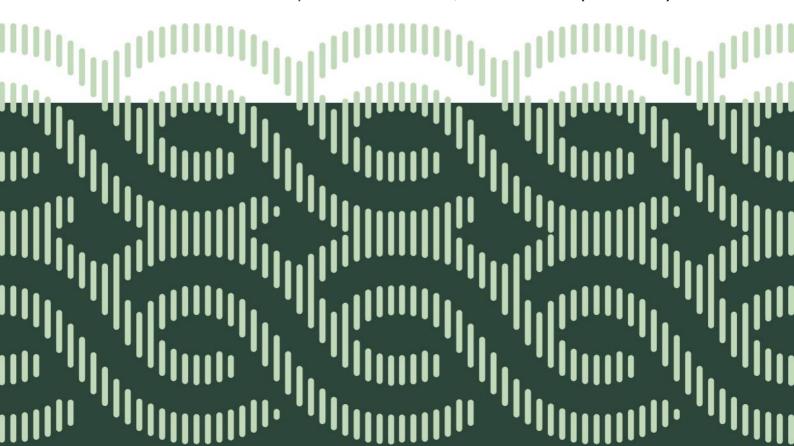




Optimal cancer care pathway for people with prostate cancer

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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, nona 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; New Zealand Urology Clinical Directors' Group; the project team; Genetic Health Service NZ; 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
- Prostate 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 whanau who contributed to developing this guidance. I am proud to present the prostate 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. Prostate cancer affects an increasing number of

people with more than 4300 diagnosed with prostate cancer this year. Around 750 men will die from prostate cancer this year. We all believe that people and their whanau 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 whanau 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 whanau. 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: New Zealand Urology Clinical Directors' Group: Genetic Health Service NZ; the project team; clinicians; and national and special interest working groups.

Our thoughts are with the many people and whanau who are living with prostate 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 prostate cancer **OCCP** information

Quick reference guide of condensed prostate cancer information

The Optimal Cancer Care Pathways (OCCP) describe the standard of care that people and whanau across Aotearoa, New Zealand should expect the public health system to be striving for. They follow eight principles1: person and whanau-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. □ 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.

¹ Optimum Cancer Care Pathway Principles

Step 2: Early detection Step 2: Checklist Assess and discuss the individual's risk of This step outlines options for early detection for the person with suspected prostate cancer. developing cancer. There is no national population-based prostate Assess family history and support the person and their whanau to follow surveillance cancer screening programme. guidance if they're at an increased risk of Early detection focuses on identifying cancer as familial cancer (genetichealthservice.org.nz). early as possible and has several benefits, including improved survivorship. Provide testing recommendations. The healthcare professional should discuss with Primary care to discuss the benefits and the person and their whanau the benefits and harm harms of Prostate Specific Antigen (PSA) testing with person/whanau in a "shared of PSA testing. decision making" model. For prostate cancer modifiable risk factors include: weight management and waist circumference Refer to clinical genetic services where hypertension appropriate. • anyone who has ever smoked. Discuss recent weight changes and monitor For prostate cancer non-modifiable cancer risks weight. include: If signs and symptoms of cancer are present • increasing age, especially for persons over 50 refer to 'Step 3: Presentation, initial investigation and referral' below. • ethnicity (e.g., Māori and Pacific men are less Communication likely to be diagnosed with prostate cancer and when they are diagnosed tend to have Ensure the person and their whanau understands: higher grade disease). PSA testing, and that they have the reference • a family history of prostate cancer to the decision support tool Kupe • having certain germline mutations, (www.kupe.net.nz) • occupational exposure e.g., cadmium, night shift work when they should receive their results and possible hereditary and/or inheritable risks how to follow up if they don't receive their such as: results their family history suggests a pathogenic what's involved if they need to be transferred BRCA2 gene variation to a specialist service. • three first or second-degree relatives have been diagnosed with prostate cancer • two first or second-degree relatives have been diagnosed with prostate cancer, with one relative being diagnosed before the age of 50 years (RACGP 2019) • voung at age of diagnosis (50-55) in a patient or first degree-relative there is a family history of prostate, breast or ovarian cancer or Lynch Syndrome. PSA testing is not recommended for asymptomatic men aged > 75, or where life expectancy <10-years.

Step 3: Presentation, initial Step 3: Checklist investigations, and referral This step outlines how to initiate the appropriate Record signs and symptoms. investigations and referrals to specialist/s in a All people with a high suspicion of cancer timely manner for the person and their whanau have a person to coordinate care. with prostate cancer. Complete all cancer assessments. The types of investigations undertaken will depend on many factors, including the preferences of the Inform the person and their whanau of person and their whānau. preliminary results. Signs and symptoms of prostate cancer to Referral options of cancer care are discussed investigate include: with the person and their whanau, including • lower urinary tract symptoms: slow flow, cost implications if private provider urgency, frequency, nocturia requested. urinary retention Complete and record supportive care pelvic pain needs assessment and refer to allied health decline in kidney function from obstruction of services as required. ureteral orifices blood in the urine or semen. Inform the person and their whanau of cultural services and relevant support groups A small percentage of people present with available. metastatic disease and may have the following symptoms: Initiate referrals and arrange further · back or bone pain investigation. leg swelling weight loss **Timeframe** fatigue If there is a high suspicion of prostate cancer. neurological symptoms including weak or submit referral immediately to hospital numb legs or feet. specialist services. Prostate cancer assessment includes the relevant: High suspicion of cancer referral is triaged • medical history, including medications: voiding within 1-2 working days and referrer is symptoms, International Prostate Symptom notified. Score (IPSS), lower urinary tract infection Confirm that the person referred urgently history, PSA with a high suspicion of cancer should have physical examination: Eastern Cooperative investigations completed within 2 weeks or Oncology Group (ECOG) Performance Status will attend their first specialist assessment Scale, frailty assessment, weight, Body Mass (FSA) clinic within 2 weeks. Index (BMI), Digital Rectal Exam (DRE). The DRE should not be a barrier to testing for prostate Communication cancer or for referral and is highly recommended Explain to person and their whanau that they • investigations (laboratory and radiology) PSA, are being referred to a hospital specialist renal function, urine culture service and why, including: • one-off elevated PSA requires a repeat for how long this may take confirmation in 6 weeks elevated PSA with symptoms of infection who to contact if their symptoms change requires a urine culture how to follow up if they do not receive their • in general, do not check a PSA if a Urinary specialist appointment within the specified Tract Infection (UTI) or prostatitis is clinically timeframe suspected, until a urine culture is negative, or an infection has been treated successfully Benefits, risks, and implications to testing for consider specialist referral if DRE is suspicious prostate cancer is discussed with the person for cancer at any PSA level. and their whānau.

- people with PSA levels above the age adjusted thresholds, should be referred to Urology for
 - o age 70 or less with PSA 4.0 or greater
 - o age 71 to 75 years with PSA 6.5 or greater
 - o age 76 years or more PSA 20 or greater
 - o urologist will then order an MRI prior to biopsy (where possible).

MRI has demonstrated reduced detection of clinically insignificant cancers and improved detection of significant cancers.

Adjunct tests such as PSA density, PSA velocity, fre to total PSA ratio can further help clinicians assess risk of a clinically significant prostate cancer and a requirement for biopsy.

- family/whānau history: including prostate cancer history of father or brothers, especially if prostate cancer diagnosed at a younger age family history of BRCA2 mutations, female family members with history of breast or ovarian cancer.
- 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 the following red flags, the referral should be triaged as a high suspicion of cancer:

- PSA > 50 and new renal failure (a decline in eGFR of 50% from baseline)
- radiological evidence suggests locally advanced or metastatic disease

Initial referral should be to the urologist who will determine relevant imaging studies which may include prostate MRI, bone scan and/or PSMA PET scan.

If advanced disease is diagnosed, the urologist ma discuss at MDM and refer to radiation oncology or medical oncology as indicated.

If a person presents with suspected advanced and acute metastatic cancer symptoms such as cauda equina, they should be sent to the emergency department for urgent evaluation.

d	The Kupe decision support tool can aid this discussion. (www.kupe.net.nz)
	Abnormal PSA results are discussed with the person and their whānau and information (including the significance of an abnormal results and the steps in evaluation) provided.
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Step 4: Diagnosis, staging and Step 4: Checklist treatment planning This step outlines the process for confirming the Confirm diagnosis. diagnosis and stage of cancer and the planning of Referral to a cancer care coordinator. subsequent treatment. П Record staging, performance status and Diagnosis for prostate cancer may include: comorbidities. • physical examination: DRE (prior to biopsy) radiology: MRI, Ultrasound Scan Discuss/register the person at a multidisciplinary meeting (MDM) and inform pathology: biopsy the person and their whanau of the treatment laboratory: PSA decision. Staging for prostate cancer requires: Consider enrolment in clinical trial. • DRE, PSA and Gleason score for clinical staging prostate MRI Consider fertility consequences with pelvic MRI if a biopsy has already been taken treatment and refer to fertility specialist as PSMA PET CT for high-risk prostate cancer required. CT abdomen and pelvis for those not eligible Assess supportive care needs and refer to for PSMA PET CT or for suspected metastatic allied health services as required. disease. Ensure primary or secondary prehabilitation **Performance status:** to optimise overall well-being is initiated. ECOG or Karnofsky scale Referral to prostate specific support services Geriatric assessment. as required: advice on pre-surgical pelvic floor **Multidisciplinary** meeting exercises • Persons with prostate cancer, meeting the exercise programs for the person having criteria as specified by MDM Terms of Androgen Deprivation Therapy (ADT) Reference, will be discussed and/or registered • following completion of primary cancer at an MDM. treatment, rehabilitation programs have considerable potential to enhance Familial cancer risk physical function. Further investigations may be required if: Give the person and their whanau • young age at diagnosis information on Cancer Society, Prostate previous history of other types of cancer Cancer Foundation and/or relevant cultural relevant family history services and available support groups. high volume metastatic disease/castrate Benefits, risks, and implications to resistance investigations for prostate cancer is abnormal immunohistochemistry/other discussed with the person and their relevant histological abnormalities whānau. The Kupe decision support tool can abnormalities on tumour genomic testing aide this discussion (www.kupe.net.nz) **Treatment planning Timeframe** Optimal cancer care requires a multidisciplinary If required, an MDM should occur within 2 weeks of approach to ensure treatment plans are tailored to the suspected or confirmed diagnosis. an individual's needs in collaboration with the whānau and health care team. Communication The lead clinician and team are responsible for: providing information, support, and adequate time to decide whether they wish to undergo prostate biopsy including an explanation of the risks and benefits of prostate biopsy

	discussing a timeframe for diagnosis and treatment options with the person and their whānau
	explaining the role of the MDM team in treatment planning and ongoing care
	encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care while clarifying wishes, needs, beliefs, and expectations of the person and their whānau and their ability to comprehend the communication
	providing appropriate information and referral to support services as required
	communicating with the GP of the person and their whānau about the diagnosis, treatment plan and recommendations from the MDM.

Step 5: Treatment Step 5: Checklist This step describes publicly funded optimal There are several options for curative intent treatments for prostate cancer by suitably trained treatment depending on the person and and experienced clinicians and team members. in disease factors. People should be offered the an appropriate environment. opportunity to have a consultation with both a urologist and radiation oncologist. Establish the intent of treatment: Health providers/professional, treating curative – to cure the cancer completely specialist has relevant qualifications. tumour control - to stop the cancer growing experience, and expertise. and spreading Discuss the intent of treatment and the risks palliative - to manage symptoms caused by the and benefits with the person and their cancer. whānau. **Treatment options** Provide the agreed treatment plan with the person, their whanau and GP. Watch and wait - The aim of watch and wait is to conservatively monitor and observe for Assess supportive care needs and refer to development of symptoms or disease progression allied health services as required. based on PSA levels and DRE results, for people Give the person and their whanau suitable for palliative, rather than curative, information on available cancer nontreatment. Treatment is initiated when necessary to governmental organisations (NGOs) cultural reduce the impact of prostate cancer symptoms on services and support groups. quality of life in a person with a limited life Consider early referral to palliative care if expectancy. appropriate. Active Surveillance - may be suitable for persons Discuss advanced care planning with the person with very low risk, low risk or favourable and their whānau. intermediate risk prostate cancer as defined by National Comprehensive Cancer Network (NCCN). **Timeframes** Persons are regularly monitored for signs of disease Based on clinical need, surgery/radiation progression so curative treatment can be initiated if therapy should begin within 4 weeks of necessary. diagnosis if high risk or within 4 months if low to intermediate risk and asymptomatic.

Surgery - (radical prostatectomy) may be suitable ☐ Based on clinical need, systemic therapy for persons with localised or locally advanced should begin within 4 weeks of diagnosis if high risk or extensive metastatic disease is prostate cancer, with at least 10 years life present on imaging or within 4 months if expectancy. asymptomatic. Radiation therapy - (external beam radiation therapy and/or brachytherapy) should be offered Communication to suitable people. Some people will receive The lead clinician and team are responsible for neoadjuvant / adjuvant hormone therapy with discussing these areas with the person and their radiation therapy. whānau: Systemic therapy - people with newly diagnosed castrate-sensitive metastatic prostate cancer, and if treatment options including the intent of clinically appropriate, a consult with medical treatment, timeframes for treatment, risks, oncology regarding the addition of systemic and benefits treatment to androgen deprivation (hormone) advance care planning therapy should be considered. This should occur within 2 months of starting hormone therapy, and options for healthy lifestyle support to may include remote consultations, if necessary, so improve treatment outcomes such as exercise they are fully informed when making decisions and nutrition. about their systemic treatment options (e.g. primary care may be involved in the chemotherapy, novel hormonal therapies). management of the person on active Most persons with metastatic disease that becomes surveillance, watch and wait or androgen castrate resistant also need to consult with a deprivation therapy. medical oncologist (Prostate QPI report, 2019). Treatment of advanced or metastatic prostate cancer may involve: Androgen deprivation therapy (ADT) is the standard treatment for the person with advanced prostate cancer. There is little survival benefit related to initiating ADT treatment early (rather than later). Other systemic therapy may be beneficial for the person with metastatic disease, cytotoxic chemotherapy, novel androgen receptor signalling inhibitors, bisphosphonates and RANK ligand inhibitors may be of benefit. Palliative care – Early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.

Step 6: Care after treatment Step 6: Checklist The person and their whanau access appropriate Provide a survivorship plan that includes a follow up and surveillance and are supported to summary of the treatment and follow-up care achieve their optimal health after cancer treatment. plan to the person, whanau and their GP. Provide a summary of the treatment and follow-up Assess supportive care needs and refer to care plan to the person, their whanau and their GP allied health services as required. outlining: Give the person and their whanau diagnosis, including tests performed and information on Cancer Society and/or relevant cultural services and support groups treatment received (types and date) available. current toxicities (severity, management and expected outcomes)

Primary care may be involved in the interventions and treatment plans from other management of the person on active health providers/professionals surveillance, watch and wait or androgen potential long-term and latent effects of deprivation therapy. treatment and care of these supportive care services provided Communication a follow-up schedule, including tests required and timing The lead clinician and team are responsible for: contact information for key health care providers/ professionals who can offer support explaining the treatment summary and follow for lifestyle modification up and surveillance care plan to the person and their whānau. a process for rapid re-entry to medical services for suspected recurrence informing the person and their whanau about ongoing assessments of the effects of secondary prevention and healthy living treatment such as: discussing the follow-up care plan with the erectile and eiaculation dysfunction GP of the person and their whanau and impotence urinary dysfunction providing guidance for rapid re-entry to bowel dysfunction specialist services. o peripheral neuropathy o depression as a result of ADT

o weight gain and fluid retention

Step 7: Palliative and end-of-life Step 7: Checklist care Palliative and end-of-life care provides the person Early referral to palliative care services as facing life-limiting conditions and their whanau required. with holistic support and coordinated services Refer to supportive care services as required. based on their specific needs. Make sure the person and their whanau are Palliative care may be provided through: aware of the prognosis and what to expect hospital palliative care when someone is dying. home and community-based care Discuss activation of advance care plan. community nursing, including access to directive, or enduring power of attorney. appropriate equipment. Early referral, identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering. End-of-life care should consider: appropriate place of care person's preferred place of death support needed for the person and their whānau. Awareness of and access to, assisted dying services should be available if the person and their whanau raise this with the health care team. Communication A key way to support the person and their whanau is by coordinating ongoing, clear communications between all health providers/professionals involved in providing cancer care.

How optimal cancer care pathways improve outcomes

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

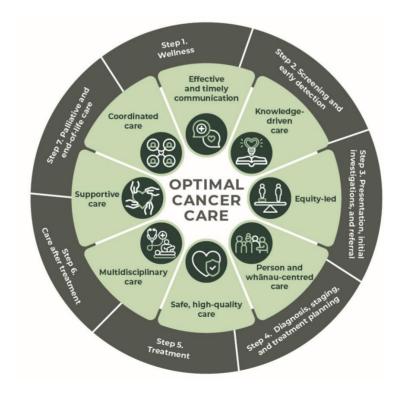
OCCPs are a framework for achieving health equity² in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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



² Optimal Cancer Care Pathway Supplementary Information

Principles of the optimal cancer care pathway

The principles³ 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



³ Optimal Cancer Care Pathway Principles



Optimal timeframes

Evidence based guidelines, where they exist, are used to inform clinical timeframes. Shorter timeframes for appropriate investigations, consultations and treatment can provide an improved experience for people and their whānau and better cancer outcomes. The three steps shown below are a guide for health providers/professionals and the person/whānau on the optimal timeframes for being assessed and receiving treatment. These timeframes are based on expert advice and consultation with the New Zealand Urology Clinical Directors' Group.

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
Step 3: Presentation, initial investigations, and referral	Initial investigations started by GP	If symptoms suggest prostate cancer, the person and their whānau are referred to urology services within 2 weeks.
	Referral to a hospital specialist	The person should see a specialist or have investigations within 2 weeks when the referral is triaged as a high suspicion of cancer.
	Diagnosis and staging	For a high suspicion of cancer referral, investigations should be completed within 2 weeks.
Step 4: Diagnosis, staging, and treatment planning	Multidisciplinary team meeting and treatment planning	Where appropriate, MDM takes place within 2 weeks of confirmed diagnosis and staging.
Step 5:	Neoadjuvant/adjuvant chemotherapy, radiation therapy or surgery	Surgery should be conducted or begin radiation therapy within 4 weeks of diagnosis for high-risk disease, or within 4 months if low to intermediate risk and asymptomatic.
Treatment		ADT or other systemic therapy treatment should begin within 4 weeks of the diagnosis if high risk or extensive metastatic disease is present on imaging or within 4 months if asymptomatic.

Optimal cancer care pathway

Seven steps of the optimal cancer care pathway

Step 1: Wellness

Step 2: Early detection

Step 3: Presentation, initial investigations, and referral

Step 4: Diagnosis, staging, and treatment planning

Step 5: Treatment

Step 6: Care after treatment

Step 7: Palliative care and end-of-life care

There are around 4,300 new prostate cancer cases and 750 deaths a year, making it one of the leading causes of cancer death in Aotearoa New Zealand. It remains the most common cancer to affect men nationwide, regardless of ethnicity, and results in significant morbidity (Te Aho o Te Kahu Quality Performance Indicators for prostate cancer).

Health outcomes, for prostate cancer, in Aotearoa New Zealand contribute to ethnic inequities with mortality rates higher for Māori (17.0 deaths per 100,000) compared with non-Māori (12.5 deaths per 100,000) (Prostate QPI Description Ministry of Health 2019c).

Māori are more likely than men of European or other ethnic descent to be diagnosed following presentation to an emergency department (8.4% and 5.8% respectively). Reasons for this are unclear but may include variation in access to primary health care. Pacific and Asian people at 10.7% and 8.0% respectively, were also diagnosed following a presentation at an emergency department. People living in areas of high social deprivation are more likely to be diagnosed following presentation at an emergency department (8.7%) than people living in areas of low social deprivation (3.9%).

Māori are also more likely to receive publicly funded curative treatment at 37.4% compared to 27.9% for European and other nationalities. Māori are also more likely to receive publicly funded curative radiation treatment (20.0% compared to 12.6%). People aged 50–59 are less likely to see a radiation oncologist prior to radical prostatectomy (14.5%) than people aged 60–69 (21.7%).



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 reduce the risk of cancer (and other conditions) with the person and their whanau and communities. Te Aho o Te Kahu (2022) produced a report outlining evidence-based, best-practice interventions to prevent cancer. Reducing cancer risk factors addresses work to achieve the goals of fewer cancers, better survival, and equity for all.

1.1 Te Tiriti o Waitangi

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

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

1.2 Modifiable cancer and wellbeing risks

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

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

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

1.3 Communication with the person/whānau receiving care

Health providers

• Raise and discuss any modifiable risk factors.

• Provide information and education regarding access to wellness programmes, including kaupapa Māori services.

Discuss advance care planning, advance directive and/or (Enduring Power of Attorney (EPA) as required (refer Principle 1)¹.

"Whānau look at prevention holistically." Person/whānau insiahts

Communication between health services

Inform the person and their whanau 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).
 - o 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.
 - o The number of vapers (aged 15 years and above) who have tried vaping and vape at least once a day as measured by the New Zealand Health Survey, by gender and ethnicity.
- The New Zealand Heath survey (NZHS) provides information about the health and wellbeing of New Zealanders.
 - Health status and behaviours.
 - Risk factors.
 - Access to health care.

Step 2: Early detection

This step outlines options for the early detection for the person with suspected prostate cancer.

2.1 Te Tiriti o Waitangi

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

- making sure 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 early detection programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to services

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

2.2 Early detection

Early detection focuses on identifying cancer as early as possible and has several benefits, including improved survivorship.

There is no national population-based prostate cancer screening programme.

Currently, PSA testing of individual men in primary care is opportunistic (that is, is offered during a routine or unrelated primary care visit, rather than as part of an organised, population-based screening programme). While while evidence is evolving, there isn't yet consensus on when PSA testing should be offered, and guidelines differ.

The healthcare professional should discuss with the person and their whanau the benefits and harm of PSA testing. The discussion should consider prostate cancer risk factors (refer 2.3), and familial cancer risk factors (refer 2.3.1).

Benefits include early detection leading to decreased morbidity and mortality from cancer. Risks include infection with biopsy and potential overtreatment with quality-of-life side effects including voiding, bowel, and sexual dysfunction.

The person and their whanau should be provided with information on the prostate cancer decision support tool (www.kupe.net.nz).

PSA testing is not recommended for asymptomatic men >75, or where life expectancy is <10 years.

For further recommendations on prostate specific antigen (PSA) testing refer to www.usanz.org.au/info-resources/position-statements-guidelines#PROSTATE

2.3 Prostate cancer risk factors⁴

While the causes of prostate cancer are not fully understood, there are some factors associated with an increased risk of developing the disease.

2.3.1 modifiable risk factors

- weight management and waist circumference
- hypertension
- anyone who has ever smoked.

2.3.2 Non-modifiable cancer risks

- increasing age, especially for persons over 50 years
- ethnicity (e.g., Māori and Pacific men are less likely to be diagnosed with prostate cancer and when they are diagnosed tend to have higher grade disease).
- a family history of prostate cancer (refer 2.3.1)
- having certain germline mutations, (refer 2.3.1)
- occupational exposure e.g., cadmium, night shift work

Currently there are no known effective preventative dietary or pharmacological interventions for prostate cancer (European Association of Urology, 2024, Prostate Cancer Guidelines).

2.3.3 Familial cancer risk

Some people may have an increased risk of developing prostate 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. Health providers encourage and support the person and their whānau to follow surveillance guidance if an increased risk of familial cancer is identified. Genetic testing can look for changes in some genes which are known to cause an increased risk of prostate cancer.

The healthcare professional discusses with the person and their whānau the possible hereditary and/or inheritable risks if:

- their family history suggests a pathogenic BRCA2 gene variation
- three first or second-degree relatives have been diagnosed with prostate cancer
- two first or second-degree relatives have been diagnosed with prostate cancer, with one relative being diagnosed before the age of 50 years (RACGP 2019)
- young at age of diagnosis (50-55) in a patient or first degree-relative
- there is a family history of prostate, breast or ovarian cancer or Lynch Syndrome.

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

2.4 Communication with the person/whānau receiving care Health providers/professionals

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

Communication between health services

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

2.5 Measuring and monitoring

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

Faster Cancer Treatment

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

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

Step 3: Presentation, initial investigations, and referral

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

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

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

Māori have worse outcomes from prostate cancer than non-Māori. Proactively discuss and follow-up early detection of prostate cancer with at-risk Māori men. Māori men are half as likely to have a PSA test and are diagnosed at a later stage of disease. They are twice as likely as non-Māori to die from prostate cancer (Community HealthPathways).

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

Most people who present with prostate cancer are asymptomatic, particularly those with early and potentially curable prostate cancer. Voiding symptoms are most likely from benign prostatic hyperplasia (BPH). However, some people may present with the following symptoms:

- Lower Urinary Tract Symptoms (LUTS): slow flow, urgency, frequency, nocturia
- urinary retention
- pelvic pain
- decline in kidney function from obstruction of ureteral orifices
- blood in the urine or semen.

A small percentage presenting with metastatic disease may have the following symptoms:

- back or bone pain
- leg swelling
- weight loss
- fatigue
- neurological symptoms including weak or numb legs or feet.

The person is assessed for signs and symptoms of prostate 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.

3.3 Assessment

Prostate cancer assessment includes relevant:

- medical history, including relevant medications: voiding symptoms based on International Prostate Symptom Score (IPSS), lower urinary tract infection history, **PSA**
- physical examination, including performance status, frailty assessment, weight, BMI, digital rectal examination. DRE should not be a barrier to testing for prostate cancer or for referral but is highly recommended
- laboratory and radiological investigations including PSA, renal function, urine culture noting:
 - o a one-off elevated PSA is repeated at six weeks
 - o urine culture is required when an elevated PSA is identified
 - o in general when prostatitis is clinically suspected, do not check PSA if a UTI is present or until a urine culture is negative or an infection has been treated successfully.
 - a PSA above the age adjusted threshold, requires the person to be referred to urology for review
 - age 70 or less PSA 4.0 or greater
 - age 71 to 75 years PSA 6.5 or greater
 - age 76 years or more PSA 20 or greater
 - o urologists may order a MRI prior to biopsy as:
 - MRI has been shown to reduce detection of clinically insignificant cancers and improve detection of significant cancers.
 - Adjunct tests such as PSA density, PSA velocity, free to total PSA can further help specialist clinicians assess risk of clinically significant prostate cancer and need for biopsy
 - o digital rectal examination (DRE) suspicious for cancer with any PSA, a specialist referral should be considered, with the patient seen by a urologist for clinical examination prior to imaging.
- familial cancer history: including prostate cancer history of father or brothers, especially if prostate cancer diagnosed at a younger age, family history of BRCA2 mutations, female family members with history of breast or ovarian cancer.
- social history.

3.4 Initiate investigations, including referrals

Referral will be required for any red flags indicating a high suspicion of prostate cancer (HSCAN definitions, BPAC and Community Health Pathways). The referral should be triaged as an 'HSCAN' if:

- PSA > 50 and new renal failure (a decline in eGFR of 50% from baseline)
- radiological evidence suggests locally advanced or metastatic disease

Initial referral will be to urology where relevant imaging such as a prostate MRI, bone scan or PSMA PET-CT scan may be requested. The urologist will determine the indication for a prostate biopsy. If there is advanced disease diagnosed, the urologist may discuss at MDM and refer to radiation oncology or medical oncology as indicated.

For the person presenting with a PSA > 50 and acute neurological symptoms (i.e., spinal cord compression, cauda equina) they should be sent to the emergency department for urgent evaluation.

Timeframe for completing investigations for the person with suspected prostate cancer

Optimally, investigations should be completed within 2 weeks.

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

When referring a person and their whanau 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
 - o financial
 - o family situation that may impact on the decision to consent to a procedure
 - o 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.

Timeframe for referring to a specialist

Any person with symptoms suspicious of prostate cancer is referred to a specialist following guidelines in Health Pathways. The specialist should see the person with proven or suspected cancer and their whanau within 2 weeks for a high suspicion of cancer referral. If necessary, prior discussion should facilitate referral (Health Pathways 2024).

Referrals must be triaged in a timely manner within 1-2 working days by an appropriately trained person (trained nurse or doctor) and consistent with FCT Business Rules and/or other prioritisation classification criteria.

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 whanau. Where appropriate, give them:

- management of physical (lower urinary tract) symptoms including difficulty starting to urinate, frequent urination (particularly at night), difficulty stopping the flow of urine and poor urine flow, incontinence, and sexual dysfunction issues
- encourage and support to increase levels of exercise
- access to investigations and care following referral, such as financial, transport and personal support
- help for dealing 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

- Benefits, risks. and implications to testing for prostate cancer is discussed with whanau. The Kupe decision support tool can aide this discussion (www.kupe.net.nz).
- Abnormal PSA results are discussed with the person and their whānau and information (including the significance of an abnormal results and the steps in evaluation) provided.
- Provide information regarding their role in the health care team.
- Explain who the person and their whanau 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 whanau 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.

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.

"Whānau face multiple barriers to primary care". "That safety net had been taken awav."

Person/whānau insights

- 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 date 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.

• 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:

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- o 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 whanau.

Health services work with the person and their whanau 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 whanau, 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 whanau and clinicians about current or intended use of rongoa or other complementary therapies to understand the potential benefits, risks and/or other implications
- consultation with the person and their whanau 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 prostate 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 and may request additional investigations. This may be before or after the first specialist appointment.

- Physical examination: DRE (prior to biopsy) is required for clinical staging by the Urologist. A significant nodule on exam is an indication for prostate biopsy. Investigative risks are relayed and may include infection with biopsy or potential overtreatment with quality-of-life side effects including voiding, bowel, and sexual dysfunction. Some early prostate cancers can be treated with Active Surveillance avoiding the impact to quality-of-life from active treatment.
- PSA Interpretation: A PSA density (PSAD) of 15 % and PSA velocity (PSAV) of 1.5 mcg/L increase over 2 years for PSA <10 may be factors influencing a decision to biopsy.
- Radiology: For biopsy naïve or prior negative biopsy, an MRI may be requested. A standard pre-biopsy multiparametric or biparametric prostate MRI should be completed and interpreted by a radiologist with adequate training and experience, and in accordance with PIRADS standards. In many cases with a normal MRI, a biopsy can be avoided. Prostate cancer index lesions are not seen on MRI in 15% of cases.

In some cases, it may be appropriate to proceed directly to a biopsy of the prostate without a prior MRI, at the discretion of the urologist.

- Pathology: Based on MRI findings a systematic and targeted prostate biopsy may be performed.
- Negative Biopsy: The person may still need to be followed closely for a time after a negative prostate biopsy if there is suspicion of a missed cancer on biopsy. Suspicion may result from a prostate nodule or an MRI lesion that was difficult to target. If no pre-biopsy MRI was obtained and a post-biopsy MRI shows a lesion that may not have been targeted, then a re-biopsy is indicated especially for anterior lesions. If there is an elevated PSAD or significant PSAV, or presence of ASAP on histology with additional concerning parameters, then a repeat biopsy may be indicated. HGPIN does not require a repeat biopsy.

Timeframe for completing investigations

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

4.3 Staging

Staging is a critical element in treatment planning and should be clearly documented in the patient's medical record. 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.

For prostate cancer, the Tumour, Node, Metastasis (TNM) classification is used, with clinical staging based on DRE only (EAU, 2024). The following additional tests may be required and should be reported separately.

- CT abdomen/pelvis with bone scan is the conventional staging for people who are not eligible for PSMA PET or for suspected metastatic disease.
- Prostate MRI multiparametric MRI (mpMRI) or biparametric MRI (bpMRI) is standard pre-biopsy to assess prostate size, PI-RADS score and regional staging of pelvic lymph nodes and bones.
- Indication for systemic staging imaging is National Comprehensive Cancer Network (NCCN) Unfavourable Intermediate Risk (ISUP 3 or 50% of cores positive or cT2b/cT2c with PSA>10). Consider conventional staging in this group of patients based on patient
- Biopsy if a biopsy is completed without an MRI, then local staging with pelvic MRI will occur.
- PSMA PET for high-risk prostate cancer (PSA>20, Gleason ≥8, T3a) that are otherwise suitable for locoregional therapy with curative intent.

PSMA PET has a 10-15% false negative rate in pre-treatment staging for disease outside the prostate. Index prostate lesions that are weakly PSMA avid on PET may not show small volume disease outside the prostate. Patients with risk factors supporting pelvic lymph node dissection at the time of surgery should still have lymph node dissection if the PSMA PET shows no avid pelvic lymph nodes.

Pathological staging occurs after surgery, and synoptic reporting is encouraged.

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). For prostate cancer the Karnofsky scale, indicating functional impairment, may be used. The degree of benefit with 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). Geriatric assessment tools can be used to identify those who will benefit most from these comprehensive assessments.

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

4.5 Clinical genetics

A clinical genetic services assessment may be considered for prostate cancer if there are genetic predispositions, such as:

- young age at diagnosis
- previous history of other types of cancer
- relevant family history
- high volume metastatic disease/castrate resistance
- abnormal immunohistochemistry/other relevant histological abnormalities
- · abnormalities on tumour genomic testing.

For further information visit Genetic Health Service New Zealand website.

4.6 Multidisciplinary meeting

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

Referral to prostate cancer MDM following nationally agreed referral criteria where available, is undertaken to inform treatment recommendations, further assessment and/or 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 whanau, their overall condition, comorbidities, 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.
- Consider discussing NCCN very low risk or low risk people at MDM prior to treatment with surgery or radiation. The person and their whanau will still have the option of choosing active treatment despite recommended active surveillance. Gleason (3+3) cancers can be NCCN intermediate risk and appropriate for standard active treatment with surgery or radiation if they have a PSA>10, stage cT2b or cT2c, or 50% positive cores.

Wellness Early detection Presentation, initial investigations, and referral planning Care after treatment treatment of life care

- 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:

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

4.6.1 Treatment options and recommendation

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

Treatment, referral options, timeframes for treatment, 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. For the person with prostate cancer, the multidisciplinary team should consider these specific prehabilitation assessments and interventions for treatment-related complications or major side effects:

- conducting a physical and psychological assessment to establish a baseline function level
- identifying impairments and providing targeted interventions to improve the persons function level
- reviewing the persons medication to ensure optimisation and to improve adherence to medicine used for comorbid conditions
- all people undergoing radical prostatectomy should be informed, before treatment begins, of the importance of pelvic floor exercises and may be considered for a referral to be seen by a pelvic floor specialist (continence nurse, Urology CNS, or physiotherapist)

Presentation, initial Diagnosis, staging Wellness Early detection investigations, and referral planning Care after treatment of life care

- exercise programs for the person having ADT. Following completion of primary cancer treatment, rehabilitation programs have considerable potential to enhance physical function
- smoking cessation
- 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 with cancer and their whānau are offered and supported to participate in research or clinical trials. Many emerging treatments are only available as clinical trials and may require referral to specific trial centres.

4.7 Supportive care and communication

4.7.1 Care coordination

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

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

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

4.7.2 Supportive Care

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

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

4.7.3 Communicating with the person/whānau receiving care

Health providers/professionals

- Provide information, support, and adequate time to decide whether they wish to undergo prostate biopsy including an explanation of the risks (not forgetting the increased chance of having to live with the diagnosis of clinically insignificant prostate cancer) and benefits of prostate biopsy.
- 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 and resources in a format that is useful to the person and their whanau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whanau from accessing services or attending treatment.
- Discuss with the person and their whanau 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 whanau have understood the information that has been communicated.
- The person and their whanau 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 whanau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whanau the need to update or complete their advance care planning and/or advance directive.

Communicating between health services

- Coordinate appointments among health services, in discussion with the person and their whānau to make best use of their time and resources and to support access.
- Communicate the diagnosis, MDM recommendations, treatment plan, and timeframes for treatment 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 Prostate Cancer Quality Performance Indicators
 - o PCQI 1. Route to diagnosis: Proportion of men with prostate cancer who are diagnosed following presentation to an emergency department (Te Aho o Te Kahu, 2021).
 - PCQI 5. Discussion with radiation oncologist before radical prostatectomy: Proportion of people with prostate cancer being considered for radical prostatectomy who see a radiation oncologist before treatment, including remote consultations.
 - o PCQI 6. Medical oncology review of patients with advanced disease: Proportion of people with advanced prostate cancer who see a medical oncologist.

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

Person/whānau insights

• MDM Standards

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

- o Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand (Te Aho o Te Kahu 2024)
- o 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 prostate cancer by trained and experienced clinicians and team members, in an appropriate environment.

The treatment of prostate cancer is informed by the following guidelines:

- European Association of Urology Guidelines, 2024 Edition
- National Comprehensive Cancer Network, NCCN clinical practice guidelines in oncology – prostate cancer, version 4, 2023
- European Society for Medical Oncology 2020, Prostate cancer: EMSO clinical practice quidelines
- National Institute for Health and Care Excellence 2019, Prostate cancer: diagnosis and management.

5.1 Te Tiriti o Waitangi

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

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

5.2 Treatment intent

The treatment intent should be documented in the person's medical record and shared with the person and their whanau as appropriate. Discuss the advantages and disadvantages of recommended treatments and associated side effects in plain language to support the person and their whanau 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 and or service early can benefit the person receiving care, so it is important to know and respect each person's preference.

The person's current or intended use of any traditional or complementary therapies, including rongoa, 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 whanau before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive).

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 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.

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 prostate cancer depends on the type, stage and location of the cancer and the person's age, health, and preferences. Treatment may include a combination of the items listed below, concurrently, or sequentially, to maximise optimal outcome.

The person may also be supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centres.

There are multiple modality options for treatment where the intent is curative. Treatment with curative intent as determined by the person and disease factors, should be offered an opportunity to consult with both a urologist and radiation oncologist.

Watch and wait

The person is observed and monitored for development of symptoms or disease progression based on PSA levels and DRE results. If necessary, palliative, rather than curative, treatment is initiated to reduce the impact of prostate cancer symptoms on quality of life.

Active Surveillance

Active surveillance may be suitable for the person with NCCN very low risk, low risk and favourable intermediate risk prostate cancer. The person is regularly monitored for signs of disease progression so curative treatment can be initiated if necessary. There is no universally accepted active surveillance protocol, but all are based on regular clinical monitoring (PSA/DRE) and interval tumour reassessment (repeat biopsy/MRI).

If patients are undergoing active surveillance, general practices should:

- clearly identify this on practice records
- o set recalls and reminders for monitoring as per their management plan
- communicate the management plan to other relevant healthcare providers, including when a person moves to a new practice.
- Surgery (radical prostatectomy)

Surgery may be suitable for people with localised or locally advanced prostate cancer with at least 10 years life expectancy.

People with biochemical recurrence after a radical prostatectomy have improved cancer specific outcomes with early salvage radiotherapy +/- pelvic lymph node radiation and ADT. A RAVES trial comparing adjuvant and early salvage radiation for high risk or biochemically recurrent prostate cancer post radical prostatectomy supported the use of early salvage radiotherapy. The results identified that biochemical control was similar to adjuvant radiotherapy, sparing around half of people from pelvic radiation, and is associated with significantly lower genitourinary toxicity (Kneebone et al. 2020).

A decision on salvage protocols should consider the risks based on pathologic staging, grade, margin status and Gleason pattern at any positive margin, time to biochemical failure and PSA doubling time after recurrence. There is no consensus on the PSA value or when salvage therapy should be offered. Evidence shows earlier treatment is better. Consider early empiric therapy based on risk factors rather than waiting for a PSMA PET scan or when PSA rises to 0.5 mcg/L. Biochemical control with salvage radiation is higher when delivered at PSA levels < 0.6.

Timeframes for starting surgery

Surgery should be conducted within 4 weeks of diagnosis if high risk or within 4 months if low to intermediate risk and asymptomatic.

Radiation therapy

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

Radiation therapy (by external beam radiation therapy and/or brachytherapy) should be offered to suitable people. Some people will receive neoadjuvant / adjuvant hormone therapy with radiation therapy. Radiation therapy may provide symptom relief for people with locally advanced or metastatic prostate cancer.

Timeframes for starting radiation treatment

Radiation treatment should begin within 4 weeks of diagnosis if high risk or within 4 months if low to intermediate risk and asymptomatic.

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).

Most people with newly diagnosed castrate-sensitive metastatic prostate cancer, and if clinically appropriate, a consult with medical oncology regarding the addition of systemic treatment to androgen deprivation (hormone) therapy should be considered. This should occur within 2 months of starting the therapy, and may include remote consultations, if necessary, so they are fully informed when making decisions about their systemic treatment options (e.g., chemotherapy, novel hormonal therapies).

Other systemic therapies may be beneficial for persons with metastatic disease and should be considered for discussion at an MDM. They may be used as monotherapy for relapse after local treatment or in combination with androgen deprivation therapy combined with radiation therapy for localised or locally advanced disease.

There should be a clear understanding with the care team as to who will undertake monitoring: the general practitioner, medical oncologist, urologist, or radiation oncologist.

Timeframes for starting systemic anti-cancer treatment

Treatment should begin within 4 weeks of the diagnosis if high risk or extensive metastatic disease is present on imaging or within 4 months if asymptomatic. Cytotoxic chemotherapy, novel androgen receptor signaling inhibitors, bisphosphonates and RANK ligand inhibitors may be of benefit.

• 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 whanau 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 whanau may experience.

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

- mood lability or depression as a result of androgen deprivation therapy, which may benefit from referral to a psychologist or consideration of mood-stabilising medication
- erectile and ejaculation dysfunction and impotence as a result of treatment, which may require referral to a medical specialist and/or nurse practitioner skilled in counselling in this area
- urinary dysfunction, including urinary incontinence, requiring pads, referral to a continence nurse and/or pelvic floor physiotherapist
- bowel dysfunction or rectal bleeding, which may require referral for endoscopic evaluation and dietitian review
- · weight gain and fluid retention, and fatigue and loss of muscle mass as a result of ADT, which may require referral to a dietitian for review and referral to an exercise physiologist or physiotherapist for an individualised exercise programme
- complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required.

5.3.1 Clinical Trials

The person and their whānau are 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 whanau 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 prostate 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 these side effects is important in protecting the person's quality of life
- managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications - referral to a pharmacist may be required
- 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.

Presentation, initial Diagnosis, staging Wellness Early detection investigations, and reatment planning Investigations and treatment planning International Presentation investigations and detection Investigations and Investigation and Investigatio

The person and their whanau may also need to manage:

- financial issues related to loss of income (through reduced capacity to work or loss of work) and additional expenses as a result of illness or treatment
- advance care planning, which may involve appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) or making an insurance, superannuation or social security claim based on a terminal illness or permanent disability.

5.5.1 Care coordination

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

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 whanau 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.
- Primary care may be involved in the management of the person on
 active
 surveillance, watch and wait, or androgen deprivation therapy, but should have
 communication lines to secondary care if required.
- Confirm the diagnosis, treatment intent, recommendations, and plan, including potential side effects.
- Communicate supportive treatment plan and referrals between health services.
- Advise of any enrolment in clinical trial as appropriate.
- Advise of changes in treatment or medications.

5.6 Measuring and monitoring

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

- Te Aho o Te Kahu Prostate Cancer Quality Performance Indicators
 - PCQI 8. Length of stay after surgery:
 - proportion of people with prostate cancer discharged more than two days after radical prostatectomy
 - proportion of people with prostate cancer discharged five or more days after radical prostatectomy.

		Presentation, initial	Diagnosis, staging	_	Care after	Palliative and end	
Wellness	Early detection	investigations, and referral	and treatment	Treatment	treatment	of life care	

o PCQI 9. Equitable access to treatment: Proportion of people treated with radical surgery, curative radiation treatment and either radical surgery or curative radiation treatment.

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

In general, persons who require prostate cancer treatment for PSA > 50 and new renal failure (a decline in eGFR of 50% from baseline) or radiological evidence that suggests locally advanced or metastatic disease, treatment is within 4 weeks and are included in the FCT 62-day indicator reporting.

• 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.
- o 62-day indicator All people triaged with a high-suspicion of cancer 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

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

Radiation oncology treatment timeframes⁵

- Category A treat within 24 hours.
- Category B treat within 10 working days.
- o Category C (palliative intent) treat within 10 working days
- o Category C (curative intent) treat within 20 days.
- o Category D combined modality treatment (determined by scheduling of the two treatment modalities).
- Category E (benign disease) treat within 80 working days.

⁵ Radiation Oncology Waitlist Data Business Rules – <u>Te Whatu Ora</u>

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 longterm 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).

Best Practice Advocacy Centre New Zealand (bpac^{NZ}) guidance informs care after treatment for the person with prostate cancer

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
- provide access to clinical, psychological, social financial and cultural support to transition back into recovery and life after cancer treatment.

6.2 Survivorship care planning

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

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

- the provision of a treatment summary
- information on what medical follow-up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information
- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment
- information about wellbeing, primary and secondary prevention 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.

- Clinicians shall enquire about common functional side effects post prostatectomy and radiotherapy:
 - urinary incontinence
 - erectile dysfunction.
- Patients who have persistent urinary incontinence and/or erectile dysfunction, or rarer side effects (not limited to: urinary flow obstruction, climacturia, Peyronie's Disease, ejaculatory or orgasmic disorders), should be referred to a clinician with the appropriate training and skills to manage these side effects.
- Access to investigation and treatment of side effects:
 - o equity of access shall be guided by the principles outlined in Step 5.1.

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 whanau.

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's been received, (refer to treatment options in section 5.3) and the needs and wishes of the person and their whānau.

Primary care has an important role in the follow-up care and ongoing PSA monitoring post treatment delivered in secondary care.

- For men following radical prostatectomy, a single PSA level 0.2 or greater is regarded as abnormal and warrants referral back to secondary care.
- For men following radiation therapy, the PSA level that warrants re-referral is set by the oncologist on discharge from secondary care.

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.

Prostate cancer signs and symptoms that necessitate further investigation include:

- people with locally recurrent disease can present asymptomatically with a rising PSA. or with symptoms such as urinary dysfunction
- the person with metastatic disease may present with symptoms such as bone pain. loss of energy or weight loss. Imaging (pelvic MRI and PSMA PET) may help to differentiate local recurrence, which may be curable with salvage therapy.

6.6.1 Rapid re-entry to specialty services

Service providers have a process for rapid re-entry to specialty services when a recurrence or metastatic disease is suspected. Advice should be given to people and their whanau of how to access these services if required.

6.7 Clinical trials

Where eligible, the person with cancer and their whanau are 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 and their whanau transition from active treatment, their needs often change, and health providers need to support people and their whanau to cope with life beyond their acute treatment (refer Principles 5, 6 and 7).

Health providers work with people and their whanau 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 the person and their whānau, where possible.

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

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

effective and timely communication

The person and their whanau are provided with a copy of their survivorship care plan, including information on any referrals that have been made. Health providers involved in the follow up care of an individual have access to the up-to-date care plan, especially if primary care is involved, and can update the plan as required.

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

Step 7: Palliative and end-of-life care

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

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

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

Dame Cecily Saunders

7.1 Te Tiriti o Waitangi

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

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

7.2 Palliative care

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

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

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

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

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

Settings include:

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

Palliative care is most effective when considered early in the course of an illness. Early palliative care not only improves quality of life for the person and their whānau but also reduces unnecessary hospitalisations and use of health care services. See section 5.3 for more detailed information.

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 whanau 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 quidance 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 whanau receive the information, support, and guidance about their role according to their needs and wishes.

7.4 Assisted dying

The person and their whanau requesting assisted dying information are supported to access this service. Health providers/professionals are required to be aware of their rights and responsibilities regarding assisted dying services should the person and their whanau raise this with the health care team. For more information visit www.health.govt.nz/ourwork/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 whanau are met. Supportive care needs may arise, including:

- assistance for dealing with emotional and psychological distress from grief and fear of death and dving
- specific support for the person and their whanau 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 whanau 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 heath care team. It is important that the different providers and services are aware of and responsive to the various facets of care that the person and their whanau require.

7.5.2 Communicating with the person/whānau receiving care

Health providers/professionals

- Encourage the person and their whanau 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 whanau 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

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.

"The difference in his wellbeing after rongoā was huge. He was still dying, but he didn't look sick anymore."

Palliative and end

of life care

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/our-work/advance-care-planning
- A Guide for Carers. (Hospice New Zealand 2019). hospice.org.nz
- Mauri Mate: A Māori palliative care framework (Hospice New Zealand.2019) hospice.org.nz/mauri-mate
- Te Ara Whakapiri: Principles and quidance for the last days of life (Ministry of Health | Manatū Hauora 2017b) health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-
- The Palliative Care Handbook (Hospice New Zealand 2019b) hospice.org.nz/resources/palliative-care-handbook
- Information on assisted dying for the public (Health New Zealand | Te Whatu Ora, nd)
 - tewhatuora.govt.nz/for-the-health-sector/assisted-dying-service/assisted-dyinginformation-for-the-public/information-on-assisted-dying-for-the-public

7.6 Measuring and monitoring

life

- 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
 - o Standard 4: Supporting and caring for the family, whanau and carers
 - Standard 5: Transitions within and between services
 - Standard 6: Grief support and bereavement care
 - Standard 7: Culture of the organisation
 - Standard 8: Quality improvement and research
 - Standard 9: Staff qualification and training
- National palliative care outcomes and reporting framework (under development).

Appendix 2b: Prostate Cancer Outcomes Registry (PCOR-NZ) Clinical Quality Indicators

PCOR-NZ supplies all Aotearoa New Zealand Urologists and Hospital Clinical Directors a full report of the last three years of all men diagnosed with prostate cancer. The report provides de-identified benchmarked patient outcomes with a goal of internal audit, quality assurance and quality improvement. Urology departments and individual clinicians may discuss these outcomes in an audit meeting, and the reports fulfil Royal Australasian College of Surgeons (RACS) requirement for Continuing Medical Education (CME) Audits.

Indicator	Participant Category	Rationale	Calculation	Consideration	
STRUCTURE					
Number of participants treated at institution per year (by treatment)	All	Participants treated in high volume hospitals have shorter hospital stay, fewer complications, lower readmission rates, and	Numerator: RP=YES, RT=YES, BT=YES, AS=YES, WW=YES Denominator: All participants	Overall volume may not detect low volume in each treatment group.	
		higher mortality than participants treated in low volume hospitals.	Risk adjustment: YES		
PROCESS	le de la companya	l = 1	The BOW A	I	
	Stratified by stage	The presence of a positive margin	Numerator: PSM ≥ 1mm	Indicator does not	
Positive margin rate post RP.	pT2	increases the risk of biochemical recurrence, local recurrence, and	Denominator: All participants	consider the location of the margin e.g., apex,	
		the need for salvage treatment.	Risk adjustment: YES	base.	
PSA level recorded at	ALL	Without a PSA it is difficult to	Numerator: PSM ≥ 1mm	Low risk: PSA ≤ 10	
diagnosis		accurately identify appropriate treatment and to calculate risk of	Denominator: All participants	Medium risk: 10 < PSA ≤ 20	
		disease progression.	Risk adjustment: YES	High risk: PSA > 20	
Documentation of clinical T stage in the	All	The clinical stage provides the best initial estimate of the extent of disease. The clinical stage is	Numerator: cT stage documented and recorded.	Low risk: stage ≤ T2a Medium risk: Stage = T2b High risk: stage = T2c or	
medical record.		based on the results of the physical examination (including DRE), biochemical tests, prostate	Denominator: All participants where DRE not refused / recorded as not taken.	T3	
		biopsy, endoscopy, and any imaging tests.	Risk adjustment: No		

Indicator	Participant Category	Rationale	Calculation	Consideration
Active surveillance / watchful waiting for men with low risk disease.	Low risk.	Men with low risk localised prostate cancer, for whom RP and RT is suitable, should be offered active surveillance as an option.	Numerator: Percent of participants with no active treatment. Denominator: All participants with low risk disease (PSA < 10; Gleason = 6; cT ≤ 2a) Risk adjustment: No	Active surveillance / watchful waiting for men with low risk disease.
Evidence that	High risk and age < 80.	Men with high risk localised prostate cancer should not be	Numerator: Percent of participants receiving active treatment.	Active treatment ≠ hormone treatment.
participants in high risk disease group received active treatment.	80.	offered active surveillance.	Denominator: All participants with high risk disease (PSA > 20; Gleason ≥ 8; OR clinical stage ≥ T2c)	Valid reasons exist why men with high risk disease do not receive active treatment,
			Risk adjustment: Age < 80 years.	including advanced age, multiple comorbidities and participant choice
Time from biopsy – confirmed diagnosis to first treatment.	High risk.	Significant increases in the proportion of adverse pathological outcomes were found beyond 75 days overall, 150 days for participants with Gleason ≤ 6, and	Numerator: Date of commencement of neo-adjuvant ADT, RT, RP minus date of diagnosis > 90 days for men with high risk disease.	Hormone treatment = active treatment. High risk participants only.
		PSA 0 – 10, 60 days for participants with Gleason 7 and PSA > 20, and 30 days for participants with Gleason 8 – 10 and PSA 11 – 20.	Denominator: All participants with high risk disease (PSA > 20 OR; Gleason ≥ 8; OR clinical stage ≥ T2c)	
			Risk adjustment: No.	
OUTCOME	T			
5-, 10 year and 15 year overall survival.	Stratified by stage and age.	An individual's prognosis depends on the type and stage of cancer, as well as their age and general health at the time of diagnosis.	Numerator: Death = Yes (death rate not null)	Survival analysis. Cox proportional hazard analysis with risk adjustment.
		In Australia, the 5-, 10-, and 15- year survival rate for men diagnosed with prostate cancer is	Denominator: Diagnosis date +5, 10 and 15 years. Risk adjustment: Stage and age.	

Indicator	Participant Category	Rationale	Calculation	Consideration
		92%, 93% and 77% respectively.		
Clinical and/or biochemical disease-free survival after primary treatment by RT or RP.	Clinical recurrence: All participants who have had RP or RT. Stratifies by stage pT. Biochemical recurrence: participants who have had RP. Stratified by stage pT.	15-30% of participants treated for prostate cancer, will experience a recurrence.	Clinical recurrence Numerator: Imaging positive for prostate cancer metastases. Denominator: All participants who have had RP or RT. Risk adjustment: Yes. Biochemical recurrence Numerator: Any PSA > 0.2 ng/mL 12 months post RP. Denominator: Participants having RP.	RT not included as 12 months post RT many men will be receiving ADT which will mask the possibility of disease progression. PCOR-ANZ collects PSA only at 12 months post treatment, so change from nadir not possible nor collection of 5-, 10- and 15 year recurrence.
Participant assessment of urinary, sexual, and bowel function.	All.	Urinary function is better post RT and BT than post RP. Sexual function is better post BT than post RT or RP. Bowel function is worse post RT and BT, than post RP. Urinary domain score, classified as 0 to 49 severe, 50 to 69 moderate and 70 to 100 mild. Sexual stratification 0 – 32 (severe), 33 – 44 (moderate), 45 – 59 (mild/moderate), 60 – 74 (mild), 75 – 100 (none). Bowel function has not been reported in terms of severity scores.	Urinary function Numerator: number of participants with severe urinary symptoms (EPIC- 26 summary score < 50) 12 months after treatment. Denominator: All participants Risk adjustment: No Sexual function Numerator: number of participants with severe sexual dysfunction (EPIC - 26 summary score < 33) 12 months post treatment. Denominator: all participants. Risk adjustment: No	Bowel function score has not been reported so an arbitrary score of 50 was selected, to match the score for urinary function. This requires further development and validation. Literature focus on minimally important differences, which require baseline and follow up scores to calculate. PCOR-ANZ does not collect baseline EPIC 26.

Indicator	Participant Category	Rationale	Calculation	Consideration
			Bowel function Numerator: number of participants with severe bowel dysfunction (EPIC – 26 summary score < 50) 12 months post RT. Denominator: all RT participants. Risk adjustment: No	Recovery of sexual and urinary function is time dependent with maximal urinary recovery requiring up to 18 months and maximum sexual recovery often taking even longer. PCOR-ANZ collects data only to 12 months post active treatment.
Participant assessment of urinary, sexual, and bowel bother.	All	Urinary and sexual bother is similar post RP, RT, and BT. Bowel bother is higher post RT and BT, than post RP.	Urinary bother Numerator: number of participants responding to the question 'overall, how big a problem has your urinary function been for you during the last 4 weeks?" with "Big problem". Denominator: All participants. Risk adjustment: No. Sexual bother Numerator: number of participants responding to the question "Overall, how big a problem has your sexual function been for you during the last 4 weeks?" with "Big problem". Denominator: All participants. Risk adjustment: No. Bowel bother Numerator: number of participants responding to the question "overall, how big a problem has	No bowel bother for non-RT participants. PCOR-ANZ does not collect baseline EPIC.

Indicator	Participant Category	Rationale	Calculation	Consideration
			your bowel function been for you during the last 4 weeks?" with Big problem.	
			Denominator: Only RT participants. Risk adjustment: NO (RT only).	
Rate of in-hospital death from surgical complications	RP only	The risk of post-operative mortality after RP is relatively low for otherwise healthy older men up to age 79.	Numerator: Death = Yes (death date not null) and RP date +/- 30 day Denominator: All participants having RP Risk adjustment: No.	

Abbreviations:

ADT adjuvant deprivation therapy

active surveillance AS

brachytherapy BT clinical stage сT

digital rectal examination DRE

Extended Prostate Cancer Index Composite **EPIC** NCCN National Comprehensive Cancer Network

PCOR-ANZ Prostate Cancer Outcomes Registry – Australia and New Zealand

prostate specific antigen **PSA** positive surgical margins **PSM**

pathological stage T pT2 radical prostatectomy RP

radiation therapy RT watchful waiting ww