

# **Increasing Rates of Deceased Organ Donation**

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Consultation document

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MANATŪ HAUORA



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# Purpose of this document

The Ministry of Health (the Ministry) is developing a strategy to increase the number of organ donations (and ultimately transplantations) from deceased people in New Zealand.

The proposed strategy is based on the findings of an initial review of national donation and transplantation rates (see *Review of Deceased Organ Donation and Transplantation*, which can be found on the same Ministry webpage as this consultation document).

This consultation document outlines the main result of that review and the proposed options for increasing donation rates in New Zealand. We are seeking feedback on those options to help ensure we achieve a workable strategy.

In addition to this consultation, the Ministry will be engaging directly with interested stakeholders for more detailed discussion on some of the options.

The initial review focused on options to increase rates of deceased person organ donation. An increase in donation rates will require transplant services to have the capacity to accommodate the increase. The Ministry is working with district health boards (DHBs) to ensure that capacity can continue to meet demand.

The full list of recommendations from the initial review is included as Appendix One.

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# Background to the initial review

The Ministry completed a review of deceased person organ donation and transplantation (the review) between September 2015 and March 2016. There is a significant body of international experience and knowledge on how to increase rates of organ donation from deceased people. In its review, the Ministry studied major taskforce reports, analysed international programmes on improving donation processes and consulted with colleagues from Australia.

The Ministry also established an expert advisory group to provide local expert advice, including advice on behaviour change; ethics; and clinical, management and cultural perspectives, and to contextualise the international lessons to the New Zealand environment.

In addition, the Ministry commissioned an independent report from consultancy firm Ernst and Young (EY), which looked at current practices in clinical settings and institutional arrangements in New Zealand.

## Limitation of the review

The review focused on measures to increase organ donations from deceased donors. It did not consider other aspects of the wider transplantation system, such as matching and allocation mechanisms, retrieval and transport systems, the transplantation process itself or post-transplant care.

It has also not considered donations by living donors as this has been the subject of recent government investment, with a number of initiatives already under way.

The review was undertaken in a relatively short timeframe, with limited opportunity for engagement with stakeholders.

# Overview of organ donation and transplantation

Organ transplantation is a life-saving treatment and is often the best, or only, option available for people with organ failure. A transplant can take a person from a situation where they have a greatly reduced quality of life and a relatively short life expectancy to a near-normal quality of life and significantly improved life expectancy.

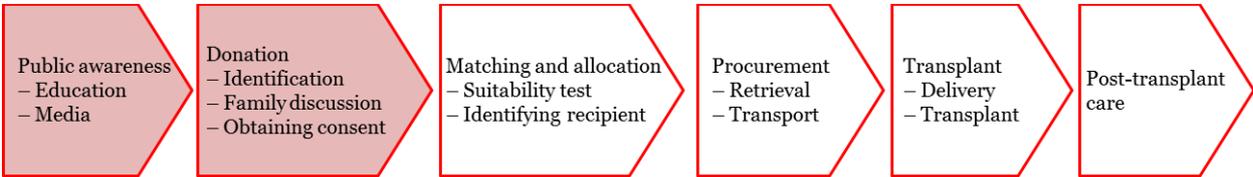
Demand for transplants, particularly kidneys, continues to rise worldwide. The key factor limiting the number of transplants is the number of organs available for transplant. Donated organs can come from both deceased and living donors (in the case of kidneys and livers). One deceased donor can offer up to seven organs and potentially save seven lives.

New Zealand’s rate of deceased person organ donation has been low relative to rates in other countries over a number of years. While it is unclear if this will continue, other countries have achieved significant improvements after introducing strategies to increase their own organ donation rates.

## The organ donation and transplant process

The organ donation and transplant process incorporates a number of components, as outlined in Figure 1. These include public awareness about the benefits of donation and transplantation; processes within intensive care units (ICUs) to identify potential donors and seek and obtain family consent; systems to match and allocate organs to potential recipients; procurement logistics for retrieving organs and transporting them to suitable transplant services; the transplant surgery itself and post-transplant care for the recipient.

**Figure 1: Steps in the donation and transplant process**



The Ministry’s initial review has focused on the first two steps in the donation process.

## Who can donate organs?

Only a small number of people (less than 1 percent) will die in circumstances that make it possible for organs to be donated for transplantation. In general, potential deceased donors are people who have suffered a fatal illness or injury that has led to severe and irreversible brain damage and have been mechanically ventilated during their treatment in an ICU. The two main circumstances where deceased person organ donation is possible are:

1. **Donation after brain death (DBD):** brain death occurs when there is irreversible and complete loss of vital brain functions and a ventilator is all that keeps the bodily organs alive.
2. **Donation after circulatory death (DCD)** (otherwise referred to as cardiac death): some people with non-survivable injuries to the brain never become brain dead because they retain some brain-stem function. DCD might be an option when it is clear that the individual cannot survive. DCD is uncommon in New Zealand, although it has been a major component in increasing donation rates overseas.

## The donation process

### 1. Obtaining consent to donate

Organs may not be retrieved for transplantation without proper informed consent to do so. It is not feasible for legally binding consent to be given by the donor before their death. Driver licence donor information does not constitute consent to donate. Because driver licence organ donation information is a simple yes or no, it is not possible to verify that the person was properly informed and fully understood the decision they were making, which are the basic requirements for confirming that consent was given properly.

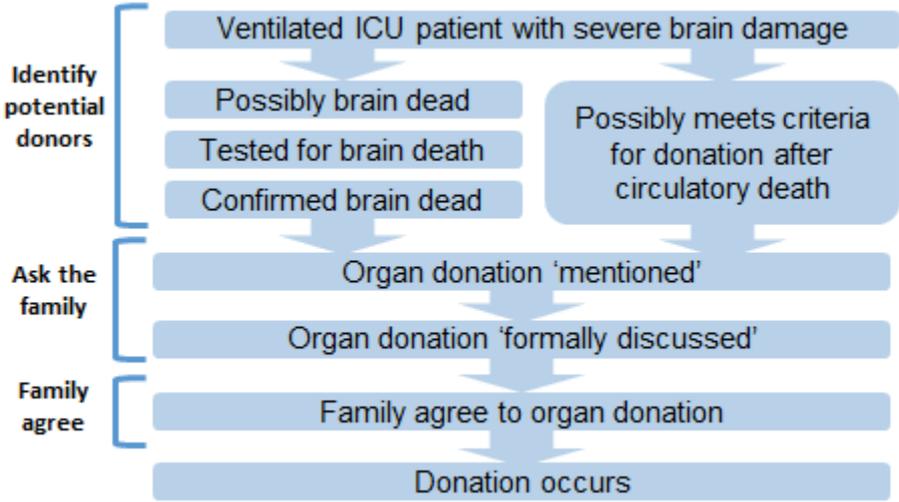
The decision to donate therefore falls to the donor's family. If the family does not agree to donation, it will not proceed. This is common practice around the world, regardless of any formal consent framework.

Once a person is identified as a potential organ donor, ICU staff will approach their family to seek their consent to donation. This can be a difficult conversation to have, and ICU staff usually receive specific training in how to handle such conversations.

Figure 2 sets out the main steps in the donation process. The order of the steps can vary slightly, depending on circumstances, but, in general, the steps follow this order.

- Potential donors are identified.
- Their families are approached about donating the donor's organs.
- The families give consent (or not) to organ donation.

**Figure 2: Deceased organ donation stages**



**2. Matching suitable donors and recipients**

Once the family of a deceased donor has agreed to donate the deceased person’s organs, the donor’s blood type is identified. Organ Donation New Zealand, the donor coordination agency, then checks waiting lists to find a suitable match and contacts the relevant transplant service.

**3. Completing the transplant**

If the transplant service has a suitable match, a specialist team is sent to retrieve the organs for transplant.

Once the transplant has taken place, the recipient receives follow-up care, such as anti-rejection drugs, from their local health services. Organ Donation New Zealand keeps in touch with recipients of organs and donor families and can pass messages between them, though donors and recipients remain anonymous.

# Potential to increase deceased organ donation rates

The Ministry’s review shows that there is potential to increase New Zealand’s rates of deceased person organ donation. It is not possible to give a firm figure for the potential increase, but other countries that have undertaken similar programmes have significantly increased their deceased person organ donation rates.

The main opportunities to increase donation rates are through:

- improving practices in clinical settings (particularly ICUs and emergency departments, EDs) and providing specialist training for clinical staff so that all potential donors are identified and their families are approached to determine if they are willing to donate a family member’s organs
- supporting more effective conversations with families about donating a family member’s organs through wider measures used to raise public awareness of the potential to donate organs and the benefits of transplantation
- expanding the types of donations considered, for example, DCD.

# Key elements of successful international organ donation programmes

Many other countries have successfully increased their deceased person organ donation rates. Their programmes to improve donation rates have eight core components:

1. An appropriate legal and ethical framework.
2. A national coordinating body to lead the change.
3. A clinical governance framework of the donation process that supports quality assurance and audits of hospital clinical practices.
4. Hospital-based clinical organ donation specialists.
5. Specialist training for clinical staff in managing the deceased person organ donation process and family donation conversations.
6. Financial support for donor and transplant hospitals to ensure that costs related to donor management are not a barrier to donation.
7. Public awareness and understanding and media engagement.
8. International cooperation to share best practices.

Key to successfully improving organ donation rates is the ability to develop a sustainable, clinically credible strategy that has a strong mandate and leadership and good support from central government.

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# A strategy to increase deceased organ donation

New Zealand has never had a comprehensive national strategy for increasing rates of organ donation from deceased people. Various initiatives have been introduced to improve specific aspects of the donation system. However, these have tended to be piecemeal and have not been sufficient to bring about a significant and sustained change.

Many of the elements of the eight core components of successful international organ donation programmes are already in place in New Zealand's organ donation system, and the initial review supported building on these existing initiatives.

However, the current approach lacks:

- an explicitly defined national strategy and commitment to increasing rates of organ donation from deceased people that is owned and driven throughout the health system and that assigns clearly defined national, regional and local roles and responsibilities for achieving specific actions
- a national coordinating body with a clear mandate to increase rates of deceased people's organ donation and transplantation
- a systematic and effective approach to improving public awareness and understanding of organ donation and the benefits of transplantation, including an effective donor registration mechanism.

Any national strategy should also include a way of tracking progress, and it must be tailored to the New Zealand environment, including the particular features of our health system and our multicultural populations.

The strategy to increase rates of organ donation from deceased people will complement initiatives already underway to increase the numbers of donations of kidneys from living donors and would align with directions outlined in the New Zealand Health Strategy 2016. In particular, it would form part of an overall response to chronic health conditions, a range of which underpin many instances of organ failure. It would also have significant potential to save lives and reduce health system (and potentially welfare) costs.

## **Proposal**

The Ministry of Health should develop and monitor a national, comprehensive and clinically credible strategy for increasing rates of deceased person organ donation and transplantation, which includes:

- a world-class donation and transplantation system in New Zealand, supported by an aspirational goal such as, 20 deceased donors per million population by 2025, or a donation rate in the top 20 percent of countries
- mandated national, regional and local roles and responsibilities to strengthen leadership, visibility and accountability for organ donation
- initial priority action areas: the national coordinating body, practices in clinical settings and public awareness including registers
- actions that are appropriate for different population groups.

## **Question for consultation**

Are these the right high-level elements of an effective organ donation strategy?

### **Other issues for consideration**

- Is an aspirational goal or vision appropriate?
- If so, what should the goal be?

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# An appropriate legal and ethical framework

## Legal framework

A credible and robust organ donation and transplantation system must be supported by a suitable legal and ethical framework.

In New Zealand, organ donation is governed by the Human Tissue Act 2008 (the Act). The Act requires informed consent for all organ donations and sets out rules around who may give consent and under what circumstances. In brief, informed consent must be given to a particular use of human tissue by a person authorised to do so. Authorised people are: the individual concerned if they are able, their nominee if they are unable or their family if the first two options are not possible.

While the Act allows people to give consent before their death, in practice, it has not been possible to determine whether the person has received sufficient information to give informed consent. Consent is therefore given by the family of the deceased. This is often thought to be a barrier to donation, allowing families to override the wishes of the deceased. However, in practice, families generally follow the deceased's wishes if they know what those wishes are.

There are various models of legal consent applied around the world. The 'presumed consent' model assumes that a person has given their consent unless they are known to have objected. The 'binding register' allows a person to give their consent and binds decision-makers to that consent after the person's death.

However, despite the various legal models, the practice around the world is for families to be asked about organ donation and for the donation to be cancelled if they object.

The presumed consent model is not possible in New Zealand under the current law, and it is doubtful that a binding register of consent is feasible. In the past, where a binding register has been proposed in New Zealand, clinicians have strongly objected to taking donor organs against a family's wishes. It is unlikely that a law change will be effective in increasing donation rates.

## Proposal

We do not consider amendments to the Human Tissue Act 2008 to be a priority at this time.

## Question for consultation

Are there aspects of the current law relating to organ donation and transplantation that you think should be reconsidered?

# Ethical framework

Organ donation involves complex ethical, social and cultural issues. In the absence of robust and readily available ethical guidance, clinicians may be reluctant to undertake new practices, limiting possible increases in donation rates. The Ministry's review found that some clinicians were uncertain about the ethical implications of some new practices, such as DCD.

Consistent ethical guidance is required to help ensure consistency in practices in clinical settings. There are various ways of providing such guidance. The United Kingdom has established a stand-alone ethics committee that deals specifically with organ donation issues. In Australia, the Organ and Tissue Authority of the Australian Government funds the development of ethical guidelines through other bodies, such as The Transplantation Society of Australia and New Zealand.

In New Zealand, the National Ethics Advisory Committee (NEAC) is an independent advisor to the Minister of Health on ethical issues relating to health and disability research and services across the health sector.

Public input is also very important in considering ethical issues, and it is vital that the public have confidence in all organ donation and transplantation practices.

## Proposal

The Ministry of Health should establish a consistent mechanism whereby health professionals around New Zealand can obtain independent assurance that new practices and processes are ethically acceptable.

## Question for consultation

How could consistent ethical guidance on organ donation and transplantation be obtained?

## Other issues for consideration

- Do you have a view on an appropriate source of ethical guidance? For example:
  - a specific stand-alone organ donation and transplant ethics committee (as per the United Kingdom)
  - The Transplantation Society of Australia and New Zealand
  - the National Ethics Advisory Committee?
- Is there another appropriate option?
- What is the best way of obtaining public input on ethical issues?

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# A national coordinating body

A national coordinating body for organ donation, with a clear mandate to encourage improvements in performance is a key element of successful organ donation and transplantation systems.

The scope and form of coordinating bodies varies internationally, with the key common element being an explicit mandate to increase the rate of organ donation. In the United Kingdom, NHS Blood and Transplant is a statutory authority that manages the entire national donation and transplantation system, from promotion to follow up with transplant recipients. In Australia, the Organ and Tissue Authority was established by legislation and, likewise, has general responsibilities across the entire national donation and transplantation system.

In New Zealand, the national coordination body for organ donation is Organ Donation New Zealand (ODNZ). It is a business unit of Auckland DHB. Auckland DHB receives funding to provide national organ donation services, including national coordination, with a small amount of additional funding for additional initiatives, such as the extended link-nurse roles.

ODNZ provides an excellent donor coordination and logistics service and a good advisory service to ICUs. However, it does not have a clear focus on increasing donation rates, and stakeholders have expressed doubts about its capability to lead a national reform agenda. Stakeholders have also raised concerns about the governance of the organisation, including its location within Auckland DHB, and have questioned the performance monitoring by Auckland DHB and the Ministry.

The independent review by EY suggested that all current ODNZ activities should be retained but that the form and function of ODNZ should be revisited, including:

- reconsidering its location within Auckland DHB
- strengthening its governance arrangements
- making a key objective be to increase the rate of organ donation from deceased people, with the mandate to lead and implement change in the organ donation system
- considering the inclusion of tissue donation roles and responsibilities within its mandate
- maintaining clear professional accountability of ODNZ clinical staff with an appropriate senior clinical lead.

There are several alternative locations for a national coordinating body. For example, it could be a stand-alone entity (such as in Australia) or located within the Ministry (as in Spain). The report by EY noted that, regardless of its eventual location, ongoing oversight by the Ministry as steward and funder would be necessary to ensure national expectations were met.

In future, it might be appropriate to extend the scope of activity to other aspects of the donation and transplantation system. This could include donation from living people (beyond the current role in the Paired Kidney Exchange Scheme) or increasing its role in organ allocation or transplantation guidance.

The costs of additional actions to be undertaken by the national coordinating body to increase organ donation rates (including funding for DHBs to manage potential donors) will be considered as part of the national strategy.

## Proposals

Clarify and extend the role and purpose of the national coordinating body for organ donation so that it is clearly mandated and funded to increase national rates of organ donation from deceased people and organ transplantation. This includes:

- leading the implementation of the strategy to increase rates of organ donation from deceased people and transplantation
- championing organ donation in the health sector and the community
- supporting an effective clinical governance framework across all DHBs
- implementing effective public awareness activities to build awareness and understanding of organ donation and transplantation benefits
- offering a range of fit-for-purpose clinical staff training.

Determine the right form and location for the national coordinating body.

The Ministry of Health must provide ongoing oversight and stewardship to ensure national expectations are fulfilled.

## Question for consultation

Are the listed functions for the national coordinating body correct and appropriate?

### Other issues for consideration

- What is the appropriate location for the national coordinating body:
  - within a DHB
  - within the Ministry
  - within another agency
  - a stand-alone Crown agency
  - somewhere else?
- Are there other roles within the organ donation and transplantation system that the national coordinating body should undertake?

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# A clinical governance framework

To support increases in organ donation and transplantation, successful countries have worked to ensure their clinical staff are supported by a structured clinical governance framework. Such a framework articulates the objectives, actions, results and measures required for an effective organ donation system. It aims to promote consistent best practice across the entire health sector.

In New Zealand, there is limited coordinated quality improvement activity. There is no clear national governance structure. In some ICUs, organ donation is a strong focus, but this is due to individual leadership, and the quality varies across the country.

## Death audit

An audit of deaths provides critical data for understanding current health service practices and areas for improvement. It identifies any missed donation opportunities and provides quality assurance feedback on organ donations to transplant services. New Zealand has such a death audit, managed by Organ Donation New Zealand. Information about all deaths in ICU is recorded to identify whether there were opportunities for organ donation, and if so, whether any action was taken.

It is not clear that the information in the audit is consistent, and reporting is often infrequent, with ICUs receiving feedback months or even years after donation opportunities have been missed. The data is anonymised, meaning that clinicians are unable to identify high-performing peers to learn from.

A key goal will be to improve the quality of performance information available and to use it more effectively to learn and improve practices. The EY report and advice from the Ministry's expert advisory group suggested a number of improvements that could be made to the death audit. In particular, they recommended: sharing the audit with clinical staff in a non-anonymised format, including ED deaths in the audit and reporting more frequently.

## Quality improvement and governance structures

Aside from the intermittent feedback on the death audit, there is limited performance management and coordinated system improvement activity. There are no clear structures in place to foster leadership on organ donation and promote quality improvement in organ donation practices. The lack of a clear focus on improving donation rates at national, regional or district levels means the responsibility for leading improvements in organ donation practices is largely left to the discretion and motivation of individual ICUs.

The national coordinating body should be responsible for strengthening the clinical governance of organ donation from deceased people. It should set clear expectations and accountabilities for clinical governance of organ donation that will flow through to the existing wider governance frameworks within DHBs to improve focus and accountability.

## Links between ICU and ED

Patients may arrive in emergency departments (EDs) with very little chance of recovery but with a high potential as organ donors. If the families consent to organ donation, these patients should be transferred to the ICUs promptly to receive the treatment required to keep their organs functioning to facilitate successful donation.

Internationally, EDs are an important source of organ donors. Countries with higher rates of organ donation have focused on ensuring that potential donors in ED are identified early and that there are clear referral pathways for potential donors to be admitted to ICU quickly.

In New Zealand, EDs have to negotiate with ICUs on a case-by-case basis for admission of potential organ donors to the ICU. This can be difficult and leads to inconsistent practices. Some stakeholders have reported a reluctance among some intensivists to admit patients from the ED solely for the purpose of organ donation.

While referral pathways from ED to ICU to support organ donation do exist in New Zealand, the uptake of them has been inconsistent.

## Proposals

The national coordinating body should work with DHBs to establish an appropriate clinical governance framework for organ donation from deceased people. Such a framework would:

- record all critical care deaths (in EDs as well as ICUs) in the death audit
- make organ donation a standing item at ICU daily meetings and/or in mortality and morbidity meetings
- establish appropriate roles and responsibilities in each DHB – donation specialists in ICUs, EDs, Chief Medical Officers, Hospital Advisory Committees
- improve the quality of information in the death audit and use it more effectively to learn and improve practices
- strengthen the relationship between EDs and ICUs
- use referral pathways and triggers from ED to ICU to support organ donation.

Reconfigure Organ Donation New Zealand's advisory committee to play a stronger role in clinical governance for the national coordinating body by, for example, establishing a clinical governance subcommittee or establishing an equivalent body to the Australian Organ and Tissue Authority's clinical governance committee.

Encourage the use of regional clinical networks (such as trauma networks).

# Question for consultation

What role should the national coordinating body have in the clinical governance of organ donation and transplantation?

## Other issues for consideration

- What would be the core components of a clinical governance framework for organ donation?
- How should a clinical governance framework be implemented?
- How could a clinical governance framework for organ donation fit into existing clinical governance systems?
- How could the death audit be improved?
- What information from the death audit should be publicly available?
- Should emergency departments be involved in organ donation?
- If so, what would be required to support emergency departments to have a greater role in organ donation?

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# Hospital-based clinical organ donation specialists

Most countries with substantially higher organ donation rates from deceased people than New Zealand have dedicated and funded specialist medical and nursing roles to manage the donation process. These specialists also act as champions and provide explicit leadership for organ donation at the local level.

New Zealand DHBs have link teams (consisting of an ICU doctor and nurse and a theatre nurse) who coordinate organ donation for their hospital. Such roles are generally not funded and come as an extra responsibility for clinical staff. Currently, four ICUs have extended link nurse roles, which are funded at a fraction of a full-time-equivalent (FTE) role, allowing dedicated time for organ donation work. Wellington ICU, for example, has used the additional funding available for extended link roles to establish a team of nurses and an intensivist with time allocated specifically to supporting organ donation and providing local leadership. Since establishing the extended link roles, Wellington's deceased person organ donation rate has increased from around four to six donations a year to 10 in 2014 and 12 in 2015.

Extended link roles could be rolled out to more ICUs around the country. Initially the focus would be on those ICUs with the greatest number of potential donors, but wider funding could be considered in the future.

## Proposals

Partially fund intensivist and nursing roles in the eight DHBs with the greatest opportunity to increase donation numbers (0.1 FTE intensivist and 0.4 FTE nursing) to champion donation and lead the implementation of the clinical governance framework in each DHB.

Maintain existing LINK teams in the remaining 12 ICUs.

Appoint appropriate hospital organ donation champions outside the ICU.

Expand funding for organ donation specialists to more ICUs.

Larger ICUs or the national coordinating body could provide organ donation support to smaller ICUs (potentially contributing specialist staff).

# Question for consultation

Does the proposal for hospital-based clinical organ donation specialists have the right elements?

## Other issues for consideration

- What is required to support clinical leadership on organ donation within ICUs?
- Do you agree that funding dedicated time for intensive care doctors and nurses would be useful to increase organ donation rates?
- Should those roles be responsible for leading implementation of the clinical governance framework for organ donation in their DHBs?
- What other roles within the broader DHB could champion organ donation?

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# Specialist training for clinical staff

Specialist training for clinical staff is a critical component of any programme aimed at increasing donation rates. It is vital that intensivists, and other clinicians involved in organ donation, have the skill to identify organ donation opportunities and discuss them appropriately and supportively with families.

Other countries have invested significant resources in training for clinical staff. In New Zealand, a training course is provided by Organ Donation New Zealand. The course is open to a wide range of clinicians.

Training in organ donation conversations is required for trainees of the College of Intensive Care Medicine of Australia and New Zealand. However, it is not required for existing fellows, or other specialists.

The Australian Organ and Tissue Authority offers a range of courses for different levels of need that could be made more widely available in New Zealand. These include: introductory donation awareness training, core family donation conversation, practical donation conversation, advanced family donation conversation and e-learning modules. In 2015, their course in family donation conversations was offered in New Zealand.

## Proposals

Work with the Australian Organ and Tissue Authority to make a wider range of courses available in New Zealand, such as, introductory donation awareness training; core family donation conversation; practical donation conversation; advanced family donation conversation and e-learning modules.

Ask professional colleges to promote specialist training to existing fellows as well as trainees in intensive care medicine, emergency medicine and anaesthesiology.

## Question for consultation

Does the proposal for specialist training adequately address clinical staff training needs in New Zealand?

## Other issues for consideration

- Is there further specialist training for clinical staff that would be useful, such as training in cultural competency?
- How could we increase the uptake of training, including by emergency medicine specialists and anaesthetists?

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# Financial support for donor and transplant hospitals

Organ donation from a deceased person is a relatively rare and unpredictable event that is difficult to plan for. The EY review found that ICUs often saw dealing with a potential organ donor as extra work rather than core business.

Internationally, strategies to increase organ donation from deceased people often include some form of financial support to donor hospitals. This ensures that the costs related to managing organ donation are not a barrier to donation. Reimbursing costs is not seen as an incentive or payment for organs.

Between 1998 and 2014, New Zealand hospitals were able to claim \$6,500 as reimbursement for the costs of managing a deceased donor. Initially, the fund was oversubscribed, but over time, hospitals claimed less often and, from 2006, the fund was undersubscribed and eventually reallocated.

## Transplant capacity

The immediate focus of this review has been on finding options to increase rates of organ donation from deceased people. However, successfully increasing donation rates will increase the needs of ICU, surgical and ED resourcing for both donations and transplants.

For every extra deceased donor, we should expect around three transplant operations. The extent to which transplant capacity needs to grow will require detailed modelling to inform funding decisions.

## Proposals

Remove the financial barrier to conducting donations by reviewing funding arrangements for organ donation, including:

- reimbursing the additional costs incurred in the donation process to the donating hospital
- instigating a national funding model.

Ensure the national strategy includes measures to address transplant capacity issues.

# Question for consultation

Are there additional funding arrangements that should be considered in organ donation and transplant events?

## Other issues for consideration

- How could the additional costs associated with managing organ donations from deceased people be quantified?
- How well did previous funding arrangements work?
- How can we make sure transplant services continue to have the capacity to transplant donated organs without putting pressure on other services?

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# Public awareness, media engagement and registers

## Public awareness and media engagement

International organ donation and transplantation strategies typically include a focus on improving public awareness and understanding about organ donation and the benefits of transplants. Countries that have successfully increased organ donation rates have made public awareness and/or media engagement a core responsibility of the national coordinating body.

Public awareness campaigns, on their own, do not affect donation rates directly but can be part of a suite of measures to increase rates. People's understanding of organ donation and transplantation is positively correlated with their willingness to donate.

One of the most important ways of improving public awareness is to encourage conversations with families. Family consent rates are significantly higher when families are aware of their family member's wishes.

Information from the DonateLife audit (an audit by the Australian Organ and Tissue Authority of hospital deaths with regard to potential and actual organ donation from deceased people) shows:

- 77 percent of families who are aware of the potential donor's decision on donation consent to donation, regardless of whether the donor has registered on the Australian Organ Donor Register or not
- 46 percent of families who are **not** aware of the potential donor's decision on donation consent to donation.

The media are a major source of information about organ donation and transplantation and can influence attitudes to donation. Successful programmes to improve organ donation rates often include a specific strategy to engage with the media to provide accurate and balanced information on the subject. Spain, the country with the highest organ donation rate from deceased people, focuses on media engagement rather than general public awareness efforts.

## Donor registers

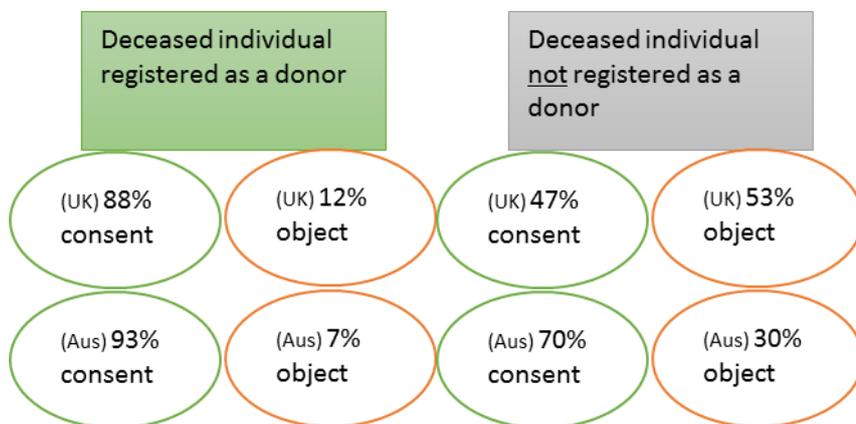
Many countries use organ donor registers. Such registers are often a key focus of public debate. The debate usually centres on how registers can be used to gain consent for organ donation after death. Discussions also often include the benefits of different types of registers and consent systems and whether families should be allowed to override an individual's wishes.

Currently, all countries, regardless of the legal framework or type of register in place, seek the family's consent to proceed with a donation. International experience therefore suggests that the real value of a donor register is as a mechanism to:

- provide a focal point for raising awareness
- enable people to record their donation wishes and discuss those wishes with their families
- indicate someone's donation wishes when they can no longer do so themselves.

Evidence from the United Kingdom and Australia, where such registers are in place shows that family consent rates are much higher when a person is registered as a donor. In the United Kingdom, research found that 88 percent of families consent to donation of a deceased family member’s organs when that person is registered as a donor, while only 47 percent consent when their family member is not registered.<sup>1</sup> In Australia, 93 percent of families consent when a family member is registered, against 70 percent when they are not.<sup>2</sup>

**Figure 3: Family consent rates when deceased family members are registered/not registered as organ donors**



While registers are an effective way of indicating someone’s wish to be a donor, registration rates are often low. In Australia, for example 69 percent of the population are willing to donate but only 32 percent are registered on a donation register. This indicates that even with an organ register available, it is important to include other strategies that encourage family members to discuss their organ donation wishes with their families.

## Types of donor register

There are various donor registers used around the world. Despite this variation, and the associated consent rules, actual practice is the same around the world. When a donation opportunity arises, the potential donor’s family is approached, and donation does not proceed if they object.

Some of the more common registers include:

- **Opt-on/opt-off/combined**

Registers can list people who wish to donate, people who do not wish to, or both.

A register may require people to expressly agree to being registered as donors, with people not listed if they do not make a decision. Alternatively, registration may be automatic, with people being registered as donors unless they explicitly remove themselves from the register – sometimes called ‘presumed consent’.

<sup>1</sup> Hopkinson C. 2015. *Potential Donor Audit Summary Report for the 12 month Period 1 April 2014 to 31 March 2015*. Bristol: National Health Service Blood and Transplant. Available at [www.odt.nhs.uk/odt/potential-donor-audit/](http://www.odt.nhs.uk/odt/potential-donor-audit/)

<sup>2</sup> Stephens HO, Pilcher DV, Opdam HI. 2013. Letter: The impact of checking the Australian Organ Donor Register on family consent rates. *MJA: The Medical Journal of Australia* 199(8): 536–38.

- **Binding/non-binding**

A register may be binding, meaning that the person registering has made the primary decision and that cannot normally be overruled. A non-binding register means that the person's family will be informed of their wishes, but donation will not proceed if the family objects.

- **Consent/intent**

A register of consent means the person registering is indicating their consent to donation, and further consent is not required. An intent register indicates the person registering is willing to donate organs if the circumstances arise, but formal consent will need to be obtained.

## **The New Zealand situation**

New Zealand has no strategy for improving public awareness of or media engagement in organ donation and no organisation clearly responsible for them. Organ Donation New Zealand attempts to correct misinformation in the media, but there is no consistent messaging or contact with journalists to build up knowledge and ensure accuracy.

The information recorded on the Driver Licence Register does not currently function effectively as a donor register. The information is not routinely accessed when donation decisions are being made, and it can be difficult for clinicians to access the register. Moreover, the information is not a reliable indicator of a person's wishes, given that the choice is mandatory and people are given little supporting information to help them make their decision.

While a register is useful in promoting public awareness of organ donation, and in prompting family conversations about organ donation, there are most likely significant costs associated with establishing a new stand-alone donation register. While the driver licence register is imperfect, it does have the advantage of being an established system that the vast majority of the public interact with at regular intervals.

## **Proposals**

Mandate the national coordinating body with explicit responsibility to develop and implement a cost-effective plan to raise public awareness and understanding and develop a strategy to engage with the media about organ donation and transplantation to:

- ensure strategies are based on sound research and are appropriate for the needs of different audiences (including Māori and Pacific peoples)
- raise awareness, promote family discussion and educate people about organ donation through a donor register.

Improve the existing driver's licence system so that it becomes a more effective register of people's wishes to donate their organs and is used to inform decision-making by:

- making better information available at the time of registration
- making information more readily accessible in the clinical setting where decisions are made
- making it easier to change information on the system by allowing multiple entry points, for example, when licencing or warranting a vehicle or through primary health care services.

# Questions for consultation

Do you agree with the proposed approach to public awareness and media engagement?

Do you agree with the proposals to improve the driver licence system for recording individual organ donation wishes?

## Other issues for consideration

- Do you agree that public awareness activity should be a core responsibility of the national coordinating body?
- What information needs to be provided at organ donation registration to help people make their decision?
- Would it help to give people multiple registration opportunities, as opposed to one collection point?
- If so, where should people be able to register as organ donors?
- How can we ensure that information recorded about an individual's donation wishes is accessible in clinical settings?

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# International cooperation

Any strategies we put in place should have a focus on learning from and adopting international best practices in how to increase organ donation rates. New Zealand already works closely with Australia, with the following shared services.

- Common medical specialist colleges – for example, the College of Intensive Care Medicine of Australia and New Zealand (CICM), the Australasian College for Emergency Medicine; and the Australian and New Zealand College of Anaesthetists
- A trans-Tasman organ-sharing agreement – where organs from New Zealand donors are transplanted in Australia and vice versa if a suitable recipient is not identified in their own country (travel times limit sharing organs further afield)
- The Paired Kidney Exchange Scheme – discussions are currently underway to make this a trans-Tasman scheme as this would increase the likelihood of compatible matches
- Professional training courses – a range of organ donation workshops are offered for clinical specialists from both countries annually
- The Clinical Director and Director of Clinical Programmes from Australia’s Organ and Tissue Authority are on the New Zealand Ministry of Health’s expert advisory group for the current review of organ donation and transplant services.

The EY review reported that stakeholders interviewed felt the current arrangements are working well. There are further opportunities for New Zealand to work closely with the Australian Organ and Tissue Authority. For example, with more training courses it might be possible to share approaches to raising public awareness.

## Proposals

Share learnings from Australia (have representatives from the Australian Organ and Tissue Authority on our national coordinating body).

Continue and expand joint trans-Tasman organ donation training opportunities.

Share experiences in developing public awareness and useful information resources across the Tasman.

## Question for consultation

Are there other opportunities for New Zealand to work with other countries?

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# Appendix One: Summary of preliminary proposals

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## **Development of a national strategy to increase rates of organ donation from deceased people**

The Ministry of Health should develop and monitor a national, comprehensive and clinically credible strategy for increasing rates of deceased person organ donation and transplantation. The strategy should result in the development of:

- a world-class donation and transplantation system in New Zealand, supported by an aspirational goal, such as, 20 deceased donors per million population by 2025 or a donation rate in the top 20 percent of countries
  - mandated national, regional and local roles and responsibilities to strengthen leadership, visibility and accountability for organ donation
  - initial priority action areas: a national coordinating body, practices in clinical settings and public awareness, including registers
  - actions that are appropriate for different population groups.
- 

## **A legal and ethical framework**

We do not consider amendments to the Human Tissue Act 2008 to be a priority at this time.

The Ministry of Health should establish a consistent mechanism whereby health professionals around New Zealand can obtain independent assurance that new practices and processes are ethically acceptable. Options might include:

- a specific stand-alone organ donation and transplant ethics committee (as per the United Kingdom)
  - The Transplantation Society of Australia and New Zealand
  - the National Ethics Advisory Committee.
- 

## **A national coordinating body**

Clarify and extend the role and purpose of the national coordinating body for organ donation so that it is clearly mandated and funded to increase national rates of organ donation from deceased people and organ transplantation. This includes:

- leading the implementation of the strategy to increase rates of organ donation from deceased people and transplantation
- championing organ donation in the health sector and the community
- supporting an effective governance framework across all DHBs
- implementing effective public awareness activities to build awareness and understanding of organ donation and transplantation benefits
- offering a range of fit-for-purpose clinical staff training.

Determine the right form and location for the national coordinating body.

The Ministry of Health must provide ongoing oversight and stewardship to ensure national expectations are fulfilled.

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## **A clinical governance framework**

The national coordinating body should work with DHBs to establish an appropriate clinical governance framework for organ donation from deceased people. Such a framework would:

- record all critical care deaths (in EDs as well as ICUs) in the death audit
- make organ donation a standing item at ICU daily meetings and/or in mortality and morbidity meetings
- establish appropriate roles and responsibilities in each DHB – donation specialists in ICUs, EDs, Chief Medical Officers, Hospital Advisory Committees
- improve the quality of information in the death audit and use it more effectively to learn and improve practices
- strengthen the relationship between EDs and ICUs
- use referral pathways and triggers from ED to ICU to support organ donation.

Reconfigure Organ Donation New Zealand's advisory committee to play a stronger role in clinical governance for the national coordinating body by, for example, establishing a clinical governance subcommittee or establishing an equivalent body to the Australian Organ and Tissue Authority's clinical governance committee.

Encourage the use of regional clinical networks (such as trauma networks).

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### **Hospital-based clinical organ donation specialists**

Partially fund intensivist and nursing roles in the eight DHBs with the greatest opportunity to increase donation numbers (0.1 FTE intensivist and 0.4 FTE nursing) to champion donation and lead the implementation of the clinical governance framework in each DHB.

Maintain existing LINK teams in the remaining 12 ICUs.

Appoint appropriate hospital organ donation champions outside the ICU.

Expand funding for organ donation specialists to more ICUs.

Larger ICUs or the national coordinating body could provide organ donation support to smaller ICUs (potentially contributing specialist staff).

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### **Specialist training for clinical staff**

Work with the Australian Organ and Tissue Authority to make a wider range of courses available in New Zealand, such as, introductory donation awareness training; core family donation conversation; practical donation conversation; advanced family donation conversation and e-learning modules.

Ask professional colleges to promote specialist training to existing fellows as well as trainees in intensive care medicine; emergency medicine and anaesthesiology.

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### **Financial support for donor and transplant hospitals**

Remove the financial barrier to conducting donations by reviewing funding arrangements for organ donation, including:

- reimbursing the additional costs incurred in the donation process to the donating hospital
- instigating a national funding model.

Ensure the national strategy includes measures to address transplant capacity issues.

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### **Public awareness, media engagement and registers**

#### *Public awareness, education and media engagement*

Mandate the national coordinating body with explicit responsibility to develop and implement a cost-effective plan to raise public awareness and understanding and develop a strategy to engage with the media about organ donation and transplantation to:

- ensure strategies are based on sound research and are appropriate for the needs of different audiences (including Māori and Pacific peoples)
- raise awareness, promote family discussion and educate people about organ donation through a donor register.

#### *Donor register*

Improve the existing driver's licence system so that it becomes a more effective register of people's wishes to donate and is used to inform decision-making by:

- making better information available at the time of registration
- making information more readily accessible in the clinical setting where decisions are made
- making it easier to change information on the system by allowing multiple entry points, for example, when licencing or warranting a vehicle or through primary health care services.

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### **International cooperation**

Share learnings from Australia (have representatives from the Australian Organ and Tissue Authority on our national coordinating body).

Continue and expand joint trans-Tasman organ donation training opportunities.

Share experiences in developing public awareness and useful information resources across the Tasman.

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# Making a submission

This consultation document is aimed at a range of audiences. The questions that accompany each section of the document are intended to help focus feedback on specific areas of concern. The primary questions are reasonably general, but there are also some more technical issues for consideration that you may wish to comment on. It would help us if you referred to some or all of these questions when preparing your submission.

Submissions can be emailed to:

organdonation@moh.govt.nz

or posted to:

Deceased Organ Donation Review  
Sector and Services Policy  
Ministry of Health  
PO Box 5013  
Wellington 6145.

All submissions are due by 29 July 2016. Any submissions received after this time cannot be included in our analysis.

Details of your submission may be requested under the Official Information Act 1982. If this happens, the Ministry will normally release your submission to the person who asks for it. If you consider there are good reasons to withhold your submission details, please clearly indicate these in your submission.

If you are an individual or individuals, we will remove your personal details from your submission, and your name(s) will not be listed in the published summary of submissions, if you ask for us to withhold them.

We appreciate you taking the time to comment.

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# Consultation submission

## Submitter details

It is helpful, when assessing submissions, if submitters provide information about themselves. However, providing this information is not required for a submission to be considered, and you can choose to withhold this information if you wish.

This submission was completed by: *(name)* \_\_\_\_\_  
Address: *(street/box number)* \_\_\_\_\_  
*(town/city and postcode)* \_\_\_\_\_  
Email: \_\_\_\_\_  
Organisation (if applicable): \_\_\_\_\_  
Position (if applicable): \_\_\_\_\_

Are you making this submission *(tick one box only)*:

- as an individual?
- on behalf of a group or organisation?

## Report

The Ministry of Health may publish a publicly available report on the submissions once the Government has made its decisions about the Regulations. No information identifying a person or an organisation will be released in this report.

## Official Information Act 1982

The Official Information Act 1982 (the OIA) applies to any submission you make and to any personal information you provide. The OIA requires information held (by the Ministry of Health) to be made available unless there is good reason to withhold it. Accordingly, if the Ministry of Health does receive a request under the OIA for your information, we will discuss that with you before responding to the request.

# Consultation questions

Although the submission form includes blank spaces for answering the questions, these do not set a limit for the length of your responses and you should take as much space as you need to answer or comment. Feel free to enlarge the boxes or attach additional pages.

## A strategy to increase deceased organ donation

1 Are these the right high-level elements of an effective organ donation strategy?

Yes

No

Please outline your reasons.

2 Is an aspirational goal or vision appropriate?

Yes

No

If so, what should the goal be?

## An appropriate legal framework

3 Are there aspects of the current law relating to organ donation and transplantation that you think should be reconsidered?

Yes

No

Please outline your reasons.

## An appropriate ethical framework

4 How could consistent ethical guidance on organ donation and transplantation be obtained?

## A national coordinating body

5 Are the listed functions for the national coordinating body correct and appropriate?

Yes

No

Please outline your reasons.

## A clinical governance framework

- 6 What role should the national coordinating body have in the clinical governance of organ donation and transplantation?

## Hospital-based clinical organ donation specialists

- 7 Does the proposal for hospital-based clinical organ donation specialists have the right elements?

- Yes  
 No

Please outline your reasons.

## Specialist training for clinical staff

- 8 Does the proposal for specialist training adequately address clinical staff training needs in New Zealand?

- Yes  
 No

Please outline your reasons.

## Financial support for donor and transplant hospitals

- 9 Are there additional funding arrangements that should be considered in organ donation and transplant events?

- Yes  
 No

Please outline your views.

## Public awareness, media engagement and registers

- 10 Do you agree with the proposed approach to public awareness and media engagement?

- Yes  
 No

Please outline your views.

- 11 Do you agree with the proposals to improve the driver licence system for recording individual organ donation wishes?

- Yes  
 No

Please outline your views.

## International cooperation

12. Are there other opportunities for New Zealand to work with other countries?

- Yes  
 No

Please outline your views.

## Supplementary questions

13 Do you have a view on an appropriate source of ethical guidance? For example:

- a specific stand-alone organ donation and transplant ethics committee (as per the United Kingdom)
- The Transplantation Society of Australia and New Zealand
- the National Ethics Advisory Committee?

- Yes  
 No

If so, please outline your view.

14 Is there another appropriate option?

- Yes  
 No

If so, please outline.

15 What is the best way of obtaining public input on ethical issues?

16 What is the appropriate location for the national coordinating body?

- Within a DHB  
 Within the Ministry  
 Within another agency  
 A stand-alone Crown agency  
 Somewhere else – please outline where below.

17 Are there other roles within the organ donation and transplantation system that the national coordinating body should undertake?

- Yes  
 No

Please outline.

18 What would be the core components of a clinical governance framework for organ donation?

19 How should a clinical governance framework be implemented?

20 How could a clinical governance framework for organ donation fit into existing clinical governance systems?

21 How could the death audit be improved?

22 What information from the death audit should be publicly available?

23 Should emergency departments be involved in organ donation?

Yes

No

If so, what would be required to support emergency departments to have a greater role in organ donation?

24 What is required to support clinical leadership on organ donation within ICUs?

25 Do you agree that funding dedicated time for intensive care doctors and nurses would be useful to increase organ donation rates?

Yes

No

Please outline your reasons.

26 Should those roles be responsible for leading implementation of the clinical governance framework for organ donation in their DHBs?

Yes

No

Please outline your reasons.

25 What other roles within the broader DHB could champion organ donation?

28 Is there further specialist training for clinical staff that would be useful, such as training in cultural competency?

Yes

No

Please outline your views.

29 How could we increase the uptake of training, including by emergency medicine specialists and anaesthetists?

30 How could the additional costs associated with managing organ donations from deceased people be quantified?

31 How well did previous funding arrangements work?

32 How can we make sure transplant services continue to have the capacity to transplant donated organs without putting pressure on other services?

33 Do you agree that public awareness activity should be a core responsibility of the national coordinating body?

Yes

No

Please outline your views.

34 What information needs to be provided at organ donor registration to help people make their decision?

35. Would it help to give people multiple registration opportunities, as opposed to one collection point?

Yes

No

If so, where should people be able to register as organ donors?

36 How can we ensure that information recorded about an individual's donation wishes is accessible in clinical settings?