

## **Appendix 18. Report to CSNZ regarding aspects of interest to its health promotion and psycho-social service work**

### **Psycho-oncology research for men**

3 August 2012

Interim report for The Cancer Society of New Zealand by Heather Heron-Speirs

### **HEALTH PROMOTION AND PSYCHO-SOCIAL SERVICE USE**

Document purpose .....	2
Acknowledgements.....	2
1. Sample.....	3
2. Diagnosis accounts.....	7
2.1 What men knew about cancer before diagnosis.....	7
Knowledge content .....	7
Knowledge sources .....	9
2.2 The trigger for diagnosis.....	10
2.3 Diagnosis delivery .....	10
2.3 Barriers to earlier diagnosis .....	11
2.4 Suggestions for health promotion .....	11
2.5 Maori.....	13
3. Treatment decisions .....	15
3.1 The offer of treatment options .....	15
3.2 Factors taken into account in making treatment decisions .....	16
Suggestion.....	19
3.3 What men wanted in treatment option discussion .....	20
4. Use and opinions of psycho-social services.....	21
4.1 Use .....	21
4.2 CSNZ services and 'We ask you to make the first contact' policy.....	22
Men's groups .....	22
Connecting with services .....	23
Suggestions .....	23
4.3 'Counselling', aka 'skills coaching' .....	26
Suggestions .....	28
4.4 Maori.....	29
Suggestions .....	30
Conclusion .....	31

### **Document purpose**

This report responds to a request from CSNZ for a summary of data relevant to its health promotion and psycho-social service work, collected tangentially to a larger research project investigating the distress experience of men with cancer. Although not specifically requested, I felt it might be useful to include some of my own thoughts by way of suggestions arising out of the implications of the data. Note that this is *not the main report* from the research project, and I have not referenced relevant literature, but have taken it into account in focussing attention on salient issues.

The report first describes the sample of participants, and then addresses each of the areas of substantive interest, namely: (1) How men came to be diagnosed; (2) What factors contributed to their treatment decision making; and (3) What psycho-social services they used, and what their opinions/perceptions were of 'counselling' (which I will refer to as 'coaching') and men's groups. Suggestions are listed for discussion, and I make separate mention of Maori experience.

Because the method of the larger project is 'action research', practical outcomes are envisaged and important for validation. I therefore request feedback as to CSNZ's application of this report, and will contact Jan Pearson, HP manager, for that in about six months.

### **Acknowledgements**

I thank my lead supervisor, Assoc Prof Chris Stephens, and supervisors and 'critical friends' (advisors on things masculine) Dr Don Baken (psycho-oncologist), Dr John Waldon (Maori Health researcher), and Mr Roger Twentyman (Manawatu Cancer Society) for their thoughtful comments.

I also thank the research funders: Movember (research expenses, allocated through CSNZ), CSNZ (doctoral scholarship) and Massey University (doctoral scholarship).

The main people to thank, however, are the participants, whose generosity and beneficence made the whole project possible. Whilst I shall more fully acknowledge their contribution in the main research report, suffice it to say here that the majority of these men assisted for no other reason than to help others, and made some significant effort to do so. For a few that meant time out of a busy work schedule, and for most that meant opening their hearts deeply. For a small number it was a gift of some of their last breaths. May the impact of this document, and the main report, be a fitting tribute.

## Sample

The project used data from 27 men with cancer interviewed in 2011. The men lived in Horowhenua, Otaki, Whanganui and South Taranaki regions, which were chosen for their lower socio-economic status and rurality, both factors known to make dealing with cancer more difficult and stressful. They were recruited with the assistance of various hospital and community health workers.

**Summary.** A good representation of socio-demographic groups was recruited, and it is particularly pleasing that lower income and Maori men were well represented. 59% of participants had prostate cancer; 26% knew they had terminal diagnosis and 26% appeared to have been treated for full cure of localised disease, the rest having some degree of disease spread; 66% were 65 years of age or older; 22% were Maori; approximately 70% were retired or beneficiaries; 40% were in the lowest income bracket while 26% were in the highest; 48% had no more than a secondary level education while 30% had partial or completed tertiary level education; and 48% had worker/labourer (former) occupations while the rest were spread evenly between businessman/farmer and managerial/professional occupations. Several men appeared to be depressed.

**Detail.** Biodata for the sample are tabled below (Table 1), together with psycho-social service use. Data from Maori participants are grouped towards the end of the table, followed by those from the one young participant.

Although the sample was not recruited by formally 'representative' means, perusal of the demographic data suggests that a fair representation of cancer types and stages and population demographics has been achieved, and, importantly, vulnerable demographic groups (low income and Maori) are well represented:

- **Age.** Except for one 23 year old, the men were aged 52 to 85, with 18 of the 27 men aged 65 years or older.
- **Cancer site/type.** Sixteen men had (primary) prostate cancer; three, lung; two melanoma; two, parotid gland; one, acute myeloid leukaemia; one, bowel; one, renal cell; and one, breast cancer. Seven understood their cancer to be terminal, but there were a number more who, from what I could tell as a lay person who has experienced cancer, also had dismal prognosis. It was disconcerting to find that many men did not have a clear understanding of their disease status and prognosis. Seven appeared to have locally contained cancers for which a full cure was expected. The remaining men were suffering some level of disease spread, from which prognosis was not clear to them and/or me.
- **Domicile.** Sixteen men lived in the Horowhenua region, two in Otaki, five in South Taranaki, and four in Whanganui.
- **Ethnicity.** There were six Maori men; 21 Pakeha; none of any other ethnicity.
- **Marital status.** Fifteen men were married, the rest were single, widowed, divorced or separated, and lived alone, except that the 23 year old lived with

his parents, one very elderly man in late stage lung cancer lived with his daughter, and one separated man had the live-in support of his wife for the period that he was in treatment. Note that none of the six Maori men were (currently) married. This is important because being married can impact recognition of symptoms and the decision to consult a GP, as well as treatment decision making and cancer-related distress.


- **Income.** The study succeeded in recruiting a good proportion of men with low annual household income: 11 men received less than \$20,000 (retired and on little if any more than government superannuation, or on another government benefit); four received \$20,000 - \$35,000; three, \$35,000 - \$50,000; two, \$50,000 - \$70,000; and seven received more than \$70,000. Of the six Maori, five were in the lowest income bracket.
- **Occupation.** Most of the sample (15) were retired, and another four (including three Maori) were in receipt of government benefits (unemployment, sickness or invalid), leaving eight in work. The spread of main occupation (former, if retired) types were: 13 workers/labourers (including all six Maori), eight self employed businessmen/ farmers (including one who was, before retirement age, a manager), and seven managers/professionals.
- **Education.** Nearly half the sample had no more than a secondary level education: Three had only primary level; ten, secondary; two had partial and four, completed trade certificates; three had partial and five, completed tertiary qualifications. The level of education of Maori men was lower, with none having received tertiary education, and two indicating to the interviewer that they had limited literacy.

Despite recruitment criteria excluding men with obvious signs of cognitive deterioration, three men appeared to be suffering this. Radar and Chang had been told that they had likely suffered stroke, and they each periodically struggled to find the word they sought, but otherwise gave me no cause for concern about the quality of their interview. Lewis's autobiographical recall, however, was not strong for more distant material, and it was not clear whether this was because of the time that had elapsed since the event or because his memory was compromised. Other features of his behaviour suggested a little general decline although he was still fully capable of the independent life he led.

Four men appeared to be depressed. Only one, Brucie, realised this and was monitoring it with his GP. A number of other men made comments indicating that they had likely been depressed at some earlier point in their cancer experience.

Table 1. Biodata and psycho-social service use

Pseudonym	Age	Cancer site/type	Domicile	Socio-economic status					Use of psycho-social services
				Ethnicity	Marital status	Gross annual household income	Predominant occupation type	Highest education	
Jacko	63	Parotid gland (m liver, lungs) ☹	H	P	Ma	H	B/F	Sec4	Nil
Hank	66	Prostate (m bone) ☹	S	P	Ma	HH	B/F	Sec2	Nil
Red Top	74	Melanoma (m parotid gland)	H	P	A* separated but wife moved in during treatment	LL	(W/L) R	Sec4	1 CSNZ monthly mixed gender support meeting (so far), CSNZ transport
Freddie	82	Lung ☹	S	P	A* living with daughter	LL	(B/F) R	Pr	Nil
Littley	76	Prostate (s)	H	P	Ma	M	(M/P) B/F	Tir	Nil
Chang	74	Prostate	H	P	Ma	L	(M/P) R	Tir-	Nil
Radar	72	Prostate	H	P	Ma	HH	(B/F) R	TC	Nil
Brucie	55	Prostate (s) ☹	H	P	Ma	HH	M/P	Tir	Nil
Reacher	59	Prostate (s)	W	P	Ma	LL	W/L U	Sec3	CSNZ monthly men's group, CSNZ transport (introduced him to men's group), CSNZ information line
Peter	52	Renal Cell (m media sternum) ☹	S	P	Ma	HH	M/P	Tir	Nil
Cluck	81	Melanoma and skin carcinoma	S	P	Ma	L	(W/L) R	Sec3	Nil

		(multiple) and historic bowel							
Arthur	68	Prostate	H	P	Ma	LL	(W/L) R	Pr	CSNZ transport, chaplain in hospital initiated by staff
Plane	74	Prostate (s)	H	P	Ma	LL	(B/F) R	Sec2	Nil
Lewis	83	Prostate (s)	H	P	A	LL	(B/F) R	TC	CSNZ monthly men's group for 2 years
Roly	85	Lung ☹	H	P	A	L	(W/L) R	TC	1 monthly CSNZ men's group (so far), 10x CSNZ weekly women's group
Bazza	76	Prostate (s) and historic skin carcinoma	O	P	Ma	HH	(M/P) R	Tir-	Nil
Paddy	79	Prostate (s?)	H	P	A	HH	(B/F) R	Tir-	DHB transport after CSNZ suggestion
Bert	73	Prostate	H	P	Ma	M	(M/P) R	Tir	Nil
TG	70	Lung (m liver) ☹	W	P	Ma	L	(M/P) R	Tir	CSNZ transport
Colin	58	Breast	W	P	A	H	W/L	TC-	CSNZ transport
Paul	56	Bowel	H	M	A	LL	W/L U	TC- 	CSNZ monthly mixed gender group, CSNZ transport, CSNZ field worker provided needed household goods, 1 visit by hospital social worker and 1 visit by Maori Cancer Coordinator but neither of these was solicited or needed
Moko	71	Prostate (s)	W	M	A	LL	(W/L) R	Sec2	CSNZ monthly men's group 2 years, CSNZ Living Well course, CSNZ transport, face to face chats with CSNZ office staff
Monty	75	Prostate (s) ☹	O	M	A	LL	(W/L) R	TC	Nil
Buck	65	Prostate (s)	H	M	A	M	W/L	Sec3	DHB transport, Maori Cancer Coordinator

TBS	59	Acute Myeloid Leukemia ⌚	H	M	A	LL	W/L U	Pr	DHB transport
Richard	52	Prostate (m bladder)	H	M	A	LL	W/L U	Sec1 🏠	CSNZ transport, home help recovering from surgery, Maori Cancer Coordinator
Jake	23	Hodgkins Lymph- oma	S	P	A* but living with parents	HH (this is his parents' income)	W/L	Sec5	Youth cancer counselling by hospital social worker and Canteen (charity for youth), but only brief and not patient initiated

*Cancer site/type:* m = metastasis, (s) = spread beyond primary organ, ⌚ = participant understands his cancer to be terminal. Note that many participants did not clearly understand their disease status, some of the status information marked '(s)' is inferred from what they said, and it is most likely that there are several more who have dismal prognosis.

*Domicile:* H = Horowhenua; O = Otaki; S = South Taranaki; W = Whanganui

*Marital status:* Ma = Married; A = Alone (Single, separated,, divorced, widowed); \* = modified A

*Income:* LL = benefit/government superannuation/<\$20,000; L = \$20,000 - \$35,000; M = \$35,000 - \$50,000; H = \$50,000 - \$70,000; HH = > \$70,000

*Predominant occupation type:* Parentheses denote former occupation; R = retired; U = unemployed or in receipt of government sickness/invalid benefit; W/L = employed worker (e.g. technician, office worker, sales representative) or labourer; B/F = self employed businessman (e.g. tradesperson, manufacturing business owner) or farmer; M/P = manager or professional (e.g. teacher, lawyer, accountant)

*Highest education:* Pr = primary (years 1-8); Sec = secondary, with 1- 5 indicating the number of years (e.g. S3 = 3 years at secondary school, aka '5<sup>th</sup> form'); Tir = tertiary (university diploma or degree, polytechnic professional certificate); TC = trade certificate (e.g. electrical, boiler making); X- = less than the full qualification (e.g. TC- = partial completion of trade certificate or an industrial certificate that is achieved after study of only a few months; Tir- = some papers towards a university degree); 🏠 = limited literacy was apparent to the interviewer (NB: men were not asked their level of literacy)

*Ethnicity:* P = Pakeha/New Zealander of European descent; M = Maori

*Use of psycho-social services:* CSNZ = Cancer Society of New Zealand; DHB = District health board, transport = private car sponsored by CSNZ or shuttle van sponsored by DHB/community

## 1. Diagnosis accounts

Men were asked what they knew about cancer before being diagnosed, how they came to be diagnosed, and whether, with hindsight, they could have been diagnosed earlier.

### 2.1 What men knew about cancer before diagnosis

#### *Knowledge content*

**Most men knew little** about cancer, other than it is 'a killer', and that smoking and sunlight posed risks of lung cancer and melanoma. They had learned this from the warnings on cigarette packets and from health messages or other programmes on TV or in media generally. Knowledge of other cancer types and of symptoms to watch for, was very scant. Some had learned through experience with significant others, and some (notably more educated men) as part of a greater general knowledge. Frequently men stated that they had

not been interested in reading about cancer before they were diagnosed, and that they had not felt comfortable pursuing questions with relatives who had suffered from it.

Among **prostate cancer** patients, those who knew symptoms before diagnosis generally learnt them from TV advertisements (Ian Scarrow: urinary flow) or from the stories of men portrayed on TV or in newspapers, rather than from health promotion leaflets at their GP's surgery. If they knew about the PSA test, it was usually because their GP had raised the matter and explained it to them.

The **image of cancer** for many was simply that 'it kills you', though others knew that some effective treatment is available.

For some men, cancer was their **first significant experience** of illness, and for many it was their first experience of the hospital system, with previous experience limited to visiting others. Buck described his dependency on his sister-in-law to coach him through the medical system as 'feeling like a child'. He highly valued her advice as to what to expect next, and the connections she made for him with services, such as the transport shuttle.

That cancer 'kills you' was the image of **Maori men** in particular, whose knowledge of cancer was primarily from the deaths of whanau members. It is to be noted that all six Maori men had little schooling and their occupations were typically labouring in primary or construction industries. At least two had limited literacy. There was evidence of lack of awareness of the most basic facts about cancer in this group. For example, Richard, who was diagnosed two years before the interview and had undergone chemotherapy and urinary stoma and prostate surgery, only learned from me, after the interview, that cancer is not contagious. TBS did not know what leukaemia was when he was diagnosed with it, but he did ask, and was told. Buck disregarded a message from his GP that his PSA reading was high and that a referral to a urologist had been made for him because he had no idea what PSA was about, was too whakamaa to ask, and in those circumstances thought that work was the priority. He also said that he had not learned that some effective treatments for cancer were now available, and put the state of affairs this way:

[Maori] don't mean to be ignorant of the fact that the medicine is improving. ( ) We don't mean... some of us are going through hard times, and ( ) we've got a living to make ( ) so we're out of the loop in a lot of ways ( ) - not because we want to be - because of the necessity of other things ( ) that's going on in our lives.

Knowledge of a risky behaviour was no guarantee that a man would act to protect his health. The normative masculine self-image is one of **invulnerability**, and, in combination with **control** - an important masculine norm - could cause men to override prudence. (Note that 'control' is used in this report to refer to governance over one's own life, rather than over the lives of others.) For example, TG knew the smoking risk very well, and overrode his family's many warnings, much to his later regret, because cancer was 'never going to happen to him'. Paddy said he was well aware of sunsmart and smoking warnings, but that he would never give up the sun because he loved it, and, on the other hand, that he had ceased smoking 'cold



turkey' when he realised that it was controlling him (every 20 minutes he would feel the need for another cigarette). He did this entirely without regard to the cancer risk. Health warnings meant nothing to him, but control was important.

### *Knowledge sources*

Men were asked about the sources of their cancer information before they were diagnosed. Few had noticed and read **CSNZ leaflets** at doctors or hospitals. Typically men were 'not interested' in reading them until after they had been diagnosed. A few read them, but could not remember anything significant they had learned from them, because 'you don't take any notice if you are not involved' (Red Top). A masculine sense of invulnerability appeared to be the cause of this: Frequently men said they had felt that they were 'bullet proof' and cancer 'would not happen' to them, so such literature was simply irrelevant and reading it was 'a waste of time' and a distraction from important matters of focus, such as work. However, men always wanted information about their condition once they were diagnosed, and were pleased to read leaflets then.

**The stories of men** who were known to participants personally (family, friends) or as celebrities, as portrayed on TV (Paul Holmes and Buck Shelford) or in the newspaper (local people), were mentioned as information sources by several men. These stories provided both cancer and treatment information, and models of the attitude that can be taken to meet the challenge of cancer. Reacher took note of prostate symptoms from the story of a man he knew which had been published in his local newspaper. Moko took courage and refrained from attempting suicide after his prostate diagnosis when he remembered how Paul and Buck came through their prostate cancer. Roly immediately ceased smoking after watching a TV programme about the removal of a diseased lung. Men also often mentioned the importance of first-hand accounts of cancer experience when deciding on treatment (refer below) saying that they would only listen to doctors and people who had 'been there'. Thus stories of personal experience were held in considerable esteem by this sample of men.

Interestingly **work** was *not* mentioned as a source of cancer information by men. One man was aware that a lump could be a symptom because he was a meat inspector, and another suggested that health advertisements placed in the kind of magazines left in smoko rooms might be helpful, but otherwise work was not mentioned in relation to cancer information.

Most of the men in this sample did *not* use the **internet** to inform themselves at any point in their cancer experience. Most relied on their doctor's, the advice of female family members, the stories of cancer survivors known personally to them, their own observations of family members with cancer, pamphlets provided by specialists or found in waiting rooms after diagnosis, or TV health promotion campaigns featuring male celebrities. Of the eight who used the internet in some capacity, two looked briefly just to get a better understanding of their condition, while of the ones who looked more seriously, one was the young man, one was a businessman who had only just retired, and the other four had tertiary education. None of the six Maori used the internet.

## *2.2 The trigger for diagnosis*

Men were diagnosed either (1) after the discovery of a suspicious or acute symptom, (2) as a result of GP monitoring or treatment for another condition, or (3) after a regular or administrative GP check-up.

When diagnosis followed the discovery of a symptom, presentation to a GP or hospital A&E was usually **on the advice of a female family member** (seven men, e.g. wife, daughter, sister-in-law), **or to address acute symptoms** (seven men, e.g. blood in urine, collapse due to breathlessness or general malaise). Four men identified a non-acute symptom and decided independently of any female to get it checked.

Frequently a symptom was detected during a **regular GP visit for another chronic condition**. For a few men it resulted from a regular general check (i.e. a check which was not associated with a chronic condition). For one it resulted from a regular check arranged at work, and for another from an insurance-related check.

A few men described, with gratitude, their GP's strong advocacy of regular PSA tests, but one told a tragic story of having asked repeatedly for a PSA test but being denied on the grounds that he was 'too young', then finally insisting, only to discover that he had prostate cancer which was already advanced beyond cure.

## *2.3 Diagnosis delivery*

Through the full length of their cancer experience, men invariably (with possibly one exception) appreciated being told the **unvarnished truth** by their health team. This gave them the information needed to take control, and also dignified them with the respect of being treated 'on the level'.

However, men did not appreciate '**blunt**' diagnosis delivery, and the result was sometimes alienation. Six men complained of this. For four of them, their diagnosis was terminal. For two of those the specialist was in a great hurry, and rushed in and out saying, essentially, 'You have advanced cancer and this is what we will do for you. Sorry, I have to go.' This left one man and his wife completely stunned, and they sat, numb, in their car, for some time afterwards before driving home. The other man 'wandered' out of the specialist's office, and was fortunately shown kindness by a nurse ('She was quite concerned – nobody else was!') who asked if he had someone to drive him home and whether he had been given any literature – which he had not. In one other terminal case the delivery was not only blunt but further bungled by the registrar, who did not realise there had been a bone scan when he primed the man to expect that he would have surgery. When the specialist arrived, he promptly declared that there was 'never any likelihood of surgery' because the cancer was 'far too advanced'. Both of the men whose cancer was in the early stages were also shocked by a bald statement of their diagnosis and recommended treatment in the next breath. Alienated, they both turned to other medical specialists for help, but for one this involved a good deal of lost time and the consequent advancement of his condition. He described the diagnosing specialist as undoubtedly expert but 'a cold stone fish' who he did not want to see again.

In sum, men wanted to be told their diagnosis in a way that could be characterised as **'straight but not blunt'**: human warmth, an explanation of the diagnostic evidence leading to the diagnosis, a clear statement of their diagnosis, and then full explanation and unpressured choice of treatments, supported by take-home written material. Fortunately this was the experience of most.

### *2.3 Barriers to earlier diagnosis*

Men often described themselves as 'ignorant' of cancer facts, including the significance of specific symptoms, and this was the most common element contributing to later-than-necessary diagnosis (eleven men, e.g. thinking the need to urinate nocturnally was due simply to old age). Confusing a symptom with a different condition also featured (four men, e.g. thinking that urinary frequency was due to diabetes). A recurring feature of symptom ignorance was the misunderstanding that one had to 'feel sick' in order to be ill.

Another frequent cause of delay in diagnosis was **GP or health system failure** (eight men, e.g. GP failing to recognise the potential seriousness of a symptom, health system delays or shortages of GPs).

A few men delayed seeking treatment despite noticing a symptom because they considered themselves 'bullet proof' or too healthy to get cancer – consistent with the masculine self-image of **invulnerability**, and the reality that many men had never needed significant medical treatment before their cancer diagnosis. Other reasons for delay included fear of cancer diagnosis, general procrastination or hoping that the symptom would resolve spontaneously, lack of interest, denial of what a symptom could mean, embarrassment to raise the issue with their GP, and being whakamaa about ignorance of the significance of a PSA test.

Ignorance of the potential significance of symptoms is thus an important factor contributing to delay in presentation.

### *2.4 Suggestions for health promotion*

Symptom ignorance and the 'irrelevance' of health warnings are suggested by this dataset as influential barriers to early diagnosis. Both issues require targeting and/or circumventing for health promotion efforts to be effective. It is also important that HP respects the self-determination of men and their need to feel in control. Thus a message that focuses less on vulnerability ('this will be good for you') and more on control is likely to be better received. Messages should also 'give it to men straight'. Here are my suggestions:

#### **Targeting ignorance:**

- **Convey the basics of cancer and treatment.** Most men have significant gaps in their knowledge e.g. what cancer is (multiplying cells) and is not (contagious), where the prostate gland is and what it does, what a typical journey through diagnosis and treatment looks like in terms of who is seen and what they do, what to do if one has a

suspicious symptom, and when (and how) it might be appropriate to get in touch with the Cancer Society.

- **Convey the potential significance of particular symptoms.** Men often lacked a vocabulary for symptoms (they just 'felt off') and had not realised that they had been experiencing a symptom of illness. In particular, it would be important to counter the misconceptions that not 'feeling sick' means that nothing is seriously wrong, and that getting up to urinate during the night is just a part of old age.
- **Materials:** Distribution of interesting material (e.g. stories in comic or poster form – refer below) at work places and sports and other men's clubs may be worth consideration, and stories rather than information pamphlets may raise interest in doctors' waiting rooms. I note that one man said that if he had received a brochure through the mail explaining symptoms for men to be on watch for, he would have been grateful to read it, and another suggested that simple advertisements in workplace magazines could be effective as men leaf through them during breaks. Both of the Maori men who suffered the worst general health mentioned what they had learned from watching TV. TV advertisements in the form of mini stories broken into a number of episodes and other TV portrayals of the stories of survivors may be effective.

#### **Circumventing ignorance:**

- **A message promoting regular health checks** may be more effective at producing early diagnosis than a message promoting presentation to a GP upon identifying a symptom because of the problems men have with identifying symptoms (ignorance, confusion, and masculine invulnerability). Men related naturally to the mechanical imagery of the 'WOF', and it is likely that they would relate well to the concept of 'keeping your machinery well maintained for the sake of work and family'.
- Health promotion efforts might also target the **convenience and affordability** of such checks. For example, by encouraging GP services after hours, or screening stations at places men frequent and are obliged to wait at such as vehicle testing stations, similar to the breast screening busses that park in shopping malls and near schools.

#### **Targeting relevance:**

- As mentioned, if regular screening is suggested in messages relating to **machine maintenance** or with the purpose of ensuring **work fitness** they should resonate with men. Men are also very conscious of their **responsibilities towards their families** (for most, the wellbeing of their families was their first thought upon diagnosis), and this theme may also be effectively used.
- **Voice:** As mentioned, the stories of cancer survivors whom men relate to are relevant to men on a personal interest level (e.g. male celebrities and local people). As will be seen below, the most relevant and authoritative sources of information for most men were their doctors and/or cancer survivors.

#### **Circumventing relevance:**

- The **stories** of cancer survivors circumvent the 'irrelevance barrier' because they are not in competition for time against the priority of work – men can read or watch such stories in their leisure time. Story is also a means of presenting messages in a way that respects the masculine norm of self-determination and control: The story receiver is offered a smorgasbord of information from which he selects what he deems relevant to his circumstances. The appropriateness of this approach was made clear by the high frequency with which men said they would not 'advise' a friend what to do about suspicious symptoms (except some would advise him to 'get to the doctor') or treatment decisions, but would simply tell their own story and let their friend take from it what he may.
- **Women** could be encouraged to be even more proactive in prompting their men to present with symptoms and, most importantly, to schedule regular health checks. Women are probably more open to direct encouragement as to their potentially vital role, and could be shown role models or tips on how to go about it.
- Similarly, **children** could be empowered with tips and encouragement as another 'back door' health promotion for men. It was notable how Maori men enjoyed their mokopuna assisting them with their health (e.g. telling people off for smoking in the house, being cheeky and providing lots of hugs and attention when they were ill). Both of the Maori men with limited literacy were nonetheless very interested in their mokos' progress at school, and I imagine that both would be delighted to be 'taught' about their health by them.
- **In time** the internet will, of course, be used by more cancer-affected men, and YouTube videos might be a useful tool for conveying stories, with links from sites popular with men (e.g. work, sport, or entertainment related).
- Because men respect each other's stories, perhaps messages that create more safety and interest around **discussing cancer** and health in general would be useful. It seemed that the efforts of Paul Holmes and John Kirwan have made important progress in normalising discussion of prostate cancer and depression. Modelling like this might be the most effective tactic.

## 2.5 Maori

I found the **ignorance** of cancer facts amongst five of the six Maori participants disturbing, and there may be an association with their poorer general level of education and literacy. The interviews indicated that all of these Maori participants acted promptly and responsibly to deal with symptoms once they realised that something significant might be wrong, but ignorance and lack of more knowledgeable whanau support delayed presentation for some.

Given the role of wives/partners in men's health, it was concerning that all of the Maori participants were **single**, although some of them did have strong female support notwithstanding (daughters, former wife, sister-in-law). A wide network of whanau who feel responsible for each other's wellbeing is an invaluable resource generally for supporting the health of Maori men, and, as mentioned, offers the opportunity to circumvent cancer ignorance through women and mokopuna.

**Sport** was prominent in the lives of three of the six Maori, and they followed their moko's sporting involvements with intense interest even when they could no longer participate themselves because of their illness. This may provide other useful HP connection points.

I was disturbed to hear that two of the six Maori men presented to their GP with symptoms that obviously demanded serious investigation (serious anal pain, blood in urine) yet were dismissed without such investigation being made (in the former case a specialist referral was arranged after repeated visits, at the patient's urging, reluctantly, and too late to be of use), so that both men felt they had no alternative but to present at A&E to obtain diagnosis and help. It is possible that both men had the same GP. Only one of the 21 Pakeha men presented to A&E after GP failure to investigate an obvious symptom (breathing failure to the point of collapse), although another may have come to that point had a nurse not intervened. It was also Maori only who said they wanted medical and psychological personnel who would not 'point the finger' and 'judge' them. The impression I gleaned was that some Maori men, though doing their best for their health with the knowledge they have, have experienced being **judged as neglectful** or otherwise blameworthy by some health professionals.

It may be also that some professionals were unaware of the prevalence of cancer ignorance and poor general education amongst Maori men of this age group, and so presumed too much, leaving their patients without understanding of critically important matters. For example, Buck was diagnosed a year later than need be, and only after his prostate cancer had advanced beyond cure, because he did not understand the significance of a high PSA reading and the referral made for him to see the urologist, was too whakamaa to ask, and consequently did not take time off work to attend. Ultimately, he was not enlightened by his GP, or his GP's nurse, who had originally phoned him with the PSA result, but by his sister-in-law some considerable time later. It is possible that this man also had the same GP as I suspect the two mentioned above had (all three came from the same town), but this does not account for the failure of the GP's nurse to explain the meaning of the PSA result. Another illustration of the knowledge gap was that Richard halted all sexual relations with his partner under the misapprehension that cancer is contagious. Because sex was central to his intimate relationship, this, coupled with losses of function associated with his surgery, caused him to withdraw from that relationship and suffer the most serious distress, twice bringing him to seriously contemplate suicide. Richard had been right through the process of diagnosis and very intensive and lengthy treatment without having his misunderstanding corrected. I spoke to him at considerable length and saw no indication of low intelligence or lack of interest.

Even if one were to leave aside the poor performance of possibly one GP, the fact that Maori were concerned about being judged and were disadvantaged by ignorance of medical facts raises a concern as to whether training sufficiently alerts medical personnel to the impact of educational disadvantage on the health knowledge of Maori men. Beyond this, there are circumstances peculiar to Maori which should be remembered in designing health promotions:

- Messages need to address basic disease and treatment facts, most importantly, that it is now possible to cure many cancers which are caught early – it is no longer 'a death sentence'.
- Media forms which overcome poor literacy are appropriate e.g. TV, or very simple written English well supported with pictures, such as comics.
- Because men who are off work due to poor health are likely to spend time watching TV, and because more Maori men have poor overall health, TV may be an effective means of reaching these men with cancer messages.
- A wide network of whanau who feel responsible for each other's wellbeing is an invaluable resource, offering the opportunity to reach men through women and mokopuna.
- The prominence of organised sport in the lives of many Maori families may provide another useful connection point for HP messages.

## 2. Treatment decisions

CSNZ wanted to understand better how men make their treatment decisions. Data was collated on whether men were offered treatment options, what factors they took into account in making decisions, and whether they were happy with how options were discussed.

### 3.1 *The offer of treatment options*

Most men were either offered treatment options or, because of the advanced stage of the disease, given a choice between a single course of action or letting the disease run its course, and were happy with the options presented. Some of the remaining cases are interesting illustrations of outstanding and poor doctor/patient relations:

Colin was presented with a single treatment plan, which he was happy to accept *en bloc* because of his great confidence in and rapport with his surgeon. The surgeon's style was characterised by warmth, informativeness, availability, generosity, expertise, and passionate advocacy of his patient's interests.

Lewis also stated that he was simply told what his treatment would be. In his case, however, it could be that the surgeon identified that Lewis is possibly suffering significant cognitive decline, and that he had a benevolent 'old school' respect for medical experts, and so would be happy to be relieved of the burden of trying to understand treatment options. Certainly it seemed that Lewis did not understand the objective of the treatment that he had had, or the fact that his medication was all for other conditions. However, he had the utmost confidence in his surgeon due to the surgeon's warm and authoritative manner, his own old-fashioned paternalistic expectation of professional benevolence and expertise (he was 83), and his coping strategy of denial.

Roly was diagnosed with lung cancer of a kind and stage that normally would have been treated effectively with surgery. However, because of other conditions, his surgeon was not willing to operate, saying he 'did not like patients dying on his

operating table'. Roly was most unhappy with this because he is completely socially isolated, having no family and being cut off from his past social contacts by the restrictions imposed by his illness. He would have preferred to run the risk of dying than the long drawn out loneliness that he now suffers. Roly insists that there was no opportunity to discuss the matter with his surgeon, emphasising that the social class disparity was impenetrable (he was 85). He felt that he was treated with more equality by his radiation oncologist. However, throughout the interview Roly insisted that it was not possible to improve various of his isolating circumstances. He was likely depressed, but also illustrated an 'old school' social inferiority which the surgeon was not sensitive to.

Bert was most unhappy with the blunt delivery of both his diagnosis and treatment plan. He went to a lot of trouble to do his own research and obtain a second opinion, and acted on a combination of that and advice from the treating hospital.

Paddy was most unhappy with the cold and directive approach of his specialist, who offered him only surgery, having diagnosed prostate cancer at an early stage. Because of his fear of medical intervention, and because of the poor quality of his relationship with his urologist, Paddy kept declining the urologist's urgings to have surgery, and finally approached – entirely of his own volition – a radiation oncologist. (The urologist had never suggested radiation.) He found her warm and reassuring, and so overcame his fear and underwent a course of radiation therapy. Interestingly, Paddy thought that had she been the specialist who had tried to persuade him to have surgery, she might have been successful. The critical issues for him were control and warm understanding.

Men wanted a relationship with their doctor in which they felt **both respected and cared for**. In two of the above illustrations, directive treatment advice was acceptable to men because of the exceptional confidence they invested in their surgeons (Colin, Lewis) who were perceived as both expert and caring. In another two, male doctors clashed with their male patients regarding who was in control. In these cases, the bluntness or coldness perceived by the patient alienated him and hardened his resolve to pursue his own solution through another specialist (Bert, Paddy).

### *3.2 Factors taken into account in making treatment decisions*

Most men expressed confidence in both their specialist doctors' expertise, and their humanity, and **relied almost entirely upon their advice**, often doing little more than defaulting to their doctors' better judgement. They often read pamphlets provided by their doctors, and (in all but one case) men who had wives/partners discussed treatment options with them, but often the doctor's treatment advice was agreed to on the spot, during the consultation.

As part of the main research analysis I will explore the involvement of masculine norms in this **ceding of control**, because the rhetoric that accompanied it in the case of a number of men revealed more than a simple acknowledgement of the specialist's expertise. Some men justified their default by explaining that they would be insulted if a novice tried to advise



them on how to do their job, so they would not be so foolish as to 'second guess' the advice of a medical expert, and that a second opinion was simply 'unnecessary'. Thus they framed the issue as a matter of expertise and professional respect – masculine norms - rather than of self-determination and of taking responsibility for one's own health, and declined to exercise their own analytical skills and control.

In Jacko's case, a narrow window of opportunity for effective treatment was missed by the taking of a decision that cost too much preparation time before treatment could start. Had Jacko been prepared to engage his own thinking in the decision making, that crucial decision may have been challenged. Jacko reflected that the decision was a mistake, but in keeping with his reverential respect for medical experts, and with the masculine norm of shouldering responsibility oneself, he was not willing to blame them for it, despite the grave seriousness of the consequences. There was another case of similar default in favour of revered medical expertise which caused me to wonder, with considerable discomfort, whether similar opportunity might have been missed by the patient's determination to put all his faith in his specialists' judgement (TG – also terminal prognosis). Interestingly, this man also resisted the obvious conclusion that his GP was blameworthy for failing to identifying the potentially serious implications of his breathlessness earlier. He arrived at A&E very close to death. The choice to cede control to medical experts did not seem to be the product of a poor education because TG was a lawyer, and, conversely, some of the men who took control of their own treatment decision making had little education. I suspect it was a matter of the degree to which a man **felt secure in his masculinity**, with those who felt insecure striving to shore up their self-image by aligning themselves with masculine hegemonic images and norms, and I will explore this suspicion in the main research analysis.

For some men, agreeing on the spot to the treatment being offered was not only an expression of confidence in their doctor's advice, but also an expression of their desire to 'get on with it'. **Decisiveness and a desire to take prompt action** were commonly coded themes and are consistent with the action orientation of normative masculinity.

**Other men engaged more actively** in the consideration of options, seeking second opinions, researching the internet, and discussing the matter with family and friends, including, importantly, people who had personal experience of cancer. Many of these efforts were quite scattered, producing a large collection of information which was not strategically useful, although it may have helped the man feel he knew more about his condition. However, the cases of three men stand out for the analytical process and utility of their research:

Brucie was diagnosed with advanced prostate cancer. He used the information he was given as to the cancer's type and stage to research international best practice from the web sites of large American cancer hospitals, thereby assuring himself that he was being offered the best treatment regime for his condition. He also did a lot of general reading and put himself on a strict diet, but later eased back to a Mediterranean diet on the advice of a dietician.

Peter was diagnosed with advanced renal cell cancer and sought the advice of a second consultant from the beginning, keeping in touch with him on an ongoing basis to ensure a range of opinion, which he highly valued. He made two choices against the advice of the hospital specialist based on this second opinion, both of which may have been critical in keeping him alive, and both of which were later reflected upon with some positivity by his hospital specialist. Peter has well outlived his initial life expectancy, and has a strategy of trying to stay alive until a curative treatment is found.

Jake's Hodgkin's Lymphoma proved resistant to standard treatments and he reached the point where he faced death. His parents then found a clinical trial of a chemotherapy drug mentioned in some literature distributed by the Leukaemia and Blood Foundation, and took the initiative to make their own direct inquiries of doctors overseas. Jake was admitted to the trial, flew to Los Angeles every two weeks for treatment at his family's expense, and was then well enough to have a bone marrow transplant, the early indications from which appear extremely positive (100% donor cells).

Both Brucie and Peter are **in their fifties and are tertiary educated professionals**. They both had a good understanding of their disease status and seemed relaxed and focussed about doing their own research and controlling their own decisions. Both had supportive and capable wives who they fully consulted with and whose support both found invaluable. (In order to maintain confidentiality, the qualities of Jake's parents cannot be described.)

It was disturbing to me how many men (11; 40%) **did not have a clear understanding of their disease status**. In most of these cases I could tell from their treatment and monitoring protocols that their disease was more serious than they understood. Obviously, a clear understanding of the disease status (prognosis, purpose of treatment) is needed as a basis for making decisions about treatment, and also about other priorities in one's life. In Buck's case (the Maori man whose diagnosis was delayed because he did not understand the significance of a high PSA result), he appeared to have been directly misled to believing that he was cured: He said that his support person (sister-in-law) "asked her, bluntly, 'Are you telling us that now he has, has not got cancer? But he will be on Zoladex injections?' And the answer came back as affirmative." The high proportion of men in this sample who lacked clear understanding of their disease status suggests that improvement in communicating this topic is required.

**Women** played critically important roles in the support of men throughout their cancer experiences. Married men invariably appreciated the support of their wives who typically reassured them, discussed treatment choices with them, accompanied them to consultations and treatments, organised their complex medications and dietary requirements, and were generally helpful and attentive. When asked how they would cope without their wife's support, men usually took pause before responding with words to the effect that it would be 'just too hard' (Bruce). Other significant women (commonly daughters) not infrequently went so far as to take control over parts of men's treatment, giving unilateral directions as to

what their man was to do - and their efforts were deeply appreciated. For example, Bazza's daughter made arrangements for him to undergo expensive vitamin C therapy, and he happily accepted the *fait accompli* and paid for it. By ironic and telling contrast, Bazza was quick to disparage his son's suggestion of an alternative therapy, saying it was a 'cure all' lacking credibility. The special influence of particular women is a theme that will be pondered further as part of the main research.

At the time I conducted the interviews I was not aware that the Palmerston North RT staff gave patients a **DVD** explaining their treatment, so did not ask directly about it use. However, even though a great proportion of the men underwent RT, none of them mentioned it when asked about what information sources they used. Indeed, one man who I interviewed within an hour of his last RT treatment for prostate cancer which had spread to the bone suggested that having a DVD might be helpful! It would be useful to know whether the RT DVD's are in fact being delivered to patients and whether they are using them, but a more effective approach may be a supervised viewing at the hospital, as discussed below.

**In sum**, most men relied on their doctors' advice confident that it was best for them and that they need inquire no further. Some took their confidence to dysfunctional lengths that might be described as reverential. Other men asserted their self-determination by consulting a range of other sources. Few had the analytical skill to make efficient strategic use of other sources but those who did were able to use them to great advantage. A significant proportion did not understand their own disease status and so were not in a position to fully control their treatment decision making or other choices in their lives that turned on their prognosis. Finally, women played important and greatly appreciated supportive roles covering the whole of men's cancer journeys, including treatment decision making, and including taking some unilateral action.

### *Suggestion*

The period shortly after diagnosis can be capitalised on to engage men in orientation to the disease and to services that can assist them. This should help patients make decisions of a better quality in terms of meeting their own priorities, while reducing anxiety by providing better understanding and control.

An orientation tour of services is used in some overseas hospitals, but is unlikely to be practical in the smaller New Zealand context. However, a **DVD could be used to orient** new patients to: the nature of cancer and the main treatment types (including footage of some of the treatments that men most commonly experience e.g. external beam radiation for prostate cancer, chemotherapy by infusion); medical and psycho-social services and resources; and the process of making treatment decisions, providing guidance as to how patients might take control of their treatment. It could be viewed at hospital at a scheduled appointment as part of a patient's orientation to treatment, and could be reinforced with a take-away leaflet.

The DVD would help patients identify: important descriptors of their cancer; their own outcome priorities (e.g. survival or particular aspects of quality of life) by which they could guide their choices; and useful research sources. It would encourage patients not to feel

overwhelmed by medical expertise but to ask questions and retain ownership of responsibility for their own health to as great an extent as they prefer. The research segment would explain how to seek out strategically useful information (useful web sites), how to obtain a second opinion, and some sensible guidelines regarding 'alternative' treatments. It could have a separate section for particular common cancers, notably prostate cancer, with an introductory discussion of some of the treatment side effects which men in the present research found most distressing: incontinence (including the need to wear a catheter after surgery, and incontinence after RT), and loss of erection. Most of the DVD would be generic to cancer services throughout New Zealand, but each should include a section tailored to local conditions, visually walking patients through the hospital and community services they are likely to use: surgery, RT, and chemotherapy at hospital, PHO cancer nurses and Hospice nurses, and Cancer Psychologists, Maori Cancer Coordinators, and local Cancer Society.

DVD format is suggested in order to bypass illiteracy problems to and provide 'face to face' for Maori. The DVD could be viewed as standard procedure prior to the first treatment consultation, and with an opportunity to ask a nurse questions after it. A copy could be offered to patients to take home, along with a take-away leaflet which includes spaces for the patient to fill out their own treatment outcome priorities and their cancer descriptors (which they would learn from their doctor). Patients could be asked to arrive an hour early for their first treatment consultation in order to view the DVD, or if they had been given diagnosis and treatment recommendations on the same occasion, they could be scheduled for a separate viewing later. It would be important to advise patients that the resource would be best viewed with those whanau/family supporters who are likely to have ongoing input into treatment decision making.

The use of such a DVD would also better ensuring that patients gain understanding of the true status of their disease, which will empower them to make the best use of treatment opportunities or the limited time they have left, and give them a sense of control which is a good counter to anxiety.

### *3.3 What men wanted in treatment option discussion*

About half the men were unreserved in their satisfaction with how medical professionals discussed treatment with them. Men liked to be talked to in ways that were:

- **Straight.** Men found the frank truth dignifying and respectful, and it gave them the facts they needed to be in control of their lives.
- **Fully explanatory.** Men wanted to know all the options and their implications. Two men were unhappy to learn belatedly of the sexual side effects of their treatments. One was aware that he had not heard everything that was told him, but he was sure this important point was not stressed. Several men showed me their medications but did not know what they were for, and two were surprised to learn from me that none of them were treatments for cancer (they were for nausea or for other conditions). One Maori man (Richard) felt disrespected when, after major surgery, he asked a nurse what his medications were for, and she told him simply that they were 'to make him feel better'. When he got home, he still could not figure out what his sixteen

different medications were for or how to keep up with them all, so he threw them all out.

- **Respectful of their self determination:** Men wanted to choose and be in control of their treatment without pressure. Confidence in doctors was severely undermined when men felt they were being directed, an option was ruled out unilaterally, or that control was being gently wrested from them, as happened in a few cases. In two cases men had done their own internet research and wanted to discuss treatment ideas but felt disparaged and degraded by the response. In one case a man chose a non-standard path suggested in a second opinion (had gold seeds implanted at his own expense before external beam radiation for prostate cancer) and was most impressed when his radiation oncologist visited him during RT to see the gold seeds being used to direct radiation more accurately. Only one man felt it was odd being offered treatment options and asked his opinion: Jacko felt it inappropriate that the expert was asking the novice.
- **Maori men** raised two issues uniquely: they wanted medical professionals (and counsellors/coaches) who did not judge them, and they wanted to see, face to face, that they were genuinely caring, sincere and honest. When this caring was conveyed, together with on-the-level straight explanation, Richard felt that his specialists were treating him as a friend. This relaxed his concerns about body tapu.

### 3. Use and opinions of psycho-social services

Data breaking out the use of services by gender provided by CSNZ regions to me in 2010 showed that men used services at rates considerably lower than women (ranging from approximately 20% to 60% of the female rate). It is important to learn the reasons for this disparity, particularly since, as men age, they are more vulnerable to social isolation and attendant psychological risks than women.

**Note** that this topic overlaps with issues which are the focus of the main research report (understanding and better addressing the distress experience of men with cancer). The thoughts expressed below are therefore to be regarded as preliminary.

#### 4.1 Use

In Table 1, above, the use of psycho-social services by participants is recorded:

- **Overall service use:** Fourteen men (half) used a service or services. This included five out of six Maori men.
- **Transport:** Seven used CSNZ transport to treatment and another three used a transport shuttle provided by the DHB and local community. Five out of six Maori men used a transport service. Eight of the ten men who used a transport service were in the low or very low income brackets.
- **Groups:** Five men attended CSNZ mens and/or women's groups (Roly is so socially isolated that he attends a woman's group as well as the men's group for company), and one had done the CSNZ Living Well course.

- **Other CSNZ services:** One visited the local CSNZ office often for a chat, one had phoned the CSNZ information line, and one had received much needed household items from the CSNZ field worker.
- **'Counselling', social work, chaplain:** Two men used and highly valued the Maori Cancer Coordinator service and another had brief contact. The young man had unsolicited contact from the hospital social worker and Canteen, which he did not find particularly valuable. (He already had excellent support from his parents.) One man received an unsolicited visit from a hospital social worker since the extensiveness of his surgery indicated suicide risk, but did not feel he needed this. One man was visited in hospital by the Chaplain at the behest of nurses due to his distress upon diagnosis, and found this good for his morale. No men used the Cancer Psychology service associated with MidCentral DHB or sought any other 'counselling' in relation to cancer-related distress.
- **Home help:** One man was given home help after major surgery but found it intrusive and was glad when it finished.

In sum, transport was the most commonly used service and it reached lower income and Maori men well; other CSNZ services and groups were not used a lot by men; and 'counselling' was not sought, except that the Maori Cancer Coordinator's services were highly valued by the two Maori men who used them.

#### *4.2 CSNZ services and 'We ask you to make the first contact' policy*

Everyone who had used and commented on the quality of CSNZ services was impressed and grateful. Men could not speak highly enough of the transport service and two men wanted to become drivers themselves in future.

#### *Men's groups*

Six men had been to at least one men's, woman's or combined group meeting. One of those men went only to help others. One went because he was desperately lonely. The other four found the group offered useful information and welcome social support from people with a common interest. One man found that it helped put his cancer in perspective when he saw others worse off than himself.

The perceived potential value of men's groups was markedly greater amongst **Maori**. This is discussed further, below.

Amongst **Pakeha**, the perception of sitting in a group with other male cancer patients was not appealing to most. For several, their off-putting perception was that men sat around 'sharing their woes', 'whining' and 'feeling sorry for themselves'. Several saw the purpose of the groups as being for 'needy' people, 'like AA'. These perceptions are at odds with masculine self concepts of strength, capability, self-confidence, positivity, and being the helper rather than the helped. Other reasons for not attending included fear of being overwhelmed by others' suffering, not wanting to allow cancer to have too much prominence in one's self-image, having enough or preferred support opportunities through family and through community groups, not 'being a communal creature' or enjoying the company of men, and

being wary of meetings for meetings' sake. One Maori man was interested but was too whakamaa to go without being taken along by someone he knew. One man who had breast cancer was interested to go but was told (incorrectly in my view) that the men's group was not suitable for him since most of those who attended had prostate or bowel cancer, and he had 'nothing in common with them'. It was common for (Pakeha) men to say that they would go to lengths to attend a men's group if it would help someone else, but would not attend for themselves.

When asked **what a group would have to be like to interest them**, men offered: some talk and information about cancer but not too much; positive; outward looking; focus on normal and interesting things that men do and could possibly help each other with (e.g. fixing cars, fishing, gardening, home building/renovations/maintenance); sharing; and being available to support each other. One man would have been interested in a group with professional facilitation that led discussion that unmasked the real person – after a nice relaxing meal and beer together. Another man mentioned the importance of talking about interests other than cancer in order to get people talking. For others it was important that the meeting not be too long, and had a clear focus with practical outcomes.

#### *Connecting with services*

Routes of connection to CSNZ services appeared **haphazard**. The following were mentioned: a district or hospice nurse asked if they could give the CSNZ field worker the man's details; a friend suggested it; a man overheard an RT therapist talking about the transport service. Two higher income/educated men found their own way to a CSNZ office to discuss services. One Maori man said he did not use CSNZ because, 'I wouldn't know who to call', and two men said they were mystified as to why CSNZ did not make contact with men proactively. One of those said he thought field workers should connect with men in RT waiting rooms.

In my opinion the CSNZ policy that clients should initiate contact poses a **serious barrier** to men connecting with needed services given the incompetence many men feel about dealing with the health system generally, and the general reluctance of men to seek help associated with masculine norms of competence and independence. When people feel uncertain like this, they need pro-active intervention and warm human contact to help them make needed connections.

#### *Suggestions*

##### **Connecting men with services:**

- **Review CSNZ policy** to enable and promote proactive steps by CSNZ workers and volunteers to connect with men (and women).
- Have a **social support screen** ('Do you have a wife or partner?'; 'Are you living alone?') built in to standard post-diagnosis nursing procedures. For men who are at risk of social isolation, permission should be sought to pass contact details to the PHO cancer nurses, the Cancer Society field worker and, if appropriate, the Maori Cancer Coordinator. These workers could also **buddy isolated men** with male volunteers,

who can coach them in what to expect and the services available. In an ideal world, all patients would be assessed for psycho-social needs more broadly. However, with limited resources available, a brief screen of this nature would target what is probably the single most important psycho-social risk factor.

- **Reach out to men who are receiving radiation or chemotherapy** at hospitals e.g. CSNZ volunteers, fieldworkers, or the ladies who already regularly visit treatment wards with trollies of sandwiches etc. could discuss services briefly with men who are in waiting rooms or receiving chemotherapy infusions and give them an information leaflet or take their contact details for follow up.
- **Train RT therapists** in services offered by CSNZ to enable them to chat with men about them during treatment. Men were universally complementary of RT therapists, telling of their warm and personal chattiness. It would not take much time out of one of the regular RT staff training meetings to brief staff on CSNZ services that are most likely to be of interest to men. **Posters** could also be put on the ceiling prompting RT patients who lie on their back while receiving treatment to ask about services.
- **Use transport as a conduit** to other services. Given that most of the men using transport services receive low income, and a high proportion of Maori interviewees used transport services, transport services may provide a golden opportunity to reach men from these vulnerable groups who otherwise tend to 'slip through the net'.
  - Provide all men (and women) beginning radiation and chemotherapy at a hospital with written information about the transport service, and display posters about the service in waiting rooms. These materials should be in very simple English and supported with pictures for people with limited literacy.
  - Have CSNZ drivers inform all men (and women) about other CSNZ services – in similar fashion to how fast food chain staff ask 'Can I up-size you?'. One of the men interviewed began attending men's group as a result of such a discussion. The driver could also offer to detour via the local CSNZ rooms on the way home for a chat with the receptionist.
  - Have CSNZ drivers provide an information leaflet and verbal encouragement to Maori men to contact the Maori Cancer Coordinator also (refer below)
- **Use the concept of 'team'** to sell the idea of engaging with a range of service providers (e.g. 'coaches', transport service, men's group) and making best use of family and friend support. HP could use the metaphor of building a rugby side to identify that there are lots of people with a role to play in getting through cancer.
- **Use an up-beat pro-active tone.** Here is an example of a promotion message that could be appropriate for men who have just been diagnosed. It incorporates the values shown by most men in this research and could be conveyed in story form or as a mixture of story and explanation from a respected male celebrity:

If you have just been diagnosed with cancer you can:



Keep it to yourself, worry about all the disease and treatment unknowns, withdraw and let your head do you in, hit the drink, drugs and maybe even the wife... in short, you can go and shrivel up in a corner....

*Or, you can*

1. *Be positive and face it* – you've been through other stuff in life, and you can get through this! See this as an opportunity to face your demons and overcome them.
2. *Build your team* – family, friends, professionals – they all want to support you, and they all have an important role to play, but you need to put them in the picture and let them know that their input is welcome
3. *Get informed and take control* - how you go through this is up to you, so ask questions and use resources – they're there for a reason!
  - Cancer Society leaflets, helpline and programmes... or drop in and have a chat
  - Doctors, specialist nurses and mental health skills coaches
  - Community based cancer nurses and social workers
4. *Work out your strategies* - cancer can cause real losses to your lifestyle. With the support of your team, you can process those and move on to other meaningful things you can do in the future. Its about processing and redefining what is important to you.

*Cancer: Build your team and take control.*

### **Men's groups:**

I am not well informed about how well attended and vibrant men's groups are, or whether CSNZ regards them as successful at meeting their purposes, however, they clearly have an image problem with many men, which may stem from insecurities around dealing with physical vulnerabilities and emotions in an overt way, and in a group. I had suggested earlier, informally, that CSNZ partner with the **Menz Sheds** movement since that initiative is attractive and beneficial to many men of the older age group for whom cancer is a common problem. I understand that this idea has been discussed although I do not know its present status. Menz Sheds are based on the concept that men connect best with each other 'shoulder to shoulder' over a practical project. It can be seen from the participants' comments above how well this practical and non-threatening approach fits with what many men said would interest them in a group (although not every man enjoys using a hammer and nails, of course). Other than the obvious benefits of the social support offered by Menz Sheds, the opportunity to assist with small building projects for others is also valuable towards rebuilding the self-image of a man who has been set back by the loss of valued roles (e.g. retirement, widowhood) and by a sense of dependency which may be associated with being a

cancer patient: masculine self image includes a sense of being the helper rather than the helped, and many of the participants in this research expressed their desire and readiness to help others with cancer. The social support, business, and opportunity to help others provided by Menz Sheds have tremendous potential as antidotes for depression.

Menz Sheds may present a number of **opportunities** for development of men's services by CSNZ:

- Patients could be **referred to their local Shed**;
- Sheds might provide good **health promotion opportunities**;
- Aspects of the Menz Sheds model might be **adopted by CSNZ men's groups**. For example, groups might become more focussed around doing practical things for others, with cancer education and discussion taking a (regular but) more minor role. Men's groups might 'take action' for four weekly or two fortnightly meetings, during the day, and then have a 'talk night' once a month, which more men might feel comfortable participating in because of having become comfortable with the others during the action days. Ideas for the action focus might be helping each other on household projects, or helping other people with serious/chronic illness, and having some men's days out e.g. fishing, visiting a model railway display etc.

Besides drawing from the Menz Sheds model, CSNZ men's groups could develop a helping agenda of **buddying** socially isolated men (see below). Again, this would give the groups a strong helping *raison d'être* which would provide participants with an outward focus, purpose, and a role consistent with a strong masculine self-image.

Finally, I suggest that men's groups work to counter misconceptions that they are about 'men sitting around feeling sorry for themselves' by removing terms like 'support' and using terms like 'action' in their descriptors e.g. 'this is the **men's cancer action group**' not the 'men's cancer support group'. Such terminology would also better describe an agenda which has been re-focussed to incorporate some of the suggestions above.

#### *4.3 'Counselling', aka 'skills coaching'*

I asked men whether they had used any 'cancer counselling' or psycho-oncology or social work services, or any other supportive services or community groups such as chaplains or Maraë. I used the term 'counselling' to cover a broad range of 'talk services', and I believe men understood it that way. However, the term is a misnomer which carries connotations that are off-putting to many men, as will be seen below. Dr Don Baken, who is a psycho-oncologist with the Cancer Psychology Service in Palmerston North, uses the term '**mental health skills coaching**', and finds this is an acceptable and more accurately descriptive term for the service he delivers. It bears comparison to the term 'coordinator' which well describes the work of Maori Cancer Coordinators, who ensured that men in this research were connected with the services they need. 'Coaching' has strong sporting and teamwork connotations, which are very acceptable to masculine culture, and I would like to see the use of this term encouraged in future, in the interests of removing barriers to men.

As mentioned above, a few men had unsolicited approaches from cancer-related 'counsellors' or social workers, but only two were keen to continue the relationship. Both of these were Maori men who found the Maori Cancer Coordinator's support most valuable, as described further below. The fact that **men generally had not taken advantage of counselling/coaching services** is concerning, given that several of them appeared to be depressed at the research interview and several more made comments suggesting that they had been earlier.

For about **two thirds of men, it was highly unlikely** or simply inconceivable that they would ever use 'counselling' services. On the face of their comments, there seemed to be two misconceptions which put them off: that counselling was/counsellors were not credible; or that counselling could not help since 'the real problem' was physical disease. However, underneath these concerns I suspect there is a deep fear of exposing emotional vulnerability.

**Misconceptions** were expressed by individuals in these terms: the science behind counselling was 'not real' but 'just abstract theory'; some people 'come out worse than they started'; there was no need for counselling because the man 'still had his head screwed on the right way'; no counsellor could provide useful advice on how to live because at his age the man knew more about how to live than any counsellor was likely to; counsellors were 'left wing, ultra liberal, school teacher... sandal wearer' types for whom the man had no respect; counselling could be of no use because it could not fix the disease or could not take a little spanner and fix an emotional problem inside the man's head. Some of the men who made these comments admitted that they were ignorant of how counselling works, and indicated they might be open to persuasion. However, it is clear that the term 'counselling' is laden with distasteful connotations.

Better conceived **reasons** for not wanting to use counselling were that the church was the appropriate place to turn for assistance with issues of an emotional-spiritual nature, and that it was not appropriate to take issues to a complete stranger when family members were available (a Maori view).

One man, after initially brushing off the idea, admitted he found the prospect of counselling **'very scary'**. Radar appeared throughout the interview to be more open about his true feelings than most men, and said he found the interview experience fascinating. He described being out of his comfort zone when dealing with emotional matters, saying that he 'lived in a world of facts – it's so long, costs so much, weighs so much...'. Psychological help (including medication) was frightening because men are supposed to be 'bullet proof' and to cry is unmanly. *His fear was of losing control.* He mused that it might be possible that he could be 'led down the garden path' to see a counsellor if someone he had confidence in, and who had the confidence to lead him - such as a senior RT therapist he knew – directed him towards it and arranged it for him, and offered to meet him there for the first session. (As mentioned above, the phenomenon of men happily accepting the unilateral direction of women to get help will be discussed more fully as part of my main research.)

The remaining third of participants saw attending counselling as a **real possibility** if the need arose. One man saw it as a matter of always getting the best advice possible, another as an opportunity to feel better by 'getting things of your system', and another said simply, '[counsellors] exist for a reason'. However, it did not appear that men could be relied upon to identify depression in themselves, and this raises a real difficulty in terms of connecting men to counselling/coaching services.

I asked men whether they would have a gender preference if they were to see a counsellor. None did. Few had to think about their answer. I asked if they had a discipline preference, and a few preferred a psychologist over a social worker either because their prior experience with social workers had left a poor impression or because they saw psychologists as more expert. Some men preferred that the counsellor have had personal experience of cancer or other difficult life experiences, and, for two, personal cancer experience was an essential qualification. For one it was important that a counsellor be highly qualified and specialised, and, for another, that he or she know about his particular type of cancer (prostate). Generally men seemed to be looking for a **mixture of formal qualification and practical commonsense/life experience**. Three Maori men and one Pakeha emphasised the importance of the counsellor having strong human qualities such as interacting 'on-the-level' rather than speaking down to them, and interacting with respect, honesty, genuine caring and without judging them.

In terms of connection, most men said they would **prefer a referral or recommendation** through a GP or CSNZ, but a few said that they would reach out independently if they had a counsellor's contact details.

**In sum**, these observations raise issues of:

- men's ignorance and misperceptions about 'counselling' services
- bridging the gap created by insecurities regarding emotional matters
- providing counsellors with the kind of qualifications that men respect (i.e. formal qualifications and life/cancer experience)
- helping men to recognise depression in themselves
- connecting men to those counsellors

These are weighty and difficult issues which might be productively addressed by combined discussion between interested parties (e.g. CSNZ, Movember, Maori Cancer Coordinators, the Cancer Psychology Service in Palmerston North....).

### *Suggestions*

- **Target women** for health promotions which explain how depression manifests in men and what can be done about it (both formal intervention and options like men's groups and Menz Sheds).
- **Target men** also for health promotions regarding how to identify depression in themselves and options for taking action. I found it ironic that some men who were clearly depressed, and for seemingly obvious reasons, were oblivious to this, and said

they would consider counselling if they ever had the need but they couldn't imagine it! John Kirwan's material is fabulous but assumes that a person can tell that they are depressed. It also leaves intact the common misconception that because a physical disease is causing a man's worries, there is nothing that can be done to make him happier. Some HP designed specifically for the older male set, which addresses both of these, would fill a gap which is pertinent to cancer.

- **Work to correct the image of 'counsellors'.** I was thrilled to see that 'Psycho-Oncology Service' run by MidCentral DHB/Massey University has recently renamed itself the 'Cancer Psychology Service'. This change was a result of client feedback and draws attention to the word 'cancer' rather than to the word 'psycho'. It is likely to be far more palatable to men, in particular. The Cancer Psychology Service has also produced new publicity material, which includes photos of their team, further demystifying their image, and providing a more personal face-to-face introduction which may be particularly important for some Maori. As mentioned, psycho-oncologist Dr Don Baken also uses the term 'skills coaching' rather than 'counselling' to describe his work. Are there other ways to give men a glimpse that such talk services are 'ok'? I hope the term 'coaching' will be taken up more broadly. Perhaps 'coaching services' of various kinds would seem a more normal part of cancer care to men if they were housed in hospitals, rather than in buildings associated with mental 'weakness', like a psychology clinic. I have also suggested that coaching services be included in a DVD for orienting men to cancer treatment.
- **Use the transport conduit** mentioned above to introduce the Cancer Psychology and Maori Cancer Coordinator services, and maybe to provide a leaflet or DVD on identifying depression in oneself and what to do about it.
- Promote the value and availability of these services to GPs and specialists, and **encourage recommendations and referrals.**
- **Use cancer buddies.** Isolation is the worst part of cancer for some men, and professional coaching may not be necessary – or even helpful – in addressing the depression that arises from this. As mentioned above, men could be screened for social support as a standard nursing practice at diagnosis, and those who are alone could be referred on to CSNZ and/or the Maori Cancer Coordinator for buddying up with a male cancer survivor volunteer. The buddy would be there to 'show him the ropes' and 'touch base' periodically. (I understand that there is a 'Zipper Club' for heart surgery patients at Waikato hospital, which comprises volunteers who visit patients prior to and after surgery. This group may have some useful 'how to' tips for cancer buddies.)

#### 4.4 Maori

Maori men particularly valued transport services and Maori Cancer Coordinator services, but they also expressed interest in men's groups (one showed his annoyance that he had not been told about this sooner).

**Men's groups** were not popular amongst Pakeha (as discussed above) but there was considerable interest from Maori, consistent with Maori collectivist cultural norms. This is

an opportunity that offers real potential for meeting the social and support needs of single Maori men in particular.

**Counselling.** The two most isolated men had had previous experience of counselling related to mental health or alcohol issues, and were reserved in their impression, one concerned about being judged, and the other that the counsellor may not know any more about the topic than he did – if the counsellor was qualified, personally experienced, and honest, then he would be interested. One of the four with more support said that he would use family support in preference to going to a stranger, and another said that he would turn to a psychologist who was a friend, or else to the social worker who had contacted him after his surgery – again, people he knew - but that his strategy was always to look ahead positively so he could not envisage ever needing counselling. The remaining two men said they would be happy to consider counselling and both had extremely positive experience with the Maori Cancer Coordinator. One of these said he would need more information and a personal introduction to a counsellor to get past his *whakamaa*. These accounts emphasise the need for personal connection and confidence, in accordance with cultural norms.

**The Maori Cancer Coordinator** was greatly appreciated by the two men who took advantage of her service. One said that he loved her caring, proactive and face-to-face yet non-invasive style. She would ring and invite him to catch up over coffee. The other had a similar experience and was particularly grateful for her assistance in overcoming *whakamaa* to deal with issues such as his benefit from WINZ and to connect him with other helpful people in the community. It was clear that Maori men find it important to make a face-to-face assessment of the sincerity of any potential counsellor, and prefer to know the person in advance or have a personal introduction.

In common with CSNZ services, **connection** routes to the Maori Cancer Coordinator's service appeared haphazard: one man happened to be visiting his sister-in-law when the Maori Cancer Coordinator visited her; the other was unsure how the connection was made but thinks it may have been through his home help; and from speaking with a couple of Maori Cancer Coordinators in the course of organising recruitment for the research, I learned that they see very few men. The present system for connecting with men is clearly not working well.

### *Suggestions*

- Discussion between CSNZ and Maori stake holders (e.g. Maori Cancer Coordinators) could be very profitable in **developing men's groups in a way that attracts more Maori** - whether the outcome involves a modification of the men's groups already run by CSNZ, the development of something new and Maori-specific which might be run under a different umbrella, or simply the development of more effective ways to connect Maori men to the groups that are already run.
- Perhaps CSNZ could work with Maori Cancer Coordinators to devise and coordinate some **strategies to improve connection** of Maori men to both of these services. I have suggested, above, that transport services be used as a conduit both to other CSNZ services, and, for Maori, to the Maori Cancer Coordinator service. Grasping

this opportunity would seem particularly important in relation to men. There must be other opportunities to develop cooperation.

### **Conclusion**

Masculine cultural norms, roles, and experience of life are different from those of women. The understandings and preferences that result must be taken into account if men are to be well served by health promotion messages and health and psycho-social services. Recent initiatives by CSNZ aiming to identify and meet the particular needs of men have the potential to make a real difference to the cancer outcomes and psycho-social experiences of men. I hope that this report provides material that will fuel discussion within the Society, and between the Society and other stake holders, to that end.