Review of deceased organ donation and transplantation rates – initial report to Minister of Health

March 2016

Ministry of Health

2016

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# Executive summary

## Overview

Organ transplantation is a life-saving treatment and for people with organ failure is often the best, or only, option available. Demand for transplants, particularly kidneys, continues to rise. The key factor limiting the number of transplants possible is the number of organs available for transplant from deceased or living donors, but internationally, demand for organs outstrips supply.

New Zealand’s rate of deceased organ donation has been low relative to many other countries over a number of years. While there has been some increase in the last two years, other countries have introduced reform programmes that have achieved significant improvements, with a resulting widening gap between our rates and theirs.

There is potential to increase our rates of deceased organ donation primarily through:

* improving practices in clinical settings (particularly ICUs and EDs) so that all potential donors are identified and families are consistently 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 to raise public awareness of donation, and through specialist training for clinical staff
* expanding the use of different types of donors, in particular Donors after Circulatory Death (DCD).

An increase in donation rates can be achieved with a national, comprehensive and clinically-credible strategy incorporating actions across eight core components that form the basis of successful reform programmes in other countries. These are:

1. an appropriate legal and ethical framework
2. a national coordinating body to lead a reform agenda
3. hospital-based clinical donation specialists
4. specialist training for clinical staff in management of the deceased donation process and family donation conversations
5. implementation of a clinical governance framework that supports quality assurance and audit of hospital clinical practice and governance of the donation process
6. financial support to donor hospitals to ensure that costs related to donor management are not a barrier to donation
7. media engagement and national community awareness and education
8. international cooperation to share best practice.

The proposals in this report draw on international evidence, experience and best practice, contextualised for New Zealand. Actions need to be appropriate for our environment, including fitting within our health system arrangements and addressing the needs of Māori and Pacific populations, whose rates of donation tend to be lower than European/Pākehā groups. Reasons for this are unclear but data suggest Māori and Pacific families are approached less frequently about organ donation in ICU and less likely to consent when they are asked.

A comprehensive strategy is needed rather than continuing with piecemeal or ad hoc initiatives, but would not require major reform in the context of the overall health system. Of the eight components above, New Zealand has many of the foundations in place already and these can be strengthened and extended, rather than having to start from scratch.

The main gaps in our current approach are:

* a national strategy and commitment to increase rates of deceased organ donation, with clear expectations, which is owned and driven throughout the health system
* a national coordinating body with a clear role and responsibilities, and a mandate to increase rates of deceased organ donation that is appropriately funded to do so
* a systematic and effective approach to public awareness and education, including a more effective donor registration mechanism than the current driver licence system.

A comprehensive strategy to increase organ donation would be consistent with both the New Zealand Health Strategy and wider Government goals. There is a strong rationale to improve this service given the significant improvement to patients’ lives that is possible. Transplantation is often an alternative to dialysis, so there are also fiscal savings to the health, and potentially welfare, systems which provide a clear investment case. It would also form part of the response to chronic conditions which underpin many instances of organ failure, alongside other initiatives aimed at prevention, early intervention and effective management (such as the childhood obesity package and the Diabetes Plan).

These preliminary proposals have been developed in consultation with an Expert Advisory Group but now need further testing and refinement to determine feasibility, costs and appropriate phasing. A key issue is to plan for the additional capacity transplant services will need in order to be able to transplant an increased number of organs. Further consultation with a wider group of stakeholders is now required.

## Summary of preliminary proposals

|  |
| --- |
| **Development of a National Strategy to Increase Deceased Organ Donation** |
| The Ministry of Health should develop and monitor a national, comprehensive, and clinically-credible strategy for increasing rates of deceased organ donation, which includes:* a vision of raising rates of donation and transplantation in NZ, supported by an aspirational goal eg, 20 dpm by 2025, or top quintile of countries
* mandated national, regional and local roles and responsibilities to strengthen leadership, visibility and accountability for organ donation
* initial priority action areas to be the national coordinating body; practices in clinical settings and public awareness and registers
* actions that are appropriate for different population groups
 |
| **1. Appropriate legal and ethical framework** |
| No changes to the main legislative framework for consent to donation in the Human Tissue Act are proposed. It is unlikely to be a barrier to achieving increased rates of organ donation and transplantation.Establish a mechanism where health professionals in NZ can obtain independent assurance that new practices and processes are ethically acceptable. Options might include:* establish a specific stand-alone organ donation and transplant ethics committee (as per the UK).
* use NEAC to provide advice and guidance. This would require changes to how NEAC’s work programme is set.
* explore how to ensure the Transplantation Society Australia New Zealand guidance provides adequate support to address any ethical concerns.
 |
| **2. A national coordinating body to lead a reform agenda** |
| Clarify and extend the role and purpose of the national coordinating body for organ donation so that it is clearly mandated and funded to deliver on an objective to increase rates of deceased organ donation in New Zealand including:* leading the implementation of the strategy to increase rates of deceased organ donation and championing organ donation in the health sector and the community
* implementing effective public awareness activities to build knowledge and understanding of organ donation and transplantation benefits
* determining the right form and location for the national coordinating body, bearing in mind the need to promote donation nationally, and influence clinical practice across the country.

Regardless of form and location, the Ministry of Health to provide ongoing and oversight and stewardship to ensure national expectations are fulfilled.Future consideration:* consider interface with wider aspects of donation and transplantation system.
 |
| **3. A clinical governance framework that supports quality improvement and governs the donation process** |
| Have the national coordinating body work with DHBs to establish an appropriate clinical governance framework for deceased organ donation including:* establishing appropriate roles and responsibilities in each DHB – donation specialists in ICUs, Emergency Departments, Chief Medical Officer, Hospital Advisory Committees
* improving the quality of information in the death audit and using it more effectively to learn and improve practice
* including all critical care deaths (including ED and ICUs) in the death audit
* making organ donation a standing item at ICU daily meetings and/or in mortality and morbidity meetings
* strengthening relationship between EDs and ICUs
* using referral pathways and triggers from ED to ICU (triggering identification); ICU to national coordinating body (donation)

Reconfigure the ODNZ Advisory Committee to play a stronger role in clinical governance for the national coordinating body, for example establish a clinical governance subcommittee or establish an equivalent body to OTA’s Clinical Governance Committee.Future consideration:* encourage the use of regional clinical networks (such as Trauma networks)
 |
| **4. Hospital based clinical donation specialists** |
| Partially fund intensivist and nursing roles in 8 DHBs with greater opportunity to increase donation numbers (0.1 FTE intensivist and 0.4 FTE nursing) to lead the implementation of the clinical governance framework in each DHBMaintain existing link teams in remaining 12 ICUsFuture consideration:* Expanding funding for donation specialists to more/remaining ICUs.
* Larger ICUs or national coordinating body to support smaller ICUs with donation (potentially sending specialist staff)

Appoint appropriate people as donation champions within the ICU and hospital more broadly |
| **5. Specialist training for clinical staff** |
| Increase the uptake of appropriate training by clinical staff in organ donation conversation, including consideration of holding a practical and advanced core Family Donation Conversation workshop in New Zealand and promoting training to CICM Fellows who have not taken the course for a long period of time to attend.Work with Australian OTA to have a wider range of courses available in NZ eg, introductory donation awareness training; core family donation conversation; practical donation conversation; advanced family donation conversation; and e-learning modulesAsk professional colleges to promote specialist training to existing fellows as well as trainees in intensive care medicine; emergency medicine and anaesthesiology. |
| **6. Financial support for donor and transplanting hospitals** |
| Remove the financial barrier to donation by reviewing funding arrangements for organ donation including:* reimbursing the additional costs incurred in the donation process to the donating hospital outside the PBFF, or
* a national funding model

Ensure the national strategy includes measures to address transplant capacity issues |
| **7. Public awareness and education, media engagement and donor 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 increase education, and to develop a strategy to engage with the media about organ donation.* Ensure strategies are based on sound research and are appropriate for the needs of different groups (including Māori and Pacific people).
* Use opportunities from a donor register to raise awareness, promote family discussion and educate people about organ donation.

*Donor register:*Improve the existing driver’s licence system so that it becomes a more effective register of intent of people’s wishes to donate and is used to inform family decision-making in ICUsFuture consideration: * Create a new stand-alone donor register.
 |
| **8. International cooperation** |
| Continue joint trans-Tasman work of professional colleges and information sharingShare learnings from Australia (have Australian OTA representative on governance for national coordinating body)Increase opportunities for increased clinical training opportunities in NZShare public awareness and information resources  |

# Introduction

## Purpose of the review

This review was commissioned from the Ministry of Health by the Minister and Associate Minister of Health. Its overall purpose was to identify, assess and recommend actions to increase solid organ donation rates to support an increase in transplantation rates in New Zealand, with a primary focus on increasing deceased organ donation rates.

The specific objectives from the Terms of Reference (Appendix One) were to report to the Minister of Health on:

* the current situation in New Zealand, including an overview of current domestic patterns and trends, practices, systems, processes and recent initiatives to increase organ donation and transplantation rates
* international experiences and features of higher performing organ donation systems
* issues in New Zealand’s donation and transplantation system, and aspects that could be changed to increase deceased solid organ donation and transplantation rates
* recommendations for change.

## Background to the review

New Zealand has relatively low deceased organ donation rates compared with other developed countries. Our donation rate has been around 10 per million people (pmp) over the last 22 years, compared to Australia, which had around 18 pmp in 2015, and Spain, which had the highest rate at around 36 pmp in 2014[[1]](#footnote-1). We have a large and growing number of people (600-700) waiting for kidney transplants in particular, with around 40 people waiting for liver, cardiac or lung transplants[[2]](#footnote-2).

## Process

The Ministry of Health carried out the review between September 2015 and March 2016. There is a significant body of international experience and knowledge on how to increase rates of deceased donation. We have therefore taken the approach of reviewing the lessons from major reform programmes elsewhere to identify the key elements that appear to be most likely to make a difference. This includes reviewing major taskforce reports, analysing international evidence and consulting with colleagues from Australia.

In order to draw on local expertise, and to ensure international lessons were appropriately contextualised to the New Zealand environment, we also established an Expert Advisory Group (EAG) to provide advice to the Ministry on this review. EAG members were selected to provide wider expertise about the organ donation and transplantation system, including behaviour change, ethics, clinical and management and cultural perspectives. The Terms of Reference and list of members are attached at Appendix Two. We emphasise that the EAG’s role was to advise the Ministry from a range of expert perspectives, rather than to reach agreement or consensus on the advice. The advice in this report is the Ministry’s.

In addition, the Ministry commissioned an independent report from consultancy firm Ernst and Young (EY), which looked at practices in clinical settings and institutional arrangements in New Zealand, to provide advice to the Ministry. EY was asked to make recommendations on improvements to practices in clinical settings, and to provide commentary on current institutional arrangements. The analysis and recommendations from the EY report have been incorporated into the wider review. A summary of the scope of the EY report is attached at Appendix Three.

## Caveats and limits of the review

The review has focused only on measures to increase **donation** by deceased donors, and not covered other aspects of the wider transplantation system such as matching and allocation mechanisms, retrieval and transport systems, transplantation itself or post-transplant care. The review has been undertaken in a relatively short timeframe with limited opportunity for engagement with stakeholders. We have therefore outlined proposals which will require further consultation and testing with stakeholders, to ensure accuracy, test feasibility and understand interfaces with other aspects of the wider transplant system. In particular, there is a need to understand and plan for the capacity needed to undertake additional transplants. The review has not focused on donation by living donors as this has been the subject of recent investment by Government with a number of initiatives already underway.

## Overview of this report

This report begins by providing **Background** **and Context** about deceased organ donation processes; outcomes of transplantation, including cost-effectiveness; demand for transplants in New Zealand and our rates of organ donation compared to other countries; information from the New Zealand audit of deaths in critical care facilities (those where there is the potential for deceased donation); and a brief discussion on the opportunities to increase rates of organ donation in New Zealand.

Next it outlines what a **Strategy** to increase deceased organ donation might look like, and the high level approaches taken by other countries who have successfully reformed their deceased organ donation systems. The remainder of the report is based around the eight common **Components** of successful strategies adopted by other countries and how these would apply in the New Zealand context[[3]](#footnote-3). These elements are:

1. An appropriate legal and ethical framework
2. A national coordinating body to lead a reform agenda
3. Hospital-based clinical donation specialists
4. Specialist training for clinical staff in management of the deceased donation process and family donation conversations
5. Implementation of a clinical governance framework that supports quality assurance and audit of hospital clinical practice and governance of the donation process
6. Financial support to donor hospitals to ensure that costs related to donor management are not a barrier to donation
7. Media engagement and national community awareness and education
8. International cooperation to share best practice.

While all these elements are covered in this report, we have paid particular attention to a national coordinating body and practices in clinical settings. We have also included some commentary on public awareness, engagement with the media and have incorporated donor registers as well.

The report then discusses **Cultural and Ethnic Issues** and presents final **Conclusions** and **Next Steps** to finalise the proposals.

# Background and Context

## Overview of organ donation and transplantation

### Rationale to increase rates of organ donation and transplantation

For people with organ failure, a transplant is often the best and at times the only treatment available. Multi-pronged strategies are needed to address many of the conditions that can lead to organ failure including prevention, early intervention, and effective management of chronic conditions. However, organ failure cannot always be avoided, and a transplant may be the only treatment option.

Transplants are a well proven health intervention, in both New Zealand and overseas, saving and improving many lives. The impact of a transplant on a person's health can be dramatic. Transplantation frequently takes them from a situation of extreme ill health, where organ failure means that they have both a greatly reduced quality of life and a relatively short life expectancy, to a near-normal quality of life and significantly improved life expectancy. In many cases they can resume a near-normal life, including: looking after their own daily living needs; being able to fully participate in everyday activities with their family and friends; and in some cases being able to resume employment.

In contrast, without a transplant, people with heart, lung or liver failure are faced with a condition that has no effective treatment. As a consequence they have a short life expectancy, during which they will often be extremely unwell and unable to live a normal life. In the case of people with kidney failure, dialysis is available as a treatment, which means that they can expect to live somewhat longer than a person with other types of organ failure (typically around seven years), but still substantially less than their life expectancy with a transplant and their quality of life will be much lower. Dialysis is a time consuming process which can be very debilitating. Most people undertaking dialysis will, for instance, be unable to sustain ongoing employment.

The cost effectiveness of organ transplantation, particularly for kidneys, has been studied extensively in the health literature, and varies markedly by transplantation type. In a 2010 study[[4]](#footnote-4) by the NHS, the authors concluded that:

*The costs of supporting each type of organ failure vary considerably and in most instances the costs associated with transplantation are higher than the costs of supporting patients in end stage organ disease who do not receive a transplant. This is not true for renal transplantation that, as an alternative to dialysis, results in significant savings that effectively cross-subsidises all other organ transplants. Whilst this is the finding, the majority of people who register as an organ donor do so as potential multi organ donors. It would not be practicable to promote different types of organ donation and as a result any organ donor initiatives will be aimed at increasing the supply of all organs resulting in some cross subsidisation between different types of transplants. It is also clear that without an opportunity of a transplant, these patients will die in a relatively short time period.*

Kidney transplants are the most common transplant type in New Zealand, accounting for over 60 percent of transplants[[5]](#footnote-5). Multiple studies overseas and in New Zealand have found that, for a transplantable person with renal failure, transplantation results in substantial overall in health system savings[[6]](#footnote-6),[[7]](#footnote-7), as transplantation is typically much more cost-effective than the alternative of providing ongoing dialysis. A recent New Zealand study[[8]](#footnote-8) estimated that it costs $280,812 to provide a 50 year old male with dialysis over his expected lifetime but only $149,654 if he is given a transplant. In addition, clinicians advise that a transplantable person can now expect to live for more than 20 years after a transplant (and survival times continue to increase) following a transplant, and will also have a significantly better quality of life than a person on dialysis.

Depending on key assumptions, such as life-expectancy and ability to work[[9]](#footnote-9) there may also be other financial gains to the Crown from renal transplants, such as reduced welfare costs[[10]](#footnote-10) and increased tax receipts[[11]](#footnote-11). We are currently doing work to estimate the overall saving to the Crown from a typical kidney transplant. While the overall saving is sensitive to key assumptions such as the ability to work post-transplant, our preliminary conservative estimate is that it could exceed $300,000 over the lifetime of the transplant.

In contrast to kidney transplantation, accurate analysis of cost-effectiveness for other transplant types is made more difficult by there being multiple conditions that can lead to organ failure, all of which can have different treatment costs, and the relatively low transplant volumes in New Zealand. However, it is clear that other transplants do not have the same fiscal cost saving as kidney transplantation. This is primarily because for many of the conditions involved the sufferer has a relatively short life expectancy in the absence of a transplant, and the alternative to transplantation is death rather than ongoing treatment with associated health and welfare costs.

Based on the comprehensive 2010 NHS study we would expect that, from a purely financial cost perspective, only kidney transplantation is associated with an overall net saving (and some lung transplants could be close to break-even). However, when health outcomes are taken into account, other types of organ transplantation also make sense.

More broadly, New Zealand also has a general obligation as a good international citizen to maximise deceased organ donation, in part as a means to reduce the incentive for organ trafficking. The World Health Organization’s Guiding Principles on Human Cell, Tissue and Organ Transplantation[[12]](#footnote-12) (endorsed by World Health Assembly resolution WHA63.22 in 2010) begin by pointing out that the shortage of donor organs has led to increased trade in organs, and firmly state that deceased organ donation should be maximised, and that payment of any kind should be prohibited.

Similar messages are found in the Madrid Resolution on Organ Donation and Transplantation, which emerged from a WHO-sponsored global conference with wide representation in 2010, and encourages national self-sufficiency in organs and lays out practical measures to meet it[[13]](#footnote-13). This position is supported by professional groups, notably in the Declaration of Istanbul on Organ Trafficking and Transplant Tourism from 2008, sponsored by the Transplantation Society and the International Society of Nephrology, and endorsed by the Transplantation Society of Australia and New Zealand. The Declaration recommends “programs to prevent organ failure are implemented and to provide organs to meet the transplant needs of its residents from donors within its own population or through regional cooperation[[14]](#footnote-14).

Overall, increasing our rates of donation and transplantation will save lives, reduce health and potentially welfare costs, and may enable more people to stay in or return to work. The key rate-limiting factor for undertaking transplantation is the availability of organs, with demand for organs outstripping supply across the world.

### The organ donation and transplant process

The organ donation and transplant process incorporates a number of components, as outlined in Figure 1. These include general societal awareness about, and support for, donation and transplantation; processes within ICUs to identify potential donors, seek and obtain family consent; systems to match and allocate organs to potential recipients; the logistics of retrieving organs and transporting them to where the transplant takes place; the transplant surgery itself; and post- transplant care for the recipient. This review has focused only on the first two steps in the process.

Figure 1: Steps in the donation and transplant process



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 those people in an ICU who have suffered a fatal illness or injury which has led to severe and irreversible brain damage and have been mechanically ventilated during their treatment in the ICU. The two main circumstances where deceased donation is possible are as follows:

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. In these circumstances donation after cardiac death might be an option when it is clear that the individual cannot survive.

Deceased donation rates achieved are determined by the outcome of a number of key steps: the identification and testing of potential donors in ICUs; families of potential donors being asked to consent to donation; families agreeing to donate. These steps are presented in a stylised diagram below (Figure 2), although in practice these may vary between ICUs or in different cases, for example some clinicians discuss potential DBD organ donation with families prior to brain death confirmation and some may not confirm brain death if the family do not agree to donation.

Figure 2: Deceased organ donation stages

**Family agree**

**Identify potential donors**

**Ask the family**


## New Zealand context

The first organ transplant in New Zealand was a kidney from a living donor to her identical twin sister at Auckland Hospital on 28 May 1965. The first deceased donor was a teenage boy at Auckland hospital in 1966, who gave his kidneys to two recipients. The first heart transplant occurred on 2 December 1987. The 1990s saw the commencement of lung transplantation in 1993 and liver and pancreas transplantation in 1998[[15]](#footnote-15). Kidney transplants are performed in three DHBs (Auckland, Capital and Coast, Canterbury), while heart, lung, liver and pancreas transplants are carried out only by Auckland DHB.

The last significant review relating to organ donation and transplantation occurred over 2002-2008. This focused on reviewing and updating the Human Tissue Act which was first passed in 1964 and updated in 2008. There was also significant debate about establishing an organ donor register, and Organ Donation New Zealand (ODNZ) was also established in 2005 to replace the National Transplant Coordination Office. More recently, the Government has invested in several initiatives to increase live kidney donations and transplants and for ODNZ to provide increased support in intensive care units in relation to deceased organ and tissue donation. (Appendix Five summarises key legislative, policy and service changes, while Appendix Six lists a number of the bodies and organisations involved in organ donation and transplantation).

### Demand for organ transplants

Like most countries, New Zealand has a growing number of people waiting for organs, particularly for kidneys. The number of people with end-stage renal failure is increasing (by an average of 4 percent per year since the mid-2000s[[16]](#footnote-16)), with 2,678 people on dialysis as at 2014[[17]](#footnote-17). Around 600-700 people have been accepted onto the waiting list for a kidney transplant(Figure 3). This does not necessarily reflect true demand for kidney transplants as some people will receive a pre-emptive transplant from a living donor before they enter end-stage renal failure, so will not appear in the waiting list figures, while others will not meet the criteria for a transplant although would benefit from one[[18]](#footnote-18).

Figure 3: Number of patients accepted for kidney transplants (total and active waiting list numbers at the end of the month) - January 2005 to February 2016

The ‘total’ line in Figure 3 includes all those patients accepted for a transplant, including a proportion who have been temporarily suspended from the list since then. The ‘active’ line includes only those patients who would be available to receive a kidney if one were to become available today.

In addition, there are around 40 people waiting for liver, heart or lung transplants. In February 2016 there were 27 people waiting for a liver transplant, 12 for a heart transplant and five for a lung transplant.

### NZ donation and transplant rates

New Zealand has historically had low rates of deceased organ donation relative to other countries. Our donation rate has been around 10 per million population (pmp) over the last 22 years (refer figure 4). There have been some fluctuations within this period, including an increase over the last two years, with a 2015 rate of 11.8pmp, but overall the rate has been fairly static.

Figure 4: New Zealand deceased donors, per million of population, 1994-2015

Source: International Registry in Organ Donation and Transplantation

Table 1: Number of deceased and live organ donors and transplants in the last decade

|  |  |  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 2006 | 2007 | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 |
| Deceased donors | 25 | 38 | 31 | 43 |  41 | 38 | 38 | 36 | 46 | 53 |
| Live donors | 51 | 62 | 76 | 75 | 66 | 66 | 57 | 61 | 77 | 77 |
| Transplants | 145 | 180 | 181 | 179 | 171 | 184 | 170 | 175 | 212 | 230 |

Source: ODNZ (Annual reports)

Until the mid-2000s New Zealand and Australia had very similar rates of deceased donation. Following the report of the National Clinical Taskforce on Organ and Tissue Donation in 2008[[19]](#footnote-19), Australia has successfully implemented a reform agenda to increase its donation rates from 9.4 pmp in 2007 to 18.3 pmp in 2015. The United Kingdom has always had higher deceased donation rates than New Zealand, but following its reform programme the gap has increased. The UK increased its deceased donation rate from 13.2 pmp in 2007 to 20.4 pmp in 2014 (Figure 5).

New Zealand’s 2014 rate of 10.2 deceased donors pmp continues to place New Zealand in the bottom half of the countries that have reported 2014 figures (note, not all countries have reported their deceased donation rates for 2014) (Figure 6). With the further increase in 2015 to 11.8 pmp, New Zealand’s deceased donation rate is in the middle third.

Figure 5: Deceased donation rates (pmp) for New Zealand compared to Australia and the United Kingdom[[20]](#footnote-20)

Post reform

Pre reform

In contrast, New Zealand has somewhat higher rates of live donors per million of population (refer Figure 6) ranking 14th out of the 47 countries that have provided 2014 live donation data to the International Registry on Organ Donation and Transplantation. There has been an increase in the number of living donors in recent years from 61 donors in 2013 to 77 donors in 2015. Living donation is primarily of kidneys and, to a lesser extent, livers[[21]](#footnote-21). For people needing hearts, lungs and pancreases, deceased donation is the only option.

Figure 6: Worldwide actual deceased and live organ donors 2014 (pmp)



### New Zealand death audit

Death audits are commonly used to provide information about what happens at each step of the organ donation pathway within ICUs. ODNZ began collecting death audit data in 2008 which currently provides data only about the DBD pathway, although ODNZ is working to also include DCD. The key focus in any strategy to increase organ donation rates is to increase the proportions of potential donors being identified, families approached, and family consent rates.

Information from the previous eight years is contained in Table 2. This data provides useful indicators about how consistently potential donors are being identified and tested, how often discussions about organ donation are taking place with families, and how frequently families are consenting to donate a family member’s organs when asked.

Table 2: Percentage of possible brain dead patients who progress though the potential donation steps[[22]](#footnote-22)

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  | 2008 | 2009 | 2010 | 2011 | 2012 | 2013 | 2014 | 2015 |
| Percentage of ‘possibly brain dead’ tested for brain death (either one or two test) | 51% | 57% | 72% | 68% | 57% | 60% | 59% | 68% |
| Percentage of ‘possibly brain dead’ patients where formal discussion with family occurred | 50% | 49% | 53% | 59% | 65% | 63% | 59% | 74% |
| Percentage of families of brain dead patients where organ donation requested and the family agreed | 52% | 66% | 58% | 61% | 52% | 52% | 48% | 44% |

The information collected by ODNZ indicates that the percentage of possibly brain dead patients tested to confirm brain death has varied by year with no clear trend. There is scope to improve consistency, with only around 68 percent of possibly brain dead patients tested in 2015. Although it should be noted this may not mean donation opportunities are being missed due to lack of determination of brain death, as the Ministry understands some ICUs are approaching families about consent prior to confirmed brain death and not determining brain death if the family decline.

Clinicians appear to be formally asking about organ donation more often according to the most recent data, although still around a quarter of families are not being asked.

The percentage of instances where families agreed to donation following a formal discussion has decreased in the last few years and remains very low, at 44 percent in 2015.

### Ethnic differences in donation

The death audit also collects information about different ethnic groups. Despite common misperceptions, Māori and Pacific people do donate organs. However, they do so at a lower rate than what might be expected given the proportion of potential donors that are Māori and Pacific. For the period 2008 – 2014, around one third of potential donors (i.e., ‘possible brain dead’ patients) were Māori or Pacific people, while only 14 percent of deceased donors were Māori or Pacific people[[23]](#footnote-23).

Table 3: Ethnicity of deceased donors

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  | 2011 | 2012 | 2013 | 2014 | 2015 |
| European | 30 | 28 | 29 | 37 | 46 |
| Māori | 3 | 6 | 3 | 4 | 5 |
| Pacific People | 4 | 1 | 0 | 2 | 0 |
| Other | 1 | 3 | 4 | 3 | 2 |
| Total | 38 | 38 | 36 | 46 | 53 |

Source: ODNZ. 2016. Annual report 2015.

Death audit information suggests that families of Māori and Pacific potential donors are asked about donation less often than European families, and that when asked, are less likely to consent.

Table 4: Various aspects of the process of organ donation by ethnicity – 2008 to 2014 inclusive

|  |  |  |
| --- | --- | --- |
| **Aspects of the process of organ donation** | **Total** | **Ethnicity** |
| **European** | **Māori** | **Pacific Peoples** | **Asian** | **Other** |
| Possibly brain dead | 892  | 534 | 195  | 78  | 61 | 24 |
| Tested for brain death | 544  | 330 | 114  | 47 | 41 | 12 |
| Organ donation “formally discussed” | 590  | 402 | 103 | 41 | 34 | 10 |
| Number of families who agreed to donation | 304  | 243 | 30 | 10 | 14 | 7 |

Source: Data provided by ODNZ

Families of possibly brain-dead European patients have organ donation “formally discussed” 75 percent of the time, while for families of possibly brain-dead Māori and Pacific patients this occurs only 53 percent of the time[[24]](#footnote-24),[[25]](#footnote-25)(the difference between European and Māori and European and Pacific people are both statistically significant). The consent rate for European families is 60 percent, while for Māori families it is 29 percent and for Pacific families it is 24 percent[[26]](#footnote-26) (the differences in consent rates between European and Māori and European and Pacific people are both statistically significant).

## Potential to increase rates of donation and transplantation in New Zealand

There is potential to increase rates of deceased organ donation in New Zealand. Our deceased donation rate is lower than other countries and has been relatively static while others have seen significant increases in rates. Stakeholders commented that there is considerable variability in organ donation numbers between DHBs and over time (Table 5).

Table 5: Numbers of deceased organ donors in New Zealand [DCD donors]

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| **Hospital** | **2011** | **2012** | **2013** | **2014** | **2015** |
| Auckland City CVICU | 0 | 0 | 1 | 0 | 0 |
| Auckland City DCCM | 7 | 6 | 9 | 6[1] | 6[1] |
| Christchurch | 5 | 7 | 7 | 7 | 8 |
| Dunedin | 4 | 3 | 1 | 4 | 5 |
| Gisborne | 0 | 0 | 0 | 1 | 1 |
| Grey Base | 0 | 0 | 0 | 0 | 0 |
| Hawke’s Bay | 2 | 3 | 2 | 3 | 2 |
| Hutt | 0 | 1 | 1 | 0 | 0 |
| Middlemore | 3 | 4 | 3 | 3[1] | 3[2] |
| Nelson | 1 | 1 | 0 | 0 | 2 |
| North Shore | 1 | 1 | 0 | 1 | 1 |
| Palmerston North | 1 | 2 | 0 | 2 | 0 |
| Rotorua | 2 | 0 | 1 | 1 | 0 |
| Southland | 0 | 1 | 1 | 1 | 3 |
| Starship Children’s | 0 | 0 | 1[1] | 1 | 0 |
| Taranaki Base | 0 | 0 | 0 | 0 | 1 |
| Tauranga | 0 | 0 | 0 | 0 | 0 |
| Timaru | 1 | 2 | 0 | 0 | 0 |
| Waikato | 5[2] | 0 | 5 | 3[1] | 8[1] |
| Wairau | 0 | 0 | 0 | 0 | 0 |
| Whanganui | 0 | 0 | 0 | 1 | 0 |
| Wellington | 4 | 6 | 4[1] | 10[3] | 12[1] |
| Whakatane | 0 | 0 | 0 | 1 | 0 |
| Whangarei | 2 | 1 | 0 | 1 | 1 |
| **Total number of donors** | **38 [2]** | **38** | **36[2]** | **46[2]** | **53 [5]** |

Note: [ ] DCD donors

Source: Organ Donation New Zealand Annual Report 2015

There is also variability in practices in clinical settings. The independent EY report notes that clinical stakeholders clearly indicated there were missed opportunities arising from a failure to identify potential donors or to consistently and effectively approach families about donation, which is consistent with the death audit data above.

Another key opportunity to increase rates is to make greater use of different types of donors. EY note that these might include:

* patients in such a serious condition that they are not admitted to the ICU but instead die in the emergency department (ED)
* marginal donors such as older patients and those with significant co-morbidities
* patients with families that have traditionally been seen as difficult to discuss donation with or are seen as likely to consent to organ donation
* DCD (donation after circulatory death) donors.

DCD donors have been a major source of increased numbers of organs in some other countries. Following its reform, Australia has increased its DCD rate by 250 percent (from 42 in 2009 to 107 in 2014), with DCD now comprising 28 percent of deceased donations[[27]](#footnote-27).

A national protocol for DCD was established by ODNZ in 2007. Donation after brain death (DBD) is still the major source of deceased donation in New Zealand, however. DCD does occur in New Zealand, but to a much lower extent than other countries. Given the current low number, increasing the number of DCD donors could be an avenue for increasing New Zealand’s overall donation rates.

Figure 7: Instances of donation after brain death (DBD) and donation after circulatory death (DCD) in New Zealand[[28]](#footnote-28)



It is difficult, however, to quantify how much New Zealand’s rate could potentially increase, or over what timeframe. The proposals in this paper follow the broad approach taken by other countries, adjusted as required for New Zealand’s context, with New Zealand being at broadly the same starting point as other countries that have introduced reforms. Their experience suggests there is considerable potential to increase deceased donation rates in New Zealand. The following sections of this report set out the key components of a strategy and suggest specific actions that together are likely to achieve an increase similar to those seen in comparable countries.

# A strategy to increase donation and transplantation rates

###

*Key Points:*

* *Countries that have had success in increasing deceased organ donation have often had a comprehensive national strategy. Piecemeal or solely locally-driven approaches have been unsuccessful.*
* *There are no silver bullets or quick fixes; improvement takes time and effort must be methodical and sustained.*
* *New Zealand has had no national strategy or overall stewardship and initiatives have tended to be one-off or piecemeal. Organ donation is not seen as “core business” by many ICUs and relies on individual clinicians to provide leadership.*
* *There are many lessons to learn from elsewhere, however, and the key elements of reform are well understood. Any approach must be tailored for the NZ context, and be appropriate for different cultural and population groups.*
* *A strategy to increase organ donation would fit well with the overarching New Zealand Health Strategy with its focus on service improvement, investment approaches, and responding to the challenge of chronic conditions. It would not require significant change in the context of the overall health system or major reform, but rather strengthening and expanding a number of foundational elements that already exist.*

## International experience

Many countries have successfully reformed their organ donation and transplantation systems. The Australian Organ and Tissue Authority notes three key themes that should underpin a strategy to increase deceased organ donation:

* **A foundational effort prior the national reform model** is needed: for example, existing infrastructure such as an established network of donation specialists or transplant coordinators;
* There must be a **methodical and sustained approach to clinical practice** **reform –** increasing consistency and reducing variation in approaches to end of life care at donation practice at the hospital level is critical, with a central role being played by the national body in driving change
* **Growth is progressive and cumulative –** while the changes in systems, practices and institutional arrangements are significant, successful reforms are implemented progressively over time. Actions are phased and prioritised and lessons learned and applied continuously. There are no “quick fixes”.

In addition, our review suggests that a strategy needs:

* a **mandate and stewardship from central government –** this is key to give visible priority to this work and therefore commission the required changes within the health sector
* to be **clinically-credible –** practices in clinical settings are critical for delivering change so any proposals must be credible with clinicians
* actions that are based on the **core elements of reform, but are suitable for the local environment** including health system arrangements, and social and cultural contexts.

More recently, Australia and the United Kingdom have implemented successful reforms based on the key elements of other successful reform programmes, contextualised to suit their health care systems and social, ethnic, economic and ethical environments. The reform undertaken by those countries can provide good guidance for New Zealand, as Australia and the United Kingdom were in similar positions to New Zealand before their reform. The Australian experience is particularly relevant given it has many similarities with New Zealand.

Both Australia’s and the United Kingdom’s reform included the establishment of a national coordinating body to lead, promote, and manage the organ donation system. The UK deceased donation rate has increased from 15 pmp in 2009 to 20.4pmp in 2015[[29]](#footnote-29). Australia’s deceased donation rate has gone from 9.4 per million in 2007 to 18.3 in 2015[[30]](#footnote-30).

A summary of key countries’ reform packages is in included in Appendix Four.

## New Zealand situation: need for a comprehensive strategy

New Zealand does not have a comprehensive national strategy or approach focused on increasing rates of deceased organ donation. While over a number of years there have been various initiatives introduced to improve different aspects of the donation system, these have tended to be piecemeal and collectively have not been sufficient to bring about a significant and sustained change comparable to what other countries have achieved.

Both the Ministry’s expert advisory group (EAG) and the independent report from EY discussed the need for a concerted and comprehensive effort to build on the initiatives already in place. The EY report suggested that the Ministry of Health should be charged with leading the development of a national and comprehensive, clinically-credible strategy for increasing rates of deceased organ donation, which should include:

* a clear vision for what New Zealand is trying to achieve
* key strategic priorities and associated actions to deliver on this vision
* clearly assigned national, regional and local roles and responsibilities and accountabilities for achieving the actions
* a measureable goal for tracking progress.

A strategy and associated actions must be tailored to the New Zealand environment, including the particular features of our health system, and be appropriate for different individuals and populations, including cultural and ethnic groups.

New Zealand is well-positioned to successfully develop and implement a national strategy to increase rates of deceased organ donation. EY note that key elements already in place include:

* a national coordinating body
* clinical positions within each ICU with a focus on organ donation (link teams)
* ICU access to 24/7 specialist advice and donor coordination/logistics
* training programmes to support clinicians in organ donation processes including family conversations
* death audit data reported and monitored from each ICU
* modest funding provided to ICUs on a voluntary basis to support the deceased organ donation process (extended link nurses).

This suggests that major reform is not necessarily required but rather that many of these elements need to be strengthened or extended as outlined in the following sections of this report.

Some key aspects are missing altogether, however, including a clear national, comprehensive and clinically-credible strategy, along with strong stewardship and leadership of the overall system. EY have raised the role of the Ministry of Health in providing this overall stewardship and setting clear performance expectations, which are then driven through the various bodies in the wider system.

A strategy to increase rates of deceased organ donation would complement initiatives already underway to increase the numbers of living kidney donors and would align with the New Zealand Health Strategy. In particular, it would provide a focus on service improvement that would directly benefit patients’ lives; it is an example of an investment approach with significant potential for saving lives and reducing health system (and potentially welfare) costs; and it forms part of an overall response to chronic conditions, a range of which underpin many instances of organ failure.

The following sections discuss each of the eight components of a possible strategy in more detail and identify the opportunities for improvement.

## Proposals

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

* a vision of raising rates of donation and transplantation in NZ, supported by an aspirational goal eg, 20 dpm by 2025, or top quintile of countries
* mandated national, regional and local roles and responsibilities to strengthen leadership, visibility and accountability for organ donation
* initial priority action areas to be the national coordinating body; practices in clinical settings and public awareness and registers
* actions that are appropriate for different population groups

# Component One: Legislative and ethical framework

*Key points:*

* *The Human Tissue Act (HTA) 2008 sets out the consent framework for deceased organ donation. NZ operates an “opt in” system whereby explicit consent to donation must be given. This compares to presumed consent systems which assume everyone is a potential donor unless they have opted out.*
* *Despite international debates about the merits of different consent models and legislative frameworks, in practice, consent is always sought from families of potential donors. This is the case in NZ. In this context, there is little value in reviewing the consent framework in the HTA.*
* *Ethical concerns about new and emerging practices, including new sources of donors, can hinder uptake e.g. DCD. Mechanisms to provide support and guidance to clinicians on ethical issues are important.*

## Legislative framework

Legal frameworks for consent to organ donation are an important underpinning feature of donation systems. New Zealand operates an “opt in” consent system, in which an individual or family must give explicit consent to organ donation. This differs from presumed consent systems in which everyone is assumed to be an organ donor unless they have explicitly opted out.

The Human Tissue Act 2008 (the Act) sets up a framework for explicit consent or objection to organ donation. The Act requires informed consent to the use of tissue, and establishes that such consent can be given by the donor personally, or after the donor’s death by a nominee of the donor, or the donor’s family. Informed consent is defined as consent to a particular use of tissue (rather than a general agreement) given freely in light of all the information a reasonable person, in that person’s circumstances, needs to make an informed decision. This framework is similar to the Health and Disability Consumers’ Code of Rights which also sets out requirements for voluntary and informed consent[[31]](#footnote-31).

The ability for the donor to give consent personally before their death[[32]](#footnote-32) has proven difficult in practice as it is challenging to consider if the donor had sufficient information for genuinely informed consent and there is no mechanism for reliably informing ICU staff or the donor’s family in the event that deceased donation becomes possible. The Act also requires the spiritual and cultural beliefs of the immediate family of the donor to be taken into account by a person consenting to donation[[33]](#footnote-33).

The Human Tissue Act specifies that the general agreement made on a drivers licence does not constitute informed consent or informed objection to organ donation[[34]](#footnote-34), therefore the drivers licence system can only be viewed as a register of “intent” [[35]](#footnote-35). The Human Tissue Act allows for an opt-in donor register to be established in the future by regulation[[36]](#footnote-36) to record informed consent, informed objections or nominations under the Act.

There is significant focus and debate both in New Zealand and internationally about different models of consent, whether an individual should be able to give binding consent or whether families may override someone’s wishes. These debates are often in the context of organ donor registers which can record someone’s wishes to donate, or not to donate.

Despite these debates and different legislative frameworks for consent, in reality, actual practice is similar virtually everywhere in that ultimately families are asked if they consent or object to their family member’s organs being donated, and donation will not proceed if the family objects[[37]](#footnote-37). This is the case even in countries that have presumed consent systems. In addition, clinicians in New Zealand have voiced strong opposition in the past to proposals to require them to uphold an individual’s wish to donate if it would mean overriding the wishes of family members.

We consider that, in this context, there is little value in reviewing the Human Tissue Act consent provisions at this time. The focus should instead be on improving other aspects of the current system within this legislative framework. The section on registers below discusses in more detail the role that registers might play in an organ donation system but concludes that they are best thought of as a mechanism to indicate a person’s wishes, which can assist in family decision-making rather than as a means to provide informed and binding consent (see Component Seven).

## Ethical framework

Organ donation is underpinned by complex socio-cultural and ethical issues. New ethical issues emerge whenever a new class of donors is proposed, for example DCD donors. It is important there is adequate guidance around ethical issues to provide support for clinical practice. This ensures the public can have trust and confidence in the transplant system and assures clinicians that that they are operating in ethically acceptable ways. In the absence of this, clinicians may well err on the side of caution and be reluctant to take up new practices.

EY’s review found a lack of clarity about ethical parameters amongst clinicians about some new approaches relating to non-traditional donors, for example, those dying in emergency departments, expanded eligibility criteria donors, or donation after circulatory death (DCD). These new practices all have ethical implications that require careful consideration[[38]](#footnote-38). Concern about ethical aspects may in part be why uptake of DCD, for example, has been low in New Zealand.

There are different possible approaches to providing ethical guidance.

The UK established an independent Donation Ethics Group[[39]](#footnote-39) that is accountable to the Academy of Medical Royal Colleges. It selects issues for its work programme based on questions asked of it by NHS Trusts, other ethics committees, and other stakeholder organisations. It regularly publishes guidance on its website such as an ethical framework for donation after circulatory death and guidance on paediatric donation[[40]](#footnote-40).

In Australia, the Organ and Tissue Authority (OTA) funds the relevant national organisations, such as the National Health and Medical Research Council (NHMRC) and the Transplantation Society of Australia and New Zealand (TSANZ), to develop or update ethical guidelines for emerging and existing practices. Recent publications include: The National Protocol for Donation after Cardiac Death and the development of the guidelines for eligibility and allocation of organs issued by TSANZ[[41]](#footnote-41).

In New Zealand the National Ethics Advisory Committee (NEAC)[[42]](#footnote-42) agrees its work programme with the Minister of Health annually. Its role is to provide advice to the Minister on ethical issues of national significance in respect of any health and disability matters, and to determine nationally consistent ethical standards across the health sector.

NEAC already has some interest in aspects of organ donation and transplantation, having recently considered access to organ transplantation and recommended further work on “how ethical principles are given effect through the decision-making processes for deceased donor transplants, following completion of the Australian National Health and Medical Research Council’s work on *Ethical Guidelines for Eligibility Criteria and Allocation Protocols for Organ Transplantation from Deceased Donors”[[43]](#footnote-43).*

## Proposals

No changes to the main legislative framework for consent to donation in the Human Tissue Act are proposed. It is unlikely to be a barrier to achieving increased rates of organ donation and transplantation.

Establish a mechanism where health professionals in NZ can obtain independent assurance that new practices and processes are ethically acceptable. Options might include:

* establishing a specific stand-alone organ donation and transplant ethics committee (as per the UK)
* using NEAC to provide advice and guidance. This would require changes to how NEAC’s work programme is set.
* exploring how to ensure the Transplantation Society Australia New Zealand guidance provides adequate support to address any ethical concerns.

# Component Two: A national coordinating body to lead a reform agenda

*Key points:*

* *A national body with a clear mandate to drive and improvement programme is essential. The scope and form of the national body might vary but the key element is that it is charged with overall responsibility for increasing rates of deceased organ donation.*
* *ODNZ has been very successful at providing an effective coordination and donor logistics service but does not have a clear role in delivering on an overall objective to increase organ donation.*
* *Major reform is not necessary but the role and mandate of the national body need to be clarified and expanded to have a clearer focus on increasing rates of deceased organ donation and to lead the implementation of a national strategy to increase deceased organ donation. Its location within a single DHB could be problematic and needs to be reviewed.*

## International experience

### Australia

The Organ and Tissue Authority (OTA) was established in Australia by legislation with the CEO and an Advisory Council to the CEO appointed by the Minister[[44]](#footnote-44). The OTA also established a Jurisdictional Advisory Group, chaired by the CEO, as its governance body, with standing committees on clinical governance, liaison with the transplant sector, and liaison with bodies promoting organ donation in the community[[45]](#footnote-45). OTA directly funds dedicated donation coordinators in a national network, called DonateLife coordinators. The DonateLife coordinators pass information to the transplant units[[46]](#footnote-46) and arrange for travel.

### United Kingdom

NHS Blood and Transplant was expanded to include all organ and tissue donation (deceased and live) to be the organ donation authority for the entire United Kingdom. It is a statutory authority established by an Order under the National Health Service Act[[47]](#footnote-47). Its functions are set out in a Direction from the Secretary of State for Health, and include organ matching and allocation, and promotion of organ donation[[48]](#footnote-48). Governance is provided through a Board, appointed by the Secretary of State. NHS Blood and Transplant is accountable to the Secretary of State for Health for its general operation, and financially responsible to the Department of Health. It is monitored by the Department of Health, in accordance with a substantial framework agreement[[49]](#footnote-49).

The NHS Blood and Transplant employs Clinical Leads in Organ Donation at NHS hospitals. In hospital donation is managed by Specialist Nurses in Organ Donation, directly employed by NHS Blood and Transplant. NHS Blood and Transplant match donors to recipients and commission dedicated retrieval teams. Detailed clinical and ethical guidance is also provided.

## New Zealand situation

### ODNZ

Organ Donation New Zealand (ODNZ) is the existing national coordination body for deceased donation. It was created in 2005 with the general aim to provide as many organs and tissues as possible of the highest quality for transplant recipients in New Zealand. ODNZ’s activities are included in the national services framework[[50]](#footnote-50).

ODNZ is a business unit of Auckland DHB and is funded by the DHB and subject to the DHBs usual accountability processes. In 2012 ODNZ received additional funding from the Ministry of Health for organ donation and transplantation. ODNZ is required to report regularly to the DHB on budget matters and provide an annual narrative report to the DHB and the Ministry of Health about its activities, including donations and training. Refer to Appendix Seven for more detail regarding ODNZ service objectives.

ODNZ has an Advisory Committee to provide input from health professionals involved in organ and tissue donation, intensive care, and from Māori and Pacific peoples and consumers. The Advisory Committee’s functions include contributing to a strategic direction to ensure initiatives to increase donation are evidence-based and co-ordinated, and to develop education strategies for the public, with a particular focus on Māori and Pacific people[[51]](#footnote-51).

The ODNZ service specification was revised in 2014 and public awareness initiatives are now a specific exclusion[[52]](#footnote-52).

ODNZ employs Donor Coordinators who liaise with ICUs and support hospital link teams and publish practice guidelines.

### Issues and opportunities

The independent review by EY found that ODNZ is recognised by clinical stakeholders as offering excellent coordination of the logistics of organ donation. It also provides a helpful advisory service to ICUs in relation to donor selection and management that has contributed to an increase in organ quality[[53]](#footnote-53). However, EY also noted a lack of overall system focus on increasing rates of deceased organ donation, including the need for a national coordinating body that is clearly responsible for driving an increase in organ donation. Stakeholders perceived that ODNZ does not have this clear focus currently and raised concerns about overall governance of the organisation, including its location with Auckland DHB, the efficacy of its advisory board, and the clarity of expectations and performance monitoring by the Ministry of Health and Auckland DHB.

EY suggest 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 governance arrangements
* making increasing the rate of deceased organ donation a clear and explicit objective, and providing ODNZ with the mandate to lead and implement change in the organ donation system
* considering including tissue donation roles and responsibilities within ODNZ’s mandate
* maintaining clear professional accountability of ODNZ clinical staff to an appropriate senior clinical lead[[54]](#footnote-54).

Stakeholders have noted the need to consider whether ODNZ has sufficient capability to take on an expanded role to lead the implementation of a strategy to increase rates of deceased organ donation.

There are several options for the form and location of the national coordinating body in addition to being housed within a single DHB, for example a stand-alone entity (as in Australia) or located within the Ministry of Health (as in Spain). EY note that, regardless of its eventual location, ongoing oversight by the Ministry of Health as steward and funder will be necessary to ensure national expectations are met.

In future it may be desirable to look at extending the scope of activity further to other aspects of the donation and transplantation system, such as living donation (beyond the current role in the Kidney Paired Exchange Scheme), but this is less critical at this time.

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

If organ donation numbers increase then the national coordinating body is likely to require additional funding so that it is adequately resourced to respond to a larger number of donation opportunities. For example, it may require an additional Donor Coordinator to be available to answer and support ICUs’ questions and attend retrieval of organs.

## 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 deliver on an objective to increase rates of deceased organ donation in New Zealand including:

* leading the implementation of the strategy to increase rates of deceased organ donation and championing organ donation in the health sector and the community
* implementing effective public awareness activities to build knowledge and understanding of organ donation and transplantation benefits
* determining the right form and location for the national coordinating body, bearing in mind the need to promote donation nationally, and influence clinical practice across the country.

Regardless of form and location, the Ministry of Health to provide ongoing and oversight and stewardship to ensure national expectations are fulfilled.

Future consideration:

Consider interface with wider aspects of donation and transplantation system

# Component Three: A clinical governance framework that supports quality assurance and governs the donation process

*Key points:*

* *Clinical staff need to be supported by a structured clinical governance framework that sets clear guidelines, expectations and accountabilities and has a focus on using performance information to learn and improve practices in clinical settings*
* *The death audit can be strengthened and better utilised to drive improvement*
* *There is variation in clinical leadership and a focus on improving organ donation is not always clearly embedded in existing DHB governance and quality improvement processes*
* *There are missed opportunities for patients in EDs to become organ donors. ED staff are not involved formally in the organ donation process and there are opportunities to improve linkages between ICUs and EDs to improve donation pathways*

## International experience

To support increases in organ donation and transplantation, successful countries have worked to ensure clinical staff are supported by a structured clinical governance framework that articulates the objectives, actions, results, and measures required for an effective organ donation system. A component of this framework is an audit of deaths to identify any missed donation opportunities and to provide quality assurance feedback to the system[[55]](#footnote-55).

#### United Kingdom

The UK has an established clinical governance framework, with detailed guidance for donation and transplantation. The clinical governance body is the Clinical Audit, Risk and Effectiveness Group (CARE), which includes senior clinicians and meets every two months to review incidents. It reviews all incidents in donation and transplantation, identifies improvement actions, and ensures the actions are completed. The UK also has clear national standards for the retrieval of organs[[56]](#footnote-56) and their transplantation[[57]](#footnote-57).

The UK operates a Potential Donor Audit covering all deaths in critical care (emergency departments and intensive care units). An annual summary of death audit data is published on NHS Blood and transplant’s website identifying a clear donation pathway and showing numbers at each step[[58]](#footnote-58).

#### Australia

Australia has made extensive change in this area as part of its reform agenda. Reporting and auditing of organ donation and tissue donation practice has been enhanced and embedded in the DonateLife Network. OTA is supported by a Clinical Governance Committee, which is the peak clinical committee for the Donate Life Network. It makes recommendations relating to clinical aspects of the national reform programme for consideration by the Jurisdictional Advisory Group.

In March 2012, the DonateLife Clinical Governance Framework and Clinical Practice Improvement Program was established to support and guide DonateLife Network staff in achieving the national objective of increasing organ and tissue donation rates across Australia[[59]](#footnote-59). The aim of the Clinical Governance Framework is to complement existing broader clinical quality frameworks and government structures within hospitals[[60]](#footnote-60).

Hospital Activity Plans were developed in every DonateLife Hospital in 2014-15. These plans are regularly reviewed and are used by staff to guide their work in implementing the national reform programme in their hospital. They are also used to support discussions about hospital performance with hospital executive teams and as part of annual performance reviews for the donation specialist staff[[61]](#footnote-61).

OTA is continuing to focus on implementing its Clinical Governance Framework. Phase two of the Clinical Practice Improvement Programme will involve a more intensive approach to the implementation of the Hospital Activity Plans and closer scrutiny and management of areas of concern. There will also be additional support for DonateLife staff from their interstate colleagues at paired hospitals[[62]](#footnote-62).

The DonateLife Audit in Australia is a nationally consistent method of retrospectively auditing deaths in DonateLife Network hospitals. Audit data is reported on a quarterly and annual basis. It has previously only included the identification of potential brain-dead donors. From early 2016 the intention is for data on potential DCD donors to also be reported[[63]](#footnote-63).

## New Zealand situation

## Overview

There is a need to embed clinical governance for organ donation into existing wider governance frameworks to provide focus and accountability for this activity within DHBs. EY note that this should begin with clear expectations and accountabilities being set by the centre, which then flow to accountable bodies including ODNZ and DHBs (noting the proposals above to reconsider the form of ODNZ and its location within a single DHB).

Within the DHB structure they suggest Boards, executive leaders and various committees could have a greater focus on organ donation in order to meet national expectations about increasing rates of deceased organ donation. For example, Community and Public Health Advisory Committees could have a greater role in promoting organ donation within their communities. In particular, Hospital Advisory Committees and Chief Medical Officers should more clearly have oversight of organ donation and could be instrumental in driving improvements in ICUs and EDs, including strengthening linkages between these two parts of the hospital.

Organ donation could be more visible in existing DHB quality improvement systems and processes. A key aspect of this would be to improve the quality of performance information available and to use it more effectively to learn and improve practice. EY and the EAG have suggested a number of improvements that could be made to the death audit which provides critical data for understanding current practice and improvement.

In addition to enhancements to clinical governance within DHBs, consideration could also be given to enhancing clinical governance relating to the national coordinating body. As discussed in the previous section, the role and purpose of ODNZ need to be clarified and expanded, including overall governance and stewardship by the Ministry of Health and reconsideration of its location within a DHB or elsewhere. As part of this, the role of its existing advisory committee should also be reviewed. One option might be to reconfigure it to fulfil a similar function to OTA’s Clinical Governance Committee, or to establish a subcommittee of it to provide explicit clinical governance.

These issues are discussed in more detail below.

#### Set clear performance management expectations

A strategy to increase rates of deceased organ donation should be supported by a greater focus on performance management, setting clear expectations at all levels of each DHB that improving organ donation rates should be a priority. This could include:

* the national coordinating body taking a stronger stewardship and performance management role of the overall system, clearly establishing expectations for the system to be driven by ODNZ (or the appropriate national coordinating body), DHBs, and ICUs
* sending death audit performance directly to the CMO of each DHB and the Ministry to ensure organ donation is given local and national visibility and priority
* encouraging DHBs to include appropriate qualitative organ donation measures in ICU clinical job descriptions and factoring these into annual performance reviews
* the Ministry establishing an aspirational national goal, supported by process objectives based on the organ donation steps to drive a reduction in variation between DHBs
* strengthening the role of Hospital Advisory Committees and Chief Medical Officers in ensuring improvements in clinical practice in ICUs and EDs.

#### Encourage more proactive clinical leadership

The greater focus on performance should be reinforced by more proactive clinical leadership throughout the DHBs. This could be encouraged by:

* widening Death Audit meetings should to include non-link staff from each ICU where possible
* making organ donation a standing item at ICU daily case meetings and/or Mortality & Morbidity meetings, with active involvement of ED clinicians as appropriate
* where appropriate, using and/or encouraging regional clinical networks (eg. trauma networks) and clinical leadership and practice models (eg support for small ICUs from larger ICUs)
* building on ICU link teams to strengthen local leadership at ICU level and between ICUs and EDs
* involving DHB Hospital Advisory Committees as appropriate.

#### Better use of performance information from the Death Audit

Death audit data is reported and monitored from each ICU by ODNZ. The death audit is focused on potential brain-dead donors. It collects information on: the number of potential donors (possibly brain dead), informal and formal discussions with families, consultation with ODNZ, consent by families to donation, and the number of actual donors. ODNZ are currently working to include potential DCD donors in the audit.

Stakeholders have reported that the institution of a national death audit is positive and a key building block for improved practice. However, they raised the following issues with the current death audit data and feedback processes:

* it is anonymised even at the institutional level – clinicians, and the Ministry, are unable to identify high performing units that could be providing examples of best practice for others to learn from
* it is unclear if coding for the death audit is completed consistently around the country
* there are delays in individual ICUs receiving feedback on performance with individual – feedback to individual ICUs is often provided months or even years after donation opportunities have been missed. This limits their ability to learn from those missed opportunities[[64]](#footnote-64).

While clinicians would like better visibility of the data to be able to compare their performance to that of their peers, they do not believe the death audit data should be publically disclosed as they consider this would be counter-productive to clinical learning[[65]](#footnote-65).

Aside from the intermittent feedback from ODNZ on the death audit, there is limited performance management and coordinated system improvement activity. There are not clear structures in place to foster leadership on organ donation and promote quality improvement in organ donation practices. The lack of a clear focus at national, regional or district level on improving donation rates means the responsibility for leading improvements in organ donation practices is largely left to the discretion and motivation of individual ICUs, with a ‘light touch’ from ODNZ[[66]](#footnote-66). In some ICUs there is a strong focus on organ donation due to strong clinical leadership, but this is variable across ICUs.

There is an opportunity to use death audit data to more effectively drive improvements in organ donation practices. In particular:

* Death audit data should be reported in a non-anonymised format that is accessible to all relevant personnel – the intention is not that the data become publically available, but that the reporting allows for improved benchmarking of practice between peer ICUs. This may need to be supported by an OIA amendment, or classifying the data as protected quality assurance activity under the Health Practitioners Competency Assurance Act 2003. This would still allow a national summary to be published, which gives the aggregate national picture of activity along the organ donation and transplantation pathway, and is consistent with how other jurisdictions public death audit data.
* Death audit reporting should be frequent and timely – at a minimum, it should be provided to and discussed with ICUs every quarter. This could be supported by more frequent electronic reporting, which we understand has recently been made possible as the death audit reports have been embedded in hospital data entry system so that ICU link nurses can now generate reports on demand[[67]](#footnote-67).

#### Better linkages with emergency departments

Patients may arrive in EDs with very little change of recovery, but the potential to be organ donors. If the families consent to organ donation, these patients should be transferred to the ICU to receive the treatment required to keep their organs functioning to facilitate successful donation.

Internationally, Emergency Departments (EDs) are a significant source of organ donors, with EDs identified as a key opportunity in Australia during its review. In 2010, the GIVE Clinical Trigger was adopted nationally in Australia to provide a consistent approach to criteria for identifying potential organ and tissue donors in all public and private hospital EDs (and ICUs). The GIVE Clinical Trigger has been endorsed by the Australasian College of Emergency Medicine. It was evaluated for its effectiveness in 2014 and a revised trigger is now being developed to improve the identification of DCD and tissue donors[[68]](#footnote-68).

In New Zealand, Emergency Departments are not formally involved in the organ donation process although ODNZ has developed best practice guidelines for EDs (covering admission to ICU from the ED specifically for donation) and is currently working to include these in its smartphone application (“the ODNZ App”)[[69]](#footnote-69),[[70]](#footnote-70).

It has been suggested that organ donation opportunities may be being missed due to insufficient communication between the ED and ICU. This can result in treatment being withdrawn (or not started) before the opportunity for organ donation can be offered to the family[[71]](#footnote-71).

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 practice. Some stakeholders have reported a reluctance among some intensivists to admit patients to ICU from the ED solely for the purpose of organ donation. ED staff are not required to take training on how to identify potential organ donors, although ODNZ has trained some ED staff who undertook the training voluntarily and the training is supported by the College of Emergency Medicine.

ED deaths are not yet included in the ODNZ death audit. Therefore, there is no data available to determine how many missed organ donation opportunities are occurring in EDs.

EY recommended a number of actions to formally involve EDs in the organ donation process. These include the development of pathways from EDs to ICUs for potential organ donation, identification of ED triggers to contact ICU, identifying appropriate champions in EDs, organ donation training for ED staff, including ED deaths in death audit data, and including ED staff at death audit meetings.

It is unclear how many additional donations will result from investing in the capacity of EDs to pursue organ donation opportunities.

Following discussion with the EAG, the Ministry considers the initial focus of the proposed national strategy should be on strengthening components of the existing system such as a clinical governance framework, hospital based donation specialists, training and financial support. Once these improvements have begun, initiatives could look to build a greater focus on organ donation in EDs. At that stage further consideration of what would support EDs to be formally involved in organ donation (eg, formal pathways and triggers) could be undertaken by the national coordinating body.

## Proposals

Have the national coordinating body work with DHBs to establish an appropriate clinical governance framework for deceased organ donation including:

* establishing appropriate roles and responsibilities in each DHB – donation specialists in ICUs, Emergency Departments, Chief Medical Officer, Hospital Advisory Committees
* improving the quality of information in the death audit and use it more effectively to learn and improve practice
* including all critical care deaths (including ED and ICUs) in the death audit
* making organ donation a standing item at ICU daily meetings and/or in mortality and morbidity meetings
* strengthening the relationship between EDs and ICUs
* using referral pathways and triggers from ED to ICU (triggering identification); ICU to national coordinating body (donation).

Reconfigure the ODNZ Advisory Committee to play a stronger role in clinical governance for the national coordinating body, for example establish a clinical governance subcommittee or establish an equivalent body to OTA’s Clinical Governance Committee.

Future consideration:

* encourage the use of regional clinical networks (such as Trauma networks).

# Component Four: Hospital based clinical donation specialists

*Key points:*

* *Link teams exist but their role as clinical leaders in improving organ donation rates is limited and variable between ICUs.*
* *Those countries with higher deceased donation rates have dedicated and partially funded intensivist positions in major hospitals to act as a donation champion.*

## International experience

Most countries with substantially higher deceased donation rates than New Zealand have dedicated and partially funded specialist and nursing roles to act as champions and provide explicit leadership for organ donation at the local level. International practice suggests that providing protected time for intensivists and nurses in organ donation is a necessary condition for raising the deceased donation rate.

#### Spain

A key element of the Spanish model is a network of Transplant Coordinators at each procurement hospital. Transplant Coordinators are intensive care specialists who are supported in their role by nurses, and are expected to facilitate the early identification and referral of possible donors. They are appointed by, and report to, the medical executive of the hospital, rather than the transplantation team[[72]](#footnote-72).

#### Australia

The Australian Organ and Tissue Authority (OTA) has also applied this model as part of their organ donation and transplantation reform programme. In 2009, OTA established the DonateLife network, comprising of DonateLife Agencies[[73]](#footnote-73) and hospital-based medical and nursing staff, to work specifically on organ and tissue donation across 78 hospitals, including those hospitals with significant donor potential.

DonateLife hospital-based medical and nursing donation specialists are responsible for organ and tissue donation processes in their hospitals. They work closely with hospital teams, particularly in the Intensive Care and Emergency Departments, to optimise the identification of potential organ and tissue donors, and the conversation of potential donors to actual donors. Medical donation specialists are mostly intensive care specialists who undertake the donation role part-time, and are responsible for ensuring optimal donation processes within the hospital, including those for donor identification and request to the family. Nurse donation specialists have the same purpose, with a subset in coordination roles undertaking the donation workup and providing 24-hour on-call availability.

Increasingly, donation specialists play an active role in facilitating the actual donation process in partnership with the DonateLife specialist coordinators and the treating clinical team. They are also responsible for raising awareness of, and providing education about, organ and tissue donation for medical, nursing, allied health staff and others who are involved in the donation process in hospitals. Donation specialist staff have in-depth donation knowledge, undergo communication training and have more frequent exposure to conversations with families about organ donation, and may therefore be better placed to undertake discussions with families about donation.

OTA provides funding to each state government to employ DonateLife staff. Funding is provided through two-year funding agreements, which require each state to maintain an organ and tissue donation service delivery model that is consistent with the national reform approach and is in accordance with relevant ethical and clinical protocols.

OTA also requires all states to employ State Medical Directors who, under the leadership of the OTA’s National Medical Director, are responsible for leading and managing all staff in their work to increase organ donation for transplantation across Australia. State Medical Directors work with the OTA and each other to act as champions and drive clinical practice and system change to increase organ and tissue donation rates.

## New Zealand situation

### Link teams

Each DHB has a link team to provide a local point of contact for ODNZ Donor Coordinators and assist other staff with the organ donation process. The link team consists of an ICU nurse, an operating theatre nurse and an intensivist.

The purpose of link nurses is to:

* be the key contact with ODNZ and co-ordinator for the link Team
* be a resource person along with the other link team members on organ donation procedures and processes
* work with ODNZ, as part of the link Team, to enhance the processes of organ and tissue donation in ICUs in New Zealand
* to ensure ongoing entry of data for the ICU Death Audit[[74]](#footnote-74).

The purpose of the ICU link Doctor is to:

* work with ODNZ, as part of the link Team, to enhance the processes of organ and tissue donation in ICUs in New Zealand
* assist the ICU link Nurse in completing the requirements for the ICU Death Audit
* be a resource person, along with other link Team members, on organ donation procedures and processes
* support the link nurse in her/his role[[75]](#footnote-75).

The purpose of the Operating Theatre link Nurse is to work with ODNZ, as part of the link Team, to enhance the processes of organ and tissue donation in each hospital in New Zealand[[76]](#footnote-76).

Typically, these roles are not funded, but they receive organ donation training and support from ODNZ. Link teams are considered to be a useful knowledge resource for the organ donation process and their presence contributes to creating a culture of organ donation within ICUs[[77]](#footnote-77). However, link team staff are not always available or called in to be involved when organ donation opportunities occur, in some cases due to rostering restraints[[78]](#footnote-78).

Organ donation is a time-consuming and challenging process, which demands a high workload and can often require a high level of nursing and support. These challenges are reported as greater outside ‘normal’ business hours when ICU staff numbers tend to be limited. Additional staff time required is sometimes dependent on goodwill, particularly on weekends[[79]](#footnote-79).

### Extended link nurse role

Following additional funding from Budget 2012, ODNZ funded an extended link nurse role in four DHBs in 2014[[80]](#footnote-80). Extended link nurses are required to ensure that all potential donors have been identified, as well as the usual link team responsibilities. This role is funded via ODNZ, unlike the other link positions, and was initially offered to ICUs where ODNZ thought it could make a difference, based on the ICU death audit data. The extended link nurse role is funded at 0.2-0.4FTE in Middlemore, Waikato, Wellington, and Christchurch hospitals. The staffing of the role varies for individual ICUs, ranging from one senior nurse to three senior nurses. Some extended link nurses have dedicated time for this role while some hospitals use the additional funding to cover the costs of the nurses being called in to facilitate a donation and for ICU death audit data entry.

Wellington ICU has been very positive about the impact of the additional funding for an extended link nurse role. They used it to establish a team approach, with 0.1 FTE used to support 3 link nurses (who will come in on a “call back” basis over and above their normal FTE to attend to supernumerary clinical organ donation work) and 0.3 FTE for a ‘Clinical Speciality Nurse’ who has a coordination and leadership role[[81]](#footnote-81).

Wellington ICU’s deceased donation has increased from 4 to 6 donation per annum to 10 donations in 2014 and 12 in 2015[[82]](#footnote-82). The number of donations in Waikato also increased in 2015, with 8 donations compared to between 3 and 5 in previous years. The number of donations in Christchurch and Middlemore have not changed since the introduction of an extended link Nurse role[[83]](#footnote-83).

### Hospital based leadership for donation

Stakeholders had strong beliefs that medical specialists should lead the organ donation processes in hospitals[[84]](#footnote-84). ICUs report that the funded extended link nurse role has made organ donation easier for them – partly due to increased resourcing to facilitate organ donation. However, nurses’ role as clinical leaders in improving donation rates is limited, and variable between ICUs.

Although link teams are valued, there is no funding for clinical leadership positions to drive clinical practice change to increase organ donation rates. In its review, EY found there is variable leadership, practices and understanding of organ donation and its role in ICUs across the country, with some ICUs not seeing organ donation as a core part of ICU business.

Wellington’s ICU has reported it has one Intensive Care specialist with 0.1 FTE dedicated to organ donation (this is not funded, but included among the intensivists’ other non-clinical duties). They consider the additional nursing support (via the additional funding for an extended link nurse of 0.4 FTE) plus a named ICU Specialist holding this portfolio has proved invaluable[[85]](#footnote-85).

Our Australian colleagues on the EAG emphasised the importance of having partially funded specialist roles in both medical and nursing roles and consider they didn’t really get traction for practice improvements until they had such roles in each hospital. The link teams include link doctors with a focus on organ donation, but they do not have any protected time for this role.

### Options for change

#### Expand the use of partially funded nursing donation specialist roles

The link team model, and the extended link nurse role, provides a strong starting point for building local cultures supportive of organ donation. However, international evidence suggests protected time is required to ensure nurses are able to maintain a focus on organ donation and this currently only occurs in 4 ICUs. The expanded link nurse scheme could be extended to include other ICUs that have a large potential for organ donation (based on the patient mix and volume).

#### Introduce partially funded medical donation specialist roles

Establishing more protected time for organ donation in ICUs would signal the importance of organ donation locally. It would also create some additional expectations on clinical staff to provide leadership for practice change and to champion deceased organ donation across the ICU and organisation.

The Ministry considers there is a strong rationale for having medical and nursing roles at a local level that are funded at a fraction of a full-time-equivalent position, with the staff in those roles being responsible for:

* Ensuring optimal donation processes at the hospital occur, including donor identification and request to the family (medical and nursing)
* Coordinating roles in donation workup (nursing)
* Facilitating actual donation processes in partnership with the treating clinical team
* Raising awareness of, and providing education about, organ and tissue donation for medical, nursing, allied health staff and others who are involved in the organ donation process in hospital.

Nearly 80 percent of possible DBD opportunities occur in eight ICUs, while 80 percent of actual donations occur in 7 ICUs[[86]](#footnote-86). Therefore, it is likely to be more cost-effective to focus any funding for dedicated organ donation medical and nursing roles in the 7-8 ICUs where the majority of organ donation opportunities occur.

If these roles are established in the larger ICUs they could provide additional support to smaller ICUs. This is starting to occur in some states in Australia[[87]](#footnote-87). We also note the recent additional funding provided to ODNZ has enabled them to send Donor Coordinators ahead of the surgical members of the retrieval team to assist the ICU and other hospital staff in some of the organisational, administrative and inter-personal aspects of the donation process[[88]](#footnote-88). This additional support is likely to be highly beneficial for smaller ICUs where organ donation opportunities are infrequent, and staff are therefore less practised.

#### Establish organ donation champion roles within DHBs

There are significant opportunities to strengthen the leadership for organ donation at the local hospital level, to align with a national strategy and national clinical governance framework.

New Zealand should explore the opportunity of establishing more formal clinical championship roles within the wider DHBs (and at more senior levels) with protected time. This may require specific funding, but could also be made a requirement for DHBs as part of any accountability framework.

Clinical champions would build a focus on organ donation and a culture of performance improvement among clinicians and across DHBs. As with specialist roles it would be more effective to focus on the 8 ICUs where the majority of donation opportunities occur.

## Proposals

Partially fund intensivist and nursing roles in 8 DHBs with greater opportunity to increase donation numbers (0.1 FTE intensivist and 0.4 FTE nursing) to lead the implementation of the clinical governance framework in each DHB

Maintain existing link teams in remaining 12 ICUs

Future consideration:

* Expanding funding for donation specialists to more/remaining ICUs
* Larger ICUs or national coordinating body to support smaller ICUs with donation (potentially sending specialist staff).

Appoint appropriate people as donation champions within the ICU and hospital more broadly.

# Component Five: Specialist training for clinical staff

*Key points:*

* *Other countries have significantly invested in enhanced training for a range of health professionals’ knowledge and education needs from introductory to advanced training packages and is useful for creating “whole of hospital” donation culture.*
* *Training in how to identify potential donors and have effective conversations with families about organ donation is vital.*
* *New Zealand training could have improved coverage and uptake especially for non-intensivist staff in smaller centres.*

## International experience

Specialist training for clinical staff is a critical component of any reform package aimed at increasing donation rates. It influences the extent to which intensivists, and other clinicians involved in organ donation, have the skill to identify organ donation opportunities and discuss it with families in a manner that supports the likelihood that they consent to donation.

### Australasian Medical College endorsed training programmes.

The College of Intensive Care Medicine (CICM) of Australia and New Zealand requires all Australian intensivist trainees to complete the ‘Family Donation Conversations Core Module’ (core FDC), which was developed as part of the Australian reform agenda. Core FDC workshops have been facilitated across Australia since 2012. The core FDC is a two-day workshop developed by OTA with the Gift of life Institute in Philadelphia (an international leader in education on family communication) and tailored specifically to the Australian context.

Trainees are required to complete the CICM eLearning programme entitled *‘Brain Death and Organ Donation’* before attending the core FDC workshop. These is also an expectation that all trainees have read and understood ‘*The ANZICS Statement on Death and Organ Donation’* prior to attending the core FDC workshop.

OTA’s professional education package for organ donation also includes:

* ‘Introductory Donation Awareness Training’ – a multidisciplinary 1 day workshop which provides introductory training and education to a range of health professionals working in organ, eye and tissue donation. This replaces the General ADAPT course as the introductory unit of the PEP (which is still offered in New Zealand)
* Practical ‘Family Donation Conversation’ module – this workshop aims to provide increased skills and practice in having conversations with potential donor families about organ and tissue donation
* Advanced Family Donation Conversations workshop – this is offered annually to experienced clinical and donation specialists. The workshop focuses on new and emerging content and specific areas of interest in the sector.
* Family Donation Conversations e-learning program – this is for professionals that have completed the core and practical FDC workshops. It provides participants with revision modules that reinforce the key training from the FDC workshops and provides access to practical tools to support family communication and practice.

Since March 2012 the Family Donation Conversations workshops have been attended by more than 1,280 health professionals in Australia[[89]](#footnote-89). The provision of specialist training continues to be a priority for OTA. OTA’s 2014-18 Strategic plan includes a number of actions to improve the content and uptake of the professional education package, including a focus on improving cultural competencies.

## New Zealand situation

New Zealand intensivist trainees are also required to complete training in organ donation by the CICM, but this can involve either ADAPT or the core FDC workshop.

The ADAPT workshop is a 1 day workshop for doctors working in ICU and ED. In Australia, the ADAPT workshop has been replaced by core FDC for intensivists and the Introductory Donation Awareness training (a 1 day workshop) for other health professionals working in organ donation.

Some intensivists have travelled to Australia to complete the core FDC workshop. ODNZ arranged for OTA to deliver a core FDC workshop in New Zealand in November 2015. This workshop was attended by 36 participants, including 10 intensive care specialist and 26 intensive care nurses. The workshop was rated very highly by participants[[90]](#footnote-90). ODNZ is currently arranging with OTA for another core FDC workshop to be held in New Zealand in August and intends to hold a core FDC workshop annually if there is demand for it[[91]](#footnote-91).

Organ donation training is not required for existing CICM Fellows. It is estimated that approximately 30-50 percent of intensivists have completed organ donation training[[92]](#footnote-92). There is also no expectation for intensivists to take refresher courses to ensure their knowledge and skills remains up to date. ODNZ does not offer any advanced courses, so if intensivists want to continue upskilling themselves following the ADAPT workshop they need to travel to Australia.

ODNZ donor co-ordinators are required to complete organ donation training. ODNZ provides educational programmes to health link teams involved in organ donation, including ADAPT. ODNZ are considering making the completion of core FDC workshop a requirement for ICU link nurses.

Some smaller ICUs are staffed by non-intensivist medical staff, such as anaesthetists, who are not expected to complete organ donation training. However, ADAPT workshop is recognised as part of a clinician’s continuing medical education by the Australasian College for Emergency Medicine, Australian New Zealand College of Anaesthetics and Royal Australasian College of Physicians. ODNZ does encourage these staff to take part in training and has trained some ED and other staff who voluntarily undertook training. For example, the 2014 ADAPT workshop included 4 anaesthetists[[93]](#footnote-93).

### Options for change

Representatives from OTA have indicated they consider training to have been one of the most important aspects of their reform. Continuing with the current level of training will not support an increase in deceased donation rates.

Increasing the update of organ donation training, both by intensivists and other health professionals involved in organ donation opportunities should be a focus of the proposed national strategy. Options for increasing uptake include:

* encouraging CICM Fellows who have not taken an organ donation course or not taken it for a long period of time to attend a core FDC workshop or the follow up practical FDC workshop
* requesting CICM consider promoting refresher training to Fellows
* promote organ donation training to other specialities, eg, anaesthetists, emergency medicine specialists.

Increasing the uptake of organ donation training is more likely to be successful if there are suitable workshops available, for example, advanced or refresher training. New Zealand could develop its own professional education package, however, this is likely to be costly. A more cost effective option would to work with OTA to run its workshops in New Zealand, either as they currently are, or a version adapted for New Zealand.

## Proposals

Increase the uptake of appropriate training by clinical staff in organ donation conversation, including consideration of holding a practical and advanced core Family Donation Conversation workshop in New Zealand and promoting training to CICM Fellows who have not taken the course for a long period of time to attend.

Work with Australian OTA to have a wider range of courses available in NZ eg, 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.

# Component Six: Financial support to donor and transplanting hospitals

*Key points:*

* *Deceased organ donation is a relatively rare event that is hard to plan and budget for. Organ donation is not always perceived as core business and is seen as requiring extra work. There may be disincentives to pursuing organ donation because organs may be allocated to recipients in a different DHB.*
* *In addition to part funding specialist organ donation positions, most countries with higher donation rates therefore provide direct compensation to donor hospitals for the additional costs associated with each donation event.*
* *New Zealand had a similar payment until recently but it became undersubscribed and has been discontinued.*
* *Increases in numbers of available organs will require attention to transplant capacity to ensure that additional organs can be utilised.*

Deceased organ donation is a relatively rare event for an ICU. In New Zealand, many DHBs deal with organ donors only on an occasional basis (see Table 5 in Background). This is likely to make it difficult to plan and budget for organ donation activity year on year in advance. Unsurprisingly perhaps, EY found that many ICUs do not seem to regard organ donation as core business and that dealing with a potential organ donor is often seen as extra work. In addition, there may be a disincentive to actively pursuing organ donation because any organs retrieved will go into the national allocation system and there is no guarantee that they will be allocated to a recipient in the same DHB the organs came from. In addition, the greatest scope for increasing donation is in the categories of donors that require greater investment of effort from ICUs (e.g. DCD)[[94]](#footnote-94).

Strategies to increase deceased organ donation therefore often include some form of financial support to donor hospitals to ensure that the costs related to the management of organ donation are not a barrier to donation. Reimbursing costs is not seen as an incentive or payment for organs.

## International experience

In Australia hospitals are provided AU$10,000 for every consent for every actual or intended donor[[95]](#footnote-95). The UK provides £2,000 to Trusts on a quarterly basis for each donation consent (even if donation does not actually proceed, e.g. due to clinical reasons). This figure was identified following the 2008 Taskforce and kept under review[[96]](#footnote-96). Other jurisdictions provide funding as a set annual contribution rather than on a per-event basis[[97]](#footnote-97).

The additional costs typically recognised are the additional staffing requirements for the coordination of the donation; maintaining the perfusion of the deceased patient’s organs prior to retrieval (the physiology changes at death and is different than for live patients); additional time in the ICU, cross matching, and theatre time.

## New Zealand situation

Between 1998 and 2014, hospitals could claim $6,500 per donation (up to $1,500 for the cost of tissue typing and $5,000 for additional ICU and operating theatre costs) from the Ministry. Initially this was oversubscribed, but after 2006 became undersubscribed for unknown reasons. The funding was reallocated in 2013/14.

Today, organ donation activity is accounted for in the population based funding formula (PBFF). The only form of direct organ donation related funding currently provided to hospitals is the funding for extended link nurse roles provided to four DHBs since 2014.

It is unclear whether the current DHB funding arrangements adequately support organ donation. However, given the difficulty in forecasting the number of donation opportunities that will occur in each ICU each year, it would seem likely that it is difficult for many DHBs to plan and budget appropriately for this activity.

One option is simply to set and enforce expectations that DHBs increase rates of organ donation and meet costs out of the PBFF funding envelope. This would need to be clearly visible to intensivists, managers and General Managers of Funding and Planning to ensure it influences prioritisation decisions. However, given organ donation is a rare event, it may be difficult for DHBs to estimate how much funding will be required each year.

A second option is to review and potentially reinstate the previous payment for organ donation that was discontinued in 2013/14. Providing specific funding for organ donation opportunities has the benefit of ensuring that the funding is directed to the ICUs undertaking the donation process and providing clinicians and managers with confidence that the additional costs associated with organ donation will be met. It would also reinforce to DHBs that increasing organ donation and transplantation is a priority for the Government and encourage a joint management and clinician focus on increasing donation rates.

There is precedent for funding outside the PBFF. For example, around 30 percent of funding for elective surgery is paid separately from the general funding. There is also the option of ring-fencing funding, as is done with funding for mental health services. Ring-fencing means funding must be spent for a specified purpose, but lets a DHB decide how funding will be spent within that restriction. A further option is to consider a national funding arrangement. This may be appropriate given how rare an event organ donation is and the fact that organ donation is a national activity, in that organs can be allocated to anyone on the national waiting list.

While these proposals are out of keeping with the general approach of providing DHBs with a funding envelope and allowing them to determine where it should be allocated, it is in line with the New Zealand Health Strategy principle of funding arrangements supporting wider sector goals rather than narrow organisational priorities.

Before the option of providing specific funding for the management of potential donors can be considered, the costs associated with managing potential donors need to be identified. Both Australia and the United Kingdom have conducted this type of analysis, which could provide a template for New Zealand.

### Is ICU capacity a barrier?

ICU capacity could also potentially provide a disincentive to actively pursue donation opportunities. New Zealand has less per capita ICU resource than comparator countries, such as Australia (which has 50 percent more). Unfortunately the National Minimum Dataset ICU bed utilisation rate data is not reliable enough to indicate how close to capacity ICUs are currently operating. However, the feedback from clinicians interviewed by EY was that the limiting factor is generally not physical capacity (i.e. beds and equipment) but rather, staffing[[98]](#footnote-98). This should be confirmed through further discussion with DHBs, in particular General Managers of Planning and Funding and Chief Operating Officers.

### Transplant service capacity

The immediate focus of this review is on options to increase rates of deceased organ donation. While the number of organs available is the key rate-limiting factor in being able to meet the demand for transplants, it is important that a strategy to increase organ donation ensures that organs are able to be utilised. The EAG emphasised that lessons from international reform programmes included planning ahead to manage increased donations.

If New Zealand is successful in increasing donation rates this will create a greater demand across the donation and transplantation sector. The increase in capacity may require a considerable lead time and will need to be resourced and planned in parallel with the strategy to increase donation. 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. This modelling will need to consider the likely increase in donors, and the increased need for ICU, surgical, and emergency department resourcing for both donation and transplantation.

EY was advised by retrieval and transplantation stakeholders that abdominal organ transplant services (kidneys, pancreas and liver) have the capacity to absorb an increase in donation rates (although this would need to be monitored depending on the rate of increase in organ donation), but concerns were raised about the capacity of cardiothoracic transplant services (heart and lung) to respond.

Under current arrangements, additional kidney transplants will be distributed across three DHBs, and other organ transplants would require capacity at Auckland DHB. Auckland DHB, as host of the national cardiothoracic service, has indicated to the Ministry that the recent increase in donation rates has put pressure on the capacity of the cardiothoracic transplant services. For example, in 2015 there were 35 heart and lung transplants, compared to 24 in 2012.

There will also be additional post-transplant costs associated with additional transplants. For patients who receive a kidney transplant as a result of the increase in deceased organ donations, this will be offset by the reduction in dialysis costs.

##  Proposals

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

* reimbursing the additional costs incurred in the donation process to the donating hospital outside the PBFF, or
* a national funding model.

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

# Component Seven: Public awareness and education, media engagement, and donor registers

*Key points:*

* *Initiatives to increase information, raise awareness and promote organ donation may help to dispel myths, prompt discussions with family members about wishes to donate, and shift attitudes to organ donation. Initiatives can take many forms but should be based on sound research about what will be effective, including with different groups.*
* *Increased awareness and understanding can support family decision-making in ICUs so that there is some prior knowledge of organ donation before families are asked to decide about donation. There is also evidence that family consent rates are higher when it is known that a potential donor wished to donate.*
* *The media are a major source of information about organ donation and transplantation and can positively or negatively influence attitudes to donation. Successful reform programmes often include a specific strategy to engage with the media to provide accurate and balanced information.*
* *Registers can be an important mechanism for signalling a person’s intent or wish to donate and informing family decision-making. There is evidence that family consent rates are higher when a potential donor is on a register and this is made known to the family. International evidence suggests families rarely override wishes when they are known. Registers themselves can also be a focal point for raising public awareness.*
* *Registration rates can be low so it is important to have other initiatives to prompt discussions about organ donation wishes amongst families.*
* *NZ has limited education and awareness activity and no specific media strategy.*
* *The driver’s licence can record intent (not consent) but is not readily accessed in ICUs. There is little information available about organ donation when people are asked to decide about donation during the licence process. There is public misconception about the driver’s licence and negative publicity about its limitations.*

## Overview

International organ donation and transplantation strategies typically include a focus on improving public awareness, education and knowledge about organ donation and the benefits of transplantation for recipients.

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 is positively correlated with willingness to donate. Accurate factual knowledge and how informed a person feels have been positively associated with donation attitudes, willingness and donor status[[99]](#footnote-99), [[100]](#footnote-100).

Critically, prior awareness and understanding of donation and transplantation, as well as knowledge of a family member’s wishes about donation, can be important factors when families are faced with a decision about donating a family member’s organs.

Knowing a person wanted to be an organ donor may result in families being more likely to give consent for organ donation. Australia’s DonateLife Audit shows that when families are aware of the potential donor’s wishes about donation, 77 percent consent to donation (regardless of whether the donor has registered on a donor register or not). When families are not aware of the person’s wishes, only 46 percent consent to donation[[101]](#footnote-101).

Figure 8: Family consent when aware/not aware of potential donor’s wishes



Clinicians on the Ministry’s Expert Advisory Group also commented that family conversations about donation are significantly easier when families have previously discussed the issue.

For this reason, awareness campaigns often focus on encouraging people to have conversations with their families about organ donation so that their wishes are known in advance. Campaigns may also encourage people to sign up to an organ donor register. Again, registers can be an important means to provide information to families about a person’s wishes to donate or not. Promotion of registers can be a focal point for awareness-raising campaigns as they provide a tangible action people can take. Registers are discussed in further detail in the section below.

Media depictions of organ donation can have an impact on attitudes to donation and can affect donation rates. In 1980, following the Panorama programme in the UK raising concerns about criteria for the determination of brain death, organ donation rates fell dramatically, and took 15 months to recover[[102]](#footnote-102). Some countries therefore also have a media engagement strategy to ensure information that is reported is accurate.

## Approaches to raising public awareness and education and media engagement

Public awareness campaigns can take various forms, mass media, interventions in schools, workplaces or communities, and a combination of initiatives.

Research has found that the source of information with the most impact on people’s attitudes towards organ donation is likely discussions with family and friends[[103]](#footnote-103), [[104]](#footnote-104). Campaigns designed to raise donor registration rates can be effective[[105]](#footnote-105). The most effective campaigns are those that combine media and interpersonal contact friends and family. Testing and trialling messages is very important. A UK study found that approaches that appealed to messages of reciprocity and fairness were the most effective[[106]](#footnote-106).

Social media channels can be significantly more cost-effective than traditional mass media campaigns and appear to be effective when they are genuinely interpersonal. Research shows that a large increase in registrations can be gained through promotion of a social media friend’s decision to register, but that it is a very short-term effect[[107]](#footnote-107). Traditional online advertising is less effective than promotional campaigns where friends encourage registration via social media, or competitions between teams using social networking sites[[108]](#footnote-108).Community-based initiatives, such as those based in workplaces and driver licence offices seem to be effective[[109]](#footnote-109),[[110]](#footnote-110).

While study results are mixed on the effectiveness of particular awareness-raising interventions, several things do seem clear:

* public awareness campaigns can have an effect on willingness to donate
* understanding about organ donation is a predictor of willingness to donate
* public awareness efforts should be focussed on increasing understanding of organ donation and encouraging conversations with family and friends (particularly since it is families who will be asked to consent to donation).
* donor registers can provide a focal point for public awareness and provide a tangible action for people to take
* messages should be tested with focus groups before being used
* initiatives with interpersonal elements appear to be more effective than others
* media portrayals of organ donation have a large impact on attitudes toward transplantation
* countries that have successfully increased donation have made public awareness and/or media engagement a core responsibility of the national coordinating body.

### International approaches

#### Spain

The Spanish system of donation and transplantation pays close attention to the media (including a communications policy) and uses the media to disseminate positive news stories.

The Spanish National Transplant Organisation has a communication policy for the media based on four principles aimed at assisting the media to handle information about donation and transplantation appropriately:

1. A 24-hour telephone line available for consultation;
2. Easy and permanent access to the media;
3. Connection with journalists built through dedicated meetings aimed at learning about mutual needs; and
4. Delivery of messages with no intermediaries.

Spain promotes organ donation through the media through the dissemination of positive news. Each year Spain conducts a training seminar in organ donation which is aimed at journalists to provide first-hand information about organ donation and transplantation processes[[111]](#footnote-111).

#### United Kingdom

The UK Organ Donation Taskforce considered there was an urgent requirement to identify and implement the most effective methods though which organ donation and the ‘gift of life’ could be promoted to the general public, and especially to ethnic populations. In response, NHS Blood and Transplant has engaged in extensive promotion activity, including mass media campaigns, and targeted community initiatives. The UK programme includes a strong emphasis on encouraging people to sign the donor register, and have family discussions. They also have an annual National Transplant Week, focussed on ‘getting people talking about organ donation’[[112]](#footnote-112). They make strong use of social media, including partnering with Tinder[[113]](#footnote-113) and community-based campaigns, such as a partnership with Hasbro to create a life-sized version of the board game O*peration* to be used as a promotional tool in shopping malls[[114]](#footnote-114).

#### Australia

Australia’s review by the National Clinical Taskforce on Organ and Tissue Donation recommended “funding a national communications campaign to simplify measures to the public, dispel myths, educate and better promote the way Australians can commit to donation based on robust social marketing methodologies”. Australia subsequently put 9 percent of the organ donation reform package funding towards national public awareness and education ($13.4 million [$3.35 million per annum] of a total of $151.1 million)[[115]](#footnote-115). The Australian programme includes significant investment in community-based activities through Donate Life (the coordination network funded by OTA), including DonateLife Week, which is focused on having people talk to their families. They have also produced specific resources for Aborigines and Torres Strait Islanders, and for schools[[116]](#footnote-116).

### New Zealand situation

There is no organisation with responsibility for public awareness or media engagement in New Zealand.

Organ Donation New Zealand is not contracted to carry out public awareness campaigns although has engaged in some activity, including producing resources for the school curriculum. Some NGOs also carry out public awareness and education activity for example Kidney Health NZ, and Give Life NZ.

There is no national strategy for engaging with the media. ODNZ have indicated that they attempt to correct the media where information has been misleading in relation to organ donation. However, there is no consistent messaging or contact with journalists to ensure that information is accurately and positively portrayed.

It is unclear what the current level of public awareness and understanding of organ donation in New Zealand is. A baseline survey is the best way to identify gaps in public awareness and understanding and therefore areas to focus campaigns on. For example, if people are unaware that families are always asked for consent to donation, then clarifying this and encouraging discussions with family will be an important area of focus.

## Donor registers

Registers have been adopted by many countries and are often a key focus of public debate. They are not generally considered essential for reforming organ donation and transplantation systems, although many countries that have shown an increase in donation rates already had a register and they have been found to be a useful tool for promoting public awareness of organ donation and prompting people to discuss their wishes with their families.

Their main value is as a mechanism to provide a focal point for awareness-raising, provide people an opportunity to record their donation wishes, and provide an indication about donation for health staff. As discussed above, their main contribution is that they enhance discussions with families and help the decision-making when they are approached about organ donation.

Data suggests that family consent rates are higher where people are on a register and the family is aware of this. In the UK, the 2014/15 audit figures revealed that when a deceased individual was known to be registered on the Organ Donor Register, the overall consent/authorisation rate was 88 percent compared to 47 percent when the individual’s registration status was not known[[117]](#footnote-117).

Similarly, Australian research[[118]](#footnote-118) found that when the individual was known to be registered as a donor, the rate of family member consent was 93 percent, compared with 70 percent when the individual was not on the register. Furthermore, the very low objection rates when someone is on a register (12% in the UK and 7% in Australia) suggest that families do not often override a person’s wishes when they are known to the family.

Figure 9: Family consent when individual registered/not registered as a donor



Australia’s research also shows that when the register was not checked, only 39 percent of families consented to donation. This suggests that checking the register increases the likelihood of consent and provides a clear case for using registers when discussing donation with families of potential donors.

Figure 10: Family consent when the register is checked vs not checked



While interventions that work toward some degree of documentation or family notification can serve much the same purpose as a register, registers are an effective way to document and provide evidence to the family of an individual’s wishes.

The proportion of people who sign up to a donor register, however, can be low and tends to be below surveyed levels of support in populations for organ donation. Studies in countries comparable to New Zealand indicate that a sizeable majority of the general public express positive support for organ and tissue donation or indicate willingness in principle to be donors. However, these levels of support are not usually matched in terms of actual numbers of people signing up for registers.

Table 6: Percentage of population willing to donate and percentage of population registered

|  |  |  |
| --- | --- | --- |
| **Country**  | **Percentage of population willing to donate** | **Percentage of population registered** |
| Australia[[119]](#footnote-119), [[120]](#footnote-120) | 69% | 32% |
| UK[[121]](#footnote-121) | 51% | 31% |

Rates of registration are not evenly spread across populations: younger people, people with higher levels of education and people with higher incomes are more likely to register as organ donors[[122]](#footnote-122).

Because registration rates in a population may be relatively low, countries often emphasise the importance of having family discussions as well as registration. For example, Australia’s priority in terms of community awareness raising has been to emphasize family knowledge of donation wishes as well as registration on the register[[123]](#footnote-123).

### Types of donor registers

Internationally, a large number of jurisdictions offer mechanisms for people to formally record their wishes regarding organ donation, through: 1) cards or other small documentation carried on the person (eg, donor cards, identity cards, health insurance cards) 2) centralised databases to which people submit information. Many jurisdictions use one or a combination of these mechanisms.

#### Opt-out, opt-in, and combined registers

As discussed in the Legislative Framework section above, the issue of registers is often intertwined with issues of consent. Opt-in registers operate in jurisdictions where an individual’s agreement to be a donor must be actively expressed (explicit), rather than presumed. They record an individual’s decision to be a deceased donor, and are often used to promote organ donor awareness and evaluate public campaigns. England, Scotland and most states in the USA operate an opt-in register.

Opt-out registers operate in jurisdictions recognising the principle of presumed consent to donation, where a deceased individual is considered as agreeing to donate by default unless they explicitly object to donation before death. They are a legal tool for individuals to express their objection. Austria, France and Portugal are jurisdictions with opt-out registers.

Combined registers provide people the opportunity to record either 1) agreement to be a donor or 2) objection to being a donor. Combined registers are used both by jurisdictions that presume agreement and where agreement must be actively expressed. Australia, Sweden, and some Canadian provinces (eg, British Colombia, Nova Scotia, and Ontario) are jurisdictions that operate combined registers.

#### Binding versus non-binding registers

A binding (hard/strong) register gives primary consent to the individual and does not allow relatives to oppose or override the individual’s recorded wishes. Legislation requires that the individual’s wishes are followed, unless it is known that they changed their mind prior to death, regardless of the family’s views.

A non-binding (soft/weak) register ensures that the family is informed if the individual is on the register and doctors can decide not to proceed if faced with opposition from family members. The family’s views are taken into consideration regardless of whether or not the individual’s wishes are known.

#### Intent or consent?

In some jurisdictions, registers indicating donor status are legally recognised as fulfilling consent requirements for donation. In others, donor registrations are regarded as indicating an intent to donate and are not legally recognised as consent. There has been much debate about the data collection processes and public education strategies that should be put in place to ensure that information is obtained in ways that properly satisfy existing legal definitions of informed consent.

It has also been noted that the debate about presumed consent is something of a red herring. Even in countries that have presumed consent systems, such as Spain, this is not regarded as the element that has made the difference to donation rates, with some commentators describing presumed consent as “unnecessary”.[[124]](#footnote-124)

In New Zealand, there is provision in the Human Tissue Act to establish an opt-in consent register but stakeholders have suggested that it would be difficult to develop a register that met the threshold for informed consent.

Regardless, however, it is well-established that in practice, transplant programmes in all countries consult families about organ donation before proceeding with donation, regardless of the type of legislative consent framework in place (opt-in/opt-out and binding/ non-binding) [[125]](#footnote-125) (see Appendix Eight). Although countries may differ in how the option of donation is presented to families (depending on the default position), nearly all countries with a transplantation programme abide by the following:

* if the deceased made a refusal known (either formally (eg, on a register) or through a discussion with their family), organs will not be retrieved
* if the family refuse donation, organs will not be retrieved
* if the deceased is not known to have refused, organs will only be retrieved if the family agree (most jurisdictions) or do not refuse (very few jurisdictions (eg, Austria, Finland, Sweden))[[126]](#footnote-126).

Thus, it may be more practical to view registers as a means to signal intent, rather than to record informed and binding consent by an individual, and to ensure that if a register does exist, it is well-designed and used in a way that best supports family decision-making about organ donation.

### International experience

#### Variability

A review[[127]](#footnote-127) of worldwide variability of deceased organ donation registers found that:

* most, but not all, donor registers are nationally operated and government-owned
* there is usually a specific minimum age requirement in order to register
* some registers expire after a period of time (for example if they are operated through a driver licence), requiring applicants to reaffirm their wishes on expiry
* combined, opt-in and opt-out registers are equally used. A few jurisdictions provide applicants more options, including “unsure”, “next of kin will decide”, or “a named individual will decide”
* some registers provide registrants the option to select specific organs to include and/or exclude from their donation decision
* in-person registration is the most frequently available method of registration, followed by paper (mail/fax), online, and telephone. The UK has the most opportunities for registration (including online, telephone, driver licence, pharmacy card, GP, and insurance card)
* registration is optional (ie, not mandatory) for all nations assessed, except New Zealand (if the driver licence is considered a register of intent)
* in most donor registers, the proportion of adults registered is modest (<40 percent), and are often even lower when opt-in only registers are considered. Registered objections in opt-out systems are rare (<0.5 percent)
* just over half of donor registers world-wide are legally recognised as fulfilling consent requirements for donation.

### Features of successful registers

Different methods of registration may limit people formally recording donation wishes, due to the location and context of registration systems, limited access, or difficultly of use because of technical or practical barriers.

Many countries use driver licence application systems to record organ donation wishes as they reach a large proportion of the population, but they do not include those who do not apply for a driver licence. Appendix Eight identifies all jurisdictions that use driver licences to register organ donation wishes.

Multiple methods of registration may have some impact on registration numbers, however the UK continually struggles to increase registration numbers, despite providing multiple opportunities for registration.

Evidence from the USA suggests the following guidelines[[128]](#footnote-128) for successful registers:

* they are housed with an agency that requires all (or at least the vast majority) of its citizens to actually come in person on a semi-regular basis and complete some form of transaction
* agents are trained to ask if an individual would like to join the register, and to provide brief, accurate answers to questions about organ donation
* the process is as simple as swiping a card through a machine or hitting a single key to indicate desired status
* well-designed point-of-decision materials should be placed strategically to enhance their effectiveness as individuals engage in their normal transactions
* space should be provided for information booths about organ donation
* there should be an online version of the register, which should be easy to complete and have the same validation as joining in person
* they should have an easy mechanism in place so individuals can change their minds
* though many jurisdictions have registers of consent, families should be taken into account and registers of intent can suffice
* data should be updated in real-time and register information should be easily accessible to those who are authorized for access (ie, ICU staff).

To be useful in family decision-making, it is important that the information on a register is able to be accessed and made available to the family. Both the UK’s National Institute for Clinical Excellence guidelines and Australia’s National Health and Medical Research Council ethical guidelines recommend checking the donor register and any advance statements when approaching the family about organ donation, to ensure fulfilment of people’s expectation that the register information will be used.

### New Zealand context

#### History

New Zealand introduced a computerised Organ Donor Register in 1987. However, it was later found that the information was unavailable to hospital staff and the scheme was not operating as planned. The register eventually lapsed, but the driver licence application continued to provide the voluntary option for people to register their intent to become organ donors. The recording of the organ donor ‘yes’ or ‘no’ information then became mandatory with the passing of the Land Transport Act 1998.

In 2006, a private member’s bill was introduced to establish a legally-binding organ donor register, which would not allow family members to refuse consent. However, this was eventually rejected due to strong opposition in public submissions. Clinicians stated that they would not ‘enforce’ binding consent to donate in the rare event that families did not wish to follow the views of the deceased. A more detailed explanation of New Zealand’s history with registers is provided in Appendix Eight.

#### Driver Licence Register

Organ donation information on driver licence applications is stored by the New Zealand Transport Agency (NZTA) on the Driver Licence Register. The driver licensing transaction process effectively forces an applicant to respond ‘yes’ or ‘no’ to question about organ donation in the event of their death. Licensing agents cannot complete the licensing transaction until applicants have made their choice.

If a licence holder changes their mind about their donor preference during the normal 10-year tenure of a licence, they can change their status on the register but if they want a replacement licence card they are required to pay for the new licence.

While the Driver Licence Register has information on people’s organ donation wishes, it does not operate effectively as an organ donor register:

* it is not routinely accessed when discussing donation with the family of a potential donor (unless the family requests it)
* the information is difficult to access when it is requested.

Currently, around 53 percent of licence holders in New Zealand have indicated a wish to donate organs in the event of their death (around 1.8 million people have indicated an intent to donation, and 1.6 million people have not[[129]](#footnote-129)). There is no information about those who do not hold a driver licence.

### Issues

There are common misperceptions and myths in relation to organ donation and the driver licence in New Zealand. Many New Zealanders think that the driver licence status:

* provides consent, when in fact it is only an indication of someone’s intent
* is binding, such that families cannot override the individual’s wishes, even though families are always asked to provide consent
* information will be taken into account in the event of their death, when current practice is not to, unless the family requests it.

A key issue is that there are no resources provided for applicants at driver licence agencies, and driver licensing agents are not qualified to provide any advice, or to answer any questions the applicants may have regarding organ donation and transplantation.

Because the driver licence organ donation question is mandatory, New Zealanders have revealed that they felt unprepared to face the question on the driver licence application, especially younger people, whose overriding goal and focus was to get their licence. Others wanted time to consult their families and reach agreement together and there was no easily accessible opportunity for changing their mind[[130]](#footnote-130).

ICU staff have indicated that the information is difficult to access when it is requested. They also feel the driver licence information is inadequate for having donation conversations with families[[131]](#footnote-131), likely because they know people receive little information when asked to indicate their intentions. The licence information can also be ambiguous because the forced choice means that not indicating agreement to donate could mean unsure or don’t know, rather than a strong wish not to donate.

### Options for change in New Zealand

Given the issues with the current Driver Licence Register in relation to organ donation, at a minimum New Zealand would benefit from a change in current practice.

Any changes would require public awareness campaigns to dispel myths and misinformation in relation to registers. This would particularly need to address misperceptions that registers constitute binding, informed consent, and emphasise the importance of family discussion.

There are two main options in relation to a register in New Zealand for organ donation. Neither option would meet the criteria for a consent register under the Human Tissue Act.

1. Improve the current driver licence system

New Zealand could continue to use the current Driver Licence Register as a *non-binding intent* register, but with improvements to ensure that it aligns with the guidelines for a successful register.

Improvements could include changes to:

* the application form, to include different response options (eg, ‘unsure’) and more information about what registration means in practice (ie, that families will always be asked)
* provide point-of-decision information and materials to ensure applicants have the information they need to make a decision
* create an easy and publicised mechanism for individuals to change their mind if they want to
* ensure that data is updated in real-time and the register information is easily accessible and clearly linked to ICUs and for those authorized for access
* make registration optional, to remove the time-pressure on applicants and give them time to consider organ donation and talk to their families. The ability to sign up outside the normal licensing time period (every 10 years) would be beneficial.

There is also an option to look at other opportunities for people to register (eg, car registration, online), however these would need to be linked to the Driver Licence Register to ensure that the data is stored in one place and easily accessible to those authorised.

The Land Transport Act may need to be changed to reflect any changes to the register, and any costs associated with the change would need to be estimated. However, it is plausible that this would be a more cost-effective option than developing a new register (Option 2).

1. Establish a new organ donor register

New Zealand could establish a new organ donor register to replace the current Driver Licence Register. This could be a *non-binding* *consen*t register or a *non-binding* *intent* register – and neither would necessarily require change to routine practice ensuring that families are always asked for consent about donation (given past issues with binding registers in New Zealand).

There are different options for implementing a new organ donor register, including: a new independent storage source (eg, online); or one that leverages from a current operating database (eg, the National Health Index).

The benefits of having a new organ donor register include options for:

* ensuring that all the guidelines of a successful register are met
* looking at different data storage places (e.g., online, as part of the NHI, or both)
* different data collection points (e.g., online, through the Census, at GPs, or at multiple places as in the UK)

However, a new organ donor register may require wider awareness campaigns to ensure that people know about the new register and what it means. Moreover, moving the register to a new “location” might cause confusion for the public, who associate organ donation with the driver licence. If New Zealand was to establish a new organ donor register, the Land Transport Act would need to be changed to reflect any changes. Cost estimates would also need to be made[[132]](#footnote-132). It is plausible that developing a register that leverages from the current system would be more cost-effective than building an entirely new register.

# Proposals

*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 increase education, and to develop a strategy to engage with the media about organ donation

* Ensure strategies are based on sound research and are appropriate for the needs of different groups (including Māori and Pasifika people),
* Use opportunities from a donor register to raise awareness, promote family discussion and educate people about organ donation

*Donor register:*

Improve the existing driver’s licence system so that it becomes a more effective register of intent of people’s wishes to donate and is used to inform family decision-making in ICUs

Future consideration:

Create a new stand-alone donor register

# Component Eight: International Co-operation

*Key points:*

*Reform strategies should have a focus on learning from and adopting international best practice in how to increase organ donation rates*

*New Zealand collaborates very strongly with Australia. The two countries have common medical specialist colleges and an organ-sharing agreement. These arrangements are reported to be working well.*

*There are further opportunities to work closely with the Australian Organ and Tissue Authority e.g. in relation to training courses and sharing of approaches to raising public awareness*

New Zealand works closely with Australia:

* We have common medical specialist colleges – for example the College of Intensive Care Medicine of Australia and New Zealand (CICM), the Australasian College of 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 than Australia.
* Discussions are currently underway to make the paired kidney exchange programme a Trans-Tasman scheme, as this would increase the likelihood of compatible matches
* New Zealand accesses the OTA’s Professional Education Package – ODNZ delivered a core FDC workshop in New Zealand in November 2015.
* The Clinical Director and Director of Clinical Programmes from Australia’s OTA are on the Ministry’s expert advisory group for the current review.

EY reported that stakeholders interviewed felt the current arrangements are working well.

## Proposals

Continue joint trans-Tasman work of professional colleges and information sharing

Share learnings from Australia (have Australian OTA representative on governance for national coordinating body)

Increase opportunities for increased clinical training opportunities in NZ

Share public awareness and information resources

# Cross-cutting issue: Cultural and ethnic considerations

Strategies to increase organ donation typically pay specific attention to ensuring actions are appropriate for different groups and individuals, particularly ethnic and cultural groups which can have different rates of organ donation.

## International experience

In Australia and the United Kingdom, aboriginal and minority ethnicities have lower donation rates[[133]](#footnote-133), [[134]](#footnote-134). Both countries have implemented targeted actions aimed at increasing the donation rates of those populations. These have involved a range of initiatives, including: national campaigns (in the United Kingdom); working with community and religious leaders to conduct community outreach activities; developing specific educational resources; promotion of culturally-appropriate information in ethnic media; community awareness grants; focus groups with clinicians; and public engagement events at various religious centres and festivals.

In Australia these initiatives are organised as part of the Culturally and Linguistically Diverse (CALD) Communication and Engagement Strategy 2012-2015. The strategy provided the national framework for communications and community engagement with CALD communities. The strategy documented the programs and activities used to address the specific information requirements of priority CALD communities to facilitate informed decision-making and family discussion about organ and tissue donation decisions.

In addition, both countries have a focus on improving the cultural training of clinicians. In the UK, faith/cultural/end-of-life care issues have been included in the Masterclass curriculum offered by the NHS Blood and Transplant service to all of its Specialist Nurses in Organ Donation[[135]](#footnote-135). While Australia is developing an advanced Family Donation Conversations module on faith and cultural perceptions and requirements[[136]](#footnote-136).

UK-based research into what approaches have been effective in increasing organ donation among ethnic monitories (within both the UK and in North America) found community-based education interventions either alone or combined with mass media approaches were more effective in increasing registration rates, than mass media interventions alone[[137]](#footnote-137).The authors suggested that effective interventions need to be matched to the populations’ stage of readiness.

Consent rates for families of donors with ethnic backgrounds in the UK have improved but continue to be lower than Europeans (36 percent compared to 63 percent for families of white donors in 2013-14)[[138]](#footnote-138).

## New Zealand situation

As discussed at the beginning of this report, there appear to be differences in donation rates between ethnic groups, although it is unclear what may underpin these differences and caution is needed in interpreting them. EAG members commented that it is uncertain to what extent these differences are the result of socio-economic factors, rather than cultural or ethnic factors, since it is well established that individuals with higher socioeconomic status are more likely to have positive attitudes towards donation and more willing to donate their organs[[139]](#footnote-139).

It is also important to note that, while donation rates may be lower, it is inaccurate to say that Māori and Pacific people do not donate organs following death. Between 2008 and 2014 (inclusive) there were 29 Māori deceased donors and 9 Pacific deceased donors[[140]](#footnote-140).

There are likely to be multiple and interrelating reasons for lower donations rates among Māori and Pacific populations. What the available death audit data can tell us is that families of Māori and Pacific potential donors are less likely to be asked if they would consent to donation and when they are asked they are less likely to consent.

Reasons for this might include a preconception by clinicians that Māori and Pacific people hold cultural beliefs that do not support organ donation. It may also reflect cultural differences in the situations surrounding the potential donation opportunity. For example, in one study intensivists stated that raising the option of organ donation with Māori will typically include immediate and extended family participants and this can involve up to 50 or 60 people in a room, with many contributing to the discussion process[[141]](#footnote-141). A higher level of skill and confidence by clinicians is likely to be required in these circumstances to discuss organ donation.

Lower consent rates amongst Māori and Pacific people might occur for a variety of reasons:

* 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[[142]](#footnote-142).
* Cultural competence of clinical staff - this affects clinician’s 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 EAG reported their experience that Pacific and Māori often first hear of organ donation in the 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.
* Mistrust of medical system based on previous experience[[143]](#footnote-143).

## Implications

It is important to note that Māori and Pacific people are not homogenous. There is variation in individual beliefs, and differences in beliefs and tikanga between hapū and iwi, which can change over time and in response to circumstances[[144]](#footnote-144),[[145]](#footnote-145),[[146]](#footnote-146),[[147]](#footnote-147),[[148]](#footnote-148), including when whanau wellbeing is involved[[149]](#footnote-149). The Pacific community is even more diverse than Māori and people of both cultures, like everyone else, are further influenced by factors such as age, gender, religion, personal experiences, education and upbringing[[150]](#footnote-150). There are also further differences between Pacific people who are New Zealand-born and Pacific people who are migrants[[151]](#footnote-151). For Pacific people, one of the dominant beliefs is now Christianity, which is supportive of organ donation[[152]](#footnote-152) [[153]](#footnote-153).

EAG members also stressed the need to not fall into cultural stereotyping when developing strategies aimed at specific cultural and ethnic groups, noting the importance in the ICU of giving all families the same opportunity to consider donation and dealing with families in ways that are appropriate for them.

Because the reasons for lower donation rates among Māori and Pacific people are not clear (including the impact of socio-economic status) further analysis and targeted consultation should be undertaken to identify and clarify the issues. Research to determine the current level of awareness and understanding of organ donation, should include an analysis of ethnicity and socio-economic status. It would also be beneficial to collect specific ethnic information as part of managing the performance of the organ donation system, to identify where variation is occurring. These actions should be the responsibility of the national coordinating body.

In the meantime, improving the cultural competency of clinicians (including addressing any misperceptions that Māori and Pacific people don’t donate) would ensure clinicians have the confidence and skill to introduce the opportunity for donation and then discuss it in a culturally appropriate and sensitive manner. This could be achieved by reviewing the content of organ donation training to ensure it covers cultural competence issues relevant to New Zealand. In particular, cultural competence in engaging with Māori and Pacific families should be covered.

Another option for ensuring donation conversations are conducted in culturally appropriate manner, would be to involve DHB cultural advisors more in these conversations. As the personal beliefs of the cultural advisors are likely to influence the advice they provide, it would be important that the cultural advisors have up to date information on the need for, benefits, and process of organ donation and transplantation.

Any public awareness campaign should include culturally appropriate strategies to raise the awareness and understanding of Māori and Pacific people. For example, a Pacific focus group the Ministry spoke to considered Pacific people’s awareness and support for organ donation could be improved if the Ministry worked with church ministers to build ministers understanding or organ donation and transplantation so they can deliver accurate messages to their congregations.

# Conclusions and Next Steps

This report has outlined a preliminary package of proposals that together would form the basis of a national, comprehensive strategy to increase rates of deceased organ donation. They are based on international evidence and best practice but have been developed for a New Zealand context. In particular, they build on existing institutional arrangements, donation and transplantation infrastructure, and organisation of the New Zealand health system. As such, while ambitious, they do not represent radical reform. Other countries have achieved significant increases in deceased organ donation rates and there is no obvious reason that New Zealand should not be able to do the same.

As noted earlier in this report, increasing transplantation is an example of an investment approach in that it saves and improves lives whilst saving health system (and potentially welfare) costs. It aligns with and supports the New Zealand Health Strategy with its focus on service improvement to improve patient lives and can be viewed as part of a wider effort to respond to chronic conditions. It will also contribute to our international obligations to maximise organ donation in order to reduce demand for organ trafficking.

The proposals in this report have been discussed with the EAG and are now intended for wider consultation in order to refine and finalise. This further testing and refinement will also provide advice on phasing and costing of proposals. It will also pay explicit attention to health system capacity to both increase donation rates and to absorb the consequential impacts on transplant service capacity, to ensure that an increase in donated organs can be utilised.

# Appendix One: Terms of Reference for the Review

**Purpose**

The Review of Deceased Organ Donation and Transplantation (the Review) will identify, assess, and recommend actions to increase solid organ donation rates to support an increase in transplantation rates in New Zealand, with a primary focus on increasing deceased organ donation rates.

**Objectives**

The Review will report to the Minister of Health on:

* the current situation in New Zealand, including an overview of current domestic patterns and trends, practices, systems, processes, and recent initiatives to increase organ donation and transplantation rates
* international experience and features of higher performing organ donation systems
* issues in New Zealand’s donation and transplantation system and aspects that could be changed to increase deceased solid organ donation and transplantation rates
* recommendations for change.

**Background**

New Zealand has relatively low deceased organ donation rates compared with other developed countries. Our donation rate is around 10 per million people (pmp), compared to Australia which has around 16 pmp, and Spain which has the highest rate at around 36 pmp. We have a large and growing number of people waiting for kidney transplants, with 600-700 people usually waiting for a kidney transplant from a deceased donor, and around 40 people waiting for liver, cardiac or lung transplants.

New Zealand’s low donation rate is a long-standing issue. To date, our approach to improving deceased organ donation has been piecemeal. The last significant review occurred over 2002-2008, and was focused on the overhaul of the Human Tissue Act and proposals for a donor register.

The Government wishes to increase organ donation rates. Recently, the Government has invested in several initiatives to increase living donations for kidney transplants and for Organ Donation New Zealand to provide increased support in intensive care units in relation to deceased organ and tissue donation. From 2013 to 2014 there has been some indication that both live and deceased organ donation rates are improving. Early 2015 data suggests for deceased organ donation this is being sustained.

A number of countries have implemented initiatives to raise rates. In particular, Australia, which has a number of similarities to New Zealand (including joint health professional bodies for a number of specialities), implemented a successful reform programme following a comprehensive review in 2008.

The Minister of Health and Associate Minister of Health have sought advice on what could be done to further accelerate and sustain the recent increases in organ donation rates and achieve the step change required to bring New Zealand in line with similar countries. Any such changes will need to occur in a way that is ethically, culturally and socially acceptable, feasible and cost-effective in the New Zealand context.

**Key Topics**

Key topics that the Review will consider are likely to include:

* alignment of New Zealand’s clinical settings and training with international best practice, particularly within emergency departments and intensive care units
* regional differences in clinical practices and donation rates
* lessons from other donation systems in New Zealand eg, tissue and blood donation
* leadership, coordination, and institutional arrangements
* health sector capacity and capability, and funding and performance arrangements
* New Zealand’s consent system, including the driver licencing system and practices for gaining consent from family members
* the role of donor registers
* initiatives to raise awareness of organ donation, including the role of media and public campaigns
* ethical, cultural, religious, and demographic factors within the New Zealand context
* opportunities to leverage or link with Australia’s systems, processes, and clinical training.

 **Scope**

The following aspects have been identified as in and out of scope:

|  |  |
| --- | --- |
| **In Scope** | **Out of Scope** |
| * solid organ donation rates following both brain and circulatory death
* linkages with living solid organ and tissue policies and practices
* the governance structure and institutional arrangement of the donation and transplantation system
* the capacity and capability of the health system to respond to increased donation and transplantation rates.
 | * options for increasing tissue donation rates (bone material, eye, tissue, skin and heart valves) unless donated at the same time as deceased solid organs
* options for increasing live donation rates (as there are a number of initiatives underway that require time to embed and be evaluated) aside from any opportunities identified by existing initiatives
* financial assistance for living donors (this is already subject to a private member’s bill that has been drawn, so will be considered separately in a shorter timeframe)
* organ transplantation waiting lists and allocation processes
* adequacy of general funding to district health boards
* review of the Human Tissue Act (although legislative options might be signalled for future work).
 |

**Approach**

Organ donation is a complex issue that generates high sector and public interest and strong competing views about what is needed to improve donation rates.

The Review will be undertaken by the Ministry, with the support of an expert advisory group chosen for their expertise in the issues under consideration. The Review will include:

* a literature review and review of existing documentation
* liaison with the Australian Organ and Tissue Authority
* targeted interviews
* issue-based workshops with clinicians, stakeholders, and consumers to identify issues and possible solutions.

**Review deliverables**

The Ministry will provide a draft report on options for increasing deceased solid organ donation and transplantation rates to the Minister of Health by 31 March 2016.

**Next Steps**

Some of the options identified, if approved by the Minister, may require further consultation or development, particularly if they represent a significant change or cost.

There is strong sector and public interest in some topical issues associated with organ donation. It is not possible to engage in full stakeholder and public consultation prior to providing initial advice to the Minister in March 2016. However, wider consultation is likely to occur after March, before decisions are taken.

**Related work**

The Review will connect with and share information where appropriate with other related work.

* The Ministry’s advice on the *Financial Assistance for Live Organ Donors* Bill, a private member’s bill, which proposes to increase financial reimbursement for live organ donors.
* The National Renal Transplant Service, established in 2014, which has a goal of cumulatively increasing the number of live donor transplants by 10 in each of the next four years.
* New funding in the 2014 Budget covering donor liaison co-ordinators and continuation of the New Zealand Kidney Exchange programme to support this target.
* A pilot to increase live organ donation rates led by Counties Manukau District Health Board. The formal evaluation of this work is due July 2016.
* The National Ethics Advisory Committee’s assessment of the *Ethical Guidelines for Eligibility Criteria and Allocation Protocols for Organ Transplantation from Deceased Donors*, which are currently being developed by the Australian National Health and Medical Research Council (expected to be complete late 2015 / early 2016).

# Appendix Two: Terms of Reference and Members of the Expert Advisory Group

1. **Introduction**
	1. The Ministry of Health (the Ministry) is conducting a Review of Deceased Organ Donation and Transplantation (the Review). The Review’s purpose is to identify, assess, and recommend actions to increase solid organ donation rates to support an increase in transplantation rates in New Zealand, with a primary focus on increasing deceased organ donation rates.
	2. To support the Review, an Expert Advisory Group (the Group) is being established to provide the Ministry with expert advice on matters related to organ donation and transplantation. This advice will inform the Review, and the advice which the Ministry provides to Ministers.
2. **Functions of the Group**
	1. The Function of the Group is to provide advice to the Ministry on key issues regarding organ donation and transplantation. These include, but are not limited to:
		* + - advice on how to increase deceased organ donation and transplantation rates, with reference to the features of higher performing international organ donation and transplantation systems;
				- advice on issues associated with the organ donation and transplantation system that may affect deceased organ donation rates;
				- advice on the societal change required to increase organ donation rates, and the ethical, cultural and social appropriateness of identified options;
				- advice on the feasibility and practical implications of suggestions to increase organ donation rates in the New Zealand context, including risks, issues, opportunities, and other alternatives;
				- advice on system enablers, including the infrastructure necessary to increase organ donation and transplantation rates.
3. **Composition of the Group**
	1. The members of the Group will be appointed by the Ministry, based on their background and expertise in matters related to organ donation and transplantation, and their credibility in the sector. Members are selected to provide wider thinking about the organ donation and transplantation system, including public health, ethics, clinical, and management perspectives.
	2. The Ministry’s Chief Medical Officer (Don Mackie), or his designate in the event of his unavailability, will chair the Group’s meetings. Employees of the Ministry will be present at Group meetings, and may participate in discussions.
	3. It is anticipated that Group members will initially serve to the end of March 2016. After this the Ministry will receive further direction from the Minister, which may result in the term of the Group being extended.
	4. The Ministry reserves the right to, at any time and entirely at the Ministry’s discretion, remove any member from the Group. The Ministry also reserves the right to add new members to the Group at any time. Members may be requested to be part of sub-committees of the Group, to address particular issues.
4. **Roles and Responsibilities of a Member**
	1. The Ministry expects members of the Group to undertake the following:
		* + - attend Group meetings;
				- share knowledge and provide advice and feedback to the Ministry on documents related to the Review;
				- conduct email correspondence and teleconferences as appropriate in order to ensure that the above is achieved, and;
				- support relevant specific issues-based workshops where agreed with the Ministry.
	2. Group members are expected to individually and collectively provide expert advice to the Ministry, and be able to provide wider system and societal thinking about factors that affect organ donation and transplantation by:
		* + - providing fresh thinking and suggestions for how New Zealand’s current system may be changed/improved;
				- working in a constructive and open manner, and;
				- helping build consensus and support needed to bring about change.
	3. There is an expectation that members will attend all meetings, abide by the ‘Ground Rules for meetings’ (to be circulated with the Agenda for the first meeting), and devote sufficient time to become familiar with the affairs of the Group and the wider environment within which it operates. The Ministry may also commission specific pieces of work from Group members.
	4. It is expected that the Group will meet three times face-to-face and/or by teleconference. Papers may be circulated for members’ review and comment.
	5. The group is expected to be able to reach consensus about any issues that arise. If the group cannot reach consensus, then the chair will endeavour to ensure that the different views are acknowledged by the Ministry.
5. **Independence of advice**
	1. The Group does not provide advice directly to the Minister. The Group’s advice is to the Ministry only. The Ministry will take the Group’s advice into consideration in formulating its advice to the Minister. The Ministry’s advice to the Minister may differ from the Group’s advice to the Ministry.
	2. Members are appointed to the Group to provide expert impartial advice to the Ministry based on their knowledge and expertise. They are not appointed to represent the interests of any particular sector or stakeholder.
6. **Conflicts of Interest**
	1. In making themselves available for appointment, members should ensure that:
		* + - there is no conflict of interest which would preclude their appointment, and;
				- they are available to serve for the full term of their appointment.
	2. Members must declare if they have a real or perceived financial, professional, organisational or personal interest (direct or indirect) that might create a conflict of interest.
	3. When members believe they have a conflict of interest on a subject that prevent them from undertaking an activity consistent with the Group’s functions, then they must declare the conflict of interest and absent themselves from the discussion and/or activity. This must be done at the earliest possible opportunity and at the point the relevant item of business comes up in the meeting.
	4. Members will be required to complete the Ministry of Health Declaration Form (attached) prior to the inaugural meeting.
7. **Confidentiality**
	1. All discussions and work circulated to, from and within the Group, whether verbal or written, shall be treated as confidential for use by the Ministry and the Group only, unless deemed otherwise by the Ministry and expressly stated. No information in any form should be released without prior approval by the Ministry. By agreeing to these terms of reference, Group members are agreeing to these conditions of confidentiality.
	2. Group members must acknowledge that all material produced for and by the Group, including correspondence, is subject to the Official Information Act. The Ministry may also elect to release some or all of this material at the conclusion of the Review.
8. **Liability**
	1. Members of the Group are not liable for any act or omission done or omitted in their capacity as a member, if they acted in good faith, and with reasonable care, in pursuance of the functions of the Group.
9. **Intellectual property**
	1. All physical and intellectual outputs of the Group shall be the property of the Crown. For the avoidance of doubt this includes, without limitation, all reports, papers, electronic documents, software and recordings.
10. **Media responses**
	1. All media communication in relation to the work of the Group will be made via the Ministry.
11. **Remuneration and expenses**
	1. Ordinary members will be remunerated at a rate of $350 per full-day meeting, consistent with the Cabinet Fees Framework for fees for statutory bodies. They will also be paid preparation fees when significant preparation time is required prior to meetings.
	2. Members who are employees of the wider State sector are not entitled to be paid fees for Group business if this is conducted during regular paid work time (ie, members cannot be paid twice by the Crown for the same hours).
	3. The Ministry will book travel and accommodation on behalf of members and will not reimburse members for travel or accommodation booked without prior approval.
	4. The Ministry will reimburse members for incidental costs directly incurred as a result of the performance of their duties as a member of the Group, provided these have prior approval.

|  |  |  |  |
| --- | --- | --- | --- |
|  | **Full Name** | **Organisation** | **Role** |
| **1** | Dr Nick Cross | Canterbury DHB | Clinical Director of NRTS and Nephrologist  |
| **2** | Ms Joanne Gibbs | Auckland DHB | Director of Provider Services |
| **3** | Dr Louise Trent | Hawke’s Bay DHB | Intensive care consultant |
| **4** | Dr Catherine Simpson | Auckland DHB | Intensive Care Consultant |
| **5** | Dr Michael Roberts | Northland DHB | Chief Medical Officer |
| **6** | Mr Max Reid | Kidney Health NZ | Chief Executive Officer |
| **7** | Dr Helen Opdam | Organ and Tissue Authority, Australia | National Medical Director |
| **8** | Ms Eva Mehakovic | Organ and Tissue Authority, Australia | Director, Clinical Programs |
| **9** | Mr Martin Wilkinson | National Ethics Advisory Committee & University of Auckland | Ethicist, Deputy Chair National Ethics Advisory Committee, Associate Professor of Political Studies  |
| **10** | Dr Stephen Streat | Auckland DHB Critical Care Medicine, Auckland City Hospital | Clinical Director of Organ Donation NZ and Intensivist |
| **11** | Sir Pita Sharples |  | KNZM CBE, Māori academic and politician, co-leader Māori Party 2004-2013, minister outside Cabinet 2008-2014. His wife recently received a kidney. |
| **12** | Dr Catherine Trundle | Victoria University of Wellington | Senior Lecturer, School of Social and Cultural Studies |
| **13** | Stephen James | Capital and Coast DHB | Charge Nurse Manager ICU  |
| **14** |  Don Mackie (Chair) |  Ministry of Health |  Chief Medical Officer |
| **15** |  Clare Perry |  Ministry of Health |  Manager, Electives and National Services |
| **16** |  Paula Martin |  Ministry of Health |  Group Manager, Sector and Services Policy  |

# Appendix Three: Terms of Reference for external review of practices in clinical settings and institutional arrangements

The supplier will provide the Ministry with an independent review, advice and recommendations to improve practices in clinical settings for deceased solid organ donation and transplantation. The supplier will focus on activities to improve practices in clinical settings regarding donation, and identify issues increased donation rates will have on the transplantation system that will need further exploration. Factors to be considered include:

* Identification and referral of potential organ donors
* Donation and consent conversations
* Workforce, training, resources and roles
* Capacity and capability constraints – donating hospital and transplanting centre perspectives
* Linkages with relevant specialties – eg ICU, ED, Neuro surgery
* Infrastructure requirements – including information exchange
* Linkages with tissue donation and the transplant sector.

The supplier will also provide commentary on the current institutional arrangements (system design) and how the institutional arrangements could be organised to provide appropriate leadership, governance, roles and responsibilities to increase rates of donation and transplantation in NZ. This is to include summary of stakeholder themes and analysis to support the Ministry’s consideration of the overall design of New Zealand’s (solid) organ donation and transplantation system. The supplier is not expected to provide recommendations on a preferred system design, assessment of associated benefits, costs and risks or necessary conditions and steps to implement the preferred design.

# Appendix Four: Country comparison of reform programme actions

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
| **Key elements of reform** | **Spain** | **Croatia** | **Portugal** | **Australia** | **United Kingdom** | **European Union (EU)** |
| An appropriate legal and ethical framework | Spain introduced organ donor legislation in 1979, which established presumed consent | Croatia implement a presumed consent system in 1988 and a new Transplant Act in 2013 | Portugal introduced transplant legislation in 1993 and revised it in 2007 | The Australian system of organ donation is based on an informed consent (‘opt in’) model. Individuals have the option to record intent to donate their organs after death on the Australian Organ Donor Register. Organ and Tissue Donation after Death for Transplantation guidelines for ethical practice for health professionals were developed by the National Health and Medical Research Council (NHMRC) in 2007 | Guidance on non-heart-beating donation was published for each country and an UK Donation Ethics Committee was established in 2010 |  |
| A national coordinating body | A national coordinating body was established in 1989 | A National Transplant Coordinator was appointed in 2001 and the Ministry of Health employs staff responsible for manage reform initiatives and a coordination office | A national coordinating body was introduced in 2007 and amended in 2012 | A national coordinating body was officially established in 2009 and is responsible for implementing the reform programme | The role of the NHS Blood and Transplant was expanded to be the organ donation organisation for the whole of the United Kingdom | The EU issued a directive requiring member states to identity a Competent Authority with responsible to ensure compliance with various quality and safety requirements |
| Hospital-based clinical donation specialists | Dedicated clinical staff were introduced in 1995 | Hospital based teams of Transplant Coordinators were initially established from 1998-2000 | Hospital Donor Coordinators were appointed in 2007 and 2008. | A network of donation specialists – the DonateLife Network - was established across Australia | Clinical leads for organ donation were appointed and the Specialist Nurse for Organ Donating network was reconfigured and expected to increase by 146% (as at 2011) | The action plan included an action to promote transplant Donor Coordinators |
| Specialist training for clinical staff in management of deceased donation process and family donation conversations | Training on organ donation was first made available in 1991 and is mandatory for all doctors specialising in intensive care | Professional training to clinicians was first made available in 2003 and remains an ongoing priority | Professional training was first made available in 2008 and all staff employed as Hospital Donor Coordinator receive specific training | Specialist training for clinical staff in management of the deceased donation process and family donation conversations are available as part of the Professional Education Package | The taskforce recommended all clinical staff likely to be involved in the treatment of potential organ donors receive mandatory training in the principle of donation | The action plan included an action to improve the knowledge and communication skill of health professionals and patient support groups on organ transplantation |
| **Key elements of reform** | **Spain** | **Croatia** | **Portugal** | **Australia** | **United Kingdom** | **European Union** |
| Implementation of a clinical governance framework that supports quality assurance and audit of hospital clinical practice and governance of donation process | Quality assurance programme is based on a continuous clinical chart review of all deaths occurring in critical care units. It includes both an internal and external audit | Hospital audits were initially commenced in 2002 and have been gradually refined into a clinical practice improvement programme and quality assurance process by 2010 | As of 2013, Portugal was planning its method for conducting hospital audits | Reporting and auditing of organ and tissue donation practice has been enhanced and embedded across hospitals in the DonateLife Network. In March 2012, the DonateLife Clinical Governance Framework (CGF) and Clinical Practice Improvement Program (CPIP) was established to support and guide DonateLife Network (DLN) staff in achieving the national objective of increasing organ and tissue donation rates across Australia | Data on donation activity is issued to the national body every six months and used to monitor performance | The EU issued a Directive requiring member states to establish and maintain a framework for quality and safety. The action plan included an action to promote quality improvement programmes |
| Financial support to donor hospitals to ensure that costs related to management are not a barrier to donation | A specific budget is allocated to fund the donation management at every hospital | In 2006 a funding model was introduced to ensure hospitals are funded for all additional costs associated with organ and tissue donation | Financial support for organ donation activity was introduced in 2006 and revised in 2011 | Organ Donation Hospital Support Funding (ODHSF) provides a contribution towards the costs associated with organ donation activity | An analysis of the costs involved in the management of potential organ donation was undertaken and additional funding provided to cover these costs |  |
| Media engagement and national community awareness and education | The national coordinating body utilises media to promote organ donation through the dissemination of positive news | Coordinated public awareness campaigns have been progressively introduced since 1998 | Since 2009, the national body has organised joint community events and has worked with the media on general awareness | National community awareness and education campaigns were implemented, including engagement with culturally and linguistically diverse communities | A high-prolife, multi-media campaign to promote organ donation was launched in 2009, followed by targeted campaigns in early 2010. | The action plan included an action to improve the knowledge and communication skill of health professionals and patient support groups on organ transplantation |
| International cooperation to share best practice |  | Joined the Eurotransplant in 2007 |  | Australia has based its reform on international best practice through engagement with high performing countries |  | The action plan included an action to facilitate the identification of organ donors across Europe and cross-border donation |

# Appendix Five: Key events in organ donation in NZ

The first organ donation in New Zealand was a kidney from a living donor to her identical twin sister at Auckland Hospital on 28 May 1965. The first deceased donor was a teenage boy at Auckland hospital in 1966, who gave his kidneys to two recipients. The first heart transplant occurred on 2 December 1987. The 1990s saw the commencement of lung transplantation in 1993, and liver and pancreas transplantation in 1998.

The following table provides a snapshot of the key legislative actions and policies that have been considered and implemented in New Zealand. Each box highlights the key years and a summary of what happened.

|  |  |
| --- | --- |
| **1964** | * Human Tissue Act 1964 passed. This was eventually repealed and replaced by the Human Tissue Act 2008.
 |
| **1987** | * New Zealand introduced a computerised National Organ Donor Register. Drivers had the voluntary option to register as donors when they applied for their lifetime drivers’ licences. This information was sent to area health boards for entry to the National Master Patient Index (NMPI) [[154]](#footnote-154).
 |
| **1993** | * The Department of Health’s National Taskforce on Organ Transplantation carried out a review[[155]](#footnote-155) of the National Organ Donor Register from 1989 to 1993 and found that it was not operating as planned, so decided that it be allowed to lapse.
* The driver licence application continued to provide the voluntary option for people to register their intent to become organ donors.
 |
| **1998** | * A review of the driver licensing process in the mid to late 1990s led to the organ donor question being formally authorised by Parliament, instead of the Secretary of Transport, and became mandatory as part of the Land Transport Act 1998.
 |
| **2002** | * Andrew Tookey presented a petition to the Health Select Committee requesting Parliament to address the organ donor shortage. The petition called for wide-ranging initiatives to increase the organ donation rate from deceased people, including establishing a national organ donor register for potential deceased donors.
 |
| **2004** | * Government (Labour) agreed to the recommendations in Tookey’s petition in principle and decided to provide additional resources to deceased organ donation by extending the services of the National Transplant Donor Coordination Office in 2005.

The Government summarised its response to the report as follows:Supported in principle – initial priority:* + additional education for health professionals involved in organ donation
	+ establishing and funding a national organ and tissue donation agency extending the National Donor Coordination Office’s existing role
	+ ensuring that all persons involved in organ and tissue donation and retrieval have appropriate expertise in these processes.
	+ development of consistent protocols for discussing organ and tissue donation with families.

Supported in principle:* + development of a system to encourage active discussion about organ and tissue donation within families.

Did not support at the time:* + an ongoing national public awareness campaign aimed at increasing the organ and tissue donor rate
	+ establishment of a dedicated national organ and tissue donor register to replace the current system linked to the driver licensing system.
* The Ministry of Health began a review of the regulatory framework of human tissue and tissue-based therapies, which previously spanned a number of acts and regulations including the Human Tissue Act 1964.
 |
| **2005** | * The National Transplant Donor Coordination Office was expanded and renamed Organ Donation New Zealand (ODNZ), with an increase in funding to:
	+ become the national deceased organ donation agency
	+ provide additional education, training and advisory activities
	+ develop nationally consistent processes to ensure that all families of potential deceased donors are given the option to donate.
* Financial assistance to living organ donors was introduced under the Social Security Act 1964. Living donors can receive support for lost income up to the level of Jobseeker Support (previously called the Sickness Benefit) and childcare assistance. The payment is administered by the Ministry of Social Development (MSD) and provided for up to 12 weeks from the surgery date. Accommodation and travel assistance is made available for live donors through the Ministry of Health’s National Travel Assistance Policy.
 |
| **2006** | * National (opposition) MP Jackie Blue introduced a Member’s Bill “Human Tissue (Organ Donation) Amendment Bill” to establish a legally-binding organ donor register, which would not allow family members to oppose the deceased individual’s wishes.This was initially supported by Government and in Budget 2006 funding was allocated to the establishment and on-going costs of a national organ donor register pending the Minister's final allocation decisions. Eventually this funding was made available for other priority health capital projects.
* Government's Human Tissue Bill was introduced and passed its first reading.
* The National Renal Advisory Board (NRAB), an independent board partially supported by the Ministry of Health, developed a scoping paper for a National Strategic Plan for Renal Services.
 |
| **2007** | * Jackie Blue’s Member’s Bill “Human Tissue (Organ Donation) Amendment Bill” was considered with Government’s Human Tissue Bill. However, the proposal for a donor register was rejected on its second reading due to strong opposition in public submissions, and clinicians stated they were unlikely to ‘enforce’ binding consent to donate in the rare event that families did not wish to follow the views of the deceased. The Ministry of Health’s view was that a register alone was unlikely to increase donation rates.
 |
| **2008** | * The Human Tissue Act 2008 was passed (and replaced Human Tissue Act 1964). It contains a provision to facilitate the establishment of a national organ donor register to record informed consent, if the Government wishes to do so.
 |
| **2009** | * The Auckland Renal Transplant Group established a national Kidney Paired Exchange scheme (now NZ Kidney Exchange), which “matches” pairs of potential recipients and their live donors who are not a suitable match for each other, with pairs in a similar position. Each paired exchange results in two transplants and two patients who will no longer require dialysis. The scheme may also facilitate exchange chains involving more than two pairs, and/or non-directed donors[[156]](#footnote-156) with a patient from the deceased donor waiting list.
 |
| **2010** | * National MP Michael Woodhouse drafted a Member’s Bill "Financial Assistance for Live Organ Donors" to increase support to living organ donors to 80 percent of lost income. This Bill eventually passed on to National MP Chris Bishop.
 |
| **2011** | * National Renal Advisory Board (NRAB) requested a review of the funding model for renal transplantation and submitted a proposal to ensure adequate capacity for the transplant service. Following this, NRAB submitted a “Five Point Plan to Increase Live Donor Renal Transplantation in New Zealand” to the Minister of Health, which included:
	+ piloting increased support at transplant units
	+ implementing proposals to meet 80 percent of live donor’s lost income as a health programme
	+ funding the development of a feasibility study for the development of a national kidney exchange programme
	+ funding live renal transplantation as a national service
	+ make increasing live renal transplantation one of the Government’s health priorities for the next three years.

In response, the National Health Board (Ministry of Health) established a Renal Transplantation Technical Advisory Group to review services and funding for kidney transplant services. This led to the establishment of the National Renal Transplant Service in 2014 and changed to allow fund transfers of inter-district kidney transplant services. |
| **2012** | * Budget 2012 included a total of $4 million for three initiatives to increase both live and deceased donation rates.
	1. $2 million funding over four years for Organ Donation New Zealand to increase deceased donation rates, including:
		+ further education and training for staff in relation to deceased organ and tissue donation
		+ increased feedback to intensive care staff around the auditing process
		+ enhanced reporting for the death audit.
	2. $1.75 million over three years to the “Live Kidney Donation Aotearoa” project at Counties Manukau District Health Board to help overcome barriers to live donor kidney transplantations in Pacific and Māori patients. The project has eight objectives with a range of initiatives, including:
		+ education resources and programmes for patients, their families, and health-care providers
		+ community engagement activities
		+ a peer support programme.
	3. $250K to formalise the kidney exchange programme at Auckland District Health Board.
* The Minister of Health released a notice in the New Zealand Gazette to allow the kidney exchange programme and its participants to be exempt from sections 56, 58, 59 and 61 of the Human Tissue Act to ensure that the exchange of kidneys in the context of the programme is legal.
 |
| **2013** | * National Ethics Advisory Committee (NEAC) began work looking at ethical issues associated with access to organ transplantation (involving organs from both living and deceased donors), including:
	+ the processes for referrals
	+ being placed on the deceased donor waiting list
	+ deciding who receives an organ when one becomes available.

NEAC will do further work after the Australian National Health and Medical Research Council’s releases their ethical guidelines in 2016. |
| **2014** | * Budget 2014 included $4 million funding over four years for three initiatives to increase living organ transplantation.
	1. Establishment of a National Renal Transplant Service. The purpose of the service is to implement the National Plan for Renal Transplant Services[[157]](#footnote-157), which aims to:
		+ improve access to live renal transplantation for patients with end-stage renal disease
		+ increase live donations by 10 each year over a four-year period
		+ improve the quality, consistency, and timeliness of the donor and patient pathways.

A new National Renal Transplant Leadership Team was established to support the service, comprising of a strategy group to provide strategic guidance and review the performance of the service, and an operational group to develop and implement the work programme. The Ministry of Health funds the Clinical Director of the National Renal Transplant Service (1 day/week), as well as a business analyst and secretariat to support the services.* 1. More donor liaison coordinators in 11 District Health Boards (three renal transplant centres and eight renal service providers). Donor liaison coordinators provide support for both existing and new renal patients who are eligible for transplantation, with a primary focus on increasing the number of people who would be willing to become living donors. This includes education to potential donors as well as support for timely assessments as dictated by the needs of the DHB’s Renal Service.
	2. Continuation of the NZ Kidney Exchange programme (NZKX), including the formation of a kidney exchange coordinator role. There have been 6 exchanges to date, all of which have included a non-directed donor. NZKX is now part of the National Renal Transplant Service.
* Ministry of Health agreed for the New Zealand Kidney Exchange (NZKX) programme to propose collaborating with the equivalent Australian Kidney Exchange (AKX) programme, to increase the number of matched pairs suitable for exchanging kidneys. Discussions are currently underway.
* ODNZ launched a smartphone application with the necessary resources for health professionals in organ and tissue donation, including ODNZ Best Practice Guidelines and other resources for intensive care units (such as how to approach families about discussing donation).
 |
| **2015** | * Minister of Health requested advice on how to increase organ donation and transplantation rates in New Zealand. The Ministry of Health is leading a review of organ donation and transplantation, primarily focused on deceased organ donation rates due to the number of initiatives already underway to improve live donation that require time to embed and be evaluated. Initial advice is due to the Minister in March 2016.
* On 25 June, Chris Bishop’s private Member's Bill “Financial Assistance to Live Organ Donors” is introduced to Parliament. The Bill has passed its first reading and is currently under consideration by the Health Committee. The Ministry of Health is providing advice to the Health Committee in evaluating the Bill.
 |

# Appendix Six: Glossary of roles and responsibilities in organ donation and transplantation.

#### Auckland Renal Transplant Group (includes pancreases)

The name *Auckland Renal Transplant Group* refers to a group of clinicians at Auckland City Hospital who provide renal (and pancreas) services to patients at Auckland District Health Board.

#### Australasian Donor Awareness Programme (ADAPT)

ADAPT was established in 1994 to provide training and education for health professionals who are involved in the care and management of dying patients, and their families, including those patients who may become potential organ and tissue donors. ADAPT in New Zealand is currently provided by Organ Donation New Zealand, and entails one-day workshops once or twice a year for intensive care staff on how to manage clinical situations involving death, understanding grief and bereavement, and caring for the family of the deceased patient.

The ADAPT programme in Australia is currently being revised and replaced under the Organ and Tissue Authority’s (OTA) Professional Education Package by the end of 2015. The College of Intensive Care Medicine have suggested that New Zealand adopt this new programme and facilitated OTA to present the core Family Donation Conversation unit in Auckland, New Zealand in early November 2015. New Zealand clinicians are evaluating the content of the workshop to consider whether it is suitable for replacing the ADAPT workshop for the New Zealand context.

#### Australasian Transplant Coordinators Association (ATCA)

In the mid-1980s transplant and Donor Coordinators established the Australasian Transplant Coordinators Association (ATCA). ATCA is a representative organisation for health professionals directly involved in organ donation. It publishes national standards for transplant coordinators (also called recipient coordinators) and national guidelines for intensive care units in conjunction with TSANZ (see below).

#### Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) and Australia and New Zealand Organ Donation Registry (ANZOD)

ANZDATA records the incidence, prevalence and outcome of dialysis and transplant treatment for patients with end-stage renal failure. ANZDATA is located at The Royal Adelaide Hospital, South Australia. The registry is a project responsible jointly to the Australian and New Zealand Society of Nephrology (see below) and to Kidney Health Australia.

ANZOD is a collaborative effort of ATCA (see above) and ANZDATA and collects and records data on all organ donors after death. This information is provided by donor hospitals and some Organ Donation Agencies. While the provision of this data is voluntary, the Registry believes that coverage is close to 100 percent.

Both ANZDATA and ANZOD are funded by the Ministry of Health, the Australian Government Department of Health, and Kidney Health Australia.

#### Australia and New Zealand Society of Nephrology (ANZSN)

ANZSN is the professional association for nephrologists with a special interest in renal diseases. The Society aims to promote and support research in kidney health and disease, and to ensure the highest professional standards for the practice of nephrology in New Zealand and Australia. ANZSN also jointly established and operates the Australian and New Zealand Dialysis and Transplant Registry (ANZDATA) with Kidney Health Australia. ANZSN has created national evidence-based guidelines for practice within many areas of renal disease, including renal transplantation.

#### The Australian and New Zealand Intensive Care Society (ANZICS)

ANZICS is the peak professional and advocacy body for medical practitioners specialising in the treatment and management of critically ill patients in public and private hospitals. ANZICS supports all aspects of intensive care medical practice through ongoing professional education, the provision of leadership in medical settings, clinical research and analysis of critical care resources, including the development of the ANZICS statement on brain death and organ donation.

#### Australian and New Zealand Liver Transplant Registry (ANZLTR)

ANZLTR is a collaborative effort of the liver transplant units in New Zealand and Australia and is coordinated through the Princess Alexandra Hospitals in Brisbane, Queensland. ANZLTR aims to collect, collate and report data relating to activity of outcomes of liver transplantation in the region. Data on all patients listed for liver transplantation and their subsequent outcomes is supplied by all the participating units. The coordinating centre is responsible for all monitoring of data quality and the preparation and publication of the ANZLTR annual report.

ANZLTR is partially funded by the Australian Government Department of Health and is also sponsored by Novartis and Janssen-Cilag.

#### The College of Intensive Care Medicine (CICM)

CICM is the body responsible for intensive care medicine specialist training and education in Australia and New Zealand. The College offers a minimum six year training program, in both general and paediatric intensive care, with a number of assessments, culminating in Fellowship of the College of Intensive Care Medicine (FCICM). The College has over 900 Fellows throughout the world. The main office is located in Melbourne, with regional committees throughout Australia, and national committees in New Zealand and Hong Kong.

#### District Health Boards (DHBs)

DHBs are funded by the Ministry of Health and are responsible for the funding and provision of intensive care, transplantation and renal services.

#### GiveLife.org

GiveLife.org is an initiative led by Andy Tookey which aims to generate awareness of New Zealand’s organ donor shortage and campaign for changes to increase deceased organ donations. The website states that the initiative is “not a charity asking for money […] all we are asking you is to consider giving 'The Gift of Life'”.

#### Kidney Health NZ (KHNZ)

KHNZ is a non-profit organisation, which relies on public contributions for support. KHNZ promotes live kidney donation for transplantation and provides information and education services relating to renal disease. It also funds research on kidney disease.

#### Kidney Kids NZ

Kidney Kids NZ is a parent driven non-for-profit organisation founded in 1990 to provide emotional support and to help parents of children with kidney disorders. They assist parents to obtain the best services possible for their kids. Their services include support group meetings, coffee mornings, educational evenings, and special events. They also hold two annual camps each year for kidney kids who are at, or near, end stage renal failure (ESRF) and kidney kids who are experiencing social distress.

#### Live Kidney Donation Aotearoa (LKDA)

A provider in Counties Manukau DHB, Clinical Research and Effective Practice (now Middlemore Clinical Trials) received funding in Budget 2012 over three years to deliver the programme Live Kidney Donation Aotearoa (LDKA).

LKDA’s main roles are to inform, promote and facilitate in the area of live kidney donation in New Zealand so that donors, recipients and health practitioners can make the best choices.

LKDA is coordinated by kidney health practitioners and scientists with strong links to community and other stakeholders in the field of kidney disease. LDKA works directly with patients and their whānau, community groups, health practitioners (including GPs) and Counties Manukau DHB.

#### National Ethics Advisory Committee (NEAC)

NEAC is a committee set up under New Zealand legislation to advise the Minister of Health on ethical issues in health services and research, and determine national ethical standards for the health sector.

NEAC acts as an independent advisor to the Minister of Health. The Ministry of Health provides policy staff and other resources to support NEAC but the Committee remains independent of the Ministry and its work.

#### National Pancreas Transplant Registry (NPTR)

NPTR collects data on all Australian and New Zealand recipients of pancreas and islets transplants. The Registry monitors the progress of pancreas transplantation activity and provides a tool to analyse the causes for success and failures. NPTR is based in Sydney, New South Wales and collects data from the two pancreas transplant units in Australia and the one in Auckland in New Zealand.

NPTR is funded by the Australian Government Department of Health.

#### National Renal Advisory Board (NRAB)

NRAB is an independent board, working in partnership and partially funded by the Ministry of Health to support the provision of renal services to patients. They provide expert advice on all aspects of renal services, including identified priorities, renal care standards, and monitoring and auditing of activities.

NRAB reports to renal departments, District Health Boards and the Ministry of Health. Representatives on NRAB are key stakeholders, clinical and managerial leaders, and consumer groups, including the New Zealand Nephrology Group, the Renal Society of Australasia (New Zealand branch), the New Zealand Board of Dialysis Practice and Kidney Health New Zealand.

NRAB has of one subcommittee ‘Audit and Standards’. The Renal Society of Australasia Nursing Advisory Group and the New Zealand Board of Dialysis Practice (NZBDP) also report to NRAB (see details below).

#### National Renal Transplant Leadership Team (NRTLT)

In 2014, a new NRTLT was established to support the National Renal Transplant Service, comprising of:

* a strategy group to provide strategic guidance and review the performance of the service
* an operational group to develop and implement the work programme.

The Ministry of Health funds the Clinical Director of the National Renal Transplant Service, as well as a business analyst and secretariat to support the services. NRTLT’s role is to provide strategic direction and drive the implementation of the National Plan for Renal Transplantation.

Their purpose is to provide expert advice to the Ministry of Health on:

* specific areas relating to renal transplantation
* improve clinical outcomes for patients with end-stage renal disease where this is linked to transplantation
* consider services / initiatives for prioritisation, as part of a strategic planning and prioritisation process, that link to the longer term view of national renal transplantation services.

#### New Zealand Blood Service (NZBS)

NZBS is the Crown agent that ensures the supply of safe blood products. NZBS takes responsibility for the development of an integrated national blood transfusion process, from the collection of blood from volunteer donors to provision of blood products within the hospital environment.

NZBS helps the organ donation process by managing the national waiting lists for organs. NZBS also facilitates transplantations by carrying out the blood tests, tissue typing tests and cross-matching tests to ensure potential donor and recipient organ(s) are compatible.

#### New Zealand Board of Dialysis Practice (NZBDP)

NZBDP is a professional society that sets goals and standards related to certification of clinical physiologists (Dialysis). NZBDP supports and maintains the education programme for quality patient care dialysis specialty.

#### New Zealand National Eye Bank

New Zealand National Eye Bank is a non-profit organisation dedicated to the prevention of blindness by the provision of donated corneal and other tissues.

#### New Zealand Kidney Exchange programme (NZKX)

NZKX is a project that ‘matches’ pairs of potential kidney recipients and their live donors, who are not a suitable match for each other, with pairs in a similar position. The Ministry of Health funds NZKX, and Auckland District Health Board is responsible for the planning, coordination and overall provision of the NZKX services, which fall under the National Renal Transplant Services.

#### New Zealand Transport Agency (NZTA)

NZTA is a crown entity governed by a statutory board. NZTA administers the Driver Licensing Register, which asks people to indicate whether or not they would like to be a donor.

#### Organ and Tissue Authority (OTA)

OTA was established in 2009 and operates under the *Australian Organ and Tissue Donation and Transplantation Authority Act 2008*, as part of the Australian Government's national reform programme. The OTA is an independent statutory agency within the Australian Government Health portfolio.

The Organ and Tissue Authority (OTA) works with Australian states and territories, clinicians and the community sector to deliver the Australian Government’s national reform programme to improve organ and tissue donation and transplantation outcomes in Australia.

#### Organ Donation NZ (ODNZ)

ODNZ is a national service that reports to the Ministry of Health, and is hosted by Auckland DHB on behalf of all DHBs, to coordinate organ donation and some tissue donation from deceased donors in intensive care units. ODNZ also refers livers and cardiothoracic organs to and from Australia. ODNZ is contracted to carry out the following:

* educating and training health professionals involved in organ and tissue donation
* providing information and ongoing support for families who have donated
* providing information to the public and advice to health professionals about organ and tissue donation in New Zealand
* auditing organ donation practices in New Zealand
* working with health professionals to ensure nationally consistent processes
* assisting the Kidney Exchange programme (by packing and transporting kidneys).

ODNZ has an Advisory Group, which provides guidance and oversight of ODNZ. Advisory Committee members include representatives from intensive care medicine and nursing, transplantation, Māori/Pacific health, consumers.

Funding for ODNZ is received through DHB top slice funding. The additional funding received in Budget 2012 is through a direct contract between the Ministry of Health and Auckland DHB.

#### The Renal Society of Australasia Nursing Advisory Group (RSA NAG)

RSA is the professional body for nephrology nurses within Australia and New Zealand. The purpose of the RSA is to share knowledge in renal replacement therapies throughout New Zealand and Australia.

The branch’s Nursing Advisory Group in New Zealand provides leadership and a primary focus on the establishment of national standards of practice and a professional development model for nephrology nursing in New Zealand.

#### Transplantation Society of Australia and New Zealand (TSANZ)

TSANZ is the professional academic association of physicians, surgeons and scientists interested in all forms of transplantation. TSANZ was formed in the 1970s to undertake education, promotion of scientific understanding and determining protocols and procedures for managing transplant organ quality and allocation.

Members of TSANZ include scientists, doctors, recipient coordinators and research students. TSANZ has a standing committee responsible for each area of organ transplantation (heart/lung, kidney, liver, pancreas and cornea), including the national allocation guidelines.

# Appendix Seven: Organ Donation New Zealand – role and objectives

ODNZ is a business unit of Auckland DHB and subject to its usual accountability processes. It is funded by the DHB and some additional funding coming from the national contract with the Ministry of Health for organ donation and transplantation. ODNZ is required to report regularly to the DHB on budget matters and provide an annual narrative report to the DHB about its activities, including donations and training.

When ODNZ was established in 2005, its high-level service objectives were to:

* Develop, maintain and enhance nationally consistent processes for deceased-donor organ donation in new Zealand
* Provide information and follow-up for the whanau/families of organ and tissue deceased-donors
* Provide information to the public and advice to health professionals about organ and tissue donation in New Zealand
* Co-ordinate organ and tissue donation and retrieval from patients who become brain-dead in intensive care units and deceased multi-tissue donors in the hospital and the community setting.
* Provide educational programmes to health professionals involved with organ and tissue donation.[[158]](#footnote-158)

ODNZ’s current staffing is:

* Three medical specialists (1.1 FTE total) who provide 24/7 clinical advice to ICUs, as well as reporting on the death audit and carrying out teaching and quality improvement activities
* Four donor coordinators (3.8 FTE total)
* One communications advisor (0.5FTE)
* One administrator (1 FTE).

ODNZ also has an Advisory Committee which is intended to provide a mechanism for input from health professionals involved in organ and tissue donation, intensive care, and from Māori and Pacific peoples and consumers. The Advisory Committee’s functions include contributing to a strategic direction to ensure initiatives to increase donation are evidence-based and co-ordinated, and to develop education strategies for the public, with a particular focus on Māori and Pacific people[[159]](#footnote-159).

In 2012, the Ministry provided additional funding of $2 million over four years to ODNZ. This funding was used to:

* Engage additional specialist medical expertise
* Engage an additional Donor Coordinator
* Fund staff time in ICU to assist donation processes
* Develop a smartphone app with organ donation clinical and administrative information.

The ODNZ service specification was revised in 2014. Public awareness initiatives were included of the initial service specification, including promoting a coordinated approach to public awareness initiatives about organ and tissue donation. Public awareness initiatives are now a specific exclusion from the updated service specification, which otherwise remains much the same[[160]](#footnote-160).

# Appendix Eight: International comparison of registers, consent systems and roles of families**[[161]](#footnote-161)**

|  |
| --- |
| **Explicit consent systems** |
| **Country** | **Register** | **Driver licence option for organ donation** | **Family approached regardless of whether the deceased’s wishes are known or not** | **Family authorisation required if wishes are unknown** | **Family’s consent is required even if deceased’s wishes are documented** |
| Australia | Combined  | No (only New South Wales operates a driver licence register) | Yes | Yes | Yes  |
| Brazil | *Donor card* | No | Yes  | Yes  | Yes  |
| Canada | Combined (varies by province) | Some provinces (varies) | Yes  | Yes  | Yes  |
| Denmark | Combined (Registrants can choose “yes”, “no”, and “unsure”. They may also add “with next of kin approval”) | No | Yes  | Yes  | Yes  |
| Germany | *Donor card* | No | Yes  | Yes  | Yes  |
| India | *Donor card* | Yes | Yes  | Yes  | Yes  |
| Ireland | *Donor card* | Yes | Yes  | Yes  | Yes  |
| Israel | Opt-in | No  | Yes  | Yes  | Yes  |
| Netherlands | Combined (Registrants can choose “yes”, “no”, “next of kin will decide”, or “a named individual will decide”) | No | Yes  | Yes  | No (a strong objection by the family about donation will stop procurement to avoid causing a major negative impact on the family) |
| Switzerland | *Donor card* | No | Yes  | Yes  | Yes  |
| UK (except Wales) | Opt-in | Yes | Yes  | Yes  | No (a strong objection by the family about donation will stop procurement to avoid causing a major negative impact on the family) |
| USA | Opt-in | Yes (in most States) | Yes  | Yes  | No(States with the first-person consent make the deceased’s registered wishes paramount and procurement can occur with consent from the family. However, families are required for a medical and social history of the potential donor before procurement can occur) |
| **Presumed consent systems** |
| **Country** | **Register** (all provide a method to opt-out) | **Driver licence option for organ donation** | **Family informed** | **Family authorisation required if wishes are unknown** | **Family can veto donation** |
| Austria | Opt-out | No  | Yes (family must be present in the hospital at the time of donation for their opinion to be considered) | No | Yes (family must be present in the hospital at the time of donation for their opinion to be considered) |
| Belgium | Combined | No  | Yes | No (the family are informed of the intended procurement but permission is not explicitly asked. An objection will be respected) | No (if the deceased expressed their wish to donate, then only they can revoke the decision and upon death their decision will be respected and the family will not be able to revoke it) |
| Finland | *Donor card* | No | Yes | Yes | No (if the deceased expressed their wish to donate, then only they can revoke the decision and upon death their decision will be respected and the family will not be able to revoke it) |
| France | Opt-out | No  | Yes | No (when the deceased’s wishes are unknown, the family is asked what the deceased’s opinion on organ donation was. However, if the family objects to donation the removal will not occur) | Yes  |
| Italy | Combined | No  | Yes  | Yes  | Yes  |
| Norway | *Donor card* | No  | Yes  | Yes  | Yes  |
| Poland | Opt-out | No  | Yes  | No (when the deceased’s wishes are unknown, the family is asked what the deceased’s opinion on organ donation was. However, if the family objects to donation the removal will not occur) | Yes  |
| Singapore  | Combined | No  | Yes  | Yes  | No(if the deceased expressed their wish to donate, then only they can revoke the decision and upon death their decision will be respected and the family will not be able to revoke it) |
| Spain | *Donor card* | No  | Yes  | Yes  | Yes  |
| Sweden | Combined  | No  | Yes  | No(if family do not object, procurement will proceed under the presumption of consent. However, families have the legal right to object and must be informed of this right. If they cannot be reached, donation may not occur) | No (if the deceased expressed their wish to donate, then only they can revoke the decision and upon death their decision will be respected and the family will not be able to revoke it) |

1. International Registry on Organ Donation and Transplantation. 2016. Database. URL: <http://www.irodat.org/> [↑](#footnote-ref-1)
2. Waiting list data provided to the Ministry by the New Zealand Blood Service March 2016 [↑](#footnote-ref-2)
3. Organ and Tissue Authority. 2013. International approaches to organ donation reform. URL: <http://www.donatelife.gov.au/fact-sheets> [↑](#footnote-ref-3)
4. West Midlands Specialised Commissioning Team, NHS UK. 2010. *Organs for Transplants: an analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation.* Provided to the Ministry of Health, 21 January 2016. [↑](#footnote-ref-4)
5. Renal transplants from both living and deceased donors made up 63% of all transplants in New Zealand in 2015. URL: http://www.donor.co.nz/reports-a-publications-/number-of-transplant-operations-in-new-zealand [↑](#footnote-ref-5)
6. Yen, E. F. et al. 2004. Cost-effectiveness of extending Medicare coverage of immunosuppressive medications to the life of a kidney transplant. *American Journal of Transplantation*. 4 (10), p1703-1708. [↑](#footnote-ref-6)
7. West Midlands Specialised Commissioning Team, NHS UK. 2010. *Organs for Transplants: an analysis of the current costs of the NHS transplant programme; the cost of alternative medical treatments, and the impact of increasing organ donation.* Provided to the Ministry of Health 21 January 2016. [↑](#footnote-ref-7)
8. Prasad, E. 2015 *The Cost of Prohibition: The law and economics of New Zealand’s organ transplant regime.* A thesis submitted in partial fulfilment of the requirements for the degree of Master of Commerce in Economics, University of Canterbury.URL: http://nzinitiative.org.nz/site/nzinitiative/Prasad%20-%20MCom%20Thesis.pdf [↑](#footnote-ref-8)
9. A proportion of people undergoing dialysis and who are unable to work may be able to resume work after a transplant. For people who are already in work with failing kidneys, a pre-emptive transplant means that most of them should be able to remain in employment. [↑](#footnote-ref-9)
10. Data from the Ministry of Social Development shows that as at February 2016, they had 1110 clients who are exempt from work testing due to kidney or renal incapacity reasons, the majority of which (928) were receiving Supported Living Payments and have had their work preparation deferred. Taking into account supplementary payments as well as the main benefit, those 928 receive on average $18,509 per year each ($20.4 million per annum in total). [↑](#footnote-ref-10)
11. For example, a person earning the New Zealand median income from wages and salaries of $865 per week would be expected to pay around $6,900 per annum in income tax. [↑](#footnote-ref-11)
12. Sixty-third World Health Assembly. 2010. Human organ and tissue transplantation. Agenda item 11.21. URL: http://apps.who.int/gb/ebwha/pdf\_files/WHA63/A63\_R22-en.pdf?ua=1 [↑](#footnote-ref-12)
13. World Health Organization. 2011. Third WHO Global Consultation on Organ Donation and Transplantation: Striving to Achieve Self-Sufficiency, March 23-25, 2010, Madrid, Spain. *Transplantation*. 91, 11s. [↑](#footnote-ref-13)
14. The Declaration of Istanbul on organ trafficking and transplant tourism. 2008. URL: http://www.declarationofistanbul.org/about-the-declaration/structure-and-content [↑](#footnote-ref-14)
15. Organ Donation New Zealand. 2011. Annual Report. URL: http://www.donor.co.nz/files/Annual%20report%20with%20cover%202011.pdf [↑](#footnote-ref-15)
16. Australia & New Zealand Dialysis and Transplant Registry (ANZDATA).URL: <http://www.anzdata.org.au/v1/index.html>. Analysis conducted by the Ministry of Health [↑](#footnote-ref-16)
17. Australia & New Zealand Dialysis and Transplant Registry (ANZDATA). 2015. 38th Annual Report. Chapter 2: Prevalence of End Stage Kidney Disease. URL: http://www.anzdata.org.au [↑](#footnote-ref-17)
18. Because of the scarcity of deceased donor organs, criteria for access to lists for deceased donor transplants seek to balance giving the greatest number of people an opportunity for a transplant, with achieving the greatest overall benefit from the organs available. Thus, potential recipients must meet strict criteria to be eligible and those with the greatest chance of a successful outcome are prioritised. [↑](#footnote-ref-18)
19. National Clinical Taskforce on Organ and Tissue Donation. 2008. *National Clinical Taskforce on Organ and Tissue Donation final report: think nationally, act locally.​* National Clinical Taskforce on Organ and Tissue Donation*.* Canberra, A.C.T.: Dept. of Health and Ageing [↑](#footnote-ref-19)
20. International Registry on Organ Donation and Transplantation. 2016. Database. URL:http://www.irodat.org/ [↑](#footnote-ref-20)
21. Organ Donation New Zealand. 2014. Annual Report 2014. URL: http://www.donor.co.nz/files/ODNZ%20Annual%20Report%202014.pdf [↑](#footnote-ref-21)
22. Data provided by Organ Donation New Zealand, 15 March 2016. [↑](#footnote-ref-22)
23. Data provided by Organ Donation New Zealand, 7 February 2016 [↑](#footnote-ref-23)
24. Data provided by ODNZ to the Ministry of Health, 7 January 2016. [↑](#footnote-ref-24)
25. This is not an exact metric, as some the families that have organ donation “formally discussed” may be related to patients where donation after circulatory death is a possibility, rather than donation after brain death. However, the vast majority of deceased donation in New Zealand occurs following brain death. [↑](#footnote-ref-25)
26. Data provided by ODNZ to the Ministry of Health, 7January 2016. [↑](#footnote-ref-26)
27. Organ and Tissue Authority. 2015. 2014-15 Annual Report, p31-32.URL: http://www.donatelife.gov.au/annual-reports [↑](#footnote-ref-27)
28. Organ Donation New Zealand. 2014. Annual Report 2014. URL: http://www.donor.co.nz/files/ODNZ%20Annual%20Report%202014.pdf [↑](#footnote-ref-28)
29. International Registry on Organ Donation and Transplantation. 2016. Database. URL: http://www.irodat.org/?p=database&c=GB#data [↑](#footnote-ref-29)
30. International Registry on Organ Donation and Transplantation. 2016. Database. URL: http://www.irodat.org/?p=database&c=AU#data [↑](#footnote-ref-30)
31. Health and Disability Commission. 2009. The code of rights. Right 1(3). URL: [http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-(full)](http://www.hdc.org.nz/the-act--code/the-code-of-rights/the-code-%28full%29) [↑](#footnote-ref-31)
32. Human Tissue Act 2008, s31 (2) (a) [↑](#footnote-ref-32)
33. Human Tissue Act 2008, s42 [↑](#footnote-ref-33)
34. Human Tissue Act 2008, s9 [↑](#footnote-ref-34)
35. Human Tissue Act 2008, s9 (1) (a) [↑](#footnote-ref-35)
36. Human Tissue Act 2008, s78 [↑](#footnote-ref-36)
37. Wilkinson, M. & Wilkinson, S. 2015. The Donation of Human Organs. In: *The Stanford Encyclopedia of Philosophy* , Edward N. Zalta (ed.). URL:<http://plato.stanford.edu/archives/spr2015/entries/organ-donation/>>. [↑](#footnote-ref-37)
38. Ernst and Young. 2016. Deceased Organ Donation and Transplantation in New Zealand: Recommendations for improving practice in clinical settings and commentary on institutional arrangements, p. 35. Provided to the Ministry of Health, 26 February 2016 [↑](#footnote-ref-38)
39. UK Donation Ethics Committee. UKDCE Terms of Reference. URL: http://www.aomrc.org.uk/uk-donation-ethics-committee/ukdec-terms-of-reference.html [↑](#footnote-ref-39)
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