Ngā whānau Māori wheako ki te tauwhiro pāmamae me te whakaoranga

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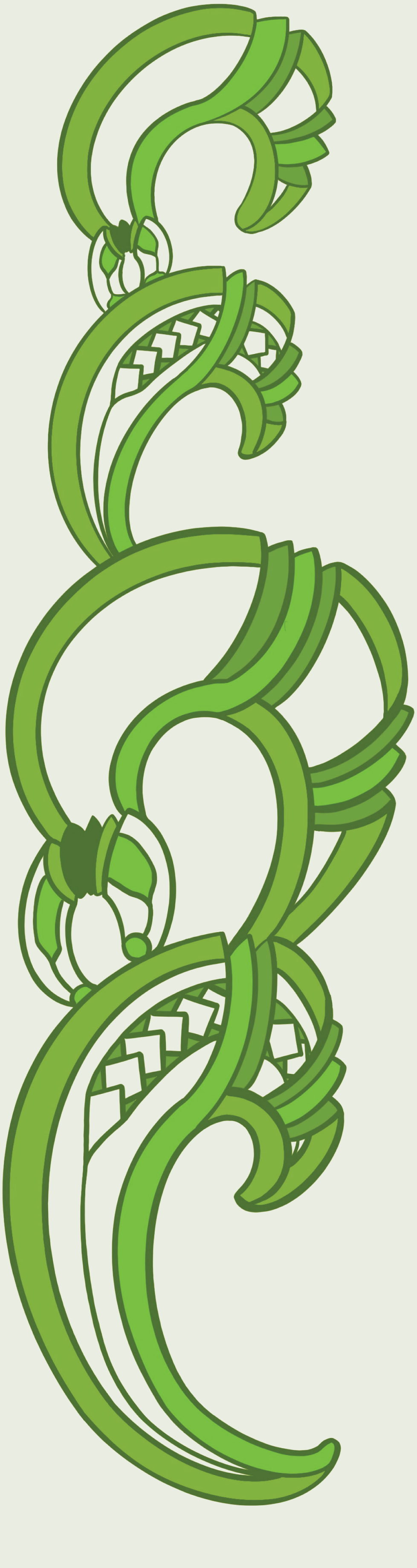
Whānau Māori experiences of major trauma care and rehabilitation



Te Hononga Whētuki ā-Motu
National Trauma Network

Te Kāwanatanga o Aotearoa
New Zealand Government

HEALTH QUALITY & SAFETY COMMISSION NEW ZEALAND
Kupu Taurangi Hauora o Aotearoa

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Kupu Taurangi Hauora o Aotearoa

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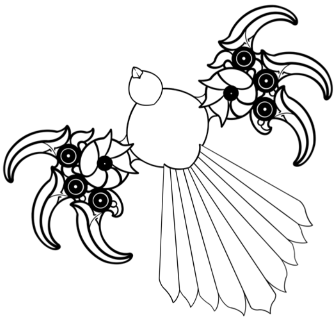


He kupu whakamihi | Acknowledgements

This report was prepared by Sharon Pihema for the Health Quality & Safety Commission and the National Trauma Network. She developed the report from information gathered during a quality improvement project on whānau Māori experiences of rehabilitation from major trauma.

Tēnā koutou, tēnā koutou, tēnā koutou katoa.

I would like to acknowledge the whānau that participated in this project. Thank you for inviting me to your homes, talking with me on the phone or Zooming online. It was incredibly humbling and a privilege to meet you all. You shared your stories to create change and so other whānau on this same journey could see they aren't alone. Your stories are ones of courage, strength and resilience, and have given us a reference point for improving the rehabilitation experience and recovery outcomes for whānau Māori.

To our expert advisory group, ngā mihi maioha ki a koutou katoa. Thank you all for your support and guidance throughout this project. Te Raina Gunn, thank you for all your awhi and tautoko and always making yourself available when I needed your advice, tēnā koe e hoa. Arawhetu Gray and Lee Taniwha, thank you for your words of encouragement, your creative 'think-outside-the-square' approach and the manaaki you provided me over this time, tēnā kōrua. To Tony Mottershead, Siobhan Isles, Sandy Ngov and the rest of the National Trauma Network team at the Health Quality & Safety Commission, thank you all so much for your ongoing support and encouragement. You are an amazing team to work with and I have always felt 100 percent supported by everyone, arohanui ki a koutou katoa.

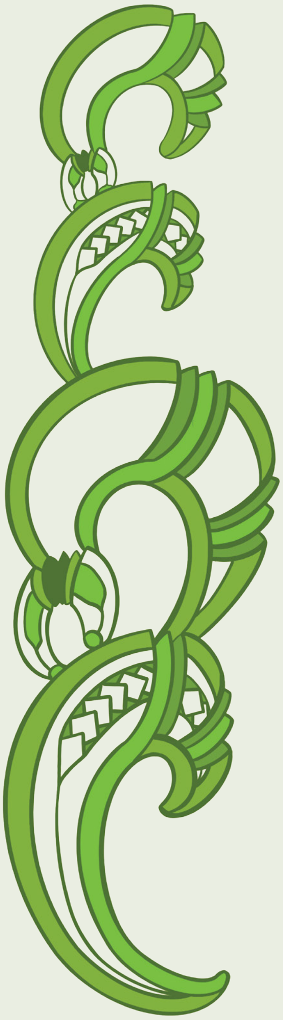
To our tohu designer, Whareahuru Gilbert. Ngā mihi ki a koe Whare. Thank you for bringing this kaupapa to life with your beautiful artwork. You captured the most important element of this project, right from the outset, and that is whānau. I'm excited to see what the future holds for you and your mahi toi.

Me mahi tahi tātou mo te oranga o te katoa.
We must work together for the wellbeing of all.

Tihei mauri ora
Ngā mihi mahana ki a tātou katoa

Sharon Pihema

He aha e mātuatua ai tēnei pūrongo | Why this report is important

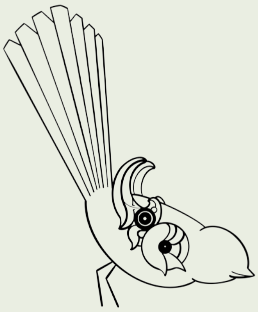


The rehabilitation journey for whānau Māori is difficult and complicated. The impact of major trauma on individuals and their whānau is significant, completely changing the way in which they are able to live, work, play and participate in everyday activities.

Trauma events often occur with little to no warning. Injuries can be extensive and, in many cases, life-threatening. People often need to spend time in intensive care, followed by weeks or months in hospital or a rehabilitation facility and then ongoing rehabilitation once they are well enough to be at home. Throughout this time, they'll encounter numerous health professionals, hospital staff, support services and case managers. Trying to understand and navigate through all this can be challenging and overwhelming for individuals as well as for their whānau, who are often their main support during this time. For many, returning to the level of wellbeing (physical, mental, emotional, social) they were at before their major trauma event is a long and difficult process; those with the most severe injuries may never get there.

The purpose of this project was to hear first-hand from individuals and their whānau about their experience of major trauma care and rehabilitation. We needed to understand their journey from the time they were injured, their experience while they were in hospital and their continued recovery and rehabilitation once they were back at home. We wanted to learn how major trauma injuries impact on every dimension of health. How has their major trauma care and rehabilitation affected their mental health, spiritual health and whānau wellbeing?

The whānau voice is a taonga. It provides direction for making the changes and improvements needed to achieve better health outcomes and experiences for whānau Māori. The whānau we interviewed wanted to give their voice to this kaupapa so others would not have to go through what they went through. They know the challenges first-hand and have expressed to us the changes that need to happen. The wero (challenge) is now with us to make it happen.



Pā harakeke

Artist and tohu design

Ingoa: Whareahuru Michael Gilbert
Iwi: Rongowhakaata, Kāitahu, Ngāti Tama,
Ngāti Toa-Rangatira

Whakamarama

Ko te whakamāramatanga o tēnei mahi toi, he whānau.

Ko te tiaki, ko te manaaki i te rito kei waenga, kei ōna tahataha, ko ngā mātua, kei ō rāua taha, ko kui rāua ko koro, ā, haere tonu, haere tonu.

Ko tā rātou mahi, he tiaki i te rito, kia tipu pai ai, kia tipu ora ai, te mahi a te whānau.

Ko ngā manaia, ngā kaitiaki o te rito, kia pai ai tōna tipu.

The meaning behind this art piece is family and the essential role they play in caring and nurturing the rito (child, younger generation, vulnerable) in the centre. To the sides are the parents and to their sides are the grandparents and so on. Their collective purpose is to protect and care for the child, enabling the child to grow healthy and strong. That is the purpose of whānau, the pā harakeke. The manaia within the harakeke are guardians and symbolise the different elements required for health and wellbeing. One rau (leaf) has been left bare, to represent that the work is ongoing and not yet complete. The inclusion of the pīwakawaka is symbolic of the external guidance whānau might need to support the rehabilitation journey. The pīwakawaka is sometimes described as the guide as you enter realms of Tāne Mahuta, god of the forest. It often flits from side to side guiding a pathway.

Additional whakaaro from Arapera Gilbert (local weaver and te māmā o Whareahuru)

The harakeke plant in itself represents the whānau unit with the baby (rito) in the centre; the parents (awhi rito) are the two fronds closest to the rito protecting the rito from the elements and the outer fronds supporting the parents are the grandparents and ancestors (tūpuna). When harvesting harakeke, the outer fronds are gathered, keeping the rito and awhi rito protected. The planting of harakeke is purposeful in itself. Harakeke plants are never planted on their own as this leaves the plant susceptible to the elements and struggling to thrive. Harakeke are planted in a circular cluster (pā harakeke) so that the positive environmental influences (and any adversities) are then shared across each harakeke plant and the pā harakeke is able to grow stronger collectively.

Te whakarāpopoto matua | Executive summary

Major trauma is one of the leading causes of injury and long-term disability. Māori experience higher rates of injury yet have less access to, and lower use of, health services that are intended to support rehabilitation. This is an important problem to solve.

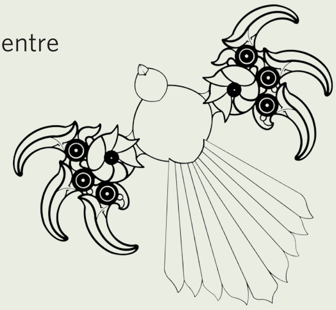
Understanding experiences of whānau Māori, from a strengths-based perspective, may help in identifying alternative views for system design and delivery of care that are culturally responsive. The goal of this project is to share the taonga of the voices of patients and whānau who have undergone a lived experience of major trauma rehabilitation. In doing so, we identify recommendations and feasible actions that can be undertaken across the trauma system, particularly hospital care and during rehabilitation, that promote positive experiences for Māori.

Tikanga | Project design

We used whānau-led kōrero (conversations) to allow an in-depth exploration of the experiences and perspectives of individuals and their whānau as they navigated life after their injury and the impacts of that injury. We invited individual patients who had experienced major trauma to have a support person or whānau member present at their interview. Where individuals took up this option, their support people were able to contribute to the interview when they thought it was relevant and appropriate to do so.

We had kōrero with 21 participants and 7 whānau that began with whakawhanaungatanga (building connection). Once participants and whānau felt comfortable, the interview began, with the main focus being on their rehabilitation journey. Topics covered during the kōrero included:

- background to the events surrounding the injuries
- their time in hospital and, if applicable, a rehabilitation centre
- their transition home
- follow-up support
- what helps and hinders recovery
- how services met their cultural needs.

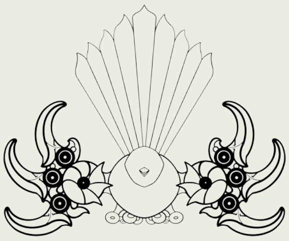


The rehabilitation experience

Patients and whānau were appreciative of the care and support received during some of the most traumatic experiences of their lives. Many described the factors that made their rehabilitation journey positive, with the result that the most important factors became evident among all 28 participants and whānau. As might be expected, these factors were related not just to physical wellbeing, but also to social, spiritual and mental wellbeing (specifically around Tā Mason Durie's health model Te Whare Tapa Whā) that affected all whānau (Table 1).

Table 1: Summary of how observed themes impacted experiences of care when they were explicitly included in the rehabilitation journey for whānau

Theme	Impact on experience of care when theme was:	
	Available (positive)	Unavailable (negative)
Cultural capability and responsiveness of health services	• Providers actively participated with patients and whānau in discussing care • They built trust	Patients and whānau did not feel trusted or valued
Culturally appropriate support	• Quality of interactions was enhanced • Health and social support became available	• Follow-up visits occurred once only and/or were very brief • Patients and whānau had limited time engaging with care teams
Whakawhanaungatanga as the basis for relationships and engagement in care	• Communication between patients and clinicians was culturally effective • Patients and whānau actively participated in decision-making	• Patients and whānau were disengaged from care • They had limited involvement in developing care plans
Psychological and emotional wellbeing, including support for whānau as informal caregivers	• Providers cared for whānau wellbeing • They dealt with all issues that mattered	• Providers did not consider or support mental wellbeing • This affected both patients and whānau • It prolonged the healing process
Communication, decision-making and service coordination	• Providers engaged whānau in care plan • Patients and whānau accessed available services • Their confidence in care plan and providers increased	Patients and whānau felt isolated, uninformed, uncertain where to turn for help and unsure what and how to ask



Recommendations and actions

With the health and disability system now in transition, the voices of whānau present an opportunity to inform a shift in the design and delivery of services to enhance experiences (and potentially outcomes) for Māori.

Applying an equity-focused lens, we have identified the following recommendations and actions as important considerations in building culturally and medically responsive health and social services for trauma care.

1. Ko te whakawhanaungatanga me noho hei whāinga matua mā ngā kaiwhakarato tauwhiro hapori | Whakawhanaungatanga must be a priority for all health and social service providers

Action: All trauma clinicians practise whakawhanaungatanga with Māori patients and whānau.

2. Me whai e ngā ringa tauwhiro pāmamae i te tikanga ahurea | All trauma clinicians must adopt and be accountable for a culturally effective approach

Action: All large trauma centres make kaiāwhina (assistants) available to be an integral part of trauma teams.

Action: Where available, and patients agree to it, routinely refer Māori trauma patients to the hospital's Māori support service.

Action: All hospital trauma clinicians receive training in cultural competency and are encouraged to learn te reo Māori.

3. Me tātari, me aro turuki me te tautoko hoki e ngā kaiwhakarato hauora me ngā kaiwhakarato tauwhiro hapori te oranga ngākau o te tūroro me te whānau | Health and social service providers must assess, monitor and support the psychological and emotional wellbeing of the patient and whānau

Action: Providers routinely screen all Māori major trauma patients for clinical signs of pain, post-traumatic stress disorder (PTSD) and concussion, with whānau engagement and referral as appropriate.

Action: All health and social service providers, where feasible, assess the wellbeing of the patient and whānau using a hauora Māori (Māori health) model.

4. Me noho tahi me te tautoko ngā rāngai i ngā whānau Māori | Agencies must involve and provide supports for whānau Māori

Action: All agencies working with major trauma patients and whānau, including regional trauma networks, use a consumer/whānau panel to inform service improvement.

Action: The Accident Compensation Corporation (ACC) and the National Trauma Network develop patient and whānau information resources specifically for Māori and actively distribute them across trauma teams and contracted provider services.

5. Me mahi tahi me tautoko hoki e ngā rāngai ngā ratonga Māori | Agencies must invest in kaupapa Māori service providers and support their use

Action: ACC and trauma services facilitate options for routinely referring Māori patients to kaupapa Māori (Māori-themed) or rongoā māori (natural medicine) services.

Action: ACC strengthens mechanisms to liaise with other agencies on complex social cases through identifying need early.

Action: All health and social service agencies invest in training staff, including ACC case managers and hospital Māori support service staff, to effectively communicate with rangatahi (youth).

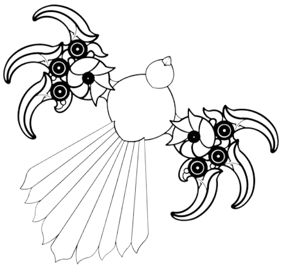
6. Me ine e ngā rāngai ngā kaupapa nui ki te Māori | Agencies must measure what matters to Māori.

Action: The Health Quality & Safety Commission continues to rework in-hospital patient experience survey tools so they include cultural competence of providers.

Action: The National Trauma Network routinely measures patient-reported outcomes for Māori.

By opening up about their care experiences, whānau have provided a taonga rich in detail about where the deficits and strengths in services lie; this can be used to optimise care experiences.

This report identifies a number of feasible actions that, when implemented effectively, will improve experiences for injured Māori and ultimately lead to improved rehabilitation outcomes.



Te pāmamae me te Māori | Major trauma among Māori

In Aotearoa New Zealand, major trauma is one of the leading causes of injury, long-term disability and, in some cases, death (Derrett et al 2017; Ministry of Health 2020a).

Whānau Māori experience health inequities across a wide range of health outcomes, compared with non-Māori, non-Pacific (Curtis 2016; Durie 2019). For major trauma injuries, these differences start from the youngest ages and continue across all age groups until the 80+ years age group (National Trauma Network 2020).

Māori experience major trauma significantly more often than non-Māori. The rate for Māori over the last two years is 56 per 100,000 compared with 43 per 100,000 in non-Māori (personal communication).

Māori aged 15–64 years have more than double the mortality risk and more than 1.5 times the risk of hospitalisation due to unintentional injuries, compared with non-Māori of the same age (Wyeth et al 2017).

Tāne Māori experience major trauma more than males from any other ethnic group. Wāhine Māori also experience major trauma more than females from other ethnic groups.

Māori are also more likely to experience disability from all types of injury (Lambert et al 2021), including higher rates of physical, psychological and financial disability at 3 months and 12 months after their injury (Kandelaki et al 2021), with the long-term effects in turn impacting on nearly all aspects of their life following that injury (Lambert et al 2021).

Despite the high rates of injury disability and mortality, Māori have traditionally had lower rates of access to ACC services than non-Māori. When they do access these services, it can take Māori longer to access them and they are likely to have fewer interactions with those services than non-Māori. This may reflect a general situation where Indigenous peoples or ethnic minorities often have lower rates of access to and use of health care services (Marrone 2007).

A major trauma is determined by the severity of physical injuries a person has suffered. Clinical specialists describe the severity of the injury using the Injury Severity Score (ISS), which ranges from 1 to 75. Any combination of injuries scoring more than 12 is classified as a major trauma.

The National Trauma Network (the Network) was established to introduce a formal system of trauma care in Aotearoa New Zealand that reduces death from injury and reduces the level of disability for those that survive. The New Zealand Trauma Registry (NZTR) collects data on every person who has had major trauma in Aotearoa New Zealand and was hospitalised as a result. Those that die on the way to hospital are not included in the NZTR. Working with the Health Quality & Safety Commission and the Accident Compensation Corporation (ACC), the Network transforms data from the NZTR into meaningful information that can support a range of initiatives, including quality improvement efforts to achieve an efficient, contemporary trauma system for Aotearoa New Zealand.

The importance of culture in major trauma rehabilitation

The combined experience for Māori of having a greater burden of injury and less access to health services intended to support rehabilitation makes improving a system of care for Māori an important problem to solve.

Over the past 10 years, researchers in the Ngāi Tahu Māori Health Research Unit at the University of Otago have been working on the Prospective Outcomes of Injury Study. This is the only longer-term study of injury rehabilitation from a Māori-led perspective and stands out among very limited research. The researchers have identified factors affecting post-injury outcomes for Māori, including the following.

- Financial security, injury severity, occupation type and job tasks impact whether injured Māori are working or not three months after injury (Wyeth et al 2017).
- Having two or more chronic conditions, having difficulty accessing health care services for injury, being hospitalised and having inadequate household income predict disability at 24 months post-injury (Wyeth et al 2017).
- Māori have higher levels of adverse outcomes (pain and discomfort, psychological distress, difficulties with mobility and usual activities) than non-Māori at 3 and 12 months post-injury (Maclennan et al 2014; Wyeth et al 2021).

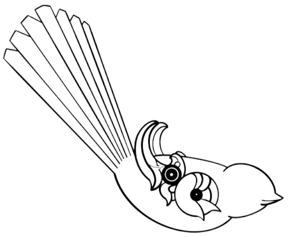
In addition, many factors influence equity in health care, particularly for Indigenous cultures. One of those factors for Māori lies in the ability of health organisations to deliver culturally responsive services that are user-friendly and accessible to Māori (Dudley et al 2014). Unfortunately, little has been done to understand the predictors, or outcomes, of injury for Māori (Wyeth et al 2021).

When services that engage Māori are not culturally responsive, or are seen as ineffective, this may increase Māori vulnerability and lead to poor outcomes. In their study of Māori living with disability 24 months after hospitalisation for injury, Lambert et al (2021) found participants were facing challenges in adjusting to life after injury, including the rehabilitation process. Participants said they were frustrated with feeling dependent on others, were bored and felt unfulfilled after their injury. They also discussed how the injury and the rehabilitation process were impacting many aspects of their lives and not always in the expected ways.

In major trauma rehabilitation, the responsibility for ongoing manaaki (care) and tautoko (support) typically falls on family members (Wharewera-Mika et al 2016). For many experiencing major trauma, whānau are considered essential to their rehabilitation and in many cases provide the manaaki and tautoko that align the dimensions of physical, mental and spiritual wellbeing.

Among Māori, whānau support is valued as an integral healing component that provides an emotional and spiritual dimension to care (Willing et al 2020). Through their involvement in care – giving comfort, supporting wellbeing and assuming the role of advocate or informal health caregiver – whānau may improve the recovery for their unwell or injured whānau member.

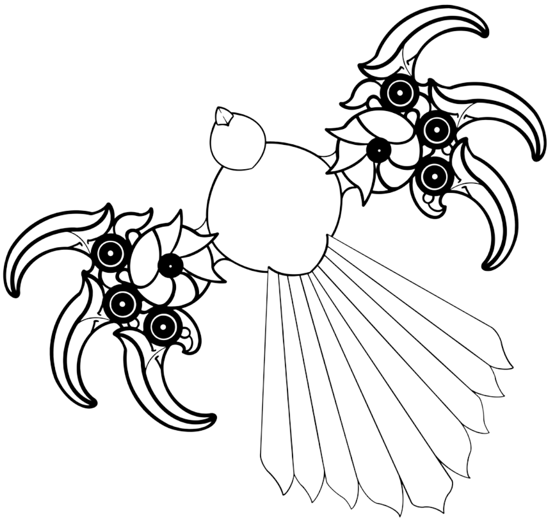
In contrast to a view of health based on te ao Māori (the Māori world), Westernised health care systems may undervalue the important role whānau can play when they are included in care. This attitude may be evident in practices such as not involving whānau in decision-making or focusing only on the person with physical injury. In many ways, that experience can also have a profound effect on health care experiences, subsequent wellbeing and outcomes. It is of utmost importance to understand and identify the key ways in which we can support whānau to flourish even while they are undergoing or supporting rehabilitation from a substantial injury (Wyeth et al 2021).



Why this report is important

We now know inequalities, inequity and culturally incongruent health service provision are clearly connected (Pihama et al 2017). When cultural concepts are included in the health and disability system, that system gains an opportunity to improve the quality of care for Māori. It is imperative that we seek opportunities to listen to the experiences of whānau Māori. This will create a stronger understanding of factors that promote positive care experiences and influence longer-term effects of injury among Māori.

The goal of this report is to add to the limited knowledge that exists about Māori experiences of major trauma rehabilitation. We identify actions that promote positive experiences for whānau Māori. In addition, we explore actions that support enhanced patient and whānau wellbeing through the rehabilitation journey. These actions must be feasible and have potential to improve health and social service provision for whānau Māori so our health and disability system can consistently enable the best possible outcomes from rehabilitation following major trauma.



Tā te kaupapa hoahoa | Tikanga – project design

The following is a summary of the project design. For a full view of the tikanga and relevant documents, see our methodology document to accompany this report.

Our project used a kaupapa Māori (Māori-themed) methodology to gain a deeper understanding of the whānau Māori experience of major trauma rehabilitation. We adopted a strengths-based approach in which, rather than seeing the problem as 'being Māori', we focused on themes that emerged from our interviews and reflected the experiences of the participants.

We used conversational interviews to allow an in-depth exploration of the experiences and perspectives of the participants as they navigated life after their injury, including the impacts of that injury. Participants were also asked whether they wanted to have a support person or whānau member present at their interview. Where they took up this option, their support people were able to contribute to the interview when they thought it was relevant and appropriate to do so.

Using a qualitative method, our goal was to engage 20 whānau Māori to participate in the study.

Criteria for participation were broad to enable interviews with whānau Māori from a range of backgrounds and locations across Aotearoa New Zealand. Specifically, to be eligible to participate in the project, potential recruits needed to:

- be of Māori descent
- have injuries that meet the criteria to be included in the National Trauma Registry
- be over the age of 16 years at the time of their accident
- have received their injuries between 1 July 2018 and 31 December 2020.

Within the National Trauma Registry database, 55 individuals met these criteria and were invited to participate. They were also given the option of having their whānau present during the interview. Twenty-one individuals agreed to take part (Table 2); within this group, seven had members of their whānau attend and participate in the interview.

All participating whānau were given an option to have their interview conducted in either te reo Māori or English, and they could choose to have it kanohi ki te kanohi (in person), over the telephone or via Zoom.

Although we had interview schedules, the interviews followed an open-ended style of discussion with whānau leading the kōrero (conversation) about their rehabilitation journey. This meant whānau were able to stop at any time if the kōrero became too mamae (painful).

All interviews began with whakawhanaungatanga (building connection). Once whānau felt comfortable, the interview focused primarily on their rehabilitation journey. Topics of discussion included background to their accident/injuries, their time in hospital and rehabilitation centre (if applicable), their transition home, follow-up support, what helps and hinders recovery and how their cultural needs were met.

Te wheako tauwhiro me te whakaoranga | The care and rehabilitation experience

Overall, most participants said services should always provide open and clear communication from the outset of their care. However, achieving this requires fostering relationships, engaging and supporting whānau and considering the health, social and cultural factors that all contribute to positive outcomes from major trauma. This section presents the findings from the analysis of major themes undertaken on all data collated from the 21 participants and 7 whānau who took part in this study.

Whānau demographics

Table 2: Summary of participant engagement and consent

Eligible	Declined	No response/reply	Participants (whānau)
55	8	26	21 (7)

Among the individual patients, a total of 15 tāne and 6 wāhine Māori were interviewed. Figure 1 shows the geographic location of participating whānau. Several whānau lived in the same area in some instances (eg, Whangārei and Ōtautahi (Christchurch)). Table 3 outlines the age of participants (at time of injury), injury mechanism and interview type.

Figure 1: Geographic location of interview participants

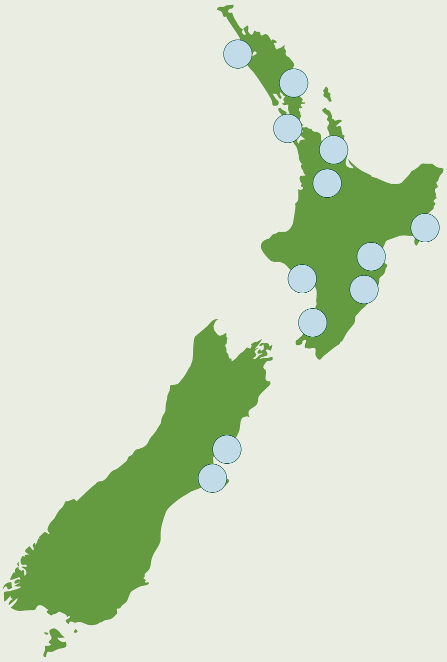


Table 3: Summary of interview types and participant characteristics

Types of interviews	
Phone	8
Zoom	1
Kanohi ki te kanohi	12
Whānau interviews	7
Individual interviews	14
Gender	
Wāhine	11
Tāne	17
Age at time of injury (years)	
16–24	6
25–40	6
41–64	7
65+	1
Not disclosed	1
Injury mechanism	
Motor vehicle	10
Motor scooter	2
Bike/scooter	1
Fall	6
Assault	1
Not disclosed	1

Describing the accident and impact of injury

During the early stage of the interview, each participant was asked to describe events leading up their accident. Most (17) participants spoke of the activities and events leading up to their accident and discussed, in graphic detail, what happened to them and how they were injured. For many, their injuries were extensive and included isolated brain injury, complex trauma (ie, multiple injuries) and amputation.

> 'I remember the impact and just going forward.' (Whaea R)

Seven participants had whānau members with them at the time of their injury who were also injured, were first responders and/or called emergency services.

> 'My brother was first on the scene. He ran 35 minutes to a house and rang Dad and the ambulance. My brother struggled… suffering psychological trauma for a very long time after the accident.' (Kōkā J)

The significance of major trauma injuries often leave patients feeling vulnerable and burdened for a long period of time. Some experience an inability to complete everyday activities that many (uninjured people) would take for granted.

> 'If I forget to take my pills on time, within hours I get a sore chest. It's just tiring, I'm still unfit… not allowed to exercise, not allowed to lift anything… it's a slow process and I'm still healing.' (Matua R)

Only four people described their entire rehabilitation experience as positive.

All whānau described the ongoing impact of their trauma event, recovery and rehabilitation on their physical, psychological and emotional wellbeing.

The majority of participants encountered numerous challenges at different stages of their recovery.

The following sections describe some of the influences on positive and negative aspects of their rehabilitation experience.

Cultural capability of health services

The way that kaupapa Māori values and practices were included within their inpatient care and rehabilitation differed for each whānau. Some drew strength from their own taha Māori (Māori culture) and that of their wider whānau to support them during their recovery and healing. They spoke of their journey being easier to deal with because they had kaupapa Māori principles to support them.

> 'I had kaupapa Māori to get through the journey. I had the wairuatanga (spirituality), the manaakitanga (caring), the whanaungatanga (family connections), the kotahitanga (togetherness). I had all of that which made my journey so much easier to deal with.' (Whaea R)

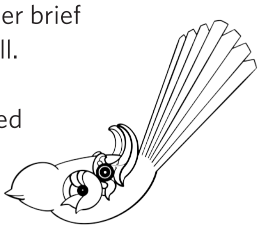
Several whānau spoke of Māori staff members within the hospital or rehabilitation centre providing valuable cultural support during their stay. They valued this type of manaakitanga and piki ora (wellbeing support, recovery) highly and were appreciative of the ways in which Māori staff helped them in their healing.

Examples participants provided included Māori staff taking the time to get to know them, who their parents were and where they were from; sharing kai with them while they were in hospital; and bringing in Māori resources and tools that would help them during their recovery. All of this helped to make them feel comfortable during their inpatient stay.

> 'She was awesome. She knew my daughter was connected to te ao Māori and she was a tohunga (expert) with puoro (music). She would bring in anything that comes from the ngahere (bush). She had a broader understanding of the world.' (Kōkā M)

> 'He knew Mum and Dad… a couple of times we did a few waiata because he saw a guitar in the room. One day he noticed my fruit bowl was a bit down. So, the next day he brought me in all this fruit. Little things like that made the stay a bit more bearable.' (Matua W)

Support provided in the hospital setting was limited. Some whānau spoke about the hauora Māori service (Māori health service) within the hospital setting and how the service would have been helpful for them but they were never offered it. Others recalled the service visiting them at the beginning of their stay, but its input was minimal. Follow-up visits were either brief or, for most whānau, did not occur at all. One wahine questioned whether high workloads and understaffing contributed to the minimal service.



> 'If they've got too many clients, you just become part of the system and they're just doing a job. I think in order for us to benefit from what services they are providing, then they need to not be overloaded with patients or clients. Then they can have an input.' (Whaea R)

As in the inpatient setting, after participants were discharged, the services they received included only limited kaupapa Māori values and practices. Whānau expressed different expectations and perspectives on how practices such as whakawhanaungatanga, manaakitanga and whānau ora could improve their rehabilitation experience.

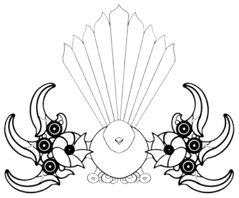
Whakawhanaungatanga

All 21 participants described their experiences with whakawhanaungatanga. Several provided examples of where this exceeded expectations, most notably with the nursing staff and Māori staff members. In these instances, staff undertook whakawhanaungatanga by taking the time to sit and talk with whānau, learning who they are and where they come from, and finding a connection through either people or places that were common or familiar and through the sharing of kai (food). Whānau were happy with this and felt at ease with the other person, which fostered a connection that remained in place for the rest of their rehabilitation.

> 'I was so happy when I saw and met a Māori doctor. Especially when he came and had some boil up. He knew where I was at, where my farm was and who owned it... that just put me at ease straight away.' (Matua W)

Fourteen participants struggled with a lack of whakawhanaungatanga.

This meant services did not provide the participants with the opportunity to form a connection or relationship with individuals in their care team. The majority of whānau were frustrated that other health professionals and support services during their in-hospital stay and after they were discharged did not practise whakawhanaungatanga. They spoke about how clinicians did not introduce themselves and only had 10 minutes for a consultation. After discharge from hospital, whānau talked about feeling frustrated with how different service providers spoke to them. Many felt they weren't being heard and that having a number of different case managers made it even harder to form a connection.



> 'The only person that I really met who gives me a handshake and introduced themselves was a student surgeon.' (Matua K)

Allowing whakawhanaungatanga to occur would have improved communication as well as engagement in care plans and shared decision-making processes. This, as one person stated, 'would have made it easier to ask questions and to have free and frank conversations with the doctors'. Such experiences, in turn, would have eased many of the frustrations associated with communication.

When health professionals, agencies and other services invested in whakawhanaungatanga, the whānau experience was much more positive.

With whakawhanaungatanga, the relationship formed was one of connection, mutual respect and shared understanding. Whānau were able to have informal conversations with their doctors and nurses, felt comfortable about asking questions and were included in discussions about their care plan. They felt valued, part of a wider group and engaged in the process. In this way, whakawhanaungatanga created a connection that continued beyond the doctor–patient interaction.

> 'When my mum passed away, all my occupational therapists, my physios, my psychiatrist, they all came in as one group, as one ope. That was really great. We really loved that.' (Matua W)

Psychological and emotional stress

Throughout participants' rehabilitation and recovery journeys, certain moments had a significant psychological and emotional impact on whānau. These began in the acute inpatient phase and continued throughout the entire healing process. Participants spoke about the impact of the injury, specifically how the outcome was creating an unintended stress that affected their mental wellbeing.

Many participants talked about having feelings of loneliness, loss of independence, work pressure and ongoing problems with their injuries. Twelve participants said their mental health struggles were more difficult than their physical injuries and they felt isolated from their everyday world while they recovered.

> 'It's not the physical pain that was the most difficult. I went from working 60 hours a week to doing nothing. That was the most difficult change, and it has been hard to step away from the world… a mental adjustment.' (Koro K)

Many participants experienced additional psychological stress because the injury and rehabilitation journey strained relationships, created financial barriers and/or introduced housing pressures. Some felt that these situations not only affected their rehabilitation experiences but prolonged their healing process.

Not being able to work impacted some participants' financial situation. One person felt so pressured that they returned to work before they had fully recovered. Within a few months, however, they had to stop working again because of their injuries.

> 'Ever since I've had this injury, I've tried to work. Work and Income helped, but I don't earn enough to be able to do the things I want to do. I only get paid $290 on a benefit. My board is $250 so I'm not really left with anything. I started trying to go to work. I couldn't stay in work because of my legs… ACC was not helpful.' (Kōkā F)

Not everyone was offered support while in hospital. Whānau found it difficult to access timely and culturally appropriate psychological support for their mental health and emotional wellbeing. During an interview, one wahine asked what a psychologist was as this service was never discussed or offered at any time during her rehabilitation. For another wahine, finding a suitable counsellor that met her needs was challenging and at the time of the interview a counsellor had still not been engaged to support her.

> 'For the last year and a half, I've been trying to get a counsellor… that I have someone to talk to about all that I was going through.' (Whaea R)

The psychological stress for several people was so difficult to manage that they had suicidal thoughts while they were in hospital and continued to do so when they were discharged. For one person, their suicidal thoughts escalated to the point where they had developed a plan and were days away from attempting suicide.

> 'I thought it would be easier if I just do it, then no one has to look after me.' (Matua K)

Another person noted they had anxiety and depression before the injury. However, following the injury they felt their anxiety and depression got worse, to the point where they believed suicide was the only way out.

> 'I created scenarios in my head about how I was going to do it.' (Kōkā R)

The majority of participants were offered psychological support at different stages of their rehabilitation. **Only three participants who received psychological support indicated that it was timely and positive and helped to improve their wellbeing**. In these cases, the person providing their psychological support was someone who they trusted and had a good connection with. The sessions were regular and consistent and often included other activities such as going for coffee or a walk on the beach. For one tāne, this helped him to feel more relaxed with his psychiatrist.

> 'We had a good old walk on the beach. After that, we're mates. I feel really relaxed talking to him. He's a great guy.' (Matua W)

Post-traumatic stress presented itself most notably in participants that had been injured in car crashes. The visions and flashbacks they experienced were traumatic and impacted them for many days after the event. One wahine describes her first flashback as being so real it was like she was experiencing her event again.

> 'I never want to have a flashback again in my life. It was so real. I was watching it happen all over again.' (Kōkā J)

Several participants continue to struggle with anxiety when travelling by car. Only one person continues to receive psychological support for his PTSD; the others are coping on their own (with and without medication).

> 'It's still hard for me to get in the car with someone else driving. Unless that person gets out of the driver's seat and is going to let me drive.' (Kōkā F)

The psychological and emotional stress many participants experienced has a far-reaching impact that sometimes goes unseen. For some participants, their experiences significantly impacted on their mental wellbeing. These experiences highlight the importance of assessing health and social factors and making resources accessible to make use of all of the factors that contribute to improved recovery.

Support for informal caregivers

Whānau provided the aroha, manaaki and tautoko when their loved one was at their most vulnerable. The ways in which whānau helped them included helping with showering and toileting, being a trusted person to talk to, bringing in kai to share, providing karakia and waiata, and looking after tamariki while the loved one was in hospital. More importantly many were advocates when needed.

Whānau support was crucial to the recovery process and all 21 patients acknowledged that the awhi and tautoko their whānau provided helped in their recovery process. Whānau provided that support in a holistic way, addressing the person's physical, spiritual, mental and social needs. Having someone there every day with them who was familiar with how they like things was helpful and reassuring.

> 'I had someone with me every single day, which really helped. I wasn't just alone with my thoughts. I think that would have helped my state of mind at the time.' (Matua F)

One wahine said a niece who lived in Rotorua packed up and came home and spent every day with her in hospital.

> 'She knew what I was like, and she wanted to be there for me. And that was a godsend.' (Whaea R)

Whānau described the heavy burden of supporting their loved one during their rehabilitation and recovery.

Close family members were trying to manage their own jobs and tamariki while supporting their loved one in hospital.

They struggled with costs such as car parking fees at the hospital and additional petrol costs.

The emotional burden took a toll. Whānau talked about the absence of any help for them as the primary support person and being treated poorly when they did ask for help.

> 'Nobody ever asked how I was coping with it all. Nobody once said, "Hey Matua, how are you coping with it all? Do you have the support that you need to be able to care for Whaea?"' (Matua S)

Another said they did try to seek support for their partner who at the time was providing care for him.

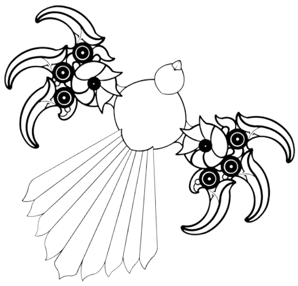
> 'I told ACC that I needed some kind of help. Because things were really rough at the time. My partner and I were on the verge of breaking up… I asked for help, got mucked around and me and my partner are not together anymore.' (Matua R)

In several situations, the wider whānau were also involved in the trauma event and had their own physical injuries and psychological and emotional impacts to cope with. This placed the whole whānau unit under intense pressure to the point of breakdown.

> 'I saw him twice in the hospital and then he stopped coming. He couldn't handle seeing me. He turned to drugs because he didn't want to sleep because he was having nightmares.' (Anonymous)

The COVID-19 pandemic also impacted on several participants who were injured just before Aotearoa New Zealand went into Level 4 lockdown in March 2020. Because of the restrictions enforced at Level 4, they were unable to have any visitors during this time. While they understood the reason for the restrictions, they still found it incredibly difficult being alone and away from whānau.

Where participants were at the post-discharge stage of recovery at Alert Levels 3 and 4, their therapies stopped during this time. The response to this experience was mixed. One tāne felt lockdown allowed him extra time to recover. In contrast, one wahine felt the break in her physiotherapy at this time hindered her recovery. Her whānau discussed whether therapies for people completing major trauma rehabilitation could be 'classed as essential services so that people with injuries could continue with their rehabilitation during this important stage of their recovery'.



Communication, decision-making and service coordination

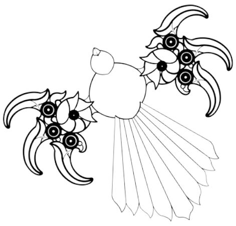
Many participants did not receive open and clear communication. When whānau wanted information about their injury or care, many were frustrated because the clinicians talked too fast or used technical terms that they found difficult to understand. One person said it would have been helpful to have had someone there to translate the information for them into simple everyday language.

> 'Someone that can talk in plain English to our people. I found myself saying to the doctors quite often, "Well that doesn't mean a thing to me. Don't come along and use your flash language that only you know what you're talking about."' (Whaea R)

In many instances, patients found it difficult to advocate for themselves at a time when they felt most vulnerable. Almost all patients wanted to be kept up to date with their care plan or the decisions that were being made about their treatment and recovery. They wanted to be included in the decision-making process. One wahine referred to a health care poster with the slogan 'No decision about me without me' to advocate to her care team that her and her husband wanted to be included in the discussions.

> 'All the way through, any issue we've had has always been lack of consultation. So that we can be part of it. That's all we're asking. We'll be there any time they want it but no, they had it somewhere else, and decisions made. No decisions about me without me. I asked for the hui to be around my bed with my husband present, but it didn't happen.' (Whaea H)

The involvement of whānau in updates around health status, the rehabilitation plan and understanding the implications for rehabilitation was extremely important. For many patients and whānau, this experience was inconsistent at best. Being treated for major trauma makes it difficult for a patient to remember or understand important details about their care plan. For this reason, it is essential to include whānau in communication and decision-making. One patient's tungāne (brother) expressed frustration with the lack of communication about his sister's care plan to him and the rest of the whānau.



> 'My brother wasn't happy with the fact that the information wasn't filtering through to him via me because I couldn't answer any questions that he had about my rehab, my health, my discharge from the hospital because I didn't know. Because the meetings weren't happening with me, he was frustrated.' (Whaea H)

For some participants, the lack of service coordination when they were discharged from hospital was a continuation of their experience as an inpatient. They were discharged home with:

- no clear transition plan
- no follow-up visits arranged
- no support or training for them or their whānau on how to recover at home safely and appropriately.

> 'It was hard getting sent home early not even knowing how to do any of that (mobilise). There were no home visits, nothing.' (Kōkā F)

Two people were in hospital during either the Christchurch mosque shooting or the Whakaari (White Island) volcanic eruption. Because of the influx of patients, they needed to be discharged earlier than planned, adding to their stress and unease.

> 'I told them I wasn't ready to go home but because they had too many patients going in, I had to go. It was the time of the White Island eruption. Half my body was still numb, and I couldn't move properly.' (Kōkā F)

Accessing ACC support was easy and straightforward for several whānau. They were able to establish a good relationship with their case manager(s), who implemented a range of support services to help their recovery. In these instances, their case managers were supportive from the outset, offering to help in any way that was needed.

> 'Whatever you want, just let me know. Anything you want, it's yours. So that's been really great.' (Matua W)

However, for the majority of whānau, engaging with ACC proved challenging. They experienced this across different stages of their post-discharge recovery. For one tāne, the difficulties occurred in the first few days of trying to contact his case manager as she wanted to see him in person while he was still bed-ridden with limited mobility.

> 'She's pressing to see me. I said I can't. Why? I have seven spinal fractures, two in my neck, five in my back, a knee reconstruction, my sternum is stuffed and I'm bed-ridden. I can't even pull myself up on my crutches. How am I going to get to the door?' (Matua K)

Other whānau found it unhelpful when they would ring ACC or Work and Income (WINZ) for support only to be told the agency wasn't able to help. Whānau in these situations found it too confusing and stopped asking for help.

> 'When you ring your ACC manager up and she says to you, "No, we don't do that", then that's just no help. That just makes me not want to ask you for anything, so I won't. I'll find my own way.' (Kōkā M)

> 'It got too confusing for me. They were telling me WINZ need to do it and WINZ were telling me ACC need to do it, so I just gave up on trying.' (Matua J)

Across the interviews, whānau provided examples of being disappointed by the supports and therapies provided post-discharge. These experiences highlight that service provision post-discharge needs to be meaningful and of value to whānau. One wahine described a home visit by a concussion clinic provider. This wahine lives rurally and the drive is 45 minutes from the main city centre. The provider that visited her was rude and offensive.

> 'She rushes in and demands to use the toilet. She was quite offensive. "Where's your toilet? What an awful drive." Goes to the toilet. Comes back up, "Oh my gosh, I've got to be gone soon." She only just arrived. "Here's a paper and here's my name"... and it had spilled coffee on it.' (Whaea H)

Following on from that, the provider asked the wahine to remove her brace, something this wahine knew she wasn't allowed to do. The whole visit was upsetting.

> 'She asked me on day one, "Can you take that thing off?" I went, "No. I'm not allowed to." Lucky I was astute enough to say that. I was really upset with that.' (Whaea H)

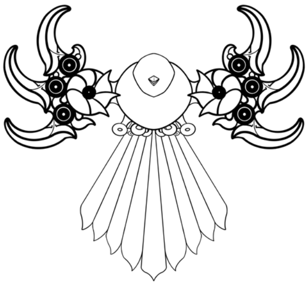
Another wahine described having her home care support changed from full time to zero, after one assessment, a change that was incorrect and should not have happened.

> 'I had one young girl who came out to do an assessment on me and she went back and told them that I was fine, that I was mobile because I was able to move around my own house. I went from full-time care to nothing. Based on one young girl's assessment. I was furious. I was upset. That all got changed and dealt with, but it should never have happened.' (Whaea R)

While whānau understood the position of ACC is to return people to work, many felt this was a challenging process and patients talked about feeling pushed to return to work and get off ACC support.

> 'Don't try and push me back to mahi (work) prematurely. This is my life ... I get it, but you're not going to push me. I want to get out of here, but I've got to wait for my body.' (Matua K)

> 'I felt as if there was a deadline for me to get off ACC. With 11 broken ribs, what is the time to get over it?' (Koro R)



Te wero: Ngā mahi hei whakapai ake i te wheako tauwhiro me te whakaoranga mō te Māori | The health system challenge: Actions to improve care and rehabilitation experiences for Māori

As our interviews showed, participants appreciated the value that culture adds to the rehabilitation experience as much as the quality of health care they receive.

With the health and disability system now in transition, the voices of whānau Māori in this report present an opportunity to inform and influence a shift in the design and delivery of services to enhance experiences (and potentially outcomes) for Māori. The equity-focused priority of the health and disability system reforms presents an additional opportunity for further investment in culturally and medically responsive mainstream health services.

Providing a culturally appropriate health service is 'essential for the delivery of effective health services to Māori'. It follows that the principle of active protection requires mainstream health institutions to incorporate and practise tikanga Māori (Waitangi Tribunal 2019).

A Māori world view, tikanga Māori (rituals), understanding the whānau context, whakawhanaungatanga (connection), the pōwhiri (introduction) process and whakarongo (listening) are all key components in working effectively with Māori (Haitana et al 2020).

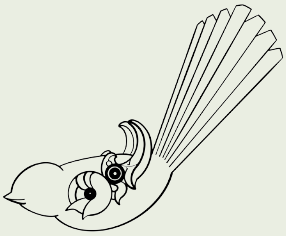
This section provides a series of strategic recommendations, along with immediate actions, that if implemented have the potential to create the conditions for positive trauma care and rehabilitation experiences for Māori.

Recommendations focus on longer-term system investments.

Actions focus on what clinicians and health or social service teams can achieve by making small but feasible changes to the way they deliver care.

The Health Quality & Safety Commission's (2019) report *He matapihi ki te kounga o ngā manaakitanga ā-hauora o Aotearoa 2019 – he tirohanga ki te ōritenga hauora o te Māori | A window on the quality of Aotearoa New Zealand's health care 2019 – a view on Māori health equity* highlights areas where health system improvements are needed to reduce Māori health inequity and achieve ōritetanga (equity). These include improved access to services and improved quality of care for Māori. The report acknowledges existing tools, strategies, programmes and resources that can be used to inform and advance Māori health equity such as Whānau Ora, He Korowai Oranga, Pae Ora, iwi hauora providers, Māori workforce development and cultural safety education.

www.hqsc.govt.nz/our-programmes/health-quality-evaluation/publications-and-resources/publication/3721/



1. Ko te whakawhanaungatanga me noho hei whāinga matua mā ngā kaiwhakarato tauwhiro hapori | Whakawhanaungatanga must be a priority for all health and social service providers

Whakawhanaungatanga is a Māori cultural concept that encompasses taking the time to get to know consumers, patients and their whānau. It is an essential component to building connections and relationships with others and is central to Māori wellbeing.

In its 2015 Te Urewera report, the Waitangi Tribunal noted a 'one size fits all' model tends, in practice, to suit the needs of the majority, who are rarely the group in most need of help (Waitangi Tribunal 2015). Even when they can access mainstream services, minority groups such as Māori have often found that what is being provided simply does not work for them or is so alienating that they prefer to disengage (Waitangi Tribunal 2019).

When services practised whakawhanaungatanga, whānau felt more engaged in their care journey, more confident about their care team and their rehabilitation plan, and that it influenced their ability to make a full recovery.

When services did not practise whakawhanaungatanga, several whānau expressed feelings of frustration, being judged and not being heard. Participants struggled mentally and emotionally during their time in hospital and found it increasingly difficult to maintain a healthy mindset. These challenges continued beyond their time in hospital and negatively impacted their entire rehabilitation experience. As a result, they disengaged from all rehabilitation services, took longer to recover, struggled on their own and were left with an overall sense of mistrust in the system.

For whānau Māori, all clinical and non-clinical professionals helping in the rehabilitation journey need to understand or have a capability to practise whakawhanaungatanga in everyday interactions.

See our tips for clinicians to practise whakawhanaungatanga.

Action: All trauma clinicians practise whakawhanaungatanga with Māori patients and whānau.

Where clinicians practised whakawhanaungatanga, whānau and clinicians gained a deeper understanding of and connection with each other.

Whakawhanaungatanga in practice involves these simple actions.

- Take time to pronounce names correctly and ask whānau if you have pronounced them correctly.
- Introduce yourself to the person and their whānau (including any new whānau members that are visiting). Try this:

  > Kia ora, he tākuta/tapuhi/kairomiromi/ringa tauwhiro e tiaki ana i tō hoa. Ko tōku ingoa ko...
  >
  > Hello, I am the doctor/nurse/physio/OT taking care of [insert patient name]. My name is...

- Share your pepeha (quotation or idiom), talk with whānau about who you are and where you come from (where you grew up, your family, your hobbies).

Note: Māori with a traumatic brain injury talked about their short-term memory loss and struggling to remember everyone who visited. They asked health professionals to accommodate this by repeatedly introducing themselves during this time.

- Take the time to share kai with and give it to whānau. Doing so encapsulates the concept of manaakitanga and demonstrates respect, friendship and kindness.
- Offer karakia at the beginning of any consultation with whānau (repeated pepeha where required).
- Show genuine interest in the person and their whānau. Friendly conversations away from the doctor–patient discussions help build trust and respect. Whānau spoke highly of how such conversations contributed to a positive experience for them during their time in hospital. This approach sets up the trust and openness for the 'What matters to you and your whānau?' questions.
- Include the person in all decisions about their care and rehabilitation and include the whānau in the discussion as well.
- Talk openly with whānau about what the rehabilitation journey will be like. This involves:
  - talking about the important components the person needs to enhance their recovery in the inpatient setting as well as when returning home, such as quiet spaces, rest and rehabilitation

  - taking the time to teach whānau how to support the injured person through rehabilitation exercises
  - providing whānau with practical information that is easy to understand on subjects like simple rehabilitation exercises, how to look for signs of psychological distress and how to access help (see the action on information resources under recommendation 4).

2. Me whai e ngā ringa tauwhiro pāmamae i te tikanga ahurea | All trauma clinicians must adopt and be accountable for a culturally effective approach

Many Māori hold alternative views of health and wellness to Western biomedical views (Wilson et al 2018). Te ao Māori focuses on the collective and places an individual within the context of whānau, hapū and iwi, which differs from Western measures that focus on improving health outcomes at an individual level (Mills et al 2012). Further, Indigenous health and, to similar degree, Indigenous rehabilitation models focus on providing health and/or disability care that achieves outcomes related to 'what matters most' to the people being served (Harwood 2010).

Physical rehabilitation outcomes for Indigenous peoples can be enhanced by addressing factors at health system, health service and individual clinician levels (Lin et al 2020). Any system improvements need to consider and include elements that are known to enhance service delivery. For Māori, those improvements should include components of culture so that all health service delivery is culturally appropriate. This change would require health systems, health services and all clinicians to acknowledge the value that culture brings to service delivery and provide culturally competent care to whānau Māori.

Action: All large trauma centres make kaiāwhina (assistants) available to be an integral part of trauma teams.

Action: Where available, and patients agree to it, routinely refer Māori trauma patients to the hospital's Māori support service.

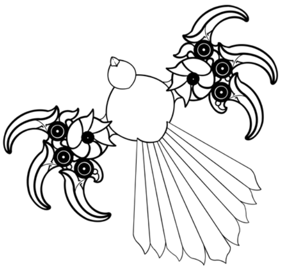
For Māori, health care and healing come from being immersed in culturally congruent environments that embrace te ao and mātauranga Māori (Hunter and Cook 2020). Evidence suggests an Indigenous-led or culturally responsive health system has the potential to improve Māori experiences of that system. Where a system has elements of culture woven all through it, it can potentially contribute to lessening the inequity that exists for Māori.

A Māori liaison on the trauma team that can support team members to develop their cultural responsiveness as well as meet the cultural requirements for whānau will be valuable in enhancing experiences of care. Specific responsibilities might include liaising with ACC and Whānau Ora staff to help people make appropriate transitions to community services for their care; and in-reach to clinicians to meet clinical needs (through shared decision-making, confidence in communication and care plans).

Action: All hospital trauma clinicians receive training in cultural competency and are encouraged to learn te reo Māori.

It could be easy to assume that mainstream health care services are culturally neutral in providing fair and equitable treatment and interventions (Curtis 2016). In relation to health care professionals, cultural safety training seeks to achieve better care through making professionals aware of diverse needs of patients and allowing the patient to determine where a clinical encounter is safe (Curtis 2016). It is important to acknowledge, and reflect on, how an inherent power imbalance impacts the clinical effectiveness of the provider and the level of clinical engagement of the patient or whānau.

Although a 'Māori support' service may help overcome some of the resistance to change, it is the responsibility of all clinical teams, and especially clinical leaders, to foster an organisational culture that becomes more confident and competent about being culturally responsive. Although this might begin with Te Tiriti o Waitangi training, it does not end there. All teams should work towards a deeper understanding of te ao Māori and embrace te reo Māori in daily practice.



Māori nurse specialists – an emerging model of care

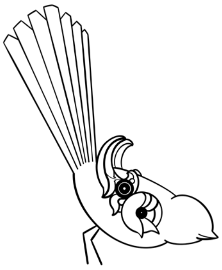
Some hospital teams are investing in staff who are primarily responsible for engaging whānau Māori and connecting them with inpatient and community services. Within the hospital environment, responsibilities include discussing diagnoses and treatment options with whānau to support shared decision-making, as well as taking time to listen to what matters to whānau, understand social, cultural, mental and physical health needs and refer to appropriate community (preferably kaupapa Māori) services. Additionally, these roles outreach to community kaupapa Māori services to understand types of supports available to whānau and to check those services follow up and complete any referrals. Lessons from clinical services investing in these roles indicate this investment has value for Māori patients. It is important to note that roles like this do not absolve clinicians of their responsibility to provide culturally responsive care. If we are to build a health system that accommodates the needs of Māori, cultural competence is everyone's responsibility. We emphasise that all clinical team members should be expected to build their own cultural competence and demonstrate leadership in cultural responsiveness when engaging with whānau Māori.

Resources for private and public health care providers looking to develop organisational capability in working with Māori

Many organisations are making investments in and progress towards enhanced cultural competency. Where they meet with challenges, resources are available. Te Arawhiti, the Office for Māori Crown Relations, developed a public sector capability framework and organisational capability guidelines. The framework has adopted a maturity model, which includes four areas where agencies or staff have asked for specific advice:

- how agencies can recruit more people with Māori–Crown relations skills
- how to make workplace environments comfortable and supportive for Māori staff
- how to demonstrate a commitment to te ao Māori through an agency's physical environment
- how to demonstrate a commitment to tikanga Māori.

For more information, go to: www.tearawhiti.govt.nz/tools-and-resources/



3. Me tātari, me aro turuki me te tautoko hoki e ngā kaiwhakarato hauora me ngā kaiwhakarato tauwhiro hapori te oranga ngākau o te tūroro me te whānau | Health and social service providers must assess, monitor and support the psychological and emotional wellbeing of the patient and whānau

In a study by Richardson et al (2021), 25 percent of a large cohort of New Zealanders with major trauma injuries reported experiencing clinically relevant distress three months after their injury and 16 percent at 24 months post-injury. These findings demonstrate the ongoing psychological impact of major trauma.

Post-traumatic stress following major trauma injuries can also continue over the long term (Bryant et al 2015; Danielsson et al 2018). Participants in this project confirm this impact: after motor vehicle collisions that involved whānau, whānau experienced PTSD that affected their daily lives.

Action: Providers routinely screen all Māori major trauma patients for clinical signs of pain, PTSD and concussion, with whānau engagement and referral as appropriate.

While providers offered many participants support for psychological and emotional distress as an option, not all participants received it and pathways to access those services were complicated. Participants spoke about the mental health difficulties they faced during their recovery. The psychological distress took a broad range of forms, including self-reported feelings of grief, guilt, anxiety, depression, post-traumatic stress and suicidal thoughts that for several participants continued into their post-discharge phase of recovery.

By implementing psychological screening early and continuing it into the rehabilitation phase, providers may find opportunities to identify distressed patients and intervene early to achieve best possible outcomes. Given the burden placed on whānau as informal caregivers, providers should extend screening to whānau wherever possible and offer support to informal caregivers. Doing so has the potential to improve experiences and outcomes and to reduce the costs of care.

As an integral part of communicating with whānau about what to expect in the rehabilitation journey of their loved one, all health service providers should be offering whānau some educational resources. Information should include how to spot signs of emotional distress and chronic pain and how (and where) to get help.

Action: All health and social service providers are, where feasible, encouraged to assess wellbeing of patient and whānau using a hauora Māori model.

Among the hauora Māori models, Te Whare Tapa Whā has been applied to improve understanding of rehabilitation outcomes for Māori (Wyeth et al 2013). The model consists of four essential, interacting dimensions that contribute to a holistic concept of overall health and wellbeing (Figure 2) (Durie 1998). It illustrates that, for Māori, health and wellbeing are strongly related to spiritual and emotional factors, rather than to physical or biological factors alone (Wyeth et al 2013).

Screening for psychological and emotional distress in major trauma patients (and whānau) undergoing rehabilitation must cut across all dimensions of wellbeing. One of the simplest tools providers are using to assess wellbeing is the Hua Oranga survey (see Appendix 1 for a copy). The Hua Oranga tool asks the individual, their whānau and the clinician the same questions to gain these different perspectives.

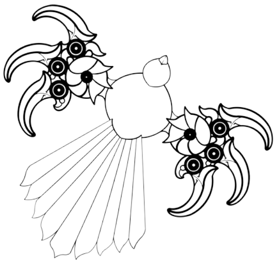
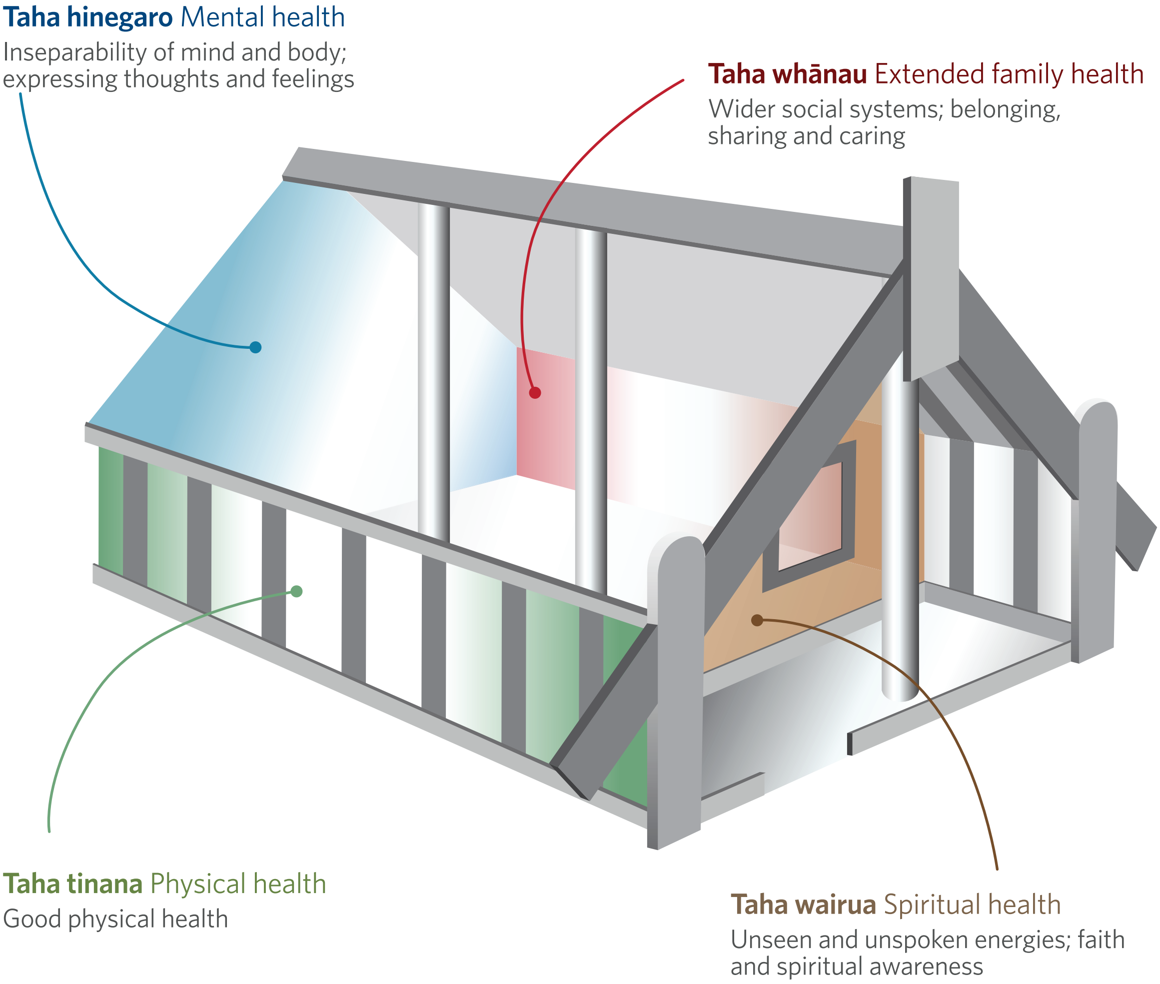


Figure 2: Te Whare Tapa Whā model of health and wellbeing



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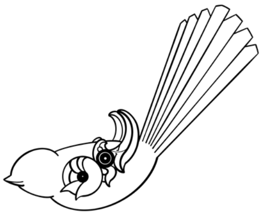
Hua Oranga measures outcomes consistent with Māori concepts of health and wellness, under the framework of Te Whare Tapa Whā, but it can be used with anyone (Māori or non-Māori) who finds the domains relevant. Hua Oranga applies the four dimensions of Te Whare Tapa Whā and can be used in a general health setting. Mental health settings are also using it extensively, as it recognises that all aspects of health are interconnected. For the same reason, Hua Oranga may be a fantastic resource for clinicians and whānau to use during major trauma rehabilitation.



4. Me noho tahi me te tautoko ngā rāngai i ngā whānau Māori | Agencies must involve and provide supports for whānau Māori

Action: All agencies working with major trauma patients and whānau, including regional trauma networks, use a consumer/whānau panel to inform service improvement.

The whānau we interviewed played an essential role in supporting the rehabilitation and recovery process. Regardless of whether participants' experiences of the process were positive or negative overall, they saw whānau support as the most important factor in their rehabilitation and overall recovery. Māori participants in the Prospective Outcomes of Injury Study reported satisfaction with life at three months post-injury (Wyeth et al 2013). It is likely that participants' whānau act as a protective factor against negative outcomes. However, the role of whānau as informal caregivers comes at a cost that must be acknowledged.

In supporting their loved one, many whānau in this report experienced immense emotional, financial and social stress, and in some cases their requests for support were ignored. Factors that amplified their stress and emotional turmoil include socioeconomic disadvantage, organisational or systemic barriers, their loved one's need for a high level of care, tensions within the caregiving household, and difficulties in accessing or effectively using respite (Nikora et al 2004). The Prospective Outcomes of Injury Study highlights the important role of whānau during injury recovery and rehabilitation processes, and shows that injury impacts extend to whānau, as with other aspects of health (Wyeth et al 2021).

The last 18 years of data on Māori experiences of the public health system in Aotearoa New Zealand suggest health professionals and systems need to overtly recognise the contribution of whānau to positive health outcomes. Such recognition could involve specific acts of affirmation or practical reimbursement such as providing parking and food vouchers or intentional information. In essence, agencies should take actions that recognise and value the contribution of the wider whānau in supporting their loved one and help to relieve the burden of caregiving.

Enabling consumer and whānau engagement

The notion of experience-based co-design has never been more relevant. The national health reforms have reinforced the need to engage Māori consumers, community providers and iwi partnership boards in the design of local programmes and services. This is no different for regional trauma systems. The Health Quality & Safety Commission has worked intensively over the years to build capability in health services to enhance their engagement with consumers. Numerous resources are available on the Commission's website at:

www.hqsc.govt.nz/consumer-hub/partners-in-care/

As an integral part of communicating with whānau about what to expect in the rehabilitation journey of their loved one, all health service providers should be offering whānau some educational resources. The information should include how to spot signs of emotional distress and chronic pain and how (and where) to get help. These educational resources need to be developed and made available.

Action: ACC and the National Trauma Network develop patient and whānau information resources specifically for Māori and actively distribute them across trauma teams and contracted provider services.

To support whānau engagement, all agencies who support care and rehabilitation of patients need to be clear about the rights of whānau. Communicating expectations of health and social sector professionals in the care journey will go a long way to enabling whanau-centred care. In turn, whānau should be encouraged to advocate for their loved ones while every health and social service professionals should actively uphold these rights and expectations.

See also our information for providers about helping whānau communicate with health and social service providers.

5. Me mahi tahi me tautoko hoki e ngā rāngai ngā ratonga Māori | Agencies must invest in kaupapa Māori service providers and support their use

Rehabilitation from major trauma has wide-reaching impacts on the psychological and emotional wellbeing of whānau. These impacts are especially concerning when whānau ask for support, only to be bounced between providers with no one responsible for matching services to the needs of the whānau. To maintain optimal wellbeing, patients and whānau must have the opportunity to choose between a mainstream or a hauora Māori service, based on which they see as more appropriate for their needs.

In terms of health services, the Crown (and by default trauma services and ACC) has a responsibility to enable Māori to have available the options of Māori or mainstream providers as they wish. Further, it must provide equitable protection under Te Tiriti o Waitangi for both of these pathways so they offer a genuine, well-supported choice for Māori (Waitangi Tribunal 2019).

Action: ACC and trauma services facilitate options for routinely referring Māori patients to kaupapa Māori or rongoā māori (natural medicine) services.

The Māori patients we interviewed had varying degrees of success in accessing the support they needed once they transitioned back home. As a result, they differed in their experiences of care and reported outcomes. They described communication challenges and a lack of continuity of care as barriers to accessing services. They also expressed frustration when trying to access supports they were entitled to receive and when services did not meet their needs or expectations.

Māori will play a central role in developing and delivering cross-sector initiatives. Services place individuals and whānau at the centre. *Whakamaua: Maori Health Action Plan 2020–2025* supports action towards better service integration across different sectors. As the health reforms bed in and locality models develop, we should begin to see the establishment of, and engagement in, partnerships across a range of sectors to allow for better service integration, planning and support for Māori and their whānau (Ministry of Health 2020b). These partnerships may not be perfect from the beginning, but the act of kotahitanga will support service improvement and create closer alignment between health and social services.

Trauma teams should undertake an environmental scan of their local or regional kaupapa Māori providers. Given their responsibilities for discharge planning, they must be aware of the full breadth and scope of these services available to whānau. Whānau will have options available in their care plans at discharge and can actively participate in decisions about services that matter to them.

As our system evolves to become equity-focused, the depth of, or imminent threat posed by, health inequity should heighten the urgency to take action (Waitangi Tribunal 2019). This action must include providing appropriate resource and support for these kaupapa Māori health services, like those described above, maintaining them equitably and making them available to Māori.

Action: ACC strengthens mechanisms to liaise with other agencies on complex social cases through identifying need early.

Optimising experiences and outcomes of care requires cooperation outside of the health sector to strengthen broader health determinants (Waitangi Tribunal 2019). Disparities in trauma and health care can be viewed as the responsibility of the patient (genes, behaviour), the environment (neighbourhood, place), the health care provider (competence, implicit bias), the health care system (access, quality) and society (social and economic inequality) (Mikhail et al 2018). Based on the experiences of whānau in this report, multiple sectors should work together to maximise wellbeing for all whānau. The sectors involved must include employment, education, justice and housing along with health.

With strong mechanisms for liaison in place, agency staff can confidently ask questions such as 'What matters to you?' or 'What matters to your whānau?', or questions in the Hua Oranga survey to check the wellbeing of whānau, knowing supports are available to deal with any issues they identify.

Early in the care process, while the patient is in hospital, an inpatient case manager, Māori liaison or Māori support team can begin to identify these issues. Encouraging health and social service providers to be acutely aware of the broader social needs of patients and whānau is essential. Service teams must foster relationships between agencies and understand the breadth of services available for whānau. Along with this understanding, they must adopt a 'how might we help' mindset and act on needs in order to offer a mana-enhancing service.

Action: All health and social service agencies invest in training staff, including ACC case managers and hospital Māori support service staff, to effectively communicate with rangatahi.

Among the interview participants, six rangatahi Māori (aged 16–24 years) offered their experience of major trauma rehabilitation. Due to their age and stage of life, these rangatahi required a broad range of health and social service supports during their rehabilitation. Supporting the rehabilitation of rangatahi involved a unique set of challenges for health and social services, setting them apart from other age groups. Common experiences included feeling unheard and judged, which led them to mistrust the system and often disengage from the services that were intended to support them.

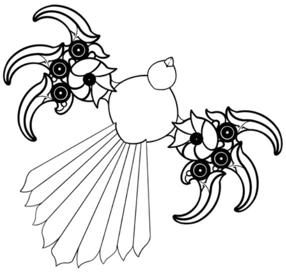
Investing in a workforce that is skilled at engaging with rangatahi may have a number of positive impacts.

- Housing pressures and homelessness affected youth who were in the process of leaving their whānau to work or study. What mattered to rangatahi in these instances was that health and social services took mana-enhancing approaches to case management.
- Rangatahi in the report returned to work due to financial hardship even though they did not feel physically or mentally ready to do so. The lack of support from social services created pressures on them to return to work prematurely. This affected the wairua of rangatahi as many were not able to work like they had before they got their injuries.
- For patients in contact with the justice system, particularly those who have had a traumatic brain injury, health services and the justice system should liaise to meet their physical, mental and spiritual needs.

Our youth are our future. Their wellbeing is important not just to them and their whānau, but to our society as a whole. Supporting their recovery in the most effective way is really important and needs special consideration.

Investing in a culturally responsive pathway

ACC is working towards commissioning Kaupapa Māori and rongoā māori services for serious injury rehabilitation. These services are intended to offer an option for healing founded on te ao Māori. Acknowledging that whānau require more than physical rehabilitation, the goal of healing is focused on overall wellbeing and will be offered through a case management model. Currently, this model is being piloted across five sites with a view to increasing the number of iwi and providers who are involved in the programme. To access the programme, whānau must request rongoā services.



6. Me ine e ngā rāngai ngā kaupapa nui ki te Māori | Agencies must measure what matters to Māori.

This project has reinforced the importance of listening to the voices of Māori to focus our attention on improvement opportunities that will enhance experiences of care. For Māori, the perspectives of wellbeing, health and outcomes of care will vary and cultural factors are likely to be a major influence on those perspectives (Kingi and Durie 2000). We need to be mindful that current health service and system measures for Māori may be inadequate. For this reason, it is vital we identify outcome tools to measure aspects of health that are important and relevant to Māori. At a service level, measures of outcomes are particularly useful in developing treatment plans, as well as in monitoring progress, staff deployment and service development (Kingi and Durie 2000).

Building on previous recommendations, measuring what matters will be further informed by engaging whānau on consumer panels, using patient experience surveys and directly measuring outcomes. Further, investing in cultural competence will increase awareness of what matters to Māori.

Investing in cultural responsiveness as a health care professional, among a team or across an organisation, can be overwhelming and create vulnerability. It will take courage and authentic leadership from clinical and administrative leaders to drive change. Some aspects of culture change can occur quickly, while others may take years of investment and reinforcing before they happen (Te Arawhiti 2019). Organisations and clinical teams will need to identify key performance indicators so they can know they are moving in the right direction. It will be equally important for teams and organisations to develop an action plan towards improving experiences of care.

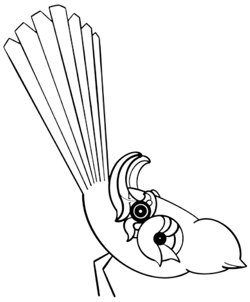
Action: The Health Quality & Safety Commission continues to rework in-hospital patient experience survey tools so they include cultural competence of providers.

Patent experience survey tools are available for organisations to use to identify opportunities for improvement. If providers are to use survey tools to improve their services, they need a clinical champion who sees value in the data and is prepared to work with providers and patients to co-design approaches to improvement.

If we are serious about evolving the system to become increasingly culturally responsive and reduce inequity, survey tools should evolve to maximise whānau Māori engagement, and to provide meaningful feedback to care teams about culturally effective care.

Action: The National Trauma Network routinely measures patient-reported outcomes for Māori.

A project is underway to measure patient-reported outcomes but is limited to a 12-month cohort injured in 2019/20. The published results will include a particular focus on outcomes for Māori. It would be helpful to extend this project to make it available for all major trauma patients on an ongoing basis.

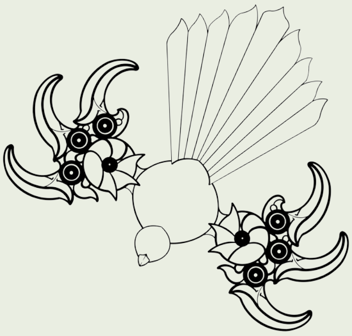


Hei whakakapi | Conclusion

Māori experience a higher rate of major trauma injuries and are more burdened by those injuries than non-Māori, yet they access and use rehabilitation services less than non-Māori. In developing this report, we have listened to whānau Māori and deepened our understanding of their experiences of major trauma rehabilitation. This has given us insights into how the health system, trauma teams and social service agencies might improve outcomes for Māori.

One of the key findings of this project is that cultural responsiveness of health services is integral to the experiences of rehabilitation for Māori. During rehabilitation from major trauma, whānau Māori have complex needs. Taking the time to foster strong relationships with patients and their whānau will go a long way to engaging whānau to support rehabilitation and to improve communication and decision-making. To do this well, however, trauma teams, regional trauma networks and national agencies must undertake intentional and feasible actions.

To achieve the priority of improving health equity, the challenge will be to translate the voices of whānau in this report into action. Whānau have opened up about their care experiences and provided a taonga, rich in details about where the deficits and strengths are, to optimise care experiences. Multiple agencies need to commit themselves to acting on the recommendations and actions identified in this report. The health sector is making significant investments to improve experiences and outcomes for Māori. This report identifies opportunities for continued and new actions that will serve to improve experiences for Māori across a broad range of health service delivery areas, not just in major trauma.



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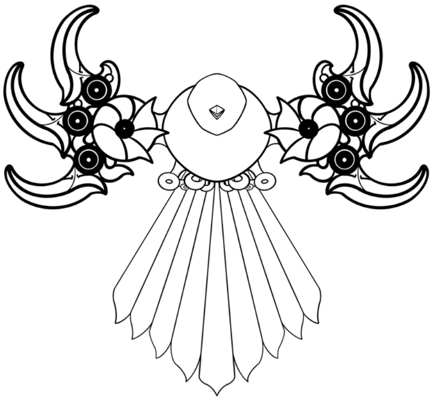


Kuputaka | Glossary of Māori terms

aroha – love, affection

awhi – embrace, hug, cuddle

awhi rito – two leaves outside the rito, metaphor for the parents

hapū – pregnant, sub-tribe

harakeke (pā harakeke) flax plant, metaphor for the family

hauora Māori – Māori health

hinengaro – mind

Hua Oranga – Health Outcome (survey)

iwi – tribe

kai – food

kaiāwhina – assistant, helper

kanohi ki te kanohi – face to face

karakia – incantation, prayer

kaupapa (kaupapa Māori) – Māori themes

kōkā – mother, aunt

kōrero – talk, speak, conversation

koro – elderly Māori man

kotahitanga – togetherness

mamae – pain, ache, sore, hurtful

manaaki – hospitality, entertain

manaakitanga – care, blessings

manaia – grotesque beaked figure

matua – parent, father

ngahere – forest

ope – troop, group of people in transit

ōritetanga – equity

pae ora – first aid kit

pepeha – quotation, idiom

piki ora – wellbeing support, recovery

pōwhiri – welcome

puoro – music

rangatahi – fishing net, metaphor for teenager

reo Māori (te reo) – Māori language

rito – centre shoot of harakeke, metaphor for the child

rongoā māori – natural medicine

tamariki – children

tāne – male, man

tangata whaiora – healthy person

taonga – treasure, gift

tautoko – support

te ao Māori – Māori world

Te Whare Tapa Whā – the four cornerstones (or sides) of Māori health

tikanga – formality, method, procedure

tinana – body

tohu – emblem, proof, symbol

tohunga – expert

tungāne – brother to a woman

tupuna/tūpuna – ancestor/ancestors

wahine/wāhine – woman/women

waiata – sing, song

wairua – spirit

wairuatanga – spirituality

wero – challenge

whaea – mother, aunt

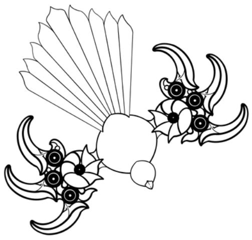
whakaaro – thoughts, think, consider

whakarongo – listen

whakawhanaungatanga – building connections

whānau – family

whānau ora – healthy family



Āpitihanga 1: Uiui Hua Oranga – tangata whaiora, whānau me te kaiako/wātaka | Appendix 1: Hua Oranga survey – tangata whaiora, whānau and coach/clinician schedules

Hua Oranga – tangata whaiora schedule

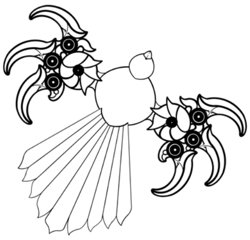
Name or NHI:

Tick the response in each category which best reflects the way you are feeling	
Wairua – spiritual wellbeing	**Tick**
1. I feel that my spiritual health is **extremely good** at present	
2. I feel that my spiritual health is **good** at present	
3. I feel that my spiritual health is **just okay** at present	
4. I feel that my spiritual health is **not good** at present	
5. I feel that my spiritual health is **very bad** at present	
Tinana – physical wellbeing	
1. I feel that my physical health is **extremely good** at present	
2. I feel that my physical health is **good** at present	
3. I feel that my physical health is **just okay** at present	
4. I feel that my physical health is **not good** at present	
5. I feel that my physical health is **very bad** at present	
Hinengaro – mental wellbeing	
1. I feel that my mental health is **extremely good** at present	
2. I feel that my mental health is **good** at present	
3. I feel that my mental health is **just okay** at present	
4. I feel that my mental health is **not good** at present	
5. I feel that my mental health is **very bad** at present	
Whānau – family and relationship wellbeing	
1. I feel that my relationships with my whānau are **extremely good** at present	
2. I feel that my relationships with my whānau are **good** at present	
3. I feel that my relationships with my whānau are **just okay** at present	
4. I feel that my relationships with my whānau are **not good** at present	
5. I feel that my relationships with my whānau are **very bad** at present	

Hua Oranga – whānau schedule

Tangata whaiora name ……………………………………………………………………………………

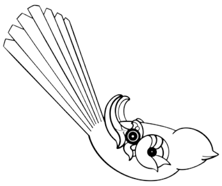
Tick the response under each category which best reflects the way you think your relative is feeling	
Wairua – spiritual wellbeing	**Tick**
1. I feel that the spiritual health of my relative is **extremely good** at present	
2. I feel that the spiritual health of my relative is **good** at present	
3. I feel that the spiritual health of my relative is **just okay** at present	
4. I feel that the spiritual health of my relative is **not good** at present	
5. I feel that the spiritual health of my relative is **very bad** at present	
Tinana – physical wellbeing	
1. I feel that the physical health of my relative is **extremely good** at present	
2. I feel that the physical health of my relative is **good** at present	
3. I feel that the physical health of my relative is **just okay** at present	
4. I feel that the physical health of my relative is **not good** at present	
5. I feel that the physical health of my relative is **very bad** at present	
Hinengaro – mental wellbeing	
1. I feel that the mental health of my relative is **extremely good** at present	
2. I feel that the mental health of my relative is **good** at present	
3. I feel that the mental health of my relative is **just okay** at present	
4. I feel that the mental health of my relative is **not good** at present	
5. I feel that the mental health of my relative is **very bad** at present	
Whānau – family and relationship wellbeing	
1. I feel that the relationships my relative has with our whānau are **extremely good** at present	
2. I feel that the relationships my relative has with our whānau are **good** at present	
3. I feel that the relationships my relative has with our whānau are **just okay** at present	
4. I feel that the relationships my relative has with our whānau are **not good** at present	
5. I feel that the relationships my relative has with our whānau are **very bad** at present	

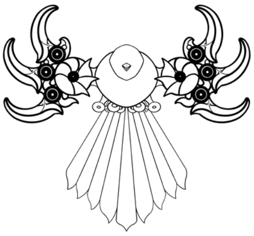


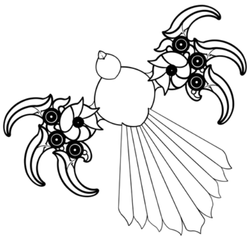
Hua Oranga – coach/clinician schedule

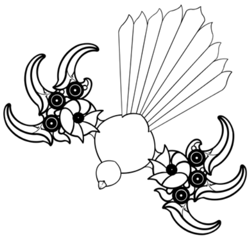
Tangata whaiora name ……………………………………………………………………

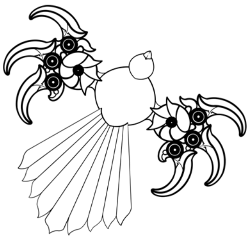
Tick the response under each category which best reflects the way you think the tangata whaiora is feeling	
Wairua – spiritual wellbeing	**Tick**
1. I feel that the spiritual health of the tangata whaiora is **extremely good** at present	
2. I feel that the spiritual health of the tangata whaiora is **good** at present	
3. I feel that the spiritual health of the tangata whaiora is **just okay** at present	
4. I feel that the spiritual health of the tangata whaiora is **not good** at present	
5. I feel that the spiritual health of the tangata whaiora is **very bad** at present	
Tinana – physical wellbeing	
1. I feel that the physical health of the tangata whaiora is **extremely good** at present	
2. I feel that the physical health of the tangata whaiora is **good** at present	
3. I feel that the physical health of the tangata whaiora is **just okay** at present	
4. I feel that the physical health of the tangata whaiora is **not good** at present	
5. I feel that the physical health of the tangata whaiora is **very bad** at present	
Hinengaro – mental wellbeing	
1. I feel that the mental health of the tangata whaiora is **extremely good** at present	
2. I feel that the mental health of the tangata whaiora is **good** at present	
3. I feel that the mental health of the tangata whaiora is **just okay** at present	
4. I feel that the mental health of the tangata whaiora is **not good** at present	
5. I feel that the mental health of the tangata whaiora is **very bad** at present	
Whānau – family and relationship wellbeing	
1. I feel that the relationships the tangata whaiora has with their whānau are **extremely good** at present	
2. I feel that the relationships the tangata whaiora has with their whānau are **good** at present	
3. I feel that the relationships the tangata whaiora has with their whānau are **just okay** at present	
4. I feel that the relationships the tangata whaiora has with their whānau are **not good** at present	
5. I feel that the relationships the tangata whaiora has with their whānau are **very bad** at present	

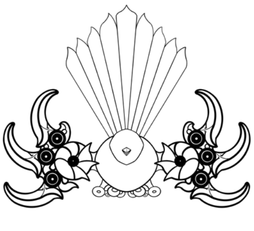


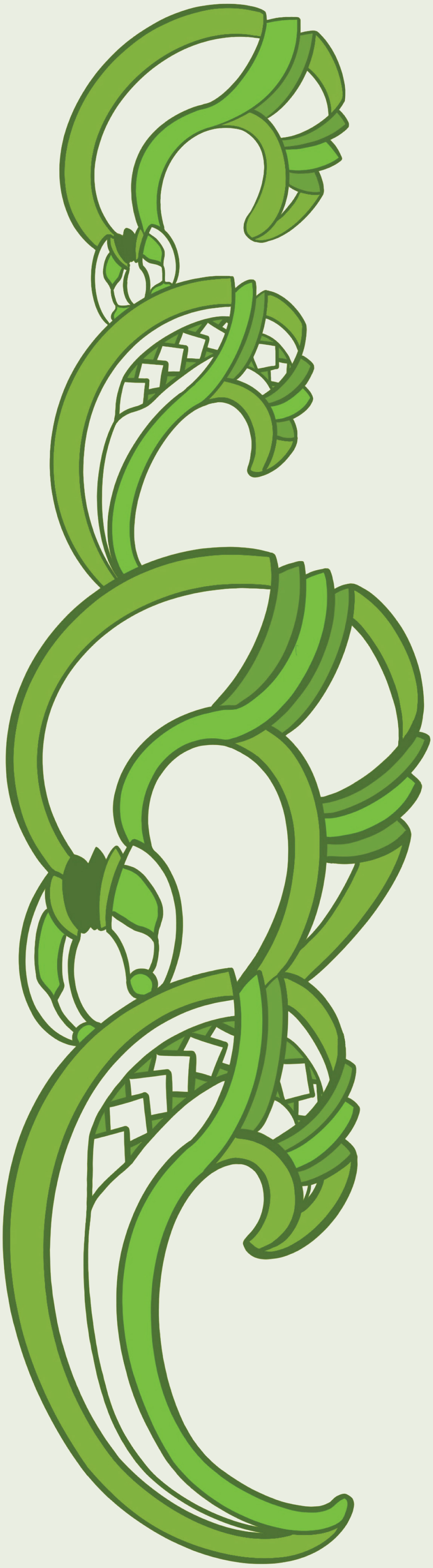












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**National Trauma
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**Te Kāwanatanga
o Aotearoa**
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