

Appendix 5. Full length interview schedule

Interview schedule: Action Research Phase 1

Content areas:

How were diagnosis and decisions around treatment approached?

What is the experience of distress of men with cancer? Which men are/not accessing services and why?

PART ONE: RECEIVING TELEPHONED EXPRESSION OF INTEREST

5 mins if possible. Cover these points:

1. **The study will help us** understand the experience of cancer for men, and help the Cancer Society and other services to be more responsive to the needs of men (hook)
2. **Check understanding** of the information sheet:
 - Interview, 1-2 hours, will be recorded (→ check palliative patients' strength to commit)
 - \$25 fuel card; will be offered results
 - Ethics provisions
 - Have you any other questions?
3. **Check eligibility:**
 - **Age** (18 years)
 - living in **Horowhenua/Otaki or Whanganui/South Taranaki** area
 - Cancer **treatment stage**: If treated curatively, through the most demanding phase but within 6 months of completion [may be in late stages of non-arduous treatment] OR is being treated palliatively or ongoing care for recurrent illness OR is in 'watchful waiting' for prostate cancer
 - Speaks **English** sufficiently to explain his thoughts and feelings
 - No obvious significant **cognitive deficit** (e.g. dementia, intellectual disability) or serious psychiatric disorder (e.g. active psychosis, severe depression)
4. **Obtain verbal consent**
5. **Arrange interview time and place [take phone number]**
6. **Who gave you the information sheet?** (to track where participants are coming from)

PART TWO: INTERVIEW

A. Introductory

Purpose of questions: Rapport and consent

- a. **Check** how been since phone call (date) – are you well?
- b. **Connect:** whakapapa, rugby, place of domicile, farming/occupation etc.
- c. Explain: Biographical detail taken **on paper**; interview is **recorded** (show how), transcription, analysis, and return of results (after 2nd phase). **START RECORDING**
- d. Any questions regarding anything in the information sheet? Ethics?
- e. Obtain written **informed consent** form, including pseudonym.
- f. Explain **structure of interview**:
 - Will progress through stages: pre dx, dx, tx, now
 - And ask two kinds of questions: re medical experience, and personal stresses

B. Biographical data (separate document)

Purpose of questions: Demographic data gathering to background substantive data and to check eligibility (strength and demographic characteristics) for phase 2 of research.

C. Substantive questions

Purpose of questions: (1) explore process to **diagnosis, and treatment decision** considerations (for separate analysis) and (2) explore **stress/personal impact, coping, use of psychosocial resources**.

i. Pre-diagnosis

- 1) Before you first became aware that you may have cancer, **what did you know about the disease?** What was your **image** of cancer? Did you know any **risk factors** or symptoms to **watch for**? Did you know anything about **ways to reduce the risk** of getting cancer? Did you try any of them? Where did you learn them from? Specifically:
 - had you seen any **Cancer Society** information/pamphlets? Where from?
 - had you talked to cancer survivors/sufferers?
- 2) What **raised your initial concerns** that you might have cancer?
- 3) How did you **react emotionally to the concerns** (before you were diagnosed)? Did you take any action to deal with the stress?

- 4) Did you take any **action to check out** your initial concerns? e.g. talk to wife or mates, get medical advice e.g. from GP or internet or Cancer Society. Did you have a **strategy or particular thoughts** in mind that guided what you did?
- 5) What was the **trigger** that made you seek medical advice (wife's role)? How long was that after your first concerns? What **factors delayed** that?
- 6) **What kind of advice were you given?**
- 7) What **else was going on** in your life at the time? Did any of that **help or hinder** your getting diagnosed?

ii. **Diagnosis**

- 8) How did you **come to be diagnosed**? How did you **feel** immediately before, at the time and immediately after?
- 9) Did you find **the way** you were diagnosed helpful i.e. was it as **early** and as **low-stress** as possible? What could have reduced the stress involved? Specifically:
 - Could medical personnel (including your GP) have helped more? Did you find their attitude supportive?
 - Did you think of contacting the Cancer Society or anyone else? What did they do? How could their services have been better?
- 10) "With hindsight, do you feel you could have been **diagnosed earlier**?" **How** could that have happened?
- 11) What was the immediate **impact of diagnosis on your life**? Did you find yourself thinking/feeling/behaving different than before? Specifically:
 - daily routine, work (concentration, motivation, employment), plans
 - Interactions (withdrawal, irritation/ conflict/easily frustrated/'kicked the dog')
 - behaviours (drinking, risk taking)
- 12) How did concerns about life threat, surgery and other treatment **impact your state of mind**? Can you give me a **metaphor** describing that (e.g. "an avalanche of stressors", "the mountains rushing up")?
- 13) How did you **handle the stress** (emotion v. problem-solving approach)?
- 14) Did you **use any support resources**? Specifically:
 - Did you **contact** /were you **aware** of **Cancer Society** services and information (information pamphlets, Info help line, Cancer Connect)? What did you know? how did you come to know it? (e.g. see any pamphlets? Where?) What prompted your contacting them? What were you seeking? Get what you wanted? **OR What**

prevented you from contacting them (personal and practical barriers)? What would it have taken to **overcome** barriers?

- **Counselling or psychological** services (e.g. POS).....(same exploratory questions)
-**any other resources - hospital or community** e.g. other cancer associations, Maori co-ordinators, hospital Chaplains, internet.....(same)

15) Did you draw any support from **non-cancer-specific support/** resources e.g.:

- wife/family
- Marae based services, Churches, **spiritual** groups.....(same exploratory questions as above)
- **Men's groups** (Rotary, Lions, sports clubs).....(same)
- internet resources (incl info, web based forums/groups)(same)

16) **Where** did you get the most personal support from? Second most? **What actions or words** did you find personally helpful, from medical personnel, Cancer Society / other community resources, friends/family?

17) **What else** would have helped? "**What advice would you now give** to someone else about how to handle the stress of diagnosis?"

iii. **Medical treatment stage** (NB many similar questions to above)

(a) Treatment decision making

18) How well did you understand **what your diagnosis meant** when you had to make decisions about treatment? Did you understand clearly the prognosis and what treatment was designed to try to achieve?

19) **Which types of treatment** were you offered (curative/palliative, surgery, radio, chemo, watchful waiting)? Were you offered a **choice** of options? Do you feel you were **offered the best** options? Did any raise particular concerns?

20) How did you approach **deciding** what treatment options to accept?

- What were **family and friends** advising? What was your thinking? Did you have a guiding philosophy or **strategy**? Did you consider any alternative strategies?
- Did you **seek extra input/assurance/information** (e.g. second opinion, internet)?
- How much did you feel decisions were **up to you v. the doctor**? How much did you feel in control?

21) **Are you happy** now with what you were offered and the choices you made? "With hindsight, how would you advise someone else to handle that process now?"

22) Did you feel the decision making process was **stressful**? Did you feel **sufficiently involved** in decision making? How could decision making be **improved**?

(b) Coping with treatment

23) Which treatments did you take? Taking **each in turn**, what aspects were the most **hassle/stressful**?

24) What were the **effects of treatment on your life**? Did you find yourself thinking/feeling/behaving different than before? Specifically:

- daily routine, work (concentration, motivation, employment), plans
- Interactions (withdrawal, irritation/ conflict/easily frustrated/‘kicked the dog’)
- behaviours (drinking, risk taking)

25) Do you have a **metaphor** to describe what it was like for you during treatment?

26) How did you **handle the stress** of making treatment **decisions and of treatment** itself (emotion v. problem-solving approach, agency)? **How did you deal with** both the practical issues that caused stress, and the stress itself?

27) Did you **use any support resources**? What? **How did you get onto it**? How did it help? OR what **prevented** you? What would it take to **overcome that barrier**? Specifically:

- **Cancer-specific:**

- Cancer Society e.g. information pamphlets, Info help line, Cancer Connect, transport to appointments, advocacy, Osnam House
- Counselling or psychological services
- other cancer resources - hospital or community e.g. other cancer associations, Maori co-ordinators, hospital Chaplains, internet

- **non-cancer-specific** community resources e.g.

- wife/family
- Marae based services, Churches, spiritual groups
- Men’s groups
- internet resources

28) **What actions or words** did you find personally helpful, from medical personnel, Cancer Society / other community resources, friends/family? **Where** did you get the most personal support from? Second most? How could people/organisations have been **more helpful at the time of your treatment**?

29) **"What advice would you now give** to someone else about how to handle the pressures of treatment?"

30) Did you **do anything else to assist your healing**, other than the medical treatment offered to you? What? How did you get onto that? Did you find it helpful?

iv. Post medical treatment stage

31) Which was the **most stressful stage** of your experience of cancer (suspicion, diagnosis, leading up to treatment, during treatment, post treatment)? Why?

32) How would you describe the **impact** of cancer on your life **now**? What are the areas most affected? Specifically:

- daily routine, work (concentration, motivation, employment), plans
- Interactions (withdrawal, irritation/ conflict/easily frustrated/‘kicked the dog’)
- behaviours (drinking, risk taking)

33) Do you have a **metaphor** to describe how cancer has left you feeling about your life?

34) **What** are your stresses now? How are you **handling** them i.e. both the practical issues that caused stress, and the stress itself?

35) Are you using **any support resources**? What? **How did you get onto it?** How did it help? OR what **prevented** you? What would it take to **overcome that barrier**? Specifically:

- **Cancer-specific:**
 - Cancer Society e.g. men’s support groups, ‘Living Well’
 - Counselling or psychological services
 - other cancer resources - hospital or community e.g. other cancer associations, Maori co-ordinators, hospital Chaplains, internet
- **non-cancer-specific** community resources e.g.
 - wife/family
 - Marae based services, Churches, spiritual groups
 - Men’s groups
 - internet resources

36) **Where** do you get the most personal support from now? Second most? **What actions or words** do you find personally helpful and from whom? How could they be **more helpful**?

37) How has your experience of cancer **left you feeling as a man/husband/father and in your community roles**? What would be useful to you to help address those impacts?

38) Could you ever have seen yourself:

- speaking **one-on-one** with a cancer counsellor/psychologist or social worker, nurse, CSNZ field worker? Who would have been acceptable? What qualifications/credibility needed? Would a man or a woman be preferable to talk to? How would you need to hear about this (e.g. credibility of referee)? What issues might you have liked to discuss? What would you have been comfortable discussing?
- attending a **men's cancer support group**? What would it have had to be like to interest you (i.e. content, run by who, frequency, locality)? How would you need to hear about this (e.g. credibility of referee)?

39) Did anything good come out of your experience of cancer? (If “No”, What aspects of your life would you like to see improvement in? Remind that counsellor/ psychologists services available.) What have you **learned about life**? Would you like to be able to pass that benefit on to others? What would you like to do?

40) Is there anything else you would like to tell me about your experience of cancer?

STOP RECORDING

PART THREE: WRAP UP

Purpose: Remind of what happens now, introduce team discussion phase of research, ensure participant is happy, thank him

- a. **Reminders:** confidentiality of data, transcription process, when interview CD/results will be available, counsellor/ psychologists services available
- b. **Check bio data: Does man meet eligibility for team discussion?**
 - Inclusion: is not currently living with a spouse or partner OR is not of Pakeha ethnicity OR is unemployed/retired/beneficiary or has a gross household income of <\$50,000/year
AND
 - Is able to arrange transport to meetings (with petrol vouchers to reimburse cost)
AND
Has not accessed psychosocial support for cancer (e.g. Cancer Society's 'Cancer Connect' service or 'Living Well' programme or the Psycho-Oncology Service)

→ **explain** next phase of research (objectives, time commitment, travel necessary, possible personal benefits) and leave information sheet. **Would you like me to ring you?**
- c. **Thank you very much!!**