

Head and Neck Cancer Research – Priority Setting Partnership Draft Steering Committee Terms of Reference

FINAL: Mar. 30, 2016

Background

The Alberta Cancer Foundation, the Institute for Reconstructive Sciences in Medicine (iRSM), and the Strategy for Patient Oriented Research (SPOR) – Patient Engagement Platform (collectively referred to as ‘the Consortium’) are interested in determining if Alberta patients who have been treated for head and neck cancer have any uncertainties or unanswered questions about their treatment and the management of their care that could be addressed through future research.

The Consortium recognizes that cancer patients and front-line clinicians often have tremendous insights into gaps and opportunities in cancer care and research but they may have difficulty advancing their ideas in ways that garner the attention of researchers and funders. As a result, clinical research topics in cancer are often determined primarily by researchers and funding agencies with minimal input from patients and treating clinicians.

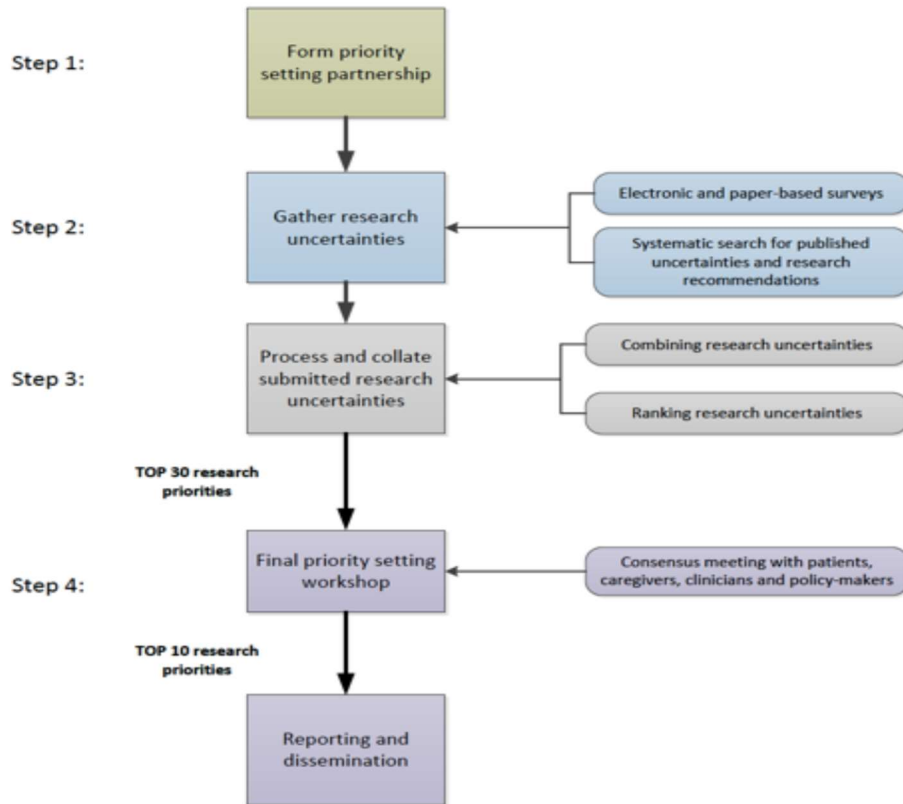
In order to gain patient, caregiver and clinician input into the most important research priorities in head and neck cancer, the Consortium is adapting and implementing an engagement protocol -- called a Priority Setting Partnership (PSP) -- that was developed by the James Lind Alliance (JLA) in the United Kingdom in 2004. The JLA PSP methodology engages patients and clinicians through a methodical and rigorous process to gather treatment uncertainties and prioritize them for consideration as future research topics.

As a first step, a steering committee is formed to help coordinate and implement the process of gathering uncertainties. During this process the committee develops partnerships with organizations that can reach and advocate for patients and clinicians, who in turn are invited to respond to a survey regarding treatment uncertainties. Following a rigorous review and vetting process, the PSP culminates in the identification of the top 10 treatment uncertainties for head and neck cancer research in Alberta. This PSP is considered a demonstration project of the Alberta Cancer Foundation to ultimately assess whether the PSP process results in viable research questions that could be considered for future funding.

The expected benefits and outcomes associated with this PSP include:

- Building patient skills and competency in contributing to research priority setting
- Demonstrating the benefits that can accrue to patients, families, clinicians and researchers when a partnership approach is used to establish treatment and research priorities
- Building confidence and capacity among clinicians and researchers to engage with patients throughout the research and care enhancement cycle.

Overall PSP process



Role of the Steering Committee

The Steering Committee is responsible for coordinating and implementing the activity of the PSP. Drawing on members' expertise and networks, the Steering Committee encourages participation in the wider PSP and, where members have the capacity and expertise, carries out the practical work associated with collating the interim and final priority lists. The Steering Committee is also responsible for ensuring research funders are made aware of the final top ten uncertainties.

Membership of the Steering Committee includes representatives of organisations that can reach and advocate for patients and clinicians, as well as PSP leadership staff. In order to ensure a collaborative, fair and non-threatening environment, the committee comprises equal numbers of patients and clinicians. Steering Committee members are expected to participate in the priority setting exercise.

Tasks

The Head and Neck Cancer PSP Steering Committee members are expected to participate in a number of specific tasks during the course of the priority setting process:

- Participate in the initial (in-person) kick-off meeting about the project
- Participate in regular teleconference calls (every 2 – 4 weeks) to update on project progress
- Prepare for all meetings
- Monitor and respond to emails as needed
- Publicise the initiative to potential partners to encourage them to join the PSP
- Help manage the collection of treatment uncertainties from patients, clinicians and existing literature.
- Participate in the interim priority setting process. This involves working with project staff to develop the interim priority setting taxonomy and identify any known sources of evidence.
- Collate the results of interim priority setting and work with committee members and project staff to produce an “interim top 20 - 30” to take to the final priority setting workshop.
- Participate in the final priority setting exercise, which is a one-day, in-person workshop in September 2016 to bring together partners to debate, rank and agree on the final top ten.
- Promote the final top ten uncertainties to the head and neck cancer community and research funders.

Level of involvement and resources

Steering group members are asked to contribute, at a minimum, their expertise and their time and to also demonstrate the following:

- An interest in the initiative and advocacy for the project’s outcomes
- An understanding of the approach being adopted
- Commitment to working with other members respectfully and constructively
- Participation in the teleconference calls
- Ready access to, and comfort with, email
- Prompt feedback on prioritisation materials
- Where appropriate, sharing of networks and contacts for membership of the PSP
- Participation in the one-day final priority setting workshop

Administration

The Alberta Cancer Foundation will provide leadership and secretariat support throughout the project. This includes making arrangements for all meetings and workshops, and ensuring:

- Requests for agenda items are discussed with the group
- Documents are available at least one week before meetings
- Meeting notes are circulated within two weeks

Methodology Consultants

Two methodology consultants have been retained to ensure the PSP meets the rigorous and acceptable standards required by Research Ethics Boards (REBs) and publication in scientific journals.

Timescales

The project will begin in late January, 2016 and is expected to conclude by November, 2016.

Key contacts

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Our promise to members of the Steering Committee

- Your views will be respected and incorporated into the project
- You will have a critical role in this important project
- We will reimburse all expenses related to this project including travel and transportation costs; parking; meeting refreshments; extra phone, printing or postage costs; etc.
- Meals will be provided for working meetings held over meal times (e.g., final priority setting workshop).
- Salaries and honoraria are not covered.

Estimated Time Commitment

The project will start immediately and is targeted to be complete by November 2016; however, it may take up to 12 months to complete the entire process. The estimated time commitment is:

- Approximately 8 – 10 teleconference meetings overall involving one to two hours per meeting between Feb. and Nov. 2016
- Preparation for meetings involving zero to two hours, depending on the phase of project
- Assistance with collecting, collating and listing uncertainties, depending on abilities. Targeted to occur during July - August timeframe.
- Interim priority setting exercise: to occur over 3-4 steering committee meetings between July – Sept. 2016
- Final Priority Setting Workshop: full day workshop targeted for September 2016
- Promotion of initiative and top 10 uncertainties from final priority setting exercise: variable time commitment.