

# **Increasing Rates of Deceased Organ Donation**

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Summary of submissions

Citation: Ministry of Health. 2017. *Increasing Rates of Deceased Organ Donation: Summary of submissions*. Wellington: Ministry of Health.

Published in March 2017  
by the Ministry of Health  
PO Box 5013, Wellington 6140, New Zealand

ISBN 978-1-98-850227-4 (online)  
HP 6575

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# Background to the submissions analysis

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

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

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

Based on this, *Increasing Rates of Deceased Organ Donation: Consultation document* was developed. This consultation document sought feedback on the Ministry's initial proposals to increase deceased organ donation and transplantation in New Zealand. The following document summarises feedback received through the consultation process.

## Scope of the review

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

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

## Profile of respondents

The Ministry received 100 submissions. Seventy submissions were from individuals and the remaining 30 submissions were from groups or organisations.

Of the individual submissions, 11 were made by clinicians, and 9 were made by respondents identified as having personal experiences with the organ donation system (eg, family/whānau of people affected by organ donation).

Most of the submissions made on behalf of organisations were from the health sector.

# Overall response to the review

Submissions were largely in favour of a comprehensive strategy to increase deceased organ donation. Several respondents reinforced the importance of a whole package, rather than picking and choosing elements. Many respondents also emphasised support for ensuring that any strategy was evidence-based and ethically sound.

Respondents generally agreed that the high-level elements of the strategy were about right. However, some submitters did not support a numerical target or goal.

Approximately half of individual respondents were in favour of a law change to presumed consent, and expressed concern that this was not considered as part of the strategy.

Most respondents who commented supported or partially supported the proposed functions for the national coordinating body. Although a few submitters said a narrow focus on increased donor numbers was inappropriate, and the success of the body should be measured more broadly.

Respondents were largely in favour of the national coordinating body developing, monitoring, and implementing a clinical governance framework.

The proposal for protected time for hospital-based clinical organ donation specialists was also generally supported, although support for ‘champions’ within the broader DHB was mixed.

Most respondents who expressed a view thought that it would be useful to have further specialist training for clinical staff in organ donation. Many respondents emphasised that any further training introduced needs to be tailored to reflect the cultural and clinical settings of New Zealand.

Responses in relation to public awareness and organ donor registers varied. Some respondents placed a high importance on public awareness, and a few showed strong support for a separate or binding organ donor register. Others said that public awareness efforts and donor registration should be a lower priority as they were not well evidenced as leading to increased rates of donation.

There were also responses related to funding, saying an increase in financial support and capacity in the donation and transplantation sector is required.

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# A strategy to increase deceased organ donation

## Proposal

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

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

### **Q1: Are these the right high-level elements of an effective organ donation strategy?**

The majority of respondents who made a comment about the strategy agreed or partially agreed<sup>1</sup> with the high-level elements proposed for an organ donation strategy.

Of the submitters that responded to this question, 22 agreed, 26 partially agreed, and 34 did not agree that the high-level elements proposed were effective for an organ donation strategy.

Those that agreed showed strong support for an organ donation strategy and the elements proposed.

New Zealand should have an explicit, agreed, published, national strategy to increase organ transplantation from deceased donors ... many countries have successfully increased their deceased donation rate through a similar range of strategies.

Many of the submitters that partially agreed showed general support for a comprehensive strategy, but favoured other elements that were not proposed or disagreed with particular elements proposed. For example, many were not in favour of an aspirational goal or target.

A world-class national clinically credible strategy is supported. It needs to be evidence based, appropriately funded, integrated, honest, transparent, ethically and legally sound. An aspiration goal or target is not supported [...] in the way it is framed [...] (we) feel that the target should be framed around the process, not the outcome.

<sup>1</sup> Where respondents ticked both 'Yes' and 'No' on the consultation document, or expressed some support in their submission, this was recorded as partial agreement.

Those that did not agree suggested elements that were not proposed. All 34 submitters who disagreed with the high-level elements suggested moving to an opt-out or presumed consent system, where people would be organ donors by default.

## **Q2: Is an aspirational goal/vision appropriate?**

The majority of submitters who responded to this question (31) agreed that an aspirational goal/vision was appropriate. Three submitters partially agreed, and 7 did not agree that an aspirational goal/vision was appropriate.

While there was general agreement for a goal or vision, there were mixed views on the type of goal/vision a strategy should have.

Some submissions (11) strongly favoured a goal or target like the ones proposed, particularly “a donation rate in the top 20% of countries”.

Others (8), particularly from clinicians and the donation sector, thought that a numerical target or goal would not recognise the complex interpersonal process of organ donation. These respondents suggested a target focussing on the process rather than the outcome. For example, the goal should be that “every donation opportunity is identified and explored”, and specific measures for number of potential donors identified and their families approached.

A vision for organ donation should include vision for integrity of process and not simply number of donors. The goal should be every opportunity for possible donation recognised, supported, every such person should be assumed to be a possible donor, supported and investigated with good clinical practice, ethics, law, every family should have donation discussed with them with expertise and have their decision accepted and respected.

Another view was that a target would be better expressed in terms of transplants, rather than donors. This would ensure that the focus was kept on the end goal of organ donation and also reflect the quality element of donation – ie, incentivise good donor management to ensure that the maximum number of organs be transplanted.

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# An appropriate legal and ethical framework

## Proposal

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

### **Q3: Are there aspects of the current law relating to organ donation and transplantation that you think should be reconsidered?**

Twenty-six respondents did not support reconsidering the law, 46 did, and 1 partially supported reconsidering the law.

Most of the submissions made by groups or organisations did not support a change in the law. In contrast, most individual submissions proposed modifying the law relating to consent.

Those proposing to change the law wanted a presumed consent or opt-out system (34), or reflected the view that individuals should be able to give binding consent to donation before their death, with no possibility of that consent being overridden (18).

Those who supported leaving the law unchanged commented that legal changes would not likely result in an increase in donation rates.

The Human Tissue Act 2008 provides a legal framework [...] that is consistent with the broader cultural norms of the country. The discussion paper clearly identifies that intensivists, and others, are reluctant to go against the wishes of the family. Changes to legislation to support presumed consent will therefore likely not result in a significant increase in donation rate.

A couple of submissions suggested changing the Land Transport Act to allow donor coordinators and link nurses access to the organ donor information on the driver licence register, as currently only medical practitioners have access.

# Proposal

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

## **Q4: How could consistent ethical guidance on organ donation and transplantation be obtained?**

Submissions that answered this question (40) supported the importance of readily available ethical guidance. Some submissions (mainly from health professionals or organisations) commented that current ethical guidance and frameworks are sufficient and that no changes are required.

A couple of submissions said that a change to a presumed consent system, or a numerical target or goal to increase donations, would require significant ethical consideration.

Some submitters pointed out that some perceived ethical issues highlighted in the review, such as concern about the ethical implications of donation after circulatory death, were education and training issues, which should be dealt with as part of a clinical governance framework, rather than requiring further ethical review.

## **Q13: Do you have a view on an appropriate source of ethical guidance?**

For example:

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

Of the submissions received, 25 respondents agreed that they had a view on ethical guidance, and 12 said they did not have a view. Of those that indicated they had a view, three respondents commented on other aspects of ethical guidance rather than the source.

Four submissions supported a stand-alone committee, as in the UK. However, others suggested there are not sufficient donation and transplantation numbers in New Zealand to justify a separate committee.

Three submissions supported the TSANZ as a source of ethical guidance, however another three submissions commented that TSANZ would not be appropriate.

Most respondents who commented (11) had a preference for NEAC as the appropriate source of ethical guidance.

One submitter said that ethical guidance is already provided by the Australia New Zealand Intensive Care Society's *Statement on Death and Organ Donation* and that change is not needed.

Some respondents additionally suggested that any group that provides ethical guidance should have consumer representatives, with independent views and from a range of cultures.

### **Q14: Is there another appropriate option?**

One respondent suggested that ethical guidance could be provided by the Australian National Health and Medical Research Council.

### **Q15: What is the best way of obtaining public input on ethical issues?**

Some submissions commented that the ethical body should have consumer representatives to provide a layperson's view. However, one submission noted that public views may not always add value.

Public input may be informative but isn't necessarily helpful e.g. academic studies show public favour of donation based on 'moral worth', incentives or disincentives for donation. Proper ethics committees on clinical issues should contain laypersons to provide a 'citizen's view' rather than support special interest groups, in addition to professionals with ethical expertise.

Other submissions gave suggestions of different methods for obtaining public input, for example "focus groups, public forums, survey monkey".

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# A national coordinating body

## Proposals

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

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

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

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

### **Q5: Are the listed functions for the national coordinating body correct and appropriate?**

Most of the respondents that answered this question agreed (26) or partially agreed (11) that the listed functions for the national coordinating body were correct and appropriate, and nine did not agree.

Submitters agreed that a national coordinating body is a vital part of successful organ donation efforts, and mostly agreed that the proposed additional responsibilities made sense. They emphasised the importance of improved governance, and greater monitoring by the Ministry and accountability to the Minister.

Generally, those listed functions are an improvement on current ODNZ role. Improved governance, public education and accountability are needed.

Submissions from clinical stakeholders in particular emphasised that ODNZ has done very good work within its current responsibilities and all its existing activities should continue.

There was some concern expressed by a couple of submitters about the phrase “championing organ donation”. They were supportive of the coordinating body being charged with ensuring that organ donation was seen as a core health service and that it is appropriately supported, however they were concerned that championing might mean promoting organ donation exclusive of wider considerations.

Some submitters (8), particularly clinicians, expressed a concern that a narrow focus on increasing donor numbers was inappropriate and were concerned it could lead to families being badgered or coerced into agreeing to donation.

## **Q16: What is the appropriate location for the national coordinating body?**

Many of the submissions that responded to this question selected multiple options. Relatively few respondents supported the location being in a DHB (4) or within another agency (6). There was considerably more support for locating it within the Ministry (16), or a stand-alone Crown agency (16). Most of those who selected 'somewhere else' (12) selected more than one of the options on the submission form.

Suggestions for other locations included the National Renal Transplant Service, a government funded charitable trust, and a trans-Tasman joint authority.

Generally, submitters emphasised the importance of the national coordinating body being seen as independent. A couple of submissions highlighted that it should be separate from transplant services on ethical grounds to discourage undue pressure on potential donor families.

There was some support for a physical location within Auckland Hospital because of access to clinical information, associated corporate support, and links to transplant services.

This should be a stand-alone agency with Ministry oversight and funding. The current arrangement within ADHB is not ideal due to the multiple other functions of the DHB distracting from appropriate governance. The location within Auckland is probably the best due to the transplantation surgery which occurs there.

## **Q17: Are there other roles within the organ donation and transplantation system that the national coordinating body should undertake?**

Most submissions did not respond to this question but of those that did, 15 said 'Yes', 1 partially agreed, and 9 said 'No'.

There was limited comment on this issue but those that did supported the national coordinating body:

- having a liaison-only role with transplantation services, as in Australia
- include clinical governance and accreditation of ICU and HDU units
- include tissue donation
- include live donation
- expand its medical advisory role to give more feedback on care of potential donors.

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# A clinical governance framework

## Proposals

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

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

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

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

## **Q6: What role should the national coordinating body have in the clinical governance of organ donation and transplantation?**

Of those that commented on this question (14), there was general agreement that the national coordinating body should be responsible for developing and monitoring a clinical governance framework as proposed in the consultation document, as well as be responsible for its implementation.

We agree with the proposal to develop a nationally determined clinical governance framework for organ donation. This is necessary to remove inconsistent practice amongst different DHBs and to ensure a standardised process. We think it is likely that some DHBs will need additional funding to support them in meeting the cost of implementing new systems and processes.

The national body should have responsibility and accountability for the definition and implementation of a cross DHB clinical governance model ... supported by appropriate terms of reference.

Submitters indicated that a clinical governance framework is a central aspect of the strategy. A common comment was that a clinical governance framework would be important for promoting more consistency and accountability.

## **Q18: What would be the core components of a clinical governance framework for organ donation?**

Some respondents agreed that the Australian model could be applied to New Zealand, as suggested in the consultation document. Some submitters highlighted specific aspects of the Australian model as a starting framework.

Others listed key components for a clinical governance framework.

The core components would be the appropriate personnel with donation expertise, adequate funding, key linkages with other (e.g. intensive care and transplantation) services, congruence between strategy, action and messaging, and a culture of openness, transparency, evidence-based practice and the highest ethical standards.

Submitters also emphasised the importance of using death audit data to drive a quality improvement focus. A couple of submitters added that the death audit should be shared among clinical staff in a non-anonymised format so that clinicians can identify high performing DHBs to learn from.

There was a warning against transplantation being included in the clinical governance framework as, while not made explicit in the consultation document, could be inferred from the phrase ‘donation and transplantation’.

There is no proposal currently to incorporate national governance of transplantation and the inclusion of this word seems likely to represent a common conflation of donation with transplantation – which is a separate (but dependent) area of clinical activity.

## **Q19: How should a clinical governance framework be implemented?**

This issue received comments predominantly from groups or organisations in the organ donation and transplantation sector.

Submitters emphasised the importance of having clear commitment and accountability at all levels that “donation is everyone’s responsibility”.

By working collaboratively with stakeholders in the development of the framework and then using thought leaders as well as others with leadership responsibilities to assist with the implementation. There will need to be a number of guidelines/protocols formulated (requiring the relevant stakeholder groupings input) and processes established.

Some submissions focused on the importance of reporting and monitoring against key performance indicators.

## **Q20: How could a clinical governance framework for organ donation fit into existing clinical governance systems?**

Few submissions (3) responded to this question. It was generally agreed that the clinical governance framework would need to align with existing clinical governance systems.

## **Q21: How could the death audit be improved?**

Most submissions that responded to this question (11) agreed that the death audit could be managed more effectively to determine why donation was sometimes not considered. Some submitters acknowledged that ODNZ has been continually working to improve the death audit structure and its utilisation.

There was generally support for more transparency within clinical settings, including sharing of regional data.

More rapid and specific linking of the information to peripheral hospitals to provide them with specific advice to improve the quality of organ donation.

The timeliness and accuracy of death audit data input was also considered to require further improvement. Collecting death audit data in EDs was also considered to be important.

Others suggested a name change or rebranding of the death audit.

## **Q22: What information from the death audit should be publicly available?**

There were differing views on whether death audit data should be publically available and if so, whether national or regional data should be available.

Submitters noted that information from the death audit is already available in a controlled way that takes account of ethical and privacy concerns.

Some respondents suggested full public access to all information in the death audit (with a preference for this being anonymised). While others were concerned this information should be confidential (anonymised or not) and that releasing this could confuse the public who may not be able to interpret it correctly. Respondents also suggested that this could undermine efforts in favour of organ donation.

## **Q23: Should emergency departments be involved in organ donation?**

The majority of submissions that responded to this question said 'Yes' (29), three partially agreed, and three said 'No'.

Some submissions acknowledged that transferring an ED patient to the ICU for the purpose of organ donation would require change from the current practice, as patients are only transferred if it will benefit them, but if this is done appropriately it would be acceptable. Although some submitters considered there would be still ethical concerns.

The following difficulties were raised in relation to initiating organ donation opportunities within EDs.

- Lack of appropriate rooms for the family donation conversation
- The time pressured nature of EDs
- Limited beds available for resuscitation
- It being harder to have the conversation with families that have been in hospital for less time
- Higher staff turnover in EDs.

One submission commented “international experience indicates ED involvement is essential to maximising donation”.

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

There were different views put forward for how the link between ED and ICU for the purpose of organ donation could be implemented. These included:

- embedding roles / champions in EDs
- providing relevant in-house training
- requesting the national coordinating body to work with EDs to develop pathways.

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# Hospital-based clinical organ donation specialists

## Proposals

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

Maintain existing LINK teams in the remaining 12 ICUs.

Appoint appropriate hospital organ donation champions outside the ICU.

Expand funding for organ donation specialists to more ICUs.

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

### **Q7: Does the proposal for hospital-based clinical organ donation specialists have the right elements?**

Most of the submissions that responded to this question (30) agreed that the proposal for hospital-based clinical organ donation specialists had the right elements, while four partially agreed and seven did not agree.

Experience from Australia suggests that the funding of dedicated specialist medical and nursing roles to manage the donation process is the single most effective initiative to increase the rates of deceased organ donation.

A couple of submissions recommended having protected time for roles in all DHBs. One submitter also commented that LINK nurses should be paid at specialist nurse level, as they are not paid for being on-call, although donations can occur at any time.

Submitters who did not agree that the proposal had the right elements commented that:

- small hospitals do not need intensivists or nursing roles funded for organ donation
- any funding would need to be linked to specific activities
- other roles could be funded for organ donation (including all medical personnel)
- nurses should be made available for all dying patients, with a focus on organ donation
- there is no rationale for funding intensivists, when it is already part of their job description.

## **Q24: What is required to support clinical leadership on organ donation within ICUs?**

There was general support for funding staff time to ensure effective implementation of a clinical governance framework, DHB commitment and support for clinicians.

However, some criticised funding a leadership position within ICUs specifically for increasing organ donation as it could place pressure on clinicians to unethically pressure families into agreeing to donate.

## **Q25: Do you agree that funding dedicated time for intensive care doctors and nurses would be useful to increase organ donation rates?**

Twenty-six respondents showed support for this proposal and four did not agree.

There was strong support in the submissions by groups and organisations, with comments providing detail about why it was practically necessary to increase funding and how such funding could be effectively allocated.

Protected time for organ donation roles was considered by some submitters to be the most important of the proposed actions based on international experience (particularly in Australia). One stakeholder commented all other improvements/changes would come from these roles.

One DHB questioned whether protected time for intensive care physicians was necessary as organ donation is already part of their role.

## **Q26: Should those roles be responsible for leading implementation of the clinical governance framework for organ donation in their DHBs?**

Of those that responded to this question, 12 submissions agreed, 2 partially agreed, and 4 did not agree.

Some of those that agreed commented that these roles have the greatest expertise, knowledge and skills to implement the clinical governance framework, but that they would need support and collaboration from their clinical colleagues and management.

## **Q27: What other roles within the broader DHB could champion organ donation?**

While there were some reservations about use of the word ‘champion’, submitters generally favoured ‘comprehensive support at all levels’ and emphasised the importance of DHB support for implementation of the clinical governance framework.

There was some support for champions outside of ICUs.

Having champions in each relevant department would ensure that those specialities that see the potential donors but fail to recognise them as such are able to be more proactive. Emergency departments and general physicians often see patients with intracranial bleeds that are not surgically amendable and therefore are put on a palliative pathway – without thought as to if they could be donors or not. If these specialities were made more aware of the possibility then more potential donors may be identified. The intensive care specialists could then evaluate the patient for suitability.

However, others questioned what was meant by champions and suggested it would be more appropriate and effective to promote a focus on improving organ donation process across the DHBs through a clinical government framework.

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# Specialist training for clinical staff

## Proposals

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

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

### **Q8: Does the proposal for specialist training adequately address clinical staff training needs in New Zealand?**

Twenty-four respondents agreed with this proposal, nine partially agreed, and nine did not agree.

Submissions from groups and organisations were predominantly in support or partial support of the proposal.

While some submissions commented that staff are already sufficiently trained, there was support for further training or more frequent undertaking of existing training options.

Many respondents emphasised that any further training introduced needs to be tailored to reflect the cultural and clinical settings of New Zealand.

There was one comment that it is important not only to make the training available, but to ensure adequate resources to free up staff to attend and audit training.

### **Q28: Is there further specialist training for clinical staff that would be useful, such as training in cultural competency?**

Most respondents that answered this question thought that further training would be useful: 22 said 'Yes', 2 partially agreed, and 6 submissions said 'No'.

There was strong support for training in cultural competency. Although this was balanced by a view in submissions from the health sector that clinicians are already expected to have an understanding of tikanga in their clinical practices. Comments about cultural competency mainly centred on Māori and Pasifika, but there was some mention of the broader New Zealand culture.

Cultural barriers to organ and tissue donation need to be addressed from within the culture and not from without. In the case of Māori culture, this should include hospital-based kaumatua or social workers, and elders in the community and on marae. ... Cultural outsiders like Pakeha clinical staff could not explain or argue such issues with a Māori whanau. In any case, it is not their duty to try to persuade a family to donate. Suggestions on how to incorporate donation into the Māori culture would need to come from cultural leaders or advisers attending family meetings or have broader discussion within Māoridom.

## **Q29: How could we increase the uptake of training, including by emergency medicine specialists and anaesthetists?**

A couple of submissions suggested organ donation training should be made mandatory for all intensive care staff and other roles involved in organ donation, while others commented that it should remain voluntary.

Some respondents agreed that anaesthetists working in ICUs should be appropriately trained in organ donation, however some showed concern that because they come across possibilities for organ donation so infrequently this would be lost over time. Instead it was suggested that formal networks should be put in place to provide them with adequate support should the occasion arise.

Submitters agreed that emergency medicine physicians and nurses had an important role in organ donation, but suggested training should be appropriate and tailored for their particular role (as the donation conversation should remain the responsibility of intensivists).

Other ideas for increasing the uptake of training by emergency medicine physicians and nurses included: accreditation, requiring each DHB to have a lead ED Senior Medical Officer for organ donation, and including an organ donation element in emergency medicine training.

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# Financial support for donor and transplant hospitals

## Proposals

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

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

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

### **Q9: Are there additional funding arrangements that should be considered in organ donation and transplant events?**

Thirty-three submissions agreed that additional funding arrangements should be considered, and six did not.

There was a strong view that any financial barriers to donation should be removed. Submitters were largely supportive of the proposal to quantify and reimburse donating hospitals for the additional costs incurred in the donation process. Several submitters noted that there were costs even when donation does not occur that need to be funded.

Some concern was also expressed about the financial challenges faced by smaller DHBs in organ donation.

Those that did not agree that additional funding arrangements should be considered commented that:

- we should only reinstitute the reimbursement that was allocated in 2014, and ensure that units are aware of this as part of a wider educational/promotional strategy
- increased funding should be considered for deceased donor families towards funeral arrangements
- the focus should be on spiritual, moral and ethical considerations.

### **Q30: How could the additional costs associated with managing organ donations from deceased people be quantified?**

Twenty-two submissions made a comment on this question, which included measuring costs in terms of ICU beds and staff, numbers of people taken off dialysis, costing methodologies.

Once the methodology around costing of such care is agreed then the costs should be easily derived from the multiple data sources within DHBs and the Ministry of Health.

### **Q31: How well did previous funding arrangements work?**

A couple of submitters commented that the previous funding arrangements did not accurately represent the true marginal costs to hospitals and the removal of that funding was seen as a lack of support for donating.

One commenter said that the previous funding arrangement was cumbersome and inconsistently used across New Zealand. They added that the funding did not reflect the all the ICU costs associated with support of possible donation opportunities.

### **Q32: How can we make sure transplant services continue to have the capacity to transplant donated organs without putting pressure on other services?**

Some submitters commented that transplant services already have capacity issues due to the recent increases in donation, which is putting pressure on other services.

There was also a comment that capacity pressures are also experienced in ICUs and extra beds and staff need to be funded for the purposes of organ donation.

This is extremely challenging. ICUs are, by their nature, variable in demands and expensive resources. Increased expectations for organ donation should be incorporated into funding models for ICU bed numbers and there needs to be additional staff to manage donations when they occur to reduce the burden on standard business of ICUs.

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# Public awareness, media engagement and registers

## Proposals

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

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

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

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

### **Q10: Do you agree with the proposed approach to public awareness and media engagement?**

Thirty-two respondents agreed with the proposed approach, 12 partially agreed, and 13 did not agree.

Submitters commented that encouraging family conversations about organ donation was the most essential part of raising public awareness and understanding. Some respondents commented that 'championing organ donation' with a message or range of information that promoted donation in a positive light was the correct strategy.

Some submissions (18) particularly emphasised a need for establishing a binding consent donor register as a mechanism for raising awareness, as the current driver licence donor registration is not considered to be effective.

While most clinicians agreed that a media and public communications strategy would make approaching families about organ donation easier, some did not support the focus to be through a donor register.

The 'No' responses, and those who partially agreed, reflected concerns that public awareness campaigns hadn't increased donations in the UK, or that such campaigns would be one-sided rather than giving accurate information on the topic from every angle. Many submissions emphasised the importance of portraying accurate and balanced information about organ donation.

Some submitters commented that it was important to ensure that any public awareness initiatives were cultural appropriate.

### **Q33: Do you agree that public awareness activity should be a core responsibility of the national coordinating body?**

Most submissions that responded to this question showed strong support for the national body having this responsibility. Thirty-four respondents agreed, two partially agreed, and two did not agree.

Comments were made that ODNZ provides a good clinical service but is ineffective in public communication. There was support for there being a separate communications role within a national coordinating body.

It is impossible to increase deceased donation rates without an intensive public awareness campaign. This would then mean [...] hospitals [...] would have a reference point for families.

### **Q11: Do you agree with the proposals to improve the driver licence system for recording individual organ donation wishes?**

Twenty-eight respondents agreed with this proposal, six partially agreed, and 21 did not agree.

While many submissions showed support for making improvements to the driver licence register, others suggested removing the driver licence register altogether as it is not currently meaningful. A few respondents (3) showed concern that the driver licence system excludes those who do not drive. Five respondents specifically said that the driver licence should record consent.

Other respondents, predominantly members of the public, showed more support for introducing a separate stand-alone register (19), and 18 suggested a register should be binding.

A few submitters (particularly groups/organisations and individuals in the health system) suggested integrating a donor register into the health system (13). Note that some respondents showed support for multiple options.

### **Q34: What information needs to be provided at organ donation registration to help people make their decision?**

Submissions generally showed strong support for providing accurate information about organ donation at registration to help people make an informed decision about their organ donation wishes.

A couple of respondents suggested applicants be provided mandatory information (ie, reading which has to be covered before answering the question), whereas others considered pamphlets/ brochures about organ donation were sufficient, with a link to further information online. A couple of respondents also added that any information should be culturally and linguistically appropriate.

Many respondents who showed support for the driver licence opt-in system suggested that information should be clear that registration is a record of intent, not consent, and provide clear information about how people can change their mind on the driver licence register if they wish to. A few respondents also added that any information should outline the donation process and what happens, and be clear that people should inform their families about their wishes.

### **Q35: Would it help to give people multiple registration opportunities, as opposed to one collection point?**

Of the submissions that answered this question, 34 agreed, four partially agreed, and 10 did not agree.

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

In addition to driver licence agencies, respondents suggested organ donor registration could be at a range of places, including:

- via a range of online methods (including phone apps)
- by post
- at doctor's surgeries, such as through a nurse, patient portals, and GP registration
- at the gym or sports services
- at the workplace
- with passports
- connected to the blood donor system
- through 0800 number such as Cervical Screening or Immunisation Register.

A couple of submissions added that it would be important to have a central record.

### **Q36: How can we ensure that information recorded about an individual's donation wishes is accessible in clinical settings?**

Some submissions (10) suggested collecting and recording donor information in the health system linked to personal NHI numbers.

The register of intent should be easily accessible within clinical settings. The method by which this is achieved should be considered as part of the overall infrastructure of the reporting system. Ideally appropriate clinicians should be able to search the register as part of the initial assessment of suitability to donate. Any new registry system developed should therefore have full connectivity with existing hospital information systems.

Other comments emphasised that clinicians should be able to access the information through a central database online, or by ringing a number that leads to a single access point where all the information is stored.

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# International cooperation

## Proposals

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

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

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

### **Q12: Are there other opportunities for New Zealand to work with other countries?**

Forty-three respondents answered this question. Most respondents supported New Zealand working with other countries, with particular support for working with Australia. Specific examples of how we could work with Australia included:

- considering how Australia's DonateLIFE project could be adapted for the New Zealand setting
- having representatives from Australia's Organ and Tissue Authority on the national coordinating body
- sharing information about donor intention between countries.