iRSM Institute for Reconstructive Sciences in Medicine

Alberta Cancer FOUNDATION

The Top 10 Treatment and Management Uncertainties in Head and Neck Cancer

Results of an Alberta Head and Neck Cancer (HNC) Priority-Setting Project

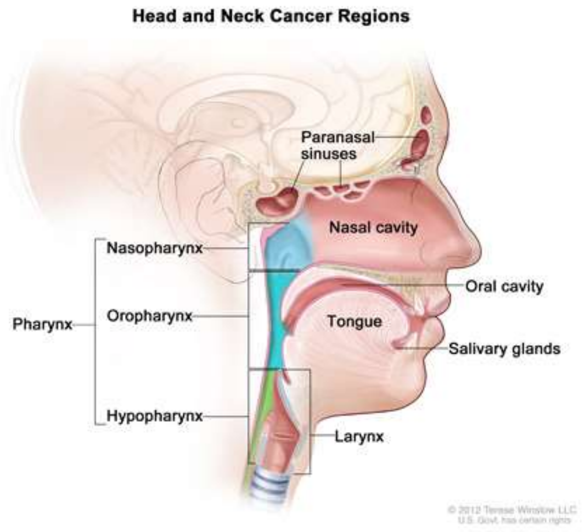
July 2017

Background

Head and neck cancer (HNC) is the sixth most common type of cancer in Canada. It is mostly seen in people who use alcohol and tobacco, although it is associated with other risk factors as well. The number of cases among people who don't use alcohol or tobacco is on the rise because HNC can be caused by certain strains of human papilloma virus (HPV). HPV is a sexually transmitted disease that is also on the rise.

HNC often first appears in the oral cavity, tongue, or upper throat. It can also occur in the nose, eye area (eyelid or socket), ear, jaw, neck or the base of the skull. If it is caught early, HNC is usually treatable.

However, early signs like sores or lumps can be missed until they produce more noticeable symptoms. As a result, HNC often isn't diagnosed until later stages of the disease, when it is more difficult to treat. For this reason, only about 60% of HNC patients survive their cancer, and many patients require invasive procedures to treat the advanced cancer once it is diagnosed.



For the National Cancer Institute
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Much progress has been made over the past two decades in detecting HNC cancer earlier and discovering less invasive treatment options. Still, there is much more to be done as many patients continue to suffer long-term consequences of treatment. Some patients may need to have their eye, nose or ear surgically removed. Others may lose all or part of their tongue. Some lose their voice or the ability to swallow effectively. And many will have life-long challenges speaking, eating, and enjoying normal social experiences.

Why the HNC Project Was Started

Given how much more could be done to improve treatment options and outcomes for HNC patients, the Alberta Cancer Foundation (‘Foundation’) and the Institute for Reconstructive Sciences in Medicine (iRSM) set out in 2016 to ask an important question: Of all the many areas that could be researched next, which ones are most important to HNC patients, their loved ones, and the health professionals (clinicians) who work so tirelessly to support these individuals?

If we knew the answer to this question, it could help inform where the Foundation might invest in research and care for this population. We can also publish our findings in Canada and internationally, which can help ‘accelerate research’ as we share our findings with researchers around the world. Some may even opt to start or expand research into the areas that our Alberta patients and clinicians identified as the most important uncertainties in head and neck cancer.

> *“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.”*

Why is accelerating research important? Because a review of the scientific literature across many disease areas shows that research *doesn’t* always address the areas that matter most to patients and clinicians. In other words, research may not focus as much as it could on the areas that are causing the most distress to HNC patients, like swallowing, speech disorders, or mental health and depression.

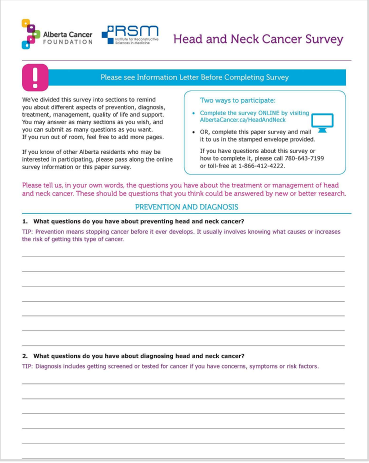
Ultimately, by understanding how priority setting approaches like this work, the Foundation can consider using similar approaches in the future to determine priorities in other types of cancer.

The Approach

‘What is most important?’ seemed like a straightforward question to ask, but it wasn’t as simple as we first thought. How do we reach this patient population? What questions should we ask them? What if their answers aren’t really research questions? Do patients, families and clinicians have different – or the same – questions? Can we get them all to agree on what’s most important?

We turned to the James Lind Alliance (JLA) from the United Kingdom. The JLA has developed a structured and well respected process to help bring patients, families and clinicians together to set research priorities, boasting more than 14 years of success working with hundreds of organizations around the world.

Our HNC project followed the six steps of the JLA method:



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Head and Neck Cancer Survey

Please see Information Letter Before Completing Survey

We've divided this survey into sections to remind you about different aspects of prevention, diagnosis, treatment, management, quality of life and support. You may answer as many sections as you wish, and you can submit as many questions as you want. If you run out of room, feel free to add more pages.

If you know of other Alberta residents who may be interested in participating, please pass along the online survey information or this paper survey.

Two ways to participate:

- Complete the survey ONLINE by visiting AlbertaCancer.ca/HeadAndNeck
- OR, complete this paper survey and mail it to us in the stamped envelope provided.

If you have questions about this survey or how to complete it, please call 780-643-7199 or toll-free at 1-866-412-4222.

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.

PREVENTION AND DIAGNOSIS

1. **What questions do you have about preventing head and neck cancer?**

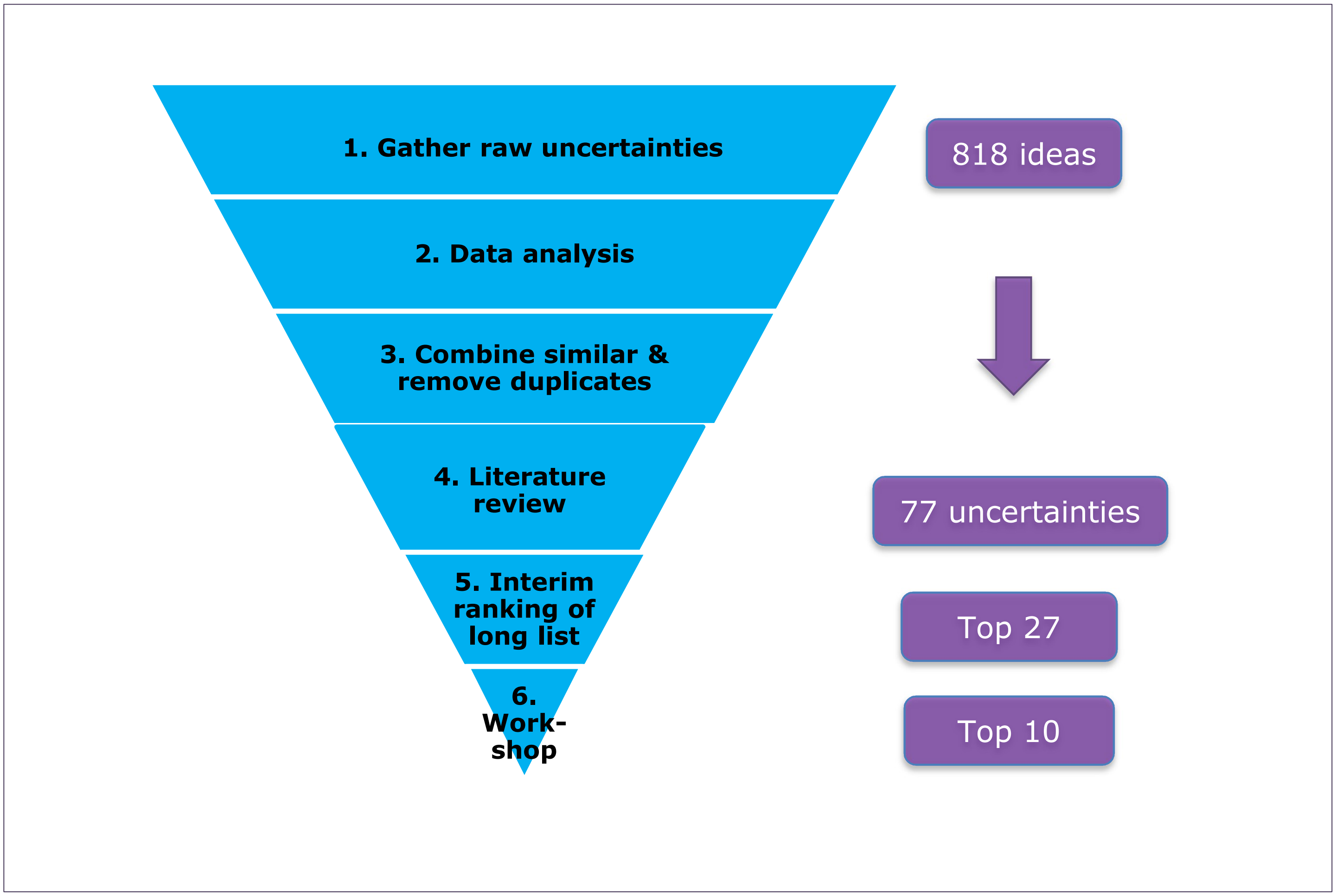
TIP: Prevention means stopping cancer before it ever develops. It usually involves knowing what causes or increases the risk of getting this type of cancer.

2. **What questions do you have about diagnosing head and neck cancer?**

TIP: Diagnosis includes getting screened or tested for cancer if you have concerns, symptoms or risk factors.

1. **Survey:** In June 2016 an anonymous survey was sent to HNC patients, family members, caregivers and clinicians. It asked respondents to say, *in their own words,* what they believed should be answered by new research. We used records from the Alberta Cancer Registry to send the survey to more than 900 Alberta HNC patients who had been diagnosed between 1995 and 2014. We also used email and social media to reach patients, family members and clinicians.
2. **Data analysis:** We received 161 completed survey responses, and each one was reviewed to see what ideas were put forth. Each idea was recorded and categorized into a theme. In all, more than 800 ideas were submitted.
3. **Combining similar or duplicate ideas:** It is common for dozens of respondents to come up with similar ideas. These duplicate ideas were all combined and then counted so we knew how many times a certain idea was mentioned.
4. **Review of the literature:** We reviewed the medical and scientific literature to find additional ideas our survey respondents hadn't mentioned, and we removed any ideas from respondents that were 'certainties' rather than 'uncertainties'. (For example, the connection between tobacco use and HNC is well established, so we took that off our list even though some survey respondents asked about it.)
5. **Interim ranking:** Steps 3 and 4 resulted in our **long list** of 77 unique research ideas. A group of 49 individuals (26 patients/family members and 23 health professionals and researchers) then went through the long list of 77 ideas and ranked their 'Top 10' in order of importance. This resulted in the 'Top 27 priorities'.
6. **Workshop**: In October 2016, a group of 10 patients and 10 clinicians/researchers spent a day discussing the Top 27 ideas. Two ideas were merged, resulting in 25 final ideas that were rank ordered from 1 through 25. The workshop focused on identifying the priority order of the 'Top 10' uncertainties.

Process at a Glance



1. Gather raw uncertainties
2. Data analysis
3. Combine similar & remove duplicates
4. Literature review
5. Interim ranking of long list
6. Work-shop

818 ideas

77 uncertainties

Top 27

Top 10

The Top 25 Treatment and Management Uncertainties in Head & Neck Cancer

Ranking	Question
1	What is the best overall treatment combination or regimen (surgery, radiation, chemotherapy, immunotherapy) and dose/schedule for various head and neck cancers to achieve a good prognosis while minimizing undesirable treatment effects?
2	How can information and treatment be coordinated and planned in advance to better integrate the diagnosis, treatment and reconstruction/ rehabilitation process?
3	Are there advances in precision medicine (e.g., genetics, bio markers) that can help clinicians personalize treatment and predict outcomes based on the patient's unique bio-chemistry and genetic profile?
4	In patients who have problems chewing and swallowing (dysphagia) following treatment for head and neck cancer, what is the best way to rehabilitate and restore chewing/swallowing as much as possible?
5	How knowledgeable are community providers (such as family physicians, dentists, speech language pathologists) about the early signs and symptoms of head and neck cancer, and would provider education result in more routine screening or more thorough assessment of presenting signs/symptoms?
6	What is the psychological impact to patients and their families of head and neck cancer, what mental health supports are needed, and how are they best accessed and delivered to optimize treatment, recovery, resiliency and long-term quality of life?
7	For individuals with oropharyngeal cancer that is linked to HPV (human papilloma virus) infection, is it safe and effective to use less intensive or aggressive treatment than the usual treatments for cancer?
8	How can patients be better supported and educated upon diagnosis and throughout planning and treatment to ensure they are involved and fully informed about treatment options, decisions, outcomes and long-term impacts?
9	How do different head and neck cancer treatments differ with respect to patient distress or impact on quality of life, overall function, and pain management, and what can be done during treatment to prevent or minimize the impact?
10	Does vaccination for human papilloma virus (HPV) affect the rate or recurrence of cancer of the oropharynx (such as the middle of the throat, back of tongue, soft palate, tonsils), and if so, is there a case for routine HPV vaccination to prevent this type of cancer?

Ranking	Question
11	What is the best way to prevent or reduce the effects of radiation and chemoradiation that are long-lasting, permanent or may worsen over time, such as radiation fibrosis?
12	Which test or method is the best way to screen for head and neck cancer, who should be screened, and which health professionals (doctors, dentists, etc.) should conduct screening?
13	Which new or alternative/ complementary therapies (such as acupuncture, herbal medicine, medical marijuana) can improve patient outcomes or reduce side effects?
14	To standardize and streamline diagnosis, which clinical criteria or findings should prompt family physicians and dentists to order further testing?
15	Which early signs and symptoms of head and neck cancer are recognizable to patients/families, and would public education programs lead to earlier detection of head and neck cancer?
16	How do delays in the assessment and confirmation of suspected head and neck cancer affect prognosis or outcomes?
17	What can be done to reduce the economic and financial burden associated with treatment and ongoing management, including support for uninsured services or extra expenses?
18	What are the causes of delays in the assessment and confirmation of suspected head and neck cancer (such as specialist wait times, diagnostic pathway) and how can these be addressed?
19	Which tests are most accurate when monitoring for local recurrence, such as magnetic resonance imaging (MRI) or CT, and which provider groups are best suited to arrange these tests?
20	How often and for how long should patients be monitored for local recurrence of cancer, and what is the role and effectiveness of annual screenings?
21	What methods and doses of radiation therapy are the least damaging to surrounding tissue?
22	What is the best way to treat head and neck cancer that has returned (recurring)?
23	To effectively reduce the risk of oropharyngeal cancer in the general population, which target groups, if any, should be a priority for HPV vaccination, including age, sex, lifestyle or other risk factors?
24	Does general screening for head and neck cancer, in people who don't have signs or symptoms, lead to earlier detection, diagnosis, and better outcomes?
25	Which lifestyle or sexual practices, such as number of partners or type of sexual activity, are most likely to increase or reduce transmission of the human papilloma virus (HPV) between partners and/or affect the risk of oropharyngeal cancer?

Next Steps

Several activities are already under way to advance this important work, including the following:

- Under the Mickleborough Interfacial Bioscience Research Program, we issued a call for proposals from Alberta researchers for research projects or programs that aim to address some of these uncertainties. In early 2018,we will fund the best proposals and begin to answer some of the uncertainties that have been identified as part of this priority setting project.
- We have produced a video to explain the project and its importance.
- We are preparing articles and academic papers to publish nationally and internationally regarding the Top 10 and the Top 25 priorities in HNC.

"Knowing that the final list could spur researchers to do research in the various areas was hopeful."

Participant Experience

Over the course of one year, five patients and seven clinicians spent many hours together, gathering input from HNC patients and family members, reviewing submissions, and discussing the most important priorities. An additional eight patients and clinicians joined the final priority-setting workshop. Overall the experience was rewarding for all participants but also grueling, as few anticipated the scope of the project.

"A great start to organize those of us in Alberta involved in the care of head and neck cancer patients."

"I felt grateful to have been included in such a worthwhile process."

"It was a refresher for why we were there and how difficult it can be for H&N cancer patients."

With Thanks

Special thanks to our Lead Workshop Facilitator, Dr. Andreas Laupacis, and the members of our Steering Committee members who were so generous with their time and expertise:

Roxana Anderson	Dr. Wayne Matthews
Katherine Cowan	Dr. Suresh Nayar
Dr. Brock Debenham	Sandra Rees
Sharon Dixon	Akhila Regunathan
Tina Huizinga	Dr. Jana Rieger
Bernie Krewski	Dr. Hadi Seikaly
Dr. Andreas Laupacis	Dr. Ameeta Singh
Leah Lechelt	Jim Traub

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ALBERTA INNOVATES

Alberta SPOR SUPPORT Unit | Knowledge Translation Platform

Finally, thanks to the clinicians and patients who participated in the final priority-setting workshop.

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