Head and Neck Cancer Quality Performance Indicators

Draft descriptions for review

2020

Acknowledgements

The Head and Neck Cancer Working Group and the Cancer Control Agency want to acknowledge the passing of Louise Elia. Louise was a kaumātua of the working group, providing guidance and advice to improve Māori health equity. She was a highly valued member of the team and will be sadly missed.

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Contents

Introduction

Tēnā koutou katoa

We are seeking your clinical review of proposed quality performance indicators (QPIs) for head and neck cancer.

The Cancer Control Agency and the National Head and Neck Cancer Working Group (the working group) have developed a proposed set of QPIs for head and neck cancer.

Appendix 1: Working group members lists the working group members involved in the QPI work.

The QPIs have been selected to measure performance and drive quality improvement in head and neck cancer diagnosis and treatment services. The working group has identified a set of 14 QPIs that measure the quality of care and outcomes for people with head and neck cancer that will support continuous quality improvement in cancer care.

Have your say

We are providing an opportunity for all clinicians involved in head and neck cancer services to provide feedback on this set of 14 proposed QPIs. In particular:

- do you think the QPIs are useful measures that can drive quality improvement for services provided to people with head and neck cancer?
- do you have feedback on the QPI descriptions and/or data descriptions?

We are seeking feedback

Primarily we are seeking feedback from clinicians who diagnose and treat people with head and neck cancer in New Zealand. Others may also wish to comment.

We expect clinicians will assess the QPIs that relate to their specialist knowledge area; but can review as many QPIs as they wish.

How to provide feedback

Complete the online form at:

https://consult.health.govt.nz/cancer-services/cancer-indicators-consultation/

You can also send your feedback, comments and any queries about the indicator development process to cancerteam@health.govt.nz.

Next steps

Feedback will be collated and considered by the working group. Feedback will be incorporated into the agreed final set of QPIs, which will be developed further.

The next phase is to develop data specifications and reporting requirements for each QPI. This will be led by the Cancer Control Agency.

Please complete your review of the QPIs and submit any other feedback by **Saturday 13 June 2020**.

Background

What is the QPI programme?

High-quality cancer care in New Zealand requires a nationally consistent, coordinated approach that enables district health boards (DHBs) to monitor the quality of care they are delivering and to implement quality improvement initiatives. Developing QPIs to measure processes and outcomes is an internationally accepted approach to drive quality improvement in cancer care.

The Cancer Control Agency is developing national tumour-specific QPIs in partnership with sector-led working groups. Key principles of the process are:

- clinical engagement
- consultation
- consensus.

The selection criteria for QPIs are:

- **importance:** address an area of clinical importance that could significantly impact on the quality and outcome of care delivered, supporting goals of achieving Māori health gain, equity and national consistency
- **evidence-based**: supported by sound, current evidence that the indicator can drive quality improvement
- **measurable:** with an end view that data collection will be national.

More information on the cancer QPI programme is on the Ministry of Health website: **www.health.govt.nz/our-work/diseases-and-conditions/national-cancer-programme/cancer-initiatives/cancer-quality-performance-indicator-programme** The QPI programme was started by the Ministry of Health; however, the project and functions were transferred to the Cancer Control Agency, established on 1 December 2019.

How the QPI programme will improve equity in cancer care

Māori currently experience a disproportionate and inequitable burden from cancer and are more likely to die from cancer than non-Māori. Addressing variation in the quality of cancer services is pivotal to delivering equitable, high-quality care.

The QPI programme will help the health sector deliver high-quality health care for Māori, in line with the Ministry of Health's equity of health care for Māori framework.[1] By stratifying QPIs by ethnicity, the Cancer Control Agency and DHBs can identify specific areas of inequity, develop quality improvement initiatives to address these and monitor progress over time.

Individual indicators provide information on different steps in the cancer care pathway. For some indicators there may be existing evidence of inequities, in which case this has been documented within the indicator specifications. However, there may not be current research or data available for other indicators. This does not preclude including an indicator, as gathering data and reporting on these indicators may improve our understanding of where inequities are along the cancer care pathway.

Developing the draft head and neck cancer QPIs

The process for developing the QPIs follows the process developed, refined and used by other tumour groups. A list of 79 potential head and neck cancer[2] QPIs was assembled based on a search of national and international grey and academic literature. The working group reviewed the list to consider which QPIs are most valuable to drive quality improvements for head and neck cancer care in New Zealand.

A shortlist of 18 QPIs was identified for further development and discussion by sub-working groups, including an initial assessment of measurability of data. Further review and refinement of the QPI descriptions has resulted in 14 proposed QPIs for wider clinical consultation and feedback.

These QPIs include seven head and neck cancer-specific QPIs and seven common indicators, which are relevant to multiple tumour groups.

1 Ministry of Health. 2014. *Equity of Health Care for Māori: A framework*. Wellington: Ministry of Health. **www.health.govt.nz/publication/equity-health-care-maori-framework**

2 Scope included acute and non-acute, complex and non-complex head and neck cancer in the following sites in adults: mucosa of the head and neck (oral cavity and lip, pharynx, larynx and cervical oesophagus), nasal cavity and paranasal sinuses, salivary glands, skin of the head and neck, in the context of high-risk and advanced non-melanoma and upper oesophagus as part of a pharyngeal or tracheal resection. Scope excluded: cancer of the thyroid.

Data for QPIs

Data requirements have been considered for each QPI and assessed if the data is available in existing national data collections.

If data is currently available in national data collections the QPI is noted 'measurable'. Where data is currently unavailable, or it is available but requires manual data entry, the QPI is aspirational. The Cancer Control Agency will prioritise the development of technical solutions to address data issues.

This document refers to the following national data sources:

- **Mortality Collection** – classifies the underlying cause of death for all deaths registered in New Zealand
- **New Zealand Cancer Registry (NZCR)** – a population-based register of all primary malignant diseases diagnosed in New Zealand, excluding squamous and basal cell skin cancers
- **National Minimum Dataset (NMDS)** – a collection of public and private hospital discharge information, including coded clinical data for inpatients and day patients
- **National Non-Admitted Patients Collection (NNPAC)** – includes event-based purchase units that relate to medical and surgical outpatient events and emergency department events
- **Pharmaceutical Collection (PHARMS)** – a data warehouse that supports the management of pharmaceutical subsidies, and contains claim and payment information from pharmacists for subsidised dispensing
- **Radiation Oncology Collection (ROC)** – a collection of radiation oncology treatment data, including both public and private providers.

For more information about the data sources, see the Ministry of Health website at: **health.govt.nz**.

Stratifying variables

As well as by DHB, the QPIs will be stratified by the following variables where possible:

- age
- sex
- ethnicity (Māori, Pacific, Asian, European/Other)
- social deprivation.

Glossary

Common indicator	Indicator of quality of diagnosis and treatment applied to more than one tumour group. Common indicators can be used for comparability and consistency across all tumour groups (eg, proportion of people who participate in a clinical trial).
Performance status	A measure of how well a person is able to perform ordinary tasks and carry out daily activities, for example, Eastern Cooperative Oncology Group (ECOG) score of 0 = fully active, 5 = dead.
Structured reports	Reports (eg, pathology) that contain structured data. Structured data is a collection of discrete values within a report, each with its own specification. A report containing structured data can be easily mined by computers for storing, sorting, and analysing the individual data elements.
TNM group stage	It is often useful to combine TNM system categories (tumour, node, metastases) into groups. Tumours localised to the organ of origin are generally staged as I or II depending on the extent, locally extensive spread to regional nodes are staged as III, and those with distant metastasis staged as stage IV.
TNM system	The TNM system is a global standard used to record the anatomical extent of disease. In the TNM system, each cancer is assigned a letter or number to describe the tumour, node and metastases. T stands for the original (primary) tumour, N stands for nodes (indicates whether the cancer has spread to the nearby lymph nodes) and M stands for metastasis.
Tumour-specific indicator	An indicator of quality of diagnosis and treatment (ie, service provision) unique to a tumour group because of the treatment regimen.

Head and neck cancer quality performance indicators

The table below lists each indicator, with a detailed description of each indicator on the following pages.

ID	Indicator title	Indicator description	Measurable
1	Timeliness of treatment*	Time from first histological diagnosis to first definitive treatment.	No
2	Stage at diagnosis*	Proportion of people with head and neck cancer by stage at diagnosis.	No
3	Multidisciplinary discussion*	a. Proportion of people with head and neck cancer discussed at a multidisciplinary meeting (MDM). b. Proportion of people with head and neck cancer undergoing curative or palliative treatment who are assigned a care coordinator or nurse navigator at the first MDM.	No
4	Clinical trial participation*	Proportion of people with head and neck cancer in a clinical trial.	No
5	Treatment survival*	Proportion of people with head and neck cancer who died within 30 or 90 days of treatment (surgery, chemotherapy, radiotherapy).	Yes
6	Overall survival*	Overall survival for people with head and neck cancer at 1, 3, 5 and 10 years from diagnosis by stage.	Yes (without stage)
7	Patient-reported outcomes*	Proportion of people with head and neck cancer who complete a generic PROM (EQ-5D-5L and EQ-VAS) and a head and neck cancer-specific PROM (FACT-H&N) at their initial MDM presentation (baseline). Proportion of people with head and neck cancer treated curatively who have a progress summary of the EQ-5D-5L and EQ-VAS PROMs scores in their clinical record at every post treatment visit.	No
8	Oral health	Proportion of people with head and neck cancer who complete their short-term treatment plan within one year after the end of their head and neck cancer treatment.	No
9	Supportive and rehabilitative care	Proportion of people with head and neck cancer who have a supportive care and rehabilitation plan in place before treatment starts.	No

ID	Indicator title	Indicator description	Measurable
10	Morbidity of treatment	Proportion of people who have had head and neck surgery and return to theatre within 30 days. Proportion of people who have had head and neck surgery and are readmitted within 30 days of discharge	Yes
11	Post-operative pathology	Proportion of surgical pathology reports of primary resection for head and neck cancer that are in a structured format, with all important parameters included.	No
12	Post-operative radiotherapy	Proportion of people with head and neck cancer who complete post-operative radiotherapy within 13 weeks of definitive surgery.	Yes
13	Review of contouring for curative radiotherapy	Proportion of people with head and neck cancer who start curative intent radiation with evidence that contours and dose were peer reviewed.	No
14	Adjuvant chemoradiation	Proportion of people with head and neck mucosal squamous cell cancer (HNSCC) resected with microscopic positive margins or extracapsular extension who receive adjuvant platinum-based chemoradiation.	No

* A common indicator, which can be used across multiple tumour groups.

1 Timeliness of treatment

Currently measurable		No
Indicator description		Time from first histological diagnosis to first definitive treatment.
Rationale and evidence		Timely, high-quality care delivers the best outcomes for people diagnosed with head and neck cancer. Timely treatment following diagnosis of cancer contributes to a better patient experience by reducing anxiety and uncertainty and minimising the risk of deterioration prior to treatment.
Equity / Māori health gain		Māori have significantly poorer survival for head and neck cancer, with a 37% higher excess mortality compared to non-Māori.[1] One contributor to poorer survival is differences in timely access to treatment;2 ensuring timely treatment will likely reduce equity gaps.
Specifications	**Numerator**	Time from first histological diagnosis to date of first treatment.
	Denominator	People having treatment for head and neck cancer.
	Exclusions	None
Data sources		NZCR, NMDS, ROC, PHARMS
Notes		The histology date currently on the NZCR is most often the date of definitive histology following surgery, rather than the earlier biopsy date (eg, when diagnosis was first made). This indicator cannot be reported in 2020.

References

1. Soeberg M, Blakely T, Sarfati D, et al. 2012. *Cancer Trends: Trends in cancer survival by ethnic and socioeconomic group, New Zealand 1991–2004*. Wellington: University of Otago and Ministry of Health.
2. Hill S, Sarfati D, Robson B, et al. 2013. Indigenous inequalities in cancer: what role for health care? *ANZ Journal of Surgery* 83(1-2): 36–41.

2 Stage at diagnosis

Currently measurable		No
Indicator description		Proportion of people with head and neck cancer by stage at diagnosis.
Rationale and evidence		Stage at diagnosis is the most important determinant of prognosis. People who are diagnosed when their cancer is at an early stage have significantly improved survival outcomes.[1] Stage is also a critical element in determining appropriate treatment.
Equity / Māori health gain		For head and neck cancer, non-Māori are more likely to have early stage of disease at diagnosis compared to Māori, who are more likely to have advanced disease at diagnosis.[2]
Specifications	**Numerator**	Number of people diagnosed with head and neck cancer by TNM group stage.
	Denominator	Number of people diagnosed with head and neck cancer.
	Exclusions	People who were registered based on a death certificate only.
Data sources		NZCR
Notes		The NZCR records extent of disease for head and neck cancer cases. Data on TNM group stage is not consistently reported to the NZCR; only individual T, N and M values can be recorded at present. This indicator cannot be reported in 2020.

References

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2. Gurney J, Stanley J, Jackson C, et al. 2020. Stage at diagnosis for Māori cancer patients: disparities, similarities and data limitations. *The New Zealand Medical Journal* 133(1508): 43.

3 Multidisciplinary discussion

Currently measurable		No
Indicator description		a. Proportion of people with head and neck cancer discussed at a multidisciplinary meeting (MDM). b. Proportion of people with head and neck cancer undergoing curative or palliative treatment who are assigned a care coordinator or nurse navigator at the first MDM.
Rationale and evidence		International evidence shows that multidisciplinary care is a key aspect to providing best-practice treatment and care for people with cancer. Multidisciplinary care involves a team approach to planning and providing treatment along the complete patient cancer pathway. Cancer MDMs are part of the philosophy of multidisciplinary care. Effective MDMs result in positive outcomes for people receiving the care, for health professionals involved in providing the care and for health services overall. Benefits include: • improved treatment planning • improved equity of patient outcomes • more people being offered the opportunity to enter relevant clinical trials • improved continuity of care and less service duplication • improved coordination of services • improved communication between care providers • more efficient use of time and resources. The cancer journey is complex, and it is not uncommon for a patient to be seen by many specialists within and across multiple DHBs and in the public and private sectors. People with head and neck cancer and their whānau should have access to care coordination through a single point of contact during all stages of the cancer journey.
Equity / Māori health gain		Māori have significantly poorer survival for head and neck cancer, with a 37% higher excess mortality compared to non-Māori.[1] Extrapolating from research into other types of cancers, Māori with head and neck cancer are likely to have higher rates of comorbidity impacting on management decisions and are likely to benefit from comprehensive MDT support.[2]
Specifications	**Numerator a**	Number of people with head and neck cancer discussed at an MDM.
	Denominator a	Number of people with head and neck cancer.
	Exclusions a	None
	Numerator b	Number of people with head and neck cancer assigned a care coordinator or nurse navigator at the first MDM.
	Denominator b	Number of people with head and neck cancer.
	Exclusions b	None
Data sources		NZCR, MDM databases, NMDS

Notes	The head and neck is a complex area. Treating head and neck cancers requires expertise from a diverse group of highly trained personnel, including: • **clinical:** ORL/head and neck surgeon, plastic and reconstructive surgeon, maxillofacial surgeon, oral health specialist and/or dental specialist, radiation oncologist, medical oncologist • **diagnostic:** head and neck radiologist, head and neck pathologist • **allied health:** dietitian, speech language therapist, physiotherapist, psychologist, social worker • **nursing:** head and neck cancer nurse specialist (CNS) • **care coordination:** nurse navigator (if not CNS) • **data management:** data manager. This indicator will initially measure the number of people who were discussed at an MDM. Over time, more criteria will be added (eg, people discussed at an MDM prior to treatment). No national data collection records whether a person's treatment has been discussed at a head and neck cancer MDM or access to a care coordinator. This indicator cannot be reported in 2020.

References

1. Soeberg M, Blakely T, Sarfati D, et al. 2012. *Cancer Trends: Trends in cancer survival by ethnic and socioeconomic group, New Zealand 1991–2004*. Wellington: University of Otago and Ministry of Health.
2. Hill S, Sarfati D, Blakely T, et al. 2010. Survival disparities in Indigenous and non-Indigenous New Zealanders with colon cancer: the role of patient comorbidity, treatment and health service factors. *Journal of Epidemiology & Community Health* 64(2): 117–23.

4 Clinical trial participation

Currently measurable		No
Indicator description		Proportion of people with head and neck cancer in a clinical trial.
Rationale and evidence		Progress in preventing, diagnosing and treating cancer predominantly comes from scientific research, including testing new, and potentially more effective medications and procedures through clinical trials. People who participate in these trials gain access to the very latest advances in cancer care developed by cancer specialists.
Equity / Māori health gain		Data is not available.
Specifications	**Numerator**	Number of people with head and neck cancer treated on a clinical trial at any time after diagnosis.
	Denominator	Number of people diagnosed with head and neck cancer.
	Exclusions	None
Data sources		Clinical notes.
Notes		There is no national data collection on people enrolled in clinical trials for head and neck cancer. This indicator cannot be reported in 2020.

5 Treatment survival

Currently measurable		Yes
Indicator description		Proportion of people with head and neck cancer who died within 30 or 90 days of treatment (surgery, chemotherapy, radiotherapy).
Rationale and evidence		Treatment-related mortality is a marker of the quality and safety of the whole service provided by the multidisciplinary team (MDT). Service providers (DHBs, clinicians, MDTs) should regularly assess outcomes of treatment, including treatment-related morbidity and mortality. People with poor performance status, who are therefore at a greater risk of treatment-related morbidity and mortality, are increasingly being considered for radical interventions. These interventions may be curative, but their impact needs to be balanced against people's overall prognosis.
Equity / Māori health gain		Māori have significantly poorer survival for head and neck cancer, with a 37% higher excess mortality compared to non-Māori.[1]
Specifications	**Numerator a**	Number of people with head and neck cancer who die within 30 or 90 days of surgery with curative intent.
	Denominator a	Number of people with head and neck cancer who undergo surgery with curative intent.
	Numerator b	Number of people with head and neck cancer who die within 30 or 90 days of starting primary radiotherapy or primary chemoradiation administered with curative intent.
	Denominator b	Number of people with head and neck cancer who start primary radiotherapy or primary chemoradiation administered with curative intent.
	Numerator c	Number of people with head and neck cancer who die within 30 or 90 days of commencing adjuvant radiation/chemoradiation.
	Denominator c	Number of people with head and neck cancer who undergo surgery with curative intent and who then commence adjuvant radiation/chemoradiation.
	Exclusions	None
Data sources		NZCR, NMDS, Mortality Collection, PHARMS, ROC
Notes		This indicator will be reported on by type of treatment (ie, chemotherapy, radiotherapy, surgery).

References

1. Soeberg M, Blakely T, Sarfati D, et al. 2012. *Cancer Trends: Trends in cancer survival by ethnic and socioeconomic group, New Zealand 1991–2004*. Wellington: University of Otago and Ministry of Health.

6 Overall survival

Currently measurable		Yes (without stage)
Indicator description		Overall survival for people with head and neck cancer at 1, 3, 5 and 10 years from diagnosis by stage.
Rationale and evidence		Overall survival measures the effectiveness of the whole cancer management pathway, including diagnosis, treatment and follow-up.
Equity / Māori health gain		Māori have significantly poorer survival for head and neck cancer, with a 37% higher excess mortality compared to non-Māori.[1]
Specifications	**Numerator**	Number of people with head and neck cancer who survive at 1, 3, 5 and 10 years from diagnosis.
	Denominator	Number of people diagnosed with head and neck cancer.
	Exclusions	None
Data sources		NZCR, Mortality Collection
Notes		This indicator is dependent on data on TNM group stage, which currently is not consistently available from the NZCR.

References

1. Soeberg M, Blakely T, Sarfati D, et al. 2012. *Cancer Trends: Trends in cancer survival by ethnic and socioeconomic group, New Zealand 1991–2004*. Wellington: University of Otago and Ministry of Health.

7 Patient-reported outcomes

Currently measurable		No
Indicator description		a. Proportion of people with head and neck cancer who complete a generic PROM (EQ-5D-5L and EQ-VAS) and a head and neck cancer-specific PROM (FACT-H&N) at their initial MDM presentation (baseline). b. Proportion of people with head and neck cancer treated curatively who have a progress summary of the EQ-5D-5L and EQ-VAS PROMs scores in their clinical record at every post treatment visit.
Rationale and evidence		PROMs provide essential data regarding the impact cancer and its treatment has on people. PROMs help inform the decision-making process for post-treatment supportive care. Patient-reported quality-of-life at 12 months post-treatment may predict survival.[1,2] The EQ-5D-3L and EQ-VAS are strongly correlated with the FACT-H&N.[3] PROMs identify areas of need and dysfunction that, when addressed, can improve outcomes.[4,5]
Equity / Māori health gain		Data is not available.
Specifications	**Numerator a**	Number of people with head and neck cancer that complete a generic PROM (EQ-5D-5L and EQ-5D-VAS) and head and neck cancer-specific PROM (FACT-H&N) at initial MDM presentation (baseline).
	Denominator a	All people with head and neck cancer who attend initial MDM presentation.
	Numerator b	Number of people with head and neck cancer who complete a generic PROM (EQ-5D-5L and EQ-5D-VAS) at every post treatment visit.
	Denominator b	All people with head and neck cancer who attend follow-up clinic.
	Exclusions	People accessing palliative and end-of-life care following MDM.* People needing interpreter services.**
Data sources		MDM databases, DHB databases
Notes		* Palliative treatment requires a separate palliation-specific PROM.[6] ** Caution is needed when using interpreters as nuance of questions can be lost. See **Appendix 2** for a copy of EQ-5D-5L and EQ-VAS and **Appendix 3** for a copy of FACT-H&N.

References

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2. Mehanna HM, De Boer MF, Morton RP. 2008. The association of psycho-social factors and survival in head and neck cancer. *Clinical Otolaryngology* 33(2): 83–9.
3. Aoki T, Ota Y, Sasaki M, et al. 2019. To what extent does the EQ-5D-3L correlate with the FACT-H&N of patients with oral cancer during the perioperative period? *International Journal of Clinical Oncology* 24(4): 350–58.
4. Richardson AE, Tennant G, Morton RP, et al. 2017. A self-regulatory intervention for patients with head and neck cancer: Pilot randomized trial. *Annals of Behavioral Medicine* 51(5): 629–41.
5. Ringash J, Bernstein LJ, Devins, G, et al. 2018. Head and neck cancer survivorship: learning the needs, meeting the needs. *Seminars in Radiation Oncology* 28(1): 64–74.
6. Ghoshal S, Patel F, Mudgil N, et al. 2004. Palliative radiotherapy in locally advanced head and neck cancer-a prospective trial. *Indian Journal of Palliative Care* 10(1): 19.

8 Oral health

Currently measurable		No
Indicator description		Proportion of people with head and neck cancer who complete their short-term oral health treatment plan within one year after the end of their head and neck cancer treatment.
Rationale and evidence		Oral complications are common for people undergoing treatment for head and neck cancer.[1] The type, extent and severity of complications depend on the cancer treatment regimen and its duration and intensity.[2] An oral assessment, including radiographs, must be done before starting cancer therapy.[3] Rationale for care is to: • identify existing and potential oral disease and risks for oral disease • remove foci of infection from the oral environment before cancer treatment • advise and provide the person with strategies to manage oral side effects of their cancer treatment, in conjunction with the multidisciplinary team • provide the person with information and care to establish and maintain a high standard of oral hygiene and cope with increasing oral health challenges during and after cancer treatment • to optimise oral health for the person in the future by formulating care plans to maintain oral hygiene, providing preventive dental care and recall, monitoring for trismus and screening for recurrence.
Equity / Māori health gain		Māori are more likely to experience poor oral health than non-Māori. They are 1.3 times more likely than non-Māori to only visit a dental health care worker because they have a problem, or never visit.[4]
Specifications	**Numerator**	Number of people with head and neck cancer who complete their short-term treatment plan within one year after the end of their head and neck cancer treatment.
	Denominator	All people with head and neck cancer seen for baseline assessment and short-term treatment planning by the oral health or dental team.
	Exclusions	None
Data sources		None

Notes	A dental baseline comprises: • compulsory orthopantomogram (OPG) and bite-wing radiographs or full mouth periapical radiographs • dental caries classified using ICDAS[5] and/or ADA Caries classification system 2015.[6] With diagnostic staging of caries based on clinical plus ICCM,[5] CAMBRA[7] or 4D Loop.[8] Standard dental charting • full periodontal assessment and soft tissue screen based on BSP Periodontal Screening 2017 and flowcharted 2019[9] • although subjective: score from Challacombe Scale[10] for oral dryness plus GC saliva buffer test[11] and baseline salivary flow assisted with paraffin chew (paraffin chew may be required for salivary flow post-XRT or surgery) • appropriate clinical photographs.

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2. PDQ® Supportive and Palliative Care Editorial Board. *PDQ Oral Complications of Chemotherapy and Head/Neck Radiation*. Bethesda, MD: National Cancer Institute. Updated 16/12/2016. URL: **www.cancer.gov/about-cancer/treatment/side-effects/mouth-throat/oral-complications-hp-pdq** (accessed November 2019).
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10. UK ADI. 2011. Dry mouth scale launched. *British Dental Journal* 211(8).
11. GC Australasia. Saliva-Check BUFFER. URL: **http://gcaustralasia.com/Products/97/Prevention/Saliva-Check-BUFFER** (accessed December 2019).

9 Supportive and rehabilitative care

Currently measurable	No
Indicator description	Proportion of people with head and neck cancer who have a supportive care and rehabilitation plan in place before treatment starts.
Rationale and evidence	Head and neck cancer multidisciplinary teams should have rehabilitation pathways covering all stages of the person's cancer journey.[1] There are multiple allied health and supportive care services that can make a positive impact on functional outcomes and quality of life following head and neck cancer treatment. All professionals caring for people with head and neck cancer should assess supportive care needs in initial treatment planning and throughout the disease course.[2] A supportive care and rehabilitation plan may include the following services. • **Speech language therapy** Continued speech language therapy is important in maintaining voice and safe and effective swallow function following head and neck cancer treatment.[1] • **Nutrition** Nutrition has been recognised as the second most important factor in predicting long-term prognosis in head and neck cancer.[3] Malnutrition can have a significant adverse impact on clinical, cost and patient outcomes such as complications (infections), treatment response, treatment interruptions, unplanned admissions, length of stay and quality of life. All people with head and neck cancer should be screened for malnutrition at diagnosis to identify those at nutritional risk and then repeated at intervals through each stage of treatment (eg, surgery, radiotherapy/chemotherapy and post treatment). If identified at high risk, refer to the dietitian for early intervention. • **Lymphoedema therapy** A head and neck cancer-specific regimen of lymphoedema therapy is effective for people with external and internal head and neck lymphoedema.[4] A lymphoedema pre-habilitation programme facilitates access to complete decongestive treatment at an earlier stage, improves outcomes for people with head and neck cancer and increases satisfaction with their treatment.[5]

Rationale and evidence (continued)		• **Psychosocial support** Psychosocial distress is common in people with head and neck cancer and distress is strongly associated with poor quality of life, poor treatment engagement and functional impairment.[6] Psychological therapy, such as cognitive behaviour therapy, has been shown to improve distress and physical functioning in people with head and neck cancer after treatment.[7] • **Physiotherapy** A head and neck-specific regimen of physiotherapy is effective for people with a diagnosis of head and neck cancer to prevent movement dysfunction and to ensure the maintenance of function. The existing evidence suggests that survivors of head and neck cancer benefit from early screening of rehabilitation needs and being involved in preventive rehabilitation programmes pre-surgery. Physical exercise programmes improve physical function, muscular endurance, range of motion, overall quality of life, and reduces pain and fatigue.
Equity / Māori health gain		Māori have poorer access to health and rehabilitation services than non-Māori.[8,9]
Specifications	**Numerator**	Number of people with head and neck cancer who have a supportive care and rehabilitation plan in place before starting treatment.
	Denominator	All people with head and cancer.
	Exclusions	None
Data sources		MDM databases, NZCR, NDMS
Notes		Supportive care and rehabilitation can be delivered by a wide range of health care services, including but not limited to: • nursing • speech-language therapy • dietetics and nutrition • physiotherapy • health psychology • social work • lymphoedema therapy.

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10 Morbidity of treatment

Currently measurable		Yes
Indicator description		a. Proportion of people who have had head and neck surgery and return to theatre within 30 days. b. Proportion of people who have had head and neck surgery and are readmitted within 30 days of discharge.
Rationale and evidence		The collection of data relating to surgical morbidity is a vital part of any unit carrying out surgery. Surgery is an important component of treatment for head and neck cancers. Unplanned return to theatre is an indicator of post-operative complication and is associated with increased morbidity.[1] Unplanned readmission may be indicative of surgical complications and a significant proportion of readmissions are preventable.[1,2] Readmission is also an indicator of the effectiveness of MDT discharge planning and community follow-up and support.
Equity / Māori health gain		Data is not available.
Specifications	**Numerator a**	Number of people who return to theatre within 30 days following initial surgery.
	Denominator a	Number of people who have had head and neck surgery.
	Numerator b	Number of people who have had head and neck surgery and are readmitted within 30 days of discharge.
	Denominator b	Number of people who have had head and neck surgery.
	Exclusions	None
Data sources		NMDS, NZCR
Notes		Care needs to be taken when interpreting and presenting this data. Head and neck cancers are relatively uncommon and are a heterogeneous group of cancers. This means that complications vary greatly depending on tumour type and site. More complex operations are likely be carried out in larger centres, meaning that high volume units will likely have higher complication rates than smaller centres.

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11 Post-operative pathology

Currently measurable		No
Indicator description		Proportion of surgical pathology reports of primary resection for head and neck cancer that are in a structured format, with all important parameters* included.
Rationale and evidence		Structured pathology reports, with standardised definitions for each component have been shown to significantly enhance the completeness and quality of data provided to clinicians. Information from histopathology reports has a key role in informing appropriate management and is used to guide clinical decision-making. Pathology reports for head and neck cancer are essential to determine correct tumour staging. This allows clinicians to make appropriate adjuvant therapy recommendations and provide accurate information about prognosis.
Equity / Māori health gain		Data is not available.
Specifications	**Numerator**	Number of surgical pathology reports of primary resection for head and neck cancer which are in a structured format with all important parameters included.
	Denominator	Total number of surgical pathology reports of primary resection for head and neck cancer.
	Exclusions	Surgical pathology reports of biopsy specimens of head and neck cancer.
Data sources		NZCR, pathology reports, NMDS
Notes		* All important parameters include: • site, laterality, size (maximum tumour diameter), tumour type, differentiation/grade, depth of invasion, pattern of invasion, margin status including distance from margins, lymphovascular invasion (LVI), perineural invasion (PNI), involvement of adjacent structures (eg. bone), pathologic stage (pT) • doing a p16 stain for oropharyngeal and tonsil cancers • if neck dissection is performed include node yield, levels, extracapsular spread, pathologic stage (pN).

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12 Post-operative radiotherapy

Currently measurable		Yes
Indicator description		Proportion of people with head and neck cancer who complete post-operative radiotherapy within 13 weeks of definitive surgery.
Rationale and evidence		People with head and neck cancer who need post-operative radiotherapy are those with more advanced stages of primary and/or nodal spread, and/or those with poor prognostic features such as positive margins, perineural spread, lymphovascular invasion and extra-nodal extension.[1,2] Re-population is greater after partial treatment.[3] Delay in starting radiotherapy is associated with poorer long-term outcomes, both loco-regional control and overall survival.[4,5]
Equity / Māori health gain		Radiotherapy is more likely to be delayed for rural populations and those with co-morbidities such as diabetes and dental caries. Māori are over-represented in these groups.
Specifications	**Numerator**	Number of people with head and neck cancer who complete their radiotherapy within 13 weeks of definitive surgery.
	Denominator	All people with head and neck cancer treated with curative intent with surgery and post-operative radiotherapy.
	Exclusions	People who die within 13 weeks of surgery.
Data sources		NMDS, ROC

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13 Review of contouring for curative radiotherapy

Currently measurable		No
Indicator description		Proportion of people with head and neck cancer who start curative intent radiation with evidence that contours and dose were peer reviewed.
Rationale and evidence		Poor quality radiation delivery has been shown to negatively impact survival outcomes for people with head and neck cancer.[1,2] Modern radiation treatment conforms tightly to the contoured planning target. Due to this the contours are critical to high-quality radiation delivery and are recognised as a potential weak link in radiation delivery.[3] Peer review of contours and dose can lead to a change in contours in up to 15% of cases.[4] The Royal Australian College of Radiation Oncologists recommends peer review of target volumes as part of standard practice.[5]
Equity / Māori health gain		Data is not available.
Specifications	**Numerator**	People with head and neck cancer treated with curative intent radiation therapy where there is evidence of pre-treatment peer review on radiation therapy patient management systems.
	Denominator	All people with head and neck cancer are treated with curative intent radiation therapy.
	Exclusions	None
Data sources		Cancer centre radiotherapy patient management systems, ROC
Notes		Peer review in this context describes a process where the treating radiation oncologist presents the salient clinical details, including imaging and pathology results, to a colleague. They review the contoured clinical targets and doses in an attempt to reduce the risk of a geographic miss or overdosing normal structures. In general, the peer reviewer would be a radiation oncologist, but in certain cases of complex surgery or reconstruction, or difficult-to-define tumours, the operating surgeon or a radiologist may be more appropriate.

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14 Adjuvant chemoradiation

Currently measurable		No
Indicator description		Proportion of people with head and neck mucosal squamous cell cancer (HNSCC) resected with microscopic positive margins or extracapsular extension who receive adjuvant platinum-based chemoradiation.
Rationale and evidence		Adjuvant chemoradiation with high-dose cisplatin after resection of mucosal HNSCC is shown to significantly improve overall survival in people with high-risk pathological features.[1,2] Positive margins and extracapsular spread are the major high-risk factors predicting benefit from adjuvant chemoradiation.[3] Adjuvant chemoradiation is associated with prolongation of overall survival compared to radiation alone.[4] Appropriate adjuvant chemoradiation has been validated as a quality performance indicator of head and neck cancer management.[5]
Equity / Māori health gain		Data is not available.
Specifications	**Numerator**	Number of people with resected mucosal HNSCC with positive margins or extracapsular extension who receive appropriate adjuvant chemoradiation.
	Denominator	Number of people with resected mucosal HNSCC with positive margins or extracapsular extension who receive adjuvant radiation with or without chemotherapy.
	Exclusions	None
Data sources		NZCR, pathology reports, NMDS, PHARMS, ROC

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Appendix 1: Working group members

The National Head and Neck Cancer Working Group members in 2018/2019 were:

Chair

Nick McIvor, ORL/Head and Neck Surgeon, Auckland DHB

Members

Robert Allison, ORL/Head and Neck Surgeon, Canterbury DHB
Riana Clarke, National Clinical Director of Oral Health, Ministry of Health
Mark Coates, Radiologist, Canterbury DHB
Charles de Groot, Radiation Oncologist, Waikato DHB
Abdul-Kade Ebrahim, ORL/Head and Neck Surgeon, Waikato DHB
Christina Edmonds, Clinical Nurse Specialist, Northland DHB
Louise Elia, Kaumātua, Waitemata DHB
Tony Goh, Radiologist, Canterbury DHB
Derek Goodisson, Maxillofacial Surgeon, Hawke's Bay DHB
Lisa Guest, Clinical Dietitian, Auckland DHB
Lyndell Kelly, Radiation Oncologist, Southern DHB
Neil Lambie, Histoathologist, Southern DHB
Jonathan Mathy, Plastic and Reconstructive Surgeon, Counties Manukau DHB
Mark McKeague, Medical Oncologist, Auckland DHB
Andrew Miller, GP/Consumer Representative, Northland DHB
Randall Morton, Head and Neck Surgeon, Counties Manukau DHB
Anita Nolan, Professor of Oral Health, Oral Health NZ
Kate O'Connor, Radiologist, Auckland DHB
Carlene Perris, Speech Language Therapist, Auckland DHB
Brian Sheppard, Consumer Representative, Wellington
Graeme Ting, Special Needs Dentist, Southern DHB

Appendix 2: EQ-5D-5L

Health Questionnaire

English version for the UK

Under each heading, please tick the ONE box that best describes your health TODAY.

MOBILITY

I have no problems in walking about ❑
I have slight problems in walking about ❑
I have moderate problems in walking about ❑
I have severe problems in walking about ❑
I am unable to walk about ❑

SELF-CARE

I have no problems washing or dressing myself ❑
I have slight problems washing or dressing myself ❑
I have moderate problems washing or dressing myself ❑
I have severe problems washing or dressing myself ❑
I am unable to wash or dress myself ❑

USUAL ACTIVITIES *(eg, work, study, housework, family or leisure activities)*

I have no problems doing my usual activities ❑
I have slight problems doing my usual activities ❑
I have moderate problems doing my usual activities ❑
I have severe problems doing my usual activities ❑
I am unable to do my usual activities ❑

PAIN / DISCOMFORT

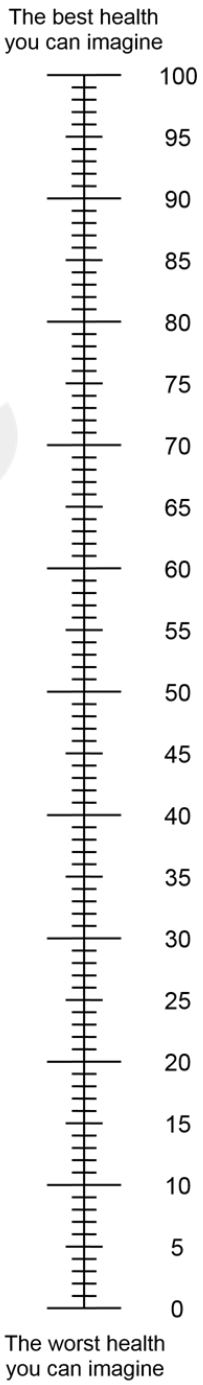
I have no pain or discomfort ❑
I have slight pain or discomfort ❑
I have moderate pain or discomfort ❑
I have severe pain or discomfort ❑
I have extreme pain or discomfort ❑

ANXIETY / DEPRESSION

I am not anxious or depressed ❑
I am slightly anxious or depressed ❑
I am moderately anxious or depressed ❑
I am severely anxious or depressed ❑
I am extremely anxious or depressed ❑

- We would like to know how good or bad your health is TODAY.
- This scale is numbered from 0 to 100.
- 100 means the best health you can imagine.
  0 means the worst health you can imagine.
- Mark an X on the scale to indicate how your health is TODAY.
- Now, please write the number you marked on the scale in the box below.

YOUR HEALTH TODAY = ☐



Appendix 3: FACT-H&N

FACT-H&N (Version 4)

Below is a list of statements that other people with your illness have said are important. **Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy	0	1	2	3	4
GP2	I have nausea	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family	0	1	2	3	4
GP4	I have pain	0	1	2	3	4
GP5	I am bothered by side effects of treatment	0	1	2	3	4
GP6	I feel ill	0	1	2	3	4
GP7	I am forced to spend time in bed	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life	0	1	2	3	4

FACT-H&N (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Some-what	Quite a bit	Very much
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

FACT-H&N (Version 4)

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	ADDITIONAL CONCERNS	Not at all	A little bit	Some-what	Quite a bit	Very much
H&N1	I am able to eat the foods that I like	0	1	2	3	4
H&N2	My mouth is dry	0	1	2	3	4
H&N3	I have trouble breathing	0	1	2	3	4
H&N4	My voice has its usual quality and strength	0	1	2	3	4
H&N5	I am able to eat as much food as I want	0	1	2	3	4
H&N6	I am unhappy with how my face and neck look	0	1	2	3	4
H&N7	I can swallow naturally and easily	0	1	2	3	4
H&N8	I smoke cigarettes or other tobacco products	0	1	2	3	4
H&N9	I drink alcohol (e.g. beer, wine, etc.)	0	1	2	3	4
H&N 10	I am able to communicate with others	0	1	2	3	4
H&N 11	I can eat solid foods	0	1	2	3	4
H&N 12	I have pain in my mouth, throat or neck	0	1	2	3	4