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# **Towards the Development of a Wellbeing Model for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease**

## **Wellbeing Study**

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## Background

Chronic diseases have a substantial impact on the lives of people living in both developed and developing countries. Of the 57 million deaths around the world in 2008, 63% were a direct result of one or more chronic diseases, principally cardiovascular disease, diabetes, cancer and chronic respiratory diseases. Given accessible healthcare services, most of these deaths are avoidable. However, ninety per cent of these premature deaths occurred in low- and middle-income countries [1] where even basic healthcare services are often unavailable for the majority of people [2].

Despite the fact the Australia is a developed country with a relatively well funded healthcare system, Australian Aboriginal and Torres Strait Islander peoples are living with similar levels of chronic disease to low-income countries. This contributes to a much higher rate of both morbidity and mortality in comparison to non-Indigenous Australians [3]. The burden this places on Aboriginal and Torres Strait Islander communities is well documented, with cardiovascular disease acknowledged as the single leading cause of death [4], type 2 diabetes at epidemic proportions [5], and rates of chronic kidney disease disproportionately higher in Aboriginal and Torres Strait Islander populations when compared to non-Indigenous Australians [6]. Collectively, these conditions account for up to 50% of the life expectancy gap [7] which is estimated to be somewhere between 10 to 20 years [8].

Access to appropriate, affordable and acceptable comprehensive primary healthcare is critical for preventing and managing chronic disease [2, 9]. Yet, despite the fact that 2.3% of the Australian population identify as Aboriginal and/or Torres Strait Islander [8], only 1.6% of general practitioner consultations were with Aboriginal and/or Torres Strait Islander peoples [9]. Given the high prevalence of chronic disease for Aboriginal and Torres Strait Islander peoples, one could expect that that this rate would be significantly higher [10, 11].

The obstacles faced by Aboriginal and Torres Strait Islander peoples attempting to access primary healthcare services are many. While appropriate infrastructure, sufficient funding and knowledgeable health care professionals are crucial, these elements alone will not lead to accessible primary healthcare services for all Aboriginal and Torres Strait Islander peoples. A focus on the biomedical model leaves little room for a more holistic sense of health, which is more in line with many Aboriginal and Torres Strait Islander peoples' understandings. Incorporating not only mental, emotional, and social dimensions, the holistic sense of health may also include links to culture, Country, community and family [12, 13]. The need to consider how the past contributes to understandings in the present is also often missing [14], including an acknowledgement of the extent to which Aboriginal and Torres Strait Islander peoples continue to be affected by colonisation and intergenerational trauma brought about by formal policies of segregation and exclusion, as well as forced removal from Country and family.

Yet chronic care models developed for use in primary healthcare settings focus more often upon the systems, resources and policies that are required to deliver care, including prepared and proactive practice teams and informed and activated patients [15]. Their primary aim is generally to reduce fragmentation while at the same time improving health outcomes at an acceptable cost to the healthcare system [16, 17]. The important roles of culture, spirituality, Country and family in maintaining health and wellbeing are notably absent from such models.

The Kanyini Vascular Collaboration (KVC), a partnership of Aboriginal and Torres Strait as well as non-Indigenous clinicians and researchers, has been identifying the systemic barriers to health care for Aboriginal and Torres Strait Islander people with chronic disease. Emerging work from this collaboration has raised important questions as to whether existing chronic care models are either acceptable to Aboriginal and Torres Strait Islander Australians or effective in managing chronic disease. In particular, the Kanyini Qualitative Study explored what care means for Aboriginal and Torres Strait Islander Australians and

how people experience, cope with and adapt to life-long illnesses. This study found numerous opportunities for improving Aboriginal and Torres Strait Islander healthcare services. Within healthcare facilities, these focused on creating 'welcoming healthcare spaces' where community members could feel they belonged, were accepted and understood. Improving the cultural safety of healthcare services and focusing on supporting people to live the life they want despite chronic disease were also important. Building relationships which led to sustained engagement whereby the patients and providers together were able to determine the ways in which care was provided appeared to be at the heart of healthcare for Aboriginal and Torres Strait Islander peoples with chronic disease [18-20].

Findings of the KVC Qualitative Study indicated that re-defining the way in which care is delivered by approaching healthcare in a way that reflects Aboriginal and Torres Strait Islander peoples' needs and values, is essential for improving the accessibility and acceptability of primary healthcare services. To do this, the KVC undertook a study entitled *Toward the Development of a Wellbeing Model for Aboriginal and Torres Strait Islander Peoples Living with Chronic Disease (Wellbeing Study)*. In keeping with the findings of the KVC Qualitative Study, the focus of the Wellbeing Study was not only on treating or managing illness but also on supporting the quality of care and quality of life for Aboriginal and Torres Strait Islander peoples living with chronic disease.

## Methods

The Wellbeing Study, comprising three integrated stages (Figure 1), was undertaken between June 2013 and December 2014. While the research team initially consisted of three Aboriginal and three non-Indigenous clinicians and researchers, by the end of the study an additional 13 Aboriginal and Torres Strait Islander Research Fellows, who also worked in Aboriginal Medical Services and therefore had intimate knowledge of providing care to Aboriginal and Torres Strait Islander peoples, had joined the team.

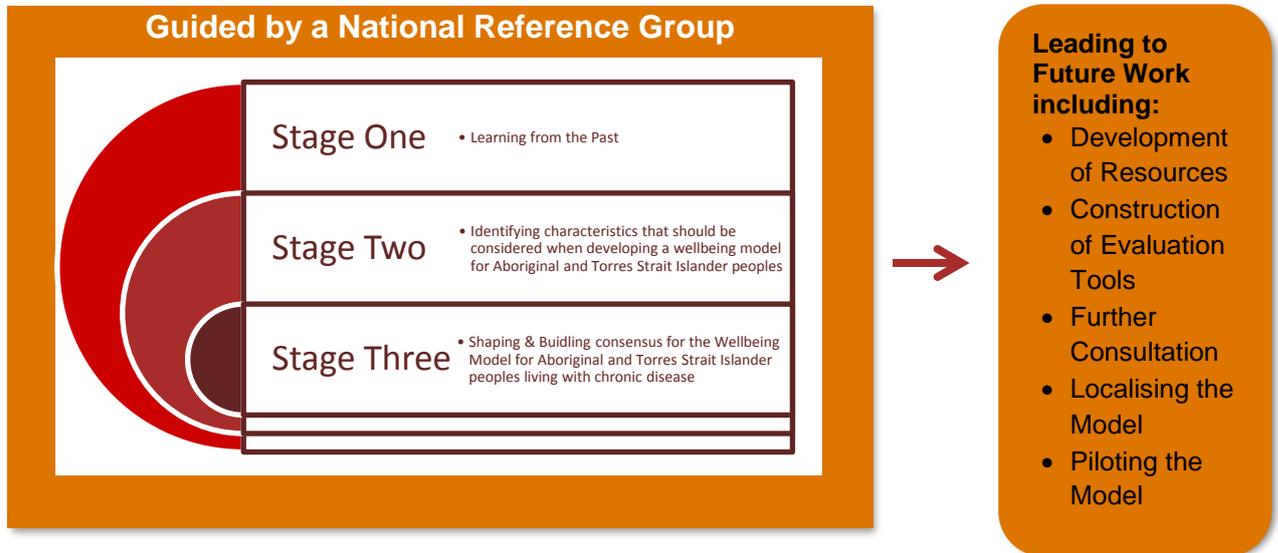


Figure 1. Study Overview

## ETHICS APPROVAL

This study was approved by nine separate ethics committees – Aboriginal Health Research Ethics Committee (04-13-533), Western Australian Aboriginal Health Ethics Committee (542), Aboriginal Health & Medical Research Council of New South Wales (980/13), Australian Institute of Aboriginal and Torres Strait Islander Studies (reference number not provided), Central Australian Human Research Ethics Committee (HREC-13-190), Human Research Ethics Committee Cairns & Hinterland, Cape York, Torres Strait & Northern Peninsula Hospital & Health Services (HREC/13/QCH/121-873), Human Research Ethics Committee of the Northern Territory Department of Health and Menzies School of Health Research (2013-2128), Metro South Human Research Ethics Committee (HREC/13/QPAH/526), and Ethics Review Committee Royal Prince Alfred Hospital (X13-0370 & HREC/13/RPAH/518).

## NATIONAL REFERENCE GROUP

The Wellbeing Study was guided by a National Reference Group, which consisted of Aboriginal and Torres Strait Islander community members including a number of community Elders, as well as representatives from Commonwealth and State governments, non-government organisations such as the Heart Foundation and Commonwealth and State based Aboriginal Community Controlled Health Organisations peak bodies. Importantly, the National Reference Group also included healthcare service representatives from ten Aboriginal Medical Services including Aboriginal Medical Services from Northern Territory, Queensland, South Australia, New South Wales, Australian Capital Territory and Western Australia. The Terms of Reference, which were agreed to at the first meeting, identified that the primary responsibilities of this group were to provide advice on appropriate methods for conducting the study, to review and provide feedback on all material produced as part of the

study and to ensure their respective organisations were kept informed of developments. In addition to being kept up to date throughout the study with regular newsletters and being offered opportunities to provide feedback via telephone or email throughout duration of the project, the National Reference Group also met face-to-face on three occasions.

Two important decisions came out of the initial National Reference Group meeting. The first related to the emphasis on supporting wellbeing rather than treating or managing chronic disease care. While not discounting the importance of evidence-based practice, members felt that this area was amply covered within the guidelines and models of care that were already in existence. The second decision related ways of defining wellbeing. In acknowledging the significant diversity both between and within Aboriginal and Torres Strait Islander communities [21], members believed that the focus of this study should be on supporting understandings of wellbeing.

Discussions at the second National Reference Group led to the defining of a set of nationally and internationally-recognised values and assumptions that would underpin the Wellbeing Study. These were:

- **The Declaration of Alma-Ata** [22], which recognises health as a state of physical, mental and social wellbeing rather than merely the absence of disease, and the right of people to participate in the planning and implementation of their healthcare services.
- **The United Nations Declaration on the Rights of Indigenous Peoples** [23], which sanctions cultural integrity and the rights of Indigenous peoples to practice and revitalise cultural traditions and customs.
- **The Ottawa Charter for Health Promotion** [24], which advocates for health promotion as a means of enabling people to increase control over, and thereby to improve, their health.
- **The vision of the National Aboriginal Community Controlled Health Organisation** [25], which seeks to “deliver holistic and culturally appropriate health and health related services to the Aboriginal community” (p.6).

## STAGE ONE – LEARNING FROM THE PAST

Acknowledging the importance of work that had already been completed within this area, the aim of stage one was to capture both the formal and informal knowledge that could inform the way in which primary healthcare services might support the wellbeing of Aboriginal and Torres Strait Islander peoples. In particular, the focus was on work that had already been undertaken to understand how community members and their healthcare providers believed that primary healthcare services could support the wellbeing of Aboriginal and Torres Strait Islander peoples living with chronic disease.

Four separate activities were undertaken during this first stage. First, a review of work that had previously been undertaken by the Kanyini Vascular Collaboration was undertaken to identify the studies that could inform this study. In particular, the Kanyini Qualitative Study (<http://www.kvc.org.au/kqs-monograph-series/>), which was designed to explore principle barriers and enablers to receiving quality chronic disease care, identified ways in which primary healthcare services might better serve Aboriginal and Torres Strait Islander clients and communities.

Second, the National Reference Group was asked to identify publications, reports and other grey literature that they felt would meet this aim. Altogether 97 publications were collected as part of this initiative and included research, program and annual reports as well as journal articles relating to Aboriginal and Torres Strait Islander peoples' health. Third, in instances where National Reference Group members were aware of a study which was relevant but had not as yet been published extensively, research staff were contacted and invited to participate in an interview in order to gather all of the evidence which could inform Stage

One of this Wellbeing Study. Altogether seven research staff members participated in these interviews.

Finally, two large systematic literature reviews to better understand the implementation of interventions within a primary healthcare setting were undertaken. The first aimed to identify the elements of existing chronic care models delivered in primary healthcare settings and to determine whether these elements were acceptable and effective. While the majority of papers reported improvements to either healthcare practice or health outcomes as a result of implementing a chronic care model, it was not possible to identify which elements or combination of elements led to these improvements. Rather these results suggested that factors, such as collegial environments which support reflective practice and ensuring that healthcare leaders support the implementation and sustainability of interventions, may also play a role in improving care and health outcomes.

The other systematic literature review focused on identifying facilitators and barriers to implementing improvements to chronic disease care for Indigenous peoples within primary healthcare settings. Studies which focused on the views of community members and healthcare providers from four countries – Australia, New Zealand, Canada and the United States of America – were included. The results of this review suggested ways in which the design and implementation of future interventions for Aboriginal and Torres Strait Islander people with chronic disease could be improved.

## STAGE TWO – EMERGING PRINCIPLES

Stage Two used a framework analysis technique to analyse the previous Kanyini Vascular Collaboration findings, the case study interviews, the literature identified by the National Reference Group and the two systematic literature reviews undertaken as part of Stage One. Framework analysis is particularly useful for dealing with a large amount of literature in a systematic way to ensure transparency in the process of analysis [26]. Given the amount of literature included in Stage Two it was important to establish a set of specific questions prior to commencing analysis in order to ensure that relevant findings were identified from often lengthy reports [27]. Framework analysis also ensured that the coding and analysis process was transparent and open to critique [28] from National Reference Group members.

Prior to commencing analysis and interpretation, the following framework, consisting of seven components, each with a set of specific questions, was developed and agreed to by the National Reference Group.

### **1. Wellbeing**

- How do Aboriginal and Torres Strait Islander peoples understand wellbeing?
- How can primary healthcare services support wellbeing for Aboriginal and Torres Strait Islander peoples with chronic disease?

### **2. Best Practice Care**

- What does best practice care comprise of for Aboriginal and Torres Strait Islander peoples with chronic disease?
- How can primary healthcare services deliver best practice care for Aboriginal and Torres Strait Islander peoples with chronic disease?

### **3. Access and Engagement**

- How can primary healthcare services promote access to and continued engagement with care for Aboriginal and Torres Strait Islander peoples with chronic disease?

### **4. Quality**

- How can primary healthcare services ensure they are providing effective and accessible care (accessible, acceptable and appropriate) to Aboriginal and Torres

Strait Islander peoples living with chronic disease?

#### **5. Implementation**

- What supports the implementation of new interventions for Aboriginal and Torres Strait Islander peoples in a primary healthcare setting?
- What impedes the implementation of new interventions for Aboriginal and Torres Strait Islander peoples in a primary healthcare setting?

#### **6. Sustainability**

- What supports the sustainability of new interventions for Aboriginal and Torres Strait Islander peoples in a primary healthcare setting?
- What impedes the sustainability of new interventions for Aboriginal and Torres Strait Islander peoples in a primary healthcare setting?

After importing all of the literature into a qualitative analysis software package (NVivo), five of the six research staff individually coded to the framework questions. The content of each code was then inductively analysed to extract answers (principles) to each of the framework questions. NVivo was particularly useful for this content analysis as the principles that emerged continued to be linked or anchored to the original literature ensuring that information about the methodology, the participants and the context within which the original study was conducted was available to assist with interpretation. While initial coding was split between the research staff, the team came together to interpret the content of each code and identify the principles.

At the second face-to-face National Reference Group, members were asked to review these principles and applications. By the end of this meeting, 29 principles, together with a number of practical applications which suggested ways in which these principles could be applied within a primary healthcare setting, had been identified. National Reference Group members were then given an opportunity to provide feedback out-of-session via a modified Delphi Survey. Feedback from the modified Delphi Survey suggested that there were a number of ways in which the principles and applications might be improved, including:

- reducing the considerable overlap amongst the principles by linking them to each other or combining together,
- clarifying terms and in some cases providing clear definitions,
- ensuring the principle relate to support for wellbeing rather than solely the delivery of primary healthcare; and
- rewording some of the principles to make their meaning clear.

## **STAGE THREE – SHAPING THE WELLBEING FRAMEWORK**

To address the issues raised by the National Reference Group and ensure that the principles and applications were acceptable to both primary healthcare providers and Aboriginal and Torres Strait Islander community members, seven of the Aboriginal Medical Services with a representative on the National Reference Group, nominated at least one Aboriginal or Torres Strait Islander healthcare provider to participate as Research Fellows in Stage Three of this study. Thus, another 13 Aboriginal and Torres Strait Islander Research Fellows (ARFs) joined the core research team.

The work of the ARFs in Stage Three began with a week-long workshop which allowed time for the research team to review and also refine the principles and applications in readiness for consultation with community members and their healthcare providers. The ARFs then completed a master-class focused on ethical research, utilising the National Health and Medical Research Council Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research [29] and the South Australian Aboriginal Health Research Accord [30]. In addition, this master-class included information on qualitative research methods with

a focus on learning about and also developing hands-on practical skills in collecting data through individual and group interviews as well as community assessment workshops [31]. The Aboriginal and Torres Strait Islander Research Fellows also practiced audio-recording mock interviews with one another.

During the subsequent eight weeks, five of the original research team members travelled to the various healthcare services in order to support the Aboriginal and Torres Strait Islander Research Fellows in conducting individual and group semi-structured interviews as well as community assessment workshops. After initial introductions and ensuring that voluntary informed consent had been obtained, participants were provided with a copy of the refined principles and using their own experiences as an example, invited to think about how these could be improved. Community participants were also encouraged to talk about what “kept them strong” which was agreed upon as an appropriate starting point exploring ideas of wellbeing. In addition, healthcare provider participants were asked to discuss any barriers and facilitators which may need to be considered when implementing these principles into primary healthcare settings.

All but two individual interviews and three community assessment workshops were recorded and professionally transcribed. Where recordings were not captured, extensive field notes were scribed. Transcriptions and field notes were de-identified prior to analysis and interpretation. A total of seventy two community members and healthcare providers participated in forty interviews or community assessment workshops across the seven participating AMS sites (Table 1).

*Table 1. Description of participants for Stage Three*

<b>Healthcare Organisation</b>	<b>Number of Interviews – Community Member</b>	<b>Number of Interviews – Healthcare Provider</b>	<b>Number of Participants – Community Member</b>	<b>Number of Participants – Healthcare Provider</b>
<b>Wuchopperen</b>	2	4	5	5
<b>Tharawal</b>	1	2	5	4
<b>Winnunga</b>	3	5	3	5
<b>Danila Dilba</b>	1	3	1	8
<b>Nunkuwarnin Yunti</b>	1	5	9	5
<b>Maari Ma</b>	3	3	6	4
<b>Wirraka Maya</b>	0	7	0	12
	40		72	

At the end of the eight week data collection phase, the Aboriginal and Torres Strait Islander Research Fellows came together once again with the aim of analysing and interpreting the data. This second week began with a master-class on analysis and interpretation techniques. The Research Fellows, with assistance of the core research staff, then manually coded the transcripts and field notes, before identifying the key concepts or themes emerging from the transcripts which would help to further refine the principles and applications. In order to ensure that the context of the interviews was not lost in this process, the Aboriginal and Torres Strait Islander Research Fellows, wherever possible, participated in coding and then interpreting data from their own site. The entire research team then came together to discuss the primary concepts, before making any adjustments. During these discussions, it was decided that some concepts were so integral to all of the principles that they were designated as core values. In addition, as part of the process the principles were

grouped under common elements. The outcome of this second workshop was a draft Wellbeing Framework which comprised two core values, four elements and 16 principles.

## BUILDING CONSENSUS

Finally, National Reference Group members, Aboriginal and Torres Strait Islander Research Fellows and other members of the research team attended a two day consensus workshop to review and finalise the principles and applications. While suggestions for improvement were provided for consideration by the ARFs, including the development of a one page introduction describing the nationally and internationally recognised values and principles which underpin the Wellbeing Framework, in-principle agreement on the structure and content was reached at this face-to-face meeting.

Importantly, core research staff provided feedback to participants as well as other community members, healthcare providers and managers at each of the sites involved in Stage Three. Feedback from these meetings confirmed the outcomes from the Consensus Workshop with participants identifying a number of ways in which the Wellbeing Framework would be useful in their particular service.

## Results

The Wellbeing Framework (Figure 2) consists of two core values that are fundamental to the provision of care for Aboriginal and Torres Strait Islander peoples. It also sets out four essential elements that can assist primary healthcare services to support the wellbeing of Aboriginal and Torres Strait Islander peoples living with chronic disease. Every element is supported by four principles. Underpinning each principle is a number of practical and measurable applications that suggest ways in which the principle could be applied. Primary healthcare services, in consultation with the communities they serve, are encouraged to use the elements, principles and applications included within this Wellbeing Framework to shape their own Wellbeing Model which specifically addresses the needs of their communities.

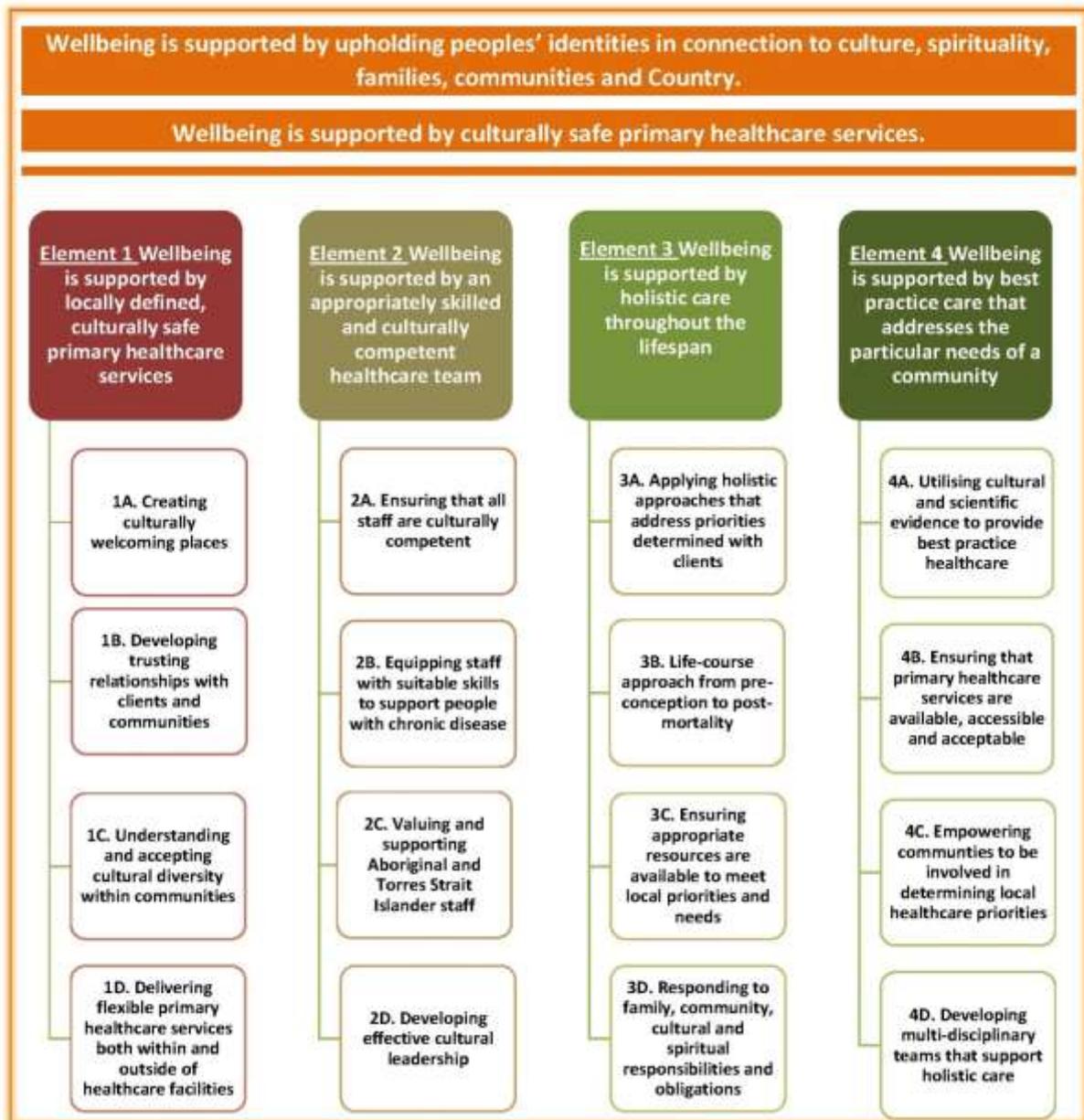


Figure 2. Wellbeing Framework

# CORE VALUES

**Core Value 1: Wellbeing is supported by upholding peoples' identities in connection to culture, spirituality, families, communities and Country.**

Supporting the wellbeing of people in the presence of chronic disease must include upholding people's cultural connectedness and balance with their families, communities, Country, culture and spirituality. For many Aboriginal and Torres Strait Islander peoples, there are complex relationships between natural and spiritual worlds involving interconnections between themselves, their community structures and their environments [32]. Creation beliefs shape people's lives, as well as their spirituality, values, attitudes, concepts, language and relationships to the physical and material world [33]. Often there can be a perception that personal illness or injury is a manifestation of struggles to maintain balance between spiritual, physical and emotional wellbeing and the wider world [34].

**Core Value 2: Wellbeing is supported by culturally safe primary healthcare services.**

Cultural safety 'involves health providers working with individuals, organisations and, sometimes, [communities]' [35 p. 23]. It extends beyond being aware of or sensitive to cultural differences. It includes a deeper level of interaction and thoughtful practice that ensures safe services, as defined by those who receive services [35, 36]. 'Unsafe cultural practice comprises any action which diminishes, demeans or disempowers the cultural identity and wellbeing of an individual' [37 p. 6] or of their families or communities [38].

## ELEMENTS AND PRINCIPLES

**Element 1: Wellbeing is supported by locally defined, culturally safe primary healthcare services.**

Locally defined, culturally safe primary healthcare services can be achieved by creating culturally welcoming space(s) as defined by Aboriginal and Torres Strait Islander communities; by developing trusting relationships between healthcare providers, clients and communities; by understanding and accepting diversity within and between communities; and by offering flexible approaches to the delivery of primary healthcare services that can address the complex needs and accommodate the competing demands experienced by many Aboriginal and Torres Strait Islander people with chronic diseases.

### **Principle 1a: Creating culturally welcoming places**

Culturally welcoming places include physical spaces as well as staff within the facility actively working towards ensuring that Aboriginal and Torres Strait Islander community members feel safe and comfortable [39]. Welcoming spaces are free from discrimination on the basis of differences, including those of race, gender and disability [40], and are reflective of dynamic local community contexts [40, 41].

### **Principle 1b: Developing trusting relationships with clients and communities**

Trusting relationships encourage confidence in primary healthcare services [18, 42, 43]. Fundamental to developing trusting relationships is communicating responsively and responsibly and ensuring that people feel respected, valued and cared for when accessing primary healthcare services [18-20, 39, 44].

### **Principle 1c: Understanding and accepting cultural diversity within communities**

Primary healthcare staff should become aware of the diversity both within and between Aboriginal and Torres Strait Islander communities in order to ensure that a wide range of healthcare needs are attended to [38]. Different communities and groups within communities have distinct laws, governance arrangements, kinship structures and ways in which they

view and maintain cultural identities [45], which are often overlooked when providing primary healthcare services to Aboriginal and Torres Strait Islander peoples.

### **Principle 1d: Delivering flexible primary healthcare services both within and outside of healthcare facilities**

In order to adequately meet the complex needs and competing demands experienced by some Aboriginal and Torres Strait Islander communities, the provision of primary healthcare services should extend beyond the geographical and temporal constraints frequently applied in conventional primary healthcare settings [46-50].

#### **Element 2: Wellbeing is supported by an appropriately skilled and culturally competent healthcare team.**

Appropriately skilled healthcare teams are comprised of staff who are culturally competent as well as appropriately skilled and qualified to provide the types of clinical care that are required. Given the crucial role of Aboriginal and Torres Strait Islander staff in linking primary healthcare services with communities, and in the provision of culturally safe care, their particular role needs to be valued. Finally, effective leaders who can ensure that primary healthcare services are responsive to the needs of local communities are essential.

### **Principle 2a: Ensuring that all staff are culturally competent**

Ensuring that all primary healthcare staff are culturally competent may effectively protect the rights and safety of both clients and primary healthcare providers [51, 52].

### **Principle 2b: Equipping staff with suitable skills to support people with chronic disease**

It is important that primary healthcare staff are appropriately skilled and qualified to meet the specific and often complex health needs of the communities they serve. Enhancing the professional development of staff can ensure the currency of clinical skills, as well as encourage retention of staff, thereby supporting continuity of care.

### **Principle 2c: Valuing and supporting Aboriginal and Torres Strait Islander staff**

As a consequence of their cultural understandings and community connections, Aboriginal and Torres Strait Islander staff bring unique contributions to primary healthcare services [42, 53, 54]. It is important to ensure that Aboriginal and Torres Strait Islander staff are not discriminated against, excluded or isolated from other members of the healthcare team [38, 41, 55]. Aboriginal and Torres Strait Islander staff may require further support in managing any additional burden resulting from the dual responsibilities associated with being both healthcare providers and members of local communities [38, 42].

### **Principle 2d: Developing effective cultural leadership**

Effective leaders, whether they sit on governing boards or occupy management positions, will be able to guide and direct the primary healthcare service to ensure that the diverse needs of communities are met and that services remain adequately transparent to maintain the trust of communities.

#### **Element 3: Wellbeing is supported by holistic care throughout the lifespan.**

An integrated cycle of care recognises that people's healthcare needs extend beyond the physical body. For Aboriginal and Torres Strait Islander peoples, healthcare needs may be closely bound to their spiritual, family, cultural, community and Country connections. An integrated cycle of care also acknowledges that people's needs differ according to where they are within their life-course. Ensuring that appropriate resources are available is also essential to meeting the often complex needs of Aboriginal and Torres Strait Islander clients.

### **Principle 3a: Applying holistic approaches to address priorities determined with clients**

Applying an holistic approach [43, 44, 50, 56, 57] includes addressing the physical, spiritual, social, emotional, psychological and cultural aspects of people's health [58]. Primary healthcare providers must be aware of and, where possible, support people to address and work toward overcoming socio-economic disparities [49, 50, 59, 60]. This may include providing opportunities for healing from trauma and stress, as well as addressing the social and cultural determinants of health as part of chronic disease care [38, 61].

### **Principle 3b: Life-course approach from pre-conception to post-mortality**

A life-course approach considers healthcare needs and priorities according to life stages [38]. In Aboriginal and Torres Strait Islander communities, a life-course approach extends from pre-conception to post-mortality [41, 49, 54]. The development of risk factors for chronic diseases is influenced by parents' health prior to conception as well as during pregnancy [58]. Likewise, the ongoing responsibilities for people who have passed, together with higher rates of morbidity and mortality, can result in an increased burden of unresolved grief, loss and trauma [39, 46].

### **Principle 3c: Ensuring appropriate resources are available to meet local priorities and needs**

Resources include guidelines, assessment tools and measures, and information that support the provision of healthcare to meet the specific needs of communities. Ideally, resources that are specific to local communities should be used or developed. However, where these are not available, it may be necessary to utilise or adapt generic resources to suit local contexts.

### **Principle 3d: Responding to family, community, cultural and spiritual responsibilities and obligations**

Primary healthcare providers need to understand and be willing to respond appropriately to people's range of cultural responsibilities, including family and kinship obligations [38, 44, 62, 63]. Wellbeing for Aboriginal and Torres Strait Islander peoples is closely connected to Country and cultural practices, as well as to the maintenance and application of traditional knowledge [58]. It is therefore important not only to respond appropriately to the diversity of healthcare needs, but also to respect cultural and social conditions at a local level [38, 49, 64-66].

### **Element 4: Wellbeing is supported by best practice care that addresses the particular needs of a community.**

For Aboriginal and Torres Strait Islander communities, broadening the definition of best practice care to include not only evidence-based medicine, but also Aboriginal and Torres Strait Islander worldviews, will support wellbeing. Best practice care should also address the availability and accessibility of services and should empower communities to actively determine local healthcare priorities. Fostering a sense of empowerment is one strategy for supporting the wellbeing of entire communities. As there are complex interplays between physical, social, emotional, and spiritual aspects to health, it is important to develop multi-disciplinary teams that can adequately address the multiple dimensions of the health and wellbeing needs of people with chronic disease.

### **Principle 4a: Utilising cultural and scientific evidence to provide best practice healthcare**

Best practice care is based on the use of evidence from well-designed and conducted research in healthcare decision-making [references still to be inserted]. This includes ensuring continuous quality improvement through ongoing monitoring and regular evaluation

[38, 39, 41, 67]. To adequately support wellbeing, it is important to expand current clinical understandings of 'best practice' to incorporate Aboriginal and Torres Strait Islander worldviews [38] and to include different types of evidence and knowledge where appropriate [38, 64].

**Principle 4b: Ensuring that primary healthcare services are available, accessible and acceptable**

By exploring with communities the factors that impede peoples' engagement with healthcare services, including financial barriers [41, 44, 55], primary healthcare services can implement strategies to increase the availability, accessibility and acceptability of services in order to adequately meet local needs [38, 68, 69]. This may include facilitating access to specialist services [44], as well as ensuring adequate follow-up care in some cases [38].

**Principle 4c: Empowering communities to be involved in determining local healthcare priorities**

Encouraging open and continuous dialogue between communities and primary healthcare providers, and ensuring that communities are able to make informed decisions, will assist in ensuring that healthcare priorities are contextually relevant [64].

**Principle 4d: Developing multi-disciplinary teams that support holistic care**

In Aboriginal and Torres Strait Islander communities, it is important to recognise a broad range of conditions that could be considered chronic, including social, emotional, mental and spiritual health issues [38, 58]. Maintaining integrated teams of healthcare staff who can provide a range of services, including those that support social and emotional health as well as chronic disease management, will better meet the needs of people living with chronic conditions [38, 39, 41, 44, 68, 70].

## APPLICATIONS

Underpinning each of the fourteen principles are a number of applications which suggest how the principle could be applied in a primary healthcare setting (not shown in Figure 2). As with the core values, elements and principles above, each application is referenced to specific evidence from participants in this study and/or findings of previous research. For example, the following applications have been suggested as ways of implementing Principle 1a: Creating culturally welcome places.

- Engaging with Aboriginal and Torres Strait Islander communities to determine what constitutes safe and welcoming healthcare spaces within the local context [18, 38, 39, 41, 69, 71-73]
- Developing resources that assist people to access primary healthcare services [38]
- Ensuring that primary healthcare facilities can be identified as culturally appropriate and welcoming to Aboriginal and Torres Strait Islander people [38], for example by displaying culturally appropriate posters, paintings and artefacts [18, 43, 71]
- Ensuring that protocols acknowledging Country are in place [40]
- Ensuring local Aboriginal and Torres Strait Islander staff are the first point of contact within primary healthcare services [18, 38, 43, 74]
- Ensuring staffing within primary healthcare services reflects an appropriate gender balance [40]
- Being responsive to peoples' diverse understandings and uses of English [38, 59, 68]
- Using interpreters when and where appropriate [38, 68]
- Ensuring that health promotion and information materials within facilities are designed to meet the needs of local Aboriginal and Torres Strait Islander peoples [18]

## CAPACITY STRENGTHENING

The development of this Wellbeing Framework provided every member of the team with opportunities to learn. For academic research staff who had never worked in an Aboriginal Medical Service there were opportunities to learn from the ARFs.

One of the most noticeable examples of this for me was being out on site and thinking that I was explaining the study simply to some community participants before we started [a Community Assessment Workshop]. The Research Fellow I was working with patiently waited for me to finish, then laughed and said to the group, “Right. Now what she just said was...” and explained things in a way that totally made more sense than what I’d just said [non-Indigenous Research Staff member].

In comparison, the learning opportunities for ARFs related more to strengthening their knowledge about and ability to conduct qualitative research.

I found the Wellbeing Study to be a valuable learning experience both personally and professionally. I had not previously had the opportunity to be a part of something like this and found it to be a great learning experience. I was pleasantly surprised with the research process, particularly the depth of consultation and the how intrinsic cultural safety was at all times [ARF].

It was felt that the success of the study was dependent on research team members feeling comfortable and able to openly discuss what some might consider to be quite confronting concepts.

I found the whole process very ethical and felt culturally safe at all times. During the process we were given the tools to understand the research process and felt comfortable to ask questions and participate freely in all aspects. This carried over into giving us a sense of ownership of the work we had undertaken and easier to describe the study and concept of the intended model to participants [ARF].

The two workshops held in Stage Three were particularly useful for reflecting on a sharing knowledge about wellbeing.

The workshops allowed for ideas to be shared in a safe and supportive space and being able to learn from so many different perspectives and understandings was extremely valuable [Aboriginal Research Staff member].

Importantly, research team members believed that the study had practical outcomes and that the “model that has been developed is user friendly and can be easily implemented within our health service” [ARF].

It is exciting to be a part of something that was developed with Aboriginal people for Aboriginal people. I can see this framework having an impact on the health outcomes of Aboriginal community members by providing healthcare providers with a clear, culturally safe, systematic process of providing care to their clients [ARF].

## Discussion

This study has led to the development of a framework which can assist primary healthcare services to improve the quality of life and quality of care, as well as the health outcomes, for Aboriginal and Torres Strait Islander peoples living with chronic disease. The final Wellbeing Framework, consisting of two core values and four elements supported by a number of principles and applications, has several key strengths. First and foremost, the Wellbeing Framework was developed by and for Aboriginal and Torres Strait Islander peoples. A team of researchers including thirteen ARFs, who were also experienced healthcare professionals working in Aboriginal Medical Services across Australia, came together to undertake this important work. The National Reference Group that guided the entire study included Community Elders, as well as Aboriginal and Torres Strait Islander and non-Indigenous policy makers, healthcare providers and administrators. Over 70 community members and healthcare practitioners who provide care to Aboriginal and Torres Strait Islander peoples contributed to the research findings by participating in semi-structured interviews or community assessment workshops during Stage Three of the study.

## DEVELOPED BY AND FOR ABORIGINAL AND TORRES STRAIT ISLANDER PEOPLES

The connections that the ARFs had to their local communities as well as to other healthcare providers were crucial for ensuring the acceptability and useability of this Wellbeing Framework. As has previously been identified [75], researchers who are embedded within participant communities are better able to understand the values and life experiences of people within particular groups. When researchers have close ties to participants in any research study this has the added benefit of facilitating a greater acceptance of researchers and strengthening rapport with participants [76]. It is important to note that the Aboriginal and Torres Strait Islander team members in this study did not just collect the data but were involved in the entire Stage Three process from developing the data collection tools, to co-facilitating interviews and community assessment workshops, to analysing and then interpreting the data. This ensured that a deeper understanding of the context within which the participants' stories were being told informed the final Wellbeing Framework [77].

Given the complex family and community relationships and the connections with Country that exist within many communities, it was important to apply a methodology that valued and privileged the knowledge of Aboriginal and Torres Strait Islander peoples in order to fully identify what is needed to understand and support the wellbeing of Aboriginal and Torres Strait Islander peoples [78, 79]. In addition to contextual and cultural knowledge, the ARFs also had crucial hands-on experience in providing care as well as collegial relationships with other potential healthcare provider participants. This further ensured that the Wellbeing Framework accounted for the practical constraints that are often manifest in models of care.

## RESPONDING TO DIVERSITY

Another key strength of this Wellbeing Framework is that rather than defining what wellbeing is, or rigidly determining how care should be provided, the outcome of this collaborative effort is a Framework that allows for more locally relevant, flexible approaches by identifying key principles necessary for supporting healthcare services to respond to a community's and individual members' understandings of wellbeing. This flexibility is particularly important given that the concept of wellbeing is difficult to define and even harder to measure [80, 81]. Terms such as health, quality of life and wellness [82] have all been used at one time or another interchangeably with what could be described as wellbeing. One reason for this confusion is the number of different disciplines, including psychology, social epidemiology, public health and medicine, that are all grappling with the concept [83]. Another reason is

that wellbeing is often a subjective concept dependent to some extent on a person's lived experiences, the people they associate with and the context in which they reside [80].

While western models focus more on individuals [83], Indigenous concepts of wellbeing are often far more holistic, incorporating connections to family, community, culture, spirituality and Country [82]. Yet there are also considerable between-population differences in the specific elements of wellbeing which are considered to be important. For Indigenous peoples in Thailand, for example, harmony with others, interdependence between family and community members, the ability to relinquish or not dwell on negative feelings and experiences, respect for others and enjoyment of life are more likely to underpin concepts of wellbeing [84]. For the Matsigenka culture in Peru, qualities of 'productivity, goodness, and maintaining harmony with their social, physical and spiritual environment' [85, p. 776] may be far more important, while from an Inuit perspective, communicating and being on the land with and sharing food with family are all believed to be closely associated with perceptions of wellbeing [86].

Given the vast number of Aboriginal and Torres Strait Islander populations across Australia the differences between how people experience wellbeing are important to consider. For example, wellbeing for Nywaigi peoples who are traditional owners in northeast Queensland is closely associated with a relationship to their ancestral lands and their ability to participate in resource management activities [87]. For the Yaegl tribe of northern New South Wales spirituality and wellbeing were closely connected [88], while in Central Australia a study involving younger Aboriginal men found that wellbeing was closely tied to "the Law [Tjukurpa], family [Walytja], the land [Ngurra], and the sense and obligations to care for and remain connected to the social, physical and emotional world around them [Kanyini]" [89, p. 5]. Therefore, rather than defining wellbeing, this Wellbeing Framework seeks to encourage primary healthcare services to engage with communities and patients in order to develop a locally relevant model based on this Framework.

## PRACTICAL APPLICATIONS

A key strength of this Wellbeing Framework is that it suggests practical ways of applying each of the principles. These applications were not only based on synthesis of previously published work, but also upon contributions of end-users (community members and healthcare providers), who were actively engaged in evaluating whether they believed the applications identified within the existing literature would be effective and acceptable for use within an Aboriginal Medical Service context. Participants were also asked to identify additional applications that they believed could assist in implementing the principles, but had not been identified by the initial search. Identifying applications which could support the implementation of principles will assist primary healthcare services to start to operationalise the Wellbeing Framework, at least to some extent almost immediately. For example, many of the applications require little or no funding, which is often a barrier to implementing improvements within a primary healthcare service [90].

In addition to assisting primary healthcare services to support the wellbeing of Aboriginal and Torres Strait Islander peoples, there are a number of other uses for the Framework. For example, some of the participating Aboriginal Medical Service sites have considered using it as part of their evaluation program. Given that the content of the Wellbeing Framework is extensively referenced, other sites have considered how it could be used to support funding applications and advocate for policy changes.

## MUTUALLY BENEFICIAL CAPACITY STRENGTHENING

Finally, there were mutually beneficial outcomes for all members of the research team. The original core researchers learnt about the contextual complexities involved with providing care in primary healthcare services, while the ARFs had the opportunity to strengthen their

capacity to undertake qualitative research. For the latter, these research skills were also of direct benefit to their Aboriginal Medical Service in so far as the ARFs will now have the skills to be able to not only contribute to other research projects but also to assist with evaluation and continuous quality improvement programs. These 'learn-by-doing' components of the study went beyond merely data collection to developing research tools, obtaining informed consent as well as analysing and interpreting the data that had been collected.

This approach is based on the principles of Participatory Action Research [91] in that there was an equal relationship built on trust between all members of the research team, the study was developed collaboratively and the original research aims were identified by communities and their primary healthcare providers. Importantly, local knowledge was valued and respected, with time during Stage Three for the entire team to reflect on the participants' stories. This is in direct contrast to the researcher as the 'expert' who collects, analyses and interprets knowledge on behalf of others [92].

## LIMITATIONS

While one of the strengths of this study was the connection that the ARFs had to the community and primary healthcare provider participants, it was also recognised that the heterogeneity of Aboriginal and Torres Strait Islander populations means that it cannot be assumed that any one individual has an understanding of nor can speak for all communities [93]. In the past, some researchers have failed to acknowledge the complexity that arises from the wide range of diverse Aboriginal and Torres Strait Islander peoples' views and experiences within and between communities [94].

Finally, while the Wellbeing Framework does suggest a number of practical applications for each principle, additional work is needed to identify and, where necessary, develop resources and tools which ensure that primary healthcare services can make full use of these applications. In the case of Principle 1a: Creating culturally welcome places, which is provided as an example in the results section of this monograph, an appropriate list of interpreting services for all available Aboriginal and Torres Strait Islander services could be developed and made available through a website. In addition, health promotion material which has been specifically designed for Aboriginal and Torres Strait Islander populations could be identified and contact details for the developer made available.

## Conclusion

This study has developed a Wellbeing Framework which will assist primary healthcare services to improve the quality of life and quality of care, as well as the health outcomes, for Aboriginal and Torres Strait Islander peoples living with chronic disease. A team of researchers including thirteen ARFs, who were also experienced healthcare professionals working in Aboriginal Medical Services across Australia, came together to undertake this important work. Similar to other studies which have used a Participatory Action Research approach, this Wellbeing Model actively engaged people with local knowledge and experience.

One of the key strengths of this Wellbeing Framework is that rather than defining what wellbeing is, or rigidly determining how care should be provided, the outcome of this collaborative effort is a Framework that allows for more locally relevant, flexible approaches by identifying key principles necessary for supporting healthcare services to respond to a community's and individual members' understandings of wellbeing. Importantly, the Wellbeing Model also includes practical examples of how the principles could be applied based on the work of other researchers as well as experiences of community members and healthcare providers that participated in this study.

## RECOMMENDATIONS

This evidence-based Wellbeing Framework is already generating substantial interest from several government health departments, which are already beginning to apply the Wellbeing Framework to chronic disease planning. A number of the Aboriginal Medical Services involved in this study have also suggested that the Wellbeing Framework will form part of their continuous quality improvement and evaluation strategies for the coming year, and members of our National Reference Group have noted that the Framework may assist to inform healthcare policy and practice more broadly.

A comprehensive four-stage plan would assist healthcare services to utilise this Wellbeing Framework:

- **Stage One:** The Wellbeing Framework, including details about the core values, elements and principles, as well as practical suggestions for applying the Framework, should be broadly disseminated through Commonwealth and State government health departments. As this material is already available on the Kanyini Vascular Collaboration website, dissemination could first occur electronically, followed by briefings. The Wellbeing Framework should also be disseminated through Primary Healthcare Networks once they are established.
- **Stage Two:** Funds should be made available to identify or develop resources to assist primary healthcare services to apply the principles within the Wellbeing Framework. Funding should also allow for the development of monitoring, evaluation and implementation plans, in order to provide a complete suite of resources for primary healthcare services that wish to implement the Wellbeing Framework.
- **Stage Three:** The Wellbeing Framework, together with the resources identified or developed as part of Stage Two, should be piloted in two Aboriginal Medical Services and one mainstream primary healthcare service. The pilot would identify whether the Wellbeing Framework was both acceptable to and effective for improving healthcare services to Aboriginal and Torres Strait Islander peoples. In addition, information from the pilot would also assist in understanding how the sustainability of such an intervention can be supported.
- **Stage Four:** The adaptability of the Wellbeing Framework to other groups within Aboriginal and Torres Strait Islander populations should be tested. In particular, the need to also support the wellbeing of older Aboriginal and Torres Strait Islander peoples has been raised by members of our National Reference Group. Healthcare

services that are able to support the wellbeing of, as well as the acceptability of services for, older Aboriginal and Torres Strait Islander peoples have a number of benefits. For example, living at home for as long as possible could ensure the presence of valuable community role models for younger people.

**Recommendation:** Adopt and fund this staged implementation plan in order to ensure that the Wellbeing Framework is disseminated and utilised more broadly. Together this comprehensive, staged approach will ensure that primary healthcare services are provided with the means to better support the wellbeing of Aboriginal and Torres Strait Islander peoples living with chronic disease.

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