Closing the Gap in childhood cancer outcomes

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Perth Children's Hospital

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I would like to acknowledge that we are meeting on the traditional lands of the Noongar Nation

I would like to pay my respects to my Elders past, present, and future, and seek their wisdom in the work we do to improve the health of our Kulunga (children)

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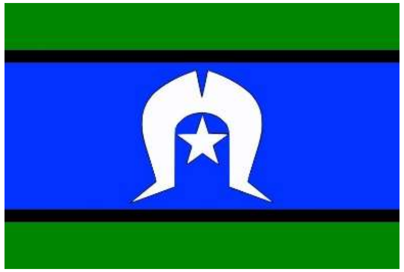
Why research cancer in First Nations children?

- Poorer survival outcomes
- Currently no dedicated research groups
- Very little existing research



Co-designing childhood cancer research with Aboriginal communities

- Consultations and relationship building
- Establish community advisory group
- Ethics applications
- Workshops and interviews
- Co-design a program of research

Community consultations

Perth – South metro – June 2024

Adelaide – July 2024

Perth – Mirrabooka – September 2024

Pilbara

Kimberley

Goldfields

Bunbury

Great Southern

We have consulted with 28 elders, 4 community members and 6 service providers so far

Childhood Cancer Community Advisory Group

- Current membership
  - 2 WA parents with lived experience of childhood cancer
- Who we want to recruit
  - Elders
  - Health care workers
  - Families outside WA
  - Men

What we heard from community

Aboriginal kids experience **worse side effects** from cancer treatment, but we don’t know why. Community members were interested in looking at how **genetics** affects side effects.

Community members were interested in how **traditional medicines** can be used to fight cancer. Any research would need to **protect Aboriginal Culture and Knowledge**

The group was interested in whether **junk food** might be making cancer more common

The group was interested in **cancer and blood samples being stored** in hospitals and laboratories. More **culturally safe** ways of storing and returning samples should be looked at

Community members were concerned about how cancer can be **common in some families,** and are interested in understanding the genetics. Any research would need to **protect Aboriginal genetic data**

What we heard from service providers

The Patient Assistance Transport Scheme in SA is **not culturally appropriate**, and red tape makes coordinating patient care difficult, particularly in patients travelling from the NT.

Hospital-provided accommodation is not able to cater for large extended families

Some **clusters of rare cancer types have been observed**, but it has not been possible to understand whether they are clinically or genetically linked

There are very few culturally appropriate **resources** to explain diagnosis, treatment, and what to expect in hospital

There are very few **Aboriginal and Torres Strait Islander mentors** for junior clinical staff

How can we improve childhood cancer research?

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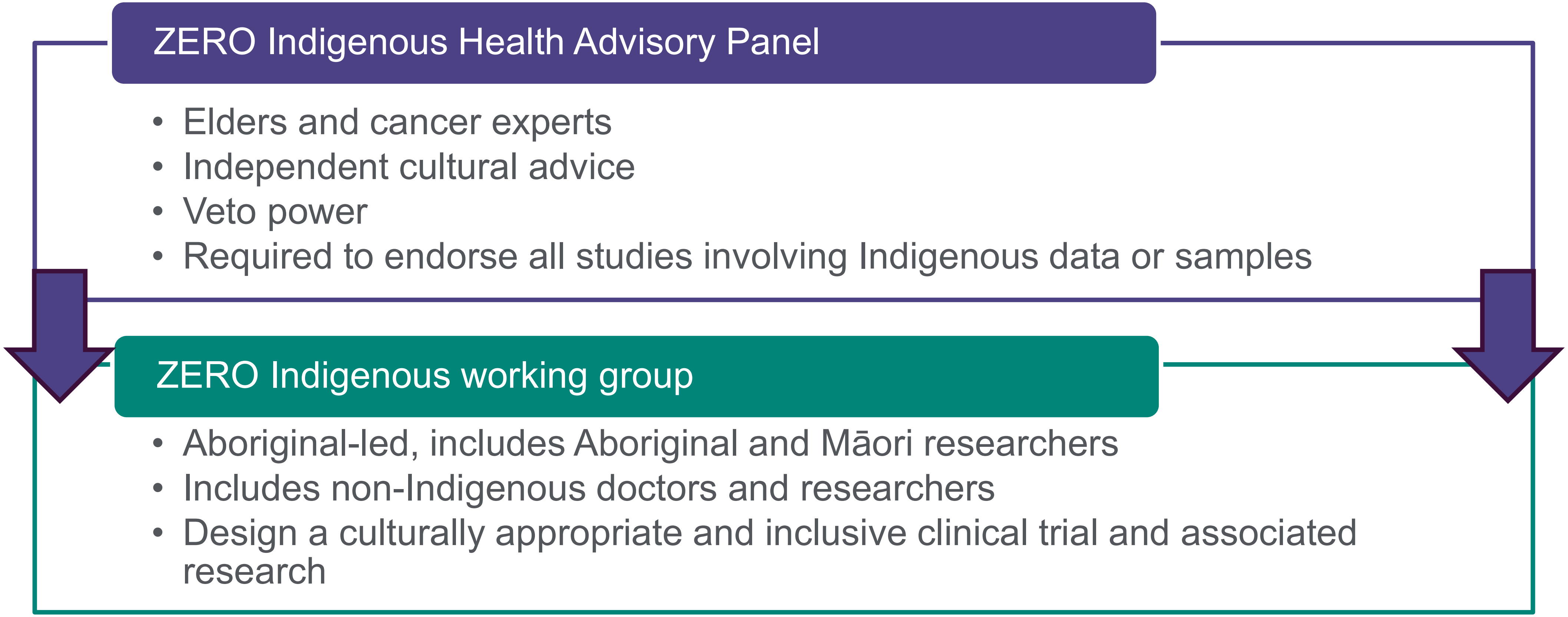
Developing Indigenous governance for the ZERO Childhood Cancer Research Program

ZERO CHILDHOOD CANCER

- National clinical trial enrolling all children with cancer for genetic testing
- How can we ensure the clinical trial is culturally safe and inclusive?
- How can we safeguard genetic results and cancer samples from Aboriginal, Torres Strait Islander and Māori kids?

Indigenous governance structure



ZERO Indigenous Health Advisory Panel

- Elders and cancer experts
- Independent cultural advice
- Veto power
- Required to endorse all studies involving Indigenous data or samples

ZERO Indigenous working group

- Aboriginal-led, includes Aboriginal and Māori researchers
- Includes non-Indigenous doctors and researchers
- Design a culturally appropriate and inclusive clinical trial and associated research

ZERO Childhood Cancer Program

What questions might the Indigenous Advisory Panel consider?

PHARMACOGENOMICS

Understand why the side effects of cancer treatment are worse in Indigenous childen

CLINICAL TRIALS

Development of culturally appropriate resources to ensure equitable access to clinical trials

BIOBANKING

Develop culturally appropriate methods for biobanking samples, developing cell lines and PDX models

IMPROVED PATIENT CARE

Personalise treatment to improve outcomes for Indigenous kids

DATA MANAGEMENT

Reconciling the existing ZERO data management systems consistent with Indigenous data sovereignty principles

Future plans

- Culturally appropriate resources
  - Booklet explaining clinical treatment
  - Videos explaining laboratory work
- National workshops, yarning circles and surveys on laboratory cancer research

What are the clinical outcomes for WA Aboriginal children with cancer?

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What are the acute and late effects of cancer treatment?

- Clinicians anecdotally report higher rates of acute and long-term side effects in Aboriginal patients

- Rotte *et al*. reported longer hospital admission, and trend towards increased rates of complications for leukaemia patients

- Is this the case in a Western Australian cohort of Aboriginal patients?

Rotte 2012 PMID:23198875

Understanding morbidity and mortality in Aboriginal children in WA

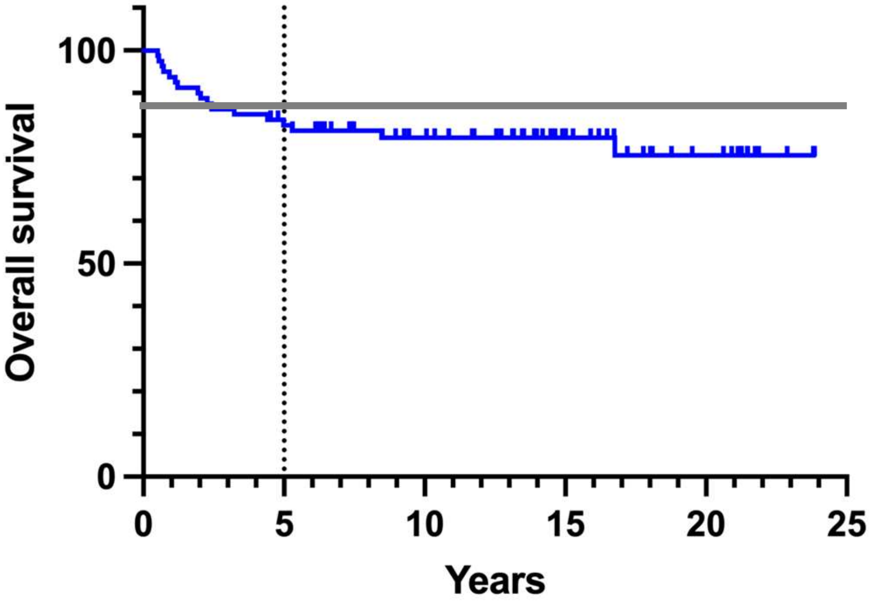
Inclusion criteria

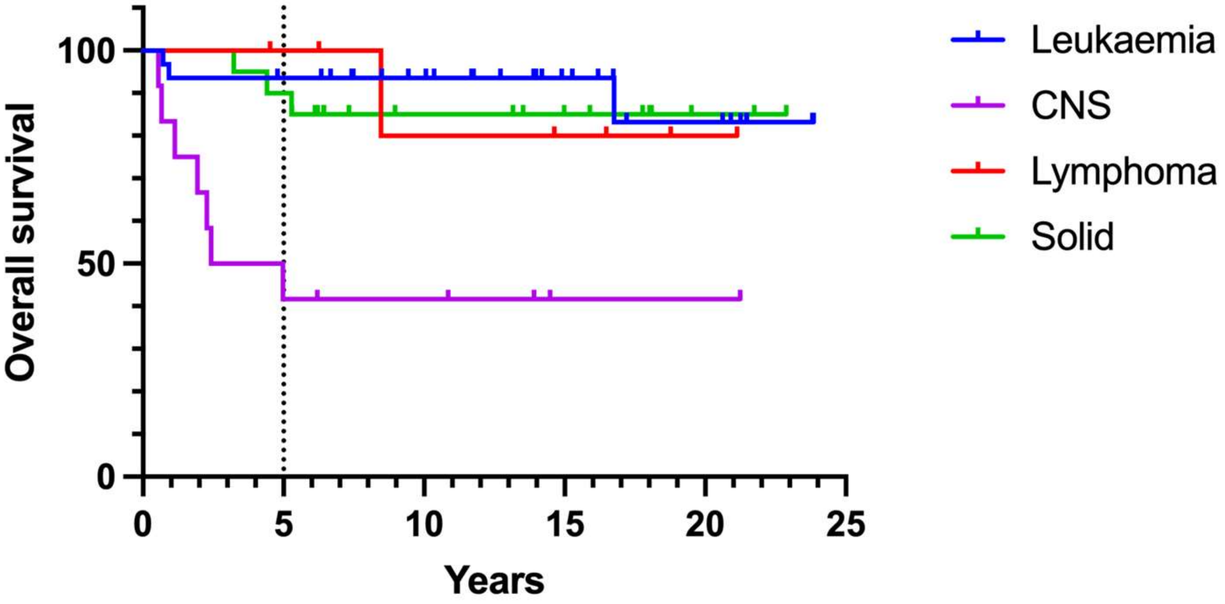
- Patients diagnosed at Perth Children's Hospital or Princess Margaret Hospital
- Diagnosed between 2000 and 2020
- 0-18 years of age
- Identified in hospital records as Aboriginal or Torres Strait Islander

Data collection

- Diagnosis including molecular subtype where available
- Demographic information
- Mortality
- Inpatient stay length
- Treatment induced side effects – CTCAE v4 criteria

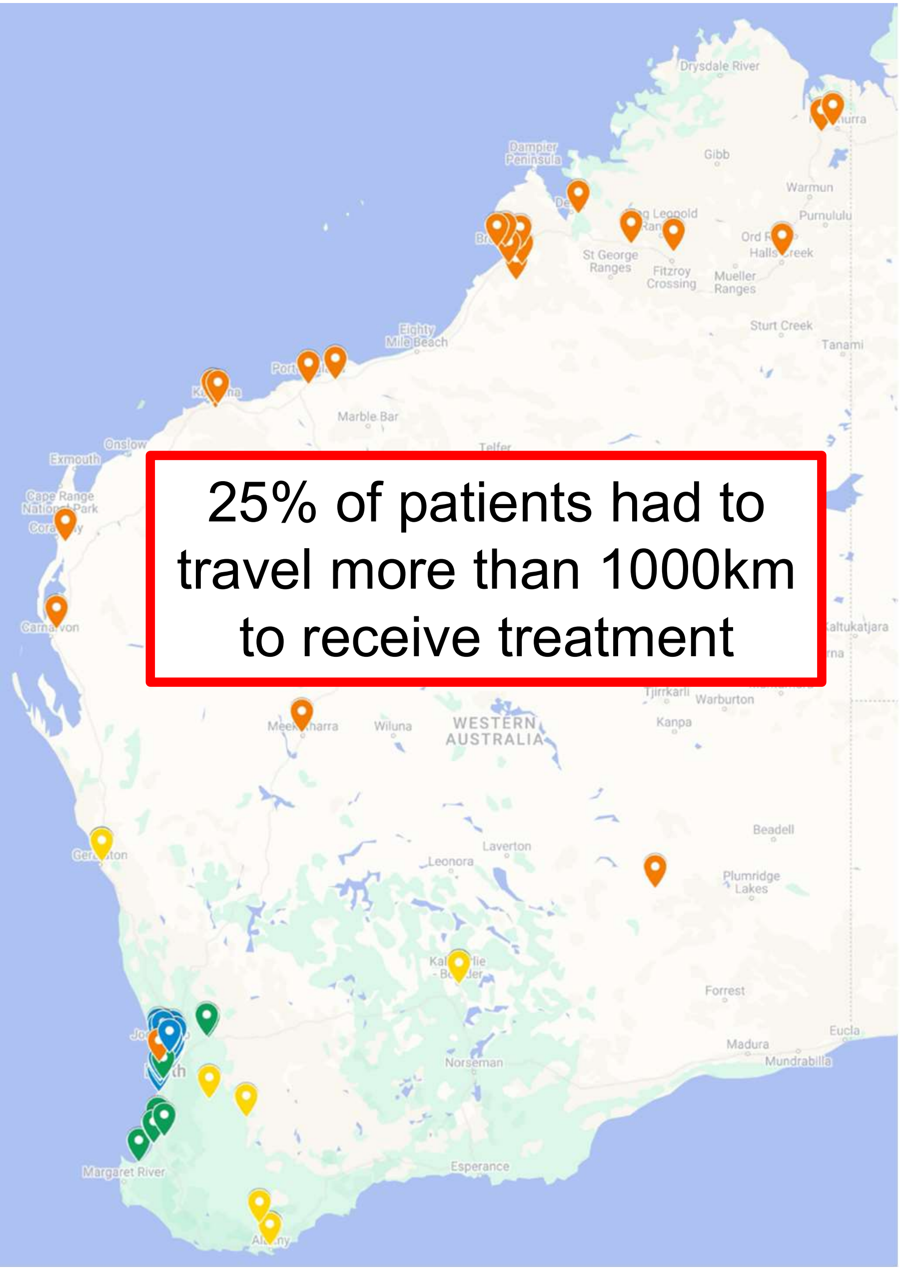
Overall survival is comparable to the rest of Australia



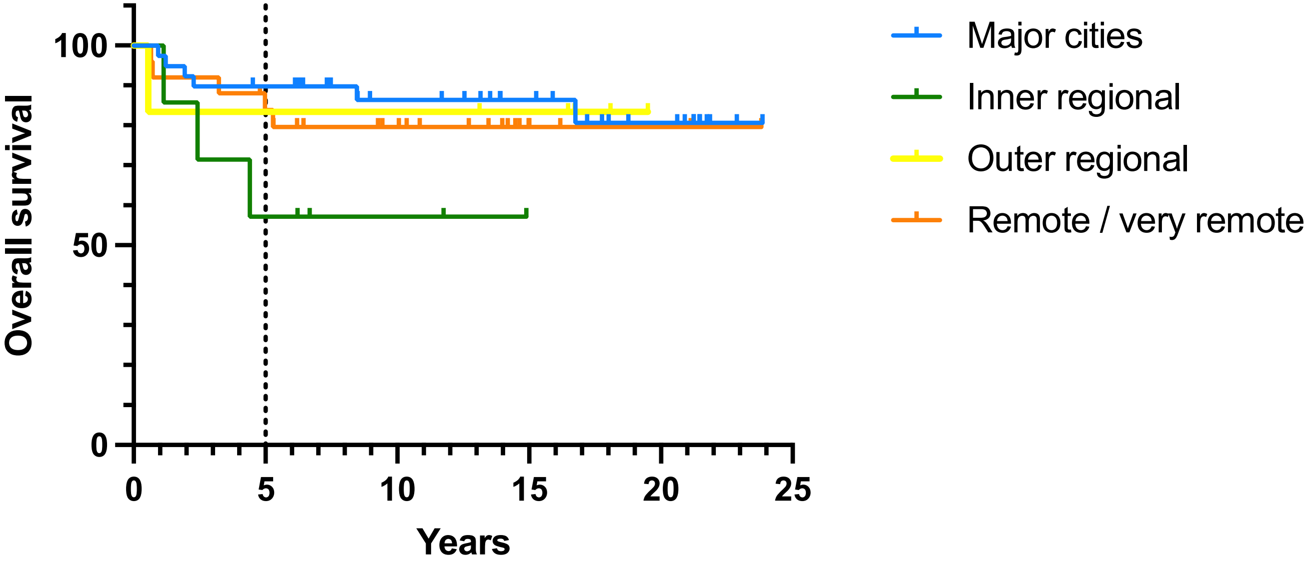


Youlden 2023 PMID:35672573

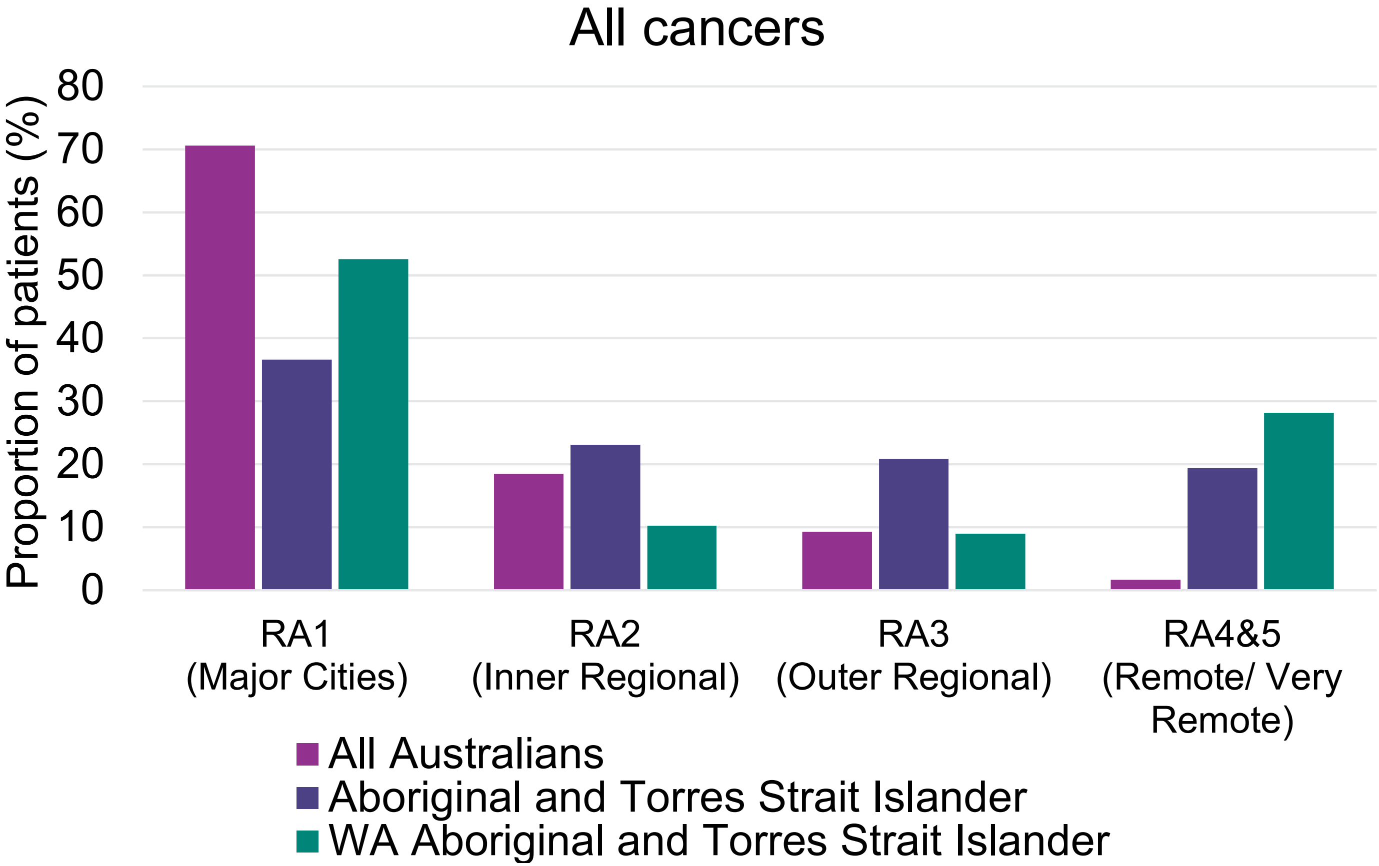
Overall survival does not vary by geographic location



25% of patients had to travel more than 1000km to receive treatment

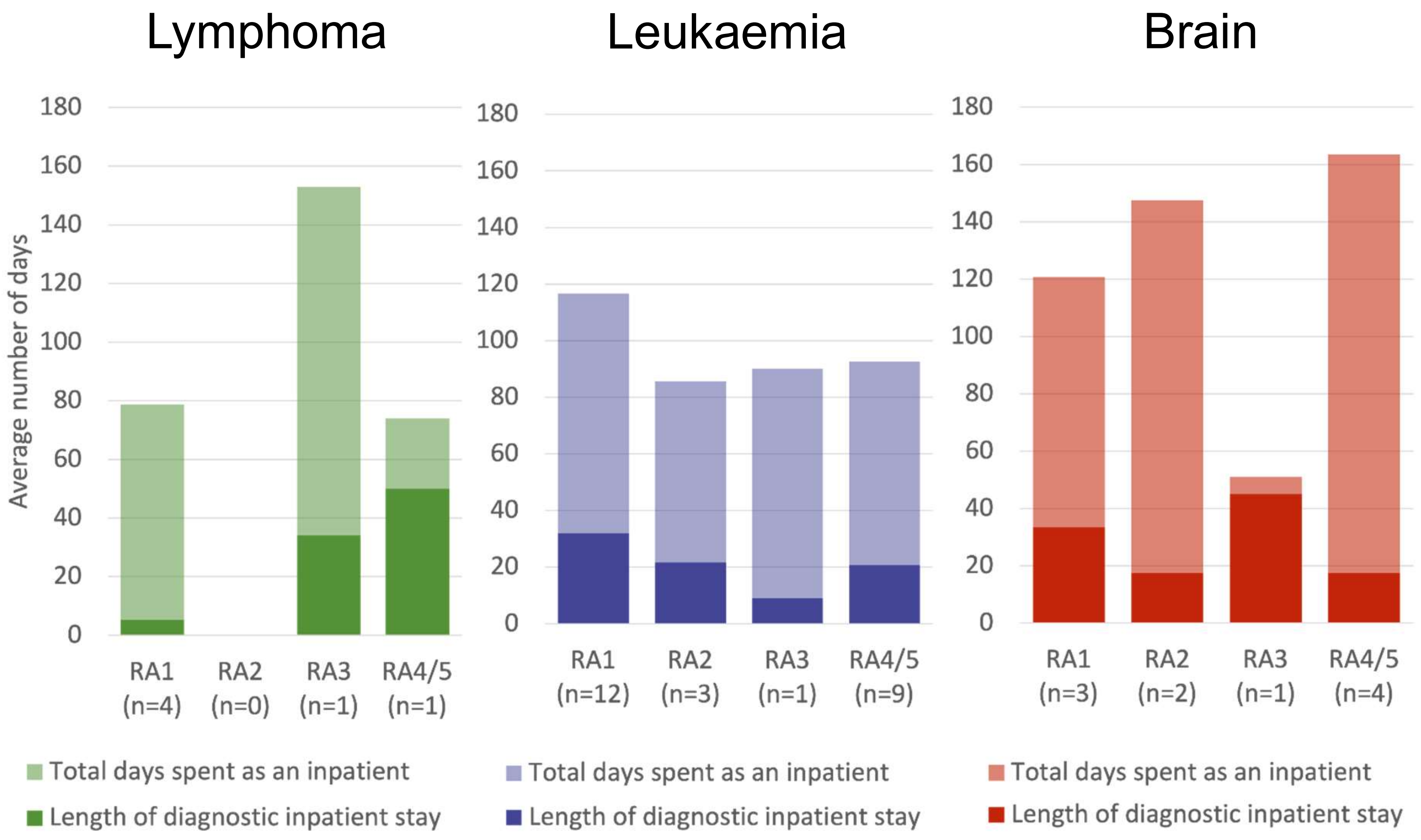


Western Australia has an increased proportion of Aboriginal patients from remote areas



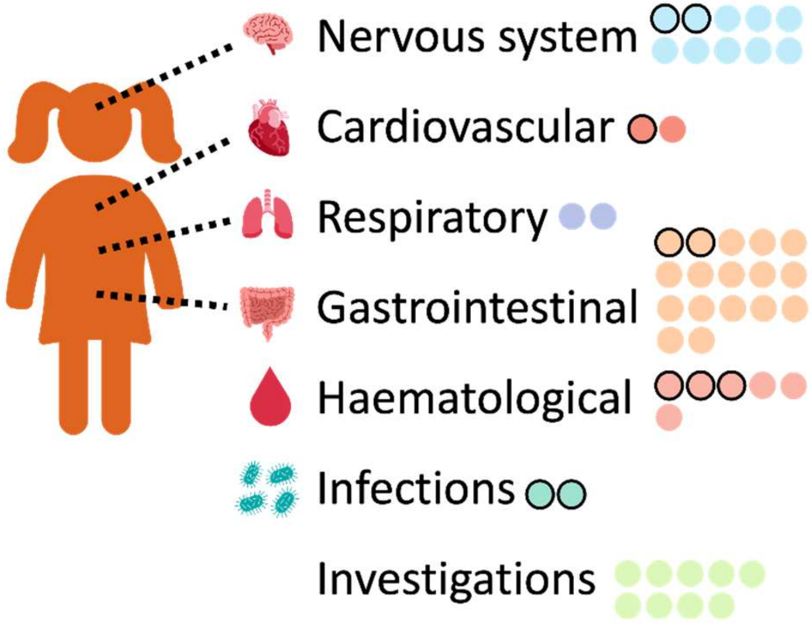
Youlden 2011 PMID:21708938, Youlden 2022 PMID:34908222

Inpatient stays vary by cancer type



Treatment-induced side effects: case studies

15 y.o. girl with leukaemia



Nervous system ○○●●●●●●●●

Cardiovascular ○●

Respiratory ●●

Gastrointestinal ○○●●●●●●●●●●●●●●●

Haematological ○○○●●●

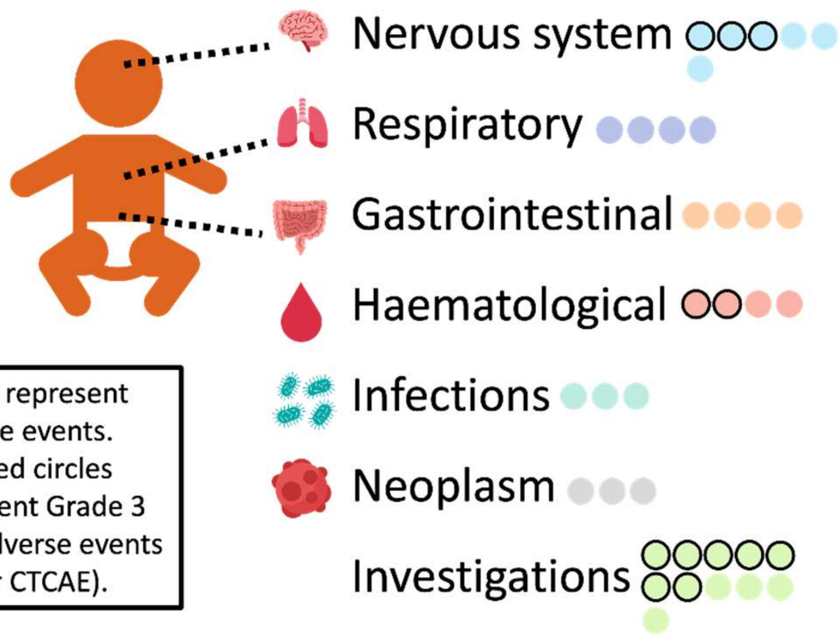
Infections ○○

Investigations ●●●●●●●●●

Total of **62 days** in hospital, including **35 days** for diagnosis and **27 days** in **7** subsequent admissions

Circles represent adverse events. Outlined circles represent Grade 3 or 4 adverse events (as per CTCAE).

Infant boy with a CNS tumour



Nervous system ○○○●●●

Respiratory ●●●●

Gastrointestinal ●●●●

Haematological ○○●●

Infections ●●●

Neoplasm ●●●

Investigations ○○○○○○○●●●●

Total of **213 days** in hospital, including **71 days** for diagnosis and **114 days** in **54** subsequent admissions

Conclusions

- Co-designing childhood cancer research priorities is important to Aboriginal communities
- Western Australia’s geography presents unique challenges to patients from remote communities

Future research directions

- Determine whether Aboriginal children experience worse treatment-induced side effects
- Understand Aboriginal community attitudes to biobanking and cell line creation
- Use national data from ZERO to address community-driven research questions
  - Pharmacogenomics
  - Predisposition

Recruiting!

- Community Advisory Group members
  - Elders
  - Health care workers
  - Families outside WA
- Students – honours, masters, PhD, MD
  - Clinical, lab-based or yarning-based projects can be designed to suit your interests
  - Scholarships available!

Acknowledgements

Brain Tumour Research Group

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Tony Chong Award

SIMON LEE FOUNDATION
TO CHAMPION THE HUMAN SPIRIT

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The pirate ship FOUNDATION

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