

# Top 10 Research Priorities in Head and Neck Cancer: Results of an Alberta Priority Setting Partnership of Patients, Caregivers, Family Members, and Clinicians

Lechelt et al. (2018)  
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## For which topic were research priorities identified?

head and neck cancer

## In which location was the research priority setting conducted?

North America - Canada

## Why was it conducted at all?

The epidemiology, etiology, and management of head and neck cancer are evolving. Understanding the perspectives and priorities of non-researchers regarding treatment uncertainties is important to inform future research.

## What was the objective?

to identify the top 10 treatment uncertainties in head and neck cancer from the joint perspective of patients, caregivers, family members, and treating clinicians in Alberta, Canada

## What was the outcome?

a ranking list of 10 research questions

## How long did the research prioritization take?

May 2016 - October 2016

## Which methods were used to identify research priorities?

JLA method

## How were the priorities for research identified exactly?

Step 1: setting up PSP: steering committee reached consensus on scope and inclusion/exclusion criteria for survey responses. Step 2: collecting research questions: participants were asked: Please tell us, in your own words, the questions you have about the treatment or management of head and neck cancer. These should be questions that you think could be answered by new or better research., 161 responses consisting of 818 raw uncertainties. Step 3: data processing: thematic analysis, removing duplicates and out-of-scope questions, 72 indicative questions identified, 5 uncertainties added from literature, resulting in total of 77 indicative questions, literature search validated longlist. Step 4: interim ranking: via survey, participants were asked to identify and rank order their top 10 out of 77, resulting in cluster of between 21 and 34 closely ranked uncertainties, failing to reveal natural cutoff point resulted in list of 34 shortlisted uncertainties, this list then recirculated to steering committee for second round of ranking, new ranking resulted in natural cutoff at 27 uncertainties. Step 5: final prioritization: workshop: participants provided with materials in advance and asked to be prepared to share their personal top 3 and bottom 3 uncertainties from the shortlist, during final workshop small group and plenary discussion with nominal group technique

## Which stakeholders took part?

Patients, caregivers, clinicians. Survey: 161 participants (19 family members, 99 patients, 1 support group member, 27 clinicians, 3 clinicians/researchers). Interim ranking: 49 participants: 20 patients and 6 family members/caregivers (non-clinicians) and 23 clinicians/clinician-researchers (clinicians). Workshop: 20 participants: 10 patients and 10 clinicians of which 5 patients and 7 clinicians of steering committee.

## How were stakeholders recruited?

An invitation to participate and a link to the survey were posted on the public website of the Alberta Cancer Foundation. Recruitment posters were placed in cancer treatment facilities; email notices were distributed through patient social networks and the email distribution networks of selected professional associations and colleges; and notices were placed in relevant health profession e-newsletters and websites. The Alberta Cancer Registry identified patients with a primary tumor corresponding to the project's inclusion criteria (larynx, hypopharynx, oropharynx, nasopharynx, oral cavity, nasal cavity, paranasal sinuses, skull base, salivary glands, neck, orbit, and ear). Additional inclusion criteria included: diagnosed between December 1, 1995 and December 1, 2014; age 18 years or older at diagnosis; and Alberta residents or nonresidents who received a majority of treatment in Alberta. Excluded from the study were patients who had requested to be excluded from research studies, and deceased patients and their next of kin. The pool of eligible patients was then stratified by year of diagnosis and cancer site. To include patients with a primary tumor, records were grouped into 5-year diagnosis bands to ensure each stratum was of a sufficient size to ensure at least 1 patient in the stratum had a chance of being selected using a proportional sampling method. A random sample of 90 patients was drawn. For the workshop, new patient participants were recruited from among initial survey respondents who requested ongoing involvement in the study. accommodated travel and rest requirements, dietary and swallowing needs, and communication requirements (written input and large-font print materials).