

The journey of treatment and care for people with cancer on the West Coast

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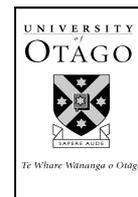
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EXECUTIVE SUMMARY

The typical journey with cancer is characterised by complexity. Despite this complexity, cancer service provision should include timely diagnosis, adequate information, appropriate treatment, seamless inter-professional communication, proactive support and exemplary palliative and terminal care. Worldwide, rural cancer care is acknowledged to be challenging as cancer treatment can often only be delivered in tertiary hospital cancer or oncology centres requiring travel and dislocation from home.

The West Coast District Health Board staff, Cancer Society West Coast Centre, and the Buller West Coast Home Hospice Trust, together with primary health care providers and Christchurch Hospital oncology staff, currently work together to provide cancer care to the people living with cancer on the West Coast, New Zealand. Their overriding concern is to provide the best possible care for people with cancer living in the region. To do this, they wished to examine the overall cancer journey more closely and in particular to understand the perspective of Māori with cancer living on the West Coast. As a result, a research project was commissioned by the West Coast District Health Board, Cancer Society West Coast Centre, Buller West Coast Home Hospice Trust, and has been funded by the Cancer Control Strategy Implementation Fund.

One possible way to look at the experience of people with cancer on the West Coast is to gain the perspectives of as many people as possible that contribute to the journey. This research project has attempted to do this by interviewing health and social services professionals, people with cancer and their family/whānau, and by surveying all those currently known to have cancer on the West Coast.

The resulting report aims to provide a snapshot of a complex interplay of diagnosis, treatment, support, and palliative care in providing a service for people with cancer. It presents an overview of the journey of people with cancer living on the West Coast from a variety of perspectives. Those interviewed believe the journey of people with cancer on the West Coast is currently characterised by a number of factors:

- Living with cancer in a rural and remote area impacts on the journey with cancer
- The health care environment has unique aspects, particularly in terms of the provision of primary health care and after-hours care
- Travelling for treatment and health care acts as a barrier and can alter choices for treatment and care
- There are specific informational needs
- Organisation and current co-ordination of care is limited by geographical distance and human resources, and as a result, there are multiple small delays
- Support agencies are limited
- Māori with cancer on the West Coast face particular challenges

Consideration has been given as to possible characteristics and components of an improved rural cancer service. These include: overall system characteristics; those that affect all people who have cancer; those which affect people with palliative care needs; those which affect those who require chemotherapy treatment in Christchurch; and, those particular to Māori with cancer.

A model of cancer care is proposed which incorporates these characteristics.

GLOSSARY

Cancer or Oncology Centre: A cancer treatment or oncology centre based in a tertiary NZ hospital. The centre treats patients with blood disorders and/or cancer and usually includes the three specialities of medical oncology, radiation oncology and clinical haematology.

Chemotherapy: The use of drugs to destroy or control the growth of cancer.

Graseby pump: Equipment used to deliver pain relieving and other medication to people with pain and other symptoms.

Haematologist: A doctor who specialises in diagnosing and treating blood disorders.

Home care: Paid or unpaid assistance provided to a person with a chronic disability or illness, living in the community.

Hui: A meeting, gathering, for purposes of discussion and/or celebration.

Oncologist: A physician who specializes in treating cancer, including surgical oncologist, radiation oncologist, and medical oncologist.

Panui: an announcement or advertisement.

Palliative Care: Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications¹.

Primary Health Care: Locally available health care that is provided by a health care professional at the first contact of a patient within the health care system. It comprises a number of services from screening for disease through to diagnosis

and treatment and is provided by a variety of different community based health professionals and support workers.

Radiotherapy: The use of high-energy radiation to kill cancer cells and shrink tumours. Radiation may come from a machine outside the body, or it may come from radioactive material placed in the body near cancer cells

Terminal care: Care when approaching death.

INTRODUCTION

Internationally and nationally, maintaining the health of rural populations is recognised to pose particular challenges, particularly in utilising service models that promote access, yet wisely using the skills of scarce numbers of health professionals. Taking into account the needs of the rural population in relation to risk and treatment of cancer poses notable issues due to the significant resources required to provide high quality screening, diagnosis, treatment (often in tertiary services) and palliative care services. It is also important to recognise that cancer care is episodic by nature. However, there is a need to provide a consistent service over a protracted period of time, with an increasing amount of this service being given in the community².

The West Coast District Health Board (WCDHB) in their strategic plan released in 2002, noted mortality rates from cancer for both Māori and non-Māori were higher on the West Coast than national rates, particularly for males. They also stated that palliative care services required improvement³.

With the release of funds through the Cancer Control Strategy Implementation Fund in 2005, the WCDHB in partnership with the Cancer Society West Coast Centre and the Buller West Coast Home Hospice Trust sought funding to more closely examine the needs and experiences of both health professionals caring for people with cancer and people with cancer and their families/whānau. There was to be a particular emphasis on those with cancer who identify as Māori. This information would be valuable for all three organisations in future service planning and possible reconfiguration. The information would also be beneficial for the Cancer Control Council of New Zealand to forward their mapping of New Zealand cancer patients' journeys and clinical pathways. As a result, a research project with both qualitative and quantitative elements was initiated in early 2006. The key objectives of the research project were:

1. To describe the journey experienced by West Coast adults with cancer from diagnosis, through to survivorship or palliative care.
2. To determine if the journey is significantly different for Māori as compared to non-Māori.
3. To discover what current human and information resources Māori and non-Māori with cancer identify as useful to them and suggest alternative options.
4. To inform the three project sponsor organisations in the future design of respective cancer services maximising their focus on patient needs in order to improve outcomes and experiences.

A selective review of the international and national literature in relation to rural cancer care was undertaken to inform the scope of the project (see appendix A). In brief, the key issues raised in the literature review were:

- Despite it being internationally recognised that rural health is generally poorer than urban health and one in four New Zealanders live in rural settings, there is no defined New Zealand rural health policy.
- Rural New Zealand is characterised by small isolated areas with significant travel times to local towns. On average, rural New Zealand has higher levels of

deprivation, higher proportions of Māori, more transient or seasonal workers, higher numbers working on the land or in heavy labour, lower educational levels, older populations, and reduced access to private or public transport. Both males and females on the West Coast have a lower life expectancy compared to the New Zealand average.

- There is a generalised (but untested) assumption that the rural lifestyle is emotionally protective and that rural people are more self-reliant and self-sufficient and as a result may generally delay seeking assistance (including health care).
- Primary health care is recognised to be a pivotal entry point for cancer services. However, primary health care and General Practitioner (GP) services in NZ rural areas are generally more limited with a high turn-over of staff.
- Internationally, a number of different models of health care/social service support have been trialled. Some of these have focused on providing cancer care in the rural community.
- Health wise, internationally rural people have higher rates of injury, diabetes, cardiovascular disease, mental health issues, alcohol consumption, and smoking. It appears there are higher cancer mortality rates on the New Zealand West Coast.
- Having to travel medium or long distances is recognised internationally to be one of the most significant barriers to accessing preventative, diagnostic, and treatment health care. Population based cancer care requires appropriate access to preventative care/screening, diagnosis, treatment and palliative care. Often treatment must occur in a tertiary centre, some hours travelling distance away. Travel time to access health care impacts on the affected person's ability to undertake paid or unpaid work or their home responsibilities, affects caregivers who may wish, or be required to, accompany the affected person, creates additional costs for petrol and accommodation, and creates isolation and adverse emotional effects. Rural people are known to (sometimes adversely) alter their treatment choices as a result of considering the impact of travelling for health care. On top of these barriers, there is an additional burden for those living in deprived circumstances.
- Some countries have comprehensive financial and accommodation support packages. New Zealand has a system of travel cost remuneration via the Ministry of Health and there are various local arrangements for supported accommodation (usually undertaken by the Cancer Society), but usually only for those on Community Services Card or High User Health Card^a. The Cancer Society West Coast Centre aims to assist both those who have Community Services Card or High User Health Card and those who do not.
- Internationally, it is known that rural people receiving cancer treatment and their carers have higher levels of unmet need, often around support for travel and transport, personal care, household needs and emotional support. This may be particularly so when palliative care support is required.
- Additional disadvantages are known to exist for rural people of particular ethnic groups, including increased barriers regarding travel, transport and paying for

^a The Community Services Card is also known as the Health Card, Exemption Card or Discount Card. The purpose of the card is to help families on low to modest incomes to pay for their GP visits and prescriptions. Any family whose gross income falls under the income thresholds set out by the Ministry of Social Development.

http://www.moh.govt.nz/moh.nsf/wpg_Index/About-Community+Services+Card

The High Use Health Care (HUHC) card gives the cardholder a higher subsidy on visits to the doctor and prescription charges. There is no income testing. The purpose of the card is to help people who do not have a Community Services Card but who face high GP and prescription costs because they have ongoing health problems that mean they visit the doctor often. http://www.moh.govt.nz/moh.nsf/wpg_Index/About-High+Use+Health+Card

accommodation. Supported accommodation (such as staying in hostel-type settings while having out-patient treatment) may not be perceived to be appropriate or welcoming, neither may hospital or in-patient hospice units.

This study aims to explore the experiences of both health professionals caring for people living with cancer and their families, and the experiences of individuals at various stages of cancer and their families, with the specific intent of exploring the needs of those identifying as Māori. The report is structured to separately report the results of the health professional focus group; individual interviews; survey data; and, hui data. All data will be brought together in the discussion and inform the final section in which the characteristics of an ideal West Coast cancer service will be identified.

CONTEXT

The West Coast of the South Island is characterised by its individual geography, climate, history and culture. The area is bordered by the towering Southern Alps on one side and the Tasman Sea on the other. The length of the area from Karamea in the north to Haast in the south is approximately the same as that from Auckland to Wellington (see Figure One)³.

Figure One: Map of West Coast superimposed onto North Island



The West Coast area covers 8.5% of New Zealand's total land mass but is occupied by only 0.8% of the country's population and this figure is projected to decline³. The region has the lowest proportion of Māori (less than 10% compared to the national average of 15%), however, the Māori population is predicted to grow over the next ten years to 14.4%, and the Māori population over fifty five years is expected to grow by 64.3% in the same time period³. The region has a very small Pacific population³.

The West Coast is a region of significant disadvantage by virtue not only of its rurality and isolation but by its low socio-economic status. Of the three Territorial Local Authorities that make up the West Coast (Buller, Grey and Westland), the Buller district consistently has the highest level of deprivation with South Westland being the least socio-economically deprived but the most disadvantaged in terms of geographical isolation⁴.

Compared to the rest of New Zealand, the overall all-cause mortality rate is significantly higher on the West Coast. Small numbers hinder confident interpretation, however, there appears to be a consistent pattern that suggests the mortality rate from cancer may be higher on the West Coast than national rates for the population overall – this is true for both Māori and non-Māori, and for males³.

Health services are provided at the base hospital, Grey Base Hospital in Greymouth, at Buller Hospital in Westport, at the hospital at Reefton, at nine general practices, and a number of health centres and rural clinics around the region. Retention of health professionals in the area is a significant issue³. The West Coast has one of the lowest ratios of GPs in the country,³ resulting in poor continuity of care and long waiting lists for non-urgent appointments. The frequent turn over of GPs also prohibits the development of long-term relationships between GPs and patients⁴. There is one Māori health care provider organisation – Rata Te Awhina – on the West Coast. Access to health care services is noted to be a particular issue for those living in the more rural areas without a car due to the lack of a public transport network on the West Coast³. Access to care becomes particularly expensive for many West Coasters when the extra travel costs of getting to the general practice or a secondary care centre are taken into consideration.

Table One below illustrates travel times from various West Coast Centres to Grey Base Hospital.

Table One: Travel times by road (one way) from various West Coast centres to Grey Base Hospital

Location	Time by road one way
Haast	5 hours
Fox	3 hours
Franz Josef	2 ½ hours
Whataroa	2 hours
Hari Hari	1 ½ hours
Ross	1 hour
Hokitika	30 minutes
Runanga	10 minutes
Blackball	30 minutes
Reefton	1 hour
Punakaiki	40 minutes
Westport	1 ½ hours
Granity	2 hours
Karamea	3 hours

Three organisations on the West Coast have primary responsibility for delivering care to people living with cancer and their families/whānau. Each organisation provides a different range of services.

The WCDHB provides a range of primary and secondary care services, including in-patient beds for treatment and management of adverse events, community palliative care nursing, specialist oncology outpatient clinics, chemotherapy, community oncology and palliative care liaison services (child and adult), home based support services, and travel and accommodation assistance. In mid 2002, the WCDHB appointed an oncology nurse specialist in a full time capacity and in early 2004 a

palliative care specialist was appointed in a 0.5 position. There is a local understanding that there are three DHB facility palliative care beds available on the Coast, one in each of the following centres, Greymouth, Westport and Reefton. These beds are not defined palliative care beds or funded as such and are beds in single rooms that can be used for people who are at the end of life.

The Cancer Society West Coast Centre provides resources and information about cancer, psychosocial and emotional support, welfare, financial advice, and advocacy services to people with cancer and their families/whānau at all stages of the cancer journey.

The Buller West Coast Home Hospice Trust provides support and advice to people living with cancer in the palliative stage and their families/whānau through a variety of services. These include:

- Financial support for services outside those available through state funding streams
- Financial support to health professionals to receive training and education in palliative care
- Loan of specialised equipment to allow people with cancer to remain in their own homes
- Patient advocacy

CANCER CARE IN NEW ZEALAND

Although there is no typical journey for people in New Zealand who have been diagnosed with cancer, there are some common elements depending on the treatment modality. An overview is given below with accompanying commentary on how the typical West Coast journey alters because of location.

In New Zealand, treatment modalities for cancer are varied, both single or multiple modalities. They generally include surgery, radiation, chemotherapy, hormones, and combinations thereof. Treatment intent can be curative or palliative. A multidisciplinary team of health professionals is recognised as essential in supporting people with cancer.

Those undergoing surgery for treatment of cancer receive treatment in secondary or tertiary New Zealand hospitals. After surgery, they stay in hospital for variable lengths of time and are discharged into the care of the GP. They may also have district nurse care. If surgery is palliative, referral for palliative care through a hospital palliative care team or a local hospice service can occur.

On the West Coast, people may have surgery for bowel and urological cancers (or other cancer surgery of a minor nature) at Grey Base Hospital but the majority of surgery is undertaken at Christchurch Hospital. The shortest road trip from the West Coast is a three and a half to four hour road trip (one way) via Arthur's Pass to Christchurch. The journey may be significantly longer for those living further north or south of either Greymouth or Hokitika (see Table One). For those travelling on the shuttle bus the journey takes approximately five hours to reach Christchurch. If convalescence is required, this is provided at Grey Base Hospital. After surgery, either at Grey Base or Christchurch Hospital, people are typically discharged into the care of the GP or district/neighbourhood or rural nurse.

Medical supplies and/or appliances for colostomy/ileostomy and so on are provided by WCDHB but need to be collected from Grey Base Hospital. There are five community pharmacies: one in Westport, one in Hokitika, and three in Greymouth. One of the Greymouth pharmacies also operates a depot in Reefton. (There is one hospital pharmacy at Grey Base Hospital). In outlying areas, if pharmacy items are required, a trip is called for to collect items or they can be ordered and dispatched on one of the tour buses with an additional payment required. If a person acquires a bad debt at a pharmacy, generally their ability to collect prescribed medication is limited until the debt is paid; this can also occur in general practice.

Surgical outpatient clinics, including clinics for those who have received surgery at Christchurch Hospital, are run at Grey Base Hospital with local and visiting surgeons. Even so, people living on the far margins of the Coast are required to undertake a round trip of up to eight hours. Some people have to return to Christchurch for follow-up.

New Zealand-wide, those with particular malignancies may be offered radiotherapy as a primary, adjuvant, or palliative treatment. Courses of radiotherapy may vary from

one (usually palliative) treatment to daily treatments (Monday to Friday). A course of treatments can last 6 weeks and sometimes longer.

West Coast people can only receive radiotherapy at Christchurch Hospital. Those having one treatment may undergo this as a day trip – a minimum of seven hours travelling time. Those who are having longer courses of treatment tend to stay in Christchurch at Davidson House, in a local motel, or with a relative or friend. The Cancer Society West Coast Centre claims the accommodation allowance from the Ministry of Health for those people staying at Davidson House or a motel and who have a community service card; this relieves individuals of more form filling and the monies then go to the Cancer Society West Coast Centre. The Cancer Society West Coast Centre directly funds people without a community service card who stay at Davidson House. People receiving ongoing radiotherapy sometimes choose to return to the West Coast in the weekends. Depending on the site of the radiotherapy, side effects may include skin reactions, nausea, vomiting, diarrhoea, sore mouth, lack of appetite, loss of hair, and fatigue; however, some people have no side effects. Side effects from radiotherapy are generally considered to be less severe than those from chemotherapy. Outpatient clinics for those having received radiotherapy are conducted at Grey Base Hospital by a visiting radiation oncologist.

Those with certain malignancies may be offered chemotherapy as a primary, adjuvant, or palliative treatment. Chemotherapy is most frequently being given as a curative-intent treatment, however, there is an international trend to give chemotherapy later in the course of malignant disease into the palliative phase to alleviate symptoms, enhance quality of life, and increase longevity. Chemotherapy is given as intravenous medication or in oral form. Courses of intravenous chemotherapy vary enormously and may be a single chemotherapy agent or multiple chemotherapy agent combination, most commonly given on a three weekly cycle, with 6 or more cycles. Chemotherapy by nature has certain side effects; some are immediate such as nausea and vomiting, whereas others occur at around seven to ten days after treatment when white blood counts falls and the person becomes at risk of developing a life threatening infection. Other side effects happen later in the course of treatment, such as hair loss. Fatigue is common throughout the course of treatment and most people have at least one side effect from chemotherapy. People having chemotherapy typically describe their lives as substantially altered throughout the course of treatment; they become focused on the time frames of the cycle including the immediate, intermediate, and late side effects as well as getting ready for the next treatment. In between courses of treatment, people are monitored by health professionals, including district nurses, oncology specialist nurses, medical oncologists, and/or GPs. Blood tests may be required during the cycle of treatment. Out-of-hours care and treatment is provided in the locality.

West Coast people receive chemotherapy in Christchurch Hospital or at Grey Base Hospital with around 50% receiving chemotherapy at each hospital (generally lower doses or less aggressive treatments are given at Grey Base Hospital). Again, even having a locally provided service can mean large travelling times for those at the north and south of the West Coast region. One form of chemotherapy, for bowel cancer, can be administered at Buller Hospital in Westport. Oral chemotherapy would usually be dispensed and taken at home on the West Coast.

Similar to having radiotherapy, West Coast people receiving intravenous chemotherapy in Christchurch may have this as a day patient, again with a minimum seven hours travelling time, while some may stay in hospital overnight. Those who are having longer courses of treatment may stay in Christchurch at Davidson House or a local motel, or with a relative/friend. Despite significant advances in anti nausea medication, many people having chemotherapy have some immediate side effects including extreme tiredness or nausea. There is variability in the monitoring between cycles of treatment with local oncology or district/neighbourhood/rural nurses involved and remote advice obtained as necessary from the Christchurch Oncology Centre. West Coast GPs are not usually actively involved with people while they are having chemotherapy treatment. If septicaemia occurs as a consequence of low white blood cell count, people may be treated by physicians at Grey Base Hospital or referred back to Christchurch Hospital. There is no formal face-to-face, out-of-hours care or treatment available locally. People are advised to contact 'Healthline'^b or ring Christchurch Hospital Ward 27 if they have been provided with the 0800 number, or report to Accident and Emergency at Grey Base Hospital. Outpatient clinics are held with visiting medical oncologists at Grey Base Hospital (this may be with an oncologist the person is not familiar with), however, sometimes people may also have to travel over to Christchurch for clinic attendance.

The trajectory of having cancer can also include receiving palliative care. In New Zealand, palliative care is delivered in a variety of different ways, depending on the availability and type (and funding^c) of hospice services available in each region. This results in variability of in-patient beds and/or community services, the ability and willingness of health professionals to refer to these services, the ability of people to self-refer, and the distance from services that are available. Palliative care services need to be available over the twenty four hour period as symptoms can occur at any time and family members if involved, require significant support in order to care for the person.

For those people where community support and inpatient beds are available, and there is a willingness of cancer treatment specialist and GPs to refer, the service can be seamless. This can involve a package of care provided with a variety of input from secondary care staff, staff from the local hospice service including specialist palliative care physicians, hospice nurses, and allied health as well as district nurses and GPs. In other situations care can be fragmented.

On the West Coast the WCDHB District Nursing Service holds the contract to provide community palliative care nursing services. The district nurses already know many of the people with cancer requiring palliative care services because they have provided care while these people were receiving active cancer treatment. Other referrals are made by oncologists, general practitioners, practice nurses, and rural or neighbourhood nurses. People can also self refer. If a person with cancer requires palliative care, district nurses undertake an assessment of what the person and their family may need and either provide the services themselves or arrange for others to do so. Unlike many other areas in New Zealand, there is no funding available for

^b Healthline is a free 24 hour phone health help-line.

^c Local DHBs provide less than 50% of funding required to provide a hospice service; the balance is raised from local funds.

WCDHB funded home support services to assist the district nurses by providing personal hygiene and home care during the palliative care phase.

There is a home hospice trust on the West Coast. This service does not have in-patient beds or community based staff but can provide funding for specialist or other equipment that the hospital cannot provide. As stated, there are three DHB (informally designated) palliative care beds one in each of the three following locations: Westport, Reefton and Greymouth. There is a 0.5 DHB funded palliative care coordinator position for the whole of the West Coast. This position involves assessment of need and coordination of the delivery of services largely through the local district and rural nursing service. The oncology nurse specialist's role also includes palliative care coordination. GPs are tangentially linked into this framework of care but there is variability in involvement. People in the palliative care phase are eligible for free GP visits if the GP applies for the palliative care subsidy for them. There is no formal after hours cover and similar to those having chemotherapy, people are advised to contact Healthline or ring Accident and Emergency at Grey Base Hospital

METHODS

In order to elicit a range of opinion about the journeys of people with cancer on the West Coast, it was decided to use a mixed methods approach to collect the data:

1. Focus groups would be undertaken with health professionals holding different stakeholder perspectives in cancer treatment and care and representing the care of the West Coast population of approximately 30,000⁴.
2. Individual interviews would be undertaken with people with cancer.
3. All those known to have cancer on the West Coast would be surveyed.
4. Hui would be undertaken with Māori living with or affected by cancer.
5. Ethical approval to undertake the research was obtained from the Upper South B Regional Ethics Committee.

Researchers from the Wellington School of Medicine and Health Sciences were chosen to partner in this research because of their research interests in Māori and cancer treatment (DC) and peoples' experience of active and palliative cancer treatment (EMcK).

Focus groups are a validated qualitative method of data collection⁵⁻⁷ and yield information unlikely to be obtained through individual interviews^{5, 8}. Individual interviews are an appropriate methodology to use to determine personal experience, especially when the subject is of a sensitive nature⁹. To ensure consistency, all individual interviews would be undertaken by the same interviewer. The focus group discussion was to follow the standard focus group interview process with key questions being asked by the interviewer who would then facilitate communication between the group participants rather than between the interviewer and individuals^{10, 11}. The key aim was to derive data using language and understandings common to the group^{12, 13}.

The individual interviews were to follow standard semi structured interview technique¹⁴, using question zones to guide the interview and utilising an iterative process of adding free questions if the participants talked about additional issues particular to their personal experience or not explored in other previous interviews.

Table Two: Chronological table of data gathering techniques

<i>Data gathering techniques</i>	<i>Remarks</i>
Focus group with health professionals	Semi structured, with participants from primary, secondary, tertiary and non-government health organisations
Face-to-face interviews	In-depth, face-to-face , open-ended individual interviews
Surveys	Dichotomous responses with room for comments
Hui	Informal meetings utilising an interview schedule

Focus group with health professionals

A focus group was used at the preliminary stage of the study to facilitate an understanding of different health professionals' perspectives and to inform the generation of questions¹⁵ for the interviews and survey. To frame the purpose of the focus group, a discussion guide was developed which described the purpose of the meeting, set ground rules, and overviewed the questions to be asked. A moderator and note taker were allocated. Invitations were circulated to those chosen to participate. These included:

- Oncologist
- Primary Care Practitioners
- Practice nurses
- District, neighbourhood and rural nurses
- Oncology and palliative care nurse specialists
- Community pharmacists
- Cancer Society West Coast Centre
- Buller West Coast Home Hospice Trust

The focus group was scheduled to allow one of the visiting oncologists to participate, and similarly a video link was arranged to enable primary care teams outside of the Greymouth area to contribute. Two groups of health professionals who interact with people living with cancer and their families/whānau on the West Coast were not present at the focus group meeting (FDN arranged to meet with them at a later time and venue convenient to them). The usual oncology nurse on the Coast was also due to leave for a sabbatical in the UK before the health professional focus group hence a meeting with her together with the manager of the Cancer Society West Coast Centre was arranged prior to the focus group. Following the focus group, the note taker collated and summarised the notes and these were then circulated to all present allowing for immediate feedback and validation of the information.

Face-to-face interviews

Pragmatic considerations of the project limited the number of participants to approximately 20 with the proviso that if data saturation was reached earlier, then the sampling would cease. Each General Practice was sent a letter (see appendix B) asking them to nominate five patients from their practice who fitted the following criteria:

- Adults (18 years +)
- English speaking and cognitively intact
- Diagnosed with cancer (except minor skin cancers) within the last five years
- Not in the imminently terminal phase

(If possible one of the five possible participants nominated was to identify as Māori). This would give a possible sample population of 45 people. A poster was developed that practices were asked to display in their waiting areas. The poster asked people who were interested in taking part to give their names to the receptionist who would forward it to the study investigators. The Cancer Society West Coast Centre also exhibited the poster in their rooms as they receive many visitors who are living with

cancer. All potential participants were entered into an excel spread sheet with the following variables documented:

- Gender
- Age
- Māori or non-Māori
- Address and phone number
- Decile
- General Practice setting
- Type of cancer
- Phase of cancer, active or palliative
- Centre of main treatment; Christchurch or Greymouth or treatment incomplete
- Type of treatment
- Living in urban, rural, very rural, or of no fixed abode
- Use of complementary or alternative therapies

A sampling frame was then developed which was appropriate for the research objectives. Variables considered within the frame were:

- Māori or non-Māori
- Below 40 years or over 40 years,
- Type of cancer
- Stage of cancer, active or palliative
- Male or female
- Urban dweller, rural dweller or very rural dweller
- Decile of domicile

From the potential participants nominated, twenty were initially approached: eight who fell into the active treatment group, seven in the palliative care group and five who identified as Māori. The manager of the Cancer Society West Coast Centre (a person independent to the study) contacted each potential participant by phone and asked, utilising a set script (see appendix C), if they would be prepared to receive a letter about the study and an invitation to take part. If agreeable, a letter of explanation regarding the study was sent to them, along with a consent form (see appendices D and E) and a prepaid reply envelope addressed to the manager of the Cancer Society West Coast Centre. Only after a person had agreed to participate and returned this form did one of the investigators (FDN) contact them to arrange a time and venue for the interview. All Māori participants were given the choice of having a Māori support person present during the interviews.

Two interview schedules were developed: one for those in the active cancer treatment group and the other for those in the palliative care group (see appendices F and G). The schedules were informed both by the evidence from the literature review and the text data from the health professional focus group. The interviews took place over a three-week period and during this time the interviewer FDN undertook inter-interview summarisation of the interviews and phone/email reflection with EMcK and DC, enabling consideration of early emergent themes and informing changes to the interview schedules.

All interviews were audio-tape recorded and audio-tapes were transcribed by trained confidential bibliographers from the Buller West Coast Home Hospice Trust. Once each transcript was returned to FDN it was sent with an accompanying letter back to participants for them to read and check; a return stamped addressed envelope was included.

Tapes were copied and sent to researchers EMcK and DC to listen to prior to receipt of the transcripts. All transcripts were copied and forwarded as well, allowing for independent coding of themes; a procedure that facilitates the assessment of the trustworthiness of the data analysis⁴.

A general inductive approach was taken to analyse the text data allowing the extensive and varied raw data to be condensed and themes to emerge. Coding categories were identified by project team group consensus and each transcript was reviewed and coded separately into broad subject areas by two members of the project team (FDN and EMcK). Further coding and analysis within these subject areas was undertaken to identify themes.

The process of inductive analysis is illustrated in Table 3.

Table 3: The coding process in inductive analysis¹⁶

Listening and re-listening of audiotapes. Initial read through of text data	Identify specific segments of information	Label the segments of information to create categories	Reduce overlap and redundancy among the categories	Create a model incorporating most important categories
				
Many pages of text	Many segments of text	30-40 categories	15-20 categories	3-8 categories

Surveys

Two self administered survey tools were developed: one for people currently living with cancer on the West Coast and who had not been already been interviewed; and, the other for relatives (see appendices H and I) who had lost a loved one to cancer within the last two years. The questions that formed the content of the survey were either closed questions requiring Yes or No responses, or questions where participants could tick multiple boxes. Each type of question was followed by space for comment should people choose to offer these. Participants were also given the option of contacting one of the researchers, FDN, and discussing the survey questions if they preferred. Both surveys were tested for face validity with a group convened by the Cancer Society West Coast Centre prior to the mail out and amended accordingly. Before the mail-out of the survey all participants were sent a letter of invitation (see appendix J) explaining why the survey was being undertaken and offered the ability to opt out of the survey by contacting the manager of the Cancer Society West Coast

Centre. Survey responses were entered into an Access database. Analysis of the quantitative survey data was undertaken using EpiInfo (version 6) to generate frequencies and percentages. Written responses were collated, analysed and coded in the same manner outlined above for the interview transcripts.

Hui

Three hui were planned, one in each of the three territorial areas of the West Coast: the Buller, Grey District, and Westland. The planning of these hui was undertaken in collaboration with two nominated Māori representatives. The representatives were nominated by Tatau Pounamu (the Māori advisory committee to WCDHB). Pānui (fliers) were designed and circulated to Māori organisations and key Māori individuals in the towns where the three hui were to be held. An interview schedule for the three hui was developed based on the text data from the focus group and individual interviews and the literature. A moderator and note taker were assigned. Following the hui, the notes were collated and sent to the two Māori representatives who were present at all hui to consider and give feedback.

RESULTS

Health professionals focus group meetings

Thirty two people attended focus group meetings including one visiting oncologist, two oncology nurse specialists, nine GPs, three community pharmacists, eleven nurses from a variety of areas including district, neighbourhood, rural, and practice based, five representatives from the West Coast Māori provider, and a representative from both the Buller West Coast Home Hospice Trust and the Cancer Society West Coast Centre (note not all of these attended the main meeting but were from the other meetings).

Face-to-face interviews

Seventy people were either nominated by their general practice or volunteered to take part in the face-to-face interviews. Using the sampling frame described earlier, nine people in the active phase of their cancer treatment, ten in the palliative care phase, and five Māori either in the active or palliative care stage, were initially approached to take part in the interviews. One person in the active group declined, two in the palliative care group died and one declined; there was no response received from one of the selected potential Māori participants.

Nineteen people with cancer including those receiving active or palliative care were interviewed in their homes. Some interviewed also had partners or family members present and some who identified as Māori had a support person or whānau present.

Interviews included 11 people in the active phase and 8 people in the palliative care phase. Seven were male and 12 female; 4 were Māori and 15 non-Māori; 4 were under 40 years of age and 15 over. Ten lived in an urban location, 6 in a rural location, and 3 lived very rurally. Four interviewees lived in deprivation deciles 1-5 and the remainder in deciles 6-10. Interview participants had a range of cancer types including breast (5), bowel (5), prostate (2), lung (1), renal (1), leukaemia (1), throat (1) and other (3).

Interviews were semi structured using one of two interview schedules depending on the participant's treatment phase. Conversation, however, was not limited to these questions and people talked often at length of matters of concern to them. Interviewing people with (or families who have experienced) cancer is recognised to be emotionally intense. Many of those who were interviewed recounted experiences, which provoked emotion, and time was needed to explore these issues with sensitivity. Some people and family expressed the interview process as having been important in allowing them to reflect on these experiences.

The surveys

Forty-four people were sent invitations to take part in the cancer survey and twenty-six to be part of the relative's survey. All those invited to be part of the cancer survey agreed to take part; two people declined to be part of the relative's survey. The

survey was closed to responses after three weeks. It was decided not to send out a prompt for responses at the end of week two due to comments that had been received in some of the survey responses indicating that recalling the events had been emotionally painful. There was a 64% response to the cancer survey and a 50% response to the relative's survey. There were multiple written comments included in the responses, some of considerable length.

The hui

Three hui took place, in Hokitika, Greymouth and Westport. Attendance at each hui was twelve, eleven and ten respectively.

FINDINGS

This section summarises the findings from the hui, interviews, surveys and focus groups. The project aimed to identify the range of experiences and viewpoints of those with cancer and their family/whānau as well as those involved in the provision of support and care across the cancer continuum. In terms of the findings, there were issues and experiences that were common across the different groups and individuals involved, while others were more relevant for certain people or at particular times of the cancer journey.

Discussion at the hui corroborated the themes that had emerged from the face-to-face interviews. Hui attendees expanded the dialogue on a number of key issues identified in the individual interviews. The surveys of those with cancer (past or present) and relatives who had lost a loved one to cancer also focussed on the key issues that had been identified from the in-depth interviews.

People with cancer and their families were aware that the overall intention of the project was to improve the journey for those following them and thought carefully about measures that would assist others. As well as describing positive things, many of the things they discussed as being problematic are recognised to be difficult for people with cancer whether or not they live in rural settings. In this section, issues that are known to often affect people with cancer but are additionally influenced by distance and rurality have been given a particular focus.

The results are organised under the main themes that arose from the hui, interview surveys and health professional focus groups. The findings from the interviews and hui are reported first, followed by the survey findings and then findings from the health professionals.

Findings from in-depth interviews and hui

Support for those with cancer and their family/whānau

People with cancer and families interviewed frequently described some very supportive actions by several different groups of people that enabled them to travel the cancer journey with more fortitude^d. This included support from spouses and partners, family/whānau, and the community, as well as from particular agencies or organisations, and from health professionals.

Support from spouses, partners, family/whānau, the community, and others who had walked the same road

While it is not unique to those living in a rural location, receiving support from spouses, partners, and family/whānau was highly valued by those interviewed.

^d Text data is used to illustrate the themes identified from the interview: (A) refers to people with cancer receiving Active treatment, and (P) refers to people with cancer receiving Palliative care.

“He (husband) was very good to me while I was sick. How he coped with me that way, I don’t know, but he did” (2A)

“...my mother and father have become very active in my life again...” (1A)

“Well my family, they’re very supportive, of course” (1P)

“...I might be in there (visiting parents) with darkness and have a talk to them, but I come out with light, you know” (9A)

“I’ve had great support from my family and my friends and my workmates” (4P)

Perhaps more than in urban areas, the actions of local community and friends were recognised as being noteworthy. One sole parent described how both the school and the local church supported her when she became the second member of her family to be treated for cancer.

“...the church have been really good,...when * got diagnosed they started sending over things, a box of cheer up stuff, like toys and soaps and little gifts,...another thing the church did they sent around people with prepared meals and popped them into the freezer and that’s been really handy; ...and the school are wonderful...they have given us petrol vouchers and New World vouchers...the community’s been just great” (1A)

“Oh the best things that have happened are the wonderful friendships because um you just discover that friends have hearts of gold and they want to be there for you and that’s been the amazing part of it” (8A)

The benefit of talking to someone else who had cancer was a powerful theme in the interviews.

“And the thing that you’re associated with people with similar problems that you can sit and talk to them about it and I think it helps to talk to another person” (1P)

“You pick up a lot of tips from other patients; you get to know because they’ve been through the mill; discussion among patients I think is a good idea” (4A)

“...she (a friend) rings me regularly, “How’re you going?” What’s happening?”...so we have this phone thing going on...” (1A)

Support from the Cancer Society West Coast Centre

The work of the Cancer Society West Coast Centre, both locally and in Christchurch via Davidson House, as well as the volunteer ‘drivers’ they provide, was highly valued by many interviewed.

“If I have been stuck for money the Cancer Society has been good ... would give me the petrol vouchers because there has been the odd time I have been stuck” (8P)

“... feel they were there all the time, I feel really supported...” (1A)

“... its a marvellous facility, Davidson House” (1P)

“... we stayed at Davidson House. They were very caring” (2A)

“The drivers that came to get us every day were lovely people” (2A)

“...and Cancer Society manager she would pop in...she got me wood and that” (10A)

When Davidson House is full, people are funded to stay at a local motel close to the hospital if possible. People said they felt this deprived them of the psychosocial support that people experienced by staying at Davidson House (both people with cancer and their carers).

“And you get to know people in their situations, and you and you do make good contacts” (2A)

Supportive care of the visiting oncologists, oncology nurses and the district nurses

People specifically mentioned certain health professionals and groups of health professionals whom they clearly valued for their input along the journey.

“He (the oncologist) was brilliant, he was always straight up and down he would always give his answer” (2P)

“She’s very, very nice, caring oncology nurse” (2A)

“She (the oncology nurse) was great; she explained everything, she was a great help to me anyhow and she’d experienced life out on the farm and she was a marvellous girl...it was a wonderful thing that she did, she told me what to expect...” (6A)

“...the district nurses and I think they do a bloody marvellous job...” (9A)

“The district nurses have been very good as well. They come and sit and talk and I think that’s the best help you can have, is to talk about it” (2A)

Perception of care and support given by health and social care professionals

Individual health professionals and their actions were described warmly by most participants:

“...the district nurses and I think they do a bloody marvellous job and they, they’re switched people on and yeah.... I just been helped so immensely, even ah, even I would say without them realising it, emotionally and spiritually by them and physically” (9A)

However, the overall health professional and social service system (Work and Income^e) was not perceived by people with cancer or their families to meet their needs. This ranged in extent from some feeling totally unsupported: “*I got to be honest I really didn’t get it (support) from anywhere ...*” (10A), to others who described receiving support from one service and not from another.

In the following excerpt a young man having active cancer treatment spoke at length of having to stop employment because he was ill and his subsequent experience with Work and Income in not being able to access a benefit to feed his family or to provide them adequate warm shelter. As a result he said:

“I’ve lost faith in the whole bloody system and I feel that even my dignity has been shat on. And I am quite angry about it – I’ve fallen in and out of depression, get really anxious about providing for my sons...” ...“...it’s been the most undignifying experience I’ve ever had....I just felt as if I was walking around as an empty shell of a man ...Days got so bloody dark,...and it would just permeate your whole being” (9A)

Issues with Work and Income were also raised at the hui and support from them was generally not considered to be satisfactory:

“You would think it is coming out of their own pocket”.

“They stick to the box, they don’t use discretion; it all comes back to inexperienced case workers...”

^e A service of the Ministry of Social Development, which provides financial benefits and employment assistance. Participants tended to refer to Work and Income as WINZ.

Hui participants remarked that Work and Income staff let their prejudices show and because the three main centres on the Coast are in relatively small towns, some members of staff may have personal issues with people that influenced the level of support given. Another observation offered was that people with low literacy are perceived to receive a poorer service from Work and Income.

Support in general for spouses/partners and family/whānau did not appear to be either recognised as important or addressed by any health or social service professionals on the West Coast. Usually this kind of support is provided through primary care, however this link was very shaky and people either consulted irregularly or if they did consult, were likely to see a new face.

“I don’t know that they’ve (the partner) been supported at all” (8A)

“The support person does need help” (2P)

“She wouldn’t have had any (support). No, she wouldn’t have had any. Initially she was fairly devastated about it all ... and we don’t talk about it all that much... apart from when I am having a bad day. (She talks to the lady next door) they talk a lot together a lot, but what they talk about um, I don’t know” (1P)

A perceived lack of a holistic focus from health professionals was also seen as an issue by hui participants.

“GPs just want to give everyone a pill and see them leave the room, there is no focus on caring for the “whole” person, just the tumour”.

When there are sole practices in a town, either pharmacies or general practices, this limits choice and hui participants spoke of inconveniences if you fall out with a sole provider, as accessing care becomes more difficult and costs increase. The journey with cancer was described as a “*long and lonely journey, a journey you discover yourself*”.

Communication issues

People with cancer and their families noted that effective communication during the cancer journey was an essential factor and particularly so when they are required to travel a long way to see the specialist. The interviews highlighted a variety of communication issues at different points along the cancer journey.

Firstly, having adequate time with doctors was an issue for many people. People generally (or some people) felt as if the doctors, GPs and specialists were working to the clock. In the following excerpt a patient had travelled from Ross to Christchurch (a round trip of 8 hours) to wait for an hour and a half to see his specialist for a 5-minute follow-up.

“I had to wait an hour and three quarters.....and I was really disappointed that he couldn’t spend a bit more time with me and I thought, “geez man all that way for five minutes” (9A)

The patient later in the interview makes it clear that despite this experience, he was very appreciative of the specialist and felt well cared for, feeling that on this occasion both parties were frustrated by time limitations.

People with cancer noted that geographical distance appeared to alter the quality of communication between Christchurch specialists and West Coast GPs, and between specialists: *“There doesn’t seem to be a lot of co-ordination between the specialists and the GPs”*; as well as issues between specialists, *“each of them will say something to me, but they don’t seem to say it to each other, if you know what I mean”*(3P).

Communication interfaces between the different hospital services and support centres involved in the cancer patient’s journey were a problem for a number of people with cancer. In the following excerpt, a young family with a very sick child with a cancer diagnosis had been instructed to urgently travel that day from Greymouth to Christchurch (a three and a half hour trip) and they arrived late at night to be admitted to Christchurch Hospital. Apparently no assistance had been given by health professionals to help them travel to Christchurch. When they arrived at Christchurch Hospital late at night they had not been able to gain urgent admission, either because instructions on how to be urgently admitted had not been given/understood or Christchurch Hospital admissions were unprepared.

“...the admitting clerk said no they won’t take you at this time of night, we got there about nine thirty at night. We tried three times to get into the ward and got turned down”.
“...we went to the Ronald McDonald house and by this time it was ten twenty...and the guy that was waiting for us was really grumpy....it was a horrible experience because we had just found that our daughter had (an acute haematological disorder)...the hospital didn’t take us, and the guy at the Ronald McDonald house- well he took us up in the lift and they put us in this cold dark room and shut the door on us”. “The hospital rang us in the morning and they had been waiting all night for us and they said “where are you?”
(1A)

At the hui, people also noted that it was frustrating to have to keep repeating their story to multiple health and social care professionals. This is related to the interface issues discussed further below.

Because of the distances involved, health information including diagnoses are not always given face-to-face. The method, timing and mode of communication were upsetting for some people.

“...and this is one of the few things that I have a problem with, with the whole cancer thing is communication...my GP rang and she said oh we’ve got your bone scan results, it’s in your back, it’s in your ribs, it’s in your hips, and it doesn’t mean to say that you’re going to die this year, next year or within five years. And I thought that was disgusting...they shouldn’t do it over the phone like that...” (1P)
“...an older doctor came through with attendants and he said “of course you’ll have to have chemotherapy” and that was the first inkling I had that I had cancer. To me it was a terrible way to let anyone know that they had cancer” (6A)

Hui participants talked about taking a support person along with you as essential. One person relayed an experience of a person who had asked a GP if she could have a friend to support her during the consultation but this was refused because the GP said

there was only a short time available for the appointment. Similarly, a comment was made about people being given the diagnosis without a support person present.

Access to primary care and continuity of care from GPs was recognised as being very limited particularly from those living in the Westport area and this influenced the quality and continuity of communication.

“...when you can't see the Dr, even to see him just recently I had to wait three weeks...” (8P)

“Ironically the GP I saw, we've had so many through the practice, um, when I went to confirm what I should do about the tests,- too late- he had gone home to (overseas)...that's when I had to see another GP. So that delayed things a wee bit” (4A)

Health professionals often advise people with cancer to discuss matters with friends and family. In rural areas there may be more limited opportunities to talk with people other than direct family members. A number of people interviewed either did not want to trouble their family or for a variety of reasons did not feel their friends were appropriate people to talk to.

“I can't really talk to them too much. They start pussy footing around and walking around like on glass...” (9A)

“It was especially with my mother I found that quite awkward because I didn't want to offend her but without her realising it there were times when it was putting more pressure on me to try and cope because she was finding it difficult to take it all on. That was hard” (11A)

Despite the limitations described above people in the study spoke of the need and benefit of being able to talk to other people in similar situations.

“...you wish to know the road beyond, perhaps those who have travelled before...” (6A)

“...but the last time I saw him was at Ikamatua at the two day chopping (wood chopping event) there and we sat and had a good old yarn because we both knew what we were talking about because others would often go “I know how you feel”. Like hell they did, they didn't have a clue, whereas he did” (11A)

Some Māori on the West Coast viewed communication with them as being insensitive or inappropriate.

“They treat you like you've got no brains if you're Māori...”; “The Drs been there for a long time, he could learn to talk to the patient, not wave his arms around at you as though you don't understand what's going on and you tend to get doctors that tend to do that with Māori patients...” (8P)

Many of the communication issues identified in interviews were also raised at the hui. This included participants finding some health professionals to be insensitive to people's needs when they have cancer. Hui attendees also identified that time to adequately discuss results in order that they are understandable was rarely available, and that the language used by health professionals could sometimes result in people leaving the consultation with a different perception of what was said from that of the health professional.

People living in rural settings recognised they have additional challenges in making arrangements for health care. They felt the impact of rurality was not fully appreciated by either Grey Base or Christchurch Hospitals. In particular, people waiting for surgical intervention as a mode of treating their cancer spoke of the need to be kept in the loop regarding the date for surgery.

“...if you get no communication you don’t know where you are with it,...I feel more communication while people are waiting” (5A)

Information issues

A diagnosis of cancer is a stressful life experience that can be partly alleviated by being well informed at all stages along the cancer journey. Some of those interviewed appeared to be satisfied with information regarding their condition illustrated by the following comment made by an interviewee:

“ I think basically I got everything I should have, the only thing that’s confusing you get so much in such a short time, it takes a lot of soaking up” (4A)

Trying to get information about how and where to access assistance and support was identified as a fraught process for both interview and hui participants.

“- no one tells you where to get help from, and what you are entitled to; there’s all these different departments...so you end up on this bloody big paper chase” (9A)

“Trying to get into WINZ I found that probably the most frustrating, and then being told to come down and see us when I could barely get into the car...” (11A)

People frequently spoke of feeling that support services and people might possibly be available, however they felt the onus was on them to seek out the information and help. They (and their families) described how difficult this was especially when they were feeling unwell.

“..you’ve got to pick up the phone and do it yourself and go looking for answers. I mean, it’s all there, don’t get me wrong, it’s all there but I feel that just occasionally it would be nice for someone to pick up the phone and say, “how’s it going?”” (2P)

“I mean if I pick up the phone and ask for things, things do happen quite quickly”.

“...they will do what I ask but they make no initiatives, they don’t inquire” (3P)

As hui participants noted, it was felt that questions were answered but information was not volunteered and finding answers is not easy when you don’t know what you don’t know. GPs were described as people they would seek answers from, however comment was made that they don’t have the time to tell you.

Whilst radiotherapy and most chemotherapy treatments are not privately available in New Zealand, private surgery is available in most New Zealand cities including Christchurch. Given there are additional challenges for people on the West Coast arranging their lives when having oncological surgery, it seems reasonable that people should be offered the option of choosing between private and public surgery.

“all of them haven’t even asked the question, we were never asked the question, “Have you got private health insurance?” Never not once” (2P)

This issue was also noted at the hui. Participants felt private surgery options were not discussed with Māori and perceived that Māori are prejudged as not wanting private health care or of not having the means to take up the option.

There was an expectation amongst those interviewed that health professionals would provide the information they required at every point of their journey but this expectation was not always met. This lack of information was made more difficult for people on the Coast because not all have easy access to public libraries and for many economic circumstances make having a home computer with access to the internet more unlikely.

“...nobody has ever explained anything about bone cancer to me,...I’ve had books out and I’ve read a lot myself and what I’ve learnt about it is certainly not what I’ve been told from the professionals”; “...there should be more direction, from the professionals, they’re the experts...” (1P)

People also spoke of the need to ensure the person with cancer understands the information being given:

“Well I think they thought ‘palliative’ but nobody ever explained to me what ‘palliative’ was” (8P)

“It’s really making it quite clear, not everyone is up to medical understanding...” (4P)

“I’ve got friends in the health (system) that I can discuss this with them and they can give me answers that I would, that I as a layman, can understand” (2P)

Comments were also made at hui around the “technical jargon” used in letters. Information available in pamphlets and so on was deemed to require a high level of literacy to understand the content - one person spoke of going to the library to access a medical dictionary so she could understand a pamphlet.

Access to and/or continuity of care from specialists, physicians, nurses, and GPs was identified as an issue by West Coast people, particularly in relation to trying to get consistent information.

“I can’t even get to see the same one twice, they change”(3P)

“...I wanted to have a discussion with the Stoma Nurse for the West Coast. I saw her when I was in the surgical ward in Greymouth...and she is extremely good, she explains everything for you, but it is the only time I’ve seen her. I would have liked to discuss something again later but she’s very hard to get hold of” (4A)

“I was expecting to see my normal oncologist, his name was on the appointment list, but a very young chap, I’d never seen before, who hadn’t even read my notes, so I mean how do you get reviewed every three months if he didn’t even read it, and he didn’t have the x-rays and that, I had to ask him” (3P)

There were many references to the significant effects that chemotherapy had on wellbeing. This was exacerbated on the West Coast because of more limited access to health professionals or other sources for information and day-to-day support. In particular, lack of information in relation to the side effects of chemotherapy was notable.

“No the side effects, I think if anything they under emphasize them” (4A)

“It didn’t say the terrible effects it had” (6A)

People interviewed who had received a surgical intervention as part of their cancer treatment either at Grey Base or Christchurch Hospitals said they did not get clear information regarding where to access medical supplies from after discharge. The following patient lived in Westport and after an unsuccessful visit to Buller Hospital in Westport had to then travel to Grey Base Hospital to purchase colostomy bags (a round trip of 3 hours).

“I think something that was possible explained to me and I didn’t get a grasp of where to get supplies of stuff that I needed to carry on with. The stoma bags and all the rest of it. I had to flounder a bit to find out, who do I ring up, who do I get one of those from, well I don’t know. As I say, possibly I was told verbally and it just went in one ear and out the other. So in the end I found when I run of colostomy bags for instance, I went to Buller (hospital, Westport) and no, no we don’t have them here, they have to come up from Greymouth. In the end I had to go to the Stores in Greymouth Hospital and get some” (4A)

It appeared possible that on the West Coast there may be delays in medical and/or diagnostic information being available and important information did not always appear to be given to people in a timely manner.

“...umm waited quite a while, two weeks I had to wait for my results whether it’s the Greymouth health system or what I don’t know. And then when I saw my results they had URGENT results right across the top” (1A)

Access to care and support services

Ability to access chemotherapy locally

Being able to locally access certain chemotherapy regimes was viewed by some as a bonus but not by all - others felt more confident going across to Christchurch.

“That made a big difference (being able to have chemotherapy at Buller Hospital). There’s just as many side effects of course but its only four blocks down the road” (4A)

“I decided to go to Christchurch and I had the option, I could have Greymouth but I was sort of, to me that was the unknown and a bit of a worry” (11A)

A communication booklet^f designed by the oncology nurse on the Coast to capture clinical details, record appointments and facilitate communication was viewed as a valuable resource.

“...a book and that’s, that’s our Bible” (2P)

People spoke how the book assisted with communication between centres.

^f In 2005 this booklet was nominated for the Health Innovation Awards and got through to the final

“..I would have all his blood results, myself...we’d go to the appointment in Christchurch and they’d all be running around looking for them, I said, ...here they are in the book” (2P)

People with cancer and their families interviewed also described actions that made the cancer journey difficult or created distress.

Provision of after hours support

Unlike those living in New Zealand urban settings, West Coast people with cancer do not generally have an expectation that after hours care will be provided. This was noted as a major concern for people and their spouses/partners and families/whānau living with cancer especially those interviewed in the palliative care stage. People seemed to rely on personal contacts or had been instructed to call the national health phone help-line.

“um...I got a lady that we know very well, a friend that’s in A and E and um she’s been great, she has been really, really great. If I have a problem, I just pick up the phone and ask, and I am talking about after-hours when (the nurse) and (the doctor) are not there” (2P)

“I mean they advertise an 0800 number for Healthline or whatever, but we are just, they don’t know the situation, they don’t know *; whereas these two people, these two particular ladies that I talk to, they do know *, they know him personally” (2P).

“I feel apprehensive about what’s s going to happen towards the end and if I didn’t have a (family member) that lived around the corner, that I knew that I could ring – it doesn’t matter what time of the day or night – she’s going to be there for me um...I don’t know how the situation works, with if * gets sick in the middle of the night ... (2P)

People who have friends or relatives who work in the health care system appear to be somewhat better off; if you have actually got a friend or someone, that’s got some medical knowledge as well because you can’t get hold of the oncology nurse in the middle of the night and you can’t get hold of her after 5 o’clock at night” (2P)

“My brother is a registered psych nurse and the other two friends are both enrolled nurses in the psych....yeah all the confidence on the family, on the friends side,...” (4P)

People having active cancer treatment can become acutely ill and need immediate hospitalisation.

“So it took about a month to get this bloody, to get this telephone, and here’s a hard case thing, the day it got installed, that evening I needed to use it to- my temperature shot right through the roof, and I ended up in hospital. I ended up in hospital twice over that next month” (9A)

People at the hui commented that professional palliative care support was missing and that this was largely undertaken by whānau. They commented that in their experience whānau members were not allowed to be paid to look after whānau with cancer. Thus those of least means missed out on a payment that is available to a formal caregiver. Participants said that whānau generally refuse the support from a formal caregiver because they feel safer with their own whānau member. People spoke of services being promised in relation to palliative care by health professionals but they did not eventuate.

Issue of multiple interfaces

Receiving treatment for cancer is complex wherever it happens and often the patient feels no one person appreciates all they are going through. On the West Coast many

people described the apparent lack of co-ordination between the various services and described themselves as the only link between the multiple providers. One person said “*it’s a bit of a jigsaw*”(9A). Overall they felt this added to their burden.

“Everybody’s telling you to go here, and so you’re stretching yourself out like a , like a spider with eight legs, ... putting your web out to catch all these things that you need, but instead, it would be good to sit down in the middle of the web and God, dare I say it, have somebody work for you” (9A)

“I said Dr* asked me to come down for a mammogram, and she said oh no, you ring this 0800 number and I said, oh no, he said to come here. She said no, you’ve got to ring that 0800 number. Now I’m not blaming her, mmm cos it was my own self too, but I just put it (the referral) in my pocket and went off to the Ballantyne’s sale and forgot about it. What she should have said was if you’re going to have it here, you’re going to have to pay for it...” (4P)

Discharge from hospital

Among some hui attendants, discharge arrangements from Grey Base hospital were viewed as limited and poorly co-ordinated. For example, if a person is transported by an ambulance to Grey Base and then discharged they have to find their own transport back and this can be a major stressor.

Travel issues

For the majority of people living with cancer on the West Coast, travel is a necessity, rather than an option. Transportation barriers are not just limited to travelling to a point of care but also include:

- Accessing care when you don’t own your own vehicle,
“Travel to Christchurch when you don’t own your own vehicle: “Yes it is very tiring – the Coast to Coast bus”(10A)
- Relying on a member of the family who may be working and who would need to take leave was an issue for some:
“It was at times because my son works and he took me” (6A)
- Driving in a strange city,
“I would have liked to have someone or some organisation in Christchurch to do the driving for me” (4A)
- Travelling while feeling unwell,
“...going up and down to Greymouth and I just couldn’t have the last one (chemotherapy regimes)” (6A)
- The weather,
“They tried to get us in earlier so that we could get back over the mountain pass... and that was an issue in the winter time, we struck a few, few hairy times going backwards and forwards” (2P)

The West Coast has no public transport system and for those who don’t own or have access to a private vehicle, travel between the different health centres can be more difficult than going across to Christchurch.

“I found it harder getting to Greymouth than I did to Christchurch” (10A)

None of the participants ever mentioned receiving help with the actual journey even though in one case the sole carer faced a multitude of problems.

“...they said you’ve got to go home and pack for six months they want you in Christchurch...today...coming home with the thought in my head...we had to pack for at least six months and we had a cat, a dog, a bird and a fish and we had a house...that we just packed and left. (* had) a brother,...and we had (* another sick relative) on oxygen and he was really sick and * was just lying there yeah and limp and unwell. So I raced around and packed and we got to Christchurch”. (1A)

There seems to be some appreciation by health professionals of appropriate appointment times for people from the West Coast going to Christchurch or those who live in the Buller or South Westland going to Greymouth. However this consideration wasn’t consistent.

“...they don’t realise the distance and the time...they would say “oh be here at nine o’clock in the morning”...” (6A)

Financial concerns

For those people without means or limited means as often people on the Coast are, the process of reimbursement was problematical.

“You get a petrol reimbursement but it’s quite a hassle. It’s good but so what if you haven’t got money to put in your car in the first place...” (1A)

Reimbursement of money for travel was not the only concern. The process of claiming the reimbursement was traumatic for many.

“Oh man, that fare shook me up. It really actually stressed me”. “And they never did pay it – as they said, what they wanted me to do was, they wanted me to come over on the bus on Monday, have the drain, go back on the Tuesday, come back on the Wednesday for another drain. You know, those people, down in that office should be taken around oncology for a couple of days to let them see how people with cancer...” (4P)

“...the Ministry of Health...terrible, they’re terrible. Terrible phone contact, you put a claim in and they always dispute what you claimed...and it’s so stressful” (1A)

This was also an issue for hui participants. Claiming fuel reimbursement was seen as a major problem - it was described as “stressful” and “a drama”. People remarked that they knew of people who did not complete the process of claiming fuel reimbursement because it was so frustrating. The increased waiting time for the refund since the system has become centralised in Dunedin was commented on as problematic. Comment was made that those living remotely may have a car, but lacked the financial means of filling it with fuel or getting a Warrant of Fitness. Those present at the Buller hui described the process of accessing petrol vouchers from the hospital social worker as degrading and the fact that you require a community services card was another barrier to those who just miss out on qualifying for the card. This impacted on their ability to access care, which was further exacerbated by the lack of a public transport network on the West Coast.

Having someone to support you when you receive cancer treatment is accepted as an essential component of psychosocial care. For some family members this was clearly difficult as it impacted more significantly on their paid work responsibilities more so than it would have had they lived closer to a cancer treatment centre. Family members described the impact the cancer had on the family's financial circumstances as well as its influence on their ability to sustain even the most basic of lifestyle.

"I had to employ staff while I took the day off, or two days because if the appointment was early in the morning we had to go the night before and stay there um...because I was working and * was sort of working as well, we weren't entitled to anything. And we, we found, I found that very, very stressful and my business did suffer....financially, financially it's been horrendous" (2P)

"Since I have had to quit work and rely on WINZ, life's been pretty much a shit sandwich, and it's always been lunch time". "So we basically lived off charity – off other people, and that hurts my pride. Um what else, where was I? Oh (my child) this is no shit, .. would leave his lunch at home, secretly stash it for me, or bring it home with him, and go, 'Oh I wasn't really hungry", so that I would have (sound of crying) – so I would have the nutrition that I needed. I trained myself to eat only one meal a day, that's about all I could afford, plus to feed the boys three meals a day..." (9A)

Those who are financially challenged on the West Coast seek care that is free at the Emergency Department rather than go to the GP even if they have a Community Services Card because even a small part charge is a barrier to care. This also applies to people receiving cancer treatment, and those receiving active cancer treatment and were experiencing problems said they felt inhibited from approaching their GP for assistance. Anecdotally people were accessing the oncology nurse because access to her was free as opposed to the GP or practice nurse. For the following sole parent with children the cost of \$5 to go to a GP was too high, as it meant he could not feed his children.

"\$5 is, man a couple of loaves of bread" (9A)

People at the hui commented that to even get a diagnosis costs money and if money is not available obtaining a diagnosis was delayed. Many commented that frequently GPs will only let you discuss one issue at one appointment, thus two issues require two appointments and two charges. Trying to find information frequently resulted in a cost, such as a toll call. Cost was also highlighted as an issue if people wanted to explore complementary/alternative or rongoa (traditional Māori medicine) options. Those present described the rift between traditional western medicine and alternative therapies as unhelpful.

Lack of financial means also had an impact on access to medications. Hui participants described getting prescriptions filled at a later date when they had the money or of cutting the tablet in two so the medication would last longer

Asking questions and making decisions at a time of stress

Making choices about cancer treatments is a complex and sometimes overwhelming experience. Isolation and lack of people to talk with about this enhanced this difficulty. In New Zealand generally, this is typically a role that a GP or practice

nurse fulfils whereby a patient may go and talk about options for treatment or care that have been presented to them.

“I had a choice put to me that I could have.....my head was spinning and then I stopped sleeping...I felt so down,...I couldn't walk, I couldn't get up, I was crying, my whole life was coming at me....” (1A)

“...I was set to have my breasts removed, like I've got to do it and you know because everyone's telling me get it off they're saying, get it off and don't muck around”. “...he said you do not have to have your breast removed”... I was staring into this decision thing again...decisions were just floating around...” (1A)

People on the West Coast noted they wanted specific guidance from specialists whom they viewed as experts to assist them in their decision making. This is perhaps because of the lack of ready access to primary health care professionals, exacerbated by difficulties in accessing other forms of information to help make treatment choices. In particular, men with prostate cancer felt this was not met.

“...but they will not tell you what, how to go about it, which is wrong sometimes because they are the ones that know and you don't hmm” (5A)

“...they don't recommend anything, the oncologists, they won't say surgery or hormone treatment or radiation, they'll leave it to the individual with advice that what you should do is to talk to people in your district that you know have had one of these treatments” (1P)

Making decisions after hearing bad news was identified as being particularly difficult.

“...they ask you, you know, “have you got any questions, do you need to know anything?” and of course your (mind) goes blank...” (2P)

The initial stage of the cancer treatment journey was singled out as being a difficult time to make decisions.

“...meeting all these new people and new facts and hearing all these new words of these new drugs and I didn't cope with any of it...” (1A)

Recommendations voiced by hui participants:

At the three hui, participants made a number of recommendations about ways in which the cancer care journey could be improved on the West Coast.

1. Anyone with a diagnosis of cancer seeking social support via Work and Income should not have a trainee case manager but a senior person should act as case manager.
2. All participants were vocal in their support of the idea of an advocate/navigator to assist Māori with cancer and their whānau. The feeling was that more than one position was required due to the geographical distances that need to be covered on the West Coast and to ensure the position was responsive to the different needs of the three territorial areas. They described the person as being:
 - A people person

- Knowledgeable about where to go to find things out both in the health and social care systems

They saw the role as encompassing more than just supporting the person with cancer. They thought the person(s) could:

- Work at ensuring the health promotion and cancer prevention messages got through to Māori
 - Support the spouse and whānau
3. A Māori support group to be formed to work with the local branch of the Cancer Society to increase its responsiveness to Māori with cancer on the West Coast.
 4. The need to have a lay male Māori support person as there are issues male Māori do not want to discuss with females even Māori females.
 5. Whānau to be supported (financially) to look after whānau with cancer when the time comes.
 6. Development of a permanent voice for Māori on the West Coast irrespective of which Māori are working at a senior level; Māori need to have training on how to advocate for themselves. The need for Māori in the Buller to have somewhere “to stand to be Māori” was voiced as a wider need.

Findings from the surveys

The surveys aimed to further investigate issues that had been raised in the literature and in the in-depth interviews and focus groups, as well as to identify any other issues that had not previously emerged.

There were 28 surveys returned from people with cancer (past or present) and 11 surveys from relatives of a loved one with cancer^g. As with the interview and hui findings, the survey findings are organised under themes.

Access to health and social services

In both surveys, respondents were asked a range of questions about their or their relative's access to various services, including health care and social services along the cancer care pathway.

Most of those in the patient survey indicated that they were able to see a GP promptly when something was wrong (23, 96%) and felt that tests and investigations to establish a diagnosis were undertaken without delay (24, 92%). However, a few respondents did identify that there had been delays for them:

Action from the GP was immediate, thereafter eleven weeks till I was examined and treated in hospital

It took about two months before I was seen by a specialist at Grey Base Hospital

No doubt the hospital done my tests as soon as possible, but it was six long weeks to me and my GP

One respondent also noted that private medical insurance had helped them to access tests.

Most people also felt that their treatment was commenced in a timely manner (25, 93%), and a number of these people also made comments, including:

Some of my treatment was delayed

Within six weeks

As soon as my biopsy confirmed my condition I was referred to an oncologist who began my treatment as soon as possible

However, two respondents did not feel that their treatment had commenced in a timely manner.

It took sixteen weeks when the normal was eight to ten weeks

Provision of palliative care and support

^g Numbers and percentages are reported at times in this section. Not all participants answered or were eligible to answer each questions, and percentages are therefore calculated based on the number of eligible responses rather than the total number of survey participants.

People were asked about whether or not they had thought about who they would like to provide care at the end of life. Of the four who indicated they had thought about it, three reported they would like to receive care at home and one at hospital.

Relatives reported that palliative/end of life care was generally a mixture of care provided at home and in hospital. Health professional support at home was mostly received from GPs, district nurses, and oncology nurses. Other people providing support at this time included practice nurses, palliative care nurses, neighbourhood nurses, occupational therapists and physiotherapists. These people performed a range of activities, such as helping with personal care (washing, dressing) and medication and pain control.

All of those relatives surveyed indicated that they had also received support from other people, including family (8, 80%), friends (6, 60%), neighbours (5, 50%), and church (2, 20%) as well as from the Cancer Society West Coast Centre (9, 90%) and the Buller West Coast Home Hospice Trust (2, 20%). These people provided general support, including conversation and sitting with the patient, shopping, help with personal care, and pain control.

Relatives noted that when they need to phone someone for help with health problems out of hours, they phoned a range of people including the GP, district nurse, Health line, oncology nurse or GP.

Support for those with cancer and their family/whānau

In the survey of those with cancer, people were asked how well they felt supported throughout their experience with cancer overall. Twenty-four people (86%) indicated that they felt either very well or well supported, while 2 (7%) felt neither well nor poorly supported and 2 (7%) poorly supported. As with the interview participants, they identified a range of people and organisations that had provided support, and various types of support activities.

A number of those in the patient survey made comments about their experience of support, including those that had indicated that they felt well supported.

Have been well served by health professionals in Christchurch and local medical centre. At odd times results of blood tests, biopsy received late influences support experienced – but overall impressed with service provided.

Organisations and local GP and nurses were wonderful. Feedback from Grey Hospital is very poor. Until I went to Christchurch Hospital I had to go to Grey Hospital in person to get results, sometimes this was unsuccessful.

Respondents identified partners, family, friends, and the wider community including neighbours and the church as providing support during this time. For relatives, these people performed a range of supportive activities, such as helping with shopping, sitting with the person with cancer and providing company, dropping in for a chat and so on.

Relatives indicated that they undertook a range of support activities for their loved one with cancer, including providing transportation to GPs and hospitals, housework,

caring for them when unwell, collecting medication, sourcing information, and organising and/or attending appointments.

In the relatives' survey, nine (90%) people identified that the Cancer Society undertook supportive activities. Of those with cancer surveyed, 19 (68%) people identified that they had accessed the Cancer Society. It was also one of the organisations approached (by two people) for support around issues of anxiety and depression.

For those people with cancer who had identified anxiety, depression or stress as an issue at least some of the time (17, 63%), their partner/spouse (8, 47%), other family (7, 41%), friends (7, 41%) and/or the church (3, 18%) were among those whom they approached for support, along with the GP (6, 35%), oncology nurse (6, 35%), cancer specialist (4, 24%), district nurse (4, 24%), practice nurse (2, 12%), social worker (2, 12%) and/or the Cancer Society (2, 12%).

Although a number of people (17, 74%) indicated that they felt that this was an area of care that received adequate recognition and appropriate care, about a third of those with cancer (6, 35%) indicated that they did not think this was the case.

Firstly the word support means different things to different people. In some cases, the support is provided by someone who is "paid to do the job" and one feels like just another statistic. In other cases the mention of the dreaded word cancer and people just don't want to know. There maybe competent practitioners out there but I haven't tried to find them. It is all very well offering support, what about actually giving it and how about defining what it is

To get home help times was a battle

When asked if they thought their partner/family/whānau had received adequate emotional support, many of those with cancer said yes (16, 80%) but a few said no (4, 20%). Their comments included:

My partner had supported me however the only support he has received has been from family and friends

Didn't know of any service available

Communication issues

The majority of those with cancer surveyed indicated that they had received their results in person (22, 89%), with a further two receiving their results over the phone and three getting given the results using a combination of in person, phone and/or letter. It was felt by almost all the participants that the results were given to them in a sensitive manner, although several made comments:

As sensitive as a phone call can be

I don't think there is a sensitive way to tell someone they have cancer

About half of the respondents (15, 56%) had someone with them when they received the results.

Information issues

Survey respondents were asked a range of questions about the information that they received. Almost all of those surveyed with cancer reported that they had received information about the test/s undertaken to confirm diagnosis, and that the information was useful and relevant (26, 96%). The person who had received no information noted that they had contacted the Cancer Society and used books to inform themselves. Respondents also indicated that they had received information about their condition after diagnosis (26, 96%) that was relevant and useful, although two people made comments:

Urology nurse told me what she knew but had to wait for further information from specialist, only came over every four weeks

The information I was given was relevant HOWEVER on both occasions I sometimes felt I wasn't asking the "right" questions – my questions were answered but had the feeling that the specialist was waiting for me to ask him but I didn't know what to ask...

When people were asked about whether or not this was enough information, most said yes (22, 82%) but some participants said no (5, 19%). They identified that they had therefore sought further information from various sources, including GP, district nurse, oncology nurse, family, friends/neighbours, the internet, Cancer Society and hospital nursing staff.

The majority of those with cancer surveyed (21, 91%) reported that they received information about the treatment options. This information was most commonly given verbally, although people also received pamphlets and/or written information in some case. Most people noted the information was easy to understand (24, 96%) and useful (22, 92%). Relatives also generally noted that they had received enough information to help them make decisions about treatment options (8, 80%). One of these people however, noted that their partner was given information that they would die within a few months while they were alone, instead of waiting until their relative arrived. The two people who felt that they had not received enough information commented:

We (the family) felt the information given whilst professional in its coverage, did not cover any negative reactions that could occur

The medical staff wanted them to have the radiation

Financial issues

A number of people indicated that they had stopped work (including for part of the time) because of their cancer. In several cases, it also impacted on their partner's ability to work or care for other family members.

Half of the respondents were on a benefit/pension when they started their treatment (14, 58%). Five respondents (26%) sought financial assistance from Work and Income as a result of changing financial circumstances. For these five people, two found the process very straightforward or straightforward, two found the process neither straightforward nor complex, and one person found it complex. One person

who had not sought financial assistance noted that they were not aware that this was available.

How does one know of any options or assistance

Of the five people who sought assistance from Work and Income, four were told they were eligible for a sickness benefit and one was told they were eligible for invalids benefit.

Travel issues

For most respondents to the patient survey, their main mode of transportation to both treatment in Christchurch (21, 75%) or Greymouth (18, 86%) was their own car. These people generally had someone to drive them (16, 59%), drove themselves (5, 19%) or shared driving with someone else (6, 22%).

Most people in the patient survey had received some assistance with transport costs from the Ministry of Health (22, 96%), with one respondent receiving travel assistance from both the Ministry of Health and the Cancer Society. When asked how they found the process of claiming travel assistance, over half the people (15, 63%) noted that they had found it easy or very easy. Some of these people made comments, however.

Once my case information got into the hospital system it became easy...

Very easy when you know the protocol

...rather than waste Doctors precious time in having to sign approval forms for application for travel fund maybe nurse could do the same when appointment is attended.

I felt reluctant to waste Drs time in seeking assistance

For some respondents, it was neither difficult nor easy (4, 17%), while for others (5, 21%) it was difficult or very difficult to claim travel assistance. In some comments, particular reference was made to delays in payments.

It was easy to start with but latterly the delay in payments was most frustrating when on a low income

...In 2006 I have had no problems so far apart from the fact that in 2004 it took ten days to process a claim, now it takes six weeks

Payment is made quite some time after travel. This can be a financial burden and cause more anxiety

Although the need to travel to Christchurch did not influence choice of treatment options for many respondents, for two people it did. A number of people stayed in Christchurch while receiving treatment (20, 80%). People used a range of options for accommodation, most commonly Davidson House (8, 42%) or staying with family (6, 31%). Other accommodation options included funded motels, paying for own accommodation, Ranui House or a combination of accommodation. About 70% of these people had a partner or support person staying with them when they were in Christchurch for treatment.

One of the survey respondents indicated that they would have preferred to have been in Davidson house, but that it was full.

“(partner) was in hospital and I was in a motel. Would dearly loved to be in Davidson House for support, I felt very alone”.

Other comments

A number of people also added comments to the survey, about their experience and where things were at for them now. Some of these comments noted positive things about their care or their health.

As my case was acute I would like to take my hat off to the speed and compassion of hospital staff both here in Westport, Greymouth and Christchurch. For all the bad things I have read about the DHB I found nothing to back the stories

If there had been no breast cancer support group I would not have been so settled now. They have been of great assistance

I might be a stubborn bat, I had ... cancer, it has been operated on and dealt with and now I am getting on with life and full time work. I deal with “if I have to” a reoccurrence when it happens. Life is too short to dwell on set backs

In the relatives’ survey, people were asked about things that they felt were managed well. A number of people noted positive aspects of health care that they had received.

Her care from nursing staff at home and while in hospital

Availability and quick response from both GP and hospital services were excellent

Staff at Barclay Ward were of great comfort and very caring to our needs as were the district nurses

Relatives also identified areas that they felt could be improved including interface issues between providers, more support from health professionals, improved communication and the availability of chemotherapy locally. For example,

Information flow between Christchurch and Grey Base on patient position and follow-ups to be actioned

Travel to Christchurch for radiation was always a huge effort. If it had been available in Greymouth it would have been a great advantage

Findings from the health professional focus groups

Health professionals commented that people start their journey from different points; some suspect something is wrong and present to the GP, while in other cases people are picked up during a routine GP visit and others via routine screening. Focus group participants consider that access to ultrasound and CT scanner for investigation at Grey Base Hospital was currently good. However, it was noted that the waiting list for ultrasound was growing and the delay for access to colonoscopy was getting worse. GPs from the Buller region commented that for their patients the fact that they had to go to Greymouth for investigations was a barrier in itself. Specific comments were made around the mobile breast-screening unit; currently this is only available to undertake screening mammograms and not diagnostic procedures. An observation was made regarding differences between urban and rural centres in relation to the use of health insurance. It was felt that more people in Christchurch than on the West Coast use their health insurance to more speedily access investigative procedures and then go on to have their surgical treatment in the public system. It seems that lower levels of private health insurance in rural areas could impact on wait times for investigative procedures and consequently surgical procedures.

The journey following diagnosis to treatment was felt by participants to work well, nevertheless there were some condition specific issues. For people diagnosed with lung cancer, two routes were possible with both having particular advantages. The first route, direct referral to Christchurch, was deemed to be responsive and patients were moved quickly to the next phase of treatment. The other route involved referral to and assessment by the surgeons at Grey Base, who if necessary would then refer to Christchurch. While this route was longer, the advantage was considered to be the reduced likelihood of the person's transport subsidy being messed up. Most participants felt that for those diagnosed with colorectal cancer, the current service was good and the past problems with continuity of care due to the heavy reliance on locum surgeons at Grey Base Hospital was being addressed. However, concern was expressed in relation to the proactiveness or lack of it, in relation to opportunistic screening for this condition. As previously stated the mobile breast screening unit will not undertake diagnostic mammograms neither will it complete follow up mammograms if it is less than two years since the person's last mammogram. On a positive note, it was felt the local urology service provided a very prompt service and the local urology nurse was viewed as a great asset.

All present believed the interface with Christchurch Hospital was very good with a number of outpatient clinics being held by Christchurch Hospital specialists at Grey Base Hospital. However, between a third and a quarter of all new oncology patients are seen at clinic in Christchurch Hospital instead of Grey Base Hospital. This therefore suggests that there is an unmet need in relation to clinic times at Grey Base Hospital. Clinics take place at Grey Base Hospital every three weeks however it was noted that for someone waiting to see a cancer specialist for the first time this can seem like an eternity.

Participants identified a number of concerns about palliative care service delivery on the West Coast. The lack of palliative care beds on the Coast was commented on, as was the lack of staff to provide out of hours home care should a person want to die at

home. In the Greymouth area, there is no GP on call after 8pm in the evening and while district nurses commented that they gave families their home telephone numbers, they noted they are not contracted to provide out of hours care and felt this left them professionally vulnerable. District nurses also felt that the funding they received to provide palliative care in the home was inadequate. It was remarked on that practice nurses do not get funded for out of hours palliative care and if they visit a person in their home either the person being visited has to pay for the consultation or the practice doesn't get funded. People who are resident in rest homes and who wish to receive palliative care and die in the facility currently may not be able to do so because of a lack of expertise amongst rest home staff. Commentary was mixed in relation to the timeliness of occupational therapy assessments for people with cancer returning home. Some considered the process was working well, whereas others felt people were discharged without appropriate equipment to support them at home.

Participants were asked to consider what they thought worked well on the Coast in relation to care for people living with cancer. The following areas were suggested:

- Oncology nurse specialist
- Working relationships between GPs, community nurses, community pharmacists
- Social support networks
- Cancer Society West Coast Centre
- Oncology support from Christchurch
- Good back up for patients in between oncologists clinics
- The Communication Booklet for people living with cancer
- Work of the district nurses especially out of hours and at weekends.
- Provision of accommodation in Christchurch

When asked to comment on what they felt was not working so well, the following areas were described:

- Lack of information in relation to what is available in the way of other support services or financial benefits
- People who receive surgery as a sole treatment modality do not always get referred to the oncology nurse specialist
- The large part charge for some drugs
- Support services on the West Coast are largely provided by non-Māori and it was felt that they don't want to get involved with Māori and they don't understand whānau issues
- A nurse working for the Māori provider noted that in her experience there is a lack of knowledge amongst families around how to care for a dying person and that on occasions this led to inappropriate decision making
- There is a lack of support for whānau who are caring for a dying person
- A repeating pattern noted by the Māori provider was that people are generally not aware of their options
- Work and Income do not always provide a supportive service
- The general lack on the West Coast of a marae based environment for Māori families
- Variability in discharge planning from Christchurch Hospital
- Lack of a physician at Grey Base Hospital with a specialist interest in cancer

- Frequent change over of GPs is an issue for patients and other members of the health care team that work with them
- Access to colonoscopy
- Perceived lack of penetration and uptake of public health messages
- Lack of a permanent mammography service on the West Coast
- Older adults not wanting to go to Christchurch
- Cost of accessing care for the financially disadvantaged is perceived to be a significant issue and made especially more difficult if you live less than 90K from the main hospital as you do not meet the criteria for reimbursement.^h
- Perverse incentive in labelling a person as “palliative”. People commented that once a person is labelled as “palliative” while they get access to a certain number of free GP visits over a 6 month period other home based support services are cut back.
- The “red tape” and forms to be negotiated by patients to claim their fuel reimbursement
- The information provided by haematologists as compared to oncologists and radiologists was perceived to be more limited
- Lack of counselling services for families on the West Coast
- Sometimes when there is a crisis situation at home, those health professionals involved in caring for the person living with cancer do not react promptly enough.

Participants were then asked what they thought would add value to people living with cancer on the West Coast:

- More funded palliative care beds
- Provision of mammography services
- Review of district nurses contractual arrangements
- Being allowed to use the palliative care funding creatively, for example it would be beneficial to be able to cover prescription part charges
- Appointing a Kaimahi – Māori health promoter – similar to those used on the National Screening programme to promote the public health and screening messages to Māori but also to articulate Māori needs to non-Māori services
- Hold hui on how to care for a dying person at home and provide clear information of what services/benefits people can access
- Provision of a 0800 number for Grey Base which allowed calls to be automatically transferred to Ward 27 at Christchurch Hospital allowing for 24 hour support for people with cancer from an oncology nurse. (Currently it would seem that people who have their chemotherapy at Christchurch are given the 0800 number for Ward 27 but not all chemotherapy patients are aware of this service)
- Provision of telemedicine would add value to the patient, the oncology nurse specialist and GPs

The following health professional issues/concerns were mentioned:

- Variation in care provided by local GPs, surgeons and physicians

^h National Travel Assistance Policy ISBN 0-478-29665-7 HP 4180 August 2005 Ministry of Health
PO Box 5013, Wellington, New Zealand Access September 2006, <http://www.moh.govt.nz>

- The knowledge gap of nurses in rest homes and on the Grey Base Hospital wards was mentioned, however, it was noted that nurses are under incredible amount of pressure especially in rest homes frequently being the sole qualified staff member on duty. Shortages of nurses made it difficult to release nurses for further study
- An increase in workload was noted by some community nurses since the appointment of the oncology nurse specialist
- It was perceived that there was a lack of support for community nurses caring for people in the palliative care phase
- As the role of the oncology specialist nurse has expanded, her ability to undertake home visits has lessened.

DISCUSSION

The route of a cancer journey can span months, years or decades, occur in a variety of settings, involve several providers and include a range of treatments. Common understandings and experiences of the West Coast cancer journey have emerged from the analysis of the health professional and person with cancer and family interviews, and the hui and these largely coincide with international and New Zealand literature on rural health and rural cancer care delivery.

People with cancer generally acknowledge that health and other professionals are trying to do their best and there were individual examples given when the overall journey has worked well. However, all involved in the interviews recognised that against a background of the generic challenge of rural health care delivery there are elements of the journey for people with cancer on the West Coast that could be improved. In summary, first there is a lack of health and social service coordination across the cancer journey often resulting in the person feeling disempowered; second, services are largely orientated around what providers can offer as compared with what people feel they need; and third, as no one professional is involved in all aspects of the cancer journey, there is a perceived overall lack of recognition of the destabilising impact a diagnosis of cancer has. If the analogy of a journey is applied to the key themes that emerged from the interviews, the phases of journey would look like:

- The start of the journey including the need to ask for directions and receive them (communication issues)
- Access to the appropriate map (information issues)
- Access to an appropriate mode of transport (travel issues)
- The cost of the journey (financial concerns)
- Detours along the route (issue of multiple interfaces)
- Accidents along the way (after-hours care, unexpected admissions to hospital)
- Poorly maintained roads (perceptions of feeling uncared for and unsupported by health and social care professionals)
- Decisions about the route (decision making at a time of stress)
- The end of the journey (special support in the end stages of cancer)

Aspects of the journey people noted to be going well included:

- People to go on the journey with (support from spouse/partner, family/whānau, community)
- Refreshment on the journey (Cancer Society West Coast Centre)
- Access to good garages (access to oncology and palliative care nurses, visiting oncologists, and district nurses)

Communication emerged as a multifaceted consumer concern with the following specific issues identified as impacting, positively or negatively, on the quality of communication experienced:

- Inadequate time with the GP or specialist
- Poor or limited communication between centres and providers
- Lack of timely access to a GP and lack of continuity of primary care provider

- Ineffective styles of communication
- The benefits of talking to a person who had experience of living with cancer as opposed to just speaking to a family member or friend
- The need to have a support person present

Many of these issues were also evident in the literature reviewed¹⁷⁻²¹. Indeed the most common complaints made by people in general with cancer are about poor communication and inadequate information²².

Having inadequate time with GPs and specialists is not just an issue for rural people²³, however, the additional time and cost frequently spent getting to and from the appointment on the West Coast adds to a sense of frustration and often disillusionment with health care service provision²⁴. On the West Coast, this is a particular challenge due to the limited numbers and availability of GPs²⁵ and the brief time the visiting oncologist and radiologist have available when they visit once every three weeks and the haematologist every two months. Whilst people with cancer recognise the time limitations specialists have in seeing all of their West Coast patients and appreciate the time they are given, they also have a strong expectation that specialists should provide them with the information they need. This issue is not easily solved although the literature suggests as information technology improves, telemedicine with health professionals and people is a useful strategy. Similarly, simple measures such as use of written information, written decision support tools and the audio taping of consultations can remind or validate what people hear during their consultations²⁶⁻²⁸. Other members of the multidisciplinary team can support/validate information given by specialists²⁹⁻³¹.

The importance of family and friends during the cancer journey was unequivocally borne out by the results of the interviews and hui. However, the work of Church, Curran and Solberg²⁰ particularly supported the views expressed by people with cancer that no matter how supportive family and friends were, they could not understand what the person with cancer was experiencing and that they needed to be able to talk to a person who has or is currently experiencing the cancer journey. One possible solution discussed in the literature was the provision of an audio teleconferencing network for those people in rural areas²⁰. This solution has potential as most rural households have access to land line phones²¹.

Communication between the multiple health and social care providers involved in the care of people living with cancer on the West Coast appears for many of those interviewed and surveyed to be less than optimal and could potentially contribute to sub-optimal care for some people³². The potential for poor communication to impact on care coordination is well evidenced in the literature^{33,34}. Similar to models of care for those with chronic illness or long term condition, there is evidence to support utilising a case manager role from the point of diagnosis^{35,36}. The role of the case manager would be to work with the person along the cancer journey to either survivorship or end of life care. A pivotal role of the case manager would be to coordinate services ensuring people with cancer are linked to all necessary health and social resources.

Another model, or perhaps subset³⁷ of the case management model has been proposed to address the needs of people with cancer, particularly those who are disadvantaged

^{38, 39}; that of Patient Navigators. Patient Navigators are variously described in the literature from the original concept developed by Freeman which was someone (often a registered nurse but could be a trained lay person) to accompany the person with cancer to all follow-up appointments, provide emotional support and advocacy⁴⁰. The patient navigator was allocated when an abnormal result was given and the navigator follows the person throughout treatment assisting in accessing support and appropriate follow-up. A recently published review of the patient navigator literature since 2003⁴¹ found that navigators have a different and complementary role to that of health professionals working with cancer patients. Their orientation is that of problem solving and trying to overcome perceived or real barriers to cancer rather than advocating a defined set of services. Patient navigators can be used during screening, treatment, palliative care or survival^{42, 43}. Dohan and Schrag (2005) summarised that patient navigation is understudied and there has been limited evaluation to test utility and outcomes.

In some areas of the United States, patient navigators called Native Sisters have been instrumental in working with indigenous peoples in relation to identifying, recruiting and accompanying people to cancer screening; providing patient education on cancer risk; co-ordinating diagnostic tests; providing follow-up and referral services; arranging for child care, transportation and counselling if needed; and, providing practical advocacy including mentoring people to ask questions during the consultation^{44, 45}. Evaluation of the Native Sister programme found a high rate of screening and re-screening.

People described in detail the burden of being the key link between multiple services and providers. Added to this was the issue for many of not being able to see the same primary care provider or specialist consistently. People at the hui described as “wearying” the need to keep repeating your history to multiple providers. Although not specifically a rural issue, this has again been described in the literature^{26, 28, 46}. There are examples of assessment tools used in aged care delivery^{47, 48}, and more recently in palliative care assessments⁴⁸ that demonstrate that comprehensive information collected in a systematic and robust manner can be shared between service providers obviating the need to repeat assessments at multiple points.

Concerns around provision of information were complex and varied. Information needs fell into the following categories:

- Need for information in relation to treatment. Specifically, people with cancer and their family had a need for improved information relating to the side effects of chemotherapy and to be able to understand the information provided whether in verbal or written form.
- Need for information on available resources. Specifically, people with cancer and their family had a need for information about financial support, how to access surgical supplies following discharge from hospital and how to access after hours care.
- The need to have options of care presented for consideration, e.g. private surgical options.

Other issues impinging on the wider issues of provision of and communication of information were:

- Lack of continuity of specialists and GPs.
- The apparent onus of the patient to find out information about services and resources.
- Having to make difficult decisions at times of stress.

These issues have already been noted in the generic rural health reports developed by the Centre for Rural Health from 2001-2003^{24, 49-51} and the Rural Health Survey undertaken by Rural Women NZ²¹.

A number of participants and Māori at all three hui spoke of not being offered the option to have investigations and/or surgical treatment procedures undertaken 'privately'. It is possible health professionals may be making assumptions of people's ability to choose and pay for private health care or whether or not they may have private health insurance. While Māori have lower levels of health insurance⁵² than non-Māori and are much more likely to live in deprived areas, people at the hui felt strongly that health professionals should not assume they would be unable to choose the private option.

Participants described making decisions under stress as a distressing experience. This issue has been identified in previous research⁵³ and although not specifically a rural issue, rurality adds to the complexity of the decision making process. Lack of access to GPs, interrupted continuity of GP care, and no formal process of linking people in the local community who were currently affected or had been affected in the past by cancer limited opportunities to discuss treatment and other decisions and issues.

People also spoke of not knowing what they needed to know, and of being given answers to their questions by health professionals but the answers being limited to what was needed to answer the question and no more. Given¹⁸ points out that people with cancer are not always aware of what they need to know and of what resources they may need.

Currently there is no holistic 'needs assessment' service available on the West Coast to systematically evaluate what services are required to support people with cancer. People found trying to find out what was available to support them a particularly frustrating process, especially in relation to accessing health care services such as after-hours support and financial benefits. This was coupled with the recurrent theme that people felt the onus was on them to make contact and request a service or a resource. This exacerbated their feelings of being unsupported and cared for. Feelings of not being supported along the cancer journey have been identified in previous research²¹ and are not just related to rural people, however through isolation the problem is magnified^{21, 49}.

Financial anxiety was apparent for both people with cancers and carers in this study. A UK paper commented that people who are seriously ill do not know how to access financial help⁵⁴ and those who could most benefit from financial support may be the least likely to obtain it. Rural people are often poor people^{49, 50}. Lack of financial means impacts on timely access to health care and purchasing of medications; this was especially evident during discussion at the hui. Concerns about confidentiality within a small town and perceived personal prejudices of Work and Income staff were

highlighted at the hui as barriers to accessing potential financial support. Māori also spoke about the impact lack of financial means had on their ability to explore other options such as rongoa or organic foods.

The New Zealand rural cancer journey is characterised by the need to self-fund frequent long distance travel. Claiming for fuel reimbursement from the Ministry of Health was a significant area of discontent for many and the increased wait for the reimbursement since the system has become centralised causes additional stress. Although most people own cars^{21, 50}, many people don't always have the money to fill their car with petrol for instance let alone have the financial means to wait for a period of weeks for the reimbursement to arrive. The greater cost of fuel in rural areas does not appear to be taken into consideration with fuel reimbursement. The local Cancer Society attempts to address the shortfall with fuel vouchers. If this service was not available, people of restricted financial means would not be able to access the necessary cancer care within the present system as specialist services are only available in Greymouth or Christchurch. Those present at the Buller hui said petrol vouchers were available from the hospital social worker but felt the process of accessing these as degrading and off-putting. As a result, those most at need did not always access the financial support that is available.

Similar to international literature⁵⁵ West Coast carers spoke of the financial impact of caring for someone with cancer. One carer spoke of having to sell her business; this then allowed her and her terminally ill partner who was also self-employed to access benefits. Another person spoke eloquently about the frustration of trying to access entitlements after his diagnosis of cancer forced him to give up work. Cormack et al¹⁹ highlights this as an issue in their recent report to the Ministry of Health.

The issue of transportation is closely linked to issues of cost and geographical location^{20,23} and on the West Coast to the lack of a public transport network. It is known that often older people with cancer have to rely on a family member to take them to appointments and this may mean sons or daughters having to make a choice between going to work or taking their relative to their appointment²⁰. This was also apparent in this study. The study also drew attention to the concern people have about making the journey to Christchurch over Arthurs Pass during the winter months. None of the participants spoke of ever being offered alternative modes of transport to assist them in getting to Christchurch. In many cases, older people had to drive this long, twisty and frequently narrow route, undoubtedly adding to their stress and making attendance at appointments increasingly daunting. One person related a story of having to drive over to Christchurch with a sick child and a sick husband. As a result of the need to make frequent trips to Christchurch for follow-ups, the interviewee talked about taking out a mortgage on her home to purchase a newer car so she could feel safer driving her daughter over the pass to Christchurch. This instance illustrates the additional pressure rural people with cancer or their carers are under if they want to access health care.

The area of palliative care emerged as an area of significant concern from this study not only for people with cancer and their carers but also for health professionals. In New Zealand, the palliative care phase of the cancer journey is defined as occurring within the last year of life⁵⁶. A recently released report has noted "...major inequalities in palliative care provision and access within New Zealand. These

include inequalities due to geographical location, disease type, care setting, age and ethnic group resulting in unnecessary and unrelieved suffering towards end of life and during bereavement”⁵⁷ (p. 4). People with cancer who are in the terminal phase of illness and approaching death require varying but generally increasing amounts of care. Many people express a preference to die at home rather than in a hospital or hospice setting, however, this is not always possible if symptoms become challenging to address or if family/carers tire or become overwhelmed. Terminal care can range from the provision of medication to control pain and other symptoms; personal care to meet hygiene needs; home care to assist with the activities of daily living; and, provision of nutrition and home maintenance such as cleaning and washing of linen. Psychosocial and spiritual/existential support of the person with cancer is necessary as well as support for family or other carers. Financial support may also be necessary to facilitate family members or other carers to care for the person in their own home. On-call and after-hours support is a core palliative care service as the dying process can be unpredictable and assistance may be required at any time of day or night. Internationally and nationally, it is recognised that provision of palliative and terminal care is complex and is best delivered by a team of health, home support, and other professionals. On the West Coast, the geography and distances involved make provision of palliative and terminal care particularly challenging.

In a recent paper⁵⁸ the following was written “Care is a continuum – an iterative process. Like an intimate conversation, it cannot just be picked up by a stranger when the most difficult, sensitive and personal aspects of the story are being played out”. On the West Coast, out-of-hours support is a significant issue for those caring for a loved one with cancer⁵⁹. They are required to either phone the 0800 Healthline for advice or take their loved one to Accident and Emergency at Grey Base or Buller Hospital, which can mean dealing with a health professional who is unfamiliar with the person. Those interviewed believed this to be unsatisfactory. Discussion with West Coast district nurses interviewed said on occasions they do give their home numbers to families, however, this is not covered in their contract and so leaves them in a professionally vulnerable position. Mention was made in two of the returned relatives’ surveys of GPs giving out their private number to families at the end of life stage; in both instances the GPs mentioned were DHB employees. For GP owners, undertaking and charging for out-of-hours palliative care can create a difficulty as GPs don’t always want to charge people with cancer but have overheads that must be met. Several NZ authors^{50,49,24} point out the cost of providing out-of-hours care in rural areas can be prohibitive and describe the tension for rural health professionals of wanting to provide care but also the need to have adequate time off⁶⁰.

Home carers from the hospital social work department are mainly responsible for undertaking general household tasks for people who are assessed as requiring this. Home care includes housework, making beds and hanging out the washing, and on occasion, personal hygiene care such as showering people with palliative care needs. When people move into the palliative care phase, the funding to provide personal care support comes from the district nursing budget. However, provision of complete personal care support cannot reasonably be expected from a district nurse. Whilst generalism is a valued tool, there are simply not enough West Coast district nurses to do this work as well as have time to undertake the specialised nursing work required. On occasions, district nurses shower/wash people who have palliative care or terminal care needs. However, this puts a huge strain on the district nursing service, which is

already stretched. If a person in the palliative care phase becomes incontinent much of this care is left to the family carer due to human resource constraints.

One of the main issues regarding physical support provision is the variety of funding streams involved with some coming under the control of GPs, some under district nursing and some from social work, making the system fragmented and potentially leading to people being unable to access the full range of services which should be made available to them.

On the West Coast, there are only three funded palliative care beds located at Greymouth, Reefton and Westport. People who require an in-patient palliative care bed but do not live close to any of these three centres, end up being removed from loved ones and friends at a significant point of the journey. The West Coast does not have a hospice and establishing one would be an issue due to the geography of the Coast. The Buller West Coast Home Hospice Trust does not appear to have a high profile on the West Coast and none of those interviewed in the palliative care stage were aware of their existence or how they could support them and only two of the returned relatives' surveys mentioned any contact with them.

It would appear that on the West Coast the bulk of palliative care is preformed by informal carers, and this was especially evident for Māori from the hui. People with cancer and their carers want to feel supported by their GP and the nursing services, yet it would appear that this is not always the case and support provision can appear like a lottery potentially leading to avoidable hospital admissions. Accessibility to GPs and nurses, specifically district nursing provision, has been identified in the literature as an important factor in effective out of hours care⁶¹. Reviewing district nursing contracts and consideration of reimbursement for GPs to undertake palliative care home visits out-of-hours would address this situation. Greater partnership working with non-government organisations involved in the area of palliative such as Work and Income could potentially improve the end of life experience for the person with cancer and their family.

While people valued the opportunity of having chemotherapy given locally (at Grey Base Hospital), there can be disadvantages to having chemotherapy in a rural setting^{62, 63}. This was confirmed by West Coast health professionals involved in this aspect of care, and in particular in relation to limited support from medical colleagues to check medications or protocols and competing work demands due to nurses needing to do concurrent roles. There are three nurses trained to undertake chemotherapy clinics but only one works full time in an oncology role and this poses difficulties in covering annual, sick, or study leave. Recently due to staffing problems in the pharmacy department of Grey Base Hospital, there have been drug reconstitution issues. One of the local nurses involved in oncology care spoke of her concern in relation to the small volume of people having chemotherapy administered at Buller Hospital which inhibits staff skill development and maintenance.

LIMITATIONS OF THE STUDY

There are limitations in this study. Firstly, the timeframe to undertake the study limited the number of stakeholder interviews that could be undertaken and although a sampling framework identified key categories of people needing to be interviewed, other opinions were not canvassed.

Although every attempt was made to identify those with cancer on the West Coast to approach them for survey, it is possible the survey sample may limit generalisability. Qualitative methods identify the range of opinion rather than the proportions of participants who hold any given attitude. However, the study design included triangulation of results to minimise these effects and research protocol and standard procedures for independent qualitative data analysis was rigorously maintained.

The themes reported here recurred independently across interviews, hui, and surveys and are consistent with international and national writing on rural health care and cancer care.

CONCLUSION

This study used the experiences of people with cancer and their spouse/partner and family/whānau to identify and communicate their opinions regarding what was helpful about the current services for those living on the West Coast and where gaps were present. Similarly, the experiences of health professionals working in this area were canvassed.

This study has identified a number of significant gaps in West Coast cancer service provision for people living with cancer, their carers, and family/whānau. However, many of the components of a good service are present but connectivity between components is lacking.

Rural areas in New Zealand are heterogeneous and differ in population number and density, remoteness from urban areas, as well as financial and social characteristics. It is hoped, however, that the findings of this report will be of value to other rural areas and to cancer services in general.

The scope of this study did not include the development of recommendations for future service provision. However, analysis of the text data and review of the literature has led to the identification of ideal characteristics for a West Coast cancer service.

Characteristics of an improved service may include

When developing any new service, consideration should be given to not increasing inequalities that already exist. A recommended tool already in use on the West Coast allows a close examination of these factors⁶⁴.

All people with cancer

1. A patient navigator model for those with high needs (socioeconomic, age, vulnerability, ethnicity). This should take account of the limited international research undertaken so far to evaluate the outcomes of this model and the concurrent work by other DHBs in New Zealand already utilising the model. It is advised that collaborative research be undertaken taking account of the New Zealand context.
2. Seamless interface between health and social support needs (such as Work and Income).
3. Review of the Primary Health Care funding arrangements for GP consultations and home visits. Closer interface between cancer specialist's local hospital doctors, GPs and oncology and palliative care nurses. The use of audio-conferencing is necessary. The use of telemedicine including remote video-links between local Grey Base Hospital physicians and people with cancer/district nurses in the person's home or with oncologists or Oncology Centre staff in Christchurch.

4. Provide a face-to-face after hours service for people with cancer on the West Coast.
5. Implement a case management model. Designate one person as team leader to co-ordinate care- probably the nurse closest to where the person lives. Develop a Memorandum of Understanding or other mechanism to facilitate closer interfaces between Christchurch specialists and Grey Base Hospital physicians.
6. Review of job descriptions of ruralⁱ, neighbourhood, and district nurses to provide coverage for possible after hours consultations (phone calls or home visits).
7. Consider whether there is a way for pharmacists to modify the part charges they do or do not make, e.g. whether they could charge these to an organisation (the PHO) rather than to an individual patient.
8. Review the claiming of petrol monies to ensure this is an easy process.
9. Availability of specialist support both local and remote (palliative care, acute oncology, radiotherapy and haematological support).
10. Availability of technologies to support remote specialist expertise in the home.
11. Given the geographical restrictions, increase capability of all community based nurses on the West Coast to support people in their homes. Up-skilled community care nurses (oncology and palliative care skills) *vis a vis* one 0.5 palliative care nurse position to cover the whole West Coast area.
12. The psychosocial aspects of cancer care need to receive a high priority at all points along the cancer continuum for both people with cancer and their carers.
13. A robust process should be established to assess and provide the carer support subsidy for carers (family or another) who provide care for a person with palliative care needs.

People with palliative care needs

1. Establish the right to access after-hours support.
2. Availability of home support and personal care in the home. Valuable and scarce nursing resources should be supported by provision of home care support.
3. Greater involvement of non-government organisations engaged in palliative care to enhance service provision.

ⁱ Rural nurses work 24 hours on call for 10 days and then have four days off, but have cover from the rural nurse in the next area

People with cancer requiring treatment in Christchurch

1. Priority given to accommodation of West Coast people with cancer at Davidson House.
2. Formal assessment of the impact of travel on those receiving multiple courses of chemotherapy in Christchurch with air travel provided to those with adverse impact.

Māori with cancer

1. A service should take account of the needs of Māori including appropriate information and support.
2. This may require designated people with quasi social work skills to partner people with cancer through the cancer journey.
3. Review the service specification of Rata Te Awhina to support them to provide for Māori living with cancer and their whānau where appropriate.

System level characteristics

1. Creation of a seamless service by building on existing initiatives and developing skills available within the region.
2. An integrated service that increases its capacity to meet need by optimising the contribution of non-government agencies in the area that also work in the field of cancer care ('one stop shop' service recommended within Centre for Rural Health reports).
3. Service delivery should be multidisciplinary in nature and based on best practice to ensure optimal outcomes. Mechanisms to promote integration and coordination of care across settings and service providers should be implemented.
4. A regional coherent palliative care service be fully developed and implemented.
5. Clarification around roles and responsibilities especially in relation to who is responsible for provision of information to people with cancer – specialist or GP.

A possible model for Multidisciplinary Cancer Care for West Coast people with cancer

Oncology Multidisciplinary Team Leader: This would potentially be an oncology nurse who would be 0.5 clinical and 0.5 administrative/educational support. The role would include but not be limited to: strategic planning, communication, relationship building, act as a resource for the region, education and training, driver for change and quality improvement, audit and evaluation of services

One full time oncology nurse: This position would administer chemotherapy, support the team leader and cover for the team leader during annual leave, study leave and sickness, and support cancer case managers with expertise

Three (one in each territorial area) cancer case managers: These would report directly to the team leader; these positions may not need to be full time in each territorial area. These positions would act as the point of contact for their allocated people, and could also address some of the out-of-hours issues. Each position could work an on-call rota and one weekend in three. People would then know they would be getting in contact with one of three people

Māori advocate: This position would liaise with the case managers and accompany Māori to appointments with visiting specialists and liaise with Work and Income as well as have an input into health promotion activities targeting Māori.

Other members of the MDT would include: oncologists, radiologists, surgeons, people with cancer, general practitioner, district, neighbourhood and rural nurses as appropriate, pharmacist as appropriate, Cancer Society West Coast Centre representation. The case managers would be responsible for contacting the Buller West Coast Home Hospice Trust when appropriate, for support such as provision of equipment.

Other model components

Telemedicine to become part of usual care for people with cancer when necessary.

Trained Volunteers (possibly by Cancer Society West Coast Centre) in rural and very rural areas who could make regular calls or home visits to check on needs of people with cancer/spouse/family.

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APPENDICES

Appendix A : A selective literature review

One in four New Zealanders live in rural areas or small towns²³, and in these areas, one in five are Māori. There is no defined rural health strategy in New Zealand (NZ)⁶⁵ neither is there a defined NZ index of rurality⁶⁶ although Statistics New Zealand define rural as a town with less than 10,000 people⁶⁷. Although there is no specific NZ definition of rural health the former Centre for Rural Health defined rurality in relation to distance from main urban centres; medical on-call rosters; availability of practitioners to attend medical and trauma emergencies; distance from colleagues; the size of the territory being covered by medical practices and the servicing of peripheral clinics²³ with 'remote' being defined as no other rural GP within one hour of travel⁶⁵.

Rural NZ areas are typically small isolated areas, with higher levels of deprivation due to international downturn in primary production⁶⁸, a higher proportion of Māori and more transient, seasonal populations or tourist populations²³. Although living in a rural and remote area can be emotionally protective⁶⁹ it is recognised that there are barriers to health care access which can result in poorer health outcomes and impact on health provision and choices. Some choose to live in a rural or remote environment knowing they will need to make extra provision for health care whereas others have never known any other service.

Internationally, rural people tend to be an older aged population with less education and often work on the land or in heavy labour industry¹⁸. In NZ, there are greater numbers of people aged between 0-14 years and 45-59 years in rural areas than urban areas⁶⁷. Health wise, they have higher rates of injury, diabetes, cardiovascular disease alcohol consumption and smoking⁷⁰; there are also notable same-gender differences between urban and rural women in relation to health care issues⁷¹. It is possible there may be differences in mental health issues in rural areas with geographical social and professional isolation resulting in higher levels of alcohol intake, relationship breakdown and depression, however there are more limited mental health services available in rural compared to urban settings²³.

Health is generally defined by rural people in terms of ability to perform roles and maintain productivity⁶⁹ especially in primary production industries⁶⁸. Rural and remote people are generalised as independent, turning inward and self sufficient⁶⁹ and it takes a protracted period of time for someone to be considered part of the community and to be accepted and trust (this can include 'new' health professional staff)⁶⁸. Because of distance from mainstream services in general rural people tend to have lowered expectations of care and expect barriers to accessing specialist care⁷² which may result in them delaying seeking treatment⁶⁹. People may choose lesser treatment options in preference to relocation to attend a distant treatment centre^{73, 74}. Rural and remote people must meet higher costs than metropolitan people in terms of travel and accommodation though they are already poorer in terms of income.

In NZ, cancer is recognised to be a major public health issue in New Zealand, similar to other developed countries. It is ranked second as a cause of death (after

cardiovascular disease), and accounted for more than a quarter of all deaths by the late 1990s⁷⁵. The NZ, the Ministry of Health have undertaken analysis of cancer by region, and there is some regional variation in incidence and prevalence of cancer⁷⁶. Although internationally it is recognised there is variability between urban and rural cancer incidence prevalence as well as variation in cancer prevention and treatment⁷⁷; in NZ it is difficult to say anything generalisable from current data collection about rural people and cancer⁷⁶. Armstrong and Borman have noted there being small difference between the rates of breast cancer between urban and rural women⁷⁸. The rate of cancer for Māori is one fifth higher than among non-Māori, however Māori die at a significantly higher rate than non-Māori. Māori are less likely than non-Māori to be diagnosed at an early stage and when diagnosed the cancer has often spread. Even when diagnosed at the same stage there are inequities in survival, with Māori dying sooner. Māori are less likely to have a stage recorded on diagnosis which impacts of the decisions made about treatment offered and eventual outcomes⁷⁹.

This selective literature review examines literature in relation to: rural people who have cancer including barriers to screening and treatment, experience of treatment and support required when living in rural and remote areas, indigenous people and cancer treatment, and the impact of travel distance on cancer treatment. There is very limited New Zealand (NZ) specific literature on rural and remote health although Australian writers and researchers have usefully examined a number of aspects or issues.

General issues

NZ rural people are recognised to have unequal access to health services in general²³ and to specialist services in particular, because of unseen costs through time away from work, disruption to family life, and travelling and relocation expenses⁸⁰.

Having to travel distances to seek health care is prominent in writing on barriers to health care in rural areas. Rural areas often have high levels of deprivation and families frequently do not have access to a reliable vehicle for transport and up to 79% of rural households have none or extremely limited public transport²¹. Ambulance services are also limited with mainly volunteer drivers who would not be able to undertake ambulance transfers between hospital and health care settings in the way they might in an urban setting²³. Transport time taken to access health care may mean people are unable to be at their economic activity for several hours at a time²³. A NZ rural health survey undertaken in 2001 (prior to the introductions of the Primary Health Care Strategy with capitation payments and lowered GP part charges) the largest obstacles for rural people accessing health care were cost (63%) and distance (19%)²¹.

Similarly in Australia, it is felt that people who are locationally disadvantaged, have reduced access to quality screening or diagnostic services and variation in treatment services and as well people present later in the course of illness consequently with larger tumours which may limit treatment choices⁸¹⁻⁸⁴.

Other issues known to affect cancer treatment provision and access for people living in rural and remote areas include: financial worries due to needing to take time-off from work to support a family member including driving them to the secondary/tertiary health service and the resulting costs of travel and accommodation particularly so if a child is involved⁸⁵. In NZ there is limited flexible accommodation

available for providing convalescence/intermediate care and overnight stays for people whose homes are distant from health care facilities²³.

It is known that rural people being treated for cancer experience higher levels of unmet need; higher levels of anxiety; poorer family functioning due to limited problem solving/communication/social roles; family household/ child care disruption; lack of local care; general disruption due to treatment facility and frequency⁸⁶; lack of appropriate information⁸⁷ and experience isolation when treated for cancer in a secondary or tertiary centres⁸⁸. Particular challenges occur when people (often children) have haematological tumours where rapid commencement of treatment is necessary and transfers are often not well managed⁸⁹.

Rural people have to balance the difficulty of finding transport and making the journey (with huge travelling distances) against the benefits of having specialist treatment^{81-83, 90} and better qualitative outcomes (pain control)⁹¹. Some articulate travel and transport as a barrier to obtaining cancer treatment⁹² whereas others who need specialist treatment do not rate these issues as a significant impediment⁹¹. To address this, some countries including Australia and NZ financially support patients who need to travel for cancer treatment. In Australia, various schemes such as 'The Patient Transit Scheme' have assisted people travelling for treatment by funding their travel (and for some accommodation costs^{93, 94}), and work has been undertaken to evaluate peoples satisfaction with these services as well as examining whether further assistance is required for those to require for extended periods of time^{94, 95}.

Wilkinson and Cameron (2004)⁹⁶ found that in Australia there was little evidence of different risk factors, incidence or early detection of cancer between urban and rural dwellers, however rural people consistently had poorer survival rates and a similar study found those who live more than 58 kms had a poorer chance of survival from lung or colorectal cancer⁹⁷.

Additional disadvantages for people with cancer in a rural setting are being poor¹⁸ or/and indigenous^{74, 98, 99}. Indigenous people do not always want to be accommodated in the standard cancer treatment hostel settings and will refuse radiotherapy or chemotherapy for this reason⁸⁷. Curtis, Wright and Wall (2005)¹⁰⁰ found Māori women have a higher age specific mortality from cancer with causal factors including differential access to primary health care, screening, treatment, referral quality of care and similarly indigenous women in Ontario were less likely to access screening¹⁰¹. Poorer people of social class 5 (least education) are least likely to die in a hospice¹⁰².

In rural settings “.treatment decisions and outcomes are determined by a constellation of geographical, resource, cultural and communication factors”⁷⁴ (pg14). Having to travel for cancer treatment may alter peoples treatment choices especially when they are poor¹⁸ and when treatment is protracted eg breast conserving surgery where radiotherapy is mandatory^{82, 103} although having to travel for up to an hour for radiotherapy does not reduce radiotherapy uptake¹⁰⁴. Length of travel for complex treatment may influence choice between different treatments (which may have acceptability differences). For example, rural women tend to choose mastectomy for breast cancer rather than the more acceptable breast conservation surgery plus radiotherapy, because of the consequences of travel to a tertiary treatment centre^{81, 82, 105}

Overall, having to travel for treatment is known to result in emotional distress for a number of reasons including: separation from loved ones; attempting to maintain responsibilities whilst undergoing treatment; choosing a treatment that takes you away from home; dislike of cities/travel/parking etc; increase costs of travel and accommodation; and yet these issues do not appear to be adequately addressed by cancer support services¹⁰⁶

Access to primary care

The most frequent entry point into cancer treatment services is following a general practitioner (GP) consultation leading to a diagnosis, or referral to cancer treatment specialist. Therefore rural GPs and the primary healthcare team have a pivotal role in preventative screening, diagnosis, ongoing care and support.

NZ Rural GPs are predominantly male, aged between 35 and 44 years, more likely to have trained overseas and have smaller practices with greater through put. In certain parts of NZ there has been a significant turn-over of GPs and a GP may not stay in a rural area for more than a few years. Their patients are more likely to be from NZ Dep deprived areas with Community Services Cards and a higher number being Māori. The patients tend to present with similar problems to patient in urban settings; however rural GPs order fewer tests and investigations and undertake a lower rate of follow-up although rural practice nurses undertake a greater role and the practice in general offers a greater range of services¹⁰⁷. Rural Australian practices are smaller with less resources and higher turnover of GPs and gaps in GP resources¹⁰⁸; these issues were also noted in a study of NZ women¹⁰⁹

Internationally, rural demography tends to be older, poorer, have less private insurance and a higher number of patients per GP compared with urban settings causing patients to travel greater distances for acute and preventative care¹⁰⁸ and this may delay patients initial presentation¹¹⁰. The number of primary health care consultations declines with degree of rural and remoteness¹¹¹. It seems that novel forms of primary care including outreach clinics and expanded roles for nurses^{108, 112} can improve access¹¹³.

With disease progression, palliative and terminal care often forces people to be cared for and die outside of their community however this does not need to be the case in rural areas. There is often exceptional community support available to people with cancer from rural communities¹¹⁴. With co-ordination¹¹⁴, quality palliative care services according to palliative care principles, but with adaptations to local conditions and taking account of the needs¹¹⁵ and cultural norms of indigenous people¹¹⁶ can be delivered in rural areas as long as there is involvement by general practice and general practitioners¹¹⁷ and additional services can be made available if required¹¹⁸.

GPs may be less familiar with obscure cancer diagnoses and cancer treatment modalities¹⁸ however this does not appear to inhibit GPs overall referral to specialists¹¹⁹. Being an indigenous person also inhibits attendance in primary care¹²⁰ resulting in a reduced rates of screening¹²¹, higher death rate of indigenous people in some circumstances eg cancer of the cervix⁹⁸. There is also limited access to screening¹¹¹ and when screening is available, it may not target high risk rural women

(such as indigenous and low income women)¹⁰¹ and does not take into account the particular issues that rural women have particularly if there is a positive result¹²¹.

Access to specialist care

In rural settings, access to specialist medical clinician and/or specialised treatments is limited and travel to a tertiary treatment centre is an inevitability for many treatments. All-age, all-condition survival comparisons between urban and rural Australians with cancer show those living outside metropolitan and large rural areas are disadvantaged in five year survival rates and lower socio economic status negatively augments this differential¹²². In Australia, fewer people living in rural areas than other areas receive radiotherapy¹²³ and fewer people unless they have private insurance are offered access^{124, 125} to some types of surgical procedures, including treatment for lung cancer⁸³ and breast conservation surgery; this is particularly so if people are disadvantaged^{81, 82}. Indigenous people are less likely to receive surgery for lung cancer and for males, prostate cancer¹²⁶.

Admissions into hospital for cancer treatment are becoming less common and as a consequence people are sent home quicker, sicker and with less support; this is particularly noticeable in a rural setting because of the additional factor of having to travel long distances for treatment¹⁸.

In contrast to Australian studies^{81-83, 126}, a similar New Zealand study was not able to definitively link locational distance with poorer survival. The study identified being Māori or an older person resulted in poorer survival for upper gastro-intestinal cancer¹²⁷ although it acknowledged the relationship between locational distance and survival as complex and noted there was a poorer prognosis for those living mid urban/rural distances of between 51 and 100kms from a cancer or oncology centre.

There is variation about whether rurality and needing to travel distances for health services influences preventative screening. Bulliard (2004)¹²⁸ found those locationally challenged and⁸² those economically plus locationally challenged were less likely to attend breast screening, whereas Kreher 1995¹²⁹ and Pavlik (1995)¹³⁰ found no differences in rates for screening rural women. Ahmad & Davis (2002)¹³¹ found public transport travel time had no influence on screening, whereas McNoe (1996)¹³² found inconvenience and logistical factors influence women's choice to decline screening.¹³² Richardson et al (1994) found NZ rural women had similar degree of satisfaction as urban women¹³³.

Ways of enhancing access to specialist care include virtual home care consultations via telephone¹⁸ teledermatology for detecting cancerous skin lesions¹³⁴ and telemedicine real-time videoconferencing for cancer genetic counselling¹³⁵.

Access to treatment

Cancer treatment centres ideally should be placed as close to patients' home as is compatible with high quality safe and effective services¹³⁶. However radiotherapy is unique in that it has to be provided in a tertiary treatment centre and requires people to have often daily treatment for days to weeks thus creating difficulties with distance, geography, cost of travel and accommodation, dislocation from family and friends and consequent lack of adequate financial support¹³⁷.

Internationally, treatment modalities such as radiotherapy are only available in secondary or tertiary settings where high quality services are assured because of adequate utilisation and quality assurance processes. However this requires people living in rural and remote settings to travel long distances with significant cost, time pressure and emotional stress; all these factors act as barriers to accepting treatment¹³⁸. It is internationally recognised that although up to 60% of people with cancer could potentially benefit from radiotherapy¹³⁸, access rates are far below this¹³⁹, particularly those with locational^{87, 137} and older age disadvantages¹²³. As well there are often considerable delays in starting treatment¹⁴⁰.

Anti-cancer chemotherapy can either be given in secondary/tertiary settings or less aggressive regimes in rural and remote settings. Chemotherapy regimes delivered in rural and remote settings may mean people with cancer do not have to travel such long distances and can be treated as outpatients while still maintaining family and work responsibilities¹⁴¹. However, there are recognised disadvantages to having chemotherapy in rural settings, mainly due to small volumes of patients, which inhibits staff skill development and maintenance and limited quality assurance procedures being undertaken. Quality issues identified include: tertiary centres being unaware of the limitations existing in rural and remote settings and making unrealistic expectations; medication supply/storage/transportation/ reconstitution issues; competing work demands due to nurses needing to do concurrent roles; limited support from nurse/doctor/laboratory colleagues to check medications or protocols/ or provide comprehensive instructions/undertake blood tests/manage neutropaenia; low/intermittent numbers of patients meaning loss of skill; lack of facility policies/procedures/staff education and a general lack of staff to enrol into this work and to be educated to develop suitable skills⁶².

Access to support

Basic needs are not always systematically evaluated but must always be prioritised. These should always include an assessment of the provision of food, heating, household goods, transport, finances, family and housekeeping services, and childcare¹⁰⁶. There are some particular but generic areas, which people with cancer identify as important in the provision of support. These include conveying the diagnosis in a supportive manner; providing adequate immediate and ongoing information, through digital and electronic means especially for people who are financially unlikely to have access to these services^{142, 143}. An identified support person throughout the entire cancer experience was pivotal; this person could inform them about the various services that were available (in the UK this was identified as the role of the Macmillan Nurse). Minimising the impact of service provision restrictions including funding for travel and provision of transport assistance was noted as essential, as was referring to the local palliative care service sooner rather than later¹⁷.

Other support needs that people with cancer find problematic are transportation; accommodation treatment, information on alternative treatments. Given (1994) points out that people with cancer are not always aware of what they need and what might be available and that a thorough assessment would identify support needs¹⁸.

Carers needs are not well recognised in the provision of cancer care and need for support, information or resources is not systematically assessed. Silveira & Winstead-Fry found that in rural settings while carers needs were fewer in number they were

unmet three time more frequently than patient needs. Needs which carers noted as very important were: *personal care* including how to make a person comfortable; what health issues to observe for; knowledge of expected symptom/health changes: *involvement with health care* including need to keep informed of patients condition; assurance that patient would be admitted if necessary; help with emergencies need to be informed of changes: *interpersonal interaction* including need to communicate with patient; need for comfort and support from other family members¹⁴⁴.

Girgis found rural women with breast cancer two and a half times more likely to report a need for physical and daily assistance needs¹⁴⁵. Similarly Clavarino (2002) found both patients and carers have unmet support needs with patients having moderate to high levels of unmet psychological needs and carers having higher anxiety levels than patients resulting from having to assume more responsibility for undertaking household tasks and organising new living arrangements⁸⁶. Bain 2002⁹⁰ found rural people wanted their GPs to act as advocate rather than gatekeepers in supporting their need for treatment and care.

Appendix B Letter to GPs re Study

28 February 2006

Dear :

Re: Potential participants for the study about the journey of treatment and care for people with cancer on the West Coast

This study funded by the Ministry of Health is about to commence on the West Coast. The first stage of the study involves undertaking interviews with about 20 participants. As well as asking you to place posters in your waiting rooms in order to directly recruit participants, we would like you to assist us by identifying people with cancer whom we can approach via a letter and with follow-up by a third party not directly involved in the research. In order to do this please could you suggest five people from your practice including one person who identifies as Māori and supply us with their names and contact details. The inclusion criteria are as follows:

- Adults (18 years +)
- Diagnosed with cancer (except minor skin cancers) within the last five years
- English speaking and cognitively intact.

We anticipate that not all 5 persons you nominate will want to take part and Danielle Smith from the Cancer Society will follow up the letter inviting participation to determine a final list of participants. Please provide the names and contact details of potential participants on the form provided.

If you have any queries re the study please do not hesitate to contact either Fiona Doolan Noble: e-mail; johnnoble@xtra.co.nz or phone; 03 755 5166; or Carol Atmore; e-mail; carol.atmore@westcoastdhb.org.nz or phone; 03 768 0499 ext. 2550. Please note that this study has been approved by the Upper South Island Ethics Committee.

Yours Sincerely,

Fiona Doolan Noble
Principal Investigator

Dr. Carol Atmore
Co-investigator

Appendix C: Script to invite people to join the study

Draft Script for Danielle phoning people re participation in the cancer mapping study

Hello (name) it's Danielle here, (there may be some general chat here). The reason for my call is to ask you to consider being interviewed as part of a cancer study currently underway on the Coast; is now a convenient time for me to explain a little bit more to you?

The study involves interviewing about 20 people who have had or are living with cancer on the Coast. The researchers want to speak to people who have a variety of diagnoses, who are at different stages, are of different cultural groups and who live in different areas of the Coast to find out what people think about the services they have received, what has worked well and where each person feels the gaps are for them. Each interview is expected to take no longer than one hour and if you become tired can be completed sooner. To help the researcher recall all you have said the interviews will be taped and transcribed however you will receive a copy of the transcription to read which you can add more comments to if you think of something which you feel is important once the interview is over. You do not need to answer any questions you would prefer not too. You may need some time to think about this information before you decide whether or not to participate do you have any immediate questions.

Dependent on response:

Thank you for the giving me the opportunity to explain the study to you, it's been good to talk to you and thank you for your time.

OR

Thank you for the giving me the opportunity to explain the study to you, I will put an information sheet in the post along with a consent form and a stamped addressed envelope. If you decide to go ahead just complete the consent form and return it to me in the envelope provided. A researcher will then contact you to arrange a convenient time and location for you to be interviewed; you can of course at anytime change your mind. It's been good to talk with you and thank you for your time. If once you have read the information sheet you have any other questions please don't hesitate to call me.

Appendix D: Letter of approach to possible participants

LETTER OF EXPLANATION TO PATIENTS

Dear

Kia ora

I am writing to you to ask if you would be prepared to help in a small study we are undertaking as part of a national initiative to improve cancer services.

We would like to interview people living with cancer on the West Coast about their experience of the care they have received and what has helped and what hasn't. It will involve discussing your experiences and how you feel about your care and treatment, right from the time when you first thought you might have a problem.

Each interview should take no more than 45-60 minutes and we will tailor it to the amount of time you wish to give. We can assure you that what you tell us will be treated in confidence and at no stage in the future will you be identified in any reports from the study.

To make the discussion easier we would like to record your experiences on an audio-tape – this will make sure we do not miss anything – but if for any reason you do not wish the discussion to be taped we will simply write your thoughts down on paper. You will have the opportunity once we have typed up the contents of the tape to have the audio tape sent to you.

Please do not feel under any pressure to take part in this exercise – we do not mind if you say 'no'. If you decide not to participate this decision will in no way affect your future health care. If you have any questions you would like answered prior to making a decision regarding participation please phone the Cancer Society rooms on 03 768 9557. If you wish to take part in the study please complete the consent form and place it in the stamp addressed envelope provided. If you agree to take part a researcher will contact you to make arrangements to interview you. The interview will take place at a venue and time of your choice. You can at any time decide you do not wish to take part and you can refuse to answer any of the questions put to you.

Thank you for considering this project.

Yours sincerely

Fiona Doolan Noble
Lead Study Investigator

Appendix E: Consent Form

CONSENT FORM for participation in interviews for West Coast Cancer Study

Before consenting to take part in the study please read the following statements:

- I understand that the interview will be audio-taped
- I understand that all information gathered during the course of this study will be anonymised so that no one can track back information to a specific person
- I understand that the interview may range between 45-60 minutes but will be shorter if you are tiring
- I understand that at anytime during the interview I can decide to refuse to answer questions put to me.
- I understand that at any time during the interview I can decide to end the interview

Please tick which ever statement below applies to you

1. I do not wish to take part
2. I do wish to take part

Request for interpreter: please tick the relevant box

English	I wish to have an interpreter	Yes	No
Māori	E hiahia ana ahau ki tetahi kaiwhakaMāori/kaiwhaka Pakeha korero	Ae	Kao
Cook Island	Ka inangaro au I tetai tangata uri reo	Ae	Kare
Fijian	Au gadreva me dua e vakadewa vosa vei au	Io	Sega
Niuean	Fia manako au ke fakaaoga e taha tagata	E	Nakai

	fakahokohoko kupu		
Samoaan	Out e mana'o ia I ai se fa'amatala upu	Ioe	Leai
Tokelaun	Ko au e fofou ki he tino ke fakalilu te gagana Peletania kin a gagana o na motu o te Pahefika	Ioe	Leai
Tongan	Oku ou fiema'u ha fakatonulea	Io	Ikai

Signed

Name

Date

Appendix F: Interview Schedule for people receiving active cancer treatment

Interview Spine

- Open with: I know very little about you, would you mind telling me about when this all started for you?
 - Probe what prompted them to do something
 - Probe about their first contact with primary care

- How did you find the referral process/wait for tests? Was it ever suggested to you that you have tests done under the private system?

- What happened then (probe for the story of receiving the diagnosis)

- How did you feel the diagnosis was communicated to you?
 - Were your family given the opportunity to speak to a relevant person and ask questions

- Sometimes there are a variety of different choices offered when you have a diagnosis of cancer. Were you offered choices regarding your treatment? Were you asked to consider private options?

- How did you go about making a choice (they may say I left it up to the Dr, but maybe not. Look for impact of being Rural & Remote on treatment choice- money, transport, impact on family)

- When you received treatment or while receiving treatment what has worked well and what not so well for you? For example has getting to the point of treatment been an issue

- How has the process of being followed up worked for you?

- Probe: have appointments been given at appropriate times; has it been easy to change appointments; has transport to the appointment been an issue?
- Could you tell me during this period what has helped you the most?
 - (probe for person/organisation or a resource)
- What do you feel has been the least helpful?
 - (probe for a person/organisation or a resource)
 - Probe interfaces between health professional/carers
 - Probe access/transport/financial/communication barriers
- How did you find out about other services/organisations you mentioned such as.....
- How has the cancer impacted on other aspects of your life apart from your health
 - Probes: financial cost – losing job, cost of getting to appointments, cost of appointments with GP, cost of medication; loss of role, loss of social life

Appendix G Interview schedule for those receiving palliative care

Palliative care interview schedule

Intro statement something like.....I have very information about you except I know you have had a diagnosis of cancer

1. What can you tell me about your experience with cancer (or on the cancer journey *or any other terms they may have used*) so far (*if they mention transport or access or treatment choice issues- tease out at this point*)

2. Can you tell me a little about the services you have been involved with?

I want to focus particularly on the services that have been supporting you in the most recent stages of the illness (*maybe avoid the term palliative unless they use it- there may be some disquiet about how much they know about their stage of disease*)

3. Who have been caring for you (tease out if there is a team approach who does what) GP practice nurse, district nurses

4. How do they communicate? Has this been any better or worse than at other times in your illness?

5. At the moment what are the most important requirements your care team/family need to support you? (tease out any gaps I would wonder about after hours provision of service, respite care, acute symptom management including giving of Morphine and management of grasbey pumps, person delaying seeking help because they know staff are busy)

6. What have the most helpful thing they have done?

7. What is the least helpful thing they have done?

8. Where has most of your care been given (home, rest home, hospital)

9. Have you at any time wanted to have respite care (may need to spell out respite care)?

10. How do you think your family/support people/whānau managing?

11. *Have you thought about where you would like to be in your last (tease out if they say they don't have a choice)*

12. *Who will you want to be caring for you?*

13. How do you think services to people who are at the end of life on the West Coast could be improved?

Appendix H: Survey Instrument

Cancer Survey

Thank you for agreeing to take part in this cancer survey; the survey is anonymous. Your input is of great value and we appreciate the time you are taking to complete it. The survey is divided into sections; each section focuses on a particular part of the cancer journey. You may find that you have a lot to say about a certain question/section. If you feel you would prefer to discuss this with someone you can contact Fiona Doolan Noble on 03 755 5166 who will collect your comments/concerns over the phone. Please note that the questions are printed on both sides of the paper.

Please complete the following 3 questions prior to completing the survey.

Please tick the box that applies to you.

Male Female

Please tick which age group applies to you.

0-19 years 70-79

20-29 80-89

30-39 90 +

40-49

50-59

60-69

Which ethnic group do you belong to? *Mark the space or spaces that apply to you.*

New Zealand European Chinese

Māori Indian

Samoan Cook Island Māori

Tongan Niuean

Other (such as Dutch, Japanese, Tokelauan). Please state:

.....
.....

Section One

This first group of questions seeks to gain a greater understanding of the process of accessing services at your medical centre and the timeliness of the process thereafter.

1a. When you first suspected something was wrong were you able to get an appointment to see a General Practitioner (GP) promptly?

Yes

No

Comment:.....

.....

.....

.....

.....

.....

1b. Did you feel that any tests required to establish your diagnosis were carried out without delay?

Yes

No

Comment:.....

.....

.....

.....

.....

.....

1c. Did you feel your results were given to you at the earliest possible time?

Yes

No

Comment:.....
.....
.....
.....
.....

1d. How were the results given to you? Please tick the appropriate box.

In person

Over the phone

Other

Comment:.....
.....
.....
.....

1e. Did you feel the results were given to you in a sensitive manner?

Yes

No

Comment:.....
.....
.....
.....

1f. Did you have a family/whānau member/friend with you when you received the results?

Yes

No

Comment:.....
.....
.....
.....
.....

1g. If you received treatment for your cancer (surgery, chemotherapy, radiation, other), was it commenced in a timely manner?

Yes

No

Comment:.....
.....
.....
.....
.....

Section Two

This section seeks to explore the area of information in relation to tests, your condition, the treatment you received and on-going care.

2a. Did you receive any information in relation to the test or tests you underwent to confirm your diagnosis?

Yes

No

If yes, was it relevant and useful?

Yes

No

Comment:.....
.....
.....
.....
.....

If no, in what way was it irrelevant?

Comment:.....
.....
.....
.....

2b. After receiving your diagnosis were you given information about your condition?

Yes

No

If yes, was it relevant and useful?

Yes

No

If no, what further information would you have liked?

Comment:.....
.....
.....
.....

2c. Did you feel you were given enough information at this stage?

Yes

No

If no, who/where did you seek more information from? Please tick the relevant box/boxes (you may tick more than one).

- | | | | |
|------------------------------|--------------------------|--------------------|--------------------------|
| GP | <input type="checkbox"/> | Family | <input type="checkbox"/> |
| Practice nurse | <input type="checkbox"/> | Friends/neighbours | <input type="checkbox"/> |
| Māori provider | <input type="checkbox"/> | Internet | <input type="checkbox"/> |
| District nurse | <input type="checkbox"/> | Library | <input type="checkbox"/> |
| Neighbourhood nurse | <input type="checkbox"/> | Cancer Society | <input type="checkbox"/> |
| Rural nurse | <input type="checkbox"/> | Popular magazine | <input type="checkbox"/> |
| Oncology nurse
state..... | <input type="checkbox"/> | Other: please | |

2d. Often when people are diagnosed with cancer they have options regarding their treatment; were options discussed with you?

Yes

No

N/A

If yes, were you given information regarding the options?

Yes

No

If yes, in what format was this information given? Please tick the appropriate boxes; (you can tick more than one box).

- | | | | |
|----------|--------------------------|-----------|--------------------------|
| Verbally | <input type="checkbox"/> | Audiotape | <input type="checkbox"/> |
| Written | <input type="checkbox"/> | Videotape | <input type="checkbox"/> |
| Pamphlet | <input type="checkbox"/> | DVD | <input type="checkbox"/> |

Other, please state;

.....

2e. Was the information easy to understand?

Yes

No

Comment:.....

.....

.....

.....

.....

.....

2f. Did you find the information useful?

Yes

No

Comment:.....

.....

.....

.....

.....

.....

Section Three

For people living on the West Coast travel to health care services is frequently a part of life. This section aims to get an understanding of this aspect of your journey.

3a. Do you own your own car?

Yes

No

3b. If you had to travel to Christchurch as part of your treatment what was your main mode of transport? Please tick the appropriate box.

Your own car

Public transport

Family/whānau member's car

Friend's car

Train

Airplane

Other; please state.....

3c. If you had to travel from out of the Grey District to get to Greymouth for treatment or an outpatient appointment what was your main mode of transport? Please tick the appropriate box.

Your own car

Family/whānau member's car

Friend's car

Other; please state.....

3d. If you went to Christchurch or Greymouth by car did you; please tick the appropriate box

Drive yourself

Or did someone drive you Yes No

3e. Did you receive assistance with transport costs?

Yes No

If yes, was this in the form of; please tick the appropriate box.

Cancer Society petrol vouchers

Travel assistance from Ministry of Health

Both

Other, please state;.....

3f. How was the process of claiming travel assistance? Please circle the appropriate statement.

Very easy	Easy	Neither easy or difficult	Difficult	Very difficult
-----------	------	---------------------------	-----------	----------------

Comment:.....

- | | | | |
|---------------------|--------------------------|--------------------------------|--------------------------|
| Practice nurse | <input type="checkbox"/> | Occupational therapist | <input type="checkbox"/> |
| Māori provider | <input type="checkbox"/> | Social worker | <input type="checkbox"/> |
| District nurse | <input type="checkbox"/> | Palliative care nurse | <input type="checkbox"/> |
| Neighbourhood nurse | <input type="checkbox"/> | Home help | <input type="checkbox"/> |
| Rural nurse | <input type="checkbox"/> | Gardening services | <input type="checkbox"/> |
| Oncology nurse | <input type="checkbox"/> | Meals on wheels | <input type="checkbox"/> |
| Cancer Society | <input type="checkbox"/> | Work and Income | <input type="checkbox"/> |
| Your church | <input type="checkbox"/> | Buller West Coast Home Hospice | |
| Trust | <input type="checkbox"/> | | |

Other community organisation(s), please specify:.....

.....

4d. How did you find out about these services? Please tick the appropriate box.

They were offered to me

I found out for myself

Other, please specify:.....

.....

Section Five

Numbers of people from the Coast have to stay in Christchurch while having treatment. This section will explore the accommodation and support you received while staying in Christchurch for your treatment.

5a. Did you have to stay in Christchurch for your treatment (i.e. longer than just over night).

Yes

No

If no go straight to next section; **section six**

5b. When staying in Christchurch which option did you use in regard to accommodation? Please tick the appropriate box.

Davidson House

Other funded motel

Stayed with family

Paid for own accommodation

Other, please explain...

.....
.....
.....
.....
.....

5c. When staying in Christchurch for treatment did your partner or a support person stay with you?

Yes

No

If they were unable to stay what impact did that have on you? Please comment

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Section Six

Having cancer often results in additional expenses and sometimes people and their carers need to stop working, this may be paid or unpaid work. This section looks at these issues.

6a. Did you stop work because of your cancer?

Yes No Part of the time

6b. Did your condition impact on your partners ability to work or care for other family members?

Yes No Part of the time

6c. Were you on a benefit/pension when you started your cancer treatment?

Yes No

6d. As a result of you or your partner having to stop work for all or some of the time or as a result of changing financial needs due to the cancer did you seek financial assistance from Work and Income?

Yes No

6e. If you did seek financial assistance via Work and Income how straight forward was the process? Please circle the appropriate statement.

Very straight forward	Straight forward	Neither straight forward or complex	Complex	Very complex
-----------------------	------------------	-------------------------------------	---------	--------------

If you have any other comments please write them below:

.....

6f. Did someone assist you to access this support?

Yes No

If yes, who?

.....

6g. What benefits were you told you were entitled to? Please tick the appropriate box, you may tick more than on).

Sickness benefit

Invalid benefit

Other

Please specify:

.....

If no please explain;

.....
.....
.....
.....
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.....

7d. Do you feel your partner/family/whānau received adequate emotional support

Yes

No

If no please explain;

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.....

Section Eight

We all know that many people who have treatment for cancer live long, happy and hopeful lives. Some people for whom treatment is not ultimately

successful also continue to have long periods in which they are able to achieve many of life's goals.

In the final section we want to ask you some questions about your preferences for care at the end of life. These questions are optional and we appreciate your thoughtfulness in agreeing to respond to us.

8a. Have you given any thought about who you would like to care for you at end of life?

Yes

No

N/A

If yes, continue with the next questions. If no, thank you for taking the time to complete this survey.

8b. Where would you like to receive this care; this may be at home, at the home of a family member, in hospital etc. Please state:

.....
.....
.....
.....

8c. If you are currently receiving end-of-life care, who is looking after you? (there may be more than one person, tick as many boxes as you wish).

- | | | | |
|------------------|--------------------------|----------------------|--------------------------|
| Myself | <input type="checkbox"/> | Paid home help | <input type="checkbox"/> |
| Partner/spouse | <input type="checkbox"/> | Unpaid home help | <input type="checkbox"/> |
| Family member(s) | <input type="checkbox"/> | General practitioner | <input type="checkbox"/> |
| Friend | <input type="checkbox"/> | District nurse | <input type="checkbox"/> |
| Wider community | <input type="checkbox"/> | Rural nurse | <input type="checkbox"/> |

Practice nurse Neighbourhood nurse

Oncology nurse Palliative care nurse

Other, please explain;

.....
.....
.....
.....

8d. How do you feel this care is working for you? Please circle the appropriate statement.

Very well	Well	Neither well or poorly	Poorly	Very poorly
-----------	------	------------------------	--------	-------------

Comments;

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8e. Are there things that are being managed well?

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8f. Are there areas which could be improved?

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8g. Who can you talk to about what is happening to you in general?

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8h. Do you know who to contact if you have any particular physical issues or concerns?

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8i. Do you know how to access equipment or other things to help you, if required?

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8j. Are there particular financial worries for you at this time?

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8k. Have you any particular concerns about your family?

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Section Nine

If there is any thing else you would like to add please do so here.

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Appendix I: Survey instrument for bereaved relatives

Dear Relative

Thank you for assisting us by sharing your story of caring for someone close with cancer. We know it can be painful recollecting this story and we sincerely appreciate you undertaking this. If you feel you would prefer to discuss this with someone you can contact Fiona Doolan Noble on 03 755 5166 who will collect your comments/concerns over the phone. This survey is anonymous hence the following three questions which we would like you to complete prior to starting the survey.

Please note questions are printed on both sides of the paper.

Please complete the following 3 questions prior to completing the survey.

Please tick the box that applies to you.

Male Female

Please tick which age group applies to you.

0-19 years	<input type="checkbox"/>	70-79	<input type="checkbox"/>
20-29	<input type="checkbox"/>	80-89	<input type="checkbox"/>
30-39	<input type="checkbox"/>	90 +	<input type="checkbox"/>
40-49	<input type="checkbox"/>		
50-59	<input type="checkbox"/>		
60-69	<input type="checkbox"/>		

Which ethnic group do you belong to? *Mark the space or spaces that apply to you.*

New Zealand European	<input type="checkbox"/>	Chinese	<input type="checkbox"/>
Māori	<input type="checkbox"/>	Indian	<input type="checkbox"/>
Samoan	<input type="checkbox"/>	Cook Island Māori	<input type="checkbox"/>
Tongan	<input type="checkbox"/>	Niuean	<input type="checkbox"/>

Other (such as Dutch, Japanese, Tokelauan). Please state:

.....
.....

Q1. In which year did your loved one receive a diagnosis of cancer?

.....
...

Q1a. How old were they at the time of diagnosis?

.....
.....

Q2. Were they offered treatment?

Yes

No

Comment:

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...

Q3. If no treatment was able to be offered, many people continue to have a satisfying life for some time before their condition changes. If no treatment was able to be offered please go to question 16.

If treatment options were offered to them, did they talk to you about the treatment options?

Yes

No

Comment:

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...

Q4. Did you have enough information to help them make the decision about the treatment options?

Yes

No

Comment:

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...

Q5. After considering the options, did they then receive treatment?

Yes

No

Comment:

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...
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...

If yes, was it (you can tick more than one box):

Radiotherapy in Christchurch

Chemotherapy in Christchurch

- Chemotherapy in Greymouth
- Chemotherapy in Westport
- Chemotherapy tablets or injections at home
- Surgery in Christchurch
- Surgery in Greymouth
- Other, please state

Q6. Approximately over what period of time did the treatment continue; it may be that your loved one received several courses of treatment. If they had several courses of treatment please let us know, if possible, the number of courses of treatment and the time span these occurred over?

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 ...

 ...

 ...

Q7. What sort of care/support did you offer your loved one while this treatment was occurring? Tick as many boxes as you wish.

- Transport to GP
- Transport to Grey Base
- Transport to Christchurch
- Housework (cleaning, cutting wood, cooking meals)
- Support on the farm/business/work
- Support with childcare
- Cared for them when they were unwell-
(help with shower, assist with feeding them, give medication)

Collect medication from chemist or obtain equipment

Find information on treatments

Find information on support services

Ring and make &/or attend health professionals appointments

Ring/attend other agencies (Work & Income, chemist)

If yes, which other agencies;
.....
.....
.....
.....

7a. Did you assist with filling in application forms?

Yes

No

If yes, which forms?
.....
...
.....
...

7b. Was there any other care or assistance you offered to your loved one?
Please specify.

.....
...
.....
...

Q8. If your loved one went to Christchurch for treatment, did you drive or accompany them?

Yes

No

Q9. Did you stay with them in Christchurch?

Yes

No

If yes where did you stay?

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...

.....
...

If no, would you have liked to have stayed with them?

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...

Q10. If you would have liked to have stayed were there particular reasons why you were not able to do this?

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Q11. At what point did it become apparent that the treatment was not effective?

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Q12. Who told your loved one that this was the case?

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.....
...

Q13. Was anyone with them when this information was given to them?

Yes No

Who was this?

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...
.....
...

Q14. If you were present, how was the manner in which the information was conveyed?

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...

After treatment is discontinued, some people continue to live well and hopefully for some time. But for some their condition declines and everyone realizes they are at the end point in their life.

Q15. How long was it after treatment finished until your loved one began to decline?

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...

Q16. How was the end of life care/palliative care organised? As this happens in a number of different ways on the Coast, please can you describe this generally for us?

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Q17. Did your loved one receive some or all of their end of life care/palliative care at: please tick the relevant box or boxes

- Their home
- Someone else's home Whose home?.....
- Hospital (Grey Base)
- An aged care rest home on the Coast
- Hospital (Christchurch)
- Mix of the above
- Other, please state
.....
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.....

Q18. Did your loved one end their life at home?

Yes No

18a. If no, where did they end their life?

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.....
.....

Q19. If they were cared for all or some of the time at home, did you have health professional or other support agency people coming to your home to help you care for your loved one?

Yes

No go to Q22

Q20. If yes, who were these people? You can tick more than one box if you wish.

GP

Practice nurse

Māori provider

District nurse

Neighbourhood nurse

Rural nurse

Oncology nurse

Palliative care nurse

Respiratory nurse

Other, please specify;

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Q21. What sort of activities did they help with?

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Go now to question 23

Q22 If you didn't received any support from health professionals or other support agency representatives, would you have wanted to have support and assistance?

Yes

No

Q23 If yes, who and what would have been helpful

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Q24. Did any one else undertake other supportive activities?

Yes

No

If yes, who were they? Please tick the appropriate box or boxes

Family

Friends

Neighbours

Cancer Society

Buller West Coast Home Hospice Trust

Other, please state;

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Q25. What sort of activities did they perform?

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Q26. Were there any other things that could have been done to support your loved one?

Yes

No

If yes, what would they have been

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.....

Q27. Did you and/or your loved one have a telephone or mobile phone?

Yes

No

Q28. Who did you or your loved one telephone if they needed help with physical issues?

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Q29. Who did you or your loved one telephone if they needed help with other issues?

.....

Q30. Did you or your loved one need to telephone someone for help with health problems out of regular working hours?

Yes

No

If yes, who did you or your loved one telephone?

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Q31. Were there particular financial worries for you at this time?

Yes

No

If yes, please explain

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Q32. As someone involved in the care of your loved one, do you feel you needed support during this time?

Yes

No

Q33. If yes, what support did you require?

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Q34. Was this support provided by anyone?

Yes

No

If yes, who provided this?

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Q35. Did the support provided meet your needs?

Yes

No

Q36. If no, please can you tell us what else you needed?

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Q37. In summary, over this very difficult period of time what were the things that you consider were managed well?

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Q38. Were there things that could have been improved?

Yes

No

Q39. What were they?

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Q40. Is there anything else you would like to add?

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We really appreciate the time it has taken you to answer these questions and we acknowledge that completing this survey cannot have been easy for you. Please accept our sincere thanks

Fiona Doolan Noble
Board

West Coast District Health

Eileen McKinlay
Medical School

Otago University, Wellington

Donna Cormack
Medical School

Otago University, Wellington

Appendix J: Letter inviting people with cancer to take part in the survey

Dear

You may be aware that the West Coast District Health Board is conducting a study regarding what it is like to be living in a rural area with a diagnosis of cancer. This information will be used to ensure that the District Health Board tackles the issues that have a significant impact on people living with cancer on the Coast.

Twenty people living with cancer on the Coast have been interviewed. During the interviews various points about the systems of care and support have been raised by those being interviewed and the study team would like to explore them further through a survey of all those living on the Coast who have cancer at any stage of their treatment or care. The survey will provide a double check, if you like, by establishing whether or not the issues that arose out of the interviews apply just to the twenty people interviewed, or are widely accepted as key issues for people living on the Coast with cancer.

We would be delighted if you would be willing to fill in a brief survey form; however if you would prefer not to, that is also fine and will not in anyway affect the care you are given. It is possible that this letter may relate to the care of a loved one in your family who may have passed away recently. We would value your comments as a family member immensely, but will completely understand if you would prefer not to take part.

If you **do not wish** to take part please phone Danielle Smith at the Cancer Society 03 768 9557 and she will let the study team know.

If **you wish** to take part in the survey, you do not need to respond and the survey form along with a stamped addressed reply envelope will be sent to you shortly.

Thank you for taking the time to read this letter.

Kind regards

Fiona Doolan-Noble

Lead Study Investigator