RHDA COLLOQUIUM

Developing a framework to enable a coordinated approach to acute rheumatic fever (ARF) and rheumatic heart disease (RHD) throughout Australia

> *Integration of RF and RHD control programmes into wider health systems is a high priority to avoid the development of 'unsustainable monolithic programmes'. This risk of isolated, disease-specific programmes contributing to inefficient or narrow-spectrum care has been identified over a number of decades. Some degree of centralization is necessary for effective delivery of services, given that RHD occurs in mobile and vulnerable populations with the need for long-term follow up and timely delivery of secondary prophylaxis. Centralized registries also enable descriptive and prognostic epidemiological data to be collected, and enable research to be conducted to improve our understanding of the disease. However, this approach must be combined with improved delivery of primary health care.*
>
> (Position statement of the World Heart Federation on the prevention and control of rheumatic heart)

BACKGROUND

The Colloquium was convened by Rheumatic Heart Disease Australia (RHDA), which was established in 2009 as the National Coordination Unit to support control of rheumatic heart disease in Australia. Funded under the Australian Department of Health's Rheumatic Fever Strategy, RHDA is based at Menzies School of Health Research in Darwin.

RHDA's aim is to reduce death and disability from acute rheumatic fever (ARF) and rheumatic heart disease (RHD) in Australian Aboriginal and Torres Strait Islander people by:

- Supporting RHD control programs in Australian States and Territories
- Establishing a data collection and reporting system
- Disseminating evidence based best practice guidelines
- Increasing community awareness of ARF and RHD and its prevention

ARF and RHD are major health care problems in Australia. The majority of patients in Australia are Aboriginal and Torres Strait Islander people living in remote and rural areas where remoteness; transient population; poor living and education standards; high health practitioner turnover; and limited knowledge of the disease all contribute to delays and deficiencies in health service delivery and, ultimately, to the burden of disease.

The four State and Territory RHD programs funded under the Rheumatic Fever Strategy contribute to, and benefit from, the activities of RHDAustralia. Although each program has its own priorities and unique characteristics in terms of burden of disease, geography and service provision, the overall role of the State and Territory programs is to:

- identify people with or at risk of ARF and RHD and include their details on a disease register;
- improve delivery of long-term secondary prevention treatment which helps prevent recurrent ARF and development or worsening of RHD;
- support clinical and public health practice by increasing disease awareness and expertise among the health workforce, so that they can provide appropriate health services to people with ARF and RHD, including clinical care and follow up, in line with best practice;
- provide advice on education and self-management support for people with ARF and RHD and their families, and the community;
- promote primary prevention which focuses on preventing first episodes of ARF; and
- use information from the disease registers to monitor health outcomes, and produce epidemiological reports to help improve control program activities.

The Northern Territory (NT) RHD program is based in Darwin with a satellite program in Alice Springs. The program in Western Australia (WA) is based in Broome, in Queensland it is based in Cairns, and in South Australia (SA) in Adelaide. All programs are attached to public health units. There have been significant recent advances in New South Wales (NSW) in the development of a register for ARF and RHD, a proposed model of care, and the appointment of a RHD Coordinator for NSW.

The Colloquium provided an opportunity to learn more about the role of the RHD programs and how they work across a spectrum of health services and geographic regions.

PURPOSE

The Colloquium brought together stakeholders from policy, clinical practice and research to discuss the development of a framework for a patient-centred model of care for ARF and RHD in the Australian context. This included an assessment of the current national and jurisdictional policy contexts; an analysis of gaps within service delivery; and a review of international experience and recommendations for the control of RHD. Outcomes from the day will inform recommendations for potential reorientation of health services and systemic changes to improve outcomes for ARF/RHD patients and to reduce the incidence of ARF/RHD.

OBJECTIVES

- To share information on ARF/RHD and the current issues and activities across Australia.
- To commence an open dialogue on issues relating to ARF/RHD with a specific focus on areas where service provision could be improved by bringing together stakeholders from policy, clinical practice and research to discuss the development of a framework for a patient-centred model of care for ARF and RHD in the Australian context.
- To commence:
    - an assessment of the current national and jurisdictional policy contexts;
    - an analysis of gaps within service delivery; and
    - a review of international experience and recommendations for the control of RHD.
- To build relationships with and amongst key stakeholders, and to develop a platform for ongoing engagement.

PARTICIPANTS

The Colloquium participants comprised 73 stakeholders from policy, clinical practice and research from Northern Territory, Queensland, Western Australia, New South Wales, South Australia, Victoria and the ACT. A full participant list is provided in this post-forum report.

PROCESS

Following a series of short, targeted presentations which highlighted points of difference across the jurisdictions, systematic issues and emerging themes from research studies, participants were asked to:

- Assess current gaps in service delivery using the conceptual framework for comprehensive RHD control programmes.
- Review models of care for primary health care and chronic care.
- Make recommendations for potential reorientation of health services and systemic changes.
- Consider what an ideal model of care may look like, and whether it was possible to make a recommendation on a National model of care.

COLLOQUIUM PROCEEDINGS: PART 1: PRESENTATIONS

Welcome and introduction

Participants were welcomed to the Colloquium by Professor Bart Currie (Director RHDA) and Uncle Allen Madden (elder of the Gadigal people), who gave the formal Welcome to Country.

Perspectives from the family (Cherie McAdam)

The Colloquium program opened with Cherie McAdam's personal and heartbreaking story of her family's experience of living with RHD. In particular, Cherie spoke of her daughter's journey through ARF, to eventual RHD and valve surgery.

Cherie's experience of the health care system in relation to ARF and RHD has led her to become a champion for improved care for people with, and at risk of, RHD. Cherie would like to see doctors allocated to clinics specifically to manage ARF and RHD. She would also like to see fines for clinics that are negligent in managing ARF and RHD.

RHD in pregnancy: A case study (Professor Elizabeth Sullivan, Principal Investigator; Geraldine Vaughan, University of Technology, Sydney; National Coordinator)

RHD in pregnancy means a complicated pregnancy and poor outcomes compared with women without RHD. The aim of the AMOSS (Australasian Maternity Outcomes Surveillance System) Rheumatic Heart Disease in Pregnancy Population Study is to provide an evidence base with a view to improving clinical care and associated maternal and perinatal outcomes for Australian and New Zealand women with RHD in pregnancy.

This presentation outlined the burden of disease in relation to RHD in pregnancy in Australia and New Zealand, and some of the challenges of managing RHD in pregnancy. Issues and barriers to effective care include poor transport services, poor communication, lack of child care, patient's reception at health services, poor health literacy, high rates of transfer when women give birth, and information systems which do not support sharing of records and patient information.

Although data analysis is still in progress, the study has already found:

- Pregnancy provides an ideal point-in-time for diagnosis and monitoring. (How can we better leverage that to improve maternity and cardiac care?)
- Women with ARF, RHD or other cardiac history need echocardiograms, careful monitoring and multidisciplinary care during pregnancy.
- Women on anticoagulation medications are at additional risk of complications.
- There is a need for improved early conception counselling, and pregnancy planning.

The presentation highlighted the need for a more supportive environment and improved systems to support care of women with RHD in pregnancy; the need for improved health workforce knowledge and awareness of RHD in pregnant women; and improved understanding of early conception counselling and pregnancy planning.

Comments:

Dr. Christine Connors: Midwives need to be across basic management of chronic disease, and think holistically. The role of midwife needs to be included in the chronic care model – 'midwifery led care'. Food security is an issue. If women are worried about their children left at home, especially as it is sometimes policy to transfer women out of their communities well before they give birth, who looks after her children, and will there be food for them?

Professor Jonathan Carapetis: Echocardiograms are important. A hand held screening program for women at high risk could prevent them coming to pregnancy with RHD.

Dr. Warren Walsh: Auscultation skills are important.

Professor Bart Currie: Information is not available to health practitioners. How do jurisdictions manage this issue of sharing information and records?

Delivering best practice cardiac care for Aboriginal people in NSW (Vicki Wade, Leader, National Aboriginal Health Unit, Heart Foundation (NSW))

The Heart Foundation works in partnership with other organisations to provide coordinated care, and support communities and organisations to support healing. This presentation outlined what the Heart Foundation is doing to reduce the heart health gap, including the establishment of a model of care for ARF and RHD; increased workforce training and funding for ATSI cardiac coordinators in major hospitals, and the development of a toolkit for quality improvement: *Improving health outcomes for Aboriginal and Torres Strait Islander peoples with acute coronary syndrome: a practical toolkit for quality improvement.* The toolkit uses pictorial models for a strength based approach.

The importance of housing for health, and holistic health care was emphasised. It is important to treat the whole person, acknowledging and treating the trauma of illness. Attention to cultural safety and cultural care are also important in the healing process.

Beyond secondary prevention – revisiting primary prevention messages (Dr. Vicki Krause, Director, Centre for Disease Control, NT)

This paper emphasised the importance of primordial and primary prevention, which is perhaps perceived as an overwhelming task and “too hard” to achieve. ARF happens in clusters. We need to define populations as those with ARF, and households with ARF. The goal is to prevent progression of disease AND apply primordial and primary prevention measures. It is important to make discussion about housing/health situation a part of follow up and general care. CHECK how people are living, and deal with prevention issues at individual household level, making some “RHD house rules”.

When treating skin sores - think beyond penicillin. Use personalised documented/observed household support and strategies to carry out required activities.

Comments/discussion:

Dr. Christine Connors: It is important for the Department of Health to provide hygiene products.

Professor Dawn Bessarab: We need to work with households. Ask what stops people from having clean and healthy lifestyles?

Professor Graham Maguire posed the question - Do we evaluate our primordial and primary prevention interventions?

The NSW Story – developing a model of care (Dr. Jeremy McAnulty, Director, Health Protection, NSW)

Surveys have been conducted over the last few years to determine burden of disease (epidemiology of ARF/RHD) in NSW:

- Australian Paediatric Surveillance Unit, 2007 & 2008 (9 cases of ARF in children under 15 years).
- Children’s Hospital Westmead, 2000 to 2008 (26 children aged 5 – 15 years)

- Patients admitted to NSW hospitals 2003-2012 (~24 new diagnoses per year)
- Dr McAnulty described the steps involved in planning for the NSW RHD Program, and the objectives of the program. Some important aspects of planning have been:
    - How to facilitate links - existing GP activities/referrals, and integration with the register.
    - How to find patients? - Notification? But … no lab test, complex diagnosis, little experience. Active case finding (clinician education, hospital records, other?
    - Data systems - notification, register, follow up, evaluation.
    - How to facilitate they are linked to care - Existing GP activities/referrals, integration, register?
    - How to facilitate clinical assessment - Specialist referrals
    - How to facilitate monthly penicillin shots: Register/reminders: letter/SMS/calls/visits?
    - Planning for evaluation of the program.

Next steps for NSW will be:

- Proposal to make conditions (ARF & RHD <35 years) notifiable under the NSW Public Health Act.
- Patient consent process: allow access to contact details for follow-up from NSW Health information systems - other jurisdictional registries; Medicare?
- Develop the register and an integrated model of care.

ARF/RHD diagnosis and care – what we've learnt and still don't know (Professor Graeme McGuire, Head, Baker IDI Clinical Research Domain)

This paper discussed what we have learnt, what we have yet to learn, what areas need further research, and how we might do better in three important domains: diagnosis, models of care, and surgery.

<u>Diagnosis:</u> ARF is a syndrome – there is no single gold standard. Newer technologies may help. Minor changes can triple the population at risk of RHD, but we need to know which changes matter. Diagnosis in high risk populations is increasingly sensitive, but it creates a problem with specificity, especially if there are other causes of arthritis/arthralgia.

Echocardiograms play a key role in ARF and RHD. We need better access to echocardiograms, but there is no single model of access. Outreach screening would be good, and maybe people other than radiographers can do it?

ARF-specific carditis markers required: biomarkers and imaging for diagnosis and to identify those at eventual risk of RHD.

<u>Models of care</u>: Register and recall, and coordinated specialist teams linking with PHC all work, but we need to know how to improve secondary prophylaxis delivery and anticoagulant management.

<u>Surgery</u>: Hospital and surgical management is world class, but we need new evidence to inform timing of surgery. Preventable and irreversible changes (heart failure, pulmonary hypertension, atrial fibrillation) are still happening because we are going too late to surgery. We need to investigate why? Are people not following guidelines? More research is also needed into health service systems.

RHD Nurse Practitioner – how this position may assist in a model of care (Rosemary Harbridge, Project Officer, RHDAustralia).

The framework for a nurse practitioner role in acute rheumatic fever and rheumatic heart disease (RHDAustralia, 2015) describes how a nurse practitioner, working autonomously and in collaboration with the wider health care team, could play a pivotal role in building the capacity of the health service to provide a more systematic, timely and coordinated approach to addressing service gaps and improving outcomes in the management of ARF and RHD.

Nurse Practitioner autonomous clinical services could include:

- Assessment and management.
- Referrals.
- Specific endorsed procedural activities.
- Care planning and coordination.
- Prescribing and therapeutic interventions.
- Ordering and interpreting clinical and diagnostic investigations.

In addition to providing an autonomous and advanced clinical nursing role, a nurse practitioner in ARF and RHD would be a critical thinker and 'go to' person, providing expert leadership, support and education to the health care team, patients and community, while supporting clinical and health service systems research.

COLLOQUIUM PROCEEDINGS: PART 2: SNAPSHOTS OF THE JURISDICTIONS

Each of the RHD programs provided a snapshot summary of the program in their State/Territory, including program achievements and challenges, points of difference specific to their program, and suggestions as to what they would like to see more of from a program perspective.

Western Australia Presenter: Janice Forrester		
Highlights	**Challenges**	**The Future**
• ARF is notifiable in WA • Telethon Institute - GAS research from skin sores to assist in vaccine development • Princess Margaret Hospital – hand-held echo training for Kimberley • Kimberley healthy skin protocol / environmental health • KAMS Coordinator – Primary prevention through to tertiary intervention	• Large state – small population. Distance: program is based 2500 kms from Perth • Currently PHC- tertiary = poor communication – often find out incidentally when someone dies of RHD • Register sits behind WA Govt firewall – so clinics etc. don't have access. Currently persuading Govt to allow access • Privacy is an obstacle in obtaining information on patients with RHD • Timeliness of data collection makes a difference. New regulations about to be signed off – it will be a game changer re: data collection	• Putting RHD on the State agenda - increase the profile of the RHD register & Program • Managing another ARF outbreak (spike in cases). Need a plan for management • Community engagement is important

Northern Territory Presenters: Marea Fittock & Keith Edwards		
Highlights	**Challenges**	**The Future**
• Patient information reporting systems (Patient Care Information System (PCIS) –NT Govt; Communicare (AHS) • Shared electronic system. NT has a unique ID for patients. This helps with the mobile population • Outreach: negotiating with patient as to where LAB is given makes a big difference to adherence rates • ARF notifiable RHD is not • NT health sector have a RHD Program incorporated into the Primary Health Care Program delivery • Use of standardised treatment manuals: CARPA; Women's Health Manual and CRANA Procedure Manual. • Providing outreach patient service delivery care	• Over 100 remote communities • Days at risk – important to be aware of this - use 4th weekly recall	• Improve telephone support • Focus on primordial prevention • Sharing the rheumatic fever story with community broadly • Community based workers: weekly visits to house with ARF/RHD clients • Health hardware • Hygiene practices • Overcrowding

Queensland Presenter: Mellise Anderson		
Highlights	**Challenges**	**The Future**
• Education and capacity building are important • 2 seminars held in partnership with RHDA • Program led education sessions • Resources / material • Specific ARF / RHD data base • Investments = outcomes State funding / support • Consistent staffing	• Specific ARF/RHD database; no single point of access to patient information independent health services. (Data, data, data) • Sustainability (funding, investment) • State-wide coverage with existing capacity • Momentum and expectations	• Engagement with health care providers (strengthening existing links and establishing new partnerships) • Access to data (to and from the Register) • Advocacy and awareness • Evaluation • Transferability of learnings

South Australia Presenter: Jennifer Cottrell		
Highlights	**Challenges**	**The Future**
• SA register commenced 2012. RF strategy funding 2014 • Dedicated Program Advisory Group • State-wide approach with NGOs and Government • Engagement with PHC around register and patient management • Cert III and Cert IV in Aboriginal and Torres Strait Islander PHC • Collaboration with NT	• Low awareness of ARF and RHD among mainstream health • Hospital sector • Private GP practices. • Large urban population • Maintaining secondary prophylaxis during hospitalisation	• Plans to make ARF/RHD notifiable • Ongoing support for primary health care • Education/register promotion in hospital setting • Following up consent and active case finding

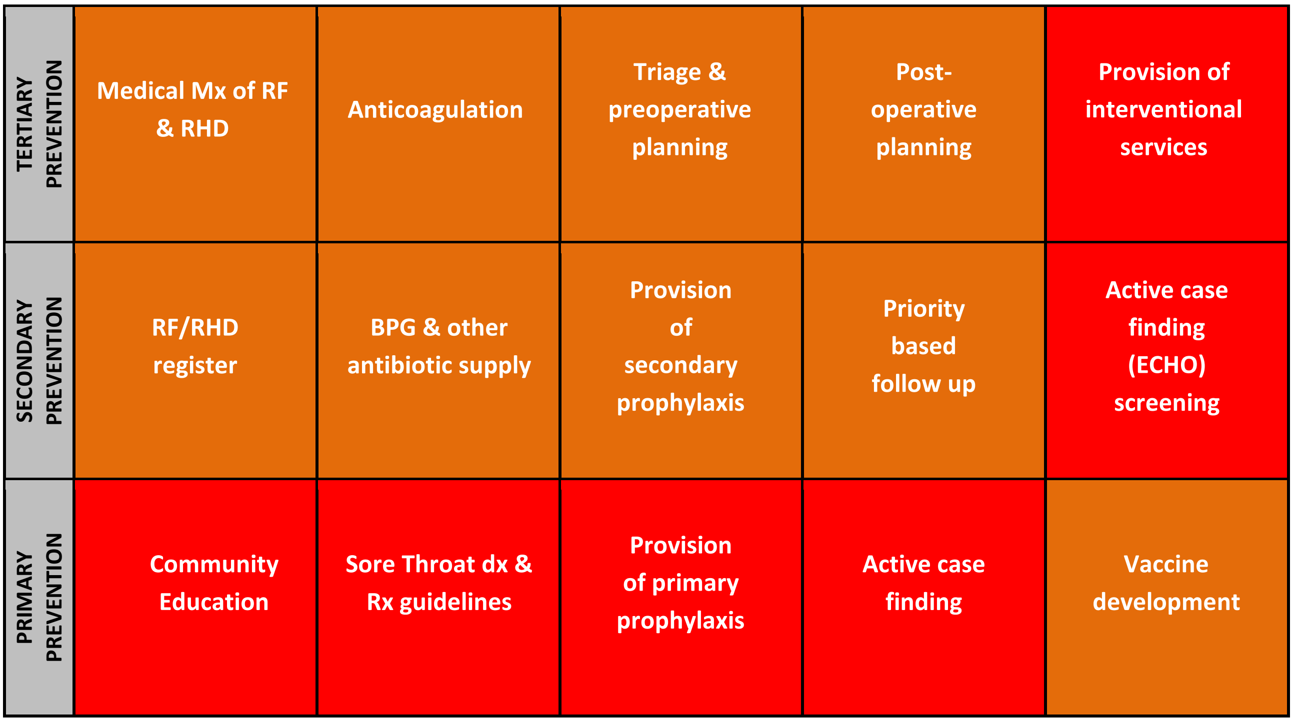
COLLOQUIUM PROCEEDINGS: PART 3: GROUP ACTIVITIES

Prior to the Colloquium, RHD control programs had completed an assessment of their programs using a conceptual framework for comprehensive RHD control programs. The results of those assessments had been compiled into a single overall assessment of performance by RHDA (Figure 1).

Working in groups, the participants were asked to review the framework, decide whether they agreed or disagreed with the RHDA assessment, identify major issues and key priorities for action, and prioritise three key areas of work for development under each domain (primary, secondary and tertiary prevention).

ACTIVITY 1: Perform an assessment of where you believe Australia is at against the conceptual framework. How does this compare with the National assessment by RHDA? Which domains to you disagree with and why?

Figure 1: Conceptual framework: assessment by RHDA.
(Assessment tool extracted from *Tools for Implementing RHD Control Handbook.* (Wyber, R. et al, 2014)



TERTIARY PREVENTION	Medical Mx of RF & RHD	Anticoagulation	Triage & preoperative planning	Post-operative planning	Provision of interventional services
SECONDARY PREVENTION	RF/RHD register	BPG & other antibiotic supply	Provision of secondary prophylaxis	Priority based follow up	Active case finding (ECHO) screening
PRIMARY PREVENTION	Community Education	Sore Throat dx & Rx guidelines	Provision of primary prophylaxis	Active case finding	Vaccine development

KEY: GREEN: Achieved ORANGE: Partially achieved RED: Not achieved

In summary most tables agreed with the assessment with one table suggesting that all boxes should be changed to red given the variation in a consistent and comprehensive approach to Primary, Secondary and Tertiary domains across Australia.

TABLE: 1

Domain	Changes /notes
Active case finding (Echo screening)	Queried “not achieved”. Role of screening uncertain. Screening papers still coming through. Economic analysis around screening is not complete.
Community Education	ORANGE. This is ongoing – someone is always educating, but everyone will never be educated. i.e. it can never be GREEN (a Sisyphean task?).
Sore throat Dx and Rx guidelines	ORANGE. Guidelines exist, but they are thin. Unknown if/how well it is implemented.
Provision of primary prophylaxis	ORANGE. Borderline partial/complete. Sore throats don’t often present for treatment. It is done well in some areas.

TABLE: 2

Domain	Changes/notes
Medical management	Unclear meaning of international guidelines. Strengthen & standardise referral pathways.
Anti- coagulation	Unclear meaning of international guidelines. Patient education /food security; Data sharing with pharmacy.
Triage & pre-op planning	? RHD Programs.
Interventional services	Queried – partial or complete? Uncertain?
BPG supply	Dosing & administration.
Provision of secondary prophylaxis	Split RED/ORANGE. Injections partially achieved. Indicator to be reviewed – “days at risk”.

TABLE: 3

Domain	Changes/notes
	No change.

TABLE: 4

Domain	Changes/notes
Provision of interventional services	ORANGE: Providing cardiac surgery. National database (all but 3 hospitals on database) ALL have access (but possibly not as quick as needed) 30 day mortality (reviewed and assessed. Outcome data (presented at meeting)
Sore throat diagnosis and treatment guidelines	ORANGE: CRE identified area Covered in a majority of guidelines and protocols across Australia. Needs evaluation of understanding and use.
	Ultimate goal is to develop a patient centred model.

TABLE: 5	
Domain	**Changes/Notes**
Tertiary prevention	Agree with the top line (should ECHO screening be there?).
Community Education	ORANGE
Provision of primary prophylaxis	ORANGE
TABLE: 6	
Domain	**Changes/Notes**
Anti-coagulation	RED
BPG & other antibiotic supply	RED
Provision of secondary prophylaxis	RED
TABLE: 7	
Domain	**Changes/Notes**
Secondary prevention	Active case finding (ECHO screening) is OK as it is, but recommendations are required.
Provision of interventional services	ORANGE

ACTIVITY 2: What do you see as the major priority areas within the framework and why? What do you see as the key priorities for action in addressing these issues?

TABLE	**PRIORITY 1**	**PRIORITY 2**	**PRIORITY 3**
1	Primary & secondary prophylaxis	National Register.	Education/awareness for clinicians & community.
2	National register. Real time, accessible to everyone, Integrated comprehensive	PHC expansion - holistic.	Vaccine – still a long way off.
3	Secondary prophylaxis – effective; proven	Community Education HPs, community, patients, carers. Engagement in shared care. Advocacy(consumer)	Register. Strengthen register – patient management, data.
4	Primary prevention: Community education. Awareness/knowledge; early diagnosis, of sore throat /ARF/RHD; health hardware; education (patients, HCWs)	ARF/RHD register; AND Secondary prophylaxis.	

5	National registry. One registry; incorporates primary, secondary and tertiary prevention; real-time integrated into all systems. Must be comprehensive.	Primary prophylaxis – within comprehensive, holistic primary health care – incorporates secondary prophylaxis, medical management.	Vaccine.
6	Secondary prophylaxis – improved PHC clinical systems with 3 monthly penicillin.	ARF/RHD register. Linked/interoperable; mandatory reporting.	Community education: including vaccines (when available)
7	Community education. Flow on benefits for diagnosis & secondary prevention.	Implementation of evaluation of secondary prevention framework.	Flow of patient information within system & to patients.

Summary of Activity 2:

The top three priorities for action identified were:

- Primary prevention & community education.
- National RHD register.
- Secondary prophylaxis.

All of these were identified as Priority 1.

Other priorities identified were:

- Development of a vaccine.
- Expansion of primary health care to a more holistic approach.
- Evaluation of the secondary prevention framework.
- Education and awareness for clinicians as well as patients and community.
- Improvements to patient information systems – to facilitate flow, and access to patient information.

Some outstanding issues identified by the groups were:

- Need for review of surgical outcomes (valve replacement surgery) - training programs?
- Adolescent transition into adult care - ACI transition network?

ACTIVITY 3: Prioritise 3 key areas for development under each domain.

TABLE	DOMAIN	KEY AREA FOR DEVELOPMENT
1	**Community education** (awareness/clinical education, integration into curriculums, shared care, education depts.)	**Clinical**: Curriculum **Community/public:** • Medical staff – locums vs permanent. • Advocacy. • Script- for patients - how to communicate with medical professionals. • Take Heart campaign (Industry support for initiatives in social marketing). • Community advocacy/partnerships (ACHO). • Champions/ambassador. • Clear, consistent messages, strong patient focus. • Self-management tools – recall/red flag (Apps) /smartphone, on-line support.
2	**Register** (integration nationally/expansion/'real time'/electronic shared eHealth record), data linkages	• Define function of register to improve patient management. • Recall systems – real time. • Integrate to determine outcomes (KPIs). • Define minimum data set for jurisdictions (National d/b). • eHealth record. • **resources for d/b development. • Quality of data 'in'. • Consent for national register (it is not unattainable). • Need minimum data set. • End game + patient controlled record. • What do you want the register to do? • Management e.g. recall. • Epidemiological information. • Surgical outcomes. • Monitor performance.
3	**Provision of BPG/Secondary prophylaxis /integration of clinical data**	**Health systems:** • Alerts/eHealth records. • Visible KPIs in PHCs. • Sentinel events investigated. • Incentive based systems?? • Health sector integration. • Recall systems – 21 days; 'dedicated' coordinator (not necessarily full time). • Information sharing/national registers, PEHR. • Pay for performance. • National KPIs . • Share success between services and jurisdictions. • Sentinel reporting – develop set of events. • Better way of giving long acting penicillin e/g/ S/C slow release like Implanon.

		Patients/families: • Stronger community voice in program delivery. • Consumer support/participation; develop patient "champions"; peer support. Awareness of disease. 'Glamorise' remote/Aboriginal TSI work: "RHD nurse" TV series? • Self-management support – hand held record ; "Medic alert' – bracelets; patient incentives - money/ goods. **Heath Professionals:** • Ongoing training. • Understanding penicillin – BLA 3-4 weekly; can give 3 days "early"; don't give oral. • Understand drivers for HPs. Engagement/education (CPD), turnover staff/capacity for new knowledge.
4	**Secondary prevention 'plus'** – primary & primordial	• Draft/recommend minimum standards/dataset for a patient living with ARF & RHD. • Housing hardware. • Disability allowance/income (Heart Kids). • Treatment. • Management /records (Guided by research and good practice models). • State by state discussions with Housing with regards to priority housing. • Advocate implementation of existing health education guidelines for non-Indigenous and Indigenous children (e.g. skin sores). • Document /disseminate examples of good practice.
5	**Implementation of sore throat diagnosis and treatment guidelines**	**Update Guidelines (3rd ed).** • Available online. Include and do further work on skin infection. (Literature search) • Current guidelines available in part (CARPA/PCCM). Must be integrated into national guidelines and make sure all guidelines are the same – re: local guidelines consistent with national best practice and other guidelines of 'cottage industries' - RACGP, HF, AB guidelines etc. • Key stakeholder engagement in health care. • Research: • Penicillin in Australian setting. • Implementation and uptake of Guidelines: **Implementation of guidelines – how?** • Assessment of guideline writing and implementation process. • Develop implementation strategy – stakeholders, i.e. remote area nurses, RACGP, CATSIN. Identify the role that each stakeholder plays in this space – how much influence this group has, and with whom. • Identify KPIs, do baseline measurement, (define measure) develop implementation plan.

6	**Integration with primary care & health systems/patient information across health sectors/models**	• Standards for health data recording (NEHTA), GP, MeTEOR. • Standards for content and reporting of patient information relating to RHD, to be met by all medical information systems. • Investigate standards for prompts/alerts in PHC/GP software health assessment alerts/diagnosis links to guidelines - algorithm for management? Replicating health pathways/functionalities). e.g. care plans for RHD patients – echocardiograms etc.; sore throat diagnosis; prompt for BPG. Who? RHD/NEHTA? • Care coordinators for RHD for both individual patients, and act as coach for PHC teams in remote areas. Who? Medicare Locals? PHNs? DOH? • Promotion of existing resources and guidelines. • Promote education modules to targeted health professionals.

COLLOQUIUM OUTCOMES AND NEXT STEPS

The Colloquium provided a valuable opportunity for building relationships with and amongst key stakeholders, sharing information on ARF/RHD and the current issues and activities on RHD across Australia. Gaps and issues in service delivery and priority actions to address those issues were identified.

RHDA will undertake further work to progress the recommendations as a priority during the next National Coordinating Unit funding agreement with the Commonwealth 2015-2017.

Recommendations regarding reporting structures will further inform the Better Cardiac Care measures that were developed to monitor and improve cardiac conditions in Indigenous people – a project supported by the Australian Health Ministers Advisory Council which aims to reduce mortality and morbidity from cardiac conditions, including RHD by:

- increasing access to services,
- better managing risk factors and treatment and,
- improving the coordination of care.

RHDA will liaise with jurisdictions about the framework and priorities identified, and seek support to progress priority areas. Progress will be monitored, and RHDA will provide an update in mid-2016.

CONCLUSION

In the near future this report and other summary activities of the RHDAustralia colloquium will be available via the RHDAustralia website: www.rhdaustralia.org.au

FURTHER INFORMATION

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September 2015

COLLOQUIUM ATTENDEES

Attendee			Title	Organisation
Ms	Wendy	Ah Chin	Chair	NATSIHSC
Ms	Sarah	Ahmed	RHD Coordinator	Aboriginal Health Council of South Australia
Ms	Mellise	Anderson	Manager - Rheumatic Heart Disease Register	Cairns and Hinterland Hospital and Health Service | Queensland Government
Dr	Sonya	Bennett	Senior Director, Communicable Diseases Unit	Department of Health - QLD Government
Prof	Dawn	Bessarab	Chief Investigator	Telethon Kids Institute
Ms	Claire	Boardman	Deputy Director	RHDAustralia
Ms	Linda	Bootle	Aboriginal Maternal Infant Health Service Clinical	Western NSW LHD
Prof	Jonathan	Carapetis	Director	Telethon Kids Institute
Ms	Bridie	Carr	Cardiac Network Manager	Agency for Clinical Innovation
Dr	Samantha	Colquhoun	Centre for International Child Health	University of Melbourne
Dr	Christine	Connors	Director	NT Primary Care
Mr	Rohan	Corpus	Program Manager	Queensland Health
Ms	Jennifer	Cottrell	SA RHD Control Program Coordinator	SA Health
Prof	Bart	Currie	Director	RHDAustralia
Ms	Agi	D'Amico	Project officer	RHD Control Program Western Australia
Ms	Heather	D'Antoine	Division Leader of Education and Capacity Building	Menzies School of Health Research
Ms	Rhona	Dawson	Program Coordinator	Kimberley Aboriginal Medical Services
Ms	Jess	De Dassel	Project Manager	Menzies School of Health Research
Ms	Karen	Dempsey	Epidemiologist	RHDAustralia
Mr	Ashok	Dixit	Portfolio Manager	Pfizer Australia
Dr	Keith	Edwards	Community Paediatrician	NT Centre for Disease Control
Ms	Cate	Ferry	Senior Manager Clinical Issues	Heart Foundation
Ms	Marea	Fittock	N.T RHD Control Program Coordinator	NT Centre for Disease Control
Dr	Drew	Fitzpatrick	Cardiologist	Nepean Hospital
Ms	Janice	Forrester	Clinical Nurse Manager – RHD	WA Rheumatic Heart Disease Control Program
Dr	Marianne	Gale	A/Medical Advisor	NSW Ministry of Health
Ms	Colleen	Gibbs	Senior Policy Officer	CATSINaM
Dr	Rob	Grenfell	National Medical Director	BUPA
Ms	Kylie	Gwynne	Director	Poche Centre for Indigenous Health
Ms	Catherine	Halkon	Project Officer	RHDAustralia
Ms	Rosemary	Harbridge	Project Officer	RHDAustralia
Dr	Kate	Hardie	Public Health Physician	NT Centre for Disease Control
Ms	Sue	Heath	Public Health Officer	Communicable Diseases Surveillance & Control, High Risk Pregnancy Clinical Midwifery Consultant Westmead Hospital

Attendee			Title	Organisation
Dr	Alex	Hope	PHMO	Central Australia Aboriginal Medical Services Alliance NT
Dr	Charles	Itty	Cardiologist	Lismore Base Hospital
Mr	Christian	James	Program Manager / Education and Training	RHDAustralia
Mr	Timothy	Johnson	Program Coordinator - RhEACH	Telethon Kids Institute
Ms	Wendy	Keech	Project Manager, ESSENCE	South Australian Health & Medical Research Institute
Dr	Vicki	Krause	Director	NT Centre for Disease Control
Ms	Dianne	Lantry	Assistant Director	Primary and Mental Health Care Division, CW Department of Health
Ms	Kate	Lorkin	Project Officer	RHDAustralia
Mr	Chris	Lowbridge	Manager, NSW Tuberculosis Program	Health Protection NSW
Ms	Laurette	Lubbers	QLD RHD Project Officer	RHDAustralia Queensland
Prof	Graeme	Maguire	Head - Baker IDI Clinical Research Domain	Baker IDI
Dr	Jeremy	McAnulty	Director	Health Protection NSW
Ms	Katharine	McBride	Research Officer, ESSENCE	South Australian Health & Medical Research Institute
Dr	Malcolm	McDonald	Consultant Physician	Apunipima Cape York Health Council & Assoc Prof School of Medicine & Dentistry, James Cook University
Ms	Melanie	Middleton	Rheumatic Heart Disease Coordinator	Communicable Diseases Branch
Ms	Cath	Milne	Data Liaison Officer	RHDAustralia
Dr	Julie-Anne	Mitchell	Director of Cardiovascular Health Programs	Heart Foundation
Ms	Sara	Noonan	Technical Officer	RHDAustralia
Prof	Michael	Peek	Professor, Associate Dean and Head of School	Sydney Medical School - Nepean
Dr	Anna	Ralph	Clinical Director	RHDAustralia
Dr	Jane	Raupach	Medical Consultant	S.A Dept for Health and Ageing
Dr	Clancy	Read	Postdoctoral Research Fellow	Telethon Kids Institute
Dr	Bo	Remenyi	Paediatric Cardiologist	Menzies School of Health Research
Mr	Marc	Remond	PhD Student	James Cook University
Ms	Ann	Richards	Public Health Manager (Southern Sector)	Torres Cape York HHS
Ms	Anne	Russell	Research Manager	Prince of Wales Hospital
Ms	Dalia	Saad	Portfolio Manager	Pfizer Australia
Ms	Brooke	Shepherd	Public Health Officer	NSW Ministry of Health
Dr	Vicky	Sheppeard	Director	Communicable Disease Branch, NSW Health
Mr	Chris	Shipway	Director - Primary Care and Chronic Services	Agency for Clinical Innovation
Dr	Dianne	Sika-Paoton	Lecturer	Graduate School Nursing, Midwifery & Health Victoria University of Wellington
Ms	Eunice	Simons	Senior Project Officer	Agency for Clinical Innovation
Prof	Elizabeth	Sullivan	Associate Dean - Research	University of Technology, Sydney
Dr	Philip	Tideman	Clinical Director of Cardiology	Country Health SA

Attendee			Title	Organisation
Ms	Geraldine	Vaughan	National Coordinator	AMOSS RHD in Pregnancy Study, University of Technology Sydney
Ms	Vicki	Wade	Leader, National Aboriginal Health Unit	National Heart Foundation Australia - NSW Division
Dr	Warren	Walsh	Cardiologist	Prince of Wales Hospital
Dr	Gavin	Wheaton	Cardiologist	SA Health - Women and Children's
Dr	Rosemary	Wyber	Deputy Director	Telethon Kids Institute
Dr	Chatu	Yapa	Epidemiology registrar	Health Protection NSW