

What participants have had to say about the project

"The project raised our awareness. The modules are really helpful. After doing the modules I had a patient with sore knee and I thought, maybe this could be ARF. So I read back through previous records and found further related symptoms. So I got the Dr and asked her to consider the case. The Dr thought it could be. The patient was sent to hospital. Now I am wondering how many cases of ARF I may have missed. Prior to this I may just have given rubbing medicine"

"This project prompted us to look at what wasn't working and identify steps that we could take to improve outcomes for our patients. We don't have the capacity for outreach... but we realised that people were coming in for their needles and not receiving their needle as they had to wait too long so we started noting LAB on the wait-list so we could fast track them. We changed our recalls to 21 days instead of 28 days because of this project".

"The SP project was good because it was our work and we got a sense of achievement because we were making the changes. Even though Sagen has gone, we don't need her to be ringing us up once per month because we are continuing to make changes ourselves"

"Thank you, and the SP Research Team, for your ongoing support. We appreciate it."

Issue 8 - December 2016

Welcome to the eighth and final newsletter from the Improving Secondary Prophylaxis (SP) for Rheumatic Heart Disease (RHD) research project.

What did we do?

We worked with ten health centres in collaboration with the NT RHD Control Program, RHD Australia and other stakeholders, to support clinics to develop and implement a package of activities to increase delivery of SP in a sustainable way.

What next?

Community visits are currently underway feeding back preliminary findings. A Darwin-based knowledge translation symposium will be held in May 2017 to which participating sites and other stakeholders will be invited, to discuss outcomes



What did the project find?

Analyses are underway. As shown above, the project had positive impacts on some individuals and some clinics. However overall, we did *not* achieve the goal of doubling the proportion of people getting $\geq 80\%$ of their scheduled needles. Part of the reason for this is that in the NT overall, adherence has already doubled compared with when the study started. In other words, things are improving independent of this study. But the findings from the study will be very valuable in working out what needs to happen next to continue to improve ARF/RHD care, and reduce the burden of these diseases. There are already positive spin-offs, such as 'On Track Watch', a new community-driven project at Yilpara.

Djambawa Marawilli, AM, Ceremonial leader of Madarrpa Clan at Yilpara and Emma Haynes (Project Coordinator, Menzies) celebrate the beginning of a new follow-on project: 'On Track Watch'. Community members will seek ways to control ARF in homes and schools.

Check out the RHD Australia website for some great ARF/RHD educational resources! RHD Australia - <http://www.rhdaustralia.org.au/>



Have you downloaded the RHD Australia Smart phone app? It's available for iPhone & Android phones. It's free to download and, once on your device, it works offline

And don't forget to visit the Take Heart website- <http://www.takeheart.tv/>



Participating Health Services

Anyinginyi Health AC
Danila Dilba Health Service
Gunbalanya Health Centre
Julanimawu Health Centre
Laynhapuy Health

Maningrida Health Centre
Pintupi Homelands Health Service AC
Wurli-Wurlinjang Health Service
Yirrkala Health Centre
Yuendumu Health Centre

Partners & Affiliations

Telethon Kids Institute
NT Department of Health
University of Sydney
Baker IDI
RHD Australia

Administering Institution

University of Western Australia



Farewell Sagen

Sagen Wilks has worked for the RHD SP study as Project Officer since August 2014. She worked extensively with six of our ten project sites collaborating with clinic staff to develop activities designed to improve the delivery of secondary prophylaxis. Sagen enjoyed the travel component of the study so much that she chose to spend five weeks from mid-August (when she left Menzies) travelling through the NT and WA before returning to her native Queensland. We thank her for her contributions to the project and wish her all the best for the future.



Thank you Jess

Jessica de Dassel has worked on the RHD SP project as Project Manager since 2013 providing direction and leadership to project officers. Her contribution to the project, attention to detail and comprehensive knowledge of the study has been invaluable. Jess has resigned from her project management position in August 2016 to focus on her PhD examining the clinical consequences of adherence to secondary prophylaxis for people with acute rheumatic fever and rheumatic heart disease in the Northern Territory. She maintains an active interest in the findings of the RHD SP study.

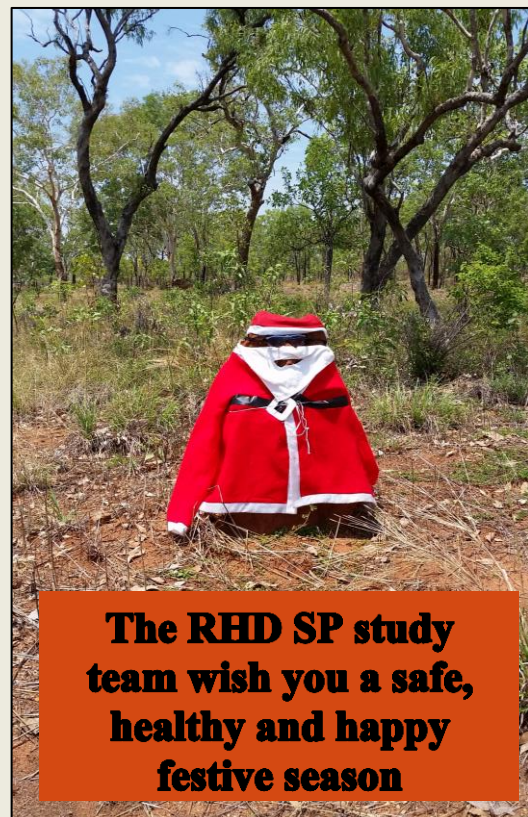


Thank you!

We have now finished data collection on the 'Improving Secondary Prophylaxis for Rheumatic Heart Disease' study.

Project staff visited participating study sites during Nov-Dec 2016 to provide feedback on preliminary results.

We would like to thank all participating Health Centres and staff for your involvement with this project. You have helped to answer questions of major importance about ARF research and service delivery. Project Officers have thoroughly enjoyed the time spent with all sites and will miss our regular visits. Staff have made us feel welcome and have ensured that our visits have been productive and engaging. Please feel free to provide further feedback on your experience of involvement in this project, either positive or negative.



The RHD SP study team wish you a safe, healthy and happy festive season