### **BACKGROUND**

Physical activity (PA; i.e., any bodily movement produced by skeletal muscles that requires energy expenditure; [1]) and exercise (i.e., planned, structured, and repetitive PA for the purpose of conditioning any part of the body, improving health, and maintaining fitness; [1]) can confer positive outcomes for children and adolescents affected by cancer. Although there are gaps in the literature, researchers have reported that PA and exercise are associated with a range of benefits from helping manage symptoms (e.g., fatigue and pain),

#### **Implications**

**Practice:** Movement is safe, beneficial, and recommended for all children and adolescents affected by cancer.

**Policy:** Policymakers who want to enhance movement among children and adolescents affected by cancer should explore sustainable physical activity or exercise programs, and include qualified exercise professionals as part of standard care to facilitate program implementation and uptake.

**Research:** Researchers should focus on conducting high-quality, multisite studies to continue providing evidence for the benefits of moving more during and after treatment for cancer.

#### Lay summary

Physical activity is safe and beneficial for children and adolescents affected by cancer. Yet, most are not active enough to receive benefits. Guideline and recommendation statements can help change individual behavior and practice. To develop such statements, guideline development procedures, stakeholder engagement strategies, and the Delphi technique were used. Four online surveys were distributed to an international network (n = 131 experts). Surveys asked closed- and openended questions informed by a literature synthesis and an in-person meeting. Findings from the online surveys resulted in the international Pediatric Oncology Exercise Guidelines statements, which highlight that it is time for children and adolescents affected by cancer to move more.

to enhancing physical and psychosocial well-being (e.g., improving body composition and reducing anxiety), to extending the length of survivorship [2–5]. This evidence has been presented in numerous cross-sectional and prospective studies [6–10], experimental articles [11–15], and systematic reviews [2–5]. Combined, findings suggest that PA, including exercise, is an important part

of treatment and recovery for children and adolescents affected by cancer.

To promote PA and exercise in this cohort, resources (e.g., manuals and pamphlets) and models have been developed [16-19] and researchers have published manuscripts detailing best practice examples for integrating PA and exercise into standard pediatric oncology care [20]. Notwithstanding these contributions, an important gap remains: there are no widely agreed upon PA and exercise guideline statements for children and adolescents affected by cancer, nor strategies for tailoring PA and exercise (i.e., recommendations) for this cohort. Guideline and recommendation statements can support PA and exercise behavior change at multiple levels (e.g., the child/adolescent, parents/guardians, and health care providers; [21, 22]). In the absence of guideline and recommendation statements, children, adolescents, and their parents may be unsure about how much PA or exercise to engage in, and clinicians may be unsure about how much PA or exercise to recommend to their patients.

Consensus methods, such as the Delphi technique, are widely used and accepted for developing guidelines and recommendations in medical and health service research [23]. For example, the Delphi technique was recently used to develop supportive care clinical practice guidelines for children and adolescents affected by cancer [24] and recommendations for PA and exercise for adults with osteoporosis [25]. Furthermore, the Delphi technique can be used in circumstances when there are gaps in knowledge as it can consolidate available evidence and expert opinion [26]. Thus, the purpose of this project was to develop internationally agreed upon PA and exercise guideline and recommendation statements (i.e., the international Pediatric Oncology Exercise Guidelines; iPOEG).

#### **METHODS**

This project was guided by literature detailing clinical guideline development procedures [27], strategies to engage a range of stakeholders using online processes [28], and the Delphi technique [26]. Ethical approval was granted by the Health Research Ethics Board of Alberta-Cancer Care Committee and informed consent was obtained from all those who responded to the online surveys. No formal eligibility criteria were specified a priori for participants; rather, individuals who were experts in the field of pediatric exercise oncology-a field covering medicine, rehabilitation, physiology, kinesiology, and psychology—were invited or self-identified to participate in English. Figure 1 provides a visual depiction of the different phases comprising the development of the iPOEG.

#### Preparation phase (September 2018–January 2019)

Identifying and recruiting international experts: core team and expert consensus committee

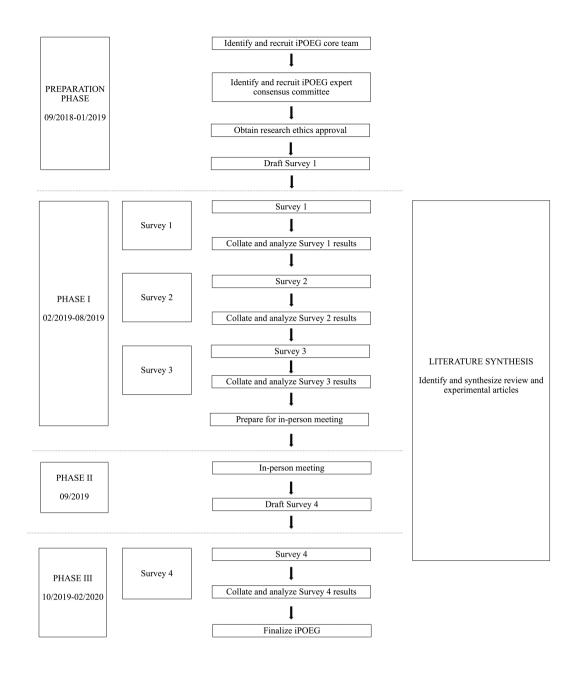
A core team of nine international experts from six countries were identified and recruited to participate via email by the first and last authors based on a recently completed international environmental scan [29] and the authors' preexisting networks. Once established, a larger expert consensus committee was recruited. Similar to above, the expert consensus committee was identified using findings from the international environmental scan [29], common adopted criteria (i.e., actively practicing, publishing, and/or working in the field of pediatric exercise oncology; [30]), and snowball sampling. The decision was made post hoc to add new members with relevant expertise throughout this project. At the end of the preparation phase (January 2019), the expert consensus committee was comprised of 115 individuals from 18 countries. Throughout Phase I (February 2019-August 2019) and Phase II (September 2019), seven additional experts from six countries self-identified or were recruited to the expert consensus committee to total 122 individuals from 21 countries. The core team (n = 9)and iPOEG expert consensus committee (n = 122) together comprise the iPOEG network (n = 131experts).

## Phase I—information gathering (February 2019 – August 2019)

Surveys

Emails were sent to the iPOEG network following guidance from Jones and Hunter [26]. These emails contained a link to the survey that collected informed consent and basic descriptive information (i.e., area of expertise, years working in field, and geographic location). Following this, a series of closed- and open-ended items were presented covering terminology and content areas for the iPOEG. Closedended items directed respondents to select the level to which they agreed or disagreed with statements, whereas open-ended items collected additional information and/or comments. Throughout, respondents could indicate "I do not feel I have the expertise to complete this section (skip to next section)" to skip a question or series of questions. Responses were anonymized [26] and data for open-ended items was analyzed via content analysis [31, 32] by two independent researchers (E.M. and D.C.). Findings were used to inform subsequent survey rounds. Consensus was defined a priori for closed-ended items as ≥80% agreement. Three surveys were administered in Phase I (February 2019-August 2019). Only those who completed Survey 1 were invited to participate in Survey 2, and only those who completed Survey 2 were invited to participate in Survey

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Note. iPOEG=international Pediatric Oncology Exercise Guidelines.

Fig 1 | Overview of the international Pediatric Oncology Exercise Guidelines (iPOEG) project.

3. Supplementary File 1 provides further details on these surveys as well as example items.

#### Literature synthesis

To provide an overview of the available evidence reporting on the effects of PA and exercise for children and adolescents affected by cancer, a literature synthesis was conducted following guidance for the design, conduct, and reporting of scoping reviews [33–35], systematic reviews [36, 37], and reviews of reviews [38]. Also, pragmatic constraints were considered. Review and experimental articles published in English, summarizing or reporting on the

effects of PA (including exercise) interventions for children and adolescents affected by cancer, were included. Articles were identified by a team of researchers through a recently published environmental scan [29], systematic searching of Google and Google Scholar, reference list scanning, stakeholder engagement, and a database update, which was conducted in MEDLINE, PsycINFO, and SPORTDiscus from January 2017 to January 2020. Data were extracted, articles were assessed for quality (reviews; AMSTAR 2 [39]) or risk of bias (experimental articles; Cochrane Handbook for Systematic Reviews of Interventions [40] or Risk of

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Bias Assessment tool for Non-randomized Studies [41] as appropriate based on study design), and narrative summaries were prepared [42]. A total of 1,380 articles were identified. Twenty reviews and 69 experimental articles were included. Articles examined the effects of PA (or exercise) on PA behavior, physical, psychosocial, cognitive, and 'other' outcomes. Improvements, no change, and mixed results were found across the majority of outcomes. Two adverse events (e.g., a treatable injury and fatigue) were described. Article quality and risk of bias varied widely. Overall, findings suggest that the field of pediatric exercise oncology is rapidly advancing, and that PA, including exercise, is beneficial and safe. Nevertheless, more adequately powered research adhering to reporting standards is required. The full literature synthesis, including all methods and results, has been published elsewhere [43].

#### Phase II—international team meeting (September 2019)

The in-person, international team meeting took place in Banff, Alberta, September 2019. This meeting included the core team, local health care providers (i.e., an oncologist and nurse administrator), and trainees. A family affected by childhood cancer was also invited; however, they were unable to attend at the last minute due to personal circumstances. Just over 2 weeks prior to the meeting, attendees received a document consisting of findings from Surveys 1-3 and a summary of the findings from the in-progress literature synthesis. The objectives of this meeting were to discuss the results from the information gathered in Phase I (February 2019-August 2019) and to draft the iPOEG guideline and recommendation statements. Also, attendees reviewed and commented on the literature synthesis to identify research and innovation needs in the field (see [44] for a manuscript detailing these needs).

## Phase III—Finalizing the iPOEG (October 2019–February 2020)

The statements drafted in *Phase II* (September 2019) were provided to members of the iPOEG network who completed at least Survey 1 or who had joined between February 2019 and October 2019. This survey explored agreement on the statements drafted during the in-person meeting. Supplementary File 1 provides the general details on the survey as well as example items, respectively. For each statement, respondents were asked to judge whether the statement should be included within the iPOEG ("yes" or "no") and to provide their thoughts. As above, consensus was defined as ≥80%.

#### **RESULTS**

The combined response rate across the four surveys was 89%. On average, most respondents self-selected being a researcher (n = 52) and had >10 years in

their field (n = 38). The majority of respondents were from Canada (n = 21), followed by Germany (n = 19), and the USA (n = 15; numbers represent averages across the four surveys; see Table 1).

#### Survey 1

Respondents agreed on the definitions for the iPOEG (see Supplementary File 2). In addition, respondents reached consensus for the content of future surveys. There was no consensus on items covering specific criteria for PA/exercise prescription in pediatric oncology.

#### Survey 2

Respondents indicated that pediatric oncology-specific evidence should be used to inform the guideline and recommendation statements and that the core team's expertise might be an important source of information. There was no consensus on how the recommendation statements could be written to address the need to tailor PA/exercise for children and adolescents affected by cancer.

#### Survey 3

Respondents agreed that only pediatric oncology-specific evidence should be used along with the core team expertise. Furthermore, a list of population-specific conditions that would require modifying or adapting PA/exercise were agreed upon (n = 21; e.g., anemia, cardiotoxicity, and veno-occlusive disease; see Supplementary File 3).

#### In-person meeting

Core team members (n=9), local health care providers (i.e., pediatric oncologist and nurse administrator; n=2), and trainees (n=8) attended the in-person meeting. During this meeting, attendees discussed and modified previously agreed upon language and terminology. Meeting attendees then drafted four guideline statements that contained information to advise children and adolescents affected by cancer, their families, and health care providers, on how to engage in movement (i.e., bodily motion that requires energy expenditure; e.g., how often and how much) and five recommendation statements for tailoring exercise based on specific needs/circumstances.

#### Survey 4

Respondents agreed with modifying language and terminology and with each statement drafted during the in-person meeting (pending minor modifications to wording). Fig. 2 presents the final iPOEG guideline and recommendation statements, which are generic in nature.

#### **DISCUSSION**

The purpose of this project was to develop PA and exercise guideline and recommendation statements

**Table 1** | Survey response rates and responder characteristics

	Survey 1	Survey 2	Survey 3	Survey 4
Response rate details				
Invited (n)	124	113	97	121
Completed (n)	113	97	93	99
Response rate (%)	91	86	96	82
Area of expertise				
Exercise/sport specialist (n)	31	28	32	30
Health care or allied health care provider (e.g., nurse, oncologist, doctor, and physiotherapist) (n)	60	46	42	50
Movement instructor/provider (e.g., PA and yoga) (n)	00	02	03	01
Researcher (n)	58	49	47	57
Years in the field				
<1 year (n)	02	02	00	02
≥1–2 years ( <i>n</i> )	07	05	04	05
>2–5 years ( <i>n</i> )	24	23	23	16
>5–10 years (n)	33	31	30	39
>10 years (n)	46	36	36	37
Respondent's geographic location				
Australia (n)	14	10	09	12
Brazil (n)	02	02	02	01
Canada (n)	23	21	21	22
Colombia (n)	01	01	01	01
Denmark (n)	03	02	02	02
Finland (n)	05	05	05	04
France (n)	02	01	01	01
Germany (n)	21	18	18	20
Italy (n)	08	08	08	08
Netherlands (n)	03	04	04	04
New Zealand (n)	00	00	00	01
Norway (n)	01	01	01	01
Portugal (n)	01	01	01	01
Qatar (n)	01	01	01	01
Spain (n)	04	03	03	03
Switzerland (n)	01	00	00	01
Turkey (n)	01	01	01	01
UK (n)	02	02	02	02
USA (n)	19	16	14	13

PA physical activity. For 'area of expertise' respondents were able to choose all categories that were applicable—the categories in this table represent those presented to the iPOEG network in the online surveys, prior to the network achieving consensus on the terminology for different groups of experts (e.g., exercise physiologist and physical therapist). For Survey 1, 112 (of 113) completed select demographic questions.

via iterative survey rounds using the Delphi technique to achieve consensus, a literature synthesis to build from existing evidence, and an in-person meeting to bring together clinical and research expertise. The guideline and recommendation statements are generic in nature as work remains to be done in this field. Nevertheless, *moving more* was described as safe—with no broad categories of contraindications for movement identified—and beneficial for all children and adolescents affected by cancer.

Notable strengths of this project include the international core team who provided varied perspectives, oversaw survey development, and offered

input throughout the ancillary literature synthesis, ensuring that statements were based on available evidence and expert opinion. Also, the in-person meeting in *Phase II* (September 2019) enabled the discussion of available evidence, reflection on current practice, and review of findings from Surveys 1–3. Finally, the iterative and open-ended nature of Surveys 1–4 enabled consensus building and utilized the iPOEG networks' feedback to refine subsequent surveys. Thus, the iPOEG statements presented herein are evidence-informed and reflect consensus from a large and diverse group of experts spanning disciplines and countries. Consensus

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#### Based on consensus, the iPOEG guideline statements are...

Choose to move. Do what you can. Do it when you can.

Movement is possible and important for every child and adolescent with cancer...

- Across all ages, abilities, diagnoses, stages, and phases; and
- Across all settings (e.g., in-hospital, community, school, daycare).

Movement might look (and feel) different day-to-day, and that is okay.

Evidence indicates movement and exercise are important for the healthy development of children and adolescents with and without chronic conditions. When looking to the literature for children and adolescents with and after cancer, evidence shows that movement and exercise are safe and may provide benefits (e.g., decreased fatigue and anxiety and improved strength, aerobic fitness, and quality of life). When transitioning from movement to exercise, or in cases where you are unsure about the safety of movement, refer to your healthcare team and the recommendation statements.

#### Based on consensus, the iPOEG recommendation statements are...

When prescribing exercise, an exercise professional (e.g., exercise physiologist, physical therapist, kinesiologist, physiatrist, or an individual with appropriate knowledge, skills, and training) is recommended. The exercise professional must consider age, the type of cancer, the setting, treatment-related considerations and contraindications, and individual factors (e.g., previous experience, preferences). Communication between the exercise professional and the healthcare team is important to ensure safety.

Communication between the healthcare team and exercise professionals is important to promote exercise among children and adolescents affected by cancer.

An exercise professional with specific pediatric cancer and exercise knowledge, gained through training and/or clinical experience, is important to ensure safety and effectiveness of exercise for children and adolescents affected by cancer.

In some cases, an exercise professional may be necessary to support children and adolescents affected by cancer with initial movement goals as well. This would be up to the discretion of, and in communication with, the healthcare team and family.

An intake form for exercise professionals working with children and adolescents affected by cancer should include the following:

- Age
- Diagnosis and date
- Treatment(s) planned, current, and previous
- Other medical issues
- Current symptoms that could impact movement or exercise
- Physical restrictions
- Other therapies (current and previous)
- Physician notes
- Participants preferences and barriers
- Current movement, exercise, and physical condition

Fig 2 | International Pediatric Oncology Exercise Guidelines (iPOEG) guideline and recommendation statements.

throughout this project was high and comparable to that reported in the literature [45], which may be due (in part) to calls for guideline and recommendation statements by researchers in this field [2–5] and the relative rarity of pediatric cancer [46, 47], which has compelled small yet coordinated efforts locally and internationally.

When interpreting the iPOEG statements, there are important limitations that must be considered. First, the survey respondents were invited based on their self-identification as 'experts' in the field

of pediatric exercise oncology. Although the intent was to develop an iPOEG network comprised of respondents with varied expertise, the full range of health care providers working with this population was not captured. It will be critical to continue to recruit and build a network that is inclusive of experts from different disciplines and who hold differing clinical and nonclinical positions. For example, including more psychologists, social workers, and child life specialists may ensure a greater emphasis on developmental perspectives and enjoyment

during movement (i.e., the fun factor), which are paramount to promoting lasting behavior change in this population. Furthermore, distinguishing within and across groups of experts (e.g., health care providers, movement-based allied health care providers [e.g., physiotherapists and kinesiologists], other allied health care providers [e.g., psychologists, social workers, and child life specialists], and researchers [e.g., kinesiology and medicine]) is needed to ensure adequate representation from different perspectives when updating the iPOEG guideline and recommendation statements. Related to this, those who participated in this project may not be completely representative of all those with relevant experiences and/or training in this field internationally. Specifically, participation in this project was limited to those who could complete the surveys in English. Nonnative English speakers may have had difficulty understanding and responding and/or may have elected not to participate. Second, while the questions presented to the iPOEG network in Surveys 1-4 were devised by the core team, it is possible that additional or different questions could have been included that may have yielded different results. To minimize such biases, open-ended response options were included, iterative survey rounds were conducted to inform subsequent rounds, and a literature synthesis was performed. Finally, findings from this project and the literature synthesis (that occurred concurrently; [43]) indicate that more evidence is required to facilitate specific guideline and recommendations statements (e.g., following frequency, intensity, time, and type to provide a higher degree of specificity and guidance). As evidence continues to accumulate, further efforts will be required to refine these statements to ensure that they reflect the current evidence, practice, and a range of expert opinions. Notably, the iPOEG network continues to expand. At the time of manuscript revisions, the iPOEG network was comprised of 158 individuals from 26 countries. Interested individuals can join the iPOEG network by visiting: https://survey.ucalgary. ca/jfe/form/SV\_2tUtHWgGmqUOPkx.

Although the publication of this manuscript is a necessary first step in knowledge translation, additional efforts are required to move these statements beyond academia and into practice. To ensure end users (e.g., health care providers, children, and adolescents affected by cancer and their families/caregivers, exercise professionals, educators, and cancer support organizations) have access to this information, a series of integrated knowledge translation projects are being undertaken to develop iPOEG Toolkits, which will consist of educational videos, infographics, brochures, and posters. These resources are being created with end users and will be hosted online to reduce barriers to access. To stay up-to-date or to learn more about this project, please see: https:// kinesiology.ucalgary.ca/labs/health-and-wellness/ research-projects/pediatric-oncology-research/international-pediatric-oncology. In addition, given the important role of exercise specialists, as detailed within the iPOEG recommendation statements, pediatric cancer and exercise education modules are being developed to help ensure that those wishing to work with this population have appropriate training Please see https://thrivehealthservices.doki.io/pediatric-cancer-and-exercise-module for more details.

#### CONCLUSION

The iPOEG guideline and recommendation statements are based on available evidence and consensus from a large team of international experts. The statements represent a first step to support end users engaging in and promoting movement and exercise among children and adolescents affected by cancer. Although further work is required, the experts agree, it is time for children and adolescents affected by cancer to move more.

#### **SUPPLEMENTARY MATERIAL**

Supplementary material is available at *Translational Behavioral Medicine* online.

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#### Compliance with Ethical Standards

**Conflicts of Interest:** The authors declare that they have no conflicts of interest.

**Authors' contributions:** A.W. and S.N.R. are coleads on the iPOEG project. E.M. and C.L. are trainees engaged in iPOEG research. The core team consists of C.C.V., S.G., L.H., S.K., F.R., M.G., and P.V.d.T. Both G.M.T.G. and K.M. provided clinical input. All coauthors contributed meaningfully to this project and critically reviewed and approved of the manuscript.

Ethical Approval: All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. Ethical approval for the design and conduct of this study was provided by the Health Research Ethics Board of Alberta—Cancer Care Committee (HREBA-CC; Ref. HREBA.CC-18—0565).

**Informed Consent:** Informed consent was obtained from all individual participants included in the study.

Study registration: This study was not formally registered.

**Analytic plan preregistration:** The analysis plan for this study was not formally preregistered.

#### Data availability

Deidentified data from this study are not available in a public archive. Summaries of the deidentified data from this study will be made available (as allowable according to institutional research ethics board standards) by emailing the corresponding author.

Analytic code availability: There is no analytic code associated with this study.

Materials availability: Materials used to conduct the study are not available in a public archive. Materials may be made available (upon reasonable request) by emailing the corresponding author.

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