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Review of Organ and Tissue Donation Procedures Select Committee

Terms of Reference

Given the relatively low organ and tissue donation rates in QLD, should a system of presumed consent or "opt-out" for organ and tissue donation be introduced in Queensland? If so,
Should:
Presumed consent for removal of organs and tissue:
1. Be absolute or should further recourse be required to the wishes of the relatives and/or legal guardians in this decision?
2. Apply to all persons, specifically considering the age, decision making capacity, cultural and religious beliefs of the person?. If not, what exemptions should apply?
3. Allow these organs and tissues to be used for other purposes such as research?
What mechanisms should be put in place to enable persons to explicitly register their objections to their organs and tissues 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 all 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 improve the organ and tissue donation rate in QLD??

Introduction to Response:

In considering the issues raised by the Review of Organ and Tissue Donation Procedures Select Committee, (known now as The Select Committee) Chaired by Ms Karen Struthers, MP (Algester); which in particular is examining Consent in the area of organ and tissue donation in Queensland; the **Transplant Nurses Association (Queensland Branch) (TNA QLD)** :

1. Reviewed the Mission Statement of the Transplant Nurses' Association Inc, which is identified as:

> *1. To promote and provide current information and education to <u>nurses and allied health professionals</u> interested in the transplant field and associated areas.*
> *2. To develop a network of members with common interests in transplantation, to discuss and explore professional and ethical issues.*
> *3. To foster and facilitate a collaborative environment for transplant professionals to provide the highest attainable level of patient care.*

2. Examined the Code of Ethics guiding the Australian Nursing Profession which is developed under the auspices of Australian Nursing and Midwifery Council, Royal College of Nursing, Australia, and the Australian Nursing Federation. This Code is framed by the principles and standards set forth in the United Nations Universal Declaration of Human Rights, International Covenant of Economic, Social and Cultural Rights and International Covenant on Civil and Political Rights; the World Health Organization's Constitution and publication series entitled Health and Human Rights; and the United Nations Development Programme Human Development Report 2004: Cultural liberty in today's diverse world.

The purpose of the Code of Ethics for Nurses in Australia is:

1. *To identify the fundamental ethical standards and values to which the nursing profession is committed, and that are incorporated in other endorsed professional nursing guidelines and standards of conduct.*
2. *To provide nurses with a reference point from which to reflect on the conduct of themselves and others*
3. *To guide ethical decision making and practice and indicate to the community the human rights, standards and ethical values it can expect nurses to uphold.*

The 8 fundamental values supported by the Nurses Code of Ethics are:

1. *Nurses value quality nursing care for all people.*
2. *Nurses value respect and kindness for self and others.*
3. *Nurses value the diversity of people.*
4. *Nurses value access to quality nursing and health care for all people*.
5. *Nurses value informed decision making.*
6. *Nurses value a culture of safety in nursing and health care.*
7. *Nurses value ethical management of information.*
8. *Nurses value a socially, economically and ecologically sustainable environment promoting health and wellbeing.*

2. Examined the Code of Ethics of the Australian Association of Social Workers (AASW), which identifies 5 core values from which social work principles are derived. These values are:

1. *Human dignity and worth*
2. *Social justice*
3. *Service to humanity*
4. *Integrity*
5. *Competence.*

Several core components of the values, include the requirement to foster individual well being, autonomy and personal/social responsibility with due consideration for the rights of others. Reduction of barriers which preserve inequitable and unjust situations is a major aim. Value is also placed on children having opportunity to indicate their assent on matters which affect them.

3. Sought the views of its Membership about the Select Committee

Through a consideration of the values and principles which underpin the professional work of members of the Transplant Nurses' Association, in conjunction of membership views, the following document has been compiled:

TNA QLD Membership largely comprises nursing and allied health staff who work within the area of solid organ and tissue transplantation, throughout Queensland (approx 35 subscribed members and a near equal number of unsubscribed but interested non-members). The membership also comprises some University academic staff. Most members of the TNA QLD have direct and significant experience working directly in a professional care capacity, with recipients of transplanted organs and tissue. A number of members also have had direct experience working with donor families within context of their current or prior work in Intensive Care Units within Queensland and beyond, or with prospective or actual live kidney, bone marrow, or possibly liver lobe donors. All TNA QLD members share an interest in and appreciation of transplantation as a treatment for End-Stage or chronic disease and all deeply recognise that transplantation is only possible because of the generous donation of organs and tissue from either deceased or live persons. Members of TNA QLD profoundly respect the decision that members of the general community make, to donate tissue and organs, and are mindful and respectful at all times, of the circumstances of donation, in both the live and deceased contexts. The complexity of this decision making is appreciated and understood, both in principle and in practice. The TNA QLD recognises that there is an enormous disparity between current organ availability and current organ requirement, which translates into there being significant medical, human, financial and community burdens and costs. Whilst observant and supportive of the many great benefits bestowed by transplantation, the TNA QLD takes the most serious responsibility for ongoing education and learning about every aspect of transplantation and organ donation – in a cautious, non-assuming, curious, learned, rigorous and optimistic manner - recognising that transplantation and organ donation occur within a legal, ethical, clinical /professional practice and societal economic and philosophic framework. Importantly, TNA QLD recognises that having end-stage or chronic disease does not in itself give rise to a disproportionate right for having a transplant or the right to access an organ from somebody else, at any cost (including the other person's potential or actual free will or autonomy). People with end-stage disease may certainly have a claim to such, and certainly do have a right to "best care", but we need to debate further whether there is such a thing as a "right to an organ", despite the fact we wholeheartedly support transplantation as a treatment process and outcome. The claims of potential transplantees do not automatically usurp those claims, even rights; of those who are potential donors. We suggest there need be more discussion around this.

The TNA QLD recognises that the success of transplantation carries with it a major responsibility to further consistently refine the knowledge base within and of all these identified areas, within ongoing context of the Nursing and Allied Health (such as social work) professional Codes of Ethics and associated underpinning values.

Overall, consideration of the issues discussed by *The Select Committee* has been vexing, particularly as the TNA QLD considers that the issue of consent – be it Opt Out or Opt In – is neither the only nor possibly the main issue, which hinders, enables or enhances organ and tissue donation in the State of Queensland.

Four key issues identified by TNA (QLD) include:

1. Inconsistent opportunities for or uptake of education programs surrounding organ and tissue donation throughout schools and in the community. Previously poor/limited government funding towards this,

2. Limited understanding still within the community about the criteria attached to organ and tissue retrieval. Many people we have spoken to informally have received the message about being "donors after death" and have even contacted or are considering contacting the Australian Organ Donor Registry (AODR) – but many seem to miss the point that solid organs cannot be retrieved outside the ICU setting. Many people we speak with believe that signing the AODR provides permission for solid organs to be retrieved upon their death – irrespective of type and place of death occurring. Many have also advised us that they hope that the consent laws would not enable relatives to overturn their decision to donate, should such circumstances arise.

3. Lack of concerted efforts to allocate specific and funded donor Emergency Department and ICU beds, and likewise funding via DRG (or similar) to acknowledge and comfortably acknowledge donor, and hence potential transplant recipients needs.

4. No or minimal government policies in place regarding reimbursement of (live) donor expenses incurred. An ad hoc system currently operates for instance, in relation to the live kidney donation program, and it is far from being concerted or comprehensive. It largely relies on good will, and has developed in and around the systems connected with the state government travel/accommodation scheme.

In considering the Terms of Reference of *The Select Committee,* **the TNA QLD responds as follows to the Issues for Comment, as they appear through the Review Paper.**

What requirements for consent to organ and tissue donation should apply? If possible please outline your reasons.

TNA QLD recognises that it is a fundamental component of the patient/doctor/treating practitioner relationship that consent is obtained prior to the conduction of any medical procedure. There is much literature around the meaning of Informed Consent , in particular the consideration of how to ascertain what constitutes a patient (or their guardian or delegate) being “informed”, in order to provide a “true “ consent. Legal precedents have tested this notion of “informed” consent, in an attempt to establish what is “reasonable” information for a “reasonable” person to have (eg, Rogers vs Whittaker 1992 175 CLR 471). The issue of informed consent of minors has been tested through establishment of the Gillick standard, where a child can consent “if they achieve sufficient understanding and have the intelligence to understand fully what is proposed”. There is copious literature addressing this topic, and whilst this response from TNA QLD is not an attempt to in any way fully address the notions and practices of Informed Consent, it does highlight how imperative such is, in any discussions, to recognise that Informed Consent is not entirely straightforward, and that underpinning Informed Consent are such important values including personal autonomy and understanding. Manson and O’Neill comment that traditional consent that notion and practice claims have been reworked and reinvented in the last 30 years, that in informed consent requirements being extended from research to clinical ethics, the standards for seeking and giving consent have been made more explicit and more demanding. There is a quest for wider scope, higher standards, better justifications and regulatory use of informed consent. (Manson Neil C. & O’Neill Onora; *“Rethinking Informed Consent in Bioethics”,* Cambridge University Press, Cambridge, 2007).

We understand that the situation as it currently stands in Queensland, is that individuals are able and encouraged during their life, to indicate their intent (now consent) to donate, via signing on to the Australian Organ Donor Registry (AODR). This is within context of the fact that the absolute majority of Australians will not die in circumstances which enable organ retrieval to occur, even if they so wished to gift their organs after death. If people signed up to the AODR, prior to 2005, then this indication is intent – it is not consent. If people signed up after 2005, the indication to donate (or not) is deemed to be consent. This is potentially a significant difference; however we understand that in practice, families of deceased potential organ donors are always sought for consent. If they agree to proceed, then the donation can go ahead – but if the deceased has consented on the AODR pre or post 2005, and if the family disagree with that consent; then generally, the wishes of the family would be taken to override the expressed consent of the deceased. If the deceased clearly consented to <u>no</u> organ donation, then the family or NOK are unable to override this decision, irrespective of whether or not they wish for organ donation to proceed. Our understanding is that even in countries which have an Opt- Out or presumed consent model, NOK consent is still sought in most (ie, the weak presumed consent system), and is abided with. Austria is identified as an exception, in that they operate on a strong presumed consent system. It is of interest to us that of the 39 Queensland (deceased) donors for 2007, only 13, ie, 33% were on the AODR, yet 24 NOK families, ie 66% - voluntarily offered organ donation without being registered on the AODR. It is well known that irrespective of whether people have registered on the AODR or not – a key determinant in families consenting to donation is a clear knowledge that this is what their loved one "*would have wanted*". The AODR can confirm what the person's wishes were , which is useful if such wish is absolutely unknown to the family - but if like the majority of Australians, the deceased person had not signed the AODR – then it is families knowledge of their loved one's wishes, or their clear(er) capacity to connect the deceased person's personality and value system with that of donation, that will result in clearer results and potentially higher conversion/NOK consent rate (information obtained from staff in Queenslanders Donate August 2008). Formal opting in or out on a register might be less relevant that that of clear understanding of donation in general, and family member wishes in particular.

In considering what requirements should apply to consent for organ donation, firstly and foremostly we believe there is requirement to be guided by law, which testifies that relevant and considered information must be provided and understood prior to any procedure being undertaken. A mass publicity campaign across the community, on the widest ranging level, would therefore be an essential first step. Whilst the idea of Opting-Out is attractive, in that on some level, and consistent with other countries; and could potentially increase availability of organs, we believe there are a number of considerations yet to be addressed, at this initial stage.

Opting- out (especially non-weak presumed consent) possibly contradicts current medical standards whereby consent is required and sought for *all* medical procedures, within reasonable timeframe of procedure occurring. Assumptions and presumptions are generally not made or accepted in relation to medical procedures; rather documents are explained and consented to (signed). Legal precedents and acceptable standards of practice shape and frame the type and nature of information provision/consent required. Organ and tissue retrieval is a procedure, so theoretically and practically, should arguably adhere to current standards and practice of consent, unless it can proved, beyond reasonable doubt that organ donation is a totally separate case and therefore follows different procedure. Consistent with the Consent framework, consent at some point within the process could arguably be requirement, even if this means that there must be a massive explanation to the public about the possibility that organ donation be treated quite separately from every other procedure requiring consent.

Until every living and competent person as fully as possible understands exactly what they are (implicitly and presumably) consenting to, or not; it would be difficult to prove beyond doubt that they meet the standards as suggested in this section, for consent to donate or to opt out. If however such understanding can be readily reached, through proper public explanation to the public, then opting- out becomes a more viable option.

Further clarification is required about the legal status of a deceased person. Can the State decide if organs are to be removed, because of the organ shortage, the individual/social goodness/utility that comes from organ donation? If upon death, people lose all their rights, then why is consent either pre or post death being discussed or sought, other than as a courtesy to families/NOK? Rather, if the deceased, and assumably their loved ones have no rights – then consent would not be required. Families/NOK could be advised that given the (nature of) the death, that organ donation/tissue retrieval will be occurring. Or is it that if something is stipulated/consented to in life, to bear relevant after death; that in itself a different moral plane operates. Even if legal status is determined, where things get difficult is the consideration of minority religious/spiritual groups who do not recognise the bodily death as death of the entire organism. Days or weeks might needs to pass for the whole death to be acknowledged. Whilst the clear majority of religious faiths do support organ donation, the fact that some individuals don't - yet may not have actively opted out – means that there is possibly room for inconsistencies to develop.

If a person signs the AODR after 2005, why is it that consent is still actively sought if the deceased has consented their wish for or not organs to be removed – and this is adhered to – then it seems inconsistent that if no such wish is expressed, that a new right can emerge whereby organs can be retrieved? No wish expressed may not equal no wish at all (one way or other) or could equal a major wish not yet expressed, or possibly not fully formulated due to lack of information to do so.

The existence of the AODR is not encouraging the majority people to consent pre-death, for donation / non donation – even though 90 – 97% of the Australian public is comfortable with the concept of organ donation. (HIC Woolcott Report, 2003). Despite a nation-wide letter box drop in 2005 encouraging people to "sign up" (ie, provide individual consent to organ donation), the take up rate is relatively low. Until there is a truly well co-ordinated and mass public campaign to explain very differently all about organ donation, quite different from anything we have ever seen – it is unlikely that people will seriously relate organ donation to something they can consider/provide pre-consent to. This campaign must carry information related to brain death and other forms of allowable donation. We believe the general public have little understanding of the donation process and this hinders their ability to make decisions regarding organ donation.

Many people we have spoken to think that one only contacts the Register to Opt- In. There is very limited recognition of the fact that individuals can equally opt out now.

We endorse that in keeping with the consent principles operating in Medicine, that there needs to be some form of proper consent process of organ donors, as the retrieval of organs is a medical procedure, irrespective of it being on a deceased person. Clarification is required about whether consent provided during life actually hold. Currently it does not, irrespective of it being "consent".

After their death, no deceased person can make a decision one way or the other about organ donation. Either the consent for such is acquired during their (competent) life or is obtained posthumously from their legal NOK.

An Opt out system operates on the notion of REVERSE CONSENT, ie, opportunity to consent to something not being done, rather than being done. This is the fundamental shift in attitude which Opt out needs to explain/marketed.

Need to explain that consent is still the cornerstone of donation – a different type of consent.

Consistent therefore with the medical requirement for Informed Consent, TNA QLD would therefore support that the practice of obtaining Informed Consent be upheld within the donation process, although we are open to looking at the various ways this can be obtained and what legal status it holds.

Should the role of the next of kin or family be different if a person has given written consent to organ or tissue donation?

If a person has provided clear testimonial that they wish to donate organs and tissue, and if the appropriate set of circumstances arose, then as with a Will and Testament written and signed during one's life, generally we believe this should be fully respected. In the same way that if a person has indicated they do not wish to donate their organs, that this too is fully respected (as it currently is). It is consistent with the values identified in the Codes of Ethics. We recognise it would be difficult for a family if they truly do not want to proceed – but if it is established legally that a persons pre-deceased wishes are legally abiding, we would hope to support this, whilst supporting the family to support the decision and the right of the deceased. Experience shows that the majority of families wish to respect the wishes of the deceased. One idea could be to explain that consent has been provided, but to still provide the family with opportunity to sign a document to state that this has been explained and discussed with them by hospital staff. Staff should then go to whatever lengths necessary to look after the family during and after the time of the retrieval/donation process. We do have concerns when the non-majority of a family try to override either the deceased or the rest of the family's wishes. The situation would need to be arbitrated by skilled organ donor staff or by a government appointed guardian.

What is the best way to use a donor register in connection with consent when donation is being considered?

If there is to be use of a Register, its purpose possibly needs to be clearer than it is currently. Many people we speak with do not seem to know that they can register their intent not to donate, as much as to donate. The website could be significantly improved upon. It does not seem to link well with donor stories, transplant stories, statistics, etc – like some of the North American ones. It looks fairly cold and bureaucratic. It lacks warmth and gratitude. If there was to be a massive community education program, different from anything seen before, then people could be advised they can contact the Register to register their consent.

If a Universal Registration system was proposed, whereby people are strongly encouraged to register one way or the other – including possibly a "*not sure – still thinking about it...*" section – then, the message is that "people's opinions matter". Many people would appreciate the opportunity to exercise their autonomy to do so. Whether there should be shopfronts, donor register caravans that go around to shopping centres, universities, etc – that could work.

Do you support introduction of an opt-out or presumed consent system?

We support ethical and community-acceptable measures which have the potential to increase the pool of potential organ donors enabling transplantation of a greater number of transplant patients. We note that although everyone in the community has blood to donate – and there is a continual shortage of blood supply and product; there has never been any suggestion that everyone should donate blood, unless they opt- out, or have conditions which contraindicate blood donation. We are mindful of the respect which is owed everyone to express their opinion about whether they (or their delegate if incompetent) wish for organs to be removed for donation. We are not totally adverse to the notion of Opting -Out, but believe that Opting -out must only be considered with an accompanying community education program, and on a NATIONAL level, and in conjunction with improvements which have already been advocated to do with improved systemic medical supports (beds, mandatory referral of potential donors, etc). It is possible that the relatively sudden introduction of an Opt -Out system could leave people feeling uncomfortable and could in fact have the reverse effect whereby people do in fact " opt-out", out of fear, misunderstanding or on principle; when otherwise they would have considered donation. It could remove the sense of gift factor, if not explained appropriately. If done well, within context of donation being a gift of boundless proportion, and the ultimate legacy /social responsibility – then the pride factor might assist people to make genuine choices. A weak presumed consent system could be the optimal way of merging the opt in/out systems, but only in conjunction with national and targeted educational programs.

What reasons do you have for supporting or not supporting an opt-out or presumed consent system?

The main thing that strikes the TNA QLD, is the importance of truly educating and informing the community, so that any individual who becomes a potential donor, has their wishes and needs recognised in the best way possible. Opt out serves those well who understand the need to opt out, if they wish. The only thing that might turn this around would be if a massive and diverse community education program was introduced to ensure full understanding. We know that there is still that idea in the community that other people needs (ie, potential transplantees) might be put before their own (if being treated in ICU). Whether this meets the current (legal) requirements of "Informed Consent" which we have discussed above, is unclear. We think that a weak presumed consent system could be viable, so long as the community is far more informed than it currently is.

Of interest to us is the comment in the National taskforce on Organ and tissue Donation report **"Think Nationally, Act Locally" (2008):**

> *Changing to an opt-out, or presumed consent, legal system is often raised as a potential solution to increase Australia's donor rate. Australia's legal system governing consent is based on the 'opt-in' principle, where informed consent is explicitly sought for each potential donor. It is an approach that balances individual and family rights with community need. However, when international comparisons in donor rates according to consent laws (and actual practice) are considered, there is no clear correlation between opt-out systems and better performance in organ donation. As a result, the Taskforce did not consider that this area should be a focus of its work.*

What role should a deceased person's family or next of kin have in consent to organ and tissue donation?

There should be every effort to contact a family and discuss organ donation, as a matter of decency, and because the retrieval of organs would impact upon events post-death. If someone has definitely provided consent through the AODR, we question whether this can legally be overridden (in the way a Will cannot unless it is taken up through the Court system). If it can, it must not be called consent as this is misleading.

It seems vital to involve the next of kin in discussions about the donor's wishes, in a highly sensitive and supportive way. They could be some documentation for them to sign, to indicate that the discussion has taken place, and to endorse their support or understanding of what it being proposed. It seems more decent than not to uphold the wishes of the deceased, and our thought is that if the discussions have taken place, the family are well informed, and the deceased was one of the 90 – 97 % who notionally supported organ donation – then the wishes of the deceased should be upheld, and generally are upheld by the family/NOK. Families need to be involved in the entire process, as they are dealing with the consequences. As stated many times, organs are not commodities to be bought and sold – they hold moral worth – and this adds weight as to why families must be involved wherever possible.

If a presumed consent system was to be introduced what mechanisms should be introduced for people to opt-out

There needs to be a massive and far reaching NATIONAL education program. This is not for one State to do alone. Advise the community that based on the 90 – 97 % agreement – the community wants to ensure that in the event of a donation opportunity – that ALL individual wishes are respected and followed through. A number of people have not had their wishes respected, as they didn't let anyone know what they wanted. Hence to ensure such and to respect the majority wishes of the community everyone will be considered as wishing for donation, but those who would like not to be considered have every right to register their non-consent. Any time, preferably sooner rather than later. Advise community that this is to make it easier for everyone, and to ensure wishes are more often respected, than not. Also, please discuss your wishes, one way or the other with your families so that everyone knows exactly what you want. Your choice, life, your body, your organs – YOUR RESPONSIBILITY........ Take charge ...NOW...whilst you can... This needs to be the essence of the message. The (2004) Western Australian proposals whereby they hold "Registration Fortnights" - could have some value – as this could enable media/school/community saturation which is short and sharp, intermittent but hard hitting – rather than mildly there all the time to which people become oblivious. Communities could be advised that in say, one month – there will be a two week period to register consent – one way or the other (the current system does not advise well enough of the opportunity to opt out – it is all about "sign on to save a life "– which is potentially ambivalent) – or as suggested above, roving caravans, an organ donor train, truck, etc. Many of these ideas could be incorporated into current services such as GP visits and Blood donation etc.

How could simple and reliable access to an opt-out mechanism be ensured?

As suggested – publicity, an 1800 number, shopfronts, caravans, far better website including pod casts, links, etc. This would need to get into every community in the country – not unlike polling stations would at federal election time.

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?

Yes, if the person has not opted out – because this would be in line with the need for best practice Informed Consent. When someone has not opted out, whilst after publicity it might be assumed they have provided consent, it would be important to frame the discussion around seeking from family/NOK the views of the deceased, and asking if they believe the deceased did not opt out due to their (tacit or otherwise) support of donation – or due to some other reason (eg, meant to phone/register to indicate their non-consent – but did not get around to such).

Should children and people with impaired decision making capacity be part of a presumed consent system?

There is a difference between a child of normal or above intelligence, and a disabled person who might be unable to form judgement. Even then there are many forms of disability, and some disabled persons would be able to make informed consent, one way or the other – and some children might struggle to understand the concepts. Refer back to the Gillick Standard. It would be totally appropriate to discuss donation with parents of a child of any age, and expect that the final decision would be with the parents as to whether to donate or not if the child was under 16 years. If there is conflict between the parents, a government Guardian should be called upon to advise an outcome. It should not be assumed that not donating carries greater priority over donating – or that this is the easier option. If the education system is working well, children would be encouraged to tell their parents their views, as rightly, their parents or guardians would have to sign on their behalf, after death.

Should particular categories of people be automatically excluded and not presumed to consent to donation?

Everyone should have equal opportunity to donate, if in position to do so. There is however, a burden of responsibility on the State to ensure that the information gets through about donation to all sectors of the community – and this is a real challenge, but not impossible. Incompetent persons would need to have decisions made on their behalf by their delegates or guardians. But we think that what goes for one goes for all – as far as application of law and ethics – which if done properly, would enable individuals to be assessed and responded to on a case by case basis. Although some religions do not practice donation, individuals within this group may not practice the faith and find donation a right and proper thing that is being undertaken.

When should children be able to opt-out of presumed consent?

Children should be encouraged to discuss and explore the value of organ donation, also within context that they themselves are far more likely in future to require a transplant rather than die in circumstances that enable donation. Up until the age of 16, children should be encouraged to talk with their families about their wishes, but legally, their parents need to make decisions on their behalf. Over the age of 16 years, children should be able to consent to organ donation or not.

What support would be required for clinical staff if a presumed consent system was introduced?

Access to the register to establish if the deceased has opted out or indicated any stipulations (ie, certain organs/tissue they do/don't wish to use for donation purposes). Good working knowledge of the consent laws, and capacity to explain things well to highly distressed families. Counselling and bereavement skills/knowledge is required. Identical really as to what is the situation now. Extra staff within the operating theatre, ICU (Current Link nursing staff in Qld) and Transplant units and Clinics would be required to deal with increased transplant numbers. This should include counsellors / social worker support to liaise with donor families.

What safeguards and limitations should apply to a presumed consent system?

This has been answered through other questions.

Are there specific religious or cultural issues that should be addressed in consent to donation of organs and tissues?

Given that there has been plenty of research already into establishing the beliefs of the world's major religions, in relation to organ donation, little extra needs to be done in that area. More importantly could be the need to again ensure that all sectors of the community have information regarding organ donation and transplantation, so that the consent opportunities are equally available. This would require a high level of government commitment. It would be beneficial to ensure that communities which experience disproportionately high levels of chronic and end stage disease (for instance due to high rates of diabetes) are delivered a particularly sharp opportunity to understand the high risk factors for disease, and can be helped to take responsibility for their health outcomes. This in turn connects with organ donation and the responsibilities they have, in line with the rest of the community to consider their choices, and capacity for contribution.

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?

Donation and research are separate – so the eduction programs would need to explain clearly that if people wish to consider donating their organs or bodies to research, that there are separate avenues to advise of this. It would be important that there is not a sense that dead bodies will all be sent off "for research" against people's wishes. There seems to be a moral and actual difference between utilising organs to enable transplantation, and for the purpose of research. Individuals should have opportunity to indicate their desire for their bodies to be donated to science , and education could assist people know where/how to go about registering for this - but this issue should not be blurred with the life saving results and the urgency of organ/tissue donation. Even if an opt-out system is introduced for organ/tissue donation – there could be value in retaining an "opt in" system for donation of organs /body to science or to research. It could be useful to promote this option also; as it is interesting how many people we have encountered who believe that your body can be donated to science for instance, without having made any prior (to death) arrangements. Community education could be placed here as well. The Transplant Co-ordinator at time of donation may be in a position to ask the family who are donating their relatives organs for transplantation that if the organs could not be used for transplanting could they then be used for education / science.

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?

So long as the system could enable people to clearly indicate what they are opting out of, that could be acceptable.

If an opt-out or presumed consent is not introduced, is the current system appropriate?

Overall, the system seems decent, in that family wishes are very well respected, and no pressure to donate is placed upon families/NOK who are amidst a sudden loss. Apart from the systemic factors which we have mentioned already, ie, a requirement of far more resources to be placed into advertising and service provision in hospitals, the system seems functional to a large extent. Queensland requires full time link nurses in Intensive Care Units and Emergency Departments throughout the state to ensure all potential donors families are approached regarding donation. There is also a need for medical staff within these units to continuously update their knowledge regarding donation and potential donor identification.

Are there changes you consider should be made to the decision-making or consent system?

One novel option would be to cancel out the Register altogether and focus on educational matters, and focus on consent at time of death/organ/tissue donation time. Focus on "*tell someone who cares*"... Given that most people will never be affected by organ donation. This may be run as a pilot program and results could determine future requirements.

What action should be taken to improve organ and tissue donation in Queensland?

1. Refer to information already provided in this document – education, better medical supports such as beds, specialist staff, Nursing and Counselling staff, mandatory referral of patients who meet determined criteria for death (Brain death or cardiac death, if DCD is to be considered)/potential donation From the Emergency Department as well as the Intensive Care Unit.

2. There should be benefit in an overhaul of the financial recompense system to LIVE donors, particularly kidney and futuristically liver donors – either in the form of a set amount (lump sum or fortnightly), payable through Centrelink, or a genuine recompense for expenses(actual or through taxation). This would be acknowledgement of the time donors need to take out of their lives, to enable the surgery and the full recovery. It would also be consistent with the *Declaration of Istanbul (May 2008)* whereby live donors were acknowledged as requiring/deserving recompense for their gift/efforts. *See attached documents for further detail.* We note that in British Columbia, the Canadian Kidney Foundation has been trialling a recompense system for donors (www.kidney.ca). There are tax rebates in Canada to assist more genuinely with accommodation, meal and travelling costs (for example, rates of travel (vehicle) subsidy around 40 – 50 cents/kilometre, (compared with 15 cents a kilometre subsidy in QLD, along with relatively meagre contribution to accommodation costs split between the treating hospital and the recipients home regional hospital) associated with dialysis and transplantation. The Australian Federal Government provides a baby bonus of $5,000 to every new baby born – as incentive and acknowledgement of costs associated therewith. Long term Carers in Australia, can access a carers payment/benefit, if they meet the specific criteria. Payment as recompense through the Centrelink system for care and support assistance to members of the community and to assist family groups is therefore a well established standard in Australia. If after the comprehensive psychosocial and medical assessment a potential live donor is deemed suitable to donate, it is vital we support them, rather than fear that assistance with costs would detract form the "gift" and "voluntary" features of donation. Rather, financial assistance would be an acknowledgement of genuine costs and could create better equity of access to the donation process. The current situation has developed randomly and whilst there is enormous good will and high professionalism and integrity within the Queensland and Australian donation process (hospital staff/systems and donors/recipients), it does not properly acknowledge the costs which donors and recipients incur. The Live donor program also saves the government significant costs over the life of the transplanted organ and is seen as a positive step for recipients. We therefore fell that reimbursement of cost would be a just and fair thing to undertake. We wonder whether live donors

require access to more support post- nephrectomy. Social Work and other services tend to focus on the assessment/transplant phase. Specific funds have not been allocated towards such long term care plans. Maybe there needs to be more specific "thank you" programs focussing on live donors – ceremonies, dinners, etc as has started through the Transplant Australia / Kidney Foundation.

3. This links in with the fact that transplant recipients and those on the transplant waiting list likewise have mixed experiences of governmental financial support - federally and state. This is in many respects a whole separate topic, but ties in with community and government attitude as to what is fair and reasonable within the donation/transplant process. *The Select Paper* refers to such costs associated with relocation to treatment centres, whilst waiting for or rehabilitating from transplantation. The Queensland Government through such schemes as PTSS struggles with this and to date holds no consistent policy and hence there are no consistent practices. This is an area which could well and truly benefit form overhaul. Many of our patients have experienced significant difficulties connected with the lack of clear policy and lack of committed government funds.

Are there particular hospital based strategies that should be considered in Queensland to improve organ donation rates?

As per indicated throughout this document - ICU/ED support, and recommendations based upon the Spanish model of hospital support. Some potential donors may be getting "missed" in the ED due to factors that may relate to educational needs of the Medical and Nursing staff.

Should any incentives be offered to potential donors for organ and tissue donation?

Our current system of offering families of deceased donors' bereavement counselling, providing well constructed information/support packages, Thanksgiving opportunities, and feedback about the progress of the donated organs, is excellent. We are unclear as to whether further support such as a set subsidy towards funeral costs is legitimate. This requires more debate and discussion. It could be perceived as a wonderful gesture or as something not befitting the spirit of donation. Refer above to our response regarding live donors.

What are you main reasons for supporting or opposing incentives?

As above.

If you support incentives, what type of incentives do you consider to be appropriate?

As above.

What action should be taken to promote better public awareness of organ and tissue donation?

The advertising could focus on comments which can be drawn from this document, and also:

Over 9/10 or 90 % of Australians support the idea in organ donation. With nearly 2000 people in Australia at any time, waiting for an organ transplant, it is wonderful to have so much support in the community for them to get better.

The fact that 90% of Australians support organ donation, is absolutely no surprise, when we consider that we are a country built on the generosity and sharing – the true blue mateship concept. Even though the majority of us feel so positive about organ and tissue donation; the majority of us will in fact, never be in a position where we have opportunity to donate solid organs (kidneys, heart, lungs, liver and pancreas ;) as for organs to be removed, our death must occur within the supportive environment of an ICU or ED. Most deaths happen in other places or in other ways. For instance, Organs usually cannot be donated from people who die at the scene, in vehicle accidents; or on their way to hospital although this could be different with DCD – Need to confirm this) Therefore, to be in a situation where one has opportunity to donate is very special/honourable. In case we are ever in the situation of being able to donate – why not do so? We would be rapt is someone helped us or our loved ones out if we were in need of an organ. This leads to education regarding how donation is possible and why it is sometimes not possible.

The average Australian has about 10 times more chance of requiring an organ transplant during their lifetime, than that of ever being in the situation where there is opportunity to donate their organs.

Legally defined criteria of death must be met. The good news is however many more of us can donate tissue after our deaths, to help people in the community regain sight, movement and bone and skin reconstruction. It is amazing to think that we can help out, if the right opportunity comes along.

It is re-assuring to know that Australians are keen to help out – if they could.

END OF DOCUMENT

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