TE AHO
O TE KAHU
CANCER
CONTROL
AGENCY

Optimal cancer care pathway for people with bowel cancer

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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.

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For further information including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Bowel 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 bowel 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. Bowel cancer affects an increasing number of people with more than 3500 diagnosed with bowel cancer this year. Around 1300 will die from bowel 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 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 bowel 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 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 • 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, including a family history of bowel or other cancer. ☐ Provide screening recommendations if eligible. ☐ 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: Screening and early detection

This step recommends options for screening and early detection for the person with suspected bowel cancer.

Primary health providers play a key role in encouraging bowel screening participation, helping achieve equity and raising awareness of bowel cancer symptoms and family history of bowel cancer.

Assessing family history and appropriate referral for surveillance recommendations can significantly impact prevention or early detection for the person with a familial colorectal cancer risk.

Screening programmes increase the chance of identifying cancer early and improve the person's treatment outcome.

General Practitioners (GP)/clinicians check if the person has any relevant screening due and arrange support to attend.

Assess family history of cancer as part of a routine wellness check.

There are three national screening programmes for breast, bowel, and human papillomavirus testing (HPV) for cervical cancer.

National Bowel Screening is free and offered every two years to people aged 60 to 74 years who are eligible for publicly funded health care.

Screening timeframes

If participating in the National Bowel Screening programme, the person will be notified of the screening test kit result **within 3 weeks.**

Early detection

The person should report any bowel symptoms to their health care provider.

Bowel cancer modifiable risks include:

- being overweight or obese
- physical inactivity
- tobacco smoking
- a low-fibre, high-fat diet
- a diet high in processed and red meat
- alcohol consumption

Bowel cancer, non-modifiable risks include:

- being over 50 years old
- a personal history of adenomas
- inflammatory bowel disease
- family history of bowel cancer.

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 are at an increased risk of familial cancer.

☐ Provide screening recommendations if eligible.

☐ For people/whānau with a family history of bowel cancer, assess risk category and provide appropriate recommendations. For further information:

Te Whatu Ora – Health New Zealand. 2023. **Update on Surveillance Recommendations for Individuals with a Family/Whānau History of Colorectal Cancer.** Wellington: Te Whatu Ora – Health New Zealand

☐ If assessed as high risk, refer the person/whanau either to the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic service for an accurate risk assessment.

For further information visit: Genetic Health Service New Zealand – **genetichealthservice.org.nz**

New Zealand Familial Gastrointestinal Cancer Service - **nzfgcs.co.nz**

☐ For guidance on the surveillance of the person with previous bowel polyps, refer:

Te Whatu Ora – Health New Zealand. 2024. **Update on polyp surveillance guidelines.**

☐ Discuss recent weight changes and monitor weight.

☐ Encourage participation in National Screening Programmes to eligible people.

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

Communication

☐ Ensure the person and their whānau understands:
  - the importance of participation in bowel screening if eligible
  - the importance of reporting symptoms early

- awareness of family history

Time to Screen: Do you have a family history of bowel cancer?

- the national bowel screening programme and how it works
- when they should receive their results
- what to do if they do not receive their results

☐ where appropriate, referral for the person/ whānau either to the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic service for an accurate risk assessment.

☐ providing appropriate information and referral to relevant specialty or support services as required

☐ what is 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 bowel 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 may present via primary care, an emergency presentation or incidental finding with a high suspicion of bowel 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.

There is a small but significant increase in the incidence of bowel cancer in younger persons, and clinicians should not discount suggestive symptoms in young person's especially if the symptoms are persistent.

Signs and symptoms of bowel cancer to investigate include:

- rectal bleeding
- unexplained iron deficiency anemia

Step 3: Checklist

☐ Complete all cancer assessments.

☐ Record signs and symptoms.

☐ 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 and arrange further investigation.

Timeframe

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

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

- change in bowel habit (loose stools or constipation), especially a recent one that does not have another explanation such as an infection or opioid use
- undiagnosed abdominal pain or tenderness
- unexplained rectal or abdominal mass.

Bowel cancer assessment includes:

- checking if eligible or participating in the National Bowel Screening Programme
- relevant medical history, including previous adenomas, bowel cancer, inflammatory bowel disease
- relevant medications and allergies: NSAIDs, anticoagulants, antiplatelets and immunosuppressants
- comorbidities
- relevant physical examination: ECOG, frailty assessment, weight, abdominal examination, digital rectal examination
- relevant investigations (laboratory, radiology): full blood count, iron studies and ferritin, liver function tests, creatinine, and electrolytes
- familial history including family history of bowel cancer and other cancers including unknown primary cancers
- relevant social history.

Referral

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

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

- known or suspected bowel cancer (on imaging, or palpable or visible on rectal examination).
- unexplained rectal bleeding (benign anal causes treated or excluded) WITH iron deficiency anaemia (haemoglobin and ferritin below the local reference range).
- altered bowel habit (looser and/or more frequent) > 6 weeks duration PLUS unexplained rectal bleeding (benign anal causes treated or excluded) AND aged ≥ 50 years.

☐ 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
  - what to do if they do not receive their specialist appointment within the specified time.

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.

Step 4: Checklist

☐ Endoscopy services should assess the persons family history in relationship to bowel cancer with appropriate on-refer to

Diagnosis for bowel cancer may include:

- **Endoscopy:** sigmoidoscopy, colonoscopy for complete colonic assessment and diagnostic purposes
- **Radiology:** virtual colonoscopy (CT colonography), CT colonography is considered as an alternative for people with comorbidities affecting their suitability for colonoscopy.
- **Pathology**: biopsies
- **Laboratory:** routine blood tests including ferritin and carcinoembryonic antigen.

Staging for bowel cancer is by:

- CT scan of the chest, abdomen, and pelvis
- MRI of the pelvis for rectal cancer to determine radiologic staging to define the extent of tumour spread and to determine neoadjuvant therapy use.

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

Prehabilitation
Initiate prehabilitation as early as possible after diagnosis to optimise the person's wellbeing prior to treatment.
Districts that provide bowel cancer surgery should have a programme such as Enhanced Recovery After Surgery, implemented and follow ERAS protocols. This may include the use of specialist nurses to provide pre and post-surgical support and education.

Familial cancer risk
Between 1 and 5% of colorectal cancers are specifically inherited (familial adenomatous polyposis and Lynch) and up to 10-15% may have some inherited component.
A referral to the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic health service for an accurate risk assessment should be made if features of the cancer suggest a genetic predisposition:

- early age onset
- histology (if available)
- multiple primary cancers

Hereditary Syndromes

All newly diagnosed cases of colorectal cancer should be tested for:

- mismatch repair deficiency, preferably on initial biopsy
- BRAF and methylation testing for tumours showing MLH1 loss

the New Zealand Familial Gastrointestinal Cancer Service or Genetic Health Service when required.

☐ Confirm diagnosis.

☐ Referral to a cancer care coordinator.

☐ Record performance status and comorbidities.

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

☐ Consider enrolment in clinical trial.

☐ Consider fertility consequences with treatment and refer to fertility specialist as required.

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

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

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

☐ Referral to bowel specific support services as required.

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

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

☐ If family history assessment or features of the cancer suggest a genetic predisposition, refer the person to either the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic service for an accurate risk assessment.

For further information visit:

- Genetic Health Service New Zealand – **genetichealthservice.org.nz**
- New Zealand Familial Gastrointestinal Cancer Service - **nzfgcs.co.nz.**
- Te Whatu Ora – Health New Zealand. 2023. *Update on Surveillance Recommendations for Individuals with a Family/Whānau History of Colorectal Cancer*. Wellington: **Te Whatu Ora – Health New Zealand**

Timeframe

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

- where there is metastatic disease, RAF status, RAS status and MMR.

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.

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 appropriate specialty or 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 optimal treatment for bowel 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 – may be used to stage the cancer and as a form of therapy. Surgery is recommended for many people with bowel cancer.

Systemic therapy – people who may benefit from systemic therapy includes those:

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

Radiation therapy – the person who may benefit from radiation therapy includes those with:

Step 5: Checklist

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

☐ Discuss the intent of treatment and the risks and benefits discussed 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 non-governmental organisations (NGOs,) cultural services and support groups available.

☐ Consider early referral to palliative care if appropriate.

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

Timeframes

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

☐ The person referred urgently with a high suspicion of bowel cancer receives their first

• Locally advanced/clinically high-risk rectal cancer • symptomatic, non-resectable locally advanced rectal cancer who may benefit from radiation therapy with or without concurrent chemotherapy given with palliative (non-curative) intent • colon cancer where the tumour has penetrated a fixed structure • definitive treatment (+/- “Watch and Wait”) for people who are unfit for surgery or who wish to avoid surgery. **Palliative care** Early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.	cancer treatment **within 62-days** from date of referral. ☐ Time to surgery, if required after neoadjuvant radiation therapy, depends on the regimen. ☐ The person with non-metastatic bowel cancer is presented in the bowel cancer MDM **within 3 weeks** after surgery for consideration of adjuvant therapy. ☐ If radiation or chemotherapy is a first treatment, treatment should occur **within 31-days** of the decision to treat. ☐ Adjuvant chemotherapy should begin **within 4 weeks** after surgery, where recovery allows. **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 ☐ finding appropriate support for exercise programmes to improve treatment outcomes if required.

Step 6: Care after treatment	Step 6: Checklist
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 • any referral to the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic health service for treatment and include types and dates of tests/treatment • 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 to the person • a follow-up schedule, including tests required and timing	☐ 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 the Cancer Society, Cancer NGOs and/or relevant cultural services and support groups available. **Communication** The lead clinician and team are responsible for: ☐ explaining the treatment summary and follow up 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 person and their whānau ☐ providing appropriate information and referral to appropriate specialty or support services as required

- 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:
  ○ changes to bowel function
  ○ formation of a stoma
  ○ fatigue
  ○ nutrition
  ○ sexual function
  ○ bladder function
  ○ peripheral neuropathy.
	☐ communicating the follow-up care plan with the GP
	☐ providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care	Step 7: Checklist
Palliative and end-of-life care provides the person facing life-limiting conditions and their whānau 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 identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering. End-of-life care should consider: - appropriate place of care - 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 raises 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 providing cancer care.	☐ Early referral to palliative care services as required. ☐ Refer to supportive care services as required. ☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone has a life limiting disease and/or is dying. ☐ Activation of advance care plan, directive, or enduring power of attorney.

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).

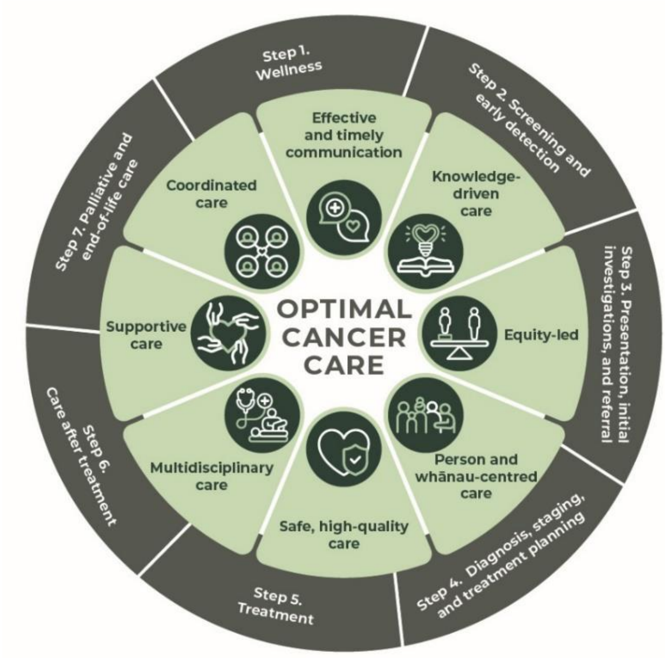
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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 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 for being assessed and receiving treatment. These timeframes are based on expert advice and consultation with the National Bowel Cancer Working Group.

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 2: Screening and early detection	Participation	Eligible people aged 60 – 74 years are encouraged and supported to participate in the national bowel screening programme every 2 years. The age at which people can start taking part in the free National Bowel Screening Programme is being lowered from 60 to 58 years of age. The first stage will begin in October 2025 and the second stage March 2026.
		People who are part of bowel screening pilots will continue until they turn 58 and will then join the wider bowel screening programme.
	Positive screening result	The person will be contacted by the primary care provider **within 10 working days** of a positive FIT and an appointment arranged to explain the positive FIT and referral process.
		The person will be referred by their GP for a national bowel screening colonoscopy **within 10 working days** of a positive FIT. If no referral is received the person will be contacted by the district bowel screening endoscopy team **within 15 working days** of a positive FIT.
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Initial investigations started by GP	If symptoms suggest bowel cancer, the person and their whānau are referred to colonoscopy or CTC **within 2 weeks** for urgent investigation or **within 6 weeks** for a routine investigation.
	Referral to a hospital specialist	The person should see a specialist **within 2 weeks** following a diagnosis of bowel cancer.

Step 4: Diagnosis, staging, and treatment planning	Diagnosis and staging	Staging investigations should be completed **within 2 weeks**
	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.
		The person referred with a high suspicion of bowel cancer and triaged by a clinician will receive their first cancer treatment **within 62 days.**
Step 5: Treatment	Neoadjuvant radiation therapy/ systemic anti-cancer therapy	If radiation therapy or systemic anti-cancer therapy is a first treatment, treatment should occur **within 31 days** of the decision to treat, regardless of how they were initially referred.
	Surgery	The person begins their first cancer treatment **within 31 days** of the decision to treat, regardless of how they were initially referred. For rectal cancer, if required after neo adjuvant radiation therapy, the time to surgery depends on the regimen.
	Adjuvant chemotherapy	The person begins adjuvant chemotherapy **4 weeks after surgery,** where recovery allows**.**

Optimal Cancer Care Pathway

Seven steps of the optimal cancer care pathway

Step 1: Wellness
Step 2: Screening and 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

Bowel cancer is cancer in any part of the large intestine (colon or rectum). It is sometimes known as colorectal cancer and might also be called colon cancer or rectal cancer, depending on where it starts. Bowel cancer is the third most common cancer diagnosed in New Zealand.

The average age that a person is diagnosed with bowel cancer is 71 years. The population age structure for Māori, Pacific is such that the average age of diagnosis is younger at 64 years.

People diagnosed through a screening programme are more likely to have their cancer diagnosed at an earlier stage and be treated with a plan to cure. New Zealand has a high proportion of people who are diagnosed with bowel cancer after presentation with bowel-related symptoms at an emergency department with evidence that this is associated with poorer outcomes (Te Aho o Te Kahu, 2024).

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 in screening participation rates for existing cancer screening programmes.

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
- accessing screening services such as breast, bowel, and HPV testing
- avoiding smoking including marijuana 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,
- preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons avoiding chronic infections (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/professionals

- 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.

- **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 Health survey** (NZHS) provides information about the health and wellbeing of New Zealanders.
  - Health status and behaviours.
  - Risk factors.
  - Access to health care.

Step 2: Screening and early detection

This step outlines recommendations for screening and early detection for the person with suspected bowel cancer.

2.1 Te Tiriti o Waitangi

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

- making sure screening and early detection of cancer services are provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care
- providing access to co-designed kaupapa Māori cancer screening and early detection 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 Screening

Cancer screening programmes detect if pre-cancer cells are present and identify cancers earlier. Screening consists of specific programmes that identify cancer before any symptoms appear. Currently, there are three national cancer screening programmes: breast, cervical and bowel.

Primary care and the national screening programmes work with the person and their whānau to enable, educate and encourage them to participate in bowel screening.

The National Bowel Screening programme includes:

- eligible people aged 60 – 74 years encouraged and supported to participate in the national bowel screening programme **every 2 years**. The age at which people can start taking part in the free National Bowel Screening Programme is being lowered from 60 to 58 years of age. Lowering the bowel screening starting age to 58 will take place in two stages beginning in October 2025 and then in March 2026.
- people who were part of a national bowel screening pilot for Māori and Pacifica pilots will continue to be invited for bowel screening – provided they remain eligible and still live in that district – until they turn 58 and join the wider programme.
- utilising person prompting tools for cancer screening services within Primary care software solutions
- improvements to the bowel screening register.
- undertaking opportunistic cancer screening conversations to encourage enrolment and participation
- discussing screening results and follow up required.

Information for health professionals, including policies, quality standards, monitoring reports and publications, can be found on the National Screening website – **nsu.govt.nz**

Further information on the National Bowel Screening Programme is available through the following links:

- **Time to screen**
- **National bowel screening programme**
- Clinical practice **guidelines** for bowel screening in New Zealand.

2.3 Early detection

Early detection focuses on detecting symptomatic people as early as possible. Early detection through screening and/or other programmes has several benefits, including better treatment outcomes and improved survivorship.

The person should report any bowel symptoms to their care provider.

For guidance on the surveillance of the person with previous bowel polyps, refer: Te Whatu Ora – Health New Zealand. 2024. **Update on polyp surveillance guidelines.**

2.4 Bowel cancer risk factors[4]

2.4.1 Modifiable risk factors

- being overweight or obese
- tobacco smoking
- physical inactivity
- alcohol consumption
- a low-fibre, high-fat diet
- a diet high in processed and red meat.

2.4.2 Non-modifiable risk factors

- being over 50 years old
- a personal history of adenomas
- a personal history of inflammatory bowel diseases
- family history of bowel cancer.

For further information relating to bowel cancer and family history refer to: Te Whatu Ora – Health New Zealand. 2024. **Update on polyp surveillance guidelines.**

2.4.3 Familial cancer risk

Some people may have an increased risk of developing bowel cancer. An individual's family cancer history is reviewed and the person and their whānau are advised of the risks of developing a familial cancer.

Assessing family history and appropriate referral for surveillance recommendations can significantly impact prevention or early detection for the person/whānau who have a familial colorectal cancer risk.

Health providers encourage and support the person and their whānau to follow surveillance recommendations if an increased risk of familial cancer is known or identified. If assessed as high risk, refer the person/whānau either to the New Zealand Familial GI Cancer Service (NZFGCS) or a genetic service for a risk assessment.

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[4] IARC, 2025

For further information visit:

- **tewhatuora.govt.nz/assets/Publications/Bowel-screening/Update-on-Surveillance-Recommendations-for-Individuals-with-a-Family-History-of-Colorectal-Cancer.pdf**
- Genetic Health Service New Zealand – **genetichealthservice.org.nz**
- New Zealand Familial Gastrointestinal Cancer Service - **nzfgcs.co.nz**.

2.5 Communication with the person/whānau receiving care

Health providers/professionals

- promote health checks
- assess personal risks and family history and raise and discuss any cancer risk factors.
- if appropriate, refer the person to either NZFGCS or genetic services for a risk assessment
- provide information and education regarding screening, genetic referrals, and early detection.
- promote and monitor participation in screening programmes, if eligible.
- discuss any investigation or screening 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 screening services (where available), and same-day access to a chest x-ray.

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

Communication between health services

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

2.6 Measuring and monitoring

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

- **National Colonoscopy Wait Times**

90% of people accepted for an urgent diagnostic colonoscopy receive (or are waiting for) their procedure in the recommended timeframe of 14 calendar days or fewer, 100% in the maximum timeframe of 30 days or fewer.

70% of people accepted for a non-urgent diagnostic colonoscopy receive (or are waiting for) their procedure in the recommended timeframe of 42 calendar days or fewer, 100% in the maximum timeframe of 90 days or fewer.

70% of people accepted for a surveillance colonoscopy receive (or are waiting for) their procedure in the recommended timeframe of 84 calendar days or fewer of the planned date, 100% in the maximum timeframe of 120 days or fewer.

- **National bowel screening**

The national bowel screening participation target rate is 60%.

95% of people who returned a positive faecal immunochemical test (FIT) have a diagnostic date that is **within 45 working days** or less of their FIT result being recorded in the National Bowel Screening Programme IT system and completed within 60 days.

Timeframes for screening and managing positive FIT results include:

  - the person will be contacted by the primary care provider **within 10 working days** of a positive FIT and an appointment arranged to explain the positive FIT and referral process.
  - the person will be referred for a national bowel screening colonoscopy by primary care provider **within 10 working days** of a positive FIT. If no referral is received the person will be contacted by the district bowel screening endoscopy team **within 15 working** days of a positive FIT.

Quality measures:

  - clinical practice **guidelines** for bowel screening in New Zealand
  - monitoring the quality of the national screening programme: **National Bowel Screening Programme Interim Quality Standards**
  - Endoscopy Standards for Colonoscopy and Bowel Cancer Screening: **endoscopyquality.co.nz**

- **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).

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 bowel 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**.

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 Timeframes 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 bowel cancer should be seen by a general practitioner **within 2 weeks.**

The person is assessed for signs and symptoms of bowel cancer, including any unexplained, persistent signs and symptoms lasting more than three 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.

Bowel cancer can occur across the lifespan and there is some recent evidence showing small but significant increases in the incidence of bowel cancer in younger people in developed countries including Aotearoa New Zealand. Therefore, clinicians should investigate symptoms in people (including younger people) that are suggestive of bowel cancer, especially if symptoms are persistent (BPAC, 2020).

The following suspicious signs and symptoms of bowel cancer include:

- rectal bleeding
- unexplained iron deficiency anemia
- change in bowel habit (loose stools or constipation), especially a recent one that does not have another explanation such as an infection or opioid use
- undiagnosed abdominal pain or tenderness
- unexplained rectal or abdominal mass.

If the person presents with one of the following red flags, the referral should be triaged as an urgent 'HSCAN'.

- Known or suspected bowel cancer (on imaging, or palpable or visible on rectal examination).
- Unexplained rectal bleeding (benign anal causes treated or excluded) WITH iron deficiency anaemia (haemoglobin and ferritin below the local reference range).
- Altered bowel habit (looser and/or more frequent) > 6 weeks duration PLUS unexplained rectal bleeding (benign anal causes treated or excluded) AND aged ≥ 50 years.

3.3 Assessment

Bowel cancer assessment includes:

- checking if eligible or participating in the **National Bowel Screening Programme**
- **medical history:** including previous adenomas, bowel cancer, inflammatory bowel disease
- **medications and allergies:** NSAIDs, anticoagulants, antiplatelets and immunosuppressants
- **physical examination**: ECOG, frailty assessment, weight, abdominal examination, digital rectal examination
- **investigations (laboratory, radiology):** full blood count, iron studies and ferritin, liver function tests, creatinine, and electrolytes
- **familial history:** including family history of bowel cancer and other cancers including unknown primary cancers
- **social history**.

3.4 Initiate investigations, including referrals

- Direct access outpatient colonoscopy if eligible (criteria available in Community HealthPathways).
- Indicate a high suspicion of cancer and/or urgent and the person needs to be seen within two weeks.
- Primary care utilises cancer screening referral pathways such as the positive FIT referral for bowel screening.
- Referrals for colonoscopy or CT Colonoscopy after a positive screening test are done by the National Bowel Screening Programme.
- Referrals are receipted back to the referring provider.

Timeframe for completing investigations for the person with suspected bowel 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 do not hear from the service referred to within the timeframe given, and any costs for accessing services.

When referring a person 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
- 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
    - they are actively 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
- if the person does not meet direct access to colonoscopy criteria and the referrer still has concerns, request a non-acute general surgery/first specialist assessment.

Timeframe for referring to a specialist

Any person with symptoms suspicious of bowel cancer is referred to a specialist following guidelines in Community HealthPathways. The specialist should see the person with proven or suspected cancer and their whānau **within 2 weeks** of diagnosis or a high suspicion of cancer. If necessary, prior discussion should facilitate referral (Community HealthPathways 2024).

Referrals must be triaged in a timely manner **within 1–2 working days** by an 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 that provide supportive care, including local Māori health service providers/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.

- **National Colonoscopy Wait Times**
    - 90% of people accepted for an urgent diagnostic colonoscopy receive (or are waiting for) their procedure in the recommended timeframe of 14 calendar days or fewer, 100% in the **maximum timeframe of 30 days or fewer.**
    - 70% of people accepted for a non-urgent diagnostic colonoscopy receive (or are waiting for) their procedure in the recommended timeframe of **42 calendar days or fewer**, 100% in the maximum timeframe of 90 days or fewer.

  - 70% of people accepted for a surveillance colonoscopy receive (or are waiting for) their procedure in the recommended timeframe of **84 calendar days or fewer** of the planned date, 100% in the **maximum timeframe of 120 days or fewer.**

- **Te Aho o Te Kahu Bowel Cancer Quality Performance Indicator**
  - BCQI 1. Route to diagnosis: Proportion of people with colorectal cancer who are diagnosed following a referral to a clinic, screening, or presentation to an emergency department (with or without surgery) (Te Aho o Te Kahu, 2022).

- **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 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 bowel 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 and include:

Endoscopy

- sigmoidoscopy
- colonoscopy for complete colonic assessment and diagnostic purposes
- endoscopy services should assess the persons family history in relationship to bowel cancer with appropriate on-referral to the New Zealand Familial Gastrointestinal Cancer Service or Genetic Health Service

Radiology

- virtual colonoscopy (CT colonography), CT colonography is considered as an alternative for people with comorbidities affecting their suitability for colonoscopy

Pathology

- biopsies

Laboratory

- routine blood tests including ferritin and carcinoembryonic antigen.

Timeframe for completing investigations

Diagnostic investigations should be completed **within 2 weeks** of the initial specialist assessment.

4.3 Staging

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. Radiological staging investigations for colon and rectal cancer may include:

- CT scan of the chest, abdomen, and pelvis
- MRI of the pelvis for rectal cancer to determine radiologic staging to define the extent of tumour spread and to determine neoadjuvant therapy use
- where there is a finding of a large bowel obstruction, a CT scan is performed preoperatively.

Following an MDM further radiological investigations may include:

- CT scan – if this shows metastatic disease confined to the liver, an MRI of the liver to assess for resectability may be indicated
- PET-CT is recommended for people who have suspicious metastatic disease at initial staging. PET-CT is also recommended for restaging for those who have potentially resectable/treatable metastatic disease (Health New Zealand/Te Whatu Ora National Indications for Publicly Funded PET-CT, 1 March 2024).

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

- Bowel cancer clinical staging occurs pre-surgery and pathological staging occurs post-surgery.
- Synoptic reporting is recommended.

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 Heredity Syndromes

If features of the cancer suggest a genetic predisposition, refer the person either to the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic service for a risk assessment. These features may include:

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

Between 1–5% of colorectal cancers are specifically inherited (familial adenomatous polyposis and Lynch syndrome) and up to 10-15% may have some inherited component. Anyone diagnosed with bowel cancer should have a detailed personal and family cancer history taken.

There is an increasing role for molecular pathology in identifying familial bowel cancer. Immunohistochemistry for the mismatch repair gene proteins (MMR) should be done routinely on all primary tumours. Molecular testing is also useful in colorectal cancer for both prognostic and predictive reasons, helping inform likely outcomes from both funded and unfunded chemotherapeutic agents. BRAF and methylation testing for tumours showing MLH1 loss should be undertaken if available. These tests help exclude Lynch syndrome. For metastatic disease, molecular pathology is important including RAS status, BRAF status and MMR.

For further information see:

- Genetic Health Service New Zealand: **tewhatuora.govt.nz/health-services-and-programmes/genetic-health-service-nz/about**
- New Zealand Familial Gastrointestinal Cancer Service: **nzfgcs.co.nz**
- **Te Whatu Ora – Health New Zealand**. 2023. *Update on Surveillance Recommendations for Individuals with a Family/Whānau History of Colorectal Cancer*. Wellington.
- Molecular testing colorectal New Zealand: **molecular-testing-colorectal-cancer-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 bowel cancer MDM following nationally agreed referral criteria is undertaken to inform treatment recommendations or further assessment and investigation.

- The 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.
- The level of discussion may vary, depending on the person and clinical and supportive care factors.
- The 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.

- The lead clinician and/or team discusses the recommendations from the MDM with the person and their whānau **within 2 weeks** of the MDM, so they are able to take part in decision-making about ongoing treatment and care.

MDMs are managed 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) (this is an unendorsed draft at this time and is for reference only)

4.6.1 Treatment options and recommendation

Following MDM, treatment intent is discussed with the person and their whānau. Treatment intent ranges from curative, tumour control and palliation to control symptoms.

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, type of cancer 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

Prehabilitation 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. Prehabilitation (preparing for treatment) is initiated and assessed by primary or hospital services and may require referral to additional services for example:

- the person that requires a stoma – whether temporary or permanent are counselled on the position and implications of a stoma before undergoing surgery. Ideally, this is given by a nurse with appropriate expertise (e.g., a bowel cancer nurse or stomal therapy nurse).
- districts that provide bowel cancer surgery should have a programme such as Enhanced Recovery after Surgery, implemented and follow ERAS protocols (this may include the use of specialist nurses to provide pre- and post-surgical support and education)
- physiotherapy or exercise programme - aerobic, respiratory training, resistance training for person/whānau preparing for surgery. Following completion of primary

- cancer treatment, rehabilitation programs have considerable potential to enhance physical function
- smoking cessation
- medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for person and their whānau preparing for surgery
- nutrition.

4.6.4 Clinical trials

Where eligible, the person 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 is in place
- prehabilitation
- fertility support
- information and education needs are met (refer to Step 3.5).

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.

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

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.

- **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** - For the 31-day pathway, the MDM and person and their whānau agreement to treatment is completed as soon as possible following MDM to enable them to meet the 31-day Health Target.
    - **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 bowel cancer by trained and experienced clinicians and team members, in an appropriate environment.

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) 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. Formally involving the palliative care team/service may 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.

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 (as appropriate) to optimise treatment outcomes, and manage any comorbidities, prior to treatment. Depending on the treatment decided, additional prehabilitation activities may need to be initiated.

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 bowel 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 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.

- **Endoscopy:**
    - endoscopic removal of early-stage cancer
- **Surgery:**
    - surgical resection is recommended for most people with colon cancer
    - surgical resection is recommended for most people with rectal cancer
    - time to surgery is dependent on the treatment regime.

Timeframes for starting treatment

Surgery should be completed within 31-days of decision to treat if no neoadjuvant therapy is required.

- **Radiation therapy**

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

Some people may benefit from radiation therapy, including those with:

- locally advanced/clinically high-risk rectal cancer
- symptomatic, non-resectable locally advanced rectal cancer who may benefit from radiation therapy with or without concurrent chemotherapy given with palliative (non-curative) intent
- colon cancer where the tumour has penetrated a fixed structure
- definitive treatment (+/- "Watch and Wait") for people who are unfit for surgery or who wish to avoid surgery.

Timeframes for starting treatment

If radiation is a first treatment, treatment should occur **within 31-days** of decision to treat.

- **Systemic anti-cancer therapy**

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).

The person may benefit from systemic therapy, including those:

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

Timeframes for starting treatment

If chemotherapy is a first treatment, treatment should occur within 31-days of decision to treat. Adjuvant chemotherapy should begin **4 weeks after surgery**, where recovery allows.

- **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.

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. Early referral to palliative care and other health services is recommended to help manage:

- changes to bowel function and rectal discharge
- nutritional support
- stoma care
- hernia
- nutritional support
- sexual dysfunction
- peripheral neuropathy
- fatigue.

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:

- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing bowel cancer care
- potential isolation from normal support networks, particularly for rural people who are staying away from home for treatment
- 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 treatment or surgically or chemically induced menopause, which requires sensitive discussion and possible referral to a clinician skilled in this area
- decline in mobility or functional status
- 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 side effects is important for 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 – referral to a specialist psychologist, psychiatrist or social worker may be required
- weight changes – may require referral to a dietitian before, during and after treatment
- 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.

The person and their whānau may also need to manage:

- financial issues related to loss of income (through reduced capacity 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 benefit 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).

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

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

- **Te Aho o Te Kahu Bowel Cancer Quality Performance Indicators**
    - BCQI 5. Length of stay after surgery: Median length of stay following surgery for colorectal cancer.
    - BCQI 7. Treatment survival: Proportion of people with colorectal cancer who died within 30 or 90 days of treatment (surgery, chemotherapy, radiotherapy).
    - BCQI 10. Lymph node yield: Proportion of people with colorectal cancer who undergo surgical resection where 12 or more lymph nodes are pathologically examined.
    - BCQI 16. Radiotherapy: Proportion of people with non-metastatic cancer who receive:
        a) no radiotherapy (i.e., surgery alone),
        b) pre-operative short-course radiotherapy (SCRT)
        c) pre-operative long-course radiotherapy (LCRT).
    - BCQI 19. Emergency surgery: Proportion of people with colorectal cancer undergoing major resection who have emergency surgery.
    - BCQI 21_a. Abdominoperineal resection: Proportion of people with rectal cancer who had major surgery and an abdominoperineal resection (APR).

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 -** 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.
    - **62-day indicator** – All people 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.

- **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 bowel cancer:

- Follow up and surveillance for people after treatment for bowel cancer: **bpac.org.nz/2021/bowel-cancer.aspx**
- Improving bowel function after treatment: **cancer.org.nz**
- Living beyond bowel cancer: **bowelcancernz.org.nz**
- Living with bowel cancer. The ileostomy and colostomy: **bowelcancernz.org.nz**

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
- any referral raised for the New Zealand Familial GI Cancer Service (NZFGCS) or to a genetic health service
- 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.

For people with bowel cancer, additional assessment for referral to the following rehabilitation or recovery services should be undertaken:

- physiotherapy
- stomal therapy
- nutritional support
- support for sexual dysfunction.

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 people and their whānau.

Care after treatment is driven by predicted risks and 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 has been received, and the needs and wishes of the person and their whānau. The type and duration of follow up after bowel cancer is determined by cancer site (colon or rectum).

Follow up investigations for bowel cancer following treatment, will be specified in the persons surveillance plan and may include CEA blood tests, radiology imaging, colonoscopy and/or flexible sigmoidoscopy.

For people with bowel cancer, follow up care will include:

- review in specialist clinic following surgical intervention, at two to six weeks from discharge. This includes discussion of histology, resolving any issues, and education of the person on their surveillance plan
- for the person who has completed treatment, ongoing follow up for colon cancer can be managed by the primary care GP or GP practice nurse
- other important aspects of follow up care include regular assessment of the persons psychological wellbeing, promotion of healthy lifestyle factors, and post-treatment symptom management. Many people experience altered bowel function because of their treatment for bowel cancer and are likely to require information on dietary changes, stoma care, bloating, excess flatus and managing diarrhoea, incontinence, or constipation. People with severe symptoms that do not respond to initial treatment with diet and stool modifying medicines may need a referral back to their specialist team
- refer to *Update on Polyp Surveillance Guidelines 2024* for **follow up for polyps**.

Note for some people follow-up appointments are reassuring; however, others 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.

The overall recurrence rate five years after curative surgery for bowel cancer is approximately twenty five percent. Most recurrences occur within the first two years following treatment and are commonly in the liver, peritoneum, lung or local to the cancer.

People with a history of treated bowel cancer continue to be at a higher lifetime risk of disease recurrence and any return of suggestive symptoms or signs should be investigated. Deciding when to stop regular follow up should be a shared decision between the person and clinician(s) and occur if it is thought that the risks of further investigations outweigh the likely benefits, or when the person can no longer tolerate further treatment (BPAC, 2020).

People with rectal cancer can experience delayed recurrence in the liver or lung after two to three years or more.

Signs and symptoms will depend on the type of cancer initially diagnosed and the location of recurrent disease. Recurrence may be discovered by the person or by surveillance in the post-treatment period. The person may be asymptomatic or have non-specific symptoms.

6.6.1 Rapid re-entry to specialty services

Service providers have a process for rapid re-entry to specialty services for suspected recurrence and advise people and their whānau of how to do this if required.

6.7 Clinical trials

Where eligible, the person 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 the person 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:

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 and their whānau, where possible.

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

Continuity of care is provided where possible for example, where appropriate the person 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.

Health providers/professionals

- The process for rapid re-entry to specialty services for suspected recurrence, is explained to the person/whānau.
- Recommended or scheduled routine follow up or surveillance assessments and investigations.
- Signs and symptoms of recurrent disease.
- How to manage any physical, psychological, or emotional issues identified.
- Provide a survivorship care plan with information on secondary prevention and healthy living.
- Advise person/whānau of lead clinician.

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

Communicating between health services

- Confirm the lead clinician and discharge as necessary.
- Update progress including treatment summary and survivorship plan.
- Where required establish shared care follow-up plan including:
    - the roles of health professionals involved
    - how to manage any physical, psychological, or emotional issues identified
    - potential treatment late effects
    - signs and symptoms of recurrent disease
    - recommended or scheduled routine follow up or surveillance investigations
    - contact details of the care team involved
    - process for rapid re-entry to services (including palliative care) for the person/whānau with suspected recurrence or if there are other concerns.
- 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 is 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: **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.

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 health 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

7.5.2 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

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

- *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).