TE AHO
O TE KAHU
CANCER
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Optimal cancer care pathway for people with head and neck cancer

February 2025 | Edition One, version 2 (12/9/25)

Citation: Te Aho o Te Kahu. 2025. *Optimal cancer care pathway for people with head and neck cancer*. Wellington: Te Aho o Te Kahu.

Published in 2025 by Te Aho o Te Kahu | Cancer Control Agency, PO Box 5013, Wellington 6140, New Zealand

ISSN: 3021-3134 (online)
TP0032

Whakataukī

Have a sense of the message in the winds…

Anei he taonga nō te mātanga nō Ahitereiria
Koutou maa I takoto te koha ki a mātou

Here is a treasure from the skilled and able specialist in Australia.
Greetings for this treasure you have gifted us here in Aotearoa to explore and use.

E ki ana te tangi o tatou manu
Ko te manu e kai ana ki te miro, nōnā te ngahere
Ko te manu e kai ana ki te mātauranga nōnā te Ao

It has been reiterated that when our manu cries, we sit up and listen.
The bird that feeds upon local berries, local knowledge will prosper.
The bird that feeds upon wisdom, our world knowledge will flourish.

It is an exciting time to feed off the wisdom of other cultures.

Matua Tau Huirama

We would like to acknowledge The Voices of Whānau Māori Affected by Cancer (2023); He Ara Tangata – Te Aho o Te Kahu Consumer Group; the project team; clinicians; and national and special interest working groups that contributed to the development of the Optimal Cancer Care Pathways.

Special acknowledgement is extended to the Cancer Council Australia, who generously shared their Optimal Care Pathways framework and provided permission for it to be adapted to support people and whānau across Aotearoa New Zealand experiencing cancer.

Contents

For further information including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Head and neck cancer references and bibliography

Refer to **Optimal Cancer Care Pathway (OCCP) supplementary information.**

Foreword

Kia ora,

On behalf of Te Aho o Te Kahu| Cancer Control Agency, the clinician community, and the people and whānau who contributed to developing this guidance, I am proud to present the head and neck cancer Optimal Cancer Care Pathway (OCCP) for Aotearoa New Zealand.

Almost everyone across Aotearoa has been affected by cancer in some way. This year over 28,000 people will be diagnosed with cancer, with thousands more supporting loved ones living with this disease. Head and neck cancer affects an increasing number of people with more than 700 diagnosed with head and neck cancer this year. More than 200 people will die from head and neck cancer this year. We all believe that people and their whānau deserve the best cancer care available.

OCCPs are designed to guide the planning, coordination and delivery of best practice cancer prevention and care services across Aotearoa for different types of cancer. Each OCCP has been designed:

- with the needs of the person and their whānau at the heart
- to reflect the best capabilities available in Aotearoa
- to provide a national standard for high-quality cancer prevention and care that we expect for all New Zealanders.

While cancer control services are expanding and improving across the motu | country, there are often unwarranted variations in the risk of getting cancer and in the care experienced by people with cancer. Also, many continue to face barriers in accessing timely and effective cancer care because of where they live, their circumstances, or their ethnic background. Research shows that following best practice guidance like OCCPs, helps to reduce variations and disparities and improves cancer outcomes for people and their whānau. In turn, this will help our overall aim of reducing the burden of cancer on people and communities.

This resource reflects the expertise and experiences from many stakeholders across the country. Many thanks to everyone involved in this initiative, particularly Cancer Council Australia, who granted permission to adapt and adopt their Optimal Care Pathways framework to meet the needs of people in Aotearoa | New Zealand. We would also like to acknowledge the insights from The Voices of Whānau Māori Affected by Cancer (2023); He Ara Tangata – Te Aho o Te Kahu Consumer Group; the project team; clinicians; and national and special interest working groups.

Our thoughts are with the many people and whānau who are living with head & neck cancer, and those who have lost loved ones. Much of this guidance reflects the voices of those who have received cancer care. We are indebted to them for sharing their experiences to help improve cancer control outcomes and achieve equity.

Ngā mihi nui,

Rami Rahal
Tumuaki | Chief Executive
Te Aho O Te Kahu | Cancer Control Agency

Summary guide of head and neck cancer OCCP information

Quick reference guide of condensed tumour stream

The Optimal Cancer Care Pathways (OCCP) describe the standard of care that people and whānau across Aotearoa, New Zealand should expect the public health system to be striving for. They follow eight principles[1]: person and whānau-centred care; equity-led; safe, high-quality care; multidisciplinary care; supportive care; coordinated care; effective and timely communication; and knowledge-driven care.

The OCCP guides health providers in ensuring the person and their whānau receive optimal, supportive care at each stage of their cancer diagnosis and treatment.

Step 1: Wellness	Step 1: Checklist
Cancer prevention efforts should be part of all cancer control pathways. This step recommends actions the person/whānau can take to improve their wellbeing and reduce the overall risk of cancer. Evidence-based research shows that general cancer and wellbeing risks can be reduced by: • eating a nutritious diet • maintaining a healthy weight • taking regular, moderate to vigorous-intensity activity • avoiding or limiting alcohol intake • being sun smart • identifying pre-disposing infections such as, Hepatitis C • keeping up to date with immunisations or vaccines such as, Human Papilloma Virus (HPV) • avoiding smoking including marijuana, chewing tobacco and exposure to second-hand smoke. o current smokers (or those who recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to a service such as Quitline. • avoiding vaping • participating in screening services such as breast, cervical, bowel cancer screening • preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons.	☐ Carry out a health and wellbeing assessment including discussions around screening services and ways to reduce cancer risk. ☐ Assess the individual's risk of developing cancer. ☐ Encourage eligible people to participate in national screening programmes. ☐ Discuss recent weight changes and monitor weight. ☐ Discuss and record alcohol intake. Offer support for reducing alcohol consumption if appropriate. ☐ Record person's smoking status and offer stop smoking advice/support if appropriate. ☐ Record physical activity. ☐ Consider referral to a dietitian, physiotherapist, or exercise programme. ☐ Give the person education on being sun smart.

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[1] Optimal Cancer Care Pathway Principles

Step 2: Early detection

This step recommends options for early detection for the person with suspected head and neck cancer.

There is no national screening programme for head and neck cancer.

Early detection

For head and neck cancer, the most important modifiable risk factors are tobacco use, alcohol consumption, and improved vaccine uptake against human papillomavirus (HPV) infection.

The use of both alcohol and smoking significantly increases risk.

For head and neck cancers, dental assessment is also important for early detection, alongside wider health checks.

Step 2: Checklist

☐ Assess and discuss the individual's risk of developing cancer.

☐ Support the person and their whānau to follow surveillance guidance if they're at an increased risk of familial cancer.

☐ Refer to clinical genetic services where appropriate.

☐ Discuss recent weight changes and monitor weight.

☐ If signs and symptoms of cancer are present, refer to 'Step 3: Presentation, initial investigation and referral' below.

Communication

Ensure the person and their whānau understands:

☐ the targeted investigations

☐ when they should receive their results

☐ how to follow up if they don't receive their results

☐ what's involved if they need to be transferred to a specialist service.

Step 3: Presentation, initial investigations, and referral

This step outlines how to initiate the appropriate investigations and referrals to specialist/s in a timely manner for the person with suspected head and neck cancer.

The types of investigations undertaken will depend on many factors, including access to diagnostic tests, the availability of medical specialists, and including preferences.

A person and their whānau may present via primary care, an emergency presentation or incidental finding with a high suspicion of head and neck cancer.

The following signs and symptoms of head and neck cancer should be investigated if they persist for more than 3 weeks, and especially if more than one primary symptom is present:

- mouth ulcer or mass
- unexplained tooth mobility and/or non-healing dental extraction site

Step 3: Checklist

☐ Record signs and symptoms.

☐ Complete all cancer assessments.

☐ Inform the person and their whānau of preliminary results.

☐ Referral options of cancer care are discussed with the person and their whānau, including cost implications if private provider requested.

☐ Complete and record supportive care needs assessment, refer to allied health services as required.

☐ Inform the person and their whānau of cultural services and relevant support groups available.

☐ Initiate referrals via the regional referral pathway and arrange further investigation.

- white or red patches of oral mucosa (leukoplakia) persisting lip ulcers or patches
- changes in the voice, such as hoarseness
- difficulty swallowing
- persistent unexplained neck or parotid lump or sore
- unilateral blockage of the nose, especially if associated with swelling or other problems with the eyes such as double vision
- Unilateral ear pain, pressure, or unilateral conductive hearing loss in high-risk groups (e.g., Māori, Asian, Pacific)
- unilateral paralysis of the muscles in the face with associated neck mass.

The following symptoms may also be present and may indicate more advanced disease although are non-specific to head and neck cancer:

- persistent sore throat (particularly together with earache) or cough
- coughing up blood (including spitting up blood)
- unilateral paralysis of the muscles in the face
- trismus (lockjaw) or reduced jaw opening
- pain when swallowing or chewing
- unilateral numbness, tingling, pins and needles or formication (feeling of insects crawling on the skin)
- unexplained weight loss.

Head and neck cancer assessment includes the relevant:

- medical history, including relevant medications: smoking and alcohol history, previous history of cancer and cancer treatment, immunosuppression
- physical examination: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight, oral cavity assessment and palpation for head & neck lymph nodes
- investigations (laboratory, radiology):
    - CXR for hoarseness
    - Ultrasound-guided fine-needle aspiration cytology (USgFNAC) of a node, if malignancy is suspected or if a neck lump persists or grows (including lumps in the thyroid, salivary gland, or lymph node)
    - structural imaging with ultrasound, CT and/or MRI.
- familial cancer history
- social history.

Referral

A clinical suspicion, laboratory, or imaging findings suggestive of cancer require further investigation and a referral to hospital specialist services.

Timeframe

☐ If there is a high suspicion of head and neck cancer, submit referral **immediately** to hospital specialist services.

☐ High suspicion of cancer referral is triaged **within 1-2 working days** and referrer is notified.

☐ Confirm that the person referred urgently with a high suspicion of cancer will attend their first specialist assessment (FSA) clinic **within 2 weeks**.

Communication

☐ Explain to person and their whānau that they are being referred to a hospital specialist service and why, including:

- how long this may take
- who to contact if their symptoms change
- how to follow up if they do not receive their specialist appointment within the specified time.

If the person presents with red flags for the following sites/conditions, the referral should be triaged as a high suspicion of cancer:

- oral/throat/lip lesions
- neck/salivary lump
- upper aerodigestive tract.

Step 4: Diagnosis, staging and treatment planning

This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment.

Following triaging in secondary care, the head and neck team immediately refer people for the appropriate examinations. At this stage, the focus is on diagnosing people who have suspicion of a malignancy and then staging their disease. The FSA with the specialist may come after initial investigations are undertaken.

The order of diagnostic investigations may vary depending on local facilities and protocols. The emphasis is to gain a tissue diagnosis promptly along with information to guide treatment planning as soon as practical.

Examinations include:

- a full clinical history including risk factors
- complete head and neck examination, including fibre-optic nasopharyngolaryngoscopy and skin inspection where necessary
- ultrasound assessment with or without guided biopsy may be used as an initial investigation prior to assessment or referral
- biopsy of primary tumour and/or neck mass.

To stage the tumour the following additional tests may be required:

- examination under anaesthetic
- structural imaging (CT/MRI/PET-CT) to evaluate the primary site, regional lymph nodes and sites of possible distant metastases.

The following additional assessments may be required:

- dental including dental assessments, minor oral surgery (biopsy and dental extractions) and dental radiology radiographs
- laboratory for blood tests
- holistic needs assessment
- nutritional assessment.

Step 4: Checklist

☐ All people with a high suspicion of cancer have a person to coordinate care.

☐ Confirm diagnosis.

☐ Referral to the head and neck CNS / CNC at the regional centre a cancer.

☐ Record staging, performance status and comorbidities.

☐ Discuss the person's diagnosis at a multidisciplinary meeting (MDM) and inform the person and their whānau of the treatment recommendation.

☐ Person assessed at a multidisciplinary clinic concurrent with the MDM.

☐ Consider enrolment in clinical trial.

☐ Assess supportive care needs and refer to allied health services for pre-treatment counselling and baseline assessments of functioning.

☐ Ensure primary or secondary prehabilitation to optimise overall well-being is initiated.

☐ Begin Enhanced Recovery After Surgery (ERAS) protocol if for surgery.

☐ Give the person and their whānau information on Cancer Society, Canteen, head, and neck cancer support groups and/or relevant cultural services available.

Timeframe

☐ Investigations should be completed **within 28 days** of referral for specialist assessment.

☐ Referral to head & neck cancer nurse **within 1 week** of definitive cancer diagnosis.

☐ If required, an MDM should occur **within 2 weeks** of the suspected or confirmed diagnosis.

Performance status
Performance status is assessed to inform prehabilitation and treatment recommendations and documented using the Eastern Cooperative Oncology Group (ECOG) Performance Status Scale.

Multidisciplinary meeting
All people diagnosed with head and neck cancer (excluding T1,2 N0 cutaneous) are assessed at a dedicated head and neck MDM for staging and treatment planning, according to agreed national and local protocol.

Familial cancer risk
There is currently no established role for germline genetic testing for most head and neck cancers.

Clinical genetic testing
Referral to clinical genetic services for head and neck cancer is considered if features of the cancer suggest a genetic predisposition, such as:

- early age onset
- immunohistochemistry (if available)
- multiple primary cancers.

Treatment planning
Optimal cancer care requires a multidisciplinary approach to ensure treatment plans are tailored to an individual's needs in collaboration with the whānau and health care team.
To facilitate early, ongoing, and integrated input by the wider multidisciplinary team, people with head and neck cancer should be reviewed in a multidisciplinary clinic (often concurrent with the MDM) in which clinicians can provide input for each person depending on their needs in one visit.

Communication

The lead clinician and team are responsible for:

☐ discussing a timeframe for diagnosis and treatment options with person and their whānau

☐ explaining the role of the MDM team in treatment planning and ongoing care

☐ encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care while clarifying wishes, needs, beliefs, and expectations of the person and their whānau and their ability to comprehend the communication

☐ providing appropriate information and referral to support services as required

☐ communicating with the GP of the person and their whānau about the diagnosis, treatment plan and recommendations from the MDM.

Step 5: Treatment

This step describes publicly funded treatments for head and neck cancer by trained and experienced clinicians and team members, in an appropriate environment.

Establish the intent of treatment:

- curative – to cure the cancer completely
- tumour control – to stop the cancer growing and spreading
- palliative – to manage symptoms caused by the cancer.

Treatment options

Surgery is recommended for many people with head and neck cancer. It may be used to stage the cancer, as a curative treatment or to salvage residual or recurrent disease.

Step 5: Checklist

☐ Health providers/professional, treating specialist has relevant qualifications, experience, and expertise.

☐ Discuss the intent of treatment and the risks and benefits with the person and their whānau.

☐ Discuss and provide the agreed treatment plan with the person, their whānau and GP.

☐ Assess supportive care needs and refer to allied health services as required.

☐ Give the person and their whānau information on Cancer Society, head and neck support groups and relevant cultural services.

☐ Consider early referral to palliative care if appropriate.

For people requiring complex surgery, please also refer to the Capability Requirements for Complex Surgery in Aotearoa New Zealand – Head and Neck (Te Aho o Te Kahu 2024).

Systemic therapy may benefit those people:

- at high risk of recurrence and who may benefit from adjuvant therapy after surgery
- with locally advanced/clinically high-risk features of head and neck cancer, treated with neoadjuvant therapy
- with non-resectable, locally advanced, or metastatic disease.

Radiation therapy may benefit those people:

- where radiation therapy is the primary curative treatment
- at high risk of locoregional recurrence post-surgery
- in a palliative care setting for symptom control.

Palliative care. Early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.

Once treatment commences, people with head and neck cancer may require additional support from members of the wider multidisciplinary team, who have specialist knowledge of head and neck cancer care. Additional support may be required for:

- emotional and psychological issues
- physical symptoms such as pain and fatigue
- oral side effects of head and neck cancer treatments
- nutrition intake (oral diet and enteral feeding), weight loss and symptom management
- oropharyngeal dysphagia, trismus, or speech and/or voice changes
- postoperative respiratory function, including secretion management, particularly in the case of laryngectomy or temporary tracheostomy
- musculoskeletal changes such as shoulder and neck pain or dysfunction following treatment
- lymphoedema
- changes in physical appearance including changes in facial appearance which may require referral to a prosthetics specialist
- a decline in mobility or functional status.

☐ Discuss advanced care planning with the person and their whānau.

Timeframes

☐ The person referred urgently with a high suspicion of head and neck cancer receives their first cancer treatment **within 62-days** from the date of referral.

☐ The person with a confirmed diagnosis of head and neck cancer receives their first treatment **within 31-days** of the decision to treat.

☐ Surgery should be scheduled **within 4 weeks** of the MDM. Time from definitive surgery to beginning adjuvant treatment (plus concomitant systemic therapy when indicated) should be **not more than 6 weeks.**

☐ If radiation therapy or systemic therapy is the primary treatment modality at the time from the MDM to starting treatment, it should begin **within 4 weeks** for curative intent and **within 2 weeks** for palliative intent. If systemic therapy is being used concurrently with radiation therapy, it should begin **within 1 week** of radiation therapy. Radiation therapy as an adjuvant treatment should begin **within 6 weeks** after surgery.

Communication

The lead clinician and team are responsible for discussing these areas with the person and their whānau:

☐ treatment options including the intent of treatment, risks, and benefits

☐ advance care planning

☐ options for healthy lifestyle support to improve treatment outcomes such as exercise and nutrition.

Step 6: Care after treatment

The person and their whānau access appropriate follow up and surveillance and are supported to achieve their optimal health after cancer treatment.

Provide a summary of the treatment and follow-up care plan to the person, their whānau and their GP outlining:

- diagnosis, including tests performed and results
- treatment received (types and date)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals
- potential long-term and latent effects of treatment and care of these
- supportive care services provided
- a follow-up schedule, including tests required and timing
- contact information for key health care providers/professionals who can offer support for lifestyle modification
- a process for rapid re-entry to medical services for suspected recurrence
- ongoing assessments of the effects of treatment such as:
    - fatigue
    - nutrition
    - speech and voice
    - swallowing
    - pain
    - disfigurement
    - oral changes

Step 6: Checklist

☐ Provide a survivorship plan that includes a summary of the treatment and follow-up care plan to the person, whānau and their GP.

☐ Assess supportive care needs and refer to allied health services as required.

☐ Give the person and their whānau information on Cancer Society, head and neck support groups and relevant cultural services.

Communication

The lead clinician and team are responsible for:

☐ explaining the treatment summary and follow-up and surveillance care plan to the person and their whānau

☐ informing the person and their whānau about secondary prevention and healthy living

☐ discussing the follow-up care plan with the GP of the person and their whānau

☐ providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care

Palliative and end-of-life care provides the person facing life-limiting conditions with holistic support and coordinated services based on their specific needs.

Palliative care may be provided through:

- hospital palliative care
- home and community-based care community nursing, including access to appropriate equipment.

Early referral, identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering.

End-of-life care should consider:

- appropriate place of care

Step 7: Checklist

☐ Early referral to palliative care services as required.

☐ Refer to supportive care services as required.

☐ Refer to allied health services as required to maximise functional outcomes and quality of life.

☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying.

☐ Discuss activation of advance care plan, directive, or enduring power of attorney.

• person's preferred place of death • support needed for the person and their whānau. Awareness of and access to, assisted dying services should be available if the person and their whānau raise this with the health care team. **Communication** A key way to support the person and their whānau is by coordinating ongoing, clear communications between all health providers/professionals involved in their providing their cancer care.	

How optimal cancer care pathways improve outcomes

Optimal Cancer Care Pathways (OCCPs) are critical tools for guiding the national delivery of consistent, safe, high-quality, evidence-based cancer care for people and whānau across Aotearoa New Zealand. Research shows OCCPs improve the outcomes and experiences of people and their whānau affected by cancer to guide the design and delivery of cancer care services that are systematic, equitable, connected, and timely (Cancer Council Australia, nd).

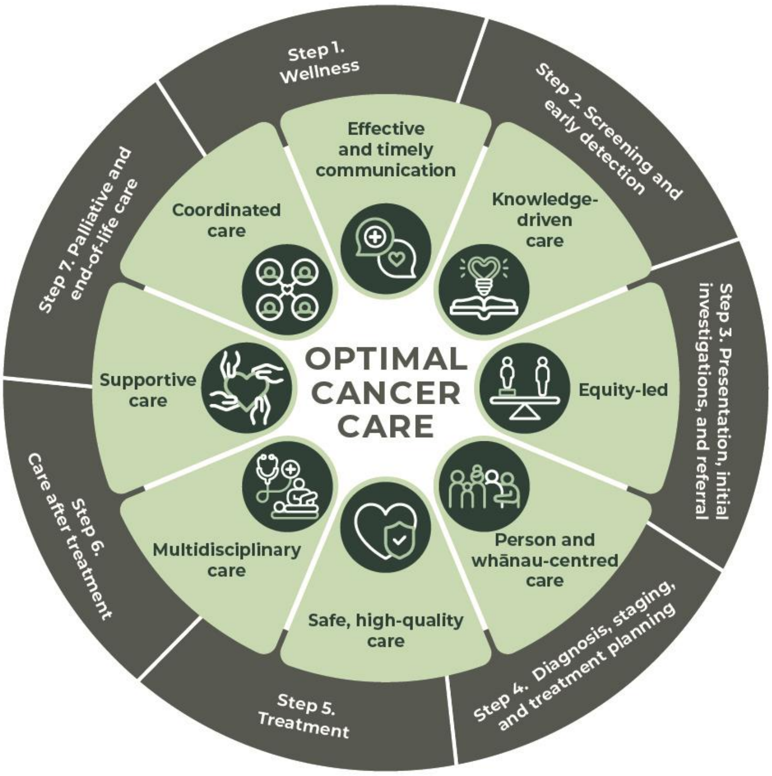
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- identify gaps in existing cancer services
- address barriers and unwarranted variations in accessing high-quality care
- identify opportunities for system improvements
- continually improve the way services are planned and coordinated.

As shown in Figure 1, the OCCPs map seven key steps in providing cancer care based on evidence-based practice, underpinned by eight principles to deliver the optimal level of care. While the seven steps appear linear, in practice, the care a person receives may not be. The steps provided will be tailored to their specific situation and needs, for example, the type of cancer they have, when and how the cancer is diagnosed and managed, the person's decisions, and how they respond to treatment.

OCCPs are designed to be used alongside clinical guidelines. The OCCPs do not constitute medical advice or replace clinical judgement or guidance.

Figure 1: Optimal Cancer Care model



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[2] Optimal Cancer Care Pathway Supplementary Information

Principles of the optimal cancer care pathway

The principles[3] underpinning OCCPs are essential to achieving the best cancer care, experience, and outcomes of the person and their whānau. OCCPs put the person and their whānau at the centre of care planning throughout their treatment/care and prompt the health care system to coordinate high-quality care. The person and their whānau are informed and involved in decisions throughout their cancer experience, according to their preferences, needs and values.

Figure 2: Principles of optimal cancer care

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[3] Optimal Cancer Care Pathway Principles

Optimal timeframes

Evidence based guidelines, where they exist, are used to inform clinical timeframes. Shorter timeframes for appropriate investigations, consultations and treatment can provide an improved experience for people and their whānau and better cancer outcomes. The three steps shown below are a guide for health providers/professionals and the person/whānau on the optimal timeframes being assessed and receiving treatment. These timeframes are based on expert advice and consultation with the Northern and Central regional head and neck cancer work groups and Te Manawa Taki and Southern region head and neck MDMs.

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Referral to a hospital specialist	If symptoms persist for more than three weeks that suggest head and neck cancer, the person and their whānau are referred via the regional head and neck referral pathway **within 2 weeks** for triaging, distribution, and urgent investigation.
The person referred with a high suspicion of head & neck cancer and triaged by a clinician will receive their first cancer treatment within 62 days.		
Step 4: Diagnosis, staging, and treatment planning	Diagnosis and staging	Investigations should be completed **within 28 days** of referral for specialist assessment. Referral to head & neck cancer nurse **within 1 week** of definitive cancer diagnosis.
	Multidisciplinary team meeting and treatment planning	All newly diagnosed people are discussed or registered in an MDM, before treatment begins. MDM takes place **within 2 weeks** of confirmed diagnosis and staging. All newly diagnosed people are seen at an MDT clinic directly following the MDM (this is generally when the pretreatment assessment and decision to treat occurs).
Step 5: Treatment	Surgery	Surgery should be **scheduled within 4 weeks** of the MDM. Time from definitive surgery to beginning adjuvant treatment (plus

	Radiation therapy +/- systemic therapy	concomitant systemic therapy when indicated) should **not more than 6 weeks.** If radiation therapy or systemic therapy is the primary treatment modality at the time from the MDM to starting treatment, it should begin **within 4 weeks** for curative intent and **within 2 weeks** for palliative intent. If systemic therapy is being used concurrently with radiation therapy, it should begin **within 1 week** of radiation therapy. Radiation therapy as an adjuvant treatment should begin **within 6 weeks** after surgery.

Optimal cancer care pathway

Seven steps of the optimal cancer care pathway

Step 1: Wellness
Step 2: Early detection
Step 3: Presentation, initial investigations, and referral
Step 4: Diagnosis, staging, and treatment planning
Step 5: Treatment
Step 6: Care after treatment
Step 7: Palliative care and end-of-life care

Head & neck cancers made up 4.13% of all cancers registered in Aotearoa, New Zealand from 2017-2021 (source: Cancer Web Tool, Te Whatu Ora, 2023). The pathway covers the following head and neck cancers: mouth or oral cancer; salivary gland cancer; pharyngeal or throat cancer, incorporating nasopharyngeal, oropharyngeal and hypopharyngeal cancers; laryngeal cancer; and nasal or paranasal sinus cancer.

Whilst this pathway is also generally applicable to thyroid cancer, cancers of the cervical oesophagus, cancers of unknown primary that first appear in the head and neck, and cancer in the skin of the head and neck in the context of high-risk and advanced skin cancer, there are additional requirements for the care of these people that are not identified in this OCCP.

Step 1: Wellness

Cancer prevention efforts should be part of all cancer control pathways. This step recommends actions the person/whānau can take to improve their wellbeing and reduce the overall risk of cancer.

Health care providers and services such as primary care, public health units, hospitals, and non-governmental organisations (NGOs) work collaboratively to prevent cancer (and other conditions) with the person and their whānau and communities. Te Aho o Te Kahu (2022) produced a report outlining evidence-based, best-practice interventions to prevent cancer. Reducing cancer risk factors addresses work to achieve the goals of fewer cancers, better survival, and equity for all.

1.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- culturally safe health care providers and practices embedded in all health services and steps of the cancer care pathway
- institutional and personal bias or racism within the health and disability system being acknowledged, identified, and addressed (Harris et al 2012)
- implementation of health and wellness approaches that support ritenga Māori (Māori customary rights) framed by te ao Māori (a Māori world view), enacted through tikanga Māori (Māori customs) and encapsulated with mātauranga Māori (Māori knowledges)
- meaningful partnerships with Māori communities and organisations that benefit Māori
- support and resource health promotion activities co-designed with Māori
- prioritise achieving equity for screening participation rates in national cancer screening programmes (cervical, breast, bowel).

1.2 Modifiable cancer and wellbeing risks

Evidence-based research shows that general cancer and wellbeing risks can be reduced by:

- eating a nutritious diet
- maintaining a healthy weight
- taking regular, moderate to vigorous-intensity activity
- avoiding or limiting alcohol intake
- being sun smart
- identifying pre-disposing infections, such as hepatitis C
- immunisations – for example, HPV
- avoiding smoking including marijuana, chewing tobacco and exposure to second-hand smoke
    - current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline.
- avoiding vaping
- screening services, such as breast, cervical and bowel cancer screening
- preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons (Te Aho o Te Kahu 2022).

Most cancer risk factors are not unique to cancer and are shared by other chronic diseases such as diabetes, heart disease and strokes. (Te Aho o Te Kahu 2022).

1.3 Communication with the person/whānau receiving care

Health providers

- Raise and discuss any modifiable risk factors.
- Provide information and education regarding access to wellness programmes, including kaupapa Māori services.
- Discuss advance care planning, advance directive and/or Enduring Power of Attorney (EPA) as required (refer Principle 1)[1].

> ***"Whānau look at prevention holistically."***
> Person/whānau insights

Communication between health services

- Inform the person and their whānau of any referrals between health care services and wellness programmes.

1.4 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Immunisation rates; HPV, hepatitis B**
  - Immunisation coverage - HPV vaccine: 75% of girls and boys fully immunised

- **Smoking and vaping rates** (note: these measures apply to every step on the pathway).
  - The number of current smokers (aged 15 years and above) who smoke daily and have smoked more than 100 cigarettes their whole life as measured by the New Zealand Health Survey, by gender and ethnicity.
  - The number of vapers (aged 15 years and above) who have tried vaping and vape at least once a day as measured by the New Zealand Health Survey, by gender and ethnicity.
- **The New Zealand Heath survey** (NZHS) provides information about the health and wellbeing of New Zealanders.
  - Health status and behaviours.
  - Risk factors.
  - Access to health care.

Step 2: Early detection

This step outlines recommendations for early detection for the person with suspected head and neck cancer.

2.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- making sure early detection of cancer is provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care
- providing access to co-designed kaupapa Māori early detection for cancer programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to cancer services.

Māori and Pacific peoples often present at an earlier age than the general population, so awareness and consideration of this needs to factor into assessment and review of signs and symptoms.

2.2 Early detection

There is no national Head and Neck cancer screening programme.

Early detection focuses on detecting symptomatic people as early as possible. Early detection has several benefits, including better treatment outcomes and improved survivorship. For head and neck cancer, the most important modifiable risk factors are tobacco use, alcohol consumption and improved vaccine uptake against human papillomavirus (HPV) infection. Dental assessment is also important for early detection, alongside wider health checks.

2.3 Head and neck cancer risk factors[4]

2.3.1 Modifiable risk factors

- smoking, chewing tobacco or chewing betel quid
- alcohol consumption
- combined smoking and alcohol consumption
- poor oral hygiene and ill-fitting dentures causing ulceration
- poor nutrition

2.3.2 Non-modifiable risk factors

- HPV infection
- UV light exposure (for skin cancer)
- pre-existing oral lesions
- age (over 40 years)
- sex (male)
- Epstein-Barr virus infection in genetically predisposed individuals (for nasopharyngeal cancer)
- immunosuppression
- ionising radiation exposure
- inherited conditions including Fanconi’s anaemia, ataxia-telangiectasia syndrome, Bloom’s syndrome and Li-Fraumeni cancer syndrome.

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[4] IARC, 2025

2.33 Familial cancer risk

Some people may have an increased risk of developing head and neck cancer. An individual's whānau cancer history is reviewed and the person and their whānau are advised of the risks of developing a familial cancer. Health providers encourage and support the person and their whānau to follow surveillance guidance if an increased risk of familial cancer is identified.

Refer to clinical genetics where appropriate if the person and their whānau have known genetic predisposition for a head and neck cancer or a familial history.

For further information visit the Genetic Health Service New Zealand website (**genetichealthservice.org.nz**).

2.4 Communication with the person/whānau receiving care

Health providers/professionals

- Promote health checks.
- Raise and discuss any cancer risk factors.
- Provide information and education regarding early detection.
- Discuss any investigative results and follow up care as required.
- Discuss available supports, such as funding for travel and accommodation, one-stop clinics, community and/or marae-based services (where available), and same-day access to a chest x-ray.

We went…… as a group…we could awhi each other". "Education ……… at a marae would be good."
Person/whānau insights

Communication between health services

- Share results and further tests or referrals required with the appropriate service/specialty.

2.5 Measuring and monitoring

Monitoring and measuring are key components of contemporary best practice. Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Faster Cancer Treatment**

Early detection through primary care that identifies a high suspicion of cancer and requires an urgent referral to specialist will be seen **within 2 weeks**. The following FCT business rules will apply:

  - **31-day Health Target -** All people will receive their first cancer treatment (or other management) within 31-days from decision to treat. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat. (**FCT business rules**, 2023).
  - **62-day indicator** – All people with a high suspicion of cancer (without a confirmed pathological diagnosis of cancer at referral) will receive their cancer treatment within 62-days from date of referral. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.

Step 3: Presentation, initial investigations, and referral

This step outlines the process for initiation of the right investigations and referral to the appropriate specialist in a timely manner for the person with suspected head and neck cancer.

The types of investigations undertaken will depend on many factors including the preferences of the person and their whānau.

Community HealthPathways provide a source of relevant detailed information for a prostate cancer assessment from a person's primary care presentation and referral to secondary care to specialist services (Community Health Pathways. 2024). You can read more in **Community HealthPathways** .

The Community-referred radiology (CRR) Referral Criteria are criteria to provide nationally consistent access to imaging. The criteria set out a mandatory minimum level of radiology access to help primary care manage imaging in the community. Refer to: **National Community Referral Criteria for Imaging » Radiology**.

There are multiple relevant pathways for symptoms of head and neck cancer and clinical judgement based on presenting symptoms will be required.

3.1 Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- prioritising Māori with a 'high suspicion of cancer' referral pathway until symptoms are proven otherwise
- engaging with kaupapa Māori services that are equipped to provide holistic Whānau Ora services in the community
- supporting Māori with access to diagnostics, investigations, and referrals through to the appropriate secondary services.

3.2 Signs and symptoms

Signs and symptoms suspicious of cancer that prompt initial investigations may be via primary care, elective care, or an acute admission. Primary care services work with the person and their whānau to assess, investigate, review, and refer to appropriate services within recommended timeframes (see Optimal Timeframe section). These timeframes are indicated by national FCT high suspicion of cancer pathways and the indicator data dictionary.

Timeframe for general practitioner consultation

A person with signs and symptoms that may suggest head and neck cancer should be seen by a general practitioner **within 2 weeks.**

The person is assessed for signs and symptoms of head and neck cancer, including any unexplained, persistent signs and symptoms lasting more than 3 weeks (or earlier in people with known risk factors). The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, may indicate an increased risk of cancer.

Māori and Pacific peoples often present at an earlier age than the general population, so awareness and consideration of this needs to factor into assessment and review of signs and symptoms.

The following signs and symptoms of head and neck cancer should be investigated if they persist for more than 3 weeks, and especially if more than one primary symptom is present:

- mouth ulcer or mass
- unexplained tooth mobility and/or non-healing dental extraction site
- white or red patches of oral mucosa (leukoplakia)
- persisting lip ulcers or patches
- changes in the voice, such as hoarseness
- difficulty swallowing
- persistent unexplained neck or parotid lump or sore
- unilateral blockage of the nose, especially if associated with swelling or other problems with the eyes such as double vision
- unilateral ear pain, pressure, or unilateral conductive hearing loss in high-risk groups (e.g., Māori, Asian, Pacific)
- unilateral paralysis of the muscles in the face with associated neck mass.

The following symptoms may also be present and may indicate more advanced disease although are non-specific to head and neck cancer:

- persistent sore throat (particularly together with earache) or cough
- coughing up blood (including spitting up blood)
- unilateral paralysis of the muscles in the face
- trismus (lockjaw) or reduced jaw opening
- pain when swallowing or chewing
- unilateral numbness, tingling, pins and needles or formication (feeling of insects crawling on the skin)
- unexplained weight loss.

3.3 Assessment

Head and neck cancer assessment includes relevant:

- medical history, including relevant medications: smoking and alcohol history, previous history of cancer and cancer treatment, immunosuppression
- physical examination: Eastern Cooperative Oncology Group **(ECOG)** Performance Status Scale, frailty assessment, weight, oral cavity assessment and palpation for head & neck lymph nodes
- investigations (laboratory, radiology):
    - CXR for hoarseness
    - ultrasound-guided fine-needle aspiration cytology of a node, if malignancy is suspected or if a neck lump persists or grows (including lumps in the thyroid, salivary gland, or lymph node) *
    - structural imaging with ultrasound, CT and/or MRI
- familial cancer history
- social history.

*Excisional biopsy of potentially malignant lesions should not be undertaken. Appropriately trained practitioners can consider biopsy of a primary site, but this should not delay referral. Lymph nodes should not have incisional or excisional biopsy without specialist input.

3.4 Initiate investigations, including referrals

Regional referral pathways aimed at “Care Coordination” are developed to facilitate single points of entry for clinicians and primary care providers (including dentists) to head and neck services.

Each region will have a regional referral pathway for people with a high suspicion of cancer where urgent triaging by the H&N team is undertaken. The referral will then be forwarded to the appropriate specialty, depending on the person’s presenting symptoms and where they live, for further investigations and FSA to be undertaken. ‘Straight to test’ pathways should be in place to schedule investigations that are appropriate to be undertaken prior to FSA.

The referral should be sent to appropriate specialties as per regional protocols.

- Indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen within two weeks. If the referrer believes there is a high suspicion of cancer, but they do not think the criteria threshold for FCT is met, then a direct conversation with the head & neck team is recommended prior to referral.
- Referrals are receipted back to the referring provider.

Timeframe for completing investigations for the person with suspected head and neck cancer

Optimally, investigations should be completed **within 2 weeks.**

Referral options are clearly communicated with the person and their whānau, including details of expected timeframes, who to contact if they don’t hear from the service referred to within the timeframe given, and any costs for accessing services.

When referring a person and their whānau for investigation or procedures, referrers must ensure that:

- the person is aware and encouraged to have a support person with them
- the procedure or investigation is explained to them in a way that they can understand, including in different formats and with a translator, as required
- Māori are referred to kaupapa Māori services if they choose and as available
- an investigation assessment is undertaken to identify if an individual can tolerate the preparation, procedure, or investigation
- they are actively coordinating appointments
- assessment and support are given to address any possible barriers of accessing services – for example:
    - transport
    - financial
    - family situation that may impact on the decision to consent to a procedure
    - coordinating appointments and/or offering the person and their whānau, whānau focused bookings.

To support accurate triage, referral information must include the following information:

- signalled as high suspicion of cancer or urgent*
- medication and allergies
- past medical history and current comorbidities
- results of relevant investigations
- notification if an interpreter service is required
- concerns that may require support or affect ability to attend appointments, undergo investigations or treatment.

*The triaging service will use the following information about red flags in the Faster Cancer Treatment business rules (Health NZ 2023) to identify people that should be triaged as high suspicion of cancer and urgent:

Red flags: Head and Neck Cancer - Oral/Throat/Lip Lesion

A visible or palpable Oral, Throat, or Lip Lesion ***and one or more*** of the following:

- unexplained ulcer/lesion/lump persisting for > 3 weeks
- leukoplakia – must be either nodular, swollen, or bleeding (flat leukoplakia requires standard referral)
- erythroplakia
- unexplained tooth mobility/ non-healing socket
- persistent numbness chin, lip, palate, or tongue.

Red flags: Head and Neck Cancer - Neck/Salivary Lump

If the patient presents with one or more of the following red flags, then the referral should be triaged as 'High Suspicion of Cancer'.

- An unexplained neck/salivary mass and one or more of the following:
    - mass > 1cm and persisting > 3weeks
    - mass is increasing in size
    - previous head and neck cancer including skin cancer
    - facial palsy
    - any new unexplained upper respiratory tract symptoms such as hoarseness, dysphagia, throat or ear pain, blocked nose, or ear.

Red flags: Head and Neck Cancer - Upper aerodigestive tract

If the patient presents ***with one or more*** of the following red flags **(new unexplained symptoms > 3 weeks)**, then the referral should be triaged as 'High Suspicion of Cancer'.

- New throat pain or referred otalgia.
- New hoarseness with a history of smoking.
- New progressive dysphagia to solids or liquids (excluding isolated globus sensation).
- Stridor/upper airway noise.
- New nasal obstruction associated with another red flag.
- New epistaxis associated with another red flag.

Timeframe for referring to a specialist

If symptoms persist for more than 3 weeks that suggest head and neck cancer, the person and their whānau are referred via the regional H&N referral pathway **within 2 weeks** for triaging, distribution, and urgent investigation.

If necessary, prior discussion with a specialist should facilitate referral (Community Health Pathways 2024).

High suspicion of cancer referrals must be triaged in a timely manner **within 1–2 working days** by an appropriately trained person (nurse specialist or doctor) and consistent with FCT Business Rules and/or other prioritisation classification criteria **(FCT data dictionary)**.

If symptoms are concerning and the referral is not accepted, primary care 'safety netting' for re-assessment is recommended.

3.5 Supportive care and communication

Assess the supportive care needs of the person and their whānau. Where appropriate, give them:

- access to investigations and care following referral, such as financial, transport and personal support
- help to deal with psychological and emotional distress – for example, anxiety, depression, interpersonal concerns, and adjustment difficulties to a potential diagnosis of cancer
- information regarding supportive services that they can engage with at a time suitable to them
- referrals to kaupapa Māori and Whānau Ora services at their request.

3.5.1 Communication with the person/whānau receiving care

Health providers/professionals

- Provide information regarding their role in the health care team.
- Explain who the person and their whānau is being referred to, the reason for the referral and the expected timeframes for appointments.
- Explain the need for the person and their whānau to return to the GP if signs and symptoms change while waiting for investigations and/or assessment.
- Request that the person notify the delegated clinic or their own GP practice if the specialist has not been in contact within the expected timeframe.
- Discuss the range of services available (including private), referral options, and any costs associated with accessing these services.
- Inform the person and their whānau that they can contact or request a referral to NGOs, including the Cancer Society and head and neck cancer support groups, that provide supportive care, including local Māori health service providers and/or professionals.
- Give written and verbal information regarding planned investigations and referral services.
- Clarify that the person and their whānau understands the information that has been communicated.

> ***"Whānau face multiple barriers to primary care". "That safety net had been taken away."***
> Person/whānau insights

Communication between health services

- Include relevant information in referrals, as identified in Steps 3.3 and 3.4.
- Notify the referrer of the acceptance of referral and expected timeframes to be seen or decline of referral and reasons for decline.
- Notify changes in referral status (either changes to symptoms or wait time changes).
- Ensure roles and responsibilities are understood, including GP/lead clinician responsible for checking and notifying results to the person and their whānau.
- Acknowledge receipt of referrals.

3.6 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

For a high suspicion of cancer and where the triaging clinician believes the referral is urgent, the person will begin the 62-day FCT pathway.

Early detection through primary care that identifies a high suspicion of cancer and requires an urgent referral to specialist will be seen **within 2 weeks**. The following FCT business rules will apply:

- **31-day Health Target -** All people will receive their first cancer treatment (or other management) within 31-days from decision to treat. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat. (**FCT business rules**, 2023).
- **62-day indicator** – All people with a high suspicion of cancer (without a confirmed pathological diagnosis of cancer at referral) will receive their cancer treatment within 62-days from date of referral. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.

Step 4: Diagnosis, staging and treatment planning

This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment in discussion with the person and their whānau.

Health services work with the person and their whānau to diagnose and stage the cancer, provide treatment options and recommendations, and help meet any identified needs. This generally occurs in secondary or tertiary health care services. Assessment and investigation results, including discussions between the appropriate multidisciplinary team members and the person and their whānau, will help to determine the treatment options recommendations and plan.

4.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- prioritising access for Māori to diagnostics, staging, and treatment planning
- supporting the person and their whānau to access holistic care, including mātauranga Māori traditional practices and emotional and spiritual support to complement medical treatment
- talking with the person and their whānau and clinicians about current or intended use of rongoā or other complementary therapies to understand the potential benefits, risks and/or other implications
- consultation with the person and their whānau regarding what they would like to happen to any bodily tissue or organs removed as part of their diagnostic workup and treatment.

4.2 Specialist investigations (diagnostic work up for head and neck cancer)

Where possible the diagnosis of cancer is established or confirmed before treatment is planned. The specialist, either before or after taking a medical history and making a medical examination of the person, may request additional investigations. This may be before or after the first specialist appointment.

Following triaging in secondary care, the head and neck team immediately refer people for the appropriate examinations. At this stage, the focus is on diagnosing people that have a malignancy and then staging their disease. The FSA with the specialist may come after initial investigations are undertaken.

The order of diagnostic investigations may vary depending on local facilities and protocols. The emphasis is to gain a tissue diagnosis promptly along with information to guide treatment planning as soon as practical.

Examinations include:

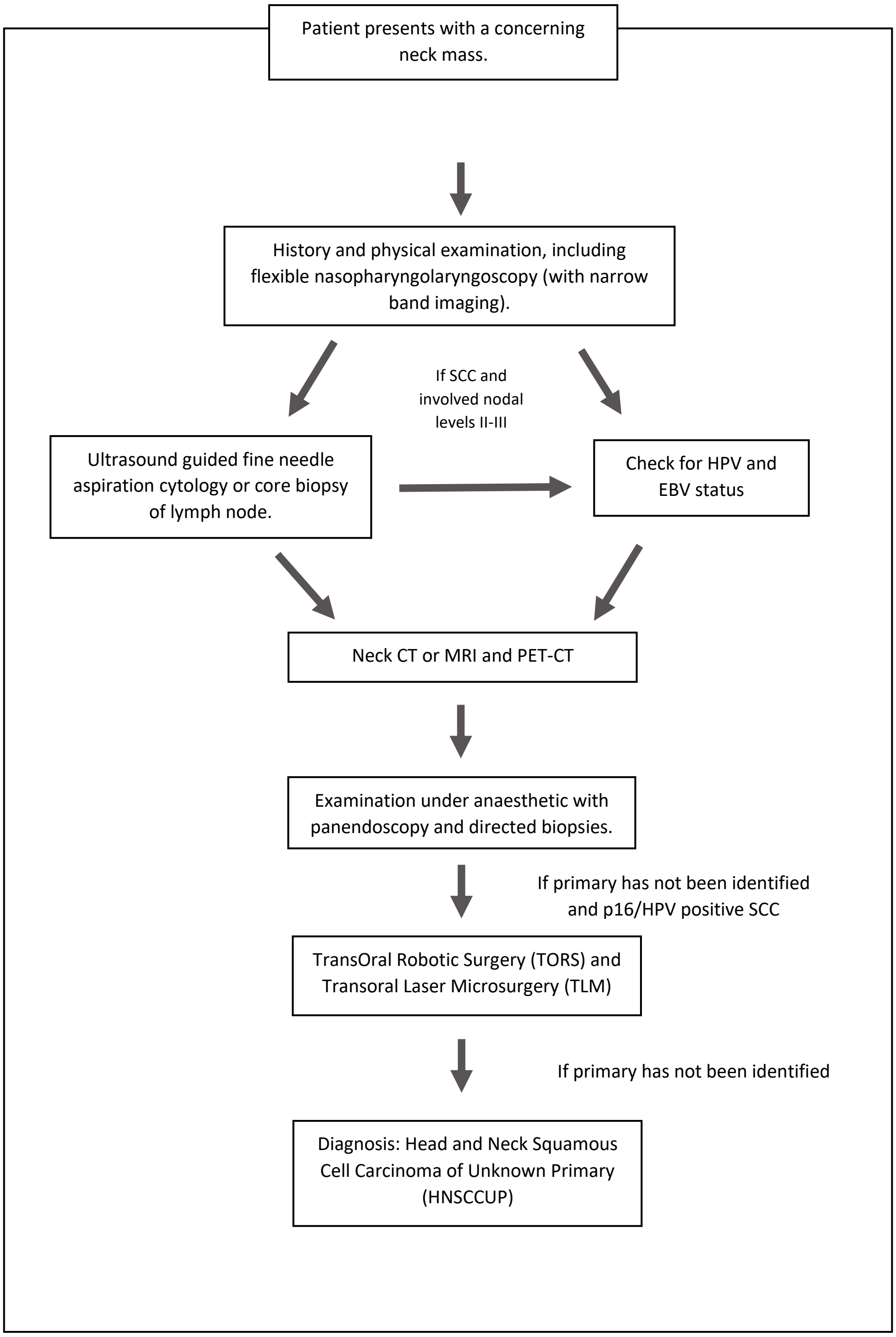
- a full clinical history including risk factors
- complete head and neck examination, including fiberoptic nasopharyngo-laryngoscopy, skin inspection where necessary and baseline function assessment e.g., swallowing

- ultrasound assessment with or without guided biopsy may be used as an initial investigation prior to assessment or referral
- biopsy of primary tumour:
    - this may be undertaken in clinic (or under general anaesthetic where necessary)
    - biopsy of laryngeal and pharyngeal lesions with trans nasal oesophagoscopy or a channeled flexible laryngoscope offers a safe and effective means of gaining a histological sample in out-patients, avoiding general anaesthetic in a significant proportion
- biopsy of neck mass
    - where a fine-needle aspiration cytology or core-biopsy is undertaken, there is compelling evidence for the use of ultrasound guidance to improve diagnostic accuracy.

Notes on diagnostic investigations

- The use of one-stop clinics is encouraged to limit the number of appointments a person may require.
- Adequacy check and rapid on-site evaluation of biopsies by a pathologist can reduce pathway delays due to reducing nondiagnostic sampling rates and achieving same-day diagnosis, speeding up subsequent steps on the diagnostic or staging pathway.
- Whilst diagnostic imaging prior to biopsy may be preferable to avoid post-biopsy distortion of anatomy, the impact of imaging after the biopsy on accurate disease staging is inconclusive. It is recognised that diagnostic time pressures may impact upon the pathway.

Recommended Diagnostic Algorithm



Investigation of the Unknown Primary

A clinical and radiological unknown primary tumour occurs in around 5% of people diagnosed with HPV-associated oropharyngeal head and neck squamous cell carcinoma. People over the age of 40 presenting with a cystic neck mass should be suspected as having a head and neck malignancy until proven otherwise.

Key components of the diagnostic work-up of an unknown primary head and neck squamous cell carcinoma:

Non-invasive work-up

- History and physical examination, including in-office flexible nasopharyngolaryngoscopy with Narrow Band Imaging
- Imaging studies
    - CT/MRI
    - FDG-PET/CT

Invasive work-up

- Exam under anaesthesia with panendoscopy and biopsies
    - Directed biopsy of abnormal findings
    - Transoral surgery (TORS/TLM)

Pathologic tissue evaluation

- p16 status
- Epstein-Barr virus status

Notes on best practice:

- Perform all radiological investigations that aim to identify the primary site prior to discussion at the head and neck MDT and before diagnostic surgery
- Offer nasopharyngeal biopsies when the cervical node sampling reveals Epstein–Barr virus positive metastasis
- Do not offer biopsies of clinically and radiologically normal upper aerodigestive tract mucosa. This excludes tonsillectomy or tongue base mucosectomy
- Offer ipsilateral tonsillectomy (rather than incisional biopsy) in all patients
- Consider ipsilateral tongue base mucosectomy in all patients
- Consider contralateral tonsillectomy (rather than incisional biopsy) in all patients
- Consider contralateral tongue base mucosectomy in all patients
- Perform tongue base mucosectomy using one of the following transoral techniques, when indicated: endoscopic, microscopic or robot assisted.

4.3 Staging (and preplanning assessments)

Accurately staging cancer helps guide treatment decisions and is a significant contributor to providing a cancer prognosis (Te Aho o Te Kahu 2021a). When cancer is diagnosed, additional investigations are often conducted to establish how much the cancer has grown and if, and how far, it has spread. The following additional tests may be required:

- examination under anaesthetic - when examination under anaesthesia and biopsy is required, a panendoscopy, examination of all the upper aerodigestive tract (oral cavity, pharynx, larynx, and cervical oesophagus), should ideally be performed, although the detection rate of second primary malignancies is very low through this
- structural imaging to evaluate the primary site, regional lymph nodes and sites of possible distant metastases – see Table 1 for CT/MRI imaging recommendations. For PET-CT scans (see Health New Zealand | Te Whatu Ora National Indications for Publicly funded PET-CT.

Table: summary of recommended MRI / CT imaging for Staging

Site	Primary tumour	Neck	Thorax*
Oral cavity	MRI ± CT for mandible	MRI or CT	CT
Oropharynx	MRI	MRI	CT
Larynx	MRI or CT	MRI or CT	CT
Hypopharynx	MRI	MRI	CT
Nasopharynx	MRI ± CT	MRI	CT
Sinonasal	CT & MRI	MRI	CT
Salivary gland	MRI ± CT	MRI ± CT	CT
CUP	MRI	MRI	CT

MRI = magnetic resonance imaging; CT = computed tomography; CUP = carcinoma of unknown primary

The following additional assessments may be required:

- dental: including dental assessments, minor oral surgery (biopsy and dental extractions) and dental radiology, the latter to include the minimum of a Dental Panoramic Tomogram (DPT) but where possible to include access to intra-oral radiographs
- laboratory: blood tests
- holistic needs assessment
- nutritional assessment.

To note, pathological staging may occur after surgery for some cancers.

Timeframe for completing diagnosis and staging investigations

Investigations should be completed **within 28 days** of referral for specialist assessment.

Referral to head & neck cancer nurse **within 1 week** of definitive cancer diagnosis.

4.4 Performance status

Performance status is assessed to inform prehabilitation and treatment recommendations and documented using the Eastern Cooperative Oncology Group (ECOG) Performance Status Scale (ECOG-ACRIN Cancer Research Group, nd). The degree of benefit of treatment for an individual may vary according to diagnostic, staging and prognostic factors and performance status.

In older people with cancer, a geriatric assessment measures their level of fitness and treatment tolerability. People over the age of 70 years should undergo some form of geriatric assessment (COSA 2022). Screening tools can be used to identify those who will benefit most from these comprehensive assessments.

Geriatric assessments can support tailoring the oncologic treatment plan, address any issues found with the multidisciplinary team, and provide interventions to optimise the person's general health status (Seghers et al 2023).

4.5 Clinical genetics

There is currently no established role for germline genetic testing for most head and neck cancers.

Nasopharyngeal carcinoma has a higher incidence in Pacific and Māori populations as well as those of Chinese and Southern European background, but there is no genetic test to identify specific individuals at risk.

Where the MDM suspects, a rare tumour is linked to a genetic condition there should be facilities and a pathway to access genetic testing.

Referral to clinical genetic services for head and neck cancer is considered if features of the cancer suggest a genetic predisposition, such as:

- early age onset
- immunohistochemistry (if available)
- multiple primary cancers.

For further information see the Genetic Health Service New Zealand website (**genetichealthservice.org.nz**).

4.6 Multidisciplinary meeting

Optimal cancer care requires a multidisciplinary approach to tailor treatment plans to the person's needs in collaboration with their whānau and the health care team.

Referral to head and neck cancer MDM following nationally agreed referral criteria is undertaken to inform treatment recommendations or further assessment and investigation. All people diagnosed with head and neck cancer (excluding T1,2 N0 cutaneous) are assessed at a dedicated head and neck MDM for staging and treatment planning, according to agreed national and local protocol. Further MDMs should take place at different stages during a cancer journey, including:

- after surgery, to discuss histopathology and options for post-operative adjuvant treatment
- after primary chemoradiotherapy, where there is concern for residual disease on post-treatment imaging

- for suspected or confirmed recurrence, or second primary cancers, after initial diagnosis and treatment

It is recommended that, as a minimum, the MDM should consist of the following professionals with specialist interest in head and neck cancer:

- appropriately trained head and neck surgeons (at least 2), at least one of whom should have specialist head and neck reconstructive skills
- radiation oncologist (with head and neck expertise)
- medical oncologist (with head and neck expertise)
- clinical nurse specialist, cancer nurse coordinator, navigators
- Speech and Language Therapist (SLT)
- dietitian
- histopathologist and cytopathologist
- radiologist
- restorative dentist.

At the MDM:

- multidisciplinary team discusses complex cancer cases and recommends a treatment plan
- results of all relevant tests and access to images must be available for the MDM
- information about the person and their whānau, their overall condition, co-morbidities, personal preferences, and social and cultural circumstances must be available for the MDM
- level of discussion may vary, depending on the person and clinical and supportive care factors
- proposed treatment plan will be recorded in the person's medical record and MDM database, and communicated to the referrer and primary care provider within 2 days of the MDM
- lead clinician and/or team discusses the recommendations from the MDM with the person and their whānau **within 1 week** of the MDM so they can take part in decision-making about ongoing treatment and care.

MDMs are managed and guided by the following standards:

- ***Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand*** (Te Aho o Te Kahu 2024)
- ***HISO 0038.4:2021 Cancer Multidisciplinary Meeting Data Standard*** (Te Aho o Te Kahu 2021b)

To facilitate early, ongoing, and integrated input by the wider multidisciplinary team, people with head and neck cancer should be reviewed in a multidisciplinary clinic (often concurrent with the MDM) in which the following clinicians can provide input for each person depending on their needs in one visit:

- primary clinician(s) (surgical or oncological) offering prime treatment or explaining treatment options
- clinical nurse specialist or cancer nurse coordinator whose role is diverse and may include:
    - co-ordinating and signposting care, advice, information, and support for people with head and neck cancer and their whānau, from diagnosis through treatment planning, treatment, and care after treatment.
    - providing clinical care including wound management, airway management, feeding, etc

    - providing expert advice to primary care physicians, district nurses, specialist palliative care teams
- allied health professionals – most often it is speech language therapists and dietitians involved in these clinics. Involvement of social work, psychology, physiotherapy, occupational therapy may also be required at this stage depending on the needs of the person
- dental assessment including orthopantomogram X-ray
- anaesthetic assessment (ideally) for people needing surgery
- clinical trial nurse if clinical trial option is available.

It is important that the person is well supported at clinics where there are multiple clinicians in attendance and procedures undertaken. The person is encouraged to bring whānau support and one of the clinical team should be identified to provide support and advocacy for the person and whānau. This role could be undertaken by the CNS, cancer nurse coordinator or cultural support provider (navigator).

4.6.1 Treatment options and recommendation

Following MDM, treatment intent is discussed with the person and their whānau. Treatment intent ranges from curative, non-curative, symptom palliation and palliative care.

Treatment, referral options and recommendations are discussed with the person and their whānau to enable informed decision-making in accordance with their rights and ability to exercise independence, choice, and control. The advantages and disadvantages of recommended treatments and associated potential side effects are discussed in plain language with interpreter support as required. Other support may be required for this discussion such as kaumātua/kuia, chaplain and nursing staff as required.

Further discussion between health services (primary care and specialists) and the person and their whānau will ensure comorbidities are well managed. This optimises the person's health to be able to cope with the proposed cancer treatment and its effects.

4.6.2 Fertility preservation

A referral to fertility preservation alongside a contraception assessment and advice should be discussed with the person and their whānau dependent on age and the treatment planned. An early, collaborative, and multidisciplinary approach with the person is undertaken, which maximises the opportunity for best practice contemporary care and consideration for future fertility.

4.6.3 Prehabilitation (also see 5.2)

Prehabilitation (preparing for treatment) is the process of optimising a person's overall wellbeing prior to undergoing cancer treatment. Ideally, prehabilitation should begin as early as possible after a cancer diagnosis to allow adequate time for interventions to take effect. A nominated service provider is tasked with coordinating prehabilitation.

For people with head and neck cancer, prehabilitation uses a multidisciplinary approach to prepare people for the challenges of cancer treatment. Team members may include anaesthetists, oncologists, surgeons, haematologists, dentists, clinical nurse specialists, cancer nurse coordinators, clinical psychologists, exercise physiologists, physiotherapists, speech-language therapists, dietitians, and cultural support, among others.

Early involvement of the wider multidisciplinary team is important to maximise a person's functional outcomes and quality of life.

Prehabilitation is initiated and assessed by primary or hospital services and may require referral to additional services for example:

- dental assessment before beginning treatment including developing a preventative dental plan
- voice rehabilitation – especially for those undergoing major laryngeal procedures
- early identification and management of dysphagia and odynophagia with speech and language therapist input
- optimisation of nutrition with dietetics input
- smoking cessation
- drug and alcohol counselling
- medications review to ensure optimisation and correct adherence
- rongoā practitioners
- psychosocial (distress screening)
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for person and their whānau preparing for surgery.

4.6.4 Clinical trials

Where eligible, the person with cancer is offered and supported to participate in research or clinical trials. Many emerging treatments are only available as clinical trials and may require referral to specific trial centres.

4.7 Supportive care and communication

4.7.1 Care coordination

Care coordination supports the navigation through diagnosis, staging, and treatment planning. The person and their whānau receive tailored education and are enabled to ask questions, seek further clarity around treatment options and recommendations, and gain support around the potential next steps in the pathway. The care coordinator will assist in the coordination and navigation of care, support the person and their whānau, and complete any additional referrals that may be required.

People and their whānau who have someone coordinating their care are often more satisfied with the opportunities provided to them and the decision-making process about their care (Cancer Institute NSW 2010).

The person and their whānau will have a clear understanding of what to expect at each step of the cancer pathway, with a clear point of contact should they require support or further information (refer to Principle 6).

4.7.2 Supportive Care

Assess the supportive care needs of the person and their whānau, including:

- care coordinator/or equivalent is in place
- prehabilitation
- contraception and fertility support
- early referral to palliative care
- information and education needs are met (Step 3.5).

"A lot of people need to travel hours to get to an appointment and don't have vehicles or family support."
Person/whānau insights

4.7.3 Communicating with the person/whānau receiving care

Health providers/professionals

- Ensure that person and their whānau have the option to have additional support people with them when having discussions.
- Explain and discuss with person's diagnosis, staging and treatment options and recommendations in plain language.
- Discuss the advantages and disadvantages of treatment options and associated potential side effects.
- Provide information, education support and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.
- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the person and their whānau have understood the information that has been communicated.
- The person and their whānau may require time to process the information that has been relayed, prior to consenting to treatment.
- Coordinate scheduling of appointments with the person and their whānau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whānau the need to update or complete their advance care planning and/or advance directive.

Communicating between health services

- Coordinate appointments among health services, in discussion with the person and their whānau to make best use of their time and resources and to support access.
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.
- Discuss and agree shared care arrangements, in symptom and co-morbidity management, supportive care and referral to local services.
- Confirm the lead clinician and provide handover details as necessary.

4.8 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

The route to diagnosis determines the FCT pathway that a person will be on.

- **Te Aho o Te Kahu Quality Performance Indicators**
  - Route to diagnosis: People diagnosed with cancer within 30-days of an emergency or acute (unplanned) hospital admission (Te Aho o Te Kahu, 2024).
- **Faster Cancer Treatment**
  - **31-day Health Target -** to meet the 31-day Health Target, the MDM, person and their whānau agree to treatment as soon as possible following MDM.

  - **62-day indicator** – If a person does not attend MDM within 28 days, they are unlikely to meet the 62-day pathway.

- **MDM Standards**

For audit compliance with standards and standards audit tool the following may be used:

  - ***Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand*** (Te Aho o Te Kahu 2024)
  - ***HISO 0038.4:2021 Cancer Multidisciplinary Meeting Data Standard*** (Te Aho o Te Kahu 2021b)

Step 5: Treatment

This step describes publicly funded optimal treatments for head and neck cancer by trained and experienced clinicians and team members, in an appropriate environment.

The treatment of head and neck cancer is informed by the following guidelines:

- National Comprehensive Cancer Network (US) clinical practice guidelines in oncology: head and neck cancers **nccn.org/guidelines/guidelines**
- European Society for Medical Oncology's clinical practice guidelines: head and neck cancers **esmo.org/guidelines/guidelines-by-topic/head-and-neck-cancers**
- Clinical Oncology Society of Australia's evidence-based practice guidelines for the nutritional management of adult patients with head and neck cancer **cancer.org.au/clinical-guidelines/head-neck-cancer**
- British Association of Head & Neck Oncologists. 2020. BAHNO Standards **bahno.org.uk/_userfiles/pages/files/final_bahno_standards_2020.pdf**
- The Journal of Laryngology & Otology. 2024. Head and Neck Cancer: United Kingdom **National Multidisciplinary Guidelines**, Sixth Edition
- NZ Formulary Systemic Anticancer Therapy Regimen Library **srl.org.nz/regimens**
- **Radiotherapy Dose Fractionation** – fourth edition, The Royal College of Radiologists United Kingdom
- The Royal College of Radiologists head and neck **consensus statements**

5.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through ensuring that:

- services achieve equity of access and outcomes irrespective of where treatment occurs
- equity in access to treatment is facilitated through active and coordinated support of financial and social barriers to treatment
- tikanga Māori and rongoā is integrated and applied in discussion with treating clinicians
- a referral to the Kia Ora E Te Iwi (KOETI) programme (Cancer Society) occurs as required
- the person and their whānau have all the information and resources to support their mana motuhake (empowerment).

5.2 Treatment intent

The treatment intent should be established in a multidisciplinary meeting/setting (see Step 4.6), documented in the person's medical record, and shared with the person and their whānau as appropriate. Discuss the advantages and disadvantages of recommended treatments and associated side effects in plain language to support the person and their whānau to make an informed decision. If there is more than one suitable treatment option, services could facilitate the decision making of the person and their whānau by having all specialties involved in the single appointment.

Timeframes for starting treatment are informed by evidence-based guidelines where available. The treatment team recognises that shorter timeframes for appropriate consultations and treatment often provide a better experience for people.

Confirm decisions, and consent for treatment. If treatment is agreed, develop a treatment care plan that includes:

- what the treatment and intent is, alongside likely impacts
- ways to improve health outcomes and wellbeing during treatment, this includes where they can receive support and information
- expected timeframes.

5.2.1 Additional considerations

Undertake a needs assessment and address any possible barriers or challenges (such as financial, social, care coordination and cultural obligations) that may prevent the person and their whānau from accessing treatment.

Initiate advance care planning discussions with the person and their whānau before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive).

Ensure prehabilitation is underway to optimise treatment outcomes, and management of comorbidities, ahead of treatment (see section 4.6.3). Assess the current prehabilitation plans and modify as required dependent on the treatment decided.

Formally involving the palliative care team/service early can benefit the person receiving care, so it is important to know and respect each person's preference.

The person's current or intended use of any traditional or complementary therapies, including rongoā, will need to be discussed.

Information resources should be provided so the person and their whānau can review and take these away for further reflection and sharing, including contact information for services and key care coordinators.

If initial treatment is declined, discuss next steps fully with the person and their whānau. This includes the option to re-engage with initial treatment if they change their minds, with the understanding it may no longer be viable and/or suitable.

Ensure an escalation plan with key contact people is developed if the person becomes unwell before treatment begins.

5.3 Treatment options

The type of treatment recommended for head and neck cancer depends on the type, stage and location of the cancer and the person's age, health, and preferences.

Treatment may include a combination of the items listed below, concurrently, or sequentially, to maximise optimal outcome. The person may also be supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centres.

- **Observation**. For example, monitoring the tumour/disease may be more appropriate than proceeding with interventional treatment.

- **Surgery.** Surgery can be used as the primary treatment of a number of head and neck cancers with curative intent. It can be used to salvage residual or recurrent disease or in the palliative management of some people. People at high risk of locoregional recurrence will also benefit from adjuvant postoperative radiation treatment.

People suitable for surgery please refer to the Capability Requirements for Complex Surgery in Aotearoa New Zealand – Head and Neck (Te Aho o Te Kahu 2024)

- **Systemic anti-cancer therapy.** Systemic therapy, concurrent with radiation therapy, can be used as the primary curative treatment or as an adjuvant treatment for several head and neck cancers. It has been shown to improve local control and add a survival benefit compared with radiation therapy alone in a high-risk person with good performance status. Neoadjuvant systemic therapy (before radiation therapy) is also appropriate in a small number of clinical scenarios. Targeted biological agents and immunotherapy are the standards of care for some recurrent head and neck cancers. Systemic therapy is also used in palliative treatment.
- **Targeted therapies and immunotherapy.** Any decision on the use of targeted and immune therapies should include input from a medical oncologist and the person. For many people, access to clinical trials should always be considered.

People suitable for systemic anti-cancer therapy (SACT) please refer to The Model of Care for Adult Systemic Anti-Cancer Therapy Services in Aotearoa, New Zealand (Te Aho o Te Kahu 2024).

- **Radiation therapy.** Radiation therapy can be used as the primary curative treatment of several head and neck cancers and may be given concurrently with systemic therapy. It can be given following surgery (postoperatively) for people at high risk of locoregional recurrence. It is also useful in palliative care. The person should have access to a dietitian and a speech-language therapist within the radiation therapy centre, who should liaise closely with their counterparts in the person's local support team. Outcomes are improved for the person receiving curative radiation therapy for head and neck cancers when they are treated by radiation oncologists who have larger head and neck cancer caseloads.

People suitable for radiation therapy please refer to The Radiation Oncology Model of Care (Te Aho o Te Kahu 2024).

- **Palliative care -** Palliative care is an integral part of cancer treatment and care. It offers specific assessments, supportive care, programmes, and services focused on living with and dying from cancer.

Early referral and access to palliative care is a critical aspect of best practice. The person and their whānau who cannot be offered curative treatment, or declines curative treatment, as well as those with a significant symptom burden, should be offered prompt access to palliative care services. Early referral to palliative care can improve the quality of life for people with cancer and in some cases may be associated with survival benefits. This is particularly true for cancers with poor prognosis.

Timeframes for starting treatment

Surgery should be scheduled **within 4 weeks** of the MDM.

Time from definitive surgery to beginning adjuvant treatment (plus concomitant systemic therapy when indicated) should be **not more than 6 weeks**. Where adjuvant treatment is not commenced within 6 weeks the reason should be documented by the MDM.

If radiation therapy or systemic therapy is the primary treatment modality at the time from the MDM to starting treatment, it should begin **within 4 weeks** for curative intent and **within 2 weeks** for palliative intent.

If systemic therapy is being used concurrently with radiation therapy, it should begin **within 1 week** of radiation therapy.

Radiation therapy as an adjuvant treatment should begin **within 6 weeks** after surgery.

Treatment includes managing the impact of cancer therapy, including the management of physical symptoms, distress, and other clinical issues a person and their whānau may experience. Once treatment commences, people with head and neck cancer may require additional support from wider members of the multidisciplinary team, who have specialist knowledge of head and neck cancer care, to help manage:

- emotional and psychological issues, including body image concerns, fatigue, quitting smoking, traumatic experiences, existential anxiety, treatment phobias, anxiety, depression, interpersonal problems, and sexuality concerns.
- support to cope with potential isolation from normal support networks, particularly for rural people who are staying away from home for treatment. This may require the input of the psychosocial care team
- physical symptoms such as pain and fatigue
- oral side effects of head and neck cancer treatments, which may require input from a specialist dentist
- malnutrition, which can occur because of disease or treatment, validated by malnutrition screening tools (MST), should be used at the key points in the care pathway to identify people at risk of malnutrition and refer to a dietitian for early nutrition intervention (all people with a head and neck cancer diagnosis receiving radiation therapy should be referred to a dietitian for assessment and intervention)
- nutrition intake (oral diet and enteral feeding), weight loss and symptom management through dietary counselling
- oropharyngeal dysphagia, trismus, or speech and/or voice changes requiring the involvement of a speech language therapist, particularly critical for people who have had a laryngectomy
- postoperative respiratory function, including secretion management, particularly in the case of laryngectomy or temporary tracheostomy requiring the involvement of physiotherapy
- musculoskeletal changes such as shoulder and neck pain or dysfunction following treatment requiring the involvement of physiotherapy
- lymphoedema requiring the involvement of therapist trained in lymphoedema management
- fatigue/endurance requiring the involvement of occupational/vocational therapy
- occupational therapy or psychology support for social skills training and/or a social worker for whānau liaison to help to reduce psychosocial difficulties
- changes in physical appearance that impact on social and mental wellbeing, including changes in facial appearance which may require referral to a prosthetics specialist
- a decline in mobility or functional status as a result of treatment, including difficulties with activities of daily living requiring the involvement of occupational therapy
- assistance with beginning or resuming regular exercise with involvement of a physiotherapist or exercise physiologist (access to an exercise physiologist may be via a referral to a cancer NGO).

5.3.1 Clinical Trials

The person is supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centers (refer principle 8).

5.4 Treatment summary

A treatment summary will be provided by the treating service for the person and their whānau and clinicians involved in their follow up care, including primary care. The summary includes:

- relevant diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals
- potential long-term and late effects of treatment
- supportive care services provided
- recommended follow up and surveillance.

5.5 Supportive care and communication

- Supportive care needs for the person and their whānau are assessed for all cancer treatment modalities, including surgery, chemotherapy, radiation, and palliative care.

Assess challenges and changes in health status that may arise for the person and their whānau due to their treatment, including:

- general health care issues (such as smoking cessation and sleep disturbance), which can be referred to a general practitioner
- altered cognitive function due to chemotherapy or radiation therapy, which requires strategies such as maintaining written notes or a diary and repetition of information
- loss of fertility, sexual dysfunction or other symptoms associated with chemically induced menopause, which requires sensitive discussion and possible referral to a clinician skilled in this area
- management of physical symptoms such as pain, arthralgia, and fatigue
- early management for acute pain postoperatively to avoid chronic pain
- side effects of chemotherapy such as neuropathy, cardiac dysfunction, nausea, and vomiting – managing these side effects is important in protecting the person's quality of life
- managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- disfigurement and scarring from appearance-altering treatment (and possible need for a prosthetic) – referral to a specialist psychologist, psychiatrist or social worker may be required
- hair loss and changes in physical appearance – referral to Look Good Feel Better
- assistance with beginning or resuming regular exercise – referral to an exercise physiologist or physiotherapist, including specialist programmes offered by cancer NGOs.

The person and their whānau may also need to manage:

- financial issues related to loss of income (through reduced capacity to work or loss of work) and additional expenses as a result of illness or treatment
- advance care planning, which may involve appointing a substitute decision-maker and completing an advance care directive

- legal issues (completing a will, care of dependent children) or making an insurance, superannuation or social security claim based on a terminal illness or permanent disability.

5.5.1 Care coordination

Care coordination will support the person and their whānau through treatment. The care coordinator supports the implementation and activation of supportive care needs through the provision of information, education and referral regarding the concerns and issues that have been raised by the person and their whānau (refer Principle 5).

It is acknowledged that, due to the complexity managing head and neck cancers, care is frequently provided in specialist centres. This provides challenges and needs to be considered as part of the ongoing care requirements.

5.5.2 Communication with the person/whānau receiving care

Health providers/professionals

- Confirm lead clinician and other treatment teams/members involved in care.
- Advise the person and their whānau of the expected timeframes for treatment and ensure they have a key contact person.
- Clarify that the person and their whānau understand the information that has been communicated.
- Refer the person to supportive care and other health care services to optimise wellbeing.

"A whānau need to have a choice of services including rongoā, mirimiri etc. and know how to access tohunga, particularly for whānau who may be disconnected from te ao Māori"
Person/whānau insights

Communication between health services

- Confirm the lead clinician and handover as necessary.
- Confirm the diagnosis, treatment intent, recommendations, and plan, including potential side effects.
- Communicate supportive treatment plan and referrals between health services.
- Advise of any enrolment in clinical trial as appropriate.
- Advise of changes in treatment or medications.

5.6 Measuring and monitoring

Monitoring and measuring are key components of contemporary best practice. Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

For those who have started on the FCT pathway, the FCT wait time indicators will apply. FCT applies to a person's first cancer treatment of a new cancer.

- **Faster Cancer Treatment**
    - **31-day Health Target** –90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat.
    - **62-day indicator** –90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.

- **Medical oncology treatment timeframes**
  - Category A – urgent within 48 hours
  - Category B – semi-urgent within 2 weeks
  - Category C – routine within 4 weeks
  - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).

- **Radiation oncology treatment timeframes**[5]
  - Category A – treat within 24 hours.
  - Category B – treat within 10 working days.
  - Category C (palliative intent) – treat within 10 working days
  - Category C (curative intent) – treat within 20 days.
  - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).
  - Category E (benign disease) – treat within 80 working days.

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[5] Radiation Oncology Waitlist Data Business Rules – Te Whatu Ora

Step 6: Care after treatment

The person accesses appropriate follow up and surveillance and is supported to achieve their optimal health after cancer treatment.

The transition from active treatment to care after treatment is critical to supporting long-term health. Survivorship care planning is the umbrella term for care described in this step, and whilst aspects of this care begin at diagnosis (prehabilitation, supportive care, etc) the term itself is not often used until this part of the pathway.

In some cases, people will need ongoing specialist care, and in other cases a shared follow up care arrangement with their general practitioner may be appropriate. This will be informed by the type and stage of a person's cancer, the treatment they have received and the needs of the person and their whānau (refer Principle 5).

The following references inform care after treatment for the person with head and neck cancer:

- The Cancer Survivorship in New Zealand - Consensus statement **cancer.org.nz/about-us/latest-news/cancer-survivorship-concensus-statement**
- The Journal of Laryngology & Otology. 2024. Head and Neck Cancer: United Kingdom **National Multidisciplinary Guidelines**, Sixth Edition.

6.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- offering options for holistic recovery and wellness care within hauora Māori models of care
- providing access to clinical, psychological, social, financial, and cultural support to transition back into recovery and life after cancer treatment
- offering options for holistic recovery and wellness care within hauora Māori models of care
- provide access to clinical, psychological, social financial and cultural support to transition back into recovery and life after cancer treatment.

6.2 Survivorship care planning

After completing initial treatment, a designated member of the multidisciplinary team (most commonly nursing or medical staff involved in the person's care) should undertake survivorship care planning with the person and their whānau.

The survivorship care plan should cover, but is not limited to:

- the provision of a treatment summary
- information on what medical follow up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information
- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment
- information about wellbeing and primary and secondary prevention health recommendations that align with chronic disease management principles (Step 1)
- rehabilitation recommendations and any referrals

- available support services, including cancer NGO survivorship programmes/services (these may be tumour specific)
- signs and symptoms to be aware of that may indicate the cancer has recurred
- the process for rapid re-entry to specialist medical services.

As people are often followed up for five or more years after treatment, this plan needs to be regularly reviewed and updated to reflect changes in the person's clinical and psychosocial status. All health providers involved in the follow up care are responsible for updating the care plan.

6.3 Treatment summary

A treatment summary will be provided by the treating service(s) to the person and their whānau and to those clinicians involved in follow up care.

The summary includes:

- the diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received (types and dates)
- current toxicities (severity, management and expected outcomes), including who to contact should they have any concerns about these
- interventions and treatment plans from other health providers
- potential long-term and late effects of treatment.

6.4 Rehabilitation and recovery

Rehabilitation may be required at any point in the care pathway. Issues that may need to be dealt with at this stage include managing cancer-related fatigue, coping with cognitive or physical changes, returning to study or work, and ongoing adjustment to cancer and its sequelae. Due to their anatomical location, head and neck tumours and their treatment result in significant morbidity, including problems with speech and voice, swallowing, pain, and disfigurement.

For people with head and neck cancer, many of the services that have been initiated to support people to prepare for treatment and then to manage treatment associated challenges continue to be relevant in this step (see sections 4.6.3 and 5.3). Ongoing care and support from allied health and nursing, with specialist head and neck cancer knowledge, to maximise functional outcomes and quality of life for people who have had treatment for head and neck cancer is important in the recovery and survivorship phase.

The treatment centre will coordinate post treatment care in the early stages of recovery and make referrals to other service providers as and when appropriate.

Dental care after treatment

Dental rehabilitation services for people who have had treatment for their head and neck cancer is not currently fully covered by the public health system. Treatment related care including dental surgery, dental implants and clinic visits are covered including if a maxillofacial prothesis is required. The provision of dentures is currently not covered in New Zealand.

Preventing recurrence includes not smoking, eating a healthy diet, being sun smart, avoiding or limiting alcohol intake, being physically active and maintaining a healthy body weight may help reduce the risk of primary recurrence or a second primary cancer.

Encourage and support all cancer survivors to reduce modifiable risk factors for recurrence as well as other chronic diseases. Ongoing coordination of care between providers should also deal with any comorbidities, particularly ongoing complex and life-threatening comorbid conditions.

6.5 Follow up and surveillance

Follow up and surveillance can have multiple functions, including:

- evaluation of treatment response
- early identification of recurrence
- early detection of new primary tumours
- monitoring and management of complications
- optimisation of rehabilitation
- provision of support to the person and their whānau.

Care after treatment is driven by predicted risks and an individuals' clinical and supportive care needs.

Care includes regular physical examinations and medical tests and is based on the medical guidelines for the specific type and stage of cancer, the treatment that's been received, and the needs and wishes of the person and their whānau.

Follow up for people who have had treatment for their head and neck cancer provides an opportunity to both assess symptom burden in the early phase after treatment, but also monitor for late and long-term effects. Examples of late effects include xerostomia, dysphagia, dental problems, osteoradionecrosis, and lethargy. Some late effects of treatment, such as dysphagia, may have a period of stability for several years before late deterioration. The wide range of morbidity experienced by head and neck cancer survivors demonstrates the need for a multidisciplinary input into follow up services.

For people with head and neck cancer, care is informed by the following:

- the person should undergo follow up on at least a 2-monthly basis for 2 years, then 3-6 monthly thereafter for a minimum of 5 years
- people should be able to access urgent clinical assessment for suspicious symptoms at any time during follow up
- follow up and clinical examination with imaging, if indicated, should aim to identify cancer recurrence as early as possible and to detect second primary tumours
- people should undergo follow up in clinics in the initial stages after treatment at, or linked to, a head and neck treatment centre, and have access to the wider multidisciplinary team (MDT), including clinical nurse specialists, speech and language therapists, and dietitians. Follow up may take place in regional units by suitably trained clinicians based on local cancer network agreements
- people receiving radiotherapy or chemoradiotherapy for stage 3 or 4 disease should undergo post-treatment surveillance imaging to assess for disease response, as well as for baseline imaging
- baseline imaging should be considered after primary surgery in which anatomy is altered
- people should undergo regular thyroid function monitoring after treatment for head and neck cancer

- if functional changes/new onset symptoms or worsening symptoms are identified at follow-up appointments that a referral to the appropriate member of the multi-disciplinary cancer care team should be made.

Planning needs to include:

- who will be providing follow up care for example, their specialists, their primary care provider (including palliative care) or if there will be a shared care approach (refer Principle 1). Generally, people will have at least one clinic visit with the specialist(s) involved in a person's treatment and care to date
- what tests (such as blood or radiological tests) need to be carried out, who is responsible for ordering them, how frequently they need to be done, and who will discuss the results with the person and their whānau
- the frequency people should be seen and for what timeframe.
- follow-up appointments are more frequent initially, becoming less frequent as time goes on.
- who the person and/or their whānau should contact if they have any concerns.

Note that for some people follow-up appointments are reassuring; however, for others this may be anxiety-inducing.

6.6 Signs and symptoms of recurrent disease

The likelihood of recurrence depends on many factors usually related to the type of cancer, the stage of cancer at presentation and the effectiveness of treatment. Educating the person and their whānau about potential symptoms of recurrence is critical for timely management.

Approximately 25% of people treated for head and neck cancer develop cancer recurrence, most of which is locoregional, and most recurrences occur within the first two years after treatment (HNC UK Guidelines 2024).

Signs and symptoms of residual disease. Symptoms can present as those previously outlined. For people treated with surgery, signs of residual disease may also include the tumour invading vital structures that cannot be resected or pathological examination identifying extensive involved margins.

For people treated with chemo and/or radiation therapy, signs of residual disease may include a clinically apparent tumour that increases in size during treatment or has not fully resolved within the timeframe expected for the specific tumour type. Diagnostic imaging evidence of residual disease on post-treatment scans may also be apparent. FDG-PET is particularly useful in assessing this.

Signs and symptoms or recurrent disease. Any recurrence of the symptoms that a person initially presented with or new symptoms (outlined in section 3.2) in the treated region should be thoroughly investigated as clinically indicated. Less commonly, the team providing surveillance in the post-treatment period may detect asymptomatic recurrence, often as a progressive mass or mucosal changes. Any new or unexplained clinical finding related to the treated area should be investigated as clinically indicated to determine if recurrent disease is present, especially when the potential to deliver additional treatment with curative intent exists.

Signs and symptoms of metastatic disease. Some people will have metastatic disease on initial presentation. Symptoms can present as those previously outlined.

6.6.1 Rapid re-entry to specialty services

Service providers have a process for rapid re-entry to specialty services via the regional referral pathway for suspected recurrence and advise the person and their whānau of how to do this if required.

Managing recurrent disease:
- consider curative, palliative, and supportive options for people with recurrent disease
- biopsy is required before active treatment and should include PD-L1 (programmed death-ligand 1) testing for immunotherapy
- the decision-making process is highly complex and requires multidisciplinary input
- people and their whānau should be aware of the prognosis, chance of treatment efficacy and complications when making decisions about possible treatment
- consider PET-CT before active treatment (see Health New Zealand | Te Whatu Ora National Indications for Publicly funded PET-CT).

Treatment will depend on the location, extent of recurrent or residual disease, previous management and the person's preferences and includes all options previously listed. The potential goals of treatment should be discussed, respecting the person's cultural values.

6.7 Clinical trials

Where eligible, the person with cancer is offered and supported to participate in research or clinical trials. These might include studies to understand survivor's issues, to better manage treatment side effects, or to improve models of care and quality of life.

6.8 Supportive care, care coordination and communication

As the person transitions from active treatment, their needs often change, and health providers need to support people and their whānau to cope with life beyond their active treatment. (refer Principles 5, 6 and 7.)

Health providers work with people and their whānau to assess and address their needs, including:

> ***"The need for care doesn't stop when treatment finishes." "Whānau feel forgotten when treatment ends."***
> Person/whānau insights

supportive care
Health providers undertake a needs assessment to inform the survivorship care plan and make appropriate referrals.

coordinated care
Follow up care is provided closer to home and appointments coordinated to make access easier for the person and their whānau, where possible.

Continuity of care is provided where possible and appropriate – for example, people and their whānau should have the ability to continue to be supported by members of the care coordination team who they have developed a relationship with during their journey.

effective and timely communication
The person and their whānau are provided with a copy of their survivorship care plan, including information on any referrals that have been made.

Health providers involved in the follow up care of an individual have access to the up-to-date care plan, especially if primary care is involved, and can update the plan as required.

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

Step 7: Palliative and end-of-life care

Palliative and end-of-life care provides the person facing life-limiting conditions with holistic support and coordinated services based on their specific needs.

Palliative and end-of-life care is an essential health service to optimise the person's quality of life until they die. This involves supporting the person's physical, psychosocial, spiritual, and cultural needs, and supporting their whānau with bereavement support. It is appropriate at any stage in a serious illness.

> **"You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only die peacefully, but also to live until you die."**
> Dame Cecily Saunders

7.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through ensuring that:

- the person and their whānau have the choice to access Kaupapa Māori support services for living with cancer (stable, progressive or end-stage)
- rurality does not restrict access to critical clinical, social, cultural and resource support for the person and their whānau
- palliative and end-of-life care is integrated across health services.

7.2 Palliative care

Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other symptoms, whether physical, psychosocial, or spiritual, and improves the quality of life (World Health Organisation 2020).

Palliative care should be provided by all health professionals. Palliative care uses a team approach with non-specialist services (primary care, community care and generalist hospital services) supported by specialist palliative care services (hospitals, hospices). Palliative care services must be integrated with primary, community and secondary care, responsive and locally appropriate.

In many cases the whānau are the primary caregivers, and it is the responsibility of health providers/professionals to support the whānau. Health and social service providers/professionals will work together to ensure that the care for the person and their whānau is seamless, and that resources are used efficiently and effectively.

Primary, secondary, and palliative care services work alongside the person and their whānau to decide an appropriate place of care and the support required to implement the advance care plan.

Palliative care is provided in different settings, depending on availability and the needs and preferences of the person and their whānau. Settings include:

- in the community/a person's own home
- aged residential care
- hospice care
- hospital care.

Palliative care is most effective when considered early in the course of an illness. Early palliative care not only improves quality of life for the person and their whānau but also reduces unnecessary hospitalisations and use of health care services.

Referral to specialist palliative care services will be appropriate for those with a level of need that exceeds the resources of the generalist palliative care provider. Referral criteria for adult palliative care services in New Zealand are available on the Ministry of Health | Manatū Hauora website.

Clinical trials may improve palliative care and support the management of a person's symptoms of advanced cancer (Cancer Council Australia, nd; Cancer Council Victoria, nd). The treatment team should support the person and their whānau to participate in research and clinical trials where available and appropriate.

7.3 End-of-life care

The person with advanced cancer may reach a time when active treatment is no longer appropriate, symptoms are increasing, and functional status is declining. Dying is a normal part of every person's life course and every person has the right to die well.

Te Ara Whakapiri: Principles and guidance for the last days of life (Ministry of Health | Manatū Hauora 2017b) defines the essential components (baseline assessment, ongoing assessment, after-death care) and considerations required to provide quality end-of-life care for adults. This covers all care settings, including the home, residential care, hospitals, and hospices.

The multidisciplinary team needs to share the principles of a palliative approach to care when making end-of-life decisions with the person and their whānau. Honest communication is essential to ensure they have time to prepare and appropriate support is in place.

If the person does not already have an advance care plan or advance directive in place, a designated member of the team should encourage them to develop one in collaboration with their whānau.

It is essential for the treatment team to consider the appropriate place of care, the person's preferred place of death, and the support needed for the person and their whānau.

The treatment team should also ensure that whānau receive the information, support, and guidance about their role according to their needs and wishes.

7.4 Assisted dying

The person requesting assisted dying information are supported to access this service. Health providers/professionals are required to be aware of their rights and responsibilities regarding assisted dying services, should the person raise this with the health care team. For more information visit: **www.health.govt.nz/our-work/regulation-health-and-disability-system/assisted-dying-service**.

7.5 Supportive care and communication

An essential component of palliative and end-of-life care is assessing and ensuring the needs of the person and their whānau are met. A number of supportive care needs may arise, including:

- assistance for dealing with emotional and psychological distress from grief and fear of death and dying
- specific support for the person and their whānau where a parent is dying and will leave behind bereaved children or adolescents
- facilitating conversations with the person and their whānau regarding an advance care plan, an advance directive and appointing an EPA
- access to appropriate equipment
- supporting whānau with carer training
- information and education around 'What to expect when someone is dying'
- identifying a key contact person
- where indicated by speech and language therapists, specialist support for optimal safety and enjoyment of oral intake and to support communication in the palliative care setting.

7.5.1 Care coordination

Palliative care services must be integrated, responsive and well-coordinated. The person receiving palliative/supportive and end-of-life care may require several different types of care from different services and/or providers. The primary care team/palliative care team assists in coordinating care with the wider heath care team. It is important that the different providers and services are aware of and responsive to the various facets of care that the person and their whānau require.

7.5.2 Communicating with the person/whānau receiving care

Health providers/professionals

- Encourage the person and their whānau to designate a lead person(s) to communicate with care providers.
- Encourage discussions about the expected disease course, considering personal and cultural beliefs and expectations.
- Discuss shared goals of care.
- Discuss palliative care options, including community-based services as well as dying at home.
- Empower the person and their whānau to determine the care that they may want to provide, with or without support services.
- Refer the person to palliative care in the community according to their wishes.
- Discuss supportive care options available.

> ***"The difference in his wellbeing after rongoā was huge. He was still dying, but he didn't look sick anymore."***
> Person/whānau insights

Communicating between health services

Clear communication between all providers/professionals involved in coordinating care is essential. This includes:

- confirming the lead clinician and handover as necessary
- providing updates on the person's prognosis
- initiating supportive and palliative care referrals
- advising on end-of-life care planning.

> ***"Palliative care is a tapu space and requires a careful, holistic approach."***
> Person/whānau insights

7.5.4 Palliative care and end of life key national guidelines

- *Advance care planning.* (Te Tahu Hauora | Health Quality & Safety Commission New Zealand. 2022.) **hqsc.govt.nz**
- *A Guide For Carers. (***Hospice New Zealand** 2019).
- *Mauri Mate: A Māori palliative care framework* (**Hospice New Zealand**.2019)
- *Te Ara Whakapiri: Principles and guidance for the last days of life* (**Ministry of Health** | Manatū Hauora 2017b)
- *The Palliative Care Handbook* (**Hospice New Zealand** 2019b)

Information on assisted dying for the public (**Health New Zealand** | Te Whatu Ora, nd).

7.6 Measuring and monitoring

- *Ngā Paerewa Pairuri Tāngata | Standards for Palliative Care* (Hospice New Zealand 2019a) **Standards for palliative care**
    - Standard 1: Assessment of needs
    - Standard 2: Developing the care plan
    - Standard 3: Providing the care
    - Standard 4: Supporting and caring for the family, whānau and carers
    - Standard 5: Transitions within and between services
    - Standard 6: Grief support and bereavement care
    - Standard 7: Culture of the organisation
    - Standard 8: Quality improvement and research
    - Standard 9: Staff qualification and training

- **National palliative care outcomes and reporting framework** (under development).

Appendix 1: Regional Head and Neck Quality Performance Indicators

Note: Whilst Quality Performance Indicators have been agreed at a national level, they have not been measured nationally. In 2024 the Northern Regional Head and Neck Cancer Service reported internally against aligned indicators for the period 2017-2023 for their region.

1. Timeliness of treatment: Time from first histological diagnosis to first definitive treatment.
2. Stage at diagnosis: Proportion of people with head and neck cancer by stage at diagnosis.
3. Multidisciplinary discussion:
   - proportion of people with head and neck cancer discussed at a multidisciplinary meeting (MDM)
   - 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.
4. Clinical trial participation: Proportion of people with head and neck cancer in a clinical trial.
5. Treatment survival: Proportion of people with head and neck cancer who died within 30 or 90 days of treatment (surgery, chemotherapy, radiotherapy).
6. Overall survival: Overall survival for people with head and neck cancer at 1, 3, 5 and 10 years from diagnosis by 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.
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.
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.
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.
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.
12. Post-operative radiotherapy: Proportion of people with head and neck cancer who complete post-operative radiotherapy within 13 weeks of definitive surgery.
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.
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.
15. Co-Morbidities.