

APPENDICES

APPENDIX 1: Paper 1



Research report

Flourishing or floundering? Prevalence and correlates of anxiety and depression among a population-based sample of adult cancer survivors 6 months after diagnosis

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ABSTRACT

Objective: To describe the prevalence of anxiety, depression and comorbid anxiety–depression among adult cancer survivors six months following diagnosis, and identify the individual, disease, health behaviour, psychological and social factors associated with psychological morbidity.

Methods: A population-based sample of adult cancer survivors was recruited from two state-based cancer registries in Australia. Data for 1323 survivors were obtained by self-report questionnaire and linkage with registry data. Anxiety and depression were assessed by the 14-item Hospital Anxiety and Depression Scale (HADS).

Results: The prevalence of psychological morbidity was 28% (95% CI: 23%–33%). Specifically, 24% (95% CI: 19%–29%) of survivors were identified as cases on anxiety (irrespective of depression), 14% (95% CI: 9%–19%) as cases on depression (irrespective of anxiety) and 10% (95% CI: 5%–15%) as cases on comorbid anxiety–depression. In addition to mental health history prior to cancer, modifiable health behaviours (physical activity, smoking status), psychological (helplessness–hopelessness, anxious preoccupation coping) and social (low positive social interaction) characteristics were stronger indicators of psychological morbidity than survivors' individual or disease characteristics.

Limitations: Psychological morbidity was assessed by self-report screening instrument rather than clinical interview. The extent to which psychological morbidity is age-related versus cancer-related cannot be determined without a gender- and age-matched control group.

Conclusion: Although lower than previously reported, psychological morbidity is prevalent six months after a cancer diagnosis and emphasises the need for routine psychosocial assessment throughout the cancer trajectory to identify those at increased risk or in need of immediate intervention. Physical activity, smoking cessation and coping skills training interventions warrant further exploration.

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1. Introduction

A cancer diagnosis is a life-changing experience that affects 1 in 5 men and 1 in 6 women before the age of 75 years

(Ferlay et al., 2008). While cancer incidence is projected to almost double over the next two decades to 21.4 million new cases annually, the number of people living with a history of cancer (i.e. 'survivors') is expected to triple to 75 million worldwide by 2030 (Ferlay et al., 2008). This increasing global cancer burden has been described as a public health crisis (Boyle and Levin, 2008). Compared to the earlier phases of the cancer continuum, relatively little is known about the nature and extent of the impact of cancer on survivors, or

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how best to deliver care that optimises their health and well-being. With their need for care typically spanning many years, the growing population of cancer survivors has recently become the focus of researchers, clinicians and policy-makers (Hewitt et al., 2006; President's Cancer Panel, 2004).

The psychological effects of cancer range from common normal feelings of uncertainty about the future and fear of cancer recurrence (Deimling et al., 2006; Hodgkinson et al., 2007) to clinically significant anxiety and/or depression (Burgess et al., 2005) and post-traumatic stress disorder (Kangas et al., 2005). Psychological morbidity among those affected by cancer is an important clinical issue because of its association with poorer quality of life across multiple domains (Skarstein et al., 2000), more intense physical symptoms, increased functional impairment and poor treatment adherence (Fann et al., 2008). Further, some evidence suggests that there may be a relationship between psychological distress and cancer progression (Antoni et al., 2006); and reduced overall survival (Groenvold et al., 2007), however this remains a contentious issue. Many approaches have been utilised to identify cancer survivors experiencing psychological morbidity and there is a range of effective pharmacological and psychological interventions to manage such morbidity (Fann et al., 2008; Jacobsen and Jim, 2008; Osborn et al., 2006; Stark and House, 2000; Williams and Dale, 2006).

Estimates of the prevalence of anxiety and depression among cancer survivors vary widely (Van't Spijker et al., 1997), largely as a result of different measurement techniques, different criteria to define anxiety and depression, and different study populations, making it difficult to compare between studies. It is generally agreed that anxiety and depression are highest at the time of diagnosis and decrease over time with levels of anxiety and depression typically returning to a level comparable to the general population around two years post-diagnosis (DiSipio et al., 2008; Mehnert et al., 2010). The transition from patient to survivor is often experienced as stressful as contact with the cancer care team decreases in frequency and the perceived safety of the hospital system is left behind (Jefford et al., 2008). At six months post-diagnosis, estimates of the prevalence of depression range from 22% to 28% (Burgess et al., 2005; De Leeuw et al., 2000; Gallagher et al., 2002; Goldberg et al., 1992; Kangas et al., 2005; Korfage et al., 2006) while one-third of survivors are estimated to experience anxiety (Burgess et al., 2005; Kangas et al., 2005; Korfage et al., 2006). However, psychological morbidity at this time has not been well documented in the wider population of recent cancer survivors, and to our knowledge, there are no published studies reporting the prevalence of comorbid anxiety–depression six months after a cancer diagnosis.

Information about the characteristics of survivors most at risk of experiencing psychological morbidity is critical for identifying those that should be targeted for screening, evaluation and monitoring or intervention. There is an extensive literature on the individual (younger age, physical disability), disease and treatment (advanced disease, fatigue, pain), psychological (history of depression, adaptive coping styles), social (socially isolated, socially disadvantaged) and lifestyle factors (insufficiently active, substance abuse) associated with psychological morbidity at various stages of the cancer continuum (Banks et al., 2010; Fann et al., 2008; Massie, 2004; Stark and House, 2000; Van't Spijker et al., 1997).

Although some studies have examined various subsets of these characteristics as predictors of poor adjustment after cancer (Hammerlid et al., 1999; Lynch et al., 2008), to date, no study has reported the relative contributions of a comprehensive range of individual, disease, psychological, social and lifestyle characteristics to the psychological morbidity experienced by cancer survivors in the late treatment to early survivorship phase of care.

There is an emerging body of high quality evidence describing the magnitude and nature of the psychological impact of cancer on survivors, particularly for breast and prostate cancer survivors. However, more comprehensive studies with representative samples of survivors with different cancer types, survival probabilities, culturally and socially diverse backgrounds and geographic locations are needed in order to accurately assess the prevalence of the psychological effects of cancer among survivors and identify vulnerable subgroups. The landmark report *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006) recommended that large-scale population-based studies with the diversity of cancer survivors be undertaken as a priority in order to guide the development and delivery of effective survivorship care.

The aims of the current study were to:

1. Determine the prevalence of anxiety, depression and comorbid anxiety–depression at six months post-diagnosis overall and by cancer type.
2. Identify the factors (individual, disease, health behaviour, psychological, social) correlated with caseness for (a) anxiety, (b) depression and (c) comorbid anxiety–depression at six months post-diagnosis. It was hypothesised that psychological morbidity would be associated with (i) being aged less than 50 years, (ii) a history of mental health problems, (iii) insufficient physical activity (iv) consuming more than two standard drinks a day, and (vi) perceived poor social support.

2. Method

This paper is based on the *Cancer Survival Study*, a population-based longitudinal study tracking the psychosocial well-being and lifestyle behaviours of 1453 cancer survivors in Australia over the first five years since diagnosis. Time 1 (T1) data reported here were collected from participants at approximately six months post diagnosis.

2.1. Participants

Cancer survivors were prospectively recruited from new notifications to the two largest state-based cancer registries in Australia. Eligible participants were (i) diagnosed in the previous six months with their first primary cancer of one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, melanoma, non-Hodgkin's lymphoma, leukaemia, head and neck); (2) aged between 18 and 80 years and living in the state of New South Wales (NSW) or Victoria (VIC) at the time of diagnosis; and (3) considered by their physician to be aware of their diagnosis as well as physically and mentally capable and proficient in English to complete a questionnaire.

2.2. Procedure

The registries attempted to contact by mail the physician of survivors identified as potentially eligible to participate. Physicians in NSW were required to provide active consent for the nominated survivor to be contacted about the study; those physicians who did not respond within four weeks received one reminder phone call. Passive physician consent was used in Victoria whereby physicians were required to notify the cancer registry within four weeks of any contraindications to the nominated survivor being contacted about the study. Potential participants with physician approval to be approached were contacted by mail by the registries to seek permission to pass their name and contact details to the research team. Non-responders received one mailed reminder package three weeks later and one reminder phone call after a further three weeks.

Using a modified Dillman (1978) approach, a study package was mailed to those survivors who agreed to be contacted about the study by the research team. Non-responders received one mailed reminder package three weeks later and one reminder phone call after a further three weeks. Consent to participate was indicated by return of a completed survey. The Human Research Ethics Committees of the University of Newcastle, Cancer Institute NSW and Cancer Council Victoria approved the study.

2.3. Measures

Data were collected through a combination of self-administered scannable questionnaire and linkage with the Cancer Registries.

2.3.1. Outcome measure

Anxiety and depression were measured by the commonly used 14-item Hospital Anxiety and Depression Scale (HADS). Items assess two subscales: anxiety (HADS-A) and depression (HADS-D). Each item is rated on a four point Likert scale and a score ranging from 0 to 21 calculated for each subscale, with a higher score indicating a higher level of anxiety or depression. A subscale score of 0–7 is considered normal (non-case), 8–11 considered borderline (doubtful case) and 12–21 considered clinically significant (probable case) (Zigmond and Snaith, 1983). Although there is debate about the optimal scoring method and cutpoint to use (Singer et al., 2009), a review of the validity of the individual HADS subscales found that the best trade-off between sensitivity and specificity was achieved using a subscale cutoff point of 8 or above for identifying 'cases' (Bjelland et al., 2002). To minimise the misclassification of survivors, we used the established subscale cutoff point ≥ 8 to identify 'cases' on HADS-A and 'cases' on HADS-D. In addition, those who were cases on both HADS-A and HADS-D were classified as 'cases' on comorbid anxiety–depression. The HADS measures aspects of depression that are not confounded by the physical symptoms of cancer or its treatment such as fatigue, and was recommended as an instrument of choice for assessing cancer patients' psychological morbidity in recent reviews of patient reported outcome measures (Lockett et al., 2010; Ziegler et al., 2011).

2.3.2. Study factors

2.3.2.1. Individual. Age at diagnosis and sex were obtained directly from the cancer registry. Current marital status, highest level of education completed, health insurance coverage, current employment situation, geographical location, size of household, and presence of any physical comorbidities were obtained by standard self-report questionnaire items.

2.3.2.2. Disease. Primary cancer type and spread of disease at diagnosis were obtained directly from the cancer registry and survivors' cancer categorised as 'early/less progressed' (in situ or localised; grade 1 or 2; T1 or T2), 'late/more progressed' (invasion of adjacent organs, regional nodes or distant metastases; grade 3 or 4; not T1) or 'not applicable' (haematological cancers). Extent of disease at six months post-diagnosis, and cancer treatments received in the last month were obtained by standard self-report questionnaire items.

2.3.2.3. Health behaviours. Smoking behaviour was assessed by two questions and participants classified as 'current smoker' (has smoked at least 100 cigarettes or the equivalent amount of tobacco in lifetime and currently smokes), 'former smoker' (has smoked at least 100 cigarettes or the equivalent amount of tobacco in lifetime but does not currently smoke) or 'never smoker' (never smoked more than 100 cigarettes or the equivalent amount of tobacco in lifetime) (AIHW, 1999). Alcohol consumption was assessed by two questions adapted from the Australian National Drug Strategy Household Survey (AIHW, 2002). Participants who consumed more than two standard drinks on any day were classified as being at increased lifetime risk of harm from alcohol related injury or disease (NHMRC, 2009). Physical activity was assessed by three items adapted from the Active Australia survey (AIHW, 2003) and participants classified as 'sufficiently active' (at least 150 min of activity over one week), 'insufficiently active' (participating in some physical activity but not enough in total time) or 'sedentary' (no physical activity) (DoHA, 1999).

2.3.2.4. Psychological. Mental health history was obtained by two self-report questionnaire items assessing treatment for a mental health illness (e.g. depression, anxiety, schizophrenia) before and since cancer diagnosis. Coping strategy was measured by the 21-item Mini Mental Adjustment to Cancer Scale (Mini-MAC). Items assess five cancer-specific coping strategies: helplessness–hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance and fatalism. Items are rated on a 4-point scale and a score calculated for each subscale with a higher score indicating a stronger use of the coping strategy (Watson et al., 1994). Raw subscale scores were standardised from 0 to 100. As the distribution of scores was highly skewed, all coping subscales were dichotomised with survivors who scored in the top 16% of each distribution classified as a 'case' on that specific coping strategy in accordance with the user manual (Watson et al., 1989).

2.3.2.5. Social. Social support was measured by the 20-item MOS Social Support Survey (MOS-SSS). Items assess four subscales of functional support: emotional/informational, tangible, affectionate, and positive social interaction. Items are rated on a 5-point scale and a score calculated for each

subscale with a higher score indicating a higher level of support (Sherbourne and Stewart, 1991). Raw subscale scores were standardised from 0 to 100. As all subscale scores were highly skewed, all social support subscales were dichotomised and survivors who scored in the bottom one-third of each distribution classified as 'low' on that particular type of social support (Sherbourne, personal communication, 19 May 2004).

2.4. Statistical methods

In accordance with recommended procedures for the HADS, in those instances where no more than one item was missing on a subscale, the mean of the remaining subscale items was imputed. If more than one item on a subscale was missing, then the subscale score was not calculated. Data from survivors of non-Hodgkin's lymphoma or leukaemia were combined to form a 'haematological' cancer type due to small numbers. Scores were calculated for the HADS-A and HADS-D and descriptive statistics computed. The prevalence of each of the three outcomes (case on anxiety, case on depression, and case on comorbid anxiety–depression) was estimated with 95% confidence intervals for each cancer type. The association between the individual, disease, health behaviour, psychological and social factors with each of the three outcomes was examined using chi-square analyses. Variables with a *p* value of 0.2 or less were included in a backward stepwise logistic regression model for each outcome. Variables were removed from the model if they had a *p* value of 0.05 or more on the likelihood ratio test. Odds ratio and 95% confidence intervals are reported for variables included in the final model.

3. Results

3.1. Sample

A total of 3877 potential participants were assessed for study eligibility. Of the 3315 deemed eligible, 1690 consented to contact by the researchers and a total of 1360 returned a T1 questionnaire (overall 41% response rate at T1; VIC = 49% and NSW = 33%). Thirty seven participants returned their T1 questionnaire more than 9 months after diagnosis and were excluded. The 1323 survivors included in these analyses were surveyed at a median of 6 months after diagnosis (*SD* = 1 month, range = 4–9 months) and their median age was 63 years (*SD* = 11 years, range = 18–80). Table 1 shows that more than half (59%) were male, about half were diagnosed with early stage disease (52%), the most common diagnosis was prostate cancer (26%) and 72% had not received any active treatment in the last month. The sample reflected the national profile (AIIW and AACR, 2008) for the top eight incident cancers diagnosed in 2005 in terms of gender and age, however survivors of colorectal cancer were under-represented and haematological and head and neck cancers were over-represented.

3.2. Prevalence of anxiety and/or depression by cancer type

Overall, cancer survivors reported low levels of anxiety (median score = 4, range = 0–20) and depression (median score = 2, range = 0–19). A total of 369 (28%; 95% CI: 23%–33%) cancer survivors reported clinical/borderline level

Table 1
Selected characteristics of study sample compared to national cancer incidence data.

	Study sample ^a	National ^b
	N (%)	N (%)
Gender	1323	58,665
Male	781 (59)	34,223 (58)
Female	542 (41)	24,442 (42)
Age at diagnosis (years)	1323	58,665
18–39	57 (4)	2826 (5)
40–49	138 (10)	6032 (10)
50–59	317 (24)	13,049 (22)
60–69	482 (36)	18,451 (31)
70 or more	329 (25)	18,307 (31)
Primary cancer	1323	58,665
Prostate	343 (26)	13,886 (24)
Breast (female)	208 (16)	10,896 (19)
Melanoma	204 (15)	9197 (16)
Haematological ^c	183 (14)	4935 (8)
Colorectal	157 (12)	10,108 (17)
Lung	133 (10)	7312 (12)
Head and neck	95 (7)	2331 (4)
Stage of disease at diagnosis	1323	
Early/less progressed	691 (52)	
Late/more progressed	254 (19)	
Not applicable	183 (14)	
Unknown	195 (15)	
Treatment in last month	1297	
Active (surgery, chemo, radio) ± passive treatment	358 (28)	
Passive only (hormone, immunotherapy)	151 (12)	
None	788 (61)	
Treatment types in last month ^d	1297	
Surgery	58 (5)	
Chemotherapy	198 (16)	
Radiotherapy	131 (10)	
Hormone	179 (14)	
Immunotherapy	29 (2)	

^a Number of observations varies across characteristics due to missing data.

^b 2005 data restricted to 8 most incident cancer types and those aged 20–79 years; data not available for all characteristics.

^c Includes non-Hodgkin's lymphoma and leukaemia.

^d Multiple responses allowed.

anxiety and/or depression at six months post-diagnosis. As shown in Table 2, 24% of survivors were identified as cases on anxiety (irrespective of depression) and 14% (95% CI: 9%–19%) as cases on depression (irrespective of anxiety). A total of 10% (95% CI: 5%–15%) were identified as cases on comorbid anxiety–depression.

There was significant variation across cancer types in the percentage of survivors that reported psychological morbidity. Lung cancer survivors were more affected than survivors of other cancer types with 40% (95% CI: 27%–53%) identified as cases on anxiety, 28% (95% CI: 14%–44%) as cases on depression and 24% (95% CI: 9%–39%) as cases on comorbid anxiety–depression. Compared to other cancer types, survivors of prostate cancer and melanoma reported the least psychological morbidity.

3.3. Factors associated with anxiety and/or depression

3.3.1. Individual characteristics

As shown in Table 3, the odds of caseness for anxiety increased with decreasing age, and were higher among

Table 2
Prevalence of anxiety and/or depression at 6 months post-diagnosis by cancer type.

	Total ^a	Prostate	Breast	Melanoma	Blood ^b	Colorectal	Lung	Head and neck
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Anxiety (irrespective of depression)								
Case	310 (24)	48 (14)	63 (30)	44 (22)	48 (27)	32 (20)	53 (40)	22 (24)
Non-case	1004 (76)	294 (86)	144 (70)	157 (78)	133 (73)	125 (80)	80 (60)	71 (76)
$\chi^2 = 44.29$; df = 6; $p < 0.001$								
Depression (irrespective of anxiety)								
Case	189 (14)	34 (10)	32 (15)	14 (7)	30 (17)	23 (15)	38 (29)	18 (19)
Non-case	1126 (86)	308 (90)	175 (85)	188 (93)	151 (83)	134 (85)	95 (71)	75 (81)
$\chi^2 = 39.13$; df = 6; $p < 0.001$								
Co-morbid anxiety-depression								
Case	130 (10)	22 (6)	26 (13)	7 (3)	20 (11)	14 (9)	32 (24)	9 (10)
Non-case	1184 (90)	320 (94)	181 (87)	194 (97)	161 (89)	143 (91)	101 (76)	84 (90)
$\chi^2 = 45.89$; df = 6; $p < 0.001$								

^a Number of observations varies across outcomes due to missing data.

^b Includes non-Hodgkin's lymphoma and leukaemia.

survivors who lived alone (OR = 1.8) compared to those who lived with another adult.

3.3.2. Disease characteristics

Cancer type, chemotherapy and hormone treatment were the only disease characteristics associated with psychological morbidity. Compared to survivors of prostate cancer, those diagnosed with lung cancer (OR = 2.3) or melanoma (OR = 2.1) had twice the odds of caseness for anxiety (Table 3). Those who received chemotherapy in the last month had almost twice the odds (OR = 1.9) of caseness for depression compared to those who didn't receive this treatment, while survivors who received hormone treatment had lower odds (OR = 0.46) of caseness for depression compared to those who didn't receive this treatment (Table 4).

3.3.3. Health behaviours

Physical activity, smoking status and alcohol consumption were associated with psychological morbidity (Tables 4 and 5). Compared to survivors who were sufficiently active, those who were sedentary or insufficiently active had two to four times the odds of caseness for depression (OR = 3.5, 1.8) and comorbid anxiety-depression (OR = 4.0, 2.4). Compared to survivors who had never smoked, current smokers had twice the odds of being a case on depression (OR = 2.47) and comorbid anxiety-depression (OR = 2.2). Survivors who consumed alcohol at a level that placed them at increased risk of harm had lower odds (OR = 0.45) of caseness for depression than those whose drank alcohol at safe levels.

3.3.4. Psychological

A history of mental health treatment and coping strategy were significantly associated with all three outcomes (Tables 3–5). Compared to those without a history of mental health problems, survivors who had been treated for mental health problems before their cancer diagnosis had at least twice the odds of caseness for anxiety (OR = 2.8), depression (OR = 2.0) and comorbid anxiety-depression (OR = 2.1) while those treated for mental health problems since their cancer diagnosis had higher odds of being a case on anxiety (OR = 2.2). Survivors who engaged in the maladaptive

coping strategies helplessness-hopelessness or anxious preoccupation had two to eight times the odds of being a case on anxiety (OR = 2.7, 8.4), depression (OR = 2.7, 4.6) and comorbid anxiety-depression (OR = 3.5, 6.4) compared to survivors who did not use these strategies. In addition, survivors who used cognitive avoidance coping (OR = 1.7) had greater odds of being a case on anxiety while those who used fighting spirit had lower odds (OR = 0.40) of being a case on depression.

3.3.5. Social

Positive social interaction was the only type of social support associated with psychological morbidity. Survivors who perceived that they had low levels of positive social interaction had about twice the odds of being a case on anxiety (OR = 1.6), depression (OR = 2.4) and comorbid anxiety-depression (OR = 2.5) compared to survivors who perceived they had at least some positive social interaction.

4. Discussion

It is undisputed that a diagnosis of and treatment for cancer is a stressful life event and therefore it is to be expected that some survivors will report psychological distress. In this population-based study, only 28% of cancer survivors at six months post-diagnosis reported clinical/borderline levels of anxiety and/or depression. A total of 24% of survivors were identified as cases on anxiety (irrespective of depression) and 14% as cases on depression (irrespective of anxiety). Overall, 10% were identified as cases for comorbid anxiety-depression. That is, about two-thirds (69%) of depressed survivors experienced anxiety at the same time, which is consistent with findings from a large heterogeneous sample of cancer patients receiving treatment at one clinic (Brintzenhofe-Szoc et al., 2009). Although comorbid anxiety-depression accounted for a relatively low proportion of survivors, these individuals are likely to be suffering greatly and should be actively identified, and vigorously targeted for intervention.

The level of anxiety and depression identified in this study is lower than that reported by other studies of survivors at a similar timeframe post-diagnosis (De Leeuw et al., 2000;

Table 3
Factors significantly correlated with caseness for anxiety.

	Adjusted OR (95% CI)	p
<i>Individual</i>		
Age at diagnosis (years)		0.023
49 and younger	2.7 (1.4–5.3)	
50–59	2.0 (1.1–3.6)	
60–69	1.8 (1.1–3.2)	
70 and older	1.00	
Number of adults live with		0.04
Nil – live alone	1.8 (1.1–2.9)	
More than 1	1.5 (0.94–2.3)	
1	1.00	
<i>Disease and treatment</i>		
Cancer type		0.027
Breast	1.4 (0.76–2.5)	
Colorectal	1.6 (0.85–3.2)	
Haematological	1.1 (0.59–2.1)	
Head and neck	0.75 (0.33–1.7)	
Lung	2.3 (1.2–4.5)	
Melanoma	2.1 (1.1–3.9)	
Prostate	1.00	
<i>Psychological</i>		
Mental health treatment before cancer diagnosis		<0.001
Yes	2.8 (1.7–4.5)	
No	1.00	
Mental health treatment since cancer diagnosis		0.002
Yes	2.2 (1.1–4.3)	
No	1.00	
Helpless–hopeless coping		<0.001
Case	2.7 (1.8–4.0)	
No case	1.00	
Anxious preoccupation		<0.001
Case	8.4 (5.6–12.6)	
No case	1.00	
Cognitive avoidance		0.007
Case	1.7 (1.1–2.4)	
No case	1.00	
<i>Social</i>		
Positive social interaction		0.021
Low	1.6 (1.1–2.3)	
Some	1.00	

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.

Table 4
Factors significantly correlated with caseness for depression.

	Adjusted OR (95% CI)	p
<i>Disease and treatment</i>		
Chemotherapy last month		0.01
Yes	1.9 (1.2–3.1)	
No/don't know	1.00	
Hormone treatment last month		0.037
Yes	0.46 (0.22–0.95)	
No/don't know	1.00	
<i>Health behaviours</i>		
Physical activity		<0.001
Sedentary	3.5 (2.0–6.2)	
Insufficiently active	1.8 (1.1–3.1)	
Sufficiently active	1.00	
Smoking status		0.044
Current	2.4 (1.2–4.8)	
Former	1.0 (0.68–1.6)	
Never	1.00	
Alcohol consumption		0.002
Increased risk of harm	0.45 (0.27–0.74)	
No increased risk of harm	1.00	
<i>Psychological</i>		
Mental health treatment before cancer diagnosis		0.005
Yes	2.00 (1.2–3.3)	
No	1.00	
Helpless–hopeless coping		<0.001
Case	2.7 (1.7–4.3)	
No case	1.00	
Anxious preoccupation		<0.001
Case	4.6 (2.9–7.3)	
No case	1.00	
Fighting spirit		0.005
Case	0.40 (0.21–0.75)	
No case	1.00	
<i>Social</i>		
Positive social interaction		<0.001
Low	2.4 (1.6–3.7)	
Some	1.00	

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.

Gallagher et al., 2002; Goldberg et al., 1992; Kangas et al., 2005). While this can be explained in part by the use of different measurement techniques or outcome measures, previous studies have tended to use convenience samples of survivors of a single cancer type recruited from one clinic and are therefore prone to selection bias. One of the major strengths of this study is the use of the two largest state-based cancer registries in Australia as the sampling frame to recruit a population-based sample of survivors in the early stages of survivorship. As the study sample is generally representative of its source population, we are confident that our findings are generalisable.

Unlike previous studies which have included only one or two cancer types (mainly breast), our large-scale study included a diversity of survivors which enabled us to directly compare psychological morbidity across seven common cancer types which together account for 70% of all new

cancer diagnoses in Australia (AIHW and AACR, 2008). Univariate analyses indicated that the prevalence of all three outcomes varied significantly across cancer type with the percentage of survivors who reported anxiety, depression and comorbid anxiety–depression highest among lung cancer survivors. However, multivariable analyses found that such variation across cancer type existed only for anxiety, and is likely to reflect the challenges associated with poor prognosis and deteriorating health that those diagnosed with lung cancer face.

A history of mental health treatment before cancer, greater use of anxious preoccupation and helplessness–hopelessness coping strategies, and perceived low levels of positive social interaction were strongly associated with caseness for anxiety, depression and comorbid anxiety–depression. In addition to these, indicators of social isolation (live alone, younger, mental health problems) and cancer type (lung, melanoma) were uniquely and strongly associated with anxiety. Health behaviours

Table 5
Factors significantly correlated with caseness for comorbid anxiety-depression.

	Adjusted OR (95% CI)	p
<i>Health behaviours</i>		
Physical activity		<0.001
Sedentary	4.0 (2.1–7.7)	
Insufficiently active	2.4 (1.3–4.4)	
Sufficiently active	1.00	
Smoking status		0.046
Current	2.2 (1.0–4.5)	
Former	0.87 (0.53–1.4)	
Never	1.00	
<i>Psychological</i>		
Mental health treatment before cancer diagnosis		0.008
Yes	2.1 (1.2–3.6)	
No	1.00	
Helpless–hopeless coping		<0.001
Case	3.5 (2.1–5.8)	
No case	1.00	
Anxious preoccupation		<0.001
Case	6.4 (3.9–10.6)	
No case	1.00	
<i>Social</i>		
Positive social interaction		<0.001
Low	2.5 (1.6–4.1)	
Some	1.00	

OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.

(lack of physical activity and current smoker) were strongly associated with both depression and comorbid anxiety-depression.

The current study found that when considered together, health behaviours, psychological characteristics and social factors were more strongly associated (demonstrated by high odds ratios and highly significant p-values) with psychological morbidity than survivors' individual and disease characteristics. While causality cannot be inferred from cross-sectional data, these findings are notable because health behaviours, coping strategies and social support are potentially modifiable and therefore have considerable promise for intervention efforts. For example, interventions targeting physical activity have been shown to reduce not only anxiety and depression, but also risk of cancer recurrence, other chronic illnesses and fatigue (Park and Gaffey, 2007; WCRF and AICR, 2007). Importantly, it has also been determined that it is generally safe and feasible for individuals affected by cancer to engage in physical activity during treatment and survivorship (Doyle et al., 2006). Reviews of the evidence have recommended that coping skills training that maximises the use of adaptive coping (Osborn et al., 2006) and social skills training that emphasises reciprocal support (Hogan et al., 2002) should be integrated within interventions to impact upon psychological distress.

Contrary to our hypothesis, drinking alcohol at levels considered to be at increased risk of harm was associated with lower odds of depression. A possible explanation for this unexpected finding is that cancer survivors may use alcohol as a strategy to block or blunt feelings of sadness. Alternatively, having faced their own mortality and survived, survivors may simply be living each day to the fullest. It is

also possible that this is a spurious finding resulting from methodological limitations. Although adapted from an existing questionnaire, the items assessing alcohol consumption were generally poorly completed with many responses missing. Further, although we conformed to current guidelines to classify survivors' drinking levels, the criteria are crude and may have resulted in misclassification of drinking levels. Given the social stigma associated with excessive alcohol consumption, it is plausible that heavy drinkers under-reported their alcohol intake or avoided answering these questions (Del Boca and Darkes, 2003). We recommend that future studies further explore the association between alcohol consumption and psychological morbidity among recent cancer survivors.

4.1. Strengths and limitations

To our knowledge, this is the first study to examine the prevalence of psychological morbidity among a large-scale population-based sample of diverse cancer survivors who at six months post-diagnosis are in the very early stages of cancer survivorship. For logistical reasons related to patient recruitment via the cancer registries, the study sample was restricted to the eight most incident cancer types. Nonetheless, the sample included survivors of understudied cancers (colorectal, head and neck, haematological, lung). The use of rapid case ascertainment procedures and registry policies prohibiting individuals being approached for more than one study meant the sampling frame from which the sample was recruited was incomplete. For example, young men (less than 55 years) diagnosed with prostate cancer and those diagnosed with early stage colorectal cancer were unable to be approached by one registry for this study due to other studies targeting these patients. This contributed to differences between NSW and VIC participants in terms of gender, cancer type, stage of disease and treatments. Ideally, the sample recruited from each state would have been stratified by cancer type proportionate to its incidence in that state.

The T1 response rate of 41% (1360/3315 eligible individuals) may raise concerns about response bias. Due to privacy, confidentiality, and adverse event concerns, the cancer registries used a multistep recruitment process to identify potential participants on behalf of the research team; this process provided many opportunities for non-response and non-consent by clinicians and survivors prior to any contact from the researchers (Clinton-McHarg et al., 2011). The reported response rate almost certainly underestimates the true response rate because it assumes that all survivors of unknown eligibility (i.e. 764 survivors for whom the physician was uncontactable or refused, and 426 survivors who were uncontactable or non-responders) were eligible and therefore included in the denominator. While it exceeds the adjusted recruitment rate (34%) achieved by another study which used an equivalent method to recruit a similarly diverse sample of recent adult survivors via cancer registries (Smith et al., 2007b), it is lower than other register-based studies which have recruited samples of recent survivors of a homogeneous cancer type (Beesley et al., 2008; DiSipio et al., 2008; Smith et al., 2007a). On the basis that the sample is generally representative of the cancer population, we

propose that the impact of the response rate on the accuracy of the prevalence estimates reported is likely to be minimal.

Although Australia has one of the most multicultural populations worldwide (ABS, 2010), survivors who were not proficient in English were excluded due to prohibitive costs involved in translation of the questionnaire into other languages. This may have resulted in an underestimate of the prevalence of anxiety and depression given that language barriers limit access to health care services and information (Butow et al., 2010; Fiscella et al., 2002). The range of static and modifiable individual, disease, health behaviour, psychological and social correlates examined in this study is considerably wider than that of previous studies. Although cross-sectional in nature, it enabled us to identify the relationships between variables that should be further explored in longitudinal analysis. The large-scale sample meant that it was not feasible to assess psychological morbidity by clinical interview, however, the HADS has good sensitivity and specificity in detecting cases of anxiety and depression compared to clinical interview. Using the recommended HADS subscale cutoff score of ≥ 8 maximised the possibility of identifying all of the survivors with 'caseness' for anxiety and/or depression. However, it is possible that by using this lower threshold, some survivors may have been misclassified as 'cases', resulting in a small over-estimate of psychological morbidity. Nevertheless, the rates of psychological morbidity found in this study are lower than that previously reported. In balancing the questionnaire breadth and length, it was not possible to measure other potential correlates such as personality traits. While the lack of a gender and age-matched non-cancer control group makes it difficult to determine if the psychological morbidity reported by survivors is age-related or cancer-related, the presence of other self-reported comorbid diseases (e.g. arthritis, hypertension) was assessed and found on multivariable analysis to not be associated with the outcomes examined. Furthermore, given that the rates of anxiety (24%) and depression (14%) were approximately double the rate of 12-month anxiety disorder (14%) and 12-month affective disorder (6%) found in the general population of Australia (ABS, 2007), it is likely that much of the psychological morbidity reported by survivors in this study is cancer-related.

5. Conclusions

About one quarter of cancer survivors in this study reported caseness for anxiety and/or depression at six months post-diagnosis, emphasising the importance of repeated assessment of psychological well-being during end of treatment and routine post-treatment follow-up care, and provision of appropriate interventions. In addition to mental health history, modifiable health behaviours (particularly physical activity and smoking behaviour), psychological characteristics (helplessness–hopelessness coping, and anxious preoccupation coping) and social characteristics (low positive social interaction) were found to be stronger indicators of psychological morbidity than survivors' individual and disease characteristics. Knowledge of the characteristics of survivors at increased risk of psychological morbidity may guide health care professionals in which survivors to target for monitoring and early intervention. These findings suggest that focusing on healthy lifestyle behaviours, coping skills training and social skills training warrant further exploration

and will likely require a multidisciplinary approach including psychosocial, medical, allied health, and community services.

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Conflict of interest

The authors declare that they have no conflicts of interest.

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Statement of contribution

I, Prof Afaf Girgis, attest that Research Higher Degree candidate Allison Boyes contributed substantially to the conception and design of the study, securing competitive grant funding, execution of the study including overall responsibility for collection and assembly of data, analysis and interpretation of data, and writing of the manuscript:

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APPENDIX 2: Paper 2

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APPENDIX 3: Paper 3

Support Care Cancer
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ORIGINAL ARTICLE

How does the Distress Thermometer compare to the Hospital Anxiety and Depression Scale for detecting possible cases of psychological morbidity among cancer survivors?

Allison Boyes · Catherine D'Este · Mariko Carey ·
Christophe Lecathelinais · Afaf Girgis

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Abstract

Purpose Use of the Distress Thermometer (DT) as a screening tool is increasing across the cancer trajectory. This study examined the accuracy and optimal cut-off score of the DT compared to the Hospital Anxiety and Depression Scale (HADS) for detecting possible cases of psychological morbidity among adults in early survivorship.

Methods This study is a cross-sectional survey of 1,323 adult cancer survivors recruited from two state-based cancer registries in Australia. Participants completed the DT and the HADS at 6 months post-diagnosis.

Results Compared to the HADS subscale threshold ≥ 8 , the DT performed well in discriminating between cases and non-cases of anxiety, depression and comorbid anxiety–depression with an area under the curve of 0.85, 0.84 and 0.87, respectively. A DT cut-off score of ≥ 2 was best for clinical use (sensitivity, 87–95 %; specificity, 60–68 %), ≥ 4 was best for research use (sensitivity, 67–82 %; specificity,

81–88 %) and ≥ 3 was the best balance between sensitivity (77–88 %) and specificity (72–79 %) for detecting cases of anxiety, depression and comorbid anxiety–depression. The DT demonstrated a high level of precision in identifying non-cases of psychological morbidity at all possible thresholds (negative predictive value, 77–99 %).

Conclusions The recommended DT cut-off score of ≥ 4 was not supported for universal use among recent cancer survivors. The optimal DT threshold depends upon whether the tool is being used in the clinical or research setting. The DT may best serve to initially identify non-cases as part of a two-stage screening process. The performance of the DT against 'gold standard' clinical interview should be evaluated with cancer survivors.

Keywords Cancer · Psychological distress · Screening · Sensitivity · Specificity · Survivor

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Introduction

The diagnosis and treatment of cancer has wide-ranging physical, psychosocial and existential effects [1]. Psychological distress is relatively common among oncology populations, with estimates of the prevalence ranging from 28 % [2] to 43 % [3]. Emotional stress has been linked to decreased social functioning, more physical and cognitive impairment, amplified somatic symptoms [4], non-adherence to treatments and health-promoting behaviours [5] and possibly cancer progression and recurrence [6]. Despite the importance of detecting and treating psychological distress, health care providers often fail to accurately recognise distressed patients [7] and many cancer services report providing psychosocial care only to patients in crisis [8]. Consequently, many people with cancer report unmet

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need for help with psychological issues [9]. Guidelines recommend that all cancer patients should be routinely screened for distress at periods of increased vulnerability during the cancer journey [10, 11]. Screening itself is not diagnostic; rather, those who have a positive result from the screening test require further evaluation to confirm or discount the presence and severity of emotional distress. Routine distress screening is acceptable to people with cancer, feasible to implement [12, 13] and estimated to take one quarter of the time and cost one third as much as conducting clinical assessments [14].

It is widely accepted that a screening tool should be brief, easy to administer and interpret, reliable and able to accurately detect most of those with and without the condition of interest based on a cut-off score [15]. Various screening tools such as the Hospital Anxiety and Depression Scale (HADS) [16], Brief Symptom Inventory-18 (BSI-18) [17] and Distress Thermometer (DT) [18] have been developed to quickly identify individuals who may be psychologically distressed. The single-item (DT) is recommended by the National Comprehensive Cancer Network [11]. Potential advantages of the DT over other screening tools are its brevity and ease of administration and scoring. Whilst the accuracy of the DT to detect psychological distress has been demonstrated against longer criterion measures including the HADS, BSI-18 and clinical interview, recent reviews have highlighted the DT's lack of specificity to rule out false-positive cases [19–21]. Furthermore, study findings are mixed regarding the optimal DT cut-off score for case-finding, with some studies supporting a cut-off score of ≥ 4 and others supporting a cut-off score of ≥ 5 [22].

Despite increased attention to the growing population of individuals transitioning to survivorship, to our knowledge, only two studies have examined the screening performance of the DT among those in survivorship. Merport et al. [23] compared the DT to the BSI-18 in a heterogeneous sample of survivors at least 2 years post-diagnosis, whilst Craike et al. [24] compared the DT to the HADS in a sample of recent colorectal cancer survivors. In both studies, the DT demonstrated poor sensitivity relative to the criterion measure for identifying cancer survivors who self-reported symptoms of anxiety and/or depression. These findings highlight the importance of establishing the performance of a screening tool prior to using it with a different population or context to that in which it was validated.

This study aimed to (1) examine the sensitivity and specificity of the recommended DT cut-off score of ≥ 4 with the HADS for detecting possible cases of anxiety, depression and comorbid anxiety–depression among a heterogeneous sample of adult cancer survivors 6 months after diagnosis and (2) identify the optimal cut-off score on the DT for detecting possible cases of anxiety, depression and comorbid anxiety–depression among adult cancer survivors

6 months after diagnosis. The HADS was selected as the criterion measure because it is among the most widely used screening tools assessing symptoms of anxiety and depression in oncology populations [21, 22] and was recommended as the tool of choice in recent reviews [25, 26].

Method

This paper is based on time 1 (T1) data collected at 6 months post-diagnosis from survivors participating in the population-based longitudinal *Cancer Survival Study*. The study protocol and some of the findings have been reported elsewhere [2, 27].

Participants and procedures

The sample was recruited from the two largest state-based cancer registries in Australia which together account for 60 % of all new cases of cancer diagnosed [28]. Eligible survivors were (1) diagnosed in the previous 6 months, with their first primary cancer being one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, melanoma, non-Hodgkin's lymphoma, leukaemia and head and neck), (2) aged between 18 and 80 years and living in the state of New South Wales or Victoria at diagnosis, (3) considered by their physician to be aware of their diagnosis, physically and mentally capable of participating in the study, and sufficiently proficient in English to complete a questionnaire and (4) alive.

Eligible survivors who consented to the cancer registry passing on their contact details to the researchers were sent a self-administered questionnaire. Non-responders were sent one reminder questionnaire 3 weeks later and received one reminder phone call after a further 3 weeks. Return of the questionnaire indicated voluntary consent to participate. Participants' disease (primary cancer type, spread of disease at diagnosis) and demographic (age, sex) characteristics were obtained from the cancer registries. The study was approved by the appropriate ethics committees.

Measures

Distress was measured by the single-item DT [18]. Respondents self-report their level of emotional distress over the past week on a visual analogue scale from 0 (no distress) to 10 (extreme distress). Most studies have identified that a cut-off score ≥ 4 indicates clinically significant distress [13, 29, 30]. However, a recent pooled analysis found that the DT yields high rates of false positives and appears to be better at ruling out possible cases of clinical distress [19], whilst a systematic review of the psychometric properties of screening instruments for emotional distress rated the DT as only fair [21].

Anxiety and depression were assessed by the HADS, a 14-item screening tool assessing self-reported symptoms of anxiety (HADS-A) and depression (HADS-D). Each item is rated on a Likert scale from 0 to 3 and a score from 0 to 21 is calculated for each subscale. Scores can be kept continuous, with higher scores indicating more anxiety or depression, or categorised with scores from 0 to 7 classified as non-case, 8 to 11 as borderline case and 12 to 21 as probable case [16]. Whilst there is ongoing debate about the optimal HADS cut-off score [31], we used the established subscale cut-off score ≥ 8 to identify 'cases' on HADS-A and 'cases' on HADS-D [16, 32, 33]. In addition, those who scored ≥ 8 on both HADS-A and HADS-D were classified as 'cases' on comorbid anxiety–depression.

Analysis

The HADS was the criterion measure for defining caseness for anxiety, depression and comorbid anxiety–depression. If one item was missing from a HADS subscale, the mean of the remaining six items was imputed in accordance with the recommendations for the measure [34]. To examine the accuracy of the recommended DT cut-off score of ≥ 4 to detect cases of psychological morbidity, participants were classified as 'clinically distressed' (DT score ≥ 4) or 'not clinically distressed' (DT score ≤ 3) and as 'cases' (HADS subscale score ≥ 8) or 'non-cases' (HADS subscale score < 8) of anxiety, depression and comorbid anxiety–depression. The sensitivity, specificity, positive predictive value (PPV), negative predictive value (NPV) and the proportion of correctly identified cases and non-cases (based on the HADS classification) was calculated for each outcome with 95 % confidence intervals (CI). In this context, sensitivity refers to the proportion of cases identified by the HADS that are correctly identified as cases by the DT, specificity refers to the proportion of non-cases as identified by the HADS that are correctly identified as non-cases by the DT, PPV is the proportion of cases identified by the DT that are cases according to the HADS and NPV is the proportion of non-cases identified by the DT that are non-cases according to the HADS.

To identify the optimal cut-point for the DT detecting cases of anxiety, depression and comorbid anxiety–depression, the sensitivity, specificity, PPV, NPV and the proportion of correctly identified 'cases' for each outcome was calculated with 95 % CI for all possible cut-off values for the DT. The optimal DT cut-off score was determined by finding the DT value which achieved the best balance between sensitivity and specificity. Receiver operating characteristic (ROC) curves were used to examine the ability of all possible cut-off values of the DT to detect 'cases' of anxiety, depression and comorbid anxiety–depression as identified by the HADS subscale score ≥ 8 . For each ROC curve, the

area under the curve (AUC) estimate was used as an indicator of the overall accuracy of the DT to identify 'cases' of the outcome of interest.

Results

Sample

A total of 3,877 potential participants were assessed for study eligibility. Of the 3,315 deemed eligible, 1,691 consented to contact by the researchers and 1,360 returned a T1 questionnaire (41 % response rate at T1). Of these, 37 questionnaires were returned more than 9 months after diagnosis and were excluded. The characteristics of the 1,323 participants included in these analyses have been reported previously [2]. In summary, participants were surveyed at a median of 6 months after diagnosis (SD = 1 month, range = 4–9 months) and their median age was 63 years (SD = 11 years, range = 18–80 years). More than half (59 %) were male and diagnosed with early stage disease (52 %). The most common diagnosis was prostate cancer (26 %) followed by breast cancer (16 %) and melanoma (15 %). Almost three quarters of participants (72 %) had not received any active cancer treatment in the last month. The sample generally reflected the age and gender profile of the top eight incident cancers diagnosed in Australia in 2005 [27].

Accuracy of the recommended DT cut-off score ≥ 4 for identifying cases of anxiety and depression

Anxiety

A DT cut-off score of 4 correctly identified 67 % of HADS cases of anxiety (sensitivity) and 88 % of HADS non-cases (specificity). Of the anxiety cases identified by the DT, 62 % (PPV) were cases according to the HADS and, of the non-cases identified by the DT, 90 % (NPV) were defined as non-cases by the HADS. Overall, 83 % of survivors were correctly classified as cases or non-cases of anxiety.

Depression

A DT cut-off score of 4 correctly identified 71 % (sensitivity) of HADS cases of depression and 82 % (specificity) of HADS non-cases. Of the depression cases identified by the DT, 40 % (PPV) were cases according to the HADS and, of the non-cases identified by the DT, 95 % (NPV) were defined as non-cases by the HADS. Overall, 81 % of survivors were correctly classified as cases or non-cases of depression.

Comorbid anxiety–depression

A cut-off score of 4 correctly identified 82 % (sensitivity) of HADS cases of comorbid anxiety–depression and 81 % (specificity) of non-cases. Of the comorbid anxiety–depression cases identified by the DT, 32 % (PPV) were defined as cases according to the HADS and, of the non-cases identified by the DT, 98 % (NPV) were defined as non-cases by the HADS. Overall, 81 % of survivors were correctly classified as cases or non-cases of comorbid anxiety–depression.

Optimal DT cut-off score for identifying cases of anxiety and depression

The sensitivity, specificity, PPV, NPV and percent correct for all possible DT cut-off values are presented in Table 1 and ROC curves are graphed in Figs. 1, 2 and 3.

Anxiety

The DT showed good overall accuracy relative to the HADS-A for discriminating between cases and non-cases of anxiety with an AUC of 0.85 (95 % CI, 0.82–0.88). The DT cut-off score for anxiety caseness which achieved the best balance between sensitivity and specificity was 3. A cut-off score of 3 detected 77 % of survivors who were true cases and 79 % of survivors who were non-cases of anxiety. In addition, half of all survivors who were identified by the DT as cases and 92 % who were identified as non-cases of anxiety were classified as such according to the HADS. Raising the cut-off score to 4 decreased sensitivity to 67 % but increased specificity to 88 %. Lowering the DT threshold to 2 increased sensitivity to 87 % but decreased specificity to 68 %.

Depression

The DT showed good overall accuracy relative to the HADS-D for discriminating between cases and non-cases of depression with an AUC of 0.84 (95 % CI, 0.81–0.87). The optimal DT cut-off score for depression caseness was 3. A cut-off score of 3 detected 78 % of survivors who were true cases and 74 % of survivors who were non-cases of anxiety. In addition, one third of all survivors who were identified by the DT as cases and 95 % who were identified as non-cases of anxiety were classified as such according to the HADS. Raising the DT threshold to 4 decreased sensitivity to 71 % but increased specificity to 82 %. Lowering the DT threshold to 2 increased sensitivity to 91 % but decreased specificity to 63 %.

Comorbid anxiety–depression

The DT showed good overall accuracy relative to the HADS for discriminating between cases and non-cases of comorbid anxiety–depression with an AUC of 0.87 (95 % CI, 0.84–0.90). The optimal DT cut-off score for detecting cases of comorbid anxiety–depression was 4. A cut-off score of 4 detected at least 80 % of survivors who were true cases and true non-cases of comorbid anxiety–depression. In addition, one third of all survivors who were identified by the DT as cases and 98 % who were identified as non-cases of comorbid anxiety–depression were classified as such according to the HADS. Raising the cut-off score to 5 lowered sensitivity to 74 % but increased specificity to 86 %. Lowering the DT cut-off score to 3 increased sensitivity to 88 % but decreased specificity to 72 %.

Discussion

The DT demonstrated good agreement relative to the HADS to discriminate between cases and non-cases of anxiety, depression and comorbid anxiety–depression among cancer survivors 6 months after diagnosis. This is consistent with previous studies which have examined the performance of the DT against criterion measures such as the HADS, BSI-18 and clinical interview to identify psychologically distressed cancer patients and survivors [20–22]. However, at the suggested cut-off score of ≥ 4 , the DT generated a high rate of false-negative or ‘missed’ cases. For instance, the DT failed to identify 96 of 288 HADS cases of anxiety, 50 of 174 HADS cases of depression and 21 of 120 HADS cases of comorbid anxiety–depression. This low level of sensitivity suggests that the recommended DT cut-off score of ≥ 4 may not be ideal for detecting cases of anxiety and depression among survivors 6 months after diagnosis. These findings add to emerging evidence illustrating the DT’s lack of sensitivity among individuals in the survivorship phase of care [23, 24] compared to those in the treatment phase [13].

The choice of optimal cut-point is a trade-off between sensitivity and specificity. Whilst lowering the DT cut-off score increased sensitivity and reduced the number of cases that were ‘missed’, it resulted in a corresponding decrease in specificity and increased the number of false-positive cases identified. Conversely, raising the DT cut-off score increased specificity and reduced sensitivity. Our study found that a DT cut-off score of ≥ 3 achieved the best balance between sensitivity and specificity. At this threshold, at least 75 % of HADS cases and 72 % of HADS non-cases of anxiety, depression and comorbid anxiety–depression were

Table 1 Performance of DT scores compared with the HADS for identifying cases of anxiety, depression and comorbid anxiety–depression

	DT score	Sensitivity (95 % CI)	Specificity (95 % CI)	PPV (95 % CI)	NPV (95 % CI)	Percent correctly classified (95 % CI)
Anxiety (≥ 8 on HADS-A)	0	100	0	23 (21–26)		23 (21–26)
	1	93 (90–96)	49 (46–52)	35 (32–39)	96 (94–98)	59 (56–62)
	2	87 (83–91)	68 (65–71)	45 (41–49)	95 (93–96)	72 (70–75)
	3	77 (72–82)	79 (77–82)	53 (48–58)	92 (90–94)	79 (77–81)
	4	67 (61–72)	88 (86–90)	62 (56–67)	90 (88–92)	83 (81–85)
	5	59 (53–64)	91 (90–93)	68 (62–73)	88 (86–90)	84 (82–86)
	6	41 (36–47)	95 (94–96)	71 (64–78)	84 (82–86)	82 (80–85)
	7	29 (24–35)	96 (95–98)	72 (64–80)	82 (80–84)	81 (79–83)
	8	19 (15–24)	98 (98–99)	80 (70–90)	80 (80–84)	80 (78–82)
	9	8 (5–11)	99 (98–99)	81 (66–97)	78 (76–80)	78 (76–80)
	10	4 (2–6)	100 (99–100)	79 (54–100)	77 (75–80)	77 (75–80)
Depression (≥ 8 on HADS-D)	0	100	0	14 (12–16)		14 (12–16)
	1	95 (92–98)	44 (41–47)	22 (19–25)	98 (97–99)	51 (49–54)
	2	91 (86–95)	63 (60–65)	28 (25–32)	98 (97–99)	66 (64–69)
	3	78 (72–84)	74 (71–76)	33 (28–37)	95 (94–97)	74 (72–77)
	4	71 (64–78)	82 (80–85)	40 (34–45)	95 (93–96)	81 (79–83)
	5	62 (55–69)	87 (85–89)	43 (37–49)	93 (92–95)	83 (81–85)
	6	44 (36–51)	91 (90–93)	45 (37–53)	91 (89–93)	85 (83–87)
	7	35 (28–42)	95 (93–96)	52 (43–61)	90 (88–92)	86 (84–88)
	8	26 (19–32)	98 (97–99)	64 (53–76)	89 (87–91)	88 (86–89)
	9	10 (5–14)	99 (98–100)	63 (43–82)	87 (85–89)	86 (85–88)
	10	5 (1–8)	99 (99–100)	57 (27–87)	86 (85–88)	86 (84–88)
Comorbid anxiety–depression (≥ 8 on HADS-A and HADS-D)	0	100	0	10 (8–11)		10 (8–11)
	1	96 (92–99)	43 (40–46)	15 (13–18)	99 (98–100)	48 (45–51)
	2	95 (91–99)	60 (58–63)	20 (17–24)	99 (98–100)	64 (61–67)
	3	88 (83–94)	72 (70–75)	25 (21–30)	98 (97–99)	74 (71–76)
	4	82 (76–89)	81 (79–83)	32 (27–37)	98 (97–99)	81 (79–83)
	5	74 (66–82)	86 (84–88)	36 (30–42)	97 (96–98)	84 (82–87)
	6	53 (44–62)	91 (89–93)	38 (31–46)	95 (93–96)	87 (85–89)
	7	42 (34–51)	94 (93–95)	43 (34–52)	94 (92–95)	89 (87–91)
	8	33 (25–42)	97 (96–98)	57 (45–69)	93 (92–95)	91 (90–93)
	9	12 (6–19)	99 (98–100)	56 (36–76)	91 (90–93)	91 (89–92)
	10	6 (2–10)	99 (99–100)	50 (20–80)	91 (89–92)	90 (88–92)

identified as such by the DT. Whilst these rates of sensitivity and specificity are at least as good as those reported in a recent pooled analysis of the DT compared to the HADS to detect self-reported symptoms of anxiety and depression in oncology populations [19], the optimal cut-point of the DT may depend upon the purpose of using the tool.

For clinical applications, it could be reasoned that optimising sensitivity is desirable in order to not miss possible cases of psychological morbidity that require further assessment and possible treatment. This would lead to over-

detection of cases and unnecessary further evaluation which in itself can be stressful. However, it could be argued that, in the survivorship context, over-detection is preferable to under-detection given the intermittent nature of contact with health care professionals and thus fewer opportunities for psychological distress to be identified. Whilst a DT threshold of ≥ 2 achieved at least 87 % sensitivity for each outcome, the false-positive rate was high with 32 to 40 % of HADS non-cases misclassified as cases by the DT. These findings suggest that, if universal DT screening of cancer survivors in the early stages of survivorship was implemented,

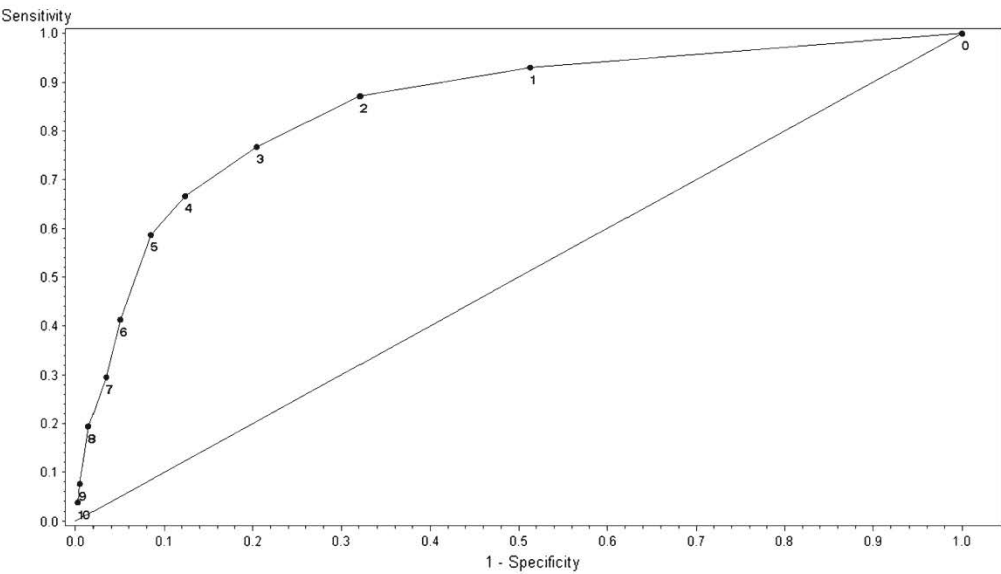


Fig. 1 ROC curve of DT scores versus the HADS anxiety subscale (score ≥ 8)

a two-stage sequential screening process would be necessary. Survivors who scored ≥ 2 on the DT in the initial screening would need to undergo a second stage of

screening, such as completion of a longer and more sensitive screening tool or further discussion with a nurse or oncologist, to determine if referral to a mental

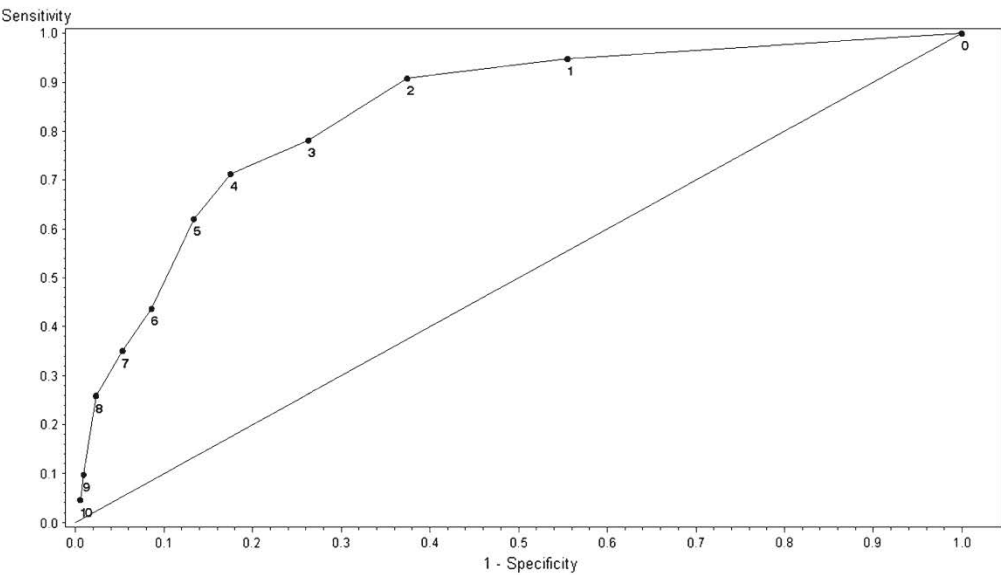


Fig. 2 ROC curve of DT scores versus the HADS depression subscale (score ≥ 8)

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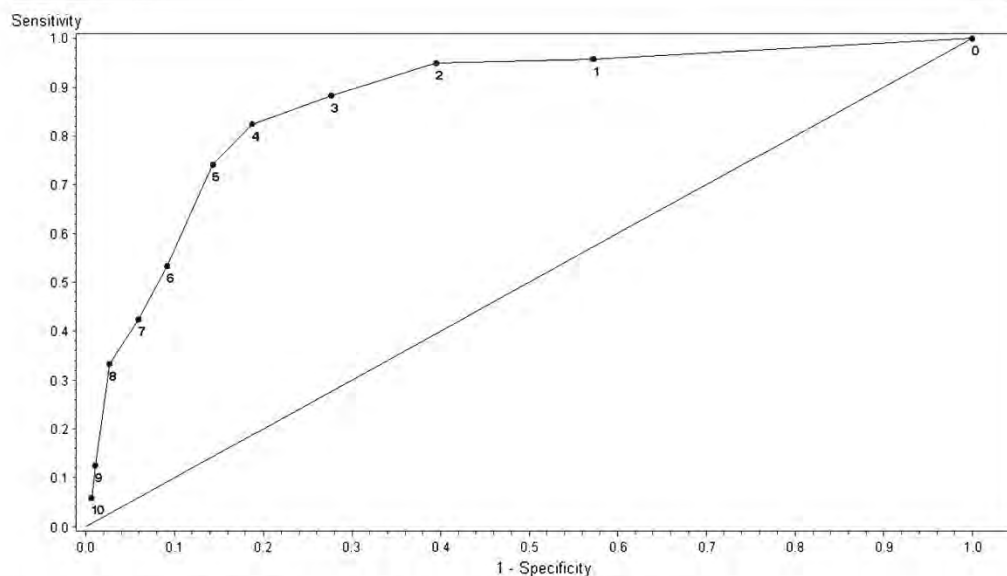


Fig. 3 ROC curve of DT scores versus the HADS (score ≥ 8 on both anxiety and depression subscales)

health professional for more comprehensive assessment was warranted.

For research or policy applications, however, it could be argued that optimising specificity is desirable in order to not over-detect cases and thereby inflate prevalence rates of psychological morbidity. This is important because decisions about the allocation of limited health care resources are based, in part, on the magnitude of a given problem. In this context, our study found that a cut-off score of ≥ 4 on the DT resulted in a false-positive rate of $<20\%$ for each outcome, yet the false-negative rate was high, with up to 33% of HADS cases misclassified as non-cases by the DT. Some clinical settings may choose to optimise specificity if there is limited capacity to follow-up people identified as possible cases using a lower threshold.

Overall, the DT demonstrated a high level of precision in identifying non-cases of psychological morbidity, with NPV ranging from 77 to 99% for all possible DT thresholds. Using the balanced cut-off score of ≥ 3 , at least 92% of survivors identified by the DT as non-cases of anxiety, depression or comorbid anxiety–depression were also identified as such by the HADS. These data corroborate evidence [19] suggesting that a strength of the DT is its ability to rule out psychological morbidity. These findings, in conjunction with the brevity and ease of scoring the DT, support the conclusion reached by others [19, 35] that the DT may be most useful as the first-stage screening instrument for

identifying the large number of non-cases of psychological morbidity in a two-stage screening process.

Our study is one of the largest to investigate the sensitivity and specificity of the DT among a diverse population-based sample of survivors in the early stages of survivorship. Whilst our findings provide support for the DT as a first-stage screening tool in this population, the accuracy of the tool is only one of several criteria that need to be fulfilled prior to implementing a screening program. One of the key principles underpinning screening is evidence that the early detection and treatment of the condition leads to better outcomes than finding and treating it later when signs or symptoms present [15]. Given the mixed evidence to date [36], well-designed studies of the effectiveness of distress screening programs among those diagnosed with cancer are urgently needed.

Limitations

The study response rate of 41% may raise concerns about the generalisability of the findings. Whilst the sample was representative of the population from which it was drawn in terms of age and gender, it is possible that the most distressed survivors may not have consented to participate. This may have contributed to the low PPV found in the current study given that this value is directly proportional to the prevalence of the outcome of interest. The HADS was the only criterion measure of anxiety and depression used

with a subscale cut-off score of ≥ 8 to identify cases. Although one of the most commonly used short screening measures, recent reviews [21, 30, 33] have revealed a lack of consistency in HADS cut-off scores compared with clinical assessments to identify cases. If we had used the HADS subscale cut-off score of ≥ 11 to identify cases, the sensitivity of the DT at each possible threshold would be higher but the specificity would be lower. Although not possible in the current study, future research should examine the optimal DT threshold against a 'gold standard' clinical interview in this population. This would assist health care professionals in the selection of the most appropriate screening tool and the most appropriate threshold to use in their setting. For all participants, the DT was presented first and the HADS second which may have had an effect on responses. Ideally, a cross-over design would be used to negate any order effect of survey administration; however, this was not possible in the current study as the two instruments were included within a scannable booklet.

Conclusions

Compared to the HADS, the DT performed well in discriminating between cases and non-cases of anxiety, depression and comorbid anxiety–depression among cancer survivors in the late treatment to early survivorship phase of care. Whilst appropriate for detecting cases of comorbid anxiety–depression, our findings did not support the recommended DT cut-off score of ≥ 4 to identify cases of anxiety and depression in this population. Our results suggest that the optimal DT threshold varies according to the use of the instrument with a cut-off score of ≥ 2 best for clinical use, ≥ 4 best for research use and ≥ 3 the best balance between sensitivity and specificity. The high level of precision in correctly identifying survivors who were non-cases indicates that the DT may best serve to initially rule out the substantial number of survivors who are not cases on anxiety, depression or comorbid anxiety–depression as part of a two-stage screening process. Future research should evaluate the performance of the DT against 'gold standard' clinical interview with cancer survivors.

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Conflict of interest None. The authors have full control of all primary data and agree to allow the journal to review the data relating to this paper if requested.

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Statement of contribution

I, Prof Catherine D'Este, attest that Research Higher Degree candidate Allison Boyes contributed substantially to the conception and design of the study, execution of the study including overall responsibility for collection and assembly of data, analysis and interpretation of data, and writing of the manuscript:

Boyes A, D'Este C, Carey M, Lecathelinais C, Girgis A. How does the Distress Thermometer compare to the Hospital Anxiety and Depression Scale for detecting possible cases of psychological morbidity among cancer survivors? Supportive Care in Cancer. In press.

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APPENDIX 4: Paper 4

Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34)

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Keywords

cancer, needs assessment, psychometrics, questionnaires, validity

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Abstract

Objective This study aimed to develop and validate a short version of the Supportive Care Needs Survey (SCNS) that would reduce respondent burden and could be used in routine cancer care, without compromising the psychometric properties of the original instrument.

Methods Secondary analyses of the data from two studies ($n = 888$ and 250) were undertaken. All 59 items of the original SCNS were assessed using psychometric analyses and evaluated for clinical utility. The 34 items retained were examined for internal consistency, ceiling and floor effects, known groups validity, convergent validity, sensitivity and readability.

Results The 34-item instrument has five factors (psychological, health system and information, physical and daily living, patient care and support, and sexuality needs) identical to the original instrument, explaining 73% of the variance. Internal consistency was high with Cronbach's alpha coefficients for the five factors ranging from 0.86 to 0.96. Correlations of the 34-item short-form SCNS (SCNS-SF34) with three other measures of psychosocial well-being demonstrated convergent validity ($r = 0.48$ – 0.56). Kappa coefficients of at least 0.83 for each domain indicated almost perfect agreement between the 34-item and 59-item surveys to identify patients needing help. The 34-item SCNS maintained the psychometric properties of the original instrument and could be readily comprehended by people with seventh to eighth grade education.

Conclusions The SCNS-SF34 is a valid instrument for measuring cancer patients' perceived needs across a range of domains, and could be utilized as part of routine cancer care.

Introduction

Morbidity in cancer patients has been estimated using a number of different strategies including the assessment of quality of life, satisfaction with care and more recently, needs assessment [1]. In contrast to other approaches, needs assessment does not infer that a patient must want help if s/he experiences an issue at an elevated level. By directly measuring patients' own perceptions of their need for help on given issues as well as the magnitude of their desire for help in dealing with those needs, finite health care resources can be allocated to those issues patients themselves have identified as most needing help with.

The long-form Supportive Care Needs Survey (SCNS-LF59) is a 59-item self-administered instrument designed to measure the perceived needs of adults diagnosed with cancer [2]. The SCNS-LF59 measures unmet needs within the defined period of the past

month, across five factor analytically derived domains: psychological, health system and information, physical and daily living, patient care and support, and sexuality needs. It assesses whether issues of need have been experienced, which of the issues experienced remain unmet needs, and the magnitude of such needs, on a five-point response scale (1 = no need, not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate need; 5 = high need). A standardized Likert summated score with values ranging from 0 to 100 can be calculated for each domain, with a higher score reflecting a higher level of need [3].

Although the SCNS-LF59 has acceptable content validity, construct validity and internal reliability [2], its correlation with other external measures of a related concept and test-retest reliability have not been determined. The SCNS-LF59 takes approximately 20 minutes to complete and can be understood by people with a reading level of fifth grade. More details on the development and

assessment of the survey's psychometric properties can be found in a previous publication [2].

A guide to the administration, scoring and analysis of the Supportive Care Needs Survey (SCNS) has been produced to assist in the standardized analysis of SCNS data [3]. The first in a series of reference values has also been produced to assist SCNS users in the interpretation of their data [4], although cut-points have not yet been established for categorizing SCNS domain scores as high, moderate or low. A number of supplementary modules have been developed for use in conjunction with the core SCNS and provide detailed information about perceived needs specific to cancer type, stage of disease and type of treatment.

To date, the SCNS-LF59 has predominantly been used in descriptive research studies to identify cancer patients' broad domains of need as well as the specific issues faced by different groups of cancer patients [5–9]. Although the high survey completion rates achieved in these studies suggest that cancer patients are willing to complete a survey of this magnitude, its length limits its utility in the clinical setting. As noted by Higginson and Carr [10], measures developed for research often cannot be easily used in clinical practice because they are not simple and quick to complete. A recent review of needs assessment tools, including the SCNS-LF59, found that respondent burden was generally considerable for those tools that reported on it [1].

Given patients' reported preference for the SCNS over other health-related quality of life questionnaires [11], our aim was to develop and validate a short form of the SCNS that would reduce respondent burden and be useful in routine clinical practice, without compromising the psychometric strengths of the original instrument.

Methods

A secondary analysis of the data from two studies was undertaken. The Supportive Care Review was conducted in 1995 and assessed the supportive care needs of 888 adult cancer patients using the SCNS-LF59 [5]. Given the large sample size, the data for half the sample were randomly selected to perform the item reduction process ($n = 444$) and the other half was used to carry out the validation process ($n = 444$). Table 1 presents the characteristics of the study populations. There were no significant differences between these two sub-samples in terms of gender ($P = 0.09$), age ($P = 0.64$) and primary cancer type ($P = 0.98$). Unpublished baseline data collected from the first 250 participants in the Cancer Survival Study was used to test the convergent validity of the short-form SCNS against other validated instruments of psychosocial well-being. The Cancer Survival Study is a population-based longitudinal study assessing the psychosocial well-being of cancer patients diagnosed with the eight most incident cancers in Australia, using the 34-item short-form SCNS (SCNS-SF34), Distress Thermometer (DT) [12], Hospital Anxiety and Depression Scale (HADS) [13] and Quality of Life Questionnaire – Core 30 (QLQ-C30) [14]. Subjects provided informed consent to participate in the studies as approved by the relevant Human Research Ethics Committees.

Item reduction

The purpose of this process was to select the subset of items that most accurately measured cancer patients' perceived needs and

Table 1 Characteristics of patients involved in the item reduction and validation procedure

	Sample 1: Item reduction ($n = 444$)	Sample 2: Validation ($n = 444$)	Sample 3: Convergent validity ($n = 250$)
Gender			
Male	189 (43%)	168 (38%)	161 (64%)
Female	228 (51%)	256 (58%)	89 (36%)
Age (years)			
≤ 50	109 (25%)	99 (22%)	31 (12%)
51–60	94 (21%)	94 (21%)	56 (22%)
61–70	110 (25%)	126 (28%)	104 (42%)
≥ 70	131 (30%)	125 (28%)	59 (24%)
Primary cancer type			
Breast	137 (31%)	139 (31%)	14 (6%)
Colorectal	74 (17%)	70 (16%)	21 (8%)
Prostate	39 (9%)	35 (8%)	82 (33%)
Lung	31 (7%)	32 (7%)	23 (9%)
Other	137 (31%)	142 (32%)	110 (44%)

were the most useful in the clinical setting. The 59 items of the SCNS were subjected to an exploratory factor analysis resulting in five factors identical to the domains of need of the original SCNS. Items with a primary factor loading > 0.70 and an item-to-total score correlation within their domain coefficient ≥ 0.65 for two domains (daily living, sexuality) and ≥ 0.75 for three domains (psychological, health information, patient care) were identified. Although somewhat arbitrary, these cut-points were selected as a means of identifying the most consistent items within a domain. The frequency distribution of each item was also examined to avoid the selection of items where more than 50% of respondents chose either the highest (ceiling effect) or lowest (floor effect) response category. The three authors reviewed the results of the statistical analysis and selected 34 items based on a combination of clinical relevance and statistical evidence. A minimum of three items per domain were selected to ensure stability of the domain [15].

Validation

In order to test the construct validity of the 34 items selected for the short-form SCNS, a confirmatory factor analysis with five factors specified was conducted. Items were attributed to the factor with the highest loading, and the proportion of the variance explained by the factor structure calculated. The internal reliability of each factor was assessed using Cronbach's alpha and item-to-total score correlations. In keeping with recommended guidelines, a minimum alpha coefficient of 0.7 and correlation coefficient of 0.4 was required to demonstrate that the items in each domain measured a common attribute [16].

Known-groups validity was tested by comparing the standardized Likert summated mean score for each SCNS domain between patients in remission and those not in remission. We expected patients not in remission to have higher mean scores on the psychological, health system and information, physical and daily living, and patient care and support domains than patients in remission. We did not expect any differences in mean scores on the sexuality domain between the two groups.

Convergent validity was assessed by correlating the short-form SCNS with other validated measures of psychosocial well-being. The correlations between the total number of moderate or high unmet needs and the score on the DT, anxiety and depression subscales of the HADS and global health status scale of the QLQ-C30 were calculated. Moderate positive correlations between 0.30 and 0.70 would indicate convergent validity of the short-form SCNS with the DT and HADS, while moderate negative correlations between -0.30 and -0.70 would indicate convergent validity with the QLQ-C30.

As an indicator of sensitivity, the ability of the short-form survey to detect patients with moderate or high needs was compared with the long-form survey. For each SCNS domain, the proportion of patients identified in the short-form survey as having at least one item of moderate or high need in that domain was calculated and compared with the proportion of patients identified in the long-form survey as having at least one item of moderate or high need in that domain. To assess the level of agreement between the two surveys, simple Kappa coefficients and the proportion of exact agreement were calculated for each domain. Kappa values of 0.41–0.6 would indicate moderate agreement, 0.61–0.8 substantial agreement and 0.81–1.0 almost perfect agreement [17].

Readability was assessed using the Flesch–Kincaid Grade Level test with the aim of achieving a reading grade score of 7–8.

Results

Item reduction

The exploratory factor analysis procedure identified 20 items that achieved both a factor loading of at least 0.70 and an item-to-total correlation meeting the specified cut-point for their domain. Six additional items were selected on the basis that their item-to-total correlation within their domain exceeded the specified cut-point for their domain and their factor loading was relatively high (0.51–0.69). Four additional items were selected on the basis of their relatively high factor loading (0.64–0.74) and their clinical importance. Four items were selected solely on the basis of their clinical importance. None of the selected 34 items showed ceiling or floor effects.

Validation

Confirmatory factor analysis identified five factors representing constructs identical to the original SCNS. These factors together accounted for 73% of the total variance. Ten items fell into the 'psychological' domain, 11 into the 'health system and information' domain, five into the 'physical and daily living' domain, five into the 'patient care' domain and three into the 'sexuality' domain. The items and their primary factor loading are displayed in Table 2.

As shown in Table 3, the 34-item SCNS achieved high internal consistency as demonstrated by Cronbach's alpha coefficients for the five factors ranging from 0.86 to 0.96. Item-to-total score correlation coefficients for all items exceeded 0.55. For each domain, less than 50% of respondents achieved either the highest (100) or lowest score (0).

As shown in Table 4, cancer patients not in remission had significantly higher mean scores on the psychological, health system and information, physical and daily living, and patient care and support domains than patients in remission. Given that higher scores indicate higher levels of need, patients not in remission showed higher levels of perceived need than patients in remission in the domains expected.

Convergent validity was confirmed by significant correlations between the 34-item SCNS and the HADS subscales, DT and QLQ-C30 global health status subscale. As expected, the correlation coefficients between the SCNS and the anxiety ($r = 0.48$) and depression ($r = 0.48$) subscales of the HADS and the DT ($r = 0.56$) were moderate. The correlation coefficient for the QLQ-C30 global health status score was -0.51 . All four correlations were statistically significant ($P < 0.0001$).

Table 5 shows for each domain the proportion of patients identified by the short-form and long-form SCNS as having some need for help as well as the overall level of agreement between the two surveys in identifying people with at least one item of unmet need. For each domain, the kappa coefficients indicated almost perfect agreement in the proportion of patients identified as having some need for help according to the 34-item SCNS compared with the long-form survey.

A Flesch–Kincaid Grade Level of 7.2 indicated that the 34-item SCNS could be readily comprehended by people with seventh-grade level of education, that is, approximately 8 years of schooling. The 34-item SCNS takes approximately 10 minutes to complete.

Discussion

We developed a short form of the SCNS to use in routine clinical practice and undertook the first steps in validating it. The results of these preliminary analyses suggest that the SCNS-SF34 may be a valid tool for assessing the needs of people with cancer. The 34-item survey measures the same constructs as the original SCNS: psychological, health system and information, patient care and support, physical and daily living, and sexuality needs [2]. The factor structure of the short-form survey explained more than 70% of the variance, thereby demonstrating good construct validity. The internal consistency of the short-form survey was comparable to its longer version, with Cronbach alpha coefficients exceeding 0.8 in all domains, and item-to-total score correlation coefficients for all items exceeding 0.55. The results also suggest that the short-form survey was able to distinguish between groups with known differences. A comparison of mean domain scores showed that patients not in remission had higher levels of psychological, health system and information, physical and daily living, and patient care and support needs than patients in remission. Furthermore, the instrument could be readily understood by people with an average level of education. Given the large sample size used for these analyses, we are confident that the 34 items will be useful in assessing needs for a wide spectrum of cancer patients in the clinical setting.

Results from preliminary analyses suggest that the short-form SCNS has good convergent validity with other validated instruments measuring similar constructs. The total number of unmet SCNS needs correlated moderately with three widely used valid

Table 2 Factor categories and item primary factor loadings

Factor	Item	Loading
Psychological	Anxiety	75
	Feeling down or depressed	78
	Feelings of sadness	80
	Fears about the cancer spreading	77
	Worry that the results of treatment are beyond your control	77
	Uncertainty about the future	77
	Learning to feel in control of your situation	74
	Keeping a positive outlook	69
	Feelings about death and dying	69
	Concerns about the worries of those close to you	63
Health systems and information	Being given written information about the important aspects of your care	78
	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	78
	Being given explanations of those tests for which you would like explanations	85
	Being adequately informed about the benefits and side-effects of treatments before you choose to have them	84
	Being informed about your test results as soon as feasible	84
	Being informed about cancer which is under control or diminishing (i.e. remission)	81
	Being informed about things you can do to help yourself to get well	78
	Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	64
	Being treated like a person not just another case	75
	Being treated in a hospital or clinic that is as physically pleasant as possible	79
Patient care and support	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	76
	More choice about which cancer specialists you see	77
	More choice about which hospital you attend	81
	Reassurance by medical staff that the way you feel is normal	57
	Hospital staff attending promptly to your physical needs	58
Physical and daily living	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	58
	Pain	68
	Lack of energy/tiredness	71
	Feeling unwell a lot of the time	68
	Work around the home	74
Sexuality	Not being able to do the things you used to do	73
	Changes in sexual feelings	89
	Changes in your sexual relationships	86
	To be given information about sexual relationships	77

Table 3 Cronbach alpha reliability coefficient and response distribution for each domain of the SCNS-SF34

Domain	alpha	Mean score		SD	% lowest score (floor)	% highest score (ceiling)
		(0–100)	Median			
Psychological (<i>n</i> = 414)	0.95	39.1	35.0	29.1	8	1
Health information (<i>n</i> = 404)	0.96	39.0	29.4	29.0	7	3
Daily living (<i>n</i> = 410)	0.86	36.6	30.6	26.6	11	1
Patient care (<i>n</i> = 406)	0.90	25.3	25.0	24.0	22	2
Sexuality (<i>n</i> = 397)	0.90	22.6	16.7	27.1	42	3

SCNS-SF34, 34-item short-form Supportive Care Needs Survey; SD, standard deviation.

and reliable measures of cancer-specific psychosocial well-being: the DT, HADS and QLQ-C30.

The cross-sectional nature of the Supportive Care Review data set did not allow us to test the ability of the SCNS-SF34 to detect changes in individual cancer patients' needs. Furthermore, we

have not yet determined what constitutes a meaningful change in level of need. When completed, our longitudinal Cancer Survival Study will be a useful data source for filling the gaps regarding further psychometric properties of the SCNS-SF34. Further testing of the instrument is required to examine other measurement prop-

Domain	Not in remission			In remission			P-value
	n	mean	SD	n	mean	SD	
Psychological	256	45.2	29.2	145	30.2	26.3	<0.0001
Health information	243	43.8	29.4	145	32.3	27.4	0.0002
Daily living	251	42.0	26.7	144	28.7	23.7	<0.0001
Patient care	250	28.3	25.4	142	20.6	20.8	0.0014
Sexuality	244	23.8	28.4	139	20.9	24.9	0.3175

SCNS-SF34, 34-item short-form Supportive Care Needs Survey; SD, standard deviation.

Table 4 Mean domain scores on the SCNS-SF34 for patients not in remission compared with those in remission

Table 5 Proportion of patients identified as having at least one moderate or high need for help by the SCNS-SF34 compared with the SCNS-LF59

Domain	SCNS-SF34 (n = 444)	SCNS-LF59 (n = 444)	% exact agreement	Kappa coefficient
Psychological	53%	59%	94	0.88
Health information	43%	44%	99	0.98
Daily living	47%	51%	94	0.83
Patient care	22%	29%	96	0.92
Sexuality	15%	15%	100	1.00

SCNS-LF59, 59-item long-form Supportive Care Needs Survey; SCNS-SF34, 34-item short-form Supportive Care Needs Survey.

erties including test-retest reliability and the ability of the instrument to predict future health status or events such as survival time.

These results provide early evidence for the construct validity and criterion validity of the 34-item SCNS in assessing the perceived supportive care needs of people diagnosed with cancer. This short-form survey was primarily developed to facilitate the routine assessment of cancer patients' needs in the clinical setting. Importantly, the 34-item SCNS showed almost perfect agreement in the proportion of patients identified as having some need for help compared with the long-form survey. Providing brief and valid information about cancer patients' needs could enable health care professionals to tailor their care to the specific needs identified by their patients.

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Statement of contribution

I, Prof Afaf Girgis, attest that Research Higher Degree candidate Allison Boyes contributed substantially to the conception, design and execution of the study; analysis and interpretation of data; and writing of the manuscript:

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Statement of contribution

I, Christophe Lecathelinais, attest that Research Higher Degree candidate Allison Boyes contributed substantially to the conception, design and execution of the study; analysis and interpretation of data; and writing of the manuscript:

Boyes A, Girgis A, Lecathelinais C. Brief assessment of adult cancer patients' perceived needs: development and validation of the 34-item Supportive Care Needs Survey (SCNS-SF34). *Journal of Evaluation in Clinical Practice* 2009; 15:602–606. doi:10.1111/j.1365-2753.2008.01057.x

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APPENDIX 5: Paper 5

RESEARCH ARTICLE

Open Access

Prevalence and correlates of cancer survivors' supportive care needs 6 months after diagnosis: a population-based cross-sectional study

Allison W Boyes^{1*}, Afaf Girgis², Catherine D'Este^{1,3} and Alison C Zucca¹

Abstract

Background: An understanding of the nature and magnitude of the impact of cancer is critical to planning how best to deliver supportive care to the growing population of cancer survivors whose need for care may span many years. This study aimed to describe the prevalence of and factors associated with moderate to high level unmet supportive care needs among adult cancer survivors six months after diagnosis.

Methods: A population-based sample of adult cancer survivors diagnosed with one of the eight most incident cancers in Australia was recruited from two state-based cancer registries. Data for 1323 survivors were obtained by self-report questionnaire and linkage with cancer registry data. Unmet needs were assessed by the 34-item Supportive Care Needs Survey (SCNS-SF34). The data were examined using chi-square and multiple logistic regression analyses.

Results: A total of 444 (37%) survivors reported at least one 'moderate to high' level unmet need and 496 (42%) reported 'no need' for help. Moderate to high level unmet needs were most commonly reported in the psychological (25%) and physical aspects of daily living (20%) domains. The five most frequently endorsed items of moderate to high unmet need were concerns about the worries of those close to them (15%), fears about the cancer spreading (14%), not being able to do the things they used to do (13%), uncertainty about the future (13%) and lack of energy/tiredness (12%). Survivors' psychological characteristics were the strongest indicators of unmet need, particularly caseness for anxious preoccupation coping which was associated (OR = 2.2-5.9) with unmet need for help across all domains.

Conclusions: Unmet supportive care needs are prevalent among a subgroup of survivors transitioning from active treatment to survivorship, although lower than previously reported. In addition to coping support, valuable insight about how to prevent or address survivors' unmet needs could be gained by examining the substantial proportion of survivors who report no unmet needs.

Background

Cancer is increasingly recognised as a chronic illness, with the number of people living with a history of the disease expected to triple to 75 million people worldwide in 2030 [1]. While most survivors adjust well over time [2], a minority are at risk of adverse physical [3,4], psychological [5,6] and social [7,8] effects which may emerge soon after diagnosis and treatment, or in the ensuing years. Detailed knowledge about the issues faced by survivors, their care

and support needs, and the extent to which these are met by current services is critical to guiding where to focus limited healthcare resources in order to deliver care that is responsive to the needs of the growing population of cancer survivors.

There are a number of different approaches for more fully understanding survivors' cancer experiences and quantifying their outcomes including assessment of quality of life, satisfaction with health care, and needs assessment [9,10]. Needs assessment not only identifies needs and their importance as perceived by the survivor, but also the extent to which they are met [10]. The key strength of this approach is that it enables resources to be focused on the

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issues that survivors have expressed they want addressed in order to achieve optimal wellbeing.

Increasing interest in the application of needs assessment to cancer care has resulted in the development of a number of valid and reliable cancer-specific tools assessing a comprehensive range of needs [9,11] and a growing literature describing their administration across a variety of settings, stages in the cancer journey, and populations. A recent systematic review found that while the prevalence of unmet need among cancer survivors varied from 30% to 50% across studies, it is typically highest in the psychological, health information, and physical aspects of daily living domains [12]. While evidence about the factors that influence survivors' unmet needs is inconsistent, a number of studies have found that those who are not in remission [13-15], are psychologically distressed [14,16-18] and geographically isolated [15,19] are more likely to report unmet needs. However, the literature is plagued by a lack of consistency in the methods used to measure, classify and report unmet needs, making it difficult to compare between studies and to generalise findings [12].

The seminal publication, *From Cancer Patient to Cancer Survivor: Lost in Transition* [20], focused the attention of the cancer control community on the survivorship stage of the cancer trajectory with a series of recommendations to accelerate progress in this area, including the need for large-scale studies using valid and reliable measures with diverse cancer populations to be conducted as a priority. Furthermore, a recent review [21] identified unmet supportive care needs as one of four main gaps in knowledge about the problems faced by adult cancer survivors. To guide care planning and help inform future health service delivery, the current study aimed to (1) describe the prevalence of adult cancer survivors' supportive care needs, overall and by cancer type, at six months post-diagnosis; (2) identify the most prevalent items of moderate to high level unmet need and (3) identify the individual, disease, health behaviour, psychological and social factors associated with survivors reporting moderate to high level unmet psychological, health systems and information, physical and daily living, patient care and support, and sexuality needs.

Methods

This paper is based on Time 1 (T1) data collected at six months post-diagnosis from survivors participating in the population-based longitudinal *Cancer Survival Study* (CSS). The study protocol and aspects of the study findings have been reported in detail elsewhere [22,23]. While the term cancer 'survivor' has varied definitions [24], this study considers 'survivor' to encompass anyone diagnosed with cancer, from the time of diagnosis to the end of life [25]. This paper focuses on survivors in the

late treatment to early survivorship phase of the cancer continuum.

Participants & procedures

The sample was recruited from new notifications to the two largest state-based cancer registries in Australia which together account for 60% of all new cancer cases diagnosed [26]. Eligibility was restricted to those who were (1) diagnosed in the previous six months with their first primary cancer of one of the top eight incident cancer types in Australia (prostate, colorectal, female breast, lung, melanoma, non-Hodgkin's lymphoma, leukaemia, head & neck); (2) aged between 18 and 80 years and living in the state of New South Wales (NSW) or Victoria (VIC) at diagnosis; (3) considered by their physician to be aware of their diagnosis, physically and mentally capable of participating in the study, and sufficiently proficient in English to complete a questionnaire; and (4) alive.

The recruitment and survey methodology have been described in detail previously [22]. Briefly, eligible potential participants whose physician had given active (NSW) or passive (VIC) consent for them to be contacted about the study received a mailed package from the registries. Eligible survivors who agreed to the registries passing on their contact details to the researchers were sent a self-administered questionnaire to complete. Non-responders were sent a reminder questionnaire three weeks later and received a reminder phone call after a further three weeks. A three week interval was used to allow adequate time for survivors to receive, respond to and return the mailed questionnaire prior to receiving a reminder. Return of the questionnaire to the research team indicated voluntary consent to participate. The Human Research Ethics Committees of the University of Newcastle (H-199-1101), Cancer Institute NSW and Cancer Council Victoria approved the study.

Measures

Data were collected by self-administered questionnaire with additional clinical information obtained from the Cancer Registries for each participant.

Outcome measure

Supportive care needs were measured by the 34-item Supportive Care Needs Survey (SCNS-SF34) which assesses cancer-specific perceived needs across five factor analytically derived domains: psychological (10 items), health systems and information (11 items), patient care and support (5 items), physical and daily living (5 items), and sexuality (3 items) [27]. For each item, respondents indicate their level of need for help over the last month as a result of having cancer on a five point Likert scale with the following response options: 1 = no need, not applicable; 2 = no need, satisfied; 3 = low need; 4 = moderate

need; and 5 = high need. For each domain, survivors were categorised as having a 'moderate to high' level of need if they selected response options 4 or 5 to at least one item in the domain or 'no to low' need if they selected response options 1, 2 or 3 to all items in the domain [28]. The SCNS-SF34 has high internal consistency with Cronbach's alpha of at least 0.86 for each subscale, and is moderately correlated with the Hospital Anxiety and Depression Scale, Distress Thermometer and Quality of Life Questionnaire-Core 30 (QLQ-C30) [27]. Furthermore, cancer patients have reported a preference for the SCNS-SF34 over the QLQ-C30, Functional Assessment of Cancer Therapy-General and Kingston Needs Assessment-Cancer as a strategy for conveying their needs to health care providers [29].

Study factors

Individual

Age at diagnosis and sex were obtained from the cancer registry. Current marital status, highest level of education completed, health insurance coverage, current employment situation, geographical location, size of household, and presence of physical co-morbidities were obtained by questionnaire.

Disease and treatment

Primary cancer type and spread of disease at diagnosis were obtained from the cancer registry, with survivors' cancer categorised as 'early/less progressed' (in-situ or localised; grade 1 or 2; T1 or T2), 'late/more progressed' (invasion of adjacent organs, regional nodes or distant metastases; grade 3 or 4; not T1) or 'not applicable' (haematological cancers). Extent of disease at six months post-diagnosis, and cancer treatments received in the last month were obtained by questionnaire.

Health behaviours

Seven questionnaire items adapted from existing measures assessed health behaviors: two items assessed smoking behavior, with participants classified as 'current', 'former' or 'never smoker' [30]; two items assessed alcohol consumption [31] and participants who consumed more than two standard drinks on any day were classified as being at 'increased lifetime risk of harm' from alcohol related injury or disease [32]; and three items assessed physical activity [33] with participants classified as 'sufficiently active' (at least 150 minutes of physical activity per week), 'insufficiently active' (participating in some activity but not enough in total time) or 'sedentary' (no physical activity) [34].

Psychological

Two questionnaire items assessed treatment for mental health illness (eg. depression, anxiety, schizophrenia)

before and since the cancer diagnosis. Coping was assessed by the 21-item Mini Mental Adjustment to Cancer Scale (Mini-MAC) which measures five cancer-specific coping strategies: helplessness-hopelessness, anxious preoccupation, fighting spirit, cognitive avoidance and fatalism [35]. The mini-MAC has demonstrated reliability with Cronbach alpha coefficients for each subscale ranging from 0.62–0.88. Raw scores for each subscale were standardised from 0 to 100 [35] and survivors who scored in the top 16% of each distribution were classified as a 'case' on that specific coping strategy [36].

Social

Social support was assessed by the MOS Social Support Survey (MOS – SSS) which measures four domains of functional support: emotional/informational, tangible, affectionate, and positive social interaction [37]. Raw subscale scores were standardised from 0 to 100 and survivors who scored in the bottom one-third of each distribution were classified as having 'low' availability of that particular type of social support (Sherbourne, personal communication). The survey has high internal consistency with alpha coefficients exceeding 0.91 for each subscale and demonstrated validity with the chronic illness population [37].

Statistical methods

Due to small numbers, data from survivors diagnosed with non-Hodgkin's lymphoma or leukaemia were combined and categorised as 'haematological' cancer. The proportion of survivors who reported either 'no needs' (ie. selected response option 1 or 2 to all 34 items), 'low needs' (ie. selected response option 3 to at least one item, but did not select response option 4 or 5 to any items) and 'moderate to high needs' (ie. selected response option 4 or 5 to at least one item) was calculated overall and by cancer type, with 95% confidence intervals. The association between cancer type with reporting 'no needs', 'low needs' and 'moderate to high needs' was examined using chi-square analyses. For each domain, the proportion of survivors who reported 'moderate to high needs' versus 'low or no needs' was calculated with 95% confidence intervals. The proportion of survivors who endorsed each SCNS-SF34 item at either a 'moderate' or 'high' level was calculated with 95% confidence intervals and the ten most prevalent items and their corresponding domain identified. Chi-square analyses examined the association between survivors' individual, disease, health behaviour, psychological and social characteristics with 'moderate to high needs' versus 'low or no needs' for each domain. Multiple logistic regression analyses were then conducted to examine factors associated with 'moderate to high needs' while adjusting for potential confounders. Variables with a p-value ≤ 0.2 on

univariate analyses were included in a backward logistic regression model for each domain. Variables were removed from the model if they had a p-value <0.1 on the likelihood ratio test; those with a p-value ≤0.05 were considered statistically significant.

Sample size

The registries were required to recruit a quota of 1660 eligible survivors who consented to being contacted about the study. Based on previous experience [6], we estimated that 80% of survivors would return a completed survey, resulting in a sample size of approximately 1320 at T1. Assuming a prevalence of moderate to high needs of 20%, a sample of this size would allow the proportion of survivors with unmet needs to be estimated with 95% confidence intervals within ± 3%, and provide 90% power to detect differences of 7% between categories of study factors associated with moderate to high needs at the 5% significance level.

Results

Sample

Of the 3877 potential participants assessed for study eligibility, 3315 were deemed eligible and of these, 1691 (51%) consented to being contacted about the study by the researchers. A total of 1360 eligible survivors returned a T1 survey (41% response rate at T1). Thirty seven participants who returned their T1 survey more than 9 months after diagnosis were excluded from analyses. The 1323 survivors included in these analyses were surveyed at a median of 6 months after diagnosis (SD = 1 month, minimum 4 months, maximum 9 months) and their median age was 63 years (SD = 11 years; minimum 18 years, maximum 80 years). More than half of the participants (59%) were male, about half were diagnosed with early stage disease (52%), the most common diagnosis was prostate cancer (26%), almost two-thirds (62%) were in remission at the time of survey completion and 72% had not received any active treatment in the last month. While the study sample reflected the national profile [24] for the top eight incident cancers diagnosed in 2005 in terms of gender and age, survivors of colorectal cancer appeared to be under-represented and haematological and head and neck cancers over-represented. Participant characteristics have been reported in detail elsewhere [22].

Prevalence of supportive care needs

As shown in Table 1, 496 (42%, 95% CI: 39%-45%) survivors reported 'no need' for help with all of the 34 items assessed. A total of 444 (37%; 95% CI: 34%-40%) survivors reported having at least one 'moderate to high' level unmet supportive care need and of these, 53% (n = 237) had one to four 'moderate to high' needs and 47%

(n = 207) had five or more 'moderate to high' needs. There was significant variation across cancer types in the percentage of survivors who reported unmet needs ($\chi^2 = 91.39$; df = 12; $p < 0.001$). 'Moderate to high' level unmet needs were most common amongst survivors of lung cancer with more than half (60%; 95% CI: 51%-69%) endorsing at least one item. Conversely, almost two-thirds (65%; 95% CI: 58%-72%) of melanoma survivors reported 'no need' for help with all items.

At the domain level, 318 (25%; 95% CI: 23%-27%) survivors reported unmet psychological needs, 251 (20%; 95% CI: 18%-22%) reported unmet physical aspects of daily living needs, and 232 (18%; 95% CI: 16%-20%) reported unmet health systems and information needs at a 'moderate to high' level. Only 167 (13%; 95% CI: 11%-15%) and 103 (8%; 95% CI: 7%-9%) survivors respectively reported 'moderate to high' level unmet need for help with sexuality, and patient care and support domains.

Most prevalent 'moderate to high' level unmet supportive care needs

The 10 highest ranked items that survivors reported a 'moderate to high' level of need for help with are shown in Table 2. Overall, individual items were endorsed by relatively few (≤15%) survivors. The highest ranked items were *concerns about the worries of those close to you* (15%), *fears about the cancer spreading* (14%), *not being able to do the things they used to do* (13%), *uncertainty about the future* (13%), and *lack of energy/tiredness* (12%). Half of the top 10 needs items were from the psychological domain, three were from the physical aspects of daily living domain and the remaining two items were from the sexuality domain.

Factors associated with 'moderate to high' level unmet need

The individual, health behaviour, disease, treatment, psychological and social characteristics associated with survivors reporting 'moderate to high' level unmet needs by domain are shown in Tables 3, 4 and 5. Domains are displayed side-by-side for ease of comparison.

Individual

Age at diagnosis and current employment status were associated with multiple domains of unmet need (see Table 3). The odds of reporting sexuality, and health system and information needs increased with decreasing age. Compared to those who were retired, survivors who were currently not working (on leave, student, unemployed) or doing unpaid work (volunteer, household duties) had about twice the odds of reporting physical aspects of daily living and sexuality needs as those who were retired. Age was marginally non-significantly associated with psychological need. Married or de facto

Table 1 Prevalence of supportive care needs at six months post-diagnosis by cancer type

	Total* (N = 1187)	Prostate (n = 309)	Melanoma (n = 188)	Breast (n = 186)	Blood (n = 164)	Colorectal (n = 145)	Lung (n = 108)	Head & neck (n = 87)
	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)	n % (95% CI)
No needs [†]	496	134	122	56	54	66	29	35
	42 (39–45)	43 (37–49)	65 (58–72)	30 (23–37)	33 (26–40)	46 (38–54)	27 (19–35)	40 (30–50)
Low needs [‡]	247	58	33	47	38	31	14	26
	21 (19–23)	19 (15–23)	17 (12–22)	25 (19–31)	23 (17–29)	21 (14–28)	13 (7–19)	30 (20–40)
Moderate to high needs [§]	444	117	33	83	72	48	65	26
	37 (34–40)	38 (33–43)	17 (12–22)	45 (38–52)	44 (36–52)	33 (25–41)	60 (51–69)	30 (20–40)

* includes those with no missing items across all domains.

[†] selected 'no' need for help to all 34 items.

[‡] selected 'low' level need for help to at least one item, but did not select 'moderate' or 'high' need to any item.

[§] selected 'moderate' or 'high' level need for help to at least one item.

survivors had three times the odds of unmet sexuality needs compared to those who were single or widowed.

Health behaviour

Physical activity was the only health behaviour associated with moderate to high level unmet needs (see Table 3). The odds of reporting unmet psychological, and physical and daily living needs increased with decreasing levels of physical activity.

Disease and treatment

Cancer status, cancer type and having received chemotherapy in the last month were associated with multiple domains of unmet need (see Table 4). Compared to survivors in remission, those not in remission (stable, recurrent, metastatic disease) had about twice the odds of unmet health system and information, and patient care and support needs. Compared with survivors of melanoma, survivors of all other cancer types except head and neck had at least four times the odds of unmet sexuality

needs, while lung, breast and haematological cancer survivors had at least two times the odds of unmet physical and daily living needs. Survivors who received chemotherapy in the last month had higher odds of unmet psychological, and physical and daily living needs than those who didn't receive chemotherapy in the last month.

Psychological

Coping strategy and mental health treatment were associated with multiple domains of unmet need (see Table 5). Survivors who engaged in anxious preoccupation coping had two to six times higher odds of reporting unmet needs across all domains compared to survivors who did not use this coping strategy. Survivors who used helpless-hopeless coping had about twice the odds of reporting unmet psychological, health system and information, and patient care and support needs compared to those who didn't use this strategy, while those who used cognitive avoidance coping had higher odds of reporting unmet psychological needs compared to those who didn't

Table 2 Ten most prevalent 'moderate' or 'high' level unmet supportive care needs

Rank	SCNS-SF34 item	Number (%) moderate or high needs	Domain
1	Concerns about the worries of those close to you	192 (15)	Psychological
2	Fears about the cancer spreading	185 (14)	Psychological
3	Not being able to do the things you used to do	169 (13)	Physical/ daily living
4	Uncertainty about the future	168 (13)	Psychological
5	Lack of energy/tiredness	157 (12)	Physical/ daily living
6	Changes in your sexual relationships	140 (11)	Sexuality
7	Changes in sexual feelings	139 (11)	Sexuality
8	Work around the home	137 (11)	Physical/ daily living
9	Worry that the results of treatment are beyond your control	128 (10)	Psychological
10	Feeling down or depressed	120 (9)	Psychological

Total number of observations for each item ranges from 1292–1302 due to missing values.

Table 3 Individual and health behaviour characteristics associated with moderate to high level unmet needs by domain*

	Psychological	Physical & daily living	Sexuality	Health system & information	Patient care & support
	<i>p-value</i> Adjusted OR (95% CI)	<i>p-value</i> Adjusted OR (95% CI)	<i>p-value</i> Adjusted OR (95% CI)	<i>p-value</i> Adjusted OR (95% CI)	<i>p-value</i> Adjusted OR (95% CI)
Individual					
<i>Sex</i>			0.089		
Female			0.56 (0.29-1.1)		
Male			1.00		
<i>Marital status</i>			<0.001		
Married/ defacto			3.0 (1.6-5.6)		
Single/ widowed			1.00		
<i>Age at diagnosis</i>	0.06		0.002	0.008	
49 and younger	1.7 (0.98-2.8)		4.4 (1.8-10.6)	2.9 (1.5-5.5)	
50-59	1.1 (0.67-1.8)		4.3 (2.0-9.1)	2.5 (1.3-4.6)	
60-69	0.88 (0.55-1.4)		2.7 (1.5-5.2)	2.2 (1.3-3.9)	
70 and older	1.00		1.00	1.00	
<i>Current employment</i>		<0.001	0.005		
Paid work		0.78 (0.51-1.2)	0.92 (0.54-1.6)		
Not working		1.8 (1.2-2.8)	2.0 (1.1-3.4)		
Retired		1.00	1.00		
Health behaviour					
<i>Physical activity</i>	0.05	<0.001			
Sedentary	1.7 (1.1-2.7)	2.5 (1.6-4.0)			
Insufficient	1.5 (0.99-2.1)	1.8 (1.2-2.7)			
Sufficient	1.00	1.00			

* also adjusted for disease, treatment, psychological and social characteristics as reported in Tables 4 and 5.
OR = odds ratio; CI = confidence interval; p-value on the Wald chi-square analysis of effects test.

use this strategy. Compared to survivors without a history of mental health treatment, those who had been treated for such problems before their cancer diagnosis had around twice the odds of unmet physical and daily living, and patient care and support needs, while those who had been treated for such problems since their cancer diagnosis had almost three times higher odds of unmet psychological needs.

Social

Compared to those with some affectionate support, survivors who perceived they had low levels of affectionate support had lower odds of health system and information, and higher odds of patient care and support needs. Compared to survivors with some positive social interaction, survivors who perceived that they had low levels of positive social interaction had higher odds of unmet sexuality, and health system and information needs. Survivors who perceived low levels of emotional/informational support also had

higher odds of unmet health system and information needs (see Table 5).

Discussion

This study found that six months after a cancer diagnosis, about one-third (37%) of survivors reported one or more items of moderate or high level unmet need, while almost two thirds (63%) reported either no or low level unmet needs. The most commonly reported moderate to high level unmet needs were from the psychological and physical and daily living domains. This is consistent with other recent needs assessments conducted with samples of cancer survivors at the end of treatment [17], in early phases of survivorship [15,18] and in long-term survivorship [14,16]. However, previous studies [13,15,17,18] found between 43%-60% of survivors reported at least one moderate or high level unmet need, compared to 37% of survivors in this study. Similarly, unlike earlier studies which found the most prevalent item of moderate

Table 4 Disease and treatment characteristics associated with moderate to high level unmet needs by domain*

	Psychological	Physical & daily living	Sexuality	Health system & information	Patient care & support
	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)
Disease					
Cancer status				<0.001	0.001
Not remission				2.0 (1.4-2.9)	2.2 (1.4-3.5)
Remission				1.00	1.00
Cancer type		0.003	<0.001		
Breast		2.3 (1.1-4.6)	9.0 (2.5-32.2)		
Colorectal		2.1 (0.97-4.5)	6.4 (1.7-24.3)		
Blood		2.2 (1.1-4.5)	4.3 (1.2-15.5)		
Head neck		1.0 (0.41-2.5)	1.1 (0.21-6.1)		
Lung		4.1 (2.0-8.7)	5.8 (1.6-21.8)		
Prostate		1.7 (0.86-3.4)	23.1 (6.7-80.4)		
Melanoma		1.00	1.00		
Treatment					
Surgery			0.093		
Yes			2.1 (0.89-4.8)		
No/DK			1.00		
Chemotherapy	0.005	0.023			
Yes	1.8 (1.2-2.8)	1.6 (1.1-2.5)			
No/DK	1.00	1.00			
Radiotherapy	0.05				
Yes	1.6 (0.99-2.7)				
No/DK	1.00				
Other				0.062	
Yes				2.3 (0.96-5.7)	
No/DK				1.00	

* also adjusted for individual, health behaviour, psychological and social characteristics as reported in Tables 3 and 5.
 OR=odds ratio; CI=confidence interval; p-value on the Wald chi-square analysis of effects test; DK=don't know.

or high unmet need occurred among 27-40% of recent survivors [13,17,18], the most commonly reported item of unmet need in this study was endorsed by only 15% of survivors.

The prevalence of unmet need reported by survivors in this study is clearly lower than previously reported, despite using the same validated instrument, and classification of unmet need. This may be because earlier studies of cancer survivors diagnosed with a diversity of cancer sites did not use population-based samples [13,17,18] and are therefore more susceptible to selection bias. In contrast, we used the two largest state-based cancer registries in Australia to assemble a population-based sample of survivors in the very early stages of cancer survivorship. Given that the study sample is generally representative of the source population, we are confident in our findings that most

survivors' supportive care needs, as measured by the SCNS-SF34, are relatively well met.

Due to the size and composition of the study sample, we were able to directly compare the prevalence of supportive care needs between seven common cancer types in Australia [26]. This bivariable analysis revealed significant variation across cancer types, with particularly low levels of unmet need reported by survivors of melanoma, 65% of whom reported no items of unmet need. This is fitting with our anecdotal experience whereby participants who were survivors of melanoma often questioned the legitimacy of their contribution to the study as they perceived themselves to have suffered less than survivors of other cancer types, and therefore less deserving of attention. Australia has the world's highest incidence rate of melanoma; it is typically identified at early stages when simple treatment such as surgery will achieve a

Table 5 Psychological and social characteristics associated with moderate to high level unmet needs by domain*

	Psychological	Physical & daily living	Sexuality	Health system & information	Patient care & support
	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)	<i>p</i> -value Adjusted OR (95% CI)
Psychological					
<i>Anxious preoccupation</i>	<0.001	<0.001	<0.001	<0.001	<0.001
Case	5.9 (4.0-8.7)	2.2 (1.5-3.2)	3.4 (2.2-5.3)	3.3 (2.2-5.1)	3.1 (1.8-5.2)
No case	1.00	1.00	1.00	1.00	1.00
<i>Helpless/hopeless</i>	<0.001			0.016	0.002
Case	2.2 (1.5-3.3)			1.7 (1.1-2.7)	2.3 (1.3-3.8)
No case	1.00			1.00	1.00
<i>Cognitive avoidance</i>	0.02		0.049		
Case	1.5 (1.1-2.1)		1.5 (1.0-2.3)		
No case	1.00		1.00		
<i>Mental health help before cancer</i>		<0.001	0.032		<0.001
Yes		2.1 (1.4-3.2)	1.7 (1.0-2.8)		2.5 (1.5-4.2)
No		1.00	1.00		1.00
<i>Mental health help since cancer</i>	<0.001				
Yes	2.9 (1.6-5.2)				
No	1.00				
Social					
<i>Affectionate support</i>				0.020	0.003
Low				0.47 (0.25-0.89)	2.1 (1.3-3.4)
Some				1.00	1.00
<i>Positive social interaction</i>		0.05	0.014	0.002	
Low		1.4 (0.99-2.0)	1.7 (1.1-2.5)	2.6 (1.4-4.8)	
Some		1.00	1.00	1.00	
<i>Emotional/informational</i>	0.04			0.002	
Low	1.4 (1.0-2.1)			2.2 (1.3-3.6)	
Some	1.00			1.00	

* also adjusted for individual, health behaviour, disease and treatment characteristics as reported in Tables 3 and 4.
OR=odds ratio; CI=confidence interval; p-value on the Wald chi-square analysis of effects test.

good prognosis [38]. It is possible that the omission of melanoma survivors from the sample composition of previous studies [17,18] may have contributed to their higher prevalence of unmet need compared to this study. In contrast, the highest levels of unmet need were reported by survivors of lung cancer, with 60% reporting at least one item of moderate or high level need. Given the high level of burden associated with lung cancer in terms of poor prognosis, treatment side effects and declining physical health, this finding is not surprising.

Subgroups of survivors with domain-specific and widespread unmet needs were identified. After adjusting for a comprehensive range of individual,

disease, health behaviour, psychological and social factors, cancer type was found to be significantly associated with moderate to high level unmet physical and daily living, and sexuality needs only. In particular, survivors of lung cancer had the highest odds of reporting unmet physical and daily living needs, while survivors of prostate cancer had extremely high odds of reporting unmet sexuality needs. These findings suggest that the type of unmet need experienced by survivors does not routinely differ between cancer types. Rather, the notion of cancer site-specific unmet needs appears to apply to only a few explicit dimensions of unmet need.

Consistent with previous studies, not being in remission was associated with unmet health system and information, and patient care and support needs; this is not surprising given this subgroup of survivors is likely to be receiving intermittent treatment and symptom management. While almost three quarters of survivors reported not receiving any active treatment in the last month, we did not assess if participants had completed all active treatments given the changeable and uncertain nature of adjuvant treatment regimes. While each treatment was considered separately, having received chemotherapy in the last month was the only treatment associated with higher odds of reporting unmet needs. Interestingly, physical activity was the only health behaviour associated with unmet needs, with sedentary survivors reporting higher odds of unmet psychological, and physical and daily living needs. Although 37% of the sample resided in regional or remote areas, our results did not support the findings from previous studies of an association between rural location and unmet needs. On account of the range of study factors examined in this study, a number of associations were established for the first time. Low levels of social support and maladaptive coping styles were associated with multiple domains of unmet need. Notably, survivors who were identified as a case on anxious preoccupation coping had more than twice the odds of reporting unmet needs across all five domains. While causation cannot be inferred, the new associations identified in this study are particularly valuable because social support and coping style are potentially amenable to intervention. In particular, attention could be directed towards exploring the contribution that targeted coping interventions focusing on anxiety and helplessness, could make towards the prevention of or reduction in survivors' unmet needs across a number of domains.

Strengths and limitations

While previous needs assessments have also included a diversity of recent cancer survivors [13,17,18], the population-based sampling method used in this study is a major strength as it increases the generalisability of the results. In Australia, the notification of cancer to the cancer registry is a statutory requirement under the state and territory Public Health Acts. Indices of registry data quality demonstrate that the level of case ascertainment is high and the data collected are accurate [39]. However, the overall response rate was 41% (1360/3315 eligible individuals) and may raise concerns about response bias. While this response rate seems low, it is higher than that achieved by other studies which also used cancer registries to recruit diverse samples of recent survivors [40,41]. Survivors who were not proficient in English were excluded due to the prohibitive cost of translating the

questionnaire into other languages and may have resulted in an underestimate of the prevalence of unmet needs given that language barriers have been associated with poorer access to health care services. Our outcome measure, the SCNS-SF34, is a well-validated tool for assessing multiple dimensions of supportive care need and was developed with diverse samples of individuals diagnosed with cancer in terms of cancer type and time since diagnosis [27]. However, it is possible that the SCNS-SF34 may not fully capture the unique needs of cancer survivors in the late treatment to early survivorship phase of care, and therefore this study may underestimate the prevalence of unmet need reported by survivors at six months post-diagnosis. Since this study commenced, two cancer survivor-specific needs assessment tools [41,42] have been developed and should be considered for use in future studies.

Conclusions

About one-third of cancer survivors in the transition from late treatment to early survivorship had moderate to high levels of unmet need, particularly in the psychological and daily living domains. Our findings directly inform health care professionals and organisations involved in the provision of survivorship care about the actions, resources and services most needed by subgroups of survivors. Our findings also suggest that coping support interventions may have the potential to contribute to the prevention or reduction of survivors' unmet needs across all domains. However, it is important not to overlook the finding that 63% of survivors in this study reported no or low level unmet needs at six months post-diagnosis and for whom current care appears to adequately meet their needs. On the basis that a valuable new perspective about how to prevent or reduce cancer survivors' unmet needs could be gained from those with no unmet needs, future research should seek to identify and better understand this subgroup of survivors.

Competing interests

The authors declare that they have no competing interests.

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Authors' contributions

AB participated in study conception, design and acquisition of funding; was responsible for implementing the study protocol; performed some of the statistical analysis; interpreted the data and drafted the manuscript. AG participated in study conception, design and acquisition of funding. CD participated in the study design and acquisition of funding, and coordinated the statistical analysis. AZ helped to implement the study protocol and performed some of the statistical analysis. All authors participated in revising the manuscript, and read and approved the final version.

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Statement of contribution

I, Prof Afaf Girgis, attest that Research Higher Degree candidate Allison Boyes contributed substantially to the conception and design of the study, securing competitive grant funding, execution of the study including overall responsibility for collection and assembly of data, analysis and interpretation of data, and writing of the manuscript:

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Statement of contribution

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APPENDIX 6: Additional publications relevant to this thesis

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ISSUES FOR CANCER SURVIVORS IN AUSTRALIA

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Abstract

As the number of people surviving cancer continues to increase, the need to know about the issues they face and how to support them becomes more urgent. Cancer is a life-changing diagnosis, with many survivors experiencing a range of both positive and negative outcomes attributed to cancer. While most survivors adjust well over time and experience relatively high quality of life, issues persist for some. Many survivors experience ongoing physical effects such as fatigue, pain and sexual problems. Some experience elevated levels of anxiety, depression or mood impairment and ongoing disruptions to daily living and social activities. New issues that emerge can include employment problems, insurance difficulties and worries about health, including cancer recurrence. Positive effects include changed values and goals, enhanced appreciation of life, improved close relationship with others, altruism and lifestyle changes. This article provides a brief overview of the psychological, physical, social and existential impact of cancer, with an emphasis on the issues faced by survivors after the completion of primary treatment.

"Two years after diagnosis, it is hard getting used to the new me." I don't have the strength, flexibility or stamina that I used to, and have to adjust to achieving less each day than my mind expects me to... Still, I am generally not in pain and happy to still be here with my family and friends. I have down-sized my career, which has had a financial impact, but I think has achieved a better work/life balance for this stage in my recovery."

The past three decades have seen significant improvements in the survival outcomes of those diagnosed with cancer, with more than 60% expected to be alive at least five years after their initial diagnosis.¹ It is estimated that about 340,000 people in Australia are living with a history of cancer, representing about 2% of the Australian population.² Many more will have an experience of cancer as a partner, family member or friend of someone with cancer. Given the multicultural nature of the Australian community, many survivors will be from culturally and linguistically diverse backgrounds (CALD). While most survivors are considered cured and/or cancer-free, others live with active disease and for many, cancer becomes a chronic disease.

The term cancer 'survivor' has varied definitions and has been used to describe those diagnosed with cancer who are alive and/or disease-free after five years, diagnosed patients who have completed primary treatment, as well as patients at any point from diagnosis.³ This article adopts the widely accepted National Cancer Institute Office of Cancer Survivorship definition of a cancer 'survivor' to encompass anyone diagnosed with cancer, from the time of diagnosis to the end of life.⁴ Mullan (1985) described survival as a three phase process: acute survival includes the diagnosis and treatment phases often dominated by fear and anxiety; extended survival starts at the

completion of active treatment or remission of disease and is characterised by fear of recurrence, physical limitations such as fatigue and monitoring for recurrence and late effects of treatment; permanent survival evolves from extended survival when the risk of recurrence is low and patterns of normal life may be re-established.⁵

A diagnosis of cancer is typically experienced as very distressing. Cancer treatments are often invasive and prolonged, placing significant demands on the person diagnosed, as well as their family and loved ones. While acknowledging that each individual's experience is unique, it is well accepted that cancer may have a significant psychological, physical, social and existential impact upon survivors with both positive (eg. feelings of gratitude) and negative sequelae (eg. distress, fatigue) reported. Although there are relatively few longitudinal studies, it is also known that some effects are long-term or permanent (eg. infertility) and others manifest some time after treatment completion (eg. lymphoedema). The extent to which these effects are experienced by survivors is known to vary according to characteristics such as age, gender, ethnicity, type of cancer, stage of disease, treatment modality, social support and coping style.⁶

In order to help the growing population of cancer survivors in Australia to 'thrive', it is important to understand the range of issues they face. Although most studies have focused on survivors in the acute survival phase, there is an emerging body of evidence describing the experience of those who have completed potentially curative treatment. Drawing on Australian research where possible, this article provides a selective and brief overview of the issues faced by cancer survivors, with an emphasis on the extended and permanent phases of survival.

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Psychological

Estimates of the prevalence of psychological morbidity experienced by cancer survivors vary widely across studies. However, it is generally agreed that distress is most common in the acute survival phase and declines over time since diagnosis; studies have found that cancer survivors' levels of distress typically return to a level comparable to the general population and individuals with no history of cancer, around two years post-diagnosis.⁷ Consistent with international research, a recent study conducted in Australia indicated that long-term survivors of cancer often report levels of psychological wellbeing that matches or exceeds population levels.⁸

Nonetheless, areas of concern may persist for some survivors. For example, many survivors report a heightened sense of vulnerability, loneliness, worries about their health, concerns about burdening their loved ones, and anxiety about the possibility of cancer recurrence. Studies undertaken in Australia consistently report fear of cancer recurrence and uncertainty about the future as the most common concerns survivors need help to manage,^{9,11} and are associated with an inability to make future plans. Adverse psychological outcomes tend to be more prevalent among female survivors compared to male survivors, and younger survivors (less than 50 years) compared to older survivors.¹²

Although many survivors find follow-up testing stressful, they also feel anxious about leaving the safety of the hospital system when they transition from the end of treatment to long-term follow-up.¹⁰ When cancer does recur, it is often experienced as more traumatic than the first diagnosis and reinforces the importance of periodic screening for distress across the cancer trajectory, including the survivorship phase.¹⁴ Anecdotally, some survivors report experiencing feelings of guilt because they survived and someone else they knew with cancer didn't, although this is not well documented in the scientific literature.

Despite the absence of evidence to support this notion, it is common for those who have experienced cancer to adopt a 'positive attitude' in the belief that this may contribute to longer survival. For some individuals, this strategy may confer a sense of control and optimism, while for others it represents a burden, especially if there is pressure, either overt or covert, to avoid discussing painful or confronting issues. Furthermore, the belief that one's force of will and attitude can influence the course of cancer poses a burden if cancer recurs, with the implication being that the individual "has not tried hard enough".

Research undertaken in Australia reveals that there are a number of issues specific to CALD communities that are an additional source of distress to CALD cancer survivors. In the Chinese, Greek and Arabic communities, cancer is perceived as incurable, sometimes connoting 'certain' and 'imminent' death, and a source of stigma for self and family that should be kept a private matter. In some parts of the Greek and Chinese communities, cancer is still viewed as contagious.¹⁵⁻¹⁷ Survivors and their families from Arabic, Chinese and Greek backgrounds also report feelings of loss of power and control, and consequent

difficulties navigating the health system due to difficulties with both written and verbal language.¹⁸

Physical

Fatigue is commonly experienced by survivors and can be profoundly debilitating: "At its worst, cancer-related fatigue is a draining, unrelenting exhaustion that impedes the ability to enjoy life and carry out daily activities".¹⁹ Unlike other visible markers of cancer treatment such as hair loss, fatigue is not apparent to others, and survivors may be reluctant to discuss fatigue because they 'look well', or intuitively believe that rest will help. Given the evidence about the benefits of exercise in reducing fatigue in cancer survivors, exploration of fatigue and provision of information about strategies to deal with this should be part of routine clinical care.²⁰

Although pain in advanced cancer is recognised as a management concern, there is emerging evidence that cancer survivors may experience chronic pain, and given its association with depression, is an area that merits closer attention.²¹ Survivors' reluctance to report pain may be due to fear that the pain represents residual or recurrent cancer.

It is now recognised that cognitive changes occur in those who have been treated with chemotherapy,²² although there is insufficient evidence about the precise mechanism of this, and risk factors for its development. The nature of the deficit is often subtle and not evident in casual social contact, but problems with new learning, organisation and ability to self-monitor and self-correct are commonly identified on neuropsychological testing, and can be disabling to the point of interfering with the ability to return to work. In Australia, research is being initiated to assess the effectiveness of computer-based programs designed to "retrain" affected individuals (Vardy J, personal communication).

There is an extensive literature describing the adverse impact of cancer treatment on body image and sexuality, and the former focus on breast cancer has expanded to include other cancers such as prostate cancer. Sexual difficulties are common and can impact upon other aspects of intimacy and relationship functioning. Sexual difficulties can be due to direct effects of treatment, such as gynaecological cancers treated with surgery and radiotherapy, and indirect effects such as chemotherapy-induced menopause, pain and fatigue. Effective treatments are available however, once established, problems tend to persist in the absence of active intervention.²³ An active approach to management is now promoted and interventions should take into account interpersonal and relationship issues, self-esteem and body image in addition to biological factors.²⁴

The loss of fertility following treatment may represent a major setback and be associated with significant psychological distress and relationship difficulties.²⁵ The impact is obvious for a young woman or man, however for those who already have children the impact may not be apparent to extended family members or social contacts. Even women who have regarded their family as "complete" prior to the development of chemotherapy-

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Induced menopause may express grief and regret about the choice of future pregnancies being taken away from them.

Social

Social relationships may change as a consequence of diagnosis; some may not provide anticipated support, others may decrease over time, while new relationships and sources of support may emerge.²⁶ Family members may rate the cancer experience as more stressful than patients,²⁷ highlighting the importance of attention to the adjustment of family members. Divergence in priorities and attitudes can result in tensions in relationships emerging, with the cancer survivor being expected to "move forward". A strong attempt to "get back to normal" can represent the desire of family members and significant others to avoid contemplating the risk of recurrence or a less certain future.

Although most survivors function effectively in a work environment following the completion of cancer treatments, a minority may take a number of years to return to work, or will return to work in a diminished capacity. Studies indicate employment discrimination, difficulties with re-entry into the workforce, dismissal, demotion and lack of career advancement can be experienced by some cancer survivors.^{28,29} Adverse socioeconomic and financial effects may be partly due to such difficulties in addition to out-of-pocket medical costs and difficulties borrowing from financial institutions. Access to insurance coverage for health care, sickness, disability, life and travel can also be problematic following a diagnosis of cancer.³⁰

Some of these difficulties (eg. relationship changes) may be accentuated in CALD survivors because of the stigma and taboos surrounding cancer, and the associated reluctance to discuss this outside of the family.^{15,16} Feelings of isolation may also be compounded by a sense of cultural isolation. Regardless of English ability, CALD survivors have described experiencing an additional level of comfort, support, and familiarity when treated by people from their own culture, and feelings of separation, isolation, and difficulty building relationships when this is absent.

Existential

Most survivors report that life is never the same after a cancer diagnosis. Many re-evaluate and change their values, goals, priorities and outlook on life as a result of facing their own mortality.³¹ Little et al described the process of 'liminality' commencing at the first experience of malignancy, whereby "each patient constructs and reconstructs meaning for their experience by means of a narrative. This phase persists, probably for the rest of the cancer patient's life."³² Learning to adjust to a new 'normal' can be challenging and two recent studies conducted in Australia identified that many survivors struggle to cope with changes to their self-identity and expectations of themselves as a cancer survivors.^{10,12} The obvious relief of survival may be tinged with sadness about the cost at which this has been achieved, for example limited functioning or inability to parent children.

Numerous positive outcomes and improvements in wellbeing have been reported in both the empirical and popular literature on cancer survivorship. Several studies have found that most survivors, including CALD survivors, perceive benefits from their cancer experience such as personal growth, enhanced appreciation for life, living fuller and more meaningful lives, closer relationships with others, existential gains, increased faith and positive lifestyle changes such as increased exercise and healthier diet.^{10,12,17,33,34} There is some evidence suggesting that women and younger survivors are more likely to identify personal growth and other positive aspects of cancer, while men and older survivors are more likely to minimise its impact and perceive it as just a part of living.³⁵ Researchers advocate the inclusion of positive change items in outcome assessments to capture the breadth of individuals' experiences and to identify opportunities for improving outcomes.³⁶

Future directions

A key perspective missing in our understanding of the issues faced by cancer survivors is longitudinal studies that follow survivors with repeated assessments to see how they fare over time. Further research exploring the specific needs of CALD survivors is also required. Recognition of the importance of this type of research has increased with the high profile report *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁵ recommending large-scale population-based studies conducted with the diversity of cancer survivors be undertaken as a matter of priority. Two studies addressing these priority areas are currently underway in Australia; the Cancer Survival Study undertaken by the Centre for Health Research and Psycho-oncology (CHeRP) is following 1455 survivors from six months to five years post-diagnosis, while the Psycho-Oncology Co-operative Research Group (PoCoG) is conducting a population based study which aims to recruit 1000 survivors from Arabic, Chinese, Greek and English speaking backgrounds from two years to five years post-diagnosis. Among other outcomes, both studies are assessing survivors' anxiety, depression, perceived needs and quality of life. The PoCoG study will provide the first population based estimates of these outcomes in cancer survivors from CALD communities in Australia, while the CHeRP study will identify the duration, onset, frequency and severity of the positive and negative effects of cancer over the disease trajectory.

It is imperative that we are able to identify the difficulties experienced by cancer survivors and develop effective approaches to help survivors manage them. The results of these two landmark studies will make a substantial contribution to providing an evidence base upon which to develop culturally appropriate policies and practices to improve the health and wellbeing of cancer survivors in Australia.

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Psychosocial Well-Being of Cancer Survivors

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Abstract

Adjusting to the diagnosis and treatment of cancer is a complex process which evolves over time, and individuals, their family members and health professionals may have diverse opinions about what constitutes the status of survivor. Whilst significant psychiatric disorder is not the norm, many of those diagnosed with cancer experience a degree of psychological distress and changes in their attitudes, beliefs and worldview as they negotiate a new and different life compared with before cancer.

This chapter describes the process of adjustment, factors which affect adjustment, and provides practical suggestions for health professionals to assist them in exploring the specific concerns of their patients. Information is provided about simple interventions which can be delivered in routine clinical care by non-specialist providers, as well as details about risk factors for the development of psychiatric disorder. Practical suggestions about facilitating referral for specialist psychosocial treatment are also provided.

Keywords: Psychosocial well-being, cancer survivors, adjustment, psychological distress, psychiatric disorder.

1. Introduction

Improved survival has resulted in increased attention to the longer-term psychosocial wellbeing of survivors, including the impact on partners and family members, and occupational and social functioning. Traditionally a five-year interval from diagnosis conferred “survivor” status, although current definitions employed by medical professionals, researchers and consumers vary widely. Terms such as short term and long term survival are used with little consistency and may have disparate meaning for different cancer types. A person may define themselves as a survivor at any time point along the continuum from diagnosis and active treatment to completion of treatment; furthermore the person may or may not have active disease. For example a woman with advanced breast cancer may define herself as a survivor, asserting that she is indeed surviving until she dies from the disease. Thus *“the word ‘survival’ can mean different things to those who have cancer, those who care for them, and those who treat their illness”* (pp. 501).¹

Health professionals should seek to understand how each patient defines themselves in terms of survival.

2. The Process of Adjustment

High rates of psychiatric morbidity have been reported in patients diagnosed and treated for cancer, resulting in calls for distress to be considered the “sixth vital sign” of wellbeing in cancer populations.² Whilst distress often declines over time, it cannot be assumed that pre-morbid levels of adjustment are invariably achieved. The process of adjustment is a dynamic process occurring over time, and whilst there may be obvious milestones (such as completion of active treatment), other less obvious factors such as social support and attitudes can also affect adjustment and so merit exploration as described below.

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2.1 Cessation of active treatment

While many patients anticipate completion of active treatment with enthusiasm, the reality may be that they feel highly ambivalent for a number of reasons. There is no longer such regular contact with health professionals who have acted as a “safety net” monitoring response to treatment, and providing support. Furthermore there is no longer a sense of being an active participant in dealing with the cancer, now being replaced by waiting to see what happens: *“As treatments finished and visits to specialists decreased, I began to feel uneasy — I felt that things could go wrong again and I wasn’t being monitored. This feeling of being ‘left alone’ after treatment finishes is a difficult one.”*³

2.2 The opportunity for reflection

Demands of active treatment are often considerable, and the person who is exhausted may have little time to reflect on what has happened, instead just “getting on with it”. Many people find that it is only when they have completed active treatment that they actually contemplate what has happened, and how this changes their life, relationships and world view. Long-standing problems may be brought into sharp focus, and the person may be more or less tolerant of adversity. *“It was a pivotal event. It made me focus on my mortality, what was important in life, how I wanted to live, and to take on my weaknesses, indulgences etc. But it took away my blissful ignorance.”*³

2.3 Residual symptoms and disability

Physical morbidity causing problems with speech, or bladder or bowel symptoms may lead to cascading losses and undermine some of the social relationships which provide support and balance. Anxiety about recurrence often makes it difficult to cope with residual symptoms which are a constant reminder of the cancer diagnosis. Even with good prognosis, few people will be “as good as new”: *“Surviving the disease is the initial challenge. Surviving the aftermath of the disease is the next major step”* (pp. 1478).⁴

2.4 *Burden of gratitude and positive thinking*

Despite the absence of confirmatory evidence, it is commonly believed that a positive attitude will favourably influence outcome. Pressure to be positive negates the enormity of the experience and inhibits the ability of the person to express their feelings, fears and concerns, all necessary steps in adjustment to a life after diagnosis and treatment of cancer. Overt pressure to “move forward” and resume “normal” function compounds the common concern that to express distress represents a lack of gratitude.⁵ *“It is very hard to find people with the time or inclination to have any understanding of the impact cancer has had on life.”*³

3. Adjustment Problems in Cancer Survivors

Approximately one-quarter to one-third of cancer survivors experience significant problems such as anxiety or depression within the first few years.^{6–8} It is important to recognise however that research has tended to focus on the diagnosis of disorder, and that absence of disorder does not necessarily mean absence of distress.

3.1 *Who is at risk?*

Some subgroups of survivors are more likely than others to experience difficulty adapting to life after cancer.^{9–11} Responses are mediated by several variables: biological vulnerability (history of depression or anxiety, drug or alcohol abuse); concurrent life stressors and caring roles; social circumstances (access to health care and social support, financial strain); sociodemographic factors (younger or older age, being female) and residual disease and treatment characteristics, in particular pain and fatigue.¹² The process of adjustment is not linear, and risk factors may exert more or less effect over time, as may medical and disease-related factors.¹³

3.2 *Common concerns*

Patients may experience concerns in a number of domains, with diverse modes of presentation. Table 1 summarises some of the

Table 1. Common psychosocial concerns of cancer survivors.

Patient's concern	Things to explore
<i>Physical</i>	
Physical limitations e.g. fatigue, lymphoedema	Weight gain, apparent difficulty resuming former roles.
Pain	Poor sleep, impaired capacity to resume former social and occupational roles.
Fertility	Depressed mood. Even if the person has children the sense of further choice being taken away can be a source of sadness.
Cognitive functioning	Complaints of poor memory, disorganisation, frustration about being 'in a fog'.
<i>Psychological</i>	
Depression/anxiety	Impaired capacity to make decisions, reduced optimism, lack of initiative, feeling 'stuck', panic, poor sleep, needing reassurance.
Fear of recurrence	Preoccupation with physical symptoms, frequent presentations, reduced sense of control, vulnerability and uncertainty, hypervigilance, inability to make plans.
Sexuality/body image	Reduced intimacy and sexual activity, difficulty re-establishing sexual relationships, anxiety about establishing new relationships.
<i>Social</i>	
Relationships	Loneliness, perceived lack of support, social withdrawal, attempts to be positive to avoid distressing others, difficulty relating to others, concerns about familial cancer risk.
Socioeconomic	Financial strain, job insecurity/discrimination, insurance matters.
<i>Spiritual/existential</i>	
Existential/grief	Feeling burdened, sad or having lost optimism; managing the expectations of self and others; survivor guilt. Sometimes feeling liberated because of letting go of previous burdens, redefining priorities and challenging or reaffirming of spiritual beliefs.

common concerns, and identifies specific issues the health professional can explore further with the patient.

3.3 How to elicit concerns

Reflecting on personal and professional beliefs about survival and appreciating the diversity of perspectives on survival is a very helpful step for those caring for people with cancer. An analogy might be that of staff at a maternity hospital who see delivery of a baby as a defining event, their job effectively completed when the mother and baby are discharged; yet for the parents, the birth is just the beginning of a long journey. Likewise, health professionals who may have considered their major role as focusing on diagnosing, initiating and monitoring cancer treatment may need to reconsider this view, as for patients the cancer diagnosis and subsequent treatment represent the beginning of a new and different life. Discussion about the tasks facing patients and their priorities can be initiated as follows: *“Although treatment is now finished, that doesn’t mean that everything is back to normal, and many aspects of life are different now. Can you tell me how things are going?”* Or: *“How would you say the experience of cancer has affected you? We know that not everything is as it seems, and I am keen to hear what you personally feel about it all, good and bad.”* The following summarises some of the specific concerns commonly experienced by cancer survivors, and outlines approaches to assessment.

3.3.1 Exploration of psychosocial issues

Cancer survivors experience psychosocial concerns and worries across the cancer continuum, with transitions from one phase of care to another being particularly stressful. Nearly all individuals experience some psychosocial impairment at diagnosis and during treatment which usually abates over time. However a range of issues such as fatigue, sexual difficulties, fear of recurrence and uncertainty about the future may not necessarily recede with time. Other issues such as difficulties in decision-making and social isolation may emerge months or years after treatment has finished. Personality style, flexibility, social support and past experiences will all influence the individual’s appraisal of the cancer experience,

and the person who appears to have recovered well may in fact be angry or fearful. The key issue is to not make assumptions about psychosocial concerns. Because the burden posed by the cancer experience and how an individual copes fluctuates over time, it is important to continue to assess adjustment, rather than assuming that over time the person has achieved their optimal adjustment.

The survivorship experience is dynamic and changes over time. Psychosocial needs should be identified, systematically followed up, and re-evaluated over time.

3.3.2 *Attention to physical concerns*

At diagnosis and during treatment, priority is given to major morbidities especially life-threatening complications. However 'medically minor' residual symptoms can erode functional capacity, adversely impacting on occupational and social functioning, this in turn leading to isolation, lack of support and financial strain, all risk factors for the development of psychosocial distress. Recognition that the patient's agenda may differ from the health professional's agenda in this regard can be addressed using open-ended questions: *"How would you say things are going for you physically? I know that during treatment we often focused on what we called 'serious' problems, but even more mild symptoms are important, especially if they persist."*

3.3.3 *Fear of recurrence*

Fears of disease recurrence are commonly reported across the survivorship continuum and have been consistently identified as the highest unmet supportive care need expressed in survivorship groups even up to 11 years after diagnosis.^{14,15} *"I used to think that once I got to the five-year mark it would be over, but I'm starting to realise it will never be over... there is always this nagging fear — will it come back?"* Whilst health professionals appraise risk in terms of statistics and evidence, the individual may appraise their risk based on

family experience, popular reading, information gleaned from Internet sources, or “gut feelings” which are not inherently logical. These concerns may not be volunteered unless directly explored, especially if they are at odds with the social expectations of being a brave cancer survivor. Awareness of the factors shaping appraisal is important: *“We have talked about the cancer and I have said that it is highly likely that you have been cured. But I know that feelings aren’t always logical, and I wonder if you could tell me what you really think in your heart about how things might go for you in the future?”*

3.3.4 Roles and relationships

It is not uncommon for individuals to feel disappointed about the response of family and friends to the diagnosis of cancer. Friends sometimes withdraw, perhaps because of uncertainty about how to respond. Family members may be reluctant to acknowledge the enormity of the diagnosis because to do so would be distressing, but this avoidance can lead to resentment as the patient feels misunderstood and isolated. Even subtle changes in roles and relationships which are not immediately apparent to observers can exert a major influence on adjustment. Feelings of disappointment or resentment may contaminate relationships long after the initial diagnosis.

3.3.5 Assessment of distress

The Distress Thermometer and associated Problem List were designed as a non-stigmatising tool for cancer patients to record their distress and delineate specific concerns to guide further enquiry and interventions.^{16,17} The patient rates their level of distress on a scale ranging from zero representing “No distress” to ten which represents “Extreme distress”. In addition, the person indicates the specific source of their distress, for example practical problems (such as childcare, finances), family problems, emotional problems (such as sadness, worry), spiritual or religious concerns, and physical problems (including fatigue and body image concerns). The tool is quick to administer and has been demonstrated to be sensitive to change over time. A score of four or more has been demonstrated to have greatest sensitivity and specificity

compared with other validated measures.^{18,19} Open questions exploring mood and adjustment are described in relevant guidelines.¹² Standardised, self-administered questionnaires such as Quality of Life in Adult Cancer Survivors²⁰ or Impact of Cancer²¹ can also be used to capture the individual's perspective across multiple areas of wellbeing.

Patients' unmet supportive care needs can be assessed across the disease continuum using the Supportive Care Needs Survey (SCNS)²² or the shorter 34 item version.²³ Persistent or new unmet care needs arising post treatment can be identified using questionnaires specifically designed to assess the unique needs of cancer survivors (Cancer Survivors Unmet Needs measure, CaSUN)²⁴ and their partners (Cancer Survivors' Partners Unmet Needs measure, CaPSUN)²⁵ and/or caregivers (Supportive Care Needs Survey — Partners and Caregivers Measure — SCNS — P & Cs).²⁶ Needs may change over time and cannot be assumed to be identical within couples.²⁷ Such measures assist the tailoring of individualised interventions as well as the evaluation of supportive care services and generation of service delivery recommendations.

Survivors should be routinely assessed about distress, particularly at times of vulnerability such as the end of treatment, remission, recurrence. Their partners' and caregivers' needs should also be considered.

4. Promoting Adjustment

The majority of cancer survivors will not require specialist psychosocial interventions, and specialist treatment should be reserved for those at particular risk or those whose distress is affecting their functioning and relationships.²⁸ However there is evidence that a range of interventions can promote adjustment and quality of life for all patients, even in the absence of significant adjustment problems. Moreover, many of these strategies are

simple and can be effectively delivered by non-specialist health professionals during routine clinical care, as described below.

4.1 Information and support

All patients are likely to benefit from the provision of appropriate information and empathic support from their health professional.¹² For example it may be helpful for cancer survivors to hear that many people report positive outcomes following treatment for cancer. This can include an enhanced appreciation of life, strengthened relationships, enhancement of self-concept, living a fuller and more meaningful life, and existential gains,^{29–31} as typified by this statement: *“I know cancer has had a very positive side effect and has taught me many lessons. I have grown in understanding and actually feel better about life than I used to. I am more assertive and spiritual.”* An acknowledgement that the experience of cancer can undermine optimism and self-confidence can be very valuable for the person who feels pressured by family or friends to ‘move forward’.

4.2 Physical activity

There is evidence about strategies to enhance adjustment, and these can be discussed with all patients, not only those who are distressed. Exercise has been demonstrated to improve physical and psychosocial outcomes in patients treated for cancer,³² in particular regarding mood, body image, quality of life and fatigue. Emerging evidence also links active lifestyle with lower risk of cancer recurrence.³³ Health professionals should explore patients’ attitudes to physical activity and encourage gentle exercise, as advice to be more active despite illness is counterintuitive for many patients. It is important to explore the personal beliefs the individual may have about any potential deleterious impact of activity especially if they have residual physical symptoms.

4.3 Lifestyle changes

Many cancer survivors spontaneously adopt lifestyle changes (e.g. dietary changes) and use of complementary therapies (e.g.

meditation, relaxation, food supplements) in the hope of achieving improved health. There is insufficient evidence specific to cancer survivors to make recommendations regarding diet and healthy weight. However cancer survivors can be advised of the existing recommendations for cancer prevention. These can be summarised as: maintain a healthy body weight; be physically active every day; limit intake of energy-dense foods, red meat, alcohol, salt; eat mostly foods of plant origin; meet nutritional needs through diet rather than supplements.³⁴

In parallel with the expanding evidence-base, complementary therapies are increasingly being integrated into conventional cancer care. For example, acupuncture is effective in reducing nausea, vomiting and pain, and relaxation therapy is effective in reducing anxiety and pain.³⁵ Given the potential harm (e.g. abandonment of conventional treatment, adverse drug interactions) associated with the use of complementary medicines, it is important that open discussions take place between survivors and health care providers. Health professionals should explore their patients' behaviour changes, including use of complementary therapies, and promote lifestyle changes that may improve the length and quality of life. The National Breast and Ovarian Cancer Centre's evidence-based Communication Skills Module *Effectively discussing complementary therapies in a conventional oncology setting* (CAM) provides an overview of the significant issues and the basis for discussion.³⁶

4.4 Psychosocial interventions

Whilst there are few evaluations of psychosocial interventions to promote well-being, a cognitive approach encouraging women to define their concerns, actively seek information, and develop strategies for responding has been highly acceptable to women after treatment for breast cancer.³⁷ Although this intervention drew on a cognitive behavioural framework, many health professionals who have not received specific training in this area could offer some assistance with a similar problem-solving approach. Details of the process are provided in Table 2.

Table 2. A structured approach to problem-solving.

Step 1:	Discuss the common feeling of being overwhelmed when facing a number of problems, leading to difficulty making decisions (commonly expressed as: <i>"I don't know which way to turn"</i>).
Step 2:	Ask the person to write a complete list of all of their concerns, even if they seem trivial. Be as specific as possible, for example, having to carry groceries upstairs after shopping being limited by lymphoedema.
Step 3:	Rank the problems in order of the stress they pose, highest stress being number 1. If the person says <i>"everything"</i> is stressful, use prompts such as: <i>"OK, what if I could magically fix just one thing on the list, what would it be?"</i> .
Step 4:	Select the most pressing problem. Generate ideas about how to approach the problem, including even <i>"out of left field"</i> options. Brainstorm all possibilities and outline how these could be enacted. This may necessitate obtaining further information, checking on potential external sources of support, etc. (For example if the problem is concerns about sexuality, options may include exploration of menopausal status, obtaining a medical review, considering the use of lubricants, possible hormonal options, couple counselling, etc.)
Step 5:	Choose a response and follow-through. Evaluate its effectiveness, and modify the priority for that stressor, or move down the list of possible options to 'value add' in dealing with the problem.

Further examples of practical approaches can be found in a text edited by Hodgkinson and Gilchrist (2008).³⁸

5. Rehabilitation

All health professionals involved in the care of patients with cancer need access to a variety of skilled professionals such as physiotherapists, occupational therapists and social workers, along with psychologists and sometimes psychiatrists. A patient with residual shoulder and chest pain after treatment for breast cancer may gradually relinquish previous activities, and over time become less fit, deskilled and socially isolated. Comprehensive assessment and active rehabilitation may limit this decline and reduce the risk of adverse psychological impact. Whilst chronic conditions can be challenging for health professionals who strive to cure, many patients are more flexible in their expectations: *"I don't*

really expect it to be fixed. But if I could just move my arm enough to be able to drive safely again that would make all the difference to my quality of life." For patients struggling to adjust to ongoing physical limitations, psychological interventions can be helpful in reducing distress (such as through relaxation therapy or guided imagery) and promoting adaptation.

6. Identification and Treatment of Psychiatric Disorder

Persistent or severe levels of distress should raise concern that the person has a significant psychiatric disorder such as Major Depression or Anxiety. Differentiating between an understandable response to adversity and a disorder can be difficult, and the desire to avoid medicalising emotional responses must be balanced against the benefits of identifying and treating a significant disorder. Features suggestive of Major Depression are feelings of guilt, worthlessness, helplessness and lack of hope for the future. Depression is also strongly implicated if the person's functional ability is affected by their mood (for example due to lack of motivation), or if there is an adverse impact on relationships or on occupational functioning. Effective treatments are available and described in *Clinical Practice Guidelines for the Psychosocial Care of Adults with Cancer*,¹² which also provides prompts which health professionals can use to explore mood.

Despite this, there remain barriers to initiation of treatment, including lack of access to specialist service providers and patient reluctance to accept referral.¹¹ Some health professionals may feel ambivalent about referral or even feel that they should be the one who helps their patient. In the same way that a surgeon does not administer radiotherapy treatment or an oncologist does not administer anaesthetics, it is not reasonable for an untrained health professional to expect that they can provide specialist treatment of disorders such as Major Depression. The development of a solid referral network of social workers, psychologists and psychiatrists represents an investment in patient care and is likely to reduce the professional stress inherent in trying to address problems outside of one's area of expertise. Strategies to facilitate acceptance of referral include using physical analogies (*"If you had a broken leg*

you would accept the need to see a specialist for treatment”); stating the evidence-base (“There has been extensive research into depression and cancer, and we now have very effective treatments”) and citing clinical experience (“I have had several patients who were struggling with depression, and treatment really helped them get back into living again”). It is important to note that the impact of disorder extends beyond the individual, powerfully affecting family relationships.

7. Summary

In contrast with the traditional conceptualisations of cancer treatment, for most patients and their families, definitive cancer treatment is not the ‘end point’, but rather the beginning of a process of adjustment, at times involving uncertainty, frustration, grief and loss, and also possible benefit-finding. All health professionals involved in the care of patients who have been diagnosed and treated for cancer need to appreciate the differing perspectives brought by individuals to their experience. Moving beyond an emphasis on disorder or a focus on only potentially life-threatening complications is necessary to appreciate the complex interplay of apparently ‘minor’ problems which impact on adjustment and so is preparedness to listen to the individual and explore their views. Challenging the notion that it is possible to provide a ‘one stop shop’ is fundamental, and liaison with a variety of health professionals from different disciplines is essential for quality care of cancer survivors.

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APPENDIX 7: Study information packages



HUMAN RESEARCH ETHICS COMMITTEE
Certificate of Approval

Applicant: (first named in application) Ms Allison Boyes
Ms Alison Zucca
Co-Investigators / Research Students: Associate Professor Raoul Walsh
Dr Christine Paul
Conjoint Professor Afaf Girgis
Protocol: NSW Cancer Survival Study

In approving this protocol, the Human Research Ethics Committee (HREC) is of the opinion that the project complies with the provisions contained in the *National Statement on Ethical Conduct in Human Research*, 2007, and the requirements within this University relating to human research.

Note: Approval is granted subject to the requirements set out in the accompanying document **Approval to Conduct Human Research**, and any additional comments or conditions noted below.

Details of Approval

HREC Approval No: H-199-1101 **Approved to:** 15-Feb-2011

Approval is granted to this date or until the project is completed, whichever occurs first. If the approval of an External HREC has been "noted" the approval period is as determined by that HREC.

Progress reports due: Annually.

If the approval of an External HREC has been "noted", the reporting period is as determined by that HREC.

Initial Approval

Approved

21 November 2001

Approved with the comment that after the initial contact by the researchers, follow-up of participants would be invited to one letter plus on phone call

Renewal of Approval

16 February 2005

Approved

Approval renewed for a further three (3) year period.

Approval covers:

- VCR and NSW CCR Letters to Clinicians and Information for Clinicians
- NSW CCR Reminder Letter to Clinicians
- NSW CCR Request for Permission to Contact Patient
- VCR Brochure
- NSW Cancer Council Study Brochures
- Letters to Patient from VCR and NSW CCR

- VCR and NSW CCR Response and General Background Forms
- Reminder Letter to Patient from VCR and NSW CCR
- Initial and Reminder Letters to Patients from Researchers
- Change of Address Form
- Secondary Contact Form
- Contact for Future Research Form
- Cancer Survival Study – Survey 1

14-May-2008

Approved

Approval renewed for a further three (3) year period.

Variations to Approved Protocol

21 July 2004

Variation to:

1. Introduce an alternative information letter for clinicians who needed to be contacted on more than one occasion to seek clinical details on patients who had consented to be in the study.
2. Amend the eligibility criteria to be more conservative. This was in response to a number of cases where it appeared that patients were not aware that they had been given a cancer diagnosis or they did not recall the diagnosis.
3. Amend the clinician's response form to verify that the patient was aware of their cancer diagnosis.

Approval granted by the Chair on 14 August 2004 with a commendation to the researcher on the response to adverse events which prompted the second and third variation above. Ratified.

19 March 2003

Variation to:

1. Amend the consent statement in the survey regarding access to information held by the NSW Central Cancer Registry, to read "Will you allow us to get information about your cancer from the NSW Central Cancer Registry?" with a Yes/No format.
2. Add a step in the consenting process in the form of a follow-up letter to verify with those participants who had not indicated either way, whether they consented to the researchers obtaining information about their cancer from the NSW Central Cancer Registry.

Approval granted by the Chair on 4 March 2003, subject to amendments to the follow-up letter. Ratified.

26 March 2003

Response received and accepted.

Approval confirmed.

19 May 2004

Variation to add to the research team, Ms Catherine Whiteman, a research higher degree student, supervised by Associate Professor Afaf Girgis.

Approval granted by the Acting Chair on 8 April 2004. Ratified.

21 July 2004

Variation to:

1. Apply protocol modifications as approved for the cross-sectional study component to the longitudinal study.
2. Eligibility Criteria. Increase from 70 to 80 years age limit at time of diagnosis and limit the sample to cases diagnosed with their first primary cancer.
3. Amendments to Cancer Survival Study – Survey 1
4. Research Team. Add Dr Raol Walsh, Dr Christine Paul, Dr Jiong Li and Ms Alison Zucca. Approval granted for Ms Boyes and Ms Zucca to use a subset of collected data for their respective research higher degree programs.
5. Amendments to Information and Consent documentation to reflect the above changes.
6. Addition of reminder letters – one from the Cancer Council Registry (CCR) to potential participants who did not reply within two weeks and one from researchers to participants who did not return their survey within two weeks.

Approval granted by the Chair on 14 July 2004. Ratified.

8 December 2004

Variation to recruit half the study sample of 3,000 via the Victorian Cancer Registry (VCR).
Approval granted by the Chair on 20 November 2004, subject to amendments to the study documents.
Ratified.

24 December 2004

Response received and accepted.

Approval confirmed.

Approval covers:

- VCR Letter to Clinicians and Information for Clinicians – Submitted with variation, 4 November 2004
- Letter to Patient from VCR – Submitted with variation, 4 November 2004
- Reminder Letter to Patient from VCR – Revised version received 12 January 2005
- Initial and Reminder Letters from Researchers – Versions dated 4 November 2004
- NSW and Victorian Cancer Council Study Brochures
- VCR Patient ID Form – Submitted with variation, 4 November 2004
- VCR Response and General Background Forms – Submitted with variation, 4 November 2004

19 October 2005

Variation to make amendments to the Victorian versions of the following study documents: Clinician Letter; Clinician Reply Form; Patient Initial and Reminder Letters; Patient General Background Form; and Study Leaflet.

Approved.

The Committee ratified the approval granted by the Chair on 6 October 2005.

21 June 2006

Variation to:

1. Amend the survey for the second wave of data collection.
2. Delete Dr Jiong Li and Ms Catherine Whiteman from the list of project investigators.

Approved.

The Committee ratified the approval granted by the Chair on 9 June 2006.

16 August 2006

Variation to:

1. Combine the two mailout packages to partners/caregivers of cancer survivors, which were passed to them by the cancer survivor, into one mailout package which would contain all the information required to commence participation in the study.
2. As part of the 12 month mailout for cancer survivors include another initial information pack for partners/caregivers who did not respond at baseline.
3. For those cancer survivors who did not return a completed Future Research Form at baseline, the form would be included as part of their 12 month follow-up.
4. Add relevant reminder mailouts for the above, to be sent to the cancer survivor after three weeks, where the cancer survivor had not returned a completed survey or Future Research Form and/or their partner/caregiver had not responded to the invitation for *The partners and caregivers study* (HREC Approval H-039-0505).
5. Amend the Information Letters to support the above changes.

Approved.

The Committee ratified the approval granted by the Chair on 27 July 2006.

Variation to amend the Study Information Sheet sent from the NSW Central Cancer Registry (CCR) to doctors (now version 2, dated 2/08/06). The word "histologically" was removed as the CCR had advised that for some of the cancer types being recruited to this study (ie, brain, lung) it was impossible to confirm them histologically.

Approved.

The Committee ratified the approval granted by the Chair on 10 August 2006.

16 May 2007

Variation for submission of the telephone script to be used when calling people who were nominated as secondary contacts for participants who are no longer contactable via the details held on record.

Approved.

The Committee ratified the approval granted by the Chair on 10 May 2007.

20 June 2007

Variation to conduct a second reminder call to the small sub-group of participants who indicated during the initial reminder call that they intended on returning the survey but who had not returned it during the next three weeks..

Approved.

The Committee ratified the approval granted by the Deputy Chair on 5 June 2007.

18 July 2007

Variation to amend the survey for the third wave of data collection.

Approved.

The Committee ratified the approval granted by the Chair on 5 July 2007.

11-Jun-2008

Variation to: Include a new research question relating to analysis of the existing data; specifically looking at the psychosocial concerns of young adults aged 19-40 years.

Approved.

The Committee ratified the approval granted by the Chair on 29 May 2008 under the provisions for expedited review.

Authorised Certificate held in Research Services

Professor Val Robertson
Chair, Human Research Ethics Committee



[date]

«TitleID» «perFirstName» «perLastName»
«perMailAddr1» «perMailAddr2» «perMailAddr3» «perMailAddr4»
«perMailCity» «perMailState» «perMailPostcode»

Dear «TitleID» «perLastName»

Cancer Survival Study

Thank you for allowing us to contact you. You are invited to take part in a project about cancer survivorship. The study aims to improve our understanding of the physical, emotional and lifestyle issues faced by cancer survivors, and how these change over time.

You have been selected as a possible participant in this study because you were recently diagnosed with cancer for the first time. We realise this is a difficult time for you, however, your experiences are important to us, and will help cancer survivors in the future to have the best care.

The study is being conducted by researchers at the Centre for Health Research and Psycho-oncology (CHERP). CHERP is the Behavioural Research Unit of the Cancer Council NSW and is based within the Faculty of Health at the University of Newcastle.

Your participation in this study is completely voluntary. Your decision whether or not to participate will in no way affect your current or future medical care. If you agree to take part in this study, you will be asked to fill in a questionnaire four times over the next five years and return it to us. The questionnaire will ask about your physical and emotional health, any needs you may have, lifestyle issues, as well as some general background questions about you and the treatment of your cancer. The questionnaire will take about 30-45 minutes to complete. The enclosed information leaflet (blue) gives you a more detailed description about what is involved.

If you decide to participate, all information you give us will remain strictly confidential. Only authorised staff of the research team will have access to the information, and your name and any other identifying information will be removed and replaced by a code number before the information is analysed. A report of the project may be submitted for publication in scientific journals. Some of the information will also be used by Ms Allison Boyes and Ms Alison Zucca as part of their higher degree studies at The University of Newcastle, under the supervision of Associate Professor Afaf Girgis. Individual participants will not be identifiable in either the reports or higher degree theses generated from this research.

If you decide to take part in this study you are free to withdraw at any time and do not have to give a reason for doing so.

Enclosed are:

- A blue **study information** leaflet - this is for you to read and keep;
- A green **change of address** form - this is for you to keep in a safe place and return to us only if your contact details change;
- A yellow **secondary contact** form - this is for you to fill in and return to us so that we can get in contact with someone who knows where you are if we can't locate you;
- A yellow **future studies** form - this is for you to fill in and return to us to let us know if you would like to be informed about other related studies as they come up;
- A **questionnaire** containing seven sections (your cancer diagnosis and treatment, your emotional well-being, your overall health, your needs, your access to social support, your coping styles and your general background and lifestyle) for you to complete and return to us;
- A reply-paid envelope;
- A sealed yellow envelope containing information about a Partners and Caregivers Study also being conducted by CHeRP researchers. This study is looking at the physical and emotional health of the partners and caregivers of people diagnosed with cancer. We would like to ask you to pass on the envelope to your husband, wife, partner, or main caregiver - a definition is given on the front of the envelope to help you select the most relevant person. This project is separate to the Cancer Survival Study. Your partner or caregiver can decide to participate in the Partners and Caregivers Study, regardless of your decision to participate or not in the Cancer Survival Study.

Please read the information leaflet carefully. **If you decide to take part in the Cancer Survival Study, simply fill in the yellow forms and the questionnaire and return them to us within the next seven days in the reply-paid envelope.** The return of your completed questionnaire will be taken as an indication of your voluntary consent to participate in this study.

If you would like to know more about this study or have any questions please feel free to contact Alison Zucca (Research Officer), or myself, by telephone: **1800 246 337 (freecall)**; email: CHeRP-survival@newcastle.edu.au; or by writing to:

Cancer Survival Study
The Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287

This information sheet is for you to keep. Thank you for considering this request.

Yours sincerely

Allison Boyes (MPH)
PROJECT MANAGER

Complaints about this research. This project has been approved by the Human Research Ethics Committee of the Cancer Institute NSW (No. 2004/05/036) and the University of Newcastle (H-199-1101). Should you have concerns about your rights as a participant in this research, or have a complaint about the manner in which this research is conducted, it may be given to the researcher, or, if an independent person is preferred, to either Ethics Manager, Cancer Institute NSW, PO Box 41, Alexandria NSW 1435, telephone (02) 8374 5624, or The Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, Callaghan NSW 2308, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au

[date]

«TitleID» «perFirstName» «perLastName»
«perMailAddr1» «perMailAddr2» «perMailAddr3»
«perMailAddr4»
«perMailCity» «perMailState» «perMailPostcode»



Dear «TitleID» «perLastName»

Cancer Survival Study

You may recall me writing to you a few weeks ago to see if you would be willing to take part in research about cancer survivorship. Enclosed with the letter was a copy of the Cancer Survival Survey. As I have not yet received your completed survey, I am writing to you again to ask you to consider taking part in our research. If you have returned your survey in the last few days, please disregard this letter.

As you may recall, the research aims to improve our understanding of the physical, emotional and lifestyle issues faced by cancer survivors and is being conducted by the Centre for Health Research & Psycho-oncology (CHeRP). Your participation in this study will help to inform us about the types of services and support desired by cancer survivors.

I have enclosed another copy of the study information leaflet, the Cancer Survival Survey, a future studies form, change of address form, secondary contact form and a reply-paid envelope.

Please read the information leaflet carefully. **If you decide to take part in the study, simply fill in the yellow forms and the questionnaire and return them to us within the next seven days in the reply-paid envelope.** The return of your completed questionnaire will be taken as an indication of your voluntary consent to participate in this study.

Your decision whether or not to participate will in no way affect your current or future medical care. If you decide to participate, all information you give us will remain strictly confidential. Only authorised staff of the research team will have access to the information, and your name and any other identifying information will be removed and replaced by a code number before the information is analysed. A report of the project may be submitted for publication in scientific journals. Some of the information will also be used by Ms Allison Boyes and Ms Alison Zucca as part of their higher degree studies at The University of Newcastle, under the supervision of Associate Professor Afaf Girgis. Individual participants will not be identifiable in either the reports or higher degree theses generated from this research.

If you decide to take part in this study you are free to withdraw at any time and do not have to give a reason for doing so. If you would like to know more about this study or have any questions please feel free to contact Alison Zucca (Project Officer) or myself by telephone: **1800 246 337** (freecall); email: CHERP-survival@newcastle.edu.au or by writing to us at;

**Cancer Survival Study
The Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287**

If receiving this request has caused you any distress and you would like to speak to a counsellor, please call the Cancer Helpline on 13 11 20.

Thank you for considering this request.

Yours sincerely,

Allison Boyes (MPH)
PROJECT MANAGER

Complaints about this research. This project has been approved by the Human Research Ethics Committee of the Cancer Institute NSW (Project No 2004/05/036) and the University of Newcastle (Approval No H-199-1101). Should you have concerns about your rights as a participant in this research, or have a complaint about the manner in which this research is conducted, it may be given to the researcher, or, if an independent person is preferred, to either Ethics Manager, Cancer Institute NSW, PO Box 41, Alexandria NSW 1435, telephone (02) 8374 5624, or, The Human Research Ethics Officer, Research office, The Chancellery, The University of Newcastle, University Drive, Callaghan NSW 2308, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au

This leaflet is about a health research project. If, after reading it, you would like more information please telephone Allison Boyes or Alison Zucca on 1800 246 337 (Freecall) or write to:

**Cancer Survival Study
The Cancer Council NSW
Room 230A, Level 2, David Maddison
Building, Callaghan NSW 2308**

What is this research about?

It is about the effect that cancer has on adults. We want to find out about the physical, emotional and lifestyle issues faced by cancer survivors. We will follow cancer survivors for up to five years after they are diagnosed with cancer to see how these issues change over time. This study will not influence any decisions made between you and your doctor about your care.

How will this study help?

This study will tell us more about the effect that cancer has on survivors and the type of help they desire at various stages of the diagnosis, treatment and recovery pathway. This research will help The Cancer Council to develop new programs and policies.

Why should I take part?

If we knew more about the physical, emotional and lifestyle issues faced by cancer survivors, it would be possible to direct resources into those areas where cancer survivors need the most help. By taking part you will be helping cancer survivors in the future to have the best care. We would really appreciate your help in our study

Who is doing the research?

Researchers at the Centre for Health Research and Psycho-oncology (CHeRP) are running the study. CHeRP is the Behavioural Research Unit of the Cancer Council NSW and is based within the Faculty of Health at the University of Newcastle. These researchers are especially interested in improving the quality of care and support for cancer survivors.

Who is paying for the research?

The National Health and Medical Research Council and the Cancer Council NSW have committed funds to the study.

Who will take part in the research?

People living in NSW or Victoria who are aged between 18 and 80 years and have been diagnosed with their first primary cancer in the last four months are being asked to take part.

How did you get my name?

You agreed for the NSW Central Cancer Registry to pass on your contact details to the research team so that we could write to you and ask you to consider participating in this study.

What will I have to do?

If you decide to participate:

- Fill in the enclosed questionnaire and return it to us within the next 7 days in the reply-paid envelope provided. The questionnaire will take about 30-45 minutes to complete. You do not have to fill it in all at once; you may fill it in over several days until it is all completed. The return of your completed

questionnaire to us will be taken as an indication of your voluntary consent to participate.

- We will send you a similar questionnaire three more times over the next five years. These surveys will be sent to you six months, one and a half years and four and a half years after the first survey.

What sort of questions will be asked?

The questionnaire will ask about your physical and emotional health, any needs you may have, your lifestyle, as well as some general background questions about you and the treatment of your cancer. Each question will have a list of answers for you to choose from.

Will my information be kept confidential?

Yes. All the information you give will be kept strictly confidential and will be stored in accordance with strict privacy protection procedures. Only authorised study staff will have access to the data. Names will be removed from records and replaced with a code number as soon as possible after collection and before analysis. You will not be able to be identified, either directly or indirectly, when the results of the study are reported.

What if I don't agree to take part?

It is your choice whether or not you take part. The care you receive for your cancer will not be affected in any way if you choose not to take part.

What if I agree and then change my mind?

Participation in the research is voluntary. The care you receive for your cancer will not be affected in any way if you change your mind.

You may withdraw at any time after you have agreed to take part by:

- Telephoning Allison Boyes (Project Manager) or Alison Zucca (Project Officer) on 1800 246 337 (freecall); or
- Sending a letter to
Cancer Survival Study
Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287; or
- Sending a fax to the Project Manager on (02) 4913 8612; or
- Sending an email to the Project Manager at: CHERP-survival@newcastle.edu.au

Need more information?

If you would like more information about the study please call Allison Boyes (Project Manager) or Alison Zucca (Project Officer), on 1800 246 337 (Freecall).

The Human Research Ethics Committees of the Cancer Institute NSW and the University of Newcastle have approved this research. If you have any complaints please contact:

Ethics Manager

Cancer Institute NSW
PO Box 41
Alexandria NSW 1435
(02) 8374 5624 or

Human Research Ethics Officer

The University of Newcastle
University Drive
Callaghan NSW 2308
(02) 4921 6333

**Postal**

Cancer Survival Study
The Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287

Freecall 1800 246 337

E-mail CHERP-survival@newcastle.edu.au



*Building a
Cancer Smart
Community*

**Cancer
Survival
Study**

Information for participants

Identification No.

0	0	0	0
1	1	1	1
2	2	2	2
3	3	3	3
4	4	4	4
5	5	5	5
6	6	6	6
7	7	7	7
8	8	8	8
9	9	9	9



Centre for Health Research
& Psycho-oncology (CHeRP)

Cancer Survival Study

S U R V E Y O N E

Cancer Survival Study
Centre for Health Research & Psycho-oncology (CHeRP)
The Cancer Council NSW/University of Newcastle
Locked Bag 10
WALLSEND NSW 2287
Phone: 1800 246 337 (freecall)
Email: CHeRP-survival@newcastle.edu.au

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CANCER SURVIVAL STUDY

Cancer Survival Study

S U R V E Y O N E

Instructions

- 1 Please use a blue or black pen or pencil. Do not use red or felt tip pen.
- 2 Fill in the oval that best describes your answer. For example: ○ ● ○ ○
 If you make a mistake, either erase or place a "X" through the incorrect oval and fill in the correct oval. For example: ○ X ○ ●
- 3 Please try to answer every question. Do not leave any questions blank unless you are asked to skip it because it does not apply to you.
- 4 The survey is divided into the following sections:
 - your cancer diagnosis and treatment
 - your emotional well-being
 - your overall health
 - your needs as a cancer survivor
 - your access to social support and your coping style
 - your general background and lifestyle

You do not have to answer the whole survey all at once - it is OK to fill it in over several days.
- 5 There are no right or wrong answers. Some cancer survivors face many ongoing difficulties in their day to day life as a result of cancer and/or its treatment while others experience only a few. We are interested in your experiences as a recent survivor of cancer. We will ask you to fill in a similar survey three more times over the next five years.
- 6 When you have completed all sections of the survey, simply put the survey in the reply-paid envelope provided and post it back within the next 7 days. No postage stamp is needed. Please don't fold or bend the survey.
- 7 The return of your completed questionnaire will be taken as an indication of your voluntary consent to participate in this study.
- 8 If you have any questions or concerns about the study please do not hesitate to contact Allison Boyes (Project Manager) or Alison Zucca (Project Officer) by telephone on (freecall) 1800 246 337 or by email: CHeRP-survival@newcastle.edu.au
- 9 If you have any concerns or complaints about the conduct of the study, you may contact the following people:
If you live in NSW you may contact the University of Newcastle's Human Research Ethics Officer on (02) 4921 6333 or Mr Rodney Ecclestone, Ethics Manager, Cancer Institute NSW on (02) 8374 5624.
If you live in Victoria you may contact Ms Woody Macpherson, Head, Research Management Unit, The Cancer Council Victoria on (03) 9635 5100.
- 10 If completing this questionnaire raises any issues of concern for you, please discuss them with your doctor or contact the Cancer Helpline on 13 11 20.

THANK YOU FOR YOUR TIME

PAGE 2

The following questions are about your cancer diagnosis and treatment.

These questions about your cancer diagnosis and treatment will help us to group your answers. This information will help us understand how things like the type of treatment a person has had might affect their needs. We will obtain clinical information about the cancer you were diagnosed with (such as cancer type and date of diagnosis) from the Cancer Registry in your state, so we will not be asking you for this sort of information in the following questions. To answer, please fill in the oval that best describes your situation.

1 Have you ever received any of the following treatments for your cancer?
(please mark one oval for each line, including item g. 'Other')

	Yes	No	Don't know
a. Surgical removal of the cancer	1	2	3
b. Chemotherapy	1	2	3
c. Radiotherapy (radiation treatment)	1	2	3
d. Hormone treatment (eg. Tamoxifen, Zoladex, Anadron)	1	2	3
e. Bone marrow/stem cell transplant	1	2	3
f. Immunotherapy (eg. Interferon, Interleukin)	1	2	3
g. Other (please specify): _____	1	2	3

2 Have you received any of the following treatments for your cancer in the last month? (please mark one oval for each line, including item g. 'Other')

	Yes	No	Don't know
a. Surgical removal of the cancer	1	2	3
b. Chemotherapy	1	2	3
c. Radiotherapy (radiation treatment)	1	2	3
d. Hormone treatment (eg. Tamoxifen, Zoladex, Anadron)	1	2	3
e. Bone marrow/stem cell transplant	1	2	3
f. Immunotherapy (eg. Interferon, Interleukin)	1	2	3
g. Other (please specify): _____	1	2	3

CANCER SURVIVAL STUDY

3 Since your cancer diagnosis, have you had to temporarily live away from home to receive cancer treatment? *(mark one oval only)*

① No
② Yes → Please specify the treatment/s you received when you lived away from home:

4 Have you ever decided **not** to have a particular cancer treatment because of the time it would take to get treatment? *(mark one oval only)*

① Yes
② No

5 About how long did it take for you to travel (one way) from your usual home address to each of the following: *(Please mark one oval for each line. Mark 'Not Applicable' if you have never received that treatment.)*

	Less than 1 hour	1-2 hours	Between 2-5 hours	More than 5 hours	Not Applicable
a. The clinic or hospital where you had surgery	①	②	③	④	⑤
b. The clinic or hospital where you had radiotherapy	①	②	③	④	⑤
c. The clinic or hospital where you had chemotherapy	①	②	③	④	⑤
d. The cancer specialist you see the most	①	②	③	④	⑤

6 At present, has your doctor told you that the cancer has: *(mark one oval for each line)*

	Yes	No	Don't know
a. Been treated and you are cancer-free (that is, in remission)	①	②	③
b. Come back after it was treated (that is, recurrent)	①	②	③
c. Spread to other parts of your body (that is, metastatic)	①	②	③

7 Since you were diagnosed with cancer, have you talked to any of the following health care providers about your cancer? *(mark one oval for each line, including item k. 'Other health care provider')*

	Yes	No	Don't know
a. General Practitioner (GP)	①	②	③
b. Surgeon	①	②	③
c. Medical Oncologist	①	②	③
d. Radiation Oncologist	①	②	③
e. Palliative Care Physician	①	②	③
f. Specialist Cancer Nurse	①	②	③
g. Psychologist, Counsellor, Social Worker or Psychiatrist	①	②	③
h. Physiotherapist	①	②	③
i. Occupational Therapist	①	②	③
j. Dietician or Nutritionist	①	②	③
k. Other health care provider <i>(please specify):</i> _____	①	②	③

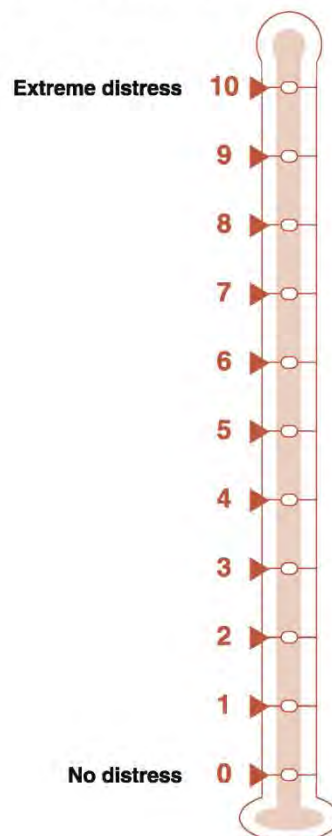
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CANCER SURVIVAL STUDY			
8 Since you were diagnosed with cancer, have you used any of the following services? (mark one oval for each line)			
	Yes	No	Don't know
	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
a. Cancer Helpline (telephone-based information & support service)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Cancer Connect (one-to-one support from a volunteer cancer survivor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Support Group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Telegroup counselling (telephone-based support group)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Living with Cancer Education Program (8 week information course)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9 Since you were diagnosed with cancer, have you used any of the following treatments to help you manage your cancer or related symptoms? (mark one oval for each line, including item t. 'Other')			
	Yes	No	
	<input type="radio"/>	<input type="radio"/>	
a. Acupuncture	<input type="radio"/>	<input type="radio"/>	
b. Aromatherapy	<input type="radio"/>	<input type="radio"/>	
c. Chiropractic	<input type="radio"/>	<input type="radio"/>	
d. Coffee enema	<input type="radio"/>	<input type="radio"/>	
e. Faith in God	<input type="radio"/>	<input type="radio"/>	
f. Herbal treatments	<input type="radio"/>	<input type="radio"/>	
g. Homeopathy	<input type="radio"/>	<input type="radio"/>	
h. Hypnosis	<input type="radio"/>	<input type="radio"/>	
i. Immune enhancing therapy	<input type="radio"/>	<input type="radio"/>	
j. Massage therapy	<input type="radio"/>	<input type="radio"/>	
k. Microwave or Tronado therapy	<input type="radio"/>	<input type="radio"/>	
l. Nutritional supplements or vitamins	<input type="radio"/>	<input type="radio"/>	
m. Osteopathy	<input type="radio"/>	<input type="radio"/>	
n. Ozone therapy	<input type="radio"/>	<input type="radio"/>	
o. Psychic surgery	<input type="radio"/>	<input type="radio"/>	
p. Reflexology	<input type="radio"/>	<input type="radio"/>	
q. Shark cartilage therapy	<input type="radio"/>	<input type="radio"/>	
r. Special Diet (eg. Macrobiotic, Gawler, Gerson, Pritikin, Plant)	<input type="radio"/>	<input type="radio"/>	
s. Spiritual healing (eg. therapeutic touch, Reiki, faith healing)	<input type="radio"/>	<input type="radio"/>	
t. Other (please specify): _____	<input type="radio"/>	<input type="radio"/>	
Please check that you have answered all of the questions in this section.			
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CANCER SURVIVAL STUDY

The following questions are
about your emotional well-being
in the past week.

- 1 Please fill in the oval (0-10) that best describes how much distress you have been experiencing in the past week including today.



From The National Comprehensive Cancer Network Distress Management Guideline, *The Complete Library of NCCN Clinical Practice Guidelines in Oncology* [CD ROM]. Jenkintown, Pennsylvania: National Comprehensive Cancer Network, March 2004. To view the most recent and complete version of the guideline, go online to www.nccn.org

CANCER SURVIVAL STUDY

The next few questions ask how you have been feeling in the last week. To answer, please fill in the oval that best describes how you have been feeling in the last week. If you make a mistake, either erase or place a cross through the incorrect oval and fill in the correct oval. Don't take too long over your answers; your immediate reaction to each question will probably be more accurate than a long, thought out answer.

2 I feel tense or 'wound up':

- Most of the time (1)
 A lot of the time (2)
 From time to time, occasionally (3)
 Not at all (4)

3 I still enjoy the things I used to enjoy:

- Definitely as much (1)
 Not quite as much (2)
 Only a little (3)
 Hardly at all (4)

4 I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly (1)
 Yes, but not too badly (2)
 A little, but it doesn't worry me (3)
 Not at all (4)

5 I can laugh and see the funny side of things:

- As much as I always could (1)
 Not quite so much now (2)
 Definitely not so much now (3)
 Not at all (4)

6 Worrying thoughts go through my mind:

- A great deal of the time (1)
 A lot of the time (2)
 From time to time but not too often (3)
 Only occasionally (4)

7 I feel cheerful:

- Not at all (1)
 Not often (2)
 Sometimes (3)
 Most of the time (4)

8 I can sit at ease and feel relaxed:

- Definitely (1)
 Usually (2)
 Not often (3)
 Not at all (4)

9 I feel as if I am slowed down:

- Nearly all the time (1)
 Very often (2)
 Sometimes (3)
 Not at all (4)

10 I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all (1)
 Occasionally (2)
 Quite often (3)
 Very often (4)

11 I have lost interest in my appearance:

- Definitely (1)
 I don't take as much care as I should (2)
 I may not take quite as much care (3)
 I take just as much care as ever (4)

12 I feel restless as if I have to be on the move:

- Very much indeed (1)
 Quite a lot (2)
 Not very much (3)
 Not at all (4)

13 I look forward with enjoyment to things:

- As much as I ever did (1)
 Rather less than I used to (2)
 Definitely less than I used to (3)
 Hardly at all (4)

14 I get sudden feelings of panic:

- Very often indeed (1)
 Quite often (2)
 Not very often (3)
 Not at all (4)

15 I can enjoy a good book or radio or TV program:

- Often (1)
 Sometimes (2)
 Not often (3)
 Very seldom (4)

The Hospital Anxiety and Depression Scale. R.P. Snaith and A.S. Zigmond, 1983, 1992, 1994.

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CANCER SURVIVAL STUDY

The following questions are about your overall health and relate to how you have felt during the past week.

We are interested in some things about you and your health. Please answer all of the questions yourself by filling in the oval that best applies to you. If you make a mistake, either erase or place a cross through the incorrect oval and fill in the correct oval. There are no "right" or "wrong" answers. The information that you provide will remain strictly confidential.

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	1	2	3	4
2. Do you have any trouble taking a <u>long</u> walk?	1	2	3	4
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	1	2	3	4
4. Do you need to stay in bed or a chair during the day?	1	2	3	4
5. Do you need help with eating, dressing, washing yourself or using the toilet?	1	2	3	4

During the past week:	Not at all	A little	Quite a bit	Very much
6. Were you limited in doing either your work or other daily activities?	1	2	3	4
7. Were you limited in pursuing your hobbies or other leisure time activities?	1	2	3	4
8. Were you short of breath?	1	2	3	4
9. Have you had pain?	1	2	3	4
10. Did you need to rest?	1	2	3	4
11. Have you had trouble sleeping?	1	2	3	4
12. Have you felt weak?	1	2	3	4
13. Have you lacked appetite?	1	2	3	4
14. Have you felt nauseated?	1	2	3	4

CANCER SURVIVAL STUDY

During the past week:

	Not at all 1	A little 2	Quite a bit 3	Very much 4
15. Have you vomited?	1	2	3	4
16. Have you been constipated?	1	2	3	4
17. Have you had diarrhoea?	1	2	3	4
18. Were you tired?	1	2	3	4
19. Did pain interfere with your daily activities?	1	2	3	4
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	1	2	3	4
21. Did you feel tense?	1	2	3	4
22. Did you worry?	1	2	3	4
23. Did you feel irritable?	1	2	3	4
24. Did you feel depressed?	1	2	3	4
25. Have you had difficulty remembering things?	1	2	3	4
26. Has your physical condition or medical treatment interfered with your family life?	1	2	3	4
27. Has your physical condition or medical treatment interfered with your social activities?	1	2	3	4
28. Has your physical condition or medical treatment caused you financial difficulties?	1	2	3	4

For the following questions please fill in the number between 1 and 7 that best applies to you.

29. How would you rate your overall health during the past week?

30. How would you rate your overall quality of life during the past week?

Please check that you have answered all of the questions in this section.

Aaronson, N.K., Ahmedzal, S., Bergman, B. et al. (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J. Natl. Cancer inst.* 85:365-76

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CANCER SURVIVAL STUDY

The following questions are
about needs you may have had
in the past month
as a result of having cancer.

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Fill in the oval which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

**NO
NEED**

- ① **Not applicable** – This was not a problem for me as a result of having cancer.
② **Satisfied** – I did need help with this, but my need for help was satisfied at the time.

**SOME
NEED**

- ③ **Low need for help** – This item caused me concern or discomfort.
I had little need for additional help.
④ **Moderate need for help** – This item caused me concern or discomfort.
I had some need for additional help.
⑤ **High need for help** – This item caused me concern or discomfort.
I had a strong need for additional help.

For example:

In the last month what was your level of need
for help with:

1. Being informed about things you can do to help
yourself to get well

NO NEED		SOME NEED		
Not applicable	Satisfied	Low need	Moderate need	High need
①	②	③	④	⑤
			<input checked="" type="radio"/>	

If you answered as we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

CANCER SURVIVAL STUDY					
In the last month what was your level of need for help with:	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
1. Pain	1	2	3	4	5
2. Lack of energy/tiredness	1	2	3	4	5
3. Feeling unwell a lot of the time	1	2	3	4	5
4. Work around the home	1	2	3	4	5
5. Not being able to do the things you used to do	1	2	3	4	5
6. Anxiety	1	2	3	4	5
7. Feeling down or depressed	1	2	3	4	5
8. Feelings of sadness	1	2	3	4	5
9. Fears about the cancer spreading	1	2	3	4	5
10. Worry that the results of treatment are beyond your control	1	2	3	4	5
11. Uncertainty about the future	1	2	3	4	5
12. Learning to feel in control of your situation	1	2	3	4	5
13. Keeping a positive outlook	1	2	3	4	5
14. Feelings about death and dying	1	2	3	4	5
15. Changes in sexual feelings	1	2	3	4	5
16. Changes in your sexual relationships	1	2	3	4	5
17. Concerns about the worries of those close to you	1	2	3	4	5
18. More choice about which cancer specialists you see	1	2	3	4	5
19. More choice about which hospital you attend	1	2	3	4	5
20. Reassurance by medical staff that the way you feel is normal	1	2	3	4	5
21. Hospital staff attending promptly to your physical needs	1	2	3	4	5
22. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	1	2	3	4	5
23. Being given written information about important aspects of your care	1	2	3	4	5
24. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	1	2	3	4	5
25. Being given explanations of those tests for which you would like explanations	1	2	3	4	5
26. Being adequately informed about the benefits and side-effects of treatments before you choose to have them	1	2	3	4	5
27. Being informed about your test results as soon as feasible	1	2	3	4	5

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CANCER SURVIVAL STUDY

In the last month what was your level of need for help with:

	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
28. Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
29. Being informed about things you can do to help yourself to get well	1	2	3	4	5
30. Having access to professional counselling (eg. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
31. To be given information about sexual relationships	1	2	3	4	5
32. Being treated like a person not just another case	1	2	3	4	5
33. Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
34. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

35. What was your level of need for easy access to the following services and resources in the last month?

NO NEED	1	Not applicable – Not applicable <u>OR</u> never interested in having access to this service or resource.
	2	Satisfied – Fully satisfied with access to this service or resource.
SOME NEED	3	Low need for help – Had a low desire for better access to this service.
	4	Moderate need for help – Had a moderate desire for better access.
	5	High need for help – Had a strong desire for better access.

In the last month what was your level of need for access to:

	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
a. Transport service to and from the hospital or clinic	1	2	3	4	5
b. Easy car parking at the hospital or clinic	1	2	3	4	5
c. Food and drink facilities in or near the clinic waiting room	1	2	3	4	5
d. Comfortable waiting room	1	2	3	4	5
e. Child-minding at the hospital or clinic	1	2	3	4	5
f. Counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family/partner	1	2	3	4	5
g. Brochures about services and benefits for patients with cancer	1	2	3	4	5
h. Library of books and videos about cancer and related issues	1	2	3	4	5

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CANCER SURVIVAL STUDY

In the last month what was your level of need for access to:

	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
i. Relaxation classes	1	2	3	4	5
j. Drop-in counselling and support service	1	2	3	4	5
k. 24-hour telephone support and cancer advisory service	1	2	3	4	5
l. Home nursing service	1	2	3	4	5
m. Home cleaning service	1	2	3	4	5
n. Home gardening service	1	2	3	4	5
o. Respite care (to provide temporary relief to family home carers)	1	2	3	4	5
p. Monetary allowance for travel, treatment and equipment expenses	1	2	3	4	5

36. Are there any other issues or needs that you would like help with? Please write them in the space below.

Please check that you have answered all of the questions in this section.

You have completed half of the survey. Please keep going. 😊

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CANCER SURVIVAL STUDY

The following questions are about your access to social support and your coping style.

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Please fill in the oval on each line that best describes your situation. If you make a mistake, either erase or place a cross through the incorrect oval and fill in the correct oval.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone you can count on to listen to you when you need to talk	1	2	3	4	5
2. Someone to give you information to help you understand a situation	1	2	3	4	5
3. Someone to give you good advice about a crisis	1	2	3	4	5
4. Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
5. Someone whose advice you really want	1	2	3	4	5
6. Someone to share your most private worries and fears with	1	2	3	4	5
7. Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
8. Someone who understands your problems	1	2	3	4	5
9. Someone to help you if you were confined to bed	1	2	3	4	5
10. Someone to take you to the doctor if you needed it	1	2	3	4	5
11. Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
12. Someone to help with daily chores if you were sick	1	2	3	4	5

Sherbourne, C.D. & Stewart, A.L. (1991). The MOS Social Support Survey. *Soc. Sci. Med.* 32(6):705-714

CANCER SURVIVAL STUDY

	None of the time ▼	A little of the time ▼	Some of the time ▼	Most of the time ▼	All of the time ▼
13. Someone who shows you love and affection	1	2	3	4	5
14. Someone to love you and make you feel wanted	1	2	3	4	5
15. Someone who hugs you	1	2	3	4	5
16. Someone to have a good time with	1	2	3	4	5
17. Someone to get together with for relaxation	1	2	3	4	5
18. Someone to do something enjoyable with	1	2	3	4	5
19. Someone to do things with to help you get your mind off things	1	2	3	4	5

Watson, M., Law, M., dos Santos, M., Greer, S., Baruch, J. & Bliss, J. (1994). The Mini-MAC: Further development of the Mental Adjustment to Cancer Scale. *Journal of Psychosocial Oncology*, 12(3):33-46.

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CANCER SURVIVAL STUDY

A number of statements are given below which describe people's reactions to having cancer. Please fill in the appropriate oval to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does not apply to you then you should fill in '1' in the first column.

	Definitely does not apply to me	Does not apply to me	Applies to me	Definitely applies to me
1. At the moment I take one day at a time	1	2	3	4
2. I see my illness as a challenge	1	2	3	4
3. I've put myself in the hands of God	1	2	3	4
4. I feel like giving up	1	2	3	4
5. I feel very angry about what has happened to me	1	2	3	4
6. I feel completely at a loss about what to do	1	2	3	4
7. It is a devastating feeling	1	2	3	4
8. I count my blessings	1	2	3	4
9. I worry about the cancer returning or getting worse	1	2	3	4
10. I try to fight the illness	1	2	3	4
11. I distract myself when thoughts about my illness come into my head	1	2	3	4
12. I can't handle it	1	2	3	4
13. I am apprehensive	1	2	3	4
14. I am not hopeful about the future	1	2	3	4
15. I feel there is nothing I can do to help myself	1	2	3	4
16. I think it is the end of the world	1	2	3	4
17. Not thinking about it helps me cope	1	2	3	4
18. I am very optimistic	1	2	3	4
19. I've had a good life what's left is a bonus	1	2	3	4
20. I feel that life is hopeless	1	2	3	4
21. I can't cope	1	2	3	4
22. I am upset about having cancer	1	2	3	4
23. I am determined to beat this disease	1	2	3	4
24. Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	1	2	3	4
25. I have difficulty in believing that this happened to me	1	2	3	4
26. I make a positive effort not to think about my illness	1	2	3	4
27. I deliberately push all thoughts of cancer out of my mind	1	2	3	4
28. I suffer great anxiety about it	1	2	3	4
29. I am a little frightened	1	2	3	4

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The following questions are about your general background and lifestyle.

Finally, we would like to ask some questions about you and your lifestyle. Some questions may seem personal but it is important that you try to answer each question. We are asking everyone the same questions. All information will be handled with the strictest confidence. To answer, please fill in the oval that best describes your situation.

- 1 For all the questions you have answered so far, were any of your answers affected by circumstances in your life not related to your cancer, such as a current illness or medical condition, psychological condition or life event?
 - ① No
 - ② Yes — Please specify the circumstances that have affected your answers, such as a current illness or medical condition, psychological condition or life event:
- 2 What is your current marital status? (mark one oval only)
 - ① Married
 - ② Defacto or living with a partner
 - ③ Separated or divorced
 - ④ Widowed
 - ⑤ Never married or single
- 3 What is the highest level of education that you have completed? (mark one oval only)
 - ① Primary school
 - ② Secondary school
 - ③ Certificate or Diploma
 - ④ University Degree
- 4 Which of the following best describes your employment situation for the 12 months or so before you were diagnosed with cancer? (mark one oval only)
 - ① Paid full-time employment
 - ② Paid part-time employment
 - ③ Self-employed
 - ④ On leave with pay
 - ⑤ On leave without pay
 - ⑥ Not employed - retired
 - ⑦ Not employed - disabled
 - ⑧ Household duties
 - ⑨ Student
 - ⑩ Unemployed
 - ⑪ Volunteer
 - ⑫ Other (please specify):

CANCER SURVIVAL STUDY

5 Which of the following best describes your current employment situation? (mark one oval only)

- ☐ 1 Paid full-time employment
- ☐ 2 Paid part-time employment
- ☐ 3 Self-employed
- ☐ 4 On leave with pay
- ☐ 5 On leave without pay
- ☐ 6 Not employed - retired
- ☐ 7 Not employed - disabled
- ☐ 8 Household duties
- ☐ 9 Student
- ☐ 10 Unemployed
- ☐ 11 Volunteer
- ☐ 12 Other (please specify):

6 Has your work situation changed as a result of your cancer diagnosis or treatment (eg. work less hours, retired, etc)? (mark one oval only)

- ☐ 1 No
- ☐ 2 Yes → Please describe how your work situation has changed as a result of cancer:

7 Do you currently have private health insurance? (mark one oval only)

- ☐ 1 No - Medicare only
- ☐ 2 Yes - hospital cover only
- ☐ 3 Yes - ancillary (extras) cover only
- ☐ 4 Yes - hospital and ancillary (extras) cover

8 What is your present gross family income each week (that is, before tax)? (mark one oval only)

- ☐ 1 Less than \$300 per week
- ☐ 2 Between \$300 - \$499 per week
- ☐ 3 Between \$500 - \$799 per week
- ☐ 4 Between \$800 - \$1000 per week
- ☐ 5 More than \$1000 per week
- ☐ 6 Prefer not to answer

9 How many adults (18 years or over) live in your household?

10 How many children (under 18 years) live in your household?
(If you do not live with any children, please write '0'.)

11 Have you ever been treated for a mental health illness (eg. depression, anxiety, panic disorder, schizophrenia, phobia)? (mark one oval for each line)

- a. Before your cancer diagnosis?
- b. Since your cancer diagnosis?

Yes	No	Don't know
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3
<input type="radio"/> 1	<input type="radio"/> 2	<input type="radio"/> 3

CANCER SURVIVAL STUDY

The next group of questions are about smoking. You will be asked to skip some questions in this section. After answering each question, please follow the 'go to' instructions on the right.

12 Would you have smoked at least 100 cigarettes or the equivalent amount of tobacco in your life? *(mark one oval only)*

☐ 1 No ▶ **GO TO Q19**
☐ 2 Yes ▶ **GO TO Q13**
☐ 3 Don't know ▶ **GO TO Q13**

13 Do you currently smoke any tobacco products? *(mark one oval only)*

☐ 1 Daily ▶ **GO TO Q16**
☐ 2 At least once a week ▶ **GO TO Q16**
☐ 3 Less often than once a week ▶ **GO TO Q16**
☐ 4 Not at all ▶ **GO TO Q14**

14 If you do not currently smoke any tobacco products at all, when did you quit? *(mark one oval only)*

☐ 1 After being diagnosed with cancer ▶ **GO TO Q15**
☐ 2 In the 12 months before the cancer diagnosis ▶ **GO TO Q19**
☐ 3 More than 12 months before the cancer diagnosis ▶ **GO TO Q19**

15 Were your cancer symptoms, diagnosis or treatment an important influence in your decision to quit? *(mark one oval only)*

☐ 1 Yes ▶ **GO TO Q19**
☐ 2 No ▶ **GO TO Q19**
☐ 3 Don't know ▶ **GO TO Q19**

16 During the past 12 months have you quit smoking intentionally for one day or longer? *(mark one oval only)*

☐ 1 Yes ▶ **GO TO Q17**
☐ 2 No ▶ **GO TO Q18**
☐ 3 Don't know ▶ **GO TO Q18**

17 Were your cancer symptoms, diagnosis or treatment an Important Influence in your decision to try quitting? *(mark one oval only)*

☐ 1 Yes ▶ **GO TO Q18**
☐ 2 No ▶ **GO TO Q18**
☐ 3 Don't know ▶ **GO TO Q18**

18 What are your intentions regarding quitting? *(mark one oval only)*

☐ 1 Will quit in next month ▶ **GO TO Q19**
☐ 2 Will quit in next 6 months ▶ **GO TO Q19**
☐ 3 May quit but not in next 6 months ▶ **GO TO Q19**
☐ 4 Never expect to quit ▶ **GO TO Q19**
☐ 5 Don't know ▶ **GO TO Q19**

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CANCER SURVIVAL STUDY

19 The next group of questions are about medical tests you might have had to detect cancer. Here is a description of the tests we will be asking you about:

- **Faecal Occult Blood Test (FOBT)** is a test for bowel cancer. This test involves taking a sample of faeces and sending it to a laboratory to test if it contains blood.
- **Colonoscopy or a flexible sigmoidoscopy** is a test for bowel cancer. This test involves a doctor passing a long tube into your back passage (rectum) to examine the inside of your bowel.
- **Mammogram** is a routine test for the early detection of breast cancer. An x-ray is taken of your breast by a machine that presses against your breast while the picture is taken.
- **Pap smear test or Pap Test** is a routine test for the early detection of cancer of the cervix. This test involves a doctor taking a few cells from the cervix and sending them to a laboratory to be tested.
- **Prostate cancer tests** can be a blood test, ultrasound or a digital rectal examination. An ultrasound uses high-frequency sound waves and a computer to view images of internal organs and blood flow through various vessels. A digital rectal examination is when the doctor inserts a lubricated, gloved finger into the rectum and feels for abnormal areas.

Please indicate whether you have ever had each of these tests. For those tests that you answer 'yes', please indicate how long it has been since you last had the test and the reason why you had it.

	Have you ever had this test?		How long has it been since you last had this test?									Why did you have this test?		
	No	Yes												
			Up to 6 months ago	More than 6 months to less than 12 months ago	1 year to less than 2 years ago	2 years to less than 3 years ago	3 years to less than 5 years ago	5 or more years ago	I had symptoms	I had a check-up (no symptoms)	Don't know			
a. Faecal Occult Blood Test (FOBT)	1	2	If 'yes' → 1	2	3	4	5	6	7	8	9	1	2	3
b. Flexible sigmoidoscopy or colonoscopy	1	2	If 'yes' → 1	2	3	4	5	6	7	8	9	1	2	3
MEN ONLY														
c. Prostate cancer test: blood test, ultrasound or a digital rectal examination	1	2	If 'yes' → 1	2	3	4	5	6	7	8	9	1	2	3
WOMEN ONLY														
d. Mammogram	1	2	If 'yes' → 1	2	3	4	5	6	7	8	9	1	2	3
e. Pap smear test	1	2	If 'yes' → 1	2	3	4	5	6	7	8	9	1	2	3

20 People diagnosed with cancer may have tests as part of their treatment or follow-up. Apart from those tests, has being diagnosed with cancer changed whether you have check-ups or tests for other types of cancer when you have no symptoms? (mark one oval only)

- ☐ 1 Yes, I am more likely to have check-ups because I have had cancer
☐ 2 Yes, I am less likely to have check-ups because I have had cancer
☐ 3 No, having cancer has not influenced whether I have check-ups
☐ 4 Don't know

CANCER SURVIVAL STUDY

The next group of questions are about alcohol. Alcoholic drinks are measured in terms of a 'standard drink'. A standard drink is equal to

- a 285ml middy of full-strength beer (4.9% alc./vol)
- a 375ml schooner of mid-strength beer (3.5% alc./vol)
- a 100ml serve of wine (12% alc./vol)
- a 60ml serve of sherry or port (18% alc./vol)
- a 30ml nip of spirits (40% alc./vol)

21 Have you ever had a full serve of alcohol (eg. a glass of wine, a whole nip of spirits, a glass of beer, etc)? (mark one oval only)

- ① Yes → **GO TO Q22**
 ② No → **GO TO Q25**

22 Before your cancer diagnosis, how often did you have each of the following number of standard drinks in a day? (mark one oval for each line)

	Every day	3-6 days a week	1-2 days a week	1-3 days a month	Less often than 1 day a week	Never
20 or more standard drinks a day	①	②	③	④	⑤	⑥
11-19 standard drinks a day	①	②	③	④	⑤	⑥
7-10 standard drinks a day	①	②	③	④	⑤	⑥
5-6 standard drinks a day	①	②	③	④	⑤	⑥
3-4 standard drinks a day	①	②	③	④	⑤	⑥
1-2 standard drinks a day	①	②	③	④	⑤	⑥

23 In the last 6 months, how often have you had each of the following number of standard drinks in a day? (mark one oval for each line)

	Every day	3-6 days a week	1-2 days a week	1-3 days a month	Less often than 1 day a week	Never
20 or more standard drinks a day	①	②	③	④	⑤	⑥
11-19 standard drinks a day	①	②	③	④	⑤	⑥
7-10 standard drinks a day	①	②	③	④	⑤	⑥
5-6 standard drinks a day	①	②	③	④	⑤	⑥
3-4 standard drinks a day	①	②	③	④	⑤	⑥
1-2 standard drinks a day	①	②	③	④	⑤	⑥

24 Has being diagnosed with cancer influenced whether you drink alcohol or how much you drink? (mark one oval only)

- ① Yes, I am more likely to drink alcohol because I have had cancer
 ② Yes, I am less likely to drink alcohol because I have had cancer
 ③ No, having cancer has not influenced whether I drink alcohol or how much I drink
 ④ Don't know

CANCER SURVIVAL STUDY

The next group of questions are about physical activity.

- 25** Before your cancer diagnosis, in a 1 week period on average how many times and how much total time did you spend doing each of the following physical activities? (If you did not do the physical activity, please write '0' for number of times and total time spent.)

	Number of times	Total time spent
a. Vigorous physical activity which made you breathe harder or puff and pant (eg. jogging, cycling, aerobics, competitive tennis, etc)	<input type="text"/>	<input type="text"/> minutes
b. Moderate physical activity which caused a moderate increase in your heart rate or breathing (eg. gentle swimming, social tennis, golf, etc)	<input type="text"/>	<input type="text"/> minutes
c. Mild physical activity (eg. easy walking, lawn bowling, fishing, etc)	<input type="text"/>	<input type="text"/> minutes

- 26** In the last week, how many times and how much total time did you spend doing each of the following physical activities? (If you did not do the physical activity, please write '0' for number of times and total time spent.)

	Number of times	Total time spent
a. Vigorous physical activity which made you breathe harder or puff and pant (eg. jogging, cycling, aerobics, competitive tennis, etc)	<input type="text"/>	<input type="text"/> minutes
b. Moderate physical activity which caused a moderate increase in your heart rate or breathing (eg. gentle swimming, social tennis, golf, etc)	<input type="text"/>	<input type="text"/> minutes
c. Mild physical activity (eg. easy walking, lawn bowling, fishing, etc)	<input type="text"/>	<input type="text"/> minutes

- 27** Has being diagnosed with cancer influenced whether you participate in physical activity? (mark one oval only)

- ☐ ① Yes, I am more likely to participate in physical activity because I have had cancer
☐ ② Yes, I am less likely to participate in physical activity because I have had cancer
☐ ③ No, having cancer has not influenced whether I participate in physical activity
☐ ④ Don't know

CANCER SURVIVAL STUDY

The final group of questions are about your behaviour in the sun and skin cancer.

- 28** Think back to the summer (December to February) before you were diagnosed with cancer. When you were out in the sun for more than 15 minutes between 11am and 3pm, how often did you: (mark one oval for each line)

	Always	Often	Sometimes	Rarely or never	Never in sun for more than 15 minutes
a. Wear a wide-brimmed hat or cap with a flap	(1)	(2)	(3)	(4)	(5)
b. Apply broad spectrum sunscreen, 15+ or higher	(1)	(2)	(3)	(4)	(5)
c. Deliberately wear more clothing to protect yourself from the sun	(1)	(2)	(3)	(4)	(5)

- 29** In the 6 months before you were diagnosed with cancer, did the following people check your skin for signs of possible cancer? (mark one oval for each line)

	Yes	No	Don't know
a. Yourself	(1)	(2)	(3)
b. Relative or friend	(1)	(2)	(3)
c. General Practitioner	(1)	(2)	(3)
d. Skin cancer specialist	(1)	(2)	(3)

You have now finished the survey. Thank you for your participation.
Please return your completed survey in the reply-paid envelope provided.

We will send you a similar survey in 6 months time.

We value your participation in this research, however you are not obligated to complete any future surveys and you may withdraw from this study at any time.

If you would like to make any other comments, please write them in the space below.

CANCER SURVIVAL STUDY

DO NOT COMPLETE

A1 (1) (2)

A2 (1) (2)

A3 (1) (2) (3) (4) (5) (6) (7)

A7 (1) (2) (3)

A9 (1) (2) (3) (4) (5)

B1 (1) (2) (3)

B4 (1) (2) (3)

B5 (1) (2) (3)

B6 (1) (2) (3) (4) (5) (6)

B9 (1) (2) (3) (4) (5)

B10 (1) (2) (3) (4) (5)

B27

a. Number of times

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

a. Total time spent

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

b. Number of times

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

b. Total time spent

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

c. Number of times

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

c. Total time spent

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

B28

a. Number of times

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

a. Total time spent

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

b. Number of times

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

b. Total time spent

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

c. Number of times

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

c. Total time spent

	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9
	0	1	2	3	4	5	6	7	8	9

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Cancer Survival Study**Change of Address Form**

□/□□□□

As you are aware, we will need to contact you again over the next 5 years. Over such a long period, people often move and change their address. When **any** of your contact details change, please fill in this form with your new contact details and send it to us at the address below (no stamp needed). We will send another copy of this form to you from time to time over the next five years in case you misplace it.

**These details are confidential and will not be given to
anyone outside the research team.**

Remember you can also contact us at any time on our Freecall number 1800 246 337 or by email:

CHERP-survival@newcastle.edu.au

Please print:

First Name	Surname
New postal address	
State	Postcode
New telephone (home)	New mobile
New email address	New fax number

Please return your completed form to:

**Cancer Survival Study
The Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287**

THANK YOU FOR YOUR CO-OPERATION

Cancer Survival Study

Secondary Contact Form



□/□□□□

As you are aware, we will need to contact you again over the next four years. Over such a long period, people often move and change their address. We realise that moving is a hectic time and people often forget to fill in *Change of Address* forms. Therefore, we are asking you to provide us with the details of a *secondary contact*.

A *secondary contact* is someone who will always know how to get in contact with you and whose contact details are different from yours. We will only contact your *secondary contact* **if we cannot reach you via any of the contact details you have already given us.**

Please print details of secondary contact:

Secondary Contact First Name	Secondary Contact Surname
Address	
State	Postcode
Telephone (home)	Mobile
Email address	Fax number

Your name

(PLEASE PRINT)

Your Signature Date

Please use the reply-paid envelope provided to return your completed form to:

**Cancer Survival Study
The Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287**

THANK YOU FOR YOUR CO-OPERATION

Cancer Survival Study



*Building a
Cancer Smart
Community*

Future Research

☐/ ☐☐☐☐☐

In the future, the Centre for Health Research & Psycho-oncology will be conducting other research involving cancer survivors. You may be eligible to take part in some of these studies. If you would like to be informed about future research with cancer survivors please let us know and we will send you an information sheet as these studies come up.

Please read this section, then tick one box to indicate **YES** or **NO**.

☐

YES

I am interested in receiving information about other studies involving cancer survivors.

I understand this does **not** mean I am agreeing to take part in a study.

☐

NO

I am not interested in receiving information about other studies involving cancer survivors.

Your name

(PLEASE PRINT)

Your Signature Date

Please use the reply-paid envelope provided to return your completed form to:

**Cancer Survival Study
The Cancer Council NSW
Locked Bag 10
Wallsend NSW 2287**

THANK YOU FOR YOUR CO-OPERATION

[date]

«TitleID» «perFirstName» «perLastName»
«perMailAddr1» «perMailAddr2» «perMailAddr3» «perMailAddr4»
«perMailCity» «perMailState» «perMailPostcode»



Dear «TitleID» «perLastName»

CANCER SURVIVAL STUDY

Thank you for being part of the Cancer Survival Study. We are now surveying everyone for the second time. Regardless of whether your wellbeing has changed since the first survey, your experiences are important to us.

We invite you to complete the enclosed survey. Completion of the survey is, of course, voluntary, and your answers will be kept confidential. If you return the completed survey to us we will use your code number (not your name) to link the information you provide this time with the information you have already given us. This will allow us to follow changes in cancer survivors' wellbeing over time.

Also enclosed is a secondary contact form. This form is for you to provide us with the details of a relative or friend who will be able to help us find you if we lose contact with you over the next few years. We would only contact this person if we can't reach you through any of the contact details you have given us. Providing us with the details of a secondary contact is, of course, voluntary, and the information will be kept confidential.

If you decide to complete the survey and secondary contact form, please return them to us in the reply-paid envelope provided. If you have any questions about the survey or the study, please ring us on our Freecall number **1800 246 337**.

We appreciate your contribution to this study. However, if at any time you decide that you no longer want to take part, please telephone or write to us. If we do not hear otherwise, we will continue to include you in the study.

Thank you again for your help.

Yours sincerely

Allison Boyes
PROJECT MANAGER

This project has been approved by the Human Research Ethics Committee of the Cancer Institute NSW (No. 2004/05/036) and the University of Newcastle (H-199-1101). Should you have concerns about your rights as a participant in this research, or have a complaint about the manner in which this research is conducted, it may be given to the researcher, or, if an independent person is preferred, to either Ethics Manager, Cancer Institute NSW, PO Box 41, Alexandria NSW 1435, telephone (02) 8374 5624, or The Human Research Ethics Officer, Research Office, The Chancellery, The University of Newcastle, Callaghan NSW 2308, telephone (02) 4921 6333, email Human-Ethics@newcastle.edu.au.

[date]

«TitleID» «perFirstName» «perLastName»
«perMailAddr1» «perMailAddr2» «perMailAddr3» «perMailAddr4»
«perMailCity» «perMailState» «perMailPostcode»



Dear «TitleID» «perLastName»

CANCER SURVIVAL STUDY

You may recall me writing to you a few weeks ago to thank you for being part of the Cancer Survival Study and to let you know that we are now surveying everyone for the second time. Enclosed with the letter was a copy of the Cancer Survival Survey 2. As I have not yet received your completed survey, I am writing to you again to ask you to consider continuing your valuable contribution to our research. If you have returned your survey in the last few days, please disregard this letter.

We invite you to complete the enclosed survey. Completion of the survey is of course voluntary, and your answers will be kept confidential. If you return the completed survey to us we will use your code number (not your name) to link the information you provide this time with the information you have already given us. This will allow us to follow changes in cancer survivors' well-being over time.

Also enclosed is a secondary contact form. This form is for you to provide us with the details of a relative or friend who will be able to help us find you if we lose contact with you over the next few years. We would only contact this person if we can't reach you through any of the contact details you have given us. Providing us with the details of a secondary contact is, of course, voluntary, and the information will be kept confidential.

If you decide to complete the survey and secondary contact form, please return them to us in the reply-paid envelope provided. If you have any questions about the survey or the study, please telephone Alison Zucca (Project Officer) or myself on our Freecall number **1800 246 337**.

We appreciate your contribution to this study. However, if at any time you decide that you no longer want to take part, please telephone or write to us. If we do not hear otherwise, we will continue to include you in the study.

Thank you again for your help.

Yours sincerely

Allison Boyes
PROJECT MANAGER

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CANCER SURVIVAL STUDY

Cancer Survival Study

Instructions

- 1 We mailed you a similar survey six months ago and would like to know how you are doing now. Most questions are the same as last time so we can better understand changes in your well-being over the past 6 months.
- 2 Please use a blue or black pen or pencil. Do not use red or felt tip pen.
- 3 Fill in the oval that best describes your answer.
For example: ☐ ☒ ☐ ☐

If you make a mistake, either erase or place a 'X' through the incorrect oval and fill in the correct oval.
For example: ☐ ☒ ☐ ☐

- 4 Please try to answer every question. Do not leave any questions blank unless you are asked to skip it because it does not apply to you.
- 5 The survey is divided into the following sections:
 - your cancer diagnosis and treatment
 - your emotional well-being
 - your overall health
 - your needs as a cancer survivor
 - your access to social support and your coping style
 - your general background and lifestyle

You do not have to answer the whole survey all at once – it is OK to fill it in over several days.

- 6 There are no right or wrong answers. Some cancer survivors face many ongoing difficulties in their day to day life as a result of cancer and/or its treatment while others experience only a few. We are interested in your experiences as a recent survivor of cancer. We will ask you to fill in a similar survey two more times over the next four years.
- 7 When you have completed all sections of the survey, simply put the survey in the reply-paid envelope provided and post it back within the next 7 days. No postage stamp is needed. Please don't fold or bend the survey.
- 8 The return of your completed questionnaire will be taken as an indication of your voluntary consent to participate in this study.
- 9 If you have any questions or concerns about the study please do not hesitate to contact Allison Boyes (Project Manager) or Alison Zucca (Project Officer) by telephone on (freecall) 1800 246 337 or by email: CHERP-survival@newcastle.edu.au
- 10 If completing this questionnaire raises any issues of concern for you, please discuss them with your doctor or contact the Cancer Helpline on 13 11 20.

THANK YOU FOR YOUR TIME

PAGE 2

The following questions are about your cancer diagnosis and treatment.

These questions about your cancer diagnosis and treatment will help us to group your answers. This information will help us understand how things like the type of treatment a person has had might affect their needs. To answer, please fill in the oval that best describes your situation. Please do not leave any questions blank – your answers of 'no', 'don't know' and 'not applicable' are just as important to us as your 'yes' answers. If a question does not apply to you, please mark the 'no', 'don't know' or 'not applicable' oval for that question.

1 Have you received any of the following treatments for your cancer in the last 6 months?

(please mark one oval for each line, including item g. 'Other')

	Yes	No	Don't know
a. Surgical removal of the cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Radiotherapy (eg. radiation treatment, brachytherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Hormone treatment (eg. Tamoxifen, Zoladex, Anadron)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Bone marrow/stem cell transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Immunotherapy (eg. Interferon, Interleukin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Other (please specify): _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

2 Have you received any of the following treatments for your cancer in the last month? (please mark one oval for each line, including item g. 'Other')

	Yes	No	Don't know
a. Surgical removal of the cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Radiotherapy (eg. radiation treatment, brachytherapy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Hormone treatment (eg. Tamoxifen, Zoladex, Anadron)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Bone marrow/stem cell transplant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Immunotherapy (eg. Interferon, Interleukin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Other (please specify): _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

CANCER SURVIVAL STUDY

3 Some people have to temporarily live in another town or city to receive their cancer treatment. They may temporarily live with a family member or friend, stay in a flat/apartment or hotel, or live in a lodge or hostel near the hospital providing treatment. In the last 6 months have you had to temporarily live away from home in another town or city to receive cancer treatment? (mark one oval only)

☐ No
☐ Yes → Please specify the treatment(s) you received when you lived away from home:

4 In the last 6 months, have you decided **not** to have a particular cancer treatment because of the time it would take to get to treatment? (mark one oval only)

☐ Yes
☐ No

5 For treatments you have received in the last 6 months, about how long did it take for you to travel (one way) from your usual home address to each of the following: (Please mark one oval for each line. Mark 'Not Applicable' if you have not received that treatment in the last 6 months.)

	Less than 1 hour	1-2 hours	Between 2-5 hours	More than 5 hours	Not Applicable
a. The clinic or hospital where you had surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. The clinic or hospital where you had radiotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. The clinic or hospital where you had chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. The cancer specialist you see the most	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

6 At present, has your doctor told you that the cancer has: (mark one oval for each line)

	Yes	No	Don't know
a. Been treated and you are cancer-free (that is, in remission)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Come back after it was treated (that is, recurrent)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Spread to other parts of your body (that is, metastatic)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

7 In the last 6 months, have you been diagnosed with another type of cancer? (mark one oval only)

☐ No
☐ Yes → Please specify the type of cancer:

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CANCER SURVIVAL STUDY

8 In the last 6 months, have you talked to any of the following health care providers about your cancer? (mark one oval for each line, including item k. 'Other health care provider')

	Yes	No	Don't know
a. General Practitioner (GP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Surgeon	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Medical Oncologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Radiation Oncologist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Palliative Care Physician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Specialist Cancer Nurse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g. Psychologist, Counsellor, Social Worker or Psychiatrist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h. Physiotherapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i. Occupational Therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Dietician or Nutritionist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. Other health care provider (please specify): _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9 In the last 6 months, have you used any of the following services? (mark one oval for each line)

	Yes	No	Don't know
a. Cancer Council Helpline (telephone-based information & support service)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Cancer Council Connect (one-to-one support from a volunteer cancer survivor)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Support Group	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Telegroup counselling (telephone-based support group)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Living with Cancer Program (6-8 week information course)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

10 'Clinical trials' are research studies that test new and promising cancer treatments on people to see if they are better than existing cancer treatments. Not all people with cancer are eligible to take part in clinical trials and there are not clinical trials for all types of cancer. Since your cancer diagnosis, have you been informed about any cancer clinical trials for which you are eligible to participate? (mark one oval only)

☐ Yes
☐ No → **GO TO Q12**

11 Since your cancer diagnosis, have you been part of any cancer clinical trials for which you were eligible to take part? (mark one oval only)

☐ Yes
☐ No → Please specify why you did or didn't take part in the clinical trial

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CANCER SURVIVAL STUDY

- 12** Please indicate whether you have used any of the following treatments in the last 6 months to help you cope with your cancer and related symptoms. For those treatments that you answer 'yes', please indicate if you discussed the treatment with a member of your cancer treatment team (eg. Oncologist, Care Coordinator, Surgeon, General Practitioner). (mark one oval for each line, including item y. 'Other')

	Have you used this treatment in last 6 months?		Have you discussed with treatment team?	
	No	Yes	No	Yes
Mind-body treatments				
a. Aromatherapy	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
b. Art, music or dance therapy	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
c. Hypnosis	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
d. Meditation, imagery or visualisation	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
e. Prayer or spiritual practices	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
f. Progressive muscle relaxation	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
g. T'ai chi	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
h. Yoga	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
Manual healing methods				
i. Chiropractic manipulation	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
j. Massage	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
k. Osteopathic manipulation	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
Biologically based treatments				
l. Nutritional supplements (eg. vitamins, minerals, enzymes, antioxidants)	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
m. Special diet & foods (eg. Macrobiotic, Gerson, Gawler, Pritikin, vegetarian, juicing)	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
n. Herbal medicines (eg. Bach plants, Essiac, Iscador or Mistletoe)	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
o. Enema or colonic irrigation	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
p. Laetrile or amygdalin	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
q. Ozone therapy	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
r. Shark cartilage	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
Energy treatments				
s. Reiki	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
t. Microwave or Tronado therapy	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
Traditional medicine				
u. Acupuncture	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
v. Homeopathy	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
w. Naturopathy	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
x. Traditional Chinese medicine	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>
y. Other (please specify) _____	<input type="radio"/>	<input type="radio"/> -If 'yes'→	<input type="radio"/>	<input type="radio"/>

CANCER SURVIVAL STUDY

13 Chemotherapy, radiotherapy, surgery and hormone therapy are the main conventional medical treatments for cancer. Some people choose to use alternative treatments instead of conventional cancer treatments. Since you were diagnosed with cancer, have you used any alternative treatment in place of conventional cancer treatment?
(mark one oval only)

☐ No — **GO TO NEXT PAGE**
☐ Yes — Please specify the alternative treatment(s) you used in place of conventional cancer treatment:

14 Why did you use alternative treatment(s) instead of conventional cancer treatment?

15 Have you discussed the alternative treatment(s) you used with a member of your cancer treatment team (eg. Oncologist, Care Coordinator, Surgeon, General Practitioner)?
(mark one oval only)

☐ No
☐ Yes
☐ Don't know

Please check that you have answered all of the questions in this section.

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CANCER SURVIVAL STUDY

The following questions are
about your emotional well-being
in the past week.

- 1 Please fill in the oval (0-10) that best describes how much distress you have been experiencing in the past week including today. (mark one oval)

Extreme distress 10

9

8

7

6

5

4

3

2

1

No distress 0

From The National Comprehensive Cancer Network Distress Management Guideline, *The Complete Library of NCCN Clinical Practice Guidelines in Oncology* [CD ROM]. Jenkintown, Pennsylvania: National Comprehensive Cancer Network, March 2004. To view the most recent and complete version of the guideline, go online to www.nccn.org

CANCER SURVIVAL STUDY

The next few questions ask how you have been feeling in the last week. To answer, please fill in the oval that best describes how you have been feeling in the last week. If you make a mistake, either erase or place a cross through the incorrect oval and fill in the correct oval. Don't take too long over your answers; your immediate reaction to each question will probably be more accurate than a long, thought out answer.

2 I feel tense or 'wound up':

- Most of the time ☐
- A lot of the time ☐
- From time to time, occasionally ☐
- Not at all ☐

3 I still enjoy the things I used to enjoy:

- Definitely as much ☐
- Not quite as much ☐
- Only a little ☐
- Hardly at all ☐

4 I get a sort of frightened feeling as if something awful is about to happen:

- Very definitely and quite badly ☐
- Yes, but not too badly ☐
- A little, but it doesn't worry me ☐
- Not at all ☐

5 I can laugh and see the funny side of things:

- As much as I always could ☐
- Not quite so much now ☐
- Definitely not so much now ☐
- Not at all ☐

6 Worrying thoughts go through my mind:

- A great deal of the time ☐
- A lot of the time ☐
- From time to time but not too often ☐
- Only occasionally ☐

7 I feel cheerful:

- Not at all ☐
- Not often ☐
- Sometimes ☐
- Most of the time ☐

8 I can sit at ease and feel relaxed:

- Definitely ☐
- Usually ☐
- Not often ☐
- Not at all ☐

9 I feel as if I am slowed down:

- Nearly all the time ☐
- Very often ☐
- Sometimes ☐
- Not at all ☐

10 I get a sort of frightened feeling like 'butterflies' in the stomach:

- Not at all ☐
- Occasionally ☐
- Quite often ☐
- Very often ☐

11 I have lost interest in my appearance:

- Definitely ☐
- I don't take as much care as I should ☐
- I may not take quite as much care ☐
- I take just as much care as ever ☐

12 I feel restless as if I have to be on the move:

- Very much indeed ☐
- Quite a lot ☐
- Not very much ☐
- Not at all ☐

13 I look forward with enjoyment to things:

- As much as I ever did ☐
- Rather less than I used to ☐
- Definitely less than I used to ☐
- Hardly at all ☐

14 I get sudden feelings of panic:

- Very often indeed ☐
- Quite often ☐
- Not very often ☐
- Not at all ☐

15 I can enjoy a good book or radio or TV program:

- Often ☐
- Sometimes ☐
- Not often ☐
- Very seldom ☐

The Hospital Anxiety and Depression Scale: R.P. Smith and A.S. Zigmond, 1983, 1992, 1994.
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CANCER SURVIVAL STUDY

The following questions are about your overall health and relate to how you have felt during the past week.

We are interested in some things about you and your health. Please answer all of the questions yourself by filling in the oval that best applies to you. If you make a mistake, either erase or place a cross through the incorrect oval and fill in the correct oval. There are no 'right' or 'wrong' answers. The information that you provide will remain strictly confidential.

	Not at all	A little	Quite a bit	Very much
1. Do you have any trouble doing strenuous activities, like carrying a heavy shopping bag or a suitcase?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Do you have any trouble taking a <u>long</u> walk?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Do you have any trouble taking a <u>short</u> walk outside of the house?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Do you need to stay in bed or a chair during the day?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Do you need help with eating, dressing, washing yourself or using the toilet?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

During the past week:

	Not at all	A little	Quite a bit	Very much
6. Were you limited in doing either your work or other daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Were you limited in pursuing your hobbies or other leisure time activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Were you short of breath?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Have you had pain?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Did you need to rest?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Have you had trouble sleeping?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Have you felt weak?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Have you lacked appetite?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Have you felt nauseated?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>


CANCER SURVIVAL STUDY

During the past week:


	Not at all	A little	Quite a bit	Very much
15. Have you vomited?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Have you been constipated?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Have you had diarrhoea?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Were you tired?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Did pain interfere with your daily activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Have you had difficulty in concentrating on things, like reading a newspaper or watching television?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Did you feel tense?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Did you worry?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Did you feel irritable?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Did you feel depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Have you had difficulty remembering things?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Has your physical condition or medical treatment interfered with your <u>family</u> life?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Has your physical condition or medical treatment interfered with your <u>social</u> activities?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. Has your physical condition or medical treatment caused you financial difficulties?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

For the following questions please fill in the number between 1 and 7 that best applies to you.

29. How would you rate your overall health during the past week?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Very poor **Excellent**

30. How would you rate your overall quality of life during the past week?

☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Very poor **Excellent**

Please check that you have answered all of the questions in this section.

Aaronson, N.K., Ahmedzai, S., Bergman, B. *et al.* (1993). The European Organization for Research and Treatment of Cancer QLQ-C30: a quality-of-life instrument for use in international clinical trials in oncology. *J. Natl. Cancer Inst.* 85:365-76

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CANCER SURVIVAL STUDY

The following questions are
about needs you may have had
in the past month
as a result of having cancer.

To help us plan better services for people diagnosed with cancer, we are interested in whether or not needs which you may have faced as a result of having cancer have been met. For every item on the following pages, indicate whether you have needed help with this issue within the last month as a result of having cancer. Fill in the oval which best describes whether you have needed help with this in the last month. There are 5 possible answers to choose from:

**NO
NEED**

- ① **Not applicable** – This was not a problem for me as a result of having cancer.
② **Satisfied** – I did need help with this, but my need for help was satisfied at the time.

**SOME
NEED**

- ③ **Low need for help** – This item caused me concern or discomfort. I had little need for additional help.
④ **Moderate need for help** – This item caused me concern or discomfort. I had some need for additional help.
⑤ **High need for help** – This item caused me concern or discomfort. I had a strong need for additional help.

For example:

In the last month what was your level of need
for help with:

1. Being informed about things you can do to help
yourself to get well

NO NEED		SOME NEED		
Not applicable	Satisfied	Low need	Moderate need	High need
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input checked="" type="radio"/>	<input type="radio"/>

If you answered as we have, it means that you did not receive as much information as you wanted about things you could do to help yourself get well, and therefore needed some more information.

CANCER SURVIVAL STUDY					
In the <u>last month</u> what was your level of need for help with:	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
1. Pain	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Lack of energy/tiredness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Feeling unwell a lot of the time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Work around the home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Not being able to do the things you used to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Anxiety	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Feeling down or depressed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Feelings of sadness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Fears about the cancer spreading	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Fears about the cancer returning	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Worry that the results of treatment are beyond your control	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Uncertainty about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Learning to feel in control of your situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Keeping a positive outlook	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Feelings about death and dying	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Changes in sexual feelings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Changes in your sexual relationships	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Concerns about the worries of those close to you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. More choice about which cancer specialists you see	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. More choice about which hospital you attend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. Reassurance by medical staff that the way you feel is normal	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. Hospital staff attending promptly to your <u>physical</u> needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Being given written information about important aspects of your care	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. Being given explanations of those tests for which you would like explanations	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. Being adequately informed about the benefits and side-effects of treatments before you choose to have them	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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CANCER SURVIVAL STUDY

In the last month what was your level of need for help with:

	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
28. Being informed about your test results as soon as feasible	1	2	3	4	5
29. Being informed about cancer which is under control or diminishing (that is, remission)	1	2	3	4	5
30. Being informed about things you can do to help yourself to get well	1	2	3	4	5
31. Having access to professional counselling (eg. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it	1	2	3	4	5
32. Being given information about sexual relationships	1	2	3	4	5
33. Being treated like a person not just another case	1	2	3	4	5
34. Being treated in a hospital or clinic that is as physically pleasant as possible	1	2	3	4	5
35. Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up	1	2	3	4	5

36. What was your level of need for easy access to the following services and resources in the last month?

NO NEED	1 Not applicable – Not applicable <u>OR</u> never interested in having access to this service or resource.
	2 Satisfied – Fully satisfied with access to this service or resource.
SOME NEED	3 Low need for help – Had a low desire for better access to this service.
	4 Moderate need for help – Had a moderate desire for better access.
	5 High need for help – Had a strong desire for better access.

In the last month what was your level of need for access to:

	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
a. Transport service to and from the hospital or clinic	1	2	3	4	5
b. Easy car parking at the hospital or clinic	1	2	3	4	5
c. Food and drink facilities in or near the clinic waiting room	1	2	3	4	5
d. Comfortable waiting room	1	2	3	4	5
e. Child-minding at the hospital or clinic	1	2	3	4	5
f. Counselling services (eg. counsellor, psychologist, social worker, nurse specialist) at the hospital or clinic for your family/partner	1	2	3	4	5
g. Brochures about services and benefits for patients with cancer	1	2	3	4	5
h. Library of books and videos about cancer and related issues	1	2	3	4	5

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CANCER SURVIVAL STUDY

In the last month what was your level of need for access to:

	NO NEED		SOME NEED		
	Not applicable	Satisfied	Low need	Moderate need	High need
i. Relaxation classes	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j. Drop-in counselling and support service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k. 24-hour telephone support and cancer advisory service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
l. Home nursing service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
m. Home cleaning service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
n. Home gardening service	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
o. Respite care (to provide temporary relief to family home carers)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
p. Monetary allowance for travel, treatment and equipment expenses	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

37. Are there any other issues or needs that you would like help with? Please write them in the space below.

Please check that you have answered all of the questions in this section.

You have completed more than half of the survey. Please keep going. 😊

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CANCER SURVIVAL STUDY

The following questions are about your access to social support and your coping style.

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Please fill in the oval on each line that best describes your situation. If you make a mistake, either erase or place a cross through the incorrect oval and fill in the correct oval.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1. Someone you can count on to listen to you when you need to talk	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Someone to give you information to help you understand a situation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Someone to give you good advice about a crisis	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Someone to confide in or talk to about yourself or your problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Someone whose advice you really want	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Someone to share your most private worries and fears with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. Someone to turn to for suggestions about how to deal with a personal problem	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. Someone who understands your problems	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Someone to help you if you were confined to bed	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. Someone to take you to the doctor if you needed it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. Someone to prepare your meals if you were unable to do it yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. Someone to help with daily chores if you were sick	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Someone who shows you love and affection	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. Someone to love you and make you feel wanted	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Someone who hugs you	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. Someone to have a good time with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Someone to get together with for relaxation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. Someone to do something enjoyable with	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Someone to do things with to help you get your mind off things	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Sherbourne, C.D. & Stewart, A.L. (1991), The MOS Social Support Survey, *Soc. Sci. Med* 32(6):705-714

CANCER SURVIVAL STUDY

A number of statements are given below which describe people's reactions to having cancer. Please fill in the appropriate oval to the right of each statement, indicating how far it applies to you at present. For example, if the statement definitely does not apply to you then you should fill in '1' in the first column.

	Definitely does <u>not</u> apply to me	Does <u>not</u> apply to me	Applies to me	Definitely applies to me
1. At the moment I take one day at a time	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. I see my illness as a challenge	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I've put myself in the hands of God	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I feel like giving up	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I feel very angry about what has happened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I feel completely at a loss about what to do	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. It is a devastating feeling	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I count my blessings	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. I worry about the cancer returning or getting worse	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I try to fight the illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I distract myself when thoughts about my illness come into my head	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I can't handle it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I am apprehensive	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I am not hopeful about the future	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I feel there is nothing I can do to help myself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I think it is the end of the world	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. Not thinking about it helps me cope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. I am very optimistic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I've had a good life what's left is a bonus	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I feel that life is hopeless	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I can't cope	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. I am upset about having cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I am determined to beat this disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. Since my cancer diagnosis I now realise how precious life is and I'm making the most of it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
25. I have difficulty in believing that this happened to me	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. I make a positive effort not to think about my illness	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. I deliberately push all thoughts of cancer out of my mind	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. I suffer great anxiety about it	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. I am a little frightened	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Watson, M., Law, M., dos Santos, M., Greer, S., Baruch, J. & Bliss, J. (1994). The Mini-MAC: Further development of the Mental Adjustment to Cancer Scale. *Journal of Psychosocial Oncology*, 12(3):33-46.

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CANCER SURVIVAL STUDY

The following questions are about your general background and lifestyle.

Finally, we would like to ask some questions about you and your lifestyle. Some questions may seem personal but it is important that you try to answer each question. We are asking everyone the same questions. All information will be handled in the strictest confidence. To answer, please fill in the oval that best describes your situation.

- 1 For all the questions you have answered so far, were any of your answers affected by circumstances in your life not related to your cancer, such as a current illness or medical condition, psychological condition or life event?

- ☐ No
☐ Yes → Please specify the circumstances that have affected your answers, such as a current illness or medical condition, psychological condition or life event:

- 2 What is your current marital status? (mark one oval only)

- ☐ Married
☐ Defacto or living with a partner
☐ Separated or divorced
☐ Widowed
☐ Never married or single

- 3 What is the highest level of education that you have completed? (mark one oval only)

- ☐ Primary school
☐ Secondary school
☐ Certificate or Diploma
☐ University Degree

- 4 Which of the following best describes your current employment situation? (mark one oval only)

- ☐ Paid full-time employment
☐ Paid part-time employment
☐ Casual employment
☐ Self-employed
☐ On leave with pay (eg. sick leave, long service leave)
☐ On leave without pay
☐ Retired or aged pensioner
☐ Not working – disabled
☐ Household duties
☐ Student
☐ Unemployed
☐ Volunteer
☐ Other (please specify): _____

CANCER SURVIVAL STUDY

5 In the last 6 months, has your work situation changed as a result of your cancer diagnosis or treatment (eg. work less hours, retired, etc)? (mark one oval only)

☐ No

☐ Yes → Please describe how your work situation has changed as a result of cancer:

6 Do you currently have private health insurance? (mark one oval only)

☐ No – Medicare only

☐ No – Medicare and Department of Veterans' Affairs Gold or White Card

☐ Yes – hospital cover only

☐ Yes – ancillary (extras) cover only

☐ Yes – hospital and ancillary (extras) cover

7 What is your present gross family income each week (that is, before tax)? (mark one oval only)

☐ Less than \$300 per week

☐ Between \$300 - \$499 per week

☐ Between \$500 - \$799 per week

☐ Between \$800 - \$1000 per week

☐ More than \$1000 per week

☐ Prefer not to answer

8 Does anyone live with you?

☐ No, I live alone

☐ Yes →

	nil	one	two	three or more
How many children (under 18) live with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
How many adults (18 years or over) live with you?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

9 In the last 6 months, have you been treated for a mental health illness (eg. depression, anxiety, panic disorder, schizophrenia, phobia)? (mark one oval only)

☐ Yes

☐ No

☐ Don't know

The next group of questions are about your behaviour in the sun and your skin.

10 Last summer (or this summer if you are answering during summer), when you were out in the sun for more than 15 minutes between 11am and 3pm, how often did you: (mark one oval for each line)

	Always	Often	Sometimes	Rarely or never	Never in sun for more than 15 minutes
a. Wear a wide-brimmed hat or cap with a flap	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Apply broad spectrum sunscreen, 15+ or higher	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Deliberately wear more clothing to protect yourself from the sun	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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CANCER SURVIVAL STUDY

11 Were your cancer symptoms, diagnosis or treatment an important influence on how you protected your skin from the sun in the last 6 months?
(mark one oval only)

- ☐ Yes
☐ No
☐ Don't know

12 In the last 6 months, did the following people check your skin for signs of possible cancer?
(mark one oval for each line)

	Yes	No	Don't know
a. Yourself	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Relative or friend	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. General Practitioner	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Skin cancer specialist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

13 Were your cancer symptoms, diagnosis or treatment an important influence on whether you checked your skin in the last 6 months?
(mark one oval only)

- ☐ Yes
☐ No
☐ Don't know

The next group of questions are about your physical activity and diet.

14 Has being diagnosed with cancer influenced whether you participated in physical activity in the last 6 months? (mark one oval only)

- ☐ Yes, I am more likely to participate in physical activity because I have had cancer
☐ Yes, I am less likely to participate in physical activity because I have had cancer
☐ No, having cancer has not influenced whether I participated in physical activity
☐ Don't know

15 Since your cancer diagnosis, have you made any changes to your diet? (mark one oval only)

- ☐ Yes ▶ **GOTO Q16**
☐ No ▶ **GOTO Q17**
☐ Don't know ▶ **GOTO Q16**

16 Since your cancer diagnosis, have you made any of the following changes to your diet? (mark one oval for each line)

	Yes	No	Don't know
a. Increased the amount of fruit and vegetables you eat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Increased the amount of fibre in your diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c. Decreased the quantity of food you eat to lose weight	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d. Decreased the amount of fat in your diet	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Decreased the quantity of red meat you eat	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f. Increased the amount of water you drink	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

The next group of questions are about smoking. You will be asked to skip some questions in this section. After answering each question, please follow the 'go to' instructions on the right.

17 Do you currently smoke any tobacco products? (mark one oval only)

- ☐ Not at all, never smoker → GO TO Q23
- ☐ Not at all, ex-smoker → GO TO Q18
- ☐ Daily → GO TO Q20
- ☐ At least once a week → GO TO Q20
- ☐ Less often than once a week → GO TO Q20

18 Did you quit in the last 6 months? (mark one oval only)

- ☐ Yes → GO TO Q19
- ☐ No → GO TO Q23
- ☐ Don't know → GO TO Q19

19 Were your cancer symptoms, diagnosis or treatment an important influence in your decision to quit? (mark one oval only)

- ☐ Yes → GO TO Q23
- ☐ No → GO TO Q23
- ☐ Don't know → GO TO Q23

20 During the past 6 months have you quit smoking intentionally for one day or longer? (mark one oval only)

- ☐ Yes → GO TO Q21
- ☐ No → GO TO Q22
- ☐ Don't know → GO TO Q22

21 Were your cancer symptoms, diagnosis or treatment an important influence in your decision to try quitting? (mark one oval only)

- ☐ Yes → GO TO Q23
- ☐ No → GO TO Q23
- ☐ Don't know → GO TO Q23

22 What are your intentions regarding quitting? (mark one oval only)

- ☐ Will quit in next month → GO TO Q23
- ☐ Will quit in next 6 months → GO TO Q23
- ☐ May quit but not in next 6 months → GO TO Q23
- ☐ Never expect to quit → GO TO Q23
- ☐ Don't know → GO TO Q23

CANCER SURVIVAL STUDY

23 The next group of questions are about medical tests you might have had to detect cancer. Here is a description of the tests we will be asking you about:

- **Faecal Occult Blood Test (FOBT)** is a test for bowel cancer. This test involves taking a sample of faeces and sending it to a laboratory to test if it contains blood.
- **Colonoscopy or a flexible sigmoidoscopy** is a test for bowel cancer. This test involves a doctor passing a long tube into your back passage (rectum) to examine the inside of your bowel.
- **Mammogram** is a routine test for the early detection of breast cancer. An x-ray is taken of your breast by a machine that presses against your breast while the picture is taken.
- **Pap smear test or Pap Test** is a routine test for the early detection of cancer of the cervix. This test involves a doctor taking a few cells from the cervix and sending them to a laboratory to be tested.
- **Prostate cancer tests** can be a **blood test**, **ultrasound** or a **digital rectal examination**. An ultrasound uses high-frequency sound waves and a computer to view images of internal organs and blood flow through various vessels. A digital rectal examination is when the doctor inserts a lubricated, gloved finger into the rectum and feels for abnormal areas.

Please indicate whether you have had each of these tests in the last 12 months. For those tests that you answer 'yes', please indicate how long it has been since you last had the test and the reason why you had it.

	Have you had this test in the last 12 months?		How long has it been since you last had this test?		Why did you have this test?			
	No	Yes	Up to 6 months ago	More than 6 months to less than 12 months ago	Why?	I had a check-up (no symptoms)	I had symptoms	Don't know
EVERYONE								
a. Faecal Occult Blood Test (FOBT)	<input type="radio"/>	<input type="radio"/>	- If 'yes' → <input type="radio"/>	<input type="radio"/>	- Why? → <input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b. Flexible sigmoidoscopy or colonoscopy	<input type="radio"/>	<input type="radio"/>	- If 'yes' → <input type="radio"/>	<input type="radio"/>	- Why? → <input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
MEN ONLY								
c. Prostate cancer test: blood test, ultrasound or a digital rectal examination	<input type="radio"/>	<input type="radio"/>	- If 'yes' → <input type="radio"/>	<input type="radio"/>	- Why? → <input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
WOMEN ONLY								
d. Mammogram	<input type="radio"/>	<input type="radio"/>	- If 'yes' → <input type="radio"/>	<input type="radio"/>	- Why? → <input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e. Pap smear test	<input type="radio"/>	<input type="radio"/>	- If 'yes' → <input type="radio"/>	<input type="radio"/>	- Why? → <input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

24 People diagnosed with cancer may have tests as part of their treatment or follow-up. Apart from those tests, has being diagnosed with cancer changed whether you have check-ups or tests for other types of cancer when you have no symptoms? (mark one oval only)

- ☐ Yes, I am more likely to have check-ups because I have had cancer
- ☐ Yes, I am less likely to have check-ups because I have had cancer
- ☐ No, having cancer has not influenced whether I have check-ups
- ☐ Don't know

CANCER SURVIVAL STUDY

The last group of questions are about alcohol. Alcoholic drinks are measured in terms of a 'standard drink'. A standard drink is equal to

- a 285ml middy of full-strength beer (4.9% alc./vol)
- a 375ml schooner of mid-strength beer (3.5% alc./vol)
- a 100ml serve of wine (12% alc./vol)
- a 60ml serve of sherry or port (18% alc./vol)
- a 30ml nip of spirits (40% alc./vol)

25 Have you ever had a full serve of alcohol (eg. a glass of wine, a whole nip of spirits, a glass of beer, etc)? (mark one oval only)

- ☐ Yes → **GO TO Q26**
- ☐ No → **GO TO END OF SURVEY**

26 In the last 6 months, how often did you have an alcoholic drink of any kind? (mark one oval only)

- ☐ Every day
- ☐ 5-6 days per week
- ☐ 3-4 days per week
- ☐ 1-2 days per week
- ☐ 2-3 days per month
- ☐ 1 day per month
- ☐ Less often than 1 day per month
- ☐ No longer drink → **GO TO Q28**

27 In the last 6 months, on a day that you have an alcoholic drink, how many standard drinks do you usually have on average?

28 Has being diagnosed with cancer influenced whether you drank alcohol or how much you drank in the last 6 months? (mark one oval only)

- ☐ Yes, I am more likely to drink alcohol because I have had cancer
- ☐ Yes, I am less likely to drink alcohol because I have had cancer
- ☐ No, having cancer has not influenced whether I drink alcohol or how much I drink
- ☐ Don't know

You have now finished the survey. Thank you for your participation.
Please return your completed survey in the reply-paid envelope provided.

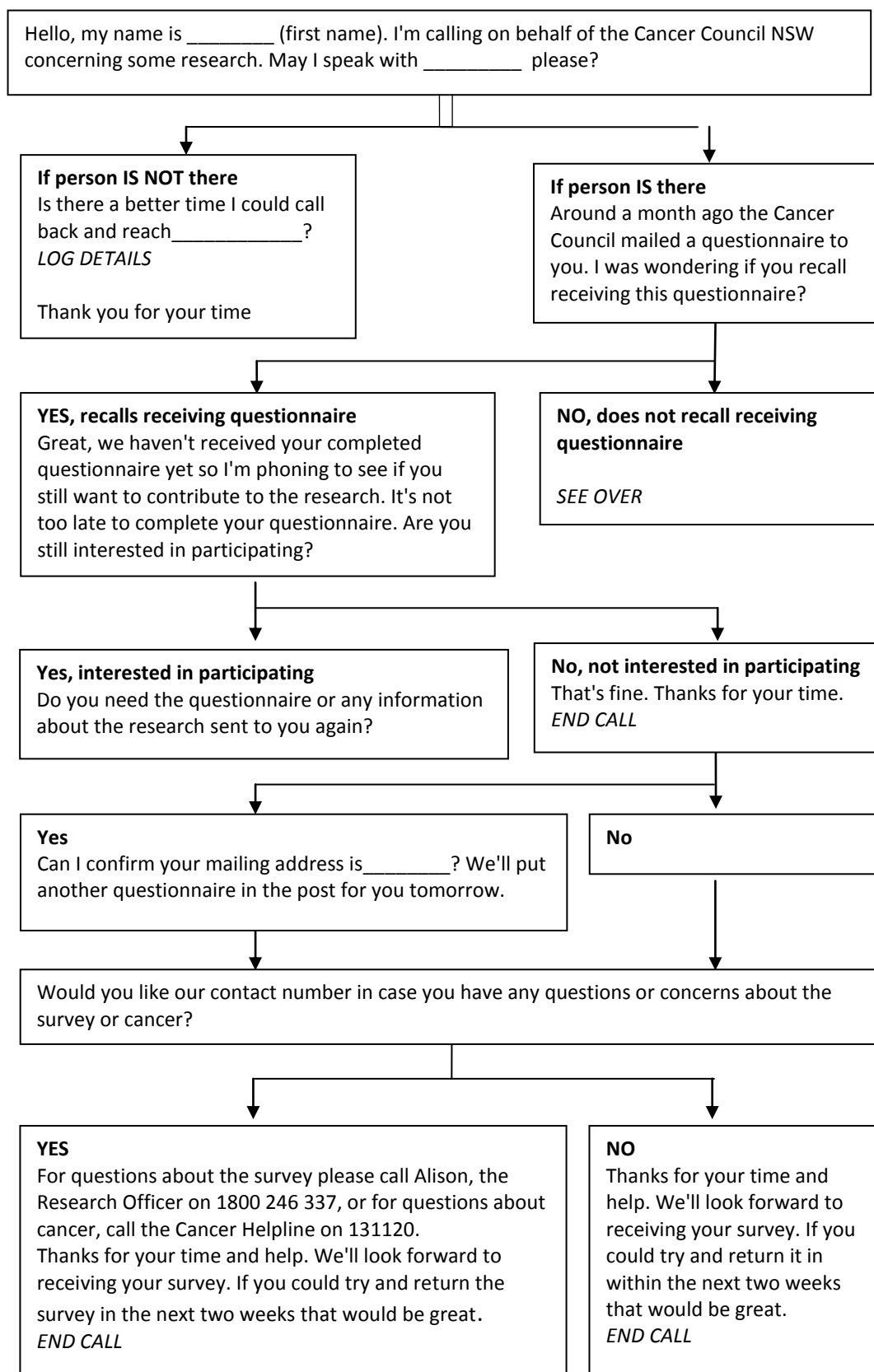
We will send you a similar survey in one year.
We value your participation in this research, however you are not obligated to complete any future surveys and you may withdraw from this study at any time.

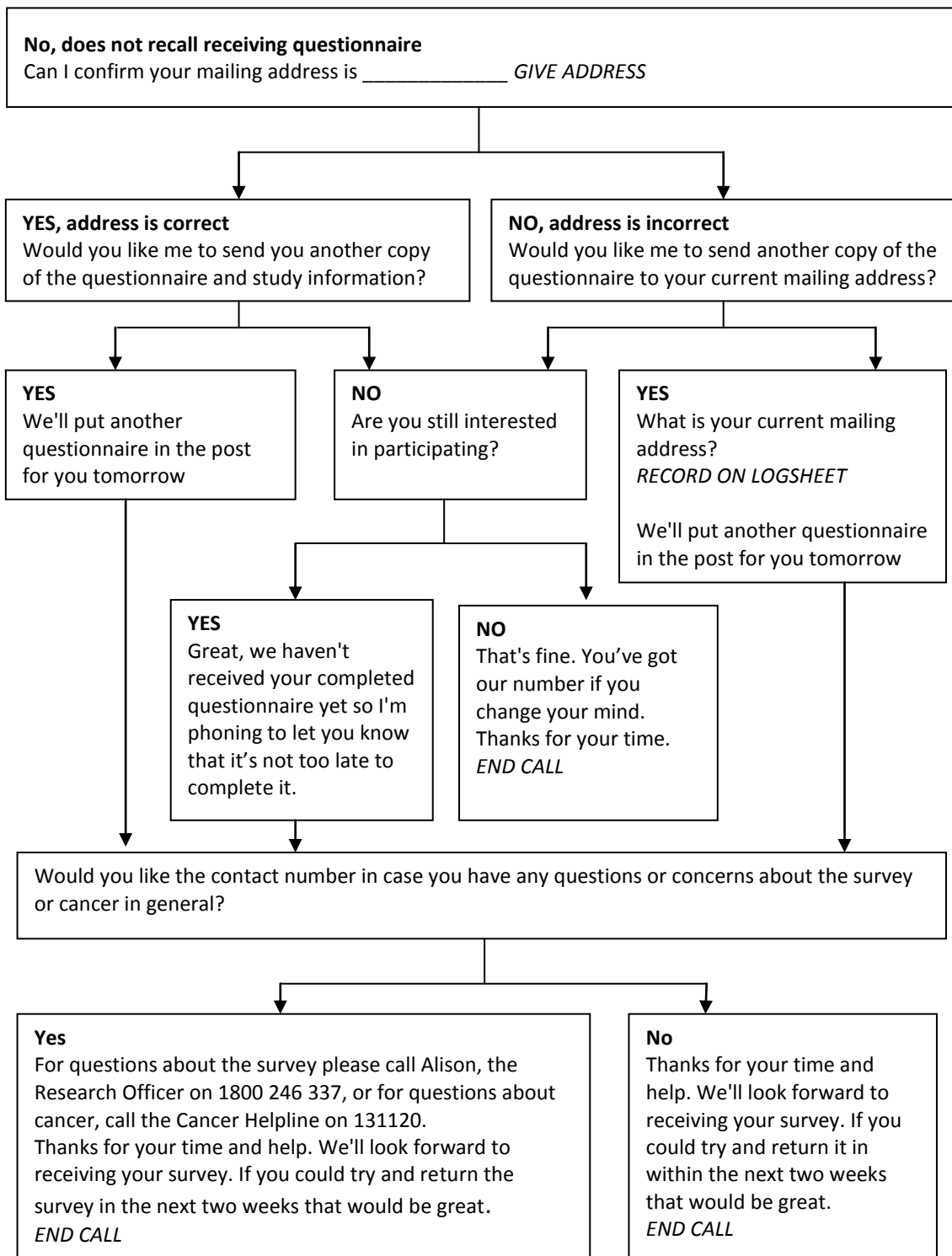
If you would like to make any other comments, please write them in the space below.

[illegible]

APPENDIX 8: Standardised study procedures

Protocol for reminder telephone calls





Frequently Asked Questions

GENERAL STUDY QUESTIONS

What is the research about?

The research is about the effect that cancer has on adults diagnosed with cancer. We want to find out about the physical, emotional and lifestyle issues faced by cancer survivors. We will follow cancer survivors for up to five years after they are diagnosed with cancer to see how these issues change over time.

How will the study help?

This study will tell us more about the effect that cancer has on cancer survivors and the type of help they desire at various stages of the diagnosis, treatment and recovery pathway. This research will help The Cancer Council to develop new programs and policies to better assist cancer survivors.

Why should I take part?

By taking part you'll be helping cancer survivors in the future to receive the best possible care. We would really appreciate your help in our study.

Who is doing the research?

Researchers at the Centre for Health Research and Psycho-oncology (CHeRP) are running the study. CHeRP is the Behavioural Research Unit of the Cancer Council NSW and is based within the Faculty of Health at the University of Newcastle. These researchers are dedicated to improving the quality of care and support for cancer survivors.

Who is paying for the research?

The National Health and Medical Research Council, The Cancer Council NSW and the Hunter Medical Research Institute are funding the study.

Who will take part in the research?

People living in NSW or Victoria aged between 18 and 80 years who have been diagnosed with their first cancer in the last 4-6 months are being asked to take part.

How did you get my name?

The Cancer Registry in your state passed on your contact details to us with your permission so that we could write to you and ask you to consider participating in this study.

What will I have to do?

If you decide to participate you will be required to fill in a questionnaire. The questionnaire will take about 30-45 minutes to complete. We will send you a similar questionnaire three more times over the next five years. These surveys will be sent to you six months, one and a half years and four and a half years after the first survey.

What sorts of questions will be asked?

The questionnaire will ask about your physical and emotional health, any needs you may have, your lifestyle, as well as some general background questions about you and the treatment of your cancer. Each question will have a list of answers for you to choose from.

Will my information be kept confidential?

Yes; all the information you give us will be kept strictly confidential. Your name will not be on the survey and you will not be able to be identified when the results of the study are reported.

What if I agree to take part and then change my mind?

That's OK. Participation in the research is completely voluntary. The care you receive for your cancer won't be affected in any way if you change your mind or choose not to take part. You can withdraw at any time after you have agreed to take part - just let us know.

Can I get a copy of the results, please?

Yes; once a year we will send a newsletter to all people participating in the study. This newsletter will contain the most recent results from the research.

SURVEY COMPLETION QUESTIONS

How long will the survey take to complete?

The survey will take about 30-45 minutes to complete. You don't have to fill it in all at once; you can fill it in over several days until it is all completed.

There are circumstances in my life that aren't related to cancer that will affect my answers.

How do I answer the survey?

For questions about:

- ***emotional wellbeing***
- ***overall health***
- ***social support***

You don't need to differentiate between your symptoms as a result of cancer, and your symptoms as a result of the other circumstances in your life.

For questions about:

- ***unmet needs)***

We are interested in your needs as a result of having cancer. If there are circumstances, other than cancer, that may affect how you respond, please have a go at trying to differentiate between the two. For example, for question 1, *in the last month what was your level of need for help with pain*, do your best at trying to differentiate your need for help with cancer-related pain, and your need for help with non-cancer-related pain. We are very interested to hear about your cancer-related pain. You may find it tricky, but just do your best.

I have recently been diagnosed with another cancer. How should I answer the survey?

You should try and answer the questions in relation to your first cancer diagnosis. You may find it tricky trying to distinguish one cancer experience from another, but just do your best.

My overall wellbeing was much worse when I was undergoing treatment. Should I answer the survey in relation to how I was feeling back then?

No; you should answer the questions in relation to how you are feeling now - unless the question tells you to think back to how you have been feeling in the last week or the last month. We don't know much about Australian cancer survivors' experiences after treatment, and this study will help to fill this gap in our knowledge.

'I FEEL GOOD' or 'I FEEL UNWELL' QUESTIONS

I feel fine. I don't think I have anything useful to contribute to the research.

It's great to hear that you're doing well. It is important that we hear from people who are experiencing ongoing difficulties, as well as those who experience only a few or none at all. Your answers will help us to obtain an overall picture of the experiences of all cancer survivors.

I don't have cancer anymore.

We're interested in finding out how people are getting on after a cancer diagnosis. This means you can still take part in the research even if you no longer have cancer.

What if I do not feel well enough to participate?

You can withdraw your participation at any time. You may choose to withdraw from the study entirely, or you may prefer to skip one of the four surveys and continue participating when you are feeling better. If you choose to participate and don't feel well enough when you receive the questionnaire in the mail, just let us know by calling our Freecall number. Alternatively, you can let us know when we call you to follow up the survey.

HOLIDAY and MOVING HOUSE QUESTIONS

I'm going on holidays soon. Can I still complete the survey?

Yes; you can still complete the survey if you are going on holidays. You can post the survey in the reply-paid envelope from anywhere in Australia. If you're holidaying overseas, it's OK if you return the survey a little later.

I will be on holidays when the next survey is due.

We can send the survey to your holiday address. Would you like to receive the survey while you are away?

I'm moving at the end of the year. Can I still take part?

We are happy to send the survey to your new address. Do you know your new address yet?
(*obtain moving date*)

(*Double check secondary contacts*)

Is _____[list secondary contact]_____ still the best person to contact if we are unable to locate you?

MAIL-OUT-SPECIFIC QUESTIONS

I've just received another survey, but I have already sent you my completed survey.

Thanks. Let me just check our records to see if we have received your survey (*check database.*)

If survey received: Yes, we received your survey on (*provide date*). It looks like the surveys have crossed in the mail. I'm sorry for the confusion and I appreciate your call. You don't need to complete the survey again, but feel free to mail the survey back to us in the reply-paid envelope.

If survey not received: No, we haven't received your completed survey yet. Did you mail it to us recently?

If recently mailed: I expect the survey is still on its way. If we haven't received your survey in the next week, would it be OK if we called you to fill in the one you've just received?

If not recently mailed: I expect the survey has been delayed at the mail room. If we haven't received your survey in the next few days, would it be OK if we called you and asked you to fill in the one you've just received?

Which forms do I send back to you?

There are three forms you need to send back to us. These are

- the questionnaire ... that is the large booklet
- and the two yellow forms; one labelled "future research form" and the other labelled "secondary contact form" .

Just place these 3 forms in the reply-paid envelope and post at any post box. No postage stamp is needed.

I have not received/lost a reply-paid envelope.

I can send you another reply-paid envelope. Alternatively, if you have a spare envelope, I can give you the address to send it to:

Cancer Survival Study
The University of Newcastle
Reply Paid 63885
CALLAGHAN NSW 2308

In the bottom left hand corner place the following details:

CHeRP

School of Medical Practice and Public Health

Faculty of Health

LMB 10, Wallsend NSW 2287

RESPONDING TO EMOTIONS

Person distressed

(Empathise with person)

If you would like, I can give you the number of the Cancer Council Helpline which is staffed by professional nurse counsellors. The Helpline is a great service that provides information, support and referral to all people affected by cancer. Would you like the number of the Cancer Council Helpline? The number is 13 11 20, and they are open Monday to Friday, 9am to 5pm.

Person angry/disgruntled with hospital/clinician/Cancer Council NSW

(Empathise with person)

Our role at the Centre for Health Research & Psycho-oncology is to study the effect that cancer has on cancer survivors so that we can assist the Cancer Council to develop new programs and policies that help cancer patients.

For people unhappy with Hospital/Doctor:

Would you like the number of the Cancer Council Helpline?

The number is 13 11 20, and they are open Monday to Friday, 9am to 5pm.

Person angry/disgruntled with the conduct of the Cancer Survival Study

Record the following details where possible

- name, address, contact details

- nature of the complaint

Would you like the Project Manager, Allison Boyes, to call you back?

Someone close to participant has died

I'm very sorry for your loss. You are welcome to complete the survey but I understand if you would prefer not to. Thank you for your time.

Participant has died

I've very sorry for your loss. Thank you very much for letting us know.

CANCER REGISTRY QUESTIONS

What is the Cancer Registry?

Each Australian state has its own cancer registry. The law requires that these registries collect details of all cancer diagnosed in their state.

- In NSW, the cancer registry is located at the Cancer Institute NSW
- In Victoria, the cancer registry is located at the Cancer Council Victoria.

The information from the registry is used:

- To monitor cancer cases and cancer deaths
- To help with planning services for the control of cancer, and care of cancer patients
- To measure the effectiveness of cancer treatments, and cancer control programs
- To assist with research (such as this one) to find out more information about cancer.

More details about the registry, if requested:

The information collected about patients with cancer includes: name, address, date of birth, country of birth, whether the person is Aboriginal or Torres Strait Islander, clinical details about cancer, and the notifying institution or doctor. Access to the information about identified cancer patients can only be obtained by health and medical researchers when certain stringent criteria are met.

Why does my doctor have to give permission for me to participate?

Your name was sourced from your state cancer registry. It is only with permission from your doctor and yourself that the registry will release information about you to us. The registry operates according to strict privacy laws and stringently protects the information it holds.

What sorts of questions does my doctor have to answer about me?

The questions the registry asks your doctor are:

- Is the patient able to read and understand English?
- Is the patient physically and mentally able to complete a survey?
- Has the patient been informed of the cancer diagnosis?
- Are there any other reasons why this patient should not be contacted?

If your doctor answers yes to all these questions, then the cancer registry will contact you and inform you about the study.

NON-STUDY-SPECIFIC QUERIES

How can I help other people with cancer?

There are a number of ways you can help the Cancer Council NSW such as

- participating in fundraiser events
- becoming a volunteer
- making a donation.

The Cancer Council NSW has a special office dedicated to fundraising. You can find out more by calling the hotline 1300 780 113 or logging onto the Cancer Council NSW website www.nswcc.org.au and following the links to 'how can you help'.

Can you tell me about cancer/ medical treatments/etc?

Unfortunately_____ is not my area of expertise. However, the Cancer Council NSW has a Helpline that is staffed by professional nurse counsellors who would be able to help you with that. Would you like the number of the Helpline? The number is 13 11 20, and they are open Monday to Friday, 9am to 5pm.

I have a friend/relative who would love to participate. Can I give you their details?

The participants for this research have already been selected. If your friend/relative has not received the survey yet, then they do not need to take part. However, your friend/relative is more than welcome to call or read the study materials if they would like some information about the study or cancer.

- For information about the study you can contact Allison Boyes, the Project Manager, or Alison Zucca, the Project Officer, on 1800 246 337.
- For any questions/concerns about cancer you can call the cancer helpline on 13 11 20.

CARERS' QUESTIONS

What is this yellow envelope for?

Other researchers in our team are conducting a separate study to the Cancer Survival Study, which is for the partners and caregivers of cancer survivors. We would like you to pass the envelope on to your husband, wife, partner or main caregiver. A definition has been written on the front of the envelope to help you to decide who to pass the information on to.

"A partner can include the husband or wife, de facto partner, boyfriend or girlfriend.

A main caregiver:

** Is the person who springs to mind as most involved in supporting you through your illness, often your partner, but sometimes a sister, child, other relative, or a friend.*

** Can be a man or woman of any age who may or may not live with you.*

** Does not necessarily do any physical tasks for you, such as cooking and cleaning; they may provide company and/or emotional support.*

** Is NOT someone who is paid to look after you (e.g. a nurse or home help)."*

What if I don't have a caregiver?

You can still participate in the Cancer Survival Study. If you do not have a caregiver (that is, someone who is supporting you through the illness, who may help you with doing tasks, or give you emotional support), then please just discard the information.

Obtain participant details and don't send a caregivers package in their reminder letter.

I have two people who support me. Who is the best person to pass the information pack on to?

Please pass the information on to the person who is closest to you, who is most affected by your diagnosis.

I have two caregivers. Can I pass information on to both of them?

No; we would like you to please pick one of your caregivers who gives you support, and has been most affected by your diagnosis.

My partner has health problems and isn't well enough to participate. I look after them.

If you have anyone else close to you who helps support you, or helps you with any tasks, or has been affected by your diagnosis, you can pass the information on to them.

My partner/caregiver is deaf/cannot speak English. Can they still participate?

If they are able to read and understand the consent form and survey, then they are welcome to participate.

My child looks after me (they are under 18 years). Can they participate?

If your partner/caregiver is able to read and understand the consent form and survey, then they are welcome to participate.

My partner/caregiver has passed away

I'm very sorry for your loss.

I DON'T IDENTIFY WITH BEING A CAREGIVER

I am his/her partner. The things I do are not related to me being their caregiver.

We are interested in your experience as their partner or caregiver. Even if you are doing things the same as you usually have, we would still like to hear from you.

My loved one feels fine and doesn't need a caregiver. I don't feel I have anything useful to contribute to the research.

We are interested in your experience of having someone close to you diagnosed with cancer. We don't know much about how Australian families are coping after someone close to them has been diagnosed with cancer, and this study will help to fill this gap in our knowledge.

I'm no longer my loved one's caregiver as they have recovered and feel fine.

That's great news that they are feeling better. The things you might do to support your loved one may change over time, and we are interested in hearing about how things are for you at the moment.

LINKING

I don't want to take part in the linking, and so I don't know if I should participate.

You don't have to agree to have your data linked. The decision is entirely up to you. If you agree to have your data linked to your loved one's data, it will help us to plan support services for patients and their families and caregivers. Simply fill in the consent form and return it.

Do I have to agree to have my data linked if I consent to do the survey?

You don't have to agree to have your data linked. The decision is entirely up to you. If you agree to have your data linked to your loved one's data, it will help us to plan support services for patients and their families and caregivers. Simply fill in the consent form and return it.

Protocol for tracking participants

Start tracking if:

- The individual is **not at the address** currently noted (e.g. Return to Sender) or
- The individual is **not at the number**

To begin tracking:

- a. Tick the start tracking box on the 'tracking' tab of the database. The survey will automatically become inactive so that wrong phone numbers and addresses are not included in the lists printed for reminder mail-outs and phone calls.
- b. Print tracking log sheet with participant's current details.

1. Check contact details against database

Check participant address on return to sender documents and/or telephone number against the study database

- If address and/or phone number are different:
 - a. record new details on log sheet
 - b. record new details in database
 - c. stop tracking by selecting FOUND in the tracking tab of the database
 - d. file tracking log sheet in participant file
- If address and/or phone number is the same, continue tracking.

2. If return to sender, contact participant by telephone

Call all telephone numbers recorded for the participant to request new postal address.

Hello, my name is _____ (first name). I was hoping to speak with _____ (person's name).

If wrong number: *Sorry to bother you. Thanks for your time*

I'm calling on behalf of the Cancer Council NSW. The researchers from the Cancer Survival Study were given your details after you gave your consent to the cancer registry. A survey was sent to the given address but it returned in the mail as "return to

sender". I am ringing today to confirm that the mailing address we have is your current address. Could you confirm that your address is _____(address on database)?

If yes: *Would you like the questionnaire sent to you again?*

Yes: *OK, we'll send out a copy as soon as we can.*

No: *That's fine. Thanks for your time.*

If no: *Would you be happy to provide us with your new contact details?*

Yes: *What is your current address?*

No: *That's fine. Thank you for your time*

- If address and/or phone number are different:
 - a. record new details on log sheet
 - b. record new details in database
 - c. stop tracking by selecting FOUND in the tracking tab of the database
 - d. file tracking log sheet in participant file
- If contact details are the same
 - a. stop tracking by selecting FOUND in the tracking tab of the database
 - b. file tracking log sheet in participant file
- If wrong number, continue tracking.

3. Contact participant by email

E-mail individual from the dedicated CHeRP-survival email account

- If address and/or phone number are different
 - a. record new details on log sheet
 - b. record new details in database
 - c. stop tracking by selecting FOUND in the tracking tab of the database
 - d. attach any correspondence to the tracking log sheet and file in participant file

- If contact details are the same
 - stop tracking by selecting FOUND in the tracking tab of the database
 - attach any correspondence to the tracking log sheet and file in participant file
- If no response, continue tracking.

4. Search the electronic White Pages

Search the White Pages to match the existing name to a new address.

- a. Go to the web site www.whitepages.com.au
 - b. Type in the individual's name, their initial and the state
 - c. Conduct a capital city search followed by search in other areas within the state.
- If participant is found in the white pages
 - a. check the new address is different from the address currently noted (that is, have you found any new information?)
 - b. record new details on the log sheet and in the database
 - c. stop tracking by selecting FOUND in the tracking tab of the database.

5. Contact the cancer registry

Ask cancer registry staff to check contact details uploaded against original consent form held by them AND the electronic electoral roll

- If address and/or phone number are different
 - a. record new details on log sheet
 - b. record new details in database
 - c. stop tracking by selecting FOUND in the tracking tab of the database
 - d. attach any correspondence to the tracking log sheet and file in participant file
- If contact details are the same, continue tracking.

6. Contact secondary contact

Telephone secondary contact to request passing on study freecall number to participant

May I speak with (secondary contact) please? This is Alison from the Cancer Council.

***If no:** Is there a better time I could call back and reach (secondary contact) Thank you for your time*

***If yes:** We've been unable to reach (participant) for a research project that s/he has been taking part in for the Cancer Council. The reason I have called you is that (participant) provided us with your details, and indicated that we could contact you if we were ever unable find him/her. I recently tried contacting (participant) but his/her letter was sent back RTS (and I was unable to reach him/her by phone). I was wondering whether you would be willing to pass on our study freecall number to (participant) so that he/she could let me know about his/her current contact details?*

***No:** That's fine. Thank you for your time*

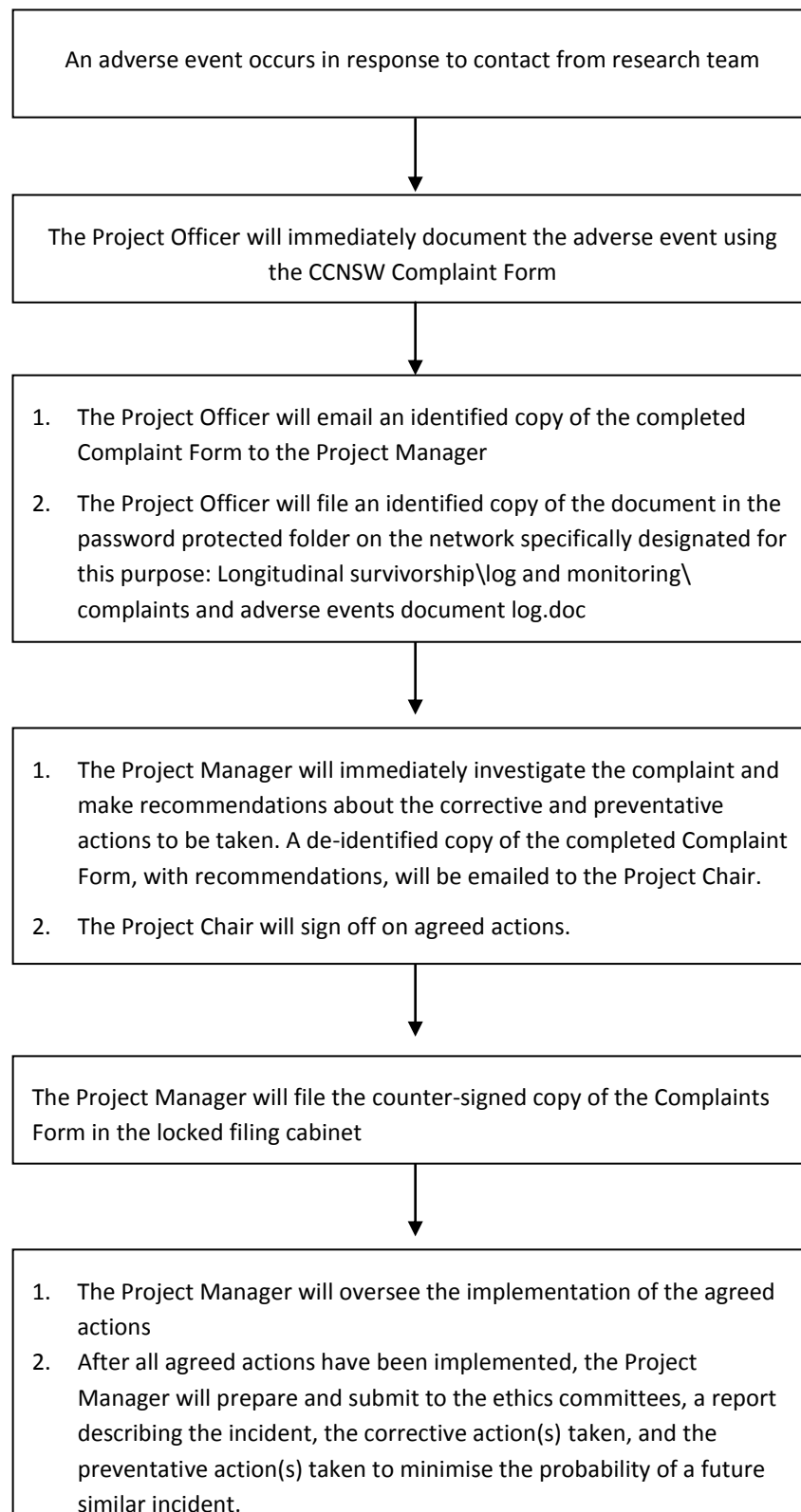
***Yes:** Great. My free call number is 1800 246 337. The research project is a survey with the Cancer Council. (If requested 'Cancer Survival Study'). My name is Alison.*

***Yes, I know his/her new details. Would you like them?** Yes, if you think that would be OK with (participant)? We will only use his/her contact details for the purpose of this research project.*

- If address and/or phone number are different
 - a. record new details on log sheet
 - b. record new details in database
 - c. stop tracking by selecting FOUND in the tracking tab of the database
 - d. file log sheet in participant file.

- If contact details are the same, continue tracking
 - a. record results on the log sheet.
 - b. select NOT FOUND in the tracking tab of the database
 - c. select WITHDRAWN –OTHER in the status tab of the database and select LOST TO FOLLOWUP.

Protocol for complaints and adverse events



APPENDIX 9: Participant newsletters



Cancer Survival Study

Newsletter 1: Autumn 2007



One in three men and one in four women in Australia will be diagnosed with cancer in their lifetime. Fortunately, cancer survival rates in Australia are among the best in the world and more than half of those diagnosed with cancer will be successfully treated.

The Cancer Survival Study aims to find out how cancer impacts upon the lives of people diagnosed with cancer, and how the issues they face change over time. So far, about 900 people from across NSW and Victoria have completed the first survey and almost 400 have completed the second survey. We read every survey that is returned to us and are heartened by the generosity of those who contribute to our research. We recognise that the surveys are quite long and thank you for taking the time and effort to complete them. We know that not only do you lead busy lives, but that many of you have completed our surveys at a time of considerable distress, while having cancer treatment, or dealing with other health issues.

Some of you have told us that the survey does not seem relevant to you because you are no longer receiving treatment or are fully recovered and doing well. We want to assure you that your answers are still very important to us - to make sure that we get a true picture of how cancer impacts upon people, we need to hear from those who have few difficulties in their day to day life as a result of cancer as well as those who continue to face challenges.

On behalf of the research team, thank you for helping us to learn how we can provide better care to people diagnosed with cancer in the future. We hope that you enjoy this first newsletter—it is our way of keeping in touch with you about how the study is progressing and letting you know about some of the findings as they become available.

Allison Boyes
Project Manager



The UNIVERSITY
of NEWCASTLE
AUSTRALIA

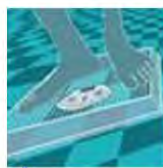


Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient + survivor link up Telephone group counselling Understanding Cancer Surveys Cancer Answers on-line www.cancer.council.com.au Living with Cancer Prognosis Cancer Information Library Cancer clinical trials Cancer Helpline 13 11 20 Multicultural Cancer



Number crunching....

Target number of study participants	1300
Number of participants so far	932
Youngest participant	20 years
Oldest participant	83 years
Provided details of secondary contact	63 %
Interested in other survivorship research	60 %
Number of surveys you will receive	4
Australian states involved	NSW & VIC



Did you know that...

Staying slim and fit is especially important for cancer survivors, because obesity raises the risk of cancer coming back, the American Cancer Society said in new guidelines issue late 2006. "The evidence really is quite strong for the need for cancer survivors to achieve and maintain a healthful weight" Wendy Demark-Wahnefried of Duke University Medical Center, one of the report's authors, said in an interview. The recommendations, updating advice issued in 2001 and 2003, were published in the society's "CA: A Cancer Journal for Clinicians."



Tips for living well

The lifestyle advice for people who have survived cancer is similar to other healthy eating and physical activity recommendations:

- Maintain healthy body weight
- Be physically active
- Eat more vegetables and fruit
- Limit or avoid alcohol
- Handle and prepare food safely
- Don't smoke

Facts and figures...

- In Australia each year, more than 88,000 new cases of cancers are diagnosed
- The survival rate for many common cancers has increased by 30% in the last two decades
- The most common cancers in Australia (excluding non-melanoma skin cancers) are colorectal (bowel), breast, prostate, melanoma and lung cancer
- Cancer costs \$2.7 billion in direct health system costs
- \$215 million spent on cancer research in Australia in 2000-01

Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient + survivor link up Telephone group counselling Understanding Cancer Surveys Cancer Answers on-line www.cancer.council.com.au Living with Cancer Prognosis Cancer Information Library Cancer clinical trials Cancer Helpline 13 11 20 Multicultural Cancer

Cancer Helpdesk 13 11 20
 Pack 1: Patient + Survivor
 115 Cancer Answers to
 Informative Library Ca

Meet the research team....

Alison Zucca is the Project Officer for the study and keeps things running smoothly! Alison makes sure your surveys are sent to you at the right time and processes your surveys when they are returned to us. Alison answers all the calls to the study freecall number 1800 246 337 and is the person who calls you to let you know that it is never too late to return your surveys to us. Alison has five years experience as a researcher and holds a Bachelors degree in Psychology from the University of Newcastle.



Alix Hall volunteers her time to help us with the study. Alix checks every page of every survey to make sure that the ovals have been coloured in correctly and any stray marks on the page have been removed before they go through the scanning machine. Alix also records and codes any additional information and comments you provide on the survey. Alix is a third year psychology student at the University of Newcastle.

We will profile other members of the Cancer Survival Study research team in upcoming newsletters.

Fruit and vegetables...

Five serves of vegetables and two fruits a day are recommended for good health and reducing cancer risk.

The Cancer Council recommends eating a variety of vegetables and fruits to ensure you get a good cross-section of the substances in plants to protect against cancer.



Although we have discovered the protective components in some fruits and vegetables, we are only just beginning to discover the many beneficial plant substances that exist.
 Cancer Council NSW

The Economic Cost of Cancer

The Macmillan cancer support survey of almost 2000 cancer survivors in the UK has found that cancer is costing patients.

18% of patients had difficulties keeping up rent or mortgage payments. Not only can cancer make it hard to work, but it can

also mean extra fuel, food, drug and hospital parking bills. The survey also found that people with children were most likely to be affected.

For more information on financial assistance programs offered by the Cancer Council, contact the Cancer Council Helpline 13 11 20

Cancer Helpdesk 13 11 20
 Pack 1: Patient + Survivor
 115 Cancer Answers to
 Informative Library Ca

Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient – survivor link up Telephone group Counselling Underwriting Cancer Insurance Cancer Answers on-line www.cancer council.com.au Link up with Cancer Programs Live Information Library Cancer clinical trials Cancer Helpline 13 11 20 Multicultural Cancer

The Cancer Council Helpline

is a telephone information and support service for people affected by cancer. It is a free and confidential service where you can talk about your concerns and needs with specialist cancer nurses. The nurses can send you written information and put you in touch with appropriate services in your own area.

You can call the Helpline on **13 11 20** from Monday to Friday for the cost of a local call.

Cancer Council Connect

Is a free and confidential service that puts men and women with cancer in one-to-one phone contact with trained volunteers who have had a similar cancer experience. Connect volunteers are typically 2-5 years post-treatment. Connect volunteers never provide professional counselling or medical advice. Their role is to provide emotional and practical support based on their own experience.

You can call Cancer Council Connect via the Helpline on **13 11 20**.



Cancer e-update is a bi-monthly newsletter for people with cancer and carers. Focusing on cancer information and support, it covers topical issues, reviews, literature searches and more. Free subscriptions and past issues at www.cancer council.com.au/eupdate

Cancer Survival Study
Locked Mail Bag 10
Wallsend NSW 2287
Australia
Freecall: 1800 246 337

Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient – survivor link up Telephone group Counselling Underwriting Cancer Insurance Cancer Answers on-line www.cancer council.com.au Link up with Cancer Programs Live Information Library Cancer clinical trials Cancer Helpline 13 11 20 Multicultural Cancer

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Cancer Survival Study

Newsletter 2: June 2008



On behalf of the research team, I would like to thank you for your continued participation in the Cancer Survival Study. Over the past 12 months we have finished the first phase of data collection and begun collating your answers. We are pleased to report some of the preliminary results from the first survey in this newsletter. These results give us a clear picture of how cancer survivors are faring about six months after diagnosis—the problems they face, the positive and negative changes in their lives, how they are coping, and the help needed.

In addition to answering the survey questions, many participants write about their cancer journey, current health, reactions to the survey, and request information. Each participant's cancer experience is unique, and we are grateful to Pam, Sue and Richard for giving us permission to share their stories with you in this newsletter. We get many requests for information about diet, nutrition, physical activity, financial assistance, support and sexuality issues. As researchers we cannot provide any specific health advice on these topics, however, on the back page of the newsletter we have suggested some credible resources that you may find helpful in addition to the Cancer Council Helpline (ph: 13 11 20). Some of you have told us that the surveys are too long and don't seem relevant to you. Based on this feedback we have revised the third survey to include questions that are more relevant to survivors who are two years down the track, as well as reformatted the survey so that you can skip over questions that don't apply to you.

Over the next 12 months, most participants will be invited to complete the third survey. We recognise that you lead busy lives, and that many of you have put your cancer experience behind you. We are grateful for the time you have given to complete our surveys, and hope that you will continue to participate in the Cancer Survival Study.

Allison Boyes

Allison Boyes
Project Manager

Pam was diagnosed with Non-Hodgkins Lymphoma and told us how she was getting on 2 years down the track...

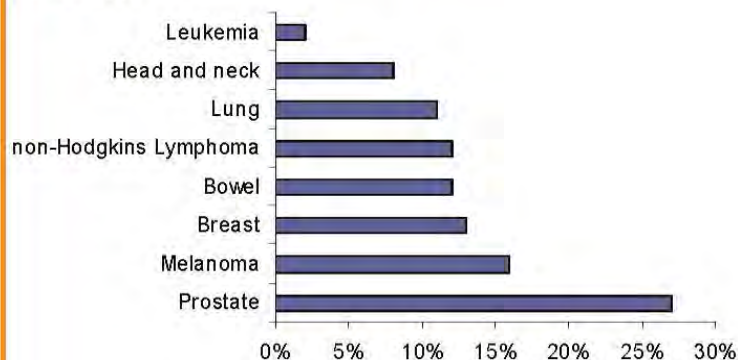
"Life is good! I have confidence to accept new challenges not attempted before the cancer. Nothing to lose! I am concerned about my memory — I feel it has deteriorated since completing chemo and mabthera. Bladder leakage was a problem — only post chemo. This problem has now ceased and I am back to normal — no leakage."

Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient – survivor link up Telephone group counselling Understanding Cancer public information Cancer Answers on-line www.cancerouncil.com.au Living with Cancer Programs Cancer Clinical Trials Cancer Helpline 13 11 20 Multicultural Cancer Information Service

Some results from Survey 1

These preliminary results give us a broad picture of the well-being of Australian cancer survivors 6 months after diagnosis. We are already able to identify the physical, emotional and social issues that are of major concern to Australian cancer survivors.

Cancer type



Who is participating?

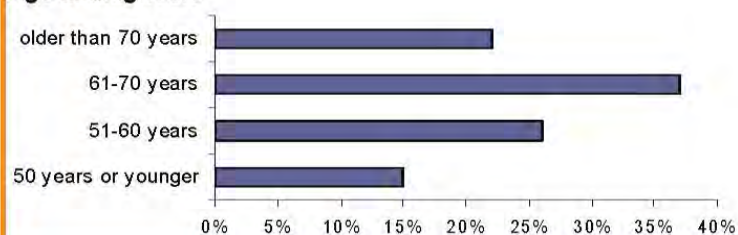
We invited people who were diagnosed with one of the 8 most common cancers in Australia to participate. These 8 cancers account for about 65% of all cancers diagnosed in Australia.

More men (61%) than women (39%) are participating in the study. This isn't surprising given that 1 in 2 men and 1 in 3 women will be diagnosed with cancer by the age of 85 years.

Most participants were diagnosed with prostate cancer (27%), melanoma (16%), breast (13%) or bowel cancer (13%).

In Australia, the median age at diagnosis of cancer is 69 years. Not surprisingly, most study participants were aged between 60-70 years when they received their cancer diagnosis.

Age at diagnosis



Emotional well-being

Previous international research has shown that up to one-third of people with cancer experience emotional distress. As shown in the two charts below, our research suggests that 6-months after diagnosis, almost 25% of cancer survivors in Australia report symptoms of anxiety and almost 15% report symptoms of depression. Although the number of cancer survivors experiencing emotional distress was lower than we expected, these results indicate that there is a small but important group of survivors who need more support. We are examining the data further to get a better picture of the characteristics of those who are at risk of emotional distress and most in need of targeted assistance.



Our research suggests that for many, a cancer diagnosis results in an enhanced appreciation of life. For example, in our study, 79% of participants agreed that since their cancer diagnosis, they realised how precious life was and were making the most of it.



Physical, practical and financial issues

COMMON PROBLEMS

Fatigue	80%
Insomnia	55%
Pain	41%
Shortness of breath	38%
Financial difficulties	35%
Appetite Loss	23%
Constipation	23%
Nausea and Vomiting	20%

Our research has helped us to identify the most common problems affecting cancer survivors 6-months after diagnosis.

At least half experienced fatigue and sleeping difficulties.

Half worried about the cancer returning or getting worse

About one-third experienced financial difficulties.

These results highlight areas for improvement in cancer service delivery. We are exploring these responses further to identify which groups of survivors were most affected by these problems.

"The hardest thing for me to face was whether I would need chemo. I have no immediate family who could care for me or make my house repayments. I have three dependent school age children. I worked full-time during my radiation treatment and that nearly destroyed me but I had no alternative. My fear is to get ill and not be able to support my family." (Sue, breast cancer survivor)

TOP TEN NEEDS

Fears that the cancer will spread	31%
Worries about those close to you	30%
Uncertain about the future	28%
Not able to do the things that you used to	25%
Changes in sexual feelings	23%
Feeling down at times	22%
Feeling that the results of treatment are beyond your control	22%
Changes in your sexual relationships	22%
Getting things done around the home	20%
Feelings of sadness	20%
Information about sexual relationships	20%

We asked you to tell us about the cancer-related issues that you needed help with.

Many participants needed help dealing with their emotions, particularly fears about cancer recurrence, worries about family and friends, and dealing with an uncertain future.

Sexuality issues were also commonly identified with many participants needing help to deal with changes in their sexual feelings and relationships.

In terms of daily living, participants mainly reported needing help to deal with not being able to do things that they used to be able to before the cancer diagnosis, and assistance with household duties.

"I had my prostate removed due to cancer. I have a positive mind, and do the same things as before (except sex). I have no concerns. I have incontinence and I find it frustrating, but I hope this will be solved in the future." (Richard, prostate cancer survivor)

Researchers from the MD Anderson Cancer Center in the USA have reported that:

- men receiving radiotherapy for localised prostate cancer have less urinary continence problems
- surgery is associated with better bowel function and less urinary irritation
- brachytherapy was associated with better sexual function.

The details of this study were published in the June 2007 issue of *The Journal of Urology* 2007; 177:2151-2156.

Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient – survivor link up Telephone group counselling Understanding Cancer booklets Cancer Answers online www.cancercouncil.com.au Living with Cancer Frontline Cancer Information Library Cancer clinical trials Cancer Helpline 13 11 20 Multicultural Cancer



**Find cancer information
and support services**

**Cancer Council
Helpline 13 11 20**

Information Booklets

Free information booklets can be ordered by calling the Cancer Council Helpline on 13 11 20, or by downloading from the website www.cancercouncil.org.au

Some titles that you may find helpful are:

- Life after cancer: A guide for cancer survivors
- After your cancer treatment: A guide for eating well and being active
- Sexuality for men with cancer
- Sexuality for women with cancer

Living Well After Cancer Program

A free community education program held throughout NSW for cancer survivors, their carers and friends. Programs are run by The Cancer Council NSW with trained survivors. The program is 2 hours long and includes practical information and open discussion about changes and challenges you may face after completing cancer treatment, tips and ideas to help you live your life well, and an opportunity to connect with others on a similar journey.

For details on program dates and locations, please contact Annie Miller on (02) 9334 1465 or by email anniem@nswcc.org.au

Cancer Support Online

An online peer support forum hosted by The Cancer Council NSW with moderated discussion boards, including a forum specifically for cancer survivors. Log onto www.cancersupportonline.org.au

Cost of Cancer in NSW

The Cancer Council NSW commissioned Access Economics to compile a report defining the total cost of cancer to affected individuals, their families and society.

Access Economics reported that the bulk of the financial costs of cancer relate to lost productivity. On average, households lose \$47,200 in financial costs when a member of that household is diagnosed with cancer. This includes nearly \$9,000 in health care and other out-of-pocket costs.

The Cancer Council has established financial assistance programs for those facing hardship as a result of a cancer diagnosis.

Cancer Survival Study
Locked Mail Bag 10, Wallsend NSW 2287 Australia
Freecall: 1800 246 337

Websites

- The National Cancer Institute: Facing forward series: Life after cancer treatment
www.cancer.gov/cancertopics/life-after-treatment
- American Cancer Society: Cancer Survivors Network
www.acscsn.org



Cancer Helpline 13 11 20 Multicultural Cancer Information Service Support and Information Pack Patient – survivor link up Telephone group counselling Understanding Cancer booklets Cancer Answers online www.cancercouncil.com.au Living with Cancer Frontline Cancer Information Library Cancer clinical trials Cancer Helpline 13 11 20 Multicultural Cancer

APPENDIX 10: Study flowchart

