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ISSUES PAPER RESPONSE

AS PART OF THE

**REVIEW OF ORGAN AND TISSUE
DONATION PROCEDURES SELECT
COMMITTEE**

BY

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INTRODUCTION

The following document outlines my responses as Regional Donor Coordinator at Rockhampton Hospital to the Issues Paper published as part of the Review of Organ and Tissue Donation Procedures Select Committee.

Part of my role as Donor Coordinator involves community engagement, from high school age to senior citizens discussing all aspects of donation including:

- the importance of family discussion
- the process of registration with the AODR
- organ and tissue donation procedures
- care of the family
- access to information in the general community
- how to promote awareness

TERMS OF REFERENCE

Item 1

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?*

RESPONSES

1. Presumed Consent?

From my experience working in the sector as a Regional Donor Coordinator, and performing community education with various groups in the Central Queensland area for the last 8 years, my recommendation to the Select Committee is to avoid changing legislation to introduce an 'opt out' system.

Queenslanders, like all Australians embrace the concept of choice. It has been expressed to me on numerous occasions that *"there is not much choice left on things these days"*. Donation of organs and tissues is still viewed by the general community as one of a *"gift"* to be embraced by those lucky enough to receive it.

The simple fact is we need to increase public awareness to convert the *"I'm not sure"* population, into the *"yes, we have talked about and we would like to donate"* population. This will only be achieved through a coordinated approach by government and health care agencies, as well as a concrete public awareness campaign which target all sectors of the community and is a recognised commodity in the advertising world.

In the current climate within Queensland Health, with the introduction of an 'opt out' system, if an individual does not register an objection and the subsequent organ donation takes place without discussion with the family, inevitably this will lead to unnecessary distress to their relatives and widespread adverse publicity.

Experience in the UK maintains that many transplant recipients add 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.

Opt-out systems have been described as "hard", as in Austria, where the views of close relatives are not taken into account, or "soft", as in Spain, where relatives' views are sought.

Different cultural attitudes to organ and tissue donation, the availability of intensive care beds, more pro-active donation programs, improved medical management of patients and the numbers of road deaths, each influence the rate of donors per million population (DPMP). The DPMP is a gauge commonly used to compare countries without consideration of the variations in legislation and type of donation, i.e. cadaveric and donation after cardiac death (DCD). However, the single most important factor so far identified in 'actualising' the potential donor is ensuring that the relatives of potential organ donors are always approached, and approached by someone specifically trained for the purpose, as happens in Spain.

Other concerns surround the potential medical risks involved in removing organs without full discussion with relatives. Families are a valuable source of information about their loved one's previous health and relatives are questioned as part of the screening process.

If an individual does not register an objection, it is possible that their silence may indicate a lack of understanding rather than agreement with the policy. It is because of these concerns that in the majority of countries operating an opt-out system, health care professionals still consult the family to establish consent.

In Queensland, regardless of the system in place, i.e. whether a person signs their consent or not (as exists currently with the AODR) or is assumed as a donor unless they sign an opt out agreement, families will still be consulted to offer their "endorsement" or "consent" of the process if there is no prior objection by the deceased. This is in line with best practice in offering the highest standard of health care in Queensland both ethically and provisionally.

As a designated requestor at the Rockhampton District Health Service, I will always offer the option of organ or tissue donation to families of eligible donors as a matter of professional obligation. I believe a system of opt out could be very damaging to the organ donation program we have worked so hard to build, if families are not consulted.

A policy of "required request" or "required referral" is operated in the United States of America. Required referral is defined "that it shall be illegal, as well as irresponsible and immoral to disconnect a ventilator from an individual who is declared dead following brain stem testing without first making

proper enquiry as to the possibility of that individual's tissues and organs being used for the purposes of transplantation".

The policy means opportunities for donation are less likely to be overlooked. Many individuals may be having their right to donate removed if their relatives are not approached. The next of kin also has a moral and legal right to know they can donate organs and tissue if they or the family so wish. Many families report that such a donation was helpful rather than harmful.

This type of approach would be required to be directed as a top down policy decision within Queensland Health. It would concur with the ANZICS guidelines for Intensive Care clinicians which states:

It is the perception of the Australian and New Zealand Intensive Care Society (ANZICS) that intensive care specialists have the ultimate responsibility to provide checks and balances in the drive for organ retrieval. Left unchecked, such a drive might become not only counter-productive, but even destructive to organ transplant programs and also pose a threat to the care of critically ill patients and their family members. The role to be played by intensive care specialists will be crucial in maintaining organ donation as a function of the doctor-patient relationship where ethical and moral values rather than legal or administrative instructions dictate our behaviour. For example, although the law states that the individual can make a decision to donate organs, the law does not require that we, as the professionals caring for the patient, have an obligation to confirm brain death, or having done so, that we must actually search for, or even act upon a donor card that has been found. Unless laws are created to make us do the above, the only people who can actually make anything happen will be, by and large, intensive care specialists. Laws such as "required inquiry or request" now exist in the majority of states of the United States and will soon become federal legislation in that country. Systems based upon "opting out" are frequently discussed. Few of us would want such laws imposed upon us.

As there is no legislation or policy directive from the Queensland Government regarding compulsory testing of individuals who exhibit the clinical signs of brain death, and also no directive on follow-up approach of the family, many ICU clinicians avoid the task, and potential for donation is lost.

From my experience in the sector, both as a bedside clinical nurse in Intensive Care and Regional Organ Donor Coordinator, to spend a significant amount of time, energy and public finances changing a system such as this with no actual change to practice, (i.e. still consulting families) would be both a waste of time and money which would be better spent on public awareness campaigns.

As a bedside clinician in critical care working under financial strain in the health system, I would fully support and work to promote the strategies I have outlined further in this response paper.

2. Mechanisms which should be put in place to enable persons to explicitly register their objection to their organs and tissue being removed:

2.1. Provide multiple avenues for AODR registration (which includes a desire NOT to donate) including at:

- General Practitioner (could be added to the practice incentive program as it is for childhood immunisation)
- Chemist outlets
- Centrelink (when applying for a health / pension card)
- Post Offices (all passport applications)
- Community and Family Health Centres
- Occupation Health Nurse clinics
- Major Health Funds
- Queensland Law Society members

3. Other considerations:

3.1. Update the Transplantation and Anatomy Act (1979).

3.2. Development of a state-wide guideline for both ***mandatory brain death testing*** of patients who demonstrate clinical signs of brain death (using a clinical trigger) and ***mandatory requesting of organ and tissue*** by a ***designated (and trained) requestor***.

3.3. Support for an annual State Based Forum to engage clinicians as champions from across the State to promote awareness from within Queensland Health facilities as part of a wider strategy of community engagement (see point 5 below for further discussion).

Item 2

In addition to the issues of presumed consent for removal of organs and tissues, 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?

Response:

The following additional factors could be considered by the Select Committee as part of the strategy to increase public awareness of and improve the organ and tissue donation rate in Queensland. Increasing knowledge within the general community is not exclusive to simply “public education” but rather should include empowering the clinician in order to facilitate a top down approach to awareness.

1. General Public Awareness Campaigns:

1.1. TV/Radio/news/general advertising on a regular basis.

- Engaging a media personality or celebrity as a recognised entity.
- Need to engage all major media outlets including TV (Ten Network, Channel Nine, Seven, SBS and ABC; investigate option of Pay TV circuit)
- Major Newspapers through APN Media etc.

1.2. All of sector involvement in the Australian Organ Donor Awareness Week using a nationally coordinated strategy including:

- A newsletter to ALL health care workers involved in the promotion, including all those employed by State Based Agencies to stay informed of the AODAW communication strategy
- Newsletter promotion articles for public and private sector organisations coordinated from the State Communications Manager. Organisations can included (but is by no means limited to) Queensland Health, Ergon Energy, all major universities, TAFE Qld, Centrelink, QR National, mining corporations, health insurance funds, all the major banks and building societies, pharmaceutical companies, APN Newspapers and their associates and Education Queensland.
- Pay slip messaging to all the above organisations

1.3. Establishing a workplace partnerships program with the above organisations to provide regular promotion and education (guest speaking) opportunities, newsletter articles and other opportunities which may arise. To make this work, an internal champion needs to be identified to ensure that opportunities are identified or created and acted upon.

2. Provide multiple avenues for AODR registration including at:

- General Practitioner (could be added to the practice incentive program as it is for childhood immunisation)

- Chemist outlets
- Centrelink
- Post Offices
- Community and Family Health Centres
- Occupation Health Nurse clinics
- Major Health Funds
- Queensland Law Society members
- Petrol stations (Caltex, Shell, BP, Woolworths/Coles)
- Universities/ TAFE
- Government transport departments ed Qld Transport

3. Revitalise the National Schools Education Program to increase awareness and registrations among teenagers about to enter the workforce.

- Continue or resurrect the Life Education Program in Queensland to visit schools and promote healthy lifestyle options which would include organ and tissue donation
- Negotiate with Education Queensland to integrate the Sign on to Save a Life campaign into the Grade 11 curriculum by way of inclusion in subject matter and/or promotion during the lead up to schoolies week.
- Expand current syllabus development being undertaken in QLD Health Education curriculum, and implement into other subjects – i.e. biology, pastoral care,

4. Integration of programs across ALL areas of health care and regular points of customer service:

4.1. Specific education programs /modules/booklets focussing on individual needs of each organisation. For example General Practitioners and GP Nurses which is currently being undertaken through DOHA). Others could include:

- Pharmaceutical network including Chemist outlets
- Centrelink
- Community and Family Health Centres
- Occupation Health Nurse clinics
- Major Health Funds
- Queensland Law Society members
- Post Offices

4.2. Development of a state-wide clinical network (as an adjunct to the ICU network) which will link regional coordinators and hospital champions on a formal network.

- Enabling projects to be undertaken
- Standardise processes and education of clinicians across Queensland through the development of an Organ and Tissue donation collaborative

5. Support for an annual State Based Forum to engage clinicians as champions from across the State to promote awareness from within Queensland Health facilities as part of a wider strategy of community engagement.

5.1. Provide the opportunity to all major hospitals in the state to contribute to the forum in order to facilitate:

- Networking for clinicians involved in the process in order to maintain currency of practice through professional development opportunities including:
 - Identifying challenges and opportunities for clinicians in the process of organ and tissue donation and the community engagement
 - Clinical education – providing updates in practice on Organ and Tissue donation in Australia
 - Opportunity to develop or review resources including clinical guidelines, clinical trigger tools and education modules
- Forum participants should include:
 - Queenslanders Donate Staff, including all Regional Organ Donor Coordinators and Medical Donor Advisors
 - Representatives from each of the major ICUs across Queensland including an intensive care specialist and clinical nurse
 - Representative from the ICU and dialysis Clinical Nurse Educators Network in Queensland
 - At least one Designated Officer from each Regional Coordinator Hospital

6. Engage the tertiary education sector to include organ and tissue donation education for both undergraduate and post graduate medical, nursing and allied health courses.

6.1. Including other RTA's such as ADAPT to offer more accessible modules, i.e. online education and advanced courses for previous participants.

6.2. Include in programs such as health administration and public health to expose health managers to the key issues.

OTHER OPPORTUNITIES

- 1.1. Update the Transplantation and Anatomy Act (1979).
- 1.2. Development of a state-wide guideline for both ***mandatory brain death testing*** of patients who demonstrate clinical signs of brain death (using a clinical trigger) and ***mandatory requesting of organ and tissue*** by a ***designated (and trained) requestor***.
- 1.3. Support for an annual State Based Forum to engage clinicians as champions from across the State to promote awareness from within Queensland Health facilities as part of a wider strategy of community engagement (see point 5 above for further discussion).
- 1.4. Examine the possibility of organ and tissue donation being added as an indicator to the ACHS Guidelines and Funding models.
 - Option for hospitals to attract funding for providing a service of organ and tissue donation
 - Develop a DRG for management of the organ and tissue donor within the ICU
 - Add donor management to Patient Nurse Dependency systems such as TREND CARE to normalise the process in the ICU
- 1.5. Introduce Organ and Tissue Donation online module via CDES as Mandatory Training for Queensland Health employees
 - As is currently for Code of Conduct
 - Currently being developed
 - Can be completed online