## RESEARCH ARTICLE

# Cancer Mortality, Early Detection and Treatment among Adult New Zealanders: Changes in Perceptions between 2001 and 2014/5

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## Abstract

**Background:** Beliefs about cancer risk and experience of early detection and treatment can impact on willingness to engage with these initiatives. This study describes changes in perceptions of cancer mortality, early detection and treatment among adult New Zealanders (NZ) between two cross-sectional studies conducted in 2001 and 2014/5. **Methods:** Data was collected via telephone interviews conducted by trained interviewers in 2001 (231 females and 207 males, 64% response rate) and 2014/5 (588 females and 476 males, 64% response rate). Participants were asked to identify the most common three causes of cancer mortality among women and then men. They were also asked to note their agreement or otherwise with statements about early detection and treatment of cancer. **Results:** There was an increase in proportions of men who correctly identified prostate cancer as one of the top three causes of cancer mortality among men, and also an increase among women who correctly identified bowel cancer as one of the top three. Most participants agreed that there were benefits from early detection for cancer outcomes. Over time, there was a significant decline in proportions which felt that most cancer treatment is "so terrible it is worse than death" and that alternative therapy has an "equal or better chance of curing cancer." **Conclusion:** Internationally, there is little information available about changes in cancer perceptions over time, these findings suggest some changes in perceptions of treatment and awareness of types of cancer with the highest mortality in NZ, which should support timely engagement with early detection and treatment services.

**Keywords:** Cancer- perception- early detection of cancer- early diagnosis- cross-sectional studies

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## Introduction

Cancer research encompasses a multi-billion dollar global network of teams working across a variety of scientific domains (Eckhouse et al., 2008). This investment has resulted in rapid evolutions in cancer detection and treatment and contributed to international declines in cancer mortality (Foreman et al., 2014). In light of the advanced cancer care now available in developed countries, there is an imperative to limit all unavoidable delays in engaging with these services so that the benefits of early detection and timely access to treatment can be fully realised (Etzioni et al., 2003; Ministry of Health, 2014; Neal et al., 2015).

Beliefs related to the cancer experience can play an important role in engagement with health services. These may include; perceived susceptibility to cancer; perceived barriers to carrying out behaviours (such as reducing risk

behaviours, participation in screening or seeking help for symptoms); and the perceived benefits of these actions (Wardle et al., 2000; Moser et al., 2007). Perceived susceptibility refers to an individual's perceptions about their risk of developing cancer (Austin et al., 2002), and has been shown to be associated with engagement with cancer screening (Lipkus et al., 2000; Katapodi et al., 2004; Moser et al., 2007). In terms of perceived benefits and barriers to cancer-related behaviours (such as screening and treatment), public attitudes to early detection and screening tend to be positive and associated with higher participation (Wardle et al., 2015). There is conflicting evidence, however, about the influence of fear or worry about cancer, which has been found to be both a motivator and a barrier to help-seeking behaviour (Dubayova et al., 2010; Vrinten et al., 2015; Vrinten et al., 2016). In the case of cancer treatment, fears about disfiguration, disability or financial burdens may delay presentation

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to health care services (Arndt et al., 2002; Meechan et al., 2003; Burgess et al., 2006). Beliefs about treatment efficacy are also important, since patient engagement with alternative therapy (defined here as therapies used instead of evidence-based cancer treatment (Trevena and Reeder, 2005)) may delay diagnosis and treatment and, in turn, negatively impact on cancer outcomes (Malik and Gopalan, 2003; Han et al., 2011).

There are few studies which describe changes in beliefs regarding cancer susceptibility, early detection and treatment over time (Carelle et al., 2002). As these beliefs may support or undermine timely access to cancer services, it is important to understand whether or not public perceptions of the effectiveness of early detection and treatment have kept up with advances in cancer care. The aim of this study is to describe perceptions of cancer mortality, early detection and treatment among adult New Zealanders in 2014/5 and identify changes in patterns of perceptions since 2001, using data from the Cancer Awareness in Aotearoa New Zealand (CAANZ) study.

### **Materials and Methods**

This study uses cross-sectional data from two cohorts and a summary of methods is provided below, with specific detail about study procedures, sample demographics, representativeness and comparability published elsewhere (Reeder and Trevena, 2003; Trevena and Reeder, 2007; Richards, 2016). Ethical approval for CAANZ01 and CAANZ15 was obtained from the University of Otago: Ethics Committee (Reference number 00/03/10) and the Department of Preventive and Social Medicine Ethics Committee (Reference number: D14/369) respectively. Informed consent was obtained from all individual participants included in the study.

## Participants

The first cohort consisted of 438 New Zealand (NZ) adults (231 females and 207 males, 64% response rate) aged 18 and over, sampled between August and September 2001, and described hereafter as CAANZ01 (Reeder and Trevena, 2003; Trevena and Reeder, 2007). This sample was selected using random digit telephone dialling, public directories and sample quotas set to reflect the age, sex and ethnicity of the general population. A booster sample of Māori (the indigenous population of NZ) was also drawn from the electoral rolls to support sample representativeness. For the second cohort (CAANZ15), 1064 individuals (588 females and 476 males, 64% response rate), were interviewed between November 2014 and March 2015 (Richards, 2016). This sample was randomly selected entirely from the electoral rolls, and telephone numbers traced from this information. As with the previous survey, a booster sample of Māori respondents was also drawn from electoral rolls.

Compared to the general adult population of NZ at the time of data collection, these cohorts had higher socioeconomic status (as reflected by occupation (CAANZ15) and education (CAANZ01)), were under-representative of Pacific and Asian ethnicities, and to a lesser degree, those of Māori ethnicity (Richards,

2016). The CAANZ15 sample also had a larger proportion of older participants than both the general NZ population and CAANZ01 (Reeder and Trevena, 2003; Trevena and Reeder, 2007; Richards, 2016). To help address sampling issues and facilitate comparison between cohorts, weighting and standardisation of the cohorts were carried out, as described further in the analysis section.

#### **Procedures**

Data was collected via telephone administered interviews, taking an average of 20 minutes, and conducted by trained interviewers. In the case of CAANZ01, interviewers made direct contact with participants over the telephone, for CAANZ15, participants were sent an introductory letter and information about the study prior to this first telephone call.

#### Measures

Both cohorts were asked a series of identical questions about mortality, early detection and treatment. First, respondents were asked to identify 'which three cancers do you think cause the most deaths among New Zealand women?' and 'which three cancers do you think cause the most deaths among New Zealand men?'. Second, participants were asked to indicate if they agreed, disagreed or were not sure in relation to the following statements, 'overall survival time is much better when cancer is identified and treated early, than when it is not identified and treated until later,' 'even with early detection there is not much chance of curing cancer,' 'most cancer treatment is so terrible it is worse than death,' 'alternative therapy for cancer has an equal or better chance of curing cancer as medical treatment'.

#### Analyses

Full details of the data analysis are provided elsewhere (Richards, 2016), in summary, survey data were weighted to adjust for poststratification of the sample population relative to the age group (18-29 (20-29 in CAANZ01), 30-49, 50-69, and 70+ years) nested within Māori/ non-Māori ethnicity distribution of the NZ population (according to 2013 NZ census data) (Statistics New Zealand, 2015). Statistical analyses were performed in Stata using the survey commands to accommodate the survey design (StataCorp, 2013). As the survey data were weighted, maximum pseudolikelihood was used to obtain the proportion estimates and Taylor linearization to compute the appropriate standard errors. The test for a difference in proportions was used to assess both intra-year sex differences and differences between cohorts. The two-sided significance level  $\alpha$ = 0.05 was specified for all statistical tests.

#### **Results**

In 2014/5, while most respondents were aware that prostate cancer (81.3%) was one of the top three causes of cancer mortality among NZ males (Table 1), only around half were aware that this was also the case for lung (53.7%) and bowel cancer (51.8%). Males were more likely than females to identify lung cancer as being in the

Table 1. Awareness of Leading Causes of Cancer Mortality among Adult New Zealanders in 2001 and 2014/5

		2001*	2015				Overall year Difference		
	male	female	total	male	female	total	Sex Difference	Difference	p
Men									
Correct responses									
Prostate	69.1	-	-	80.4	82.1	81.3	1.7 (-4.1, 7.5)	-11.3 (-19.0, -3.6)	0.004
Lung	59.5	-	-	58.6	49.8	53.7	-8.7 (-15.8, -1.7)	0.9 (-7.7, 9.5)	0.835
Bowel	40.5	-	-	47.1	55.5	51.8	8.4 (1.3, 15.5)	-6.5 (-15.1, 2.0)	0.134
Other responses**									
Melanoma	17.5	-	-	16.8	14.1	15.3	-2.6 (-7.7, 2.4)	0.7 (-5.9, 7.3)	0.842
Leukaemia	14.5	-	-	1.7	1.1	1.4	-0.6 (-2.7, 1.5)	12.8 (4.1, 21.4)	0.004
Non melanoma skin cancer	14.5	-	-	20.1	19.3	19.6	-0.8 (-6.8, 5.3)	-5.6 (-12.3, 1.2)	0.104
Liver	13	-	-	5	8.4	6.9	3.4 (0.0, 6.8)	8.0 (-0.4, 16.4)	0.061
Testicular	11.8	-	-	7.9	4.4	5.9	-3.5 (-7.4, 0.4)	3.9 (-4.6, 12.3)	0.369
Don't know	8.1	-	-	3.7	4.4	4.1	0.7 (-2.4, 3.8)	4.3 (0.0, 8.6)	0.048
Women									
Correct responses									
Breast	-	92.9	-	93.6	92.9	93.2	-0.7 (-4.2, 2.7)	0.0 (-4.2, 4.2)	0.99
Lung	-	33.8	-	30.5	26.8	28.4	-3.7 (-10.0, 2.6)	7.1 (-0.5, 14.6)	0.067
Bowel	-	17.1	-	20.3	37.6	30	17.3 (11.3, 23.3)	-20.6 (-27.2, -13.9)	< 0.001
Other responses**									
Cervical	-	56.8	-	42.8	45	44	2.2 (-4.9, 9.2)	11.9 (3.8, 19.9)	0.004
Ovarian	-	9.6	-	10	15.2	12.9	5.3 (1.0, 9.6)	-5.7 (-10.6, -0.7)	0.025
Melanoma	-	9.6	-	13.9	15.5	14.8	1.6 (-3.5, 6.6)	-5.9 (-11.0, -0.8)	0.023
Non melanoma skin cancer	-	6.1	-	20.6	18.6	19.5	-2.0 (-8.2, 4.2)	-12.5 (-17.6, -7.4)	< 0.00
Don't know	-	2.9	-	3.8	3.7	3.8	-0.0 (-2.8, 2.7)	-0.8 (-3.8, 2.1)	0.58

Note: Differences presented in bold are statistically significant (p < 0.05); \* Differences between 2001 and 2014/5 were sex-specific comparisons \*\*all those over 5% for either males or females in 2001 or 2014/5

top three, while females were more likely than males to identify bowel cancer. Between 2001 and 2014/5 there was a statistically significant increase (69.1% to 80.4%) in the proportion of males who correctly identified prostate cancer as one of these top three. Other cancer types which were also relatively frequently (but incorrectly) suggested as being in the top three causes of mortality for NZ men were non-melanoma skin cancer (19.6%) and melanoma (15.3%).

In 2014/5, most respondents (93.2%) correctly

Table 2: Perceptions About Early Detection and Treatment of Cancer Among Adult New Zealanders in 2001 and 2014/5

		2001*				2015			Overall year Difference	
	male	female	total	Sex Difference	male	female	total	Sex Difference	Difference	p
Overall survival time	e is much be	tter when c	ancer is ic	lentified and treated	early					
Agree	96.4	95.4	95.8	-1.0 (-4.7, 2.7)	96.4	95.8	96	-0.6 (-3.2, 2.0)	0.2 (-2.1, 2.5)	0.873
Disagree	1.7	0.8	1.2	-1.0 (-3.0, 1.1)	1.2	1.5	1.4	0.3 (-1.4, 2.0)	0.2 (-1.1, 1.5)	0.816
Not sure	1.9	3.9	2.9	2.0 (-1.1, 5.1)	2.4	2.7	2.6	0.3 (-1.6, 2.3)	-0.3 (-2.2, 1.5)	0.723
Even with early dete	ction there i	s not much	chance of	curing cancer						
Agree	14.7	9.3	11.8	-5.4 (-11.6, 0.8)	11.3	10.6	10.9	-0.7 (-5.1, 3.7)	-0.9 (-4.6, 2.9)	0.652
Disagree	77	80.7	79	3.6 (-4.2, 11.5)	74.6	78.6	76.9	4.1 (-2.0, 10.1)	-2.1 (-7.0, 2.8)	0.397
Not sure	8.3	10	9.2	1.7 (-3.8, 7.3)	14.1	10.7	12.2	-3.4 (-8.2, 1.5)	3.0 (-0.7, 6.6)	0.11
Most cancer treatme	nt is so terri	ble, it is wo	rse than d	eath						
Agree	25.5	18.7	21.9	-6.8 (-14.9, 1.4)	19.4	13.5	16.1	-5.9 (-11.1, -0.7)	-5.8 (-10.5, -1.0)	0.018
Disagree	56.5	55.6	56	-0.8 (-10.4, 8.8)	60	64.1	62.3	4.1 (-2.8, 11.0)	6.2 (0.4, 12.1)	0.038
Not sure	18	25.6	22.1	7.6 (-0.3, 15.5)	20.6	22.4	21.6	1.8 (-4.0, 7.6)	-0.5 (-5.4, 4.5)	0.854
Alternative therapy i	for cancer ha	s equal or l	oetter chai	nce of curing cancer						
Agree	25.9	30.3	28.2	4.4 (-4.3, 13.1)	17.1	16.7	16.9	-0.3 (-5.7, 5.0)	-11.3 (-16.4, -6.2)	< 0.001
Disagree	37.9	30.5	34	-7.4 (-16.5, 1.7)	50.3	49.3	49.8	-1.0 (-8.1, 6.1)	15.8 (10.0, 21.5)	< 0.001
Not sure	36.2	39.2	37.8	3.0 (-6.3, 12.3)	32.6	33.9	33.4	1.3 (-5.4, 8.0)	-4.4 (-10.2, 1.3)	0.128

Differences presented in bold are statistically significant (p < 0.05)

identified breast cancer as one of the top three causes of cancer mortality among NZ women. Proportions were much lower for the other two correct responses, lung cancer (28.4%) and bowel cancer (30.0%), with women more likely than men to correctly identify bowel cancer (37.6% and 20.3% respectively). Between 2001 and 2014/5 there was a statistically significant increase in the proportion of women who correctly identified bowel cancer, from 17.1% to 30.0%. Other cancer types that were also (incorrectly) suggested by respondents in 2014/5 included cervical (44.0%), non-melanoma skin cancer (19.5%) and melanoma (14.8%).

As shown in Table 2, agreement that "overall survival time is much better when cancer is identified and treated early, than when it is not identified and treated until later" remained very high across both survey years (95.8% and 96.0% respectively). For the second early detection question, high proportions of participants at both time-points disagreed that "even with early detection there is not much chance of curing cancer" (79.0% and 76.9% respectively).

In 2014/5, most respondents (62.3%) disagreed with the statement that "most cancer treatment is so terrible, it is worse than death". This was a statistically significantly increase (from 56.0%) since 2001. While no statistically significant sex differences were observed for disagreement in 2014/5, males from this cohort were more likely than females to agree with the statement (19.4% and 13.5% respectively), a sex difference which was not observed in the earlier survey. Finally, in 2014/5 around half of respondents disagreed with the statement that "alternative therapy has an equal or better chance of curing cancer". This was a statistically increase in proportion since 2001 (34.0%).

## Discussion

Internationally, there is little information available about changes in cancer perceptions and awareness over time (Richards, 2017). Our study observed several positive changes in perceptions over the 14-year period, including increases in men correctly identifying prostate cancer as a leading cause of male mortality and women identifying bowel cancer as a leading cause of cancer mortality for women. There were also significant drops in agreement that most cancer treatment is "so terrible it is worse than death" and that alternative therapy has an "equal or better chance of curing cancer." As the current study was not designed to evaluate any specific intervention, it is not possible to pinpoint specific reasons for the observed changes. Since the first survey in 2001, however, national awareness campaigns have been established for both prostate (Blue September) and bowel cancers (Bowel Cancer New Zealand). A regional pilot bowel cancer screening programme has been implemented and a national programme developed (Ministry of Health). All of these factors are likely to have contributed to raising awareness.

Although the changes described here point in a promising direction, there are aspects of the observed risk perceptions and beliefs within the 2014/5 survey that

still give cause for concern. Awareness of the mortality burden of lung and bowel cancer in NZ continues to be low, in particular lung cancer among women and bowel cancer among men. Lifting awareness of these risks may support engagement with early help-seeking behaviours for these cancers, however, given that fear of cancer can act as both a barrier and facilitator for help-seeking behaviour (Dubayova et al., 2010; Vrinten et al., 2015; Vrinten et al., 2016) any interventions would need to be carefully developed and evaluated.

An unusual finding within this study was that relatively high proportions identified non-melanoma skin cancer as a leading cause of cancer mortality. Although non-melanoma skin cancer has high prevalence in New Zealand, the case:fatality ratio is relatively low. Potentially, messages about the high prevalence of non-melanoma (and melanoma) skin cancer in NZ have been mistaken for messages about high mortality. Nevertheless, there were 133 deaths from NMSC and 356 from melanoma in NZ in 2013, but only 54 from cancer of the cervix, for example (Ministry of Health, 2016). Furthermore, melanoma was the 4th most common cause of cancer death for men and most cases are considered potentially preventable. All of this is useful information to support clarity in refining cancer messaging.

Consistent with other studies (Wardle et al., 2015), most respondents agreed that early detection was beneficial for cancer outcomes. While this is likely a positive finding in terms of facilitating timely help-seeking and participation in screening, it is worth noting that early detection is complex, with issues such as lead-time bias and over-diagnosis meaning its impact is not always entirely positive (Grimes, 2002).

Perceptions about cancer treatments were more problematic. Over a third of respondents either 'agreed' that, or were 'not sure' if, cancer treatment is so "terrible it is worse than death". While this had declined since the earlier survey, it remains a concern as fears about cancer treatment may delay presentation to health care (Arndt et al., 2002; Meechan et al., 2003; Burgess et al., 2006). In addition, around half of respondents 'agreed' with, or were 'not sure' if, alternative therapy has an "equal or better chance of curing cancer". While complementary therapies are commonly used alongside conventional cancer treatment (Trevena and Reeder, 2005; Bocock et al., 2011; Horneber et al., 2011), there is potential for alternative therapies to delay engagement with evidence based treatment (Malik and Gopalan, 2003; Han et al., 2011). Communicating evidence-based cancer information to patients and their families can be a challenge in an internet and social media environment that provides large amounts of information of variable quality. Treatment providers are actively seeking better ways to communicate the effectiveness of treatment options and the progress that has been made in reducing side-effects, in order to break down barriers to engagement (Radiation oncology; Carelle et al., 2002).

A strength of this study was its ability to describe changes in beliefs about cancer risk, early detection and treatment over time and the potential to make comparisons with experiences outside NZ. A degree of caution is required in interpreting changes, given differences in data collection procedures between the two studies, in particular, the use of random-digit dialling in CAANZ01 compared with listed landlines based on electoral roll data in CAANZ15. The change in approach was due to observations of low response rates achieved via 'cold calling' random digit dialing prior to the latter study (Richards, 2016). It was decided, on balance, that the use of non-identical sampling methods was better than a low response rate with inadequate representation of the population. A second limitation was that the study samples were under-representative of Māori, Pacific and Asian populations, which prevented analysis by ethnicity. Research to support the development of prevention, early detection and treatment services that meet the needs of these communities is a priority if government goals to reduce cancer inequities are to be realised (Ministry of Health, 2014). Another potential limitation was that the term 'alternative' therapy was not clearly defined to respondents, and therefore could have been interpreted in different ways.

One of the key targets of the NZ National Cancer Programme is to minimise delays in accessing cancer treatment (Ministry of Health, 2014). To achieve this goal it is important to understand population perceptions of susceptibility, benefits and barriers to action and how these may support early help-seeking for suspected symptoms and engagement with recommended screening and treatment. This study suggests there has been some positive changes in perceptions of treatment and awareness of types of cancer with the highest mortality. This was, however, within the context of relatively low awareness of the burden that bowel and lung cancer places on NZ communities and a need for effective communication about the experience and benefits of evidence-based cancer prevention and treatment.

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## Statement of conflict of interest

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