

# **Increasing Rates of Deceased Organ Donation**

**Submission to the Ministry of Health**

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## **Contact**

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### About the New Zealand Nurses Organisation

NZNO is the leading professional nursing association and union for nurses in Aotearoa New Zealand. NZNO represents over 47,000 nurses, midwives, students, kaimahi hauora and health workers on professional and employment related matters. NZNO is affiliated to the International Council of Nurses and the New Zealand Council of Trade Unions.

NZNO promotes and advocates for professional excellence in nursing by providing leadership, research and education to inspire and progress the profession of nursing. NZNO represents members on employment and industrial matters and negotiates collective employment agreements.

NZNO embraces te Tiriti o Waitangi and contributes to the improvement of the health status and outcomes of all peoples of Aotearoa New Zealand through influencing health, employment and social policy development enabling quality nursing care provision. NZNO's vision is *Freed to care, Proud to nurse.*

## EXECUTIVE SUMMARY

1. The New Zealand Nurses Organisation (NZNO) welcomes the opportunity to comment on the Ministry of Health *Increasing Rates of Deceased Organ Donation* discussion document.
2. NZNO has consulted its members and staff in the preparation of this submission, in particular members of regional councils, Te Rūnanga o Aotearoa and professional nursing and policy advisers.
3. As health professionals, we are aware that Aotearoa New Zealand has one of the lowest rates of deceased organ donation (67 per year) in the world<sup>i</sup>, and we strongly believe that public awareness campaigns will help to increase the number of organ donors (both live and deceased) and give hope to the 550 people who are currently on the waiting list<sup>ii</sup>.
4. Given the initial report (2016)<sup>iii</sup> to the Minister of Health clearly highlighted the organ donation situation in Aotearoa New Zealand, including the importance of cultural and ethnic considerations, it is extremely disappointing that a Ministry document lack of any reference to these essential factors.

5. We wish to raise our concerns with the following:
  - the right to good health;
  - lack of cultural and ethnic considerations;
  - disparities for Māori and Pasifika;
  - investment needed in cultural competencies for frontline staff;  
and
  - nurses' role in organ donation.
6. The document would also benefit from the inclusion of the wider aspects of transplantation system, such as matching and allocation mechanisms, retrieval, transport systems, transplantation itself or post-transplant care rather than to focus on deceased donation in isolation.

## DISCUSSION

### Right to good health

7. Article 1 of the United Nations Declaration on the rights of Indigenous people, acknowledges that Indigenous people have the right to the full enjoyment, as a collective or as individuals, of all human rights and fundamental freedom as recognised in the charter of the United Nations, the Universal Declaration of Human Rights and international human rights law<sup>iv</sup>.
8. We acknowledge that Māori have an equal right to the highest standards of health, and the State is responsible for ensuring this is achieved under article 24.2 of the United Nations Declaration on the Rights of Indigenous peoples<sup>v</sup>. We also acknowledge the rights under te Tiriti o Waitangi of Māori to good health that encompass wellness in its fullest sense and including the physical, spiritual and cultural wellbeing of Māori as individuals and collectively<sup>vi</sup>.

Lack of cultural and ethnic considerations

9. Current disparities in organ donation indicate that Māori and Pasifika people face the greatest burden of End Stage Renal Failure (ESRF), yet are least likely to receive a kidney transplant<sup>vii</sup>. It therefore is extremely disappointing that the document lacks any Aotearoa New Zealand context, and completely disregards cultural or ethnic considerations for organ donation recipients and donors.
10. The initial report (2016)<sup>viii</sup> to the Minister of Health clearly highlighted the organ donation situation in Aotearoa New Zealand, including the importance of cultural and ethnic considerations. It is unjust and unfair that these considerations are missing from the discussion document.
11. We agree that lower consent rates amongst Māori and Pacific people might occur for a variety of reasons including;
  - cultural views and beliefs - some may still hold traditional cultural beliefs that are incompatible with organ donation. For example, a belief that not to bury a body whole, or to have parts living on outside the body, would be disrespectful and have ramifications for the ancestral line<sup>ix</sup>;
  - cultural competence of clinical staff - this affects clinicians' ability to discuss organ donation in a way that is meaningful and culturally appropriate for Māori and Pacific families, which in turn may affect the response of those families;
  - lack of prior awareness of organ donation - members of the Expert Advisory Group (EAG) reported their experience that Pacific and Māori often first hear of organ donation in the Intensive Care Unit (ICU) and are completely unaware of what it does, what happens to the body, who can donate, and what difference donation can make to the people who receive the organs; and
  - mistrust of the medical system based on previous experience<sup>x</sup>.

12. Further research is also required to capture the diversity of Māori and Pasifika views on organ donation, and to explore the media misconception that presumes that all Māori have the same values for organ donation, which has never been the case<sup>xi</sup>.

#### Disparities for Māori and Pasifika

13. It is unacceptable that Māori and Pasifika people are over represented in the dialysis population and are less likely to receive a kidney transplant<sup>xii</sup>. There are barriers to finding healthy donors within their own whānau networks<sup>xiii</sup> due, in part, to the high rates of obesity and diabetes.
14. This is partly due to the transplantation BMI criteria which do not take into consideration Māori and Pasifika body shapes and sizes. Questions should be asked as to whether the BMI thresholds create an unfair disadvantage for populations that are “naturally bigger”<sup>xiv</sup>.
15. While some transplant units have increased the BMI thresholds, we recommend that further work is undertaken to review the disparities in organ donation and access to transplants for Māori and Pasifika people.
16. Recent Ministry of Health (2009) research identified other barriers to transplantation and donation for Māori and Pasifika populations including:
  - a lack of suitable educational resources that are culturally appropriate;
  - a lack of cultural competence, health literacy and advisory skills within transplant teams;
  - a lack of focus by pre-dialysis educators and renal physicians on transplantation as a first option before starting dialysis;
  - inconsistent care and referral from primary care providers; and
  - poor staffing in terms of in-house transplant coordinators<sup>xv</sup>.

17. NZNO recommends that an equity lens assessment be undertaken to assess any disparities based on culture and ethnic considerations that are missing from the current organ donation policies and processes.

Investment needed in Cultural competency training

18. Training in cultural safety should be mandatory for all frontline staff across all health professions in particular; clinicians, nurses, retrieval staff, and any other staff who have interaction with organ donors, recipients and their families in particular; Māori whānau and Pasifika families.
19. We agree that to ensure donation conversations are conducted in a culturally appropriate manner, it would be essential to involve District Health Board (DHB) cultural advisors in these conversations and provide up to date information on the needs for, benefits, and process of organ donation and transplantation.
20. Regulatory bodies such as the Nursing Council of New Zealand have included cultural safety into nursing scopes of practice which require the nurse to practise nursing in a manner that the health consumer determines as being culturally safe, and to demonstrate the ability to apply the principles of te Tiriti o Waitangi to nursing practice.
21. While most nursing students are educated on inclusive models of health and wellbeing such as Mason Durie's Te Whare Tapa Whā (Ministry of Health, 2009) that takes a holistic approaches to one's health and wellbeing based on four corner stones of a whare. It is essential that overseas registered health professionals are required to complete any bicultural training before working with Māori.
22. Our impression is that the cultural ignorance in Aotearoa New Zealand is widespread and largely unintentional, as it is a legacy of colonial education and governance systems which have precluded giving effect to the bicultural promise of te Tiriti. To embed these competencies properly and remove the structural discrimination which compromises

health equity, will require more exposure and access to Māori cultural competency information and positive public media campaigns.

#### Nurses role in organ donation

23. NZNO wish to take the opportunity to strongly advocate for the benefits of the role of nurses in any discussions with prospective donors, their whānau, and families which is currently missing from the document.
24. As with any proposed changes and increased public awareness, there is a potential for a dramatic increase in the number of deceased and live donor transplants, which will require a skilled and specialist workforce to care for the donor and recipient. We believe that specialist nurse led clinics could easily be used to manage and coordinate the donor 'work up' transplants assessment process and be well placed to facilitate any organ donation discussions with whānau.
25. In promoting organ donation for the public, nurses would be well placed to explain the transplant process, the roles of prospective donors in relation to organ/tissue retrieval, reasons why donor is kept on life support, and the process for handing back the Tūpāpaku to the family and whānau.
26. Members are supportive of any improvements that enhance public awareness about organ and tissue donation, and to the improvement of the coordination, resourcing and funding of the Organ Donation governance board to undertake this important work.
27. Members support increasing training and education to support clinical staff with skills and confidence in approaching family about a person's prospective donation, and to assistance for DHBs with costs associated with sustaining life support and retrieval. Members also support expanding education and training for Emergency Department and establishing protocols for transfer/admission to ICU of likely donors pending the outcome of consent processes.

## CONCLUSION

In conclusion, NZNO agrees that the lack of organ donation in Aotearoa New Zealand is serious, but we are not confident that this document will address the shortfall. We recommend that you:

- note **our serious concerns** with the lack of consideration of cultural and ethnic factors impacting on organ donation;
- **agree to the mandatory requirement** for cultural safety training for all frontline organ donation staff working;
- **agree** that an **equity lens assessment** is undertaken and applied to the strategy;
- **agree** to review the BMI criteria for transplantation for Māori and Pasifika people;
- **agree** that further research is necessary to capture the diversity of Māori and Pasifika views on donation; and
- **note our advocacy** for the role of nurses in organ donation processes.

Nāku noa, nā



Leanne Manson  
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