

# **Whānau Tuatahi: Māori community partnership research using a Kaupapa Māori methodology**

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**Abstract:** Whānau Tuatahi facilitates community–researcher partnerships as a way of giving voice to the concerns whānau have about their health and the aspirations they have for their wellness. This research framework was developed in the context of a Kaupapa Māori research project for the exploration of whānau experiences of tamariki with asthma. Four methods (semi-structured interviews, photovoice, drawings and a structured questionnaire) enabled whānau a variety of flexible ways of engaging with the research project over a 12-month period. The principles of the Whānau Tuatahi research framework that guided its practical implementation included: whakawhirinaki, whakawhanaungatanga, whakamana, ngāwari, utu and hurihuringa. Application of this Kaupapa Māori-based research framework resulted in very positive feedback from whānau. The framework can be used as an effective means of engaging with whānau to inform the health and policy sectors about the lived realities of whānau.

**Keywords:** interpretive phenomenological analysis; Kaupapa Māori methodology; Māori community–researcher partnership; whānau collectives research

## **Introduction**

The Whānau Tuatahi research framework was developed by way of a Māori community–researcher partnership as a medium for whānau voices to be heard and listened to by the health sector. For decades disparities have existed for Māori parents and their tamariki with asthma resulting in higher morbidity and asthma hospitalisations and poorer health outcomes (Crengle, Pink & Pitama, 2007; Ellison-Loschmann, 2004; TMG Associates, 2009). This research framework was developed in the context of, and applied to, a study exploring Māori parents’ experiences managing tamariki with asthma. The design specifically avoided the ‘deficit model’ of researching whānau and testing or checking up on parents’ knowledge (Eketone, 2006). The focus was whānau-centred, seeking to portray parents’ viewpoint within a culturally appropriate paradigm. Explicit within this cultural paradigm was the Māori community’s desire to regain tino rangatiratanga during the research process and direct their own hauora pathway.

The community–researcher partnership with Tu Kotahi Māori Asthma Trust, a Hutt Valley Māori Health Provider, formed a critical aspect of the framework development. With over 10 years of health service delivery, Tu Kotahi was pivotal in advocating for the local Māori community and was able to provide advice based on the holistic needs of the people. We wanted to make space for the realities of Māori parents to be considered valid, and to be both relevant and accountable to the Māori community throughout the research process. It was also our intention to ensure that whānau gained real benefit from their involvement with research and to make the process a culturally safe and satisfying experience for all concerned.

We will outline the Whānau Tuatahi Research Framework in three main sections. The first section provides an overview of the methodology and outline of methods used, including the application of the framework and data analysis. The second section gives an overview of the principles that form the basis of the framework and their relation to Kaupapa Māori. The third

section reports on the utility of the framework for research including: whānau realities; the ability of the framework to inform policy; and its strengths and limitations. These sections are followed by a summary and discussion.

## Methodology

The methodology underpinning this project is Kaupapa Māori. Kaupapa Māori is centred in Māori reality and upholds the mana and integrity of the participants, where the concerns and needs of Māori are the focus (Cram, 2009; Pihama, Cram & Walker, 2002; Pipi, , 2004; L. T. Smith, 1999). Kaupapa Māori was specifically chosen as the preferred methodology in order to avoid the binary trap of Western epistemologies that either challenged the knowledge of parents or whānau, or approached this knowledge from a 'compliance driven medical model framework' (Walker, Eketone & Gibbs, 2006). Key to this methodology is the tailoring of research practices to the needs and aspirations of the participants, and through genuine engagement with the community as a partnership for research i.e. 'by, with, and for' Māori. Kaupapa Māori research (KMR) is guided by a number of principles that include the following (Cram, 2009; L. T. Smith, 1999):

- Aroha ki te tangata (a respect for people)
- Kanohi kitea (the seen face, present yourself face-to- face)
- Titiro, whakarongo ...korero (look, listen ... speak)
- Manaaki ki te tangata (share and host people, be generous)
- Kia tupato (be cautious)
- Kaua e takahia te mana o te tangata (do not trample over the mana of the people)
- Kaua e mahaki (do not flaunt your knowledge).

KMR is concerned with both the methodological developments and the forms of research method utilised. In this sense Kaupapa Māori is described as both a theory and an analysis of the context of research involving Māori, with the approaches to research expressed as being by Maori and/or for Maori (L. T. Smith, 1996). We selected research methods that were compatible with KMR methodology so that the approach employed in the Whānau Tuatahi research did not compromise good science or cultural appropriateness. The methods were chosen to avoid written surveys or lengthy questionnaires; instead they focused on the oral and visual approaches that were consistent with recommendations from our earlier pilot study (Jones & Ingham, 2007). Full details of the study design including recruitment and methods have been published elsewhere (Jones, Ingham, Dean, Davies & Cram, In Press). In summary these were:

- Semi-structured whānau interviews,
- Photovoice and drawings, and
- Structured questionnaire as an interview framework

The use of these methods allowed us to capture a broader, in-depth range of whānau experiences than would have been possible from a single method. It has been acknowledged that "helping children to express themselves in a variety of complementary and congruent ways is valuable" (Darbyshire, MacDougall & Schiller, 2005), and also allows children to remain engaged with the research process. Triangulation of research methods (as part of a multiple triangulation process that examined both consistencies and contradictions) was used to improve validity of data and to reduce bias (Dootson, 1995; Mitchell, 1986).

For the semi-structured interviews we drew upon two theoretical frameworks, underpinned by KMR, to inform the development of the interview schedule: The Illness Perception Model, and the International Classification of Functioning, Health and Disability (ICF). The Illness

Perception Model concerns patients' beliefs about their health condition, its treatment, and how these beliefs can help us to understand factors affecting whether patients adopt recommended treatment (Horne & Weinman, 1999). This model has been extended to include patients' beliefs about their medication including a focus on asthma medication (Moss-Morris et al., 2002). The ICF model was synergistic with the Kaupapa Māori methodology in that it not only identifies health care and rehabilitative needs, but also identifies and measures the effect of the physical, social and environmental factors on the disadvantages that people experience in their lives (WHO, 2002).

## **Application**

The essence of the Whānau Tuatahi framework is the way in which this range of qualitative methods is utilised within a Kaupapa Māori methodology to privilege the role, view, and experiences of whānau. In practice this framework allows whānau to control the research process and interpretation of results to ensure the most accurate representation of their stories, and the issues they face. Using the metaphor of a toolbox, the framework aimed to make these 'tools' available for whānau to choose which one(s) they preferred, and how to use them best to express themselves. This section is a description of the practical application of Whānau Tuatahi as we applied it during the Pukapuka Hauora (Healthy Lungs) project.

### ***Semi-structured whānau interviews***

The semi-structured whānau interviews comprised four in-depth, face-to-face interviews (kanohi ki te kanohi), following whānau at 3-monthly intervals over a 12-month period. These repeated visits were seen as essential to whakawhanaungatanga or building a relationship based on connectedness that allowed for a richer sharing of information. It also permitted the interviews to include any seasonal variations of asthma. Parents were able to select who was present at the interview, with some preferring to be interviewed alone, others preferring whānau members to be present. Depending on what was appropriate for the whānau, these interviews included the child or were in the form of a whānau focus group. Provision had been made for interviews to be conducted in either English or the Māori language; however, participants predominantly used English with key words in the Māori language interspersed.

By way of an opening, the first interview focused on parents' experiences and their perceptions of asthma management with subsequent interviews focusing on issues affecting whānau. At each subsequent interview the researcher would recap for whānau the main topics that had been covered previously, including our interpretations of these experiences. This re-iterative approach allowed whānau to reinterpret or refocus our interpretations, and ensured that on-going data collection was meaningful, and truly reflected whānau voices.

### ***Photovoice and drawings***

Whānau were offered a disposable camera to capture visually what was important to them in terms of the managing asthma. These photographs were then able to serve as direct visual representations of aspects of asthma management but also to further elicit conversation about asthma. This use of photos, also known as Photovoice (Wang & Burris, 1997), has been used previously in other indigenous peoples (Castleden & Garvin, 2008), and is a method suitable for exploring chronic disease management (Aubeeluck & Buchanan, 2006; Drew, Duncan & Sawyer, 2010). Tamariki and their parent/whānau member were given the opportunity to draw a picture of their lungs and to indicate using the picture how asthma affects them. These drawings provided a fun educational way of involving children in the research, while at the same time allowing another avenue for both children and parents to raise questions and learn together.

### **Structured questionnaire as a qualitative interview tool**

Whānau were invited to participate in an interviewer-administered survey questionnaire in which the survey interview was used as an elicitation mechanism to promote interaction and discussion. Whānau were encouraged to elaborate or explain their answer and to contextualise their responses with personal experiences and stories. The survey contained a number of standardised questions from nationally and internationally validated instruments regarding asthma symptoms (e.g., medication use, triggers, smoking, lifestyle and environmental factors), along with a number of socioeconomic indices (including an individualised indicator of deprivation – the NZiDep score) (Salmond, King, Crampton & Waldegrave, 2005). Used alongside KMR, whānau reported that they found this survey process both useful as a prompt for further discussion and informative.

### **Analysis**

Interpretive Phenomenology Analysis (IPA) was used to complement the KMR methodology and allowed us to analyse the experiences of Māori parents managing asthma. IPA is an integrative approach (J. A. Smith, 1996) with an idiographic focus that aims to offer insights into how a person, in a given context, interprets a phenomenon or event. It allows the researcher to develop an analytical interpretation of a participant's account, which is grounded in (but may go beyond) the participant's own sense-making (J. A. Smith, Flowers & Larkin, 2009). The IPA analysis process can be described as an iterative, layered approach that uses a number of different levels; descriptive or content analysis, and a re-iterative process involving discussion and interpretation and the development of themes. IPA acknowledges the researcher's involvement in this analytical process, through which the researcher tries to make sense of the participant who in turn is trying to explain their own experiences (J. A. Smith et al., 2009).

IPA acknowledges the importance of the social and cultural context of the participants and demands that analysis pays attention to these contexts (J. A. Smith et al., 2009). In this study, a unified traditional Māori worldview (Te Ao Māori) formed the social and cultural context. 'Te Whare Tapa Wha' (Durie, 1994) which incorporates four fundamental elements of health: Te Taha Hinengaro (psychological), Te Taha Wairua (spiritual), Te Taha Tinana (physical) and Te Taha Whānau (family), was used as the analytical framework within which this cultural context was analysed.

To our knowledge IPA as a method has not previously been used with Māori; hence its application here was innovative. Phenomenology, however, (on which IPA is based) has been used successfully with other indigenous peoples in the USA and Canada (Struthers & Peden-McAlpine, 2005). In that study, phenomenology was found to be compatible because of its synergies with holistic indigenous cultural values. As a research method it was found to elicit significant implicit meaning of indigenous culture and assisted with recording the essence of experiences of indigenous societies (Struthers & Peden-McAlpine, 2005).

### **Kaupapa Māori analysis: whānau tuatahi research framework**

It is generally accepted that a Kaupapa Māori approach is inclusive of a range of methods; however, those methods need to be firstly interrogated for their cultural relevance and appropriateness with respect to researching with Māori (Cram, Smith & Johnstone, 2003). KMR provided the basis from which our research operated; it also established the framework behind decision making which occurred as an iterative process for the duration of the project where the Whānau Tuatahi framework was first tested and developed. Overall, the use of the selected methods, interrogated by Kaupapa Māori, resulted in culturally acceptable and useful outcomes for the Māori community and aligned well with KMR principles that formed the framework for this research. This was not only the view of the investigators but also verified by independent feedback from the Māori Health Provider (Tu Kotahi Māori Asthma Trust)

and whānau involved. Our design was premised on ‘Whānau Tuatahi’ (whānau first) which focused on the diverse needs of whānau as individuals, families, whānau and kaupapa whānau. This required flexibility for all aspects of the study while maintaining integrity in the process in order to produce high quality research.

The Whānau Tuatahi framework is a mechanism for the practical adaptation and application of Westernised research methods within a Kaupapa Māori methodology. This translational framework was shaped by the following concepts: whakawhirinaki (trust), whakawhanaungatanga (building relationships), whakamana (empowerment), ngāwari (flexibility), utu (reciprocity), and hurihuringa (reflexivity). Below we illustrate how the initial KMR principles (Cram, 2009; L. T. Smith, 1999) both informed and were expanded upon as a result of the present study these concepts governed how we applied the methods, and how they relate to the principles underpinning Kaupapa Māori. This is followed by whānau feedback on various aspects of the research framework.

### ***Whakawhirinaki: trust***

Our Māori-led research team had a responsibility to establish a connection with the community and to prove to whānau that we were trustworthy and reliable. Our first step was to mihi to a local Māori Health Provider that not only had a proven track record in providing asthma services to Māori, but also had a trusted relationship with the Māori community they served for over ten years. We began by using the KMR principle ‘he kanohi ki te kanohi’ (face to face) on numerous occasions where we learnt about the kaupapa of this organisation and the tikanga of the diverse community they served.

We involved kuia and kaumatua from Kokiri marae to ensure that our research process had integrity and that it would fit with the beliefs and values of the local people while at the same time benefit their community. For us this translated into establishing a trusted partnership with the Māori community through Tu Kotahi Māori Asthma Trust who articulated the needs of the local community and their aspirations for this research. Part of our relationship building involved accompanying Tu Kotahi asthma nurses on their home visits in order to gain first-hand knowledge and experience of the community, and kawa prior to the study commencing. This is a diverse community made up of whānau from multiple iwi therefore within this modern urban environment it is the families themselves that decide what aspects of tikanga they want to revive and adapt to the conditions of today (Mead, 2003). ‘Kia tupato’ (be cautious), was a principle that could not be stressed enough for us as researchers coming into the community. We needed to understand and duplicate the approach Tu Kotahi staff used for first contact and then to whakawhanaungatanga with whānau. Important aspects of Tu Kotahi’s preferred approach were incorporated into the design of our recruitment strategies, methods and interviewer training. These formed a critical part of the successful recruitment, retention and involvement of the community.

An aspect of building trust with whānau, later revealed by parents, was not only ‘he kanohi ki te kanohi’ but more so the principle of ‘he kanohi kitea’ (the seen face). This was about the researcher genuinely engaging with the lives of whānau and showing interest in repeatedly coming back. Parents became familiar with the face of the interviewer who came back every season and they in turn were able to share in-depth thoughts and aspirations concerning their unique asthma journey. It was only after researchers displayed ‘Aroha ki te Tangata’ (respect for the people) that Tu Kotahi staff trusted us to uphold the mana of their people that they introduced and recommended the interviewer to the community.

### ***Whakawhanaungatanga: building relationships***

Whakawhanaungatanga was seen as a key concept permitting a relationship built on mutual trust between the participant and the researcher and played a key role in the success of collecting in-depth, longitudinal data from whānau. Whakawhanaungatanga began at our first

visit and was woven throughout all four successive engagements with whānau. This sometimes involved multiple phone calls or follow-up visits to fit in with the busy lives of parents. Visiting during the different seasons allowed the capture of real-time experiences of whānau managing asthma but more importantly it provided the space for whānau to connect culturally and build a trusted relationship with the researcher. In some situations it was not until the final interview that parents felt comfortable to share personal fears and aspirations with the interviewer. For us, 'Titiro, Whakarongo... Kōrero' (look, listen, then speak), listening to parents, tamariki and whānau and understanding their perspective was crucial to this process. Slowly the stories would unfold, the fun times and the painful experiences, and there were times when words were not enough and it was the shared silences that conveyed the burden parents and whānau experienced from this chronic condition.

From our 'outsider' position we needed to prove we were not only understanding of individual situations and inclusive of all whānau members, but also able to maintain confidentiality and be respectful of the kawa of each individual whānau (Moewaka Barnes, 2000). This approach resulted in an in-depth sharing of personal information that almost certainly would otherwise not have occurred. Our methods permitted us to use the real-life experiences of whānau who in turn were making sense of these events and framing them in their own time and in their own words. Digitally taping all interviews allowed the researcher to engage with whānau in a more natural and meaningful manner which meant the conversation flowed and participants were more relaxed. The use of open-ended questions was more acceptable to whānau who preferred to kōrero and ask questions themselves. When asked was there anything they liked best about the research process one parent responded with

*...probably just chatting you know ... it's not just questions, it's more just the conversation. ... I thought you'd be writing the whole time and it's not like that at all... I think its better that you have that tape recorder than writing and [talking] kept the flow going which is better so you can just talk constantly rather than waiting and stopping. (Whānau A)*

### **Whakamana: empowerment**

The principle of 'tino rangatiratanga' (self determination), in terms of control and ultimately empowerment, was an important consideration in designing the methods for this research. Whānau needed to have control over decisions such as who was at the interviews and what aspects of the research they would like to be involved with. As part of being recognised as active-agents, whānau were able to select and use the method(s) that enabled them to express themselves, and to choose issues that were important to their asthma management (e.g. a damp house was the priority for some). Some whānau found using a camera as part of the Photovoice additional work and preferred to contribute their kōrero instead. For some parents Photovoice was useful as a prompt during interviews and for others it was a way of building whakawhanaungatanga and for the interviewer to be introduced to their whānau. The exercise where tamariki and parents were asked to draw a picture of their lungs was generally received well and served to not only as entertained and involvement of tamariki, but also as stimulation to further discussion.

*Oh I think it's been awesome and even my kids when they did those...the lungs [drawings] they said that was awesome! (Whānau B)*

*The camera was a great idea, so no I can't think of anything that I would want to change. (Whānau C)*

*Yeah, I think that floor exercise you did with the drawings – I thought that was great. (Whānau D)*

'Kaua e Takahia te Mana o te Tangata' (Do not trample the mana of the people). This principle was concerned with upholding the mana of the people by ensuring that issues of benefit and accountability were addressed and applied by researchers within the cultural context of each of the whānau (Bishop, 1998). This was not only about showing respect for

the opinions and thoughts of all those involved in the research but also validating and acknowledging their respected position as parents, whānau and members within the community. At each successive interview we would feed back our interpretation of the previous interview ensuring we had correctly understood the important messages whānau were entrusting us with.

The IPA method allowed Māori cultural values and beliefs to be the predominant mediating force in determining the analysis process and results. In practice this required negotiating the Western view of medicine to accommodate the priorities of Te Ao Māori (e.g. not taking prescribed Western medication was viewed through a Māori holistic lens). This alternate viewpoint appreciated that other factors (e.g., not being able to afford prescriptions, concerns about side-effects of drugs) could be impacting on taking medication rather than the narrow, judgmental view of being 'non-compliant'. The IPA process involved the PI (a Māori researcher) being immersed in the data and becoming closely involved with the participants' lived experiences; in this way the analysis emerged as a participant-researcher collaborative effort. This was in keeping with KMR principles of 'tino rangatiratanga' allowing whānau to control the direction of the analysis with the researcher continually feeding back interpretations from previous interviews.

We started from the view that parents know their children best and we explored what was going well with their asthma management – the assumption being that parents were managing aspects of the disease well. We aimed to highlight and build on those successes, as opposed to focusing on what parents didn't know, or were not managing well (a deficit-model). By understanding whānau experiences and highlighting successful asthma management we were then able to explore aspects of asthma that parents found challenging, reasons for this, and then look for useful ways that these could be addressed. This approach fitted well with KMR as it incorporates 'mana-enhancing' enquiry, and is consistent with Māori models of health (e.g. Whare Tapa Wha) which include whānau as a locus of control.

Whānau were given an opportunity to speak freely about how they would like to change the way asthma services were delivered to suit them and what could be done to change the way doctors engaged with Māori. For some this was a novel experience as they had never considered their views could contribute to designing such services. There were parents who knew exactly what they would like to communicate to health professionals about changes that were needed in order to provide culturally acceptable services and improve the way health professionals treated Māori. 'Whānau as researchers' was a concept that evolved through this process. By making sense of their own experiences, whānau gained confidence in discussing asthma and were empowered to share their experiences and knowledge, with their friends and family. A parent explained:

*I've found it quite a good experience doing the study because what I talk with you about today, will become topical conversation with someone else tomorrow. (Whānau E)*

Moving beyond what Cram describes as 'procedural' empowerment, where the research process is culturally safe and participants' voices are heard, the focus of the research also needed to be on outcomes that could influence policy or improve services that would reduce inequalities for Māori (Cram, 1997). The stories and suggestions from whānau needed to be translated into changes in the health system, particularly in the way asthma services are currently delivered for tamariki and whānau. Experiences and messages from parents have already been used to inform the undergraduate curriculum for medical students in order to improve the way future doctors engage with Māori. One parent commented:

*You know you would've empowered a lot of parents in this to make a change in the health system which would be good. (Whānau F)*

### **Ngāwari: flexibility**

In order to actively promote ‘tino rangatiratanga’ the method necessitated a high degree of flexibility not only in the design structure, but also on the part of the researchers. The semi-structured questions and phenomenological method allowed parents to control their own pathway during the interviews. In conducting the interviews this was about allowing participants to define their own space and to meet on their own terms. Parents chose where and when we visited them either in their homes, the homes of their extended whānau, their workplace or the local marae. We needed to be mindful of the diversity of whānau and respectful of tikanga practices in each and every home so that each family was treated without assumptions or expectations in regard to others.

In practical terms, whānau chose the time, place and duration of the interviews. It was the interviewer’s responsibility to fit in with the busy lives of these participants. Whānau also chose who would be interviewed, defining themselves based on their own criteria of who was relevant, appropriate or who contributed to the asthma management of the child. Some parents preferred to kōrero one-on-one without tamariki or whānau present, others were happy to have aunts, uncles, tipuna and tamariki present, and all were welcome to contribute to the research.

*I found it much easier actually, you coming in and doing it all rather than me having to find a sitter and get a car to come to you ...It was just much easier and you could see for yourself you know, when you met the kids and seeing the kids ...how well they do. (Whānau G)*

### **Utu: reciprocity**

This was an extremely important aspect of the research, and one which we had to ensure was incorporated into our protocols and way of conducting ourselves. In inviting us into their homes and sharing their stories with us, whānau were giving us a taonga (gift). We therefore owed it to them to reciprocate this gift in kind. To show respect and gratitude to all those who generously contributed to our project, we focused on putting the needs of the whānau first and tried to find small ways of returning benefits to those involved along the research journey. ‘Manaaki ki te tangata’ (share and host people, be generous). In practice this was expressed, not only through koha at the time of the visit, but through the offering of information and referrals, and acting as whānau advocates if needed. This involved stepping outside our researcher role with permission from whānau, in order to ensure pressing health, or associated issues were dealt with in a timely manner. We also took responsibility for updating and informing Tu Kotahi staff as well as all the community about the research progress and what would be happening at the next stages of it.

‘Kia Ngākau Māhaki’ (be humble in your approach). This is about not flaunting your knowledge but using your qualifications and sharing your knowledge to benefit the community (Pipi et al., 2004). For us as researchers in practical terms this was about waiting to be invited to share our knowledge of asthma, research and health and only after listening to parents and tamariki and trying to provide answers when they were requested. It was up to us to ask the right questions and let parents and whānau lead us along the path they chose to share with us. It was also about us learning from whānau and then in turn (with permission) sharing their experiences in such a way that anonymity was maintained and knowledge was passed along to others in similar circumstances. We were able to offer a secondary source of providing health information to a population that had previously not been able to access research materials. Reciprocal benefits were not always visible to us as researchers but were revealed by parents at the end of the interviews:

*[It’s been] really good, it’s helped me talk to my family ... a bit more about asthma. (Whānau H)*



*I enjoyed the knowledge that you have and what you've passed onto to us. You mightn't have realised it but when you say something to me... I think, 'Oh yes, I must get home and I might look at that'. Just little things that you've told me that other families might've done, other families may have mentioned. (Whānau I)*

### **Hurihuringa: reflexivity**

We needed to constantly evaluate our protocols to ensure that our processes were culturally appropriate and effective. We aspired to leave all those who came in contact with this project better off for their involvement and enriched by their contribution to the research (Mead, 2003). This reflexivity was an iterative process where we reflected on results at each stage of the research as a method of ensuring 'we got it right' and that our interpretations would represent the community in the most accurate and best possible way. 'Kia Tupato' (be cautious), warns us as researchers to be aware of the impact of our processes (Pipi et al., 2004) and if necessary, to revise our approach in consultation with the community.

Along with staff from Tu Kotahi who advised on local tikanga and appropriate ways of conducting research within this Māori community, our team included a senior Māori qualitative researcher with extensive expertise in similar community projects. This senior mentor role demanded ongoing reflexivity from the researchers and provided expertise in cultural safety. Safety measures were setup to enable interviewers to access support for whānau/tamariki who needed assistance outside the scope of the researcher. Community health workers and asthma nurses were able to provide assistance on several occasions either at the suggestion of the interviewer or at the request of parents.

### **Potential utility for the framework**

This section explores two components; the utility of the framework with respect to use with other whānau and the potential of the framework to inform policy.

#### **Utility with whānau**

There are potentially multiple situations where this framework could be used in research with whānau. We have outlined its use in collection of longitudinal data for asthma but it has the potential to transfer its use to other chronic diseases such as diabetes and heart disease. It could also incorporate other qualitative designs including a single or multiple case study design and is capable of being adapted as a template for the collection of quantitative data. While the application of Whanau Tuatahi was limited to an urban Māori community, due to its flexible nature the framework is also likely to be equally successful when applied in a rural setting. We sought feedback from participants during and at the completion of the project. This feedback told us they enjoyed being part of this research and liked the way it was conducted. They were comfortable about the recruitment process and spoke freely when asked the open-ended questions:

*I came into it not knowing what to expect. I've enjoyed talking about my experiences. (Whānau K)*

*Yeah it's been awesome...yes, yes, I thought it was awesome because it was easy to understand, listen and talk. (Whānau L)*

Additionally, some found this framework affirming for them as a parent:

*It's been great doing this and learning about what other parents have gone through too, which is good. ...it's learning that you are a good parent and you've done everything that you need to do for your children, you've done the best that you can and you've done good things and yes it's a good study. It's a good study. (Whānau M)*

In applying this framework participants were asked to describe their experience with it, what they liked, what they didn't like and if there was anything that could have been improved:

*No. Everything about it has been good. It's been good to actually go through everything ... I could ask the questions that I've been wanting to ask, and get some answers, yeah... the whole interview's been good. (Whānau N)*

With regard to the structured survey questionnaire and how whānau viewed this one parent stated:

*They [questions] are good 'cause that's another way of learning too, you ...think about the questions and you will relate straight to your child that has the asthma so that would be a good thing. (Whānau O)*

A parent commented she would have liked her tamariki to be more involved in the research as they were at school during some of the visits and she felt that when they were present they benefitted from hearing the discussions. For some it was seen as an educational opportunity and there was a suggestion that more activities similar to the lung drawings would be good for tamariki as a learning exercise. None of the whānau identified situations where the framework might not be able to be used. Recommendations from some parents for researchers to contact other whānau members or friends were a good indication that whānau liked this research framework. Independent, positive feedback was given to staff at Tu Kotahi Asthma Trust confirming whānau satisfaction with the usefulness of this framework.

### **Potential to inform policy**

This framework provided a genuine perspective of whānau experiences through the collection of real-life longitudinal data and is particularly appropriate for use with chronic conditions. It adds to the body of knowledge that supports research in partnership with Māori communities as opposed to academically-isolated research. It dispenses with the notion that Māori whānau dislike or don't want to be part of research and demands a Te Ao Māori holistic worldview that respects and benefits whānau and the Māori community. This method has the potential to inform policy about *the how, when and with whom* whānau want research to be conducted and more importantly *the why* they want to be part of research.

*Oh it's been great. You know, it's been good to air ...what's happened to me over the years and ... to know that it's going to be put to good use to create, well hopefully, create doctors that are a lot more community friendly and whānau friendly. (Whānau J)*

Results from this project have already been used to currently inform the University of Otago Wellington's Hauora Māori undergraduate curriculum for medical students. In our position as researchers/ lecturers we were able to act as mediators between whānau and medical students and facilitate the voices of he tangata (the people) to be heard by the future doctors responsible for the health and well-being of this population. This was a direct translation of 'research to practice' enabling whānau to provide feedback to doctors in an effort to effect change in the way doctors engage with Māori patients and provide more culturally appropriate health services.

### **Strengths of the framework**

- Enriched data sources that were mutually beneficial. Interviews were reciprocal; that is, shared learning occurred between researchers and whānau in some cases this meant having answers to questions lead to better asthma outcomes;
- The framework empowered whānau to have confidence in their own management styles. The design allowed for participants to inform us of what and who was important to them in the management of asthma, while enabling us to collect the parent/whānau perspective on factors affecting their tamariki's health;

- Initiated and driven by Māori community, met needs identified by them;
- Flexible and acknowledged diversity of whānau in an urban setting.

#### **Limitations of the framework**

- Researchers need expertise in multiple research methods along with at minimum a basic understanding of the Māori language;
- Resource intensive, expensive and time-consuming;
- Required a trained health professionals experienced with asthma and families;
- Dependent on being able to develop a relationship with a local Māori Health provider;
- The home-based interview method was not seen as advisable where the safety of the researcher could not be assured (e.g. whānau who resided within gangs);
- Interviewing in the home can sometimes prevent participants from discussing certain information if their tamariki or whānau are present.

### **Summary and Discussion**

We found that using this selection of qualitative methods, interrogated under the principles of Kaupapa Māori Research, was a highly successful approach to researching with whānau. Our model of research permitted flexibility and change so we were able to adapt to suit the Māori community involved. This contributed to participant retention rates of 100 per cent for the duration of this project. These methods were able to capture the diversity unique to this Māori population and to embrace the cultural aspects that were a part of each whānau. This design was able to be critiqued by international research standards while at the same time maintaining the core principles of KMR. Being guided in this process by KMR, and then reflecting upon how these principles might be tailored as a result of our learning, was an important exercise for establishing the kaupapa of this research.

The successful application of these methods was dependant on having a Māori research team working alongside community Māori health workers. Researchers had combined medical and nursing skills as well as research expertise, while the Māori health workers had expertise in community asthma management, and were liked and respected by the people they served. Additional non-Māori expertise was sought for input into specialised qualitative methods (IPA and Photovoice). Reflexivity from senior Māori researchers combined with feedback from the community kept the research safe and relevant for all those involved. On reflection there was a combination of interviewer skills that were seen to contribute to the successful engagement with whānau, including: a Te Ao Māori worldview; training in tikanga, and the use of basic Māori language; a health background; experience parenting a child with a chronic illness. These all contributed to a basis of 'shared experiences' that resulted in parents and whānau feeling more open to discuss issues:

*I feel really comfortable sharing this with you because if it were anybody else I'd probably have difficulty answering. Could be the same question but I could have difficulty answering because you can relate to what I'm saying and that makes it less stressful on me having to explain. (Whānau P)*

The key element of this project however, was establishing a mutually beneficial partnership with a community-based Māori Health Provider (Tu Kotahi Māori Asthma Trust). The partnership had significant benefits throughout all phases (from design, to the application, analysis and dissemination) and meant our journey through the research was mediated by an existing organisation that provided support and advice for both researchers and community participants. This empowered the community to direct the research process which in turn was a crucial component of our Whānau Tuatahi framework.

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