

shaping health



Exchanging on social power in health

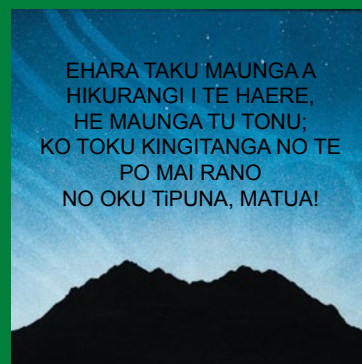
Learning from international experience
on approaches to community power,
participation and decision-making in health

Case Study: Ngāti Porou Hauora, New Zealand

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Cover photo: Mount Hikurangi © Cole Kahaki 2016 (used with permission). Photographs used throughout this report are not directly connected to quotes or discussion on the same page unless specified. Permissions obtained by the authors of all photos that are not open access. Translation of quote: *My mountain Hikurangi does not move. It remains steadfast; my authority comes from beyond, from my ancestors.* The people of Ngāti Porou have a long, proud history of maintaining their own sovereignty. From the foundations laid by their ancestors through to their new 21st century Post Settlement Governance Entity, whether fighting in wars or leading in peace, Ngāti Porou have constantly sought to maintain their own form of leadership based on their values and traditions, while maintaining strong relationships with the outside world.

Ethics: This work has been conducted in compliance with the New Zealand Health and Disability Ethics Committees Standard Operating Procedures and also with the Ngāti Porou Hauora Board's Research Policy. The approach taken is consistent with that of minimal-risk observational studies and does not require a HDEC's approval. All participants signed informed consent forms. Specific consent forms were signed for voice recordings and images.

This case study was prepared by: Lead: Prof Don Matheson; Research Assistant: Kate Matheson. Local Steering Group: Lois McCarthy-Robinson, NPH Board Member. Rose Kahaki, NPH CEO. Frances King, NPH Mental Health and Gisborne Services Manager and Dr Jennie Harré Hindmarsh, NPH Research Co-ordinator. The key informant sources were Ngāti Porou Hauora (NPH) board members; NPH management staff; NPH clinical staff; Ngāti Porou Hauora Kaiawhina; NPH community members and NPH support staff. Names withheld consistent with confidentiality agreement.

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Executive Summary

This case study reports on the experience of community participation in Ngāti Porou Hauora, an indigenous health service provider on the East Coast of the North Island of New Zealand. The case study was implemented within the Shaping Health project led by Training and Research Support Centre (TARSC) with support from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America. The case study used mixed methods: a document review, interviews with key informants, photographs and voice recordings and existing quantitative and qualitative national data sources.

Ngāti Porou Hauora (NPH) provides primary healthcare and a rural hospital service to 10,000 people, spread between an urban clinic and six rural clinics situated along 200km of rural coastline. All people resident in the area can access the health service, the majority of whom are of Ngāti Porou descent. The people resident in the area have a higher level of material deprivation and poorer health status compared to the rest of the population of New Zealand.

The concept of participation held by NPH is shaped by the tribe's history and cultural beliefs. From the time of first settlement, independence and unity have been strongly held values. This was further reinforced following European settlement, when Ngāti Porou, alongside other New Zealand tribes, entered into a treaty with the British Crown. The Treaty of Waitangi of 1840 reinforced this deeply held sense of independence, and to this day it defines how Māori as a people view their relationship with the state, including the provision of health services. Participation is not primarily seen through utilitarian eyes, where motivation comes from its potential to improve programme effectiveness. It is seen as a fundamental right and entitlement.

Ngāti Porou do not see themselves as mere recipients of state provided health services, in which they are claiming the right to participate. Rather, they see themselves as in control of their own destiny. 'No decision about me without me' could imply subservience in the relationship between service provision and the community - this does not reflect NPH's view. Rather, they are pursuing their own destiny, and the onus is on the external party (such as the state) to participate as an equal partner in their processes or journey.

There are features in the structural arrangements of the New Zealand health system that have influenced NPH in the development of its health service. Specific government health strategies on primary healthcare and Māori health at the beginning of this century strongly emphasised the importance of community participation. New organisations were formed enabling NPH to become a primary health organisation, one of 36 nationally, with a focus on primary healthcare and population health.

NPH sees participation as a two-way process. The health service actively participates in the life of the local community, and this is seen as inseparable from communities participating in the health services. Health workers live within the community they serve and are personally involved in community events. This interplay between the health service and the community is seen in the way health workers, such as *Kaiawhina* (community health workers), operate. They are active in community activities, many of which would not usually come under a health mandate. Across the workforce there is a high level of local participation, with the majority of staff recruited from within the local community. Families and close relatives of health workers make up the bulk of the patients.

NPH contributes significantly to the local economy directly by providing employment, and this in turn supports wider economic activity in an area where there are few local economic opportunities to earn incomes.

The organisation faces considerable challenges. The high level of health need is not adequately reflected in the level of resourcing available. While it is understood nationally that the population being served is poorer and more geographically isolated than most other communities in the country, this is not then reflected in national funding arrangements. Also its relationship with the District Health Board (DHB) responsible for the area has also been tense. The DHB itself has been running a deficit for a number of years and reduced its financial support for NPH as a mechanism to address its own financial

problems. In addition, the finances NPH receives are tied to specific activities, limiting the ability of the organisation to tailor services to meet local needs, thus weakening the confidence the local communities have in NPH. Furthermore NPH has difficulty attracting and retaining skilled health workers, a challenge experienced worldwide in such communities. This combination of issues has challenged the practice of community participation in recent years.

Even in the presence of these challenges, NPH has been able to provide a level of service coverage for its population above that of many other PHOs in New Zealand. It has also demonstrated an ability to develop innovative practices such as the use of sleeping baskets for babies, mobilisation of communities in preventive programmes to combat non-communicable diseases, and development of protocols accepted by the community related to genomic research and bio-banking. This latter initiative has then informed national guidelines on this topic.

The key lesson from this case study is that participation can be sustained when it is embedded in the existing cultural practices and belief systems already held by the community. Exploring and understanding the specific cultural and historical context and designing participation from that basis are likely to build stronger participatory models than when participation arises primarily from a functional need of the health service.

The second lesson is in the two-way nature of the participatory process. Health service participation in the community is recognised as integral to community participation in health. The various methods by which this interplay occurs in NPH have relevance to other sites, such as the bias towards recruitment of local community members as staff for the service and a broad concept of what health work involves. A key comment made by NPH staff is that community members are more likely to speak their minds when on their own ground, rather than when they interact within the health service. Having staff members engaged in community events means the service is more likely to hear community views and opinions.

The establishment of the 'economic value' that the service adds to the community is another approach that other sites could consider. In communities such as this, health services not only are having a direct impact on health, but are also influencing the wider determinants of health in their impact on the economy and local employment opportunities.

Finally, this case study also illustrates the influence of national health policies and structures and how these are not always translated into lower levels of the system. At the national level, New Zealand developed a strategic approach to health that was favourable to community participation and addressing health inequities, which provided opportunities for services such as NPH to flourish. However, over time the national focus has wavered, and the meso-level structures such as district health boards, when faced with their own financial pressures, have not been able to sustain this policy direction. The lesson here is to ensure both national and meso-level incentives stay aligned and focused on these important outcomes over an extended period of time to allow community participatory approaches to develop.

1. Introduction

The focus of the case study is to describe the origins and current status of the Ngāti Porou Hauora (NPH) model of community ownership and control and the opportunities and challenges that it presents in the delivery of health services. It also explores NPH's engagement with other sectors relevant to improving health.

The case study draws from a shared framework developed in the Shaping Health project. It uses the concept of social participation, which may include (but is not restricted to) participation in:

- health literacy and health information
- identifying and assessing health needs and priorities
- health planning and budgeting
- health policy deliberation
- designing, implementing and co-ordinating health action
- oversight, monitoring, evaluation and review of health services/actions
- direct or indirect resourcing of health services
- health research.

In the NPH context, the main 'actors' within the health system are:

- Community leaders, Pakeke/Koroua and Kuia (elders)
- The communities where health centres are sited: Te Araroa, Tikitiki, Ruatoria, Tawhiti, Tokomaru Bay, Uawa (Tolaga Bay) and Puhi Kaiti (Gisborne city)
- NPH board members
- Te Runanganui o Ngāti Porou (TRONPnui) (Tribal Authority)
- NPH CEO and managers
- Medical and nursing staff
- Other staff members, including community health workers (*kaiawhina*)
- District health board, its CEO and purchasing branch
- Gisborne hospital and tertiary referral hospitals and their personnel
- Ministry of Health.

1.1 Case study objectives

The case study objectives are to describe:

- How social participation is organised in NPH
- The key health challenges that NPH faces
- NPH's response to the key health challenges
- The perceived and reported outcomes that NPH has achieved
- The extent that social participation has influenced NPH and reported outcomes
- The features that support or block social participation by affected communities
- NPH's approach to the features that support or block social participation
- To share the practices that may be adapted/adopted in other settings and the insights/ learning from the NPH.

The case study was implemented within the Shaping Health project led by Training and Research Support Centre (TARSC) entitled 'Learning from international experience on approaches to community power, participation and decision-making in health' that includes five sites in the USA and case studies in twelve sites in twelve selected high-, middle- and low-income countries, with support from the Robert Wood Johnson Foundation Global Ideas Fund at CAF America.

1.2 Case study design and methods

The case study used mixed methods: a document review, interviews with key informants, photographs and voice recordings and existing quantitative and qualitative national data sources. This work has been conducted in compliance with the New Zealand Health and Disability Ethics Committees Standard Operating Procedures (Health and Disability Ethics Committees, 2014) and also with the Ngāti Porou Hauora Board's Research Policy.

The documents were mainly in working papers or unpublished documents, identified and sourced from NPH senior staff and board members, as well as identified through interviews. Relevant national policy documents were sourced from the [Ministry of Health website](#), as well as publications known to the lead researcher on primary healthcare and the New Zealand health system.

A series of questions were developed from the case study objectives and these were harmonised across the different study sites. These formed the basis of a semi-structured interview with participants. Written notes on the interview responses and, on occasion, audio and photographs were taken.

Interviewees were chosen in discussion with the steering group, with interviewees invited to a half hour face-to-face interview with the researchers. Interviewees were sought from the board, management, clinical staff, non-clinical staff, and community members. A total of fifteen interviews were conducted.

The notes were entered into INvivo software and coded into responses to the interview questions, as well as additional grouping of ideas and themes that emerged from the interviews. These were then used as the basis of this report. The researchers produced an initial draft, which was reviewed by the NPH steering group. Changes were made, and the NPH Board gave its approval for external review. Further reviews were then undertaken by a New Zealand reviewer with expertise in community participation in health in New Zealand, by TARSC personnel and an external reviewer. The final draft took the reviewers' comments into account.

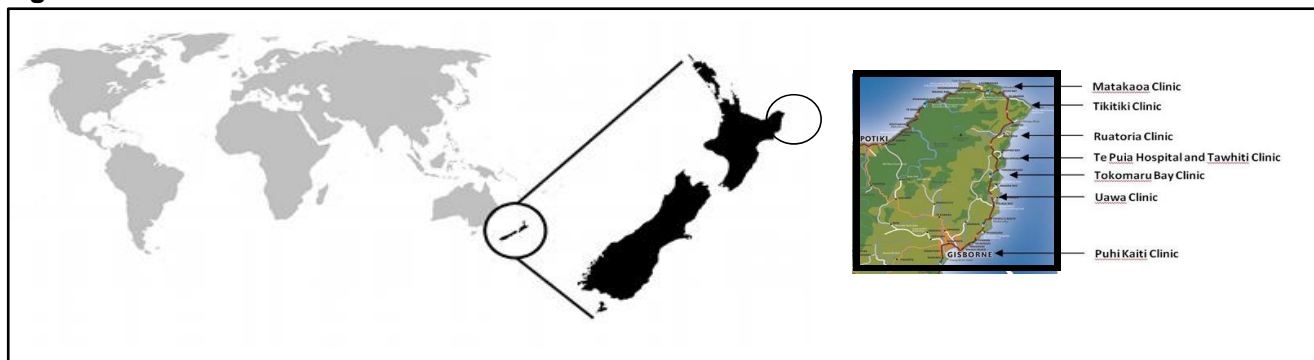


Source: Te Puia Hospital © Ngāti Porou Hauora 2017

1.3 The site

Ngāti Porou Hauora (NPH) is a health service provider serving an area that stretches across 200km of coastline on the East Coast of the North Island of New Zealand. It is one of the first places in the world to see the sun each day. NPH services are delivered through seven primary healthcare centres, including one urban health centre on the northern side of the city of Gisborne, and through Te Puia rural hospital situated 110km north of Gisborne. The majority of the population served outside of Gisborne city is classified as rural or highly rural (Statistics New Zealand, 2017) and 99% of this population live in very deprived areas in terms of socio-economic conditions (Ngāti Porou Hauora, 2016). NPH also provides primary care services in an economically deprived suburb of Gisborne city.

Figure 1: Location of NPH



Source: Figure created for this report

NPH is a primary health organisation (PHO) owned by the local indigenous Māori tribe (Ngāti Porou) and provides health services to everyone resident in the area, irrespective of ethnicity. Its aim is to improve the health status and increasing the life expectancy of the local population. The services provided include:

- primary healthcare
- rural hospital
- rural nursing, child health
- maternity
- dental
- physiotherapy, occupational therapy
- home-based support
- mental health services; and
- research co-ordination.



Ruatoria Health Centre. © K Matheson 2017

2. Context

2.1 The population of Ngāti Porou Hauora area

At the 2013 Census the population of the geographical area where NPH provides services consisted of more than 4,300 people in the coastal rural area, where 89% of people are of Māori ethnicity, and more than 7,100 in the urban area, where 78% are of Māori ethnicity ([Statistics New Zealand, 2013](#)). This population is declining. Compared with the 2006 Census, the population in the coastal rural area declined by about 9% and by about 8% in the urban area. North of Gisborne the East Coast is sparsely inhabited and isolated, with small settlements mainly in seaside bays and river valleys. Today 10,000 people are enrolled in the NPH health services. The enrolled population is 88% indigenous Māori, with the remainder mainly being of European heritage.



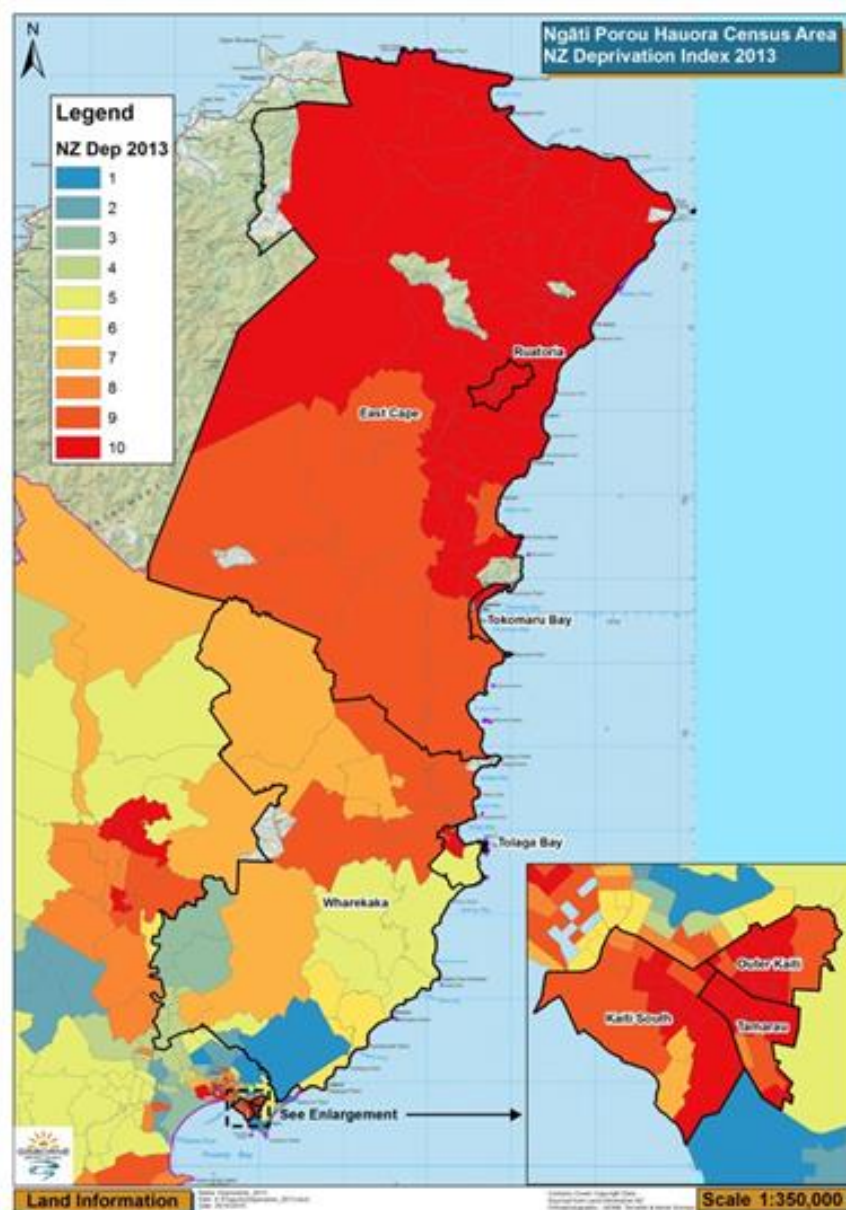
Street mural in Ruatoria. Photographer Kate Matheson 2017

Māori culture is alive and highly visible in the area. Exquisitely carved *marae* (meeting ground) complexes dot the landscape, and *te reo* and *tikanga* (the language and customs) are alive and well, with more than 50% of the population speaking both Māori and English (the highest level of Māori language use in the country) (Statistics New Zealand, 2013). Māori language-based schools are available across the area, and the language is used extensively in formal gatherings, churches and community occasions.

The main sources of employment are in the health sector, the education sector, farming and forestry. The region has one of New Zealand's highest levels of material deprivation. Young people who are not in education, employment or training are at more than twice the risk of a range of negative outcomes including poorer health, depression and early, unplanned parenthood. Almost one-third of young people are unemployed, and the average income (US\$ 27,430) is one-third less than the national average for New Zealand ([Ngāti Porou Hauora, 2016](#)).

New Zealand measures relative deprivation in geographical areas (called meshblocks) through the use of a [Deprivation Index](#). This index uses nine indicators of material deprivation (such as income, housing, education) and then groups communities into deciles; the 10% of the population who live in the most well off areas are in decile 1, the least well off 10% are in decile 10.

Figure 2: Boundary of NPH Census 2013 areas and NZ Deprivation 2013



Source: Ngāti Porou Hauora 2016

Figure 2 shows the 2013 Census boundary of the Ngāti Porou area from which their patients are drawn, and the concentration of very deprived meshblocks within these boundaries. 96% of the NPH population lives in very deprived areas (NZ Deprivation Decile 9-10) compared with 20% nationally. Of the total area served by NPH, 99% in the coastal rural areas live in Decile 9-10, and 91% in the urban Gisborne area served by NPH are in Deciles 9-10. The high level of material deprivation has multiple effects on the health for this predominantly Māori population, and the continuing inequity of income and resource distribution poses the biggest challenge for NPH in improving health and reducing health inequality (Ngāti Porou Hauora, 2016).

2.2 The status of health in the region

The social conditions contribute to the health status of Māori in the Ngāti Porou region being significantly worse than that of the rest of the country. People in the Ngāti Porou region have the highest mortality rate in New Zealand (66% above the national rate). The Māori mortality rate in the area is 12% above the national Māori rate. These comparisons are influenced by the difference in the Māori density in Ngāti Porou (compared with 16% in New Zealand) as well as the relative deprivation (91% NPH compared with 20% in New Zealand) (Ngāti Porou Hauora, 2016).

Access to primary care

New Zealand operates a capitation funding policy for primary care, where patients enrol with their chosen service provider and the government pays a lump sum for each person enrolled. Capitation as a funding system enables the service provider to identify a specific population (those enrolled) and potentially take a population approach to their care. This has important implications for community participation as it helps define the community served by the provider. NPH provides free access to all its services in the rural areas, and has a modest part charge for standard consultations with clinicians for registered patients 14 years and over in its urban health centre (US\$3.5 for those aged 14-17, and \$8.30 for those 18 years and over). Current central government health policy is that consultations are free throughout New Zealand for young people and children 13 years of age and under.

NPH has the highest proportion of Māori enrolled in a primary health organisation (PHO) (explained later) in NZ - 88% of NPH patients are Māori compared with 16% Māori in the total New Zealand PHO enrolment. ([Ngāti Porou Hauora, 2016](#)). *Appendix 1* includes a table of summary results from this Ngāti Porou Hauora Dashboard, published in 2016.)

NPH has enrolled the bulk of the population in the East Coast rural areas (98%), but there is room to increase enrolment, particularly in the urban area. In recent times NPH has consistently achieved high levels of primary care service coverage for disease screening and immunisation, compared with the rest of the country (Ngāti Porou Hauora, 2016). However, the overall health status in terms of premature and amenable mortality is poor compared with non-indigenous New Zealanders, reflecting the important but only partial impact health services play in improving health in the context of poor social and economic determinants.

2.3 NPH in the context of the New Zealand health system

New Zealand has a predominantly tax-funded health system, providing free access to hospitals, but user charges apply for most population groups accessing primary care services (except those 13 years and under). As noted above, NPH is an exception in this regard, as it does not charge users for its services in the rural areas. The 4.6 million population of New Zealand enjoys high-health status overall, but with significant inequalities in Māori (16% of the population), Pacific (8% of the population), and low-income people of all ethnicities.

The health system structure in New Zealand (see *Appendix A3*) consists of a central Ministry of Health (MOH) that oversees the health system, while 20 district health boards (DHBs) are responsible for planning and funding health services for their geographical areas. DHBs receive funding from central government on a population basis and provide services directly at the district hospital, as well as buy services from community-based providers. Ngāti Porou Hauora is a community healthcare provider within the Tairāwhiti District Health Board (Hauora Tairāwhiti). Tairāwhiti has one of the smallest DHB populations in the country.

The DHBs are run by local boards, with a membership that is mainly publicly elected and partially appointed by the Minister of Health. Their empowering legislation is the [New Zealand Health and Disability Act, 2000](#) (Government of New Zealand 2000). This Act specifies that DHBs are expected to show a sense of social responsibility, to foster community participation in health improvement, and to address health inequalities (New Zealand Ministry of Health, 2017). These broader goals for the health sector have not been consistently monitored or made a part of the boards' accountability measures (Matheson and Loring, 2011). Successive governments have instead introduced more specific targets that have increasingly focused on clinical interventions and patient flow, such as immunisation, waiting times in hospital emergency departments.

There are no user charges for inpatient or outpatient services in publicly owned hospitals. Primary health care (PHC) is funded through primary health organisations (PHOs). Presently there are 36 PHOs, of which NPH is the smallest in the country. PHOs receive capitation funding for their enrolled populations and work with general practices and other providers to deliver comprehensive PHC in the community.

The Pharmaceutical Management Agency (PHARMAC) manages the New Zealand Pharmaceutical Schedule and negotiates the purchase of drugs from suppliers, successfully controlling supply-side expenditure. The cost of drugs in New Zealand is substantially lower than in the US, as a consequence of this purchasing arrangement. The Accident Compensation Corporation (ACC) is a comprehensive, social insurance, no-fault, personal injury scheme that funds treatment, rehabilitation and compensation for people who are injured in New Zealand. It sits alongside the tax-funded health system and can fund a wider range of services. NPH has a funding stream from ACC for the activities it carries out for accident victims (WHO Regional Office for the Western Pacific, 2014).

Current challenges for the nation's health system include reducing inequalities in health, managing noncommunicable diseases and chronic conditions, reducing waiting times, improving productivity, and ensuring greater integration and co-ordination of services within and between primary and secondary care, and intersectorally with other social services (WHO, 2014).

Consumer and community participation in primary care organisations had been a reality for only a small proportion of providers in New Zealand prior to 2000, with NPH as an exception. Community participation became an explicit part of government policy with the advent of New Zealand's Primary Health Care Strategy and the emergence of primary health organisations in 2002, as demonstrated in the following government policy statements (King, 2001, p.4):

PHOs must demonstrate that their communities, iwi [tribal authorities], and consumers are involved in their governing processes and that the PHO is responsive to its community. The DHB must be satisfied that community participation in PHO governance is genuine and gives the communities a meaningful voice. In addition, DHBs will require PHOs to show how they respond to their communities.

However, since 2011 the requirements for communities to be engaged at PHOs' governance level has been relaxed and less stringent requirements are being discussed (Northland DHB, 2013, p. 3):

Have in place governance arrangements that are inclusive of diverse multidisciplinary clinical/management/community/commercial expertise and ensure a patient and community voice.

The public health function in New Zealand usually refers to those aspects of health that are influenced through legislation and the organised efforts of society. Examples include tobacco control, health promotion in regard to drug and alcohol abuse, and nutrition and physical activity. These functions are provided through publicly funded services provided through public health units sitting with one or more DHBs and specific NGOs. Some DHBs have engaged in wider determinants of health, such as investing in healthy housing initiative; however, in the main, their practice is centred on traditional public health functions. With the exception of tobacco, in recent years there has been a move away from public health engaging directly with industry over issues such as taxing unhealthy products. The perception that public health activity was an action of 'the nanny state' when it strayed outside the domain of health service provision became a popular political rallying call of the National (conservative) government in power since 2008 and has led to a muted public health response to major issues such as obesity in recent years.

Community participation in the New Zealand health sector has waxed and waned over the last 16 years. At the beginning of the period it was central to government health policies, and more recently it has taken a back seat. NPH's community engagement preceded these government initiatives and continues amidst these oscillations.

NPH differs from most primary healthcare providers in New Zealand in a number of respects. It is both a PHO and a provider of services (these organisations are usually discrete); it services a smaller population than other PHOs; it is owned and managed by the local tribe (most primary care is provided by private general practices, normally doctor owned); it services one of the most remote parts of the country; and it serves a predominantly Māori population, as noted above.

2.4 NPH in the context of an indigenous organisation in New Zealand

Central to understanding NPH's concept of community participation is their strong sense of identity and independence, which has its roots both in the tribe's oral history of how New Zealand was initially settled, and in modern legal instruments arising from a treaty between Māori and the British monarch in 1840.

According to oral history:

When Māui hauled up the North Island from the ocean depths, the first point to emerge was the mountain that Ngāti Porou claim as their sacred icon: Hikurangi. For Ngāti Porou, independence and unity are as enduring as their mountain, Mt Hikurangi (Reedy, 2017a).

Reedy goes on to explain how leaders within the Ngāti Porou tradition have strongly reinforced this sense. The story of Te Kani-a-Takirua in the first half of the 19th century is illustrative:

When the high-born Te Kani-a-Takirau was offered the position of Māori king, he famously replied: "My kingship comes from my long line of ancestors. My mountain Hikurangi is not one that moves, but one that remains steadfast." This statement of fierce independence (some say arrogance!) characterises the tribe even today (Reedy, 2017b).

[The Treaty of Waitangi](#) further reinforced this deeply held sense of independence. This treaty, made in 1840, still defines how Māori as a people view their relationship with the state, including provision of health services. The Treaty of Waitangi was between the British Crown (the monarch) and more than 500 Māori chiefs, including 17 from Ngāti Porou. After that, New Zealand became a colony of Britain and Māori became British subjects. However, Māori and Europeans had different understandings and expectations of the Treaty, and it is only in the last 40 years that a credible



Mount Hikurangi © Ngāti Porou 2017

legal instrument has been adopted to give it expression. Some of the reasons why chiefs signed the Treaty included wanting controls on sales of Māori land to Europeans and on European settlers (mainly from the United Kingdom). They also wanted to trade with Europeans and believed the new relationship with Britain would stop fighting between tribes. Those who didn't sign the Treaty (including some Ngāti Porou chiefs) were concerned they would lose their independence and power and wanted to settle their own disputes. Some chiefs never had the opportunity to sign it, as it was not taken to all regions.

The Treaty had two versions and the meaning of the English version was not exactly the same as the meaning of the Māori translation. The Māori version guaranteed *Tino Rangatiratanga* which means retaining 'chieftainship' or complete control and authority by *hapū* (sub-tribe) and *iwi* (tribe) Māori over their land, other resources, villages and *taonga* (treasured things). This is often referred to as the Treaty's 'self-determination' clause. In the Māori version, tribes ceded *kawanatanga* to the Crown, which translates as governorship, not sovereignty. Both versions gave Māori the Queen's protection and the rights of British subjects (Orange, 1987).

In the 19th century the British government interpreted the Treaty as placing all Māori under British authority. Conflicts arose between Māori and European settlers as the latter wanted more land. The government often ignored the protections the Treaty (both versions) was supposed to give Māori. By the end of the 19th century most land was no longer in Māori ownership and Māori had little political power, despite their attempts to have the treaty honoured. An exception was Ngāti Porou, who maintained most of their territory and resisted attempts by the Crown to purchase their land. Following a period of conflict with a neighbouring tribe that had spread into Ngāti Porou traditional lands in the mid-19th century, the government attempted to buy Ngāti Porou land, but the Ngāti Porou leaders met this challenge with characteristic resistance: *Take your money away, the fight was mine, not yours, the Pākehā (non-Māori)* (Reedy, 2017a)

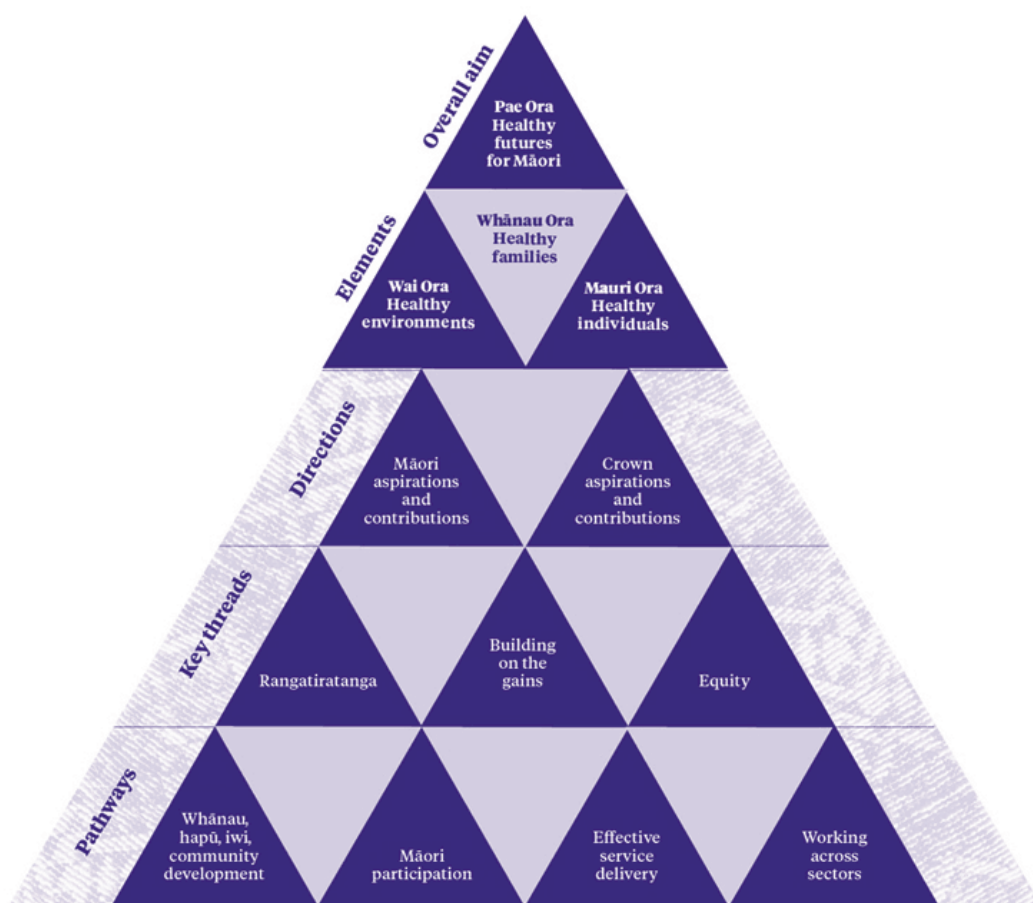
In the early 20th century leaders such as Sir Āpirana Ngata (a politician from Ngāti Porou) introduced schemes to develop Māori land, and the government began to support Māori farming ventures. In the 1920s the government acknowledged some fishing rights. By the 1970s and 1980s protests about Māori treaty rights became more common. [The Treaty of Waitangi Act 1975](#) established the Waitangi Tribunal to consider claims that the government had breached the Treaty and to make recommendations to the government (New Zealand Ministry of Health 2014a). The principles of the Treaty – a ‘partnership’ between the government and Māori including the principles of ‘protection’ and ‘participation’– began to be mentioned in other New Zealand law, and knowledge about the Treaty became more widespread (Orange, 2016). More recently, the government’s view has moved beyond focusing on the three ‘principles’ to ‘relationships’ between *iwi* and *hapū* and the Crown as equal entities. However, resolution of grievances under the Treaty remains an ongoing process.

The New Zealand Ministry of Health (2014b) now interprets the Treaty in terms of its Māori health strategy, with ‘participation’ being a central feature:

- **Partnership** involves working together with *iwi*, *hapū*, *whānau* and Māori communities to develop strategies for Māori health gain and appropriate health and disability services.
- **Participation** requires Māori to be involved at all levels of the health and disability sector, including in decision-making, planning, development and delivery of health and disability services.
- **Protection** involves the government working to ensure Māori have at least the same level of health as non-Māori, and safeguarding Māori cultural concepts, values and practices.

The Ministry’s Māori Health Strategy (2016), known as *He Korowai* (Figure 3), is built on key concepts that had their origin in the Treaty. The Māori Health Strategy has Māori participation and works across sectors as its base pathway for health development and *Rangatiratanga* as a ‘key thread’. *Rangatiratanga* captures people’s right to control and participate in making decisions about their health and to have meaningful ways to decide how health services might be provided for their benefit.

Figure 3: New Zealand’s Māori Health Strategy, *He Korowai Oranga* Framework



Source: New Zealand Ministry of Health 2014b

This concept of self-determination leads the [Ngāti Porou tribe's own strategic document](#) (Te Runanganui o Ngāti Porou, 2013): *Ko te whare mairi ka tu ki roto i te Pa-tuwatawata he tohu no te Rangatira.* (A carved ancestral house standing within a fortified pa is a sign of chieftainship.)

The concept of participation held by NPH is shaped by the tribe's history and strongly reinforced in their current strategic intent. They do not see themselves as mere recipients of state provided health services, in which they are claiming the right to participate. Rather, they see themselves as in control of their own destiny 'standing within a fortified pa (village)'. 'No decision about me, without me' could imply subservience in the relationship between service provision and the community. That does not reflect NPH's view. Rather, they are pursuing their own destiny, and the onus is on the external party (such as the state) to participate in their processes or journey. This view is also reflected within the government's own Maori health policy as discussed above.



Iritekura Marae © Ngāti Porou Hauora 2015

3. The participatory work

3.1 The nature of the community

This section describes some of the features of the community that influence participation. The historical and cultural roots of the Ngāti Porou concept of participation have been described in section 2.4. As one elder succinctly put it: *Ngāti Porou is a kingdom unto itself.*

Participation is not primarily seen through utilitarian eyes, where motivation comes from its potential to improve programme effectiveness. It is seen as a fundamental right and entitlement.

Ngāti Porou fondly refers to itself as *Te Wīwī Nāti*. Coined by Sir Āpirana Ngata, the name compares the people to *wīwī* – close, compact-growing rushes (Reedy, 2017a). The isolation and remote nature of each community means that everyone knows each other. When interviewed, people often mentioned the close-knit nature of the community and the strength this provides when it comes to caring for one another. NPH was seen as an extension of this already existing community culture.



Sir Āpirana Ngata, politician and Ngāti Porou image sourced from Te Ara. Image part of [Alexander Turnbull Library](#), New Zealand Free Lance Collection licensed under the Creative Commons Attribution-NonCommercial 3.0 New Zealand licence (Creative Commons Attribution-NonCommercial Licence)

The East Coast is one of the few places in New Zealand where traditional Māori social structures determine how the whole community is organised and functions. First, the communities are grouped by tribe, sub-tribe and wider family (see *Appendix 2* for map of sub-tribes). At each level they may compete between each other to look after their needs and point of view, but if a higher level comes into play, they are able to rally together. Second, the elders are a significant traditional structure. In Māori society elders are held in high esteem. They have a variety of roles in their wider family, sub-tribe and tribe: being the storehouses of tribal knowledge, genealogy and traditions; acting as guardians of *tikanga* (Māori customs); nurturing children – traditionally elders looked after children while their parents worked or went away to fight, and often brought up the first grandchild; providing leadership; and helping resolve disputes (Higgins and Meredith, 2011).

3.2 The nature of the actors

NPH staff at all different levels of the organisation, along with their family members, are consumers of the health service and are themselves part of the community. Many belong to families who have resided on the East Coast for many generations. The border between the health service and the community is blurred by the small size of each community, where everyday life creates an extensive network of links between each actor. NPH staff are consistently involved in other community activities such as local schools, *marae* committees, advocacy groups and local sports clubs and, often, hold leadership roles in these groups.

I am Ngāti Porou, so I care about our wellness and future existence from Monday to Sunday, not 9-5 Monday to Friday. This is extremely personal. If things go wrong it is my whānau (family) that is ultimately going to be well or unwell – KI community member and NPH Board member, 2017

This has a moderating effect on everything you say and do. It's about members of your own whānau/hapū/iwi (family, sub tribe, tribe)– KI community member and NPH Board member, 2017

Community connectedness is highly valued when considering potential employees, especially for leadership positions within the health service. There is constant tension in trying to find a balance between clinical/technical knowledge and skills and standing in the community.

If you maintain Te Tiriti – the founding document for all care in New Zealand – then that means we must protect the rights of the tangata whenua (the people of the land), let them make decisions, and let them be at the level of decision-making. – KI community member and NPH employee, 2017

Case example: Kaiawhina - Frontline of the healthcare team

The health team for each of the rural communities and for some urban-based services has positions for *Kaiawhina* (community health worker) in addition to nurses and doctors. The numbers of each vary, depending on the size of the community.

The *Kaiawhina* come from the community the particular health centre serves and are recruited based on their knowledge of the community and their past history of active engagement in community affairs. “I ran the rugby club before this.” They are chosen in consultation with their communities and have salaried positions. They are considered as a formal part of the health service.

They take a holistic approach to health, depending on the needs of the area. A major part of their role is connecting people with health and other services.

We are a referral system for whānau (families) to health and others – depending on needs. It might be housing or a specialist.

But it is much more than passive referral:

We advocate for whānau that feel shy - might go to an appointment with someone if they don't want to go by themselves. This could be to help explain things for those who have trouble understanding. No good them walking out of an appointment saying “So what do I have to take these pills for?”, so I go in with them, that way I can take the time to explain things.

They also take a proactive role in maintaining that connection with patients:

Kaiawhina make home visits – sometimes planned but often random or on a hunch. If I haven't seen someone for a while. If someone that hasn't attended an appointment and isn't responding to a letter, then I take them to an appointment if need be. We come from each community and we know everyone – they can't hide from us.



NPH Kaiawhina © Ngāti Porou Hauora 2017

Kaiawhina facilitate a wide range of community-based programmes, including research, as well as instigating support programmes where the community has identified a need (see *Wahakura* programme in a separate box).

The value of their community connection was noted by a board member:

Conversations in the community have the ability to influence budget items. A lot of this comes back through the staff in the individual centres, especially Kaiawhina, communicated through management and the CEO, then shared at planning time. Sometimes it's more about operating better at that level, allowing the community to have their say and recognising where there are some gaps that operations are unaware of.

The frontline is amazing. It is a measure when community members feel free to communicate their thoughts. This is a measure of their community connect.

3.3 The nature of participatory practices

Participatory practices in NPH have a long and proud history, but interviewees raised concern that current organisational challenges around health system financing are driving organisational changes that make it more challenging to sustain participatory practices.

History of participation

The culture of participation within NPH is intrinsic, as previously noted, and this equally applies to the health services. When the hospital at Te Puia was first established in 1907, the management and trustees at the time gathered any patient who was well enough and gave them a paintbrush to help paint the walls. Over the years NPH has also gone through phases where participation has been stronger or weaker. Many people referred to a past structure where each sub-tribe had a representative on the NPH Incorporated Society Board who would liaise monthly between the board and their



Georgina Paerata - Retired NPH Manager and Matron. Photographer Kate Matheson 2017

community. This structure was seen as effective because every community (Tokomaru Bay, Ruatoria, Tikitiki etc) had a voice. The routine nature meant that the community knew when, where and to whom they could voice their thoughts, and what the process would be for follow up. A restructure, precipitated by financial difficulties, led to this mechanism being deprived of its official status, and community board members are now appointed by and report to a higher level organisation, TRONPnui, the tribal Trust Board. Tribal members elect the TRONPnui board every four years, and the majority of tribal members live outside of NPH's geographical boundaries. Since 2011, TRONPnui has been the owner of the NPH Charitable Trust and is providing the organisation with additional financial assistance, as adequate Crown funding has not been forthcoming.

Traditional processes are routinely used to facilitate important discussions in the community. These include features such as honouring the wisdom of the elderly, acknowledging the relationship with the land and sea, and the sanctity of decisions made in traditional meetings houses. Components of this ran through the responses of all interviewees. The rights of Māori people as articulated in the *Te Reo Māori* version of The Treaty of Waitangi were also often quoted when discussing why community participation was important in decision-making around a health system.

If you maintain Te Tiriti (The Treaty of Waitang Te Reo Māori version) – that means we must protect the rights of the tangata whenua (indigenous people, people of the land) to make decisions, and let them be at the level of decision-making. – KI NPH community member and employee, 2017

Participation in NPH is carried out in many different ways and changes depending on the situation.

For example, every Monday morning the NPH executive team attends a meeting on the ward at Te Puia Hospital, where staff and patients gather. This meeting begins with a prayer, then all present have an opportunity to raise current issues or provide updates on events in the coming week. Issues may be raised by the executive team, nursing staff, cleaners or patients. Topics not only include those related to the health service, but also those of concern to the community.

What stays the same are the principles or values shared between the community and the organisation, and these inform how participation happens. NPH does not have a manual or toolkit specifically for community participation. Where examples of community participation are articulated in operational documents, they often have been put there for compliance rather than to inform or enforce practice. NPH personnel expressed that any such practices or systems should be flexible and that the overarching embedded values and associated principles were more important.

Frequently articulated values were honesty and transparency. The community strongly expressed an expectation that NPH will take the time to explain a situation thoroughly before asking for feedback. This includes being upfront about finances, key people, politics and how external processes and mechanisms may influence the subject of discussion. Discussions are not public relations exercises. They are expected to be explained in everyday language and have a clear intention as to whether the meeting is to inform, consult, discuss or listen. There is also an internal culture of valuing honesty. While other organisations may take a punitive approach toward staff for criticising the organisation or advocating on behalf of community, at NPH this is thought of as a given expectation. The NPH management does however insist this is done constructively.

You have to tell the community everything, warts and all. Sometimes you will get a pat on the back, other times you will get your butt kicked. At the end of the day people appreciate transparency, and we end up on the same page when all the information is there, because we have the same long-term kaupapa (principle) – KI community member and NPH employee, 2017.



Bill Blane, NPH Cultural Advisor. © K Matheson 2017

Health service participation in the community

The practice of community participation in NPH places considerable emphasis on the way the health service participates in the community. Interviewees believed there is a high level of community participation in the health service, because the health service personnel have a high level of participation in the community. In fact, it was out in the community, at community events, where many great examples of caring for, sustaining and building relationships with and in communities occurred. Representatives from NPH acknowledged that this was costly in terms of time, personnel and other resources, and it wasn't funded under any government funding mechanism. However, they consistently believed it was not just valuable but one of the things they do that has the most impact.

People aren't shy to say what they think, but they don't do it in here, they will do it out there. So we have to be out there if we want to know what they think – KI community member and NPH employee, 2017.

This statement encapsulates the NPH approach to participation. It reflects their understanding of the limitations of effective communication in institutional settings (even in NPH). To truly engage in community issues requires the health service personnel to step outside their institutional setting and hear the feedback spoken in community settings.

From observations during this research and from the interviewees themselves, health service personnel clearly were active in practically every phase of community life. Examples include home visits, where regular contact is made, often on the initiative of the health workers, as discussed earlier in the *Kaiawhina* case study. Another example is participation in funerals. Called *Tangi*, funerals are a major community event within the culture, and last approximately three days with extended family members participating from all over the country and increasingly from overseas. NPH staff, many of whom will have connections with the deceased, often attend. For larger *tangi*, temporary clinics are established. Community members, who include NPH staff, have specific roles in hosting these events, including food preparation and catering, direct support to the bereaved family, through to formal roles in greeting arriving mourners. Often open discussions occur during *tangi* on health issues, relating to the deceased or more broadly.

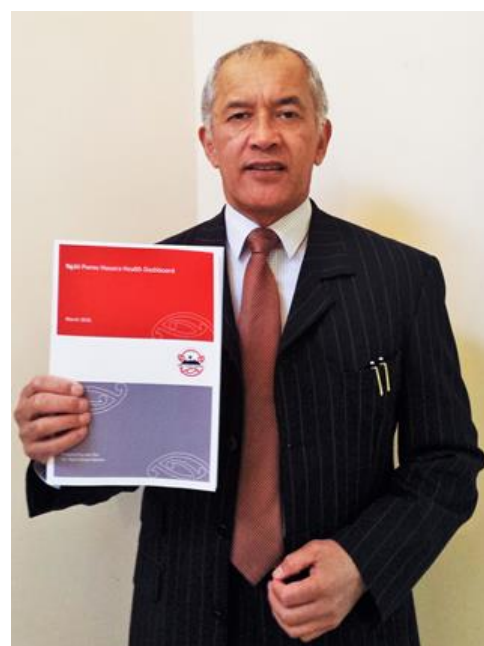
Apart from these more formal events, NPH staff take part in whatever events are of significance to the community. For instance, the mental health service cultural advisor attends an average of ten community gatherings per month. Although health may not be the stated topic of discussion, most issues have a health dimension, and health workers in attendance are able to address issues as they are raised, or bring issues from these meetings to the attention of the NPH management. These interactions are a crucial component in building direct communication channels and trust between the health service and the community.

3.4 Community participation in the health system

NPH board members and senior management directly engage in discussions with communities over issues of strategy and resource allocation. This engagement has been less extensive in recent years, but interviewees agreed on its importance and hope there would be greater engagement in future.

Major formal discussions often have a traditional format. The meetings are held in community settings, such as the meeting house. The *Pakeke* (elder) from the particular community lead the meeting, beginning with *karakia* (prayer), acknowledgement of history, connection to land and ancestors and song. Once this is complete the forum is opened to facilitate debate, and people will keep talking until a consensus is reached. A considerable amount of time is often needed for this to occur, and as aforementioned, it will ideally occur multiple times as the meeting is taken to each of the coastal communities.

The first discussion took all day. You must have enough time set aside for deep discussion. There are adverse effects if it's not done properly – KI Community member, 2017.



Teepa Wawatai - NPH Chairperson © Ngāti Porou Hauora 2016

Board members reflected on the importance of knowing what else is going on in the community so the different issues that may be impacting on a community are co-ordinated. Without this consideration, communities can end up feeling exhausted or over-consulted. If an engagement can be scheduled to take place when the community is already getting together for another reason, then this can work well. Care needs to be taken, however, not to 'hijack' another gathering with the health agenda.

Interviewees felt the community's time is precious, and therefore discretion needs to be shown when deciding what needs to be taken to the community and what doesn't. These engagements with the community are not formally minuted, but shape the decision-making of the board members and senior managers. In their view, the health service can only make good decisions if there is a good understanding of the community. NPH currently aims to have a comprehensive formal meeting with each community (Tokomaru Bay, Ruatoria, Tikitiki etc.) once per year, and then smaller engagements as appropriate. However, the past practice of having a regular monthly meeting was remembered as having been most effective. Communities would get into a routine of regular engagement and would know what the next opportunity would be for them to bring something to the table.

I try and tell a personalised story that people can relate to, and keep it as short as possible. What I present I want them to remember. If people give you their time you want to reward them, not subject them to long boring speeches about nothing. – KI Community member and NPH Board member, 2017.

NPH uses other community communication channels such as [websites](#), [social media](#), community newsletters and [radio](#), thus giving the community more options around where and how it engages.

The engagement in the community is not limited to the *Kaiawhina*, discussed earlier. All staff members, including doctors and senior management, participate in community events and receive feedback directly from the community on service performance. Board members are from the community, staff are predominantly from the community, and the selection process has direct community participation, as discussed below.



Ken Eruera - Community member. Photographer Kate Matheson 2017

Case example: Community participation in human resource processes

It is common practice for a community member (usually an elder, or a consumer of the service), to sit on recruitment interview panels. These representatives are given the responsibility of assessing the potential candidates' ability to serve the community and their cultural competency. This representative will be given an equal share of time allocated to ask questions during the interview, is involved in all follow-up panel discussions, and has equal input into the final decision.

3.5 Support and input from other levels and actors

Interviewees described a variety of responses to the level of input and support from other level actors. NPH's most important relationship within the health sector is with Tairāwhiti District Health Board (TDH). The relationship has been tense for a number of years over issues of funding, prescriptive contracting and future service direction.

The area of most contention is the funding relationship. There is widespread perception in NPH that TDH is reluctant to support the future development of NPH's health services, and at times does not provide funding that it has available. There is some external support for this view, with a recent New Zealand Treasury report (2016) showing that TDH has been reducing the amount budgeted for its funder arm (which funds NPH), and underspending those resources that were budgeted. The community is well aware of this tension:

Everyone on the Coast knows NPH is a second-class cousin to Tairāwhiti (TDH) – KI community member, 2017

Attempts by the central government to encourage a more integrated alliance between the DHBs and the primary care sector have not had the expected result.

They (TDH) push their own agenda by using a so-called participatory template. You don't get true participation – KI community member and NPH employee, 2017.

On the other hand, the Māori division within the Ministry of Health had provided much needed support:

They provided excellent support. Got key people to come and help with planning to match our vision with the funding mechanisms – key people who were good at data came to help with our reporting – everything that we were actually doing – poor technical performance at the time was because we weren't recording the data well – KI Community member and NPH Board member, 2017

Similarly, positive experiences were reported from partnerships with the universities that understood the importance of participatory approaches:

Otago is involved in research with Ngāti Porou. They take a careful and considered approach. They know it requires good long-term relationships and feedback with the community – KI community member and NPH Board member, 2017

NPH's enmeshed relationship with its community means that the organisation is involved in the wider determinants of health. Staff members engage in education, sport, community affairs and in the local economy. This engagement is both formal and informal. The nurses and Kaiawhina work closely with the schools in their locality, attend significant community events, and many are office holders in community organisations and on school boards. As the majority of staff members live in the community, they participate in sports clubs and community activities, such as in funerals, as discussed above. Their children attend local schools adding to rolls, increasing the resources coming into the area for education. An assessment of the impact of NPH on one sector, the economy, is discussed below, however its positive impact on other sectors, such as education, may be equally significant.

Recently, NPH commissioned research to document the extent its activities contributed to the local economy. [The report](#) concluded:

This assessment determined that the total economic impact of the activities of Ngāti Porou Hauora on the Gisborne [district] economy is an additional New Zealand\$13.7 million (US\$9.5 million) in GDP in 2014 and the employment of an additional 152 full-time equivalents (FTEs, people who work 30 hours or more per week) (Nana, 2015).

According to the report, NPH directly employs 100 FTEs, and the economic activity that these employees generate in the local community employs another 50 FTEs. This has a substantial and positive impact on the local economy, an area of high unemployment and low economic growth. The report, however, points out that this is not the main goal of the organisation. The report strongly recommends that considerations of 'value' of NPH cast a wider net than the economic assessment above:

From an economics point of view the value of Ngāti Porou Hauora lies in the contribution it makes towards its goal, and this is the core outcome against which the success, or the value, of Ngāti Porou Hauora should be measured (Berl, 2015, p.8).

Case example: Research Informing Māori Guidelines for Bio-banking and Genomic Research

Twelve years ago, NPH was flooded with requests from other agencies wanting approval or assistance to do their research 'on' NPH patients and communities. Often NPH was requested to convene focus groups for agencies to interview. NPH wanted to shift this towards NPH-led and driven projects, which addressed NPH priorities and which were conducted in partnership with NPH and other agencies.

NPH was one of the first health providers in New Zealand to develop its own research policy and procedures. These guidelines are used as examples nationally. A research co-ordinator position was put in place to help manage these requests and processes and to strategically move NPH towards a position where it had more ownership of and participation in decisions about, and governance and co-management of, health research taking place in the community.

The principles and procedures of community participation also have set a precedent of ensuring proper resourcing of participation in project budgets. This enables NPH to hold community forums to discuss research proposals, progress, recent findings and next priorities to focus on.

A specific example of this is an ongoing genomic research programme with universities that has involved into several projects over the last ten years. In 2006 local elder and general practitioner, Dr Paratene Ngata, suggested that NPH undertake genetic research into gout and related conditions. The genetic and now genomic research programme officially began in 2007 in partnership with the University of Otago and includes the Genetics of Gout, Gout and Related Conditions, and Urate and Gout: genetic control, environmental and drug interactions (extension to analysis and dissemination) research contracts. It is co-led by the Otago University lead genetics researcher with a Māori human nutrition researcher and the NPH research co-ordinator.

The initial suggestion by Dr Ngata was around the same time another researcher had inappropriately analysed some Māori genetic data in what is known in New Zealand as the '[warrior gene debacle](#)', so people were nervous about going down this path. Nevertheless, NPH invited the researchers from Otago to the East Coast, and open meetings took place in every community to see what they thought. The word 'gout' brought out a wide range of participants from the community because gout is such a prevalent issue in the area. NPH and the researchers both wanted to discuss issues around the cultural safety of collecting people's DNA (articulated by Māori as 'the embodiment of their *whakapapa*' or genealogy). However, when it came to the meetings, they found the community so desperate to find answers to 'the gout' that they were willing to take the risks - provided that their DNA was looked after and protected in the process.

The NPH research co-ordinator remembers being concerned that the community thoroughly understood the complex issues. After much discussion, she remembers a young man from one of these meetings sticking his arm out, and saying:

Just take our bloods and get on with it will you? We are desperate about gout, and we will trust you to look after us and our DNA.

This was the general message from these community meetings and consequent board meetings that gave approval to proceed with the research programme – they are willing to participate for the benefit of their families and community's health, and will hold NPH and researchers accountable for looking after the ownership and protection of their blood samples and the genomic data.

From this, NPH developed a specific research agreement in discussion with the University research leader and his department's head, which put detailed conditions on the storage and use of genomic data – effectively an additional layer to that required by national health research ethics. The agreement for the protection, storage and use of the genomic data of participants covers the following:

- Who protects and owns the data;
- Where data are stored and what security measures are in place;
- What specific purposes the data can be used for based on what the participants have given informed consent for;
- Conditions around processes to be taken if researchers want to use the data for a new or broader purpose, for example re-consenting with participants.

The agreement came into play when the Gout Research Programme proposed a second phase to include not just gout but related conditions linked to the DNA variants and underlying metabolic syndrome. A major change in this second phase is the addition of genomic analysis, where the DNA is transferred into computer-based data and stored on a server as opposed to being kept in fluid form. Another whole round of community and staff consultation was carried out to discuss this, leading to the decision to develop a specific agreement in addition to the more general health research approvals. Given this experience, more recently NPH, Ngāti Porou community members and the genetics researcher have actively contributed [Te Mata Ira](#), a national research project that has culminated in the publication of Māori guidelines for genomic research and bio-banking (Hudson et al., 2016). (See the Ngāti Porou [scenarios](#) in this report.)



Jennie Harré Hindmarsh - NPH research co-ordinator © Ngāti Porou Hauora 2017

3.6 The challenges for ongoing community participation

Community goals in a contracting environment.

Underpinning and supporting community participation is the notion that needs identified by the community and approaches to meeting those needs will be met with a positive response by the service provider. Both the community and NPH share a common overarching purpose that enables NPH and the community to make difficult and strategic decisions in partnership. NPH has a mission to develop a health service that improves the health and life expectancy of all the people. Furthermore, it is understood that role of officials in NPH are as guardians, not as owners, of this mission. It is their obligation to represent the community first and foremost, before any other agency or even NPH itself.

The contracting environment under which NPH operates with the Ministry of Health and the DHB is one where specific service deliverables are designed far away from the reality on the ground. This makes the development of locally informed and designed models of care particularly challenging. It is widely recognised that the mainstream westernised model of care with its emphasis on treatment technologies isn't sufficient to achieve the communities' shared goals. Over a number of years, NPH has been keen to support wellness approaches, within a contracting environment.

We have to try to raise the banner of Ngāti and Healthy and bring each individual contract back to how it relates to this greater vision. This includes recognising what the active groups and people within the community are already doing and how we can draw that in. It's about maintaining wellness, not maintaining a hauora (health service) that just looks at giving tablets out and dealing with sick people. What will drive and mobilise the community? Connectedness between us as individuals, communities and as Ngāti Porou – KI NPH community member and employee, 2017.



Lois McCarthy Robinson, NPH Board member. © K Matheson 2017

The tensions between the contracting environment and NPH's (and the communities') aspirations are apparent in relation to differing views of access equity. For many years, there has been considerable pressure to close the hospital, and move services to Gisborne. NPH has resisted this pressure, but at the same time is transforming the model of care it delivers to improve the efficiency and safety of the services it offers, without sacrificing the community's access to care.

Individual government contracts for different services create fragmented activity that is often stop/start. For example, contracts for primary care services are separate from those of emergency and inpatient services, while NPH is attempting to deliver the service in a fully integrated way. It also creates competition between existing groups and means that new groups come in to try to implement programmes and services.

The following impacts on community participation were described:

- Services and programmes delivered aren't necessarily in line with what the community wants
- Multiple groups competing for the community's time, input and approval
- Focus on including the community perspective is replaced by focus on funder priorities and initiatives
- Funder enforced partnerships and alliances with other entities, leading to the voice of the NPH community being diluted.

Funding also does not cover the costs of NPH's constant engagement with the community at every level of the service. Where there was funding for community consultation, this was usually to 'tick a box' or fulfil a bureaucratic agenda. Over time these types of activities have been destructive to NPH's relationship with the community. When there has been no visible benefit to the people, participants have become sceptical and reluctant to participate in the future.

Another challenge in terms of funding is the perception from funders that if the community wants to own it, then they can pay for it themselves. NPH's experience is that the government's responsibility to provide sufficient health care to its communities has decreased and that it has little enthusiasm for community ownership and design of service delivery. Recently, in several incidents, NPH have been told they should use money received through the tribe's Treaty settlement claim with the Crown to pay for their health programmes and services. This reflects a lack of understanding of the Treaty, where the Crown took on this responsibility.

A strong participatory culture within NPH in the context of rigid (and inadequate) contracting mechanisms can place staff members in a difficult position. From the NPH perspective, one of the key challenges is balancing the sense of obligation to meet the expectations or requests of the community with the operational and resource challenges of the organisation. Sometimes this may lead to the organisation having to make difficult choices between the level of community clinical services and what the community is asking for. For example, communities want the health service to be run their way, funders want the health service run their way, and staff often feel caught in the middle as they need to keep both parties happy in order to continue to have a health service.

Reaching diverse representation

Interviewees were asked about which groups in the community are more marginalised in service delivery and participating in NPH processes. They held many differing views as to which are the most marginalised group in the NPH community. The most common view was young people. Some respondents believed that the tradition of honouring the wisdom of the elders could be stifling the participation of young people. When asked if more young people could be brought along to meetings, one respondent said: *Yeah, but the oldies would probably still send them out to clean the toilets and do the dishes instead of involving them in the discussions* – KI community member, 2017.



Dr Helen Gardyne – NPH General Practitioner. © K Matheson 2017

The second most commonly identified group were 'men'. Other groups recognised as marginalised included those with addictions, those with mental health issues, those geographically isolated, the poor, people without their own transport, the old, and the very young.

Existing cultural practices around leadership and decision-making strongly influence who participates. Older people are specifically sought out for discussion and consultation and also make up a strong majority at open community meetings. The views of existing hierarchies from the community were also identified as an aspect of society that gets reflected when it comes to community participation. Individuals with lineages of traditional leadership and wealth were often seen to have more power within NPH and other major organisations acting in the community. Both of these factors were acknowledged during the interviews as a challenge for NPH. Key informants expressed a desire for improved equity and diversity in community representation - specifically, increasing the engagement of young people, the poor and other groups acknowledged as marginalised. Poor infrastructure conditions (particularly road, telecommunications and lack of any public transport) on the rural East Coast create additional barriers, especially for the most marginalised. This requires NPH to be innovative in the way that it delivers services and creates engagement opportunities for communities.



Cheryl Johnson – NPH Rural Health Nurse and Team Leader.
© K Matheson 2017

Finding balance

Prioritising community perspectives can be challenging, while also trying to manage clinical best practice and the operational and resource challenges of the organisation. This often leads to the organisation having to make difficult choices.

NPH is currently running 'nurse only days' in several of the health centres, as the community has requested a number of clinic days that is more than the number of doctors NPH can supply. While nurse only days has, on one hand, been seen as a positive solution to this dilemma, on the other hand it is felt by some that other health services in New Zealand wouldn't do this. This was expressed as one example of many, where NPH is perceived by some of its own staff members as over stretching itself to please the community (other parts of New Zealand, including urban areas, do hold nurse-led clinics). However, as in many health services, the issues of rationing access to health resources and changing professional roles within a service tend to get conflated.

Another example of how the tension is played out between community expectations and clinical best practice is described in managing NPH involvement in the *Lean On Me Concert*.

Case Example: Lean On Me Concert

Following a number of youth suicides in the region, families of those who had died got together and wanted to do something in the community to prevent further tragedies. Their major concern was that families were not able to recognise the warning signs, so they wanted to raise awareness. The other aim was to bring the community together after suffering such loss. The community group started holding meetings to develop the idea of holding a concert. NPH was invited to be part of these meetings and a partner in holding the event.

While NPH wanted to support the community initiative, there were tricky discussions to be had internally around the safest way to do this and what messages NPH was going to give to the group who already had some definite ideas about what they wanted to do. NPH had to ensure it was safe to do this and held multiple meetings and planning sessions across several months.

As plans progressed, NPH carried out background work consulting with experts on what the do's and don'ts are regarding big events around suicide. This was challenging, as there are some who believe such an event would do more harm than good. The NPH found little solid evidence to guide them.

NPH's main goal was to try and support the outcomes the community group had identified and not to take over with clinical advice.

We were very mindful that the whānau (family) group owned the idea and the hosting – we were there just in a supportive role. – Community member and NPH employee

At the concert, the group asked NPH just to be visible. On stage they introduced the mental health team members, what we do, how to access us, and where we would be if anyone wanted to talk. One team member got up and spoke about her own personal experience. This was very different to the usual clinical approach that wouldn't include self-disclosure. – Community member and NPH employee



Frances King - NPH Mental Health and Gisborne Services Manager standing in front of poster for Lean On Me Concert.
© K Matheson 2017

How participation is perceived

Interviewees from both the community and NPH felt that participation wasn't as strong as it used to be and needed to be improved. The community felt that while links were still strong with some members of the community, a divide had started to grow between NPH and the greater population. They said that too often meetings were to bring bad news and that they would find out information when it was too late for them to contribute to a solution. People weren't sure what the process was to engage with the Board under the current model, or what they could expect in terms of feedback or follow up from their suggestions. The disestablishment of the community representative model was often cited as a reason for this, and a possible solution was to get it back to how it was. Although participation often happens at the frontline, community members said they are happiest when they have a direct link to the Board or executive leadership.

How is participation sustained?

Some believed that participation has been sustained due to the East Coast community having been under constant threat of losing their health services. For at least 20 years TDH and its predecessors have been floating plans to close the Te Puia Hospital facility. This has brought people together, and may be the reason the community is very active and vocal when it comes to issues to do with NPH. The organisation currently faces a financial crisis, and participation is sustained because the people genuinely believe NPH is important, often offering time and resources in kind to keep it alive. Participation is also sustained when people feel their input is benefitting their own community, and this has a self-perpetuating effect.

An alternative view was expressed that financial difficulties were undermining participation. Because people feel they have been fighting so long to get ownership of their health service, they are now struggling to transition into focusing or shaping it and making it what they want. The organisation's external focus on the struggle for ownership and adequate resourcing is itself undermining community confidence around adequate service delivery. They feel they are currently in the position where they have ownership only in theory. They are having to run the health services how the government tells them to. They feel the Crown has not honoured its commitments, with a level of resourcing that is well below Treaty expectations.

The failure of the Crown to live up to its Treaty obligations was the substance of a legal claim mounted by a Ngāti Porou doctor from Tolaga Bay, the late Dr Paratene Ngata. Dr Ngata wrote the claim in 2008 from his deathbed:

I have brought the claim in the hope that the Crown will meet its Treaty obligations to Ngāti Porou by investing in and providing Ngāti Porou Hauora with the resources to help restore the health and wellbeing of Ngāti Porou, so that they can enjoy the same level and quality of life as others in Aotearoa (Ngata, 2008).

The Crown has recently settled this and other outstanding Treaty claims with Ngāti Porou, but this settlement is yet to have a material impact on the health services or the people's health. Provision of health services remains the government's responsibility.

3.7 Motivations, burdens and risks

The most common and strongly expressed motivation was people's connection to the community and sense of responsibility to serve them. Although to some this may be seen also as a burden, no interviewee expressed this. When asked, they responded that it was a privilege.

In terms of burden, this was expressed in a more practical sense. People often expressed stretching themselves too thin in order to try and please all the competing interests. This can lead to burnout.

The main risk expressed is that of compromising personal relationships in the community. It is sometimes difficult to meet the expectations of people in the community while balancing operational responsibilities, and through this, representatives felt concern that people may lose faith in them.

Loss of decency and credibility, if we care enough.... in trying to achieve the long-term goal, we risk the short-term relationships when we have to make tough decisions. – Community member and NPH employee, 2017.

During the time these interviews were being conducted, a tragedy occurred in the community, with one of NPH's health centres being burned to the ground.

Case Example: Tikitiki Health Centre

On 27 January 2017 a fire destroyed the Tikitiki health centre operated by NPH. This has devastated both staff and the community, not just due to the loss of the building, but there is a real threat that NPH may be unable to financially justify rebuilding and running the clinic.

After visiting the still smoking remains of the building, the NPH CEO went directly to Radio Ngāti Porou where she was able to communicate initial messages of condolence and reassurance to the community. What was important was to recognise that the community was deeply worried about the future of their service, and NPH wanted to reassure them that no decisions would be made without their involvement. A few days later, NPH took another opportunity to send a representative along to a gathering taking place to welcome a local schoolteacher in Tikitiki. Here members of the community were able to ask questions and speak directly with NPH decision-makers. Over the first week, the community made offers to run the clinic from other local community buildings, such as a school building and the fire station.

NPH have many difficult decisions ahead of them. This situation is a live example of balancing tragedy, resource based decision-making, and community expectations.



NPH CEO Rose Kahaki and Ruatoria Station Officer Monty Manuel outside the remains of Tikitiki Clinic © Gisborne Herald 2017

3.8 The enabling factors

The profound influence that cultural practice has on participation has already been described.

The future

As well as improving wellness and life expectancy for people on the East Coast, NPH has an aspirational vision for the future. Strategic plans include:

- To develop innovative and locally relevant services that reflect Ngāti Porou people, and harness the commitment, creativity and capability of Ngāti Porou;
- Leveraging existing relationships with New Zealand universities to become a centre of excellence training facility in rural and Māori health;
- Honouring the people's connection to the land by becoming an eco-friendly hospital and health service;
- Create global partnerships and initiatives with other rural and indigenous health services to improve access to expertise and inspire people in the health workforce to work in rural areas.



Gina Chaffey-Aupouri (right) – NPH rural health nurse with Kate Matheson, research assistant. © K Matheson 2017

As one respondent put it:

Within its whānau and human resources Ngāti Porou has vast capability. They are spread across the country and across the world. We have achieved much. I want future generations to be proud of who they are and to have connections back to their homeland and to continue to be able to cement a way to keep those connections and make a contribution. Enable people to take ownership of their health. Provide for future generations to enjoy their heritage – live better, live longer. – KI community member and NPH Board member, 2017.

While IT and social media tools are being used successfully (and NPH wants to better utilise this), most people held the view that it mustn't replace face-to-face discussion. The [Huringa Pai Facebook page](#) is one example of a community initiative that NPH is involved in, where a lot of interaction happens online.

Case Example: Huringa Pai

The Huringa Pai programme is a community designed and developed programme to address the large numbers of people in the community developing diabetes and associated heart disease. The project was initiated by patients of NPH's Puhi Kaiti Medical Centre and supported by the centre's health professionals.

At the heart of this was a firm belief that only an intervention that is 'by families, for families' will be effective. Organisations such as NPH are involved in a supporting role. In its development, a meeting was held for all those interested in being involved. The theme of that meeting was: What would help you or your family to stay as healthy as you would want it to be? After opening the meeting with a traditional prayer, a NPH GP gave a presentation on the current state of health of the community, particularly in relation to diabetes. This set the scene for the issue that desperately needed to be addressed. Participants then broke into groups and brainstormed ideas about what the programme should include, and what communication channels the group should use.

The ideas that came out of this meeting have been used to develop the content of the programme. This began with a selected few to start things off and as the programme has grown, more ideas from the initial list have been added. Popular components of the programme include:

- weekday lunchtime walking group
- weekend walking group
- regular challenges, such as 'the Everest challenge' where a local hill had to be climbed a certain number of times to reach the equivalent height of Mount Everest
- Zumba dancing and exercise
- information sessions on nutrition and reading food labels
- cooking classes.

It was decided that a public Facebook community group page would be used to manage communications, share ideas, record the journeys of the members and inspire others. This page now has over 550 followers.

A NPH GP is heavily engaged in following up the progress of each participant and attends the programme sessions himself along with several other NPH staff members.



Community member Maaka Rewiri © K Matheson 2017

The [Huringa Pai](#) Facebook page states that:

Various others have tried to replicate this model and there are a lot of organisations that have tried to gain from it by using it for funding applications for their own gain. It is only Huringa Pai that has been proven to make a difference for our whānau (families) (which remains a zero budget, nil funded whānau movement).

To learn more about Huringa Pai, listen to the [Huringa Pai audio interview](#) with community member Maaka Rewiri as he shares his experience.

Although the challenges of recent years have distracted people from focusing enough on the community participation aspect of NPH, actors across all levels expressed a commitment to reprioritise this. Specific plans included exploring different channels to increase participation of young people and others in the community who may not currently be engaged and collectively recommitting to the greater long-term mission.

4. Outcomes

The outcomes from community participation in NPH are inseparable from the outcomes of the service itself. In assessing health outcomes, poor social and economic conditions underpin the poor health outcomes. Effective health services can help moderate adverse social conditions.

NPH's performance as a health service has been compared favourably with other health services in the district and nationally, despite dealing with a population with the country's highest level of morbidity and mortality. As noted in *Appendix 1*, NPH general practitioners and nurses have provided higher rates of consultation compared with the national average. NPH's needier patients (mostly Māori and people from high-deprivation areas) have visited 1.5 times every quarter compared with 1.2 times in NZ as a whole. In 2015, NPH outperformed both Tairāwhiti DHB practices and New Zealand in breast cancer screening, childhood immunisations for 2-year olds, and cardiovascular disease risk assessment. In terms of geographical access, the service goes to great lengths to make services available and

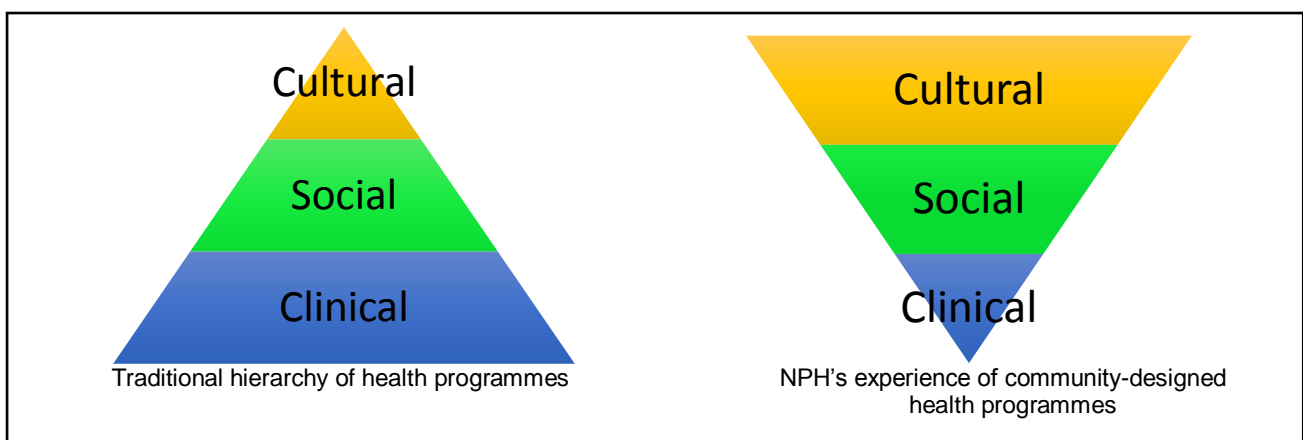
acceptable. Within the NPH population, relative access inequalities remain for particular population groups; however, informants had a variety of views as to which groups those were, suggesting they may differ in different clinics. Overall, NPH is a high-performing health service in a geographically challenging environment. Despite the positive contribution of health services, they have a limited impact on the overall health of the population, due to the overwhelming influence of other health determinants.

NPH has also looked at its impact on the local economy. As the majority of the 150 staff employed are from the local area and are Māori, the economic impact of the health service is significant, as previously noted. Ultimately, it was viewed that strong community participation will lead to services that better fit the needs and requirements of the people. This in turn will increase the number of people addressing their health issues and being in control of their health destiny. It will mean a healthier population.

When people are assertive around their own care – my care isn't sitting there in a file on the doctor's computer, it's me and my actions – KI community member and NPH employee

It was observed that strong social participation often changes the hierarchy of what is considered important in a programme or service model. Models move from being largely (or completely) clinically focused to prioritising social and cultural components. This is outlined in Figure 4.

Figure 4: Traditional vs NPH community-designed health programmes



Source: Figure created for this report by researchers

This concept is demonstrated in the design of the *Wahakura* programme:

Case Example: Wahakura Programme

In response to high rates of Cot Death (sudden unexplained infant deaths occurring while sleeping) in Māori children, the Nukutere Weavers' Collective in Gisborne developed the *wahakura* in 2006, the country's first Māori safe-sleeping device. Research shows that Māori families like and embrace the *wahakura* as a cultural device to keep baby safe (Baddock SA, 2017). It is also an effective vessel around which to pass on a range of antenatal messages.

NPH initially launched the *wahakura* programme by holding a weaving workshop to make the safe-sleeping devices. However, attendees ended up being mostly NPH staff rather than the young mothers they had hoped would attend. Having learnt the skill in the workshop, NPH *Kaiawhina* (community health workers) started offering to teach expecting mums one on one. This format was much more successful and *Kaiawhina* have been able to use the time together to talk about safe sleeping, breastfeeding and also develop health plans with each mum. In the Tokomaru Bay area, all new mothers on the *Wahakura* programme are breastfeeding and are following complete health plans.



Photos clockwise:

1. Tiare White with her *wahakura*
2. Baby White in his *wahakura*
3. Santana Duncan with her *wahakura*

All photos © Ngāti Porou Hauora

5. Discussion

Ngāti Porou Hauora demonstrates a high level of community control and participation in health. Even the framing of this study, 'No decision about me, without me,' underplays the extent of participation observed. Community participation in Ngāti Porou is not confined to a 'community' participating in a health service or programme. The extent of the health service, and its workers, participating in the community is seen as relevant, or more relevant, and inseparable from communities participating in the health services. This interplay between the health service and the community is evident in the high level of local participation in the health workforce. Families and close relatives of health workers make up the bulk of the patients. In economic terms, NPH's contribution to employment directly addresses the determinants of health by improving local incomes and opportunities.

A similar conclusion has been reached about Health in All Policies in other parts of the world. Their success depends as much on health participation in other sectors as the reverse (Kickbusch 2011).

However, participation in Ngāti Porou Hauora is not being pursued primarily because of its functional value in improving health service effectiveness. Instead, it arises from a long running historical belief system that places a high degree of importance on Ngāti Porou sovereignty over all things Ngāti Porou, including health and health services. This historical belief system is reinforced through cultural and customary practices, including the role of elders and the conduct of public forums and gatherings.

The implication of this is that these underlying values shape the participation agenda and are not wholly reliant on formal policies and protocols for its sustenance. In fact, the formal documents of the organisation do not have a strong emphasis on participation; they appear to have been written for

external audiences in this regard, rather than as policy direction that reflects actual practice of the organisation. The advantages of this value-based approach is that participation guided by deeply held values can be exercised in a fluid and flexible way, whereas more definitive structure and tools may run the risk of 'going through the motions' rather than applying participatory practice as it is intended.

The success of the Ngāti Porou Hauora activities includes their survival as the only Māori controlled rural hospital in New Zealand and their commendable performance in the delivery of health services. Despite that success an increasing gap has developed between what the government and the local DHB are prepared to fund and the actual cost of services. This exposes a fundamental fault line between community control of health services in a situation where resourcing is controlled by parties outside the community.

Despite a long standing Treaty obligation to pursue health equity, and abundant evidence that Ngāti Porou people on the East Coast suffer from the worst health status in the country, the government's health funding arms have not supported the model of service delivery currently pursued by NPH and the community. This funding tension also is impacting in turn on the participation of the community with the health service. The community correctly perceives its health services to be under threat, the service itself is focused primarily on trying to address its budget deficit, and has less time and resources to interact with and respond to the health service needs of the community.

Interviewees from Ngāti Porou believe the level of participation in their service could be improved, and some relate back to previous decentralised configurations where each *rohe* (area) had a more direct input into the organisation's activities. As noted above, the current financial difficulties are seriously undermining the relationship between NPH and the community, putting the service under considerable pressure.

5.1 Learning for other settings

There are a number of lessons relevant to other sites from the experience of Ngāti Porou Hauora.

First and foremost is to make the connection between participation and the existing cultural practices and belief systems already held by the community. Just as Ngāti Porou history is unique to Ngāti Porou, all communities have their own unique history and long running cultural belief systems. Exploring and understanding the specific cultural and historical context and designing participation from that basis is likely to build stronger participatory models than when they are health-service inspired. The challenge for other settings will not be to invent a system, or apply tools to make community participation happen, it will be for them to participate enough themselves in the activity of the community so that the existing local practice starts to shape all interactions, including those of the health sector. Most health systems undertake a health needs assessment, and use this as the basis for health planning. While useful, it is inadequate on its own, as it seldom describes the social and cultural milieu giving rise to those conditions nor does it lead to a sense of ownership. This wider knowledge is integral to the communities themselves, hence the argument in favour of their participation in policy and planning processes. Ngāti Porou achieves this through its blurring of the institutional distinction between health and wider community functions.

Participatory processes are two-way in nature. Health service participation in the community is recognised as integral to community participation in health. There are various methods by which this interplay occurs in NPH that have relevance to other sites, including:

- Community members' participation in recruitment practices;
- Recruitment of health staff predominantly from the community being served;
- Community participation in planning and policy processes;
- Community participation in research, with regular feedback to communities;
- Health staff participation in community discussions not directly related to health;
- Health staff participation in community events not directly related to health.

This broadens the 'value' a health service contributes to the community beyond the provision of health services to include its contribution to cultural practice and the economy. The process of participation described above tends to follow long established cultural practices of how meetings are held, consensus reached, and decisions made. Such approaches are unique and may not be replicated in other communities, who will have their own cultural practices in this regard. More recently, NPH has established the 'economic value' that the service adds to the community. Thus a health service is seen

as an economic contributor to the community, alongside its cost and the economic benefits arising from direct health provision.

Finally, this case study also illustrates the influence of national health policies and structures, and how these are not always translated into lower levels of the system. At the national level in 2000, New Zealand developed a strategic approach to health that was favourable to community participation and addressing health inequities, which provided opportunities for services such as NPH to flourish. However, over time, the national focus has wavered, and the meso-level structures such as district health boards, when faced with their own financial pressures, have not been able to sustain this policy direction. The focus on overall policy was replaced with an extreme focus on specific targets, to the detriment of system goals such as equity. The lesson here is to ensure both national and meso-level incentives stay aligned and focused on these important outcomes over an extended period to allow community participatory approaches to develop and flourish.

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7. Appendices

7.1 Ngāti Porou Hauora Dashboard: Summary of results as of July 2015

Indicator	Legend Conditions
Urgent attention	NPH % is worse than Tairāwhiti by at least 10%
Warning	NPH % is worse than Tairāwhiti by at least 3% but less than or equal to 10%
Fair - could be better	NPH % is about the same as Tairāwhiti within +/- 3%
Keep up good performance	NPH % is better than Tairāwhiti by at least 3%

Domain/ Indicator	Indicator measure by:	Data period	NPH	Tairāwhiti	Total NZ	Target
Social Determinants						
NZ Deprivation Index	1a Percentage of Mesblocks with high deprivation (9-10)	Census 2013	91%	52%	19%	
Income	1b Equivalised Household Income	Census 2013	38,700	47,500	57,800	
Ethnicity	1c Proportion of Māori in population	Census 2013	70%	49%	16%	
Housing	2a Children (Under 15 years) living in crowded households	Census 2013	5%	4%	5%	
Education	3a Early childhood education (0-6 y)	Sep-14	94%	95%	93%	98%
	3b 18 year olds with NCEA Level 2 or equivalent	2013	74%	66%	63%	85%
	4a Unemployed people 15y and over	Census 2013	14%	9%	7%	
Employment	4b Youth not in education, employment or training 15-19 y	Census 2013	16%	14%	11%	
	4c Youth not in education, employment or training 20-24 y	Census 2013	32%	28%	15%	
Population Coverage and Service Access						
	5a NPH PHO Enrolment in Tairāwhiti population	Jan-Mar 2015	19%	97%		
Access to PHO	5b PHO Coverage for the Coast Rural Areas (East Capte to Tolaga)	Census 2013	98%			
	5c PHO Coverage for Urban Areas (Kaiti and Tamarau)	Census 2013	27%			
	5d PHO GP+Nrs consults High Need	Jan-Mar 2015	1.50	1.26	1.16	
Intermediate Performance Outcomes						
	6a Full or exclusive breastfeeding (6 wk)	Apr-Jun 2015	71%	74%	74%	75%
	6b Full or exclusive breastfeeding (3 m)	Apr-Jun 2015	33%	60%	55%	60%
	7a Proportion of smokers 15 - 75y	Jan-Mar 2015	43%	34%	18%	
Prevention	8a Childhood Immunisations 24 Month Olds Total Population	Jan-Mar 2015	100%	96%	93%	95%
	8b Childhood Immunisations 24 Month Olds High Need	Jan-Mar 2015	100%	95%	94%	95%
	8c Childhood Immunisations 8 Month Olds Total Population	Jan-Mar 2015	90%	94%	94%	95%
	8d Childhood Immunisations 8 Month Olds High Need	Jan-Mar 2015	90%	92%	93%	95%
	9a Cervical Screening All 25 - 69 y	Jan-Mar 2015	73%	76%	79%	
	9b Cervical Screening High Need 25 - 69 y	Jan-Mar 2015	74%	71%	72%	
	10a Breast Screening Coverage All 50-69 y	Jan-Mar 2015	71%	74%	74%	
	10b Breast Screening Coverage High Need 50-69 y	Jan-Mar 2015	71%	69%	69%	
Primary Health	11a CVD Risk Assessment Total Population	Jan-Mar 2015	91%	88%	87%	
	11b CVD Risk Assessment High Need	Jan-Mar 2015	91%	87%	86%	
	12a Diabetes Detection Total Population	Jan-Mar 2015	92%	92%	119%	
	12b HbA1c <=64mmol/mol in the last year Total Population	Jan-Mar 2015	52%			
Health Outcomes						
	14a Premature babies Total Population	2009-2013	8.4%	7.8%	7.5%	
Births	14b Premature babies Māori	2009-2013	8.5%	7.9%	8.0%	
	15a Low birth-weight Total Population	2009-2013	7.7%	7.6%	5.9%	
	15b Low birth-weight Māori (less than 2500g)	2009-2013	8.2%	8.5%	6.8%	
	16a ASH (0 - 74 y) Total Population	2011-2013	3,116	2,875	2,136	
Ambulatory Sensitive Hospitalisations (Age-standardised rate per 100,000)	16b ASH (0 - 74 y) Māori	2011-2013	3,487	3,552	3,134	
	16c ASH (0 - 4 y) Total Population	2011-2013	8,037	7,163	4,641	
	16d ASH (0 - 4 y) Māori	2011-2013	7,994	7,616	5,640	
	16e ASH (45 - 64 y) Total Population	2011-2013	3,321	3,077	2,674	
	16f ASH (45 - 64 y) Māori	2011-2013	4,598	4,778	5,022	
	17a All cancers Total Population	2009-2012	206	200	192	
Cancers (Age-standardised rate per 100,000)	17b All cancers Māori	2009-2012	253	227	231	
	17c Lung cancers Total Population	2009-2012	33.7	23.7	15	
	17d Lung cancers Māori	2009-2012	50.4	46.2	42	
	17e Cancers of the Digestive organs in Total Population	2009-2012	42.4	33.1	35	
	17f Cancers of the Digestive organs in Māori	2009-2012	51.9	41.7	47	
Hospital Admissions	18a Avoidable Admissions Total Population	2011-2013	5,089	4,738	4,195	
	18b Avoidable Admissions Māori	2011-2013	5,681	5,480	5,571	
	19a Avoidable Deaths Total Population	2007-2011	219	194	106	
Mortality	19b Avoidable Deaths Māori	2007-2011	294	265	227	
	20a Amenable Deaths Total Population	2007-2011	169	114	74	
	20b Amenable Deaths Māori	2007-2011	222	194	162	

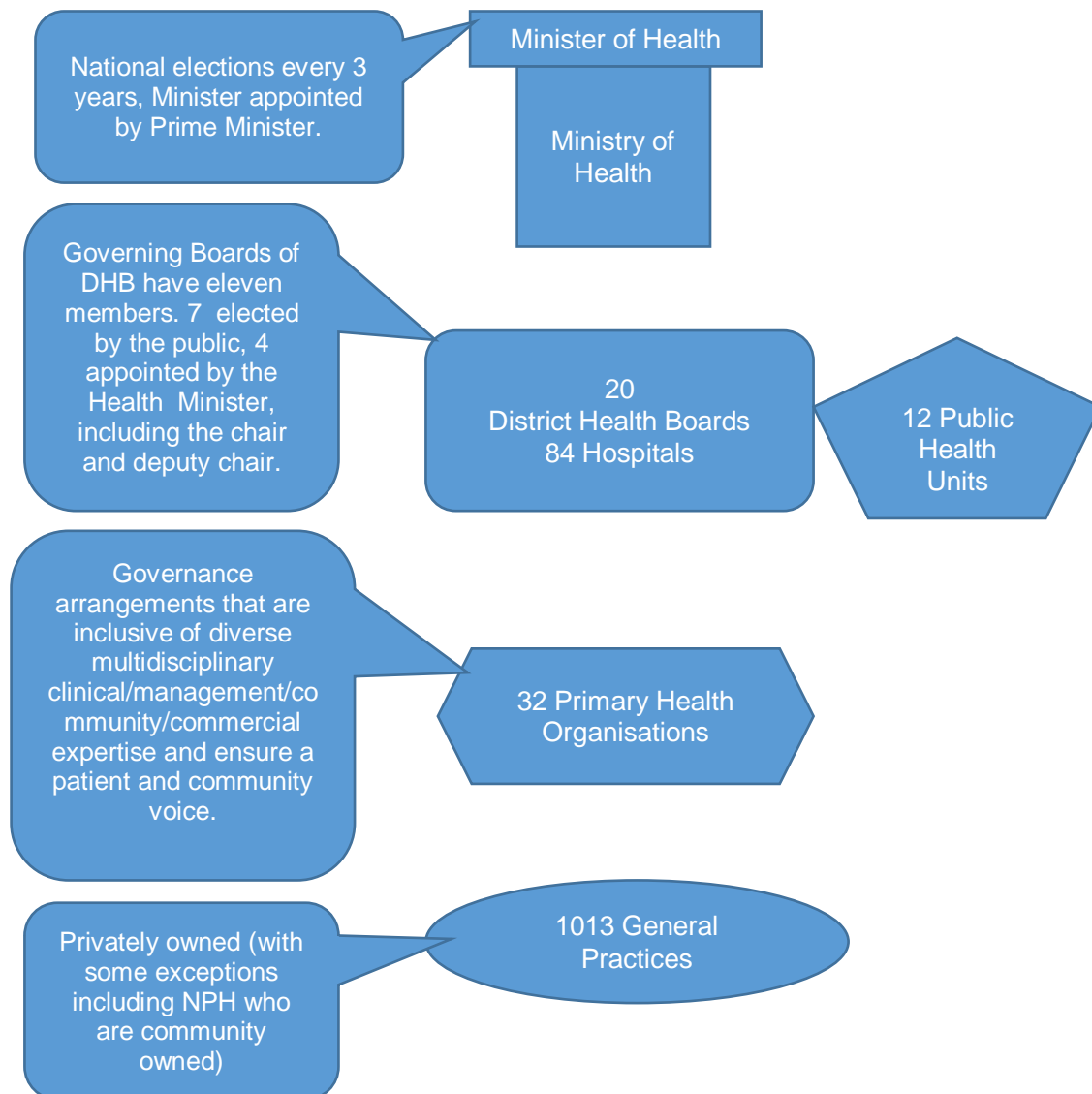
Source: Ngāti Porou Hauora 2016

7.2 Map of sub-tribes (rohenga) and meeting houses (marae) in the Ngāti Porou area



Source: Te Runanganui o Ngāti Porou 2017a

7.3 New Zealand publicly funded health system structure from a public participation perspective



Source: Prepared by the authors, from information on the New Zealand Ministry of Health website.

Changing socio-political and economic conditions and social inequalities in wellbeing within and across countries affect health in ways that call for strategic collective leadership and action.

Health services need to craft approaches that successfully prevent and care for complex co-morbidities and promote health in populations that are diverse, literate and socially connected. Participation in health and in decisions on services is increasingly viewed not simply as a means to better health, but claimed as a democratic right.

How are local health systems organising social participation and power to meet these opportunities and challenges?

There are many innovative, practical experiences and insights from those involved that we can learn from.

Shaping Health, an international project, is gathering and sharing evidence and learning on how community members are participating in decisions on and actions in local health systems across a range of high, middle and low income countries. It aims to build peer to peer dialogue and exchange on approaches and practices that can be adapted in the USA and in other countries.

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Exchanging on social power in health

NPH and TARSC,
2017