

Developing a Cancer Survivorship Monitoring System for South Australia

research prevention support

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Research Team

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Presentation Overview

- National Age Profile
 - Cancer Statistics Nationally and for the State
 - Variations in Health Outcomes
 - Cancer Survivorship Monitoring
 - Establishing a survivorship monitoring system for SA
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National Age Profile Predictions

Between 1982-2013:
number of people > 60 years of age has doubled from 2 million to 4.5 million

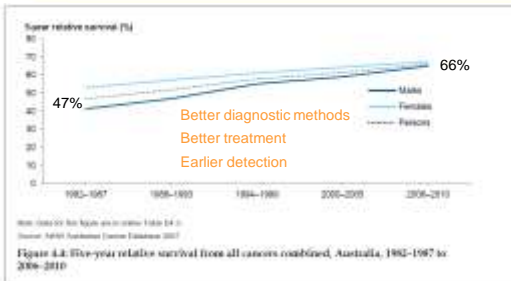
Estimated to be:
5.5 million in 2020.



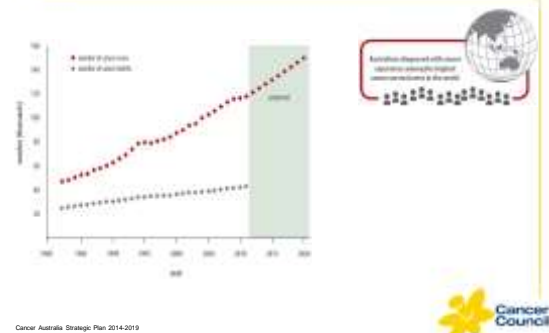
Cancer Australia Strategic Plan 2014-2019



More people surviving cancer



More People Living with Cancer



Variations in outcomes



About 1/3 of people affected by cancer live in non-metropolitan areas. Mortality rates are higher for those in remote areas.



Cancer incidence and mortality rates are higher for those living in lower socioeconomic status areas than those in higher.



Aboriginal and Torres Strait Islander (ATSI) peoples are 6% more likely to be diagnosed with cancer and 50% more likely to die from cancer than non-ATSI Australians.

We know the statistics but don't monitor psychosocial needs at a population level



How many does this impact in SA?



1 in 2 Australians will be diagnosed with cancer by the age of 85.
28% of all deaths in South Australia are due to Cancer.
In 2013 there was a total of 51,000 people with Cancer in SA

Cancer Registry, 2014



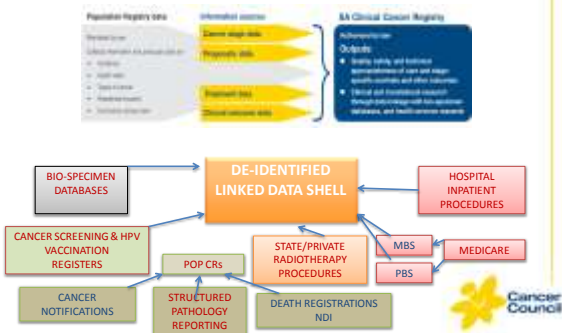
How does Cancer Council SA currently support survivors?



Activities in cancer support across domains of unmet needs



Cancer Registry Data in SA



Gap in Monitoring Cancer Survival

There is NO Patient Reported Outcome (PRO) monitoring tool that measures a comprehensive range of physical and psychosocial outcomes with no agreed minimum dataset for survivorship in Australia at a population level.

- ◆ Quality of life
- ◆ Co-morbidities before and after Cancer diagnosis
- ◆ Psychological distress
- ◆ Utilisation of health care services
- ◆ Treatment satisfaction
- ◆ Understanding the patients experience



NHMRC Partnership Grant:
Cancer Data and Aboriginal Disparities (CanDAD)

Background:

Plan to develop an advanced data system for describing cancer stage, co-morbidity, clinical management and outcomes of Aboriginal People with cancer in SA and then monitor progress and serve as an exemplar.

Next stage:

Develop and pilot test a methodology for gathering qualitative data around access cultural safety and patients perspectives of their care. Plan is to link the narratives to health outcome data.



Why is Monitor important?

- ✓There is no mechanisms for collecting survivorship data in SA at a population level
- ✓Identify gaps in services
- ✓Identify high risk groups
- ✓Challenge Assumptions
- ✓Inform support services
- ✓Inform clinicians
- ✓Inform Policy makers
- ✓Monitor impact of changes of health service or support service delivery on the consumer
- ✓Drive research into improving psychosocial outcomes
- ✓Inform Advocacy strategy
- ✓Targeted communication planning



FCIC Pilot Study

Study aim

- To determine acceptability and feasibility of collecting information from people about their experiences following cancer treatment.

Method

- Survivors recruited via Survivorship Clinic (over 6 months)
- Completed treatment with curative intent
- Initial survey + survey at 12 months



Review of international models



Existing registries



Set up, processes and governance



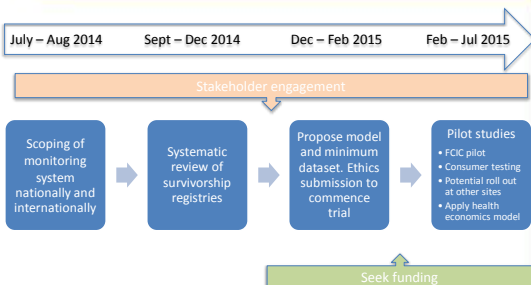
Minimum datasets



Data linkage



Project Plan: Phase I



Stakeholder engagement

Key stakeholders

- Clinicians
- Policy makers
- Cancer Registry
- Researchers
- Consumers



Existing relationships with key stakeholders



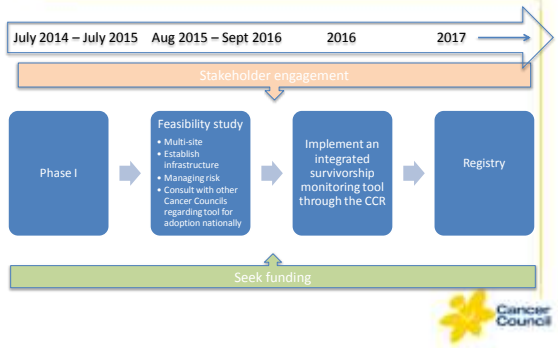
FCIC Pilot Study

Data Analyses

- What % of eligible patients take part initially?
- What % are retained at follow-up?
- Feedback on the survey (questions, online vs paper preferences, how often willing to complete surveys?)
- Quality of the data collected (e.g., missing responses, reliability)



Project Plan: Long-term strategy



Draft Survey

Content area	Measure	Number of items
Health-related Quality of Life	Functional Assessment of Cancer Therapy – General (FACT-G) + Cancer Specific Symptom Indexes	27 items + 7-24 depending on cancer type.
C-morbidities before and after cancer	The Self-administered Co-morbidity Questionnaire	14 items (includes open-ended responses).
Cognitive functioning	The FACT-Cognitive function (version 3) - perceived cognitive impairments subscale	20 items
Psychological distress	K10 Distress Thermometer for Patients	K10 = 10-items 1 item + checklist of possible concerns
Post-traumatic growth	Post-traumatic Growth Inventory – short form (PTGI)	10 items
Utilisation of health care and support services	Questions from PROFILES	5
Wellbeing	Questions from the South Australian Health Monitor Survey	5
Unmet needs	Cancer Survivors Unmet Needs Survey	35
Employment status	Questions from UK Dept Health Longitudinal Study of Cancer Survivors	3
Problems with insurance and loans	Questions from PROFILES	3
Treatment satisfaction	Questions from UK Dept Health Longitudinal Study of Cancer Survivors	4

Summary

- More people surviving cancer but there are many adverse affects
- Quality data is needed to build a greater understanding to inform service delivery and advocacy
- Develop good systems, not just good luck.
- A dedicated registry is the best model to meet this need
- Cancer Council SA is undertaking a program of research and stakeholder engagement to establish a survivorship registry



Thank you

