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## **Kaupapa Maori Action Research to improve heart disease services in Aotearoa, New Zealand**

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Action Research can be a powerful tool for change and improvement in health services for indigenous people when utilised within an appropriate framework. The project *Maori Utilisation & Experience of Ischaemic Heart Disease Management* illustrates this convergence in its use of Kaupapa Maori Action Research methods in its efforts to improve the health and well-being of Maori within the northern region of Aotearoa/New Zealand. We outline the research processes and outcomes obtained through the application of 'by Maori for Maori' approaches to understanding Maori pathways and barriers to care for ischaemic heart disease. Maori understandings of their illness and experiences of treatment, and healthcare providers' perspectives on care of Maori with ischaemic heart disease, were combined into Maori-led actions to improve service provision. The paper examines critical factors in an action research approach to health service innovations and implications for efforts to reduce entrenched health disparities.

**Keywords:** ischaemic heart disease; Maori; indigenous; Aotearoa/New Zealand; Action Research; Kaupapa Maori

### **Introduction**

Cardiovascular disease is the leading cause of death in Aotearoa/New Zealand, accounting for 40% of all deaths annually (Hay 2004), and indigenous Maori – 14.6% of the total population (Statistics New Zealand 2007) – are disproportionately affected. In ischaemic heart disease (the most common cardiovascular disease), between 2000 and 2004 the mortality rate for Maori males aged 45–64 years was three times (343.4 per 100,000), and for Maori women 45–64 years (131.4 per 100,000) four times higher than non-Maori (Curtis *et al.* 2007). These ethnic disparities in ischaemic heart disease have persisted over three decades despite investments in technology, medical and surgical management, and health promotion (Tobias *et al.* 2006, Blakely *et al.* 2007, Reid and Robson 2007).

Although ischaemic heart disease is related to current disadvantage, it is determined by disadvantage across the entire life course (Davey Smith *et al.* 2001, Kauhanen *et al.* 2006, Davey Smith 2007). The Maori population experiences greater social and economic disadvantage that is reflected in persistent health inequalities including ischaemic heart disease (Reid and Robson 2007). These outcomes remain even when socio-economic variables are controlled for, suggesting that they arise

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partly from processes of ethnic marginalisation (Ajwani *et al.* 2003). Such disparities are clear evidence of the failure of health systems to deliver health equity (CSDH 2007), which remains a pressing goal for social justice. We report research investigating the experiences behind the high mortality and morbidity rates from ischaemic heart disease among Maori in Te Tai Tokerau (Northland) where death rates are higher than other areas (Penney *et al.* 2006).

We utilised an indigenous Kaupapa Maori Research (kaupapa meaning ‘guiding principle’) approach in concert with Action Research methodology,<sup>1</sup> an amalgamation well-oriented to Maori aspirations for social change (Smith 1999, Moewaka Barnes 2000). We describe the processes and outcomes by which the project contributed to improvements in the management of Maori with ischaemic heart disease by health service providers.

### **Kaupapa Maori and Action Research**

Kaupapa Maori Research is based on Maori worldviews (Smith 1999) and yet its major concerns parallel many of the values and principles underpinning Action Research (Smith 2003). Both arose in reaction to a lack of generalisability (beyond dominant populations) and unexplicated power dynamics in conventional positivist research (Smith 1999, Pihama *et al.* 2002, Reason and Bradbury 2006). Both seek to centre community concerns in research and interrogate systems of power to reposition some control with those directly affected (Cram 2001, Reason and Bradbury 2006).

Kaupapa Maori Research utilises Maori frameworks – ecological, holistic and communitarian – for understanding the world, human activity and well-being within it (Smith 1999, Durie 2000) with important implications for approaches to research. Our worldviews have profound effects on how we see and utilise methodologies and fundamentally shape our relationships to knowledge and practice (Moewaka Barnes 2006).

Kaupapa Maori Research focuses on Maori advancement, adopting a theoretical position and multimethods approach born of the need to challenge colonising power, norms and assumptions, so that Maori ways of knowing and operating are central (Smith 1999, Walker *et al.* 2006). Moewaka Barnes (2000) emphasises three defining principles of this approach:

- It is by Maori for Maori.
- Maori worldviews are the normative frame.
- Research is for the benefit of Maori.

Kaupapa Maori Research naturalises Maori epistemologies, methodologies and practices so that Maori are not articulated as the ‘other’. Action Research works in empowering, participatory ways (Reason and Bradbury 2006) to generate research-based solutions to problems that impact on the well-being of the people and communities. It focuses on participation and change, using qualitative, quantitative or mixed methods depending on the issues and context, in cycles where each revolution consists of planning action, implementing change and evaluating the results. Knowledge created in the process of solving problems becomes the basis for further actions (Khanlou and Peter 2005). Participation by diverse stakeholders in

processes that mediate power differentials, improves buy-in to work on democratically identified problems, building community capability in skills, advocacy and community cohesion.

Reason and Bradbury (2006) argue for the importance of evaluation components in Action Research and have mooted key questions against which projects can be assessed. We have adapted these as follows for our project:

- Were collaborative relationships established and maintained?
- Were there useful processes and outcomes?
- Were plural ways of knowing generated?
- Was democracy actioned?
- Was the project worthwhile?

Action Research is supported by a growing body of literature showing effectiveness in providing innovative solutions to health issues in a wide variety of settings (Panelli *et al.* 2006, Patten *et al.* 2006).

Both Kaupapa Maori Research and Action Research are context-specific and tailored to purpose and desired outcomes (Moewaka Barnes 2000, Israel *et al.* 2003). Action Research, emphasising empowerment, aligns with the Kaupapa Maori Research requirement for research to be conducted in Maori ways, dealing with issues important to Maori and likely to be of benefit to us. This congruence allows incorporation of the Action Research processes into a Kaupapa Maori Research framework.

## **Methodology**

### ***Maori Utilisation & Experience of Ischaemic Heart Disease Management***

*Maori Utilisation & Experience of Ischaemic Heart Disease Management* was a three-year project funded by the Health Research Council of New Zealand and approved by the Northern Region Health and Disability Ethics Committee. The research aimed to improve healthcare practice and Maori access to and experience of healthcare by developing an understanding of Maori pathways to and through healthcare for management of ischaemic heart disease. It involved collaboration among Maori patients and *whanau* (extended family), Maori primary care providers, general practices and health service funders in Te Tai Tokerau (Penney 2005) to identify barriers and enablers to optimal healthcare outcomes.

The project leaders (Liane Penney [LP] and Helen Moewaka Barnes [HMB]) are both tangata whenua (indigenous – literally translated means people of the land) of Te Tai Tokerau region, firmly grounded in local communities with linkages to Maori and other service providers and local Maori tribal authorities. These linkages, plus LP's professional networks through previous roles in health service planning and development in the region, were critical to the design and implementation of the research proposal.

The project consisted of three phases: enquiry and data collection; analysis and action; and reflection on impacts. Maori participants were selected through Maori primary healthcare providers and general practices using a purposive sampling strategy to identify participants within a range of age, gender and locational variables and differing experiences of ischaemic heart disease treatment and

outcomes. Healthcare professionals spanned organisations including secondary care, general practice and Maori primary healthcare and included eight general practitioners (GPs), five practice nurses, three community nurses, a medical specialist, a nursing specialist and a community health worker, with a range of length of experience.

### ***Phase One***

Interviews of 1–2 hours were held with 25 Maori with ischaemic heart disease and their families (to extend service-user perspectives) and 19 healthcare professionals to enable comparison of differing experiences. We explored Maori understandings of ischaemic heart disease and experience of healthcare, including responses to treatment/referral options offered. Interviews with healthcare professionals canvassed experiences and understandings from work with Maori with ischaemic heart disease.

### ***Phase Two***

Phase Two worked with service-users and providers using analyses of the data to explore barriers, possibilities and actions for improving ischaemic heart disease services and care. The process involved a series of *hui* (Maori gatherings) and meetings during 2005, prior to which participants were sent a draft report on Phase One findings, and from which actions were developed, prioritised and put in place.

Gatherings were held firstly with the research participants, and then other stakeholders including Te Tai Tokerau Primary Healthcare Organisation, Te Tai Tokerau Maori Purchasing Organisation, Northland District Health Board, Ministry of Health and consumer groups.

### ***Phase Three***

Phase Three interviews were conducted in 2006 with all of those available to be re-interviewed from the sample groups, to assess impacts from involvement in the research project. Twenty follow-up interviews were conducted with Maori patients and 15 with healthcare professionals. Additional interviews were recorded with three health professionals by Sandy Kerr (SK) in 2007 to ascertain perspectives on project impacts two years after the completion.

## **Findings**

We analysed data from Phases One and Three, using thematic analysis to draw out patterns and variations (Patton 1990, Wetherell *et al.* 2001, Edwards *et al.* 2005, Braun and Clarke 2006). For Phase Two we offer a descriptive account based upon participant observation (Kearns 2005) of the outcomes of the Kaupapa Maori Action Research.

### ***Phase One – different worlds***

Themes from interviews with Maori patients and their families and with healthcare practitioners included understandings of ischaemic heart disease, pathways to and

pathways through healthcare. We report our syntheses of the themes illustrated with excerpts from the transcribed data.

### *Understandings*

Maori patients generally had good knowledge of ischaemic heart disease including associations with diet, physical activity and smoking. They had less understanding of the life-course impact on ischaemic heart disease, often stating that family history indicated a genetic component.

Patient: On my mum's side there's probably about 8 or 10 in our family that's died from heart attacks, but two brothers have had heart attacks and on my father's side there's one on my father's side that died of a heart attack so it's quite strong in our genes. (P14)

Perceptions of genetic causality without an analysis of the influence of environmental and behavioural factors gave rise to a feeling of powerlessness to change outcomes. Most commonly, however, the Maori patients viewed stress as the major contributor to Maori ischaemic heart disease. They talked about stress associated with life events like unemployment and financial hardship but also loss and grief.

Patient: It really came on bad at the time my dad had a heart attack and it actually brought mine on as well. (P8)

Although Maori patients and *whanau* demonstrated knowledge of causes of ischaemic heart disease, when talking about their own health problems, women in particular were less sure about how or why they had developed. Studies of other populations have also found that the most commonly held belief is that ischaemic heart disease, particularly myocardial infarctions and strokes, is caused by stress (Gans *et al.* 1999, Meischke *et al.* 2000, Mosca *et al.* 2000, Newman 2003).

Although some healthcare practitioners acknowledged the impact of social and economic factors on Maori health, they generally focused their talk on Maori lifestyle factors.

Health practitioner: You know, everyone smokes, well not everyone smokes, but huge, a very high percentage of people smoke. They drink a lot, take drugs, don't exercise, and eat very high fat food. It's just a huge amount of risk taking, you know, has a big input into how healthy they are. (HP12)

In focusing on risk factors, systemic issues seemed obscured to practitioners. Without an understanding of broader determinants of health, it is a very short step to blaming the individual choices of people in difficult circumstances for their plight (McCreanor and Nairn 2002a, 2002b) an approach that does little to promote positive relationships between practitioners and patients or improve their health.

### *Entering pathways*

Maori patients entered a pathway of care for ischaemic heart disease at different points along the continuum from risk factor management through to emergency admission for acute coronary syndrome. Those who came to care as a result of illness described varying symptoms and diverse health-seeking responses. Reasons for delay included interpreting symptoms as due to other conditions such as asthma, indigestion or ageing, and efforts at self-management.

Patient: I was just passing it off as indigestion because I was thinking well indigestion really isn't this bad. But then it would go away. So I thought oh no, because I used to think that if you have a heart attack, it's just like one big pain and it's just constant. But it wasn't. No, I think people should go and get checked, especially when you've got heart disease in the family. (P2)

Other motivations included fear, disbelief and trying to avoid wasting the time of health professionals. Some participants experienced quite different difficulties related to systemic factors that blocked their efforts to get care.

Patient: He did an ECG and sent me up to the hospital here and they sort of they were really busy in the A&E and they just said oh nah it's a pulled muscle go home and so I went home and I went oh yeah okay and then six o'clock that night I still didn't feel well but I couldn't put my finger on what it was I just didn't feel myself . . . but six o'clock that night I just suddenly went really hot like I was burning from the inside out and I didn't know whether I would pass out or be sick or what . . . and then my husband said 'that's it I'm ringing an ambulance'. (P7)

As mentioned in this extract, *whanau* members and sometimes work colleagues were influential in getting patients to seek help if there were delays. Participants' descriptions of responses were consistent with the findings from other studies exploring patient variation in response to cardiac events (Dracup *et al.* 1995, 1997, Ottesen *et al.* 1996, Norris and UK Heart Attack Study Collaborative Group 1998, Ruston *et al.* 1998).

Many healthcare practitioners described Maori as unlikely to participate in screening and expected late presentation with ischaemic heart disease, leading to a delay in diagnosis and treatment. These behaviours were explained in terms of ambivalence about health, fatalism around illness and lack of long-term vision. Practitioners also argued that once in care some Maori concealed symptoms and withheld information undermining assessment and diagnosis.

Health practitioner: They'll come up with all these other problems that are just not really what they're worried about, they might have wasted half an hour by the time, then you say 'OK then Bill, so you've covered pretty well everything?' – yeah, and as they're going out the door 'Oh by the way I've had a bit of chest pain'. (HP2)

This participant clearly recognises the process as unsatisfactory, but the interpretation (obfuscation, time wasting, minimising) reveals a blaming stance that makes the patient responsible for the miscommunication.

### *Travelling pathways*

Participants described a wide range of treatment pathways following recruitment into healthcare, from lifestyle advice and medical management to surgical intervention. Both Maori and health practitioners clearly expressed concern about the effectiveness of communication within clinical systems. From the perspective of most Maori patients and *whanau*, service providers didn't take enough time to build relationships and Maori reported health professionals failed to listen appropriately leaving them feeling misunderstood.

Patient: I couldn't get anywhere with the doctor down here. I felt at some stage he didn't believe me, which was disappointing to me. It was on my mind for several weeks and months because there's no other doctor here . . . I don't think he even concerned himself

with [me]...he was more like a traffic cop issuing tickets. He just writes out a prescription. (P24)

Health professionals were seen to create barriers, using difficult language and not discussing their decisions. They failed to take account of, or value the supportive roles of *whanau* in listening and sharing information. Service users felt the poor communication could be an effect of cultural difference and some talked of discrimination against Maori.

From the perspective of health practitioners Maori were passive or non-compliant by not fully and effectively communicating problems and symptoms, not keeping their practitioner informed and not giving feedback on their health.

Health practitioner: It really is very dependent on us understanding the patients and being aware of the fact that we don't get told the truth, and we don't get told how bad it is and even though I knew this person very well, and very experienced at it, I didn't get out of her how bad it was until she was better. (HP6)

Health practitioners felt that the poor communication was a cross-cultural issue and that it was critical to overcome this but had no clear strategies to improve the situation.

Together these data and analyses demonstrate the different understandings that Maori and providers had on the nature, diagnosis and management of ischaemic heart disease. The findings here provided the materials for the next phase of the work that brought the parties together to share the divergent views they carried and to formulate possible responses to the problems. The aim was not to apportion blame or to examine the extent to which these views were attributable to culture, marginalisation or other factors. Through Kaupapa Maori Action Research processes we aimed to present different perspectives in order to reach understandings that would create shared pathways for change.

### ***Phase Two – change facilitation***

The Kaupapa Maori Action Research process acknowledges that time is needed in any project that is seeking systemic change. We allowed a period of six months for work with the research participants and stakeholders to develop ideas and projects for change and innovation. Initially, four community-based meetings were held – two with patients and their families and two with health practitioner participants. To discuss the research findings and generate interest in change projects, 13 further meetings were held with stakeholders.

Rather than the researchers prescribing outcomes, we presented the findings of the Phase One interviews, ideas for improvements and facilitated discussion. The prioritising of possibilities and developing actions emerged from the groups and LP provided ongoing input and support for plans that emerged.

Concurrently, the Northland District Health Board invited LP to manage the development of the Northland Cardiovascular Disease (CVD) Strategy. This presented opportunities to disseminate the findings of Phase One interviews and to influence policy and practice that was relevant to improving healthcare for Maori with ischaemic heart disease. Key elements that emerged directly from the project included the following.



*Improved access to coronary angiography*

National and regional data show a lower rate of coronary revascularisation for ischaemic heart disease among Maori than is expected given its epidemiology in Aotearoa/New Zealand (Westbrooke *et al.* 2001, Tukuitonga and Bindman 2002, Ellis *et al.* 2004). Access to intervention cardiology services such as coronary angiography is further limited in geographic areas such as Te Tai Tokerau that do not have these services available locally (CMDHB 2003). The Coronary Care service of Northland District Health Board collaborated with Auckland District Health Board angiography services to implement a new angiography booking system. Reserving a set number of cases each week for Te Tai Tokerau/Northland patients has significantly improved access to this service.

A useful measure of relative access to a range of surgical interventions in New Zealand is the standardised discharge ratio taking into account the particular sex, age, ethnicity and social deprivation mix of a District Health Board's population. A rate higher than one indicates provision of a procedure at a rate higher than the average in New Zealand, and a rate lower than one indicates less than the average rate. As a measure of outcome of the new angiography booking system, we observe that the rate for angioplasties for the 2004/2005 year was 0.82 and for coronary artery bypass grafts 0.92. By the last six months of 2008, the rates for angioplasty and coronary artery bypass grafts were 1.06 and 1.51, respectively (New Zealand Health Information Service 2009), showing improvements that coincide with the timing of our interventions.

*Pre-hospital fibrinolytic therapy service*

Despite a New Zealand guideline for pre-hospital fibrinolytic therapy and good evidence for its effectiveness in reducing mortality following an acute coronary syndrome for people living more than 60 minutes from a hospital, the service was not available in Te Tai Tokerau. The researchers supported information gathering and initial meetings with St John Ambulance services, general practitioners (GPs) and the District Health Board to progress planning towards the implementation of a pre-hospital fibrinolytic therapy service. In 2009 it is reported that the Northland St John Ambulance service now provides pre-hospital fibrinolytic therapy on 14 ambulances in remote rural areas, and in the first three months of 2009, four cases have been treated, all from the Mid-North locality (K. O'Keefe, Nurse Manager Cardiac Services, Northland Health, personal communication, 1 April 2009). The main barrier to earlier implementation of the service was available funding – eventually community fundraising contributed NZ\$70,000 and a further NZ\$30,000 is required to provide coverage for all ambulances in the Northland District Health Board (DHB) area (K. O'Keefe, personal communication, 1 April 2009).

*Manaaki Manawa*

Health provider and funder stakeholders prioritised the development of new home-based cardiac rehabilitation for Maori following diagnosis of coronary syndrome to be known as Manaaki Manawa. The research team networked with cardiac rehabilitation experts, a Maori cardiac rehabilitation provider and the national

Maori heart health service to create the service and also had input into the 'Heart Guide Aotearoa' trial. Over the six months the service concept was researched, the necessary relationships formed and a successful funding proposal submitted, resulting in two initiatives that provide *Manaaki Manawa* services in three localities of Te Tai Tokerau – Mid-North, Far North and Whangarei. Evaluation of *Manaaki Manawa* shows highly positive impacts, including lifestyle change, uptake of medical advice, self-confidence and satisfaction for clients and strengthened service integration and coordination among primary care providers (Henwood and Moewaka Barnes 2008).

*Analysis of barriers to outpatient appointment attendance*

Maori non-attendance for specialist services was thought by many health professional participants to be a significant problem impacting on access to best practice treatment, yet little analysis had been undertaken to provide evidence of the magnitude of the problem or why it occurs. The researchers worked with Primary Healthcare Organisation providers and District Health Board staff to develop a short outpatient department study of the extent of non-attendance at medical outpatient appointments by Maori and non-Maori, barriers to accessing outpatient appointments and recommendations for change, funded through the Elective Services Initiative Fund. Improved systems for outpatient appointment booking and communication to patients has led to significant improvements in attendance – a 21% 'did not attend' rate in 2006 had been reduced to 10% in 2008 (C. Rood, Operations Manager and DNA Project Manager, Northland Health, personal communication, 1 April 2009).

*Community placement of automated external defibrillation*

The need for community placement of automated external defibrillator equipment throughout Te Tai Tokerau and training of community members in its use and cardiopulmonary resuscitation was a consistent theme in the data. Poor access to equipment and trained personnel for advanced life-support following an acute coronary event was considered a limiting factor, particularly in the rural areas. Subsequently, a proposal was submitted to the Te Tai Tokerau Primary Healthcare Organisation from a Maori Provider for the placement of equipment in their rural communities. An ongoing District Health Board project is scoping the strategic placement of units and trained personnel throughout the region.

*Audio-visual resource development*

To improve information-sharing with Maori, the District Health Board Coronary Care Unit planned the development of an audio-visual resource to support Maori in cardiac rehabilitation.

***Phase Three – research reflection***

Scriven (1991) suggests checking that any observed changes attributable to interventions are logically consistent outcomes of the activities and processes of

the project. One of the most effective ways to know if a project was responsible for observed changes, or if there are other explanations, is to ask the people involved (Brinkenhoff 2003). Here, we reflect on the research using the questions posed by Reason and Bradbury (2006) and drawing on data from the project and three evaluative interviews carried out in 2007 by SK. These data were overwhelmingly positive, expectedly from Maori patients but even more strongly so from health practitioners, for many of whom the project represented a disruption of established practice that was valued because it improved service provision to Maori.

*Were collaborative relationships established and maintained?*

Research relationships in this project were developed to re-align power so that work was controlled by Maori, empowering to the least powerful Maori participants and focused on producing knowledge and actions beneficial to Maori. The outcomes were evident from the comments of many of the patient participants in Phase Three interviews where improvements in relationships with providers were a feature.

Patient: My blood pressure's been quite good just when I had the flu there it was up a bit but oh no they're right on my case [giggles] ... I'm lucky I really am I'm grateful ... but I've had you fellas there you know and I never really had it before and this is where you know, it was hard, I didn't know who to go to or ... I never had people checking on me and things like that and now I have and it's marvellous. (P2006)

In terms of the relationships within the research project, both patient and provider participants repeatedly drew attention to the importance of the researcher and her ability and commitment to connect, engage and remain accountable to community people and interests.

Health professional: The researcher herself is actually very well regarded in this whole, in this region up here, so people actually, I think that was an important part of this research as well that there is a degree of trust and knowledge about her competency around this area. (HP2007)

The idea for the ischaemic heart disease project grew from LP's grounded observations as a Maori health worker/researcher from Te Tai Tokerau. She nurtured or built relationships within her community and professional networks to address the area of research and seek possible solutions.

LP's close engagement with Maori community health workers meant Maori with ischaemic heart disease and their families were introduced to the research by someone they knew and trusted (Edwards *et al.* 2005). These conventionally powerless participants generated and prioritised ideas for action. The project also generated awareness that empowering community people was a desirable outcome.

Health professional: I think the real answer is going to be actually getting training people in the community to take leadership you know and to form groups, community groups based on the old system you know like the marae, whanau, hapu, iwi. (HP2006)

The acknowledgement of the importance of relationships with communities is a useful advance in the cultural sensitivity that clinicians increasingly require (Medical

Council of New Zealand 2006) and highlighted the importance of communication between cultures of care and those of patients and their families.

*Were there useful processes and outcomes?*

The outcomes from Phase Two represent the substantive contribution of the project. Phase One findings on Maori perspectives on ischaemic heart disease may explain the motivation of healthcare providers to make changes. The stories were particularly effective in conveying the sub-optimal treatment of some Maori.

Health professional: ... Maori with heart disease get a different series of options of management offered to them, and that really stunned me. I mean I had known it intuitively but the extent of that was actually validated by the research. I think it was people's stories that really were profound. (HP2006)

The research highlighted ways in which the fine-grained detail of process and patient management were constituent of their experiences and therefore important sites for improving professional performance.

A key process was the managed introduction of the findings of Phase One to both groups, which allowed the valuing of the rarely heard patient/*whanau* experience to be given appropriate weighting in the deliberations about actions. The differences between patient and practitioner perspectives of Maori use of medical advice (McCreanor and Nairn 2002a, 2002b) were a revelation to some practitioners and provided a stimulus for change. A delicate balance was needed in order to manage the tensions between professional and experiential knowledge bases in ways that kept the two groups communicating and receptive to the possibilities for change. This was achieved through trust-based negotiation among the parties mediated by the relationships that LP established before and during the project.

A number of innovative ideas were implemented in communities as for example reported by this Maori health professional.

Health professional: What came out of that research project was a proposal for a cardiac rehab programme in the community which I am now part of doing. Manaaki Manawa [is] community rehab for, mostly focused on Maori ... So a huge thank you to [the researcher] for that because that has happened because of this research programme that she's done. (HP2007)

The research processes highlighted problems and possible solutions that were already held by participants or their communities, as well as identifying some of the champions of change to lead innovations. The research design, especially the processes of the research-action spiral, was identified as a key to generating innovative solutions to tough problems.

Health professional: What it did was actually unleash a whole lot of information that would not be captured if you were just doing a quantitative analysis of something, you wouldn't actually understand the meaning of why these things were like they were. So it was very profound actually. (HP2007)

That the actions prioritised were predominantly system-oriented reflects the reality that there were many aspects of service provision that were inadequate for Maori clients. It may also be that health planners and funders working at a systems level

had the capacity and readiness for change and that the new knowledge provided a sense of direction not necessarily available from within.

*Were plural ways of knowing generated?*

Kaupapa Maori Action Research values Maori knowledge and in this project the articulation and dissemination of these experiences was at the heart of its success.

Patient: I thought it was awesome ... I can see there are a lot of changes going to be taking place ... yes I was quite surprised with some of the uh things that were said inside [the report] there cos I didn't realise how much problems we had you know. (P2006)

Health service providers identified the participation of Maori patients and their families as crucial to service changes.

Health professional: But with patients that's where you get the true perspective, their perspective, and that's the one that you need to work with, that's the one that will make a research project successful, cause it's how they feel and how you can make the difference with them, it's having that buy-in from those patients that makes the big difference. (HP2007)

*Was democracy actioned?*

Although Kaupapa Maori Action Research principles designed to address power imbalances took precedence, democratic processes were utilised within this project. The research was clearly conducted by Maori for Maori and many of the Phase Three participants, Maori and Pakeha articulated this as a success.

Health professional: We already know that it's helping our communities, helping our Maori people, and the result of it is, has been evidence round the service that's now being provided, so this is a really good way of doing research. (HP2007)

The Kaupapa Maori imperative centring Maori concerns worked to ensure that all participants were given a voice through participant feedback processes that kept the groups apart at crucial stages. Maori patients and their families were free to discuss the results openly without fear about the reactions of health service providers, and vice versa. In addition, the results were disseminated to the different groups in forums familiar to them resulting in new knowledge for patients and a sense that their views were being heeded.

Patient: It's only when your report came out and discussions with your report that I found out, no you're not on your own, it's very much a widespread thing sort of situation so in that case yes I do really like the report that you gave out and that's really getting into the professional areas of course like doctors, hospitals. (P2006)

Hearing the stories, understandings and experiences of Maori ischaemic heart disease patients' pathways of care in this 'one step removed' way gave health professionals the space to examine and compare these stories with the results from their sector. The process allowed the interrogation of power to occur so that health professionals were challenged about their assumptions and practices.

Health professional: I think one of the significant things for me was actually hearing the stories about patients' experience of the health services and on the other hand hearing

the providers' stories about how they actually saw the situation with their Maori clients, and just the huge gulf between those two stories, so that has given us a real challenge in terms of improving cultural competency of our providers, it's really the basis for a lot of the work that we're actually doing now. (HP2007)

That changes were instigated by power-holders in response to the data, without the need for activism by the Maori ischaemic heart disease patients and their families, can be seen as another form of democratic action.

#### *Was the project worthwhile?*

Reason and Bradbury's (2006) ultimate question invites us to make an assessment of overall worth of the project. The ischaemic heart disease project provided connections between community, public health managers and policy-makers, leading to system changes that will have long-lasting impacts on the provision of healthcare and Maori community capacity to make changes for health and wellness.

Patient: No I'd just say keep up the good work really ... I think in the long run it will be the greatest thing for you know especially for up here where they're really quite closed I find our people and I think if we can sort of try and just that promotion or health promotion, educating them would be so much easier for them. (P2006)

Health professionals were also clear about the value of the project.

Health professional: I think it was actually a very important piece of work at that point in time and has been pivotal in launching a whole sort of range of different strategies since that time, where it's still got a place in the sun because you know we, at the moment for example we're developing a regional Maori health plan with the district health board, all of the PHOs, the Maori alliance and the MAPO up here which is pretty significant. (HP2007)

The project generated solutions from patients, providers and policy-makers in the health system in response to their new awareness of the needs of Maori patients and their families.

#### **Discussion**

This paper describes an innovative use of indigenous action research to tackle a serious and deep-seated source of health inequity (Braveman and Gruskin 2003). Kaupapa Maori research principles guided and resourced the development and implementation of the research–action–reflection process that contributed to multiple material changes that reduced suffering and stress for Maori with ischaemic heart disease and their *whanau* in Te Tai Tokerau.

Having lived under an imposed colonial system for 160 years, Maori have developed first-hand experience and a good knowledge of medical systems, including how we are perceived within them (Cram *et al.* 2003, Harris *et al.* 2006, Reid and Robson 2007). Other research (McCreanor and Nairn 2002a, 2002b) reveals that health professionals do not appear to have a reciprocal understanding of the Maori world. Our approach allowed Maori experiences to be articulated and developed as a resource to facilitate change. The most significant outcome from the sharing of narrated experience is that health systems have been modified, primarily by health professionals who wield the most power to effect systemic change, allowing Maori

participants to work for change without having to take all the responsibility for creating it.

Achieving improvements primarily in the policies and practices of health service providers helps to entrench them as self-sustaining, making them less vulnerable to the vagaries of professional behaviour, service provider agendas or broader political climate. Once established, they have become part of the service experience of users who are thereby empowered to expect and insist on these new standards of provision. Interventions informed by the project are ongoing, suggesting that the strategy of working at policy and systems level through key provider personnel has generated sustainability of outcomes beyond the end of project.

To our knowledge there are no comparable completed projects on ischaemic heart disease in this country but studies of cancer survival (Hill *et al.* forthcoming) and other conditions (Reid and Robson 2007) suggest that the problems of differing worldviews between patients and service providers identified in this project are general. While it is clear that the changes and developments that occurred in this project are particular to the sites we believe that there are methods and outcomes that should be generalisable to other conditions, locations and settings of health inequity, both locally and internationally. Health practitioners' limited understanding of Maori patients' experiences is unlikely to be limited to practitioners in Te Tai Tokerau or apply only to Maori patients with ischaemic heart disease. The research findings indicate the need to investigate the impact of epistemological difference between health practitioners and their patients across the sector and action research is demonstrated to be a potentially useful tool for moving past investigation towards generating solutions. At the local level, the research indicates that more work is needed to improve cultural competency amongst professionals (Medical Council of New Zealand 2006) and to develop health services that are able to engage more appropriately with Maori in order to improve delivery and outcomes.

Kaupapa Maori Action Research, as practised here, entailed working with stakeholders to gather information and facilitate engagement in order to bring about change; researchers and participants negotiated mutual goals, aspirations and pathways for change and divisions of insider/outsider were less relevant. While such approaches may raise anxieties over the neutrality of data gathering, analysis and interpretation, our professional ethics and the inclusion of an evaluation stage by an evaluation specialist (SK) who was not directly involved in the project, means that we are confident that our presentation of the findings is a fair and balanced account. In addition, the fact that the lead researcher (LP) has been repeatedly invited to present the project to the Ministry of Health and other audiences, along with numerous spontaneous 'updates' from stakeholders speaks to the high regard with which the process and outcomes are regarded in the Tai Tokerau community.

It is important to emphasise that the characteristics and resources available at our sites – particularly the skills, networks and commitment of the participants including the researchers – are vital for the success of such projects. This research has contributed to smoother pathways to care, better access to treatment and more appropriate ongoing care for Maori with ischaemic heart disease in Te Tai Tokerau. These are good outcomes for a small-scale, short-term action research project.

The principal factor limiting the effectiveness of the project was the timeframe that allowed only a single iteration of the research–action–reflection cycle and a six-month 'action phase' that was too short to allow for a focus on patient, family and

individual practitioner change. With more time and resources change at individual level, as well as systems levels may have been evident and measurable. Despite these limitations, the research continues to impact on the provision of services to Maori in Te Tai Tokerau.

Our findings emphasise the potential of action with patients and *whanau*, the health system and individual practitioners, towards improved prevention and management of ischaemic heart disease in the Maori population. Kaupapa Maori Action Research represents a significant tool in opportunities to work with Maori communities toward the goals of health equity supported by recent work on the social determinants of health promoted by the World Health Organization (CSDH 2007). For research funders, the fact that action research eschews set processes and works with the specific dynamics and contexts of communities in the action reflection cycle, may well be regarded as too risky to support. However, in the setting of skilled, connected and well-resourced research teams, the pay-back in terms of sustainable systemic change that makes a real difference to people's lives can be very rewarding. We hope that this report of our project will encourage other research teams and funders to invest in these innovative and constructive approaches to improving population health and well-being.

#### Note

1. Here, Action Research includes variations such as Participatory Research, Participatory Action Research and Community-Based Participatory Research.

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