Scoping review of contributors to critical congenital heart disease infant survival by race and ethnicity

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“E le tu fa'amauga se tagata”

– no one stands alone, no one succeeds alone

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Presentation overview

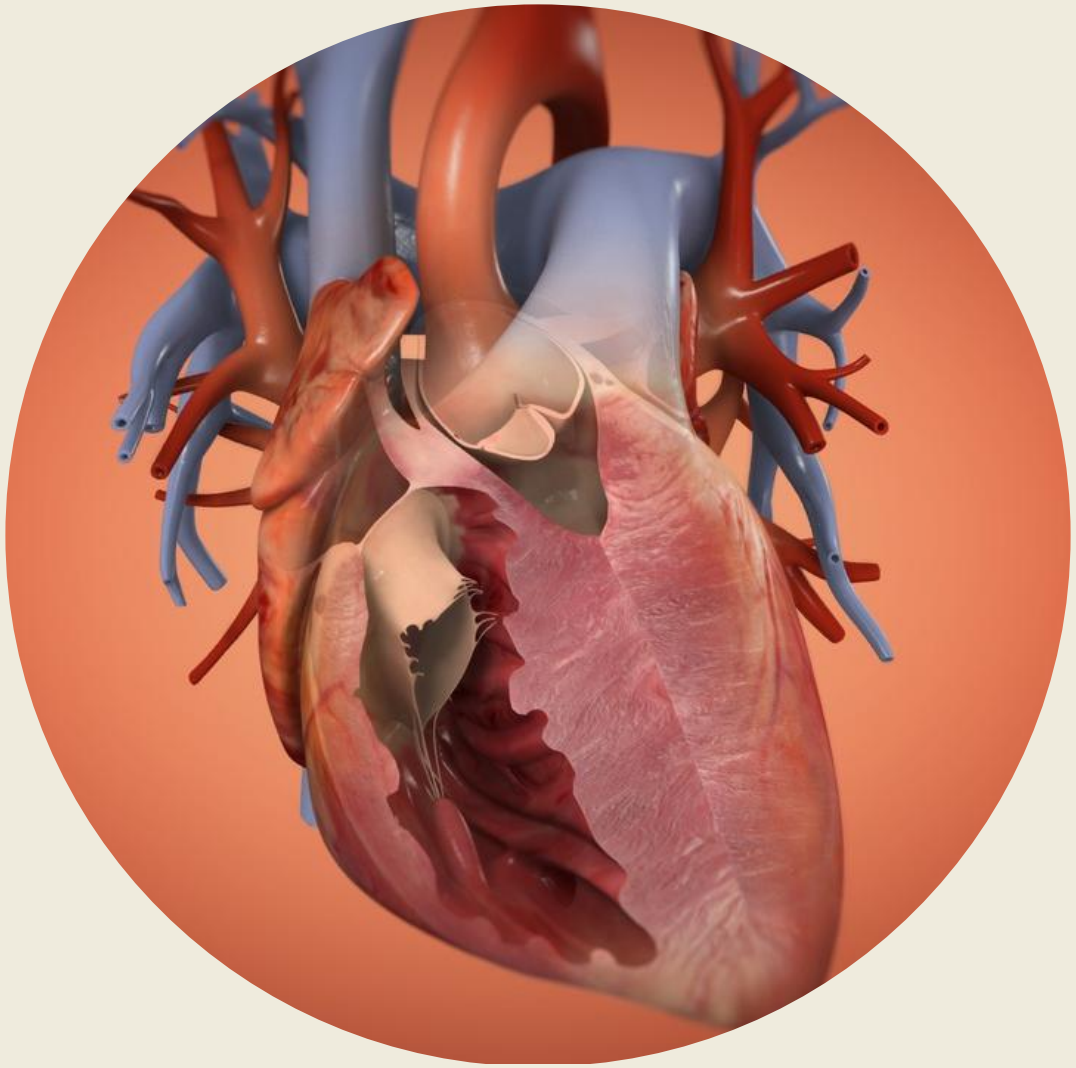
- Background
- Method
- Results
- Discussion
- Application
- Limitations
- Conclusion

Background

- Equitable healthcare is a human right.
- Congenital heart disease (CHD) is one of the leading causes of infant mortality globally.
- Infants with *critical* CHD (CCHD) require life-saving intervention before one month of age.
- Outcomes of CCHD differ by racial and ethnic group, with minoritised and Indigenous ethnic groups experiencing poorer outcomes.

Aim

To understand the key factors influencing ethnic and racial disparities in CCHD outcomes.



Method: Systematic scoping literature review

Database Search

A comprehensive search was conducted using key terms related to critical congenital heart disease and race.

Databases included MEDLINE, Web of Science, and SCOPUS.

Inclusion Criteria

Studies were included if they reported on race or ethnicity and involved a cohort of critical congenital heart disease cases.

Eligible articles also needed to mention infant mortality in their results.

Exclusion Criteria

Articles that were reviews, conference abstracts, or preliminary results were excluded from the review.

Case studies, guidelines, and commentaries that did not meet the inclusion criteria were also omitted.

Data Extraction

Data extraction was performed by the lead researcher, focusing on the review questions.

Papers were categorized based on emergent key findings and critically reviewed for quality.

Synthesis Process

The findings were synthesized to identify gaps in the literature and inform future research directions.

Co-authorship input was sought to validate the findings presented in the framework model.

Results

- 311 • Unique records identified from Ovid, Web of science and SCOPUS
- 120 • Screened by abstract
- 83 • Screened by full text
- 40 • Included studies

Open access Original research

BMJ Open

Factors influencing the choice-of-care pathway and survival in the fetus with hypoplastic left heart syndrome in New Zealand: a population-based cohort study

Natalie Soszyn,[1] Elza Cloete,[2,3] Lynn Sadler,[4,5] Monique W M de Laat,[4] Sue Crengle ,[6] Frank Bloomfield,[2]

Congenital left heart obstruction: ethnic variation in incidence and infant survival

Elza Cloete,[1] Lynn Sadler,[2] Frank H Bloomfield,[1] Sue Crengle,[3] Teuila Percival,[4] Thomas L Gentles[5]

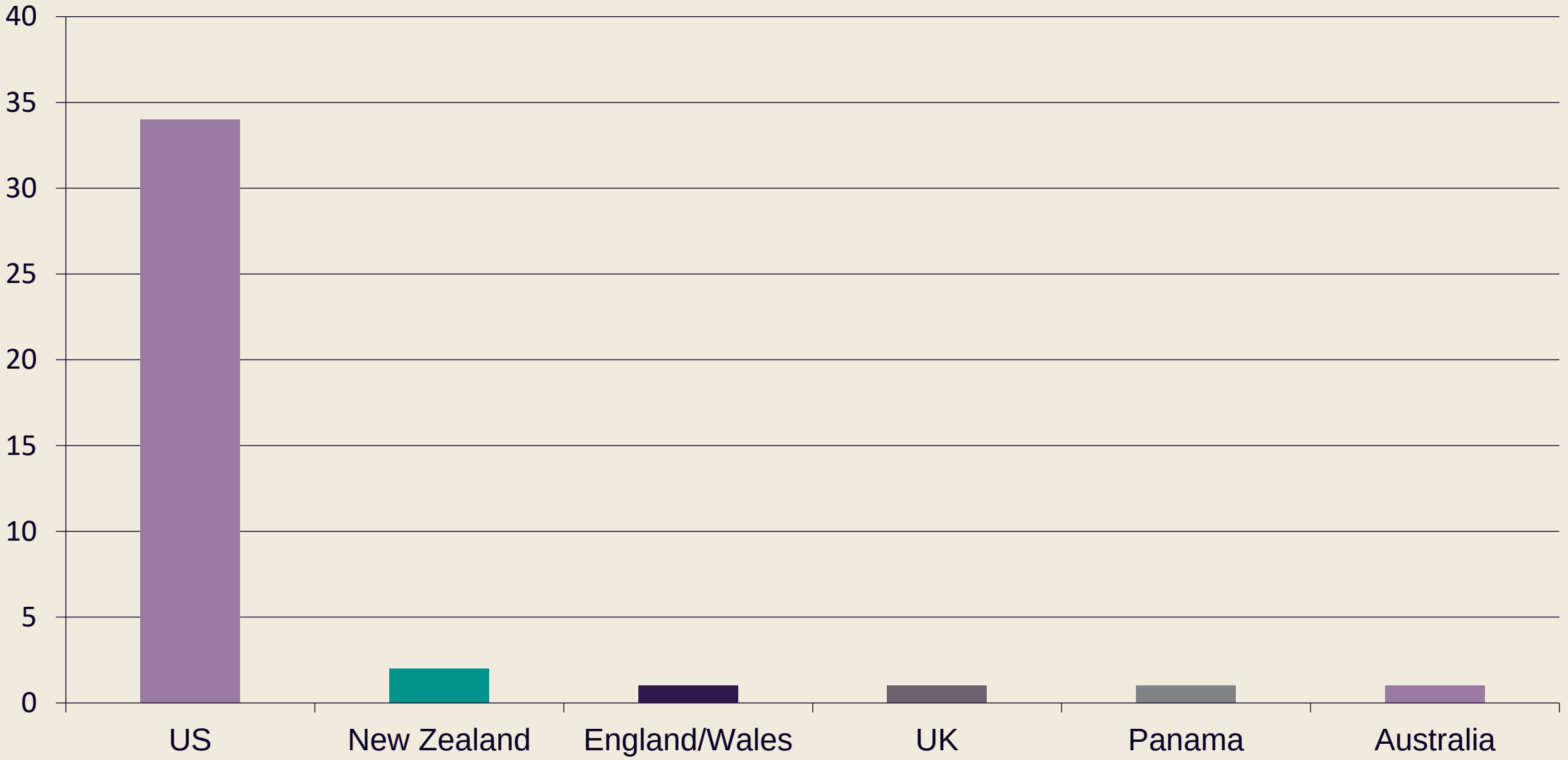
Birth Defects Research Part A | Clinical and Molecular Teratology

Research Article

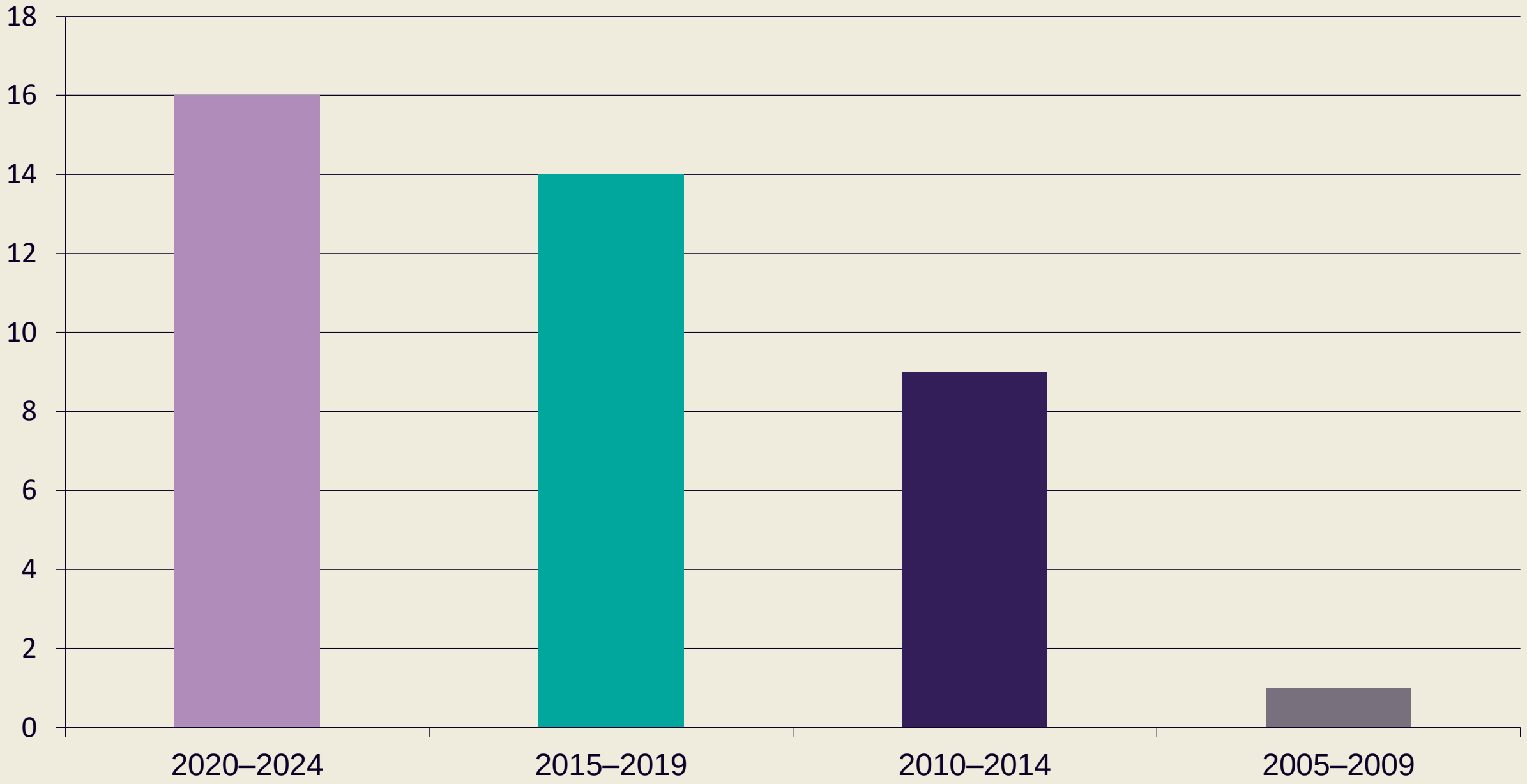
Twenty-five–year survival for aboriginal and caucasian children with congenital heart defects in Western Australia, 1980 to 2010

Wendy N. Nembhard, Jenny Bourke, Helen Leonard, Luke Eckersley, Jingyun Li, Carol Bower

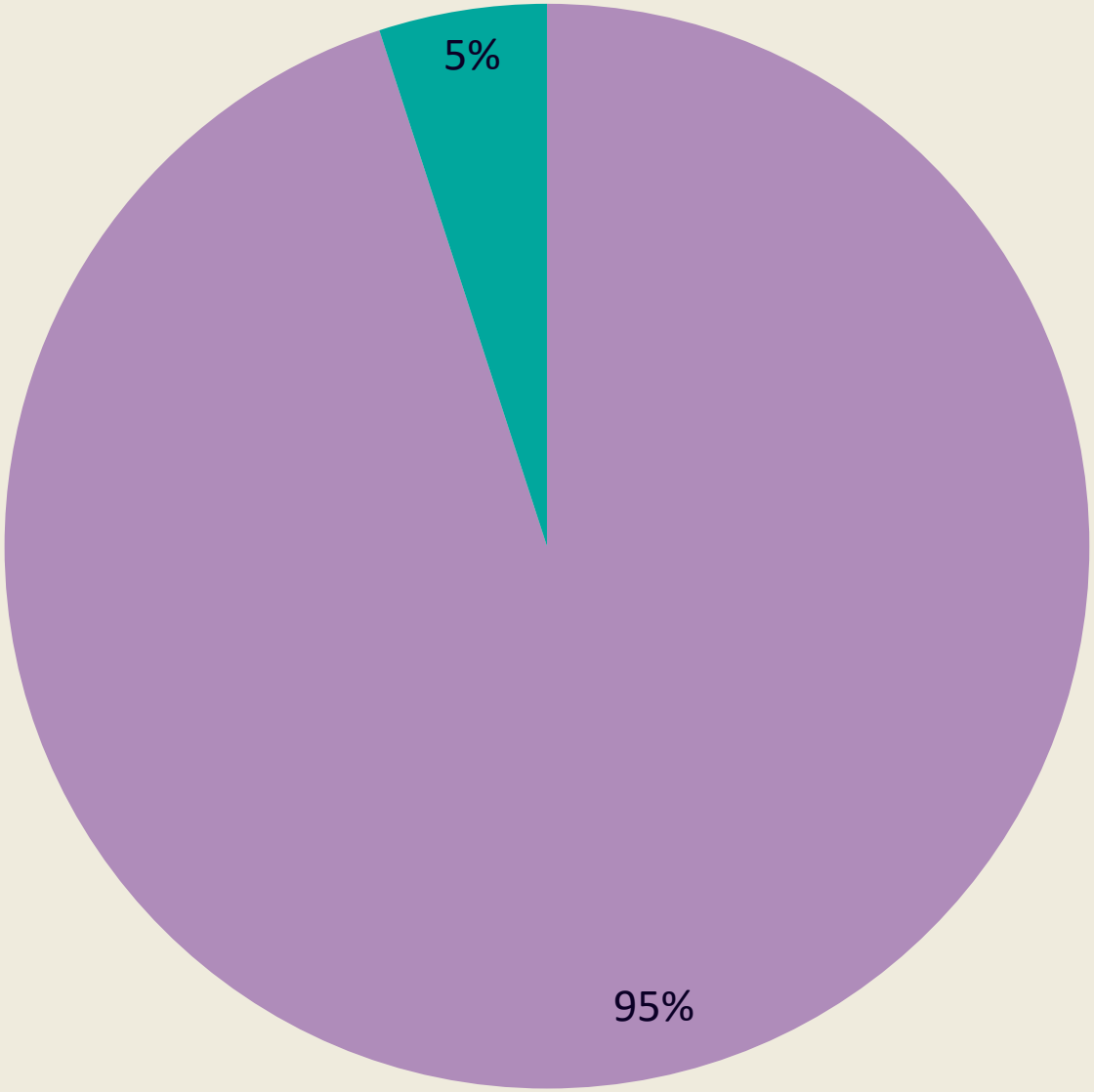
Publications by Country



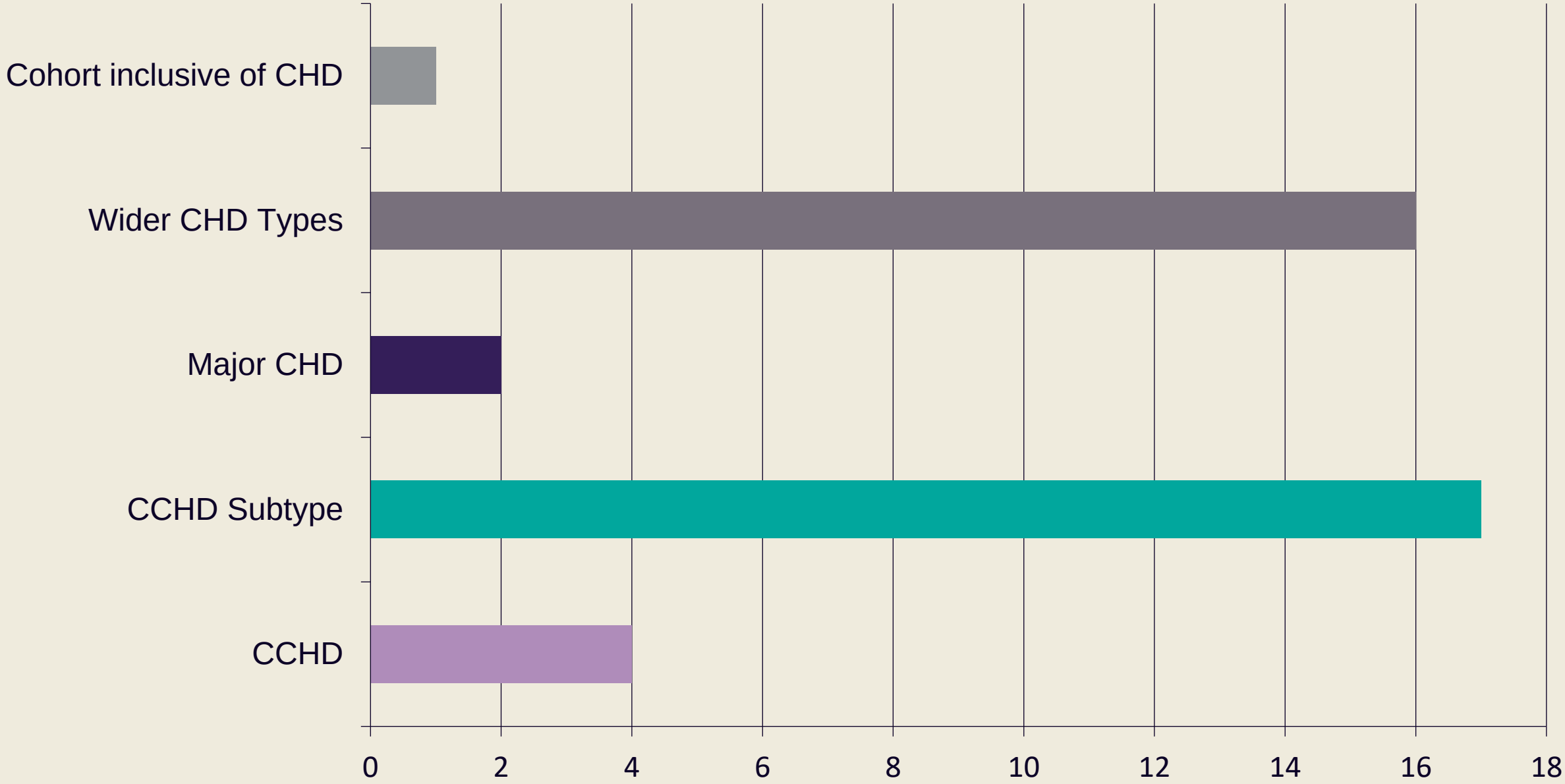
Publications by year range

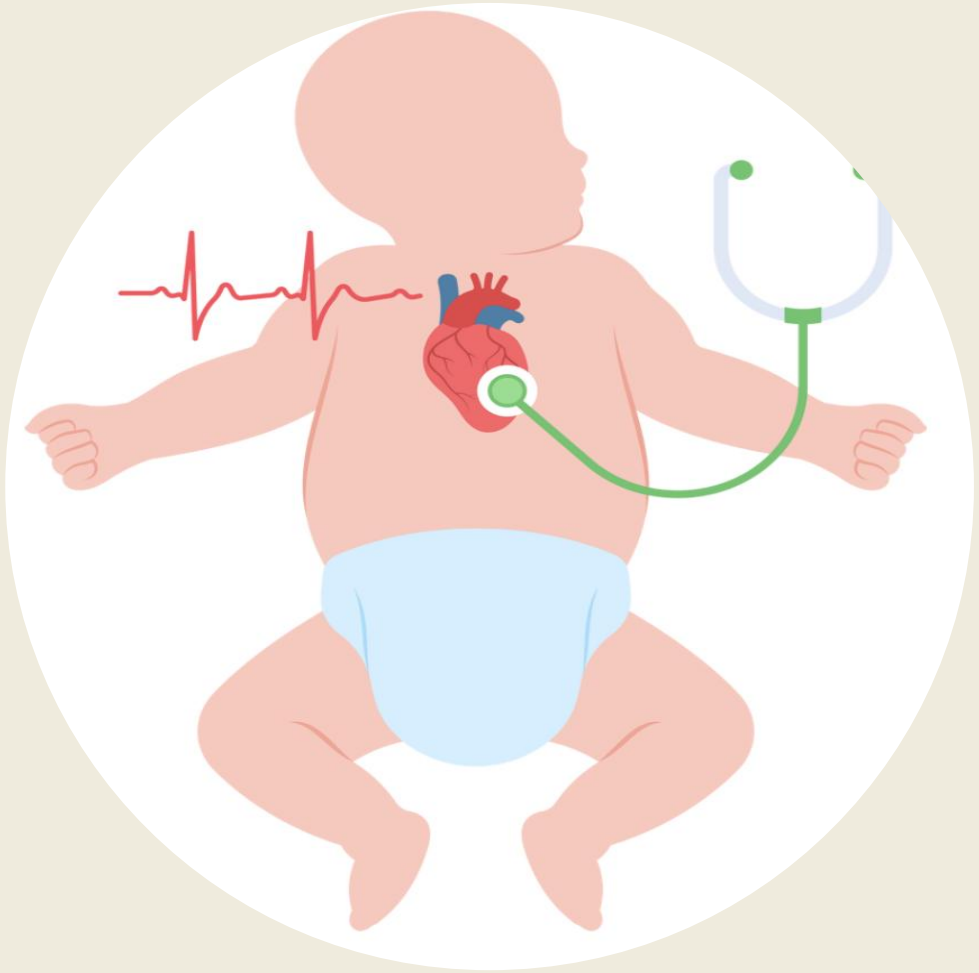


Study Method Distribution → cohort studies (purple)



Types of Participants in Studies





Patient-level

- **Ethnicity/Race was strongly associated in the current literature with mortality risk in CCHD**

Government & institutional level

- Differential access to care due to the geographical location of a specialist service
- Maternal access to high education levels
- Timely diagnosis and referral access
- High quality hospital care access (higher volume centres had better outcomes)

Patient-provider level

- Potential implicit bias in clinical care quality and options within:
- Timing of diagnosis;
- Referral timing/existence;
- Post-operative care processes (i.e. ECMO rates) and complications, and
- Length of stay.

Maternal level

- Differential risks of exposure to adverse maternal-fetal environments (leading to higher rates of preterm birth/low birth weight infants) are present by ethnicity/race.
- Differential access to health-promoting education and environments are present by ethnicity/race.
- Proportion living in rural settings differs by ethnicity/race.
- Socio-economic positioning differs by ethnicity/race.
- Pregnancy decision making differs by ethnicity/race.

Non-European race/ethnicity are confirmed markers of risk for poor infant survival in CCHD due to disparate risk factor distribution, as well as disparate access to and decisions within healthcare policies and systems.

Knowledge gaps for future research

- Increase in local knowledge required.
- Equity implementation research would be beneficial.
- Monitor quality of care or standardization of care.
- Address upstream health determinants and monitor impact.
- Identify and understand if implicit bias is contributory to clinical decisions.
- Investigate the impact of socially assigned ethnicity as it is currently unknown.

Conclusion

Results suggest a wide array of complex, entangled, and compounding factors drive inequitable CCHD infant survival outcomes by race and ethnicity.

Future research could explore the impact of multi-level equity interventions on identified modifiable factors which influence CCHD mortality risk within the Australasian setting.

Thank you. Questions?

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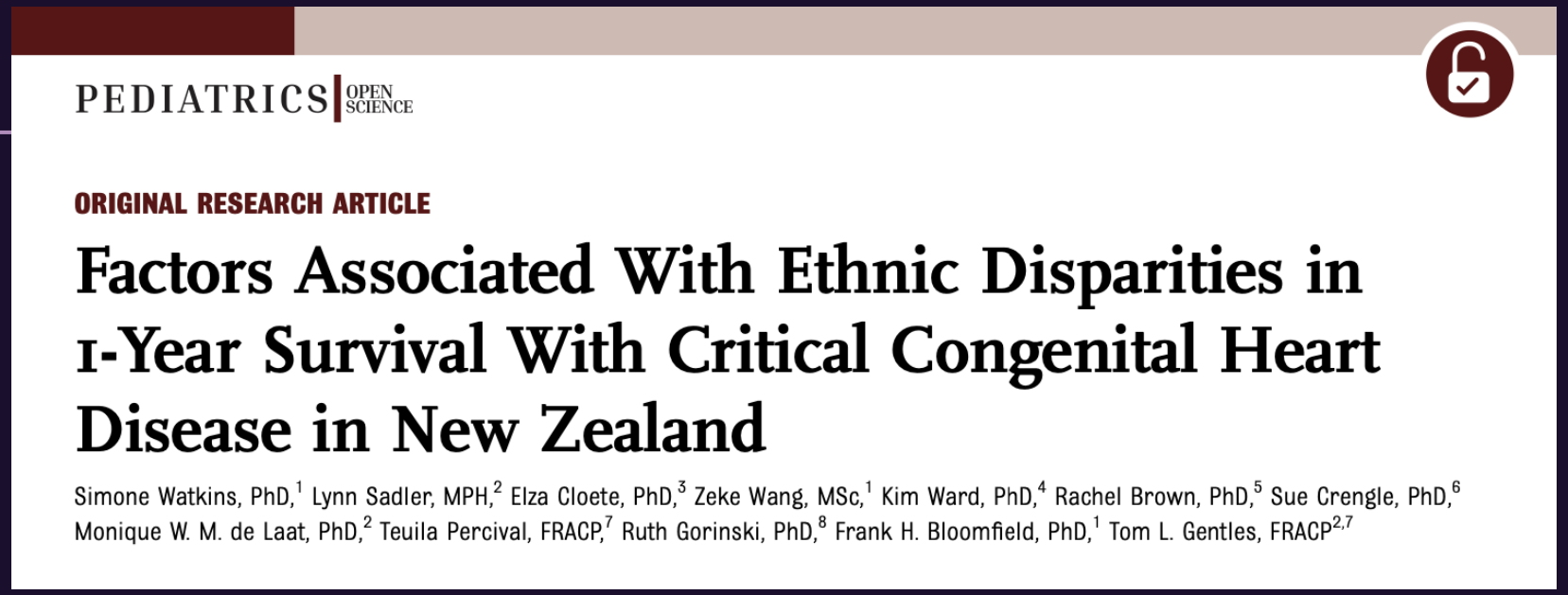
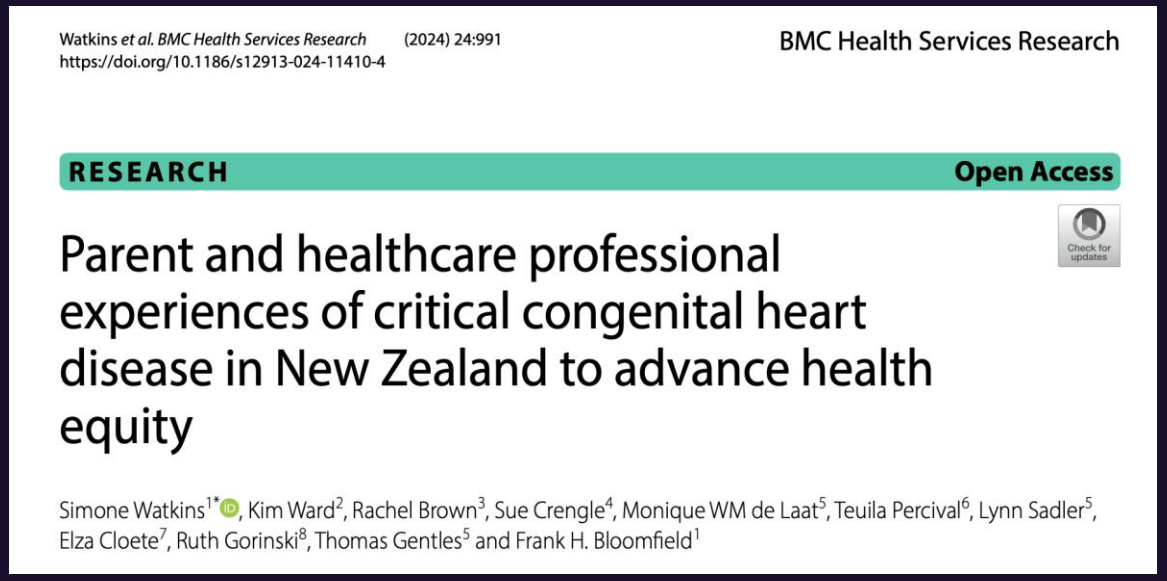


PEDIATRICS | OPEN SCIENCE

ORIGINAL RESEARCH ARTICLE

Factors Associated With Ethnic Disparities in 1-Year Survival With Critical Congenital Heart Disease in New Zealand

Simone Watkins, PhD,[1] Lynn Sadler, MPH,[2] Elza Cloete, PhD,[3] Zeke Wang, MSc,[1] Kim Ward, PhD,[4] Rachel Brown, PhD,[5] Sue Crengle, PhD,[6] Monique W. M. de Laat, PhD,[2] Teuila Percival, FRACP,[7] Ruth Gorinski, PhD,[8] Frank H. Bloomfield, PhD,[1] Tom L. Gentles, FRACP[2,7]



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BMC Health Services Research

RESEARCH Open Access

Parent and healthcare professional experiences of critical congenital heart disease in New Zealand to advance health equity

Simone Watkins[1*], Kim Ward[2], Rachel Brown[3], Sue Crengle[4], Monique WM de Laat[5], Teuila Percival[6], Lynn Sadler[5], Elza Cloete[7], Ruth Gorinski[8], Thomas Gentles[5] and Frank H. Bloomfield[1]