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ORIGINAL ARTICLE

Rheumatic heart disease in pregnancy: strategies and lessons learnt implementing a population-based study in Australia

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Background: The global burden of rheumatic heart disease (RHD) is two-to-four times higher in women, with a heightened risk in pregnancy. In Australia, RHD is found predominantly among Aboriginal and Torres Strait Islander peoples.

Methods: This paper reviews processes developed to identify pregnant Australian women with RHD during a 2-year population-based study using the Australasian Maternity Outcomes Surveillance System (AMOSS). It evaluates strategies developed to enhance reporting and discusses implications for patient care and public health.

Results: AMOSS maternity coordinators across 262 Australian sites reported cases. An extended network across cardiac, Aboriginal and primary healthcare strengthened surveillance and awareness. The network notified 495 potential cases, of which 192 were confirmed. Seventy-eight per cent were Aboriginal and/or Torres Strait Islander women, with a prevalence of 22 per 1000 in the Northern Territory.

Discussion: Effective surveillance was challenged by a lack of diagnostic certainty, incompatible health information systems and varying clinical awareness among health professionals. Optimal outcomes for pregnant women with RHD demand timely diagnosis and access to collaborative care.

Conclusion: The strategies employed by this study highlight gaps in reporting processes and the opportunity pregnancy provides for diagnosis and re/engagement with health services to support better continuity of care and promote improved outcomes.

Keywords: Health information systems, Health services, Indigenous health, Pregnancy, Public health, Rheumatic heart disease

Introduction

Rheumatic heart disease (RHD) is a condition of paradox in the high-income countries of Australia and New Zealand (ANZ), rare overall, but common in disadvantaged populations, with the burden of RHD among Indigenous and Pacifica peoples in ANZ among the highest documented rates in the world.[1–3]

This non-communicable disease of inequity is a serious sequela of (usually repeated) episodes of the Group A streptococcus infection of rheumatic fever (RF), resulting in chronic damage to heart valves. Two-to-four times as many women as men are diagnosed with RHD.[2,4,5] Together with other high-income countries, the overall incidence of RHD in Australia dropped dramatically in the second half the twentieth century (Figure 1). However, for Aboriginal and/or Torres Strait Islander women, RHD is among the leading 20 causes of fatal burden (years of life lost) and among the 20 specific diseases contributing to the gap in total burden (disability-adjusted life years (DALYs)), with a rate ratio of 6.9 Indigenous compared with non-Indigenous Australian women.[2]

An increased cardiac workload in pregnancy can unmask undiagnosed RHD and exacerbate clinical symptoms in women with known disease. The risk of poorer maternal and perinatal outcomes escalates, particularly for women requiring anticoagulant

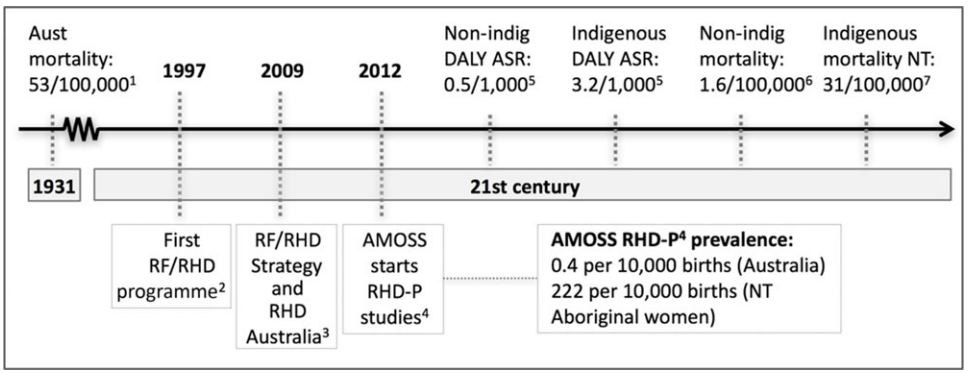

Figure 1. RHD prevalence and surveillance timeline in Australia. [1]'All-female Australia age-standardized RHD death rate' (Mortality and Morbidity: Cardiovascular disease: 20th century trends, 2002). Section 127 of the Australian Constitution excluded Aboriginals from official statistics until 1967. The first regular collection of Aboriginal health data began in 1957 (NT). Jurisdictional legislation did not allow for registration of vital statistics by race until after 1979.[32] [2]First Rheumatic Fever (RF)/RHD control programme established Northern Territory (NT) jurisdiction of Australia.[33] [3]Register and control programmes in three jurisdictions (five of eight jurisdictions by 2016); National coordination to develop resources and data collection system through RHDAustralia.[34] [4]2012–2016: Rheumatic heart disease in pregnancy. National Health and Medical Research Council (NHMRC) project grant #1024206. An AMOSS study. [5]Australian Institute of Health and Welfare (AIHW). Australian Burden of Disease Study: Impact and causes of illness and death in Aboriginal and Torres Strait Islander people 2011. Canberra, Australia: AIHW, 2016. BOD 7. [6]Table 1.1 'Underlying cause of death, All causes, Australia' (All-female age-standardized).[35] [7]Table 12.5 'Underlying causes of death, leading causes by Aboriginal and Torres Strait Islander status, NSW, Qld, SA, WA and NT, 2010–2014' (All-female age-standardized). In: 3303.0 Causes of Death, Australia, 2014. ABS 2016. **Notes**: DALY, ASR, disability adjusted life years age-standardized rate; all rates except AMOSS RHD-P prevalence are for females with RHD.

therapy and for women with mitral stenosis.[6] The burden of RHD in pregnancy is under-researched—the majority of studies examine severe disease in non-pregnant adults, all-cardiac disease in pregnancy or single-site studies, mostly in high-prevalence countries of sub-Saharan Africa, Asia and South America.[7–10] There are no known national population-based studies of RHD in pregnant women.

Commencing in 2013, a 2-year surveillance and descriptive study of the prevalence, management and outcomes of rheumatic heart disease in pregnancy (RHD-P) across ANZ was undertaken against a backdrop of increased advocacy and growing recognition of the burden—both global and country-specific—of RHD.[11–14]

Objective

The Australasian Maternity Outcomes Surveillance System (AMOSS) RHD in pregnancy study aimed to identify all pregnant women with RHD who presented at any of 284 participating AMOSS maternity sites across Australia (n=262) and New Zealand (n=22) during 2013 and 2014, for inclusion in a descriptive study of clinical backgrounds, models of care and cardiac, obstetric and perinatal outcomes. The objective of this paper is to identify the challenges of surveillance in the Australian arm of the study, and the strategies developed to strengthen reporting by—and improve awareness among—health services.

Materials and methods

Inclusion

The AMOSS study used World Heart Federation (WHF) criteria based on echocardiographic diagnosis of RHD[15] to identify women for inclusion. Pregnant women (20 or more weeks' gestation) were included if they had confirmed RHD based on their most recent echocardiogram report, or a historic echocardiogram where the most recent echocardiogram report was not available. Because a case was defined during pregnancy, women could potentially be included more than once during the 24-mo study period. Women were excluded if they had a miscarriage or termination of pregnancy before 20 weeks' gestation, or if the baby's date of birth was outside the study period (1 January 2013 to 31 December 2014).

Reporting

The study was conducted under the umbrella of the AMOSS.[1] This hospital-based surveillance and research system was established across ANZ in 2009 in response to the lack of national information on the incidence, risk factors, management and sequelae of rare and serious conditions in pregnancy. Volunteer site coordinators at participating AMOSS maternity sites (predominantly midwives and obstetricians—'AMOSS data collectors') report and complete web-based surveys on nominated conditions over defined study periods. De-identified data are entered from case notes.

Negative reporting was employed; monthly emails were sent to AMOSS data collectors during 2013–2014 asking whether or not they had any women under their care with RHD in the preceding month. This established AMOSS reporting system (Figure 2) was supplemented by additional notification methods in the RHD-P study (Figure 2 and Table 1), although the AMOSS remained the central notification point. This extensive network of stakeholders helped optimize surveillance and strengthen awareness of the study.

Specific approaches to case ascertainment were developed according to jurisdiction and site. AMOSS maternity site data collectors primarily used perinatal data and health information systems. The AMOSS project coordinators from the study team

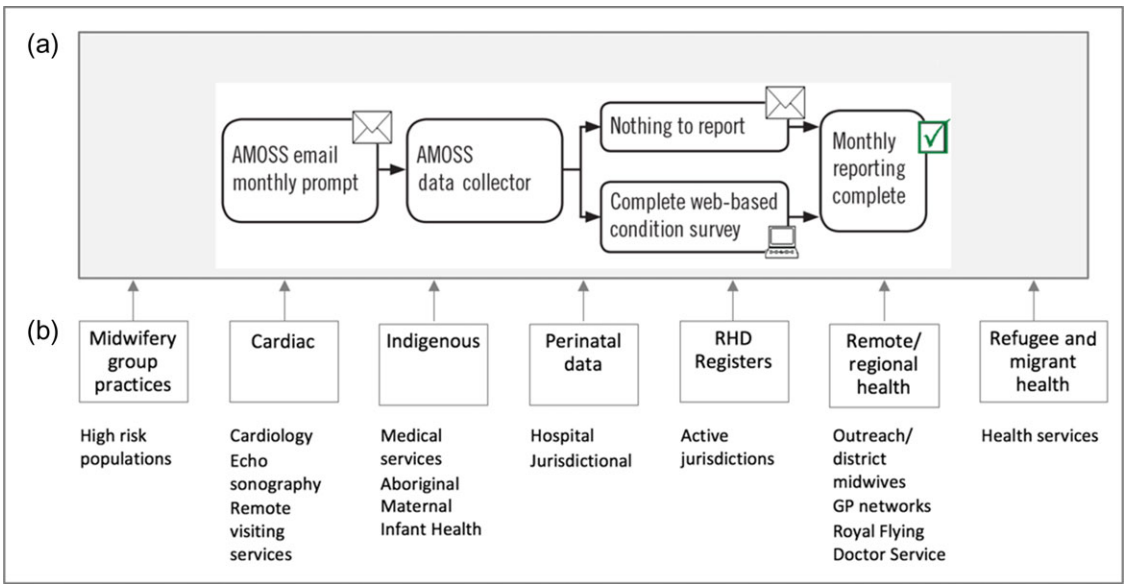

Figure 2. AMOSS surveillance and research platform (262 maternity units in Australia). Usual AMOSS reporting cycle (a) supplemented by RHD-P enhanced network (b).

Table 1. Confirmed cases of women giving birth with RHD reported according to source[a]

Confirmed cases: notification source	n	% of total 192 cases
AMOSS		
AMOSS participating maternity site data coordinator (sole notification)	106	55%
All Australian cases: AMOSS participating maternity site data coordinator or NT AMOSS coordinator (multiple notification with other sources possible)	181	94%
NT cases: AMOSS NT coordinator (multiple notification with other sources possible)	59	31%
Other sources (non-AMOSS coordinator)		
Midwifery group practice/antenatal care/remote area or district midwife/remote medical officer/general practitioner	22	11%
Obstetrician/obstetric physician/obstetric registrar	7	4%
Aboriginal maternal and infant care/Aboriginal medical service/Indigenous Cardiac Outreach Program	6	3%
Cardiologist/cardiac nurse/anaesthetic/echocardiogram technician/other specialist service	8	4%
RHD registers (four active jurisdictions during study)	26	14%
Total	**192**	

[a]More than one source notification possible, percentages are of the total 192 cases.

queried additional systems in high prevalence regions, including remote/primary health information systems and RHD control registers, using the broad search terms 'cardiac' and 'rheumatic' in the search criteria, and reviewing individual case notes. Similar enhanced case note reviews of perinatal data systems were conducted by the study team at three major tertiary sites outside the NT. In the NT, which has the highest reported rates of RHD in Australia among Aboriginal women, a dedicated project coordinator conducted a validation study. Where the echocardiogram report was inconclusive in this jurisdiction, the actual echocardiogram was reviewed by a cardiologist.

In New South Wales (NSW), through consultation with Western NSW Aboriginal Maternal Infant Health Service and the 'ObstetriX/eMaternity' perinatal data working group, questions for women at the antenatal booking visit were revised to include detailed prompts on RF/RHD history, including whether the woman remembered having regular intramuscular injections (prompt for secondary prophylaxis) as a child, as well as her heart history.

Following case confirmation, AMOSS site data collectors or the project coordinators completed web-based surveys, covering demographic, general medical/obstetric history, pregnancy pathway, and maternal obstetric/cardiac and perinatal outcomes. The authors

revised the study protocol during a 2-mo pilot phase to send echocardiogram reports directly to the study team for entry, in order to confirm case inclusion, reduce resource burden and achieve optimal consistency. In addition to the NT, AMOSS project coordinators supported case note review and completion of surveys in other high prevalence regions, particularly the Kimberley region of (north) Western Australia and far north Queensland, and/or where the resource burden meant that onsite staff required assistance.

Specific data items identified whether the woman had been reported in a previous pregnancy during the study period, as well as number of months since the last pregnancy.

Duplication was checked through a tiered process, including continual monitoring of the reporting database, probabilistic methods (using a series of concatenated data fields) and checking with the AMOSS site data collector. The survey was completed at the site where the woman gave birth.

Ethics and consultative processes

Ethics approval requests under the aegis of the AMOSS were submitted to 32 Australian ethics committees and over 200 affiliated governance sites.[1] Subsequent amendments repeated this process as the study protocol was revised during the pilot phase. Access to sites for case note review and/or data entry directly by the research team was also approved where requested by the AMOSS site coordinator and for all NT. De-identified data were collected and reported at an aggregate level only. No consent was required for this quantitative arm of the RHD-P study. Aboriginal health services and Aboriginal Maternal Infant Health Services endorsed the study through letters of support.

Formal and informal consultative processes were established and continued throughout the research project in order to build awareness of the study (and more generally about the impact of RHD-P), optimize notification processes and provide avenues for dissemination of findings (Figure 2).

An Advisory Group comprised Australia and New Zealand investigators, the study team, invited representatives from Aboriginal, cardiac and maternity services, public health, jurisdictional and RHD organizations, and related policy bodies.

Results

Surveillance

The AMOSS network of 262 Australian sites notified of 495 potential cases (Figure 3a). Of these, 246 did not meet the inclusion criteria. There was no evidence of RF or RHD in 99 cases (identified predominantly through the perinatal data system search), and in 147 cases there was RF only or a valvular RHD lesion that had resolved. An additional 32 women gave birth outside the study period, and eight women who miscarried or who had a surgical termination of pregnancy before 20 weeks' gestation were excluded. No data were received for four cases and 13 cases were duplicate notifications. A total of 192 pregnancies of Australian women with confirmed RHD (according to WHF criteria for echocardiographic diagnosis of RHD) who gave birth (≥20 weeks' gestation) were included in the Australian arm of the study.

In the NT, where the validation study was performed, 126 of 211 cases reviewed did not meet inclusion criteria. Sixty-eight cases reviewed were excluded due to lack of evidence of RF or RHD, and a further 58 had either RF only or resolved RHD (Figure 3b).

Data collection processes

Notification and data collection processes varied according to jurisdiction, geography and site.

Notification

Cases were principally notified by data collectors at participating AMOSS maternity units or the NT-based AMOSS coordinator (181/192 94% eligible women), supported by other notifications such as Midwifery Group Practices, antenatal clinics and cardiac, community, remote, primary health and Aboriginal health services, including the Indigenous Cardiac Outreach Project (Table 1, with multiple notifications possible). In the NT, notification sources were documented by health group and location (Figure 4).

The RHD-P study partnered with jurisdictional RHD control programmes to promote register functions and purpose, with registers assisting in notification. Additionally, RHD programme staff in some jurisdictions had developed care plans and notification prompts that aided reporting.

A total of 106 cases (55%) were notified solely by the AMOSS maternity site data collector.

Where transfer of care occurred, a post-hoc review of data to ascertain any duplication of cases was conducted. Two women were lost to follow-up when they moved away in early pregnancy from the maternity site where they attended the antenatal 'booking' visit.

Data collection

Case note reviews entailed querying up to seven distinct information systems, in addition to reviewing paper-based files in sites where hybrid electronic-paper systems were active. In the high prevalence NT, the seven information domains included two discrete primary healthcare information systems that did not integrate with each other, and a privately run cardiac practice that provides services to the predominantly government-funded NT health system (Figure 5). Jurisdictional RHD registers are separate entities from each other, which may or may not articulate with the hospital and primary health information systems.

Prevalence

The Australian rate of RHD in pregnancy was 4.3 per 10,000 women giving birth. Of the confirmed 192 cases from six jurisdictions included in the study, overall rates ranged from 0.7 per 10,000 women giving birth in Victoria to 74.3 per 10,000 women giving birth in the NT (Figure 6). There were no confirmed cases in two jurisdictions. Rates among Aboriginal and/or Torres Strait Islander women ranged from 7.0 per 10,000 women giving birth in NSW to 222.2 per 10,000 in the NT

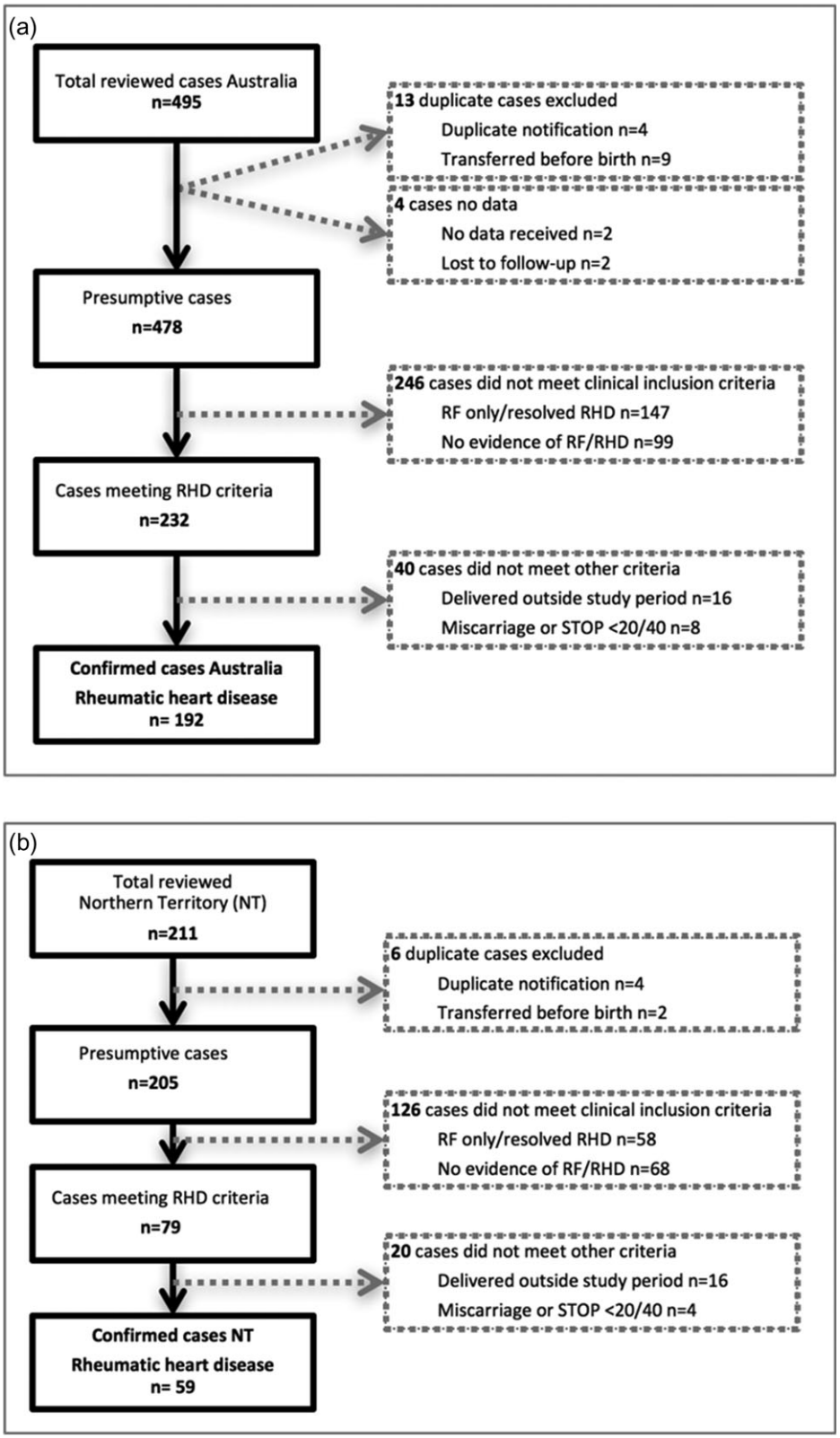

Figure 3. Surveillance of pregnant women with RHD: (a) Australia and (b) Northern Territory 2013–2014.

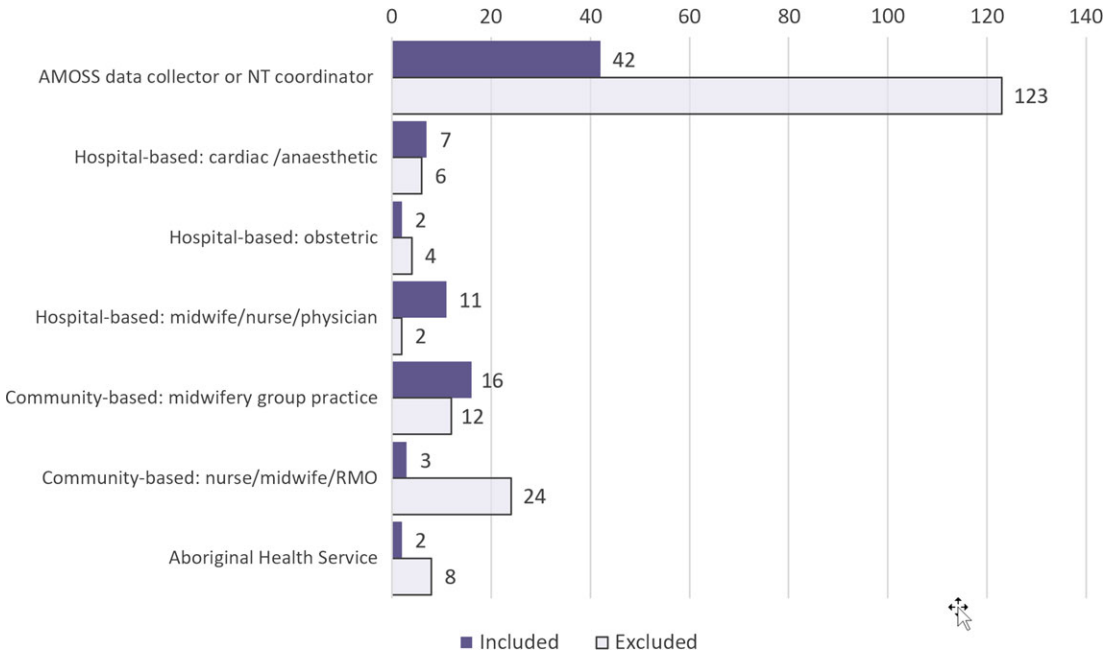

Figure 4. AMOSS surveillance and research platform (262 maternity units in Australia. NT breakdown of reported cases by health group/location and inclusion.

(Figure 6). Overall, 78% (n=150) of Australian women included in the study were Aboriginal and/or Torres Strait Islander. The NT had 59 (31%) of cases, 99% of whom were Aboriginal women.

Discussion

As well as providing multidisciplinary clinical care for women with known RHD, pregnancy provides the opportunity to identify newly diagnosed cases of RHD, re-engage with women who may have 'dropped out' of care as they transition from paediatric to adult specialist cardiac services, and provide language-appropriate health education that promotes a shared understanding of the impact of RHD and its implications in pregnancy.[16] However, this study highlights challenges to effective provision of care across several tiers, relating to case ascertainment, burden of reporting and health information systems. These factors impacted on a group of at-risk women with complex health needs and high rates of co-morbidities. Strategies developed to help support case notification underscored the value of an extended reporting network across health sectors, and reinforce the value of collaborative care.

Case ascertainment

High false positive rates (Figures 3 and 4) are consistent with preliminary active case finding work being undertaken by jurisdictional RHD Registers (personal communication) and the 'End RHD' Centre for Research Excellence[17]), which suggests significant over-ascertainment of hospital cases of RHD through ICD 10 coding, including valvular heart disease of unspecific origin. In the NT, where the validation study was conducted, a shortened case survey data collection was performed of the 58 women excluded from the study with either RF only or resolved RHD, with the aim of examining the burden on NT health services of being incorrectly diagnosed with RHD according to WHF criteria.

As well as over-reporting, under-reporting is assumed to have occurred of women with mild asymptomatic RHD without a case history or resultant complications who did not have an echocardiogram and were not reported. A number of women with a history of RF were reported, but definitive diagnosis or exclusion of RHD could not occur due to lack of supporting evidence (by echocardiogram/cardiac review), including five women born overseas.

The AMOSS system is based on reported cases of women with RHD admitted to maternity units at 20 weeks' gestation or more: yet RHD is associated with higher rates of miscarriage, as well as perinatal death.[18] In the NT review, an estimated 7% of otherwise eligible women with RHD miscarried, or were recommended for termination of pregnancy due to their cardiac condition. Thus, the true prevalence of RHD-P is higher than documented in this study.

Burden of reporting

The AMOSS system researches morbidities in pregnancy with an (overall) estimated prevalence of less than 1:1000 women giving birth – completed studies included – for example, H1N1 influenza, amniotic fluid embolism, vasa previa. Smaller maternity sites typically report an AMOSS condition once every several years, if at all. However, in this study, there was a significant burden on data collectors in high prevalence regions, where sites with 200–300 births per year had eight or more cases of women with RHD. This site burden was compounded by the

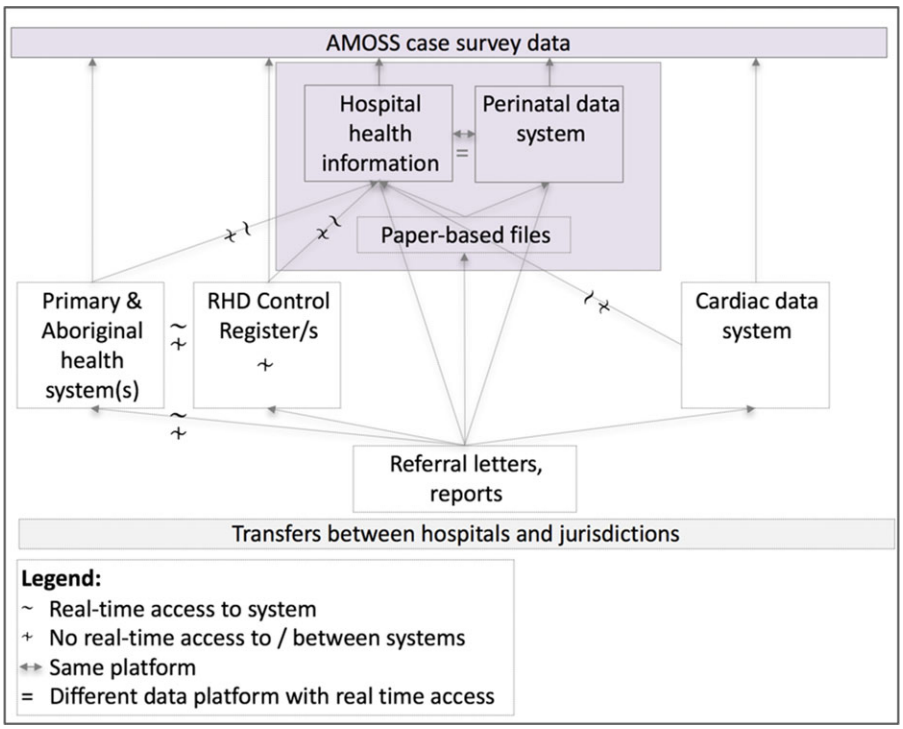

Figure 5. Data sources: surveillance and data collection.

work involved in information retrieval (Figure 5 and the next section).

Health information systems

Our study found a lack of cohesion in standard data collection systems, including multiple systems, gaps in accurate case ascertainment, and effective transfer of information between and across health services and jurisdictions. There were multiple sources of data, with some sites employing a mix of electronic and paper-based record systems, various electronic data systems in remote and primary healthcare networks that did not articulate, and gaps in sharing that information across networks, including Aboriginal health services.

There was a significant variation in the amount and quality of information provided in echocardiogram reporting used to determine inclusion. Reports ranged from detailed records to handwritten excerpts. They were often not included in patient notes where women were transferred or had the echocardiogram performed by a private provider, or were unavailable for women born outside of Australia. Additionally, the lack of standardized reference values in echocardiogram reporting impacts on data integrity and clinical decision-making,[19] particularly for pregnant women.

The World Health Organization Roadmap for Action[20] notes that 'Only by disaggregating and analysing data can populations in need of health services be identified and included in informed policies and programmes'. Our study highlights the need for improved RHD annual reporting and analysis at a national level with disaggregation by gender together with Indigenous identification and age.

The National Data Collection System (NDCS; RHDAustralia-managed during the study period) is the central repository for the collection and reporting of RF and RHD data, yet it only reports on data from the jurisdictional register-based control programmes for RF/RHD (four out of a total of eight Australian jurisdictions during the study period).[21] Pregnancy status was a recommended data item in the NDCS recommended dataset in 2011. However, no jurisdictions currently monitor pregnant status within RHD Registers. This sharing of health information would be further strengthened by including pregnant status as a data item in RHD Registers.

Strategies to improve surveillance and build awareness

Streamlined, multi-tiered surveillance processes were established in this study to identify pregnant women with RHD across ANZ. While the AMOSS system remains a timely and reliable primary source of notification of (overall) rare conditions in pregnancy, these multi-tiered processes demonstrated that employing additional reporting sources can provide an effective surveillance adjunct,[22] and a useful augmentation strategy to better inform the research of health risk, diagnosis, management and pregnancy outcomes of women with RHD. This is particularly significant for RHD, where a missed diagnosis or lack of awareness can have such a detrimental impact in pregnancy.

The call for multi-disciplinary care that straddles specialist cardiac and obstetric disciplines for pregnant women with cardiac disease is not new.[6,23] However, this study highlighted the

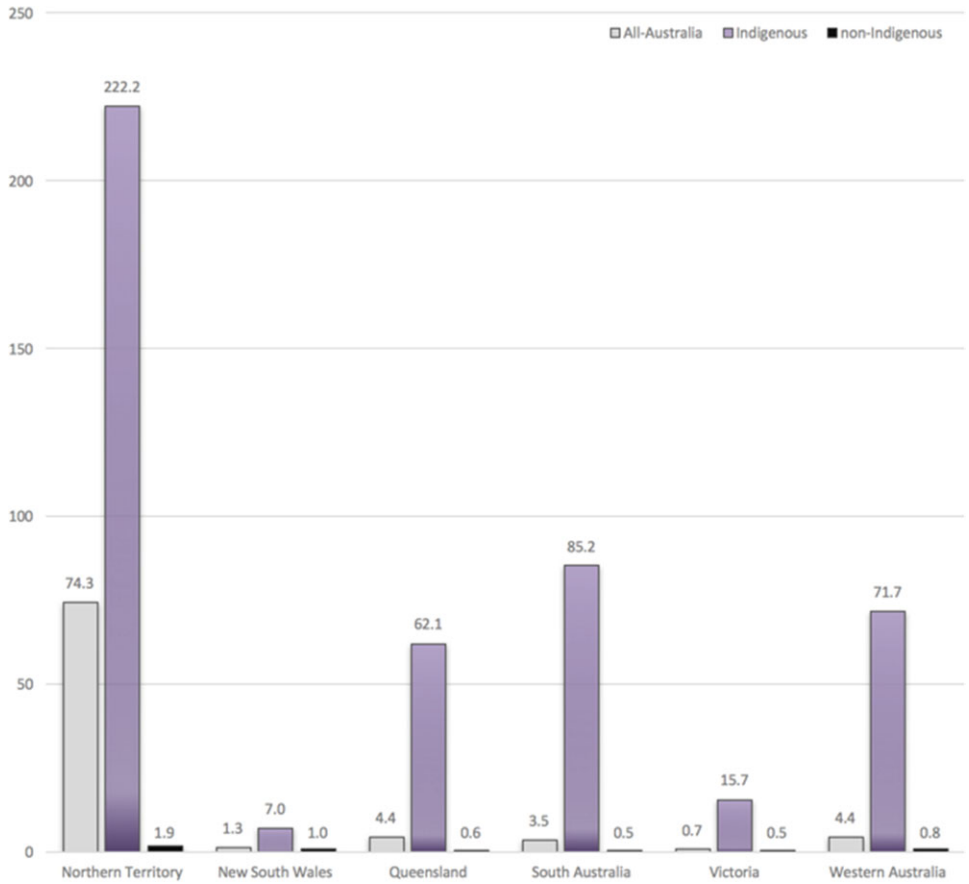

Figure 6. Rates per 10 000 Australian women giving birth with RHD by Australian jurisdiction 2013–2014.

benefit – and imperative – of building integrative, diagonal approaches to care[14,24] across all maternity, Aboriginal, and primary and public healthcare services (including RHD programmes), in order to support an optimal pathway of care, particularly early diagnosis and assessment.

This more integrative approach to care is consistent in study findings and reports ranging from chronic disease in Aboriginal peoples to international studies of maternal mortality[25,26] and to global RHD initiatives. Many chronic conditions face similar hurdles in achieving effective health information and communication sharing, particularly at the interface of primary and hospital-based care, and especially with remote Aboriginal and Torres Strait Islander health communities.[27] In their critique of Aboriginal health cardiac rehabilitation, DiGiacomo et al. similarly argue that inadequate referral systems, fragmented health information systems and gaps in coordinated health services create significant barriers to access for Aboriginal patients. They also point to inadequate resourcing of the Aboriginal health worker workforce, instrumental in supporting continuity of culturally competent care and making connections with various health agencies, also emphasized by Kelly et al.[28] Integration of RHD interventions with essential packages of health services, including maternal and child health, is consistent with strategies called for by RHD advocacy groups and initiatives at the global public health level.[11,29,30]

Study limitations

Miscarriage or surgical termination of pregnancy often occurred outside participating AMOSS maternity units. Thus, accurate case ascertainment of all women with pregnancy outcomes at <20 weeks' gestation was not possible across Australia in this cohort of women with a higher risk of pregnancy complications due to their cardiac status.

The study reports on one high-resource country and findings may not be as applicable in low-income countries. These findings do, however, parallel the overall health status of Aboriginal and Torres Strait Islander peoples in Australia. Indigenous identification was probably under-reported and thus the burden of RHD is under-estimated in this population, highlighting the need for health professionals to ask all women whether they identify as being of Aboriginal and/or Torres Strait Islander descent.

Moreover, themes raised by this study related to RHD awareness among maternal and primary health services are consistent with conclusions and recommendations in studies of RHD in pregnancy in endemic regions, and in global RHD strategies.

Conclusions

Optimal outcomes for pregnant women with RHD demand timely diagnosis, access to integrative, appropriate models of

care and health systems. The potential consequences of undiagnosed RHD in a pregnant woman demonstrate the value of enhanced reporting. Our study of the implementation of a population-based study of RHD in pregnancy identifies gaps in reporting and health information at a system level, as well as strategies developed to address these.

Our study findings call for implementation of pregnant status as a data item in jurisdictional RHD registers, specific questions related to RF/RHD history built into perinatal data systems, improved real-time access to RHD register information by hospital sites (and to other registers), improved education to support a more informed health workforce,[31] and a more granular reporting of RHD in national data sets of prevalence and mortality, broken down by gender. The study highlights the need to promote greater awareness among the maternity sector in order to detect RHD, provide early monitoring in pregnancy, and strengthen collaboration between disciplines in the care of pregnant women with this preventable condition.

The AMOSS RHD in pregnancy study investigators (NHMRC #1024206): (Chief) Professors Elizabeth Sullivan, University of Technology Sydney, Faculty of Health, Australian Centre for Public and Population Health Research (ACPPHR), Sydney, Australia, Lisa Jackson Pulver, Western Sydney University, Parramatta, Australia, Jonathan R Carapetis, Telethon Kids Institute, University of Western Australia and Princess Margaret Hospital for Children, Perth, Australia, Dr Warren Walsh, University of New South Wales and Prince of Wales Hospital, Sydney, Australia, Professor Michael Peek, The Australian National University and Centenary Hospital for Women and Children, Canberra, Australia, Dr Claire McLintock, National Women's Health Auckland City Hospital, Auckland, New Zealand, Professor Sue Kruske, Maternal and Child Health Institute for Urban Indigenous Health, Brisbane, Australia, Dr Suzanne Belton, Menzies School of Health Research, Darwin, Australia. (Associate) Professor Alex Brown, South Australian Health & Medical Research Institute (SAHMRI), Adelaide, Australia, A/Professor Elizabeth Comino, Centre for Primary Health Care and Equity, University of New South Wales, Sydney, Australia, Ms Heather D'Antoine, Menzies School of Health Research, Darwin, Australia, Dr Simon Kane, Lyell McEwin Hospital, Adelaide, Australia, Dr Bo Remenyi, Royal Darwin Hospital and NT Cardiac, Darwin, Australia, Professor Juanita Sherwood, University of Sydney, Sydney, Australia, Dr Sujatha Thomas, Royal Darwin Hospital, Darwin, Australia, Geraldine Vaughan, University of Technology Sydney, Faculty of Health, Australian Centre for Public and Population Health Research (ACPPHR), Sydney, Australia.

Authors' contributions: GV was responsible for the study design and implementation, analysis and interpretation of the data, contributed to the writing of this article, and read and approved the final version. KT was responsible for the study design and implementation, and read and approved the final version. MJP, BR and EAS were responsible for the study design, and the analysis and interpretation of the data. LJP was responsible for the study design, analysis and interpretation of the data, contributed to the writing of this article, and read and approved the final version. SB was responsible for the analysis and interpretation of the data, and read and approved the final version.

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