

# Rheumatic heart disease in pregnancy: gaps and facilitators of care

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## Certificate of original authorship

This thesis is submitted in fulfilment of the requirements for the award of Doctor of Philosophy in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise referenced or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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## Thesis format

This thesis comprises two published papers in peer-reviewed journals, and a third qualitative study as part of the thesis.

## Published work

### Research outputs

#### **Study one**

**Vaughan G**, Dawson A, Peek M, Carapetis J, Sullivan EA. *Standardising clinical care measures of rheumatic heart disease in pregnancy: a qualitative synthesis*  
Birth: Issues in Perinatal Care 2019 00:1-14 [early view]

#### **Study two**

**Vaughan G**, Tune K, Peek M, Jackson Pulver L, Remenyi B, Belton S, Sullivan EA. *Rheumatic heart disease in pregnancy: strategies and lessons learnt implementing a population-based study in Australia*. International Health. 2018;10(6):480-9.

## Other work - national guideline development

Vaughan, G (lead author) of the **Women and RHD** chapter in the 3rd Edition Australian Guidelines for Rheumatic Fever and Rheumatic Heart Disease currently in development.

As the lead author of the Women and RHD chapter of the 3rd Edition Australian Guidelines for Rheumatic Fever and Rheumatic Heart Disease<sup>1</sup> currently under development, I have coordinated the structure of the writing group, working with the selected core writing (Dr Miriam Wheeler and Linda Bootle) and broader review groups, alongside coordinator Sara Noonan. Notably, the Chapter was reviewed and informed by community-based and senior Aboriginal leaders Vicki Wade and Karrina Demasi. I have led the development and structure of the chapter and co-written, co-edited and reviewed content. This collaborative work was substantively a new addition; the previous Edition had been a short section in the Guidelines focused on pregnancy only.

The content and direction of the chapter has been informed by (and in turn informs) this thesis. It is an important translational outcome of the research and is in part a response to recommendations based on research findings of the Australasian Maternity Outcomes Surveillance System (AMOSS) NHMRC #1024206 RHD in pregnancy project. It reflects the

increasing recognition that effective models of care must be grounded in respectful, collaborative systems with a life-course approach, working with women and communities.

### **Statement of contributions to jointly authored works contained in the thesis**

Chapters 4 and 6 have been published in peer-reviewed journals. For each of these manuscripts, I have been responsible for deciding the research question, conducting the analysis and drafting the manuscript.

Specific contributions to each published paper and author signatures are listed in Appendix 7.

I take responsibility for the accuracy of the results presented in these manuscripts.

## Preface

The principal motivations that have guided this work include:

- The belief that skilled, appropriate, respectful health care during pregnancy is a right for all women;
- Provision of this quality health care for pregnant women with RHD requires integrated services and information systems;
- The experience of implementing the AMOSS study of rheumatic heart disease in pregnancy (RHD-P), which highlighted several challenges and gaps in providing integrated services for women with RHD across multiple disciplines and health services;
- Those gaps in providing integrated care generated inefficiencies and potentially compromised optimal outcomes for mother and baby;
- Conversely, pregnancy provides an ideal time to engage (or re-engage) with women to review cardiac status and ensure that optimal care is provided to maximise best outcomes through the life-course.

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## Indigenous and First Nation peoples: terminology

The recommendations from 'Communicating Positively, A guide to appropriate Aboriginal terminology' <sup>2</sup> and 'The Australian Indigenous HealthInfoNet guidelines for Aboriginal and Torres Strait Islander terminology' <sup>3</sup> have guided reference to Aboriginal and Torres Strait Islander peoples in this thesis.

Terms such as Aboriginal peoples, Aboriginal and Torres Strait Islander peoples and Indigenous have all been used in the literature. I have used the terms non-Indigenous and non-Aboriginal interchangeably when referring to all other non-Indigenous Australians.

The term Indigenous is capitalized as a form of respect. When making international comparisons I have used the term Indigenous in general; when quoting from other sources I have used the term used in that material.

The term Māori refers to Indigenous peoples of New Zealand (NZ) and Pasifika refers to people living in New Zealand (or Australia) who have migrated from the Pacific Islands or who identify with the Pacific Islands because of ancestry or heritage <sup>4</sup>.

# Abstract

## Background

In the twenty-first century, rheumatic heart disease (RHD) persists in low- and middle-income countries as well as vulnerable populations in high-income countries, particularly Indigenous peoples. RHD in pregnancy (RHD-P) is associated with an increased burden of maternal mortality and morbidity, poorer perinatal outcomes, and compromised care pathways. There is inadequate knowledge regarding models of care for women with RHD-P. This research identifies and examines gaps and facilitators of optimal care for women with RHD-P with a focus on Australian health services.

## Methods

The mixed methods research employed a transformative parallel design lens, providing a mechanism with which to address the political and social complexities of research in the RHD-P arena and in turn establishing a framework for change.

The study comprises three elements. The first involved a systematic review and qualitative synthesis of the peer-reviewed literature, that explored approaches to care provision for women with RHD-P and examine reported measures. It applied content analysis to examine models of care and clinical care reporting measures.

The second element entailed a descriptive qualitative study that explored 19 health professionals' perspectives of care pathways for women with RHD-P. The semi-structured interviews were analysed thematically.

The final study conducted a process evaluation of the implementation of a population-based study of RHD-P in Australia. It examined the operationalising of the research project, and evaluated strategies developed to strengthen reporting and improve awareness of the impact of RHD during pregnancy among health services.

## Findings

The studies identified gaps related to health systems, health workforces and health information that impacted on effective models of care.

The systematic review found that key reporting measures in studies that refer to RHD-P were poorly recorded.

The qualitative study of health professionals' perspectives of RHD-P identified a constellation of factors that challenged the provision of cohesive women-centred health care. Themes included *conduits of care* - helping to break down silos of information, processes and access; *'layers on layers'* – reflecting the complexity of care issues; and *shared understandings* – factors that contributed to improved understandings of disease, informed decision-making, and the inclusion of family and community members.

The process evaluation of the population level study of RHD-P exemplified several of the themes arising from the previous two studies. Effective reporting was negatively impacted by a lack of diagnostic certainty; incompatible health information systems and varying clinical awareness among health professionals.

## Discussion

This research found that, despite often complex care requirements, pregnancy for women with RHD provides a unique opportunity to strengthen health system responses, improve care pathways, address whole of life health and ultimately reduce the burden of RHD for women. To respond effectively, structural and cultural changes are required to improve health system agility and capability. This includes enhanced investment in education and capacity building – particularly in maternal health – to support a better informed and skilled workforce; and improved information systems and reporting of core indicators to more accurately benchmark care pathways, outcomes and burden of RHD-P.

## Conclusion

Central to the provision of informed, respectful collaborative care for women with RHD is timely diagnosis, access to health services and continuity of care. The research recommendations based on study findings aim to better achieve these goals and, in doing so, ensure the needs of vulnerable women with RHD are better met.