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Queensland Health Submission to the Review of Organ and Tissue Donation Procedures Select Committee

Queensland Health is fully supportive of the Review of Organ and Tissue Donation Procedures Select Committee and their determination to maximise the rate of organ and tissue donation for transplantation in Queensland. This submission has been developed in consultation with Queenslanders Donate, key clinical stakeholders involved in organ and tissue donation and transplantation, the Queensland based tissue banks, and with experts in organ and tissue donation policy.

This submission has been made in the face of significant national reform through the $151.1 million National Reform Package on Organ and Tissue Donation for Transplantation (The National Plan for Organ Donation) that was announced by the Australian Government on 2 July 2008 and endorsed by the Council of Australian Governments (COAG) on the following day. This reform package includes the establishment of a National Authority to coordinate and lead organ and tissue donation services in Australia, funding to increase medical specialists and other clinicians dedicated to organ and tissue donation and a major national community awareness and education program.

For this reason, the reforms proposed in this submission are based, where possible, on local Queensland issues that should be reformed in parallel with the creation of the National Authority. These proposals complement the national activities and will ensure a robust and nation-leading organ and tissue donation sector in Queensland. This builds on the achievements of Queenslanders Donate, our tissue banks and dedicated individuals across the health sector in Queensland.

Before introducing a suite of proposals for reform, Queensland Health requests that the Select Committee is cognisant of the work being performed every day in Queensland by the dedicated staff of Queenslanders Donate, the Queensland tissue banks and a range of individuals across our intensive care, emergency and coronial clinical disciplines. These individuals have ensured that Queensland maximises the rate of organ and tissue donation in Queensland and that many thousands of individual lives have been saved or dramatically improved through their commitment to organ and tissue donation. Particularly, Queensland Health would like to recognise the work of Ms Tina Coco, Manager of Queenslanders Donate and Professor Russell Strong AC, Medical Director of Queenslanders Donate for their leadership.

We offer the following submission to guide the development of your report to Parliament.

1. Current Activity

A key support for organ donation in Queensland is priority access to the Queensland Government Air Wing, which comprises two fixed wing aircraft. Since 1985 the Air Wing's first priority has been emergency support to the Queensland community through support for organ transport retrievals and to other search and rescue operations. Surgical teams regularly fly to regional centres across the State as well as interstate and New Zealand to retrieve solid organs. This level of priority access is not provided in many other Australian jurisdictions.

1.1. Queenslanders Donate

Organ and tissue donation processes have been supported in Queensland since the mid 1980s. Queenslanders Donate was formally named in 1999 to co-ordinate all deceased organ and tissue donation across Queensland. Based at the Princess Alexandra Hospital, Queenslanders Donate reports to the Executive Director, Medical Services at the Princess Alexandra Hospital.

Through this agency Queensland Health provides a comprehensive framework for organ and tissue donation across Queensland through:

- Four intensivists as part-time Medical Donor Advisors in the four key organ and tissue donation hospitals in Queensland. These individuals act as clinical experts within their facilities and provide high-level peer support and advice on organ and tissue donation;
- Nine intensive care nurses as part-time Regional Donor Coordinators in regional hospitals, supported by 3.4 full-time State-wide Donor Coordinators. These positions provide around-the-clock support for the coordination and facilitation of organ and tissue donation in Queensland.

At the national level Queenslanders Donate is leading the development of a number of key national projects to improve organ and tissue donation resources available to the community. This work involves a new online resource and training material for general practitioners to facilitate discussions with their patients. A second project is the addition of organ and tissue donation to the senior science curriculum for secondary school students to assist in improving awareness of organ and tissue donation for transplantation and allowing young adults to form an informed view on this issue.

The program combines the strengths of other organ/tissue donation models but takes into account the vast geographical area of the State. Currently the ongoing future of Queenslanders Donate is unclear due to the $136.4 million Australian Government Reform Plan for Organ Donation.

1.2. The Queensland Eye Bank

The Queensland Eye Bank was established in 1992 to retrieve eye tissue from people who have consented to donation and have died in a hospital, but they also accept eye tissue collected from

the coronial system. Based at the Princess Alexandra Hospital, the Queensland Eye Bank also reports to the Executive Director, Medical Services at the Princess Alexandra Hospital.

The Queensland Eye Bank is one of the most efficient and productive Eye Banks in Australia and provides eye tissue to surgical units across Australia. A great deal of credit for the Eye Bank's efficiency can be attributed to both Australia Post and Australian Air Express, who generously donate their services through the 'Wings & Wheels for Vision' program.

1.3. The Queensland Bone Bank

The Queensland Bone Bank, based at the Queensland Tissue Transplant Service, Coopers Plains, was established in 1987 and is the largest bone bank in Australia and provides tissue to other states as requested. The Bone Bank also reports to the Executive Director, Medical Services at the Princess Alexandra Hospital.

1.4. The Queensland Heart Valve Bank

The Queensland Heart Valve Bank is located at The Prince Charles Hospital and has been operational since 1969. It is responsible for the retrieval, process and storage of adult and paediatric heart tissue allografts from multi-organ donors, deceased donors and transplant recipients. They supply tissue to other states when requested. Of the tissue that is processed, 85 per cent is utilised in paediatric congenital defect surgery. The Heart Valve Bank reports to the Director, Cardiac Surgery, The Prince Charles Hospital.

1.5. The Queensland Skin Bank

The Queensland Skin Bank, based at the Queensland Tissue Transplant Service, Coopers Plains, was re-established in 2007 and is currently completing the regulatory requirements to commence tissue retrieval, processing and release according to the requirements of the Therapeutic Goods Administration. The Skin Bank also reports to the Executive Director, Medical Services at the Princess Alexandra Hospital.

2. Issues not canvassed in the Issues Paper

2.1. Review of the current structure of tissue donation for transplantation in Queensland

The current arrangements for tissue donation and tissue banking in Queensland are in need of review as they are primarily based on the history of each organisation. Each group currently reports through their host hospital leading to potential inefficiencies and conflicts between the acute care needs of the particular institution and the responsibility to provide a state-wide service. Further, with the introduction of a new funding model in 2007 that redirects funding from historic budget allocations to activity based funding, the reporting and funding systems of the Queensland organ and tissue donation sector needs to be considered for review.

Any review of the current structure for Queensland must be complementary to the national reform process that was endorsed by COAG on 3 July 2008. This reform process will result in the establishment of a National Authority to oversee the strategic direction of and coordinate organ and tissue donation in Australia. Presently it is proposed that the National Authority will include a network of Organ and Tissue Donation Agencies (the current State Based Agencies, eg Queenslanders Donate). It is therefore important to ensure the review takes into account the requirements of the new National Authority.

Options that could be included in a review of the current structure include:

a) **Improved Reporting Arrangements**. A relatively simple modification to the current governance structure would involve modifying the reporting arrangements to require each of the tissue banks, and potentially Queenslanders Donate (depending on the outcomes from the National reform process), to report to a single individual.

Potential Benefits

- Improved central support for organ and tissue donation in Queensland Health
- Greater ability to negotiate budgets and manage expenditure
- Improved coordination of current activities and resources
- No re-location costs or disturbances to existing staff

Potential Risks

- Depends on the individual responsible for managing new arrangements
- Reduced linkages with clinical environments and clinical 'champions'
- Potential to appear as step towards consolidation

b) **Consolidation or Co-Location of Tissue Banks**. A potential model for investigation is the Donor Tissue Bank of Victoria (DTBV). The DTBV was established in 1988 and now operates as a single organisation for the donation, retrieval, processing, storage and distribution of bone, tendon, skin and heart valves in Victoria. The Victorian Eye Bank is

still separate and other smaller tissue banks do exist in Victoria, but they manage non-coronial tissue.

Potential Benefits:

- more cost effective processing, storage and release due to the ability to capture economies of scale and scope across the range of functions
- centralised database for activity and costs including regulatory requirements
- ability to capitalise on state purchasing power
- co-ordination of services will maximise the potential for tissue retrieval including multi-skilling tissue retrieval officers to reduce the time required for retrieval
- all tissue services placed on a mutual footing, reducing competition for scarce resources
- more access to, and control over, tissue stocks and reduced administrative overlap of storage records
- greater research opportunities and sharing of research facilities
- a greater flexibility to incorporate new tissue types and technological change

Potential Risks:

- risk is not spread across a number of organisations (for example, other facilities have tissues available if one centre has infection problems)
- relocation and disruption of staff, particularly for the QHVB that would involve a move from Chermside to Coopers Plains
- loss of identity of units and the long history of individual tissue banks in Queensland (for example the Queensland Heart Valve Bank has been operational since 1969)
- potential damage to existing non-government support including the sponsorship currently provided to tissue banks in Queensland based on historical relationships and the impacts of a new corporate identity (eg the Queensland Eye Bank is supported by the Prevent Blindness Foundation, the Lions Kidney & Medical Research Foundation, Australian Air Express and Australia Post.
- cost of relocation and available site space
- reduced linkages to current university partners available through co-location (for example the University of Queensland has a significant presence on the Princess Alexandra Hospital campus).

2.2.A measurement framework for organ and tissue donation that improves accountability

While the new National Authority will implement a measurement and performance framework for the Organ and Tissue Donation Agencies, Medical Directors and other specialist clinicians involved in the work of the National Authority, there is an ongoing need to establish a measurement framework for other Queensland Health employed individuals.

Currently the majority of hospital management and those involved in tissue donation outside of the hospital (eg Forensic Pathologists) are not held directly accountable to their managers or to Queensland Health for the performance of organ and tissue donation in Queensland. The introduction of a new measurement framework could include measurement indicators for District CEOs and Clinical CEOs, the Directors of Intensive Care Units and Emergency Departments and for those involved in non-hospital based donations, Coronial and Pathology staff.

These indicators could potentially include:

- The number of potential organ donors identified*
- Potential organ donors identified where consent was requested*
    - How many
    - By whom
    - Consent rates (including informed refusals)
- Potential tissue-only donors (Coronial system) where consent was requested
    - How many
    - By whom
    - Consent rates (including informed refusals)

* Would be measured through death audits and reviews by clinical specialists or national clinical triggers that will be established by the new National Authority.

The introduction of a new measurement framework will increase the level of recognition for organ and tissue donation in supporting the quality of care for Queensland patients. Currently, most measurement indicators that are reported between hospital administrators focus on the safety and quality of their facility, elective surgery rates, available beds, sentinel events and the incidence of 'ambulance ramping'[1]. Including additional indicators about organ and tissue donation would improve the awareness of this valuable component of the health system and lead to a 'top-down' recognition of organ and tissue donation.

2.3. Increased Capacity to Support Permanently Ventilated Patients in Queensland

Options to increase capacity to support patients who are permanently ventilated in a non-Intensive Care Unit (ICU) setting could potentially be examined. Presently, there is anecdotal evidence that indicates a number of ICU beds are often used to support permanently ventilated patients who could otherwise be supported in other facilities. The ability to support these patients in an alternative environment would potentially free up existing ICU beds for other patients, including potential organ donors requiring ventilation prior to organ retrieval.

[1] Where an ambulance will wait at a hospital entrance with the patient, due to limited emergency department capacity

3. Issues canvassed in the Issues Paper

3.1. Chapter 3: Consent to Organ and Tissue Donation

3.1.1. First Person Consent

The present legislation already allows the practice of first person consent and does not require the family of the individual to agree to donation if a valid, written legal consent had been obtained during the life of the individual.

However, Queensland Health supports the continuation of current medical practice that ensures a donation does not proceed if the family of the individual does not consent to the donation. This is consistent with practice across Australia and is considered to represent good medical practice in supporting the grieving process by ensuring the family is appropriately supported regardless of the decision they make.

3.1.2. Mandated Choice

The decision to register your intent or consent to be an organ and/or tissue donor must be based on an informed decision and mandated choice is not considered appropriate given the multiple registration points for the Australian Organ Donor Register that currently exist. There should be ongoing community education and awareness that seeks to increase the level of registration, but Queensland Health does not believe registration levels should be the primary focus of education and awareness.

Mandated choice does not sufficiently highlight the importance of discussing your decision with your close family and friends so that your wishes will be complied with if the situation arises. Queensland Health, therefore, strongly advocates a balanced community education and awareness program that highlights the importance of discussing your decision as well as registering your intent or consent on the Australian Organ Donor Register.

3.1.3. Presumed Consent

Queensland practice demonstrates that the existence of a registered intent or consent to organ donation is not the primary constraint in the organ and tissue donation process. During 2007 in Queensland over 60% of multi-organ donations involved a direct approach from the family of the deceased – an approach that is not reliant on a 'yes' on the Australian Organ Donor Register.

At present, a shift to presumed consent is not recommended as the Australian Organ Donor Register has undergone significant change in 2005 and modifications to consent processes in Australia would potentially lead to further community confusion. Further, the Australian community may see a move to presumed consent as perpetuating the myth that organ donation status has a negative impact on the quality of care received in an emergency and there might be a rush to register the safe, 'no' option. A reluctance in Australia to consider end-of-life issues or to

discuss these with family may mean this spike in 'no' registrations would be impossible to reverse, and given that the current legislative framework makes it difficult to override a registered 'no', these individuals would potentially be restricted from becoming donors in the future.

The preferred approach of Queensland Health is to continue community awareness and education on all aspects of organ and tissue donation, and investigate other avenues to support registration on the Australian Organ Donor Register.

3.1.4. Use of organs for purposes other than transplantation

A public misconception with the current organ and tissue donation system is that a registered 'yes' allows the health care system to utilise the organs and tissues of the individual for both transplantation and research. Long running efforts have attempted to overcome this myth and it is not recommended to link donation for transplantation with donation for other therapeutic and research uses.

In Australia there have been media accounts of the misuse of human remains by schools of anatomy and research that has damaged the donation for research sector. Queensland Health believes that while it is practical to link the current consent process to allow purposes other than transplantation, this should be avoided to minimise negative public opinion.

3.2. Chapter 4: Other Options to Improve Organ and Tissue Donation in Queensland

3.2.1. National and regional coordination

Queensland Health is continuing to work with health jurisdictions from around Australia to finalise the new National Authority for Organ and Tissues. The approach preferred by Queensland Health is the continuation of existing State Based Agencies (such as Queenslanders Donate) with a central reporting and coordinating structure. This structure is expected to include a CEO, a Medical Director and a board of advisors that will include representatives from across the sector.

3.2.2. Hospital based strategies – transplant coordinators

Queensland Health strongly supports the employment of two tiers of organ and tissue donation specialists, Medical Directors (similar to the Medical Donor Advisors currently employed by Queensland Health) and Donor Coordinators (DCs). A third category, Recipient or Transplant Coordinators are not considered within this submission but are explained below.

In the Australian system, it is recommended that Medical Director and Donor Coordinator roles are kept distinct where possible. In this way, Medical Directors provide peer advice and support on specialist queries regarding brain death, donor criteria etc. Donor Coordinators provide a first point of contact for queries from the public, medical staff and other hospital administrators.

In any case, *the individual staff member's profile is the most important aspect of the process*, not the title of the position. A list of required skills and attributes is included below. For this reason, there should be flexibility in selecting and appointing these individuals in each hospital.

These positions provide a vital leadership role in developing and implementing strategies that could include the development of performance indicators, conducting audits, introduction of national clinical triggers, support for NGOs, increasing training for critical care staff and all other staff dealing with end-of-life issues as well as community education and promotional opportunities.

Queensland Health welcomes the announcement of the Australian Government to expand the current network of organ and tissue donation specialists and is working to ensure an appropriate model is adopted. The Queensland Health preference is for a model that recognises the different resource requirements between acute care facilities, and utilises a three-level tiered grading system that assesses the ICU trauma category and potential organ and tissue donation rate in that facility.

It is considered that the use of part-time specialists will allow these individuals to maintain their clinical expertise, their peer networks and will ensure they maintain high-levels of peer credibility and respect.
The broad expectations would be:

a. Recipient Coordinators (also known as Transplant Coordinators)

Recipient Coordinators are typically involved in supporting the transplant recipient, from recipient work-up through to post-surgical support and ongoing case management. They seek to ensure the ongoing health and wellbeing of the recipient.

These individuals are referred to as Transplant Coordinators and they are involved in the pre-surgical care of the individual recipient and their ongoing health and welfare following the transplant procedure. These individuals are not considered further in this submission.

b. Medical Directors

Medical Directors are typically not involved in every potential organ and tissue donor case but are available for specialist advice, peer support and provide high-level education to medical professionals. They are typically medical practitioners specialising in intensive care medicine, although they can be specialists in emergency medicine, nephrology, cardiology, hepatology or thoracics. Generally, a Medical Director is not involved in every donation and will only be involved if the individual donor is their patient.

In Australia, Queensland Health, the Western Australia Department of Health, the South Australian Department of Health and the Northern Territory Department of Health each fund specialist Medical Donor Advisors to provide high-level assistance as organ and tissue donation advocates /

clinical champions, be on-call for questions that require specialist advice, provide education and training for medical professionals and offer general support to their peers in their facility.

Medical Donor Advisors in Queensland

In Queensland there are 4 Medical Donor Advisors who provide expert advice, peer support, ongoing education and training to medical professionals from intensive care, emergency medicine, neurology and anaesthetics. These individuals are intensive care specialists and they are employed part-time in their role as a Medical Donor Advisor.

Medical Directors would support organ and tissue donation in Queensland Health by:

- Being a 'champion' for organ and tissue donation in their facility and discipline (majority of their role)
- Providing strategic advice to the organ and tissue donation agency
- Providing community education or education of clinicians in their facility
- Primary contact for expert advice in their facility on organ and tissue donation, eg brain death guidelines
- Supporting Nurse Donor Coordinators in consent processes
- Being involved in major Statewide committees with relevance to organ and tissue donation

c. (Organ) Donor Coordinators

Donor Coordinators are typically the first point of call for all queries relating to organ and tissue donation and are central to the facilitation of the organ procurement and transplantation process. They are available 24 hours a day, 365 days a year and can answer any questions families may have, discuss consent for donation, and coordinate the process of donation by:

- Facilitating legal and medical criteria for donation and facilitating family consent, coronial and designated officer consent
- Arranging for necessary blood tests to be performed to ensure tissue compatibility between donor and recipient, and to exclude any infectious diseases the prospective donor may have that could be passed on to the transplant recipient
- Allocation of organs and tissues to transplant units and tissue banks
- Organising surgical teams involved in the donation surgery
- Providing and coordinating follow-up and support for the family.

Donor Coordinators are generally experienced intensive or critical care nurses with expertise in organ and tissue donation. They can be either full-time or part-time in their role as a Donor Coordinator, and may cover a defined regional area, particular hospital or perform a state-wide role. Donor Coordinators can be involved in the entire process from patient identification to final delivery of the organs and the transplantation process.

All States and Territories provide Donor Coordinators to identify, provide advice on and/or facilitate the donor and transplantation process in their jurisdiction. NSW and Queensland also provide

part-time donor coordinator positions (known as Regional Donor Coordinators or Area Health Nurses) which are based in regional or area health centres to provide local coordination services.

Donor Coordinators in Queensland

Queensland Health funds nine part-time (employed at 0.1 – 0.4FTE) Regional Donor Coordinators (Link Nurses), who are Intensive Care Nurses in regional hospitals, to identify donors, coordinate consent from the family and advise the Statewide Donor Coordinators who will then facilitate the donation process.

The Statewide Donor Coordinators (4 individuals, 3.4 FTE in total) facilitate all donations in the State and provide on-call advice across the State on any organ and tissue donation issues. Queries requiring specialist medical advice are passed on to the Medical Donor Advisor team.

3.2.3. Hospital based strategies – mandatory reporting of ICU or emergency department deaths

Queensland Health notes that a suite of clinical triggers will be developed and implemented by the National Authority for the identification of potential organ donors in the ICU or emergency department during 2009. These triggers will assist clinicians in identifying potential organ donors and improve awareness of the value of organ and tissue donation in our hospitals. Currently, in Queensland, the level of tissue donation is generally adequate and this strategy is not considered a priority.

The Select Committee may wish to refer this matter to the National Authority for review and implementation across Australia to ensure national consistency.

3.2.4. Hospital based strategies – mandatory request

This is not supported by Queensland Health at this time. At present more than 60% of organ donors in Queensland involve the family of the deceased (brain death) approaching the medical staff with an intention to donate the organs and tissues of the individual.

Given the variable knowledge of consent practice, organ and tissue donation laws and protocols, it is considered the appropriate strategy at this time is to continue with clinical education and training and the expansion of the Medical Donor Advisor roles in Queensland Health. Once the current reforms that have been announced by the Australian Government have been introduced and the full recruitment of the organ and tissue donation specialists has occurred this situation will be reviewed.

It is not considered necessary to introduce new legislation to deal with this practice. If required, it is considered more appropriate to adopt new Queensland Health policy and undertake an education campaign across the major trauma hospitals in Queensland. These activities would need to recognise it is essential that organ and tissue donation is supported at all levels in Queensland Health.

A preferred alternative to mandatory request is the requirement to mandate the treating clinician to inform the family of the option of donation. This proposal would require appropriate consultation and agreement from the relevant professional organisations and individual clinicians.

3.2.5. Hospital based strategies – pressure on intensive care units

The allocation of ICU facilities dedicated to organ and tissue donation is not supported. However, increased capacity to support permanently ventilated patients in non-Intensive Care Unit beds and other options to reduce the pressure on intensive care could be examined. Some patients who are supported for extended periods in the ICU may be able to be supported in alternative settings and this could be examined.

3.2.6. Donation after cardiac death

Donation after Cardiac Death (DCD) is currently being trialled in Queensland Health with outcomes from other jurisdictions showing strong numbers of DCD organ donors. It is important to balance the use of DCD for patients who would otherwise have progressed to brain death if continued to be supported on ventilation. In these situations, it is important to recognise that DCD currently doesn't support the donation of the heart – thereby an increased DCD donor rate may actually benefit less people.

At present Queensland Health is continuing to pilot the DCD program and will review this pilot once sufficient DCD donors have been identified.

3.2.7. Living donation

Queensland Health supports living donation through directed living kidney donation and living donor liver transplantation procedures. The use of Paired Kidney Exchange is currently under investigation as a national program.

Queensland Health is continuing to work with health jurisdictions from across Australia to finalise protocols for national Paired Kidney Exchange (subject to review of the current legislative framework in Queensland) and for living donor liver transplantation.

Non-directed living kidney donation (the 'good-Samaritan donor') procedures are not permitted in Queensland and. It is not anticipated that the current policy of preventing non-directed living kidney donation will be reviewed in the short-term. It is considered that the rate of unsuccessful donors, due to the inability to accurately determine true motivation, and the smaller medical risk to the donor than can be accepted for non-directed altruistic donation does not warrant this program being established at this time.

Transplantations using genetically or emotionally related donors are routinely conducted by Queensland Health and should continue. Also, some non-directed living kidney donation occurs as a result of a medically necessitated nephrectomy (eg due to a tumour) and this practice should continue.

3.2.8. Public Awareness and Education

Public awareness campaigns must be based on continual research and empirical evidence from national and international sources. The costs of ongoing research are often not incorporated into public awareness and education campaigns and this should be addressed.

A social marketing campaign will be introduced under the National Plan for Organ Donation. Queensland Health is working with the other Australian jurisdictions and the Implementation Group for the National Authority to ensure that this campaign is research based, provides a national approach but also allows regional adaptation for culturally and linguistically diverse communities, regional needs and based on the level of community awareness in each state. It will require significant input from a Communications Manager in each state as they have the best access to current information on community awareness and knowledge of community needs.

3.2.9. Incentives – financial and other

Queensland Health does not support the introduction of any incentives for cadaveric organ and tissue donation beyond the recognition of the donor and their family as having saved or improved the lives of multiple unknown individuals.

Queensland Health does not consider financial or other incentives to be a valid method of increasing the organ donation rate. The use of incentives, financial or otherwise, is considered to be ethically unacceptable as it would influence members of the public who are most at risk of exploitation. This is considered to apply for both living and cadaveric donors.

In-line with the donation of bone marrow, Queensland Health provides the medical treatment associated with donor work-up and the transplantation procedure at no cost.

For living donors, the concept of reimbursement for legitimate costs associated by organ donors is considered to be valid. The Select Committee might like to investigate the potential to improve reimbursement rates for living organ donors for non-procedure costs.