Ambassadors as key stakeholders—working better together with community

Vicki Wade
Rheumatic Heart Disease Australia

Acute rheumatic fever (ARF) and rheumatic heart disease (RHD) are preventable conditions which have been eliminated from developed countries globally. However, Australia a well -resourced and developed country has one of the highest rates of ARF in the world. These rates regrettably are almost exclusively seen in one of the most vulnerable and disadvantaged group in Australia, Aboriginal and Torres Strait Islander peoples (1). ARF is almost entirely preventable and is caused by an autoimmune response to a group A streptococcal infection, with recurrent episodes causing heart valve damage known as RHD. Children aged 5-14 are most at risk of ARF, which can lead to the chronic and often fatal RHD. In the Northern Territory Aboriginal children are 122 times more likely to have RHD than non- Aboriginal young people (2).

There are many complex social, economic and cultural factors contributing to this disparity, including poverty, poor living conditions, delayed access to care, cross-cultural miscommunication, racism and discrimination (3). These factors present enormous challenges in providing optimal health care for people most in need of early detection and prevention, secondary care, tertiary and ongoing management. Young people with ARF undergo painful monthly injections for at least 10 years from diagnosis and often miss out going to school and normal childhood activities. Many patients with RHD require a life time of health care interventions experiencing multiple admissions to hospitals and countless encounters with numerous health care providers.

Adding to these complexities is that Aboriginal and Torres Strait Islander peoples living remotely are often required to leave family and country to undergo treatment in a hospital far away from home. The trip alone can take up to three days, it is often lonely and frightening and the fear of the unexpected can be very overwhelming. They are often unprepared and thrown into a chaotic and alien environment. Health care systems are built on western ideologies and constructs, are multidimensional and fragmented making it almost impossible for Aboriginal and Torres Strait Islander peoples to navigate. Rheumatic Heart Disease Australia (RHDA) believe those living with ARF or RHD are key stakeholders to help those with the condition to navigate the complexities of the health care system while providing great comfort to those experiencing social and emotional hardships throughout their health journey. Those with a lived experience, with support, can help health services gain a deeper understanding of the lived experience and what this means for service provision. With this in mind, RHDA set out to address these concerns by bringing people with ARF and RHD and Aboriginal Health Practitioners from across Australia together to design a program from the ground up.

It is important that Aboriginal leadership was maintained throughout the process and that those with grass roots experience including the lived experience designed the program. To this end RHDA has developed an Australian first national Ambassador program for RHD. At the first orientation workshop held in Darwin in late 2018 participants wanted to change their title from Ambassadors to 'Champions' as they thought this more descriptive of who they are. The Program is now known as Champions4change, with a vision of 'sharing, caring and inspiring'. *Sharing stories, caring about others and inspiring to make a difference.*

Prior to the workshop RHDA identified critical areas along the age and care continuum where people may slip through the gaps adding to sub optimal health care. These areas include; pregnant women or women planning to have a baby, first few years after initial diagnosis of ARF, disengaged young men, transition from children to adults, adherence to secondary prophylaxis, those with increasing signs and symptoms of worsening valvular disease, end stage RHD and palliative care. Champions especially those with the lived experience are in an ideal position to close these gaps by supporting patients and educating health staff in these areas. The Champions4change program will also be instrumental in building upon work RHDA has already done in these areas. Work such as, culturally appropriate and translated resources, the Treatment Tracker app, DVDs aimed at pregnant women with ARF/RHD and school based DVDs. Transitioning from a child to adult is an area that requires a lot of attention and support. Transitional care involves engaging and valuing local navigators or peers who can address language and cultural barriers to provide a sustainable alternative to transition coordinators in mainstream programs (4). The champions also bring to these critical areas knowledge of how culture impacts care.

Acknowledging a person's culture and providing culturally safe care is a major component in the provision of optimal health care, yet it has been largely ignored in Australia. It is important that broader Australia acknowledges and understands the unique culture of Aboriginal and Torres Strait Islander peoples to be able to work effectively with Aboriginal and Torres Strait Islander communities. As one of the oldest living cultures on this planet the richness, diversity and complexities of their culture needs to be acknowledged and understood in a respectful and competent way. It is also necessary to acknowledge the impacts that colonisation has had, and continues to have, on the health and wellbeing of Aboriginal and Torres Strait Islander peoples.

The Champions4change program embraces and supports cultural spirituality while empowering communities. It is based on traditional Aboriginal and Torres Strait Islander culture where complex social structures with roles and responsibilities kept communities functioning safely. These roles that included passing on and sharing knowledge and are at the heart of traditional Aboriginal culture based on the kinship system.

> "Mothers and grandmothers had a shared responsibility to look after all children in the community. Elders helped children grow into adults often in sacred ceremony, helping children navigate the complexities of traditional social structures. 'In traditional Noongar life the women connected, educated and supported families through teaching spiritual and social connections. They done this with no formal education or training.....they done this because it was their way of life. These roles have been passed down for generations" Lily Hayward Noongar Elder.

Programs such as Champions4change both internationally and nationally have proven to assist 'hard to reach' communities with complex social and cultural needs (5). Peer leaders or champions have the potential to play a critical role in closing the unacceptable gap in health care of Aboriginal and Torres Strait Islander peoples with ARF or RHD. Within Australia they have been used broadly across patient populations, health conditions, continuum of care and health care settings. Within the

literature they have been described in programs for Cancer, Diabetes, Asthma, Child and Maternal Health, Drug and Alcohol and Sexual health.

Education and training of the person undertaking this role is also inconsistent, ranging from ad hoc work based training to accredited courses and train the trainer programs. There is also inconsistency of titles and roles where they have been referred to as ambassadors, community based workers, community health workers, lay health advisors, lay educators, peer support person and care navigators. Despite the various titles, they all share common ideals such as; individuals committed to helping improve the health and wellbeing of individuals in their community, and community members with a lived experience of the disease or condition they are helping to improve. They also assist in identifying the needs of the community, facilitate change and improve access to services. They all provide emotional, social and practical assistance on how to achieve and sustain healthy behaviours. Some ambassador programs employ high profile community members that may not have the condition or lived experience but have the desire to make a difference.

Despite the inconsistencies in role definition and titles they have shown to be effective across a variety of chronic conditions and complex health behaviours. They have all been valuable in engaging and benefiting those "hard to reach," populations, promoting behavioural change support, health care, and reducing avoidable, unwanted emergency or hospital care (6). Peer leaders have also been used successfully to improve knowledge transfer and enhance decision making while breaking down complex colonial relations and power imbalances for First Nations, Inuit and Metis people with cancer (7).

Aboriginal and Torres Strait Islander peoples have a younger age profile, with adolescents bearing a high burden of health problems. Social and cultural factors impact care that they receive, this is related to both historical and contemporary trauma including intergenerational trauma. Aboriginal peer leaders have been used in sharing information about sensitive topics that may cause fear or shame if discussed with adults (8). Elders also have a place in these programs, they are a trusted group who understand and incorporate multiple sources of knowledge and deliver it in culturally meaningful ways. Including the voices of elders may improve the impact and uptake of health information and community engagement (9). They can also provide younger Aboriginal and Torres Strait Islander mentors or peer leaders cultural guidance (10).

Almost all peer led or ambassador programs are located within primary health care settings using the principles of health promotion and various health promotion strategies and frameworks. There are also many theories purporting why peers have been successful in changing health behaviour. Most theories used in these programs stem from social psychology emphasising role modelling, self - confidence, self-efficacy and empowerment as central tenants. Regardless of the theory, peer led strategies align with Aboriginal and Torres Strait Islander peoples culture and ways of being (as described earlier by Lilly Hayward, Noongar Elder). There have also been successful programs implemented in marginalised and vulnerable communities throughout the world. These are important to consider when looking at a program for Aboriginal and Torres Strait Islander peoples with ARF or RHD.

The champions4change program was designed by community members, who understand and value Aboriginal people's ways of knowing and ways of thinking. The champions share and translate the meaning of health from an Aboriginal perspective into ways that help service providers understand what and how those living with ARF and RHD are feeling and thinking. This two- way or trans cultural learning benefits the community and the health service. The champions all have their individual life story that they draw strength from to help inform the priorities that contribute to the champion

program. They are advocates and help others to take action by motivation, leadership and compassion.

Some of our champions had prior leadership roles in their community, as health workers or practitioners, others have identified the desire to become leaders and support community members. They are all considered emerging leaders in their own right, and are at different levels of leadership along their personal journeys. As stated, Elders are also a very important part of the program, if the champions feel they need a little more cultural knowledge and authority they are linked with an Elder. Linking the younger ones with an Elder helps with ongoing development and builds leadership within. It is very important to acknowledge and nurture Aboriginal leadership at all levels.

It was acknowledged early that each champion brings their own strengths with them to the program. During the orientation workshop the champions workshopped their strengths and then shared with the group how these strengths can be incorporated within the program. Our aim is to continually build on the strengths of the individual champions and the program itself. The program was set up using a strength based and inclusive framework. The champions were happy to share their experiences with others in a safe and relaxed environment and for these experiences to inform the program plan. By exploring patient journeys and their personal situation along the health continuum, champions can share their experience to support the community. They will identify the Elders and support people and structures available to them in their community. Having Elders in the group will also engender a positive influence as noted Elders seem to encourage and validate cultural meanings and interpretations.

The program is versatile and flexible enough for each community to adapt the program to local needs, engaging the community governance structures, community programs, people and spaces as required. The champions will continually support each other and build the strength base by sharing stories and learning from each other. It is expected that the champions will help to breakdown long standing systematic structural barriers across the health services. The champions will be critical in educating people on the provision of culturally safe ways of navigating the health system. They have experienced their own challenges, and have something to offer each other, and those newly entering the health system.

It is also expected that the champions will feel a sense of purpose and fulfilment as they assist others navigate the health path along their health journey. Leadership and interpersonal skills will be developed and refined as they support each other in this role. The positive health and well- being affects that champions will receive are very important, they have a sense of pride of giving and helping, this makes them feel happy and stronger. We also have a motto to ‘look after yourself first’ - if champions need to talk to us or a traditional healer we encourage that.

The following attributes were identified at the first orientation workshop these attributes can be used to define the roles of the champions. They can also be used to guide professional development. Attributes identified by champions;

- motivation
- their heart needs to be in it
- visible
- ability to inspire
- passionate

- compassionate
- be able to walk alongside other professionals
- be able to empower others
- advocates
- promote healthy lifestyles
- good listeners
- non-judgmental
- forward thinking
- role models
- make people feel welcome and happy
- ability to influence others
- able to describe ARF and RHD in simple terms that community can understand using lingo such as heart scans (Translator/interpreter)
- likeable
- good attitude
- up to date with facts and figures
- be able to identify at risk people and communities
- be able to educate staff
- approachable
- leadership qualities
- love people
- community engagement
- identify relevant resources
- mobilising support people from community
- knowing patient and people you work with and community
- regular visits
- situational awareness.

The following resources were identified by Champions and considered important for them to be able to perform their roles as champions.

- support from their workplace
- a job description
- a Toolkit or Dilly Bag; content to include simple educational resources
  - Links to websites-educational sessions (already completed)
  - DVD on tips for media presentations
  - Self -care strategies and links to healers
  - Community engagement tips

  - Ideas on physical activities for groups
  - Cultural awareness and providing cross- cultural education tips and accessing interpreters
  - Simple fact sheets on visiting specialists, having tests (echocardiograms and going to surgery)

- USB with presentations from toolkit
- Facebook page
- business cards (not sure of message on these)
- talking story books
- posters
- interactive story boards especially for playgroups, preschool and schools.
- simple pamphlets
- IPAD – with activities and resources already uploaded and linked to RHDA.
- Games Journey for IPAD.
- resources to be able to show and explain – tactile things
- lanyards
- resources for hospitals
- support from RHDA staff
- wrist bands, stickers, caps and posters for children
- flyers
- evaluation sheets
- Tshirts
- advertising banner.

An important aspect of the program is the support that RHDA can offer the champions. It is important that champions do not feel isolated within their community and they have connections to other champions and feel part of a larger network. The following is a list of things that the champions felt important to help create a sense of collaboration and connectedness.

- Have an annual camp for kids and carers
- Design shirts with logo – for identification and message delivery
- Regular networking with all RHDA Champions
  - Meet Face to face yearly
  - Set up a group email
  - Regular contact and support from RHDA staff
  - To be managed by RHDA
- Develop carers package
- Integrate culture into messages and program

- Education on changing the minds of individuals families and communities –open people's minds and hearts to RHD.
- The Champions felt they need support from Elders especially at community level where they may require Elders to help with community engagement.

Other groups that the champions thought will be important in their program are;

- schools and teachers, including the Clontarf schools
- men's health - camps with footy sport and youth groups, men's groups
- Stars women's health
- social media – Radio, TV, Twitter and Facebook
- playgroups
- community groups
- stands at festivals such as NAIDOC and careers expos (Champion led stalls)
- ante natal groups
- mums and bubs groups
- nurses in clinics and schools (especially new ones)
- Elders.

The champions were encouraged to reflect on their own self beliefs and expectations. The following six quotes are important messages and are embedded into our vision.

> "Do not promise what you cannot deliver"
>
> "Believe in yourself -life is about learning"
>
> "Keep learning we already have a lot from our background to build on and draw strength on"
>
> "Love yourself and be empowered"
>
> "Always be proud of your Aboriginality"
>
> "Always be strong don't take things personally we cannot fix everything"

As discussed rates of ARF and RHD in Aboriginal and Torres Strait Islander peoples are amongst the highest in the world, the Australian health care system is struggling to provide adequate care. This is the first Australian wide champion program for RHD and will provide the much- needed patient's perspective and ways of knowing and thinking and being Aboriginal into health care planning, setting and delivery.

Evaluation of the program is planned in one year. To date, insights include the enthusiasm for this program in many communities, and the wide variety of priorities identified by each champion. The underlying intent of the program is to continuously build on the premise that Aboriginal Torres Strait Islander peoples have designed the program for their own people using their own knowledge and are actioned with creating

References

1. Australian Human Rights Commission. Close the Gap: Indigenous Health Equality Summit - Statement of Intent. Canberra: AHRC2008; Available from: **https://www.humanrights.gov.au/publications/close-gap-indigenous-health-equality-summit-statement-intent**
2. Australian Institute of Health and Welfare. Rheumatic heart disease and acute rheumatic fever in Australia: 1996 – 2012. 2013.
3. Living the Social Determinants of Health: Assemblages in a Remote Aboriginal Community. RD Chenhall, K Senior - Medical anthropology quarterly, 2018 - Wiley Online Library.
4. Transition to adult care for Aboriginal children with rheumatic fever: a review informed by a focussed ethnography in northern Australia. CSIRO publishing. Alice G. Mitchell, Suzanne Belton, Vanessa Johnston and Anna P. Ralph. *Australian Journal of Primary Health.* 2017.
5. Peer-led Aboriginal parent support: Program development for vulnerable populations with participatory action research. A Munns, C Toye, D Hegney, M Kickett, R Marriot & R Walker. *Contemporary Nurse, Vol 53, 558-575.*
6. Peer Support. EB Fisher, PY Tang, MM Coufal, Y Liu, W Jia - Chronic Illness Care, *Social Science Sport and Leisure. Feb 2018.*
7. Tailoring and field-testing the use of a knowledge translation peer support shared decision making strategy with First Nations, Inuit and Métis people making decisions about their cancer care: a study protocol. J Jull, M, Mazereeuw, A Sheppard, A Kewayosh, R Steiner and I Grahahm. *Research Involvement and Engagement.* 2018 4:67).
8. The Strong Family Program: an innovative model to engage Aboriginal and Torres Strait Islander youth and Elders with reproductive and sexual health community education. P. Duley, J. R. Botfield, T. Ritter, J. Wicks and A. Brassil . *Health Promotion Journal of Australia* 28(2) 132-138.
9. Safe and effective cultural mentorship in general practice. Liaw, Siaw-Teng; Wade, Vicki; Lau, Phyllis; Hasan, Iqbal. *Australian Family Physician*, Vol 45 (6) 2016.
10. Evaluation of the Peer Education component of the *Young Nungas Yarning Together* program. August 2008. Michael Bentley South Australian Community Research Unit, Flinders University.

Presenter

Vicki Wade has close to 40 years' experience working in health in many roles, including nurse educator, clinical nurse consultant in cardiology, manager of a state-wide Aboriginal vascular health program, Area Director of Aboriginal health, researcher and cultural leader of the Heart foundation. Vicki is a strong advocate for her people and followed her matriarchal lineage as her grandmother was a healer and helped with the Noongar women in birthing on country, in the mission and later reserves south-west of Perth. Her mother was one of the first enrolled nurses in Perth and her daughter is carrying on the tradition as a doctor. Vicki is well known across Australia and is well respected for the work she has done in helping to close the gap. She sits on the National Close the Gap steering committee and is a board member of the Congress of Aboriginal Nurses and Midwives. Vicki hopes that the work she does will see her grandchildren have better opportunities that she and her family were afforded.