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Meaningful engagement with Aboriginal communities using Participatory Action Research to develop culturally appropriate health resources

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Abstract:	<p>Introduction This paper outlines the processes used to meaningfully and authentically engage Australian Aboriginal communities in Northern New South Wales, Australia with the aim of developing culturally appropriate stroke health resources.</p> <p>Methodology Participatory Action Research (PAR) using the Research Topic Yarning (RTY) framework was adopted as a collaborative and culturally safe way to uncover vital information and concepts to guide the development of culturally-specific health resources. There were two stages to engagement with the Aboriginal community before the PAR project commenced.</p> <p>Results The development of a stroke education resource, <i>Written by the Mob for the Mob</i>, was the primary outcome of the PAR study.</p> <p>Discussion The development of culturally suitable, localized health resources to improve health literacy was the result of meaningful authentic engagement with the Aboriginal community that resulted in positive outcomes for both mainstream health and the Aboriginal community, promoting mutual learning opportunities.</p>

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Abstract**Introduction**

This paper outlines the processes used to meaningfully and authentically engage Australian Aboriginal communities in Northern New South Wales, Australia to develop culturally appropriate stroke health resources.

Methodology

Participatory Action Research (PAR) using the Research Topic Yarning (RTY) framework is a collaborative, culturally safe way to uncover vital information and concepts. There were two stages in the PAR project; community engagement and evaluation of the processes involved in developing the localised, culturally appropriate health resources.

Results

Establishing relationships built on trust, mutual sharing of knowledge, and bringing together the wider community, enabled the health message to be embedded within the community, ensuring the message was culturally appropriate and sustainable.

Discussion

The stroke education resource is a tangible outcome and a major achievement; however, the process of authentic engagement to achieve the final product was the ultimate accomplishment.

Key words: Australian Aboriginal, Indigenous, health literacy and engagement, cultural sensitivity, community ownership, collaboration, evaluation, participatory action research.

Introduction

Improving Aboriginal health in Australia is a high priority for Aboriginal and Torres Strait Islander communities and the government (Mikhailovich et al., 2007). On average, the life expectancy of Australian Aboriginal people in Australia is 11 years lower than the Australian average, depending on age, gender and residence (Phillips, Morrell, Taylor, & Daniels, 2014), and is linked to high levels of chronic disease related to social deprivation and low health literacy (McCalman, Tsey, Clifford, Earles, Shakeshaft, & Bainbridge, 2012; Penm, 2008; Wise et al., 2012).

Nationally, the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS), (2012) and the Institute of Health and Welfare (AIHW) (2018) reports that cardiovascular disease remains responsible for the GAP in the burden of disease between Indigenous and non-indigenous Australians. A local health district encompassing a number of small rural towns in regional New South Wales Australia, identified high prevalence of chronic disease—such as diabetes and cardiovascular disease—among Aboriginal and Torres Strait Islander people, which are known precursors for stroke. In this district the primary health care service covers a population of 1.2 million people, with 65,183 people (5%) identifying as either Aboriginal and/or Torres Strait Islander, compared to 2.8% nationally (Hunter New England and Central Coast Primary Health Network, 2016) (HNECCPHN).

The Aboriginal population in this primary health network comprised about 10% of the total patient population (HNECCPHN, 2016). Very few Aboriginal people from the region were found to be accessing local healthcare services when experiencing the symptoms of stroke (HNECCPHN, 2016). The district reported that, between 2014 to 2015, 4.2% of stroke admissions for one sector of the district were identified as Aboriginal people. While this was an improvement on the 2008 to 2009 figure of 2.7% for this sector, the number of Aboriginal (Gamilaraay/Gomeroi) people accessing the stroke service was low, particularly considering that rural towns within this sector have the highest population of Aboriginal Gomeroi/Gamilaraay) people in the HNELHD. The assumption could be made that the number of Aboriginal people accessing health services for stroke in these areas should have been much higher (HNECCPHN, 2016; RAP, 2017), considering 20% the total Aboriginal

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3 population of the HNELHD (approximately 48,000 in 2011) reside in this area.
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6 Anecdotally, members of the community had reported that many Aboriginal community
7 members presenting with symptoms of stroke to the local health service Emergency
8 Department had been turned away because they were assumed to have the signs and
9 symptoms associated with alcohol and other drug use and were often not adequately
10 assessed.
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17 The challenge was to find a way to provide culturally appropriate stroke information to this
18 Aboriginal community in a way that was relevant to them. This paper outlines the
19 processes used to meaningfully and authentically engage Australian Aboriginal
20 communities in Northern New South Wales, Australia with the aim of developing
21 culturally appropriate stroke health resources.
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26 27 **Aboriginal Health Resources** 28

29 The absence of culturally-suitable health resources has had a negative impact on Aboriginal
30 and Torres Strait Islander people, leading to disempowerment in regard to accessing
31 appropriate healthcare and services (Davis et al., 2004). Developing culturally-sensitive
32 approaches to health resources embedded in the knowledge and ways of learning of the local
33 Aboriginal group is one way to close the current health gap and ensure the health resources
34 are accepted by the community (Davis et al., 2004). To overcome this gap, Jamieson, Parker,
35 and Richards (2008) recommend the need for community-owned and developed health
36 resources that encompass social, emotional, and cultural wellbeing.
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44 According to Nutbeam (2006), health literacy is a term used when describing not only a
45 person's functional literacy levels but their ability to understand or make sense of
46 information and relate it to their condition and treatment. Health literacy encompasses the
47 relationship between understanding what is required and practically applying the knowledge
48 to improve health outcomes (Nutbeam, 2006). When people understand the information in
49 what ever form it is presented, they are able to actively participate and apply what they
50 understand (Nutbeam, 2006).
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58 A common theme in the literature is that the success and local acceptance of health
59 promotion projects and resources is built on community pride, engagement and
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3 empowerment (McCalman et al., 2012; Wise et al., 2012). In Australia, Aboriginal health
4 promotion resources are often developed as whole-of-population or state-wide endeavors
5 (Crengle et al., 2014; Laliberte, Haswell, & Tsey, 2012). As a result, local Aboriginal
6 communities are often left alienated from the process of developing these resources and
7 are thus subsequently disengaged from the resulting product (Barnett & Kendall, 2011;
8 Schoen, Balchin, & Thompson, 2010).
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15 **Methodology**

17 **Participatory Action Research Design**

19 Participatory Action Research (PAR) using the Research Topic Yarning (RTY) framework
20 is a collaborative, culturally safe way to uncover vital information and concepts. PAR
21 methodology was chosen by the local Aboriginal Elders as the “natural fit” for their
22 community and afforded a process they felt comfortable and safe with.
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27 The PAR research approach flowed from the Aboriginal community’s belief system that is
28 at the center of their community decision making. While mainstream Western science aims
29 to separate the subjects from the researcher, the PAR model of interconnectedness between
30 the researcher and participants is central to the design and data collection—the participants,
31 some of whom had lived experience of stroke, became co-researchers in the PAR (see
32 [Figure 1](#)).
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37 There were two stages in the PAR project; community engagement and evaluation of the
38 processes involved in developing the localised, culturally appropriate health resources.
39 In developing the health resource and research plan, various types of yarning were used, (1)
40 Collaborative Yarning, (2) Social Yarning and (3) Research Topic Yarning (RTY). The co-
41 researchers had agreed on the content that was to be covered in the RTY during the social
42 or collaborative yarning phase as outlined by Bessarab and Ng’andu (2010).
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48 **ADD**

49 *Figure 1. Participatory Action Research diagram. Adapted from: Bessarab and Ng’andu*
50 *(2010, pp, 37-50).*
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55 Through social yarning the catalyst for this project emerged when the local health service
56 tried to implement an Aboriginal stroke education booklet from another region. The inland
57 community was not at all accepting of this resource and did not relate to it. One Elder placed
58 his hand on the book and gently pushed it to the side, saying, ‘that’s coastal—don’t mean
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3 nothing to us’.

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5 The pictures, language and coastal theme did not resonate with the people of the inland area
6 and it was decided that the health resource had the potential for cultural insensitivities and
7 offence if forced on the local community.
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11 At the same time the lead author was working with a local Aboriginal Elder, Aunty Pam
12 who had experienced several small strokes and been turned away from a general
13 practitioner’s office and local hospital on two occasions, without receiving appropriate
14 treatment. Deeply distressed by this experience, angry and frustrated by the health service,
15 Aunty Pam asked the lead author to help spread the message to her community about her
16 experience and the importance of stroke care. Her idea was discussed among the wider
17 Gamilaraay/Gomeroi community and, because she was a well-respected Elder who wished
18 to tell her story, the community embraced the idea of developing their own stroke resources.
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27 In order to achieve this outcome, we realized we needed to come to know the community on
28 their terms. Through volunteering at a university student-led clinic we developed
29 relationships with members of the community, and as a result there were many trips out to
30 the wider Gomeroi/Gamilaraay community that focused on listening and sharing laughs,
31 food and stories, leading to authentic engagement over time.
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38 **Stage 1. PAR: Mutual Sharing of Knowledge through Collaboration & Developing**

39 The Gamilaraay/Gomeroi community expressed their wish to develop health resources that
40 related to their community, moving away from the stereotyping that infers that Aboriginal
41 and Torres Strait Islander people are to blame for their own poor health (AIATSIS, 2012).
42 The community wanted to convey a mixture of truthful, real stories and artwork based on
43 personal experiences and analogies from within the community.
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50 This initial process led to ‘lunch and laugh’ gatherings that began as an Aboriginal stroke
51 survivors outing, and extended to include anyone wishing to be involved, provided a
52 relaxed environment and the ideal situation to work collaboratively and plan in an
53 inclusive manner.
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58 From the beginning, it was evident that the community wanted the health resources to be
59 their own. For example, one of the Elders said: ‘don’t go sanitising the stories—we need to
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3 tell it how it is'. Thus, members of community guided the flow of the book by setting the
4 theme, and after presenting many ideas and sharing stories, the booklet began to take shape.
5 Aboriginal Elders and stroke survivors from the Gamilaraay/Gomeroi community identified
6 the need for the stroke resource to be based on their own stories, art, lived experience and
7 connection to country. Connection to country is significant to the Gamilaraay/Gomeroi
8 community, as they hold a deep connection to their ancestral lands, and this connection is
9 central to their concept of wellness (Kingsley et al., 2013). These resources can be viewed
10 on the Australian Indigenous HealthInfoNet website (<https://healthinfonet.ecu.edu.au/>)
11 (2016).
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20 Photographs taken by an Elder are displayed throughout the book to reflect these strong
21 beliefs and experiences. The Aboriginal stroke survivors adopted the analogy of the river to
22 express themselves and explain what stroke meant to them through art and stories. The
23 analogies to the river provided the community with a simple connection to both their physical
24 and spiritual environment to draw comparisons of how stroke appears and is caused.
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31 *“When our river was healthy and flowed strong, the codfish, animals downstream and*
32 *our people were well. In the past we used to come together as a community along the*
33 *river. The river connects our family and communities together.” (NM) He compared*
34 *stroke to a blockage in the river, “If the river fills up with man-made rubbish no water*
35 *gets past and what is downstream dies.”(NM Elder)*
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41 People were pleased to have the opportunity to tell their stories and help educate their own
42 people. One Elder suggested using digital stories to “get the word out there”. The idea of
43 digital stories was embraced by the community. Through this process, the voices from within
44 the community emerged. These stories are easily accessible through the internet and appear
45 on many sites for example, The National Aboriginal Community Controlled Health
46 Organisation (NACCHO) (2016), *NACCHO Aboriginal health #Stroke Stories : Written by*
47 *the mob for the mob* and Stroke Foundation (2016), *Enable Me: Written by the Mob for the*
48 *Mob*.
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56 The Aboriginal nursing student (co-researcher) and first author, used the strategy of
57 educating the local Aboriginal children about stroke. The children used that knowledge to
58 produce artwork that interpreted their understanding of stroke. This artwork became the
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3 cover of the book generating great pride and sustainability of knowledge within the
4 community. This process was a way of giving back to the community.
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8 The Community were committed to informing mainstream health that they would like to
9 improve their health literacy by developing health resources in the future. The Elders felt
10 that medical terminology could be intimidating for their people. Medical jargon left people
11 feeling confused, afraid and unable to ask for explanations. One Elder highlighted the
12 importance of bridging the GAP in the health knowledge of her people by merging their
13 lived experiences, stories and art with mainstream health terminology. Her rationale was :
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'you don't know what you don't know, and if you don't know, you can't have a say' (Aunty

She believed that if the people understood what medical staff were telling them, individuals
and the community could take some ownership and control of the health decisions that
could be made. The community took the information that was explained to them by main
stream health and interpreted it using art and stories, and analogies of the river. The way the
information was presented resonated with the whole community, increasing health literacy
about stroke. This collaboration was a respectful, mutual learning experience. Thus, the
research team positioned themselves within the epistemology of this Aboriginal community,
by acknowledging the strength, knowledge and wisdom of the Elders and key community
members (Loppie, 2007; Walker et al., 2013).

Resources

A key strategy was sharing information and experiences that led the co-researchers to self-
reflect and analyse practice and current knowledge. This led to evolution of the cycle of
analysis and reflection, which prompted actions to improve health literacy from within the
local community.

PAR reflects the way Aboriginal people embrace learning through action, collective
decision making and empowerment, which occurs via group activity over time. The mutual
enquiry and learning experience in this study was aimed at reaching agreement and mutual
understanding of the situation, thereby resulting in an unforced consensus about what to do
and what could be achieved together that would be legitimate for the co-researchers and
their community (Kemmis & McTaggart, 2005).

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5 As such, many informal gatherings took place, during which key people from within the
6 community expressed their belief or agreed that it would be useful to implement a
7 collaborative, conversational research approach to uncover the key mechanisms that make
8 health resources acceptable and sustainable in their local community. Attaining trust and
9 endorsement by a respected Elder who provided guidance through cultural sensitivities and
10 community politics was essential to the successes of authentic engagement and the PAR
11 project.
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19 Strong relationships were developed between the community co-researchers during the
20 project. Many different subjects were discussed, including family, community health and
21 wellbeing, and intercommunity relationships, since most people were related through family
22 or marriage and community. When meeting for the first time, the community co-researchers
23 incorporated their family history into the greeting to establish connection and understanding
24 about where they came from. Within minutes, they had identified people in common. This is
25 the yarning process to establish connection with community:
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33 *“We can tell stories from somebody over in Western Australia, but it means nothing*
34 *to nobody here. Where these people live in the local communities and even though*
35 *the area of this book covers the Gamilaraay area, everybody’s related and knows*
36 *everybody, and, it makes it more likely to be read and digested. Well, it’s more*
37 *localised; it’s not from Sydney or from Northern Territory or anything like that”*
38 *(Uncle J, Elder and cultural advisor).*
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45 Participating in their local area also gave community co-researchers a sense of
46 belonging, which enabled strong bonds and relationships to develop with the researcher
47 and students. The community co-researchers felt this was a sign of respect for their
48 country and culture:
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53 *“I felt I was able to speak, you know, and pick and choose where I spoke, and that’s*
54 *important too—that it wasn’t in a clinical area, had to be somewhere comfortable,*
55 *that I felt comfortable” (Aunty C, Elder and wife of a stroke survivor).*
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The PAR facilitated mutual learning opportunities for everyone involved and the knowledge

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3 gained along the way was multifaceted, and encompassed the nursing students, Aboriginal
4 children and adults, other healthcare professionals, and general community. Community
5 members greatly appreciated the opportunity to engage authentically with the research team:
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10 *“It was being recorded, my story, not someone else’s story that I had to tell. Well,*
11 *it’s what I’ve experienced, not no one else” (Uncle B, Elder).*
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15 *“But the thing is ... you’ve actually asked the people what they need, and what have*
16 *they actually got at the moment. And you’re finding that out and you’re putting that*
17 *resources altogether, and you’re getting information that this family over here’s got*
18 *something, that family’s over there’s got nothing. That family’s up there’s got part*
19 *of it, but this family out here has got no response whatsoever from anybody. So*
20 *they’re the ones who need this booklet more than anything else” (R, son of a stroke*
21 *survivor).*
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29 **Equal Distribution of Power**

30 The adoption of PAR as the approach for the study provided a realistic understanding of the
31 social, economic and cultural position that defines the people within this community and
32 their actions. The people of the community had a ‘voice’ in the project, felt confident and
33 had a sense of empowerment to drive the process in collaboration with healthcare
34 professionals. The Aboriginal community wished to change the way the community and
35 individuals interacted and worked with mainstream health services, thus it was important
36 for the community to have a sense of control and ownership, and to work in partnership
37 with mainstream health, rather than being told what to do as outlined by others (Kemmis &
38 McTaggart, 2005, p. 567).
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48 **Principles of engagement between community and mainstream health**

49 A key strategy to maintain the principles of engagement throughout the project, was
50 obtaining advice from the Aboriginal cultural advisors. This was essential to ensure
51 culturally-appropriate interactions with the community. Seeking constant feedback and
52 advice from across the wider community promoted trust, respect and authentic
53 relationships. Collaboration unfolded in many ways, with one interaction leading to
54 exposure to other community members who wished to become involved. Engagement and
55 community involvement gave the community a strong voice. Humour and participating in
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3 social occasions were effective ways of developing and sustaining collaborative
4 relationships:
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8 *“Engaging with the community was important because consultation is very*
9 *important in each community we went to and we were always asked about if that’s*
10 *okay if we go here, what are your thoughts, you know, and it was so good because,*
11 *to me, that felt that that respect was there all the way through, and for each area—*
12 *not just for me, but each area—and the way the staff, too, were involved in it—how*
13 *they got back to us as, you know, we were the stroke survivors, but we also felt so*
14 *important that we were able to express how we felt” (Aunty A, Elder).*
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22 The community felt empowered by working together. The process of consultation and
23 asking for permission at every stage worked well and was seen as respectful:
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25 *“The book wasn’t forced up on us, it was just, you know, just to get the message*
26 *out there about my sister and hoping that it will help other people” (Aunty E,*
27 *Elder and sister of a stroke survivor).*
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32 *“The process that was used was absolutely fantastic because everyone got to say*
33 *what they had to say. But we kept on going back and rechecking and everyone*
34 *agreed that it was the right process—everyone had a chance to see what they had*
35 *already spoken about and what they needed to be put in the book and what*
36 *needed to be taken out. So that was a really good process. And it was in*
37 *consultation with the people that actually were supplying the stories, and that*
38 *give them complete ownership of what was said” (Aunty A, Elder).*
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46 The challenge associated with engaging the community not only ensured the success of
47 the resource development, but also demonstrated to the community that, as health
48 professionals and students, members of the local health community were willing to learn
49 from them:
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52 *“The students they were given a really good insight into how you was accepted in*
53 *by us before, like say you could come in ... to our homes. And with them, they’d be*
54 *able to take that information back with them, and hopefully discuss it in their*
55 *studies with their lecturers, so that they could put that as one of their criteria”*
56 *(Uncle N, Elder).*
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3 Central to the stories were the notions that if one person is sick or in trouble, the whole
4 community is affected and the importance of family and community shone through. It was
5 imperative to have a critical mass of people contribute to the development of the resources
6 as it ensured that the wider community was linked by family connections. Every person
7 from the community is connected to someone who contributed to the book. This strategy
8 was key to the feeling of acceptance and ownership of the resources by the wider
9 community. As stated by the cultural advisor:

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17 *“For every name that they may have a conflict with, there will be several others*
18 *they are related to and respect. This helped the resources be accepted across the*
19 *community. The resources fly above the black politics” (Uncle J, Elder, and*
20 *cultural advisor).*
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25 As reported by Aunty Pam (Aboriginal Elder), at times intercommunity conflict can hinder
26 the success of projects. This challenge was discussed up front and the wider community
27 consensus about putting conflict aside and sharing with the whole community and being
28 inclusive was described by the following quote:
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34 *“We would like to get the whole community involved with this because it’s not just*
35 *one family, it’s a majority of all families out here, so typically you know what I mean*
36 *and really for all of us, not just one family” (Uncle C, Elder).*
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41 During Stage One, the engagement phase, collaborative yarning with Aboriginal Elders was
42 used to establish the need for the health promotion material. This led to a series of
43 collaborative working groups drawn from the communities, which developed visual and
44 oral representations of what stroke meant to them. The groups met and were facilitated by
45 key community members and Elders. The co researchers took their lead from these
46 community leaders. Following this period of collaborative yarning, co-researchers who had
47 experienced stroke became involved in the project through social yarning centered around
48 sharing food and stories.
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56 Social Yarning underpins all aspects of RTY and through social yarning, relationships
57 between the researcher and co-researchers were formed. The community co-researchers
58 guided the research team and the university nursing students and mutual learning was
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3 derived from listening, observing and interacting. The social yarning and social
4 occasions provided the opportunity to brainstorm within the Gamilaraay/Gomeroi
5 people, thereby promoting community discussion and planning that facilitated
6 acceptance of the health promotion material.
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10 11 12 **Stage Two Participatory Action Research**

13 In Stage Two, the RTY became a natural extension of the social yarning, as it is a relaxed
14 and culturally-safe way to conduct conversational research and collect data (Bessarab &
15 Ng'andu, 2010; Kingsley et al., 2013). By using RTY, one Elder commented that '*we can*
16 *keep the conversation safe*'. The co-researchers could lead the conversation away from
17 topics that made them feel uncomfortable or unsafe, and lead the conversation towards less
18 sensitive topics. Thus, RTY proved to be a flexible method to explore what was important to
19 the co-researchers by using their stories, analogies and examples of their lived experience:
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27 *"Well, it's what I went through and how I dealt with it. My own experience,*
28 *wasn't someone else's experience"* (Aunty D).
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32 The RTY interviews were recorded and transcribed. The process of hearing other people's
33 stories and sharing their own stories was valuable in bringing people together and making
34 sure the information was authentic and credible:
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40 *"So, once I started writing it, to me, it sort of broke everything down and I felt*
41 *really comfortable and I thought it was cathartic—I think that's the word. I just kept*
42 *writing and writing and couldn't stop. I thought, oh gee, this is making me feel so*
43 *good just to know that, where I'm at and then I was sort of on the right track in*
44 *terms of getting better and I could actually see"* (Aunty P, Elder).
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49 The co-researchers' interpretation of how they perceived an experience was continually
50 linked to the metaphor of the river. The river appears different depending on where it is
51 viewed from and through whose eyes it is being seen. The interpretation may vary from
52 person to person, yet the common factor is that it is still the same body of water, linking
53 everything and everyone together.
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Ethical and access issues

The co-researchers and Aboriginal healthcare providers were provided with both written and oral information about the PAR. The cultural advisor was available to discuss the research and answer questions about the implications of being part of the study. No participation incentives were required because the process had the strength and determination of the community behind it.

Constant contact was maintained with the co-researchers via the telephone, as well as monthly visiting to maintain contact and relationships. During this time, signed support letters for the impending PAR were obtained from local Aboriginal organisations. The co-researchers assisted with the ethics application and were consulted about how ethics would protect them as co-researchers. To obtain informed consent from each co-researcher, they were provided with a Plain Language Statement that was read and explained to them with the cultural advisor present. The cultural advisor helped answer questions about the research and place the co-researchers at ease about the process.

Ethical approval was sought and granted from the University (HE15-222) and the local health district ethic committees (HREC 115/HNE/386).

Data collection

Data was collected using Research Topic Yarning (RTY). Yarning is an Aboriginal cultural way of communicating or having a conversation (Bessarab & Ng'andu, 2010; Walker et al., 2013). Yarn and yarning are not just pleasantries shared in a casual way but are a unique form of communication in Aboriginal culture that is linked to beliefs and spirituality (Walker et al., 2013).

Results

Participatory Action Research Cycle outcomes

The development of the stroke education resource, *Written by the Mob for the Mob*, was the primary outcome of the PAR study. Working on this book and digital stories gave stroke survivors an opportunity to express themselves, while simultaneously educating their community. This personalised approach is more powerful than using mainstream and Aboriginal healthcare professionals alone to develop and evaluate health resources (Crengle et al., 2014; Demaio et al., 2012).

The process spiraled through cycles of critical and self-critical action and reflection. It was

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3 a process of learning together and changing the ways we interacted in the world of
4 mainstream health and the world as seen by the Aboriginal people within the community.
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8 The contributors to the stroke resources realised they needed to understand the medical
9 terminology to be able to discuss and question the medical staff about their medical
10 condition. One community member, who was a stroke survivor, made the following
11 statement to the group of community members who were discussing if they needed to add
12 medical terminology to future health resources:
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18 *“Even though I can’t read and don’t write, it don’t (sic) mean I am stupid. I can*
19 *learn from pictures and by yarning with other people. If I had some idea of what*
20 *was going on, I could ask questions to the nurses and doctors.”(Aunty D, Elder)*
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25 The *Written by the Mob for the Mob* resources are now being used to educate staff who
26 work in local health facilities and accident and emergency departments. This is an important
27 outcome of this research as it has the potential to improve Aboriginal community members’
28 experience when attending the local health service.
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33 Drawing on a positive achievement, the most recent health district report (HNELHD, 2017)
34 revealed that 9.5% of the local Aboriginal people were accessing the health service with
35 signs and symptoms of stroke. This snapshot indicates a marked improvement in Aboriginal
36 people accessing medical attention for stroke in comparison to the 2008 to 2009 HNELHD
37 report, which indicated that only 2.7% of the community were accessing these services.
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44 **Discussion**

45 This research process can be described as ‘wheels within wheels’ that included action,
46 reflection and change occurring simultaneously and at many different levels. The wheels
47 turned at different speeds and there were groups within groups, yet all were working
48 together to improve the way the education resources were developed and the process was
49 evaluated.
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55 Pride in sharing knowledge leads to sustainability of the health message when it is derived
56 from within the community (Wise et al., 2012; Yancura, 2010). As recommended by
57 Kuipers et al. (2012), in this project local stories, artwork and dialect were used to make
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3 the resource more meaningful and relevant to the local community. Research suggests that
4 when resources are from out of country (not their mob), Indigenous communities will
5 often not engage with the resource (Crengle et al., 2014; Demaio et al., 2012; Kuipers et
6 al., 2012). It is important to recognize that Aboriginal people have their own
7 understandings and values that influence their reactions to health issues, based on their
8 beliefs, traditions and connection to country; they know their community and can identify
9 opportunities for change and identify how change should be implemented (Jeffries-Stokes
10 et al., 2011).

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19 As a result of developing the local resource, the community has now adopted this booklet
20 and the digital stories are being used as a local health education resource. These resources
21 have given the community the knowledge to be able to articulate their stroke symptoms,
22 required assessment and treatment to main stream health professionals as needed. One of the
23 strengths of this work was the research process that developed local capacity as well as the
24 health resource. Developing local capacity by enabling key people from within the
25 community to conduct health education or 'spread the word' is considered more powerful
26 than the community being instructed by an outsider (Crengle et al., 2014; Demaio et al.,
27 2012; Kuipers et al., 2012).

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36 The *project* was driven by the community, and, while the resulting health resource may not
37 have been what a healthcare professional would have developed, it is what the local
38 Aboriginal community wanted and have accepted. Importantly, the booklet included what
39 the community considered important and explained stroke to their people through personal
40 experiences, artwork and analogies, which resulted in some very powerful messages. As the
41 resources were accepted by the community, it was the sharing of information and
42 connections that created the ripple effect that spread the word. The project demonstrated
43 that, when a community is given a voice and successful engagement occurs, based on
44 respectful relationships, meaningful and sustainable health messages and resources can
45 result. The confidence, leadership, strength, capacity and skills the community developed
46 are now being used to identify other health issues that they feel require culturally-
47 appropriate and localised health resources.
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Conclusion

A key message to emerge from this research is the need to use targeted approaches that involve the community when establishing health resources. This cannot be achieved without first cementing relationships that are based on trust, respect and mutual understanding. This facilitates the collaborative approach to resource development. It is also imperative to have a good understanding of the culture, employ the most effective ways of seeking information through yarning, and develop a sense of community ownership of health resources.

The lessons learnt from the time with the community were invaluable and led to a sense of responsibility to share this learning with mainstream health to improve the way we engage with and deliver health to our Aboriginal and Torres Strait Islander patients.

The process undertaken in this study provides a road map for healthcare professionals when working with Aboriginal communities. Identifying key people from within the community, alongside interested healthcare professionals and students, to become a part of the process leads to mutually beneficial learning experiences and facilitates the creation of culturally relevant and fit-for-purpose resources to enhance health literacy within communities.

While the process used to develop these resources can be replicated, there is no template for developing health education resources that can be transferred for use by all Aboriginal and Torres Strait Islander communities. Although the process is transferable, the document is not— merely changing totems and faces on a generic document will not lead to community acceptance. Rather, the development, engagement and ripple effect of sharing information is most valuable, and ultimately leads to acceptance. For healthcare professionals to be effective in closing the gap, they need to accept that it will take time to build trust, financial investment and patience to deliver culturally-appropriate, locally-relevant health educational resources.

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Figure 1.

