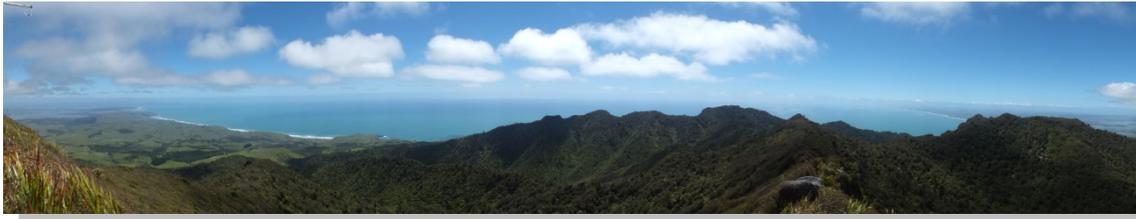


# THE MIDLANDS PROSTATE CANCER STUDY



**LIVING WITH PROSTATE CANCER:  
FINAL REPORT FOR PATIENT & PARTNER**



## EXECUTIVE SUMMARY

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Prostate cancer is the most commonly registered cancer in New Zealand with approximately 3000 registrations every year. The majority of men will be diagnosed with localised prostate cancer and will be successfully treated. However, previous research has identified that there are issues in the cancer journey including; access to culturally safe and appropriate health information and care, variation in care, communication, advice and follow-up provided and in some cases symptoms and reduced quality of life from treatment.

Partners too have been identified as being pivotal in the prostate cancer journey and are impacted by the disease.

The aim of this phase of the project was to estimate the cost and complications of treatment, including the psychosocial impact on men and their partners.

Men were identified from the New Zealand Cancer Registry (NZCR). They were approached by their specialist and/or specialist nurse to be part of the study. For those men who were successfully recruited an interviewer-assisted questionnaire was undertaken on an iPad using PollDaddy software. 106 men and 55 partners and caregivers were interviewed.

An optional questionnaire was completed with any willing partner or caregiver if they wished to participate in the project. The questionnaire included validated and widely used scales (e.g., ED-5D, EORTC-C30, PR25, SCNS, IIEF-SF). Analyses was undertaken. Scored questionnaires were compared with reference groups.

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”.

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.



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# 1. INTRODUCTION

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## 1.1 BACKGROUND OF STUDY

During 2010 the Health Research Council (HRC) released a request for proposals (RFP) looking at the costs and complication of screening for prostate cancer. This included an intention to consider consequences for individuals diagnosed with prostate cancer, risk of complications and effect on quality of life.

Overall the RFP described insight into the spectrum of care for men, including, the types of care received by men and the equity issues, costs and complications arising from this care. The costs were not to be limited to financial, but they were interested in learning more about the social, economic, psychological and physical costs.

The University of Auckland, in partnership with the Midlands Cancer Network (MCN) responded to and won this bid, combining four studies into one cohesive project looking at the spectrum of care on the prostate cancer journey. These included:

1. PSA testing in general practice;
2. National trends in incidence and survival;
3. The management of men with prostate cancer; and
4. The costs and complications of living with prostate cancer.

This report covers the final phase of the project. The full report can be

downloaded:<http://www.fmhs.auckland.ac.nz/en/som/about/clinical-schools/waikato/research/cancer.html>.

The aim of this phase of the project 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 questionnaires (validated measures) to assess key outcomes including general health and quality of life<sup>1</sup>, prostate-specific quality of life<sup>2</sup>, anxiety, depression<sup>3</sup>, and stress<sup>4</sup>.

## 1.2 PATIENT PERSPECTIVE

Prostate cancer is the most commonly registered cancer in New Zealand with approximately 3000 registrations every year. The

majority of men will be diagnosed with localised prostate cancer and will be successfully treated. Many of these men with localised prostate cancer will have been identified after being screened by their general practitioner (GP). A national screening programme has not been recommended because of the concerns about the extent of complications caused by treatment and the belief that there are many men who are “over-diagnosed”, i.e., while they have cancer the cancer would not have caused them harm in the long-term. In recent years much research has been undertaken to understand the harms and benefits of screening for prostate cancer. Our research to date has shown that the current pathway for diagnosis and treatment varies considerably from practice to practice<sup>5</sup>.

An understanding of the patient experience of prostate cancer adds considerably to researcher and clinician understanding across the cancer care pathway. The patient perspective can provide insight into access to diagnosis and treatment; availability of information and advice; access to health care and support services; real and perceived barriers along the pathway; impact on themselves and their partners; and quality of life following treatment. Patients are also able to provide information about the in-direct costs of prostate cancer.

Previous research has highlighted issues in the cancer pathway including; access to culturally safe and appropriate health information and care<sup>6</sup>, variation in care, information, advice and follow-up provided and in some cases symptoms and reduced quality of life from treatment<sup>7</sup>. Partners too have been identified as being pivotal in the prostate cancer journey and are impacted by the disease<sup>8</sup>. However, the support structures, needs and impact of living with prostate cancer were previously not been quantified before in a population-based sample of New Zealand men and their partners.

### **1.3 STRUCTURE OF THE MIDLANDS PROSTATE CANCER STUDY**

The project partners were the University of Auckland and the Midlands Cancer Network. 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 researchers dealing day to day with the issues of men with prostate cancer. This group included a general practitioner, urologists, medical and radiation oncologists and expert nurses, as well as university based researchers.

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 and local self-help groups. This group provided a consumer and community perspective to the Midlands Prostate Cancer research project and met on a regular basis to discuss the implications of the findings.

Hei Pa Harakeke was the Māori advisory group. This group was formed by the Midland Cancer Network and Te Puna Oranga (Waikato DHB) to advise on all aspects of care for Māori with cancer – including prostate cancer.

The study team engaged with a wide group of stakeholders. Two of the investigators (Professor Ross Lawrenson and Dr Nina Scott) participated in the Ministry of Health Prostate Cancer taskforce. We 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. We will continue to disseminate findings and information to the wider community to help inform men and their families about prostate cancer.



## **2. METHOD**

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### **2.1 PATIENT AND PARTNER RECRUITMENT**

Within an earlier study for this project we had identified 600 men aged between 40 and 85 years of age diagnosed during 2007-2010 in the Midland Cancer Network region. We randomly selected 200 of these men and mailed out invitations to participate in the study. Access to patients was through the specialist identified from the patient's clinical notes and with the assistance of the Midland region Specialist Urology Nurse.

### **2.2 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 a 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:	<i>DOB, ethnicity, partner details, income, medications</i>
Reasons For PSA/PCA investigation:	<i>Has he had symptoms (urinary, ED), elevated PSA, abnormal DRE? Has he had previously raised PSA?</i>
EORTC QLQ-C30: General Health & Quality Of Life	<i>Quality of life with cancer (past week)</i>
EORTC PR25: Prostate Specific Quality Of Life:	<i>Urinary dysfunction (past week). Bowel dysfunction (past week). Weight, masculinity, sexual activity (past 4 weeks)</i>
Factors Influencing Patient Treatment Choice:	<i>What was important in the decision making process? Understanding of treatment options, Doctors recommendation, Medical insurance, Wait time to see specialist</i>
Anxiety, Depression And Stress	<i>Hospital Anxiety &amp; Depression Scale plus Stress scale from DASS (past week)</i>
Dyadic Adjustment Scale	<i>Philosophy of life, aims, time; Relationship happiness(now)</i>
Miller Social Intimacy Scale	<i>Social intimacy of individual in significant relationships(now)</i>
Supportive Care Needs	<i>Level of help needed; (past month)</i>
EQ-5D	<i>Current health state (now)</i>
IIEF-SF & FSFI-SF	<i>Sexuality queries and sexual function scales</i>

## 2.3 RECRUITMENT

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 approximately 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.

In total, 329 invitations were mailed out to eligible New Zealand European men in the Midland region, 36 of which were sent back unopened.

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

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
<b>Stage 1 recruitment</b>	n/a	<b>11 interviewed</b>
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
<b>Stage 2 recruitment</b>	n/a	<b>9 interviewed</b>
<b>TOTAL</b>	n/a	<b>20 interviewed</b>

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

## 2.4 ANALYSIS

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).

Please refer to glossary for clarification of terms.

## 2.5 ETHICAL APPROVAL

Ethical approval for MPC was gained through Northern Y: NTY/10/09/070 (pilot) and NTY/11/02/019.

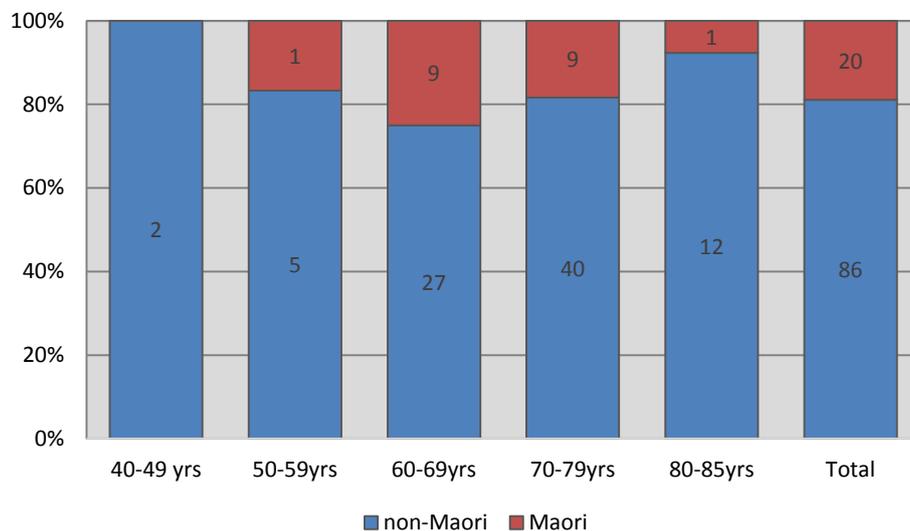
## 3 SECTION 1: PATIENT RESULTS

### 3.1 PATIENT CHARACTERISTICS

#### 3.1.1 Age/Ethnicity/Region

In total we interviewed 106 men. The majority of men surveyed (73.6%) were aged 50-70 years. This included 86 NZ European men (classified as non-Maori within the report) and 20 Maori men. We had a spread across the district health board (DHB) regions with 63 men (59%) from Waikato, 14 men (13%) from Lakes and 29 men (27%) from Bay of Plenty.

Figure 3-1: Age and ethnicity of male participants



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, 54 of whom were able to be recruited and interviewed, 52 partners and 2 caregivers. Partner results are discussed in Section 2 of this report.

#### 3.1.2 Education status

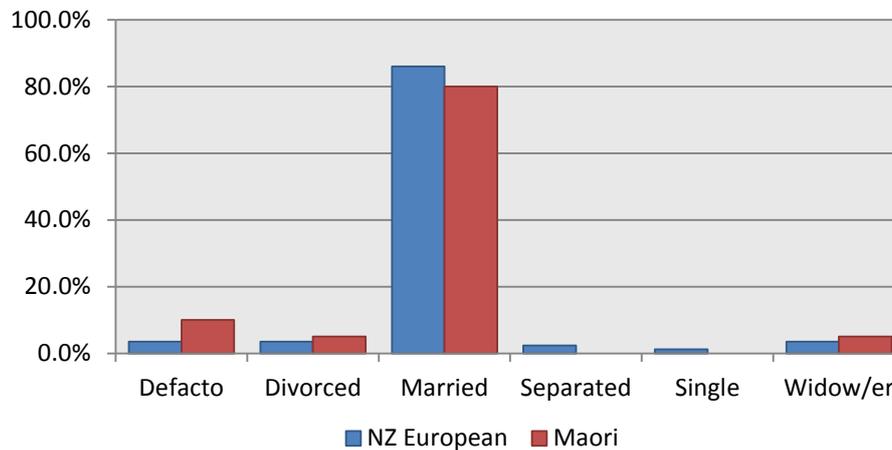
Nearly half (48%) of the men had no qualification beyond high school. Twenty-four percent of men had a trade qualification and 28% held a professional qualification, diploma or degree.

#### 3.1.3 Relationship status

Ninety five men (89.6%) were in either a marriage (84.9%) or defacto relationship (4.7%) at the time of the interview. Approximately 10% of men identified as being divorced, separated, single or widowed.

For those men who did have partners they provided some basic information about their spouse. The majority of partners (60%) were aged between 50-70 years. Four percent were less than 50 years old, while 36% were over 70 at the time of the interview.

Figure 3-2: Relationship status of participants



### 3.2 ECONOMIC FACTORS

#### 3.2.1 Individual and household income details

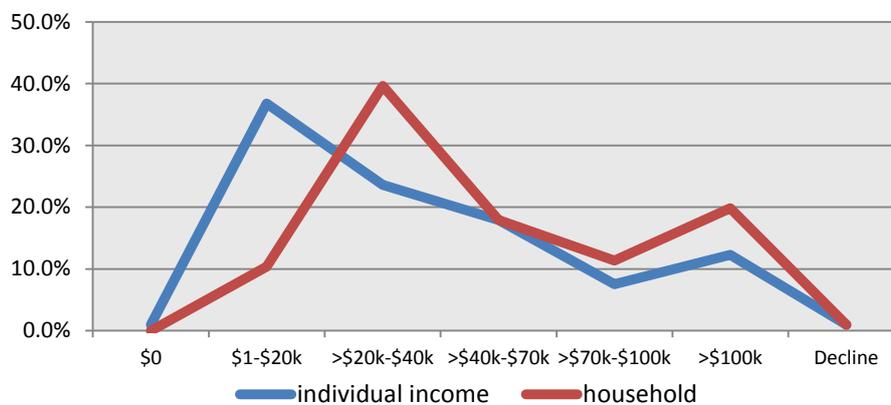


Figure 3-3: Individual and household income

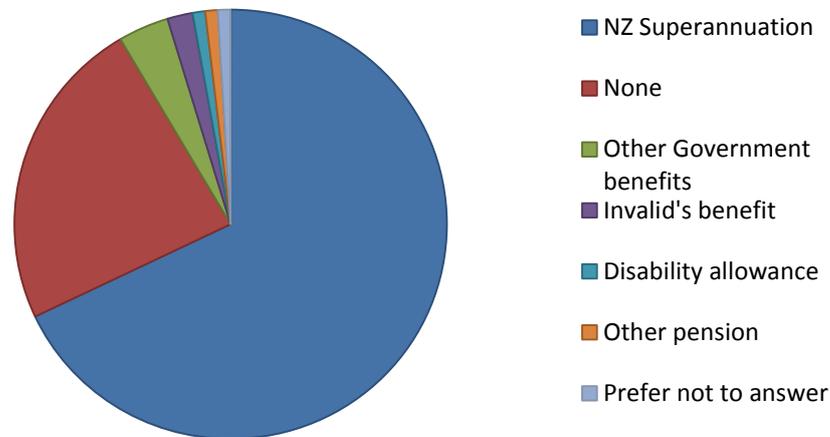
Men were predominantly retired at the time of the interview (62%); with 44% of men either in part or full-time employment. Half of the households in our cohort were receiving between \$35,000 and \$40,000 per annum. The average annual household income in New Zealand in June 2012 was ~\$81,000<sup>10</sup> therefore many of the families in our cohort were living on half the national average income.

#### 3.2.2 Type of Government support

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.

Figure 3-4: Government income support

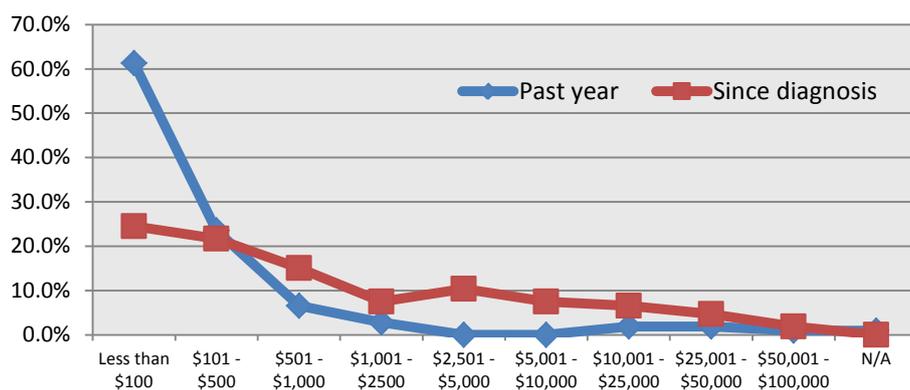


### 3.2.3 Patient costs for Prostate Cancer

Patients identified costs that they had paid because of prostate cancer over two time periods, the first was in the past 12 months and the second was since diagnosis.

Because of the length of time since diagnosis, many men did not have on-going costs in the prior 12 months; rather the greatest burden of expense fell in the earlier stages of diagnosis when there was high demand for specialist consultations, costs of treatment and other related products.

Figure 3-5: Patient treatment costs for prostate cancer



### 3.3 HOW DID YOU FIND OUT ABOUT YOUR ORIGINAL DIAGNOSIS?

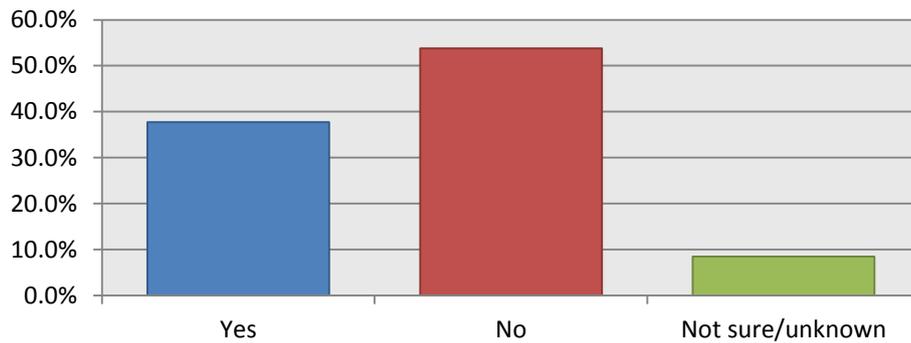
To understand more about the pathway men took to discovering their diagnosis we asked about the initial process with their general practitioner (GP). This provided some insight into how men were

diagnosed, if they had received a prostate-specific antigen test (PSA), who started them on this journey and what happened prior to finding out that they had prostate cancer.

### 3.3.1 Was this the first time you had a PSA test (at diagnosis)?

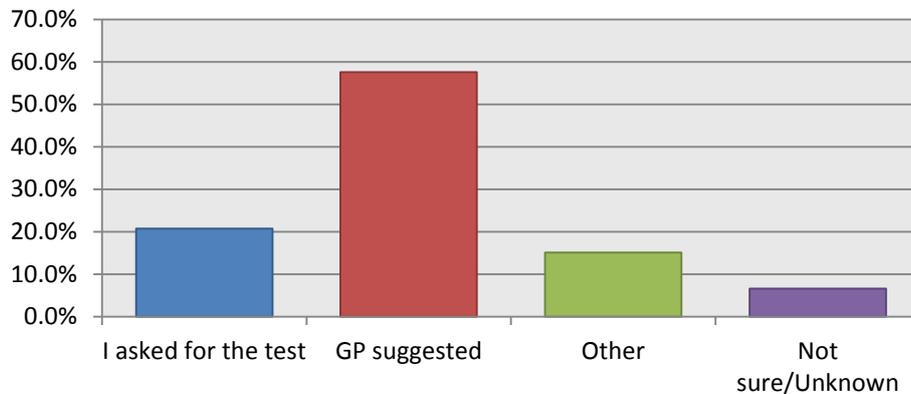
Over half of the men (53.8%) interviewed knew they had been previously PSA tested by their GP. Nearly 38% of men identified that had not been tested before, and around 8% of men did not know if they had a testing history.

Figure 3-6: PSA testing history



### 3.3.2 Did you ask for the test or was it suggested by your GP?

Figure 3-7: PSA test initiation



Most men (57.5%) felt that their GP had suggested the PSA test directly prior to their referral to see a specialist. Around 15% of men stated that there were ‘other’ reasons for getting that test, most of these men identified that they had symptoms at the time and the test was necessitated due to these. Approximately 21% of men felt they had initiated the test themselves.

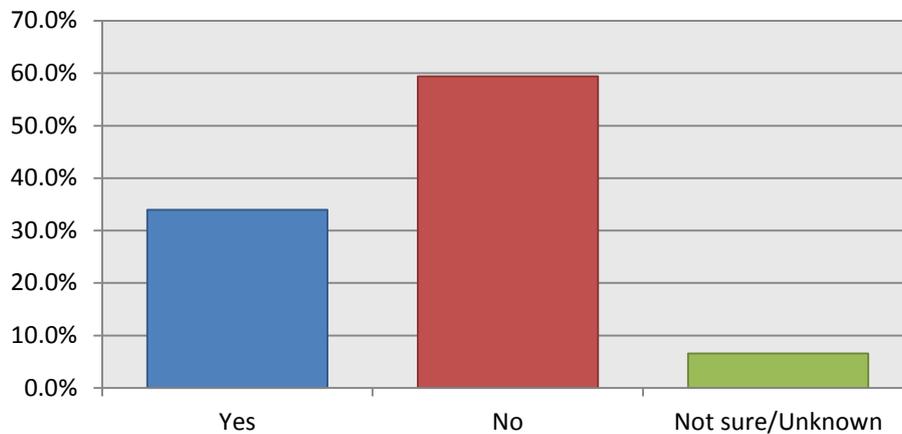
### 3.3.3 Did you have symptoms at the time of your test?

Symptoms identified by men primarily focused on those that were urinary related, also known as ‘LUTS’. Lower urinary tract symptoms (LUTS) include: dysuria, nocturia, frequency, urgency, not emptying

bladder completely, incontinence, weak urine flow, hesitancy and haematuria. Any one of these may be a reason for further investigation, or may necessitate monitoring to assess any change. However, it is very difficult to know if symptoms in a man are related to an aggravated prostate and possibly associated to prostate cancer or one of a number of other unrelated urinary issues.

Thirty four percent of men were symptomatic at the time of the test, and the majority of these men (56%) were the same men who had a previous testing history. Nearly 60% of men were asymptomatic, (had no symptoms) at the time they were tested, while 6.6% could not be sure if they had symptoms at that time. Overall, frequency, flow problems, and nocturia were the symptoms most often identified.

Figure 3-8: Symptoms at time of PSA test



### 3.4 WHAT WAS IMPORTANT IN DECIDING ON YOUR TREATMENT?

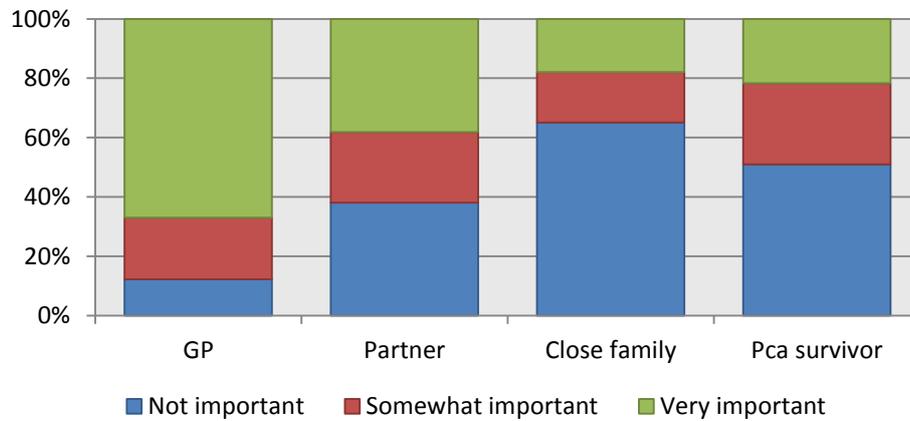
#### 3.4.1 Factors influencing men’s choice of treatment

During the interview men anecdotally identified that “...getting rid of the cancer...” was the factor that was most important at the time of selecting the treatment. When asked to decide if there were any other factors that were important the majority of men (67%) considered that the ‘doctor’s recommendation’ was very important. This was less than a US based study<sup>9</sup> which found that 90% of men rated the ‘doctor’s recommendation’ as ‘very important’. 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

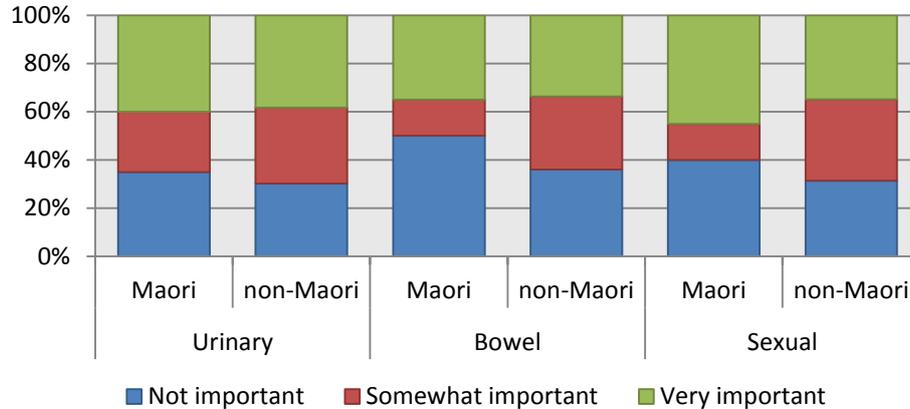
treatment' (41%), 'chances of urinary problems' (38%) and 'wife or partner preference for treatment type' (37%).

Figure 3-9: Person most impacting choice of treatment



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.

Figure 3-10: Physical function importance related to treatment choice



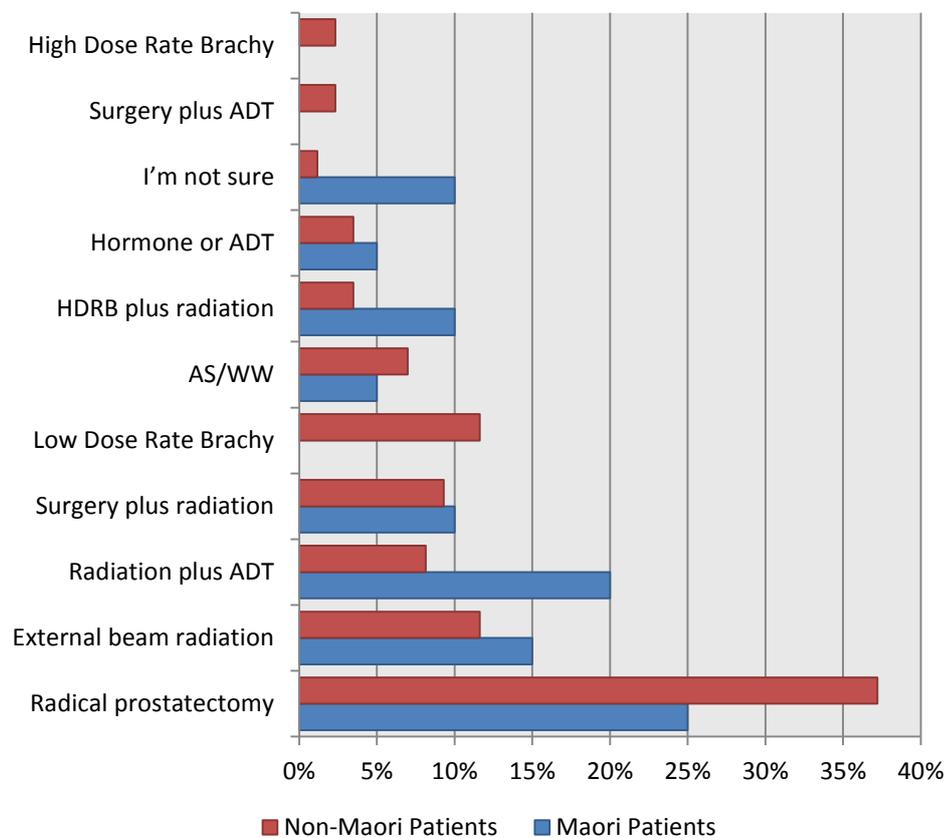
In US men who were contemplating surgery, the 'chance of sexual problems' was rated as 'very important' by fewer men than those contemplating other types of treatment<sup>9</sup>. Our study showed that 34% of men who had surgery rated 'chance of sexual problems' as 'very important' at the time they were deciding what type of treatment to have, compared with 39% of those who had other treatment types. Men described this by acknowledging that in many cases they were just not aware of the chance of sexual problems occurring at the time of treatment choice.

Things that men felt were ‘not important’ 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%).

### 3.4.2 Patient self-report treatment

Men were asked what type of treatment they had been recommended/ had undergone. All but four men recalled some form of treatment.

Figure 3-11: Proportion of self-reported treatment type by ethnicity



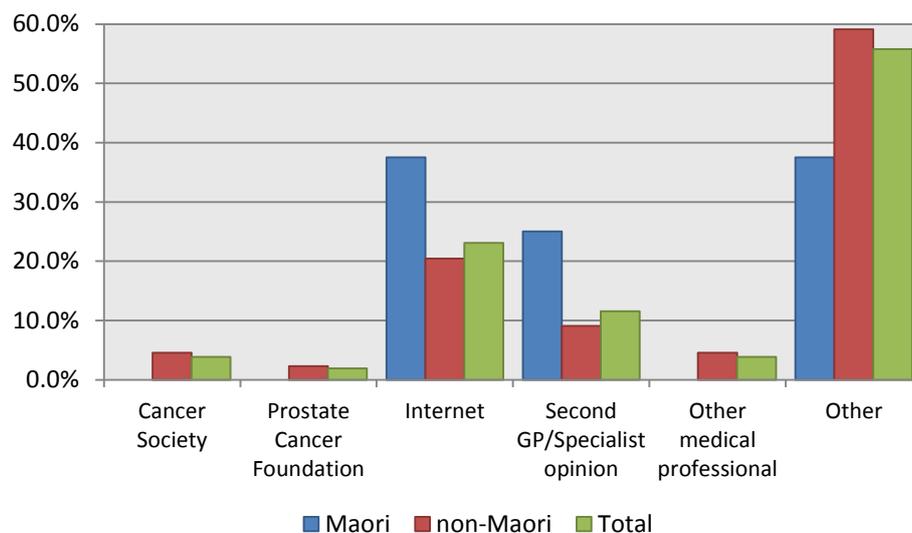
Twenty-five percent of Māori men had surgery, compared with 37% non-Māori men. Māori men were more likely to have had external beam radiotherapy (EBRT) with or without androgen-deprivation therapy (ADT) (35% vs. 20% of non-Māori). Twelve percent of non-Māori men had low-dose brachytherapy (LDR) and 2% had high-dose brachytherapy (HDR). Ten percent of Māori men were not sure about their type of treatment.

The outcomes from treatment did not seem to vary across treatment types, so regardless of what treatment a man had gone with, within

our study men were in a similar position regardless if they had surgery or other treatment options.

### 3.4.3 Treatment choice and information

The vast majority of men (73%) thought they had treatment options from which to make a choice. 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%).



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.

### 3.4.4 Public vs. Private

When men went to hospital 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 is reflective of 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 age-based increasing premiums. Twenty percent of Māori and 42% non-Māori had medical insurance.

## **3.5 WHAT IS YOUR CURRENT HEALTH AND QUALITY OF LIFE LIKE?**

### **3.5.1 Overall physical and mental health**

The majority of men reported no problems with mobility (75%), self-care (93%), usual activities (69%), pain/discomfort (65%) or anxiety/depression (79%), meaning that most men had returned to some level of “normality”. 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. Examining these groups by age, we found that the pain/discomfort increased with age; 28% of the youngest group (<70 years), 38% by 70-80 year olds, and 63% by those aged >80 years.

Anxiety/depression problems were reported by 35% of the Māori men and 17% of the non-Māori men. 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 identify whether the pain/discomfort and anxiety/depression were specifically related to prostate cancer, prostate cancer treatments and/or comorbidities.

### **3.5.2 Anxiety, depression and stress**

If we compare the level of anxiety that men in our study said they had to international studies on men with prostate cancer (refer final report), we see that men in our study have significantly lower levels of anxiety. Māori men were more likely than non-Maori men to have higher levels of anxiety and depression, but the majority of the men were in the ‘normal’ range. Seven non-Maori men were found to have higher than ‘normal’ levels of anxiety and depression.

Ten men in our study 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. These stress levels are similar to Australian men answering the same questionnaire<sup>11</sup>.

### **3.5.3 Quality of life**

The quality of life section used in the questionnaire is utilised across all types of cancer patients<sup>1</sup> and supplemented by some prostate specific questions<sup>2</sup> (PR25) to describe the aspects of prostate cancer that can be problematic. To understand these results better we have compared our findings with another study of men (which is called the

‘reference group’) who had recently been diagnosed with localised prostate cancer (pre-treatment)<sup>21</sup>.

The overall health scores of the men in our study were significantly better than those for the in other studies of men with early stage prostate cancer pre-treatment. When we compared physical and role function between the groups, we found that men in our study scored significantly lower than the men recently diagnosed with localised prostate cancer. When we looked at health and function by the type of treatment that men had (either surgery or non-surgery treatment) we found that men who were treated by surgical methods had slightly lesser levels of physical function. There was a significantly better level of urinary function across the men in our study when compared with other comparison groups.

#### **3.5.4 Sexual function issues**

Overall, 61% of 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 medications to assist with erectile dysfunction (ED), nor other devices recommended for penile rehabilitation such as injections to aid erectile function (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.

### **3.6 DO YOU HAVE ANY HEALTH-CARE OR SUPPORT NEEDS CURRENTLY?**

When we asked men about any support needs they might have we found that overall men were ok with the way things were for them at the current time. Notable exceptions to this were that Maori men identified a greater need for health system support and information, and with patient care and support needs.

Sexual support needs were significantly higher for men in our study compared to men in other prostate cancer studies. Only 11% of the men in our study had received any counselling assistance; others

acknowledged they would have benefitted from assistance in this area.

## 4 WHAT DID PARTNERS HAVE TO SAY?

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

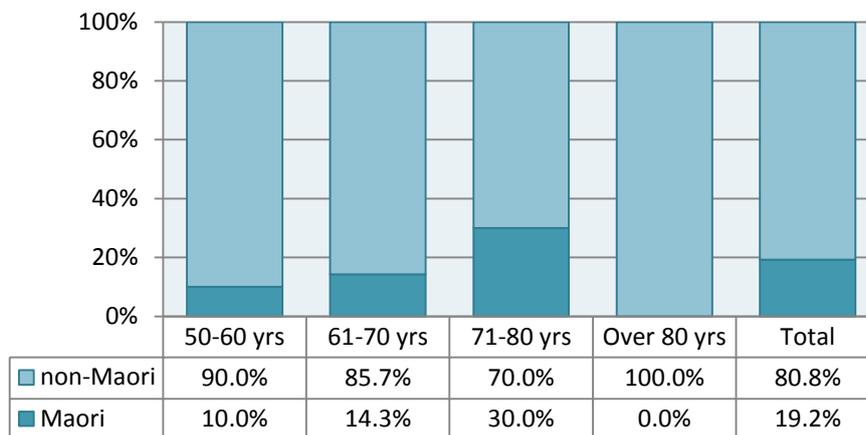
Within the following section when we refer to men, it is only discussing the men who had a partner who was involved in the study and participated in answering a questionnaire.

### 4.1 PARTNER CHARACTERISTICS

There were 53 partners; 52 female and 1 male. Two caregivers also participated in the project. We have had to remove the male partner and caregiver data from the analysis for the purposes of this report, due to lack of comparative data (we have identified that this as an area requiring additional research into).

#### 4.1.1 Age/Ethnicity

Figure 4-4-1: Age and ethnicity of partners



The ethnicity of the couples was similar between men and women, 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). 'NZ European' and 'other' ethnic groups are classified as 'non-Maori' within the report.

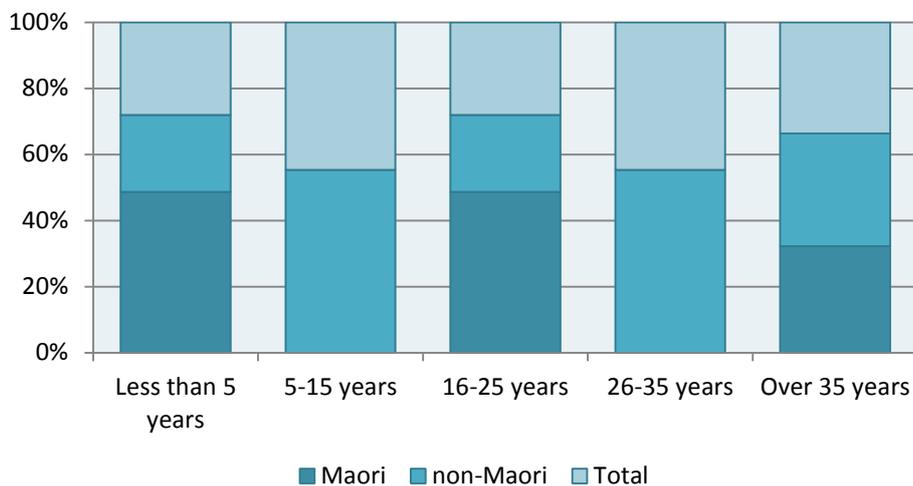
### 4.1.2 Education

Over half of the men and women in the couple's cohort had school education only (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%).

### 4.1.3 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.

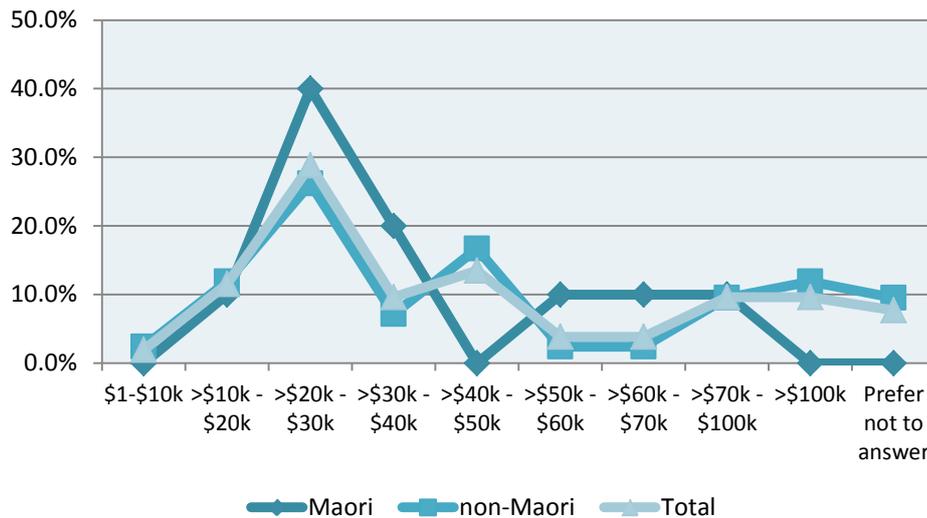
Figure 4-2: Length of time in relationship by ethnicity



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%).

### 4.1.4 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.

#### 4.2 FACTORS INFLUENCING MEN’S CHOICE OF TREATMENT

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%); chances of pain caused by treatment (men 13%, partners 31%); and recommendations from someone the patient knows who was treated for prostate cancer (men 26%, partners 9%). Partners also felt similarly positive about the available choice of treatment options for the patients.

#### 4.3 CURRENT HEALTH AND QUALITY OF LIFE OF MEN

When we looked at quality of life measures, we found that patients and their partners had similar responses. This was the case for health status, role, emotional and social function. However, there was a difference in the way partners perceived men’s physical and cognitive function, which they scored higher than the men did.

When we looked at the questions that related to prostate-specific issues (PR-25) we found that most responses between men and their partners were similar, apart from sexual activity and function. For sexual activity, men reported a higher score, meaning they felt they

had a higher level of sexual activity than their partners thought they had.

Where the sexual function responses were dependent on sexual activity, the responses were less varied but there were still significantly different responses between men and their partners. Men identified that they had a higher level of sexual function than their partners felt that they had.

#### **4.3.1 Anxiety, depression and stress**

There were significant differences between our patients and other studied groups for anxiety, depression and stress. Our men scored lower for anxiety and higher for depression than the reference group but had similar scores for psychological distress and stress. In other words, men had men in our study did not really feel much anxiety, but had higher levels of depression.

Partners/caregivers recorded anxiety scores that were significantly higher than those of the patients but lower than for the reference group. Midlands men recorded higher depression scores than their partners/caregivers, who also recorded lower depression scores than the reference group.

Midlands men's anxiety correlated significantly with their partner/caregivers' depression ( $p=0.016$ ) and psychological distress ( $p=0.032$ ). In other words, 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 ( $p=0.036$ ), meaning that if a partner was suffering from depression or distress then it had a negative impact on the other individual in the relationship.



## 5.0 DISCUSSION

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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 prostate cancer and the 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 was significant in 30% of the women and 15% of men in the study. Stress was at higher levels than in the normal population.

Partners 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 men and their partners is the impact on their sex lives after 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. There should be adequate assistance for both the patient and their partner 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.



## **6.0 RECOMMENDATIONS**

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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.

### **6.1 Improved information to patients and partners**

6.1.1 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.

### **6.2 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.

6.2.1 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.

### **6.3 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.

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

#### **6.4 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.

- 6.4.1 We recommend that post-diagnosis and post-treatment men are informed about and have regular, on-going and subsidised access to PDE5 inhibitors, injections and other devices.
- 6.4.2 We recommend that dedicated sexual function support (as at the Bay of Plenty) be funded as part of post-treatment rehabilitation.

## 7.0 GLOSSARY

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ADT	Androgen-deprivation therapy
EBRT	External beam radiotherapy
LDR	Low-dose rate brachytherapy
HDR	High-dose rate brachytherapy
RP	Radical Prostatectomy – surgery to remove the prostate
ED	Erectile dysfunction
DHB	District Health Board
RFP	Request for proposals

## 8.0 REFERENCES

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1. Aaronson NK, Ahmedzai S, Bergman B, Bullinger M, Cull A, Duez NJ, et al. The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J Natl Cancer Inst.* 1993 Mar 3; 85(5):365-76. PubMed PMID: 8433390. Epub 1993/03/03.
2. van Andel G, Bottomley A, Fosså SD, Efficace F, Coens C, Guerif S, et al. An international field study of the EORTC QLQ-PR25: A questionnaire for assessing the health-related quality of life of patients with prostate cancer. *European Journal of Cancer.* 2008; 44(16):2418-24.
3. Zigmond AS, Snaith RP. The Hospital Anxiety and Depression Scale. *Acta Psychiatrica Scandinavica.* 1983; 67:361-70.
4. Lovibond PF, Lovibond SH. The structure of negative emotional states: Comparison of the Depression Anxiety Stress Scales (DASS) with the Beck Depression and Anxiety Inventories. *Behaviour Research and Therapy.* 1995; 33:335-43.
5. Hodgson F, Obertová Z, Brown C, Lawrenson R. PSA Testing in General Practice. *J Prim Health Care.* 2012; 4(3):199-204.
6. Ellison-Loschmann L, Pearce N. Improving access to health care among New Zealand's Maori population. *American Journal of Public Health.* 2006; 96(4): 612-617.
7. O'Brien R, Rose P, Campbell C, Weller D, Neal R D, Wilkinson C, Mcintosh H, Watson H (on behalf of the Prostate Cancer Follow-up Group). "I wish I'd told them": A qualitative study examining the unmet psychosexual needs of prostate cancer patients during follow-up after treatment. *Patient Education and Counselling.* 2011. 84: 200-207.
8. Lawrenson R, Brown C, Obertova Z, Lao C, Conaglen H. 2014. Final Report. The Midlands Prostate Cancer Study: Understanding the pathways of care for men with localised prostate cancer. Hamilton, UniServices, University of Auckland. Access: <https://cdn.auckland.ac.nz/assets/fmhs/som/wcs/docs/FINALREPORTLawrenson11-052.pdf>
9. Ramsey SD, Zeliadt SB, Arora NK, Blough DK, Penson DF, Oakley-Girvan I, et al. Unanticipated and underappreciated outcomes during management of local stage prostate cancer: A prospective survey. *The Journal of Urology.* 2010; 184(1):120-5.
10. Statistics New Zealand website: [www.stats.govt.nz/people\\_and\\_communities/Households/HouseholdEconomicSurvey\\_HOTPYeJun12.aspx](http://www.stats.govt.nz/people_and_communities/Households/HouseholdEconomicSurvey_HOTPYeJun12.aspx)
11. Crawford J, Cayley C, Lovibond PF, Wilson PH, Hartley C. Percentile Norms and Accompanying Interval Estimates from an Australian General Adult Population Sample for Self-Report Mood Scales (BAI, BDI, CRS-D, CES-D, DASS, DASS-21, STAI-X, STAI-Y, SRDS, and SRAS). *Australian Psychologist.* 2011; 46:3-14.
12. Scott NW, Fayers PM, Aaronson NK, Bottomley A, de Graeff A, Groenvold M, et al. EORTC QLQ-C30 Reference Values 2008.



## THE FINAL WORD

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