



NB/pjc/tw
15 August 2008

Ms Sue Cawcutt
Research Director
Review of Organ and Tissue Donation Procedures Select Committee
Parliament of Queensland
Corner George and Alice Streets
BRISBANE QLD 4000

Dear Ms Cawcutt

Re: Submission to the Parliamentary Select Committee Review of Organ and Tissue Donation Procedures

I write in response to your Issues Paper dated July 2008 inviting public comment on matters within the terms of reference of this Review.

The Australian Red Cross Blood Service (ARCBS) commends the Queensland Government for their comprehensive analysis of the current organ donation and transplantation situation in Australia and for the opportunity to make submissions to the Select Committee's Review into the sector.

ARCBS, through LifeGift NSW/ACT and LifeGift Victoria, provides a range of Organ Donation services to these communities in keeping with its mission as a third sector organisation. These services include the co-ordination and case management of individual donation events, bereavement services and the provision of relevant education to healthcare professionals and community groups. The success of such organ donation programs is absolutely dependent on the maintenance of community trust.

The ARCBS has been involved in organ donation for more than 30 years and performs nearly 60% of all retrievals in Australia. ARCBS supports the major new national reform package as recently announced by the Federal Government to establish Australia as a world leader in organ donation for transplantation. This initiative was subsequently endorsed by all States and territories at the COAG meeting on 3 July 2008.

It is in that context that I provide this input into the Select Committee review for consideration by the Honourable Members of the Committee. I will provide my comments in line with the Terms of Reference provided with your Issues Paper:

Terms of Reference 1 – Should Queensland introduce a system of Presumed Consent for Organ and Tissue Donation?

The ARCBS position on Presumed Consent is that currently there is no compelling need to resort to a unilateral adoption of such a system without first seeking to optimise the current system across Australia.

Several research studies in the past decade have confirmed that between 94 and 100% of Australians will respect the known wishes of their family members regarding organ donation. Even amongst those who are not personally in favour of organ donation, 94% report that they would support the known wish of family members to donate.

If the wishes of a loved one are unknown, the likelihood of family support for donation drops dramatically. Of those next-of-kin who are personally in favour of organ donation 80% report that they would support donation by a deceased family member even if they did not know their wishes. But only 48% of those who are not personally intending to donate organs report a willingness to support donation by a family member if they do not know that that was their wish.

Fully 50% of Australians do not know the intentions of their loved ones regarding organ and tissue donation. The reality is that in any Australian hospital organ donation will not occur in the absence of family support for donation. This gap in knowledge of the wishes of our loved ones regarding deceased organ and tissue donation must be addressed if we are to optimise our nation's donation performance.

Any future Australian investment in programs targeting the general public must go beyond the traditional focus on "awareness" and "understanding" of organ transplantation and the consequent need for organ donation. We must instead directly address the social behavioural changes needed to optimise organ donation performance.

We should treat our lower than desired organ donation performance as a typical Public Health issue. We wish to see a change in a health-related behaviour. We wish to see a system where whenever anyone dies in circumstances where organ donation is possible, their wishes regarding donation are known, these wishes are enabled by our healthcare systems and are supported by the family of the potential donor.

If this were to happen we believe that we can achieve donation rates nationally of 20 donors per million population. This does not require a system of Presumed Consent.

In the context of the national reform agenda, the Queensland Government could make a major contribution by offering to host a national public forum to fully explore the socio-cultural acceptability of a system of Presumed Consent for organ donation by the Australian community.

Members of the Queensland community are able to register a legally valid consent to become an organ or tissue donor using the Australian Organ Donor Register. This requires completion of an AODR registration form. These forms are available at all Medicare Australia offices and most retail pharmacies and can be mailed out to individuals in response to telephone, e-mail or internet requests.

All citizens also receive a copy of this AODR registration form and a related explanatory brochure at the time of renewal of their Medicare card.

Following lengthy deliberations Medicare Australia decided that there was a legal requirement for individuals to sign a registration form, thus precluding use of some potentially simpler means of registering consent (such as direct internet enrolment or use of SMS messaging). We recommend that the Queensland Government consider introducing an on-line AODR registration process if electronic recording of consent alone satisfies Queensland legal requirements. This would be in line with the recommendation of the National Clinical Taskforce. In addition the Queensland Government through its departments that have a high level of public contact could promote the AODR and make registration forms freely available to the community.

Terms of Reference 2 – Additional options that should also be considered to increase public awareness and the organ donation rate in Queensland.

Organ Donor rates reflect the cumulative effects of:

- The number of deaths occurring where donation is medically feasible.
- The ability of the healthcare system to identify and manage these potential donors (and their families) and
- The willingness of individuals and their families to support donation.

Clearly we only wish to improve organ donation performance by improving the outcomes in the second and third of these inter-related processes.

We also believe that individual Australians who wish to donate organs and tissues, should this be medically possible at the time of their deaths, should have access to appropriate organ donation services as an integral component of high quality end-of-life care. This "right" of access to donation services is perhaps not always recognised by some that fund, manage and deliver healthcare.

Some of the possible reasons for relatively low donation rates in Australia, from the perspective of the organ donation sector, that may be amenable to intervention include:

- identification of potential donors in hospital;
- hospitals not requesting donation at time of death;
- coordination of donation procedures in hospital;
- personal discomfort at planning something associated with death; and
- non-consent from a potential donor's family at the time of death.

We can only manage and improve performance of any system when we have access to meaningful and comparable measures of current system performance and an understanding of preferred levels of performance.

The adequacy of identification of potential donors can only be addressed by a formal audit of deaths occurring where donation may have been possible, using a national standardised methodology, as per the ANZICS pilot project proposal in the recommendations of the National Clinical Taskforce (p. 219). We are aware that in Queensland a modified audit instrument has been in use for some time.

We would encourage the Queensland Government to champion the adoption of a standardised national audit instrument across its major hospitals and intensive care units so that Intensive Care specialists engaged in the care of potential organ donors in Queensland could implement such audits as a routine part of monitoring the quality of this aspect of acute hospital care.

We would also recommend the participation by major Queensland hospitals in the national Breakthrough Collaborative on Organ Donation, currently being coordinated by the National Institute of Clinical Studies. This Commonwealth funded program has the potential to significantly impact the way we administer organ donation programs in Australian hospitals through this learning methodology.

Currently there are consultants working for the Commonwealth Department of Health and Ageing who have recommended a national communications program to enhance organ donation performance, based on commissioned social marketing research and analysis.

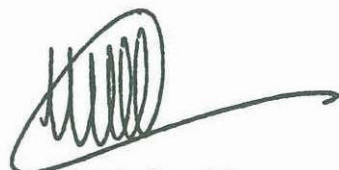
We recommend that the Queensland Government supports further socio-cultural research by credible researchers to better understand the psychosocial dynamics underpinning the decision to donate or not, and the development of appropriate social marketing messages based on that research. This will also help to eliminate public confusion and provide strong, simple and consistent messages to the general public.

In conclusion we thank the Select Committee for the opportunity to participate in this process and urge the Honourable Members to seek an appropriate leadership role for Queensland in the new National Reform Package on Organ and Tissue Donation for Transplantation.

Yours sincerely,



Robert Hetzel
Chief Executive Officer



Dr Patrick Coghlan
Manager,
National Transplantation Services

Presumed Consent:

Queensland Parliamentary Select Committee Terms of Reference

The Select Committee is required to investigate and report on the following issues:

1(a) Given the relatively low organ and tissue donation rates in Queensland, should a system of presumed consent or 'opt-out' for organ and tissue donation be introduced in Queensland?

1(b) If so,

- should presumed consent for removal of organs and tissue:
 - (i) be absolute, or should further recourse be required to the wishes of relatives and/or legal guardians in this decision?
 - (ii) apply to all persons, specifically considering the age, decision making capacity, cultural and religious beliefs of the person? If not, what exemptions and safeguards should apply?
 - (iii) allow these organs and tissue to be used for other purposes such as research?
- what mechanisms should be put in place to enable persons to explicitly register their objection to their organs and tissue being removed?
- what would be the implications, including financial implications, of introducing a system of presumed consent for organ and tissue donation on the operation of all existing legislative, administrative and governance frameworks, including in other jurisdictions?
- what, if any, other matters should be considered in the regulation of this issue?

2. In addition to the issue of presumed consent for removal of organs and tissue, are there any additional options that should also be considered to increase public awareness of and improve the organ and tissue donation rate in Queensland?