



Research into the experiences of  
men with cancer - Interviews



Information for participants

**Background and aim.** Men tend to suffer worse cancer statistics than women, and may suffer more cancer-related stress as well. They tend to be diagnosed at a later stage and make less use of services designed to help patients manage the stresses of the illness. This may be because current services do not sufficiently match men's needs. This research aims to investigate men's particular experience of diagnosis and treatment and also of the stresses related to cancer and the services provided to help. Results will help plan later research projects, with the ultimate aim of designing earlier cancer detection and better services for men.

**What is involved?** We want to recruit 40 men with cancer from the Horowhenua/Otaki and Whanganui/South Taranaki to interview them individually about their experience of (1) how they came to be diagnosed, (2) how they made treatment decisions, (3) what cancer-related stresses they suffered, and (4) whether they used any services to help with that stress. The interviews should take 1-2 hours each and will be held wherever is convenient for the participant (e.g. in his home, if he likes). They will be recorded and then transcribed into written form, and then analysed for common themes. The researcher who conducts the interviews will analyse the transcripts on topics (3) and (4), and other researchers will analyse topics (1) and (2).

**Who is running it?** The research is funded out of Movember money administered by the Cancer Society of New Zealand. The Principal Investigator is Associate Professor Dr Christine Stephens, a health psychologist at Massey University in Palmerston North. The researcher who will conduct the interviews is Heather Heron-Speirs, a Doctoral candidate in psycho-oncology at Massey. Psycho-oncology is about the psychology relating to cancer.

**What will participants get out of it?** Participants will be making a voluntary offering of their time and experience for the purpose of advancing our understanding of the needs of men with cancer. The main benefit is in simply knowing that you are helping to 'make a difference'. It can also be an enjoyable experience. However, we will also offer participants a \$25 fuel card for their time, a copy of the interview sound recording on CD at no cost, and a summary of the research results, also at no cost.

**What are the risks to participants?** Although talking through cancer experiences can be very valuable, it can also be distressing. You may not want to participate because of this. However, we can take our time in the interview and do not need to discuss anything that you don't want to. Also, you can stop at any time, and also withdraw permission for us to use the recording at any time up until it is transcribed. Finally, we do have professional cancer counselling services available, free of charge (detail overleaf).

**Do I have to meet any special criteria?** You have to be at least 18 years of age, have been diagnosed with cancer, and have had at least some of your treatment already. You also need to 'feel up to it' - we don't want to trouble anyone who is presently undergoing demanding cancer treatment, such as chemo. Finally, you need to speak good English ~~or have someone available at the interview who can translate\*\*\*\*\*~~.

**How do I find out more?** Contact the researcher, Heather Heron-Speirs, by phoning her on **freephone 0800 156 519**. She will explain the details to you on the phone or, if you prefer, come and discuss the project with you in person. If you are interested in going ahead she will arrange a convenient time for the interview.



### **Participants' safety and rights**

**Professional cancer counselling services provided free of charge to participants.** If you feel distressed and would like to use these services the contact details are:

- For participants from the Horowhenua/Otaki: The Psycho-Oncology Service run jointly by the MidCentral DHB and Massey University (phone 06 350-5180).
- For participants from Whanganui/South Taranaki, phone your local Cancer Society and ask to be referred to the counselling service arranged for this study (Whanganui phone 06 348-7402; Taranaki phone 06 757-3006).

**Confidentiality.** You can be assured that only the research team will have access to 'raw data' (i.e. the interview recordings before they are analysed) and, specifically, that *no personally identifiable information* will be passed to any member of a health care team or published. Recordings will be kept securely and identified only by a pseudonym. A list associating pseudonyms with real names will be held separately and securely by the researcher and destroyed when the research is complete. Transcription of interview recordings will be conducted under confidentiality agreement and, in any case, both recordings and transcripts will be identified only by pseudonym.

**Withdrawal.** You are entitled to withdraw at any time without the need to give a reason. Simply tell the researcher or phone her or the Principal Investigator (contact details below). You can also withdraw permission to use your interview recording provided you do so before it is transcribed. Be assured that *withdrawal from participation will not affect cancer treatment or use of support services in any way.*

**Code of rights.** The Code of Health and Disability Services Consumers Rights 1996 applies to this research. For details see [http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-\(summary\)](http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-(summary)).

**Complaints.** You can complain or make further enquiry about your rights directly to the researcher or the Principal Investigator, or by contacting the Head of the School of Psychology, Massey University, Palmerston North, or an Advocate working with the Health and Disability Commission (see <http://advocacy.hdc.org.nz>), or the Central Region Health and Disability Ethics Committee (phone 04 8162405 or see <http://www.ethicscommittees.health.govt.nz/moh.nsf/indexcm/ethics-about-central#contact>).

**Your right to research results.** You will be offered an abbreviated or full copy of findings, free of charge.

### **Research team contact details**

**Researcher:** Heather Heron-Speirs, freephone 0800 156 519, or contact through the Principal Investigator.

**Principal Investigator:** Dr Christine Stephens, Associate Professor, School of Psychology, Massey University, Private Bag 11 222, Palmerston North, phone (06) 350 5799 ext.2081, email [C.V.Stephens@massey.ac.nz](mailto:C.V.Stephens@massey.ac.nz)

### **About the researcher**

Heather Heron-Speirs has a Masters degree in clinical psychology and is now studying for a Doctorate. She grew up on a farm, is in her late 40's, married with three grown up children, and has spent much of her adult life caring for them and various folk with physical and psychological needs. Two years ago she was diagnosed and treated for breast cancer. She has also experienced depression. Now her health is good and her research is full time.

**Testimonial** from Jeff Bignall, Cancer Society Men's Group, Palmerston North. Jeff says, "I allowed Heather to do a practice interview for this research on me. Although she was a complete stranger, I found her easy to talk to and she could empathise well with my experiences. It was an interesting and enjoyable experience and I hope other men will step up and help with this project."

