

Facilitating Effective Maori Participation in Research: Experiences of the National Mental Health Classification and Outcomes Study Maori Monitoring and Review Group (CAOS-MMRG)

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1.0 Introduction

The purpose of this paper is to provide a summary of key issues relevant to facilitating effective Maori participation in research. Written primarily from the perspective of the Mental Health Research and Development Strategy (MHRDS) and based on the experiences of the National Mental Health Classification and Outcomes Study Maori Monitoring and Review Group (CAOS-MMRG), this paper seeks to inform project managers, researchers and research funding agencies of issues relevant to effective Maori participation in national research projects which are of relevance to Maori. Although this paper is written specifically within the context of the MHRDS, the principles identified regarding effective Maori participation in research may also be applicable within the broader research context.

The MHRDS is a Ministry of Health funded strategy, which aims to use research and development, which is consistent with the Treaty of Waitangi and the needs of consumers, family, whanau and other stakeholders, to identify ways that will improve the planning, purchasing and delivery of mental health services in New Zealand. The principles of Maori participation at all levels, active partnership in service delivery, and the protection and improvement of Maori health status are explicit in He Korowai Oranga: Maori Health Strategy¹ and Te Puawaitanga: Maori Mental Health National Strategic Framework².

Three key threads woven throughout He Korowai Oranga are relevant to research funded by the MHRDS: Rangatiratanga; Building on the Gains; and Reducing Inequalities. Rangatiratanga acknowledges whanau, hapu, iwi and Maori aspirations for rangatiratanga, to have control over the directions and shape of their own institutions, communities and development as people. This includes the involvement of iwi in decision making as representatives and partners, continuing Maori provider development and strengthening the capability of Maori communities to develop initiatives that meet their needs across the social, cultural and economic sectors. Building on the gains refers

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¹ Ministry of Health (2002). *He Korowai Oranga: Maori Health Strategy*. Wellington: Ministry of Health.

² Ministry of Health (2002). *Te Puawaitanga: Maori Mental Health National Strategic Framework*. Wellington: Ministry of Health.

to maintaining and building on the gains already made in Maori health. Reducing inequalities in health and disability outcomes refers to the need to, when implementing services changes, ensuring these are contributing to reducing inequalities and not increasing them. This requires a focus on identifying priorities where a difference for Maori can be made. These national policy directions serve to provide clear expectations regarding Maori participation in government funded mental health research in Aotearoa.

2.0 Background to the CAOS-MMRG

The New Zealand Classification and Outcomes Study (CAOS) was a national research project that aimed to develop the first version of a national casemix classification for specialist mental health services in New Zealand. The aim of the study was to assist in informing understandings of “who receives what services, from whom, with what effect, and at what cost”. The second objective of the study was to trial the introduction of outcome measurement into routine clinical practice in New Zealand. Initial planning for this project commenced in 1997. Maori participation in this project was limited until the establishment of the CAOS-MMRG in June 2001. It is important to note that the establishment of the MMRG resulted from significant concern and frustration that Maori participation had not been adequately considered in the design and planning phases of the CAOS study. The lack of participation by Maori was considered by the MMRG to be unacceptable in a government funded national project of this magnitude.

The MMRG started its role in CAOS from a position of identifying limited Maori participation in the project, both in terms of the identification of CAOS as a priority research area and in project design and development. Much discussion was held before the MMRG actually reached a consensus that the project was important for improved service delivery to tangata whaiora. Given the reactive nature of its origins, the major focus of the MMRG was the management of risk for Maori. This focus led to the development of the Risk Register, which documented any items that arose during discussions, along with any action taken to mitigate the risks. The Risk Register has proved to be a valuable tool, providing an important framework for the Group to monitor the issues identified over time, as well as maintain a process of transparency and accountability for themselves and other key stakeholders. Key activities of the MMRG were the provision of advice in relation to general study design issues; the cultural responsiveness of the CAOS methodology, tools, data collection, analysis and interpretation; and future analysis of data.

Regardless of its reactive and somewhat negative origins, on completion of the project in 2003, the MMRG concluded that the MMRG had been an effective vehicle for Maori participation in the CAOS project. The MMRG also identified several specific factors which may be useful in informing Maori participation in other projects. ‘Maori participation’ is used in its broadest sense. However, it is in no way intended to imply Maori are a homogenous group. Maori participation means involving all different key stakeholder groups, including, of essential importance in mental health, tangata whaiora and whanau. Seven essential elements of successful participation are outlined below.

3.0 Essential Principles of Successful Participation

3.1 Maori involvement in the prioritization of research projects

When first participating in the CAOS project, the MMRG questioned whether consultation had occurred in relation to the CAOS project being a priority for Maori mental health stakeholders. This raises the broader issue of Maori involvement and influence in the decision making processes surrounding the identification and prioritization of areas for national research. Included within this is the importance of selecting projects which have as a central focus contributing to Maori mental health gains and service development.

3.2 When to involve Maori?

Facilitating Maori participation in the CAOS project was left too late, impacting significantly on the way in which Maori participation subsequently evolved. It is important to ask whether Maori participation in CAOS would have evolved differently, had key Maori stakeholders been involved early in the project? For example, would Maori participation have originated from a proactive, as opposed to, reactive position? Would the focus of Maori participation have been “benefit maximization” as opposed to “risk management?” Did the establishment of the Group based on risk mitigation stifle innovation and creativity?

The answer to when Maori should be involved is clear. Maori should be involved in the identification of the research priorities and topics. Once identified, Maori should be actively involved in the design and development of the project from the outset. To do anything less is to risk:

- The project not being consistent with the obligations contained in the Treaty of Waitangi;
- Limited buy-in from Maori to the research;
- Research results being open to criticism if they have not have addressed the needs of a significant proportion of mental health service users (Maori); and
- Research results potentially putting Maori and future Maori mental health sector development at risk.

3.3 Terms of Reference

The first task for the MMRG was the development of the Terms of Reference for the group. Deemed a ‘living’ document, able to be amended as the MMRG understandings of the project developed, the Terms of Reference clearly outlined the responsibilities and importantly the self determining powers of the Group. For example, the Terms of Reference provided a mandate for the MMRG to provide direction in the analysis of the final data set for Maori, the appropriate application of findings, determine parameters for data use, including addressing issues which require contextual qualification and possessing the right of veto in relation to the interpretation and dissemination of data relating to Maori.

Whilst the tasks evolved over time, the overall role and positioning of the MMRG remained constant via the Terms of Reference. The Terms of Reference clearly mandated the role of the MMRG and were considered an expression of tino rangatiratanga, self determination and power within the project. The importance of the Terms of Reference providing the MMRG with more than simply an ‘advisory’ role was critical. The Terms of Reference conveyed to the MMRG the principle of good faith, in relation to their ability to make sound and reasonable decisions, that their participation was important, their ideas and views valuable and that these would be respected accordingly.

It is important to note that a conscious decision was made by the MMRG not to use the title ‘Advisory’ group. ‘Advisory’ suggests a passive role, whereby the ‘advice’ provided can be taken or not, as opposed to actively stating a position and the action to be taken. The two roles are very different. The MMRG assumed that the presence of the word ‘monitoring’ conveyed our interest in monitoring issues of relevance to Maori across the various stakeholder groups. In addition, our role was not marginalised or relegated to providing ‘advice’ only on ‘cultural’ issues but reflective of our interest in total project quality. The MMRG recommended to the MHRDS that any future groups established to facilitate Maori participation **not** be titled an ‘Advisory’ group.

3.4 Facilitation of Group Membership

The key objective of the MMRG, as stated in its Terms of Reference, was ‘working with the project to help develop its responsiveness to Maori’. Much thought was given to the composition of the Group, in terms of the expertise required, the availability of individuals to participate and the ability to co-opt expertise as required. Tangata whaiora representation and participation in the group was critical. On completion of the study, the MMRG was comprised of 14 members, each with various interests in Maori mental health, including representation from clinical, academic, policy, research, tangata whaiora, nursing, forensic and child and youth sectors. In addition, a member of the MMRG was a member of both the National CAOS Reference Group and the MHRDS Steering Committee, ensuring continuity between the varying stakeholder governance groups in the project. Membership fluctuated over the course of the study and as circumstances changed. This provided the opportunity to alter membership as required, to source additional expertise and to ensure that alternative perspectives were obtained.

There were two key components relating to the Group membership and the facilitation of participation which contributed to the success of the Group. The first was that the membership of the Group was flexible according to the skill set required at each stage of the project. An important part of this flexibility was that the differing strengths of members would be utilised at different times, with members able to participate as required and as able. This included the flexibility to co-opt additional expertise as the need was identified. For example, in the analysis phase of the project, input was sought from a Maori researcher with expertise in epidemiological issues. Often, it can be difficult for people to enter midway through a process or project. However, this was not an issue for the MMRG, primarily due to the effective way in which the Group was managed and facilitated.

The second component was that the members of the MMRG were kaupapa driven, that is working towards a common goal of the improvement of service delivery to tangata whaiora. This meant that issues were raised and discussed within the wider context of this goal, without individual or hidden agendas influencing the discussion.

3.5 Ability to address wider context

The MMRG viewed the CAOS project within the broader framework of Maori mental health. Working from this paradigm, it was unavoidable that issues not specifically encompassed by CAOS project, yet of significant importance to Maori mental health would arise. A number of the issues identified by the MMRG were outside the specific parameters of the CAOS study. However, to merely state they were outside of the current project brief, and therefore unable to be progressed, would have been unacceptable to the MMRG. It was vitally important, in order to maintain the integrity of the MMRG in the process, that the MMRG were provided with a mechanism to progress such issues as they arose, for example, raising them with the appropriate agency. This ensured that some long term gain was able to be facilitated by the MMRG through their involvement in the CAOS project. Contributing significantly to this was the Project Manager who, in unreservedly recognising the importance of this particular function of the MMRG, was proactive in seeking out ways to effect wider change.

3.6 Appropriate Resourcing

Facilitating the effective participation of Maori required appropriate resourcing. Without adequate resourcing for meetings, hui, co-opting of expertise, and the provision of administrative assistance, the MMRG would have been hampered in its ability to participate effectively.

3.7 Project Management

Underpinning the effectiveness of all elements identified above was the role of the National Project Manager and Team. Effective participation by the MMRG required significant commitment and genuine understanding by the National Project Team of the importance of addressing the cultural responsiveness of the project. A point of critical importance is that the National Project Team perceived the study's responsiveness to Maori to be their core responsibility, as opposed to the sole responsibility of the MMRG. Effectively addressing issues raised by the MMRG was considered by the Project Manager to be a fundamental part of her job. The total acknowledgement and demonstration of this responsibility significantly influenced the National Project Team's ability to facilitate and support effective participation of the MMRG, through encouraging the open discussion and debate of the issues as they arose. This facilitation included a willingness to investigate and discuss all issues as they were raised and to address these as determined by the MMRG. It is a significant point that this occurred even if the issues raised were not directly within the parameters of the CAOS study. That the MMRG was able to investigate and address a wide range of issues is due largely to the National Project Team being able to effectively facilitate this input.

Responsibility for the management and administration of the MMRG lay with the National Project Team and the MMRG Administrator, all of whom played a significant

role in ensuring the effective and efficient functioning of the Group. Tasks undertaken by the National Project Team and the MMRG administrator included the drafting of key documents such as newsletters and correspondence, distribution of information, organisation of meetings, and collation of feedback.

Many of the components of success raised by the MMRG can be described as 'intangibles'. That is, they are components which cannot be easily encapsulated within a prescribed plan for researchers and project managers to simply follow. Whilst a list can be provided of generic principles, such a list is ineffectual if the Project Team lacks the ability to effectively operationalise those principles. To work successfully with Maori, an individual must carry these 'intangibles' with them. Such 'intangibles' exist within the skills, values and beliefs the person brings with them, for example personal qualities such as shared commitment, vision and leadership. These cannot be easily described or quantified and a list cannot be produced which prescribes how one reaches a state of genuine commitment to progress Maori mental health development and understanding of their core responsibilities. However, although intangible, they cannot be overlooked; their importance is paramount and the necessity of selecting the right Project Team, who possess such qualities cannot be emphasised enough.

Essential components of Project Management in the CAOS project included:

- Understanding the limited capacity of MMRG members, due to other significant commitments, to dedicate to the CAOS project;
- Ensuring that the time resources and skills of members were effectively utilised;
- Actively seeking out additional members to ensure that the MMRG possessed the right skill set for each stage of the project;
- Effective presentation and management of information provided to the MMRG;
- Effective ongoing communication with MMRG members;
- Actively seeking advice from key members of the MMRG on progress and acting on that advice;
- A sincere commitment to genuine consultative processes with the MMRG on all issues impacting on Maori;
- A willingness to progress all issues raised and a commitment to acting on the decisions of the MMRG;
- Ensuring that the issues raised by the MMRG were of central importance to all tasks being undertaken by the members of the National Project and analysis team;
- A commitment to Maori mental health workforce development within CAOS, for example supporting the MMRG administrator;
- Understanding the variety of roles needed by the Project Manager, that is fulfilling an important support role which involved exercising leadership, sometimes keeping quiet until being asked for directions, with ultimate responsibility for making key decisions resting with the MMRG members; and
- Implicitly trusting that, despite the differences in viewpoints, the MMRG and National Project Team would all arrive at an agreed destination in the end.

4.0 Summary Framework of Key Principles

Principles	Implications	Actions³
Maori involvement in research prioritisation	<ul style="list-style-type: none"> • Facilitating positive Maori participation • Selection of research projects which contribute to Maori mental health gains 	<i>Active involvement and influence in prioritisation processes by Maori</i>
Ongoing active Maori participation	<ul style="list-style-type: none"> • Facilitating positive Maori participation focused on obtaining maximum benefits for Maori • Greater buy-in from key stakeholders 	<i>Facilitating a process for sustained, comprehensive, and active Maori participation.</i>
Active participation in decision making	<ul style="list-style-type: none"> • Facilitating positive Maori participation by creating mechanisms for active and genuine decision making. 	<i>The development of a “Terms of Reference” designed by Maori and which enables tino rangatiratanga, self determination and control</i>
Facilitating effective participation	<ul style="list-style-type: none"> • Facilitating positive Maori participation by ensuring those with required expertise and perspectives are able to contribute 	<i>Flexibility and creativity in the development of processes for Maori participation</i>
Facilitating opportunities to influence wider context	<ul style="list-style-type: none"> • Facilitating positive Maori participation by recognising the importance of contributing to broad and long term Maori mental health gains and sector development 	<i>Mechanisms are provided to progress issues of relevance to the wider context of Maori mental health development</i>
Appropriate resourcing	<ul style="list-style-type: none"> • Facilitating positive Maori participation by ensuring necessary resourcing is available to achieve required tasks 	<i>The resource implications for Maori participation is adequately considered within the initial project specifications</i>
Effective project management	<ul style="list-style-type: none"> • Facilitating positive Maori participation through a project management approach which is based on: • A genuine understanding of Maori needs and expectations, and: • A commitment to viewing responsiveness to Maori as a core responsibility 	<i>Ensure Project Teams have a genuine commitment and understanding of how to progress Maori mental health development</i>

³ These are suggested examples only

5.0 Conclusions

Based on the experiences of the National Mental Health Classification and Outcomes Study Maori Monitoring and Review Group (CAOS-MMRG), this paper identifies seven essential principles of successful participation by Maori in national research projects which are of relevance to Maori. It is important to note that the ideas contained in this paper are not intended to suggest that a 'one size fits all' approach can be applied to Maori participation in research. They are simply principles and issues to consider and possibly adapt, depending on specific research requirements. Maori participation may or may not be composed of a MMRG structure, however the underlying principles identified may have relevance to a variety of situations.

National mental health policy directions provide clear expectations regarding Maori participation in government funded mental health research in Aotearoa. The aim of this paper is to provide information which will assist research funding agencies, project managers and researchers to meet those expectations.