

THE HOSPITAL TRANSFERS PROJECT: Supporting whānau engagement during hospitalisations

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Re-vising should include a re-imagining and re-memembering of
Indigenous health systems for transformed hospital systems

Whānau support is vital during hospitalisations, particularly for patients transferred or hospitalised away from home. A significant reorientation of the health system is required to facilitate the active engagement of Māori whānau in the healthcare of a whānau member.

*Poipoia te kākano, kia puawai
Nurture the seed and it will blossom*

I INTRODUCTION

For Māori, as the Indigenous peoples of Aotearoa New Zealand, the care of those who are unwell has always been the concern of whānau (family) and community. Māori have established knowledge systems relating to health and wellbeing, and long-standing practices for both promoting good health and responding to illness (Taskforce on Whānau Centred Initiatives [hereafter referred to as the Taskforce], 2009; Waitangi Tribunal, 2001). These systems recognise the importance of relationships between peoples and broader environments to health and wellbeing (Mark & Lyons, 2010; Taskforce, 2009), something which has been more recently acknowledged in Māori health strategy and policy by government (Ministry of Health, 2014b).

In contrast, prevailing health service models, including hospitals, still largely reflect the imported health system that was imposed in Aotearoa New Zealand through colonisation. Our research on hospital transfers found that whānau often wanted to meaningfully participate and become or remain

active decision-makers in away-from-home hospitalisations for their whānau member (Masters-Awatere et al., 2017). However, hospital policies and practices did not always facilitate engagement. While whānau-centred care is acknowledged as an aspiration for Māori (Ministry of Health, 2002; Taskforce, 2009), significant shifts to the ways in which hospitals are organised and resourced are necessary to create environments that foster whānau involvement in the care of their loved one during a hospital admission.

The Hospital Transfers team sought to explore facilitators and barriers to whānau engagement in the process of a hospital transfer or an away-from-home hospitalisation. Drawing attention to the relationship between Māori cultural

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practices and the New Zealand health system, our focus is on highlighting opportunities for whānau-centred practices to be operationalised as promised within existing policy. This paper provides an overview of findings from the Hospital Transfers project and their relation to related national policies and frameworks. Firstly, a brief overview of the context of the hospital system for Māori is provided. Key findings relating to hospital policies for supporting whānau engagement in hospital transfers and away-from-home hospitalisations from whānau interviews and an environmental scan are then discussed. Finally, the paper identifies key areas of policy relevance and strategic points for leveraging change at the level of health providers, hospitals and the overall health system in order to better support whānau engagement with their loved one.

II THE INTRODUCTION OF PUBLIC HOSPITALS AND THEIR SERVICES

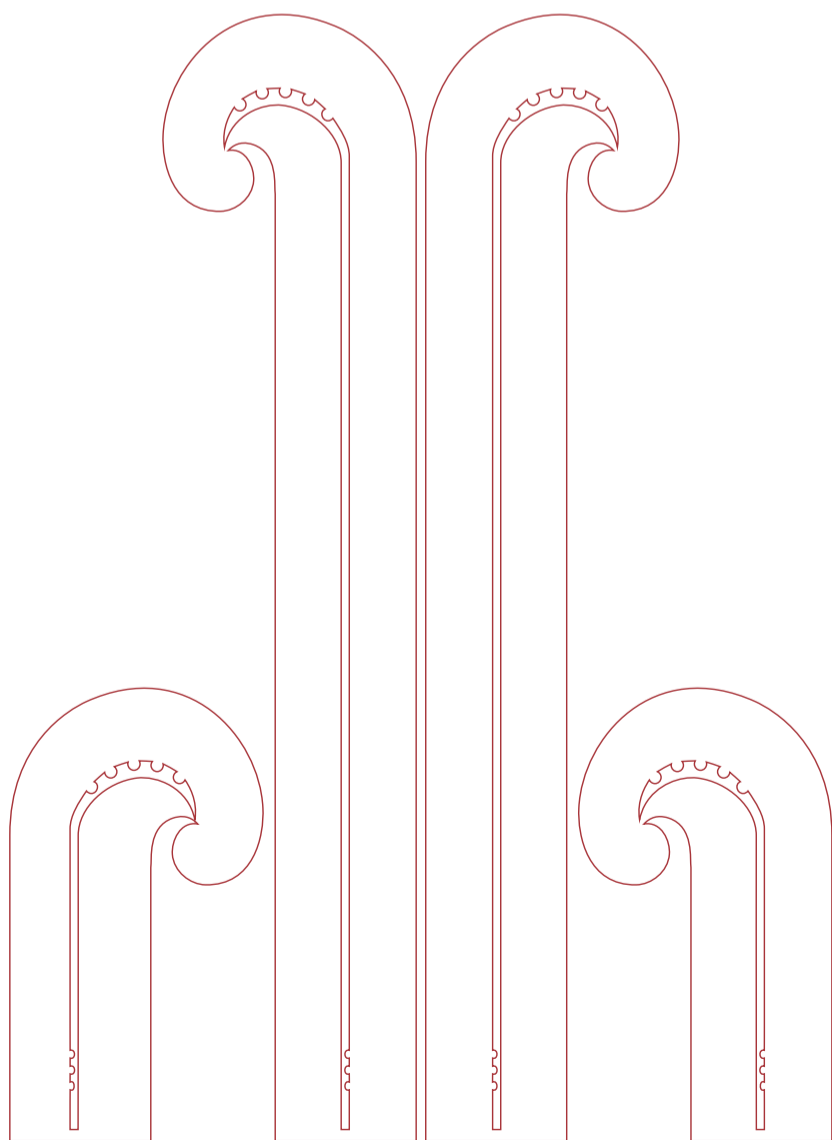
New Zealand's hospital system was modelled on the British health system and oriented towards colonial notions of medical science and "care" (Waitangi Tribunal, 2001). Health services, particularly those designed and delivered by colonial governments, reordered the provision of healthcare to align with these approaches. Government involvement in healthcare provision for Māori followed the signing of the Treaty of Waitangi (Waitangi Tribunal, 2001). Although privately funded hospitals already existed in a number of areas, four state-funded hospitals (in Wellington, Auckland, New Plymouth and Whanganui) were established by the beginning of the 1850s (Salesa, 2001, p. 17) as part of a public hospital programme under Governor Grey (Waitangi Tribunal, 2001). From early on, hospitals were linked with broader state goals of assimilation and "civilisation" (Salesa, 2001; Waitangi Tribunal, 2001):

The maintenance of these hospitals is a matter of paramount importance to the native race; whilst, if the question is also viewed as a means for the diffusion of civilization, by showing the natives the value of and accustoming them to European houses, food, and comforts, and also as a means of gaining their attachment to the British Government and British race, I think it becomes still more evident that the proper and effectual maintenance of these hospitals is a matter of great importance. (Governor Grey to Secretary of State, 1852, as cited in Waitangi Tribunal, 2001, p. 87)

[Wellington hospital] a beautiful one, as fine as any you would see in England for its size. It is a powerful engine for gaining an influence over the Native Mind, for the alleviation of suffering ... (J Fitzgerald to Earl Grey, 1855, as cited in Salesa, 2001, p. 17)

The first quote shows the colonial intention of showing Māori the value of European comforts and attachment to the British. Given the current state of Māori health, the irony is not lost; especially given the earlier observation by John Liddiard Nicholas in 1817 that Māori were a well-built, muscular and healthy people. Nicholas's comment that Māori "health [was] drawn from such sound principles must make physicians almost useless" (as cited in Kingi, 2011, p. 92) highlights the success of traditional Māori health and healing practices.

The second quote, from J. Fitzgerald, clearly states the intended strategy of hospitals as a colonial tool to influence the 'Native Mind'. The Waitangi Tribunal (2001) notes that although these early hospitals were to provide care to Māori populations, they were built in areas (Wellington, Auckland, New Plymouth and Whanganui) where Pākehā colonial populations were concentrated, immediately creating a need for many Māori to travel for hospital care. This phenomenon of travelling for hospital care has, therefore, been a long-standing feature of state hospital provision for Māori and is linked to broader issues of Māori communities' access to



the health system and the system's lack of responsiveness to Māori.

During the 1850s, Māori were the dominant group in Aotearoa New Zealand, possessing the majority of land (R. Walker, 1990). Consequently, a key contribution of land by Māori for the establishment of hospitals in New Zealand was necessary. In the years that followed the establishment of state hospitals, changes were made to the ways in which they were funded and governed, with decreasing central government control and greater regional and local involvement over time (Waitangi Tribunal, 2001). As the Waitangi Tribunal (2001) notes, the effect of this shift in focus and governance was that “a hospital programme targeted mainly at Maori [sic] that also provided a safety net for indigent settlers had been converted into a settler-controlled public hospital service with limited subsidies for the treatment of Maori patients” (p. 121). While Māori comprised the majority of patients in the early years of the state hospitals, increasingly Pākehā patients outnumbered Māori patients, and barriers to hospital access for Māori grew (Waitangi Tribunal, 2001). Hospitals were publicly funded. Barriers for Māori to publicly funded hospitals in the 1860s included user-pay hospital service fees, which made early access to hospital services incredibly difficult for Māori (Barton, 2008; Waitangi Tribunal, 2001).

District hospital boards were set up under the Hospitals and Charitable Institutions Act 1885, but without provisions for Māori representation (Waitangi Tribunal, 2001). As the number of state hospitals increased over time, they continued to be located in areas that served Pākehā, not Māori, populations. Māori access to hospitals and other health services in the early 20th century remained restricted and partial (Wanhalla, 2006), despite a number of initiatives, such as Māori councils, district nurses and those led by Māori communities (King, 2019; Waitangi Tribunal, 2001). As Charlotte Williams notes,

... Māori use of hospital services, which remained low, depended on their circumstances, including ability to afford both travel and treatment—promises of free hospital services where Māori had provided land or income from native reserves were not consistently kept (Williams, 2007, p. 7, as cited in King, 2019, p.74)

The amount of barriers that existed for Māori in accessing hospitals is astonishing considering public hospitals were often established in New Zealand on the goodwill of Māori who originally gifted their land. Now that we are able to review historical documents and observe British colonial intentions for hospitals as a tool of colonisation, the context of the current negative experiences of whānau Māori can be better understood.

The structure of the public hospital system

New Zealand's health system currently comprises 20 District Health Boards (DHBs) located around the country. DHBs are responsible for the management of publicly funded hospitals in their area, with differing levels of hospital services and specialisation between hospitals and across the

DHBs (Ministry of Health, 2013b). According to the Ministry of Health (2019), there are currently 84 “certified public hospital providers” across the 20 DHBs providing a range of levels of services, although many of these providers will only be providing some limited, specialist services.

The structure of the contemporary health system, including the public hospital system, is such that the provision of secondary and tertiary care services¹ often necessitates referral and transfer to settings beyond where patients usually live; in other words, patients are transferred to a large secondary or tertiary hospital in another town or city, where they can receive more specialist care (Butt et al., 2013; Freebairn, 2012). Specialised tertiary health facilities are situated in the major cities of New Zealand (Brabyn & Skelly, 2002), meaning access to specialist care requires patients and their support people to leave their home and community (Mbusi, Fulbrook, & Jessup, 2017). The need to leave family and friends can be financially and emotionally difficult for Māori who live “in rural areas and therefore have longer travel times to their nearest GP” (Brewer, Pearce, Day, & Borman, 2012, p. 336). Additionally, locating specialised health facilities geographically means that hospital services of small, relatively isolated facilities can be more costly than larger facilities that have the ability to provide more complex services (Barnett, 1984). The drive to centralise care has resulted in different levels of specialist services being available at different hospitals.

Māori hospitalisations and experiences of hospital services

Inequities in hospitalisation between Māori and Pākehā are well documented (Barton, 2008; Ministry of Health, 2014b; Reinfeld & Pihama, 2007; Robson & Harris, 2007). Historically, these inequities have manifested as lower hospital admissions for Māori relative to other population groups. Barton (2008) identifies that lower utilisation of hospitals by Māori was influenced by the orientation of hospitals to colonial healthcare models, preferences of Māori patients for treatment informed by Māori worldviews, mistrust in hospital services and staff, and constraints on whānau visiting arrangements. Colonial care models have been further entrenched in a health system that has followed a neoliberal agenda since the mid-1980s (Masters-Awatere, 2015).

In the contemporary Māori context, a pattern of higher rates of hospitalisation for conditions that should be amenable to prevention or primary care intervention is relatively long-standing (Ministry of Health, 2013a; Robson & Harris, 2007). Māori have a higher likelihood (relative to non-Māori) of being hospitalised for a range of conditions, including cardiovascular disease, stroke, heart failure, rheumatic heart disease, asthma and chronic obstructive pulmonary disease (Ministry of Health, 2015). Although Māori hospitalisation rates are higher for many health conditions, the rates do not necessarily reflect health need; that is, Māori hospitalisation rates are not as high as they should be given the prevalence of health conditions and mortality rates among Māori (Robson,

Robson, Harris, & Purdie, 2007). In the next section, we outline how multiple forms of discrimination may impact negatively on the experience of Māori when they present at hospital.

III INEQUITIES IN HOSPITAL SERVICES FOR MĀORI

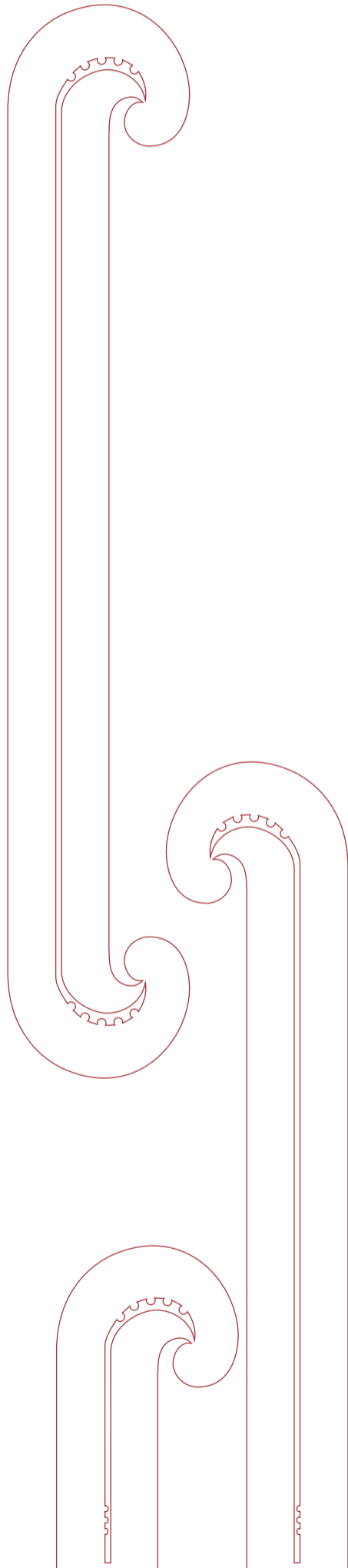
Documented inequities in hospitalisation experiences and quality of care received by Māori include shorter average hospital stays in medical and surgical settings (Wilson & Barton, 2012) and a higher likelihood of having a preventable adverse event compared with non-Māori/non-Pacific peoples during a hospital admission, which is a marker of “suboptimum care” (Davis et al., 2006). Further differences in the quality of care for Māori during hospitalisation have been reported (Barton, 2008; Cormack, Stanley, & Harris, 2018; Rumball-Smith, Sarfati, Hider, & Blakely, 2013; Wilson & Barton, 2012). However, information that comprehensively explores the experiences of Māori and their whānau and how they feel about the care they receive during hospitalisation is limited (Barton, 2008).

Hospitals can be anxiety-inducing environments with unfamiliar routines, practices and encounters that may at times be intimidating, strange or intrusive. Multiple people are involved throughout a patient’s interaction with hospital services. Research has identified these feelings of unfamiliarity for Māori in the hospital environment (Arlidge et al., 2009; Barton, 2008; Wilson & Barton, 2012). In a study of Māori experiences of health services, participants identified a number of experiences with regard to accessing or receiving hospital care, including the location of hospitals, waiting times, communication and levels of information provided by staff, and whether there was the feeling that they had been treated with respect (Jansen, Bacal, & Crengle, 2008). A desire to be treated with respect and dignity, and for improved communication (such as receiving adequate and appropriate information) has been identified in other studies that explored Māori experiences of hospitalisation (Arlidge et al., 2009; Barton, 2008; Cram, Smith, & Johnstone, 2003; Dew et al., 2015; Gilmour, Huntington, & Robson, 2016; Wilson & Barton, 2012).

Whānau-centred health care and whānau ora

Contemporary health system strategies, policy and literature in Aotearoa New Zealand, and internationally, talk about the importance of the involvement of families and support people in healthcare. For example, the New Zealand Health Strategy (Minister of Health, 2016) notes that “putting families and whānau at the centre of service delivery through Whānau Ora” is a priority for cross-sector work (p. 8). The Strategy also states that a measure of success will be a move from “service-centred delivery to people-centred services” (p. 14) and, in relation to the Strategy’s theme of “One Team”, outlines the importance of “strengthening the roles of people, families, whānau and communities as carers” (p. 29).

This holistic focus is not a new one for Māori, for whom whānau involvement and engagement has always been a part of care for people who are sick. Although the introduction of British healthcare institutions and structures to Aotearoa disrupted the ability of Māori to be engaged actively in self-determined ways as they had before colonisation, the



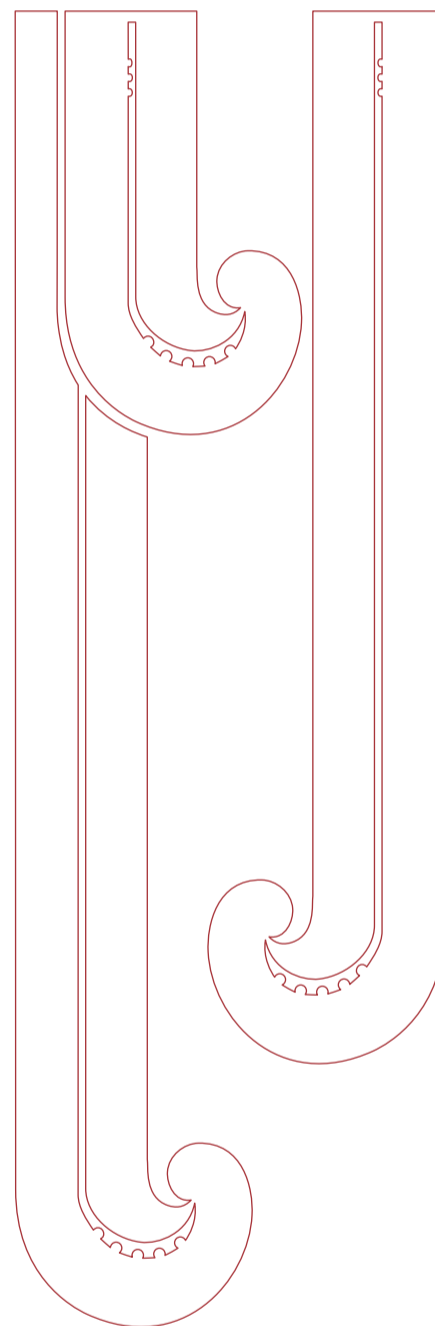
importance of whānau in the care of whānau members during a hospitalisation is well recognised by Māori (Barton, 2008; T. Walker et al., 2008; Wilson & Barton, 2012). This whānau-centred approach was reaffirmed in the original He Korowai Oranga—Māori Health Strategy, which promoted the centrality of whānau to health and wellbeing, and to Māori society more broadly: “Whānau (kuia, koroua, pakeke, rangatahi and tamariki) is recognised as the foundation of Māori society. As a principal source of strength, support, security and identity, whānau plays a central role in the wellbeing of Māori individually and collectively” (Ministry of Health, 2002, p. 1). He Korowai Oranga called on the health system to recognise the importance and primacy of whānau in terms of both wellbeing and healthcare provision, and noted the need for health services to be configured for communities rather than to suit health providers: “Services should be organised around the needs of whānau rather than the needs of providers. This includes removing infrastructural, financial, cultural, geographical, physical and other barriers (including arbitrary divisions between health and social services)” (Ministry of Health, 2002, p. 11).

Boulton, Tamehana and Brannelly (2013) note that Māori involvement in the health sector has evolved in recent years in parallel with changes to the public sector in the 1980s. They also observe increasing recognition of the Treaty of Waitangi in the 1990s, stating that the “practice of delivering services according to a Māori worldview and in accordance with Māori principles and values was occurring throughout the country by the late 1990s” (p. 23). During this period there were increasing calls for Māori involvement in determining healthcare priorities and funding, as well as in the provision of health services (King, 2019; Masters-Awatere, 2017). More recently, there have been changes to governance requirements for DHBs, and these changes reflect aspirational recommendations for Māori involvement in decision-making that were made almost 20 years earlier in the Public Health and Disability Act 2000.

The Taskforce (2009) was set up with the objective of developing a framework which included “whānau-centred services”. These were defined by the Taskforce as services “that focus on the whānau as a whole”. The Taskforce (2009) identified what they felt were “six key operational elements”, specifically:

- whānau-centred methodologies shaped by the values, protocols and knowledge contained within te Ao Māori
- commitment across government
- the establishment of an independent Trust with a dedicated government appropriation
- a primary focus on best outcomes for whānau, through integrated and comprehensive delivery
- strong regional direction
- building on existing provider capabilities. (p. 8)

Whānau ora approaches have been included in policy and service delivery approaches. One key dimension of a whānau ora approach is the need for “whānau-centred services that are shaped by te Ao Māori values and philosophies” (Mauriora-ki-te-Ao, 2010, p. 17). While Māori involvement in healthcare delivery has increased in recent decades, with funding of Kaupapa Māori health services and other Māori providers, and more recently whānau ora policies, barriers to the active ongoing engagement of whānau Māori in healthcare remain (Taskforce, 2009).



IV BACKGROUND TO THE RESEARCH PROJECT

The Hospital Transfers project was interested in exploring the research question: How can whānau maintain active engagement in the care of their whānau member when they need hospital care away from their home base? The project involved three main phases, each involving smaller projects and a range of methods to better understand whānau experiences and priorities for engagement during an away-from-home hospitalisation (Masters-Awatere et al., 2017).

The Description Phase was focused on gaining a comprehensive understanding of patterns of hospital transfers and experiences of whānau who wished to stay actively engaged in care. This first phase involved analysis of hospitalisation data to identify patterns of Māori away-from-home hospital care (Cormack, Masters-Awatere, Rata, Boulton, & Lee, 2019); an environmental scan of current policies, programmes and/or interventions associated with hospital transfers and hospitalisation away from home; and a series of whānau interviews focused on whānau experiences of away-from-home hospital transfers.

The Engagement Phase involved developing relationships with various stakeholders to better understand how the hospital system and broader policy contexts facilitate or hinder active whānau involvement. For this second phase, we engaged relationships with key stakeholders that would support our progression into the third phase.

The Uptake Phase intends to contribute to long-term gains and includes the development of a position paper, an implementation strategy and an evaluation framework (Masters-Awatere & Cormack, 2019). The known undercount of hospitalisations and hospital transfers for Māori (Cormack et al., 2019; Cormack & McLeod, 2010) highlights a critical ongoing issue that needs more attention. Hospitalisation admissions are a relatively common experience for Māori, and in a context where Māori cultural values and practices require that unwell whānau are not left alone, the wider implications for Māori make this an issue worthy of further discussion. Building on our Uptake Phase aspirations of meaningful contribution towards whānau-centred practice, this paper draws from the environmental scan and whānau interviews to offer some practical strategies at systems, organisational and practitioner levels for whānau-centred care.

Environmental scan of policies, services and programmes

An environmental scan was carried out to identify and review publicly available information (including policies, services and programmes) relating to hospital transfers and/or away-from-home hospitalisations. Environmental scan methods were employed as a tool to guide the process of mapping the information that was available in relation to hospital transfers and away-from-home hospitalisations, at both a local and a national level (Rowel, Moore, Nowrojee, Memiah, & Bronner, 2005). The environmental scan aligned with the broader Kaupapa Māori approach of the project, recognising the interdependence of people with each other and with the environment, as well as the need to locate whānau within broader social, political and economic contexts. The specific methods chosen for the scan reflect our intention of centring whānau Māori in this project. That meant we were primarily interested in identifying and mapping public information that whānau might access.

The broad scope of the environmental scan was to identify and summarise publicly available documents and information associated with hospital transfers and hospitalisation away from home, and with supporting active whānau engagement in hospital care. While the focus was on public hospitalisations, non-governmental organisations and private providers were also included where they had relevant or significant roles in relation to hospital transfers and/or away-from-home hospitalisations. The environmental scan strategy included searching all of the 20 DHB websites for information relevant to hospital transfers or away-from-home hospitalisations, as well as searches of websites of other key organisations or providers. Additionally, Google searches were undertaken to identify relevant information for the New Zealand context. Further to the identification and summarising of publicly available information, the environmental scan also considered the accessibility of documentation obtained, taking into consideration whānau who may need to search for resources relevant to their needs.

Interviews with whānau Māori

In order to understand whānau experiences of away-from-home hospitalisations and hospital transfers, we undertook interviews with 24 whānau who had experienced a transfer to Waikato Hospital, either as a patient or as whānau support, in the 12 months prior to recruitment. Waikato DHB was selected for a number of reasons. The host institution for this research, the University of Waikato, was located in Waikato, and we had previously established relationships with Waikato DHB. In addition, Waikato DHB serves a relatively high population of Māori, includes a major tertiary hospital (located in Hamilton) with a regional trauma centre, and covers a large geographical area. The Waikato DHB has a total Māori population of 91,800, which is estimated to become 23.3 per cent higher by 2026 (Waikato District Health Board, 2017). The Waikato-Tainui iwi rohe (tribal region) covers and extends beyond the geographic bounds of the Waikato DHB. As stated by Waikato-Tainui (2018), “Our rohe is vast and

stretches from Auckland in the north, Te Rohe Potae in the south and extends from Kaawhia in the west coast to the mountain ranges of Hapuakohe and Kaimai in the east.” Thus the Waikato DHB is inconsistent with the spatial regions of Waikato-Tainui iwi, which affects the provision of healthcare services for members of Waikato-Tainui.

Twenty-four interviews with whānau Māori were carried out by three researchers in 2016–2017. Those interviews were then transcribed and initial, surface-level analysis was completed. Upon completion of the interviews, an analysis wānanga was held by four researchers on the project. The wānanga was focused on analysing the content relevant to the interactions whānau Māori had with staff and services throughout the hospital transfer process. Through reflexive analysis during the first wānanga, the research team has been able to engage with the changing nature of self-identity and the constituent parts of being a whānau Māori in contemporary times (see Masters-Awatere et al., 2017). Given the known power difference in the hospital environment (Arlidge et al., 2009; Cormack et al., 2018; Cram et al., 2003), we have specifically chosen to privilege the perspective of whānau to ensure that whānau Māori voices and their experiences are prioritised within our research and dissemination activities.

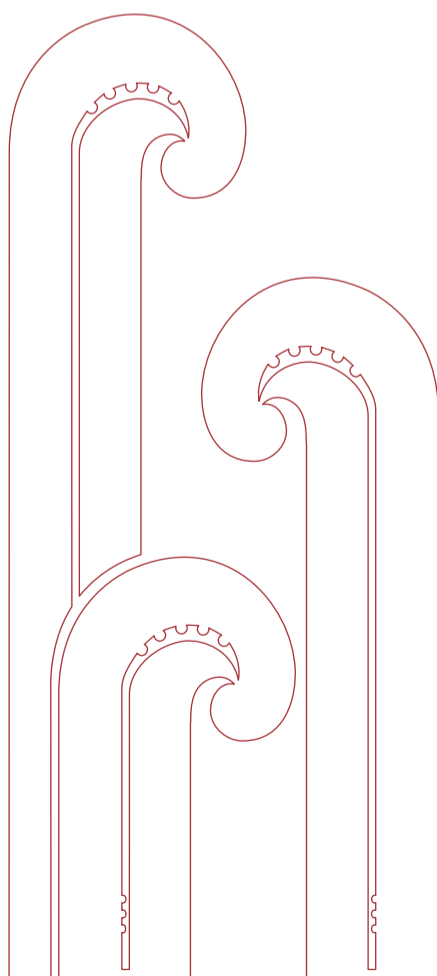
V WHĀNAU ENGAGEMENT IN TRANSFER AND AWAY-FROM-HOME HOSPITALISATIONS

Being hospitalised can be stressful for patients and their whānau. Hospital admissions involve the transferring of a whānau member away from their home and from the familiar context of their everyday lives. When hospitalisations involve the transfer of patients away from their usual place of residence, to a different town, city or region, this can present multiple issues for whānau. These include, but are not limited to, whānau decision-making processes about key supports for the patient; negotiation of the distance between home and the hospital where a whānau member has been transferred to; whānau unfamiliarity with the different town, city or region; unfamiliarity with the hospital and its staff; how whānau remain active in decisions regarding the care of their whānau member; and how whānau seek help and advice, and access the support services to which they are entitled. This paper highlights project findings, connecting them to the focus of the National Travel Assistance (NTA) Policy and the Taskforce (2009) on achieving best outcomes for whānau through integrated and comprehensive delivery.

Both the environmental scan and interviews with whānau identified a range of issues related to hospital policies and their application that impacted on the ability of whānau to remain involved in the care of their whānau member. These included policies on support for costs incurred by being away from home for whānau, including accommodation, transport and parking, as well as visiting policies and rules, both formal and informal. Hospital policy and practice reflects national policies, regional and DHB policies, and those determined at the individual hospital level. The key national policy instrument for supporting whānau engagement in hospital care is the Ministry of Health’s NTA Scheme. Established in 2005, the NTA is intended to assist people with costs when receiving specialist treatment (Ministry of Health, 2009). Although it is a national policy set by the Ministry of Health, the Scheme is administered at the DHB level. It has recently undergone a review for which our Hospital Transfers team made a submission, drawing upon whānau interviews to highlight key issues and make recommendations (Masters-Awatere et al., 2017). The NTA review report was released in 2019, and made a number of recommendations for changes to the Scheme (Ministry of Health, 2019) that were consistent with our recommendations.

Support for whānau while away from home

Support available for whānau to facilitate their active engagement in the care of a whānau member during an away-from-home hospitalisation, or a hospital transfer admission, is variable. When a patient is hospitalised away from their usual home base, whānau who travel with the patient are often required to find accommodation to be able to remain close to their whānau members. Our environmental scan identified that most DHBs provide some accommodation for Māori whānau located on or close to larger hospitals, although information was not always easily accessible about these accommodation options on DHB websites. A number of



websites had limited information, requiring whānau to make further contact to get more details about options by talking to nurses, social workers, Māori services or others at the hospital. Whānau talked about difficulties experienced with finding out about hospital accommodation options, and the problems they had with the accommodation once they found it:

...we weren't even offered access to accommodation there, but at that time I was very much aware that there was whānau accommodation there somewhere. I don't remember the name of the whare [house], but it was quite a traumatic procedure. (Whānau support interview #3)

In light of whānau experiences with accommodation, the environmental scan included searching for the types of accommodation available for whānau. The costs and eligibility criteria varied across DHBs and the individual accommodation provider. Eligibility could depend on the type of condition of the patient, the seriousness of the condition, and the distance whānau lived from the hospital. Some hospital-based accommodation had restrictions on the number of whānau members who were able to stay at any given time, and the maximum length of a stay, varying by DHB. Most providers seemed to have a cost associated with accommodation, although this information was not always clear on the DHB websites, with costs ranging from \$5–\$10 per night per person to \$120 per night per family.

Some support for accommodation is also provided through the NTA Scheme for patients or whānau who are eligible for assistance as an approved support person, and who meet the other NTA criteria, including travel distance (Ministry of Health, 2009). The current NTA Policy indicates that accommodation costs also can only be paid up to \$100 per night and additional surcharges may be applied on top of this by the accommodation provider. This level of financial support is unlikely to reflect actual accommodation costs, particularly in larger cities and at times when there is high demand.

Some support for travel was available to whānau who qualified under the NTA Scheme; however, this is generally in the form of reimbursement for mileage or transport costs, meaning whānau are faced with upfront costs. There are distance and/or frequency criteria that a patient needs to meet to be eligible for travel assistance, and NTA assistance requires a clinician's sign-off. Such processes are potentially mana (a sense of power and control) diminishing, in that they take away resources that would otherwise enable whānau to plan for their future, and also demand an engaged relationship that makes whānau reliant on clinicians, thus maintaining a power imbalance. A further contributing factor that reduces the best outcomes for whānau is the cost of transportation. Travel costs borne by whānau act as a potential barrier to providing support:

I guess with my own family, like financial constraints aren't as much of a barrier for us. So we were able to do it. But there probably are whānau that are like, shoot

we need to drive to [city] but we don't even have like gas money or we don't have a reliable car that is warranted and registered. Yeah, so that could be a real thing for other whānau. (Whānau support interview #4)

While DHBs provided some shuttle services at different hospital sites, many of these services were for patients, rather than caregivers, visitors or whānau. Where they were available for whānau to use, whānau were not always proactively made aware of their entitlement and/or were required to book in advance, which could be difficult given the unpredictable nature of some hospital transfers. Related to transport is the price of parking at the hospital, which was a major issue raised by all the whānau interviewed.

Parking at the hospital while supporting a whānau member was identified in the project as a significant cost for whānau. The environmental scan found that while free parking was available at some smaller hospitals, or hospitals located in smaller cities, many of the larger hospitals had daily parking fees. The cost of parking ranged across DHBs, with the highest daily rates in the South Auckland region. Policies on whether or not there were concessions or discounted parking rates for whānau, particularly for extended stays, seemed to vary by DHB:

I just happened to speak to my sister who lives up there and she just said to speak to them about a parking ticket, because I was going in and out of the carpark and there was a ticket we could get from them for \$7 and it covered us for 7 days. (Whānau interview #12)

The NTA Scheme does not currently cover parking costs, although the report on the review of the Scheme recommends that “the cost of parking to attend appointments should be considered for inclusion within assistance provided by the NTA Scheme” (Ministry of Health, 2019, p. 12). However, it is unclear whether this recommendation would cover parking during an away-from-home hospitalisation.

Whānau noted that they were not always able to travel alongside their whānau member during a hospital transfer, impacting their ability to provide ongoing support. Potential communication disruptions between hospital staff and whānau occur through the process of a transfer. Sometimes whānau arrived after office hours and did not have information about policies and practices:

When we arrived it was late at night, so there was no one on reception. There was a lot of people around and there was a buzzer there, and there were people that we knew in the waiting room, so they more or less told us what was happening. During the day there was someone at reception and I could see new people coming in and so they would relay the message on what the process was. (Whānau support interview #5)

Overall, hospital policies and practices to support whānau involvement in care during an away-from-home or transfer hospitalisation were variable and did not always provide support for the actual cost incurred. Often upfront payment was required. We found that administration of the NTA Scheme differs across the DHBs. Our findings reaffirmed the Taskforce's (2009) earlier call for strong regional direction as well as integrated and comprehensive delivery. Additionally, our findings are complementary with the NTA Scheme review report, which identified the differential interpretation and application of NTA eligibility and entitlements between DHBs. Furthermore, there were differences between DHBs in the way support was provided, regardless of whether patients or whānau support were eligible for NTA resources (Ministry of Health, 2019).

Visiting policies for whānau

The environmental scan identified that policies on visiting for whānau differed by hospital. Within hospitals, policies could also vary by ward or clinical service. Usually hospitals had recommended hours for visiting, with some also specifying a recommended number of visitors at one time. Whānau experienced constraints on visiting, in terms of the times they were permitted to visit, whether or not they were able to stay overnight, and the number of visitors permitted. As one participant commented, "I don't even think the support person was able to stay that night. I don't think they were. There was visiting hours and once those were up they had to go and come back the next day" (Whānau support interview #1). Some hospitals made a distinction between family and friends, and nominated support persons, who were able to stay with the patient without the same restrictions on visiting hours. The difference in terminology, while helpful for clinical staff, was confusing for family and friends who could also be the nominated support person for the patient.

Whānau wanted to be present during ward rounds, as important information was often conveyed during clinician rounds. Ward rounds were identified as times when whānau could ask questions, particularly leading up to patient discharge. However, ward rounds did not always align with visiting hours, making it difficult to be present because the exact timing of the rounds was unclear or was not constant across the hospitalisation. One whānau recounted their experiences of trying to make sure they were present during ward rounds for their father:

...we were told they [doctors] do their rounds about 9 in the morning. They had done their rounds at 9ish in the morning for the last 3–4 rounds that we were there for over those two visits. So we got in about 8.30ish, because we had to pack up from where we were staying. We got there and we got to the front door of the ward and as we were going in this nurse stopped us and said, it's a bit early for visiting isn't it? We said, look we're just here to pick up our dad when he's discharged and we've got a long trip home to [town]. Oh, well it's still early. We thought, oh wow...he's got his papers ready, all he's waiting for is the tick. The other thing is, I need to be

with my dad when the doctors see him because I need to ask the questions—like what can Dad do? What do we need to watch out for? When does he have his next check-up? There is some stuff on discharge summaries, but there is those added questions that we ask as a whānau (Whānau support interview #9)

Similar to the whānau above, who were trying to time their arrival to match ward rounds so they could receive any vital information about care post-discharge, another whānau was impacted by the inconsistency of timing of ward rounds. However, for the second whānau the discomfort felt after asking the times of ward rounds on multiple occasions meant it was a matter of luck whether they were present for ward rounds:

I didn't feel comfortable in asking and I just thought the doctors...sometimes the doctors come around in the evenings. They all go around in the mornings but then now and again there would be one that would come around in the afternoons. But on the particular days when I was there in the afternoons, they didn't come around. They said it wasn't required on those particular days. It was bad timing. (Whānau support interview #12)

Whānau were identified as key supports for patients before, during and after their admission and transfer. Stress and tension caused by variable practices and policies across DHBs highlight the need for a primary focus on the best outcomes for whānau (Taskforce, 2009). Barriers relating to transport, accommodation, parking and communication by medical staff highlight the need for improvements in the provision of supports for whānau.

Summary

Information about policies was not always clear or consistent, meaning that whānau were not always aware of their entitlements. The application of some policies was discretionary, resulting in inconsistent delivery. Where information was not readily provided by the hospitals, patients and whānau had to find other ways of gathering information. Some talked to other whānau in the hospital and searched the relevant DHB's website. Searching for information often requires whānau to know something about what services might be available. We found that DHB websites vary in their layout and the type and level of information available. In addition, information was not always in accessible language or terminology that might be familiar to patients or whānau.

VI POLICY IMPLICATIONS

Support people play a vital role when loved ones are transferred to a hospital that is far away from home. In this project, there were multiple ways in which whānau support was beneficial. Whānau often assisted with provision of care before, during and after hospitalisation. During the patient's hospital stay, whānau reduced the patient's level of anxiety and stress by being familiar, helping with communication, and sharing information with extended whānau and friends. After discharge from hospital, the support person provided continued support by assisting with "aftercare" needs when patients returned to their usual place of residence and medical staff were no longer nearby. However, the project identified a number of areas where hospital policies did not support whānau engagement during a hospital transfer or away-from-home hospitalisation.

We have drawn on the Ministry of Health's (2014a) Equity of Healthcare for Māori framework to identify potential points of intervention in order to facilitate active involvement in achieving optimal wellbeing outcomes for a whānau member who is hospitalised away from home. The equity focus of the framework allowed us to not only centre whānau aspirations, but also identify how the health sector needs to shift to enable whānau engagement. The Equity of Healthcare for Māori framework identifies three key elements: leadership, knowledge, and focusing on three levels for intervention, namely the health system, health organisations and health practitioners (Ministry of Health, 2014a). We now examine each of these in turn.

Leadership for whānau engagement in hospital care

Over 15 years ago, He Korowai Oranga clearly identified the need for the reorientation of health services to the priorities and aspirations of whānau rather than providers (Ministry of Health, 2002). Whānau ora approaches also support whānau-centred services. Leadership requires the health system to be explicit about expectations of health provider services supporting whānau engagement in all strategies and policies. In contrast, our research findings suggest that whānau often experience hospital services that are not configured to the needs of whānau. Leadership for the health system and health organisations requires Māori representation in governance and decision-making about hospital policies, at national and local levels. The health system, health organisations and health providers need to be strong advocates for policies that enable whānau-centred care, and for broader system change. For care to become whānau-centred requires a willingness to critically reflect on whom current hospital policies serve, as well as an openness to interrogation of the models of care and worldviews underpinning hospital services and policies. Here is where the Taskforce's (2009) recommendation to establish an independent trust would be useful as a means to ensure health provider organisation accountability. For DHBs, leadership in this space could mean stepping aside to allow other providers with more capability and who are better positioned to enable whānau engagement to take the lead.

Knowledge and information to support

whānau-centred hospital care

There remains little comprehensive or routine information on Māori hospital transfers or away from home hospitalisations (Cormack et al., 2019). Our project identified that there are still gaps in understanding Māori experiences of hospitalisation and particularly away-from-home hospitalisations. From the perspectives gathered from whānau, there is a clear desire for information that would assist during the transfer process. This includes knowledge about:

- NTA entitlements for both the patient and the support person/carer travelling with them;
- accommodation options for whānau, either on the hospital grounds or with a provider the hospital has a relationship with;
- key staff involved in the care of their loved one so that whānau know whom they can ask questions that may arise; and
- policies, such as carer and visitor rules, that allow whānau to designate (a) key person(s) to liaise with clinical staff.

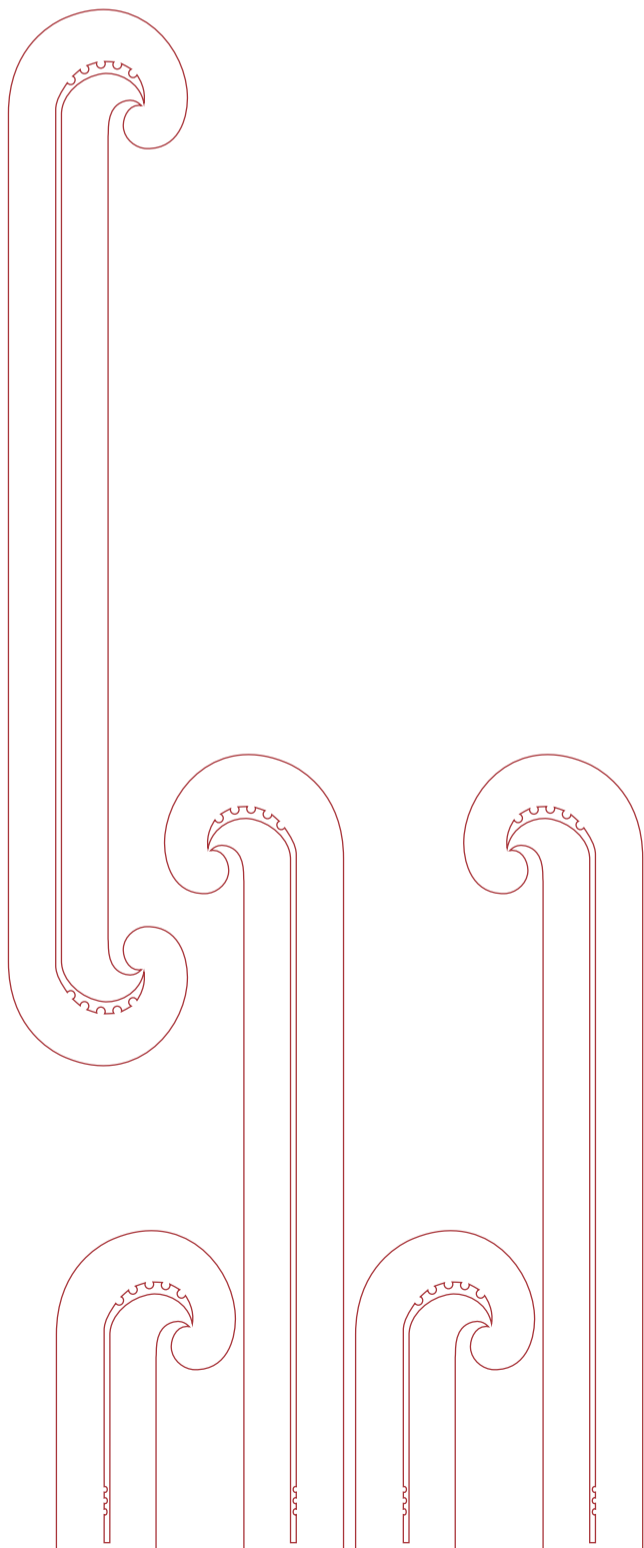
Providing whānau with knowledge in these areas identified as key stressors during a hospital transfer or an away-from-home hospital admission works to benefit the patient, whānau and clinical staff, and the provision of care more broadly as well. For example, whānau would know their rights, and entitlements, and the policies relevant to the care of their loved one. Whānau would then be less frustrated and more likely to engage with staff from a position that allows for a smoother merging of whānau values, protocols and knowledge into clinical care.

The NTA review identified the need for more transparency in the NTA policies and their application (Ministry of Health, 2019). We also found in our project that the information available was inconsistent, or not easily accessible for whānau. Ten years ago, the Taskforce (2009) called for six key operational elements of whānau-centred care. Our research has found that these elements are still relevant but are yet to be implemented in the context of a hospital transfer or away-from-home hospitalisation. Comments from whānau align with the environmental scan findings that knowledge gaps within the health system and hospitals continue to disadvantage Māori whānau. Further research is needed with Māori communities and providers to identify information and service delivery gaps, such as what information Māori communities need, to support goals of whānau engagement and whānau-centred hospital care.

A focus on the three levels of intervention in

whānau-centred care

Forecasted growth in New Zealand's Māori population (Statistics New Zealand, 2015), and the tendency of Māori to live outside of major urban centres, which has continued into the 21st century (Statistics New Zealand, 2004), means there will be an ongoing need for away from home hospitalisations and transfers impacting on Māori whānau. It is crucial that whānau-centred care at the health system, hospital and health provider levels is provided through strong and meaningful relationships with Māori that include Māori governance and full participation in decision-making. Given the problems identified by whānau with away-from-home hospitalisations, there is room for improvement in the provision of whānau-centred care. Similarly, there is potential to explore other methods of care (such as travelling specialist teams, distance medicine) that could better enable provision of whānau-centred care that aligns with both the Treaty of Waitangi and the United Nations Declaration on the Rights of Indigenous Peoples.



VII FINAL WORDS

Our interviews with whānau highlight the need to include whānau in healthcare decision-making. Additionally, better commitment to being proactive about providing information to whānau about entitlements and available support services, as a way to facilitate whānau-centred care, is needed. Currently, whānau are often required to seek out this information themselves, rather than being provided it as a matter of course. While statements are often made about the importance of centring whānau in care, including in key strategy documents at the national level, the operationalisation of these statements is not always evident. Commitment needs to be demonstrated through meaningful transformation that supports Māori priorities and aspirations. To action these strategies requires a shift in the hospital policy environment, including the way in which hospitals are funded and organised, as well as a commitment to supporting alternative models of care that are underpinned by Māori ways of being and knowing. A conscious commitment to change is required to disrupt the status quo.

A radical shift and meaningful change are required at the health system, organisational and practitioner levels to improve implementation of whānau-centred care during hospitalisation. If, at each level, consideration is given to whānau-centred healthcare that privileges whānau knowledge, needs and aspirations, a transformed hospital system can emerge. Through our work on the Hospital Transfers project, we have highlighted the importance, impact and change needed with regard to supporting whānau engagement during a hospital admission. While staff operating at the health system, organisational level or practitioner level may face particular challenges in implementing change, the clear desire for change is nevertheless evident. Whānau, DHBs and the Ministry of Health all want to better facilitate and support whānau engagement during the admission of a loved one into hospital. Research of this nature is clearly important.

Findings from the Hospital Transfers project have shaped our call for a re-visioning of the prevailing hospital system. This re-visioning should include a re-imagining of alternative approaches and a re-membling of Indigenous healing systems to bring about transformed hospital systems within which whānau aspirations for active involvement and engagement with care are able to be fully realised.

Poipoia te kākano, kia puawai.

Nurture the seed and it will blossom

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Endnotes

- ¹ Primary level services mainly deal with internal medicines and include general practice. Secondary care services are recognised as having 5–10 clinical services, with 200–800 beds, and often referred to as provincial hospitals. Tertiary care services are highly specialised services and technical equipment. They can range from 300–1,500 beds (Mulligan, Fox-Rushby, Johns, & Mills, 2003).

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ABOUT THIS RESEARCH PROJECT

This work is embedded in a Ngā Pae o te Māramatanga Foundational project entitled “Hospital Transfers: Whānau Involvement in the Healing Equation” that commenced in 2016. The primary research question is: How can whānau maintain active engagement in the care of their whānau member when they need hospital care away from their home base? Our long-term objective is to help create a whānau-centred health system. The project is led by Dr Bridgette Masters-Awatere (University of Waikato) and Dr Donna Cormack (University of Auckland).

<http://www.maramatanga.co.nz/project/hospital-transfers-wh-nau-involvement-healing-equation>

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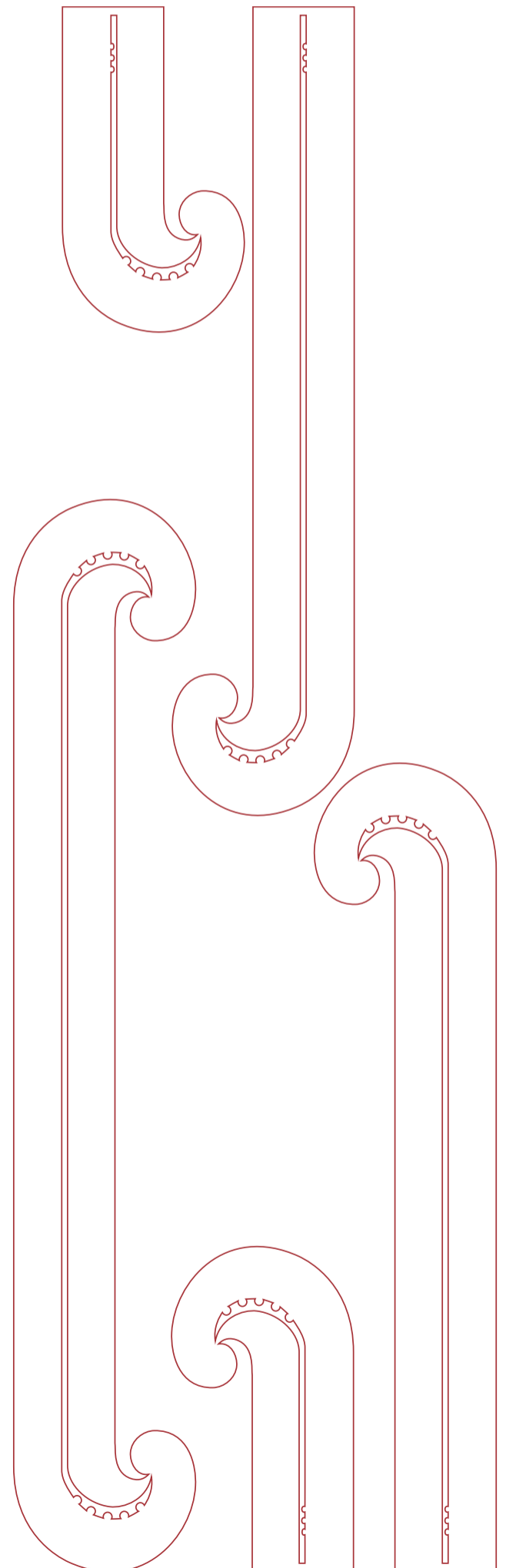
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FURTHER HOSPITAL TRANSFERS ARTICLES

COMING SOON:

Cormack, D., Masters-Awatere, B., Rata, A., Boulton, A., & Lee, A. Understanding the context of hospital transfers and away from home hospitalisations for Māori. Manuscript submitted for publication.

Masters-Awatere, B., Murphy, S., Rimu, K., Helmhout, B., & Cormack, D. National Travel Assistance entitlements are inaccessible to whānau Māori. Manuscript submitted for publication.



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Ngā Pae o te Māramatanga (NPM) is a Centre of Research Excellence, funded by the Tertiary Education Commission and hosted at the Waipapa Marae Complex at the University of Auckland, comprising 21 research partners and conducting research of relevance to Māori communities. Our vision is Māori leading New Zealand into the future. NPM research realises Māori aspirations for positive engagement in national life, enhances our excellence in Indigenous scholarship and provides solutions to major challenges facing humanity in local and global settings.

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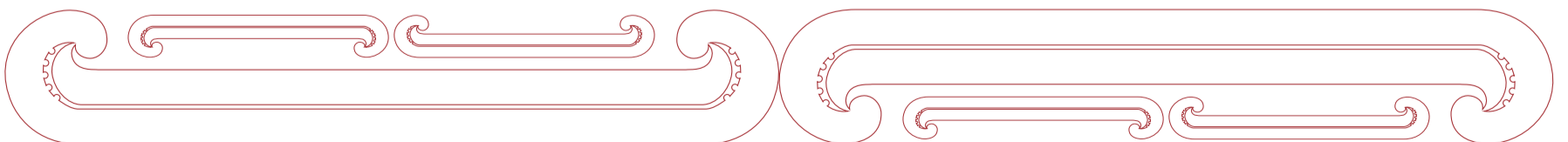


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