

# What matters for pregnant women with rheumatic heart disease - perspectives of health service providers: A qualitative study

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## Abstract

**Objective:** Rheumatic heart disease (RHD) persists in low-middle-income countries and in high-income countries where there are health inequities. RHD in pregnancy (RHD-P) is associated with poorer maternal and perinatal outcomes. Our study examines health care perspectives of models of care for women with RHD-P. **Design:** Descriptive qualitative study exploring health professionals' perspectives of care pathways for women with RHD-P. **Setting:** Australia **Population:** Nineteen participants from maternal health and other clinical and non-clinical domains related to RHD-P. **Methods:** Thematic analysis of semi-structured interviews. **Results:** A constellation of factors challenged the provision of cohesive women-centred care, related to health systems, workforces and culture. 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 and informed decision-making. **Conclusions:** Pregnancy for women with RHD provides an opportunity to strengthen health system responses, improve care pathways and address whole-of-life health. To respond effectively, structural and cultural changes are required including enhanced investment in education and capacity building - particularly in maternal health - to support a better informed and skilled workforce. Aboriginal Mothers and Babies programs provide useful exemplars to guide respectful effective models of care for women with RHD, with relevance for non-Indigenous women in high-risk RHD communities. For key goals to be met in the context of RHD, maternal health must be better integrated into RHD strategies and RHD better addressed in maternal health.

## Title page

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### Running title

RHD in pregnancy – health service perspectives

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## Tweetable abstract

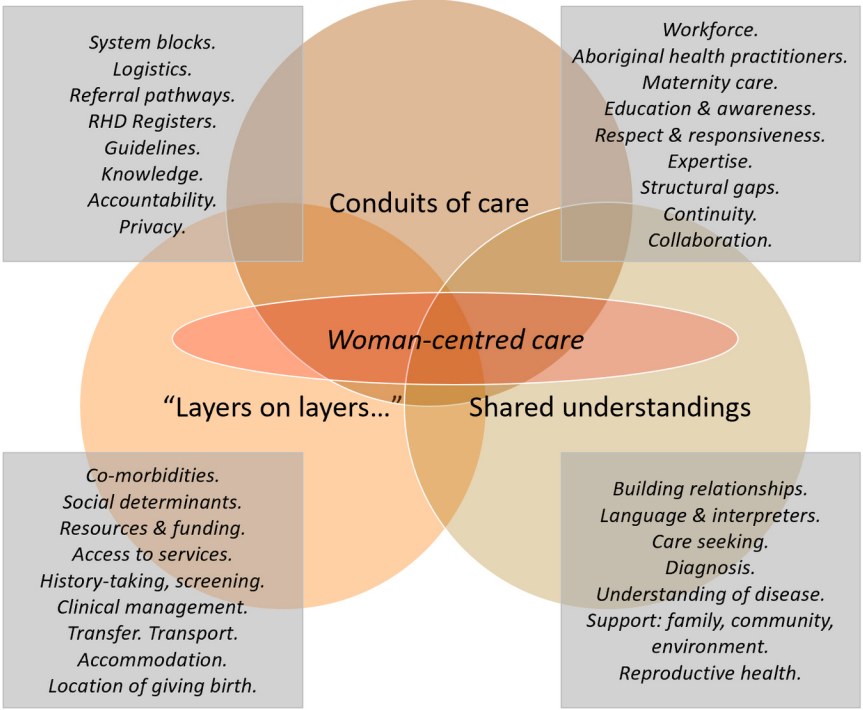
Qualitative study highlights care gaps for women with rheumatic heart disease (RHD). RHD must be better addressed in pregnancy.

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Access to services	Education & awareness. Guidelines	Health information systems	Workforce, health sectors	Integrated care	Clinical management	The big picture
Collaborative trans-disciplinary care						
 Transport	 Knowledge. Awareness. Respect	 Data systems - perinatal, cardiac, community, RHD	 Expertise. Skill. Respect	 Mapping care. Preconception. Pregnancy	 Diagnosis. Transition to adult cardiac & SRH care	 Social determinants - priorities
 Obstetric, Cardiac, other specialist services Medications	 Guidelines	 E-health, paper-based	 Continuity of care. Short-term locums	 Women, families, community. Shared understandings	 Risk assessment. Monitoring. Surgery	 Causes of causes: Housing. Inequity
 Logistics, system blocks. Language	 Checklist. Asking right questions, right way	 Intra/interjurisdictional. Public/private sectors	 Indigenous health practitioners & workers	 Co-morbidity. Chronic disease management	 Secondary prophylaxis. Anticoagulation. Dental	 Global burden
 Built environments	 Education. Curricula	 System blocks. Referral pathways	 Resources	 Vertical v horizontal v diagonal delivery	 Complications. Outcomes	 Advocacy. Initiatives. Changing landscape