

The Voice of Experience

Part 2

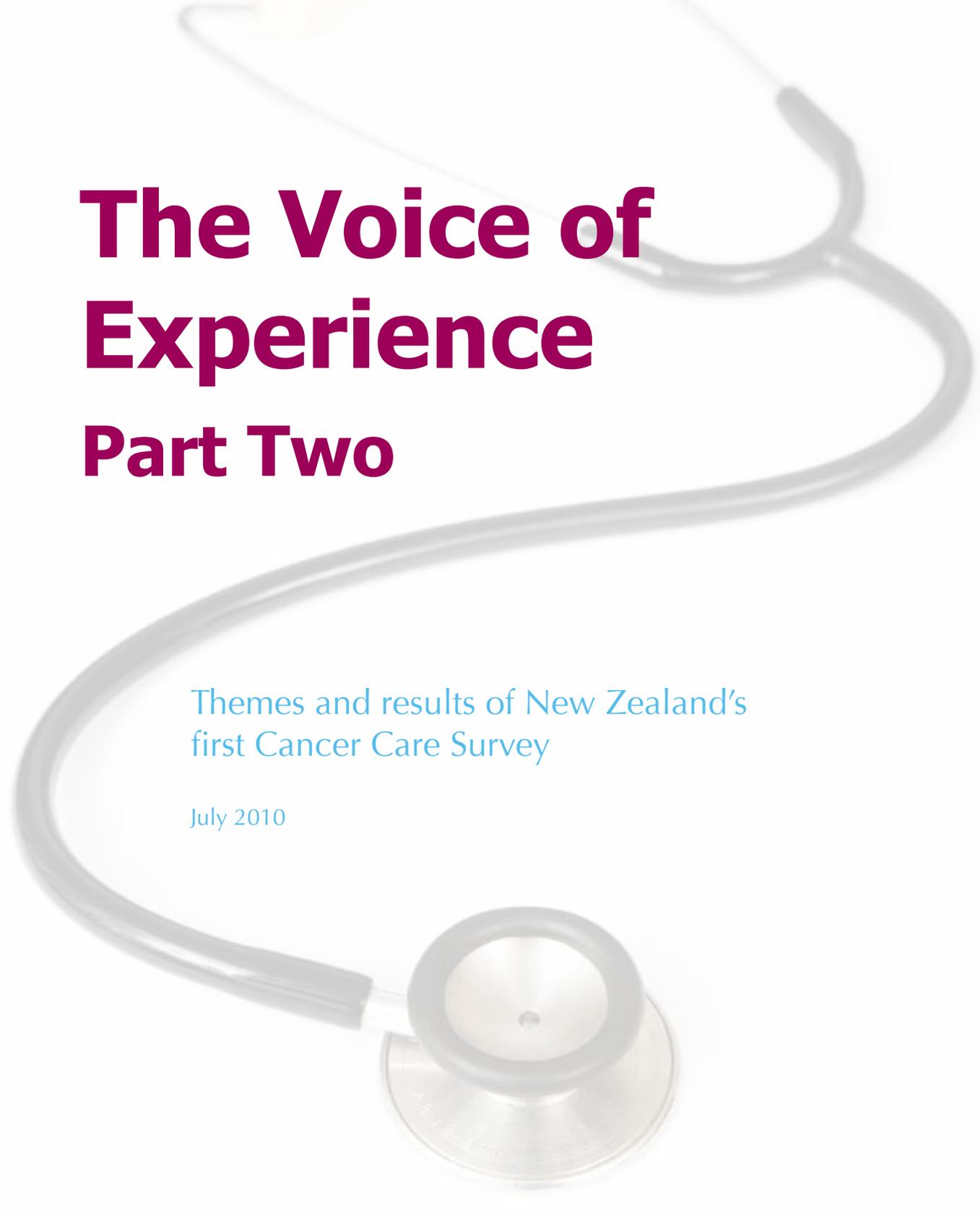
Themes and results of New Zealand's first Cancer Care Survey

July 2010



CANCER CONTROL NEW ZEALAND

Mana Whakahaere Matepukupuku Aotearoa



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Part Two

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first Cancer Care Survey

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Cancer Control New Zealand

Cancer Control New Zealand was established in 2005 to provide independent and expert advice to the Minister of Health and to report on New Zealand's performance in providing cancer care.

Published in July 2010 by:

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Executive Summary

Patients' views and experiences of health care performance are critical to improving health care provision in New Zealand. This *Voice of Experience: Part Two* report integrates current and previous research related to the cancer patient experience with descriptive, thematic and ethnic group analyses of data from *The 2009 Cancer Care Survey*. Cancer Control New Zealand (CCNZ) aims with this report to provide cancer care services a snapshot of cancer outpatients' views on health care delivery.

Background

In 2009, the Cancer Control Council of New Zealand (predecessor to CCNZ) developed the first national cancer patient experience project. Surveying cancer patients' experiences can show if the services patients receive match their needs and expectations. This type of survey puts the patient at the centre of the evaluation of care and provides a unique perspective on New Zealand's performance in providing quality cancer care. The current government has strongly signalled that it wants better, sooner, more convenient patient-centred care and analysing patients' experiences of care can inform that vision.

Results

The 2009 Cancer Care Survey was completed by 2221 people resulting in a 68% final response rate. The key findings from the survey were:

1. Overall satisfaction with the publicly funded outpatient cancer care system in New Zealand was very high (over 97% positive).
2. New Zealand's results were similar to comparable results of NRC+Picker surveys recently administered in British Columbia, Canada and New South Wales, Australia. However, New Zealand's national results were comparatively better around chemotherapy waiting times and slightly worse for providing confusing information to patients.
3. The aspects of care that received the highest scores demonstrate perceived strengths in the cancer care provided. Survey respondents were highly positive about specialist care coordination (91% positive response; 95% CI: 90–93), the level of privacy (87% positive response; 95% CI: 85–89), and dignity and respect provided by health care professionals (86% positive response; 95% CI: 85–88).
4. The aspects of care where many patients highest expectations were not met, indicating opportunities for improvement, included provision of emotional support (*as illustrated by a 36% positive response; 95% CI: 33–39; to a question on being put in touch with care providers to help with anxiety and fear if needed*), provision of information (*as illustrated by a 34% positive response; 95% CI: 30–37; to a question on whether an adequate explanation was received for any treatment waiting times*) and consideration of patients' circumstances in treatment planning (*as illustrated by a 49% positive response; 95% CI: 46–51 to a question on whether their living situation was taken into account in treatment planning*).

5. Responses to 12 questions showed significant inter-treatment service variation with at least a 20% difference in scores reported.
6. Dimensions of care found to be of greatest importance for the patient experience, based on exploratory factor analysis of the New Zealand survey data, were relationships with health care professionals, information, and facilities and amenities.
7. Māori and New Zealand European responses tended to follow similar patterns with the 'emotional support' and 'information' dimensions of cancer care scoring lowest.
8. Emotional support and provision of information on aspects of daily living are key components of supportive care. The survey analysis to-date suggests that improvements in supportive care may be the best way to improve the cancer patient experience.
9. Cancer patient experience surveys can achieve high response rates and generate useful patient-focused information about the quality of care overall and at the individual cancer treatment service level.

Recommendations

The survey findings inform six recommendations for linking patient experiences with national, regional and service-level quality improvement. Patient-focused change is one aspect of quality improvement. Technical skills, necessary for effective diagnosis and proper treatment of disease, are highly rated by most patients (varying on specified aspect of care) and can be seen as strengths in this report. Service skills, necessary to ensure non-clinical expectations of people affected by cancer are met, generated lower ratings and can be seen as opportunities for improvement. Several strategies must be pursued simultaneously by clinical and non-clinical leaders to work towards an effective balance between the technical and service aspects of quality cancer care.

Overall, cancer patient experience surveys can achieve high response rates and generate useful baseline data about the quality of care nationally and at the individual cancer treatment service level. However, the survey should be repeated every three to five years in order to be an effective tool for monitoring quality improvement over time. Five of the recommendations included in this report address potential opportunities for further analysis of the baseline data and for expanding patient experiences research to cover the breadth of the cancer continuum and depth of information available to be harnessed by the use of alternate methodologies.

Recommendations

Recommendations are made in regard to linking patient experience, as reported in this survey, with quality improvement and opportunities for further research.

Patient experience and quality improvement

CCNZ recommends that:

1. *The 2009 Cancer Care Survey* results should be distributed widely throughout the sector and the community. This project shows that cancer patient experience surveys can achieve high response rates and generate actionable data on patient perceptions which should be integrated with evidence-based practice to inform efforts to improve quality.
2. Service providers should let consumers know they are listening as part of quality improvement frameworks. This can help build patient trust. The survey found that overall outpatient cancer care experience is rated highly by patients. CCNZ would like to congratulate each participating cancer treatment service for providing such highly regarded services. Sharing this type of information can help build the services' reputation and can show that the health service values patient feedback.
3. Actionable and standardised patient-reported outcomes can be utilised to assess the impact of quality improvement efforts on the patient experience of care. The 2010/2011 Ministry of Health performance measures for District Health Boards (DHBs) include effectiveness and efficiency indicators but also incorporate access and equity measures alongside one overall patient-reported quality measure (i.e. patient satisfaction) (Ministry of Health 2010b). NRC+Picker state that collecting data on patient experiences, as opposed to overall satisfaction, can generate more actionable patient-reported outcomes (NRC+Picker 2010b). Regional networks and treatment services, in collaboration with CCNZ and the Ministry of Health, should consider developing actionable patient-reported outcomes that drive quality improvement toward the goal of a more responsive health system.
4. Patient-focused change should be actively led by both clinical and non-clinical leaders. Just as this analysis found that there is not one 'best' patient experience of care model, it is unlikely that there will be one solution to improve the patient experience. Multiple strategies and voices are required to advocate for the need to balance the technical and service aspects of providing effective cancer care. Better systems and processes can help streamline technical aspects of providing effective care. Service skill professional development can support integrating patients' needs and wants into care plans. Several strategies must be pursued simultaneously by clinical leaders to work towards an effective balance between the technical and service aspects of quality cancer care.
5. Professional debate is encouraged around the results of this survey. Possible questions to be addressed include: How can information obtained from surveys best be integrated into quality improvement frameworks? Who in the multidisciplinary team (doctor, nurse, allied health or Cancer Society staff) is best placed to respond to the supportive care gap identified by patients? How can the results of this survey link in to the Supportive Care Guidance (Ministry of Health 2010a) implementation process being undertaken by the Ministry of Health? How can regional champions for key aspects of care share their models of care and successes with other service providers?

6. There is an opportunity to link national, regional and service-level patient experiences information to ongoing rapid improvement reviews or contemporary lean thinking processes. This provides opportunities to examine the patient experience along the diagnosis and treatment pathway. These processes can help multidisciplinary teams address, for example, better ways to incorporate the patient living situation into treatment planning, or what customised information is needed at particular times to match the evolving health literacy of patients navigating a cancer journey.

Opportunities for further patient experience research

CCNZ recommends that:

1. The survey should be repeated every three to five years. These patient experience surveys can then form part of the national monitoring and evaluation of initiatives aimed at improving patients' experiences of cancer care.
2. There should be further analysis of the rich information gathered in *The 2009 Cancer Care Survey*. Potential opportunities for further analyses include: conducting more detailed international comparisons; qualitative analyses of the patients' comments; analysing these data according to deprivation; and comparing the results of this survey with data from District Health Board satisfaction surveys.
3. There should be support for both quantitative and qualitative patient experience research. One way forward for future patient experience surveys would be to purposively select a diverse sample of those included in the survey to take part in hui, focus groups or face-to-face interviews, to further explore their experiences of care. The results from this qualitative analysis could then be used to cross-check and validate the results of the survey and form a much richer picture of the patients' experiences. This would be particularly useful for informing sub-groups comparisons.
4. Administrators of patient experience surveys should use booster samples for Māori and Pacific Island populations to enable robust analysis of the results for these ethnic groups. Ideally, Māori participation rates should equal or surpass those of New Zealand Europeans. In order to increase the response, particularly from Māori and Pacific Islanders, it would be important to engage with Māori and Pacific communities and groups with an interest in cancer prior to initiating a survey. Providing translations of the survey and survey posters in other languages to increase awareness about the survey project would also be beneficial.
5. Patients' experiences should be considered and measured across the entire cancer care continuum. The current survey gathered data only at the outpatient cancer treatment service level. Consequently, primary care, in-patient and palliative care experiences were not captured in this project. Cancer treatment service outpatient experience data only represents a snapshot of a subsection of the patient's cancer experience. System-level research can help identify macro-system dimensions that can impact on the patient experience and the coordination of quality cancer care.

1 Introduction

There is no one type of patient and no single way of treating everyone. Moreover, every patient has a different view on the quality of his meal or her environment. But there is a way to be sure each patient gets the care needed in a nurturing environment — by providing that care “that consciously adopts the patient’s perspective.”

(Through the Patient’s Eyes, pg. 5) (NRC+Picker 2010b)

Cancer Control New Zealand provides independent advice to the Minister of Health with the aim of driving change and improving the quality of cancer services. In 2008 the Cancer Control Council (the Council) was asked by the former Associate Minister of Health to provide strategic advice on cancer patient experiences and expectations, as part of the Council’s 2008/09 Annual Work Plan. The current government has strongly signalled its support for this project to inform its vision of better, sooner, more convenient patient-centred care. The first-of-its-kind national cancer patient experience survey, titled *The 2009 Cancer Care Survey*, was subsequently administered to 3525 people affected by cancer.

New Zealand’s five-year cancer survival rates are on par with rates in Australia, Canada and the USA (Commonwealth Fund 2010). However, questions remain about the quality of cancer services available to New Zealanders. Patients’ experiences of care are increasingly being sought to provide insight into how well health services are meeting patients’ needs and expectations (Murray and Frenk 2001).

The overall aim of this project was to provide cancer care leaders with a snapshot of patients’ views on cancer care delivery. CCNZ’s specific *2009 Cancer Care Survey* objectives were to:

- generate and analyse data on patients’ experiences of cancer care, to inform advice to the Minister of Health and other key stakeholders
- provide baseline data on cancer patient experiences that can be compared with data collected in subsequent surveys, so that the impact of system changes on patients’ experiences of care can be explored over time.

The preliminary results from the first national *2009 Cancer Care Survey* were published in *The Voice of Experience: Part One* report and *The Voice of Experience: Companion report*, released in December 2009/January 2010 (available from www.cancercontrolnz.govt.nz).

Following on from these reports, *The Voice of Experience: Part Two* report provides an overview of research related to patients’ experiences of care. It also includes a summary of key findings from descriptive, thematic and ethnic group analyses of data from *The 2009 Cancer Care Survey*. Recommendations are made on linking project findings to quality improvement and further research.

2 Patient Experience Measurement

Capturing the patient's perspective of health care is becoming increasingly important as health systems strive to be more responsive to the needs of the people using their services. The OECD has identified measurement of patient experiences as a priority for indicator development (OECD 2010).

2.1 Overview

With the general public, health care professionals, and the Government all looking for improvements in the quality and delivery of cancer care, surveying cancer patients' experiences is a promising method for exploring whether the services patients receive match their needs and expectations. This type of survey puts the patient at the centre of the evaluation of care and provides stakeholders with a unique perspective on New Zealand's performance in providing quality cancer services.

Consumers of health services want improved health, but they also want to be treated with dignity and respect in a holistic manner. The WHO has stated that, in conjunction with improving the health of the population, improving the "responsiveness of the health system to the legitimate expectations of the population for the non-health improving dimensions of their interaction with the health system" (Murray and Frenk 2001) should be a key goal of a health system. A responsive health system is likely to be more beneficial for health outcomes by being "more conducive for individuals to seek care earlier, to be more open in their interactions with health care providers and to better assimilate health information" (Valentine et al 2003). Quality cancer care received from a responsive health system includes both technical components, including accurate diagnosis and proper treatment, and service components, to holistically meet the needs of patients' and address their expectations.

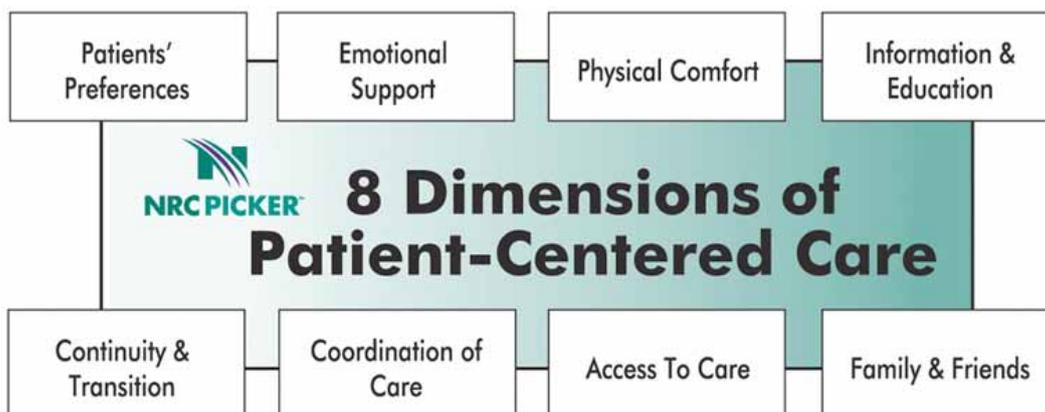
Previous research has proposed that satisfaction is related to better adherence by individuals to medical advice (Clemes et al 2001), compliance with cancer treatment regimens (Borras et al 2001) and improved health status (Bredart et al 2005). It has been further proposed that positive perceptions of health care delivery can act to provide health care organisations with 1) a better reputation in the community; 2) less staff turnover; and 3) increased efficiency (Clemes et al 2001).

A variety of approaches, including qualitative, quantitative, Kaupapa Māori and mixed methods, have been used in the past to try to understand patients' experiences of care. Many of the reviewed patient experience studies primarily used a quantitative approach. However, rigid questionnaire formats can limit the amount and type of information gathered. Qualitative studies can provide richer, more in-depth information on the context of the experience, as the respondents are not confined within the structure of the questionnaire and so can introduce new information and ideas (Dew 2007). Nevertheless, the quantitative approach has the advantage of providing standardised, measurable data for analysis. Additionally, this approach can allow a large number of people to be assessed, even with a short time frame and limited resources, which increases the likelihood that the results will be representative of the population being studied.

2.2 The Picker family of surveys

NRC+Picker have mainly used a quantitative survey approach to gather data on patients' views of health services in many countries. The concept of the patient experience is multi-dimensional and these surveys have been designed to reflect eight higher-order dimensions of patient-centred care (NRC+Picker 2010a).

Figure 1: NRC+Picker eight dimensions of patient-centred care



The Picker family of surveys have published psychometric properties (NRC 2005) and are in routine use in the United Kingdom (UK), Australia, and Canada. Table 1 presents some of the key findings identified by the Picker ambulatory oncology surveys administered in relation to health services within the UK, Australia and Canada.

Table 1: Select findings from Picker ambulatory oncology surveys conducted overseas

Country	Areas of strong performance	Areas for improvement
UK (Department of Health 2002)	<ul style="list-style-type: none"> Confidence and trust in doctors (lower for nurses) Facilities/amenities 	<ul style="list-style-type: none"> Emotional support Pain control Waiting times (in waiting room from scheduled to actual appointment) Provision of information
Canada (Watson et al March 2007)	<ul style="list-style-type: none"> Waiting times (in waiting room from scheduled to actual appointment) Patients treated with dignity and respect Family and friends involved 	<ul style="list-style-type: none"> Emotional support Provision of information on relationship and emotional changes
Australia (Cancer Institute NSW July 2009)	<ul style="list-style-type: none"> Service provision Staff trust and staff doing everything to treat cancer and help with side effects Patients treated with dignity and respect 	<ul style="list-style-type: none"> Emotional support Provision of information on treatments and activities of daily living Pain control

Emotional support and information are the higher-order dimensions consistently identified by patients as those in need of health service improvement. In 2007, the UK National Health Service (NHS) focused on the emotional support dimension results and undertook further research to develop a definition of 'patient experience' that focuses on emotional support. They found their patients' valued:

- getting good treatment in a comfortable, caring and safe environment, delivered in a calm and reassuring way
- having information to make choices, to feel confident and to feel in control
- being talked to and listened to as an equal; being treated with honesty, respect and dignity (Department of Health 2007).

2.3 Survey themes and dimensions of care

Although no one 'best' patient experience of care model has emerged from this survey or previous patient experience research, numerous process and human factors have emerged as themes of importance to the patient's experience of, or satisfaction with, care (Calnan and Rowe 2008; Clemes et al 2001; Hall and Dornan 1988; Parasuraman et al 1988, Table 2).

Table 2: A selection of themes found in select patient experience/satisfaction research

Process factors	Human factors
• Access	• Access
• Resources	• Communication
• Safety	• Reliability
• Effectiveness	• Responsiveness/respect
• Cost	• Trust
• Information	• Emotional support
• Timeliness	• Equity
• Integration	• Empathy
• Outcome	• Continuity

A thematic analysis reviews higher-order themes or dimensions that are addressed by the questions and responses to the survey questionnaire. The resulting themes or dimensions consist of composites of questions. The statistical technique of factor analysis can be used in both an exploratory or confirmatory fashion to identify questions which group together and have a common theme. The emerging themes or dimensions can help identify important elements and drivers of the patient experience of care. The UK Department of Health conducted a factor analysis of their Picker survey data and identified numerous themes of importance which differed from those identified by NRC+Picker (Department of Health 2004).

NRC+Picker has not conducted a confirmatory factor analysis on New Zealand survey data. Therefore, it is not clear if the eight dimensions of patient-centred care on which the survey is based (NRC 2005) translates to New Zealanders. Appendix 3 includes a table of the relevant survey questions and their common or alternate dimension designations.

2.4 Patient experience research in New Zealand

Patients' views on the quality and accessibility of cancer services are key to informing the Government's goal of better, sooner, more convenient health care. The importance of including the patient's perspective in evaluating care is reflected in key New Zealand government documents, such as, *The New Zealand Health Strategy* (2000) which has an underlying fundamental principle that there should be "active involvement of consumers and communities at all levels". Additionally two of the guiding principles of *The New Zealand Cancer Control Strategy* (2003) are that activities should "reflect a person-centred approach" and "actively involve consumers and communities". Furthermore, the 2009 report of the Ministerial Review Group called *Meeting the Challenge: Enhancing sustainability and the patient and consumer experience within the current legislative framework for health and disability services in New Zealand* has described the "...Government's vision of a public health and disability service that is more patient- than provider-centric, giving patients more control" (Horn et al 2009). The current government has strongly signalled that it wants better patient-centred care and analysing patients' experiences of care can inform that vision.

Previous quantitative, qualitative and mixed methods studies of patient experience in New Zealand found that patients tended to be satisfied with their overall experience of care (Blendon et al 2002; Commonwealth Fund 2010; Donelan et al 1999; Schoen et al 2007; Schoen et al 2004; Waitemata DHB 2006; Zwier 2009). Participants in these studies also tended to consistently rate certain aspects of care positively, such as health care providers treating them with dignity and respect (Blendon et al 2002; Blendon et al 2003; Jansen et al 2008; Richardson et al 1994). However, there were some key areas that were repeatedly identified as aspects of the patients' experience that could be improved. These included the communication of information, the consistency of care providers, waiting times, the provision of a holistic approach to care, and access to care.

Communication of information

The need to improve the communication of information was a recurrent finding in the literature on patients' experiences of care (Davis et al 2008; Hutt Valley DHB and Wairarapa DHB 2006; Schoen et al 2004). In particular, these studies identified issues with the communication of information by health care providers to patients and the communication between health care providers in coordinating care. Several of the studies identified patients' concerns that health care providers had not initiated discussions on certain topics, such as potential changes in sexuality and emotions (Doolan-Noble et al 2006; Walton et al 2009). In one telephone survey, which included 1400 New Zealanders, 71% of the surveyed New Zealanders that utilised primary care services reported that their primary care doctor had not asked about emotional issues (Schoen et al 2004). In a qualitative study of Tongan health care experiences in New Zealand, the limited time spent in the actual consultation was highlighted as compounding communication issues (Basset and Holt 2002).

Consistency of care providers

Another issue, raised by patients in several of the studies, was the lack of consistency in health care providers, with many people reporting they had to visit multiple doctors for their care (Blendon et al 2003; Doolan-Noble et al 2006; Hutt Valley DHB and Wairarapa DHB 2006). Blendon et al (2003) conducted a telephone survey, that included 750 adults (with chronic care needs or with more acute, intensive care needs) from New Zealand, and reported that 30% of these patients had seen more than five doctors in the past two years. Doolan-Noble et al (2006), in their study of the patient journey on the West Coast, also found that typically there was no one professional involved throughout the journey of cancer, which raised concerns of fragmented care and a poorer patient experience.

Waiting times

Waiting times have also been identified as an issue in some of the studies of patients' experiences. Donelan et al (1999) found in a telephone survey that included 999 New Zealand participants, that 29% of these New Zealanders felt waiting times were a concern. However, other studies did not find that waiting times were an issue for patients. Doolan-Noble et al (2006) found, in their small survey of 44 patients who had received cancer treatment on the West Coast, that 93% of patients rated their cancer treatment as timely and 92% reported no delays in diagnostic tests.

Holistic approach

Another recurring issue was the need for a more holistic approach to care (Hutt Valley DHB and Wairarapa DHB 2006; Walker T al 2008; Walton et al 2009). A lack of emotional support, particularly in relation to cancer care, was highlighted in the results from several of the studies (Schoen et al 2004; Walton et al 2009). Walton et al (2009) found, in their study of 28 women with gynaecological cancer, that half of those who had wanted assistance with distress or concern had not been offered a referral. The need to involve patients and family or whānau more in decisions about their care was also raised in several of the studies, especially by Māori and Pacific Islanders (Hutt Valley DHB and Wairarapa DHB 2006). Greater tolerance of traditional or spiritual care was another aspect of a holistic approach that patients felt could be improved (Hutt Valley DHB and Wairarapa DHB 2006).

Access

Difficulty accessing care was raised as an issue in several of the studies (Basset and Holt 2002; Donelan et al 1999; Doolan-Noble et al 2006). In a telephone survey that included 750 chronically ill New Zealand patients, 31% of these reported an access problem due to cost in the past two years (Schoen et al 2008). However, a series of Commonwealth Fund surveys repeated at regular intervals over the past decade found that, for the general adult population, the perception of cost related access improved in those surveyed in New Zealand over time (Schoen et al 2007). The need to travel long distances for care was identified by some participants as adversely affecting access, and hence experiences of care, in several studies in rural areas (Doolan-Noble et al 2006; Hutt Valley DHB and Wairarapa DHB 2006). Racism and limited access to culturally appropriate carers were also issues identified as impeding access and affecting experiences of care, especially for Māori (Walker et al 2008).

2.5 Ethnicity and patient experience research in New Zealand

Between 1996 and 2001 Māori were found to be "18% more likely to be diagnosed with cancer overall (all sites combined) than non-Māori during this period, [and] they were nearly twice as likely (93% higher) to die from cancer" (Robson et al 2005). Although a few types of cancer tend to have a higher incidence in non-Māori than Māori (Blakely et al 2010 (in press)-a; Blakely et al 2010 (in press)-b; Robson et al 2005) cancer survival rates are generally poorer for Māori (Blakely et al 2010 (in press)-a; Blakely et al 2010 (in press)-b; Jeffreys et al 2005; Robson et al 2005). Previous studies have found that differences in health service care may partially explain survival disparities between Māori and non-Māori with cancer (Cormack et al 2005; Hill et al 2010; Hill et al 2010 (in press); Hutt Valley DHB and Wairarapa DHB 2006; Priest et al 2010; Rumball-Smith 2009; Stevens et al 2008; Walker et al 2008).

If a health system is more responsive to one group's expectations than another's, this is likely to cause inequalities in access and outcomes (World Health Organisation 2000). The New Zealand government has a particular obligation under *The Treaty of Waitangi* (1840) to actively work to reduce inequity in the provision of health care services between Māori and non-Māori. Therefore it is important that information is gathered to fully assess whether the health system is being responsive to both Māori and non-Māori needs and expectations. Analysing and comparing different ethnic groups' experiences of health care could potentially assist in improving outcomes for all and reducing disparities in outcome.

A small number of previous studies have been conducted that specifically focus on exploring Māori and Pacific Islanders' experiences of health care in New Zealand (Basset and Holt 2002; Doolan-Noble et al 2006; Hutt Valley DHB and Wairarapa DHB 2006; Jansen et al 2008; Walker et al 2008). These studies identified aspects of the patients' experiences that could be improved, that were similar to the wider population studies, including better communication of information, consistency of care providers, improving waiting times, and access to care. They also highlighted the need for involving whānau, developing a more holistic approach to care, eliminating racism and increasing access to culturally appropriate carers (Hutt Valley DHB and Wairarapa DHB 2006; Walker et al 2008).

Previous research has also found that patients' satisfaction and experiences vary across different ethnic groups and across other social groups, with those who are older (Jansen et al 2008; Zwier 1999; 2009), male (Zwier 2009), New Zealand European (Zwier 2009) and higher average income earners (Blendon et al 2002) tending to be more satisfied with their care.

Although previous studies of patient satisfaction or patients' experiences of care in New Zealand have provided valuable information, many of these studies were limited by their small sample sizes, low response rates (particularly for Māori and Pacific Islanders), lack of ethnicity analyses or by being focused on only one particular ethnic group or geographic area (Blendon et al 2002; Commonwealth Fund 2010; Donelan et al 1999; Schoen et al 2007; Schoen et al 2004; Waitemata DHB 2006; Zwier 1999; 2009). *The 2009 Cancer Care Survey* data was based on a large representative sample across New Zealand, with relatively high response rates for New Zealand European and Māori. Consequently, this survey provided the opportunity to conduct exploratory factor analyses and robust ethnic group analyses of New Zealand specific data.

3 Survey Method

3.1 Survey instrument and administration

The 2009 Cancer Care Survey was a nation-wide stratified postal survey, with eight cancer treatment centres forming the strata. The survey adopted for the project was the NRC+Picker (USA) ambulatory oncology survey instrument. The questionnaire included 96 questions, with multiple response options, covering a variety of patient experiences related to their cancer treatment, including their diagnosis, treatment (surgery, chemotherapy and radiotherapy), symptom management, health care team, care environment and overall impressions of care. The questionnaire also contained demographic questions including questions on the respondent's age, gender, household annual income after tax and ethnicity. Nine of the 96 survey questions were slightly adapted to reflect New Zealand demographics and services.

The target population for the survey was patients 18 years of age and older, with a confirmed diagnosis of cancer, who had undergone, or were undergoing, publicly funded outpatient cancer treatment (specifically chemotherapy or radiotherapy) in New Zealand. Patients were excluded from the survey if they had no fixed address, had moved out of New Zealand, were not residents of New Zealand, had received only inpatient services, or were deceased. Prior to proceeding with the survey, ethics approval was obtained from the Multi-Region Ethics Committee (MEC/09/22/EXP).

The six regional cancer centres (Canterbury Oncology Service, Northern Region Cancer Centre, Palmerston North Regional Cancer Treatment Service, Southern Blood and Cancer Service, Waikato Regional Cancer Centre, and Wellington Blood and Cancer Centre) and two satellite chemotherapy treatment facilities with full-time vocationally registered oncologists on staff (Nelson Oncology service and Tauranga & Whakatane Cancer Centres) provided lists of all their outpatients who met the criteria for the study during the six month period from 1 October 2008 to 31 March 2009. The sample was randomly drawn from these lists with an aim to select 500 people from each cancer treatment service. If less than 500 people were submitted by a cancer treatment service then all individuals were selected. All those who had their ethnicity recorded as Māori but had not been randomly selected, were also included in the sample. This oversampling process aimed to increase the precision of the estimates for Māori.

Surveys were posted to selected participants and were also available online. To increase the response rate, posters about the survey were placed in cancer treatment service waiting rooms and patient support service buildings. Reminder post cards and a second survey were sent out to those who had not responded to the initial survey and a telephone help line was set up to answer any queries from survey recipients. A covering letter explaining why the survey was important was also attached to each survey form.

3.2 Descriptive analysis

The distribution of the target, survey and the eligible respondent populations were compared across key demographic characteristics. The response rates were compared across the different ethnic, age, gender, income and cancer treatment service groups.

The data was weighted according to the selection probability for different ethnic groups from each cancer treatment service. Post-stratification weights were also calculated for each respondent using the age and ethnicity distribution of the target population in each cancer treatment service.

Sixty-five of the 96 survey questions had ordinal categorical response options which could be grouped into positive and negative categories (Appendix 3). In this part of the analysis only the 'ideal' response, such as 'always' or 'definitely', was equated with a positive experience. The categorisation process allowed the questions to be rank ordered, from those with the highest percentage of positive responses to those with the lowest, so the questions in the upper and lower quartiles could be examined nationally and at the individual cancer treatment service levels.

3.3 Thematic analysis

The thematic analysis of the data from *The 2009 Cancer Care Survey* was carried out using exploratory factor analysis techniques. It aimed to see if alternate themes to those identified by the survey developer, NRC+Picker, emerged as important in the general New Zealand population. It also explored if the themes differed by ethnicity. Results are viewed in regard to existing New Zealand legislation and previous research related to the cancer patient experience. Further, this thematic analysis forms the basis for future identification of key drivers of the overall cancer care experience.

In order to prepare the data for factor analysis, the 65 survey questions with ordinal categorical response options were coded so that all missing, multiple responses and those such as 'does not apply' or 'did not have' were excluded. The survey questions were recoded to ensure each question had only four possible response options. Stata® (StataCorp LP) version 9.2 was used to analyse the data and generate factors, factor loadings and reliability scores reported as Cronbach's coefficient alpha scores.

3.4 Ethnic group analysis

The key objectives of the ethnicity analyses were to analyse the Māori and New Zealand European responses to the survey and explore whether there were differences in how these groups perceived their experiences of cancer care.

Ethnicity was assigned based on the information gathered in the survey, using the prioritisation methods in order of Māori, 'Other' and New Zealand European. Where ethnicity was missing in the survey, the cancer treatment service data was used. There was not enough power to examine the Pacific Islander or Asian data separately. Consequently, ethnicity data was grouped into Māori, New Zealand European and Other/Not Stated. The Other/Not Stated group was not included in the analysis because it was made up of multiple different ethnic groups.

The frequency and distribution of Māori and New Zealand European positive responses were analysed for each question separately. The multiple response options were then arranged so that the most negative possible answer was given a 0 and the most positive possible answer was given a 3. For each participant a dimension score was then calculated based on the Cancer Institute NSW/IPSOS-defined dimensions of care (Appendix 3). The dimension scores were obtained by finding the mean response for the questions allocated to each dimension and then dividing by the most positive possible score for each question. This process obtained a dimension score between 0 and 1, with 0 as the most negative possible response and 1 the most positive possible response. Unadjusted dimension scores were compared across patients' demographic characteristics.

Regression analyses were conducted to assess whether the dimension scores were influenced by ethnicity, whether age or gender confounded this relationship, and whether income or cancer treatment services mediated this relationship. Self reported data on age, gender and income was obtained from the survey responses. Age was included in the models in three and six categories to assess the impact of any residual confounding. The linear regression models were developed using Stata® (StataCorp LP) versions 9.2 and 10.

4 Survey Results

4.1 Descriptive results

The *Voice of Experience: Part One* report focuses on individual question results from *The 2009 Cancer Care Survey* (Cancer Control Council of New Zealand 2009). *The Voice of Experience: Companion Report* provides the results for the eight participating cancer treatment services (Cancer Control Council of New Zealand 2010). The following section contains a summary of the national-level results.

Overall satisfaction with the publicly funded outpatient cancer care system in New Zealand is very high (over 97% positive — combined score of good, very good and excellent response options). This was comparable to ratings in Canada, Australia and the United Kingdom.

The key national strengths and opportunities for improvement in cancer outpatient care were identified by ranking and reviewing the survey questions and selecting high and low scoring questions from the upper and lower quartiles. Aspects of care with a high percentage of positive responses were identified as strengths. Table 3 presents key strengths identified by analysing the data at the national level.

Table 3: National strengths of outpatient cancer care, as indicated by the high percentage of positive responses to the survey

Aspects of care	National % positive response (Confidence Interval)	Comments
Coordination of specialist care	91 (90–93)	Many of the surveyed patients reported they had visited multiple doctors, with nine out of ten people (91%) indicating that the specialist care co-ordination was good, very good or excellent.
Ease of understanding directions/signs	90 (89–92)	Nine out of ten people (90%) found the directions and signs at the cancer treatment service good, very good or excellent.
Noise control at the cancer treatment services	90 (88–91)	Nine out of ten people (90%) felt noise was kept to a minimum at the outpatient cancer treatment service.
Level of privacy provided	87 (85–89)	Almost nine out of ten people (87%) felt they had enough privacy during their care.
Dignity and respect provided	86 (85–88)	Almost nine out of ten people (86%) felt that they were always treated with dignity and respect by the health care team.
Care providers doing everything they could to treat cancer	83 (81–85)	Eight out of ten people (83%) report that they felt doctors, nurses and other health care professionals did everything they could to treat their cancer. A similar proportion (81%) reported they would recommend their health care team to family and friends.

Aspects of care with a low percentage of positive responses were identified as opportunities for improvement. Table 4 presents key opportunities for improvement identified by analysing the data at the national level.

Table 4: National opportunities for improvement in outpatient cancer care, as indicated by the low percentage of positive responses to the survey

Aspects of care	National % positive response (Confidence Interval)	Comments
Information (when needed) provided on changes in relationships and changes in sexual activity	32 (29–35) 31 (28–34)	Less than half of those surveyed (32% and 31% respectively) reported always getting enough information on these aspects of daily living.
Explanations provided for any treatment waiting times	34 (30–37)	Seven out of ten people reported (34%) that they did not feel the wait for their first cancer treatment appointment was adequately explained to them. However, only three out of ten people (27%) reported that they felt that they waited too long to get their first cancer treatment appointment.
Being put in touch with care providers to help with anxiety and fear (when first told of illness)	47 (44–50)	More people, about half of those who had anxieties and fears (47%), felt that they were put in touch with other health care professionals who could help them at the time of their initial diagnosis compared with post diagnosis, when only four out of 10 (36%) reported being provided satisfactory emotional support.
Being put in touch with care providers to help with anxiety and fear (if this was required in the 12 months post diagnosis)	36 (33–39)	
Information provided on changes in emotions (when needed)	39 (36–42)	Less than half of those surveyed (39%) reported always getting enough information on this aspect of daily living.
Living situation taken into account when planning for treatment	49 (46–51)	Approximately half of those sampled (49%) reported that they did not feel that health care providers did their best to take their family or living situation into account when planning for treatment. A similar number (48%) had travel concerns they felt were not adequately considered in their treatment planning.

Responses from different cancer services tended to follow similar patterns to national level results. However, as shown in Table 5, twelve survey questions demonstrate at least a 20% difference between the lowest and highest treatment service scores. This indicates a significant difference in patient experience, varying on where you receive outpatient cancer services in New Zealand, for certain aspects of outpatient cancer care.

Table 5: Aspects of care with substantial differences in positive scores between cancer treatment services

Survey question response indicating positive outcome	Highest cancer treatment service % positive score (Confidence Interval)	Lowest cancer treatment service % positive score (Confidence Interval)
Never waited longer than expected for first treatment appointment	92 (82–96)	67 (62–72)
Travel concerns definitely considered in treatment planning	71 (54–83)	43 (37–50)
Waited less than 30 minutes for scheduled chemotherapy treatment appointment	88 (82–93)	62 (54–69)
Never waited longer than expected for chemotherapy treatment	85 (74–91)	51 (43–58)
Staff always did everything they could to make the wait for chemotherapy comfortable	88 ^a (69–96)	63 (53–72)
Never waited longer than expected for radiation therapy	63 (56–68)	36 (30–42)
Staff always did everything they could to make the wait for radiation therapy comfortable	96 (75–99.6)	53 ^a (20–84)
Someone always told the patient how to manage any side effects of radiation therapy	95 (82–99)	71 (61–80)
Patient always offered counseling or support relating to issues such as concerns about cancer or coping at home/work	57 (42–71)	36 (31–42)
Over the past 12 months, someone at the hospital definitely put the patient in touch with other doctors, nurses or health care professionals who could help with anxieties and fears, if it was needed	55 ^a (40–70)	28 (22–34)
Patient always got as much help as he / she wanted in figuring out how to pay for any extra costs related to cancer care	79 (65–89)	56 (46–65)
Availability of parking good, very good or excellent	84 (80–88)	38 (27–51)

4.2 Resulting themes

A review of the internal consistency of the dimensions, as defined by NRC+Picker and IPSOS/Cancer Institute NSW, resulted in findings of low internal consistency for some dimensions. An exploratory factor analysis of the New Zealand data was carried out to identify themes of importance. Four clear constructs related to the experiences of New Zealand cancer patients emerged. These four factors initially explained only 34% of the variance present in the data. Nevertheless, these resulting themes correspond in part with the themes the UK Department of

^a For these Confidence Intervals the sample sizes in the strata were very small, so strata were collapsed together to calculate the Confidence Intervals. The Confidence Intervals here are very wide indicating that the point estimate is not a reliable indicator of the 'true' value.

Health generated in their factor analysis of the Picker-based National Survey of NHS Patients (Department of Health 2004) lending validity to the results.

Forty-eight questions were retained in the final model with factor loadings greater than 0.7. Each factor generated had an eigenvalue equal or higher than 1. The themes that the four factors represented along with the Cronbach's alpha coefficient scores are presented below:

1. relationships with health care professionals/trust in health care professionals ($\alpha = 0.88$)
2. information sharing and shared decision-making at diagnosis ($\alpha = 0.88$)
3. information provided during/after treatment ($\alpha = 0.87$)
4. facilities/amenities ($\alpha = 0.79$)

The data was also analysed by ethnicity focusing on Māori and New Zealand European prioritised ethnicity sub groups. The resulting factor models are not static and show minor differences in the number of retained factors/themes. The factor structure for Māori (n=309) was more complex with six retained factors. Results for New Zealand European identified ethnicity (n=1693) show four retained factors with the first factor accounting for the vast majority of the variance. However, the factor compositions for the first four factors for both were similar. The resulting differences that emerge when the data is analysed by ethnicity are not surprising given previous research regarding the factor structure differences seen between New Zealand European and Māori in the SF-36 (Scott et al 2000). The factor analysis ethnicity differences point to issues of cross-cultural validity in the measurement of patients' experiences of care. However, this thematic analysis is exploratory and further research is needed to confirm these results.

The themes retained through exploratory factor analysis were reviewed in light of key New Zealand national quality assurance mechanisms and requirements. The rights outlined in *The NZ Code of Health and Disability Services Consumers' Rights* ('The Code') regulation which became law in 1996 (HDC 1996) closely align with the themes emerging from the New Zealand survey data (Table 6). The Code is of importance to both consumers and providers because it "...establishes the duties and obligations of providers to comply with the Code, to ensure they promote awareness of it to consumers and enable consumers to exercise their rights" (HDC 1996). The Code acts as a mechanism for providers to let patients know they can exercise rights to become a partner in cancer treatment decisions. It is not just the four themes from the factor analysis that align with The Code, many of the factors considered important in health care service quality as cited in section 2.3 of this report (e.g. responsiveness/respect, equity, empathy, safety, communication, information, and emotional support) can relate back to The Code. It is worth noting that there is no agreement on the full compliment of factors deemed important for a positive patient experience, nevertheless, the Code reflects an important subset of legitimate factors of importance to health consumers as reported in the survey.

Table 6: The four factors and their extrapolated relationship to *The NZ Code of Health and Disability Services Consumers' Rights*

Strong themes in NZ survey data using exploratory principal factor analysis	Related rights found in the NZ Code of HDS Consumers' Rights
Factor 1— relationships with health care professionals/trust in health care professionals ($\alpha = 0.88$)	Right 1 — to be treated with dignity and respect Right 2 — freedom from discrimination Right 3 — services provided that respect dignity and independence Right 4 — services of high standard
Factor 2 — information sharing and shared decision-making at diagnosis ($\alpha = 0.88$)	Right 6 — full disclosure Right 7 — informed choice Right 9 — choice of participating in teaching or research, if appropriate
Factor 3 — information provided during/after treatment ($\alpha = 0.87$)	Right 5 — effective communication Right 8 — right to support Right 10 — right to complain without repercussions
Factor 4 — facilities/amenities ($\alpha = 0.79$)	Right 4 — services of high standard ^b

4.3 Resulting ethnicity comparisons

The results from this survey found that both Māori and New Zealand European (NZE) patients' experiences of cancer care were generally very positive, but there were opportunities for improvement in certain aspects of care. The ranking of the percentage of positive responses, from the least positive to the most positive, identified perceived strengths and opportunities for improvement that were similar for both Māori and New Zealand Europeans (Table 7 and 8).

Table 7: Key strengths of outpatient cancer care identified by Māori and New Zealand Europeans

Aspects of care	Māori % positive response (Confidence Interval)	NZE % positive response (Confidence Interval)
Coordination of care	94 (91–96)	91 (89–93)
Ease of understanding directions/signs	91 (88–94)	90 (88–92)
Noise control at the cancer treatment services	90 (83–95)	90 (88–92)
Level of privacy provided	90 (87–93)	88 (86–90)
Dignity and respect provided	93 (90–95)	87 (85–89)
Care providers doing everything they could to treat cancer	86 (80–91)	84 (82–86)

^b Right 4 of The Code encompasses services that extend beyond facilities/amenities.

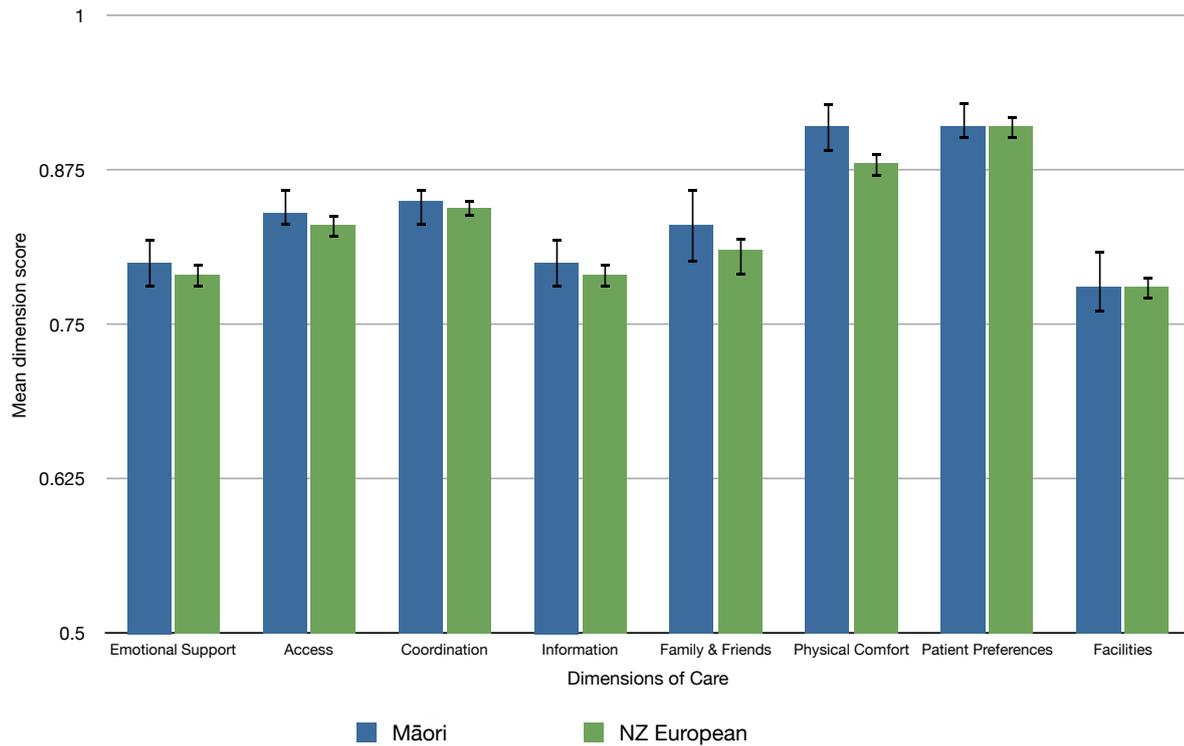
Table 8: Key opportunities for improvement in outpatient cancer care identified by Māori and New Zealand Europeans

Aspects of care	Māori % positive response (Confidence Interval)	NZE % positive response (Confidence Interval)
Being put in touch with care providers to help with anxiety and fear (if this was required in the 12 months post diagnosis)	31 (26–37)	36 (32–39)
Information provided on changes in sexual activity (when needed)	40 (31–49)	30 (27–33)
Information provided on changes in relationships (when needed)	42 (34–51)	31 (28–35)
Explanations provided for any treatment waiting times	48 (40–56)	31 (27–35)
Information provided on changes in emotions (when needed)	49 (42–57)	37 (34–40)
Easily understandable information provided on the different treatment options	51 (45–57)	56 (54–59)
Information provided on changes in ability to do work/ activities (when needed)	53 (46–61)	49 (46–52)
Information provided on changes in nutritional needs (when needed)	53 (46–61)	47 (44–50)
Offered counselling/support for concerns/coping with cancer	54 (48–61)	41 (38–44)
Comfortable talking with health care professionals about alternative therapy	55 (46–63)	48 (44–52)
Living situation taken into account when planning for treatment	57 (50–65)	50 (47–53)

Dimension of care scores

All of the mean dimension scores were skewed towards the positive end of the scale. The number of missing scores varied across the dimensions, with the highest number of missing scores in the 'physical comfort' dimension (i.e. 363 missing scores). The unadjusted Māori and New Zealand European dimension mean scores tended to follow a similar pattern, with the 'emotional support' (Māori: 0.80; 95%CI: 0.78–0.82 ; NZE: 0.79; 95%CI: 0.78–0.80), 'information' (Māori: 0.80; 95%CI: 0.78–0.82; NZE 0.79; 95%CI: 0.78–0.80) and 'facilities' (Māori: 0.78; 95%CI: 0.76–0.81; NZE: 0.78; 95%CI: 0.78–0.79) dimensions of care scoring the lowest (Appendix 4). However, the New Zealand European scores tended to be slightly less positive than the Māori scores (Figure 2, over).

Figure 2: Mean unadjusted dimension scores for Māori and New Zealand European ethnic groups



(Note: Scale starts at 0.5 to enhance the visualisation of the Confidence Intervals)

Unadjusted mean dimension scores tended to be higher in the older age groups and in the lower income groups, except for the 'family and friends' dimension. The unadjusted mean dimension scores tended to be the same for males and females (Appendix 4). However, a regression analysis found that on average, across all dimensions of care, the dimension scores for Māori would be higher (more positive) than the dimension scores for New Zealand Europeans, controlling for age, gender, income and cancer treatment service.

5 Limitations

The concept of the patient experience is multi-dimensional and measurement of multidimensional constructs is complex. Consequently, there is no agreement on the best method to research the patient experience, in part because there is no single definition of 'best patient experience'. Expectations and perceptions of health care experiences differ across population groups which complicates sub-group comparisons. Nevertheless, gathering information on patient experiences of care can provide policymakers with a valuable perspective on the standard of service provision and assist in developing more patient-centred care.

The 2009 Cancer Care Survey was a relatively large nation-wide survey of a randomly selected group. It used a questionnaire that was based on material that had been well tested and used internationally, with minor adaptations for a New Zealand context. The survey achieved a high response rate for a postal questionnaire. All these factors helped reduce the chances of erroneous conclusions being drawn from the survey responses. The study did, however, have several limitations.

The large population in this survey ensures high statistical precision. However, small numbers of Pacific Islander or Asian people included in the study precluded separate ethnic analysis of these groups. Given the varying incidence, mortality and burden of cancer in Pacific Islanders (often higher than in New Zealand Europeans) and Asians (usually lower), this is an issue that should be addressed if possible in any subsequent surveys.

Although the response to this survey was high for a mail survey at 68%, the response rate for Māori was 51%. Therefore, there was the potential for response bias in that Māori with different experiences of the health care system may have tended to not respond or engage with the survey. In light of this limitation, it is recommended that the results of this study be reviewed within the context of previous research on patient experiences in New Zealand, particularly research that has used Kaupapa Māori, qualitative or mixed method approaches (Basset and Holt 2002; Davis et al 2008; Doolan-Noble et al 2006; Jansen et al 2008; Waitemata DHB 2006; Walker et al 2008).

Timing the survey relatively close to the period of treatment and targeting the survey towards a motivated patient group is likely to have reduced recall bias and the use of a confidential mailed survey is likely to have reduced social desirability bias. However, there is the potential that social desirability bias may have been more of an issue for one ethnic group than for another, leading to differential misclassification of responses. Although the questionnaire was tested and refined by NRC+Picker, some of the concepts or questions in the survey may have been misunderstood by respondents, particularly those with lower levels of education or literacy in English.

The study excluded those who had only received inpatient treatment or treatment from private facilities, or only received alternative treatments, or had watch-and-wait experiences. Additionally, those without a fixed address or residency were excluded, which could have systematically excluded some of the more marginalised groups in our society. Excluding the experiences of those who died soon after treatment could also have influenced the results, as this group could potentially have had different experiences.

The classification of the data into ethnic groups was based primarily on self-reported data from the survey, which were cleaned and checked prior to analysis to reduce the likelihood of misclassification. The use of an 'ever' Māori population (where Māori may have indicated they also belonged to other ethnic groups) rather than a 'sole' Māori ethnicity group (those who only chose Māori as their ethnic group) may have minimised undercounting of Māori (Te Ropu Rangahau Hauora a Eru Pomare 2000) but is unlikely to have altered much the relative comparisons between ethnic groups.

As the survey questions and dimensions were not developed with, or for, a New Zealand population they may not be as relevant or applicable to this population, particularly for non-New Zealand European ethnic groups. Traditional Māori views of health and well-being tend to be more holistic than 'Western' European views, encompassing spiritual, family, psychological and physical aspects of health (Durie 1994). Consequently, the constructs being measured in this survey may not accurately reflect Māori experiences of care. This issue has previously been highlighted by a principal component factor analysis of the internationally utilised SF-36 health status questionnaire. This analysis found that the validity of using this tool for cross-cultural comparisons in New Zealand was questionable at older ages, although New Zealand Europeans and younger Māori were found to have similar factor structures to Western European countries (Scott et al 2000).

6 Summary

The 2009 Cancer Care Survey data provides important, but often overlooked, patients' perspectives on the performance of cancer outpatient services. The results can be further developed to add a patient-focused element to the disease-specific (e.g. incidence, survival, mortality) and clinic-specific (e.g. waiting times) health outcomes by which the provision of effective care tends to be assessed. This would be a valuable contribution toward better defining and measuring the quality of cancer care.

The 2009 Cancer Care Survey was completed by 2221 people resulting in a 68% final response rate. The key findings from the survey were:

1. Overall satisfaction with the publicly funded outpatient cancer care system in New Zealand was very high (over 97% positive). The results from the eight participating cancer treatment services followed similar patterns to the national results around strengths and opportunities for improvement.
2. New Zealand's results were similar to comparable results of NRC+Picker surveys recently administered in British Columbia, Canada and New South Wales, Australia. However, New Zealand's national results were comparatively better around chemotherapy waiting times and slightly worse for providing confusing information to patients.
3. The aspects of care that received the highest scores demonstrate perceived strengths in the cancer care provided. Survey respondents were highly positive about specialist care coordination (91% positive response; 95% CI: 90–93), the level of privacy (87% positive response; 95% CI: 85–89), and dignity and respect provided by health care professionals (86% positive response; 95% CI: 85–88).
4. The aspects of care where many patients highest expectations were not met, indicating opportunities for improvement, included the provision of emotional support (*as illustrated by a 36% positive response; 95% CI: 33–39; to a question on being put in touch with care providers to help with anxiety and fear if needed*), the provision of information (*as illustrated by a 34% positive response; 95% CI: 30–37; to a question on whether an adequate explanation was received for any treatment waiting times*) and consideration of the patients' circumstances in treatment planning (*as illustrated by a 49% positive response; 95% CI: 46–51 to a question on whether their living situation was taken into account in treatment planning*).
5. Responses to 12 questions showed significant inter-treatment service variation with at least a 20% difference in scores reported.
6. Dimensions of care found to be of greatest importance for the patient experience, based on exploratory factor analysis of the New Zealand survey data, were relationships with health care professionals, information, and facilities and amenities.
7. Māori and New Zealand European responses tended to follow similar patterns with the 'emotional support' and 'information' dimensions of cancer care scoring lowest.
8. Emotional support and provision of information on aspects of daily living are key components of supportive care. The survey analysis to-date suggests that improvements in supportive care may be the best way to improve the cancer patient experience.

9. Cancer patient experience surveys can achieve high response rates and generate useful patient-focused information about the quality of care overall and at the individual cancer treatment service level.

Thematic analysis

Four clear factors of importance for the New Zealand patient experience were generated by this exploratory factor analysis:

- relationships with health care professionals/trust in health care professionals
- information sharing and shared decision-making at diagnosis
- information provided during/after treatment
- facilities and amenities provided

Three of these factors closely align with the eight dimensions of patient-centred care that NRC+Picker identified. However, the strongest connection across the two factor structures is related to the 'information' dimension. Beyond the dimension of 'information' as a key theme in patient experience research, more research needs to be done in order to clearly identify higher-order constructs that can represent what is most important for the health system to provide for people in New Zealand affected by cancer. Further, more research is needed to review the intersection of the four to six factors generated by these exploratory factor analyses with the eight dimensions of patient-centred care that NRC+Picker identified.

Ethnicity analysis

The key opportunities for improvement and lowest scoring dimensions of care identified in this study were similar for both Māori and New Zealand European groups, with the 'emotional support' and 'information' dimensions of care scoring the lowest. This implies that targeting initiatives towards improving these aspects of care could be beneficial for both ethnic groups. However, the results of this survey are best viewed in the context of the overall approach to cancer care and service priorities, and different approaches for each ethnic group may be required to successfully address these issues and avoid increasing inequalities. Additionally, further research is needed to explore constructs or dimensions of cancer care that may be more applicable and relevant to the different ethnic groups within the New Zealand population.

The finding that Māori perceptions of their experiences of cancer outpatient care across key dimensions were more positive than New Zealand Europeans could be seen to be reassuring in some regards, potentially reflecting the efforts by the cancer treatment services to reduce ethnic inequalities. However, this study's findings on patient satisfaction perception may not be generalisable to objective quality of care, as the results from this survey reflect expectations as well as experiences of care. Different population groups may therefore respond differently to survey questions, even though they may have had the same experience (Murray and Frenk 2001). Potentially, Māori may have responded more positively in this survey than New Zealand Europeans because they were less likely to expect that the services would meet all their needs, due to past experiences of institutional or interpersonal racism (Jones 2000) (Walker et al 2008). Māori have been found to have poorer cancer related outcomes than New Zealand Europeans (Robson et al 2005) and an accumulating number of studies have indicated that Māori sometimes have less access and lower quality of care (Cormack et al 2005; Hill et al 2010; Hutt Valley DHB and Wairarapa DHB 2006; Rumball-Smith 2009; Walker et al 2008). Consequently, the findings in this study cannot be confidently generalized to mean that Māori receive better quality of care. In future research, these issues with sub-group comparisons could be potentially addressed by considering the incorporation of vignettes, such as those used by the World Health Organisation, to calibrate sub-group responses or by including qualitative components to verify the findings (Murray and Evans 2003).

The need for better provision of emotional support and/or information has emerged as themes of importance for the cancer patient experience both for Māori and New Zealand European. This finding has been previously mentioned in other studies of patient experience of care in New Zealand (Blendon et al 2003; Doolan-Noble et al 2006; Hutt Valley DHB and Wairarapa DHB 2006; Schoen et al 2004). Information needs that were not being adequately met, as identified by respondents to *The 2009 Cancer Care Survey*, included those related to patient's activities of daily living and recovery (Cancer Control Council of New Zealand 2009; 2010). *The Guidance for Improving Supportive Care for Adults with Cancer in New Zealand* (Ministry of Health 2010a), highlight the important role information provision and supportive care services can play in improving the cancer experience for those affected by cancer.

The results of this first ambulatory oncology survey in New Zealand will act as a benchmark against which the results of future cancer patient experience surveys can be compared. This will be crucial for monitoring the impact of new initiatives to improve the quality of cancer care. Furthermore, comparing the results of this survey with subsequent patient experience surveys could provide a valuable perspective as to how new initiatives impact on the experiences of cancer care for different ethnic groups and consequently inform providers in their efforts to reduce inequalities in cancer outcomes.

Recommendations

Recommendations are made in regard to linking patient experience, as reported in this survey, with quality improvement and opportunities for further research.

Patient experience and quality improvement

CCNZ recommends that:

1. *The 2009 Cancer Care Survey* results should be distributed widely throughout the sector and the community. This project shows that cancer patient experience surveys can achieve high response rates and generate actionable data on patient perceptions which should be integrated with evidence-based practice to inform efforts to improve quality.
2. Service providers should let consumers know they are listening as part of quality improvement frameworks. This can help build patient trust. The survey found that overall outpatient cancer care experience is rated highly by patients. CCNZ would like to congratulate each participating cancer treatment service for providing such highly regarded services. Sharing this type of information can help build the services' reputation and can show that the health service values patient feedback.
3. Actionable and standardised patient-reported outcomes can be utilised to assess the impact of quality improvement efforts on the patient experience of care. The 2010/2011 Ministry of Health performance measures for District Health Boards (DHBs) include effectiveness and efficiency indicators but also incorporate access and equity measures alongside one overall patient-reported quality measure (i.e. patient satisfaction) (Ministry of Health 2010b). NRC+Picker state that collecting data on patient experiences, as opposed to overall satisfaction, can generate more actionable patient-reported outcomes (NRC+Picker 2010b). Regional networks and treatment services, in collaboration with CCNZ and the Ministry of Health, should consider developing actionable patient-reported outcomes that drive quality improvement toward the goal of a more responsive health system.
4. Patient-focused change should be actively led by both clinical and non-clinical leaders. Just as this analysis found that there is not one 'best' patient experience of care model, it is unlikely that there will be one solution to improve the patient experience. Multiple strategies and voices are required to advocate for the need to balance the technical and service aspects of providing effective cancer care. Better systems and processes can help streamline technical aspects of providing effective care. Service skill professional development can support

integrating patients' needs and wants into care plans. Several strategies must be pursued simultaneously by clinical leaders to work towards an effective balance between the technical and service aspects of quality cancer care.

5. Professional debate is encouraged around the results of this survey. Possible questions to be addressed include: How can information obtained from surveys best be integrated into quality improvement frameworks? Who in the multidisciplinary team (doctor, nurse, allied health or Cancer Society staff) is best placed to respond to the supportive care gap identified by patients? How can the results of this survey link in to the Supportive Care Guidance (Ministry of Health 2010a) implementation process being undertaken by the Ministry of Health? How can regional champions for key aspects of care share their models of care and successes with other service providers?
6. There is an opportunity to link national, regional and service-level patient experiences information to ongoing rapid improvement reviews or contemporary lean thinking processes. This provides opportunities to examine the patient experience along the diagnosis and treatment pathway. These processes can help multidisciplinary teams address, for example, better ways to incorporate the patient living situation into treatment planning, or what customised information is needed at particular times to match the evolving health literacy of patients along a cancer journey.

Opportunities for further patient experience research

CCNZ recommends that:

1. The survey should be repeated every three to five years. These patient experience surveys can then form part of the national monitoring and evaluation of initiatives aimed at improving patients' experience of cancer care.
2. There should be further analysis of the rich information gathered in *The 2009 Cancer Care Survey*. Potential opportunities for further analyses include: conducting more detailed international comparisons; qualitative analyses of the patients' comments; analysing these data according to deprivation; and comparing the results of this survey with data from District Health Board satisfaction surveys.
3. There should be support for both quantitative and qualitative patient experience research. One way forward for future patient experience surveys would be to purposively select a diverse sample of those included in the survey to take part in hui, focus groups or face-to-face interviews, to further explore their experiences of care. The results from this qualitative analysis could then be used to cross-check and validate the results of the survey and form a much richer picture of the patients' experiences. This would be particularly useful for informing sub-groups comparisons.
4. Administrators of patient experience surveys should use booster samples for Māori and Pacific Island populations to enable robust analysis of the results for these ethnic groups. Ideally, Māori participation rates should equal or surpass those of New Zealand Europeans. In order to increase the response, particularly from Māori and Pacific Islanders, it would be important to engage with Māori and Pacific communities and groups with an interest in cancer prior to initiating a survey. Providing translations of the survey and survey posters in other languages to increase awareness about the survey project would also be beneficial.
5. Patients' experiences should be considered and measured across the entire cancer care continuum. The current survey gathered data only at the outpatient cancer treatment service level. Consequently, primary care, in-patient and palliative care experiences were not captured in this project. Cancer treatment service outpatient experience data only represents a snapshot of a subsection of the patient's cancer experience. System-level research can help identify macro-system dimensions that can impact on the patient experience and the coordination of quality cancer care.

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8 Appendices

8.1 Appendix 1: Survey population characteristics

Surveys were completed by 2221 people resulting in a 68% final response rate. Table 9 shows details of the survey population selection process. 3525 surveys were mailed out. A total of 410 people (136 during pre-mailing checks, 254 post mailing and 20 post data cleaning) were excluded. Reasons for exclusion included: being deceased, not having received treatment for cancer, being too unwell or unable to complete the survey, the survey being returned to sender as undeliverable, or the returned questionnaire being illegible or damaged. The 136 exclusions made during pre-mailing checks were replaced from the appropriate and corresponding patient lists. The final total survey population was 3251. The final Māori survey population (as classified by the cancer treatment services) was 586 and there were 296 eligible respondents resulting in a final Māori response rate of 51%. The final New Zealand European response rate (as classified by the cancer treatment services) was 74%.

Table 9: Survey population selection process

Group	Total (n)	Māori (n)	NZ European (n)
Total target population	7177	697	4885
Excluded pre mailing	136	46	72
Top up sample	147		
Total number in sample	3525	651	2214
Completed surveys returned ^c	2495	360	1702
Excluded post mailing	254	62	148
Excluded post data cleaning	20	3	15
Survey population (the subset of sample that was in-scope)	3251	586	2051
Final number of eligible respondents (as classified by cancer treatment services)	2221	296	1525
Final number of eligible respondents (as self reported in the survey)	2221	309	1693

Table 10 shows demographic characteristics of the eligible respondent populations. Target, sample and respondent populations were found to be similarly distributed by ethnicity, age, gender and cancer treatment service. Across all ethnic groups the highest proportion of respondents were in the 50–69 years age group. Compared with NZ European, a higher proportion of Māori were in the under 50 years age group, were female and were in the low income group (32% cf 14%; 69% cf 55% and 40% cf 31% for Māori and NZ European respectively).

^c 95% of surveys were completed as hardcopies and 5% were completed online.

Table 10: Characteristics of the Māori and New Zealand European respondent populations

Characteristics	Māori respondents % (n)	NZ European respondents % (n)	All respondents % (n)
Age group (years)			
<50	32 (99)	14 (243)	18 (407)
50–69	53 (164)	52 (888)	52 (1148)
>=70	15 (46)	33 (562)	30 (666)
Gender			
Male	30 (94)	43 (727)	39 (887)
Female	69 (214)	55 (934)	60 (1299)
Missing	0.3 (1)	2 (32)	2 (35)
Household income after tax (\$)			
Low (<=\$30,000)	40 (124)	31 (517)	32 (716)
Medium (\$30,001-60,000)	20 (63)	28 (473)	26 (587)
High (>\$60,000)	14 (43)	21 (355)	20 (434)
Missing	26 (79)	21 (348)	21 (484)
Cancer treatment service			
Northern Region Cancer Centre	27 (84)	12 (202)	16 (354)
Tauranga and Whakatane Cancer Centres	17 (51)	16 (275)	16 (348)
Canterbury Oncology Service	6 (17)	17 (295)	15 (337)
Wellington Blood and Cancer Centre	10 (31)	17 (293)	17 (369)
Southern Blood and Cancer Service	1 (3)	4 (74)	4 (83)
Palmerston Nth Regional Cancer Treatment Service	19 (60)	16 (268)	16 (352)
Nelson Oncology Service	1 (2)	4 (66)	3 (70)
Waikato Regional Cancer Centre	20 (61)	13 (220)	14 (308)

8.2 Appendix 2: Key findings from select patient experience research

Patient experience survey	Key findings	Key issues/limitations
<p>WHO Global Health Survey responsiveness module (Ustun et al November 2001)</p> <ul style="list-style-type: none"> In 2000, the survey study tested novel techniques to control the reporting bias between different groups of people in different cultures or demographic groups (i.e. differential item functioning) so as to produce comparable estimates across cultures and groups. Final sample size 3401 New Zealanders (including Māori oversample) yielding a 68% survey response rate. 	<ul style="list-style-type: none"> Data from the surveys could be calibrated for assessing health of populations in a comparable manner. Data also found to be useful for improving the measurement of the responsiveness of different health systems to the legitimate expectations of the population. Domains were autonomy, choice, communication, confidentiality, dignity, quality of basic amenities, prompt attention and access to family and community support. Most important domains rated to be prompt attention, dignity and communication (Valentine et al 2003). 	<p>Cross-national survey design. Survey not designed with NZ-specific population in mind. No ethnicity comparisons. Excluded those not on electoral roll (~10% of population) and those who may have moved on without a forwarding address or without a permanent address. Survey only available in English for New Zealand. No specific findings could be accessed from the WHO website although this data could be obtained by the Ministry of Health upon request.</p>
<p>The Commonwealth Fund</p> <ul style="list-style-type: none"> The Commonwealth Fund sponsors cross-national surveys of public perceptions of and experiences with health care systems (Blendon et al 2002; Donelan et al 1999; Schoen et al 2007; Schoen et al 2004) in which New Zealanders participate. Between 1000 and 1500 New Zealanders participate in these telephone surveys. 	<ul style="list-style-type: none"> Survey domains include safety, coordination, access and communication (Schoen et al 2005). No one country is doing consistently and substantially better across the board than another commonwealth country in regard to health care experiences. Selected NZ results from 2004: 19% felt complete reform of the health system was needed (decline from 1999). 27% very confident they would get quality and safe care if needed. 37% felt hospital staff did everything to treat pain. 40% had seen 3 or more doctors. 22% felt results of tests not clearly explained. 23% felt family doctor not up to date. Quality of care from doctor rated as excellent, very good or good by 89%. 71% felt the doctor had not asked about emotional issues. Selected NZ results from 2007: Public views becoming more positive about the health system. Cost related access was felt to have improved, 80% said the doctor explains things understandably, 67% felt they were involved in treatment decisions and told about options. 78% rated overall quality of care as excellent or very good. 19% had received conflicting information from providers. 	<p>Cross-national survey design. Survey not designed with New Zealand-specific population in mind but New Zealand researchers were consulted. No ethnicity comparisons. Excluded those without a telephone. Survey only available in English for New Zealand.</p>

Patient experience survey	Key findings	Key issues/limitations
<p>Consumer Assessment of Health Care Providers and Systems (CAHPS); Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) (Agency for Healthcare Research and Quality 2010)</p> <ul style="list-style-type: none"> The HCAHPS survey asks patients 27 questions about their experiences in the hospital and about their demographic characteristics. 	<ul style="list-style-type: none"> Responses to 14 of the questions are reported in 6 domains as composites: communication with physicians, communication with nurses, communication about medications, quality of nursing services, adequacy of planning for discharge, and pain management. Composite results from 2007 as follows: “Communication with doctors” received the highest percentage of “always” responses, followed closely by “Communication with nurses.” The lowest scoring composite was “Communication about medications,” with only 54 percent of respondents saying “always” to the two questions asking about hospital staff explanations of the purpose of any new medicines given and their possible side effects. 	<p>National survey with large focus on health plan experiences. Surveys only available for use in the USA. USA results only available for a non-representative subset of hospitals (for HCAHPS). The survey respondents are not representative of all patients who are admitted to hospitals. However, information on the types of hospitals and respondents included in the database is provided.</p>
<p>The Picker family of surveys of patient experience (NRC+Picker 2010a; Picker Institute Europe 2010)</p> <ul style="list-style-type: none"> In the 1980’s, the first of the Picker family of surveys was developed to capture patients’ perspectives about what is important for their healthcare (NRC 2005). Reports on patient experience as assessed by the Picker ambulatory oncology instrument are available in the USA (NRC+Picker 2010b), UK (Department of Health 2002), Canada (Watson et al March 2007), and Australia (Cancer Institute NSW July 2009) 	<ul style="list-style-type: none"> Eight dimensions of patient-centred care are patients’ preference, emotional support, physical comfort, information and education, continuity and transition, coordination of care, access to care, family and friends. Lowest scoring and dimensions consistently emotional support and information & education. 	<p>Surveys used nationally and results are not routinely compared cross-nationally. Survey not designed with NZ-specific population in mind.</p>
<p>EORTC IN-PATSAT32 (European Organisation for Research and Treatment of Cancer 2010)</p> <ul style="list-style-type: none"> The EORTC IN-PATSAT32 is a 32-item satisfaction with care questionnaire to measure patients’ appraisal of hospital doctors and nurses, as well as aspects of care organisation and services. 	<ul style="list-style-type: none"> Domains include technical competence, information provision, interpersonal skills, availability, waiting time, access, comfort and overall care perception. 	<p>Survey designed to enable cross-national comparisons in Europe. Only assesses in-patients.</p>
<p>Patient Experiences Questionnaire (PEQ) (Pettersen et al 2004)</p> <ul style="list-style-type: none"> The PEQ is a 7–10 dimension self-report instrument. The outpatient version (OPEQ) has 6 dimensions. 	<ul style="list-style-type: none"> OPEQ dimensions include clinic access, communication, organisation, hospital standards, information and pre-visit communication. 	<p>National survey for use in Norway.</p>

NZ patient experience research	Key findings	Key issues/limitations
<p>The journey of treatment and care for people with cancer on the West Coast (Doolan-Noble et al 2006)</p> <ul style="list-style-type: none"> • Aimed to examine the overall cancer journey, in particular the Māori perspective. The mixed methods approach included focus groups of 32 health care providers, face-to-face interviews with 19 cancer patients, surveys of 44 cancer patients and 24 family members/supporters of these patients and 3 hui (consisting of 10–12 people each). 	<p>There was a 64% response rate to the patient survey part of this project. 96% were able to see GP promptly, 92% had no delay in diagnostic tests, 93% felt treatment was timely and 86% felt well supported. Some participants felt there needed to be a more holistic approach to care and that there were communication and coordination issues, particularly between providers compounded by geographical distances. Some raised concerns regarding access to care, especially local care, after hours support and palliative care.</p>	<p>The interviews excluded those who could not speak English or who were in the imminently terminal phase. Small sample sizes.</p>
<p>Te Huarahi o Nga Tangata Katoa. An analysis of the cancer journey of people from the Hutt Valley and Wairarapa District Health Boards (Hutt Valley DHB and Wairarapa DHB 2006)</p> <ul style="list-style-type: none"> • Aimed to investigate the cancer experience journey of cancer patients and their whānau/families, with a focus on Māori, Pacific Islanders and those from disadvantaged communities. They conducted face-to-face interviews with 80 key representative providers of cancer care and 22 people with experience of cancer. 	<p>Many respondents reported positive relationships with providers. However, some reported potential barriers such as fear, cultural/religious beliefs, embarrassment, transport issues, cost, lack of Māori/Pacific Islander providers. Some respondents also felt there was a lack of information on services, especially face to face or interpreted/translated information and that the family and patient were not involved enough in care decisions.</p>	<p>The sample were selected by their providers, which potentially could have introduced some systematic bias. Small patient sample. Results for providers and patients not reported separately.</p>
<p>A survey of urban and rural participants in the Otago-Southland pilot breast cancer screening programme (Richardson et al 1994)</p> <ul style="list-style-type: none"> • Aimed to measure satisfaction with the Otago/Southland pilot breast screening service. 474 women included by randomly selecting ten in every 50 women screened in urban centres and all women screened in the mobile rural unit to receive a mailed survey. 	<p>93% response rate. 95% were happy with the way staff treated them. 49% thought up to 30 minutes was an acceptable wait.</p>	<p>Questionnaire had been piloted but unclear if any other tests of its validity. Very few Māori participants so difficult to assess cultural acceptability. Those attending the programme were self selected, so may be systematically different from target population.</p>

NZ patient experience research	Key findings	Key issues/limitations
<p>Colorectal Cancer Service Improvement Project (Waitemata DHB 2006)</p> <ul style="list-style-type: none"> Aimed to provide feedback on the quality of the journey for colorectal cancer patients in Waitemata DHB. Patients were selected from the Colorectal Unit patient database. They conducted 10 face-to-face interviews (selected randomly with priority to non-NZ European) and surveyed 131 patients by mail (all patients from 2004-05 annual intake). 	<p>49% response rate to the survey. 98% were satisfied or very satisfied with service. 26% waited at the hospital more than 30 minutes to see a doctor. 20% had difficulty accessing service due to transport, time off work etc. Cleanliness, staff and privacy rated highly but food and noise levels rated low. Communication was highlighted as being important for patient resilience.</p>	<p>Difficult to assess as full report could not be accessed.</p>
<p>The road we travel: Māori experiences of cancer (Walker et al 2008)</p> <ul style="list-style-type: none"> Aimed to explore Māori experiences of cancer. They conducted 5 hui (with 44 participants) and 8 interviews to obtain the views of Māori affected by cancer and their whānau. 	<p>Both positive and negative experiences with providers were reported, with the importance of good communication highlighted. High levels of satisfaction with Māori health providers were reported, especially for their world view, style of practice and support. However, ethnicity was reported as being less important than the qualities of the provider. Involvement of whānau in cancer journey and a holistic approach were felt to be important.</p>	<p>Some of those recruited had experiences 20–30 years ago, increasing the potential for recall bias and may not be reflective of current experiences. No comparative ethnic group. Research conducted in central region and may not be generalisable to Māori in other areas.</p>
<p>Gynaecologic cancer patients' needs and experiences of supportive health services in New Zealand (Walton et al 2009)</p> <ul style="list-style-type: none"> Aimed to identify met and unmet needs over the cancer continuum for women diagnosed (or with a recurrence of) gynaecological cancer. They conducted face-to-face unstructured interviews with 28 women recruited from outpatient clinics at an Auckland teaching hospital. 	<p>Concerns differed with individual living situation and specific cancer type. Most were positive about participation in treatment decisions and support groups. Some participants requested more support for diverse beliefs and CAM. Better communication was requested by some participants especially for timely, tailored information about treatment effects, recovery, wellness and on potential changes in sexuality and emotions. Half of those who wanted help for distress/ concerns perceived they had not been offered a referral.</p>	<p>Participants were recruited at outpatient clinic, which may have introduced bias. Generalisability limited by only conducting study at one cancer centre. Small sample size. No Asian participants. Only 9 classified as Māori or Pacific Islander.</p>

NZ patient experience research	Key findings	Key issues/limitations
<p>New Zealand resident Tongan peoples' health and illness beliefs and utilisation of the health care system (Basset and Holt 2002)</p> <ul style="list-style-type: none"> • Aimed to explore Tongan health, illness and disability beliefs and the perceived value of western orthodox medicine. They conducted semistructured interviews with 20 Tongan people. 	<p>The majority of participants defined health holistically. Six participants thought service from staff was professional and that there was good coordination. Some dissatisfaction with cost, waiting times, medications, and the length of time spent consulting. Five participants reported being uncomfortable due to cultural differences, language or surroundings.</p>	<p>Sample found through networks (not random), people volunteered and had to speak English fluently. No comparative ethnic group.</p>
<p>Patients' perceptions of service quality dimensions: an empirical examination of health care in New Zealand (Clemes et al 2001)</p> <ul style="list-style-type: none"> • Aimed to identify the dimensions of service quality and assess their relative importance as perceived by North Canterbury health care patients. Telephone interviews of 389 people who had a hospital admission in past three years. Factor analysis of results to create dimensions. 	<p>Service quality dimensions were identified as: reliability, tangibles, assurance, empathy, food, access, outcome, admission, discharge, responsiveness.</p>	<p>Generalisability limited by only assessing North Canterbury patients. No ethnicity analysis/ comparisons. Excluded those without a telephone.</p>
<p>Patient dissatisfaction recorded in hospital notes in New Zealand: their occurrence and pattern (Davis et al 2008)</p> <ul style="list-style-type: none"> • Aimed "to describe the occurrence and pattern of patient dissatisfaction and/ or litigation recorded in medical notes in NZ public hospitals." 6579 records were screened and 173 incidents of complaint were identified for analysis. 	<p>2.7% of medical notes contained record of patient dissatisfaction. A qualitative review found that incidents related to systemic clinical, organisation and communication issues. No consistent social background patterns were identified.</p>	<p>Likelihood of considerable variation in extent of recording of incidents between individuals and institutions. Based on records in 1998, so results may no longer be applicable.</p>
<p>You can't ask if you don't know what to ask: a survey of the information needs and resources of hospital outpatients (Harris 1992)</p> <ul style="list-style-type: none"> • Aimed to test the demand for health information and find out the sources of information used by the public. Structured interviews were conducted with 274 outpatients. 	<p>54% felt they knew enough about illness information, 61% felt they knew enough about treatment information. Minority groups (excluding Māori) were more dissatisfied with information received. Health providers then friends/ family/neighbours/support organisations were identified as the most used sources of information.</p>	<p>The selection of clinics and patients was not random. The survey was delivered in person at the outpatient clinic, which may have introduced social desirability bias.</p>

NZ patient experience research	Key findings	Key issues/limitations
<p>Kaupapa Māori Action Research to improve heart disease services in Aotearoa, New Zealand (Kerr et al 2010)</p> <ul style="list-style-type: none"> This project aimed to use Kaupapa Māori Action Research methods to understand “Māori pathways and barriers to care for ischaemic heart disease” and to develop “Māori-led actions to improve service provision.” Phase 1: interviews with 25 Māori with ischaemic heart disease (IHD) and 19 health care providers (HCP). Phase 2: Series of hui exploring barriers possibilities and action for improvement. Phase 3: Follow up interviews with 20 Māori with IHD and 15 HCPs. 	<p>Concerns were raised by some participants about the effectiveness of cross-cultural communication, with HCPs “using difficult language and not discussing their decisions”. There was also concern that health care professionals were not taking into account the value of involving whānau in discussing the care of a patient. Patients experiences were found to be useful in challenging health care professionals’ assumptions and practices and in driving systemic changes in practice.</p>	<p>Small sample size, may not have been representative of all view points, (although purposive sampling used to try to obtain a diverse sample) and may not be generalisable to other geographic areas.</p>
<p>Māori Ora Associates work (Māori Ora Associates 2009)</p> <ul style="list-style-type: none"> Aimed to understand the expectations, preferences and experience of Māori consumers in the health care system. They used a Kaupapa Māori approach and conducted a series of ten hui from which they developed and delivered a survey. 	<p>The hui found that some participants had experienced barriers to health care due to organisational processes, cost, racism from health providers and cultural differences. The survey found that overall satisfaction with care ranged from 48% for ACC services to 79% for GP services. Cluster analysis of attitude responses found that the younger group was less likely to agree they had been treated well or with respect.</p>	<p>No comparative group. Views of participants may not have been representative of all Māori.</p>
<p>How well do we monitor patient satisfaction? Problems with the nation-wide patient survey (Zwier 1999)</p> <ul style="list-style-type: none"> Aimed to assess the “accuracy and usefulness” of the nationwide patient satisfaction survey. A slightly modified nationwide patient survey was sent to 4007 South Auckland inpatients. Māori and Pacific non-responders were contacted by phone to assess for non-responder bias. 	<p>Response rate of 31.1%. NZ European twice as likely to respond than Māori and Pacific Islanders Pacific Islander respondents more positive than non-respondents. Māori respondents were less likely to be satisfied with courtesy from staff. Pacific Islander respondents were less likely to be satisfied with cultural and spiritual aspects.</p>	<p>Generalisability of findings limited by only assessing South Auckland inpatients. Potential for social desirability bias to have affected results from non-responders who were contacted by telephone.</p>

NZ patient experience research	Key findings	Key issues/limitations
<p>Patient satisfaction in New Zealand (Zwier 2009)</p> <ul style="list-style-type: none"> To determine whether New Zealand Patient Survey Guidelines are being adhered to and what can be learnt about patient satisfaction. Reviewed patient satisfaction surveys, (229,000 inpatient and 254,000 outpatient) from the 21 DHBs. 	<p>Response rates low (35%). Lack of representativeness of sample especially for young, Māori and Pacific Islanders. Survey questionnaire itself found to be reliable and valid on testing. Hospitals with more female, more non-European, younger patients tend to have lower satisfaction. 91% of outpatients in 2008–2009 were satisfied (improvement over 8 years).</p>	<p>Low response rates, especially for Māori and Pacific Islanders could have biased results.</p>

8.3 Appendix 3: Survey questions and dimensions

If a question is highlighted it indicates that it was one of the 41 questions graphically displayed in table form in the *Voice of Experience Part One* report. If a cell is blank under any one of the last three columns, it indicates that no specific dimension designation was assigned to that question.

65 of 96 questions from the 2009 Cancer Care Survey (i.e. those with a categorical ordinal response option structure)	NRC+Picker care dimension	Cancer Institute NSW / IPSOS-defined care dimension	CCNZ exploratory care dimension
Q4: Were you told of your diagnosis in a sensitive manner?	Emotional support	Emotional support	
Q5: When you were first told of your illness, did someone put you in touch with other health care professionals who could help you with anxieties and fears or issues?			
Q7: Did someone discuss different treatments for cancer with you?			Information sharing and shared decision-making at diagnosis
Q8: Did you understand the information you were given about the different treatment options?		Information and education	Information sharing and shared decision-making at diagnosis
Q9: Were you given enough information about cancer treatments?	Information and education	Information and education	Information sharing and shared decision-making at diagnosis
Q10: Was the information you were given about cancer treatment/its side-effects provided at the time that you needed it?		Information and education	Information sharing and shared decision-making at diagnosis
Q11: Were you involved in decisions about your care as much as you would have wanted?	Respect for patient preferences	Respect for patient preferences	Information sharing and shared decision-making at diagnosis
Q12: Did your doctors, nurses or other health care professionals take your family or living situation into account in planning for your treatment?			Information sharing and shared decision-making at diagnosis
Q13: Did your family or friends have enough opportunity to be involved in your care and treatment?	Respect for patient preferences	Family and friends	Information sharing and shared decision-making at diagnosis
Q14: Do you think the doctors, nurses or other health care professionals knew enough about therapies for treating cancer?			Information sharing and shared decision-making at diagnosis

65 of 96 questions from the 2009 Cancer Care Survey (i.e. those with a categorical ordinal response option structure)	NRC+Picker care dimension	Cancer Institute NSW / IPSOS-defined care dimension	CCNZ exploratory care dimension
Q15: If you had questions about clinical trials or new treatments for your cancer, did you feel comfortable talking to staff about them?	Information, education, communication	Emotional support	
Q16: Was your case reviewed by a number of specialists/health professionals consulting together (a multi-disciplinary team) before the final treatment plan was decided?		Coordination of care	
Q17: After you knew what your treatment was going to be, do you feel you had to wait too long to get your first treatment appointment?	Access to care	Access to care	
Q18: If you had to wait for your first appointment for treatment, did someone explain why?	Information, education, communication	Access to care	
Q19: If you had to travel for any tests or treatments did your doctors nurses or other staff consider your travel concerns when planning for your treatment?		Access to care	
Q20: Did the doctors, nurses, or other health care professionals explain why you needed tests in a way you could understand?			
Q21: After the tests were done, did someone explain the results in a way that you could understand?	Information, education, communication		
Q24: Were you given enough information about how long you would have to wait until the day of your surgery?	Surgery-specific	Information and education	
Q25: Were the results of your surgery explained in a way you could understand?	Surgery-specific	Information and education	
Q29: How long did you usually have to wait from your scheduled appointment until your chemotherapy treatment?	Access to care		
Q30: How often did you wait longer than expected for your chemotherapy treatment?	Access to care	Access to care	

65 of 96 questions from the 2009 Cancer Care Survey (i.e. those with a categorical ordinal response option structure)	NRC+Picker care dimension	Cancer Institute NSW / IPSOS-defined care dimension	CCNZ exploratory care dimension
Q31: If you had to wait for your chemotherapy, do you think the staff did everything they could to make you feel comfortable?	Access to care	Physical comfort	
Q32: Did someone tell you how to manage any side effects of chemotherapy?	Physical comfort	Information and education	
Q33: Do you think the staff did everything they could to help you with chemotherapy side effects?	Physical comfort	Coordination of care	
Q36: How long did you usually have to wait from your scheduled appointment until your radiation treatment?	Access to care		
Q37: How often did you wait longer than expected for your radiation treatment?	Access to care	Access to care	
Q38: If you had to wait for your radiation treatment, do you think the staff did everything they could to make you feel comfortable?	Access to care	Physical comfort	
Q39: Did someone tell you how to manage any side effects of radiation therapy?	Physical comfort	Information and education	
Q40: Do you think the staff did everything they could to help you with your radiation therapy side effects?	Physical comfort	Information and education	
Q42: Do you think the staff did everything they could to control your pain and discomfort?	Physical comfort	Physical comfort	
Q43: Did you get enough information about possible changes in your physical appearance?	Information, education, communication	Information and education	Information provided during/after treatment
Q44: Did you get enough information about possible changes in your emotions?	Emotional support	Information and education	Information provided during/after treatment
Q45: Did you get enough information about possible changes about your nutritional needs?	Information, education, communication	Information and education	Information provided during/after treatment
Q46: Did you get enough information about possible impact on your capacity to do work or do your usual activities?	Emotional support	Information and education	Information provided during/after treatment

65 of 96 questions from the 2009 Cancer Care Survey (i.e. those with a categorical ordinal response option structure)	NRC+Picker care dimension	Cancer Institute NSW / IPSOS-defined care dimension	CCNZ exploratory care dimension
Q47: Did you get enough information about possible changes in your energy levels?	Information, education, communication	Information and education	Information provided during/after treatment
Q48: Were you offered counselling or support relating to issues such as concerns about cancer or coping at home/work?		Emotional support	Information provided during/after treatment
Q49: Did you get enough information about possible changes in your relationship with your spouse or partner?		Information and education	Information provided during/after treatment
Q50: Did you get enough information about possible changes in your sexual activity?	Emotional support	Information and education	Information provided during/after treatment
Q52: Did you feel comfortable talking with the staff about complementary, alternative, or non-traditional therapies?	Respect for patient preferences	Information and education	
Q55: Did you know who was in charge of your care for each of your therapies?	Coordination and continuity	Information and education	Trust in health care professionals
Q56: How well handled was the transfer of your case between specialist groups (care coordination)?		Coordination of care	
Q57: In the past 12 months, after initial diagnosis, has someone at this hospital or clinic put you in touch with other doctors, nurses, or other health care professionals who could help you with anxieties and fears?			Information provided during/after treatment
Q58: How often were the doctors, nurses or other health care professionals familiar with your medical history?		Coordination of care	Trust in health care professionals
Q59: How often were the doctors, nurses, or other health care professionals aware of the test results?		Coordination of care	Trust in health care professionals
Q60: How often were you given confusing or contradictory information about your health or treatment?	Coordination and continuity	Coordination of care	Trust in health care professionals
Q61: How often did you know who to ask when you had questions about your health problems?	Coordination and continuity	Emotional support	Trust in health care professionals

65 of 96 questions from the 2009 Cancer Care Survey (i.e. those with a categorical ordinal response option structure)	NRC+Picker care dimension	Cancer Institute NSW / IPSOS-defined care dimension	CCNZ exploratory care dimension
Q62: How often did you know what the next step in your care would be?	Coordination and continuity	Information and education	Trust in health care professionals
Q63: Did you feel you could trust the doctors, nurses, or other health care professionals with confidential information?		Respect for patient preferences	Trust in health care professionals
Q64: Did the doctors, nurses or other health care professionals treat you with dignity and respect?	Respect for patient preferences	Respect for patient preferences	Trust in health care professionals
Q65: Did you get as much help as you wanted in figuring out how to pay for any extra costs for your cancer care?	Emotional support	Emotional support	
Q66: Did a doctor, nurse or other health care professional go out of his or her way to help you or make you feel better?		Emotional support	Trust in health care professionals
Q67: If you had a visit with your family doctor in the past 12 months, did you feel your family doctor knew enough about your cancer care?		Coordination of care	
Q68: Did you feel that the doctors, nurses and other health care professionals at this hospital or clinic did everything they could to treat your cancer?			Trust in health care professionals
Q69: Overall, how would you rate the quality of care at this hospital or clinic over the past 12 months?			Trust in health care professionals
Q70: Would you recommend the doctors, nurses, and other health care professionals at this hospital or clinic to your family and friends?			Trust in health care professionals
Q71: Do you feel you had enough privacy during your care?			
Q72: In the past 12 months, did you receive all of the services you thought you needed for your cancer treatment?	Access to care		
Q73: Overall, how would you rate the quality of all of your care in the past 12 months?		Respect for patient preferences	Facilities and amenities

65 of 96 questions from the 2009 Cancer Care Survey (i.e. those with a categorical ordinal response option structure)	NRC+Picker care dimension	Cancer Institute NSW / IPSOS-defined care dimension	CCNZ exploratory care dimension
Q74: Were you given as much information as you wanted about your rights and responsibilities as a patient?		Respect for patient preferences	
Q75: Using any number from 0 to 10, where 0 is the worst hospital or clinic possible and 10 is the best hospital or clinic possible, what number would you use to rate this hospital or clinic?			Facilities and amenities
Q76: Would you recommend this hospital or clinic to your friends and family?			
Q77: Ease of understanding directions and signs inside and outside this hospital or clinic?		Facilities and amenities	Facilities and amenities
Q78: Availability of parking?		Facilities and amenities	Facilities and amenities
Q79: Keeping noise levels to a minimum?		Facilities and amenities	Facilities and amenities
Q80: Was the department or clinic as clean as it should have been?		Facilities and amenities	Facilities and amenities
Q81_8: All areas were clean?		Facilities and amenities	Facilities and amenities

8.4 Appendix 4:

Table 11: Unadjusted mean dimension scores for ethnicity, age, gender, income and centre

Variables	Emotional support	Access	Coordination	Information	Family and friends	Physical comfort	Patient preferences	Facilities
All observations	0.78 (0.20)	0.83 (0.18)	0.84 (0.15)	0.79 (0.19)	0.81 (0.28)	0.88 (0.20)	0.91 (0.13)	0.78 (0.21)
Ethnicity								
Māori	0.80 (0.19)	0.84 (0.16)	0.85 (0.15)	0.80 (0.19)	0.83 (0.27)	0.91 (0.17)	0.91 (0.14)	0.78 (0.23)
NZ European	0.79 (0.20)	0.83 (0.18)	0.84 (0.15)	0.79 (0.19)	0.81 (0.28)	0.88 (0.20)	0.91 (0.13)	0.78 (0.21)
Age								
<40yrs	0.75 (0.21)	0.80 (0.19)	0.80 (0.17)	0.75 (0.19)	0.84 (0.24)	0.86 (0.21)	0.86 (0.16)	0.74 (0.23)
40–49yrs	0.74 (0.20)	0.80 (0.18)	0.81 (0.15)	0.76 (0.18)	0.79 (0.27)	0.85 (0.21)	0.88 (0.16)	0.75 (0.20)
50–59yrs	0.77 (0.20)	0.82 (0.18)	0.83 (0.15)	0.78 (0.18)	0.82 (0.26)	0.88 (0.20)	0.90 (0.13)	0.79 (0.19)
60–69yrs	0.79 (0.20)	0.84 (0.18)	0.85 (0.15)	0.79 (0.20)	0.80 (0.30)	0.89 (0.21)	0.91 (0.12)	0.79 (0.20)
70–79yrs	0.81 (0.19)	0.83 (0.18)	0.86 (0.14)	0.81 (0.18)	0.81 (0.28)	0.89 (0.19)	0.92 (0.12)	0.79 (0.22)
>80yrs	0.81 (0.19)	0.82 (0.18)	0.86 (0.14)	0.78 (0.21)	0.79 (0.30)	0.92 (0.14)	0.91 (0.12)	0.79 (0.24)
Gender								
Male	0.78 (0.20)	0.83 (0.18)	0.84 (0.16)	0.79 (0.19)	0.78 (0.30)	0.89 (0.19)	0.91 (0.13)	0.77 (0.22)
Female	0.78 (0.19)	0.83 (0.18)	0.84 (0.15)	0.79 (0.18)	0.82 (0.26)	0.88 (0.20)	0.91 (0.13)	0.79 (0.20)
Household annual income after tax								

Low	0.80 (0.19)	0.84 (0.17)	0.85 (0.14)	0.79 (0.19)	0.79 (0.29)	0.89 (0.19)	0.91 (0.12)	0.79 (0.20)
<=\$30,000	0.78 (0.21)	0.81 (0.19)	0.84 (0.15)	0.79 (0.19)	0.81 (0.27)	0.89 (0.19)	0.91 (0.14)	0.79 (0.20)
Medium	0.77 (0.19)	0.83 (0.17)	0.83 (0.15)	0.78 (0.18)	0.82 (0.26)	0.86 (0.21)	0.90 (0.13)	0.78 (0.20)
\$30,001–60,000	0.77 (0.19)	0.83 (0.17)	0.83 (0.15)	0.78 (0.18)	0.82 (0.26)	0.86 (0.21)	0.90 (0.13)	0.78 (0.20)
High	0.77 (0.19)	0.83 (0.17)	0.83 (0.15)	0.78 (0.18)	0.82 (0.26)	0.86 (0.21)	0.90 (0.13)	0.78 (0.20)
>\$60,000	0.77 (0.19)	0.83 (0.17)	0.83 (0.15)	0.78 (0.18)	0.82 (0.26)	0.86 (0.21)	0.90 (0.13)	0.78 (0.20)
Cancer treatment service								
Northern Region Cancer Centre	0.76 (0.21)	0.80 (0.18)	0.83 (0.15)	0.78 (0.18)	0.79 (0.29)	0.87 (0.20)	0.90 (0.13)	0.74 (0.21)
Tauranga & Whakatane Cancer Centres	0.76 (0.20)	0.82 (0.21)	0.83 (0.16)	0.75 (0.20)	0.79 (0.27)	0.87 (0.22)	0.89 (0.14)	0.74 (0.23)
Canterbury Oncology Service	0.79 (0.19)	0.81 (0.18)	0.85 (0.13)	0.80 (0.18)	0.81 (0.26)	0.87 (0.21)	0.91 (0.12)	0.76 (0.19)
Wellington Blood & Cancer Centre	0.78 (0.19)	0.84 (0.17)	0.84 (0.15)	0.80 (0.19)	0.81 (0.28)	0.88 (0.19)	0.90 (0.14)	0.84 (0.20)
Southern Blood & Cancer Service	0.79 (0.20)	0.83 (0.21)	0.83 (0.14)	0.79 (0.19)	0.78 (0.32)	0.87 (0.26)	0.92 (0.12)	0.80 (0.19)
Palmerston Nth Regional Cancer Treatment Service	0.80 (0.19)	0.85 (0.17)	0.84 (0.15)	0.80 (0.19)	0.83 (0.28)	0.89 (0.19)	0.92 (0.13)	0.80 (0.21)
Nelson Oncology Service	0.81 (0.16)	0.91 (0.14)	0.87 (0.10)	0.81 (0.14)	0.89 (0.20)	0.93 (0.15)	0.93 (0.08)	0.78 (0.15)
Waikato Regional Cancer Centre	0.79 (0.21)	0.83 (0.17)	0.84 (0.17)	0.79 (0.20)	0.80 (0.29)	0.91 (0.17)	0.90 (0.15)	0.80 (0.23)
Missing	2	11	3	2	37	363	3	0
Observations	2219	2210	2218	2219	2184	1858	2218	2221

8.5 Appendix 5: Acknowledgements

Project funding provided by Cancer Control New Zealand and The New Zealand Population Health Charitable Trust.

Survey advice generously given by The 2009 Cancer Care Survey Advisory Group: Dr Diana Sarfati, Associate Professor Barry Borman, Professor Neil Pearce, Professor Tony Blakely, Dr Andrew Simpson, Ms Astrid Koorneef and Dr Lis Ellison-Loschmann.

Statistical advice provided by Mr Robert Templeton and Mr Roy Costilla from the Ministry of Health and Dalice Sim of Victoria University.

Report contributions made by Cancer Control New Zealand and Palliative Care New Zealand staff: Inga O'Brien, Dr Emma Britton, Wayne Naylor, Craig Tamblyn, Dr Mary Clare Tracey, Scott Trainor and Vanessa Thomas-Holding.

Peer review provided by Dr Diana Sarfati, Dr Andrew Simpson, Craig Tamblyn, Anna Hughes, Mr Robert Templeton, Nadine Hackl, Rachael Hadwen, Dr John Waldon, Dr Kate Grundy and Shelley Campbell.

It is with much gratitude that we acknowledge the willingness of people affected by cancer to share their views and experiences of health services they received.



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