Deepening understandings of rehabilitation in the Cook Islands: An action research study with Te Vaerua Rehabilitation Service

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Abstract

This study is a qualitative research project with Te Vaerua, a community based rehabilitation service in the Cook Islands, that had the aim of establishing a culturally-congruent framework for rehabilitation services provided by the organisation. It employed participatory action research (PAR) methods, drawing on data from focus groups, interviews and observations to look at the meanings and values of rehabilitation held by Te Vaerua. The participants included individuals associated with Te Vaerua: Board Members, therapists, funders, and the researcher, who was also employed as a physiotherapist during the data collection phase of August to October 2013.

Thematic analysis identified three key emergent values: 1) **rehabilitation is available**, 2) **rehabilitation has heart**, and 3) **rehabilitation gives hope**, with an overarching concept of 'people are the most important thing: ***Ko te iti tangata te mea maata*****'**. In addition, Te Vaerua identified action points which were considered important to achieve a service that matched their values: the need for accurate data collection, the importance of service visibility, the importance of service links with other island-based providers and a strategic plan that aligns values with measurable goals in order to show success. Furthermore, this thesis provides guidance for other projects within the Pacific when establishing a new service: the importance of taking time to build relationships within the community and to offer contributions and reciprocal generosity as a basis for relationship building and service visibility.

PAR as a research framework is explored in the context of community based rehabilitation (CBR), with discussion of the alignment evident between the underlying principles of PAR and CBR. This suggests that PAR is a good fit for qualitative research in these settings. Existing literature discusses challenges for both CBR and

PAR related to gaining participation and the tension of reliance on overseas ‘experts’ to manage such projects. This study discusses these challenges as they arose in this research journey and reflects on three learnings related to the use of PAR: the need for flexibility to gain shared control, the importance of a research question that engages the participants, and early identification of key informants or project champions.

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To Te Vaerua. I have such respect for your determination to make something amazing for the people with disabilities in your community, and the way you have created a rehabilitation service that is useful and meaningful. I have been blessed to be part of the story.

To Nadine, Eric, Marie, Graeme, Nicky and Toke and your families. You accepted me and my family and offered love and hospitality. You are treasures.

And to Pareina Mokoroa Tangata. You are an inspiration.

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List of abbreviations

BMF	Biweko Millennium Framework
CICS	Cook Islands Community Service
CRPD	Convention on the Rights of Persons with Disabilities
DAT	Disability Action Team
DPO	Disabled Persons Organisation
ICF	International Classification of Functioning, Disability and Health
ICIDH	International Classification of Impairment, Disability and Handicaps
MOH	Ministry of Health
NGO	Non-governmental agency
WHO	World Health Organisation

Glossary of Maori Kuki 'Airani terms

Maori Kuki 'Airani (Cook Island Maori) terms and phrases have been used in this thesis. It is accepted that the Rarotongan dialect is widely considered to be Maori Kuki 'Airani, but it is noted that there are several variations and dialects throughout the islands. Terms, words or phrases and interpretations are used as spoken by the participants.

While Maori Kuki 'Airani shares some similarity in structure, sounds and words to New Zealand Māori, it is a distinct, independent language. Some words such as ‘tangata’ (people) have the same meaning in both languages. Other words are similar in each language: ‘vaka’ compared to ‘waka’ (boat); ‘kia orana’ compared with ‘kia ora’ (greetings), ‘are’ compared with ‘whare’ (house). Yet other words are distinctly different, such as ‘maata’ compared with ‘nui’ (big). Some publications represent New Zealand Māori words with macrons over some vowels. Similar sounds in Cook Islands Maori are expressed with a double vowel.

Words used in this thesis:

Koha	gift or contribution (NZ Maori)
Manu’iri	Visitor
Ora’anga	health
Pa enua	Outer Islands: Cook Islands excluding Rarotonga
Pakipaki-tai	Disabled person
pati pati	Wanting for oneself
va’ine	Woman
vaka	boat/canoe

Chapter 1: Introduction

1.1 Research question

The purpose of this study was to explore how rehabilitation is understood within the Te Vaerua in the Cook Islands, with the aim of establishing a culturally-congruent framework for rehabilitation services provided by the organisation. The study was designed to address the following questions:

1) What meanings and values are attributed to clinical rehabilitation by Cook Islanders, and how is rehabilitation understood within this cultural context?
2) How could rehabilitation be provided in a way that is most consistent with these meanings and values?

1.2 Background

In 2009/2010 I had the opportunity to work in Rarotonga – the most populous land mass in the Cook Islands; an island nation in the South Pacific. My role was to help establish rehabilitation services to those in the community with need for support. I was employed by a community-based organisation called Te Vaerua Community Rehabilitation Inc. (Te Vaerua). Te Vaerua was established by a small group of women, who took the initiative to secure funding for a rehabilitation non-government organisation (NGO), initially as a response to the high morbidity and mortality following stroke on the island. This group had visions of a clinic-based multidisciplinary service, but in 2009 the clinic space was not yet established, and there was only funding for one therapy: 20 hours of physiotherapy per week, providing hospital based services and community visits. This is the service I was employed to provide.

Prior to Te Vaerua, a Rehabilitation Service had not previously been provided in Rarotonga, where health care usually consisted of primary and secondary care, with limited tertiary services. While I came to Rarotonga with 14 years of clinical experience as a rehabilitation physiotherapist, I had no experience of working in a small community, being an ethnic minority in another country, being a visiting ‘specialist’, or even working outside a team structure. I also soon realised that the only alternative to me offering a service was that no service would be provided – so this lead me to work with populations of people who I would normally have referred on to other health care providers – children with autism for instance.

I was very aware that my understanding of the human health and wellbeing was incomplete, and that there would be other viewpoints, remedies and treatments that fell outside my bio-psychosocial approach that were equally valid and potentially successful within this context. I was unprepared however for the cultural differences in health view, and how this influenced the expectations that individuals had for recovery. Why were otherwise healthy young men who sustained a structural physical injury, such as a ruptured knee ligament, apparently prepared to accept a prognosis of long term disabling impairment rather than engage in treatment to assist them with this problem? Why did family members accept elderly relatives home after a stroke with no expectation of recovery or support? What were the cultural expectations of rehabilitation in Rarotonga, and could I fit my Western healthcare skill set into this world view in order to provide a useful service? I assumed that the previous lack of rehabilitation services on the island was likely to have been a significant reason that families had low expectation of health outcome, but was this the only factor?

These types of questions challenged me on a daily basis. How did the interplay of cultural norms, environment, political situation, family expectations, health beliefs, patient expectations, health funding, primary health service capacity and me as a foreign, non-Maori-speaking physiotherapist fit together? How could I personally make sense of what the Cook Islanders on Rarotonga recognised as rehabilitation in order to offer physiotherapy services that would meet their needs and expectations?

As none of the Te Vaerua Board members were health professionals, we did not share a common ‘healthcare language’ to discuss what Te Vaerua considered core ideas regarding provision of rehabilitation, and therefore what they wanted to achieve, and how this could best be offered to the community. This led to some challenges for me in understanding what my role was, and how best to support patients and families towards a goal and process that they may have understood in a completely different way.

Te Vaerua was (and currently is) reliant on employing rehabilitation therapists from overseas, predominantly from New Zealand, to provide expertise and services to their community. Without an explicit framework to express the values and principles underlying the rehabilitation that Te Vaerua wishes to provide in Rarotonga, the organisation was reliant on a Western-trained therapist to be sensitive and responsive to the local need.

While I believed my initial time in Rarotonga had resulted in some very positive outcomes (for patients and families, for Te Vaerua as an organisation, and for my own professional and personal development) I felt it would be have been valuable to have a more in-depth understanding of the scope of the practice of rehabilitation in Rarotonga, what this scope should be, and in particular an understanding of how Te Vaerua viewed my role as a physiotherapist. As a result of my experiences, I felt it would be valuable to explore what rehabilitation could look like for Te Vaerua in the Cook Islands setting, and hopefully offer the Te Vaerua therapists of the future a framework on which to base expectations and understandings in their work with the Cook Islands people. This intention informed the subject of my Master's research project. As I wanted to include the people of Te Vaerua in the direction and interpretation of this research (rather than risk further imposing Western perspectives into a Cook Islands context) I chose to explore participatory action research (PAR) as my research methodology. This thesis describes the background to the work, my implementation of a PAR research design, and the findings and outcomes that eventuated.

In this thesis 'Western' is used to describe mainstream medicine as practiced in English speaking European first world countries. It is acknowledged that this definition is limited and that within 'Western' medical practice there are many healthcare approaches and models. All presume a bio-medical tradition.

1.3 Thesis structure

Chapter 2 of this thesis will frame the research, introducing the Cook Islands and Te Vaerua and exploring concepts related to rehabilitation and disability. Chapter 3 provides an overview of the methodological framework and methods utilised in the current study. The results from the research are collated in Chapter 4, with emerging themes described in detail. Finally, Chapter 5 discusses these results in light of the existing published literature, and makes recommendations for future research.

Chapter 2: Background

2.1 Situating the study: The Cook Islands

Geography

The Cook Islands are a group of 15 small, sparsely populated, isolated islands spread over a large geographical area of the Pacific Ocean. Each island is unique in geography, flora, culture and local language idiom. Similarly to other subsistence communities, in recent history there has been a demographic shift of working age adults to urban areas within the Cook Islands, but also significantly to New Zealand and Australia. Rarotonga is the most populous island within the nation and is the administrative hub. Other islands are collectively termed *Pa Enua* (the 'outer islands').

There are language and custom differences between islands, most marked between the Southern Group (eight islands including Rarotonga) and the geographically isolated Northern Group (seven islands). Travel to the Northern Cook Islands is by charter plane or boat (four hour flight or five day boat trip), meaning that access to healthcare and other offshore supplies and services are limited in these places.

Language and ethnicity of the Cook Islands population

Cook Islands Maori have tribal affiliations, with a *vaka* (literally 'canoe') defining the geographical and family area. Rarotonga has three vaka: *Takitumu*, *Te Au-o-Tonga* and *Puaikura*. Traditionally, islanders will identify with their home island and vaka more strongly than being 'Cook Island' (MacPherson, 2001; Mitaera & Laing, 1994).

Ethnically, most of the resident population identifies as full (81%) or part (7%) Cook Islands Maori, with the remaining 12% comprised of New Zealand or Australian nationals (5%) other Pacific nationalities, of which Fijian (2%) is the largest individual group, people from the Philippines (1.3%) being a second largest, and the remainder comprised of people from the rest of the world. Of those living on the Cook Islands, 84% speak Maori; and a similar number can speak English (Ministry of Finance and Economic Management, 2012a). Of the total population, Cook Islands Maori (*Kuki Airani*) is spoken by 72% people. Kuki Airani is distinct from New Zealand Maori, but like other Polynesian languages shares language roots, and some words. The ability to speak Cook Islands Maori is seen as an important aspect of ‘being Maori’ (Kauraka, 2003, p. 337).

Income and educational background

A significant proportion of the Cook Islands income is from family and organisation remittances from overseas, particularly New Zealand (Crocombe, 1992). Local income differs on each island, with more isolated islands relying to a greater degree on subsistence living. For example in the northern group, 80% of adults earn under $10,000 per annum, while in Rarotonga the number is 40.5% (Central Policy and Planning Office, 2010). Literacy and education mirrors this statistic with 65% of the isolated Northern Islands having no secondary education, compared with 35% of Rarotongan-based adults (Ministry of Finance and Economic Management, 2012a).

Socio-political relationship between Cook Islands and New Zealand

New Zealand took on responsibility for administering the Cook Islands from Britain in 1901. The Cook Islands became self-governing with free association with New Zealand in 1965, meaning it administers its own affairs but nationals are New Zealand citizens and have open access to work and residency in New Zealand

(Crocombe, 1992; Short, 1987). Nuie is the only other Pacific Island to share this unique relationship.[1] In 1973, New Zealand affirmed the right of the Cook Islands people to 'make their own laws and control their own constitution' (Short, 1987, p. 180). This change meant that the Cook Islands could coordinate their own foreign affairs. In 1981, the nation's Constitution was amended so that the Cook Islands Legislative Assembly became the Cook Islands Parliament, and the Premier became Prime Minister (Short, 1987). Since 1981, the Cook Islands have assumed full constitutional capacity to conduct its own external relations and have entered many international arrangements, including involvement with the South Pacific Forum, the United Nations Economic and Social Commission for Asia and the Pacific, and the Asian Development Bank (Short, 1987).

Transnationalism and the migration trend towards New Zealand

The majority of the Cook Islands resident population lives in Rarotonga, but most Cook Islanders are based off shore in New Zealand and Australia (Statistics New Zealand Tatauranga Aotearoa, 2014). New Zealand citizenship in 1965, the advent of regular air travel in the mid-1970s, and national financial collapse in 1996 led to large emigration waves from the Cook Islands to New Zealand and Australia (Statistics Office, 2011). While there has been a significant decline in permanent residency from the Cook Islands, there has also been a significant urban shift that occurs in the outer islands towards Rarotonga in search of education, work and opportunities (Futter-Puati, 2010; Ministry of Finance and Economic Management, 2012a). This shift causes a 'major issue [that] increases the challenge of providing core services to outer islands' (New Zealand Ministry of Foreign Affairs, 2014, pp. para 2, Development Challenges).

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[1] Nuie established a free association agreement with New Zealand on 19 October 1974. Tokelau has been moving towards free association status, but remains a dependent state of New Zealand (Fraenkel, 2012).

Urbanisation of indigenous populations, where it leads to residential instability is considered to be a risk factor for reduction in wellness (King, Smith, & Gracey, 2009).

As New Zealand citizens, Cook Islanders are able to travel between Rarotonga and Auckland without visa restrictions. Health services are provided in New Zealand, and many with either sufficient funds, and/or family based in Auckland, will send children to further their education. This ‘transnationalism’ (multiple ties with home and host societies) is a normalised behaviour for Cook Islands people (Futter-Puati, 2010) which influences family structures and expectations, economic health, and social communities and activities such as volunteerism.

Migration is considered economically important as the Cook Islands have ‘resource constraint and [pressures from] environmental change’ (Bedford & Hugo, 2012, p. 31) which inhibit sustainable population growth. As a result there is a high value on personal and social remittances from overseas based workers (R. Brown, Leeves, & Prayaga, 2012). However, there are also strong disadvantages arising from this economic development in terms of loss of the capacity of skilled labour, seen in ‘key professional areas such as health but also in teaching, construction, technical fields, trades, tourism and management’ (Bedford & Hugo, 2012, p. 29). In addition there are social and cultural disadvantages including the loss of traditional skills such as language, arts and crafts, diet, navigation, and alienation from tribal lands and customs (Ingram, 2004).

Cultural expression in the Cook Islands

Culture and tradition plays a large part in the day to day life and understandings of Cook Islanders. Shared Pacific values include an emphasis on faith, community and family, with interdependence with others. Kauraka (2003) talks about what it is to be Cook Islands Maori, with strong emphasis on social responsibility, faith and language:

it '…means to regard money as a means to social happiness. Material wealth is shared to bring happiness… …the key to being a true Maori is through re-examination of our religious beliefs; to be in touch with nature, man and god and live in harmony.' (Kauraka, 2003, p. 337).

Cook Islanders embraced Christianity after Tahitian missionaries from the London Missionary Society arrived in Aitutaki in 1821. Missionaries bought European material and societal structures, such as formal schooling, churches, gender roles, a cash economy and established nuclear family housing in coastal villages, rather than highland villages. Incorporation of these new ideas and beliefs was largely a peaceful process, but many locals died from new diseases, such as smallpox and dysentery which reduced the population in Rarotonga by two thirds over 30 years. In addition, traditional religious practices were abandoned, tribal marae were destroyed, and pre-Christian beliefs play a very minor role in modern Cook Islands cultural contexts (Religion in the Cook Islands, n.d).

As a result, Christian religious beliefs shape much of the contemporary cultural values and social structures. For instance, during my time in the Cook Islands, I observed that prayers are said before and after any formal occasion: the school day, assemblies, sport events, hospital/council meetings, and daily devotions are held twice a day for hospital inpatients. Church ministers have a large influence in the local village level. For example churches have been used as a vehicle for health change, basing healthy eating, weight loss and exercise public health initiatives inside churches with church elders leading by example (Ministry of Health, 2012).

Respect is a strong value for Pacific culture, and exhibited as respect for elders, people in authority and foreign guests, particularly those working in positions of responsibility, such as medical doctors or business leaders (Kauraka, 2003).

Charity and volunteering as part of Cook Islands traditions

Voluntary organisation has always been a big part of Cook Islands life, with traditional ties based on principles of kinship, locality, seniority and gender (Monga-Maeva, 2003). Changes due to paid employment, high mobility, new activities and international communication have altered the traditional practice of volunteering, with a reduction in community involvement and a growth of formal special interest groups (Monga-Maeva, 2003).

For example, historically *Au va'ine* (local women committee) took responsibility for monitoring community cleanliness, such as litter, managing roaming animals, and imposing fines (Monga-Maeva, 2003). Modern life, including higher education and employment for women have resulted in fragmentation of this role, where only some outer islands maintain this traditional volunteer structure (Monga-Maeva, 2003).

Health status and access to healthcare in the Cook Islands

Changes accompanying modernisation have been cited as responsible for epidemiological decline in health status, where 'prevalence for strokes, diabetes mellitus, injuries, chronic pain syndromes and other potentially debilitating conditions are rapidly increasing' (Fitzgerald & Barker, 1993, p. 52). This phenomenon is not isolated to the Cook Islands, and is well documented in other developing and Pacific nations (Gracey & King, 2009; Hodge, Dowse, Zimmet, & Collins, 1995). This change in status leads to an increased need for primary care and public health information alongside a need for rehabilitative services and disability prevention programmes.

All islands have access to locally-based medical care, which may be a single nurse practitioner. Larger southern islands have small hospitals which open as required, and all islands share access to an electronic health record system, MedTech32.

(MedTech32 is a management system is available worldwide for primary and secondary healthcare. It is for instance also utilised in primary health care in New Zealand.) Secondary medical support is via phone or air transfers to Rarotonga.

Compared with healthcare in an urban setting, a significant portion of the health budget is utilised to cover transport costs for healthcare needs from and within the Cook Islands for patient transport – both for charted flights from Pa Enua to Rarotonga, and for onward flights to New Zealand when needed (Ministry of Finance and Economic Management, 2013b).

These international referrals include acute tertiary care and secondary diagnostic needs for traumatic injuries, chronic disease management such as renal failure, prosthetic fitting following amputation, high risk pregnancies, and cancer treatments. This arrangement has been in place since 1974 and ensures that Cook Islanders have access to tertiary services not otherwise available in this small isolated population. The funding pays for transport to a New Zealand hospital, and as New Zealand citizens tertiary healthcare provision is funded within the New Zealand health service. An air ambulance flight from Rarotonga to New Zealand for critical and acute patient referral requiring medical personnel to travel with the patient can cost $100 000, and transfer from Pa Enua to Rarotonga $20 000 (Ministry of Finance and Economic Management, 2013a). As such, travel to tertiary supported services out of the Cook Islands represents a potentially significant cost to the health budget. Reductions in the requirement for health related travel are required, and local options such as the Health Specialist Visit programme or Community Based Rehabilitation (CBR) are useful strategies to explore.

Health services are primarily funded by the Cook Islands Government, with 7% of health care budget attributed to overseas government aid (World Health Organisation & Cook Islands Ministry of Health, 2012). New Zealand provides $30 million aid for the

Cook Islands with a specific allocation (averaged at $500k per annum) to the Health Specialist Visits programme (Ministry of Finance and Economic Management, 2012b, 2013b; New Zealand Ministry of Foreign Affairs, 2014).

The Health Specialist Visits programme is funded by New Zealand together with Australia and brings specialist health services mainly to Rarotonga, with some Pa Enua visits (Ministry of Finance and Economic Management, 2013b). These services include but are not limited to neurology, orthopaedic, urology, and diabetes specialists as well as services like mammography screening, vision and hearing clinics. While providing patient assessments this service also provides peer-to-peer learning and training for locally based medical personnel. The specialists provide a critical and necessary service otherwise only available overseas, and a reduction in patient referrals to New Zealand is a measure of the success of this programme (Ministry of Finance and Economic Management, 2013b; Ministry of Health, 2012, p. 24). Allied health services, such as speech language therapy and developmental specialists are on occasion identified as required services, but to date have not been funded through this programme. In recent years, Ministry of Education has funded these specialist visits to support school children with identified needs (Ngaria Stevenson, personal communication, July 12 2013).

In the Cook Islands there were no healthcare training institutes[2], leading to a dependence on Western trained health professionals providing services in the Cook Islands. This includes visiting specialists attending for one to two weeks of intense consultations; short term health staff working for periods less than 12 months, overseas trained doctors and nurses, who may or may not be permanent residents (Ministry of Health, 2014b). There is also support for indigenous Cook Island Maori to travel

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[2] The School of Nursing was closed between 2008-2014

overseas for health training, such as attendance at Universities in New Zealand or Fiji (Ministry of Health, 2014b).

Foreign nurses on contract make up 30% of the workforce with ‘most new nurses recruited from neighbouring low income countries like Fiji, Solomon Islands, Vanuatu and Tonga’ (Ministry of Finance and Economic Management, 2013a, p. 80). Reliance on overseas health workers has limitations for provision of health care as ‘though most Pacific countries are small in size, they have such complex cultures that unless outsiders take the time and effort to understand them they will never do so’ (Sevele, 1987, p. 74). For example, Kauraka (2003) described how Cook Island Maori ‘attribute white Westerners with greater education and understandings than they themselves hold; and that their culture of hospitality denies in themselves the ability to lead their own destiny – by being humble and subservient to the *manu’iri* (visitor)’ (p. 337). Locals, particularly in the role of patients, defer to this greater knowledge, such that they will not disagree, ask for clarification or offer alternative viewpoints to the specialist, but then may not assimilate instructions or advice as given by the health provider (Pareina Tangata, personal communication July 10, 2013). This illustrates how lack of understanding of the cultural beliefs of health and rehabilitation can result in a service that does not meet the needs of the community.

Foreign aid funding provides a substantial support for the Cook Islands, and the independent constitutional capacity allows the Cook Islands to negotiate foreign aid from different sources and countries. However, aid is not without its restrictions, and donations often reflect and protect the donor’s political, business or financial interests (Sevele, 1987). Historical and political commitments mean that New Zealand spends a significant proportion of its overseas aide in the Pacific with aid is dispersed according to the policies of the current New Zealand Government. Historically, the New Zealand

Government has tied about 70% of its financial support to bilateral aid; that is 70% of aid funds must be spent on New Zealand goods and services (Crocombe, 1992) and this pattern continues. Te Vaerua had funding from NZAid 2007/09 and currently has programme funding via the ‘Social Impact Fund’, New Zealand aid funding administered by Cook Islands Ministry of Internal Affairs. The Asian Development Bank funds caregiving programmes throughout the wider Cook Islands, and Te Vaerua has responsibility for oversight of this programme in Rarotonga.

2.2 Formation of Te Vaerua

Relevant policy frameworks

A number of national and international policy frameworks related to disability in the Pacific region informed the development of Te Vaerua. One key document has been the Biweko Millennium Framework (BMF), which was established as a ‘regional framework for action toward an inclusive, barrier-free and rights-based society for people with disabilities in Asia and the Pacific’ (Economic and Social Commission for Asia and the Pacific, 2002, p. 3) aiming to support governments and stakeholders towards meeting Millennium Development Goals and targets. The Cook Island Government endorsed the BMF with other Pacific Forum Leaders in 2003 and formed a *National Policy on Disability* and a *National Action Plan* (2003-2008) which was reviewed in 2008. The BMF focuses on changes in legislation and policies, the formation of Disabled People Organisations (DPOs), and the provision of appropriate, multi-sectorial, community based approaches for prevention, early intervention and rehabilitation (Economic and Social Commission for Asia and the Pacific, 2002).

The Cook Islands ratified the Convention on the Rights of Persons with Disabilities (CRPD and Optional Protocol in its own right on 8 May 2009, and was the first Pacific Island country to submit an initial report to the Secretariat of the Pacific Community in 2011 (Government of the Cook Islands, 2011; Ministry of Finance and Economic Management, 2013a). A ‘Pacific Regional Strategy on Disability’ was adopted in October 2009 as a practical way for the Pacific Islands Forum to support governments to implement the CRPD over a five year period from 2010-2015.

Te Vaerua works within these frameworks to assist the Cook Islands Government meet its obligations in areas of key strategic health targets particularly rehabilitation, capacity building, awareness raising and disability data collection (Te Vaerua Community Rehabilitation Inc., 2010). They are an associate member of the Pacific Disability Forum for DPOs.

Background history

The establishment of the Cook Islands National Disability Council in 2000 supported each of the Outer Islands (Pa Enua) to set up a ‘disability committee’ in the local communities with a goal of running services in the islands as deemed appropriate by those local communities. In the main, these committees and support groups were run by nuns from Daughters of Charity International. To explore and frame this work, an NZAid project in 2001 surveyed national disabilities and need, and one recommendation from this survey of stakeholders was that there needed to be national oversight and support of local disability services in their communities.

In 2003-2006 this was provided in the form of the Cook Islands Community Service (CICS) which was affiliated with the Cook Islands Red Cross. The CICS received referrals from the Cook Islands Red Cross to visit homes and provide basic support for those identified with disabilities. In 2005/06 the CICS ran the ‘Outer Islands High Needs Project’ to identify and support young people/children with ‘high needs’ and provide therapy, equipment and training/education to enable them to ‘live a full and meaningful life' (Te Vaerua Community Rehabilitation Inc., 2010). Provision of the Outer Islands High Needs Project was funded by NZAid in partnership with the Cook Islands National Disability Council and the Ministry of Internal Affairs and called the Disability Action Team (DAT). DAT continued to work with Pa Enua setting up Disability Centres, encouraging inclusive education, applying for funding for specialist equipment such as wheelchairs, and arranging visiting therapist visits to Southern Group Islands.

DAT identified that there was a no 'after care' for the people who had cerebrovascular accidents, and particularly highlighted the need for rehabilitation and support services based in Rarotonga to continue expanding the work that DAT had been doing. When CICS was disbanded in 2006, the members of DAT agreed to ensure the progress made for people with disabilities in the Cook Islands would be maintained, and Te Vaerua was established informally in 2006 as a result of the motivation of these individuals.

From the outset, the intention of leaders of Te Vaerua was to establish a 'multi-disciplinary approach to cater for the needs of persons with disabilities, their caregivers and families and to ensure access to appropriate and affordable services, devices and other assistance for disability-related needs... [by providing] a health service to people who require therapy or rehabilitation within the Community to maximise their potential and quality of life' (Te Vaerua Community Rehabilitation Inc., 2014).

Te Vaerua became an NGO in 2007 and comes under the umbrella of the Cook Islands Association of Non-Government Organisations and is affiliated with the Cook Islands National Disability Council. The NGO obtained a Memorandum of Understanding with the MOH in 2008 to provide Ministry-funded support for part-time (20 hours per week) physiotherapy services. This, along with private fundraising, supported Te Vaerua until core funding was gained in 2013. Te Vaerua was granted New Zealand Registered Charity status in 2010.

In 2009 Te Vaerua leased a site in Aorangi to set up a therapy clinic, and I was employed as the physiotherapist. The building was run down, with neither running water nor electricity, but allowed Te Vaerua to plan and establish a purpose built clinic space. During my time working, a rental company (Island Car and Bike Hire) gifted free hire of a vehicle to allow me to visit patients in the community and home visits continued to be an important and valuable aspect of the service.

With much local support the clinic was opened in 2012. Due to funding restrictions, a long term physiotherapist was not present on the island from 2011 until a funding proposal was successful in 2013; so the clinic was utilised mainly as an equipment store and workshop. In May 2013 Te Vaerua gained programme funding for services from NZAid, via the Social Impact Fund administered by the Cook Islands Ministry of Internal Affairs. This funding provided support for a physiotherapist and a part time Maintenance/Equipment Coordinator. An American physiotherapist had been appointed in May 2013 with a start date of September 2013. The proposal for an occupational therapist was not accepted by the funding agency, and the importance of employment of an occupational therapist, and funding of this position has been an ongoing discussion for the organisation to this day.

2.3 Relationships between culture, ethnicity and healthcare

Culture and ethnicity have been long associated with health status. Culture has been identified as socially constructed expressions of knowledge, attitudes, beliefs, customs, language, morals, arts and personality which are shared by a particular cultural group and passed between generations. They are a system of meanings that shape one’s view of the world and influence behaviours and social relationships by informing protocols and behaviours to create a shared sense of personal and community purpose, identity, and belonging in a way that identifies one social group from another (Banja, 1996; Eckersley, 2006; Groce, 1999; Horne et al., 2004; Ministry of Health, 2014a; Papps & Ramsden, 1996; Wong-Hernandez & Wong, 2002). As culture is created between interpersonal interactions, it has an effect on how we see, understand and respond to physical and social phenomena, working as ‘powerful filters through which information is received’ (MacPherson & MacPherson, 1990; S. B. Thomas, 2004, p. 2050). Culture is not a static entity, but an evolving process, dynamic in nature and changing with time (Bradby, 2003; Ministry of Health, 2014a; Tiatia, 2008). Culture should not be viewed as simply limited to ethnicity, as it includes sub-groups such as religion, gender, class and sexual orientation (Papps & Ramsden, 1996; Tiatia, 2008).

While much of the literature discusses health outcomes and ethnicity, culture will also strongly influence individual and societal health (Eckersley, 2006; Horne et al., 2004). Indeed Durie (1994) stated that health does not have meaning outside of a cultural context where cultural concepts of well-being, wealth and spirituality all interplay to create and influence health status, as well as affect concepts affecting health, such as expectations related to food and activity. Fitzgerald (1992) suggested that there are cultural bases for health beliefs related to explanations for ill health and causes; normal health seeking behaviour, what keeps us well; and illness related behaviour, what to do when you are unwell. Therefore health depends on environmental factors, beliefs and attitudes as well as biomedical factors (Hughes, 2008).

Ethnicity is defined as a socially constructed category of shared ancestral, historical and cultural heritage and is often used interchangeably with race or nationality as a grouping for health statistics and epidemiological studies (D. R. Williams, 2001). Such studies tend to assume that there is homogeneity within groups, however there is more genetic variation within ethnic groups than between them, and socio-economic differences also exist within groups (Bradby, 2003; Tiatia, 2008; D. R. Williams, 2001).

The interplay between ethnicity, socioeconomic factors, and health outcomes are complex (e.g. Hughes, 2008; King et al., 2009). It is acknowledged that while low socio-economic status negatively affects health for all ethnic groups, they do not account completely for differences seen in health status between ethnic groups (King et al., 2009). For example, while New Zealand Māori are disproportionately negatively affected in health statistics, and an over representation in low socio-economic strata accounts for at least half of this result, Māori in the top socioeconomic brackets of New Zealand society experience significantly lower life expectancy than even the most socioeconomically deprived non- Māori (Ratima, Waetford, & Wikaire, 2006). This illustrates that socioeconomic status is very much an incomplete reason for poorer health outcomes among indigenous populations, and it has been criticized as a measure of social determinants of health (Lillie-Blanton & Laveist, 1996; Reid, Robson, & Jones, 2000).

Rather, indigenous health is understood to be affected by a range of additional cultural factors, such as loss of cultural identity and language, loss of social cohesion and traditional land connections and is affected by racism (Harris et al., 2012; King et al., 2009). However, most literature regarding health and ethnic groups describes immigrant minority groups or colonised indigenous people rather than people groups in traditional geographical settings (King et al., 2009; D. R. Williams, 2001). Very little research has been completed with Pacific cultural or ethnic groups within their own island nations, where connections to cultural identity, language and traditional land remain. There may be marked differences between outcomes and health experiences of immigrant or colonised groups compared with Pacific based groups as demonstrated in a lower life expectancy in 2006 for New Zealand based Pacific people compared with Cook Islanders in the Cook Islands (Ministry of Finance and Economic Management, 2012b; Ministry of Health, 2014a)[3]. Table 1 shows the statistic for Cook Islands based individuals is similar to that in 2010-12 of non-Maori New Zealanders and is in contrast with a significantly lower expectancy for New Zealand Maori males (Statistics New Zealand Tatauranga Aotearoa, 2012). This suggests that findings from health research based on immigrant or colonised groups is not necessarily directly relevant to indigenous populations.

Table 1: Comparison of life expectancy (years) of NZ and Pacific based individuals

	NZ non-Maori	**NZ Maori**	**NZ Pacific Islanders**	**Cook Islands based**
Data from year	2010-12	2010-12	2006	2006
Gender				
Male	80.2	72.8	71.3	79.3
Female	83.7	76.5	76.1	83.9

Cultural safety and health

Cultural safety does not simply refer to provision of care in a cross-cultural setting, but rather seeks to acknowledge and explore the power differential between health care professionals and patients, and to recognise that provision of all health care is a bicultural exchange (Richardson, 2004). Fitzgerald (1992) goes a step further and explains that clinical intervention works at the intersection of three different cultural groups: the cultures of the provider, the patient and the medical culture.

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[3] It is noted that the data available represents different years, and that the New Zealand data does not identify Cook Islanders separate to Pacific Islanders more generally. Cook Islanders who are transferred for tertiary care in New Zealand from Rarotonga and subsequently die will be included in NZ based statistics

Cultural safety identifies that providers and therapists hold their own culture; with shared health language, knowledge production and structures including concepts of health and wellness, and encourages providers to contemplate their own cultural identity (Iwama, 2006; Tiatia, 2008). Cultural safety requires interactions that 'recognise, respect and nurture the unique cultural identity of each person to safely meet their needs, expectations and rights, and involves showing respect and sensitivity to people, and taking into account their spiritual, emotional, social and physical needs' (Tiatia, 2008, p. 4). Ratima (2006) talks about 'culturally relevant clinical treatment' with the example that a busy mother of four may not have time to do specific exercises which could instead be incorporated into functional activities; and a good way to get an elderly gentleman to increase his exercise tolerance would be to park the car further from his destination. Neither of these examples is specific to the cultural needs of any particular indigenous group; and instead demonstrates that all treatment plans need to be aware of the 'cultural reality' of the patient, including but not limited to ethnicity.

Fitzgerald (1992) recognised that this interplay occurs in all clinical interventions, with shared aspects of health understandings occurring more or less in each individual situation. She uses the example of 'explanatory models' which are always cultural constructs and involve aspects of causation, symptoms, pathophysiology, illness course and treatment options and encourages all practitioners to be aware of the disparities and cultural differences in health viewpoint and the challenge that this holds for effective outcomes (Banja, 1996; Fitzgerald, 1992).

Working in a traditional culture setting, there is also often a traditional medical approach or culture that may or may not intersect with a Western or biomedical medical model. Western medicine including physiotherapy and rehabilitation is taught in English around the Pacific, so concepts of wellness, illness, physiology and treatment models are explained from a Western perspective. Even for ethnic Polynesian health providers, understandings of health and treatment are learned using Western concepts and words that do not necessarily translate into local languages or understandings. Although these health providers may be locals, the language and ideas of health they have been taught may be foreign to the people in the countries they serve, and health provision remains a bicultural activity.

When working in an ethnically cross cultural setting, it is vital to have an understanding and appreciation of the values, traditions and customs of the patient group, and to be able to integrate these values, attitudes and practices into the care and delivery of service. This is termed ‘cultural competence’, and the degree of success of health care delivery in providing culturally appropriate care is often described as cultural sensitivity (Tiatia, 2008).

Health models

Similar to NZ Maori models of health, such as Te Whare Tapa Wha and Te Wheke (Barton & Wilson, 2008), the Cook Islands concept of health is a holistic one, expressed as an overall wellness or *ora’anga* which refers to a variety of dimensions that affect health: physical, spiritual, emotional, relational or environmental (Mitaera & Laing, 1994). Wellbeing can be referred to as ora’anga pertaining to each area such as *ora’anga kopapa* (physical) or *ora’anga tevaerua* (spiritual) (Moore, Owens, & Finau, 2003). A Pacific model of health was developed by Pulotu-Endemann (Pulotu-Endemann, 2009) to support understanding Pacific health in the New Zealand context. It describes health as a meeting house surrounded by a personal context built on a foundation of family, sheltered by cultural values with four posts connecting family and culture as the tenets of wellness. This model can be used as a basis for understanding the Cook Islands health concept (Figure 1).

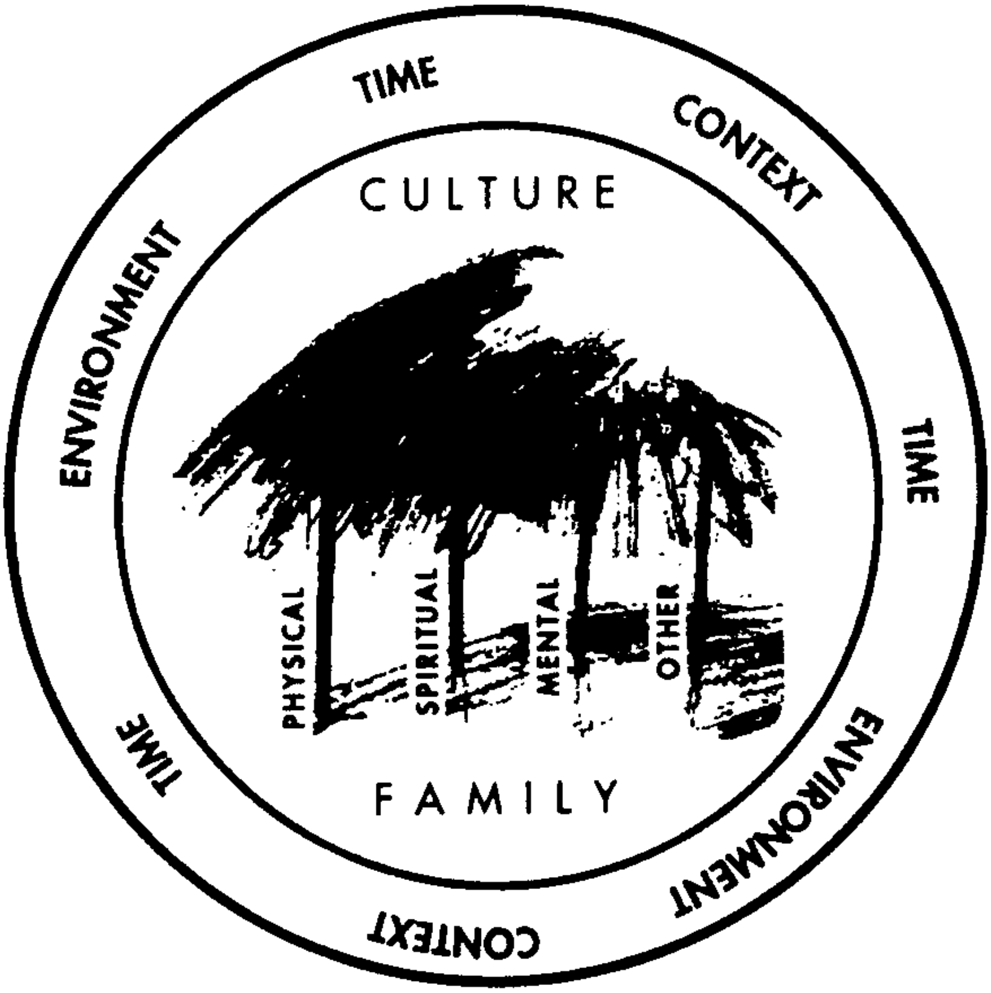

Figure 1: Fonofale – a model of Pacific health

Retrieved from(Nonu-Reid, Lui, Erik, Puloto-Endemann, & Bridgman, 2000). Reproduced with permission.

A further underlying difference with these indigenous models is a sense that illness or sickness is inevitable and a part of the normal process of life, a concept which contrasts sharply with a Western idea that illness is a problem or abnormal situation (Mitaera & Laing, 1994).

2.4 Health literature related to Pacific interests

There is a wide array of literature related to Pacific health, much of it for New Zealand or American-based Pacific groups (e.g. Braginsky, Inouye, Wang, & Arakaki, 2011; Fang & Yeung, 2002; Hampton, 2000; Kim-Rupnow, Chan, & Starbuck, 2005; Moore et al., 2003), as comparative studies to other ethnic groups (e.g. Harwood et al., 2012; Mauiliu et al., 2013), regarding mental health services (e.g. Harwood et al., 2012; G. Roberts, Cruz, & Puamau, 2007; Suaalii-Sauni et al., 2009) or cultural safety and education (e.g. Tamasese, Peteru, Waldegrave, & Busch, 2005; Tiatia, 2008). Little has been written regarding Pacific rehabilitation concepts, models of healthcare practice and services (Tiatia, 2008).

One such publication is a resource booklet for New Zealand based health professionals regarding Pacific Health practice and outlines the following important concepts for Pacific people: relationships, holistic health and spirituality, contribution and responsibility, correctness and respect, faith, integrity and dignity (Mauri Ora Associates, 2010). These general concepts underpin the similar values between Pacific group cultures and give some insight into expectations and beliefs about health and healthcare provision. However, they reflect experiences within the New Zealand health system, rather than individual Pacific nations. A qualitative study by Lefono (2014) explores the information needs of Pacific people following spinal cord injury and showed value placed on roles, family involvement and spiritual/mental health by patients (Lefono, 2014). This small study is the only discovered qualitative research related to rehabilitation needs or values for Pacific peoples, but is also based on a New Zealand population.

One paper that reflects island-based rehabilitation from a Western perspective is a 1996 article outlining geographic, ethnic, language and political constraints in the seven entities served by the American ‘Rehabilitation Research and Training Centre of the Pacific’ based in Hawaii (McFarlane, Huff, Guerrero, & Galea'i, 1996). The personal opinion piece outlines many of the challenges faced by people with disabilities and availability of health services in small geographically isolated communities but does not engage with expectations or views of Polynesians living in the Pacific, and explore what rehabilitation means in this setting.

McFarlane et al. (1996) suggested that issues related to provision of rehabilitation in the Pacific include: ethnic and social diversity, communication and language, familial and kinship systems, political influences (independence vs reliance on ‘outside forces’), employment and economy (includes environment barriers). These aspects relate both to the logistic challenges in providing rehabilitation services and cultural challenges. Small developing nation islands have unique political, socioeconomic, employment and infrastructure situations which balance requirements for basic human needs such as safe water, power and sewage alongside healthcare, employment opportunities and education, using limited resources and a degree of reliance on external aid funding. In these situations, logistical challenges exist for provision of culturally appropriate rehabilitation services, to individuals who are diverse in need across a sparsely populated, geographically spread, often rural environment. Urbanisation and migration further isolates remaining populations making provision of services more difficult (New Zealand Ministry of Foreign Affairs, 2014) and a rural location has been found to be a barrier to access adequate healthcare (Marrone, 2007).

Cultural considerations for rehabilitation provision in the Pacific include how to cater for the wide ethnic, social and dialect diversity amongst Pacific nations, both between and within different Pacific groups. Language particularly is an important aspect of cultural identity, and is a key aspect of understanding health, wellness and other culturally determined concepts (King et al., 2009; Marrone, 2007; McFarlane et al., 1996). Language differences can create significant barriers to the provision of healthcare and rehabilitation services. Family ties and kinship systems are strong concepts in Pacific cultures, and inform community and family roles and expectations, including interdependence, respect and responsibility for land, elders, and dependent family members (Mauri Ora Associates, 2010; McFarlane et al., 1996). There may be an unwillingness to share 'problems' with those outside the family, which may limit access to or the degree of engagement with rehabilitation services (McFarlane et al., 1996).

McFarlane's conclusion was that 'much more must be done' (McFarlane et al., 1996, p. 9) to implement successful provision of services in the diverse and isolated Pacific region. Provision of any rehabilitation services in a Cook Islands setting should incorporate the cultural health beliefs and expectations of the individual, the interaction of the person within the different dimensions of their being, as well as the physical and societal situation. It also must be recognised that as Westernisation changes the expression of traditional culture in the Cook Islands, beliefs and concepts about health and the expectation of wellness will also alter (Mitaera & Laing, 1994).

2.5 Rehabilitation: A Western perspective

In the Western context, rehabilitation is a word used to describe the complex process improving an individual's health and quality of life via (usually) multidisciplinary management and interventions to enable the individual to improve and maximise their function (Davis, 2006; Davis & Madden, 2006; Dean, Siegert, & Taylor, 2012; Stucki, Ewert, & Cieza, 2002). It can be described as 'an educational, problem-solving process that focuses on activity limitations and aims to optimize patient social participation and well-being' (Wade, 2005, p. 184). It is useful to consider rehabilitation interventions as a cycle of: identifying needs and areas of limitation, defining targets (goals), and interventions, implementing change and assessing outcome where the eventual outcome is a restoration of the individual's quality of life and involvement in life roles (Davis & Madden, 2006; Levack & Dean, 2012; Stucki et al., 2002). Assessment of need should take into account both the health impairments and situation as well as individual factors: environmental, social and socio-cultural situation; goals and expectations; individual interests, values and background; health and disability beliefs and expectations of involvement of significant others, such as family (Levack & Dean, 2012). When an individual assessment of need has been completed, a cycle of goal setting, intervention and evaluation occurs until rehabilitation is 'completed'.

It is widely accepted that goal setting is one of the characteristics of rehabilitation (e.g. Bovend'Eerdt, Botell, & Wade, 2009; Davis & Madden, 2006; Levack & Dean, 2012; Playford et al., 2000) where rehabilitation goals are centred on individual and work towards a desired outcome, usually an activity or participation in a life role. Goal setting determines the direction and plan of intervention for each individual as part of the intervention process (Levack & Dean, 2012), and therefore the values, expectations and health beliefs of the patient and family will influence rehabilitation involvement and outcomes. It should follow that rehabilitation concepts and practices vary across cultures and societies, and may reflect the unique socio-political and cultural histories of those societies (Mpofu, 2001).

Rehabilitation can be considered primarily a developed world concept as for many people around the world 'every injury or illness event has only two possible outcomes – full recovery or death' (Fitzgerald, 1992, p. 41). Therefore the very idea of rehabilitation as understood by Western trained providers may be incompatible with a non-Western patient or family’s cultural beliefs or explanatory models.

WHO model of rehabilitation – the ICIDH and ICF

The World Health Organisation (WHO) framework for rehabilitation language was first published in 1980 as the ‘International Classification of Impairment, Disability and Handicaps’ (ICIDH) which enabled health professions shared descriptions for processes of disability and rehabilitation (Levack, 2004; Wade & Halligan, 2003; World Health Organization, 1980). The framework gave rehabilitation therapists a language to identify their area of intervention: which was at the time described as a focus on reducing disability or handicap rather than ameliorating impairments, and which was not easily described in a biomedical model that focused on pathology and treatment.   The ICIDH is useful when communicating goals in rehabilitation and for explaining how the rehabilitation interventions can improve health outcomes without a specific focus on impairment or disease treatment.

The ICIDH has a biopsychosocial model underpinning this description which gives understanding to the multiple aspects of ill health and recognition to the difference between a physical illness or impairment, the functional effect of these symptoms or disability, and the social implication of these for the individual person or handicap (Wade & Halligan, 2003).

In 2001 the ICIDH was superseded by the International Classification of Functioning, Disability and Health (ICF) which has some significant improvements regarding the framework around classification of disability (World Health Organization, 2001). The ICIDH talked of ‘disability’ and ‘handicap’ whereas the ICF used the less pejorative terms ‘activity’, ‘activity limitation’, ‘participation’ and ‘participation restriction’ (De Kleijn-de Vrankrijker, 2003; Levack, 2004). The ICF also recognised the significant influence which environmental factors have on an individual’s ability to function and therefore, for example, the physical environment, aids and appliances, social policies or attitudes were considered potential ‘barriers’ or ‘facilitators’ in the ICF (Levack, 2004).

Disability is no longer viewed as merely the result of impairment. The social model of disability has increased awareness that environmental barriers to participation are major causes of disability. The International Classification of Functioning, Disability and Health (ICF) includes body structure and function, but also focuses on activities and participation from both the individual and the societal perspective. The ICF also includes five environmental factors that can limit activities or restrict participation: products and technology, natural environment and human-made changes to it, support and relationships, attitudes, and services, systems and policies. While removal of barriers is the goal, no nation has eliminated all of the environmental barriers that contribute to disability, and this may not be entirely possible. (International Labour Organization, United Nations Educational Scientific and Cultural Organization, & World Health Organization, 2004, p. 3).

Furthermore, the ICF recognised that personal factors such as ethnicity, personality and gender could also affect activity and participation (Levack, 2004) thus introducing sociocultural dimensions into the language of disability and functioning (Levack, 2004). This gives a broad basis for understanding health and rehabilitation within a framework of personal, cultural, community, societal and economic factors. These influence how diagnoses and impairments impact on an individual and reflect that cultural, community and societal factors can influence understandings and expressions of disability. Therefore rehabilitation practices must be conscious and responsive to cultural interactions, and a western model of rehabilitation practice may not be suitable in different cultural settings.

Culturally based rehabilitation models

Most rehabilitation theories and frameworks, including the ICF are based on Western ideas of ‘cultural norms’ and do not necessarily fit with other cultural experiences of health and wellness. For example, most models of rehabilitation consider the individual to be central, and separate from social, family, physical and political environments (Iwama, 2006). Pacific cultures tend away from an individualistic viewpoint, with greater family, spiritual and community interactions (Mauri Ora Associates, 2010). The Kawa or ‘River’ model of rehabilitation allows a cultural experience to be reflected in the provision of rehabilitation, by situating the patient in a culturally based knowledge of self that situates the person and their world as parts of an integrated whole, a complex dynamic where environment and circumstances can alter the flow of the ‘wellness of life’ described as a river with walls (environment) rocks (circumstances) and driftwood (assets and liabilities). Rehabilitation is the enhancement of life flow by encouraging harmony between all of these elements (Iwama, 2006). This model allows recognition of the interdependence between an individual and their place and context and more thoroughly allows consideration of the health as interplay of diverse elements (figure 2).

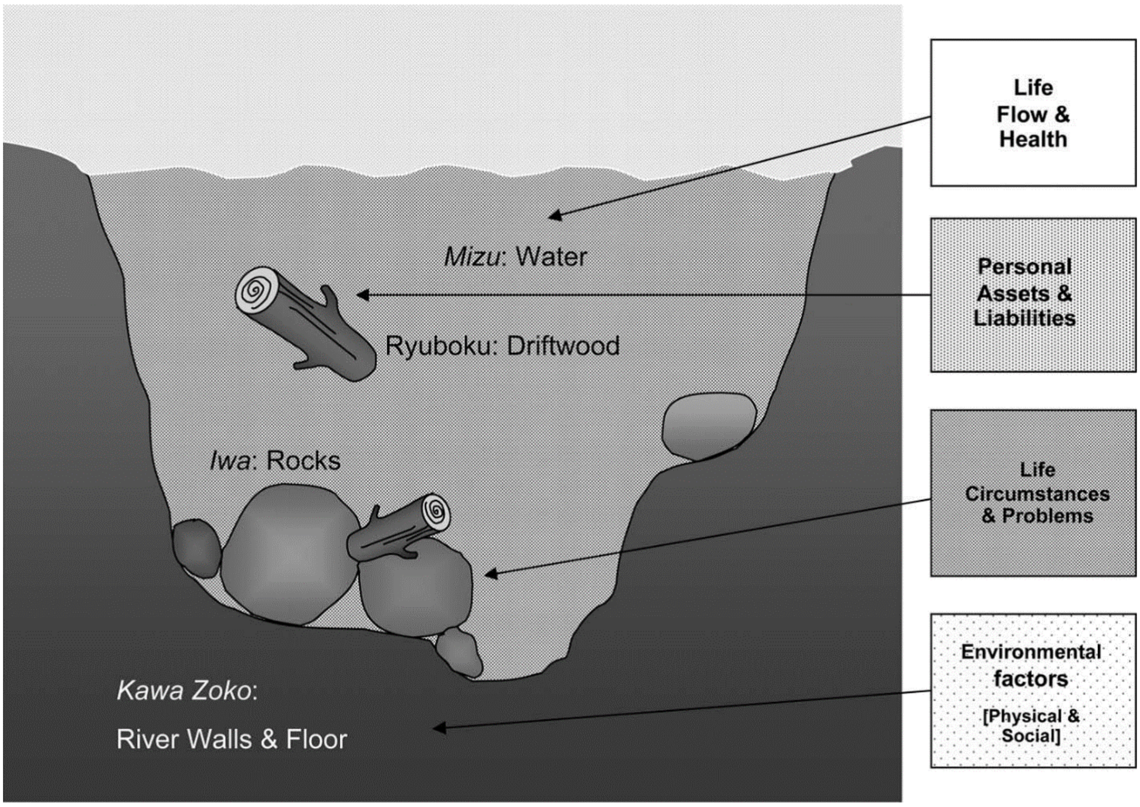

Figure 2: The Kawa model of health Reproduced with permission

2.6 Disability in the Cook Islands

The traditional view of people with disabilities in the Cook Islands has been that they are to be looked after and are unable to take a full and active part in the life of the community (Government of the Cook Islands, 2011). Historically throughout the Pacific, disability and illness were considered to have a spiritual cause, such as a curse or punishment (MacPherson & MacPherson, 1990) and families would often isolate members with disabilities for fear or shame, or for protection of the individual from the perceived scorn of the village (Miles, Lene, & Merumeru, 2014). These traditional and spiritual attitudes are altering with the intervention of Western ideas and viewpoints, and particularly with the provision of international development aid funding for health and disability projects. These often hold the assumption that disability beliefs will move from traditional attitudes and practices to a Western based charity or medical model in line with funding goals and measures (Groce, 1999). While there are benefits in change from these traditional concepts, there are disadvantages with projecting a Western model of health and disability into a developing country.

The charity model perceives that disability is a ‘tragedy’ and the person with the disability to be a victim who requires charitable donations of care and support (Clare, 2001). This model disempowers the individual, and denigrates them to a lesser entity, and is the dominant model advertised in requesting donations to developing world aid programmes. The medical model has been the traditional underpinning of the Western medical framework, where disability is the result of a physiological process due to damage or disease, with an inference that the disability is located within the person, and can be treated (Llewellyn & Hogan, 2000). Neither of these models is particularly useful to meet the goal of empowering people with disabilities to be full and active members of society.

Another model often cited is the social model of disability which describes disability as socially constructed; that people are disadvantaged by the attitudes and environment of society rather than defined merely by a physical dysfunction (Burchardt, 2004). The disability rights movement in the 1960s gave voice to people with disabilities who had previously been marginalised and depersonalised as ‘the disabled’ (Mertens, Sullivan, & Stace, 2011; Oliver, 2009). This new movement suggested that disability was a product of the interaction between a person with impairments and his or her environment, thus different environments, social or cultural contexts created different disabilities. The basis for this change was underpinned by moving from a positivist approach to an interpretative paradigm, where all knowledge is viewed as being socially constructed within a specified environment (Mertens et al., 2011). This locates the cause of disability as within the social organisation, rather than the individual (Llewellyn & Hogan, 2000) and is useful to consider how social and environmental structures can be altered to enable those with impairments to participate more fully. Te Vaerua has a strong resonance with this concept as is seeks to draw attention to, and alter the physical and social environment to enable the population of people with disabilities in Rarotonga.

As in other areas of the world, the attitude towards people with disabilities in the Cook Islands is beginning to change:

> *While the situation of people with disability in the Cook Islands, particularly in the Pa Enua, is not fully documented and understood, there is sufficient evidence to confirm that to achieve the full promotion and protection of the rights of people with disability, considerable changes in attitudes are required, and legislation, policies and programs would benefit further review and strengthening. It is acknowledged that these are long-term processes, which require multiple and sustained interventions and support, led by the Cook Islands Government, its Disabled Persons Organizations and supported by donors (Ministry of Finance and Economic Management, 2013a, p. 149).*

There is no clear definition of what constitutes a disability in the Cook Islands, and the traditional term '*pakipaki-tai'* (shaking of the hand like ocean waves, Margaret Dwane, personal communication, August 20, 2013) is often considered derogatory. Attempts are being made to implement a multi-agency disability database based on the WHO framework of participation and barriers, of individuals who are considered disabled (Ministry of Internal Affairs, 2015). Research is also being undertaken to identify the long term costs and implication of injuries related to traffic accidents ("Cookie doctor studying disability," 2014). Both of these national projects will require a definition of disability to be established for the Cook Islands.

Community based rehabilitation (CBR)

The question remains of how best to provide culturally appropriate services to people with disabilities who live in isolated or developing nations in a sustainable way. CBR is one possible approach explored through the joint work of the International Labour Organization, United Nations Educational, Scientific and Cultural Organization and WHO. CBR takes a rights–based approach to rehabilitation, and an emancipatory approach to enhancing the quality of life for people with disabilities and their families by meeting basic human needs and ensuring inclusion and participation (World Health Organisation, 2010). It is implemented through the ‘combined efforts of disabled people themselves, their families and communities, and the appropriate health, education, vocational and social services’ (International Labour Organization et al., 2004, p. 2).

CBR has traditionally concentrated on health issues, however in order to improve participation, the guidelines recognise the need for collaboration in five key areas of life: health, education, livelihood, social and empowerment (World Health Organisation, 2010). Since the goal of CBR is the full inclusion of people with disabilities into all areas of life, the approach recognises that concentrating on the individual is only part of the solution: a need for environmental and community change also exists. In order to gain sustainable change, CBR should be created in association with the community, rather than determined by an external agency and as a result, it should recognise and accommodate cultural values and community expectations (Pollard & Sakellariou, 2009). Literature states that although CBR is a culturally-based, locally run programme specific to the needs and requirements of the community, there remains a tendency for reliance on overseas 'experts' (Mpofu, 2001) and therefore a risk that programmes will not be successful due to misunderstandings of the cultural and community climate. This is a long held challenge to all aid funded endeavours (M. Thomas & Thomas, 1999).

CBR is a new conversation for the Pacific Region, with the first Polynesia Region Community-based Rehabilitation Workshop in Apia, June 2013, and a Cook Islands representative was present. Currently there are no CBR organisations in the Cook Islands, but Te Vaerua refers to the framework of CBR to inform policies and processes, and works within the umbrella of CBR, providing rehabilitation and assistive devices. Te Vaerua's structure lacks the multi-agency overview required for a comprehensive CBR (Ministry of Internal Affairs, 2013) but is consistent with a CBR organisation in provision of health services.

2.7 Summary

Te Vaerua is a community-based rehabilitation organisation based in the Cook Islands that relies on Western therapists to provide healthcare services to Cook Island locals with disabilities. Te Vaerua needs to be able to communicate their understanding of locally appropriate rehabilitation to the therapists involved as employees and volunteers. For Te Vaerua to be able to describe expectations of rehabilitation within their cultural setting; they need to be able to explore what this means to them, and tease out some of the cultural and social contexts that define their epistemology and the unseen elements that underpin day to day life.

This research aimed to support Te Vaerua to explore their views and understandings of rehabilitation, and how rehabilitation should look to best support the needs of the wider Cook Islands community. An action research model was chosen in order to allow Te Vaerua to participate fully in the research process and to formulate concepts and plans that are within the cultural context of the Cook Islands.

Chapter 3: Methods

This chapter describes the research method used in this project. First, participatory action research (PAR) is described along with the key concepts underpinning the methodology. Next, the rationale for selection of PAR is presented in the context of the research question for this particular project. Finally the methods employed in this project for data collection, data analysis, and interpretation of findings is outlined.

3.1 Participatory Action Research

PAR is one type of a broader category of research called action research. Action research is a political movement and scientific methodology that has change or 'action' in a particular setting or context as its prime motivation. Action research requires that researchers go beyond merely observing and documenting to ensure that practical solutions or activities that benefit study participants are an integral part of the research process. Action research has not evolved into a unified theory, rather it is considered an umbrella term for a variety of research activities that are intended to foster change on a personal, organisational or societal level through group decisions and a shared commitment to improvement (Dickens & Watkins, 1999; Drummond & Themessl-Huber, 2007). It is usually employed to address a specific issue or question for a defined group of people, whether this is a professional, organisation or community group (Drummond & Themessl-Huber, 2007). Early action research was seen as an alternative social science methodology, and arose from dissatisfaction with the traditional scientific premises of neutrality, objectivity and value-free research (Tandon, 1996). Action research has evolved out of two distinct historical journeys: organisational reform and transformative political action.

Action research was a term coined by Lewin in the 1940s in response to social problems he perceived in organisations. He recognised that the best people to collaborate and develop hypotheses about any particular situation were those who were grounded in the context, that is, the local people. Lewin felt that it is not possible to be both a passive observer and gain understanding of a social system (Karlsen, 1991), nor that it was possible to understand a system without changing it. The value of participation was paramount, with 'the goal of involvement [being] no less important than improvement' (Dickens & Watkins, 1999, p. 132).   This is considered the 'Northern tradition' of action research, which has a focus on reform, particularly organizational reform (Dickens & Watkins, 1999; Minkler & Baden 2008). It seeks to alter systems and organisations to improve outcomes for all involved groups of people (L. D. Brown & Tandon, 1983; Khanlou & Peter, 2005).

In contrast, participatory approaches to action research reflects 'Southern' roots, which draws its origins from 'grassroots' research movements in the 1970's (Khanlou & Peter, 2005; Wallerstein & Duran, 2008) such as that of Fals Borda in social change and empowerment (Borda, 1979) and Friere on liberation education in South American countries (Martinson & Su, 2012). PAR involves an ideological commitment to transformative social change when the legitimacy of power and resource distribution is questioned, and seeks to reduce the burden of oppressed groups by giving voice to their lived experience.

PAR has been influenced historically by collective social struggles such as human rights, peace, and women's and workers' movements (Brydon-Miller, Mofke, & Sabhlok, 2011) which are all based in political and social action towards social justice. These movements were based on the idea that 'ordinary' people can understand and change their own lives and the surrounding social injustices. These movements reinforced that participation was a critical variable in action research (Tandon, 1996). In more recent times, PAR has moved outside of traditional roots of development, education and business management to become a useful health research tool. Increasingly education, knowledge and learning have been recognised as vital aspects of personal health, and community-led research and action into health initiatives have become more commonplace (Khanlou & Peter, 2005; Liamputtong, 2009; Tandon, 1996).

Participatory action research (PAR) is thus underpinned by an agenda of social change and a belief that people have the capacity to create progressive knowledge by analysing their own circumstances (Frisby, Reid, Millar, & Hoeber, 2005; Langan & Morton, 2009). It is vital to the integrity of PAR that there is participation of individuals personally affected by the research issue, that there is respect for their knowledge and ability to understand the issues confronting them, and that the process seeks to empower them to engage in collective action to improve conditions (Brydon-Miller, 2001; Brydon-Miller et al., 2011; Chataway, 1997; Neuman, 2011).

While PAR is a methodology, it is also an orientation or attitude towards research (Khanlou & Peter, 2005). There is no prescriptive or ‘right’ form of PAR, but instead PAR involves a progression of choices which influence direction, processes and outcome (Bradbury & Reason, 2008). These choices are based on a transparent process of collaborative decision making by the participants, as these emerge throughout the research process (Maiter, Simich, Jacobson, & Wise, 2008; McTaggart, 1991).

There are defining characteristics that are shared by all PAR methods. The validity and quality of the research is impacted by the ability to hold to the underlying characteristics of action research which include: participation, trust and democracy, knowledge creation, (correcting) power imbalance and action (Maiter et al., 2008). These characteristics are described below.

Participation

Participation defines the nature of participatory action research where participants share in every stage of the research process (McTaggart, 1991) and are active and equal members of the research team. These stakeholders are referred to in the literature as participant members, co-researchers or co-investigators (Ledford & Mohrman, 1993; McIntyre, 2008). Participation is the very heart of PAR, however, there are different methodological ways in which participation can be implemented along a scale describing degrees of involvement from utilitarian to empowerment (Jacobs, 2010; Wallerstein & Duran, 2008), and all of these are equally defined as ‘participatory research’ in the literature (de Koning & Martin, 1996).

Trust and democracy

PAR requires researchers to effectively engage with local people to employ their knowledge and experience to help create meaningful research to directly benefit the participants’ community (L. W. Roberts, 2013). In order to achieve this, there must be trust and alliances built between researcher and participants and a commitment to engage and educate participants throughout all parts of the research process (Maiter et al., 2008; McIntyre, 2008).

The literature describes a tension between the participants and the researcher in that the researcher has skills and abilities that the participants require in order for the research to be effective, but the participants have the knowledge required to progress the project (Karlsen, 1991). Therefore PAR exists as a balanced relationship between different perspectives of knowledge and power: local knowledge and researcher knowledge (Liamputtong, 2009). Trust is particularly important between researcher and participants in the cross-cultural setting where there has been a history of colonialism in research that denies local knowledge, and has not traditionally recognised the right of self-determination of individual and local cultures (Tuhiwai Smith, 1999).

Knowledge creation

Knowing is based within cultural and social contexts, and while traditional scientific knowledge is based within a positivist framework with a dominant culture or ‘majority world view’, theories that underpin PAR consider the social constructs around minority ways of knowing. It is this shared emergent knowledge that facilitates change which is at the heart of PAR. Traditional social science values production of public knowledge that is valid to be generalised or applied to a wider context (Herr & Anderson, 2005), however PAR recognises the value in production of local knowledge for participants by allowing them to reflect and reassess their values and understandings. Significantly, this learning may not be able to be generalisable to other settings (Rappaport, 1970).

Power imbalance

PAR has traditionally been used by disempowered groups of participants to create social change and to correct power imbalance in their communities (Cameron & Gibson, 2005; McTaggart, 1991; Neuman, 2011). A goal of using the PAR framework is to give traditionally oppressed groups the opportunity to experience control and ownership by recognising and valuing their own intellectual property, to understand and be motivated by the potential for change, and to take steps towards change (Chataway, 1997). This self-determination in a research agenda reflects the traditional role of PAR in social justice and can be expressed through psychological, social, cultural and economic ways (Tuhiwai Smith, 1999).

Not only can new emergent shared knowledge (and understanding of the implications of that knowledge) emancipate people towards positive change, but a key outcome of utilising the PAR framework is to increase local capacity to access and implement research methods and be developed as self-sufficient local action researchers (Chataway, 1997).

The action cycle

Some see the goal of action research as improving practice or developing individuals, both participants and the researcher, whereas others see its goal as transforming practice and participants (Herr & Anderson, 2005; Smith, Bratini, Chambers, Jensen, & Romero, 2010). In either view, the ultimate goal of any action research is to change a situation by working collaboratively to observe and understand it (Neuman, 2011). The process engaged in PAR is often referred to as the action cycle of research (Figure 3).

Lewin's original description of action research consisted of a repetitive spiral of investigation, evaluation, planning and action (Dickens & Watkins, 1999; Drummond & Themessl-Huber, 2007) however the process has been described variously as a cycle (Dickens & Watkins, 1999; Khanlou & Peter, 2005) spiral (Dickens & Watkins, 1999; Karlsen, 1991; McIntyre, 2008; Robson, 2011) braid (McIntyre, 2008) or interconnecting circles (Drummond & Themessl-Huber, 2007). These descriptions all recognise the need for flexibility and responsiveness to alter plans as people learn and change from the experience of the research process (McIntyre, 2008; McTaggart, 1991). The co-existing periods of dialogue, action, reflection and analysis separates PAR from the concise and linear stages that define many other research approaches.

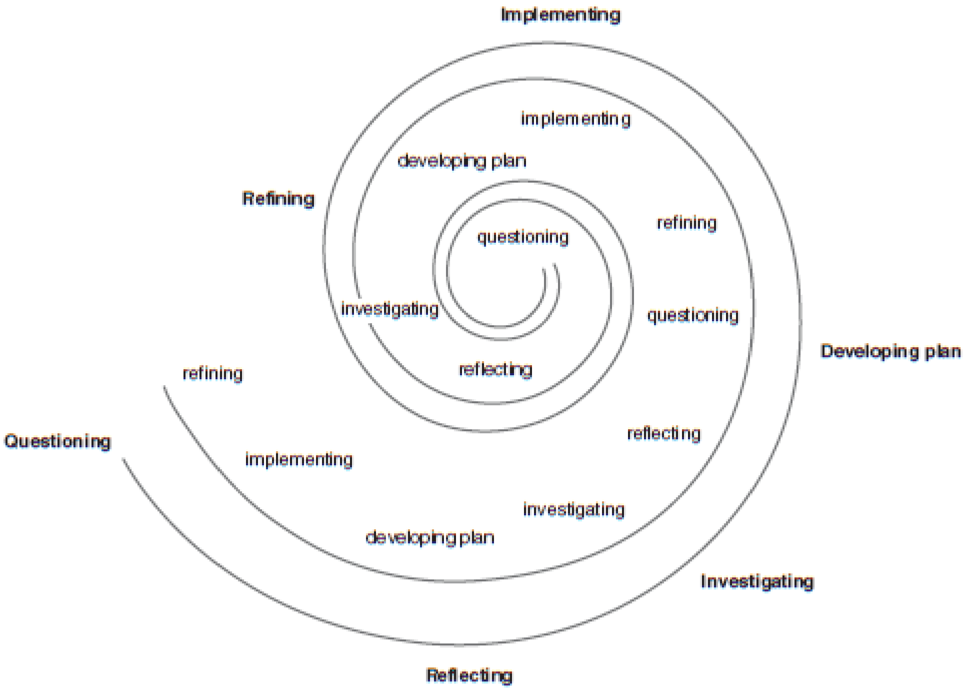

Figure 3: The recursive practice of PAR

Retrieved from McIntyre, 2008. Reproduced with permission

3.2 Challenges and considerations for PAR

As with all forms of research, there are a number of challenges related to implementation of the PAR methodological approach. In particular these include time constraints, ownership and control of the process, academic and ethical considerations, and researcher positioning (Minkler & Baden 2008; Szala-Meneok & Lohfeld, 2005). These are discussed further below.

A specific challenge facing researchers attempting PAR is the time required to implement the methodology. PAR is a time intensive process, so participants need to have a high level of interest and be motivated in the research question, and be committed to change in the study area. The formulation of a research question is key to engagement, and an understanding of the research process and expectations of how action research works is vital. Individuals who are used to the structure of positivist research will not necessarily implicitly agree or understand the action research process (Martin, 2008). This requires reflection and clarification as well as time to explore all the assumptions and issues of participants and researchers alike to ensure understandings are aligned (Martin, 2008).

Implementing change in any community or organisation is a goal of PAR which requires an agreement of what changes should be implemented. Unlike other forms of investigation where the lead researcher owns, drives and analyses the research, PAR is owned by the participant community. This democratic structure may lead to diversification of ideas which is beneficial for theory generation, but can result in difficulties regarding the direction and implementation of change if there is a lack of consensus (Martin, 2008). The facilitator of PAR must also be alert to the risk that the dominant view (i.e. that of those in positions of power) can become the overriding agenda (Martin, 2008). This risk particularly recognised in the literature in cross-cultural settings where ‘issues of power become increasingly important as funded participatory international development projects are led by researchers from so-called developed nations working in developing nations’ (in Herr & Anderson, 2005, p. 36) and the opportunity to use researchers to unwittingly reinforce power arrangements within organisations by lack of local understanding (Smith et al., 2010).

Academic PAR challenges

PAR is, by its nature, a democratic community process. This however creates a vulnerability for the academic PAR practitioner who has less control over the research process, when this can have extreme influence on personal academic achievements (Szala-Meneok & Lohfeld, 2005). Therefore there can be a tension between the academic expectations and goals of the researcher compared with the action/outcome goals of the participant community.

Another additional challenge for academic study is the requirement for ethical and departmental approvals, and often the need for external funding. These committees and grant bodies expect an *a priori* research question, methodology and time frame, which is difficult with a PAR study where exploring and deciding a research question and methods are part of the PAR journey (Szala-Meneok & Lohfeld, 2005).

Ethics

Without a positivist framework, ethical dilemmas in PAR look different to those in conventional research action. Although the high level of participation involvement and control suggest that PAR might pose few ethical dilemmas, critics see collaboration as masking subtle exploitations, such as tensions between the different agendas of involved parties: management, practitioners and researchers (Badger, 2000). Confidentiality and informed consent also pose ethical dilemmas.

Confidentiality of participants and individual stories present an ethical dilemma, when research ethics require that individuals not be identified. In a small community environment such as Te Vaerua and the Cook Islands, individuals are easily identified by their role as they may be the only person fulfilling that role in the organisation or even the island. This leads to challenges protecting the security of the individual, while maintaining the integrity of involvement by reflecting the context and understanding to both the ideas expressed, and actions implemented. Any individual view may be enhanced when the role, position and context of the individual is understood.

Informed consent can be a difficult concept when observation of group dynamics and practices are involved, particularly related to withdrawal from a research process (Badger, 2000) as excluded individuals may not be able to be eliminated from the observed group activity within an organisational structure. When research involves observation of a whole community, it may not be possible to gain informed consent from every individual involved compared to research involving individual interviews only. Instead the equivalent of consent at an organisational level or community level may be required.

In the case of my research, I was aware that both the individuals and the organisation involved were vulnerable to my interpretations of themes or findings and to the study process, which raised potential for tensions and disagreement. When conducting the research, it was important that I was sensitive to any potential for harm by writing up and disseminating results for academic purposes as these results would then become available to funding agencies and service partners. Decisions regarding the dissemination of findings were therefore discussed with Te Vaerua participants prior to completion of the study.

Researcher Positioning and reflexivity

In all qualitative research, the researcher must be sensitive to how personal beliefs, values and experiences affects subjectivity and interpretation of situations (Somekh, 2005). With PAR, the placement of the researcher, and how they consider their position within the organisation and the research structure influences decisions about power relations, ethics and the eventual trustworthiness of the project (Herr & Anderson, 2005). The researcher must look at ‘what is happening here’ and ‘why are things the way they are’ (Adams-Smith, 2002, p. 75) while exploring their own positioning and being aware of the multiple realities surrounding them. This involves consistently engaging in reflexive practice (McIntyre, 2008). Good reflexivity should increase the honesty and transparency of the research process and findings (Adams-Smith, 2002).

It is vital to obtain some perspective on the research process and findings (Karlsen, 1991) and an ‘other’ is vital to obtain a different, separate viewpoint from someone who is not imbedded in the research project (McIntyre, 2008; McTaggart, 1991). Adams-Smith (2002) talks about a 'critical friend' as an imperative, and colleagues such as research supervisors are also a useful resource for self-reflection. In my study, I was privileged to be able to discuss areas of question or lack of understanding with locals in the community and hospital as critical friends, in particular with the local Cook Islands physiotherapist who had worked at the hospital for more than 15 years. This allowed me to discuss many points of local health history, language, and cultural knowledge, in relation to the research topic.

However, there are also disadvantages with doing PAR within previously known environments, particularly work environments, which also require researcher reflexivity on how this affects the process. The literature describes these challenges as: pre-understanding, role duality, and managing organisational politics (Coughlan & Casey, 2001). Prior understanding of the context, jargon, and the participants may allow greater depth of inquiry as the researcher draws on their own experience to explore concepts with more nuance and in more detail. It can allow the researcher to participate without raising barriers or attention to the research specifically, giving the opportunity to observe, reflect and be involve in natural processes, i.e. '[to] understand the inner and outer context of the change process story' (Coughlan & Casey, 2001, p. 676). However, prior understandings can also lead the researcher to assume too much, and not to probe as deeply as they might otherwise if they came to the research as a naïve inquirer. Researchers in this context may not expose their current thinking to reframing if they feel they already have the answer. Conversely, rather than gain rich depth of data from known environments, insider researchers may be denied access to some information areas due to the normal political or departmental boundaries and structures that exist within an organisation; which may be more accessible to an outsider (Coughlan & Casey, 2001).

Role duality speaks of the tension and dilemma associated with having two roles as practitioner and researcher. This can be practical, in terms of separating oneself from workload and expectations to be able to concentrate on the research process, and political, such as role conflicts, ‘loyalty tugs’, and identification of self in the dual role of workmate/practitioner and researcher. This dual nature can lead to an alteration of relationship with other participants, either opening or restricting. Personal interactions and existing relationships in the organisation will influence the relationships with others encountered in the research process, and therefore affect the data generated within these relationships and discussions (Coughlan & Casey, 2001).

Role duality also reflects potential tension in motivations for the study, an altruistic reason for involvement versus an intention of academic advancement. These different roles come with differences in expectations, challenges around limited timeframes available to the researcher, sensitivity of information and conflicting perspectives between the role of participant/professional and researcher/academic (Coughlan & Casey, 2001). Tensions such as these can be echoed in the political environment or the organisation, where expectations of the management may be different to participants. In PAR change of the status quo is a goal, so PAR should always challenge and therefore has the potential for conflict within an organisation.

Cross cultural considerations

An additional issue related to this study which required particular attention was that of the management of cross-cultural issues in PAR (Keys, McMahon, Sanchez, London, & Abdul-Adil, 2004). When undertaking cross-cultural research, thought must be given to ensure that the research processes are appropriate, usable and moral. For cross cultural research to be valid, the researcher must be reflexive about each part of the research process, and cannot assume to ‘know’ just by being the researcher. They should be respectful of cultural practices and values, and aware of personal cultural ways of mediating knowledge (Liamputtong, 2008; Tuhiwai Smith, 1999).

Indeed, there is a long academic history of research being done by white researchers to indigenous subjects (Tuhiwai Smith, 1999) often based within the positivist paradigm that views the researcher as the ‘norm’ and the subjects of the study as the other to be observed, researched, and pulled apart. Traditional research methods have been termed ‘smash and grab’ models, and likened to an ‘open cast mining approach; see, take and destroy’ (Tuhiwai Smith, 1999, p. 118) where the researcher comes in, takes and leaves, without adding discernible benefit to the participant group; or valuing the local voice (Badger, 2000). The dominant culture of colonialism is played out in these historical research methods and traditions, with a loss of control of intellectual property for the participants in the research (Liamputtong, 2008; Tuhiwai Smith, 1999).

Codes of conduct for researchers carrying out research with indigenous groups are outlined in declarations such as the ‘Mataatua Declaration on Cultural and Intellectual Property Rights of Indigenous Peoples’ (signed in Whakatane, 1993) and research ethical principles and responsibilities for use with Maori are outlined in Kaupapa Maori Research practices. These respectful values can also be modified as needed and applied to research with other indigenous groups (Tuhiwai Smith, 1999).

PAR is a valuable approach for cross cultural projects as it allows the community itself to identify and define all aspects of the research process and so embed the research within the participants’ cultural setting. As a result, the methodology will be reinterpreted and reconstituted by participants with questions, context and understandings culturally appropriate to the participants' situation, to help create meaningful research to directly benefit the participants' community through change (Maiter et al., 2008; McTaggart, 1991; L. W. Roberts, 2013).

3.3 Methods used in this study

Overview of the action cycle

This study began with early community consultation, involved action cycles which consisted of multiple stages of participant recruitment, data collection and analysis, and ended with dissemination and 'handing back' of the research findings to the Te Vaerua Board. Each stage of the research journey is described below. For an overview of the full research process, including participant recruitment and data collection see Figure 4.

Ethics approval

The research project undertook consultation with Maori (Appendix 1) and received approval from the Rehabilitation Board of Studies, University of Otago Ethics Committee A (Appendix 2), National Research Council (Cook Islands) and Cook Islands Research Committee (Health) (Appendix 3).

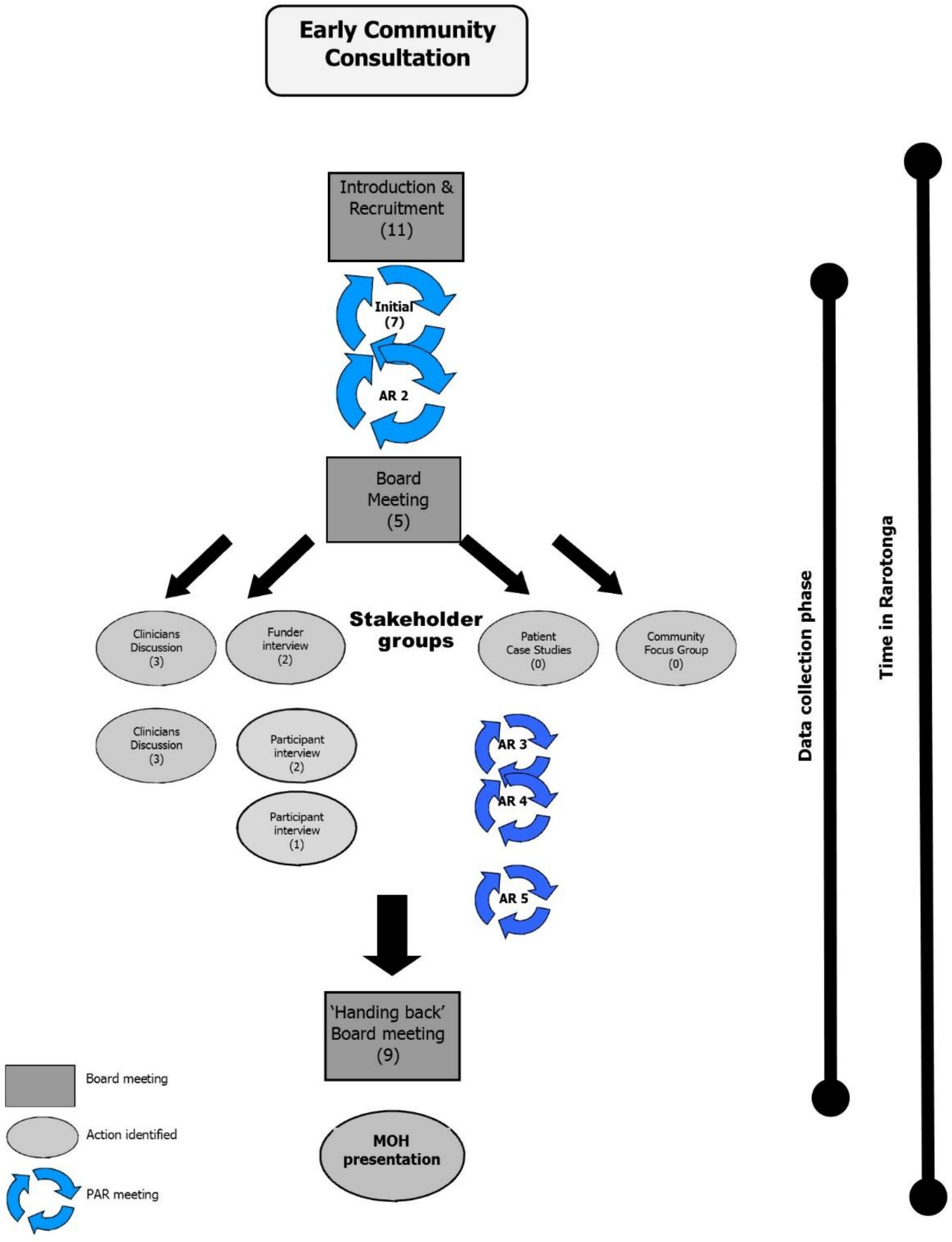

Figure 4: Overview of the research process

Early consultation and development of the research question

This PAR study sought to engage with Te Vaerua members to explore their views and meanings of rehabilitation in the Cook Islands. The topic for this research emerged from early discussion with Te Vaerua where they indicated a wish to use research to improve their provision of sustainable rehabilitation services in the Cook Islands.

I drafted a preliminary research proposal and approached Te Vaerua by email in January 2013. The proposal was reviewed and altered by the organisation's Board via email prior to ethics and research council submissions.

Once I was located in Rarotonga, I attended a Board meeting and formally invited Te Vaerua Board members to participate in this study, inviting interested members to attend an initial meeting, formalise a research question and the direction of the research process. The discussion regarding the utility of the research question and direction focused on the upcoming 5-year strategic plan (2014-2019), which was due for submission to external funders by October 2013. This document was to outline the activities and direction of the service, setting objectives against which funders would evaluate the service. During the meeting it was noted by a Board member that that the research project would be a valuable tool to clarify, prioritise and direct thinking by allowing reflection on what was held as important about rehabilitation, and that it would be timely to use this process to inform the strategic plan writing.

Te Vaerua Board members expressed interest in exploring what an ideal rehabilitation service could look like without consideration of the constraints of funding, situation and staffing realities, and to identify where the current gaps were between the ideal service and the current service delivery. They wished to review and clarify the core values they held regarding service delivery of rehabilitation, and what key ideas underlined their core values of rehabilitation.

During the meeting the agreed foci of the research project were identified as follows:

> *What is the ideal rehabilitation service and to identify the gaps in service?*
>
> *We want to identify our core values and service and the key things that are important.*

Participant recruitment

PAR requires engagement with local people to create meaningful research which directly benefits the participants' community. In this study, the community was the Te Vaerua service, which includes both those who provide and benefit from rehabilitation.

Initially, participants were recruited by self-selection, with Board members offered the opportunity to be part of the research process. All participants were given an information sheet and a memorandum of understanding as part of the consent process for participants (Appendix 4).

Board members were invited to attend an initial research meeting. These members include both Cook Islanders and Europeans resident in the Cook Islands and consisted of both men and women who had been involved in Te Vaerua for periods of time ranging from prior to inception (i.e. before 2006) with the most recent members becoming involved in 2012. Seven members attended and two formal apologies were received.

Through action cycle meetings, stakeholder groups were identified by participants to approach and invite to explore the expectations and understandings of rehabilitation. These identified groups were: Funders of Te Vaerua service; Te Vaerua rehabilitation staff; Te Vaerua Service Users and Community Members. Three groups of stakeholders were approached in different ways by different participants to seek their opinions and preferences for the focus of Te Vaerua. Thus the study employed in part a snowball sampling method to participant recruitment (Sadler, Lee, Lim, & Fullerton, 2010). The three identified groups included were:

i) <u>Funders of Te Vaerua service</u>

Te Vaerua is funded by NZAid via the ‘Small Impact Fund’ and Asian Development Bank Japan Fund for Poverty Reduction, overseen by Ministry of Finance and Economic Management and administered by Ministry of Internal Affairs in the Cook Islands. These funders were locally represented by two Cook Islands Maori women. Their viewpoints were considered valuable by participants for Te Vaerua to be able to formulate a strategic plan with clear goals and objectives in language that was understood by the funders and therefore successful to secure ongoing funding. The funding representatives were known to me from prior to the beginning of the study and were interviewed together at a local café in Rarotonga.

ii) <u>Te Vaerua rehabilitation staff/clinicians</u>

This group include those individuals who worked directly with patients and service users, referred to as ‘therapists’. It consisted of me as the researcher and physiotherapist, an occupational therapist, the equipment maintenance coordinator, and the family support visitor (a voluntary role). It was hoped that the contracted physiotherapist who was yet to arrive on the island would also join this group later in the study, but this did not eventuate. This group consented to be involved at a Board meeting and agreed to meet at the Te Vaerua clinic during work time to discuss the research question.

iii) Current patients

These stakeholders were to be approached informally by their therapists during normal therapeutic interactions, with individual case studies brought by the participating therapists to inform discussion at a group level. Initially the intention was for these case studies to be formally documented before being shared at a research meeting for Te Vaerua rehabilitation staff. However, participants found formal reporting of case studies challenging. So instead, patient perspectives were informally incorporated into information provided and discussed by the participating therapists. Through this informal approach, therapists were able to reflect on their own beliefs and expectations of rehabilitation and to discuss these with patients in a non-confrontational manner to gain patient feedback during the research process.

Community members were another stakeholder group identified by the participants. My intention was to collect data on perspectives of Te Vaerua and rehabilitation from the wider community by meeting with a village group organised by a Board member participant who is also a village elder. This was suggested by another participant but did not eventuate due to time pressures and other commitments of the village elder.

Data collection

The data collection period was from August to October 2013, during which time I was immersed as a clinician in the day-to-day provision of physiotherapy services for Te Vaerua in the community and at the hospital. The Te Vaerua Board was aware of the limitations related to my time in Rarotonga, and had indicated their commitment to the data gathering phase occurring within this timeframe. Three types of study data were gathered: 1) audio-recordings and transcriptions of meetings, 2) member-checked, summary sheets of interviews and meetings, and 3) my personal observations and reflections recorded in written and audio research journals over a three month period.

In total, 13 meetings were conducted during the course of this study, with each meeting typically lasting between one and two hours. All meetings were recorded. Data from the audio-recordings were transcribed verbatim. However, as the study process involved recording a lot of data in the field (as opposed to just formal interviews in meeting rooms), the audio-recordings contained a lot of information not directly relevant to the study topic. Furthermore, because I was known to the participants, interviews were often punctuated with informal conversation on other topics. Transcripts of the audio-recordings were therefore undertaken only for those parts of the audio data that were related to the specific objectives of the research. Board meetings were used for observational data rather than as a source of audio-recorded data due to the varied topics and discussion points in these meetings.

Participants were identified in the transcriptions by code. I have chosen to refer to all members as participants, and code them with a number (P1, P2 etc) and exclude any role context.

Summary sheets were completed directly after interviews and focus group meetings based on my notes and initial analysis of the audio-recordings. These were emailed to meeting participants for verification. Summary sheets were viewed alongside the audio-recordings and transcriptions of meetings to allow a greater thematic analysis of data.

In addition to the interviews and focus group meetings, I maintained a chronological reflection diary of both written notes and audio recordings. These diaries contained auto-ethnographic observations and reflections of living and working in the Cook Islands, as well as reflections on conversations, interactions with patients and locals, challenges, and areas of personal cultural context and journey. My observations of patient and hospital staff interactions, Te Vaerua organisational structure, decision making and communication, interpersonal interactions and cultural norms, both in the organisation and wider community forms part of my rich tapestry of experiences and understandings about values and how they are expressed in the Cook Islands environment.

These written and audio diaries also held my reflections on the meetings, including the environmental setting, communication process, participants' involvement, body language, my overall impression of the discussion, and the external context that I felt may have influenced direction of discussion.

Meeting structure

The President of Te Vaerua was able to offer counsel and guidance regarding cultural expectations and processes. Formal meetings are opened and closed with a prayer, and this was conducted by the President, or another senior participant. It is not always customary to pray in situations when meeting with another individual or a small group, but participants were offered the choice. As all Te Vaerua Board meetings are held in English, all research meetings were also held in English, with any Maori phrases and terms translated by the speaker for the other members.

It is traditional to provide refreshments at organised events, but this was not the practice at Te Vaerua Board meetings. Nevertheless, as recognition of time offered, I provided coffee, juice and snacks at all interactions, and purchased food when interviews were held at a café. Reimbursement for participants was considered, but I was advised by key informants that a *koha* (gift) to research participants was unnecessary in this situation. I understood that this was due both to the collaborative nature of the research and interest in the outcomes, and also that I was providing specialist physiotherapist services to Te Vaerua while I was in Rarotonga.

Key informants

As implied above, this study involved interaction with a large number of people and at different levels of engagement. Some individuals within this wider cohort of people were found to be particular useful in progressing with both data collection and understanding of this data during its analysis. I came to view these individuals as 'key informants' during the research process.

The concept of a key informant (Tremblay, 1957) originated in cultural anthropology but has been used more widely in other social sciences including health care research (Marshall, 1996).   A key informant technique is one in which more in-depth interviews are held with key individuals who are able to provide a description of the social and cultural patterning of the community (Tremblay, 1957).   It involves strategic choice of individuals with a view to the structure and context of the enquiry, and selective sampling of their specialised knowledge. Two individuals were identified in this study as key informants, both of whom were formative members of Te Vaerua, actively involved in most aspects of the organisation, respected members of the business and Maori communities, and fluent in Maori language and cultural practices. These women were used extensively during the initial formation of the research question as well as interviewed during the process.

Data analysis

The analysis consists of a thematic analysis of concepts arising iteratively from the data. Action research holds that the journey of the process includes ongoing cycles of investigating, actions, outcomes, and learnings related to these, and analysis is shared within the action cycle as a process of reconsideration and change. This ongoing process occurred throughout the data collection phase. The process used for theme identification is outlined in Figure 5.

During data analysis each audio-recording was listened to alongside the verified summary sheet. Full transcriptions of four interviews were completed to allow thematic analysis by academic supervisors to ensure transparency and integrity of thematic extraction. Transcriptions were read alongside audio recordings and corrected as required. Initial themes emerging from the transcripts were documented in the transcript margins.

I listened to audio-recordings again after initial themes were identified to ensure all concepts related to the research question had been captured. Transcriptions were read alongside summary sheets while also listening to audio recordings, and I jotted further reflections into the margin and highlighted passages. I underlined participants' words to use as textual terms capturing the essence of the theme, and wrote this word as an emergent theme in the margin. Themes and links between passages were also noted in the margin of the tabulated data.

Emergent themes, subthemes, transcribed quotes and my reflections were tabulated. Quotes related to these reoccurring themes were revisited to check context. As I recognised emerging concepts, these were discussed informally with participants and a critical friend for personal clarity. Diagrams of links between categories and ideas (subthemes) were created and eventually refined into a thematic index. The thematic index was discussed, clarified and refined with input from supervisors and key informants.

These initial themes were presented back to the Board at a formal meeting on 15 October 2013 for discussion and member checking. Feedback from the Board was that the presentation was representative of what was valued and expressed by their organisation and community.

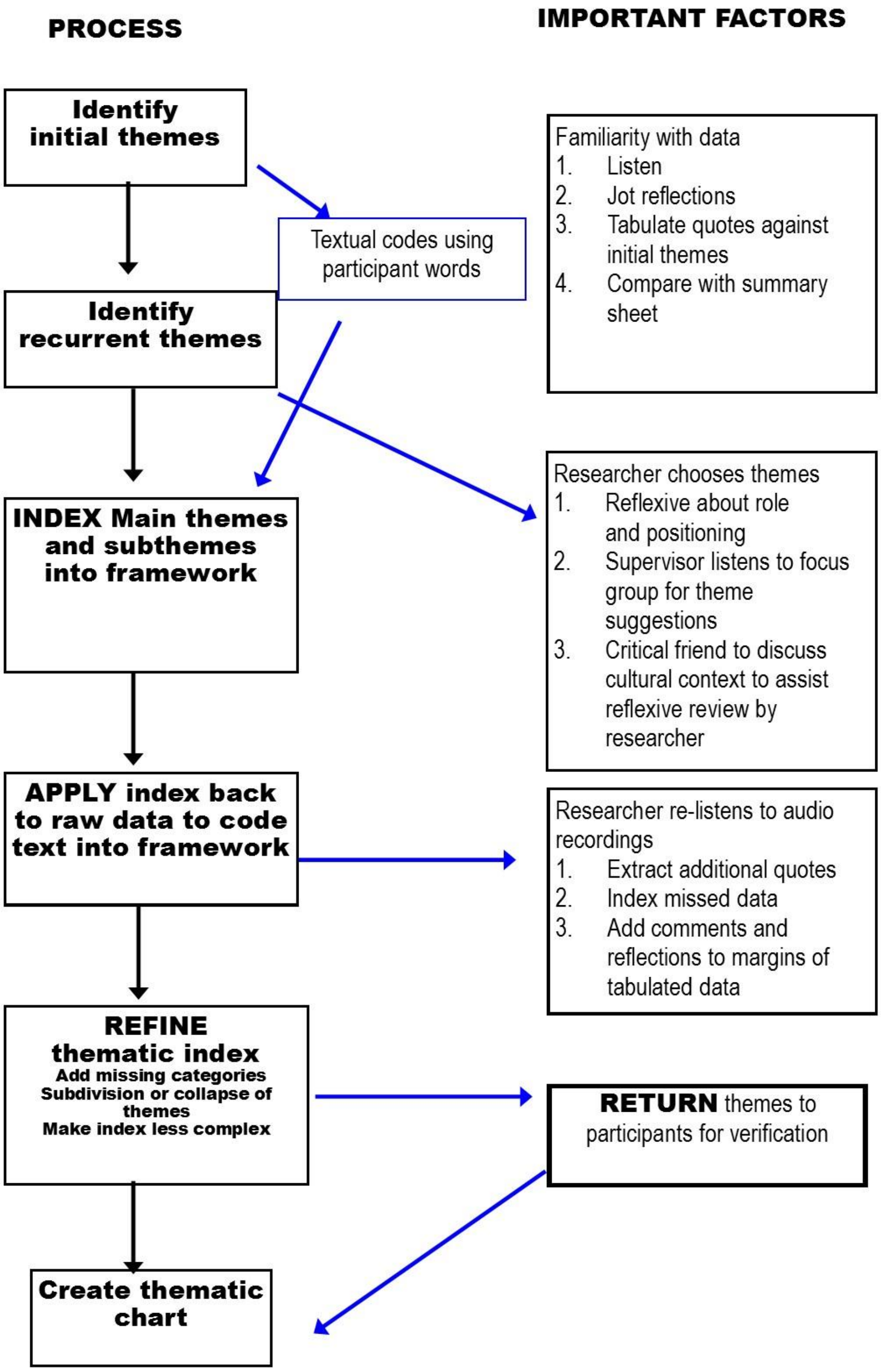

Figure 5: Flowchart of theme identification

Derived from (Ritchie, Spencer, & O'Connor, 2003)

Dissemination of results and implementation of action points

The initial research focus centred on development of a 5-year strategic plan for Te Vaerua. While participants were motivated towards production of this document, only two participants were responsible for this. Key informants were valuable in this situation to explore how discussion points from meetings could influence or alter this document.

As noted above, each meeting had a summary sheet completed, which was a summary of participant discussions, and agreed actions. These summary sheets were completed within 24 hours of the action research meeting and emailed to the participants of the meeting for verification. A follow up email was sent within seven days of the meeting to reflect the discussion and actions identified.

During action cycles participants recognised that they wished to explore a wider view of Te Vaerua services, and identified additional individuals to approach as discussed above. A condition of approval from the Cook Islands Health Research Council was for me to deliver a presentation to the Grand Round at the hospital. This weekly meeting was open to all clinical MOH staff, and includes a presentation of inpatient cases, and an inservice. This presentation was planned as part of the action arising from this work. However, following the principles of PAR, there was an intention for other action points to arise from the research rather than being predetermined prior to data collection and analysis.

3.4 Methods used to enhance scientific rigour

The term rigour refers to the systematic study of a research question by application of appropriate methodologies in order to be assured of the quality of findings (Allison & Rootman, 1996). Traditional, positivist standards of rigour are difficult to apply to PAR where quality, goodness, trustworthiness, credibility, and workability have all been suggested as alternate terms to describe criteria for good action research (Herr & Anderson, 2005).

In addition to the sound application of methodology, PAR should be measured against the values and goals it holds, that is: creation of new knowledge, achievement of action-oriented outcomes including participant and researcher learning, and results that are locally relevant (Herr & Anderson, 2005). The actions and changes that occur with a PAR project are a vital measurement of success whether they exist as self-reflexive changes in practice, or organisational change.

PAR, based in a participatory paradigm should show instead whether the project 'does good work' by reflecting on the core values of PAR and how well it reflects these. Trustworthiness considers how much the 'facts' of the research findings resonate as true with the research participants and throughout the wider community (K. A. L. Williams, 2001). It is noted that trustworthiness does not necessarily reflect success with action oriented outcomes (Herr & Anderson, 2005). Involvement of participants in all aspects of PAR should lead to high trustworthiness of findings. Sustainability of outcomes is also increased with local ownership of the project, including improved local confidence in the community's capacity to identify and solve their problems (Ehde et al., 2013; Jagosh et al., 2012).

Credibility can be enhanced with triangulation which suggests that several different perspectives should reflect a similar theme or fact to improve the reliability of the collected data (Herr & Anderson, 2005). Triangulation can be considered to add breadth or depth to analysis through multiple perspectives or different types of reading, thus giving a fuller picture of the theme or phenomenon (Ritchie, 2003). For this study, summary sheets were used (as noted above) to allow participants to reflect on, comment and correct ideas raised. Previous discussions were also reviewed at the next meeting, and participants were encouraged to reflect on what they had been thinking about, or if/how the discussion had influenced their ideas. Emergent themes were discussed with key informants to gain further depth of understanding and clarity.

Other aspects of rigour for this study will be explored in Chapter 5.

Chapter 4: Results

4.1 Introduction

This chapter will outline findings related to how rehabilitation is conceptualised and put into practice within the Te Vaerua setting. First, themes related to rehabilitation which emerged from discussion with key informants and other stakeholders will be described in detail. Next, my observations on the actions and processes arising from the research (which for a PAR study are considered *part* of the results) will be discussed. Finally, an observation of long-term changes in the organisation and provision of rehabilitation following the will be presented.

4.2 Overview of findings

Through the data analysis process, several key themes emerged as important to Te Vaerua related to rehabilitation. The raw themes and categories were presented back to the Board and agreed as being an appropriate representation of their community's views, values, and experiences. These raw themes and emerging concepts were refined into main and subordinate themes (Table 2).

An overarching concept was expressed as a framework for service provision: that 'people are the most important thing': that the wellbeing of the community and each individual within it is highly valued, with rehabilitation aiming to 'cater for the needs of people with disabilities living in the Cook Islands'. Another related key concept was the awareness of the need to maintain families together on the island, with support in their communities.

Table 2: Themes and Subthemes

Central concept: Ko te iti tangata te mea maata. People are the most important thing	
Main themes	Subordinate themes
Rehabilitation is available	Rehabilitation is: • Local (i.e. based in Rarotonga) • Visible (i.e. to the community; to funders) • Practical (i.e. everyday solutions for everyday needs; solution focused) • Strategic (i.e. forward thinking; building on existing linkages)
Rehabilitation has ‘heart’	Rehabilitation is: • Relational (i.e. interpersonal skill are more vital than clinical skills; personal stories and self-sharing is valued) • Charitable (i.e. ‘for to whom much is given, much is expected’) • Generous (i.e. manaaki ki te tangata - be generous)
Rehabilitation gives hope	Rehabilitation: • Reduces family burden • Values independence • Shows possibilities and build awareness

Central concept: Ko te iti tangata te mea maata. ‘People are the most important thing’

All participants shared a common motivation for their involvement with Te Vaerua and the expectation of why rehabilitation is important.

> *At the end of the day, the people driving it, you know, there is a purpose, and the purpose is always the people. (P1).*

Participants expressed the view, grounded in Christian tradition, that each person is a unique individual, worthy and valued despite disability or status; and also expressed a shared view of their role and responsibility to the community in easing the burden of others. An interconnectedness of people as part of a shared community was evident throughout discussions. An underlying theme was that the provision of service must align with the needs of the people of the Cook Islands, and in particular, people who were less privileged or required assistance:

> *Before, rich people, like me, like my family, got on a plane, and fly to NZ and get all the rehab we need... I need it, get on a plane, bang bang… [others] can't afford that, you know. And in this day and age, why should people miss out, just because of money, that is not right (P1).*

In this extract, the speaker describes an understanding of privilege, and that she (and Te Vaerua) were in a position to give back to the people in their community by offering rehabilitation services, with those services targeting people who are most in need.

> *The service is for our people, at the most difficult of situations (P2).*

The name Te Vaerua was described as reflecting the values that the group held. The name illustrated how rehabilitation was considered and enacted in the Cook Islands by Te Vaerua. The words 'te vaerua', explained one participant, 'means an inner spirit, a spirit of goodwill, a spirit of giving… it embodies everything, the giving of time, the giving of you know… someone who has that heart' (P1). Another participant reported that the name Te Vaerua referred to 'a spirit of giving without expecting return' (P3).

These two quotes, providing an explanation of the Maori meaning for the word ‘Te Vaerua’, also reflected the vision behind of the establishment of the service: a not-for-profit organisation that sought to support locals.

> *For me that is what Te Vaerua is. Te Vaerua’s purpose is to make Cook Islanders lives better (P2).*

From this central concept, and related discussion around it, three key themes emerged. Firstly, it is important that rehabilitation is available, locally present and accessible for people who require it, providing practical and pragmatic solutions. Secondly that rehabilitation has ‘heart’, being built on interpersonal relationships and a shared responsibility for each other, expressed as a cultural expectation of giving and providing support. Thirdly, rehabilitation should provide hope by offering the possibility of a better life. These three themes will be described in more detail below.

4.3 Rehabilitation is available

One significant theme identified was that rehabilitation should be available. At first this idea might seem simplistic, but the concept of the availability of rehabilitation on Rarotonga was closely associated with family wellbeing and with the accessibility of service for members of the community. According to the participants, for rehabilitation services to be available, they also had to be locally-based, visible, practical, and strategic.

> *What happens is – Te Vaerua enabling Cook Islanders to get treatment at home, here, it is enabling families to stay together, because, in the past, if, say my dad had a stroke, and then he had to*

> *go to NZ to get the treatment that he needed, then, I would have to take my dad there, I would have to take my family there, you know, we would leave and then we would never come home (P1).*

Rehabilitation needs to be local

Participants in this study often stated that they did not necessarily understand the process of rehabilitation, but they did know that they want services to be available in Rarotonga. The protectorate agreement with New Zealand means that Cook Islands residents are eligible for Auckland based tertiary medical services, including rehabilitation. It was common for families to take their family member to New Zealand with the whole family and emigrate, or to split families between the countries for the duration of medical need, particularly if there was ongoing disability that did not receive financial support in the Cook Islands.

> *They have decided to (take) their mum to NZ for what she needs… .. yeah, she had a hip replacement and stuff, and now she has had a stroke, and is back over there, and so now, [her daughter] and her sister, her sisters, they alternate one goes for 3 weeks, and [the mum] has regular physio, and they alternate, and that is how they are living right now (P2).*

This created a burden on families, both those in the islands, and families that are in New Zealand and expected to support the visiting patient, to the Cook Islands to send patients and an economic loss of families that may not return.

Rehabilitation needs to be visible

In order to continue to exist in the Cook Islands, Te Vaerua presented itself to a variety of services, funding agencies, and the community as a long term, successful service worthy of investing time, money and involvement, include to those who would fund, refer to and/or support the service, and to the patients and families in the organisation was established to serve. It was vital therefore for Te Vaerua to be visible, and to be visible in a variety of fields. There was recognition that in order to meet the underlying goal of providing services to the people Te Vaerua needed to present a recognisable face to funders, including to the MOH. The importance of visibility to Te Vaerua was evident in discussions related to the importance of a physical clinic space, and this example showed how visibility was considered with different groups of stakeholders in strategic ways.

Visibility through the clinic

The clinic building, as a physical representation of the service, was important to Te Vaerua because of the way it contributed to service visibility, even though there was a shared view that the patient's home was the preferred venue for treatment. Thus the clinic was a physical symbol of the organisation and much time, effort and fundraising had been put into renovating it to the point where it was suitable and operable for patients.

The clinic provided a public base for Te Vaerua, and evidence of needing to be visible in a variety of ways was apparent in discussions about the clinic. The clinic provided a stable base for Te Vaerua: somewhere that showed where the NGO was placed on the island, a tangible 'sense of place' for the service, and a drop in place for patients. However, the participants offered a variety of different reasons why the clinic was so important to the vision and understanding of Te Vaerua. As well as offering a practical space for rehabilitation, administration space for therapists, and a workshop and storage for equipment, there were three strategic viewpoints related to the clinic.

Visible to funders

The clinic provided a physical evidence of a professional service, showing Te Vaerua to be more than just a community group. The clinic represented a long term, specialist service that fitted with perceived expectations of external funders and agencies. To present a professional clinic gave Te Vaerua the opportunity to show itself to be credible in line with these expectations. Aligning with such expectations was considered an important strategy.

> *[We] are trying to lift ourselves up from where it is and justify our self on a whole different kind of level now, and… about hand cleaning stations and plastic pillows, at the end of the day, you know, it actually breeds credibility to the service to have those look nice with those hospital like things (P2).*

Visible to external health services

It was also considered important to not only show a professional service to funders but also to the MOH. A long term goal for the service was that eventually rehabilitation would be viewed as a core health service alongside other secondary and tertiary health care in the Cooks Islands, as this was considered to provide the best seamless care option for patients. While ‘looking like a hospital clinic’ was not seen as an important use of financial resources in order to provide the current service, it offered a strategic opportunity as a point of recognition for the MOH.

> *We actually need to lift it up to that standard so that we can be considered on that standard, so it is kind of difficult because we are not publically funded, it is still a charitable organisation, but it is important… Some of the stuff is over the top for us, but it is really important for the health service to see that as well, cause when [the Secretary of Health] sees that, when she comes down and sees these wee elbow things [hands free taps], that's no language to us, but to her, ok, to her it fits in with her [idea of] health services (P1).*

Visible to patients

Another strategic aspect of how the clinic looked was how it appeared to the patients themselves, and how this might have contributed towards the goal of giving people with disabilities hope and raising possibilities. Associated with this was the idea that the clinic also represented the respect given to the patients that Te Vaerua worked with:

> *Making the physical facility pleasing on the eye… so that when disabled people came here they felt valued, by what they were looking at and that they felt valued because what they were going to, was, was great. You know, that if people have a wonderful facility, just for them and they feel that they want to use it and do use it for better well health, then that is a wonderful strategy. (P8).*

The clinic had a bathroom and toilet that were accessible, and the service was in the process of completing the construction of a wheelchair accessible kitchen. These rooms were both used to give ideas of about how homes could be easily adjusted to be more accommodating of wheelchair accessibility, and to show how a pleasant and respectful space for people with disability could be achieved. There was a tension within this discussion however as to whether the kitchen should be extremely basic, with the type of taps and bench units that are easily and cheaply purchased from local hardware stores (i.e. affordable for local families) or whether it should be a top-of-the-line kitchen which showcased the best options available, adding dignity and value with the aim of giving hope and raising possibilities. Eventually, pragmatics and limited funding dictated an available and affordable option would be more suitable for the clinic.

Visibility within the community

In order to meet the overarching goal of meeting the needs of the people, it was vital to be visible to the community; to those individuals and families who may choose to access the service. Referral criteria and services offered were key components of the information thought to be important to be available to the community. A primary source of community information was word of mouth.

Visibility through personal stories - a culturally mediated way of sharing information

The Cook Islands use face to face communication as a major source of information sharing. Personal stories form a large part of how individuals and services are viewed, and how a trust relationship is formed. It was vital therefore for Te Vaerua to have good stories about the service spread by word of mouth as impressions of the therapist or service were formed quickly, shared widely, and slow to change once established.

> *What it takes is word of mouth, if somebody says, he's good! You know, that is what will build your reputation more than anything else. It is also what will destroy your reputation (P7).*

Raising awareness of the needs within the community was also considered important, and personal stories were vital to be able to do that. Participants talked about the impact of having one man (M) travel to Mangaia (a Southern Group Island) and tell his story about becoming and being disabled. This personal story challenged listeners that people with disabilities are peers and community members, and to reflect on whether individuals can remain an active part of the community after they acquire a disability.

> *[M] going out to the outer islands was that huge, and the reason was, [M], when he was well worked in conservation - they knew him before he got sick. To find a man, that they knew well, that had it [a disability], got it from fish poisoning, cause most of those guys get fish poisoning, somewhere along the line, cause they are fisherman. So for them to hear that, that was a huge thing.*
>
> *He was one of the really pivotal, and I really, I don't think people give him enough credit for what he did… [M] really made a huge difference in the outer islands, because it made visible, it made it… when you get that shift, that creates huge awareness. People look different, you look with different eyes when you see somebody's story like that (P6)*

In addition to personal stories, other aspects of visibility were considered useful adjuncts to providing a good service. Physical visibility, such as through use of a clinic sign or staff uniforms were discussed. I observed that use of media such as human interest stories in the daily newspaper, a TV documentary and holding fundraising events were all successful in raising the profile and visibility to the Te Vaerua service and raising awareness of disability in the Cook Islands. One participant described other ways of increasing community visibility alongside a recent article in the newspaper.

> *Do the locals know? You need to do it through other things, like telly, community people, community notices in the paper – you should put it in there. It is more of an awareness thing, people need to be aware… but talk to people also, and go with the NGO adverts in the paper – put some signage up. (P6)*

Rehabilitation needs to be practical

For the participants in this study, it was important for rehabilitation to be practical and solution focussed. For example, provision of therapy equipment, such as wheelchairs, walking frames, showering and toilet equipment was seen as an important part of rehabilitation and a practical solution.

> *People expect equipment. When we are seen as providing equipment, we are providing something. It's a visible thing (P5).*

Provision of equipment not only met a practical need. It was also a tangible gift (i.e. a visible way of giving) and one that was understood by patients and families as such. Giving equipment was valued highly by all participants, who linked equipment with improvement in function.

> *Without equipment there is no independence (P9)*

Equipment also had a role in the visibility of the service. When equipment was named and obviously supplied by Te Vaerua it formed another strategic way of increasing visibility in providing rehabilitation to the community and a way of offering rehabilitation in a way that was understood as valuable.

> *Equipment is a tangible thing, is it visible, it is what they identify to do with rehabilitation (P1).*

Decisions were often based on finding a solution rather than on expectations of what rehabilitation should involve from a Western perspective. A participant noted that it's 'the way that we work… .. if there is something that you need to do, you just go off and do it in our own way, and just get it done' (P1). Value was placed on identifying issues and providing solutions. With rehabilitation and disability awareness relatively new concepts for the Cook Islands, there were limited policies or procedures to guide decisions or to implement solutions. A participant recalled her experience of a government office improving physical accessibility.

> *Well you know how you got the ramp to the immigration office, for wheelchairs don't you, no? Well, I kept an eye out, and there was a little narrow door, and I said why are you putting in a little narrow door? Isn't this for people who can't walk up stairs, and most of the people who can't walk up stairs are in wheelchairs aren't they, cause they can't walk. This door isn't going to take a wheelchair. 'Oh my golly gosh you are right' so he put in the wide door. So I said, that's great, you have got two great big steps going up, who is going to pull a wheelchair up those two steps in the sandy wet thing, and he looked at me, and I said, you had better put a decent ramp,*

> *and get a person in a wheelchair to try it and see if they can drive up it. So they did. So that is why I stood out there every day and said, no, that's not wide enough, no that's too slanty' (P8)*

In New Zealand, if a therapist were to identify an environmental barrier in a patient's home, such as no wheelchair access or uneven ground causing falls, the therapist would refer on to the appropriate agency for funding and provision of a solution. In Rarotonga however there was no specifically allocated funding or third party organisation responsible for these activities, so alternative solutions were undertaken instead. Stories reported during this study included one of a patient who received a home ramp following an timely conversation with a local politician, and another of a front yard being levelled to accommodate safe access after a request was put to a construction team who were employed to repair a village road. Of note: neither of these solutions were open to me as non-indigenous health professional without community support and neither could be planned for as a part of a standardised policy or procedure in any future solutions for other patients.

Rehabilitation is strategic

In order to offer a successful service in the Cook Islands, Te Vaerua has to be able to secure funder and community support as well as government ministry acceptance, particularly the MOH and Internal Affairs. It also has to be suitable to the expectations of the patients and families that it seeks to serve. As a result, Te Vaerua has to show different 'faces' to different places, and be understood in a variety of political and cultural contexts.

> *We are talking two different languages, we are talking community based rehabilitation language and we are also talking, donor*

> *funding, like how it fits with, into, all that kind of stuff, language, and they are not always the same (P2).*

These multiple views and the importance of utilising all available avenues to ensure that rehabilitation was present and successful in the Cook Islanders was recognised and implemented by Te Vaerua in a variety of ways. For example, it was viewed as important to have a range of people on the Board who both reflected the community and who were able to add credibility to the service by their presence. Each member's involvement was requested by the founders due to their skills, community position or disability.

Board members were not the only strategic use of individuals to ensure that rehabilitation was able to be offered. For example, Te Vaerua was keen for my presence in Rarotonga in 2013, not primarily to be involved in the research, but in order to have a physiotherapist present. The presence of a full time physiotherapist was needed to put Te Vaerua in a position to sign an arranged Memorandum of Understanding with the MOH, and receive funding for rehabilitation. A contracted physiotherapist was due to arrive in September, but my presence in July meant that this funding stream was able to be accessed for rehabilitation earlier. An additional benefit of my presence was to be able to introduce the new physiotherapist (D) to the service, and strategically consolidate links within the community and other services.

> *And I think that is how you do if that with someone who has already got the trust passed on that relationship, 'well you trust me, and I now trust the Te Vaerua person, and um, and I would like to bring them round and introduce them to you' and then let the person begin to build the relationship on a higher platform than going in*

> *cold. And I think that is really important in the community. And I think that what you have done with D, with the ones that already trust you, [it has] assisted D for them to trust him [more] than if you hadn't been there (P8)*

4.4 Relationship has heart

The theme of giving was paramount to the understanding of rehabilitation, with 'having the right attitude and heart' being vitally important to provision of quality service. This theme was presented in three different interlinked ideas of relationship, charity and generosity. All of these aspects of a 'heart for the people' are reflected in the involvement of the Board member group, who have been motivated to generously contribute time and effort, and to be part of Te Vaerua in order to serve their people. During the study, an often heard response from the Board members was a denial of any understanding regarding the provision of rehabilitation.

> *I can't help you with your research – I don't know anything about rehabilitation (P4).*

> *I don't know anything about a health service (P2).*

Initially, this seemed to me an unusual response for a group dedicated to the formation, funding and running of the only rehabilitation service in the Cook Islands. However, during immersion in the data and personal observations, I came to understand that the Board worked with a shared understanding of serving the people of the Cook Islands rather than a commitment to rehabilitation as a clinical activity per se. In other words, the Board did not have a cohesive and structured view of rehabilitation – what it involved, and what was important to implement it – because understanding rehabilitation was not strictly important to a group of people dedicated to serving. It was considered enough to ‘have the heart’, then leave the details of service provision to the ‘experts’, such as the employed therapists.

It was viewed as more important to have the heart for the people as your motivation and a personal attitude to assist others than to be a fully trained therapist or to be a Board member with a strong personal understanding of rehabilitation.

> *You know, that it takes a special kind of person to be a physio, or someone who runs a charity, or someone, you know, who has that heart (P1).*

When a patient or service need was identified and recognised, action was taken. The response was not based on a set process or protocol of service delivery. Te Vaerua was not driven by an external expectation of what rehabilitation should ‘look’ like in terms of services, therapies or professions, but by an emotional response to community need; by ‘heart’. This created a challenge for the provision of local, culturally appropriate services, when overseas experts in rehabilitation are employed to facilitate service provision, but are foreign to the culture and environment of the Cook Islands and Te Vaerua. This has the potential to create a tension between an expected, fluid model of locally relevant service that ‘has the heart’ and an introduction of a Western cultural model of rehabilitation care with a different framework of values.

> *It took several months when I was the sole employed therapist to realise that I would not receive any clinical direction or expectation from the Board, and that I was free to offer services in any format or setting that I felt most appropriate. While this was very exciting, I was reluctant to impose my understanding of how the service*

> *should be run, acutely aware of myself as an outsider, a white female with limited cultural understanding and no local links. (self reflection diary, reflections on my employment, early consultation period)*

Rehabilitation is relational

Within the concept of having the right heart for rehabilitation work, personal relationships were described as key to providing a service.

> *I think that relationship is a really important part of any health professional role. The links that you make with people, that can be the main, if you don't have the relationship, there isn't going to be a good outcome (P5).*

There was no perspective on rehabilitation without this being viewed through the lens of a trust relationship between patient/family and the individual therapist, and it was considered vital to assess what needs people had.

> *That's why the relationship that you build is absolutely fundamental if you want to know what is happening, really happening in their lives, then you have to build that up over a period of time (P7).*
>
> *If you build a good relationship with these people, then they will tell you: they can't get on the toilet, or they can't get off the toilet, those kind of things (P6).*

Aspects that influence how the therapist was viewed by the community (which included individuals who were patients and local funders) were based on the way the therapist was able to establish relationship and trust with patients, families and referrers. Taking time to establish an initial relationship; being culturally aware, such as removing shoes outside the house; smiling; use of Maori language; maintaining confidentiality; accepting food and presence in the wider community (such as children in local schools, attendance at church) were all important factors that were mentioned.

Relationship building was not only considered important on an individual level, but also related to the service as a whole.

> *It is also about building up the relationship, it is really important that our people get to trust you, and consistency is really important, having the same person again and again and again, that does a really good job (P6).*

This example reflects the expectation of sustainability of service, that people are more likely to engage with a service that is seen to be part of the community for an extended time, rather than a short term project.

> *Once they realise that you are there, for the long run, that you are going to be a constant, being there, then they will commit (P5).*

Many aid funded services are seen as short term projects, and therefore lack the relationship with the community required to be able to offer effective services. One notable characteristic of Te Vaerua was the blurred line that appeared to exist between personal and professional relationships – at least from the perspective of a Western-trained physiotherapist. It appeared that the service was in fact built on a series of personal relationships on different levels, which included strategic use of family or community relationship. For example board members were initially co-opted by the founders due to their skills, community position or disability.

> *We coerced them on so that it would be a community service, and we wanted them to provide the community perspective (P8).*

In many of the observed planning meetings, solutions to problems were discussed in terms of approaching a family member or known individual as an organic process. For example, a Health Administrator was approached after her own mother had a stroke, which facilitated Te Vaerua to strategically work with MOH to offer improved services, and to gain visibility for Te Vaerua in the Ministry and with patients.

> *We have been talking to her about it for years, but finally she can see it [i.e. the value of Te Vaerua]... yeah, her mum has had a stroke (P2).*

Rehabilitation is charitable: 'for to whom much is given, much is expected'

The concept of charity runs closely with the theme of rehabilitation being 'for the people', suggesting that 'to whom much is given, much is expected' (P1). A strong theme throughout the data, both transcribed interviews and observations was that those involved felt a duty to support those in their families and communities, and that serving 'our people' was paramount. All participants expressed a feeling of responsibility to use their skills, time and money to support and care for those who required it.

The view that people in the Cook Islands give to their communities because it is their duty, and their way of giving back was reflected in interviews with the funders.

There was a strong expectation that people will do things in their community because they are a member of the community rather than because they are being funded to do so. However, the funders also expressed a feeling that with the advent of external aid funding, these ‘old ways’ were being lost. The view was expressed that the traditional approach to healthcare (and other ventures) based on community support and community fundraising were diminishing, and that a ‘*patipati*’ way (i.e. taking for oneself) was extremely damaging to the respect and love for each other that existed within a community.

> *I think, it is one of the downsides of this work, that people have got less focus on the community way of dealing with issues, and more focussed on the outside donor help – you know (P6).*

Rehabilitation is generous

An important aspect of Cook Islands Maori tradition is the concept of ‘*manaaki ki te tangata’* (be generous) towards others, where ‘*manaaki*’ speaks of looking after or care, but also of respect and kindness. From a Cook Islands perspective, generosity should be viewed an exchange of gifts, rather than a philanthropic benefactor. This reciprocal giving resulted in many generous gifts of food to my family. The fundamental concept of generosity underlies the relational heart of rehabilitation provided by Te Vaerua. Indeed, the term Te Vaerua was translated for me as ‘a spirit of giving without expecting return’ (P3). Generosity was seen in the voluntary time given by Board members, particularly the key informants, as well as the financial and practical support offered by the community, particularly with fundraising.

4.5 Rehabilitation gives hope

Hope was a major theme regarding rehabilitation expressed by Te Vaerua. This was communicated as offering people and families the hope that there was the possibility of positive change and a future, without having to leave Rarotonga. The concept of hope included hope for physical improvement, but also for managing the practical requirements following a stroke, reducing family burden and alleviating fear of the unknown. This hope was therefore not only for the individual but also for the families in a situation that they may feel 'hope-less'. Providing hope was considered a vital part of successful rehabilitation. This was expressed in a number of ways: early intervention in order to support families acutely, provision of tangible services such as equipment, visibility in the community to aid accessibility, provision of rehabilitation on Rarotonga (rather than New Zealand), prompt response to community referrals, and the sharing of positive outcomes by way of case studies or the employment of a person with disabilities.

> *I needed somebody to show me the possibility'. Perfect. And that is it – it is the hope, the possibility of being better than what you are right now after this accident (P8).*

Reduces family burden

Reducing family burden was a high priority for participants, giving support to families in their time of need.

> *[With Te Vaerua] they know when they get home there is going to be some follow up care and they are not just going to be on their*

> *own, and then, and try and wing it, you know, or try and get better without really understanding what, what is wrong with them (P2).*

The provision of locally based rehabilitation, rather than travelling to New Zealand was a significant part of that support. Early intervention with stroke patients was in discussion between the MOH and Te Vaerua during the data collection phase, and this was seen as valuable by participants. The reason that Te Vaerua felt that this was an extremely positive shift was related to the support that families would gain by knowing that there were rehabilitation and support services on Rarotonga, and that they were not alone in their time of need. Interestingly, there was no discussion about whether early intervention was clinically valuable for patient outcome.

> *…and that will make a difference to these people who are, okay right, yeah, when we came up [to the hospital] there was a whole programme put together, there was a physio there, and there was the doctor there. And the plan for that person, already, from day one, includes rehab (P2)*

As well as decreasing anxiety and stress for families at the initial stage after a stroke, it was also hoped that this would prevent the emigration of patients with some or all of their families to New Zealand.

> *Te Vaerua is enabling Cook Islanders to be treated at home, and families can stay together, it is taking off that burden off them, it is taking that worry off them (P1).*

Values independence

Gaining independence was an integral part of the expectation of rehabilitation, particularly related to personal cares, but also in terms of participation in life roles.

> *When I think about rehab, I think about um giving people um access to do the things that they used to do before their accident their stroke, their whatever it was that made them in the state of disability and I kinda look at it like it's not the ambulance at the bottom of the cliff, that it is about lifting a person's dignity to be able to manage the things they need to, to be self-sufficient (P8).*

Gaining participation in normal activities was valued by most, but often goals around improvements were not explicitly stated as the expectation or the hope for improvement was low. This was strongly linked to lack of awareness about rehabilitation and possibilities due to the previous lack of any rehabilitation service. As a result, visibility of Te Vaerua was highly valued by participants in terms of raising this awareness.

> *I think there has been a low expectation. I think that people do want to improve, once they realise that someone is actually going to help them. You know, there is a low expectation about getting better, but when someone actually goes and sees them, and says 'we can actually improve on these areas' then they want it – they want to improve (P9).*

In addition lack of visibility, participants also highlighted that there can be a cultural limitations on engaging with a rehabilitation service, particularly a reluctance to ask for assistance, and health beliefs viewing illness as a normal and acceptable part of life. Both of these cultural concepts were considered to be minor reasons for low expectations of improvement, and that visibility/awareness was the main rationale.

Building awareness

It was important to Te Vaerua to increase the visibility of the service, in order to be accessible to those people who would benefit from the service. However, increased visibility was also important related to the needs and lives of people with disabilities in the community.

> *It is changing the attitudes and actions that is going to make the difference. And I think that Te Vaerua can do that by being visible, talking about the work that is undertaken, about building trust relationships in the community (P8).*

Participants expressed that increasing the awareness and acceptance of the presence of people with disabilities in the community, and how they are able to participate more fully was very important.

> *The thing is, there is such a big picture, it is not just about the home, it is actually about changing community, changing support organisations, it is about, you know that transition, cause I think that is where we are at, we are in that transition phase of going - merging two cultures together – some of the old and the new. It is definitely getting better (P6)*

4.6 Action points and processes arising from the research

PAR is a tool for exploring, informing and implementing change in clinical practice or organisations. Change can encompass alteration in clinical provision of care, policy or theory implementation, or clarification of concepts or values. It can occur as self-reflexive change in practice, or organisational change. The actions and changes that occur with a PAR project are considered part of the results of the study and should be analysed as such. In the case of this study, changes are considered in two parts: 1) actions, ideas and dialogue arising from discussions during the research process and 2) observed organisational changes occurring within a 10 month period following data collection.

Changes arising from discussion

Throughout the research process the Board Member group considered aspects of rehabilitation process of value to them, the implications of these for practice, and how they could be implemented in the context of the Cook Islands. There were several actions identified by the research participants in the initial meetings as being important to the group, and reinforced throughout the data collection phase. The action points that Te Vaerua identified as important to put into place were:

- That data needed to be collected to:
    - identify the extent of rehabilitation need on the islands
    - plan strategically for the longer term to meet identified needs
    - provide service delivery feedback to funders
    - validate how Te Vaerua was adding value to people’s lives
- That the service needed to be increasingly visible to reach those who had need

- That the service needed to link with other healthcare providers on the islands
- That the strategic plan should encompass measurable goals for the service

Prior to the start of the study, one condition of approval for my research from the Cook Islands Health Research Council was for me to deliver a presentation to the 'Grand Round' at the hospital. I had intended to present a brief synopsis of the research question and my research design, but following my preliminary analysis of data and feedback, the Te Vaerua Board requested that information be shared about the service with the MOH as well. This was a result of one of the core themes from the research emphasising the importance of visibility. Consequentially, the 'Grand Round' presentation included a brief overview of the research question but concentrated on a presentation of the services and contact details for Te Vaerua to support communication and referral processes for clinical MOH staff.

These actions all reflect different aspects of how to ensure that Te Vaerua was visible and seen as a useful organisation for rehabilitation in Rarotonga as part of a wider health strategy. There was an awareness that the strategic plan needed to be specific and measurable, reflecting the values and goals of Te Vaerua and the provision of local, practical rehabilitation services for the good of the people. Goals had to be able to justify funding, and data collection was imperative for reporting outcomes. However, data collection was also vital to show the need within the community and to plan efficiently for the future.

Data collection

Data collection was an ongoing thread of discussion. One aspect of this related to the collection of population data related to people with disabilities and their needs, with the aim of using this information to determine the breadth of the requirement for the service. Te Vaerua had previously developed a Disability Database in association with the Ministry of Internal Affairs based on the WHO ICF framework. With research discussions related to identifying need within the community, renewed interest in multiagency use of a shared database was established, and meetings were held with the Ministries of Internal Affairs, Health and Education.

Within the research meetings, it was acknowledged that Te Vaerua may not be able to meet all rehabilitation needs when identified, and some discussion occurred regarding the need for data to inform prioritisation and targeting of service provision.

> *From my perspective, until Te Vaerua really know the size of the elephant, we can't grow and grow and grow and become more and more visible because we can't provide the service. There is a limit to what we can provide with the resources we have got right now (P8).*

Another aspect of data collection related directly to the current work and activities of Te Vaerua, and what data was considered important to gather. Data was considered valuable for planning as well as meeting stakeholder requirements, and validating the 'usefulness' of Te Vaerua. Alternatively, the strategic plan goals and performance indicators needed to be in line with outcomes that were able to be measured and recorded. Consideration of these concepts together strengthened the alignment between service data gathering and feedback to funding agencies.

It was strongly agreed that this data needed to focus on stories reflecting 'real' people, not just statistical data, and case studies were highlighted as a valuable learning and feedback tool for Te Vaerua board members, therapists and funders. Personal stories also have a high value as a medium of relationship and trust in the community, and are important to share with patients and families to show what others have been through or achieved.

> *I think that if, yeah, I think if you can do those case studies, and just show actual stories of people and their situation, I was speaking to [H], was thinking, get that as part of our data and like, ones that have really worked well, and ones where there are challenges and we don't have the resources, like, not just focus on our successes but focus on the really sad tragic ones as well, and try and identify what is going on, so it doesn't happen again (yeah) like, warning, we have got to like, to make these things real, they are not just numbers and figures, they are real people's lives. (P2)*

Service links

Discussion included how and where Te Vaerua should interface and support other health and wellness agencies and services on the island to ensure that patients/families had the support that they require. This included supporting hospital inpatients, both with family education and inpatient therapy support and being an active participant in the discharge process. Also considered was how Te Vaerua should fit with other agencies.

> *We are just part of this patient wellness – it is a holistic view of disabled people and those that are rehabilitating.. ..* Te Kainga

> *looks after the mental health bit, that* Punanga Tauturu *look after the women and families, the men's group look after the violent alcoholic men, that we support them, and we link all these services together (P8).*

Strategic Plan

An initial focus of the PAR identified by participants was to formulate a five year strategic plan within the action cycle of research process. However, responsibility for writing the strategic plan was given to two participants, rather than shared within the group, and discussion of how Te Vaerua's values of rehabilitation may influence and direct the strategic plan did not occur. Therefore the PAR study was unsuccessful in this aspect of facilitating a shared vision and strategic plan owned and shared by participant members during the research timeframe.

Long term observations

Ten months following the period of data collection, I was able to return to Rarotonga and Te Vaerua for a month as a locum physiotherapist. This enabled me to return the collated themes for consideration to the key informants as well as observe changes in the organisation or provision of rehabilitation following the research timeframe. While the study was set within a PAR framework, much of the process of the study felt like my external observation rather than a clear pathway to agreed communal change. It was beneficial to be able to return and view how participation in this study may have contributed to progression of the service. I was able to reflect on my own participation with Te Vaerua, and how this had impacted the lives of individuals, shaped the expression of rehabilitation provision in the Cook Islands, and altered my own expectations of what rehabilitation should be.

My observed changes in the organisation cannot be attributed directly to the research as many external influences and decisions also affect the organisation over time, however some apparent changes were in line with discussions that had been held during the data collection phase of the study.

Local content

An identified challenge for Te Vaerua, as with many CBR projects, was how to ensure provision of local, culturally appropriate services, when overseas 'experts' in rehabilitation are employed to facilitate service provision. One option is to increase the voice and involvement of local people who are trained and skilled to be able to perform roles in the organisation.

The Board underwent significant change over the 10 months following the end of data collection. The Board continued with the same Chairperson, but changed from a Board comprised 50:50 European and Maori members to one that consists entirely of local Maori individuals. Each Board member had an identified area of responsibility such as human resources, website and media management, financial officer, and equipment/building management.

With fundraising support, Te Vaerua had identified and employed a local Maori (NZ trained) occupational therapist, as well as a rehabilitation assistant, fluent in Maori language and custom. Both of these women were well known and respected community members, which added significant depth to provision of culturally appropriate rehabilitation. The rehabilitation assistant provided both independent visits with patients/families as well as visits with the physiotherapist. This allowed for therapy support, but also provide a cultural interface between a foreign physiotherapist and patient/families.

Te Vaerua identified that a Cook Islands physiotherapist would be ideal for the service, and had a long term plan to facilitate this happening. New Zealand based Cook Island Maori physiotherapists had been approached for potential return to the Cook Islands in 2017/18.

Service links

Te Vaerua was providing a weekly therapy morning with the Creative Centre, an education centre for adults with disabilities. This service previously employed a full time physiotherapist but no longer had funding for this. Supporting this population was intended to produce health benefits for individuals, but also provide closer links between the two services.

Discharge support from hospital was occurring with greater frequency and doctors would often seek out an occupational therapy home assessment in order to have equipment in place prior to a patient returning home.

Self-reflection

My practice has been strongly affected by my time in Rarotonga in more ways than I can easily verbalise. Returning to rehabilitation in New Zealand I am aware of a plethora of systems that require layers of written assessments, plans, goals and reporting – all important and urgent. There is an expectation that my intervention will result in an outcome, which will be measurable. The idea that rehabilitation might be more about relationships than outcomes resonates, but is often difficult to capture within Western time pressures. I need to be mindful that my patient is a person within a family; within a community. In Rarotonga, the small population meant that there were often shared social and personal contacts with patients so a sense of natural social relationship existed with little divide between personal and professional roles. This felt both restrictive and refreshing! I recognise that as a result of this experience, I feel more empowered to take the time to learn who my patient is as a person, and comfortable that my relationship with them is part of the therapeutic process.

4.7 Summary

Participants in this study expressed strong views regarding the provision of rehabilitation and the value of this in Rarotonga. The themes of availability, heart and hope all embodied the importance of provision of rehabilitation to service the community and people in their ‘time of greatest need’. Participants were committed to Te Vaerua because of a personal value of giving and charity in service to their communities rather than a clinical or technical understanding of rehabilitation. This was reflected in the expectations of how rehabilitation would be offered by therapy staff, that they would ‘have the heart’ to serve people with disabilities and their family. Alongside this was a realisation that Te Vaerua needed to be more than a charity, and should be visible to the community, to MOH and to funding agencies as a professional organisation that offers quality rehabilitation.

While the participants did not seem to want to be as involved in the research process as was initially expected – with participants providing information but not wanting a high level of control over what was done with that information – actions did occur during and after the data collection phase that were in line with expressed values of rehabilitation held by the participant group.

Chapter 5: Discussion and conclusions

5.1 Introduction

The purpose of this PAR study was to explore how rehabilitation was understood within Te Vaerua in the Cook Islands. This chapter will focus on three aspects of the research journey: emergent themes of rehabilitation, a reflection on the ideology and framework of CBR as it relates to this study, and experiences of PAR including success and limitations of the method. The chapter will explore these aspects with regards to existing literature, consider areas of learning for clinical practice, and identify areas for future research.

5.2 Rehabilitation themes in the literature

The need for rehabilitation service to be present was an importance concept. The themes arising from this study are similar in many ways to Western perspectives on rehabilitation; however the emphasis on ideas differs. For example, improving independence is seen as a key goal for Western rehabilitation services (Wade, 2009) and personal goal setting provides a significant part of best practice rehabilitation structure (Levack & Siegert, 2014). Neither of these aspects appeared to be highly valued by Te Vaerua, with goal setting or goal attainment hardly ever being mentioned.

Western practitioners will be comfortable with the idea of the importance of rehabilitation services being available, but the presentation of this idea was different than I had previously encountered. Similarly, ideas of relationship building and offering hope are not foreign concepts to Western healthcare provision, but do not necessarily represent the framework of service provision and expectation. Each main theme is discussed in more detail below.

Rehabilitation is available

Available was chosen as a representative word, rather than an alternative 'accessible' for two reasons. Firstly, the word was directly taken from transcribed text of the participants' discussions about rehabilitation being available to those who required it in the Cook Islands. Secondly, the term 'accessible' is a widely used 'buzz word' in Western literature regarding services/systems related to people with disabilities. While it refers to services that are available, it has deeper meaning regarding whether those services are suitable for and acceptable to people with disabilities. The less commonly used term 'available' was chosen in this study to avert any potential cultural misinterpretation by a Western reader on what the term might refer to within this setting.

Within this study, rehabilitation that allowed people to remain with their families and village communities was of utmost importance. This had implications both for individuals and families, but reflected also a wider economic concern of migration and population shift, with associated eventual loss of traditional cultural practices and links. While Western complex rehabilitation services are available to Cook Islanders in New Zealand, the cultural impact with transfer to New Zealand in loss of support networks or loss of family units by migration is a source of significant distress for both the individual and the wider family/community, and is a negative economic impact, due to loss of economically productive adults. This economic factor would not occur in a Western urban setting as a primary motivation of rehabilitation services, but may be a consideration in rural settings.

Literature shows that ethnic minorities do less well than Western patients in rehabilitation services. Keightley et al. (2009) looked at services for Aboriginal people with acquired brain injury where rehabilitation provision moved clients from rural to metropolitan areas. The study showed comparatively worse outcome for Aboriginal patients which they attributed to separation from patient support systems, lack of traditional cultural care pathways, limited professional understanding of the home environment for discharge planning and cultural norms of the patient that do not facilitate positive interactions with (Western style) services (Keightley et al., 2009). Rehabilitation services within a CBR framework provide the possibility for rehabilitation for patients within their cultural understandings, family support networks and local communities, but may lack the specialist level of service provision available in a larger metropolitan area, such as Auckland.

The people of Te Vaerua were aware that in order to provide locally based services, it need to be visibly successful, visible to service users but also to funders and aligned health services. They aimed to achieve this with case studies and stories, personal relationships and strategic linking. This relational rather than process-oriented service also fit with my personal experience of providing therapy in a Pacific culture, where people are interested in who you are, where you stay, and how you ‘fit’ within the community. Building personal relationship and taking the time to connect provide the space to give professional services within a trust relationship.

Rehabilitation has heart

The concept that rehabilitation is based on personal connection differs from a Western approach that values specialist knowledge. Westerners will often be referred to specialist practitioners in a particular area of expertise, seek out the ‘best’ person for the job, or ask for a second opinion. While decisions may be made on pragmatic grounds, such as travel distances to services, seldom is a treatment decision based primarily on interpersonal skills or whether the professional is ‘liked’, rather trust is linked to an expectation of knowledge and ability of the health professional. There is some evidence in the literature related to the positive effect of a ‘good working relationship’ between the patient and clinician, particularly in mental health services (Hall, Ferreira, Maher, Latimer, & Ferreira, 2010; Howgego, Yellowlees, Owen, Meldrum, & Dark, 2003) and that a ‘human approach’ to care, where patients felt listened to and understood, is an important factor alongside, but not as a replacement for, technical competence (Fadyl, McPherson, & Kayes, 2011).

Charity and contribution are seen as a key concept for Pacific peoples, and the ability to be able to give is highly valued (Mauri Ora Associates, 2010). This was reflected in this study where much discussion related to the motivation and the ‘heart’ of those involved in Te Vaerua. It was strongly agreed that those who had service to others as a prime motivation were more closely aligned with Te Vaerua’s central value of ‘people being the most important thing’. This was seen in expectations of those involved in every level of the organisation: Board members, therapists and volunteers, and extrapolated to expectations of external funders. The ability to be charitable and generous is a basis not only for service provision, but the initial formation of the service.

My personal observation was that throughout the Cook Islands in different aspects of community, there seemed to be a strong sense of responsibility for the wellbeing of the community as a whole, and a strong value placed on charity, whether in gifts of money or time. There seems to be a general expectation that this is how community functions here.

Rehabilitation gives hope.

Hope is a theme that was reflected in several facets: giving hope to families by reducing burden of care, awareness building regarding disability in the community and personal hope of getting better and becoming more independent. This theme is reflected in literature, where hope is considered an important factor for long term outcomes and a source of motivation and support through recovery (Bright, 2011; Bright, Kayes, McCann, & McPherson, 2011). In Western rehabilitation literature hope tends to take a back seat to the more commonly voiced goal of personal independence. In this study, personal improvement was valued as important, but was seen within the context of that person in connection with their family and community, and their ability to contribute.

Hope is considered to be important to recovery, supporting perseverance, adjustment and positive outcomes (Bright et al., 2011). For example, in the context of brain injury rehabilitation, Levack et al. (2009) found that family involvement in goal setting was considered by health professionals as a way of ‘allowing and supporting family members to retain hope’ (Levack, Siegert, Dean, & McPherson, 2009, p. 196).

Participants in this study referred to not only to a hope for the recovery of the individual, their family, and community, but also to the importance of giving hope to people with disabilities in the community by creating opportunities and expectations through changing the perceptions of society. The ICF based on the social model of disability shows that environmental barriers to participation are major causes of disability, therefore to reduce disability relies on minimising social barriers, such as practical access, societal views and government policy (De Kleijn-de Vrankrijker, 2003). Influencing these factors is an explicit objective of Te Vaerua, through raising awareness by sharing stories, personal experiences and strategic use of media.

5.3 Reflections on CBR and PAR used in this study

In 2004, CBR was positioned as a WHO strategy within general community development for rehabilitation, equalization of opportunities, poverty reduction and social inclusion of all people with disabilities (Madden et al., 2013).

CBR takes a rights based approach to promote access to healthcare services for people with disabilities. It aims to achieve this by a combined effort of disabled individuals, disability groups, communities, governments, service/social agencies and NGOs (International Labour Organization et al., 2004). It was developed in response to dissatisfaction with the success of ‘top down’ implemented programmes in the developing world in a variety of settings.

Previously, many developing world projects expected that Western skills, knowledge and attitudes would be sufficient for addressing local needs regarding service delivery. It has been suggested however that there tends to be low utilization of these types of project services, and a similar pattern is noted in rural or ethnic minority communities in the developed world (Kuipers & Allen, 2004; O'Toole, 1987). One explanation for the failure of Western approaches in developing countries is that this is a ‘result of dissonance between the cultural orientation, values and expectations of service providers and potential clients’ (O'Toole, 1987, p. 180). CBR was a response to these failures, and is a ‘grass roots’ approach that uses the local understandings of the social/environmental setting as well as knowledge of the issues presented.

However, while perhaps more theoretically sound, the evidence base supporting the effectiveness of CBR is still in its infancy. There is anecdotal evidence for the effectiveness of CBR, but for individualised, local projects (e.g. Balasubramanian, Dhanesh, & Amarnath, 2012; Nuri, Hoque, Waldron, & Akand, 2012) and the long term effect of this approach has yet to be demonstrated. Evidence for the efficacy and outcomes of CBR is limited (Bowers, Kuipers, & Dorsett, 2015; Madden et al., 2013) and due to the nature of CBR ‘as a social movement, [it] lacks a coherent core of research, experimental studies or systematic reviews’ (Kuipers & Allen, 2004, p. 5). This means that while CBR programmes may be effective within the communities that they are situated in, it is very difficult to quantify outcomes, to implement effective programmes into other settings , or to grow a small scale project into a routine service (Kuipers & Allen, 2004; O'Toole, 1987).

Te Vaerua operates from a rights based approach, and is recognised by the Pacific Disability Forum as an associate DPO. While it is not an official CBR programme, Te Vaerua refers to the framework of CBR to inform policies and processes. It is a good example of a service within the CBR framework: identification of a local need, involvement of people with disabilities and other locals, creation of a service with multi-agency support, inclusion of external experts and international funding.

Action for CBR is often initiated by a stimulus from outside the community, with the community choosing if and how to address the issue, and whether CBR will be a part of the community action. CBR requires the active involvement of the community and people with disabilities, with support from various partners as required. It can be run from the community, or by a CBR programme manager (International Labour Organization et al., 2004). There are parallels between the framework for CBR and that of PAR, where community participation is central to the success of the project and to the process of implementing change in a situation.

As PAR and CBR share a common ideology, it is easy to foresee that they may share similar tensions and challenges, and this project highlights some of the challenges faced. For instance, in CBR there can be a tension between the need to develop locally-based, culturally-relevant solutions and the need for services to draw on outside (international) rehabilitation expertise in order to establish knowledge and skills for a particular service.   Similar, for PAR, there can be a tension (as there was in this study) between the need for research to be owned and directed by the community participants and the need for an external research/facilitator to provide direction with research skills and knowledge.

In the case of Te Vaerua, the Board members or staff did not actually have strong opinions about how the clinical aspects of rehabilitation should be a) structured or b) run – these issues being almost incidental to them – instead they wanted the development of an understanding of rehabilitation to be provided by external, international experts. This conflicted with the ideals of both CBR and PAR regarding the community participant owning and driving the clinical development and research process. Two of these issues are discussed in a more detail below.

The quandary of 'expert' involvement in CBR

Te Vaerua recognised that it was important to have rehabilitation in Rarotonga to meet the needs of the local people. However the founding members and Board did not express the desire to be involved in the development of the framework for provision of rehabilitation services, expecting that experts in rehabilitation would be best placed to facilitate this. These 'experts' were then foreign to the culture and environment of the Cook Islands, creating a tension between locally relevant 'grass roots' services and introduction of a Western cultural model of rehabilitation care. Fitzgerald (1992) suggested two ways of decreasing the negative impact of using a foreign expert: use of an intermediary or 'cultural broker', or training a local provider. A cultural broker is a person who is able to interpret both language and cultural difference to provide a bridge between local understandings and Western trained health professionals. Te Vaerua have now employed a rehabilitation assistant who can provide this link with Western therapists. However, a more ideal solution would be ‘decreasing the number of cultures involved’ (Fitzgerald, 1992, p. 41) by training locals as health professionals. While Te Vaerua continues to rely on overseas therapists, they have identified that culturally Cook Islands therapists would be ideally placed to offer culturally relevant rehabilitation services and are currently pursuing this goal.

Training and maintaining local health professionals is a significant issue for small Pacific Island nations, where local wages, support structures and education may not be sufficient to maintain trained staff (Connell, 2004). Certainly many known Cook Islands individuals work in New Zealand: medical specialists, GPs, nurses and allied health professionals whose expertise and professional success is celebrated within their families, but who are based in New Zealand. This is a concern and challenge across the health service for the Cook Islands.

The challenge of participation and collaboration

In PAR studies, the researcher is an ostensibly an equal participant. Participation is the very heart of PAR, such that ‘the goal of involvement is no less important than improvement’ (Dickens & Watkins, 1999, p. 132). One challenge arising for this research however was around encouraging the involvement of the participants in the study. Some meetings which were scheduled did not occur and those that did occur often had fewer participants than expected. This is a common challenge with both CBR and PAR projects.

A systemic review of CBR project evaluation by Kuipers, Wirz, & Hartley (2008) identified three key recommendations for CBR projects. These included **training** (of local people), **funding** (transparent financial processes must be a key priority), and **collaboration**. Interestingly, there ‘were numerous recommendations for CBR to be more participatory at an organisational and service level, and more inclusive of families, communities and people with disabilities'(Kuipers, Wirz, & Hartley, 2008, pp. "Qualitative discussion", para. 4), so while the CBR framework requires participation as a key component, there are often challenges to this occurring in practice.

Participation is a prerequisite of PAR, and the extent, ethics, challenges and implementation of participation in PAR are widely discussed in the literature (Arieli, Friedman, & Agbaria, 2009; Greenwood, Whyte, & Harkavy, 1993; McTaggart, 1991; Minkler, 2004). While participation is a key component, it is difficult to predetermine or control. Indeed, Greenwood et al. (1993) stated that 'no one may mandate in advance that a particular research project will become a fully developed participatory action research project. [It is] a process that must be generated... by building participatory processes into the activity' (Greenwood et al., 1993, p. 176)

Participants were involved in this study from the outset including research question formation, identifying required actions and reflecting and refining emergent themes. The agreed goal of the study was that a strategic plan with manageable goals in line with values and expectations of the participants would provide a framework for Te Vaerua to continue to offer rehabilitation services over the proceeding five years. This was intended to be a valuable resource for the organisation, and a workable, sustainable 'good work' outcome from the study.

Initially the participants included only the Te Vaerua Board members. These participants were representative of the defined Te Vaerua community, and the majority of the members were involved in aspects of the research process. It is noted that Te Vaerua operates within a wider community structure and other stakeholders were identified during action cycles. While service users and community voices were identified as important stakeholders, time restrictions and lack of clear facilitation as to how to achieve involvement meant these voices were not heard. This is a clear limitation of this study.

During the data gathering process it became apparent that the Board had been assembled strategically, with each member's involvement being requested by the founders due to their skills, community position or disability. Aware that the Board members while interested in Te Vaerua offering services to the people, did not necessarily have the available time, or knowledge about rehabilitation to fully engage in all activities; the key informants essentially ran the service, with support and ratification from other Board members. In this context, the Board, while welcoming of my research and my involvement in the organisation, were not used to (or even necessarily terribly interested in) the kind of in-depth reflect on their service that was required of a PAR study. The participants were more interested in just taking action rather than spending too much time analysing what should be done and why.

It was not within the normal culture of the Board to be personally involved in organisational activities, and therefore engagement in a PAR process was not likely to be a successful strategy with the wider Board group. For example, while Board members stated that considering values of rehabilitation and how these should translate into a strategic plan would be valid and useful, the actual writing of the strategic plan was eventually carried out by just two individuals. Other Board members may therefore have felt that their direct contribution to the research was not an activity that was particularly important. As a result, engagement with the research process was limited to the participants that normally complete the vast majority of the 'actions' for Te Vaerua. Through all of this there was an expectation that I, as the external expert, should really be the one telling Te Vaerua what they should do. This conflicted with my desire to undertake a collaborative, locally-led PAR study, and at times during the process I felt stuck and restricted.

On a more positive note, through this study I was able to facilitate Te Vaerua to consider the values and expectations of the rehabilitation service offered. My participation also included physiotherapy services to Te Vaerua for the period of the data collection. This aspect of involvement was very important to Te Vaerua as it allowed funded rehabilitation services to be offered, meeting the aims of rehabilitation being available and visible, and allowed a smooth transition to the new physiotherapist.

Success and limitations of PAR in this study: The problem of achieving transformative action

PAR methods differ from other qualitative research methods often used in the health science, such as grounded theory or interpretative phenomenological analysis, which have an established framework of participation, data collection and analysis, and the reporting structure for these methods. As a result, to be more descriptive or prescriptive with methodology would impose other frameworks onto the study and lose integrity and intent of the PAR process. For example, in PAR the process of data collection and analysis is less formalised, the steps are less clear, and a defined end is difficult to identify. In this study, multiple sources of data were used, and community observation formed a part of my reflections and reflexivity. In this way, my study was closer to ethnography in design, except that the emphasis of the analysis was not primarily on culture. Similarly, the notion of ‘study participants’, as described above, was more fluid, and not easily reduced to a discrete number of people. The sample size of the study could potentially be considered ‘one’ as the focus of the study was one community, with different individuals providing data in a variety of ways, and with their involvement changing with time.

The actions and changes that occur with a PAR project are a key way of evaluating success, whether they exist as self-reflexive changes in practice, or organisational change and whether the research results are valued and implemented by the participants and wider community. This is as termed social validity (Seekins & White, 2013). In this study, while the research produced knowledge about Te Vaerua and about the views and perspectives of its members and funders, the actions arising from it within the research timeframe were minimal, and not really reaching the ideal of creating transformative change. However, as identified in my return to Te Vaerua, the rehabilitation service continues to provide successful services in the Cook Islands, with increased community links and involvement of locals as rehabilitation providers. The strategic plan outlines their 5 year goals and measures.

Social validity can be threatened by several methodological decisions, including: ‘selecting irrelevant topics for research, a lack of clarity about important consumer goals, misunderstanding the acceptability of research methods, misunderstanding the range of intervention acceptability, ignoring criteria that potential adopters would use to judge the significance of outcomes and impacts, misinterpreting results, and lacking generality of findings in real-life application’ (Seekins & White, 2013, p. S21). Three of these threats have been used as a framework to critically examine this research journey: 1) exploration of the research question, 2) research method acceptability, 3) research outcomes and impacts.

Exploration of the research question

One possibility is that, despite the consultation that occurred at the beginning of the study, the research aims and objectives were not very important to the study participants – or at least insufficiently important to generate the level of engagement required to influence concrete action. Formation of a research question that is valued by the community group is seen as a vital aspect of successful PAR (Khanlou & Peter, 2005; Van der Eb et al., 2004). My research began with the aim of establishing a culturally-congruent framework for rehabilitation services provided by the organisation.

The research question was considered and refined by the participant group and an identified key action/outcome of the project was to inform the development of the Te Vaerua strategic plan. However, participation was a challenging aspect for this study, which suggests that the intention to explore the research question may not have been a priority. Minkler (2004) suggested that a 'key preliminary step [should] involve determining whether the proposed subject really is high on the agenda of the affected community' (Minkler, 2004, p. 687). Te Vaerua had been providing rehabilitation since 2007 without the organisation having a formal framework for rehabilitation and may not have considered this important.

While at the outset of this study, Te Vaerua may not have been able to collectively identify a framework for service provision, existence of a framework was required in order to apply for and receive external funding, validate service outcomes to funders and partners and to be able to communicate their understanding of locally appropriate rehabilitation to the Western therapists who are employed from overseas. Therefore the context of the research question had seemed appropriate and meaningful at the time.

Research method acceptability

PAR was chosen as the methodology of 'best fit' for the community and research question in order to support and sustain Te Vaerua to understand and strengthen the provision of rehabilitation in the Cook Islands. Alignment with the framework of CBR was a significant advantage as similar concepts and processes underline both ideologies and Te Vaerua recognised itself within a rights-based CBR framework.

i) Cultural expectation of research

There are clear limitations with cross cultural research such as this study where I am ‘other’ to the cultural community, in language, customs and understandings. The literature describes PAR as useful for cross-cultural studies to allow the community itself to identify and define all aspects of the research process, and minimise potential external researcher influence and interpretation from outside the participants’ cultural setting (McTaggart, 1991). In addition PAR is considered to be a useful framework for sustainability of projects after the research component has been completed due to the motivation and experience of local participants (Jagosh et al., 2012).

Rarotonga, as an accessible Pacific Island, has long been the destination for First World researchers, particularly in the area of health. As with many indigenous peoples, it was recognised that much ‘outsider’ research was being completed at the expense of participants, and ‘carried away’ without benefit to the people of the Cook Islands. The Cook Islands Health Research Council was established particularly to ensure that any research was for the benefit of Cook Islanders, that research findings would be shared with Cook Islanders, and that research did not negatively impact on their wellbeing.

However, despite increased ownership and control of research conducted, methodologies recognised as research remain as those with positivist research methods. This includes the expectation that the researcher is the prime gatherer and analyser of data, and PAR studies therefore fall outside of the widespread expectation of what research is like.

Possibly as a result of these historical expectations, the shift in paradigm seemed unexpected for the Board. Even though I felt that I had been clear in my explanation of the process, the amount of personal engagement that PAR requires from participants may not have been understood by Board members, and in retrospect I should have been far more explicit about the framework of PAR research, and more directive about expectations of participation.

Kauraka (2003) describes that being hospitable to the visitor/maniuri extends to a strong desire to avoid offense to outsiders and visitors, at the expense of acknowledging local expertise and exerting intrinsic control. Is it possible as a visitor/research specialist to have a democratic participatory structure as defined in Western understanding within a culture that is hierarchical and defers to an external 'expert' view? Is it therefore possible for a study such as this to employ a cross cultural PAR process that would be truly outside of the research framework of the 'dominant culture of colonialism' (Tuhiwai Smith, 1999)?

ii) Time limitations

PAR is more time consuming that traditional research due to the consultation process, and the need to explain and negotiate the research methods (Szala-Meneok & Lohfeld, 2005). Within a time-limited study such as is required for a Master's thesis, sufficient time to completely fulfil all aspects of successful action research is significantly restricted. Time is required in order to develop the participants as co-researchers, to explore the research question and design with a group of stakeholders who may differ in opinion, to develop and implement actions, and to consider and reflect on change. This is a time consuming exercise, particularly in a community which has limited time together, and multiple other roles and foci.

This study involved a group of people who were known to each other, and to me as the researcher. Completing the study part time alongside clinical commitments gave a longer period of time to consider and reflect on discussions and actions. However, it was apparent that time constraints were a consideration, with the data collection period alongside other significant traditional and cultural events and responsibilities which limited the capacity of the participants to invest time in the study.

iii) Data collection

Data collection methods in this qualitative study included interviews, focus groups, use of written material such as funding proposals and policies, observation of Board meetings, personal experience of patient interactions and general cultural immersion in a self-reflection diary. The methods were emergent and based on discussions and actions from participant meetings. While these were ecologically valid and organic data collection modalities which gave rich and in-depth data, it was a challenge to collect and collate the different mediums, and a challenge to bring together into a cohesive and meaningful way.

A patient viewpoint was considered valuable by participants, and these views were gathered organically through clinical contact, and shared with the group. These 'patient viewpoints' were therefore filtered through the lens of another participant and may not fully reflect the understandings of individual patients.

Research outcomes and impacts:

At the initial Board meeting discussion it was acknowledged that the presence of research by Te Vaerua is a way of validating the service, which would be positive for future funding proposals. In addition, at the time that I was looking to return to

Rarotonga in order to complete this research, Te Vaerua had a requirement for a physiotherapist to work until September 2013, when the contracted therapist would arrive. They were motivated to have me ‘on island’ for two reasons: firstly that the memorandum of understanding with the MoH would not be signed until there was a physiotherapist present on Rarotonga, and Te Vaerua required that funding stream to commence; and secondly to allow a full handover to the new physiotherapist by funding a four week overlap.

As a result, the Board were more than happy to agree to involvement in research as it met their immediate goals, and may not have fully understood the process or expectation that was involved in a PAR study, or planned to engage personally in the process. As well as immediate service provision and service validation, through the research process Te Vaerua identified actions and changes to implement which support their values and goals for the service. Few of these actions were brought to completion during the data collection phase, but provide a framework for the sustainability of the project. Therefore the research project provided value to the provision of rehabilitation services in Rarotonga, both immediately with the participation of the researcher as a therapist, but also to give a framework of expressed values that may influence future service development.

5.5 Implications and recommendations

This study has a number of implications for new clinical services in the Pacific region, and considerations when facilitating PAR projects.

Clinical considerations

This small study involved a sub-section of the wider Cook Island community, and excluded service users, but the themes identified give some insight into the provision of rehabilitation in the Pacific region. While the beliefs and values of the Te Vaerua group are their own, and are not necessarily applicable to all settings, these themes could be considerations in the development of rehabilitation services in similar settings, such as other Pacific Island nations and Western therapists providing services in this region should be aware of some of the key points identified.

A limitation of this study was the lack of engagement with service users and the wider community. Both of these stakeholder groups would offer vital viewpoints to future research and clinical service implementation.

Where services have not existed previously, local people may not have a strong opinion regarding how new rehabilitation services should be delivered. It is therefore important that studies which set out to gain a perspective of what an emerging rehabilitation service should be like within a setting do not simply ask participants for their opinion. In this study it was clear that there was not a shared understanding or expectation of what rehabilitation should be like, instead there was a reliance on the expert understandings of Western health professionals to guide services. This is a common experience of CBR projects in the literature. However, it was clear that a precursor to successful rehabilitation services is establishing a positive relationship with the community. This can be difficult to achieve in many aid-funded ventures, where the timeframe and expectation of the project limits the ability to form the groundwork for a relationship.

Contribution and reciprocal generosity is required to establish relationships between a new service or therapists and the community. For new services, it is important to be able to be explicit about how rehabilitation contributes to the community in order to be recognised and acceptable. Therefore tangible giving, such as equipment provision is an important part of establishing rehabilitation services. Particularly where other rehabilitation services, such as physiotherapy treatments may be less tangible, offering a physical item establishes trust and relationship as well as a practical solution to an identified need. In this study, equipment was highly valued, and seen as an integral part of offering rehabilitation.

Visibility was also seen as a vital part of establishing a successful service, and equipment was a useful way to gain some visibility. In addition, marketing the new service, and demonstrating effectiveness of rehabilitation are important for acceptance of a rehabilitation service and therapists. Shared stories of successful rehabilitation case studies, personal stories and word-of-mouth are potentially positive ways of marketing services as well as increasing awareness.

PAR research considerations

PAR is a qualitative research methodology useful for projects that have a participant group who wish to address an issue. For me, the most difficult aspect of using this framework was the lack of control of the process. By the very nature of PAR, the researcher is unable to plan a research question, determine degree of participation or the direction of any actions arising from the study. Indeed, it is impossible at the beginning of a PAR project to be certain that a study will eventuate! To assist with the success of future PAR studies, three considerations may be taken from this experience: 1) the challenge of shared control, 2) engagement with a research question, and 3) early identification of project champions.

PAR research requires the researcher to be flexible with the research process, as the whole research journey is an emergent and flexible process. This can be a challenge with time-framed projects such as an academic study, or if reliant on external funding. As relationship building and enabling participants is a vital part of the success of the study, time must be invested in these aspects even when it feels the study is not actively moving forward as a result. The high investment of time is also required in order to identify a suitable research question.

The research question is a vital aspect of the PAR project. The chosen question must of interest to the participant group such that they have an agenda to engage with the research in order to address the issue. Without this agenda towards the research question, there will be limited buy-in of participants to engage the level of commitment and time required to bring about meaningful change. Involvement of participants in creating the research question is ideal, but it can be difficult to gain ethical or departmental approval prior to an academic project starting without a defined research question.

With any project or service, communication is an important part of success. Shared understandings are a challenge in most spheres of life, and are made more difficult in cross-cultural conversations, where misunderstandings due to different language or cultural expectations are easy to create. It is valuable to have participants within the group that are able to mediate smooth communication through sharing socially and culturally relevant information as a background for the research. This study used key informants in this role, and it was beneficial to identify these key individuals early on in the research process. The concept of project champions encompasses this role, but also suggests participants that are wholly engaged in the success of the project, and will motivate other participants to also maintain focus and enthusiasm.

5.6 Conclusion

This study has identified emergent themes of rehabilitation that were expressed by the participants, and these have been compared with current existing literature. It has also looked at the process of CBR and PAR within the Cook Islands setting as it relates to Te Vaerua. The themes of the study suggest that for the Cook Islands it was important to look outside of a Western framework to explore locally held values of rehabilitation service delivery.

While overseas experts contribute to the provision of rehabilitation, it is important for Te Vaerua to understand what they consider to be important indicators of a successful service and make this explicit to visiting or overseas providers and funders. There is recognition of the multifaceted presentations required to facilitate stakeholder and funder understanding and support of the rehabilitation service, and an increased awareness that data collection should reflect the values and successes of the service to stakeholders, particularly related to funding.

PAR appears to be a valid option for cross cultural research in the Pacific island setting, particularly for CBR projects which have alignment of ideology. Time limitations, participant availability and gaining a shared vision for the research are significant challenges for studies using PAR methods, and PAR may not always be the most appropriate choice in all settings. Exploration of values and expectations of rehabilitation would be useful for other small Pacific nations as they embark on CBR projects in their communities.

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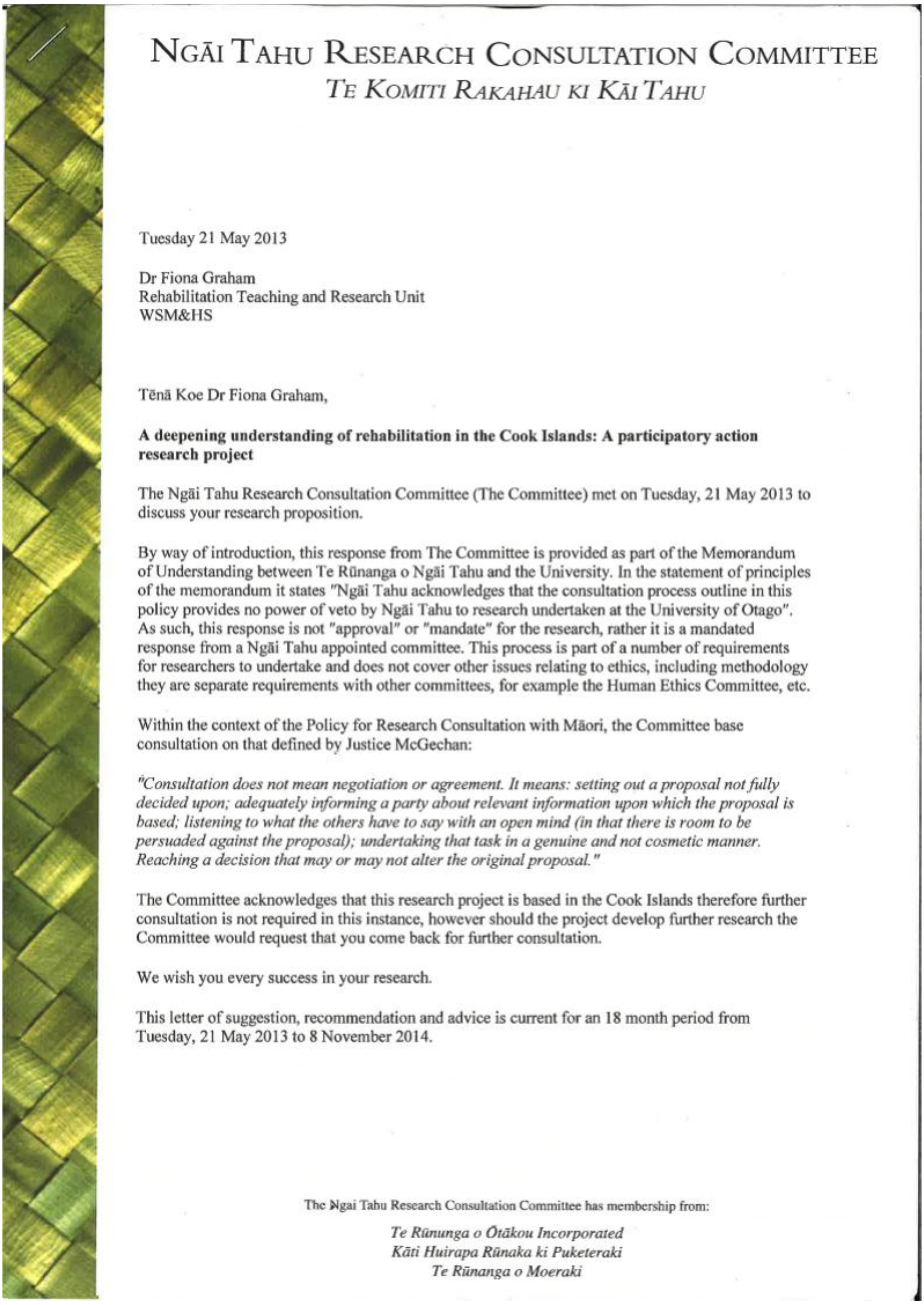
Appendix 1: Consultation with Maori



NGĀI TAHU RESEARCH CONSULTATION COMMITTEE
TE KOMITI RAKAHAU KI KĀI TAHU

Tuesday 21 May 2013

Dr Fiona Graham
Rehabilitation Teaching and Research Unit
WSM&HS

Tēnā Koe Dr Fiona Graham,

A deepening understanding of rehabilitation in the Cook Islands: A participatory action research project

The Ngāi Tahu Research Consultation Committee (The Committee) met on Tuesday, 21 May 2013 to discuss your research proposition.

By way of introduction, this response from The Committee is provided as part of the Memorandum of Understanding between Te Rūnanga o Ngāi Tahu and the University. In the statement of principles of the memorandum it states "Ngāi Tahu acknowledges that the consultation process outline in this policy provides no power of veto by Ngāi Tahu to research undertaken at the University of Otago". As such, this response is not "approval" or "mandate" for the research, rather it is a mandated response from a Ngāi Tahu appointed committee. This process is part of a number of requirements for researchers to undertake and does not cover other issues relating to ethics, including methodology they are separate requirements with other committees, for example the Human Ethics Committee, etc.

Within the context of the Policy for Research Consultation with Māori, the Committee base consultation on that defined by Justice McGechan:

"Consultation does not mean negotiation or agreement. It means: setting out a proposal not fully decided upon; adequately informing a party about relevant information upon which the proposal is based; listening to what the others have to say with an open mind (in that there is room to be persuaded against the proposal); undertaking that task in a genuine and not cosmetic manner. Reaching a decision that may or may not alter the original proposal."

The Committee acknowledges that this research project is based in the Cook Islands therefore further consultation is not required in this instance, however should the project develop further research the Committee would request that you come back for further consultation.

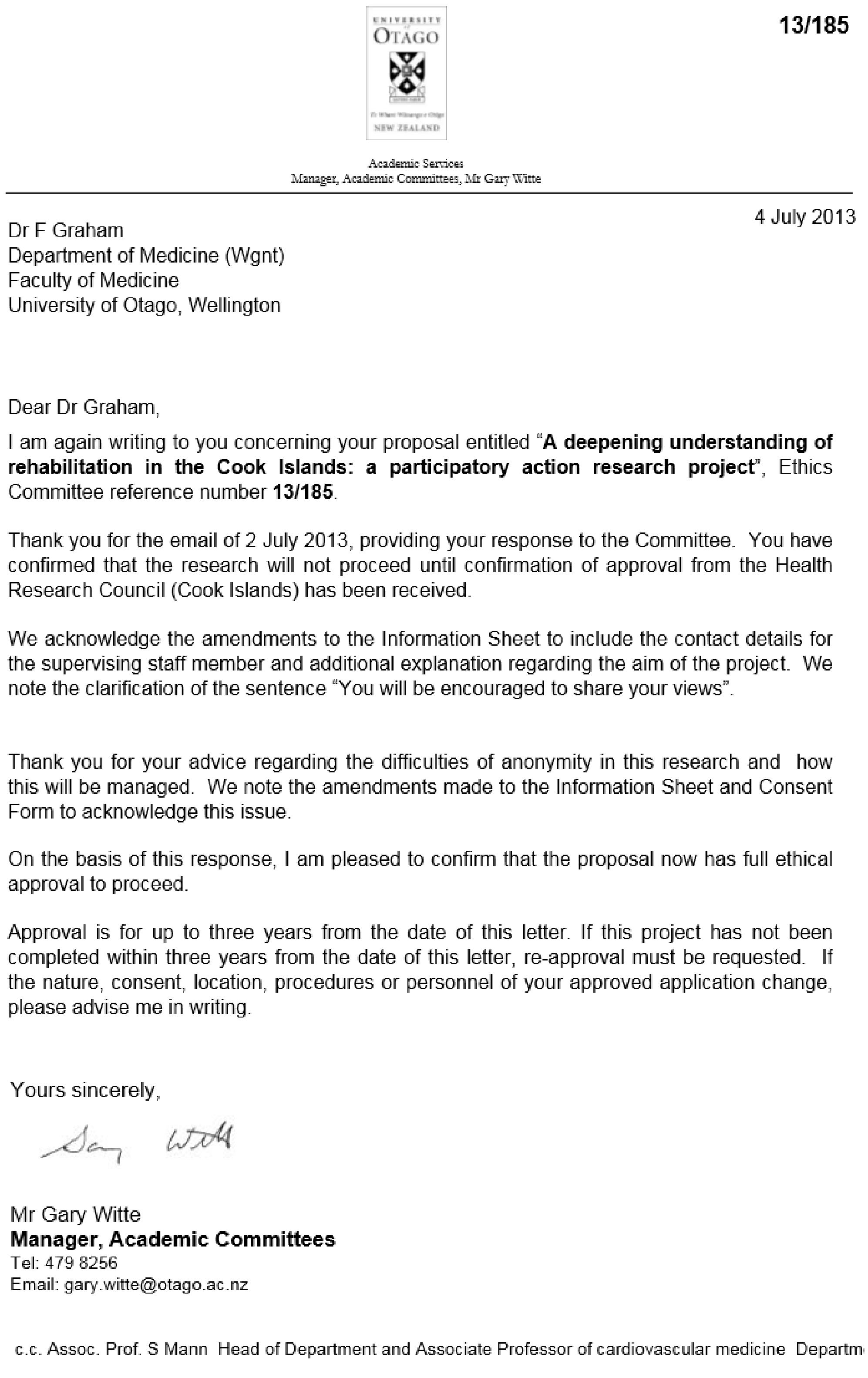
We wish you every success in your research.

This letter of suggestion, recommendation and advice is current for an 18 month period from Tuesday, 21 May 2013 to 8 November 2014.

The Ngai Tahu Research Consultation Committee has membership from:

Te Rūnunga o Ōtākou Incorporated
Kāti Huirapa Rūnaka ki Puketeraki
Te Rūnanga o Moeraki

Appendix 2: Ethics Committee Approval



13/185

UNIVERSITY OF OTAGO
NEW ZEALAND

Academic Services
Manager, Academic Committees, Mr Gary Witte

4 July 2013

Dr F Graham
Department of Medicine (Wgnt)
Faculty of Medicine
University of Otago, Wellington

Dear Dr Graham,

I am again writing to you concerning your proposal entitled "**A deepening understanding of rehabilitation in the Cook Islands: a participatory action research project**", Ethics Committee reference number **13/185**.

Thank you for the email of 2 July 2013, providing your response to the Committee. You have confirmed that the research will not proceed until confirmation of approval from the Health Research Council (Cook Islands) has been received.

We acknowledge the amendments to the Information Sheet to include the contact details for the supervising staff member and additional explanation regarding the aim of the project. We note the clarification of the sentence "You will be encouraged to share your views".

Thank you for your advice regarding the difficulties of anonymity in this research and how this will be managed. We note the amendments made to the Information Sheet and Consent Form to acknowledge this issue.

On the basis of this response, I am pleased to confirm that the proposal now has full ethical approval to proceed.

Approval is for up to three years from the date of this letter. If this project has not been completed within three years from the date of this letter, re-approval must be requested. If the nature, consent, location, procedures or personnel of your approved application change, please advise me in writing.

Yours sincerely,

Gary Witte

Mr Gary Witte
Manager, Academic Committees
Tel: 479 8256
Email: gary.witte@otago.ac.nz

c.c. Assoc. Prof. S Mann Head of Department and Associate Professor of cardiovascular medicine Departm

Appendix 3: Cook Islands Research Committee Approval

COOK ISLAND RESEARCH COMMITTEE
OFFICE OF THE PRIME MINISTER
PRIVATE BAG, RAROTONGA, COOK ISLANDS
Phone +682 211-50 Facsimile +682 20-856
Email: cos@pmoffice.gov.ck Web: www.cook-islands.gov.ck

File ref: 510.3
Letter no: 175

2 August 2013

Rebecca Washbourn
PO Box 280
Avarua
Rarotonga
COOK ISLANDS

Kia Orana Rebecca,

RE: APPROVED RESEARCH APPLICATION

I am pleased to advise that the National Research Committee has granted approval for your research titled **"A deepening understanding of rehabilitation in the Cook Islands, a participatory action research project with Te Vaerua Community Rehabilitation Service"** on **Rarotonga** from **August 2013** to **September 2013**

Enclosed is your research permit issue **# 16/13**

The following conditions listed below have been imposed by the National Research Committee

-To comply with Immigration requirements

-Provide a preliminary report to the Office of the Prime Minister at your earliest

-Submit 3 hard copies + 1 e-copy of your final findings to the Office of the Prime Minister by August 2014

Kia Manuia

Elizabeth Wright-Koteka
CHAIRPERSON

- 1 -

Appendix 4: Participant Consent Form

A Deepening understanding of rehabilitation in the Cook Islands:
A participatory action research project

What is the aim of the project?
The purpose of this participatory action research (PAR) project is to deepen the understanding of rehabilitation within the Te Vaerua Community Rehabilitation Team in the Cook Islands, and reframe provision of rehabilitation services with a more culturally congruent lens.

I agree that:

- ☐ I have had an opportunity to be involved in the development of this research proposal
- ☐ I agree to continue to be involved through focus group discussions
- ☐ I understand that these discussions will be audiotaped and portions of the focus groups may be transcribed if they will be quoted directly in summary sheets or reports. I understand that these focus groups will be confidential, and information not shared outside of the group.
- ☐ I agree to respect the confidentiality of other members of the research team
- ☐ I understand that I may withdraw from involvement in this research project at any time
- ☐ I agree to participate in activities outside of the focus groups as agreed with the research team during focus groups, and to complete these within the agreed timeframe
- ☐ I understand that the data collected will be stored securely, and my personal data will not be available to anyone else apart from the researcher.
- ☐ I understand that this research will also be used in a student thesis (University of Otago), and the research may be submitted to scientific journals.
- ☐ I am aware that any quotes used will be reported with pseudonyms unless I prefer to be identified as the author. I am aware that there is a risk of identification within the Cook Island population, given the small number of participants.
- ☐ I understand that at the end of the project audio recordings and summary sheets will be kept at the University of Otago, Wellington for 10 years and then destroyed.

Statement of Approval
This project has received ethical approval from the Otago University Ethics Committee (A) and the Cook Islands Research Council. [ethics approval 13/185]

I am a member of Te Vaerua Community Rehabilitation Team

☐ Board member ☐ Board member/employee

I ______________________________ agree to be an active member of this participatory research project.

Signed ______________________________ Date ______________________________