

Research on cancer survivorship in Australia

Current status, gaps and needs

Agnès Vitry, Julie Marker

Cancer survivorship research is important for understanding and interpreting the heterogeneity of cancer survivors and their survivorship care needs:

- cancer is a **heterogeneous set of diseases** with varied treatments and toxicities;
- cancer treatments themselves are evolving rapidly, and hence the chronic and late consequences constantly need identification and monitoring
- during **different phases of care**: active curative treatment, disease-free, chronic treatment, end-of-life care
- at **various ages and stages of life**: children, adolescents and young adults, middle-age and older adults, parents with young children

This overview of recent cancer survivorship research literature highlights the current status, gaps and needs around objectives, data collection and analysis.

Three key research areas

Epidemiology of cancer survivorship

We have

- National epidemiological statistics on cancer prevalence and incidence
- Patchy, one-off surveys on needs and survival disparities

We need

- Synthesis and in-depth analysis of available data
- National, longitudinal data on mental, physical and psychosocial care needs of **cancer survivors and families**

Current health care practices

We have

- A limited number of studies examining current health care practices using
- self-report surveys,
 - clinical registries,
 - PBS data
 - linked datasets

We need

- More studies on
- **health outcomes, costs and long-term adverse effects** of cancer treatments in the Australian setting,
 - compliance with clinical guidelines and quality use of cancer medicines
 - equity and quality of care **across public and private** sectors
 - **coordination of care** between hospital and community sectors

Interventions that improve health and quality of life of survivors

We have

- Limited research on the development and evaluation of interventions to improve health and quality of life e.g. telemedicine model of care, rehabilitation services

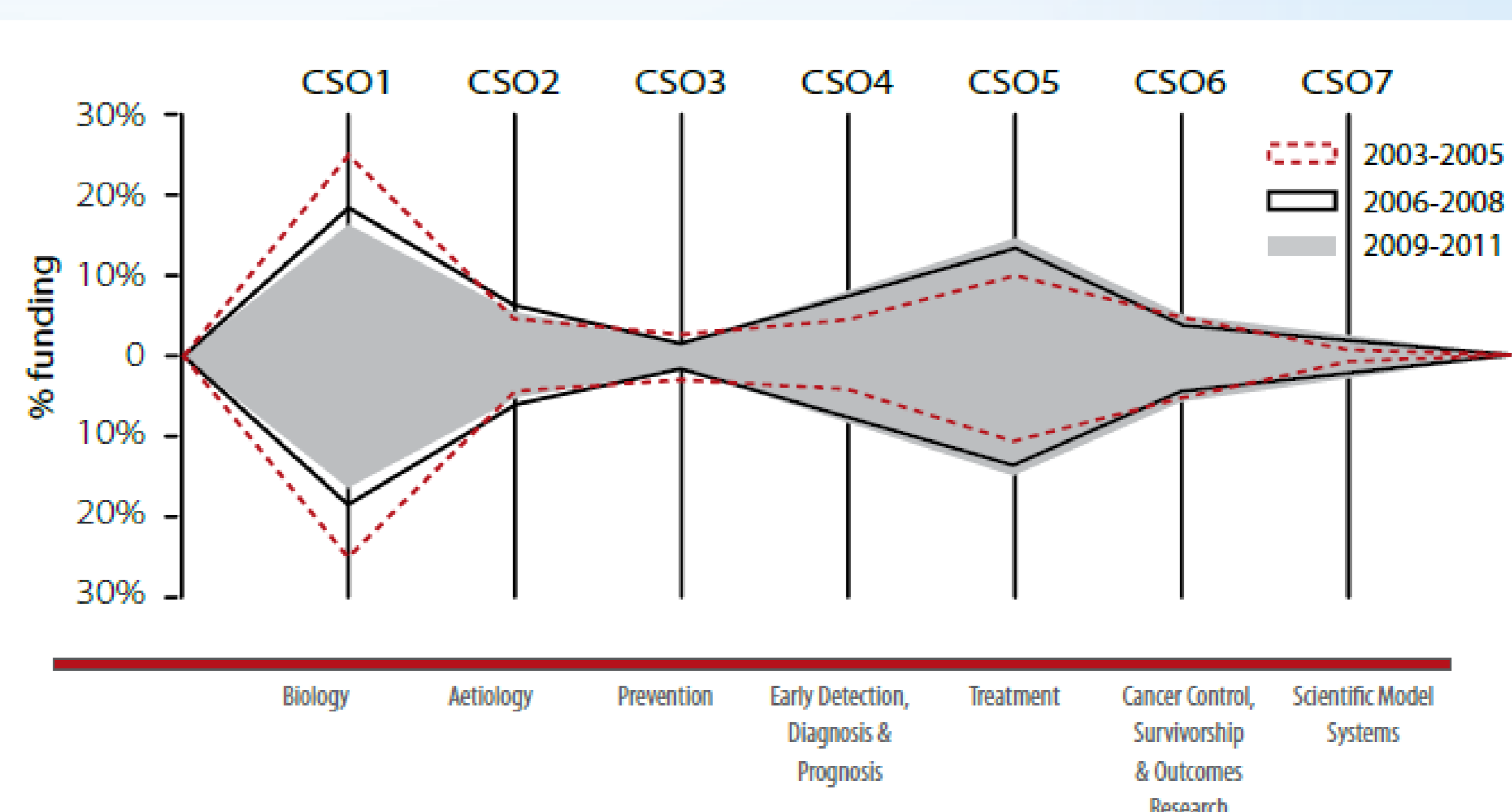
We need

- Routine data collection and evaluation
- Mapping of risk-stratified care management pathways and quality indicators (e.g. quality of life, return to work and availability of cancer rehabilitation services)
- **National strategy for achieving high quality cancer survivorship care**
- Development of policies and services on how to best address the long-term challenges of cancer survivors in their health care

Funding for survivorship research

Funding is a major challenge, limiting the quality and quantity of survivorship research. Outcomes may need monitoring for long durations, with lifestyle and chronic disease comorbidity interactions accounted for. We need also Better access to publicly-funded data for health research.

In 2009-2011, **only 9 % of funded research in Australia focused on cancer control, survivorship and outcomes research.**



Ref: Cancer Australia 2014 Cancer research in Australia. An overview of funding to cancer research projects and research programs in Australia 2006 to 2011.