**SUPPORTIVE INFORMATION**

**SUPPLEMENTARY TABLE 1** Detailed information about measures used

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| Outcome | Measure | Description of scale |
| Survivor or parent-reported health | Experienced treatment-related late effects were indicated on a list of 19 common late effects. | Late effects provided include: Pain, thyroid problems, osteoporosis, sexual problems, fatigue, cardiac problems, lymphoedema, psychological problems, dental problems, hormone problems, vision/hearing problems, pregnancy problems, immunity problems, mobility problems, fertility problems, pulmonary problems, memory or learning difficulties, blood pressure problems and gastrointestinal problems. |
| Treatment intensity  | Intensity of Treatment Rating scale (ITR-3)[1] | Survivor or parent-reported stage of cancer at diagnosis and treatment modalities received was used to categorise survivors into four treatment intensity levels.Level 1: Least Intensive TreatmentsLevel 2: Moderately Intensive TreatmentsLevel 3: Very Intensive TreatmentsLevel 4: Most Intensive Treatments |
| Perceived risk and worry regarding cancer recurrence and developing late effects | Rated on a 5-point scale. | Perceived risk of cancer recurrence and perceived risk of developing future late effects were rated on a 5-point scale (1=‘not at all at risk’, 5=‘a great deal at risk’), grouped for analysis as ‘at no risk’ (answers 1-2) and ‘at risk’ (answers 3-5). Worry regarding the possibility of cancer recurrence and the development of late effects on a 5-point scale (1=‘not at all’, 5=‘a great deal’), grouped for analysis as ‘no worry’ (answers 1-2) and ‘worry’ (answers 3-5).  |
| Health related quality of life (HRQoL) and self or proxy-perceived health | Overall health in the past four weeks was rated on a 6-point scale.Self or proxy-reported perception of survivors’ overall health on the day of survey and HRQoL score was determined using the 5-level EQ-5D (EQ-5D-5L) instrument. | Participants were asked to rate their perception of the survivors’ overall health in the past four weeks on a 6-point scale (1=very poor, 6 =excellent), grouped for analysis as ‘poor’ (answers 1-3) and ‘good’ (answers 4-6).Self or proxy-reported HRQoL score was determined based on five dimensions (mobility, self-care, usual activities, pain/discomfort and anxiety/depression) while self or proxy-reported perception of their overall health on the day of survey was determined using the visual analogue scale (EQ VAS)[2]. EQ-5D-5L health states were measured on a 5-point scale (1=‘no problems’, 5= ‘I am unable to’) and were weighted using England EQ-5D-5L value set[3] to calculate the EQ-5D index value from 0-1 (0=the health state equivalent to dead, 1=the value of full health). Data from the 5-point scale was then dichotomised as ‘no problems’ (answer 1) and ‘any problems’ (answers 2-5). EQ VAS was measured on a 0-100 scale (0=‘The worst health you can imagine’, 100=‘The best health you can imagine’). Since standard value sets for EQ-5D-5L have yet to be published for Australia or New Zealand, these values were compared to a large adult community sample in South Australia which likely reflects Australian norms[4]. The EQ-5D-5L scale was used as it has demonstrated validity and reliability[5]. |
| Healthcare use | Frequency of hospitalisations and reasons for hospitalisation were asked in an open-ended question.Types of health professionals visited by survivors since treatment completion for cancer-related care were indicated on a list of 16 health professionals. Frequency of healthcare professional visits was asked in an open-ended question. | Provided health professionals included oncologist, general practitioner, ears/eyes specialist, dentist, cardiologist, endocrinologist, nurse, surgeon, psychologist, neurologist, social worker, dietician, radiologist, fertility specialist, physiotherapist and geneticist. At analysis, frequency of visits were categorised as ‘infrequent’ if the survivor visited every two-years or less frequently.  |
| Late effect experiences, knowledge, and information needs | Open-ended interview question(s). | Interview schedule1. Some survivors experience late effects after finishing cancer treatment. As you may be aware, late effects can include a range of different physical and emotional conditions that develop as a result of cancer or its treatment. Have you experienced any late effects since finishing your cancer treatment?

If yes: Did you know there was a chance you might experience late effects as a result of your cancer or its treatment? Are you aware of whether you have a low/medium/high risk of experiencing late effects? (probe: how were you informed – written info (from where) /verbally explained (by who), and when (on/off treatment)?)If no: Have you been given any information about late effects? Are you aware of whether you have a low/medium/high risk of experiencing late effects? (probe: how were you informed – written info (from where) /verbally explained (by who), and when (on/off treatment)?)1. Would you like to receive more information specifically about your chance of developing late effects?
2. Do you believe your chance of developing late effects will decrease as time passes, or do you believe your chance will increase as you age?

Due to the semi-structured nature of interviews, every question may not have been asked to every interviewee.  |

**SUPPLEMENTARY TABLE 2** Clinical and demographic factors associated with the total number of experienced late effects.

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| --- | --- | --- | --- |
|  | B | **Univariate**95% CI | *p* |
| Survivor sex\* | -0.44 | -2.9, 2.08 | *0.73* |
| Age of survivor | -0.07 | -0.24, 0.11 | *0.45* |
| Self-reported ethnic background\* | 1.15 | -1.70, 4.00 | *0.42* |
| Religion a\* | 0.32 | -2.04, 2.68  | *0.78* |
| Area of residence\* | -0.51 | -3.56, 2.54 | *0.74* |
| Education\* | -0.39 | -2.84, 2.06 | *0.75* |
| Income\* | -0.90 | -3.56, 1.77 | *0.50* |
| Employed | **-2.70** | **-5.37, -0.03** | ***0.05*** |
| Married/de-facto | -0.98 | -3.41, 1.45 | *0.42* |
| Age (months) at diagnosis | -0.004 | -0.04, 0.04 | *0.85* |
| Era of diagnosis (based on treatment regimen)\* | -0.87 | -3.52, 1.77 | *0.51* |
| Level of risk\* | **3.69** | **0.23, 7.16** | ***0.04*** |
| Treatment received b |  |  |  |
|  Chemotherapy | **3.44** | **-0.28, 7.15** | ***0.07*** |
|  Radiotherapy | **4.00** | **1.78, 6.23** | ***0.001*** |
|  Bone marrow transplant | **4.59** | **2.67, 6.51** | ***<0.001*** |
| Treatment intensity (according to ITR-3)\* | 2.39 | -1.56, 6.33 | *0.23* |
| Years since diagnosis | -0.03 | -0.23, 0.16 | *0.73* |
| Attendance at Survivorship clinic | **2.95** | **0.60, 5.31** | ***0.02*** |
| Self-reported overall health | **-4.68** | **-7.36, -2.00** | ***0.001*** |
| Quality of life index | -7.90 | -16.25, 0.46 | *0.06* |

a Buddhism was not included in the analysis as it was endorsed by only 1 participant.

b Surgery was not included in the analysis as only 3 participants endorsed the ‘No’ category.

\*Survivor sex was coded as 0=Male (reference category) and 1=Female. Self-reported ethnic background was coded as 0=Australian/New Zealander (reference category) and 1=Not Australian/New Zealander. Religion was coded as 0=No religion (reference category), 1=Christian. Area of residence was according to Area of Remoteness Index Australia (ARIA) classifications; and coded as 0=Metro area (reference category) and 1=Regional or remote area. Education was coded as 0=High school only or apprenticeship (reference category) and 1=Post school education including TAFE/university. Income was coded as 0=Annual income less than AUD$60,000 (reference category) and 1=Annual income more than AUD$60,000. Era of diagnosis was coded as 0 = <1974, 1=1974-2004, 2= >2005. Level of risk was coded as Low-intermediate risk=0 (reference category), High risk=1. Treatment intensity (according to ITR-3) was coded as Levels 1-2=0 (reference category), Levels 3-4=1. Self-reported overall health was coded as very poor=0 (reference category), good=1.

Abbreviations: ITR, Intensity of treatment rating scale.

**SUPPLEMENTARY TABLE 3** Illustrative quotations from interviews with survivors (or their parents) of survivors' perceived risk of developing late effects, their experiences and knowledge of late effects, and information needs

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| --- | --- |
| **Theme** | **Illustrative quotations** |
| **Perceived risk of developing late effects over time** |
| Increasing risk | “I'd probably, I'd say a higher chance maybe compared to others. I don't know.” (Father of survivor aged 8)“I believe that he has a high chance of increasing. Not only because of what he's been through but also because of my family with cancer.” (Mother of survivor aged 13)“Unfortunately increase in terms of other cancers developing and the consequence of treatment for the other cancers. We have breast cancer possibly in our family…and leukemia, all kinds of cancers that you run a bigger risk of.” (Mother of survivor aged 14 years)“It's hard to say because [name of child] is amazing at dealing with things but I do wonder if it may increase as she deals with things like not having children when everyone else is” (Mother of survivor aged 13 years)“I think it could increase, yeah. Just because, yeah we don't know if that affected fertility or not.” (Female survivor aged 16 years) |
| Decreasing risk | “I'd say it would decrease. But I might be wrong, I don't know.” (Father of survivor aged 8 years)“I do think eventually my scoliosis may cause things, like, you know, problems, when I get extremely old. But in terms of anything else, not really.” (Female survivor aged 23 years) |
| Unsure  | “Look I think, I don't know. But I think I've got a well-adjusted 17-year-old. I couldn't be happier with his mental state.” (Mother of survivor aged 17 years) |
| **The impact of late effects** |
| Notable impact | Physical impact | “He’s been left with a very ulcerated bowel that he hasn’t had a normal bowel movement since…he does have problems with that.” (Mother of survivor aged 11 years)“She has difficulty in doing physical exercise…there was some nerve damage to her legs that she finds it hard to run. She's overcome it but it's not easy… and she does find that she gets puffed very easily and gets tired and fatigued.” (Mother of survivor aged 13 years) |
| Emotional impact | “He went through some funny mood swings…I think kids may have taken advantage of that gave him a bit of a hard time…because he was smaller.” (Mother of survivor aged 16 years)“Emotionally, he does get a bit angry sometimes. I think his scars kind of affect him emotionally. The first time I ever saw him click …he stood there and he got quite tearful…because I think he actually was old enough to realise, wow, this is something pretty major.” (Father of survivor aged 13 years)“She's got ovarian failure in the other one, so that's been quite a major for her. That's where probably the emotional side came for her is around going through puberty and having to have drugs to do so and having to choose to have her period as opposed to it just happening. That's not been so much fun for her.” (Mother of survivor aged 13 years)“She had a lot of distress and she coped with it by disassociating. I think she still does it a bit now.” (Mother of survivor aged 14 years)“I mean the conscious memories that I've got, the ones that are very vivid are often things where I was very very fearful…I developed a very very severe fear to injections…as soon as I lie down I burst into tears…I now suffer from depression and anxiety. So I think that it's a combination of both the cancer itself but more importantly because of all the side effects and things often having surgery…it still to this day does cause issues in the way of how I bond with my family.” (Female survivor aged 19 years) |
| Minimal impact | “It’s only like a mild scoliosis and it hasn’t affected me throughout my life in any way, pretty much” (Female survivor aged 23 years)“High frequency hearing loss…I mean it's not really a biggie, it doesn't have a big impact on me or anything.” (Female survivor aged 16 years) |
| **Knowledge of late effects** |
| No knowledge or minimal knowledge | “I don't know whether it's just that we got told that it may come back later, and that was sort of it.” (Father of survivor aged 8)“His adult teeth are smaller than his children's teeth but again you say well that was his teeth, it was done all on his tummy...” (Mother of survivor aged 13)“He's quite a bit smaller than his peers. We think some of that is do with the radiation, I think.” (Mother of survivor aged 16)(When asked whether they had heard of the term ‘late effects’) “Not really.” (Mother of survivor aged 16)“Were you ever given like an indication of whether he had, say, a low, medium or high risk of experiencing late effects? I don't recall ever being really told.” (Mother of survivor aged 16) |
| Unaware of some late effects experienced | “We knew the prognosis wasn’t great, so um I certainly was aware. I wasn’t aware of his teeth I’ve got to say.” (Mother of survivor aged 11)“I think the only thing that they were kind of not told… just me being short.” (Female survivor aged 19 years) |
| **Information needs** |
| Adequacy of information given | Enough information given | “There's more than enough information. It's the old story of the facts and who can tell the facts what's going to happen 10 years down the track…It's just a wide unknown” (Mother of survivor aged 13) |
| Too much information may induce anxiety | “The problem with that is that we read this information, it scares us and also we are not educated… it’s sort of a two-edged sword because I obviously want to be informed about what possibly is around the corner and what to look out for, but at the same time, I have struggled terribly with anxiety” (Mother of survivor aged 11) |
| Nature of information needed | Personalised | “…more of an access for an information site that's Australian based. A lot of the sites that we go to are American…it's all go to see this doctor in this hospital. But if they're in America there's no way we're going over there… If possible WA based so that you can say okay, I need to go to this department of this area.” (Mother of survivor aged 13)“Only if it was relevant to [name of child]’s cancer.” (Mother of survivor aged 13) |
| Up to date  | “…being updated regularly. I guess there is a lot of information out there that is outdated.” (Mother of survivor aged 13)“Every now and then I'll go and have a look and see what is new, only because we've been told at the current point that [name of child] finished treatment that there was nothing more that they knew they could do if the cancer returns.” (Mother of survivor aged 13) |
| Lifestyle focus | “We’d like to know factors like diet… you know if someone were to say to me tomorrow…by managing his sugar uptake and dietary factors today, you are reducing a risk of diabetes by you know 70% into the future… that would be wonderful to know and we could add a quality of life to that person into the future.” (Father of survivor aged 8)“I think he needs to know things like smoking and what he eats… say going out and doing sort of social party drugs, smoking with his friends…it'd be great for a young guy of his age to sit down with some people who've said, hey this would be a really bad idea if you were to do that…rather than hearing it from parents.” (Father of survivor aged 13) |
| Warning signs for late effects development or cancer recurrence | “The concerns of it coming back as another type of cancer or something like that…more what to look out for…it's been a while since we dealt with all of the issues to start with. But what to look out for if it was something coming back.” (Father of survivor aged 8) |

**SUPPLEMENTARY FIGURE 1** Types of health professionals survivors or parents reported that survivors had visited for cancer-related care since treatment completion.

Abbreviations: GP, general practitioner.

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