

Prostate Cancer Awareness and Quality Improvement Programme

**Improving outcomes
for men with
prostate cancer**



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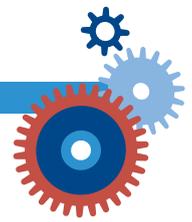
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From the Minister of Health

Prostate cancer is the most common cancer diagnosed in New Zealand. Every year, about 3000 men are diagnosed with the disease and more than 600 die from it.

The Ministry of Health has developed an action plan to ensure men have improved access to quality information and care.

The Prostate Cancer Awareness and Quality Improvement Programme will raise awareness of prostate cancer, improve the quality of care men receive, reduce the harms caused by over treatment and enable better outcomes. New Zealand is among the first countries internationally to develop a comprehensive national programme.

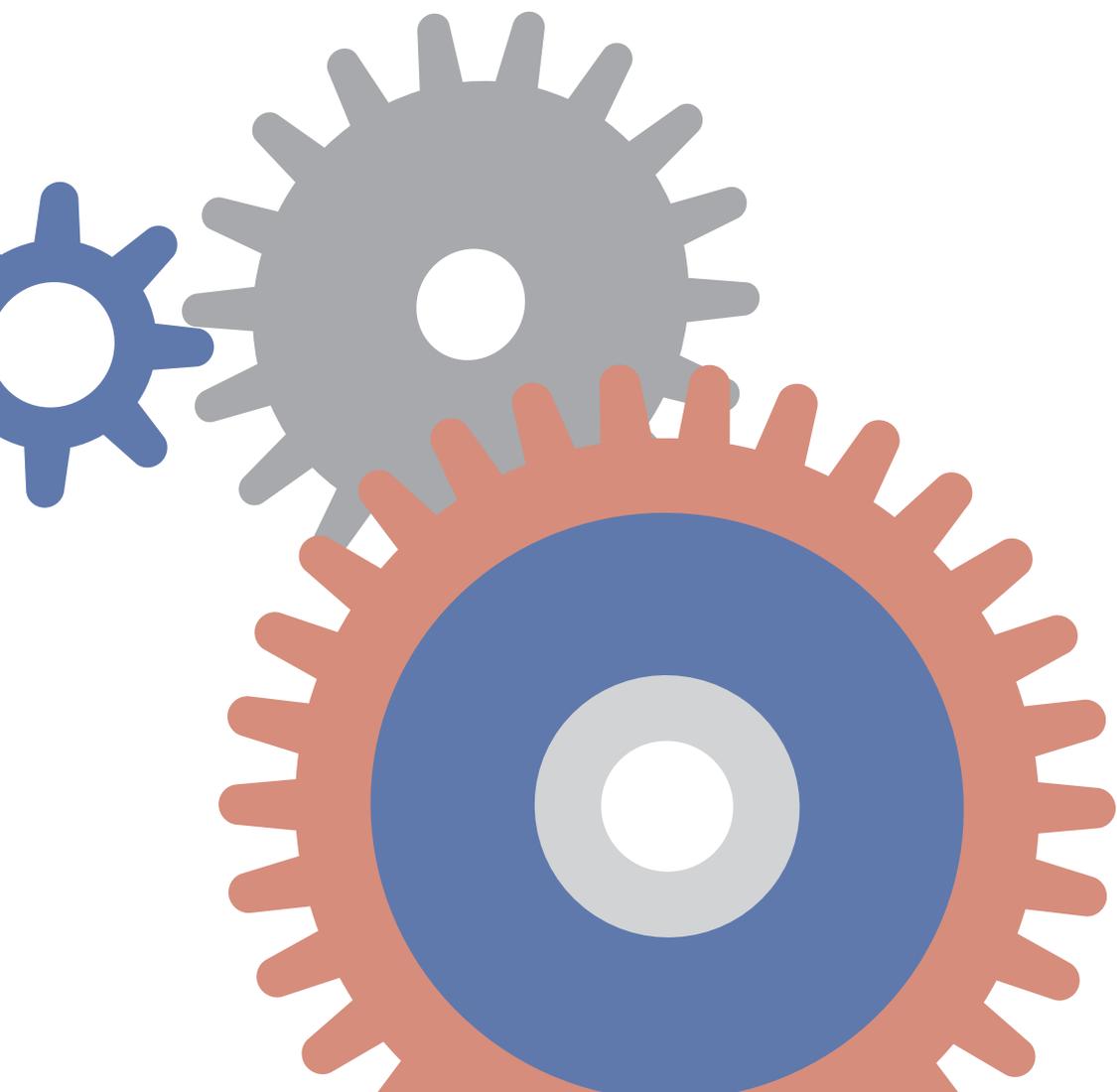
It will ensure men have access to clear, evidence-based information about the risks, benefits and side effects of prostate cancer tests and treatment, so they can make active and informed decisions. Easily understood booklets have been developed for men and their families, using information agreed by an expert clinical group. These will be made widely available.

Work will begin to help GPs identify and manage men at risk of prostate cancer. Electronic prompts will be developed which remind doctors to talk to their patients about prostate cancer. A decision aid will help men and their doctors agree on what action to take.

Guidelines and standards will be developed to ensure men have equal access to specialist services for assessing and treating prostate cancer. The standards will enhance early detection while limiting the harms and complications that can be caused by unnecessary treatment.

I would like to acknowledge the work of the Health Select Committee and the Prostate Cancer Taskforce led by Dr John Nacey.

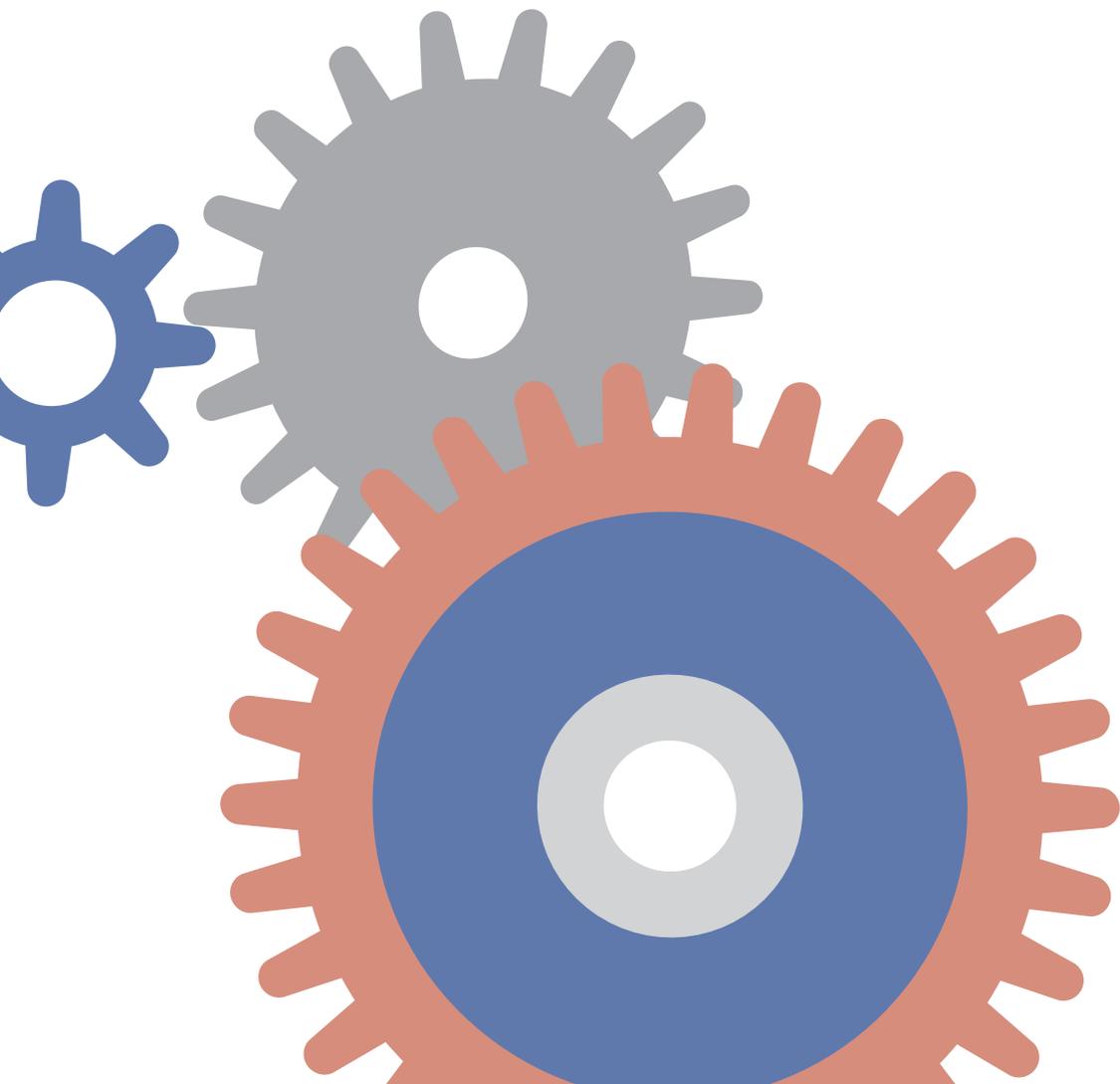
Hon Tony Ryall
Minister of Health

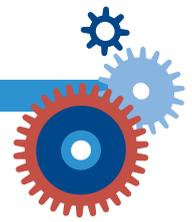




Contents

| | |
|--|------------|
| From the Minister of Health | iii |
| Executive summary | vii |
| How men and their families and whānau will benefit from the prostate cancer quality improvement programme | viii |
| Developing a Prostate Cancer Awareness and Quality Improvement Programme | 1 |
| Prostate cancer is an important men's health issue in New Zealand | 1 |
| Prostate cancer has unique challenges and issues | 2 |
| The New Zealand population is predicted to age and become more diverse | 2 |
| The Health Committee's inquiry into prostate cancer detection and treatment | 3 |
| The Prostate Cancer Taskforce supported the development of the awareness and quality improvement programme | 3 |
| Taskforce recommendations inform the quality improvement programme | 4 |
| The awareness and quality improvement programme aims to improve outcomes for all New Zealand men | 5 |
| National Prostate Cancer Working Group | 6 |
| Document structure | 6 |
| Greater access to information | 7 |
| The issues | 7 |
| Summary of the Taskforce recommendations | 7 |
| Implementing the recommendations | 8 |
| Monitoring, evaluation and research | 15 |
| The issues | 15 |
| Summary of the Taskforce recommendations | 15 |
| Implementing the recommendations | 15 |
| Next steps | 18 |
| References | 19 |
| Appendix 1: The Taskforce membership | 20 |
| Appendix 2: The Taskforce recommendations | 21 |
| Glossary of terms and abbreviations | 26 |





Executive summary

The Prostate Cancer Awareness and Quality Improvement Programme (AQIP) outlines the current issues for the early detection and treatment of prostate cancer in New Zealand. The AQIP also provides solutions to these issues and identifies the next steps for the Ministry of Health (the Ministry) and the wider health sector.

Currently, men in New Zealand can receive confusing information on the early detection and treatment of prostate cancer. In addition, there are differences in the quality of care available to men throughout the health service, from primary to tertiary level care. Men who may benefit from early diagnosis and treatment can have limited opportunity for access to appropriate health services while men who would otherwise not have any complications from prostate cancer may suffer harms from overdiagnosis and overtreatment.

The AQIP aims to address current deficiencies by:

- providing all men with equitable access to information about prostate cancer
- ensuring general practitioners (GPs) have the appropriate knowledge and resources to effectively manage men presenting for assessment of prostate cancer or prostate cancer risk
- removing barriers that restrict the effective use of diagnostic and treatment services
- ensuring that all men have consistent care across the whole prostate cancer care pathway¹
- focusing on achieving equitable outcomes from care.

The Ministry appointed the Prostate Cancer Taskforce (the Taskforce) to support the development of the AQIP. The Taskforce was an expert group established to provide recommendations that improve outcomes along the prostate cancer care pathway. Members of the Taskforce included clinicians as well as representatives from primary care and non-governmental organisations.

The Taskforce recommended providing men with clear, relevant, unambiguous and culturally appropriate information about prostate cancer through community organisations and primary health care. This information is to be particularly targeted to men:

- aged 50 to 70 years
- from 40 years of age where there is a family history of prostate cancer
- with symptoms.

The Taskforce also recommended that men with low risk prostate cancer have active surveillance as a management option where their cancer is closely monitored but not actively treated. Through this approach, men who have prostate cancer with a low risk of progression can avoid or delay potential treatment-related side effects. Other recommendations included providing diagnostic guidelines and to monitor prostate cancer treatment times.

The Ministry used the Taskforce recommendations to inform the development of the AQIP. The AQIP achieves clear benefits for men and their families and whānau through the early detection and treatment of prostate cancer. The table on the following pages summarises the key outcomes and actions of the AQIP over the first four years.

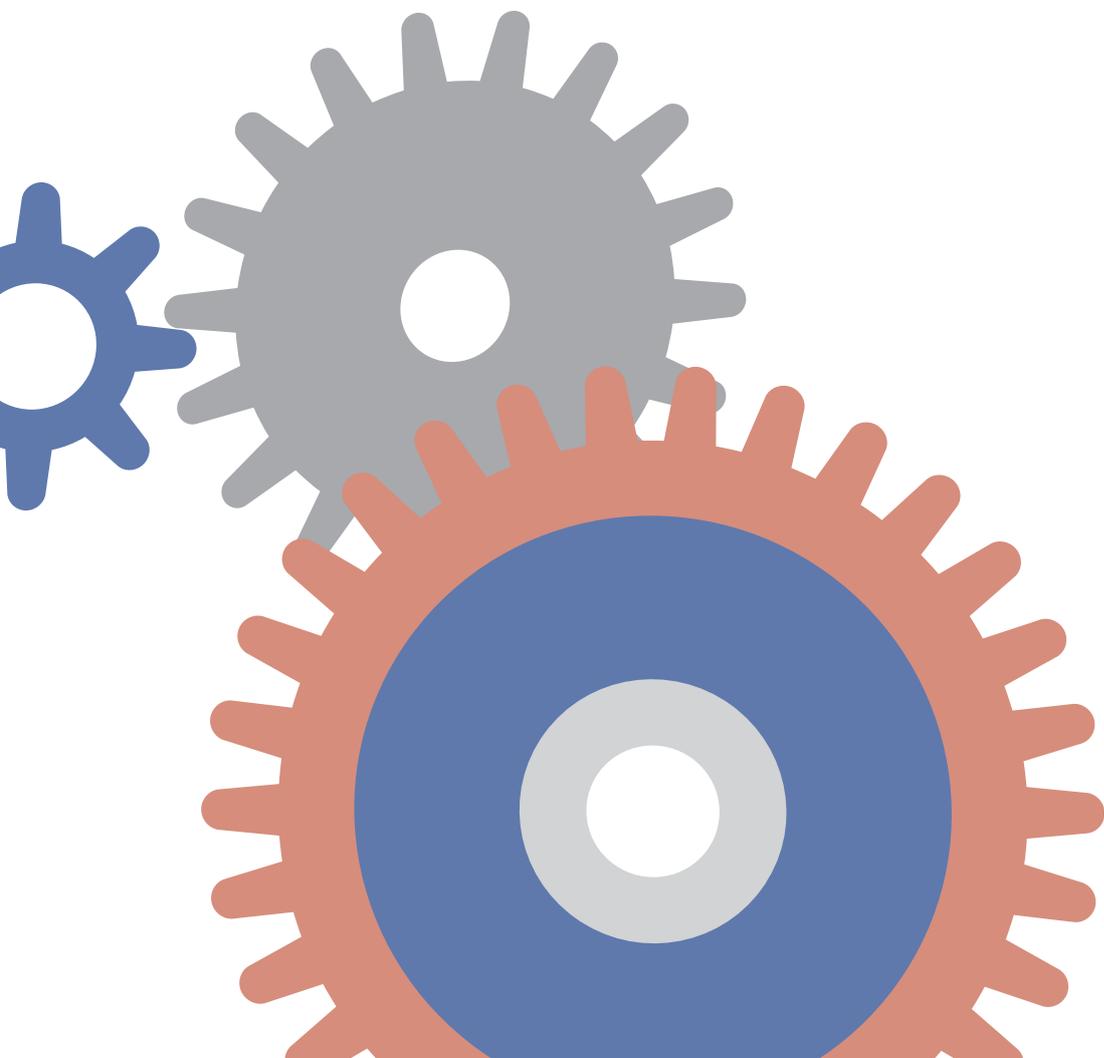
The Ministry will establish and support a National Prostate Cancer Working Group to guide the successful implementation of the awareness and quality improvement initiatives.

¹ A pathway is the route that a patient takes from their first contact with a health professional (usually their GP) through referral to a hospital specialist, to the completion of their treatment. It includes palliative and end of life care. The full pathway is illustrated in Figure 1 in 'Care along the prostate cancer pathway' on page 11.

How men and their families and whānau will benefit from the prostate cancer quality improvement programme

| Benefits and priorities of the prostate cancer quality improvement programme | When |
|---|---|
| <p>What will be achieved</p> <p>Men and their families and whānau will be able to make informed decisions and receive consistent support for the early detection and treatment of prostate cancer.</p> <p>How this will be done</p> <p>Men and their families and whānau will have greater access to information on prostate specific antigen (PSA) testing.</p> <ul style="list-style-type: none"> • Make information on the early diagnosis and treatment of prostate cancer available in suitable formats and languages. • Develop and distribute information resources from a range of locations. <p>GPs and other health care providers will be supported to provide men and their families and whānau with consistent information on prostate cancer testing and treatment options.</p> <ul style="list-style-type: none"> • Develop a decision support tool to assist men and GPs in shared decision-making about early detection and treatment of prostate cancer. • Develop information on the benefits and risks of prostate cancer treatment options, including the impact on health-related quality of life. • Implement a prompt in GP patient management systems to help identify men who should be offered information. • Provide consistent information for providers of national telephone advice services. • Include content on prostate cancer in training and education for GPs and health care providers. • Develop the capability of GP patient management systems to track prostate cancer patients against agreed care plans. | <p>under way</p> <p>year 1</p> <p>years 1–2</p> <p>year 2</p> <p>year 2</p> <p>year 2</p> <p>years 2–4</p> <p>years 2–4</p> |
| <p>What will be achieved</p> <p>Men will have consistent and appropriate referral to specialist care.</p> <p>How this will be done</p> <p>GPs will be better supported to both refer men to specialist care and monitor men who are diagnosed and treated for prostate cancer.</p> <ul style="list-style-type: none"> • Develop referral guidelines. • Incorporate prostate cancer referral guidelines into e-referral process. | <p>year 1</p> <p>years 2–4</p> |
| <p>What will be achieved</p> <p>Men will have more accurate diagnosis and staging of their prostate cancer.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Develop standards and indicators for staging investigations of prostate cancer. • Develop guidelines for staging and risk assessment of prostate cancer. • Support professional development of pathologists through education and audit programmes on pathology of prostate cancer. | <p>year 1</p> <p>year 2</p> <p>year 2</p> |

| Benefits and priorities of the prostate cancer quality improvement programme | When |
|---|--|
| <p>What will be achieved</p> <p>Men will have better access to health services, experience shorter wait times and receive consistent treatment for prostate cancer in New Zealand.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Develop national standards and key indicators for prostate cancer. • Implement monitoring of prostate cancer diagnosis and treatment times. • Develop and implement guidelines on the use of active surveillance. • Develop and implement guidelines for treatment of prostate cancer. • Improve access to multidisciplinary advice. | <p>year 1</p> <p>year 1</p> <p>years 1–2</p> <p>years 2–4</p> <p>years 2–4</p> |
| <p>What will be achieved</p> <p>Men with advanced and metastatic prostate cancer will have higher-quality care.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Develop guidelines for managing advanced and metastatic prostate cancer. | <p>year 1</p> |
| <p>What will be achieved</p> <p>Overall, men and their families and whānau will experience continuous improvements in the early detection and treatment of prostate cancer.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Monitor and evaluate the progress and impact of changes. • Develop systems for improved data collection, reporting and analysis. • Implement structured reporting for prostate cancer biopsies and prostatectomy specimens. • Implement indicators to enable monitoring across the pathway. • Undertake research to support continuous service improvement. | <p>years 1–4</p> |





Developing a Prostate Cancer Awareness and Quality Improvement Programme

Prostate cancer is an important men's health issue in New Zealand

Prostate cancer is an important men's health issue and is the most common cancer diagnosed in New Zealand. It is the third most common cause of cancer death in men. In 2009, a total of 3369 New Zealand men were diagnosed with prostate cancer and 562 men died from the disease (Ministry of Health 2012a) Prostate cancer most commonly occurs in men over 65 years of age and is rare in men under 50 years (Ministry of Health 2011).

There are inequities in prostate cancer outcomes between different population groups. Available data indicates that the largest inequities are between non-Māori and Māori in prostate cancer survival and death rates. There may also be disparities in outcome for Pacific peoples and other ethnic groups in New Zealand; however, current registration and mortality numbers for these groups are too small to convert to meaningful rates.

According to current data, prostate cancer has the second-largest inequity in cancer survival between Māori and non-Māori after lung cancer. Although Māori men are approximately 25 percent less likely to be diagnosed with prostate cancer than non-Māori men, they are twice as likely to die from the disease. While survival rates have improved for non-Māori from 1998 to 2008, they have not improved for Māori men (Ministry of Health. 2012b; Robson et al 2010).

Evidence suggests that level of access to health care is associated with the quality of the outcome in prostate cancer: men living in remote or deprived areas have poorer survival outcomes (Haynes et al 2008). Some differences in access and quality of outcome are also likely to relate to socioeconomic position, as mortality rates for prostate cancer increase and survival rates decrease with increasing levels of socioeconomic deprivation.

Figures from 2011/12 indicate inequity in the distribution of prostate specific antigen (PSA) testing for men aged over 50 years across New Zealand Deprivation deciles.² PSA testing is a simple blood test widely used to assess the risk of prostate cancer in men. In a six-year period, 70 percent of men living in decile 1 had one or more PSA tests compared with 48 percent of men in decile 10 (Moore et al 2013).

There are also likely to be regional differences in access to and quality of treatment for men with prostate cancer. Available data is insufficient to determine the exact extent of this inequity. However, the largest differences in mortality and survival remain those between Māori and non-Māori.³

2 The New Zealand Deprivation Index is a measure of the level of socioeconomic deprivation in small geographic areas of New Zealand (meshblocks). A score of 1 indicates that people are living in the least deprived 10 percent (decile) of New Zealand. A score of 10 indicates that people are living in the most deprived 10 percent of New Zealand.

3. Refer to the Midland Prostate Cancer Study.

Prostate cancer has unique challenges and issues

Prostate cancer often has a slow rate of growth and, for many men, may not cause complications during their lifetime. However, a number of men will have more aggressive, potentially life-threatening prostate cancer for which early treatment can reduce the risk of serious complications, morbidity or death. Researchers continue to work on finding a reliable way of detecting prostate cancer early and of assessing the risk for cancer progression. If this information could be established reliably, health professionals could provide men with improved advice on appropriate management options for prostate cancer.

While PSA testing is the most widely used test for assessing the risk of men having prostate cancer, elevated PSA levels can be caused by both cancer and non-cancerous conditions. Additionally, not all men with prostate cancer will have an elevated PSA. A prostate biopsy is required to confirm whether an elevated PSA is due to prostate cancer.

Currently, men in New Zealand can receive confusing information about the early detection and treatment of prostate cancer. Prostate cancer services lack consistency and New Zealand men experience differences in quality of care. Men who may benefit from early diagnosis and treatment can have limited opportunity for access to appropriate health services while men who would otherwise not have any complications from prostate cancer may suffer harm from overdiagnosis and overtreatment.⁴

The New Zealand population is predicted to age and become more diverse

Data from the National Ethnic Population Projections: 2006–2026⁵ indicates that the proportion of Māori, Asian and Pacific populations in the overall New Zealand population will increase (Table 1).

Table 1: Actual and projected share of total population for Māori, Asian and Pacific populations, 2006 and 2026

| Total populations | Share in 2006 | Predicted share in 2026 |
|--------------------------|----------------------|--------------------------------|
| Māori | 14.9 | 16.2 |
| Asian | 9.7 | 15.8 |
| Pacific | 7.2 | 9.6 |

The New Zealand population is also ageing. The median age (the age at which half the population is older and half is younger) of New Zealand's population increased from 26 years in 1971 to 36 years in 2006. According to projections, half of the population will be aged 40 years or older by 2027.

The implications of these changes are that the number of prostate cancer registrations will increase in the future as the population ages. The higher proportion of Māori, Pacific and Asian peoples in the population overall may also produce greater disparities if these disparities are not understood and adequately addressed.

⁴ Harms from overdiagnosis and overtreatment can include negative psychological effects such as persistent worry, unnecessary biopsies with risk of complications, and treatment related harms including impotence and incontinence of the bladder and bowel.

⁵ More information is available from Statistics New Zealand (www.stats.govt.nz).

The Health Committee's inquiry into prostate cancer detection and treatment

The Health Committee conducted an inquiry into early detection and treatment of prostate cancer in order to more clearly understand the New Zealand context. The Health Committee's report contained 17 recommendations and was presented to the House of Representatives on 21 July 2011.

During the inquiry, the Health Committee received submissions and expert advice and reviewed current evidence on prostate cancer testing and treatment. One international randomised study of prostate cancer screening showed no reduction in prostate cancer mortality. However, two other international randomised studies reported a 20 to 44 percent relative reduction in the risk of death from prostate cancer for men who have PSA screening (Andriole et al 2009; Schröder et al 2009; Hugosson et al 2010). Despite this result, the two trials were unable to definitively establish whether the benefits of screening outweigh the harms.

The Health Committee stated that the main harms experienced by men are due to prostate cancer treatment. These harms are therefore of particular concern when they occur as a consequence of overdiagnosis and overtreatment. The report highlighted the impact of the continuing side effects of incontinence and sexual dysfunction on a man's quality of life and noted that there is currently limited information available on the psychological impacts of prostate cancer diagnosis and treatment.

The Health Committee heard that there are inequities in the process of investigating and treating prostate cancer. Māori men in particular tend to be diagnosed at later stages of the disease and have a higher mortality rate than non-Māori men. Although the reasons for the inequality are not yet well understood, the Health Committee concluded that it appears to be due to differences in access to, and quality of, diagnosis and treatment.

The Health Committee recommended against having an organised national population screening programme for prostate cancer. However, it found that a quality improvement programme would provide a foundation for a national screening programme if future studies confirm a favourable benefit-to-harm ratio. The report further stated that the programme should ensure that all men with prostate cancer have access to good-quality information and care.

In its report, the Health Committee defined quality improvement as the:

prevention of problems, control of unintended variations in process and consistent improvement through quality assessment and quality assurance.⁶

The Government supported the Health Committee's recommendations and directed the Ministry of Health to develop a quality improvement programme and report back with associated costs.

The Prostate Cancer Taskforce supported the development of the awareness and quality improvement programme

In February 2012, the Ministry appointed the Prostate Cancer Taskforce (the Taskforce) to support the development of the quality improvement programme. The 19-member Taskforce included clinicians as well as representatives from primary care and non-governmental organisations. For the full list of members, see Appendix 1. For the 40 recommendations made in the Taskforce report, *Diagnosis and*

⁶ *Inquiry into Early Detection and Treatment of Prostate Cancer. Report of the Health Committee. 49th Parliament, Dr Paul Hutchison, Chairperson, 2011.*

Management of Prostate Cancer in New Zealand: Recommendations from the Prostate Cancer Taskforce (Ministry of Health 2013), see Appendix 2.

Among the key Taskforce recommendations are that:

- men aged 50–70 years and their families and whānau (and men aged from 40 years with a family history of prostate cancer) are provided with relevant, unambiguous and culturally appropriate information about prostate cancer
- men diagnosed with prostate cancer have active surveillance as a management option
- measures recognise the important role of the general practitioner in supporting the shared decision-making with men about checking for prostate cancer and the management of men with diagnosed prostate cancer
- guidelines are developed for specific points along the prostate cancer care pathway.

Taskforce recommendations inform the quality improvement programme

The Ministry has reviewed the Taskforce recommendations and used these to form the basis of the Prostate Cancer Awareness and Quality Improvement Programme (AQIP). Some of these recommendations are achievable through the health sector's wider programme of work. Many are aligned with current Government priorities, as summarised below in relation to the Faster Cancer Treatment programme, Clinical Integration and a whānau-inclusive approach to coordinated care through Whānau Ora.

Faster Cancer Treatment programme

The Ministry is working with the health sector to ensure patients have timely access to appointments, tests that detect cancer, and cancer treatment. This work is being implemented by the Faster Cancer Treatment programme (the programme).⁷ The aim of the programme is to improve the quality and timeliness of services for patients along the cancer care pathway.

The programme has four workstreams:

- reporting of three Faster Cancer Treatment indicators
- patient pathway coordination
- tumour specific standards
- multidisciplinary meetings.

Many of the recommended improvements to the prostate cancer care pathway in the AQIP can be supported within these Faster Cancer Treatment initiatives.

Clinical integration (better care closer to home)

Integrated care enhances the patient's experience and health outcomes by improving the coordination of care, systems and information and by being patient-centred. The Ministry is supporting the sector to create a more integrated health care system that improves access to health care and delivers that care closer to home.

Actions to establish this system include strengthening primary care through integrated structures (eg, electronic shared health records and Integrated Family Health Centres), using the health

⁷ For more information, see www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/faster-cancer-treatment-project

workforce effectively and applying integrated models of care. District health boards (DHBs) and provides primary health care will be using care pathways more often, developing stronger clinical governance and supporting patients to be active participants in managing their care. Improving access through reconfiguring services and making greater use of multidisciplinary teams in community settings will also support better-coordinated, more integrated care.

A whānau-inclusive approach to coordinated care

The Taskforce identified that men in some population groups may not have equitable access to health services or appropriate care pathways. One measure to improve this situation is a whānau-inclusive approach to coordinated care, from which some men, including many Māori men, may benefit. Initiatives are already in place that aim to improve service access and recognise the important role of whānau (family or extended family unit) in the health and wellbeing of individual members.

As an example, the Whānau Ora programme led by Te Puni Kōkiri is an inclusive approach to providing services and opportunities to all families and whānau in need across New Zealand.⁸ It empowers families and whānau as a whole, rather than focusing separately on individual family members and their problems. Whānau Ora requires multiple government agencies to work together with families and whānau, and is driven by a focus on outcomes. The objectives of Whānau Ora are:

- family and whānau self-management
- healthy family and whānau lifestyles
- full participation in society by families and whānau
- confident participation in Te Ao Māori
- economic security and successful involvement in wealth creation
- cohesion and resilience of families and whānau (Taskforce on Whānau-centred Initiatives 2010).

Whānau Ora will work in a range of ways, influenced by the approach the family or whānau chooses to take. Some families and whānau may have a ‘navigator’ to work with them to identify their needs, help develop a plan to address those needs and broker their access to a range of health and social services. Other families and whānau may have a health practitioner in a coordinating role.

The awareness and quality improvement programme aims to improve outcomes for all New Zealand men

The AQIP aims to improve the access to health services, consistency of care and health outcomes for all New Zealand men entering the prostate cancer care pathway. Improved health outcomes include reduced risk of death and higher survival rates from prostate cancer and lower morbidity from advanced disease.

Implementing the AQIP will provide the following benefits.

- Men and their families and whānau will be able to make **informed decisions** and receive **consistent support** for the early detection and treatment of prostate cancer.
- Men will have consistent and **appropriate referral** to specialist care.
- Men will have **more accurate diagnosis and staging** of their prostate cancer.
- Men will have better access to health services, experience **shorter wait times** and receive **consistent treatment** for prostate cancer in New Zealand.

⁸ For more information, see www.tpk.govt.nz/en/in-focus/whanau-ora

- Men with advanced and metastatic prostate cancer will have **improved quality of care**.
- Overall, men and their families and whānau will experience **continuous improvements** in the early detection and treatment of prostate cancer.

Quality improvements for the prostate cancer care pathway need to address inequities, reduce harm to men and be cost-effective. The additional needs of those men who currently have poor access to health services must be recognised and supported.

National Prostate Cancer Working Group

To guide the successful implementation of the quality improvement initiatives, the Ministry will establish and support a National Prostate Cancer Working Group (the Working Group). The core membership of the Working Group will include:

- clinical specialists from general practice, pathology, radiology, urology, radiation oncology, medical oncology and palliative care
- nursing experts
- expertise in epidemiology and population health (particularly for Māori, Pacific and hard-to-reach populations)
- district health board representatives
- consumer representatives.

Members with expertise in other areas may need to be seconded as required.

The Working Group will work to a prioritised work plan and will need to ensure the sector is fully engaged with the quality improvement initiatives.

Document structure

The following AQIP sections are based on the benefits and priorities detailed in Tables 2–4 (at the end of each section). Each section describes the main issue or problem that the AQIP must address and summarises the relevant Taskforce recommendations. It also details the actions the Ministry will take with an indicative timeframe required to implement the recommendations. Ministry and sector developments already in progress are noted where relevant.

The AQIP sections cover:

- greater access to information
- care along the prostate cancer pathway
- monitoring, evaluation and research.



Greater access to information

The issues

Currently, highly variable information is provided to men and their families and whānau on PSA testing, diagnosis and treatment of prostate cancer. While a large amount of information is available, it frequently fails to provide clear facts for men and their families and whānau, and different sources of information often conflict with each other.

The following are some areas of concern.

- The conflicting content can make it difficult to easily understand the basic concepts related to the prostate gland, the diagnosis of prostate cancer and the treatment options available.
- Existing resources often do not account for the health literacy levels of all populations in New Zealand.
- Services may neglect to discuss and work through information with men and their families and whānau to check their understanding of the material.
- Information resources are not available in ways that all men can easily access.

The role of health care providers

Primary health care providers have a central role in the shared decision with men about checking for prostate cancer and the management of men with diagnosed prostate cancer. For most men, general practitioners (GPs) are the first point of contact in the health care system. The outcome of this interaction often determines whether men will have a PSA test and influences whether men are referred to a urologist for a prostate biopsy. Currently men receive varied information about and care for prostate cancer from their GP.

Summary of the Taskforce recommendations

The Taskforce recommended that GPs or primary health care services provide clear, relevant, unambiguous and culturally appropriate information about prostate cancer to men:

- aged 50 to 70 years
- from 40 years of age where there is a family history of prostate cancer
- with symptoms.

The Taskforce also recommended:

- providing information on benefits and harms of PSA testing
- initiating PSA testing only after obtaining informed consent
- shared decision-making with the patient once a diagnosis of prostate cancer is confirmed.

The Taskforce recommended that the information men receive needs to be available at a level of understanding relevant to the needs of the individual and should take into account different perspectives such as age, co-morbidity and family history. The Taskforce recommended that information should:

- be in a variety of formats such as written text, diagrams, video and internet, and take account of issues such as sight or hearing problems
- reflect best evidence

- be culturally appropriate
- be developed in consultation with Māori
- be available in the major languages appropriate for New Zealand (including Māori, and Chinese and Pacific languages).

The Taskforce recommended that a national telephone information service should be available for information on prostate cancer. This service would be staffed by experienced and trained prostate cancer nurses with access to good-quality, written patient information to mail out to callers in response to enquiries and to support phone discussions.

The Taskforce noted that men entering an active surveillance programme as a cancer treatment option should have a care plan agreed between the specialist, patient and GP. The Taskforce commented that the care plan needs to be tracked and monitored in the general practice's information technology (IT) system.

Implementing the recommendations

The Ministry intends to implement the recommendations through the following activities.

Developing information resources

The Ministry, with clinical advice from the Taskforce, has developed an overview pamphlet and a more detailed information brochure containing balanced information on prostate cancer, testing and treatment. The resources encourage men to visit their GP and they also provide general information to assist with decision-making. The information resources form the basis from which future resources will be developed.

Distributing information resources

The Ministry is developing options for the best ways to distribute the information resources, including by raising general awareness through available media and other outlets. Further work is required to ensure the information resources will be accessible for all men, as population groups such as Māori, Pacific and Asian peoples and new immigrants may require information in other languages and/or delivered in other ways. The Taskforce recommendations are supported by focus group findings, that:

- messages are effective when also aimed at other key influencers, such as women in the men's family and whānau
- valued sources of health information for Māori and Pacific men are health promoters, community health providers and public health nurses who engage with the community.

Decision support tool and Patient Management Systems

It is essential that GPs receive adequate support to provide clear guidance to men on the possible harms and benefits of tests and treatment options along the prostate cancer care pathway. GPs must be ready and able to answer questions that patients and their families and whānau may ask, in a manner that they can easily understand and with the information they need to make informed decisions about their prostate care. The GP must also check that men understand the information they are receiving.

Decision aid and decision support tools will facilitate discussion between GPs (and other primary care providers) and men about tests and treatment options, including covering information on the possible harms and benefits of each decision. These tools will be part of a shared decision-making process that is in line with international evidence and best practice.

Patient (or Practice) Management Systems (PMS) can provide key tools to support GPs in their management role for men with prostate cancer. Some PMS may need to be modified to support the management of men as they progress through the prostate cancer care pathway and to integrate the system more closely with DHB information systems.

Modifications to management systems could enable (prompt) GPs to identify which men should be provided with information on prostate cancer. Such modifications could also support GPs in tracking men who are on active surveillance or on follow-up after completion of treatment.

National telephone information service

Telephone advice services need to be coordinated so that men and their families and whānau receive consistent, evidence-based information and advice on prostate cancer. Several non-governmental organisations currently provide telephone information services that the public can call with questions or concerns about prostate cancer. In addition, the national Healthline service is available to provide information on any health topic, including prostate cancer.

The Ministry will work with all providers to enable consistent information on prostate cancer to be provided to callers.

Training and education for GPs and health care providers

The Ministry will need to implement the Taskforce recommendations in collaboration with primary health care leaders and organisations. GPs will need to be supported by a revised GP education programme on prostate cancer. With this support, GPs will be in an increasingly stronger position to be proactive in providing advice and, if required, in the subsequent management of prostate cancer.

Care plans

Primary health care clinicians also have an important role in supporting the management of men once prostate cancer has been diagnosed and in treatment follow-up. This role will be strengthened by improvements to support better-integrated care in primary health care practice.

Men entering active surveillance must be monitored and tracked within the general practice's PMS. Management systems must be able to manage monitoring and tracking of each patient's care and must reflect the patient's agreed care plan.

Current sector initiatives support the recommendations of the Taskforce in this area. The Ministry will work to align prostate cancer with the progress being made in electronic care planning of long-term conditions.

The National Health IT Board National Shared Care programme has been developed to support the vision of e-health and to help deliver the goals of 'Better, Sooner, More Convenient Health Care'. The programme is seeking a collaborative approach with all care providers supporting people with long-term conditions, to develop a comprehensive and coordinated electronic care plan. The aim is for all New Zealanders and the health professionals caring for them to have electronic access to a core set of personal health information by the end of 2014.

Quality of life

Decisions about testing and treatment for prostate cancer are influenced by understanding the benefit to a man versus potential harms, with the aim to reduce harm where possible. Although the focus is often on treatment-related physical complications, it is important to understand the influence of prostate cancer and its treatment on a man's quality of life. This is especially important as for many men diagnosed with prostate cancer, it may never progress to cause them any physical complications.

Quality of life refers to generic aspects of wellbeing, including physical, social, emotional and cognitive functioning, vitality/fatigue, pain, general health status and life satisfaction (Eton and Lepore 2002). Assessing health-related quality of life involves a man's own perceptions of his health and ability to function in life and is usually calculated by completing a standardised questionnaire.⁹

The various forms of treatment for prostate cancer (radical prostatectomy, brachytherapy, external beam radiation therapy and active surveillance) can affect health-related quality of life in different ways and to different extents. While individual studies on the impact of these treatments exist, a comparative study specific to the New Zealand context would contribute to a more complete understanding of the potential benefit and harms of prostate cancer tests and treatments.

Once this information is available, resources need to be developed so that health providers and men and their families and whānau are more able to understand the impact of the various tests and treatments on health-related quality of life. Resources should identify the range of support services available to men and their families and whānau that best meets their individual needs.

Activities and priorities

Table 2 outlines the activities and priorities that will help to improve access to information in the first four years of implementing the AQIP.

Table 2: Activities and priorities to improve access to information

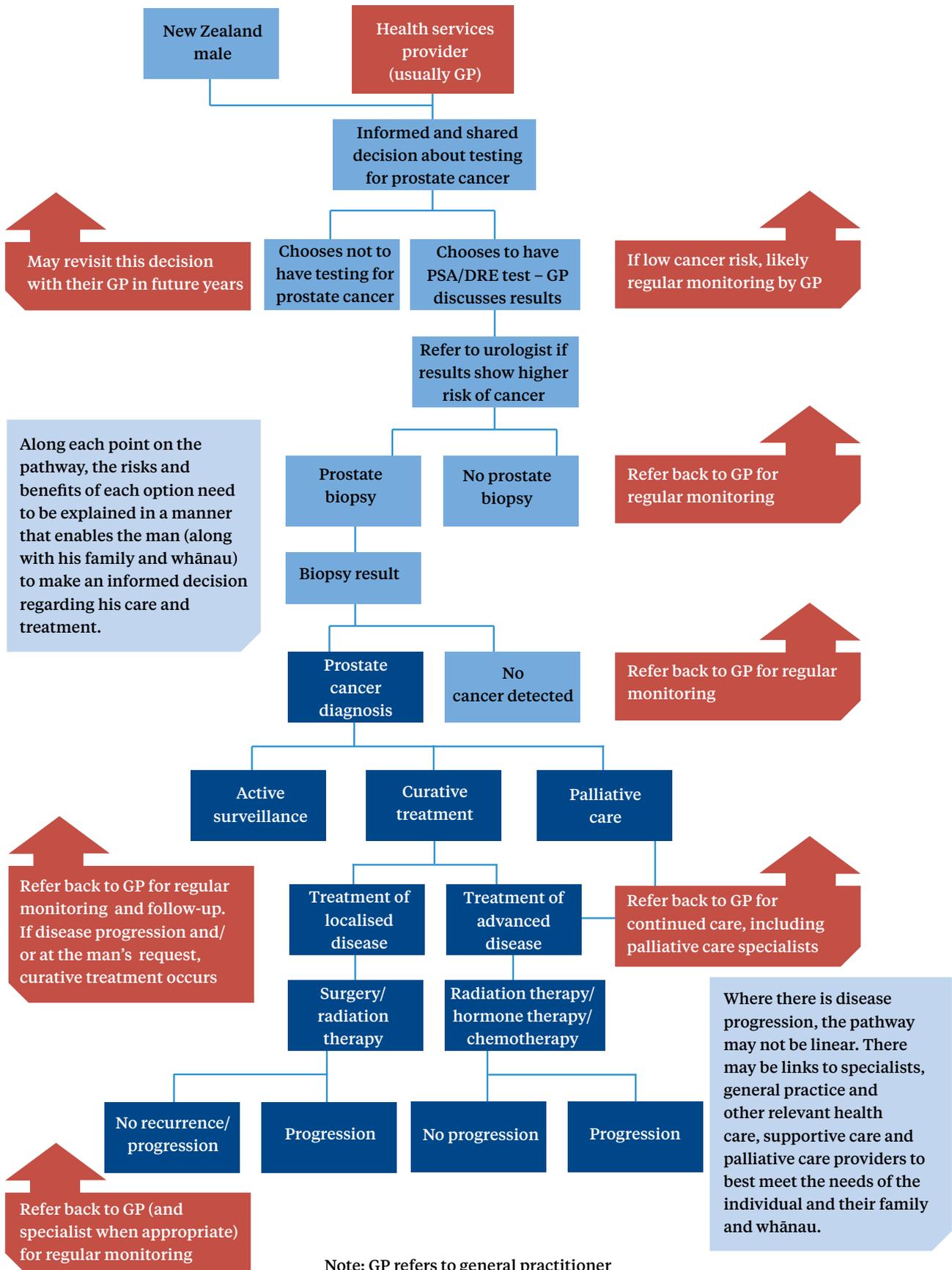
| Benefits and priorities of the prostate cancer quality improvement programme | When |
|--|--|
| <p>What will be achieved</p> <p>Men and their families and whānau will be able to make informed decisions and receive consistent support for the early detection and treatment of prostate cancer.</p> | |
| <p>How this will be done</p> <p>Men and their families and whānau will have greater access to information on PSA testing.</p> <ul style="list-style-type: none"> • Make information on the early diagnosis and treatment of prostate cancer available in suitable formats and languages. • Develop and distribute information resources from a range of locations. | <p>under way</p> <p>year 1</p> |
| <p>GPs and other health care providers will be supported to provide men and their families and whānau with consistent information on prostate cancer testing and treatment options.</p> <ul style="list-style-type: none"> • Develop a decision support tool to assist men and GPs in shared decision-making about early detection and treatment of prostate cancer. • Develop information on the benefits and risks of prostate cancer treatment options, including the impact on health-related quality of life. • Implement a prompt in GP patient management systems to help identify men who should be offered information. • Provide consistent information for providers of national telephone advice services. • Include content on prostate cancer in training and education for GPs and health care providers. • Develop the capability of GP patient management systems to track prostate cancer patients against agreed care plans. | <p>years 1–2</p> <p>year 2</p> <p>year 2</p> <p>year 2</p> <p>years 2–4</p> <p>years 2–4</p> |

⁹ For more information, see www.proqolid.org

Care along the prostate cancer pathway

A cancer care pathway (Figure 1) is the route that a patient takes from their first contact with a health professional (usually their GP) through referral to a hospital specialist, to the completion of their treatment. It includes palliative and end of life care.

Figure 1: The prostate cancer care pathway



The issues

Some men who may benefit from early diagnosis and treatment can have limited opportunity for access to appropriate health services. Other men who would otherwise not have any complications from prostate cancer may suffer harm from overtreatment.

Currently, there are no national standards or guidelines for the referral, diagnosis, staging, management and care of men in relation to prostate cancer. As a result, there are inconsistencies in access to services and in the quality of care and treatment men receive in New Zealand.

Summary of the Taskforce recommendations

The Taskforce recommendations covered the entire prostate cancer care pathway. They included:

- primary care
- diagnostic guidelines
- pathology reporting of prostate cancer biopsies
- active surveillance
- curative treatments
- metastatic prostate cancer.

In particular, the Taskforce recommended the development of guidelines for each part of the pathway, including:

- diagnosis and staging of prostate cancer
- supporting the increasing role of active surveillance
- care of men with metastatic prostate cancer.

The Taskforce also recommended the establishment of an expert panel of pathologists to regularly review a selected proportion of reported tumour pathology specimens.

The Taskforce made a number of recommendations that support improving the quality and consistency of clinical practice. Among those recommendations were to:

- assign a 'risk category' to all men diagnosed with localised prostate cancer
- provide access to multidisciplinary teams
- provide guidance for radical prostatectomy and radiotherapy as treatment options (including men receiving advice from both urologists and radiation oncologists).

Implementing the recommendations

Many of the issues identified in the Taskforce recommendations will be addressed by developing prostate cancer tumour standards. They will also be supported by other health sector initiatives under way.

Development of standards

A key focus of the Faster Cancer Treatment programme is to develop tumour standards. Tumour standards set out best practice management of specific tumour types across a patient pathway and enable a nationally coordinated and consistent approach to service provision. Standards have been developed for lung cancer and are being developed for eight other tumour types.

The development of tumour standards specific to prostate cancer will be important to ensure a man experiences a standardised approach to prostate cancer care.

Electronic referral systems

Electronic referral systems (e-referral) linking primary care with DHB specialist services are being gradually implemented across New Zealand. These systems will enable faster, more efficient and equitable access for men who need a biopsy, other investigations or treatment for prostate cancer.

The Working Group needs to provide advice so that these e-referral systems support the requirements for referral of men for the diagnosis and treatment of prostate cancer. Supportive systems can be achieved by:

- developing nationally consistent templates for referral to urology and specialist management of prostate cancer
- implementing referral guidelines for men with an elevated PSA or suspected prostate cancer.

The development of referral guidelines should reflect the New Zealand Guidelines Group's guidelines on the referral of people with suspected cancer (NZGG 2009).

Professional development of pathologists

To help standardise biopsy pathology, the Royal College of Pathologists of Australasia is currently developing a web-based tutorial programme for pathologists. Once this tutorial programme is completed, its use should be promoted as an additional tool that supports the aims of the AQIP.

Development of guidelines

The development of guidelines is central to improving the consistency of outcomes for men with prostate cancer in New Zealand. Guidelines are needed to cover a range of situations so that prostate cancer management is consistent. Guidelines related to active surveillance are seen as a priority for reducing harm as they will provide men with the options for delaying or avoiding the need for curative treatment.

Guidelines for the treatment of localised prostate cancer need to be available to specialists and general practitioners, as well as to men who require detailed information. Guidelines on staging and risk classification are also required to assist with treatment decisions, including active surveillance. These guidelines should be based on the Taskforce recommendations and best available evidence.

The clinical practice guidelines for metastatic prostate cancer will be based on current Australian National Health and Medical Research guidelines (NHMRC 2010). The Working Group (or expert workstream) will need to review the guidelines to adapt them to the New Zealand setting and to support equity of access for all men.

Multidisciplinary meetings

The management of prostate cancer can be strengthened by making better use of multidisciplinary meetings (MDMs) to inform decisions, particularly where the cancer is more advanced.

The Faster Cancer Treatment programme is working to extend MDMs to all main tumour types. MDMs are regular meetings at which health professionals from a range of different specialties consider relevant treatment options and together develop a recommended individual treatment plan for each patient. The Ministry has developed national guidance for DHBs to use in implementing high-quality multidisciplinary meetings. The guidelines will assist the Working Group when the role of MDMs in prostate cancer is investigated.

Further work is required to examine ways to improve access by men and their families and whānau to advice from all members of the multidisciplinary team.

Palliative care

There is a range of management options for men who have incurable, locally advanced or metastatic prostate cancer. Palliative care has an important role in the management of patients with metastatic prostate cancer and needs to be integrated into the patient's care as early as possible.

Providing appropriate and effective palliative care is important for the quality of life of men with metastatic prostate cancer. The Ministry is already working to improve the consistency of available palliative care services in New Zealand. This work includes implementing the *Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand* (Ministry of Health 2012c).

Activities and priorities

Table 3 outlines the activities and priorities that will support care along the prostate cancer care pathway in the first four years of implementing the AQIP.

Table 3: Activities and priorities to support care along the prostate cancer care pathway

| Benefits and priorities of the prostate cancer quality improvement programme | When |
|--|---|
| <p>What will be achieved</p> <p>Men will have consistent and appropriate referral to specialist care.</p> <p>How this will be done</p> <p>GPs will be better supported to both refer men to specialist care and monitor men who are diagnosed and treated for prostate cancer.</p> <ul style="list-style-type: none"> • Develop referral guidelines. • Incorporate prostate cancer referral guidelines into e-referral processes. | <p>year 1</p> <p>years 2–4</p> |
| <p>What will be achieved</p> <p>Men will have more accurate diagnosis and staging of their prostate cancer.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Develop standards and indicators for staging investigations of prostate cancer. • Develop guidelines for staging and risk assessment of prostate cancer. • Support professional development of pathologists through education and audit programmes on pathology of prostate cancer. | <p>year 1</p> <p>year 2</p> <p>year 2</p> |
| <p>What will be achieved</p> <p>Men will have better access to health services, experience shorter wait times and receive consistent treatment for prostate cancer in New Zealand.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Develop national standards and key indicators for prostate cancer. • Implement monitoring of prostate cancer diagnosis and treatment times. • Develop and implement guidelines on the use of active surveillance. • Develop and implement guidelines for treatment of prostate cancer. • Improve access to multidisciplinary advice. | <p>year 1</p> <p>year 1</p> <p>year 1–2</p> <p>years 2–4</p> <p>years 2–4</p> |
| <p>What will be achieved</p> <p>Men with advanced and metastatic prostate cancer will have higher-quality care.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Develop and implement guidelines for managing advanced and metastatic prostate cancer. | <p>years 1–2</p> |



Monitoring, evaluation and research

The issues

At present there is no agreed national data set for prostate cancer. No organised systems are ensuring appropriate data is regularly collected or analysed to support evaluation and monitoring of service delivery across the prostate cancer pathway. Without such a system, it is not possible to:

- measure the progress of men across the entire prostate cancer care pathway, including the measurement of wait times
- monitor standards of service delivery across the prostate cancer care pathway
- measure the impact of improvements to the prostate cancer care pathway
- regularly update the overview of any inequities along the pathway.

Summary of the Taskforce recommendations

The Taskforce recommended collecting data to support monitoring of service delivery and outcomes and to further assist with managing patients on the prostate cancer care pathway. Other Taskforce recommendations were to:

- establish a quality monitoring framework to promote and monitor change towards equity-focused improvement
- improve data collection (including by ethnicity)
- conduct further research in a range of identified areas.

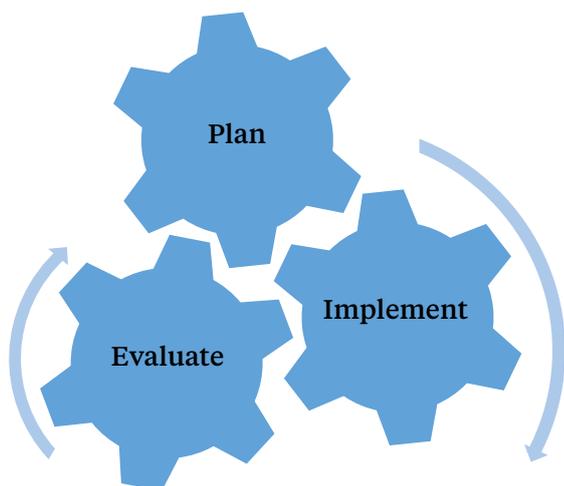
Implementing the recommendations

The Ministry intends to implement the recommendations through the following activities.

Monitoring and evaluation will enable continuous improvement

Collecting and analysing data are central to the function of a quality improvement initiative in any health service. Evaluating and monitoring the progress of improvement and the impact of changes will likewise be a key component in implementing the AQIP. This activity will set up a continuous quality improvement cycle so that it is possible to make further refinements and to identify new priority actions (Figure 2).

Figure 2: The continuous improvement cycle of the quality improvement programme



Systems for improved data collection, reporting and analysis

Collecting and analysing relevant data are critical to improving outcomes along the pathway. Determining the future data requirements and implementing a pragmatic approach to collecting data (including ethnicity data) will be required to support reporting and programme monitoring.

To improve services and examine issues related to data collection, the Working Group would benefit from aligning with the primary health organisation (PHO) performance programme.¹⁰

The Ministry is also integrating all major sources of existing cancer data into a National View of Cancer (NVC). An NVC will provide high-quality, accurate and timely data on cancer incidence, treatment and outcomes, which can be used to achieve better control of cancer. The Ministry expects to begin working on the NVC in mid 2013.

Improving utility of the New Zealand Cancer Registry

Cancer Control New Zealand and the Ministry have established a project to link clinical cancer staging data with the Cancer Registry and to upgrade the Registry to include structured (synoptic) pathology reporting.

The collection of clinical cancer staging data (TNM data) is starting with reporting for colorectal cancer. The next step will be to support collection of data on prostate cancer clinical staging. This clinical staging information can then be linked with information in the Cancer Registry and over time, such linkages will improve the information on staging of all registered cancers.

Structured reporting on prostate cancer is planned to begin during 2013. Based on the Royal Australasian College of Pathologists' recommendations, there will be two structured reports for prostate cancer: one for prostate core biopsies and the other for prostatectomy specimens.

Indicators

Consideration should be given to the development of key quality performance indicators for the management of prostate cancer, similar to those developed by Healthcare Improvement Scotland (Scottish Cancer Taskforce 2012). These will need to include indicators for biopsy, radiological staging, pathology reporting, surgical margins, volume of cases per surgeon, hormone therapy, post radical treatment, post-surgical incontinence, post radiotherapy toxicity and PSA relapse rate. The indicators must include parameters that allow monitoring of higher risk groups such as Māori men.

¹⁰ For more information, see www.health.govt.nz/our-work/primary-health-care/primary-health-care-services-and-projects/pho-performance-programme

Current research projects

The Ministry and the Health Research Council are currently funding a study into the pathways of care for men who have had an abnormal PSA result for prostate cancer. The research is investigating the range of complications arising from the diagnosis and treatment of prostate cancer, along with the estimated cost of providing care to individuals and of the health services. Pathways for Māori and non-Māori, urban and rural men are being compared and analysed. Final results of the research are due in early 2014 and are likely to identify areas for further prostate cancer research.

The Ministry and the Health Research Council are also supporting research in the area of palliative care. Among the topics under investigation are palliative care of urban and rural Māori¹¹ and kaumātua-led (older people-led) models of palliative care.¹²

Future research requirements

In addition to the monitoring and evaluation component of the AQIP, further research is needed in specific areas so that the AQIP can be continuously improved. With the appropriate research, it will be possible to understand the exact cause of issues and to address them in the most cost-effective and appropriate way. Research priorities include:

- the harms and benefits of interventions in testing and treatment along the prostate cancer care pathway
- the possible system-wide consequences if the number of assessments and referrals to urology/ oncology services increases
- prostate cancer incidence, including the extent and causes of inequities between different ethnic groups such as Māori, non-Māori and Pacific men, and men of other ethnicities
- metastatic prostate cancer to determine the burden of disease and reduce inequities.

Activities and priorities

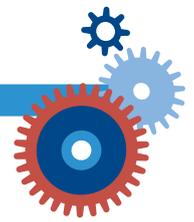
Table 4 outlines the activities and priorities that will support monitoring, evaluation and research in the first four years of implementing the AQIP.

Table 4: Activities and priorities to support monitoring, evaluation and research

| Benefits and priorities of the prostate cancer quality improvement programme | When |
|---|------------------|
| <p>What will be achieved</p> <p>Overall, men and their families and whānau will experience continuous improvements in the early detection and treatment of prostate cancer.</p> <p>How this will be done</p> <ul style="list-style-type: none"> • Monitor and evaluate the progress and impact of changes. • Develop systems for improved data collection, reporting and analysis. • Implement structured reporting for prostate cancer biopsies and prostatectomy specimens. • Implement indicators to enable monitoring across the pathway. • Undertake research to support continuous service improvement. | <p>years 1–4</p> |

11 Auckland UniServices (University of Auckland).

12 Rauawaawa Kaumatua Charitable Trust (Waikato).



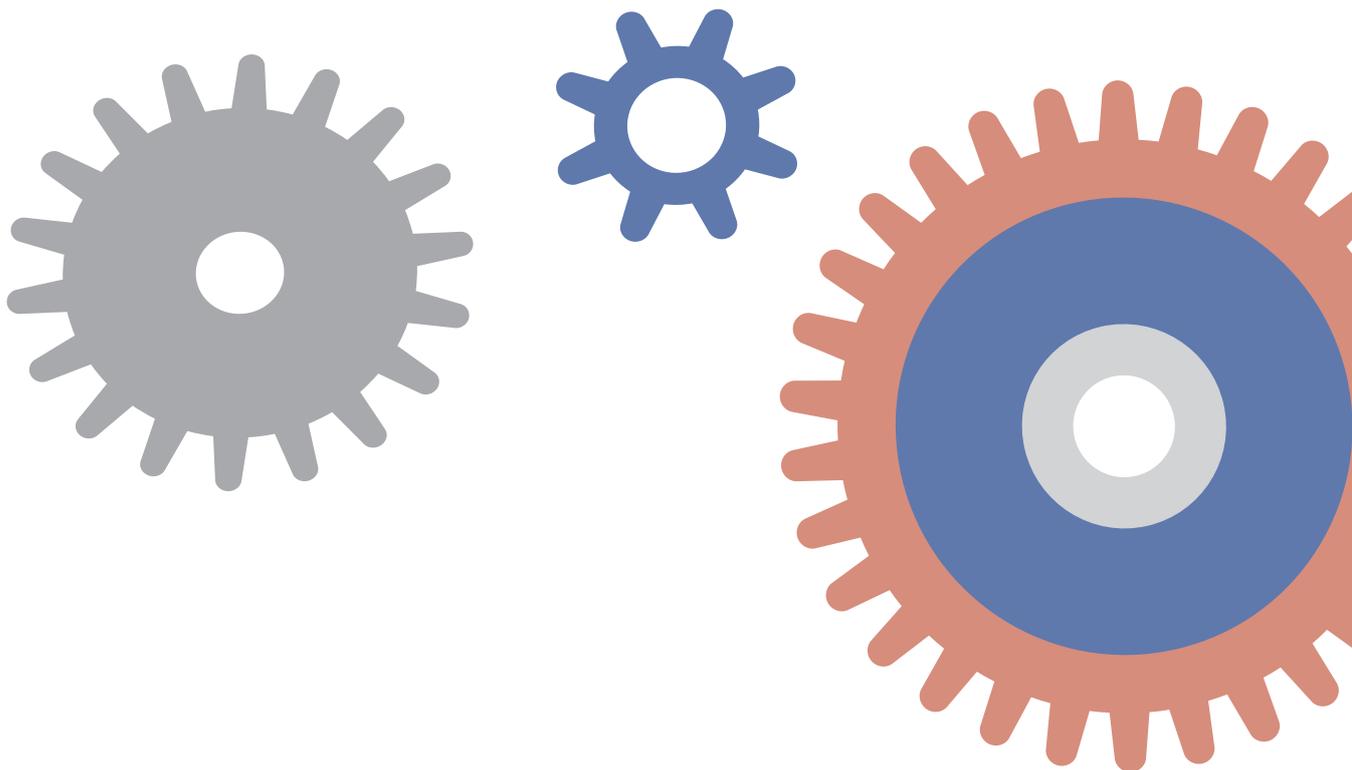
Next steps

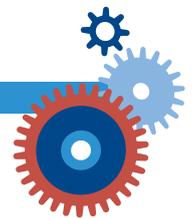
The Ministry will lead implementing the Prostate Cancer Awareness and Quality Improvement Programme by phasing the workplan over several years. The aim of the workplan is to address the most immediate concerns in year 1 and to develop a strong evaluation and monitoring framework to further inform the focus areas of years 2–4.

The priority activities for year 1 are to:

- establish and support a National Prostate Cancer Working Group
- develop and distribute information resources from a range of sources
- begin development of a decision support tool to assist men and GPs in shared decision-making
- develop national standards along with key indicators for prostate cancer
- develop guidelines on the use of active surveillance, the management of advanced and metastatic prostate cancer and appropriate referral to specialist care
- establish a monitoring and evaluation programme
- implement monitoring of prostate cancer diagnosis and treatment times
- examine areas of research to support continuous service improvement.

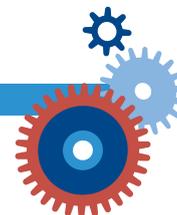
The current workplan will involve the Ministry working with key partners including other government agencies, PHOs, colleges and member organisations. The success of the AQIP will depend on key stakeholders acknowledging the role they play in improving the access to health services, consistency of care and health outcomes for all New Zealand men entering the prostate cancer care pathway.





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Appendix 1: The Taskforce membership

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Appendix 2: The Taskforce recommendations

The Taskforce presented the following recommendations.

1. A National Prostate Cancer Working Group is established to oversee the implementation of the recommendations made by the Prostate Cancer Taskforce. This must include a high level of Māori health expertise.

Equity

2. The National Prostate Cancer Working Group works with key stakeholders to develop and implement strategies to support Māori health professional workforce development along the prostate cancer care pathway.
3. The National Prostate Cancer Working Group oversees the development and implementation of an equity-focused Quality Improvement Plan for the prostate cancer care pathway for men and their families and whānau. This should include:
 - development and implementation of a change management programme to raise awareness among health providers of the need to focus on and achieve equity along the prostate cancer care pathway
 - working collaboratively with prostate cancer researchers to promote an equity focus, enhance outcomes and engage in dissemination of information. Ongoing research must be encouraged (for example, research on the impact of prostate cancer on the socioeconomic position of men and their families and whānau, and ways to mitigate those impacts).
4. The National Prostate Cancer Working Group develops and promotes the use of measures to prevent or lessen the social and economic impact of prostate cancer on men and their families and whānau. This should include measures based on areas of impact along the prostate cancer care pathway, as identified through research.
5. A quality monitoring framework is developed to promote and monitor change toward equity-focused quality improvement. This should include:
 - indicators based on areas of inequity along the pathway identified through appropriate research
 - a minimum national data set
 - professional and organisational standards
 - data collection and management frameworks.

Indicators should be reported by ethnicity so that inequities can be identified and addressed, and progress toward achieving equity can be monitored and reported.

Independent Māori monitoring and reporting should be established following methods similar to those used for BreastScreen Aotearoa.

Public domain

6. Through public information, men and their families and whānau are provided with concise material that will allow them to develop a basic level of knowledge about the prostate gland and prostate cancer. This material should include a description of:
 - the prostate gland, including where it is and what it does
 - cancer in general and how it develops and spreads
 - the natural history of prostate cancer, including its ability to progress over time and spread to other organs. Prostate cancers may be fast or slow growing. Slow-growing prostate cancers are common and may not cause symptoms or shorten life. Others may develop into a serious cancer, growing within the prostate gland and later spreading to surrounding areas or to elsewhere in the body.
7. Through public information, men and their families and whānau are advised that there is no proven prevention for prostate cancer. There is some evidence that lowered intake of animal fat may be of small benefit.
8. Through public information, men and their families and whānau are advised that men with a first-degree relative with prostate cancer are at much greater risk of developing prostate cancer themselves.
9. Through public information, men and their families and whānau are advised that Māori men have a lower chance of surviving prostate cancer than non-Māori men and that the Ministry of Health is working with health professionals and Māori leaders to improve the quality of the prostate cancer care pathway in order to address this inequity.
10. The Cancer Registry provides sufficient detail on prostate cancer incidence and survival to allow research on the differences between Māori, non-Māori and Pacific men.
11. Through public information, men and their families and whānau are advised that men with urinary symptoms should request assessment by their general practitioner. This assessment is likely to include a PSA blood test and digital rectal examination (DRE). The general practitioner may suggest referral to a specialist depending on the severity of the symptoms or if there is a suspicion that there may be underlying prostate cancer.
12. Through public information, men and their families and whānau are advised of the procedure of prostate biopsy and its associated risks. Men also need to be advised that a negative biopsy does not rule out the presence of underlying prostate cancer and that, if the biopsy is negative, ongoing observation will probably be recommended.
13. Through public information, men and their families and whānau are advised of the consequences of prostate biopsy with respect to the likely requirement of staging investigations. They should also be presented with a general guide to the currently available treatment options. This should include a commentary on the place of ‘non-mainstream’ curative treatments and the current developments with chemotherapy and immune therapies. The guide should also consider the potential benefits and harms of treatment.
14. Information needs to be available at a level of understanding relevant to the patient and should take into account different patient perspectives such as age, co-morbidity and family history.
 - Information should be in a variety of formats such as written text, diagrams, video and internet, and take account of issues such as sight or hearing problems.
 - Information should reflect best evidence.
 - Information should be culturally appropriate.

- Information resources must be developed in consultation with Māori.
- Information should be available in the languages of major ethnic groups within New Zealand (Māori, Chinese languages, Pacific languages).

Primary care

15. Primary health care should provide high-quality, culturally appropriate information on prostate cancer and PSA testing to men aged 50 to 70 years. All men who are concerned about prostate cancer or are requesting a PSA test must be presented with high-quality, culturally appropriate information.
16. Systems must be introduced to general practices to facilitate the informed consent process.
17. Screening for prostate cancer must be by both PSA and DRE testing. PSA testing alone is acceptable only where DRE is considered a barrier to testing.
18. All men presenting with lower urinary tract symptoms, and men with systemic features of malignancy, must have an appropriate examination and assessment, which includes checking for prostate cancer. This check will include a serum PSA and creatinine, other appropriate blood tests, urinalysis and a clinical examination including digital rectal examination.
19. In the presence of a normal DRE, PSA values of <4.0 ng/mL do not generally merit specialist referral. A significant PSA rise in a man whose PSA has previously been low may warrant referral.
20. General practitioners should refer patients to a urologist according to the following criteria:
 - men aged 50–70 years – when the PSA is elevated to ≥ 4.0 ng/mL
 - men aged 71–75 years – when the PSA is elevated to ≥ 10.0 ng/mL
 - men aged ≥ 76 years – when the PSA is elevated to ≥ 20 ng/mL
 - men with a palpable abnormality in the prostate on DRE
 - a significant PSA rise in a man whose PSA has previously been low may warrant referral.
21. The primary health organisation or clinical network in which the patients are enrolled must support general practices in meeting some of the requirements of a Quality Improvement Programme. The Ministry of Health must lead a national process to define a prostate care pathway with provision of appropriate resources.
22. A national telephone information service should be available. This would be staffed by experienced, educationally prepared prostate cancer nurses. The nurses would have access to good-quality, written patient information to mail out to callers in response to enquiries and to support phone discussions. The nurses would work under strict guidelines and would not offer direct treatment decision advice.

Diagnostic guidelines

23. The PSA modifications should be restricted in their use to those men in whom the decision on whether or not to biopsy is difficult, based on the grounds of either age or co-morbidity.
24. Men meeting the following criteria should be considered for prostate biopsy after taking into account clinical considerations, elimination of benign causes of high PSA, age, co-morbidity and patient choice:
 - suspicion of malignancy on digital rectal examination
 - men up to the age of 70 years with a PSA ≥ 4 ng/mL

- men between 71–75 years with a PSA \geq 10 ng/mL
- men aged \geq 76 years with a PSA \geq 20 ng/mL
- a significant PSA rise in a man with previously low PSA values.

Pathology reporting of prostate cancer biopsies

25. Cores of tissue from each biopsy site are submitted in a separate specimen container and a record is made of the location from which the biopsy is taken.
26. Findings are in a structured (synoptic) format according to each biopsy site, with the minimum data set being the presence or absence of tumour, the tumour type, extent of involvement of the core by tumour, the presence or absence of extraprostatic extension and the grade of the tumour.
27. A web-based tutorial programme is made available for routine use by pathologists.
28. In order to improve consistency and reduce interobserver variation, an expert panel of pathologists should be convened to provide regular review of a proportion of tumours reported over a defined timeframe by all pathologists involved in the diagnostic reporting of prostate cancer specimens.

Active surveillance

29. The most suitable patients for active surveillance are those with low volume T1a or T1c, Gleason score \leq 6 and PSA \leq 10. T1b and T2a tumours may be considered for active surveillance with caution. Careful monitoring of men in an active surveillance programme is essential.
 - All men diagnosed with localised prostate cancer and considering active surveillance should be offered the chance to discuss their options with both a urologist and a radiation oncologist, and most should consult with both specialists.
 - Monitoring during active surveillance must be meticulous and include regular PSA monitoring, DRE and an early repeat biopsy within 12 months of initial biopsy and further repeat biopsies as clinically indicated.
 - All patients diagnosed with localised prostate cancer should be appropriately informed about active surveillance as a treatment option.
 - Men entering an active surveillance programme as a cancer treatment option need to be tracked in the general practice IT system. This should reflect a care plan agreed between the specialist, patient and general practitioner.

Curative treatments

30. Men at significant risk of metastases and those with locally advanced disease should be considered for appropriate staging investigations.
31. All men diagnosed with localised prostate cancer should be assigned a ‘risk category’ to help assess appropriate management options.
32. All men diagnosed with localised prostate cancer should be offered the opportunity to discuss their options with both a urologist and a radiation oncologist, and most should consult with both specialists.
33. The option of radical prostatectomy should be considered for localised prostate cancer in men who are fit and have a good life expectancy.
 - Radical prostatectomy is most suitable for men with low and intermediate risk tumours but can be considered in selected high risk patients

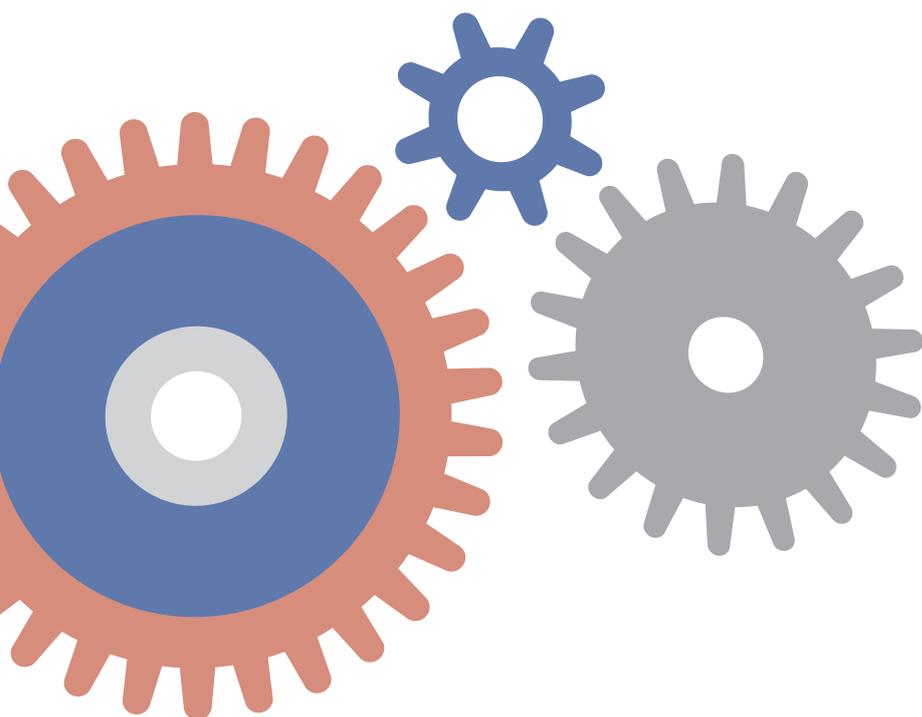
- Men considering radical prostatectomy should be informed about the options of open incisional, laparoscopic or robotic-assisted laparoscopic techniques.
 - Men considering radical prostatectomy should be informed about active surveillance and radiation therapy alternatives and have the opportunity to consult appropriate specialists.
34. Radiation treatment should be with contemporary techniques of intensity modulated radiotherapy (IMRT) with daily image guidance (image guided radiotherapy, IGRT).
35. All the appropriate radiation treatments, including external beam, low dose rate and high dose rate brachytherapy, should be discussed with men considering curative treatment.

Metastatic prostate cancer

36. New Zealand Clinical Practice Guidelines are developed for metastatic prostate cancer.
37. Research is undertaken to determine the burden of disease and reduce inequities in Māori men with metastatic prostate cancer.

Access to health services

38. Data must be collected on wait times for all men undergoing assessment for possible prostate cancer and those undergoing prostate cancer treatment through all stages of the cancer care pathway. These data must be analysed and reported according to ethnicity.
39. A regional and national stocktake and review of data collected on prostate cancer diagnosis and management, including wait times, should be undertaken. This should include district health boards and private and public sector providers.
40. A national core prostate cancer data set should be developed and implemented to permit monitoring of a national quality plan. Quality indicators, which should include monitoring treatment pathway times, must be developed and implemented.





Glossary of terms and abbreviations

| | |
|---------------------|---|
| active surveillance | active surveillance is a management option for prostate cancer which aims to avoid or delay treatment in men with low risk prostate cancer. Monitoring involves regular repeated clinical evaluation, PSA measurements and, if required, further prostate biopsies. Curative therapy is recommended to those men where there is evidence of cancer progression that may present a more significant threat than initially assessed |
| biopsy | removal of small pieces of tissue for examination under a microscope to determine the diagnosis and, if shown to be malignant (cancerous), to determine the tumour grade (degree of aggression) |
| curative treatment | treatment and therapies provided to a patient with an intent to improve symptoms and cure the patient's medical problem |
| DRE | digital rectal examination |
| equity/inequity | inequity has a moral and ethical dimension, resulting from avoidable and unjust differentials in health status. Equity is concerned with creating equal opportunities for health and with bringing health differentials down to the lowest possible level |
| evidence base | the body of clinical studies from which the benefits and harms of diagnostic tests and treatments can be evaluated. The quality of evidence from those clinical studies can be evaluated according to the type of study as well as other factors including statistical validity, clinical relevance, currency and peer-review acceptance |
| guidelines | guidelines are designed to support the decision-making processes in patient care. Guideline management recommendations are derived from systematic review of clinical evidence |
| indicators | a measure of a process or outcome to monitor whether the care was delivered within acceptable clinical parameters according to appropriate standards of care. A monitoring component of a standard (eg, 100 percent of patients start radiotherapy within 4 weeks of agreement to treat) |
| inequality (health) | differences in health status or in the distribution of health determinants between different population groups |
| metastatic | the spread of cancer from one part of the body to another |
| morbidity | disease, disorder, illness; incidence of ill health |
| mortality | a fatal outcome, death |

| | |
|------------------------------|---|
| prostate cancer care pathway | clinical/care pathways – also known as critical pathways, care paths, integrated care pathways, case management plans, clinical care pathways or care maps – are used to systematically plan and follow up a patient-focused care programme. A prostate cancer care pathway is a standardised algorithm of the best way to manage prostate cancer |
| PSA | prostate specific antigen. The higher the PSA level, the more likely it is that a cancer is present |
| standards | a benchmark for best clinical practice, often developed by expert committees using an independent, consensus-based and transparent process |
| TNM data | TNM stands for: <ul style="list-style-type: none"> – Tumour (indicates the size or involvement of a malignant tumour) – Node (indicates whether lymph nodes have cancer cells in them) – Metastasis (indicates whether cancer has spread to other parts of the body). <p>The stages are called T1, T2, T3 and T4, N0 and N1, and M0 and M1.</p> |
| whānau | a collective of people connected through a common ancestor (whakapapa) or as the result of a common purpose (kaupapa) |
| Whānau Ora | an inclusive interagency approach to providing health and social services to build the capacity of all New Zealand families and whānau in need. It empowers families and whānau as a whole rather than focusing separately on individual family members and their problems |

