28 July 2016

Deceased Organ Donation Review
Sector and Services Policy
Ministry of Health
PO Box 5013
WELLINGTON 6145
Email: organdonation@moh.govt.nz

Re: Increasing Rates of Deceased Organ Donation: Consultation Document
The New Zealand Society of Anaesthetists (NZSA) welcomes the opportunity to make a submission on the above Ministry of Health Consultation Document.

About the New Zealand Society of Anaesthetists
The NZSA is a professional medical education society established in 1948. It represents over 500 medical anaesthetists in New Zealand and works to foster education and research into anaesthesia, and support the professional interests of its members. Members include specialist anaesthetists in public and private practice, and trainee anaesthetists. The NZSA is a Member Society of the World Federation of Societies of Anaesthesiologists (WFSA).

Overview
The NZSA is strongly supportive of developing a comprehensive national strategy to increase New Zealand’s deceased organ donation rates and believes a multifaceted approach is required, with a particularly strong focus on raising public awareness through an effective media engagement platform. This would help to facilitate conversations within families about individual wishes regarding organ donation, and would help to promote the processes around organ donation and its benefits. Cultural considerations also need to be a major focus of any workable strategy, much more so than is conveyed in the consultation document.

Specific issues

An appropriate legal framework
We believe legislation could be used to require families to be made aware of the deceased person’s wishes (if known) prior to making a decision on donation. This could be conveyed in a form for the family to sign, including the decision to decline a transplant, e.g. “I am aware of the deceased’s wishes in this matter and do not consent to donation.” This form would remove the potential decision staff may have to make on whether to tell family or not when they are clearly against donation. The inclusion of the patient’s wishes may provoke discussion that would otherwise be shut down. While a person can indicate whether they are willing to become a donor on their driver’s licence, they should also be required to nominate or disclose someone
who can indicate intent. The purpose of providing the name of someone who can indicate intent, is that it would prompt the person to have a conversation with this person about organ donation so that when the question is asked it can be said that this person has been nominated as knowing the person’s intent. This named person could also be appointed as their enduring power of attorney (EPA) to have legal authority to provide consent (as is the case for Advanced Care Plans where the individual patient can appoint an EPA to make health care decisions on their behalf when they no longer have the capacity to do so).

These requirements would have the benefit of facilitating a conversation between an individual and their family ahead of time and provide some steps toward eliminating the guilt and/or stress family members deal with when making the decision at a critical time when they are also faced with bereavement. It could also allow family members to better understand the views and feelings of the donor. We agree that the binding consent model is not feasible or advisable. One of the fundamental tenets of consent is that it should always be able to be withdrawn. Ultimately, discussion amongst family members will ideally occur well ahead of time in relation to the wishes of the individual and will break down current barriers to donation at the time of request.

In the experience of many of our members, donation may be declined due to the undue influence of a single family member. Often they are the most vocal opponents to either withdrawing care or declining donation. Anaesthetists/Intensivists have often seen these dynamics play out with the result of no donation. It is important to ask families for their reasons for not agreeing to donation when the deceased has said ‘yes’ on their driver’s licence.

An appropriate ethical framework
Obtaining public input on ethical issues is best achieved through education and interaction. A major area of relevance in New Zealand regarding ethics is differing views based on ethnic background and people’s cultural beliefs. In addressing these issues it is important for members of any ethical committee to be aware of these beliefs and for any strategies aimed at increasing organ donation rates to respect other people’s beliefs while also developing means to overcome barriers to transplantation associated with these beliefs. Therefore, while a national stand-alone committee has its advantages it must engage and seek input from local communities. With the advent of research and development in organ procurement and storage, technology clinicians will encounter more Donation after Circulatory Death (DCD) patients. Increased exposure will go a long way to overcoming clinicians’ ethical issues related to this and we do not view this as a barrier to donation.

A national coordinating body
We believe that it would be appropriate for a national body to sit within a national institution, such as the Ministry of Health, or as a stand-alone body as exists in the UK. It would be essential to remove any question of self-interest. The organisation’s mandate would need to clearly be to increase organ donation rates.

The link between ED and ICU is fraught in many hospitals, and achieving a bed can be difficult. A national body would need to work with EDs to flag these patients, and with ICU to promote a pathway for admission to ICU. Audit is a useful way to highlight poorly performing departments and is used to this effect in the UK, serving as a stimulus for change in departments with poor recruitment. In relation to the clinical governance role of a national coordinating body, Wellington’s model could be implemented in other hospitals, and should be held up as an example.

Specialist training
We agree that specialist training for clinical staff, including anaesthetists, is a critical component of increasing organ donation rates. Currently the course provided by Organ Donation New Zealand is not on the list of
funded courses at most hospitals. While not a complete barrier, this list is used as an indication of which courses are to be completed during training. DHBs could be encouraged to include the course on the list of courses covered for Anaesthesia and ED trainees. We agree with the proposal for this training to incorporate cultural competency.

**Hospital-based clinical organ donation specialists**

We agree with the recommendations for hospital based clinical organ donation specialists. These specialists would be able to manage the organ donation process, while also providing leadership for organ donation at a local level. As proposed in the document these roles would need to be appropriately funded.

**Funding issues**

Transplant recipients in many cases are less expensive to care for than those with organ failure. It is recommended that the Ministry of Health provide a significant proportion of the funding for the costs of transplant systems. The costs of patient care should come out of the usual DHB budgets.

**Public Awareness**

The consultation document recognises that the involvement in organ harvesting is emotionally, ethically, spiritually and even intellectually draining and difficult. It is, for lack of a better word – unnatural, and for some it seems to violate rules and practices around death. Raising public awareness of organ donation, and the issues associated with this, must be a key priority and central component of any national strategy. People find safety in numbers and advertising/campaigns should touch on the human side of organ donation. For many families the organ donation is a great ray of hope and comfort after a tragic event, especially for young patients such as children or young adults who die of trauma or suicide.

As proposed in the consultation document, a media strategy with strong media engagement is fundamental to communicate key messages to raise public awareness of organ donation. We agree with proposals in the consultation but would also recommend that communications utilise the most up-to-date technology and social media platforms. A simple yet very effective tool would be app technology to see the number of donors per area and try and increase this. A strong example of effective use of technology is in the Blood Registry’s campaign to show how donated blood is used, while also showing ways to make it easier to donate.

**Donor Register**

We would support the formation of a national ‘intent register’ which people would be able to sign up to after being provided with more information than what is currently offered through driver licensing, although this would still not fulfil the requirements of informed consent. Additional initiatives for the Government to consider are:

- A campaign to promote the ability for young people to register online.
- A tick box on an individual’s inpatient record (or attached to their NHI) stating that they have had a discussion and are happy to go on the register.
- The capture of all inpatients/outpatients, who are given the opportunity to discuss with a Nurse Specialist the option of signing a register. Or simply provision of information packs similar to smoking cessation, with ward nurses only having to ask if the individual is happy to go on the register. The ward clerk could then update patient NHI with this information.

**International cooperation**

We support a national strategy that includes international best practices that have successfully increased organ donation rates. The shared services that we have with Australia are all positive initiatives, including the range of annual organ donation courses offered for clinical specialists from both countries.
Cultural considerations
The consultation document does not adequately address the specific needs and complexities in relation to Maori and Pacific Peoples' values and beliefs around death, which affect rates of organ donation. Health care professionals must be sensitive to different cultural perspectives and how decisions are made and by whom. Differing beliefs and values need to be upheld and respected. Education and public awareness campaigns alone are not sufficient. Cultural change is required and is a much broader and wider issue than the scope of this document. We need to engage Maori and Pacific Island 'champions' from the roots up. Top down approaches will not work.

Principles from advance care planning
Advance Care Planning: A guide for the New Zealand health care workforce was developed in 2010 by clinicians and healthcare providers. It ensures that individuals are able to decide on their future treatment and care so that these are aligned to their personal preferences, values and beliefs. This information is recorded ahead of time, while the individual is competent to do so. The advanced care plan can be provided to the family if the individual agrees. It has the benefit of facilitating discussion with the family about an individual's wishes and preferences before the time when they have lost capacity to express their wishes.

While the advanced care plan is legally binding, and we are not proposing this for organ donation, there are aspects of advanced life plans that could be included in a national strategy for organ donation including appointing a person to advocate on your behalf when you are unable to i.e. as your enduring power of attorney. Ultimately, the Advance Care Planning process can provide a strong platform to initiate conversations between individuals and their families and enables a strong understanding of an individual’s future healthcare wishes.

Thank you for the opportunity to make a written submission on this consultation. I am happy to discuss this submission further and can be contacted at president@anaesthesia.org.nz.

Yours sincerely

Dr David Kibblewhite
President