

# Why aren't we 'measuring what matters to cancer survivors' in Australia?

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## Introduction

Despite **around one million cancer survivors living in Australia today, very little is known about our 'survivorship' experience and what happens in the interval between cancer diagnosis and death.**

As survivor advocates we highlight mismatches between the:

- **priorities and concerns of post-treatment survivors** versus the narrow clinical focus of the healthcare system;
- and
- **limited data collected, collated and analysed to monitor survivors' care and outcomes in Australia,** versus the level of survivorship analysis undertaken in other countries such as USA and UK.

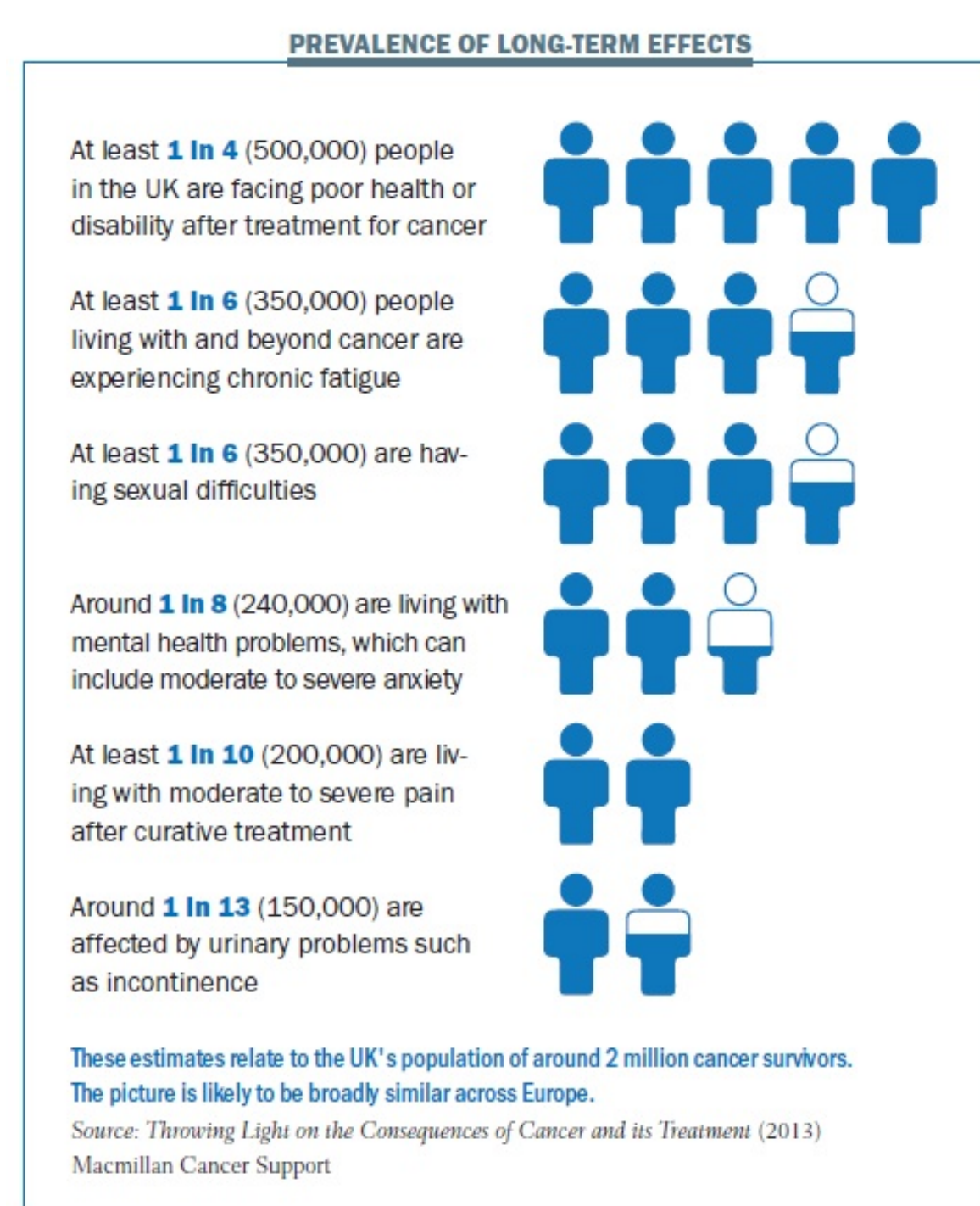
Survivor advocates are concerned about broader issues of the 'survivorship' population as well as individual cancer survivors' perspectives. We consider survivorship spans from the time of a cancer diagnosis for the rest of our life.

## Background

Data from the USA and UK show that **25-30% of cancer survivors**

- **are in poor health or disabled,**
- **unable to return to work or**
- **have limitations in cognitive, mental and physical functioning and psychological distress (1,2,3);**

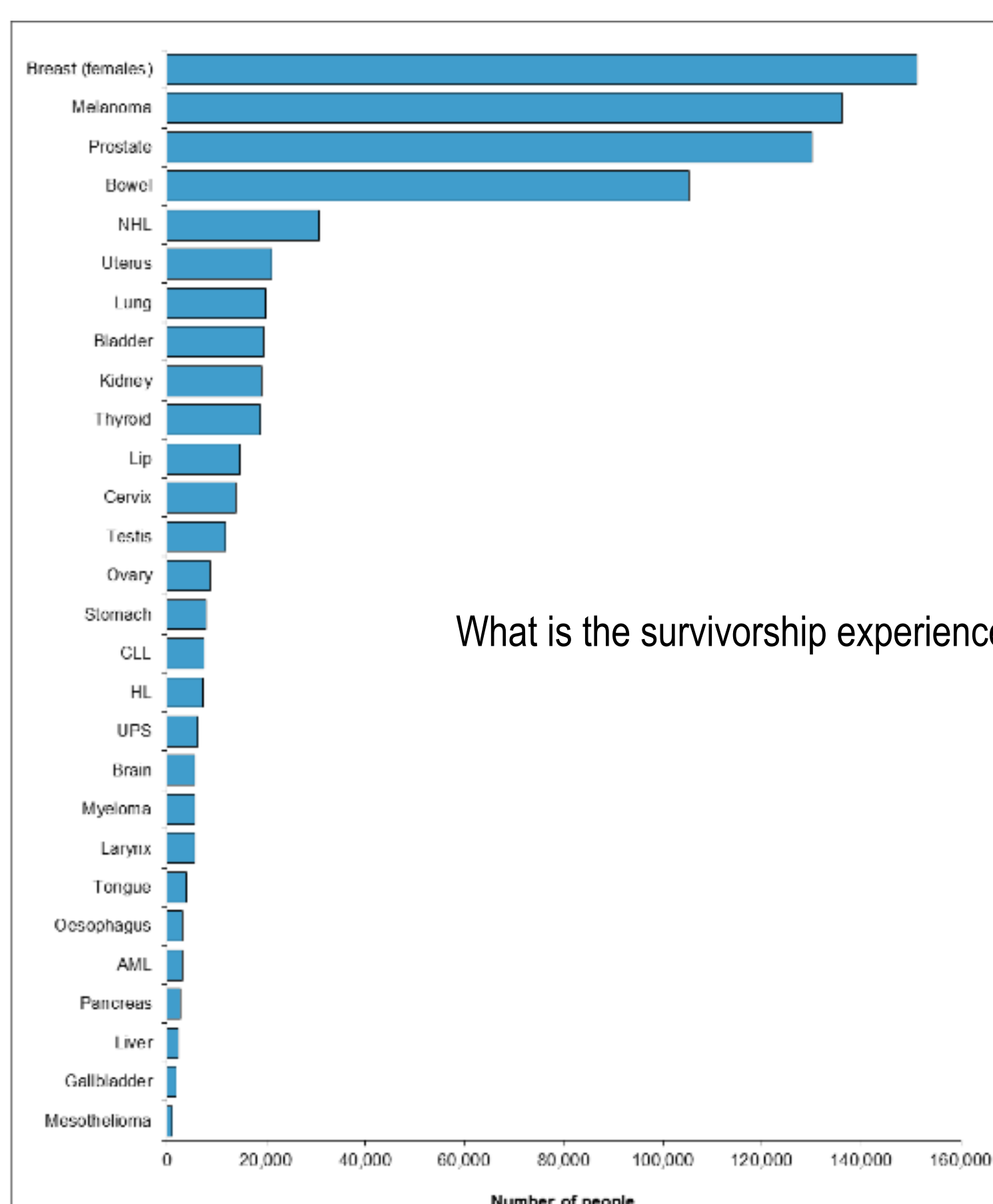
What is the situation in Australia?



prevalence in Australia?

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From the Australian Institute of Health and Welfare (AIHW), we know approximately how many survivors of different types of cancer ... but not a lot more detail about the quality of life they experience.



What is the survivorship experience of these survivors?

## What matters to survivors?

Fellow cancer survivor advocates were asked to identify and rank the 'front of mind' survivorship priorities or concerns, from their experience.

The data required to answer these questions were then sought in open access sources to determine if this was available for cancer survivors in Australia, the UK or US.

This is a pragmatic review from survivors perspectives.

Table 1. Data on priorities & concerns of post treatment **cancer survivors.**

Questions	Data & analysis	Is this data recorded in		
		Australia	UK	US
<b>Priorities/ concerns of Cancer Survivors</b>	<b>National data needed to answer the questions</b>			
Will the cancer come back?	% who have a cancer recurrence, progression to metastases - by stage at diagnosis	✘	✓	✓
Risk of relapse -how soon, how long at risk?	Time to recurrence or progression	✘	✓	
Where would it come back, how would I know?	Location of recurrences, metastases; Screening/ follow-up monitoring	✘	✓	
Financial toxicity, \$ cost of cancer *	% who return to work or usual activities; Cost eg. loss of income, out of pocket costs	✘	✓	✓
How to overcome the cancer/ treatment effects eg fatigue, fear, chemo-brain, anger, grief, lymphedema, incontinence, impotence...	What are the challenges for survivors: physical, emotional? Who, how many are suffering or doing well?	✘	?	✓
How to get life back on track at home, work, relationships, finances; get & stay well – exercise, nutrition	What are the practical challenges . Who, how many are suffering or doing well?	✘	✓	✓
The impact on carers; Caregiver issues	What are the challenges for carers: physical, emotional, practical?	✘	?	✓
What rehabilitation services are needed & available?	What rehab services, who refers & outcomes	✘	?	✓
My chances of survival from here?	Conditional survival eg after surviving 1, 5, 10yrs	✓	?	?
Risk of other cancers? Where?	Second/subsequent primary cancer	✓	✓	✓
Risk of other problems, chronic disease because of cancer or treatments?	Long term treatment consequences, Late effects, comorbidities	✘	✓	✓

- Survivors experiencing financial toxicity ranked this as their 2<sup>nd</sup> highest concern or priority, as it affected almost everything else. For others, this was not such a high priority.

Table 2. Data on **advocates questions** about the 'survivorship' population.

Questions	Data & analysis	Is this data recorded in		
		Australia	UK	US
<b>From survivor advocates perspective</b>	<b>National data needed to answer the questions</b>			
<b>Disparities by stage at diagnosis, socioeconomic status, geographical location, age, racial/ethnicity ...</b>	Survivorship outcomes by cancer type, <b>stage at diagnosis</b> , demographic details	✘	?	✓
Long term outcomes of treatments	Outcomes by stage at diagnosis, treatments delivered,	✘	✓	?
Quality of Life?	Quality of Life measures, Patient Reported Outcome Measures	✘	✘	✘
Outcomes by genetic & lifestyle factors: obesity, smoking, nutrition, physical activity	Associations with lifestyle factors, Genetic testing - data, monitoring,	✘	?	✓**
Availability of rehabilitation services?	What services, who refers & what outcomes	✘	?	✓
Financial toxicity, \$ cost of cancer, burden & disparities	What is the cost of cancer - burden & disparities	✘	✓	✓
Caregiver issues	Disparities in challenges for carers: physical, emotional, practical?	✘	?	✓

\*\* US National Health interview study 2000-2008: 40% of cancer survivors 18-44yrs are current smokers compared to 24% of the general population.

## Conclusions

Limited data is accessible to address survivors 'front of mind' concerns ie. how we live our life and maintain functions within our social environment.

We don't know the characteristics of who, when, where experiences

- financial toxicity
- long-term cancer or treatment impacts:
  - physical (eg pain, fatigue, impotence, incontinence, lymphoedema.),
  - emotional (eg anxiety, relationship breakdown, disfigurement)
  - practical (eg financial, work concerns);
- cancer recurrences;
- caregiver issues
- the need or impact of rehabilitation or support services;
- the impact of lifestyle factors on survivorship
- the presence and/or development of comorbidities.

We don't really know how effective the current followup process is to detect recurrence or progression, address priority concerns of survivors (let alone carers) or the impact of followup regimes on outcomes.

Survivor advocates also care about outcome disparities and vulnerable groups eg. cultural, socioeconomic, regional, age, gender, sexuality, cancer type, stage, treatment, access to care and other diversity.

## Recommendations

**Consumers, clinicians, researchers, policymakers and health-economists need to work together to determine succinct and meaningful measures for monitoring cancer survivors in Australia,** across all domains of health care, community care and social spheres.

**Survivor reported outcomes should be collected and collated not just as population surveys but should also be used at 'point of care' to inform personalised follow-up survivorship care.**

Survivor reported outcomes should be integrated with social wellbeing needs.

**Measures adopted in Australia must enable national and international comparisons of survivorship outcomes, including social wellbeing factors, and monitor changes across cancer types and health care sectors.**

**We need better data about cancer survivors.** About one million cancer survivors are living in Australia today, and very little is known about our 'survivorship' experience.

"With the number of cancer survivors expected to increase by more than 30 percent in the next decade, medical and public health professionals must be diligent in their efforts to help reduce the burden of cancer on survivors and their families"(1)

## References

- References:**
- 1 Ekwueme DU et al. Medical Costs and Productivity Losses of Cancer Survivors. Oncology Times Oct 2014 [http://journals.lww.com/oncology-times/Fulltext/2014/10100/Cancer\\_Related\\_News\\_from\\_the\\_CDC\\_Medical\\_Costs\\_26.aspx](http://journals.lww.com/oncology-times/Fulltext/2014/10100/Cancer_Related_News_from_the_CDC_Medical_Costs_26.aspx)
  - 2 Macmillan Cancer Support UK . Throwing light on the consequences of cancer and its treatment. 2013 <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Throwinglightontheconsequencesofcanceranditsreport.pdf>
  - 3 MacMillan Cancer Support UK. Routes from Diagnosis 2014 <http://www.macmillan.org.uk/Documents/AboutUs/Research/Researchandevaluationreports/Routes-from-diagnosis-report.pdf>

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Survivorship Conference, 6-7 Feb 2015 in Adelaide.