

An Empathic Indigenous Virtual Agent to Encourage Medication Adherence

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Glossary, Abbreviations and Acronyms

IVA	Intelligent Virtual Agent
ECA	Empathic Conversation Agent
IIVA	Indigenous Intelligent Virtual Agent

Abstract

Australia's First Peoples suffer from poor health and significantly lower life expectancy than most Australians. In response, the Australian Government launched the Closing the Gap Campaign, Intelligent Virtual Agents (IVAs) have been used to promote health in many situations using empathy to build a working alliance. While the results of prior work using IVAs is very encouraging, there has not been an attempt to use IVAs to help with the Closing the Gap campaign by Australian governments. This study created an IVA, an Indigenous IVA (IIVA) called Aunt, with Australia's First Peoples characteristics (including appearance, voice and name) to encourage adherence to prescribed medication, healthy eating and exercise to a group of Australia's First Peoples attending a medical centre on the NSW Central Coast. The poor uptake of the delivered technology highlights the endemic issues with reaching this group. Nevertheless, the artefacts developed and experiences resulting from this study aim to shape further development of IVAs to suit specific populations and inform researchers of the effectiveness of this technology.

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Statement of Originality

This work has not previously been submitted for a degree or diploma in any university. To the best of my knowledge and belief, the thesis contains no material previously published or written by another person except where due reference is made in the thesis itself. The Macquarie University Ethics Approval reference is No: 5201700728

(Signed)_____ Date: _____

Chapter 1 Introduction

1.1 Introduction

This research addresses the issue of Aboriginal and Torres Strait Islander Health in Australia by targeting adherence to prescribed medication, healthy eating and exercise by using an IVA in the form of a smartphone application. These things have been trialled previously [1], but not with an Australia's First Peoples Virtual Agent. While some reject the term Indigenous for Australia's First Peoples, it is used in the title because this research may extend beyond Australia's First Peoples to Indigenous groups Worldwide.

1.2 Personal Background

As an Aboriginal person, it is customary to introduce myself. I am by birth a member of the Kalari Tribe of the Wiradjuri Aboriginal nation. By adoption through my wife's (Dr. Hayley Charters) family I am accepted into the Gunnwinggu Mob of Western Arnhem Land, centered around Kunbarllanjja where my wife grew up.

The first Aboriginal man to call me brother was Moogudoo from the town of Kunbarllanjja. Every time I visited we would seek each other out. The last time I was there, Moogudoo was gravely ill because he had slipped through the cracks of the health system and no one had checked that his medication had been prescribed or taken. Moogudoo has since died, along with many others. His passing hit me hard as it did my wife who was a great friend of his wife. My wife is a Medical General Practitioner who has worked in this town and nearby. We have discussed how to help, and it seems that adherence to prescribed medication is a big problem. Once this problem is addressed and people begin to feel well, there is a need for proper nutrition and exercise to maintain good health. When crops were cultivated [2, pp. 19–21] and animals hunted before the Western diet illness was treated with bush medicine consisting of topical application of mixtures or medicines made from plants [3, pp. 246–251]. The Western diet leads to Type 2 Diabetes in many of [4, p. 1] — complications from this disease account for most of the hospitalisations of Australia's First Peoples. "Hospital episodes of care involving dialysis accounted for 44% of all hospitalisations for Aboriginal and Torres Strait Islander peoples (compared with 12% for non-Australia's First Peoples) [5, p. 1]."

1.3 Historical Background

Australia has a unique population. There are people from many nations who have settled here while the original inhabitants are still here and have been for an estimated 80,000 [4, p.1] to 120,000 [2, p. 91] years. These original inhabitants are called Australian Aboriginal and Torres Strait Islanders or Australia's First Peoples, the term used throughout this paper. From 1788 when the English claimed the country, the health of Australia's First Peoples declined [7]. Introduced diseases like smallpox decimated the population, and scientific racism (the idea that Australia's First Peoples were of an inferior genetic makeup and would die out) [3, pp. 38–40] saw Australia's First Peoples regarded as less than human and a hindrance to the development of the nation. This attitude of superiority resulted in the Frontier Wars from 1788 – 1838 [4] and policies like Assimilation [5, p.1]. We have not died out, and now the health problems of Australia's First Peoples are more likely to be related to the Western diet.

1.4 Health Problem

This research starts with the existing problem as outlined in the Australian Government's Close The Gap Campaign [8][7, pp.126-136]. This campaign aims to close the health, and now education, gap between Australia's First Peoples and non-Australian First Peoples. Currently Aboriginal and Torres Strait Islander Australians live ten years less than their non-Australian First Peoples counterparts [9, p. 126]. The main killers of Australia's First Nations People are "coronary heart disease 12%, diabetes 8%, chronic lower respiratory disease 7% and 6% from lung and related cancers [4, p. 7]." Close the Gap as a government strategy was proposed by Professor Tom Calma when he was a Social Justice Commissioner in 2005 [8]. This strategy has so far not lived up to expectations. While there are many strategies, improvement in Australia's First Peoples health is very slow. After assessing the current skills and knowledge of the research team, it was decided to target adherence to prescribed medication, healthy eating, and exercise. The ongoing problems of "racism, discrimination, forced removal of children, loss of identity, language, culture and land [5, p. 2]" were considered beyond the scope of this research but are significant factors in continuing health problems.

1.5 Artificial Intelligence as a unique solution

Adherence to prescribed medication is a global problem with adherence rates around 50% in developed countries with rates likely to be higher in developing countries [6]. When behaviour change is part of the treatment, the non-adherence rate can be up to 70% [7]. Creating a working alliance [8] between the patient and health professional is a predictor of adherence [9]. However, this typically requires face-to-face contact. Such a strategy is problematic for reaching Australia's First Peoples because there are many cultural differences and a distrust of non-Australia's First Peoples people and ways which varies across the country [13 p, 50-51]. A novel AI-based approach is the use of an *Indigenous* Intelligent Virtual Agent (IVA), an IVA is an artificial character that has been useful in improving adherence to treatment advice by overcoming poor health literacy barriers and building a working alliance [8], [10]–[12] An IVA, sometimes called an avatar, is created and equipped with empathic face-to-face conversational dialogues to encourage specific behaviour. As a technology, it can be deployed on devices such as laptops and phones that also address limited access to healthcare workers, a problem particularly for rural and regional communities.

Regarding social agents with empathic skills, “As such, a social agent—that is, an agent with social ability—must be endowed with the capability to understand others and their intentions, motivations, and feelings. Such capability entails perceiving and understanding others’ affective states and acting accordingly, a capability often referred to as empathy [13] In line with many other researchers in this area, they adopt Hoffman’s definition of empathy, “considering it as a process that makes a person (or agent) have “feelings that are more congruent with another’s situation than with his own situation.”. (Hoffman in [13])

Hiebert uses set theory to try to explain cultural differences that a relationship-based culture like Australian Aboriginal and Torres Strait Islanders live in and a First World Western Culture based on precise activities and achievements [14].

1.6 Research Question and Approach

Addressing the problem of poor health and low adherence to medication, while exploring the possibility of using artificial intelligence as a solution, this thesis asks the research question:

Can a virtual human that is empathic and culturally safe help Australia's First Peoples adhere to prescribed medication, healthy eating and exercise through a smartphone application?

This project is part of a broader project that is working on Empathic Agents to Support Education and Health. Empathic or relational agents are a type of IVA that seeks to respond emotionally appropriately to the user. This strand of the wider research project is to look for the best way to improve Australia's First Peoples adherence to prescribed medicines by using an Australia's First Peoples IVA that will build a therapeutic alliance by working alongside the user in the form of a smartphone application that will be available 24/7. This specific research looks at creating an Australia's First Peoples Intelligent Agent who shows empathy and is culturally safe for Australia's First Peoples to encourage adherence to prescribed medication in an attempt to close the life expectancy gap. An Australia's First Peoples has not been used for this purpose before. Aunt has dialogues on reminding and encouraging users to take prescribed medication, eat well and exercise.

The Indigenous IVA (IIVA) is called Aunt. Australia's First Peoples use the term Aunt or Aunty for a female Elder with knowledge. A person called Aunt or Uncle may not necessarily be related to the person using the term [15, pp. 3–13]. Aunt has the appearance and voice of an Australian First People's character. The name of the character was decided after discussions with Australia's First Peoples postgraduate students at Macquarie University, including Liesa Clague who is the voice of Aunt/Aunty. Her language has been checked to be both empathic and culturally safe by the writer and Dr Liesa Clague who is the voice of Aunt and an experience Aboriginal nurse. A study will be conducted with real Australia's First Peoples patients to capture data about their experience with Aunt.

1.7 Structure

Chapter two will review the literature on the health of Australia's First Peoples the concept of an IVA and how they have been used in health, how IVAs have been used for medical adherence then Cultural Differences that should be considered in the development of the IIVA. Chapter three will present the methodology and process undertaken to obtain ethics clearance. Chapter four presents the results and summarises the findings and looks at barriers to Australia's First People taking up the application and not wanting to be part of

the research. The barriers to taking part in research are reviewed with discussion of the study in the light of the literature. Chapter five presents conclusions and future work.

1.8 Summary

There is a need to improve the health of Australia's First Peoples, and the creation of an Australian First Peoples IVA is worth building and testing based on previous research. A greater explanation and justification for this work is covered in the following literature review.

Chapter 2 Literature Review

2.1 Introduction

The poor health of Australia's First Peoples, the cultural differences between Australia's First Peoples, empowerment to improve their health, Intelligent Virtual Agents and their uses in health particularly for encouraging adherence to treatment advice [16, p.122] are the key areas of research that are most pertinent to the addressing the research question stated in chapter 1 and the development of the IIVA.

The literature review first introduces the health of Australia's First Peoples Australian (Section 2.2), reasons for lack of adherence to treatment and also cultural differences. In Section 2.3, the concept of an IVA and how they have been used in health and key concepts that are related to encouraging adherence including building a long-term relationship, empowerment and self-efficacy, nudge theory and gamification. See Appendix G for a summarised table and link to an overview of the technology created for Australia's First Peoples.

2.2 Health of Australia's First Peoples

Australia's First People's Health in Australia is very poor and results in a much lower life expectancy for the Australia's First Peoples population compared to the non-Australia's First Peoples population [16][17]. In 2005 then, Social Justice Commissioner Professor Tom Calma suggested a policy to close this life expectancy gap which became a Federal Government campaign called Close the Gap [18]. Close the Gap has failed to reach the targets as can be seen in Table 1.

Survey years recorded in CTG		2005-2007	2010-2012	2015-2017	Change over 10 years
Australia's First Peoples Life Expectancy	Men	67.5	69.1	71.6	4.1
	Women	73.1	73.7	75.6	2.5
Non-Australia's First Peoples Life expectancy	Men	78.9	79.7	80.2	1.3
	Women	82.6	83.1	83.4	0.8
Gap in years	Men	11.4	10.6	8.6	2.8
Gap in Years	Women	9.6	9.5	7.8	2.0

Table 1. Life expectancy in Australia [19, pp. 1-11]

The slow progress of Close the Gap alone is a great motivation to explore the possibilities of an IIVA being used to improve Australian First Peoples' health.

Out of this campaign two very helpful research groups have grown: HealthInfoNet and the Lowitja Institute. HealthInfoNet is a website which serves as a repository of Australia's First Peoples Health Research with easy to find reports and statistics. HealthInfoNet is based at and supported by Edith Cowan University [20]. The Lowitja Institute is Australia's National Institute for Aboriginal and Torres Strait Islander Health Research [21]. These two research groups have contributed greatly to the Close the Gap campaign and have been a resource in the research covered in this thesis. The Lowitja Institute has produced 40 Australia's First Peoples Health Reports on topics such as diabetes, kidney, eye, cardiovascular, ear health and more [5].

According to Eades:

The current state of health of Indigenous Australians is a cause for national shame and has its roots in the wholesale exclusion of Indigenous people from Australian society since 1788. [22, p. 3].

2.3 Reasons for Indigenous non-adherence to medication regimes

The main reason why there is such a disparity in life expectancy and health between Aboriginal people and the rest of the population is the disconnect between Western and Indigenous thinking, along with the marginalisation of Australia's First Nations Peoples [23, p. 124]. In some instances the remoteness of many Australia's First Peoples Australian communities adds to the difficulty of providing health care [25, p 1-11] [26 p.473]. Research has been undertaken on medication adherence from an Aboriginal community in Victoria [26]. This study used in depth interviews with 20 patients to show that while health workers were the main source of information on prescribed medication many patients did not make health workers aware of over the counter medications they were taking and more importantly for this study adherence to long term medication was not well understood. This was one of the few studies that involved involvement and comment by Australia's First Nations People that could be found in my research.

The health worker role in Aboriginal and Torres Strait Islander communities is complex [24, p.1]. In reality, Health workers are just not available every 4, 6 or 8 hours to make sure medication is taken. A study by Coffin [28] showed that even Aboriginal health workers can

fail to connect. One study looks at cultural differences from the point of Aboriginal People and drills down past the token effort to have staff culturally trained through to the needs of Aboriginal patients. They explain:

For example, employing only one Aboriginal liaison officer who is female, not from the area and with no cultural connections in the area, means that the officer cannot fulfil all of the responsibilities of her role. In reality, the health service does not have an Aboriginal “face” and Aboriginal people do not have an adequate point of contact [29, p. 22].

The paper also points out that there is a history of distrust of all white people and some Aboriginal Australians die because of this distrust. The cold clean clinics are also a deterrent as it is likely that in the past a family member has died in a hospital.

As well as the problems above there are reasons that prevent all people from adhering to a regime of prescribed medication [30, pp. 17–21]. One of the most frightening statistics is that up to 30% of scripts are never filled, also only 50% of patients will complete any prescribed regime of medication. Reasons given include:

- Cost of drugs, this is generally not an issue for Indigenous Australians because remote area clinics give free or subsidised medication and people with chronic conditions get subsidised drugs.
- Denial that the patient has a life-threatening condition.
- Forgetfulness.
- Confusion regarding multiple drugs.

2.4 Cultural Differences

Cultural differences are a further stumbling block to adherence. Australia’s First Peoples Australian Culture developed in isolation for many thousands of years [31]. Despite some contact with Indonesian and Dutch people in the far north of Australia a few hundred years before the British, Australia’s First Peoples culture remained largely untouched [41 p.70, p.77] [2, p. 92]. This culture still exists despite government policies like assimilation [33, pp. 43–46] which assumed that the Aboriginal race would die out. The Stolen Generations came from a policy that took children who did not have two Aboriginal parents

and trained those children to work within European society, farm work for the boys [34, p. 238] and domestic duties, as well as, farm duties for the girls [35, p. 37]. There was no written language but an ability to remember information as well as law and lore through remarkable oral histories [46, 268-283] [37, p. 1].

This ancient culture is based on relationships (Appendix E) rather than the western ideas of rank or achievement, so a clash was inevitable. Examples of this clash can be found in Martin's *Please knock Before Entering* [49, p.168] and Harrison and Murray's *Reflective Teaching Practice in a Darug Classroom: How Teachers can Build Relationships With an Aboriginal Community Outside the School* [50, p121].

Another level of relationship is the concept of having a skin group which is lost on many newcomers to remote Australia's First Peoples communities [40, pp. 53–111]. I have attempted to explain this in Appendix E with the example of my own family in Arnhem Land. In an Australian Aboriginal community who you can marry or even talk to is governed by your skin group. Arnhem Land has been an Aboriginal Protected Area since 1931 [41] and has examples of communities where children start school able to speak a number of local dialects but very little English [52, p.1]. See a Nation/Language map in Appendix F.

Another important relationship for Australia's First Peoples is the land we live on. We were taught from an early age that we belong to the land, while the Western/Christian way is to dominate the land [43]. We do not own the land – the land owns us [40, pp. 212–216].

As stated, "Aborigines then are inseparably related to the land. The spiritual link between the person and his/her ancestor through the land and animal species means that his/her link with a particular area of land cannot be taken away or transferred to somewhere else [44, p. 1]."

The relational nature of Australia's First Peoples culture has to be considered in developing the avatar that appears in the smartphone application. Creating a character who could build a working relationship is most important, so Australia's First Peoples culture has been considered carefully in the development of the IIVA.

2.5 Empowerment

The need for empowerment comes from the marginalisation of Australia's First Peoples [23] that came from British settlement and the breakdown of culture and dislocation from land and way of life for all but a few Australia's First Peoples in remote communities [40,

p. 1]. This disempowerment is blamed for high suicide rates [55, pp.345-349], high levels of incarceration compared to the rest of the Australian population [56, p.56] and poor education [8, Chapter 3], as well as poor health [8, Chapter 6]. Embarrassment and not wanting to stand out are Aboriginal traits as are poor literacy, including poor health literacy.

Considering poor literacy and avoiding embarrassment, the need for consistent information, and an empathic approach to the patient are important for the IIVA the ability to build a working alliance [5 p.1].

2.6 Intelligent Virtual Agents and Health

IVAs have been used to overcome health literacy barriers [49] [50] by providing a familiar conversational face-to-face means of interaction. Timothy Bickmore [51] leads a team of researchers looking into medical uses of IVAs who have set a standard of quality in research and a benchmark for those working with IVAs towards building long term relationships between humans and IVAs. Bickmore defines IVAs “as computational artefacts designed to establish and maintain long-term social-emotional relationships with their users [52, p. 294].”

Another way to look at Intelligent Virtual Agents (IVAs) is that they are a human like character built in software that reacts to users in a human like way. They are also called Enhanced Conversation Agents (ECA), Chatbots and Avatars. There are “161 synonyms to address humanlike conversational AI entities [53]”. To have a clear understanding of what an IVA is and in particular the view taken for this study this definition has been chosen: “Intelligent Virtual Agents (IVAs) are embodied digital characters situated in a virtual, augmented, or mixed reality environment that look, communicate, and act like ‘living’ creatures, real, or fictional. A distinctive characteristic of IVAs is that their behaviour should exhibit some aspects of human intelligence, including autonomous behavior, communication and coordination with other IVAs, dialogues with humans, and learning capabilities. Additionally, IVAs are expected to be believable, i.e., to have a consistent behavior, to exhibit some form of personality and emotions, to communicate and interact in a plausible way, etc. [40 p. 1].”

IVAs are being used to give information in many areas including museum guides [55], some are used for answering phones in call centres [29, p. 53-55], even in hospitals [57, p. 22], while others are used to promote or improve health education [52], telephone answering [58] and for support of medical teams [8][59] [49][60]. A body of research looks at creating

empathic IVAs. Adding empathy to an IVA adds a more human like aspect to exchanges between IVAs and humans [61]. Timothy Bickmore has said, “Empathy—inferring the feelings and thoughts of others—is a prerequisite for comforting, and is also crucial for establishing trust and working alliance between users and therapeutic agents [62, p. 2292].” An IVA that can develop and continue a working alliance will be useful in areas where patience and access to human help are in short supply. Intelligent Virtual Agents have been used in improving health for a few years now and some of the more successful work is presented below.

Christine Lisetti published the 10 Advantages of Using Avatars in Patient-Centred Computer-based Interventions for Behaviour Change [30, p.28] and Embodied Conversational Agents for Psychotherapy [31, p. 1-12]. While we are not delving into psychotherapy, we are trying to change patient behaviour by encouraging patients to adhere to prescribed medication. The main points to be taken from Lisetti’s work is that an IVA can be tailored to the need at hand.

There is a reluctance to divulge information when dealing with medical professionals and this has been addressed by Lucas et al. in ‘It’s only a computer: Virtual humans increase willingness to disclose [32, p. 94-100]’. This study found that patients would disclose more information if they knew they were communicating with a computer. The IIVA will not be recording any conversations in this iteration but will be conversational in nature and give users a chance to vent without being monitored.

Gordon et al., [62] conducted a study concerning avatar-assisted therapy to reduce substance abuse. This study addressed the question: “are individuals who present for outpatient treatment interested in receiving Avatar Assisted Therapy? [66, p. 1]” After screening, 59 participants were accepted, 28 of these completed the program. This gave two groups that were compared for outcomes. Those who completed the program showed evidence of lower or no drug use and none were arrested during the program. The limitations were that the program was voluntary, and the participants were selected because they were drug users who had trouble attending sessions. Thus, control of the group was difficult.

Fortier et al. [63] evaluated an animated panda in their Pain Buddy tablet application. The panda character was chosen for children (see Figure 1.). Pain Buddy [67] is an avatar that helps children with cancer report and deal with their level of pain. Pain Buddy aimed to enhance pain management and foster improved quality of life in 12 children ages 8–18 years

undergoing cancer treatment. Each participant was selected because they were undergoing outpatient cancer treatment. Pain Buddy [67, pp. 202–214] worked on desktops and laptops connected to the Internet, so reports would go to the relevant clinic. This allowed for better management of pain by patients and doctors.

The Pain Buddy study included daily pain and symptom diaries completed by children, initial interviews and baseline quality of life measures and follow up remote monitoring of symptoms by uploading patient's data through internet to a cloud server [67, p. 202] . There were problems with data upload, so the planned 10-day trial was disjointed. Despite this the patients reported satisfaction with pain buddy and found it useful in reducing pain symptoms. Development of Pain Buddy is ongoing.

Pain Buddy

"Pain Buddy is a web-based program that allows children to report pain at home, as they have it," says Fortier. "It arms kids with things they can do to give them more of a sense of control over symptoms and pain."



The novel program works on any desktop or laptop computer that is connected to the Internet. A walking, talking Panda avatar helps children navigate and complete the diary each day. It asks questions like:

- Have you had pain, nausea, or fatigue today?
- How much do these symptoms bother you?
- What are you doing to make yourself feel better?

Kids earn digital coins for each pain diary they complete, which can be used to unlock additional avatars or fun accessories, like hats or glasses. Background and splash pages can also be personalized to the child's liking.

The daily diary information is sent to a server at the clinic, where the child's health care provider can access it at any time. If a child reports pain or symptoms that suggest he or she needs more help, Pain Buddy delivers real-time alerts to the health care team.

Figure 1. Pain Buddy as he appears on-screen. SOURCE Fortier et.al. 2016 [55 p. 207]

For adult patients, Bickmore has many projects. Noteworthy is Hospital Buddy [33, p. 183-196] a companion to patients in hospital. The Buddy appears when called by the patients and relieves the isolation patients can feel in hospital. Future studies by this team are in palliative care, atrial fibrillation, spinal cord injury and CBT for Depression.

Bickmore et al. [49], also trialled a Virtual Discharge Nurse to improve the hospital discharge experience for patients, particularly those with poor medical literacy. An IVA as a discharge nurse was imbued with empathy and all of the knowledge needed to inform a patient about their hospital discharge and ongoing treatment of rehabilitation. 94% of users were satisfied with the Virtual discharge Nurse. Patients appreciated the amount of information and that there was no time limit to their interaction as they could ask questions to clarify points about the discharge. Empathic language was added to the scripts used in this study after collecting data from medical staff and videotaping mock discharge sessions carried out by discharge nurses. Also participants each received a tailored After “Hospital Care Plan” [49, p. 1256] in booklet form. This is a very important real-life example of an empathic IVA in action. The patients in this study had a mix of illnesses while the patients in the following study by Bickmore only had depressive symptoms.

Bickmore [69] followed the study above on patients with symptoms of depression. The same method of adding empathy was used along with the same kiosk as shown in Figure 2. These patients with depression were given the opportunity to have part of their discharge done by an empathic IVA. The empathic character talked about the activities patients should take part in after discharge. The IVA is part of a kiosk with a touch screen that can be taken to each bed. The IVA discharge nurse is equipped with all of the information a patient needs after leaving hospital including medication information, food to eat, exercise where necessary and tests or appointments that follow discharge.



Figure 2. Discharge Nurse Kiosk at patient's bedside SOURCE: Bickmore & Zhou [70, p. 290]

A working relationship was developed with patients preferring the interaction from a time rich IVA that they felt confident to ask questions and clarification. The IVA discharge nurse was used by 139 patients.

Richards et al. [10] created a web site with a virtual specialist to negate the long waiting list for specialist treatment. This specialist was designed to “capture patient history and provide tailored treatment advice[10, p. 1699]”. An empathic IVA was used and resulted in a 74% increase in adherence to treatment and 38% of users had treatment advice that led to them not needing to see a specialist in person.

There is an ongoing study “Examining the Frequency and Contribution [71, p. 2] of Foods Eaten Away From Home in the Diets of 18- to 30-Year-Old Australians Using Smartphone Dietary Assessment (MYMeals): Protocol for a Cross-Sectional Study” by Wellard Cole et.al., 2018. “The study will determine how frequently young adults purchase and consume foods away from home in the context of their entire diet, and what types of foods they are purchasing and consuming [71, p. 2].” A smartphone app, EaT has been developed to collect data [71, p. 5], this app has no IVA, and is used via a web-site interface. This study will be followed to determine the engagement of users without an IVA.

While testing the Clevertar Platform [72, pp. 107–112] for IVA development Luerssen and Hawke completed two studies using an IVA. “The larger of the two trials involves a Low-Intensity Cognitive Behavioural Therapy (LiCBT) coach that helps people with mild to moderate levels of anxiety or depression and promotes self-management of their condition [72, p. 112].” Of the 240 participants only 163 completed the course with 6 dropping out at the first screen, 10 did not wait for the 2 minute download of the IVA. 205 visited the IVA [72, p. 111]. In the second trial on patients with heart failure 37 of 39 registered patients completed the first session while 21 completed the complete course with the Companion [72, p. 111]. Dropout rates are an issue in conducting studies with real patients, as will be discussed in Chapter 4.

2.7 Building an Empathic Intelligent Virtual Agent

The empathic IVA is built with dialogue and facial expressions designed to reach the user. Below in 2.6.3 and 4 Gamification, Captology, Nudge Theory and Persuasive Technologies are considered. Social Power Dynamics [73, pp. 147–152] was considered but found to be not empathic. Richards et. Al., 2018 have studied different dialogues to build an empathic IVA in “Users’ perceptions of empathic dialogue cues: A data-driven approach to provide tailored empathy [74, pp. 35–47]”. This research has influenced the dialogue and character of the IIVA. As evidenced in the examples in the previous Section, overcoming health literacy barriers and building a relationship between the patient and health workers is important for encouraging adherence and has also been found to result in greater satisfaction for the patient [35, pp.610-615]. This relationship is often called a working or therapeutic alliance [76, p. 48] where there is a shared goal, shared plan and sense of caring and trust between the patient. Abdulrahman et. al., are also looking into building a therapeutic alliance with shared planning [77, pp. 335–336].

Other concepts are also relevant when considering how to improve patient adherence to treatment advice. We consider below building a working alliance and long-term empathic relationships, self-efficacy and empowerment, nudge theory and gamification.

2.7.1 Building a working alliance and long-term empathic relationship

Establishing and maintaining rapport over extended periods is important when dealing with chronic disease management. Bickmore et al. [8] have studied IVA-based approaches

need to build long-term empathic human-computer relationships . The IVA Laura [63, pp. 335–336] [79] was created to support long-term relationships as she assisted patients to use the FitTrack system. The FitTrack system was designed to get people exercising who had not exercised for some time. Two versions of Laura were built. One with empathy and one without. Empathic Laura was readily accepted by many users, but not all, for four weeks. The relationship building Laura had much the same results for increasing activity as the non-relational Laura. Bickmore et al. [8] created a computer interface using relational skills like empathy, social dialogue, as well as, non-verbal and other related behaviours that built and maintained a working relationship that improved physical activity over 30 days of interaction with the interface by 27 subjects. They reviewed studies in social psychology, sociolinguistics, communication and other social sciences to build a character who could build and maintain a relationship. To avoid their character being perceived as irritating like Microsoft’s failed character “Clippit [80, p. 12]”, they aimed to make Laura in FitTrack build a “trusting and empathic relationship [81].” A working-alliance was built and results were compared to an interface without empathic abilities where an alliance was not built. The experimental group continued to seek health information without prompting. Laura was so successful that subjects expressed a desire to continue using FitTrack after the 4-week trial.

2.7.2 Empowerment and Self-efficacy

These terms mean a lot to Australia’s marginalised [23] Indigenous population. Anything that can bring empowerment, enablement, as well as, emancipation, encouragement and confidence building is foreign to Australia’s First Peoples. Empowerment leads to gaining control of life by building self-efficacy with its self-worth, self-value and belief in ability.

“Patient empowerment through provision of a mobile application for medication reconciliation: a proof of concept study [64]” looked at an app to keep track of which medications a patient was taking so practitioner and patient would be on the same path. The results showed use of the MyMedication smartphone application improved adherence to the correct medication. The information on medication could be incorporated in any software we produced if deemed necessary [82]. That patients were empowered by a simple smartphone application is encouraging for my project.

Empowerment through education is possible and beneficial as endorsed in the statement: “Empowerment through gaining health literacy by intentional and unintentional medication non-adherence in hypertension while being illness specific [50, pp. 111–115]”. A study involving adults with Type 2 Diabetes showed that providing adults with knowledge of treatment and the condition was empowering and of great benefit [83]. This sample of 378 patients were given diabetic education which resulted in diabetes empowerment which was related to better diabetes knowledge, medication adherence and improved self-care behaviours. Emphasis on empowerment and self-efficacy is relevant to improve outcomes in the management of diabetes.

Ryan et al., did a comprehensive study to determine how much prescribed medication was being taken by testing the blood of over 800 patients. Even before that they revealed these frightening statistics, “Approximately 25% of patients do not pick up their medications after the initial prescription, and 40% do not refill prescriptions for medications prescribed for chronic conditions [80, p. 2/19 ”. Zullig et al., looked at what worked in medical adherence as their initial research showed less than 50% of patients with chronic disease were taking their medication [37, p. 2611]. They found that the following interventions helped and that there is a need for further research: patient knowledge, self-monitoring, personalised programs and a need to lower the cost of medication. The most pertinent finding for the IIVA came under their heading of Counselling and Accountability “Supportive counseling helps patients become and remain engaged in their health, provides a forum to address questions, and may build patients’ self-efficacy in their medication-taking behaviors [85, p. 2611]”.

2.7.3. Nudge Theory and Captology

Nudge Theory appeared first in the book “Nudge: Improving decisions about health, wealth, and happiness” [86] The publication was aimed at economists but has been developed into an approach to changing many behaviours by nudging people’s choices rather than demanding change. The ethics of this approach has been explored by J. S. Blumenthal-Barby & Hadley Burroughs in “Seeking Better Health Care Outcomes: The Ethics of Using the “Nudge” [87]. This paper examined the problems with governments and corporations using Nudge Theory to influence people for their own gain. This is not an issue with this IIVA.

Arno et al., [88, p. 1] used an:

adapted systematic review methodology to collect and consolidate results from current Nudge papers and to determine whether Nudge strategies were successful in changing adults' dietary choices for healthier ones. It was found that nudges resulted in an average 15.3 % increase in healthier dietary or nutritional choices, as measured by a change in frequency of healthy choices or a change in overall caloric consumption. All of the included studies were from wealthy nations, with a particular emphasis on the United States with 31 of 42 included experiments. Nudge holds promise as a public health strategy to combat obesity. More research is needed in varied settings, however, and future studies should aim to replicate previous results in more geographically and socioeconomically diverse countries. The dialogues created for the Aunt IIVA sought to encapsulate Nudge theory by offering manageable small steps rather than suggesting dramatic lifestyle changes.

Persuasive Technologies and Nudge Theory have been considered in the development of Aunt and her empathic dialogue. Persuasive Technologies also known as Captology include smartphones and methods, from T. J. Fogg [38, p. 1-6], in building applications to influence users of technology. Nudge theory has been used in studies to ethically influence patient behaviour by suggestion rather than badgering [39, p.1][40, p. 676].

2.7.4 Gamification and Megatrends

Changing behaviours is a form of re-education. Gamification and Megatrends are technology related concepts predicted to disrupt education and learning. To gamify the Indigenous IVA is not to turn it into entertainment by trivialising it. There are thousands of serious games used for educating at all levels including games to teach science inquiry [90], Water Management [91], and even a blood transfusion game [92]. Closely aligned to the goals of this project is the use of gamification to improve treatment adherence [93]. Richards and Caldwell did a thorough literature search on the reasons for previous failures in medication adherence, came up with a solution and trialled it on paediatric incontinence patients. Their findings were that “a therapeutic alliance was a key indicator in treatment success and factor in adherence.”[93] p. 69. Particularly important for my research are their findings that serious gamification is able to overcome poor literacy and that “A computer-based counsellor can provide a more acceptable alternative in situations where there is fear

of the consequences of disclosure, such as punishment or judgement, or the more likely situation that a human caregiver is not accessible.” [94, p. 69]

Finally, megatrends is a term used by Curtis Bonk [95, pp. 6–20] to describe the future of education using technology. Three trends are predicted:

“Megatrend #1: Learner Engagement: Learner engagement is a key concern across all educational sectors today. Fortunately, a wide array of learning technologies has arisen to offer new opportunities for fostering greater learner involvement and concerted effort in the learning process. As an example, nearly everyone reading this article has probably used a mobile device to learn something new that interested them in the past 24 hours, if not the past few minutes.[95, p. 8] ”

“Megatrend #2: Pervasive access: The next set of 10 learning and technology trends relates to our ability to increasingly access learning anyway and anytime. It is perhaps this notion of pervasive access to learning and education, more than anything else, that has educators, politicians, and learners adopting a more optimistic outlook when it comes to the human race.[95, p. 8] “

“Megatrend #3: Customisation: Finally, we are in the midst of an age filled with opportunities for the customisation and personalisation of learning. These are described below, with ideas about how to blend our learning pursuits as well as ideas about self-directed learning[95, p. 9]“

The relevance of megatrend to the development of the IIVA are engaging learners, the empathic nature of the IIVA, pervasive access, the smartphone goes where you go, taking the IIVA with you, and customisation, which comes under the ability to tailor the IVA for Australia’s First Peoples.

2.8 Chapter Summary and Conclusion

Considering the poor state of Australia’s First Peoples Health, the limited availability of health workers, cultural differences, introduced and lifestyle diseases, the need for empowerment and the possibility of using an IVA we think that an IIVA could become a Health Worker in your pocket. Someone you relate to who will work with you to improve your health. The need to improve the health of Australian Aboriginal and Torres Strait islander health is not in dispute. However, the methods are with many of them being out of

the control of the populace. The results of previous research suggest that an IIVA might work, making this research worth pursuing.

Chapter 3 Methodology

3.1 Personal Standpoint

I am Wiradjuri by birth and Gunninggu by marriage Man. I care for my people and see Aunt/Aunty as a valid tool to help with improving the health and well-being of all Aboriginal and Torres Strait Islander peoples.

3.2 Project Standpoint

Underpinning this project is the viewpoint that cultural sovereignty and ethical use of artificial intelligence can be used to improve the health of Australia's First Peoples in line with the Federal Government strategy known as Close The Gap. [8].

3.3 Approach and Method

3.3.1. Overview

Given the importance of family and community, an App that supports a humanlike social-relationship was desirable. For these reasons, we chose to create dialogues involving an Intelligent Virtual Agent. We chose to create dialogues about adherence to taking medication, exercise and healthy eating as they are common health-related issues faced by Australia's First Peoples, see Appendix A.

A smartphone application known as the Aunt App was developed. Initially we wanted to call the app Aunty as it sounds more friendly. However, after discussion with other indigenous people, the term Aunty was seen to be reserved as a name of respect for individuals who had earned that respect in their community. Using Aunty as the name of an App was seen as potentially disrespectful of this position and relationship. Calling the app Aunt was deemed to be acceptable. This App uses an avatar called Aunt designed to work alongside Aboriginal people to assist them to take prescribed medication, eat well and exercise. In order to test if the Aunt App can achieve its intended goals, an evaluation study was planned. Ethics approval was gained from Macquarie University's Human Research Ethics Committee for evaluation of the smartphone application with patients of a private medical clinic. See Appendix D for the ethics approval letter.

Due to concerns and controls around studies involving Australia's First Peoples populations, gaining approval from the Human Research Ethics Committee was a lengthy

process that took several months. Due to contacts that Wayne Charters has with communities in the Northern Territory at Gunbalanya and Ngukkur, originally the study planned to include participants from these community groups. However, this recruitment aspect of the ethics application had to be removed because only verbal approval from Elders in these communities was received and the committee required written approval. It became too difficult to identify who had the authority and interest to prepare written approvals. Also there had been support from Bungee Bidgel [96], this is the Aboriginal Health Clinic based at Hornsby Hospital and offering an Aboriginal led health service. The original ethics application, including an extensive protocol, included interviews with health care workers and indigenous community groups in Hornsby to help us codesign the App. However, despite numerous face to face meeting and phone calls, and verbal interest and agreement, after months of persisting it seemed overly hard and potentially harmful to the relationships to pursue getting written confirmation of their agreement. Also, since some individuals and groups were affiliated with a public hospital, it meant that we would have had to submit National Ethics Application Form (NEAF) ethics approval that was deemed to be overly time consuming and problematic since we were not ourselves part of a hospital or health organisation connected to the NEAF system. We also sought the guidance of Walanga Muru, the Department of Indigenous Studies at Macquarie University in design of the App as well as for preparation of the ethics application. Thus, it was not possible to go through a formal process of codesign involving focus groups, surveys or interviews. Instead, design of the app relied on anecdotal comments from those who had been contacted and expressed interest and from my personal experience and the opinions of my family and friends.

The Stakeholders Section describes the parties involved in the design, development and evaluation of the smartphone application. The Design Considerations Section presents the issues, questions and constraints that shaped the design and implementation of the App. The Materials Section describes the technology used to create the dialogues and the App. The Dialogues Section describes the dialogues and how they were created, including the process, source of information and structure. The Evaluation Section describes the design of the study to collect data concerning the usability and efficacy of the Aunt App.

3.3.2 Method

The smartphone application is available for patients to download. A control group was not considered necessary due to the specific aim of only reaching Australia's First Peoples taking medication and the possibility that a control group would add complexity and not provide any additional relevant information. The following evaluation trial was planned:

Trial Duration: 30 Days

Participant Inclusion Criteria:

Australia's First Peoples

Taking prescribed medication

Patients of Karalta General Practice

Patients will be sent 3 reminders on their phone per week to remind them to check in with Aunt. Reminders will be discussed with patients so that the patients can choose the time for the 3 reminders each week that are deemed necessary to ascertain usage and any other reminders that patients choose. In an effort to empower patients to manage themselves, they will be encouraged to set the reminders themselves.

3.3.3 The Stakeholders

Patients of Karalta General Practice – these are our main stakeholders and the target of the intervention to improve adherence and health outcomes.

Dr Hayley Charters – General Practitioner who grew up in an Aboriginal Community and whose medical practise has been used to recruit participants in this research and advise on cultural differences, especially considering remote communities.

Sue Pinckham - Aboriginal Cultural Advisor - Macquarie University and the group of Australia's First Peoples post-graduate students at - Macquarie University have been consulted throughout the project.

Wayne Charters, MRes candidate and author of this thesis, and Professor Deborah Richards, supervisor of this project, both in the [Department of Computing](#) at Macquarie University and involved in the design, development and evaluation of this project.

3.3.4 The Design Considerations

Design was conducted following a process of meeting with stakeholders each week to discuss, discount and add to the design of the IIVA. It was decided that the IIVA will be given an empathic nature that is both understanding and positive as has been used in the Pain Buddy project [67] and also in the Dr Evie project led by Prof. Richards. The IIVA has been

chosen to relate to Australia's First Peoples and will send usage data to a Macquarie University secure server when the user's phone is in range of the internet.

A number of design questions, issues and constraints were identified as follows:

A female character was chosen because currently most Aboriginal health workers are women. Men as carers are not common and were considered unlikely to engage empathically the way a woman would. Research into this was done by discussion with Aboriginal people and medical staff, as well as a literature search that confirmed women are seen as expressing more empathic behaviours [97, p. 200].

Australia's First Peoples cultural safety will always be an essential ingredient of the project, so this was always in the forefront of discussions. Any culturally unsafe or offensive comment or character could lead to failure. This mainly consists of avoiding any terminology that would offend and giving as much power to each user to develop the App by accepting feedback and allowing for reminders to be controlled by the user.

Aunty became Aunt after discussions with the post graduate Australia's First Peoples cohort at Macquarie University. There was some difference of opinion regarding the acceptability of either name. After further discussions involving a wider group, Aunt and Aunty were both considered acceptable, particularly when Dr Liesa Clague became the voice of Aunt/Aunty. She was an experienced Australia's First Peoples nurse before joining the medical faculty at Macquarie University. Nevertheless, we kept the name as Aunt App to avoid confusion with multiple names and in case others had similar reservations to those voiced by the postgraduate group. Below Aunt is used interchangeably to refer to the Aunt App or the Aunt Avatar.

The choice of application platforms became an availability issue with most Aboriginal people not being wealthy. Thus, Android smartphones were considered as first choice followed by iPhones. The development process allowed us to create an application for each type of smart phone. The choice of smartphones came about because few Aboriginal people have computers or tablets while mobile phone use is very high. Shaw found that: "mobile phones are heavily used in these communities, albeit in unique and unusual ways that may be difficult to comprehend beneath 'top-down' measurements " [59, pp. 480-483]. The concept of Persuasive Technologies [37, pp.1-6] was an ongoing consideration which confirmed the choice to use mobile phones as the delivery platform.

3.3.5 The Materials

To create Aunt, there were two main elements: creation of the dialogues and creation of the avatar. Dialogues were entered into an MS Excel .csv file that allowed a dialogue tree to be generated based on current and next states. Then a tool created by Prof Richards' research assistant Meredith Taylor was used to import the .csv file and generate C# code that would be used by the Unity 3D game engine to run Aunt. The design of the dialogues is presented in the next subSection.

Mixamo was used to create a number of avatar models. Due to their success in reaching indigenous audiences, the creation of an avatar that resembled the Yarramundi puppet characters [99] shown in Figure 3 below was considered. However, the idea was abandoned because the characters were childlike and did not appear to be sufficiently authoritative for the more serious, health-related subject matter discussed in the Aunt App.



Figure 3. Yarramundi Characters SOURCE:[99]

Aspects of the avatar models that were considered included hairstyle as shown in the set of models in Figure 4. The models were shown to the stakeholders and model 3 was selected.



Figure 4. Possible hair styles. SOURCE: Meredith Porte



Figure 5. Cartoon Like Character SOURCE Meredith Porte

Also, while developing the avatar the concept of the Uncanny Valley [100] was investigated. The concept was first proposed by Masahiro Mori in 1970 and explains that unnerving feeling that occurs when as Mori describes: “I have noticed that, in climbing toward the goal of making robots appear like a human, our affinity for them increases until we come to a valley

which I call the uncanny valley.” It is a place where you begin to realise that the robot or avatar does not act fully human, in the worst case it is like dealing with a psychopath who does not recognise or display emotion. This had led to a more cartoon-caricature like avatar than those first developed, as shown in Figure 5.

The final character is shown in figure 6 below.



Figure 6. Final version of Aunt SOURCE: Meredith Porte

This face of Aunt was developed from photographs and models of Aboriginal women, as well as, meetings with the cultural advisor at MQ and ATSI people.

To access the Aunt App, the user clicks on her face on their phone as shown in Figure 7.

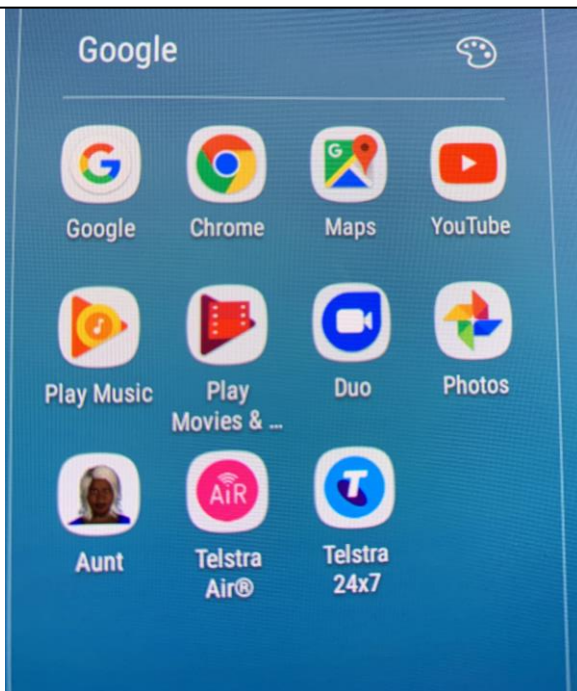


Figure 7. Aunt Appears as an Application on a Smartphone Screen

Aunt waits for the participant to press START (Figure 8):

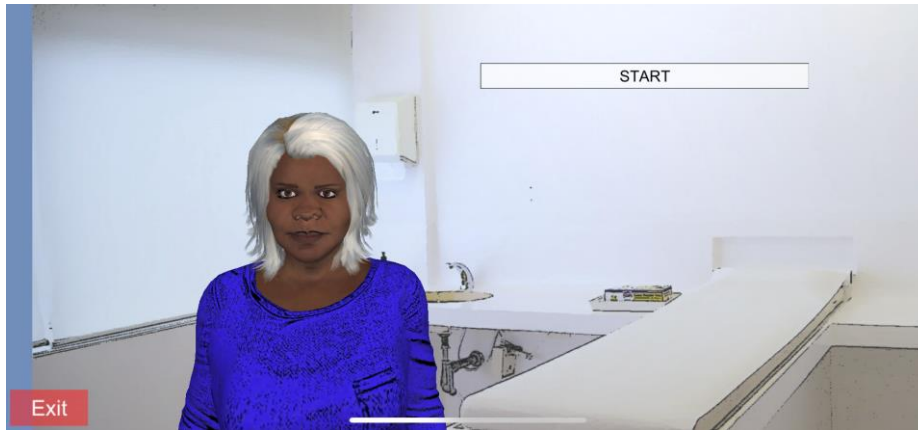


Figure 8. Aunt Opening Screen

Then Aunt introduces herself (Figure 9):



Figure 9. Aunt Introduction

After the introduction, Aunt asks how you are going, based on the day of the week (Figure 10).

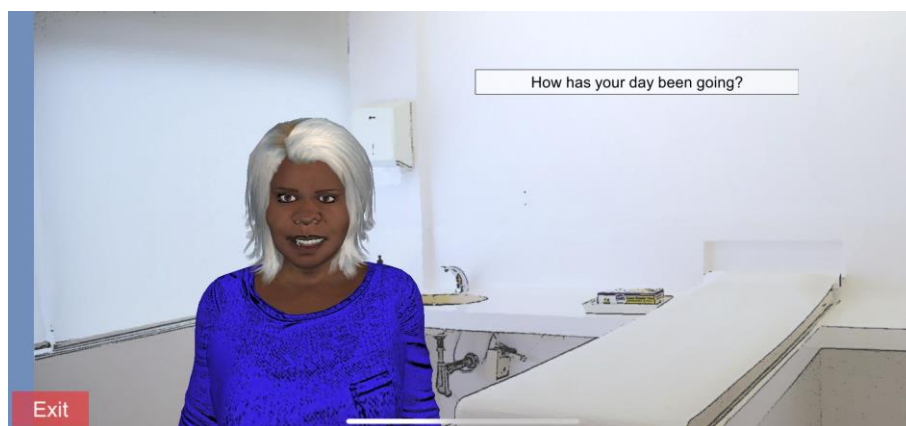


Figure 10. Aunt Empathic Chat

Participants then have a chance to respond (Figure 11):



Figure 11. Aunt Providing Choices for Feedback

From here, if the choice is “not so good”, Aunt will answer (Figure 12):



Figure 12. Aunt Responding in Audio and Text

The user chooses an option to navigate between the main functions covering medication, food and exercise (Figure 13):



Figure 13. Aunt Seeking Direction

The Aunt App also provided links to online resources such as the Good Tucker website [101], see Uncle Jimmy in Figure 14. As shown in Figure 15, the Good Tucker App allows



users to scan barcodes on packaged food. The Good tucker App then gives a thumbs up for good food or in the example of Sustagen, a thumbs down. If the food is not recorded or is a meal from a takeaway or café Good Tucker gives the option of a Food search. The convenience of a hand held 24/7 App is very useful to Australia's First Peoples.

Figure 14 Good Tucker Icon for Smartphones

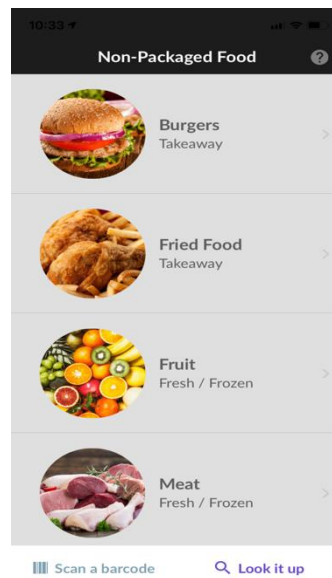
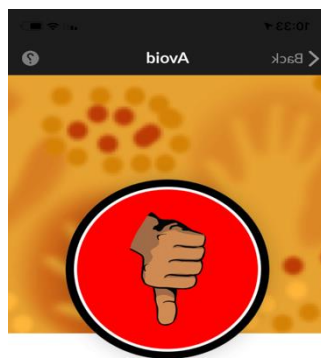


Figure 15 Screenshots from the Good Tucker App.

3.3.6 Dialogue Design and Creation

It was necessary to design and create dialogues for this project because very few researchers have released the dialogues they have used, and it was necessary to use language that was familiar and easily understood by Australia's First Peoples participants. Appendix A includes the full dialogue showing the responses of the agent and user.

The length of interactions and topics were considered to determine the structure and content of the dialogues. Short interactions were chosen for this research as people are being

prompted or nudged to help themselves. This decision is supported by the recent findings of Bickmore [102, pp. 38–44] that report that short interactions were preferred/responded to more frequently.

The possibility of just using hints about good behaviours was discussed but building a working relationship is a goal so short conversations that are more like a discussion were chosen. Humanlike conversations involving everyday language and turn-taking also seek to overcome health literacy barriers [49]. Given that health outcomes are primarily affected by medication, diet and exercise, the topics of the dialogues included discussions around taking medication as well as knowledge of healthy eating and exercise benefits. I, Wayne Charters, have taught healthy eating and exercise in the past and I drew on this knowledge as well as information from government sources [62, pp. 3-33].

Drop down lists with further information were considered but lack of time and resources precluded this. Participant responses were obtained through clicking on answer options provided by the Aunt App. The style or tone of the dialogues was influenced by previous work that shows the importance of empowering and empathic dialogues. [63].

Nudge Theory [39, p.1] was a natural fit for conversational dialogue used in the Aunt App. A confrontational style was the first thing ruled out because a working or therapeutic alliance was the desired aim when we asked the questions like - What conversations are useful? When and how should conversations be triggered? These discussions have led to the current dialogues in Appendix A.

3.4 Patient Recruitment and Support

Patients identifying as Aboriginal or Torres Strait Islander were emailed by Karalta General Practice followed by a text message to their mobile phone making them aware of the study. A poster explaining the research and inviting patients to participate was displayed on the medical practice's digital notice board. The email and poster advised patients to ask the doctor for more information.

If a patient requested further information, a nurse or doctor was allocated to the patient to work through the consent form and the pre-study introductory questionnaire, then download the application to run through how it worked. This staff member can also suggest reminders be put into the phone should the patient wish to use them. This is followed by questions on what the initial thoughts of the user were about the application. Completion of a quality of life survey finished the initial meeting with the staff member. Patients are

encouraged to contact the surgery should they have any medical difficulties and to contact the researcher with any technical problems.

3.5 Data Collection

The consent form and pre and post surveys were created using Qualtrics Research Survey software. In addition, usage of the application was recorded to a secure Macquarie University database to allow analysis of which options were taken and by which (anonymous) participants. It was hoped that this would provide us with usage data showing frequency of interaction, when interaction was most common and what conversations were most frequently used.

The initial questionnaire, in Appendix B, establishes the gender, age, Aboriginality and computer experience of the user. Analysis of this data may show trends in usage for particular demographics particularly when compared to exit surveys. Data collected from the rapport questionnaire, in Appendix C, would give us knowledge about the character and dialogue used by Aunt as well as guide future development of IVA's, both non-Indigenous and Indigenous. There is also a before and after quality of life questionnaire that could be taken by users, the AQoL-4D, found here http://www.aqol.com.au/documents/AQoL-4D/AQoL-4D_Data_Collection_Copy.pdf. This is one of the standardised questionnaires produced and made available by the Centre for Health Economics at Monash University [104][105].

3.6 Chapter Conclusion/Summary

The methodology included a variety of processes necessary to build the application with cultural sensitivity and empathy by careful, consultative design. The data collection process only aimed to collect the most relevant data and gained ethics approval from Macquarie University.

Chapter 4 Results & Discussion

4.1 Introduction

The Aunt Application was offered to 33 Aboriginal and Torres Islander patients of Karalta General Practice. Ten patients agreed to take part. Ten answered that they would not like to take part. thirteen made no commitment. One patient downloaded and tested the application.

Of the nine remaining patients who indicated that they would like to trial Aunt all preferred to have the information sent to them by email or text. This was done, however, none of these nine did the first survey or participated in any way.

The responses of the one participating patient are shown in Section 4.2. In Section 4.3 the possible barriers to the use of Aunt are discussed. These include Australia's First Peoples being over-researched, and the marginalisation of Australia's First Peoples since 1788.

4.2 Demographics

The one patient who took up the offer a downloaded Aunt was a 60-year-old woman. She used the Aunt App once and from her responses did not need Aunt as she had no trouble remembering to take her medication, eat well and exercise. For an unknown reason, after Patient 11 took the consent form online, she did not answer any of the surveys. Table 2 shows the Dialogue Tree as accessed and answered by Patient 11. Red shows what Aunt says, black shows the options offered, blue shows the option selected by the patient.

START

Hello, before we start, I am Aunt and I am here to work alongside you to improve your health.

I'm very happy to meet you and hope you'll find our sessions together worthwhile.

How has your day been going?

Not so good.

It's going well.

It's great.

I would like to talk about my medication

I would like to talk about food and exercise

I don't want to talk about anything today. Good bye.

These tips are that you drink water and get up and move: if you are sitting then stand,

if you are standing then walk, if you are walking go faster. Do you think you could try these tips?

Yes

No

That's great!

OK every drink does not need to be water, but increasing the amount of water you drink instead of sugary soft drinks is better for you. While moving more is much better for you.

Now that you are hopefully moving more could we try exercising every day and eating smaller portions at meal times? Just like if you were collecting Bush Tucker. Do you think you could eat smaller portions and move more?

Yes, I can do that.

No, I don't think I can.

That is good news I hope it helps.

Are you aware that it is good to eat 5 servings of veggies and 2 pieces of fruit every day?

Yes

No

How many veggies are you eating? Do you think you could eat 5 lots of veggies each day?

No, never

Sometimes I eat 5 lots of veggies a day

Most days I will eat 5 lots of veggies a day

Good job, try to eat veggies most days. I suppose you know you can use frozen veggies if that's easier than using fresh veggies.

What about fruit?

I don't usually eat any fruit

I have one or two pieces of fruit most days

I have at least two pieces of fruit most days

Why is that?

That's good

Most fruits have sugar in them. So it might be good to replace some fruit with vegetables because they don't contain sugar.

Are you aware that you can eat well and exercise at the same time?

Yes I am

Tell me how

One way to do this is to walk to the shop to buy your fruit and veggies.

I can do that

It's too far

Okay it's all good.

Fantastic. You will see results soon.

There is a deadly app you can use to find out which foods are good to eat. It is called Good Tucker and is great for our mob. Would you like to download it?

Yes

No

That's great.

Is there anything else you want to talk about?

I want to talk more about my medication

I want to talk about food and exercise

Nothing for now. Good bye.

Table 2 Dialogue Tree for Patient 11

4.3 Review of the Aunt Application

The application works on Android and iPhone. This was no small feat and required writing and recording dialogues with consultation. Sections 3.3.3 to 3.3.6 cover this process. The use of software included MS Excel and Unity3D, as well as, specific software for the Android and iPhone builds.

In designing the application an extensive body of literature was consulted to identify a number of key issues and features including: IVAfor health [106], Cultural Differences and needs [29][107], Empowerment [108], Self-efficacy [109], Building a working alliance and long-term empathic relationship [81][77], Nudge Theory [86], Captology [110], Gamification [111] and Megatrends [95] were all considered.

4.4 Efforts to aid Participation and Data Collection

As described in the methodology chapter, this study sought to collect data to understand whether the Aunt App was well received and if it was helpful in encouraging adherence. Testing by the team showed that it was functional and correctly collecting the data. Paper-based versions of surveys were provided to the clinic in case patients preferred to enter their consent and data on paper rather than online. A computer at the Karalta Medical Practice was set up to conveniently enable online data entry. To capture usage data, if the patient was not online, the data would be uploaded next time they were connected to the internet. This did not required any action on their part.

When the Australian Aboriginal patients of the targeted medical practice said they could not attend the clinic to load the application an information sheet and instructions was sent

out. Please note that in this medical practice it is common for Australian Aboriginal patients to make 3 or 4 appointments before seeing a doctor.

This is the final instruction sheet sent to those patients who expressed a desire to take part in the research:

Hi,
Just sending this again because it is designed to download to phones.
Here is another link to the phone apps: This is another access point, but you need to be added by email.

https://mqoutlook-my.sharepoint.com/personal/meredith_porte_mq_edu_au/_layouts/15/onedrive.aspx?e=5%3a065c95d9df01447f9b18fe967737fe43&at=9&id=%2fpersonal%2fmeredith_porte_mq_edu_au%2fDocuments%2fAuntStandaloneBuilds&FolderCTID=0x012000513C71F0C6938F4A9715BAA041D3CDD4

Please download and try for a few days and I will send another questionnaire in two weeks.
Some information did not get to all of the testers, so if you have any technical problems please call 0448 247285 or email wayne.charters@hdr.mq.edu.au
Thank you for helping to test this phone app.
Please go to

https://mqedu.qualtrics.com/jfe/form/SV_1Y5qq7l76vsfW5L

[Here you fill in a consent form and a survey](#)

[Please create an ID by typing in the last 3 digits of your mobile phone number then and fill in the consent form. This number will also be the one you use once to access Aunt on your phone.](#)

[After filling in the consent form please download Aunt to your phone and have a look at how it works.\(see links for Android and iPhone below\).](#)

[After a quick look at Aunt we would like you to continue the survey.](#)

[We recommend that you choose a suitable time when you would like to be reminded to use Aunt and/or take medication then add a reminder or alarm to your phone.](#)

Or download from here.

Android download
https://drive.google.com/drive/folders/19EV_5TCZjFCcv4P1NoQ5OwUCzEnPcpan?usp=sharing

iPhone download – you will need your Apple ID for this
<https://testflight.apple.com/join/Zj2jrG2D>

After 30 days a review survey will be sent for you to fill in.

This is another access point, but you will need to send your email address to be added to the list of users before you can gain access.

https://mqoutlook-my.sharepoint.com/personal/meredith_porte_mq_edu_au/_layouts/15/onedrive.aspx?e=5%3a065c95d9df01447f9b18fe967737fe43&at=9&id=%2fpersonal%2fmeredith_porte_mq_edu_au%2fDocuments%2fAuntStandaloneBuilds&FolderCTID=0x012000513C71F0C6938F4A9715BAA041D3CDD4

Cheers,

Wayne

When this failed to get a response, reasons for this failure were sought. The reasons are many. Suggested reasons are offered in 4.5 below with a possible solution in Section 4.7 where it is suggested that there is a need for people to own the application and be involved in its development.

4.5. Barriers to Use of Aunt

This Section discusses the possible barriers to the uptake of Aunt by patients. We believe that Aunt failed to be taken up by indigenous patients for the same reasons that interventions conducted as part of the Close the Gap campaign also failed to be adopted by Australia's First Peoples [48]. All of the barriers found in this research mirror the reasons for the failure of the Close The Gap campaign [112] [48]. Close the Gap programs have not been able to address the ongoing impact of generations of poor health and education nor the reasons for these issues. This is why we have not seen significant change in behaviours or in outcomes, despite good intentions and allocation of resources.

As shown in Section 4.4 development of an application might work best done in local communities. The limitation to this, along with ethics approval, is the software needed to create an application like Aunt without a few staff in a remote area. The application would need to be simplified technically while expanding to include recorded Australian First Peoples languages. The Clevertar Platform [72, pp. 107–112] is a likely candidate for these builds in remote areas. Building the application in communities could lead to a different Avatar, definitely in voice but also in look and possibly gender. Another possible approach comes from Zhang and Bickmore's work on shared patient-agent decision making that describes the use of a virtual coach [113]. An IVA is used to coach patients through decisions with information and logic. The shared decision making appealed to patients and could well overcome some of the difficulties felt by marginalised Australians.

Empowerment of Australia's First Peoples to use such an application as Aunt was underestimated. This lack of empowerment most likely comes from the marginalisation of this group [23]. The concept of empowerment to take control of health and medication is

valid as can be seen in Bickmore et al. [64], Werumeus et al. [82], Nafradi et al. [50, pp. 111–115] and Hernandez-Tejada et al. [83].

Previous research has shown that IVAs have connected with patients to improve health outcomes. Building a therapeutic alliance has shown benefits those with illness the Pain Buddy trials by Fortier et al. [67] with childhood cancer patients was particularly successful. Bickmore et al. [70] produced the Virtual Discharge Nurse who was trusted to give discharge information to low health literacy patients in a Boston hospital. Richards et al. [114], [77] and [9] have looked at the therapeutic alliance.

Bickmore [115] found that simple and short interactions have worked with low health literacy populations. This concept has also been applied to the Aunt App.

The paper above by Bickmore [115] also used a smartphone as the platform. Experience of this research team has found that a smartphone is the first data technology taken up by Australia's First Peoples and will continue to be the primary target for Aunt and following applications, while tablets and computers may be added at any time. Wellard-Cole et al. [71] used smartphones to study the eating habits of younger Australian adults because this group all have smartphones and often eat out in the early morning hours away from a computer. A review of the situation of Australia's First Peoples position in Australian society is required to gain a complete understanding of the situation of Australia's First Peoples. One of these is summed up in a statement by the journalist Stand Grant "I'm tired of seeing us as an anthropological curiosity to be wrapped in possum skin and welcome you to our country.[116, p. 5]" The gist of his article is that too little has been done to address the problems imposed on Australia's First peoples since the British came and that Australia's first Peoples are tired of being examined and researched. A quick Macquarie University Multi Search on "Australian Aboriginal Research" gives 118,216 results.

The concept of marginalisation encompasses the problems faced by Australia's first peoples so this topic will be explored first, followed by the resultant, poor health, family and societal dysfunction as well as the lack of empowerment that may have led to the lack of interest in using Aunt.

4.5.1 Marginalisation and Exhaustion

Australia's First Nations Peoples have been marginalised since 1788, that is, pushed to the margins of society.

“It is widely agreed that Aboriginal and Torres Strait Islander people are the most disadvantaged population category in [Australia](#). They are excluded in their limited capacity to participate in the decision making of the wider society and control their own and the mainstream social and cultural environment. They are disadvantaged in terms of educational achievement, [health](#), employment, and quality and adequacy of housing, amongst other dimensions. Their marginality was established in the first 100 years of settlement, with the dislocation, [segregation](#), neglect and structural marginalisation of the colonial period. It was confirmed in the 'indifferent' inclusion and [assimilation](#) of the early national period McGregor in [23, p. 124]”

It is possible that a smartphone application like Aunt might be seen as scraps thrown to placate a marginalised group in society. This was never the intention of the designers.

There is an exhaustion at being examined, studied and having behaviour recorded and then having nothing done about it. On successive trips to the Arnhem Land town of Gunbalanya we were greeted with surprise that we returned to complete a project. People in this town were not expecting us to complete anything and were accustomed to promised government programs not happening or not being completed.

4.5.2. Closing the Health and Well Being Gap

Tom Calma suggested closing the gap in 2005 [117] implementation began in 2008. Ten years later: “Aboriginal leader Professor Tom Calma says political instability has held back progress on Close the Gap over the last decade [48].” While Australian governments show interest and some commitment to closing the gap they are not in government with the same committed ministers to achieve goals. This is a drain on Australia’s First peoples who have shown surprise when Macquarie University has committed to long term projects in remote areas. An example is the Bush University [118] in Eastern Arnhem Land in Australia’s Northern Territory. The Bush University was established with the local people who had come to trust a researcher who had developed trust for over ten years. It is possible that building a relationship over years may be needed to see the acceptance of Aunt.

The Close the Gap campaign highlights the issues of health and wellbeing for Australia’s First Peoples but has done little to improve these issues. There is a tiredness and frustration with politicians talking the talk and not walking the walk.

4.5.3. Family Dysfunction

All families are complex and multifaceted and are faced with issues such as poverty, child maltreatment, substance use, and stability. These things have an impact on the development of children [119].

The issues for Australian Aboriginal families are compounded by the struggle to overcome the negative effects of the country's colonial past [120], traumas associated with the 'Stolen Generation' [121], and the fact that even this generation of Australia's First Peoples children is haunted by the legacy of the history of forceful removal of children from the homes of Australia's First Peoples families [122]. These factors above have led to inter-generational trauma [123].

4.5.4 Societal Dysfunction

The marginalisation of Australia's First Peoples has taken away the natural way of life that existed before 1788 and has denied Australia's First Peoples a place in society. Thus, we have incarceration rates of Australia's First Peoples well above those Australians who are not part of these First Peoples. The large number and overrepresentation of Australian First Nations people in care [124], and in juvenile or senior justice systems [22], are symptoms of the marginalisation and are signs of societal dysfunction. Delfabbro et al. studied the child system in South Australia and found that:

“As of January 2007, 4410 children born in 1991 had been the subject of at least one child protection notification (22.5% of the birth cohort). Ten percent of these children were recorded as being Aboriginal or Torres Strait Islander. This is an over- representation of ATSI children in the notified population of approximately three times. [124, p. 1420]“

This team found that:

“In conclusion, these analyses, like those undertaken in the US using similar techniques, suggest that certain minority groups appear to have significantly different levels of contact with child protection services. The extent to which this reflects broader patterns of disadvantage, systematic differences in treatment by the system or other factors remains an important topic for ongoing investigation [124, p. 1424].”

These are not the findings one would expect for a group functioning optimally in any society.

Bickmore et. Al., have looked at “Managing Chronic Conditions with a Smartphone-based Conversational Virtual Agent [115] “and found that human like animated agents

produced better results than text alone and non-animated agents [115, p. 2]. They also found that simple, short conversations helped with users who had poor health literacy. This particular study included a heart monitor built into the phone which eliminated manual entry of health data [99, p. 3]. This confirms that the design of Aunt was on track.

As was found in the trial with the Clevertar Platform uptake and completion of beneficial applications to improve health can be difficult. Gaining data of why people do not engage would be difficult to collect from people who do not engage.

4.7 Solutions/ Future

The results and feedback lead to the conclusion that a restorative approach is needed. Not only do Australia's First Peoples need a relationship with the IIVA they need input into what the IIVA says. This approach may invigorate the character. At the suggestion of a group of Aboriginal Students from the Roper River region of the Northern Territory, a study into whether an IIVA could be developed "on country" (within the community) with stakeholders is an interesting way to look at further research. Input to and ownership of the chosen character could result in increased usage. This group of healthy students who were not on medication also thought retaining the IIVA's empathic nature might allow local people to develop their own version of Aunt, possibly in the local language and with English text/subtitles. These students were graduates of the Bush University [118] and had varied skills in language and technology.

Povey in "Acceptability of mental health apps for Aboriginal and Torres Strait Islander Australians: a qualitative study 2015." found that "Specific adaptations, such as local production, culturally relevant content and graphics, a purposeful journey, clear navigation, meaningful language, options to assist people with language differences, offline use and password protection may aid uptake [73, p.23]."

This is encouraging for further research to be done in remote communities.

Chapter 5 Conclusion & Future Work

This final chapter first provides an overview of the work conducted in this thesis. Section 5.1 Contains an overview of the project. The research question posed in chapter one is discussed in Section 5.2. In Section 5.3 limitations and future work are presented. Final remarks are given in Section 5.4.

5.1 Project overview

This project used an original and novel approach to build an *Indigenous IVA* designed to improve the adherence to prescribed medication in Australia's First Peoples using a smartphone application. The IIVA was given the name Aunt to ease the connection with Australia's First Peoples. The dialogues were designed to be culturally sensitive and empathic. The face of the IIVA is that of an Australian Aboriginal woman and the voice used is that of an Aboriginal nurse who now lectures at Macquarie University. The research into this IIVA was exhaustive and showed the need for improvement in Australia's First Peoples health and that current programs were not progressing at target rates. Many studies of IVAs in health situations showed the high probability that this innovative use of artificial intelligence would work. This research included successful use of smartphone to provide access to an IVA at any time and place. Aunt was built and trialled.

5.2 Answering the Research Question

This Masters' project sought to contribute towards finding solutions to improve the health of Australia's First Peoples Australian and thereby contributing towards "closing the gap". The research question is: Can a virtual human that is empathic and culturally safe help Australia's First Peoples adhere to prescribed medication, healthy eating and exercise through a smartphone application?

The answer is that we do not know yet. It was found that of the thirty-three targeted people only one used the application and as that person did not have a problem taking medication of being healthy, they did not continue using the application. Ongoing discussion with Australian First Peoples has led to possible new directions for this research. These discussions have continued to affirm the poor state of the health of Australia's First Peoples and the need for further development of a culturally safe approach to this work.

5.3 Limitations

One limitation is the small number of people the Aunt Application was offered to. The way around this is to seek ethics approval for use in any government funded clinic. This would allow us to offer the Aunt App to thousands of potential users. The possible barriers to the target group not taking up the app, see Section 4.5, are definite limitations and may be overcome by building a similar application insitu. See 4.5 for further discussion.

5.4 Final Remarks

This project started with a vision to Close The Gap between Australia's First Peoples and Australia's general population through a smartphone application. The vision has not vanished with a poor uptake of the Aunt Application. Aunt is alive and looking for new ways to connect to her people. This poor uptake has spurred on the desire to seek a larger group of prospective users and in the upcoming iterations Aunt will include groups of Australia's First Peoples in her development. This Section of our population is spread throughout the country and in remote and rural areas many speak their original language. Access to participants in health research is difficult and more so in this population who are marginalised and distrusting of government institutions. So new iterations will be based on the one size does not fit all. The solution to the ongoing development of an IIVA could mean an IIVA who speaks an Aboriginal Language and has text in English. These iterations of an IIVA may be developed in conjunction with Local Aboriginal Land Councils and Aboriginal Community Health Centres.

In conclusion future steps are to seek an ethics approval to reach a wider target group and find software that will allow the application to be built in any community with input and ownership by that community.

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Appendix A: Dialogues Page 1

Current State	Next State	Utterance
Start	pre_greeting	START
pre_greeting	re_pre_greeting	Hello, before we start, I am Aunt and I am here to work alongside you to improve your health. When you are ready to start please press the button BEGIN.
re_pre_greeting	firsttime	BEGIN
Firsttime	firsttime_greeting	
firsttime_greeting	whichday	I'm very happy to meet you and hope you'll find our sessions together worthwhile.
Firsttime	nexttime_greeting	
nexttime_greeting	whichday	This is Aunty again. I am so glad you have chosen to talk today.
Whichday	greeting2_Mon	
Whichday	greeting2_Tue_We	
Whichday	greeting2_Tue_We	
Whichday	greeting2_Thu_Fri	
Whichday	greeting2_Sat_Sun	
greeting2_Mon	re_greeting2_Mon	How was your weekend?
re_greeting2_Mon	con_weekend_sorr	It was not that good.
re_greeting2_Mon	con_happy	It was good.
re_greeting2_Mon	con_happy	It was great.
greeting2_Tue_Wed_	re_greeting2_Tue_	How has your day been going?
re_greeting2_Tue_W	con_day_sorry	Not so good.
re_greeting2_Tue_W	con_happy	It's going well.
re_greeting2_Tue_W	con_happy	It's great.
greeting2_Tue_Wed_	re_greeting2_Tue_	How is your day?
re_greeting2_Tue_W	con_happy	It was great.
re_greeting2_Tue_W	con_happy	It was good.
re_greeting2_Tue_W	con_eve_sorry	It was not that good.
greeting2_Thu_Fri	conv1	I hope you have something nice planned for your weekend.
greeting2_Sat_Sun	re_greeting2_Sat_S	How was your weekend?
re_greeting2_Sat_Su	con_happy	It's great.
re_greeting2_Sat_Su	con_happy	It's going well.
re_greeting2_Sat_Su	con_weekend_sorr	Not so good.
con_happy	conv1	That's good to hear.
con_weekend_sorry1	conv1	Sorry your weekend wasn't great; I hope I can help you can start feeling better.
con_day_sorry	conv1	Sorry your day isn't going well, I hope you start feeling better.
con_eve_sorry	conv1	Sorry you had a bad day, I hope you start feeling better.
con_weekend_sorry2	conv1	Sorry your weekend isn't great, I hope you start feeling better.
conv1	re_conv1	I am here to encourage you to take your medication.
re_conv1	conv2	Sounds good

re_conv1	conv2	I am not sure that I need help.
conv2	re_conv2	Firstly do you understand that the medication you have been given is important for you get better?
re_conv2	conv2_other	Maybe, can you explain more?
re_conv2	conv2_other	No
re_conv2	conv3	Yes
conv2_other	conv3	Your medicine will make positive changes to your health so stopping it suddenly or missing your medicine can be dangerous. If you do not understand why you have been given
conv3	re_conv3	Let's check some basic things about taking your medicine. Do you have your medication available today?
re_conv3	conv3_yes	Yes
re_conv3	conv3_no	No
conv3_no	conv4	If you have a repeat prescription you can take it to the chemist to get it filled. If you have run out of prescriptions contact the doctor's clinic and ask if you could be given you a
conv3_yes	conv4	Great
conv4	re_conv4	Are you sure of the times when you need to take the medicine?
re_conv4	conv4_no	No
re_conv4	conv4_yes	Yes
conv4_yes	conv5	Okay that is great
conv4_no	conv5	OK, check the instructions of the bottle or package . If they are not clear ask for help from the nurse practitioner or doctor.
conv5	re_conv5	Do you need to take medicine now?
re_conv5	conv5_yes	Yes
re_conv5	conv5_no	No
conv5_yes	conv6	Great, I'll wait for you.
conv5_no	conv6	Taking it the next time it is due is important.
conv6	re_conv6	Is there anything else about your medication that you are worried about?
re_conv6	conv6_no	Not really
re_conv6	conv6_yes	I have some worries
conv6_no	conv7	Good.
conv6_yes	conv7	If you are not sure about the medicine you are taking it should be printed on the package, bottle or an information sheet the doctor or nurse practitioner or chemist gave you.
conv7_no	conv99	We all forget sometimes to take our medicine we should work out a way of reminding you to take it at the right time. You could try setting reminders on your phone or computer.
conv7	re_conv7	Are you remembering to take your medicine each time it is due?
re_conv7	conv7_no	No.
re_conv7	conv7_yes	Yes
conv7_yes	conv99	Way to go.
conv99	re_conv98	Is there anything else you want to talk about?
re_conv98	re_conv99	Medication
re_conv98	conv15	Food and exercise
re_conv99	conv8	I feel embarrassed to take my medicine
re_conv99	conv9	I am too tired caring for others
re_conv99	conv10	Medication makes me feel sick
re_conv99	conv11	Don't have the medication with me.
re_conv99	conv12	I feel too down

re_conv99	conv13	I don't feel like I need my medication
re_conv99	conv14	My medications are too confusing
conv8	re_conv8	Sometimes taking medicine in front of people can be uncomfortable. Would this be a concern for you?
re_conv8	conv8_no	No
re_conv8	conv8_yes	Yes
conv8_yes	conv99	If you are uncomfortable remember to find a safe and comfortable place to take your medicine away from people. Being comfortable is important.
conv8_no	conv99	That's good.
re_conv9	conv9_no	No
conv9	re_conv9	I want to talk about when you are taking care of another family member. This is hard work and can stop you taking care of yourself. Is this a concern for you?
re_conv9	conv9_yes	Yes
conv9_no	conv99	OK
conv9_yes	conv99	Finding someone who can help is important. It allows you to have a break so you can take care of you, allowing you to take your medicine as well as rest.
conv10	re_conv10	Have you ever felt sick, when you cannot take your medicine you have been given? Sick to the stomach?
re_conv10	conv10_no	No
re_conv10	conv10_yes	Yes
conv10_no	conv99	OK
conv10_yes	conv99	If you have ever vomited or thrown up when you are taking medicine this might be a good time to check the instructions on the packet. It is important to call the clinic if you are
conv11	re_conv11	When you are away from home have you missed your medication? How often may this happen?
re_conv11	conv11_no	Often
		Not very often
re_conv11	conv11_yes	Never
conv11_no	conv99	OK
conv11_yes	conv99	It is always a good idea to carry your medicine with you when you are away from home or when you have left your medicine at home.
conv12	re_conv12	Do you ever feel really down and do not want to take your medication?
re_conv12	conv12_no	No
re_conv12	conv12_yes	Yes
conv12_no	conv99	Alright.
conv12_yes	conv99	This can be a problem for lots of people. I am available to help you remember to take your medicine.
conv13	re_conv13	Have you felt well and do not need the medicine anymore?
re_conv13	conv13_no	No
re_conv13	conv13_yes	Yes
conv13_no	conv14	Fair enough.
conv13_yes	conv14	You may be right however it is good to complete your course of medicine. Most importantly if you have an infection.
conv14	re_conv14	Do you ever think that you have too much medicine and it is confusing to take?
re_conv14	conv14_no	No
re_conv14	conv14_yes	Yes
conv14_no	conv99	Alright.
conv14_yes	conv99	Some people get their Chemist to set up a Webster Pack. They cost a little bit more but show you when to take the tablet. You can also buy cheap pill organizers from chemist or
conv15	re_conv15	Now that you have lots of information about taking medication I would like to talk to you about eating well and exercising. Eating and exercise go together because the more you

re_conv15	conv15_no	No
re_conv15	conv15_yes	Yes
conv15_no	conv16	That is OK if you do not feel well enough to start. When you do I am here to help.
conv15_yes	conv16	That is so good. There is no better time to start increasing your activity and healthy eating than now. My first suggestion is to drink a bottle of water and take lots of walks.
conv16	re_conv16	The aim of increasing exercise is to be healthy and be able to do half an hour each day. While you are working on this it is fine to have a day or two between walks. Changing
re_conv16	conv16_no	No
re_conv16	conv16_yes	Yes
conv16_no	conv17	Working on being healthy is normal.
conv16_yes	conv17	That is good. I will give you more tips next time.
conv17	re_conv17	These tips are that you drink water and get up and move: if you are sitting then stand, if you are standing then walk, if you are walking go faster. Do you think you could try these
re_conv17	conv17_no	No
re_conv17	conv17_yes	Yes
conv17_no	conv18	OK every drink does not need to be water but increasing the amount of water you drink instead of sugary soft drinks is better for you. While moving more is much better for you.
conv17_yes	conv18	Great you may be my best patient ever.
conv18	re_conv18	Now that you are hopefully moving more you could we try exercise every day and eating smaller portions at meal times. Just like if you were collecting Bush Tucker. Do you
re_conv18	conv18_no	No
re_conv18	conv18_yes	Yes
conv18_no	conv19	OK, I have lots of tips. I will find one that works for you.
conv18_yes	conv19	That is good news I hope it helps.
conv19	re_conv19	Are you aware that it is good to eat 5 servings of veggies and 2 pieces of fruit every day?
re_conv19	conv19a	No
re_conv19	conv19a	Yes
conv19a	re_conv19a	How many veggies are you eating? Do you think you could eat 5 lots of veggies each day?
re_conv19a	conv19a_no	No
re_conv19a	conv19a_mostly	Sometimes
re_conv19a	conv19a_yes	Most days
conv19a_yes	conv19b	That's fantastic! Well done. I suppose you know you can use frozen veggies if that is easier than using fresh veggies.
conv19a_mostly	conv19b	Good job, try to eat veggies most days. I suppose you know you can use frozen veggies if that's easier than using fresh veggies.
conv19a_no	conv19b	Try to work out how you can add more veggies to your meals. You know you can use frozen veggies if that's easier than using fresh ones.
conv19b	re_conv19b	What about fruit?
re_conv19b	conv19b_none	I don't usually eat any fruit
re_conv19b	conv19b_mostly	I mostly have fruit juice
re_conv19b	conv19b_oneOrTwo	I have one or two pieces of fruit most days
re_conv19b	conv19b_overtwo	I have at least two pieces of fruit most days
conv19b_none	conv19c	Why is that?
conv19b_mostly	conv19c	There can be a lot of sugar in soft drinks. It's better to eat a piece of fruit.
conv19b_oneOrTwo	conv19c	That's good
conv19b_overtwo	conv19c	Most fruits have sugar in them. So it might be good to replace some fruit with vegetables because they don't contain sugar.
conv19c	re_conv19c	Are you aware that you can eat well and exercise at the same time?

re_conv19c	conv19_d	Tell me
conv19_d	re_conv19d	One way to do this is to walk to the shop to buy your fruit and veggies?
re_conv19d	conv19d_yes	I can do that
re_conv19d	conv19d_no	It's too far
conv19d_no	conv20	Okay it's all good.
conv19d_yes	conv20	Fantastic. You will see results soon.
conv20	re_conv20	There is a deadly app you can use to find out which foods are good to eat. It is called Good Tucker and is great for our mob. Would you like to download it?
re_conv20	conv20_no	No
re_conv20	conv20_yes	Yes
conv20_no	conv21	That's great.
conv20_yes	conv21	Go on just try it.
conv21	finish	If you would like to track the number of steps there are many apps and devices you can use, some apps are free to download to your phone.
Finish	finish	Bye

Appendix B: Data Collection Questionnaire Page 6

Tick the box that best describes your situation

Question 1

- ☐ I am Aboriginal.
- ☐ I am Torres Strait Islander
- ☐ I am both Aboriginal and Torres Strait Islander.
- ☐ I am neither Aboriginal nor Torres Strait Islander.

Question 2

- ☐ I am taking prescription drugs.
- ☐ I am not taking prescription drugs.

Question 3

- ☐ I am male.
- ☐ I am female
- ☐ I do not identify as either male nor female.

Question 4

- ☐ I am 18 years of age or over.
- ☐ I am not 18 years of age or over.

Question 5

- ☐ I have a smartphone.
- ☐ I do not have a smartphone.

Question 6

- ☐ I play computer games.
- ☐ I do not play computer games.

Appendix C: Rapport Questionnaire

Please select your level of agreement/disagreement with each of the following statements in the 5-point Likert Scales form strongly agree to strongly disagree.

1. I liked Aunt.
2. Aunt was weird.
3. I felt I had a connection with Aunt
4. I think that Aunt and I understood each other.
5. I would like to have someone like Aunt help me.
6. I would recommend Aunt to a friend.
7. I felt uncomfortable during the sessions.
8. I felt embarrassed during the sessions.
9. I had difficulty understanding Aunt.
10. I don't like the way she looks.
11. It would be difficult to meet and talk with Aunt.
12. Communicating with Aunt felt natural.
13. Interacting with Aunt was believable.
14. Aunt was not empathic towards me.
15. Aunt was warm and caring.
16. I felt that Aunt was interested in what she was doing.
17. I felt I was able to engage with Aunt.
18. I think being advised by Aunt would be impossible
19. Seeing Aunt helped me to focus nonmedication, eating good food and exercising.
20. Following Aunt's advice helped me focus on my health.

Appendix D: Ethics Approval Letter Page 7

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8 December 2017

Dear Professor Richards,
Reference No: 5201700728

Title: Australia's First Peoples Intelligent Virtual Agent (IIVA)

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)).

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted by:
• Macquarie University

This research meets the requirements set out in the National Statement on Ethical Conduct in Human Research (2007 – Updated May 2015) (the National Statement).

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the National Statement, which is available at the following website:
<http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research>

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol and associated documents must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely

Dr Karolyn White Director, Research Ethics & Integrity, Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice.

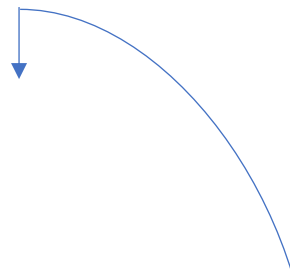
Skin Groups as a Barrier to Communication

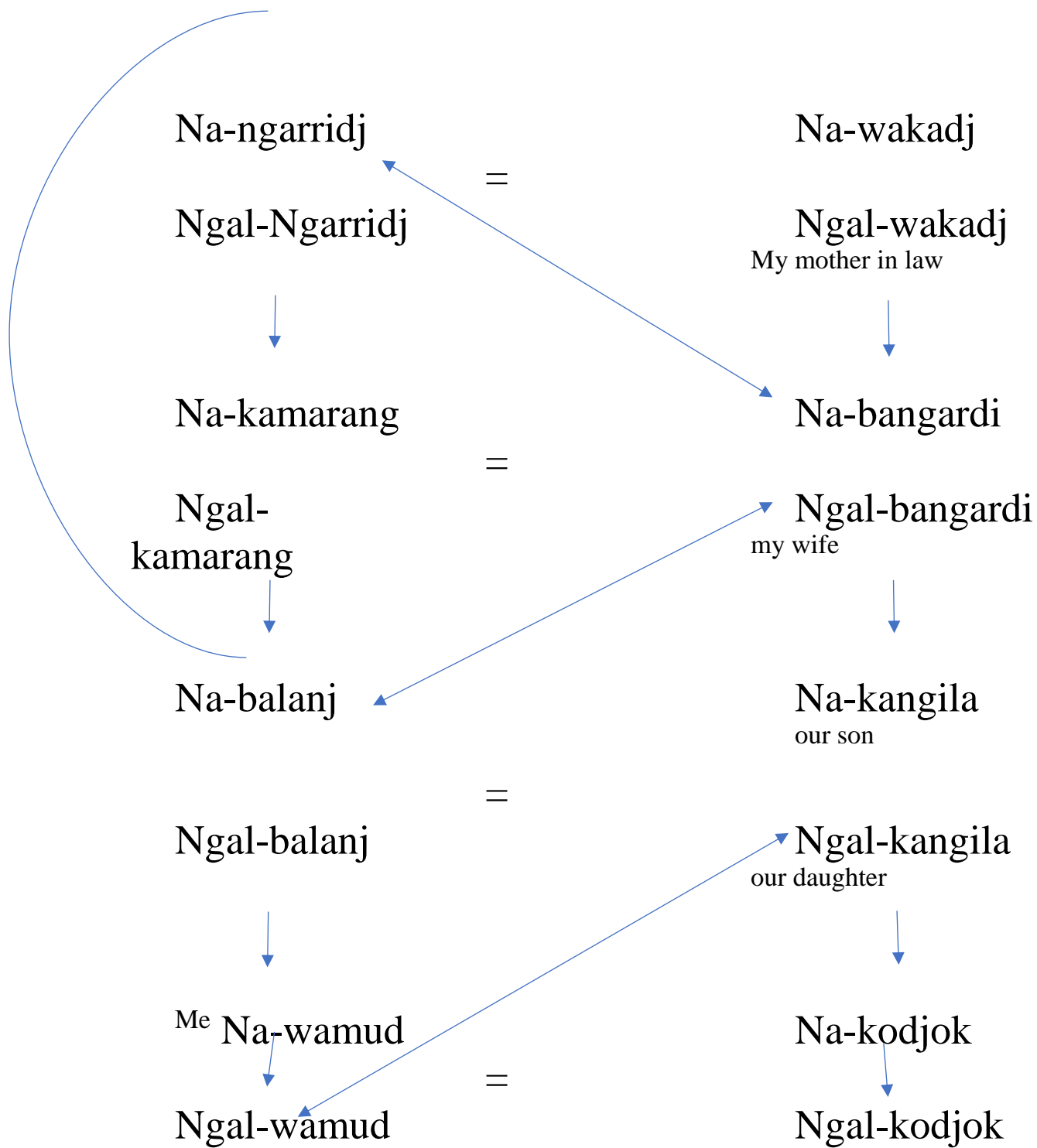
In some Australia’s First Peoples Australian communities your assigned skin group or skin name has powerful control over your relationships. In Kunbarllanjnja I am of the Na-wamud skin group. My wife is of the Ngal-Bangardi skin group. There is only one other skin group that I could have married into and the skin group of my mother in law and her sisters I cannot talk to.

As you can imagine if I were a health worker sent to help my mother in law this would not work because I am not allowed in the same room as her or to talk to her. These skin groups cannot just be changed. They are the basis of communication in the society built on relationships as opposed to any given or perceived status that might arise in a European society and they handed down from the mother or allocated to people who live in the town long enough to earn respect and therefore a place in that society. This is a consideration ignored by the Western medical system in Australia. The empathic agent used in this research can bypass this problem.

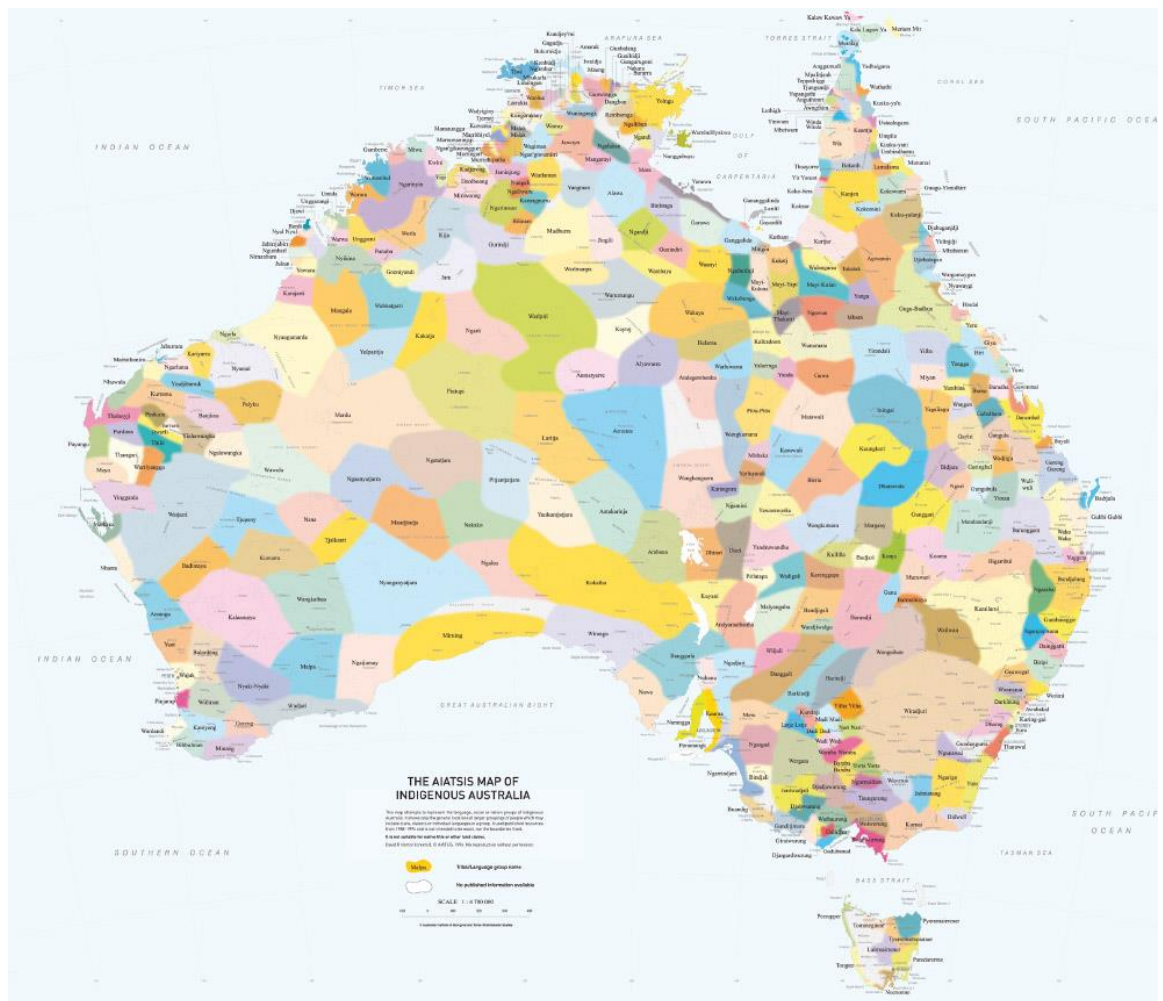
The table below shows the all-important skin groups and family connections.
Skin groups are passed down from the mother as shown by the vertical arrows.
Female is Ngal
Male is Na

The = and ↔ show possible marriage choices. If there is no such connection, you cannot marry into that skin group.





Appendix F: Australian Aboriginal Nations Map Page 10



Appendix G: Technology Use by Australian's First Nations Peoples Page 11

An extract is provided below of a table that summarises some of the technology identified.

Paper title	Authors / Year	Topic/aim	Technology	Who	Methodology
Ontology based intercultural patient practitioner assistive communications from qualitative gap analysis	Wongthongtham, Pornpit Forbes, David: 2014	Enhance communication between medical staff and patients	Database	Indigenous and non-Indigenous people with relevant cultural expertise and extended family relationships. Among these advisers are health care practitioners, academics, trainers, Aboriginal education researchers and workshop attendees.	Collection and localization of data concepts, their attributes and individual instances were gathered from an Aboriginal trainee nurse focus group and from a qualitative gap analysis (QGA) of 130 criteria-selected sources of literature.
Mediating Tragedy: Facebook, Aboriginal Peoples and Suicide	Carson, Bronwyn Farrelly, Terri Frazer, Ryan Borthwick, Fiona: 2015	Suicide Prevention	Social Media	8 Aboriginal communities across Australia Ages 18-60	Qualitative data collected with advice from Elders Data from Survey Monkey
Developing a database for Australian Indigenous kinship terminology: the AustKin project	Dousset, Laurent Hendery, Rachel Bowern, Claire Koch, Harold McConnell, Patrick: 2010	Kinship	Database	Indigenous and non-Indigenous academics and university students	Data collected from publications and Aboriginal Communities was added to a database using a modular, object-oriented incremental programming
Experiencing Indigenous Knowledge Online as a Community Narrative	Kutay, Cat Mooney, Janet Riley, Lynette Howard-Wagner, Deirdre: 2012	Indigenous knowledge learning through serious games	Online learning	Indigenous and non-Indigenous academics and university students	This is ongoing research incorporating knowledge from USYD, USYD Koori Centre, UNSW
An evaluation of the telehealth facilitation of diabetes and cardiovascular care in remote Australian Indigenous communities: - protocol for the telehealth eye and associated medical services network [TEAMNet] project, a pre-post study design	Brazionis, Laima Jenkins, Alicia Keech, Anthony Ryan, Chris Bursell, Sven-Erik: 2017	Diabetes treatment	Tablets/iPads	600 Indigenous Australians with type 2 diabetes recruited from 3 primary care facilities in remote NT	1. Baseline retinal imaging [as a real-time patient education/engagement tool and telehealth screening strategy]. 2. A lifestyle survey tool administered at = 6-months. 3. At = 6- and 18-months, an electronic cardiovascular disease and diabetes decision-support tool based on current guidelines in the Standard Treatment Manual of the Central Australian Rural Practitioner's Association to generate clinical recommendations. 4. Mobile tablet technology developed to enhance participant engagement in self-management.
Determinants and gaps in Preventive care Delivery for indigenous Australians: a cross-sectional analysis	Baillie, Christopher Matthews, Veronica Baillie, Jodie Burgess, Paul Copley, Kerry Kennedy, Catherine Moore, Liz Larkins, Sarah Thompson, Sandra Baillie, Ross Stewart: 2016	Preventing Chronic Disease	Database	3,623 healthy Indigenous clients ages 15-64, from 101 health centres. P 1	Summary statistics were used to describe the delivery of each service item across jurisdictions. Multilevel regression models were used to quantify the variation in service delivery attributable to health centre and client level factors and to identify factors associated with higher quality care. P 1
Probes and prototypes: a participatory action research approach to co-design	Madden, Dianna Cadet-James, Yvonne Atkinson, Ian Watkin Lui, Felecia: 2014	Culturally Appropriate Design	Web-site	12 women of the the Gugu Badhun language group whose traditional country is in rural northwest Queensland, Australia, including the present-day town of Greenvale (population 250) and environs.	Technology Probes where the participants themselves define the problem and the actions to be taken. This is in direct contrast to much research conducted 'on' indigenous people that views them as the problem rather than the economic environments and social realities which they inhabit.
Acceptability of Mental Health Apps for Aboriginal and Torres Strait Islander Australians: A Qualitative Study	Povey, Josie Mills, Patj Patj Janama Robert Dingwall, Kylie Maree Lowell, Anne Singer, Judy Rotumah, Darlene Bennett-Levy, James Nagel, Tricia: 2016	Mental Health	Smartphone Applications	This study aimed to explore Aboriginal and Torres Strait Islander community members' experiences of using two culturally responsive e-mental health apps and identify factors that influence the acceptability of these approaches.	A series of three 3-hour focus groups with nine Aboriginal and Torres Strait Islander community members.
Complexity and the science of implementation in healthIT—Knowledge gaps and future visions	Abbott, Patricia A. Foster, Joanne Marin, Helmar de Fatima Dykes, Patricia C.: 2014	IT implementation: determining and solving barriers	eHealth	Feedback came from Indigenous and non-Indigenous health care workers in remote WA who implemented and used the eHealth record system	A literature review resulted in the identification of six health IT related implementation-mentation best practices which were subsequently debated and clarified by participants attending the NI2012 Research Post Conference held in Montreal in the summer of 2012. Using the framework for implementation research (CFIR) to guide their application, the six best practices were applied to two distinct health IT implementation studies to assess their applicability.
"Like Drawing Into Sand": Acceptability, Feasibility, and Appropriateness of a New e-Mental Health Resource for Service Providers Working With Aboriginal and Torres Strait Islander People	Dingwall, Kylie M. Puska, Stefanie Sweet, Michelle Nagel, Tricia: 2015	Mental Health Resource Development	Smartphone Application	Health care workers in NT reported on the use of the App with clients in remote areas.	Eleven semi-structured interviews were conducted with 15 service providers and managers from a range of rural and remote primary health care service settings in the Northern Territory. All participants were given the resource to trial for at least 1 month before being interviewed about perceived barriers and enablers, acceptability, and feasibility.