



PARTNERS:

South Australian Health and Medical
Research Institute (SAHMRI;
CanDAD Host Organisation)

University of South Australia (UniSA;
CanDAD Administration and Finance
Control)

Aboriginal Health Council of South
Australia (AHCSA)

Beat Cancer Project SA (BCPSA)

Breast Screen SA (BSSA)

Cancer Clinical Network (CCN)

Cancer Council SA (CCSA)

SA Department for Health & Ageing
(SA DH&A)

SA NT DataLink

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

Project Summary

The project seeks to develop an integrated, comprehensive cancer monitoring system with a particular focus on Aboriginal people in SA that will integrate cancer registry, hospital, radiotherapy, pharmacy, clinical, screening and health insurance data to comprehensively monitor cancer incidence trends, cancer management and survival. Uniquely, the data system will incorporate Aboriginal patients' experiences with cancer services to guide continuous service improvement, community engagement, advocacy and outcomes research, providing data infrastructure for health services, population research, and for training Aboriginal (and non-Aboriginal) researchers. The purposeful linkage of accurate and complete registry and administrative data alongside narratives of Aboriginal people with cancer will facilitate assessment of existing service quality and appropriateness, secular trends in cancer risk, burden and determinants, will highlight areas of immediate need and provide a robust system for performance monitoring and evaluation.

Aims: The aims of CanDAD are to develop an advanced cancer monitoring system that:

1. Improves cancer diagnosis, treatment and survival among Aboriginal people;
2. Decreases the disparity between Aboriginal and non-Aboriginal peoples' access to cancer prevention, screening and treatment; and
3. Improves the health service experiences of Aboriginal people at risk of, or diagnosed with, cancer.

Objectives: The objectives of CanDAD, across the three distinct elements of the research project, include:

Element I – Improving the quality and completeness of SA cancer data

1. To ensure accurate and comprehensive recording of data for Aboriginal and non-Aboriginal people in SA across a range of cancer, cancer screening, treatment, diagnostic and health service indicators;
2. To establish methods for accurate, complete and sustainable ongoing monitoring of cancer by type of cancer, mode of detection and treatment, and for monitoring outcomes among Aboriginal cancer patients;
3. To assess disparities between Aboriginal and non-Aboriginal South Australians in incidence, mortality, survival, stage, stage adjusted survival, extent of co-morbidity and technical appropriateness of treatment by socio-demographic descriptors

Element II – Exploring Experiences of Cancer Care

4. To develop a comprehensive understanding of patient and provider perspectives on service access, barriers and enablers to care, service quality, acceptability and appropriateness;
5. To develop a brief culturally-sensitive self-report instrument for recording and quantifying Aboriginal cancer patient's satisfaction with system performance that can be deployed as part of routine service delivery;
6. To prioritise service improvements to enhance Aboriginal people's cancer experiences

Element III – Towards a more streamlined and integrated data system

7. To develop a streamlined, integrated data system and linkage infrastructure for monitoring cancer, cancer services and outcomes for guiding health policy.
8. To explore the potential for automated cancer data collation for SA into the future and to collaboratively plan its implementation with partner organisations

These elements will provide data for knowledge translation activities across the partners that will assist in targeting services and service development, improving access to care and for monitoring the impact of health-service initiatives on inequalities.

Background Development for CanDAD

In July 2012 Professor David Roder, Chair in Cancer Epidemiology at UniSA, received ethics approval (AHREC, SA Health HREC and UniSA) to 'Develop an advanced data system for describing cancer stage, co-morbidity, clinical management and outcomes of Aboriginal people with cancer in South Australia'. The proposal also noted future work on monitoring Aboriginal people's experiences with cancer and cancer services. In line with this prediction, in April 2013 ethics approval (AHREC, SA Health HREC and UniSA) was granted, to Professor Alex Brown, Program Leader, Aboriginal Research SAHMRI, to 'Develop and pilot test a methodology for gathering qualitative data around access, cultural safety and patient's perspectives of their care to produce narratives of Aboriginal cancer experience; and to explore the issues and methods around linking the coded narratives to 'health outcome data'. Dr Paul Yerrell was responsible for the application and the consequent management of the work.

The critical target of the parallel, complementary working of these developments was to inform the production of a unique exemplar cancer data system, which incorporates the broader experience of Aboriginal people with cancer in order to monitor and improve systems of care. In recognition of the sensitivities of the topic, both developments included a Steering Committee of mostly Aboriginal stakeholders.

The experiences of those, providing cancer care to Aboriginal people, will also be incorporated. Issues in care, which derive from both the experiences of Aboriginal patients and service providers, pointed to the need for a 'negotiated narrative' of what needs changing and what is feasible to change.

These two pilot projects were planned to run until May/June 2014 and are known as, respectively:

- The Advanced Cancer Data System Pilot (ACaDS); and
- The Aboriginal Cancer Stories Study (ACceSS)

Update on Pilot Work

Advanced Cancer Data System (ACaDS):

Professor David Roder has initiated a range of activities which include:

- Using SA NT DataLink's knowledge and experience from processing multiple datasets to enhance the reporting of Aboriginality within Cancer Registry records
- Identifying Aboriginal cancer cases occurring from 1990 onward and their respective non-Aboriginal controls (matched for diagnostic year, gender, age at diagnosis and cancer type)
- Collating information on the degree of spread for each Aboriginal person's cancer
- Developing a protocol for linking each case and control's Cancer Registry record with other relevant administrative datasets such as hospital admission summaries

The Aboriginal Cancer Stories Study (ACceSS)

Recruitment, through Cancer Care Coordinators, is in progress at Royal Adelaide Hospital and Kanggawodli. Both Aboriginal and non-Aboriginal, male and female interviewers have attended workshop to establish interview protocols.

The vision and the exploration of methodology in these pilots were the foundation of the Partnership Grant Application in April 2013. The Grant was awarded in November 2013...