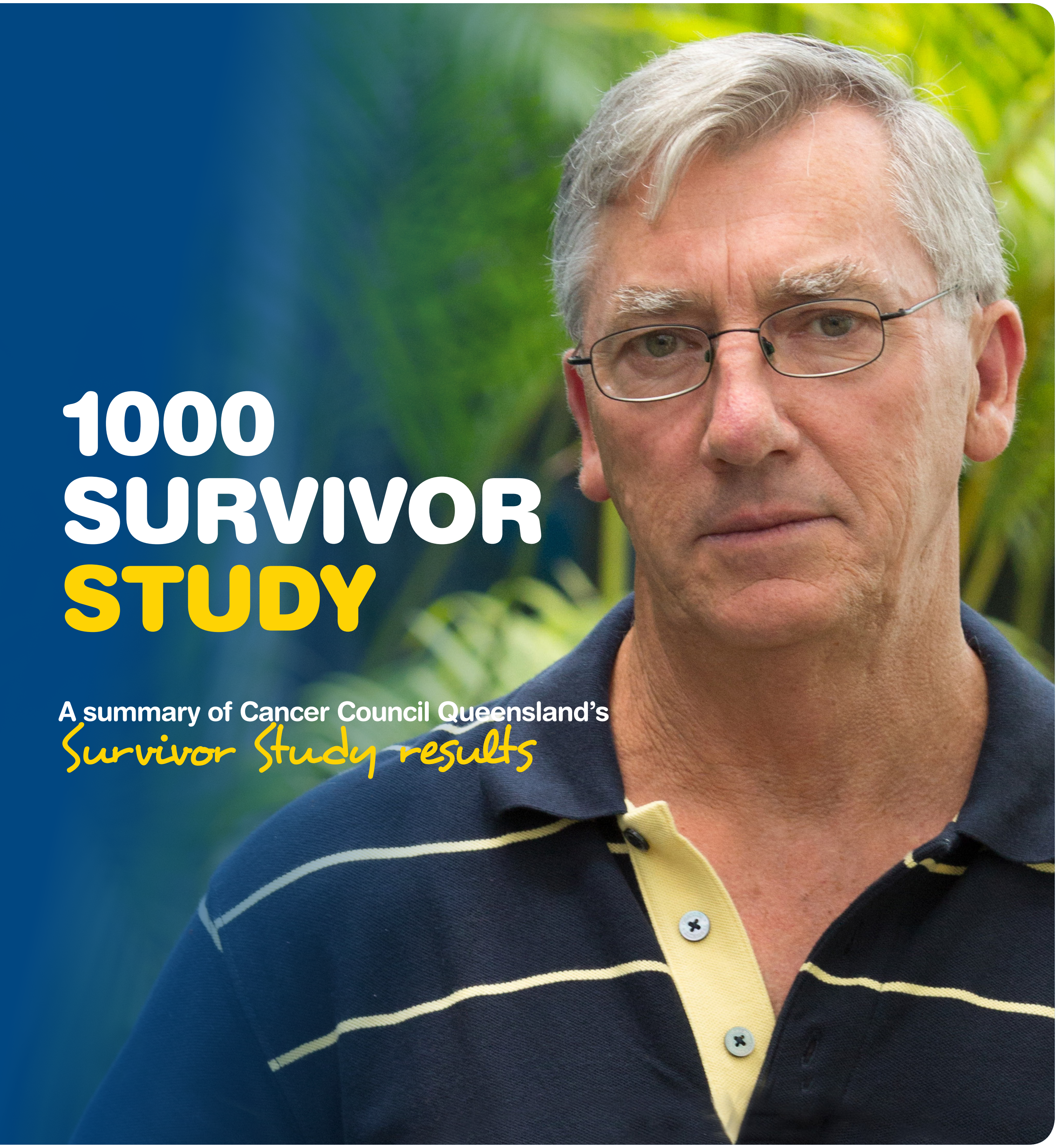

1000 SURVIVOR STUDY

A summary of Cancer Council Queensland's *Survivor Study results*

Cancer Council Queensland

SURVIVOR STUDY

Contents

Acknowledgments

Cancer Council Queensland (CCQ) would like to acknowledge the LIVESTRONG Foundation for their collaboration, and use of their survivorship survey.

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Executive Summary

In Australia, the five year survival rate for cancer has steadily increased over the past three decades. This is largely due to improvements in diagnosis and available treatments. While this is encouraging, there is now a great need for more information about how people in their post-treatment phase cope in order to better support those affected by cancer.

Recognising this need, Cancer Council Queensland (CCQ) collaborated with the LIVESTRONG Foundation to utilise their national online survivorship survey, piloting it for a Queensland audience. The aim of the study was to better understand the concerns and support-use behaviour of cancer survivors in Queensland to further inform, develop and identify support mechanisms required to help improve quality of life, and to support advocacy efforts and provide an evidence base for CCQ's service provision strategy for survivorship.

The survey specifically addressed the physical, emotional, and practical challenges that Queenslanders with cancer, who have completed treatment, may face. The results are taken from 1031 Queenslanders who completed the online survey. The average age of the participants was 57.9 years at the time of survey completion. Just over half the participants were female (54.8%), 66.8% had completed a college / TAFE certificate or a university degree and 57.8% lived in major cities within Queensland. It had been less than five years post-treatment for 66.3% of the sample and the most common cancer types represented were breast, prostate and colorectal cancer.

The results show that almost all of the participants experienced at least one type of physical concern (94.6%). However, the proportion of participants who reported to receive care for each physical concern varied widely. Participants were more likely to seek care for less-common concerns e.g., thyroid issues (71 reported the concern and 85.9% received care) and lymphoedema (239 reported the concern and 70.7% received care). Care was sought less often for more common physical concerns including concentration issues (557 reported the concern and 18.1% received care), sexual dysfunction (549 reported the concern and 30.4% received care) and incontinence (309 reported the concern and 37.9% received care).

For emotional concerns the story is different. Almost all of the participants experienced emotional worries (94.4%), however, participants consistently did not receive care. On average, more than 70% of participants who reported a particular emotional concern did not receive care. The most common concerns that participants did not receive care for were cancer-related stigma (323 reported the concern and 79.6% did not receive care), personal appearance (372 reported the concern and 78.6% did not receive care) and family member risk (545 and 75.6% did not receive care). Help was most likely to be sought for sadness and depression, however more than half of the participants who reported this concern still did not receive care (644 and 52.6% did not receive care).

Practical issues included being negatively affected at work because of cancer (45% of 686 employed) and financial difficulties (29.7%). Participants reported being unable to work in the same way as prior to their cancer diagnosis, experiencing difficulties returning to work and being unable to work full-time. Of the participants who reported work-related problems, 66.1% did not receive help.

Across each of the three areas of concern, the foremost reason participants did not receive care was that they 'have learned to live with' their physical, emotional or practical issue. Further investigation is needed to identify the meaning behind this response, in order to fully understand the longer term circumstances of people who have been diagnosed with cancer and are living with it as a chronic disease.

The results of this survey do not represent the views and experiences of all post-treatment cancer survivors in Queensland due to the sampling methods. However, this study shows clearly that the concerns cancer survivors encounter are wide-ranging and many do not receive or seek care for concerns they are experiencing. It will be important to identify the relationships between these concerns, in addition to the facilitators and barriers surrounding receipt of care, in order to provide the most effective and appropriate services and support after treatment has finished.

"I feel that cancer has changed my life forever, and that I will never return to being the person I was before, but that is not a bad thing." *CANCER SURVIVOR*

Survivor study highlights

1031

participants who were diagnosed with cancer and finished treatment took part in the survey

Participants

- **Breast** (26%), **prostate** (22%), **colorectal** (10%) , **all lymphomas** (8%) and **gynaecological** (6%) cancers represented the most common cancer types on the sample
- **66%** completed their treatment less than five years ago
- **The most common types of treatment** were surgery (69%), chemotherapy (45%), and radiation (45%)

"I learned to live with it"

Was the most common reason participants did not receive care for their physical, emotional and practical concerns following completion of treatment

Physical

- **95%** experienced at least one physical concern following treatment
- **72%** received care for at least one of their physical concerns
- **82%** did not receive care for at least one of their physical concerns

Emotional

- **94%** experienced at least one emotional concern following treatment
- **46%** received help for at least one emotional concern
- **87%** did not receive help for at least one emotional concern

Practical

- **30%** reported being negatively affected at their job as a result of their diagnosis and treatment for cancer
- **More highly educated** received help for their work concerns
- **30%** reported that they and/or their loved ones had financial problems because of cancer and younger participants struggled more with financial concerns compared to older participants

Meaning Making

- **70%** reported that they have been trying to take better care of their health following their cancer treatment, by being up to date with screening and partaking in more regular physical activity
- **10%** reported that their life would never be good again

Treatment Guidance & Quality of Care

- **81%** reported that they had received instructions about where to go for post-treatment care
- **58%** did not have a dedicated person to help guide them through their cancer experience
- **61%** never received a written summary of all the cancer treatments they received
- **45%** felt included (as much as they wanted) in their health care decisions
- **68%** were frequently offered the opportunity to ask questions of their health care team
- **30-40%** reported that their health team did not ask about their emotional well-being on a regular basis
- **15%** reported that health professionals never helped them deal with their feelings of uncertainty about their situation

Advocacy and Engagement

- **61%** felt there should be more funding directed towards cancer research
- **48%** wanted more resources for people affected by cancer
- **41%** believed Australia should have a national cancer plan

Alternative Treatments and Support

- **Exercise** (44%), **nutritional supplements** (29%), **massage** (23%) and **meditation** (19%) were common forms of alternative treatment
- **24%** did not use alternative treatments
- **53%** reported it was helpful to connect with others who had been diagnosed with cancer
- **40%** found it beneficial to receive emotional support from another person with cancer

Introduction

Around 128,000 new cases of cancer will be diagnosed in Australia this year, with that number set to increase to 170,000 by 2025 (1, 2).

However, more people are surviving cancer today than any other time in history – around 66% of people diagnosed with cancer in Australia survive for at least five years after their diagnosis (3). The combination of increasing cancer incidence and longer survival is reflected in the national prevalence statistics showing that over 850,000 Australians who were alive in 2009 (3) had been diagnosed with cancer in the previous 28 years. In Queensland, the most recent estimates (2011; Queensland Cancer Registry; unpublished estimates 2014) suggest that 129,824 Queenslanders are living with a diagnosis of cancer in the last 10 years, and this number is expected to increase to nearly 200,000 people by 2024.

Increases in survival rates are attributed to diagnostic and therapeutic advancements (3). Researchers and clinicians have discovered better ways to control cancer and consequently health services, diagnostic tests and treatments have rapidly changed and improved. While this pursuit is still underway and vitally important, the changing landscape of cancer begs for research in the field of cancer as a chronic disease, and to examine its long temporal reach as well as its relationship to the onset of other non-communicable diseases and comorbidities. However, the primary focus has been on identifying the effects at diagnosis, during treatment and the period shortly following treatment, yet it is likely that the challenges that exist for long-term 'survivors' are different and they are currently poorly understood. These late effects may take many forms with some coping well and experiencing few effects, while others face ongoing and long-lasting problems.

Of the research that has been conducted, it shows the persisting effects of cancer can have a range of potential impacts on a person's individual circumstances, including quality of life and broader social and economic effects. The common physical concerns that are encountered post-treatment are pain, fatigue and tiredness and cognitive problems, usually related to chemotherapy treatment (4). Other late effects can include, but are not limited to, sexual dysfunction, lung damage, bone density loss and lymphoedema. After treatment, fear of cancer recurrence is quite prominent, however, late effects of diagnosis and treatment can include general distress, depression, social life disruption and worry about family member risk (5) all of which negatively affect one's quality of life. In addition to this, practical challenges relate to loss of income, insurance issues, and employment and physical limitations relating to one's ability to return to work or being able to work in the same pre-cancer capacity (6).

Problematically, these issues are often under-reported or misdiagnosed (7-9). Follow-up care typically focuses on cancer recurrence, spread and early detection of new cancers, while evidence suggests there remains unmet needs for supportive care and the ongoing management of post-treatment concerns. Current methods of service delivery involve a hybrid model of care whereby oncologists and/or primary care physicians provide follow-up treatment to cancer patients. However, there are barriers to optimal care when utilising this approach (10) and patients can too easily be lost to follow-up (9). Given this, there is increasing pressure for a different model of care in order to manage the long-term physical and emotional needs and ongoing provision of information that would help patients to better cope with the ebbs and flows of post-treatment life.

"The more that we know about the impact of cancer, the more that can be done to support those affected – you children, your partner, your parents, and of course, you."
KYLEE SANSON, MELANOMA SURVIVOR

Increases in the numbers of cancer diagnoses as well as survival numbers signals an urgent need to conduct well-directed and in-depth studies to thoroughly understand the needs and the best ways to develop and evaluate responsive, equitable and accessible interventions for those diagnosed with cancer. Improving psychosocial outcomes and informing clinicians and primary health care professionals about the challenges faced, as well as to inform advocacy strategies and policy, is of paramount importance.

The purpose of this report is to share the results of CCQ's Survivor Study, examining the physical, emotional and practical concerns of people who have been diagnosed with cancer and completed treatment. Through better understanding of the concerns and support-use behaviour of cancer survivors in Queensland, CCQ hopes to further inform, develop and identify support mechanisms required to help improve patient quality of life, support advocacy efforts to improve health service delivery and provide an evidence base for CCQ's service provision strategy for survivorship.

Method

PROCEDURE

The online survey was piloted from June 2013 to December 2013 to assess suitability and ease of use. The pilot sample was 149 participants.

Following the pilot, a broad-based marketing and media campaign was initiated from January 2014 to June 2014 and a further 882 participants completed the survey. Recruitment methods included: statewide newspaper articles, community service announcements, online and print advertising, pamphlets, posters, emails, letters, newsletter articles, and social media posts. CCQ's Cancer Support and Information staff promoted the study through their daily contact with the community and affiliated organisations, and health professionals were also approached to help promote the study through their networks. A snowballing approach was also employed, whereby those who heard about the study were encouraged to invite others to participate. In addition to being available online, the survey was also administered via telephone for those who were visually impaired, had difficulties with written English or did not have access to a computer or a viable internet connection.

Study inclusion criteria were as follows: Queenslanders over 18 years of age who have completed primary treatment for a diagnosis of cancer. Only participants living in Queensland are included in the current report.

STUDY INTEGRITY

Ethical approval for this study was obtained from Griffith University Human Research Ethics Committee.

SURVEY STRUCTURE

The survey for this study was based on an instrument designed and developed by the LIVESTRONG Foundation via a multi-stage process of refinement with consumers and medical experts as well as subsequent testing (11). Survey content was then reviewed by CCQ research and support staff and, where relevant, response items were changed to reflect the local environment. Health care questions that were irrelevant to the Australian context were excluded.

Following modification, the survey contained six content sections. In the first three sections participants were asked about physical, emotional and practical concerns associated with their cancer experience (Appendix A lists the items assessing each concern).

1. Physical concerns. The survey assessed 15 physical concerns: concentration, energy and rest, hearing, heart problems, infertility, lungs and breathing, lymphoedema, neuropathy, oral health, pain, sexual functioning and satisfaction, thyroid condition, feeding/swallowing, urinary incontinence, and vision.
2. Emotional concerns. The survey assessed eight emotional concerns: personal appearance, faith and spirituality, family member risk of cancer, grief and identity, impact on personal relationships, fear of recurrence, sadness and depression, and cancer-related stigma.
3. Practical concerns: The survey assessed concerns around employment, school, insurance and finances.

Participants were asked whether they experienced each concern (response format: 'Yes', 'No', and 'I don't know'), at what point in time they experienced the concern (response format: 'Before my experience with cancer', 'Since completing treatment for cancer, and in the last six months', and 'Since completing treatment for cancer, but not in the last six months) and how much it impaired their functionality (response format: 'Not at all', 'A little', and 'A lot').

Participants also reported whether they received care from a list of care providers and the extent that the care met their needs (response format: 'None', 'Very few', 'Some', 'Many', and 'All'). If the participant did not receive care for an identified concern, they were asked to select the reason/s why from a pre-specified list (Figure 1).

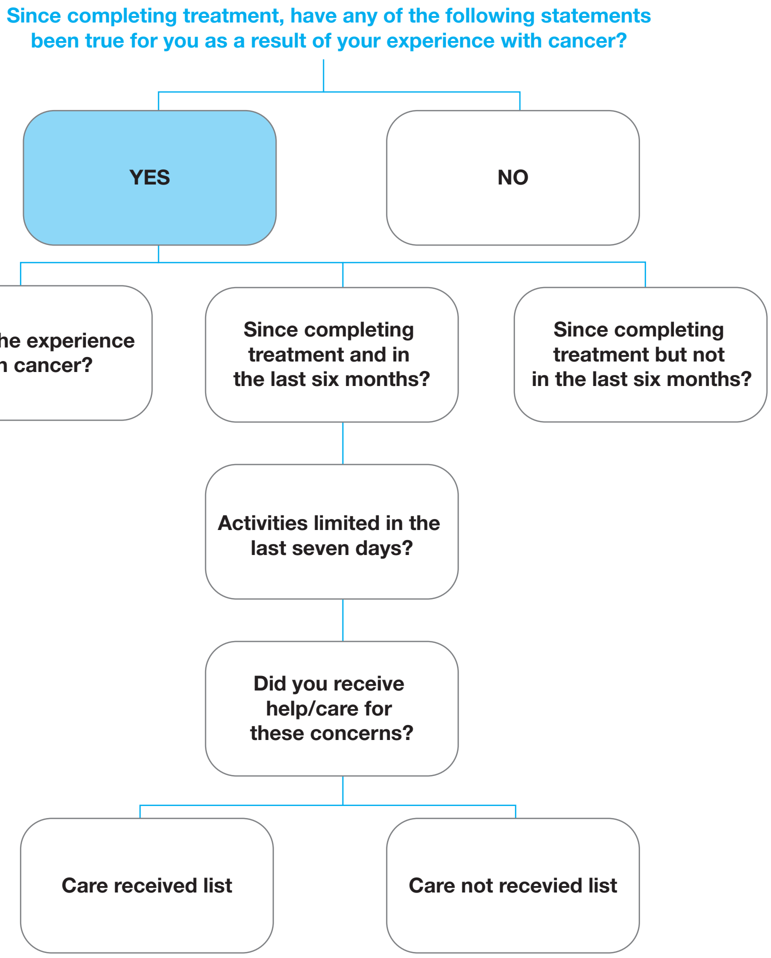


Figure 1. Survey structure flowchart (source: LIVESTRONG 2011)

Survivor Study Recruitment Materials

The next two sections were Meaning-Making and Information Seeking and Advocacy and Engagement.

1. Meaning Making and Information Seeking. This section assessed the individual's post-traumatic growth throughout their diagnosis and treatment, and the extent to which they identify as a 'survivor'. Data were also collected on the effectiveness of the participant's healthcare team throughout their cancer experience. Help-seeking behaviour was measured as well as the helpfulness of support received.
2. Advocacy and Engagement. This section asked about the participant's perceptions and attitudes towards health care support in Australia.

The final section obtained socio-demographic and cancer-related information. Socio-demographic data included date of birth, gender, country of birth, relationship status, education level, annual income, private health insurance status, postcode and suburb. Participants' postcode and suburb was geocoded and assigned a level of remoteness using the following categories: major city, inner regional, outer regional, remote, very remote (12). Medical information included type of cancer, date of diagnosis (most recent diagnosis) and type and date of multiple cancer diagnoses, type of treatment received, and date of last treatment.

STATISTICAL ANALYSES

A series of summary statistics were used to describe the socio-demographics of participants and their medical history, as well as the survivorship concerns experienced and receipt of care. For some questions participants were allowed to select more than one answer, therefore percentages may equal more than 100.

Logistic regression analyses were used to model receipt of post-treatment care for physical, emotional and practical concerns. Consistent with key predictors of cancer-related concerns, age, gender, education, geographical location and time since treatment were examined.

Results

PARTICIPANTS

Socio-demographics

Of the 1584 who began the survey, 1031 men (45.2%) and women (54.8%) who had been diagnosed with cancer and had finished treatment were included in the study. The mean age was 57.9 years (SD=12.9, range: 18 – 87) and 74.8% were married or had a partner. 63% of participants had obtained a university degree, trade/technical certificate or diploma; 42.9% of the sample had a gross annual income of more than $80,000 while 33.7% earned between $20,000 - $60,000 per year; the majority of the sample reported they held some form of health cover (64.8%; full health cover, either hospital or basics, or Department of Veteran Affairs cover) while 22% did not have private health insurance. Most (78%) were born in Australia and more than half (57.8%) lived in major city centres at the time they completed the survey. Further socio-demographic details can be found in Appendix B.

Medical Information

At the time of survey completion, 54.3% of participants had been diagnosed less than five years ago, 21.6% were diagnosed between five and 10 years ago and 24.2% were diagnosed more than 10 years ago. Mixed cancer types were represented, with the five most common cancers being breast (26.1%), prostate (21.7%), colorectal (9.6%), all lymphomas (7.9%), and gynaecological (6.3%) cancer. 82% of participants indicated that they had not been diagnosed with multiple cancers.

For 66.3% of participants it had been less than five years since their last cancer treatment and for 33.7% it was more than five years since their last treatment. The most common types of treatment were surgery (68.8%), chemotherapy (45.5%), and radiation (44.7%). The majority of participants had received three treatments or less (91.4%). See Appendix B for a table of medical information.

Supportive Care

Participants reported using several types of support following their cancer treatment: Online, individual, face-to-face, and group support; with 47.9% reporting that they participated in either one or more services for support (Figure 2). Over half (52.5%) of the sample had another person with cancer share information about their diagnosis or treatment, 40.2% had been provided with emotional support by someone with cancer, and 15.3% had help to tell other people in their life about their cancer (Figure 3).

Participants were also asked about other treatments they used for their cancer or late effects of the disease. Exercise, nutritional supplements and special diets, massage and meditation were the most popular forms of self-managed therapy (Table 1).

Table 1. Alternative treatments utilised

Alternative Treatments	n	Percentage
Acupuncture	97	9.4
Herbs	124	12.0
Massage	235	22.7
Nutritional Supplements	295	28.6
A Special Diet	191	18.5
Hypnosis	18	1.7
A Traditional Healer	24	2.3
Guided Imagery	34	3.3
Art Therapy	24	2.3
Music Therapy	49	4.7
Exercise	457	44.3
Meditation	198	19.2
Complementary of alternative medicine	124	12.0
No alternative treatment	252	24.4
Addressed this on my own	178	17.2

n = number of participants who reported the concern

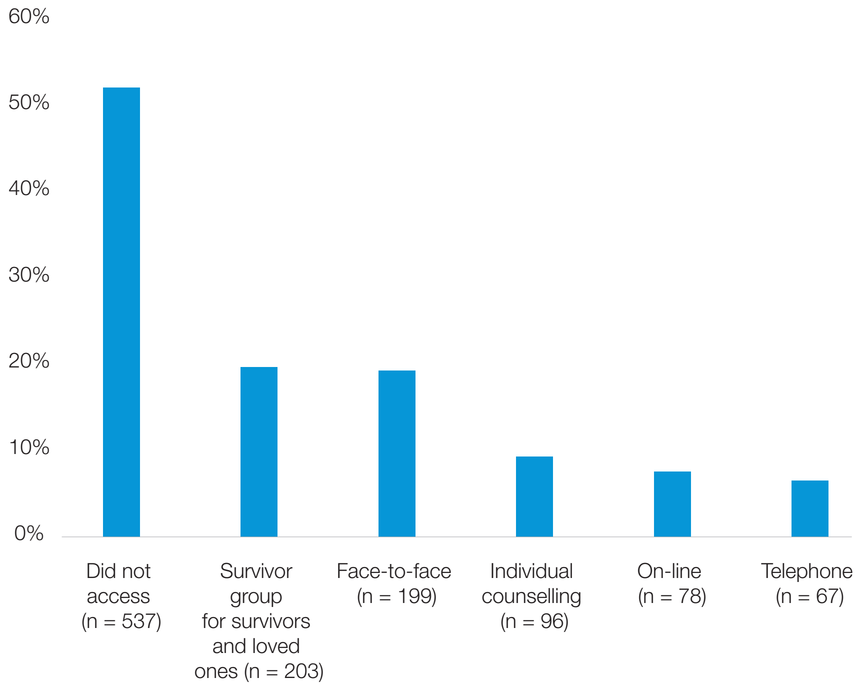


Figure 2. Types of support used by participants after their cancer treatment (n = 1031)

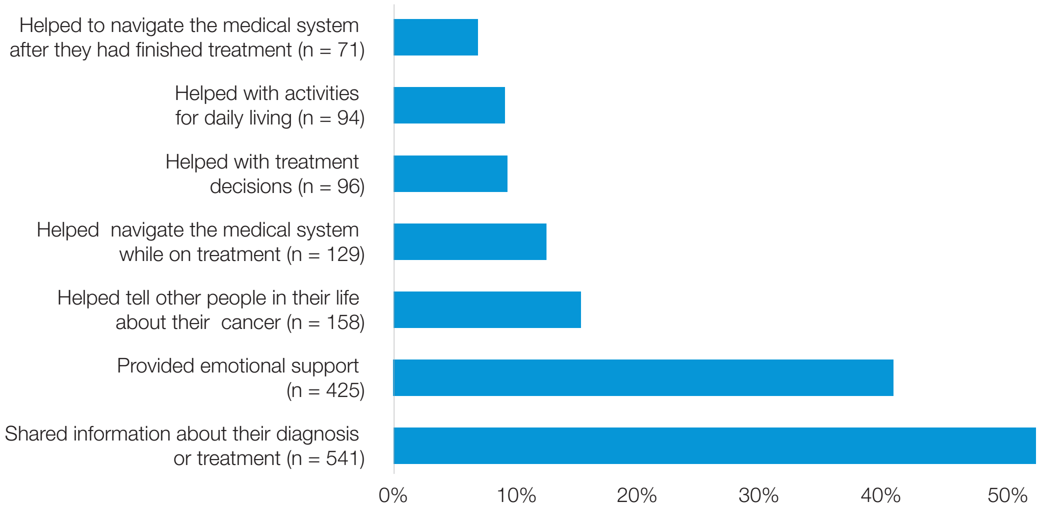


Figure 3. Types of help received from another cancer survivor (n = 1031)

Physical Concerns

KEY SUMMARY

- 94.6% of the survey participants experienced one or more physical concerns following cancer treatment. Energy, sexual function and concentration were the three most common concerns.
- Breast, prostate and colorectal cancer patients reported similar physical concerns post-treatment, including energy, concentration, sexual function and neuropathy.
- Participants reported some recent functional impairment due to their physical concerns, particularly sexual function, pain and energy.
- The percentage of participants who received care for each concern varied widely. Thyroid, oral and lymphoedema concerns were most commonly cared for, while concentration, energy, and neuropathy were least commonly cared for.
- Key participant demographics differentiated those who sought care.
- There were a large number of men who had been diagnosed with prostate cancer (21.9%) for which common treatment side-effects included incontinence and sexual dysfunction. This is likely to have influenced the high proportion of participants who experienced and sought care for sexual and incontinence concerns.
- Medical health care professionals (GPs, medical specialists and oncologists) were the most common source of care for physical ailments associated with cancer treatment, and satisfaction with care was high for the most common providers.

> **"While I was carefully explained the possible side effects of surgery and treatment I never believed that these things would happen and stay with me forever."** *CANCER SURVIVOR*

FREQUENCY OF CONCERNS

Ninety-five per cent (94.6%, n = 975) of survey participants experienced one or more physical concerns since completing cancer treatment. The most frequently reported concerns were energy (71.2%), sexual function (62.3%), concentration (60.4%), neuropathy (45.8%), and pain (41.1%) (Figure 4). Sexual function, pain and energy were causing the most amount of impairment for participants in the last seven days (Table 2, Page 16).

The most common physical concerns remained similar for breast, prostate and colorectal cancer patients (Appendix C, Table 1). For breast cancer, the highest reported concerns were energy, concentration, sexual function, pain and neuropathy. Lymphoedema was also a commonly reported physical challenge for breast cancer patients. Sexual function and incontinence were the most commonly reported ailments for men with prostate cancer, followed by energy, concentration and neuropathy. For colorectal cancer the most common concerns were energy, sexual function, concentration, neuropathy and incontinence.

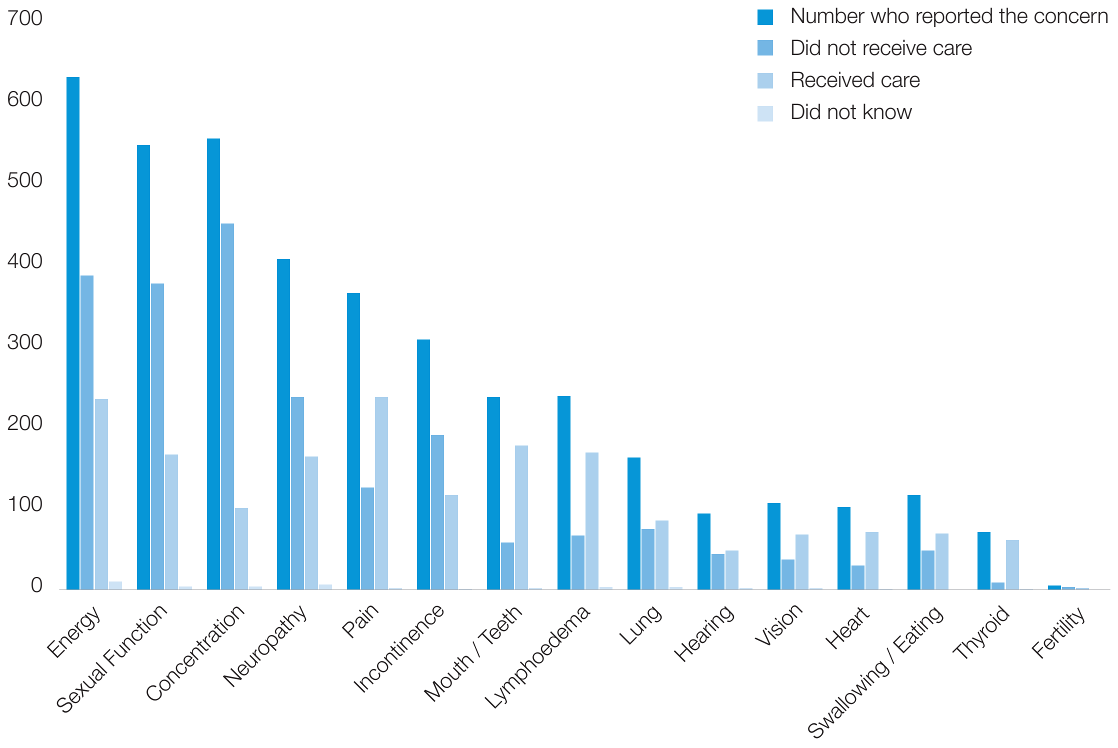


Figure 4. Number of participants who experienced a physical concern and receipt of care (n = 1031)

Table 2. Percentage of participants reporting functional impairment from their physical concerns

Physical Concern	n	A lot (%)	A little (%)	Not at all (%)
Energy	626	20.6	57.2	21.1
Concentration	556	13.5	52.5	32.6
Sexual Functioning	549	28.4	28.2	38.8
Neuropathy	407	9.8	36.4	53.1
Pain	366	24.3	58.7	15.9
Lymphoedema	238	11.8	37.8	50.0
Incontinence	307	4.2	38.1	57.7
Oral Health	238	6.3	32.4	60.1
Lungs	162	10.5	40.1	48.2
Vision	107	10.3	39.3	47.7
Thyroid	71	4.2	14.1	77.5
Feeding	117	15.4	48.7	35.9
Hearing	92	8.7	38.0	53.3
Heart	102	8.8	34.3	54.9

n = number of participants who reported the concern

RECEIPT OF CARE

71.5% (n = 697) of participants had received care for one or more of their physical concerns since completing treatment. Thyroid problems, oral issues (i.e., mouth and teeth) and lymphoedema received care most often (Figure 4, Page 16). The three most common providers of care for physical concerns were general practitioners (GPs) (71%, n = 495), medical specialists (66.3%, n = 462), and oncologists (30.2%, n = 211) (see Appendix C, Table 2 for the breakdown of providers of care for each physical concern). Over 70% of participants reported that these health care providers met 'All' or 'Many' of their needs (GPs: 75.9%, n = 376, medical specialists: 53.1%, n = 370, and oncologists: 80.1%, n = 169).

82.8% of participants (n = 807) did not receive care for one or more of their concerns. The most common concerns for which care was not received were concentration, sexual function and incontinence (Figure 4, Page 16). The most frequently reported reasons were 'I have learned to live with this concern' (72.5%, n = 585), 'I was told it was a side effect that would go away with time' (39.4%, n = 318), and 'I have addressed this on my own' (31.5%, n = 254) (see Appendix E for a complete list of reasons).

There were some key differences among the sample in regards to receipt of care. Older participants were more likely to receive help for their neuropathy concerns than younger participants. Males, more than females, sought care for incontinence struggles and sexual issues. Geographic location influenced whether participants received care for concerns related to energy, sex and concentration, whereby recipients of care were more likely to reside in major city centres as opposed to those living in inner and outer regional QLD.

> **"I have been offered very little support or help with any problems or concerns not directly related to medical treatment - apart from a few generic brochures. It has been up to me to handle any issues."** *CANCER SURVIVOR*

Emotional Concerns

KEY SUMMARY

- Emotional concerns were common for participants, with more than 94% reporting they had experienced at least one concern since completing cancer treatment.
- Emotional concerns caused recent functional impairment for participants, most often for sadness and depression and social relationships.
- Breast, prostate, and colorectal cancer patients experienced similar emotional concerns post-treatment.
- Receipt of care for emotional concerns following cancer treatment was generally low, with the percentage of participants who did not receive care consistently higher across each of the emotional concerns than those who did receive care.
- Key participant demographics differentiated those who did not receive care.
- GPs were the most likely source of care for cancer patients. Participants also relied on their partner as a source of support.
- Of the participants who did receive care for their emotional difficulties, the quality of that care was deemed to be high.

> **"Getting back to normal life is not easy at all, you are not the same person you once were. The fight for your life has changed you completely, and trying to rediscover yourself is not an easy path. Also constantly scared the cancer will come back, that fear never goes away."** *CANCER SURVIVOR*

FREQUENCY OF CONCERNS

94.4% of participants (n = 973) indicated they had experienced one or more emotional concerns since completing treatment for their cancer. Depression, grief and identity, fear of recurrence and family member risk were the most commonly reported challenges (Figure 5).

For breast, prostate and colorectal cancer (i.e. the three most highly represented cancers) the pattern of emotional concerns was similar to the larger sample (See Appendix D, Table 1). The most commonly reported emotional concerns were sadness and depression, grief and identity, fear of recurrence and family member risk. For prostate cancer and colorectal cancer, family member risk was the most common emotional concern. Grief and identity was the most common concern for those with breast cancer.

More than 50% of participants who reported that sadness and depression and social relationships were a concern also reported that these concerns impaired their functionality either 'A little' or 'A lot' in the last seven days (Table 3).

Table 3. Percentage of participants reporting functional impairment from their emotional concerns

Emotional Concern	n	A lot (%)	A little (%)	Not at all (%)
Sadness and Depression	643	10.3	40.8	47.3
Grief and Identity	624	6.3	35.7	55.6
Faith and Spirituality	106	11.3	33.0	51.9
Fear of Recurrence	719	5.6	32.4	60.1
Social Relationships	303	16.5	53.1	27.7
Cancer-Related Stigma	319	3.8	37.6	55.5
Family Risk	542	2.8	22.0	73.1
Personal Appearance	372	6.7	33.9	57.8

n = number of participants who reported the concern

RECEIPT OF CARE

45.6% (n = 444) of participants received help for one or more emotional concerns. Sadness and depression, grief and identity and fear of recurrence were the most common concerns participants sought help for, although the proportion who sought help was still less than half who identified this as a concern (Figure 5). Care or support was most commonly sought from general practitioners (68%, n = 302), psychiatrists or psychologists (36.7%, n = 163), and partners (28.4%, n = 126). Participants reported that these health care providers met ‘All’ or ’Many’ of their needs – 66.6% (n = 201), psychologists/psychiatrists: 66.3% (n = 108), partners: 73.8% (n = 93).

The majority (86.7%, n = 844) of the participants did not receive help for one or more of their emotional concerns. Lack of care was common across the eight emotional concerns examined and was particularly high for cancer-related stigma, personal appearance and family member risk concerns (Figure 5). For those who indicated they had not received care, the top three reasons were ’I have learned to live with this concern,’ (66.7%, n = 563), ‘I have addressed this on my own,’ (42.5%, n = 359), and ‘I did not want to bother anyone,’ (16.9%; n = 143).

Analyses revealed that age, gender, location and education influenced whether participants received care for their post-treatment concerns (Appendix D, Table 5). Specifically, women were more likely to receive care for their concerns associated with fear of cancer recurrence and family member risk than males. Further, those residing in major cities were also more likely to receive assistance for fear of recurrence concerns than those living in inner and outer regional QLD. Younger participants were more likely to seek assistance for concerns about social inhibition and starting new relationships than older participants. Lastly, participants who had completed a university degree or trade certificate more frequently received care for personal appearance concerns than those who’s highest level of educational attainment was high school level or lower.

> **"Every pain, lump and bump causes some stress and anxiety, as does the lead up to oncology follow-up appointments, and I think that over time it gets a bit easier but those feelings will always be there to some extent. As a mother I worry about my child being diagnosed, and also about how my possible relapsing would affect them, which scares me."**
> *CANCER SURVIVOR*

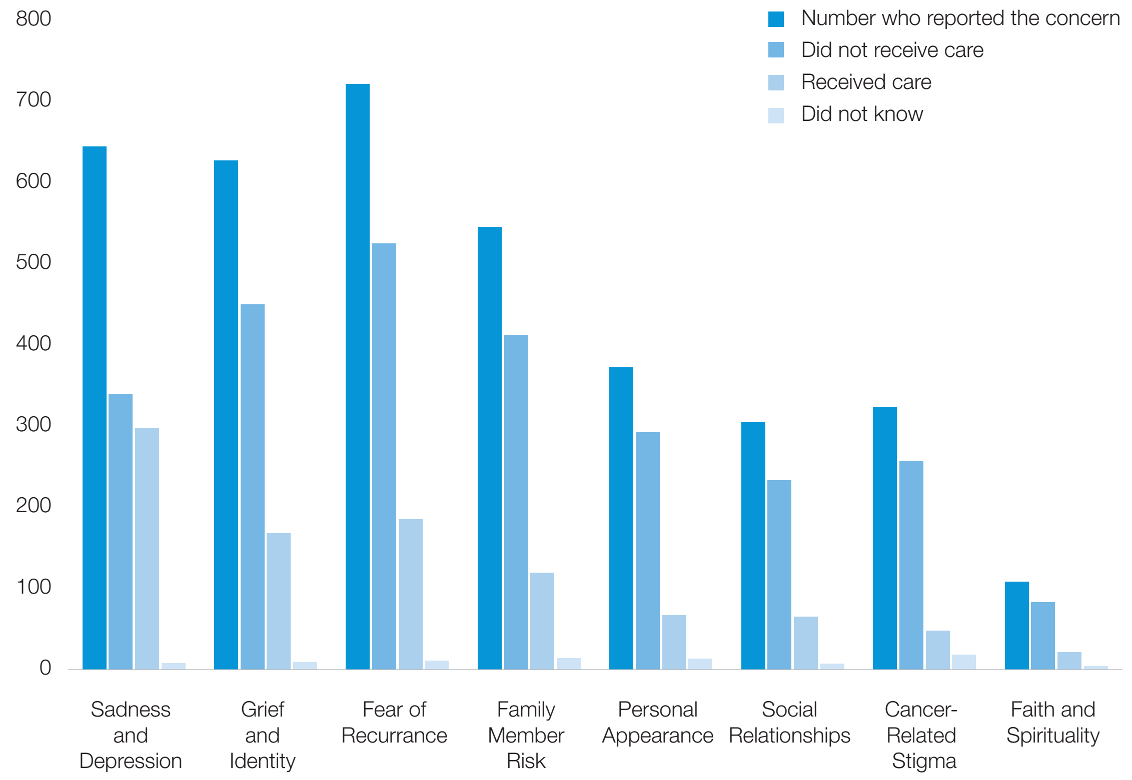


Figure 5. Number of participants who experienced an emotional concern and receipt of care (n = 1031)

Practical Concerns

KEY SUMMARY

- A diagnosis of cancer negatively affected many at their job, often leaving them unable to return to work or work in the same capacity.
- Degree of education impacted whether care was received for work concerns.
- Although only a small portion of participants of the overall sample were in schooling during and after their cancer diagnosis, they reported being negatively affected, most notably by missing large amounts of school, and having trouble keeping up. However participants' concerns with school were often dealt with on their own.
- Insurance and financial issues were experienced by both individuals and their families.
- Education level and age were associated with the likelihood of experiencing financial difficulties.

> **"I find my work colleagues do not have any understanding of the way cancer has changed the way I lead my life. I don't feel part of the team."** *CANCER SURVIVOR*

WORK

66.5% of participants (n = 686) indicated they were either working or had worked since their cancer diagnosis. Almost half who were employed at the time of diagnosis (45%, n = 309) reported they had been negatively affected at their job as a result. The participants stated their negative experiences were due to: being unable to work in the same way as before their cancer diagnosis (48.5%, n = 150), having difficulty with returning to work (31.7%, n = 98), and being unable to work full-time (30.4%, n = 94).

28.2% of participants (n = 82) received help for their work concerns and the top health care providers were GPs (40.2%, n = 33); partners (30.5%, n = 25); friends (26.8, n = 22); and psychiatrists or psychologists (26.8, n = 22). 46.3% of participants (n = 38) reported that the help they received met 'All' or 'Many' of their needs.

Of those who experienced concerns at work since completing treatment (94.2%, n = 291), the majority indicated that they did not receive help (66.3%, n = 193). The three most common reasons for this were: 'I have learned to live with my concern' (37.8%, n = 73), 'I have addressed this on my own' (30.6%, n = 59), and 'I was unsure of where to go' (10.4%, n = 20).

Further analyses were performed to determine whether gender, age, time since treatment, education and geographical location influenced the likelihood that participants received care for their work concerns. The results indicated that education influenced whether care was received. Specifically, those who reported their highest level of educational attainment as a trade certification, technical college or university degree were more likely to receive care for their work concern, compared to participants whose highest level of education was a high school certificate or lower (Appendix E, Table 4).

SCHOOL

Only 4.8% (n = 49) of participants were in school when they received a cancer diagnosis (including primary or high school, and part-time or full-time TAFE or university). 63.3% (n = 31) of these participants indicated they had been negatively affected at school because of their diagnosis. The main reasons for this were: 'I missed a large amount of school' (64.5%, n = 20); 'I have had difficulty in keeping up with my school' (38.7%, n = 12); and 'I felt my classmates did not know how to support me when I returned to school' (35.5%, n = 11).

29 participants reported a school concern only since completing treatment for cancer, and of these 41.4% (n = 12) received help for their school concerns. Friends (50%, n = 6), and family members (41.7%, n = 5) were the most common sources of support. Participants indicated that the help they sought met 'All' or 'Many' of their needs (91.7%, n = 11).

48.3% (n = 14) who experienced a concern associated with schooling did not receive help. The main reason was: 'I have addressed this on my own," (28.6%, n = 4).

FINANCE AND INSURANCE

Responses indicated that only 8.1% (n = 83) of participants experienced an insurance concern since completing treatment. The most common insurance concern was 'I have problems with private health insurance because of cancer as a pre-existing condition,' (42.2%, n = 35).

29.7% of participants (n = 306) reported that they and/or their loved ones had financial problems because of cancer, treatment, or late effects of cancer. Younger participants, compared to older participants, were more likely to have financial concerns (see Appendix E, Table 5).

Of those who indicated that either themselves or their loved ones had financial problems, approximately 15% (15.1%, n = 46) accrued up to $ 5000 in debt, 16.4% (n = 50) between $5000 and $9 999, 18.4% (n = 56) between $10 000 and $24 999, and 7.2% (n = 22) between $25 000 and $49 999. A further 4.9% (n = 15) accumulated upwards of $50 000 and 19.7% (n = 60) indicated that they amassed debt but either preferred not to say or did not know. Approximately 18% (18.1%, n = 55) reported that they had financial difficulties but did not go into debt.

> **"I am self-employed so experienced a huge loss of income over the past few years. I feel that I will never be able to work at full capacity (as I don't want to tire myself out). I also am having trouble doing work that I don't find meaningful. It seems like such a waste of precious time."**
> *CANCER SURVIVOR*

Meaning Making

KEY SUMMARY

- The majority of the participants surveyed (70%) tried to take better care of their health after their diagnosis. Almost 50% were up-to-date on all recommended cancer screenings, around 48% participated in regular physical activity and 44% were leading a healthier lifestyle than before their diagnosis.
- 14.5% of cancer survivors felt cancer interfered with the achievement of their life goals, and 9.7% felt their life would never be good again.
- Approximately 40% of the sample indicated that they identified with the term "survivor".
- Positive behavioural changes such as trying to take care of their health, being up-to-date with recommended screening tests, and engaging in more physical activity were common after cancer treatment.

HOW DO YOU FEEL ABOUT YOUR CANCER?

Participants were asked to select statements that were true pertaining to how they felt about cancer. The responses from highest to lowest were as follows:

- My experience with cancer has made me a better person (43.3%, n = 446)
- I have made a complete recovery from my illness (33.9%, n = 349)
- Cancer is serious, but I will be able to return to life as it was before my illness (33.8%, n = 348)
- I am the same person I was before my illness (24.4%, n = 252)
- Cancer is something I will never recover from (19.1%, n = 197)
- Having cancer has interfered with my achievement of the most important goals I have set for myself (14.5%, n = 149)
- Cancer has changed my life permanently, so it will never be good again (9.7%, n = 100).

IDENTIFICATION AS A 'SURVIVOR'

Participants were asked how they would describe themselves having experienced a diagnosis of cancer. Nearly half (45.4%, n = 468) of the sample identified with being a cancer survivor, 40.3% (n = 415) described themselves as a person who has had or has cancer. Few participants identified as 'I am a cancer patient' (1.9%, n = 20) and 'I am a cancer victim' (1.6%, n = 16).

> **"It [my cancer diagnosis] has given me more of a career related purpose. As a result I am currently enrolled at uni studying to become a social worker, with the aim of working with people affected by cancer."** *CANCER SURVIVOR*

POSITIVE BEHAVIOUR CHANGE FOLLOWING CANCER

Participants indicated a number of positive behavioural ways cancer impacted their lives. The majority reported that they tried to take care of their health as a result of their experience, with almost 50% stating they were up to date with all recommended cancer screenings and participated in regular physical activity (Figure 6).

> **"The world looks different now & I take every chance to live my life better than I did before. I have more empathy with other cancer survivors."** *CANCER SURVIVOR*

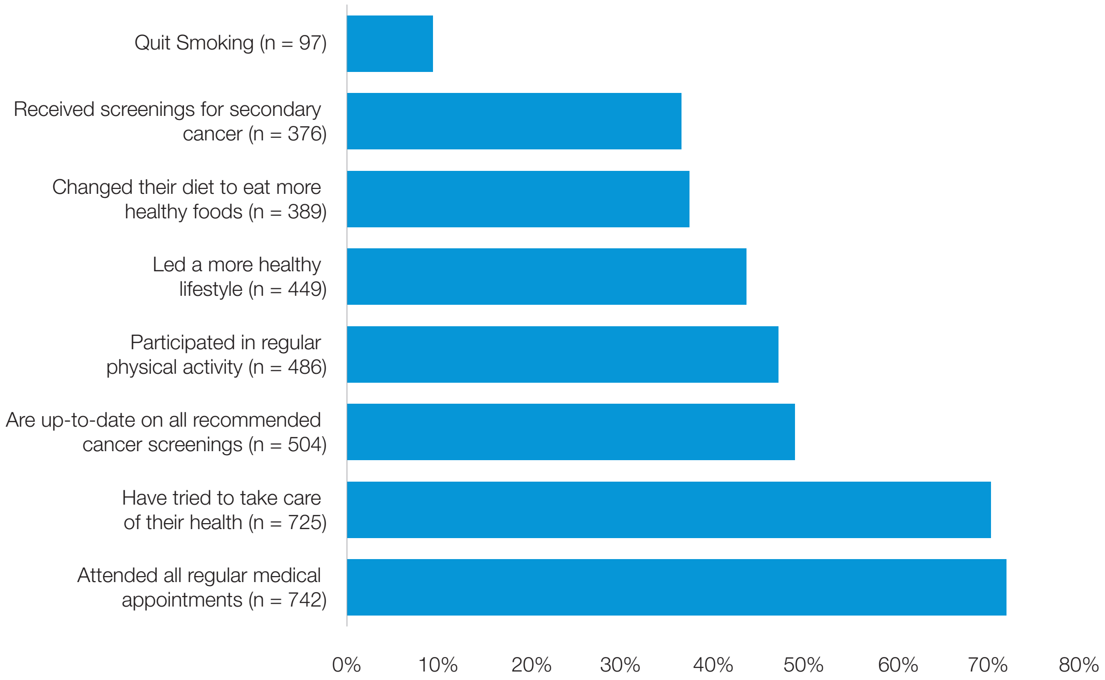


Figure 6 . Postive changes in post-treatment daily routine (n = 1031)

Treatment Guidance & Quality of Care

KEY SUMMARY

- The majority of participants indicated they did not have a dedicated health professional to guide them through their cancer experience and few received a copy of their treatment history.
- 81.2% of participants reported that they had received instructions about where to go for post-treatment care.
- Participants reported that their health care team frequently involved them in decisions, offered opportunities for questions and instructed them on how to deal with their illness.
- Approximately 30-40% of participants indicated that their health care team infrequently managed their emotions and uncertainty.

> **"The post-treatment support and information services offered to me were minimal at best. There was little support coordination and I was left without any emotional or social support from my treatment team. I had to source that myself."**
> *CANCER SURVIVOR*

14.8% of participants reported a nurse was the predominant health care professional who aided them on their cancer journey (Figure 7). Other responses (13%) included: family member, oncology professional, specialist nurse and surgeon. However, the majority of the sample indicated that they did not have a dedicated person on their health care team to help guide them through their cancer experience (58.3%).

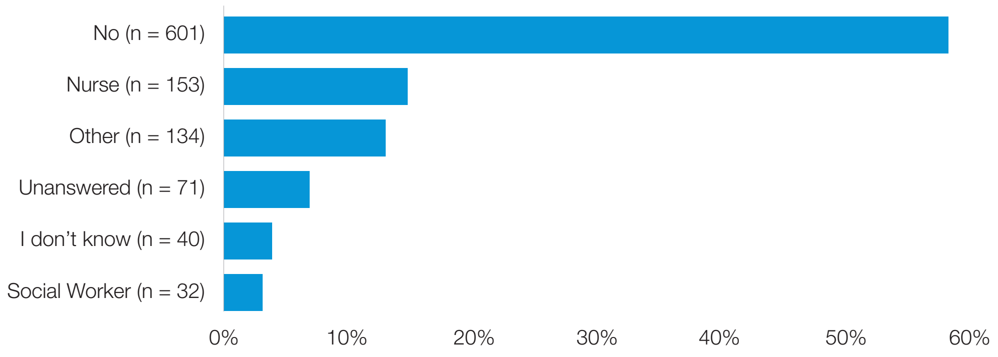


Figure 7. Dedicated health care professional throughout cancer experience (n = 1031)

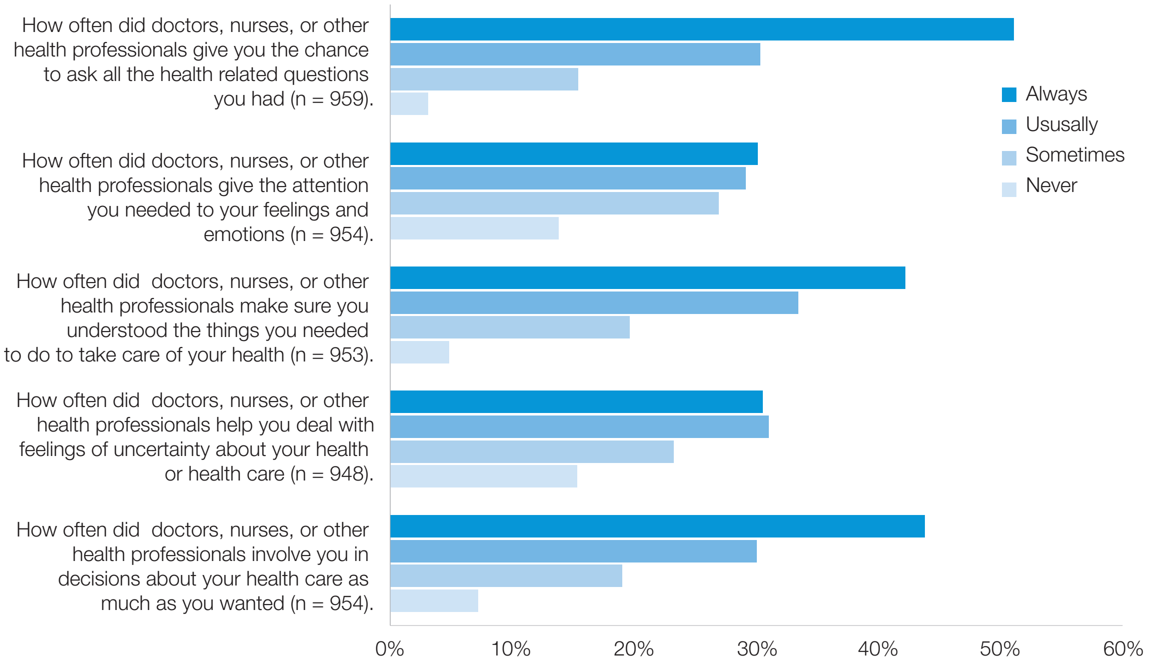


Figure 8. Quality of health care communication (n = 1031)

61.4% (n = 633) reported that their doctor, nurse or other health professional never provided a written summary of all cancer treatments they received. However, after completion of cancer treatment, 81.2% (n = 837) of participants reported that they received instructions from their health care team about where they should return to for routine check-ups.

Participants were also asked about the quality of the communication they had with their health care team (Figure 8). About two-thirds (68.3%) of the participants reported that their health care team either 'Usually' or 'Always' involved them in decisions, made sure they understood the things they needed to do to take care of themselves and gave them the opportunity to ask all the health-related questions they needed. A slightly lower percentage reported that their health care team 'Usually' or 'Always' addressed their emotions and feelings of uncertainty (56.5%).

Advocacy and Engagement

The most frequently endorsed advocacy and engagement activities were more funding for research (61.0%; n = 629), more resources for people affected by cancer (47.9%; n = 494), and development of a national cancer plan (40.5%; n = 417) (Figure 9). 'Other' responses were various with no major themes emerging.

> **"More care for people in rural and regional areas - it is much harder for them than for people in cities."**
> *CANCER SURVIVOR*

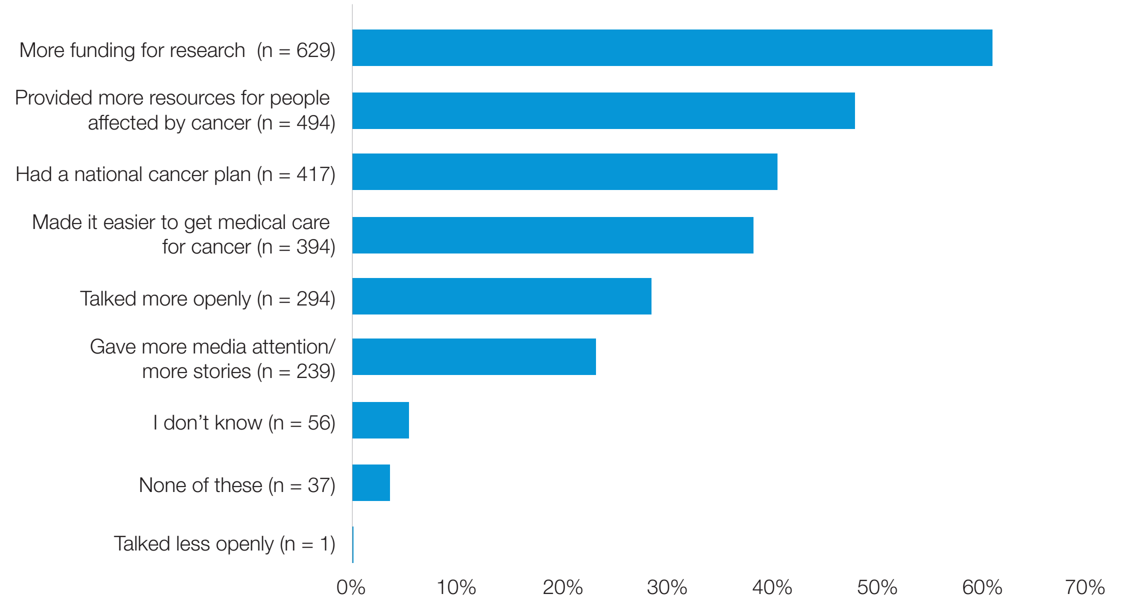


Figure 9. Attitudes towards health care support in Australia (n = 1031)

Key Concluding Comments

The Cancer Council Queensland Survivor Study of over 1000 Queenslanders shows participants experienced a large number of concerns that persisted after their cancer treatment finished - and, for many, these concerns were not actively addressed.

Overall, physical and emotional concerns were very common, with almost all of the sample indicating they had experienced at least one concern. The most common physical concerns were energy, concentration, and sexual function, and the most common emotional concerns were fear of cancer recurrence, issues associated with grief and identity, and sadness and depression. Interestingly, those who had been diagnosed with the most common cancers represented in the sample (i.e., breast, prostate and colorectal cancer) reported similar physical function issues and emotional concerns, suggesting that cancer type does not influence longer term adjustment following treatment.

Receipt of care for identified concerns varied by the type of physical concern, with care more often received for concerns involving the thyroid, mouth/teeth and lymphoedema but less often for cognitive concerns (e.g., concentration), neuropathy, and sexual function. By comparison, the proportion of participants who did not receive care for their emotional concerns was consistently high, especially for concerns such as cancer-related stigma, personal appearance and family member risk.

Age, gender, education level, time since last treatment and geographical location influenced whether the participants received care for some of their physical, emotional and practical concerns. A notable difference between the demographic factors that predicted seeking help for physical concerns compared to emotional concerns was education level, where those with a higher degree of education were more likely to seek emotional support (for sadness and depression and personal appearance) and were also more likely to seek help for issues associated with returning to work and financial difficulties. Age, gender, time since last treatment and geographical location also emerged as significant predictors of seeking emotional help. This information can be used to target services and support towards Queenslanders who are less likely to seek care and support.

A limitation of this study is the sampling method, meaning the results cannot be generalised to the wider population. While the most common cancers represented were comparable to population trends, the results are likely skewed by the high proportion of participants who attended some type of support group (~ 48%). The number of participants residing in major city centres (57.8%) as opposed to outer regions of Queensland is also a limitation. Other practical limitations include the survey length and predominant online administration of the survey, which may have precluded participation.

Cancer Council Queensland recognises the importance of connecting those who have been affected by cancer with the services they require. However, the results of this study indicate a substantial gap in this connection. It is crucial to do all we can to reduce this gap and to continue to offer and advocate for improved services and support for all cancer patients.

IMPLICATIONS AND NEXT STEPS

To carry this important work forward three key steps have been identified:

1. Communication of research findings
2. Informing practice
3. Conducting further research

COMMUNICATION

Communication of these findings is crucial. Being a grass-roots organisation, Cancer Council Queensland will disseminate survey results to consumers, volunteers, the research community, health professionals, and the wider healthcare network to raise awareness and contribute to the survivorship movement. This will help to ensure a shared understanding of, and ultimately advocating for, increased attention towards the experiences and difficulties of those in the post-treatment phase.

INFORMING PRACTICE

The results of this survey indicate that despite the large number of concerns reported by participants, receipt of care was low, particularly for emotional challenges. This finding highlights a gap in post-treatment care which may be attributable to individual (i.e., patients and health care providers) factors and/or health system factors.

Previous work has called for health care professionals to have a better understanding of survivorship concern symptoms, a greater ability to identify these symptoms as well as better patient-centered care and communication. Further, despite high unmet needs, some survivors are reluctant to seek help for their concerns, which in some cases is associated with gender-based norms. Combined with this, current methods of service delivery which involve an uncoordinated mix of specialist and primary care models are limited in regards to delivering optimal care.

Avenues to better healthcare and outcomes may be through survivorship care plans, yet in Australia, the evidence supporting this strategy is limited and requires further attention. The role of primary care in the post-treatment phase is becoming more and more necessary and educating professionals to routinely screen and improve their ability to identify patients whose concerns may not be explicit is also key. Streamlining referral pathways and increasing the awareness of these pathways (to both patients and health care professionals) may also assist with ensuring patients are provided with the appropriate options and opportunities for care.

As a result of this study, Cancer Council Queensland aims to:

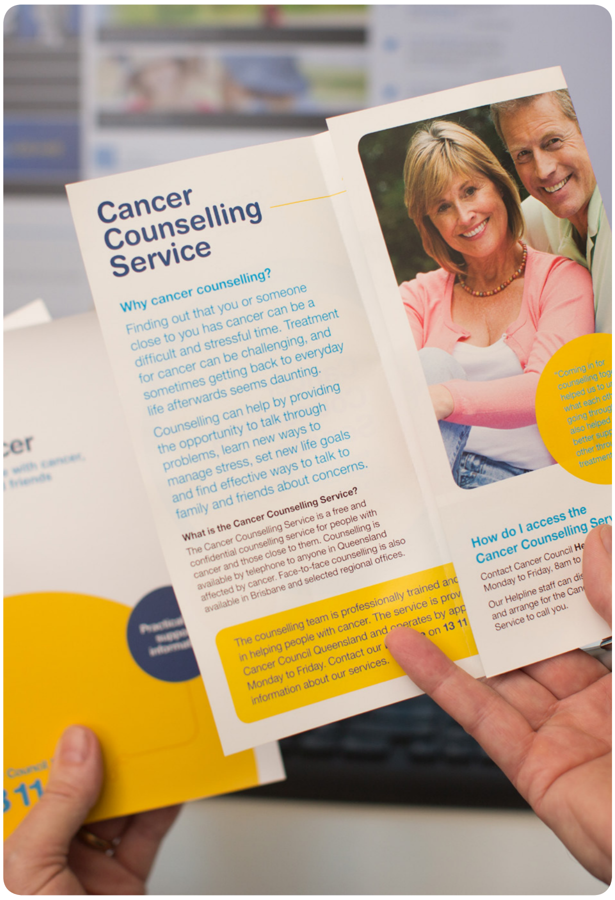
1. Further embed the referral pathway between primary care health professionals and support services (i.e. Cancer Council Queensland's Information and Support line 13 11 20 and the Cancer Counselling Service) in the health system to ensure survivors are connected with the care they need.
2. Work closely with general practitioners, nurses, pharmacists and allied health providers by continuing to provide professional education opportunities.
3. Continue to provide a high standard of emotional and practical support via resources, peer support programs, access to community-based support groups and health and wellbeing programs as well as assistance with accommodation and transport costs.
4. Advocate for legislation, policy and funding to improve cancer control and health outcomes.

FURTHER RESEARCH AND COLLABORATION

Further research is required on the post-treatment experiences of those who have been diagnosed with cancer. Potential research areas may include:

1. Continued monitoring of the needs of cancer survivors, at the State and National level, with representative samples
2. Investigating in greater detail how demographic differences (i.e., place of residence) impact receipt of care
3. Understanding how cancer survivors cope over time and how experiences change
4. Gaining a greater understanding of the barriers and facilitators to receipt of care (i.e., individual and health system factors) for survivorship concerns

To do this work, Cancer Council Queensland will continue to coordinate and collaborate with other research bodies to further examine and understand survivorship, and how this phase is experienced in Queensland as well as Australia.



Cancer Counselling Service

Why cancer counselling?

Finding out that you or someone close to you has cancer can be a difficult and stressful time. Treatment for cancer can be challenging, and sometimes getting back to everyday life afterwards seems daunting.

Counselling can help by providing the opportunity to talk through problems, learn new ways to manage stress, set new life goals and find effective ways to talk to family and friends about concerns.

What is the Cancer Counselling Service?

The Cancer Counselling Service is a free and confidential counselling service for people with cancer and those close to them. Counselling is available by telephone to anyone in Queensland affected by cancer. Face-to-face counselling is also available in Brisbane and selected regional offices.

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APPENDIX A - SURVEY CONCERNS

PHYSICAL CONCERNS

Heart concerns

I have had trouble with my heart.

I have been told by a doctor that I have heart problems.

Lungs and breathing concerns

I have had trouble breathing.

I have been told by a doctor that I have damage to my lungs.

Vision concerns

I have had trouble seeing.

I have been told by a doctor that I have problems with my vision or sight.

Hearing trouble concerns

I have had trouble hearing.

I have been told by a doctor that I have problems with my hearing.

Oral health concerns

I have had problems with my mouth.

I have had problems with my teeth.

I have been told by a doctor that I have problems with my mouth.

I have been told by a doctor that I have problems with my teeth.

Lymphoedema concerns

I have had swelling in my legs, arms or other areas of my body.

I have been told by a doctor that I have lymphoedema.

Swallowing and feeding collection of concerns

I have had problems swallowing naturally and easily.

I have had problems eating solid foods.

Neuropathy collection of concerns

I have lost feeling or had strange sensations in my hands or feet.

I have experienced dizziness, such as when getting up from a chair.

I have been told by a doctor that I have neuropathy.

Thyroid collection of concerns

I have been told by a doctor that I have a thyroid condition.

Urinary incontinence collection of concerns

I have not been able to control when I urinate.

I urinate more frequently than I used to.

I have been told by a doctor that I have urinary incontinence.

Infertility collection of concerns

I have been pregnant or fathered a pregnancy since cancer treatment ended…

Sexual functioning and satisfaction collection of concerns

I have been bothered by difficulty or inability to function sexually.

I have been dissatisfied with my sex life.

I have avoided sexual activity or lacked interest in sex.

I have had difficulties with impotence.

Pain collection of concerns

I have had aches or pains for long periods of time.

I have had pain that kept me from doing the things I wanted to do.

Concentration collection of concerns

I have had difficulty doing activities that require concentration.

I have been bothered by having a short attention span.

I have had trouble remembering things.

I have been bothered by forgetting what I started to do.

I have had "chemo brain."

Energy and rest collection of concerns

I have not had the energy to do the things I wanted to do.

I have felt tired a lot.

I have had trouble getting the rest that I need.

I have had trouble sleeping for several nights in a row.

EMOTIONAL CONCERNS

Sadness and depression collection of concerns

I have felt blue or depressed.

I have been bothered by mood swings.

I have felt anxious.

I have felt a constant state of worry, tension or stress.

I have been told by a doctor that I am suffering from depression.

I have dates or events that make me think more about cancer. (For example, the date you were diagnosed or the date treatment ended.)

I feel blue or depressed each time these dates or events occur.

Grief and identity collection of concerns

I have felt that I have lost a sense of security in my future.

I have felt that I have lost a sense of my identity.

I have felt grief about the death of other cancer patients.

I have felt guilt over the death of other cancer patients.

Faith and spirituality collection of concerns

I have felt that I have lost a sense of my faith or spirituality.

I have felt that my faith or spirituality has been negatively affected.

Fear of recurrence collection of concerns

I have been preoccupied with concerns about cancer.

I have worried about dying from cancer.

I have worried about cancer coming back.

Personal relationships impact collection of concerns

I have been reluctant to start new relationships.

I have not wanted to participate in social gatherings.

I have not wanted to be around my friends.

I have been reluctant to meet new people.

I do not go to events that I used to enjoy.

Cancer-related stigma collection of concerns

I have not wanted to tell others that I have had cancer.

I have felt ashamed because I have had cancer.

I am afraid others will judge me negatively if they know I have had cancer.

I feel others have avoided me because I have had cancer.

Family member risk of cancer collection of concerns

I have worried about whether my family members should have genetic tests for cancer.

I have worried that my family members were at risk of getting cancer.

I have worried about whether my family members might have cancer-causing genes.

Personal appearance collection of concerns

I have felt unattractive.

I have felt people have treated me differently because of changes to my appearance.

I was bothered by hair loss from cancer treatment long after treatment ended.

PRACTICAL CONCERNS

Employment issues collection concerns

I have been affected at my job because of my cancer diagnosis in the following negative ways: (Please check all that apply.)

I lost my job.

I left my job.

I am unable to work at all now.

I am unable to work full time now.

I am unable to work in the same way I did before my cancer diagnosis.

I have been treated poorly on the job.

I have received a decrease in pay.

I have experienced employment discrimination.

I have felt that my employer would not make reasonable changes or accommodations in my job to help me.

I was passed over for a promotion.

I have returned to work at a lower level than I was at before my diagnosis.

I have stayed in my job because I did not want to lose my health insurance.

I have stayed in my job because I did not want to lose my life insurance.

I had difficulty with the return to work.

I had to take on a second job because of debt due to cancer.

I have felt that I did not get a job because of my cancer diagnosis.

Other____

School issues collection concerns

I have been affected at my school because of my cancer diagnosis in the following ways: (Please check all that apply.)

I left school.

I missed a large amount of school.

I felt my teachers did not know how to support me when I returned to school.

I felt my classmates did not know how to support me when I returned to school.

I have had difficulty keeping up with my school work.

I have had trouble with my classmates since receiving a cancer diagnosis.

I did not have any special accommodations while I was in school.

I had to drop out of school because of debt.

I was unable to attend college.

Other____

Debt collection concerns

My loved ones or I have had financial problems because of cancer, treatment or late effects of cancer.

Due to a cancer diagnosis, I have the following amount of debt. (Please select one.)

No debt

Up to $5,000 in debt

Between $5,001–$10,000 in debt

Between $10,001–$24,999 in debt

Between $25,000–$49,999 in debt

Between $50,000–$74,999 in debt

Between $75,000–$99,999 in debt

$100,000 or more in debt

Insurance collection concerns

Since completing treatment, I have (or the primary policy holder of my insurance has)…

lost my health insurance.

been denied health insurance.

not been able to get health insurance for the first time.

not been able to get additional health insurance.

reached the health insurance lifetime maximum.

problems with health insurance because of cancer as a pre-existing condition.

not been able to get the prescriptions that I needed because of my health insurance.

not been able to get the treatment that I wanted because of my health insurance.

not been able to get the screenings that I wanted because of my health insurance.

not been able to get the follow-up care that I wanted because of my health insurance.

not been able to get the medical care I wanted because of the costs I would incur above and beyond what insurance covers.

Other______________________________

APPENDIX B - SOCIO-DEMOGRAPHIC AND MEDICAL INFORMATION

Table 1. Socio-demographic information

	Total Sample (n = 1031)
Gender (n = 915)	
Male	45.3
Female	54.8
Education (n = 923) %	
Primary School	1.2
High School	30.4
Trade Certificate, College, or TAFE	32.6
University Degree	34.2
Prefer Not to Answer/Other	1.52
Income (n = 915) %	
< $20, 000	8.4
$20, 000 to less than $40, 000	19.6
$40, 000 to less than $60, 000	14.3
$60, 000 to less than $80, 000	14.0
$80, 000 or More	28.9
Prefer Not to Answer/I Don't Know	14.9
Marital Status (n = 922) %	
Single	8.8
Married or Partner	75.0
Separated	3.4
Divorced	7.6
Widowed	4.0
Prefer Not to Answer	1.3
Health Insurance (n = 916) %	
Full Health Insurance	60.6
Basic Hospital Cover Only	7.9
Extras Cover Only	3.1
Department of Veteran Affairs	2.1
I Don't Know/Other	1.5
No Private Health Insurance	24.9
Geographical Location (n = 887) %	
Major Cities	57.8
Inner Regional	24.9
Outer Regional	16.4
Remote/Very Remote	0.9
Type of Cancer (n = 915) %	
Breast	26.1
Prostate	21.8
Colorectal	9.6
All Lymphoma	8.0
Gynaecological	6.3
Years Since Diagnosis (n = 881) %	
< 5 years	54.4
> 5 years	45.6
Years Since Treatment (n = 858) %	
< 5 years	66.3
> 5 years	33.7
Medical Treatment (n = 1031) %	
Surgery	69.0
Chemotherapy	45.6
Radiation	46.0
Hormone Therapy	16.7
Self-managed Treatment (n = 1031) %	
Exercise	44.3
Nutritional Supplements	28.6
Massage	22.8
Meditation	19.2
Special diet	18.5
Types of Support (n = 1031) %	
Did not access support	52.1
Group for survivors and loved ones	19.7
Face-to-face	19.3
Individual counselling	9.3
Online	7.6
Telephone	6.5

Not all variables sum to 1031

Table 2. Medical information

	Total Sample (n = 1031)
Type of Cancer (n = 906) %	
Breast	23.3
Prostate	22.0
Colorectal	9.7
All Lymphoma	8.1
Gynaecological	6.4
Years since diagnosis (n = 1031) %	
≤ 5 years	54.3
> 5 years	45.8
Treatment (n = 915) %	
Surgery	77.5
Chemotherapy	51.4
Radiation	50.4
Hormonal Therapy	18.6
Years since last treatment (n = 1031) %	
≤ 5 years	55.8
> 5 years	44.2

APPENDIX C – PHYSICAL CONCERNS

Table 1. Cancer type by the number of participants who reported each physical concern

	Physical Concern														
Cancer Type	**Energy**	**Sexual Function**	**Concentration**	**Neuropathy**	**Pain**	**Incontinence**	**Mouth**	**Lymphoedema**	**Lung**	**Hearing**	**Vision**	**Heart**	**Swallowing**	**Thyroid**	**Fertility**
Breast (n = 239)	194	133	170	116	125	50	62	105	38	20	38	28	17	25	2
Prostate (n = 199)	106	175	74	55	50	120	16	26	18	28	18	28	6	5	0
Colorectal (n = 88)	61	55	55	54	30	33	20	8	7	10	11	10	6	5	0
All Lymphomas (n = 73)	56	39	51	43	31	22	29	13	33	13	15	13	11	4	0
Gynaecological (n = 58)	46	39	43	29	25	20	12	18	9	9	6	4	4	7	1
Multiple (n = 39)	30	23	25	21	23	18	20	16	16	7	12	7	10	8	1
Melanoma (n = 34)	19	11	9	14	8	3	4	12	4	4	7	7	2	4	0
Head and Neck (n = 34)	29	18	21	19	16	10	28	12	6	12	5	4	27	8	0
Trachea/Bronchus/Lung (n = 20)	16	9	13	11	6	2	6	3	17	8	5	1	4	2	1
Brain/Meninges/Cns (n = 20)	17	11	17	13	6	5	5	4	3	7	10	1	3	4	1
All Leukaemias (n = 18)	15	12	13	6	5	3	5	2	2	2	1	1	2	3	0
Skin (n = 15)	10	6	8	7	4	5	11	4	3	6	2	1	8	3	0
Kidney and other Renal Tract (n = 13)	7	8	6	2	6	6	3	2	2	2	1	4	1	0	0
Thyroid (n = 10)	8	3	7	7	4	1	3	1	4	2	0	1	2	6	0

Cancer types included when n≥10

Table 2. Percentage of participants who sought care from different care providers for each physical concern

Care provider	Heart (n =133)	Lungs (n = 196)	Vision (n = 156)	Hearing (n = 163)	Oral (n = 272)	Lymphoedema (n = 254)	Feeding (n = 125)	Neuropathy (n = 472)	Thyroid (n = 102)	Incontinence (n = 347)	Fertility (n = 8)	Sexual Function (n = 642)	Pain (n = 424)	Concentration (n = 623)	Energy (n = 734)
GP	39.1	31.1	13.5	11.0	24.3	26.8	32.8	24.8	49.0	16.1	12.5	15.4	43.9	10.9	25.1
Medical oncologist	6.8	11.7	1.3	1.8	11.4	14.2	18.4	10.2	11.8	6.1	0.0	2.8	17.5	6.4	8.6
Medical specialist	42.1	25.0	30.1	22.1	51.1	32.3	28.0	9.5	28.4	21.0	12.5	13.9	22.2	4.0	6.4
Other medical personnel	7.5	4.1	9.6	1.2	9.2	18.5	20.0	7.6	5.9	7.8	0.0	2.2	10.4	1.1	1.8
Psychologist or psychiatrist	4.5	4.6	2.6	0.1	1.8	1.6	3.2	2.8	2.0	2.6	0.0	2.5	5.0	5.5	7.6
Social worker or counsellor	3.0	2.6	2.6	0.0	1.1	2.0	0.8	0.2	2.0	0.6	0.0	1.1	1.7	1.9	3.0
Complimentary or alternative therapy	3.0	3.6	1.3	0.6	2.9	9.4	4.8	4.2	5.9	2.0	0.0	1.1	9.7	1.6	4.9
Support group	1.5	1.5	0.6	0.0	3.3	3.5	3.2	1.1	2.0	3.7	0.0	2.6	1.4	1.6	1.6
Self	7.5	5.1	2.6	0.6	8.8	14.2	6.4	5.1	6.9	6.1	0.0	5.9	9.0	3.5	6.1
Partner	6.8	4.6	1.9	2.5	5.5	8.3	6.4	3.8	4.9	4.0	0.0	5.3	8.5	3.9	5.3
Family	6.0	2.0	0.0	0.6	2.9	3.9	2.4	2.1	5.9	1.4	0.0	0.2	3.5	1.6	3.4
Other cancer survivors	2.3	2.6	1.3	1.2	3.7	3.5	7.2	2.1	1.0	3.5	0.0	2.6	3.5	2.1	2.2
Friend	2.3	2.6	0.6	1.2	2.6	3.1	1.6	2.1	6.9	1.4	0.0	1.2	3.5	2.1	2.7
Cancer Council Queensland	1.5	1.0	1.3	1.2	1.8	1.6	2.4	1.7	2.9	2.3	0.0	2.0	1.2	1.3	1.4
Other not for profits	3.0	1.5	0.6	0.6	1.8	0.4	0.0	0.6	1.0	0.3	0.0	0.6	1.2	1.0	0.8
Religion	0.8	1.0	0.0	0.0	0.7	0.4	0.8	0.4	0.0	0.3	0.0	0.0	0.0	0.2	0.0
Government	0.0	0.0	0.0	0.0	0.7	0.0	0.0	0.0	0.0	0.9	0.0	0.2	0.2	0.2	0.0
Private health	7.5	2.0	4.5	3.1	8.8	4.7	4.8	1.9	2.9	1.4	0.0	0.6	3.1	0.3	0.7

Percentage is a proportion of the number of participants who indicated that sought care for a particular concern

Participants could choose more than one response

Table 3. Percentage of participants whose needs were met for each physical concern

Physical Concern	None of my needs	Very few of my needs	Some of my needs	Many of my needs	All of my needs
Energy (n = 235)	1.7	8.5	39.2	39.6	11.1
Concentration (n = 101)	4.0	12.9	28.7	31.7	22.8
Sexual functioning (n = 166)	7.2	11.5	31.9	31.9	17.5
Neuropathy (n = 164)	1.8	5.5	35.4	29.9	27.4
Pain (n = 238)	2.1	10.5	42.9	31.9	12.6
Lymphoedema (n = 169)	1.2	7.7	22.5	36.7	32.0
Incontinence (n = 117)	2.6	7.7	25.6	37.6	26.5
Oral health (n = 178)	0.0	6.2	28.1	29.2	36.5
Lungs (n = 85)	0.0	7.1	30.6	34.1	28.2
Vision (n = 68)	0.0	2.9	27.9	33.8	35.3
Thyroid (n = 61)	1.6	3.3	16.4	32.8	45.9
Feeding (n = 69)	1.5	1.5	26.1	39.1	31.9
Hearing (n = 48)	0.0	8.3	25.0	22.9	43.8
Heart (n = 71)	4.2	8.5	23.9	29.6	33.8
Fertility (n = 2)	0.0	0.0	0.0	0.0	100.0

Percentage is a proportion of those who received care for each concern

Table 4. The reasons participants did not receive care for physical concerns

Reason for not receiving care for physical concerns	**Percentage**
I plan to receive help in the future	9.7
I tried to receive help but was unsuccessful	7.3
I was told it was a side effect that would go away with time	39.4
I have learned to live with this concern	72.5
I was told nothing could be done	19.1
I have given up on trying to find care	10.4
I am afraid of finding out what is wrong	4.1
I did not want to bother anyone	10.7
I have not had time	3.3
I was unsure of where to go	12.4
I was unsure of who to see	11.8
My Dr. did not refer me to care	12.6
My insurance would not pay the costs	0.9
Medicare would not pay the costs	1.6
I could not pay for the services	2.9
I did not have transportation to get to services	0.6
I did not know help was available	13.3
I have addressed this on my own	31.5
I did not want to receive care	7.2
I do not know	5.9

Percentage is a proportion of participants who did not receive care for their physical concern (n = 807)

Participants could select more than one response

Table 5. Predictors of receipt of care for physical concerns

	Neuropathy OR [95per cent CI]	***p***	**Incontinence OR [95per cent CI]**	***p***	**Energy OR [95per cent CI]**	***p***	**Sex OR [95per cent CI]**	***p***	**Concentration OR [95per cent CI]**	***p***
Age	1.03 [1.01 – 1.05]	0.005	1.01 [0.99 – 1.04]	0.31	1.00 [0.98 – 1.01]	0.73	1.00 [0.98 – 1.03]	0.69	1.00 [0.98 – 1.02]	0.77
Gender[a]	1.19 [0.72 – 1.96]	0.68	2.26 [1.17- 4.38]	0.016	1.06 [0.70 – 1.62]	0.77	3.36 [1.94 – 5.82]	<0.001	1.30 [0.76 – 2.23]	0.33
Education[b]	1.12 [0.67 – 1.86]	0.43	1.12 [0.62 – 2.02]	0.71	1.01 [0.67 – 1.53]	0.96	1.33 [0.82 – 2.14]	0.25	0.88 [0.51 – 1.51]	0.65
Location[c]	1.41 [0.88 – 2.27]	0.15	0.96 [0.56 – 1.64]	0.87	1.63 [1.10 – 2.42]	0.016	1.58 [1.01 – 2.47]	0.05	1.89 [1.12 – 3.20]	0.02
Time - last tx[d]	0.69 [0.41 – 1.15]	0.16	0.83 [0.48 – 1.45]	0.52	0.68 [0.46 – 1.02]	0.07	0.64 [0.41 – 1.02]	0.06	0.73 [0.43 – 1.24]	0.24

OR = odds ratio; CI = confidence interval; *p* significance level

[a] Gender: Males = 1 and Female = 0

[b] Education: University/Trade or Technical Certificate = 1 and High School and lower = 0

[c] Location: Major City Centres = 1 and Inner/Outer Regional = 0

[d] Time since last treatment: ≤ 5 years = 1 and >5 years = 0

APPENDIX D – EMOTIONAL CONCERNS

Table 1. Cancer type by the number of participants who reported each emotional concern

Cancer Type	Emotional Concern							
	Sadness and Depression	Grief and Identity	Fear of Recurrence	Family Member Risk	Personal Appearance	Social Relationships	Cancer-Related Stigma	Faith and Spirituality
Breast (n = 239)	199	202	192	165	142	86	83	28
Prostate (n = 199)	116	118	109	129	29	53	35	22
Colorectal (n = 88)	63	59	62	70	15	24	22	7
All Lymphomas (n = 73)	53	57	60	32	43	31	34	13
Gynaecological (n = 58)	51	46	47	33	29	21	27	7
Multiple (n = 39)	32	28	34	24	16	16	12	3
Melanoma (n = 34)	24	27	29	21	10	7	7	5
Head and Neck (n = 34)	27	26	28	18	13	13	12	6
Trachea / Bronchus / Lung (n = 20)	16	15	13	8	6	6	8	2
Brain / Meninges / Cns (n = 20)	18	20	15	7	13	12	10	3
All Leukaemias (n = 18)	14	16	15	7	10	5	7	3
Skin (n = 15)	11	10	10	6	7	8	8	4
Kidney and other Renal Tract (n = 13)	10	9	11	8	3	6	6	0
Thyroid (n = 10)	9	6	9	9	3	5	7	2

Cancer types included when n≥10

Table 2. Percentage of participants who received help from health care providers for each emotional concern.

Care Provider	Sadness and Depression (n = 297)	Grief and Identity (n = 168)	Faith and Spirituality (n = 21)	Fear of Recurrence (n = 185)	Personal Relationships (n = 65)	Cancer-related Stigma (n = 48)	Family Risk (n = 119)	Personal Appearance (n = 67)
GP	70.4	55.4	38.1	51.4	50.8	45.8	48.7	32.8
Medical oncologist	16.5	13.1	19.0	28.1	7.7	10.4	36.1	10.4
Medical specialist	8.4	7.1	9.5	21.6	4.6	0.0	37.0	10.4
Other medical personnel	8.1	7.7	19.0	4.9	3.1	4.2	11.8	9.0
Psychologist or psychiatrist	44.4	53.0	33.3	40.0	61.5	56.3	6.7	26.9
Social worker or counsellor	16.2	21.4	23.8	15.1	21.5	29.2	7.6	13.4
Complimentary or alternative therapy	8.4	8.3	19.0	7.6	4.6	6.3	0.0	7.5
Support group	13.5	14.9	4.8	14.6	9.2	12.5	7.6	10.4
Self	20.9	19.6	23.8	20.5	10.8	20.8	12.6	28.4
Partner	24.9	23.8	33.3	26.5	16.9	22.9	18.5	34.3
Family	16.2	17.9	23.8	22.2	16.9	25.0	20.2	22.4
Other cancer survivors	13.8	19.0	23.8	18.9	6.2	14.6	7.6	13.4
Friend	20.2	20.8	28.6	22.2	18.5	18.8	11.8	25.4
Cancer Council Queensland	12.8	12.5	9.5	14.6	6.2	8.3	7.6	16.4
Other not for profits	3.0	2.4	0.0	3.2	0.0	2.1	1.7	3.0
Religion	1.0	1.8	14.3	1.6	1.5	2.1	0.0	0.0
Government	0.0	0.0	0.0	0.0	0.0	0.0	0.0	1.5
Private health	1.7	3.0	9.5	1.1	1.5	6.3	0.0	4.5
Other	0.0	0.6	0.0	0.0	0.0	2.1	0.0	4.5

Percentages presented as the proportion of those who received care for a particular emotional concern

Participants could select more than one response

Table 3. Percentage of participants whose needs were met for each emotional concern

Emotional Concern	None of my needs	Very few of my needs	Some of my needs	Many of my needs	All of my needs
Sadness and depression (n = 297)	1.0	6.7	37.0	44.8	10.4
Grief and identity (n = 168)	1.2	7.1	39.3	42.9	9.5
Faith and spirituality (n = 21)	0.0	19.1	38.1	28.6	14.3
Fear of recurrence (n = 185)	2.2	7.6	33.5	42.2	14.6
Personal relationships (n = 65)	1.5	18.5	49.2	29.2	1.5
Cancer-related stigma (n = 48)	4.2	8.3	43.8	37.5	6.3
Family risk (n = 119)	0.8	3.4	24.4	37.8	33.6
Personal appearance (n = 67)	3.0	7.5	34.3	34.3	21.0

Percentage is a proportion of those who received care for each concern

Table 4. The reasons participants did not receive care for emotional concerns

Reason for not receiving care for emotional concerns	Percentage
I plan to receive help in the future	5.6
I tried to receive help but was unsuccessful	3.8
I was told it was a side effect that would go away with time	8.5
I have learned to live with this concern	66.7
I was told nothing could be done	4.6
I have given up on trying to find care	5.8
I am afraid of finding out what is wrong	3.1
I did not want to bother anyone	16.9
I have not had time	3.6
I was unsure of where to go	11.7
I was unsure of who to see	11.1
My Dr. did not refer me to care	5.5
My insurance would not pay the costs	1.3
Medicare would not pay the costs	1.7
I could not pay for the services	3.3
I did not have transportation to get to services	0.6
I did not know help was available	8.5
I have addressed this on my own	42.5
I did not want to receive care	14.1
I do not know	12.2

Percentage is a proportion of participants who did not receive care for an emotional concern (n = 844)
Participants could select more than one response

Table 5. Predictors of receipt of care for emotional concerns

	Sadness OR [95per cent CI]	*p*	Grief & Identity OR [95per cent CI]	*p*	Spirituality OR [95per cent CI]	*p*	Fear of Recurrence OR [95per cent CI]	*p*	Social Relationships OR [95per cent CI]	*p*	Stigma OR [95per cent CI]	*p*	Family Risk OR [95per cent CI]	*p*	Appearance OR [95per cent CI]	*p*
Age	0.99 [0.97 – 1.00]	0.12	0.99 [0.97 – 1.01]	0.18	0.98 [0.94 – 1.03]	0.48	0.99 [0.97 – 1.00]	0.09	0.97 [0.95 – 1.00]	0.032	0.98 [0.95 – 1.01]	0.15	0.99 [0.97 – 1.01]	0.53	0.99 [0.96 – 1.01]	0.40
Gender[a]	0.74 [0.49 – 1.09]	0.13	0.77 [0.49 – 1.20]	0.25	0.61 [0.13 – 2.79]	0.52	0.61 [0.39 – 0.96]	0.03	1.37 [0.67 – 2.82]	0.39	0.56 [0.24 – 1.35]	0.20	0.37 [0.21 – 0.65]	<0.001	0.63 [0.27 – 1.48]	0.29
Education[b]	1.45 [0.98 – 2.14]	0.065	1.22 [0.78 – 1.93]	0.38	0.79 [0.22 – 2.92]	0.73	1.53 [0.97 – 2.41]	0.07	0.96 [0.47 – 1.96]	0.92	1.09 [0.49 – 2.46]	0.83	1.23 [0.72 – 2.11]	0.45	2.21 [1.05 – 4.63]	0.04
Location[c]	0.99 [0.68 – 1.43]	0.94	1.76 [0.96 – 2.26]	0.08	0.88 [0.25 – 3.13]	0.84	2.11 [1.38 – 3.24]	0.001	1.93 [0.97 – 3.83]	0.06	1.00 [0.47 – 2.10]	1.00	1.55 [0.93 – 2.57]	0.09	1.27 [0.67 – 2.43]	0.47
Time since - last tx[d]	0.82 [0.56 – 1.22]	0.34	1.06 [0.68 – 1.66]	0.78	0.62 [0.17 – 2.19]	0.46	0.96 [0.63 – 1.47]	0.85	1.21 [0.59 – 2.51]	0.61	0.52 [0.24 – 1.15]	0.11	1.21 [0.71 – 2.07]	0.48	0.76 [0.39 – 1.48]	0.42

OR = odds ratio; CI = confidence interval; p significance level

[a] Gender: Males = 1 and Female = 0

[b] Education: University/Trade or Technical Certificate = 1 and High School and lower = 0

[c] Location: Major City Centres = 1 and Inner/Outer Regional = 0

[d] Time since last treatment: ≤ 5 years = 1 and >5 years = 0

APPENDIX E – PRACTICAL CONCERNS

Table 1. Percentage of different ways participants were negatively affected at their work

Negative ways affected at work because of cancer diagnosis	Percentage
I lost my job	9.4
I left my job	30.0
I am unable to work at all now	10.1
I am unable to work full time now	30.6
I am unable to work in the same way as I did before	48.9
I have been treated poorly on the job	10.1
I have received a decrease in pay	7.5
I have experienced employment discrimination	12.7
I have felt that my employer would not make reasonable changes or accommodation	9.4
I was passed over for a promotion	6.2
I have returned to work at a lower level than I was at before	9.4
I have stayed in my job because I did not want to loser my health insurance	4.2
I have stayed in my job because I did not want to lose my life insurance	4.6
I had difficulty with the return to work	31.9
I had to take on a second job because of debt due to cancer	1.3
I have felt that I did not get a job because of my cancer diagnosis	5.9
Other	24.4

Percentage is a proportion of the number of participants who indicated that they had been affected negatively at work (n = 307)

Participants could select more than one response

Table 2. Percentage of participants who received help from health care providers for work concerns.

Care Provider	Percentage
GP	40.2
Medical oncologist	14.6
Medical specialist	11.0
Other medical personnel	7.3
Psychologist or psychiatrist	26.8
Social worker or counsellor	15.9
Complimentary or alternative therapy	3.7
Support group	7.3
Self	17.1
Partner	30.5
Family	17.1
Other cancer survivors	6.1
Friend	26.8
Cancer Council Queensland	7.3
Other not for profits	1.2
Religion	1.2
Government	0.0
Private health	2.4
Other	22.0

Percentages presented as the proportion of those who received care for a particular work concern (n = 82)

Participants could select more than one response

Table 3. The reasons participants did not receive care for employment concerns

Reason for not receiving care for emotional concerns	**Percentage**
I plan to receive help in the future	1.6
I tried to receive help but was unsuccessful	5.7
I was told it was a side effect that would go away with time	1.0
I have learned to live with this concern	37.8
I was told nothing could be done	6.2
I have given up on trying to find care	4.7
I am afraid of finding out what is wrong	0.5
I did not want to bother anyone	5.7
I have not had time	1.0
I was unsure of where to go	10.4
I was unsure of who to see	9.8
My Dr. did not refer me to care	3.1
My insurance would not pay the costs	1.0
Medicare would not pay the costs	1.0
I could not pay for the services	1.0
I did not have transportation to get to services	0.5
I did not know help was available	7.3
I have addressed this on my own	30.6
I did not want to receive care	7.3
I do not know	8.3
Other	10.9

Percentage is a proportion of participants who did not receive care for an employment concern (n = 193)

Participants could select more than one response

Table 4. Predictors of receipt of care for work concerns

	Work Concerns OR (95per cent CI)	**p**
Age	0.99 [0.96 – 1.02]	0.66
Gender[a]	0.69 [0.36 – 1.32]	0.26
Education[b]	2.55 [1.20 – 5.43]	0.02
Location[c]	0.91 [0.49 – 1.69]	0.77
Time - last tx[d]	1.31 [0.68 – 2.50]	0.42

OR = odds ratio; CI = confidence interval; *p* significance level

[a] Gender: Males = 1 and Female = 0

[b] Education: University/Trade or Technical Certificate = 1 and High School and lower = 0

[c] Location: Major City Centres = 1 and Inner/Outer Regional = 0

[d] Time since last treatment: ≤ 5 years = 1 and >5 years = 0

Table 5. Predictors of financial concerns

	Financial Concerns OR (95per cent CI)	**p**
Age	0.95 [0.94 – 0.97]	0.001
Gender[a]	0.86 [0.61 – 1.21]	0.38
Education[b]	0.70 [0.49 – 0.98]	0.04
Location[c]	1.07 [0.77 – 1.49]	0.67
Time - last tx[d]	1.24 [0.89 – 1.74]	0.20

OR = odds ratio; CI = confidence interval; *p* significance level

[a] Gender: Males = 1 and Female = 0

[b] Education: University/Trade or Technical Certificate = 1 and High School and lower = 0

[c] Location: Major City Centres = 1 and Inner/Outer Regional = 0

[d] Time since last treatment: ≤ 5 years = 1 and >5 years = 0

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