Establishing the capacity for Indigenous South Australians to benefit from cancer care: Developing and piloting an Advanced Cancer Data System

WARDLIPARINGGA
Aboriginal Research

WORLD INDIGENOUS CANCER CONFERENCE 2016
12th April, 2016

SAHMRI
South Australian Health & Medical Research Institute

CanDAD Project Principals: Professors Alex Brown and David Roder

Today's presenter: David Banham for the CanDAD Aboriginal Community Reference Group and other CanDAD investigators

Acknowledgement of Country

We acknowledge the Turrbal and Yuggera peoples as the traditional custodians of the Brisbane region.

We also pay respect to their Elders past and present.

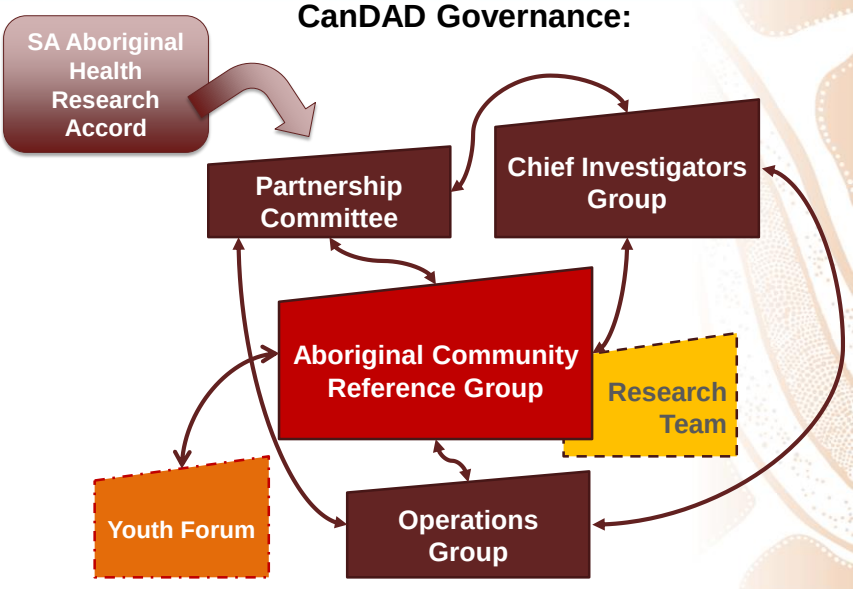
Cancer Data & Aboriginal Disparities (CanDAD)

NHMRC Partnership Project for Better Health (1072243):

- Wardliparingga Aboriginal Research Unit, SAHMRI
- Aboriginal Health Council of SA
- Cancer Council SA
- SA Cancer Services
- Breast Screen SA
- Beat Cancer Project
- SA-NT DataLink
- University of South Australia

Cancer Data & Aboriginal Disparities (CanDAD)

CanDAD Governance:



Cancer Data & Aboriginal Disparities (CanDAD)

AIMS:

Develop and "road test" a cancer data system in SA for Aboriginal people for use in:

- targeting interventions at areas of most acute need and monitor progress; and
- serving as an exemplar data system for other jurisdictions.

Undertake this work with emphasis on governance by Aboriginal people.

OBJECTIVES:

To quantify disparities between Aboriginal and non-Aboriginal Australians in:

- Cancer stage at diagnosis
- Cancer mortality
- Cancer case survival
- Extent of co-morbidity
- Risk-adjusted survivals
- Exposure to screening services
- Treatment completeness and appropriateness.

To assess inequalities in cancer stage, treatment and survivals, and in participation in cancer screening by selected socio-demographic descriptors.

Apply these data to target services, monitor implementation and evaluate effects on inequities.

Cancer narratives

Cancer Narratives

- **Aboriginal People**
- **Service Providers**

>>>>>>>>>>>>>>>>

The Negotiated Narrative:
What works (or not) for whom, in what circumstances, and why?

Realist Synthesis & Evaluation

Enhancing narratives with numbers

Cancer Narratives
- Aboriginal People
- Service Providers

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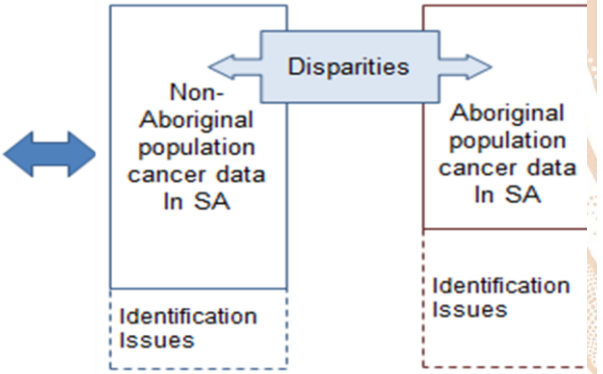
The Negotiated Narrative:
What works (or not) for whom, in what circumstances, and why?

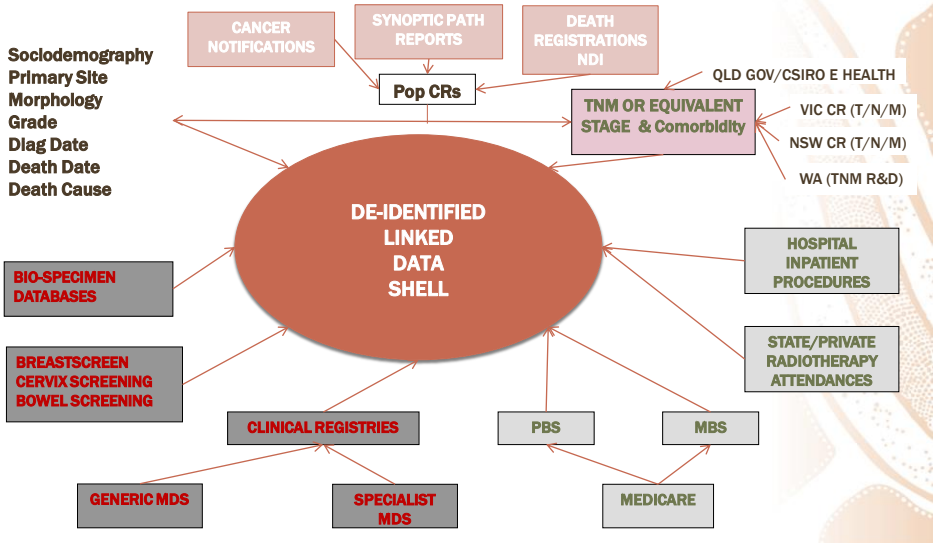
Realist Synthesis & Evaluation

Advanced Cancer Data System (ACaDS)

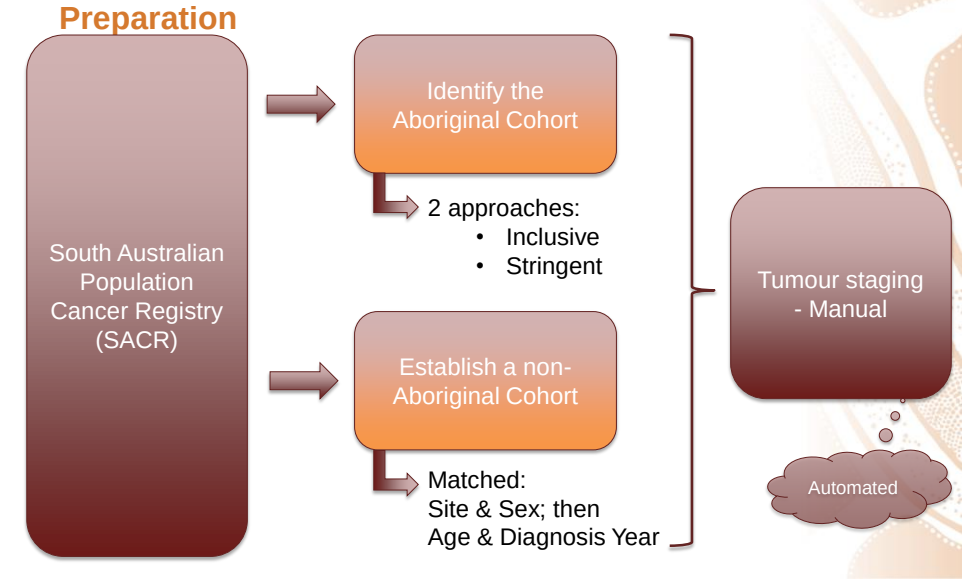


Advanced Cancer Data System Pilot

Linked clinical cancer data: A proposed pathway



ACaDS: What's being done?



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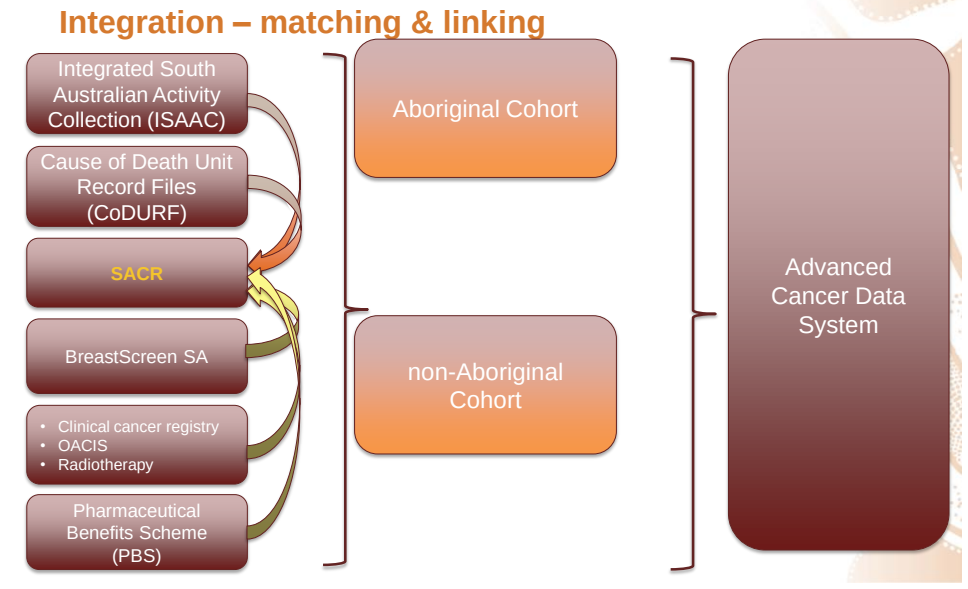
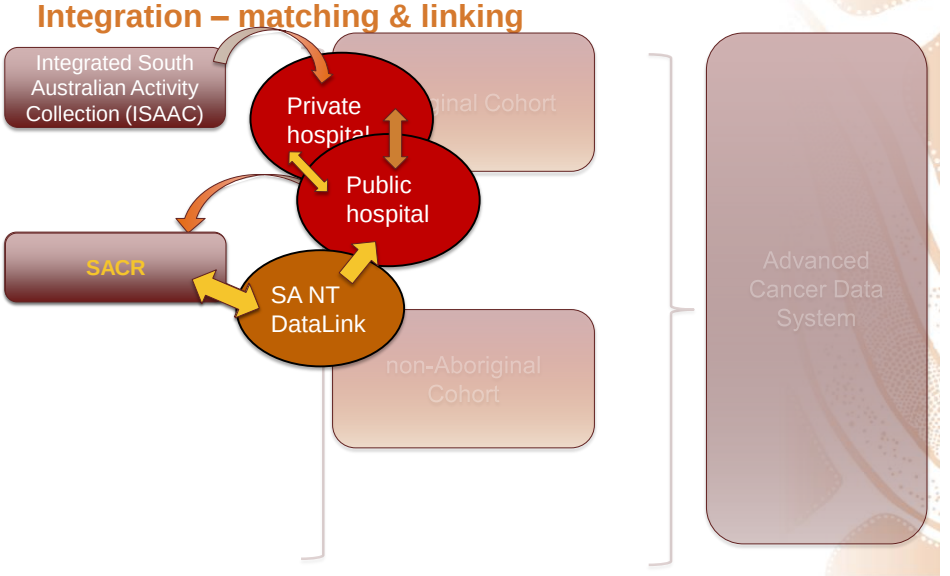


ACaDS: What's being done?

Integration – matching & linking



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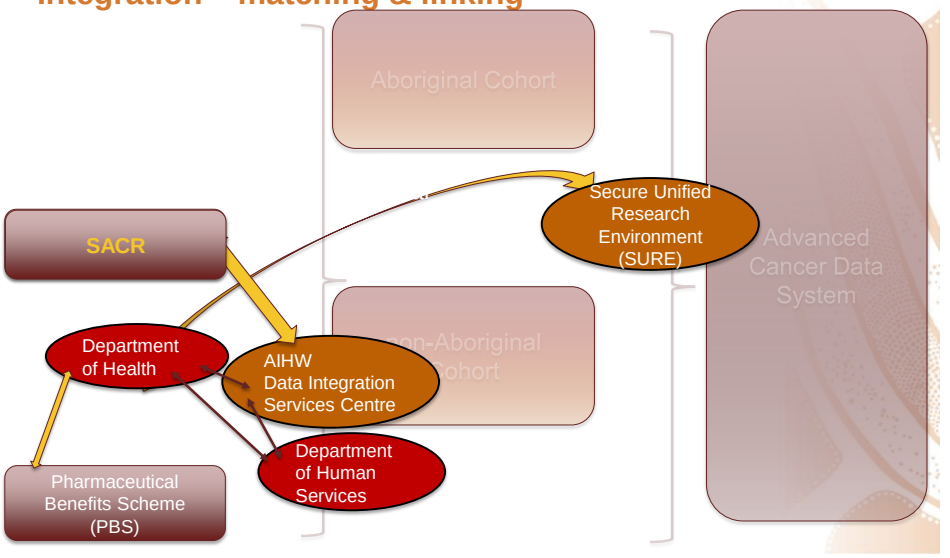
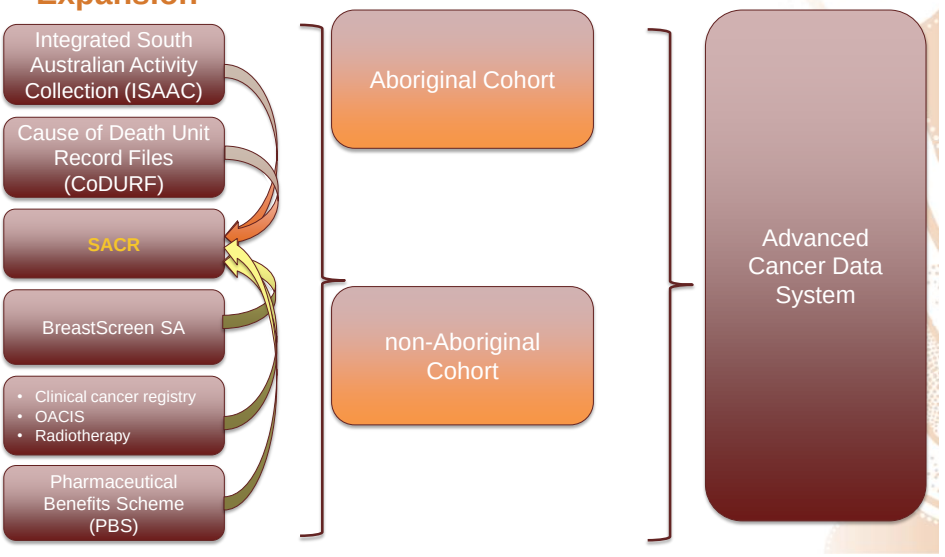


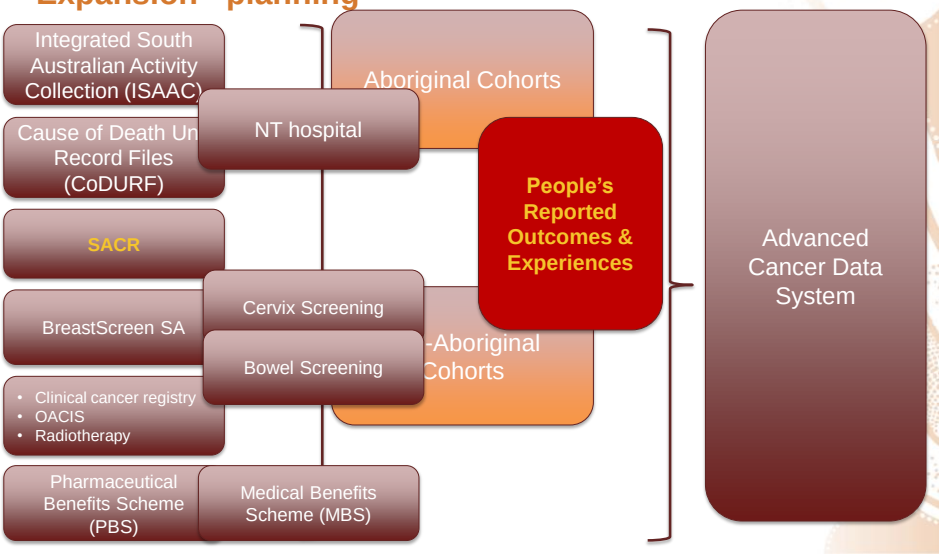
ACaDS: What's being done?

Expansion



ACaDS: What's being done?

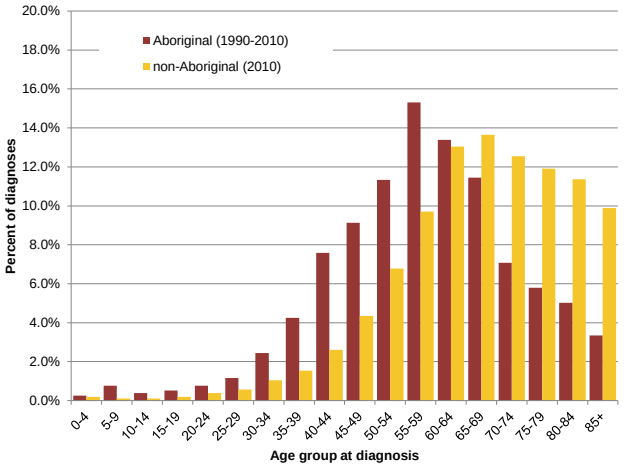
Expansion - planning



ACaDS: What's been learned?

AGE at INCIDENCE

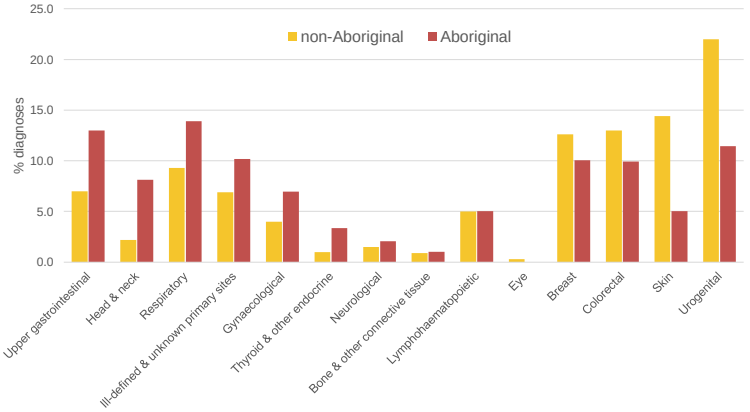
… South Australia



ACaDS: What's been learned?

TYPES OF CANCER

… Clinical grouping by Aboriginality, South Australia 1990-2010



ACaDS: What's been learned?

SURVIVAL AFTER DIAGNOSIS

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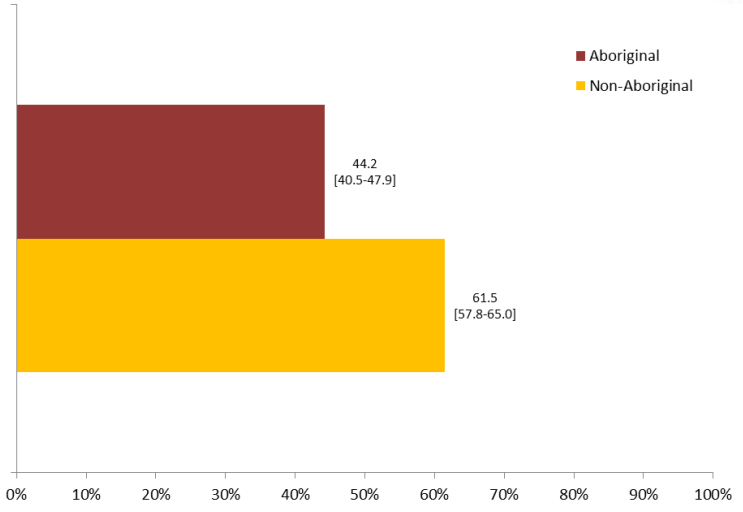
SURVIVAL AFTER DIAGNOSIS



ACaDS: What's been learned?

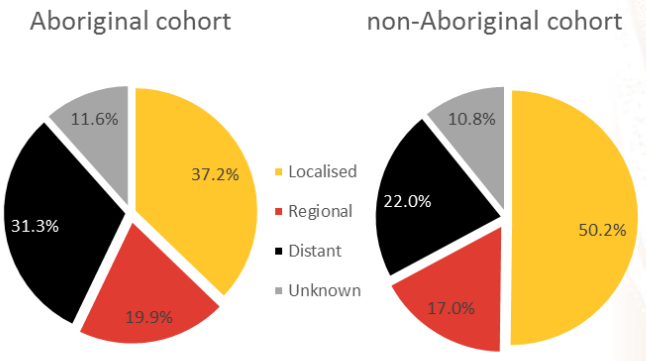
STAGE AT DIAGNOSIS

Localised (to tissue of origin)
Regional (invaded adjacent tissue)
Distant (metastasised or disseminated)
Unknown or Unstageable

ACaDS: What's been learned?

STAGE AT DIAGNOSIS

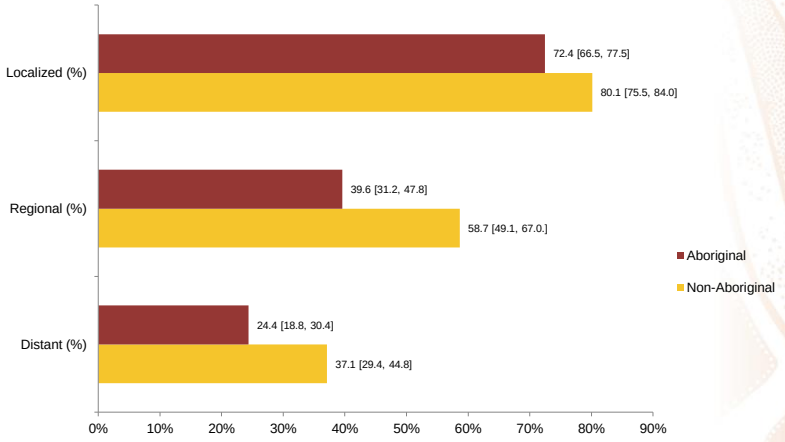
… within cohorts



ACaDS: What's been learned?

SURVIVAL BY STAGE

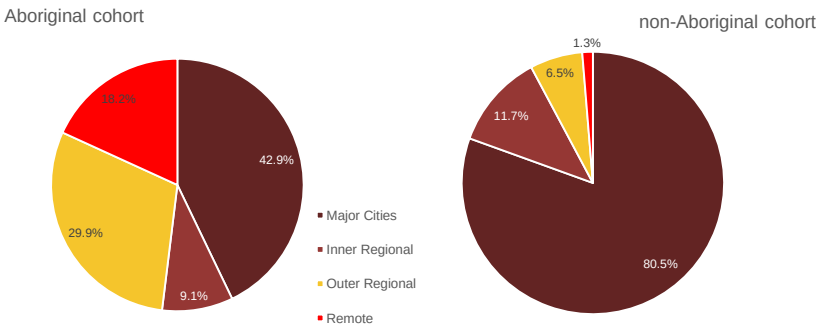
… Five-year crude, disease survival within cohorts



ACaDS: What's been learned?

REMOTENESS

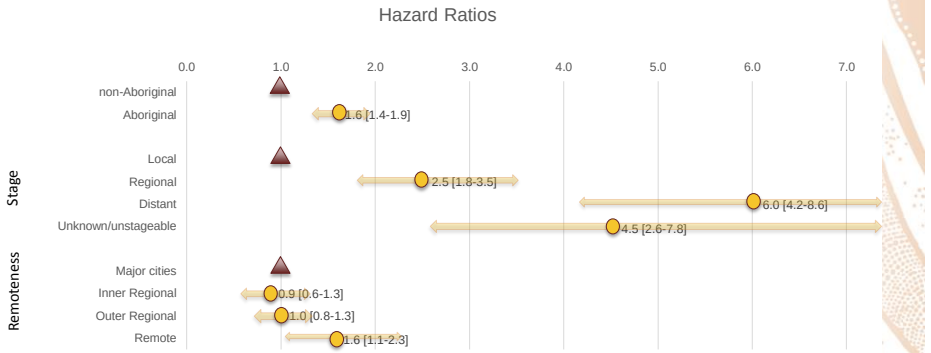
Geographic remoteness at time of breast cancer diagnosis



ACaDS: What's been learned?

SURVIVAL BY STAGE AND REMOTENESS

… Five-year disease survival within cohorts



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SURVIVAL BY STAGE AND REMOTENESS

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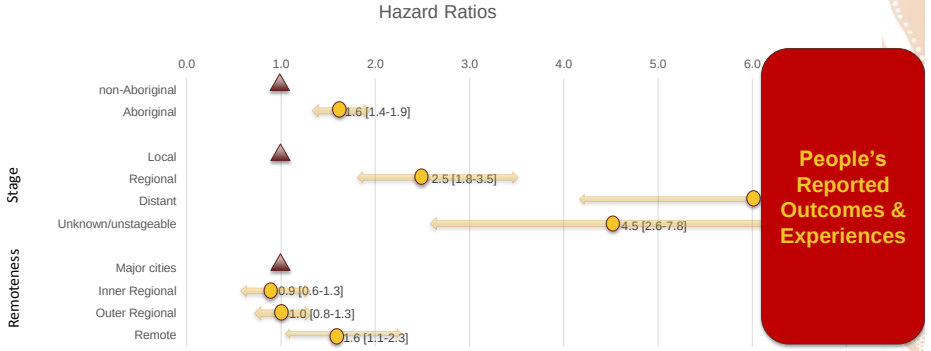

ACaDS: What's been learned?

Continuing learning

ACaDS is:

- ✓ Feasible;
- ✓ Flexible;
- ✓ Expandable;
- ? Sustainable

Important strategies include:

Incorporating sensitivity analyses;

Contribute to a broader knowledge base; &

Aboriginal Community Reference Group & governance

… a critically important sounding board

… referral source &

… partner.

ACaDS: What's yet to be learned?

COMORBIDITIES

TREATMENT

Patterns of care

ACaDS: What to do with it?

INFORM

Community

Planning & Policy

ACaDS: What to do with it?

SYSTEM PERFORMANCE

Monitoring

Evaluation