Global Perspectives on Pediatric and Congenital Cardiovascular Health: Australia

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Population of Australia = 26 million

crocodile

Darwin

1957 miles

Brisbane

Perth

Sydney#

Adelaide

Melbourne*

1000km = 620 miles

0 1000

Kilometres

People per sq km

100.0 or more

10.0 to 100.0

1.0 to 10.0

0.1 to 1.0

Less than 0.1

*only pediatric transplant centre until 2020

now also transplant centre

Geographic Challenges

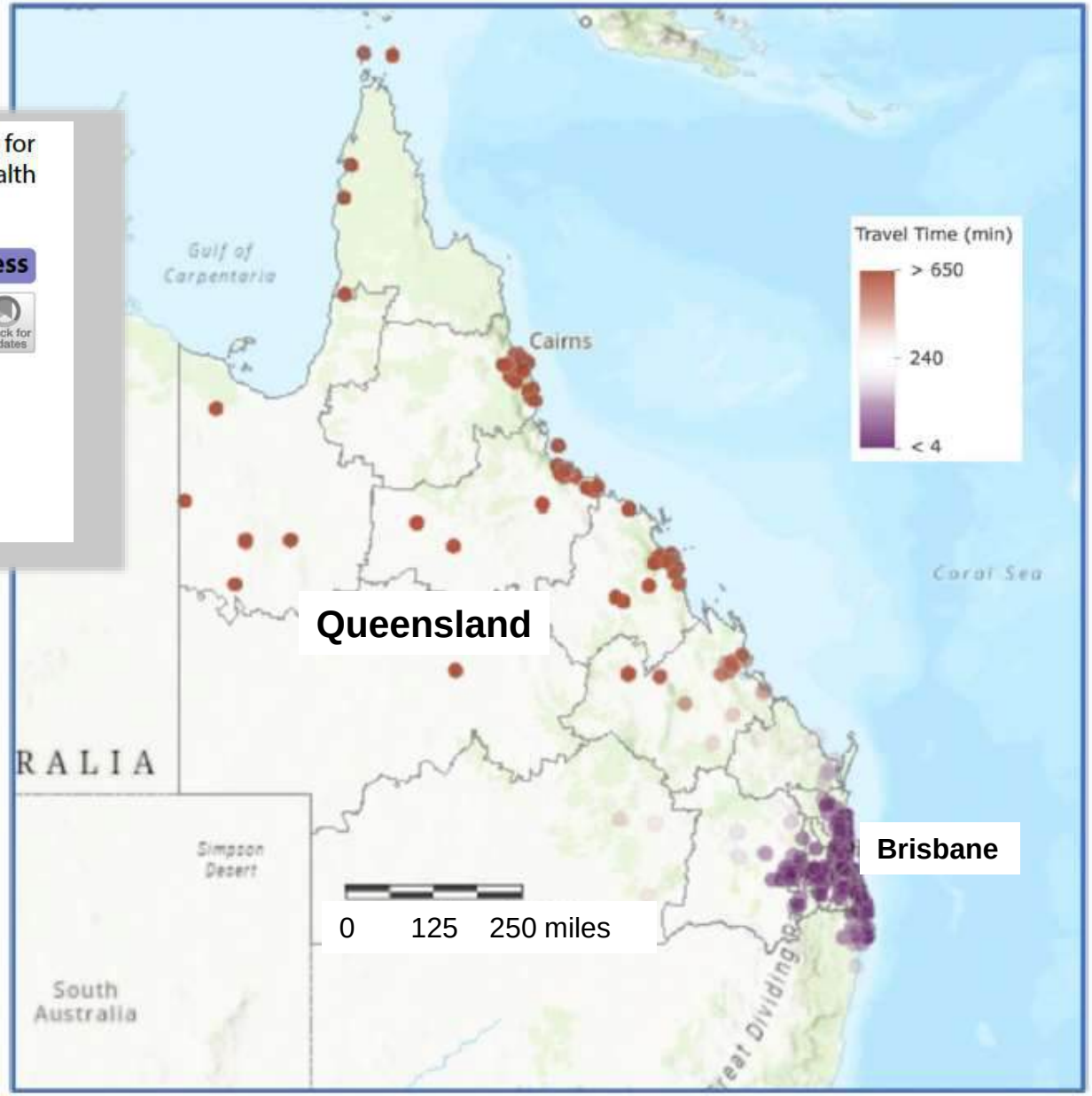
Auld *et al.*
International Journal for Equity in Health (2023) 22:229
https://doi.org/10.1186/s12939-023-02040-z

International Journal for Equity in Health

RESEARCH Open Access

Geographical challenges and inequity of healthcare access for high-risk paediatric heart disease

Benjamin C. Auld[1,2*], Bridget Abell[2], Prem S. Venugopal[1] and Steven McPhail[2]



Indigenous Health Outcomes and Social Disadvantage

- 40% live without 2 or more essentials
- Median income is 60% less
- In my state although only 4% of the population is Aboriginal, 25% of the goal population is Aboriginal

Infant death rates by state, Australian Institute of Health and Wellbeing

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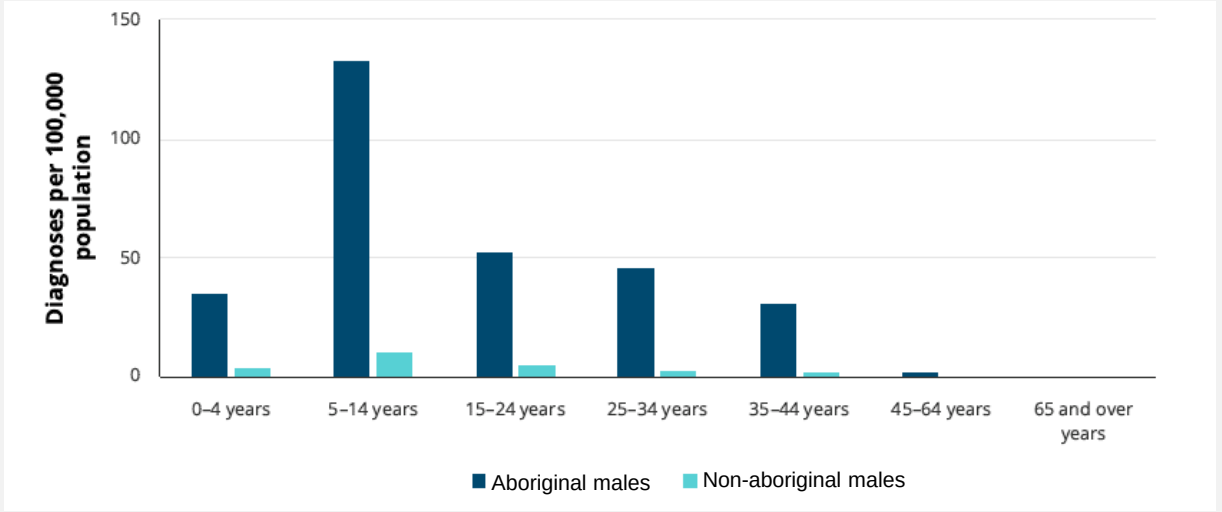
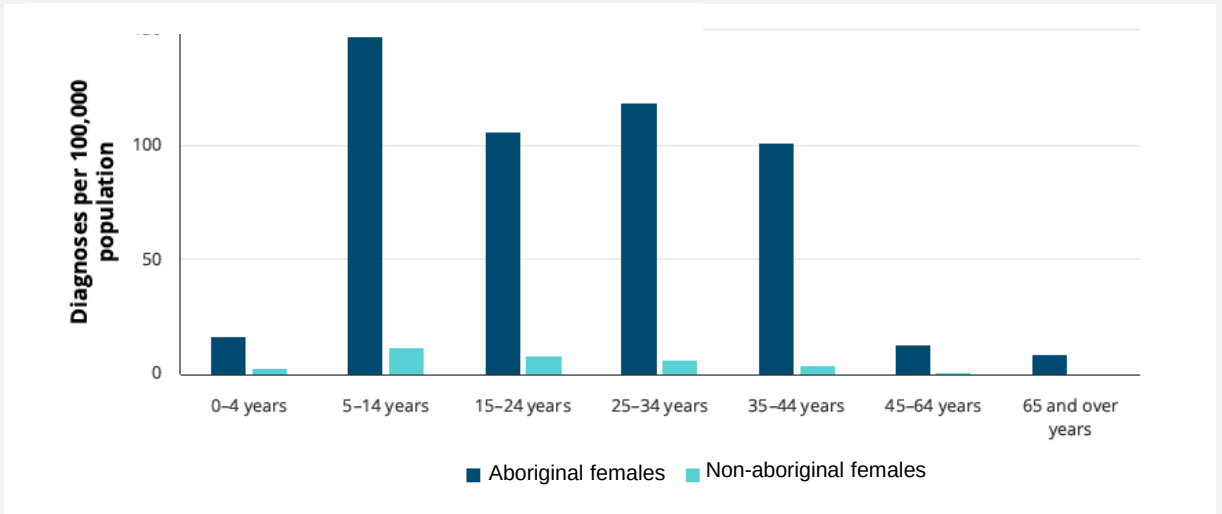
Rheumatic Heart Disease





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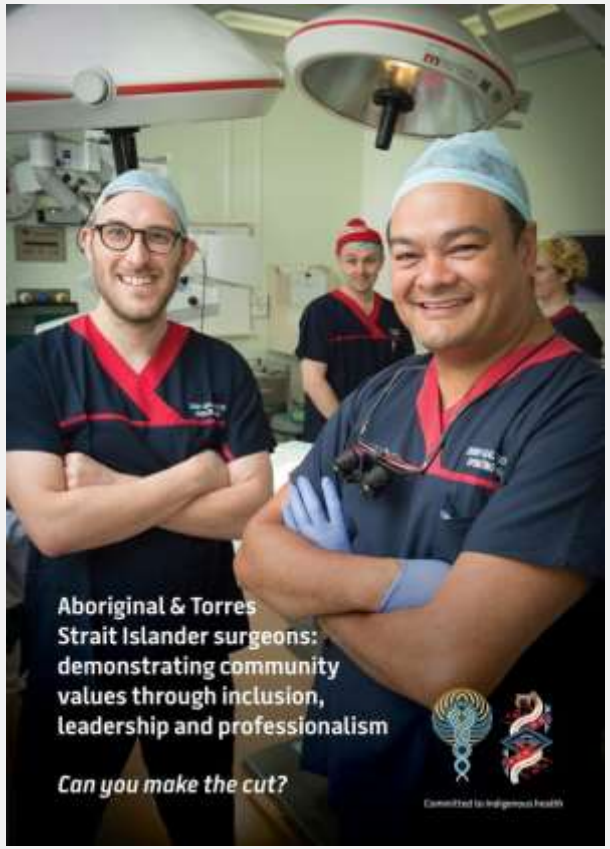
Aboriginal & Torres
Strait Islander surgeons:
demonstrating community
values through inclusion,
leadership and professionalism
Can you make the cut?

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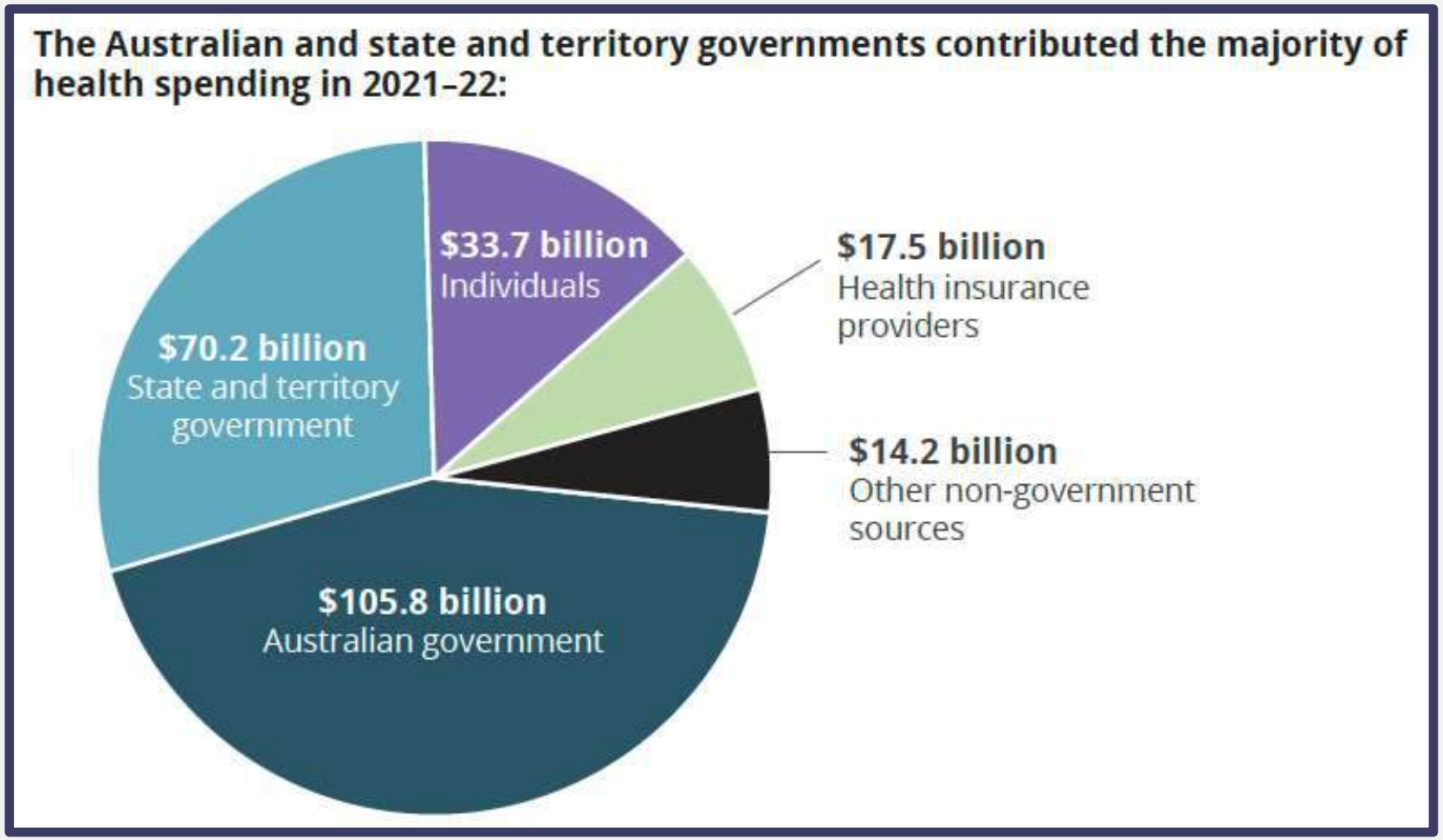
Strengths – Australian Health System



Median and 90th percentile waiting times
for *Cardiothoracic surgery* in my state (NSW) are 20 days and 120 days, respectively

Strengths – Research and Collaboration

Prof Yves d’Udekem

Prof David Celermajer

The ANZ Fontan Registry

Circulation
Volume 130, Issue 11_suppl_1, 9 September 2014; Pages S32-S38
https://doi.org/10.1161/CIRCULATIONAHA.113.007764

CLINICAL SCIENCE

Redefining Expectations of Long-Term Survival After the Fontan Procedure

Twenty-Five Years of Follow-Up From the Entire Population of Australia and New Zealand

Yves d'Udekem, MD, PhD*, Ajay J. Iyengar, MBBS(Hons), BMedSci, GCALL*, John C. Galati, BSc, PhD, Victoria Forsdick, MBBS, Robert G. Weintraub, MBBS, FRACP, Gavin R. Wheaton, MBBS, FRACP, Andrew Bullock, MBBS, FRACP, Robert N. Justo, MBBS, FRACP, Leeanne E. Grigg, MBBS, FRACP, Gary F. Sholler, MBBS, FRACP, Sarah Hope, BSc, BMedSci(Hons), MBChB, FRACP, PhD, Dorothy J. Radford, MBBS, MD, FRACP, Thomas L. Gentles, MBChB, FRACP, David S. Celermajer, MBBS, PhD, DSc, FRACP, and David S. Winlaw, MBBS(Hons), MD, FRACS

BACKGROUND— The life expectancy of patients undergoing a Fontan procedure is unknown.

METHODS AND RESULTS— Follow-up of all 1006 survivors of the 1089 patients who underwent a Fontan procedure in Australia and New Zealand was obtained from a binational population-based registry including all pediatric and adult cardiac centers. There were 203 atriopulmonary connections (AP; 1975–1995), 271 lateral tunnels (1988–2006), and 532 extracardiac conduits (1997–2010). The proportion with hypoplastic left heart syndrome increased from 1/173 (1%) before 1990 to 80/500 (16%) after 2000. Survival at 10 years was

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https://doi.org/10.1161/CIRCULATIONAHA.120.048202

ORIGINAL RESEARCH ARTICLE

Neurocognitive Dysfunction and Smaller Brain Volumes in Adolescents and Adults With a Fontan Circulation

Editorial, see p 892

Charlotte E. Verrall, BSc (Hons), Joseph Y.M. Yang, MBChB, PhD, Jian Chen, ME, Adrian Schembri, DPsych, Yves d'Udekem, MD, PhD, Diana Zannino, MSc, Nadine A. Kasparian, BA Psych, PhD, MAPS, Karin du Plessis, PhD, Stuart M. Grieve, MBBS, DPhil, Thomas Welton, PhD, Belinda Barton, BA (Hons Psych), PhD, Thomas L. Gentles, MBChB, David S. Celermajer, MBBS, PhD, DSc, Chantal Attard, PhD, Kathryn Rice, MBChB, Julian Ayer, MBBS, PhD, Simone Mandelstam, MBChB, David S. Winlaw, MBBS, MD, Mark T. Mackay, MBBS, PhD*, and Rachael Cordina, MBBS, PhD*

BACKGROUND: Neurocognitive outcomes beyond childhood in people with a Fontan circulation are not well defined. This study aimed to investigate neurocognitive functioning in adolescents and adults with a Fontan circulation and associations with structural brain injury, brain volumetry, and postnatal clinical factors.

METHODS: In a binational study, participants with a Fontan circulation without a preexisting major neurological disability were prospectively recruited from the Australia and New Zealand Fontan Registry. Neurocognitive function was assessed by using Cogstate software in 107

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1443-9506/04/$34.00
https://doi.org/10.1016/j.hlc.2019.09.010

POSITION STATEMENT

Management of People With a Fontan Circulation: a Cardiac Society of Australia and New Zealand Position Statement

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Gary Sholler, MBBS, FRACP, FCSANZ[i,j,3],

Fontan Registry

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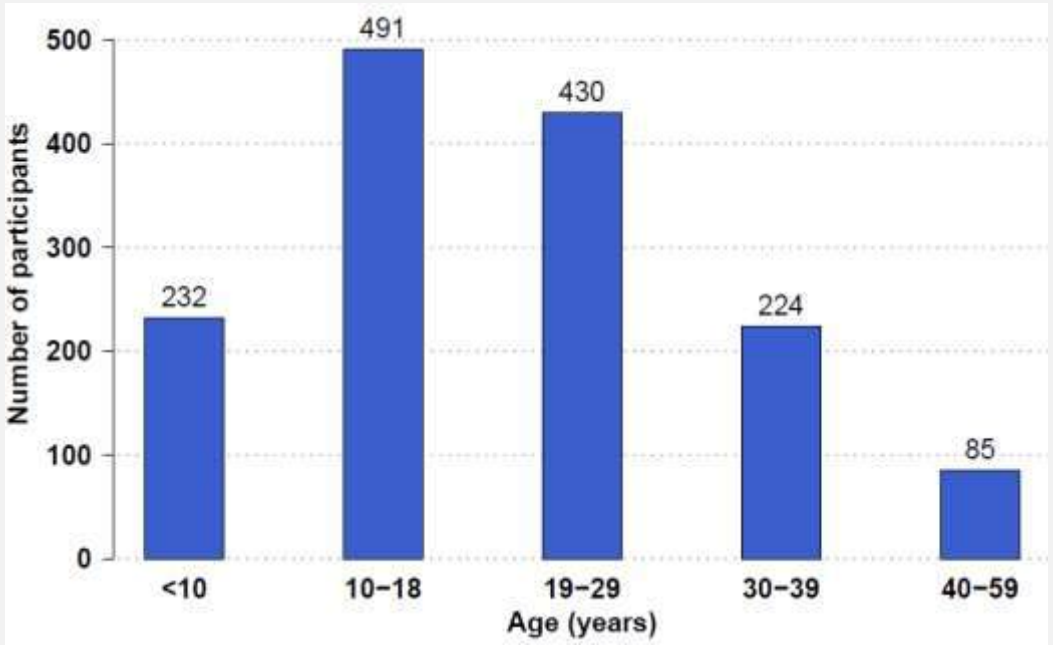
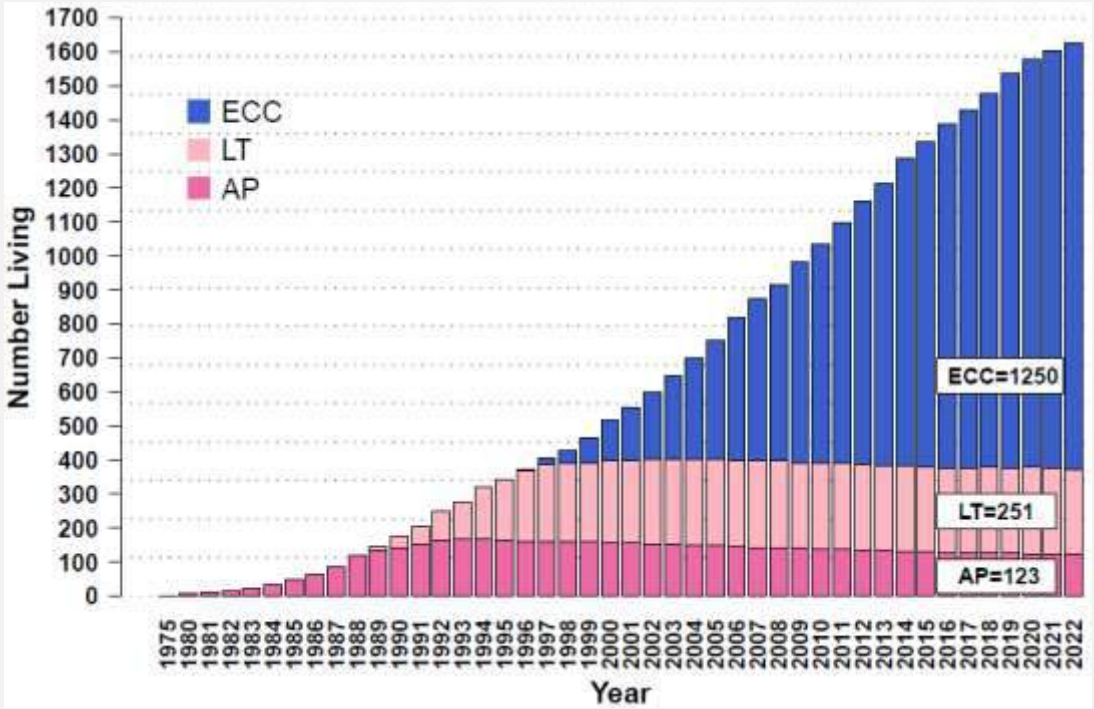
The ANZ Fontan Registry – Living participants

Mean age 21 ± 11 years (range 2-57)

n >1800





Note: AP=Atriopulmonary, LT=Lateral tunnel, ECC=Extracardiac conduit

Fontan Registry

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Annual Education Day

Social Media

Fontan Registry

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Strengths – Research and Collaboration

The Australia and New Zealand Congenital Outcomes Registry for Surgery (ANZCORS): methodology and preliminary results

Supreet P. Marathe,*†‡ Jessica Suna,*†‡ Kim S. Betts,§ Greg Merlo,¶ Igor E. Konstantinov,‖** Ajay J. Iyengar,††‡‡ Prem Venugopal*†‡ and Nelson Alphonso,*†‡ ANZCORS Collaborative

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‡‡Department of Surgery, University of Auckland, Auckland, New Zealand

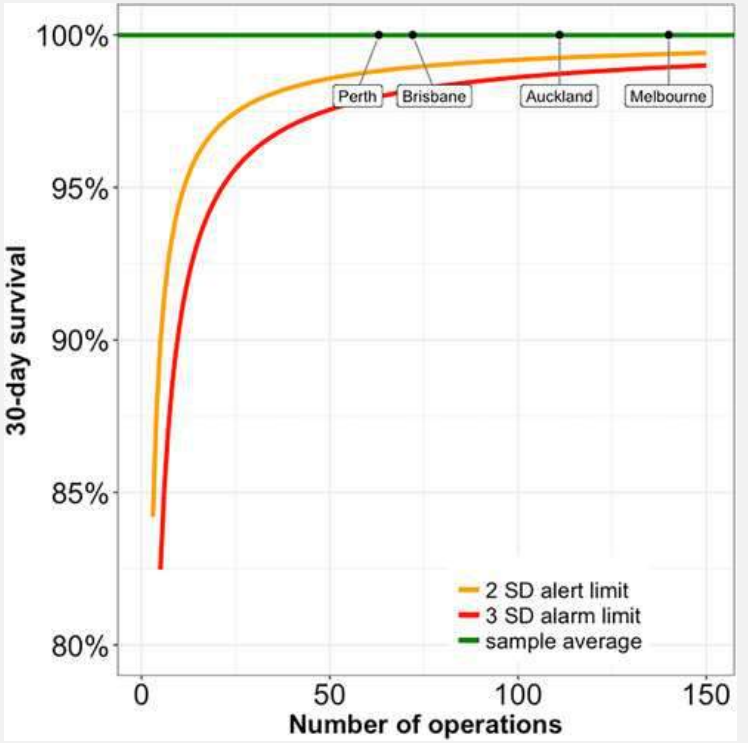

Table 1 ANZCORS database 2013–2020

Centre	Auckland	Brisbane	Melbourne	Perth	Sydney	Total
Neonates 0–28 days (*n*)	951	900	1356	214	1368	4789
Infants 29–365 days (*n*)	1211	1186	1838	431	1703	6369
Children 1–16 years (*n*)	1537	1275	1980	431	1556	6779
>16 years (*n*)	561	161	158	19	33	932
Total procedures (*n*)	4260	3522	5332	1095	4660	18 869

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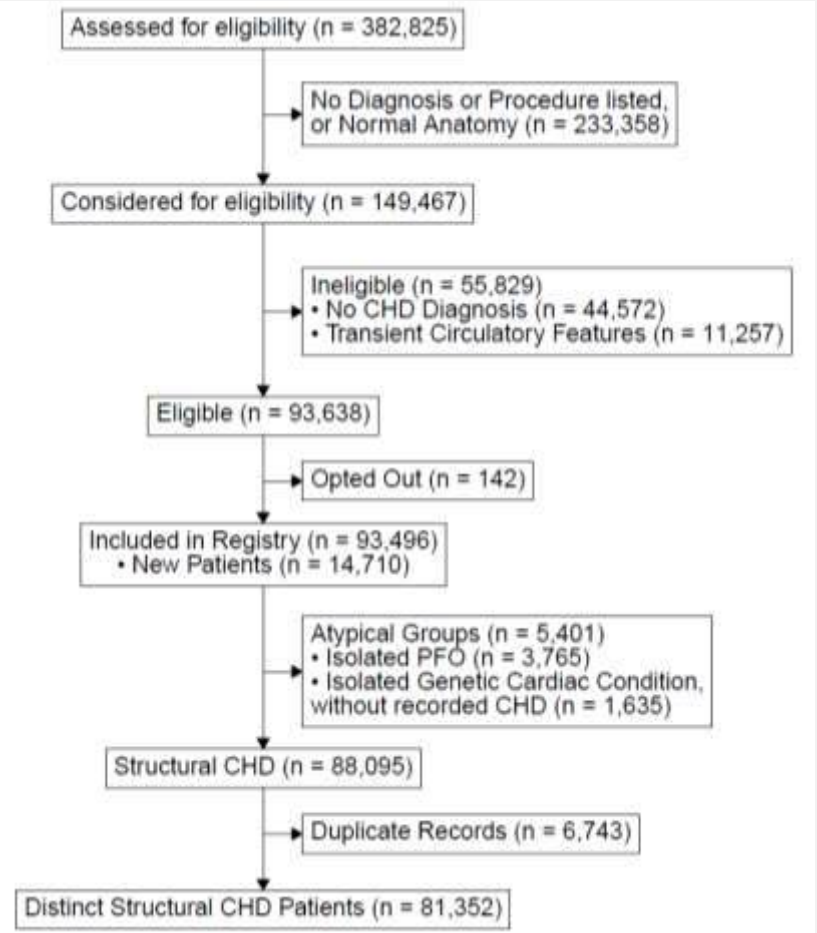
CONGENITAL HEART ALLIANCE
OF AUSTRALIA AND NEW ZEALAND


Assessed for eligibility (n = 382,825)
No Diagnosis or Procedure listed, or Normal Anatomy (n = 233,358)
Considered for eligibility (n = 149,467)
Ineligible (n = 55,829)
• No CHD Diagnosis (n = 44,572)
• Transient Circulatory Features (n = 11,257)
Eligible (n = 93,638)
Opted Out (n = 142)
Included in Registry (n = 93,496)
• New Patients (n = 14,710)
Atypical Groups (n = 5,401)
• Isolated PFO (n = 3,765)
• Isolated Genetic Cardiac Condition, without recorded CHD (n = 1,635)
Structural CHD (n = 88,095)
Duplicate Records (n = 6,743)
Distinct Structural CHD Patients (n = 81,352)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CONGENITAL HEART ALLIANCE
OF AUSTRALIA AND NEW ZEALAND

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Strengths – Government Investment (?!)

HeartKids

Prof Gary Sholler

Conclusions

- Despite the geographical challenges overall the “universal” health system in Australia works well but there are still major inequities for Aboriginal people

- Our small population and collaborative community of medical professionals has been key for national registries and research partnerships

Ancient rock art, East Arnhem Land

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My Country, Nyunmiti Burton from Pitjantjatjara, Southern Desert