



Mauri Ora Associates

Māori Pacific Attitudes Towards Transplantation: Professional Perspectives

A report commissioned by the Ministry of
Health for Renal Services

National Renal Service Improvement Project

Honoa te pito ora ki te pito mate

Graft the live shoot to the ailing shoot



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Executive Summary

*Honoa te pito ora ki te pito mate
Graft the live shoot to the ailing shoot*

Historically, a kumara shoot that appeared to be struggling would have another shoot planted in the same mound. In the context of this discussion, the proverb refers to the grafting of a healthy kidney to support a failing kidney, thus promoting such a practice as tikanga Māori.

The Ministry of Health (MoH) has contracted Mauri Ora Associates (a health and communications consultancy) to survey clinical and allied health staff in renal transplant units on their experiences of providing renal transplantation for Māori and Pacific people and their perceptions of the causes of disparities in the rates of renal transplantation for Māori and Pacific peoples. The Ministry also requested expert advice on whether there are significant cultural issues in relation to renal transplantation, and advice on targeted education programmes for Māori and Pacific populations about renal transplantation and engagement with these populations, in particular any important considerations when raising the issue of organ donation with Māori and/or Pacific families or different processes in dealing with potential donors from these communities.

The project is informed by a literature review, a survey and interviews with renal transplant team members and interviews with Māori and Pacific cultural advisors.

This report provides a summary of renal departments' experiences of working with Māori and Pacific people on transplantation, with a brief summary of renal departments' views on the reasons for the observed disparities.

The report describes the clinical team's attitudes and their perceptions of their Māori and Pacific patients' attitudes in making decisions about transplantation and provides advice to renal departments and the Ministry on working with Māori and Pacific communities, on attitudes to transplantation, and on developing educational resources to support that work.

The literature review confirms the enormous range of views and attitudes about transplantation and donation within the Māori and Pacific communities. It is inappropriate to assume a blanket refusal from anyone; individual circumstances influence decisions as much as cultural beliefs do, and all options must be explained to all patients in the context of clear and understandable information about the realities of renal failure and the various renal replacement therapies which are available. It is worth noting that many interviewees felt that such clear and understandable information is not currently being provided to patients on a routine basis, contributing to uncertainty, confusion, and disinterest regarding transplants.

There is no single Māori or Pacific view that is universally accepted and efforts to promote transplantation and donation within the Māori and Pacific communities must be tailored to the individual patient and their family, whose cultural perceptions as to the palatability of such procedures will likely have come from a multitude of different sources and will be further influenced by their own individual circumstances. The communication skills and cultural competence of transplant team members will be critical in dispelling inaccuracies and improving outcomes for the Māori and Pacific communities in New Zealand.

Interviews with transplant team members have identified a number of consistent themes and areas of concern.

The transplant pathway for patients and for potential donors is lengthy, expensive, time consuming, and difficult. Staffing issues include the dearth of full-time coordinators and most other clinical roles and the difficulty of providing specialised care to patients in distant locations. Some team members identified an attitude wherein some patients have to 'prove' they are worthy of a transplant and the concomitant belief that patients who demonstrate non-compliance are less likely to get a transplant. The subtle bias that lies behind these views may result in Māori being less likely to be offered a transplant or other treatments that 'require' a high level of compliance, as cultural discordance is often associated with perceptions of non-compliance. Many pre-dialysis educators and renal physicians seem more focused on dialysis than pre-emptive transplant and are, as a result, more likely to influence patients and families to proceed down that track.

Broad support existed for both addressing the educational needs of Māori and Pacific patients and establishing more transparent and coordinated processes. Improved communication between patients and clinicians was frequently acknowledged as a requirement to improve transplantation rates for Māori and Pacific patients. The transplant teams themselves have identified knowledge needs, and it is apparent that a process is required to bring cultural advisory services into the team. In addition, past experience among the teams strongly indicated the value of in-house transplant coordinators who can engage with the teams at the transplant centres as required.

Contentious areas such as the current BMI criteria also require on-going attention and discussion. That discussion should be underpinned by rigorous data collection and analysis, and regular evaluation of the evolving international evidence.

Problems were identified with elements of the renal pathway such as inconsistency in referrals from primary care providers. Similarly renal consultants have significant variation in their rates of listing patients for transplantation, and attention to standardising protocols is therefore advised.

Recommendations based on the experience of the renal transplant teams and consistent with the literature review address these key areas. The recommendations are grouped as follows:

Transplant pathway processes: Renal transplant teams should review their transplant processes and guidelines to ensure: (1) timely and appropriate advice on renal transplant options and (2) the establishment of pathways with a focus on the needs of Māori and Pacific patients, and (3) improved referral pathways from primary care providers that lead to streamlined and efficient transplant work-ups.

Regional coordination and shared experiences: Renal transplant teams should ensure that opportunities are provided for the various teams to reflect jointly on their experiences and share their successes. The focus on sharing successful approaches can support a developing best practice for New Zealand.

Research: Research should be undertaken into Māori and Pacific patient experiences of renal transplant pathways and barriers to care, including issues of access to care, geographic limitations, informational shortfalls, and financial difficulties. Further data collection and analysis should be undertaken on Māori and Pacific renal failure pathways for each renal replacement therapy clinic. This should extend to data collection for potential and actual donors.

Education and health promotion: Educational resources should be developed that are culturally appropriate for Māori and Pacific audiences (including patients, whānau and potential donors) and should support all aspects of the renal replacement therapy pathway, from detection and diagnosis to treatment and transplantation. This will be facilitated by the Takawaenga/Cultural Advisors into renal transplant teams. Health promotional materials should be developed for use with Māori and Pacific communities and should support all aspects of the renal replacement therapy pathway, from raising awareness, detection and diagnosis, to treatment, transplantation and promoting donation.

Training: Communication skills training focusing on engaging and working with Māori and Pacific patients and their whānau should be provided to clinicians of renal transplant teams. This training could include attention to unconscious or organisational sources of bias and promote effective communications with other members of the treatment team, as well as with patients and whānau. Clinical knowledge training should be provided to cultural advisors/Takawaenga on chronic renal disease and treatment pathways to support their effective integration into and contribution to renal transplant teams.

Introduction

Māori and Pacific peoples are over-represented in the dialysis population yet are less likely than others to receive a kidney transplant. This project was primarily motivated by the need to address the increasing demand for renal replacement therapy in ways that will ameliorate or eliminate the current disparities.

About 90 renal transplants are performed annually in New Zealand, just over half of which are from living donors to a related recipient. Amongst the 15-59 year old age group, the proportion of Māori and Pacific people who received a transplant in 2006 were 1.7% and 1.2% respectively, compared with 12.3% for Caucasian and 6% for Asian dialysis patients (ANZDATA 2007).

Mauri Ora Associates Limited was contracted by the Ministry of Health to undertake a survey of clinical allied health staff in renal transplant units and to provide advice on this topic to renal departments in District Health Boards (DHB) and the Ministry.

The Ministry sought a paper that would provide a view on the value of targeted education programmes for local Māori and Pacific populations about renal transplantation, and also offer advice on whether there are significant cultural issues in relation to renal transplantation. The Ministry further sought advice on any key principles and practices that a renal department might use to support transplantation when working with Māori clients, in particular any important considerations when raising the issue of organ donation with Māori and/or Pacific families or different processes in dealing with potential donors from these communities.

The project included interviews with several key stakeholders, including clinical and allied health staff of renal transplant units around New Zealand and knowledgeable people from Māori and Pacific communities. The Ministry intends that this advice will also be made available to the national transplant services that cover the small number of non-kidney organ transplants in New Zealand.

Background

This report is based on an analysis of interviews with transplant coordinators, clinicians and support staff about their experiences and is further informed by a brief review of relevant literature on best practices when discussing major medical problems with Māori and Pacific peoples. The project is not informed by patient experiences of care, and no interviews were conducted with patients who have had or are awaiting renal transplants, nor with patients who have refused or been turned down for renal transplants.

A brief review of relevant literature was conducted into Māori and Pacific people's attitudes towards transplantation and initiatives to address cultural issues in renal services.

The Ministry facilitated introductions to the coordinators at the regional transplant centres. Cultural stakeholders, including DHB kaumatua, cultural advisors, cultural support workers, and Pacific liaison staff, provided comment on the acceptability of transplantation and on how to reference relevant cultural information and frame the messages.

The key questions asked of renal transplant coordinators included:

- *What proportion of Māori and Pacific peoples in your service receive living related or deceased donor kidney transplants? Is this similar to European patients?*
- *What in your view are the reasons for any differences?*
- *Do Māori and Pacific peoples relate differently to the renal team than people of other ethnicities over the issue of transplantation? In what ways is this different?*
- *Is the topic of transplantation introduced or dealt with differently by the team with Māori and Pacific peoples in contrast to other ethnicities? What differences have you noted? How do ensure Māori and Pacific patients are supported during this discussion?*

This report provides a summary of renal departments' experiences of working with Māori and Pacific people on transplantation, with a brief summary of renal departments' views on the reasons for the observed disparities.

The report describes the significance of cultural attitudes in making decisions about transplantation, both in terms of the clinical team's attitudes and their perceptions of their Māori and Pacific patient's attitudes. The report also provides recommendations to renal departments and the Ministry on working with Māori and Pacific communities, on Māori and Pacific attitudes to transplantation, and on developing educational resources to support these communities.

Literature Review Summary

There is an enormous range of views within the Māori and Pacific communities regarding health-related topics, and attitudes about transplantation and donation are no different.

While there can be culturally-based concerns regarding the importance of an intact cadaver which can influence the consideration of kidney donation (for both cadaveric and live donors), it is inappropriate to assume a blanket refusal (or acceptance) from anyone. Candid and respectful discussion of the benefits and risks must be provided so that a truly informed decision can be made. As with any other community, individual circumstances can and do influence decisions as much as cultural beliefs, and it is only when people are given a clear understanding of the present and future health of themselves and their family members that they can make the decisions that are best for them. For that reason, all options must not only be explained to all patients, but this also must be done in a culturally supportive context with clear and understandable clinical information about the realities of renal failure and the various renal replacement therapies which are available.

There are no universally recognised cultural authorities within the Māori or Pacific communities from whom a ruling or pronouncement as to the acceptability of transplantation would settle the matter once and for all. Rather, most people will seek advice from a unique combination of sources including older relatives, respected community leaders, religious authorities, and/or their peers. As a result, there is no single Māori or Pacific view that is universally accepted and/or enforced. For this reason, efforts to promote transplantation and donation within the Māori and Pacific communities must be tailored to the individual patient and their family, whose cultural perceptions as to the palatability of such procedures will likely have come from a multitude of different sources and will be further influenced by their own individual circumstances (encompassing not only cultural but also clinical, financial, familial, age, gender, and other concerns).

Accordingly, the communication skills and cultural competence of transplant team members, as well as the rest of the health care profession (and particularly primary care providers), will be critical in dispelling inaccuracies and improving outcomes for the Māori and Pacific communities in New Zealand.

Methods

Transplant Coordinators at six DHBs (Northland, Auckland, Counties Manukau, Waikato, Capital & Coast and Canterbury) were approached using contact information from Nick Polaschek (Senior Project Manager, Sector Capability & Innovation Directorate MoH). See Appendix One for the initial contact letter. With the assistance of the coordinators, site visits to renal units at each DHB were arranged, with the specific intention to meet with as many staff members as possible. We asked to speak with (at a minimum) the transplant coordinator and cultural liaison advisors. We also asked to speak with any available nephrologists, pre-dialysis educators, social workers, dietitians or other team members that interact with the renal patients. We held one interview via phone; the rest were face to face.

In total, we spoke with 39 people in both individual and group meetings; a listing of job titles is below:

- Transplant Coordinator (7)
- Psychiatrist (2)
- Social Worker (3)
- Dietitian (1)
- Renal Consultant (9)
- Other Clinicians (3)
- Pre-Dialysis Nurse Educator (2)
- Clinical Leader/Clinical Director/Lead Renal Consultant (4)
- Nurse Manager (1)
- Cultural Support Worker/Takawaenga (7)

Before the scheduled meetings, we sent staff a questionnaire designed to elicit their opinions on topics related to renal transplants, disparities, and the patient populations of interest. Separate questionnaires were sent to clinicians and cultural liaisons/social workers – copies of the questionnaires can be found in Appendices Two and Three, respectively.

We requested that staff return the completed questionnaire before the scheduled interview time, and twenty respondents did so. Several others returned the questionnaire during or after the face to face interviews, for a total of 33 survey responses.

At each of the meetings, we discussed the questionnaire and used open ended questions to elicit the perceptions held by renal team members regarding disparities and their causes, the transplant process, Māori and Pacific Islander cultural beliefs, experiences with patients and whānau, barriers to access, and limitations under which the team members operated. In addition to taking notes contemporaneously, we also requested permission to audiotape sessions for later transcription and confirmation of quotations. Confidentiality was assured.

Where possible, we proposed meetings with a single team member, in order to encourage informants to speak freely, but time constraints often dictated the need to meet with two or more people simultaneously. When this occurred, we proposed to limit each interview to a single discipline or specialty (e.g. social workers or nephrologists), but this was not always possible, and on occasion we met with mixed groups (e.g. nurses and doctors).

Questionnaire Results

Clinicians' Answers

25 clinicians answered most questions. A summary of their responses can be found in Appendix Four.

As expected, the vast majority of respondents reported that they 'often' discussed transplantation with patients, whānau, and/or potential donors. A somewhat smaller number reported often discussing transplantation with Māori or Pacific patients. No clinician reported that they 'often' involved cultural liaison workers in transplantation discussions with Māori or Pacific patients. Slightly more than half said they did so 'rarely', the rest 'never' did. Reasons for this included:

- *'As a service we rarely engage the Māori Health Directorate Takawaenga to talk specifically about renal transplant as this does not fit into the scope of the Takawaenga's role'*
- *'Cultural advisors are invited only at the patient's request but they[can] participate in the family meetings when all modalities of RRT are discussed'*
- *'When we have a family meeting we have a cultural advisor present. We will usually discuss transplants at that time. However I do not have an advisor present in clinics'*
- *'Not easily available and clinic time limitation'*

Very few respondents reported observing 'no' differences in how Māori and Pacific people think about transplants compared to Europeans. The majority confirmed that they did see differences, while a small number were unsure. The vast majority felt that Māori and Pacific people have the same level of willingness as Pākehā to accept transplants (i.e. to receive a donated organ), though it was pointed out that many of the respondents see a self-selected, pro-transplant group of patients. As many team members pointed out in the interviews, 'if a patient isn't interested in a transplant, they'd never get to us.'

Most respondents felt that Māori and Pacific people are just as comfortable discussing transplants with them as are European New Zealanders, and most also believed that there were no cultural prohibitions against transplantation in Māori or Pacific cultures. Comments included:

- *'I have not had an encounter in a family meeting to suggest that they (Māori and Pacific patients) are (uncomfortable)'*
- *'Only one or two (Māori or Pacific) patients in ten years have said this'*
- *'Not as far as I'm aware'*
- *'I do not think this is really a cultural issue – more psychological/emotional'*
- *'While there may be different cultural attitudes regarding transplantation, I understand that these inform discussion rather than inevitably prohibiting transplantation.'*

One respondent, who is Pacific, commented, '[I] am unsure of cultural prohibition against transplantation in Māori [culture], other than the belief that one leaves this world with an intact body, as you were born with, but [I] haven't heard of any [such prohibitions] in Samoan society or other Pacific cultures.'

A few respondents noted that they believe such prohibitions existed ('from what I have been told, read or seen on TV'), but many remarked that these beliefs were either influenced by other issues such as religion and age or were dwindling.

- *'Decreasing, much less compared to 5-10 years ago'*
- *'With this issue being more widely discussed, attitudes appear to be changing'*
- *'I feel religious beliefs also play a role especially with Pacific Patients'*
- *'In older generations - yes, in younger - no'.*

It is interesting to note that clinicians often characterised such beliefs as 'problems'. One respondent commented 'there appears to be less of a problem now, we only see ones who are willing to accept a transplant.'

Most clinicians agreed that they had experienced few, if any, differences when discussing transplant issues with Māori and Pacific people and other groups. A small number of respondents reported spending less time speaking with their Māori or Pacific patients, despite their statements during interviews (and evidence from the literature) that these patients generally have more co-morbidities and tend to present later in the course of their disease¹.

Respondents were evenly divided on whether their Māori and Pacific patients have a poorer understanding of health issues, but almost no one reported that it was harder to discuss health issues with their Māori and Pacific patients. One respondent wrote, 'I use different analogies. [These] patients are less selfish about their own health, discuss more whānau impacts.' Another reported, 'I provide the same information to all patients - in various formats,' while a third wrote that because she was a member of the culture, it was easy for her to address the necessary issues in an appropriate way.

About half the respondents *disagreed* with the statement, 'I see no differences in attitudes about transplantation among Māori and Pacific patients compared to Europeans,' while the remainder were evenly divided between those who agreed with the statement and those who were unsure. As one person again commented, 'I [only] see a self-selected pro-transplant group.'

Roughly a third of the clinicians felt that Māori and Pacific patients need a special approach when discussing transplantation, commenting that:

- *'Need to consider cultural, spiritual issues'*
- *'They look awkward and you need to understand the family/whānau dynamics'*
- *'Need to spend more time talking about receiving someone else's organs and where they come from'*
- *'Cultural aspects need to be paramount with working with patients of any culture different to my own (Pākehā), therefore, I would seek cultural advice from the individual, their family, and support people and services within the health system and community where needed.'*

Comments from respondents who disagreed or were unsure that a special approach was required included:

- *'I don't feel that any special approach is required in terms of acceptance of transplantation. However, a different approach may be required to educate them about their general health'*
- *'Other than accepting that there will often be children present and the session might take longer'*
- *'I don't think so. No one has told me I cannot speak to them'*

No respondents agreed with the statement, 'Māori and Pacific people are generally uninterested in transplants.' Clinicians commented that they are 'just as keen' and 'they are all interested.'

¹This finding is consistent with the result reported in NatMedCa 6, where GPs stated they spent less time with their Māori patients, despite their higher burden of disease.

The majority of respondents were unsure whether there should be a special advisor to discuss transplant issues with Māori and Pacific patients. One person wrote, 'maybe 10 years ago, probably not now'. A few dismissed the need entirely, though one informant noted, 'Most of my Māori and Pacific Island patients decline the offer of cultural advisor input'. The rest favoured the notion, commenting:

- *'If it means that patients get a better understanding of transplantation then a cultural advisor would be good. If it means improving the rate of donations then that would be great'*
- *'I have no difficulty discussing the issues but recognise there may be a need for an advisor/support to subsequently augment this discussion'*
- *'[It] would be helpful in many cases [of] cultural communication situations'*
- *'Prior to evaluation all renal patients of Māori and Pacific descent would benefit from open forum discussion regarding transplantation'*
- *'The more support the better'*

As mentioned above, however, none of the clinicians (including those who answered this question positively) actually make use of cultural support personnel on a frequent basis. It is interesting to contrast these opinions with the findings that few, if any, units provide any training about renal disease or transplants to their cultural support personnel, instead relying upon the cultural workers' picking things up informally 'along the way'.

About a third of respondents agreed that they would like (or need) training on discussing transplantation with Māori or Pacific patients, while another third were unsure and the remaining third did not favour it. By contrast, about half the respondents either felt they did not have a good understanding of Māori and Pacific cultures as it relates to beliefs about health, or were unsure if they did. Some people noted that they were themselves Māori or Pacific, or had a spouse who was Māori or Pacific. Others remarks included:

- *'I consider that the important thing is not to offend e.g. sitting on a table, feet on a chair'*
- *'[I] have some [understanding] but appears that these [cultural beliefs] can vary between iwi'*
- *'I have some understanding [but] do not know what I do not know.'*

The majority of informants felt that Māori and Pacific patients do not get equal outcomes from the health system with regards to transplants. Several suggested reasons for this:

- *'One of the biggest issues is the BMI criteria for transplantation. The levels need to be adjusted for Pacific and Māori'*
- *'Exclusionary criteria - BMI'*
- *'These patients are less likely to get a transplant, and they do less well with a transplant'*

And one informant pointed out, 'this is true also of many aspects of healthcare.' Others felt the disparity was due to issues related to patients and whānau, rather than system barriers:

- *'Co-morbidities and obesity. Lack of matched donors'*
- *'Less likely to undergo live donor transplant - probably due to reduced numbers of suitable donors. Less likely to be fit for transplantation e.g. higher rate if diabetes'*
- *'Over-represented in ESRF'*
- *'High percentage of diabetes which can exclude patients from transplant'*

Of those who stated Māori and Pacific people do get equal outcomes, comments included:

- *'However there is a statistical difference because of the prevalence of such health issues such as diabetes and associated co-morbidities in the Māori and Pacific population.'*
- *'[These patients are] treated in the same way'*
- *'They may have less opportunities because Māori are less willing to give their kidneys'*
- *'I cannot comment on outcomes - but here they have equal access to assessment'*

Despite the above comments regarding the higher incidence of co-morbidities in these populations, only a few people agreed with the statement that 'Māori and Pacific people are generally too sick to **receive** a donated organ.' Several felt the question was 'unanswerable' or could only be answered by a doctor, despite being members of renal teams who therefore might be expected to understand the epidemiological demographics of their patient population.

In an interesting finding, although the majority of respondents disagreed with the statement, the bulk of comments actually offered reasons why it might be true:

- *'Statistics for Māori in terms of co-morbidities e.g. diabetes would suggest that this may be true.'*
- *'Māori and Pacific people statistically present to treatment centres a lot later than their European counterpart and seek alternative traditional medicine more readily, so maybe this adds to them presenting late and therefore chronic illness is advanced to the point that they generally become too sick to be transplanted.'*
- *'Often do not address their health issues in a timely manner. Often present to health professionals late preventing optimal outcomes'*
- *'Māori and Pacific people are more likely to be too sick to receive a transplant'*
- *'Not generally but certainly more likely to have co-morbidities that exclude transplantation'*
- *'Probably no, but they take longer to come into the hospital system. More acute presentation'*
- *'High rates of diabetes & cardiac. Discussion on obesity with them often, less suitable recipients'*
- *'Often this is so'*

Similarly, while only a few informants agreed with the statement, 'Māori and Pacific people are generally too sick to **provide** a donated organ,' the majority of comments reflected covert support for this sentiment:

- *'Type II DM, hypertension and obesity [are] epidemic [in these groups]'*
- *'Difficult problem - concerns about the risks obesity/diabetes/metabolic syndrome in some cases have precluded donation - but this is an area with a lot of controversy and not enough evidence'*
- *'BMI and family history of diabetes often precludes Māori and Pacific people from being live donors'*
- *'Statistics for Māori in terms of co-morbidities, e.g. Diabetes, would suggest that this may be true'*
- *'When people's illnesses are too advanced they cannot be donors and organs are unsuitable to be donated.'*
- *'Because of familial co-morbidities'*
- *'Familial conditions e.g. diabetes exclude many'*
- *'It generally isn't about being too sick - if you are talking about living donors - it is often about risk or developing diabetes and being overweight'*
- *'True to some extent - overweight & DM'*

About a third of respondents felt that there was a need to discuss transplant differently with Māori and Pacific people:

- *'Mostly in terms of exploring ways for acceptance of donation'*
- *'Need to discuss cultural/spiritual issues'*
- *'Less use of scientific/medical jargon, [and] more aware of spiritual/body holiness'*

Others commented:

- *'I guess if there is an identifiable, specific fixable remedy to improve transplantation amongst Māori and Pacific people, then it is worthwhile exploring how to do things differently. I believe that if we address issues such as keeping good health by healthy eating, healthy action, achieving healthy BMIs for our ethnicity, reducing cardiovascular disease and we become a generally well population then we can get the optimal health outcomes as our European counterparts, including getting transplants.'*
- *'[Discussing differently] is not needed on an individual level. May be different if talking to groups about ...deceased or living donation - but needs to be done by representatives of their own culture'*
- *'Integrate Māori and Pacific health professionals into Nephrology service'*

Respondents were invited to identify the most important ideas that they need to discuss with Māori and Pacific patients. Most comments reflect the benefits, long-term monitoring, risks and complications of renal transplants:

- *'Risks/benefits of proceeding, what life is like after a transplant, that their own kidneys are not removed [and] what makes a good donor.'*
- *'The 'downside' of transplantations – complications'*

Other comments suggest a particular approach to the discussion:

- *'The need to discuss live donor transplantation with family and friends'*
- *'That it is acceptable for Māori and Pacific people to receive or donate'*
- *'Where do I get a transplant from? And is it difficult to ask my family?'*
- *'Transplant is best treatment for kidney failure'*
- *'One kidney is enough if it is a healthy one.'*

Clinicians were asked to reflect on how Māori and Pacific patients responded to questions about live transplantation. Responses are consistent with earlier statements from the respondents, demonstrating an enthusiastic and open attitude towards live donation:

- *'Adult children are very enthusiastic to donate to a parent'*
- *'Generally keen to pursue the topic of donation'*
- *'Not dissimilar to Pākehā'*
- *'Willingness to accept if donor available'*
- *'Rarely any reservations'*
- *'Positive feedback when they've been accepted/listed.'*
- *'Offering a kidney to their relative'*

Several comments suggest specific aspects of the different communications preferences of Māori and Pacific patients:

- *'Asking questions, having whānau involved, wanting time to discuss with whānau'*
- *'Expressing a lot of interest, wanting to follow up however, wanting more information'*
- *'They seem to prefer to talk in groups about issues like this, involving significant others in the discussions/family meetings'*
- *'A lot of hope pinned on transplant listing, but not sure about how to best manage from then on.'*
- *'Others who haven't been listed (yet) are usually very "ho-hum" about transplant prospects and this is usually because they aren't necessarily sure about how to approach it.'*

Two informants noted that Māori and Pacific patients sometimes have specific barriers to live renal transplantation:

- *'Parents very reluctant (often flatly refuse) to even discuss donation from an adult child'*
- *'Hesitancy in talking to family/friends regarding organ donation'*

Respondents were also asked to share their thoughts on the best way to improve renal transplantation rates in Māori and Pacific patients. A broad range of suggestions was provided including education and public awareness about renal disease and prevention, treatment and transplantation. Other suggestions included remuneration for donors, changing organ allocation criteria, addressing the BMI restrictions, and changing to an 'opt-out' cadaveric donor identification system (rather than our current 'opt-in' system).

Several comments suggested a community education focus:

- *'Community/marae information/educational sessions by appropriate health professionals'*
- *'Increase live donations by discussion with wider whānau'*
- *'Kaumatua could discuss on marae'*
- *'Involve whānau, group education of communities'*
- *'Have culturally appropriate educators'*
- *'Work through the elders/leaders in those groups'*
- *'Educate the family of Māori patients'*
- *'Māori people in the community need to understand how they can help their own people by donating their kidneys'*
- *'Perhaps to be able to discuss transplant in the home (if there were more staff) and therefore reach the wider whānau with the education especially about live donation.'*
- *'Need to get prominent members of community onside i.e.: Kaumatua, ministers, people of standing in community, good persuader's.'*
- *'Videos of case studies to show patients'*
- *'Group discussion, from other post-transplant Māori and Pacific patients & their families.'*

One respondent noted that 'We did try education sessions at three different marae and although they were well received attendance was poor.' Other comments identified a broader systems focus:

- *'Increase pre-emptive transplantation by earlier review'*
- *'If there is overwhelming feedback that confirms that culture plays an important barrier to transplant then devise strategies to enhance the donation rate by addressing the key issues'*
- *'Improve Māori and Pacific engagement with the health system'*
- *'Consider live donor transplants from un-related donors and raise awareness about living donor transplants, especially with healthy younger Māori and Pacific people'*
- *'Interventions at all levels, health prevention, assisting to break down barriers to access the service'*
- *'Intervene early before overall health deteriorates'*
- *'Improve management of chronic illness/disability'*

Some informants suggested that more involvement of Māori and Pacific health professionals at various levels of the clinical pathway would contribute:

- *'Involvement/consultation with Māori and Pacific Health Professionals'*
- *'Māori and Pacific advisors at a national strategy'*
- *'Māori and Pacific Health Professionals involved on Nephrology Quality committee'*

Additional research projects were identified by several informants:

- *'Identify through research the rates of listing, and potential patients who were not considered or were not put forward; match to co-morbidity rate.'*
 - *'Of these listed - how long on list, reassess inactive/suspended if so was a live donor ever an option?'*
 - *'Of these not listed -*
 - *Ideally what reasons not listed?*
 - *Live donor ever considered?*
 - *Co-morbidity?*
 - *Non-adherence?*
 - *Psychological/psychiatric issues'*
- *'Identify points at which to intervene e.g. pre-dialysis education'*

Finally respondents were asked to describe their own knowledge needs in regards to talking with Māori and Pacific people about transplantation. Once again, a range of issues were raised around which respondents desired more information in order to better help their patients:

- *'Family dynamic [and the] individual'*
- *'Dynamics of live donation within family groups i.e. who should donate etc?'*
- *'Spiritual and cultural issues around transplantations'*
- *'Other reasons that may make it difficult to receive or donate organs'*
- *'Beliefs about transplantation'*
- *'Expectations of transplantation'*
- *'Cultural beliefs (especially if there are tribal or island differences)'*
- *'Fears or cultural concerns about receiving an organ or about donating an organ'*
- *'How patients can make themselves more "presentable candidates".'* (this last reflected a desire for knowledge not from Māori and Pacific cultural experts, but rather from other members of the renal team, as the speaker wished for more information on how to help their patient maximise their chances of receiving a transplant)

Cultural Advisors' Answers

Eight people responded to most questions. Of these, one was a Māori Social Worker; the rest were Cultural Liaisons/Takawaenga. For the purposes of this project they were invited to provide Māori perspectives on the renal transplant services. A summary of their responses can be found in Appendix Five.

None of the Cultural Advisors responded that they often discussed transplantation with Māori or Pacific patients. None reported being consulted by the clinical team or by the patient/whānau. They consistently rated their knowledge of transplantation as poor (5) or average (3), and none had received training on transplantation.

Consistently Cultural Advisors felt that patients' and whānau's knowledge of transplantation issues was less than adequate. Six of the eight agreed with the statement that Māori and Pacific people have a poorer understanding of health issues compared with Europeans. However, only one respondent felt that it was harder for doctors to discuss transplantation with Māori and Pacific patients. Six respondents agreed (one was unsure and none disagreed) that Māori and Pacific patients needed a special approach from clinicians when discussing transplants. Consistent with that view, six respondents agreed that a special cultural advisor should be available to discuss transplantation issues with Māori and Pacific patients. Only one of the eight informants agreed that Māori and Pacific patients get equal health outcomes with regards to transplants.

This group of Cultural Advisors acknowledged that additional resources would be helpful for themselves. Seven of the eight respondents agreed that there are differences in the way that Māori and Pacific people think about transplantation.

Cultural Advisors were evenly divided on several issues: whether Māori and Pacific patients are more uncomfortable compared to other patients when discussing transplants with the transplant team; whether Māori and Pacific patients were more comfortable discussing transplants with Cultural Liaisons compared to Clinicians; and whether there are Māori and Pacific cultural prohibitions against donating or receiving transplants.

Cultural Advisors were uniformly unsure about whether Māori and Pacific people are more likely to be too sick to receive or donate a kidney. They declined to comment on the adequacy of the Transplant team's ability to communicate with Māori and Pacific patients.

Interview Results

In general, interviews were one hour in length. Most people appeared comfortable with the interview and seemed to speak frankly about the frustrations and satisfactions they experience.

Overall themes that emerged are presented below:

- *Patient issues*
 - *Education and expectations*
 - *Patient behaviours*
 - *Enthusiasm*
 - *Anxiety*
- *Healthcare team issues*
 - *Expectations and the 'deserving' patient*
 - *Perceptions of disparities*
 - *Data, lack of data and personal experience*
- *Clinical Pathways*
 - *Finding a live donor*
 - *Being a professional patient*
 - *Understaffing and systemic barriers*
 - *Delays and deviation from the ideal*
- *Cultural differences*
- *Communication issues*
- *Suggestions for improvements*

Many of the clinicians we spoke with, particularly the non-physicians, do not seem to be focused on pre-emptive transplants. Instead, they seem to spend more time discussing dialysis and how to 'make it work for you'. This appeared to be part of the renal clinical culture. All of the Renal Physicians, and likely most of the renal transplant teams in general, registered and trained in a health system where dialysis was the standard, most widely available treatment. The new gold standard treatment is pre-emptive live donor renal transplant, but much of the renal clinical pathway still reflects the earlier ethos, and this impacts many areas of care, including when transplants and the need to locate potential donors are first discussed with patients.

In many cases, these discussions are held at a time in the patient pathway that, for many patients, effectively precludes pre-emptive transplants because of the time required to locate and clinically clear a potential donor. In other words, the current ethos and processes in many transplant sites delay transplant discussions to a sufficiently late stage that by the time a suitable donor can be found, the patient will have already become ill enough to require dialysis. This is not necessarily a function of the patient's disease but rather reflects inappropriate timing of clinician intervention and inadequate understanding of renal disease by the general public.

This may be particularly true for Māori and Pacific patients whose family members (i.e. the most likely donors) are likely (a) to require additional time to discuss the matter and (b) to

have or be at risk from diabetes or other disqualifying conditions, thus requiring longer assessments. This can cause the donor selection process to take longer, even as these patients' renal disease is likely to progress more rapidly. The combination of these two factors further lessens the chance for a pre-emptive transplant, unless these discussions (and potential donor workups) can take place very early in the process.

Similarly, many clinicians don't feel it is their role (or their place) to encourage patients to seek donors or to encourage whānau to consider donation (live or cadaveric). Such an advocacy role is not felt to be part of their job, leaving open the question of whose role it *is*, given that many patients and families will look to their medical team for guidance and advice.

In most centres, clinicians were open and apologetic about not having any data on which to base their beliefs, but they nevertheless seemed to accept that data deficit as a matter of course and to base their opinions (only) on their personal experiences. In one location, however, the lack of data was rejected as an inevitable problem. There, the clinical director made it his business to obtain the necessary data and to analyse it for trends and causes. He then used his research findings to justify the hiring of an in-house transplant coordinator, whom the entire team now lauds as the direct cause of their increasing transplant numbers. This attitude of self-evaluation and evidence-driven practice was not evidenced in the other sites, yet it is sorely needed in order to truly understand what is going on within the individual centres and what underlies the disparities in New Zealand's renal transplant rates.

Posing the question of disparities as being linked to cultural differences can elicit many different responses or perspectives. From one perspective there can be a genuine inquiry to understand how the needs of Māori and Pacific patients may require different educational approaches, communication skills or clinical pathways. At another level it represents a pre-determined expectation that 'normal' attitudes reflect the dominant cultural paradigm. Any deviation from mainstream opinion, including different Māori and Pacific cultural preferences, are then considered to be unacceptable or abnormal, with the corollary that they should be changed. This is the 'deficit model' – in which the cause for the disparities or barriers to care is attributed to the target population. From that position it is likely to perceive cultural differences as the problem, with the solution being to 'educate' (or assimilate) members of these populations until they too adopt the opinions of the cultural mainstream. Both of these perspectives were evident amongst the transplant teams.

We note the following brief caveat for the reader. Some of the following quotes contain contradictory statements from respondents. The contradictions sometimes reflect different understandings from various team members or even conflicting views elicited from the same person in response to different questions. Some of the quotes reveal a lack of understanding or inaccurate beliefs held by members of the transplant team or the support services. The quotes accurately reflect the information and statements made to the interviewers.

Common Themes

The comments have been attributed to the following roles for the purposes of maintaining anonymity: Renal Clinical Director (includes Clinical Leader; Clinical Director; Lead Renal Consultant and Renal Clinical Director); Renal Physician (includes Clinician; Nephrologist; and Renal Physician); Cultural Advisor; (includes Cultural Support Workers; Takawaenga and Cultural Advisors); Pre-dialysis Nurse (includes Pre-dialysis Nurse Educators and Pre-dialysis Nurse); Transplant Coordinators, Psychiatrists; Dietitians; Social Workers. Similarly, in order to ensure respondent anonymity, responses were blinded as to the speaker's location or worksite.

As mentioned above, most clinicians pointed out that they see a pre-selected, pro-transplant group of patients and have little if any experience with patients who do not wish to have a transplant:

- *'We only see patients who are pro-transplant. People who don't want a transplant wouldn't come to see us, so we have no sense of why people who don't want a transplant don't want one.'* (Transplant Coordinator)

Patient Education and Expectations

The central place of patient knowledge and expectation was described repeatedly by all members of the transplant teams.

- *'Attitudes to transplants depends on the exposure to the information, as well as their experience of what transplants are: what they have heard on the news, who they know who has had a transplant, whether they had a really good experience or not. Then there is fear about 'Why go there when I am fine on dialysis?'* (Pre-dialysis Nurse)

Informants were open about the critical importance of patient education.

- *'It's not so much [a problem with] misinformation as it is getting the right information at the right time. It's the right kind of information and it's the right way of giving the information.'* (Social Worker)

There were conflicting views about the relative importance and order of the information that patients needed, as well as how the clinical teams can best share that information.

- *'We talk about what their options are. First option I talk about is conservative management because I find it is easier for me to get that out and get it over and done with before I go too far. Next option is usually transplant ... I make sure they know that it is all done [at the transplant centre] and that there is a long workup process, and I usually tell them it is a year before they get a date to get it done if they come with their own kidney [donor]. Longer if they have to get in line and wait.'* (Pre-dialysis Nurse)
- *'There is a lot of misperceptions [amongst clinicians] especially about Māori and Pacific people. My colleagues wait for the patient to bring up questions showing their interest in transplant. I ask everyone [if they're interested].'* (Transplant Coordinator)
- *'Sometimes people don't necessarily get that you need to have a meld of the medical and the cultural [when speaking with patients].'* (Psychiatrist)
- *'Many people have an unrealistic expectation [about transplants] but most perceive it as the best option.'* (Transplant Coordinator)
- *'When I mention transplant to patients, it's generally a new topic for them, and most patients are receptive and interested.'* (Renal Physician)

Patient Enthusiasm

Almost all members of the transplant teams described the enthusiasm of Māori and Pacific patients towards transplantation.

- *'So many Māori and Polynesian people have had relatives on dialysis who died horribly that they are quite keen to go down the transplant path.'* (Renal Clinical Director)
- *'In my experience, all patients are interested in transplant.'* (Transplant Coordinator)
- *'More people need to be persuaded that they CAN'T have a transplant than need persuading that they SHOULD get one.'* (Pre-dialysis Nurse)
- *'Māori are all enthusiastic about being live donors, but they have high BMI and they're hypertensive, so it's hard to find a match.'* (Transplant Coordinator)
- *'There is a lot of desire for transplant... perhaps a perception that this is a cure treatment. There is a lot of communication required [to explain the realities to patients].'* (Renal Physician)

Patient Behaviours

Team members freely shared their perceptions about Māori and Pacific patient behaviours, though on further questioning, it became clear that some of these perceptions are not supported by evidence, either personal or published. Failure by Māori and Pacific patients to attend clinic (Did Not Attend - DNA) or education sessions was cited often, and this was attributed to patient behaviour, along with late presentation and low motivation (even though late presentation must logically include issues of primary care services and referral).

In many cases, there was a sympathetic understanding of some of the possible reasons for such 'noncompliant' behaviours, yet this rarely translated into actions on the part of the team to address those aspects of the system that led or contributed to those behaviours.

- *'Key barriers for Māori and Pacific people are related to the patient himself or herself. They don't come to clinic often, they're scared, their pre-dialysis education is delayed, they only present in full renal failure and we have problems with vascular access.'* (Renal Physician)
- *'We want to start dialysis with a fistula [in place] for at least 50% of patients. In 2006, only 17% started with one because of late presentation, DNAs, late referral from the GP (usually because the patient doesn't go to the GP), not attending pre-dialysis education, and that sort of thing.'* (Renal Physician)
- *'Our DNAs are predominantly Māori - [probably due to their] not understanding priorities and why the appointment is important.'* (Transplant Coordinator)
- *'We prefer to do a pre-emptive transplant before they get on dialysis [but] some of our patients turn up late, or deny that they have a problem. They say that they do not want treatment, and then of course at the last minute they change their mind... They miss that opportunity of a pre-emptive transplant. There is a lot more of our Māori population in that group.'* (Renal Clinical Director)
- *'We may see them [late presenters] after they have been on dialysis for a while, [but] had they come when they were in the pre-dialysis stage, they would have been in much better shape to go through the transplant process. Some, if they had only come in earlier, would have been great candidates for a pre-emptive transplant.'* (Transplant Coordinator)

- *'Often first there is the barrier of acceptance that a person has kidney failure and is going to require renal replacement therapy. You have to have had acceptance of that fact before you can then move on to discuss the treatments that are available. It really emphasised again the need for early timely referrals, so that rapport and trust can be built up as well. These discussions can't really happen without having established a patient/doctor relationship.'* (Renal Physician)

Many clinicians commented on the need for patients to 'push' the system and advocate on their own behalf if they are to receive a transplant, particularly in an expedited fashion, yet there were few systems in place by which patients could learn how to work on their own behalf. The sense was that patients simply needed to 'figure it out for themselves', and that those who did not or could not assume such a role were at a disadvantage. As many Māori and Pacific Island people may view questioning their doctors or engaging in self-advocacy as rude or inappropriate and instead believe it appropriate to leave their care entirely in the hands of their clinician, it would seem that they might be placed at a disadvantage when their cultural beliefs clash with a system that expects (and/or rewards) such behaviour. Comments about the importance of such 'self-motivation' included:

- *'Patients should themselves be proactive if they really want to receive transplants.'* (Pre-dialysis Nurse)
- *'Patient motivation is incredibly important in getting the type of treatment they want.'* (Pre-dialysis Nurse)
- *'Patients need to be in the transplant doctors' faces to get a transplant. They need to be proactive about asking for one, seen regularly in clinic, and perceived as good patients.'* (Renal Physician)

Patient Anxiety

Patients enter the renal disease pathway from different starting points in terms of chronic renal failure, co-morbidities and acuity. The transplant pathway itself may contribute various concerns and stresses. Many transplant team members identified issues for patients, their families and potential donors that cause anxiety around transplantation and organ donation.

Some concerns revolved around how to broach the topic of donation, which can be particularly hard for families who do not normally discuss personal health issues, as well as a concern about the perceived stigma of chronic disease.

- *'There are so many questions that need to be answered for patients, and a very common one is 'how do I approach my family member to ask if they would be a donor?''* (Social Worker)
- *'There is a stigma associated with kidney disease. Some patients do not want other people to know what they have got.'* (Pre-dialysis Nurse)
- *'Most patients find it very hard to ask relatives for a kidney. Parents especially are very reluctant to take a kidney from their [adult] child. That's pretty universal.'* (Renal Physician)

Perhaps the patient anxiety most frequently noted was the fear of harming a potential donor by taking their kidney:

- *'Māori and Pacific especially are more concerned with live donation as they are worried about the damage they might cause to a donor by taking their kidney.'* (Transplant Coordinator)
- *'Patients are definitely concerned about family history of diabetes. They don't want to take a kidney away from someone who is very likely to develop diabetes [in the future] and therefore kidney disease.'* (Pre-dialysis Nurse)
- *'Two young guys recently both stated they would not take any [organ donation] from their family in case something went wrong with the family member.'* (Pre-dialysis Nurse)

Healthcare Team: Expectations and the Deserving Patient

The renal patient must not only cope with the many challenges of their illness, but they must also meet the many clinical requirements for transplant. Whilst many of these criteria are overt, many members of the transplant teams also recognised and referred to covert criteria; in particular, the patient must appear to be a 'deserving' patient. Attendance at clinic, engagement with the healthcare team, and 'fitting in' metaphorically (in terms of making decisions within the expected timeframes and working well with the team) were all cited as important to the concept of being 'worthy' of a new kidney.

Ironically, for some clinicians, dialysis is seen as a means by which patients can demonstrate these 'good' qualities and thus prove they meet the more subtle requirements for a transplant. Using dialysis as a kind of proving ground is a two-edged sword, as it can be significantly difficult for ill patients to meet all of the requirements of a dialysis patient, including such things as fluid restrictions, numerous appointments, and so on, particularly when they have other challenges, such as poverty, lack of social support, cultural discordance, and low health literacy. In these cases, this practice may well be setting some patients up to fail.

- *'I warn them [the patients] that they have to be good to get a transplant. At the end of the day, it's up to them to take responsibility to ensure that they show up for appointments, like their ultrasound. The view is that this tends to reflect how much they really want the transplant.'* (Pre-dialysis Nurse)
- *'[The renal transplant patients] have got a very strict set of parameters that they need to operate within: they have to be on dialysis, stay on their machines for a certain amount of time... plus they have got fluid restrictions that they are expected to maintain... The [transplant] team may not wish to take onboard someone who is difficult, someone who has got a reputation of abuse within the staff...'* (Psychiatrist)
- *'I tell our patients that every time they are naughty in this clinic they almost get a black mark against their name and someone else may jump into their [transplant] spot... You tend to favour people who have not missed their ultrasound appointments and things like that, which can be frustrating for the transplant team due to shortage of resources and time.'* (Pre-dialysis Nurse)
- *'[Renal patients] have a lot of opportunity to show that they are a team player, but a lot of opportunity to be highlighted if they are not. One of the things I say to people that come see me is that there are a lot of people that want kidney transplants. The people they find are the best transplant candidates – are people who are 'team players'. A transplant is a process, not an event. It's not 'you get a kidney and that's it'. It is exchanging one form of medical management for a different form, and so obviously if they have got offside with their treatment team, and they have got personal issues that mean that everyone struggles'* (Psychiatrist)
- *'I would agree that patients who are labeled as non-compliant have a lower likelihood of getting a transplant.'* (Renal Physician)
- *'I have a perception, though I can't prove it, that patients who are considered difficult or non-compliant will not have transplant workups and other necessary preliminary stuff pushed as vigorously by the health care team.'* (Renal Physician)

- *'The diabetes statistics are that Māori and Pacific Islanders are not as good at attending clinics and maintaining their blood sugar levels, and so if you extrapolate that data to any sort of chronic condition, yes is the answer.'* (Psychiatrist), responding to the question as to whether Māori and Pacific patients are likely to be perceived as non-compliant patients and thus less likely to receive a transplant.
- *'The 'non-compliance' label is very difficult to shake off. The health system is very unforgiving.'* (Social Worker)
- *'When someone comes in, young ones in particular, who will say yes, they would like a kidney transplant, they need to show some compliance with their dialysis, with their medication, first [in order] to receive a precious, precious organ. We are not going to put them forward until and unless they show that compliance.'* (Renal Physician)
- *'A transplant cannot be successful without adhering to a medication schedule, and so demonstrating an understanding of the need for the medication and the need for medical reviews are part of that process.'* (Renal Physician)
- *'The kidney people [patients], because they often have a lot more interface with other clinicians, and quite strict parameters, they can often derail themselves more than other patients.'* (Psychiatrist)

Some respondents appear to recognise this bias and compensate by identifying and promoting 'borderline' patients. In other cases, the teams have their own preferences as to which patients they may promote more aggressively.

- *'We try to do more transplants, especially for patients who are compliant, young, and more suitable, as they're seen as the best transplant recipient candidates.'* (Renal Physician)
- *'The general rule is that no one should be excluded from a transplant workup. If there isn't an obvious exclusion, they'll get a workup. We'll consider everyone until there's a reason not to consider them. I tend to work up borderline patients, especially compliant ones. If they're non-compliant, I won't work them up because usually they won't even come to the appointment to get worked up.'* (Renal Physician)
- *'I'm more likely to refer a patient for transplant if the patient asks me to, even if they're marginal. Lots of those patients will fail their transplant evaluation.'* (Renal Physician)

Healthcare Team: Perceptions of Disparities

Respondents provided several different explanations for the disparities in rates of renal transplants for Māori and Pacific. These included deficit rationalisations (due to cultural beliefs or lack of compliance), cumulative privileging (the additive effect of multiple incremental advantages), regional variation, medical suitability (co-morbidity or HLA tissue typing), and systemic reasons (late referrals). Many of the wide variety of reasons postulated for the disparities by some team members were simultaneously refuted by other team members (for example cultural preferences or systemic barriers).

On the other hand, some informants frankly denied that any disparity exists.

- *'Māori and Pacific have fewer live related donors and therefore have to wait for cadaveric donors, and therefore have longer waiting times and therefore drop off the transplant lists more and therefore don't get transplants as often.'* (Transplant Coordinator - the implication in this statement is that any disparity is due to the (ir)responsibility of the Māori and Pacific communities in not recruiting more donors.)
- *'The problem is NOT a lack of referral of patients by nephrologists.'* (Transplant Coordinator)

- *'Non-Māori, non-Pacific patients tend to get their ducks lined up quicker. They know how to use the system better. They are more proactive in requesting services and therefore get services Māori and Pacific patients don't, or don't until later.'* (Social Worker)
- *'There is a lot of regional variation in placing patients on lists and on providing patient education about transplants.'* (Renal Clinical Director)
- *'I don't see a disparity [in transplant rates].'* (Renal Clinical Director)
- *'At today's clinic meeting with the [transplanting centre's] transplant team, there were 8 patients, 6 of whom were Pākehā, 2 were Māori. If you look at the people sitting on the dialysis ward, there is a very different demographic.'* (Cultural Advisor – referring to the lack of Māori getting transplants compared to Pākehā; it is interesting to note that this person was located at the same site as the person who provided the quote immediately preceding, insisting that disparities don't exist)
- *'I do believe that cultural differences, particularly fixed beliefs, play a role in the disparities.'* (Psychiatrist)
- *'The barriers for recipients are physiological issues and some compliance issues (which can lead to cardiovascular problems that disqualify them), but NOT to cultural notions.'* (Transplant Coordinator)
- *'For live donation, there is no cultural barrier for Māori or Pacific people, nor are there any systemic barriers. Donors are keen, but just not medically suitable.'* (Renal Physician)
- *'Late referral is associated with a lower rate of transplant because they are sicker and it takes time to get them stable before the transplant workup can begin. We can't plan ahead for transplant; we have to work on fixing the existing problems first.'* (Renal Physician)
- *'I don't know why some patients on dialysis are not listed for transplant while others are. No clear data is collected or analysed about this, but there is a 50% listing rate discrepancy between what we expect to see and what is actually seen.'* (Renal Physician)
- *'Another important factor is Māori and Pacific may be more complacent in accepting dialysis. We haven't really done any studies on this but I think it is [a lack of] awareness of what is available and what they themselves know.'* (Renal Physician)
- *'[Māori and Pacific] people have often a lower level of understanding about their health, and particularly about kidney disease. It can be a barrier to transplantation and that does contribute to them presenting later as well.'* (Renal Physician)
- *'The worst aspect is the silent nature of renal disease, where people don't realise the severity of the disease until irreversible changes have occurred.'* (Dietitian)

Healthcare Team: Lack of Data

Informants identified several areas where the data is incomplete. Others estimated rates or relied exclusively on their own clinical experience for various milestones in the renal transplant journey because of the lack of information available, either from their own location or nationwide.

- *[There are] 'worrying things like the fact that less than half of the people who are under 50 on dialysis are on the transplant list, and that is clearly crap.'* (Renal Clinical Director)
- *'I'm not aware of any Māori or Pacific pre-emptive transplants that have been done here ...or anywhere.'* (Renal Physician)
- *'There isn't a lot of standardisation about which patients get a transplant.'* (Renal Physician)
- *'In my experience, about a third of patients rule themselves out [from being considered for a transplant] because of physiological issues. Two thirds are*

considered, of which 5-15% decide they're not interested and the rest are.' (Renal Physician)

- *'The data shows that the increased level of co-morbidities among Māori and Pacific peoples is NOT the whole story in terms of why they receive so many fewer transplants. There's more to it than that. It's NOT just that they are sicker and that causes them to be disqualified more often. There is a disparity above and beyond that.'* (Renal Physician)
- *'We don't keep our donor data with ethnicity.'* (Renal Clinical Director)
- *'There are hundreds of people who we turn down and a lot of those people would have been turned down before they get to us [at the transplanting centre]. We wouldn't know about them.'* (Renal Clinical Director- in response to a question about disparities in transplant rates)

Pathway: Finding a live donor

The challenges of finding a live donor are well known to transplant team members. The conversation usually focused on reasons for declining a potential donor (such as BMI or co-morbidities). BMI as a criterion was mentioned very often. Not all informants described the same cut-off points, but it was commonly identified as a significant focus of dispute. The national rugby team was occasionally brought into this discussion, whether past great players (such as Jonah Lomu, whose BMI was reported variously as less than 30 and more than 35 when he was a recipient of a transplant) or the current team, most of whom are technically considered obese and would therefore be ruled out as donors.²

- *'We [transplanting centre] have talked about [shifting BMI acceptance criteria for Māori and Pacific peoples] a million times, and clearly, probably the real problem [with the current cut-off] is with the Asians who are probably much fatter than they really are, as donors, who are therefore at risk of getting obesity-related disease.'* (Renal Clinical Director)
- *'It is not that the [potential donor] is unhealthy per se. [But] they just have to drop [their BMI] and become malnourished to qualify.'* (Pre-dialysis Nurse)
- *'We just pick 30 [as our BMI cut-off] between being mildly at risk and being at risk. And so we are being paternalistic almost and saying to people, 'No, you can't take that risk yourself.' And so there is a lot of discussion around that point of view. Every couple of years we review it... None of us want to go beyond 35. We are then getting into surgical complications. Most of us would be happy with between 30 and 35, and getting people to sign an extra bit of consent form saying that they take responsibility for their ongoing health, the same as if you smoke.'* (Renal Clinical Director)
- *'[The transplant centre] has the best outcomes in all of Australasia, so it's difficult to argue that their criteria doesn't work. [That said, they are] very inflexible, especially with BMI, even when we have gone to them, for example, with a very fit body builder and asked them to reconsider.'* (Renal Clinical Director)
- *'BMI is very problematic for our population, but there is no data to support not relying on BMI.'* (Renal Clinical Director)

² NZ Herald Saturday 18 July 2009

- *'If the BMI is high, especially in Māori, we have had a couple of people who are in this situation, a son had come through and wanted to be a donor. We worked him up and he was a big muscular guy; he would never be able to get his BMI down to 28, but he is so healthy and his muscle bulk is fit, [yet] we can't use him until he drops down.'* (Pre-dialysis Nurse)
- *'Even the WHO recognises that the BMI is inaccurate for some ethnic groups. There is a lot of literature that says that people with increased BMI have poor post-surgical outcomes. Yet some literature says that an obese 40 year old will do better with a transplant than a skinny 70 year old, but in that case [the transplant centre] will give the transplant to the skinny 70 year old because of their BMI cut off.'* (Renal Clinical Director)
- *'Weight is quite a big barrier... [In terms of weight loss], they can be very successful. They are very motivated. They lose the weight because they have a specific target, but the concern is that they will put it back on again, after the kidney has been removed, and then they are high risk again, so they are now beginning to get concerned about accepting a donor even if they can lose weight and get under the BMI requirements.'* (Renal Clinical Director)

It is clear that age and family medical history are also related to finding a potential donor.

- *'[For] children, there are very few of them that haven't got a kidney coming forward. Look at children, and there will be parents, grandparents, uncles, aunties, friends... It is amazing how people will come forward for a child. We wanted a non-blood related donor [for one girl], and her stepdad came forward. People will do it for young ones.'* (Renal Physician)
- *'Some of the patients have family with similar conditions and are therefore not good candidates so this can make it difficult to find live donors.'* (Pre-dialysis Nurse)

Another potential barrier is the somewhat delicate issue of how to recruit potential donors. Most members of the transplant teams were adamant that it was not their role to seek out donors, and many felt that any behaviour that might lead to the perception that they were 'chasing' a donor would be at best unprofessional and at worst unethical. This led to the widespread practice of leaving donor recruitment squarely in the hands of the patient and whānau, many of whom (as mentioned above) were uncertain or apprehensive about initiating such discussions.

- *'I make it clear that it is up to the recipient to approach other people and then have them approach us. It is not up to me to approach potential donors. They have to come forward to us of their own volition.'* (Renal Physician)
- *'We [the health team] will not ask for donors; we rely on the family to ask. We can raise the topic in front of the family, though.'* (Renal Physician)
- *'To be a live donor, you need to be quite proactive and put your hand up. If you are waiting for people to come to you, it won't happen.'* (Transplant Coordinator)

There are also financial barriers to becoming a donor:

- *'It's very hard for patients and especially donors to meet all the criteria to qualify for NTA benefits – such as travel costs.'* (Pre-dialysis Nurse)
- *'There are a lot of costs associated with transplants to the recipients and the donor: travel to appointments, downtime from work for the donor, accommodation costs when they have to go to [the transplanting centre] for treatment or transplant...'* (Pre-dialysis Nurse)

- *'The hepatitis B vaccine series is not funded, except for some members of some Māori health providers, so if a person needs the series to qualify for the transplant or to be a donor, then they are out of pocket. Also it's a long series and that can delay things.'* (Transplant Coordinator)
- *'The dental letter of fitness is also necessary and is not funded and is expensive. WINZ can loan the person \$300, but that won't cover much, and this in particular can be a big hurdle especially for Māori and Pacific people.'* (Transplant Coordinator)

Pathway: Being a Professional Patient

Team members described several onerous requirements for the patient being considered for renal transplantation. This was often described in terms of many clinic appointments, multiple tests and procedures, and the long periods waiting (both at each of these clinics and for many of these appointments). In addition, the tests and procedures may need to be repeated when the work up process extends beyond the accepted timeframe of the results. In these cases, the patient's work up has taken so long (e.g. over a year) that the first test must be repeated before their 'application packet' can be presented to the transplant team. This means that the patient must wait for an appointment to repeat the first test(s), not only increasing their waiting time for the transplant and creating inconvenience for themselves and their whānau, but also placing redundant burdens on the health care system itself.

The concept of a 'professional patient' - i.e. someone who must devote their entire life to the coordinating of and attendance at various healthcare related appointments – was used by some team members to describe the burden placed upon prospective transplant recipients and some potential donors as well.

- *'Most renal patients' have to attend renal clinic, diabetes clinic, eye clinic, pre-admission clinic, pre-dialysis education, and so on and so on. It's almost impossible for them to do all that and still have a normal life.'* (Pre-dialysis Nurse)
- *'The system creates difficulties for patients to carry on with their lives because they have to keep all of these appointments – many of which may be cancelled unexpectedly. Any lack of compliance is a black mark against them.'* (Pre-dialysis Nurse)
- *'The distance between us [at the non-transplanting centre] and the patients [in our catchment area] and the time required for the workup make it very hard for a lot of patients.'* (Transplant Coordinator)
- *'It can be very hard for patients and donors to get time off work. The whole workup can severely interfere with their lives and employment. It's like the workup itself is a full time job for both the patient and potential donor.'* (Transplant Coordinator)
- *'It is like managing a small business, there is so much to be learned. I'm still learning medical words [as a member of the profession] and it's a huge thing [for our patients to try to cope with].'* (Social Worker)
- *'The workup for a transplant is quite slow. Often patients aren't kept in the loop. They'll call me and ask if I can find out what's going on. They've gone for all their tests, but no one has called with the results, next steps, that sort of thing. They don't understand the delay; they feel very out of touch. Poor communication causes great stress and anxiety for them.'* (Dietitian)
- *'I've wanted to have pamphlets or a bulletin board with displays that change monthly or a video playing in the waiting room, because patients spend HOURS there.'* (Dietitian)

- *'Here [in our area], the transplant workup takes, let's say, 6 months. All complex procedures tests must be done at [the main hospital]; a few have to be done at [the transplanting centre]. For example, the echo's can only be done [at the one hospital] on certain days... All the labs have to go to [the transplanting centre]. A lot of people do not have cars, but we do have a bus service that comes from [remote location] that brings patients down to [the hospital] and that is a free bus. As a team, we try to fit in all the tests they need on that day. That comes from knowing your patient, knowing their limitations and the barriers that are there for them.'* (Pre-dialysis Nurse)
- *'A lot of time is wasted waiting for tests, waiting for cardiac tests, waiting for cardiac assessment.'* (Renal Physician)

Pathway: Waiting List

The frustrations of the waiting list were described by many team members, this included the completion of test and investigations for a patient to be formally confirmed as a recipient, the on-going processes to be maintained as an active patient on that list, and the parallel processes for potential donors. There were many differing opinions on the actual average length of the donor work-up process, ranging from three months to well over a year.

- *'Patients don't understand that there isn't a 'kidney cupboard' and that live donors are 'catch your own'. They don't understand that there is a LONG wait for a cadaveric organ. They assume the health system has a good supply of organs waiting for them and don't realise that they are responsible for finding their own organ if they don't want to wait.'* (Social Worker)
- *'Māori and Pacific people wait longer for cadaveric donors because of tissue matching issues.'* (Transplant Coordinator)
- *'Māori and Pacific renal disease is usually due to diabetes, so they tend to have many other co-morbidities and therefore require longer and more intensive workups when they do present for transplant.'* (Transplant Coordinator)
- *'I spend a lot of time going over the reasons for the transplant waiting times, blood groups, and so on.'* (Transplant Coordinator)
- *'[One of our kaumatua] has got his body ready for a transplant and he's now waiting for an organ, but he's been waiting for so long!'* (Social Worker)

Pathway: Understaffing and Systemic Barriers

Staffing, resources and the complexity of the clinical pathway were common themes raised by informants. This is a striking counterpoint to the ideal pathway described in the following section, and is also reflected in the suggestions for improvement – elements of an ideal system that would produce better results were clearly elucidated.

Some of the barriers are, predictably, about lack of funding and staffing:

- *'We [transplant coordinators] can't go out to pre-dialysis or dialysis units to do ground-work there about transplants because we don't have enough staff.'* (Transplant Coordinator)
- *'Renal Physicians [in our location] cover a huge district... and that makes it extraordinarily difficult for them to provide the sort of service we expect.'* (Renal Clinical Director)
- *'I don't have time to do group meetings or travel to [remote sites to] see patients, even though I'd like to and I think it would be helpful if I could.'* (Pre-dialysis Nurse)
- *'We need to do more transplants. I think we can find more donors. It's mainly money issues for staffing.'* (Renal Physician)

Other issues relate to barriers imposed upon patients or staff by the system:

- *'We have a free taxi service to dialysis appointments – but we don't have this for transplant or clinic appointments.'* (Social Worker)
- *'I used to call the patients and send my own appointment forms, but now it's done by a scheduler with a standard first appointment letter. This way lets us keep track of DNAs but I have a sense that the DNA rates have gone up as a result.'* (Transplant Coordinator)
- *'Patients in Gisborne get worked up there, but then they must travel to Hamilton to be seen by the Auckland team at their satellite clinic. They can't be seen at Auckland because of funding issues, even though you can fly direct from Gisborne to Auckland, but not from Gisborne to Hamilton.'* (Transplant Coordinator)
- *'Cardiac workup time is a big issue for us. Because of that, I try to get it out of the way as soon as possible, so they don't sit around with the rest of the workup done, waiting for their cardiac appointment. If they pass, then I can schedule the rest which is done more quickly. It's the most efficient way for both our DHB services and for the patient.'* (Transplant Coordinator)
- *'The transplant evaluation is poorly coordinated. Patients are not able to get all the necessary tests within a single year, so as they finish up the last required tests, they need to go and get the first ones done again. There is gross inefficiency and poor co-ordination.'* (Renal Physician)
- *'A significant number of our listed transplant patients are on (temporary) suspension at any time. Usually it's because they're waiting for tests. Cardiology is a big one – they're waiting for cardiology review, or a treadmill or echo test. Sometimes it's because they're waiting for other tests or they've missed an appointment. Or they need another test based on the results from the first. Sometimes it takes so long to do everything that by the time they finish, we need to redo the first test because the test is only good for a year.'* (Transplant Coordinator)
- *'Parathyroidectomies are another problem. If they require one, it has to be prior to listing, and they will be suspended from the waiting list if they get to the point where they require a parathyroidectomy. The waiting list is enormous for that. This is a big problem and causes a lot of waiting. The waiting list for an echocardiogram here is 12 months, and no priority is given to renal patients in scheduling the tests. People get tired, frustrated, disappointed while waiting.'* (Transplant Coordinator)
- *Cardiac issues are the main reason [that will keep someone off the transplant list temporarily]. Often it is because they are waiting for a cardiologist review to take place. We may have as many as 20% temporarily off our list for this reason.'* (Transplant Coordinator)
- *'Waiting time for an echocardiogram here can be nearly 12 months, and then people DNA their appointment because they don't have a good perception as to why they need to go to that appointment, which may have been made 9 months earlier. It may take us a while, because of the number of patients on our books, to realise a patient has been a while since we have seen them or that they have been missed, and because they are having their workups done in other areas, we may not even be aware they have missed an appointment.'* (Transplant Coordinator)

Still other barriers are associated with conflicts between non-transplanting locations and the transplant centre.

- *'We [from the transplanting centre] would be happy to go to [a non-transplanting site] and assess their patients [there]. We used to go to [another site], but their management won't fund us to use their outpatient clinics'* (Renal Clinical Director)
- *'We have sent patients to other transplant centres when [our transplant centre] has refused and we felt their decision was wrong. We sent one person to Australia.'* (Renal Clinical Director)

- *'One reason for the long delays is that we need to double guess [the transplanting centre] and get [what we consider unnecessary] tests done just in case, because if the centre rejects the patient and demands additional tests, then it takes even longer and more of the tests that were already done will expire in the meantime and need to be repeated.'* (Renal Physician)

Pathway: Delays and Deviations from the Ideal

The ideal pathway is described by one team member as below:

- *'The ideal way that people would be found to be eligible for a transplant is that they would have been coming along with chronic kidney disease for a long period of time, since they have discovered that they have renal disease... Those people would have received a lot of education about chronic kidney disease: what it means, what's going to happen when they become severe enough that they have to have some treatment for it. They will have had it talked through by doctors, dietitians, and nurse specialists, and the options would have been gone through with them, which would include not doing anything, and therefore dying, or dialysis, different sorts of dialysis, or transplant. And so the ideal thing is that those people will all have been sorted out to go onto the transplant list before they actually get to that stage.'* (Renal Clinical Director)
- *'When should people consider discussing transplant? Right when you first learn you have diabetes? People don't know about transplants in time and aren't told early enough [to have the necessary korero with their families, to start looking for donors, to make the decisions they need to make, especially if the goal is to have a pre-emptive transplant.]'* (Cultural Advisor)

It is worth noting then that if this is indeed an ideal pathway, clearly a large proportion of patients do not follow it. Further, this described pathway is not resourced by social workers, cultural support workers or others who can help patients understand the non-medical issues and assist in the process.

The actual pathway described by most respondents is one in which the work up may take many months or even years, particularly because often times the initial potential donor is disqualified and another must be found and worked up in turn. (For the sake of economy, only one donor at a time is considered and undergoes a workup, regardless of how many willing donors the patient may have recruited.)

- *'We often assess four or five potential donors before one is acceptable.'* (Transplant Coordinator)
- *'We don't like having a huge list [of potential donors] because otherwise you end up with a whole lot of people that we have to go through and also if there is four people who all think they are being worked up, you will often get no one to come forward because they all think it is going to be one of the others. I can offer you a kidney, but it is going to be one of the other 3, so I don't have to. We usually suggest that people pick one and he is the primary donor who gets worked up, and then we go down to the second one...'* (Renal Clinical Director)

Many other clinicians also describe how there has been a deliberate decision not to start the transplant work up too early in the patient's renal dysfunction, lest the patient stabilise unexpectedly. In that case, the argument goes, the team will have wasted their time and system resources in completing a workup that will now be out of date by the time the transplant is required. In order to avoid this, the system would seem to err on the side of delaying until most patients are actually on dialysis before the workup for recipient and donor are completed (or, in some cases, even started).

- *'We don't want to see patients too early because if their renal function stabilises, then we'd need to do another transplant work up later on and we'll have just wasted time and money doing two, not one.'* (Transplant Coordinator)

Considering the widespread acknowledgement among specialists that pre-emptive transplants are the gold standard, it was curious to hear so many comments that indicate that the system is not at all aligned with promoting them:

- *'Social workers are mostly warned to focus on and support home dialysis, not transplant.'* (Dietitian)
- *'We know that some patients can go from pre-dialysis directly to transplant without dialysis (e.g. pre-emptive transplant), but this is rare – and to date, nonexistent for our Māori and Pacific patients.'* (Social Worker)
- *'When we talk to patients, we need to be careful about information overload. If the patient is getting ready for dialysis, then we need to focus on getting them ready for that. We don't want to talk about transplant for fear of overloading them and being less effective or helpful.'* (Social Worker)

The impact of this approach will be to decrease pre-emptive transplants as the dialysis pathway is emphasised or resourced (at least in an educative sense). That is, a patient is taught to focus on dialysis first, and transplant (possibly) later. This is especially so because it's clear that many patients, especially Māori and Pacific people, rely heavily on the Social Worker's ability to explain things more clearly (i.e. with less jargon) than doctors, nurses or transplant coordinators. It also appears that this conversation – about preparing for transplant, discussing options with whānau, and so on – does not take place at the primary care level (either before or after referral to the renal specialists), although the GP might reasonably be expected to have the greatest rapport with the patient and whānau.

Other comments describe variations from the ideal pathway, issues with the current pathway, or strategies to overcome the multiple obstacles to the patient work-up process.

- *'If you don't get on the transplant list before you start dialysis, it takes a while to get on the list... As people come up needing therapy, we often see them regularly, but once they are on home dialysis, they may not get seen by a doctor for 6 months. It doesn't get reviewed. It's just a process – part of it is lack of staff and things like that.'* (Renal Clinical Director)
- *'Preferably you get people onto the [transplant] list before they start dialysis, because they tend to start and then they get a different doctor... and then it can take too long to get people onto the transplant list.'* (Renal Clinical Director)
- *'GP referrals are variable in quality. Some patients are referred too early and some too late.'* (Renal Physician)
- *'The workup tests can occur in multiple hospitals, some of whom we have good ties with, but many of whom we don't, so we don't learn that a patient DNA'd for a cardiac echo until the patient has already been taken off the schedule entirely and a letter sent to their doctor.'* (Transplant Coordinator)
- *'People [donors and patients] must repeat their testing many times at many hospitals.'* (Transplant Coordinator)
- *'[Even for the patient, who is not yet on dialysis,] you wait for the tests and you always wait for the cardiologist and you wait for the cardiac assessment, this can take up to a year. Echo cardiograms take nine months, and exercise tests takes maybe 3 months, stress tests can take six months, and that straight away puts you back 6 months, and then waiting for a slot for the transplant team to see the patient takes another month. So you can see straight away that it takes six to 12 months down the track before a patient goes to the next step.'* (Renal Physician)
- *'Pre-emptive [transplants] are the gold standard but hard to achieve in practice. There is no reason to think that Māori and Pacific groups are disadvantaged in this regard. They would be equally considered, but there are other factors that would prevent Māori and Pacific patients from being referred in a timely manner.'* (Renal Physician)

Cultural differences

The diversity of experience reported by the transplant team members and the broad range of their responses was remarkable. Some team members asserted that culture had no contribution to the patient response to chronic kidney failure, or that the range of reactions from patients was essentially part of the broad continuum of all individuals. Others reflected experiences in which Māori or Pacific culture was a central feature of the experience of the patient and their whānau.

Some team members seemed almost overwhelmed by their perception of the cultural dimension evident in Māori and Pacific patients, others expressed their passionate interest in engaging in effective ways with Māori and Pacific patients, and still others voiced some defiance in the face of what they perceive to be self-sabotaging cultural beliefs. In all of this, of course, there is little in the way of a shared understanding among team members.

- *'Personally, in my experience as a clinician, I have never seen a Māori or Pacific predilection to refusing to be a live donor or to not accepting a transplant organ, whether live or cadaveric.'* (Renal Clinical Director)
- *'Māori and Pacific have more of an issue with having another person's kidney inside them; they need to talk to their family more.'* (Transplant Coordinator)
- *'Some Māori people who are going to be live donors will ask what happens to the kidney when the recipient dies, and I do not think I have ever had a white person ask that.'* (Renal Clinical Director)
- *'Cultural issues are important right from the start.'* (Transplant Coordinator)
- *'I don't think there are any [Māori or Pacific] cultural or religious beliefs to accepting a kidney. If there's any problem, it's with giving, and even that is more of an individual choice than an issue about Māori or Pacific culture.'* (Renal Clinical Director)
- *'We have plenty of Māori willing to donate in our population.'* (Transplant Coordinator)
- *'The whole thing that Māori people won't be donors, well that is crap. They are very happy to be live donors, but there will be extra questions from some of those people... and yes, some Māori people are not so keen about having deceased donor organs.'* (Renal Clinical Director)
- *'I haven't seen any cultural barriers for Māori or Pacific live donors, but I have seen them for cadaveric donation though not to receive a cadaveric organ.'* (Renal Physician)
- *'I don't see Māori and Pacific patients as more reluctant to ask family for a donated organ compared to other cultural groups. I think that most people of any ethnicity have a problem doing that.'* (Renal Clinical Director)
- *'Māori patients are more concerned about [the welfare of their] live donors, the potential damage to the donor.'* (Transplant Coordinator)
- *'A Māori patient once told me that 'We've got a modern disease [ESRD] and our older Māori need to understand that we need a modern solution [transplant] to a modern disease.'* (Transplant Coordinator)
- *'It can be very delicate to deal with issues of home remedies and alternative therapies, like kumara juice or Chinese pills... Usually the patients and whānau have heard so many doom and gloom messages from the doctors by then that they are willing to try anything and everything.'* (Dietitian)

There were divergent views about whether Māori and Pacific patients preferred live or cadaveric transplants.

- *'Some Māori are more accepting of a live donor than a cadaveric transplant, and that's a cultural issue.'* (Transplant Coordinator)
- *'Māori greatly prefer cadaveric donors to live donors because then they don't have to worry about potentially negative impacts on the donor/whānau.'* (Social Worker)

- *'I'm not sure which [live donor vs cadaveric] Pacific patients prefer, because many Pacific patients don't really understand where the donor kidney comes from – again in keeping with their general lack of understanding/awareness and disinclination to voice their questions.'* (Social Worker)

Many team members felt that health issues were often not discussed or understood in Māori and Pacific families:

- *'This topic [of transplants and organ donation] just is not discussed in a lot of Pacific families.'* (Social Worker)
- *'More Pacific people turn down all interventions (transplant, home dialysis, haemodialysis...) than other groups.'* (Renal Physician)
- *'Pacific patients want to talk about transplants. They may become focused on it and somewhat unrealistic.'* (Social Worker)
- *'Māori prefer not to discuss [transplants] early in renal failure. They don't like either cadaveric or live donor options.'* (Social Worker)
- *'Tongan people are very frightened of transplants. Not a lot of information is available, and it is not discussed in families. The families tend to expect the doctor to do everything, provide all information, and therefore won't do research or bring up topics/questions on their own. Families tend to be very frightened of and uncomfortable with new technology or anything unfamiliar. They keep worrying 'what if...' and are very hard to reassure.'* (Social Worker)
- *'Māori have more issues with transplants than Pacific Islanders do.'* (Social Worker)
- *'I can only say from personal experience because it is not based on studies, that Māori and Pacific Islanders have less understanding of the scientific basis [for transplant]: the background of transplants and what is involved, what actually happens during a transplant.'* (Renal Physician)

Others made comments that revealed tacit opinions about the relevance of culture and cultural communication:

- *'I think [that it is] a misperception that Māori culture says you can't donate. You're dead. What are you gonna know?'* (Renal Physician)
- *'The vast majority of people who come along who are clearly Māori or Pacific Islanders, I ask them are there any cultural issues in your family about this? Is there anyone in your family that is uneasy about this, particularly in Māori families, with the elders or anything like that? And if they ever identify it as being an issue, I would say to them, 'would you like to see our cultural people?''* (Psychiatrist)

There are several issues that arise from the above statement - that this clinician does not ask everyone about culture (how does one decide who is 'clearly' Māori or Pacific?) and that 'our cultural people' are only needed if there is an elder in the family who is uncomfortable.

Similarly, in the following response, it appears that the Māori health personnel are not routinely involved.

- *'Māori health team [members] are not involved with the transplant team normally – they only become involved if a problem develops... And usually, if there is a problem, we call in Liaison Psychiatry, not Māori Health.'* (Renal Clinical Director)

Other people talked about different communication strategies or topics that seemed to arise with Māori and Pacific patients:

- *'There was a young woman in a Māori or Pacific Island family and we felt that she was being put under more pressure [to donate] than say you would normally find in a European family.'* (Psychiatrist)
- *[Māori and Pacific] 'people have a lot of concerns about what will happen if they can't afford their post-transplant medications, what if the side effects of these medicines after the transplant are problematic – for example if they interfere with pregnancy. All these 'what if?' questions can make Māori and (especially) Pacific patients very wary of transplants.'* (Social Worker)
- *'Māori and Pacific people tend to be less interested, more automatically negative [when told about various support services that are available]. Once we [Social Workers] talk them up or 'sell' the organisation's services, explaining what they can do, then they often become more interested. But it takes pushing, not just a passive 'Do you want to see X? No? Oh, okay.'* (Social Worker)

Some clinicians denied that culture played any role:

- *'I have a very strong opinion that it has absolutely nothing to do with Māori culture – it is to do with socioeconomic deprivation. We find the same story in [overseas location] where I have worked and [another overseas location] where I have also worked, anywhere where there is socioeconomic deprivation. Those who are most at risk of renal disease are the ones who turn up late, deny it, have 1001 other reasons for not wanting to entertain dialysis, let alone a transplant. So they are the ones who crash land, where everything just goes pear-shaped. It is a long, long time to get them back on track again. They also seem to be the ones that do not comply.'* (Renal Physician)
- *'I've seen the same disparities [overseas] – it isn't about Māori culture.'* (Renal Clinical Director)

The false deduction here seems to be that if disparities exist in other places, there cannot be a cultural component, since the cultures are different in different places.

Others mentioned the role of race or culture, but only insofar as it had been used to obfuscate other issues:

- *'We did have a Māori family where we had a woman donor and a good donor. Fabulous. And a recipient who had already been non-compliant with the kidney that he had received from his mother and had lost that kidney and was coming up [with this new donor] in short order... There was a sense of entitlement. There was no ownership [of his own responsibility]. Oh no, the doctors must have lied about him... Sometimes people do come in and say I am going to get the cultural services onboard, because you are denying me my Māori rights, and it has nothing to do with culture. It was purely about, this was a young person who was the actual donor and she was a mother, who was going to go through a completely unnecessary operation. So we wanted to make sure that the kidney was going to someone who would look after it...' (Psychiatrist)*

Others appeared to appreciate different cultural beliefs that may play a role not only in receptivity to transplant but also in related issues such as late presentation, 'noncompliance', and interactions with the health team:

- *'If Pacific patients feel well, i.e. no symptoms, then they find it hard to understand how they can be ill and why we're saying that they need dialysis or a transplant.'* (Social Worker)
- *[Māori and Pacific people] 'have a different understanding to health than I do... Pacific patients are more likely to think that we are talking a load of bollocks or some sort of whitey propaganda crap when we talk about obesity. I don't have any doubt about that. They just all roll their eyes and you can tell that they are not vaguely interested in that, so you may as well get on with the next subject. And that is the problem... Male Māori are the same. They include drinking too much in there.'* (Renal Clinical Director)

This suggests that Pacific people tend to be strongly guided by how they feel, not by what the lab test results describe or by what (non-Pacific) doctors might say. This would be a particular barrier to pre-emptive transplant in this population.

- *'The fact that it is very hard to engage with [Māori and Pacific] patients before symptoms start makes pre-emptive transplants very, very hard in this group.'* (Social Worker)
- *'Pre-dialysis they [patients] feel well, and they look at the plan and think, 'what is everybody talking about?' I feel perfectly fine and I have got some oral things that I can take, and my family has got this and they will look after me, and we really don't need all this [transplant] stuff.'* (Social Worker)

Other culturally-influenced behaviours were also mentioned:

- *'Transplants are NOT culturally inappropriate per se, but there are cultural traditions that may make Māori and Pacific patients less proactive about seeking information, asking questions, and more uncertain about unfamiliar procedures or options. These patients are also more influenced by what happened to other Māori and Pacific patients that they know or hear about, so we need a higher profile and awareness about transplants in these communities.'* (Social Worker)
- *'Many Pacific patients have different belief systems – e.g. God can heal, God will provide – and they take a very passive approach to their own health, relying on God and so forth. We try to explain that they can use Western medicine as well as their faith in God and that it will not be at odds with God's healing power.'* (Social Worker)
- *'Tongans prefer to come to Tongan-only group meetings for donors and recipients, more than attending 'all comers' meetings. They are less comfortable in mixed groups especially on sensitive topics like transplants.'* (Social Worker)

Many clinicians quoted their Māori or Pacific patients, as their informants. This may underlie the reason why so few clinicians saw any value in using cultural liaison staff – because they felt that their patients had already adequately explained the relevant cultural beliefs:

- *'[One Māori patient has two adult daughters who are] quite active [in Māori affairs]. One of them works in an iwi organisation; they speak Māori. But both of them said [culture] was not an issue here [in their parent's transplant]. It's not an issue about the kidney, it's about well being.'* (Psychiatrist)
- *'I have heard [Māori and Pacific patients] say that some of the leaders are resistant about them getting a transplant.'* (Social Worker)

Some clinicians recalled receiving very definite cultural advice regarding the inappropriateness of transplantation, and some cultural advisors evidenced such an approach. This may also lead to wariness amongst clinicians in calling in cultural support personnel, lest these personnel provide advice contrary to what the clinician feels is in the patient's best interests:

- *'We did invite Māori and Pacific community leaders to come and address our working group on transplants and donation. We were told that the Māori belief is that once a person dies, the body belongs to the whānau, not to the deceased person. [This is why family can override an individual's decision to be an organ donor.] There is also a cultural belief that when buried, the body needs to be whole. The Pacific view is slightly different; we were told that the individual might be comfortable with cadaveric donation, but they would be unlikely to have a live donor due to cultural and religious beliefs around keeping the [living] body whole.'* (Renal Clinical Director)
- *'We are brought up to see that the body is tāpu and needs to go back intact. We respect our body as tāpu. If we're unfortunate enough to be born with an illness, then we take on karakia. When that stops working, it's time to move on to the next stage [the afterlife].'* (Cultural Advisor)
- *'We do see situations where the patient wants a transplant and the family doesn't – usually they say 'it's not the right thing to do.'* (Social Worker)

Differing opinions were provided by other cultural advisors, and similarly some clinicians were aware of those opinions.

- *'Our tamariki are our future. I would give anything, any organ, to my kids. If it's whānau who needs an organ, it makes a huge difference. It goes back to our principles of aroha and manaakitanga.'* (Cultural Advisor)
- *'Historically, Māori would sacrifice ourselves or part of oneself to save our whānau, so why not give an organ now?'* (Cultural Advisor)
- *'I'm seeing a shift [in patient attitudes] with more education as the message gets out, but it's slow. I do see an increased willingness [towards transplant] in Māori and Pacific these days.'* (Social Worker)
- *'One of our patients, a Māori lady who received a transplant was incensed by the comment [that Māori don't accept donations and transplants] and said, 'I wish I was there, I would have told him exactly what I thought!' I am not sure where in Māori culture it comes from that says you cannot donate.'* (Renal Physician)

One thing that might promote the integration of cultural liaisons into clinical teams is the specific assignment of a known individual to the team. Many clinicians commented that they had no way of knowing who might appear if they requested the assistance of a cultural liaison. The following comments reveal the value of established, long-term relationships in promoting mutual respect among team members and improving patient care:

- *'There is a kaitiaki attached to the renal service. It's very helpful to have a specific person whom I know and work with all the time. He learned about transplants by osmosis, not formal training, and he's been with the unit for 4-5 years.'* (Renal Physician)
- *'We met with [a cultural worker from the transplanting centre] who told about a Māori young man who felt suicidal after his transplant. And she pointed out that he had never welcomed the new organ into his body or thanked the old one for its service. She led a karakia and he did better. The clinical team would never have approached it this way...'* (Cultural Advisor).

Many clinicians stressed their awareness of cultural issues and described actions that they (or the system) took to try to ensure people's preferences and needs were addressed:

- *'People need to be comfortable, and we try hard to make people comfortable. That's why we'll have family meetings and open with a prayer if that's what people desire. That's why we do home visits. We want people to be comfortable, but this is across all groups and cultures.'* (Renal Clinical Director)
- *'[Growing up in my family] we were always very aware of Māori cultural beliefs that are very diverse around transplantations and blood transfusions and that sort of thing. There [are] no hard and fast rules. I am very aware of that in my work, and I am aware that it may affect a patient's decision to accept transplantation... With whānau, iwi, culturally, it all depends on how the people identify with these topics. It could change over a period of time... I would always refer to our cultural experts... As yet I have not had to cross that bridge, but I am prepared to do it if it needs to be done.'* (Social Worker)
- *'If I walk into a room and someone has a Māori surname, it's not to say that I am going to start by asking if they want to have a karakia before we sit down. I always ask in my questions, how do you guys usually do things in your whānau? How do you identify ethnically? What can I do to respect the way of doing things with you and your whānau? Patients actually respect that. They realise that I am not an expert on everything in life and I do not want to step on their toes. I do that with the Chinese families as well, I just have a little bit more knowledge about Māori families.'* (Social Worker)
- *'The pathway is that I see them maybe 1, 2, 3 times, and then we have a formal family meeting when they are past 20 [GFR]. We have to have the family meeting [at the main hospital] mainly because of the availability of the doctors. If they are Māori, we ask if they want to have our [cultural liaison] involved. We have the physician for the patient, a transplant coordinator, a social worker, a dietitian, the cultural liaison, and the family. The family meeting is usually coordinated by the social worker... we encourage the patient to bring whoever they want to bring. We also send out a copy of the minutes of the meeting to the patient and their families. They may want to send them out to children that are overseas. We send also a copy to the GP. From that meeting, we come out knowing what the patient wants to do.'* (Pre-Dialysis Nurse)
- *'I have a standard approach to patients, though I do use a more collective approach with Māori. I ask all patients if they want kaitiaki involved – about half say yes – and I also ask if they want karakia.'* (Renal Physician)
- *'We try very hard to hold a family meeting before anybody comes onto dialysis. [It] is a full meeting where the patient comes, the family and friends, whoever the patient wants as their support. [Medical Team attendees are] the nephrologist, the pre-dialysis nurse who has usually gone to visit them in their home before the meeting, the social worker who will also have gone to visit them in their home. If they are a Māori family, if they want it, then there will be a Māori liaison officer at that meeting. We schedule a full hour, and we go through the range of options for them for their kidney failure. Usually that will involve discussion about transplant. We talk about home dialysis, haemodialysis; [transplant]; for some of them that may simply be saying, 'I am sorry but it [transplant] is not an option for you as your heart is bad', or 'it may be an option for you in the future, but you're 30 kg too heavy'... and for the late people that turn up, we tell them 'that may be an option in the future; it's not available immediately [because] you urgently need dialysis'. 'These are your options.'* (Renal Clinical Director)

This last comment is instructive because it emphasises that, to this clinician, one hour is a long period of time. It is likely, however, that to a family struggling with a complex disease and critical issues such as who might donate a kidney, a single hour appears woefully inadequate. In addition, the quote emphasises that cultural support must be requested by the family, when some families may be uncomfortable doing so, and also highlights the importance of having many of the topics already discussed by team members during the home visit(s).

Communication Issues

Communication occupies a very central place in relationship with patients and their families. The members of the transplant teams provided ample illustration of the importance of communication, and these comments describe issues in terms of communication skills, styles and preferences.

Many respondents noted that doctors and nurses (including transplant coordinators) do not present information in ways that patients find easy to understand:

- *'Especially with Pacific patients, we often see DNA's because the patient hasn't understood what the appointment with us is all about or what it's for.'* (Transplant Coordinator)
- *'I always ask, 'what did the doctor or nurse say to you today?' and a lot of the patients haven't understood a word because of the poor communication styles of the doctors and nurses. They [the patients] feel comfortable enough with me to share their confusion and ask me to explain what was said.'* (Dietitian)

Others commented on the way that the messages given by clinicians can themselves contribute to undesirable patient behaviors, such as fatalism and despair that lead to DNA's and non-compliance.

- *'The medical system gives very doom and gloom messages to patients and this leads to fatalism, noncompliance, despair, lack of interest in their care, and so on.'* (Dietitian)

Some seemed to understand the problems of providing too much information at once, yet often the system requires such behaviour because of the difficulty in scheduling appointments with the relevant specialist. This is especially true for patients who must travel significant distances to see renal team members:

- *'At our meeting, we educate them about the evaluation process, why tests are done and what the team is looking for, the transplant operation – how it's done, where, that they'll need to live in Auckland for 4-6 weeks post op, follow up care, the waiting list for cadaveric vs live organs... It is completely dependent on their GFR. Sometimes patients need to be stabilised on dialysis before the transplant discussion can take place.'* (Transplant Coordinator)
- *'Communication varies a lot, and problems with communication are a part of the problem. I don't see it as being a failing of the clinician, except where there is information overload. I see the communication difficulties as something the system imposes.'* (Transplant Coordinator)

Many talked about the value of going to the patient's home and/or arranging things so that key messages can be delivered by several people in several ways over several months:

- *'I think it is all... about the information given as early as possible and using a different number [of methods of communication] and as many different means as you can. So that if you have got coordinators talking to people about it and you have doctors talking to them about it, and they have been to group sessions – and a variety of group sessions – and that more and more opportunities to meet other people and talk about some things, the more aunties they have who have been on dialysis and died, [that helps them make their informed decision re transplant.]'* (Renal Clinical Director)

- *'The first time I see them, it's just meeting and greeting. It's because they're more likely to attend a second meeting after they've met me and have a face to face relationship established. Then they know who I am and why they should attend the next meeting. I don't load them with a lot of information right there. I arrange [another] meeting. Then we do a home visit with the social worker and do a social assessment – how they are coping, what support they have. They get booklets and cards for contact numbers. We see them, we get a feel for how far they have to travel... By the time we really start talking renal replacement therapy, we have formed a rapport with them, we know how much information to load on them or to ease off.'* (Pre-dialysis Nurse)
- *'When you go to a Māori or Pacific patient's home, usually you get to address a large whānau, so it's a good use of our time.'* (Transplant Coordinator)
- *'We sometimes see a different side of the patient. Whereas the doctor may only see them for 15-20 minutes in the clinic, we sit with them for a few hours and can see they are better than what you have been referred.'* (Pre-dialysis Nurse)

Using blunt language and avoiding jargon was also mentioned by several people as being fundamental:

- *'I tell patients, 'This will keep you from getting a transplant'. It's tremendously powerful, more so than saying 'your renal function is decreasing and it's therefore important for you to take your phosphate medication.' It's very important to use plain language to explain things so that patients can understand the situation.'* (Transplant Coordinator)
- *'When we do the full pre-dialysis education, we discuss what their kidney failure is caused by... We need to sit down and make time to talk about their medications. Making sure they know how many times a day they have to take [their medicine], where they go for their lab tests, who is their pharmacy... Often we follow up with the pharmacist or their GP or practice nurse. I'll talk to anyone to give seamless care for our patients. We send them a booklet so they know about our patient and ensure we're all on the same page.'* (Pre-dialysis Nurse)
- *'We talk about the basics: what a transplant is, what a transplant will do for them, how easy or hard it is to get, who might qualify, they might not qualify at the moment but will they qualify in the future... Some of the people say they have a donor already, so we discuss whether the donor is the same blood group, is the donor well or unwell, that sort of thing.'* (Pre-dialysis Nurse)
- *'There can be difficulty communicating with patients if you use scientific or medical jargon. I always use plain English, like 'crap', not 'waste products'.'* (Pre-dialysis Nurse)

Suggestions for Improvement

Informants provided abundant advice on how to improve transplant rates for Māori and Pacific and suggested a wide range of actions. These suggestions have been grouped as follows: patient education, community/whānau education, financial remuneration, staffing, training, processes, criteria, screening, coordination, integration, information and information technology.

Suggestion Patient Education

- *'Patients need to understand what is happening to them EARLIER so that they can feel empowered to intervene and make good changes. If they know how to intercept problems in time, they can help protect themselves or a beloved family member.'* (Dietitian)
- *'I show them graphs [of their renal function and other lab values] and compare their labs pre- and post-treatment. They may not understand the specifics numbers, but they can see and understand the trends.'* (Dietitian)
- *'Patient education can help address the increased co-morbidity rates of Māori and Pacific patients. It would also improve the overall health of the communities, which would lead to more donors being available, less of a need, and better outcomes.'* (Renal Clinical Director)
- *'[People] need to meet and talk with people who have been through the transplant process and can answer questions.'* (Cultural Advisor)
- *'I would rather see the patient caught earlier and be educated earlier.'* (Renal Clinical Director)
- *'We need more education on pre-emptive transplants especially, because we can then stop [patients] from needing to get here. To do that, we need to be more involved in chronic disease management, before patients get to the bad renal failure stage.'* (Pre-dialysis Nurse)
- *'There is a need for more patient education. Patients need to understand why they are having the test and so on.'* (Transplant Coordinator)
- *'Giving talks on marae would be great, but there's no time to do it.'* (Transplant Coordinator)
- *'I think it does really come back to education, education around our processes and how things work, because our ways [in health care] are predominantly based on Pākehā ways, so being able to bridge that gap between one culture and another to actually make sure that they really understand what is available and how it works...'* (Social Worker)

Suggestion Community/Whānau Education

- *'[There was] a programme that had been run somewhere around Washington DC where the coordinators there instead of doing education clinics, were doing recipient transplant education in their [the patient's] home, and it was made clear that they were coming out to talk to the recipient plus their extended family and other friends or people that they thought might like to know about transplants... and they would do it at [their] home. And they had a dramatic increase in rates for live donor transplants, because people who were potential donors had come along to this education in the home because they felt more comfortable about doing that.'* (Renal Clinical Director)
- *'[Home assessments] are really useful because they are there with their family and they can sort of talk about what is happening, including some of the things that might happen, like having to accept that they won't be at work for a while, or they have an access [placed] in their arm. Or they are worried about their job, the other family members, children, housing; all of those things come up, so we quite often are able to talk through [the issues] and assist people.'* (Social Worker)
- *'I think groups [group education sessions] make a [positive] difference too; people are always more keen on asking stupid questions in groups, heaven knows why... Part of it is that people listen in a different way when they are in a group than they do when it's individual.'* (Renal Clinical Director)
- *'It is very useful to have meetings where patients [pre- and post-transplant] get together and have discussions amongst peers... We encourage people to talk not to us, but ask the real people [who have had a transplant]'* (Social Worker)

- *'We do education workshops in group settings and we always have a Māori or Pacific transplant recipient at the meeting to give a lot of peer support. The transplant recipients are always very successful at piquing the interest in transplants. We haven't had donors at the meetings thus far. Patients like to ask the recipients questions more than asking questions of the nurses or social workers or doctors.'* (Social Worker)
- *'Often families [especially Pacific families] don't know what to ask. Medical people need to prompt them and even pose the first questions themselves – 'in your shoes, I would want to know...', 'a lot of people at this stage ask...' Once that's been done, after 1-2 posed questions, the family will start to speak up.'* (Social Worker)
- *'We need word of mouth in these [Māori and Pacific] communities to help change attitudes.'* (Social Worker)
- *'There should be more working through the elders and leaders of the Māori and Pacific communities to get them on-side [in promoting transplants and donation].'* (Psychiatrist)
- *'Positive stories [about transplants and donation] in the media help. More good publicity helps. Increased awareness is also very helpful.'* (Pre-dialysis Nurse)
- *'The question shouldn't be how to get more Māori and Pacific live donors, but how to get more Māori and Pacific involved in their own health care... Māori have to take more interest in their health.'* (Dietitian)

Suggestion Financial Remuneration

- *'A constant source of frustration is the lack of financial remuneration for the costs to the donors. Our DHB is very good at thinking about costs, for example paying donor travel costs for them to come so they can donate.'* (Pre-dialysis Nurse)
- *'I would like to see better support and financial recognition for live donors. I haven't had anyone refuse yet, but this might be one reason patients are so reluctant to approach family and friends.'* (Renal Physician)
- *'Rewarding the donor is a complex issue, but ... I think if someone comes forward to donate a kidney, they often lose 6 weeks of annual leave and 6 weeks of pay when they go through the donation, and I think at the minimum, that should be recognised and that should be compensated for.... We are not encouraging donation by paying someone, but we will compensate them for their loss. That should be actively pursued.'* (Renal Physician)
- *'It's all very well and good having money from the government put into programme and initiatives around different medical and social needs, but getting people to and from and getting them able to actually do it, sometimes it's the difference between a \$2 bus fare and a \$10 petrol voucher. The national travel assistance from the Ministry of Health does help, but I think there is a lot of work that needs to be done around the distance criteria: how far patients have to travel before they get paid and the frequency criteria. You need to visit a specialist 22 times in 2 months before you are eligible for funding and travel 350km one way before you are eligible for funding. Most of the people I see do not fit the criteria at all [yet need the assistance].'* (Social Worker)
- *'Travel funding is huge...People cannot get to their appointment, it doesn't matter what it's for, they just cannot get to their appointments. It all comes down to money, and we all need more money. I just think that the criteria for funding from MSD and MOH is far too tight. I'm not saying we need special funding for different ethnic groups. I think everyone would benefit from more realistic funding, and that would require actually looking at what is happening in the demographics.'* (Social Worker)

Suggestion Staffing

- *'We need more live donor recruitment, but any programme that increases potential donors also needs to provide the associated infrastructure and access to care. We can't just suddenly increase the number of donors without allowing for more coordinators to evaluate them and so on.'* (Renal Clinical Director)

- *'We don't have time to spend with patients from [outside our immediate area] to give them the kind of sustained support and encouragement that is often needed, especially for Māori and Pacific patients adrift in an unfamiliar and confusing medical system.'* (Social Worker)
- *'Before we had an in-house coordinator, we relied on the coordinators from the transplanting centre, and they weren't as aggressive as I am. They didn't chase up the patients, and I do with very, very good results...'* (Transplant Coordinator)
- *'We need to make nephrology a more appealing specialty for trainees.'* (Renal Physician)
- *'Having in-house ownership [of the transplant patients and donors] by someone who understands [our] demographic has made a big difference.'* (Transplant Coordinator)
- *'We need increased funding for more [social workers] that would allow assessment of all transplant patients, not just pre-dialysis patients [when transplant often isn't discussed or is minimised because the focus is on preparing the patient/whānau for dialysis]. This way, with the current staffing, we can only be reactive and jump in when there's a problem, and then we only have time to solve the immediate problem, not look for underlying problems or provide the long term support the patients and whānau need.'* (Social Worker)
- *'I think one of the keys to success is having an on-site coordinator who has organisational knowledge of this place, relationships with the other services, and also an understanding of our patients and routines.'* (Transplant Coordinator)
- *'It would be great if we could have a liaison psychiatrist here to investigate those patients with questionable compliance.'* (Renal Clinical Director) – interestingly, the speaker gave no thought to asking for assistance from their cultural support group.
- *'Now that we have [an in-house transplant coordinator], it's much better and things go much quicker now.'* (Renal Physician)

Suggestion Training

- *'Cultural advisors need to be knowledgeable about transplants, so that they can be of assistance. They need to be careful not to confuse their own beliefs with what is the true cultural teaching.'* (Renal Clinical Director)
- *'Our people [Māori] need to have communication with their family about what beliefs and ideas about transplant are. We need to get used to having korero about this.'* (Cultural Advisor) suggesting that the health care system can and should encourage this private korero.
- *'Māori need to develop new rituals around transplants. We need to find a pathway that sits well with us as Māori... The key is finding tools in tikanga to make transplant Māori, such as new karakia to introduce the new organ to the other organs in the body or a way to thank the removed organ for its service and farewell it.'* (Cultural Advisor)
- *'There's no way in the current medical [transplant] process to acknowledge our tikanga. The [donated] organ is a huge gift and Māori have a lot of tikanga around accepting gifts, but we can't use any of that within the medical system. It makes it very uncomfortable for some.'* (Cultural Advisor)
- *'They [the health team] should use the Te Whare Tapa Wha model to discuss transplants with Māori – they need to realise the need to address all aspects of life, especially with respect to the whānau's role. This often underlies issues like 'noncompliance', but if they don't take that into account, it's easy to just look at the physical aspects of health and label the patient as difficult.'* (Cultural Advisor)
- *'The pre-dialysis nurse educators have an annual meeting in Auckland, and that's helpful.'* (Pre-dialysis Nurse)

Suggestion Processes

- *'If you get people worked up for a possible transplant before they need dialysis, the chance of finding a live donor is much greater, and then they can get a pre-emptive transplant, which leads to better outcomes.'* (Renal Clinical Director)
- *'The two critical factors is that 80% of patients are overweight and have diabetes. Diabetes there is not a lot you can do about it; weight is also something there is not a lot they can do, because it is close to impossible to get patients to lose weight. But late presentation is something we should be able to do something about.'* (Renal Physician)
- *'[We need] to see if we can streamline the [transplant] process, make it [a] clear and easy process... And similarly with streamlining the process for beginning renal replacement therapy... Often what we have seen is that we know the person and they know they are going to begin dialysis within the next 3 to 6 months, and the cardiac investigation still hasn't been done 6 months down the track. Apart from everything else, that causes a lot of frustration [with] the system.'* (Renal Physician)
- *'[One particular location] is extremely good... They get everybody sorted out. We see people there who might start dialysis sometime in the next 10 years... They advocate for all their people. They have a good process there that everybody gets seen early. [In] other parts of the country, that doesn't happen.'* (Renal Clinical Director)
- *'There would be value in a standard protocol for ALL renal failure patients to be seen in the same way and under the same rules and at the same time/stage of their disease.'* (Psychiatrist)
- *'We need a more standardised process. Outside [this location] there is huge variability as to whether patients see social workers at all, and if so what kind of support they get.'* (Social Worker)
- *'In the ideal world, the transplant group would decide who was going to be put into the transplant waiting list, with input from their local nephrologist... The further you move away from the transplant group [making all the decisions], the more likely it is that people withhold transplants from patients [unnecessarily]... we want to make sure that does not happen.'* (Renal Clinical Director)
- *'The solution is in having a multi-disciplinary team for the transplant team where all decisions [for all patients in our transplanting region] are made by the team regarding eligibility, and the process is transparent and well known.'* (Renal Clinical Director)
- *'We need more honesty and transparency about who should get renal treatment, whether dialysis or transplant.'* (Renal Physician)
- *'It's important [for people from non-transplanting sites] to go to the [transplanting centre's] monthly meetings and have a seat at the table. The face to face contact when they are making their decision is very important. Having me there as someone from another hospital also tends to modify people's behaviour.'* (Transplant Coordinator)
- *'There is no doubt that us [from a transplanting centre] going to [a non-transplanting centre] to do the clinics is better than bringing the people from [there] here to do their assessment... People like us going there.'* (Renal Clinical Director)
- *'We take our pre-dialysis educator, our social worker, our renal doctors, and our dietitian to remote clinics and try to do everything for the patient in one visit.'* (Pre-dialysis Nurse)
- *'Remote clinics are a very good use of our time. It establishes a relationship with the patients and prevents them from having to travel very far so often.'* (Pre-dialysis Nurse)

- *'You need to understand that 'straightforward' doesn't work with our patients. For example, before we had an in-house coordinator, the transplanting centre's coordinator would just send a letter to the patient, even if they weren't an English speaker. I know the DHB demographic, so I'll send the letter to the next of kin along with a note asking him to explain it to his mum. I'll also phone them and chase them up, remind them of appointments, follow up after the test...'* (Transplant Coordinator)
- *'It's very important to understand the local process and the transplant team's criteria. I organise matters. I pick up on where the patient is in the process and make sure they get those things done. So if they are cleared by cardiology, then I'll physically walk down to the ultrasound room to make sure they get an appointment for their gall bladder ultrasound, for example. My process is to establish what is the biggest barrier and to focus on that. I personally check that the patients are getting the tests done and I check the results.'* (Transplant Coordinator)
- *'When we get the go-ahead from [the transplant centre] to put our patients on the transplant list, I do all the follow up to make sure they actually get put on it.'* (Transplant Coordinator)
- *'I do very close follow up with my patients, and I've seen it make a huge difference. We've reduced the number of patients who are eligible to be listed but aren't composed to those who are actively listed.'* (Transplant Coordinator)
- *'A lot of Māori DNA because they don't understand why they have the appointment, what the appointment's purpose is, they have other things coming up... If I ring them up the day before, then Māori patients do attend, but usually I don't have time to keep track of all the appointments so I don't do this.'* (Transplant Coordinator)

Suggestion Criteria

- *'We need to have clear criteria for exclusion and a process where all rejections are evaluated/reviewed.'* (Renal Clinical Director)
- *'To reduce disparities, we need to change the criteria that [the transplant centre] is using – change the weighting for HLA match versus waiting time for cadaveric organs, change their inflexibility about BMI. We also need more education for Māori and Pacific people to improve their health literacy about consequences, benefits, and risks of donating a kidney.'* (Renal Clinical Director)

Suggestion Screening

- *'There is a need for more effective, targeted screening in a nationally based and coordinated program that will lead to early intervention in the disease and prevent progression to renal failure.'* (Renal Physician)

Suggestion Coordination

- *'Non-transplanting hospitals should meet with their transplant centre at least annually to identify process issues and concerns and have a half-day or full day of work-shopping. The lack of coordination and communication that exists now suggests there's a real need for such a meeting, and it could potentially improve the harmony among the teams.'* (Renal Physician)
- *'We need better co-ordination of the workup – it now can take literally years to get some patients evaluated.'* (Renal Physician)
- *'GPs could do more to help educate people in the early stages of renal disease.'* (Pre-dialysis Nurse)

Suggestion Integration

- *'There is a need to have cultural support integrated into clinical services. We can help with all patients, bridging the clinical/medical culture to the patient's own, non-medical culture or world view.'* (Cultural Advisor)
- *'Ideally the [cultural support worker] can be the bridge between the two worlds of the patient and the doctor.'* (Cultural Advisor)
- *'Doctors can't spend a lot of time with the patient, but [cultural support workers] can and then share what they've learned with the clinicians who would otherwise miss a lot of things. But this means that the clinicians need to listen to us and take us seriously.'* (Cultural Advisor)

Suggestion Information

- *'We need better 'translation' of medical knowledge to patients.'* (Social Worker)
- *'Demystify [medical language] a bit. We come in with more of a plain language talk, you know – how are you going to feel on dialysis, what do you feel about transplants, and often they [the patients] will have heard all of this stuff and they will say... it's like gobbledegook.'* (Social Worker)
- *'Doctors [and the health care team] are too 'wishy washy' most of the time. They need to communicate with us clearly and then we can decide. We need clear guidance about transplants: how, when, where... Then acceptance will increase, but if there's doubt or miscommunication then people become hoha and say, 'forget it'.'* (Cultural Advisor)
- *'To make a choice, [people need] as much information as possible, but it must be clear, simple, and informative.'* (Cultural Advisor)

Suggestion Information Technology

- *'It would be good to have a unified, integrated communications IT system throughout New Zealand... GPs connect to the hospital so you don't have papers getting lost... Why do you have different labs? It has got to be unified.'* (Renal Clinical Director)
- *'We should all be working from one database. The GPs are much more IT savvy than the hospitals. Their computer systems are much better than the hospitals'. We should be up to the same standard. We still manually write our prescriptions, and then complain of the poor quality of hand writing. We shouldn't do it anymore. The GPs do it with the push of a button.'* (Renal Clinical Director)

Discussion

The conversations with transplant team members have identified a number of consistent themes. Several areas can be addressed immediately, while others require that a process for change be established. Improvements will require commitment and focus. The interviewees have identified a large number of areas of concern.

The pathways for patients and for potential donors are lengthy, expensive, time consuming, and difficult. Staffing issues include the lack of full-time coordinators and most other clinical roles, and the difficulty of getting specialized staff to distant locations. Some team members identified the notion that some patients have to 'prove' they are worthy of a transplant and that patients who demonstrate non-compliance are less likely to get transplant. In this context the dialysis pathway provides ample opportunities to demonstrate one's unsuitability. In fact, many pre-dialysis educators and renal physicians seem more focused on dialysis than pre-emptive transplant. For some patients the timing of the pathway is such that pre-emptive transplant is very unlikely to be possible, and the longer that a patient is on dialysis, the better their chances of proving non-compliant.

Increased attention to the education and information needs of Māori and Pacific patients and transparent and coordinated processes appear to have broad support. Improved

communication between patients and clinicians was frequently acknowledged as required to improve transplantation rates for Māori and Pacific patients. The transplant teams themselves have identified knowledge needs, and it is apparent that a process is required to bring cultural advisory services into the team. Some of the reasons that cultural advisors are not part of the current teams include some clinicians not realising that culture plays a role in a patient's response to renal disease, its progression and treatment options. Cultural advisors can at times portray an orthodoxy which is disinclined to transplantation, yet it is clear that this apparent intransigence is not widely held by Māori patients who are broadly recognized as having an enthusiasm for transplantation when the opportunity is presented. A lack of clinical knowledge inhibits cultural support workers from engaging effectively with transplant teams.

Experience strongly recommends the value of in-house transplant coordinators who can engage with the teams at the transplant centers' as required.

Contentious areas such as the BMI criteria require on-going attention and discussion. That discussion should be underpinned by rigorous data collection and analysis, and evaluation of the evolving international evidence.

Problems were identified with elements of the renal pathway such as referrals from primary care providers. Some clinicians perceive late presenters as unmotivated or disinterested (i.e. those who 'ignore their disease until it can't be ignored'), while other clinicians see opportunities for improving knowledge of renal replacement therapy. Similarly, renal consultants have significant variation in their rates of listing patients for transplantation, and attention to standardising protocols is required.

In summary, the project records that members of the transplant teams identified the following areas as needing attention:

- Need for standardisation and transparency in transplantation pathways.
- Need for more efficient, streamlined transplant workups.
- Need for donor reimbursement.
- Need for research on Māori and Pacific community opinions and beliefs.
- Need for more data collection, examination and analysis of evidence.
- Need to promote renal disease awareness.
- Need to promote transplant consideration among patients much earlier in the process.
- Need to access culturally appropriate imperatives that support transplantation, mainly to inform the team members, but also to resource cultural advisors in their work.

Limitations

This report is not informed by the experiences of patients. As the interviewees frequently reminded us, many of them see only patients who have already expressed an interest in transplant. As a result, they do not have insight into why some patients reject the notion of a transplant outright or whether Māori and Pacific patients are more likely to do so. This is a crucial limitation as it means that we have no information about those patients (or potential donors) who may be opting out of the transplant process early on, whether for substantive reasons or out of a misperception.

Furthermore, in this study we asked the clinicians and cultural workers for *their* perceptions of what Māori and Pacific patients think and believe with regards to transplants. How accurately those perceptions reflect the actual beliefs and preferences of Māori and Pacific patients is questionable.

Members of the health care team will obviously see the issue through the lens of their own education, training, culture and experience, which is often very different from that of their Māori and Pacific patients. They will also tend to lend their own interpretation as to the

patient's behaviour, such as why the patient may have missed an appointment or what underlies apparent 'non-compliance'.

In order to gain a true understanding of the views of Māori and Pacific patients, whānau, and communities, it is necessary to ask these groups directly, through community meetings and interviews with patients and whānau (including those who have refused transplants or have been declined for transplant, those who are waiting for a transplant, and those who have received a transplant).

While we did our best to include cultural support personnel in this study, we found that many renal units do not have a specific kaumatua on whom they rely and/or rarely use such resources. Those that do, almost uniformly report that they only do so at the request of a patient or whānau. There is some anecdotal evidence from informants to support the idea that some patients and whānau are reluctant to request such intervention, even when they desire it, and therefore the practice of not routinely involving cultural support personnel may be flawed and contribute to cultural discordance.

This lack of use of cultural liaison services by renal teams may be because the clinicians believe their patients do not desire such support, but it may also reflect a lack of cultural liaison availability, clinician preference (based perhaps on their own lack of familiarity with cultural liaison services or a perception that such staff provide no added value), or patient shyness in making such a request. Without having spoken to patients, it is impossible to identify the actual reason(s).

In addition, there can be a subtle incentive for cultural liaisons to propose and defend a cultural orthodoxy – that is, to champion the idea that there is a single, formal set of beliefs that are widely held by Māori which they then propound. This sets the scene for a standoff between cultural liaisons and clinicians: any perception on the part of the cultural liaison that clinicians are questioning their role or input may generate a more strident retreat into this apparent cultural orthodoxy. On the other hand, clinicians may rely on the hierarchy of clinical authority and evidence based practice. Each person is retreating into their specialist knowledge field and oversimplifying it in discussions with the other side. Having cultural support personnel more integrally linked to the transplant team can enhance the relationships increase mutual respect and further the exchange of knowledge between the two groups, thus leading to better, more knowledgeable help for the patients and whānau.

Adding to the confusion around the 'Māori' or 'Pacific' view on transplants is the fact that there is no universally accepted authority for such views. Māori tikanga varies by iwi and is largely based on teachings of individual kaumatua. These teachings can and will vary by person, whānau, hapu and iwi. While there are gross generalisations that can be made, these tend to be oversimplifications that can confuse rather than help when contemplating as complex an issue as renal replacement therapy.

The Pacific community is even more diverse than Māori, and people of both cultures are, like everyone else, further influenced by factors such as age, gender, religion, personal experiences, education and upbringing.

Recommendations

Transplant Processes

- Renal transplant teams should review their transplant processes and guidelines to ensure:
 - That all patients are provided with timely and appropriate advice on renal transplant options and pathways. The focus needs to be kept on the populations with the greatest need (that is, on Māori and Pacific patients).
 - That primary care providers are well informed of early consideration of renal transplant options and pathways, with clear expectations of referrals to support those pathways, as well as being encouraged to broach the topic of transplant and to encourage, in turn, whānau to korero on these topics.
 - That streamlined and efficient transplant work-up pathways are described to patients and clinical teams.

Regional Coordination

- Renal transplant teams should ensure that opportunity is provided to reflect on their experiences and share their successes. The focus on sharing successful approaches can support a developing best practice.

Research

- Further research should be undertaken into Māori and Pacific patient experiences of renal transplant pathways. This should include patients who are current or potential recipients, patients who have declined or been refused transplants, as well as families of these patients and potential donors (including the general public). This should include research into barriers to care, including access to care, geographic, informational and financial (including donor remuneration).
- Further data collection and analysis should be undertaken on Māori and Pacific renal failure pathways, for each renal replacement therapy clinic. This should extend to data collection for potential and actual donors.

Training

- Communication skills training focusing on engaging and working with Māori and Pacific patients and their whānau should be provided to clinicians of renal transplant teams. The training should be based on a sound understanding of the clinical pathways and the needs of Māori and Pacific patients, and it should allow opportunity for reflection and feedback.
- Clinical knowledge training should be provided to cultural advisors/Takawaenga on chronic renal disease and treatment pathways to support their effective contribution to renal transplant teams.

Education and health promotion

- Educational resources should be developed that are culturally appropriate for Māori and Pacific audiences (including patients, whānau and potential donors). These resources will still have utility for mainstream audiences, but the focus for any educational resources should be on the populations with the greatest need (rather than the largest population), and should support all aspects of the renal replacement therapy pathway, from detection and diagnosis, to treatment and transplantation.
- Health promotional materials should be developed for use with Māori and Pacific communities. These resources will have utility for mainstream audiences, but the focus for any educational resources should be on the populations with the greatest need (rather than the largest population), and should support all aspects of the renal

replacement therapy pathway, from raising awareness, detection and diagnosis, to treatment, transplantation and live donation.

Culturally appropriate messages

- Culturally appropriate messages can be crafted to engage with Māori and Pacific audiences. As on the cover of this report, the examples given below use Māori proverbs to facilitate a discourse that can resonate with a Māori audience. These could be used to develop a public health campaign aimed at the Māori population and designed to promote discussion and awareness of renal donation and preemptive transplants. It is not intended that health professionals unfamiliar with Māori communication or care preferences simply adopt such messages as a quick fix; rather they are given as examples of how existing Māori beliefs could be amenable to a transplantation discussion. Read together, they are illustrative of the concept of using culturally based messages to support positive messages about early detection and management of renal disease and to promote ultimately renal transplantation. (The examples below by no means exhaust the potentially useful Māori proverbs; different proverbs would naturally be required to promote discussions among the different Pacific audiences.)
 - *I hea koe i te tangihanga o te riroriro?* (Where were you at the time of the singing of the grey warbler?) This proverb is a reproach which implies that you're hungry now because you didn't prepare at the appropriate time. This can be used to encourage people to make preparations early to avoid negative consequences later. This idea has relevance in early diagnosis of renal failure, or in considering preemptive transplants to avoid further progression of renal failure.
 - *Tukua atu ki tua, ki nga ra o te waru.* (Put it aside for the days of the eighth month.) This proverb urges people to prepare now for the (predictable) times of scarcity. Again this proverb promotes an attitude of planning and preparation, but does so with a sense of predicting what is likely to happen rather than regret or remorse for a failure to prepare.
 - *Ehara i te ti e wana ake.* (It is not like the cabbage tree shoot.) This proverb teaches that death is final and irreversible. It conveys a potent warning since chronic renal failure is irreversible for most patients.
 - *Tena te ringa tango parahia.* (There is the hand that pulls up weeds.) This proverb reminds that careful preparation and vigilant weeding is what prevents the kumara plantation from becoming choked with weeds. Similarly, hard work and planning are needed if kidney failure is to be averted.

Appendix 1: Initial Contact Letter to Transplant Coordinators

Tēnā koe e te rangatira,

I am Sue Levett from Mauri Ora Associates; we have been commissioned by the Ministry of Health to assist with the Renal Service Improvement Project. Specifically we will be exploring potential causes for the disproportionately low renal transplant rates amongst Māori and Pacific people.

We have been asked to speak with both transplant Coordinators and cultural liaison advisors at the DHB's to gather data about patient and whānau interest and concerns regarding kidney donation by living relatives.

We would very much like to meet with you for approximately one hour to learn about your experiences. We will be in your area on ... June; would that date be convenient for you?

In addition, prior to meeting you, we would like to send a questionnaire to you, so that we can gain some background information ahead of time that will help us to make the most of our time together.

I would like to thank you in advance for your assistance with this important project.

If you have any questions please contact me either directly by telephone or by reply email.

Nāku noa, na

Appendix 2: Questionnaire for Renal Team Clinicians

Survey Form for Renal Team

(please note that the questions below deal specifically with the topic of live related kidney donation/transplants)

Name:..... Job Title:..... DHB.....

(Thank you for completing this questionnaire, your feedback will not be shared with others)

How often do you discuss transplantation (either being a donor or being a recipient) with patients?

Often Rarely Never

Comments (optional, but much appreciated): _____

How often do you discuss transplantation with Māori and Pacific patients?

Often Rarely Never

Comments: _____

How often do you involve cultural advisors (kaumatua, kaiatawhai, etc) in discussions about transplantation with Māori and Pacific patients?

Often Rarely Never

Comments: _____

I see differences in how Māori and Pacific people think about transplants compared to European/Pākehā.

Yes Unsure No

Comments: _____

I think Māori and Pacific people have the same level of willingness as European/Pākehā to accept transplants (i.e. to receive a donated organ).

Yes Unsure No

Comments: _____

I think Māori and Pacific people have the same level of willingness as European/Pākehā to provide transplants (i.e. to donate an organ).

Yes Unsure No

Comments: _____

I think Māori and Pacific people are less comfortable discussing transplants than European/Pākehā.

Yes Unsure No

Comments: _____

There are cultural prohibitions against transplantation in Māori and Pacific cultures.

Yes Unsure No

Comments: _____

I spend more time with my Māori and Pacific patients.

Yes Unsure No

Comments: _____

Survey Form for Renal Team (continued)

My Māori and Pacific patients have a poorer understanding of health issues.

Yes Unsure No

Comments: _____

It's harder for me to discuss health issues with my Māori and Pacific patients.

Yes Unsure No

Comments: _____

I see no differences in attitudes about transplantation among Māori and Pacific patients compared to European/Pākehā.

Yes Unsure No

Comments: _____

Māori and Pacific patients need a special approach when discussing transplantation.

Yes Unsure No

Comments: _____

Māori and Pacific people are generally uninterested in transplants.

Yes Unsure No

(If yes, why?

There should be a special advisor to discuss transplant issues with Māori and Pacific patients.

Yes Unsure No

Comments: _____

I'd like training on how to discuss transplantation issues with Māori and Pacific people.

Yes Unsure No

Comments: _____

I have a good understanding of Māori and Pacific culture, at least as it relates to their beliefs about health.

Yes Unsure No

Comments: _____

Māori and Pacific patients get equal outcomes from the health system with regards to transplants (ie there is no statistically significant difference).

Yes Unsure No

(if no, why not?

I have found no differences when discussing transplant issues with Māori and Pacific people and other groups.

Yes Unsure No

Comments: _____

Māori and Pacific people are generally too sick to receive a donated organ.

Yes Unsure No

Comments (optional, but much appreciated):

Survey Form for Renal Team (continued)

Māori and Pacific people are generally too sick to provide a donated organ.

Yes Unsure No

Comments: _____

We need to discuss transplant differently with Māori and Pacific people.

Yes Unsure No

(if yes, how?)

When I discuss transplantation with Māori and Pacific people the most important ideas for me to share are:

- 1.
- 2.
- 3.

When I discuss transplantation with Māori and Pacific people, I would find it really helpful if I knew more about:

- 1.
- 2.
- 3.

My Māori and Pacific patients usually respond to discussion about live transplants by:

- 1.
- 2.
- 3.

The best way to increase transplants among Māori and Pacific people would be to:

- 1.
- 2.
- 3.

Thank you very much for your assistance.

Please return this questionnaire to Mrs Sue Levett at:

sue@mauriora.co.nz

Post:

PO Box 33577

Takapuna

North Shore City 0740

Fax: 09 486 7150

Appendix 3: Questionnaire for Takawaenga & Social Workers

Survey Form for Cultural Advisors

*(please note that the questions below deal specifically with the topic of
live related kidney donation/transplants)*

How often do you discuss transplantation with Māori and Pacific people?

Often Rarely Never

Comments (optional, but much appreciated): _____

How often are you consulted by the clinical team to discuss transplantation with a patient/whānau?

Often Rarely Never

Comments: _____

How often are you consulted by a patient/whānau to discuss transplantation?

Often Rarely Never

Comments: _____

I would rate my understanding of live related kidney donation/transplantation as:

Excellent Average Poor

Comments: _____

How much training on the topic of transplantation (from a clinical, not a cultural, standpoint) have you received?

A great deal Some None

Comments: _____

The training on the topic of transplantation that I received from the clinical team was:

Extensive Adequate Inadequate

Comments: _____

I would find additional resources on the topic of transplantation

Wonderful Potentially useful Unnecessary

Comments: _____

I feel that patients' and whānau's understanding of transplantation is

Excellent Generally sufficient Inadequate

Comments: _____

I believe that the transplant team's ability to explain transplantation to Māori and Pacific patients and whānau is

Excellent Somewhat lacking Poor

Comments: _____

Survey Form for Cultural Advisors (continued)

I see differences in how Māori and Pacific think about transplants compared to Europeans.

Yes Unsure No

Comments: _____

I think Māori and Pacific people are less comfortable discussing transplants with their clinicians than Europeans are.

Yes Unsure No

Comments: _____

I think Māori and Pacific people are more comfortable discussing transplants with cultural liaisons than they are with their their clinicians.

Yes Unsure No

Comments: _____

There are cultural prohibitions against receiving a donated organ in Māori and Pacific cultures.

Yes Unsure No

Comments: _____

There are cultural prohibitions against donating an organ in Māori and Pacific cultures.

Yes Unsure No

Comments: _____

Māori and Pacific patients have a poorer understanding of health issues than Europeans.

Yes Unsure No

(If yes, why?

It's harder for doctors to discuss health issues with my Māori and Pacific patients.

Yes Unsure No

(If yes, why?

Māori and Pacific patients need a special approach when discussing transplantation.

Yes Unsure No

Comments: _____

There should be a special cultural advisor to discuss transplant issues with Māori and Pacific patients.

Yes Unsure No

Comments: _____

Māori and Pacific patients get equal outcomes from the health system with regards to transplants.

Yes Unsure No

(if no, why not?

Survey Form for Cultural Advisors (continued)

Māori and Pacific people are generally too sick to receive a donated organ.

Yes Unsure No

Comments: _____

Māori and Pacific people are generally too sick to provide a donated organ.

Yes Unsure No

Comments: _____

Māori and Pacific people are generally uninterested in transplants.

Yes Unsure No

(If yes, why?

We need to discuss transplant differently with Māori and Pacific people.

Yes Unsure No

(if yes, how?

When I discuss transplantation with Māori and Pacific people...

The best way to increase transplants among Māori and Pacific people would be to...

Common themes that are brought up by Māori and Pacific people about transplantation are:

Common messages that I give Māori and Pacific people about transplantation are:

I base my clinical understanding of the transplant process on:

I base my cultural understanding about transplantation on:

What would be very helpful to me in my work with patients/whānau about transplantation would be:

Thank you very much for your assistance!
Please return this questionnaire to
Ms Sue Levett at sue@mauriora.co.nz or
PO Box 33577,
Takapuna,
Auckland.

Appendix 4: Clinicians' Survey Responses

Clinicians' Survey Responses			
How often do you discuss transplantation (either being a donor or being a recipient) with patients?	Often 23	Rarely 3	Never 0
How often do you discuss transplantation with Māori and Pacific patients?	Often 19	Rarely 5	Never 1
How often do you involve cultural advisors (Kaumatua, etc) in discussions about transplantation with Māori and Pacific patients?	Often 0	Rarely 17	Never 9
I see differences in how Māori and Pacific think about transplants compared to Europeans.	Yes 14	No 4	Unsure 6
I think Māori and Pacific people have the same level of willingness as Pākehā to accept transplants (i.e. to receive a donated organ).	Yes 20	No 2	Unsure 3
I think Māori and Pacific people have the same level of willingness as Pākehā to provide transplants (i.e. to donate an organ).	Yes 10	No 8	Unsure 5
I think Māori and Pacific people are less comfortable discussing transplants than Europeans.	Yes 8	No 12	Unsure 6
There are cultural prohibitions against transplantation in Māori and Pacific cultures.	Yes 9	No 7	Unsure 6
I spend more time with my Māori and Pacific patients.	Yes 6	No 13	Unsure 5
My Māori and Pacific patients have a poorer understanding of health issues.	Yes 10	No 8	Unsure 5
It's harder for me to discuss health issues with my Māori and Pacific patients.	Yes 2	No 23	Unsure 2
I see no differences in attitudes about transplantation among Māori and Pacific patients compared to Europeans.	Yes 12	No 6	Unsure 6
Māori and Pacific patients need a special approach when discussing transplantation.	Yes 8	No 9	Unsure 5
Māori and Pacific people are generally uninterested in transplants.	Yes 0	No 24	Unsure 3
There should be a special advisor to discuss transplant issues with Māori and Pacific patients.	Yes 8	No 7	Unsure 11
I need (I'd like) training on how to discuss transplantation issues with Māori and Pacific people.	Yes 9	No 8	Unsure 9
Clinicians' Survey Responses (continued)			

I have a good understanding of Māori and Pacific culture, at least as it relates to their beliefs about health.	Yes 10	No 3	Unsure 11
Māori and Pacific patients get equal outcomes from the health system with regards to transplants.	Yes 16	No 4	Unsure 4
I have found no differences when discussing transplant issues with Māori and Pacific people and other groups.	Yes 6	No 11	Unsure 6
Māori and Pacific people are generally too sick to receive a donated organ.	Yes 5	No 12	Unsure 6
Māori and Pacific people are generally too sick to provide a donated organ.	Yes 4	No 12	Unsure 5
We need to discuss transplant differently with Māori and Pacific people.	Yes 8	No 8	Unsure 6

Appendix 5: Cultural Advisors' Survey Responses

Cultural Advisors' Survey Responses			
How often do you discuss transplantation with Māori and Pacific people?	Often 0	Rarely 5	Never 2
How often are you consulted by the clinical team to discuss transplantation with a patient/whānau?	Often 0	Rarely 5	Never 2
How often are you consulted by a patient/whānau to discuss transplantation?	Often 0	Rarely 4	Never 3
I would rate my understanding of live related kidney donation/transplantation as:	Excellent 0	Average 3	Poor 4
How much clinical training on the topic of transplantation have you received?	A Great Deal 0	Some 1	None 6
The training on the topic of transplantation that I received from the clinical team was:	Extensive 0	Adequate 1	Inadequate 4
I would find additional resources on the topic of transplantation	Wonderful 1	Potentially Useful 5	Unnecessary 1
I feel that patients' and whānau understanding of transplantation is	Excellent 0	Generally sufficient 1	Inadequate 3
I believe that the transplant team's ability to explain transplantation to Māori and Pacific patients and whānau is	Excellent 1	Somewhat Lacking 1	Poor 0
I see differences in how Māori and Pacific patients and whānau think about transplants compared to European/Pākehā patients and family	Yes 6	Unsure 1	No 0
I think Māori and Pacific people are less comfortable discussing transplants with their clinicians than European/Pākehā are.	Yes 3	Unsure 2	No 1
I think Māori and Pacific people are more comfortable discussing transplants with cultural liaisons than they are with their clinicians.	Yes 3	Unsure 3	No 0
There are cultural reasons against <u>receiving</u> a donated organ in Māori and Pacific cultures.	Yes 4	Unsure 3	No 0
There are cultural reasons against <u>donating</u> an organ in Māori and Pacific cultures.	Yes 4	Unsure 3	No 0
Māori and Pacific patients have a poorer understanding of health issues than European/Pākehā.	Yes 4	Unsure 0	No 1
It's harder for doctors to discuss health issues with Māori and Pacific patients.	Yes 1	Unsure 5	No 0

Cultural Advisors Survey Responses (continued)

Māori and Pacific patients need a special approach when discussing transplantation.	Yes 6	Unsure 1	No 0
There should be a special cultural advisor to discuss transplant issues with Māori and Pacific patients.	Yes 5	Unsure 1	No 0
I think that Māori and Pacific patients get equal outcomes from the health system with regards to transplants.	Yes 1	Unsure 4	No 1
I think that Māori and Pacific people are generally too sick to <u>receive</u> a donated organ.	Yes 0	Unsure 5	No 1
I think that Māori and Pacific people are generally too sick to <u>provide</u> a donated organ.	Yes 1	Unsure 4	No 2
I think that Māori and Pacific people are generally uninterested in transplants.	Yes 1	Unsure 2	No 3
I think that we need to discuss transplant differently with Māori and Pacific people.	Yes 4	Unsure 2	No 1