Deceased Organ Donation and Transplantation in New Zealand

Recommendations for improving practice in clinical settings and commentary on institutional arrangements.
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1. Acronyms and abbreviations

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<tr>
<th>Acronym</th>
<th>Description</th>
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<tr>
<td>ADAPT</td>
<td>Australasian Donor Awareness Program</td>
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<td>cFDC</td>
<td>Family Donation Conversation Core Module</td>
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<td>DBD</td>
<td>Donation by Brain Death</td>
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<td>DCD</td>
<td>Donation by Circulatory Death</td>
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<td>DHB</td>
<td>District Health Board</td>
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<td>DPMP</td>
<td>Donors per million of population</td>
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<td>EAG</td>
<td>Expert Advisory Group</td>
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<td>ICU</td>
<td>Intensive Care Unit</td>
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<td>ODNZ</td>
<td>Organ Donation New Zealand</td>
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<td>OTA</td>
<td>Organ and Tissue Authority (Australia)</td>
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<td>PBFF</td>
<td>Population Based Funding Formula</td>
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2. Summary

New Zealand has a relatively low rate of deceased organ donation, with limited increase in recent years.

Recognising that deceased (solid) organ donation can contribute significantly to enhanced length and quality of life for transplant recipients, the Minister of Health requested the Ministry of Health in 2015 to lead a review of deceased organ donation and transplantation within New Zealand (‘the Review’). The last major Review to have considered organ donation and transplantation was conducted in 1993. It should be noted that the primary focus of the 1993 review was transplantation services.

As part of the Review, EY was asked to provide recommendations to enhance deceased organ donation practice in clinical settings and commentary on the institutional arrangements relating to deceased organ donation.

In assessing practice in clinical settings, EY was asked to:

- Identify issues with current practice in clinical settings for deceased organ donation and transplantation
- Provide recommendations for practice in clinical settings that could improve deceased organ donation rates
- Identify potential impacts of increased deceased organ donation rates upon transplantation services.

In providing commentary on institutional arrangements, EY was asked to consider:

- Governance arrangements;
- Leadership (national, regional and local); and
- Roles and responsibilities within the deceased organ donation system.

In undertaking the above, EY has:

- Interviewed a set of key stakeholders as agreed with the Ministry of Health, including site visits to a number of Intensive Care Units (ICUs)
- Undertaken a high-level comparison of practices in clinical settings and institutional arrangements in New Zealand with health systems that have higher deceased organ donation rates
- Analysed relevant and available New Zealand data.

Overall, we conclude that there are opportunities for increasing the deceased organ donation rate through enhancing practice in clinical settings, most notably through:

- Strengthening the role of the Emergency Department (ED) in identifying organ donation opportunities, and the relationship between EDs and ICUs
• Making better use of data to drive performance improvement
• Using more efficient clinical workforce models to make the organ donation process easier for clinicians
• Increasing the uptake of deceased organ donation training, and ensuring that this training incorporates appropriate cultural factors to assist clinicians to work with families during the organ donation process.

With respect to current institutional arrangements in New Zealand, we consider that many of the basic components are in place for an efficient and effective deceased organ donation system. Given this, we do not believe that radical reform of the organ donation system is required. Rather, a clearer emphasis on increasing the deceased donation rate is needed, with this emphasis established and supported nationally but driven locally by DHBs, their executive management and clinicians.

Finally, we note the following caveats and limitations to our findings:
• The scope of our work has been tightly focused on two aspects of the wider Ministry of Health Review. The Ministry has provided EY with information relating to other aspects of the Review including preliminary findings. However, the findings presented in this report are naturally limited by the scope of work commissioned from EY, and should be read as such – particularly with respect to institutional arrangements.
• Stakeholder engagement has been focused on gaining a reasonable indication of current practices in clinical settings and perspectives on institutional arrangements as they relate to deceased donation and transplantation. It is noted that the Ministry of Health will engage further with stakeholders as part of the Review.
• We note that we have used our best professional endeavours to fairly and accurately report the themes arising from our engagement with stakeholders. Emerging themes were tested with the Review’s Expert Advisory Group but we have not sought to test the identified themes with all stakeholders engaged during the course of the project.
• We have built upon relevant work undertaken by the Ministry as part of the Review, and have taken the Ministry’s data and findings as reasonable and accurate.
• Our scan of international practice in clinical settings and institutional arrangements has focused on identifying high-level key learnings from other jurisdictions. It has not intended to be nor should be considered as a comprehensive and exhaustive review of available literature.
• The data and analysis presented in this report is naturally limited by the quality of available data. Where appropriate, we alert readers to important caveats regarding the analysis presented in this report.

Finally, we note that the contents of this report, including our recommendations, do not represent or constitute government policy.
3. Key Issues related to practice in clinical settings

Based on the findings outlined in this report, EY considers the following to be the key issues requiring resolution with respect to practices in clinical settings for deceased organ donation:

- **Organ donation is not seen as a core part of ICU business**: Many ICU clinicians view organ donation as an important activity but one that is ultimately secondary to caring for patients likely to make a recovery. This view can mean clinicians may not always look for solutions that may allow organ donation to be accomplished on top of caring for other patients. This view, coupled with the challenging reality of facilitating organ donation, means that organ donation opportunities can be missed or passed over.

- **Increasing the deceased donation rate is likely to require a focus on specific categories of potential donors**: While stakeholders believed there was some scope to improve deceased donation rates by focusing on traditional categories of organ donors (primarily Donation by Brain Death [DBD] candidates in an ICU environment), substantial gains in the donation rate will require increasing donations from:
  - Patients in such a serious condition that they are not admitted to the ICU for end-of-life care and instead die in the ED;
  - Marginal donors such as older patients and those with significant comorbidities;
  - Patients with families that have traditionally been seen as difficult to discuss donation with, or are seen as less likely to consent to organ donation; and
  - Donation by Circulatory Death (DCD) candidates (defined below).

These donors typically require greater investment and effort per successful donation than is required for the current population of deceased organ donors.

- **Making better use of available data to drive improvement**: The Organ Donation New Zealand (ODNZ) Death Audit collects valuable data but its ability to drive performance improvement is not being fully realised. Many clinicians spoken to expressed concern that they were unable to view performance data from their peers. They felt knowing who the high performing units were would enable them to learn from these units by replicating some of their successful practices. Furthermore, feedback to individual ICUs is often provided months or even years after missed opportunities have occurred. The limited and untimely nature of the data limits ICUs in both their focus on organ donation and their ability to improve their performance.

- **Variable clinical leadership**: In the absence of a clear and ongoing national emphasis on raising donations rates, the responsibility is largely left to the discretion of individual ICUs, with a ‘light touch’ from ODNZ. ICUs with strong
leadership (ie, clinicians with an interest who self-select to promote donation), whether medical or nursing, tend to have higher donation rates than ICUs without this focus.

- **Insufficient (but improving) training uptake:** The training workshops facilitated by ODNZ are considered to be fit for purpose but do not reach all staff who would benefit from the training. At present approximately 30-50% of intensivists have completed a training course on organ donation. Completing a training course is a requirement for intensivist trainees with the College of Intensive Care Medicine (CICM), but refresher courses are not required for existing Fellows. Furthermore, non-CICM medical staff in ICUs (such as anaesthetists in smaller ICUs) are not required to undertake the course, although they are able to access ADAPT training.

- **ED staff are not involved formally in the organ donation process:** Internationally, the ED is a significant source of organ donors, and has been identified as a key opportunity area in Australia\(^1\). EY recognises that there are some differences in practice in ED settings between Australia and New Zealand which may mean there are fewer missed donation opportunities in New Zealand. However, it is prudent to investigate the possibility that enhancing ED and ICU relationships could contribute to maximising donation. We understand that in some hospital settings opportunities may be being missed through insufficient communication between the ED and ICU. This results in organ donor candidates not being intubated or being extubated in the ED without offering families the opportunity for organ donation. Furthermore, ED staff are not trained to identify potential organ donors and therefore may not communicate with the ICU about these patients. ED deaths are also not included in the ODNZ death audit.

- **Non-European consent rates are substantially lower:** Māori, Pasifika and Asian families tend to have significantly lower deceased donation rates. While factors beyond the control of clinicians are likely to contribute to this, the cultural competence of staff and the consent request process may also be relevant. The Australasian ADAPT and cFDC workshops may not reflect all of the cultural considerations relevant to the New Zealand context, meaning that staff may not be fully equipped to lead a culturally sensitive donation discussion. It is also unclear whether DHB cultural units are well-linked into deceased organ donation processes. These units could assist clinicians to understand the best approach for donor conversations with families from different communities.

- **Suboptimal use of available staff resource makes the donation process more difficult for ICUs:** While donation is always a demanding process for clinicians, it is apparent that in some cases available clinical resources are not being utilised optimally to facilitate organ donation.

Three major types of suboptimal resource allocation have been identified:

- **Brain death determination**: In some ICUs, the lack of a second intensivist outside of business hours to test for brain death is cited as a reason why organ donation is burdensome (creating a disincentive to maximise all opportunities). However, there does not appear to be any legal or good practice reason why a neurosurgical, neurological or internal medicine consultant on-call or a senior register on-site could not complete the second (confirmatory) brain death test. This is likely to be much more important in small and medium sized ICUs.

- **LINK nurses**: ODNZ has recently funded an extended LINK nurse role for four ICUs, which has reportedly made organ donation easier through lessening resource constraints and providing a level of leadership to contribute to improvement locally. However, stakeholders noted that LINK nurses, specifically funded to help enable organ donation, are not utilised consistently during donor workup and organ retrieval operations.

- **Insufficient nursing involvement in organ donation leadership**: In some ICUs, organ donation is a process for which nursing staff take a large amount of ownership. Transferring more responsibility for organ donor identification and coordination to nursing staff could reduce the burden on ICU medical staff, which is often suggested as a reason why organ donation is not considered.

- **There is a lack of strong clinically-led national focus on lifting donation rates**: International practice suggests clinical leadership is important at a national level as well in each ICU. Without a clear focus on improving organ donation rates, the performance of each ICU falls largely to the motivation of the staff in each ICU. Stakeholders were unclear whether increasing the deceased organ donation rate is an objective of ODNZ, either formally or informally.

- **New Zealand’s ICU configuration and current practices in clinical settings may impact on the deceased donor rate**: New Zealand has a dispersed ICU configuration, with many small ICUs where potential donors are relatively rare. These units may also be staffed by non-intensivist medical staff (such as anaesthetists) who are unlikely to be trained in organ donation. This may mean that staff will be less familiar and skilled with handling organ donation – either in terms of identifying donors or undertaking key process steps such as donor conversations. This could result in missed opportunities.

It is also important to note that New Zealand has less per capita ICU capacity than comparator countries such as Australia. In 2014, Australia had approximately 50% more ICU resources than New Zealand (8.62 and 5.84 beds...
per 100,000 people respectively\(^2\)). This means that Australia has greater capacity to support organ donation.

\(^2\) ANZICS Centre for Outcome and Resource Evaluation Annual Report 2012-2013, ANZICS Melbourne.
4. Recommendations for enhancing practice in clinical settings

There is good reason to believe that deceased organ donation rates in New Zealand can be increased through improved practices in clinical settings – and this is the message from the majority of stakeholders EY spoke with. We consider the biggest opportunities lie in improving donor identification and the frequency of consent requests. This means:

- Ensuring all possible donors are identified in both ICU and ED; and
- Reducing the demands that organ donation can place on clinical or supporting staff.

It is important to note that there is no clearly defined international standard of best practice for all elements of deceased organ donation. Some of the following recommendations draw on international evidence while others are based on EY’s experience in other health care reforms as well as the opinions of consulted expert stakeholders.

Furthermore, it is important to note that some specific improvements to organ donation systems may be effective for particular ICUs and not for others. Therefore the following recommendations centre on themes that can be applied to most or all clinical settings. The recommendations are non-exhaustive and are likely to incentivise local innovation beyond the recommended changes set out below.

Emergency Department: Patients arriving in hospital can be so catastrophically injured or ill that they have very little chance of recovery but have the potential to be organ donors. At present, treatment may not be started, or may be withdrawn, before the possibility of organ donation can be offered to the family. The potential pool of organ donors could be increased by instituting measures to identify these patients and facilitate their admission to the ICU.

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<tr>
<th>Number</th>
<th>Recommendation</th>
<th>Priority</th>
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<tr>
<td>1.1</td>
<td>Pathways for admission to the ICU from ED solely for the purpose of organ donation should be developed and rolled out to all relevant clinical sites.</td>
<td>High</td>
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<tr>
<td>1.2</td>
<td>ED triggers to contact the ICU should be developed and implemented.</td>
<td>High</td>
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<td>1.3</td>
<td>ED staff should receive training on the identification and management of potential donors and their families.</td>
<td>Moderate</td>
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<tr>
<td>1.4</td>
<td>The ODNZ Death Audit should be expanded to include ED deaths.</td>
<td>High</td>
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<td>1.5</td>
<td>ED staff should be involved in the ODNZ death audit meetings.</td>
<td>Moderate</td>
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<tr>
<td>1.6</td>
<td>Clinical sites with ED nurses with a research portfolio responsibility should consider extending this role to cover the identification and coordination of potential organ donors.</td>
<td>High</td>
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Use of data to improve practice: A large amount of audit data is collected but it is not distributed in a manner that fosters peer learning and accountability. Without robust measurement and benchmarking of performance, it is unlikely that organ donation will consistently remain front of mind for clinicians.

| Recommendations: Use of data to improve practice | |
|---|---|---|
| **Number** | **Recommendation** | **Priority** |
| 2.1 | ICU death audit data should be reported in a non-anonymised format that is accessible to all relevant personnel. | High |
| 2.2 | Death Audit reporting should be frequent and timely. It is suggested that publication of data every 6 months could be appropriate. | High |
| 2.3 | Death Audit performance should be sent directly to the Chief Medical Officer of each District Health Board (DHB) and to the Chief Medical Officer of the Ministry of Health to ensure organ donation is given both local and national priority. (DHB Hospital Advisory Committees should be involved as appropriate.) | High |
| 2.4 | Death Audit meetings should be widened to include non-LINK staff from each ICU where possible. | Moderate |
| 2.5 | An appropriate qualitative organ donation measure (or set of measures) should be included in ICU clinician job descriptions and factored into their annual performance reviews. | Moderate |
| 2.6 | ICUs should make organ donation a standing item at daily case meetings and/or Mortality & Morbidity meetings, with the active involvement of ED clinicians as appropriate. | High |
| 2.7 | The Ministry should consider establishing a ‘soft’ national target for the deceased donation rate, with appropriate timeframes and apportionment for achievement between DHBs (either at a regional or individual DHB level). Once the system has matured, a ‘harder’ target regime could be established with public reporting. | High |

Clinical resource utilisation: Existing clinical staffing resources could be used more effectively to ease the time and staffing constraints that stakeholders report sometimes makes organ donation difficult to facilitate.

| Recommendations: Clinical resource utilisation | |
|---|---|---|
| **Number** | **Recommendation** | **Priority** |
| 3.1 | ICUs should be encouraged to explore the potential for models of organ donation with greater nursing involvement, with the support of the Ministry of Health and Health Workforce New Zealand. | Moderate |
| 3.2 | The Ministry of Health should liaise with the Australian and New Zealand Intensive Care Society regarding the feasibility of ICU medical staff using senior registrars or consultants from allied specialties such as anaesthesia and neurosurgery to perform brain death testing where a second intensivist is not available, with a view that this will be included in future clinical guidelines. | Moderate |
| 3.3 | Larger ICUs should establish and/or extend the scope of ‘on-call supernumerary intensivist(s)’ to include on-call organ donation duties as well as related duties such as trauma, MET and flight calls. | Moderate |
| 3.4 | The feasibility of sending additional temporary personnel to smaller ICUs to support organ donation efforts be studied further. | Moderate |
**Training:** Consent rates could be lifted in population groups with very low rates if more staff were able to learn and update their organ donation communication skills.

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<td>4.1</td>
<td>ADAPT, cFDC or another fit for purpose training workshop should be offered to non-CICM ICU medical staff.</td>
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<td>4.2</td>
<td>Refresher versions of the ADAPT, cFDC or another fit for purpose training workshop should be offered to CICM Fellows who have not taken the course for a long period of time. The CICM could also consider making a refresher course mandatory for Fellows.</td>
<td>Moderate</td>
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<td>4.3</td>
<td>The content of the ADAPT, cFDC or other training workshops should be reviewed to ensure it covers cultural competence considerations relevant to the New Zealand context. In particular, cultural competence in engaging with Māori and Pasifika families should be covered.</td>
<td>High</td>
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5. Overview of commentary on institutional arrangements for deceased organ donation

New Zealand has many of the basic components in place for an efficient and effective deceased organ donation system including key elements such as:

- 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 donor 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).

However, to deliver on the recommendations we suggest for enhancing practice in clinical settings, we believe a clearer emphasis on increasing the deceased donation rate is necessary, which is established and supported nationally but driven locally. We also think it is important to recognise that deceased organ donation is but one clinical process within New Zealand's highly devolved health system; unless the wider health system supports deceased organ donation, it is unlikely that a sustained lift in the deceased donation rate will be achieved.

Given the above, we suggest the following are key priority actions:

- Establishing a clinically credible national strategy for increasing the deceased donation rate which includes a clear vision for the organ donation system and measurable goals to track progress on achieving this vision
- The Ministry to take a stronger stewardship and performance management role of the overall system, clearly establishing expectations for the system to be driven through ODNZ, DHBs, ICUs and EDs
- 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)
- Strengthening the role of DHB Boards and Community Public Health Advisory Committees (CPHACs) in promoting awareness of organ donation, and leading conversations with local communities on the benefits of donation, and linking this to the broader discussions around end of life care
- Strengthening the role of Hospital Advisory Committees and Chief Medical Officers (CMOs) in ensuring improvements in practices in ICU and ED settings
- Placing the appropriate level of expectation on DHBs to ensure that they are committed to achieving a lift in the deceased donation rate and making local budgeting decisions which are supportive of both therapeutic care and deceased organ donation
- Building on the ICU LINK teams to strengthen local leadership at the ICU level, and between ICUs and EDs. This may need consideration of the appropriate level
of dedicated time for these positions to enable local championship of organ donation.

While we do not consider that major reform is necessary, we believe that ensuring successful delivery on the priorities listed above will require:

- Clarifying the role ODNZ is expected to play in achieving the proposed national strategy for deceased organ donation
- Evaluating whether ODNZ’s location within Auckland DHB is appropriate, given its national coordination role across 20+ ICUs
- Considering whether ODNZ has sufficient capability to lead and implement change across the sector
- Revisiting the quantum of funding allocated to ODNZ, and whether this is supportive of the organisation being able to deliver on national objectives
- Exploring the costs and benefits of including tissue donation within ODNZ’s scope
- Whether current DHB funding arrangements support organ donation, and what adjustments may be necessary to provide sufficient incentives to DHBs to promote and facilitate organ donation locally (at the clinical and community level)
- Working with the transplant sector to ensure that there is sufficient capability and capacity to make best use of a higher level of procured organs.
6. Introduction

Organ transplantation is an effective medical therapy and is often the only remaining treatment available to patients on a transplant waiting list. Receiving an organ transplant can save and transform the life of the recipient. Advances in medical science have expanded the scope of transplantation therapy and offered hope to more patients.

For transplantation to occur, a person must first act as an organ donor. While living donors can donate a kidney or a section of liver, the predominant source of organs within New Zealand is from deceased donors. Only a small proportion of deaths occur in a manner which allows a person to be a potential organ donor (~1-2% of hospital deaths). Patients who donate organs have typically died unexpectedly and have suffered catastrophic injuries such as a traumatic brain injury (often related to road traffic accidents) or an intracranial haemorrhage. These contexts are defined by the tragedy and grief of an unexpected death, making the process of organ donation even more complex.

There are two categories of deceased organ donors; those that die by brain death, and those that die through circulatory death.

Brain death is the most common situation where organ donation may occur. Brain death is when pressure within the skull is raised, cutting off all blood flow to the brain and causing death of the entire brain. These patients are unable to breathe independently and are kept alive by an artificial ventilator within ICU. These patients have no possibility of regaining brain function and are unable to survive without ventilator support. Donation after brain death (DBD) makes up approximately 90% of all deceased organ donors in New Zealand.

Donation after Circulatory Death (DCD) is the other pathway to organ donation. DCD patients typically have catastrophic brain injuries but do not meet the criteria for brain death. In this instance, life supporting treatment is withdrawn as it is judged to be in the best interests of the patient. Treatment withdrawal results in the DCD patient’s heart ceasing to beat and circulatory death being pronounced. Because of the time delay between treatment withdrawal and death, there is a time period where a DCD patient’s organs are not supplied adequately with oxygen. This causes stress and damage to the organs, which can reduce their quality and limit their transplant potential. By contrast, the heart of a patient donating organs after brain death continues to beat due to artificial ventilation being maintained. This means that DBD theoretically results in higher quality organs for transplantation as compared to DCD.

However, clinical experience suggests that kidney, lung and pancreas transplants

3 Approximately 75% of New Zealand organ transplants in 2014 were from deceased donors. It should be noted however that for kidneys there were slightly more transplants from living donors than deceased donors. Source: 2014 Organ Transplant data, International Registry in Organ Donation and Transplantation.
from DCD and DBD patients have similar levels of effectiveness. Only liver transplants have significantly better outcomes when the organ is from a DBD patient as opposed to a DCD patient\textsuperscript{4}.

In New Zealand, it is possible for deceased donors to donate the following organs:

- Heart;
- Lungs;
- Kidneys;
- Liver; and
- Pancreas.

It is also possible for deceased donors to contribute a range of tissues including corneas, skin, musculoskeletal tissues and heart valves.

Kidney transplantation occurs in Auckland, Capital & Coast and Canterbury DHBs. Auckland DHB is New Zealand’s sole provider of heart, lung, liver and pancreas transplant services.

\textsuperscript{4} 5.2 DCD Graft Survival, The ANZICS Statement on Death and Organ Donation, Australia and New Zealand Intensive Care Society
7. Background

**Ministry of Health review**

Recognising that deceased (solid) organ donation can contribute significantly to enhanced length and quality of life for transplant recipients, the Minister of Health requested the Ministry of Health in 2015 to lead a review of deceased organ donation and transplantation within New Zealand (“the Review”). The last major Review to have considered organ donation and transplantation was conducted in 1993. It should be noted that the primary focus of the 1993 review was transplantation services.

The Review’s objective is to identify, assess and recommend actions to increase deceased solid organ donation rates.

The Review will consider:

- Alignment of New Zealand’s clinical settings and training with international best practice, particularly within EDs and ICUs.
- Regional differences in clinical practices and donation rates.
- Lessons from other donation systems in New Zealand, including 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 licensing 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.

The Review will not consider:

- Transplant waiting list and organ allocation processes.
- Options for increasing tissue donation and live organ donation rates.
- Financial assistance for living donors.
- Adequacy of general funding for DHBs.

**Expert Advisory Group**

As part of the Review process, the Ministry of Health established an Expert Advisory Group (EAG) to provide advice to the Ministry on key components of the review. The group comprises organ donation and transplantation sector experts including clinicians, management staff, cultural leaders and ethicists.
The role of EY
The Ministry commissioned EY to contribute to the Review process. Specifically, EY was asked to provide recommendations to enhance deceased organ donation practice in clinical settings and commentary on the institutional arrangements relating to deceased organ donation.

In assessing practice in clinical settings, EY was asked to:

- Identify issues with current practice in clinical settings for deceased organ donation and transplantation.
- Provide recommendations for practice in clinical settings that could improve deceased organ donation rates.
- Identify potential impacts of increased deceased organ donation rates upon transplantation services.

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 (e.g., ICU, ED, Neurosurgery);
- Infrastructure requirements – including information exchange; and
- Linkages with tissue donation and the transplant sector.

In providing commentary on institutional arrangements, EY was asked to consider:

- Governance arrangements;
- Leadership (national, regional and local); and
- Roles and responsibilities within the deceased organ donation system.

EY was not expected to provide recommendations or preferred options for any potential changes to institutional arrangements related to deceased organ donation and transplantation.

On 29 January 2016, the EAG considered EY’s initial findings, with their feedback incorporated into the findings and recommendations presented in this report.

Key EY personnel involved in developing this report include:

- Stephen McKernan: Engagement Lead
  - Partner at EY, former Director-General of the Ministry of Health & CMDHB Chief Executive.
- Dr David Sage: Clinical Associate
  - Clinical Lead for the Health Quality & Safety Commission Reportable Events programme & former Auckland DHB Chief Medical Officer.
Dr Tony Sherbon: Quality Assurance
- Partner at EY Australia, former CEO of the Independent Hospital Pricing Authority, South Australian Health Department and ACT Health. Dr Sherbon has significant experience in healthcare reform and the delivery of healthcare strategy.

EY’s recent experience in organ donation reform: EY has recently conducted a review of the implementation of Australia’s national reform agenda for organ donation and transplantation. The review has given EY significant insight into the internal workings of a similar organ donation and transplantation system in the context of major reform. The review was led by Dr Tony Sherbon.
8. Methodology

In developing its findings and recommendations, EY has built on work already undertaken by the Ministry of Health to inform the Review. In particular, we have considered confidential working draft documents prepared for the EAG that detail:

- Background information on organ donation and transplantation in New Zealand.
- Donation rates and trends in New Zealand and the potential scope to increase deceased organ donation.
- Summaries of international experience of deceased organ donation reform programmes.

EY has taken this work further through:

- **Stakeholder engagement:**
  - Targeted individual interviews with key clinical and non-clinical stakeholders. This included interviews with organ donation and transplantation clinicians, EAG members and ODNZ representatives.
  - Site visits to meet with ICU and ED clinicians. This included site visits to Auckland Hospital, Hawke’s Bay Hospital, and Wellington Hospital. Group interviews were conducted with intensivists, ICU nurses, theatre nurses and ED representatives. We also spoke with Whangarei Hospital staff.
  - Analysis of selected international literature: Practices in clinical settings and guidelines from health systems with higher deceased donation rates were assessed and compared to those in New Zealand - building on work already conducted by the Ministry of Health as provided to the Review’s EAG in December 2015. The review focused on the developed country with the highest sustained rate of deceased organ donation: Spain. In addition, the UK and Australia were studied on account of the similarity of their health systems to New Zealand’s, and the success of their own reform programmes. EY also considered analyses performed by comparator countries of their own reforms and what elements were considered to be the most or least successful. The analysis of international literature was focused on identifying key learnings rather than exhaustive and comprehensive analysis of practice in other jurisdictions.
  - Analysis of New Zealand data: EY has analysed available New Zealand data to provide insight into current practices in clinical settings and trends. This has included analysing:
    - Records from ODNZ detailing national and ICU level data organ donation processes (the New Zealand death audit).
    - National hospital data to identify ICU patient mix and utilisation.

Due to the quality some of the data analysed, it is not included in this report.
Organ donation and transplantation are well established clinical services within New Zealand with Auckland Hospital being New Zealand’s major transplantation centre. Deceased organ donation occurs across New Zealand’s network of 24 widely dispersed ICUs, some of which are relatively small and may be staffed by non-intensivist medical personnel. Given this configuration of the donation and transplantation system, New Zealand faces some unique challenges when compared to larger health systems (such as the UK and the US).

Organ Donation New Zealand (ODNZ)

ODNZ is New Zealand’s national coordinating body for deceased organ donation. ODNZ was established in 2006 by expanding and renaming the National Donor Coordination Office (located within Auckland DHB). This change was precipitated by a 2002 petition to the Health Select Committee requesting that Parliament address a perceived shortage of deceased organ donors. As a result, ODNZ received more funding than the former Coordination Office and had its scope expanded to include education and advisory activities as well as a national role to bring consistency to organ donation processes across clinical settings.

ODNZ provides a central contact point for ICU clinicians in the event of having a possible deceased organ donor in their care. ODNZ then coordinates the medical testing and logistical organisation required for organ donation to occur. ODNZ also provides telephone access to 24/7 specialist intensivist advice including on how to optimise physiological management of the donor until the organs can be retrieved.

ODNZ donor coordinators (who are mainly from a nursing background) organise logistical coordination for the organ retrieval teams, and travel to the donor hospital with the retrieval team. The coordinator will often speak with the donor’s family as well as assisting in the organ retrieval surgery.

In each DHB, ODNZ also works with a LINK team. The LINK teams have been established by ODNZ to provide a local point of contact for the organisation, and to assist other local staff with the donation process. Typically, these roles are established as portfolio roles, with no funding from ODNZ. The LINK team consists of a LINK ICU nurse, an operating theatre nurse and a LINK intensivist. ODNZ has recently instituted a funded extended LINK nurse role (0.2-0.4 FTE), which ICUs have been able to voluntarily take up. The extended LINK nurse role is intended to make organ donation easier for ICUs including by acting as a local knowledge resource.

ODNZ funds training workshops on organ donation for medical and nursing staff. ODNZ also runs two workshops per year for LINK staff to provide further upskilling opportunities. At one of the annual LINK team meetings, the ICU death audit data is displayed on an ICU specific level. This data is not made available outside of these meetings. Every 1-2 years ODNZ staff also visit each ICU and provide specific
feedback on the Unit’s death audit data to support discussion on missed donation opportunities, and improvements in process.

ODNZ is structured as a business unit within the Auckland DHB, with ODNZ employees being employed by the DHB. It is funded primarily through funding allocated to the DHB as part of the national ‘top-slice’ for heart and lung transplantation. EY understands that ODNZ’s operational budget is ~$1.9M per annum\(^5\). In 2012, ODNZ received an additional $500,000 of funding annually in a contract between the Ministry of Health and Auckland DHB, which lasts until 30 June 2016 (we understand that the $500,000 is included in the organisation’s $1.9M operational budget). The funding has been used to fund extended LINK nurse positions in four ICUs (as noted above). This role is paid, unlike the other LINK positions.

ODNZ is also responsible for coordinating tissue donation in ICU, hospital and community settings. Referrals from ODNZ are made to the appropriate tissue donation or banking services as required. Eye tissue is only coordinated by ODNZ if the donor is in an ICU environment. ODNZ does not coordinate live donor activities but does provide logistical support for the transport of kidneys for the Paired Kidney Exchange Programme.

EY understands that ODNZ’s current staffing includes:
- Three medical specialists to provide 24/7 clinical advice to ICUs alongside specific portfolio responsibilities (eg, clinical director; NZ Death Audit; teaching and quality improvement) (1.1FTE)
- Four donor coordinators (one team leader) (3.8FTE)
- One communications advisor (0.5FTE - reduced from 1FTE)
- One administrative position (1FTE).\(^6\)

We understand that ODNZ is recruiting an additional donor coordinator.

**Configuration of donation and transplant services**

There are four major clinical components in organ donation and transplantation:
- Donor identification, management and consenting (core responsibility of individual New Zealand hospitals - ICU, EDs);
- Donor coordination and retrieval (responsibility of ODNZ and organ retrieval teams);
- Transplantation (responsibility of transplant teams); and
- Donation system improvement including training, quality improvement and advice (responsibility of ODNZ).

**Donor identification, management and consenting**
Potential deceased organ donors are identified within New Zealand’s 24 ICUs.

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\(^5\) Auckland DHB and Ministry of Health correspondence with EY.

\(^6\) Staffing profile as discussed with ODNZ Clinical Director.
When the treating intensivist judges it appropriate, they may raise the possibility of organ donation with the family. If the family consents to organ donation and the donor is medically suitable then the ICU team will keep the patient physiologically stable until the organs are retrieved.

**Donor Coordination Services**
As outlined above, ODNZ provides a central point for ICU clinicians to contact in the event of having a possible deceased organ donor in their care. ODNZ provides advice on the medical suitability of potential donors (including organising medical testing), advice on their physiological management, liaison with transplant services and coordination of the organ retrieval process.

**Transplant Services**
If a transplant service accepts an organ offered to them by ODNZ, then an organ retrieval team is formed. This team will travel with an ODNZ donor coordinator to the hospital where the donor is located and surgically remove organs from the donor. The retrieval teams are composed of surgeons, nurses and other clinical staff from hospitals providing a transplant service. The logistical support and coordination for the retrieval teams is provided by ODNZ.

**Donation system improvement including training, quality improvement and advice**
ODNZ is contracted by the Ministry of Health to undertake deceased organ donation system improvement, with roles including (but not limited to):

- Educating and training health professionals in organ and tissue donation;
- Working with health professionals to ensure nationally consistent processes; and
- Auditing organ donation practices in New Zealand.

Figure 1 provides an overview of the key institutional arrangements of organ donation and transplantation services in New Zealand.
Figure 1. Key institutional arrangements of organ and transplantation services in New Zealand

Figure 2 indicates the steps taken in DBD and the key determinants of progress from one step to the next. It is important to note that there is some variation in the order of the processes between different clinicians, ICUs and clinical circumstances.


**Figure 2. Organ Donation Pathway (DBD specific)**

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**Trends in organ donation in New Zealand**

**Deceased organ donation rates**

Although there is significant year to year variability in donor numbers, there has been no clear and sustained increase in deceased donation rates over the past two decades in New Zealand. Figure 3 shows donation rates declined substantially in the mid-2000s, reaching a low of 6 donors per million of population (dpmp) in 2006 before steadily returning to previous levels. The average rate over the past 20 years has been 9.3 dpmp, with some significant variation around this average. Although complete 2015 deceased organ donation data was not available to the EY, it is noted that in 2015 New Zealand achieved its highest number of deceased organ donations. Over the course of the year, 53 people donated organs after their death. This is equivalent to a rate of approximately 11.9 dpmp which is approximately equal to the record deceased donation rate achieved in 1998. This is a significant achievement but we note that when viewed over the 20-year period there has not been a discernible trend improvement in overall donations - noting that over recent years, dpmp have increased from the low in 2006. This is in contrast to achievements made in the UK and Australia (see Figure 7).
Figure 3. The rate of deceased donors (per million of population) over the past 20 years (1994-2014)

Source: International Registry in Organ Donation and Transplantation as presented in Ministry of Health report 'Donation rates and trends in New Zealand and the potential scope to increase deceased donation' [working draft].

Transplantation rates by organ type
Transplant rates vary markedly by organ with kidneys comprising approximately half of all organs donated (refer Figure 4). Liver transplants are the second most common transplant type. Heart and lungs are transplanted at a similar rate - approximately between 50-70% of the liver transplant rate.

Pancreas transplants are comparatively rare within New Zealand, as they are in most other countries.

It is important to note that each deceased donor can donate multiple organs. This means that the total number of organs available for transplant is higher than the number of deceased organ donors.
Figure 4. Organ transplantations from deceased donors by organ type

![Figure 4: Organ transplantations from deceased donors by organ type](image)

Source: Table 5, Organ Donation New Zealand Annual Report 2014. En-bloc kidneys and double adult transplants have been included in these figures. Note: 2015 figures are not included in the graphs, as these numbers are still being finalised.

Profile of deceased organ donors
Deceased organ donation can occur at any New Zealand ICU. However, given their relative size and patient mix, deceased organ donation is most common at New Zealand’s major tertiary hospitals: Auckland, Middlemore, Waikato, Wellington, Christchurch and Dunedin.

People of European ethnicity have a considerably higher rate of donation compared to other population groups. For example, Europeans donate at about twice the rate of Māori. Europeans also comprised over 80% of all deceased organ donors in 2014.

Deceased donors have a median age of approximately 50 years but there is considerable spread in donor ages - indeed in 2014, donors younger than 6 months and older than 80 years became deceased organ donors.

| Table 1: Ethnicity of deceased organ donors in 2014 |
|-----------------|-----------------|-----------------|
|                 | Number of donors | Rate (dpmp)     |
| European        | 37              | 12.5            |
| Māori           | 4               | 5.7             |
| Pacific Peoples | 2               | 6.9             |
| Other           | 3               | 5.4             |
| Total           | 46              | 10.2            |

Note: Donation rates have not been age-standardised.
Source: Table 4, Organ Donation New Zealand Annual Report 2014. PMP rates calculated by EY using 2014 Statistics New Zealand population estimates.
Donation after Circulatory Death (DCD)

Donors who have died of circulatory death, often after a catastrophic brain injury that does not meet the criteria for brain death, represent a small but increasing proportion of total deceased donors. DCD numbers are volatile from year to year but the technique appears to be growing in prevalence.

Figure 5. Instances of donation after brain death (DBD) and donation after circulatory death (DCD)

International comparison of donation and transplantation rates

New Zealand has a relatively low deceased donation rate when compared to other countries (refer Figure 6). The country with the highest sustained deceased donor rate is Spain, which has a deceased donation rate of 36 dpmp - more than three times New Zealand’s rate of 10.2 dpmp (2014).

New Zealand’s deceased donation rate is also much lower than those observed in Australia and the UK. Australia and the UK have engaged in significant reform programmes, which have increased their donation rates from levels similar to New Zealand’s to 16.1 pmp (Australia) and 20.4 pmp (UK). As a result, their respective deceased donation rates are 60% and 100% higher than New Zealand’s (refer Figure 7).

| Table 2: Age distribution for deceased organ donors in 2014 |
|------------------|------------------|
| **Median**       | 49.7             |
| **Mean**         | 45.6             |
| **Minimum**      | 0.2              |
| **Maximum**      | 82.5             |

Source: Table 3, ODNZ Annual Report 2014
Figure 6. International comparison of deceased donation rates (pmp)

Deceased donation rate (per million people)

Source: Figure 2.1, Chapter 2, 2015 Australia and New Zealand Organ Registry Annual Report
Figure 7. New Zealand donation rates (dpmp) compared to Australia and the United Kingdom

![Graph showing donation rates from 1995 to 2014 for New Zealand, Australia, and the United Kingdom. The graph includes a peak in 2009 for New Zealand and a lower peak for Australia and the United Kingdom in 2011.](image_url)

Source: International Registry in Organ Donation and Transplantation

**Utilisation of organs**

Compared to other countries, New Zealand utilises donated organs effectively. On average, three organs are transplanted for every deceased donation that occurs. This compares favourably to countries with considerably higher deceased donation rates, and is approximately equal to the Australian rate (Figure 8). New Zealand’s higher rate of organ utilisation means that the overall organ supply is higher than suggested from the donor rate alone.

The total number of organs from deceased donors used for transplant from 2005 to 2014 in New Zealand has tended to be proportional to the number of deceased organ donors in a given year (Figure 9). However, there is considerably greater year-on-year variation in the number of organs transplanted than there is in the number of deceased donors. From 2005 to 2014 there has been a greater increase in the number of organs transplanted from deceased donors than in the number of deceased donors, both in proportional and absolute terms.

It is important to note that donors are not a homogenous group and that some will be eligible to donate a greater number of organs than others. To ensure the number of organs available for transplantation is as high as it can be (within

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7 It is noted that the Review EAG has advised that comparing the total number of organs donated to the total number of organs transplanted is likely a superior measure than utilisation of organs by deceased donor as the latter measure is influenced by the composition of the deceased donor pool in a given country (and a given year) and the average number of organs retrieved per deceased donation. Unfortunately, data to undertake this analysis was not available in time for this report.
appropriate legal and ethical frameworks), it is important to focus on the number of organs each donor can donate and not focus solely on the number of donors. **Figure 8.** International comparison of utilised organs per deceased donor for select countries (2014)

![Graph showing international comparison of utilised organs per deceased donor](image)

*Source: International Registry in Organ Donation and Transplantation.*

**Figure 9.** Total numbers of deceased donors and organs transplanted that were from deceased donors.

![Graph showing total numbers of deceased donors and organs transplanted](image)

*Source: International Registry in Organ Donation and Transplantation.*
10. Findings

This section sets out our key findings from stakeholder engagement, comparison of New Zealand practices in clinical settings with those observed in other key health systems, and analysis of New Zealand data.

Key findings from stakeholder engagement

Organ Donation New Zealand:

ODNZ is seen to offer an excellent coordination and advisory service to ICUs
A consistent theme from stakeholders was that ODNZ provides very helpful and timely clinical advice, support and coordination services. A practice of contacting ODNZ early in the organ donation process was common and was perceived positively both by ICU clinicians and ODNZ.

Clinicians spoken with also attributed improvements in organ quality to ODNZ’s advice on donor selection and physiological management. However, it was noted by some ICU clinicians that the level of patient information requested by ODNZ is greater than warranted, and is time consuming to collate. While this was not reported as reducing ICU clinician willingness to initiate organ donation processes, it may have increased the friction in the process. That said, it is likely that access to specialist advice has enabled some opportunities to proceed which in past years may not have.

Stakeholders perceived that the organisation is not focused on improving the overall deceased donation rate, suggesting that ODNZ considers logistical coordination and organ quality as higher priorities. It was also suggested by some stakeholders that Auckland DHB and the Ministry of Health have operated in a relatively arms-length way from ODNZ.

Stakeholders are not convinced that ODNZ should be configured as part of Auckland DHB
Stakeholders suggested that ODNZ’s national leadership role and mandate is curtailed to some extent due to it being subsumed within Auckland DHB. There is a perception amongst some that more pressing local priorities push organ donation down the DHB’s agenda.

This is perhaps evidenced by Auckland DHB management and clinical leaders taking a limited role in managing the performance of ODNZ. Indeed, the ODNZ Clinical Director has never been given a performance review during his longstanding tenure.

The efficacy of ODNZ’s advisory board was also queried by some stakeholders.

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8 Note: While monitoring of services delivered by a Crown Funding Agreement (such as ODNZ’s activities) is a DHB responsibility, the Ministry of Health is directly responsible for system stewardship of the overall health system including the deceased organ donation system.
There were mixed views among stakeholders on whether the board is able to effectively shape the strategic priorities of ODNZ, particularly with respect to increasing the deceased organ donation rate.

Stakeholders were generally in favour of considering the costs and benefits of changes to ODNZ’s configuration:

- Exploring the benefits of ODNZ becoming a stand-alone entity (e.g., the Australian model) or being integrated into the Ministry of Health (as is the case in Spain).
- Strengthening ODNZ’s governance arrangements, regardless of where the organisation is ultimately configured.
- Providing greater mandate to ODNZ to drive practice improvements across ICUs, as well as being clearly responsible for achieving an increase in the rate of deceased organ donation, within the bounds of good clinical and ethical practice.

They noted the creation of OTA in Australia, and the increase in the Australian deceased donor rate. They felt that an OTA-like model in New Zealand is worth exploring, including the inclusion of further tissue donation functions within ODNZ. However, there was some comment that the OTA is too bureaucratic in approach and that New Zealand should be careful to not introduce any unnecessary processes which create barriers to practice change in clinical settings.

*Clinicians feel death audit data can be used more effectively... and performance reporting and data-led quality improvement activities are seen as a key activity for the national coordinating body*

Stakeholders reported that the institution of a national death audit is positive, and a key building block for improved practice.

It was noted that ICU stakeholders believe that death audit feedback has made them aware of missed donation opportunities and is contributing to improved practices in clinical settings. However, it was also stated that the anonymisation of ICUs is impacting on opportunities for peer learning and continual improvement. Some also stated that the time delay between data collection, feedback to ICUs, ODNZ engagement with individual ICUs on quality improvement significantly reduces the ability of the death audit to contribute to an increase in donations. Moreover, some commented that given that some of the quantitative data in the audit is highly subjective, there is limited opportunity for ICUs to compare experience and interpretation, which detracts from its value.

Stakeholders also noted that the death audit could be enhanced through inclusion of ED deaths, which should support increased engagement between ICU and ED clinicians (see below).

As such, many stakeholders suggested that more effective use of death audit data would include (but not be limited to):

- Improved benchmarking of practice between ‘peer’ ICUs (e.g., peer grouping by size and/or patient mix);
More timely feedback to ICUs;
- Giving non-LINK staff access to more data; and
- A clearer programme of work for sharing learnings and quality improvement ideas.

It was strongly noted by ICU stakeholders that they do not believe the death audit data should be publicly disclosed as they consider this would be counter-productive to clinical learning (however, many were surprised it was not shared with the Ministry of Health, and felt the data should be).

Discussions with stakeholders also suggest variable review of organ donation opportunities (identified and missed) during ICU Mortality & Morbidity meetings, and the review of ED deaths and involvement of ED clinicians in organ donation improvement opportunities more generally.

Training on organ donation is of a good quality but has limited penetration

Clinical stakeholders strongly support ADAPT and Core Family Donation Conversation (cFDC) training workshops provided through ODNZ. However, some also felt that the requirement to undertake these training workshops should be extended to other professional groups. As the cFDC course is required for trainee intensivists to achieve CICM fellowship, the uptake is high for new and future CICM Fellows. However, other doctors who may staff smaller ICUs (such as anaesthetists) are not CICM Fellows, and are not required to complete the course. Some stakeholders also expressed the view that a refresher course would be helpful for those who had completed the course some time ago.

ODNZ was noted to be focusing on increasing training uptake among medical staff.

Stakeholders reported the cFDC course to be considerably more effective at teaching the skills related to conducting family donation conversations that are likely to improve consent rates. While this is the case, it should also be noted that the ADAPT (or IDAT) and cFDC courses are designed to accomplish different purposes (see Appendix 3 for further information). It is important for clinicians to have not only effective communication skills to handle donation discussions, but also the technical training required to facilitate the donation process.

Improved cultural competence training may support clinicians to better understand the needs of donor families during donation conversations

Stakeholders acknowledge that different cultures have differing views on death and treatment of loved ones when deceased. This includes differing views of when a person is considered to be ‘dead’.

Families also have mixed understandings of the organ donation process and the benefits for transplant recipients. This can make donor conversations more challenging and time consuming for intensivists. It was suggested that targeted educational programmes might make things easier, alongside improved cultural competency training for health professionals involved in donor conversations.
While the ADAPT and cFDC training courses provide helpful training for handling consent conversations, it was suggested that cultural considerations important to Māori and Pasifika families may not be sufficiently incorporated. Insufficient consideration of cultural issues may be partially responsible for lower consent rates from Māori and Pasifika families. It was also suggested by some stakeholders that consideration should be given to the role of including ‘culturally competent’ people in relevant donor conversations.

**LINK team roles are considered valuable**
Each ICU has a LINK team with expertise in organ donation. Many stakeholders reflected that where LINK nurse roles had been funded, donation had been made easier. LINK teams tend to be considered as useful knowledge resources for the organ donation process and their presence contributes to creating a culture of organ donation within ICUs. However, some stakeholders did suggest that clinical leadership in ICUs could be strengthened particularly with respect to championing organ donation within the ICU and the hospital more broadly. Some acknowledged that this is the approach used in the Australian system, with dedicated and funded time for intensivists and/or nurses (depending on size of ICU). There were mixed views from ICU clinicians on how much impact dedicated and funded time would have on increasing the deceased donation rate.

It was reported that LINK nurses were not always called in to assist with donor workup procedures or retrieval operations (in some cases due to rostering constraints). Some stakeholders commented that there may be opportunities for greater role of LINK nurses in tissue retrieval.

**Increasing organ donation rates:**

**Most clinicians believe that the deceased donation rate can be raised by modifying practices in clinical settings**
The key finding of stakeholder engagement is that most clinicians believe that the deceased donation rate can be raised by modifying practices in clinical settings, and that this would contribute to better health outcomes for patients on organ waiting lists. They also acknowledge that there is substantial variation in practice both within and across ICUs, and likely between ICUs and EDs services on hospital sites.

**Increasing the organ donation rate is likely to involve tackling more difficult categories of potential organ donors**
Several stakeholders noted that the easy to facilitate potential organ donors were already likely to be utilised relatively well. Stakeholders referred to the Australian reform process and noted that gains in the organ donation rate were likely to come from more difficult categories of potential donors.

Four categories of more difficult potential donors that could contribute to an increase donation rate are:
• Patients in such a serious condition that they are not admitted to the ICU for end-of-life care and instead die in the ED;
• Marginal donors such as older patients and those with significant comorbidities;
• Patients with families traditionally seen as difficult to discuss donation with, or who are seen as less likely to consent to organ donation; and
• DCD candidates.

**Donation after Circulatory Death (DCD) is believed to offer opportunity to increase New Zealand’s deceased donation rate**

DCD was mentioned as a key contributor to increases in donation rates in Australia and the UK. Many stakeholders believe that the same potential exists in New Zealand. Lungs in particular were identified as an especially promising organ due to their viability for transplant even after a relatively long period of oxygen deprivation (90 minutes).

Stakeholders reported that DCD protocols and pathways exist in some ICUs but have not been adopted in other units (number unknown to EY).

Some stakeholders also indicated concerns regarding the ethical acceptability of some clinical practices used for DCD. This primarily related to concerns regarding end-of-life medication management of potential DCD candidates.

**There is no consensus on the role of Emergency Departments in organ donation pathways**

Some stakeholders expressed the view that some potential donors are being missed in ED, and that treatment was being withdrawn (or not started) without organ donation being offered to the patient’s family. They suggested greater involvement of ED staff in the identification of potential donors could improve donor rates.

However, interviews also identified reluctance among some intensivists to admit patients from the ED to the ICU solely for the purpose of organ donation. The reasons for this were varied including beliefs about the role of the ICU, capacity pressures and ethical concerns regarding the prolongation of life for the purpose of donation without prior discussions with the family.

**Some Emergency Departments would like to pursue organ donation more actively**

Some ED stakeholders indicated that they would like to develop an organ donation pathway which would enable ICU admission for the purpose of organ donation. These stakeholders stated that negotiating with the ICU on a case by case basis is difficult and can be inconsistent. One ED estimated that they did not act on around 10-25 potential organ donors annually and this number could be reduced if an ED to ICU organ donation pathway was implemented.

Some stakeholders also noted that research nurses, who are already used in the ED to identify potential study participants, could also be used to identify potential organ donors and organise staffing. Because this role is well developed at some clinical sites, stakeholders believed it would be straightforward and cost effective...
to extend the role to cover organ donation at these sites.

Additionally, Auckland City Hospital’s ED was noted to be a particularly promising candidate for an ED pathway due to its Helicopter Emergency Medical System. This is a partnership between Auckland DHB and the Auckland Rescue Helicopter Trust that places doctors on board the Auckland Westpac Rescue Helicopter. This means that Auckland City Hospital’s ED routinely receives community intubated and resuscitated patients, who may often later develop brain or circulatory death in the ED. This means that Auckland ED’s overall potential as a source of deceased organ donors is believed to be especially high.

**Current practice in clinical settings:**

**Organ donation requires additional work from ICU staff**
Clinicians consistently referred to organ donation as a time consuming and challenging process.

It was reported that organ donors can often require a high level of nursing and medical support due to being more physiologically unstable. This increased workload lasts for the time typically required to facilitate an organ donation (12-48 hours).

It was also emphasised that discussing organ donation with a family is very challenging for clinicians, even when they have received specialist training. While clinicians did not generally report shying away from these conversations, they felt that those without firsthand experience may not fully appreciate the challenges they face.

These challenges were reported as greater outside of ‘normal’ business hours when ICU staffing tends to be limited – particularly over weekends when one intensivist may be on-call. Because the organ donation process typically takes between 12 and 48 hours, it is common for a donation opportunity to occur partially or completely outside of ‘normal’ business hours.

Some stakeholders acknowledged that organ donation opportunities have been missed because staff felt they could not cope with the additional workload of organ donation given the competing pressures of (primarily) therapeutic responsibilities.

It was noted that the limiting factor is generally not physical capacity (i.e. beds and equipment) but rather, staffing. Clinicians reported that when organ donation became a possibility they generally always strived to ‘make things’ work.

**Staff time to facilitate organ donation can be on a ‘good will’ basis**
Stakeholders reported that additional staff time to facilitate organ donation can be done out of goodwill particularly on weekends. For example, under current practice (at least in some ICUs), two intensivists are required to confirm brain death. However, if brain death testing needs to be undertaken outside of ‘normal’
business hours, only one intensivist is likely to be rostered on call, with second intensivist undertaking brain death testing in an ‘unpaid’ capacity.

Stakeholders from ICUs with an extended LINK nurse role (funded by ODNZ) reported that this funding had made organ donation easier for them – partly due to increased resourcing to facilitate organ donation.

*There are variable views among ICU staff regarding the priority of organ donation*

Clinicians stated that they believed organ donation was important but for most it was secondary to their day to day clinical workload. This means that organ donation is facilitated where possible but is often not prioritised when ICU resources are limited. However, some clinicians commented that they will strive to make sure that organ donation opportunities are maximised even when staffing resources are limited.

There were mixed views on the role of ICU in ‘end-of-life’ care and whether organ donation should be considered as an element of this. According to stakeholders, the priority given to organ donation at individual ICUs is significantly shaped by local clinical culture as well as the pressures on clinical staff.

*Some ICUs view the challenge of organ donation as an opportunity while others perceive it as a threat (to core business)*

All ICUs spoken with acknowledged that organ donation is an extremely challenging process but their attitudes toward this challenge varied. Some ICUs displayed an ‘improvement mindset’ where challenges are seen as learning opportunities rather than simply barriers to organ donation. In contrast, other ICUs see the challenges as a justification to not proceed with organ donation opportunities.

While clinicians feel that local leadership and ownership of organ donation is important, most believe that stronger national leadership will be required to substantially lift the deceased organ donation rate.

*Stakeholders had strong beliefs that intensivists should lead the organ donation process*

Intensivists generally reported a strong view that organ donation processes should be led by medical staff particularly donor conversations (see below). However, it was also reported by some stakeholders that in some ICUs, nursing staff play a significant role in facilitating organ donation, with nurses undertaking the majority of the process aside from the initial family donor conversation and the statutory duties of medical staff, such as declaring death.

*Opinions differed over the ethics of raising the possibility of organ donation with families and who should raise the topic of organ donation with the family*

Some ICUs considered organ donation to be an important part of the end of life process. However, other clinicians felt there was a tension between end of life care for a patient and initiating the organ donation process. Beliefs on this issue drove clinician willingness to discuss organ donation with families as well as views on who should seek consent from the family.
Some clinicians believe that the intensivist responsible for the patient’s care should be responsible for seeking consent for organ donation – although it was noted that given rostering, it can be the case that more than one intensivist will be responsible for patient care, and the donation process. Some medical stakeholders noted that intensivists responsible for a patient’s care build rapport with families, which can make the organ donation conversation easier and more likely to result in consent for donation. They also noted that undertaking challenging conversations with families with diverse backgrounds or beliefs is a core part of medical training and practice that is not unique to organ donation.

Some stakeholders feel that a largely medically-driven model is anachronistic, and does not make best use of medical staff time. In particular, it was suggested that specialty nurses or donor coordinators trained in donation conversations could lead the request conversation. This was on the grounds that some international evidence has shown that such models can have significantly higher consent rates. However, it was also noted that the evidence base is equivocal, with other evidence also suggesting medically-led donor conversations and processes result in higher consent rates.

**Concern was noted over the ability of non-intensivists and Foreign Medical Graduates to initiate and handle organ donation processes**

Some concern was raised over the ability of non-intensivists staffing smaller ICUs to handle organ donation discussions without prior training. Concern was also raised over the competence of Foreign Medical Graduates (FMGs) in these discussions. Some stakeholders suggested that a portion of FMGs may be uncomfortable discussing death and are even more uncomfortable broaching the topic of organ donation.

**Other issues:**

**Incentives on individual DHBs to promote organ donation are limited, with local and regional pressures and priorities likely to be dominating service delivery**

Clinicians spoken with reported that organ donation patients can demand a greater level of work than a typical ICU patient. When ICU staff resources are scarce, the increased workload accompanying organ donation can discourage clinicians from pursuing donation opportunities - despite recognising their value.

While not explicitly stated, stakeholder discussions suggest that since the benefits of organ donation may not accrue for the DHB ICU undertaking the donation process, this can push donation down the local agenda. This may be partly related to the cost of donation since many of the costs of facilitating donation fall on the donor’s DHB, while the benefits may not. Thus despite organ donation being beneficial to all DHBs, it is unlikely to be prioritised by individual DHBs.

It should be noted that ODNZ previously considered implementing a payment arrangement to incentivise good practice in clinical settings. EY understands this...
Proposal provoked a strong negative response from intensivists, and was thus never implemented. It is understood the negative response arose from the payment being seen as a ‘reward’ for organ procurement. Another alternative explanation suggested by some was that clinicians did not want to be seen to be being paid for what they should be doing anyway.

**Because elective surgery volumes are a national Health Target they receive strong clinical and managerial leadership focus**

Stakeholders stated that a significant amount of ICU capacity is utilised by elective surgery patients, resulting in competition between elective surgery and organ donor patients for ICU resource. Given the focus on elective surgery targets at local and a national level, it is possible that contributing to meeting electives targets is prioritised over other activities, including the prioritisation of resourced ICU bed availability by intensivists. This could be exacerbated by the uncertainty of whether a patient admitted to ICU on the possibility of organ donation will indeed go on to be a donor (eg, suitability; family consent). As discussed in pp 50-51, elective surgery patients are likely to comprise a large workload for some ICUs. However, based on the data available to EY, we have not been unable to ascertain the effective utilisation of ICU resource in total or by patient type. This means we cannot validate stakeholder feedback with respect to elective surgery patients impacting on donation opportunities.

**Retrieval and transplantation stakeholders generally felt that a substantial increase in deceased organ donation could be accommodated except for heart and lungs**

Due to the structuring of different transplant services the ability of each service to respond to an increased organ supply differs. Abdominal organ transplant services (kidneys, pancreas, liver) were seen to have the capacity to absorb an increase in donation rates but concerns were raised regarding cardiothoracic transplant services. While the abdominal organ transplant services have specifically staffed rosters for organ retrieval and transplant, cardiothoracic organ teams are still staffed on a voluntary basis. This is partially due to the strong demand for other cardiothoracic surgical services meaning there is little surplus staffing for organ donation. At present organ retrieval is sometimes delayed due to the availability of cardiothoracic retrieval teams. Stakeholders believed the service was effectively operating at capacity at the current donation rate and could not absorb more donations. Some suggested operating theatre capacity will require expansion if transplant numbers are to increase.

It was also noted that local anaesthetist and anaesthetic technician resourcing can delay abdominal organ transplant retrieval. Unlike the cardiothoracic retrieval team, the abdominal retrieval teams do not take anaesthetist resourcing for retrieval. If a local service has an acute surgical event(s) during the retrieval time period, organ retrieval is delayed until the acute surgical event(s) have been

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9 It was noted by many stakeholders that physical bed capacity is generally not the primary barrier for admission to ICU but rather the ability to resource bed capacity is (ie, staffing). This suggests that ‘surge’ staffing could be used in some situations to enable organ donation opportunities to proceed.
resolved. This limitation is exacerbated by the fact that most retrievals happen at night when staffing levels are lower. This does not affect the success of the retrieval or limit donation numbers, but creates inefficiencies in the retrieval process, which are more important to manage in instances of DCD retrieval.

It was also noted that in larger countries, specialist retrieval teams that can retrieve any organ are usually deployed. Stakeholders considered that this approach is unlikely to be cost-effective in New Zealand given much smaller retrieval volumes.

EY understands the Ministry of Health supported a business case from DHB GM Planning & Funding for additional funding for cardiothoracic transplant services. The GMs have agreed to an interim funding increase for 2016/17, with further funding increases dependent on future decisions. EY was advised that the 2016/17 funding increase will provide short-term support for the service, but longer-term service planning is still required. It was noted by some stakeholders that there will be considerable lead time in determining and developing the necessary transplantation capacity to accommodate a sustained uplift in deceased donation rates particularly for heart and lung transplants. As such, they advised that transplantation capacity and deceased organ donation planning will need to be done in parallel to ensure that optimal use can be made of donated organs.

The Driver's License register is not clinically useful
Clinicians indicated that the Driver’s License register is used infrequently because it is difficult to access, does not constitute informed consent (rather, it signals intent) and has a relatively low donor intent rate (53%). Indeed it was referred to as very unhelpful for donor conversations by some clinicians (we note that these clinicians are of the impression that the donor intent rate is very low, with a figure cited of 20%). In spite of the shortcomings of the current system, there was mixed support for a donor registry as employed in some other countries. Some stakeholders believed it would improve consent rates while others felt it would not be cost-effective.

Stakeholders have mixed views on the likely effectiveness of public awareness campaigns
Stakeholders were aware of the role that national coordinating agencies in other jurisdictions have in promoting organ donation to the public through education and awareness campaigns. Many stakeholders felt this would be a useful function for ODNZ to take on while others felt such campaigns would not be cost-effective - they felt that given the number of organ donors is so small, projecting the message to the general public is unlikely to be cost-effective.

However, one ICU site with a very diverse population suggested that targeted public awareness campaigns could help support more effective donor conversations. In this instance, a targeted public awareness campaign would provide information to specific communities on brain death, the organ donation process and the benefits of transplantation for recipients. Stakeholders suggested that targeted public awareness campaigns would be important for Māori, Pasifika,
Chinese and Indian communities.

Non-ICU stakeholders and some intensivists suggested that it would be useful and cost-effective to link organ donation awareness into the increasing community discourse on end of life care options and future care directives.

**Some clinicians suggest that funeral grants could be offered to the estates of organ donors**

While there is no appetite among clinicians to offer incentive payments to the families of organ donors, some clinicians felt it could be appropriate to cover their funeral costs. They saw this as similar to ACC’s policy of paying funeral grants to the estate of people who die in an accident. It should be noted that some potential organ donors are likely to be already eligible for an ACC funeral grant under current policy (i.e. their death is the result of an accident).

**International comparison of practices in clinical settings**

New Zealand practices in clinical settings compare reasonably well with a selection of countries with higher deceased donor rates (Spain, Australia and the UK) although there are some areas where practice appears to differ. This highlights possible areas for improvement.

However, it should be noted that the quality of evidence linking aspects of practices in clinical settings to donation rates is limited. This is because many relevant variables are different between each country, making isolating the effect of any one practice very difficult. Thus it is not possible to definitively indicate which practices in clinical settings would be the most effective at contributing to lifting donation rates.

Tables 3 - 5 compare New Zealand practices in clinical settings to international practices across three key domains. For each practice, New Zealand’s alignment with international good practice in high performing countries has been graded according to the following scale:

- **Grey** = Strong alignment with international practice standards.
- **Light yellow** = Some alignment with international practice standards but with significant deficiencies.
- **Yellow** = Little or no alignment with international practice standards.
### Table 3: Clinical pathways and leadership

<table>
<thead>
<tr>
<th>Function</th>
<th>New Zealand practice</th>
<th>International practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clear ED to ICU pathways for donation</td>
<td>Variable.</td>
<td>Yes</td>
</tr>
<tr>
<td>Clear pathways make it easier for ED and ICU staff to understand when patients should be admitted to the ICU. They also help establish ICU admission for organ donation as a practice norm in the hospital.</td>
<td>Some hospitals have strong informal systems for ICU admission specifically for organ donation but most hospitals do not have any formal pathway.</td>
<td></td>
</tr>
<tr>
<td>Formal ED and ICU triggers</td>
<td>No.</td>
<td>Yes</td>
</tr>
<tr>
<td>ED triggers aid the identification of potential donors in the ED and their admission to the ICU.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ICU triggers typically require that the local donation coordination agency be notified.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Clinical champions in hospitals</td>
<td>Limited</td>
<td>Yes.</td>
</tr>
<tr>
<td>Clinical champions build a focus on organ donation and a culture of performance improvement among clinicians.</td>
<td>Leadership is highly variable between ICUs. Positions are mostly accommodated within core ICU funding but it appears there is limited expectation of ‘championship’ and leadership at the local ICU level.</td>
<td>Positions generally formalised and funded, with clear leadership expectations.</td>
</tr>
<tr>
<td>Staff leading the organ donation process</td>
<td>Mostly medically led.</td>
<td>Most countries use a medically-led model.</td>
</tr>
<tr>
<td>Increased nursing involvement can relieve medical staff of the additional time pressure of organ donation.</td>
<td>Nursing involvement varies by ICU centres.</td>
<td>The UK and the US use specialist organ donation nurses as well as intensivists.</td>
</tr>
</tbody>
</table>

### Table 4: Organ donation training

<table>
<thead>
<tr>
<th>Function</th>
<th>New Zealand practice</th>
<th>International practice</th>
</tr>
</thead>
<tbody>
<tr>
<td>Training programmes</td>
<td>Training is required for new College of Intensive Care Medicine (CICM) Fellows.</td>
<td>In Spain, organ donation training is mandatory for all intensivists. In the...</td>
</tr>
<tr>
<td>Training can equip staff to better identify potential organ donors</td>
<td>However, approximately 50-70% of...</td>
<td>...</td>
</tr>
</tbody>
</table>
and manage difficult family conversations in a manner that can improve consent rates.

Existing CICM Fellows have not completed an organ donation training course. Likewise non-CICM medical staff in ICUs (such as anaesthetists) are not required to complete any organ donation training. This is also the case for ED staff. However, it should be noted that ODNZ encourages these staff to take part in training courses and has successfully trained ED and other staff who voluntarily undertook training.

There is also no specific coverage of Māori, Pasifika or Asian beliefs with regards to death, dying and organ donation in the New Zealand training courses. Given the increasing proportion these communities represent of the total New Zealand population, it is a significant oversight that specific training for engaging with these communities is not included.

UK, all clinicians likely to be involved in the treatment of potential organ donors receive mandatory training.

In Australia, CICM fellows are required to complete a training course as a Registrar but, like in New Zealand, existing Fellows may not all participate in these training courses. Some ED staff also receive organ donation training.

<table>
<thead>
<tr>
<th>Table 5: Central coordinating body functions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Function</td>
</tr>
<tr>
<td>Performance monitoring &amp; improvement</td>
</tr>
<tr>
<td>Performance reporting is present but does not allow for transparent comparison between peers. Data publication and feedback also lacks timeliness.</td>
</tr>
<tr>
<td>Organ allocation on a national level.</td>
</tr>
<tr>
<td>Allows for efficient organ matching and improves equity.</td>
</tr>
<tr>
<td>International organ offering</td>
</tr>
<tr>
<td>Improves the likelihood that all possible donor organs will be utilised.</td>
</tr>
<tr>
<td>Early contact with organ donation authority?</td>
</tr>
</tbody>
</table>
Key elements of an effective organ donation system

Eight key elements necessary for effective system reform were identified\(^\text{10}\) during the Australian reform process. This framework provides a useful way to compare international practices in clinical settings and institutional arrangements across a number of key domains. Upon assessment of the eight elements, the New Zealand system appears to have the necessary building blocks for each but could consider changes in terms of clinical governance structures and financial support for donor hospitals.

\(^\text{10}\) *International approaches to organ donation, Organ and Tissue Authority, 2013*
### Table 6. New Zealand compared to select countries on eight key elements of effective donation systems

<table>
<thead>
<tr>
<th>Element</th>
<th>Rating</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>Appropriate legal &amp; ethical framework</td>
<td></td>
<td>New Zealand laws are similar to those in comparator countries with substantially higher deceased donation rates. Presumed consent laws are used in some of these countries but are not considered vital to achieve a high donation rate. Stakeholders raised some concern with respect to the emerging clinical practices in Australia regarding DCD. Clear guidance on good clinical practice in the New Zealand setting may be needed particularly if an increase in DCD is sought to increase the overall donation rate.</td>
</tr>
<tr>
<td>National coordinating body</td>
<td></td>
<td>New Zealand has a national coordinating body that is effective at coordinating the technical process of organ donation. However, the organisation has a limited focus on improving donation rates. ODNZ is also seen to operate in a relatively opaque manner. For example, stakeholders do not know the membership of the ODNZ’s Advisory Board and do not have easy access to the Board’s advice to the organisation. Many stakeholders also perceive that the advisory board has limited influence on the organisation.</td>
</tr>
<tr>
<td>Hospital-based clinical donation specialists</td>
<td></td>
<td>LINK teams exist but their role as clinical leaders in improving organ donation rates is limited and variable between ICUs. It appears that most countries with substantially higher deceased donation rates have dedicated and partially funded intensivist positions in major hospitals to act as a donation champion.</td>
</tr>
<tr>
<td>Training for clinical staff</td>
<td></td>
<td>Training appears to be fit for purpose but coverage and uptake could be improved, especially for non-intensivist staff in smaller centres. Training for new College of Intensive Care Medicine Fellows is compulsory in New Zealand, which is in line with international practice. Training for ED staff could also be helpful depending on what an audit suggested the size of the missed donor pool in the ED is. It would also support a ‘whole-of-hospital’ donation culture particularly if Chief Medical Officers were more explicitly involved in local organ donation clinical leadership processes.</td>
</tr>
<tr>
<td>Appropriate clinical governance</td>
<td></td>
<td>New Zealand has limited performance reporting and benchmarking, which notably does not include the ED. It appears that the degree of clinical leadership in clinical settings is largely dependent on local clinical culture. There do not appear to be clear structures in place to foster leadership on organ donation and quality improvement. For example, it appears entirely dependent on local clinical culture whether organ donation is discussed during ICU Mortality &amp; Morbidity meetings.</td>
</tr>
</tbody>
</table>

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| Financial support to donor hospitals | Countries with substantially higher deceased donation rates typically have audit and performance reporting processes directly integrated into a quality and performance improvement programmes. As discussed above, clinical leadership positions are also generally (part) funded in most ICUs (e.g. 0.1 FTE of intensivist time). In addition to (part) funding permanent intensivist positions, most countries with higher donation rates provide direct compensation to donor hospitals for the additional costs associated with each donation event. Some jurisdictions provide funding as a set annual contribution rather than on a per-event basis. Organ donation activity is accounted for in the PBFF, and extended LINK ICU nurse time is funded by ODNZ. It is not clear whether the current PBFF funding model appropriately accommodates the costs associated with organ donation or incentivises an improvement in the donation rate. However, it could be expected that DHBs would make appropriate budget decisions to account for organ donation costs within the funding of their ICUs. It is noted that organ donation opportunities are unpredictable, and the cost is in the region of 1-2 ICU bed-days ($5,000 per day). Organ donation costs are likely to impact most on the budgets of DHBs with high donation rates. |
| Media engagement and community awareness | Comparator countries have their national coordinating bodies engaging in public awareness campaigns. Several countries have a specific focus on communities that have substantially lower donation rates. ODNZ is not contracted to carry out public awareness campaigns. Despite this ODNZ has produced material for the NCEA curriculum, and engaged in small public awareness campaigns. More public engagement than current in New Zealand is supported by the majority of stakeholders interviewed. However, many noted that international evidence suggests that public awareness campaigns may not be cost-effective. |
| International cooperation | 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. |


Deceased organ donation and transplantation: Recommendations to improve practice in clinical settings and commentary on institutional arrangements
Given the similarities between New Zealand and Australia including joint professional colleges, it is prudent to compare system leadership for organ donation between the two countries. Australia has embarked on a significant reform agenda for organ donation since 2007/08. This has included the establishment of the Australian Organ & Tissue Authority (OTA) and significant government investment. Refer Appendix Three for further information.

Comparing ODNZ and OTA:

**Similarities:**
- Both are national coordinating bodies for organ and tissue donation.
- Both fund training for hospital based staff.
- Both organisations have a form of performance reporting and have a quality improvement function.

**Differences:**
- OTA has a wider scope than ODNZ, covering additional activities such as public awareness campaigns and greater involvement in tissue donation processes.\(^{13}\)
- The OTA has an explicit focus on raising deceased donation rates. They regularly report on progress towards this goal.
- The OTA has significant funding for hospital based specialists.
- ODNZ is not contracted to carry out public awareness campaigns.
- DonateLife agencies rather than the OTA are responsible for the coordination activities of actual donors.
- The OTA is constituted as an independent statutory agency.
- OTA funding per capita and per donation is considerably larger in Australia compared with New Zealand.

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\(^{13}\) OTA works in partnership with State and Territory Governments in respect to transplantation.
Analysis of New Zealand data related to organ donation and ICU care

Although the data available for the purposes of this report is limited, what is available reveals significant variation in practice across most stages of the deceased organ donation process. Some of this variation may be due to factors outside the control of ICU clinicians but the extent of variation suggests differences in practices in clinical settings are highly likely to be driving a large part of the observed variation.

**Indicative overview of ICU patient mix and utilisation**

Intensive care services are a relatively scarce resource in New Zealand. ICUs face demands for their resources from many different patient groups, including organ donors. As such, variations in ICU patient mix and utilisation rates may mean that different ICUs have varying scope to facilitate organ donation opportunities.

To provide an indicative overview of likely variation in patient mix between ICUs, EY has analysed data available in the National Minimum Dataset (NMDS). In particular, the ICU flag (which notes the number of hours spent in an ICU) was used to select patients who had spent at least one hour in the ICU. Data under this flag was variably recorded and no indication as to the reason for admission was available apart from diagnosis and procedure codes that relate to the whole admission period (not just the ICU stay). However, the data can still be somewhat illustrative in the absence of a bespoke data collection.

**Hospital admissions with an ICU stay**

Larger hospitals providing tertiary level care tend to have a higher proportion of elective hospitalisations that involve an ICU stay when compared to secondary care hospitals. This is because complex elective surgeries can require ICU level care during the peri-operative period.

As can be seen in Figure 10, almost 1 in 3 hospital admissions (on average) in the five main tertiary hospitals with a stay in the ICU were for elective admissions. In contrast, for all other hospitals, about 1 in 6 recorded ICU stays were for elective admissions (see Figure 11).
**Figure 10.** Average proportion of elective and acute admissions to hospital that included an ICU stay in the five largest elective surgery centres (Auckland, Waikato, Wellington, Christchurch, Dunedin), 2014

Note: Acute includes acute arranged admissions.
Source: 2014 National Minimum Dataset

**Figure 11.** Average proportion of elective and acute admissions to hospital that included an ICU stay in all other hospitals, 2014

Note: Acute includes acute arranged admissions.
Source: 2014 National Minimum Dataset

To illustrate the variation in ICU patient mix, it is helpful to consider two examples - an ICU located in a large tertiary centre and an ICU located in a moderately sized rural hospital.

At the tertiary centre, the most common cause of admission was circulatory causes, with injuries, congenital malformations and neoplasms also being
significant contributors. Many of the circulatory cases will be peri-operative care for elective cardiac surgeries (Figure 12).

Figure 12. Ten most common causes for hospital admissions with an ICU stay at a large tertiary hospital, 2014

![Bar chart showing the ten most common causes for hospital admissions with an ICU stay at a large tertiary hospital, 2014.](chart)

In contrast, the smaller ICUs had a large number of respiratory admissions as well as those due to injuries and cancer surgery (Figure 13).
These statistics demonstrate a key challenge for improving the deceased donation rate - that large ICUs with a high number of potential organ donor cases also tend to face competition from elective surgical services for ICU capacity.

Many potential organ donors would be in the Injury category in the figures above. Injuries make up a greater proportion of ICU admissions in smaller ICUs but because the absolute number of patients in this category is low, the potential for organ donation is lower than in large centres. As suggested by some stakeholders, the very high proportion of patients admitted for circulatory reasons (such as cardiac surgery) in large ICUs likely means some organ donation opportunities are crowded out.

**ICU utilisation rates**

Another factor that may influence the potential of ICUs to facilitate donation rate is the demands upon ICU resource. Some ICUs, especially those in tertiary hospitals, tend to have higher utilisation rates. In these centres it is possible that some organ donation opportunities may not be taken advantage of due to higher priority demands on limited ICU capacity.

*Source: ICU bed-hour data from the 2014 National Minimum Dataset. January 2016 resourced ICU bed numbers provided by the Ministry of Health. Utilisation calculations carried out by EY.*
Using information contained in the NMDS and ICU resourced bed numbers provided by the Ministry, EY attempted to estimate average bed utilisation by ICU across New Zealand. However, it quickly become apparent that variability in the recording of ICU hours in the NMDS means this dataset cannot be used to analyse ICU utilisation. Therefore, to better understand potential capacity to facilitate organ donation at an ICU level, the quality of the ICU hours flag data in the NMDS needs to be addressed.

**Patient populations more likely to have organ donation potential**

While it is difficult to accurately predict the size of the potential organ donor pool, approximations can be made as to which hospitals have a patient mix more amenable to organ donation.

For this analysis, EY considered patients to be in a sub-group potentially amenable to organ donation if they:

- Died in hospital at an age of between 1 and 70 years.
- Had a primary diagnosis of an intracranial injury, cerebral infarction, non-traumatic sub-arachnoid haemorrhage, non-traumatic intracerebral haemorrhage.
- Did not have an HIV, AIDS or cancer diagnosis.

While most patients in this subgroup are unlikely to be organ donor candidates, they do represent a hospital population from which most deceased organ donors will come from.

The proportion of hospital deaths in sub-groups more likely to contain organ donors varies substantially between hospitals. In hospitals with a high proportion of such patients it is more likely that a clinical focus on organ donation could be established. It is notable that the large tertiary centres contain the highest proportion of patient groups likely to contain organ donors as well as having the largest absolute number of such donors. It is however notable that Middlemore Hospital has a relatively low proportion of such patients but the absolute number is large due to the size and characteristics of the hospital’s catchment area. Because the absolute numbers and proportions of patients in sub-groups more likely to be organ donors varies between different hospitals (even those of similar size), it is important to consider patient mix in a systematic way in order to understand an ICU’s organ donation potential.
Figure 14. Proportion of hospital deaths in sub-groups most likely to have organ donation potential, 2010-2014

Note: Number in brackets refer to the absolute number of patients in the identified sub-groups in each hospital.

Source: 2010-2014 National Minimum Dataset. Calculations by EY.

Patients were considered to belong to a sub-group more likely to organ donation potential if they were aged between 1-70 on discharge from hospital (via death) and had one of the following ICD codes recorded as their primary diagnosis: ICD60-63 (Cerebral infarction and non-traumatic sub-arachnoid or intracerebral haemorrhages), SO6 (Intracranial injury), V00-Y99 (External Causes of Morbidity – includes motor vehicle injury).

Clinical variation in deceased organ donation is evident across New Zealand ICUs

Analysis of ICU data provided to EY (death audit data) indicates that some key steps in the organ donation pathway display significant variability between ICUs of a similar size.

The steps in the organ donation process with the greatest variability are:

- whether the mentioning of organ donation proceeds to a formal discussion, and
- the consent rates between different ICUs.

Many ICUs have good results for some organ donation processes, however, there are few ICUs with consistently good results across the entire deceased organ donation pathway. It is also notable that some ICUs perform relatively less well

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14 Note to minimise the effects of random variation upon the analysis, only data from ICUs with over 350 deaths during the period 2008-2014 were analysed.
across most of the process steps.

When assessing the clinical performance of ICUs it is important to consider more than one step in the process, such as consent rates. Single metrics can be misleading as they do not reflect how many patients have proceeded along the organ donation pathway to that step. For example, ICU 1 in Table 7 has a lower consent rate than other ICUs but had organ donation conversations with a higher proportion of patients than other ICUs. Therefore, solely considering consent rates would not accurately reflect that ICUs performance across the entire organ donation process.

Some of the variation between the large ICUs will be for valid clinical reasons but when taken in context with the themes from stakeholder engagement, it seems likely that unnecessary practice variation in clinical settings is also a driver of inter-ICU variability.

This suggests there is scope for improvements in the organ donation process at individual ICUs and, more broadly, at a system level across all ICUs. While it could be the case that patient casemix might explain some level of variation, it is likely that casemix has a limited role in explaining the observed variation between ICUs.

EY strongly cautions that the information shown in Table 7 and Figure 15 should not be read as showing the level of missed deceased donation opportunities in New Zealand. Instead, they are provided to highlight variation in practice and process outcomes across ICUs. Further more detailed analysis (including validation of underlying data) is required before any indicative judgments of the level of missed donation opportunities can be made.
Table 7: Performance of the 8 ICUs with the most deaths at selected stages of the DBD pathway. (Bolded and underlined values indicate the highest performing ICU for each process). Data covers 2008 - 2014

<table>
<thead>
<tr>
<th>ICU Number</th>
<th>Proportion of patients who died in the ICU who may have been potential organ donors</th>
<th>Patients who could be potential organ donors* where organ donation had been ‘formally discussed’</th>
<th>Consent Rate**</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>57% (n=390)</td>
<td>33% (n=128)</td>
<td>46% (n=59)</td>
</tr>
<tr>
<td>2</td>
<td>40% (n=375)</td>
<td>22% (n=81)</td>
<td>56% (n=45)</td>
</tr>
<tr>
<td>3</td>
<td>36% (n=319)</td>
<td>23% (n=73)</td>
<td>51% (n=37)</td>
</tr>
<tr>
<td>4</td>
<td>27% (n=250)</td>
<td>24% (n=60)</td>
<td>57% (n=34)</td>
</tr>
<tr>
<td>5</td>
<td>34% (n=195)</td>
<td>20% (n=39)</td>
<td>46% (n=18)</td>
</tr>
<tr>
<td>6</td>
<td>36% (n=142)</td>
<td>27% (n=38)</td>
<td>71% (n=27)</td>
</tr>
<tr>
<td>7</td>
<td>19% (n=90)</td>
<td>6% (n=5)</td>
<td>40% (n=2)</td>
</tr>
<tr>
<td>8</td>
<td>23% (n=455)</td>
<td>31% (n=32)</td>
<td>53% (n=17)</td>
</tr>
</tbody>
</table>

*ICU patients with severe brain damage who had been ventilated before their death\(^{15}\). Note that not all deaths with severe brain damage would be suitable for donation. However, given the potential deceased donor pool is not able to be clearly identified within existing data sources, we have used this measure to identify the maximum pool of ICU deaths which have some possibility of progressing to deceased donation. We strongly note that the figures should not be interpreted as implying that all deaths with severe brain damage should have a formal discussion of organ donation.

**DBD only. Calculated as the number of patients where the family consents to organ donation divided by the number of patients where a formal discussion about organ donation is carried out.

Source: Death audit data from Organ Donation New Zealand as provided to EY by the Ministry of Health. Calculations by EY.

Figure 15. Consent rate variation (DBD only) in the 8 largest ICUs* by number of deaths.

*Size based on the number of deaths in the ICU over the period 2008 to 2014 (inclusive).

Note: Average consent rate was calculated by taking the mean of the consent rates for the 8 largest ICUs. Consent rate was

\(^{15}\) As described by Dr Streat in “Notes provided by Organ Donation New Zealand (ODNZ) to accompany data prepared for the Ministry of Health for the Expert Advisory Group on Organ Donation” (6\(^{th}\) November 2015), patients ‘ventilated with ‘severe brain damage’ are those who die in ICU, having been ventilated at some time during their ICU admission, and (in the opinion of the senior nursing and/or medical staff) had ‘severe brain damage’ (not otherwise specified). Although this is clearly subject to varied interpretations, all organ donors (DBD and DCD) will come from within this group of patients.
calculated as the number of patients where the family consents to organ donation divided by the number of patients where a formal discussion about organ donation is carried out.

Source: Death audit data from Organ Donation New Zealand as provided to EY by the Ministry of Health. Calculations by EY.

**Larger ICUs tend to progress more potential donors through the pathway to organ donation**

The proportion of patients with possible brain death whose families consent to organ donation is both greater on average and also less variable in large ICUs compared to the total ICU population (Table 8). However, it is notable that the highest performing ICUs have greater levels of performance than that of the large ICUs.

This suggests that large ICUs may provide the regularity of donation opportunities, as well as sufficient resource capacity, to support better utilisation of donation opportunities. However, the results also demonstrate that smaller ICUs can make very good use of organ donation opportunities under the right circumstances. The results of the best performing ICUs also indicate that the larger ICUs may have scope to increase their donation opportunities.

**Table 8: Patients with possible brain death whose families consent to organ donation**

<table>
<thead>
<tr>
<th></th>
<th>Large ICUs*</th>
<th>All ICUs**</th>
</tr>
</thead>
<tbody>
<tr>
<td>Minimum</td>
<td>31%</td>
<td>13%</td>
</tr>
<tr>
<td>Lower Quartile</td>
<td>34%</td>
<td>23%</td>
</tr>
<tr>
<td>Median</td>
<td>37%</td>
<td>34%</td>
</tr>
<tr>
<td>Upper Quartile</td>
<td>40%</td>
<td>41%</td>
</tr>
<tr>
<td>Maximum</td>
<td>50%</td>
<td>71%</td>
</tr>
</tbody>
</table>

Source: Death audit data from Organ Donation New Zealand as provided to EY by the Ministry of Health. Calculations by EY.

* ICUs with over 350 between 2008 and 2014 (inclusive).

** Includes all ICUs ODNZ has provided data to EY for - except of ICU23 and 24 (which had incomplete data).

**Consent rates differ markedly between ethnicities**

Variation by ethnicity along the organ donation pathway is also evident (see Table 9 and Figure 16). The greatest source of variation in this context was in consent rates. European patients have a far higher consent rate than other ethnicities. For example, the European consent rate is more than twice the consent rate for Pasifika families.

Notably there was some uniformity across population groups in terms of the proportions of patients where a formal discussion on organ donation occurs and in the proportion of probably brain dead patients who are formally tested. It is also notable that the proportion of patients who die in an ICU who may have been potential organ donors is considerably higher for people who do not identify as European.

Patients who identify as Māori or Pasifika tend to be almost as likely as European
patients to have the potential for organ donation to be mentioned to their families. However, these ‘mentions’\textsuperscript{16} are considerably less likely to proceed to a formal discussion. This suggests that clinicians are appropriately identifying organ donation opportunities and broaching the topic with families to some degree but:

- Some families are less willing to more formally discuss possible deceased donation.
- Language and/or cultural barriers make organ donation more difficult.
- Clinicians may not think that these population groups will be as receptive to organ donation and therefore may not attempt to engage as actively as they would with other families.
- Clinicians may be less comfortable dealing with the additional cultural factors that may need to be considered during conversations with, for example, Māori or Pasifika families. (Notably, EY understands that there are no practising intensivists in New Zealand from Māori or Pasifika backgrounds).

Given the large number of potential explanations listed above plus likely differences in ICU reporting on the NZ Death Audit, it is difficult to be definitive in identifying what may account for differences in rates of formal discussions and ultimately deceased organ donation by ethnicity\textsuperscript{17}. It may be the case that when formally asked, Māori and Pasifika families are less likely to consent to organ donation. But this does not explain why they are less likely to do so, including whether they are provided with sufficient and appropriate information to make an informed decision.

EY strongly cautions that the information shown in Table 9 and Figure 16 should not be read as showing the level of missed deceased donation opportunities in New Zealand. Instead, they are provided to highlight variation in practice and process outcomes across ICUs. Further more detailed analysis (including validation of underlying data) is required before any indicative judgments of the level of missed donation opportunities can be made.

\textsuperscript{16} Upon review of NZ death audit data and available documentation, it remains ambiguous to EY what constitutes a ‘mention’. It is highly likely that there are variable interpretations of what constitutes a ‘mention’ across ICUs.

\textsuperscript{17} It is noted that similar differences between ethnic and cultural groups are observed in other health systems.
Deceased organ donation and transplantation: Recommendations to improve practice in clinical settings and commentary on institutional arrangements

Note that not all deaths with severe brain damage would be suitable for donation. However, given the potential deceased donor pool is not able to be clearly identified within existing data sources, we have used this measure to identify the maximum pool of ICU deaths which have some possibility of progressing to deceased donation. We strongly note that the figures should not be interpreted as implying that all deaths with severe brain damage should have a formal discussion of organ donation.

# Calculated as the number of patients who had a ‘formal discussion’ divided by the number of patients who may have been potential organ donors (row 1)

**DBD only. Calculated as the number of patients where the family consents to organ donation divided by the number of patients where a formal discussion about organ donation is carried out.

+ The ‘Other’ ethnicity group also contributes to the total but is not displayed separately in this table.

Source: Death audit data from Organ Donation New Zealand as provided to EY by the Ministry of Health. Calculations by EY.

Limitations to the above analysis in Table 9 include:

- Clinical variation in the identification and approach of potential organ donors is not captured by the data used for this analysis.
- ICUs with less than 400 deaths in the period from 2008-2014 were not considered in this analysis. Smaller ICUs are also likely to exhibit substantial variation; however interpretation of this data is more difficult due to the increased effects of random variation in smaller datasets.
- The filters used in the death audit data analysed do not adequately assess the processes relevant for potential DCD patients.

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18 As described by Dr Streat in “Notes provided by Organ Donation New Zealand (ODNZ) to accompany data prepared for the Ministry of Health for the Expert Advisory Group on Organ Donation” (6th November 2015), patients ‘ventilated with ‘severe brain damage’ are those who die in ICU, having been ventilated at some time during their ICU admission, and (in the opinion of the senior nursing and/or medical staff) had ‘severe brain damage’ (not otherwise specified). Although this is clearly subject to varied interpretations, all organ donors (DBD and DCD) will come from within this group of patients.
**Figure 16.** Consent rate by ethnicity

![Consent rate by ethnicity](image)

*Note: Only Donation by Brain Death is included in this analysis.*  
*Source: Death audit data from Organ Donation New Zealand as provided to EY by the Ministry of Health. Calculations by EY.*

**Some ICUs have very high year on year variation in organ donor numbers**  
While total donor numbers nationally stay moderately stable from year to year, some ICUs exhibit significant variation (see Table 12).

Notably Waikato had 11 deceased donors in 2010 before falling to 0 in 2012 and rising marginally to 3 donors in 2014. Likewise Wellington went from having 4 donors in 2013 to 10 in 2014 - a 2.5x increase. Dunedin also had between 3 and 4 donors per year from 2010 to 2014, except for 2013 where the number fell to 1 donor.

The volatility present in the results for these ICUs may represent year on year fluctuations in patient mix although given the size of variation it is unlikely this is only contributor. It is also likely that clinical practice is contributing to the scale of these fluctuations.
Table 12: Deceased Organ donation in New Zealand ICUs from 2010-2014

<table>
<thead>
<tr>
<th></th>
<th>2010</th>
<th>2011</th>
<th>2012</th>
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<th>2014</th>
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<td>Auckland City DCCM</td>
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<td>38(2)</td>
<td>38</td>
<td>36(2)</td>
<td>46(6)</td>
</tr>
</tbody>
</table>

Note: Numbers in the square brackets refer to Donation by Circulatory Death.

**One third of ICUs have had less than two deceased donors in the past five years**

Three New Zealand ICUs have not produced any deceased donors in the past five years while five ICUs have only produced one donor in the past five years. Overall one third (8 out of 24) of New Zealand ICUs have produced less than two donors in the past five years.

While small ICUs will always have fewer donation opportunities it is surprising that

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19 Department of Critical Care Medicine (DCCM) provides intensive care and high dependency care for adult patients (>15 yrs) with all conditions except heart, lung and blood vessel surgery which is provided by the Cardiothoracic and Vascular ICU, and burns which is provided by Middlemore Hospital ICU. Specialist areas include intensive care for liver, kidney and pancreas transplantation and neurologic (brain) conditions.

20 Cardiothoracic and Vascular ICU. See footnote 12.
such a large number of ICUs have produced virtually no donors. A likely explanation for some of these smaller sites is that their patient mix differs to larger sites (eg, neurosurgery is not offered on site) and patients that do go on to become deceased donors have been transferred to larger ICUs during therapeutic care - for example, transfer from Nelson Hospital to Wellington (or Christchurch) Hospital, or similarly from North Shore Hospital to Auckland City Hospital.
11. Commentary on institutional arrangements

New Zealand’s organ donation system is arranged broadly in line with international practice. However, improvements to New Zealand’s institutional arrangements could contribute to improving the rate of deceased organ donation.

In considering how New Zealand’s institutional arrangements could be improved, we have focused on three areas:

- Governance arrangements;
- Leadership (national, regional and local); and
- Roles and responsibilities within the deceased organ donation system.

We have also considered how each of these may be best configured at national, regional and local levels, and what will be required to make this work from an overall system perspective.

In summary, we consider that New Zealand has many of the basic components in place for an efficient and effective deceased organ donation system including key elements such as:

- 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 donor conversations
- Death audit data reported and monitored from each ICU.

Given this, we do not believe that radical reform of the organ donation system is required. Rather, a clearer emphasis on increasing the deceased donation rate is necessary, which is established and supported nationally but driven locally. We also think it is important to recognise that deceased organ donation is but one clinical process within New Zealand’s highly devolved health system; unless the wider health system supports deceased organ donation, it is unlikely that a sustained lift in the deceased donation rate will be achieved.

We suggest the following are key priority actions with respect to institutional arrangements:

- Establishing a clinically credible national strategy for increasing the deceased donation rate coupled with an aspirational and measurable vision for the system
- The Ministry to take a stronger stewardship and performance management role of the overall system, clearly establishing expectations for the system to be driven through ODNZ, DHBs, ICUs and EDs
- 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)
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- Strengthening the role of DHB Boards and Community Public Health Advisory Committees (CPHACs) in promoting awareness of organ donation, and leading conversations with local communities on the benefits of donation, and linking this to the broader End of Life Care community discussion
- Strengthening the role of Hospital Advisory Committees and Chief Medical Officers (CMOs) in ensuring improvements in practice in ICU and ED settings
- Placing the appropriate level of expectation on DHB GM Planning & Funding Officers and Chief Operating Officers to ensure that local budgeting decisions are supportive of both therapeutic care and deceased organ donation
- Building on the ICU LINK teams to strengthen local leadership at the ICU level, and between ICUs and EDs. This may need consideration of the appropriate level of dedicated time for these positions to enable local championship of organ donation.

While we do not consider that major reform is necessary, we believe that ensuring successful delivery on the priorities listed above will require:

- Evaluating whether ODNZ’s location within Auckland DHB is appropriate, given its national coordination role across 20+ ICUs
- Considering whether ODNZ has sufficient capability to lead and implement change across the sector
- Revisiting the quantum of funding allocated to ODNZ, and whether this is supportive of the organisation being able to deliver on national objectives
- Exploring the costs and benefits of including tissue donation within ODNZ’s scope
- Whether current DHB funding arrangements support organ donation, and what adjustments may be necessary to provide sufficient incentives to DHBs to promote and facilitate organ donation locally (at the clinical and community level)
- Working with the transplant sector to ensure that there is sufficient capability and capacity to make best use of a higher level of procured organs.

A national strategy for deceased organ donation is required

Overall system leadership provided by ODNZ appears to have gradually lifted the standard of practice with regards to deceased organ donation. However, it is apparent that the organisation has been largely focused on donor logistics and organ quality. These are of course crucial responsibilities within the organ donation system, and it is a credit to ODNZ that stakeholders speak so highly of the organisation in reference to these.

However, it is also apparent that New Zealand’s deceased donation rate has not kept pace with that of comparator countries. While there may be local cultural factors (both clinical and community) contributing to New Zealand’s relatively lower donation rate, we believe that a lack of overall system focus has also greatly contributed. With this in mind, it is important to acknowledge that while New Zealand has successfully developed a live kidney donation strategy, and has been successful in increasing live donations, there is no corresponding strategy for deceased donation.
As such, we think that a key starting point for enhancing system leadership is to develop a clinically credible national strategy for increasing the deceased donation rate. This should include:

- A clear vision which articulates what New Zealand is aspiring to achieve in deceased organ donation
- Key strategic priorities and associated supporting actions for increasing the deceased donation rate and deliver on the vision
- Clearly assigned national, regional and local roles and responsibilities for achieving the strategy’s priorities and actions
- A measureable goal(s) for tracking progress against the strategy, for example, to achieve 80% of Australia’s deceased donation rate by 2020 etc.

Within current arrangements, ODNZ’s Advisory Board should drive the development of a deceased organ donation strategy, with appropriate leadership and support from the Ministry of Health. We note that the National Renal Advisory Board developed a ‘Five Point Plan’ to increase liver donor renal transplantation within New Zealand, which was provided to the Minister of Health in 2011.

**The Ministry will need to take a stronger role in overall organ donation system stewardship and performance management**

The Ministry of Health is the ultimate funder of the ODNZ, and sets the national service specification for the organisation. This means that the Ministry should have a strong role in ensuring the performance of ODNZ through its Crown Funding Agreement with Auckland DHB and contractual relationship with the DHB and ODNZ.

The Ministry of Health’s 2014 (update on 2006) service specifications require ODNZ to:

‘...provide, within the bounds of best clinical practice, as many highest quality organs and tissues as possible for transplant recipients in New Zealand and Australia’.

The time-limited contract established in Budget 2012 states:

‘The key objective of the service being specified is to increase the number of people receiving transplanted organs and tissues, by maximising the number of organ and tissues available from deceased organ donors.’

While there has been an increase in deceased organ donation rates in 2015, discussions with stakeholders strongly suggest that ODNZ has been working in relative isolation to meet its contractual objectives. Our view is that the Ministry can more actively support the achievement of ODNZ’s objectives through ensuring the necessary enablers are in place (discussed further below).

Additionally, EY considers that the Ministry has a crucial role directly and indirectly
through ODNZ to ensure that deceased organ donation matters are discussed at appropriate times by key decision-makers in New Zealand’s highly devolved health system. For example, we have been informed that deceased organ donation matters have very little visibility on the agendas of DHB boards and their committees, DHB executive management or in inter-DHB forums. In particular, at Auckland DHB we have been informed that deceased organ donation has not been on the agenda for the organisation in a material manner, and that when the organ donation and transplantation system is discussed, transplantation issues dominate).

While a national strategy would support raising the visibility of deceased organ donation, the Ministry will need to maintain an active role in ensuring that organ donation is a priority for DHBs following development of such a strategy for example, through incorporation in DHB annual and/or regional planning guidance and processes.

**Regional models may assist the sector to maximise donation opportunities**

Over recent years, regional clinical networks, leadership and models of care have been established in the sector to:

- Overcome inter-DHB barriers to effective service planning and delivery
- Support smaller DHBs in delivery of specialised clinical services, and encourage equity of access to care for more remote populations.

There may be opportunities to build on existing regional clinical structures such as regional trauma networks to support improved consistency in practice and share learnings between hospital sites. For example, we understand that intensivists and ED clinicians are part of regional trauma networks. These networks could therefore take some responsibility for developing improved pathways for identification of donors in ED and admission pathways to ICU.

Regional clinical leadership and practice models could also be encouraged to support hub and spoke arrangements between larger ICU sites and smaller ICUs (usually staffed by non-intensivists). Telemedicine is an obvious medium for larger sites to support smaller sites, with access to local intensivist expertise provided to smaller ICUs during donor identification and workup. This would buttress access to national specialist advice provided via ODNZ by creating strong local clinical relationships along the organ donation pathway. LINK team clinical leaders from larger ICU sites could also act as champions for organ donation at smaller sites. Since these sites are likely to have only a small number of donation opportunities over time, and potentially, more transient workforces, using a regional clinical champion model may make better use of workforce resources.

**Strengthening the role of DHB Boards and CPHACs**

DHB Boards and CPHACs have strong links into their local communities, providing the opportunity for them to lead conversations locally regarding the benefits of organ donation. In particular, they should have strong linkages with communities that tend to have lower rates of deceased donation. It is suggested that community
discussion and promotion of the uptake of end of life directives could usefully include organ donation options. At this time, the ability of DHB Boards and CPHACs to work with local communities appears to be a missed opportunity.

Furthermore, the nature of deceased organ donation and the national allocation of organs create a system within which local DHB populations may not accrue the benefits of organ donation made locally (via patients within an individual DHB’s ICU). While the national allocation of organs is appropriate, this may create a disincentive for an individual DHB to prioritise deceased organ donation particularly in the context of a constrained funding environment and the need to deliver on government expectations. Galvanising the support of DHB Boards and CPHACs in promoting organ donation locally on the basis that increasing the national pool will increase the chance their local population will benefit from transplantation is likely to be necessary condition for increasing the overall deceased donation rate.

**Strengthening the role of HACs and CMOs**

It is apparent that deceased organ donation is not accorded high priority at the individual DHB level except for where individual ICUs have embraced donation as a core activity. HACs and CMOs are the key local governors and clinical leaders responsible for ensuring the successful delivery of clinical services including achieving expectations established nationally, regionally and locally. At this time, they appear to have little role in deceased organ donation processes including visibility of Death Audit data and performance of ICUs in deceased donation. We consider that HACs and CMOs (in particular) need to become more active in fostering a culture of organ donation locally and working with their ICUs and EDs to lift performance. An early opportunity would be to have Death Audit data made available to the CMO (confidentially), and CMOs to be expected to provide summary reports to HACs on the performance of ICU and ED, and initiatives underway to support enhanced performance.

**Placing stronger expectations on key DHB Executive Leaders**

Fostering a culture of organ donation locally through strengthening the role of DHB Boards, subcommittees and CMOs needs to be supported by appropriate resourcing and investment decisions made by DHB Executive Leaders (eg, GM’s Planning & Funding and COOs). Each DHB receives its share of PBFF and makes allocation decisions based on local population health needs. In most DHBs, the rising prevalence of diabetes and chronic kidney disease is placing significant financial pressure on DHB specialist services. However, it is not clear that local DHB decision-makers are effectively prioritising deceased organ donation, which could contribute to improved health outcomes for their populations (eg, through kidney transplantation) and reduction in longer-term costs. We think better guidance to GM’s Planning & Funding and COOs regarding the likely cost/benefits to each DHB individually could result in them being more active in prioritising deceased organ donation via appropriate budget setting and resource allocation models. The Ministry and ODNZ should have lead roles in disseminating information regarding the cost-effectiveness of organ donation.
**Building on the LINK team model**

The LINK team model, and the extended LINK nurse role, provides a strong starting point for building local cultures of organ donation. International practice suggests providing protected time for intensivists and nurses in organ donation championship is a necessary condition for raising the deceased donation rate. In sites that have extended LINK nurse roles (part funded protected time), these roles appear to have made organ donation easier.

Protected time signals the importance of organ donation locally, and should create some additional pressure on clinical staff to actively champion deceased organ donation (ie, a clear expectation is placed upon them above and beyond other core activities of the department). This is important since deceased organ donation does not exact the same immediate pressure on clinicians as avoiding patient morbidity and mortality.

We consider that New Zealand should explore the opportunity of establishing more formal clinical championship roles with protected time at large and medium sized ICUs, with outreach of these roles to smaller ICUs on a regional basis. Protected time should not be excessive particularly for intensivists (eg, 0.1 FTE).

Additionally, there may be some duplication of effort between the tissue banks and ODNZ to obtain tissue donations particularly with respect to overlap with Donor Coordinator tasks. There may be the opportunity for LINK nurses to undertake some of the tissue donation processes. Clarification in this area is needed.

**The future location and role of ODNZ**

Alongside developing a national strategy, we believe that the institutional arrangements for system leadership of deceased organ (and tissue) donation should be reconsidered. Most notably, we consider that the form and function of ODNZ should be reconsidered with appropriate reference to what has worked in other health systems, and what is likely to work in the New Zealand setting. This should include:

- Revisiting the most appropriate location of the organ donation systems’ national coordinating body, ODNZ
- Strengthening the governance of ODNZ
- Making it a clear and explicit objective of ODNZ to increase the rate of deceased organ donation
- Retaining all current ODNZ activities
- Providing the appropriate mandate accorded to ODNZ to lead and implement change in the organ donation system
- Consider including tissue donation roles and responsibilities within ODNZ
- Maintaining clear professional accountability of ODNZ clinical staff to an appropriate senior clinical lead (currently this occurs through the Auckland DHB Cardiovascular Services’ clinical lead to the Auckland DHB CMO).

The current location of ODNZ within Auckland DHB provides benefits in locating roles and responsibilities for organ donation and retrieval close to transplantation.
services. It also provides benefits in having clear and established clinical governance processes, with the Clinical Director of ODNZ being professionally accountable to senior clinical leaders within the DHB. However, these benefits may come with the limitation of the organisation (and therefore its roles and responsibilities) being subsumed within a very large organisation with many competing local, regional and national pressures. These competing pressures make it difficult for ODNZ to figure highly on the agendas of the DHB board, executive management and clinical leadership. Furthermore, given the stated pressures on Auckland DHB’s heart, lung and liver transplantation services, a perverse consequence of current arrangements is likely to be that significant increases in the donation rate are considered unmanageable within the organisation. Finally, ODNZ is intended to have an ongoing and active role with all ICUs across New Zealand’s 20 DHBs. This is fundamentally different to transplantation services, which may have infrequent contact with any particular hospital site or DHB, driven on a case by case basis.

Managing the risks to the effective functioning of ODNZ within status quo arrangements requires strong governance of the organisation, which is influential enough to promote ODNZ within the DHB. At this time, it appears that ODNZ’s advisory board provides technical advice rather than organisational governance (ie, establishing strategic priorities, promoting these within the DHB and sector, and holding the organ to account for delivering on priorities). While it has been an expectation that the advisory board establish strategic priorities for the organisation, we understand that these have never been codified into a strategic plan and subsequent work programme. The board meets approximately two times a year. While the board is appointed by Auckland DHB’s Board, stakeholders held mixed views on the influence of the advisory board on either ODNZ or Auckland DHB. Reinforcing the role of the advisory board in establishing the strategy for the organisation appears to be necessary, with this clearly communicated to the organisation’s executive leadership and to the board of Auckland DHB and its executive team (in this context strategy refers to the overarching national strategy described earlier and how the organisation will go about achieving this). Executive leadership delivery on the strategy should then be the basis of organisation performance reviews. We also believe the strategy and subsequent work programme should be published so the sector and public understand the direction of travel of the organisation.

Given feedback from stakeholders and international trends in organ donation system reform, we think it would be prudent to consider the benefits (and limitations) of locating ODNZ’s roles and responsibilities either in a standalone national entity (eg, the Australian model) or as part of the Ministry of Health (eg, the Spanish model).

The standalone model could be achieved with revised ODNZ terms of reference for role, responsibilities and governance structures, a completely separate funding stream, and physical location in metropolitan Auckland (facilitating the
employment of Transplant Coordinators and medical staff, and interaction with retrieval teams). Close Ministry of Health governance and oversight linkages could be built in to this model. It is not incompatible with an arms-length DHB model for landlord for physical facilities and selected corporate services such as clinical IT and HR via a service agreement. These can be advantageous in continuity of employment terms and conditions for part time medical staff, and for clinical health record access.

The second alternative suggested apart from the status quo is ODNZ as part of the Ministry. All the reasons for physical location in metro Auckland remain, and staff would be Ministry employed and directed.

### Table 13. Options for the configuration of Organ Donation New Zealand

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<thead>
<tr>
<th>Option</th>
<th>Benefits</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
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<td><strong>Status quo</strong></td>
<td>• Established clinical governance framework</td>
<td>• ODNZ is perceived to be part of Auckland DHB rather than a national service</td>
</tr>
<tr>
<td></td>
<td>• Coordination &amp; logistics functions located close to retrieval and transplantation teams</td>
<td>• ODNZ priorities are given less emphasis compared with local Auckland DHB priorities</td>
</tr>
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<td></td>
<td>• Access to clinical systems and established back-office functions (IT; HR etc)</td>
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</tr>
<tr>
<td><strong>Standalone entity</strong></td>
<td>• Clear separation of function from the host DHB</td>
<td>• Increased bureaucracy and administration costs</td>
</tr>
<tr>
<td></td>
<td>• Governance structure independent of the DHB</td>
<td>• Added complexity in Donor Coordinators’ use of ADHB retrieval resources</td>
</tr>
<tr>
<td></td>
<td>• Establishment of terms of reference giving status of an independent authority, providing increased mandate and impetus to change practices in clinical settings</td>
<td>• Dislocation of close links to retrieval and transplant teams if not physically located in Auckland, which if not well managed could result in poorer organ donation coordination</td>
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<tr>
<td><strong>Business unit of the Ministry of Health</strong></td>
<td>• Close links to national health planning and increased ability to function as system regulator where needed, giving authority and thus impetus to change practices in clinical settings</td>
<td>• Isolation of a very small business unit in Auckland geographically distant from Wellington base (or vice versa)</td>
</tr>
<tr>
<td></td>
<td>•</td>
<td>• Complexity in supplying the required clinical business systems</td>
</tr>
<tr>
<td></td>
<td>•</td>
<td>• More disruptive transition than standalone alternative</td>
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</tbody>
</table>

In the event that ODNZ be relocated to a separate national entity or the Ministry of Health, a board similar to the current advisory board will be necessary but accountability arrangements will change with respect appointment and reporting of the board. However, the development of a strategy and subsequent work programme will remain crucial.
We note that irrespective of where ODNZ is ultimately located, it will only be with the ongoing oversight of the Ministry of Health as system steward and funder that the organisation will discharge its responsibilities in line with national expectations.

**Ensuring system funding arrangements support deceased donation**

Financial support to donor hospitals is an international practice to assist with increasing the deceased donation rate. Financial support is intended to ameliorate cost and resource barriers to deceased organ donation. Under current New Zealand funding arrangements, funding for organ donation is notionally factored into each DHB’s PBFF allocation via the national pricing programme, DRG caseweights and costweights per person. There is limited targeted financial support for donor hospitals. The only instance of targeted support is via ODNZ’s funding of extended LINK nurses (ODNZ’s funding of donor coordinator and logistics is indirect financial support to donor hospitals). It is voluntary for ICUs to take up ODNZ’s targeted financial support, and we were informed by the organisation’s Clinical Director that some ICUs had declined to take-up this funding. It is currently in place at four ICUs.

It has been reported to us by stakeholders that deceased organ donation is resource intensive and some work is currently conducted on a ‘goodwill’ basis. It was never reported to us that organ donation was not pursued for cost reasons; rather the prioritisation of effort and clinical demands could result in missed opportunities given staff constraints.

The availability of per-event funding could help support the costs an ICU incurs in facilitating an organ donation but prior uses of such funding have met with mixed success. Previously DHBs could and did claim for direct Ministry funding to compensate for the costs of tissue typing (up to $1,500) and additional ICU and operating theatre costs ($5,000) associated with organ donation and retrieval. After 2006/7, the number of claims by DHBs decreased for reasons which are unclear (although deceased donations declined during this period), and the funding was halted in 2013/14. EY understands cessation of this funding met with no resistance from DHBs. This suggests the funding was not seen as especially important, and was not closely linked to driving greater pursuit of organ donation opportunities.

During the time ODNZ has functioned there have been multiple attempts to incentivise (or remove disincentives towards) good practice in clinical settings around organ donation. These schemes have had varying degrees of success and no scheme has seemed to adequately align financial and clinical goals. For example, ODNZ has also previously raised the concept of paying DHBs for completing various organ donation processes. ODNZ proposed to provide payments every time particular events such as potential donor identification and the initiation of a formal discussion occurred (ie, providing funding to support good practices in clinical settings). While some ICUs were receptive to this idea, many LINK team stakeholders did not want to receive additional ‘reward’ payment for what they perceived as one of their normal clinical duties.
EY considers that ODNZ’s proposed payment model for good clinical practice has merit but the system is not ready for such an approach. Notwithstanding this, we think it prudent for the Ministry to consider alternative funding arrangements that may support ICUs to maximise deceased donation opportunities. Alternative funding arrangements could include (but are not limited to):

- Nationally held funding pool for compensation of additional costs of organ donation, paid on a per case basis, and recognising that organ donation is an irregular event, which has collective benefit for all DHBs (this is as per previous Ministry funding arrangements prior to 2013/14)
- Building on the extended LINK nurse scheme, making this mandatory for appropriate ICUs (those with patient mix and volume likely to need additional local championship and resourcing)
- Part funding protected time for ICU medical champions of organ donation (eg, 0.1FTE).

We consider that these arrangements could be accommodated within the current overall New Zealand funding arrangements without eroding the expectations and accountabilities associated with PBFF. However, they would need to be underpinned by a clear expectation of a lift in the deceased donation rate at individual ICU levels and nationally.

**Heart and lung transplant services capacity is unlikely to be able to absorb a substantial increase in the organ supply**

Demand for cardiothoracic surgical services is high, meaning that there is no formal availability roster for organ procurement and transplantation services. Instead staffing is managed on an ad hoc basis that is likely to mean hearts and lungs will sometimes be unable to be retrieved if deceased donor numbers increase substantially.

It is advisable for the Ministry to consider reviewing the configuration of organ transplantation services in New Zealand - noting that a systematic review has not taken place since 1993\(^\text{21}\). Moreover, we consider that planning for lifting the deceased donation rate should be done in parallel with planning to determine and develop the necessary transplantation capacity to make optimal use of donated organs.

**It is important to consider the cost-effectiveness of deceased organ donation**

While EY believes that increases in the deceased donor rate are possible without substantial additional funding for organ donation, it is likely that significant increases in deceased organ donation and transplantation activity will require additional direct investment. In particular, the marginal cost of increasing cardiothoracic organ transplant capacity is likely to be significant. In this context, it is important that the direct and opportunity costs of deceased organ donation are...

\(^{21}\) Final Report to the Director - General of Health from the National Taskforce on Transplantation, August 1993, National Taskforce on Transplantation, Ministry of Health.
It may be advisable to focus donation improvement efforts on major clinical sites in the short-term while other system-wide strategies take effect

In light of the potential of cost-effectiveness considerations the Ministry of Health should consider focusing improvement efforts on larger clinical sites in the short-term. Although EY has not had full access to death audit data to ascertain the number of potential donors at each clinical site, it is likely that most donation opportunities are clustered in larger ICUs. In larger ICUs staffed by intensivists (rather than anaesthetists) it is more likely that a culture focused on organ donation could arise. Larger clinical sites are also more likely to have staff rostering flexibility to accommodate organ donation.

Focusing on maximising donor identification and consent requesting at large ICUs is likely to be the most cost-effective way of improving donation rates in the short-term. A particular emphasis should be placed upon ICUs where transplant services are located in the hospital. At these sites the costs of organ retrieval are considerably lower, as is the amount of ICU staffing time (as there is minimal travel involved). It is also more likely that transplant, ICU and ED staff at the hospital will be able to regularly communicate and build a culture valuing transplant opportunities.
12. Conclusion

New Zealand has a relatively low rate of deceased organ donation compared to other Western countries, and the average donation rate has remained relatively static for the last two decades. However, when deceased organ donation does occur in New Zealand the donation is well utilised, with a high number of organs transplanted per donor relative to international benchmarks.

Countries that had similar donation rates to New Zealand have been able to institute reforms which have been able to substantially increase the deceased donation rate (eg, Australia and the UK). An assessment of practices in clinical settings in New Zealand indicates that there is the potential to increase the deceased donation rate. The key issues identified relating to practices in clinical settings were centered on the processes of donor identification and requests to family for donation.

In particular, it was found that many ICUs do not consider organ donation to be part of their core business. This is partly attributed to the resource constraints on ICUs, resulting in staff needing to make prioritisation decisions between potential organ donors and patients likely to make a recovery. Further analysis is required to establish a strong evidence base for how far resource constraints impact on maximising organ donation opportunities.

The lack of a robust performance reporting regime and variable clinical leadership means organ donation is not front of mind for clinicians. The fact that a rise in the organ donation rate does not seem to be clearly advocated in the system, limits the priority clinicians place on donation in a context of many competing needs.

Further issues with practices in clinical settings include the lack of ED involvement in organ donation and the suboptimal use of existing clinical resource to facilitate donation. These factors limit the size of the potential donor pool and making the most of each donation opportunity.

We believe there are clear potential enhancements to practices in clinical settings that will support an increase in the deceased organ donation rate. Measures such as further development of the LINK team concept, inclusion of the ED in the organ donation pathway, expanding the scope and transparency of the death audit, improving the utilisation of existing clinical staffing and broadening the number of clinical staff receiving training on organ donation are all achievable reforms that are likely to be effective.

While the context in which organ donation takes place is challenging and clinicians are undoubtedly under considerable stress, targeted changes can support more effective practices in clinical settings. We believe that the recommendations outlined in this report hold considerable potential to raise deceased organ donation rates in New Zealand, without the need for significant investment.
We also believe that the institutional arrangements of the organ donation system need to be revisited but do not require radical reform. In particular, we emphasise that without the collective effort of DHB boards, executive management and relevant clinical leaders, it is unlikely a sustained lift in the deceased donation rate will occur within New Zealand’s highly devolved system. Achieving such a lift will require a clear national vision for what New Zealand is aspiring to achieve in deceased organ donation, a clinically credible strategy for achieving this vision and appropriate expectations placed on key institutions to implement the strategy.

Finally, should an increase in deceased organ donation rates occur, the capacity of transplant services to cope will also require considered review. Stakeholders have indicated that while kidney, liver and pancreas transplant services should have the capacity to manage an increased organ supply, heart and lung transplant services are currently operating at capacity. If further investment in transplantation services is required then the cost-effectiveness of the overall level of organ transplantation should also be considered.
### 13. Appendix One: Stakeholders interviewed

<table>
<thead>
<tr>
<th>Name</th>
<th>Position</th>
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<tbody>
<tr>
<td>Dr Nick Cross</td>
<td>Clinical Director – National Renal Transplantation Service, Nephrologist (Canterbury DHB)</td>
</tr>
<tr>
<td>Dr Ian Dittmer</td>
<td>Clinical Director – Renal Services (Auckland DHB), Transplant Nephrologist</td>
</tr>
<tr>
<td>Dr Mark Edwards</td>
<td>Cardiovascular Director (Auckland DHB), Anaesthetian</td>
</tr>
<tr>
<td>Joy Farley</td>
<td>General Manager Cardiovascular Services (Auckland DHB)</td>
</tr>
<tr>
<td>Dr Les Galler</td>
<td>Intensivist (Auckland DHB)</td>
</tr>
<tr>
<td>Jo Gibbs</td>
<td>Director of Provider Services (Auckland DHB)</td>
</tr>
<tr>
<td>Janice Langlands</td>
<td>Donor coordinator - ODNZ</td>
</tr>
<tr>
<td>Dr Murray Leikis</td>
<td>Chair – National Renal Advisory Board, Nephrologist (Capital &amp; Coast DHB)</td>
</tr>
<tr>
<td>Eva Mehakovic</td>
<td>Director, Clinical Programmes - Organ and Tissue Authority (Australia)</td>
</tr>
<tr>
<td>Professor Stephen Munn</td>
<td>Clinical Director - Abdominal Transplant Service (Auckland DHB), Transplant Surgeon, Member - ODNZ Advisory Group</td>
</tr>
<tr>
<td>Dr Anil Nair</td>
<td>Clinical Director - Department of Emergency Medicine (Auckland DHB), Emergency Medicine specialist</td>
</tr>
<tr>
<td>Dr Mark O’Carroll</td>
<td>Respiratory Physician (Auckland DHB), former President of the New Zealand Branch of the Thoracic Society of Australia and New Zealand</td>
</tr>
<tr>
<td>Dr Helen Opdam</td>
<td>National Medical Director - Organ and Tissue Authority (Australia)</td>
</tr>
<tr>
<td>Dr Katherine Perry</td>
<td>Clinical Director – Whangarei ICU (Northland DHB)</td>
</tr>
<tr>
<td>Dr Nick Polaschek</td>
<td>Board Member - Kidney Health New Zealand, former Senior Project Manager - Ministry and Health, former nurse.</td>
</tr>
<tr>
<td>Janine Rouse</td>
<td>LINK Nurse, Intensive Care Unit (Auckland DHB)</td>
</tr>
<tr>
<td>Dr Catherine Simpson</td>
<td>Intensivist (Counties Manukau DHB)</td>
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<tr>
<td>Dr Louise Trent</td>
<td>Intensivist (Hawke’s Bay DHB)</td>
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<tr>
<td>Dr Stephen Streat</td>
<td>Clinical Director – ODNZ, Intensivist (Auckland DHB)</td>
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<tr>
<td>Stephen James</td>
<td>ICU Charge Nurse Manager</td>
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<tr>
<td>Chris Sutherland</td>
<td>ICU nurse (Capital &amp; Coast DHB), former LINK nurse</td>
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<tr>
<td>Auckland DHB</td>
<td>ICU LINK team representatives</td>
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<tr>
<td>Hawke’s Bay</td>
<td>ICU representatives</td>
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<tr>
<td>Northland DHB</td>
<td>ICU representative</td>
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14. Appendix Two: Description and comparison of the ADAPT and cFDC training workshops

**Australasian Donor Awareness Program (ADAPT):** A professional education programme designed to provide participants with an understanding of the major aspects of deceased organ donation. It is understood that the emphasis of the course is technical and procedural but includes sections on conducting family conversations. The ADAPT course is offered in two forms; a medical ADAPT offered to ICU or ED doctors and a General ADAPT that nurses and other health professionals can attend. The two ADAPT variants have different content and emphases but the extent of these differences is not known to EY. It should be noted that the ADAPT course has been superseded as of 1 October 2015 by the Introductory Donation Awareness Training (IDAT) course in Australia. Stakeholders spoken to during development of this report did not have experience with the IDAT course.

**Family Donation Conversation Core Module (cFDC):** A two day multidisciplinary training workshop solely focused on how to conduct organ donation discussions with the families on potential donors. A trial version of the cFDC was conducted in New Zealand in late 2015 and has reportedly received good feedback from participants.
15. Appendix Three: Overview of the Australian Organ and Tissue Authority (OTA)

The OTA was established in 2009 by the Australian Federal Government as a national governance body for the Australian organ, eye and tissue donation and transplantation sector. The OTA is responsible for implementing a donation reform agenda recommended by an earlier Taskforce on organ donation.\(^{22}\)

The Australian reform agenda was to:

- Establish a new national approach and system for organ and tissue donation: a national authority and network of organ and tissue donation agencies.
- Establish specialist hospital staff and systems dedicated to organ donation.
- Provide new funding for hospitals.
- Provide national professional education and awareness.
- Provide coordinated, ongoing community awareness and education.
- Provide support for donor families.
- Establish a safe, equitable and transparent donation and transplantation network.
- Enact national eye and tissue donation and transplantation.
- Undertake additional national initiatives, including living donation programs.

The OTA works with the DonateLife network to administer the reform agenda. The DonateLife network consists of:

- State and Territory Medical Directors.
- DonateLife Agencies (one in each state or territory).
- Hospital-based medical and nurse specialists in organ and tissue donation.

The DonateLife agencies coordinate organ and tissue donor activities across their respective territory or state. They are also for public awareness activities, support for donor families and monitoring clinical service effectiveness. Each DonateLife agency is funded by the OTA, via state and territory governments.

The OTA administers $AUD151.1 million in Commonwealth funding to be allocated over four years. This is approximately $AUD38 million per year.

The most recent information available to EY states that the funding has been allocated as:

- $67 million ($16.75M/annum): Funding of staff in public and private hospitals. This was chiefly to fund dedicated specialist organ donation doctors.
- $46 million ($11.5M/annum): To fund the OTA and its administered programmes. This includes funding for the DonateLife agencies.

- $24M ($6M/annum): Organ and Tissue Authority
- $20M ($5M/annum): DonateLife Agencies in each jurisdiction.
- $17 million ($4.25M/annum): Funding for hospitals to meet additional costs associated with organ donation.
- $13.4 million ($3.35M/annum): National public awareness and education.
- $1.9 million ($475,000/annum): Counselling for families of potential donors.
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