FINAL REPORT

THE MIDLANDS PROSTATE CANCER STUDY:
UNDERSTANDING THE PATHWAYS OF CARE FOR MEN
WITH LOCALISED PROSTATE CANCER

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Prepared for:

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Tēnā rā koutou, e te iwi nui tonu, me te whaikorōria tonu i te Atua Kaha Rawa. Kia tau, tonu, ōna manaakitanga maha ki runga i a Kiingi Tūheitia, me tona Whare Ariki nui tonu!

Kua tangihia, kēngia, ngā mate o te wā! No reira, ka waihongia rātou ki a rātou! Tātou, kē, o te ao morehu, ki a tātou!

Ka kitea, i raro nei, he kaupapa whakahirahira ka pa ki te kaupapa rangahaua ngā āhuatanga e pā ana ki te oranga, kore oranga rānei, o te taha-a-tinana o te tāne, e mōhiotia ana ko te repe tātea; i runga anō i te mōhiotanga, ko te mate pukupuku o te repe tātea, o te tāne, tētehi o ngā momo mate pukupuku e peehi kino ana i a tātou tāne Māori.

Ma te aata mātai, aata whakawetewete i aua āhuatanga, ka taea, pea, te kitenga i te ara haerenga whakamua; hei oranga ,ake, mo a tātou tāne; ara, me pēwhea te tū ‘Kia hiwa rā...’ o ngā tāne, kia kaua rātou e peehi kinohia e taua momo mate.

Ma te Runga Rawa e tiaki, e manaaki tonu, i a tātou katoa;

Pai Marire!

MESSAGE FROM THE PRINCIPAL INVESTIGATOR

This report is the synthesis of 3 years work from a multi-disiplinary team of clinicians and researchers. We describe the pathways that men go through to a diagnosis and subsequent treatment for prostate cancer. This has led us to make a number of recommendations, which we hope will improve the journey for men and their families.

I would like to thank all those who have helped us in our endeavors – including Auckland UniServices Ltd, our project partners the Midland Cancer Network, our clinical colleagues, the general practices that participated in the PSA study, the patients and partners who shared their personal experiences, Pathlab, Waikato, Bay of Plenty and Lakes district health boards, members of our governance and advisory groups and of course the Ministry of Health and Health Research Council for their support.

We hope you find this report informative.

Sincerely,

Ross Lawrenson

EXECUTIVE SUMMARY

Background

The Health Research Council of New Zealand along with the Ministry of Health issued a request for proposals (RFP) during 2010 to increase the evidence-base about the current prostate cancer pathway from diagnosis to outcomes. The specific objectives of the RFP included:

- The pathways of care following an abnormal PSA test
- The costs of care to the individuals and the community
- The spectrum of complications arising from diagnosis and treatment
- The implications for equitable access for Maori men to care

The following report is the response to this RFP and covers the full pathway of care for men diagnosed with localised prostate cancer.

Introduction

For New Zealand men, prostate cancer is the most commonly registered cancer. Māori men are less likely to be diagnosed with prostate cancer, but when diagnosed they are twice as likely to die. Prostate specific antigen (PSA) testing is commonly carried out in New Zealand with approximately 80% of testing done on asymptomatic men and can be described as opportunistic screening. Little is known about what occurs once an asymptomatic man has an abnormal PSA result. Treatment options in New Zealand vary and differences in outcomes of screening have not been evaluated in the local setting. There is evidence that treatment for prostate cancer can commonly cause moderate-to-substantial harms. We have less reliable information about the wider complications, including social and psychological impact. We also do not have a good understanding of the financial costs associated with diagnosis and treatment of prostate cancer in New Zealand and who pays.

Our aim was to examine the pathways of care following an abnormal PSA test for prostate cancer, with a focus on differences within the pathway for Māori vs. non-Māori and rural vs. urban men.

Methods

We developed a four phase approach:

For the first phase, prostate cancer registrations were obtained from the New Zealand Cancer Registry (NZCR) for the period 1996-2010 These data were linked to the national mortality data. Temporal trends in incidence and survival were analysed to identify differences between age groups, Maori and non-Maori and between the four Cancer Networks.

Phase two explored PSA testing in general practice. GP clinics in the Midland region were recruited. Access to laboratory data was gained and each practice Medtech system was searched. Patient surveys were undertaken to identify reasons why men believed they received their initial PSA test. We also investigated the health care costs involved in the primary to secondary diagnosis process.

Phase three focused on the management of localised prostate cancer patients within the Midland region. All Māori men (n=150) from the Midland region diagnosed with prostate cancer during 2007-2010 were identified from the NZCR and age matched to three NZ European men (n=450). We recreated the cancer care pathways of the 600 patients from original referral to post-treatment outcomes. A decision tree for the management of prostate cancer was developed.

Finally, phase four examined the impact of prostate cancer diagnosis and treatment on patients and their partners using structured questionnaires to measure key outcomes. Men were recruited from the phase three cohort.

Results

Men with localised prostate cancer have a good prognosis, with a high proportion surviving more than 10 years without treatment. Men in the MCN

were more likely to die of prostate cancer than men in any of the other three CNs. Māori men were more likely to die with and of prostate cancer compared with non-Māori men. This is despite the fact that survival improved in both Māori and non-Māori men. The survival gap between the groups has not reduced with time.

9,344/35,734 men were PSA tested during 2010. 85% of the testing was screening. PSA testing varies considerably between general practices (from 7% to 41%). Māori men and men in rural areas are less likely to be PSA tested. Surprisingly much of the testing in men aged 70 years plus was asymptomatic screening. About 12% of PSA tests were deemed to be elevated, although only 2.1% were identified from screening. 43% of men with elevated PSA levels were referred to a specialist. When referred 65% of men were biopsied with 55% having a positive result. When tested and biopsied, Māori men are more likely to have a positive result.

Prostate cancer patients in the Midland region were primarily diagnosed with localised prostate cancer (76.1%). 11.8% with locally spread prostate cancer and 12.1% with metastatic prostate cancer. Māori men were significantly more likely to have metastatic cancer at the time of diagnosis than non-Māori. Treatment options in men with localised cancer varied and were influenced by age, risk score and the presence of co-morbidities. Non-Maori men more likely to have surgical intervention or low-dose rate brachytherapy, Maori men were more likely to have external beam radiotherapy.

106 men and 54 partners were surveyed to understand treatment choices and the impact of living with a prostate cancer diagnosis and treatment. The main factor identified by men as influencing their treatment choice was the doctor's recommendation. 73% of men thought they had good treatment options before making a decision about what treatment to undergo. Overall men expressed a good rate of return to normal life 3-6 years post diagnosis. However, men still had information and supportive care needs post-treatment. Partners also identified a high level of on-going stress.

Recommendations

This study makes recommendations to inform and help improve the pathways of care for men with prostate cancer. There are clear recommendations for GPs regarding PSA testing, referral to specialist and the need to monitor men after an abnormal PSA test. Recommendations also cover improving the recording of cancers and add to the management of men after diagnosis and treatment.

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1. BACKGROUND

This study was commissioned by the Ministry of Health and the Health Research Council as a partnership project. Cancer Control New Zealand has a clear strategy to:

- Reduce the mortality from cancer
- Reduce the impact of cancer
- Reduce inequalities in access to cancer services due to ethnicity, economic status and place of domicile
- Evaluate how effectively new initiatives have been implemented.

Cancer Research Partnership issued a Request for Proposals (RFP) in 2010 to inform the evidence base of patterns of care and reasons for care within prostate cancer. The purpose of the research was to provide a description of the types of care received by men and to demonstrate the equity issues, costs and complications arising from this care. The RFP noted that costs of care were not to be limited to financial costs; social, economic, psychological and physical costs should all be considered. The RFP indicated that the research should also provide details of the proportion of men who are likely to undergo biopsy after a prostate-specific antigen (PSA) test. Other areas to be considered included:

- The pathways of care following an abnormal PSA test
- The costs of care to individuals and the community
- The spectrum of complications arising from diagnosis and treatment
- The implications for equitable access to care for Māori and Pacific men

A requirement was that the proposed research should also aim to show at an individual level the consequences, risk of complications such as incontinence and erectile dysfunction and the associated cost and effect on quality of life.

A major aim was that the research should inform advice and subsequent care provided by health professionals, and to improve health outcomes and equity for New Zealand men diagnosed with prostate cancer.

It was indicated that the identification and engagement of key stakeholders was essential. The overall research process was intended to inform key stakeholders, including the Ministry of Health, to increase sector buy-in to the initiative and eventually to allow groups to better prioritise issues relating to prostate cancer within their sector.

The University of Auckland (UniServices) responded to the RFP. The team was principally based in the Midland Cancer Region, made up of the Waikato, Lakes and Bay of Plenty District Health Boards (DHBs). This cancer region has the largest proportion of Māori men in New Zealand and so was well placed to examine the issues of equity of access to cancer care for Māori. The region also includes a substantial rural population, allowing research into the influence of geography on cancer care. The project team included two urologists, a radiation oncologist, a general practitioner (GP), an expert on screening and a Māori public health physician, as well as a statistician, health economists and social researchers.

To help guide the project we brought together an academic advisory board of researchers and stakeholders as a reference body for the different phases of our research. We also developed a consumer advisory group with representatives from Waikato/BOP Cancer Society, New Zealand Prostate Cancer Foundation, the Midland Cancer Network, District Health Boards and survivors of prostate cancer. Finally, we were fortunate in having easy access to the Waikato DHB Te Puna Oranga and Midland Cancer Network Māori advisory group, Hei Pa Harakeke, for guidance on our research with Māori men in our region.

Although the project had a large scope we have limits; however, we are fortunate that we have been able to attract further funding to look at related topics.

The Waikato Medical Foundation funded a pilot study of PSA testing in general practice which helped inform the design of our main study.

The Ministry of Health funded support for a health economic evaluation of our findings through a PhD scholarship.

We have applied to the University of Auckland for additional scholarships using funding from the Sara Fitzgibbons bequest to look at a study of bone health in men with prostate cancer.

Finally, we have been successful in an application to Janssen-Cilag Pharmaceuticals for funding to look at the use of anti-androgen therapy for men with metastatic prostate cancer.

The study team has already engaged with a wide group of stakeholders. Two of the investigators (Professor Lawrenson and Dr Scott) have participated in the Ministry of Health Prostate Cancer Taskforce. We have made presentations to the Urological Society of Australia and New Zealand (USANZ), the Royal New Zealand College of General Practitioners, the UK Royal College of General Practitioners, the New Zealand Rural General Practice Network, the Midland Health Network, the Midland Cancer Network, the Prostate Cancer Foundation and the Prostate Cancer World Congress. All peer-reviewed outputs have been noted in the publication list at the end of this report. We will continue to disseminate findings and information to the wider community to help inform men and their families about prostate cancer.

MIDLANDS PROSTATE CANCER PROJECT

BACKGROUND

For New Zealand men, prostate cancer is the most commonly registered cancer. Māori men are less likely to be diagnosed with prostate cancer, but when diagnosed they are twice as likely to die. Despite two studies that suggest reduced mortality from prostate cancer in men that have been screened, uncertainty as to the benefits, the extent of complications arising from treatment and concerns about over-treatment has meant that universal screening has not been recommended. Opportunistic screening for prostate cancer is widely practiced by general practitioners in New Zealand. Treatment options in New Zealand vary and differences in outcomes of screening have not been evaluated in the local setting. There is evidence that treatment for prostate cancer can commonly cause moderate-to-substantial harms. We have less reliable information about the wider complications, including social and psychological impact. We also do not have a good understanding of the financial costs associated with diagnosis and treatment of prostate cancer in New Zealand and who pays.

RESEARCH AIMS

1. To identify pathways of care following an abnormal PSA test for men aged 40 years and older.
2. Compare pathways for Māori and non- Māori and for those living rurally compared with those living in a major urban center.
3. Explore the epidemiology and natural history of prostate cancer.
4. Investigate the spectrum of complications arising from the diagnosis and treatment of prostate cancer. Also, estimate the costs of care to individuals, comparing Māori and non-Māori communities.

THE STUDY

There are four phases to this study outlined below:

PHASE 1: GP PSA TESTING

We recruited 31 GP clinics in the Midland regions (eligible patient cohort of 36,000-enrolled men 40yrs and over). Recruited clinics gave permission to track PSA testing done and the medtech system was searched to identify reasons for patient attendance on date of PSA test; symptoms; referral; diagnostic tests; treatment; etc. Patient surveys were also undertaken to identify reasons why men believe they received a PSA test.

PHASE 2: NZ CANCER REGISTRY SEARCH

All prostate cancer registrations were obtained from the New Zealand Cancer Registry (NZCR) for the period 1990-2008 including information on age, ethnicity, stage at diagnosis, domicile code and whether death has occurred (for 3 years post-diagnosis). These data were linked to information retrieved from the Mortality Collection and death certificates and were analysed with regard to cause(s) of death for men with prostate cancer between 1990 and 2010. Relevant data was also extracted from the National Health Index and NMDS to establish the pathways and outcomes for individual patients. These data were subsequently evaluated with regard to ethnic group, rural/urban residence and distance from a cancer centre to ascertain whether there were inequities in access and availability of treatment options. From this we examined epidemiological trends for prostate cancer incidence and mortality in NZ men aged 40 years and over.

PHASE 3: IDENTIFYING ALL NEW CASES OF PROSTATE CANCER (2007-2010)

For phase three, we would compose a list of all newly diagnosed patients in the four year period, 2007-2010. We randomly selected 600 NHIs from the Midland region, identified from the NZCR. We have recreated the cancer care pathways of all patients from original GP referral to post-treatment outcomes. From this we will develop a decision tree to aid in understanding likelihood of outcomes for men, depending on age, stage.

We are also interested in understanding the costs of complications for each pathway. We shall investigate the health care costs involved in the key pathways identified by our mapping exercises. An economic model will be developed to determine the costs and outcomes associated with each pathway of care. The model will allow us to explore the impact of different treatment options on costs and outcomes and enable us to undertake sensitivity analyses where the data are uncertain. We would aim to estimate the direct costs for each pathway, including those incurred in primary care, through the public health system and where appropriate costs incurred in specialist private practice. Costs would be measured over a 12 month period following the positive PSA test.

PHASE 4: THE COSTS AND COMPLICATIONS OF PROSTATE CANCER

Whilst we know that treatment for prostate cancer can cause physical symptoms we also believe that, as with any cancer, there will be a psychological and social impact on the lives of patients. This has not been quantified in a population based sample of New Zealand men before. Complications and their impact on patients were identified using structured questionnaires to measure key outcomes. From our sample of men we have recruited a sample of 106 men aged 40 – 75 years of age to help us assess the costs and complications of treatment at an individual level. Fifty-seven partners of these men have also participated in this phase. This has highlighted the indirect costs of living with prostate cancer, for both the patient and his partner.

BENEFITS

This study will help us improve the pathways of care for men with prostate cancer. It will help general practitioners with their decision making as to when to refer men after a PSA test. It will also better inform patients as to their likelihood of needing intense follow up for suspected prostate cancer. We also believe there will be important benefits in improving the pathways of care for men with diagnosed prostate cancer. Information from this study should allow us to gain more insight into the costs and complications from the treatment of prostate cancer.

Midland Cancer Network

The Midland Cancer Network are partners for this research project. For more information on prostate cancer visit our website under "Your Health"

www.midlandcancernetwork.org.nz

Do you still want to know more...?

If you are interested in finding out more about this project, its progress and dates for findings to be realised or if you are interested in being a part of this research please contact us

chanis.brown@auckland.ac.nz

If you would like any further information on PSA testing or Prostate Cancer, or if you have concerns about your health please discuss these issues with your GP.

This study is funded by the Health Research Council and the Ministry of Health. It is based at the Waikato Clinical School, Peter Rothwell Building, Waikato Hospital, Hamilton.

2. STRUCTURE

This project was developed with the assistance of multiple organisations. Project partners were the University of Auckland and the Midlands Cancer Network. We worked with various external and internal groups to assist in our understanding, through advising and guiding our research process. External groups included:

- The Waikato District Health Board Iwi Māori Council
- The Waikato District Health Board Kaumatua Kaunihera
- The Waikato District Health Board and Midland Cancer Network Maori Cancer Advisory Group: Hei Pa Harakeke
- Academic peer reviewers

The identification and engagement of key stakeholders was seen as essential for the research project. We therefore set up three key advisory groups. The first was an Academic Steering Group (ASG) that included clinical academics dealing day to day with the issues of men with prostate cancer. The ASG included a general practitioner (GP), urologist, radiation oncologist and expert nurses. The group also included key academics. The ASG provided academic and clinical governance and assured the quality of the Midlands Prostate Cancer research project. The purpose of this group was to provide expert academic advice and clinical support to the researchers, ensuring that any risks identified were assessed and managed.

The second advisory group was the Community Advisory Group (CAG), which included lay representatives from the Prostate Foundation, the Cancer Society, the Midland Cancer Network (MCN) and local self-help groups. The CAG met on a regular basis to discuss the implications of findings. This group was established to provide a consumer and community perspective to the Midlands Prostate Cancer research project. The purpose of the CAG was to provide advice on methods of consultation with end users, support with advice to men (referrals) and input into the study to ensure that the end user perspective is heard. The third group was the Māori cancer advisory group, Hei Pa Harakeke. This was a generic cancer group formed by the WDHB and MCN to advise on all aspects of care for Māori patients with cancer – including men with prostate cancer.

Governance

Academic Steering Group

Dr Leanne Tyrie (Waikato DHB)
Ms Jan Smith (Midland Cancer Network)
Dr Charles DeGroot (Formerly Midland Cancer Network)
Mr Michael Holmes (Waikato DHB)
Ms Lyn Walker (Waikato DHB)
Dr Nina Scott *Ngati Whatua, Waikato* (Waikato DHB)
Associate Professor Peter Gilling (Bay of Plenty DHB, UOA)
Dr Helen Conaglen (UOA)
Associate Professor John Conaglen (UOA)
Dr Fraser Hodgson (UOA and GP)
Associate Professor Alistair Stewart (UOA)
Associate Professor Paul Rouse (UOA)
Professor Toni Ashton (UOA)
Mr John Woodford (Pathlab)
Dr Barry Smith *Te Rarawa, Ngati Kahu* (Lakes DHB)
Professor Lynn Fergusson (UOA)
Dr Jim Watson (Caldera Health)
Dr Geraldine Leydon (University of Southampton, UK)
Mr David Musgrave (Formerly Caldera Health)
Dr George Laking: *Te Whakatōhea* (Auckland DHB and UOA)
Dr Richard Edlin (UOA)

Consumer Advisory Group

Mr Graham Harbutt (Formerly Waikato Cancer Society)
Mr Dene Ainsworth *Te Ātiawa* (NZ Prostate Cancer Foundation)
Mr Jack Porima *Ngati Hikairoa* (Raukura Hauora O Tainui)
Mr Jeffery Morse (Counsellor)
Mr Rawiri Blundell *Ngati Porou ki uawa* (Midland Cancer Network)
Ms Margie Hamilton (Midland Cancer Network)
Dr Nina Scott *Ngati Whatua, Waikato* (Waikato DHB)
Mr Tamati Peni *Raukawa* (Waikato DHB)
Mrs Tiffany Schwass (Waikato DHB)
Mrs Lauren James *Ngati Whakaue, Te Arawa, Tuhoe* (Lakes DHB)

Team Members
Professor Ross Lawrenson (University of Auckland (UOA)) – Principal Investigator
Dr Charis Brown - Project Manager
Dr Fraser Hodgson – Pilot Project/Advisor
Dr Zuzana Obertova - Cancer Epidemiology PhD Student
Ms Chunhuan Lao - Health Economics PhD Student
Ms Alice Wang - Health and Nutrition PhD Student
Mrs Thilini Alwis - Research Assistant
Mr Tamati Peni – Research Assistant
Mrs Diana Benfell - Data Entry
Dr Helen Conaglen – Researcher
Dr Nina Scott *Ngati Whatua, Waikato* Equity Advisor

Clinical Workshop
A clinical workshop was held to gain agreement on recommendations made from the findings of the report. Members of this workshop were:
Professor Ross Lawrenson
Mrs Jan Smith
A/Professor Peter Gilling
Mr Michael Holmes
Dr Leanne Tyrie
Dr Nina Scott
Mrs Tiffany Schwass
Dr Helen Conaglen
Dr Charis Brown
Dr Zuzana Obertova
Ms Chunhuan Lao
Ms Alice Wang
Mrs Thilini Alwis

3. AN INTRODUCTION TO PROSTATE CANCER

Prostate cancer is the most common cancer in New Zealand men. It is almost always due to an adenocarcinoma developing within the prostate gland, a small gland found at the base of the bladder. Prostate cancer is usually a slowly growing tumour that occurs in old age. Most cancers have an indolent course during the first 10 to 15 years. For example, three fair-quality cohort studies show that most men with prostate-specific antigen (PSA)-detected, non-palpable, localised prostate cancer have good health outcomes up to 10 years after diagnosis [1-3]. In 1997 Johansson showed that in a population-based cohort of men with prostate cancer, after 15 years of follow-up, 80% of men who had initially presented with localised disease were still alive and survival was unaffected by whether or not they had received treatment [4].

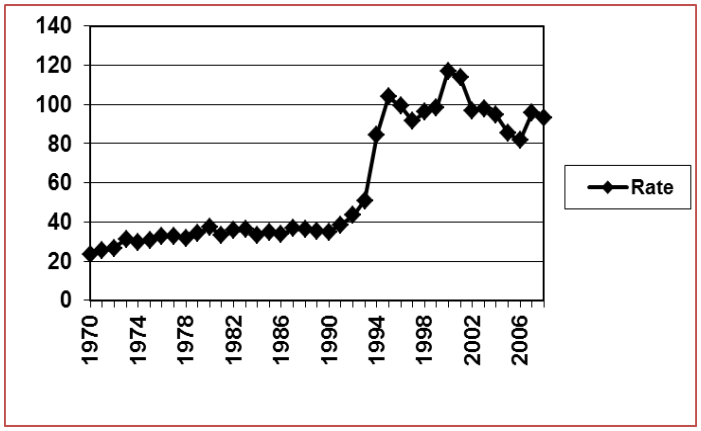

Figure 3-1: Incidence-new cases of prostate cancer in New Zealand.

Further follow-up at 15 to 20 years revealed a substantial decrease in cumulative progression-free survival [5]. However, it is also recognised that prostate cancer can occur in middle-aged men in their 50s and 60s and even occasionally in men in their 40s. While most cases are slow-growing, some men present with aggressive tumours, which seem to progress more rapidly and are more likely to metastasise.

In New Zealand in 2008, 2,939 men were diagnosed with prostate cancer, corresponding to a rate of 93.4 per 100,000. The age-standardised incidence of prostate cancer increased substantially with the introduction of PSA testing in the mid-1990s.

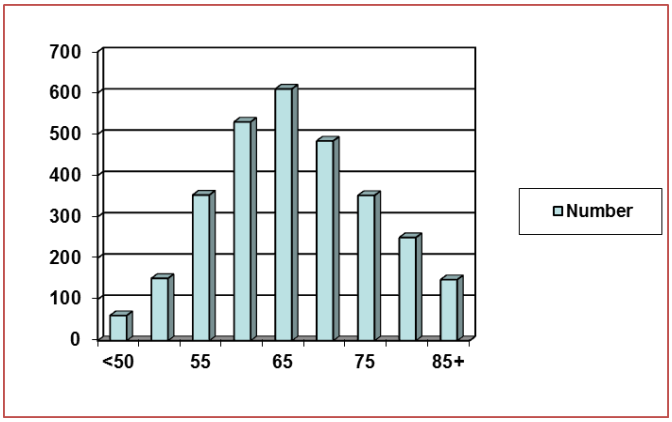

Figure 3-2: Number of new cases of prostate cancer in New Zealand by age (2008).

There were 670 deaths due to prostate cancer in 2008, with an age-adjusted incidence rate of 16.6 per 100,000. This is similar to the mortality rate in 1970. Most men are diagnosed with cancer in their 60s and 70s. However, most deaths occur in men aged 75 years and older.

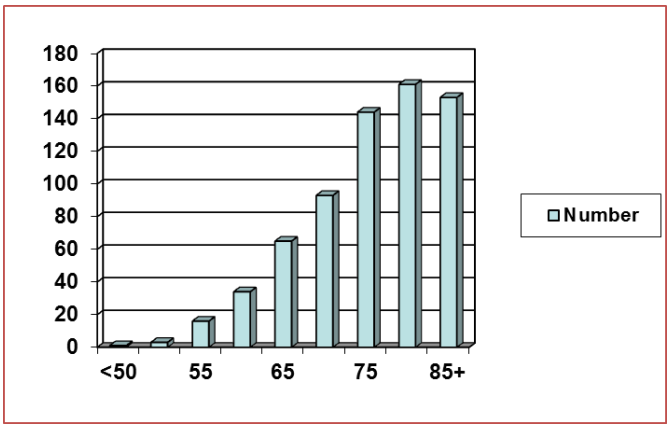

Figure 3-3: Number of deaths from prostate cancer in New Zealand by age (2008).

We know from international literature that there is a higher incidence rate of prostate cancer in urban men. This finding suggests that rural men are less likely to be screened and hence less likely to be subsequently diagnosed with prostate cancer [6].

Although mortality patterns tended to be heterogeneous, there is some evidence that rural residents with prostate cancer experience higher death rates. For Māori men, while their prostate cancer incidence rate was lower than for the overall male population in 2008 (74.9 per 100,000), their mortality rate due to prostate cancer was higher (32.9 per 100,000). For Pacific men, the prostate cancer incidence (98.5 per 100,000) and mortality (23.2 per 100,000) rates in 2008 were similar to the rates for all men.

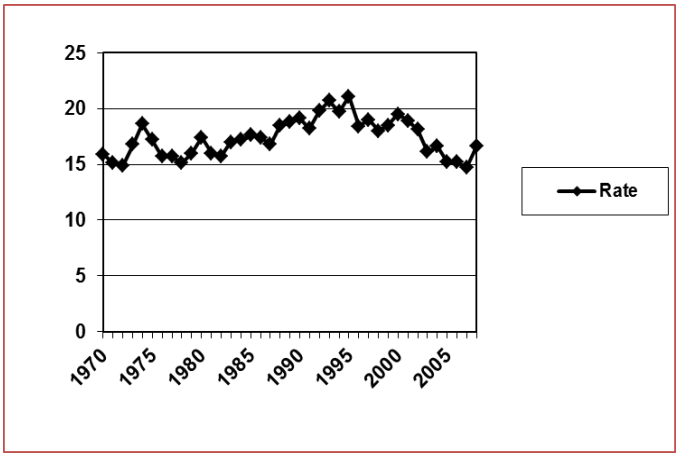

Figure 3-4: Mortality rate of prostate cancer in New Zealand 1970-2008.

Diagnosis and treatment of prostate cancer

Prostate cancer is generally diagnosed either after presentation to a general practitioner with symptoms or following screening for prostate cancer. Men that present with symptoms tend to have more advanced disease then those identified through screening. Indeed, some men present with metastatic disease, affecting other organs.

Typically, asymptomatic men who have been diagnosed with prostate cancer will have an early stage tumour confined to the prostate gland. In these cases the options for treatment include radical prostatectomy, radiotherapy (focussed beam or brachytherapy) or active surveillance. A randomised controlled trial of radical prostatectomy versus watchful waiting in men identified from a number of sources including screening found that during a median follow-up period of 8.2 years, fewer men in the radical prostatectomy group than in the watchful waiting group died of prostate cancer (30 vs. 50, P=0.01) [7]. The benefit was mostly seen in men aged 65 years and under, for whom the outcomes of watchful waiting in this study were worse than those seen with similar management in the older patients. There is little convincing evidence that brachytherapy or focussed beam radiotherapy have different survival outcomes than prostatectomy. There is evidence that treatment for prostate cancer can cause moderate-to-substantial harms, such as erectile dysfunction, urinary incontinence, bowel dysfunction and, on occasion, death. A study of long-term outcomes from radical prostatectomy, external beam radiation therapy and brachytherapy, around 20% of men experienced urinary incontinence, 60% had erectile dysfunction and 10-15% had problems with bowel function after 2 years. Urinary incontinence was more common after radical prostatectomy, bowel dysfunction was more common after radiation therapy and all three treatment modalities profoundly affected sexual function [8]. These harms are important because many men with prostate cancer who are treated would never have developed symptoms related to the cancer during their lifetime.

Treatment options in New Zealand vary between District Health Boards (DHBs), and differences in outcomes of the various options have not been evaluated in the local setting.

The Select Committee report of 2011 [9] recommended that effort should be made to:

- Decrease the risk of harm and improve the current unorganised prostate cancer screening pathway in New Zealand
- Provide monitoring of outcomes from international randomised trials on prostate cancer screening and clinical management to decrease harms from screening

• Work to assess the current cost of prostate cancer service provision

In 2012 the Ministry of Health set up the Prostate Taskforce to review the diagnosis and management of prostate cancer in New Zealand men. This Taskforce has released its report and recommendations [10, 11]. The Taskforce report covers the whole spectrum of prostate cancer management, whereas our study has concentrated on the diagnosis and management of men with localised prostate cancer.

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4. PUTTING THE MIDLAND PROJECT IN CONTEXT: UNDERSTANDING PROSTATE CANCER TRENDS NATIONALLY, REGIONALLY AND BY ETHNICITY

Prostate cancer is the most commonly registered cancer (28% of male cancer registrations) and the third most common cause of male cancer deaths (15%) among New Zealand men [1]. As the world population is ageing, it is predicted that prostate cancer will become a leading cause of cancer deaths [2].

From 1998 to 2008 only five men younger than 40 years were registered with prostate cancer in New Zealand [this study]. The incidence of prostate cancer is generally extremely rare before the age of 40 years [1]. Therefore, for the purpose of our study we have considered only men aged 40 years and older as the population at risk. All calculations following this statement, including GLOBOCAN rates, are based on populations of men aged 40+ years [3].

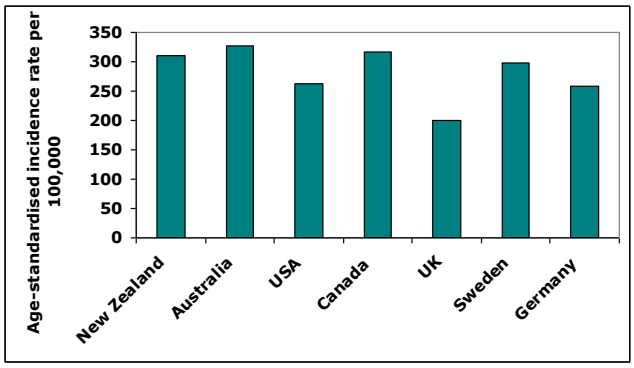

Figure 4-1: Age-standardised (WHO men 40+ years) incidence rates of prostate cancer for New Zealand, Australia, USA, Canada, UK, Sweden and Germany [3].

New Zealand has one of the highest age-standardised incidence rates of prostate cancer in the world, which is largely attributed to high screening rates for prostate cancer [3-5] (Figure 4-1). Furthermore, the mortality rate due to prostate cancer in New Zealand is comparably high, exceeding death rates in Canada and the USA, and the UK in particular, which has a low prostate cancer incidence and low screening rates [3] (Figure 4-2).

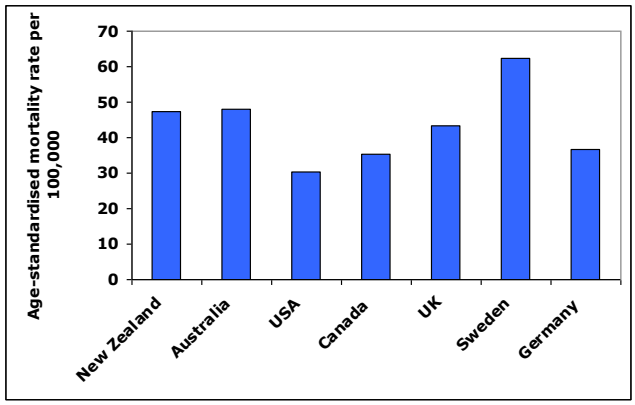

Figure 4-2: Age-standardised (WHO men 40+ years) prostate cancer mortality rates for New Zealand, Australia, USA, Canada, UK, Sweden and Germany [3].

Prostate cancer incidence rates provide information on the uptake of screening and access to early detection in a population. However, they may also reflect regional differences in cancer registration practices. The incidence rate of prostate cancer in New Zealand increased dramatically (Figure 4-3) since PSA testing became available in 1993 [6].

Although mortality has been decreasing slightly since 1996 [1], it is unclear whether this decline may be attributed to PSA screening and/or to improvements in treatment [7, 8].

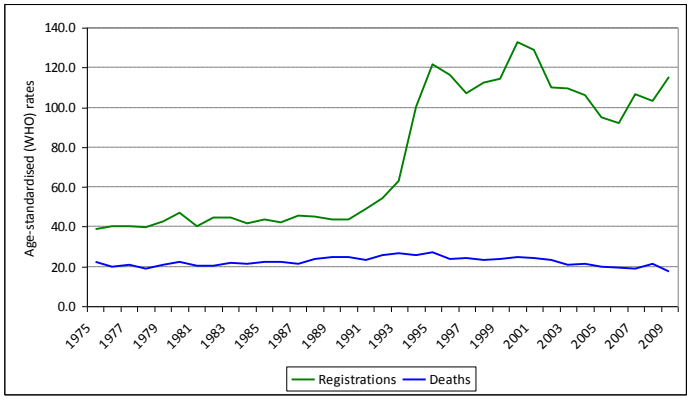

Figure 4-3: Annual age-standardised (WHO) prostate cancer incidence and mortality rates in New Zealand men [3].

In New Zealand, prostate cancer is the cancer with the highest 5-year prevalence when compared with

other common cancers, such as breast cancer in women or colorectal cancer in both men and women [3] (Figure 4-4).

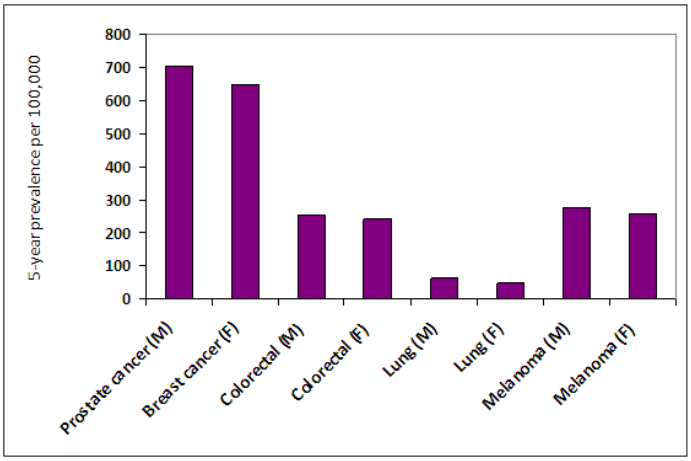

Figure 4-4: Five-year prevalence of common cancer in New Zealand [3].

For the purpose of our study, we used national data to "set the scene" for more detailed regional analyses. We used incidence and survival data to assess temporal trends and also to explore the effects of ethnicity and region on these outcomes. Mortality rates were not used because in the case of prostate cancer mortality rates are considered to be an inconsistent measure. This is due to the fact that annual death rates represent a mixture of cases, some of which were diagnosed decades ago and some of which were diagnosed recently. Therefore, annual mortality rates are liable to the effects of period-specific changes in incidence rates and treatment options [9].

The disadvantage of using survival as an outcome measure is that, in contrast to mortality, survival can be improved not only by preventing or curing the disease but also by early diagnosis and, in the case of prostate cancer, by over-diagnosis. Therefore, we would not be able to assess the extent to which any of the three factors – screening, treatment and early diagnosis – drives the result. However, using survival as an outcome measure allowed us to address our main aim for this part of the study, which was to assess current trends in outcomes and differences between ethnic groups and regions.

Aim

The aim of our study was to assess temporal trends in prostate cancer incidence and survival, and to explore differences between Cancer Networks, and between Māori and non-Māori men. Since most of our research was undertaken in the Midland Cancer Network (MCN), the comparison of registration and survival rates between Cancer Networks (CNs) will allow us to assess the situation in the MCN with respect to the national framework. We can also estimate to what extent the results obtained within the MCN may be extrapolated to other regions. Individual factors, such as age, ethnicity, geographical residence and socio-economic status were also explored since they may have an effect on registration and survival rates.

The MCN covers the District Health Boards (DHBs) of the Waikato, Bay of Plenty and Lakes regions. The MCN has a leadership, facilitation and co-ordination role in bringing together and working with stakeholders across organisational and service boundaries to reduce the impact of cancer, reduce inequalities in care and improve the experience and outcomes for people with cancer.

In July 2012 the Tairawhiti DHB joined the MCN. By this time, however, the data collection for our study had been completed. Thus, our analysis only included data from the three original DHBs. These three DHBs have a combined population of 680,000, of whom 24% are of Māori descent [10].

Four major hospitals are located in the region covered by the MCN: Waikato Hospital (the regional Cancer Centre), Tauranga Hospital, Whakatane Hospital and Rotorua Hospital. These hospitals all offer specialist urological services. Approximately 45% of the population within these three DHBs lives rurally or in a minor urban centre [11].

Methods

We created a study sample of men diagnosed with prostate cancer between 1 January 1996 and 31 December 2010. We used two main information sources for data extraction: the New Zealand Cancer Registry (NZCR) and the Mortality Collection (MORT). Data linkage by the National Health Index (NHI) number was used to ascertain the cause of death for deceased men identified from the NZCR. The data on vital status from MORT were available from 1 January 1996 to 25 May 2011 (the most recent data available at the time of request).

The final study population included 37,529 men from the original 41,583 men after men aged younger than 40 years at the time of diagnosis, diagnosed at death, of unknown ethnicity and/or with domicile abroad were excluded. Furthermore, cases with morphology codes not consistent with adenocarcinoma of the prostate were excluded.

Predictor variables

Age at diagnosis was used as a continuous variable as was year of diagnosis. Prioritised ethnicity was used in the analysis. Prioritised ethnicity is assigned as Māori if one of the three possible self-identified ethnicity responses is Māori. Men not identified as Māori were described as non-Māori. In this group, 95.8% were NZ or other Europeans, 2.4% Pacific Islanders, 1.5% Asians and 0.03% of other ethnicity.

Extent of disease is one of the major confounding factors when analysing cancer survival. In the NZCR the extent of disease at diagnosis is coded as B for localised disease, C for invasion of adjacent tissues or organs, D for invasion of regional lymph nodes, E for distant metastases and F for unknown extent. Unfortunately, the extent of disease at diagnosis has been listed as known for only about one quarter of prostate cancer patients. Therefore, we used extent as a contributing factor in our analyses but a sub-group analysis was not attempted.

Domicile (residence) at diagnosis from the NZCR was used to assign each patient to the New Zealand Index of Deprivation 2006 [12]. The NZDep06 is a measure derived from nine variables (income, benefit receipt, single parent family, home ownership, employment, qualifications, living space, access to communication and to transport) collected in the Statistics New Zealand 2006 Census of Population and Dwellings and provides a summary deprivation score ranging from 1 (least deprived) to 10 (most deprived) for small geographical areas (with a resident population of approximately 100 people) [13]. For the purpose of this study, the deciles have been collapsed into quintiles.

Domicile at diagnosis was also used to classify each patient into the following urban/rural categories: main urban area, satellite urban area, independent urban area, rural area with high urban influence, rural area with moderate urban influence, rural area with low urban influence, and highly rural/remote area. This urban/rural classification was developed in 2004 using the 2001 Census meshblock patterns and the Statistics New Zealand standard classification, which was based on population size only by adding a measure of the degree of urban influence to the respective areas [Statistics New Zealand 2005]. This new measure was determined by the usual residence and workplace addresses of the employed population in the area. For the analysis, the seven categories were further grouped into 1) main urban area, 2) urban influence (satellite urban area, independent urban area, rural area with high urban influence), and 3) rural/remote area (rural area with moderate urban influence, rural area with low urban influence, highly rural/remote area).

New Zealand is divided into four CNs: Northern (NCN), Midland (MCN) and Central (CCN) on the North Island, and the Southern (SCN) covering the whole of the South Island. Table 4-1 lists the four CNs with their respective DHBs. The DHB domicile

from the NZCR was used to assign each patient to one of the four CNs.

Table 4-1: List of DHBs by Cancer Network.

Midland Cancer Network (MCN)	Northern Cancer Network (NCN)	Central Cancer Network (CCN)	Southern Cancer Network (SCN)
Waikato DHB	Auckland DHB	Taranaki DHB	Nelson/Marlborough DHB
Bay of Plenty DHB	Waitemata DHB	Whanganui DHB	Canterbury DHB
Lakes DHB	Counties Manukau DHB	MidCentral DHB	Otago DHB
	Northland DHB	Hawke's Bay DHB	West Coast DHB
		Tairawhiti DHB (MCN since 1 July 2012)	South Canterbury DHB
		Wairarapa DHB	Southland DHB
		Hutt Valley DHB	
		Capital & Coast DHB	

Outcome variables

The age-specific and age-standardised incidences of prostate cancer were calculated by year of diagnosis. The Census 2001 New Zealand male population aged 40+ years was used as the population at risk (denominator) for the standardisation. Men aged younger than 40 years were not considered as being at risk of prostate cancer.

Age-standardisation is used to enable comparisons of groups that differ with regard to their age structure, such as Māori and non-Māori groups in New Zealand. Direct standardisation based on the New Zealand population was used in our study. Age is an important determinant in prostate cancer since the incidence increases with age [14], therefore age-specific rates were also analysed.

All-cause and prostate cancer-specific survival were calculated from the date of diagnosis to the date of death. Survival time after diagnosis was measured in months. Men who were still alive on the day of last follow-up (25 May 2011) were censored. For the cancer-specific mortality analysis, men who had prostate cancer listed as the underlying cause of death were considered as cases, while men who died of causes other than prostate cancer or were still alive at the date of last follow-up were censored.

Statistical analysis

The differences in the distribution of population characteristics of men with prostate cancer between the MCN and the other three CNs and between Māori and non-Māori men were tested using the chi-square statistic.

One-year and five-year survival for men in the MCN compared with those in the other three CNs and for Māori compared with non-Māori men were estimated using the Kaplan-Meier method, and the equality of survivor functions was compared by log-rank test.

Cox proportional hazard regression models were used to estimate the relative risk of dying from any cause and from prostate cancer for men in the MCN (compared with the other three CNs) and Māori men (compared with non-Māori men) before and after adjustment for age, diagnosis years, residence, and socio-economic status.

Ethics approval for the access and use of the data from the national databases (NZCR and MORT) was granted by the Chairperson of the New Zealand Multi-Region Ethics Committee (Ref. No. MEC/11/EXP/044).

Results and discussion

Study population

Our study population included 37,529 men, of whom 5748 (15.3%) resided in the MCN at the time of diagnosis, and 1916 (5.1%) were Māori. Appendix tables 9-1 and 9-2 summarise patient characteristics by CN and ethnicity.

A higher proportion of Māori men were registered with prostate cancer in the MCN compared with the other three CNs. The MCN and SCN had similar proportions of men living in rural/remote areas, while the NCN and CCN had fewer men in this area. The proportion of men in the most deprived quintile was higher in the MCN than in the other three CNs. A lower proportion of men were diagnosed between 1996 and 2000 in the MCN compared with the other CNs. The number of new registrations continually increased up to the most recent period (2006-2010) in the MCN, while no such obvious trend was observed in the other three

CNs. Men in the MCN were more likely to die due to prostate cancer than those in the NCN, while they were less likely to die of other causes than men in the SCN.

More Māori men were diagnosed under the age of 70 years compared with non-Māori men. Māori men were more likely to reside in rural/remote areas and to be in the most deprived quintile. Māori men were more likely to die during the follow-up period, and when they died they were more likely to die of prostate cancer than non-Māori men. The ratio of Māori men dying of other causes to those dying of prostate cancer was 1, while in non-Māori men this ratio was 1.4; this indicates that non-Māori men were more likely to die of causes other than prostate cancer.

Since age is an important factor in the natural history of prostate cancer and also in the follow-up of patients, particularly regarding treatment options [15, 16], we also summarised the patient characteristics by two age groups, under 70 years and over 70 years at the time of diagnosis (see appendix Table 9-3). Men under the age of 70 years were more likely to live in rural/remote areas, and to be in the least deprived quintile. More men were diagnosed before the age of 70 years between 2006 and 2010, while an opposite trend was observed between 1996 and 2000. Naturally, younger men were more likely to be alive at the end of the follow-up. A similar proportion of men aged less than 70 years at diagnosis died due to prostate cancer and other causes, while a higher proportion of men aged 70+ years died of other causes than of prostate cancer.

To summarise, men diagnosed with prostate cancer between 1996 and 2010 in the MCN were more likely to be Māori, live in rural/remote areas and in the most deprived quintile and die of prostate cancer than men in the other Cancer Networks. We also found that Māori men were more likely than non-Māori men to reside in rural/remote areas and in the most deprived quintile and to die of prostate cancer. Therefore, the differences between the MCN and the other CNs may have been largely driven by the higher proportion of Māori men with prostate cancer identified in the MCN.

In addition, Māori men tended to be younger (under 70 years) at the time of prostate cancer diagnosis compared with non-Māori men, and while younger men are naturally less likely than older men to die, a similar proportion of men younger than 70 years died of prostate cancer and of other causes, while in men older than 70 death was more likely due to causes other than prostate cancer.

Incidence

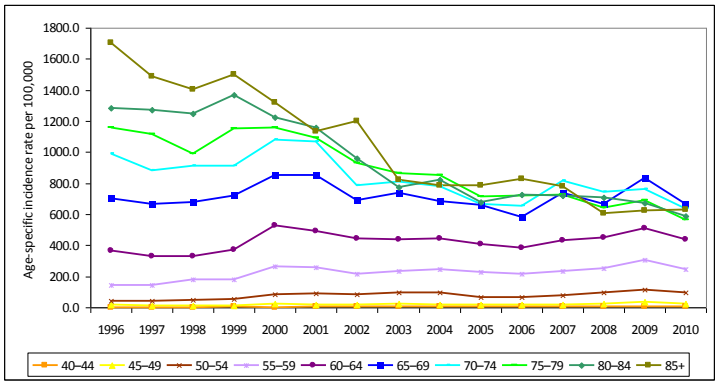

Figure 4-5: Age-specific incidence rates of prostate cancer in our cohort.

Temporal trends in the incidence of a disease reflect screening behaviour and changes in diagnostic methods. Figure 4-5 shows age-specific incidence rates of prostate cancer in our cohort of New Zealand men diagnosed between 1996 and 2010. From 1996 to 2003 there was a clear decline of new diagnoses of prostate cancer in men aged 70+ years. On the other hand, after 2000 there was a slight increase in new cases detected in men younger than 54 years. There were two relatively distinct peaks in new prostate cancer diagnoses in men aged 55 to 69 years between 2000 and 2001 and then between 2007 and 2009.

The first peak coincides with intensified cancer control debate in New Zealand and also with advances in prostate cancer detection, especially in biopsy techniques [7, 17]. In addition, between 1997 and 2000 there were several patient and physician surveys concerning PSA testing and prostate cancer detection in New Zealand, which may have resulted in an increase in PSA testing and thus prostate cancer diagnosis [18, 19, 8]. There is anecdotal evidence that the second peak in 2007-2009 may be associated with intensification of prostate cancer awareness campaigns such as Blue September and Movember in New Zealand, prompting younger men (aged 40-69 years) in particular to get their prostate health checked [20]. Interestingly, the incidence rates in Māori men differed slightly from those in non-Māori (Figures 4-6 and 4-7). The incidence of new prostate cancer cases has been declining with time in both groups. However, the increase observed between 2007 and 2009 was driven mainly by non-Māori men.

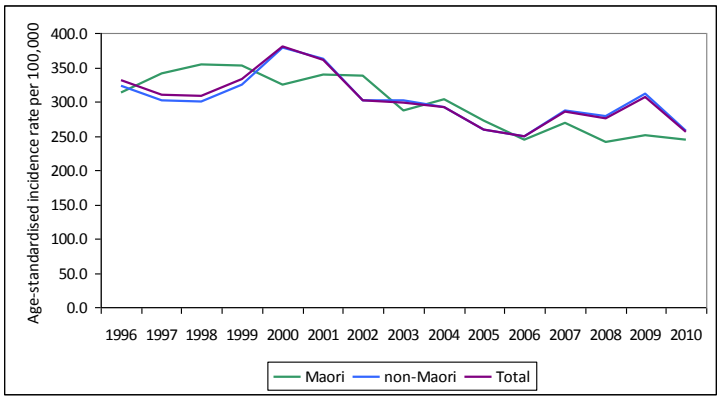

Figure 4-6: Age-standardised (NZ men aged 40+ years from 2001 Census) incidence rates total and by ethnicity.

Although a small peak occurred in Māori men in 2007, the incidence decreased again after this. When the curves were divided by age groups, the downward trend for older men and increasing trend in younger men was similar for both Māori and non-Māori men, but Māori men did not follow the upward trend resulting in the 2009 peak in non-Māori men. It seems that non-Māori men were more likely to follow the awareness campaigns, which prompted them to get a prostate check-up.

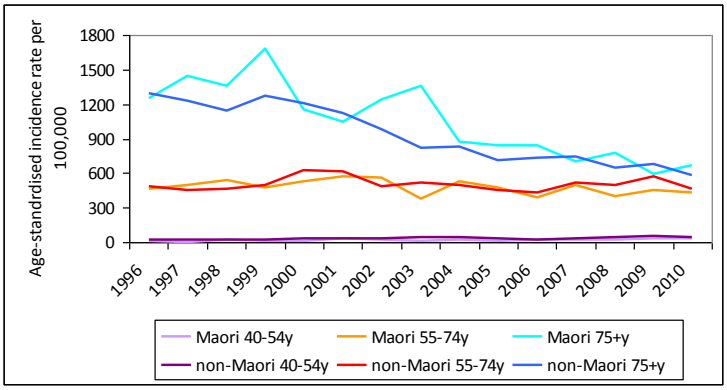

Figure 4-7: Age-standardised (NZ men aged 40+ years from 2001 Census) incidence rates by ethnicity and age group.

The temporal trends varied slightly by CN (Figure 4-8). Interestingly, in the MCN a marked decrease in new registrations occurred between 1998 and 2000, while in the other three CNs the number of new cases increased significantly during that period. There was generally a slight increase in new registrations since 2006 in all four CNs, although the curve was relatively flat in the SCN, while in the MCN and CCN the number of new registrations peaked in 2009.

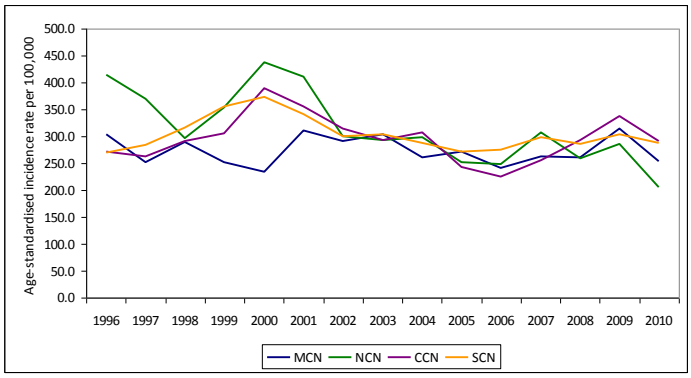

Figure 4-8: Age-standardised (NZ men aged 40+ years from 2001 Census) incidence rates by Cancer Network.

It is assumed that the number of new prostate cancer cases positively correlates with the number of PSA tests undertaken in the population. In 2010, fewer PSA tests were ordered in the SCN and CCN, the CNs with the highest incidence rates of prostate cancer in that year, while the highest number of PSA tests was ordered in the NCN, which had the lowest prostate cancer incidence

[21] (Figure 4-9). This trend indicates that monitoring by PSA testing increases in men with existing prostate cancer, but also that a large proportion of PSA tests do not result in the identification of a new cancer case.

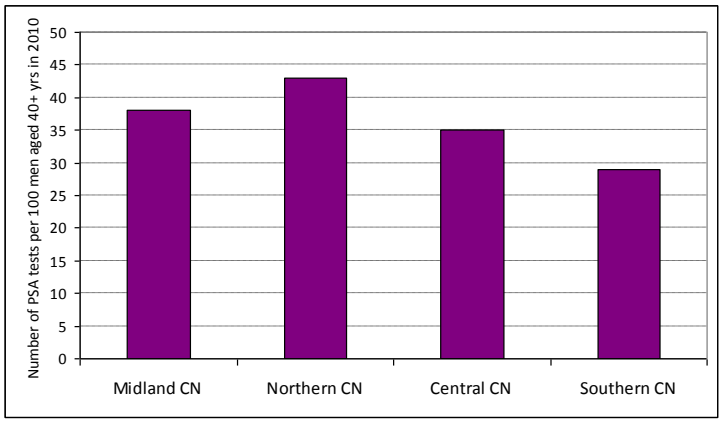

Figure 4-9: Number of PSA tests per 100 men aged 40+ years by Cancer Network [21].

Survival

We used the Kaplan-Meier method to estimate the 1-year, 5-year and 10-year all-cause and cancer-specific survival by CN and by ethnicity (see appendix Table 9-4). This method shows what proportion of men survived the respective periods of time. Approximately 90% of all men survived the first year after prostate cancer diagnosis; 95% when cancer-specific survival was considered. Of men who died of any cause, approximately 70% were still alive after 5 years and 50% after 10 years. Of the men who subsequently died of prostate cancer, 85% were alive after 5 years and 75% after 10 years. The proportion of men surviving was similar among all CNs, but a higher proportion of men were still alive in the NCN compared with the other CNs.

Māori men had consistently worse all-cause survival, with 87% surviving 1 year, 59% 5 years and 35% 10 years, compared with 91%, 70% and 49% of non-Māori men, respectively. A similar pattern was observed for cancer-specific survival.

We used the Cox proportional hazards regression models to estimate hazard ratios for the MCN compared with the other three CNs and for Māori compared with non-Māori men, while successively adjusting for variables such as age at diagnosis, year of diagnosis, extent of disease at diagnosis, residence and socio-economic status. In this report we present the results from only the unadjusted model and the full model (see appendix Table 9-5).

Based on the unadjusted model we found that the hazard ratios for all-cause survival were similar for men in the MCN, CCN, and SCN, while men with prostate cancer in the MCN were 19% more likely to die of any cause compared with those in the NCN. The cancer-specific hazard ratios showed that men in the MCN were 31% more likely to die of prostate cancer than men in the NCN, 10% more likely to die than men in the CCN and 15% more likely to die than men in the SCN. After adjusting for age, year of diagnosis, extent of disease at diagnosis, ethnicity, residence and socio-economic status, men with prostate cancer in the MCN were 12% more likely to die of any cause than those in the NCN. When cancer-specific survival was considered, men in the MCN had 23%, 9% and 14% worse chances of survival than men in the NCN, CCN and SCN, respectively.

The unadjusted hazard ratio for all-cause survival in Māori (compared with non-Māori) men diagnosed with prostate cancer between 1996 and 2010 was 1.49 [95% CI; 1.40, 1.60], i.e. Māori men were 49% more likely to die of any cause than non-Māori men. The hazard ratio adjusted for age, year of diagnosis, extent of disease at diagnosis, CN, residence and socio-economic status was 1.72 [95% CI; 1.60, 1.84].

The unadjusted hazard ratio increased when cancer-specific survival was considered, with Māori men having 1.7-fold [95% CI; 1.54, 1.86] risk of dying from prostate cancer compared to non-Māori men. After adjustment for age, year of diagnosis, extent of disease at diagnosis, Cancer Network,

residence, and socio-economic status the hazard ratio was reduced to 1.64 [95% CI; 1.49, 1.82].

Since treatment options for prostate cancer are highly dependent on age at diagnosis [15, 16], we analysed cancer-specific survival by age groups (<70 years, 70+ years). The hazard ratios from the unadjusted model were similar for men aged <70 years at diagnosis in the MCN, CCN, and SCN, while men with prostate cancer in the MCN were 28% more likely to die of prostate cancer compared with those in the NCN. When men aged 70+ years at the time of diagnosis were considered, men in the MCN had 30%, 17% and 24% worse survival chances than men in the NCN, CCN and SCN, respectively. In the full model, adjusted for age, year of diagnosis, extent of disease at diagnosis, residence and socioeconomic status, a similar pattern was observed, with the differences between the MCN and the other CNs reducing slightly.

The unadjusted hazard ratio for cancer-specific survival in Māori (compared with non-Māori) men aged <70 years was 2.46 [95% CI; 2.13, 2.84], while after adjustment for age, year of diagnosis, extent of disease at diagnosis, CN, residence and socio-economic status, the hazard ratio dropped to 1.59 [95% CI; 1.40, 1.81]. Māori men aged 70+ years at diagnosis were 1.73-fold (unadjusted model) and 1.57-fold (model adjusted for age, year of diagnosis, extent of disease at diagnosis, CN, residence and socio-economic status) more likely to die of prostate cancer than their non-Māori peers.

Figures 4-10 and 4-11 show cancer-specific survival by years of diagnosis (1996-2000, 2001-2005, 2006-2010), CN and ethnicity, respectively. The survival improved over time in all CNs as well as in Māori and non-Māori men. However, the survival differences, particularly between Māori and non-Māori men remained constant.

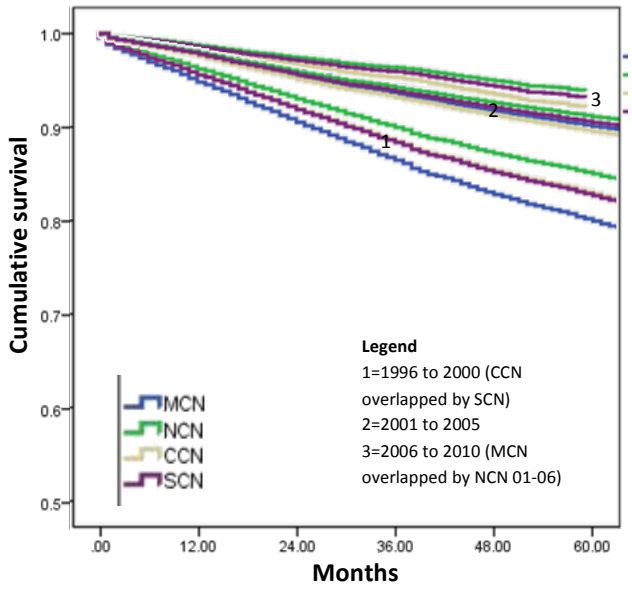

Figure 4-10: Cancer-specific survival by years of diagnosis and Cancer Network.

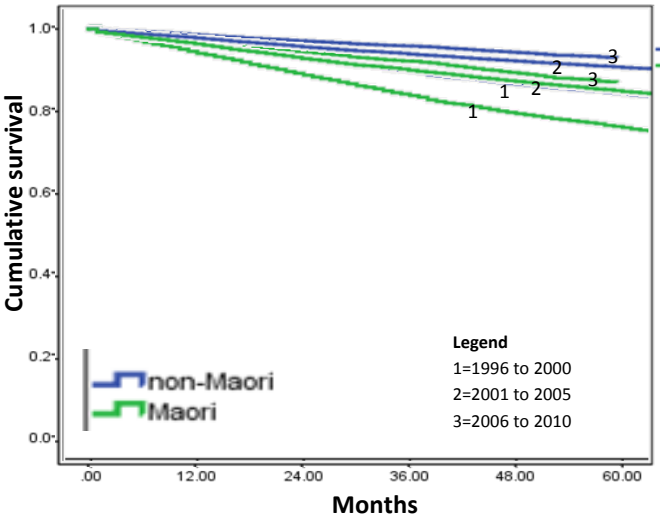

Figure 4-11: Cancer-specific survival by years of diagnosis and ethnicity.

Conclusions

Incidence rates of prostate cancer were similar among the CNs, but higher rates of PSA test use was observed in the NCN. Without reliable information on the extent of disease at diagnosis, the number of men being PSA tested may be used as a proxy for the number of prostate cancer cases detected early (i.e. with localised prostate cancer). Men with localised prostate cancer have a good prognosis, with a high proportion surviving more

than 10 years without treatment [22]. Therefore, the better survival in men in the NCN can be explained to some extent by early detection rather than by differences in treatment. This statement is also corroborated by the particularly high proportion of men surviving 10 years in the NCN compared with the other three CNs.

Men in the MCN were more likely to die of prostate cancer than men in any of the other three CNs. These differences remained after adjusting for potential confounders, such as age, year of diagnosis, extent of disease at diagnosis, ethnicity, residence and socio-economic status. Therefore, it seems that the findings are contributory to the observed survival disparities.

By analysing survival differences for men younger and older than 70 years at diagnosis separately, we found that the differences between the MCN and the other three CNs in cancer-specific survival were driven by the older age group. Since curative treatment is mostly offered only to men younger than 70 years old [23, 15, 16], it seems that other factors such as co-morbidities may explain the survival differences between CNs in older patients.

The number of new registrations was found to be lower for Māori men than for non-Māori men. However, Māori men were more likely to die with and of prostate cancer compared with non-Māori men. When all-cause survival was considered, the adjusted hazard ratio was higher than the unadjusted value, indicating that there were other factors (for which the model was not adjusted) contributing to the survival disparity, such as co-morbidities and treatment modalities. However, the unadjusted and adjusted cancer-specific hazard ratios were similar, which suggests that the differences in all-cause survival were most likely due to factors other than treatment for prostate cancer.

We also analysed cancer-specific survival by diagnosis years, and we found that there was an improvement in survival particularly after the year 2000, which coincides with changes in treatment for prostate cancer in Australasia and may be also attributed to earlier diagnosis due to higher public awareness about PSA testing [7, 8]. However, despite the fact that survival improved in both Māori and non-Māori men, the survival gap between these groups has not reduced with time, which is concerning.

Based on our primary care study (chapter 5) we know that Māori men are less likely to be tested for prostate cancer [24]. However, the NZCR does not contain enough information on the extent of disease at diagnosis to draw conclusions on whether Māori men are more likely to be diagnosed with advanced disease, which would reduce their survival chances compared with non-Māori men. We have also found that other factors, such as residence and socio-economic status, contribute to survival disparities. Therefore, these and other factors, including co-morbidities, will be further explored on the regional level within the MCN.

Recommendations

Most (80%) prostate cancer registrations are not staged on the New Zealand Cancer Registry, making interpretation of outcomes speculative.

1.1 Regional Collection

1.1.1 We recommend that the regional cancer networks record basic information on all men newly diagnosed with prostate cancer in their region – including age, ethnicity, domicile, PSA levels, cancer grade and stage, presence of comorbidities, pre-existing conditions and first treatment – in a standardised format.

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5. PROSTATE-SPECIFIC ANTIGEN TESTING IN GENERAL PRACTICE: PATHWAYS OF CARE FOLLOWING A PSA TEST

Prostate-specific antigen (PSA) testing is commonly carried out in New Zealand, with over 350,000 tests performed annually. Although there is no organised prostate cancer screening programme in New Zealand and prostate cancer screening in general practice is not recommended by the Ministry of Health, PSA testing is frequently used as the first test to screen asymptomatic men for prostate cancer [1]. However, PSA testing is also useful in monitoring prostate cancer in men who have had a previous raised PSA level or who have an existing diagnosis and have been treated with radical prostatectomy or radiotherapy, or are being treated for metastatic disease [2]. PSA testing is also used as a diagnostic aid in men with lower urinary tract symptoms (LUTS).

Increasing prostate cancer screening has triggered a series of problems, including increasing medical costs. The published screening costs are outdated and vary widely, and the studies often did not clearly report which medical resources were included and how they were valued [3].

There were two overarching aims for this phase of the project. The first was to explore the patterns of testing, including differences in care between Māori and non- Māori and identifying reasons why a PSA test was undertaken in Midland general practices. We wanted to identify the pathways of care following an abnormal PSA test result, including what happens after a referral to a specialist. The second aim was to explore the costs of identifying a new case of prostate cancer by age group, ethnicity and previous PSA testing history, using data collected from the general practices.

METHOD

Thirty-six general practices in the Midland region were approached during 2011 to participate in this study. Clinics were purposefully selected with a focus on rural and Māori populations. Thirty-one clinics agreed to participate, with a total eligible currently enrolled male population aged 40 years and over of 36,740. We excluded 1006 (2.7%) men aged over 40 years who had a co-existing diagnosis of prostate cancer, leaving an eligible baseline population of 35,958. Just over 5,000 were of Māori ethnicity.

We sought permission from participating clinics to access all local laboratory and DHB data for men in our baseline population who had received a PSA test during 2010. We identified men who had a PSA test during the period 01 January 2010 to 31 December 2010 and the result of the test. For these men we looked at individual frequency of testing and velocity of PSA back to 2007. Testing rates were analysed by practice location (main urban centre/rural, District Health Board [DHB]), the ratio of patients to general practitioners (GPs) in the practice and whether the practice was a Māori provider. PSA tests were categorised as raised if they exceeded the age-specific levels recommended by Pathlab (Table 5-1).

Table 5-1: Age-specific PSA ranges recommended by Pathlab

Age	Normal value range (ng/mL)
40-49y	0 - 2.5
50-59y	0 - 3.5
60-69y	0 - 4.5
70-79y	0 - 6.5
>80y	0 - 7.0

Medtech Search

The electronic general practice records (Medtech) of men with a raised PSA test were then examined to ascertain:

- Was this a patient with known prostate pathology (e.g. already diagnosed with prostate cancer) or were they a new "case" requiring further investigation?
- If they were a new "case" (i.e. a positive test), did they present to the GP with symptoms or were they identified through screening?
- Had the patient ever had a PSA test before and, if so, when was it performed and what was the result?
- At what level of PSA test were they referred for specialist opinion/biopsy?
- If the patient was not referred for a specialist opinion, what was the management plan for that patient?
- If the patient had a biopsy, what was the result of the biopsy?
- If the patient was found to have cancer, to whom were they referred?
- If the patient was treated, what treatment did they receive?

When we searched the general practice records the reasons for PSA testing were defined into four categories: A. screening; B. previous prostate issues (including previously raised PSA); C. patient request (included in screening for analysis); and D. symptoms, including lower urinary tract symptoms and erectile dysfunction.

To estimate costs, the patient's National Health Index (NHI) number was linked to the data used for capitation payments. The information collected on patients' characteristics from the general practices, including ethnicity and age was 100% complete. Patients enrolled in general practices are required to provide these data before their enrolment is complete.

Cost estimation

We estimated direct medical costs in 2010 and 2011 from a health service perspective. Indirect costs were excluded. A Decision Tree was constructed to map the screening pathway and to document the costs associated with each node (see appendix Figure 9-1). Medical resources considered in this study comprised initial general practitioner consultations (the first consultation related to PSA testing), follow up general practitioner consultations, PSA tests, first specialist assessments (FSA), follow-up specialist consultations, prostate biopsies, pathology reports of prostate biopsy and hospitalization due to complications after prostate biopsy. (All costing tables in appendix: Tables 9-6, 9-7, 9-8). The volumes of the PSA tests, FSAs, prostate biopsies and pathology reports were calculated from the data we collected. The number of general practitioner consultations was estimated based on records of PSA tests ordered by general practitioners. The number of follow-up specialist consultations was estimated from the number of prostate biopsies and PSA tests ordered by specialists. A 2% complication rate [4] and a 4.87 days mean length of hospital stay for complications of prostate biopsy [5] were assumed to quantify the hospitalization after prostate biopsy.

The quantity of healthcare resources was multiplied with the unit cost of each type of medical resource to generate an aggregate cost. The unit costs of medical resources are provided in appendix Table 9-6, alongside the sources. The subsidy per general practitioner consultation was estimated by dividing the capitation rate by the average number of general practitioner consultations per patient [6] (see appendix Table 9-6). The unit costs corresponding to different time periods were converted into 2010 values (as the base year of this analysis) by applying the NZ Inflation Calculator developed by the Reserve Bank (the central bank in NZ). All costs were valued in NZ dollars (NZ$). The conversion rates per NZ dollar in 2010 were 0.540 European euro (€) and 0.447 Pound sterling (£), estimated from the prices and purchasing power parities of different currencies

provided by Organisation of Economic Co-operation and Development [7].

The time spent on discussion about PSA testing in the initial GP consultation varied between from general practices. This discussion is related to the level of informed consent, ranging from almost no time (ticking the box of a laboratory form) to the whole consultation spent on discussing the harms and benefits associated with prostate cancer screening. Three percentages (20%, 50% and 100%) of the cost of an initial GP consultation were assumed to be attributed to prostate cancer screening. This and further information and specific detail on the method used for the cost calculations have been published [8].

Ethical approval for the Midlands Prostate Cancer study was gained through Northern Y: NTY/10/09/070 (pilot) and NTY/11/02/019.

Results

The total enrolled population of men aged 40 years and older in the 31 clinics was 35,958. There were 14% Māori (5,030) and 84% non-Māori (30,153) in the sample (775 men of unknown ethnicity were excluded).

The clinics were spread over the Midland region: 19 Waikato, eight Bay of Plenty, and four Lakes DHBs. The population sizes of the communities were well spread: <10,000 for 11 clinics; 10,000-30,000 for nine clinics; and >30,000 for 11 clinics. Thirteen clinics were in main urban areas and 18 were considered to be in rural locations. Rural allowance was only applicable for 11 clinics. Rural allowance criteria include general practices located in settlements with <15,000 inhabitants and for which the distance to the nearest urban centre is >35 km.

There is only one Cancer Centre in the Midland region, located in Hamilton. Therefore, the distance from practice to Cancer Centre was substantial, with half (15) of the clinics being 100km away or further. Nine clinics were 10-99km from the Cancer Centre, while seven were located less than 9km away.

In total, nine clinics were identified as being a Māori Health Provider, defined by the Ministry of Health as "a provider that is owned and governed by Māori and is providing services primarily but not exclusively to Māori". Clinics where there were communities of high Māori population were purposefully selected and recruited. Overall, we found strong representative numbers from Māori men, with 14 clinics having >20% of patients being Māori males aged 40 years and over.

Questionnaire

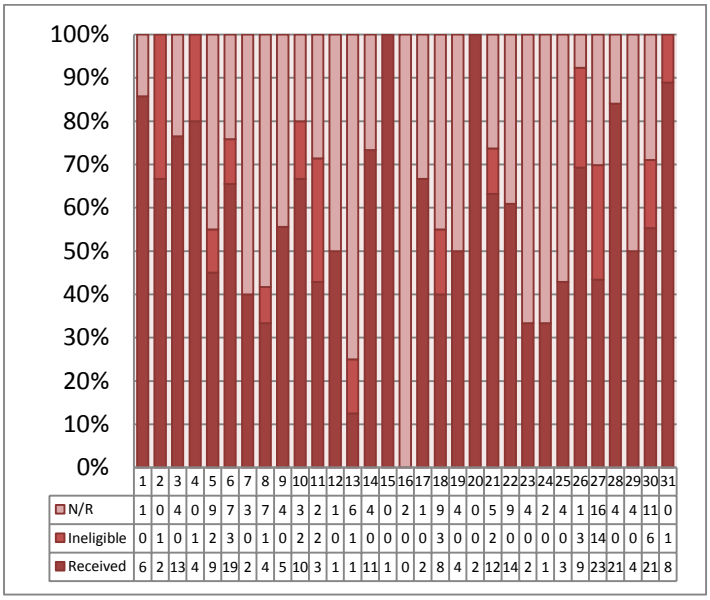


Figure 5-1: Response rate to questionnaire by practice.

A questionnaire was mailed out to all men within the 31 practices with a first raised PSA test during 2010; the questionnaire was sent from and back to the general practice. Out of the 1082 men who had a raised PSA result during 2010, 391 were identified as being 'first-raised' tests. However, 84 of these men were later identified as ineligible for multiple reasons, including vital status, comorbidities, death, previous prostate cancer diagnosis, clinic transfer and lack of a current contact address (Figure 5-1). In total 113 (37%) patients did not respond. There were 194 eligible

responses (63%). Seventeen men self-identified as Māori (9%).

Aim 1: PSA testing in general practice

PSA testing and screening were defined for the purposes of this study as the following:

> **Testing** is used to determine the presence or absence of prostate cancer in a patient who has symptoms or is known to have a raised PSA level and is being monitored.
>
> **Screening** is done on an asymptomatic patient and is either requested by the patient or done by the GP – with or without discussion with the patient.

Practices varied considerably in the way that they tested/screened men. In eight practices, 30% or more of men were tested in 2010, whereas in three practices less than 10% of men were tested (Figure 5-2). Overall 9,344 men aged 40+ years had a PSA test. While 15% (1,408/9,344) of tests were performed because of symptoms or previous prostate problems, the bulk of the tests 7,936/9,344 (85%) were considered to be for screening.

Figure 5-2: Proportion of testing/screening by practice during 2010.

Overall 26% (9,344/35,958) of men 40 years and older in the 31 general practices underwent PSA testing during 2010. In all age categories, men who were tested were more likely to have been screened, rather than having been tested because of symptoms or previous prostate problems. In total, the asymptomatic screening rate was 22.1% (7,936/35,958).

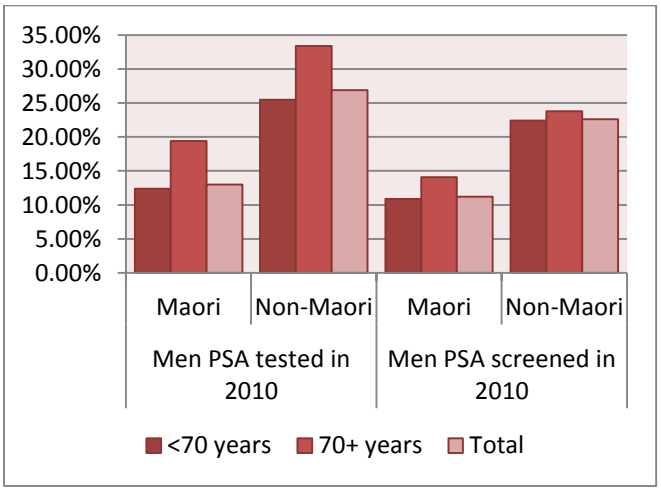


Figure 5-3: Proportion of testing/screening during 2010 by age and ethnicity.

A considerable amount of screening was undertaken on men aged 70+ years (24.4%) (Figure 5-3). The highest screening rates were observed in men aged 60-69 years (31.5%) and in asymptomatic men 70 years and older with no prior history of a raised PSA result in the previous three years (27.7%). This was also the case for 17% of men aged 80+ years.

PSA testing was performed in significantly more non-Māori (26.9%) than Māori men (13.0%) in 2010. Māori were 53% less likely to be tested than non-Māori [1].

Elevated PSA

Patients were identified as having an elevated PSA result using the laboratory guidelines (Table 5-1). Overall, 1,082/9,344 (11.6%) of men had an elevated PSA result (Figure 5-4). The proportion of men who underwent testing for screening with an elevated PSA result was 2.1% (170/7,936).

We found that elevated PSA tests were significantly more commonly detected in screened men with no previous tests compared with those tested prior to 2010 [9].

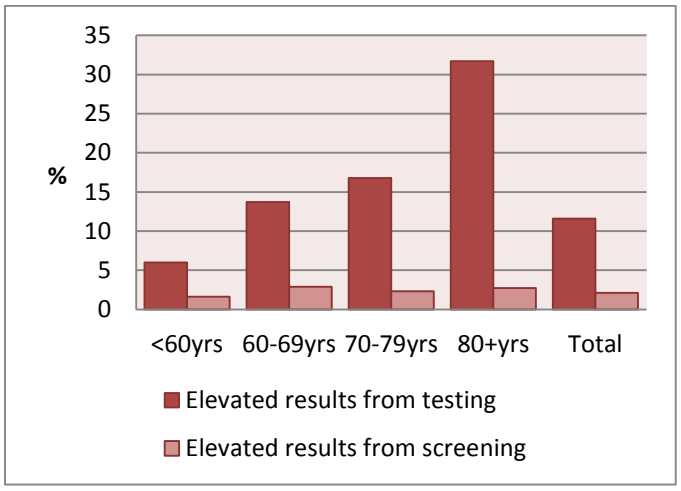


Figure 5-4: Proportion of elevated PSA during 2010 from testing/screening by age group.

When tested for PSA, Māori men aged 40-69 years were more likely than non-Māori to have an elevated result. This was the same for screening rates, with more non-Māori (22.4%) than Māori men (10.9%) having been screened. For all men aged 70 years or over, the screening rates remained high regardless of ethnicity.

Frequency of screening

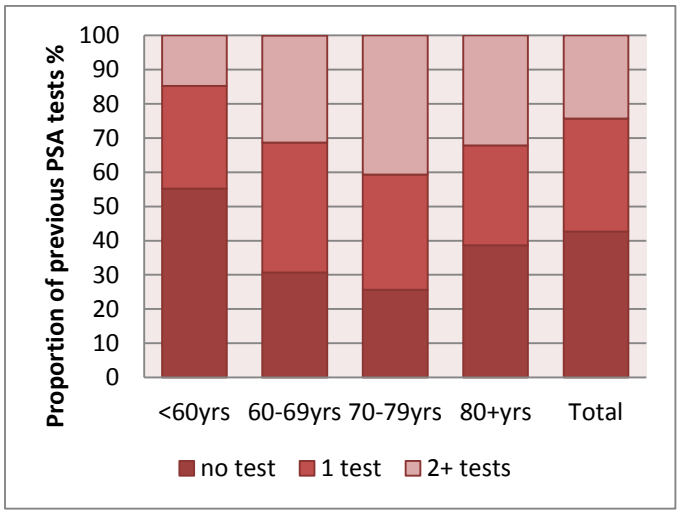


Figure 5-5: Previous PSA tests (2007-2009) in screened men.

Fifty seven percent of men screened in 2010 had a record of at least one previous PSA test between 2007 and 2009 (Figure 5-5). Māori men who were tested during 2010 were significantly less likely than non-Māori to have had a PSA test in the previous three years. We found that 43% of men had no prior PSA test during the previous three years. A quarter of the screened men in the 70-79 year age range had not had a PSA test in the previous three years. Nearly 40% of men screened in the 80+ year age range had not had a PSA test in the previous three years.

Among the tested men, the overall proportion of men without previous PSA tests between 2007 and 2009 was 38.7%, while 29.5% of men had two or more PSA tests prior to 2010.

Rural patterns

Eighteen of the 31 general practices were classified as 'rural practices'. In total 47% of men (16,951/35,958) were enrolled in rural clinics. Rural practices had a larger proportion of Māori men compared to practices in urban regions. Men in rural practices were less frequently screened than men in main urban centres (20.2% vs. 26.8%; $x^2P<0.0001$). Depending on the size of settlement, the proportion of men who underwent PSA testing fell by nearly 15% from the highest populated locations to the smallest settlements (Figure 5-6).

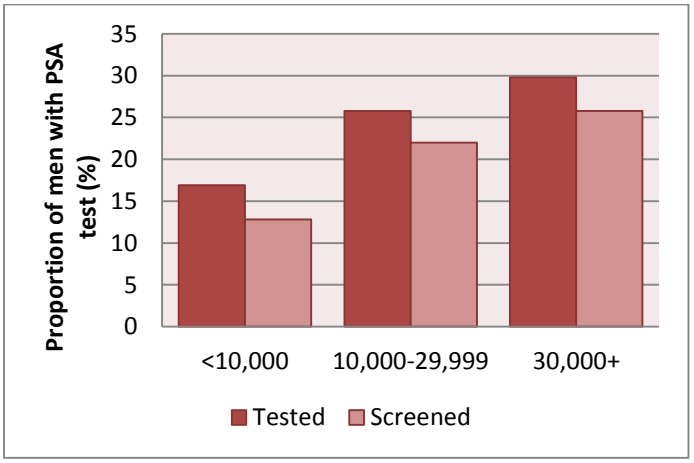


Figure 5-6: Proportion of overall PSA testing and screening by settlement size.

Among those screened, elevated PSA levels were found in 2.6% of men in rural practices, compared with 1.8% of men in main urban centres. Māori were more likely to have a PSA test if they were based in a main urban area than in a rural area (14.1% vs. 11.7%) and this was the same for non-Māori (26.6% vs. 21.2%).

Reduced screening rates were seen in practices with more than the average number of patients per

GP (x2P<0.0001), and in Māori Health Provider practices (x2P<0.0001). General practices in the Lakes DHB had the lowest PSA screening rate (21.2%), while the practices in the Bay of Plenty DHB had the highest rate (26.0%).

Specialist Referral

Table 5-2: Median PSA level at referral (and non-referral) during 2010.

	Median PSA Level for Referral (TESTED - ALL) ng/mL	Median Level of elevated PSA levels for Referral 43% (N=467) ng/mL		Median level for non-referral 57% (n=615) ng/mL	
Age	Median (min; max)	Screened (n=66)	Non-Screened (n=401)	Screened (n=104)	Non-Screened (n=511)
40-49y	3.2 (1.7; 9.1)	3.5	3.3	3.0	2.9
50-59y	5.9 (2.7; 203.3)	6.1	5.3	3.8	5.0
60-69y	7.5 (2.1; 170.3)	6.5	7.4	5.0	6.0
70-79y	9.9 (1.9; 320.0)	10.7	9.8	8.0	8.4
>80y	16.6 (7.0; 409.6)	38.5	15.4	15.4	10.2

Overall, 43% (467/1082) of men with an elevated PSA result during 2010 were referred by their GP to a specialist (Table 5-2). The referral rate was 34.8% for Māori men and 44.1% for non-Māori men (the difference is not statistically significant). Fifty seven percent of men who had an elevated PSA level were not referred and were still being managed by their GP. In general, the median level of referral reflected the levels recommended by the Prostate Taskforce. [11]

The Prostate Taskforce [11] recommendations for referral to urologist (p. 23):

- 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
- significant PSA rise in a man whose PSA has previously been low may warrant referral.

Of the men who were referred to a specialist, those men aged 50-59 years were most likely to be referred (over half (50.5%) of patients in this age group). Overall, 16% of the total referrals were as a result of GP screening. The majority of men (84%) referred were identified because of symptoms or previous prostate problems.

	Referral rate	Biopsy rate	Positive biopsy rate
40-49 years	18/44 (40.9%)	9/18 (50.0%)	5/9 (55.6%)
50-59 years	111/220 (50.5%)	81/111 (73.0%)	37/81 (45.7%)
60-69 years	187/398 (47.0%)	142/187 (75.9%)	79/142 (55.6%)
70-79 years	107/264 (40.5%)	57/107 (53.3%)	39/57 (68.4%)
80+ years	44/156 (28.2%)	13/44 (29.5%)	5/13 (38.5%)
Total	467/1082 (43.2%)	302/467 (64.7%)	165/302 (54.6%)

Table 5-3: Referral rates, biopsy rates and positive biopsy rates.

Table 5-3 shows the referral, biopsy and positive biopsy rates for those men who were referred after an elevated PSA level. Of those men who were referred to a specialist, 302 were biopsied (64.7%). 56.3% Māori men were biopsied compared to 65.4% non-Māori men. Men in the 50-59 and 60-69 year age ranges were the most likely to be biopsied (73% and 76% of referrals, respectively). The proportions of men biopsied that were identified by screening and symptoms were the same as for referrals (16% and 84%, respectively). Of those who underwent a biopsy, 165 men (55%) were

found to have a positive result. In Māori men 66.7% of the biopsies were positive compared to 54.3% in non-Māori men. Sixteen percent (27/165) of detected cancers were identified by screening and 1% (2/165) were identified without an elevated PSA, on digital rectal examination (DRE).

In Māori men 66.7% of the biopsies were positive compared to 54.3% in non-Māori men. The cancer detection rate from men with elevated PSA test was 13.0% for Māori men and 15.6% for non-Māori men. None of these differences was statistically significant. Most of the positive biopsies in both Māori (58.3%) and non-Māori men (60.8%) returned a Gleason score of 6 [1].

In total, 165/1082 (15.2%) of men with elevated PSA tests were found to have prostate cancer. Nearly 70% of men in the 70-79 year age range were found to have a positive biopsy result. This showed that 137 men had a negative biopsy; however, these men are still at increased risk of developing prostate cancer. In addition, 615/1082 (57%) of men who were not referred will need follow-up in general practice.

Questionnaire

In the 31 clinics, 1082 men had at least one raised PSA result during 2010. Of these 1082, 391 had a first raised PSA result in that year. Once the ineligible men were omitted (n=84), 307 (40 to Māori; 267 to non-Māori) questionnaires were mailed out by the general practice for patients to fill out and return to their GP.

Findings from patient questionnaires

Table 5-4: Age and ethnicity

n/N (%)	40-49 years	50-59 years	60-69 years	70-79 years	80 plus years
Māori	1/17 (5.9%)	5/17 (29.4%)	9/17 (52.9%)	2/17 (11.8%)	0
non-Māori	9/177 (5.1%)	49/177 (27.7%)	69/177 (39.0%)	36/177 (20.3%)	14/177 (7.9%)
Total	10/194 (5.2%)	54/194 (27.8%)	78/194 (40.2%)	38/194 (19.6%)	14/194 (7.2%)

One hundred and ninety four eligible responses were received (Table 5-4). Seventeen Māori (17/40, 42.5%) and 177 non-Māori (177/267, 66.3%) responded.

PSA frequency

Fifty three percent of men identified that this was the first time they had been PSA tested. Forty percent of men said it was not their first test; (7% unsure). Significantly more Māori men (p=0.0197) identified that this was their first PSA test (82.4%) compared with non-Māori (50.8%). [10]

Reasons for PSA

Twenty seven percent (53/194) of men said that they had asked for the PSA test, while 66% of men (128/194) felt that the testing was initiated by the GP. Of those men who had their GP recommend the test, 47.7% identified that they had some type of symptom at the time of the test. Men aged 40-49 years and 80 years plus were most likely to have a test by their GP because of symptoms at 60.0% and 53.8% respectively. Much of the testing in men aged 70-79years (84.2%) and 80 years plus (92.9%) was GP initiated. Māori men were just as likely as non-Māori to identify that the test was suggested by the GP, 64.7% and 67.2% respectively. [10]

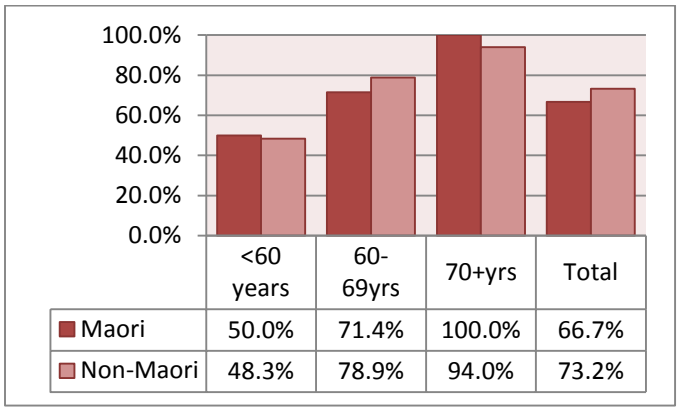
For those men who self-initiated the test we asked what their main reason was for doing this. Having a family history of prostate cancer (18.9%; 10/53) or being prompted by the media or a friend or family member (47.2%; 25/53) were the main reasons. [10]

The majority of men (54.1%; 105/194) said they did not have symptoms at the time of the test, while 42.8% of men (83/194) stated they did have symptoms. Ninety percent of men with symptoms identified that they had LUTS. [10]

Digital Rectal Examination

141/189 (74.6%) identified that a DRE had been performed at the time of their first raised PSA test (Figure 5-7). Men in the 60-69 year age range were the most likely to receive a DRE by their GP

(85.9%). Twenty-five percent of men (n=48) identified they did not receive a DRE. The Prostate Taskforce recommends that screening should be done by both PSA testing and DRE. It should be noted that in our study two asymptomatic men with normal PSA levels were found to have prostate cancer on DRE. [10]



	<60 years	60-69yrs	70+yrs	Total
Maori	50.0%	71.4%	100.0%	66.7%
Non-Maori	48.3%	78.9%	94.0%	73.2%

Figure 5-7: Proportion of self-reported patient DREs at time of raised PSA test during 2010.

Post-elevated PSA

Fifty eight percent of men (113/194) were referred by their GP to see a specialist; 40.2% (78/194) of men reported that they were not referred. Māori men were significantly less likely to be referred (p=0.0418) than their non-Māori counterpart at 35.3% and 60.5% respectively. The split between the public and private setting was close to even at 46.9% and 44.2% respectively. In addition, three men saw specialists in both the public and private setting. [10]

For those men that did see a specialist, 65 men (68%) received a biopsy. (Some men who had a biopsy did not identify that they had been referred by their GP). Forty four men (22.7%) were monitored post-PSA testing by either the GP or a specialist, or by both. The majority of men (69.0%, 134/194) thought that they were not currently monitored. Of the men referred 20.4% went on to receive an operation. [10]

For men who attended a private practice for their first specialist appointment (78.4% 40/51) waited 4 weeks or less. For the men who went to a public hospital, the wait times for 0-4 weeks and 4-8 weeks were 29.1 (16/55) and 43.6% (24/55) respectively. [10]

These data and further information on the questionnaire are in the publication process [10].

Costing Results

Of the 7936 men who were screened in 2010, 27 men were immediately referred to a specialist after the first PSA test, while 146 men were followed up by GPs, of whom 42 were referred to specialists during 2010 to 2011. Of the 69 men referred to specialists, 46 men underwent biopsies, and 29 men were diagnosed with prostate cancer (see appendix Figure 9-1).

The number of asymptomatic men who needed to be screened to identify a new case of prostate cancer was 274 for the whole screening group, but differed according to patient characteristics. The number of asymptomatic men who needed to be screened was below this average figure of 274 for the following groups: those aged 60-69 (127); Māori men (139); and men who had not previously had PSA tests between 2007 and 2009 (188). [8]

Quantity of medical resources

The unit costs of medical resources are identified in appendix Table 9-6. The quantity of medical resources for prostate cancer screening is reported in appendix Table 9-7. This consisted of 7,936 initial GP consultations, 197 follow-up GP consultations, 8,165 PSA tests (ordered by general practitioners and specialists), 69 first specialist assessments (FSAs), 78 follow-up specialist consultations, 46 biopsies, 46 pathology reports, and 4.48 hospital bed days. [8]

As shown in appendix Figure 9-2, the costs incurred in general practice, including the cost of initial GP consultations (37.3%), the cost of follow-up GP consultations (4.6%) and the cost of PSA tests ordered by GPs (28.8%), accounted for 70.7% of

the total costs if 20% of the GP time was spent on discussing the harms and benefits of prostate cancer screening. The proportion of total costs for each type of medical resource cost incurred in hospitals was 10.5% for pathology reports, 6.3% for biopsies, 5.9% for FSAs, 5.8% for follow-up specialist consultations, 0.6% for hospitalisation after prostate biopsy and 0.1% for PSA tests ordered by specialists. If we assumed more GP time was involved in a PSA test, the proportion of the cost of GP consultations increased substantially, while the costs of the other health resources as a proportion of total costs decreased. [8]

Cost per prostate cancer identified

The total costs from initial consultation through to hospitalization after biopsy to identify a prostate cancer are shown in appendix Table 9-8. When 20% of GP consultation cost was considered to be attributable to prostate cancer screening, the costs per cancer detected were NZ$10,777 (€5,820; £4,817), compared with NZ$16,814 and NZ$26,877 when 50% and 100% of GP consultation cost was utilised in the cost estimation, respectively. [8]

The costs per cancer identified were lowest for men aged 60-69 years (NZ$6,268 to NZ$13,721 if 20% to 100% of the GP consultation cost was included), followed by the costs for Māori men (NZ$7,685 to $NZ15,877) and the costs for men without a PSA testing history in 2007-2009 (NZ$8,887 to $NZ19,970). The costs for men aged 40-49 years (NZ$24,290 to $NZ66,472), 50-59 years (NZ$30,022 to $NZ81,089) and 70+ years (NZ$10,957 to $NZ28,501) were 3.9-4.8 times, 4.8-5.9 times and 1.7-2.1 times the costs for men aged 60-69 years, respectively. The costs for non-Māori men (NZ$11,272 to $NZ28,637) were 1.5-1.8 times the costs for Māori men. The costs per cancer detected for men with a prior history of PSA testing in 2007-2009 (NZ$13,870 to $NZ38,178) were 1.6-1.9 times the costs for men without previous PSA tests during that period. [8]

Discussion

PSA testing was commonly carried out in the practices that took part in our study, although testing varied considerably between practices. Screening of asymptomatic men for prostate cancer is widely practiced in NZ. Most PSA testing (85%) was screening, while 15% was done by the GP because the patient had presented with symptoms or previous prostate problems.

PSA screening rates differed with respect to the characteristics and location of the general practices in the Midland region. For example, practices with more GPs per population were found to do more testing. Urban practices screened more than rural practices. These findings suggest that organisational factors as well as patient characteristics influence patient care.

Almost 60% of men screened in 2010 had undergone at least one PSA test between 2007 and 2009, but only 2.1% of screening PSA tests in 2010 were elevated. The screening rate in Māori men was significantly less than in non-Māori. However, if a Māori man was tested, he was more likely than a non-Māori man to be found to have an elevated PSA result. Once found to have an elevated PSA, Māori men were less likely to be referred to a specialist and less likely to be biopsied, but more likely to be found to have a positive biopsy result.

A significant number of men over 70 years of age were screened. This was even the case for men over 70 years who were asymptomatic with a history of negative PSA results. Only a few of these men were referred or went on to be biopsied and treated.

Most of the estimated costs of screening were incurred in general practice. Calls for men to receive increased information on the harms and benefits of screening will substantially increase the costs per cancer identified. The costs could be reduced by better targeting of screening [8].

Referral to a specialist by the GP occurred for 43% of men with an elevated PSA result. This raises some questions about the management of care for men with an elevated PSA result but no referral to specialist. Further research is needed to follow up general practice management of men with a first raised PSA result, including specialist referrals.

While we recognise that screening for prostate cancer is controversial, we found significant differences in the delivery of health services, particularly in the frequency of PSA testing and biopsy rates in Māori men. The differences in screening help explain the lower incidence of prostate cancer in Māori men. The relationship between screening and all-cause mortality is unclear and so the reduced use of screening in Māori does not explain the higher mortality rate [1].

Recommendations

Primary care recommendations are based on our audit of PSA testing and screening in general practice. We found that most PSA testing is for screening purposes and most screening is initiated by general practitioners rather than by patients. Recommendations aim to improve patient management at the time of testing and screening and once an elevated PSA result is identified. We found that Māori were significantly less likely to be screened and tested than non-Māori.

Patients can be transferred to and from primary to secondary care multiple times in their prostate cancer journey. Improving the transitions in the handling of patients between the two settings is important to ensure continuity, quality and equitable access to care.

1.2 At the initial PSA test:

1.2.1 We found evidence that many men are tested by GPs without extensive information being available. We support the recommendation from the Prostate Taskforce [11] that primary health care should provide high-quality, culturally appropriate information on prostate cancer and the potential harms and benefits of PSA testing to all men aged 50 to 70 years.

1.2.2 We recommend that the primary care providers discuss the implications of a positive PSA result prior to undertaking the test, including the need for repeat testing and the option of referral to a specialist if the test is positive (>4 ng/mL).

1.2.3 We recommend that primary care practitioners are made aware of the inequities in access to prostate cancer screening between Māori and non-Māori men.

1.2.4 We found evidence of PSA testing being undertaken annually. This resulted in only a small number of additional positive cancers being identified. We recommend that asymptomatic men without known family history of prostate cancer who have a normal PSA test and digital rectal examination (DRE) can be reassured and should not need to be screened for another 4 years unless they develop prostatic symptoms.

1.2.5 Seventy percent of men appear to have had a DRE at the time of their first raised PSA result. This suggests that 30% of men have not been comprehensively assessed. We found 2 men who had a normal PSA but were subsequently diagnosed with prostate cancer, by DRE. We recommend that all men who are screened for the first time should have a DRE to assess the size of the prostate and presence of any abnormality.

1.2.6 We recommend that men with prostatic symptoms have a DRE, and if PSA is raised they be referred to a specialist even if the symptoms alone do not warrant referral.

1.3 After an elevated PSA result:

1.3.1 We noted more than 50% of men had a raised PSA level but did not warrant referral. More Māori men (65%) were not referred than non-Māori (56%) (n.s). These men are at high risk of cancer and robust strategies need to be in place to ensure they are followed up. We recommend that practices should have a clear strategy for management of men with an elevated PSA result which includes regular follow-up and/or referral.

1.4 Where screening is not warranted and may cause harm:

Screening asymptomatic men over 70 years of age with previous normal PSA tests has not been shown to be of benefit and could lead to unnecessary treatment and harm. Men in this age group are rarely referred for specialist assessment. Of the 1491 men aged 70+ years screened, only 13 were referred and five biopsied, and all of those men had cancer. For those with a positive diagnosis: one had hormone therapy; one had radiotherapy plus hormone therapy; one had a radical prostatectomy (at 70 years) and two had no active treatment. No one over 72 years old was treated.

1.4.1 We recommend that men aged over 70 years who have had previous negative PSA tests should not continue to be screened.

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6. MANAGEMENT OF LOCALISED PROSTATE CANCER IN SECONDARY CARE: TREATMENT CHOICES, OUTCOMES AND COMPLICATIONS FOLLOWING DIAGNOSIS

A US study showed that approximately 80% of the newly diagnosed prostate cancers were localised [1]. The management of prostate cancer also plays a crucial role in the decision-making of prostate cancer screening, since the aim of prostate cancer screening is to detect the cancer at an early stage and provide possible management strategies [2, 3]. The major treatment options for localised prostate cancer include active surveillance (AS), watchful waiting (WW), radical prostatectomy (RP), high-dose brachytherapy (HDR), low-dose brachytherapy (LDR – only available privately) and external beam radiotherapy (EBRT). There are many uncertainties with regard to the treatment options for localised prostate cancers [4]. They differ in curative efficacy, complications and costs. No consensus has been reached in terms of the optimal treatment option [5].

Low grade, localised prostate cancer is not likely to progress within the first 10-15 years after diagnosis. Even without definitive treatments, most men will die with, rather than from, prostate cancer [6, 7]. As there is a low likelihood of benefiting from definitive treatments and an increased risk of treatment-related side effects, conservative management, including AS and WW, is regarded as a reasonable treatment option for localised prostate cancer [5, 8]. Recent studies have suggested that men with low-risk prostate cancer managed with WW have similar outcomes to those who are treated with RP [9]. However, in the USA only 10% of patients with localised prostate cancer are on AS or WW [7]. This phase of the Midlands Prostate Cancer study looked at the management patterns for localised prostate cancer in the Midland Cancer Network region in New Zealand.

Method

Men aged 40 years and over, diagnosed with prostate cancer in the Midland Region (Waikato, Bay of Plenty and Lakes District Health Boards [DHBs]) from 1 January 2007 to 31 December 2010 were identified from New Zealand Cancer Registry (NZCR). All eligible Māori patients were included in the cohort. Men diagnosed with prostate cancer at death were excluded. Three New Zealand European men were age-matched and randomly selected for each Māori man. The final cohort comprised 600 patients (150 Māori, 450 New Zealand European).

Data extracted from the NZCR included the National Health Index (NHI) number, ethnicity, date of diagnosis, domicile, DHB and date of birth. Patients' general records, urology and oncology notes from the Waikato, Lakes and Bay of Plenty DHBs, were recorded and linked with the NZCR data using patient NHI numbers. Local laboratory data from Pathlab was collected to record prostate-specific antigen (PSA) test dates and results, imaging and biopsy histology.

Data extracted included the date and results of tests including PSA, digital rectal examination (DRE), biopsy and imaging, consultation dates, comorbidities, pre-existing conditions, treatments and post-treatment issues. The data collection began in November 2011 and ended in June 2013. The censor date of each patient was when his clinical records were last examined. The access to and linking of data was approved by Northern Y (Ref. No. NTY/11/02/019) and Multi-Region Ethics Committees (Ref. No. MEC/11/EXP/044).

Patient files were reviewed to identify the stage of prostate cancer at diagnosis and the original diagnosis date. Pathological stage was identified

from histology, while clinical stage was recorded from DRE results and imaging. Specialist notes and/or letters to other health professionals (e.g. oncologist to general practitioner [GP]) were reviewed to identify either pathological or clinical stage recorded. The stage prior to treatment (if any) and any change in stage were also recorded. Staging pre-treatment (e.g. LDR planning notes) was recorded as stage at diagnosis if there was no other stage identified. Finally, for any un-staged patients a urologist and/or urology registrar staged men using DRE, PSA result and biopsy result based on the American Joint Committee on Cancer (AJCC) TNM system and the D'Amico Classification System for risk.

Patients with localised prostate cancer were identified to examine treatment patterns for different age groups (<70 years, ≥70 years), ethnicity (Māori, non-Māori), DHB, PSA level (<4, 4~10, 10~20, or ≥20 ng/mL), Gleason score (GS) and Charlson score. A Decision Tree was constructed to display the management pattern for localised prostate cancer in the Midland Cancer Network region.

Findings

Of the 600 patients with prostate cancer, 64 were excluded for further study, including 20 patients who were diagnosed before 2007, 9 patients with benign, suspicious or Gleason 5 biopsy results, 22 patients without information of biopsy, imaging and treatment, four patients who were diagnosed with other cancer, and nine patients whose cancer stage at diagnosis could not be confirmed from the records.

Cohort characteristics

The mean age of men in our cohort was 66 years. Significantly more Māori men lived in most deprived areas (NZDep2006 Index of Deprivation score of 9-10) than non-Māori: 58.1% vs. 20.8% (Fisher exact test p<0.0001). There was no significant difference between Māori and non-Māori in domicile (DHB or rurality), but slightly more non-Māori men lived in main urban areas (52.5% vs. 43.4% of Māori men). Overall, the distribution of men with localised prostate cancer between DHBs was: Waikato 44.3%, Lakes 19.2% and Bay of Plenty 36.5%.

PSA at GP Referral

The median PSA level at GP referral was slightly higher for Māori than non-Māori (11.7 vs. 8.6 ng/mL). Approximately half of the men had a PSA of 4~10 ng/mL at GP referral. Significantly more non-Māori men had a PSA of <10 ng/mL at GP referral (Fisher exact test p=0.0002).

Gleason Score at diagnosis

At biopsy, most Māori and non-Māori men had a GS of 6 or 7 (76.0% and 84.3%, respectively). Significantly more non-Māori men had GS 6 (54.9% vs. 43.0%; Fisher exact test p=0.0281), while more Māori men had GS 8+ (24.0% vs. 15.7%; Fisher exact test p=0.0549).

Stage at diagnosis

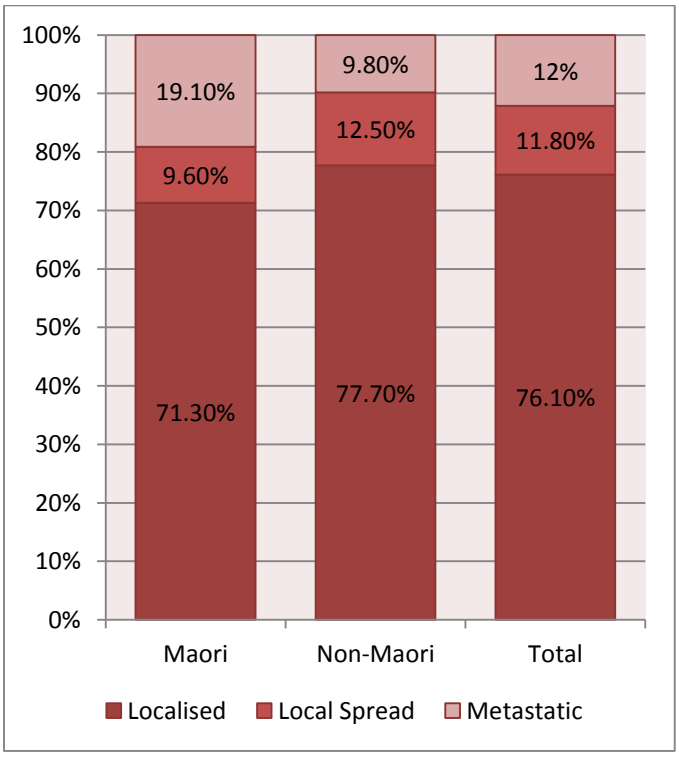
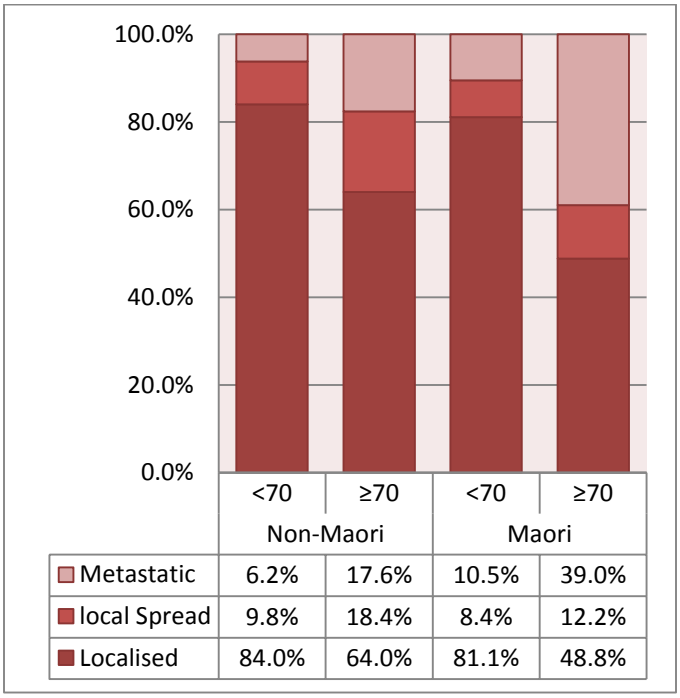


Figure 6-1: Stage at diagnosis by ethnicity.

Among the 536 eligible patients (Figure 6-1), 76.1% (408/536) were diagnosed with localised prostate

cancer, 11.8% (63/536) with locally spread prostate cancer and 12.1% (65/536) with metastatic prostate cancer. Just over 71% of Māori men were staged as localised at the time of diagnosis, compared with 78% of non-Māori. More non-Māori than Māori were diagnosed with locally spread cancer (12.5% vs. 9.6%). Māori men were significantly more likely to have metastatic cancer at the time of diagnosis than non-Māori (Fisher exact test p=0.0018).

These proportions varied by age group (Figure 6-2). For patients aged <70 years, 83.2% (308/370) had localised cancer and 16.8% (62/370) had locally spread or metastatic cancer. The percentages of localised versus non-localised cancer for patients aged ≥70 years were 60.2% (100/166) and 39.8% (66/169) respectively.



	<70	≥70	<70	≥70
	Non-Maori		Maori	
Metastatic	6.2%	17.6%	10.5%	39.0%
local Spread	9.8%	18.4%	8.4%	12.2%
Localised	84.0%	64.0%	81.1%	48.8%

Figure 6-2: Stage at diagnosis by age and ethnicity.

As the groups were aged-matched when the cohort was established the age distribution is similar between Māori and non-Māori. However, if we look at differences based on age range, Māori men aged 70+ years were significantly more likely to have metastatic disease at diagnosis (Fisher exact test p=0.0091). The difference was not statistically significant for Māori men under 70 years old.

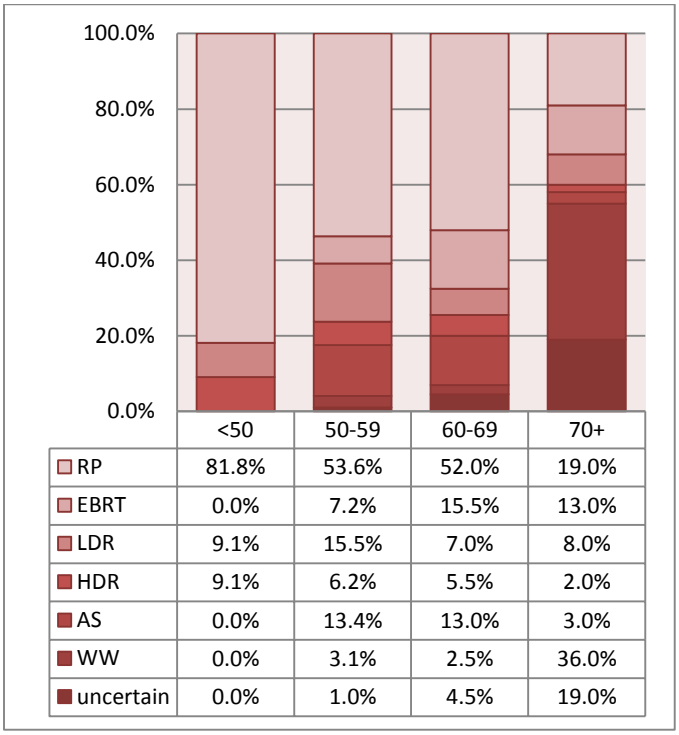
All men aged <70 years were more likely to be diagnosed with localised disease and less likely to be diagnosed with metastatic disease compared with those aged 70+ years (both Fisher exact test p<0.0001).

Treatment pathways for localised prostate cancer

In terms of the initial treatment for localised prostate cancer (see appendix Figure 9-3), 190/408 (46.6%) patients underwent RP, 60/408 (14.7%) had EBRT, 40/408 (9.8%) had LDR, 21/408 (5.1%) had HDR, 34/408 (8.3%) were on AS and 53/408 (13.0%) were on WW. The post-operative reports of RP showed that 20 patients had locally spread cancer at the time of treatment, and two had metastatic cancer. Post-treatment reports of HDR indicated that two patients were found to have locally spread cancer. In addition to EBRT, eight patients underwent HDR and one had LDR. After other radical treatments, 40 patients received EBRT.

Treatment patterns

Figure 6-3: Treatment type by age group.



	<50	50-59	60-69	70+
RP	81.8%	53.6%	52.0%	19.0%
EBRT	0.0%	7.2%	15.5%	13.0%
LDR	9.1%	15.5%	7.0%	8.0%
HDR	9.1%	6.2%	5.5%	2.0%
AS	0.0%	13.4%	13.0%	3.0%
WW	0.0%	3.1%	2.5%	36.0%
uncertain	0.0%	1.0%	4.5%	19.0%

Figure 6-3 displays the treatment type by age with increasing age, from 81.8 for patients aged <50 years to 19.0% for patients aged 70+ years. In contrast, the probability of having EBRT increased with age, from 0.0% for patients aged <50 years to 13.0% for patients aged 70+ years. For patients aged 50-59 years and 60-69 years, 13.4% and 13.0% were on AS respectively, whilst patients aged 70+ years had a 36.0% possibility of being on WW.

The most common main treatment was RP (45.1%). Significantly more non-Māori men underwent RP (Fisher exact test p=0.0071) and LDR (Fisher exact test p=0.0153), while Māori men were more likely to receive EBRT (Fisher exact test p=0.0081) and HDR (Fisher exact test p<0.1033).

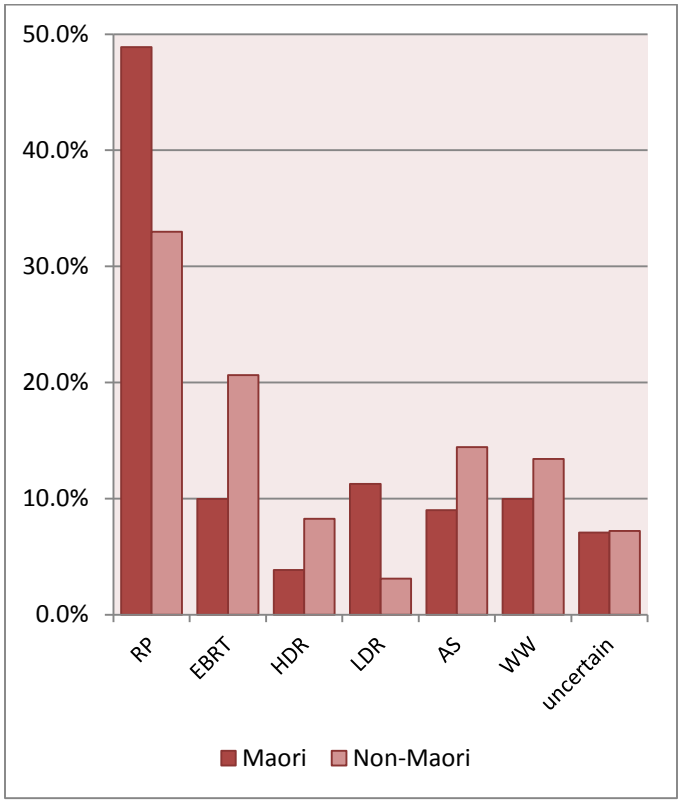
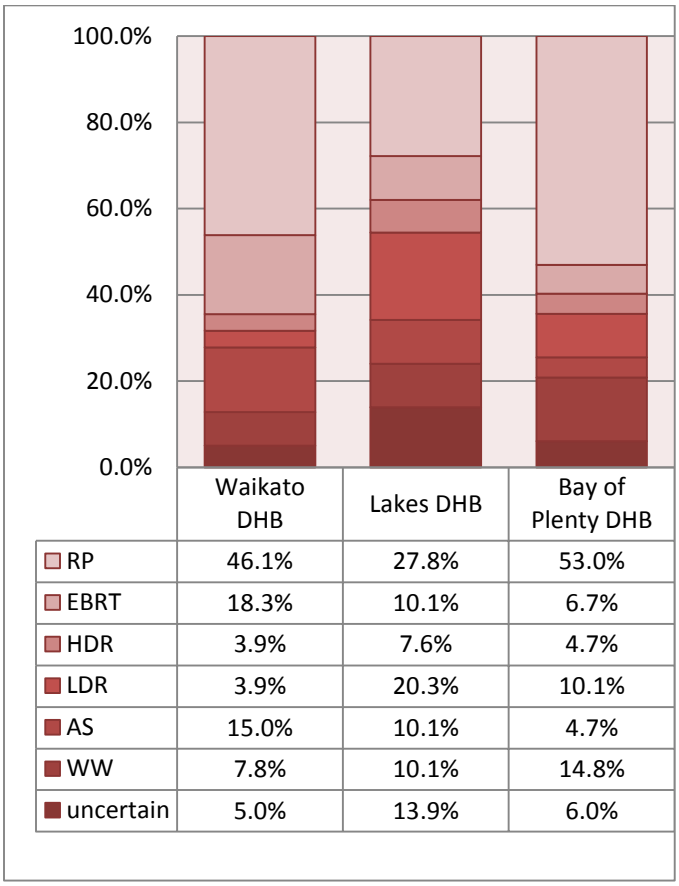


Figure 6-4: Treatment type by ethnicity.

The differences in treatment type between Māori and non-Māori are presented in Figure 6-4. Māori patients were less likely to undergo LDR (3.1%) and RP (33.0%), compared with non-Māori patients (LDR: 11.3%; RP: 48.9%). Māori had a high possibility of undergoing EBRT (20.6%) and HDR group. The likelihood of undergoing RP decreased (8.2%), and being on AS (14.4.1%) and WW (13.4%). Corresponding probabilities for non-Māori were 10.0%, 3.9%, 9.0% and 10.0%, respectively.



	Waikato DHB	Lakes DHB	Bay of Plenty DHB
RP	46.1%	27.8%	53.0%
EBRT	18.3%	10.1%	6.7%
HDR	3.9%	7.6%	4.7%
LDR	3.9%	20.3%	10.1%
AS	15.0%	10.1%	4.7%
WW	7.8%	10.1%	14.8%
uncertain	5.0%	13.9%	6.0%

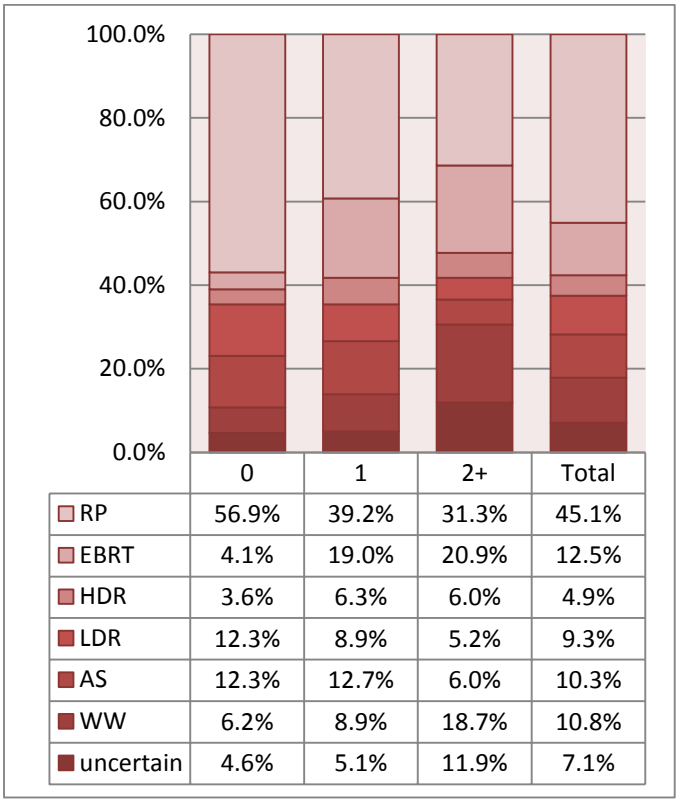
Figure 6-5: Treatment type by DHB.

Figure 6-5 shows the variation of the management of localised prostate cancer among the three DHBs. A larger proportion of patients in the Waikato DHB underwent EBRT (18.3%) compared with the Lakes (10.1%) and Bay of Plenty (6.7%) DHBs. The highest likelihood of patients having RP was in the Bay of Plenty DHB (53.0%), followed by the Waikato DHB (46.1%) and Lakes DHB (27.8%). Patients in the Lakes DHB had the highest possibility of undergoing LDR (20.3%), whilst patients in the Waikato DHB had the lowest (3.9%). Patients in the Waikato DHB were less likely to be on WW (7.8%), but more likely to be on AS (15.0%).

Charlson Score

The treatment pattern by Charlson score is shown in Figure 6-6. The probability of having RP declined with increased Charlson score, from 56.9% for a

score of 0 to 31.3% for patients with a score of 2+. In contrast, patients with higher Charlson scores were more likely to receive EBRT, increasing from 4.1% for a score of 0 to 20.9% for a score of 2+.



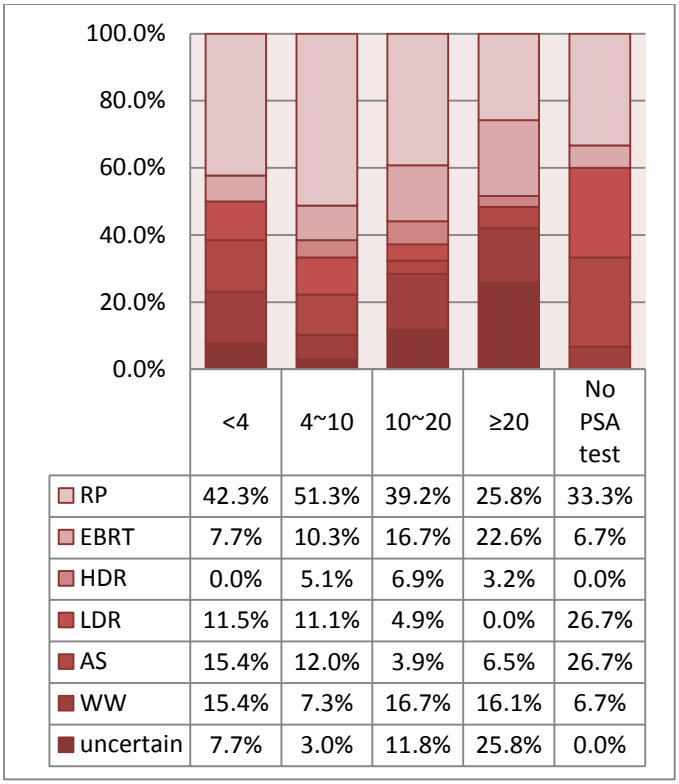
	0	1	2+	Total
RP	56.9%	39.2%	31.3%	45.1%
EBRT	4.1%	19.0%	20.9%	12.5%
HDR	3.6%	6.3%	6.0%	4.9%
LDR	12.3%	8.9%	5.2%	9.3%
AS	12.3%	12.7%	6.0%	10.3%
WW	6.2%	8.9%	18.7%	10.8%
uncertain	4.6%	5.1%	11.9%	7.1%

Figure 6-6: Charlson score by treatment type.

A similar pattern was also observed for WW, from 6.2% for patients with a score of 0 to 18.7% for patients with Charlson scores of 2+. Significantly more non-Māori men had a Charlson Co-morbidity Index (CCI) of 0 (52.4% vs. 33.0% of Māori; Fisher exact test p=0.0011), while significantly more Māori had a CCI of 2+ (43.3% v. 29.6% of non-Māori; Fisher exact test p=0.0135).

PSA Level

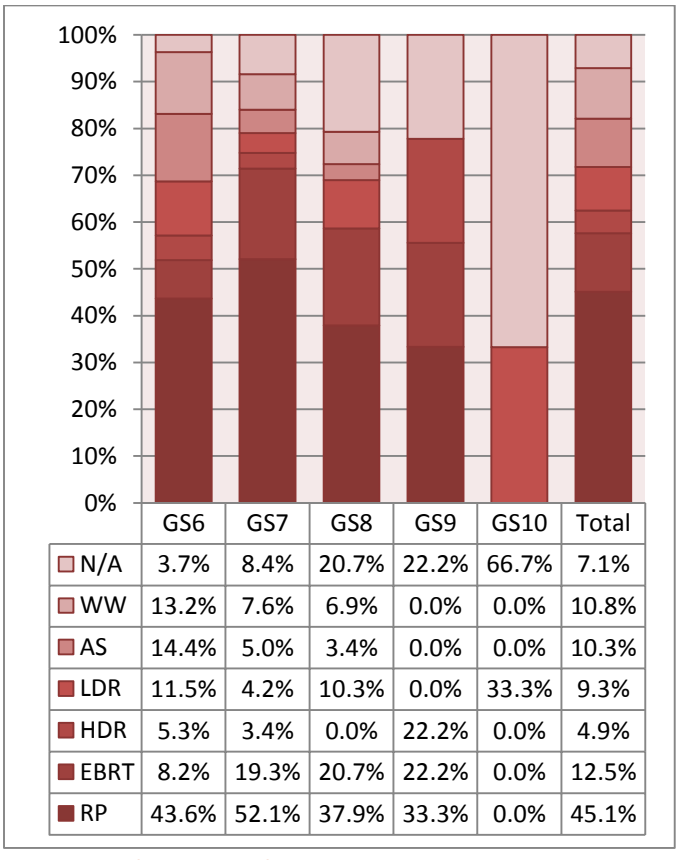
The impact of PSA level on the treatment type is shown in Figure 6-7. The possibility of RP decreased with the PSA level, from 42.3% for patients with a PSA level of <4 to 25.8% for patients with a PSA level of ≥20. In contrast, the likelihood of undergoing EBRT increased with the PSA level, from 7.7% for patients with a PSA level of <4 to 22.6% for patients with a PSA level of ≥20.



	<4	4~10	10~20	≥20	No PSA test
RP	42.3%	51.3%	39.2%	25.8%	33.3%
EBRT	7.7%	10.3%	16.7%	22.6%	6.7%
HDR	0.0%	5.1%	6.9%	3.2%	0.0%
LDR	11.5%	11.1%	4.9%	0.0%	26.7%
AS	15.4%	12.0%	3.9%	6.5%	26.7%
WW	15.4%	7.3%	16.7%	16.1%	6.7%
uncertain	7.7%	3.0%	11.8%	25.8%	0.0%

Figure 6-7: PSA level by treatment type.

Gleason Score



	GS6	GS7	GS8	GS9	GS10	Total
N/A	3.7%	8.4%	20.7%	22.2%	66.7%	7.1%
WW	13.2%	7.6%	6.9%	0.0%	0.0%	10.8%
AS	14.4%	5.0%	3.4%	0.0%	0.0%	10.3%
LDR	11.5%	4.2%	10.3%	0.0%	33.3%	9.3%
HDR	5.3%	3.4%	0.0%	22.2%	0.0%	4.9%
EBRT	8.2%	19.3%	20.7%	22.2%	0.0%	12.5%
RP	43.6%	52.1%	37.9%	33.3%	0.0%	45.1%

Figure 6-8: Gleason score by treatment type.

Treatment type by GS is shown in Figure 6-8. Three hundred and ninety eight patients (97.5%) had available GS results. We were unable to identify GS for ten patients. Patients with a higher GS were less likely to undergo RP. The possibility of having RP decreased from 43.6% for patients with GS 6 to 0.0% for patients with GS 10. The probability of undergoing EBRT increased with GS, from 8.2% for patients with GS 6 to 22.2% for patients with GS 9.

Discussion

Overall we found that 76% of men with prostate cancer had localised disease at diagnosis. There are a wide variety of treatment options and the use of these varied depending on age, the PSA level at diagnosis, the grade of the tumour, the presence of comorbidities and the DHB in which the patient resided.

We found that Māori men were more likely to be diagnosed at a younger age and with more advanced disease than non-Māori men. It was also interesting to note Māori men were more likely to have higher grade (Gleason 8+) than non- Māori men. Variations in treatment options for Māori men were influenced by the grade and stage of disease and the presence of comorbidities.

An advantage of our study is that we were able to review the variations in treatment options by comparing a cohort of Māori men with non-Māori. We have relatively good information on the factors which are shown to influence treatment.

Unfortunately, in a study based on a retrospective review of patients' clinical notes there is the problem of missing data due to files being lost or key information such as the result of a DRE being absent or poorly recorded.

Recommendations

We found variations in the time to treatment following biopsy and little formal use of Multi-Disciplinary Meetings (MDM). Clear national guidelines are needed for men managed with localised prostate cancer.

1.5 Multi-Disciplinary Meetings

1.5.1 Whilst the use of MDMs has increased since this study was conducted, we believe it is good practice, as regular quality assurance is of value.

While we know that national recording of prostate cancer stage is low at approximately 20% of new cancers. Even reviewing patient files did not always allow us to identify stage and or grade of cancer. We found that it was often difficult to evaluate the appropriateness of cancer treatment due to low levels of recording of key information such as the grade and stage of disease, the presence of comorbidities, pre-existing conditions (e.g. measure of urinary function score) and treatment type (if any).

1.6 Pathological reporting

1.6.1 We also found variations in the recording of biopsies and pathological specimens, and would support the Prostate Taskforce recommendations [10, 11] on the standardisation of pathology of both biopsies and histology at diagnosis and following prostatectomy.

1.7 Active Surveillance

We found that 13% of men aged <70 years with localised prostate cancer were being managed through active surveillance (16.9% Māori, 11.3% non-Māori). We believe that active surveillance might be a suitable for an increased proportion of men with low-risk disease to reduce the risk of unnecessary harm from treatment.

1.7.1 We would recommend that clear guidelines are developed for the management of men with localised prostate cancer with active surveillance. The D'Amico classification system, Charlson Score Index and UCSF-CAPRA can be used for risk assessment.

1.7.2 We recommend regular review of the outcomes of men being managed with active surveillance.

Equity

We identified significant differences in the management of Māori men compared with non-Māori men. To mitigate the differences in patient care and outcomes we believe that regular monitoring of the pathway and improving awareness of inequities amongst health professionals will result in the reduction of inequities on the pathway.

1.8 Differential care for Māori compared to non-Māori men

1.8.1 We recommend that each step of the pathway be regularly audited to identify variations between Māori and non-Māori men.

1.8.2 We recommend that further research is undertaken to identify causes of the higher prostate cancer mortality rate for Māori men compared to non-Māori.

1.8.3 We support the 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.

Metastatic disease

While this study concentrated on complications of treatment following localised disease we were aware of the significant morbidity related to metastatic disease.

1.9 We would like to recommend that further research be carried out on the management of men with metastatic prostate cancer.

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7. LIVING WITH PROSTATE CANCER: ASSESSING THE SPECTRUM OF COSTS AND COMPLICATIONS ALONG THE PATHWAY

While we know that treatment for prostate cancer can cause physical symptoms we also believe that, as with any cancer, there are psychological and social impacts on the lives of patients and their partners. [1]. Men entering the prostate cancer journey invariably have information and care needs and may require additional support during their diagnosis and treatment pathway, over and above that which is provided by their primary medial practitioner. These support networks are pivotal in providing men with additional reserve to buffer stress, depression and anxiety. Men may access this through the support of their existing networks, including family and friends, or through sporting or social groups. Wives and/or partners of men may also provide necessary support during this time. However, the support structures, needs and impact of living with prostate cancer have not been quantified before in a population-based sample of New Zealand men and their partners.

The aim of this phase was to estimate the cost and complications of treatment, including the social and psychological impact on men and their partners. Complications and their impact on patients were identified using structured questionnaires to measure key outcomes, including general health and quality of life [2], prostate-specific quality of life [3], anxiety, depression [4], and stress [5]. Validated measures and questions were selected by our Academic Steering Group and Consumer Advisory Group.

Method

We took a cohort of men from the phase three study - 600 men under 85 years of age diagnosed during 2007-2010 in the Midland region (from the phase three study) - and we randomly selected 200 National Health Index (NHI) numbers to mail out invitations to participate in the study. Access to patients was initially through the specialist identified from the patient's clinical notes and with the assistance of the Midland region Specialist Urology Nurse. She provided access to all patients in our cohort and was able to send out invitations to men on our behalf.

Interviewer-administered questionnaires

Once participants had made contact with the research team by phone, email or return post, the men were phoned by a researcher to discuss the content of the interviews and to arrange a time to meet. Participants could undertake the interview in a two-stage process. Patients would have an initial meeting with the researcher prior to the interview to confirm consent. A second meeting was scheduled at another date/time to undertake the interview. The majority of men opted to undertake the interview at the first meeting.

The questionnaires were administered via an iPad using the Polldaddy web-based interface. This method allowed for either the participant to use the iPad and go through the questionnaire unaided (except when requiring assistance by the researcher) or to have the researcher verbally ask the individual questions and input participant responses.

A range of seven measures were used in the patient questionnaire, plus additional questions requested by the governance team. Questions were grouped as follows:

PATIENT DETAILS:	*DOB, ethnicity, partner details, income, medications*
Reasons for PSA/PCA INVESTIGATION:	*Has he had symptoms (urinary, ED), elevated PSA, abnormal DRE? Has he had previously raised PSA?*
EORTC QLQ-C30: GENERAL HEALTH & QUALITY OF LIFE	*Quality of life with cancer (past week)* [2]

EORTC PR25: PROSTATE SPECIFIC QUALITY OF LIFE:	*Urinary dysfunction (past week). Bowel dysfunction (past week). Weight, masculinity, sexual activity (past 4 weeks)* [3]
FACTORS INFLUENCING PATIENT TREATMENT CHOICE:	*What was important in the decision making process? Understanding of treatment options, Doctors recommendation, Medical insurance, Wait time to see specialist* [6,7]
ANXIETY, DEPRESSION AND STRESS	*Hospital Anxiety & Depression Scale plus Stress scale from DASS (past week)* [4,5]
DYADIC ADJUSTMENT SCALE – SF	*Philosophy of life, aims, time; Relationship happiness (now)* [8]
MILLER SOCIAL INTIMACY SCALE	*Social intimacy of individual in significant relationships* (now) [9]
SUPPORTIVE CARE NEEDS	*Level of help needed; (past month)* [10,11]
EQ-5D	*Current health state (now)* [12]
IIEF-SF & FSFI-SF	*Sexuality queries and sexual function scales* [13,14]

Analyses

Scores were compared with population standards and reference levels for each measure where possible. Correlations between measures were examined and P values of <0.05 were considered significant. Analyses used Statistica version 11 (Statsoft Inc).

Findings

We aimed to recruit 100 men: 50 Māori and 50 non-Māori. From the total phase three cohort of 600 (150 Māori; 450 non-Māori) men nearly a third of the Māori cohort were deceased at the time of recruitment. Of the 100 Māori men still alive at the time of recruitment, 55 were ineligible, declined to participate or the applicable District Health Board (DHB) did not have their current contact details (Table 7-1).

To recruit higher numbers of Māori men, after the initial mail-out phase was complete we had a second invitation phase, followed by a phone call from a male Māori researcher to talk with all eligible Māori men about the project. Utilising this method we were successful in recruiting an additional nine Māori men, giving a total of 20 for the study. By far the most limiting part of the recruitment of Māori men was not having current contact details within the DHB, as this was our only avenue to accessing men in accordance with our ethical approval for the study.

REASON FOR EXCLUSION	REMOVED	REMAINING
Total Cohort	n/a	150
Deceased	42	108
Ineligible (age/stage/current location)	20	88
DHBs had no current mail contact details*	22	66
Declined to participate^	13	53
Non-responders	42	11
Stage 1 recruitment	n/a	**11 interviewed**
Stage 2 – Had access to a phone number (n=53)		
DHBs had no current phone contact details*	23	30
Declined to participate on phone call^	17	13
Other reasons (e.g. spousal death)	4	9
Stage 2 recruitment	n/a	**9 interviewed**
TOTAL	n/a	**20 interviewed**

Table 7-1: Māori men stage 1 and 2 recruitment.

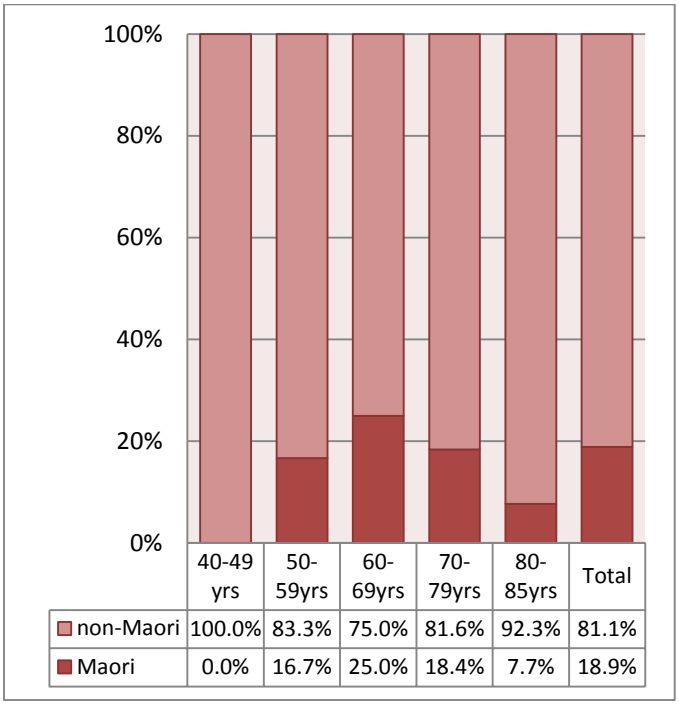
*= some men were contacted in both groups via mail or phone; ^= some men declined both in the mail out and via phone.

329 invitations were mailed out to eligible New Zealand European men in the Midland region, 36 of which were sent back unopened. We received 91 acceptance responses from the initial mail-out. In total, 86 NZ European men were recruited and available to be interviewed.

Partners/caregivers of the recruited men were also invited to participate in the study. There were 58 partners willing to be involved in the study, 55 of whom were able to be recruited and interviewed.

Patient demographics

There were 106 men who completed questionnaires. 19% (n=20) were Māori and 81% (n=86) identified as NZ or other European.



	40-49 yrs	50-59yrs	60-69yrs	70-79yrs	80-85yrs	Total
non-Maori	100.0%	83.3%	75.0%	81.6%	92.3%	81.1%
Maori	0.0%	16.7%	25.0%	18.4%	7.7%	18.9%

Figure 7-1: Number of men interviewed by age group and ethnicity.

Prostate cancer is typically more common in advancing years, and the age distribution of men participating in the study reflected this (Figure 7-1). We had a cut-off age of 85 years for study participants. The majority of men (58%) were aged 70 years and older and 42% were aged 40-69 years.

Education

Nearly half (48%) of the men had no qualification beyond high school. Twenty-eight percent held a professional qualification, diploma or degree and 24% of men had a trade qualification.

Relationship status and duration

Figure 7-2 shows that the majority of men in the cohort had a current partner (90%), and were either married (85%) or in a de facto relationship (5%). Eleven men were not in a current relationship. For those men with a partner, over 60% had been in that relationship for longer than 35 years. A further 21% of men had been in the same relationship for 16-35 years, while only 7% of men were in a relationship for less than 16 years.

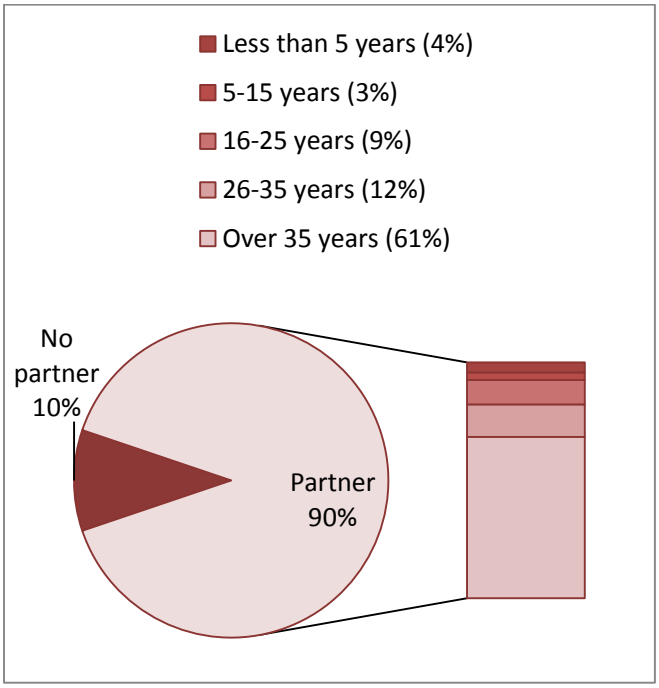
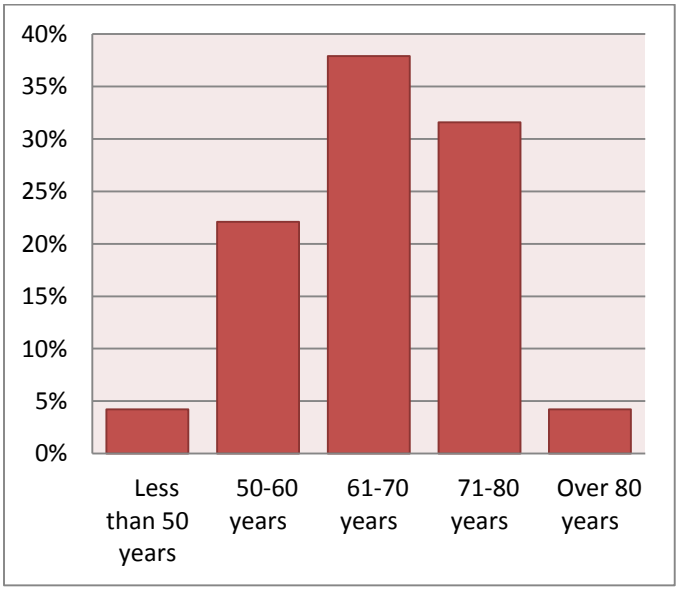


Figure 7-2: Relationship status and duration.

The partner's age (Figure 7-3) was slightly younger than the male patient's, with only 36% of partners aged 71 years or older. The majority of partners were between 50-70 years (60%).

Diagnosis and first treatment

Figure 7-3: Partner's age group.



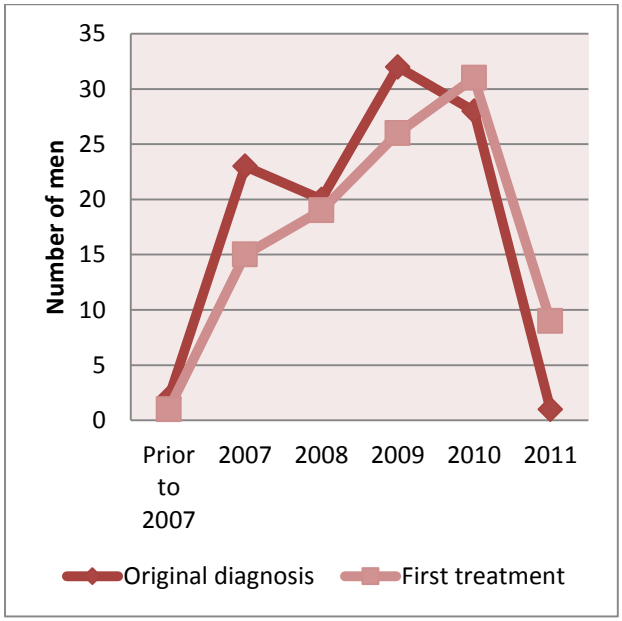


Figure 7-4: Original diagnosis and first treatment by year (number).

In identifying and then interviewing men from the New Zealand Cancer Registry (NZCR) we found some anomalies. Two men in our cohort had been diagnosed prior to the date of diagnosis recorded in the NZCR. This was due to a number of factors, for example: a clinical rather than pathological diagnosis, or a diagnosis abroad. The cancer is only included in the NZCR once it has been identified by pathological means or via imaging. Therefore it can take many years for a cancer to be registered. For one of the two men diagnosed prior to 2007 his original diagnosis was in 1999, the other was originally diagnosed in 2002. However, for the vast majority of men in our cohort the original diagnosis was consistent with the NZCR and was followed shortly after with the first treatment (Figure 7-4).

Economic factors

Men were predominantly retired at the time of the interview (62%); 44% of men were in either part- or full-time employment. Seventy three percent of men received income from New Zealand national superannuation and/or a government benefit or pension; 25% of these men simultaneously worked in a full- or part-time position.

The national median weekly income for June 2012 was $721. Annual income based on this would be $37,500. Thus 56% of participants earned less than the New Zealand median weekly wage. Seventy five percent of Māori earned less than $35,000 per annum. Fifty percent of non-Māori men earned less than $35,000 per annum. Household income increased for many when spousal income was included. Half of the households in our cohort were receiving between $35,000 and $40,000 per annum. The average annual household income in New Zealand in June 2012 was ~$81,000 [15] therefore many of the families in our cohort were living on half the national average income.

Treatment factors

Public vs. Private care

When men accessed secondary healthcare for either diagnosis or treatment, 50% went to a public hospital and 41% went through private care. Seven percent of men utilised both the public and private health care systems. This reflects the level of medical insurance among the cohort – 42% were currently insured, 38% did not have insurance and 21% did have insurance but had cancelled it, in most instances due to increasing premiums. Twenty percent of Māori and 42% non-Māori had medical insurance.

Factors influencing men's choice of treatment (see appendix Table 9-9).

When beginning this section of the questionnaire, most men identified that "getting rid of the cancer" was the factor that was most important at the time of selecting the treatment. When probed to decide if there were any other competing factors, unsurprisingly, many items came out as deemed 'not important'. These included:

- Need for escort to/from treatment [67%]
- Out of pocket expenses [65%]
- Chances of pain caused by treatment [63%]
- Family preference for treatment type [65%]

- Recommendations from someone they know who had prostate cancer [51%]
- Chances of depression/anxiety [53%]

Overall 67% of men in our cohort regarded the 'doctor's recommendation' as very important and this was the most frequent response. In comparison, the The Prostate Cancer Treatment (PCATS) Study in the USA [6] reported 'Doctor's recommendation' rated as 'very important' by 90% of US men. In our study, 80% of Māori men saw the 'doctor's recommendation' as very important, compared with 64% of non-Māori men. Fifty percent of Māori men regarded time factors (amount of time required to complete treatment and recover from treatment) as very important in their choice of treatment. The factors most frequently rated as very important by non-Māori men were 'time to complete treatment' (41%), 'chances of urinary problems' (38%) and 'wife or partner preference for treatment type' (37%).

Half of the Māori men (50%) identified the 'chances of tiredness or fatigue following treatment' as being somewhat important, whereas 51% of non-Māori rated it as not important. 'Inconvenience and burden on family' was ranked as not important by 55% of Māori and 31% of non-Māori men.

In US men who were contemplating surgery, the 'chance of sexual problems' was rated as 'very important' by fewer men than those contemplating other types of treatment [6]. Our retrospective investigation showed that 34% of men who had surgery rated 'chance of sexual problems' as 'very important', compared with 39% of those who had other treatment types; the difference was not statistically significant.

Making comparison about treatment choice with Ihrig and colleagues' study (2011) [7] in which patients choosing radical prostatectomy (RP) were younger, 60% of the Midlands sample choosing RP were youngest age group (<70), while 52% of middle age group (71-80) chose radiation therapies. In the Midlands sample, the oldest age group (>80) most frequently chose radiation therapies (63% of group).

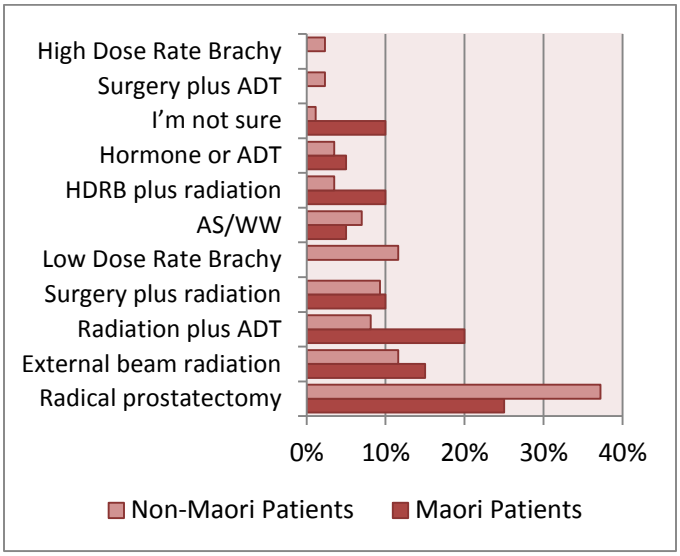


Figure 7-5: Proportion of self-reported treatment type by ethnicity.

Patient-reported treatment

Figure 7-5 shows the type of treatment that men self-reported undergoing. Twenty-five percent of Māori had surgical intervention, compared with 37% non-Māori. Māori were more likely to have had external beam radiotherapy with or without androgen-deprivation therapy (35% vs. 20% of non-Māori). Twelve percent of non-Māori had low-dose brachytherapy and 2% had high-dose brachytherapy. Ten percent of Māori men were not sure about what type of treatment they had.

Treatment choice and information (see appendix Tables 9-9, 9-10, 9-11)

The vast majority of men (73%) thought they had treatment options from which to make a choice (72% Māori, 75% non-Māori). When asked which options their doctor or specialist had told them about prior to treatment, the three options most commonly recalled by men in study were surgery (RP) (87%), radiation or external beam radiation therapy (87%) and active surveillance (81%). Other options were recalled by 65%-26% of men.

Forty-four percent of men sought information beyond their doctor's advice before making a decision about treatment: 26 used the internet, 17 sought further medical opinion, seven consulted books from urology sources, seven obtained information from the Cancer Society and three sought information from the Prostate Cancer Foundation of New Zealand. (See Supportive Care Needs findings for further findings about information needs.)

Treatment outcomes did not differ significantly across the various measures according to whether they had surgery alone or with other options or other treatment options without surgery.

EQ-5D-3L – European Quality of Life Group, 5 Dimension, 3 Level (see appendix Table 9-12).

The majority of men reported no problems with mobility (75%), self-care (93%), usual activities (69%), pain/discomfort (65%) or anxiety/depression (79%). However, there were men for whom pain/discomfort was moderate or extreme (35%) and anxiety/depression were moderate or extreme (21%). Among the men who experienced pain/discomfort, were 50% of the Māori men and 31% of the non-Māori men. Anxiety/depression problems were reported by 35% of the Māori men and 17% of the non-Māori men. Examining these groups by age, we found that the pain/discomfort reported was experienced by 28% of the youngest group (<70 years), 38% by 70-80 year olds, and 63% by those aged >80 years. The age group most affected by anxiety and depression was the 70-80 year old group (27%), while 16% of the younger men and 13% of the oldest men reported these issues. However, it is not possible to determine whether the pain/discomfort and anxiety/depression were due to prostate cancer, prostate cancer treatments and/or comorbidities. These men should be assured of support for this aspect of their on-going health issues.

European Organization for Research and Treatment of Cancer-C30 Quality of Life Scale (see appendix Table 9-13).

This scale is utilised across all types of cancer patients, [2], and supplemented by the PR25 [3] to describe the specific aspects of prostate cancer that can be problematic. Reference data exist for men who had recently been diagnosed with localized prostate cancer (pre-treatment) [16].

The Global Health Status scores of the Midlands men were significantly better ($p<0.01$) than those for the reference group of men with stage I-II prostate cancer pre-treatment. In addition, we found that the Māori men had significantly lower mean scores than the non-Māori men in the Midlands sample ($p<0.05$).

Among the function scales, the Midlands men scored significantly worse on physical function ($p<0.0001$) and role function ($p<0.01$) than the reference group, but there were no significant differences between Māori and non-Māori in these areas. Social function was significantly better in the Midlands men than the reference group men ($p<0.05$).

Examining the global health, physical function, role function and social function scales according to whether the men had surgical or non-surgical interventions, we found the differences in the physical function scale ($p=0.06$) to be the most notable; the standardized mean score for surgically treated men was 94.39, while for non-surgically treated men the mean was 84.72, indicating lesser levels of functioning in the latter group. The remaining function scales did not differ by treatment group.

There were no significant differences across the symptom scales within this measure, either between the whole Midlands sample and the reference group, or between the Māori and non-Māori men within the Midlands sample.

European Organization for Research and Treatment of Cancer-PR25 Prostate Cancer Scale – (see appendix Tables 9-14)

There was a significantly better level of urinary function as measured by the PR-25 across the Midlands men when compared with a reference group at various stages (0, & 3 months) of treatment for prostate cancer reported in Van Andel et al., (2008) [3], ($p<0.05$). However, the proportion of men using incontinence aids (pads, catheter plus bag) was high in the Midlands sample (34%); comparison with the van Andel study men was limited to the observation that 16% of the 146 men responding scored a floor score, while 1.1% scored a ceiling score on this sub-scale in that study. Sixty-one percent of the Midlands men using incontinence aids had been treated with surgery, while the other 39% had received other types of treatments. Mean standardized scores for surgical versus non-surgical treatments were 14.1 and 18.8, respectively ($p=0.08$). Thirty percent of Māori men and 35% of non-Māori men in the Midlands sample used incontinence aids. The majority of men did not find the use of these aids to be a problem, but 19% said they had some problem and 8% said they had quite a bit of difficulty. Contrary to expectations, most of the men using an incontinence aid were in the <70 (47%) and 70-80 (50%) year age groups.

Hospital Anxiety & Depression Scale (see appendix Tables 9-15, 9-16)

Mean anxiety scores on this measure were significantly lower than in the comparison sample of adults from a UK study [17], ($p<0.0001$), as were the depression scores ($p<0.01$). However, the UK sample included females and the authors of that study found females scored higher levels than males for anxiety and depression on this scale.

Examining the Midlands men we found significantly higher mean anxiety ($p<0.01$) and depression ($p<0.05$) scores in Māori men than in non-Māori men. However, all of the mean scores were within the 'normal' range, and when 'cases' (those scoring >11 on either scale) were examined, all were found to be non-Māori men (n=5 for anxiety; n=2 for depression).

There were 35 men (33%) who were prescribed androgen-deprivation therapy post-diagnosis to end-2012 (9 Māori vs. 26 non-Māori). At least 17 men (16%) were prescribed antidepressants; and nine men [8.5%] were prescribed both medications.

Stress Scale (see appendix Tables 9-15, 9-16)

Mean scores on the stress sub-scale were comparable to those of an Australian sample completing the same questionnaire [18]. In the Midlands sample, 10 men were identified as experiencing mild stress, and four as having moderate stress. Six of the mildly stressed men were Māori and all of the moderately stressed men were non- Māori; the mean scores of the Māori men were significantly higher than for non-Māori, ($p<0.01$).

Supportive Care Needs Survey (see appendix Tables 9-17 (raw scores) and 9-18 (standardised scores). Other appendix tables 9-19 (comparison), 9-20 (some need).

The SCNS is presented as a series of sub-scales; the psychological scale showed no differences between the reference sample [19] and the Midlands men, nor between Māori and non-Māori men within the Midlands group.

For the Health System & Information scale, Māori patients scored significantly higher than the comparison group ($p<0.05$), indicating greater needs for assistance with the health system and information, this despite having been some years since diagnosis. Non-Māori men were not significantly different from the reference sample, but did score significantly less than the Māori men ($p<0.05$), indicating lesser need in this area.

Physical and Daily Living Scale scores for the non-Māori men were significantly lower than for the reference group ($p<0.05$), but it should be remembered that the Midlands men were 3-6 years post-diagnosis, while the men in this reference group were only 5-9 months post-diagnosis.

Patient care and support needs were significantly higher in the Midlands Māori men than in the reference sample, ($p=<0.05$), again despite the time elapsed since diagnosis being much greater in the Midlands Māori men.

Sexuality scale needs were significantly higher in the Midlands men than the reference sample, ($p<0.0001$). This was also the case for both the Māori and non-Māori sub-groups of the Midlands sample, again probably a reflection of the greater time since diagnosis in the Midlands men, with concomitant expectations of a return to better sexual functioning. Only 11% of the Midlands men had received any counseling assistance; others acknowledged they would have benefitted from assistance in this area.

The second analysis compared the Midlands men with a longer-term prostate cancer sample of 126 men from the SCNS dataset [19]. For this comparison the Māori patients recorded significantly higher needs for *Psychological care* than the reference men, $p<0.05$. They also reported higher need for *Patient care and support*, $p<.05$, but all other scales were comparable to the reference men for the non- Māori and overall group.

The final analysis of these data identified the numbers of men recording at least 'some need' in each domain of the SCNS. The Midlands group as a whole did not differ from the reference group on any of the SCNS domains, but again Māori reported more need of assistance within the *health* system and information than the non-Māori men ($p<0.0001$).

Sexual Function Concerns (see appendix Table 9-21)

There were no differences in mean ratings of importance of sexual activity across the Midlands men sub-groups.

Overall, 61% of the men reported that they had been asked about their sexual function by their medical specialist, and a similar percentage thought they had been given good advice on options for sexual activity. However, 76% of men had not received phosphodiesterase-5 (PDE5) inhibitors for erectile dysfunction (ED), nor other devices recommended for penile rehabilitation such as intracavernous injections of vasoactive agents (91% untried), vacuum devices (94% untried), and penile rings (93% untried).

Most men (87%) reported experiencing changes in their sexual experience since their cancer diagnosis, but fewer (58%) thought their partner's sexual experience had also changed since the diagnosis of prostate cancer. Most men (82%) talked with their partners about sexual activity but, despite the reported changes and discussions, less than a quarter of the men had used medications to assist their erectile function. In addition, less than 10% of men had tried any other options to assist their erectile function.

Sexual Health Inventory for Men (SHIM) or International Index of Erectile Function-Short Form (IIEF-SF) (see appendix Table 9-22*)*

Comparisons were made with a dataset describing 29 age-matched New Zealand men diagnosed with ED and no prostate cancer before and after treatment for their ED (Conaglen & Conaglen, unpublished dataset). Pre-treatment scores for the ED men were similar to the Midlands men for confidence. However, the men without prostate cancer scored significantly higher on the confidence sub-scale ($p<.0001$) after treatment with oral PDE5 inhibitors (Viagra or Cialis). The total scores for the SHIM were significantly different between these groups, mainly because

the majority of the Midlands men did not record any sexual activity. While we have little indication of sexual function in the Midlands men prior to treatment, these data highlight the sexual costs in men with PCa in this cohort, and compare with other studies carried out in PCa populations internationally [1,20-23]. In several, rates of impotence after PCa treatments range between 28 and 88% post radical prostatectomy [24-5].

Part 2: Couples - Patients and partners or caregivers [N=55]

To gain further insight into the impact of living with prostate cancer we included exploration into the impact of prostate cancer for partners and/or caregivers of patients. We incorporated a partner and caregiver questionnaire to be undertaken at the time of the male patient questionnaire or at a time suitable to the partner or caregiver. This included the partner questions that complemented the male patient measures.

The questionnaires included:

Aspects of well-being that were assessed
• Quality of life with cancer • Specific prostate cancer treatment effects associated & choices involved • Anxiety, depression, stress • Couples' dyadic adjustment • Social intimacy • Whether supportive care needs were being met • Sexual function
Measures
• EORTC-C30 quality of life with cancer, adapted [2] • EORTC-PR25 prostate specific module, adapted [3] • Factors involved in treatment choice [6,7] • HADS plus Stress scale from DASS [4,5] • DAS measure of couples adjustment [8] • Social Intimacy Scale [9] • Supportive Care Needs – Partner/Caregiver [10,11]
• Sexual function scales – IIEF-SF & FSFI-SF [12,13]
Analyses
• Scored questionnaires were compared with reference groups • Patients' & partners' responses were compared • Correlations between measures were examined • P values <0.05 were considered significant • Analyses used Statistica version 11 (Statsoft Inc)

The following section comprises only the men who had a partner/caregiver who was involved in the study and answered a questionnaire.

Partner demographics

There were 53 partners; 52 female and 1 male. Two caregivers also participated in the project. We have removed the male partner from the analysis for the purposes of this report, due to lack of comparative data.

Distribution of partner participants by age and ethnicity

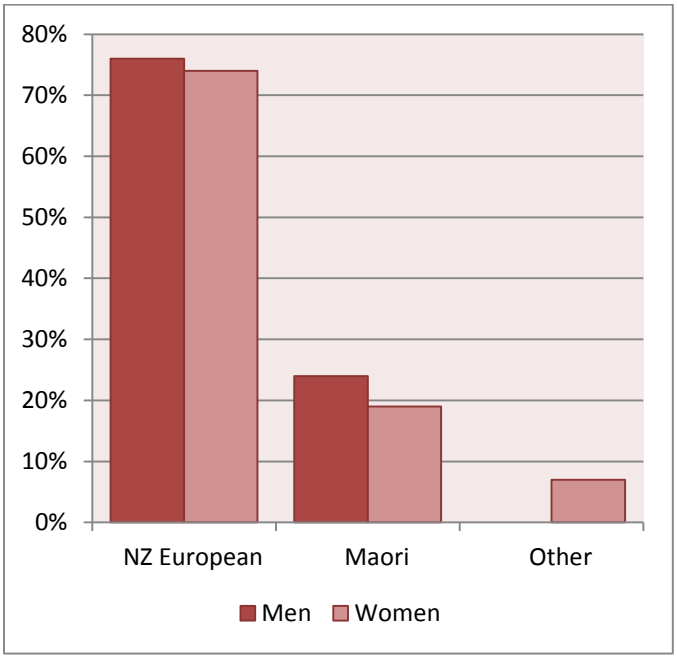


Figure 7-6: Couples' ethnicity.

The ethnicity of the couples was similar between men and women (Figure 7-6), with New Zealand Europeans being the most represented (74%); 19% of partners were Māori and 7% were of 'other' ethnicity. Women were slightly younger than the

male patient (68% of women vs. 58% of men aged 70 years or younger).

Education

Over half of the men and women in the couples cohort had no education beyond school (53% women vs. 60% men). Women in the couple's cohort were more likely to have a professional qualification, diploma or degree than their male counterpart (43% vs. 21%). Women were less likely to have a trade qualification (4%) than men (19%).

Relationships

Nearly all couples (caregivers excluded) identified that they were married (90%); the rest were either in a civil union (4%) or de facto relationship (6%). Most couples had been together for a long time: 73% for over 35 years; 8% for 26-35 years; 11% for 16-25 years; 2% for 5-15 years; and 6% for less than 5 years.

*Year of diagnosis and first treatment (*Figure 7-7*)*

Most of the men were diagnosed during 2009 (29.6%) and 2010 (29.6%). The greatest proportion of men had their first treatment during 2010 (38.9%), followed by 2008 (22.2%) and 2009 (18.5%).

Economic factors for couples

The majority of men were not in paid work and were not looking for a job (59%). More than three quarters received national superannuation (78%). The national median weekly income from wages and salaries for the year to June 2012 was $806; $41,912 pa [15] 60% of men earned less than the NZ median weekly wage. Sixty-two percent of Māori and 59% of non-Māori men earned <$35,000 per annum.

The average annual household income in New Zealand for the year to June 2012 was ~$81,000 [15]; 75% of this sample earned <$81K. The majority of households in this cohort had incomes less than the national average.

Thirty one percent of Māori and 44% non-Māori patients had medical insurance. This was reflected in the use of public/private care, with 85% of Māori and 46% of non-Māori patients treated in the public health system.

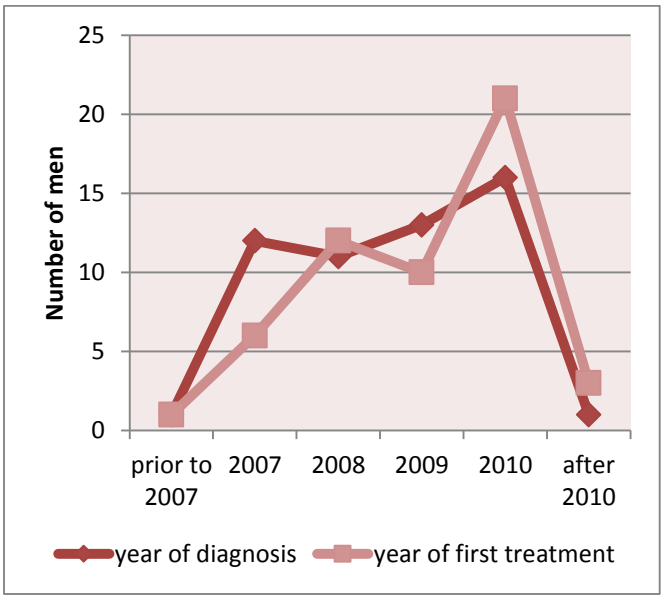


Figure 7-7: Original diagnosis and first treatment by year.

Factors influencing men's choice of treatment (see appendix Table 9-23)

Within the 54 couples, 65% of the men and 81% of the partners regarded the doctor's recommendation as a very important factor in the treatment choice process; this was the most frequent response. The factors for which there were the greatest differences in being rated as very important between the men and their partners were: the need for an escort to and from treatment (men 9%, partners 28%; $p<0.01$); chances of pain caused by treatment (men 13%, partners 31%; $p<0.05$); and recommendations from someone the patient knows who was treated for prostate cancer (men 26%, partners 9%; $p<0.05$). For the rest of the factors, ratings were similar for the men and their partners or caregivers. Partners also felt similarly positive about the available choice of treatment options for the patients.

The proportion of partnered men experiencing problems on the EQ-5D-3L quality of life measure

was not different from the men-only group (see appendix table 9-24).

*European Organization for Research and Treatment of Cancer-C30 Quality of Life Scale (*see appendix Table 9-25*).*

Patients and partners agreed on the majority of responses in this measure, which was adapted so the females responded about their male partner; global health status, role function, emotional function, and social function were not significantly different. However, partners rated the men's physical and cognitive function more highly than the men did ($p<0.05$).

When compared with a reference group of men with a stage I-II diagnosis of prostate cancer who had not received treatment [16], scores on physical function, role function and emotional function were significantly less in the Midlands men at this time, i.e. 3-6 years after diagnosis.

*European Organization for Research and Treatment of Cancer-PR25 Prostate Cancer Scale (*see appendix Table 9-26*)*

Patient and partner/caregiver assessments on this measure were similar across most areas except for sexual activity and sexual function. For sexual activity the men reported a mean score of 22.8±15.3, while their partners reported a score of 6.7±17.7, the difference being statistically significant ($p<0.0001$). Where the sexual function responses were dependent on sexual activity, the responses were less varied but still significantly different (men 50.3±24.9, partners 37.8±27.7; $p<0.05$ (Standard score ie 100=possible maximum).

Hospital Anxiety & Depression Scale (see appendix Tables 9-27, 9-28) - comparison group, UK General population sample [17]. *Stress Scale – sub-scale from the Depression, Anxiety & Stress Scale (DASS),* and comparison group Australian sample [18].

There were significant differences between the patients in Midlands sample and the reference groups for anxiety, depression and stress. Midlands men scored lower for anxiety ($p<0.0001$) and higher for depression ($p<0.01$) than the reference group but had similar scores for psychological distress and stress (differences not statistically significant).

Partners/caregivers recorded anxiety scores that were significantly higher than those of the patients ($p<0.05$) but lower than for the reference group ($p<0.05$). Midlands men recorded higher depression scores than their partners/caregivers ($p<0.0001$), who also recorded lower depression scores than the reference group ($p=0.0196$). There were no significant differences between men and their partners for psychological distress or stress.

Midlands men's anxiety correlated significantly with their partner/caregivers' depression ($p=0.016$) and psychological distress ($p=0.032$), i.e. men's anxiety was higher when their partner's depression or distress was higher. Couples' depression levels also correlated significantly ($p=0.036$), and men's psychological distress was significantly correlated with the partners' depression ($p=0.007$) and psychological distress ($p=0.036$).

There was no effect of main treatment type on these psychological parameters when tested by analysis of variance (ANOVA).

The higher depression scores in the Midlands men fits the observations in the literature regarding the frequency with which men diagnosed with prostate cancer experience depression – for a review see Bennett & Badger [26].

In the Midlands men, 15% were 'cases' scoring above the clinical limit for psychological distress and 13% reported mild stress. The proportions of Māori men scoring in the 'case' range for psychological distress and stress were 23% and 25%, respectively. Thirty percent of Māori partners/caregivers scored in the 'case' range for psychological distress and 20% reported mild stress, while 16% of non-Māori partners/caregivers

recorded psychological distress at 'case' levels and 11% reported moderate levels of stress.

*Dyadic Adjustment Scale-Short Form (*see appendix Table 9-29) - comparison with Hunsley et al., [8]

Couples in this study were in long-term relationships and their responses on this measure of adjustment showed them to be well adjusted, although the men recorded significantly lower scores than their partners ($p<0.0001$). Despite this the men's scores were significantly higher than those of a community sample ($p<0.0001$), [9], which was in turn significantly higher than a sample of men seeking marital therapy at a clinic ($p<0.01$) [9]. Similarly, the partners' scores were higher than those of both the community sample ($p<0.0001$) and the clinical therapy sample with which we compared them ($p<0.0001$). Within the Midlands sample the Māori men scored higher than the non-Māori men ($p<0.01$), but the partner scores did not differ by ethnic group.

Miller Social Intimacy Scale (see appendix Table 9-30) - comparison with two different reference groups: Reference 1 = couples (mean age 40 years) and Reference 2 = couples (mean age ~60 years with prostate cancer diagnosis treated by RP) [28].

This measure generates an intensity scale and a frequency scale, which are totalled to give an overall score. There were no differences between Midlands men and their partners on this measure. Midlands total mean scores for patients ($p<0.0001$) and their partners ($p<0.0001$) were significantly higher (indicating more social intimacy) than those of the first reference group, which was [27], made up of younger married couples from a US convenience sample.

With respect to the second reference group [28], we were unable to test the significance of the differences (no standard deviation given in the Canadian data) but mean scores for our cohort of men and their partners were less overall than those of the men and partners in a Canadian RP group surveyed after diagnosis but prior to surgery. While the ideal would have been to obtain baseline data for the Midlands men, this comparison suggests a negative effect of prostate cancer treatment on men with a diagnosis. The data allowed comparison of social intimacy using the intensity and frequency sub-scales completed by our post-treatment men and partners with the Canadian couples [28]. Midlands men scored significantly lower with respect to intensity ($p<0.01$), but higher in terms of frequency of intimate events ($p<0.01$) than the Canadian males. Partners of the Midlands men also scored lower on intensity ($p<0.0001$) but higher on frequency of social intimacy ($p<0.0001$).

Supportive Care Needs Survey – initial comparison made with reference dataset describing 70+ year old patients with prostate cancer 5-9 months post-diagnosis [19] – see appendix Tables 9-31 (raw scores) and 9-32 (standardised scores). Second comparison made with long-term survivors of prostate cancer [19] – see appendix Tables 9-33 and 9-34.

Within the Midlands sample there were no significant differences between Māori and non-Māori patients on any aspects of this measure. Comparison with the reference group men who were surveyed at 5-9 months post-diagnosis showed Midlands men to be similar on the psychological, health systems and information, physical and daily living and patient care and support sub-scales. There was a highly significant difference, however, on the sexuality sub-scale ($p<0.0001$), with the Midlands men recording much higher levels of need for help in this area than the reference group men (who were closer in time to their treatment). Comparison with a more similar group of men who were long-term prostate cancer survivors showed similar scoring on all sub-scales. When an ANOVA was carried out by main treatment type (surgery or radiation), the physical

and daily living scales for the Midlands men who had surgery were significantly lower than for the men who had radiation ($p<0.02$), indicating greater needs in this area in men receiving radiation.

An additional analysis quantifying the numbers who expressed at least 'some need' in any of the areas measured by this scale demonstrated that a significantly greater proportion of the Midlands men (56%) felt some unmet psychological need compared with the reference group men (56% vs. 29%; $p<0.01$), indicating more psychological assistance could be useful for prostate cancer patients in the New Zealand context.

Supportive care Needs Survey – Partner & Caregiver – see appendix Tables 9-35 and 9-36 - comparison with reference group from Girgis et al., [29] and within sample.

This measure is designed for partners and caregivers of patients. Examining within-group differences relating to various sub-scales, Health Care Service Needs were significantly higher in Māori than non-Māori responders ($p<0.05$), and Work and Social Needs were also significantly greater in Māori than non-Māori ($p<0.05$).

Looking at those who expressed at least 'some need' in any of the domains on the measure, Midlands partners and caregivers did not have greater needs than the Australian comparison sample overall. However, the proportions of Māori partners and caregivers expressing at least some need were higher for the Health Care and Service Needs ($p<0.05$), Psychological and Emotional Needs ($p<0.01$), and Work and Social Needs ($p<0.05$) domains of the measure. There were no significant differences relating to Information Needs.

*Sexual Function Concerns (*see appendix Table 9-37*).*

In response to the query 'How important is sexual activity for you (rated on a scale of 0-10) the Midland patients median response was 7/10 overall, while Māori and non-Māori recorded median scores of 5/10 and 8/10, respectively. The majority of men reported that they had been asked about their sexual function by their medical specialist (70%), thought they had received good advice on their options for sexual activity (74%), had experienced changes in their sexual experience since prostate cancer (83%), and had communicated with their partner about this (87%), while 55% noticed change in their partner's sexual experience since prostate cancer diagnosis. Only 26% of men had used an oral erectile function medication, and very few had tried vacuum pumps (2%), penile rings (4%), or penile injections (7%); 92% of Māori men had not tried any of these options.

Looking at these findings in conjunction with the men's sexual function measure, SHIM/IIEF-SF, the median score for confidence in ability to have an erection was 1/5 for these men, and only 19/54 of the men were sexually active; thus there is a group of men for whom sexual activity is important but not happening.

Sexual Health Inventory for Men (SHIM) or International Index of Erectile Function-Short Form (IIEF-SF) [13]. Comparisons drawn with dataset describing 31 age-matched New Zealand men diagnosed with ED and no prostate cancer before and after treatment for their ED (see appendix Table 9-38).

While all the men responded to the confidence question, and thus were included in the SHIM total scores, only 35% of Midlands men were sexually active. There were no differences in sexual activity when categorised by main treatment (surgery or radiation). Within the Midlands group, Māori men reported more difficulty with their erectile function than non-Māori men ($p<0.01$), and the overall total was also lower for Māori men compared with non-Māori in this sample ($p<0.05$).

*Partners Sexual Function (*see appendix Tables 9-39 & 9-40).

Seventy-two percent of the women agreed to answer sexual activity questions. Although 89% of partners were post-menopausal and a further 9% had had a hysterectomy, only 7% of the women utilised hormone replacement therapy or estrogen cream to counter the effects of menopause, whether surgical or natural.

The Female Sexual Function Index-SF (FSFI-SF) [14] is used as a screening tool and studies have recommended a cut-off score for suspected female sexual dysfunction of ≤19/30. Midlands women's mean sexual function scores indicated problems with sexual function (mean, SD: 17.1±7.8), although the range was between 1 and 28 out of a possible score of 30. Forty-three percent of the women scored better than the cut-off level on this measure, leaving 57% experiencing sexual difficulties. However, it is known from prior studies in this area [30-33], that men's problems result in difficulties being experienced by their partners, so the low rate of sexual confidence and ability to engage in intercourse among the men is likely to have been the cause of the women's low scores in our study. There were no differences between Māori and non-Māori on these scores.

*Partner correlations regarding sexual function (*see appendix Table 9-41).

Significant positive correlations were found between men's confidence and their partner's arousal ($p<0.001$), partner's orgasm ($p<0.04$), partner's satisfaction ($p<0.013$) and FSFI-SF totals ($p<0.002$). Men's ratings of hardness on the SHIM correlated with their partner's pain on penetration ($p<0.004$), and men's ability to penetrate was correlated with women's arousal ($p<0.04$), and pain levels ($p<0.003$). Male satisfaction was correlated with partners' pain ($p<0.005$) as was the men's SHIM total score ($p<0.005$).

Pain concerns for the women might well be lessened if they were to use vaginal estrogen cream post-menopause [34-5], concerns that would be covered if couples were to receive adequate sexual assistance before, during and after prostate cancer treatments.

Discussion

While we identified differences in what Māori and non-Māori men found important in their decision-making process regarding treatment preference and in their unmet post-treatment needs, three to six years post-diagnosis overall men expressed a good rate of return to “normality”. Choices for treatment tended to parallel international reporting on these factors, and outcomes for the men did not vary greatly by type of treatment undergone. Urinary symptoms overall were better than the groups with which the men were compared, but 34% of the Midlands men were using incontinence aids when surveyed; this figure seems high particularly in view of the longer time frames involved than in the comparison groups. We also noted that 11% of men reported receiving counselling since their diagnosis; with several others stating that they feel it would have been beneficial had it been offered. These findings confirm our expectations that a diagnosis of PCa and subsequent treatment processes will seriously impact men even if their cancer is dealt with.

We further expected that the partners and caregivers of male patients would be impacted as well. Looking at the smaller couples group, most men and their partners felt that they had good choice of treatment options. At the time of making their final decision on treatment type, the most important factor for men and their partners came down to the recommendation/s of the doctor. This was particularly so for Māori men. Most couples reported that chances of sexual problems were ‘somewhat important’ or ‘very important’ in choosing between treatment options for their prostate cancer.

However, there were clear areas of need for Māori men, even 3-6 years post-treatment. These included assistance with the health care system, access to information, and patient care and support needs.

Sexual function support was identified as an on-going issue for the majority of men (85%). Most men identified a very low level of confidence in their ability to have an erection. This was aggravated by barriers such as limited access, excessive cost and lack of awareness of options for sexual function support, including sexual function medication and devices.

Undeniably, the impact of prostate cancer occurs across a relationship, affecting men's partners as much as or even more than the patient. Female partners were still in some psychological distress or some stress, and this was higher for partners of Māori men. Psychological distress (HADS) was significant in 30% of the women and 15% of men in the study. Stress was at higher levels than in the normal population. Women should have access to care that assists them to overcome this distress. Despite this, most couples were well adjusted, with 87-90% reporting their relationships as being 'happy', 'very happy', 'extremely happy' or 'perfect'.

Clinicians should be aware that patients with prostate cancer can experience anxiety, depression and stress, and require appropriate assessment and treatment. Psychological assistance would help with meeting, unmet support needs for both Māori and non-Māori men and their partners.

One area contributing to anxiety and depression in the men and their partners is the impact on their sex lives of treatments for prostate cancer. Despite the pre-treatment state of the relationship, the impact of the surgery and/or radiation therapies is known to affect couples and for this reason both partners should be involved in the treatment choice information distribution prior to surgery. Equally, there should be adequate assistance for couples post-treatment so they do not experience untoward distress due to a lack of information or assistance with their sexuality should they require it. We found this area to be one of the most discrepant with other international care needs assessments. Participants within our study also requested further assistance with these matters.

Recommendations

We found that while most patients felt they had enough information prior to treatment there was a lack of information post-treatment. A long-term need for assistance with the health care system and a need for further information were identified by Māori men, despite it being some years beyond diagnosis.

2.0 Improved information to patients and partners

2.1.1 We recommend the development of improved information to assist with the on-going expectations and outcomes for men who have had treatment for localised prostate cancer and their partners. Illustrations in printed material should reflect target population demographics and cultural practices.

2.1 Improved access to long-term support

We found that 26/106 24.5% of men (30% of Māori men (6/20) and 23% of non-Māori men (20/86)), accessed support services (counselling, social or spiritual) for the prostate cancer journey. Patients and partners expressed a need for counselling services at multiple stages of the prostate cancer pathway, post-diagnosis and post-treatment.

2.1.2 We recommend continuing access to counselling services for men and their partners at the time of diagnosis and improving access to long-term support services post-treatment, particularly for Māori men and their partners, who identified a high long-term need.

2.2 Sexual function

We noted that there was difficulty in accurately assessing the need for sexual function support in the absence of information recorded on patients' pre-treatment condition. Whilst there is some movement toward improving recorded patient sexual function history, we believe this can be standardised and made a regular part of the initial assessment of patients.

2.2.1 We recommend the maintenance of standardised records of patients' pre-existing sexual function prior to intervention.

2.3 Improved access to ED medication

While it is known that erectile dysfunction (ED) medication is an important tool for penile rehabilitation, the majority of men had not received phosphodiesterase-5 (PDE5) inhibitors nor other devices recommended for penile rehabilitation (intracavernous injections of vasoactive agents, vacuum devices, penile rings). Among the 30% of men that did use sexual aids at some point or as an on-going requirement, many spoke anecdotally about cost as an impediment to maintaining their use.

2.3.1 We recommend that post-diagnosis and post-treatment men are informed about and have regular, on-going and subsided access to PDE5 inhibitors, injections and other devices.

2.3.2 We recommend that dedicated sexual function support (as at the Bay of Plenty) be funded as part of post-treatment rehabilitation.

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8. REPORT RECOMMENDATIONS

The recommendations included in this report have been developed as a result of findings from across the four studies in this three-year project. These are detailed in the relevant chapter of this report and collated here for ease of reference. It should be noted that overall, men and their partners who were interviewed were happy with their care and showed high levels of adjustment 3-6 years post-treatment. In making our recommendations we have referred to key national and international guidelines where available. Recommendations have been classified into the following groups:

- Recording of prostate cancer
- Primary care
- Management of localised disease
- Equity
- Metastatic disease
- Patient access to information and support

Recording of prostate cancer

Most (80%) prostate cancer registrations are not staged on the New Zealand Cancer Registry, making interpretation of outcomes speculative.

1.1 Regional Collection

1.1.1 We recommend that the regional cancer networks record basic information on all men newly diagnosed with prostate cancer in their region – including age, ethnicity, domicile, PSA levels, cancer grade and stage, presence of comorbidities, pre-existing conditions and first treatment – in a standardised format.

Primary care

Primary care recommendations are based on our audit of PSA testing and screening in general practice. We found that most PSA testing is for screening purposes and most screening is initiated by general practitioners rather than by patients. Recommendations aim to improve patient management at the time of testing and screening and once an elevated PSA result is identified. We found that Māori were significantly less likely to be screened and tested than non-Māori.

Patients can be transferred to and from primary to secondary care multiple times in their prostate cancer journey. Improving the transitions in the handling of patients between the two settings is important to ensure continuity, quality and equitable access to care.

1.2 At the initial PSA test:

1.2.1 We found evidence that many men are tested by GPs without extensive information being available. We support the recommendation from the Prostate Taskforce [11] that primary health care should provide high-quality, culturally appropriate information on prostate cancer and the potential harms and benefits of PSA testing to all men aged 50 to 70 years.

1.2.2 We recommend that the primary care providers discuss the implications of a positive PSA result prior to undertaking the test, including the need for repeat testing and the option of referral to a specialist if the test is positive (>4 ng/mL).

1.2.3 We recommend that primary care practitioners are made aware of the inequities in access to prostate cancer screening between Māori and non-Māori men.

1.2.4 We found evidence of PSA testing being undertaken annually. This resulted in only a small number of additional positive cancers being identified. We recommend that asymptomatic men without known family history of prostate cancer who have a normal PSA test and digital rectal examination (DRE) can be reassured and should not need to be screened for another 4 years unless they develop prostatic symptoms.

1.2.5 Seventy percent of men appear to have had a DRE at the time of their first raised PSA result. This suggests that 30% of men have not been comprehensively assessed. We found 2 men who had a normal PSA but were subsequently diagnosed with prostate cancer, by DRE. We recommend that all men who are screened for the first time should have a DRE to assess the size of the prostate and presence of any abnormality.

1.2.6 We recommend that men with prostatic symptoms have a DRE, and if PSA is raised they be referred to a specialist even if the symptoms alone do not warrant referral.

1.3 After an elevated PSA result:

1.3.1 We noted more than 50% of men had a raised PSA level but did not warrant referral. More Māori men (65%) were not referred than non-Māori (56%) (n.s). These men are at high risk of cancer and robust strategies need to be in place to ensure they are followed up. We recommend that practices should have a clear strategy for management of men with an elevated PSA result which includes regular follow-up and/or referral.

1.4 Where screening is not warranted and may cause harm:

Screening asymptomatic men over 70 years of age with previous normal PSA tests has not been shown to be of benefit and could lead to unnecessary treatment and harm. Men in this age group are rarely referred for specialist assessment. Of the 1491 men aged 70+ years screened, only 13 were referred and five biopsied, and all of those men had cancer. For those with a positive diagnosis: one had hormone therapy; one had radiotherapy plus hormone therapy; one had a radical prostatectomy (at 70 years) and two had no active treatment. No one over 72 years old was treated.

1.4.1 We recommend that men aged over 70 years who have had previous negative PSA tests should not continue to be screened.

We found variations in the time to treatment following biopsy and little formal use of Multi-Disciplinary Meetings (MDM). Clear national guidelines are needed for men managed with localised prostate cancer.

1.5 Multi-Disciplinary Meetings

1.5.1 Whilst the use of MDMs has increased since this study was conducted, we believe it is good practice, as regular quality assurance is of value.

Management of localised disease

While we know that national recording of prostate cancer stage is low at approximately 20% of new cancers, even reviewing patient files did not always allow us to identify stage and or grade of cancer. We found that it was often difficult to evaluate the appropriateness of cancer treatment due to low levels of recording of key information such as the grade and stage of disease, the presence of comorbidities, pre-existing conditions (e.g. measure of urinary function score) and treatment type (if any).

1.6 Pathological reporting

1.6.1 We also found variations in the recording of biopsies and pathological specimens, and would support the Prostate Taskforce recommendations [10, 11] on the standardisation of pathology of both biopsies and histology at diagnosis and following prostatectomy.

1.7 Active Surveillance

We found that 13% of men aged <70 years with localised prostate cancer were being managed through active surveillance (16.9% Māori, 11.3% non-Māori). We believe that active surveillance might be a suitable for an increased proportion of men with low-risk disease to reduce the risk of unnecessary harm from treatment.

1.7.1 We would recommend that clear guidelines are developed for the management of men with localised prostate cancer with active surveillance. The D'Amico classification system, Charlson Score Index and UCSF-CAPRA can be used for risk assessment.

1.7.2 We recommend regular review of the outcomes of men being managed with active surveillance.

Equity

We identified significant differences in the management of Māori men compared with non-Māori men. To mitigate the differences in patient care and outcomes we believe that regular monitoring of the pathway and improving awareness of inequities amongst health professionals will result in the reduction of inequities on the pathway.

1.8 Differential care for Māori compared to non-Māori men

1.8.1 We recommend that each step of the pathway be regularly audited to identify variations between Māori and non-Māori men.

1.8.2 We recommend that further research is undertaken to identify causes of the higher prostate cancer mortality rate for Māori men compared to non-Māori.

1.8.3 We support the 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.

Metastatic disease

While this study concentrated on complications of treatment following localised disease we were aware of the significant morbidity related to metastatic disease.

1.9 We would like to recommend that further research be carried out on the management of men with metastatic prostate cancer.

Patient Access to information and support

We found that while most patients felt they had enough information prior to treatment there was a lack of information post-treatment. A long-term need for assistance with the health care system and a need for further information were identified by Māori men, despite it being some years beyond diagnosis.

2.0 Improved information to patients and partners

2.1.1 We recommend the development of improved information to assist with the on-going expectations and outcomes for men who have had treatment for localised prostate cancer and their partners. Illustrations in printed material should reflect target population demographics and cultural practices.

2.1 Improved access to long-term support

We found that 26/106 24.5% of men (30% of Māori men (6/20) and 23% of non-Māori men (20/86)), accessed support services (counselling, social or spiritual) for the prostate cancer journey. Patients and partners expressed a need for counselling services at multiple stages of the prostate cancer pathway, post-diagnosis and post-treatment.

2.1.2 We recommend continuing access to counselling services for men and their partners at the time of diagnosis and improving access to long-term support services post-treatment, particularly for Māori men and their partners, who identified a high long-term need.

2.2 Sexual function

We noted that there was difficulty in accurately assessing the need for sexual function support in the absence of information recorded on patients' pre-treatment condition. Whilst there is some movement toward improving recorded patient sexual function history, we believe this can be standardised and made a regular part of the initial assessment of patients.

2.2.1 We recommend the maintenance of standardised records of patients' pre-existing sexual function prior to intervention.

2.3 Improved access to ED medication

While it is known that erectile dysfunction (ED) medication is an important tool for penile rehabilitation, the majority of men had not received phosphodiesterase-5 (PDE5) inhibitors nor other devices recommended for penile rehabilitation (intracavernous injections of vasoactive agents, vacuum devices, penile rings). Among the 30% of men that did use sexual aids at some point or as an on-going requirement, many spoke anecdotally about cost as an impediment to maintaining their use.

2.3.1 We recommend that post-diagnosis and post-treatment men are informed about and have regular, on-going and subsided access to PDE5 inhibitors, injections and other devices.

2.3.2 We recommend that dedicated sexual function support (as at the Bay of Plenty) be funded as part of post-treatment rehabilitation.

9. APPENDICES

Table 9-1: Patient characteristics by Cancer Network (CN).

	Midland CN		Northern CN		Central CN		Southern CN	
	n	%	n	%	n	%	n	%
Age								
<70 years	2889	50.3	6437	52.4	4467	48.3	4877	47.6
70+ years	2859	49.7	5847	47.6	4774	51.7	5379	52.4
Ethnicity								
Māori	513	8.9	637	5.2	573	6.2	193	1.9
Non-Māori	5235	91.1	11647	94.8	8668	93.8	10063	98.1
Residence								
Main urban area	3069	53.4	9980	81.2	6688	72.4	5773	56.3
Urban influence	1936	33.7	1379	11.2	1870	20.2	3065	29.9
Rural/remote area	743	12.9	925	7.5	683	7.4	1418	13.8
Socio-economic status (NZDep06)								
1-2 (least deprived)	443	7.7	2693	21.9	1464	15.8	1957	19.1
3-4	877	15.3	2334	19.0	1489	16.1	2362	23.0
5-6	1275	22.2	2784	22.7	1829	19.8	2184	21.3
7-8	1661	28.9	2278	18.5	2322	25.1	2749	26.8
9-10 (most deprived)	1492	26.0	2195	17.9	2137	23.1	1004	9.8
Years of diagnosis								
1996-2000	1601	27.9	4225	34.4	2918	31.6	3215	31.3
2001-2005	2001	34.8	4036	32.9	3068	33.2	3341	32.6
2006-2010	2146	37.3	4023	32.7	3255	35.2	3700	36.1
Vital status								
Alive	3468	60.3	7750	63.1	5506	59.6	6147	59.9
Death due to prostate cancer	1094	19.0	1806	14.7	1633	17.7	1714	16.7
Death due to other causes	1186	20.6	2728	22.2	2102	22.	2395	23.4

Table 9-2: Patient characteristics by ethnicity.

	Māori		non-Māori	
	n	%	n	%
Age				
<70 years	1129	58.9	17541	49.3
70+ years	787	41.1	18072	50.7
Residence				
Main urban area	1053	55.0	24457	68.7
Urban influence	532	27.8	7718	21.7
Rural/remote area	331	17.3	3438	9.7

Socio-economic status (NZDep06)				
1-2 (least deprived)	107	5.6	6450	18.1
3-4	190	9.9	6872	19.3
5-6	292	15.2	7780	21.8
7-8	460	24.0	8550	24.0
9-10 (most deprived)	867	45.3	5961	16.7
Years of diagnosis				
1996-2000	525	27.4	11434	32.1
2001-2005	664	34.7	11782	33.1
2006-2010	727	37.9	12397	34.8
Vital status				
Alive	989	51.6	21882	61.4
Death due to prostate cancer	455	23.7	5792	16.3
Death due to other causes	472	24.6	7939	22.3

Table 9-3: Patient characteristics by age group.

	<70 years		**70+ years**	
	n	%	n	%
Residence				
Main urban area	12702	68.0	12808	67.9
Urban influence	3805	20.4	4445	23.6
Rural/remote area	2163	11.6	1606	8.5
Socio-economic status (NZDep06)				
1-2 (least deprived)	3728	20.0	2829	15.0
3-4	3608	19.3	3454	18.3
5-6	3859	20.7	4213	22.3
7-8	4143	22.2	4867	25.8
9-10 (most deprived)	3332	17.8	3496	18.5
Years of diagnosis				
1996-2000	4930	26.4	7029	37.3
2001-2005	6245	33.4	6201	32.9
2006-2010	7495	40.1	5629	29.8
Vital status				
Alive	14954	80.1	7917	42.0
Death due to prostate cancer	1835	9.8	4412	23.4
Death due to other causes	1881	10.1	6530	34.6

Table 9-4: Kaplan-Meier all-cause and cancer-specific survival rates for men diagnosed between 1996 and 2010 by Cancer Network and ethnicity.

	Kaplan-Meier all-cause	**Kaplan-Meier cancer-specific**

	survival (95% CI)			survival (95% CI)		
	1-year	5-year	10-year	1-year	5-year	10-year
Cancer Network						
Midland	0.89 (0.88, 0.90)	0.67 (0.65, 0.68)	0.47 (0.45, 0.48)	0.94 (0.93, 0.94)	0.82 (0.80, 0.83)	0.71 (0.69, 0.73)
Northern	0.91 (0.91, 0.92)	0.72 (0.72, 0.73)	0.53 (0.52, 0.54)	0.96 (0.95, 0.96)	0.87 (0.86, 0.87)	0.79 (0.78, 0.80)
Central	0.90 (0.90, 0.91)	0.68 (0.67, 0.69)	0.46 (0.45, 0.48)	0.95 (0.94, 0.95)	0.83 (0.83, 0.84)	0.73 (0.72, 0.75)
Southern	0.91 (0.91, 0.92)	0.68 (0.67, 0.69)	0.46 (0.45, 0.48)	0.96 (0.95, 0.96)	0.84 (0.83, 0.85)	0.74 (0.73, 0.75)
Ethnicity						
Non-Māori	0.91 (0.91, 0.91)	0.70 (0.69, 0.70)	0.49 (0.49, 0.50)	0.95 (0.95, 0.95)	0.85 (0.85, 0.85)	0.76 (0.75, 0.76)
Māori	0.87 (0.85, 0.88)	0.59 (0.56, 0.61)	0.35 (0.32, 0.38)	0.92 (0.90, 0.93)	0.76 (0.74, 0.78)	0.63 (0.59, 0.66)

Table 9-5: Hazard ratios for all-cause and cancer-specific survival in men diagnosed with prostate cancer between 1996 and 2010 by Cancer Network and ethnicity.

Hazard ratio from Cox proportional hazard regression models (95% CI)		
	Model I unadjusted	**Model II adjusted for age, year of diagnosis, extent at diagnosis, residence, and socioeconomic status**
Cancer Network[a]	**All-cause**	
Midland CN	1.0 (Ref)	1.0 (Ref)
Northern CN	0.81 (0.77, 0.86)	0.88 (0.83, 0.92)
Central CN	0.99 (0.94, 1.04)	0.96 (0.91, 1.01)
Southern CN	0.97 (0.92, 1.02)	0.97 (0.92, 1.02)
Ethnicity[b]		
non-Māori	1.0 (Ref)	1.0 (Ref)
Māori	1.49 (1.40, 1.60)	1.72 (1.60, 1.84)
Cancer Network	**Cancer-specific**	
Midland CN	1.0 (Ref)	1.0 (Ref)
Northern CN	0.69 (0.64, 0.74)	0.77 (0.72, 0.84)
Central CN	0.90 (0.84, 0.98)	0.91 (0.84, 0.98)

Southern CN	0.85 (0.78, 0.91)	0.86 (0.80, 0.93)
Ethnicity		
non-Māori	1.0 (Ref)	1.0 (Ref)
Māori	1.69 (1.54, 1.86)	1.64 (1.49, 1.82)

[a] also adjusted for ethnicity

[b] also adjusted for Cancer Network

Figure 9-1: Pathway of screening for prostate cancer in New Zealand.

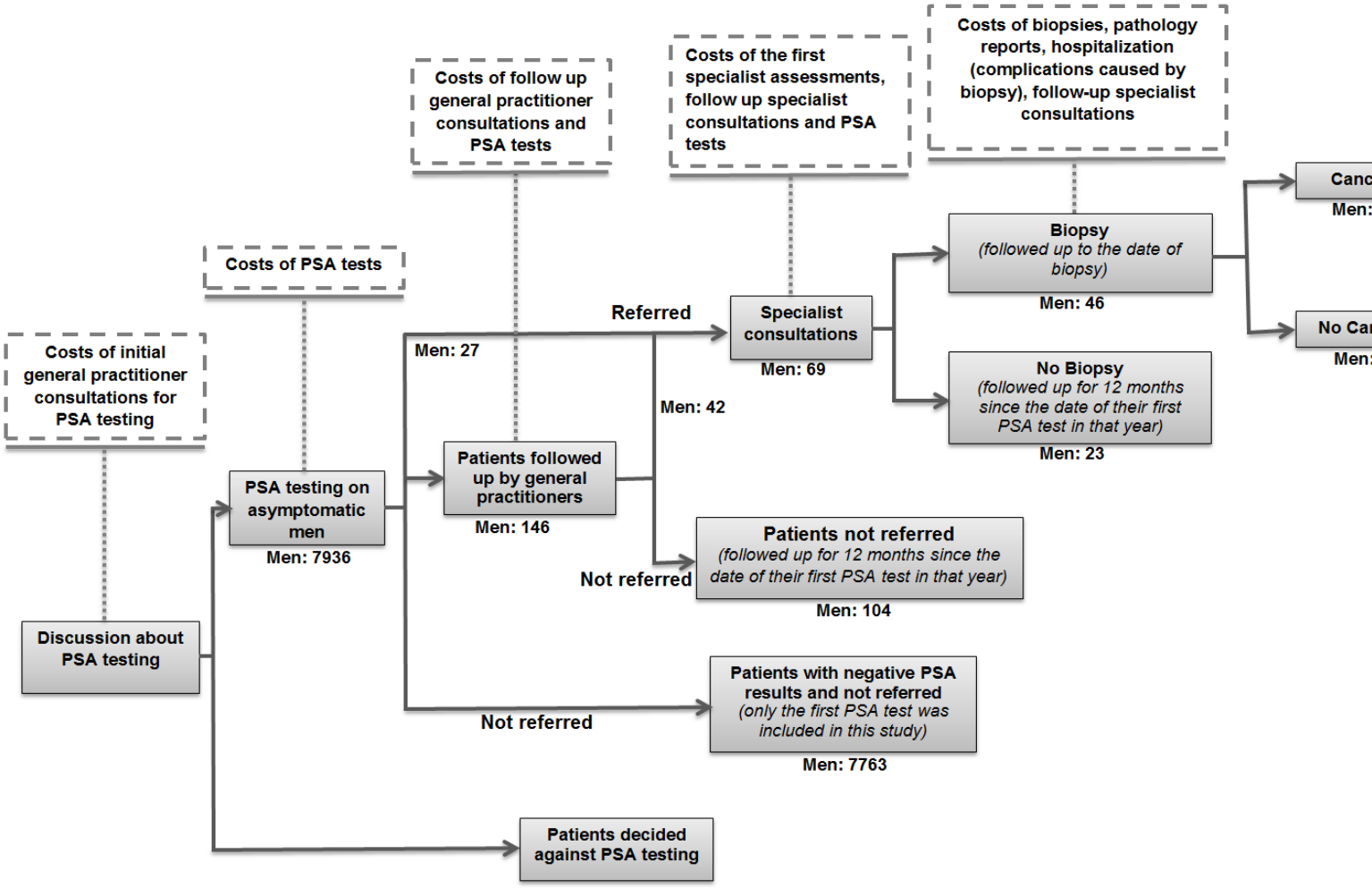

Figure 9-2: Proportion of the costs of each type of medical resources in total cost.

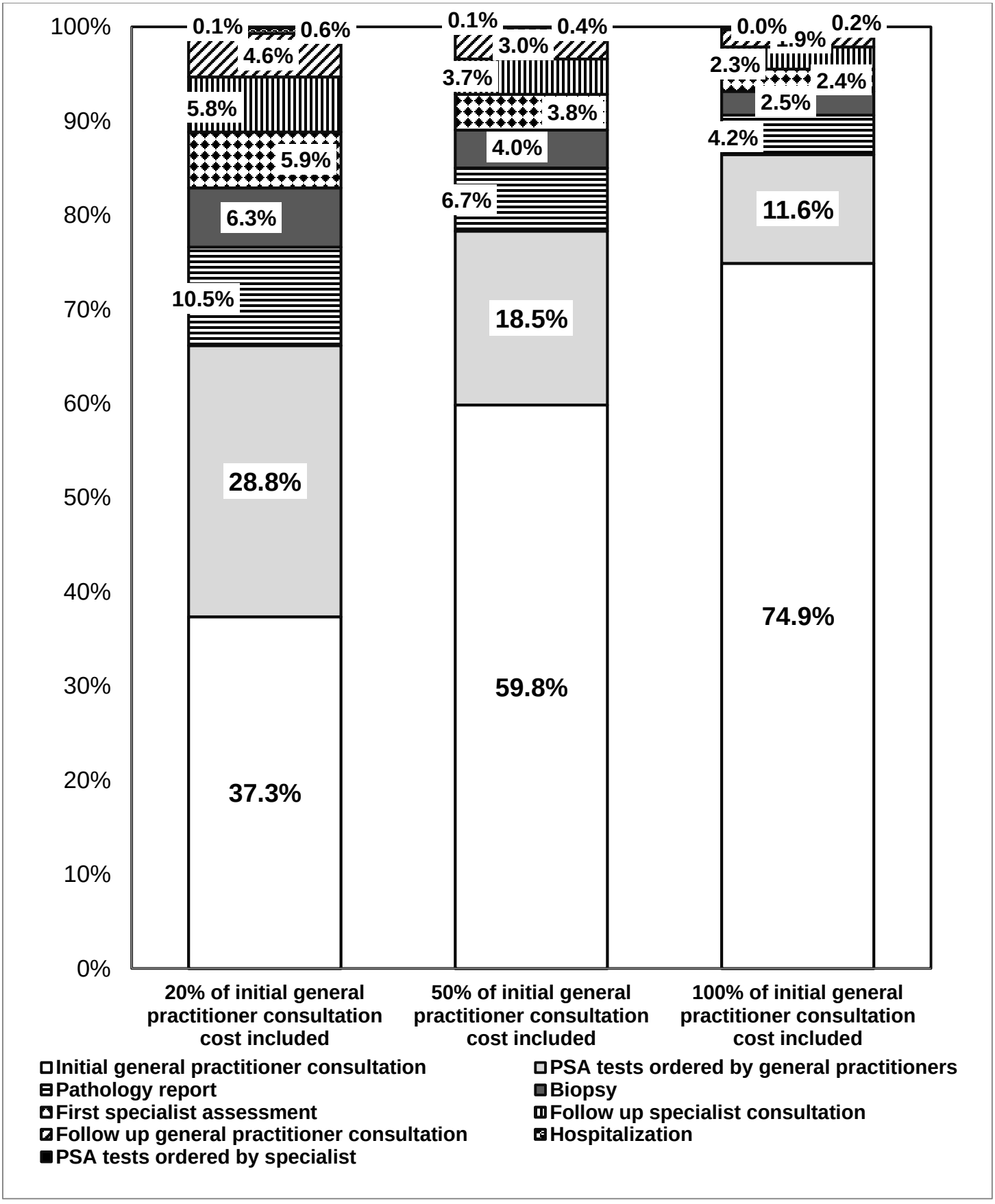

Table 9-6: The unit costs of medical resources.

Medical resources	Corrected cost in 2010 New Zealand Dollars	Unit cost collected		
		Reported cost	Year	Data source
PSA test	NZ$11.07	NZ$10.44	2008-2009	Report from MoH [#1]
general practitioner consultation	NZ$73.54			
charge	NZ$35.88	NZ$36.73	2012	Unpublished data from MoH
subsidy	NZ$37.66	NZ$38.69	2012	Website of MoH [#2], Report from the Royal New Zealand College of General Practitioners [#3]
First specialist assessment	NZ$268.79	NZ$276.36	2012	Unpublished data from Urology Services Ltd & Venturo Ltd
Follow-up specialist consultation	NZ$233.64	NZ$213.09	2006-2008	Report from MoH [#1]
Biopsy	NZ$427.96	NZ$440.00	2012	Unpublished data from Urology Services Ltd & Venturo Ltd
Pathology report of biopsy	NZ$710.02	NZ$730.00	2012	Unpublished data from Waikato Hospital in WDHB
Hospitalization after biopsy (per bed day)	NZ$405.82	NZ$349.50	2005	Website of World Health Organization [#4]

Please note: All the unit costs of medical resources in hospitals were based on data from public hospitals.

#1. Ministry of Health. *The Price of Cancer: The public price of registered cancer in New Zealand.* Wellington, New Zealand. 2011.

#2. Ministry of Health. *Summary of Capitation Rates from 1 July 2012*. 2012; http://www.health.govt.nz/our-work/primary-health-care/primary-health-care-services-and-projects/capitation-rates (accessed on 20 January 2013).

#3. Frette J, Pande M. *Forecasting GP Workforce Capacity: Royal New Zealand College of General Practitioners.* 2006.

#4. World Health Organization. *Estimates of Unit Costs for Patient Services for New Zealand*. 2005; http://www.who.int/choice/country/nzl/cost/en/ (accessed on 12 February 2013).

Table 9-7: Quantity of medical resources for prostate cancer screening.

Categories	PSA test ordered by general practitioner	Initial general practitioner consultation	Follow up general practitioner consultation	First specialist assessment	Follow-up specialist consultation	PSA test ordered by specialist	Biopsy	Pathology report	Hospitalization after biopsy (bed days)
Age group									
40-49	1448	1434	14	8	10	5	5	5	0.49
50-59	2645	2604	41	17	18	9	9	9	0.88
60-69	2492	2407	85	31	41	14	27	27	2.63
≥70	1548	1491	57	13	9	4	5	5	0.49
Ethnicity									
Māori	570	557	13	11	17	10	7	7	0.68
Non-Māori	7563	7379	184	58	61	22	39	39	3.80
PSA testing history									
No PSA tests in 2007-2009	3490	3391	99	48	57	25	32	32	3.12
Had PSA tests in 2007-2009	4643	4545	98	21	21	7	14	14	1.36
Overall									
	8133	7936	197	69	78	32	46	46	4.48

Table 9-8: Costs per prostate cancer identified.

Categories	20% of initial general practitioner consultation cost included	50% of initial general practitioner consultation cost included	100% of initial general practitioner consultation cost included
Age group			
40-49	NZ$24,290	NZ$40,108	NZ$66,472
50-59	NZ$30,022	NZ$49,172	NZ$81,089
60-69	NZ$6,268	NZ$9,063	NZ$13,721
≥70	NZ$10,957	NZ$17,536	NZ$28,501
Ethnicity			
Māori	NZ$7,685	NZ$10,757	NZ$15,877
Non-Māori	NZ$11,272	NZ$17,784	NZ$28,637
PSA testing history			
No PSA tests in 2007-2009	NZ$8,887	NZ$13,043	NZ$19,970
Had PSA tests in 2007-2009	NZ$13,870	NZ$22,985	NZ$38,178
Overall	NZ$10,777	NZ$16,814	NZ$26,877

Conversion rates in 2010: 1 NZ$ = 0.540 €, 1 NZ$ = 0.447 £

Figure 9-3: Treatment pathways for men with localised prostate cancer.

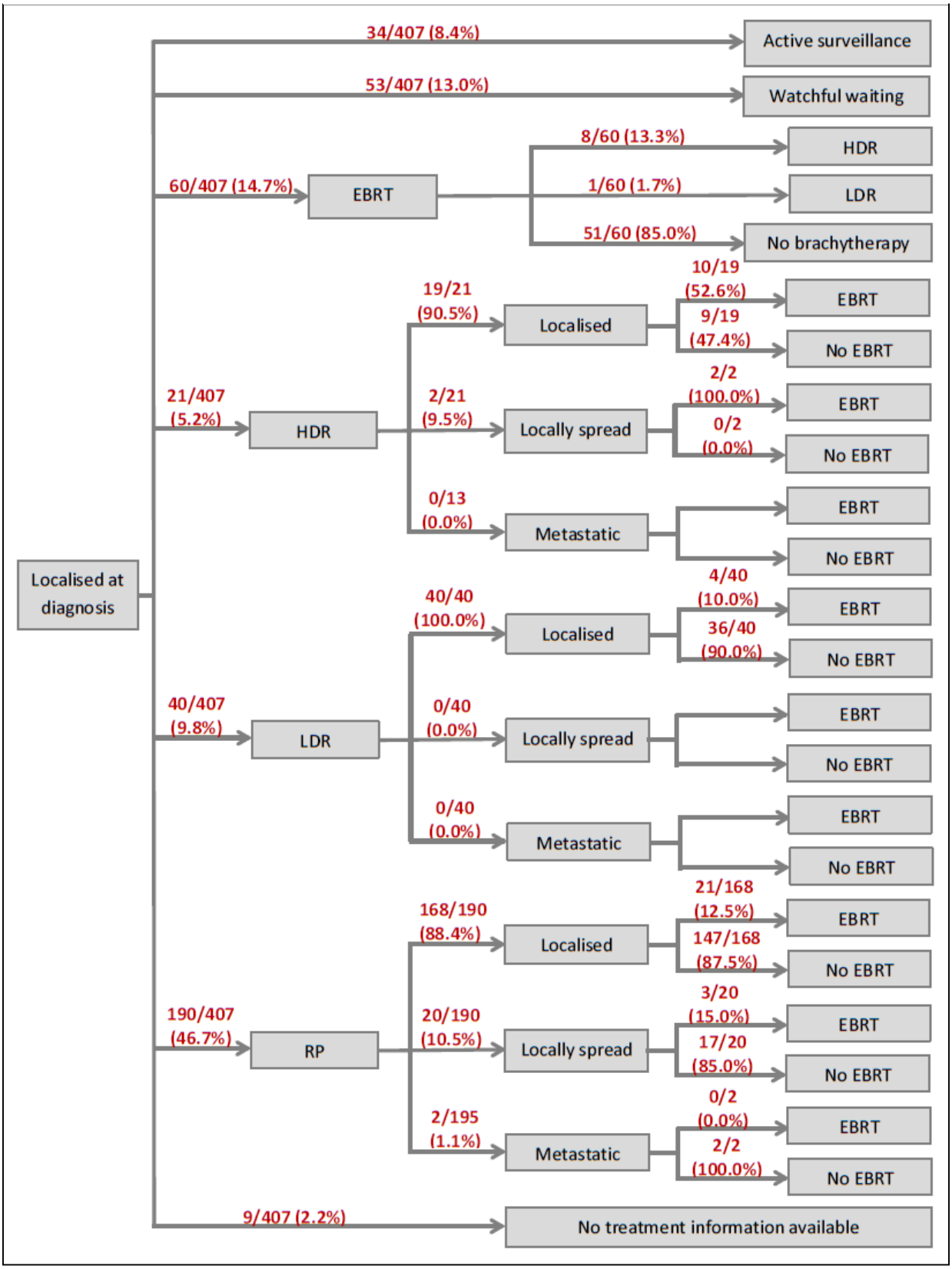

Table 9-9: Factors influencing men's treatment choice.

Item	Patient endorsed [n=106]			Māori patients [n=20]			Non-Māori patients [n=86]		
	Not important	Somewhat important	Very important	Not important	Somewhat important	Very important	Not important	Somewhat important	Very important
Amount of time required to complete treatment	44 [42%]	17 [16%]	45 [43%]	7 [35%]	3 [15%]	10 [50%]	37 [43%]	14 [16%]	35 [41%]
Amount of time required to recover from treatment	42 [40%]	32 [30%]	32 [30%]	6 [30%]	4 [20%]	10 [50%]	36 [42%]	28 [33%]	22 [26%]
Impact on usual daily activities	35 [33%]	38 [36%]	33 [31%]	7 [35%]	6 [30%]	7 [35%]	28 [33%]	32 [37%]	26 [30%]
Need for escort to/from treatment	71 [67%]	28 [26%]	7 [7%]	12 [60%]	5 [25%]	3 [15%]	59 [67%]	23 [27%]	4 [5%]
Inconvenience and burden on patient's family during treatment and recovery	43 [41%]	43 [41%]	20 [19%]	11 [55%]	4 [20%]	5 [25%]	32 [37%]	39 [45%]	15 [17%]
The amount of out-of-pocket costs that patient expects will not be covered by any type of insurance	69 [65%]	24 [23%]	13 [12%]	15 [75%]	4 [20%]	1 [5%]	54 [63%]	20 [23%]	12 [14%]
Chances of problems with urinary function	33 [31%]	32 [30%]	41 [39%]	7 [35%]	5 [25%]	8 [40%]	26 [30%]	27 [31%]	33 [38%]
Chances of problems with bowel function	41 [39%]	29 [27%]	36 [34%]	10 [50%]	3 [15%]	7 [35%]	31 [36%]	26 [30%]	29 [34%]
Chances of problems with sexual function	35 [33%]	32 [30%]	39 [37%]	8 [40%]	3 [15%]	9 [45%]	27 [31%]	29 [34%]	30 [35%]
Chances of pain caused by treatment	67 [63%]	25 [24%]	14 [13%]	12 [60%]	6 [30%]	2 [10%]	55 [64%]	19 [22%]	12 [14%]
Chances of tiredness or fatigue following treatment	52 [49%]	38 [36%]	16 [15%]	8 [40%]	10 [50%]	2 [10%]	44 [51%]	28[33%]	14 [16%]

Chances of depression/anxiety	56 [53%]	34 [32%]	16 [15%]	9 [45%]	7 [35%]	4 [20%]	47 [55%]	27 [31%]	12 [14%]
Recommendations from patient's doctor(s) who are managing the cancer	13 [12%]	22 [21%]	71 [67%]	3 [15%]	1 [5%]	16 [80%]	10 [12%]	21 [24%]	55 [64%]
Wife or partner preference for a particular treatment	40 [38%]	25 [24%]	40 [38%]	10 [50%]	2 [10%]	8 [40%]	30 [35%]	23 [27%]	32 [37%]
Close family member preference for a particular treatment	69 [65%]	18 [17%]	19 [18%]	15 [75%]	-	5 [25%]	54 [63%]	18 [21%]	14 [16%]
Recommendations from someone the patient knows who was treated for prostate cancer	54 [51%]	29 [27%]	23 [22%]	10 [50%]	5 [25%]	5 [25%]	44 [51%]	24 [28%]	18 [21%]

Note. Endorsements ≥ 50% highlighted.

Table 9-10: Patient recall of treatment options discussed.

Treatment options	Yes	No	Don't know
Active surveillance – watchful waiting – checking Prostate regularly	81	15	10
Surgery – Radical prostatectomy	87	17	2
Open surgery	65	30	11
Laparoscopic or keyhole surgery	37	57	12
Robotic surgery	26	67	13
Radiation or external beam radiation therapy	87	16	3
Hormone or Androgen deprivation therapy	53	38	15
Surgery plus radiation	64	40	2
Surgery plus hormone	32	53	21
High Dose Rate Brachytherapy	46	49	11
High Dose Rate Brachytherapy plus radiation	39	49	18
Low dose brachytherapy	45	42	19
Radiation plus hormone	42	45	19

Table 9-11: Treatment participants reported undergoing.

Treatments	**All Midlands Patients**	**Māori Patients**	**Non-Māori Patients**
	N=106 [%*]	N=20	N=86
Surgery – radical prostatectomy	38 [36%]	4 [20%]	32 [40%]
Radiation - External beam radiation therapy	13 [12%]	3 [15%]	10 [12%]
Radiation plus ADT	11 [10%]	4 [20%]	7 [8%]
Surgery plus radiation	10 [9%]	2 [10%]	8 [9%]
Low Dose Rate Brachytherapy	9 [9%]	-	9 [11%]

Active surveillance – watchful waiting – checking Prostate regularly	8 [8%]	2 [10%]	6 [7%]
HDRB plus radiation	5 [5%]	2 [10%]	3 [4%]
Hormone or Androgen deprivation therapy (ADT)	4 [4%]	1 [5%]	3 [4%]
I'm not sure/I don't know/Doctor made no recommendation	4 [4%]	2 [10%]	2 [2%]
Surgery plus ADT	2 [2%]	-	2 [2%]
High Dose Rate Brachytherapy (HDRB)	2 [2%]	-	2 [2%]

*Note. Percentages rounded. One man reported AS then surgery so coded as AS.

Table 9-12: EQ-5D

	Mobility	Self-care	Usual Activities	Pain/ Discomfort	Anxiety/ Depression
No problems	80 [75%]	99 [93%]	73 [69%]	69 [65%]	84 [79%]
Some problems	26 [25%]	7 [7%]	33 [31%]	-	-
Moderate problems	-	-	-	35 [33%]	21 [20%]
Severe or extreme problems	-	-	-	2 [2%]	1 [1%]

Table 9-13: EORTC-C30 Quality of Life

	All Midlands patients n=106			Reference Men PCa Stage I-II n=959			Maori n=20			Non-Maori n=86		
	Mean±SD	Median	IQR	Mean±SD	Median	IQR	Mean±SD	Median	IQR	Mean±SD	Median	IQR
Global health status	77±19.6b	83.3	66.7–91.7	70.8±20.5[b]	75	58.3-83.3	67.1±20.9c	75	50-83.3	79.3±18.7c	83.3	66.7-91.7
Functional scales *(Higher scores better)*												
Physical function	86.6±18.8a	93.3	80-100	93±12[a]	100	93.3-100	80.3±24.1	90	63.3-100	88.1±17.2	93.3	86.7-100
Role function	84.6±22.6b	100	83.3-100	90.6±20.3[b]	100	83.3-100	76.7±21.9	83.3	66.7-100	86.4±22.5	100	83.3-100
Emotional function	82±16.8	83.3	75-91.7	78±22.8	83.3	66.7-100	76.7±16.4	83.3	66.7-91.7	83.3±16.7	91.7	75-91.7
Cognitive function	83.2±22.2	91.7	66.7-100	86.1±19.3	100	83.3-100	80±23.3	91.7	58.3-100	83.9±22	91.7	83.3-100
Social function	89.1±19.9c	100	83.3-100	83.9±25[c]	100	66.7-100	92.6±16.9	100	100-100	88.2±20.7	100	83.3-100
Symptom scales/items *(Higher scores worse)*												
Fatigue	13.1±16.4	11.1	0-22.2	18.9±22.7	11.1	0-33.3	18.3±18.8	11.1	0-33.3	11.8±15.6	11.1	0-22.2
Nausea & vomiting	5.7±11.7	0	0-0	2.4±9.1	0	0-0	5.8±12.4	0	0-8.3	5.6±11.6	0	0-0
Pain	15.2±20.4	16.7	0-16.7	14.6±24.5	0	0-16.7	18.3±20.9	16.7	0-33.3	14.5±20.3	16.7	0-16.7
Dyspnoea	20.4±30	0	0-33.3	12.2±22.6	0	0-33.3	28.3±39.4	0	0-66.7	18.6±27.3	0	0-33.3
Insomnia	14.2±23.4	0	0-33.3	20.9±28.8	0	0-33.3	21.7±24.8	16.7	0-33.3	12.4±22.9	0	0-33.3
Appetite loss	4.1±14.3	0	0-0	4.9±16.3	0	0-0	8.3±18.3	0	0-0	3.1±13.2	0	0-0
Constipation	10.7±23.3	0	0-0	8.8±20.3	0	0-0	10±24.4	0	0-0	10.9±23.1	0	0-0
Diarrhoea	5.3±13.1	0	0-0	8.5±20.2	0	0-0	6.7±17.4	0	0-0	5±12	0	0-0
Financial	8.8±18.9	0	0-0	8.5±21.2	0	0-0	11.1±23.6	0	0-0	8.8±18.9	0	0-0

Table 9-14: EORTC-PR25

Symptom Scale	All Midlands patients n=106			Reference Men PCa Van Andel et al. 2008		Maori n=20			Non-Maori n=86		
	Mean±SD	Median	IQR	N	Mean±SD	Mean±SD	Median	IQR	Mean±SD	Median	IQR
Urinary	16.5±13.9a	12.5	8.3-25	457~	22.7±18.1a	21.5±12.1	22.9	10.4-29.2	15.4±14.1	12.5	4.2-20.8
Bowel	4.8±6.8	0	0-8.3	423~	5.4±9.4	6.3±7.6	4.2	0-8.3	4.5±6.6	0	0-8.3
Hormone Treatment Related Symptoms	11.3±14.9	5.6	0-16.7	457~	11.9±10.7	15±18.7	11.1	0-19.4	10.5±13.8	5.6	0-11.1
Sexual Activity	71.6±33.9	83.3	50-100	454~	27.8±26	75.8±29.9	91.7	50-100	70.6±34.9	83.3	50-100
#Sexual Function	48.6±24.2	50	33.3-66.7	454~	53.6±25.4	40±28.2	33.3	16.7-66.7	50.6±23.0	50	41.7-66.7
Continence Aid -[if used]	n=36 [34%] Mean [SD]: 18.1±32			n=41 [9%] Mean [SD]: 10.6±26.3		n=6 [30%] Mean [SD]: 33.3±25.8			n=30 [34.9%] Mean [SD]: 15±32.6		
Note. ~ Measure recorded in an international sample of men at various disease stages post-treatment for PCa. Difference of means significance: a p<.05. # indicates scales answered only if sexually active.											

Check for other differences of means here

Table 9-15: HADS and Stress Scales

Scale	All Midlands patients n = 106			Reference Check for a number			Maori Patient n = 20			Non-Maori n = 86		
	Mean±SD	Median	Range	Mean±SD	Median	% cases	Mean±SD	Median	Range	Mean±SD	Median	Range
Anxiety # [11+ = case]	3.49±3.26	3.0	0-15	6.14±3.76	6.0	12.6%	5.3±2.90	5.5	0-10	3.07±3.20	2.0	0-15
Depression [11+ = case]	2.61±2.69	2.0	0-14	3.68±3.07	3.0	3.6%	3.8±2.38	3.5	1-10	2.34±2.70	1.0	0-14
Stress*	3.86±2.91	3.0	0-11	3.99±4.24	3.0	-	5.35±2.83	6.0	0-9	3.51±2.83	3.0	0-11
Note. # Anxiety and depression reference data from UK sample reported in Crawford et al., 2001. * Stress reference data from Australian sample reported in Crawford et al., 2011.												

Table 9-16: Cases identified using HADS and Stress Scales

Scale	All Midlands patients n = 106	Māori Patient n = 20	Non-Māori n = 86
Anxiety [11+ = case]	5 [4.7%]	0	5 [5.8%]
Depression [11+ = case]	2 [1.9%]	0	2 [2.3%]
Stress mild moderate	10 [9.4%] 4 [3.8%]	6 [30%] -	4 [4.7%] 4 [4.7%]

Note. There were 22 men [21%] prescribed ADT at some stage; 17 men [16%] prescribed antidepressants; and 9 men [8.5%] prescribed both medications.

Table 9-17: Supportive Care Needs Survey – raw scores

Domain	All Midlands patients n=106			Maori Patient n=20			Non-Maori n=86		
	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range
Psychological	17.1±8.5	14	12	19.3±9.6	19	15.5	16.6±8.2	14	10
Health system & information	17.4 ±10.2	11.8	11	21.6±14.5	15.7	11.8	16.4±8.7	11	11
Physical & daily living	7.8±4.2	5	5	9.0±4.8	6.5	8	7.6±4.1	5	5
Patient care & support	7.5±3.6	6	4	8.8±5.1	6.5	5	7.2±3.1	6	4
Sexuality	6.9±4.2	6	7.5	7.4±4.7	6	7.5	6.9±4.1	6	7.5

Table 9-18: Supportive Care Needs Survey – standardised scores for comparison with SCNS dataset for 70+ yr old CaP patients 5-9 months post-diagnosis

Domain	All Midlands patients		Reference Group~		Maori Patients		Non-Maori Patients	
	Mean±SD	N	Mean±SD	N	Mean±SD	N	Mean±SD	N
Psychological	17.8±21.3	106	16.9±18.4	245	23.3±23.9	20	16.5±20.6	86
Health system & information	14.6±23.2	106	15.3±15.4a	246	24.1±33a,g	20	12.4±19.8g	86
Physical & daily living	14.4±21.1	106	18.3±22.3b	245	19.8±24	20	12.8±20.4b*	86
Patient care & support	12.5±18.1	106	11.2±13.6c	243	19.0±25.7c*	20	11.0±15.6	86
Sexuality	32.9±35.3d***	106	15.4±20e,f	245	36.3±39.5e***	20	32.1±34.5f***	86

Note. ~Reference group: 70+ yr old CaP patients 5-9 months post-diagnosis.
*p<.05 and ***p<.0001 compared to reference group.
Maori versus non-Maori testing differences of means significant where indicated, p<.05.

Table 9-19: Supportive Care Needs Survey – standardised scores for comparison with SCNS dataset for long term CaP survivors

Domain	All Midlands patients		Reference Group~		Maori Patients		Non-Maori Patients	
	Mean±SD	N	Mean±SD	N	Mean±SD	N	Mean±SD	N
Psychological	17.8±21.3	106	13.3±18.9*	126	23.3±23.9*	20	16.5±20.6	86
Health system & information	14.6±23.2	106	14.1±19.2	128	24.1±33	20	12.4±19.8	86
Physical & daily living	14.4±21.1	106	18.2±23.7	128	19.8±24	20	12.8±20.4	86
Patient care & support	12.5±18.1	106	9.0±14.6*	128	19.0±25.7*	20	11.0±15.6	86
Sexuality	32.9±35.3	106	28.1±33.6	128	36.3±39.5	20	32.1±34.5	86

Note. ~Reference group: long-term CaP patients 5-6 years post-diagnosis.
*p<.05 and ***p<.0001 compared to reference group.

Table 9-20: Supportive Care Needs Survey – Participants reporting at least 'some need' by domain

Domain	All Midlands patients n=106		Reference Group~ n=128		Maori Patients n=20		Non-Maori Patients n=86	
	N	%	N	%	N	%	N	%
Psychological	35	33	36	29	10	50	25	29
Health system & information	16	30	30	24	11	55***a	5	6***a
Physical & daily living	31	29	41	32	9	45	22	26
Patient care & support	24	23	21	17	5	25	19	22
Sexuality	44	42	50	39	9	45	35	41

Note. ~Reference group: Long-term CaP patients (5-6 years post-diagnosis).
'Some need' means low, moderate or high need response to at least one item in that domain.
***p<.0001 significant difference of proportions comparing labelled groups.

Table 9-21: Miscellaneous sexual activity questions

Query	All Midlands Patients		Maori Patients		Non-Maori Patients	
How important is SEXUAL ACTIVITY for you? [Scale 0-10]	Mean: 6.2 ± 3.5 Median: 7.0 Range: 0-10		Mean: 5.4 ± 3.5 Median: 5.0 Range: 0-10		Mean: 6.3 ± 3.5 Median: 7.0 Range: 0-10	
	YES	NO	YES	NO	YES	NO
Have you been asked about your sexual function by any of your medical specialists?	56 [61%]	36 [39%]	14 [78%]	4 [22%]	42 [57%]	32 [43%]
Do you think you have had good advice on options for you and your sexual activity?	57 [62%]	35 [38%]	12 [67%]	6 [33%]	45 [61%]	29 [39%]
Have you experienced any changes in your sexual experience since this cancer?	80 [87%]	12 [13%]	16 [89%]	2 [11%]	64 [86%]	10 [14%]
Do you communicate with your partner about sexual activity?	75 [82%]	17 [18%]	13 [72%]	5 [28%]	62 [84%]	12 [16%]
Have you noticed any change in your partner's sexual experience since your prostate cancer diagnosis?	53 [58%]	39 [42%]	12 [67%]	6 [33%]	41 [55%]	33 [45%]
Do you use Viagra, Evigra, Levitra, Silvasta, Cialis or similar medications?	25 [24%]	81 [76%]	2 [10%]	18 [90%]	23 [27%]	63 [73%]
If no medications, do you use any of the following:						
Vacuum pump	5 [5%]	101 [95%]	-	-	4 [5%]	82 [95%]
Penile ring	7 [7%]	99 [94%]	-	-	6 [7%]	80 [93%]
Penile injections	10 [9%]	96 [91%]	1 [50%]	1 [50%]	7 [8%]	79 [92%]
Other erectile devices	2 [2%]	104 [98%]	-	-	2 [2%]	84 [98%]

Note. Endorsements ≥ 50% highlighted. Percentages rounded.

Table 9-22: Sexual Health Inventory for Men or International Index of Erectile Function-Short Form

Scale	All Midlands Patients			Age Matched Erectile Dysfunction Study Group Pre- & Post-treatment♦			Maori Patients			Non-Maori Patients		
	Mean±SD	Median	Range	Mean±SD	Median	Range	Mean±SD	Median	Range	Mean±SD	Median	Range
Confidence Max:5 *n=104; #n=18; ~n=86.	1.83±1.28*	1.0	1-5	ED pretreated (n=31): 1.74±0.68	2	1-3	1.22±0.65#	1.0	1-3	1.95±1.35~	1.0	1-5
				ED post-treated (n=28): 3.04±1.29a	3	1-5						
Hardness Max:5 *n=38; #n=2; ~n=36.	3.39±1.39*	4.0	1-5	ED pretreated (n=31): 2.13±1.23b	2	0-5	2.5±2.12#	2.5	1-4	3.44±1.36~	4.0	1-5
				ED post-treated (n=28): 3.71±1.58	4	0-5						
Penetration Max:5 *n=37; #n=2; ~n=35.	3.49±1.46*	4.0	1-5	ED pretreated (n=31): 2.29±1.47b	2	0-5	3.0±2.83#	3.0	1-5	3.51±1.42~	4.0	1-5
				ED post-treated (n=28): 3.82±1.52	4	0-5						
Difficulty Max:5 *n=37; #n=2; ~n=35.	3.81±1.20*	4.0	1-5	ED pretreated (n=31): 2.0±1.34a	2	0-5	1.0±0#	1.0	1-1	3.97±1.01~	4.0	1-5
				ED post-treated (n=28): 3.82±1.56	4	0-5						
Satisfaction Max:5 *n=37; #n=2; ~n=35.	3.73±1.39*	4.0	1-5	ED pretreated (n=31): 2.23±1.43a	2	0-5	1.5±0.71#	1.5	1-2	3.86±1.31~	4.0	1-5
				ED post-treated (n=28): 3.75±1.58	4	0-5						
IIEF-5 total Max:25 *n=104; #n=18; ~n=86.	6.99±8.66*	1.0	1-25	ED pretreated (n=31): 10.39±5.50c	11	1-23	2.11±3.51#1	1.0	1-15	8.01±9.07~	1.0	1-25
				ED post-treated (n=28): 18.21±6.50a	21	1-25						

Note. Only small number of Midlands Study men opted to complete this measure in its entirety, but those who did not complete reported having erection problems.

Table 9-23: Factors influencing choice for patients and their partners

Item	Patient endorsed			Partner endorsed			
	Not important	Somewhat important	Very important	Do not know	Not important	Somewhat important	Very important
Amount of time required to complete treatment	24 [44%]	8 [15%]	22 [41%]	6 [11%]	13 [24%]	12 [22%]	23 [43%]
Amount of time required to recover from treatment	20 [37%]	16 [30%]	18 [33%]	6 [11%]	11 [20%]	12 [22%]	25 [46%]
Impact on usual daily activities	16 [30%]	20 [37%]	18 [33%]	7 [13%]	10 [19%]	14 [26%]	23 [43%]
Need for escort to/from treatment	33 [61%]	16 [30%]	5 [9%]a	3[6%]	27 [50%]	9 [17%]	15 [28%]a
Inconvenience and burden on patient's family during treatment and recovery	18 [33%]	22 [41%]	14 [26%]	3[6%]	24 [44%]	12 [22%]	15 [28%]
The amount of out-of-pocket costs that patient expects will not be covered by any type of insurance	33 [61%]	14 [26%]	7[13%]	5 [9%]	25 [46%]	13[24%]	11 [20%]
Chances of problems with urinary function	15 [28%]	16 [30%]	23 [43%]	7 [13%]	5 [9%]	11 [20%]	31 [57%]
Chances of problems with bowel function	20 [37%]	15 [28%]	19 [35%]	9 [17%]	9 [17%]	9 [17%]	27 [50%]
Chances of problems with sexual function	14 [26%]	20 [37%]	20 [37%]	7 [13%]	13 [24%]	15 [28%]	19 [35%]
Chances of pain caused by treatment	34 [63%]	13 [24%]	7 [13%]b	8 [15%]	13 [24%]	16 [30%]	17 [31%]b
Chances of tiredness or fatigue following treatment	22 [41%]	22 [41%]	10 [19%]	8 [15%]	14 [26%]	16 [30%]	16 [30%]
Chances of depression/anxiety	27 [50%]	18 [33%]	9 [17%]	8 [15%]	16 [30%]	13 [24%]	17 [31%]
Recommendations from patient's doctor(s) who are managing the cancer	8 [15%]	11 [20%]	35 [65%]	5 [9%]	-	5 [9%]	44[81%]
Wife or partner preference for a particular treatment	15 [28%]	11 [20%]	28 [52%]	6 [11%]	14 [26%]	11 [20%]	23 [43%]
Close family member preference for a particular treatment	33 [61%]	6 [11%]	15 [28%]	11 [20%]	23 [43%]	8 [15%]	12 [22%]
Recommendations from someone the patient knows who was treated for prostate cancer	26 [48%]	14 [26%]	14 [26%]b	13 [24%]	18[33%]	18 [33%]	5 [9%]b

Note. Endorsements ≥ 50% highlighted.
Proportions of respondents rating item as very important significantly differs: a, p<.01; b, p< 05.

Table 9-24: EQ-5D –patients only

	Mobility	Self-care	Usual Activities	Pain/ Discomfort	Anxiety/ Depression
No problems	42 [78%]	50 [93%]	39 [72%]	36 [67%]	45 [83%]
Some problems	12 [22%]	4 [7%]	15 [28%]	-	-
Moderate problems	-	-	-	17 [31%]	8 [15%]
Severe or extreme problems	-	-	-	1 [2%]	1 [2%]

Table 9-25: EORTC-C30 as completed by patients and partners

Scale	All Midlands Patients [n=54]			Patients' Partners~ [n=54]			Reference Group: PCa Stage I-II [n=959]			Maori Patients only [n=13]		
	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range
Global health status	76.2±20.4	79.2	66.7-91.7	72.5±24.2	79.2	58.3-91.7	70.8±20.5	75	58.3-83.3	67.3±22.4	75	58.3-83.3
Functional scales												
Physical	65.8±19.3	73.3	60-80	74.4±14^	73.3	73.3-80	93±12	100	93.3-100	62.6±23.0	73.3	53.3-80
Role	82.4±25.4	100	66.7-100	87.3±14	100	83.3-100	90.6±20.3	100	83.3-100	76.9±27.7	83.3	66.7-100
Emotional	85.9±16.4*	91.7	79.2-100	88.6±21.1	91.7	75-100	78±22.8	83.3	66.7-100	84.6±16.6	91.7	83.3-100
Cognitive	83±19.1*	83.3	83.3-100	91±20.9^	100	83.3-100	86.1±19.3	100	83.3-100	80.8±13.3	83.3	83.3-83.3
Social	88.5±19.0*	100	83.3-100	87.7±25.3	100	66.7-100	83.9±25	100	66.7-100	94.4±9.6*	100	83.3-100
Symptom scales/items												
Fatigue	22.9±20.9*	22.2	0-33.3	24.2±23.4*	22.2	11.1-33.3	18.9±22.7	11.1	0-33.3	28.2±24.3	33.3	0-44.4
Nausea & vomiting	2.5±6.8	0	0-0	2.3±7.5*	0	0-0	2.4±9.1	0	0-0	2.6±6.3	0	0-0
Pain	17.9±23.8*	8.3	0-33.3	15.1±25.8*	0	0-16.7	14.6±24.5	0	0-16.7	20.5±27.3	0	0-33.3
Dyspnoea	16.7±28	0	0-33.3	13.5±22.1*	0	0-33.3	12.2±22.6	0	0-33.3	25.6±30.9	33.3	0-33.3
Insomnia	16.7±28	0	0-33.3	15.4±24.2*	0	0-33.3	20.9±28.8	0	0-33.3	20.5±32	0	0-33.3
Appetite loss	4.9±17.6	0	0-0	5.6±18	0	0-0	4.9±16.3	0	0-0	7.7±20	0	0-0
Constipation	11.1±24.2	0	0-0	8.7±17.6*	0	0-0	8.8±20.3	0	0-0	12.8±29	0	0-0
Diarrhoea	6.8±13.6	0	0-0	7.3±19.4*	0	0-0	8.5±20.2	0	0-0	5.1±12.5	0	0-0
Financial difficulties	4.2±11.4*	0	0-0	9.3±21.3*	0	0-0	8.5±21.2	0	0-0	0*	0	0-0

Note. ~Partners were given option of 'Do not know' response; only affected symptom scales (no more than 4 data points in scales affected).
^ Partners responses different to men's, p<.05.
*Missing data. Highlighted function scale means significantly differ from reference group, p<.05.

Table 9-26: EORTC-PR25 as completed by patients and partners

Symptom Scale	Midlands Men n=54			Midlands Partners n=54			Reference Men PCa van Andel et al. 2008		Midlands Maori n=13		
	Mean±SD	Median	IQR	Mean±SD	Median	IQR	N	Mean±SD	Mean±SD	Median	IQR
Urinary	16.4±11.7[a]	12.5	8.3-25.0	13±15.0^	12.5	4.2-20.8	457~	22.7±18.1[a]	23.7±11.2	25.0	16.7-29.17
Bowel	4.9±6.8	0	0-8.3	-3.9±9.5^	0	-8.3-0.0	423~	5.4±9.4	6.4±6.9	8.3	0-8.3
Hormone Treatment Related Symptoms	11.3±15.8	5.6	0-16.7	8.7±16.0	5.6	0-16.7	457~	11.9±10.7	15.4±19.4	16.7	0-16.7
Sexual Activity	22.8±15.3[b]	33.3	16.7-33.3	6.7±17.7^[b]	0	0-16.7	454~	27.8±26	79.5±25.6	100	50-100
*Sexual Function	50.3±24.9[c]	50	41.7-66.7	37.8±27.7^[c]	41.7	25-58.3	454~	53.6±25.4	45.1±25.2	45.8	25-66.7
Continence Aid -[Problems if used]	n=7[+] [13%]			n=8[#] [15%]			n=74/146 [16%]		n=6[30%] 2 Not at all; 4 A little.		

Note. ~ Measure recorded in an international sample of men at various disease stages post-treatment for PCa. ^n<54 since Do not know responses not included.
[a] Difference of means significance: p<.01. [b]Difference of means significance: p<.0001 (Partner n=42). [c]Difference of means significance: p<.05. * indicates scales answered only if sexually active.
[+]Continence Aid question answered by 33 men; 25 no trouble at all [46.3%]; 6 a little trouble [11.1%]; 1 quite a bit of trouble[1.9%]
[#] Continence Aid question answers where used by patient: 5 said no trouble, 5 [9.3%] reported 'a little trouble'; 1 [1.9%]quite a bit of trouble, 2 [3.7%]very much trouble.

Table 9-27: HADS and Stress Scales for patients and partners^

Symptom Scale	Midlands Men n=54			Midlands Partners n=54			Reference Men PCa van Andel et al. 2008		Midlands Maori n=13		
	Mean±SD	Median	IQR	Mean±SD	Median	IQR	N	Mean±SD	Mean±SD	Median	IQR
Urinary	16.4±11.7[a]	12.5	8.3-25.0	13±15.0^	12.5	4.2-20.8	457~	22.7±18.1[a]	23.7±11.2	25.0	16.7-29.17
Bowel	4.9±6.8	0	0-8.3	-3.9±9.5^	0	-8.3-0.0	423~	5.4±9.4	6.4±6.9	8.3	0-8.3
Hormone Treatment Related Symptoms	11.3±15.8	5.6	0-16.7	8.7±16.0	5.6	0-16.7	457~	11.9±10.7	15.4±19.4	16.7	0-16.7
Sexual Activity	22.8±15.3[b]	33.3	16.7-33.3	6.7±17.7^[b]	0	0-16.7	454~	27.8±26	79.5±25.6	100	50-100
*Sexual Function	50.3±24.9[c]	50	41.7-66.7	37.8±27.7^[c]	41.7	25-58.3	454~	53.6±25.4	45.1±25.2	45.8	25-66.7
Continence Aid -[Problems if used]	n=7+ [13%]			n=8# [15%]			n=74/146 [16%]		n=6[30%] 2 Not at all; 4 A little.		

Note. ~ Measure recorded in an international sample of men at various disease stages post-treatment for PCa. ^n<54 since Do not know responses not included.
[a] Difference of means significance: p<.01. [b]Difference of means significance: p<.0001 (Partner n=42). [c]Difference of means significance: p<.05. * indicates scales answered only if sexually active.
+Continence Aid question answered by 33 men; 25 no trouble at all [46.3%]; 6 a little trouble [11.1%]; 1 quite a bit of trouble[1.9%]
#Continence Aid question answers where used by patient: 5 said no trouble, 5 [9.3%] reported 'a little trouble'; 1 [1.9%]quite a bit of trouble, 2 [3.7%]very much trouble.

Table 9-28: Cases identified using HADS and Stress Scales

Scale	Midlands patients n = 54	Māori Patients n = 13	Non-Māori Patients n = 41	Māori Partners/caregivers n = 10	Non-Māori Partners/caregivers n = 44
Anxiety [11+ = case]	2 [4%]	-	2 [5%]	1 [10%]	4 [9%]
Depression [11+ = case]	1 [2%]	-	1 [2%]	1 [10%]	-
Psychological Distress	8 [14.8%]	3 [23%]	5 [12%]	3 [30%]	7 [16%]
Stress mild moderate	7 [13%] 1 [2%]	4 [25%] -	[7%] 1 [2%]	[20%] 1 [10%]	[7%] 5 [11%]

Table 9-29: Dyadic Adjustment Scale-Short Form

Group	Mean±SD	Median	Range
All Midlands Patients n = 54	29.22±5.40***a***e	28	19-41
All Partners n = 52	33.46±4.29***a***f	34	24-42
Reference~ Males Community sample [n=122] Clinic sample [n=75]	25.3±4.7**b***e***g**h 17.8±5.5**b		
Reference~ Females Community sample [n=122] Clinic sample [n=73]	26.4±4.7**c***f**i***j 17.3±5.8**c		
Māori Patients n = 13	33.46±5.53**d***g	35	21-41
Non-Māori Patients n=41	27.88±4.66**d**h	27	19-38
Māori Partners n = 10	31.9±5.67**i	32.5	24-39

Non-Māori Partners n=42	33.83±3.89***j	34	26-42

***p<.0001: **p<.01; * p<.05. a: significant differences between groups labelled with same letter.
~ Reference groups from Hunsley et al. 2001, describing couples from a newspaper recruited community sample, and a clinic sample of couples seeking marital therapy.

Table 9-30: Miller Social Intimacy Scale couples compared with reference groups

Group	Mean±SD	Median	Range
All Midlands Patients n = 54	134.8±19.1***a Intensity: 89.9±13.8**b Frequency: 44.9±7**c	140	77-162 53-110 24-60
All Partners n = 54	134±19.4***d Intensity: 90.7±13.3***e Frequency: 43.3±7.6***f	138	66-163 37-108 29-55
Reference1 Males~ n = 98 Mean age 40.3 ±10.2	108.2±23.3***a	-	35-162.5
Reference1 Females n = 104 Mean age 40 ±10.9	118.7±21.3***d	-	35-170
Reference2 Males` n = 143 Mean age 61.5±6.5	Intensity: 95.8±10.8**b Frequency: 48.5±7.6**c Full mean: 144.3	-	
Reference2 Females` n = 104 Mean age 57.3±7.3	Intensity: 98.6±9.3***e Frequency: 50.1±7.2***f Full mean: 148.7	-	
Māori Patients n = 13	130.2±25.2	142	77-161
Non-Māori Patients n=41	136.3±16.8	138	85-162
Māori Partners n = 10	131.9±18.3	136.5	94-152
Non-Māori Partners n=44	135±19.8	138	66-163

~ Reference Group1 from McCutcheon et al. 1998, US convenience sample.
`Reference Group2 from Davison et al. 2012, Canadian Radical Prostatectomy Couples.
***p<.0001; **p<.01

Table 9-31: Supportive Care Needs Survey – raw scores

Domain	All Midlands patients n=54			Maori Patients n=13			Non-Maori Patients n=41		
	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range	Mean±SD	Median	IQ Range
Psychological	16.8±7.6	14.5	10-21	20.1±6.6	21	16-23	15.8±7.6	14	10-20
Health system & information	17.1±9.0	12.6	11-22	20.3±12.4	17.3	11-22	16.1±7.6	11	11-22
Physical & daily living	11.4±5.8	8.4	7-14	13.9±6.4	14	7-21	10.6±5.5	7	7-14
Patient care & support	7.6±3.4	6	5-10	8.6±4.1	7	5-10	7.2±3.1	6	5-10
Sexuality	6.8±4.0	6	3-9	7.9±4.2	7.5	4.5-9	6.4±3.9	6	3-9
Maori versus non-Maori testing differences of means not significant on any scales.									

Table 9-32: Supportive Care Needs Survey – standardised scores for comparison with SCNS dataset for 70+ yr old CaP patients 5-9 months post-diagnosis

Domain	All Midlands patients		Reference Group~		Maori Patients		Non-Maori Patients	
	Mean±SD	N	Mean±SD	N	Mean±SD	N	Mean±SD	N
Psychological	17.0±18.9	54	16.9±18.4	245	25.2±16.6	13	14.5±19.1	41
Health system & information	14.0±20.5	54	15.3±15.4	246	21.2±28.1	13	11.7±17.3	41
Physical & daily living	16.3±8.3	54	18.3±22.3	245	19.8±9.2	13	15.2±7.8	41
Patient care & support	12.8±16.8	54	11.2±13.6	243	18.1±20.4	13	11.1±15.4	41
Sexuality	31.3±32.9***b	54	15.4±20b	245	40.4±35	13	28.4±32.1	41

Table 9-33: Supportive Care Needs Survey – standardised scores for comparison with SCNS dataset for long term CaP survivors

Domain	All Midlands patients		Reference Group~		Maori Patients		Non-Maori Patients	
	Mean±SD	N	Mean±SD	N	Mean±SD	N	Mean±SD	N
Psychological	17.0±18.9	54	13.3±18.9	126	25.2±16.6	13	14.5±19.1	41
Health system & information	14.0±20.5	54	14.1±19.2	128	21.2±28.1	13	11.7±17.3	41
Physical & daily living	16.3±8.3	54	18.2±23.7	128	19.8±9.2	13	15.2±7.8	41
Patient care & support	12.8±16.8	54	9.0±14.6	128	18.1±20.4	13	11.1±15.4	41
Sexuality	31.3±32.9	54	28.1±33.6	128	40.4±35	13	28.4±32.1	41
Note. ~Reference group: long-term CaP patients. Midlands patient group not significantly different to Reference group on any scales. Maori versus non-Maori testing differences of means for Midland groups not significant on any scales.								

Table 9-34: Supportive Care Needs Survey – Participants reporting at least 'some need' by domain

Domain	All Midlands patients n=54		Reference Group~ n=128		Maori Patients n=13		Non-Maori Patients n=41	
	N	%	N	%	N	%	N	%
Psychological	30	56**a	36	29**a	3	23	20	49
Health system & information	7	13	30	24	2	15	5	12
Physical & daily living	18	33	41	32	7	54	11	27
Patient care & support	13	24	21	17	3	23	10	24
Sexuality	22	41	50	39	7	54	15	37
Note. ~Reference group: Long-term CaP patients. Percentages rounded. 'Some need' means low, moderate or high need response to at least one item in that domain. **p<.01 compared to comparitor group as labelled.								

Table 9-35: Supportive Care Needs Survey-Partner & Caregiver – raw scores

Domain	All Midlands Partners/Caregivers n=54			Maori Partners/Caregivers n=10			Non-Maori Partners/Caregivers n=44		
	Mean±SD	Median	Range	Mean±SD	Median	Range	Mean±SD	Median	Range
Health Care Service Needs	9.1±12.4	2.5	0-45	16.4±13.7*a	13	0-45	7.4±11.6*a	2.5	0-39
Psychological & Emotional Needs	9.8±12.3	3	0-49	15.9±7.5	17	0-27	8.5±12.8	1.5	0-49
Work & Social Needs	4.9±7.2	1	0-26	8.9±8.5*b	5.5	0-26	4±6.6*b	0	0-26
Information Needs	3.8±5.9	0	0-22	6.4±7.9	4	0-22	3.2±5.3	0	0-18
* p<.05. Significant differences between means in groups labelled with same letter.									

Table 9-36: Supportive Care Needs Survey-Partner & Caregiver – Participants reporting at least 'some need' by domain

Domain	All Midlands Partners/Caregivers n=54		Reference Group~ n=175	Māori Partners/Caregivers n=10		Non-Māori Partners/Caregivers n=44	
	N	%	%	N	%	N	%
Health Care Service Needs	19	35	23.7*a	6	60*a	13	30
Psychological & Emotional Needs	20	37	29.8**b	8	80**b,**d	12	27**d
Work & Social Needs	13	24	15.3*c	4	40*c	9	20
Information Needs	14	26	20.6	3	30	11	25

'Some need' means low, moderate or high need response to at least one item in that domain.
~Reference Group from Girgis et al, 2011 – Australian Prostate Cancer partners/caregivers group.
Percentages rounded.
* p<.05; **p<.01. Significant differences in proportions for groups labelled with same letter.

Table 9-37: Miscellaneous queries re sexual activity - patients

Query	All Midlands Patients n=53		Maori Patients n=13		Non-Maori Patients n=40	
How important is SEXUAL ACTIVITY for you? [Scale 0-10]	Mean: 6.4 ± 3.2 Median: 7.0 Range: 0-10		Mean: 5.6 ± 2.8 Median: 5.0 Range: 0-10		Mean: 6.7 ± 3.3 Median: 8.0 Range: 0-10	
	YES	NO	YES	NO	YES	NO
Have you been asked about your sexual function by any of your medical specialists?	37 [70%]	16 [30%]	11 [85%]	2 [15%]	26 [65%]	14 [35%]
Do you think you have had good advice on options for you and your sexual activity?	39 [74%]	14 [26%]	10 [77%]	3 [23%]	29 [73%]	11 [28%]
Have you experienced any changes in your sexual experience since this cancer?	44 [83%]	9 [17%]	12 [92%]	1 [8%]	32 [80%]	8 [20%]
Do you communicate with your partner about sexual activity?	46 [87%]	7 [13%]	10 [77%]	3 [23%]	36 [90%]	4 [10%]
Have you noticed any change in your partner's sexual experience since your prostate cancer diagnosis?	29 [55%]	24 [45%]	8 [62%]	5 [38%]	21 [53%]	19 [48%]
Do you use Viagra, Evigra, Levitra, Silvasta, Cialis or similar medications?	14 [26%]	40 [74%]	1 [8%]	12 [92%]	13 [32%]	28 [68%]
If no medications, do you use any of the following:						
Vacuum pump	1 [2%]	53 [98%]	1 [8%]	12 [92%]	-	41 [100%]
Penile ring	2 [4%]	52 [96%]	1 [8%]	12 [92%]	1	40 [98%]
Penile injections	4 [7%]	50 [93%]	1 [8%]	12 [92%]	3	38 [93%]
Other erectile devices	-	-	-	-		

Table 9-38: Sexual Health Inventory for Men [SHIM] or International Index of Erectile Function-Short Form [IIEF-SF]

Scale	All Midlands Patients			Maori Patients			Non-Maori Patients		
	Mean±SD	Median	Range	Mean±SD	Median	Range	Mean±SD	Median	Range
Confidence Max:5 *n=54; #n=13; n=41.	1.76±1.18*	1.0	1-5	1.31±0.75#	1.0	1-3	1.90±1.26~	1.0	1-5
Hardness Max:5 *n=19; #n=2; ~n=17.	3.58±1.54*	4.0	1-5	2.5±2.12#	2.5	1-4	3.71±1.49~	4.0	1-5
Penetration Max:5 *n=19; #n=2; ~n=17.	3.63±1.57*	4.0	1-5	3.0±2.83#	3.0	1-5	3.71±1.49~	4.0	1-5
Difficulty Max:5 *n=19; #n=2; ~n=17.	3.53±1.47*	4.0	1-5	1.0±0#**a	1.0	1-1	3.82±1.24~**a	4.0	1-5
Satisfaction Max:5 *n=19; #n=2; ~n=17.	3.58±1.61*	4.0	1-5	1.5±0.71#	1.5	1-2	3.82±1.51~	4.0	1-5
IIEF-5 total Max:25 *n=54; #n=13; n=41.	6.80±8.82*	1.0	1-25	2.54±4.10#*b	1.0	1-15	8.51±9.51~*b	1.0	1-25

*p<.05; **p<.01. Significant differences in means for groups labelled with same letter.

Table 9-39: Miscellaneous queries re sexual activity – partners.

Query	All Partners n=53		Maori Partners n=10		Non-Maori Partners n=42	
	YES	NO	YES	NO	YES	NO
Are you happy to answer questions about sexual activity?	39 [72%]	13 [24%]	5 [50%]	5 [50%]	34 [77%]	8 [18%]
Menstrual status Post menopausal (no period >1 year) Surgical menopause/hysterectomy	48 [89%] 5 [9%]		10 [100%]		38 [86%] 5 [11%]	
Do you use Hormone Replacement Therapy, or Estrogen Cream?	4 [7%]	49 [91%]	1 [10%]	9 [90%]	3 [7%]	40 [91%]

Responses >50% highlighted. Percentages rounded.

Table 9-40: Female Sexual Function Inventory-Short Form

	All Responding Partners n=44			Māori Partners n=8			Non-Māori Partners n=36		
	Mean±SD	Median	Range	Mean±SD	Median	Range	Mean±SD	Median	Range
Sexual desire	2.52±0.79	3	1-4	2.25±0.71	2	1-3	2.58±0.81	3	1-4
Arousal	2.47±1.41	3	0-5	2.25±1.39	3	0-4	2.53±1.42	3	0-5
Lubrication	2.47±1.86	2	0-5	2.38±1.85	2	0-5	2.5±1.89	2	0-5
Orgasm	2.84±2.02	4	0-5	2.38±2.07	2.5	0-5	2.94±2.03	4	0-5
Satisfaction	3.65±1.34	4	1-5	3.38±1.51	4	1-5	3.71±1.32	4	1-5
Pain on Penetration	3.3±2.23	5	0-5	2.75±2.31	4	0-5	3.43±2.23	5	0-5
FSFI-SF Total	17.11±7.79	20	1-28	15.38±7.41	17.5	4-23	17.5±7.92	20	1-28

Māori versus non-Māori testing differences of means not significant on any scales.

Table 9-41: Correlations between male and female sexual function scales

Scale	IIEF-SF 1 Confidence	IIEF-SF 2 Hardness	IIEF-SF 3 Penetration	IIEF-SF 4 Difficulty	IIEF-SF 5 Satisfaction	IIEF-SF Total

Sexual desire or interest	.3140, ns*	.0578, ns	.0715, ns	.1103, ns	.0544, ns	.1138, ns
Arousal	.7537, p=.001	.4595, ns	.5167, p=.04	.2794, ns	.3287, ns	.4854, ns
Lubrication	.4962, ns	-.1742, ns	-.2134, ns	.2517, ns	.0547, ns	.0487, ns
Orgasm	.5120, p=.043	.0925, ns	.1224, ns	.2035, ns	.1151, ns	.1988, ns
Satisfaction	.6047, p=.013	.3097, ns	.3443, ns	.2212, ns	.2085, ns	.3440, ns
Pain on penetration	.4153, ns	.6812, p=.004	.6860, p=.003	.4964, ns	.6680, p=.005	.6680, p=.005
FSFI-total	.7200, p=.002	.3329, ns	.3502, ns	.3912, ns	.3593, ns	.4446, ns
* P values shown only where correlations were statistically significant.						

Publication list

Reference/Proposed Title	Status
Phases one and two	
Obertová Z, Scott N, Brown C, Hodgson F, Stewart A, Holmes M, Lawrenson R. Prostate-specific antigen (PSA) testing in Māori and non-Māori men in New Zealand. (submitted)	Submitted
Obertová Z, Hodgson F, Scott-Jones J, Brown C, Lawrenson R. Rural-urban differences in prostate-specific antigen (PSA) testing and its outcomes in New Zealand. *Rural and Remote Health* (submitted)	Submitted
Lawrenson R, Obertová Z, Hodgson F, Scott N, Brown C. 2013. Screening for prostate cancer in rural men in New Zealand. Abstract. *BJUI Suppl*. 112 (1): 14.	Published
Obertová Z, Hodgson F, Holmes M, Brown C, Lawrenson R. Characteristics of men diagnosed with prostate cancer in New Zealand general practice. Abstract. The New Zealand Medical Journal, 18 October 2013, 126 (1384).	Published
Do prostate-specific antigen (PSA) screening rates depend on general practice characteristics	Being drafted
Brown C, Hodgson F, Lawrenson R, Obertová Z, Scott N, Holmes M. The patient perspective on a first raised PSA test.	Drafted
Obertova, Z., Brown, C., Holmes, M., and Lawrenson, R. (2012) Prostate cancer incidence and mortality in rural men – a systematic review of the literature. Rural and Remote Health 12:2039.	Published
Hodgson, F., Obertova, Z., Brown, C., and Lawrenson, R. PSA testing in general practice. Journal of Primary Health Care. 2012; 4(3): 199–204.	Published
Obertová Z, Hodgson F, Scott N, Brown C, Lawrenson R. Prostate-specific antigen (PSA) testing in Waikato general practices. Abstract. Journal of the New Zealand Medical Association, 30 March 2012, 125 (1352).	Published
Obertová Z, Lawrenson R, Hodgson F, Brown C, Stewart, Tyrie L, Holmes M, Gilling P. 2013. Screening for prostate cancer in New Zealand general practice. Journal of Medical Screening 20: 49-51.	Published
Brown, C., Lawrenson, R., Obertova, Z., Hodgson, F. (2012) Prostate Specific Antigen Testing in Primary Care. 6th Annual Lakes DHB Health Research Seminar: Rotorua, New Zealand.	Presented
Lawrenson R, Obertová Z, Hodgson F, Brown C. Management of prostate cancer in New Zealand General Practice. Royal College of GPs Conference: London (October 2013)	Presented
Obertová Z, Brown C, Hodgson F, Lawrenson R. What do men say about diagnostic pathways? From prostate-specific antigen (PSA) test to prostate cancer. 14th Australasian Prostate Cancer Conference in Melbourne (6-10 August 2013; poster presentation).	Presented
Obertová Z, Brown C, Hodgson F, Lawrenson R. 2013. What do men say about diagnostic pathways? From prostate-specific antigen (PSA) test to prostate cancer. Abstract. *BJUI Suppl*. 112 (1): 14.	Published
Lawrenson R, Obertová Z, Hodgson F, Scott N, Brown C. Screening for prostate cancer in rural men in New Zealand. 14th Australasian Prostate Cancer Conference in Melbourne (6-10 August 2013; poster presentation).	Presented
Lawrenson R, Obertová Z, Hodgson F, Scott N, Brown C. Screening for prostate cancer in rural men in New Zealand. Abstract. BJU Suppl. 112(1).	Published
Lawrenson R, Obertová Z, Hodgson F, Brown C. Utilisation of electronic general practice records in the Midlands Prostate Cancer Study. Oral presentation at AEA Workshop Measuring the Burden of Disease, 30 Nov 2012, University of Otago, Dunedin.	Presented
Lawrenson R, Obertová Z, Brown C, Scott N. Ethnic differences in screening rates with prostate-specific antigen (PSA) test in New Zealand general practice. 13th Australasian	Presented

Prostate Cancer Conference in Melbourne (1-3 August 2012; poster presentation)	
Lawrenson, R., Brown, C., Obertová, Z., Hodgson F. Midlands Prostate Cancer Study. Royal NZ College of GPs Conference: Through the patients eyes: Auckland, New Zealand.21-23 September 2012	Presented
Lao C, Brown C, Obertová Z, Edlin R, Rouse P, Hodgson F, Holmes M, Gilling P, Lawrenson R. Economic evaluation of prostate cancer screening: a systematic review. NZMJ, 5 April 2013, 126, 1372.	Published
Lao C, Brown C, Obertová Z, Edlin R, Rouse P, Hodgson F, Holmes M, Gilling P, Lawrenson R. The costs of identifying undiagnosed prostate cancer in asymptomatic men in NZ general practice. Waikato Biannual Research Seminar (14th March 2013).	Presented
Lao C, Brown C, Obertová Z, Edlin R, Rouse P, Hodgson F, Holmes M, Gilling P, Lawrenson R. The costs of identifying undiagnosed prostate cancer in asymptomatic men in New Zealand general practice. RNZCGP conference (July 11-13 2013; oral presentation)	Presented
Lao C, Brown C, Obertová Z, Edlin R, Rouse P, Hodgson F, Holmes M, Gilling P, Lawrenson R. 2013. The costs of identifying undiagnosed prostate cancer in asymptomatic men in New Zealand general practice. *BMC Family Practice* Sept 21	Published
Economic evaluation of prostate cancer screening: a systematic review	Being drafted
Survival disparities between Māori and non-Māori men with prostate cancer in New Zealand	Being drafted
Obertova, Z., Scott, N., Brown, C., and Lawrenson R. (2012) Disparities in survival rates between Māori and non-Māori men with prostate cancer in New Zealand. Abstract for Population Health Congress: Adelaide, Australia.	Presented
Scott, N., Obertova, Z., Hodgson, F., Brown, C., and Lawrenson R. (2012) Prostate-Specific Antigen (PSA) testing in New Zealand: Inequities for Māori vs. non-Māori men. Abstract for Population Health Congress: Adelaide, Australia.	Presented
Obertová Z, Scott N, Brown C, Stewart A, Lawrenson R. Survival disparities between Māori and non-Māori men with non-localised prostate cancer in New Zealand. 14th Australasian Prostate Cancer Conference in Melbourne (6-10 August 2013; poster presentation). Abstract to be published in BJU International.	Presented
Obertová Z, Scott N, Brown C, Stewart A, Lawrenson R. 2013. Survival disparities between Māori and non-Māori men with non-localised prostate cancer in New Zealand. Abstract. BJUI Suppl. 112 (1): 14.	Published
Obertová Z, Brown C, Scott N, Lawrenson R. The pathway from prostate-specific antigen (PSA) test to prostate cancer in Māori and non-Māori men in New Zealand. 13th Australasian Prostate Cancer Conference in Melbourne (1-3 August 2012; poster presentation)	Presented
Obertová Z, Brown C, Scott N, Lawrenson R. The pathway from prostate-specific antigen (PSA) test to prostate cancer in Māori and non-Māori men in New Zealand. 13th Australasian Prostate Cancer Conference in Melbourne (1-3 August 2012; poster presentation)	Presented
Brown C, Obertova Z, Lao C, Hodgson F, Scott N, Lawrenson R. Differences in the prostate cancer care pathway between Māori and non-Māori men in New Zealand. 7th Annual Lakes DHB Health Seminar (18th November 2013)	Presented
Ten questions you should ask your GP about PSA testing for Prostate Cancer. Prostate Cancer foundation seminar in Auckland, New Zealand. (28th July 2013).	Presented
Phase three	
Characteristics of men treated with radiotherapy compared with those not treated with radiotherapy	
Outcomes for men treated with radiotherapy by patient characteristics (survival)	
A comparison of treatment options for Māori and non- Māori men	Being drafted

Obertová Z, Lawrenson R, Lao C, Brown C, Scott N, Holmes M. Ethnic differences in the management of prostate cancer in New Zealand.	Abstract submitted
Characteristics of men treated (not with radiotherapy)	
The costs of testing overall	
The costs of complications from testing	
An overall cost modelling paper using the tree structure	
High level conceptual model based on the tree structure but with a Markov process plus some illustrative cost data applications	
White, J., Lao, C., Brown, C., Alwis, C., Holmes, M., Gilling, P., Tyrie, L., Lawrenson, R. 2013. Management pattern for gleason score 6 prostate cancer in the Midland Cancer Network region. USANZ Conference (6-8 November: poster presentation).	Presented
Phase four	
Conaglen H, Brown C, Conaglen, J, Lawrenson R. Depression, anxiety and stress in men with prostate cancer: Is all well? International. 14th Australasian Prostate Cancer Conference in Melbourne (6-10 August 2013; poster presentation). Abstract published in BJU International.	Presented
Social and psychological: Māori vs non-Māori	
Sexuality and prostate cancer	
Conaglen H, Brown C, Conaglen, J, Lawrenson R. The psychosocial impact of prostate cancer on couples. 14th Australasian Prostate Cancer Conference in Melbourne (6-10 August 2013; poster presentation). Abstract to be published in BJU International.	Presented
Treatment pathways and complications	
Couples	
QoL in Men with PCA	
Methods for oversampling	
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REPORTS	
GP Report	Drafted: being reviewed by GPs
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- Waikato District Health Board
- Lakes District Health Board
- Bay of Plenty District Health Board
- Waikato, Bay of Plenty and Lakes DHB General Managers Māori
- Waikato District Health Board Iwi Māori Council
- Waikato District Health Board Kaumatua Kaunihera
- Te Puna Oranga and Midland Cancer Network Maori cancer advisory group: Hei Pa Harakeke
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- Patients and their partners
- Venturo
- Waikato Urology
- Promed Urology
- Pathlab
- Southern Community Laboratories
- Healthscope NZ
- NZ Institute of Rural Health
- NZ Prostate Cancer Foundation
- Waikato Cancer Society
- Our advisory groups
- Gillian Hunn, Raewyn Wooderson and other staff from the Waikato Clinical School