Prevention and Control of ARF and RHD in Indigenous Australian Communities: A Developmental Evaluation of the Take Heart Resources in the NT

Final Report

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Implementing & Evaluating to Maximise Impact

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Table of Contents

BACKGROUND

Acute Rheumatic Fever and Rheumatic Heart Disease

What are these conditions?

Acute rheumatic fever (ARF), is an inflammatory disease that can affect the heart, joints, skin, and brain [1]. Signs and symptoms include fever, multiple painful joints, involuntary muscle movements, and a characteristic non-itchy rash known as *erythema marginatum*.

Rheumatic Heart Disease (RHD) is permanent damage to the heart valves, and usually only occurs after multiple attacks of ARF – however it may occasionally occur after a single case of ARF.

The damaged heart valves may, in turn, result in heart failure and also increase the risk of developing atrial fibrillation [1]. These issues cause progressive disability, reduce quality of life, and can cause premature death in young adults. Heart surgery can manage some of these problems and prolong life, but it does not cure RHD.

What causes ARF and RHD?

Although genetics may also play a part, the main risk factor for the development of ARF and RHD is exposure to *Group A Streptococcus* bacteria [2]. These bacteria are known as the 'strep' bacteria and they usually cause throat infections and skin sores.

Unfortunately, the autoimmune response that takes place when there's a strep infection in the body can sometimes cause ARF.

Exposure to the strep bacteria that leads to ARF and RHD is thought to be due to overcrowded housing conditions. In fact, RHD is a disease of poverty, and the associations with lower socioeconomic status are well documented [3].

Being linked to poverty, poor living conditions, and limited access to health services, ARF is largely preventable.

Importantly, RHD is 100% preventable.

Who is affected by ARF and RHD?

In Australia, ARF and RHD continue to affect Aboriginal and Torres Strait Islander People – hereafter respectfully referred to as Indigenous Australians – disproportionally and represent the greatest disparity in cardiovascular health conditions between Indigenous and non-Indigenous Australians [2, 4-8].

ARF remains almost exclusively experienced by Indigenous Australians across the nation [9]. Indigenous Australian children and young adults in Australia are the most affected by this disease, with rates being among the highest in the world [2, 6, 7, 9, 10].

Indigenous Australians do not receive the same level of primary prevention and management, emergency and acute care, rehabilitation, ongoing management, and secondary prevention care for cardiovascular disease as non-Indigenous Australians do.

How many new and recurrent cases of ARF and RHD have there been?

There were 317 notifications of new and recurrent cases of ARF in the Northern Territory (NT) in 2005-2010. Of these cases, 311 (98%) were Indigenous Australians. Recurrent cases made up 24% of all cases. Almost two-thirds (58%) of the Indigenous Australian notifications were for children aged 5-14 year [11].

The rates of ARF were highest for Indigenous Australian females in the 5-14 years age group. Indigenous Australian females accounted for more notifications for ARF than Indigenous Australian males among those aged five years and over [11].

How many cases of RHD are there in total?

In 2010, there were 1,479 registered cases of RHD in the NT. Almost all cases involved Indigenous Australians (1,379 cases, or 93%). After age-adjustment, rates for Indigenous Australians were 26 times higher than those for non-Indigenous Australians [11].

How many hospitalizations for ARF and RHD have there been?

In Australia in 2009-10, there were 2,666 hospitalisations for ARF and RHD. The NT had the highest level of hospitalisations (86 per 100,000) compared to Queensland (15 per 100,000) and Western Australia (12 per 100,000) [11].

During 2008-10, there were 702 hospitalisations in Australia for ARF and RHD for Indigenous Australians (four percent of total hospitalisations for ARF and RHD). After age-adjustment, hospitalisations rates for ARF and RHD were 6.8 times higher for Indigenous Australians than for non-Indigenous Australians [11].

How many deaths from ARF and RHD have there been?

In Australia in 2007-2009, there were 897 deaths with RHD as the underlying cause.

These deaths represented 0.6% of all cardiovascular disease deaths, and 0.2% of all deaths. Females had higher rates of deaths from RHD, with one and a half times as many deaths as males. This is consistent with the higher levels of hospitalisation for RHD among females [11].

How can ARF and RHD be treated?

Secondary prophylaxis with benzathine penicillin G (BPG) injections is recommended for all people with a history of ARF or RHD [11, 12]. Four-weekly BPG is currently the treatment of choice, except in patients considered to be at high-risk, for whom three-weekly administration is recommended.

The benefits of three-weekly BPG injections are offset by the difficulties of achieving good adherence, which is a challenge even for the standard four-weekly regimen [11, 12].

All people with ARF or RHD should continue secondary prophylaxis for a minimum of 10 years after the last episode of ARF or until the age of 21 years (whichever is longer) [6, 7, 10, 11, 13]. Those with moderate or severe RHD should continue secondary prophylaxis up to the age of 35-40 years.

Adherence to treatment remains inadequate

Data from the NT show that few, if any, recurrences of ARF occurred among people who fully adhered to a four-weekly BPG regimen. Persistent high rates of recurrent ARF in Australia highlight the continued failure of secondary prevention [11]. Patients from the NT with recurrent ARF receive on average less than 50% of their scheduled injections, and few patients receive the recommended benchmark of 80% of their scheduled injections. Indeed, many Indigenous Australians with a past history of ARF or RHD do not receive the recommended levels of penicillin prophylaxis [11]. In 2002-2006, only 18% of eligible people in far north Queensland and in the Kimberley region of Western Australia received 80% or more of their recommended doses in the preceding 12 months. The low levels of prophylaxis are reflected in the proportion of ARF notifications classified as recurrences – 27% of cases for the Top End of the NT and 30% for central Australia [2].

There is an urgent need for effective health campaigns to: (i) raise awareness about the symptoms of ARF and RHD; (ii) raise awareness about appropriate health seeking behaviour for those with ARF; and (iii) improve adherence to treatment among those on secondary prophylaxis.

Take Heart

The Take Heart initiative was created by Moonshine Agency and generously sponsored by The Bupa Foundation and other organisations. Take Heart aims to apply digital health promotion techniques to reduce the incidence of ARF and RHD in Indigenous communities across Australia (takeheart.tv).

Take Heart is part of an international initiative to put ARF and RHD on the global media and public health agendas in Australasia, Africa, the Middle East, Asia, Latin America, and elsewhere.

Take Heart includes a long feature documentary, which is accompanied by short videos, a free action toolkit, a free smart-phone application (app), photography exhibitions, and an interactive website with social-media resources.

In Australia, a community outreach program supported by Bupa provides local communities with access to the documentary, short videos, interactive app, and website including essential information to recognise symptoms and access treatment for RHD.

One of the Take Heart posters

The Take Heart community outreach program and resources are the focus of this evaluation; together, they comprise three components:

- Self-management support for children and young adults who are on secondary prophylaxis for ARF or RHD;
- A face-to-face awareness raising campaign for Indigenous communities where the population is at high risk of developing ARF and RHD;
- A nation-wide set of social media, online, and mass media resources

These components are nested within each other, as shown in Figure 1. The shaded text boxes show key features of each component.

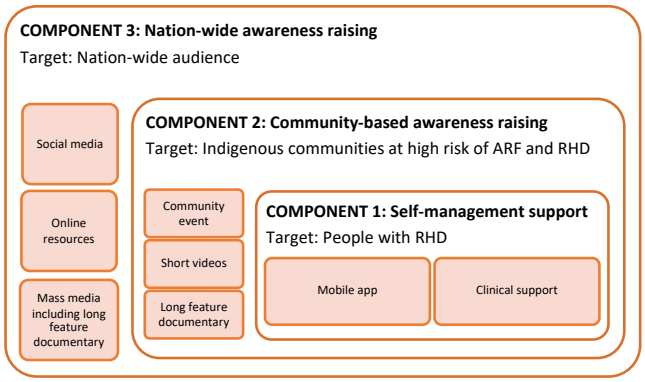


Figure 1. The Take Heart components

Component 1 of Take Heart: Self-Management Support

This component aims to encourage and improve adherence to treatment among Indigenous Australian children and young adults who are on secondary prophylaxis for ARF or RHD. A key feature of this component is a mobile phone app that facilitates self-management in those with these conditions. The app is designed to assist patients remember to present at a clinic to receive their BPG injections and to help them monitor their progress.

Component 2 of Take Heart: Awareness Campaign

The second component of Take Heart consists of face-to-face events that may span across several days and which take place in Indigenous communities in the NT where a large proportion of

the population is at risk of or suffers from ARF and RHD. The events ultimately aim to raise awareness about the potential symptoms of ARF and RHD, and to increase preparedness for taking appropriate action when symptoms are present. This component uses a variety of media to achieve its aim, including screening of the feature documentary, short videos, distribution of toolkits, and photography exhibitions.

Component 3 of Take Heart: Social Media and Mass Media Campaign

The third and final component of Take Heart is a wide-reaching campaign to raise awareness about ARF and RHD as well as to provide a support network for those affected by these conditions and for those close to them.

EVALUATION OBJECTIVES

The evaluation of Take Heart aims to assess:

1. the acceptability and implementation of Take Heart
2. the reach and spread of Take Heart within the communities where it is implemented and at a national level through online and other media outlets
3. whether Take Heart contributes to increasing awareness about ARF, RHD, and associated risk factors
4. whether Take Heart contributes to increasing compliance to treatment among RHD patients

METHODS

Approach

This was a developmental evaluation. Developmental evaluations differ from 'traditional' evaluations in a number of key features – most notably, the purpose of developmental evaluations is to support the development of innovations and their adaptation in a dynamic environment. Consequently, the lead evaluator and the evaluation itself are placed as an internal function integrated into the process of gathering and interpreting data, framing issues, and surfacing and testing innovation developments closely with the program development team.

Design

The evaluation used a mixture of qualitative and quantitative multiple case study design to explore the implementation of the Take Heart outreach program and resources in four Indigenous communities in the NT. Case study methodology allows data to be collected and combined from multiple sources (e.g. interviews, surveys, meeting minutes, documentation), and can augment external validity and help guard against observer bias [14].

The evaluation included: a survey of community members who attended the community events; interviews with health professionals caring for children and young adults with ARF and RHD, an anonymous online survey, analytics from app usage and usage of online resources, field observations, and a mass media scan.

Data collection occurred at two time points – when the community events took place in each of the evaluation communities (between August 2017 and January 2018), and then again in September 2018.

Setting

The community event and evaluation tools were piloted in one Indigenous community in the NT and Take Heart was then evaluated in a further four communities in the NT. Given the small number of communities and the small number of participants within communities, the names and locations of those communities will not be disclosed in this report.

The evaluation team travelled more than 6,000KM within the NT to set up the evaluation and complete data collection.

Ethics Approval

This evaluation received approval from the Human Research Ethics Committee (HREC) of the NT Department of Health and Menzies School of Health Research, in Darwin – NT (Approval code: HREC-2016-2622).

RESULTS

The evaluation involved holding community events in one pilot community and in four evaluation communities. Eight staff caring for children and young adults with ARF or RHD were interviewed across the communities at the time of the events and then again at follow-up, in September 2018. Eighty community members were also anonymously surveyed across all communities at the time of the community events, and 116 anonymous surveys were completed online by people who accessed the Take Heart Facebook page and online resources.

The evaluation team intended to recruit children and young adults with ARF or RHD and their families for participation in the evaluation, with a view to collect detailed data about usage of the Take Heart resources and adherence to treatment. This, however, was not possible. This challenge is explored further in the limitations sections of this report.

Kicking off the developmental evaluation

During the project set-up phase, the lead evaluator met with the Take Heart team to establish the parameters of the evaluation. During these early meetings, the team worked together to discuss the existing Take Heart resources, the key aims and target audience for each type of resource, and the associated key messages. This process then informed the description of the components included in this report, as well as communications efforts going forward.

The community event and evaluation tools were piloted in one community in the NT. Based on the pilot, some changes were made to one of the data collection tools. Letters of support were also obtained from each of the communities where evaluation activities were held, and decisions were made about the best time and approach to hold community events in consultation with people from the communities.

Objective 1 – Assessing the acceptability and implementation of the Take Heart resources

The Take Heart short videos and other resources have been well-received and are being used regularly in practice

Feedback about the Take Heart short videos – as well as the photography exhibition – from healthcare staff caring for children with ARF and RHD and their families was overwhelmingly positive.

A common theme that emerged is the ability of the Take Heart resources to readily engage Indigenous children and young adults. Clinics staff reported that ARF and RHD patients engaged with the short videos and identified with the children in the resources. This was attributed to:

- the choice of media used (i.e. videos)
- the fact that children in the short videos are Indigenous and from the NT
- the fact that the short videos are in language
- the fact that some of the imagery in the short videos is thought-provoking and memorable

These characteristics were perceived to set the Take Heart resources apart from the vast majority of health promotion resources that target Indigenous communities. In fact, health promotion messages are typically disseminated through printed materials that are handed out to members of the community by (allied) health professionals or which are displayed on the walls of service providers.

This is consistent with the findings from a meta-analysis of the effectiveness of different communication channels for health messages. The metanalysis, which compared the effectiveness of print-based narratives with narratives delivered by audio and video across 25 studies, found that audio-visual narratives produced significant persuasion effects, whereas print-based narratives did not. What's more, narratives like those presented in the Take Heart videos and resources that advocated for detection and prevention behaviours led to significant effects,

whereas those advocating for cessation behaviours did not have significant effects [15].

Interviews also revealed that the videos and resources are being used in practice, with healthcare staff at the clinics in three separate communities reporting that they have shown the short videos on their personal mobile phones to children with ARF or RHD and their families, when they attended the clinic.

Notably, in one of the evaluation communities, the nurse responsible for providing BPG injections visits the families of children with ARF and RHD in their homes when the first three injections are due (i.e. across the course of approximately three months). The nurse reported that during these visits they show the short Take Heart video in language to those who are present in the house. This is done in a bid to communicate the risk factors for ARF and RHD to the extended families of sick children and to encourage carers to support children to have their injections when they are due.

Evidence about the extent to which the short videos and other Take Heart resources are appreciated by members of the community is also available from the responses to the online survey. One respondent had this to say:

> *'The resources are all wonderful. […] Your documentaries particularly show the human side to this terrible disease and just how young people are affected by it'*

Opportunities for further adaptation of the resources to the local context – Resources in language

It is estimated that more than 300 Indigenous languages are spoken in Australia; many Indigenous children and their families only speak English as a second language and have difficulties in engaging with health promotion materials in English. The Take Heart short videos are distinctive in that they have been translated to more than 15 Indigenous languages, including those that are most commonly spoken in the NT.

As already mentioned, people surveyed and interviewed praised the fact that the Take Heart videos are in language. In some instances, members of the community appeared positively surprised that anything at all was available in their language.

Community members – including Elders – in one of the evaluation communities requested that one of the short videos be made available in at least one more of the languages that is commonly spoken in their community. This is an indication of perceived value from the part of the community – an important factor for the success and sustainable implementation of any program. Accordingly, during the evaluation, the audio script for the short video was interpreted and translated by a local linguists team together with a member of the Take Heart team and RHD nurse.

The interpretation and translation process itself highlighted the importance of engaging into a genuine knowledge exchange process, whereby key concepts and terms such as 'germs', 'infection', and 'inflammation' were discussed, and appropriate translation – including paraphrasing where necessary – took place. A quality assurance process of backtranslation from the local language into English was also followed. This process involved speakers of the local language who had not been involved in translating the Take Heart script from English to the local language.

The newly translated video is now available online along with the other Take Heart resources, and the Take Heart team reported that many other communities have also requested for the videos to be made available in other languages.

When asked about the resources in language, one of the healthcare staff interviewed said that these were "*Ok*" and a group of youth said that some of the language from another community had some flow issues. It should be noted, however, that the key health messages were not compromised.

Nonetheless, this further underpins the importance of a rigorous interpretation, translation, and backtranslation process. Should the videos be made available in additional languages, a formal quality assurance process should be established to make sure that they are as adequate for the purpose as possible.

The Take Heart short video script is interpreted and translated into a local Indigenous language

Opportunities for further adaptation of the resources to the local context – New videos

The inclusion of Indigenous children and their families in the short videos as well as the long feature documentary was one of the features of the Take Heart resources that was widely praised by evaluation participants.

Nonetheless, in one of the communities it was pointed out that the Indigenous people featured in the videos were from Aboriginal Countries other than the one where the evaluation was taking place. The respondent pointed out that it was immediately obvious to them that the people in the video were from a different Aboriginal Country and that the language of the voiceover (which was in the local language) was at odds with the appearance of the individuals in the video. In another community, another video on ARF and RHD had previously been filmed by local youth. During the evaluation, several members of that community referred to this video and, in some cases, showed this to the evaluation team.

Together, these findings suggest that additional videos, with children and families from their country, would be popular among the local community and perhaps most effective in promoting health messages.

The Take Heart online resources have also been well-received

The evaluation included an anonymous online survey of individuals from across Australia who engaged with the Take Heart Facebook page and online resources. More information on this is provided later in this report; in this section we introduce the findings from the survey that are relevant to the engagement with and acceptability of the Take Heart resources.

More than half of respondents (58.2%) engaged with the short documentary, compared with 23.6% who saw the photos, and 16.4% who saw the long feature documentary. Notably, 7.3% of respondents indicated that they had attended a Take Heart community event; whilst this is a relatively small percentage, it suggests that the community events are effective in ensuring that individuals engage with the resources and encourage them to follow up and learn more after the event.

The survey also revealed that some people exclusively engage with the Take Heart Facebook posts, rather than with any of the other resources available (e.g. short videos). This should be noted, as it may present opportunities to further tailor the messages that are posted to the Take Heart

Facebook page, to ensure that they provide comprehensive information to users who may not access the other Take Heart resources, and to encourage them to access these. The Facebook posts could also be used to prompt those already engaged to 'spread the word' and encourage anyone they know who may be at risk of ARF and RHD to engage with the Facebook page and Take Heart resources.

Community events present an opportunity to increase exposure to Take Heart resources and engage in health promotion activities – Tailoring of these events may further increase impact

The community events have been one of the key features of the Take Heart initiative in Australia. Prior to the commencement of the evaluation, the Take Heart and the evaluation teams planned to hold events that consisted of a community screening of the long feature Take Heart documentary and holding a photo exhibition.

The first Take Heart event was made to coincide with a community sporting event in the pilot community. In piloting the event and engaging with evaluation communities, the evaluation team learnt that this format may be suitable for some, but not all settings.

In line with the developmental evaluation approach, the evaluation team has since developed and trialled the different approaches described below to increase exposure of Take Heart at festival-held events, and to engage community members outside of festival events.

Leveraging a community festival: In one of the communities, the Take Heart team planned the event so that it coincided with a yearly festival that is held locally. In this case, the team set up a Take Heart stand at the festival, which was attended by at least one team member at all times. The stand consisted of a table that displayed some Take Heart resources (i.e. postcards and DVDs), a large screen on which the Take Heart short videos were projected on loop, and a banner with one of the Take Heart posters. Headphones were also available for anyone who wished to stop by and listen to the audio from the videos.

This approach had mixed success. The festival was attended by locals and visitors alike, including both Indigenous and non-Indigenous people. Throughout the day it became evident that the festival stands – including, but not limited to the Take Heart stand – were more likely to attract visitors and non-Indigenous Australians than members of the local community. Nonetheless, Indigenous families and youth were successfully engaged, and they provided positive feedback and were able to demonstrate that they had learnt the key messages; some also demonstrated engagement with the content by returning to the stand with friends and family (more on this later).

During the festival, the stand was also more successful in attracting the attention of adults than that of children and their families. In contrast, other stands that had activities and props specifically set up for kids were able to engage a younger audience. In future, it may be possible to integrate some of the activities from the RHD health unit for the school curriculum (also described later in the report) into a Take Heart stand at festivals.

Setting up RHD-specific community events: In another community, an RHD specific community event was set up. Members of the community were invited to attend an evening screening of the Take Heart long feature documentary at the local sports hall. Refreshments were provided and both RHD experts and a Community Leader gave brief presentations. The screening was well attended, however the audience only provided their undivided attention to the local Community Leader.

This suggests that building the capacity of Community Leaders to advocate for the prevention and control of ARF and RHD prior to holding community events may be effective in sharing key health messages among community members.

In addition to holding the evening screening of the feature documentary, the Take Heart team set up a table at the local shopping mall with a laptop and headphones. Passer-by who engaged with the Take Heart team were invited to watch the short Take Heart videos in a local language of their choosing. This approach was successful in obtaining the undivided attention of the target audience and the feedback received was positive (as mentioned earlier in this report).

This community event also demonstrated that making the Take Heart resources available in a context where there are limited distractions and a more captive target audience may be a more effective way to ensure that people at risk of ARF and RHD engage with the Take Heart resources and its important health messages.

Setting up small-group sessions with target groups in the community: In two communities, the Take Heart and evaluation teams set up small ARF and RHD information sessions with community groups (e.g. a sewing centre), childcare centres, and schools. As it was done in the event described above, a local Community Leader was engaged prior to the visit.

On this occasion, the Take Heart team was able to identify a Community Leader who had prior knowledge of ARF and RHD, and therefore no capacity building was necessary. During the sessions with the community groups, the Community Leader and an RHD nurse and member of the Take Heart team provided information about the conditions to the groups' members and displayed the short videos in language.

This approach was successful in engaging members of the community with the Take Heart resources and messages. Evidence of the extent to which the events were able to raise awareness in these communities is provided later in this report.

At all events, the clinics staff were engaged and informed about the community event taking place.

Evidence from the Take Heart app usage provides an indication of the impact of the community events and engagement with the clinics

Data about the amount of times the Take Heart mobile app has been downloaded and accessed also provides some evidence about the impact of the community events. App downloads and usage peaked around the times of the community events and engagement with the clinics (Figure 2) and it has been following an upward trend over time, beyond the community events.

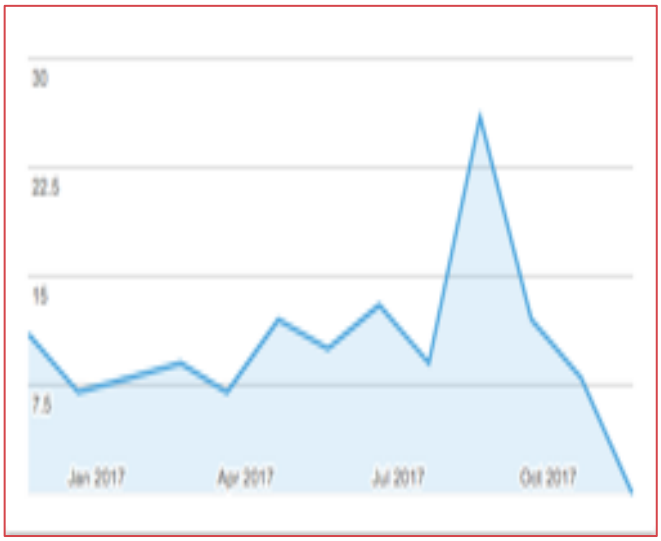


Figure 2. Take Heart app installs by Android user in 2017

Although the number of installs dropped following the community event in September, engagement – i.e. active users – continued to increase.

It is not possible to establish a causal link between these trends in app usage and the community events, however the data suggests that the community events had a positive impact on app downloads and usage.

Findings also suggests that regular, ongoing engagement with the clinics and communities may be important to prevent a decline in usage of the app.

The Take Heart mobile app – An important tool that is being continuously improved

The Take Heart app is one of the key resources in the self-management component of Take Heart. This evaluation sought to assess the extent to which the app is acceptable and implementable. Interviews were held with eight healthcare staff who look after children and young adults with ARF and RHD and their families.

The Take Heart app for a mock patient who had two injections in the month of September

The app was designed to be used by children and their families to record when injections are given – and it gives prompts to go to the clinic when the next injection is coming up or is needed. Prompts become more frequent and communicate a greater sense of urgency as the latest possible day to have an injection without putting one's health at risk becomes closer.

Overall, the response to the development of the app was positive. The key positive aspects of the app that were praised by users include the fact that the app is free, it does not take up a lot of memory on the phone, and it is simple in appearance and easy to use. A feature of the app that stood out to users is the fact that – once it is downloaded – the app can be used offline. This means that the app can be used even if the user 'runs out of data' or if they are in an area where there is no mobile phone reception. Users also noted that multiple children can be added on the same phone, which means that carers who look after more than one child with ARF or RHD can use the same app to track the injections of all their children.

There were key setbacks that hampered the implementation and uptake of what was otherwise perceived to be a tool with huge potential. Some changes were made in a bid to improve usability of the app after baseline data collection. In spite of these improvements, interviews held at follow up still indicated that few – if any – families had taken on to using the app on a regular basis and that healthcare staff were still experiencing glitches that impaired normal functioning and usefulness of the app. This is exemplified by the challenges experienced by two respondents who reported that they had entered multiple children on their app, but that glitches prevented notifications from displaying properly.

These findings are supported by the app analytics. An Android and an iOS (Apple) version of the app are available for free download. Android app analytics indicate that, since it was released, the app was installed on 368 devices and then uninstalled from 190 devices. This suggests that 178 devices still have the app installed (although some of these devices may no longer be in use). However, app usage data indicates that only 44 users were active in the month of September 2018. A peak in installations was recorded at the time when a cluster of community events were held.

A similar trend can be observed for the iOS version of the app, with 354 downloads since it was launched and only six active users in the last 30 days as of October 2018.

AN UNINTENDED IMPACT

An RHD unit for the health curriculum of NT schools

Additional evidence about the impact of Take Heart on increasing awareness – as well as on health seeking behaviour – can be found in an unintended impact of the rollout of the Take Heart community events and evaluation.

During a visit to one of the communities to hold the Take Heart event, the evaluation team was invited to visit a team of linguists at the local school and to meet with teachers. During the meeting, overlapping interests, complementary competencies, and a shared goal to prevent and better manage ARF and RHD resulted in an agreement to seek funds for and to develop the content for an RHD unit within the health curriculum at the school.

The group was successful in securing funding and the unit was developed in close collaboration between the school linguists, teachers, and the Take Heart team.

The unit included teaching children about germs and how they are spread, about the heart's anatomy and its function, and about how ARF and RHD can be transmitted and affect the heart. The unit also taught children about the importance of seeking healthcare when symptoms appear, and about the importance of adhering to the injection schedule.

The unit included highly interactive sessions for children. For example, children learnt about the impact of hand washing by comparing bacterial growth on bread that had been touched with clean hands with the growth on bread that had been touched with unwashed hands. Children were also asked to put 'invisible' glitter on their hands and then just go about their morning. The glitter used was in fact only visible under ultraviolet, purple light. Some time later the children were then asked to use a purple light to see how the glitter had spread among themselves and onto objects that they had touched. Finally, children were involved in physical play which mimicked the functioning of the heart.

Notably, children were also tested on their knowledge of ARF and RHD after the unit was completed. Tests included paper-based quizzes, whereby children were asked to match pictures with meanings, and also oral tests.

There is also anecdotal evidence that children who participated in the RHD unit at the school are now more attentive to skin sores and sore throats. During the follow-up visit, a school nurse reported that children are now bringing their friends along to the sick bay to have any skin abrasions and sores looked at.

This experience and the related preliminary evidence for the increase in knowledge and improvement in practices warrants attention.

Objective 2 – The reach and spread of Take Heart within communities and across Australia

In this evaluation we sought to collect information on the individuals who engaged with the Take Heart resources, their use of the resources, and their communication with others in their social networks about Take Heart. We did this through field observations, interviews, and through an online survey.

We also performed a retrospective mass media scan together with an independent supplier; this provided a detailed description of the nature and number of print, radio, and TV mentions of Take Heart and allowed us to assess the reach of the campaign to national audiences.

Youth from Indigenous communities at high risk of ARF and RHD are becoming role models for their peers

Both reports from healthcare professionals and field observations during the community events suggest that some youth who have engaged with the Take Heart resources then go on to spread Take Heart messages among peers in their communities.

For example, there have been reports of male teenagers rallying younger children in their community to '*go listen to the heart lady*' (i.e. a Take Heart team member who had shown them the Take Heart resources). Similarly, during the community event in a different community, a male teenager who had stopped by to watch one of the short videos later led peers and younger children to the Take Heart stand that had been set up for the occasion and pointed out the Take Heart resources and encouraged them to engage with the short video. Given the importance of social networks and role models in Indigenous communities, spokespersons and role models from within the community could play a central role in the spread of the Take Heart messages.

The Take Heart Facebook page – A rapidly growing success

The online resources that are nationally available include a Take Heart Facebook page (https://www.facebook.com/TakeHeartProject/). Since being set up, the Take Heart Facebook page has seen a huge increase in popularity, with a surge in the period between August and October 2018. This surge aligned with an increased focus on the online resources – including social media – from the Take Heart team (e.g. more frequent uploads and curated content).

The page currently has more than three and a half thousand followers, which is more than three times as high as Facebook pages curated by key stakeholders in the RHD sector in Australia.

As of October 2018, over a period of just 28 days the Facebook page had amassed a maximum of 8,685 engaged users, had reached more than 82,000 people, and its contents had appeared on the screen of people across the country more than 200,000 times. Engaged users refers to the number of unique (different) users who actively engaged with the Facebook page (e.g. clicked on any of its content). Reach refers to the number of people who have seen any content from the Take Heart Facebook page, such as posts, check-ins, social information from people who interact with the page, and more. A steep increase can be observed in all three metrics between August and October 2018 (Figures 3-5).

Figure 3. Total number of people who engaged with the Take Heart Facebook page over a 28-day period

Figure 4. Total number of people who were reached by the Take Heart Facebook page over a 28-day period

Figure 5. Total number of times that the Take Heart Facebook page was displayed on screens over a 28-day

Between August 1st and October 15th2018, on average, the Take Heart Facebook page reached 3,351 people and engaged 307 people; within this same time period, the largest number of people reached and engaged in only one day were 9,721 and 1,382, respectively.

As mentioned, we implemented an online survey, which targeted individuals from across Australia who engaged with the Take Heart Facebook page and online resources. The great majority of respondent (89.1%) identified as female and just over half (50.9%) were aged between 46 and 65 years. There were no respondents in the 18 to 25 years age group. Twenty percent of respondents identified as Aboriginal and 5.5% preferred not to disclose whether they identified as Indigenous Australians; the remainder didn't identify as Aboriginal nor Torres Strait Islander. Almost all respondents (89.1%) also reported that they did not have ARF or RHD, with only one respondent preferring not to share this information.

The demographic profile of those who chose to respond to the online survey may not be reflective of the profile of all those who engage with the online Take Heart resources; however, this evidence suggests that those most likely to be affected by ARF and RHD – that is, young Indigenous Australians – may not be accessing the online Take Heart Facebook pages and resources.

These findings from the survey are supported by analytics data from Facebook, which shows that 86.3% of people who liked the Take Heart Facebook page are women and that 62.8% are aged 45 years or older (Figure 6).

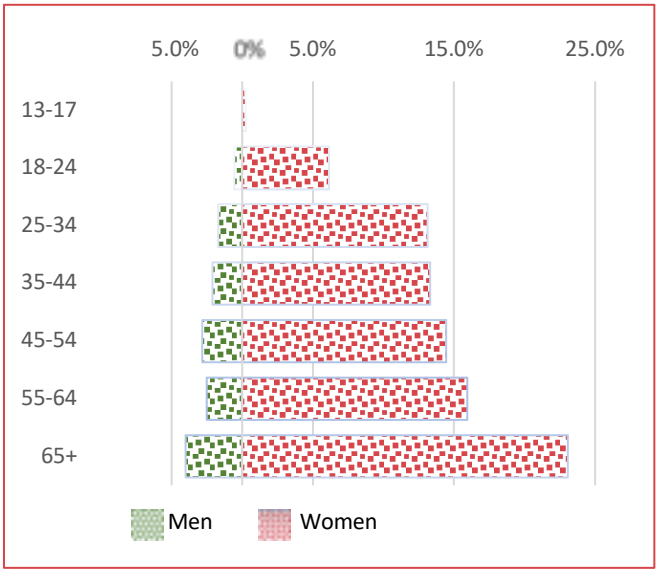


Figure 6. Age and gender distribution of people who liked the Take Heart Facebook page (October 2018)

On the other hand, the survey responses suggest that health professionals who work with families affected by ARF and RHD are engaging with the Facebook page. The Take Heart team may wish to leverage this opportunity to disseminate messages that target health professionals and

encourage them to share their interest and knowledge about ARF and RHD with colleagues.

The most common way for survey respondents to become engaged with the Facebook page was through Facebook itself – thus, 38.2% of respondents were invited to access the Take Heart Facebook page either through the automatic suggestions feed or through related posts from friends who have an interest in Take Heart and ARF/RHD. Approximately one in five respondents (18.2%) indicated that they engaged with the Take Heart resources because a friend had told them about them, and 14.6% indicated that a health professional had told them to engage with the online Take Heart resources. These findings are shown in Figure 7. Combined, these findings support the evidence that word of mouth is one of the most effective ways to encourage a target population to engage with specific resources. The Take Heart team might want to tailor messages to encourage people to share the word with those whom they know are affect by ARF or RHD or who live in high prevalence areas.

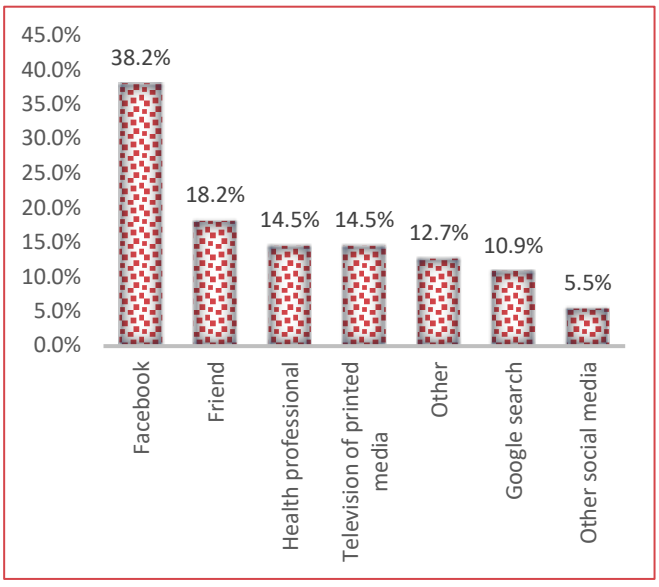


Figure 7. How did survey respondents learn about the Take Heart Facebook page?

The majority of respondents found the information on the Facebook page to be extremely or very easy to understand (87.3%) and reported that the page met their needs extremely or very well (81.8%). No respondent said that it was not easy to understand or that it not met their needs well at all. Almost one in five (18.2%), however, reported that the page met their needs not so well. The Take Heart Team may wish to seek feedback from Facebook users about ways in which the page could be improved. We sought to protect anonymity of respondents, and it's therefore not possible to further follow up with those individuals who indicated that the page did not meet their needs well.

Approximately two thirds (63.6%) reported that they were extremely likely to recommend the Facebook page to someone they know. Facebook analytics provide additional information about the extent to which the Take Heart Facebook page and online content are spreading.

In the period between August 1st and October 15th 2018, the average number of people who were 'talking' about Take Heart increased more than ten-fold (Figure 8). In this case, 'talking' refers to not only engaging with the Facebook page and its content (e.g. clicking on a video or post), but also either liking it, mentioning it, commenting, or sharing it. When Facebook users take any of these actions, their own feed will reflect this and all their friends and followers will see this also.

Figure 8. Total number of people who were 'talking' about the Take Heart Facebook page posts over a 28-day period

Take Heart has been extensively covered by the Australian media and reached a wide audience over the years

Data on the extent to which Take Heart has been covered in the media across Australia was obtained by an independent media monitoring company (iSentia) and analysed for the evaluation. This data relates to the time period from the launch of Take Heart in March 2016 until October 2018.

Since its launch in 2016, Take Heart has been mentioned in the media more than 1,300 times and it is estimated to have reached a total audience of more than 12 million people.

The majority of media reports relating to Take Heart were in online news and in the press, followed by broadcasts on radio and television (Figure 9).

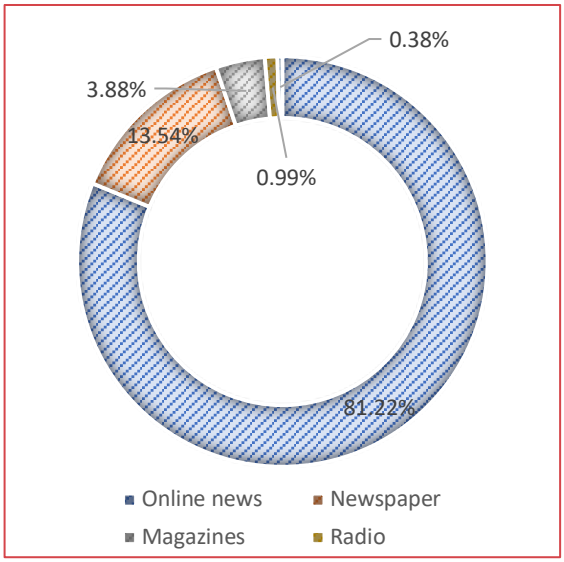


Figure 9. the proportion of reports in press, radio, television and internet media outlets since March 2016

The reach (audience or circulation) and advertising space rates (ARS) of reports in each media type are provided in Table 1. ARS provide the cost of purchasing the equivalent amount of media space and/or time as advertising and are a quantitative statistic used to evaluate publicity. ARS is calculated based on size of content and advertising rates for print, on timeslot, duration of content, and 30 second cost per thousand for radio and television, and on size of content, monthly page impressions/unique visitors, and cost per thousand for internet-based coverage.

Since March 2016 the Take Heart coverage in the media has an estimated ARS of more than AUD13 million.

Table 1. Volume, reach, and ARS of Take Heart reports by media type

MEDIA TYPE	**VOLUME**	**REACH**	**ARS**
Online news	1068	770,958	$8,816,850
Newspaper	178	7,348,393	$1,364,050
Magazines	51	3,105,724	$2,454,976
Radio	13	545,300	$327,402
Television	5	390,000	$50,105

Data on volume and reach by state shows that reports of Take Heart in the media were most common in Queensland, New South Wales, and in NT. However, reach was highest in Queensland, Vitoria, and New South Wales. This is not surprising, given the higher population density in the East coast states.

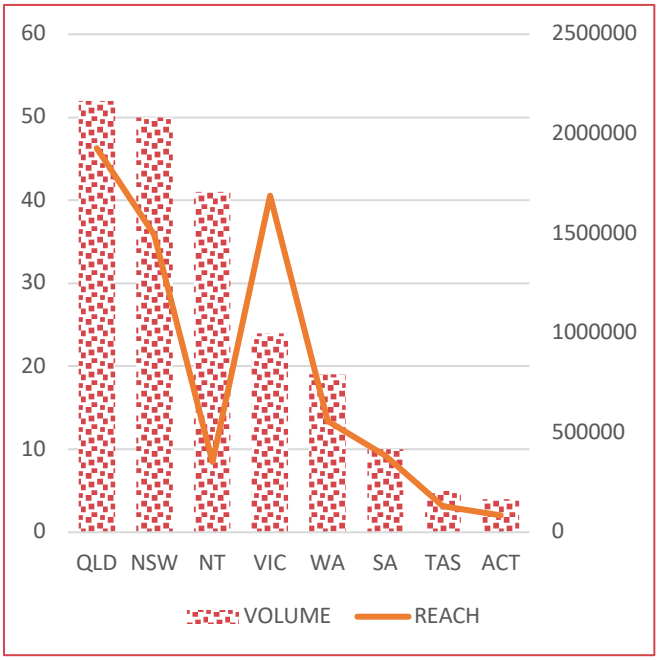


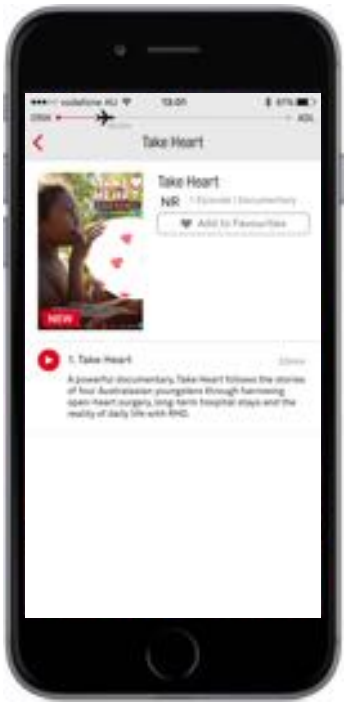
Figure 10. Volume of reports and reach in each state in press, radio, and television coverage (excludes online news)

In addition, media reports that were available in all or multiple states reached a further 4,766,450 people (Table 2).

Table 2. Volume, reach, and ARS of Take Heart reports in the press and broadcasts by state and territory

STATE or TERRITORY	**VOLUME**	**REACH**	**ARS**
ALL	37	4,376,450	$2,733,917.14
QLD	52	1,927,958	$200,239.75
NSW	50	1,495,109	$602,107.84
NT	41	352,305	$94,561.19
VIC	24	1,689,171	$253,826.32
WA	19	558,837	$20,612.36
SA	10	384,375	$81,084.00
TAS	5	130,349	$27,680.40
ACT	4	84,863	$132,398.35
MULTIPLE	5	390,000	$50,105.09

In addition to the reports in the media that have been identified in the media scan, the Take Heart long feature documentary has been screened at numerous events across Australia and on Australian television. The documentary has also been featured on the Qantas entertainment app, meaning that passengers were able to watch the documentary during flights.



The Take Heat long feature documentary on the in-flight Qantas entertainment app

Objective 3 – Did Take Heart contribute to increasing awareness?

The evaluation team surveyed 80 members of the community who engaged with the Take resources (e.g. short videos and/or long feature documentary and/or printed materials) at the community events.

The team asked consenting respondents whether they knew about ARF and RHD prior to engaging with the resources, and if so, what they knew about these conditions. Following engagement with the Take Heart resources, respondents were then asked what, if anything, they had learnt about ARF and RHD and what they thought of the Take Heart resources.

Evidence about the extent to which Take Heart messages are learnt and retained from the resources also comes from the interviews with health professionals, from the online surveys, and from field observations.

The Take Heart messages surprise and "stick"

The short videos held the attention of all respondents and many reported that they were surprised to find out that ARF and RHD could be '*so serious*' and that they could lead to major heart surgery or even death. Many were also surprised that the people affected needed injections so often and for so many years.

After watching the short Take Heart video, survey respondents relayed the key messages on the importance of keeping an eye out for skin sores and sore throats among children – with many noting that they would now make sure to encourage anyone caring for children with suspected symptoms of ARF or RHD to seek medical attention. One respondent who was attending a local festival said:

'I work in [nearby community]. When I get back I'm going to tell families with little ones to get them checked for skin sores'

Two girls from one of the Take Heart evaluation communities show off their drawings following a Take Heart community event. Their t-shirt designs show the importance of keeping up with the injections schedule

At one of the community events, children who were in attendance were shown the short Take Heart video in language and they were then given an opportunity to create designs for a t-shirt using paper and coloured markers. The results were striking, with children drawing designs that reflected the key Take Heart messages – this suggests that children had assimilated at least some of the information provided in the videos.

Field observations in one of the communities also suggest that community members who took part in the community events had retained some of the messages from the Take Heart resources. In one of the communities, the Take Heart event involved small group sessions with a women's sewing centre (more information about the different formats of the community events is provided earlier in this report); at follow-up, a number of t-shirts with ARF, RHD, and Take Heart 'slogans' had been painted and made available at the centre. Whilst it is unlikely that those t-shirts will be accessible to and used by children in the community, this suggests that the women who painted the t-shirts had in fact taken on board the key messages and chosen, by their own volition, to paint the t-shirts even after the Take Heart event was completed and the Take Heart team and evaluation team had left. This is important, given that these women are likely to know, if not care for, children at risk of or with ARF and RHD.

Additional evidence about the messages that are learnt from the Take Heart resources comes from

the online survey that was administered to users of the Take Heart Facebook page. The survey shows that eight in ten respondents (83.6%) learnt that RHD is preventable, seven in ten (70.9%) learnt that those affected must take medications for ten years or more, and more than half (56.4%) learnt that children with sore throats should receive a medical check-up (Figure 11).

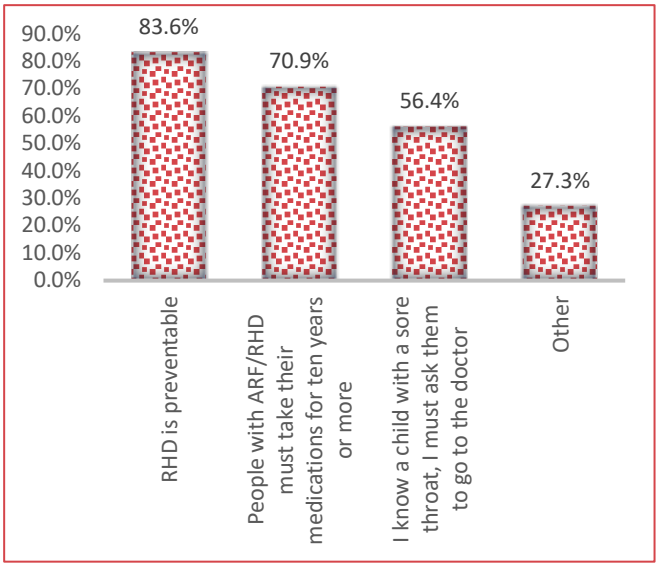


Figure 11. Key messages learnt by online survey respondents who accessed the Take Heart Facebook page

Other key messages that respondents said that they had learnt from the resources include the link between ARF, RHD, and hygiene, as well as the fact that these conditions are still very common and disproportionately affect Indigenous communities. One survey participant wrote:

> *'RHD is still a huge issue in Aboriginal populations and more needs to be done to prevent, diagnose and treat it. I already knew the other bits of information, I just didn't realise the magnitude of the problem'.*

Similarly, the great majority of respondents were able to correctly identify symptoms and risk factors for ARF and RHD after engaging with the Take Heart Facebook page and online resources.

Approximately nine in ten respondents correctly identified skin infections (92.7%) and sore throats (89.1%) as potential symptoms of ARF and six in ten (61.8%) identified overcrowding as a risk factor. Only 5.5% reported that sore joints could also be a symptom of ARF (Figure 12).

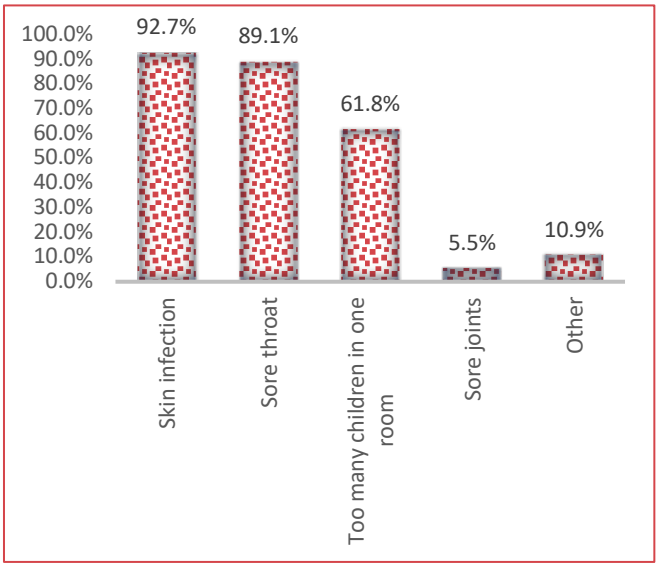


Figure 12. Symptoms and risk factors identified by online survey respondents who accessed the Take Heart Facebook page and online resources

More findings from the online survey are provided earlier in this report.

It is well established, however, that knowledge does not always result in behaviour change. The evaluation design did not allow for an investigation into whether increased awareness as a result of exposure to Take Heart resources led to a change in health seeking behaviour among community members and other target groups.

Nonetheless, the case study described in this report (see the "Timmy's story" text box later in the report) suggests that the Take Heart resources can have – and in fact have already had – an important impact on behaviour.

Take Heart and RHD t-shirts at the sewing centre in one of the evaluation communities

Common and potentially harmful misconceptions about ARF and RHD persist

Most people surveyed during the community events did not know what ARF and RHD are. Rather, findings suggest that common misconceptions about ARF and RHD persist.

For example, the majority of respondents believed that these conditions were *'a thing of the past'*. Notably, with only a few exceptions, respondents were either unable to identify causes of ARF and RHD or believed that the conditions could be 'passed down' (i.e. that it was hereditary and therefore non-communicable). Finally, almost all respondents were unaware that, once an episode of ARF is experienced, treatment must be continued for at least ten years.

In a context like the NT, where ARF and RHD are still common and lethal, these observations underpin the importance of persisting with health promotion campaign about these conditions and ensuring that approaches to health promotion, secondary prevention, and management are optimised.

Findings also highlight an alarming lack of awareness among some healthcare professionals

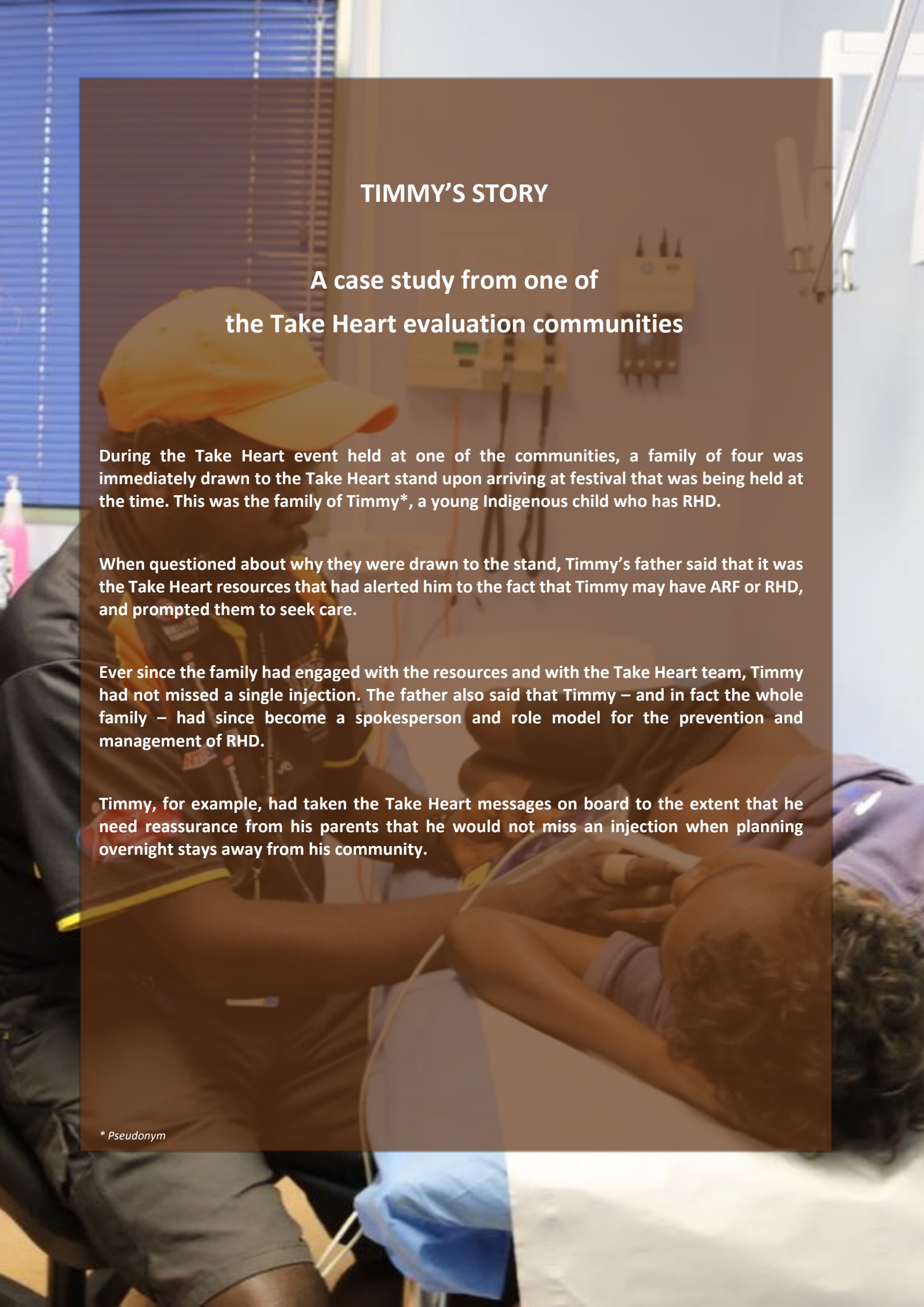
During the community events, two healthcare professionals who regularly come into contact with children with ARF and RHD were also surveyed. Notably, neither of these respondents were able to correctly identify risk factors for ARF and RHD, and one respondent did not know what treatment entailed (i.e. injections), nor how long it had to be administered for (i.e. a minimum of ten years).

It should be noted that these two healthcare professionals practiced in communities other than the those that participated in the evaluation of Take Heart.

These observations suggest that health promotion messages and strategies should not only target Indigenous children and their families, but also the health professionals caring for them.

Objective 4 – Assessing whether Take Heart contributes to increasing compliance to treatment among RHD patients

The evaluation team intended to recruit families with children with ARF and RHD with support from the clinics staff and to collect comprehensive data about their adherence to treatment following exposure to the Take Heart resources. This, however, was not possible in practice and it is a limitation of this evaluation. It is regrettable that families could not be recruited for comprehensive data collection on adherence to treatment, however staff turnover within the clinics combined with high workloads meant that it was not possible to have clinics staff dedicated to the ongoing recruitment of families into the evaluation. Nonetheless, a wealth of useful evidence has been collected through interviews, community surveys, and online surveys. The media scan and app usage data also provide useful information.



TIMMY'S STORY

A case study from one of the Take Heart evaluation communities

During the Take Heart event held at one of the communities, a family of four was immediately drawn to the Take Heart stand upon arriving at festival that was being held at the time. This was the family of Timmy*, a young Indigenous child who has RHD.

When questioned about why they were drawn to the stand, Timmy's father said that it was the Take Heart resources that had alerted him to the fact that Timmy may have ARF or RHD, and prompted them to seek care.

Ever since the family had engaged with the resources and with the Take Heart team, Timmy had not missed a single injection. The father also said that Timmy – and in fact the whole family – had since become a spokesperson and role model for the prevention and management of RHD.

Timmy, for example, had taken the Take Heart messages on board to the extent that he need reassurance from his parents that he would not miss an injection when planning overnight stays away from his community.

** Pseudonym*

Moderating factors – Contextual issues

It is important to acknowledge that Take Heart operates within a complex context. While self-evident, this also emerged during the evaluation interviews and when trialling different approaches for the community events.

Although not immediately within the scope of this evaluation, in this section we report some of these observations and themes. We also acknowledge that this section only begins to scratch the surface of the complex historical and social context within which the lives of Indigenous Australians unfold and the impact that these contextual factors have on the health of Aboriginal and Torres Strait Islander people.

Later, some recommendations are also made in relation to what the Take Heart team may consider within their sphere of influence.

Overcrowding and social housing in Australia

During the surveys and interviews insufficient housing and inadequate social housing policies emerged as a priority among both community members and health professionals.

In one of the evaluation communities with the highest prevalence of ARF and RHD, there are on average more than seven individuals per dwelling.

It is also important to note that during the evaluation we came across reports of families with children with ARF and RHD who were aware of the link between overcrowding and the conditions, and therefore requested more adequate housing through the appropriate formal channels. These requests, however, have been in processing for years – in spite of efforts from health professionals to fast-track applications given the important health implications.

The Western model of health and cultural safety, and staff turnover.

Surveys, interviews, and field observations confirmed that, in most locations, the healthcare system and associated services are set up in a way that could be better aligned with the cultural beliefs and expectations of care of Indigenous Australians.

It is well established that Indigenous Australians have often found health services to be unreceptive to cultural needs and it is not uncommon for patients to discharge themselves from hospital against advice. This also emerged during the interviews, and examples were provided of children with ARF and RHD who had been transported to Darwin for care only to then be discharged by the families ahead of time against medical advice.

On the other hand, there are numerous examples of successful health initiatives that have been initiated, developed, and implemented by Indigenous people in their communities.

Another issue that was frequently reported as a challenge in the provision of ARF and RHD care is staff turnover. This was also experienced first-hand as a challenge by the evaluation team when setting up the community events and evaluation activities.

In three of the communities the interviewees pointed out that retention of clinic staff is challenging and that new staff, although always well-intentioned, sometimes lack sufficient exposure to the NT context let alone ARF and RHD. There were reports of children with ARF who were not checked for the disease at presentation because ARF and RHD symptoms are not normally associated with such serious health conditions in other parts of Australia.

Staff turnover was also linked with the issue of cultural safety, in recognition of the fact that social network and relationships are central to Indigenous Australian culture and take a long time to establish and foster.

A significant body of literature exists in relation to improving acceptability and uptake of services in Indigenous communities – with some focussed on the very communities included in this evaluation. Nonetheless, some of the practical suggestions that were made to the evaluation team in relation to the provision of ARF and RHD care included engaging extended families into the care of affected children and developing in-depth training curricula relating to ARF and RHD for new staff who will work in high-prevalence communities.

Coordinating efforts to integrate different technologies

The development and implementation of the Take Heart app took place at a time when other groups have also been developing complementary technology-based solutions for the management of ARF and RHD.

Other apps are now available for download, which also support the tracking of treatment with BPG injections. Some apps also target specific sub-groups with ARF and RHD (e.g. adolescents) and encourage them to engage with relevant resources.

Advances have also been made in relation to approaches to detection and referral of children with ARF and RHD.

Researchers at the Menzies School of Health Research are testing an accessible and quick protocol to identify children with RHD in schools. Screening for RHD typically involves exposure of the chest – which can be time consuming, invasive, and inadequate for settings outside of the clinic. Menzies' Pedriño Study is investigating whether a handheld echocardiogram machine that is linked to a mobile phone can be used by trained staff other than paediatricians and heart specialists to correctly identify children with RHD in schools. This has huge potential, and early findings are very promising. If successful, this may result in the introduction of screenings in school across high risk areas.

Nonetheless, these solutions have largely been developed in isolation. Gaps also remain in terms of the technologies that can support healthcare staff in different locations to effectively track patients' adherence to treatment, and which can readily/automatically establish a communication link between services and patients.

Taken together, evidence from this evaluation highlighted that there is a need for an integrated health information management system, which allows clinicians and families alike to identify and keep track of children and young adults with ARF or RHD and their treatment status.

The eye health sector provides examples of the successful development and implementation of such solutions. The Peek Vision group developed a mobile app which can be used by individuals who are not eye health professionals to assess visual acuity. This is comparable – in its function and overall objective – to the solution developed and tested in the Pedriño study for the detection of ARF and RHD among school children by staff other than paediatricians and heart specialists. Once the visual acuity test is completed, the Peek app automatically sends a notification of the results to the person screened (or their carer) and to the nearest (most appropriate) eye health professional. This notification can be an SMS, a voice message in the local language, or an e-notification, and it's tailored depending on whether it's directed at health professionals or otherwise; thus, health professionals receive a detailed preliminary diagnosis, and individuals being tested or their carers receive a notification in lay terms letting them know whether there are any issues and whether follow up is needed. When visual acuity screenings are done in schools, the head teacher or contact person for the school also receives an SMS list of the children in their school who require further support and reminders to

those who have not yet received it. The app is also linked to a software that is downloaded on computers at participating service providers, which can be used to track whether patients have attended the clinic or not. The software, in turn, can send notifications (SMS or emails) to clinicians and patients to remind them of clinical appointments when they are coming up or when they have been missed (much like the Take Heart app and other apps to for BPG injections).

Exploring and implementing similar systems for the detection and management of ARF and RHD in Australia is beyond the scope of the work of the Take Heart team and requires a coordinated approach across the sector, nonetheless it is important. Such a system, in the hands of trained school screeners, clinics staff, and families with children with ARF and RHD has the potential to have a significant positive impact on the prevention and control of ARF and RHD.

Making sense of complexities

Evidence from the evaluation and in particular from the rollout of the community events highlighted the complexity of ARF and RHD as a health issue in Indigenous Australian communities.

A one-size fits all approach – including some evidence-based practices – is inappropriate when addressing health issues that are particularly complex and involve multiple determinants (especially social determinants) and a range of different stakeholders.

In such context is it important to take the time to try and make sense of the complexities in each different context where a health promotion program is rolled out and adapt approaches so that they are as operational and as effective as possible within the local context.

LIMITATIONS

This evaluation had some limitations that should be noted and taken into account when interpreting its findings.

Through the clinics, we intended to recruit families with children with ARF/RHD and collect comprehensive data about adherence to treatment. This was not possible in practice and it is a limitation of this evaluation. It is regrettable that families could not be recruited for comprehensive data collection on adherence to treatment, however staff turnover within the clinics combined with high workloads meant that it was not possible to have clinics staff dedicated to the ongoing recruitment of families into the evaluation. Nonetheless, a wealth of useful evidence has been collected through interviews, community surveys, and online surveys.

Competing demands in the communities, staff turnover at the clinics, and seasonal weather patterns had an impact on how readily the Take Heart and evaluation teams were able to set up and implement community events and evaluation activities. This, in turn, had an impact on the time lag between when the events took place and when follow up data collection was carried out. At minimum, however, this time lag was six months.

The design of the evaluation does not allow to conclusively establish causality between exposure to the Take Heart resources, any increase in awareness relating to ARF and RHD, and changes in practices.

RECCOMMENDATIONS

Implement tailored community events

Evidence from this evaluation suggests that the Take Heart community events and the utilisation of the Take Heart audio-visual materials in language can be an effective way to communicate important ARF and RHD prevention and control messages.

Additional events should be held in priority communities – that is, communities that have requested involvement from the Take Heart team and communities where the prevalence of ARF and RHD is high.

In line with findings from the evaluation and the literature relating to working in complex settings, it is recommended that a highly tailored approach is used for the implementation of further community events.

Such an approach could include carrying out an initial situational analysis. Although this could be done remotely, in most cases this should include a preliminary visit to a selected community to identify and begin engagement with key members of the community, with clinics, schools, and with any relevant community groups and stakeholders. Other stakeholders should include any local health boards or Aboriginal Corporations and families with children with ARF and RHD.

These preliminary engagement activities and situational analysis should be followed by a workshop (or multiple workshops as appropriate) with engaged community members, groups, and other stakeholders to tailor the Take Heart resources. Specifically, the resources should be translated in language and where possible additional short videos should be filmed.

A community-wide event could then be set up, which should be hosted by Community Leaders together with the Take Heart team and should include the screening of short videos in language that are filmed in the local community if available.

Finally, health promotion sessions and screenings of the short videos should also be held with the pre-identified community groups and at the local school(s).

Translate the short videos in additional Indigenous languages

The evaluation indicated that the short videos in language are one of the most distinctive features of Take Heart and that they are effective in engaging Indigenous youth at risk of ARF and RHD, their carers, and their communities. Requests for the video voice-overs to be interpreted and translated to additional languages have already been received from Indigenous Leaders from many communities.

It is recommended that the video voice-overs continue to be translated into additional languages.

The interpretation and translation process should include knowledge exchange activities with Community Leaders and other relevant stakeholders to ensure that key concepts and messages are adequately and effectively communicated. Priority should be given to all languages spoken in communities where ARF and RHD are highly prevalent, and to requests that may be received from Community Leaders.

Where the voice-over script has already been translated, the Take Heart team should engage with relevant stakeholders in a process like the one described above to ensure that the videos that are already translated are in fact as adequate as they can be.

Film additional short videos

The inclusion of Indigenous children and their families in the short videos as well as the long feature documentary was one of the features of the Take Heart resources that was widely praised by evaluation participants. However, findings from the evaluation suggest that videos that are highly contextual (i.e. filmed in the local community) would be most engaging.

It is recommended that consideration is given to filming additional short videos with local children, families, and members of the community, which would contain the same messages as the short videos already available. Priority should be given to communities where ARF and RHD are prevalent, and to requests that may be received from Community Leaders.

Tailored messages, resources, and engagement and communication strategies for a broader set of audiences

Findings from this evaluation indicate that a broad audience – both within the community and at the national level – engage with the Take Heart resources. This includes health professionals, teachers, as well as parents of children with ARF and RHD, who have traditionally been the target of the Take Heart resources.

When presented with multiple challenges, many families with children with ARF and RHD may understandably find it difficult to prioritise healthcare appointments. As mentioned earlier, school teachers and clinics staff are well-placed to support children and their families in engaging in positive health seeking behaviours.

It is therefore recommended that additional key Take Heart messages and resources are developed to target specific sub-groups within the audience. For example, key messages and videos that target teachers could be developed, in line with a strengthened focus on schools. Similarly, key messages and videos that target health professionals who have only recently joined the NT workforce could be developed.

Make schools an explicit key focus

Albeit unexpected, one of the most important impacts from the rollout of the Take Heart events and evaluation is the development of the content for an RHD unit for the school curriculum. The unit was very well received by the community and anecdotal evidence suggests that children have learnt key messages and improved health seeking behaviour.

Themes that emerged from the interviews as well as field observations also suggest that schools – and the educational system more broadly – may be a good setting for further Take Heart (and RHD) activities in the future. This is because schools provide a captive audience of children and families in an environment that is relatively stress free when compared, for example, to the clinics.

Accordingly, it is recommended that the Take Heart team continue to contribute to the refinement of the unit content and that it acts within its sphere of influence to encourage the take up of the unit in other schools and, in the future, at Territory level.

If possible, a formal trial or rigorous evaluation of the impact of the RHD unit on awareness and take up of health services should be carried out. This would provide evidence for advocacy purposes for the broader rollout of the unit in the NT.

In addition, it is recommended that future community Take Heart events specifically target schools. Teachers could be shown the Take Heart resources (including the feature documentary) and parents and children could be shown the short videos in language (for example, during parent-teacher meetings).

Continue to leverage Facebook and deliver tailored messages

Since being set up, the Take Heart Facebook page has seen a huge increase in popularity.

Findings also suggest that individuals who access the Take Heart Facebook page tend to be aged 40 years or older and do not have ARF or RHD. Health professionals were also found to engage with the Facebook page. Word of mouth was the most commonly reported way in which people were encouraged to access the Take Heart resources.

Current efforts should be maintained and strategies should be considered to: (i) increase engagement and spread among target groups; and (ii) tailor content so that it is immediately relevant to different audience sub-groups (e.g. health professionals, school-staff, etc.).

Lobby for policy change and investment of resources for ARF and RHD prevention and management

The Take Heart team has made great strides in terms of increasing exposure of national audiences – including politicians – to key ARF and RHD messages. The selection of Dr Bo Reményi as Northern Territory Australian of the Year has provided a renewed impetus to efforts in the sector.

In line with observations about the complex context within which Take Heart operates, the Take Heart team should continue to focus efforts on lobbying for additional funding and political will to be injected in the fight for the prevention and control of ARF and RHD in Indigenous Australian communities across the country.

Since the beginning of the evaluation, the Take Heart team has already developed a new communication strategy that targets Australian policy makers. Complementary efforts should be made to encourage government to inject funds towards:

- Increasing awareness of ARF and RHD, what causes these, and how to prevent them
- Reduce household crowding and therefore reduce household transmissions of strep throat bacteria within households
- Improve access to timely and effective treatment for strep throat infections in priority communities.

These three main strategies are currently being implemented by the newly established Ministry's Rheumatic Fever Prevention Programme in New Zealand.

Encourage coordination of efforts among key stakeholders for the development and implementation of tech-based solutions

Technology-based solutions that facilitate the detection of ARF and RHD and which support adherence to treatment exist. These include the Take Heart app and other apps that are designed to support patients in adhering to treatment, as well as the recently developed handheld echocardiogram machine and screening protocol. Health providers caring for children with ARF and RHD have also welcomed such solutions.

Nonetheless, challenges remain in terms of the usability of the existing solutions and integration of complementary solutions is yet to take place. In addition, clinics supporting patients with ARF and RHD management still find it challenging to track down patients for their regular injections.

Given that the development and deployment of other treatment tracking app has taken place since the development of the Take Heart app, the Take Heart team should consider focussing on encouraging coordination of efforts to improve and consolidate learnings for existing apps.

The existing apps have been designed for children with ARF or RHD and their families. Evidence from this evaluation suggests that an app would in fact be a welcome tool for healthcare staff. This should be kept in mind in any future iterations of the app. It may be possible to consider variations of the app, which would be tailored to different audiences. Health professionals, for example, may benefit from information about adherence to treatment that is presented in a format that is not immediately useful to youth with ARF and RHD and their families.

Similarly, it may be of great benefit to families with children with ARF and RHD if the Take Heart app was able to send SMS reminders about BPG injections.

Any changes to the app – or new iterations of the app – that target health professionals and are used for the management of patients should be developed in compliance with the current regulatory environment.

Lobbying to integrate existing solutions and develop a health information management system that can be used by clinics staff should also be considered.

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