



Pacific Health Research Guidelines

May 2014



The Health Research Council of
New Zealand

**Pacific Health Research Guidelines
2014**

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Published in May 2014 by the Health Research Council of New Zealand

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This document is available on the Health Research Council of New Zealand website:
www.hrc.govt.nz

ISBN 978-1-877495-11-3

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Acknowledgements

This revision of the *Guidelines on Pacific Health Research*¹ was made possible thanks to the support of the following people:

The Pacific Health Research Guidelines Working Group – Dr Tai Sopoaga, Dr Ieti Lima, Dr Karlo Mila, Dr Julia Ioane, and Dr Mele Taumoepeau for their guidance on the content of this publication.

The Health Research Council of New Zealand (HRC) Board and the HRC Pacific Health Research Committee – Dr Etuate Saafi, Dr Mele Taumoepeau, Dr Robin Olds, Ms Hilda Fa’asalele, Dr Colin Tukuitonga, Dr Josephine Herman, Dr Havea Palatasa, and Dr Vili Nosa.

The HRC Secretariat for their support of this publication, in particular the following staff members: Dr Nuhisifa Seve-Williams who provided direction and guidance throughout the revision; Sharon McCook for supporting the review process; Suzy Botica and Kristine Scherp for advice on formatting and proofreading the guidelines; Luke Garland for proofreading; Catherine Ramzan for administrative support; and Dr Robin Olds for final oversight of the publication.

The following individuals reviewed the draft document and provided useful advice: Professor Philip Hill, Associate Professor Joseph Keawe‘aimoku Kaholokula, Dr Barry Smith and Dr Rosalina Richards.

Finally, thank you to Associate Professor Steven Ratuva who was commissioned by the HRC to revise these guidelines.

¹ Health Research Council of New Zealand (2005). *Guidelines on Pacific Health Research*. Auckland.

About the Health Research Council of New Zealand

The Health Research Council of New Zealand (HRC) is a Crown Agent that invests in health research for the benefit of the people of New Zealand. As a Crown Agent, the HRC is responsible to both the Minister of Health and the Minister of Science and Innovation. The Minister of Health is the ownership minister, although HRC funding comes primarily from Vote Science and Innovation. The HRC works across the health and science and innovation sectors to deliver investment and support in agreed priority areas, and to establish and retain strong stakeholder engagement and support.

The HRC's mission is to *Benefit New Zealand through health research*, with a vision of *Improved health and quality of life for all*.² Its major activity is investing in health research. The HRC uses best practice processes to ensure that only high quality research projects that will deliver important health, social, and economic outcomes for New Zealand receive funding support. The HRC also establishes priorities for research investment to ensure that funding has maximum impact. Researchers applying to the HRC are required to demonstrate how their research will meet the goals of New Zealand's health research, such as enhancing high level knowledge, and improving health conditions and life situations for the population.

Research that contributes directly to improved health outcomes and health equity for those with the greatest need is prioritised across all four of the HRC's Research Investment Streams:

1. Health and Wellbeing in New Zealand – Keeping populations healthy and independent throughout life.
2. Improving Outcomes for Acute and Chronic Conditions in New Zealand – Improving outcomes for people with illness or injury.
3. New Zealand Health Delivery – Improving health and disability service delivery outcomes over the short-to-medium term.
4. Rangahau Hauora Māori – Supporting Māori health research that upholds rangatiratanga and utilises and advances Māori health knowledge, resources, and people.

A competitive process ensures that high quality and relevant research is supported across the four Research Investment Streams, which include biomedical, clinical, public health, and health services, as well as Māori health and Pacific health research sectors. All of the HRC's applicants are encouraged to engage stakeholders and end-users from the outset of the research, with some funding opportunities requiring researchers to work in collaboration with health service providers, decision makers, and communities.

As part of the broader research framework, the HRC builds partnerships, engages communities and end-users, and develops skilled health researchers who are able to address the unique needs of New Zealand's communities. The HRC has worked with more than 30 different government and non-government stakeholders to proactively address knowledge gaps and deliver the evidence needed.

² The government strategy for strengthening primary health care through a durable and dynamic patient-centered health system is outlined in Ministry of Health (2011). *Better, Sooner, More Convenient Health Care in the Community*, Wellington: Ministry of Health. Ministry of Health and Ministry of Pacific Islands Affairs (2010). *'Ala Mo'ui: Pathways to Pacific Health and Wellbeing 2010–2014*. Wellington, provides the strategic policy direction for achieving this for Pacific peoples.

The Partnership Programme funding model brings together agencies that have not traditionally worked together to focus on problems that cannot be solved by one sector alone.

Bringing partners together to identify research needs and oversee the research process increases the level of public participation in the health sector or community.³ Over the past 12 years, the HRC has invested in a number of partnership initiatives focused on improving health outcomes for Pacific peoples.

Pacific health research requires the active involvement of Pacific peoples (as researchers, advisors, and stakeholders), and not just as subjects of research. Pacific health research helps to build the capacity and capability of Pacific peoples in research and contributes to the Pacific knowledge base.

The HRC's Pacific Health Research Committee mission statement is to *Discover Pacific health solutions through research*. The vision statement is *Optimal health for Pacific peoples*.

Moreover, in recognition that Pacific peoples and the Māori population are affected disproportionately by the burden of disease in New Zealand, with significant inequalities spanning a wide range of diseases, research that seeks to enhance the health and wellbeing of these populations is an important priority for the HRC.

The HRC has a special interest in Pacific health research and is working to improve health equity by investing in emerging Pacific health researchers who are best placed to identify and resolve health issues in their communities.

This work is supported by a number of groups and initiatives. These include the HRC's Pacific Health Research Committee; the guidelines developed for the inclusion of Pacific peoples and communities in research; targeted career development awards that aim to build critical Pacific research capability; and funding opportunities accorded to Pacific health research through the HRC's annual funding round and Partnership Programme contracts.

³ See Southwick M, Kenealy T, Ryan D (June 2012). *Primary Care for Pacific People: A Pacific and Health Systems Approach*. Wellington: Pacific Perspectives.

Foreword

Warm Pacific greetings.

It is with much excitement that I announce the completion of this tremendous piece of work – the second edition of the HRC’s *Pacific Health Research Guidelines*.

There are many factors that impact on Pacific people’s health. Health research as a tool allows the systematic investigation, study, and analysis of these issues, in search of new knowledge and information from which practical solutions can be derived to help improve Pacific people’s health.

It is vital that researchers gather the information to solve these health issues in a culturally appropriate manner that does not harm or offend the Pacific population groups participating in each particular study.

The HRC’s first response to this need was in 2005 with the development and publication of the first edition of the *Guidelines on Pacific Health Research*. This key document was developed through a process of wide consultation with relevant stakeholders. It also laid the initial foundations for the consideration of the ethical principles of Pacific health research.

Almost a decade later, the HRC’s Pacific Health Research Committee acknowledges that there have been huge advancements in the plethora of methodologies available for the study of Pacific people’s health. Hence, there was a need to update the original guidelines, to keep pace, and remain relevant to the progress in research methodologies that are now being applied to Pacific health research.

The target audience for this second edition of the HRC’s *Pacific Health Research Guidelines* are those engaged in HRC-funded health research conducted among Pacific populations residing in New Zealand, and the realm countries of New Zealand (Cook Islands, Niue, and Tokelau). Researchers conducting non-HRC-funded studies among Pacific populations may also wish to use this document.

The aims of the guidelines are three-fold:

1. To ensure that the research undertaken is beneficial and does not harm, by informing, and empowering Pacific peoples about health research within their own communities, and their rights as research participants.
2. To provide an ethical and operational guide for health research to ensure that it is conducted in an appropriate and effective manner that contributes to the attainment of the highest level of health and wellbeing for Pacific peoples in New Zealand.
3. To provide a common template and shared vision on Pacific health research for the various Pacific health research stakeholders, including the HRC, researchers, research participants, and Pacific communities.

This second edition of the guidelines has been updated using five main sections titled:

1. Pacific culture and knowledge
2. Defining Pacific research
3. Framing Pacific health research: Guiding themes
4. Research steps and application of guidelines, and
5. Other issues

It has also been broadened from the local micro-research environment and made relevant to the macro-research environment by embedding Pacific health research into our global consciousness and relevance.

Finally, I wish to acknowledge the HRC and its Chief Executive, Dr Robin Olds, for commissioning this revision of the HRC's *Pacific Health Research Guidelines*; Associate Professor Steven Ratuva who revised the guidelines; the HRC Pacific Health Research Committee and the HRC Pacific Health Research Project Manager, Dr Nuhisifa Seve-Williams, for driving this piece of work; and Dr Tai Sopoaga, Chair of the working group and its members: Dr Mele Taumoepeau, Dr Karlo Mila, Dr Julia Ioane, and Dr Ieti Lima for their counsel in bringing this revision and publication to its completion.

To all Pacific health researchers and Pacific peoples – this one is for you!



Dr Edward Saafi, PhD, MBA
Chair, HRC Pacific Health Research Committee

Introduction

In 2012, the HRC Pacific Health Research Committee recommended to the HRC that the *HRC Guidelines on Pacific Health Research*⁴ be updated to reflect changes in the Pacific health research landscape, and ensure that the guidelines were still relevant to a wide range of stakeholders. This recommendation was approved by the HRC Board.

The following guidelines build on the principles outlined in the HRC's *Guidelines on Pacific Health Research* (2005), and address some of the fundamental issues relating to contemporary Pacific health research in an evolving global environment. The guidelines consider important aspects of the research spectrum from conceptualisation, Pacific population engagement, and design and conduct of the study, to information dissemination and policy implementation. The guidelines can be used by Pacific and non-Pacific researchers alike to improve the quality and standard of Pacific health research, promote best research practices, support the development of Pacific research skills and capability, and strengthen the use of research to inform Pacific health policies.

The revised HRC *Pacific Health Research Guidelines* provide advice that involves Pacific populations in New Zealand. The guidelines reflect the broad policy framework of the HRC, the Crown entity responsible for investing in health research.

Revision process

In 2012, the HRC Pacific Health Research Committee appointed a working group and chair to oversee the revision of the guidelines. The working group was made up of a cross-section of Pacific health researchers, a representative of the HRC Pacific Health Research Committee, and a member of the HRC's Secretariat staff. A consultant was also appointed to revise the guidelines.

An initial face-to-face meeting of the working group was held in early 2013 to discuss the terms of reference for the guidelines. Subsequent meetings were held on a need-to-basis. The HRC Pacific Health Research Committee was kept abreast of progress through reports tabled at their meetings.

Feedback on the guidelines was gathered via an electronic survey⁵ and at the HRC Pacific roadshow presentations held throughout New Zealand. The final draft guidelines document was reviewed by the working group and the HRC Pacific Health Research Committee in October 2013. The HRC Pacific Health Research Committee endorsed the final document on 20 November 2013.

Purpose

The main purpose of this document is to provide a guide for HRC-funded health research that involves Pacific populations residing in New Zealand. Researchers conducting non-HRC funded studies among Pacific populations may also find this document useful.

⁴ Health Research Council of New Zealand (2005). *Guidelines on Pacific Health Research*. Auckland.

⁵ The survey was sent to over 300 Pacific researchers on the HRC's database.

The guidelines aim to:

1. Ensure that research is beneficial and does not cause harm, by informing and empowering Pacific peoples about health research within their own communities, and their rights as research participants.
2. Provide an ethical and operational guide for health research to ensure that research is conducted in an appropriate and effective manner, and contributes to the attainment of the highest level of health and wellbeing for Pacific peoples in New Zealand. It is recognised that it may be challenging to apply aspects of these guidelines to some components of basic biomedical research, which focuses on molecules, cells, and physiological processes. The HRC's position is that the principles remain salient in all forms of research.
3. Provide a common template and shared vision on Pacific health research for the various Pacific health research stakeholders, including the HRC, researchers, research participants, and the Pacific communities.

Te Tiriti o Waitangi

Pacific peoples acknowledge, support, and respect Te Tiriti o Waitangi as the foundation for their relationship with Tangata Whenua, and recognise the Tangata Whenua status of New Zealand Māori and their right to exercise tino rangatiratanga. Pacific peoples also recognise the mandate accorded under citizenship rights and the entitlements that comply with international declarations and other legal instruments regarding the rights of human beings.

Pacific peoples and Tangata Whenua are related and bonded culturally and genealogically through the Moana Nui a Kiwa (greater Oceania kinship connections). This relationship is embedded in history, mythology, and cosmological beliefs, and transcends state boundaries and legal jurisdictions.

Pacific peoples in New Zealand

Health research conducted among Pacific populations in New Zealand should take into consideration the complex configurations and multiple ethnic identities of Pacific peoples and cultures. While the HRC does not have a standard definition of Pacific peoples, it recognises the diverse and unique cultures of the various Pacific ethnic groups.⁶

In this document, the term 'Pacific peoples' refers to those from the Pacific Island nations who have made New Zealand their home, those of Pacific Island parentage born in New Zealand, and those from the Realm of New Zealand Pacific countries: the Cook Islands, Niue, and Tokelau who are automatic New Zealand citizens.⁷ It excludes New Zealand Māori who are accorded a unique political and cultural status in New Zealand as the Tangata Whenua. Pacific peoples is a broad category encompassing a variety of Pacific Island nations and communities who are linguistically, culturally, and

⁶ See Southwick M, Kenealy T, Ryan D (2012). *Primary Care for Pacific People: A Pacific and Health Systems Approach*. Wellington: Pacific Perspectives.

⁷ The term 'Pacific peoples' is recommended by the Ministry of Pacific Island Affairs for use in official government documents. See Ministry of Pacific Island Affairs (2001). *Pacific Consultation Guidelines*. Ministry of Pacific Island Affairs, Wellington.

geographically distinct from each other.⁸

Many Pacific Island groups also share some common cultural and genealogical links which have been passed down through generations and become part of Pacific people's common heritage, creating sustainable bonds and solidarity in New Zealand. Identification with other Pacific peoples provides them with a sense of collective identity and security in the midst of less familiar cultures in a globalised multicultural society. Factors which connect Pacific peoples together in New Zealand include similar notions of kinship, links between languages, common historical experiences as island-based communities, cultural networks, and shared genealogical heritage.

The basic component of any Pacific country's knowledge system is its indigenous knowledge. It encompasses the skills, experiences, and insights of people, which are applied to maintain or improve their livelihood.

Many continue to maintain aspects of their cultural heritage in New Zealand through churches, communal gatherings, reciprocal exchange of goods, ceremonial occasions, and transfer of stories and values to their children.

There are also significant differences in terms of language proficiency, world views, and understanding of identity between those born in the islands and those born in New Zealand. The different social conditions in which they have been socialised have shaped their perceptions and behaviours differently. For the new generation of Pacific peoples born in New Zealand, loss of native language competence is common. However, this does not necessarily mean loss of identity since there are other markers of identity other than language.

Intermarriage is common and some identify with more than two or three ethnic groups. This redefines the boundaries of individual and group identities as they embrace diversity. Some may not emphasise their Pacific heritage at all. Through the New Zealand national census, people's ethnic categories are self-defined. For Pacific peoples, this provides them with the opportunity to explore and affirm their individual and group identities in the context of New Zealand.⁹

These diversities and complexities should be taken into consideration when framing a research project. Some research projects may involve a broader pan-Pacific approach; some may involve an ethnic-specific focus; while others may be based more specifically on gender, age, employment or other social variables. Some research, especially that which involves the older generation, may require translation and perhaps more face-to-face formal protocol. However, this may not be needed in research involving young people who speak English and probably prefer a more informal approach. The specific cultural, ethnic, and social context of the research is an important factor for Pacific health research.

⁸ Other words that are used in a similar fashion include Pacific Islanders, Pasifika Peoples, Tagata Pasefika, and Pacificans. See Ministry of Pacific Island Affairs (2001). *Pacific Consultation Guidelines*. Ministry of Pacific Island Affairs, Wellington.

⁹ These include people who originate from Samoa, Tonga, Fiji, Cook Islands, Niue, Tokelau, Tuvalu, and other Pacific countries. For details of New Zealand's Pacific population, see Statistics New Zealand: www.stats.govt.nz/browse_for_stats/people_and_communities/pacific_peoples/pacific-progress-demography/population-growth.aspx.

Section 1: Pacific culture and knowledge

Ka kite'ia tātou 'e mutu kore 'ua atu nā roto i te ara tapuae tā tātou ka vai'o
The tracks we leave behind will forever be a shining path into the future

This document incorporates various aspects of indigenous Pacific cultures and knowledge. These values are communal relationships, reciprocity, holism, and respect for other members of the community (see Figure 1, page 5). Pacific cultures and knowledge systems are resilient and adaptive to changing conditions. They play a significant role in defining Pacific people's sense of place, identity, and being in contemporary New Zealand society.

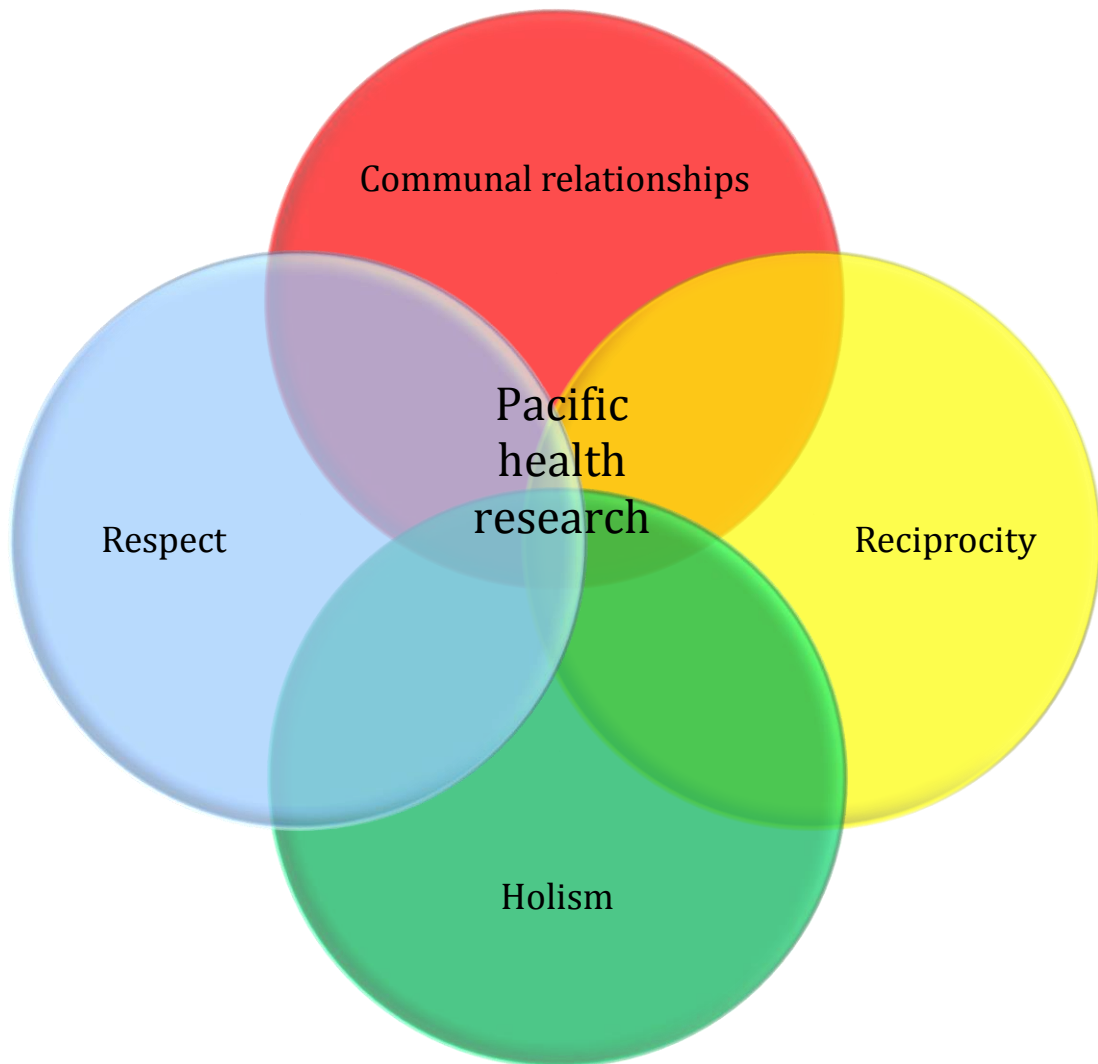
The Pacific indigenous knowledge systems are based on cumulative and purposeful life experiences built over generations and include: culturally coded ways of communication through language; preservation and reproduction of innovation through art, dances, and songs; and genealogical ties and close integration with the environment and the larger cosmology.¹⁰

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 from relevant Pacific groups. Even when a pan-Pacific approach is chosen, ethnic-specific considerations must be taken into account.

The health research approaches in this document are framed around the Pacific cultural values of communal relationships, reciprocity, holism, and respect from the beginning to the end of the research process. These are emphasised where relevant (see sections 2 and 3).

¹⁰ See Huffer E and Qalo R (2004). Are We Thinking Up-Side-Down? *The Contemporary Pacific*, 16 (1): 87–116. Also see Hauofa E (1994). Our Sea of Islands. *The Contemporary Pacific*, 6(1): 148–161.

Figure 1: Links between the four important cultural values and Pacific research



Section 2: Defining Pacific research

Lavaki tale nai kara ki Lasakau

To create more knowledge and skills based on what is already known

The western scientific notion of research involves a specialised process of generating formally constituted knowledge to better understand specific issues, and is sometimes driven by the need for the commodification of knowledge. The Pacific cultural process of generating knowledge involves an ongoing process of life-learning experiences over generations, and relationships between people and their environment and cosmology, as well as among people themselves. Knowledge of the various aspects of life is interwoven with cultural values and beliefs, integrated in a holistic manner, and passed on through socialisation and genealogical connections. In this regard, Pacific knowledge is part of the living being, providing some insight of the complex relationships within the kinship group, and the means by which people transform their world.

Pacific research in this context 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. Therefore, Pacific health research should aim to gain and enhance knowledge and understanding that will improve the health of Pacific peoples. It should also aim to deepen and enrich the intellectual and professional expertise of Pacific researchers to empower them to contribute to the development of a strong Pacific knowledge base.

The source material for Pacific health research should be derived from Pacific peoples, their world views, social contexts, and real-life experiences. Pacific research design, methods, and approaches will be informed, first and foremost, from within the continuum of Pacific world views.

Pacific approaches to research should be responsive to changing Pacific contexts. Pacific research should be underpinned by Pacific cultural values and beliefs, and conducted in accordance with relevant ethical standards, values, and aspirations.

Pacific cultural values and research ethics

This section defines and discusses four important Pacific cultural values: communal relationships, reciprocity, holism, and respect, which should inform some of the ethical and conceptual approaches discussed in section 3. While the concepts of values and ethics do not technically mean the same thing, there is a very close link between them. For example, values can provide the basis for determining what is right or wrong, appropriate or inappropriate, in a particular situation. Framing health research in the context of cultural values is important to ensure that the people studied are treated with respect and protected from exploitation. These cultural values are inseparably linked to each other and they contribute in various ways to the sustenance of people's health and wellbeing.

Communal relationships

In most Pacific cultures, communal relationships are usually defined in terms of communal engagement and links, either through kinship or other forms of social connections and groupings to maintain social cohesion and capital. They also include links between people and their environment; the social and the spiritual; and the earth, sea, and heavens.

In a globalised and fast-changing social environment there is often a complex interplay between communal relationships and rights on one hand, and individual relationships and rights on the other. Researchers need to be conscious of these complex sets of relationships as some members of the community may emphasise one over the other, or even both at the same time, depending on their beliefs and circumstances. For instance, some members of the younger generation of New Zealand-born Pacific peoples may choose individual relations and rights ahead of communal rights and relationships.

A significant aspect of communal relationships is the notion of community duty of care. Health and wellbeing is commonly considered within Pacific cultures to be the responsibility of the entire community rather than the role of a specialised group. The community provides social and psychological support for sustenance of good health. Health is seen as a holistic phenomenon that incorporates physical, social, and spiritual life. While in some cases particular individuals and families may hold special knowledge relating to particular traditional medicines or healing powers, this is freely used within the community to sustain good health and wellbeing.

Reciprocity

Reciprocity is a key aspect of Pacific cultures and involves the exchange of goods, services, trust, loyalty, and social goodwill. It is a two-way process that ensures a sense of balance is maintained. The relationship between the researchers and the participants should be reciprocal so that both sides benefit from the research. Researchers provide skills and resources while participants provide data, knowledge, and wisdom. The researchers benefit in terms of enhancing their professional development while the community benefits through improved health. This reciprocal relationship should underpin the respective roles of the different research parties throughout the research process. Reciprocity is a way of establishing good harmonious relationships between researchers, participants, and the community and also to avoid exploitation and harm. These are discussed further in section 3.

Holism

A holistic approach revolving around a balanced and integrated relationship between social life, the environment, spiritual world, and cosmology reflects the way many Pacific cultures frame their world. This balance contributes to an integrated and holistic life that helps Pacific cultures adapt in a rapidly changing world. Imbalance can undermine people's sense of continuity, community, and wellbeing. Research in Pacific communities should help sustain this sense of balance through greater consultation with communities. What is taken out should be balanced with what is given back to the community. The community knowledge used should be replaced with positive outcomes and benefits. Improvements in health conditions help to restore balance between the individual and community, and between physical life and social life.

Respect

Respect is a significant pillar of relationships in Pacific cultures. There are different types of relationships and situations, whether formal or informal, where particular forms of respect are shown. This can be defined by one's position within the social hierarchy or kinship system and is often reciprocal. It may be based on social status, genealogical links, age, gender, achievement or general recognition of the importance of humility and acknowledgement in a communal relationship. It usually ensures that people know their place in the community, relationships are cordial, and social solidarity is maintained.

Respect is important for cooperation and sustainable relationships. Sometimes it may require formal and ceremonial processes to affirm communal respect and sometimes it is informal and more interpersonal. It can involve individuals conforming to the collective norms and expectations of the community, or involve the community acknowledging the individual.

For researchers, respecting the local cultures and world views represents affirmation and validation as a Pacific health researcher, and a way of being accepted into the community. Respect has to be a key factor in the relationship between the researchers and the communities from the beginning to the end of the research process.

Section 3: Framing Pacific health research: Guiding themes

Liu kitekite ki tua to kitia maali atu ki mua
Learn from the past so you may see what your needs for the future are

This section outlines some of the ethical and conceptual themes which can be used as broad guides for researchers and participants. These are largely informed by the cultural values discussed under Pacific cultural values and research ethics.

Meaningful and reciprocal engagement

Meaningful engagement involves forming a relationship that is sustained and maintained. When meeting each other for the first time, Pacific peoples usually try to make genealogical, historical, cultural or socio-political links as a way of affirming a sense of familiarity and connectedness. This may involve formal rituals or informal processes aimed at making outsiders feel at home and part of the community. For researchers, this provides a great opportunity to understand some of the deeper and less obvious aspects of the culture and the various social dynamics within the community.

This sense of deep connection needs to be maintained throughout the research process and should involve a two-way reciprocal process. Reciprocity is an important aspect of meaningful engagement and must help guide the relationship between the researchers and the community. This relationship must involve all the research partners, including the researchers, participants, and funders. Researchers should try to become familiar with the values and expectations of the community. At the same time, the communities should be fully aware of the purpose of the research; who is involved in the research; the approach to be used; how the data will be stored; and how the results will eventually be used and shared with the community. This process will provide the necessary information for communities to give their prior, free, and informed consent. The dialogue and mutual relationship between both parties should continue at every stage of the research process; from pre-research preparation, fieldwork, and data analysis to report writing, publication, and application of the report recommendations. This ensures the transparency of the process and that the benefits of the research to the community are fully realised.

Consultation

Consultation that affirms relationships between researchers and Pacific communities should be a continuous process that is open to feedback from the early development of the research ideas to completion of the research. Consultation is important to ensure acceptance, legitimacy, and relevance of the research. It is also to ensure direct participation of the communities in the research process and to avoid any differences and conflict which may arise later. A diverse group of people relevant to the research should be consulted, including community leaders, health providers, women, young people, church leaders, health authorities, and leading professionals and researchers in the community. These diverse groups may have different ideas and visions to contribute to the research in terms of information and data, and how to frame and implement health policies emanating from the research.

It should be recognised that consultation is not always a mutual process since there are power dynamics relating to different expectations and cultural viewpoints which need to be overcome. Hence researchers should be ready to negotiate and make reasonable concessions with the community. Researchers should ensure that they respect and adhere to the research agreement with the communities because failure to do this may lead to the severance of trust and thus undermine the research project.

One of the important aims of consultation is to ensure that the community is given all the relevant information regarding the objectives of the research, how the research will be conducted, who will conduct the research, and the role of the community. The communities must be given a chance to discuss the research issues among themselves and they should be allowed to provide input, which needs to be discussed with the researchers and research institutions involved. To nurture more transparency, trust, and goodwill in the relationship, the process on how discussions take place, whether face-to-face or via electronic means, must be agreed upon by all parties. In the context of many Pacific cultures, this gives researchers a sense of legitimacy and acceptance into the community. Presentation of appropriate gifts or traditional offerings or other culturally appropriate items in some cases may assist in acknowledging and affirming the relationship.¹¹

Cultural sensitivity and respect

Health involves matters that are often deeply personal and private, and health research may unintentionally cause offence, both to individuals and to cultural groups. There should be recognition that people of different cultures hold differing world views, basic beliefs, different value systems, and practice different modes of behaviour. It is important that researchers respect the values, identities, sense of wellbeing, and expectations of the communities they are researching. For this to happen, researchers should undergo briefings relating to protocols, cultural sensitivities, and social taboos to avoid insulting people and creating negative feelings, which would undermine the aims of the research. Researchers should understand that any expression of prejudice, whether explicit or subtle, can be counter-productive.

The research methodology, ethics, and approach conducted in Pacific communities should be responsive and sensitive to Pacific cultures. Rather than just acknowledging Pacific cultures, they should be sensitive to Pacific cultural values and incorporate the views of local communities identified through consultation.

Researchers should also be more proactive in their attempt to understand unfamiliar communities. This is a vital aspect of relationship and respect and entails developing some basic understanding of the culture of the communities researched. This involves learning and using some key words; understanding the meaning of some cultural symbolisms; developing an appreciation of the cultural psychology of the communities; and understanding and respecting the common values and differences between groups within the communities. It is also important to appreciate diversity in terms of socio-economic inequality; gender differences; religious beliefs; tribal membership; educational attainment; professional background; political ideology; and status

¹¹ As an example of best practice, see Perese L, Uiuigia-Veukiso A, Samu K, Sepuloni C, Peteru, C (2009). *Pacific Non-Regulated Health Workforce Study*. Auckland: Pacific Health Section.

differences. These factors shape Pacific people's world views, values, and attitudes in a significant way.¹²

Researchers may consider a measure of ensuring respect for Pacific culture and potential by encouraging the participation of Pacific peoples in the research process, either as researchers, research leaders, advisors, stakeholders, or active participants, rather than just subjects of research. This also supports Pacific health research capacity building, increases the likelihood that the research is more relevant to Pacific communities, and empowers Pacific peoples as participants in the research.

Significance of Pacific people's knowledge

The knowledge and world views of Pacific peoples should be respected and considered just as important as other forms of knowledge. Pacific indigenous knowledge is often holistic and can be crucial in understanding the deeper socio-cultural meanings of health and healing. However, use of this knowledge must be first approved and consented to by the community in accordance with the expectations of the people and relevant ethical guidelines.¹³

Expanding critical knowledge

Pacific health research should generate critical information, knowledge, and insight into the health of Pacific peoples. It should also raise awareness and enable government, non-governmental organisations, and communities to formulate appropriate policy responses. Expanding the knowledge base through research is a vital tool to improve the health of Pacific peoples.

Linking health research to a social protection framework

Pacific peoples are among the most vulnerable groups in New Zealand.¹⁴ Health research involving Pacific peoples should be sensitive to the social and economic factors which influence health outcomes for Pacific peoples. Pacific health research should incorporate a 'social protection' framework. Therefore initiatives which are gender responsive and human rights-based can act to address the underlying structural economic and political status of the most vulnerable in society.¹⁵ The World Health Organization advocates this approach as a means towards achieving social justice for vulnerable populations; a mechanism which is now adopted globally by major aid agencies, civil society organisations, and governments.¹⁶ Health research should function not only as an

¹² See Taumoeofolau M (2012). Respect, Solidarity, and Resilience in Pacific Worldviews: A Counseling Perspective. *Pacific Identities and Well-being: Cross-Cultural Perspectives*. M. Agee, et al (eds). London: Routledge.

¹³ See Huffer, E and Qalo, R (2004). Are we Thinking Up-Side-Down? *The Contemporary Pacific*, 16 (1): 87-116; Nabobo-Baba U (2006). *Knowing Learning: An Indigenous Fijian Approach*. Suva: Institute of Pacific Studies; Taumoeofolau M (2012). Tongan Ways of Talking. *Journal of Polynesian Studies*, 121 (4): 327-372. Also see UNESCO (2005). *Universal Declaration on Bioethics and Human Rights*. New York: UNESCO.

¹⁴ Ministry of Health (2008). *A Portrait of Health: Key Results of the 2006/07 New Zealand Health Survey*. Wellington: Ministry of Health. (www.health.govt.nz/publication/portrait-health-key-results-2006-07-new-zealand-health-survey).

¹⁵ Commonwealth Secretariat (2013). *Anticipatory Social Protection: Claiming Dignity and Rights*. London: Commonwealth Secretariat.

¹⁶ World Health Organization (2008). *Closing the Gap in a Generation: Health Equity through Action in the Social Determinants of Health*. Geneva: World Health Organization.

independent, technical, and academic process, but also as a social protection strategy to improve the lives of Pacific peoples. This entails not only researching and understanding the health conditions of Pacific populations but also the socio-economic, political, psychological, and cultural factors which influence, either directly or indirectly, these health conditions. As a social protection tool, health research can be of immense benefit to enhancing the wellbeing of Pacific communities.

Non-maleficence: Protecting Pacific communities

The principle of non-maleficence refers to commitment and obligation not to cause any harm and to guard against avoidable harm to research participants. Care must be taken to ensure that Pacific peoples are protected from the harmful aspects and results of research. Research must not threaten the way of life and wellbeing of the community, nor should it reinforce racial stereotypes that undermine their sense of identity and being as a group. Researchers need to be transparent and honest when dealing with the community and must not manipulate the situation for private gains and exploitation. The reciprocal relationship of providing feedback is important to avoid this.

Beneficence: Providing benefits

The principle of beneficence refers to the ethical obligation to maximise possible benefits. The benefits of the research should be shared equally between Pacific communities and researchers. For researchers, the benefits are in terms of professional advancement and job satisfaction. For individual members of the Pacific community, it should lead to the improvement of their individual health, and for Pacific peoples more generally it should contribute to improving their wellbeing. Benefits from patents of cultural knowledge for health and pharmaceutical purposes should assist members of the community from which the knowledge was derived.

Prior, free, and informed consent

Prior, free, and informed consent¹⁷ should result from affirmation of relationships and respect for local individuals and communities. It ensures that participants are fully aware of the entire process of research, including pre-research preparations; research assumptions; methodology; data collection and analysis; how the data will be used; how it will be kept; timeframes; option of withdrawal from participation; and possible impact of the research on the individuals and community.

The term 'prior' refers to consent taking place before the research. The term 'free' means that individuals and communities should not be put under pressure or any obligatory responsibility to provide consent. The term 'informed' means that the individuals and communities involved in the research should be given as much information as possible and they should make their decision in their own time and space, and based on their freewill and initiative.¹⁸

¹⁷ The notion of prior, free, and informed consent is strongly emphasised by the United Nations' *Declaration on the Rights of Indigenous Peoples* as a way of protecting the wellbeing, intellectual property, and knowledge of vulnerable groups. As an example of best practice, see Tiatia J (2008). *Reasons to Live: New Zealand-born Samoan Young People's Responses to Suicidal Behaviours*. PhD thesis, University of Auckland.

¹⁸ As an example of this approach, see Le Ala (June 2009). *Alcohol Community Interventions and Services for Pacific Peoples*, Stocktake Report (www.alcohol.org.nz/research-resources).

Balance between science and human dignity

There should be a balanced relationship between health research and Pacific human dignity. Science must not override human values but rather complement them. Freedom of research needs to be contextualised in relation to the needs of the community and the social situation. This is succinctly expressed by UNESCO's *Universal Declaration of Bioethics and Human Rights*, which states that:

Recognizing that, based on the freedom of science and research, scientific and technological developments have been, and can be, of great benefit to humankind in increasing, *inter alia*, life expectancy and improving the quality of life, and emphasizing that such developments should always seek to promote the welfare of individuals, families, groups or communities and humankind as a whole in the recognition of the dignity of the human person and universal respect for, and observance of, human rights and fundamental freedoms.
Recognizing that health does not depend solely on scientific and technological research developments but also on psychosocial and cultural factors. Also recognizing that decisions regarding ethical issues in medicine, life sciences and associated technologies may have an impact on individuals, families, groups or communities and humankind as a whole...¹⁹

Permission and protocol

Permission for research is part of building relationships and respect, and it needs to be sought at the earliest possible time. The appropriate protocol should be used to acquire prior, free, and informed consent from individuals and groups as part of the pre-research dialogue and consultation process. Different Pacific communities have different protocols and systems for granting permission. Some Pacific communities require formal and ceremonial processes, while others require less formal forms of engagement. Researchers should seek advice about the culture and context of the communities they are engaging with.

Granting of permission by individuals or the community can be verbal or in written form. In New Zealand, individuals may live in scattered groups and would have different social and professional affiliations. Some are more closely associated with their cultural and church communities compared to others and there are different generations of people who may define their identity and sense of place differently. Thus it is important to understand these varying situations and researchers should frame their approaches accordingly.

Face-to-face verbal communication can be effective among some individuals, while the use of electronic communication is convenient for others. Granting of permission should be taken seriously as a form of social contract and expression of respect between the researcher and individuals or community, and the researchers must have ethical commitment to the relevant responsibilities.²⁰

¹⁹ UNESCO (2005). *Universal Declaration on Bioethics and Human Rights*. New York: UNESCO.

²⁰ For best practice in relation to this, see Perese L, Uiugia-Veukiso A, Samu K, Sepuloni C, Peteru, C (2009). *Pacific Non-Regulated Health Workforce Study*. Auckland: Pacific Health Section. Also see Southwick M, Kenealy T, Ryan D (2012). *Primary Care for Pacific People: A Pacific and Health Systems Approach*. Wellington: Pacific Perspectives.

Respect for indigenous knowledge and genetic heritage

It is important to acknowledge and respect indigenous knowledge and genetic heritage. Researchers need to distinguish between two contending notions of knowledge ownership. The first is intellectual property rights, which is based on individual ownership prescribed under such international instruments as *Trade Related Aspects of Intellectual Property Rights of the World Trade Organization*. The second is cultural ownership, which is recognised under the United Nations-related World Intellectual Property Organizations, the United Nations' *Declaration on the Rights of Indigenous Peoples*,²¹ and UNESCO's *Universal Declaration of Bioethics and Human Rights*.²² Awareness of this distinction is important to help understand how to approach health research in Pacific communities to avoid exploitation of culturally owned knowledge and genetic material.

Some regional agreements and declarations have been framed with the primary purpose of protecting indigenous Pacific knowledge and genetic heritage. These include *Treaty for a Life form Patent-Free Pacific and Associated Protocols* (1995); *Model Law and Traditional Biological Knowledge* (2000); *UNESCO Pacific Declaration on Bio-piracy* (2007), and *Call of the Earth Submission on the Pacific* (2005).²³

It is important for researchers to realise that for Pacific communities, collective ownership of knowledge is important for sustaining their collective identity and sense of being.²⁴ In many Pacific cosmologies, some forms of knowledge are considered sacred (tapu) and need to be treated with respect.²⁵ In a global market environment where knowledge is presumed to be free and individually owned, and which can be readily commodified (to sell for profit), there is often pressure to individualise and commodify communal knowledge and genetic tissues.²⁶ Researchers need to be aware of both explicit and subtle pressures, and forces which threaten communal knowledge and sense of being, and must proactively engage in mitigating the negative impacts.

Collection of human tissues and genetic materials

New forms of technology and research relating to genetic engineering, creation of transgenic life-forms, and the human genome to investigate genetic diversity in indigenous populations have been of concern to Pacific populations in recent years. It is important to have prior mutual agreement between parties in particular relating to how the samples are kept, ongoing storage in tissue banks, establishment of cell lines, tissue being sent overseas, use within genetic studies, and future use.²⁷

²¹ See United Nations (2007). *Declaration on the Rights of Indigenous Peoples*. New York: United Nations.

²² UNESCO (2005). *Universal Declaration of Bioethics and Human Rights*. New York: UNESCO.

²³ See Pacific Concerns Resources Center (1995). *Treaty for a Life form Patent-Free Pacific and Associated Protocols*. Suva; Pacific Islands Forum (2000). *Model Law and Traditional Biological Knowledge*. Suva: Pacific Islands Forum; UNESCO (2007). *UNESCO Pacific Declaration on Bio-piracy*. Suva/Bangkok; and Call of the Earth (2005). *Call of the Earth Submission on Pacific*. Wellington/Suva: Call of the Earth.

²⁴ See Secretariat of the Pacific Community (2002). *Regional Framework for the Protection of Traditional Knowledge and Expression of Culture*. Suva: Secretariat of the Pacific Community.

²⁵ For instance, knowledge of medicinal plants and healing can be specialised and sacred and is often kept exclusively by particular groups for the community generally. In other cases, they can be commonly shared and are considered communal property.

²⁶ See Ratuva S and Mead A (ed) (2007). *Pacific Genes and Life Patents: Pacific Indigenous Experiences and Analysis of the Commodification and Ownership of Life*. Tokyo: United Nations University.

²⁷ See Ratuva S and Mead A (ed) (2007).

For most Pacific cultures, the human body is tapu and is considered the embodiment of spirituality and sacredness. There should be recognition that in the context of Pacific cosmology, bodies are not considered simple biological entities but are part of a bigger genealogical system that forms the very fabric of a kinship group's sense of being. It is the embodiment of socio-cultural and spiritual continuity between the past, the present, and the future.

The consent of the individual, the family, and the larger kinship group should be sought and adherence to the ethical guidelines of the HRC²⁸ and relevant research institutions should precede extraction of human tissues and genetic materials.²⁹

Research competence

In the initial consultation, the community needs to know about the profile of the researchers as a way of consolidating good relationships and trust. The researchers should have a proven record of good research experience, be professionally competent and well qualified. This information often makes participants feel comfortable about research, especially if they have had a negative experience before. Inexperienced and unskilled researchers have the potential to cause harm to the Pacific community and this may jeopardise future research opportunities. This is why it is important to have experienced Pacific researchers as part of the research team to mentor younger researchers as part of the capacity building exercise.

Ethics approval

It is important that research proposals conducted in Pacific communities proceed through the relevant ethics committees of the institutions in which the researchers are affiliated.

²⁸ See the Ministry of Health's *Operational Standard for Ethics Committees* (2006).

²⁹ Most, if not all, universities and research institutions in New Zealand have their own research ethics committees and guidelines.

Section 4: Research steps and application of guidelines

*'Ua sau le va'a na tiu, 'ae tali le va'a na tau, 'olo'o mamaulago i le va'a na faoāfolau
Fishing for new ideas is a journey that deserves celebration*

The application of cultural values and themes to the actual research is a challenging exercise given the new forms of research methodologies, techniques and computer software that are increasingly available. Another challenge is how to use these new approaches on Pacific health research to ensure that it provides the best possible result with minimal harm.

This section incorporates Pacific values discussed in section 2 and the research approaches and themes identified in section 3, into the different stages of the actual research process. These guidelines suggest what should be considered; however, in the actual research situation, the research teams themselves will need to determine what will work best in the situation they are confronted with. The steps that follow provide an element of flexibility and support the identification of innovative approaches by researchers.

Step 1: Framing and conceptualisation

Framing and conceptualisation of research involves thinking about what the health research will focus on, the rationale for the research, and the purpose for which it is going to be used. Of particular significance is how it will benefit the health of Pacific communities, and the appropriate approach, which would take into consideration the expectations, cultures, and world views of Pacific peoples. It is important to think about how a researcher should relate to and understand the cultures of Pacific peoples. The cultural context is very important. Research does not take place in a social vacuum but in a culturally dynamic context, which shapes the design, theoretical assumptions, and process of research.

In ethnic-specific research, being aware of the specific contexts and circumstances is advisable. This may involve reviewing the literature and engaging initially with experts and informed individuals on the cultural psychology, social structure, normative values, and expectations of the specific community where research will take place. This background information should inform the framing of the research proposal, methodology, research questions, and questionnaires.

Guiding questions for researchers

1. Are the rationale and purpose of the research well thought out?
2. Have I consulted other researchers and experts about the feasibility of the research project?
3. Have I considered how it might impact on Pacific peoples, either positively or negatively?
4. Do I have the professional competence to carry out the research?
5. How much have I understood about the Pacific community that I intend to study?

Step 2: Pre-research consultation

This is when initial discussions between the research stakeholders, including the researchers, funders, sponsors, and Pacific community take place. Initially these groups may have different expectations and it is important to consult at this stage to determine how the research will be conducted, when it will start, how the research outcomes are going to be used in relation to health policies, and the role of the community. Different types of health research would require slightly different approaches and modes of negotiation.

Consultation is an important part of meaningful engagement and relationships. Meaningful engagement goes beyond consultation to the formation of a relationship that is sustained and maintained, enduring and genuine.

In Pacific communities, when people first meet, they often try to find out the social connection between each other. Making a connection on an emotional level with people who are not yet known is an important part of building relationships. Sometimes the relationship forged may take precedence over the importance of the issues or business at hand. For researchers, this requires negotiating between one's professional and personal identity and ensuring that one does not undermine the other. The cultural approach used by the researcher in engaging with his or her own community would be different from those used in engaging with another community.

In Pacific cultures, individuals are part of a complex web of socio-cultural relationships. Usually, certain individuals are regarded as community leaders and representatives who will negotiate on behalf of the community. It is important to create a good rapport with them. This relationship should be maintained throughout the research process.

It is also important to engage with groups such as Pacific advisory groups and reference groups for professional guidance.³⁰ They engage regularly with their communities and thus have good information and insight about the social, political, and cultural dynamics in the community.

Guiding questions for researchers

1. How do I conduct appropriate consultation with the community participants and other stakeholders?
2. How do I know who to consult for my research?
3. What type of information should I provide and how do I provide it?
4. How do I make sure that all the stakeholders agree on the purpose and approach to the research?

Step 3: Drafting the research proposal

The research proposal is the blueprint for the study and sets out the aims and objectives, rationale, methodology, and other mechanics of the research. It guides the health researchers and profiles and frames the proposed method of engagement with the participants.

³⁰ There are a number of groups that provide an advisory role on Pacific issues in New Zealand. For instance, most universities and some government departments have Pacific advisory units or reference groups. There are other civil society organisations that have a special focus on Pacific issues. There are also church groups, cultural groups, and other social groups that are part of Pacific communities.

Putting together a good research proposal requires analytical skills, information about the research process, knowledge of the subject, and some understanding of the community where the research will take place. The process involves framing what the research is about; justifying why the research is being carried out; describing how the research will be conducted and analysed; identifying and providing a rationale for the research methodology; and outlining how the results are going to be disseminated.

Proposals for Pacific health research should encapsulate the spirit of relationships, balance, and trust. It should also aim to build the capacity of the Pacific research community. Both the researchers and the Pacific health research participants are bound by the same template so it is important that their specific roles are clear. In particular, the roles and expectations of Pacific participants should be highlighted to gain their trust and give them a sense of empowerment and co-ownership of the process.

The Pacific community involved should be provided with the opportunity to examine, discuss, and provide feedback on the proposal. This would allow for differences to be identified and ameliorated and the opportunity for consensus to be reached by the final proposal. This process ensures collective and mutual participation and therefore serves the interests of all parties.

The proposal should discuss in full some of the dilemmas and paradoxes relating to health research among Pacific peoples and how these can be navigated and/or mitigated to avoid conflict situations arising or escalating. Some of these are outlined below.

Balance between professional research and community participation

Often researchers conducting research in Pacific communities are faced with the dilemma of creating a balance between their role as professional researchers and their close relationship with the community. This balance is important for maintaining good relationships. A demanding and overpowering approach by researchers may alter the delicate balance and create discord. This is why constant communication and dialogue at all stages of the research is important.

Researchers should be flexible and respond to emerging issues with the aim to restore balance in the relationship.

The two roles are not mutually exclusive but can be easily harmonised to ensure that each party supports and sustains each other. However, both sides should be aware of their respective areas of responsibilities, convergence space, and their own limits.

Social justice and cultural norms

The relationship between notions of social justice and cultural norms is complex and can be morally and culturally exhausting to deal with. Sometimes these two approaches concur and sometimes they contradict each other. Examples of this include gender equality versus patriarchal dominance, and individual human rights versus communal obligation. Researchers undertaking research in Pacific communities may often find themselves in challenging situations where they have to make ethical and professional choices, or on some occasions, initiate a process towards harmonious compromise between two parties. Again the issues of relationships, respect, and balance are important to inform one's approach to some of these issues. Through wider consultation and dialogue with participants, researchers should make decisions based on the interests of the communities and other relevant stakeholders.

Capacity building

Capacity building for the Pacific research community should be a central component of the research project and should be integrated into the research design. This entails participation of Pacific peoples at all levels of research, including research governance and decision-making, applied and professional research, and implementation of the research project.

Pacific peoples should participate in the research team in different aspects of the project, including as interviewers, research assistants, investigators, and advisors. This ensures that the project is responsive and accountable to the research needs of the participant research population.

There should be a training programme for research assistants and others involved in the research to ensure sustainability of research capacity. 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.

Building Pacific research capacity is a tangible example of meaningful reciprocity since it involves important skills and knowledge exchange. Through building Pacific health research capacity, a research team demonstrates commitment to the wider Pacific community by helping to develop and enhance the human capital of that community.

Research interest and health needs

Balancing the need for robust academic research and serving the health needs of the community should be maintained. Sometimes, there may be contradiction between the desire to complete a research assignment for one's professional or commercial purpose and the actual health needs of the community. This is a major ethical issue, which is often overlooked because of the expectations placed by funders or research/academic institutions to complete the research project within a particular time period.

Because health research deals with people's lives, it must take into consideration the importance of social conscience and responsibility and must have a meaningful moral purpose. It is for this reason that the health needs of the Pacific community must take precedence over the interests of the researchers and other professional institutions and relevant stakeholders. While professional interests such as career advancement are important as a form of inducement, they should not overshadow the social and moral purpose of the research. A harmonious balance needs to be created between the two.

Generic Pacific research and community-specific research

Because of the diversity between various Pacific communities, it is not viable to use the same assumptions about a generic Pacific culture when conducting research in an ethnic-specific community. Often languages, world views, norms, and cultural meanings differ across different Pacific communities and it is critical for researchers to take note of these differences. It is often easier for researchers from a Pacific community to carry out research in their own community because of their familiarity with language, protocol, and culture.

Insider and outsider researchers

For Pacific researchers researching within their own communities, the dilemma of defining one's identity as a member of the community (insider) and professional researcher (outsider) can be a major ethical dilemma. One needs to keep a sense of balance in negotiating the two positions with care and ensure that the different expectations are clearly identified as one shifts from one to the other. Supervision by more experienced researchers and learning from other researchers' experiences is important.³¹ Through dialogue with participants, researchers need to consider the most appropriate way to maneuver the situation when it arises and ensure that issues of self-interest or conflict of interest are avoided.

Guiding questions for researchers

1. How can the proposal incorporate appropriate technical and cultural components of health research?
2. How can it address the emerging dilemmas relating to differences between the researcher and Pacific people's expectations?
3. Has the proposal been reviewed by representatives of the target group and other relevant stakeholders?
4. What value does the proposal provide for the enhancement of Pacific people's health?

Step 4: Framing the research approach

This involves framing the methodology or approach which is appropriate to the type of research that will be conducted. Quantitative approaches would be different from qualitative methods; however, the cultural, ethical, and scientific contexts of these are important to consider.

Collection and analysis of qualitative data usually involves people's perception and behaviour and the research methodology selected would be based on engaging with people's subjective feelings and cultural background. On the other hand, quantitative research may involve the collection of statistics or biological samples, and the research techniques used would be different from those undertaken in qualitative research. However, the social and cultural contexts where the two approaches are applied may be the same. The use of qualitative and quantitative approaches must follow ethical procedures that do not harm the community or individual participants. They should be culturally sensitive, evidence-based, and easy for people to understand and relate to. Thus the choice of methodology or approaches should be based on a number of important factors outlined below:

- easy for people to understand and relate to;
- participatory to ensure that community members can play an active role in the research process;
- culturally inclusive and sensitive to ensure that they are empowering rather than exploitative;
- effective in dealing with disadvantaged and vulnerable groups in the communities;

³¹ For examples of the HRC's best practice in this regard, see Le Ala (April 2006). *Alcohol Community Interventions and Services for Pacific Peoples – Literature Review*; Le Ala (June 2009). *Alcohol Community Interventions and Services for Pacific Peoples*, Stocktake Report.

- flexible enough to be used in specific ethnic and cultural communities, and
- subject to peer review by other researchers who engage in a variety of research approaches.

Guiding questions for researchers

1. How culture-friendly and responsive is the methodology or approach I have opted to use?
2. Have I chosen a methodology or approach which is relevant to enhancing the health of Pacific peoples?
3. Have I discussed my methodology or approach with participants and experts in this area?
4. Has the methodology or approach previously been used in past best practice research and how effective were they?

Step 5: Carrying out research

The different approaches to field research are determined by whether one is undertaking qualitative social research, quantitative research, or intervention research in community or clinical settings. These may also require peer review.

Asking questions

The questions should be tested first within the community to ensure that they are community friendly prior to their use. This involves making pilot runs in the community to provide feedback, which should be incorporated in the final questionnaire. The questions asked, whether in the focus group discussion or formal questionnaire, must be carefully constructed to avoid being condescending, patronising, insulting or presumptuous.

It is important for researchers to ensure that prejudices, which can be subtly embedded in people's subconscious, are identified, examined, and removed from questions. Racial and cultural stereotypes can unconsciously permeate questions. Before they are used, questionnaires should be first screened by people familiar with the culture of the community being studied, especially during the piloting phase of the questionnaire design.

Extraction of tissues and genes

Extraction of tissues and genes should be guided by appropriate ethical rules and procedures after prior, free, and informed consent is provided by individuals and communities involved in the research. Genetic materials are part of the broader genealogical complex and identity of Pacific peoples. The individual researchers and institutions involved should take full responsibility as entrusted to them by the participants. The participants should be fully aware of how the samples will be used, stored, and disposed of later.

Knowledge and cultural gaps

For those conducting qualitative research, the use of metaphors and genealogical narratives is common among Pacific oral responses and researchers should be aware of

the knowledge gap and cultural gap between themselves and the community. The literal interpretation of words and narratives could be misleading, may distort the research findings, and undermine the integrity of the research. It is for this reason that consultation with cultural experts in those communities is important to understand unique expressions of culture, and to determine what the community needs are.

For those conducting quantitative research, for example on tissue and genetic extraction, it is important to understand that the various parts of the body have socio-cultural and spiritual significance and should be treated with respect. Proper cultural protocol and prior, free, and informed consent is required before the extraction of samples takes place.

Intra-communal diversity

Within a Pacific ethnic group there are diversities in terms of gender, generation gap, level of education, language competence, religious affiliation, and socio-economic class. These diversities need to be taken into consideration when framing and asking the questions, because these nuances shape the way Pacific peoples perceive the world around them and help define their individual and sub-group identities in a changing New Zealand environment.

Contested culture

The reality in many Pacific communities is that conceptualisation and interpretation of culture can be contested and not be necessarily consensual. For instance, there are different perceptions regarding the role of chiefs, ownership of titles, the role of women, and the role of culture in the community. Responses to questions on health may reflect these diverse positions and thus questions should be designed to embrace and reflect these diversities. To assume that there is only one legitimate response based on community consensus is to disregard the realities of socio-cultural dynamics and diversity among Pacific peoples. This is where continuing consultation is required.

Use of Pacific languages and translation

Sometimes questionnaires may need to be translated into the relevant Pacific language, particularly if some participants are not familiar with the English language. However, this may not be necessary, especially when dealing with younger participants. Some members of the Pacific communities who understand English may prefer to use their mother tongue because it enables them to express themselves in a deeper and meaningful way. If translation is required, it should be conducted by an expert in consultation with key members of the community. In this case, translation may be required at all stages of the research, from community consultation to the publication of the final report.

Translation can be complex because it entails more than just the literal translation of the words. It also involves the deeper process of cultural meaning and representation. Because some verbal discourses in many Pacific communities are based on metaphors and symbolism, the Pacific language translators employed to undertake this task should be culturally and technically competent in that particular language and its use.

Balancing responsibility

While community participation is critical, there should be a sense of balance between what is essential and what becomes burdensome to the community. This is important to ensure that the communities do not suffer from 'research fatigue', and that the researcher does not place unnecessary demands on people's time, resources, and effort. Again, constant communication and consultation is important to gauge the mood in the community.

Balance between anonymity and public acknowledgement

Public acknowledgement of the knowledge and wisdom of participants is an important part of the relationship built during the research process. At the same time, there are those who may wish to remain anonymous for various reasons. This needs to be respected also. However, if the nature of the research does not allow for anonymity then the participants concerned should be given the right to withdraw from the research if they so wish.

Guiding questions for researchers

1. Have the questions been vetted by technical and cultural experts?
2. Have the appropriate ethical guidelines and rules been observed in the extraction of biological samples?
3. Have the questions taken into consideration the differences between and within cultures?
4. Does the questionnaire need to be translated into the relevant Pacific language?
5. Does the field research put a lot of burden on the community participants?
6. Have I complied with anonymity and confidentiality requirements?

Step 6: Compilation and analysis of data

The end of the field research does not necessarily mean the end of the relationship between the researcher and the community. In fact, the relationship needs to continue for a number of reasons.

Compilation of data for qualitative and quantitative research may differ. Increasingly, many researchers use both, and in some cases, the line between both analytical approaches can be blurred. For instance, quantitative statistical analysis and qualitative narrative can be integrated in a mixed-method approach. Likewise, extraction and analysis of biological and genetic samples often involves qualitative judgment in relation to the best method to be used, the social and cultural context of the research, and the ethical issues involved.

Data analysis

Firstly, the researcher needs to seek clarification on relevant concepts and ideas from the community. Secondly, the community needs to be provided adequate space and time to provide further information if required. Thirdly, the data may reveal anomalies in the methodology or interviews and may need revisions with the assistance of the participants (including repeating the interviews for instance).

Often researchers use the opportunity to pursue their own line of interpretation of data

based on their pre-framed theoretical framework and pre-conceived assumptions. Analysing the data using the community's system of meaning would help provide more rigor, authenticity, and originality to the research.

Some members of the community may be interested in raw data and may request access to them, so researchers should allow for transparency and openness in this regard. Rules about access to data can be open and flexible. Where this has the potential to undermine requested anonymity and confidentiality, negotiation should take place to make sure that the wishes of some participants for anonymity and confidentiality are observed.

Biological and genetic samples

The community needs to know how the samples are going to be used; how and how long they are going to be kept; and details about the issue of ownership. Respect for prior, free, and informed consent and the wishes of the individuals and community are required. A safe process of establishing trust is through a written contract. If any biodiverse extract is going to be used for commercial purposes, such as a patent, then proper legal advice should be sought and the owners of the samples should be financially compensated through an agreed formula. The agreement should be reciprocal, balanced, and beneficial to the individual or group participants.

Guiding questions for researchers

1. How do I provide access to raw data if requested by participants and other stakeholders?
2. How do I allow community access to results of data analysis?
3. Does the data analysis reflect the original aims and objectives?
4. If the method of data analysis is changed, what was the reason?
5. What is the most culturally appropriate and ethical means of disposing of the samples?

Step 7: Report writing

Report writing often takes place in various stages with various drafts produced before the final report is completed. To ensure that the research is balanced and participatory, the researchers should be open to engagement with the community, but avoiding any unnecessary burden. It is an opportunity for the researcher and the community to be involved in further dialogue regarding the entire research process and how things could be improved in the future. These challenges can be incorporated into the recommendations. The recommendations should be the result of consultation between the researchers and the community because the community will be the major target group for the policy prescriptions emanating from the recommendations.

The research drafts may be discussed widely within the community through a systematic consultation process and the feedback should be incorporated into the final document. This ensures that the implementation of health policy recommendations resulting from the research is readily accepted since the community feels that it is also part of its ownership. The balance between research aims and policy outcomes is important here.

Guiding questions for researchers

1. How will the participants be involved in the drafting of the recommendations?
2. At what point do I send the draft for feedback? After completion of various parts of the draft? After the whole draft?
3. How do I ensure that consensus on the recommendations is reached?

Step 8: Dissemination of information

The final research publication should not only acknowledge the participants from the relevant Pacific community, it should also reflect the sense of co-ownership by the community who have provided the knowledge and information, which made the research possible. As much as possible the publication should contain Pacific terms and narratives which are relevant to the research. Researchers could consider inviting a suitable and relevant community member to provide a one-or-two-page section on the role of the community in the research. The results of the research should be publicised using multiple means to ensure wide coverage. Complex quantitative and qualitative data must be simplified to ensure that they are understood by non-experts and ordinary members of the communities.

Effective, responsive, adequately resourced, and appropriate dissemination is an effective form of reciprocity in research. The results of research should be returned to communities. The dissemination should involve the same degree of attention and care that has been taken to solicit 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 wellbeing of Pacific peoples.

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, in particular, through publication in a peer-reviewed journal or book, which allows for greater participation, informed support, and appreciation of the completed work.

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. This may include using Pacific media, existing networks, promotional activities within the community, and promotion within church notices or ministers' sermons/homilies.

Guiding questions for researchers

1. How have the participants been acknowledged?
2. How can participants, researchers, and other stakeholders benefit from the publicity of the research?
3. What are some of the best ways to disseminate the results of the research to raise awareness about Pacific health?
4. How will the final research report be shared with the participants and their communities?

Step 9: Post-research and policy follow-up

It is important that the relationship between the researcher and the community continues as part of a long-term relationship. Since health research is geared towards improving people's wellbeing, it needs to be transformative and action oriented. The follow-up process is to ensure that the health policies based on the research are conceptualised and implemented in a way that maximises the benefits for the community. It should also ensure that any harm or mistakes arising as a result of the research can be rectified in the future.

The relationship between policy and research is often complex. Sometimes research-based policies can go wrong if the implementation process is not carried out effectively. Also, sometimes some of the recommendations of the research could be based on erroneous assumptions about the community and things may not work out as expected. In this case, researchers should be ready to admit responsibility to the Pacific community concerned. Admission of responsibility should not be viewed negatively, but rather viewed as a sign of the researcher's moral strength and steadfastness.

Guiding questions for researchers

1. How can the relationship between the Pacific peoples and researchers continue?
2. How can the researchers, Pacific communities, HRC, and other stakeholders continue to cooperate in the post-research policymaking stage?
3. What lessons and challenges have been learned from the research, and how can this be used to improve Pacific health research in the future?
4. What are some areas for future research that this particular research has highlighted?

Section 5: Other issues

*To'u kai mo hono lohu
There is a right season and time for everything*

Access, human rights, and social justice

Access to the “highest attainable level of health is one of the fundamental rights of every human being.”³² Health is not merely an absence of disease or infirmity but involves the complete physical, mental, spiritual, and social wellbeing of a person and community. For Pacific peoples in New Zealand, attainment of good health is a building block for a vibrant, prosperous, and peaceful community in the future.

The social conditions under which people are born, live, and work are significant determinants of good health or ill health, of a long productive life or a short and miserable one.³³ The effort to promote good health among Pacific peoples in New Zealand should be linked to social justice initiatives associated with addressing inequality, poverty, and social marginalisation.³⁴ These social conditions have had a detrimental impact on Pacific people’s health.³⁵

International collaboration

International collaboration between Pacific and non-Pacific researchers in New Zealand, the realm countries of New Zealand, and further abroad is critical. This is to facilitate exchange of skills, expertise, new innovation, and information dissemination. It is also an opportunity for Pacific researchers in New Zealand to explore new professional avenues which would enrich their own capacity to carry out research among Pacific peoples.

International collaboration should be based on mutually beneficial and transparent partnerships and relationships. Due diligence should be undertaken to ensure that the integrity of indigenous Pacific knowledge and genetic material is protected and not shared without prior, free, and informed consent. International collaboration must be based on equal terms and must be guided by a transparent and mutually beneficial relationship.

While the contribution of Pacific health research to global knowledge is important, it is also vital to ensure that indigenous knowledge is not exploited and unjustly expropriated as suggested by such international legal instruments as the United Nations’

³² World Health Organization (1946). *Constitution of the World Health Organization*. New York: World Health Organization; p1. Also see UNHCHR (1976). *International Covenant on Economic, Social and Cultural Rights*. Geneva: Office of the United Nations High Commissioner for Human Rights.

³³ For details, see World Health Organization (2008). *Closing the Gap in a Generation: Health Equity through Action in the Social Determinants of Health*. Geneva: World Health Organization.

³⁴ An example of research which has used this approach is: Le Ala (June 2009). *Alcohol Community Interventions and Services for Pacific Peoples*, Stocktake Report.

³⁵ Tukuitonga, C (2012). Pacific Island health - Causes of poor health. *Te Ara – The Encyclopedia of New Zealand*, updated 13 July 2012.

*Universal Declaration on Bioethics and Human Rights, Convention on Biological Diversity and Declaration on the Rights of Indigenous Peoples.*³⁶

Research by Pacific and non-Pacific researchers on Pacific people's health issues in New Zealand needs to have a global reach through the publication and dissemination of information via the Internet and other means, so encouraging international collaboration is a welcome initiative.

³⁶ See UNESCO (2005). *Universal Declaration on Bioethics and Human Rights*. New York: United Nations; United Nations (1992). *Convention on Biological Diversity*. New York: United Nations; and United Nations (2010). *Declaration on the Rights of Indigenous Peoples*. New York: United Nations.

Conclusion

Central to revising the *Pacific Health Research Guidelines* is the need to situate them in the context of Pacific values and world views, and how these would help advance the wellbeing of Pacific peoples in New Zealand. Given the health issues facing Pacific peoples in New Zealand, concerted effort must be made to develop the best possible approach for Pacific research to help address the situation.

This revised version of the guidelines attempts to address some critical issues relating to Pacific health research and provides guidelines for researchers and the Pacific peoples who may participate in the research in various capacities.

This is an evolving document which needs to be reviewed from time to time given the changing research landscape and continuing transformation of the social, cultural, and personal life of Pacific peoples, either as groups or as individuals. Research provides a critical cornerstone for devising appropriate and effective health policies for Pacific peoples.

Pacific health research is an important priority for the HRC. It actively ensures that good research becomes the basis for good health policies and practices, which ultimately lead to good health for Pacific peoples. The collection of data and samples and the creation of new ideas and innovation emanating from research are important inputs to help improve the health and wellbeing of Pacific peoples in New Zealand, and the New Zealand Realm countries.

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