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

Comments:

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I would like to acknowledge the considerable work undertaken by the Review of Organ and Tissue Donation Procedures Select Committee and thank them for the opportunity to make a submission on this important public health matter.

The following comments are offered for consideration by the Committee:

Section 1.3
The terms of reference of the committee start from a foundational premise that, as the supply of organs for transplantation does not meet the demand, measures must be undertaken to boost supply. However, the critical question of whether the demand for organs is falsely elevated, or that unrealistically high expectations with respect to transplantation have been fostered in the community also warrant exploration. If this issue is to be framed simply as one of 'supply and demand', the issue of potentially excessive or unrealistic 'demand' deserves equal consideration. The numbers of transplants requested as a result of lifestyle induced disease also warrants consideration as these represent a potentially preventable demand and may point to areas of public health education campaigns that may reduce future 'needs'.

Section 2.1
'Success' of transplantation cannot be measured solely in terms of 'survival'. Issues of post transplant quality of life form a critical part of such deliberations, and these are not adequately captured by simple survival statistics. While many studies report good quality of life [see 1 for example], there is a growing body of literature noting increased incidence of anxiety, insomnia, and psychological distress, experienced by patients, families and caregivers [2-7]. Transplantation unquestionably prolongs life, however, may produce a diminished quality of life with reduced wellbeing. The myth of 'transplant as cure' must therefore equally be challenged in addressing growing demand.

Section 2.2.2
Community awareness and education programs are an essential public health response, however, the purpose of such education should not be primarily directed at persuading or convincing individuals to adopt a pro-donation stance. The purpose of such education is to inform with a view to enabling broader understanding of the complex issues surrounding organ donation, to equip individuals to make considered choices, either for or against donation, in line with their own moral frameworks. Low consent rates do not necessarily reflect 'failure', when the decision not to donate is informed, understood and intentional.

Section 2.6
This section confirms that ‘dpmp’ is an overly reductionist and poor indicator of donation attitudes and practices; therefore, Australia’s seemingly ‘poor’ performance based on this statistic alone may not be a particularly significant measure.

Section 3.2.1
Consultation with next of kin is important as there will always be likelihood that persons may have changed preference (either for or against) without recording their new wishes in the medically preferred place, such as AODR. The exclusion of grieving family members from this process is potentially very harmful and may generate additional emotional burden, as well as ongoing legal and ethical issues.

Section 3.2.2
The solution adopted in the Netherlands appears to be a good compromise between acknowledging the wishes of the deceased person, but also respecting the feelings and insights of their family.

Section 3.2.5
While there are clearly demonstrated goods that flow from organ donation, there are numerous potential harms in mandating an ‘opt out’ default position for donation at a population level. Potential harms that should be considered by the Parliamentary Select Committee may include:

- The potential erosion of public trust in the health service by being seen to subvert the expression of individual autonomy. A change to health policy, such as ‘opt out’, may communicate the view that the autonomy of all citizens can be subverted to benefit a very small number of organ recipients. This is inconsistent with other areas of governmental policy response, for example, the whole population is not presumed to wish to donate money to provide aid to the few victims of natural disasters.
- Such a policy may convey the ethically contentious message that individual organs are public property.
- Creating a normative pathway of unquestioning donation may further limit opportunities to become adequately informed for the purpose of giving informed consent prior to donating. This undermines the ethical integrity of any interventions that follow.
- As organ donation is considered by society to be an altruistic act, the notion that government can mandate such altruism in its citizens is flawed as it circumvents the moral act of ‘gifting’ that is central to donation.
- The presumption of a positive attitude to organ donation may present additional and unwelcome emotional pressure on families at the difficult time of an unexpected death and may be perceived as coercive.
- The emotional complexities surrounding the family decision to consent to donation are more likely to be short-circuited when a positive attitude to donation is presumed by medical staff. The ongoing physical treatment of the donor, such as the (potentially) aggressive physiotherapy that preserves organ function, the place of death, and the need for relatives to leave the deceased persons body on the strict timetable of the retrieval/transplant teams may present additional emotional burdens to under-prepared families.
- Acting upon an individual donor’s beliefs surrounding their intention to donate lies at the crux of ethical practice. It is ethically more acceptable and respectful

to educate for, rather than compel towards, participation. This educative approach has been adopted in Canada.

- Ultimately the medical community may have to accept that many members of the public do not share the conviction that increasing donor rates is a national health imperative.
- While procurement under a so called ‘strong presumed consent’ model may be legally permissible it is ethically problematic and may significantly erode public trust in our health care system.

As acknowledged in the Select Committee Report (p.18), ‘opt out’ is not a critical determinant of donation patterns and outcomes. Hence, given the potential harms outlined above and the likelihood that the imposition of ‘opt out’ will not achieve the outcomes sought, its adoption should not be supported.

Section 3.5

Given the recent concern generated by the release of NHMRC DCD guidelines, which prompted the NHMRC to issue a statement entitled “NHMRC calls for calm in organ-donation-after-death debate”[1], an additional issue for comment may be,

“What public perceptions may be raised by imposing an ‘opt out’ stance on donation?’

Section 3.6

Issue for comment,

“How do clinical staff feel about being mandated to act as proactive organ recruiters?”

The potential burden on clinicians of mandating this discussion with an already grieving family warrants fuller consideration and should not be imposed on this professional group prior to a full consultation process.

Section 4.3

The requirement that the potential donor’s treating clinician broach the subject of organ donation raises a tension that may be perceived by the public as a potential conflict of interest, as the line between acting in the patients’ best interest, and acting in the interest of a potential organ recipient may become blurred. The DCD guidelines make the clear point that separation between treating and organ retrieval teams must be maintained; however, if discussion of donation becomes mandatory in the ICU, this separation may become blurred.

Section 4.9

The high school curriculum material developed by Queenslanders Donate must be structured to promote understanding, and not to persuade or entrench students to adopt a particular pro-donation stance. It is imperative that balanced information be given using non-emotive language. The purpose of such education is to promote fair and balanced understanding of the positive and potentially negative aspects of donation, to equip students in developing an informed and considered stance. In terms of community education, it is also imperative that such education is balanced, and proactively includes disclosure of what may be perceived as the negative aspects of donation, such as restrictions on the time and place of death, presence of family during withdrawal of life support, pre-mortem interventions, and the strict time limits (5 minutes) that accompany DCD etc.

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[1] http://www.nhmrc.gov.au/health_ethics/health/organ.htm

Finally, the "success" of organ donation programs cannot be measured purely in terms of the numbers of donations. Rather 'success' should be measured in terms of how many persons and their families gave intentional, informed and understood consent, based on consideration of full and balanced information, either to embrace or reject donation. It is important that an ideological commitment to improve donation rates does not over-ride an evidence-based reflection and analysis of the multiple competing factors that inform medical and community attitudes to transplantation. It is also important that when the parliamentary committee makes its' recommendations that it can demonstrate that a range of ethical, legal, medical, cultural and social perspectives have been authentically considered as this will inspire public confidence and trust in the policy reform process.

References

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