Submission Number 40.

Received from Mr Steven Nailer, Chair of the Australasian Tissue and Bioptherapeutics Forum and member of the Cognate Committee on Organ and Tissue Donation and Transplantation, Department of Health and Ageing.

Submission in response to the Review of Organ and Tissue Donation Procedures Select Committee's issues paper by the tissue representative on the Cognate Committee on Organ and Tissue Donation and Transplantation

Issues for comment

- *What requirements for consent to organ and tissue donation should apply? If possible, please outline your reasons.*
- *Should the role of next of kin or family be different if a person has given written consent to organ and tissue donation?*
- *What is the best way to use a donor register in connection with consent when donation is being considered?*
- *Do you support introduction of an opt-out or presumed consent system?*
- *What reasons do you have for supporting or not supporting an opt-out or presumed consent system?*
- *What role should a deceased person's family or next of kin have in consent to organ and tissue donation?*

The current requirements for consent are adequate for donation. However, a holistic approach needs to be undertaken. Organ and tissue donation for transplantation is only a small area in the overall end of life care and options available to families. Until a systematic team approach is taken and where all options available to families are openly discussed then I believe only relatively small increases to the donation rate will be achieved.

It is my opinion the role of the next of kin should not change in a presumed consent role but the role of the clinicians and coordinators in their approach to the family will be enhanced if written consent has already be granted.

The AODR should be utilized as this will ensure a more positive approach to the next of kin when the wishes of the deceased are known. If the clinical staff considers this to be a conflict of interest then a designated coordinator should access the AODR prior to a team approach to the family

If an opt out system was to be considered it would have to happen in all jurisdictions to ensure conformity and at this stage I consider it would confuse the issue of donation with the community more than it would help. While an opt out system takes advantage of an apathetic population the ramifications of a possible community backlash must be considered. I do not consider an opt out system to be a silver bullet to fix the problems associated with donor rates and until all jurisdiction have standard legislation framework regarding this issue I would not consider it plausible. For the reasons above I do not support an opt out system at this time.

The role of the family in consent for donation should be used by all donation programs within each hospital, used as a community guide to the programs in place and should be used to effect changes in order to facilitate improvements in donations rates. For this reason I believe the families play an important role and even when consent is not obtained something can be learnt to improve practices which can then lead to a cultural shift within a local community to allow donation to become the norm.

Issues for comment

- *If a presumed consent system was to be introduced, what mechanisms should be introduced for people to opt-out?*
- *How could simple and reliable access to an opt-out mechanism be ensured?*
- *If presumed consent was introduced, should the family be asked if they object to organ donation if the deceased person has not opted out of donation?*
- *Should children and people with impaired decision making capacity be part of a presumed consent system?*
- *Should particular categories of people be automatically excluded and not presumed to consent to donation?*
- *When should children be able to opt-out of presumed consent?*
- *What support would be required for clinical staff if a presumed consent system was introduced?*

If opt out were to be introduced the AODR would appear to be an appropriate mechanism for opting out. However, the AODR being administered by Medicare Australia under the Commonwealth makes it impossible for any single jurisdiction to control and therefore ensuring a simple mechanism to opt out where the data is current and correct would be a decided disadvantage. Therefore, a jurisdiction in a going alone undertaking of a presumed consent policy would need to maintain its own mechanism. This may be a state based information system for this specific purpose. This would need easy access for the community with multiple entry points to register the individual's wish and would also require security of the data ensuring only those authorised to view the data could do so. Any mechanism put in place should only apply to those residents of that jurisdiction.

A simple and reliable access to opt out would require enormous resources that would be better used in ensuring other systems are in place to facilitate donation.

If an opt out system was implemented the Spanish model should be used and adopted where families are approached.

Those with impaired decision making capacity and children should not be considered to be part of presumed consent process and next of kin should take the decision making role.

Whatever age children would be able to opt out should be consistent in all jurisdictions to ensure conformity.

I could not see clinical staff supporting presumed consent system without family consultation and therefore there needs to be a support system to allow these clinicians to perform their role. There would also need to be clear demarcation of the clinical treatment and donor coordination roles and support to ensure good communication between the groups would go along way in supporting the system.

Issues for comment

- *What safeguards and limitations should apply to a presumed consent system?*
- *Are there specific religious or cultural issues that should be addressed in consent to donation or organs and tissue?*

If a presumed consent system was to apply there would need to be systems in place to ensure the accuracy of the data and that the most recent decision was accessed by the donation coordinating team. The system would need to be available to all those who reside in that jurisdiction including remote areas not currently cover for this type of service. If this were to become policy then a safeguard may include the requirement to ensure families are aware of the processes to follow including a discussion to ensure no objection has been raised by the deceased prior to their passing.

There are many cultural and religious issues associated with organ and tissue donation but most religions support the family's decision whatever that may be and cultural influences of the Aboriginal and Torres Strait islanders must be explored specific for this issue.

Issues for comment

- *If an opt-out or presumed consent system is introduced, should it apply only to transplantation to another person, or also to other purposes such as research?*
- *In an opt-out or presumed consent system, should it be possible to opt-out of donating for one purpose, but continue with presumed consent for another purpose?*

The process for procuring tissue for research follows the same procurement protocols as for organ and tissue for transplantation and perhaps the Select Committee should also consider the autopsy consenting protocols at the same time. All tissues require a similar consenting mechanism and therefore should be considered under the same opt out protocols. The NHMRC suggests that a single approach should be made to the family although this rarely occurs when autopsies are thrown into the mix. A consenting process should be uniform for all options available including autopsy, research tissues, and the bequeathal of whole body to medical science or for transplantation purposes.

Opting out must be specific for the purpose and tissues being procured therefore each individual organ and tissue type must be specified as well as the individuals wishes for the use of the organs and tissues procured. Eyes and heart tissues are emotive for some segments of the community and while one individual may want to donate all organs and tissues others may wish to specify what they donate.

Issues for comment

- *If an opt-out or presumed consent is not introduced, is the current system of consent appropriate?*
- *Are there changes you consider should be made to the decision-making or consent system?*

The current legislative instruments are sufficient to ensure an ethically appropriate system is used. The system should be a team approach ensuring those involved are supported. Burnout of clinical staff should be considered in any consenting system.

Areas which could be explored include next of kin options ensuring national standardisation and who should provide the role of designated officer. The designated officer should have mandatory training and education prior to filling the role. They should have an understanding of all aspects of the role as it pertains to the Transplantation & Anatomy Act and ensure the consenting protocols are adhered.

Issues for comment

- *What action should be taken to improve organ and tissue donation in Queensland?*
- *Are there particular hospital-based strategies that should be considered in Queensland to improve organ donation rates?*
- *Should any incentives be offered to potential donors for organ and tissue donation?*
- *What are your main reasons for supporting or opposing incentives? If you support incentives, what type of incentives do you consider may be appropriate?*
- *What action should be taken to promote better public awareness of organ and tissue donation?*

The one thing all hospitals do well is look after patients while they are alive, what they do poorly is care for the deceased. To increase organ and tissue donation the taboos surrounding this must be removed to enable an open discussion between families and clinicians alike. Clinical education on end of life options must be a priority area to be addressed with consideration of a team approach when caring for the deceased and their families.

As for incentives this is an ethical question which is difficult to answer. I believe the altruism of donation should be protected and nurtured to include those outside of the donation spectrum in much the same manner as research foundation has.
If incentives were to be introduced it should be for a living donor's out of pocket expenses including medical treatment and no further.

I would support any system that standardised the process of donation and removed the taboos associated with the discussions surrounding end of life care including all options available to families after the passing of a family member. A single jurisdiction changing its legislation to a presumed consent process would not be helpful in standardising protocols and unless all jurisdictions took up this legislation perhaps under the National Law Reform Agenda the resources required to ensure this type of consent system meets ethical guidelines and has a positive impact on the community would be prohibitively expensive.

Public awareness needs to be conducted in a sustained manner with a national consistent message by all stakeholders. However there is a requirement for education of clinical staff to gain a cultural shift to facilitate the sufficient facts are given to the general community as ill informed clinical staff can do more harm than good.

This must be considered a personal submission from me being the representative of the tissue sector on the Cognate Committee. Gaining consensus on this issue would be impossible as many differing views could be gathered from Australasian Tissue and Biotherapeutics Forum members. The thoughts above represent my many years of experience in dealing with families and clinical staff and I believe if a holistic systematic team approach was supported that it would have a considerable effect on donation rates.

From the National Organ Donor Summit held in Adelaide in July this year and from the mouth of the Spanish speaker, it is the recognition and requesting of donors which puts Spain as a world leader in donation rates. The fact that Spain has an opt out policy is of little consequence.