



The future of organ donation in Australia: moving beyond the 'gift of life'

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Executive summary

- Australia's organ donation and transplantation system does not meet the nation's present demand for organs and is unlikely to meet its future needs. This is especially so given that the demand for transplanted organs is anticipated to continue to grow with the ageing of Australia's population and the increased incidence of lifestyle diseases such as obesity and Type 2 diabetes.
- It was in recognition of the failings of Australia's organ donation and transplantation system that the Howard Government established the National Clinical Taskforce on Organ and Tissue Donation in 2006. This Taskforce was to provide evidence-based advice to government on how the system might be changed so as to improve the rate of safe, effective and ethical donation for transplantation in Australia. The Taskforce submitted its final report in January 2008, and some of this report's recommendations are reflected in the Rudd Government's proposed new national reform package, announced on 2 July 2008. The Australian Organ and Tissue Donation and Transplantation Authority Bill 2008, introduced to the Parliament on 18 September 2008, would, if passed, provide the legislative framework for the proposed reform package.
- Some of the Taskforce's recommendations and the government's proposed reforms would be likely to improve, in the short- to medium-term, Australia's overall rates of organ donation and transplantation. However, to the extent that the Taskforce's recommendations and the government's proposed reforms do not depart from the terms of a 'gift of life' doctrine, they are unlikely to result in increased organ donation rates sufficient to meet Australia's current or future needs.
- The 'gift of life' doctrine insists that organ donation is an altruistic, egalitarian and essentially moral act. This paper argues that the 'gift of life' doctrine may be viewed as being flawed on a number of grounds, and that any changes made to Australia's organ donation and transplantation system in the future should be premised, first and foremost, on an understanding of the act of donation as that of a rational, autonomous decision-maker.
- Not only would this provide an accurate basis for Australia's organ donation and transplantation system, but it would also allow for the widest possible range of motivations for organ donation while not compromising people's ability to make ethical choices in donation. At the same time, grounding Australia's organ donation and transplantation system on the notion of a rational, autonomous decision-maker could enable a number of changes to this system, the ultimate outcome of which may be an increased number of organs available for transplantation and more saved Australian and New Zealand lives.

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List of acronyms

ADAPT	Australasian Donor Awareness Program
ACCORD	Australian Coordinating Committee for Organ Registries and Donation
AHMAC	Australian Health Ministers' Advisory Council
AHMC	Australian Health Ministers' Conference
ALRC	Australian Law Reform Commission
ANZICS	Australian and New Zealand Intensive Care Society
ANZOD	Australia and New Zealand Organ Donation Registry
AODR	Australian Organ Donor Registry
dpmp	Donations per million population
IRODaT	International Registry of Organ Donation and Transplantation
NHMRC	National Health and Medical Research Council
NODC	National Organ Donor Collaborative
ONT	Organización Nacional de Trasplantes (Spanish National Organisation for Transplants)
RTA	Roads and Traffic Authority (NSW)
TGA	Therapeutic Goods Administration

Introduction

Despite widespread public support for the concept of organ donation in Australia, the nation has one of the lowest rates of organ donation in the world.

Without an increase in the rate of organ donation in Australia, Australians suffering from life-threatening illnesses and awaiting an organ donation will continue to die at an ever increasing rate.

In this context, there is substantial interest in finding ways of translating Australians' stated commitment to organ donation into improved actual organ donation rates. It was with this goal in mind that a National Clinical Taskforce on Organ and Tissue Donation was established by the Howard Government in October 2006. The Taskforce was to provide the Australian Government with evidence-based advice on ways to improve the rate of safe, effective and ethical organ, eye and tissue donation for transplantation in Australia. In January 2008, the Taskforce submitted its final report, which was intended to serve as the 'road map' for reform of the sector with a view to lifting the organ donor rate in the future. This report identified significant systemic problems within the Australian organ donation and transplantation sector, and contained six critical areas for action and 51 separate recommendations for improving Australia's organ donation and transplantation system. On 2 July 2008, the Rudd Labor Government announced a proposed national reform package intended to 'establish Australia as a world leader in organ donation for transplantation'.¹ The reform package was endorsed by the Council of Australian Governments on 3 July 2008, and a Bill to implement the measures contained in the package introduced to the Parliament on 18 September 2008.² The proposed package follows in all its essentials the recommendations of the Taskforce.

It is likely that implementation of a number of the Taskforce's recommendations would improve the rate of organ donation and transplantation in Australia, at least in the short- to medium-term. International experience and, closer to home, South Australia's experience, has shown that a standardised donation process in hospitals, combined with a proactive donor detection program performed by well-trained transplant coordinators, can help to convert many potential donors into actual donors.³

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1. N. Roxon and K. Rudd, *\$136.4 million national plan to boost organ donation and save lives*, media release, 2 July 2008, http://parlinfoweb.aph.gov.au/piweb/TranslateWIPILink.aspx?Folder=pressrel&Criteria=CITATION_ID:6NYQ6, accessed on 1 September 2008.
 2. Australian Organ and Tissue Donation and Transplantation Authority Bill 2008.
 3. For an analysis of the reasons behind South Australia's success in organ donation rates relative to Australia's other states and territories, see Australians Donate, *Review of factors influencing the Donor Organ Rate in South Australia*, available from http://www.australiansdonate.org.au/index.php?option=com_content&task=view&id=43&Itemid=80, accessed 4 August 2008. The National Organ Donation Collaborative, established in July

However, the Taskforce's recommended changes are neither likely to meet the existing need for organs, nor to provide for a sustainable supply of organs into the future.

In certain key respects, the Taskforce's considerations may be viewed as being confined within the terms of a 'gift of life' doctrine. This doctrine emphasises that donation is and must be grounded in altruism and egalitarianism. Such a doctrine does not allow for consideration of a number of possible options for improving organ donation systems' operations and for expanding the amount of organs available for transplantation—options that have been implemented in other countries. To the extent that the Taskforce did not depart from aspects of the 'gift of life' doctrine, the range of options proposed by the Taskforce for improving the organ donation system in Australia, and for expanding the number of organs available for transplantation, was delimited. In the terms of its own analogy, it may be argued that the Taskforce provided the government with only a partial 'road map' for reform, one that represents only a portion of the territory. Moreover, in as much as the Taskforce's 'road map' does not challenge the principles that are central to the 'gift of life' doctrine, it is, arguably, premised on a flawed and unrealistic notion of organ donation, and of human nature.

The paper is divided into two separate parts. The first part is largely descriptive. It examines the organ donation sector in Australia as it currently stands, and the National Clinical Taskforce's assessment of this sector. The paper then identifies the perceived merits of the Taskforce's recommendations for change, and the source of the constraint on the Taskforce's recommendations for reforms.

The second part of the paper explains an alternative basis and approach to organ donation in Australia. It discusses the 'gift of life' and problems with this doctrine, before identifying policy options for improving organ donation in Australia that are foreclosed through such a doctrine. Specifically, the paper considers opt-in versus opt-out (or presumed consent) arrangements, questions of transparency and informed consent in donation, the issue of directed and non-directed donation, next-of-kin consent arrangements and the option of payment and incentives for organ donation.

2006, saw donation rates rise by 36 per cent compared to the average result over previous years in participating hospitals. This Australian initiative was based on the US Organ Donation Breakthrough Collaborative which began in 2003 and claimed success in lifting donation rates through promotion of known best practice in terms of hospital procedures. See Australians Donate, *Collaborative hospitals increase organ donor rates by one third*, media release, 18 February 2007, http://www.australiansdonate.org.au/images/downloads/DonationsIncreased_FinalRelease18Feb07.doc, accessed on 27 August 2008, and Institute of Healthcare Improvement, 'Spreading the Gift of Life: Organ Donation Breakthrough Collaborative', <http://www.ihl.org/IHI/Topics/Improvement/ImprovementMethods/ImprovementStories/SpreadingtheGiftofLifeOrganDonationBreakthroughCollaborative.htm>, accessed on 27 August 2008.

Part 1

Organ donation

Organ donation involves the removal of tissue from one person's body to allow the transplantation of that tissue into another person's body. Whole organs such as the heart, lungs, liver, pancreas and kidneys can be donated, as well as sections of tissue such as heart valves, corneas, tendons and skin. Organs and tissue are usually removed from people who have recently died. Indeed, because organs for transplantation need to be removed soon after death, very few people die in a way that enables them to donate organs. However, kidneys and parts of the liver and pancreas may also be removed for transplantation from living donors. The removal of organs and tissue is a surgical procedure that, in Australia, takes place in a hospital operating theatre. Organ transplantation is an effective procedure for those people who are facing the possibility of organ failure, leading to debility or death.

Organ donation in Australia

The process of donating and transplanting organs in Australia is complex and involves a large number of people and organisations acting in diverse roles. Apart from individual donors and recipients and their families themselves, there is a large organ transplantation sector and many mechanisms in place to allow for transplantation to occur.

The National Clinical Taskforce has identified a number of key stakeholders that make up the organ donation and transplantation sector in Australia. These stakeholders, along with the roles they fulfil, are:

- regulatory bodies, such as the Therapeutic Goods Administration (TGA), are responsible for regulation and licensing, and the National Health and Medical Research Council (NHMRC) provides advice on ethical issues
- professional colleges and societies are involved in developing clinical guidelines and representing health workers. Professional education programs are developed through agencies such as the Australasian Donor Awareness Program (ADAPT)
- eye and tissue banks, which are usually state-based, coordinate the retrieval of eyes, bones, skin, heart valves and musculoskeletal tissue
- state-based organ donation agencies are responsible for promoting and coordinating organ donation within their jurisdictions
- transplant centres within hospitals are specialised locations where transplantation of certain organs can occur

- organ donation-related data collection is primarily undertaken through the Australia and New Zealand Organ Donation Registry (ANZOD). ANZOD draws together information collected through organ-specific registries
- the Australian Organ Donor Register (AODR) and the NSW Roads and Traffic Authority act as registers of consent for the donation of organs following death, and
- community organisations, including peak bodies and foundations, develop awareness campaigns, while other disease-specific groups such as Kidney Health Australia are also involved in promoting organ donation.⁴

Statistics

A wide range of data on organ donation and transplantation in Australia, including rates of donation, characteristics of organ donors and rates and outcomes of organ transplantation, are collected and made available. The following tables present the most recent available data from the Australia and New Zealand Organ Donation Registry (ANZOD) on actual deceased donors along with a summary of actual deceased donor and donors per million population (dpmp) rates by year and by state and territory for the years 1989 to 2007.

These data indicate that the overall number of organ donors in Australia has remained relatively constant over the years, with some variation evident between jurisdictions. The median rate of dpmp for Australia as a whole is 10 dpmp. As indicated above, in terms of dpmp, South Australia has consistently out-performed the other states, with a median rate of 17 dpmp.

There are no accurate figures available on what percentage of those who have died were potential organ donors. Obtaining statistics on the number of potential donors has been identified as a crucial factor in being able to improve actual donation rates as well as to assist in comparing the performance of different methods used to improve rates.⁵ The Australian Organ Donor Register (AODR) states that less than one per cent of all those who die in hospital each year are declared brain dead and are able to donate their organs.⁶ However, a 2006 study of potential donors in Victorian hospitals found that it was the practice of some clinicians to not formally diagnose brain death in patients unless family members have consented to organ donation.⁷ This study audited deaths in 12 hospitals between 2002 and

4. National Clinical Taskforce on Organ and Tissue Donation, *Final Report – 2008: Think nationally, act locally*, Department of Health and Ageing, Canberra, 2008, p. 34.

5. *ibid.*, p. 145.

6. Medicare Australia, 'Frequently-asked AODR questions', 2008, <http://www.medicareaustralia.gov.au/public/services/aodr/faq.jsp#N100D5>, accessed on 3 September 2008.

7. H. Opdam and W. Silvester, 'Potential for organ donation in Victoria: an audit of hospital deaths', *Medical Journal of Australia*, vol. 185, no. 5, 4 September 2006, p. 251.

2004. Of 17 230 deaths, 106 were actual donors. Of the remainder, 280 were identified by the audit as realistic potential donors and 116 as potential donors with next-of-kin consent.⁸ These figures indicate that 1.6 per cent of all hospital deaths in the audited hospitals were realistic potential donors. The study found that there was a next-of-kin consent rate of 53 per cent and, after taking into account the unavoidable loss of 10 of the potential donors with next-of-kin-consent, only 38 per cent of potential donors became actual organ donors.⁹ Although the number of potential organ donors is not entirely clear, the study of Victorian hospitals and AODR figures indicate that this number is very low, and highlight the importance of maximising the actual donors within this cohort.

The final tables in this section detail the number of Australians on waiting lists for organs by type of organ and jurisdiction as well as over time. Waiting list numbers for organ transplantation have not changed significantly over the past decade. A significant majority of those patients on organ transplant waiting lists are awaiting kidney transplants, with livers and lungs the next most frequent organs in demand. In 2006, the average waiting time for a kidney transplant was 3.79 years from a deceased donor and 1.38 years from a living donor. In the same year, the average waiting time for a liver transplant was 205 days, for a heart transplant, 145 days and for a lung transplant, 187 days. The mean waiting time for a pancreas in 2006 was 1.9 years and for a pancreas islet, 1.4 years.¹⁰

8. *ibid.*, p. 253.

9. *ibid.*

10. National Clinical Taskforce on Organ and Tissue Donation, *op. cit.*, p. 67.

2008 monthly totals - number of actual deceased donors

	Jan	Feb	Mar	Apr	May	Jun	Jul	Aug	Total
ACT	1	0	0	0	1	0	0	2	4
NSW	5	6	2	4	4	5	10	6	42
NT	0	0	0	1	1	0	1	0	3
QLD	6	4	2	3	6	5	3	7	36
SA	3	4	3	2	3	1	4	6	26
Tas	0	0	2	0	1	0	1	2	6
Vic	10	4	8	3	5	5	1	7	43
WA	1	0	2	4	1	2	2	3	15
Australia	26	18	19	17	22	18	22	33	175

Summary of donors by year 1989–2007: number of actual deceased donors

	ACT	NSW	NT	QLD	SA	Tas	Vic	WA	Australia
1989	3	86	2	37	19	2	65	17	231
1990	5	74	1	38	27	2	45	11	203
1991	4	72	2	46	15	2	45	23	209
1992	0	70	0	66	20	4	42	14	216
1993	6	68	3	44	23	6	52	19	221
1994	2	71	1	38	23	6	26	16	183
1995	7	60	1	34	23	4	38	17	184
1996	6	63	3	35	25	1	49	12	194
1997	4	65	4	37	25	5	42	8	190
1998	2	63	3	40	35	0	40	13	196
1999	2	48	3	20	30	6	42	13	164
2000	5	55	2	37	30	1	44	22	196
2001	7	47	2	48	25	3	40	13	185
2002	6	55	2	44	31	6	47	15	206
2003	8	46	1	40	22	2	42	18	179
2004	6	63	1	39	39	2	45	23	218
2005	9	54	4	35	20	2	50	30	204
2006	4	49	2	36	36	8	46	21	202
2007	1	53	3	39	27	1	55	19	198
Total	87	1162	40	753	495	63	855	324	3779

Summary of donors by year 1989-2007: donors per million population

	ACT ^a	NSW ^a	NT	QLD	SA	Tas	Vic	WA	Australia
1989	11	15	12	13	13	4	15	11	14
1990	18	13	6	13	19	4	10	7	12
1991	14	12	12	16	10	4	10	14	12
1992	0	12	0	22	14	9	9	8	12
1993	20	11	17	14	16	13	12	11	13
1994	7	12	6	12	16	13	6	9	10
1995	23	10	6	10	16	8	8	10	10
1996	12	10	16	10	17	2	11	7	11
1997	8	11	21	11	17	11	9	4	10
1998	4	10	16	12	23	0	9	7	10
1999	4	8	16	6	20	13	9	7	9
2000	10	9	10	10	20	2	9	12	10
2001	14	7	10	13	17	6	8	7	10
2002	12	9	10	12	20	13	10	8	10
2003	15	7	5	11	14	4	9	9	9
2004	12	10	5	10	25	4	9	12	11
2005	17	8	20	9	13	4	10	15	10
2006	7	7	10	9	23	16	9	10	10
2007	2	8	14	9	17	2	11	9	9
Median	12	10	10	11	17	4	9	9	10

^a NSW population excludes residents of the Southern Area Health Service (included in ACT population)

Source: Australia and New Zealand Organ Donation Registry (ANZOD), 'Summary of Organ Donation 2008': <http://www.anzdata.org.au/anzod/Updates/anzodsummary.htm#Donors>, accessed on 12 August 2008.

Waiting lists

Waiting lists for organs (number of people): January 2008

Organs	NSW/ACT	QLD	SA/NT	VIC/TAS	WA	Australia
Kidney	731	124	69	368	96	1388
Liver	64	32	18	37	12	163
Heart	26	6		13	8	53
Heart/Lung	2	1		3		6
Lung	30	13		51	6	100
Pancreas/Kidney	22			16		38
Pancreas only	1			1		2
Pancreas Islets	4			3		7
Total	880	176	87	492	122	1757

Source: Australia and New Zealand Organ Donor Registry, *Registry Report 2008*, ANZOD, <http://www.anzdata.org.au/anzod/ANZODReport/anzodreport.htm#2008>, accessed on 26 August 2008.

Number of donors, transplants and number on waiting list 1991-2007

	Donors	Transplants	Waiting List
1991	209	662	1308
1992	216	719	1706
1993	221	717	1529
1994	183	674	1678
1995	184	699	1839
1996	194	686	1697
1997	190	706	1766
1998	196	692	1711
1999	164	564	1788
2000	196	675	1764
2001	185	616	1955
2002	206	721	1788
2003	179	634	1824
2004	218	789	1663
2005	204	736	1716
2006	202	740	1690
2007	198	668	1757

Sources: Australia and New Zealand Organ Donor Registry, *Registry Report 2008*, ANZOD, <http://www.anzdata.org.au/anzod/ANZODReport/anzodreport.htm#2008> and *Registry Report 2002*, <http://www.anzdata.org.au/anzod/v1/AR-2002.html>, accessed on 26 August 2008.

Policy and legislation

Under Australia's federal legal system, legal regulation of organ donation is the responsibility of the states and territories. Each state and territory has separate legislation covering organ donation and transplantation, including laws governing consent for organ donation. Not only is there no Commonwealth legislation governing organ donation, but there is also no national coordinating body or agency with legislated powers. As a result, legislation and regulation of Australia's organ donation and transplantation sector, which covers a broad range of activities and procedures, differs across the country. While there is no Commonwealth legislation concerning organ donation, there are some general guidelines and protocols that are applicable to all states. These guidelines and protocols are discussed below.

Consent

State and territory legislative frameworks relating to transplantation are based on the notion of informed consent. Individuals can choose to express consent for their organs to be taken in the event of their death. Where people give their consent for their organs to be used for transplantation purposes, this consent is recorded on a centralised register. This consent takes the form of a legal agreement that their organs can be used, if needed, for transplantation. However, registration of consent is not a legally-binding directive. Under different state and territory legislation, consent can be expressed in a variety of different ways. In NSW and Queensland, for example, donation may only proceed where the deceased has previously given written consent. In Victoria, consent can be given in writing or orally during the last stages of illness of the deceased. In other states and territories, the form that the expression of consent for organ donation must take is not specified.

In cases where no legal consent has been registered, next-of-kin or close family members are able to give consent for organs of the deceased to be donated. Where the deceased person's next-of-kin cannot be contacted, the states and territories differ with regard to the question of whether or not they allow donation to proceed. In NSW, WA and Tasmania, where no consent was registered by the deceased and a next-of-kin cannot be contacted, donation may not proceed. In Victoria, SA, NT and ACT, where reasonable attempts have been made to contact the next-of-kin and there is no reason to believe that either the family or the deceased would object to the deceased's organs being donated, then donation can lawfully proceed.¹¹

Not all state and territory legislation requires that family members be consulted as to whether or not organ donation should occur. However, in practice, whether or not an individual has expressed their consent for donation, family members are always consulted.¹² Donation will not occur where family members are strongly opposed to such a procedure, even when the deceased person's consent has been registered.

11. National Clinical Taskforce on Organ and Tissue Donation, *op. cit.*, p. 125.

12. *ibid.*, p. 43.

Definition of death

For the purposes of organ donation and transplantation within a given jurisdiction, it is necessary to have an agreed-upon definition of death. The two most frequently used definitions are brain death and/or cardiac death.

In 1977, an Australian Law Reform Commission (ALRC) report on organ donation and transplantation recommended that a statutory definition of death be introduced into Australian law that could be applied generally, and not only in the context of transplantation.¹³ All state and territory legislation that applies to organ donation includes a definition of death, with the exception of SA and WA. South Australia has the separate *Death Definition Act 1983* and WA legislation does not explicitly define death. The ALRC report recommended that death be defined as either the 'irreversible cessation of all function of the brain of the person' or 'irreversible cessation of circulation of blood in the body of a person'.¹⁴ Although these definitions leave the determination of detailed criteria to medical professionals (see below), they form the basis of state and territory statutory definitions. The definition used in Queensland's *Transplantation and Anatomy Act 1979* is used only for the purposes of that particular act.

As indicated above, Western Australia is the only state or territory not to include a definition of death in its legislation. However, the section of the WA *Human Tissue and Transplant Act 1982* relating to the authority of designated officers, states that tissue or organs shall not be removed from a body for the purposes of transplantation unless two medical practitioners with specific qualifications (that vary from state to state) have declared that the 'irreversible cessation of all function of the brain of the person has occurred'.¹⁵

The main pieces of state and territory legislation relating to organ donation and transplantation are the:

- *Transplantation and Anatomy Act 1978* (ACT)
- *Human Tissue Act 1983* (NSW)
- *Human Tissue Transplant Act 1979* (NT)
- *Transplantation and Anatomy Act 1979* (QLD)
- *Transplantation and Anatomy Act 1983* (SA)

13. Australian Law Reform Commission, *Human Tissue Transplants*, AGPS, Canberra, 1977, p. 63.

14. *ibid.*

15. Section 24(2) of the Human Tissue and Transplantation Act 1982 (WA).

- *Human Tissue Act 1985* (Tas)
- *Human Tissue Act 1982* (Vic) and the
- *Human Tissue and Transplant Act 1982* (WA).

Australian Organ Donor Register

The Australia Organ Donor Register (AODR), which is overseen by Medicare Australia, is now the primary register of consent in Australia. It is a register of consent for donated organs to be used for transplantation purposes alone, and not for scientific or other purposes. The AODR was established in 2000 as a national register of people's intent to donate. Following a review in 2004–05, the Australian Health Ministers' Conference (AHMC) decided that the AODR would be changed from a register of *intent* to a register of *consent*. The stated aim of this change was 'to ensure that the known wishes of the deceased, whether consenting or objecting, are respected and followed through'.¹⁶ However, as indicated above and discussed in further detail later in this paper, to register consent is not to make a legally-binding directive. In most states and territories, legislation only makes provisions for the expression of a *wish* to donate. Therefore, as it stands, the AODR can not meet the stated aims of the AHMC.

It is currently possible to register consent, intent to consent or an objection to donation. Registrations of consent or objection to organ donation are only possible for people who are over the age of 18, through signing the appropriate form. Registrations of intent can be performed online by anyone over the age of 16 with a Medicare number. A registration of an objection to organ donation by the person concerned is recognised by most jurisdictions in Australia, and will override any other decision made by a family member. However, based on anecdotal evidence, the National Clinical Taskforce has reported that, in some jurisdictions, donation can still occur if the next-of-kin have given their consent, despite a registered objection by the deceased.¹⁷

NSW and SA continue also to operate their own donor registration system through the Roads and Traffic Authority and Transport SA, respectively. Under this system, individuals are able to indicate their consent or objection on their driver's licence application form (in addition to registration on the AODR). Before the introduction of the AODR, all states collected information on organ donation through the driver's licence application process. Almost all of the state-collected registration data was transferred to the AODR as registrations of intent.

16. Australian Health Ministers' Conference, *Joint Communiqué: Transplant donor's wishes to prevail*, media release, 28 January 2005, <http://www.health.gov.au/internet/main/publishing.nsf/Content/health-mediarel-yr2005-jointcom-jc005.htm>, accessed on 26 August 2008.

17. National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 128.

Some concerns have been expressed regarding the quality of these data.¹⁸ Consent registrations transferred to the AODR can be accepted as consent to donate in all jurisdictions except Queensland. SA continues to collect registrations but provides the information to the AODR. NSW does not automatically transfer registrations it collects through the RTA to the AODR.

Ethical guidelines

Following the changes made to the AODR in 2005, the Australian Health Ministers' Advisory Council (AHMAC) charged the National Health and Medical Research Council (NHMRC) with undertaking a review of its guidelines, *Recommendations for the Donation of Cadaveric Organs and Tissues for Transplantation* (1996). This review also considered background papers from the Australian Health Ethics Committee and conducted consultations with relevant groups and stakeholders. The new NHMRC guidelines, *Organ and Tissue Donation After Death, For Transplantation*, provide a guide to ethical standards relating to organ donation for health professionals. The guidelines are based on the principles that:

- donation of organs and tissues is an act of altruism and human solidarity
- organs and tissues for transplantation should be obtained in ways that:
 - demonstrate respect for all aspects of human dignity
 - respect the wishes, where known, of the deceased
 - give precedence to the needs of the potential donor and the family over the interests of organ procurement
 - as far as possible, protect recipients from harm and
 - recognise the needs of all those directly involved, including the donor, recipient, families, carers, friends and health professionals
- organ and tissues should be allocated according to just and transparent processes
- the choice not to donate should be respected and the family shown understanding for the decision.¹⁹

18. *ibid.*

19. National Health and Medical Research Council, *Organ and Tissue Donation After Death, For Transplantation*, NHMRC, 2007, p. 5, available from http://www.nhmrc.gov.au/PUBLICATIONS/synopses/e70_1_4_5syn.htm, accessed on 1 September 2008.

The guidelines also provide advice as to how authorisation of donation should be determined where there is no next-of-kin available, as well as providing ways to ensure that family members make an informed decision regarding the donation of the deceased's organs.

Clinical guidelines and protocols

A number of guidelines and protocols have been prepared to guide the clinical procedures involved in organ donation. The primary protocols are the *Australian and New Zealand Intensive Care Society (ANZICS) Statement on Death and Organ Donation*, the *Australian Transplant Coordinators Association National Guidelines for Organ and Tissue Donation*, and the Transplantation Society of Australia and New Zealand's protocols on organ allocation.

The purpose of the *ANZICS Statement on Death and Organ Donation* is to provide a resource for intensive care specialists and other health care workers who are involved in the determination of death and the care of potential organ donors.²⁰ The statement emphasises a view of death as a process rather than as an event and, in keeping with this emphasis, the determination of death indicates that an irrevocable point in this process has been reached, and not that the process has ended.²¹ A determination of when this irrevocable point has been reached with the occurrence of brain death requires that: there is unresponsive coma, there are no brainstem reflexes, and the respiratory centre has ceased to function. These function failures must be considered irreversible and there must be clear evidence (through clinical tests or imaging) of the irreversible loss of neurological function.²²

The ANZICS statement points out that the definition of brain death that is used in Australia and New Zealand is different from that which is primarily used in the United Kingdom, in that whole brain death must occur to meet legal requirements for the determination of death in Australia and New Zealand, whilst in the UK brainstem death is the standard (even when there is still blood flow in other cerebral areas).²³ The ANZICS statement outlines the clinical tests that may be used in making a determination of brain death and makes clear that it is more difficult to ascertain brain death in infants, requiring slightly different procedures.

The ANZICS statement also provides detail on the determination of death for cases of donation after cardiac death. Cardiac death was the primary determinant of death for the purposes of organ donation prior to the recognition of brain death as death. Circulation is maintained for the removal of organs from brain-dead patients. This allows for the

20. Australian and New Zealand Intensive Care Society, *ANZICS Statement on Death and Organ Donation*, (Draft, Version 29), ANZICS, p. 7, <http://www.anzics.com.au/uploads/ANZICSDODstatement-v29.pdf>, accessed on 1 September 2008.

21. *ibid.*, p. 9.

22. *ibid.*, p. 10.

23. *ibid.*

preservation of organs and for an extended timeframe in which to proceed to donation. However, organs can also be removed and used for transplantation within a short period following cardiac death. In the past, it was mostly kidneys that were able to be successfully transplanted following cardiac death.²⁴ Following improvements in clinical procedures and the development of specific protocols for the donation of organs after cardiac death there has been an increase in the number of organs such as livers and lungs that are available for transplantation.²⁵ Donation after cardiac death usually occurs where patients are not considered to fulfil brain death criteria but are awaiting cardiac arrest and will not survive. Treatment is withdrawn from these patients following family discussion and agreement.²⁶ Donation can also occur following cardiac arrest in a patient already considered brain dead.

The ANZICS statement also takes a stance on a number of other issues, including questioning the validity of consent registered with the AODR:

Opinions differ on whether a person can truly “consent” to the performance of a post-mortem process on their body and whether the concept of “autonomy” persists after death. The situation is not analogous to an advance directive for personal health services ... Even if “consent” were possible under these circumstances, the process of registration in the AODR does not meet the general standard of “informed consent for personal healthcare”.²⁷

ANZICS supports the view that any objection by the family to organ donation, even when it is in conflict with the known intention of the deceased, should be respected. In keeping with this stance, ANZICS does not endorse any sort of pressure being placed on the family to acquiesce to the deceased’s wishes (although it does concede that it is reasonable that those wishes be discussed) including any recommendation that compliance with these wishes is expected, mandated by law or regulation, or is of a greater moral worth.²⁸

The *Australasian Transplant Coordinators Association National Guidelines for Organ and Tissue Donation* provide similar clinical guidelines to those contained in the ANZICS statement, albeit with more detail on transplantation procedures and specific clinical methods.

24. P. Mohacsi et al, ‘Donation and retrieval of cadaveric organs in Australia: Accepting the challenge’, *Medical Journal of Australia*, vol. 158, 18 January 1993, p. 122.

25. ANZICS, Statement on Death and Organ Donation, op. cit., p. 36.

26. See Australian and New Zealand Intensive Care Society, *Statement on Withholding and Withdrawing Treatment – Version 1*, ANZICS, Melbourne, 2003, <http://www.anzics.com.au/uploads/200407/withholdwithdraw.pdf>, accessed on 1 September 2008.

27. ANZICS, Statement on Death and Organ Donation, op. cit., p. 26.

28. *ibid.*

These guidelines also differ from the ANZICS statement in that they provide an overview of different religious views on organ donation.²⁹

The Transplantation Society of Australia and New Zealand's organ allocation protocols provide guidelines for assessing the suitability of organs for transplantation and for determining their allocation to recipients. There are separate protocols for liver, pancreas, heart, lung, kidney and cornea transplantation, as well as basic principles regarding the exchange of organs between Australia and New Zealand. The exchange of organs between the two countries is not based on a formal inter-governmental agreement but upon operational agreements between relevant agencies.

National coordination and registries

The first national coordinating body established to deal with issues relating to organ donation was AHMAC's Donor Organ Working Party, established in 1987. This body identified some of the key issues facing the transplantation sector, including the fragmented nature of coordination, separate procedures in each state for donation and procurement, limited information for the development of awareness campaigns and inadequate funding of coordination mechanisms.³⁰ In response, AHMAC established the National Coordinating Committee on Organ Transplantation in 1989 which was later revised and became the Australian Coordinating Committee for Organ Registries and Donation (ACCORD). ACCORD was responsible for the development of the Australasian Donor Awareness Program (ADAPT), aimed at the education of medical professionals involved in the donation process, and the setting up of heart-lung, liver, pancreas, and bone marrow registries. ACCORD also established the National Organ Donor Registry in 1990. This registry is now known as the Australia and New Zealand Organ Donation Registry (ANZOD). ANZOD now functions as a collaborative effort between the Australasian Transplant Coordinators Association and the Australia and New Zealand Dialysis and Transplant Registry, compiling data on donation and transplantation in Australia and New Zealand.

Until recently, Australians Donate served as the officially recognised peak national body for organ donation for transplantation purposes. Australians Donate was established by the Commonwealth Government 'in recognition of the need for a more concerted, coordinated national donation and transplantation program'.³¹ The organisation was charged with raising public awareness about organ donation and with developing programs to increase rates of

29. Australasian Transplant Coordinators Association Incorporated, *National Guidelines for Organ and Tissue Donation*, 3rd Edition, ATCA, 2006, pp. 18–21, <http://www.atca.org.au/files/ATCA%20guidelines%20online%20oct06.pdf>, accessed on 1 September 2008.

30. National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 35.

31. M. Coleman, 'Handing over ... Australians Donate 2002–2008', http://www.australiansdonate.org.au/index.php?option=com_content&task=view&id=44&Itemid=81, accessed on 28 August 2008.

organ donation in Australia. A 2007 review of Australians Donate found that the organisation was not successful in meeting many of its objectives and had not performed effectively in terms of acting as a peak body or in terms of project delivery.³² As a result, Australians Donate was disbanded on 1 April 2008 and, following the recommendations of the National Clinical Taskforce on Organ and Tissue Donation, legislation to establish a proposed new national organ and tissue donation authority was introduced to the Parliament on 18 September 2008.

History

Transplantation in Australia

The transplantation of tissue and organs began in Australia in the 1940s, with the first report of a cornea transplant appearing in the *Medical Journal of Australia* in 1941.³³ The first Australian attempt at a kidney transplant from a deceased donor occurred at the Royal Melbourne Hospital in 1956, but was unsuccessful. Following a number of organ transplantation successes overseas and the development of improved methods, further liver transplants were undertaken in Australia in 1963 and 1964. However, in each case, the transplanted organs only functioned for a very short period of time. The first noteworthy success in renal transplantation in Australia occurred at the Queen Elizabeth Hospital in Adelaide in 1965, with the live transplantation of a kidney to a young man from his father-in-law, who shared the same blood type. The kidney began working immediately and continued to do so for 10 years, after which the recipient died from liver failure.³⁴ Successful liver, heart, pancreas, lung and bone marrow transplants were to take place in the following decades. The first Australian heart transplant was undertaken in 1968, but the recipient only survived for a further 45 days. Subsequent attempts were made at heart transplantation, but it was not until the establishment of the National Heart Transplant unit at St Vincent's Hospital in Sydney in 1983 that high success rates in heart transplantation were achieved.

A number of factors have influenced the success or otherwise of tissue and organ transplantation in Australia and elsewhere. These include the development of surgical techniques in transplantation, the use of different immunosuppressants, the compatibility of donors and recipients, the establishment of cooperative registries nationally to improve the coordination of donation and transplantation, the experimental nature of many of the operations, the shortage of potential donors and, of particular importance, the legal definition

32. Australian Healthcare Associates, *Independent Review of Australians Donate*, AHA, 2007, p. 9, [http://www.health.gov.au/internet/main/publishing.nsf/Content/69D4850C82C168E5CA257295001C692D/\\$File/ADReview_FinalReport.pdf](http://www.health.gov.au/internet/main/publishing.nsf/Content/69D4850C82C168E5CA257295001C692D/$File/ADReview_FinalReport.pdf), accessed on 3 September 2008.

33. J. Chapman, 'Transplantation in Australia: 50 years of progress', *Medical Journal of Australia*, vol. 157, July 6, 1992, p. 46.

34. *ibid.*

of death.³⁵ Prior to the concept of brain death, the clinical criteria for the determination of death were based upon the cessation of respiration and the circulation of blood. This meant that it was necessary to discontinue artificial respiration and to wait until the heart had stopped beating before an organ retrieval operation could begin.³⁶ This delay not only prevented the possibility of routine transplantation of organs such as hearts and lungs, but it also resulted in frequent damage to donated kidneys.³⁷

Transplantation today

The transplantation of organs is now an established procedure for those at risk of end-stage organ failure or suffering from diseases which severely limit their life expectancy. In some cases, a patient's condition may require more than one organ to be transplanted—such as a heart and lungs or kidney and a pancreas. Other transplantation procedures include the replacement of corneas, heart valves and musculoskeletal tissue in the case of, respectively, eye conditions, major heart valve disorders and damaged tissue and skin. Advanced surgical procedures and technological innovations are allowing for greater success in transplantation, for new conditions to be treated, and for an increase in the availability of suitable organs and tissue. One example of this is the procedure of split liver transplantation, in which a small part of a donated liver is able to be transplanted into a child and the larger part of the same liver into an adult. Other procedures being developed and trialled include the use of animal organs and tissue (xenotransplantation), multiple limb transplants, and the growth of organs in laboratories for use in transplantation.³⁸

The international perspective

Legislation, regulation, coordination and medical practice relating to organ donation and transplantation are markedly different in countries around the world. Key differences relate to

35. Immunosuppressants are a class of drugs that suppress the human body's immune responses from recognising or attacking foreign organs or tissues. They are used to prevent the rejection of transplanted organs by the recipient's body.

36. Mohacsi et al, op. cit., p. 122.

37. *ibid.*

38. The National Health and Medical Research Council's moratorium on animal to human transplants is currently being reviewed. See S. Ryan, 'Rethink due on banned transplant of animal organs', *The Australian*, 25 April 2008, http://parlinfoweb.aph.gov.au/piweb/TranslateWIPILink.aspx?Folder=pressclp&Criteria=CITATION_ID:ZE9Q6%3B, accessed on 25 August 2008 and the NHMRC website at http://www.nhmrc.gov.au/health_ethics/health/xeno.htm, accessed 12 August 2008. See also ABC News, 'Medical team completes double arm transplant', 2 August 2008, <http://www.abc.net.au/news/stories/2008/08/02/2322144.htm>, accessed on 25 August 2008 and E. Barry, 'Grow your own organs', *Sunday Herald Sun*, 13 July 2008, http://parlinfoweb.aph.gov.au/piweb/TranslateWIPILink.aspx?Folder=pressclp&Criteria=CITATION_ID:GBZQ6%3B, accessed on 25 August 2008.

the way in which the entire transplantation sector is coordinated nationally, different systems of consent (opt-in and opt-out), the way in which organ donation and transplantation is carried out within hospitals and public attitudes towards and awareness of organ donation. Comparisons between countries typically aim to identify the reasons for widely differing donation rates, both as a means to develop ways to raise rates of donation, and to improve coordination efforts and clinical practice.

Donor rate comparisons

The most widely-used methodology for measuring and comparing organ donation rates internationally is the 'donors per million population (dpmp)' method. This method compares rates of donation against population counts. This statistic does not take into account either the number of potential donors (those located in an intensive care unit and identified as being suitable) or the number of organs taken from each individual donor. Different countries also define 'deceased organ donor' in different ways when compiling their statistics.³⁹ Nevertheless, this method remains the current means of international comparison. The table below compares the rates of various countries, as at 2007.

Country	Total Number	Donors per million population
Spain	1550	34.3
Belgium	291	28.0
France	1604	25.4
USA	7413	24.6
Austria	187	23.6
Italy	1192	20.9
Norway	94	19.9
Germany	1313	16.0
Netherlands	257	15.5
Sweden	133	14.5
Argentina	493	12.2
Poland	352	9.2
Australia	198	9.0
New Zealand	38	9.0
Israel	56	7.7
Iran	170	2.4
Japan	13	0.1

Source: A. Sanz et al, '2007 International donation and transplantation activity. IRODaT preliminary figures', *Organs, Tissues and Cells*, Vol. 1, No. 7–10, 2008, <http://www.etco.org/irodat/new/Irodat07.pdf> accessed on 1 September 2008.

39. National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 112.

The Spanish system

As can be seen from the above table, Spain currently has the highest rate of organ donation in the world—largely due to its commitment to improving organ donation rates throughout the country's entire health care system. As a result, many other countries have drawn on aspects of Spain's organ donation and transplantation sector in an attempt to lift their own rates—selectively so in Australia's case. Elements of the Spanish system that have been emulated by other countries include the national coordination of all aspects of the organ procurement and transplantation system, dedicated organ donation coordinators and transplant teams within hospitals, and presumed consent legislation.

The Organizacion Nacional de Trasplantes (or National Organisation for Transplants-ONT) coordinates organ donation and transplantation activities in Spain. This agency maintains waiting lists, registries, compiles statistics and operates training programs for medical professionals. Within each major hospital specific organ transplant units operate on-call under the direction of designated organ transplant coordinators. Coordinators—who are preferably physicians—work within an intensive care unit and are responsible for recognising potential donors, providing information and counselling to families, and for the organ retrieval process. Regional coordination centres support activities in smaller hospitals. Coordination teams work apart from the surgeons who are actually involved in the process of transplantation, and are therefore focussed on identifying potential donors and on supporting the families of the deceased.⁴⁰

Transplant law in Spain operates under a presumed consent, or opt-out system. However, families must be approached and sign an authorisation in order for the procedure to take place. Presumed consent was introduced in Spain in 1979 but it was not until 1989 when the ONT was established and a comprehensive government effort made that organ donation rates began to rise. In 1989, the donation rate in Spain was 14.3 dpmp. This rate rose steadily over a ten year period and has remained close to the current rate of 34.3 dpmp since. Key contributory factors to the rise in the number of donors in this period were the establishment of national coordinating efforts, a change in donor profiles, with those over the age of 60 coming to represent more than a third of donors, improved identification of potential donors and specific funding for organ donation and transplantation activities in hospitals.⁴¹

The Spanish national health system comprises all facilities and public services devoted to health, with public health care available for almost the entire population.⁴² Organ transplantation has a specific budget allocation which pays for: the organ procurement network, the salaries of coordinators and retrieval teams whilst involved in transplantation activities, any tests to determine donor suitability, ICU bed costs, and training and education

40. B. Miranda et al, 'Optimising Cadaveric Organ Procurement: the Catalan and Spanish Experience', *American Journal of Transplantation*, vol. 3, 2003, pp. 1191–1192.

41. *ibid.*

42. *ibid.*, p. 1190.

programs. The reimbursement by national and regional authorities of hospital costs related to the transplantation process is seen as being of key importance in sustaining the involvement of smaller hospitals in the organ donation process.⁴³

Australia—proposed changes

National Clinical Taskforce on Organ and Tissue Donation

The National Clinical Taskforce on Organ and Tissue Donation was established by the then Minister for Health and Ageing, Tony Abbott, in October 2006. The Taskforce was charged with providing 'evidence-based advice to the Government on ways to improve the rate of safe, effective and ethical organ, eye and tissue donation for transplantation in Australia'.⁴⁴ This advice was to be 'considered by all Australian governments under the framework of the [10 point] National Reform Agenda on Organ and Tissue Donation, agreed to by all state Health Ministers in July 2006'.⁴⁵

The Taskforce, which comprised key stakeholders in the organ, eye and tissue sector, provided an early report to Abbott in December 2006, outlining its intended working approach and key policy directions. It subsequently submitted a mid-term report in June 2007, and its final report in January 2008.⁴⁶ Upon the submission of its final report, the Taskforce was disbanded, with the 51 recommendations and six critical areas for action identified in the report to set the direction or 'road map' for reform of the sector.

Main findings of the report

Donation rates in Australia—poor performance of the sector

In terms of the most frequently used national performance measure for organ donation, the donor rate per million population (dpmp), at 10 dpmp, Australia performs poorly in relation to comparable industrialised nations.⁴⁷ While there are methodological problems related to the dpmp measure and comparisons based upon it, as noted above, it is nevertheless clear that Australia is under-performing where it comes to organ and tissue donation. Australia is

43. R. Matesanz, 'Factors influencing the adaptation of the Spanish Model of organ donation', *Transplantation International*, vol. 16, 2003, p. 737.

44. National Clinical Taskforce on Organ and Tissue Donation Supporting Evidence, op. cit., p. 1.

45. Department of Health and Ageing, Organ Donation, National Clinical Taskforce on Organ and Tissue Donation at <http://www.health.gov.au/internet/main/publishing.nsf/Content/organ-donation-nctf-report.htm>.

46. National Clinical Taskforce on Organ and Tissue Donation, op. cit.

47. The Taskforce notes that, to some extent, this is a result of Australia's strong performance where it comes to population health and safety measures (a reduced rate of road traffic and gun-related fatalities) and improvements in medical technologies.

unable to meet existing demand for organ transplantation and this situation is expected to deteriorate in the future as the ageing of the population and increased incidence of lifestyle diseases—such as obesity and Type 2 diabetes—lead to further increases in demand for donated organs. Even if Australia were to meet the performance goal of 15 organ donors per million population (a 50 per cent increase above trends over the past 10 years), as recommended by the Taskforce, this would only provide organs for up to an additional 370 patients a year.⁴⁸ This figure is well short of existing—not to mention anticipated—demand.

To make matters worse, despite a long list of reports, reviews and organisations that have been created in an attempt to increase the nation's organ donation rate over time, no significant inroads have yet been made.⁴⁹

The Taskforce attributed Australia's inability to increase organ donation rates to a number of factors, chief of which was the fragmented nature of the organ donation and transplantation sector.

Australia's organ donation and transplantation sector—a fragmented system

As noted above, unlike other comparable nations, Australia does not have a national organ donor coordination network or single coordinating agency. Instead, the system is state- and territory-based, with each jurisdiction operating under its own organ and tissue donation-related legislation, procedures and practices. Indeed, not only is there variation between jurisdictions, but also within them, with individual hospitals and clinics operating according to their own different practices.⁵⁰ In short, the sector is characterised by fragmentation and a lack of effective coordination and cohesion. This was viewed by the Taskforce as posing a major impediment to increasing rates of donation and transplantation. A majority of the report's recommendations, which are effectively summarised under six critical areas for action, are oriented towards addressing these structural impediments.

Essentially, the Taskforce highlighted the need for national coordination of all major aspects of Australia's organ donation and transplantation system. These aspects include: communications with the public about donation, clinical triggers and notification protocols to identify potential donors, waiting list criteria and organ allocation protocols and data collection and dissemination on Australia's organ donation and transplantation performance. It proposed the establishment of a national donation and transplantation authority, comprising clinicians and governments, to coordinate on a national basis the above activities and any future organ donation-related reforms.

48. *ibid.*, p. 147.

49. National Clinical Taskforce on Organ and Tissue Donation, *op. cit.*, p. 143.

50. *ibid.*, p. 148. Many barriers to increased organ donation have been identified as lying within Australia's hospital system. See *Medical Journal of Australia*, vol. 182, no. 5, 7 March 2005.

This proposed approach would represent a significant departure from and improvement over existing arrangements. If the recommendation to establish a National Authority were to be taken up through the passing of the Australian Organ and Tissue Donation and Transplantation Authority Bill 2008, this could be the first step on the road to bringing Australia's system into closer alignment with Spain's highly successful nationally coordinated system. While specific aspects of Australia's system have in the past been conducted on a national basis—such as awareness raising and programs for increasing donation rates under Australians Donate—these have not, on the whole, been successful. This is undoubtedly because they were not part of a broader and more consistent program of national coordination.

It is worth noting that the proposed Australian Organ and Tissue Donation and Transplantation Authority is a statutory agency with no legislative power. While the Authority could require compliance with a policy or protocol, standard or code of practice (as determined by the Authority) as a term or condition of financial assistance, it could not compel the states and territories to comply. As a result, were any of the states or territories to choose to introduce an opt-out system—as some have indicated they are considering—they would be free to do so.⁵¹

Discussion

Implementation of the Taskforce's recommendations, with their emphasis on national coordination, would be likely to have a positive impact on both organ donation and transplantation rates. As noted above, nationally coordinated arrangements—especially in the hospital setting—can help to improve rates of actual donors.⁵² Nevertheless, it is unlikely that

51. For example, a Queensland Parliamentary Committee is currently exploring the option of introducing an opt-out system to that state. Among other things, the Committee is seeking crown law advice on whether or not the state could adopt an opt-out system independent of the other states and territories. The Committee is due to report back to state parliament by October 2008. See R. Desmond, 'Opt out system puts organ donation back on agenda', Australian Associated Press, 2 May 2008. A recent summit convened by the Western Australian Government also examined the option of an opt-out system for that state and a large number of MPs in WA have indicated their support for the consideration of such a policy in the state. See D. Guest and Y. Phillips, 'Opt-out scheme "would see organ donations double"', *West Australian*, 20 May 2008 and D. Guest, 'Let's debate organ plan: Hames', *West Australian*, 24 March 2008.

52. On 18 February 2007, Australians Donate Executive Chairman, Marcia Coleman stated that during the first seven months of the National Organ Donation Collaborative (NODC), organ donation rates had increased by more than a third across the 22 participating hospitals. Coleman reported that between July 2006 and January 2007, these hospitals had increased their collective donation rate by 36 per cent compared to the average result for the same period over the previous five years. Australians Donate, '*Collaborative' hospitals increase organ donor rates by one third*', media release, 18 February 2007. From July 2006 to June 2007 the collaborative achieved a total of 135 donors, some 60 per cent of the 225 donors, Australia-wide. In its

these changes alone would be sufficient to solve Australia's current—much less future—organ deficit.

The Taskforce was asked to provide the government with advice across the complete spectrum of donation and transplantation. However, an unstated principle underpinning the Taskforce's activity and eventual recommendations was that there was to be a continued reliance on voluntary donors. Moreover, would-be donors were not to be compelled or pressured in any way to make a decision about whether or not they would donate their organs. As a result, the Taskforce could not be said to have addressed all of the relevant issues.

For example, the Taskforce rejected the introduction of an opt-out, or presumed consent system—such as that implemented in Spain, and being considered by some of the states—as a potential solution to Australia's low donor rate. It did so on the grounds that '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'.⁵³ However, a recent study of opt-in and opt-out systems, conducted over a ten-year period for 22 countries, indicates otherwise. This study concluded that, when other determinant factors affecting donor numbers were accounted for, those countries with opt-out legislation in place had deceased organ donor rates that were 25 to 30 per cent higher than those with opt-in legislation.⁵⁴

In rejecting an opt-out system, the Taskforce also cited the possibility that the introduction of such a system could exacerbate the 'pre-existing element of medical mistrust within the Australian community' as a reason for its recommending that no Australian state or territory

second year of operations, the NODC was expanded to 26 participating hospitals. See *Australians Donate, Newsletter*, March 2008.

53. National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 147. Tim Richards, convenor of the Transplant Waiting List Advocacy Group, has identified some obvious contradictions in the Taskforce's report where it comes to the alternative of an opt-out system for Australia. Richards notes that while the Taskforce highlights the success of the Spanish organ donation system in achieving higher rates of organ donation, and views it as providing a useful model for identifying best practices, the Taskforce goes on to downplay what is arguably the most significant feature of this system: that is, its opt-out basis. Richards also points out that while the Taskforce indicated early in its report that it did not consider that an opt-out organ donation system should be a focus of its work, it then went on to recommend against the introduction of a presumed consent approach in any of Australia's jurisdictions. At various points in the report the Taskforce provides reasons for not introducing an opt-out system in Australia. No corresponding effort is made to identify the potential benefits of an opt-out system. T. Richards, 'Government considers organ donation, 11 people die', *Crikey*, 14 March 2008.
54. A. Abadie and S. Gay, 'The impact of presumed consent legislation on cadaveric organ donation: A cross-country study', *Journal of Health Economics*, vol. 25, 2006, pp. 599-620.

introduce an opt-out system.⁵⁵ The Taskforce went on to express the view that 'a presumed consent system may feed these fears and most likely lead to an increase in the proportion of registrations of objections to donation'.⁵⁶ While the Taskforce claimed that surveys have indicated this level of mistrust, no citations to these surveys were provided. Nor did the Taskforce furnish any other supporting evidence.

In summing up its consideration of the presumed consent option, the Taskforce argued that when Australia's predominant social attitudes and legal traditions are considered, the current system better balances individual rights with the community's need for organ, eye and tissue donation. It is debatable whether or not the current system does indeed better balance individual rights with the need for donation, especially with respect to the arrangements that allow the next-of-kin to overrule a deceased person's decision to donate their organs. This point will be considered in some detail in the course of discussion below.

However, for the moment it is worth noting that the Australian Law Reform Commission (ALRC) has argued that, once the social value of tissue donation in Australia is clear, 'there would be nothing undesirable in [moving toward an opt-out system] because there is little potential for conflict of interest between the community and the individual on this subject'.⁵⁷ The ALRC was supportive of the introduction of an opt-out system as a means to increase the supply of human tissue for transplantation and other purposes, and viewed the introduction of such a system as being simply a matter of time. As the Commission saw it:

It would seem paradoxically, that the more the public accepts the desirability of giving human tissue the more it will tolerate the creation of exceptions to consensual donation, and the closer it will move to a position of 'contracting out' [or, an opt-out system] ... The question is one of changing outlook and of growing acceptance of the use of dead bodies for the relief of suffering of the living. If there develops a community attitude that tissues from dead bodies may be so used, instead of being cremated or interred intact, and that such use is a better demonstration of support for human dignity, people may see [an opt-out system] as an improvement on the present.⁵⁸

In addition to its firm commitment to the maintenance of Australia's existing opt-in arrangements, the Taskforce also sought to preserve the current system's basis in altruism and egalitarianism and its next-of-kin arrangements. The possibility of introducing payment or any other form of consideration for organ donation was certainly off the agenda.

55. National Clinical Taskforce on Organ and Tissue Donation, op. cit., p. 157.

56. *ibid.*

57. Australian Law Reform Commission, *Human Tissue Transplants*, Report no. 7, 1977, para. 26. In 1977, the ALRC conducted an inquiry into the appropriate legislative means of providing laws in the Australian Capital Territory (ACT) for the preservation and use of human bodies for various purposes, including the use of organs and tissues for transplantation.

58. *ibid.*

In a number of important respects, the Taskforce's deliberations were based within the parameters of what may be described as a 'gift of life' doctrine. The main features of this doctrine are described in the following section.

Part 2

The 'gift of life'

What is the 'gift of life'?

The gift of life describes the voluntary donation of blood or organs in which an altruistic individual donates blood, an organ or organs to an anonymous recipient or recipients without expectation of financial or other reward. In theory, where the gift is concerned:

... there is no formal contract, no legal bond, no situation of power, domination, constraint or compulsion, no sense of shame or guilt, no gratitude imperative, no need for penitence, no money and no explicit guarantee of or wish for a reward or return gift. They are acts of free will; of the exercise of choice; of conscience without shame.⁵⁹

Thus, 'the gift' may be contrasted with the buying and selling of blood or organs, wherein blood and/or organs are treated as a commodity to be bought and sold in the marketplace.

Perhaps the staunchest and most influential advocate of the gift (in relation to blood) was British sociologist Richard Titmuss.⁶⁰ In the late 1960s Titmuss conducted a comparative study of the blood transfusion and donor systems of various countries and, in particular, those of Britain and the United States (US). While in Britain all blood was provided by voluntary, unpaid donors, in the US, at that time, a significant proportion of the nation's blood supply came from paid donors. This situation provided Titmuss with a base from which to compare the merits of voluntary, unpaid donation over paid donation.

Titmuss found that there were higher rates of hepatitis in recipients of blood who received blood sourced from paid donors and lower rates among recipients who received blood sourced from voluntary, unpaid donors. This he attributed to voluntary donors' altruistic motivation, which, he argued, meant that it was less likely that they would donate blood that was diseased and that would harm the recipient.

Titmuss' research indicated that paid donors were more likely to be poor and unhealthy and, driven by the need for money, to lie about their health status. Largely as a result of their

59. R. Titmuss, *The Gift Relationship: from human blood to social policy*, Penguin Books, Harmondsworth, England, 1970, p. 102.

60. *ibid.* While Titmuss' analysis of the importance of the gift was set in the context of blood donation, his arguments are, for the most part, applicable to organ donation. The main difference between blood and organ donation is that while blood donation is necessarily 'living' donation, most organ donation is currently from deceased donors.

transient and uncertain circumstances, paid donors were also less likely to be regular contributors. This meant that their health status could not be checked regularly over time and resulted both in an increased risk to the blood supply and an inconsistent supply of blood. This inconsistency in blood supply led to US hospitals frequently running short of blood and to more blood being wasted than in Britain.

In sum, the reliance upon paid donors was found to pose risks to the health and well-being of blood recipients, as well as to result in a less efficient system.

Based on these findings, and on the unique attributes of blood, Titmuss stressed the considered importance of promoting altruism in blood donation. He argued that altruism in blood donation contributes to the 'ties that bind' a society, both through the development of social solidarity between citizens and by providing evidence of the social contract around which a particular society is organised. Because British donors gave their blood without the expectation that they would receive any reward—even a future blood transfusion for themselves or their family, as this could not be guaranteed—Titmuss held that they were signifying their belief in the willingness of others to act altruistically in the future. They were expressing their confidence in the behaviour of future unknown strangers and thus, their faith in the moral sense of their fellows. In effect, for Titmuss, voluntary blood donation was held to reflect important ethical and socio-cultural norms.

It should be noted that in Titmuss' thesis, a clear line is drawn between society and the market. Markets are represented as arenas in which the exchange of goods and services takes place in an impersonal, self-interested and amoral manner, with the ultimate goal that of profit maximisation. This is contrasted with voluntary blood donation systems that are characterised by the moral nature of their transactions, which 'bring about and maintain personal relationships between individuals and groups'.⁶¹

Titmuss was especially clear and emphatic where it came to the considered social importance of the gift and necessity of ensuring that blood should not be treated as a commercial commodity. As he saw it, a voluntary system based on 'the gift' brings out the best in people; it fosters 'the individual expression of altruism and regard for the needs of others'.⁶² In doing so, Titmuss argued, the gift, as well as being ethical, helped to ensure the safety and efficacy of Britain's voluntary, unpaid blood donation system (see above).

Titmuss' work has been hugely influential. On its original publication in 1970 *The Gift Relationship* provoked substantial debate regarding the relative qualities and worth of voluntary unpaid and paid blood and organ donation systems, a debate that continues to this day. It has also contributed to the gift of life's having become the dominant organising principle and doctrine for a majority of the world's blood and organ donation systems. Blood and organ donation is considered an altruistic act in most countries, with legislation in these

61. *ibid.*, p. 82.

62. *ibid.*, p. 17.

countries (including Australia) outlawing any material benefit for donation.⁶³ Not only does the gift doctrine underpin these countries' legislation, but it also dominates in many countries' transplantation systems, education campaigns and campaigns to promote donation.

In Australia's case, the gift of life doctrine is clearly expressed in and underpins the principles that guide the clinical sector and community awareness and education activities. Information provided to the Australian community by the organ donation sector, awareness campaigns, and clinical and ethical guidelines make constant reference to the gift of life doctrine as the basis for current practice. For example, the ANZICS guidelines, *Statement on Death and Organ Donation*, state that current practice is based on the donation of organs and tissues as 'being an unconditional altruistic, non-commercial act'.⁶⁴ The NHMRC guidelines, *Organ and Tissue Donation After Death, For Transplantation*, adhere to the same principle. They state that 'donation of organs and tissues is an act of altruism and human solidarity that potentially benefits those in medical need and society as a whole'.⁶⁵ The AODR website emphasises that organ donation is 'the greatest gift one human being can give another – the gift of life', and state-based agencies make constant reference to 'the gift'.⁶⁶

Thus, voluntary blood and organ donation has come to be viewed as a selfless and altruistic act, and one that should not be compelled in any way. As such, the act has been associated with strong moral connotations. This poses a number of problems, as outlined below.

Problems with 'the gift'

Organ donation is not necessarily an heroic act; nor is it necessarily a moral act. People do not always or entirely donate their organs for selfless or altruistic reasons.⁶⁷

63. L. Wright, 'Is presumed consent the answer to organ shortages', *British Medical Journal*, vol. 334, 26 May 2007, p. 1089.

64. ANZICS, *Statement on Death and Organ Donation*, op. cit., p. 9.

65. NHMRC, op. cit. p. 5.

66. Medicare Australia, 'Organ donor register', 2008, <http://www.medicareaustralia.gov.au/public/services/aodr/index.jsp>, accessed on 4 September 2008.

67. The same holds for volunteering. Former Chief Executive Officer of Volunteering Australia, Sha Cordingley has noted that very few people volunteer out of a pure sense of altruism. If volunteering is to become sustainable, she has argued, people have to 'get something as well as give something'. Other commentators have observed that there is more to volunteering than selfless unpaid work. Indeed, Kerbaj argues that 'voluntary organisations are well aware that some people, if not most, are eager to advance their personal status through volunteering'. R. Kerbaj, 'What's in it for me', *The Australian*, 10 May 2005. This poses a challenge for community organisations, which have to be prepared to invest time and energy in their volunteer programs and to be creative in their approach if they are to recruit and retain volunteers. See D. Morgan, 'Volunteers aren't in it for nothing', *Courier-Mail*, 6 October 2000.

For example, Siminoff and Chillag found that families of deceased donors often regard organ donation as a way of giving meaning to the death or of allowing the person to 'live on' in others.⁶⁸ In the case of living organ donors, they found that these spouses and siblings need not be acting primarily out of a sense of altruism, but rather to experience the personal reward of seeing the recipient's well-being restored.⁶⁹ Matas observes in a similar vein that where living organ donation takes place, there is often a component of family pressure or of secondary gain.⁷⁰

The Institute of Medicine of the National Academies argues that the motives of organ donors are no less complex than those of regular gift givers. These, the Institute contends, may reflect 'a combination of generosity, perceived obligation, and a desire to be regarded with favour'.⁷¹ But it is not only recent commentators who have questioned the notion that it is primarily altruism that drives people to donate their organs, and that underpins the gift. Indeed, Titmuss himself acknowledged that blood donors give their blood for a variety of different reasons:

No donor type can, of course, be said to be characterised by complete, disinterested, spontaneous altruism. There must be some sense of obligation, approval and interest; some awareness of need and of the purposes of the blood gift; perhaps some organised group rivalry in generosity; some knowledge that fellow-members of the community who are young or old or sick cannot donate, and some expectation and assurance that a return gift may be needed and received at some future time.⁷²

To 'donate', Titmuss notes, is to 'give implying an altruistic motive'.⁷³ Thus, based on his above observation, and the fact that his study dealt with paid as well as unpaid blood donors, Titmuss remarked that, strictly speaking, he should have used the term 'suppliers' rather than 'donors' in the context of his survey.

All this is not to suggest that altruism plays *no* role in people's decision whether or not to donate their organs; clearly it does, to a greater or lesser degree. It is, instead, to point out that

68. L. Siminoff and K. Chillag, 'The fallacy of the 'gift of life'', *Hastings Centre Report*, 29: 6, 1999, pp. 34–41.

69. *ibid.*

70. A. Matas, 'A Gift of Life deserves compensation. How to increase living kidney donation with realistic incentives', *Policy Analysis*, 604, 7 November 2007, p. 8. It is thus also necessary to question in these instances whether or not the gift is a *voluntary* act. The National Health and Medical Research Centre guidelines *Organ and Tissue Donation by Living Donors: Guidelines for Ethical Practice for Health Professionals* consider the issue of ensuring that living organ donation is a result of non-coerced choice.

71. Institute of Medicine of the National Academies, *Organ Donation – opportunities for action*, National Academies Press, Washington, 2006.

72. Titmuss, *op. cit.*, p. 111.

73. *ibid.*, p. 81.

it is mistaken on empirical grounds to base a donation or gift system (entirely) in altruism and morality. While flattering, such a position presents neither an accurate nor a complete picture of the phenomenon—the act—itsself.

At the same time, a romanticised view of organ donation and human nature, and an insistence on pure altruism and voluntarism in donation also represents a poor starting point for policy-making. Arguably, a far more realistic and effective approach is to institute a system that accounts for the widest possible range of motives for donation, while not compromising people's ability to make ethical choices in donation. Much of the logic behind such a policy approach has been clearly expressed by London School of Economics economist, Julian Le Grand.

Rethinking organ donation

Julian Le Grand argues that the post-war system of social security in the UK was based on certain assumptions concerning human motivation and behaviour. Crudely speaking, UK policy makers (Democratic Socialists, in the main) constructed the welfare system based on the implicit assumption that the state and its agents were, along with tax payers, selfless altruists, or 'knights'. Individuals in receipt of welfare benefits, on the other hand, were assumed to be essentially passive recipients of state largesse, or 'pawns'.

All of these assumptions were subsequently challenged, as it became increasingly apparent that welfare recipients were not happy with the low variety and level of services with which they were provided; that public officials and professionals were, respectively, not necessarily operating in the public interest or with only the welfare of their clients in mind; and, that those paying for welfare were typically resistant to this redistribution.⁷⁴

Thus, according to Le Grand, welfare recipients could not be said to have been pawns, or public officials, professionals and taxpayers, knights. There were found to be elements of the knight (selfless altruism) and knave (self-interest) in each of these players and their actions.⁷⁵

74. The welfare system was adapted in various ways, in line with these revised assumptions.

75. On this point see Ross Gittins, 'Selfishness goes only so far, we also like a fair system', *Sydney Morning Herald*, 22 March 2008, <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;adv=:db=:group=:holdingType=:id=:orderBy=:page=0;query=Id%3A%22media%2Fpressclp%2FCYYP6%22;querytype=:rec=0;resCount=>, accessed on 1 September 2008. Gittins presents the results of experimental research conducted by economists, anthropologists, biologists, sociologists and psychologists that indicates that 'people are not the selfish, materialistic creatures assumed by economic theory, but rather "conditional co-operators"'. This is to say that people behave altruistically as long as others are doing so as well. Not only do people behave altruistically where others are doing so, but they insist that their fellows behave fairly according to the prevailing norms of cooperation. People were found to 'care about process as well as outcomes, and care about the deal others are getting – not just their own deal'. On the strength of their findings, the researchers argued that 'effective policies are those that support socially valued outcomes not only by harnessing

To craft social policies based on the assumption that individuals are more likely to be self-interested than public-spirited—or the other way around—is, therefore, Le Grand argues, to over-simplify the situation. It is difficult, if not impossible, to determine in most instances whether people will behave as knights, knaves 'or indeed in some more complex fashion'.⁷⁶

In such a situation of ignorance concerning human motivation, and bearing in mind that grounding social policy on a knight-, knave- or pawn-based strategy could have disastrous results (turning knights into knaves, for example), Le Grand advocates the adoption of what he terms 'robust strategies': 'strategies or institutions that are robust to whatever assumption is made about human motivation'.⁷⁷ Such strategies or institutions could appeal to both the knight and the knave—to self-interest and to the collectivist spirit of altruism.

Consistent with this argument, and with the evidence outlined above, organ donors and potential donors should not be viewed simply as altruistic and selfless knights. Nor should they simply be understood as knaves—as calculating or economic agents who donate, or who would donate, largely out of self-interest. Rather, in policy terms, arguably it is best to hedge one's bets and conceive of donors and potential donors as knights *and* knaves—to posit the coexistence of social commitment and self-interest. Instead of being understood and treated primarily as selfless altruists, as is the case under current arrangements, donors and would-be donors would need to be understood and treated in neutral terms where it comes to their motivation and behaviour; they would need to be treated, first and foremost, as rational, autonomous decision-makers.

This would be to recognise that many organ donors donate their organs simply because they have thought about it and consider it a sensible and necessary thing to do.⁷⁸ These donors appreciate the act as being a responsibility, and as a matter that concerns many of us. Such a move would also be to bring Australia's organ donation system in line with most of the

selfish motives to socially valued ends, but also by evoking, cultivating and empowering publicly spirited motives'. See H. Gintis et al., *Moral Sentiments and Material Interests: The Foundations of Cooperation in Economic Life*, The MIT Press, Cambridge Massachusetts, 2005.

76. J. Le Grand, 'Knights, Knaves or Pawns? Human Behaviour and Social Policy', *Journal of Social Policy*, 26:2, April 1997, p. 161.

77. Le Grand, op. cit., p. 163.

78. Most respondents to the 2006 Community Perceptions on Organ and Tissue Donation for Transplantation survey nominated as their main reasons for becoming a donor or for considering registering to become a donor *to help others/to give others a chance at life or a better quality of life and I won't need them when I'm dead/no point in keeping what you don't need when you're dead*. Australians Donate, *Community Perceptions on Organ and Tissue Donation for Transplantation*, February 2006, http://www.australiansdonate.org.au/index.php?option=com_content&task=view&id=43&Itemid=80, accessed on 3 September 2008, p. 36.

nation's other public institutions—including citizenship—which are premised on the assumption of a rational, autonomous decision-maker.⁷⁹

It should be noted that treating people as rational, autonomous decision-makers need not necessarily mean that they are acting as such in the context of organ donation. Personal beliefs—mystical thinking, ancient fears and non-rational responses—figure more or less prominently in people's decisions about whether or not to donate their organs, or to allow their relatives to donate.⁸⁰ Indeed, many people are aware that they are making a non-rational decision about organ donation, and explicitly acknowledge this.⁸¹ Similarly, public education to overcome perceived deficits of knowledge need not necessarily result in increased organ donation rates, as personal beliefs may be relatively impervious to attempts to shift them.

Nevertheless, it is necessary to treat people as rational, autonomous decision-makers. Perhaps the most important reason for doing so is that this encourages people to behave as active and responsible citizens. This is a generic good and one that is independent of specific policy considerations, such as how to increase rates of organ donation. With regard to organ donation, people need to be treated as rational, autonomous decision-makers: firstly, for the reasons discussed above and throughout the remainder of this paper; secondly, because there is evidence that personal beliefs can be counterbalanced by rational arguments and the presentation of factual information; and, thirdly, because the provision of factual information and the full range of relevant issues is necessary to ensure informed consent on the part of donors.⁸²

Thinking about the act of organ donation in such terms is not only a more accurate rendering of the situation, but also one that would be likely to increase rates of organ donation in the

79. This does not, of course, preclude donors themselves and/or their families from viewing the act of donation in heroic or moral terms. However, both the Taskforce and Australians Donate note that organ donation communications strategies need to go beyond raising awareness to encourage 'attitudinal change and behavioural change so that registration and family consent to donation become normal events'. An essential first step in normalising organ donation is to treat it as an exercise in rational decision-making, rather than as a predominantly moral or heroic act. This, in turn, entails doing away with the doctrine of the gift.

80. See M. Lawlor, I. Kerridge, R. Ankeny and F. Billson, 'Public education and organ donation: Untested assumptions and unexpected consequences', *Journal of Law and Medicine*, 14: 3, 2007, pp. 360–366. In an Australian context see Novartis Pharmaceuticals 1999, Stollznow Research 2004, Woolcott Research 2003 and Campbell Research 2006.

81. L. Siminoff and K. Chillag, *op. cit.* This should not be construed as a reference to religious beliefs. Indeed, it is worth noting that most organised religions support organ donation as a humanitarian act. The Roman Catholic Church, Protestant faiths, Judaism, Islam, Buddhism and Hinduism all regard donation as a personal decision for individual members. See Australasian Transplant Coordinators Association Incorporated, *op. cit.*

82. M. Lawlor, I. Kerridge, R. Ankeny and F. Billson, *op. cit.*; L. Siminoff and K. Chillag, *op. cit.*

long-term, through appropriate institutional and cultural change. At the very least, it would result in more meaningful and productive policy debates.

Re-casting organ donation to view the act of donation as one of rational utilitarianism rather than of selfless altruism would have a number of implications for Australia's organ donation system as it currently stands. These implications are briefly discussed below.

Opt-in vs opt-out (or presumed consent)

As noted above, the National Clinical Taskforce on Organ and Tissue Donation argued in its report that Australia's opt-in system is fairer and gives people more of a choice than does the alternative opt-out or presumed consent system. This position has parallels with the notion that people should not be 'forced' into making moral decisions, a notion that is central to the gift doctrine. Rather, they should arrive at decisions such as whether or not they wish to donate their organs in an entirely un-coerced manner. Under a system dominated by the gift doctrine, their assumed altruism must not be compromised.

However, where the would-be donor is assumed to be a rational, autonomous decision-maker, and the act of donation viewed as being not necessarily a moral one, there is no real impediment to obliging people to make such decisions.⁸³ This is especially so given that Australians express almost universal support for the concept of organ donation.⁸⁴ People could still refuse to donate their organs for whatever reason, or reverse their commitment to donate their organs at any point.⁸⁵ Nor would they be required to justify their decision. The

83. At present, public opinion is divided as to whether or not an opt-out system should be introduced in Australia. See *Australians Donate, Community Perceptions on Organ and Tissue Donation for Transplantation*, op. cit., p. ii; David Hookes Foundation, 'Most favour organ donation law change but opinion divided on opt-out scheme', 24 March 2004.

84. Many Australians express a commitment to organ donation, yet fail to register to donate their organs. According to the *Australians Donate* survey conducted in 2006 and cited above, the primary reasons for Australians not becoming organ and tissue donors were their either being too busy or simply not having thought about it. See *Australians Donate, Community Perceptions on Organ and Tissue Donation for Transplantation*, op. cit., p. 39. A number of commentators attribute the discrepancy between a commitment to organ donation and actual registration to donate to apathy. In instances such as this, where people want to do 'the right thing' but are either too busy or too lazy to do so, Thaler and Sunstein recommend the use of what they call 'choice architecture'. Choice architecture involves influencing the context in which people choose, to help them to do the right thing. To achieve this, the environment is changed to influence behaviour through nudging rather than coercing. Thaler and Sunstein cite the substitution of an opt-out for an opt-in system of organ donation as one such example of choice architecture. R. Thaler and C. Sunstein, 'Easy does it. How to make lazy people do the right thing', *The New Republic*, 9 April 2008, pp. 20–22.

85. This is the current situation, and one that apparently needs to be made clearer to potential donors. According to research conducted by Eureka Strategic Research, some people have not registered a decision to donate because they assume that such a decision cannot be altered. See *National Clinical Taskforce on Organ and Tissue Donation*, op. cit., p. 156.

point is that they would need to think about the question of organ donation, and to make a commitment, one way or the other.⁸⁶ They still have control over the decision, the only difference being that they are obliged to make one. This requirement is not unlike a number of other obligations currently placed upon Australian citizens. It is merely a matter of reciprocal or mutual obligation for people who may in the future need to draw on the pool of available organs.

Transparency and informed consent

Treating organ donors as rational, autonomous decision-makers would be to empower them (and recipients) in several important ways.

Firstly, *all* organ donation system-related processes, including those associated with equity of access and fairness in the allocation of organs would need to be made genuinely transparent. This would be a necessary prerequisite in order for people to give their informed consent to donate under an opt-out system, rather than a focus on appeals to people's altruism, as is currently the case. At present, the emphasis is placed on education and awareness campaigns to increase knowledge of and support for organ donation in Australia. But this is not the same thing as providing information on and engaging potential donors in all aspects of donation and allocation processes.

It should be noted that much of the lack of transparency evident in Australia's current transplant sector is a result of variations in the processes used for different organs as well as differences between the states and territories. The Taskforce has recognised this problem and acknowledges the need for increased transparency, as well as for the need to 'involve consumers and the wider community in the policy development process' around organ allocation.⁸⁷ That this consumer and community involvement should be based on an informed understanding of the relevant issues, rather than simply through polling results (in which there is no guarantee that respondents have such an informed understanding), is also acknowledged by the Taskforce.⁸⁸

86. In doing so, people could spare their next-of-kin from having to make the decision when they have died or are dying, and thereby potentially alleviate them from some unnecessary grief. As Veronica English, the British Medical Association's deputy head of medical ethics, sees it, a move to presumed consent could also benefit: those who want to donate, because they have to make no effort to ensure that their wishes are followed; those who do not wish to donate, because their wishes will be formally recorded and must be followed; and, for those requiring a transplant, because more organs are likely to become available under such a system. V. English, 'Is presumed consent the answer to organ shortages?', *British Medical Journal*, 334, 26 May 2007, p. 1088.

87. National Clinical Taskforce on Organ and Tissue Donation, op. cit., pp. 173–5.

88. *ibid.*, p. 175.

The Taskforce has recommended the development of national waiting list criteria and allocation protocols, algorithms and processes. It has indicated that these must be seen to be transparent, equitable and must appropriately address the associated ethical, social and value concerns. While the Taskforce has flagged the need for greater community involvement in the consideration of such issues so as to better inform policy, protocol and criteria development, it did not consider the possibility of further donor involvement in the transplant sector. More specifically, it did not consider the possibility of directed donation for deceased organ donors as well as for living organ donors. This would be to give donors themselves more of a say in how and where their organs are used.

Directed and non-directed donation

At present, only living organ donation can be directed as well as non-directed. Where directed donation occurs, a donor agrees to donate to an identified recipient, usually a relative or friend.⁸⁹ The living donor is also able to make an altruistic non-directed donation and, in this instance, the donor donates to any suitable person on the waiting list.⁹⁰

The question is, why is the option of directed organ donation not made available to deceased organ donors? The Taskforce notes that the allocation of organs is a complex process that entails the consideration of factors such as medical need, urgency and capacity to benefit.⁹¹ Clearly, ultimate decisions on the allocation of organs, such as these, must be the preserve of those surgeons, physicians, organ donation committees and advisory groups who are directly involved in the transplant process.⁹² That said, while these decisions must take priority, there is still scope—in theory at least—for donors to indicate their preferences with regard to the allocation of their organs, and for these preferences to be considered. It should be noted that were conditions to be applied to organ donation, this could potentially lead to wastage of organs and increased administrative complexity. Nevertheless, this possibility should not discount consideration of the option.

89. Snyder, Miller and Rosenstein question why directed donation between family members and friends should be permitted where directed donation between strangers is not. Public policy respects the pre-existing emotional relationships and sense of moral obligation that exists between families and friends in donation. But should it not also respect the fact that some people (members of a religious community, for example) may experience a sense of moral obligation to donate to a particular person in need, despite not having a pre-existing relationship with this person? V. English, *op. cit.*, p. 2427.

90. *ibid.*, p. 51. The Taskforce notes that Australia is one of a number of countries where the living donor rate is higher than the deceased donor rate. p. 116.

91. *ibid.*, p. 53.

92. It is worth noting that the Australian Private Doctor questions the equity of current organ distribution practices based on medical criteria. It claims that, contrary to popular opinion, these criteria are 'riddled with subjective value judgements'. *Australian Private Doctor*, 10, August 2004, p. 24.

The problem with the directed organ donation option, of course, is that it introduces the possibility that donors could exercise discrimination in their choice of to whom their organ or organs should be allocated. In the worst case scenario, such an option would allow people to give vent to their biases and personal preferences at the expense of certain groups and individuals.⁹³

To illustrate, given that donated organs are a scarce community resource, a healthy-living organ donor may object to their organs being allocated to somebody who is affected by 'lifestyle diseases', rather than to somebody who is viewed as being in need of a transplant through no fault of their own. The hypothetical donor may reason that to donate an organ to somebody who leads a less-than-healthy lifestyle would be to waste a precious resource.⁹⁴ On these grounds, such a donor might request that, if their organs were to be allocated to a recipient suffering from lifestyle diseases, this would be on the precondition that the recipient agreed to make healthier lifestyle choices in the future.⁹⁵

Alternatively, deceased donors could indicate that they are happy for their organs to be allocated on an entirely non-directed basis, as is currently the case.

According to the gift doctrine, donors give their organs in a selfless, altruistic and egalitarian manner. Thus, there can be 'no prescribed and specified discrimination in the destination of the gift'.⁹⁶ The moral decision is to give to strangers. In the case of Britain's blood donor system, Titmuss argued that 'by not doing something – by not giving donors a 'right' to prescribe the group characteristics of recipients – the [National Blood Transfusion and National Health Services] thus presume an unspoken shared belief in the universality of

93. This view of directed donation—that it should not be allowed in order to prevent against the possibility of discrimination—is, Spital argues, simplistic. Given that we would be likely to object to directed donation to advantaged people (rich, white), but not to directed donation to disadvantaged people (a poor person, a disabled person or a child), he maintains that the real issue is that directed donation might favour those people and groups that are already advantaged. He notes that if donations were to be directed on the basis of race, this could be deemed altruistic and acceptable so long as the recipient was from a disadvantaged group that typically does badly where it comes to the receipt of organs. A. Spital, Solicitation of Deceased and Living Organ Donors, To the Editor, *New England Journal of Medicine*, 356: 23, 7 June 2007, p. 2427.

94. Given the possibility of directing their organ donation, some people might choose to donate their organs only to those people who had also committed to donating their organs. This would be to tackle the 'tragedy of the commons' situation that currently exists in the organ donation sector. At present, 'the incentive to become an organ donor is diminished by the fact that everybody can access the available organs although only those who have agreed to become organ donors have contributed to their availability'. *Australian Private Doctor*, op. cit., p. 25.

95. Were a number of organ donors to make similar decisions with regard to their directed donations, certain segments of the population could suffer as a result.

96. Titmuss, op. cit., p. 268.

need'.⁹⁷ As Titmuss saw it, his own case study provided some vindication for this policy position. Because he found that donors shared a sense of social responsibility towards the needs of other members of society, Titmuss argued that, by implication, this demonstrated their commitment to the provision of services on the basis of common human needs, that is, on an indiscriminate basis.

There are a number of problems with Titmuss' argument and with the gift in relation to the question of directed and non-directed donation. However, for the purposes of this paper the main problem is that it assumes that the decision to donate one's organs is *necessarily*—and must be—a moral decision, and one that must be made on an altruistic and egalitarian basis. This is primarily because, from the perspective of the gift, a donation system is assumed to 'actualise the social and moral potentialities of all citizens' (in effect, it helps to 'create' knights).⁹⁸

The key point is that an organ donation system does not necessarily need to enable the altruistic and egalitarian capacities of would be donors through prescribing alternative forms of human motivation or decision-making in donation. As the system currently stands, a deceased donor has the choice of donating their organs on an altruistic and egalitarian basis, or not donating at all.⁹⁹ In the terms of Le Grand's analogy, outlined above, the system allows only for knights and for a particular form of knave—one that is not necessarily self-interested, but who need not subscribe to the indiscriminate egalitarianism that underpins the system.

If one assumes a donor who is a rational, autonomous decision-maker, one who may or may not choose to direct their organs (or, act as a knight or knave), but who is given the possibility of doing so, then this allows for the widest possible range of motivations and choices. It does not preclude people from making moral decisions (however interpreted) in organ donation. Indeed, it might be argued that the introduction of the possibility of directed as well as non-directed deceased organ donation could increase people's scope and ability to make truly moral decisions.

That said, Australians may choose not to allow directed donation as an expression of their shared commitment to the universality of need, and as recommended by Titmuss, above. They already prohibit certain other forms of behaviour as an expression of shared values, such as constraining private health insurers from discriminating against unhealthy or older members or not allowing states to charge wealthy patients for using public hospitals. The point is that, because we cannot assume that people are knights, the possibility of directed donation needs to be at least considered.

97. *ibid.*, p. 268.

98. *ibid.*

99. And entrusting to the relevant transplantation staff ethical decisions around who the recipient should be.

Organ donation and next-of-kin

The explicit assumption of a rational, autonomous decision-maker as the basis for future organ donation policy in Australia would—if taken seriously—demand the revision of existing arrangements where it comes to next-of-kin's ability to overrule a deceased person's decision to donate their organs.

Australia's current system of organ donation largely relies on consent from family or next-of-kin for the donation of a deceased person's organs. Although a deceased donor may have registered their consent to donate their organs via the Australian Organ Donor Register (AODR), or through written means—both forms of registration that are considered to be legally binding and that may be acted upon—in practice, clinicians always seek the approval of next-of-kin for the donation. In this manner, the deceased person's wishes may be overridden.

A Newspoll conducted in 2004 indicated that almost three quarters of Australians (73 per cent) believe that a person's decision to donate their organs should be legally binding. These respondents also believed that the law should be changed to ensure that a deceased person's next-of-kin cannot overrule the decision.¹⁰⁰ Of these seventy-three per cent, fifty-six per cent were strongly in favour of such a change. These results are borne out by research conducted by Novartis Pharmaceuticals in 1999, Stollznow Research in 2004 and Australians Donate in 2004. Respectively, these national surveys found that 74, 87 and 73 per cent of respondents did not believe that a person's next-of-kin should be able to overturn their decision to become a donor after death.

Despite this consistent and overwhelming support for donors' wishes being upheld where it comes to their decision to donate, the Taskforce did not question the current arrangement. Indeed, the Taskforce recommended that 'any promotional AODR material should emphasise that next-of-kin views are always taken into account when donation is being considered'.¹⁰¹ This stance is somewhat ironic given the Taskforce's emphasis in various other sections of the report on the need to balance individual rights with the community's need for donation.

100. David Hookes Foundation, 'Most favour organ donation law change but opinion divided on opt-out scheme', 24 March 2004, http://www.davidhookesfoundation.com.au/index.php?option=com_content&task=view&id=17&Itemid=1, accessed on 2 September 2008.

101. National Clinical Taskforce on Organ and Tissue Donation, *op. cit.*, p. 157. The NHMRC ethical principles for organ, eye and tissue donation after death are of little assistance in this instance. These guidelines state that organs and tissues for transplantation should be obtained in ways that respect the wishes, where known, of the deceased. However, this statement is qualified by the requirement that the needs of all those directly involved, including the donor, recipient, families, carers, friends and health professionals must be recognised.

Given that the refusal rates of families in Australia are higher than those in other countries, the current next-of-kin arrangements pose a substantial problem not just in terms of donor's rights, but also in terms of increasing the number of donor organs available for transplant.¹⁰²

Payment and incentives for organ donation

The introduction of a system of payment for organs in Australia would be a radical policy option, and one with which many Australians would be likely to be uncomfortable. Few countries allow the sale and purchase of organs and such an option would represent a last resort to most people. Nevertheless, the shortage of organs in the rest of the international community has led many commentators to begin seriously considering this alternative. While introducing financial incentives for organ donation is antithetical to the way that we currently do things in Australia, it is something that may need to be seriously considered in the future, if other options for increasing the supply of organs available for transplantation fail to yield results.

Humans are not, as Titmuss observes, born altruistic or self interested: they *learn* to give, or not to give. Thus, an important consideration in the realm of public policy is 'the extent to which specific instruments of public policy encourage or discourage, foster or destroy the individual expression of altruism and regard for the needs of others'.¹⁰³ It is crucial, as noted above, that knights or potential knights should not be turned into knaves as a result of flawed or poorly designed public policy.

Titmuss' main argument in support of the gift in the context of blood donation was that voluntary blood donation systems foster giving to unnamed strangers. As such, voluntary systems were held by him to facilitate the expression of people's moral sense. Markets, on the other hand, were portrayed by Titmuss as promoting possessive egoism. If human blood was to be morally sanctioned as something to be bought and sold, Titmuss argued that each individual 'would act egoistically for the good of all by selling his blood for what the market would pay'.¹⁰⁴ In effect, Titmuss' argument is that if people are *permitted* by society to sell their blood (or organs), then this effectively takes away their *ability* to behave altruistically and to exercise moral choice. The ultimate and logical consequence of blood being treated as

102. L. Hoffman, 'Organ donor reality falling short of hopes', *Weekend Australian*, 1 December 2007, <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;adv=:db=:group=:holdingType=:id=:orderBy=:page=0;query=Id%3A%22media%2Fpressclp%2FDD4P6%22;querytype=:rec=0;resCount=>, accessed on 3 September 2008; P. Pottinger and M. Papadakis, 'Organ-donor crisis', *Sunday Times*, 22 February 2004, <http://parlinfo.aph.gov.au/parlInfo/search/display/display.w3p;adv=:db=:group=:holdingType=:id=:orderBy=:page=0;query=Id%3A%22media%2Fpressclp%2FFHQ6%22;querytype=:rec=0;resCount=>, accessed on 3 September 2008.

103. Titmuss, *op. cit.* p. 17.

104. *ibid.*, p. 16. This argument may be similarly applied to organ donation.

a consumption good, as Titmuss saw it, would be that all policy would become economic policy, with the only values that count being those that could be measured in terms of money.

Titmuss' argument can be seen as flawed on two main grounds: firstly, it draws a crude and unrealistic dichotomy between the market and society and, secondly, it paints altogether too dim a view of markets and of people's capacity and willingness to act in a moral and rational fashion in market societies.

Titmuss' defence of the gift in relation to blood donation is very much a product of the historical moment and social and political context in which it was written. It has, to an extent, been overtaken and undermined by subsequent developments as a result. As noted above, the post-war system of social security in the UK was largely premised on various assumptions concerning human motivation and behaviour. It was on the basis of these assumptions that a clear line was drawn between 'individualistic private markets' and 'social services' in the development of welfare institutions.¹⁰⁵ Since then our understandings concerning human motivation and behaviour have become more complex, and we have seen the development of private markets in health, education and employment services, among other areas. Few people would now argue, as did Titmuss, that private markets cannot coexist with redistributive social welfare institutions and processes without inevitably corrupting these institutions and processes, along with people's altruism and regard for the needs of others.¹⁰⁶

As noted above, Titmuss' argument is that if people are to be *able* to act altruistically in giving their blood, then this demands that they should not be given the option of selling their blood. But making available the option of selling one's blood or organs does not entail curtailing the moral choice of giving to strangers.¹⁰⁷ This would only be the case if the option of altruistically donating one's organs were outlawed altogether, with the sale of one's organs rendered the only available option. It should also be noted that giving to strangers is not the only moral choice available. To suggest that this is so would be to subscribe uncritically to the gift doctrine and to the notion that the act of donation is pure, selfless and altruistic. The decision to become a paid donor can still be understood as a charitable act.¹⁰⁸ People do not *have* to become a donor, either paid or unpaid. That said, some people are freer than others where it comes to making such decisions. This issue is considered below.

105. *ibid.*

106. *ibid.* For example, Titmuss argued that if blood were sanctioned as something to be bought and sold, then 'what ultimately is the justification for not promoting individualistic private markets in other component areas of medical care, and in education, social security, welfare services, child foster care, social work skills, the use of patients and clients for professional training, and other 'social service' institutions and processes'.

107. As Potts argues, 'even if laws legitimising organ commerce were passed, citizens would still be free to donate their organs without receiving any remuneration.' W. Potts, 'Increasing the supply of transplant organs by way of financial incentives', *Monash University Law Review*, vol. 31, no. 2, 2005, p. 219.

108. See W. Potts, *op. cit.*

Titmuss' other key argument in support of the gift in the context of blood donation was that blood sourced from voluntary, unpaid donation was safer than that sourced through paid donation. Since the 1960s, when Titmuss' research was conducted, 'stricter donor-screening protocols, more sophisticated testing and viral inactivation methods' have been developed and introduced.¹⁰⁹ These new protocols and methods ensure that 'blood products sourced from paid donors are as safe as those sourced from voluntary, unpaid donors'.¹¹⁰ The same holds for organs.

Rethinking organ donation so as to adopt as a starting point a rational, autonomous decision-maker does not lead inexorably to the introduction of a system of payment for organs; it does, however, demand serious consideration of the option. This is because to treat people as rational, autonomous decision-makers would be to truly give them control of their own bodies. The question of whether or not they would then be allowed to sell parts of their bodies is a secondary one, and one that is for society as a whole, and not simply lawyers, doctors and hospitals, to debate and resolve.¹¹¹ The question of whether or not payment for organs was likely to increase the number of organs available for transplantation is also not a primary consideration.

That said, the introduction of a system of payment for organs is something that most Australians would probably have some difficulty in accepting, and would only be likely to seriously consider when all other avenues to increase the number of available organs had been exhausted.

At present, the fundamental tenet of liberal philosophy that prioritises individual autonomy is not supported by the law. Individuals are denied property in their own bodies and body parts.¹¹² Thus, while people are allowed to give their organs (but only under the restrictive conditions outlined above) they are not allowed to sell or otherwise trade their body parts. Nor are they allowed to purchase body parts—in Australia, at least.¹¹³

109. A-M. Farrell, 'Is the gift still good? Examining the politics and regulation of blood safety in the European Union', *Medical Law Review*, vol. 14, Summer 2006, p. 161.

110. *ibid.*

111. W. Potts, *op. cit.*; and K. Woods, 'Donor Debate', *Medical Observer Weekly*, 6 April 2007, pp. 25–26.

112. W. Potts, *op. cit.*, p. 226.

113. Recently, an Australian woman travelled to the Philippines for a kidney transplant, for which she is reported to have paid \$65 000. A small percentage of this sum was to be paid to the Filipino live donor, with the remainder paid to the National Kidney and Transplant Institute (NKTII) which conducted the operation and its Hope Foundation which is responsible for finding matches between donors and recipients. C. Weaver, 'woman pays \$65,000 for kidney', *Daily Telegraph*, 2 March 2008.

An increasing number of commentators argue that laws specifically prohibiting the sale of organs should be repealed and that legislation that recognises the right of individuals to buy, sell and otherwise trade their body parts should be introduced.¹¹⁴ For the most part they do so on the grounds that introducing a system of payment for organs could significantly increase the number of organs available for transplant.¹¹⁵ Were this the case, the number of people suffering and dying whilst waiting for an organ transplant could be reduced, along with hospital and other health care-related funding and resources.

The sale of organs raises a number of issues. However, arguably the main issue has to do with the question of equity and with the related possibility of exploitation. This was certainly the issue of most concern to Titmuss. Objections to the sale of organs on the grounds of equity have it that the essentials of life, including medical care, should be available to all members of society, regardless of their ability or willingness to pay. According to these arguments, were the sale of organs to be permitted, this would discriminate unfairly in favour of wealthier patients who are able to purchase organs that poor people cannot afford. Not only would the introduction of a system of payment for organs discriminate unfairly in favour of wealthier patients where the purchase of organs is concerned, but such a system would also, it is argued, lead to the poor being exploited for their body parts. On this view, were the opportunity to sell their organs made available to poor people, then they would be likely to do so as a solution to their parlous circumstances.¹¹⁶

The argument against the sale of organs on the principle of equity is difficult to sustain under current conditions. Discrimination on the basis of people's ability to pay is already firmly

114. See for example W. Potts, op. cit.; Australian Private Doctor op. cit.; M. Cherry, 'Cash and compassion', *New Scientist*, 13 August 2005, p. 20; J. Shearmur, 'The real body shop, Part 1: Blood and corpses', *Policy*, vol. 23, no. 4, 2007–08; A. Friedman, 'Payment for living organ donation should be legalised', *British Medical Journal*, vol. 33, 7 October 2006, pp. 746–8. Other commentators, such as A. Matas, propose the introduction of a system of compensation (for living kidney donors), rather than a system of *payment* for organs. Under such a system, compensation for organs could include fixed payments, long-term health insurance, education fees, tax deductions or other forms of compensation. While supporting a system of compensation for organ donation, Delmonico et al. argue that such compensation should not involve any form of payment for organs or the assignment of a monetary value to organs donated for transplantation. They do so on the grounds that while a payment-based system is ethically unacceptable, nonmonetary recognition of donation 'appeals to our notions of equity and...does not subvert the altruistic social good that must be preserved in a revised system of organ donation'. F. Delmonico et al., 'Ethical incentives—not payment—for organ donation', *New England Journal of Medicine*, vol. 346, no. 25, 20 June 2002, p. 2005.

115. There is some debate as to whether or not the introduction of paid organ donation would result in reduced numbers of potential altruistic donors. As noted above, Titmuss was of the view that it would. However, Matas has argued that there is no evidence to support this concern.

116. Kidneys are already transplanted from impoverished donors into wealthy recipients for payment in third world countries. See D. Rothman and S. Rothman, 'Organic commerce', *Australian Financial Review*, 17 October 2003.

entrenched in Australian society—and in such areas of basic need as medical care and education. Thus, if organ sale is wrong on the grounds of people's varying capacity to pay for necessary organs, then arguably 'all benefits available to the rich, including all private medicine', are wrong.¹¹⁷ Indeed, some commentators maintain that to not allow poor people the option of selling their organs is to deprive them of one possible means of achieving a better life (along with, of course, the recipients of these organs).¹¹⁸ In any case, problems such as those described above are not insurmountable and, as far as some commentators are concerned, should not serve as a justification for prohibition of the sale of organs.

Were a system of payment for organs to be introduced, equity could be assured through regulation of the market to guarantee that transplantable organs were allocated on the basis of need and urgency, as is currently the case. This would circumvent the possibility of wealthy patients 'jumping the queue' by outbidding poorer patients. In addition, poorer patients could draw on public assistance (such as Medicare) to enable them to afford required organs.

A possible means of dealing with the potential problem of poor people being exploited for their organs would be to only permit deceased donation market transactions. Limiting market transactions to deceased donations (where these organs were sufficiently healthy for transplantation purposes) would ensure that there was no acquisition of organs from live donors, and therefore no exploitation of the poor (with respect to their organs while they are alive, at least). Payment for organs would be made to the relatives or nominated recipient of the organ donor.¹¹⁹

Such an option raises two related issues. Insistence on a system of payment for deceased people's organs alone would be to pose limits on the autonomy and self-ownership that would be a necessary prerequisite for any form of organ sale. If property were to be recognised in the human body then this would, in principle, allow people to sell their organs while they were alive and not just when deceased. Further, such a system would not directly benefit the poor donor.

However, few people would countenance either leaving organ donation entirely to market forces or allowing people absolute freedom in the sale of their own organs. There would clearly be a role for state intervention to ensure that any organ market was regulated in the public interest, and that individuals—especially poor people—were prevented from exploitation and harm. In keeping with this principle, prohibiting people's sale of their organs while alive might (or might not) be justifiable on health grounds. The extent of the state's role in regulating a system of payment for organs—for example the question of whether or not the state would be responsible for the purchase and sale of organs or simply for setting

117. J. Radcliffe-Richards et al., 'The case for allowing kidney sales', 351, *The Lancet*, 1998, cited in W. Potts, op. cit., p. 220.

118. See A. Matas, op. cit.

119. For further details on such an option see W. Potts, op. cit.

and enforcing prices—is something that would need to be determined in the event that such an option were to be considered.

Conclusion

It is widely recognised that Australia's organ donation and transplantation sector is in need of significant reform, if the nation's present and future need for organs is to be met.

However, so long as proposed reforms do not, for whatever reason, depart from the terms of a gift of life doctrine, policy debates over organ donation will be constrained and many possibilities for increasing organ donation and transplantation rates go unexplored.

It is important to place organ donation into its proper perspective. Without wishing to underplay the merit of the act of organ donation, it is an act that should be viewed with objectivity. Freeing debates and policy considerations from the terms of the gift doctrine would serve to open up a broader debate around organ donation. This would, in turn, enable serious consideration of the presumed consent system option and the possibility of a system of payment for organs—should such an option prove necessary. The consequence of such a debate could be more realistic and innovative approaches to organ donation and, ultimately, more saved Australian and New Zealand lives.

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