

Review of Organ and Tissue Donation Procedure Select Committee

Issues Paper July 2008

Response Submission from Donor Coordinators, Queenslanders Donate, describing their opinions as private citizens who are health professionals and does not necessarily reflect the opinions of Queensland Health.

*This submission is being presented **NOT** taking into account the recent Federal national reform package announcement - \$136 million for "A World's Best Practice Approach to Organ and Tissue Donation for Australia" and the national changes that the authority will most certainly be introducing in 2009.*

Introduction of Presumed Consent or Opt-out for organ and tissue donation in Queensland

Firstly, the success of introducing a presumed / opt-out consent system relies entirely on strong majority support by the community to such a radical change. There is no published evidence that the majority of Queenslanders are asking for, or are indeed ready for a system of presumed consent. Anecdotal evidence suggests that if the ability to choose is taken away then an opposite reaction can occur. Organ and tissue donation is a personal choice as an end of life decision. A successful change to a presumed consent system should be community driven.

In theory a presumed consent system may be appealing as it uses public lethargy to work for the donation register and only the highly motivated will actively register a "no". There are however ethical issues with this concept of exploiting an apathetic society when the freedom of choice is lost by inaction.

It is important to note that research indicates that Registers do not always increase donor rates as exemplified by the article "Opt-out systems: no guarantee for high donation rates." Coppen, R., Friele, R., Marquet, R., and Gevers, S. (Transplant International **18** (2005) 1275-1279.)

"... the donor efficiency rate shows that opting-out systems do not automatically guarantee higher donation rates ..."

Secondly and most importantly, the decision to change to an opt-out system **should be a national system change**. We would not recommend that Queensland stand alone from the rest of Australia with the introduction of a state based consent system. If implemented, presumed consent / opt-out would have to be a national system based on strong majority community support across Australia with accurate and comprehensive community awareness and education programs.

In the UK, Prime Minister Gordon Brown is currently calling for national debate on whether to change to an opt-out system. The British Medical Association has

conducted surveys which find that there is growing support in the population for a change to presumed consent.

Therefore it is vital that prior to any introduction of an opt-out system for Australia, the following would need to occur:

- National debate
- National survey/referendum
- Large community education/awareness programs providing information to the Australian community on both organ and tissue donation and the implications of an presumed consent / opt-out system to enable informed debate and decision making

However, regardless of the consent system in place, the family should always remain central to the donation process and that a "soft" option would always be used. That is, if the family, following an interview with the Donor Coordinator/Intensivist and having all the correct information regarding the donation process, does not wish to proceed then donation would not go ahead.

To proceed against a family wish would risk extreme negative publicity and a loss of confidence in the donation process which could in turn cause a decrease in donation rates.

If a presumed consent / opt-out system is not introduced, then the current system of consent within Queensland is appropriate and change to clinical practice is not required.

Other Options to Improve Organ and Tissue Donation in Queensland

Public awareness strategies

- **A contemporary website:** current Queensland Health restrictions on development and style of websites limits the ability to create an interactive and engaging contemporary website that will grab and hold the attention of the public. Compared to other interstate government organ and tissue websites Queensland Health's official site is lacking due to these restrictions
- **Consistent and ongoing social marketing campaigns:** Neither Queensland or Australia is yet to have an effective prime time media campaign that ensures organ and tissue donation remains on the community agenda. The issue of organ and tissue donation and community awareness/education needs to be addressed in the same manner that the anti-smoking, speeding and drink driving campaigns have been supported. Lines such as "If you drink and drive you're a bloody idiot" have been embedded in the community psyche. One of the most effective national public health campaigns was the HIV/AIDS grim reaper commercials in the 1980's which was a large contributing factor to the low infection rates in Australia compared to international figures and the high community awareness. This level of campaign is what is required to produce the generational change and heightened community awareness of organ and tissue donation and

transplantation needed to improve donation rates. Increasing community awareness through effective prime time media campaigns will lead to the increase in families volunteering organ and tissue donation and instigating the discussion with the medical staff. As Donor Coordinators we know that when a family volunteers donation, potential donors are not missed due to either the option not being raised by medical staff or treatment being withdrawn prior to brain death testing. Medical staff have a clear indication of the patients and families wish and the possibility of donation is then explored.

- Continual research is required to ensure the development of accurate and effective awareness/media campaigns.
- **Ongoing support and funding for school education and awareness programs:** Currently Queenslanders Donate and Queensland Education are working in partnership (Commonwealth funded pilot program) developing units of work focussing on organ and tissue donation and transplantation appropriate for inclusion within Senior Health Education. Much work has been done by both parties and the units of work are currently being trialled in a number of high schools. The program has been received enthusiastically at this point with the aim for generational change and the long-term affect of donation being accepted as a normal end-of-life decision within the Australian community.
- **Ongoing support and funding for General Practitioners and General Practice Nurses education:** Queenslanders Donate received Commonwealth funding in 2007 to develop education recourses for General Practitioners and General Practice Nurses throughout Australia. Following consultation with RACGP and the Divisions of GP Practice and other organisations involved in education of general practice staff the staff of Queenslanders Donate engaged the services of Med-E-Serv and together are developing an on line education resource which meets the requirements for GP education points.
- Engage tertiary education sector to include organ and tissue donation for undergraduate and post graduate medical, nursing and allied health courses
- Multiple avenues for AODR registrations
- Workplace partnerships

Hospital based strategies

It is widely recognised that a major impediment to the operation of our intensive care units is a distinct lack of skilled ICU clinicians, especially nursing staff. ICU bed shortages also pose major problems and pressures. Until intensive care units are adequately resourced to care for the living, caring for the dead will not be a priority (despite transplantation being a cost effective treatment). There are no simple, easy, quick or cheap solutions to this situation of under-resourcing but it underpins everything else, including improving organ and tissue donation in Queensland.

The three major factors which influence the donation rate are

- Identification rate: the percent of medically suitable organ donors identified by hospital staff;
- Request rate: the percent of families that were asked to donate; and
- Consent rate: the percent of families that consented to donation.

With regard to the identification rate, collecting and reporting performance data is currently limited to 11 Queensland Health hospitals. There are approximately 30 hospitals state-wide with donation potential (albeit very small in some facilities). In our 4 biggest hospitals which regularly refer donors and therefore have experience, identification and consent rates are relatively high with identification rates ranging at 88 -92% and consent rates at 60 - 70% (2007 - 2005). The introduction of standard clinical triggers and referral guidelines/pathways to ensure that all potential donors are identified may improve identification in the hospitals with less experience. However, we do not know our true donor potential in Queensland as there are no current standards of donation performance across all hospitals.

Early notification of a potential donor and the introduction of a Donor Coordinator as a designated requester early in the donation discussion with family (especially if the subject is raised by the family) maybe helpful in increasing consent rates. 'Long contact models' – extended time with the family by the coordinator (as used in the USA) have been shown to increase consent rates.

Continuing support and education to medical and nursing staff in ICU and DEM is vital. The national ADAPT program is a recognised resource for staff and is mandatory for training intensive care clinicians and recommended for nursing staff. Further incentives and support for nursing staff to attend ADAPT workshops could be beneficial.

Incentives

Incentives to donate organs and tissues for donation should not be considered. Donation is an altruistic gift and should be given freely with no thought of reward.

The potential for the donation to be influenced by an incentive is a step towards the illegal trading in organs and tissues. The current legislation and clinical practice keeps donation and transplantation risk-free of manipulation and it also is reassuring to the general public that it cannot be abused to profit any individual.

Anecdotal experience in the UK shows that many transplant recipients state that a donated organ is more easily accepted because they know it has been positively given by the deceased as opposed to donation by default.