



The Health Research Council
of New Zealand

Guidelines on Pacific Health Research

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Foreword

*Halo Olaketa, Malo ni, Fakaalofa Lahi Atu, Ni sa Bula, Malo e Lelei, Talofa Lava,
Kia Orana, Kia Ora, Greetings*

It gives me a great deal of satisfaction to see the HRC Guidelines on Pacific Research come to fruition. This work has culminated through the need to define and express what Pacific health research is - in its application and uniqueness. The document has developed after a process of wide consultation and debate on what makes us different and how to articulate the future direction for Pacific health research.

What is proposed here is not the blueprint, but the beginning of a dialogue where wider debate is welcomed. Hence, I urge you to read the document critically and to actively comment in a constructive manner, to assist us with shaping future editions.

On behalf of the Pacific Health Research Committee and the Health Research Council of New Zealand, I would like to thank Karlo Mila-Schaaf for drafting this document; and Jacinta Fa'alili and Dorothy Alofivae, the HRC Pacific Secretariat staff who supported the development of this project. I wish especially to thank the HRC Expert Panel on Pacific Peoples Health, led by Ms Lita Foliaki, for all of their guidance with this project. Thank you to all of those involved in the development and strengthening of this document.

Mr Kiki Maoate (FRACS)

Chair, Pacific Health Research Committee

Member, Health Research Council

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Dr 'Ana Koloto;
Dr Ate Moala;
Moera Grace (formerly Douthett), and
Maiava Carmel Peteru.

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Introduction

The Health Research Council of New Zealand (HRC) is an independent Crown Entity, the government purchase agent for health research. The HRC has a special interest in Pacific health research.

The Guidelines have been written purposely to assist research with Pacific peoples living in Aotearoa, New Zealand. They focus on the New Zealand context of Pacific health research. The scope of the guidelines is not intended to encompass health research in the Pacific region outside of New Zealand. There is an acknowledgement that the expertise for the development of research guidelines for undertaking health research in Pacific nations, lies with Pacific nations themselves.

The Guidelines are written expressly to guide research funded by the HRC. However, the document may assist all researchers, Pacific and non-Pacific, undertaking research on the health of Pacific peoples.

The Guidelines on Pacific Health Research is an evolving document. It is the beginning of work that seeks to articulate Pacific ethical standards of research. Despite undertaking a process of extensive consultation, the Guidelines before you, are best conceived as the initiation of a dialogue. The Guidelines will, with constructive criticism and care, be refined over time and improve with each revision.

The Guidelines, because they expressly focus on research with people (populations), are most readily applicable to public health and social science research. It is recognised that it is not as easy to apply these Pacific ethical guidelines to biomedical research that is of a fundamental nature and focuses on understanding molecules, cells and physiological processes. The HRC's position is that the ethical principles remain salient in all forms of research.

The Guidelines begin with a Treaty Statement. This acknowledges the tangata whenua status of Maori and affirms the teina - tuakana relationship of Pacific and Maori within the Aotearoa/New Zealand context. It also affirms the ancient whanaungatanga relationship, of tuakana - teina within te Moana nui a Kiwa, the Pacific region.

The inclusion of a 'Pacific Diversity Statement' honours the ethnic-specific differences found within the broad descriptor of 'Pacific peoples'. The 'Diversity Statement' outlines the difficulties and limitations, as well as the convenience of using this term. This statement is followed by the provision of a historical overview of the HRC's involvement in Pacific research. This leads on to the current vision for Pacific health research.

The introductory section closes with an overview of Pacific research and knowledge. The operating paradigms and key concepts are introduced, and a Pacific health research definition is provided.

The Guidelines then focus on the "Ethical Principles of Pacific research". The overarching principle is that relationships are the foundation of all ethical conduct. It is within the context of relationships that all significant ethical decisions, actions and

practice occurs. Therefore, the development, cultivation and maintenance of principled relationships - or 'relationship conduct' - is integral to all ethical practice.

The centrality of relationships directly reflects a Pacific perspective. To develop guidelines for Pacific health research requires using a Pacific world-view as a reference point.

Several guiding principles for forming/maintaining ethical research relationships with Pacific peoples are examined. These are:

Relationships

- respect;
- cultural competency;
- meaningful engagement;
- reciprocity;
- utility;
- rights;
- balance;
- protection;
- capacity building, and
- participation.

Every principle has a Pacific word (or phrase) that is one of the core concepts that the English translation attempts to capture. Each principle is provided in a variety of Pacific languages reflecting the linguistic diversity of the region. The languages chosen reflect the Pacific population base of Aotearoa/New Zealand. The concepts are provided in the languages of Samoa, the Cook Islands, Tonga, Fiji, Niue and Tokelau.

For each principle there is an additional section on putting these principles into practice, within the context of the research process. The same headings are used, however, instead of high-level descriptors of the ethical value of the concepts, this section is applied. It aims to give more practical advice and 'best practice' guidance, and explain how to translate the principles into culturally effective research practice.

In the final section, the Pacific research framework developed at the HRC is outlined. This section describes policy development and classifications of Pacific health research at the HRC. The classifications of Pacific health research include Pacific Relevance, Pacific Partnership, Pacific Governance and research.

A summary of the Pacific research ethical principles and directions for 'putting them into practice' is provided at the end of the document. This lists all of the guiding ethical principles and their accompanying statements and positions. These principles are highlighted throughout the Guidelines in text-box form. The purpose of the summary is to provide a concise overview of all the Guidelines for reference purposes.

Te Tiriti o Waitangi Statement

The interface of relationships and connections between the indigenous peoples of Te Moana Nui a Kiwa, have, through generations been safeguarded by chant that is 'committed to the ears' and enshrined within covenants. The systematised gathering, validating and maintenance of this knowledge underpinned rituals and protocols that protected and reinforced the substance of sovereignty and institutions of healing, within each Pacific nation and their peoples.

The Health Research Council is committed to reducing inequalities and improving the health status of Pacific peoples. The intention is to develop and strengthen our internal processes and systems to fulfil our obligations regarding meaningful engagement with Pacific research communities and Pacific peoples.

This approach recognises the Tangata Whenua status of Maori and their right to exercise tino rangatiratanga. It also recognises the mandate accorded under citizenship rights and the entitlements that are consistent with compliance to international forums regarding the rights of human beings, the grounds upon which Pacific peoples lay claim to action.

The researchers, whose work validates the experiences and visions of Pacific peoples in Aotearoa, acknowledge and actively support the prior place and reserved rights of Maori as Tangata Whenua in this land.

They further acknowledge that where Maori and the diverse Pacific populations experience comparable social, economic and cultural disparities, Pacific research contributes to the empowerment of Pacific populations and their families by addressing the factors that bring about and perpetuate social, economic and cultural disparities.

The migration of Pacific people to Aotearoa under the 1840 covenant between the Tangata Whenua of Aotearoa and the British Crown, rearticulated through subsequent policies of entry and entitlements, the arrangements of relationships that once defined places of identity and belonging, and duty of care between Tangata Whenua and Tangata Moana Nui a Kiwa.

Pacific Diversity Statement

The term 'Pacific peoples' is used throughout this document. 'Pacific peoples' is an 'umbrella' term that is used to encompass a variety of Pacific Island nations and communities who are linguistically, culturally, and geographically distinctive from each other. Pacific Peoples¹ (as opposed to 'Pacific People') is used to accentuate plurality and acknowledge the many Pacific nations and territories that are grouped together when this term is used. Other words that are used in a similar fashion include Pacific Islanders, Pasifika Peoples, Tagata Pasefika, and Pacificans.

In this context, 'Pacific peoples' is exclusive of Maori. In its broadest sense, 'Pacific peoples' covers indigenous peoples from the Island Nations in the South Pacific, and in its narrowest sense, Pacific peoples in New Zealand².

The concept of island 'nations' in the Pacific is understood to be a relatively recent introduction. There are other ways that indigenous people of the Pacific have identified themselves in the past and these structures of governance and government have a much longer history.

It is a common joke in Pacific circles that there is no such thing as a 'Pacific person' outside of New Zealand. Yes, there are Tongans, Samoans and Niueans, however, it is only when people arrive at Auckland airport that these Tongans, Samoans and Niueans become known as 'Pacific peoples,' and that the identity label 'Pacific' has meaning.

The term 'Pacific peoples' embraces commonalities but should not encourage homogenizing the differences between Pacific nations and ethnic groups. It is important that the differences are recognised and honoured. Each Pacific nation is different, and within each nation there is further diversity. It is important to recognise that status, authority, tradition, obligations and power structures are different for each group³.

Pacific peoples have migrated widely across the globe and have settled and formed new communities in many other countries (including New Zealand). These migrant Pacific communities are increasingly distinctive - from those living in the Pacific - and from other migrant Pacific settlements.

Pacific peoples are dealing with rapid social change and are facing inter-generational and cultural transformation⁴. It is useful to take into account Anae's perspective of the Pacific community:

¹ 'Pacific peoples' is a term that is recommended by the Ministry of Pacific Island Affairs for government documents: Ministry of Pacific Island Affairs (2001:3) "Pacific Consultation Guidelines"

² Anae, Melani et al (2001) "Pasifika Education Research Guidelines", Ministry of Education

³ Ministry of Pacific Island Affairs (2001:3) "Pacific Consultation Guidelines"

⁴ Ministry of Pacific Island Affairs (2001:3) "Pacific Consultation Guidelines"

“There is no generic ‘Pacific community’ but rather Pacific peoples who align themselves variously, and at different times, along ethnic, geographic, church, family, school, age /gender-based, youth/elders, island-born/NZ-born, occupational lines, or a mix of these. Therefore it is important that these various contexts of ‘Pacific communities’ are clearly defined and demarcated in the research process⁵.”

The grouping together of many peoples who have richly diverse sets of languages, customs, cultures and homelands, is a tension that will never easily be resolved. The rationale for trying is perhaps best articulated by the Tongan writer Epeli Hauofa, who emphasises both the connections and Pacific unity through the sharing of common waters.

“We are the ocean, we must wake up to this ancient truth and together use it to overturn all hegemonic views that aim ultimately to confine us physically and psychologically in tiny spaces which we have resisted and from which we recently liberated ourselves” (Hau’ofa cited Thaman 2002:8).“

When planning research projects, there are advantages and disadvantages to taking either a pan-Pacific approach, or an ethnic-specific approach. This is an issue that will need to be considered carefully by the research team, and it is an issue where advice should be sought. Even when a pan-Pacific approach is taken, ethnic-specific considerations must be taken into account.

At the time of writing this document, the most current information sourced from the 2001 Census states that in New Zealand, one in sixteen (231,801) people were of Pacific ethnicity ⁶. Half, or 115,017 of those Pacific peoples were Samoan, followed by Cook Island Maori (52,569), Tongan (40,716), Niuean (20,148), Fijian (7,041), Tokelauan (6,204) and Tuvalu (1,965).

The Pacific population in New Zealand will change as time passes and the information provided here will quickly become out of date. According to statistical projections, over the next fifty years, the Pacific community in New Zealand will grow naturally by some 3.3 percent a year, over three times the total population growth rate which is currently under one percent⁷. It is widely acknowledged that there will be a significant increase in the Pacific population living in New Zealand through fertility alone, and potentially also through further immigration.

⁵ Anae, Melani et al (2001:7) “Pasifika Education Research Guidelines”, Ministry of Education

⁶ Statistics New Zealand (2002) “2001 Census Snapshot 6: Pacific Peoples”

⁷ Statistics New Zealand (2003) “The Future for New Zealanders: Pacific Profile”

✦ Historical Overview: Pacific Research at the HRC

The HRC (previously known as the Medical Research Council) has been involved in funding Pacific health research since 1946. The “Island Territories Research Committee” was formed with the following objectives:⁸

- the accumulation and recording of all information related to health and disease in the Pacific area;
- determination of the specific health problems which exist within its own geographical square;
- active research leading to the solution of these problems, and
- liaison.

The Island Territories Research Unit concentrated largely on nutritional, infectious and parasitic diseases, particularly filariasis. The Island Territories Committee became the South Pacific Medical Research committee in 1968 and the emphasis changed to support specific investigator initiated projects. One of these significant projects, conducted by Dr Ian Prior, studied the health of a group of Tokelau and people before and after their migration to New Zealand, for more than 20 years.

In the 1980s, the Committee asked the heads of health services in five Pacific nations to elect their own research priorities. The research carried out in this period ranged from respiratory diseases, hepatitis, filariasis, rheumatic fever, peptic ulcers, heart disease, gout and hypertension.

In 1990, when the MRC became the HRC, the renamed South Pacific Health Research Committee brief was extended to include health research relevant to Pacific people living in New Zealand, as well as the Pacific. In 1995, Dr Colin Tukuitonga became the first Pacific person to chair the Pacific Islands Health Research Committee. Mrs Moera Douthett was appointed to be the first Pacific Islands Health Research Co-ordinator.

The HRC’s commitment to improving the health outcomes of Pacific peoples has not changed over a fifty-seven year period. However, the nature of Pacific health research itself has evolved significantly. Pacific people are shifting from historically being the subjects of research, to becoming active agents of research. Research has had a chequered history in Pacific communities. Although there have been positive outcomes, there have also been instances where research has resulted in Pacific peoples being presented inaccurately, or in a negative light. There is also a history where the benefits of research have not been shared with the research subject population.

⁸ Rankin, Jenny (1997) “History of HRC Support for Pacific health research”, Pacific Health Dialog Vol. 4, No. 2, Sep, 1997

The path that leads to a new vision of research has been paved with good intentions and some bad practice. There are many barriers to doing Pacific research. There are issues of Pacific peoples feeling over-researched, issues of research not being valued as a useful tool by some members of the community. While there is a legacy of some mistrust, there is also a new vision that has the energy to propel us into the future.

 **HRC Pacific Health Research Vision****Vision****Optimal health for Pacific Peoples through promoting and funding health research**

The vision of optimal health for Pacific peoples reflects the aim of the best possible health outcomes for the Pacific community. Research has a significant contribution to make to improving the health status of Pacific Peoples.

Mission**Discovering Pacific health solutions through research**

Research that is strongly linked to improving health outcomes for Pacific peoples is prioritized by the HRC. The HRC is focusing on workforce development initiatives to build the capacity and capability of Pacific researchers.

Pacific Health Research Committee (PIHRC)

The Pacific Health Research Committee (PIHRC) provides the HRC with advice about Pacific health research issues and gives strategic level direction and guidance to the HRC Pacific Team. The Committee also functions as an assessing committee that selects successful applicants for career development awards.

Current Membership 2003

Chair: Mr Teariki Maoate (FRACS)
Ms Lita Foliaki
Dr 'Ana Koloto
Professor Cliff Tasman Jones
Dr Wame Baravilala
Professor Neil Pearce
Dr Ate Moala
Dr Teuila Percival

Building research capacity and capability has been the main focus of the HRC's Pacific Health Research Committee for a number of years. The Pacific Health Research Committee continues to provide valuable advice, guidance and direction to the HRC, and supports the Secretariat in achieving Pacific health research goals.

Mr Teariki Maoate (FRACS) is the Chair of the Pacific Health Research Committee, and is a member of the HRC Board. He is a paediatric surgeon and urologist at the Christchurch Public Hospital and Children's Specialist Centre. Mr Maoate holds various leadership positions within the Pacific health community, as well as his role at the HRC.

Pacific Team at the HRC

The Pacific Team is responsible for Pacific initiatives at the HRC. Promoting health research in the Pacific community and funding research that will improve the health outcomes of Pacific peoples are the broad objectives of the Team. The Pacific Team core work involves:

- strengthening the capacity and capability of the Pacific health research workforce;
- offering scholarship opportunities for Pacific peoples in health and health research;
- administering the promotion, assessment, and contractual agreements of Pacific awards;
- promoting Pacific health research in New Zealand and in the wider Pacific region;
- developing Pacific health research networks;
- improving the access of Pacific peoples to HRC funding opportunities;
- developing Pacific health research policy;
- providing Guidelines on Pacific health research;
- building funding partnerships with other agencies for Pacific health research, and
- maximising funding opportunities for research that will improve the health outcomes for Pacific peoples.

The Pacific Team consists of the Manager, Pacific Health Research, Ms Karlo Mila-Schaaf, the Pacific Health Co-ordinator, Ms Jacinta Fa'alili and the Pacific Projects Administrator, Dorothy Alofivae.

Introduction to Pacific Research and Knowledge

Searching for a definition for Pacific health research is not an easy task. The challenge is to find an appropriately wide-spanning definition - that is exclusive enough to be useful. Within Pacific cultures, orators revel in the layers of meaning, nuance and metaphor that can be found in language⁹. The art is in the shimmering nuances, the shifting meanings, and multiple possibilities of perception. There is less pleasure found in unambiguous definition.

In this simple task of searching for a definition, one can see how two different paradigms collide. One can observe the interface between Western social science practice, and an approach that reflects the conventions of fine Pacific oratory. While developing the Guidelines, there has been a consistent negotiation of two very different approaches to understanding the world that we live in. This is reflective of today's contemporary and complex Pacific realities.

Each Pacific society has a framework of knowledge that is systematically gathered and formulated within a paradigm of general truths and principles. Knowledge gathering and systems of validating knowledge and legitimising information are processes that are often determined and regulated (but not exclusively) by a select group within the traditional hierarchy of leadership.

In Pacific worlds, one of the primary functions of knowledge is to protect and enhance the quality of well-being of people. Distinctions can be made between knowledge that is protected and sacred, and knowledge that is owned and shared by the community. Ownership is both familial and collective because knowledge centred on the continuation of reciprocal relationships is an interactive and dynamic process.

Ethical principles are central to the way in which knowledge is utilized. Ethical principles facilitate the maintenance and nurturing of the knowledge system. These Guidelines begin the work of documenting ethical principles that are integral to the collection, validation and production of knowledge in Pacific worlds.

Pacific theoretical frameworks are emerging from the work of Pacific researchers, such as the "Metaphor of Kakala" (Helu-Thaman - Tonga) the "Fa'afaletui Model" (Tamasese, Peteru and Waldegrave - Samoa) and the "Tivaevae" (Maua-Hodges - Cook Islands). These are valid theoretical frameworks for Pacific research. These are frameworks that are based on Pacific values, and necessitate the use of methods that are most appropriate for Pacific peoples.

The vision is one of 'Pacific research, by Pacific for Pacific'. Experience shows that whomsoever has the power of definition will define and give name to the realities of its citizens - as perceived through the social and cultural lenses of those who control access to knowledge. Knowledge that contains the societal beliefs, values and conceptions of a specific group of people, determines its scientific and technological

⁹ Tamasese Efi, Tuiatua Tupua (2002) "More on Meaning, Nuance and Metaphor" (Keynote Speech, Pacific Fono, Moving Ahead Together, Pataka Museum)

enterprises and its political and social arrangements. The vision is one of Pacific peoples participating in the production of knowledge, in order to enhance the quality and well-being of Pacific people.

It is beyond the scope of these Guidelines to document the many methodological approaches and theoretical frameworks developed by Pacific researchers and theorists. This document is designed to provide a guide that will inform a variety of approaches to research, those that are culturally innovative as well as those that are scientifically conservative.

A Pacific health research definition¹⁰

Pacific research is a broad descriptor that encompasses various approaches to research. The primary role of Pacific research is to generate knowledge and understanding both about, and for, Pacific peoples. The primary role of Pacific health research is to gain knowledge and understanding that will improve the health of Pacific peoples.

Pacific research requires the active involvement of Pacific peoples (as researchers, advisors and stakeholders), and demonstrates that Pacific people are more than just the subjects of research. Pacific research will build the capacity and capability of Pacific peoples in research, and contribute to the Pacific knowledge base.

The source material for Pacific health research will most likely be derived from Pacific peoples, and from within Pacific realities - past, present and future.

Pacific research design, methods and approaches, will be informed, first and foremost, from within the continuum of Pacific world-views. Pacific approaches to research will aim to be responsive to changing Pacific contexts. Pacific research will be underpinned by Pacific cultural values and beliefs, and will be conducted in accordance with Pacific ethical standards, values and aspirations.

¹⁰ The HRC is indebted to members of the Tertiary Education Committee's Pacific Advisory Committee (for the Performance Based Research Fund) for helping to shape this definition of Pacific research.

Ethical Principles of Pacific Health Research

Introduction

Developing Pacific health research ethical guidelines requires using a Pacific world-view as the primary reference point. This ethics guidelines document begins with the premise that relationships are the foundation for all ethical practice.

The centrality and importance of relationships is the overarching principle that binds each of the following ethical research principles: Respect, Cultural Competency, Meaningful Engagement, Reciprocity, Utility, Rights, Balance and Protection. These have been identified as the guiding principles for conducting ethical relationships for research.

The following section is structured so that the guiding ethical statements for each principle are highlighted in text boxes. These numbered statements are explicit, prescriptive and unambiguous. For each ethical statement, a descriptive and contextual *discussion* is provided to help researchers further understand the meaning and position of the guiding principle.

For each principle, a word from six Pacific languages in New Zealand is used. In most cases, these are the 'root' words or core concepts, from which the English translation has been derived. Different languages are used, affirming the linguistic diversity of the Pacific population in New Zealand and the wider Pacific region.

Putting Principles into Practice

The 'Putting into Practice' sections aim to provide practical information for researchers, to enable them to engage in research that is consistent with the principles outlined. Instructions are given about how to conduct research and research relationships that encompass the Guideline's ethical principles.

This 'practical' section is included to affirm the importance of translating ethical ideals into everyday practice. It also acknowledges the difficulty of bridging ethical theory with research reality. The recommended steps and instructions are clearly outlined in the text boxes. These are discussed in detail to provide further context and meaning.

1. Relationships

*Faiā (so'otaga vāvālalata), Piri'anga Tau Tēta'i ki Tētai'i, Fekau'aki, Fehagaiaga,
Na veiwekani, Va Fealoaloa'i, Va fakafeagai*

1.1 To develop, cultivate, and maintain principled relationships is integral to all ethical practice.

“I am not an individual,
I am an integral part of the cosmos.
I share divinity with my ancestors, the land, the seas and the skies.

I am not an individual because
I share a tofi with my family, my village, and my nation.
I belong to my family and my family belongs to me.
I belong to a village and my village belongs to me.
I belong to my nation and my nation belongs to me.
This is the essence of my sense of belonging¹¹.”

Tui Atua Tupua Tamasese

Discussion

“Through you, my being is contextually meaningful and whole. Through myself, you are given primacy in light of our collective identity and places of belonging (fa'asinomaga), our genealogical lineage (tupuaga), and our roles, responsibilities and heritage (tofiga)¹².”

Ethical Guidelines have a tradition of being ‘rights based’ documents which advocate the rights of individual research participants, and operate based on the assumption that the rights of the individual are paramount. Working within a Pacific framework, the focus shifts away from individual rights and the emphasis is instead given to both the group and interpersonal relationships¹³. This does not negate individual rights, rather, it recognises the limits of an individual rights-based approach for a people who have a relational theory of personhood¹⁴.

¹¹ Tamasese Efi, Tui Atua Tupua cited: Tamasese, Kiwi; Peteru, Carmel; Waldegrave, Charles (1997). “O le Taeao Afua The New Morning, A Qualitative Investigation into Samoan Perspectives on Mental Health and Culturally Appropriate Services”

¹² Tamasese, Kiwi. Peteru, Carmel. Waldegrave, Charles (1997) “O le Taeao Afua The New Morning, A Qualitative Investigation into Samoan Perspectives on Mental Health and Culturally Appropriate Services”

¹³ Helu-Thaman, Konai (2002) “Re-presenting and Re-Searching Oceania: a suggestion for synthesis”

¹⁴ Helu Thaman, Konai (2002) “Re-presenting and Re-Searching Oceania: a suggestion for synthesis”

Research relationships have tended to be conducted based on the values and needs of research, which can result in an exploitative relationship that meets the needs and interests of the researchers, as opposed to the interests of the research participants.

Building ethical relationships is integral to undertaking ethical research. The action of 'caring for, developing and maintaining relationships' is fundamental to sustaining the dignity, respect and care of the individual. The term *Va Fealoaloa'i*, refers to the various spaces and places within which Samoan people interact in a meaningful and non-coincidental way.

Putting into Practice

The action of building relationships is essential to undertaking successful Pacific research. The substance of these relationships will provide a lifelong impact on the lives of researchers, Pacific peoples, and the generations to come.

The essence of *Va Fealoaloa'i* recognises that people are sacred. Protocols and etiquette define how relationships between people are to be conducted to ensure that personal and collective well-being is maintained.

✦ Build and maintain ethical relationships.

By:

- understanding your role in relation to **who** the participants are, and within the context of the reality of their social and cultural environments;
- observing the etiquette of language and behaviour appropriate to the place and the participant community;
- working with and seeking advice from members of the participant community on how best to establish and maintain meaningful and functional relationships;
- ensuring that identified points of consultation and feedback are met in a timely and appropriate manner, and
- ensuring that communication enables reciprocation.

2. Respect

*Fa'aaloalo, Vaerua 'Akangāteitei, Feveitokai'aki, Fakalilifuaga,
Na veirokorokovi se veidokai, Fakaaloalo*

2.1 The relationship between the researcher and the research participant is based on respect for the inherent value of each human being.

Discussion

Respect, in the context of building and maintaining relationships, is integral to conducting ethical research. Respect is expressed towards the individual but acknowledges and encompasses who the individual is in the communal context. As respect is expressed towards an individual, it is correspondingly accorded to the group to whom that individual belongs.

In a Pacific context, respect is an underlying value linked to the expectation by Pacific cultures that the individual will subjugate his or her personal autonomy to a great extent, so that the group will reach consensus. The individual does this because physical and emotional survival is not possible without membership of the group. Respect and consideration of others necessarily becomes an important value, where co-operation and collaboration between individuals is the only way individuals can survive as a collective.

Respect and humility are attitudes that provide space whereby agreement can be negotiated, and where a group of individuals willing to subjugate many of their personal preferences, feel in the end, that their needs have nevertheless been adequately addressed. An attitude of respect provides space for individual dignity within the drive for collective consensus.

Respect continues to be an important principle of conduct within Pacific cultures today. If respect and humility are not demonstrated by both Palangi and Pacific researchers, Pacific people will often disengage.

Humility

Humility is a practice that finds its roots in the broader principle of respect. Humility, which requires giving priority to the needs of others before your own, is expected of everyone, but it is most effective when it is expressed by the most highly ranked in a particular gathering or situation. It is most powerful when displayed by the person who is acknowledged as the expert in a particular field. Genuine humility can best be shown by those most secure in the social hierarchy, independent of what this status is, in relation to others. In research practice, it means that the researcher must give priority to the needs of the participants ahead of their own.

Putting into Practice

Respect and humility are attitudes that need to be brought by researchers to any interaction with Pacific peoples, and indeed any interaction between a person/group with more resources than another. It is important to understand that expression of respect is dependent on the specific context of interaction, and the stage of the relationship itself. The more distant the relationship, the more formally respectful the interaction needs to be. If the relationship develops, with trust, then the expression of respect becomes less formal and the interaction more affectionate. While informality and affection may be the case in the private sphere, it is important to understand that in Pacific cultures, for a variety of reasons, formality remains as the most appropriate and respectful form of interaction in public.

Respect is most meaningful when at its source, is a deep recognition of the inherent value of each human being. Ultimately respect and an understanding of what this means for Pacific people is demonstrated through behaviour and language. Listed below are some of the ways in which an understanding of respect can be demonstrated.

 Demonstrate respect

By:

- practising behaviour and language appropriate to place and people;
- ensuring that senior people of the research project interface with the community of participants, and are accessible to the participants when appropriate;
- sharing full and frank information about the purpose and intent of the research;
- consulting effectively with the right people;
- engaging meaningfully with the Pacific community;
- upholding the rights of Pacific participants;
- addressing Pacific health priorities;
- contributing positively to the body of knowledge about Pacific people;
- understanding the importance of reciprocity;
- sharing the benefits of research;

- disseminating research findings back to the community in an appropriate and accessible way, and
- building Pacific health research capacity and capability.

3. Cultural Competency

*Tofā Manino i le aganu'u, Kia Tūkatau te Tangata I tāna 'ua'orāi Peu, Poto'i anga,
Pulotu-Aga Faka Niue, Na matau kei na kila no tovo na vakarau,
Mau ake o to iloa ki te agānuku*

- 3.1 To practice in a culturally competent manner, the researcher must have awareness of their own cultural beliefs, values and practices, and an awareness of how these impact upon their interaction with others.
- 3.2 The beliefs, knowledge and experience of the research participant is true to himself/herself, and the researcher must respect this even if it is different from his/her own beliefs, knowledge and experience.
- 3.3 Researchers are encouraged to build their cultural knowledge of the Pacific communities they work with.
- 3.4 Researchers are encouraged to create a safe and enabling research environment that supports culturally competent practice.

Cultural competence is a process of becoming, not a state of being
(Campinha-Bacote 2002)

Discussion

As health involves matters which are often deeply personal and private, procedures for health research can very easily cause offence, both to individuals, and to ethnic groups, even though none has been intended. Allowance must be made for diversity of culture and religious belief. Practices and beliefs of an ethnic/and or religious nature must be fully respected. Researchers must recognise that people of different cultures hold differing basic beliefs, have different value systems and regard differing modes of behaviour as acceptable to them.

Being (culturally) aware of the importance of differences and commonalities amongst diverse ethnic people and communities, is an important aspect of conducting ethical research. Cultural awareness is defined as having an understanding of one's own culture and biases towards other cultures. This comes about through self-examination and through the in-depth exploration of one's cultural and professional background¹⁵. Cultural awareness requires knowing yourself, in the context of the communal.

¹⁵ Campinha-Bacote (2002) "The Process of Cultural Competence in the Delivery of Healthcare Services: A Culturally Competent Model of Care"

Researcher commitment to growing their cultural knowledge and building a sound information base about Pacific culture, values, language and practices, will help inform and guide culturally competent practice.

Conducting research with an attitude of respect is essential to culturally competent practice. Even when a person has limited cultural knowledge, if they work with an attitude of respect, they are often able to operate in a culturally safe manner.

Research environments - teams, organisations, departments, institutions - should facilitate and encourage culturally competent practice and behaviour. Researchers should endeavour to create spaces and environments that are culturally safe.

Putting into Practice

✧ Seek ethnic specific and context specific advice on cultural competent practice

Pacific cultures have expectations and standards of what is appropriate and acceptable within specific environments and of identified individuals or groups. To varying degrees, the customs and conventions of Pacific people are **context-specific** and **ethnic-specific**. Consulting with people who have ethnic-specific, indepth cultural knowledge and expertise provides important guidance on protocol and practices, such as:

1. appropriate dress;
2. personal space and touching;
3. traditional or customary practices e.g. lotu, prayer, appropriate speaking spaces;
4. understanding ethnic-specific social and cultural hierarchy and one's place and responsibility within this, and
5. fundamental protocols and etiquette that extend respect and reciprocation.

It is difficult to give direct advice on some of these issues because of the importance of context-specific and ethnic-specific influences. The safest course of action is to seek advice from someone who will know. It is important to consult with someone who has credibility in their own community. With regard to appropriate dress, it is generally safer to dress conservatively. With some Pacific groups, and in certain contexts and settings, the requirement for appropriate dress is important as a mark of respect and acceptability. Always seek advice.

Although all Pacific cultures have been heavily influenced by Christianity, when it comes to lotu (or prayer), it is better to have a flexible and responsive approach, rather than have expectations about 'Pacific' behaviour. It is always advisable to 'give people the opportunity' to lotu (pray), or engage in forms of ritual if they so wish.

✦ Understand the importance of communicating appropriately translated information to Pacific people

It is important to ensure that information is available in the language which the research participant understands best. It is advisable to take care with translation of language, and to be aware of the difficulties with direct, literal translations. The key to effectively communicating information across cultures is the ability to translate concepts in the idiom of specific participant groups, within a specific ethnic community. The most reliable translations are undertaken by Pacific researchers who are bilingually fluent, have an excellent understanding of research process, and understand the world-view of the participants. Translation of information to ethnic-specific groups is context specific.

Researchers should avoid the use of transliterations as these are often confusing. A skilled translator is able to use a range of linguistic devices to explain concepts that are foreign to, or absent from, a Pacific person's experience and context.

It is best to employ translators who work in the area of health that you are researching. When practitioners and people from the health sector are engaged, they have a better understanding of the appropriate language to use, and which words are acceptable to Pacific communities. Direct translations that involve sensitive body parts, or bodily functions, can often be offensive (equated to swear words), if not managed carefully. Translators with experience of the health sector tend to have a better understanding of these issues.

4. Meaningful Engagement

*Tāua o le pululimatagau fa'atasi, Te 'Ō'ō'anga Tēta'i ki Tēta'i, Fe'ilongaki,
Fakafetuiaga mahuiga, Na veitaratara se cakacaka vata ka vakaibalebale,
Ko tau galuega e tatau o na iei he uiga*

4.1 To conduct ethical research with Pacific peoples there must be meaningful engagement.

Discussion

Consultation is an important part of engagement, but the term 'consultation' refers to a relationship that is generally temporary in nature. Meaningful engagement goes beyond consultation, to forming a relationship that is sustained and maintained, ongoing and deepening.

In Pacific communities, when people first meet, they will usually search to find the connection they have with one another before embarking on business or work. Making a connection on an emotional level with people who are not yet known, is an important part of building relationships. It is often felt by Pacific people that the development of the relationship is integral, and this takes precedence over the importance of the issues or business at hand.

In order to make such a connection, it may require the researcher to shed a powerful professional identity and 'de-role' from a 'professional' identity, to connect on a personal level. It may take a number of meetings before this occurs. The boundaries between personal and professional in a Pacific context are often more fluid and flexible.

It is also important to understand other people 'in context', which essentially means understanding the ways they are connected with others and how they are bound within their relationships. Therefore, to understand an individual fully, one must understand how that individual is located as a 'participant' in their own world, which fundamentally means understanding how they belong.

The action of 'locating someone' is not done just to understand a person's place hierarchically, but rather, it is done recognizing that the context is needed. That to understand a person, one must appreciate where they are from, who their people are, (e.g. who they are affiliated and related to), and how they came to be where they are now. Through appreciating the context and location of a person, one can enhance their understanding of that person's individual competencies.

In order to address and respect the diversity within the Pacific in New Zealand, it may be very important to engage meaningfully across different Pacific ethnic groups. Depending on the nature of the research, securing the trust and support of representative 'ethnic-specific' advisors, may be integral to the success of the project.

Meaningful engagement is essential to building and maintaining relationships and conducting ethical research with Pacific communities. This is accentuated further as many Pacific people may prioritise the relationship with the researcher over the research itself.

Putting into Practice

When two parties meet for the first time, it is helpful and often necessary, that something is known about each party by the other. This may require the involvement of a 'broker' who understands the position of each party within their own communal context and to communicate this to each party before their initial meeting. Very often, the Pacific member(s) of the research team are required to perform this 'brokerage' role between the research team and the Pacific community.

It is important to acknowledge that sometimes Pacific researchers, especially junior researchers, do not have the skills or social standing to perform this role successfully. The Pacific member of a research team, may also be hampered in performing an effective 'brokering' role by virtue of their obvious association and alignment with the needs and objectives of the research team in question. It is helpful to have some understanding of the well-documented research politics surrounding the insider/outsider researcher dynamic, or to be more technically formal, the issues of the emic and the etic.

These issues should be fully considered by the research team to ensure that meaningful engagement can occur on a foundation that is not flawed with false (albeit well-meaning) assumptions. When forming and establishing cross-cultural relationships between individuals or small groups the interaction often carries the weight and imprint of deeper historical collective relationships – that have structural and political implications – for cultural and ethnic groups.

✘ Effective 'face-to-face' consultation is critical to establishing meaningful relationships with Pacific people

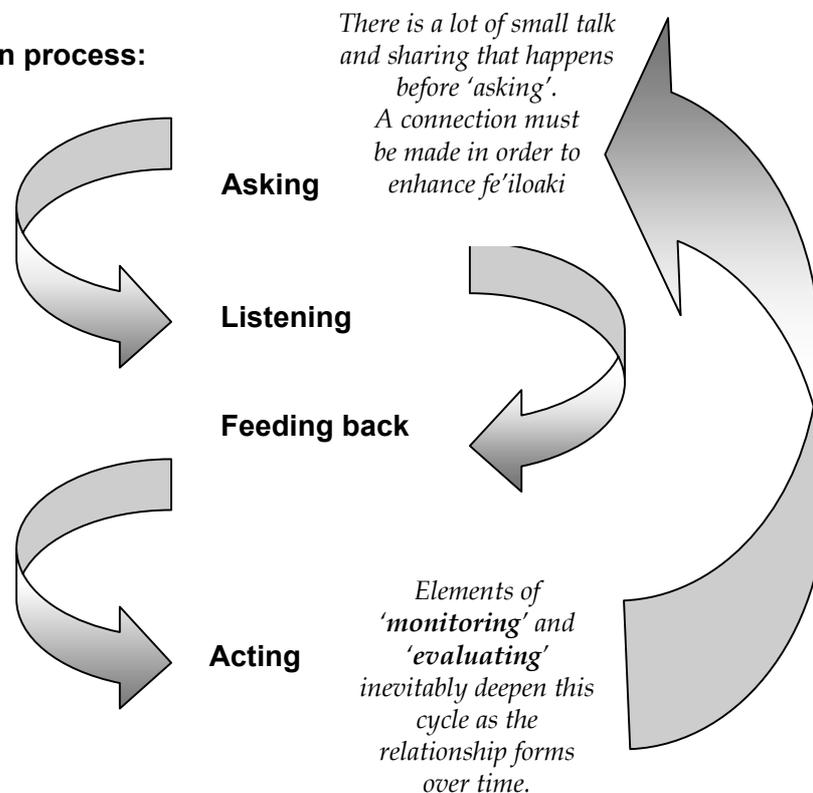
Consultation that recognises the importance of understanding and faithfully responding to the needs of participants provides the basis for establishing a relationship of respect and reciprocity. It is a duty that encompasses an ethical obligation to address the concerns and challenges faced by participant communities in a collaborative and participatory manner. The relationship between researcher and 'the researched' becomes one that is deeply meaningful.

It is important for researchers to recognise that even when consultation sessions are targeted to be one-off events and regarding a specific issue, these meetings are the beginning or part of an on-going dialogue and developing relationship with the Pacific communities.

✦ Understand the consultation process

- consult right from the beginning of a research project;
- formulate objectives and research questions in consultation with the Pacific community;
- set priorities for research and formulate the research questions in partnership with 'consumers', 'end-users' and 'insiders' who hold vast amounts of useful knowledge, and
- give people sufficient notice and sufficient information about the issues to be discussed.

Consultation process:



Consultation involves several stages:

Establishing a relationship, Asking, Listening, Feeding back, Acting.

 Identify with whom you should consult

It is recognised that different sections of a community will be consulted depending on the specific needs of the research group. It is important to select people who are reasonably informed about the particular issues and hold the specialized knowledge that the research team needs to access.

It can also be important to include individuals who are leaders within the community and are commonly called upon to represent the community. These may be elders, matai, chiefs, ministers, nobles, long-serving community workers, professional people or public servants, who have credibility within the Pacific community. Inviting participants who have credibility and are recognised for their seniority, leadership or specialist expertise, may bring authority to the consultation process.

When deciding whom to consult within a Pacific community, it is helpful to have some awareness of the hierarchies and ranking systems that potentially may constrain some members' ability to participate freely. Situations arise whereby different levels or groups within the same community recognise that it is not their role to speak publicly, or on behalf of the group. For example, it is very often the case that Pacific youth find it difficult to voice their concerns and views in public gatherings where senior adults are present. It can also be difficult for some adults to freely articulate their opinions and concerns when the representatives of leadership (e.g. church, traditional, political, familial or economically influential) are present.

Depending on the requirements of the research team, it may be strategically useful to facilitate separate 'consultations' with targeted groups. Issues of seniority, rank and respect are not the only influential factors with regard to Pacific group dynamics. Most gatherings of Pacific people will result in a group of people that have a variety of connections to one another, e.g. historical relationships, familial ties, political alliances, etc. These relationships and connections between members of the group may hinder free participation, depending on the context of the situation and the issues discussed.

One should be aware that there are societal rules that govern interconnectedness and appropriate conduct. These are gender, culture and location-specific. The primary purpose of these culturally-located codes of conduct are to protect and maintain the physical, mental and spiritual well-being of people. Seeking ethnic-specific advice about these issues is encouraged. Some understanding of the social structures and hierarchies of specific Pacific communities will aid in understanding group dynamics and will lead to more effective consultation.

Pacific Advisory Committees and Reference Groups

As seeking advice about how to work safely and knowledgeably with Pacific communities is critical, research teams are advised to develop an 'infrastructure' that allows for consultation to take place in a regular and systematic way. An example of this is a 'Pacific Advisory Committee'. Such a committee is made up of Pacific

people with appropriate expertise who are able to advise, give guidance, and support to the project in an ongoing manner.

Depending on the target population of the research and the scope of the project, it may be appropriate to seek out ethnic-specific advice. When putting an advisory group together, the ethnic distribution of the membership (across different Pacific communities) should be considered carefully.

It is necessary to fund such committees adequately and to compensate people for their time, travel costs and expertise. These groups should be provided with terms of reference (that are negotiable), so that the role and function of the 'reference', 'governance' or 'advisory' group is very clear.

Establishing an advisory group allows the research team to make informed choices and decisions when interacting with Pacific communities. The provision of such a resource should assist in strengthening the cultural competency of the research team. The ongoing nature of this type of consultative relationship enables deep and meaningful engagement with Pacific peoples.

A Pacific advisory group also has a monitoring function. The group should ensure that the research project is responsive to Pacific peoples. For example, the Pacific advisory group will oversee and be informed about the Pacific people involved in a project, e.g. capacity building positions, interviewers and investigators. The advisory group will ensure that the training and support provided is appropriate and effective for Pacific peoples.

Advisory Group members should:

- have a deep understanding of the research;
- be familiar with the subject matter;
- have credibility within the community;
- have a consumer understanding, and
- be **targeted** carefully recognizing the need for:
 - ethnic specific balance/representation;
 - awareness of cultural/political factors that may influence group dynamics, and
 - regional representation/balance (across New Zealand).

5. Reciprocity

*Toe tau'i atu i 'auala aloa'ia, Tauturu atu Tauturu mai, Maka fetoli'aki,
 Fe Tau'iaga, Na veidinadinati ni veisolisoli, Loto Fakataualolofa,
 Fakataufōki (o te, pe ko na tino hukuhuke ma te,
 pe ko na tino e fai ki iei na hukehukega)*

- 5.1 Reciprocity should be a guiding principle for research relationships. It should be demonstrated in practical ways (e.g. capacity and capability building, reimbursement for time, accessible dissemination).
- 5.2 Reciprocity in research requires that knowledge gained through research will be used to benefit research participants and (where relevant) other people.
- 5.3 If knowledge acquired from research generates significant financial returns, then the people from where the original knowledge came must share in the financial gain from the research.

Discussion

Reciprocity is an important principle in all Pacific cultures, where the interchanging of gifts and goods or services is fundamental to the maintenance and sustenance of relationships. Inequity or imbalance in the processes of exchange/interchange/interaction, indicates either a lack of respect for the relationship, or purposely highlights and reinforces the inequitable power hierarchy of the relationship.

It is important to be aware that reciprocity in the Pacific world is founded on kinship relationships. Spatially and temporally, the system of reciprocity plays out across and down through the generations. It is misleading to conceive of reciprocity as a quick quid-pro-quo formula. Bearing this in mind, reciprocity should be a general guiding principle for researchers working with Pacific communities.

Reciprocity should be demonstrated in attitude and spirit, as well as in tangible ways. There has been growing criticism in the Pacific community of exploitative research relationships that do not demonstrate reciprocity; unfavourable references have been made to 'mosquito researchers' and 'parachute consultants'¹⁶.

It is possible for relationships of reciprocity to become unhealthy, particularly when they are structured to engender an exclusive exchange of privileges. Systems of reciprocity can be self-serving and have the potential to become corrupt. Balance is essential to keeping reciprocity healthy.

¹⁶ Finau, Sitaleki (2002) "Research Imperialism in the Pacific: the case of Tonga"

Putting into Practice

✦ Build the research and health knowledge of the participants

All research projects should provide an opportunity to build the health and research knowledge of participants. Aside from providing training opportunities, interaction with participants makes available an opportunity to share knowledge and increase the participants understanding of the health issue being researched. Informing participants about symptoms, risk factors, access to appropriate services and so on, follows the basic principle of exchanging one type of knowledge for another. This is an important and practical example of reciprocity in action.

✦ Reimburse the costs of participation in research

Reimbursement, monetary compensation or a material contribution for people's time, effort and participation efforts, is an important example of reciprocity in action. This does not translate into payment for information, but reimburses the costs to people for their participation in research.

✦ Potential financial gains from research should be shared equitably with research participants (or the research participant community)

When knowledge acquired from research results in the creation of a treatment, cure or medicine that will generate financial returns, then the people from where the original knowledge was gained must share in the financial returns. This requires open communication, meaningful engagement and a spirit of reciprocity.

At the beginning of the research, the possibility of financial return must be planned for and negotiated in a transparent and accountable way. It will require the development of an equitable arrangement that is acceptable to all parties.

✦ Disseminate research findings so that they are accessible to Pacific communities

Effective, responsive, adequately resourced and appropriate dissemination is the most obvious form of reciprocity in research. The results of research should be returned to communities. Some researchers have argued that dissemination should involve the same degree of attention and care that has been taken to extract the information from participants.

The dissemination of the research findings is a significant part of the ongoing relationship of respect and reciprocity. It is about acknowledging the contributions of the participant community and the work of the researchers in improving the health and well-being of its people. Its achievement is that through partnership, the community has contributed to and helped define how it can best be empowered.

The conventional way of disseminating research findings is through the provision of the final report either formally or otherwise. There are often other ways of disseminating this information, which allow for greater participation, informed support and appreciation of the completed work. Strategic marketing of the research and its findings may bring about the potential for interest in supporting ongoing implementation of the research recommendations; to gather wider community interest and support; or to identify potential workforce interest.

Well-resourced dissemination strategies should be targeted, culturally appropriate, and accessible to Pacific communities. Discussions with key informants within the participant community will inform what is appropriate and how best to achieve this. They may include:

- using Pacific media;
- using existing networks;
- using promotional activities within the community, and
- promotion within church notices or minister's sermon/homily.

6. Utility

*Aogā o le soalaupule, Te Pu'apinga ka Rauka Mai, Faka'aonga, Fakaaogaaga,
Na yaga raraba, Fakaaoga fakalelei*

- 6.1 Improving the health outcomes of Pacific peoples should be the key objective of all Pacific health research.
- 6.2 Researchers should always endeavour to explicitly link research and its findings with tangible improvements in health outcomes.
- 6.3 Researchers should work closely with the health sector, where possible, to ensure the pragmatic utility of the research.

Discussion

Given the relatively low level of Pacific health research conducted compared with the enormity of the Pacific health burden, it is imperative that research topics chosen address Pacific health priorities. Consultation with Pacific health professionals, community leaders and Pacific health consumers, offers additional guidance regarding critical health issues facing Pacific communities.

It has often been argued that the Pacific health 'problems' have been well described and widely documented. However, Pacific health solutions have remained far more elusive. Intervention research, developed in collaboration with the Pacific community is now of great importance. Given the poor health status of Pacific peoples in New Zealand the translation of research into tangible health outcomes is essential.

It has been identified by indigenous research commentators that the subjects of research have the 'greatest potential stake', or are the 'key users' of research. However, they are very rarely identified as such¹⁷. In order for Pacific health research to have utility, research should involve stakeholders from the outset, considering the needs of the various 'users' of research, and providing research in a format that is accessible to the relevant Pacific populations. Many effective Pacific networks exist that are both traditional and technologically advanced, i.e. 'virtual'.

It is fair to say that research has not always been perceived as a valuable endeavour by the Pacific community. The aversion to research in the Pacific "is largely due to the connotations of experimental search for knowledge in an abstract and intellectual context¹⁸". Given this context and the widespread ambivalence that exists within the Pacific community, it is especially important for research to be seen as a useful tool.

¹⁷ Matthews, Sally et al (2002:viii) "Indigenous Research Reform Agenda: Promoting the Use of Health Research", CRC, Australia

¹⁸ Finau, Sitaleki (1995)

The probability of undertaking health research that will lead to real improvements in health outcomes can be enhanced by forming relationships of mutual trust with key stakeholders. Health professionals, health-policy writers, end-users, patient advocates and clinicians, can be enormously helpful in giving practical advice to help ensure research will be useful and applicable in the current health environment. Developing mutually beneficial relationships with the health and policy sectors will progress the effective translation of research findings into policy initiatives, and improve health services.

Putting into Practice

✦ Clearly explain the potential of the research to improve health outcomes

It is important from the outset that researchers communicate to the Pacific participants and stakeholders exactly how the research will have utility. The most significant aspect of the research is how the findings will improve the health status of the Pacific community. Make the link and make it explicit.

✦ Address priority health issues

The most effective way to ensure that the research team is addressing the significant aspects of a health issue that is of priority to the Pacific community, is by engaging meaningfully with Pacific people - right from the outset of the research. This should begin when formulating the research questions. Similarly, other key stakeholders include clinicians who work in the area of interest, as well as other health professionals. Pacific health priorities are well documented in the literature, particularly in Ministry of Health publications¹⁹. Documents such as the 'Pacific Health and Disability Action Plan' may give guidance²⁰.

✦ Demonstrate how the research will inform policy

It is important to demonstrate how the research will potentially develop and impact upon policy. This will require the identification of specific policies that are relevant to the research. It will also require an understanding of the current policy gaps, as well as familiarity with how policy is developed. Developing working relationships with health policy analysts and advisors can be mutually beneficial for both parties.

¹⁹ For example: "Priorities for Maori and Pacific Health: Evidence from Epidemiology" (2001) Ministry of Health, Wellington

²⁰ "Pacific Health and Disability Action Plan" (2002) Ministry of Health, Wellington

✦ Develop Pacific methodologies, frameworks, models, analyses and approaches

The development of 'Pacific' methodology, frameworks, models, analysis and general approaches to research is a valuable endeavour in itself. This may be demonstrated in the modification of a standard research approach so that it is more effective with a Pacific population. It may involve a Pacific researcher radically reworking a Western research approach. It may involve using traditional or contemporary Pacific knowledge, values, or perspectives, to transform or adapt standard research methods. It may involve the development of completely new research methods that are based on Pacific values.

The development of Pacific models for research - such as the Tongan Kakala model²¹ or the Samoan Fa'afaletui model²² - make a very important contribution to Pacific health research.

²¹ Helu-Thaman, Konai (2002) "Re-presenting and Re-Searching Oceania: a suggestion for synthesis" Unpublished Conference paper, HRC Pacific Health Research Fono, Auckland

²² Tamasese, K., Peteru, C., & Waldegrave C. (1997) "Ole Taeoa Afua: The New Morning", The Family Centre, Wellington

7. Rights

*Amana'ia o aiā a tagata lautele po'o e o 'auai, Tō te Tangata au Tikia'anga,
Totonu fakaetangata, Na dodonu ni tamata ya dua, Tau Tonuhia, Aiā*

- 7.1 Research should not be detrimental to research participants, as individuals, as members of a community, or as members of an identified ethnic group.
- 7.2 Each individual, group, or community, has the right and freedom to make an informed choice as to whether to participate or not, in any research.
- 7.3 Any risks inherent in a particular type of research must be made clear to the research participant and they must feel completely free as to their decision whether to participate or not.
- 7.4 Participants must be able to withdraw at any stage of the research process with dignity, respect, and without any disadvantage.
- 7.5 All research relationships are embedded with both rights and responsibilities to the other.

Discussion

An emphasis on collective rights, relationships and ethical interaction does not negate the importance of the individual rights of research participants. It is often understood in Pacific communities, that rights are inextricably linked with responsibilities, and may be collectively defined.

Knowledge is also associated with responsibilities. Sharing relevant and accurate information with research participants is integral to participant rights, so that they understand the potential outcomes of the decision made.

With regard to seeking and withdrawing consent, in Pacific culture, people may be reluctant to make an explicitly negative statement (i.e. 'no'), even when it is meant. It is considered much more polite to be indirect, and perhaps 'save face' (of the researcher making an unreasonable or inappropriate request), rather than saying no. It must be made clear to the participants that they have the right to withdraw at any stage of the research, and they can withdraw at any time with dignity and respect.

Putting into Practice

✦ Recognise that participants must be properly informed in order to consent

The following issues must be made clear to those who are invited to participate in the research:

- who the researchers are;
- what the objectives of the research are;
- the methodology of the research;
- the type of knowledge that is being sought from him/her, whether it is
 - his/her opinions
 - knowledge about his/her lifestyle or the lifestyle of a group of people
 - knowledge about cultural beliefs and practices
 - whether it is blood, DNA or any part of his/her body is required
- how the knowledge will be used;
- who can access this knowledge;
- whether the individual or group will be identified;
- who owns the knowledge, and
- how can he/she access the results of the research.

✦ All participants should receive all of the information

There has been a tendency for researchers to ask Pacific leaders to give consent and access to the community they are a part of. For example, researchers have approached matai, church ministers, or community leaders, to give their approval for research projects and enable access to the participant population. This is often appropriate. What is important, however, is that each person who is a member of the community, organisation, or religious group, is given the same amount of information as those in leadership positions, so that they can make an informed decision about whether to participate or not.

It is not appropriate to assume that the consent of the leadership extends to each and every participant. Each individual has the right to receive information that affects

themselves and their families, in order to make a decision regarding participation to a research study.

✦ Researchers must uphold the right of participants to withdraw

Research participants must be given the opportunity to withdraw safely, with dignity, and without repercussions. It is the responsibility of the research team to uphold this right, by not putting pressure on the participants themselves, and by effectively managing situations whereby external pressure may arise. The safety and dignity of the participants is paramount, as is the responsibility of the researchers to ensure that there is no harm to participants.

8. Balance

*Tafesilafa'i, Kia Tau te Ravenga Paruru, Pasapasanga malie, Fakatataiaiga,
Na veivakatautauvatataki, Fakatutuhaga*

- 8.1 Balance is critical when practicing the ethical principles of Pacific research.
- 8.2 Any research partnerships formed with Pacific peoples should be equitable and fair for both parties, engendering symmetry in the balance of power.

Discussion

Balance is integral to many of the guiding principles outlined. Balance in reciprocity is the basis for relationship development. Balance is what keeps reciprocal systems healthy. Balance is an important principle of maintaining equilibrium and the well-being of self and others. All of the principles outlined benefit from an appreciation and understanding of balance. Respect that is one-sided or extreme can be harmful and unwise. Rights that are disconnected from responsibilities can become damaging for all involved.

Relationships where member partners do not respect or reciprocate are relationships where one or more have disengaged and abdicated responsibility to the well-being and good of others. It implies that balance and wholeness no longer exists. It suggests that the dialogue and behaviour that engages respect and reciprocity has no meaningful context. It says that one part of the relationship has become 'rudderless'. This situation creates the potential for abusive and exploitative behaviour within primary relationships. Balance exists when respect through reciprocity is the cornerstone to developing and maintaining ongoing relationships between people. Balance encourages the exchange and interchange of knowledge and education. Balance encourages a sharing of responsibility and skills.

The business of developing, gathering, sharing and utilising knowledge takes different forms across many sectors, in as many cultures. Ultimately, the business of knowledge development and maintenance in any culture is a position of privilege and power. The core business of a Pacific research environment is to build, consolidate, share, and shape knowledge, to improve the well-being of Pacific people as an investment in a healthy future.

Pacific research is heavily reliant on the way in which resources are prioritised, allocated and accounted for. The relationship between researchers, funders and policy writers requires an optimum level of balance. This ensures that the relationship extended to Pacific participants, holds to the principles and practices of respect and reciprocity.

Putting into Practice

✦ Aim for balance in who benefits from research (reciprocity)

When research teams enter into research partnerships with Pacific researchers, Pacific stakeholders, and Pacific communities, it is important to undertake an analysis of who benefits. Who will benefit from:

- Research publications?
- From potential commercial profit?
- From the training opportunities provided by the research?
- From the potential findings and knowledge generated by the research?
- Which institutions will benefit and why?

When an analysis of this sort is carried out, one can identify whether there is balance in who benefits from research²³.

✦ Aim for balance in research relationships and partnerships

To achieve balance in research relationships researchers should share information and responsibility for the research. Researchers should monitor and evaluate the success and functional nature of relationships²⁴. Monitoring and evaluation facilitates accountability, transparency and responsiveness, which all enable balance to thrive in the research relationship.

²³ Swiss Commission for Research Partnership with Developing Countries, (1998) KFPE

²⁴ Ibid

9. Protection

*Malupuipuia o e fa'asoa ma 'auai, Te au Rāvenga Pāruru, Malu puipuia,
Puipuiaga, Na veitagomaki, Puipuiga*

- 9.1 Primary knowledge that is based on experience and expertise belongs to the research participants and should be acknowledged as such.
- 9.2 Where appropriate, researchers should uptake protective measures that will safeguard indigenous Pacific knowledge and knowledge holders appropriately.
- 9.3 Recognising that Pacific research relationships are often based on structural societal inequalities, care must always be taken to protect those less powerful.

Discussion

Protection is a principle that arises for a number of important reasons. The first reason is that protection is a principle that has traditionally been associated with the generation, validation and dissemination of knowledge in Pacific communities.

Ownership of knowledge is both familial and collective. The transmission of knowledge is centred on the continuation of reciprocal relationships. While there is ownership of familial and community knowledge, there is also protection. The Samoan word for protection is 'malu puipuia'. It points to the safeguarding and preservation of human dignity expressed in ritual, behaviour and language.

Defining knowledge as sacred, placing protective measures around knowledge, and restricting access to knowledge, is a practice that collides with Western-enlightenment understandings of knowledge for all. In Pacific societies, knowledge is often closely linked to particular roles, functions, families and select groups within the traditional leadership.

There is a core belief in many Pacific communities that knowledge should be used responsibly, and with wisdom, so as to not harm others. Pacific knowledge is very much tied to praxis for the collective good. To transmit knowledge to those who are not able to care for that knowledge, process it appropriately, or keep the meanings safe, is often seen as an irresponsible and reckless approach to knowledge. In the Pacific context, one earns the right to know; one proves that they are worthy, and ready for the information. This prevailing attitude may mean that some researchers face barriers that they might not experience if working with a different population.

The statement that knowledge is centred on the continuation of reciprocal relationships underpins the decision of the writers to make 'relationships', the central focus for the ethical guidelines on Pacific research. It is unlikely that knowledge will

be forthcoming if a relationship has not been established. If the relationship is not ethically sound, Pacific participants and communities will often disengage.

The guiding principles have been developed on the premise that relationships are central. The wider context of the relationship between Pacific and non-Pacific peoples (and between researchers and research participants) must be analysed. Both of these 'collective' or 'communal' relationships are partly defined by structural and societal inequalities.

Within New Zealand, Pacific peoples are politically and economically marginalised²⁵ ²⁶. On one level, any interaction with Pacific peoples can be seen as the personalised interface of a broader relationship that is characterised by structural inequalities. Similarly, many relationships between researchers and research participants are characterised by inequalities. It is wise to be cognisant of the structural inequalities within the wider (communal) relationship between ethnic groups, and understand how the politics of this collective relationship may impact upon individual relationships.

An awareness of the characteristics of wider collective and shared relationships, will give rise to a broader understanding of the need for protection of Pacific peoples. This extends to a protection of indigenous Pacific knowledge, as well as protection of individual participants.

Putting into Practice

✂ Determine from the knowledge source, the appropriate function of the knowledge that is shared.

There are differences and commonalities across cultures regarding the ways in which knowledge is valued, and how it should be utilised by researchers. Access to knowledge may involve cultural politics that the researcher does not understand the full implications of. Integrity around the gathering of knowledge for institutional research purposes, acknowledges the context in which each Pacific group views the roles and functions that knowledge has within their familial and collective contexts.

Researchers need to ask about the appropriate function of knowledge that is shared, and who may have access to it. This is not always done, nor is it always a relevant line of enquiry, but is especially important when research involves traditional knowledge and understandings.

²⁵ "Pacific Vision: Social and Economic Report: (1999) Ministry of Pacific Island Affairs, Wellington

²⁶ "Pacific Progress: A report on the Economic Status of Pacific People in New Zealand" (2002) Statistics New Zealand, Wellington

✦ Researchers should always acknowledge that the ownership of primary knowledge and data lies with the people who contribute that knowledge

The question of who owns the primary knowledge that is derived from the experience and expertise of participants, suggests that this knowledge indeed belongs to the research participants. The question as to who owns the combined outputs of the accumulated primary knowledge, suggests that this belongs to the community of Pacific families and the community of researchers. Researchers should, where appropriate, protect indigenous Pacific knowledge and knowledge holders.

10. Capacity Building

*Tulitulimatagau Langa tangata o toutai tangata, Te 'Akamātūtū'anga,
Fakalaulahi Lotomatala, Na vakacokotaki ni kila ka, Fauga o na hikili*

- 10.1 Capacity and capability building is critical to improving Pacific health outcomes through research.
- 10.2 Capacity and capability building is a tangible example of reciprocity in action and demonstrates a commitment to the empowerment of the Pacific community.

Discussion

Developing a Pacific health research workforce is critical for the delivery of Pacific health research outcomes. The Pacific health research workforce capacity and capability is still limited, in terms of numbers, experience and seniority. Building the critical mass of Pacific health researchers is one of our most immediate challenges. Ensuring that the training opportunities are available for the different Pacific ethnic groups, is an important consideration. All Pacific ethnic groups require capacity and capability building initiatives to strengthen their communities.

This will involve Pacific people conducting original investigation in order to gain knowledge and understanding about the problems and challenges that face the Pacific community, within Aotearoa, within the Pacific region, as well as within a wider global context.

This translates into Pacific people being actively involved in enquiry that is of an experimental or critical nature, driven by hypotheses or intellectual positions that will withstand or stand-up to rigorous assessment.

This requires training Pacific people with specialist knowledge about the theories, methods and information concerning their field of enquiry, and about making connections to Pacific world-views and ways of knowing. It is about Pacific people generating findings that are then open to scrutiny and formal evaluation by others in the field. It is about Pacific people being involved in developing Pacific-centred solutions to problems that are owned (and not owned) by Pacific communities.

Putting into Practice

✦ Build Pacific health research capacity and capability to extend reciprocity

Building Pacific research capacity and capability is a tangible example of meaningful reciprocity as it involves important skills and knowledge exchange. By building the Pacific health research capacity and capability, a research team demonstrates commitment to the wider Pacific community – by effectively developing and enhancing the human capital skills of that community.

✦ Provide training opportunities

When researchers embark on large Pacific health research projects, it is important to review the possible training opportunities available via the funding of that project, in order to foster the growth of Pacific researchers. Experienced mainstream research groups who have significant expertise and authority in their areas of research are in a strong position to provide support, and contribute to the development of Pacific researchers.

When Pacific peoples are specifically targeted and recruited as interviewers for research projects, it provides employment and new skills for members of the Pacific community. There has been growing criticism of research projects that train ‘Pacific’ data collectors to perform the ‘less’ skilled tasks of research. For example, with qualitative research projects, the analysis of data is critical. It has been argued that the analysis of Pacific transcripts by Pacific peoples is integral to a deep and correct understanding of the discourse, dialogue, and epistemological issues that arise.

While the training of Pacific interviewers may be viewed as inadequate in itself (and has been criticised as tokenism), as a capacity building measure, it *cannot* be conceived as a negative step. Employing Pacific interviewers is one of the most effective ways of ensuring that the research is pragmatically and ‘operationally’ responsive to Pacific communities.

✦ Provide formal qualification opportunities for Pacific people

Increasingly, what is being argued for is ‘equity’ of training opportunities. For example, if through the funding of the research, individuals on the research team gain masters, doctoral, or post-doctoral opportunities, then the training of Pacific people as interviewers cannot be compared equitably to this level of formal research capacity and capability building.

It is often possible to factor into a research proposal the provision of a Masters research position or a doctoral opportunity for a Pacific graduate. The HRC is often

able to assist with providing contacts for eligible Pacific students. Many Pacific networks exist that can be utilised to ensure that these positions are advertised in Pacific communities.

If a research project is funded and offers formal postgraduate qualification opportunities to identified and 'named' Pacific students, then capacity and capability building is being addressed, i.e. this demonstrates a serious commitment from the research team to developing the Pacific health research workforce. At the HRC, through our funding mechanisms and criteria, research teams are recognised for building Pacific research capacity and capability in this way.

It is only through the formal training of Pacific peoples that capacity and capability building in the Pacific health research workforce will be realised. It is only when Pacific people achieve the highest level of qualifications that they are in a position to supervise the next generation of Pacific researchers.

11. Participation

*Tapulima fa'atasi, Kau ki he fekumi, Te Piri'anga ki roto i te 'Anga'anga,
Hakahakauaga, Na kena ugetime ra Okati taumada ka vakaitavitaki, Ke iei he hāo*

11.1 Research that targets the Pacific population entails the participation of Pacific peoples at all levels of decision-making and implementation of the research project.

Discussion

Participation is an important principle of Pacific research. Pacific research requires the active involvement of Pacific peoples (as researchers, advisors, and stakeholders) and demonstrates that Pacific people are more than just the subjects of research.

Where a research project targets Pacific populations (or over-samples for Pacific participants) Pacific people should participate in the research team at all levels (e.g. interviewers, research assistants, investigators and advisors). This ensures that the project is responsive and accountable to the research needs of the participant research population.

It is recognised that while Pacific health research workforce numbers and training continues to be developed and strengthened, representation at all levels of a research project is not always possible or practical. Therefore, the commitment of research teams to building Pacific health research capacity and capability becomes even more of a priority (see capacity building).

A Pacific advisory group will often have the role of ensuring that the level of Pacific participation in a project is appropriate for the scope and nature of the research. Ideally, all projects that research the health of Pacific peoples will include a Pacific health researcher with an academic role on the research team. If there is poor representation of Pacific peoples at senior levels of the research, more frequent interaction and relationship building with Pacific advisors and advisory committees will be necessary.

Putting into Practice

✦ Participation of Pacific peoples in a research project is encouraged on a number of levels, e.g. investigators, advisors, students, interviewers etc

Employing Pacific interviewers is one of the most effective ways of ensuring that the research is pragmatically and 'operationally' responsive to Pacific communities. It is important that the interviewers of a project are reflective and representative of the participants' communities. Characteristics that may need to be considered include ethnicity, language, age and gender.

Many large research teams (e.g. national scale epidemiological projects that over-sample the Pacific population) have credited their well-trained ethnic-specific interviewing teams with achieving extremely high response rates from Pacific participants.

Interviewers that have different Pacific backgrounds, speak different Pacific languages, and have access to different Pacific communities, will be beneficial to a large-scale research team. When employing interviewers it is important to consider the English language speaking ability of the population targeted.

When Pacific peoples only participate in a research project at the interviewer level a number of concerns arise. One concern is the practice of allocating Pacific people roles as data-collectors, but not involving them at the data analysis phase of research. Data analysis and interpretation is often seen to be where the academic influence lies. It is also a site where cultural knowledge and understanding is of paramount importance.

A second concern is the absence of Pacific peoples in decision-making roles within a research project. Ensuring that Pacific peoples have influence and power with regard to executive decision-making as well as the overall management of a project is very important. Another related and sensitive issue of concern is equitable remuneration.

Finally, the training of interviewers is seen to be inadequate as a capacity building measure in itself. Although the training of interviewers is necessary, the commitment to providing formal training opportunities is highly desirable.

✦ Provide support for the Pacific members of the research team

When Pacific peoples are involved in a research team at a senior level, there are a number of considerations that should be taken into account. It is important to proactively address the safety of the Pacific researcher on a research team and to ensure that they are supported. It must be recognised that this person cannot be conceived of as a 'one-stop shop' for all Pacific issues. It is not safe to make

assumptions about the cultural 'competency' of the Pacific health researcher, nor is it fair to delegate all 'Pacific' issues as the sole responsibility of this individual.

The Pacific researcher exists in a continuous flux of shifting relationships within their own ethnic-specific groups and within the wider pan-Pacific communities. They have responsibilities and obligations to both groups. The Pacific researcher understands the boundaries of relationships between his or her self with their own ethnic community, and recognises the boundaries of relationships with other Pacific groups.

In any Pacific context, unless there is a process of agreement, it is disrespectful and inappropriate for any individual or group to speak on behalf of another Pacific ethnic group, to which they do not have claim through descent, kinship and/or service.

It needs to be recognised that where a Pacific researcher has relative seniority and experience in the research world, it should not be assumed that this status will be perceived in the same way within all Pacific communities. The privileges of seniority and responsibilities of leadership are based on standards that are specific to families and communities.

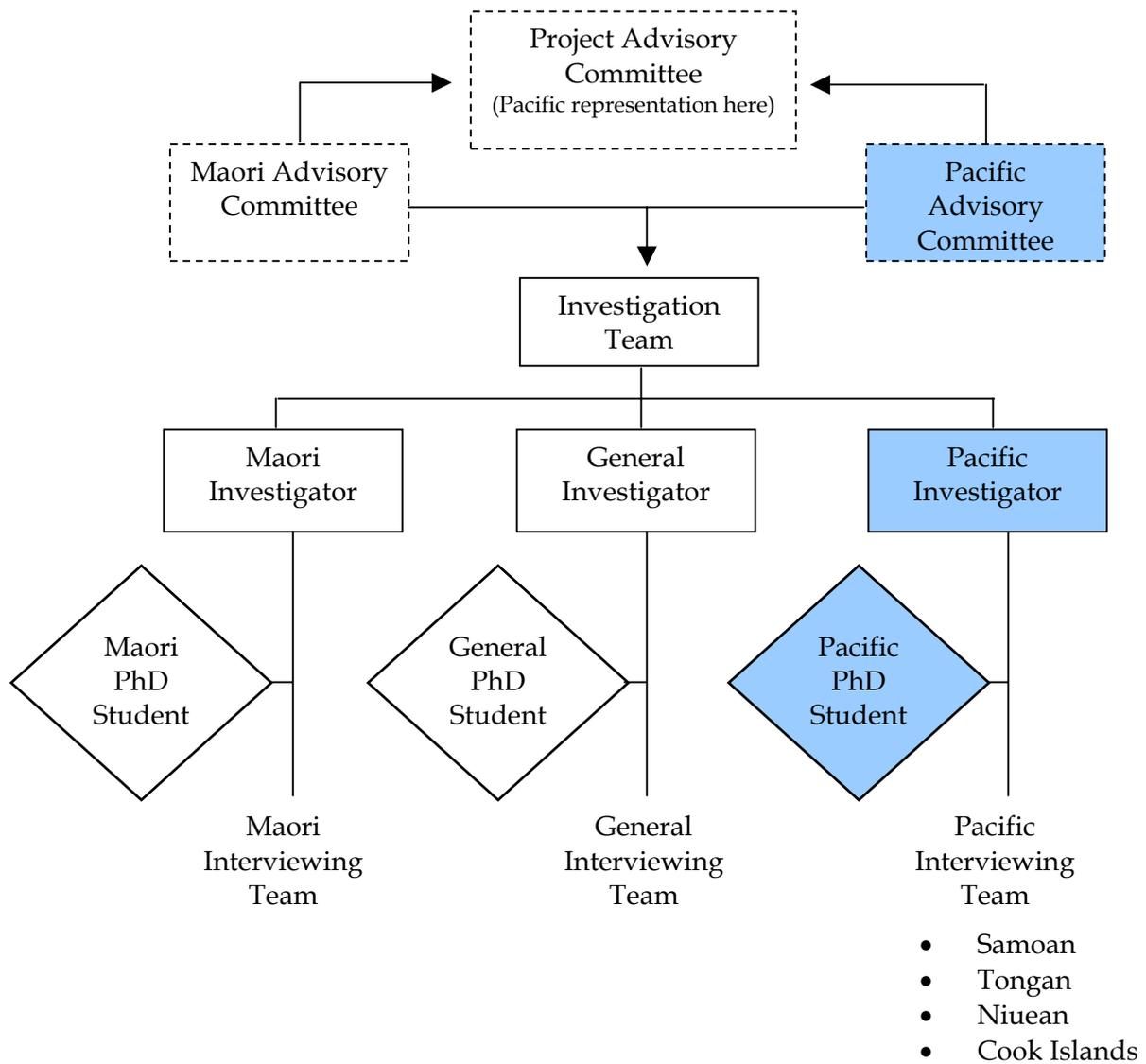
A Pacific researcher is required to have a range of skills that enables them to synthesize diverse cultures and to balance the demands of academic institutions and Pacific communities. In this way, Pacific researchers are often required to negotiate difference and search for workable commonalities, or arrangements between two very dissimilar and often conflicting perspectives. A combination of well-developed professional skills and cultural confidence is important.

There are a variety of tensions that can be resolved by putting into place Pacific reference groups or advisory committees that have a 'governance' role over the Pacific component of the research (see meaningful engagement section).

Consultation with the participant community is an important ethical consideration in any research project. Research teams that include strong representation from Pacific researchers still need to consult with Pacific communities.

It is important to recognise that a Pacific researcher is accountable to the Pacific community in ways that non-Pacific researchers are not. Their personal and community credibility will be judged on the conduct of the research team and project. All research team participants have a responsibility to uphold the reputation and integrity of the Pacific member, by conducting themselves in a manner that is respectful and which mutually enhances the well-being of the research team and the participant community.

The organisation of human resources employed for a research project has both politically and operationally important implications. The diagram on the next page illustrates an example of the human resource hierarchy and structure for a national survey that over-samples for Pacific and Maori populations. The diagram illustrates how Pacific peoples are represented at all levels of the project to ensure that it is responsive, balanced and effective in targeting the Pacific population. This includes participation at the highest level of governance.



Pacific Research at the HRC

This section has been included to inform the reader about HRC policies and frameworks that have been developed for Pacific health research. For further information about HRC portfolios and policy please go to: www.hrc.govt.nz

HRC Pacific Health Research Committee

The Pacific Health Research Committee (PIHRC) is a Standing Committee that provides guidance and advice to the Health Research Council. The PIHRC leads and directs the work of the HRC Pacific Team at a governance level. The Committee is chaired by Mr Kiki Maoate (FRACS) and determines the strategic direction of Pacific health research for the HRC.

HRC Expert Panel on Pacific Peoples Health

The Expert Panel on Pacific Peoples Health is one of five 'Expert Panels' that inform the HRC policy-making process. There are five priority populations at the HRC: Maori, Pacific peoples, children and youth, people with disability and older adults. The Expert Panel on Pacific Peoples Health is made up of Pacific people who have significant health research expertise.

The Panel meets at critical stages of the policy process to provide advice, direction and guidance to the HRC. The Expert Panel ensures that Pacific perspectives and issues are incorporated into policy development. The Expert Panel on Pacific Peoples Health is one of the ways that the HRC engages meaningfully with Pacific Peoples.

The Expert Panel makes annual Pacific recommendations to the Research Policy Advisory Committee, who in turn makes recommendations to Council. There is Pacific representation at both the Research Policy Advisory Committee level and on Council.

The Expert Panel on Pacific Peoples Health acted as the governance and advisory group for the development of the Guidelines on Pacific Health Research.

HRC Pacific Health Research Frameworks

Introduction to Pacific Relevance, Governance and Partnership Research

Pacific Governance and Pacific Relevance criteria were established by the HRC 'Expert Panel for Pacific Health' to identify to what extent, research aims to produce Pacific health solutions. The criteria can be used as a tool to measure the level of responsiveness of the research to the needs and aspirations of the Pacific population.

Since developing this framework, it has been recognised within the spectrum of Relevance and Governance definitions that another type of Pacific research has emerged: namely "Pacific Partnership" research. All three research categories are discussed in this section.

Pacific Relevance Research

Research classified as Pacific Relevance will be significant to the Pacific community, will aim to improve Pacific health outcomes and will add to the general body of Pacific health research knowledge. Pacific relevance research will usually be led by non-Pacific researchers, although there may be junior Pacific health researchers on the team. While it involves research that addresses a priority Pacific health area, in terms of ownership of the research, Relevance research cannot be classified as 'by Pacific for Pacific'.

Pacific Relevance research will involve some Pacific participants, usually a significant Pacific cohort, that will allow for an ethnic specific analysis of data. It might, for example, make statistically significant comparisons between Pacific data and data sourced from the other population groups.

A Pacific Relevance research project will demonstrate effective consultation with appropriate Pacific representatives. This may include the participation or training of junior Pacific research team members, or an advisory appointment of a senior Pacific consultant.

In recognition of the Pacific component of the research, Pacific relevance research will modify and adjust standard research practice to ensure cultural safety and cultural competence. Pacific Relevance research can be defined as research that is relevant to the Pacific community and is appropriately responsive to that community.

Pacific Governance Research

Pacific Governance is best described as research that is Pacific-led. Pacific Governance research is clearly owned, driven and directed by Pacific peoples. Pacific Governance research requires the active participation of Pacific peoples as agents of research. Pacific people are not limited to having the role of research participants and/or potential end-users.

It is envisaged that Pacific Governance research will tackle many different Pacific health challenges on many different levels. It will aim to improve health outcomes, but it will also aim to build and strengthen the capacity and capability of the Pacific health research workforce.

Pacific Governance research will contribute significantly to the body of knowledge generated, 'by Pacific for Pacific'. Pacific research methodologies, frameworks, paradigms, and models will be developed. Pacific Governance research will actively seek to use and develop Pacific approaches to research.

As Pacific Governance research builds the research capacity of the Pacific community, ideally Pacific people will gain formal research qualifications through the funding of the research project.

The concept of Pacific Governance research is linked to principles of self-determination and autonomy. Fostering the development of Pacific Governance research acknowledges the intrinsic value of research being owned and undertaken by the community from which it draws.

With Pacific Governance research, high-level consultation and direction should be provided through the research team, as well as establishing infrastructure to facilitate ongoing consultation with Pacific community representatives. This is often achieved through the establishment of advisory committees.

Pacific Governance research is funded from the 'Health and Independence of Population Groups' portfolio. A special nexus for Pacific-led research has been created in this portfolio. The relevant sections of the portfolio strategy are documented below.

Health and Independence of Population Groups Portfolio Strategy

Excerpt 1

The HRC acknowledges that real health gains will not be made or maintained if participants are not involved in shaping the research agenda. By fostering consumer-driven approaches and enabling population groups to guide research, they establish what keeps their community well, allowing them to function in society in a satisfying way. To further strengthen this principle, the Council has decided to create a specific focus for health research that is 'by Pacific peoples for Pacific peoples' within this portfolio strategy. All such research will be mapped to this portfolio, regardless of the topic. The move recognises that creating a nexus of

Pacific-led research will strengthen the capacity and capability of the Pacific research community to tackle Pacific health priorities, which include the increasing burden of communicable and non-communicable diseases. Research that addresses Pacific health issues and is not Pacific-led will be mapped to the other portfolios, and will also be considered a priority under those strategies.

Excerpt 2

Pacific Peoples

Strengthening the Pacific health research workforce capacity to empower Pacific peoples to produce solutions that work for their own communities has been consistently identified as a pressing need. The statistics that are available on the health of Pacific people in New Zealand show that they have the poorest health status of all New Zealanders. Pacific people have the highest national rates for meningococcal disease, measles, rheumatic fever and rheumatic heart disease, and obesity. Higher rates of diabetes, tuberculosis, liver cancer in adults and sudden infant death syndrome are also reported for Pacific peoples. Reducing the incidence and serious impact of these diseases within this population group is of the highest priority. Despite the wellness and well-being focus of this portfolio, given the current health climate and the stage of development for Pacific peoples, research that is led by Pacific for Pacific must be encouraged to address the areas of utmost priority.

Excerpt 3

Research Priorities for Pacific-led Research

As previously mentioned, Council has created a nexus for Pacific-led research within this portfolio strategy. Hence, all research that is by 'Pacific peoples for Pacific peoples' comes under the scope of this strategy and will be considered a priority. The following topics cover particularly pressing issues for Pacific-led research:

- research relating to those conditions which impact disproportionately on Pacific peoples, such as diabetes, rheumatic fever and rheumatic heart disease, and meningococcal disease;
- research on Pacific understanding and experiences of natural life-processes, such as birth, developmental milestones, menopause and ageing;
- Pacific models of well-being and conceptualisations of health, and
- Pacific child and youth health.

✦ Pacific Partnership Research

Since establishing the Pacific Relevance/Governance framework, research has emerged that does not fit neatly into either category. This research is ground breaking in that it goes far beyond meeting the minimum responsiveness required for Pacific relevance, however, because it is not 'by Pacific for Pacific', it cannot theoretically be classified as Pacific Governance research.

Pacific Partnership research sits between the two polarized descriptors on the research classification spectrum. Partnership research deeply engages the Pacific community and significantly goes a step further by **sharing leadership** of research projects.

International Collaborative Research Grants Scheme Initiative

The growth in Pacific partnership research can partly be attributed to initiatives such as the International Collaborative Research Grants Scheme (ICRG) funded by HRC, NHMRC, and the Wellcome Trust (UK). Pacific Partnership research is not captured using the two-pronged classification tool of Relevance and Governance, yet it is a significant and growing body of Pacific research.

The ICRG Assessing Criteria required a collaboration between Australia and/or New Zealand and 'developing' country partners in the Pacific region.

If the proposed research programme is to succeed in achieving its objectives it will need to demonstrate cohesion between the research team members in Australia and/or New Zealand and in developing countries and the complementarity (added value) of the partnership. Assessment of the strength of the partnerships will examine the extent of existing collaborations, the appropriateness of any new collaborative arrangements and the commitment and contributions to be made by investigators. For new partnerships, the potential of the proposed collaborations to develop synergies and to add value will be taken into consideration.

The ICRG also measured and scored the capacity building opportunities provided by the research team.

Development of research capacity in the developing countries of the region and in Australia and New Zealand is a major objective of the Grants Scheme. It is an expectation that the partnership between research teams, host institutions and countries will provide opportunities for demonstrable gains in capacity to conduct health research. It is expected that research training will be relevant to the needs of individual countries involved in the programme and that plans to provide for sustainable development of research capacity are identified.

✧ Indicators to define Pacific Relevance, Pacific Partnership and Pacific Governance

Pacific relevance		Partnership		Governance
Some Pacific participants	Pacific population and/or Pacific data-set	Pacific researchers on the research team		Pacific-led research team
Pacific health priority issue		Pacific population focus		Pacific research paradigms
Consultation with Pacific peoples	Training opportunities for junior Pacific researchers	Pacific data analysis		Pacific population focus
<i>(eg. a mainstream study identifying a Pacific proportion to be sampled)</i>	Pacific dissemination	Formal training opportunities to build Pacific health research capacity		Pacific data analysis
	Pacific Advisory Committee	Targeted Pacific dissemination		Pacific outcomes
				Pacific ownership

✧ Consultation – Best Practice at the HRC

In 2003, the HRC included a new section in the application form for funding. This section asks researchers to document evidence of consultation with specific populations groups they are targeting (for full application form please go to www.hrc.govt.nz).

This section is similar in principle to the 'Responsiveness to Maori' section of the HRC application form. The section is included below.

Section 4B – Research with Population Groups (2 page maximum)

Only complete this section if your research involves human participants. Consultation with Maori should be described in Section 4A and not this section.

1. If your research has relevance to a specific population group, there is an expectation that appropriate consultation with stakeholders will occur. The HRC considers this to be a 'best practice' principle for research (*see*

application notes). If consultation is not appropriate in this case, please give the reasons why and proceed to Section 5.

(Delete these words and start typing here)

2. Please identify the stakeholder groups that were consulted regarding this proposal and describe the ongoing role they will have in the further development and/or implementation of this research project (please append any documentation resulting from that consultation). Please also include details of any stakeholder participation on the research team.

(Delete these words and start typing here)

3. In what ways has the research been designed to ensure that recruitment, data analysis and dissemination will be appropriate for the population group concerned?

(Delete these words and start typing here)

4. Does your research target one or more of the HRC's priority population groups, other than Maori? If not, please proceed to Section 5.

Pacific peoples	
Children and youth	
Older adults	
People with disability	

5. Will the research generate data specific to one or more of these population groups? If so, please give details below.

(Delete these words and start typing here)

6. Will the research provide a training opportunity or otherwise contribute to building the research capacity of one of the HRC's priority population Groups?

Please explain.

✦ Explanatory Notes for Section 4B

Section 4B – Research with Population Groups (2 page maximum)

The HRC wishes to make certain that research is conducted in partnership with specific stakeholders, and that checks have been put in place to ensure that the study design, methodology and dissemination of the resulting findings are appropriate for the participants involved.

Populations groups can be defined in terms of demographic factors (e.g. ethnicity, gender and age), culture, by special needs (e.g. people with a disability) or behavioural factors (e.g. tobacco, drug or alcohol consumption).

The HRC has five priority population groups, Maori, Pacific peoples, children and youth, older adults, and people with disability.

The HRC is committed to ensuring that all research involving human participants meets ethical standards and complies with international best practice. Best practice in this instance includes the expectation that researchers consult with the participants of research. Applicants should refer to the HRC's guidelines for Research with Maori, the Pacific Health Research guidelines, and the Ethics guidelines, located on the HRC's website (www.hrc.govt.nz).

In some cases it may not be either reasonable or feasible to consult with population groups involved in the study. However, consideration should be given to consultation with other key stakeholders and representative bodies (e.g. relevant non-government organisations (e.g. Alzheimer's Association), support groups, parents or care givers).

If the research involves the general population, with no sub-cohorts for specific populations and no over-sampling to allow separate data analysis for specific stakeholder groups, this should be stated under question 1 and the rest of the section should not be completed.

Applicants do **not** need to complete this section if:

- the research does not involve human participants (e.g. research in cell, tissue or animal models or the development of medical technology), and
- Maori are the only specific stakeholder group (all applicants must complete Section 4A).

Conclusion

The purpose of the HRC Guidelines on Pacific Health Research is to guide Pacific research funded by the HRC that is carried out in New Zealand. The Guidelines primarily aim to assist Pacific researchers and non-Pacific researchers to undertake health research with Pacific peoples. The Guidelines have been developed in the context of similar work carried out by the HRC, such as developing Guidelines for Health Research in New Zealand and Guidelines on Maori Health Research. The Guidelines reflect events that affect Pacific peoples, New Zealand, and related work that is being undertaken in the health sector to articulate Pacific cultural responsiveness and competence.

It is acknowledged that this document is a construction that emphasizes differences in a fairly general manner. The Guidelines stress points of difference between Palangi and Pacific perspectives. This broad approach is further emphasised by the fact that the Guidelines do not provide an ethnic-specific analysis of health research issues. The Guidelines do not attempt to provide a definitive answer as to what Pacific ethics are. However, they do aim to use Pacific world-views as the primary reference point for the development of this document. In developing the document there was a search for common characteristics and a drawing together of these as defining features.

The fundamental tenet of the document is that relationships are central. Through our relationships with others we become contextually meaningful and whole. The Guidelines on Pacific health research are ultimately an attempt to define the nature of an ethical relationship.

Ten principles have been named as essential to guiding ethical research relationships:

- respect;
- cultural competency;
- meaningful engagement;
- reciprocity;
- utility;
- rights;
- balance;
- protection;
- capacity building, and
- participation.

The Guidelines are the result of a series of dialogue with Pacific researchers and Pacific peoples. It is important to recognise that this is an evolving document. The second edition is already under discussion. This is a contribution to a much wider and more complex conversation, as Pacific peoples seek to name and articulate what is culturally salient with regard to research and the pursuit of knowledge.

The final section of the Guidelines provides a checklist for those embarking on research with Pacific peoples. This should be read in conjunction with the more comprehensive analysis of Pacific research issues provided elsewhere in the document.

Final Checklist for Researchers

Undertaking Pacific Health Research

A series of issues and questions for researchers to consider when undertaking Pacific health research.

Consultation

With whom have you consulted?

e.g. about the research design, scope, approach, methodology and objectives.

Are the people you have consulted sufficiently representative? (See Meaningful Engagement section.) Have you consulted with the key stakeholders? Have you considered:

- a) the communities you are targeting, and
- b) the research area you are approaching.

If you have very few Pacific health links, then a good person to start with is the Pacific Manager at the District Health Board nearest you. They tend to have good links with the Pacific community and an extensive knowledge of Pacific people within the health sector. The Health Research Council's Pacific Health Research Team is available to assist with identifying Pacific networks or individuals.

It is often useful to ask within Pacific networks, what research has already been undertaken in the area. Many unpublished projects have been carried out in Pacific communities that are otherwise hard to access. Letters of support from Pacific organisations and key individuals should be attached to proposals for funding.

Ongoing advisory relationships

Have you organised and put in place mechanisms for receiving continued advice and support throughout the research project? What relationships have you established? Who is advising you on 'best practice' when working with Pacific communities? What kind of supports do you have in place for the research team and lead investigators who are working with the Pacific community? Note: If it is a large project with a significant Pacific component, you are best to establish a Pacific advisory committee that meets regularly to advise you on relevant issues (see Meaningful Engagement section).

Capacity Building

How are you committed to building the research capacity of Pacific peoples? Have you provided training opportunities, jobs for interviewers, and/or opportunities for Pacific researchers to gain qualifications or research experience from being involved with your project? What kind of knowledge and skill transfers can you arrange? How can you facilitate some form of research capacity and capability strengthening for the Pacific community while undertaking the research? Within the scope of the

project, what is possible? Be innovative and keep the importance of research capacity building amongst the Pacific community on the agenda.

Research Design and Data Analysis

Are your recruitment measures going to work effectively with Pacific peoples? If you are researching a health problem, have you identified Pacific health providers who can provide follow up support for participants, during, or after the research ends? Have you named key people who are approachable, appropriate and accessible for Pacific participants if they have questions or concerns about the research?

How are you planning to deal with 'English as a second language' speakers? Are you planning to include translations? Is there anyone on your research team who is bi-lingual or multi-lingual?

Pacific research methodologies and theoretical frameworks are being developed. Does your research build on any of these, employ Pacific approaches, or display specific methodological innovation? Contributing to the body of knowledge about appropriate research methods with/for Pacific peoples is a valuable endeavour.

Quantitative/Epidemiology

If it is a quantitative project, have you included a Pacific cohort of sufficient size to achieve sufficient statistical power for a separate analysis of Pacific data? (Note: this may require over-sampling). If you are collecting blood or tissue samples, what is happening to these after the research is over? Is it being stored and treated in a way that is not in conflict with Pacific views on blood and body parts?

Qualitative

If it is qualitative research, how are your researchers planning to analyse the transcripts? Does the methodology work well cross-culturally? What are the paradigms and 'world-views' you are operating from? Will it be effective and/or appropriate when analysing Pacific perspectives? Is it an approach that allows for and addresses cultural diversity? Is a Pacific researcher doing the Pacific analysis? If not, how will you ensure that the research team is culturally safe?

Dissemination

What is your plan for disseminating the research findings to the Pacific community in an appropriate and effective manner? This needs to be considered and budgeted for at the beginning of a project. Make linkages with people during the project who may be helpful in assisting with feeding the research back to the right people (see Reciprocity section for further detail).

Budgets

Where appropriate, has the cost of interpreters and translators been included in the budget?

Other costs may include:

- a meaalofa (koha) for participants (see reciprocity section for further discussion);
- costs of travel for participants and for people with whom you wish to consult;
- catering for Pacific community network consultation meetings, and
- funding a Pacific Advisory Committee.

Summary of Principles

The following section provides a summary of all the Pacific research ethical principles within the guidelines. All of the summary material is placed in text-boxes throughout the main document.

1. Relationships

1.1 To develop, cultivate, and maintain principled relationships is integral to all ethical practice:

- build and maintain ethical relationships

2. Respect

2.1 The relationship between the researcher and the research participant is based on respect for the inherent value of each human being:

- demonstrate respect.

3. Cultural Competency

3.1 To practice in a culturally competent manner, the researcher must have awareness of their own cultural beliefs, values, practices, and an understanding of how these impact upon their interaction with others.

3.2 The beliefs, knowledge and experience of the research participant is true to himself/herself, and the researcher must respect this even if it is different from his/her own beliefs, knowledge and experience.

3.3 Researchers are encouraged to build their cultural knowledge of the Pacific communities they work with.

3.4 Researchers are encouraged to create safe and enabling research environments that support culturally competent practice:

- seek ethnic-specific and context-specific advice on culturally competent practice, and
- understand the importance of communicating appropriately translated information to Pacific people.

4. Meaningful Engagement

- 4.1 To conduct ethical research with Pacific peoples there must be meaningful engagement:
- effective 'face-to-face' consultation is critical to establishing meaningful relationships with Pacific people;
 - understand how to consult, and
 - identify with whom you should consult.

5. Reciprocity

- 5.1 Reciprocity should be a guiding principle for research relationships. It should be demonstrated in practical ways (e.g. capacity and capability building, reimbursement for time, and accessible dissemination).
- 5.2 Reciprocity in research requires that knowledge gained through research will be used to benefit research participants and (where relevant) other people.
- 5.3 If knowledge acquired from research generates significant financial returns, then the people from where the original knowledge came from must share in the financial rewards generated by the research:
- build Pacific health research capacity and capability to extend reciprocity;
 - provide training opportunities;
 - provide formal qualification opportunities for Pacific people;
 - build the research and health knowledge of the participants;
 - reimburse the costs of participation in research;
 - share potential financial gains of research equitably with research participants (or the research participant community), and
 - disseminate research findings so that they are accessible to Pacific communities.

6. Utility

- 6.1 Improving the health outcomes of Pacific peoples should be the key objective of all Pacific health research.
- 6.2 Researchers should always endeavour to explicitly link research and its findings with tangible improvements in health outcomes.
- 6.3 Researchers should work closely with the health sector, where possible, to ensure the pragmatic utility of the research.
- clearly explain the potential of the research to improve health outcomes;
 - address priority health issues;
 - demonstrate how the research will inform policy, and
 - develop Pacific methodologies, frameworks, models, analysis, and approaches.

7. Rights

- 7.1 Research should not be detrimental to research participants, as individuals, as members of a community, or as members of an identified ethnic group.
- 7.2 Each individual, group, or community, has the right and freedom to make an informed choice as to whether to participate or not, in any research.
- 7.3 Any risks inherent in a particular type of research must be made clear to the research participant and they must feel completely free as to their decision to participate or not
- 7.4 Participants must be able to withdraw at any stage of the research process with dignity, and respect, and without embedded disadvantage.
- 7.5 All research relationships are implicated with both rights and responsibilities to the other.
- recognise that participants must be properly informed in order to consent;
 - all participants should receive all of the information, and
 - researchers must uphold the right of participants to withdraw.

8. Balance

- 8.1 Balance is critical when practicing the ethical principles of Pacific research.
- 8.2 Any research partnerships formed with Pacific peoples should be equitable and fair for both parties, engendering symmetry in the balance of power:
- aim for balance in who benefits from research (reciprocity), and
 - aim for balance in research relationships and partnerships.

9. Protection

- 9.1 Primary knowledge that is based on experience and expertise belongs to the research participants and should be acknowledged as such.
- 9.2 Where appropriate, researchers should take protective measures to safeguard indigenous Pacific knowledge and knowledge holders appropriately.
- 9.3 Recognising that Pacific research relationships are often based on structural societal inequalities, care must always be taken to protect those less powerful.
- determine from the knowledge source, the appropriate function of the knowledge that is shared, and
 - researchers should always acknowledge that the ownership of primary knowledge and data lies with the people who contribute that knowledge.

10. Capacity Building

- 10.1 Capacity and capability building is critical to improving Pacific health outcomes through research.
- 10.2 Capacity and capability building is a tangible example of reciprocity in action and demonstrates a commitment to the empowerment of the Pacific community:
- build Pacific health research capacity and capability to extend reciprocity;
 - provide training opportunities, and
 - provide formal qualification opportunities for Pacific people.

11. Participation

11.1 If research targets the Pacific population, Pacific Peoples should participate at all levels of that research project:

- participation of Pacific peoples in a research project is encouraged on a number of levels, e.g. investigators, advisors, students, and interviewers, and
- provide support for Pacific members of the research team.

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