

The PSANZ Research Toolkit:

Engaging consumers in perinatal research

March 2018

Natasha Donnelly
Victoria Bowring
Dell Horey
Tracy Reibel
Vicki Culling

Introduction

There is a vast array of resources available to assist researchers to engage with consumers in meaningful and sustainable ways. Ultimately, this will benefit their research projects by making research outcomes more relevant to consumers and the choices they face, and by making the research process more accessible to the wider public. The NHMRC, HRC and consumer organisations such as the Consumer Health Forum have long encouraged consumer engagement in research but it can often be difficult for researchers to locate an appropriate resource and this can be a barrier to success.

Recognising this, the PSANZ Consumer Advisory Panel (PSANZ CAP) has developed the **PSANZ Research Toolkit** to assist PSANZ members engage with consumers in their research activities.

This toolkit combines a dynamic repository of resources and a virtual Directory of Consumer Organisations (DoCO). The toolkit will be updated regularly by the PSANZ CAP. Each section in the toolkit provides a summary of supporting evidence and links to available resources and references to help researchers locate these more readily. The DoCO contains contact information for consumer organisations relevant to perinatal health and medical research, to help locate potential consumers in areas related to your research. The directory will be updated regularly, so please make sure to check the website for the latest version.

This toolkit is not a finite resource and there are many more useful resources and organisations that you may have already identified. We would like to include in our toolkit any resources that you may wish to share with other PSANZ researchers. Just let us know by contacting the CAP through the PSANZ Secretariat at admin@psanz.com.au.

Contents

Abbreviations	3
Engaging consumers in research	4
Common issues faced by consumers	13
Cultural safety	24
Culturally safe research with Aboriginal and Torres Strait Islander populations	30
Culturally safe research with Māori populations.....	34

Consumer Organisation Directory: [Click here to download](#)

Abbreviations

The following abbreviations appear in the toolkit:

Abbreviation	Meaning
ACCHO	Aboriginal Community Controlled Health Organisations
AIATSIS	The Australian Institute of Aboriginal and Torres Strait Islander Studies
ARC	Australian Research Council
CALD	Cultural and linguistic diverse/diversity
CAP	Consumer Advisory Panel
CHF	Consumer Health Forum
HRC	Health Research Council of New Zealand
NHMRC	National Health and Medical Research Council
NICU	Neonatal Intensive Care Unit
QCOSS	Queensland Council of Social Service
RA	Rheumatoid arthritis
SAHMRI	South Australian Health and Medical Research Institute
VM	Vision Mātauranga

RESEARCH TOOLKIT: Engaging consumers in research

KEY MESSAGES

- Engaging consumers in research benefits the public, researchers, research institutions and participants
- Consumers can be involved in all stages of the research cycle
- Acknowledge consumer participation
- Consumers are not content experts, but provide an informed consumer perspective to the decision-making process

Inside

- 1 Purpose of this section
- 2 Introduction - why involve consumers in research?
- 3 How and when to involve consumers
- 4 Summary of Resources
- 5 References

1 Purpose of this section

Engaging with consumers in the planning and design of health research can change the questions that are asked and how they might be answered. It can increase the likelihood that the research will have a direct impact on those to whom it is most important. Traditionally, consumer involvement in research has occurred after most of the major decisions about the research focus, study design and selection of study outcomes have been made. This has led to research that is misaligned with the needs of health consumers and the health choices they face.

There are many ways to engage with and involve consumers in research. This section of the toolkit provides information, resources and tips on how and when to involve consumers, from research priority setting to dissemination of study findings.

2 Introduction – why involve consumers in research?

The leading premise behind engaging with consumers in research is that those people directly affected by the research should have a say in what is being researched and how it is conducted. Consumers become involved not to provide scientific or research expertise, but to provide informed consumer perspectives (often derived from their lived experience) to influence decision-making. Consumers want a say on research that matters to them, and at all stages of the research cycle.

In the UK, a systematic literature review commissioned for INVOLVE in 2009, found strong and consistent themes showing that public involvement had positive impacts on research recruitment and gave particular value to both qualitative research and clinical trials that benefitted both researchers and research participants[3].

In Australia, the NHMRC and CHF Statement on Consumer and Community Participation in Health and Medical Research was first released in 2002 with the aim that consumers and researchers would become “equal partners in the development of research goals, questions, strategies, methodologies and information dissemination”[1]. The Statement was revised and updated in 2016 to provide a more concise document for stakeholders[2]. Benefits of consumer involvement listed in the Statement include:

“Benefits to the public:

- Research being conducted that is relevant to community needs
- Public awareness of, and support for, science and research, and
- More effective translation of research to deliver improved health outcomes.

Benefits to researchers and research institutions include:

- Increased community relevance, through improved research priorities and projects informed by consumer and community perspectives and lived experiences
- Public confidence in research through improved openness and transparency in the conduct of research
- Public confidence in research through improved accountability and openness over the use of public money
- Communities being better informed and having a greater understanding of research, and
- Increased opportunities to continuously improve the quality of research.” [2]

3 How and when to involve consumers

Involving consumers in research can take many forms and levels. The figure below¹, shows consumer involvement as a continuum. The level of consumer engagement can and will vary across, and within, research projects.

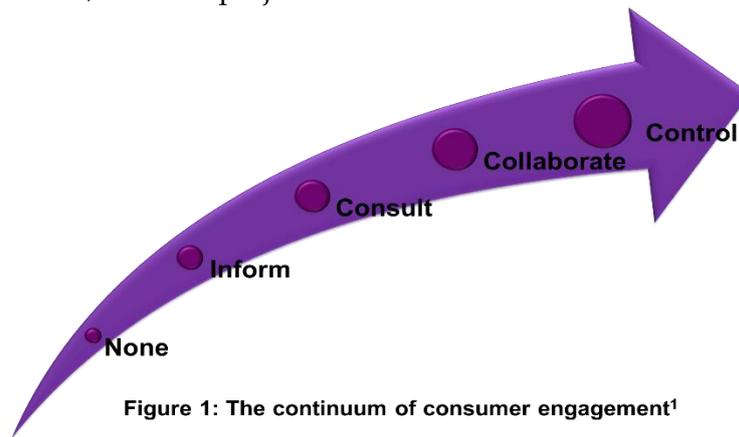


Figure 1: The continuum of consumer engagement¹

Importantly the NHMRC/CHF Statement does not limit consumer engagement as a role for individual researchers, but details the commitments that research institutions should make to involve consumers and the community. More information, tips and resources about how and when to involve consumers for both individual researchers and or institutions are available and make useful resources to start your consumer engagement journey[4, 5]:

NHMRC A Model Framework for Consumer and Community Participation in Health and Medical Research. https://www.nhmrc.gov.au/_files_nhmrc/file/publications/r33.pdf

NHMRC Resource Pack for Consumer and Community Participation in Health and Medical Research. https://www.nhmrc.gov.au/_files_nhmrc/file/publications/r34.pdf

¹ Adapted from Hanley B, Bradburn J, Barnes M, Evans C, Goodare H, Kelson M, et al.(2004) Involving the public in NHS, public health and social care research: briefing notes for researchers. INVOLVE and Brager & Specht (1973) In Consumer Focus Collaboration (2000) Improving Health Services through Consumer Participation: A Resource Guide for Organisations

3.1 Research priority-setting

Involving consumers in research priority-setting ensures that research questions are relevant to consumers affected by the research and are more likely to translate into practice. This is important as the perspectives of clinicians and researchers may not always accord with what consumers, including mothers, parents and families, believe is important when considering research priorities or research questions.

For example, rheumatoid arthritis (RA) research changed direction when consumers became involved in the process of setting core outcome measures, shifting from 6-minute walk to exploration of more subjective experiences of RA such as sense of well-being, fatigue, and disturbed sleep.

Recognition that consumers and clinicians have different perspectives is a critical aspect of the research priority setting exercises undertaken by the James Lind Alliance in the United Kingdom, where the involvement of all stakeholders is considered critical to long-term success. The James Lind Alliance website has a guidebook and resources to assist researchers and research institutions on how to involve consumers in research priority-setting. You can also find lots of examples from their own priority-setting program at www.jla.nihr.ac.uk/.

3.2 Programme and project planning

Knowing what is important to parents is information that should be considered when developing your team's research priorities. As with other stages of the research cycle, involving consumers from the outset in programme, or project, steering committees will help to make sure that your research is relevant to those affected.

3.3 Involving consumers in funding decisions

If your organisation funds research or needs to prioritise research proposals, involving consumers in the review process is another way to improve the relevance of research and its translation into practice. Some ways this can be achieved include:

- Inclusion of consumers (more than one) on funding review panels
- Criteria for consumer review of research proposals
- Incorporating a consumer review panel to work alongside existing review processes.

One example of the successful implementation of consumer involvement in funding decisions was described by the Cancer Council NSW, which adopted the CHF/NHMRC model framework in its 'Consumer Involvement in Research Project' [6].

www.ncbi.nlm.nih.gov/pmc/articles/PMC1913530/

3.4 Preparing a grant application

Most funding bodies now require clear evidence that consumers will be involved in some way with the proposed research project, and grant applications include sections for applicants to describe how this will happen.

The following is included in the current NHMRC funding rules [7]:

Researchers are encouraged to consider the benefits of actively engaging consumers in their proposed research, noting that section 1.13 of the Australian Code for the Responsible Conduct of Research states 'Appropriate consumer involvement in research should be encouraged and facilitated by research institutions and researchers'.

To get the most from consumer involvement, researchers should work to ensure that such involvement is not 'tokenistic' and that consumers are involved throughout a project's lifespan. The process can be assisted by developing ongoing relationships with experienced consumers who can review and contribute to grant applications meaningfully.

3.5 Preparing material for consumers

Consumers should be included in the development and review of written material for research participants and other consumers. A Cochrane review found that involving consumers in these roles for patient information resulted in more relevant and readable material that was understandable to patients [8].

Involving consumers in this way can result in:

- Making sure the right language is used for the target audience
- Improving the way questions are posed so that they are acceptable to the target group
- Ensuring that content is relevant and not too onerous
- Translating into other languages such as te reo Māori when appropriate.

Consumers can assist with Patient Information material, Statement of Consent forms, questions and instructions in surveys/questionnaires, recruitment material, and the content and format of health information brochures/leaflets, posters and handouts.

If your project involves developing clinical guidelines, an accompanying consumer brochure can assist to educate consumers affected by the target treatment/intervention and assist with consumer decision-making and informed consent. Involving consumers in the development of these brochures can help to make sure that messages are conveyed appropriate and easily understood.

3.6 Feedback on data collection methods and recruitment

Involving consumers in the development of data collection tools (surveys, interviews etc) and in decision-making around different data collection methods has led to improved study design and response rates[3]. Consultation with consumers who have experience of the research focus can assist to determine appropriate data collection methods. For example, consulting parents with past experience of NICU care can help to identify ways to best collect information from parents currently experiencing NICU care for their babies. Such consultation can also identify barriers to recruitment that researchers may not have considered.

Some studies have suggested that involving consumers in data collection itself has improved recruitment and response rates. Consumers can be trained to conduct peer and telephone interviews and recruit study participants with appropriate support and remuneration[3].

Consumers may also provide advice on recruitment strategies for research studies, such as where to find study participants and how to approach them appropriately. Potentially, consumers can provide researchers with introductions into specific communities.

3.7 Data analysis and interpretation

Consumers are often excluded from the data analysis stages of research projects due to beliefs that their involvement adds no value. However, according to INVOLVE, some research projects in the UK were enhanced by consumer involvement in analyses and the interpretation of results, particularly when qualitative measures were involved [3]. Consumers assisted by:

- Correcting researchers' misinterpretations
- Identifying themes that researchers would have otherwise missed
- Highlighting results most relevant to consumers
- Changing how results were described.

3.8 Dissemination and reflection

Involving engaged consumers in reflection on the meanings of results and dissemination of study findings to the broader public and/or relevant community groups can be of considerable benefit to researchers. Translation of evidence into practice is one of the most challenging aspects of research, and engagement with relevant consumers can assist to create consumer-led demand for change. In some cases, this may involve the development of a “plain language” summary of a study’s results that could be distributed to the research target audience (e.g. parents in a NICU, women experiencing hypertension in pregnancy etc) or it may involve consumer contribution to or review of publications. One study reviewed by UK’s INVOLVE concluded that:

“...involving community members in reporting back the findings encouraged ‘further rich dialogue’ amongst the various stakeholders. It also ensured continued community involvement in the development of ‘plans for subsequent education and action.’” [3].

Other benefits of involving consumers in the dissemination of research results include:

- Making the results more accessible to target audiences
- Enhancing the credibility of the findings
- Finding novel ways to disseminate the results.

3.9 Acknowledging contribution and participation

When engaging with consumers in research, particularly when involvement is ongoing through the research cycle, it is important to clarify expectations, including what consumers hope to get from their involvement.

Appropriate acknowledgement of the contribution that consumers make to a research project is important. There are different ways that this can occur that will vary depending on the level of involvement and the expectations of different stakeholders. In some cases, co-authorship on publications may be justified and valued by consumers, in other cases a simple acknowledgement in publications and reports will be sufficient.

While remuneration for consumer involvement is not usually expected, some researchers ensure that their research budget includes reimbursing consumers for any expenses incurred due to their participation. This can include parking and travel costs, childcare, meals and consumables.

4 Summary of Resources

1. **INVOLVE** – part of the NHS National Institute for Health Research, to support active public involvement in NHS, public health and social care research.

<http://www.invo.org.uk/>. Resources include:

- Evidence Library: <http://www.invo.org.uk/resource-centre/libraries/evidence-library/>
- Guide to meetings involving consumers: <http://www.invo.org.uk/getting-started/>

2. The Resource Library of the **Health Issues Centre** has a wealth of resources on involving consumers in research. www.healthissuescentre.org.au/. Type “research involvement” in their search engine. Some of the things you will find include:

- Ways to measure patient experience (<http://www.healthissuescentre.org.au/images/uploads/resources/Measuring-patient-exp.pdf>)
- The WA Health Consumer Care and Community Engagement Framework (<http://www.healthissuescentre.org.au/images/uploads/resources/WA-Health-Consumer-Engagement-Framework.pdf>)

3. The **University of Western Australia** has a comprehensive website dedicated to involving people in research, which includes a page for researchers and how they can involve consumers. www.involvingpeopleinresearch.org.au/. Valuable resources here include:

- ‘The Purple Book’ which aims to provide guidance to researchers who are planning to actively involve consumers and community members in research[9]. www.involvingpeopleinresearch.org.au/find-out-more/our-resources/the-purple-book
- ‘The Green Book’ which is a practical guide for research organisations to establish consumer and community involvement at an organisational level[10]. www.involvingpeopleinresearch.org.au/find-out-more/our-resources/the-green-book

4. The **NHMRC** website resources for engaging consumers in research:

- *A Model Framework for Consumer and Community Participation in Health and Medical Research*[4]. https://www.nhmrc.gov.au/_files_nhmrc/file/publications/r33.pdf
- *Resource Pack for Consumer and Community Participation in Health and Medical Research*[5]. https://www.nhmrc.gov.au/_files_nhmrc/file/publications/r34.pdf

5. The **James Lind Alliance** for information and resources on involving consumers in research priority-setting: www.jla.nihr.ac.uk/.

5 References

1. National Health and Medical Research Council and Consumer Health Forum: **Statement on consumer and community participation in health and medical research.** Canberra: Commonwealth of Australia; 2002.
2. National Health and Medical Research Council and Consumer Health Forum: **Statement on consumer and community participation in health and medical research.** Canberra: Commonwealth of Australia; 2016.
3. Staley K: *Exploring impact: Public involvement in NHS, public health and social care research.* Eastleigh: INVOLVE; 2009.
4. National Health and Medical Research Council: **A model framework for consumer and community participation in health and medical research.** Canberra: Commonwealth of Australia; 2005.
5. National Health and Medical Research Council: **Resource pack for consumer and community participation in health and medical research.** Canberra: Commonwealth of Australia; 2005.
6. Saunders C, Crossing S, Girgis A, Butow P, Penman A: **Operationalising a model framework for consumer and community participation in health and medical research.** *Australia and New Zealand Health Policy* 2007, **4**:13.
7. **NHMRC Funding Rules 2016** [<https://www.nhmrc.gov.au/book/nhmrc-funding-rules-2016/NHMRC-funding-rules-2016>]
8. Nilsen ES, Myrhaug HT, Johansen M, Oliver S, Oxman AD: **Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material.** *Cochrane Database of Systematic Reviews* 2006.
9. McKenzie A, Hanley B: *Planning for consumer and community participation in health and medical research. A practical guide for health and medical research organisations.* Australia: The University of Western Australia and The Telethon Institute for Child Health Research; 2014.
10. McKenzie A, Hanley B: *Consumer and community participation in health and medical research. A practical guide for health and medical research organisations.* Australia: The University of Western Australia and The Telethon Institute for Child Health Research; 2007.

RESEARCH TOOLKIT: Common issues faced by consumers

KEY MESSAGES

- Engaging consumers in research benefits the public, researchers, research institutions and participants
- Consumers do want to participate yet frequently identify barriers to their engagement
- Key enablers can be adopted by researchers that support consumer participation

Inside

- 1 Purpose of this section
- 2 Introduction
- 3 Common barriers to consumer involvement
- 4 Hints and hurdles to involving consumers in research
- 5 Summary of resources
- 6 References

1 Purpose of this section

Researchers have identified numerous reasons for involving consumers. Consumers can offer insights that can lead to research outcomes that are more relevant to consumers and the community. Endorsement from consumers and the community groups can lead to wider community support of the research project and can help to establish longer-term beneficial relationships.

Many consumers wish to engage in research but face barriers to involvement. The purpose of this section is to inform researchers of issues identified by consumers that impede their involvement and to offer possible ways to address these concerns to achieve better outcomes for both consumers and researchers.

RESEARCH TOOLKIT: Common issues faced by consumers

2 Introduction

Many consumers and organisations are currently involved in the co-design of research. Whilst this type of involvement has great benefits for researchers and the community, it comes with frequent challenges in engaging consumers. This section provides a quick outline of the barriers from a consumer perspective and key enablers that researchers can adopt to support consumer participation.

Two recent projects have identified challenges to consumer engagement in research. The South Australian Health and Medical Research Institute (SAHMRI) partnered with Health Consumers Alliance to generate an evidence-based framework for consumer engagement [1], and through that process several challenges were identified at both the institutional and consumer level. Identifying these issues is useful as it gives opportunity to address them to ensure successful and sustainable consumer engagement. The SAHMRI Framework is summarised in Figure 1 below.

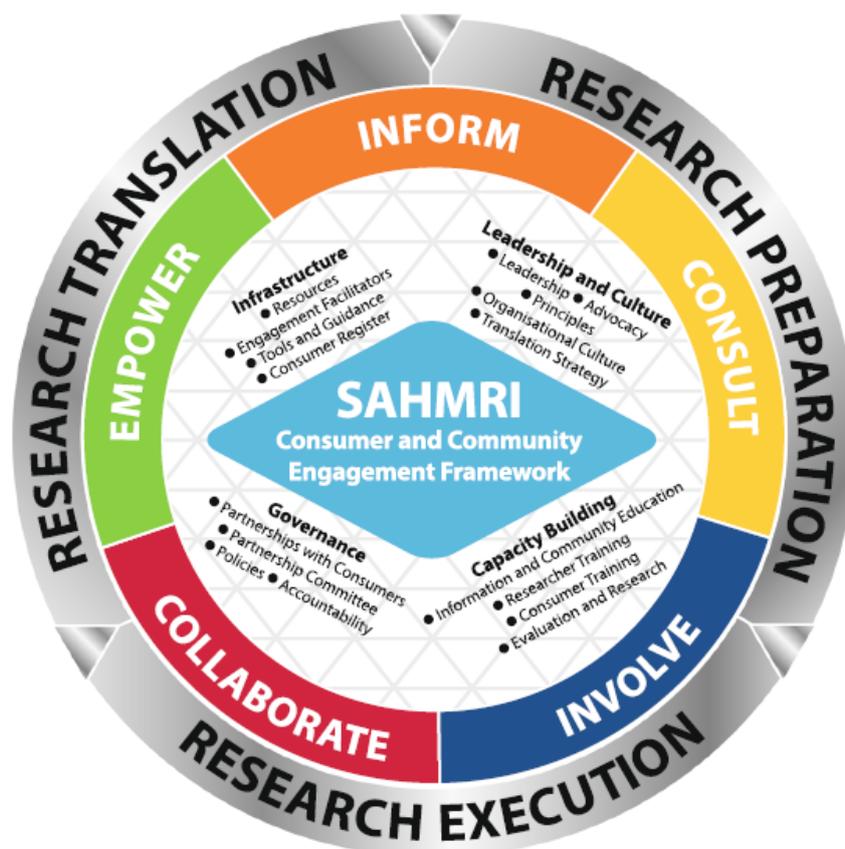


Figure 1: SAHMRI's framework for consumer and community engagement in research. Miller et al. 2017

RESEARCH TOOLKIT: Common issues faced by consumers

In the second project, undertaken by Health Consumers NSW and Research4Me, the aim was to identify barriers and enablers to engaging consumers in research, with a clear focus on a consumer's perspective [2].

Both projects reviewed the literature and consulted consumers, and there was clear agreement that the success of long-term consumer engagement in research was dependent on: individual relationships; the context of the research; the skill and experiences of those involved; and the type of research being undertaken.

Common issues identified in both projects as likely to impact the level of involvement of consumers in research:

- Consumer availability and experience
- Consumer training and support
- Consumer beliefs and culture
- Clarity about consumer roles and responsibilities
- Information available in plain language
- Clear expectations around confidentiality
- Financial Support

3 Common barriers to consumer involvement

3.1 Consumer availability

It can be easy to forget that consumers have responsibilities outside of a research project, even when the research is addressing an issue of high importance to them. It can be difficult for many consumers to attend meetings and appointments during regular business hours. Ways to address this include: consider holding meetings and other activities in times outside normal business hours, including weekends. Remember too, provide meeting documents in sufficient time for consumers to review and to offer to provide them in hard-copy prior to meeting to help consumers be more involved.

3.2 Consumer training and support

Fear of feeling out of their depth or of being not “qualified” can make consumers reluctant to participate in research. Making training available to consumers can build confidence and help consumers know that their contribution is valuable, relevant, and appreciated. Lack of general knowledge about research and research processes is widespread, so people can be encouraged to participate if they feel that they have the skills required. The role of consumers may be different for different projects, so it helps to be clear about what is needed.

Some consumers find it difficult to talk about their health experiences, or may lack confidence to do so and in these circumstances, coaching and/or mentoring may be helpful to facilitate their connection with researchers.

More and more, consumer training and education workshops are available to assist overcome these hurdles. The following resources illustrate the importance of consumer training and also provide details of available consumer training workshops:

<http://www.involvingpeopleinresearch.org.au/community/training>
<http://www.involvingpeopleinresearch.org.au/community/support>

3.3 Consumers beliefs and cultures

Clinician and/or researcher perspectives or ideas may not always reflect consumers' beliefs and cultures. Recognition of different perspectives is a critical aspect of successful engagement with consumer participation. This toolkit also has a section specifically addressing cultural considerations when engaging with Aboriginal and Torres Strait Islander peoples, however consideration and appreciation of different beliefs and cultures applies to all consumer engagement activities.

3.4 Clarity around expectations

The value consumers can add to a research project may be limited if the consumer role and the associated expectations are not properly defined by the researchers. Consumers have reported uncertainty about how to contribute, or what type of contribution they were expected to make. Issues such as these often arise from lack of clarity and/or poor communication between the researchers and the consumers. Poor consumer experiences can leave consumers feeling that their input is not meaningful or valued.

The following example from a workshop held by Health Consumers NSW and Research4Me describes some of the things that can go wrong with consumer engagement in research [2]:

Expectations

An attendee shared one of their experiences as the consumer representative in a research team on a highly technical research project. They were asked to review and sign off on the lay summary for a funding application. They were unclear on exactly what they were being asked to do. For example, were they supposed to review the science of the project, the context of the project, the meaning and impact of the project to the consumer, or the lay language used to describe the project. They didn't have any idea of the context or validity of the science (given that was not their primary occupation), and they didn't understand some of the language used in the lay summary. They didn't have the confidence to seek clarity from the research team and didn't want to be seen as blocking the research, so just signed off on it. So while the researchers had sought consumer input, the lack of clarity regarding the consumer role meant the consumer input received was possibly less valuable than it could otherwise have been.

It is also valuable for researchers to ask about the expectations consumers have about what they want, or can, contribute. Communication is critical and requires both researchers and consumers to develop common understanding of their expectations, for partnerships to succeed.

RESEARCH TOOLKIT: Common issues faced by consumers

3.5 Language

The terminology used in research is often not familiar or accessible to consumers, or in some cases is understood in different ways. This can be a significant barrier to consumer involvement and greater use of plain language by researchers is highly encouraged. There is an Australian organisation, *Involving People in Research* that runs workshops for researchers to help them use plain language:

<http://www.involvingpeopleinresearch.org.au/researchers/training>

INVOLVE UK also have a useful resource around plain English summaries, the importance and benefit of them and how to effectively write them: <http://www.invo.org.uk/resource-centre/plain-english-summaries/>.

INVOLVE also have a useful tool for explaining technical terminology for consumers, called their Jargon Buster. Although UK-centric, it is a handy resource for researchers to find alternative phrases, descriptions and explanations for research 'jargon' to assist with communicating more effectively with consumers. <http://www.invo.org.uk/resource-centre/jargon-buster/>

The following references also provide comprehensive definitions of medical terms, abbreviations and acronyms:

<http://www.health.gov.au/internet/main/publishing.nsf/content/glossary>
<http://familymed.uthscsa.edu/residency/maternityguide/abbreviations.htm>
<http://www.medicinenet.com/medterms-medical-dictionary/article.htm>

3.6 Confidentiality

Research by Health Consumers NSW and Research4Me identified that some consumers expressed concerns about the confidentiality of consumer representatives' personal details, diagnoses, and experience, especially given the sensitive nature of some health conditions [2]. For noting, one organisation which matches consumers with researchers does not disclose information about the person for that reason. They use information provided by the researchers about the consumer they are seeking to find a match based on what they know about consumers on their database. They then refer the consumer to the researchers, but leave it up to the consumer to disclose what they feel is appropriate to share with the researchers.

RESEARCH TOOLKIT: Common issues faced by consumers

3.7 Financial Support

Funding can be an issue for both researchers and consumers, though not all researchers respect and consider this for consumers. More and more, consumers are of the opinion that they should, as a minimum, be reimbursed for actual expenses they incur. It is difficult to assess whether consumers should be paid for their time, or what an appropriate payment would be. This may need to be explored on a case-by-case basis. Unfortunately, there is not a clear pathway for funding consumer involvement in research. One possible approach is for researchers to apply, at a minimum, for reimbursement of consumer expenses as a line item in their research funding budgets.

4 Hints and hurdles to involving consumers in research

(Source: Saunders and Girgis 2011 [3]).

Hints	<p>Organisational development</p> <p>Become informed about consumer involvement in all aspects of research.</p> <p>Gain commitment for consumer involvement from all involved including consumers.</p> <p>Plan and develop consumer involvement in spite of reservations.</p> <p>Identify and include the costs of consumer involvement in funding submissions and negotiations for new programs with management.</p> <hr/> <p>Leadership and human resource support</p> <p>Ensure there is a committed organisational leader who appreciates the usefulness that diverse knowledge has on achieving effective research outcomes.</p> <p>Identify and support an organisational driver to coordinate the involvement process.</p> <p>Draft a staff member who has expertise in knowledge bridging to identify and plan functional strategies and support effective partnerships between professionals and consumers.</p> <hr/> <p>Consumer-researcher collaboration</p> <p>Consumer-researcher partnerships require investments of time and patience.</p> <p>Become respectful of different strengths through adequate training and information for both parties on the potential and practical applications of involving consumers in research.</p> <p>Spend time on deciding how the partnership will work and be sustained.</p> <p>Identify the preferred approach of consumers for involvement in any research.</p> <p>Ensure each party's role is well defined and agreed early.</p> <p>Allow adequate time for activity development and strong relations to be nurtured.</p> <p>Establish regular checkpoints to determine whether the partnership is working as planned, giving each party the opportunity to recommend changes, voice concerns, and address issues before they escalate.</p>
--------------	---

Continued...

RESEARCH TOOLKIT: Common issues faced by consumers

Hurdles **Comprehension**

Greater awareness among consumers and professionals of the benefits of consumer involvement.

Ensuring consumer and researchers place a similar level of importance on the other.

Resources

Adequate funding to support appropriate consumer involvement programs and initiatives. Involvement, particularly if it is to involve those who are the most marginalised in our society, requires substantial input of resources to support the process of providing people with the resources and skills they require to effectively take part.

Ability to meet the time commitment for the set up and ongoing management of consumer involvement activities and programs.

Expectations

Misaligned expectations for the results produced by the consumer researcher collaboration.

Assuring each party is successful in the collaboration.

Not losing individual autonomy while joint working and learning take place.

Managing changes in expectations and strategy over the term of the collaboration.

Addressing the increasing expectation of research funders for significant consumer involvement when resources and commitment are in short supply.

5 Summary of Resources

1. **INVOLVE** – part of the NHS National Institute for Health Research, to support active public involvement in NHS, public health and social care research.

<http://www.invo.org.uk/>. Resources include:

- Jargon Buster: <http://www.invo.org.uk/resource-centre/jargon-buster/>
- Writing plain English Summaries: <http://www.invo.org.uk/resource-centre/plain-english-summaries/>

2. The **University of Western Australia** has a comprehensive website dedicated to involving people in research. www.involvingpeopleinresearch.org.au/. Valuable resources here include:

- Training for Consumers and Community Members: <http://www.involvingpeopleinresearch.org.au/community/training>
- Support: <http://www.involvingpeopleinresearch.org.au/community/support>

3. The **Health Consumers NSW** has invaluable resources about consumer involvement, including:

- ‘Involving Health Consumers in Health and Medical Research: Enablers and Challenges from a Consumer Perspective. An outcome of the workshop held on 31 Oct. 2016 by Health Consumers NSW and Research4Me - February 2017’
http://www.hcnsw.org.au/data/Involving_health_consumers_in_health_and_medical_research_online_print.pdf
- Training for consumers: <http://www.hcnsw.org.au/pages/training-events.html>

RESEARCH TOOLKIT: Common issues faced by consumers

6 References

1. Miller CL, Mott K, Cousins M, Miller S, Johnson A, Lawson T, Wesselingh S: **Integrating consumer engagement in health and medical research - an Australian framework.** *Health Research Policy and Systems* 2017, **15:9**.
2. Research4Me, Health Consumers NSW: **Involving health consumers in health and medical research: Enablers and challenges from a consumer perspective,** Health Consumers NSW and Research4Me. Sydney; 2017.
3. Saunders C, Girgis A: **Enriching health research through consumer involvement-learning through atypical exemplars.** *Health Promotion Journal of Australia* 2011, **22:196-202**.

KEY MESSAGES

- CALD women can feel that health care professionals rely too heavily on “stereotyped assumptions”
- The development of cultural safety begins with awareness of your own cultural expectations and how these can differ from others
- Cultural practices are considered unsafe if an individual feels demeaned or disempowered
- Researchers should consider their assumptions when facing study populations that are comprised of diverse cultures

Inside

- 1 Purpose of this statement
- 2 Introduction
- 3 Awareness of cultural safety
- 4 Acknowledge your starting place
- 5 What can you do?
- 6 Resources
- 7 References

1 Purpose of this section

This section of the toolkit provides information on how to work with diverse cultural groups to create research that is culturally “safe”. It includes a number of resources and links to assist researchers in identifying ways to help achieve culturally inclusive practice. There are separate chapters in this toolkit which specifically address cultural safety when working with Aboriginal and Torres Strait Islander peoples and with Māori.

2 Introduction

Cultural and linguistic diversity (CALD) is a feature of contemporary Australia and New Zealand. In 2014 about one third of women who gave birth in Australia were born in other countries (33%) and more than one in seven were born in an Asian country[1]. In 2014 in New Zealand 24% of women who gave birth were Maori and 50% were European or of other ethnicity. Australia offers a model of health care – and health research – that a significant proportion of women are not familiar with, and which does not necessarily accommodate their cultural needs, practices and traditions[2]. Poor English language skills often exclude women from participation in research studies, and the voices of these women can be lost and their needs overlooked.

3 Awareness of cultural safety

While women from CALD backgrounds generally speak favourably about health services in Australia and New Zealand several areas of concern have been identified, particularly in regard to expectations and attitudes. CALD women can feel that health care professionals are too busy to deal with them as individuals and rely too heavily on “stereotyped assumptions” when dealing with women from different ethnic backgrounds[2]. Researchers can be unaware of their own cultural expectations and their impact on others. The transgression of cultural boundaries can have far-reaching consequences if it leads to feelings of loss of cultural safety and cultural identity. Cultural practices are considered unsafe if an individual feels demeaned or disempowered[3].

The development of cultural safety begins with awareness of your own cultural expectations and how these can differ from others[3]. Awareness of any assumptions about another cultural group is an important step in developing effective communication as research participants need to feel included, respected, and heard if they are to trust researchers and be willing to share information with them[3].

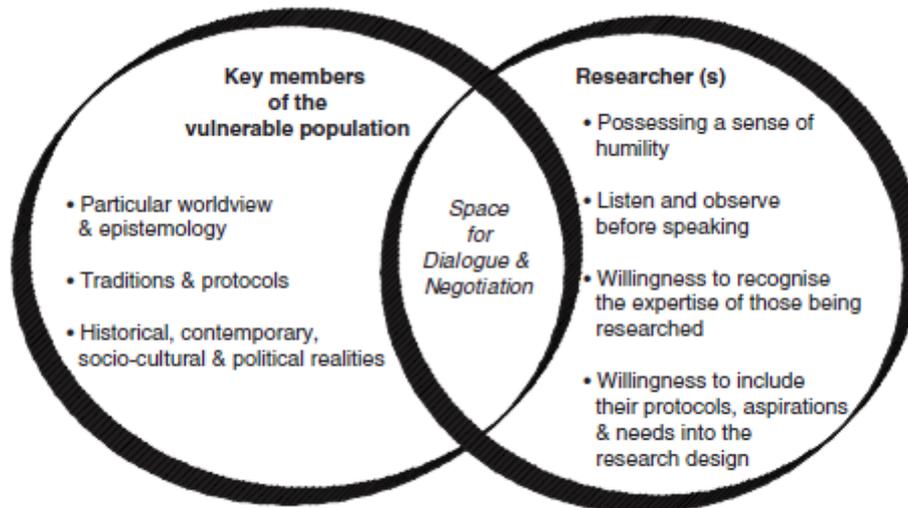


FIGURE 1: CREATING THE SPACE FOR DIALOGUE AND NEGOTIATION

Figure 1 shows the sorts of things that researchers need to consider to enable negotiation with members of vulnerable populations[3].

4

Acknowledge your starting place

The following “Tips for Taking action” [4] are intended to help service providers ensure that they are meeting the needs of a diverse range of people. They are taken from an online course offered by the Queensland Council of Social Service (QCOSS)[5] however are applicable across settings all over Australia and New Zealand. These tips provide a useful checklist for researchers to consider their assumptions when facing study populations that are comprised of diverse cultures.

- Know what culture(s) you belong to.
- Understand that culture is pervasive. It influences the way you act, see, feel, do, interact, and behave.
- Accept that quite a lot of your own behaviour is rule-governed and ritualised. You are a member of a culture which regulates your behaviour.
- Don't make assumptions about other people's culture based on their ethnicity or nationality.
- Don't draw conclusions about a person's culture based on some aspect of their lifestyle.
- Don't assume that when you see something familiar in another culture that it has the same meaning and significance as in your own culture.

RESEARCH TOOLKIT: Cultural safety

- Accept cultural difference as a reality. Underneath, the people of the world can be profoundly different.
- Don't make the mistake of thinking that your culture is more complex than others.
- Allow yourself to like and dislike aspects of other cultures, but don't condemn entire cultures.
- Remember that when you judge another culture you are probably using your own culture's standards as a measurement.
- Don't make the mistake of thinking that the people in your culture are diverse individuals, whereas the people in other cultures are indistinguishable.
- Accept that, although goodwill and tolerance provide a reasonable start, they are not enough. Look for the knowledge, awareness and skills needed to improve intercultural communication.
- Don't feel that you have to change your culture.
- Remember that your aim is to become a more skilled communicator, not a 'better' person.
- Remember that people have always succeeded in intercultural communication and always will.
- Try to avoid 'discounting' ("I don't like those people, but I like Ekes, he's different"). If you are reacting positively to one person from that culture, there will be many other people in that culture you will relate to. He or she is not necessarily 'different'.
- If you meet someone from another culture whom you don't like, don't generalise. Remember that this happens in your culture too (and you don't generalise and dismiss all of the people in your own culture).
- Don't automatically assume that a person's negative behaviour is due to and typical of their culture. ('They're all like that.') That person's behaviour may be due to personality or to particular circumstances.
- Accept that stereotyping is inevitable, but be aware that you are doing it, try to diminish it if possible, and don't use it as the only basis for your attitudes and interpretations.
- Finally, be realistic. Realise that, like all interpersonal matters, intercultural communication can be enjoyable, frustrating, puzzling, rewarding, irritating, fruitful, difficult and fascinating.

Source: Kerry O'Sullivan, *Understanding Ways: Communication Between Cultures* (1997) Southwest Press P/L, NSW.

5 What can you do?

Start by acknowledging that possible cultural differences and understandings exist, then work to seek clarification about issues that may affect your research. The QCOSS online course (2016) also offers this list of suggestions to help achieve culturally inclusive practice (see Section 1: Cultural Awareness; *The needs of culturally diverse clients* para 7 *Culturally inclusive practice*). These suggestions provide a helpful guide for researchers as it is not feasible to know about every cultural practice.

Potential areas of difference	Suggested questions for ensuring culturally inclusive practice
Physical contact	When is touching appropriate? Which part of the body should not be touched? For example, touching a person's head could be a cultural taboo for some cultural groups. Is it appropriate to touch or be touched by the opposite sex?
Eye contact	Is it appropriate to make direct eye contact? For example, in some cultures, not having direct eye contact shows respect to others.
Emotional expression	Would it be appropriate to express emotions (such as grief and loss) overtly or covertly? When should a person smile? For example, in some Asian cultures, people sometimes use smiles to cover sadness, anger, and worry, to save face or to be polite.
Personal appearance	What is considered appropriate clothing? What are definitions of 'clean and tidy'?
Personal belongings or possessions	What is the perception of ownership? How should a person's personal belongings be handled?
Forms of address (e.g. greetings)	What is the appropriate way to address the co-worker or client? What is the correct way to pronounce their name? Is there any difference in addressing people who are older or younger than you?
Attribution	What is the reason for a client's behaviour? Don't make assumptions of the person's behaviour based on what would make sense in your own culture.

6 Summary of Resources

The Queensland Council of Social Service (QCOSS) eTraining package *Work with diverse people* is a free online training program covering cultural awareness, development of culturally diverse relationships, creative cultural communication, and dealing with misunderstandings and conflict. You can work through the entire training program or hand pick relevant sections and resources.

Access the course here: <http://etraining.communitydoor.org.au/course/view.php?id=10>

7 References

1. AIHW: **Australia's mothers and babies 2014 – in brief. Perinatal statistics series no. 32. Cat. no. PER 87** Canberra: AIHW; 2016.
2. Mengesha ZB, Dune T, Perz J: **Culturally and linguistically diverse women's views and experiences of accessing sexual and reproductive health care in Australia: a systematic review.** *Sexual health* 2016, **13**:299-310.
3. Wilson D, Neville S: **Culturally safe research with vulnerable populations.** *Contemporary Nurse* 2009, **33**:69-79.
4. QCOSS: **Work with diverse people Section 3: Creative cultural communication; Strategies for effective communication para 13, Tips for Taking action** [<http://etraining.communitydoor.org.au/mod/page/view.php?id=308>] Accessed: March 2017
5. QCOSS: **Work with diverse people Section 1: Cultural Awareness; The needs of culturally diverse clients para 7 Culturally inclusive practice** [<http://etraining.communitydoor.org.au/mod/page/view.php?id=285>] Accessed: March 2017

RESEARCH TOOLKIT: Culturally safe research with Aboriginal and Torres Strait Islander populations

KEY MESSAGES

- It is essential that Indigenous people are full participants in research projects that concern them.
- All research with Indigenous people should respect cultural and human rights and be culturally safe.
- NHMRC and AIATSIS provide comprehensive principles and guidelines relevant to conducting research with Indigenous people.
- Ethics approval may be required from an Aboriginal specific HREC.

Inside

- 1 Purpose of this section
- 2 Introduction
- 3 Questions researchers may be required to address
- 4 HREC supporting Indigenous health and medical research applications
- 5 Resources to support research development with Indigenous people
- 6 References

1 Purpose of this section

Researchers who are interested in addressing health and medical issues of direct concern for Aboriginal and Torres Strait Islander peoples, or, who aim to improve the health and wellbeing outcomes of Aboriginal and Torres Strait Islander populations are required by the NHMRC, ARC, AIATSIS and other funding bodies to address specific guidelines.

This section of the toolkit provides guidance on how researchers can work towards creating research concepts and design/methods which are culturally safe for Aboriginal and Torres Strait Islander populations, with links to relevant ethics and other guidelines.

In addition to the NHMRC research principles and guidelines relevant to conducting research involving humans, additional requirements for research which is primarily focussed on Aboriginal and Torres Strait Islander people are set out to support researchers in achieving meaningful research engagement and reciprocity with Indigenous peoples.

RESEARCH TOOLKIT:

Culturally safe research with Aboriginal and Torres Strait Islander populations

2 Introduction

Researchers have a responsibility to make sure research that will involve Aboriginal and/or Torres Strait Islander people respects their cultural and human rights and is culturally safe for all research participants. This can only be achieved through appropriate consultation with Aboriginal and Torres Strait Islander researchers and professionals in relevant fields, and organisational representatives (such as from Aboriginal Community Controlled Health Organisations (ACCHO)) when a health issue of concern is identified and before significant research planning takes place.

The AIATSIS Guidelines for Ethical Research in Indigenous Australian Studies state that “it is essential that Indigenous people are full participants in research projects that concern them, share an understanding of the aims and methods of the research, and share the results of the work” [1].

The South Australian Aboriginal Health Research Accord identifies nine principles to follow when conducting Aboriginal health research: Priorities; involvement, partnership, respect, communication, reciprocity, ownership, control, and knowledge translation [2].

3 Questions researchers may be required to address

The following questions should be considered when identifying a health issue of concern and before commencing research proposals:

- Have Aboriginal and Torres Strait Islander people identified the research question as relevant or a priority?
- Will Aboriginal and Torres Strait Islander researchers be involved in the conceptualisation, design, and conduct of the research?
- What research partnerships or capacity building for Aboriginal and Torres Strait Islander people is associated with the proposed research?
- Is the research question or issue relevant and important to the future health and wellbeing of Aboriginal and Torres Strait Islander people?
- What benefit is the research expected to create for Aboriginal and Torres Strait Islander people? (Is there evidence to support this purported benefit?)

A short video – Aboriginal Solutions to Aboriginal Health – is providing at <http://www.lowitja.org.au/making-research-work> together with a companion document: Cooperative Research Centre for Aboriginal Health: Facilitated Development Approach <http://www.lowitja.org.au/sites/default/files/docs/FDA-july-2007.pdf>

RESEARCH TOOLKIT:

Culturally safe research with Aboriginal and Torres Strait Islander populations

4 Human Research Ethics Committees supporting Indigenous Health and Medical Research applications

Specific State and Territory ethics requirements may apply to research. For example, in Western Australia, approval must be granted by the WA Aboriginal Health Ethics Committee before other WA HRECs will consider an ethics application which is primarily concerned with, or is focussed on Aboriginal people. A Chief Investigator needs to demonstrate the support of Aboriginal Community Controlled Health Organisations, Aboriginal Medical Services, and/or other relevant Aboriginal representative bodies, in the health region where the research is proposed. Requirements may vary from state to state. Seek advice from:

- Aboriginal Health and Medical Research Council of New South Wales, Ethics Committee <http://www.ahmrc.org.au/>
- Aboriginal Health Council of South Australia, Aboriginal Health Research and Ethics Committee <http://ahcsa.org.au/research-overview/ethical-review-ahrec/>
- Aboriginal Health Council of Western Australia, Western Australian Aboriginal Health Ethics Committee (WAAHEC) <http://www.ahcwa.org.au/ethics>
- The Australian Indigenous HealthInfoNet lists a range of HRECs which may provide specific services for Aboriginal and Torres Strait Islander research ethics applications, depending on the location of the research <http://www.healthinfonet.ecu.edu.au/healthinfrastructure/ethics/organisations/hrec>
- A comprehensive list of HRECs registered with the NHMRC is available at <https://www.nhmrc.gov.au/health-ethics/human-research-ethics-committees-hrecs>

5 Resources to support research development with Indigenous people

Current guidelines setting out the ethical processes associated with the conduct of Aboriginal and Torres Strait Islander health and research:

- *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research* (2003), see: <https://www.nhmrc.gov.au/guidelines-publications/e52> (Note: the Guideline is currently under review)
- *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics* (2006). Available at: <https://www.nhmrc.gov.au/guidelines-publications/e65>
- *Researching Indigenous Health: a practical guide for Researchers* (2011) Lowitja Institute. See: <https://www.lowitja.org.au/lowitja-publishing/L009>
- The Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) Research Ethics Committee is responsible for reviewing AIATSIS research projects involving Aboriginal and Torres Strait Islander participants to ensure the appropriate ethical standards have been met. For further information see: <http://aiatsis.gov.au/research/ethical-research>
- The South Australian Aboriginal Health Research Accord: Companion Document https://www.sahmriresearch.org/user_assets/2fb92e8c37ba5c16321e0f44ac799ed581adfa43/companion_document_accordfinal.pdf

6 References

1. Australian Institute of Aboriginal and Torres Strait Islander Studies: **Guidelines for ethical research in Australian Indigenous studies**. Canberra: Australian Institute of Aboriginal and Torres Strait Islander Studies; 2012.
2. Wardliparingga Aboriginal Research Unit: **The South Australian Aboriginal Health Research Accord**. [<https://www.sahmriresearch.org/our-research/themes/aboriginal-health/research-list/south-australian-aboriginal-health-research-accord>]. Accessed: March 2017.

RESEARCH TOOLKIT: Culturally safe research with NZ Māori populations

KEY MESSAGES

- It is essential that Māori are full participants in research projects that concern them.
- It is important to consider Māori concepts that will impact on your interactions with Māori individuals and groups (tikanga Māori, mana, whānau, tapu/noa)
- There are resources available to assist you in your development of a research project or programme that includes Māori consultation from the outset.

Inside

- 1 Purpose of this section
- 2 Introduction
- 3 Questions researchers may be required to address
- 4 Resources to support research development with Māori populations
- 5 Glossary (from the Māori Dictionary <http://maoridictionary.co.nz>)

1 Purpose of this section

Undertaking research with Māori participants, whether as individuals or whānau, requires consideration of Māori concepts, values and practices. In this section we present recommendations from various New Zealand resources that describe aspects of the Māori worldview and the importance of considering these when creating research concepts and designs.

2 Introduction

Recommendations for working with Māori as a research population or in a health capacity are numerous and well documented. Recommendations from a number of guidelines make up this section of the toolkit.

He Korowai Oranga is the NZ Government's Māori Health Strategy setting the overarching framework that guides the Government and the health and disability sector to achieve the best health outcomes for Māori. The three principles of the Treaty of Waitangi - **partnership, participation and protection** - underpin the Strategy.

The Ministry of Health suggests three Māori health models that can be used when developing and planning programmes and research that impact on Māori health and may include Māori participants.

Professor Mason Durie's *Te Whare Tapa Whā* model describes health as an interrelated phenomenon, integrated and harmonious with the environment. *Te Whare Tapa Whā* (the four sides of the whare or house) demonstrates the interconnectedness of four areas of wellbeing - te taha wairua (spiritual dimension), te taha hinengaro (emotional or mental dimension), te taha tinana (physical dimension) and te taha whānau (extended family dimension).

Rose Pere's *Te Wheke* acknowledges the link between the mind, spirit, the human connection with whānau, and the physical world. She notes that until the introduction of western medicine, there was no division between them. Pere uses the image of the octopus to convey the model - the head represents the whānau, the eyes represent waiora (total wellbeing of the individual and family) and each of the eight tentacles represent a specific dimension of health. They are - Wairuatanga - spirituality; Hinengaro- the mind; Taha tinana- physical wellbeing; Whanaungatanga - extended family; Mauri- life force in people and objects; Mana ake- unique identity of individuals and family; Hā a koro ma, a kui ma- breath of life from forbearers; and, Whatumanawa- the open and healthy expression of emotion.

Te Pae Mahutonga, also developed by Professor Mason Durie, draws upon the concept of the Southern Cross constellation to present elements of contemporary Māori health and health promotion.

The four central stars of the Southern Cross represent four key tasks of health promotion:

- 1) Mauirora (cultural identity)
- 2) Waiora (physical environment)
- 3) Toiora (healthy lifestyles)
- 4) Te Oranga (participation in society)

The two pointers within the constellation represent Nga Manukura (community leadership) and Te Mana Whakahaere (autonomy).

RESEARCH TOOLKIT: Culturally safe research with NZ Māori populations

These three models provide concepts that support researchers as they develop proposals and programmes that include working with Māori individuals and whānau. Essential elements such as spirituality, whānau and mana, as well as the interconnectedness of these and other concepts, are important to have at the front and centre of research considerations.

The Health Research Council of NZ (HRC,) in its comprehensive 2010 publication *Guidelines for Researchers on Health Research Involving Māori*, discusses the benefits for both researchers and Māori when consultation is carried out as a research proposal is being devised. They suggest that the benefits for researchers include the opportunity for researchers to articulate the research question to a particular audience and building appropriate relationships in the initial stages of the research which will be invaluable later in the process. (p6) They also describe benefits for Māori, which include providing the opportunity for a voice in a project that may affect their region, whānau, hapū or iwi. (pp 6-7)

In *Te Ara Tika: Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members*, an appendix to the HRC publication above, the authors recommend consideration of tikanga Māori, or Māori protocols and practices, when researchers or ethics committee members are engaging in consultation or advice about Māori ethical issues. (pp 27-38)

A Māori ethical framework is proposed, which references four tikanga-based principles that should be taken into consideration when entering into a research or ethical relationship with Māori. They are whakapapa (relationships), tika (research design), manaakitanga (cultural and social responsibility) and mana (justice and equity).

Within this framework, each principle is divided into three parts, illustrating and describing progressive standards of ethical interaction. Minimum standards are those expected to have been met by researchers before ethical approval is granted; the middle standard describes good practice that reflects a more Māori responsive approach to the research project; while the third standard, or best practice, aligns with expectations of behaviour within Te Ao Māori.

This guideline also offers questions that might be asked at every stage of the research development in order that the research is more responsive to Māori.

The Medical Council of NZ provides a resource booklet produced by Māuri Ora Associates, *Best Health Outcomes for Māori: Health Implications*, that covers a wide range of topics that impact on working with, and undertaking research with, Māori. Concepts of whānau (family), the role and status of women, and tapu and noa (sacredness and absence of tapu), are discussed and their importance is highlighted.

RESEARCH TOOLKIT: Culturally safe research with NZ Māori populations

For example:

For Māori with traditional views, the wairua or spiritual well-being is not only key to one's identity but also provides the link with one's whānau, thus connecting the individual with the larger community that provides sustenance, support and safety.

The mental (hinengaro) and physical (tinana) health are inextricably linked with the wairua and the other elements of a healthy life, including the physical environment. The relationship between Maori and the environment (te ao tūroa) is one of stewardship (tiakitanga). (p14)

The importance of whānau within te ao Māori is also discussed:

Whānau means family, sometimes in the direct and circumscribed sense of parents and children, but more often in the sense of a wider kinship group who share a common ancestor. The whānau is the basic unit around which Māori society is organised, and the welfare of one member is of concern to all. (p14)

They also provide guidance on typical issues that may be important to Māori:

Māori pronunciation and communication -

Māori language (te reo Māori) is the basis of Māori culture and is considered a gift from ancestors. It expresses the values and beliefs of the people and serves as a focus for Māori identity. For this reason, language and pronunciation are very important. Learning how to pronounce Māori names correctly is perhaps the single greatest way to show respect. (p17)

Karakia and use of cultural experts -

Wairua (the spirit) is intrinsically connected to health, and many Māori regard karakia (blessings or prayer) as an essential way of protecting and maintaining spiritual, physical and mental health. (p23)

Physical contact -

For Māori, the head is the most sacred (tapu) part of the body. For this reason, you must be careful to ask consent before touching the head and avoid touching it casually. As part of the tapu/noa separation, it is also important that anything that comes into contact with the body (or bodily substances) should be kept separate from food (or items associated with food, such as dishes or tea towels). Because food is considered noa, you should never pass food over a person's head, which is tapu. Doing so could be considered to strip the person of all personal tapu. (p21)

Finally, in their soon to be published rubric, *Māori Responsive Good Practice Expectations: Culturally appropriate components to embed in death reviews, reports and recommendations*, the Health Quality & Safety Commission's mortality committees' Māori caucus identifies four principles to assist those working with Māori, particularly in the death review process.

RESEARCH TOOLKIT:

Culturally safe research with NZ Māori populations

Those principles are:

- 1) Tika – getting the story and the interpretation right;
- 2) Manaakitanga – being socially and culturally responsible;
- 3) Mana – advancing equity, self-determination and social justice;
- 4) Mahi Tahi – establishing relationships for positive change.

These principles cover all aspects of the mortality review process, from the undertaking of the death review through to what is embedded in the death review, reports and recommendations. They identify benefits to Māori, how to incorporate a systems and equity approach, how to make the review Māori-centred, instilling ethical practice, and, recommendations around governance, data sources, collection and storage of data.

3 Questions researchers may be required to address

The HRC suggests asking these questions when developing a research project. They endorse starting initial consultation and conversations with a variety of Māori and Māori groups before putting the research proposal together.

- Does the research topic involve Māori as a population group?
- How will this proposed research project impact on Māori health?
- What are the benefits for Māori?
- How will Māori be involved? (e.g. as researchers, participants, advisors etc.)
- Which Māori could possibly be involved in this research project?
- If Māori researchers are involved in the research team, can a Māori researcher be the lead researcher?

4 Resources to support research development with Māori populations/References

- Health Quality & Safety Commission, Mortality Review Committees Māori Caucus Rubric *Māori Responsive Good Practice Expectations: Culturally appropriate components to embed in death reviews, reports and recommendations*, by Dr Denise Wilson, Dr Terryann Clark, Fiona Cram and Keri Te Aho Lawson. (Publishing pending).
- HRC, Guidelines for Researchers on Health Research Involving Māori 2010 https://gateway.hrc.govt.nz/funding/downloads/Guidelines_for_researchers_on_health_research_involving_M%C4%81ori.pdf
- Māori Health Models <https://www.health.govt.nz/our-work/populations/maori-health/maori-health-models>
- Ministry of Health, He Korowai Oranga: NZ's Māori Health Strategy <https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga>
- Ministry of Social Development, Oranga Tamariki Practice Centre 'Working with Māori' <https://practice.mvcot.govt.nz/policy/assessment-and-decision-making/resources/working-with-maori.html>
- Te Ara Tika: Guidelines for Māori Research Ethics: A Framework for Researchers and Ethics Committee Members <https://www.fmhs.auckland.ac.nz/assets/fmhs/faculty/tkham/tumuaki/docs/teara.pdf>
- Te Pou o Whakaaro Nui: The National Centre of Mental Health Research, Information and Workforce Development 'Working with Māori' <https://www.tepou.co.nz/uploads/files/resource-assets/Lets-Get-Real-Working-with-Maori-Practitioner-Level-Learning-Module.pdf>
- Treaty of Waitangi Principles <https://www.health.govt.nz/our-work/populations/maori-health/he-korowai-oranga/strengthening-he-korowai-oranga/treaty-waitangi-principles>

5 Glossary (from the Māori Dictionary <http://maoridictionary.co.nz>)

- Ao Tūroa* - light of day, world, Earth, nature
Hā - breath, essence, breathing
Hapū - kinship group, tribe, subtribe
Hinengaro - mind, thought, intellect
Iwi - extended kinship group, tribe, nation, people
Karakia - incantation, ritual chant or prayer, grace, blessing
Korowai - cloak
Mahi tahi - to work together, collaborate, cooperate
Mana - prestige, authority, control, power, influence, status
Mana ake - unique identity of individuals and family
Manaakitanga - hospitality, kindness, generosity, support
Manukura - person held in high esteem
Mauri - life principle, life force, vital essence
Noa - to be free from the extensions of tapu, ordinary, unrestricted, void
Ora - to be alive, well
Oranga - livelihood, health, living
Tapu - sacred, prohibited, restricted, set apart
Te Ao Māori - the Māori world
Tiakitanga - guardianship, caring of, protection, upkeep
Tika - to be correct, true, upright
Tikanga - correct procedure, custom, lore
Tinana - body
Toiora - to be sound, uninjured
Waiora - health, soundness
Wairua - spirit or soul
Whakahaere - to organise, operate, lead
Whakapapa - genealogy, lineage, descent
Whānau - extended family, family group
Whanaungatanga - relationship, kinship, sense of family connection
Whare - house
Wharenui - meeting house
Whatumanaawa - seat of emotions, heart, mind
Wheke - octopus